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References Committee

The cancer journey: informing choice

Report on the inquiry into services and treatment options for persons with cancer

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Senate Community Affairs References Committee Secretariat:

Mr Elton Humphery (Secretary)

Ms Lyn Beverley (Principal Research Officer)

Mr Ian Kemp (Seconded adviser)

Ms Leonie Peake (Research Officer)

Ms Ingrid Zappe (Executive Assistant)

The Senate
Parliament House
Canberra ACT 2600

Phone: 02 6277 3515
Fax: 02 6277 5829
E-mail: community.affairs.sen@aph.gov.au
Internet: http://www.aph.gov.au/senate_ca

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TABLE OF CONTENTS

LIST OF ACRONYMS

ACN	Australian Cancer Network
ACNEM	Australian College of Nutritional and Environmental Medicine
AHMAC	Australian Health Ministers' Advisory Council
AHWOC	Australian Health Workforce Officials Committee
AIHW	Australian Institute of Health and Welfare
CAM	Complementary and Alternative Medicine
CCA	Cancer Council Australia
COSA	Clinical Oncological Society of Australia
DoHA	Department of Health and Ageing
HIC	Health Insurance Commission
ICS	Integrated Cancer Services
IM	Integrated Medicine
MBS	Medicare Benefits Schedule
MDC	multidisciplinary care
MOGA	Medical Oncology Group of Australia
NACCHO	National Aboriginal Community Controlled Health Organisation
NCCAM	National Centre for Complementary and Alternative Medicine (US)
NCCI	National Cancer Control Initiative
NCI	National Cancer Institute (US)
NHMRC	National Health and Medical Research Council
NHPA	National Health Priority Area
NMSC	Non-Melanocytic skin cancer
NSIF	National Service Improvement Framework
PBS	Pharmaceutical Benefits Scheme
RDAA	Rural Doctors Association of Australia
ROJIG	Radiation Oncology Jurisdictional Implementation Group
RORIC	Radiation Oncology Reform Implementation Committee
TGA	Therapeutic Goods Administration

PROLOGUE

A cancer diagnosis is a devastating and life changing experience.

While dealing with their own feelings of shock and being overwhelmed, the patient is also faced with the strain of telling family and friends and making decisions regarding treatment. At this point, the start of what is called by many the 'cancer journey' can be a bewildering experience. There is the health system to navigate, choices to be made regarding specialists and treatments, endless information to sort through and unfamiliar medical terms to learn. There are also a myriad of questions such as: Where do I obtain information on my type of cancer? Which information can I trust? How do I find a specialist which deals with my type of cancer and how experienced are they? Which treatments will be the most effective for me? Should I pursue complementary and/or alternative treatments, how effective are they and how do I find out about them? Where do I find the latest research findings on new treatments and how do I evaluate them?

More often than not the timeframe to find information and make decisions on treatment can be very short and needs to occur while the patient is struggling to come to terms with their own feelings and perhaps their own mortality.

This could be daunting enough for most people but the majority of people diagnosed with cancer will also face practical, emotional and psychological challenges in addition to their physical treatment. If you live in rural or remote Australia, a cancer diagnosis brings additional concerns of access to services, transportation to treatment and possibly large periods of time spent away from family and local support networks. If you are an Aboriginal or Torres Strait Islander, the remote locality issues can be compounded by cultural and linguistic differences.

Thanks to greater access to medical and health information on the Internet and through national preventative health campaigns, Australians are becoming better informed about health issues. There is also a growing trend that people want to take greater responsibility for their health and well being. As a result, when a disease like cancer is diagnosed, many patients wish to be active participants in their treatment plans. They want and need to feel a greater degree of influence and control.

In order to be active participants and to make informed decisions, patients want to understand the cancer treatment choices that are available to them. In addition to the range of conventional treatments, the use of complementary and alternative medicines and therapies is increasing as patients seek to extend their healthcare choices. This may result in a patient investigating and evaluating possible alternative treatments and therapies relevant to their condition, often with little assistance from the conventional medical practitioners who can be sceptical of their benefits. This scepticism may result in patients choosing not to inform their medical practitioners that they are investigating or using complementary or alternative therapies, some of which may have the potential to affect conventional treatments. However, increased usage of such therapies indicates that patients are voting with their feet.

Cancer control in Australia is largely a positive story with our survival rates being second only to the USA and the number of deaths falling each year. However, these improvements are not equal across the community with disproportionate rates of cancers in disadvantaged groups, including Indigenous Australians and those living in rural and remote areas.

Australia has an ageing population and consequently the incidence of cancer will increase. With earlier detection from enhanced screening and technological advances in treatment, the number of people living longer with cancer will also increase in the future. A number of recent reports, while acknowledging the gains made in recent years in the area of cancer survival, have argued that Australia must provide a national, integrated, evidence driven and consumer focussed approach to cancer care.

In this report the Committee examines key areas of multi-disciplinary and integrated service delivery and the use of complementary and alternative treatments. The report outlines ways in which Australia can continue to optimise choice and improve outcomes for cancer patients as they travel their cancer journey.

RECOMMENDATIONS

Availability of information at diagnosis and referral

Recommendation 1

3.9 The Committee recommends that Cancer Australia, in association with consumer based organisations such as Cancer Voices NSW and the Breast Cancer Action Group in Victoria, coordinate the development of information about cancer treatment services in each State and Territory. This information would be based on the successful breast cancer treatment directory developed by the Breast Cancer Action Group in NSW, published in 2002, which is also available on the Internet.

Recommendation 2

3.13 The Committee recommends that Cancer Australia, in conjunction with State and Territory Governments, develop appropriate referral pathways for the optimal management of all cancers for all Australians regardless of where they live.

Recommendation 3

3.23 The Committee recommends that, Cancer Australia, together with the Clinical Oncological Society of Australia and the Cancer Council of Australia develop and introduce accreditation and credentialing systems.

Recommendation 4

3.32 The Committee recommends that Cancer Australia in its role of providing national leadership and to foster improvements in the integration of networked cancer services, play a primary role in facilitating the sharing of information about Commonwealth and State and Territory Government cancer initiatives to improve treatment services.

Promoting multidiscipinary care

Recommendation 5

3.61 The Committee recommends that the use of and adherence to clinical guidelines is an essential component of multidisciplinary care and must be part of any system of accreditation of cancer treatment services.

Recommendation 6

3.62 The Committee recommends that multidisciplinary care, consisting of an integrated team approach in which medical and allied health care professionals develop collaboratively an individual patient treatment plan, continue to be widely promoted within the medical and allied health care professions.

Recommendation 7

3.65 The Committee recommends that the curriculum for medical professionals at the undergraduate and postgraduate levels include enhanced communication skills training and that professional Colleges also undertake a more active role in the provision of such training for their members. This training could be based on the National Breast Cancer Centre's communication skills training workshops that have been developed to improve the awareness and capacity of health professionals to communicate effectively with women with cancer.

Recommendation 8

3.72 The Committee recommends that the Cancer Funding Reform Project, established under the auspices of the Health Reform Agenda Working Group and reporting to Australian Health Ministers, include the differences in public and private hospital billing arrangements as an item for investigation and resolution.

Recommendation 9

3.73 The Committee recommends that the Department of Health and Ageing, in consultation with Cancer Australia, enhance current Medicare Benefit Schedule arrangements for relevant specialists and general practitioners to support participation in multidisciplinary care meetings in both hospitals and the community.

Recommendation 10

3.74 The Committee recommends that five multidisciplinary cancer centre demonstration projects be set up in consultation with consumer groups and be funded over three years in different parts of Australia. At least one demonstration project should be in the private sector. Within these multidisciplinary centres different models of psychosocial support, incorporating a range of complementary therapies and taking into account the cultural needs of patients, should be assessed. The assessment of all aspects of the demonstration projects should be scientifically based and involve consumer representatives in the process.

Improving coordination of cancer services

Recommendation 11

3.98 The Committee recommends that all State and Territory Governments that have not yet done so, establish designated care coordinator positions to help cancer patients navigate their way through treatment and provide support and access to appropriate information.

Recommendation 12

3.99 The Committee recommends that use of the breast cancer nurse care coordinator model should be adopted for all cancers and that States and

Territories undertake a recruitment drive for skilled health professionals such as retired nurses to help fill these positions.

Recommendation 13

3.105 The Committee recommends that Cancer Australia provide access to authoritative, nationally consistent, evidence based information on services, treatment options, government and non-government assistance and links to appropriate support groups which can be used by health professionals including care coordinators, cancer patients and their families. This information should be available in different forms.

Improving support for cancer patients

Recommendation 14

3.121 The Committee recommends that the Department of Health and Ageing improve health professional and consumer awareness of allied health services for people with chronic conditions and complex care needs that can be claimed under the Medical Benefits Schedule. Current claim usage of allied health services should be determined and an evaluation should be conducted 12 months after promotion of the Medical Benefit Schedule items available.

Recommendation 15

3.122 The Committee recommends that Cancer Australia examine appropriate funding mechanisms for programs and activities like those operated by the Gawler Foundation, which specialise in providing learning and self-help techniques based on an integrated approach for cancer patients and their carers. This examination should include consideration from a health and equity point of view of providing Medicare deductibility for cancer patients accessing these services.

Recommendation 16

3.126 The Committee recommends the continued implementation and dissemination of the *Clinical practice guidelines for the psychosocial care of adults with cancer* to health professionals and people and families affected by cancer.

Recommendation 17

3.132 The Committee recommends that psychosocial care be given equal priority with other aspects of care and be fully integrated with both diagnosis and treatment, including the referral of the patient to appropriate support services.

Recommendation 18

3.133 The Committee recommends that patients and carers should be made aware of additional support services provided by organisations such as The

Gawler Foundation in VIC, Balya Cancer Self Help and Wellness Inc in WA and Bloomhill Cancer Help in QLD.

Recommendation 19

3.135 The Committee recommends that State and Territory Governments consider ways to increase the availability of psychosocial support services.

Travel and accommodation issues for regional Australians

Recommendation 20

3.169 The Committee recommends States and Territories adopt and implement the consistent approach to the benefits for travel and accommodation recommended by the Radiation Oncology Jurisdictional Implementation Group to ensure that benefits are standardised across Australia. These benefits should be indexed or reviewed annually for increases in travel and accommodation costs.

Improving cancer care for Indigenous Australians

Recommendation 21

3.184 The Committee recommends Cancer Australia, in consultation with Aboriginal and Torres Strait Islander people and the States and Territories, auspice work to improve access to cancer screening, diagnosis and treatment for Aboriginal and Torres Strait Islander people that is culturally appropriate.

Increasing research into complementary therapies

Recommendation 22

4.39 The Committee recommends the National Health and Medical Research Council provide a dedicated funding stream for research into complementary therapies and medicines, to be allocated on a competitive basis.

Recommendation 23

4.49 The Committee agrees with the recommendation of the Expert Committee on complementary medicines in the health system, that the NHMRC convene an expert working group to identify the research needs addressing the use of complementary medicines, including issues around safety, efficacy and capacity building. The Committee recommends that this working group should include complementary therapists in order to develop a strategy to coordinate and prioritise a dedicated research funding stream for complementary medicine and therapy research, taking into account research conducted overseas. The group should also encourage the development of collaborative partnerships across disciplines.

Recommendation 24

4.50 The Committee recommends that the NHMRC develop workshops for complementary therapy researchers intending to compete for funding, where experienced researchers discuss their preparation of research proposals.

Recommendation 25

4.51 The Committee recommends that the NHMRC appoint two representatives, (including one consumer), with a background in complementary therapy, to be involved in the assessment of research applications received by the NHMRC for research into complementary and alternative treatments.

Improving access to and information on complementary therapies

Recommendation 26

4.70 The Committee recommends that complementary therapy organisations form a collaborative group with the authority to negotiate with representatives from the established medical organisations and to make recommendations to government. This body should organise a regular forum for representatives of complementary therapies to come together and discuss issues affecting their members such as regulation, research funding issues, collaboration and health and cancer initiatives at the Commonwealth, State and Territory levels.

Recommendation 27

4.90 The Committee recommends that Cancer Australia access the information available internationally on different complementary therapies ad alternative products in order to provide up-to-date, authoritative, evidence-based information which can be regularly updated. This information should be made available in different forms and made available to cancer patients and their families as well as health professionals and other interested individuals.

Recommendation 28

4.98 The Committee recommends that where quality of life may be improved by complementary approaches, methods to make such therapies more accessible be discussed by State and Territory cancer services, including consumer representatives.

Recommendation 29

4.104 The Committee recommends that State and Territory governments include the views of peak complementary therapy bodies in each State and Territory regarding the planning and delivery of cancer services.

Access to breast screening

Recommendation 30

5.12 The Committee recommends that the target age groups for BreastScreen Australia and the National Cervical Screening Program should be reviewed regularly, given the increasing trends in life expectancy for Australian women. In addition, a review should be conducted of how women outside the age limits are made aware of their cancer risk.

Cancer care for adolescents

Recommendation 31

5.30 The Committee recommends that Cancer Australia consider the development of appropriate referral pathways that take account of the particular difficulties confronted by adolescents with cancer.

Recommendation 32

5.36 The Committee recommends that State and Territory Governments recognise the difficulties experienced by adolescent cancer patients being placed with inappropriate age groups and examine the feasibility of establishing specialised adolescent cancer care units in public hospitals.

Improving data collection

Recommendation 33

5.55 The Committee recommends that Cancer Australia, in consultation with State and Territory Governments and the Australian Institute of Health and Welfare, take a leadership role in coordinating the development of a national approach to the collection of cancer staging data.

CHAPTER 1

INTRODUCTION

Terms of reference

1.1 On 10 February 2005 the Senate, on the motion of Senator the Hon Peter Cook, referred the following matters to the Committee for inquiry and report by 23 June 2005:

- (a) the delivery of services and options for treatment for persons diagnosed with cancer, with particular reference to:
  - (i) the efficacy of a multi-disciplinary approach to cancer treatment,
  - (ii) the role and desirability of a case manager/case co-ordinator to assist patients and/or their primary care givers,
  - (iii) differing models and best practice for addressing psycho/social factors in patient care,
  - (iv) differing models and best practice in delivering services and treatment options to regional Australia and Indigenous Australians, and
  - (v) current barriers to the implementation of best practice in the above fields; and
- (b) how less conventional and complementary cancer treatments can be assessed and judged, with particular reference to:
  - (i) the extent to which less conventional and complementary treatments are researched, or are supported by research,
  - (ii) the efficacy of common but less conventional approaches either as primary treatments or as adjuvant/complementary therapies, and
  - (iii) the legitimate role of the government in the field of less conventional cancer treatment.

Conduct of the Inquiry

1.2 The inquiry was advertised in *The Australian* and through the Internet. The Committee wrote to interested individuals and groups inviting submissions. The Committee received 105 public submissions and 8 confidential submissions from a range of organisations, individuals and Commonwealth and State departments. Many of the submissions were from individuals describing their personal cancer journey of being diagnosed with cancer and the impact it has had on their lives and that of their families. A list of individuals and organisations who made a public submission or provided other information that was authorised for publication by the Committee is at Appendix 1.

1.3 The Committee held public hearings in Perth, Melbourne, Sydney and Canberra. In organising its hearing program, the Committee endeavoured to hear from the major organisations which made submissions to the inquiry, including all the groups who represent or support individuals with cancer. A number of these individuals also gave personal testimonies about living with cancer. The Committee also spoke via teleconference with individuals from acknowledged best practice hospitals and organisations in the USA and UK. A list of witnesses who gave evidence at the public hearings is at Appendix 2.

1.4 Some important issues and questions arose from the submissions and evidence received by the Committee. Professor D'Arcy Holman, Head, School of Population Health at the University of Western Australia, was commissioned to provide a response to these issues. The advice and Briefing Paper provided by Professor Holman (Holman report) proved a valuable contribution to the Committee's inquiry.[1]

Background to Inquiry - Cancer in Australia

What is cancer?

1.5 'Cancer' is a broadly used expression. The Holman report describes cancer as not a single disease but rather it is a diverse group of diseases characterised by the proliferation and spread of abnormal cells, which cannot be regulated by normal cellular mechanisms and thus grow in an uncontrolled manner. These abnormal cells may then invade and destroy surrounding tissue and spread (metastasise) to distant parts of the body via the circulatory or lymphatic system. Cancer can develop from most types of cells, with each cancer having its own pattern of behaviour and metastasis.[2] This description reflects that of the *National Service Improvement Framework for Cancer* which notes that 'Cancer is a chronic and complex set of diseases with different tumour sites. For some cancers, there is considerable knowledge about their causes and optimal treatment. This varies for other cancers.'[3] These views are succinctly drawn together by the Australian Institute of Health and Welfare (AIHW) which defines cancer as:

> …a diverse group of diseases in which some of the body's cells become defective, begin to multiply out of control, can invade and damage the tissue around them, and may also spread (metastasise) to other parts of the body to cause further damage.[4]

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[1] Professor Holman's response and a Briefing Paper prepared by Rachel Moorin, Centre for Health Services Research in the School of Population Health at the University of Western Australia were authorised for publication by the Committee.

[2] Professor D'Arcy Holman, Commissioned report, Briefing Paper, p.1.

[3] *National Service Improvement Framework for Cancer*, National Health Priority Action Council, March 2004, p.4.

[4] *Australia's Health 2004*, Australian Institute of Health and Welfare, May 2004, p.64.

The good news

1.6 Internationally, Australia compares well with other developed countries in terms of its cancer survival rates. The AIHW report *Cancer in Australia 2001*, shows that Australia's cancer mortality rate is low when compared with other developed countries. In addition, over the past ten years, total cancer death rates declined by an annual average of 1.9 per year.[5] Further good news is that five-year survival rates for the most common cancers affecting men (prostate) and women (breast) are now more than 80 per cent.[6] This indicates that cancer survival in Australia is relatively very good and suggests our health system is performing comparatively well in the areas of early detection and treatment of cancer.[7] Whilst this is welcome news it is no excuse for complacency and one of the motivations of this report is to discover if we can do better. Based on the international evidence provided, it is clear that cancer treatment is dynamic and evolving with new aspects of medicine continuing to provide new opportunities.

The increasing burden of cancer in Australia

1.7 Given these achievements in decreased mortality and increased survival, why was an inquiry into the delivery of services and treatment options for persons diagnosed with cancer in Australia needed? Firstly, cancer currently places a huge burden on the community and this is set to rise in the coming years. Despite advances, cancer remains a leading cause of death in Australia accounting for 28 per cent of all deaths in 2003.[8] Cancer currently accounts for 31 per cent of male deaths and 26 per cent of female deaths. In 2005 we can expect that there will be around 36 000 deaths in Australia due to cancer. Cancer also accounts for an estimated 257 458 potential years of life lost to the community each year as a result of people dying of cancer before the age of 75.[9]

1.8 In addition to the existing burden, the cancer incidence rate has been increasing over the past 10 years. Recent trends in cancer data produced by the AIHW indicate that the annual number of new cancer cases diagnosed rose by 36 per cent between 1991 and 2001, compared with population growth of 12.3 per cent. The AIHW noted that there is likely to be an increase of similar magnitude over the next 10 years. Currently, one in three men and one in four women will be diagnosed with cancer before the age of 75 years (see Figure 1.1).[10] In fact, the sentiment that 'every

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[5] Australia's Health 2002, AIHW May 2002, p.53.

[6] *Cancer Survival in Australia 2001*, AIHW, September 2001, pp.46, 62.

[7] *Cancer in Australia 2001*, AIHW, p.xvi.

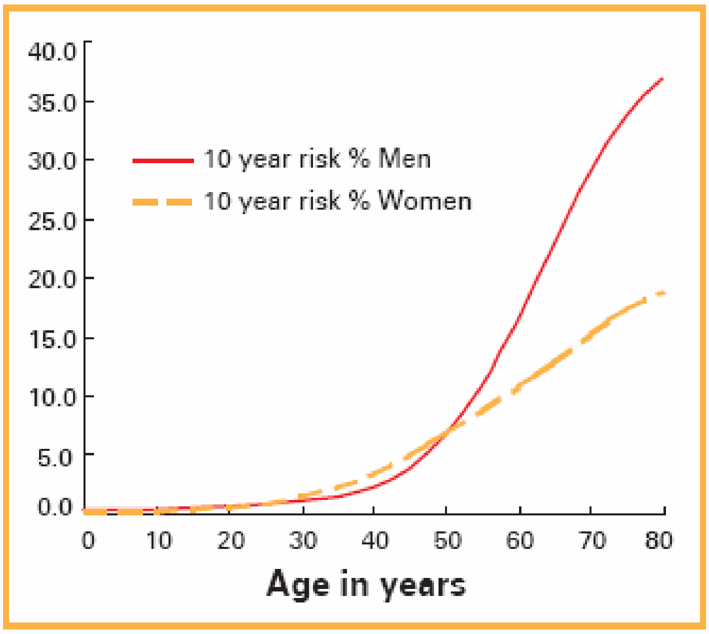
[8] *Deaths, Australia*, 3302.0 Australian Bureau of Statistics, 15 December 2004, p.3.

[9] *Cancer in Australia 2001*, AIHW, December 2004, p.6.

[10] *Submission 3*, Additional information 20.4.05, p.1 (AIHW) and *Cancer in Australia 2001*, AIHW, December 2004, p.xi.

Australian is likely to be affected by cancer, either through personal experience or the diagnosis of a loved one'[11] was typical of that expressed in many submissions.

Figure 1.1: Risk of being diagnosed with cancer in the next 10 years



Source: Cancer in Australia: An update for GPs, *Australian Family Physician*, v.34, January/February 2005, p.43.

1.9 The increase in the incidence of cancer is partly explained by Australia's ageing population as cancer incidence is lowest in late childhood and increases with age. The most rapidly increasing age group in the population is aged 65 and over and the average age of first diagnosis for cancer is 66 years for males and 64 years in females.[12]

1.10 Along with increased incidence of cancer we can also expect detection, treatment and survival rates for cancer to continue to improve, meaning that there will be more people living with cancer for longer in the future but with relatively fewer taxpayers to support them. The Australian Bureau of Statistics notes that 'currently more than 267 000 Australians are living with cancer, many with persistent and incurable forms'.[13] Professor Holman noted that cancer patients living longer 'is the single most important reason why so many of us are now in contact with a relative or friend who is living with cancer'. He provided data from the WA Data Linkage System which shows that 'in WA the prevalence of active cancer (ie, people 'living

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[11] *Submission* 65, p.3 (COSA, CCA, NCCI and NACCHO).

[12] *Australia's Health 2004*, Australian Institute of Health and Welfare, p.67.

[13] *Cancer in Australia: A snapshot* 4822.0.55.001, Australian Bureau of Statistics, 1 September 2004.

with cancer' that requires ongoing clinical management) increased from 5.1/1 000 to 7.4/1 000'.[14]

1.11 The growing number of people being diagnosed with cancer and living with cancer for longer will inevitably increase the demand for cancer resources and services. AIHW data shows that:

- there was a 31 per cent increase in inflation-adjusted cancer expenditure from 1993-94 to 2000-01;[15]
- Average cancer expenditure per person was $146 for males and $135 for females in 2000-01. This was much higher in the older age groups. In the 65-74 year age group, average cancer expenditure per person was $641 for males and $389 for females while in the 75 years and over age groups, the averages were $984 for males and $480 for females[16]; and
- New cases diagnosed in 2001 showed an increase of 22 000 on 1991 figures.[17]

1.12 These trends will place added pressure on the national health budget and will pose ongoing challenges to the delivery of optimal cancer care in Australia.

The need to ensure the best use of cancer resources

1.13 Witnesses from the Australian and State governments informed the Committee about the cancer initiatives being undertaken to improve treatment and services. The Committee was concerned about the potential for uncoordinated systems to emerge and how sharing information on the development of initiatives between jurisdictions would occur. The Committee considers that Cancer Australia should have a role to ensure the development of well coordinated cancer initiatives in the various jurisdictions and provide a forum for jurisdictions to report progress on their respective initiatives to facilitate the sharing of information.

1.14 During the course of the inquiry the Committee was advised that there were more than 100 government and non-government organisations that contribute to cancer policy or are involved in cancer treatment or support around Australia (see Appendix 3). The Committee recognises the valuable role played by these services, however, given the increasing burden that cancer will place on the community in the coming years the Committee believes that there is a need to ensure that cancer resources are well organised, used efficiently and effectively and that any potential for duplication and overlap is addressed.

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[14] Professor D'Arcy Holman, Commissioned Report, p. 2.

[15] *Submission* 3, Additional information 20.4.05, p.4 (AIHW).

[16] *Cancer in Australia 2001*, AIHW, December 2004, p.xv.

[17] *Submission* 65, Additional information 19.4.05, p.2 (COSA, TCC, NCCI and NACCHO).

1.15 The large number of organisations involved in cancer policy or support was also raised by some witnesses. Professor Coates described the functions of various bodies to the Committee but added:

> I do have a PowerPoint presentation which I call 'the alphabet soup', which goes through some of these myriad acronyms. It contains a diagram, which looks rather like one that was put up to an ALP conference, of the spaghetti connections between various bodies in the cancer universe.[18]

1.16 The Committee also noted the large numbers of tumour specific support groups which, although filling a void for information and support, may benefit from the promulgation of best practice models. Dr Hassed spoke to the Committee about evidence that not all cancer support groups seem to be as effective as every other. He noted that effective cancer support programs significantly improve the mental, emotional and social health of participants and are associated with significantly longer survival.[19]

1.17 The potential for improved organisation of support services was acknowledged by Mr Davies, Department of Health and Ageing, who told the Committee that the Department has commissioned The Cancer Council Australia to undertake a review of the cancer support networks and also to examine overseas experience. The objective would be to identify best practice models and promulgate these to be shared among the organisations.[20]

1.18 The necessity for cost-efficient delivery of cancer care services was reinforced by Professor Holman:

> …the increasing prevalence of active cancer has profound implications for the planning, provisions and financing of health services. An increasing proportion of health care resources will inevitably need to be allocated to cancer care, and more cost-efficient ways of delivering that care will become imperative.[21]

Increasing patient focus and empowerment

1.19 People being diagnosed with cancer are demanding more information about their cancer, their treatment options and the role they can perform. As Dr Gawler noted: 'There is huge public interest in how much an individual can affect the outcome of their illness'.[22] Cancer patients are becoming more active participants in their treatment and there are growing demands for:

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[18] *Committee Hansard* 19.4.05, p.14 (Professor Coates).

[19] *Committee Hansard* 18.4.05, pp.57-58 (Dr Hassed).

[20] *Committee Hansard* 20.4.05, p.82 (Mr Davies, DoHA).

[21] Professor D'Arcy Holman, Commissioned Report, p.3.

[22] *Committee Hansard* 18.4.05, p.54 (Dr Gawler).

- Patient-focussed, coordinated multidisciplinary care to address the current cancer care lottery and provide best practice care along the care continuum;
- Support throughout the cancer journey;
- Access to evidence-based quality care, including clinical trials, and a willingness by medical practitioners to discuss treatment options, including complementary therapies;
- Greater and easier access to understandable and authoritative information, including complementary therapies, to assist patients with making informed treatment decisions and to enable dialogue with health professionals; and
- Equitable access to care for rural and Indigenous Australians.

Patient-focussed, coordinated multidisciplinary care to address the current cancer care lottery and provide best practice care along the care continuum

1.20 This issue has been precisely described by Lance Armstrong, one of the world's most recognised athletes who challenged his cancer head-on:

> From that moment on, my treatment became a medical collaboration. Previously, I thought of medicine as something practiced by individual doctors on individual patients. The doctor was all-knowing and all-powerful, the patient was helpless. But it was beginning to dawn on me that there was nothing wrong with seeking a cure from a combination of people and sources, and that the patient was as important as the doctor.[23]

1.21 Cancer patients spoke to the Committee about the 'cancer lottery' starting at the point of diagnosis where they found the referral process ad hoc, with many finding specialists through serendipitous connections and word of mouth. Patients wanted more information to be able to choose a specialist they felt comfortable with.

> One of the critical issues in terms of the health system in Australia is that it is absolutely fragmented – the left hand does not know what the right hand is doing.[24]

1.22 Witnesses also reported their care had been fragmented and disorganised and individual support needs had not been met. The National Breast Cancer Centre noted:

> In Australia, screening, diagnosis, treatment and supportive care for patients with cancer are typically provided by different services, often with little coordination, leading to fragmented care, sub-optimal management and high health care costs.[25]

1.23 Cancer patients wanted greater coordination of care along the care continuum through a multidisciplinary approach and combined with better support mechanisms.

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[23] *It's not about the bike*, Lance Armstrong, Allen & Unwin, 2000, p.90.

[24] *Committee Hansard* 31.3.05, p 7 (Dr Fong, Department of Health WA).

[25] *Submission* 39, p 3 (NBCC).

Cancer patients told the Committee how they experienced feeling 'lost' in the current cancer treatment system which led to additional personal distress and many reported stumbling over information which should have been provided to them or readily available in a range of formats.

Support throughout the cancer journey

1.24 The impact of being diagnosed with and living with cancer was graphically described by many witnesses:

> Cancer affects every aspect of a person's being if they are touched by it. It affects the patient, friends and health professionals in their physical life, their emotional life, their mental life and their spiritual life.[26]
>
> You are in a constant spin. There is not one thing in your life that remains the same. It is a complete up-ending. I had to deal with psychological problems, practical problems.[27]

1.25 The Committee heard that people diagnosed with cancer want recognition that cancer is not just a physical disease but has an emotional and practical impact on them, their family and carers and that referral to support services should be standard practice from the beginning of their cancer journey. This impact on life was vividly described by one cancer patient:

> A diagnosis of cancer brings with it so many other practical problems and issues. Life on the home front had to go on. My marriage imploded, my children struggled to cope with the diagnosis. Coping with this whilst undergoing chemotherapy was a nightmare, but regular psychotherapy helped me to keep my head above water. Then there were the medical bills, we have top cover health insurance with Medibank but the gaps that I had to pay left, right and centre (especially for the psychotherapy as I soon used up my annual allowance) meant I could not pay my other bills.[28]

1.26 However, cancer patients told the Committee that access to support in many cases was not automatic, most stumbled across support groups and government assistance and most did not obtain the support they needed. One notable exception was in the case of breast cancer where the amount of information and support services was recognised and praised. Patients also wanted assistance to navigate their way through the health and hospital systems as for some it was their first time dealing with these areas. This aspect was described by the following witness:

> One day John was fit – he was riding his bicycle and running – and the next day he was in hospital with a brain tumour. I had never been in a hospital. If someone had given me a brochure saying what a registrar is and what an intern is, I would have known. I would have had a much better idea of how

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[26] *Committee Hansard* 18.4.05, p.53 (Dr Gawler).

[27] *Committee Hansard* 20.4.05, p.37 (Ms Vivian).

[28] *Submission* 21, p.2 (Ms Betsy Bush).

> the hospital system worked. It would have been brilliant. I just needed a map of the hospital on the very first day.[29]

Access to evidence-based quality care, including clinical trials, and a willingness by medical practitioners to discuss treatment options, including complementary therapies

1.27 Witnesses were unanimous in their call for treatment to be patient instead of disease focussed. Evidence indicated that cancer patients were voting with their feet to find practitioners who were willing to take the time to discuss treatment options, including the use of complementary therapies, so that they could make informed treatment choices. The following illustrates this view:

> Our experiences with the 'system' were characterised by…a complete unwillingness to discuss any potential action other than the medical treatment being provided by the specialists…[and] a failure to provide any advice that alternative sources of information existed – beyond the very limited, and medically oriented handouts from the hospital – and that this information might not only enhance the treatment, but make it more palatable.[30]

Parents of a cancer patient described their experience:

> We were not given options in respect of treatments. Medical conventions knew best. We were patronised at every point. No choices. We accepted that the radiotherapy and chemotherapy as presented was the only way to go. Our daughter was very keen to do something for herself, although told there was nothing that she could do.[31]

1.28 The Committee was advised that in comparison to overseas cancer centres such as Memorial Sloan-Kettering in New York, the number of cancer patients enrolled in clinical trials in Australia is very low and clinical audits are rare.[32] These issues are discussed further in chapter 5.

Greater and easier access to understandable and authoritative information, including complementary therapies, to assist patients with making informed treatment decisions and to enable dialogue with health professionals

1.29 Australians are becoming better informed about health issues thanks to greater access to medical and health information on the Internet and national preventative health campaigns. There is a growing trend for people wanting to take responsibility for their health and well-being. As a result, when a disease like cancer is diagnosed, many patients wish to be active participants in their treatment plans to feel a greater degree of influence and control. Cancer support organisations in Australia and

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[29] *Committee Hansard* 20.4.05, p.35 (Ms Paice).

[30] *Submission* 92, p.1 (Mr Bill and Ms Frances Parker).

[31] *Confidential Submission* 3, p.6.

[32] *Committee Hansard* 31.3.05, p.67 (Mr Deverall).

overseas support and promote the view that knowledge is power for cancer patients, as exemplified by the comments of Mr Ulman from the Lance Armstrong Foundation:

> We believe that in your battle with cancer knowledge and attitude is everything. We really strive to not only inspire but also empower those people with cancer so that they have the tools and information they need to live with a very high quality of life.[33]

1.30 Cancer patients are requesting more information in order to better understand treatment options and to be an active participant in decision making. Patients wish to engage in a dialogue with their medical practitioners and are seeking the information to do so. Witnesses told the Committee that they struggled to find authoritative information and more often than not just stumbled across information on the Internet and through talking to people.

> I had to constantly ask for information, and I still found out so much by accident and from other people making a comment.[34]

1.31 This call for greater information has resulted in publications such as the *Directory of Breast Cancer Treatment and Services for NSW Women* produced by the Breast Cancer Action Group NSW in association with the NSW Breast Cancer Institute.[35] However, the call for more information from cancer patients is relevant for all stages of the cancer journey.

Equitable access to care for rural and Indigenous Australians

1.32 The Committee heard evidence of inequalities in the health system for rural and Indigenous Australians. Mr Gregory from the National Rural Health Alliance referred to data that people in country areas who are diagnosed with cancer are 35 per cent more likely to die within five years than cancer sufferers in the city. Mr Gregory also provided alarming statistics for Indigenous Australians where evidence from the Northern Territory and South Australia shows that Aboriginal and Torres Strait Islanders with cancer are twice as likely to die from the disease as non-Indigenous people with the disease.[36]

The Call for Reform of Cancer Care in Australia

> Cancer services in Australia are in what are probably the early stages of a major paradigm shift. I think this shift in the approach to treating cancer has been fuelled primarily by the interest of the public and by their interest in the better outcomes that have been achieved in recent years. It is supported by a great deal of research…it is also being driven by progressive

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[33] *Committee Hansard* 12.5.05, p.1 (Mr Ulman).

[34] *Committee Hansard* 20.4.05, p.38 (Ms Vivian).

[35] *Directory of Breast Cancer Treatment and Services for New South Wales Women*, Breast Cancer Action Group NSW and NSW Breast Cancer Institute, 2002.

[36] *Committee Hansard* 20.4.05, p.49 (Mr Gregory).

> universities providing more graduate training and postgraduate training…and it is starting to show up in progressive hospitals.[37]

1.33 The consumer needs outlined above have been recognised and a number of recent reviews and publications by consumers, practitioners and cancer care providers have recommended the reform of cancer care in Australia. They acknowledge that some improvements are occurring but suggest that cancer care is now at a crossroads and that the next step to improve cancer treatment and services in Australia is the development of a national, evidence-driven approach, involving greater coordination of the cancer patient's journey and recognising the need for a consumer-focussed approach to cancer care.

1.34 These publications include: *Optimising Cancer Care in Australia*, produced by the Clinical Oncological Society of Australia, The Cancer Council Australia and the National Cancer Control Initiative. The key issue highlighted in the report is the failure of the health system to provide integrated cancer care.[38] Other reports, *Priorities for Action in Cancer Control 2001-2003* and the *National Cancer Prevention Policy 2004-06*, have identified priorities for new developments in cancer control and made recommendations on how Australia can enhance its achievements in cancer prevention. National Breast Cancer Centre publications, the *Report of the Radiation Oncology Inquiry, A Vision for Radiotherapy 2002* (the Baume Inquiry) as well as Cancer Council Reports and consumer forums have also called for reforms to the funding, operation and integration of cancer services.

1.35 Key aspects of the recommendations in these reports are that cancer care should focus on the patient not just the disease and that emotional and practical support should be included as standard components of care. They highlight the differences in the public and private systems and also identify inequalities in the system where cancer outcomes and services for regional and rural patients and particularly Aboriginal and Torres Strait Islanders are far from optimal and must be improved.

Conclusion

1.36 Australia can feel justifiably proud of its internationally recognised achievements in the areas of decreased mortality and increased survival for people with cancer. However, the increasing numbers of people being diagnosed with cancer and living longer with cancer will present further challenges to the delivery of optimal cancer care services in Australia. The increasing number of people being diagnosed with cancer will mean that there will be a need to ensure that resources for cancer treatment and support are organised efficiently and are directed to areas of most need to improve outcomes.

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[37] *Committee Hansard* 18.4.05, p.53 (Dr Gawler).

[38] *Optimising Cancer Care in Australia*, Clinical Oncological Society of Australia, The Cancer Council Australia and the National Cancer Control Initiative, 2003.

1.37 These future consumer needs are being recognised by cancer organisations, practitioners and care providers. Recent reports have called for reform of cancer care in Australia to develop a national, evidence-driven approach, involving greater coordination of the cancer patient's journey and recognising the need for a consumer-focussed approach to cancer care.

1.38 Based on the submissions and evidence presented during the inquiry the Committee was pleased to note that the areas of consumer need have been recognised by the Federal and most State and Territory Governments. Early steps are being taken to address the calls for reform with a focus on building national service frameworks at the Commonwealth level and implementation strategies at the State and Territory level, though some jurisdictions are more advanced than others. The different role and responsibilities of the Commonwealth and the States and Territories and the strategic framework that has been developed for the delivery of cancer treatment and services are discussed in chapter 2.

1.39 However, despite some achievements and advances in treatment, there remain inequalities and serious gaps in the system and not all Australians have access to best practice cancer care. This is true even in some outer metropolitan areas but particularly for rural and Indigenous Australians. Achieving improved equality in cancer treatment and services for rural and Indigenous Australians is a key challenge for the health system and is discussed in chapter 3.

1.40 The gaps in the system include lack of data relating to the incidence and treatment of Indigenous Australians; a poor record of clinical audit, especially in the private sector, including poorly organised hospital based cancer registries (in both public and private settings); poor access to psychosocial support and systemic rejection by conventional health professionals of complementary therapies or integrative medicine.

1.41 People diagnosed with cancer are becoming more active participants in their cancer treatment and are demanding greater coordination of care through multidisciplinary teams, access to authoritative information to assist them in making treatment decisions, assistance to navigate their way through the health care system and more emotional and practical support for them and their families and carers. These issues are discussed in more detail in chapter 3.

1.42 The Committee also heard evidence from hospitals, organisations and support groups who are challenging themselves to meet the needs of cancer patients using more innovative models of care, sometimes despite the health system surrounding them. These successful models, as well as the barriers to their further implementation, are also discussed in chapter 3.

1.43 The trend towards taking more responsibility for one's health is also evident in the increased use of complementary medicines and therapies. Chapter 4 discusses the issues of efficacy and safety and moving towards integrating the best of mainstream treatments with evidence-based complementary therapies. Integrative medicine and the use of complementary therapies as practiced overseas at leading cancer institutions and in Australia are also discussed in chapter 4.

1.44 The Committee acknowledges that improving cancer outcomes is a multifactorial field that extends far beyond the scope of this inquiry. While the Committee's investigations were necessarily focussed by the terms of reference, other specific issues relating to cancer treatment and care including early detection through screening, the special needs of adolescents, research and clinical trials, data collection and palliative care were also raised during the inquiry. These issues are considered in chapter 5.

1.45 The important aspects of cancer prevention or risk reduction, including ongoing public health programs addressing issues such as tobacco control, skin cancer and diet, were not part of this Inquiry but recognised by the Committee as highly relevant to Australia's health system.

Acknowledgments

1.46 The Committee is grateful for the many submissions received from institutions, professional associations, government and non-government organisations, support groups and particularly individuals. The patients, families and carers provided the Inquiry with extremely valuable information in submissions and at the hearings which enabled the Committee to better understand a patient's cancer journey and where improvements could be made.

1.47 The Committee recognised that cancer treatment and care is an area where there is enormous goodwill, outstanding dedication and where everyone involved is working towards the same goal to improve the cancer journey, eliminate the cancer lottery and achieve the best possible outcomes for cancer patients.

1.48 The Committee acknowledges the work already undertaken in the government and non-government sectors to develop strategic direction and a national framework for cancer care in Australia. The significant work and consultation undertaken to produce documents such as *Optimising Cancer Care* and the *National Service Improvement Framework for Cancer* has meant that the existing cancer care system has been the subject of recent review and that many areas for improvement have been identified and remedial action recommended. It is timely that these reports and plans for action be built upon by the Committee's report.

1.49 The timeframe for the Committee to inquire and report upon this very important subject was especially tight and the Committee acknowledges the assistance received from many individuals and organisations, but particularly from Mr Clive Deverall. The Committee also expresses its thanks to Professor D'Arcy Holman and Rachael Moorin, School of Population Health at the University of Western Australia, for their detailed response to issues and Briefing Paper that provided a valuable contribution to the Committee's deliberations.

Barb's story - Informing choice in her cancer journey

In the last days of December 1988, at the age of 30, I was taken to hospital with a very painful and bloated stomach and a fever that my GP could not get under control. The day after some exploratory surgery I was told by a young intern doing his ward rounds that I would need further treatment - chemotherapy or radiotherapy. That was the first information I was given post surgery. The doctor delivered the news, pulled the curtain back around my bed and disappeared on his rounds again. I was in shock. At no stage during my stay at the hospital or, indeed, afterwards was I offered any kind of counselling or given any acknowledgment that I might be upset or need help. I was diagnosed with adenocarcinoma of the peritoneal cavity…My surgeon and, subsequently, the initial oncologist I consulted told me that I had better do everything I wanted to do before next Christmas and that there was no treatment to be had that would help me. Wanting another opinion, I consulted another oncologist a few weeks later. This one told me that probably nothing would work but, if I liked, he could try some extremely aggressive chemotherapy that would make me very sick and that anything else I tried to do for myself - in particular, any changes I made to my diet - would be useless and a waste of time…

I had found a copy of Ian Gawler's book, You Can Conquer Cancer, and had read most of it. Everything he said in there made sense to me and, besides, I obviously had nothing to lose by taking on an approach in which I took an active and positive role in the recovery I hoped to make. I did not dismiss what the doctors had to say; I used it as a starting point and did heaps of research on my cancer and the exact types of chemotherapy drug treatments that had been tried in the past. I found yet another oncologist who was prepared to try the slightly unorthodox chemo that I had uncovered in my research… My doctor was sceptical but, with no other real options, he decided there was nothing to lose and he got on with it…I also enrolled in the Gawler Foundation's 10-day course at the Yarra Valley Living Centre. What I learned and how deeply I changed during those 10 days changed not only the length of my life - I am totally convinced of that - but also the quality of my life. In particular, I realised that there were things that I could do that could change not only the course of the disease but the quality of the journey along the way…

After the course, I had tonnes of information - and I knew how to go about finding tonnes more - about how to maximise my chances of healing through eating well. Although one of the first doctors I saw told me that fresh juices were a waste of time and that all that would happen was that my skin would turn orange from the carrots, which it did a bit, it just made total sense to me that every nutrient or toxin I put into my body would have some influence on my immune system and my outcome. I also grew to love and value my time out while meditating. Again, I am absolutely certain that it influenced my outcome.

Committee Hansard 18.4.05, pp.55-6 (Ms Barb Glaser).

CHAPTER 2

ROLE OF THE COMMONWEALTH AND STATE/TERRITORY GOVERNMENTS

2.1 This chapter provides a brief overview of the role of the Commonwealth Government and State and Territory Governments in the Australian health system. It provides details of cancer initiatives and strategies being undertaken by the Commonwealth, Cancer Institute New South Wales, the Victorian Department of Human Services and the Department of Health Western Australia. The chapter outlines the national framework within which issues raised during the Inquiry that affect government in relation to the delivery of cancer services, and which are discussed in the following chapters, are addressed.

The Australian Health Care System

2.2 The Australian health care system is complex with multiple levels of government and shared responsibility for health care.

Overview of health system funding

2.3 Australia's health system is financed by a mix of public and private funding arrangements. In 2002-03 a total of $72.2b, or 9.5 per cent of Gross Domestic Product, was spent on health. Of this:

- Public or government funding accounted for $49b, or 67.9 per cent;
  - Commonwealth Government - $33.4b (46.2 per cent);
  - State and Territory Governments - $15.6b (21.6 per cent); and
- Private sector financing was $23.2b, or 32.1 per cent.

Roles and responsibilities

2.4 The World Health Organisation has identified four key functions of health systems: resource generation; financing; service provision; and stewardship. These four functions underlie the organisation of the Australian health system, where both public and private sectors fund and provide health care and all levels of government are involved.

Commonwealth government

2.5 The Commonwealth government takes a leading role in the provision of universal and affordable access to medical, pharmaceutical and hospital services.

2.6 Through Medicare, the Commonwealth subsidises access to primary care providers, including medical practitioners, and to a range of specialist and diagnostic services. The Pharmaceutical Benefits Scheme provides subsidised access to pharmaceuticals. The Commonwealth also contributes funding to public hospitals through the Australian Health Care Agreements. The Commonwealth government's main role in the provision of care for older people includes financing and regulating residential aged care and community care. In addition to these roles, the Commonwealth provides leadership in broader social policy issues concerning an ageing population as well as the general population, including promoting the health, independence and wellbeing of all Australians.

2.7 The Commonwealth also takes a leadership role in areas of national policy significance, including protecting the overall health and safety of the population, improving access to health services for the Aboriginal and Torres Strait Islander population, guiding national research and evaluation, trialling innovative service delivery approaches and coordinating information management. In addition, the Commonwealth has various regulatory responsibilities carried out by bodies such as the Therapeutic Goods Administration and Food Standards Australia New Zealand.

State and Territory and local governments

2.8 States and Territories have primary responsibility under the constitution for the provision of health services, including most acute and psychiatric hospital services.

2.9 The State and Territory governments are the main providers of publicly provided health goods and services in Australia. They provide public hospital infrastructure and services, including in emergency department and outpatient settings, and are the major providers of community based health programs. Allied health services have traditionally been a State government responsibility and continue to be so, either through the public hospital system, or through State funded community health services. State and Territory governments also have primary responsibility for the provision of population health programs.

2.10 The local government sector also delivers health programs, often contributing a portion of funds through cash or 'in-kind' contributions.

Private Sector

2.11 Within the Australian health system, the private sector delivers a significant proportion of primary, specialist and allied health care through general practitioners, specialists, pharmacists, physiotherapists, dentists and the like. Access by individuals to private providers is often subsidised through Medicare or through private health insurance.

2.12 The private sector plays an important role in providing the infrastructure and health providers required to meet the increasing demand for health services. The private sector operates private hospitals and, through health funds, offers private health insurance.

Non-government sector

2.13 Non-government bodies play an important role within the Australian health care system in research, education, and programs for prevention, detection, diagnosis, treatment and associated policy. Of particular importance are the consumer and support groups, community organisations, professional bodies and educational institutions that provide a range of services alleviating the burden on the government sector.

Joint government policy forums

2.14 The different roles and responsibilities of the various levels of government have made it essential that there be ongoing cooperation between jurisdictions in the interests of the health and wellbeing of all Australians.

2.15 The Australian Health Ministers Conference and the Australian Health Ministers Advisory Council are the key coordinating bodies comprising Ministers and officials from the Commonwealth and State and Territory governments with responsibility for health matters. The Australian Health Ministers Conference provides a forum for governments to discuss matters of mutual interest concerning health policy, health services and programs and aims to promote a consistent and coordinated national approach to health policy development and implementation. The Australian Health Ministers Advisory Council advises the Australian Health Ministers Conference on strategic issues relating to the coordination of health services across the nation and operates as a national forum for planning, information sharing and innovation.

2.16 The Australian Health Ministers Advisory Council has established two groups to look at planning and reform issues in the areas of workforce and health reform.

Medical workforce

2.17 The Commonwealth undertakes to ensure that there is an adequate number of health professionals to meet population need now and into the future; that the health workforce is appropriately distributed to meet that need; and that suitable education and training arrangements are put in place for the health workforce. The health care workforce is a shared issue between the Commonwealth and the States and Territories.

2.18 The Australian Medical Workforce Advisory Committee (AMWAC) is an independent body set up at a national level in 1996 to promote strategic workforce planning and to provide advice on national medical workforce matters. In 2000, the Australian Health Workforce Advisory Committee (AHWAC) was founded to oversee wider workforce planning needs such as the nursing, midwifery and allied health workforces. Commonwealth and State and Territory health workforce policies are coordinated through these mechanisms.

Health Reform Agenda Working Group

2.19 The health system needs to be responsive to the changing needs of the population and the way that health services can be delivered. For a number of years, Health Ministers have recognised the need for substantial reform in the health system and have sought to progress reform through more effective use of available resources. In the 12 months before the end of the 1998-2003 Australian Health Care Agreements, Health Ministers agreed to pursue a substantive and cooperative reform agenda and appointed the Health Reform Agenda Working Group to manage this work.

2.20 One of the identified areas of reform was cancer care. A cancer funding reform project has subsequently been established under the auspices of the Health Reform Agenda Working Group to make recommendations, based on available evidence, about specific alternative funding arrangements and implementation options to improve access to coordinated, best practice cancer care. This project is being managed by a multi-jurisdictional group (led by the ACT Health).[1]

Coordination of cancer activities

2.21 Specific national bodies have been established by the Australian Health Ministers Advisory Council to coordinate information, advice and program implementation including the National Health Priority Action Council, which aims to drive improvements in National Health Priority Areas.

2.22 The National Health Priority Area conditions include cancer, diabetes, asthma, cardiovascular disease and stroke, and arthritis and musculoskeletal conditions. The National Health Priority Action Council comprises representatives from each jurisdiction, as well as a consumer representative and an Aboriginal and Torres Strait Islander representative.

2.23 Cancer became a National Health Priority Area condition in 1996. The Commonwealth and State and Territory governments work together on cancer through this National Health Priority Area initiative. Eight priority cancers have been identified by all jurisdictions where significant health gains may be made through prevention, early detection and evidence-based management. These are breast cancer, cervical cancer, bowel cancer, lung cancer, melanoma, non-Hodgkins lymphoma, non-melanocytic skin cancer and prostate cancer.[2]

Expenditure on cancer

2.24 The recent AIHW Report, *Health system expenditures on cancer and other neoplasms in Australia, 2000–01*, emphasises the massive expenditure on cancer by providing a systematic analysis of Australian health expenditure in 2001 to treat or

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[1] DoHA Submission to House of Representatives Standing Committee on Health and Ageing Inquiry into health funding, pp.4-14.

[2] *Priorities for Action in Cancer Control 2001-2003*, Cancer Strategies Group, 2001, pp.72-73.

prevent cancer and other neoplasms (an abnormal and uncontrolled growth of tissue; a tumour), and to care for those with neoplastic disease. The report shows that expenditure on cancer and other neoplasms in Australia in 2000-01 was $2.9billion. This is 5.8 per cent of the total health expenditure allocated by disease.

2.25 The expenditures for cancer and other neoplasms attributed to the seven health sectors were as follows:

- Hospitals - $1,988m;
- Out-of-hospital medical services - $343m;
- Research - $215m;
- Total pharmaceuticals - $183m;
- Aged care homes - $37m;
- Dental and other professional services - $24m; and
- Public health programs (non-Medicare Benefits Schedule) - $130m.

2.26 Total expenditure for cancer (malignant neoplasms) was $2.15b, for public health programs $130m, and for other neoplasms $634m, giving a total of $2.9b. Expenditure on treatment for cancer and other neoplasms was $2.6b representing around 90 per cent of total expenditure on cancer and other neoplasms.

2.27 The most expensive cancers overall were non-melanoma skin cancers, a less threatening form of skin cancer ($264m), followed by breast cancer ($241m), colorectal cancer ($235m), and prostate cancer ($201m). Non-melanoma skin cancer was easily the most common of all the cancers with 374 000 cases. These figures are consistent with the burden of disease across different tumour sites.[3]

National Service Improvement Framework for Cancer

2.28 In 2002, the Australian Health Ministers Advisory Council agreed to the development of National Service Improvement Frameworks for the National Health Priority Areas (cancer, diabetes, asthma, cardiovascular disease and stroke, and arthritis and musculoskeletal conditions) under the auspices of the National Health Priority Action Council.

2.29 The National Service Improvement Frameworks are joint initiatives of the Commonwealth and State and Territory governments and are an integral component of a proposed National Chronic Disease Strategy, being developed by the National Health Priority Action Council under the health reform agenda.

2.30 The National Service Improvement Framework for Cancer is the first developed and draws on existing international and national plans including the United

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[3] Health system expenditures on cancer and other neoplasms in Australia 2000-01, AIHW, May 2005, p.1.

Kingdom's National Cancer Plan and Australia's cancer plans and policies, notably those developed by State and Territory governments. It also draws on a number of other recent documents developed including *Optimising Cancer Care in Australia.*

2.31 The Cancer Framework is specifically designed to be ‘patient centred’ and provides clarity about what the evidence suggests about timely and effective care across the continuum (encompassing prevention, screening, detection, management, rehabilitation and palliation). It supports patients being treated with respect, dignity and autonomy, having access to care when it is needed, being involved in informed decision-making, including when and where health services require multidisciplinary input and coordination. It provides national consensus about aspects of care through focusing on critical service intervention points across the care continuum, which offer the greatest potential to improve health outcomes for patients.[4]

Strengthening Cancer Care

2.32 The Commonwealth Government recently announced the Strengthening Cancer Care Initiative. The Initiative has drawn from the *National Service Improvement Framework for Cancer* and is targeted at ensuring better coordination of the national cancer effort, more research funding for cancer care, enhanced cancer prevention and screening programs, and better support and treatment for those living with cancer.

Cancer Australia

2.33 A key element of the Strengthening Cancer initiative is the establishment of a national cancer agency, to be called Cancer Australia. The new agency will be accountable to the Federal Minister for Health and Ageing and 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.[5]

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[4] *Submission* 87, pp.8-9 (DoHA).

[5] DoHA Health Fact Sheet 1, Investing in Australia’s health: Strengthening Cancer Care, accessed at: http://www.health.gov.au/internet/budget/publishing.nsf/Content/health-budget2005-hbudget-hfact1.htm on 26 May 2005.

State and Territory Cancer Initiatives

2.34 State and Territory governments are developing and implementing a range of initiatives to improve cancer services and treatment. The initiatives include cancer plans, frameworks and monitoring mechanisms that are based on, and integrate with, the *National Service Improvement Framework for Cancer*.

2.35 The following examples of initiatives to address cancer treatment and care at the State level have been drawn from submissions and evidence provided by the Cancer Institute New South Wales, the Victorian Department of Human Services and the Department of Health Western Australia.[6] As these were the only jurisdictions that provided submissions, it is unclear if the approaches outlined in this evidence is representative of the other States or if the initiatives are transferable to other jurisdictions, given the different ways in which services are organised and resourced across Australia.

New South Wales - The Cancer Institute

2.36 The Cancer Institute New South Wales was established by the NSW Government in 2003. The Cancer Institute and the New South Wales Department of Health work collaboratively as the key agencies for cancer control in NSW. The objectives of the Cancer Institute are to:

- Improve cancer survival;
- Reduce cancer incidence;
- Improve the quality of life of cancer patients; and
- Provide expert advice to government, the public and key stakeholders.

2.37 The Cancer Institute has developed the *New South Wales Cancer Plan 2004-06*. The promotion and coordination of cancer control activities for better cancer outcomes has been identified as a key goal of the Cancer Plan which builds on other initiatives in cancer control including the *New South Wales Chronic Care Program* and the *Clinical Service Framework for Optimising Cancer Care in New South Wale*s. The Framework describes the optimal structure of care for a cancer service at an Area Health Service Level, to ensure equitable access to best practice care for all patients.

2.38 The Cancer Institute's major programs include:

- Clinical enhancements - cancer nurse coordinators; lead clinicians; psycho-oncology support and state wide cancer streams;
- A research program- research fellowships, Infrastructure and 'bench to the bedside' translational research grants;

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[6] *Submission* 53 and *Committee Hansard* 19.4.05, pp.47-56 (Cancer Institute NSW); *Submission* 66 and *Committee Hansard* 18.4.05, pp.1-13 (Victorian Department of Human Services); *Submission* 44 and *Committee Hansard* 31.3.05, pp.1-23 (Department of Health WA).

- Information program – clinical data analysis, standard treatment protocols; and
- Area Health Services – Cancer service streams.

2.39 A central philosophy of the *New South Wales Cancer Plan* is the patient-centred approach, which recognises the important role and views of consumers and patients in developing policy. It provides enhancement funding throughout New South Wales in clinical services, research, information and registries, prevention and screening and in cancer education.[7]

Victoria - Department of Human Services

2.40 The Victorian Government has made a major commitment to policy and service development in cancer control. The key cancer reform activities in Victoria include:

The development and implementation of the Cancer Services Framework

2.41 The *Cancer Services Framework* aims to ensure that the right treatment and support is provided to cancer patients as early as possible in their cancer journey. The integration of cancer service delivery is a major theme. The reforms are being delivered through:

- The establishment of Integrated Cancer Services that have been designed to support improvement in the integration and coordination of care within both metropolitan and regional areas; and
- The delivery of clinical treatment and care through ten major tumour streams that are designed to reduce variations in care and promote best practice.

2.42 The integrated service model involves three metropolitan and five regional Integrated Cancer Services based on geographic populations (Metropolitan Integrated Cancer Services and Regional Integrated Cancer Services). The philosophy of an Integrated Cancer Service is that hospitals, primary care and community health services will develop integrated care and defined referral pathways for the populations they serve.

2.43 Delivery of clinical treatment and care through major tumour streams has been established to reduce variations in care and to promote best practice.

The Fighting Cancer policy

2.44 The *Fighting Cancer policy* identifies a number of areas to improve cancer services including the upgrading and expansion of radiotherapy equipment, enhancement of screening and prevention programs, and training and recruitment incentives for radiation therapists.

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[7] *Submission* 53, p.2 (Cancer Institute NSW).

The Ministerial Taskforce for Cancer

2.45 The Taskforce was established in November 2003 to provide strategic advice and clinical leadership on the implementation of cancer reforms. It provides advice to the Victorian Minister for Health on the implementation and evaluation of Government directions for cancer services reform.

Establishment of Cancer Coordination Unit

2.46 The Cancer Coordination Unit has been established to oversee the implementation of the Victorian Government's Fighting Cancer policy and to coordinate the cancer service reform agenda including the implementation of the *Cancer Services Framework*. The unit has particular responsibility for policy commitments around improving the coordination of cancer services. It also supports the Ministerial Taskforce and associated working groups.[8]

Western Australia - Department of Health

2.47 The Department of Health Western Australia established a Health Reform Committee to examine cancer service delivery in Western Australia. *The Review of Cancer Services* report was finalised in October 2003. In response to the report, a Health Reform Implementation Taskforce was established.

2.48 To implement the cancer service recommendations, the Western Australian Cancer Services Taskforce was established in January 2005 to formulate a comprehensive state-wide framework for cancer services to ensure an integrated approach to cancer care and delivery. The Taskforce consists of clinical experts in cancer care and community representatives.

2.49 The cancer services framework will cover the continuum of cancer care as well as cancer research, education, training and workforce development, patient information and genetic counselling and the private hospital/service interface. The work of the Taskforce is due for completion in mid 2005.[9]

2.50 Dr Neale Fong, Acting Director-General, Department of Health WA advised the Committee that 'The Western Australian health system is undergoing some radical reforms and will be the centre of a lot of activity in reforming both health service delivery and health planning over the coming few years'.[10] Professor Christobel Saunders, Chair of the WA Cancer Services Taskforce told the Committee that by June the Taskforce will have developed a framework for cancer services in WA and an implementation plan. This will include the appointment of a Director of cancer services, who will further develop the plan and implement it. Professor Saunders said

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[8] *Submission* 66, pp.1-6 (Victorian Department of Human Services).

[9] *Submission* 44, pp.1-2 (Department of Health WA).

[10] *Committee Hansard* 31.3.05, p.1 (Dr Fong).

they intend to develop referral guidelines, tumour networks which will cover the whole State and collect data to conduct audits. The implementation plan will also involve accreditation of services and credentialing of practitioners.[11]

Conclusion

2.51 Australia has one of the best systems of cancer care in the world. The Committee noted that the Australian health care system is however complex with multiple levels of government and shared responsibility for health care.

2.52 Efforts to coordinate Commonwealth and State and Territory cancer activities occur through the National Health Priority Area initiative. Cancer was identified as a National Health Priority in 1996 and a National Service Improvement Framework for Cancer has been developed jointly between the Commonwealth and the States and Territories.

2.53 The Committee also notes that the establishment of Cancer Australia will provide a valuable national leadership role in cancer control.

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[11] *Committee Hansard* 31.3.05, p.3 (Professor Saunders).

CHAPTER 3

IMPROVING CANCER CARE IN AUSTRALIA

> Australia's record in treating cancer is among the world's best and age-adjusted mortality rates have steadily declined over the past two decades. However, this statistical success is little consolation to the thousands of Australians diagnosed with cancer every week. The news is usually devastating and bewildering, starting a journey into a complex world of advice, therapies and services, compounded by changes in emotional well being, relationships, work and plans for the future.[1]

3.1 This chapter provides an overview of cancer treatment services in Australia, paying particular attention to recognised best practice models of care. It also examines current barriers to the implementation of best practice and makes recommendations to address them.

3.2 In terms of cancer management there are two distinct models of cancer care in Australia. Firstly, the traditional model, where a general practitioner refers a patient to a specialist, usually a surgeon, who conducts the primary intervention and then refers the patient on to other cancer specialists. Secondly, the multidisciplinary model that describes an integrated team approach by all healthcare professionals involved in the patient's care.

Traditional care model

3.3 In the traditional model, a general practitioner refers a patient to a specialist, usually a surgeon, who may remove a tumour and/or refer the patient to a medical oncologist or a radiotherapist. Patients may then see specialists in an ad hoc way (depending on the level of involvement and coordination provided via the GP or surgeon) for opinions and treatment.[2]

Referral issues

> I feel extremely concerned that patients' outcomes often are not optimal because they are not referred to the right person.[3]

3.4 Witnesses likened the traditional model of care to a 'cancer lottery'. There was confusion right from the time of diagnosis with the referral process mentioned as a major concern due to ad hoc processes and a lack of information for the medical practitioner and the patient. A number of cancer patients told the Committee that the

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[1] *Submission* 65, p.3 (COSA, CCA, NCCI and NACCHO).

[2] *Optimising Cancer Care in Australia*, COSA, CCA and NCCI, February 2003, p.xi; *Submission* 65, p.7.

[3] *Committee Hansard* 31.3.05, p.14 (Professor Saunders).

matter of finding a specialist to suit them was pure luck. One witness told the Committee:

> How do we find out who is a good person to go to? We were lucky – we had this contact.[4]

Another stated:

> It was a serendipitous connection…I had a private medical connection of my own – my mother's partner is friends with a paediatric surgeon who knew the people in Sydney. She sent a list of the five best neurosurgeons in Australia. It was only through those means, which the general public would not have access to that I was given a list of the people who I should be seeing and I was able to find what I would call the best surgeon for me in Australia.[5]

3.5 Information at the time of diagnosis and referral is particularly important. Evidence is available to show that referring patients to doctors who treat high volumes of particular cancers improves survival. A study undertaken in Western Australia looked at women with invasive breast cancer managed by surgeons with a high breast cancer caseload compared with women who are managed by surgeons who treat breast cancer less frequently. The study found the women treated by high caseload surgeons had better outcomes with a reduction in mortality of 30 percent.[6] The National Health and Medical Research Council (NHMRC) *Clinical Practice Guidelines for the Management of Early Breast Cancer* recommends that women with breast cancer should be treated by specialists who have a demonstrated expertise in breast cancer. Although the *National Service Improvement Framework for Cancer* notes that 'the evidence about caseload, care provision and outcomes in the treatment of cancer in Australia is somewhat inconsistent', it also notes that 'there are opportunities to significantly improve referral pathways by providing information to primary care providers and to people with cancer about cancer services'.[7] For a lot of diseases and particularly the less common ones, GPs do not necessarily know who to refer patients to or they refer to people they have known for a long time and to whom they have historical referral patterns.[8]

3.6 Cancer patients are increasingly demanding more information at the diagnosis and referral stage to enable them to make an informed decision regarding their choice of specialist. As stated by a representative of Breast Cancer Network Australia:

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[4] *Committee Hansard* 20.4.05, p.31 (Mrs Paice).

[5] *Committee Hansard* 20.4.05, p.33 (Mr Pitt).

[6] Ingram, D.M, McEvoy, S.P, Byrne, M.J, Fritschi, L, Joseph, D.J and Jamrozik, K, Surgical caseload and outcomes for women with invasive breast cancer treated in Western Australia, *The Breast*, 2005; 14, 11-17.

[7] *National Service Improvement Framework for Cancer*, National Health Priority Action Council, March 2004, p.36 and p.32.

[8] *Committee Hansard* 31.3.05, p.14 (Professor Saunders).

> Breast cancer consumers want to know whether or not their clinician and their cancer service are practicing best practice. They want to know if they follow the guidelines. They want to know if they are going to be treated in a multidisciplinary team and have access to psychosocial services. This is a real issue for women; they want information.[9]

3.7 The *Directory of Breast Cancer Treatment and Services for NSW Women*, referred to in chapter 1, is an example of how meeting the need for greater information at the time of diagnosis can be successfully met. This Directory is designed to help women, through their GPs, to find the treatment and other breast cancer services which are most appropriate for their needs.

3.8 The Committee received very positive feedback about the Directory and regards it is an important resource which can serve as a model to develop other directories. The Committee considers that the development of a national directory of cancer treatment and services is a vital first step to providing more authoritative and useful information to medical practitioners and cancer patients at the time of diagnosis and referral.

Recommendation 1

3.9 The Committee recommends that Cancer Australia, in association with consumer based organisations such as Cancer Voices NSW and the Breast Cancer Action Group in Victoria, coordinate the development of information about cancer treatment services in each State and Territory. This information would be based on the successful breast cancer treatment directory developed by the Breast Cancer Action Group in NSW, published in 2002, which is also available on the Internet.

3.10 Another way to address the 'cancer lottery' issue and provide more information at the time of diagnosis and referral is to develop preferred referral guidelines for particular tumours. This would provide GPs with the information to know who best to refer patients to and patients would feel reassured that they would be getting the best care.

3.11 *The National Service Improvement Framework for Cancer* supports defined referral pathways between diagnostic and treatment services.[10] Some cancers, such as those affecting the breast, head and neck and advanced gynaecological malignancies, have organised referral pathways in most States. Clinical Oncology Groups, associated with the State cancer councils, have facilitated their introduction in association with specialist colleges. However, there are exceptions and the majority of cancers do not have clear referral pathways, which is not in the best interests of patients. Defined referral pathways are particularly important to assist cancer patients in rural areas.

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[9] *Committee Hansard* 18.4.05, p.43 (Ms Timbs).

[10] *National Service Improvement Framework for Cancer*, p.32.

3.12 The Committee noted that work is being undertaken in NSW and Victoria to develop referral guidelines and processes so GPs and cancer patients can quickly find the best specialist cancer services to treat their condition. The Committee considers that this work is vital to ensure that people are referred to high quality treatment services in a timely manner.

Recommendation 2

3.13 The Committee recommends that Cancer Australia, in conjunction with State and Territory Governments, develop appropriate referral pathways for the optimal management of all cancers for all Australians regardless of where they live.

Accreditation of cancer services and credentialing of practitioners

3.14 It is important that the referral pathways be linked to services which are accredited and physicians who have appropriate credentials. The move towards accreditation has been assisted by the vigour of the National Breast Cancer Centre (NBCC), the Australian Cancer Network (ACN) and The Cancer Council Australia (TCCA). In 2004, a scoping study of current international and Australian cancer service accreditation systems and processes was commissioned, with a view to developing a discussion paper identifying common themes, principles, criteria and processes that may inform an Australian model of accreditation for cancer services. *A core strategy for cancer care: Accreditation of cancer services – a discussion paper* was released in February 2005. The discussion paper defines accreditation as 'a process of external peer review of an organisation's processes and performance using defined standards with the aim of quality improvement'.[11]

3.15 The move towards accreditation of cancer treatment services was endorsed in evidence. It was pointed out to the Committee that accreditation already occurs in the USA and Professor Coates expressed the view that it will inevitably come about in Australia as a result of consumer advocacy and demand.[12]

3.16 Professor Elwood, Director of the National Cancer Control Initiative told the Committee that he thought there would be 'wide acceptance within the profession of an accreditation system if it was well constructed, if it was responsive and if it was open and transparent'.[13]

3.17 The Committee noted the difference between accreditation of services or clinics that met certain standards and the credentialing of individual specialists be they a surgeon with a special interest in breast cancer or cancer of the head and neck, or a medical oncologist or radiotherapist.

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[11] *A core strategy for cancer care: Accreditation of cancer services – a discussion paper*, TCCA, ACN and NBCC, 2005, p.13.

[12] *Committee Hansard* 19.4.05, pp.17-18 (Professor Coates).

[13] *Committee Hansard* 19.4.05, p.8 (Professor Elwood).

> Credentialing is vitally important because the GPs need to know who they are referring to and the patient, above all, should feel some degree of comfort as to where they are being sent.[14]

3.18 Credentialing can be defined as 'the formal process used by health care organisations to verify and evaluate the qualifications and experience of a health care professional prior to appointment, reappointment and at other times as required by the organisation, for the purposes of forming an opinion about the health care professional's training, skills, experience and competence'.[15] Credentialing of individual practitioners would involve providing data on outcomes such as the volume of patients they treat, side effects and recurrence rates. Ms Swinburne stated that there is quite a lot of resistance among some members of the College of Surgeons to make such data public.[16] This view was supported by Mr Deverall:

> On credentialing: whereas you accredit a centre or clinic, credentialing is for the individual. The colleges do not like this. Their members do not like it. They do not want to have their names in a guidebook, like Cancer Voices NSW did for breast cancer. They prefer the status quo.[17]

3.19 However, Ms Marine from the Medical Oncology Group indicated that her organisation has been supportive of a general move towards credentialing. The National Breast Cancer Audit was referred to as an example of progress by the Breast Cancer Network Australia.[18] The audit has been endorsed by the Royal Australasian College of Surgeons and the Section of Breast Surgery as an appropriate means of assessing early breast cancer. Through the audit, surgeons are able to review their results against national aggregated results for certain indicators.[19]

3.20 Accreditation and credentialing needs to be driven at the national level, with witnesses suggesting that Cancer Australia would be the appropriate organisation to drive this change and provide standards and guidance.[20]

3.21 The Committee notes that credentialing is likely to take more time to develop and implement than the accreditation system although both are essential if cancer services in the public and private sectors are to be better organised and improved in the best interests of patients.

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[14] *Committee Hansard* 31.3.05, p.69 (Mr Deverall).

[15] Australian Federation of Medical Women *Reply to Issues Paper on Credentials and Clinical Privileges* accessed at http://www.afmw.org.au/pubs/pub40_ccp.htm on 9.6.05.

[16] *Committee Hansard* 18.4.05, p.45 (Ms Swinburne).

[17] *Committee Hansard* 31.3.05, p.69 (Mr Deverall).

[18] *Committee Hansard* 18.4.05, pp.43-44 (Ms Timbs).

[19] Information accessed at http://www.surgeons.org/asernip-s/auditBreast.htm on 8 6.05.

[20] *Committee Hansard* 31.3.05, p.8 (Professor Saunders).

3.22 Accreditation and credentialing are critically important in the development of sustained, high-quality multidisciplinary treatment and support for patients. The issue now remains as to how quickly and efficiently accreditation of cancer treatment services and credentialing of practitioners can be introduced. The Committee was disappointed that none of the medical colleges provided a submission to the inquiry as they must be the gatekeepers to the successful and speedy introduction of both accreditation and credentialing.

Recommendation 3

3.23 The Committee recommends that, Cancer Australia, together with the Clinical Oncological Society of Australia and the Cancer Council of Australia develop and introduce accreditation and credentialing systems.

Fragmentation of care

3.24 Cancer patients experiencing the traditional model of cancer care felt their care was fragmented as they were passed from specialist to specialist with no clear pathway of care. They reported feeling abandoned:

> We were essentially abandoned right at the jump, after the big operation.[21]
>
> After I had the medical treatment, the process called, I think, 'a feeling of abandonment' happened to me.[22]

3.25 The Department of Health WA indicated that there is a lack of a coordinated integrated network of cancer services in Western Australia.[23] Professor Bishop, CEO, Cancer Institute NSW added that there should be a more integrated and coordinated approach between primary practitioners and cancer centres.[24] Likewise, the Victorian Department of Human Services identified that:

> Clear referral pathways and role designation of services to outline appropriate levels of specialisation for the delivery of cancer services will improve awareness and choice for patients, and will ensure that patients have access to the highest quality care.[25]

3.26 The establishment of integrated and networked cancer services to improve continuity of care is also a key priority action of the *National Service Improvement Framework for Cancer.*

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[21] *Committee Hansard* 20.4.05, p.28 (Mr Argall).

[22] *Committee Hansard* 20.4.05, p.29. (Mr Pitt).

[23] *Submission* 44 p.8 (Department of Health WA).

[24] *Committee Hansard* 19.4.05, p.48 (Professor Bishop).

[25] *Submission* 66, p.2 (Victorian Department of Human Services).

3.27 In response to the perceived fragmentation, New South Wales, Victoria and Western Australia have established initiatives to improve the integration and coordination of cancer services.

3.28 The New South Wales Department of Health's *Clinical Service Framework for Optimising Cancer Care in NSW* and the *New South Wales Cancer Plan* address these issues by ensuring equitable access to best practice care for all patients and the promotion and coordination of cancer control activities. Better integration between general practice and cancer treatment centres is also being fostered by a General Practice liaison program between the New South Wales Divisions of General Practice and the Cancer Institute New South Wales.[26]

3.29 The Victorian Department of Human Services *Cancer Services Framework* has the integration of cancer service delivery as a major theme. Improved integration of care is being delivered through the establishment of Integrated Cancer Services and the delivery of clinical treatment and care through ten major tumour streams that are designed to reduce variations in care and promote best practice.[27]

3.30 The Western Australian Government has established a Taskforce to formulate a comprehensive state-wide framework for cancer services that will ensure an integrated approach to cancer care and service delivery.[28]

3.31 The Cancer Institute New South Wales also suggested that, when established, Cancer Australia could offer an opportunity for improved coordination between Commonwealth and State and Territory based cancer control initiatives.[29] The Committee considers that the establishment of Cancer Australia will provide an excellent opportunity for the improved integration and coordination of activities between jurisdictions as well as the wider range of non-government bodies with an interest in cancer.

Recommendation 4

3.32 The Committee recommends that Cancer Australia in its role of providing national leadership and to foster improvements in the integration of networked cancer services, play a primary role in facilitating the sharing of information about Commonwealth and State and Territory Government cancer initiatives to improve treatment services.

3.33 In contrast to the traditional model of care, cancer patients experiencing some form of multidisciplinary care reported greater satisfaction with services, less personal distress and improved outcomes.

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[26] *Submission* 53, p.4 (Cancer Institute NSW) and *NSW Cancer Plan 2004-06*, pp.22, 37.

[27] *Submission* 66, p.2 (Victorian Department of Human Services).

[28] *Submission* 44, pp.1-2 (Department of Health WA).

[29] *Submission* 53, p.22 (Cancer Institute NSW).

> I had such a good medical team, they were my support. They were at the other end of the phone, even my specialist. My strategy was relying on them. Because you're having a whole team opinion you know you're taking the right course don't you?[30]

Multidisciplinary Care

> Overseas studies have shown that survival improves and best practice is followed, when treatment is provided by experts working together as a team. This team approach to care is often referred to as multidisciplinary care as it includes a wide range of health professionals. The treatment options are considered by the whole team of specialists with all the relevant expertise present. The result is better organisation and delivery of essential cancer treatment, with fewer delays and improved pathways of care.[31]

3.34 As stated by Dr Page, 'cancer is perhaps unique in that it does usually require a whole range of different services. It requires not just surgical services but also chemotherapy, radiotherapy, psychological services, the network of family and palliative care'.[32] In multidisciplinary care (MDC), team members agree on a precise diagnosis and staging of the disease, the best treatment option for the patient and the development of a treatment plan. The patient and the team communicate closely, enabling the patient to make decisions about treatment and care on the basis of the team's comprehensive advice. Communication and the provision of care are managed by a designated care coordinator or the most appropriate specialist member of the team.[33]

> The benefits of multidisciplinary care in the management of cancer have been demonstrated in a number of studies both in Australia and overseas. There is evidence that decisions made by a multidisciplinary team are more likely to be in accord with evidence-based guidelines than those made by individual clinicians. Patient satisfaction with treatment and the mental well-being of clinicians has been shown to be improved by a multidisciplinary approach to care.[34]

Definitional Issues

3.35 Multidisciplinary care is now regarded as a basic requirement for the delivery of cancer services. However, it was clear from the evidence provided to the inquiry that there are differences in the use of this term nationally and internationally. Some witnesses who were cancer specialists saw it, exclusively, as a medical model encompassing only surgeons, radiographers, oncologists and pathologists and such.

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[30] *Submission* 71, p.6 (Breast Cancer Action Group quoting Gail who was diagnosed in July 2001).

[31] *Submission* 87, p.3 (DoHA).

[32] *Committee Hansard* 19.4.05, p.82 (Dr Page).

[33] *Submission* 65, p.7 (COSA, CCA, NCCI and NACCHO).

[34] *Submission* 39, p.2 (NBBC).

Consumers, on the other hand felt it was critical that psychosocial support was included in any setting where multidisciplinary treatment was provided. Other witnesses believed a multidisciplinary team should include people such as dieticians and complementary therapists and, most importantly, the patient. However, in submissions and at hearings, it was clear there was universal support for multidisciplinary care as an approach, regardless of who was included in the team.

3.36 The Chief Medical Officer described a multidisciplinary team as 'the surgeon, the medical oncologist, the radiotherapists, nursing staff, dietician and so on. It is a very large group of people with the patient at the centre.'[35]

3.37 Professor Zalcberg from the Peter MacCallum Cancer Centre, where multidisciplinary care is practiced, defined it as:

> A multidisciplinary approach is the bringing together of the relevant disciplines that can address the goals of treatment for that stage of the disease…That is what we try and do at Peter Mac in terms of bringing the expertise together around the table when patients are being discussed.[36]

3.38 The Committee accepted that sustained multidisciplinary treatment is an integrated team approach including surgeons, oncologists, pathologists, radiologists, physiotherapists, occupational therapists, psychologists and/or others including social workers to provide ongoing psychosocial support if requested by a patient. It may also include practitioners in non-medical disciplines. The Committee acknowledged advice that the composition of a treatment team may alter according to the medical and social needs of a patient at any one time.

The situation overseas

> Multidisciplinary care is now an accepted standard for best practice in the delivery of cancer care internationally.[37]

3.39 In the USA and more recently in the UK, multidisciplinary care is the recommended approach for most or all cancers. Some level of MDC is required by the US Cancer Center's accreditation system and by the UK Cancer Plan.[38] It is incorporated in the UK Manual of Cancer Service Standards 2004[39] and features in the Canadian[40] and USA strategies for cancer control.[41]

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[35] *Committee Hansard* 20.4.05, p.91 (Professor Horvath).

[36] *Committee Hansard* 18.4.05, p.27 (Professor Zalcberg).

[37] *Submission* 36, p.1 (Peter MacCallum Cancer Centre).

[38] *Optimising Cancer Care in Australia*, COSA, TCCA and NCCI, February 2003, p.xii.

[39] Manual for Cancer Services 2004, accessed on 5 May 2005 at http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4090081&chk=hq28gu.

[40] *Canadian Strategy for Cancer Contro,* accessed at www.cancercontrol.org, on 5 May 2005.

[41] *Ensuring Quality Cancer Care*, accessed at http://www.iom.edu/report, on 5 May 2005.

The situation in Australia

3.40 The Committee received conflicting reports regarding how multidisciplinary care is currently delivered in Australia. The Committee heard that some doctors thought they were already providing multidisciplinary care by discussing a case in the corridor with a colleague.[42] Even treatment at a larger centre does not necessarily mean the care is multidisciplinary.

> The fundamental flaw in the current approach is that it is dominated by the particular perspectives of the medical specialities. In this context 'multidisciplinary' refers only to small teams of closely related medical personnel…[43]

3.41 Professor Holman commented in his report to the Committee that it is difficult to know at a population level how typical a multidisciplinary approach is. The exception is breast cancer where the NBCC undertook a National Survey of Coordinated Care in Breast Cancer in 2004 and found MDC meetings were conducted on new cases of breast cancer in 86 per cent of cases in high-caseload hospitals, 62 per cent in medium-load hospitals and 17 per cent in low-load hospitals. Professor Holman reported that the 'literature suggests that MDC for cancer patients is practiced most frequently where there is a high degree of centralisation of cancer services in tertiary hospitals. This applies in particular to treatment services for children's cancers, gynaecological cancers and cancers of the head and neck'. The Professor concluded that 'at this time, most public tertiary hospitals in Australia's capital cities support a range of multidisciplinary cancer care teams'.[44]

3.42 Multidisciplinary care is recommended in clinical practice guidelines approved by the NHMRC. It has been recognised by the Commonwealth government as part of the National Service Improvement Framework for Cancer and is supported by the Australian Labor Party.

National Breast Cancer Centre leading the way in multidisciplinary care

3.43 The most advanced models of multidisciplinary care in Australia are in breast cancer and children's cancer. The 1994 House of Representatives Report on the Management and Treatment of Breast Cancer recommended MDC as a means of achieving best practice in the management of breast cancer. The National Breast Cancer Centre was established in 1995 and has been leading the way in the treatment of breast cancer and in providing a model for the management of other cancers.

3.44 The question that follows is to what extent can the evidence of improved outcomes for breast cancer when using MDC be generalised to the treatment of other cancers? Professor Holman addressed this issue commenting that:

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[42] *Committee Hansard* 31.3.05, p.66 (Mr Deverall).

[43] *Submission* 92, p.4 (Mr CW and Ms F Parker).

[44] Professor D'Arcy Holman, Commissioned Report, p.4.

> In fact, to the limited extent that we understand how MDC exerts its beneficial effect on breast cancer outcomes, the postulated mechanisms are of a generic nature, concerning issues in the organisation and delivery of health care and the patient's holistic well being rather than any specific aspect of the nature of the disease. This leads me to the conclusion that generalisation of the evidence on breast cancer to other cancers treated by a range of interventions is defensible.[45]

The development of multidisciplinary care in Australia

3.45 To further the development of MDC in Australia, the NBCC was commissioned by the Department of Health and Ageing to establish a *National Multidisciplinary Care Demonstration Project* for breast cancer in Australia. For the purposes of the project, the NBCC defined MDC as:

> An integrated team approach to health care in which medical and allied health care professionals consider all relevant treatment options and develop collaboratively an individual treatment plan for each patient.[46]

3.46 The project was designed to provide information about the impact, cost and acceptability of implementing MDC for women with breast cancer and to obtain information about MDC that would be applicable to other cancers and other chronic diseases and provide recommendations about the implementation of MDC. The project found that MDC improved supportive care, improved communication between clinicians and provided clinicians with greater emotional and intellectual support. The participating clinicians also reported that the multidisciplinary strategies were worthwhile and had improved the care of women with breast cancer.[47]

3.47 The project recommended the following principles to underpin a flexible approach to MDC:

- A team approach, involving core disciplines integral to the provision of good care, with input from other specialities as required;
- Communication among team members regarding treatment planning;
- Access to the full therapeutic range for all women regardless of geographical remoteness or size of institution;
- Provision of care in accord with nationally agreed standards; and
- Involvement of the women in decisions about their care.[48]

3.48 The NBCC undertook a follow up study to the *National Multidisciplinary Care Demonstration Project*, with the *Sustainability of Multidisciplinary Cancer Care*

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[45] Professor D'Arcy Holman, Commissioned Report, p.4.

[46] *National Multidisciplinary Care Demonstration Project*, NBCC, p.2.

[47] *National Multidisciplinary Care Demonstration Project*, NBCC, pp.18-28.

[48] *National Multidisciplinary Care Demonstration Project*, NBCC, p.5.

Study being published in January 2005. This study explored the sustainability of changes resulting from strategies implemented during the National Multidisciplinary Care Demonstration Project and locally relevant strategies to implement or improve the provision of MDC for women with breast cancer were trialled. They found that the majority of changes resulting from strategies implemented during the demonstration project were sustained in the three multi-site collaborations of health care services located in different States.[49]

3.49 The Committee understands that the NBCC will shortly release a practical guide to assist health service providers in setting up and running multidisciplinary treatment planning meetings. A series of State and Territory based forums to promote the uptake of multidisciplinary cancer care is also being planned.[50]

3.50 The Committee commends this work undertaken by the NBCC as a vital step to increase the practice of multidisciplinary care in Australia.

Palliative Care

3.51 Palliative care is another important part of multidisciplinary treatment. It was raised in submissions as an area in need of further investigation. Although issues relating to palliative care are much broader than this inquiry, a brief summary of the issues raised in evidence is provided in chapter 5.

Conclusion

3.52 The Committee was disturbed to receive evidence which clearly described fragmentation of services, a lack of coordinated care and a lack of application of standard best practice management. The Committee acknowledges that multidisciplinary care is recognised as a key element of best practice in the treatment of cancer and wishes to see it facilitated by the health care system. The Committee notes that there is little data available on the costing of multidisciplinary care as yet, though in terms of improved cancer outcomes the development of models should be actively pursued.

Barriers to implementing multidisciplinary care

3.53 The Committee recognised that MDC for all cancers is an important objective for Australian health services and that structural change will be required to ensure that multidisciplinary care and the practitioners providing it are supported by the health system.

3.54 Barriers to the implementation of MDC raised in submissions and by witnesses included the attitudes and resistance to change of medical practitioners; funding models; the Medical Benefits Scheme and differences in the private and

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[49] *Sustainability of Multidisciplinary Cancer Care Study,* NBCC, January 2005, p.vi.

[50] *Submission* 39, p.2 (NBCC).

public systems; lack of time, resources and clinical staff; and the challenge of covering large geographical areas and the Indigenous population.

A question of patient ownership

3.55 The issue of 'patient ownership' was raised as a barrier to multidisciplinary care as cancer patients become the 'property' of an individual consultant once referred or admitted to hospital. This practice often meant that the patient was not treated by a team as required with standardised multidisciplinary care and did not have the benefit of input from other cancer specialists. It was reported as being more common in the private sector where private hospitals have no full time medical teams backing up the individual consultants, though it could also occur in a public hospital, especially when an individual was admitted as a private patient.[51]

Resistance to change

> Having sat with cancer patients consulting their oncologists I witnessed questions like 'well what else can be done if I'm terminal like you say?' being told 'nothing' and when probed on complementary/alternative (CAM) treatments received off hand dismissal or being told that 'you can but why waste your money! One oncologist just rolled his eyes upward in dismissal…
>
> So what we have here is a deliberate barrier being put up to deter cancer patients from details of all known evidence-based cancer treatments. This very narrow focus on patient treatment must be removed as a matter of urgency if medical costs are to come down and survival rates improved i.e. GP's, Oncologists and the Public made fully aware of all the treatments already available and their efficacy.[52]

3.56 The resistance to change of some medical professionals was seen as a generational issue with greater acceptance occurring among younger practitioners. The *National Multidisciplinary Care Demonstration Project* experienced initial resistance to change from some clinicians but this was overcome as participants experienced the benefits of improving care for patients and enhancing communication between those involved in providing that care (reported by 88 per cent). Clinicians also reported a sense of reassurance in being able to discuss complex cases with the team.[53]

3.57 To facilitate change in these areas, clinical practice guidelines for cancer have been developed primarily by the Australian Cancer Network, supported by the Australian Cancer Society, the National Cancer Control Initiative and the National Breast Cancer Centre and many other speciality and community groups. The NHMRC has assessed and endorsed these guidelines, which are evidence-based, and were

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[51] *Committee Hansard* 31.3.05, p.67 (Mr Deverall).

[52] *Submission* 94 (Mr Cope).

[53] *National Multidisciplinary Care Demonstration Project*, NBCC, pp.23-27.

developed in many cases by multidisciplinary teams. They recommend the use of multidisciplinary care to improve patient outcomes and are designed for use by all health professionals who come into contact with people during the course of their cancer journey.

3.58 Guidelines endorsed by the NHMRC are currently available for most of the priority cancers and include:

- Early Breast Cancer;
- Advanced breast cancer;
- Skin cancer and melanoma;
- Non-melanoma skin cancer;
- Bowel cancer;
- Prostate cancer;
- Familial aspects of cancer;
- Lung cancer;
- Ovarian cancer; and
- Guidelines for the psychosocial care of people with cancer.[54]

3.59 Witnesses suggested to the Committee that the guidelines should be adopted nationally. Mr Davies, DoHA, noted that there were no incentives to follow the guidelines and no sanctions for failing to do so. Professor Horvath, CMO, added that 'certainly the colleges, most importantly the college of surgeons, have been very forthcoming in encouraging their fellows, as do hospital quality committees. Guidelines tend to come into practice by professional pressure of a multidisciplinary sort rather than by carrot or caveat'.[55]

3.60 The Committee agrees that the NHMRC clinical practice guidelines should be used nationally to provide support for health professionals to deliver best practice care and to better inform cancer patients. To facilitate this, the Committee recommends including the use of clinical guidelines as a criteria for assessment in the accreditation process.

Recommendation 5

3.61 The Committee recommends that the use of and adherence to clinical guidelines is an essential component of multidisciplinary care and must be part of any system of accreditation of cancer treatment services.

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[54] *National Service Improvement Framework for Cancer*, p.41.

[55] *Committee Hansard* 20.4.05, p.89 (Mr Davies and Professor Horvath).

Recommendation 6

3.62 The Committee recommends that multidisciplinary care, consisting of an integrated team approach in which medical and allied health care professionals develop collaboratively an individual patient treatment plan, continue to be widely promoted within the medical and allied health care professions.

3.63 Witnesses also mentioned that the communication skills of some medical practitioners they had dealt with left a lot to be desired. For example:

> The registrar said that we can see the surgeon at 5pm that day when he does his rounds. We did see him. He spent less than one minute at our daughter's bedside. Instead, we, her parents, had to run after him down the corridor to speak to him'.[56]

3.64 A number of reports such as *Optimising Cancer Care in Australia* and the *National Service Improvement Framework for Cancer* have identified the need for cancer care providers to improve their communication skills, including specialists, GPs and through the whole care team. The Committee considers that enhanced communication skills training is required at undergraduate and postgraduate levels and that the Colleges should undertake a more active role in the provision of such training for their members. The Committee also notes that the NBCC runs communication skills training workshops for health professionals working with breast cancer patients and that this model could be developed to provide training for all cancers.

Recommendation 7

3.65 The Committee recommends that the curriculum for medical professionals at the undergraduate and postgraduate levels include enhanced communication skills training and that professional Colleges also undertake a more active role in the provision of such training for their members. This training could be based on the National Breast Cancer Centre's communication skills training workshops that have been developed to improve the awareness and capacity of health professionals to communicate effectively with women with cancer.

Medical Benefits Scheme (MBS)

3.66 Despite the evidence regarding best practice and improved outcomes for patients, the Committee found that the practice of multidisciplinary care is very limited beyond some major public hospitals. Although models of cancer care have changed over the last few years, the Committee heard that inflexible funding models are currently acting as a barrier to the implementation of best practice cancer care. Professor Holman identified the general philosophy of the fee-for-service model as a barrier to the development of integrated MDC.[57]

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[56] *Confidential Submission* 3, pp.2-5.

[57] Professor D'Arcy Holman, Commissioned Report, p.6.

3.67 This area appeared to be complicated and confusing within the health sector with witnesses providing different accounts of what is and is not funded by the MBS as indicated by the following comments:

- Currently only two clinical areas have access to MBS rebates for MDC, GPs and Physicians. The remainder of clinicians have no access to rebates for MDC. This means there is no incentive for the entire cancer team, which usually includes a broader base of clinicians to provide MDC.
- Private medical, surgical, medical and radiation oncologists can each claim a relevant MBS item only if they review a patient together when the patient is present. This does not reflect best practice in which clinicians may attend multidisciplinary care meetings where several patients are discussed, only one of whom may be their patient, or in cases, where due to the technical aspects of the discussion, it is often not appropriate for the patient to attend.[58]

Current Medicare provisions

3.68 The Department of Health and Ageing provided advice about the current Medicare provisions for multidisciplinary care:

> A range of items for Enhanced Primary Care (EPC) were introduced into the Medicare Benefits Schedule (MBS) in 1999. These items focused on prevention and better coordination of care, particularly for older Australians and those with chronic illnesses, including cancer, undertaken in the community by primary care practitioners. The items covered health assessments (700 to 712), care plans (items 720 to 730) and case conferences (items 734 to 779). The care planning and case conferencing items covered provision of these services in the community and at the time of discharge from hospital for private patients.
>
> Case conferencing items were extended to consultant physicians and consultant psychiatrists in the November 2000 and 2002 MBS respectively. The items were limited to out of hospital community case conferences and discharge case conferences (which are seen as making arrangements for a patient's return to the community from hospital).
>
> These items enable medical practitioners (GPs, psychiatrists and consultant physicians) from different disciplines to work collaboratively with each other and other allied health providers in a team-based approach in the management of a patient's complex care needs. The case conference must be held with a minimum number of health professionals attending, there must be at least 4 participants when a case conference is organised by a physician and 3 participants where the case conference is organised by a GP or psychiatrist. The current arrangements do allow for each consultant physician from a different discipline to be paid for attendance at a case conference.

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[58] *Submission* 53, p.8 (Cancer Institute, NSW).

> Patients and/or their carers are able to attend case conferences, but do not count towards the minimum number of health practitioners who must participate.
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> The case conferencing items have been modified over time to better reflect clinical use and this process is on-going. The Department has also been approached to consider the development of sequential case conferencing for private in-patients with complex medical problems managed by geriatricians and rehabilitation physicians and to allow access to the case conferencing items to anaesthetists who provide chronic pain services.[59]

3.69 The NSW Cancer Institute noted the differences in the public and private hospital billing arrangements, saying gap payments for non-admitted services in the private sector can be substantial and may result in some patients making treatment decisions based on financial considerations. The Institute advised that:

> in many instances, staff specialists providing non-admitted radiotherapy services to private patients in public hospitals are limited to charging the MBS schedule fee (ie. Patients are bulk billed). However, in the private sector, the gap payments for those non-admitted services can be substantial which places the patients at a significant financial disadvantage.[60]

3.70 The Committee noted that the issue of cancer funding reform is being addressed by the Cancer Funding Reform Project. The Project, reporting through the Health Reform Agenda Working Group to Australian Health Ministers, is examining specific alternative funding arrangements and implementation options to improve access to coordinated, best practice cancer care, including the provision of multidisciplinary care. It is being managed by a multi-jurisdictional group led by ACT Health and will provide options for cancer funding reform by the end of 2005.

3.71 The Committee considers that the establishment and maintenance of multidisciplinary care meetings must be adequately and explicitly resourced by those funding health services.

Recommendation 8

3.72 The Committee recommends that the Cancer Funding Reform Project, established under the auspices of the Health Reform Agenda Working Group and reporting to Australian Health Ministers, include the differences in public and private hospital billing arrangements as an item for investigation and resolution.

Recommendation 9

3.73 The Committee recommends that the Department of Health and Ageing, in consultation with Cancer Australia, enhance current Medicare Benefit

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[59] *Submission* 87, supplementary information, (DoHA).

[60] *Submission* 53, p.8 (Cancer Institute NSW).

Schedule arrangements for relevant specialists and general practitioners to support participation in multidisciplinary care meetings in both hospitals and the community.

Recommendation 10

3.74 The Committee recommends that five multidisciplinary cancer centre demonstration projects be set up in consultation with consumer groups and be funded over three years in different parts of Australia. At least one demonstration project should be in the private sector. Within these multidisciplinary centres different models of psychosocial support, incorporating a range of complementary therapies and taking into account the cultural needs of patients, should be assessed. The assessment of all aspects of the demonstration projects should be scientifically based and involve consumer representatives in the process.

Workforce issues

> The issue that I would like to focus on today is the importance of workforce shortages in the provision of multidisciplinary care. I am sure you have heard from other presenters that there are workforce shortages in just about every category of cancer support and every professional area. Lack of personnel in those areas is a bit of a barrier to implementing multidisciplinary care because it is hard, particularly in a rural area, to find the appropriate practitioners to be part of your multidisciplinary group and also because many of these people are very busy anyway and trying to schedule in additional meetings can be problematic. I have members, for example, in certain regional areas of Australia who are working 80 hour weeks and cannot take more than a week off at any one time because they cannot find a locum to fill in. Trying to find time to provide multidisciplinary care and attend meetings is difficult under those sorts of circumstances.[61]

3.75 Many witnesses indicated that a major challenge to cancer patients accessing appropriate services was the availability of a sufficient number of skilled health professionals to deliver care. Workforce shortages occur in almost all categories, especially in rural and remote areas, with particular concern being shortages in nursing, general practice, radiotherapy (ie. radiation therapists and medical therapists), and psychosocial support.

3.76 Witnesses mentioned the already heavy workload on some clinicians and expressed concerns about burnout, emphasising the need for health professionals to be adequately supported.[62] It is important that in order to avoid overload and burnout, especially in the context of the increasing incidence of cancer, the Department of Health and Ageing continue to engage the Colleges in order to develop strategies that

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[61] *Committee Hansard* 19.4.05, p.73 (Ms Marine).

[62] *Committee Hansard* 19.4.05, p.7 (Professor Currow).

will alleviate the identified problems and cope with future demands. The Committee considers that there needs to be more active debate and policy development to enable nurses and other health professionals to undertake procedures that are currently identified as exclusive to doctors.

3.77 In response to a question regarding the resistance to the introduction of nurse practitioners, Professor Saunders stated that it would be important to look at outcomes, 'if the outcomes for the patients, in terms of whatever benchmarks you show for a particular cancer, are as good by another practitioner then that would be reasonable. But there are lots of other complex things such as indemnity cover and insurance. So there is not an easy answer'. Dr Fong responded to the same question by asserting that 'we need new types of health care workers'.[63] Professor Bishop also spoke about the need for strategic workforce development and upskilling of staff. He stated 'clearly there is a worldwide and Australian shortage of high-quality nursing staff. We think a lot of effort should be put into skilling the current staff as well as developing new roles in key areas of discipline.'[64]

3.78 The likelihood of further losses from the workforce was highlighted by Ms Dane from the Australian Council of Community Nursing Services who told the Committee that around 50 percent of their workforce could retire within the next couple of years.[65]

3.79 The Cancer Institute New South Wales has called for the better identification of the cancer workforce and suggested its development should be linked to cancer projections and the distribution of cancer patients. The Institute has also identified the need for the development of cancer subspecialisation, especially within multidisciplinary teams and indicated that the maintenance and promotion of specialist skills in rural and outer urban areas could be achieved through education.[66]

3.80 Cancer workforce issues are being addressed through the Australian Medical Workforce Advisory Committee and Australian Health Workforce Advisory Committee. The Australian Medical Workforce Advisory Committee has been established to promote strategic workforce planning and provide advice on national medical workforce matters. The Australian Health Workforce Advisory Committee has been founded to oversee wider workforce planning needs such as the nursing and allied health workforces. The Radiation Oncology Reform Implementation Group has also been established by Australian Health Minsters to address many of the issues raised by the Report of the Radiation Oncology Inquiry, *A Vision for Radiotherapy*, including workforce.[67]

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[63] *Committee Hansard* 31.3.05, p.18 (Professor Saunders and Dr Fong).

[64] *Committee Hansard* 19.4.05, p.49 (Professor Bishop).

[65] *Committee Hansard* 20.4.05, pp.8-9 (Ms Dane).

[66] *Committee Hansard* 19.04.05, p.49 (Professor Bishop).

[67] *Submission* 87, p.22 (DoHA).

3.81 The Commonwealth is undertaking a number of workforce initiatives, with the medical workforce being a focus of the $4b package for Strengthening Medicare. Substantial funding has been expended on a range of workforce initiatives designed to improve the number of radiation therapists and medical physicists. The Commonwealth's Strengthening Cancer Care Initiative also provides considerable funding over the next four years to support cancer health professionals. The funding will go towards more radiation therapy undergraduate places and professional training packages for nurses, cancer professionals, counsellors and general practitioners. In 2003, the Commonwealth Government announced the creation of 4,000 new publicly funded university places to study nursing over the period 2005-08, with additional funding also being made available over four years towards the costs associated with clinical placements for nurses.[68]

3.82 The Cancer Institute New South Wales is also progressing a range of cancer workforce related initiatives including supporting the professional development year for radiotherapists, establishing new academic posts in the radiation sciences and providing specialist trainee positions.

The cost of Multidisciplinary Care

3.83 There is very little data available on the cost of implementing multidisciplinary care**.** The Holman Report notes that 'the health economics for MDC for cancer is barely embryonic in its development'. However, the Professor reported that a formal cost analysis of a multidisciplinary melanoma clinic in the US suggested reduced health care costs and a study of multidisciplinary care for breast cancer in NZ documented a reduction on outpatient visits and administrative overheads.[69]

3.84 The *National Multidisciplinary Care Demonstration Project* did not include a formal health economics analysis but provided indicative costs for the set-up and implementation of MDC strategies which focussed on establishing and maintaining MDC case conference meetings. The study seemed to indicate that newly established meetings resulted in a higher average cost but the expectation was that as the meetings become more routine and efficient that there would be an increase in the number of cases discussed and the time required would decrease.[70]

3.85 The Committee recognised that at the State and Territory level and at a service level, adequate resourcing will be required to ensure ongoing sustainability of multidisciplinary care.

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[68] *Submission* 87, p.31 (DoHA).

[69] Professor C. D'Arcy, J. Holman, Commissioned Report, p.5.

[70] National Multidisciplinary Care Demonstration Project, NBCC, pp.28-31.

Rural and Indigenous Australians and multidisciplinary care

3.86 Regarding multidisciplinary care for rural areas, Mr Gregory, the Executive Director of the National Rural Health Alliance pointed out to the Committee that the multidisciplinary cancer support team is rare in rural and remote areas. He emphasised that it is currently very hard to put together the necessary multidisciplinary team for cancer care[71] and you would have to include the people who are available. In an Indigenous community, you would include the Aboriginal health worker.[72]

3.87 With tele or videoconferencing, multidisciplinary team meetings can take place over a distance. Witnesses referred to the successful model between Adelaide and Alice Springs which has been in existence for several years and a trial in Victoria from Geelong across the Western District.[73]

Care coordination

3.88 The terms of reference and evidence have used the terms care coordinators and case managers interchangeably. This report will use the term care coordinator.

3.89 While there would appear to be no precise definition of care coordination in the medical literature, it refers to the 'efforts to reduce fragmentation of services for patients with complex care needs'.[74] Best practice multidisciplinary care means that the team includes an individual who has responsibility for 'coordinating the patient's transit through the various stages of assessment, treatment and follow-up; for ensuring a patient is well informed; and for advocating that the patient's own decisions and requirements are respected'.[75] There is evidence that a care coordinator can play a valuable role to ensure continuity of care and deliver the full benefits of a multidisciplinary model which results in better outcomes for the cancer patient.[76]

> A person diagnosed with cancer can receive multiple treatments in a variety of settings over extended periods. For example, a recent UK study reported that cancer patients had met an average of 28 doctors within a year of their diagnosis. Add to this the many other health professionals involved and it is clear that patients face a bewildering array of consultations, therapies, options and advice, at a time when they are already distressed by their diagnosis.[77]

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[71] *Committee Hansard* 20.4.05, p.50 (Mr Gregory).

[72] *Committee Hansard* 20.4.05, p.7 (Ms Grealish).

[73] *Committee Hansard* 18.4.05, p.50 (Ms Swinburne).

[74] *Submission* 65, p.12 (COSA, CCA, NCCI and NACCHO).

[75] *A Cancer Service Framework for Victoria*, The Collaboration for Cancer Outcomes Research and Evaluation July 2003, p.xiii.

[76] *Submissions* 65, p.12 (COSA, CCA, NCCI and NACCHO) and 27, p.4 (Mr and Mrs Moran).

[77] *Submission* 65, p.13 (COSA, CCA, NCCI and NACCHO).

3.90 Witnesses told the Committee that the 'cancer lottery' referred not only to diagnosis and referral but also to the care they received over the sometimes lengthy period of their treatment. They reported a lack of continuity of care across treatment modalities and the private and public sectors. Witnesses said that cancer patients often felt lost in the cancer system and isolated from assistance and information.

> I will quickly mention the story of one person who lives in a country town who was a senior nurse in our organisation. She had sarcoma of the face and underwent radical surgery. Her nose was removed and a flap was put in its place. This lady is very intelligent and has worked in nursing for many years. She told me something that I have not forgotten – how abandoned she felt by the medical and health service and the lack of continuity in care. This was from a person who actually knew how to get herself around the health care system. So I keep that in mind and think: what of the people who do not know how to navigate our complicated system?[78]

3.91 The need to improve coordination of the patient journey has been highlighted in a number of national reports including *Optimising Cancer Care in Australia. The National Service Improvement Framework for Cancer* states:

> People with cancer will have a designated co-ordinator of care who knows about all aspects of their disease, treatment and support. The care co-ordinator will help people with cancer move between treatment components, ensure that they have access to appropriate information and support and ensure the treatment team is fully aware of a person's preferences and situation. The care coordinator might be a cancer nurse, general practitioner, case manager, cancer specialist or other health professional. The care coordinator may be a different person at different times in the cancer journey but the person with cancer should always be clear about who is their care coordinator.[79]

3.92 The need for a coordinator of care has also been recognised by the States and Territories. For example, the *NSW Cancer Plan 2004-06* has identified care coordination as a critical role to facilitate the optimal sequence and timeliness of care and the Cancer Institute NSW is establishing a Cancer Nurse Co-ordinators Program. Similarly, the Cancer Services Framework for Victoria indicates that specific care coordinators are needed to improve the efficiency of cancer care and recommends the need for multidisciplinary coordinated care.[80] The Western Australian Government has also recognised the valuable role of care coordinators and is appointing 20. The model of care coordination is to be different depending on where care coordinators are based and what group of patients they are looking after.[81]

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[78] *Committee Hansard* 20.4.05, p.2 (Ms Dane).

[79] *National Service Improvement Framework for Cancer*, National Health Priority Action Council, March 2004, p.34.

[80] *Submission* 87, p.21 (DoHA).

[81] *Committee Hansard* 31.3.05, p.4 (Professor Saunders); *Submission* 44, p.6 (Dept of Health WA.

3.93 However, the question remains, who is best placed to undertake the role of the care coordinator? For example, it could be a cancer nurse, GP or other health professional.

Breast Care Nurse Model

3.94 Specialist breast cancer nurses fill the role of care coordinator effectively in many settings where breast cancer patients receive multidisciplinary care.[82] GPs are aware of breast cancer treatment centres and the breast cancer screening programs are also linked in, making sure that the majority of women, once diagnosed, have their ongoing management well coordinated. This was identified as of critical importance when women develop progressive breast disease requiring long-term care and support.[83] Also, many more elderly patients may have other medical conditions, the management of which needs to be coordinated within the treatment program for breast cancer. This issue was seen by the Committee as of great significance for planning for the future as Australia faces an increasing incidence of all types of cancers due primarily to its ageing population. As the forecast increase in incidence occurs, so the survival of patients is also forecast to improve and Australia will have more people living with their cancer who will require coordinated care.

3.95 The Committee was impressed by the excellent results achieved in the management of breast cancer following the national and regional efforts to improve outcomes in terms of survival and quality of life. It was emphasised that a dedicated breast care nurse played a very important role in helping women through their cancer journey. However, it was also made clear by two breast cancer advocacy groups that this sort of professional resource is not available in every setting where breast cancer is treated.[84] In their submission, the Peter MacCallum Cancer Centre advised that they have appointed nurse co-ordinators for almost all major cancer types in the past four years. They also reported that they have recently completed an evaluation of a nurse practitioner role in malignant haematology which may act as a model.[85]

3.96 But what happens with the management of other cancers? It appears from evidence that care coordination can be a hit and miss affair. Some specialised units dealing with lung cancer or bowel cancer or head and neck cancers do have senior nurses who 'organise' the clinic and what happens in it, but most settings are not as patient-focussed and could not be directly compared with the breast care nurse.

3.97 The Committee was mindful of the shortages of nurses and of retired nurses wanting work in a capacity such as the care coordinator role for which they would be highly skilled.

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[82] *Submission* 39, p.3 (NBCC).

[83] *Committee Hansard* 18.4.05, p.47 (Ms Manaszewicz).

[84] *Committee Hansard* 18.4.05, p.46 (Ms Lockwood).

[85] *Submission* 36, p.2 (Peter MacCallum Cancer Centre).

Recommendation 11

3.98 The Committee recommends that all State and Territory Governments that have not yet done so, establish designated care coordinator positions to help cancer patients navigate their way through treatment and provide support and access to appropriate information.

Recommendation 12

3.99 The Committee recommends that use of the breast cancer nurse care coordinator model should be adopted for all cancers and that States and Territories undertake a recruitment drive for skilled health professionals such as retired nurses to help fill these positions.

Role of case manager

When I was diagnosed with cancer I felt fear, anxiety, and confusion. My decisions regarding conventional treatment evolved quite naturally. They were taken on the basis of professional advice given with the best possible intentions. They all seemed to make sense at the time - I am talking about surgery, chemo and radiotherapy. If I had known then what I know now about other factors some of those major decisions about some of those conventional treatments would have been quite different. I was given little general information about cancer. There was no discussion or referral to credible complementary services as either a primary or adjuvant treatment. I can certainly see a role for a case manager as a source of information about cancer generally, and also as a source of information regarding referral to the whole range of services, conventional and complementary.

So it is at that initial stage that information could be provided by that case manager, but they would have to be well-informed and unbiased. In my experience, the oncologist did that for me in the conventional medicine sense, but the oncologist has a bias towards conventional medicine. GPs are too busy to provide that service. I see a possibility for that sort of case manager role being fulfilled by a clinically trained educational nurse, as seems to be the case with patients diagnosed with heart disease or diabetes.

Committee Hansard 18.4.05, p.60 (Mr Peter McGowan).

Who is best placed to coordinate?

3.100 The Committee heard a range of opinions and options regarding from which discipline care coordinators should originate. The options presented included oncology or general nurses, specialist GP nurses, GPs, medical social workers or community pharmacists. The Pharmacy Guild proposed that community pharmacists monitor the symptoms of patients undergoing chemotherapy in their home,[86] though the Guild representative acknowledged that such a role would involve his organisation in additional ongoing education and training. Several health professionals emphasised

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[86] *Submission* 32, pp.3-4 (Pharmacy Guild).

the importance of having the care coordinators closely integrated into the multidisciplinary team and working to agreed standards and protocols.

3.101 Witnesses also mentioned that there is a lot more outpatient care being undertaken[87] and as a result, links with the community need to be stronger so that there is continuity of coordination and support for people when they go home from hospital. Ms Lockwood stated that at the moment there are no links between the hospital sector and the community sector and suggested that there are some easy things that can be achieved 'like faxing a discharge plan to the community health nurse so that she knows a woman with breast cancer is coming'.[88]

3.102 Brian Tumour Australia noted that a care coordinator is particularly needed for brain tumour patients', families and carers as the brain tumour may have started to affect the patient's cognitive abilities. They suggested that if the numbers did not warrant a specific brain tumour case coordinator that there may be some value in a dedicated staff member to assist with the less common or minority cancers.[89]

3.103 In some circumstances an organisation may be the care coordinator. Ms Revell told the Committee that the Cancer Council played a fundamental role in the coordination of her treatment:

> I have no problems at all with the treatment in either system (public or private) – it was terrific; it was great – but there was no continuity of treatment or care. It was the Cancer Council that provided that. They stepped in where, in my case, the health service was not adequate…so the main co-ordinator for my well being was actually the Cancer Council.[90]

The need for information

3.104 Witnesses also spoke about their ongoing need for information throughout their cancer journey and that one of their biggest challenges was finding and accessing appropriate, authoritative information. Further along the cancer journey, they needed information about support groups, treatment options, complementary therapies and government assistance. While recognising that the care coordinator is a vital source of information for cancer patients, the Committee considered a common entry point for people with cancer was required to provide consolidated and authoritative information.

Recommendation 13

3.105 The Committee recommends that Cancer Australia provide access to authoritative, nationally consistent, evidence based information on services,

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[87] *Submission* 36, p.4 (Peter MacCallum Cancer Centre).

[88] *Committee Hansard* 18.4.05, p.46 (Ms Lockwood).

[89] *Submission* 6, p.3 (Brain Tumour Australia).

[90] *Committee Hansard* 31.3.04, p.26 (Ms Revell).

treatment options, government and non-government assistance and links to appropriate support groups which can be used by health professionals including care coordinators, cancer patients and their families. This information should be available in different forms.

Conclusion

3.106 Management of cancer is a complex process that should follow a continuum from the point of screening and/or diagnosis through treatment and supportive care to follow-up and in some cases palliative and end-of-life care in both hospital-based and community settings.

3.107 There was no doubt in the view of the Committee that care coordinators should be an essential part of the treatment of cancer. As to who performs the role should be left to the State and Territory cancer services and will necessarily vary with individual patients. The successful model of the breast care nurses should also be taken into account when determining the most appropriate person to be the care coordinator. In the context of patients in rural and remote areas, care coordinators can play an important part in improving their more complex patient journeys, especially for Indigenous Australians.

Psychosocial support

> If people feel supported and feel better, they comment less negatively on every other aspect of their life and their care.[91]

3.108 Clinical guidelines state that: 'Optimal care of the patient with cancer incorporates effective physical and psychological care'.[92] Psychosocial services were consistently identified by witnesses as difficult to access and seen as optional by many clinicians. Major cancer centres throughout Europe and the USA automatically provide access to psychosocial support for cancer patients at the time of diagnosis and thereafter throughout their episodes of treatment. Psychosocial support is as much a part of multidisciplinary care as surgery, radiotherapy or chemotherapy. Not every patient requires support but some require much more assistance than others.

> People tend to have been living their life and then they get their cancer diagnosis and it is a different life they move into. They have been working full-time and then all of a sudden they have to negotiate systems like Centrelink, the ministry of housing or palliative care services out in the community - a whole array of services. They have never had any contact with those agencies before, so I find that a large part of what I do is to try to introduce people to the services in a way that I recognise as being at their own time and pace. Often they are still thinking: Hang on, I've got cancer, have I? What does that mean? – let alone trying to put food on the table and

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[91] *Committee Hansard* 11.5.05, p.10 (Dr Maher).

[92] *Clinical practice guidelines for the psychosocial care of adults with cancer*, NBCC, NCCI and NHMRC, p.3.

> making sure they have an income. There is so much for the person to try to integrate at one time.[93]

3.109 It is well documented that emotional distress is very common in cancer patients. Many studies have looked at distress levels and quality of life in cancer patients. Quality of life covers a broad spectrum of issues in cancer care, including physical, social, cognitive, spiritual, emotional and role functioning as well as psychological symptomatology, pain and other common physical symptoms. Emotional distress refers to problems such as anxiety, depression and fears around the cancer experience. The *Clinical practice guidelines for the psychosocial care of adults with cancer* reports that 'up to 66 per cent of people with cancer experience long term psychological distress; 30 per cent experience clinically significant anxiety problems; and that rates for depression range from 20 to 35 per cent'.[94]

3.110 Reviews and meta-analytical studies show that psychological interventions help patients to cope better with cancer and treatment, and that this may lead to an increased survival rate as well as lower rates of service utilisation and pharmacological intervention. As noted by Dr Hassed:

> We can say that effective psychosocial support programs that significantly improve the mental, emotional and social health of the participants who go through them are associated with significantly longer survival and better survival.[95]

3.111 Research also shows that psychological intervention can be useful in the areas of adherence to treatment regime, pain management, treatment of negative mood, self-management interventions, managing communication and complementary therapies.[96]

> …Cancer is a multifaceted disorder, and psychosocial factors, which are so easily forgotten, have a major influence on the incidence, progress and outcome of cancer.[97]

3.112 Although the prevalence of distress, anxiety and depression is common, medical practitioners have been found to have difficulties identifying, or are unaware of, the psychological concerns of their patients or of disorders such as depression. Hence the true prevalence of psychosocial distress amongst cancer patients is under-reported and ultimately under-treated. Consumers believe that clinicians are not sufficiently aware of the psychosocial aspects of care and that the clinical guidelines

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[93] *Committee Hansard* 18.4.05, p.93 (Ms Todd).

[94] *Clinical practice guidelines for the psychological care of adults with cancer*, NBCC, NCCI and NHMRC, p.vi.

[95] *Committee Hansard* 18.4.05, p.57 (Dr Hassed).

[96] *Submission* 38, pp.4-6 (APS).

[97] *Committee Hansard* 18.4.05, p.78 (Mr Stokes).

should be implemented for all cancer services and their use encouraged through medical and nursing training.[98]

> If we continue to have our services offered in cancer care based around medical treatment, we will continue to have patients feeling abandoned. When the treatment finishes…people are abandoned by the system. Once they do not access medical services, the other supportive services are not available.[99]

3.113 Witnesses reported that appropriate and timely referral of cancer patients in need of psychosocial services is not routinely undertaken[100] and that this is much more difficult in a work culture that emphasises physical, rather than emotional patient needs. As noted by Professor Zalcberg:

> Psychology and social work in the community are particularly the areas not adequately supported by current systems.[101]

3.114 Mr Ulman, Director of Survivorship at the Lance Armstrong Foundation told the Committee about a survey the Foundation undertook in November 2004 where 1,000 cancer survivors across the USA were asked what they were dealing with as a result of their cancer diagnosis:

> 49 per cent of these people interviewed said that their non-medical needs - that is, their emotional, practical and physical non-medical needs - were currently going unmet by the health care system…more than half – 53 per cent of the people surveyed said that they agreed that the practical and emotional consequences of dealing with cancer were harder than the medical issues.[102]

3.115 Evidence presented at the hearings and in written submissions indicated that few public hospitals in Australia provide adequate funding to sustain the provision of psychosocial support for cancer patients and their carers. Whilst most hospitals can report the existence of general consultant liaison psychiatry and clinical psychology programs, very few of these services are funded to the extent whereby dedicated services for cancer patients could be provided. The Peter MacCallum Cancer Centre reported that:

> At Peter Mac we are very lucky. We have managed to employ psychologists and we have a strong bank of social workers and limited psychiatry, but that would be unusual in most hospitals across Australia…[103]

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[98] *Committee Hansard* 19.4.05, p.44 (Ms Crossing).

[99] *Committee Hansard* 20.4.05, p.3 (Ms Grealish).

[100] *Committee Hansard* 19.4.05, p.35 (Ms Crossing).

[101] *Committee Hansard* 18.4.05, p.37 (Professor Zalcberg).

[102] *Committee Hansard* 12.5.05, p.2 (Mr Ulman).

[103] *Committee Hansard* 18.4.05, p.29 (Professor Aranda).

3.116 Professor Bloch, who will spend time at Memorial Sloan-Kettering Cancer Centre in New York, which is a recognised world leader in the field of cancer treatment, stated by way of comparison that they have 'no fewer than 10 psychiatrists, 10 psychologists, six training posts and 11 doctoral and postdoctoral fellowships. He acknowledged that Sloan-Kettering is the largest cancer centre in the USA but said 'it seems to me to be a reflection of how much we still have to catch up'.[104]

3.117 The Australian Psychological Society told the Committee of the limited services they are able to provide to cancer patients:

> We may have either a clinical or a health psychologist whose speciality is not oncology, who might see at best – as a passing acquaintance – half the patients in the ward. I worked in an oncology ward. At best you met perhaps half of those patients at the bedside. You did serious work with no more than 10 per cent. That is just the public hospital sector. We have not even talked about the private hospital sector, where in many instances you would not find a psychologist anywhere in the centre.[105]

3.118 Witnesses working in the sector said that due to the lack of staff, the emergency medicine model prevails where social workers may be called in for emergency cases, when someone is in serious distress[106] and referral to psychiatrists occurs if there is a major problem such as suicidal depression. Oncology social workers agreed, saying that due to the critical shortage of specialist oncology workers, they operate largely on a crisis driven model of service'.[107] Mr Hochberg emphasised that most services are inpatient focussed and to access social work services as an outpatient you need to be in crisis.[108]

3.119 Witnesses reported that the provision of psychosocial care is hampered by the absence of positions funded either through State health systems or through Medicare. They reported that under Medicare, the rebate for psychosocial health professionals is limited and does not meet the needs of most cancer patients.[109] Published HIC information indicates that last year new Medicare benefit items were introduced for allied health services for people with chronic conditions and complex care needs. The items allow for a 'maximum of five services per patient per 12 month period. Patients need to have a chronic condition and complex care needs which are being managed by their GP under an Enhanced Primary Care multidisciplinary care plan. The need for allied health services must also be identified in the patient's care plan'.

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[104] *Committee Hansard* 18.4.05, p.82 (Professor Bloch).

[105] *Committee Hansard* 18.4.05, p.85 (Mr Stokes).

[106] *Committee Hansard* 18.4.05, pp.85-86 (Mr Stokes).

[107] *Committee Hansard* 18.4.05, p.89 (Mr Hochberg).

[108] *Committee Hansard* 18.4.05, p.96 (Mr Hochberg).

[109] *Committee Hansard* 18.4.05, p.29 (Professor Aranda).

3.120 Eligible services include those provided by Aboriginal health workers, audiologists, chiropractors, chiropodists, dieticians, mental health workers, occupational therapists, osteopaths, physiotherapists, podiatrists, psychologists and speech pathologists. [110] However, the existence of the MBS items did not seem to be well known. The Committee was concerned that a five services maximum per 12 month period may be insufficient for chronic cases involving complex care needs.

Recommendation 14

3.121 The Committee recommends that the Department of Health and Ageing improve health professional and consumer awareness of allied health services for people with chronic conditions and complex care needs that can be claimed under the Medical Benefits Schedule. Current claim usage of allied health services should be determined and an evaluation should be conducted 12 months after promotion of the Medical Benefit Schedule items available.

Recommendation 15

3.122 The Committee recommends that Cancer Australia examine appropriate funding mechanisms for programs and activities like those operated by the Gawler Foundation, which specialise in providing learning and self-help techniques based on an integrated approach for cancer patients and their carers. This examination should include consideration from a health and equity point of view of providing Medicare deductibility for cancer patients accessing these services.

3.123 In the past few years, the Australian peak cancer organisations have released several clinical practice guidelines for the management of specific cancers that have also been endorsed by the NHMRC and the Australian Government. Increasingly these guidelines are including sections on the psychosocial aspects of cancer care and some have been dedicated totally to this area. In 2003, the NBCC and NCCI developed *Clinical practice guidelines for the psychosocial care of adults with cancer*. These guidelines were produced for use by all relevant health professionals who come into contact with cancer patients during their journey and were endorsed by the NHMRC.

3.124 These evidence based guidelines have been internationally recognised as a significant contribution to the field of psychosocial aspects of cancer care. Some psychosocial interventions with cancer patients are summarised below:

- Appropriate counselling improves the well being of people with cancer;
- Providing patients psychosocial support before undergoing treatment reduces psychological distress;

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[110] Accessed at http://health.gov.au/internet/wcms/publishing.nsf/Content/health-medicare-health_pro-gp-pdf-allied-cnt.htm on 19.5.05.

- A variety of psychological interventions, including cognitive behavioural supportive group, family and couples therapy as well as relaxation techniques are useful for decreasing distress in patients;
- Cognitive, behavioural, supportive and crisis interventions, as well as combinations of education and behavioural or non behavioural interventions and anti-anxiety medications, are effective in the treatment of anxiety and depression;
- Supportive psychotherapy, in combination with anti-depressants is effective for the management of post-traumatic stress disorder; and
- Relaxation therapy, guided imagery systematic desensitisation, supportive interventions and education together with cognitive behavioural interventions, are beneficial for patients with physical symptoms.[111]

3.125 The Cancer Institute NSW and the Department of Health WA called for the broad application of the NHMRC-approved guidelines for the psychosocial care of adults with cancer. The Committee is aware that in 2003 the NCCI, in conjunction with the NBCC, developed a dissemination and implementation strategy for these guidelines involving four modules including interactive educational workshops for health professionals, health professional summary cards, consumer summary cards and a rural and remote strategy. The strategy commenced in 2004.

Recommendation 16

3.126 The Committee recommends the continued implementation and dissemination of the *Clinical practice guidelines for the psychosocial care of adults with cancer* to health professionals and people and families affected by cancer.

3.127 Non-Government Organisations, especially the State and Territory Cancer Councils, strongly advocate the provision of psychosocial support and are currently the major service providers in this field.

3.128 The Cancer Help Lines, run by the Cancer Councils throughout Australia, are often the first port of call for many newly diagnosed cancer patients and their carers who are seeking more information and support. Professor Hill provided statistics on Cancer Help lines calls, reporting that '80 per cent of them talk about management and treatment; 45 per cent, diagnosis; 30 per cent, side effects; 45 per cent are interested in psychological and emotional support issues and 35 per cent are interested in recurrence and advancement of the disease'.[112]

3.129 It would seem that Australia does reflect some international practices with non-government organisations overseas providing information resources and

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[111] *Clinical practice guidelines for the psychosocial care of adults with cancer*, NBCC, NCCI and NHMRC, pp.7-10.

[112] *Committee Hansard* 18.4.05, p.15 (Professor Hill).

guidance. Mr Ulman advised that at the Lance Armstrong Foundation 'we are always encouraging and empowering people to seek out resources that may or may not be beneficial to them but are not always easily accessible or that physicians are not always referring people to'.

3.130 The provision of psychosocial support for cancer patients was identified as one of the 13 priorities in the report *Priorities for Action in Cancer Control 2001-2003*. The report recommended 'Improving the psychosocial care of people with cancer through provision of psychologists in cancer centres and clinics'.[113] The recommendations were all subjected to intensive scrutiny in order to assess the levels of scientific evidence and were developed for the benefit of Commonwealth and State and Territory governments in their development of cancer treatment services. The report confirmed that a high proportion of people diagnosed with cancer suffered from severe psychological problems such as anxiety and depression. Psychosocial interventions such as cognitive behavioural therapy were identified as effective in reducing morbidity in the acute phase of the illness and longer-term psychotherapies as effective in helping patients with advanced cancer. Of significance to the provision of health services, the report stated that:

> An intervention that aims to reduce psychosocial morbidity in people with cancer, both when newly diagnosed and in the latter stages of recurrent or persistent cancer, would address an important heath problem and could have a substantial impact on cancer-related morbidity.[114]

3.131 Evidence suggests that where psychologists and psychiatrists are available in public hospitals, the service they are able to provide for cancer patients and carers is limited. The importance of providing psychosocial care for the patient and carer was repeatedly stressed in the *Optimising Cancer Care in Australia* report.

Recommendation 17

3.132 The Committee recommends that psychosocial care be given equal priority with other aspects of care and be fully integrated with both diagnosis and treatment, including the referral of the patient to appropriate support services.

Recommendation 18

3.133 The Committee recommends that patients and carers should be made aware of additional support services provided by organisations such as The Gawler Foundation in VIC, Balya Cancer Self Help and Wellness Inc in WA and Bloomhill Cancer Help in QLD.

3.134 The Committee recognised the underprovision of psychosocial support services in the public sector and considers that State and Territory health budgets need

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[113] *Priorities for Action in Cancer Control 2001-2003,* Cancer Strategies Group, p.viii.

[114] *Priorities for Action in Cancer Control 2001-2003,* Cancer Strategies Group, p.50.

to address service delivery funding arrangements to deal with this significant unmet need confronting cancer patients.

Recommendation 19

3.135 The Committee recommends that State and Territory Governments consider ways to increase the availability of psychosocial support services.

3.136 It became evident to the Committee as the Inquiry progressed that, without the input from voluntary support groups in the non-government sector, most cancer patients would be unable to access professional help when needed. Health professionals presenting evidence also expressed their frustration at consistent inadequate funding for psychosocial support. The exception to this rule appeared to be the support provided for breast cancer patients, especially at major centres and where breast care nurses were employed.

Conclusion

3.137 Ideally, every cancer patient in Australia should have a right to appropriate psychosocial assessment and intervention from the time of diagnosis, as close as possible to where their primary treatment is being delivered. The Committee agreed that there is ample evidence to indicate that appropriate psychosocial service provision can improve a cancer patient's journey by alleviating clinical levels of distress, in particular anxiety and depression.

3.138 The Committee noted that all descriptions of multidisciplinary care in whatever setting, included the provision of psychosocial support. It was evident to the Committee that the availability of adequate psychosocial support in 2005 is as haphazard as properly funded multidisciplinary cancer care in Australia. The Committee supports greater use of the *Clinical practice guidelines for psychosocial care of adults with cancer* as a resource for all relevant health professionals involved in any aspect of the patients cancer journey and recommends their usage be encouraged by professional colleges. The Committee also supports the continuation of the implementation and dissemination strategy for the psychosocial guidelines.

3.139 The Committee considers the various cancer support groups play an important role in assisting people to deal with the psychosocial impact of cancer.

Robert's story

During an internal bladder inspection by the surgeon, I was informed that I had a large and dangerous tumour in my left kidney and that it and the surrounds had to be removed urgently. Whilst in discomfort and some pain from this medical procedure I attempted to ask questions of the surgeon as to potential alternatives and what this meant for me but received only brief answers that added up to zero choice. This was traumatic for me both as a result of the diagnosis and from the lack of knowledge of my condition and personal options.

I did have a further chance to consult with the surgeon prior to the operation and discovered more information regarding the medical procedures but was not advised as to survival potential either from the operation or from potential metastasis of the cancer. I was not offered or advised of any other services that may have assisted me through this traumatic time, e.g., psychological counselling. I was under the distinct impression that a surgeon will comment only on the area directly under his expertise…

At the six monthly post-operative checkup a large tumour was detected in my left lung and I was referred to a cardio-thoracic surgeon who rapidly admitted me to Fremantle Hospital for a lower left lobectomy (removal of a lung lobe) for a diagnosed renal cell carcinoma metastasis. Subsequent histology reported that it was not that cancer type but a lung cancer. (bronchio-alveolar non-small cell carcinoma).

Post-operative tests showed metastasis of this cancer and that it was inoperable. The cardio-thoracic surgeon, while sympathetic, would not advise me on future medical possibilities or probabilities and simply referred me to an oncologist and said goodbye.

The oncologist briefly described the cancer in laymans terms and advised me that this particular cancer did not respond to any currently available medications. He could not or would not offer me any projections on my survivability and simply advised me to come back when the pain became difficult. This was rather depressing.

While arranging my affairs and attempting to investigate palliative care options I was advised by my house cleaner about an experimental cancer drug trial underway at Sir Charles Gairdner Hospital in Perth… I contacted the State Department of Health and was referred to the research team under Professor Millward at that hospital. After much testing and a requested referral from my oncologist, I was accepted on to a drug trial in October, 2004. My oncologist had not advised me about the existence of these trials.

Whilst there have been some difficult times on this experimental trial the results after one cycle of treatment were that there has been some reduction in the cancer mass, there are no new metastatic sites and there has been a major improvement in my wellbeing. I have now chosen a different oncologist.

Throughout this period, any assistance I have received to ease my way through the medical maze, to attempt to deal with the knowledge of imminent death and to finally arrange my financial and legal affairs has generally been accidental and usually the result of a few good people volunteering their help. The only group of people in the medical system who showed what I interpreted as a level of continuing 'genuine care' were the nursing staff. I cannot rate them highly enough both for their technical expertise and for their humanity.

Submission 83, pp.2-4 (Mr Robert Bergman)

Cancer care in regional, rural and remote areas

> Significant health system changes are required if rural and remote patients are to be treated in line with Medicare principles and have equity of cancer care and outcomes[115]

3.140 It is estimated that around 30 per cent of people with cancer live outside a major population centre[116] and studies indicate that this places them at a disadvantage to survive their cancer. The Rural Doctors Association of Australia (RDAA) reported research which shows that people in country areas who are diagnosed with cancer are 35 per cent more likely to die within five years than cancer patients in the city. The figures are even worse for gender specific cancers like cervical or prostate cancer with death rates three times higher in the country compared with metropolitan areas.[117]

3.141 The reasons given for the different rates of survival include: access to treatment; presenting with more advanced conditions at diagnosis; lower levels of education; lower social and economic status and increased risky lifestyle behaviours.

3.142 Ms Hall, a lecturer at the School of Population health in the University of WA, reported 'access issues and barriers exist at diagnosis, referral and treatment stages' for the rural cancer patient.[118] The RDAA believes difficulties in accessing screening and diagnostic services are part of the reason for the imbalance between cancer outcomes for rural and urban Australia. [119] As an example, Dr Page from the Rural Doctors Association reported that breast screening services are not provided in rural and remote areas in a consistent way.[120] Dr Rogers-Clark also noted that a common theme for rural women with breast cancer is 'the current fragmentation of care, with limited referral and significant gaps in the provision of ongoing supportive care'.[121] At the referral stage, rural medical practitioners may not always have adequate information for appropriate referrals due to the low numbers of cancer patients they see. The RDAA suggested this could be addressed by the development of well defined referral pathways tailored to the needs of rural patients.[122] Witnesses suggested that the combination of referral pathways with greater use of clinical practice guidelines would assist to alleviate disparities.

3.143 The Committee considered that because of the low numbers of cancer patients, rural GPs and their patients would benefit from the development of defined

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[115] *Submission* 5, p.2 (Ms Sonja Hall).

[116] *Submission* 87, p.23 (DoHA).

[117] *Submission* 41, pp.2-3 (RDAA).

[118] *Submission* 5, p.1 (Ms Sonja Hall).

[119] *Submission* 41, p.4 (RDAA).

[120] *Committee Hansard* 19.4.05, p.81 (Dr Page).

[121] *Submission* 46, p.1 (Dr Rogers-Clark and Ms Ellem).

[122] *Submission* 41, p.3 (RDAA).

referral pathways for cancer sites to ensure they are referred to the appropriate care as quickly as possible. The use of existing clinical practice guidelines should be further encouraged for rural medical practitioners.

3.144 The RDAA highlighted that 'even when cancer is detected early, more country people are dying because of a service fragmentation and a lack of adequate treatment facilities in regional areas'.[123] Witnesses reported that many regional and rural centres in Australia have only limited access to specialist cancer services. 'In the case of medical oncology, 86.5 per cent of medical oncologists are located in a metropolitan capital city, with a further 8 per cent in large regional centres and 5.5 per cent in smaller rural or remote areas'.[124]

3.145 As with other parts of the health sector, there are serious workforce shortages in rural and regional Australia[125] which means that, as noted earlier, multidisciplinary teams are rare, there is even less access to psychosocial support and cancer patients are disadvantaged in accessing complementary therapies.[126]

Accessing complementary services in regional Australia

In my experience with conventional services in regional Australia - and Albury-Wodonga is a large provincial city - they were excellent. Hospitals, oncologist, radiotherapists and chemotherapy were all available. Referrals to Melbourne hospitals and visits to Melbourne hospitals for surgery were all there and efficient. From my regional point of view that worked extremely well. Complementary services are a little bit more difficult. They are mostly sited in main cities, in my case Melbourne, and it was quite difficult to transpose what you learned in a complementary medicine sense to the rural setting. It is very difficult to get sympathetic doctors to assist you in your complementary program in the regional centres.

Committee Hansard 18.4.05, p.60 (Mr Peter McGowan).

3.146 Witnesses believed that coordination of care was particularly important for rural cancer patients to ensure they are making informed choices regarding the most suitable treatment for their situation.

3.147 Research shows that rural people are more likely to smoke, drink to excess, eat a diet high in animal fat and are less likely to be exercising regularly. 'They are also exposed to occupational risks including chemical pollution and sun exposure.'[127] Despite this, witnesses informed the Committee that rural people have less access to public health education programs due to limited television transmission and the

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[123] *Submission* 41, p.4 (RDAA).

[124] *Submission* 37, p.3 (MOGA).

[125] *Submission* 61, p.5 (NRHA).

[126] *Submission* 61, p.8 (NRHA).

[127] *Submission* 41, p.5 (RDAA).

tendency to leave school earlier. They emphasised that national public health programs are failing in rural areas as they have not been adjusted for relevance to the rural environment and suggested the development of new public health programs targeting rural Australians.[128] The need to tailor information and programs to reduce risk in communities and individuals with special needs has been recognised in the National Service Improvement Framework.

3.148 Public health programs focusing on disease prevention for rural Australians also need to be better targeted. Although this issue is broader than the terms of reference, it was mentioned as a concern by a number of witnesses. The Committee accepted that more targeted health education programs are required for rural Australians to address the higher levels of risky lifestyle behaviours as these can lead to later diagnosis and complex cancer.

3.149 Economic and physical barriers such as distance, lack of transport and the need to travel, impact on treatment choices for the rural cancer patient.[129] Some people with cancer do not wish to travel away from their family and support networks to obtain treatment and may accept levels of treatment which are not going to give them the best chance of survival or the best results.[130] Dr Page reported that researchers have found that not only are rural women with breast cancer less likely to have radiotherapy, they are less likely to have breast conserving surgery. Dr Page explained that if a patient with breast cancer has breast conserving surgery and has radiotherapy, their five-year survival prognosis is as good as if they had radical surgery such as a mastectomy. She added that if they do not have radiotherapy, there is an unacceptably high rate of recurrence.[131] Dr Page indicated that studies have found rates of radiotherapy are low because it is primarily available only in metropolitan areas and would involve too much travel.[132]

The way forward

> In principle, tackling rural inequality in cancer care and outcomes requires a combination of improved primary healthcare, access to expert multidisciplinary services, and co-ordination of the two.[133]

3.150 Witnesses reported that successful rural cancer services are usually linked to a major hospital in a capital city which provides a visiting outreach service in a shared care arrangement with local practitioners.[134] 'Outreach services involve transporting

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[128] *Committee Hansard* 19.4.05, p.87 (Ms Stratigos).

[129] *Submission* 33, p.5 (Breast Cancer Network Australia).

[130] *Submission* 41, p.4 (RDAA).

[131] *Committee Hansard* 19.4.05, p.82 (Dr Page).

[132] *Committee Hansard* 19.4.05, p.87 (Dr Page).

[133] Jong, K.E, Vale, P.J and Armstrong, B. K, *Medical Journal of Australia* 2005; 182 (1) 13-14.

[134] *Submissions* 4, p.6 (Mr Deverall) and 68, p.1 (Ms Heathcote).

city-based specialists to remote locations to treat people living in those communities and to provide advice to regional physicians'.[135] Witnesses supported the development of outreach specialist services from comprehensive cancer centres.

3.151 More comprehensive cancer centres are evolving in some larger regional centres. Several of these centres are conducting multidisciplinary meetings and are providing outreach services to smaller towns in their area. The centre at Albury-Wodonga was mentioned, which now has 'five resident oncologists, a clinical trials unit, oncology pharmacist and a two-machine radiotherapy service'. Regional cancer centres have also been established in Ballarat, Bendigo Wagga Wagga, Port Macquarie, Lismore and Townsville.[136]

3.152 Enhancing links between metropolitan and rural centres can be achieved in a number of ways including visiting specialists and participation in multidisciplinary case conferencing through videoconferencing or by telephone.[137] To improve professional networks, the Federal Government has committed to a mentoring program linking metropolitan teaching hospitals to regional centres to help promote multidisciplinary approaches.[138] 'Over the four years from 2005-06, the Government is allocating $14.1m in new funding to assist hospitals, providers and support networks to develop and implement cancer care mentoring. The national agency, Cancer Australia, will oversee this measure. Funding will be used to help link major urban teaching hospitals to regional and bush nursing hospitals in regional centres and help foster multidisciplinary approaches in regional areas where on the ground support is less comprehensive. The measure will encourage specialists and other leading health professionals from centres of excellence in cancer treatment to spend more time in rural and regional areas and be available to consult with regional colleagues'.[139]

3.153 Some cancer patients do receive components of their care outside major treatment centres and close to their place of residence[140] and witnesses suggested there are opportunities to develop this aspect of care. As an example, Dr Page suggested that with improved education and training, chemotherapy could be provided in more rural areas and there have been successful pilots in NSW. She stated:

> There is no reason that I can see why you can't have GPs and nurses trained up with advanced skills, specialist oncologists linking in by videoconferencing or teleconferencing and the individual patient perhaps

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[135] *Submission* 65, p.21 citing the Cancer in the Bush, Optimising Clinical Services conference report, 2001, The Cancer Council Australia, COSA, Department of Health and Ageing.

[136] *Submission* 65, p.21 (COSA, CCA, NCCI and NACCHO).

[137] *National Service Improvement Framework for Cancer*, p.37.

[138] The Howard Government Election 2004 Policy, *Strengthening Cancer Care*, p.4.

[139] Accessed at http://www.health.gov.au/internet/budget/publishing.nsf/Content/health-budget2005-hbudget-hfact1.htm on 1.6.2005.

[140] *Submission* 87, p.24 (DoHA).

> doing a once or twice a year visit back to the metropolitan centre, if that is required.[141]

Video and Teleconferencing

3.154 With videoconferencing, multidisciplinary team meetings can take place over a distance. Witnesses referred to the successful model between Adelaide and Alice Springs which has been in existence for several years and a trial in Victoria from Geelong across the Western District[142] but noted that the cost of technology is the biggest problem in rural areas.

3.155 Telemedicine (or telehealth as was preferred by some witnesses) uses telecommunication to give regional and rural clinicians access to practitioners in metropolitan cancer centres, other disciplines and to enable case conferencing by phone or video link. Telemedicine has a role in managing remote or very complex cases. It may also have a role in linking regional providers into metropolitan multidisciplinary teams in areas where there are not sufficient practitioners to set up a local multidisciplinary team. However, criticisms of telemedicine include that it can be 'time consuming, constrained by technical limitations, unable to support the high numbers of cancer patients in regional areas. It is also unsupported by Medicare'.[143] The National Rural Health Alliance also mentioned legislative difficulties where the person may be operating over a State border and need to be registered in more than one jurisdiction.[144]

3.156 The Committee accepts that the challenge is to provide services in regional, rural and remote areas using a multidisciplinary approach with specialist input as required. They agreed work needs to be done to establish clear referral pathways to assist GPs refer cancer patients to the best care quickly. The Committee agreed services outside major treatment centres should be encouraged to develop links with centres of expertise and commended the Federal Government initiative to establish a mentoring system to link health professionals in regional hospitals with cancer professionals in metropolitan teaching hospitals.

3.157 The Committee accepts that rural patients should be provided with access to and choices of treatment so that they are not disadvantaged by virtue of their place of residence. The Committee also notes that cancer patients in rural areas will not be able to access all cancer services locally as it is impractical to fund the infrastructure for cancer treatment such as radiation in rural areas due to the expense, the small numbers of patients and absence of cancer specialists. Therefore, there will be an ongoing need for people to travel for some components of their treatment and the Committee spoke to witnesses at length about the State travel and accommodation schemes.

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[141] *Committee Hansard* 19.4.05, p.83 (Dr Page).

[142] *Committee Hansard* 18.4.05, p.50 (Ms Swinburne).

[143] *Submission* 65, p.21 (COSA, CCA, NCCI and NACCHO).

[144] *Committee Hansard* 20.4.05, p.51 (Mr Gregory).

Travel and accommodation assistance schemes

3.158 Cancer is a difficult disease to treat remotely and cancer patients living in rural and remote areas of Australia often have to travel significant distances to larger centres for assessment and treatment. They may also need to relocate for lengthy periods of time for treatment, resulting in loss of income, separation from family and support structures, and occasionally patients refusing adjuvant therapy (usually radiotherapy and chemotherapy) because of the huge disruption to their lives. Dr Page expressed the following view:

> Having services like radiotherapy only available in metropolitan areas and expecting people to have to travel to them and to pay for their accommodation in order to be able to attend them – quite apart from depriving them of their family and social supports at the time – I really think it is not okay. It is shifting the costs of medicine onto the people who are least able to afford it, those who are sick and those who come from low socio-economic groups.[145]

Organisations and cancer patients were vocal in their criticism of the travel and accommodation schemes due to variation between States and Territories of the rules and the ways they are applied (See Table 3.1). Witnesses reported that funding is sometimes by reimbursement which is problematic for those without means and some reported that patients were simply unaware of the schemes. For others, the paperwork was so onerous at a time when they were very unwell, that they did not utilise it.

3.159 Dr Page provided an example of the costs involved:

> I have a colleague in the state who, at the moment, has a patient with prostatic cancer, that man is in Sydney now having radiotherapy, and he will be having it for six to eight weeks. The radiotherapy is being given in a 15 minute dose on a daily basis for the six to eight week period. After taking into account his travel and accommodation assistance package, which is provided, it is costing him $85 a night in accommodation. This is not an amount of money that an impoverished low socioeconomic and particularly low-educated rural person can afford.[146]

3.160 The Commonwealth originally funded the travel and accommodation assistance schemes but handed both the funding and the responsibility to the States in 1987. Now the Commonwealth provides block funding to the States and Territories but its application is determined by the States.

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[145] *Committee Hansard* 19.4.05, p.81 (Dr Page).

[146] *Committee Hansard* 19.4.05, p.81 (Dr Page).

Table 3.1: Summary of IPTAAS in Australia

State/ Territory	Eligibility requirements	Travel assistance	Accommodation assistance	Patient contributions
NSW	Patient must usually live more than 200 km from the nearest treating specialist	Assistance provided at economy surace rail or bus rates Fuel subsidy of 12.7c/km for private car	Commercial:$33/night (single) or $46/night (double) Private: $30/week after 1^{st} week for pensioner patients with a Health Care Card	$40 ($20 for pensioner or Health Care Card holders) personal contribution deducted from the total benefits paid per claim
VIC	Patient must live more than 100 km from the nearest treating specialist	Assistance provided for the most direct means of public transport (economy rate) Fuel subsidy of 13c/km for private car	Commercial: Up to $30/night for a maximum of 120 nights in a treatment year Private: Not eligible	Patients who are not concession card holders will have the first $100 deducted from their payment each treatment year
QLD	Service must be more than 50 km from the patient's nearest public hospital	Assistance provided at the cost of the least expensive form of public transport from the town of local hospital to the transport terminal of the town the patient is travelling to Fuel subsidy of 10c/km for private car	Commercial: $30/night for concession card holders; non-concession card holders must pay for the first four nights accommodation in a fiscal year Private: $10/night for concession card holders; non-concession card holders to meet first four nights accommodation	Nil
SA	Patient must live more than 100 km from the nearest treating specialist	Assistance provided at economy rate for bus/ferry/train less a patient contribution of $30 Fuel subsidy of 16c/km for private car	Commercial: Up to $33/night, no reimbursement on first night for non-concession card holders Private: Not applicable	Patient contribution of $30 deducted from total travel benefits: means tested exemption for genuine hardship

State/ Territory	Eligibility requirements	Travel assistance	Accommodation assistance	Patient contributions
WA	Patient must live more than 100 km from the nearest treating specialist	Assistance provided at economy rate for the least expensive form of transport (bus/train/plane) Fuel subsidy of 13c/km for private car	Commercial: Up to $35/night. Non-concession card holders are required to pay for the first three nights accommodation Private: $10/night	Non-concession card holders pay the first $50 for a maximum of 4 trips in a financial year
TAS	Patients must live more than 75 km from the nearest treating specialist	Assistance provided at economy bus travel from patient's residence Fuel subsidy of 10c/km for private car	Commercial: up to $30/night Patients not on a pension are required to pay for the first two nights Private: not applicable Limit of $2000 travel and accommodation costs/patient paid each year by Government	Card holders: $15/trip; maximum contribution $120/fiscal year Non card holders: $75/trip; maximum contribution $300/fiscal year
NT	Patient must live more than 200 km from the nearest treating specialist	Assistance provided at the cost of an economy return bus trip from the bus depot closest to the patient's residence Fuel subsidy of 15c/km	Commercial: Up to $30/night Private: $10/night	Nil
ACT	Available to permanent residents of the ACT who are required to travel interstate for specialist medical treatment which is not available in the ACT	A maximum entitlement for travel by coach/train (Can/Syd/Can) is $40/adult and $20/child Greater reimbursement for travel to cities other than Sydney Travel by private car receives $40/trips (Can/Syd/Can)	Commercial: Up to $30/night Private: $10/night	Nil

Source: Optimising Cancer Care in Australia, 2003, pp.116-7.

3.161 In most State capitals the Cancer Councils have hostel accommodation of a high standard and arrange transport to the various clinics. They also provide a level of support for patients and their carers. Whatever the patient receives by way of the accommodation scheme is accepted by the Cancer Councils. For those patients who don't qualify for assistance the rate is negotiated on the basis of the ability to pay.

3.162 Ronald McDonald House provides a service for children (mostly the parents) being treated at children's hospitals. There are 12 Ronald McDonald Houses. Their policy is relative to the government assistance scheme in each centre and they accept whatever the government scheme pays for accommodation. If the family doesn't qualify for assistance the rate is by negotiation.[147]

3.163 It appears there is not enough accommodation of a reasonable standard to meet current demand. The cash amounts provided by each State and Territory for accommodation differ, but, universally, cannot meet the costs of reasonable accommodation, should accommodation not be available in a Cancer Council hostel or similar. This places a heavier and unfair burden on patients from rural and remote areas of Australia. If accommodation is a continuing problem at present, it is going to get worse as the incidence of cancer increases. It appears the non-government sector is the best qualified to deal with this aspect of support, however, they will not be able to sustain all accommodation services on their charitable donations.

3.164 Representatives from the Breast Cancer Network Australia and Breast Cancer Action Group recommended that accessible and reasonable cost accommodation for patient and spouse/carer close to treatment centres should be provided. They also asked for greater flexibility to be able to judge each case on its merits rather than hard and fast rules. Ms Swinburne gave the following example:

> Patient Assistance Transport Scheme (PATS) reflects more than just the problem with the travel scheme, it reflects a bigger problem concerning the states and the Commonwealth and the relationship between them. An example is women who live near borders. A women who lives in Byron Bay has to travel to a treatment centre in NSW to be able to get PATS, even though Brisbane or the Gold Coast are much closer and her family and support could be there. There are a lot of things that are not sensible as part of the scheme. There are a lot of bureaucratic difficulties and challenges for women.[148]

3.165 Mr Gregory told the Committee that the eighth National Rural Health conference in Alice Springs in March 2005 recommended there should be an immediate national review of the State schemes that assist patient and carer transport and accommodation. The purpose would be to introduce a uniform approach which provides people from remote and rural areas with reasonable reimbursement for

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[147] Mr Deverall, personal communication, 5.5.05.

[148] *Committee Hansard* 18.4.05, p.48 (Ms Swinburne).

accessing services that are not available in their own communities.[149] This echoes proposals from the National Rural Health Alliance, the Baume Inquiry, and submissions for a collaborative Commonwealth, State and Territory task force to address the problems associated with the existing travel and accommodation subsidy schemes for people from rural and remote areas.

3.166 Mr Gregory suggested the characteristics of an improved scheme would include: 'more information about it, less variation within and between jurisdictions, carers and escorts being eligible; assessment being based on psychosocial needs and not merely medical grounds; consideration being given to those on low incomes and who incur a major loss of income; and attention to boundary and eligibility issues relating to a second opinion and treatment of choice'.[150]

3.167 The Radiation Oncology Jurisdictional Implementation Group (ROJIG) Committee of Inquiry reviewed the issue of travel and accommodation. Both the Baume report and ROJIG have recommended that, States and Territories, at the very least, observe a uniform standard of benefits to be paid under the travel assistance schemes. The report provided a set of principles to help jurisdictions improve patient access, which include the following issues:

- Eligibility, accommodation, transport and mileage benefits – including assistance continuing to be based on distance rather than time taken to travel to a specialist treatment centre;
- Patient contributions – with a focus on targeting maximum financial assistance towards those most in need;
- Escort/carer eligibility and benefits – aiming to reduce financial barriers to the participation of an escort/carer in supporting eligible patients;
- Research – building on the evidence base for parameters of patient travel assistance schemes;
- Awareness raising – both at facility level and through collaborative Commonwealth, State and Territory strategies;
- Availability of subsidised accommodation facilities for radiotherapy patients – to be considered in the service development framework for radiation oncology; and
- Community involvement – including enhancing patient navigation of the local care system through greater involvement of the community and non-government sector.[151]

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[149] *Committee Hansard* 20.4.05, p.48 (Mr Gregory).

[150] *Committee Hansard* 20.4.05, p.48 (Mr Gregory).

[151] Radiation Oncology Jurisdictional Implementation Group Final Report, September 2003, p.10.

3.168 The Committee endorses these standards and recommends fixed term reviews for the amount allocated by the Commonwealth to cope with the increasing incidence of cancer in the Australian population.

Recommendation 20

3.169 The Committee recommends States and Territories adopt and implement the consistent approach to the benefits for travel and accommodation recommended by the Radiation Oncology Jurisdictional Implementation Group to ensure that benefits are standardised across Australia. These benefits should be indexed or reviewed annually for increases in travel and accommodation costs.

Cancer care for Indigenous Australians

> One of the greatest challenges facing the Australian health care system is to prevent the occurrence and progression of disease and reduce suffering for Indigenous Australians as effectively as it does for Australian's generally.[152]

3.170 Cancer is a leading cause of death for Indigenous and non-Indigenous Australians but the improved cancer outcomes for non-Indigenous Australians are offset by the situation for Indigenous Australians. Research from the Northern Territory and South Australia show that Aboriginal people and Torres Strait Islanders with cancer are twice as likely to die from the disease as non-Indigenous people with the disease.[153] Also research has shown that in the NT, cancers affecting Indigenous Australians are largely preventable.[154]

3.171 The reasons for poorer cancer outcomes for Indigenous Australians are complex but include less access to prevention programs, later-stage diagnosis, higher rates of deadlier cancers, linguistic and cultural differences and beliefs about cancer contributing to a reduced likelihood of completing a treatment program. Despite the identification of these factors, the reasons why successes in cancer control have not been shared by Indigenous Australians are not fully understood and the lack of a national data set is impeding an increased understanding.[155]

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[152] John Condon, Aboriginal and Torres Strait Islander Primary Health Care Review: Consultant Report No 5, *Cancer, Health Services and Indigenous Australians*, p.1.

[153] Lowenthal, R.M, Grogan, P and Kerrins, E.T, Reducing the impact of cancer in Indigenous communities: ways forward, *Medical Journal of Australia 2005: 182(3): 105-106.*

[154] Condon, J.R, Barnes, T, Cunningham, and Armstrong, B, Long-term trends in cancer mortality for Indigenous Australians in the Northern Territory, *Medical Journal of Australia* 2004; 180 (10):504-507.

[155] Lowenthal, R.M, Grogan, P.B, Kerrins, E.T, Reducing the impact of cancer in Indigenous communities: ways forward, *Medical Journal of Australia* 2005; 182 (3): 105-106.

Problems with data quality

3.172 There are considerable limitations to our understanding of cancer in Indigenous Australians as information on cancer is not as comprehensive for Indigenous as for non-Indigenous Australians. A number of reports and publications call attention to the fact that no national information is available for Indigenous people on cancer mortality, incidence, survival and services such as screening programs.[156]

3.173 As noted in *The National Cancer Prevention Policy 2004-06* produced by the Cancer Council of Australia 'only two States and one Territory collect reasonable data which indicates that Aboriginal and Torres Strait Islander cancer deaths are much higher than the general population'.[157]

3.174 Information gathering is improving but this lack of data and data limitations are barriers to the development and implementation of more targeted heath policies and service delivery. *Australia's Health 2004* suggests data collection and better identification of Indigenous Australians in surveys and administrative records is necessary to provide better quality information about their health and to assess improvement.[158]

3.175 It is important to note that much of what is reported may represent under-estimates of numbers of Aboriginal and Torres Strait Islander peoples as identification of persons of Aboriginal and Torres Strait Islander origin is incomplete.[159]

3.176 A recent paper in the *Medical Journal of Australia* reported that between 1991 and 2000 in the NT, Indigenous people with cancer of the colon and rectum, breast, cervix and non-Hodgkins lymphoma were more likely to be diagnosed with advanced disease than non-Indigenous people, and this is likely to reduce chances of survival.[160] It appears likely that the more advanced disease at diagnosis in Indigenous people is due to low awareness of potentially dangerous early symptoms, lateness in seeking medical advice and poor access to or low quality of primary care, diagnostic or specialist services.[161] Further research is required to investigate the reasons for later

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[156] Condon, J.R, Armstrong, B.K, Barnes, A and Cunningham, J, Cancer In Indigenous Australians: a review, *Cancer Causes and Control* 14; 109-121, 2003.

[157] *The National Cancer Prevention Policy 2004-06*, The Cancer Council Australia May 2004, p.7.

[158] *Australia's Health 2004*, p.336.

[159] Condon, J.R, Armstrong, B.K, Barnes, A and Cunningham, J, Cancer in Indigenous Australian's: a review, *Cancer Causes and Control* 2003, 14; 109-121, p.111.

[160] Condon, J.R, Barnes, T, Armstrong, B.K, Selva-Nayagam, S and Elwood, J.M, Stage at diagnosis and cancer survival for Indigenous Australians in the Northern Territory, *Medical Journal of Australia* 2005; 182 (6): 277-280.

[161] *Submission* 61, supplementary information, p.1 (NRHA).

diagnosis and Dr Condon suggests this research should focus on the primary care services and Indigenous people themselves.[162]

3.177 A review of the Commonwealth's Aboriginal and Torres Strait Islander primary health care program was completed in 2003-04. One of the consultancy reports was *Cancer, Health Services and Indigenous Australians*. This paper looked at the performance of the Australian health system in relation to cancer control for Indigenous Australians in the Northern Territory as one way of providing insight into the relationship between health care and a range of issues including survival rates for Aboriginal and Torres Strait Islander Australians. Key findings of the report included:

- An examination of cancer data which shows that the health system is not operating as effectively for Indigenous as for other Australians;
- While different patterns of incidence of cancer for Indigenous compared to non-Indigenous Australians can be partially explained by different cancer risk factors, Indigenous survival is lower for almost all sites which is partially due to delayed diagnosis and lower chance of cure;
- Primary health care has a key role in significantly improving survival for non-Indigenous Australians; and
- Similar improvements are possible for Indigenous Australians if primary health care programs are strengthened and access improved to primary and specialist services.[163]

3.178 Like rural cancer patients, distance is often a factor in accessing services for Indigenous Australians in remote or rural areas. The Australian Bureau of Statistics reports that 25 per cent of Indigenous Australians were living in remote or very remote areas compared to only two percent of non-Indigenous Australians.[164]

3.179 As with rural Australians, specialist outreach services were suggested to improve cancer services for Indigenous Australians. Research suggests that specialist outreach services which interact with primary health care providers, such as Aboriginal health care workers, can improve access to specialist care for Indigenous people in remote areas and can reduce communication and cultural barriers.[165] Further research on the model has shown that specialist outreach can provide a more equitable means of service delivery than hospital based services alone. The outreach model

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[162] Condon, J.R Cancer and Indigenous Australians in the Northern Territory, Doctoral thesis, Charles Darwin University, 2004.

[163] *Submission* 87, pp.24-25 (DoHA).

[164] Australian Bureau of Statistics 4704.0 *The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples*, 2003.

[165] Gruen, R.L, Bailie, R.S, d'Abbs, P.H, O'Rourke, I.C, O'Brien, M. M and Verma N, Improving access to specialist care for remote Aboriginal communities: evaluation of a specialist outreach service, *Medical Journal of Australia* 2001; 174 (10): 507-511.

should be responsive to local community needs, have an adequate specialist base and be able to integrate with and have capacity to build a multidisciplinary framework.[166]

3.180 In August 2004, a forum on 'Reducing the impact of cancer on Aboriginal and Torres Strait Islander Communities: Ways Forward' was held in Darwin. A report of the forum was recently published in the *Medical Journal of Australia*. It highlighted that the challenges in healthcare delivery for rural and remote Australia are compounded by the cultural, linguistic and socioeconomic barriers unique to Indigenous communities. [167]

3.181 The Cancer Council Australia is developing a national advocacy strategy aimed at reducing the disparities in cancer outcome between Indigenous and Non-Indigenous Australians. The strategy will be based on the recommendations made at the discussion forum in Darwin.

3.182 As with rural Australians, witnesses suggested that national health education programs are not suitable for most of the Aboriginal population and the development of targeted programs is required.[168] The need to tailor information and programs to reduce risk in communities and individuals with special needs such as Indigenous Australians has been recognised in the National Service Improvement Framework.

3.183 Dr Condon provided an example of two successful models which have been largely responsible for improved outcomes in the area of cervical cancer. Between 1991 and 2001 the incidence of cervical cancer decreased by 25 per cent and mortality decreased by over 50 per cent over a similar period. The two programs which have played a major role in this result are firstly the NT Well Women's Screening Program which is suggested as a service delivery model that overcame many barriers which have been identified such as lack of knowledge about cervical cancer and awareness of pap test screening and communication difficulties between mainstream health services and Indigenous women. The second program is the Gynaecology Outreach Service which has improved access to specialist services for women with pap test abnormalities. Dr Condon suggests these results can be achieved for other cancers with such innovative and targeted programs. [169]

Recommendation 21

3.184 The Committee recommends Cancer Australia, in consultation with Aboriginal and Torres Strait Islander people and the States and Territories,

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[166] Gruen, R.L, Weeramanthri, T.S, and Bailie, R.S, *Journal of Epidemiology and Community Health* 2002; 56: 517-521.

[167] Lowenthal, R.M, Grogan, P.B, Kerrins, E.t, Reducing the impact of cancer in Indigenous communities: ways forward, *Medical Journal of Australia*, 2005;182 (3):105-106.

[168] *Submission* 65, p.29 (COSA,CCA, NCCI and NACCHO).

[169] *Submission* 43, p.2 (Dr Condon).

auspice work to improve access to cancer screening, diagnosis and treatment for Aboriginal and Torres Strait Islander people that is culturally appropriate.

Conclusion

3.185 The fragmentation of cancer services and the need for a more integrated and networked approach to cancer services was identified as a major problem by a number of witnesses and jurisdictions. The Committee noted the many national and State cancer initiatives from the submissions provided and that the *National Service Improvement Framework for Cancer*, a joint Commonwealth and State and Territory government initiative, has been developed. The Framework provides clarity about what the evidence suggests about timely and effective care across the continuum, including where health services require multidisciplinary care and coordination. The Committee was informed that three jurisdictions, New South Wales, Victoria and Western Australia, are developing initiatives designed to improve both the integration and coordination of their cancer services.

3.186 The Committee accepts multidisciplinary care as best practice and sees benefit in defining standards. However, the Committee notes that given the mix of private and public services and significant regional variations in delivery and access to services, a flexible principle-based approach to MDC is required to tailor care according to local services, stage of the disease and wishes of the patient.

3.187 The Committee accepts that promotion of the benefits of MDC is needed at a national level through the *National Service Improvement Framework for Cancer* and notes that adequate resourcing at the State/Territory level will be required to ensure the ongoing sustainability of MDC. The Committee recognises that current funding models do not adequately support the use of multidisciplinary care, particularly in the private system, and a review of this area of the MBS is necessary to ensure the further development of multidisciplinary care in Australia.

3.188 The Committee recognises the work undertaken by the National Breast Cancer Centre, acknowledges the successes achieved in the area of breast cancer treatment and care and recommends breast cancer care as a model for the development of services and support for patients with other cancers.

3.189 To provide more information to patients at the time of diagnosis and referral the Committee acknowledged the success of the NSW Breast Cancer Services Directory and the Committee recommends that Cancer Australia coordinate the development of such a directory in each State and Territory.

3.190 The Committee commends and encourages the work underway in many areas to develop tumour streams which will include referral pathways. This will particularly assist rural cancer patients to obtain appropriate and timely care. To drive this work, the Committee recommends Cancer Australia commission the States and Territories to develop appropriate referral pathways for the management of all cancers.

3.191 The Committee commends the development of the discussion paper regarding the accreditation of cancer services and acknowledges the need to move quickly towards the accreditation of cancer services and credentialing of practitioners to increase the amount of information available for the GP and patient at all stages, but particularly at the diagnosis and referral stage. The Committee recommends Cancer Australia facilitate the development and introduction of accreditation and credentialing systems. The Committee would encourage individual health practitioners and hospitals to utilise available clinical practice guidelines approved by NHMRC and suggests that use of the guidelines be included as a criterion for accreditation.

3.192 Care coordinators are of vial importance to assist cancer patients navigate their way through the system and help them find high quality, evidence based information to make informed decisions regarding their treatment. Although there are differing opinions on who is best placed to take on this role, the Breast Cancer Nurse is a successful model which could be adapted to suit individual circumstances and different clinical settings.

3.193 The Committee recognises that a diagnosis of cancer can bring with it not only physical but emotional and practical challenges as well. The need for psychosocial care is well documented and the Committee commends the implementation and dissemination strategy for the *Clinical practice guidelines for the psychosocial care of adults with cancer*. The education of medical students at the undergraduate and postgraduate levels about psychosocial support and better communication with patients is also supported by the Committee.

3.194 A further challenge identified during the course of the Inquiry was cancer workforce shortages in almost all categories, especially in rural and remote areas. Of particular concern were shortages in nursing, general practice, radiotherapy (ie. radiation therapists and medical therapists), and psychosocial support. Jurisdictions acknowledged that workforce shortages are being experienced internationally as well as nationally. The Committee acknowledged that cancer workforce issues are being addressed by the Commonwealth and State and Territory Governments in a collaborative manner through the Australian Medical Workforce Advisory Committee, the Australian Health Workforce Advisory Committee and the Radiation Oncology Reform Implementation Group. The Committee recognises the shortages in the health care workforce and encourages investment in the cancer workforce, strategic workforce development and upskilling of staff to ensure the further development and usage of the multidisciplinary care model.

3.195 The Committee is encouraged by the development of regional cancer centres and supports the development of outreach services and tele/videoconferencing to address access issues for the regional cancer patient and to support the development of a multidisciplinary approach. The Committee also supports training and education of rural health professionals so that more cancer services can be provided closer to home, thereby reducing the burden of patient travel. The Committee was very concerned to hear from many witnesses about the inequalities of the State travel and accommodation assistance schemes and recommends the standardisation of the schemes to ensure consistency of entitlements.

3.196 The Committee recognises cancer in Indigenous people as a health priority and wishes to involve Indigenous groups in developing a national response. The Committee saw the development of culturally appropriate care as a priority, and recommended that Cancer Australia, in consultation with Indigenous people and the States and Territories, work to improve access to cancer screening, diagnosis and treatment.

Justus – An indigenous story

Justus had been sick for some weeks and his grandmother who was often his primary carer, had taken him to the Princess Margaret Hospital a number of times. In each instance though, they had been sent home with no diagnosis save inferences raised by medical staff that Justus may have had some emotional problems due to his home situation. My mother finally tracked down an old family doctor who demanded the hospital undertake a CT scan upon Justus who was by now very sick, and that did then reveal his tumour. Unfortunately, as Justus was not a private patient and as the PMH did not have an MRI scan it was a number of days before the hospital could tell us more about the tumour and whether an operation might be possible. The emergency doctor indicated to Justus's mother, and myself who was also present, that it was unlikely he could be treated and therefore he would die. The PMH surgeon met Justus mother at the hospital on Saturday and told us there would be no operation… A number of days had passed between the emergency room diagnosis and the surgeon's opinion. Not once in that time had we been offered any counselling despite the overwhelming tragic news we had been given…

Even after Justus was admitted to the cancer ward, it was really only his mother who was offered counselling and information about cancer services. This was despite the fact that his grandmother had also been a primary carer, and I had been, in the Aboriginal sense, his second mother. My family felt that the hospital did not understand the extended Aboriginal family, in which family members other than parents often had close relationships…

The Charles Gairdner Hospital offered alternative treatment, and once Justus (and myself) had a reiki treatment. Although Justus's steroid treatment had made him ravenous most times, I noticed after the reiki a calmness had descended on him and he walked straight past the candy bars on the way out. I really think it is children who should have first preference for alternative treatment, and PMH should talk to the Browne's treatment centre at SCGH so that children can take advantage of the treatments at the hospital. In the days that Justus was passing, it would have been good to have had alternative treatments to help him, but as it was we couldn't even seem to get toys or paints from the cancer OT.

I know that his own doctors at the hospital and the nurses, were very kind and did the best they could. I also understand a psychologist may have been appointed after Justus passed. Not long before Justus passed a baby owl flew into the hospital and was kept a few days until better. Justus had passed the morning he was to be released and all his family were there to see the baby owl fly off. We would have liked to have said something in his name, however, there was no opportunity given.

I have wondered since if Aboriginal families are just not reached out to the same way as white families, perhaps people think we deal with cancer in our own way. It's not true, we need support and help like everyone else.

Submission 95 (Ms Hannah McGlade).

CHAPTER 4

COMPLEMENTARY AND ALTERNATIVE THERAPIES

> Cancer is a chronic condition. In order to get the best result, you need to be able to use every possible resource.[1]

4.1 Although the terms of reference refer to less conventional treatments, this chapter will refer to the more commonly used terms complementary and alternative therapies and distinguish between them. It will outline the current approaches to complementary and alternative cancer treatments, paying particular attention to efficacy and research. The role of government in this field is also discussed. This chapter also considers what is required to progress the acceptance of complementary therapies by mainstream medical practitioners, improve the information available for health professionals and patients on complementary therapies and describes a model of integrative medicine for the health system to work towards.

The great divide: conventional and complementary treatment

4.2 From the evidence presented, there is no doubt that there is a division in Australia between conventional cancer treatment services and the health professionals who work in them and the complementary therapies offered, most often by practitioners outside the conventional system. The Brownes Cancer Support Centre at Sir Charles Gairdner Hospital summed up this divide by commenting that 'in the minds of many mainstream healthcare practitioners all less conventional therapies are tarred with the same brush of being alternative'.[2]

Definitional issues

4.3 It was clear from witnesses that terminology is a very important issue to take into account and the terms currently in use must be clearly defined. In Australia, the proposed Therapeutic Goods Administration (TGA) definition of complementary medicine is:

> Complementary medicines (also known as 'traditional' or 'alternative' medicines) include vitamin, mineral, plant or herbal, naturopathic and /or homeopathic preparations and some aromatherapy products.[3]

4.4 The definition of complementary therapies and complementary medicines used in the report *Complementary Medicines in the Australian Health System* was:

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[1] *Committee Hansard* 18.4.05, p.61 (Professor Sali).

[2] *Submission* 30, p.8 (SCGH Brownes Cancer Support Centre).

[3] Accessed through http://www.tga.gov.au/docs/html/cmfact3.htm on 11.5.05.

> 'Complementary therapies' include a diverse group of health-related therapies and disciplines that are not considered to be part of mainstream medical care in Australia. 'Complementary medicines' include herbal medicines, vitamin and mineral supplements, other nutritional supplements, traditional medicines such as Ayurvedic medicines and traditional Chinese medicines, homoeopathic medicines, and aromatherapy oils.[4]

4.5 The Gawler Foundation stated that 'the definition of key terms as they apply to cancer medicine has been the subject of some debate. There are many terms that are used to describe this area and there is a pressing need for agreement on what these terms actually mean'. Based on definitions used by the USA's National Centre for Complementary and Alternative Medicine (NCCAM), the Gawler Foundation offered the following clarification:

> 1. Complementary medicine or therapy is used together with conventional medicine. Another interpretation is a medicine or therapy that is used in addition to mainstream medicine or complements health or specific therapies or treatment; and
> 2. The term alternative medicine is used in place of conventional medicine.[5]

4.6 Overseas, complementary and alternative medicine and therapies tend to be grouped together. The definition proposed by the National Centre for Complementary and Alternative Medicine at the US National Institute of Health, is used by the National Cancer Institute (NCI) and reported in scientific literature:

> Complementary and alternative medicine is a group of diverse medical and health care systems, practices and products that are used to diagnose, treat and/or prevent illness and are not used in conventional medicine…The term complementary represents those taken in addition to generally accepted practice, while alternative therapies are those undertaken instead of conventional medicine.[6]

4.7 Complementary and Alternative Medicine (CAM) was explained by Mr Lerner in the following way:

> Terminology is a floating issue but I can offer the following rough guide. Alternative therapies tend to refer more to the hard therapies that I spoke of: alternative pharmaceuticals and things like that. Complementary therapies tend to refer to therapies that are used in combination with mainstream therapies. The term of art in the field these days is 'CAM therapies' - complementary and alternative medicine.[7]

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[4] *Complementary Medicines in the Australian Health System*, Expert Committee on Complementary Medicines in the Health System, September 2003, p.12.

[5] *Submission* 45, p.4 (The Gawler Foundation).

[6] Accessed through NCCAM website http://nccam.nih.gov/health/whatiscam/#1 on 11.5.05.

[7] *Committee Hansard* 12.5.05, p.5 (Mr Lerner).

4.8 Mr Lerner spoke of making a distinction between 'soft' and 'hard' therapies, describing soft therapies such as massage, visualisation, imagery and support groups as working on psychological, physical and spiritual levels and hard therapies being such things as alternative pharmaceutical intervention, and alternative herbal intervention. He stated that 'the hard therapies are looked at with much more questioning – and with good reason, because the soft therapies intrinsically enhance quality of life'.[8] He suggested that the 'soft therapies do not require that kind of evaluation because they intrinsically enhance quality of life, and that is reasonably associated, to some degree, with life extension for some people with some cancers'.[9]

4.9 Cancer Support UK, based at the Royal Marsden Hospital defines complementary therapies as a range of therapies based on holistic treatment. They are not seen as an alternative to conventional treatment but help to live with cancer and to cope with the side effects of treatment.[10] Dr Kohn, Complementary and Alternative Medicine Adviser from Macmillan Cancer Relief in London, supported this definition but added that patients now want to know if there are any therapies that apart from making them feel better, may have an effect on the cancer. She said the problem with any alternative cancer cell killing therapies such as alternative diets and alternative immune therapies is that there is currently no robust evidence for their effectiveness.[11]

4.10 Some witnesses recommended that the Committee distinguish between complementary and alternative therapies by the claims being made and the way they are being promoted. If the claim being made was that the treatment would treat or cure cancer then it was classed as 'alternative'. If the treatment was used to support the patient undertake conventional cancer treatment then it was termed 'complementary'.[12] Dr Cassileth, Chief, Integrative Medicine Service, Memorial Sloan-Kettering Cancer Centre, New York, commented that there are no viable alternatives and that 'if they were useful and beneficial, they would not be alternatives; we would all be using them in cancer practices. Dr Cassileth was also of the view that if 'something is promoted as a cancer treatment, as a cancer cure, as something that is as good as or better than surgery, chemotherapy and radiation, and we know that that is not viable, that it is bogus'.[13] A similar view was expressed by Professor Currow who stated 'cancer is a diverse group of illnesses under one umbrella term, and the person who has the 'universal cure' does concern me'.[14]

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[8] *Committee Hansard* 12.5.05, p.2 (Mr Lerner).

[9] *Committee Hansard* 12.5.05, pp.2-3 (Mr Lerner).

[10] Accessed through http://cancersupportuk.nhs.uk/mean/default/.asp?cancer_network=0&lang=en%page=5_home.html on 11.5.05.

[11] *Committee Hansard* 11.5.05, p.3 (Dr Kohn).

[12] *Submission* 36, p.4 (Peter MacCallum Cancer Centre).

[13] *Committee Hansard* 12.5.05, pp.7, 11 (Dr Cassileth).

[14] *Committee Hansard* 19.4.05, p.20 (Professor Currow).

4.11 The NSW Cancer Institute recommended to the Committee that the TGA definition of complementary medicine be adopted nationally but that it be adapted to make reference to the USA and UK definitions in order to further clarify terms.[15]

Conclusion

4.12 Witnesses from the USA and UK emphasised the value of developing a shared language between mainstream and complementary therapists and the Committee believes that this should start with terminology. The Committee received evidence that the definition of key terms, while similar, are not standardised and this could promote confusion and distrust. While complementary and alternative therapies are often talked about together, the Committee believes it is important to make the distinction between them to facilitate greater understanding between mainstream and complementary therapists.

4.13 For the purpose of this report, the Committee accepts that complementary therapies and complementary medicines are used alongside mainstream cancer treatments. Research has been undertaken and there is either scientific evidence to support their use or it is widely accepted that they do no harm. Alternative therapies and medicines are used in place of conventional treatments, are generally unproven and may cause harm. However, the Committee recognises that some cancer patients choose not to use hospital-based conventional services or for whom conventional treatment options have been exhausted and that in their circumstances alternative therapies are a valid choice.

4.14 There are a diverse range of complementary therapies which according to NCCAM can be grouped into five categories:

- Alternative Medical Systems: including naturopathy, Traditional Chinese Medicine, Ayurveda and homeopathy;
- Mind-body interventions: including patient support groups, cognitive-behavioural therapy, meditation, prayer, mental healing and therapies that use creative outlets such as art, music or dance;
- Biologically based therapies: including herbs, vitamins, minerals and dietary supplements;
- Manipulative and body-based methods: including therapeutic massage, chiropractic and osteopathy; and
- Energy therapies: including acupuncture, therapeutic touch, reiki, qi gong, therapeutic touch, electromagnetic fields, magnetic fields.[16]

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[15] *Submission* 53, p.11 (Cancer Institute NSW).

[16] *Submission* 45, pp 5-6 (The Gawler Foundation).

Prevalence and cost of complementary therapies

4.15 The acceptance and use of complementary therapies is increasing. People want to be more active participants in their own healthcare and this is evident in the increasing use of complementary therapies in Australia and overseas. A systematic review conducted in 13 countries found that between 30 to 64 per cent of people have used complementary therapies. Other studies have found prevalence rates of up to 83 per cent depending on the definitions of complementary therapies used.[17]

4.16 Witnesses confirmed that complementary therapies are being extensively used in Australia, with research showing that about 60 per cent of the population use complementary medicines at least once a year.[18] The 2002 Datamonitor Survey covering the United States and Europe indicates that 80 per cent of cancer patients use alternative or complementary modalities.[19] The use of complementary therapies by cancer patients in Australia is reported to vary widely between seven to 83.3 percent.[20] These figures are significant and cannot be ignored by the health system or health professionals.

4.17 The amount spent on complementary therapies confirms the extent of their use with CAM being a billion dollar business in Australia and a multibillion dollar business globally. Between 1990 and 1997, expenditure in the United States doubled from $US14b to $US28b and this situation is likely to be mirrored in Australia.[21] The Gawler Foundation noted that:

> A South Australian Survey in 2000, estimated that approximately 52 per cent of the Australian population used complementary medicines and 23 per cent consulted practitioners of complementary medicine. This represents an estimated out of pocket spending of $2.3b which is a 62 per cent increase since 1993 and four times the out of pocket spending on pharmaceutical drugs.[22]

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[17] Cassileth, B, Deng, G, Vickers, AJ, Yeung, KS, *Integrative Oncology: Complementary Therapies in Cancer Care*, Ontario Canada, BC Decker, p.3.

[18] TGA website accessed at http://tga.gov.au/docs/html/cmfact1.htm on 16.5.05.

[19] Cassileth, B, Deng, G, Vickers, AJ, Yeung, KS, *Integrative Oncology: Complementary Therapies in Cancer Care*, Ontario Canada, BC Decker, pp.3-4.

[20] *Submission* 53, p.9 referencing Verdoef et al, Complementary therapies and cancer care: an overview, *Patient Education and Counselling*, 1999: 38: 93-100 and Richardson et al, Complementary/Alternative medicine use in a comprehensive cancer centre and the implications for oncology, *Journal of Oncology* 2000; 18 (13): 2505-14.

[21] Eisenberg DM, Davies RB, Ettner SL, et al. Trends in alternative medicine use in the United States, 1990-1997. *JAMA* 1998; 280: 1569-1575 quoted in *Medical Journal of Australia*, Complementary and alternative medicine: an educational, attitudinal and research challenge, 2000:172: 102-103.

[22] *Submission* 45, p.6 (The Gawler Foundation) quoting a study by MacLennan, AH, Wilson, DH, Taylor, AW, The escalating cost and prevalence of alternative medicine, *Prev Med* 2002; 35:166-173.

4.18 Estimates provided by industry suggest that the current retail turnover of complementary medicines in Australia is approximately $800m.[23] In 1993 the figure was $621m with $309m spent on visiting complementary practitioners.[24]

What motivates people to use complementary therapies

> …As orthodox physicians, complementary therapies are helping us reassess the basic tenets of good care, such as the value of things like good healing partnerships. This is not just about compliance. Patients will often say they have a wonderful therapeutic relationship with their complementary therapy practitioner. So there is a lot that orthodox medicine can lean from this too.[25]

4.19 The reasons behind the growth in complementary therapies include: patients receiving greater individual attention from practitioners, holistic values, dissatisfaction with medical outcomes, a desire for improved health, increased access to health information as well as a growth in research based evidence supporting the effectiveness of complementary medicine.

4.20 People who experience limited success with conventional medicine will turn to complementary medicines and complementary therapies and this includes people with illnesses such as cancer. Some are dissatisfied that medical practitioners do not allow sufficient time to discuss their health concerns or provide adequate explanations. Complementary practitioners generally have longer consultation times and focus on a patient's lifestyle as well as symptoms. There is a shift towards a more holistic view of health, encompassing mind, body and spirit as well as an increased interest in health prevention strategies such as diet and stress management.

> The mental state of mind as well as the physical strength of the body are two major areas of neglect in traditional medicine. Strength of body and mind can only improve a person's overall ability to fight this disease.[26]

4.21 There has also been a growth in evidence based research into the safety and effectiveness of complementary medicines and complementary therapies which means that more general practitioners are referring their patients to complementary health practitioners, with some undertaking training to provide it in their practice.[27]

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[23] *Complementary Medicines in the Australian Health System*, Expert Committee on Complementary Medicines on the Health System, 2003, p.37.

[24] *Complementary Therapies Literature Review*, Cancer Institute NSW, p.1.

[25] *Committee Hansard* 11.5.05, p.10 (Dr Kohn).

[26] *Submission* 84 (Mrs de Vries)

[27] Much of the information from this section was drawn from the Women's Health Queensland Wide Inc, Health Information – Health journey Summer 1999 *Complementary Medicine* accessed at http://womhealth.org.au/healthjourney/complementarymedicine.htm on 17.2.05.

> If these therapies are helping them to get through the uncertainty, to live better with their cancer, then there is no doubt that there is something that is of great importance.[28]

Comparisons with overseas practises

4.22 What happens in 2005 in terms of complementary therapies is very different to the attitudes and hostilities during the 70s and into the 90s. There has been a softening in attitude by most areas of the medical profession due to some complementary therapies beginning to be used in the conventional sector, especially in palliative care; the support of complementary therapies by a few conventional practitioners who sought out scientific evidence to back up the application of complementary therapies; a surge in the adoption of these therapies in overseas cancer centres and an ever increasing consumer demand.

4.23 In Europe, complementary medicines have a long tradition and have been routinely used side by side with conventional cancer treatments for many years. In the USA and the UK, complementary therapies are also widely accepted and used to assist patients with mainstream cancer treatment. However, from the submissions received and evidence heard by the Committee, Australia would seem to be a long way behind the USA, UK and Europe in terms of the acceptance of complementary therapies by medical practitioners and their automatic inclusion in the treatment plan for a cancer patient.

4.24 In Australia, complementary therapies are not used in most settings as a primary treatment of cancer and this was heavily emphasised by several complementary therapies witnesses representing professional organisations.[29] Primary treatment is provided in the conventional setting by orthodox medical practitioners and complementary therapies are provided to involve and empower the patient, reduce side-effects and contribute to their well being. Witnesses also said that complementary therapy could help the patients extend survival time.[30] Dr Cassileth, Memorial Sloan-Kettering Cancer Centre, New York, reported that the many kinds of pain, side-effects and symptoms associated with cancer cannot be well addressed by mainstream treatments.[31] Complementary therapies are also used to help prevent cancer in healthy people, especially those who may have a genetic predisposition, or to prevent cancer re-occurring in patients who have been successfully treated.

4.25 The view of Nutritional Medicine Doctors and the Australasian College of Nutritional and Environmental Medicine (ACNEM) is that the nutritional status, from

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[28] *Committee Hansard* 11.5.05, p.10 (Dr Kohn).

[29] *Submission* 64, p.3 (Australian Traditional Medicine Society); *Committee Hansard* 19.4.05, p.94 (Mr Khoury).

[30] *Submission* 45, p.16 (The Gawler Foundation); *Committee Hansard* 12.5.05, pp.1-2 (Mr Lerner).

[31] *Committee Hansard* 12.5.05, p.7 (Dr Cassileth).

a biological perspective, of cancer patients is not taken into account in the Australian health system. It is their view that many patients suffer nutritional deficiencies and metabolic imbalances as a consequence of their disease and sometimes because of the severity of the treatment. Dr Peter Eng stated that these patients need to be managed nutritionally and with diet and appropriate supplements. Dieticians in conventional hospitals do not have the time and, in general, are not trained in the practice of nutritional medicine as utilised by nutritional doctors trained by ACNEM. Also, very few doctors in Australia have had any training in nutritional medicine or have had specific training in the management of cancer patients using diet, nutrients, micronutrients etc to either improve the outcome of orthodox management (drugs, surgery and radiotherapy) or reduce the impact of the cancer on the individual patient and thus improve the prognosis.[32] Examples of research supporting this argument were provided by Dr Eng.[33]

Evidence for complementary therapies

> My belief and my experience in doing research is that complementary and alternative treatments are going to provide us with much better ways of dealing with chronic cancer than we had before.[34]

4.26 The Committee heard conflicting statements by witnesses regarding whether sufficient scientific evidence for complementary therapies is available. There is continuing criticism by conventional doctors that there is a lack of hard scientific evidence to support the widespread use of complementary therapies in the health system. However, witnesses from Australia and overseas expressed surprise at this view, indicating that many complementary therapies have been studied and scientific evidence of their efficacy have been published. Indeed, a number of submissions included extensive bibliographies of published evidence.[35]

4.27 Mr Lerner advised that there is a very substantial research literature showing that some of these therapies can enhance quality of life. He commented that evidence is well established in psychosocial therapies for cancer such as meditation, support groups and relaxation. Dr Cassileth emphasised that many people have published randomised clinical trials at the highest levels of science on the merits of acupuncture, music therapy, yoga, tai chi massage therapy, meditation and others.[36] 'There is

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[32] Dr Peter Eng, Personal communication 18.5.05.

[33] *Cancer Research* Vol 54 Issue 22 5848-5855, 1994. *Cancer Research* 59, 3991-3997, August 15. 1999; Qinghui, M, Yuan, F, Goldberg, I,D, Rosen, E.M, Auborn, A, Fan, S, Indole-3-carbinol is a negative regulator of oestrogen receptor – Signaling in Human Tumour Cells, *The Journal of Nutrition*; Dec 2000: 130, 12. *Submission* 67, Information dated 23.5.05 (ACNEM).

[34] *Committee Hansard* 11.5.05, p.11 (Professor Maher).

[35] *Committee Hansard* 12.5.05, p.8 (Dr Cassileth), *Committee Hansard* 18.4.05, p.75 (Mr Spijer); *Submission* 45, p.8 (The Gawler Foundation); *Submission* 26, pp 14-15 (National Herbalists Association of Australia); *Submission* 67 (ACNEM); *Submission* 12 (Professor Bloch); *Submission* 59 (Oncology Social Work Australia).

[36] *Committee Hansard* 12.5.05, p.8 (Dr Cassileth).

evidence from randomised trials supporting the value of hypnosis for cancer pain and nausea; relaxation therapy, music therapy, and massage for anxiety; and acupuncture for nausea'.[37]

4.28 Mr Michael Lerner, offers a scientific appraisal of complementary therapies in his book *Choices in Healing: Integrating the Best of Conventional and Complementary Approaches to Cancer.* When speaking to the Committee he stated that 'it was the first book on integrative cancer therapies to be well reviewed in the scientific literature as well as the lay press'.

4.29 In support of complementary therapies, Mr Lerner described the benefits of a healthy body and mind in living with cancer:

> Any human being who starts taking care of themselves physically, mentally, emotionally and spiritually tends to become a healthier human being. That means you are a healthier human being with cancer. That means you have what oncologists call better functional status. Functional status in drug tests is reliably associated with longer survival, which is why they control for functional status when they test pharmaceuticals, otherwise they cannot figure out to what degree you are living longer because you are in good shape and to what degree you are living longer because of the new pharmaceutical.[38]

4.30 Some witnesses suggested that natural and traditional therapies should not be judged according to the paradigm of mainstream medicine.[39] Supporters of complementary therapies pointed to the overwhelming influence of the pharmaceutical industry in the conventional health sector and claimed that it is in the best interests of this industry that complementary therapies do not gain a foothold in Australia's public health system.[40] This negative attitude within mainstream medicine was taken a step further, with some submissions arguing that alternative cancer therapies are being suppressed as they challenge the prevailing cancer paradigm and serve the vested interests of the status quo.[41] Several witnesses commented on this viewpoint. Mr Lerner indicated that:

> In the course of studying complementary and alternative cancer therapies over the last 25 years I have reached a number of conclusions that I think have stood the test of time. The first is that I have seen no clear-cut cure for any form of cancer among the complementary and alternative cancer therapies in the sense of any treatment that reliably reverses any form of

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[37] Vickers, A.J and Cassileth, B.R, Unconventional therapies for cancer and cancer-related symptoms, *Lancet Oncology,* 2001; 2:226-232.

[38] *Committee Hansard* 12.5.05, pp.1-2 (Mr Lerner).

[39] *Submission* 60, p.5 (Australian Natural Therapists Association) and *Submission* 26, p.6 (National Herbalists Association of Australia).

[40] *Submission* 56 (Burke Road Medical Centre).

[41] *Submission* 15 (Cancer Information and Support Society); *Submission* 56 (Burke Road Medical Centre); *Submission* 104, p.1 (Mr Colin McQueen).

> cancer. This is a very important statement, because there are many people in the field of these therapies who claim that there are cures out there that are being suppressed. I have never seen that phenomenon.[42]

Dr Kohn commented:

> The difficulty lies in the fact that most of those (alternative) therapies today remain unproven rather than disproven. So as physicians we feel that to justify their use we want to see more robust research evidence, to make sure that they work and that they are safe.[43]

4.31 Conventional practitioners to their credit are vigilant in the context of potential harm to their patients, especially when therapies are offered as a primary alternative to conventional cancer treatment, sometimes at an exorbitant cost and with unrealistic promises of positive results. Negative interactions with conventional chemotherapy and/or radiotherapy were also of concern to conventional practitioners. Dr Kohn from the UK agreed that better information needed to be provided on whether some complementary therapies might interact with orthodox therapies and negate their effects. She mentioned encouraging studies to be available through the mainstream information sources so that clinicians are alerted. She also mentioned looking for more ways to educate physicians and make the information easily accessible to facilitate a dialogue between patients and medical practitioners.[44]

4.32 To improve the information available on complementary therapies and ensure safety, Professor Maher suggested three steps. First, an information strategy to get information to health professionals and patients by making use of information, studies and research produced by other countries, backed up with information on safety. Second, a national research program and third, an exemplar centre that is associated with a very highly respected cancer centre.[45]

Research into and regulation of Complementary Therapies

> If we can take a message away from some of this it is not to be unquestioning in our examination of the evidence but that at the same time we need to invest a lot more time and resources into the research which can be not only effective for quality of life, mental health and emotional health, but also potentially can save large amounts of resources for the system itself in that it supports people and helps to prevent or make more simple the management of various complications as well.[46]

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[42] *Committee Hansard* 12.5.05, p.1 (Mr Lerner).

[43] *Committee Hansard* 11.5.05, p.3 (Dr Kohn).

[44] *Committee Hansard* 11.5.05, p.6 (Dr Kohn).

[45] *Committee Hansard* 11.5.05, p.6 (Professor Maher).

[46] *Committee Hansard* 18.4.05, p.59 (Dr Hassed).

4.33 The vast majority of research on complementary therapies and medicine has been conducted in the USA where a significant effort has been made with research primarily funded by government. In the USA, the Office of Cancer Complementary and Alternative Medicine (OCCAM) was established in 1998 within the National Cancer Institute (NCI) to coordinate and enhance activities of the NCI in CAM research as it relates to the prevention, diagnosis, and treatment of cancer, cancer related symptoms and side effects of conventional cancer treatments. Since its creation funding has almost tripled to $119m in FY 2003.[47] In 1998, the National Center for Complementary and Alternative Medicine was also established and is dedicated to exploring complementary and alternative healing practices in the context of rigorous science training complementary and alternative medicine researchers and disseminating authoritative information to the public and professionals. In FY 2005 it received $123.1m from Congress.[48]

4.34 Dr Kohn reported that in the UK the National Cancer Research Institute has a complementary therapies clinical studies development group which is looking at prioritising areas for study and methodological issues.[49] Professor Maher emphasised that dedicated money from government is necessary for research in this area to develop, as was the case in the USA.[50] Australia has no such equivalent organisations directing and prioritising research into complementary therapies.

4.35 The Committee heard from a number of witnesses suggesting that research funding for complementary therapies in Australia is inadequate.[51] Research grants are made available by the National Health and Medical Research Council (NHMRC) which is a statutory body within the health portfolio. Since 2001, of the $1b allocated to research on pharmaceutical drugs, no more than $85,000 has been made available for research into complementary therapies.[52]

4.36 As therapies cannot be patented, which limits the amount of profits that can be made, the government cannot rely on industry alone to undertake research and has a role to allocate adequate funding for complementary therapy research.

4.37 Mr Lerner stressed the need for an ongoing research agenda and described a snowball effect when underway:

> Once you create a budgetary stream without increasing your research expenditure – simply saying, 'Let's put one per cent into this area' – then

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[47] Accessed at http://www.cancer.gov/cam/cam_at_nci.html on 16.5.05.

[48] Accessed at http://www.nccam.nih.gov/about/appropriations/index.htm on 16.5.05.

[49] *Committee Hansard* 11.5.05, p.7 (Dr Kohn).

[50] *Committee Hansard* 11.5.05, p.9 (Dr Maher).

[51] *Submission* 64, p.3 (ATMS); *Submission* 26, p. 7 (National Herbalists Association of Australia); *Submission* 45, p.34 (The Gawler Foundation).

[52] *Submission* 26, p.7 quoting Benoussan, A, Lewith, G.T, Complementary medicine research in Australia: a strategy for the future, *Medical Journal of Australia* 2004; 181 (6): 331-333.

> you begin to get the academics competing for those research dollars. Those academic competitions for those research dollars make it credible in cancer institutes to study these issues. When they are studied, the oncologists recognise that they are being studied and they are being studied by, obviously, the most credible people, since they want it to be done carefully, and so there is a cascade effect down through the system of beginning a research program. There are certainly a lot of people around the world who could support the able researchers in Australia interested in those kind of things.[53]

4.38 As a first step in developing further research in this area, the Committee suggests dedicating a percentage of research funding each year to ensure a funding stream for research into this area which impacts on the lives of so many Australians.

Recommendation 22

4.39 The Committee recommends the National Health and Medical Research Council provide a dedicated funding stream for research into complementary therapies and medicines, to be allocated on a competitive basis.

4.40 The Committee notes that the *Expert Committee on Complementary Medicines in the Health System* recommended that dedicated funding be made available for complementary therapy research in Australia for a minimum of five years. The government response notes that no decision can be made prior to the consideration of research needs and priorities. The Committee therefore would encourage the speedy implementation of recommendation 34 of the Expert Committee's report.

4.41 The field of complementary medicine is very diverse and trials have been criticised for being methodologically weak. However, this argument was rebuffed by Australian and overseas witnesses who said that while there can be methodological challenges in designing research, randomised controlled trials are possible for complementary therapies.[54] In fact the Committee was told that there is a substantial body of overseas clinical research into complementary medicine. As an example, in 2003, the Cochrane Controlled Trials Register recorded 641 clinical trials of acupuncture, 666 of herbal medicine, and 124 of homeopathy.[55] 'The Cochrane Collaboration is an international non-profit and independent organisation, dedicated to making up-to-date, accurate information about the effects of healthcare readily available worldwide. It produces and disseminates systematic reviews of healthcare interventions and promotes the search for evidence in the form of clinical trials and other studies of interventions'.[56]

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[53] *Committee Hansard* 12.5.05, p.7 (Mr Lerner).

[54] Ernst, E, Obstacles to research in complementary and alternative medicine, *Medical Journal of Australia* 2003; 179 (6): 279-280; *Committee Hansard* 12.5.05, p.8 (Dr Cassileth).

[55] *Submission* 87, p.18 (DoHA).

[56] Information accessed at http://www.cochrane.org/docs/descrip.htm on 10.6.05.

4.42 Mr Spijer, Chief Executive Officer of ACNEM, suggested the overseas studies should be used as the basis for studies to be conducted in Australia.[57] Professor Hill, supported this use of research, saying that sometimes NHMRC grant applications fail to take account of existing knowledge.[58]

4.43 The Committee agreed that with the amount of evidence based research available overseas, there is an opportunity for Australia to further tap into that research and make it more widely available for medical practitioners and cancer patients.

4.44 The NHMRC reported that applications for project grants to support complementary medicines research to date have been minimal, with the number of applications ranging from eight to 15 in any one year. The success rate of the applications has varied from 0 per cent in 2004 to 21.4 per cent in 2003, the latter figure being close to the normal success rate for all project grant applications. The NHMRC highlighted that the low success rate reflects a lower competitive standard of the applications as assessed by the NHMRC's peer review process. To improve the success rate they suggested that institutions identify researchers in that area and for the NHMRC to provide mentoring and advice from experienced NHMRC recipients on strategies to improve the number and quality of applications.[59]

4.45 Professor Hill advised that the Cancer Council also funds research on a competitive basis on aspects of cancer research. He also noted that it is difficult for researchers to get funding and suggested mentoring as a way to improve applications.[60] Dr Snyder from the Cancer Council Victoria, highlighted the need for research infrastructure and suggested recognising that non-commercial research should be part of any quality cancer program.[61]

4.46 Dr Kohn emphasised that collaboration is needed across research and practice communities to make sure trials are meaningful in their design. Witnesses, including Professor Aranda from the Peter MacCallum Cancer Centre, also suggested greater collaboration and partnerships to build up complementary therapy research expertise and credibility and agreed specific funding would be required to develop the research infrastructure in this area. Professor Currow also emphasised collaboration and stated 'you have got to get the right relationships; you have got to get the right expertise; you have got to form the right collaborative groups that actually bring the clinical – including complementary care – the research and the ability to attract research dollars together. That is about building collaboration'.[62]

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[57] *Committee Hansard* 18.4.05, p.75 (Mr Spijer).

[58] *Committee Hansard* 18.4.05, p.18 (Professor Hill).

[59] *Submission* 9, p.7 (National Health and Medical Research Council).

[60] *Committee Hansard* 18.4.05, p.19 (Professor Hill).

[61] *Committee Hansard* 18.4.05, p.21 (Dr Snyder).

[62] *Committee Hansard* 19.4.05, p.20 (Professor Currow).

4.47 The demand for complementary therapy from the general population and for people with cancer make it essential that the government exercise its social and ethical obligations to ensure complementary therapies are appropriately researched. The Committee agreed that in order to protect the public, the same rigorous evaluation needs to be applied for complementary therapies as for mainstream treatments. Further, the demonstrated potential of complementary therapies to manage chronic illness and in preventative care represent important national research priorities. In research, Bensoussan also suggests that Australia could become an international leader in evidence-based complementary therapies as medical research expertise is high and clinical trial costs are relatively low.[63]

4.48 However, the fledgling state of Australia's complementary therapy research needs dedicated government funding to develop the infrastructure and expertise. The Committee suggests the body of complementary therapy research conducted overseas is an opportunity for Australia to use and adapt on so that medical practitioners and patients are assisted to make informed decisions. The Committee also agreed that to develop the complementary therapy research infrastructure in Australia, collaborative work needs to be coordinated and prioritised by a central agency.

Recommendation 23

4.49 The Committee agrees with the recommendation of the Expert Committee on complementary medicines in the health system, that the NHMRC convene an expert working group to identify the research needs addressing the use of complementary medicines, including issues around safety, efficacy and capacity building. The Committee recommends that this working group should include complementary therapists in order to develop a strategy to coordinate and prioritise a dedicated research funding stream for complementary medicine and therapy research, taking into account research conducted overseas. The group should also encourage the development of collaborative partnerships across disciplines.

Recommendation 24

4.50 The Committee recommends that the NHMRC develop workshops for complementary therapy researchers intending to compete for funding, where experienced researchers discuss their preparation of research proposals.

Recommendation 25

4.51 The Committee recommends that the NHMRC appoint two representatives, (including one consumer), with a background in complementary therapy, to be involved in the assessment of research applications received by the NHMRC for research into complementary and alternative treatments.

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[63] Bensoussan, A, Lewith, GT, Complementary medicine research in Australia: a strategy for the future, *Medical Journal of Australia* 2004: 181 (6): 331-333.

Safety and efficacy of complementary therapies

4.52 The Government has a duty of care to ensure that complementary therapies are safe for the public. The regulation of complementary therapies provided by healthcare practitioners is not addressed in any Federal legislation. As such, the Commonwealth has no direct power or authority over the way in which health practitioners conduct their professional practice.

4.53 Complementary medicines are, however regulated under the Therapeutic Goods Act 1989 (the Act), which is administered by the Therapeutic Goods Administration. The Act aims to provide a national framework for the regulation of therapeutic goods in Australia and to ensure their quality, safety and efficacy. Under the Act, 'complementary medicines' that make therapeutic claims are regulated as therapeutic goods. All complementary medicines in Australia are scrutinised for safety and quality by the TGA. The overall objective of the Act is to ensure the quality, safety, efficacy, and timely availability of therapeutic goods, including medicines, supplied or exported from Australia.[64] In Australia, the Office of Complementary Medicines was set up within the Therapeutic Goods Administration to focus exclusively on the regulation of complementary healthcare products.

4.54 Australia has a risk-based system where the level of evaluation and regulatory control of a therapeutic good is based on the relative safety of the product and the seriousness of the condition for which it is intended to be used.

4.55 Generally, therapeutic goods must be either Listed or Registered in the Australian Register of Therapeutic Goods before they can be supplied in Australia. Before a product can be included in the Australian Register of Therapeutic Goods, a sponsor is required to submit an application to the Therapeutic Goods Administration, together with relevant supporting data.

4.56 Whether a product is Listed or Registered in the Australian Register of Therapeutic Goods depends primarily on three matters:

- The ingredients;
- The dosage form of the product; and
- The promotional or therapeutic claims made for the product.

4.57 Registered medicines are assessed as having a higher level of risk, and are subjected to a high level of scrutiny. They are individually assessed by the Therapeutic Goods Administration for quality, safety and efficacy prior to market entry.

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[64] Expert Committee on Complementary Medicines in the Health System, Report to the Parliamentary Secretary to the Minister for Health and Ageing, *Complementary Medicines in the Australian Health System,* September 2003, p.55.

4.58 Listed medicines are lower risk than Registered medicines and may only contain ingredients approved by the Therapeutic Goods Administration as being of low risk.

4.59 Indications/claims related to neoplastic diseases (cancers) may only be made after evaluation of the product (and the claims) through Registration of the product. Therefore, claims related to cancer may not be made for Listed medicines. There are currently no complementary medicines Registered for indications/claims related to cancer.[65]

4.60 In May 2003, to reassure the public and maintain confidence in Australia's reputation as a supplier of high quality and safe medicines, the Australian Government established the *Expert Committee on Complementary Medicines in the Health System*. In the wake of the Pan Pharmaceuticals recall it was asked to focus on issues around the supply of safe high-quality complementary medicines, quality use of and timely access to those medicines, and the maintenance of a responsible and viable complementary medicines industry. The Committee recognised three fundamental principles: 'firstly, the need to protect the public health and safety; secondly, the primacy of the right of consumers to be able to make informed choices on matters of healthcare; and thirdly, the ethical responsibilities of all healthcare providers – from manufacturers to healthcare practitioners'.[66]

4.61 The Expert Committee report recommended that the government take a more active role in ensuring that consumers have access to reliable information about complementary medicines, and the skills to interpret this information to be able to make informed decisions. The report also recommended creating a greater awareness among all health professionals and consumers of the potential for complementary medicines to interact with other medicines, and ensuring that consumers are better informed about the potential risk of importing medicines for personal use. It also called on State and Territory governments to introduce legislation to regulate practitioners of traditional Chinese medicine and dispensers of Chinese herbs, based on existing Victorian legislation as soon as possible. The report recommended that internet advertising be considered part of mainstream advertising and be subject to mainstream advertising requirements and protocols. The report also made a number of recommendations about improving the level of research and funding available for complementary medicines.[67]

4.62 In March 2005, the Government responded to the Expert Committee's report, accepting most of the recommendations and stating that it will develop and implement a range of initiatives to improve the regulation of complementary medicines.

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[65] *Submission* 87, pp.17-19 (DoHA).

[66] *Complementary Medicines in the Australian Health System,* September 2003, p.7.

[67] *Complementary Medicines in the Australian Health System,* September 2003, pp.15-34.

Towards Integrative Medicine - Integrating complementary therapies and conventional medicine

A fully integrated approach

People often asked me - and they still do - whether it was the chemo or the other things that made me get well. As far as my experience goes, that is not the right question. What helped me get my health back was a fully integrated approach, which was more than any one discipline could offer. I needed the chemo, the meditating, the diet and the psychological help. From what the doctors said at the time, they certainly did not think that just the drugs could do it. Whether I would have got well without the drugs at all, I suppose I will never know, and I do not think it matters. What did matter at the time was that the Gawler Foundation helped me to pull all the different strands together. There is a lot of expertise in a lot of fields out there but, as a cancer patient, you need them to work together. I just cannot stress that point too strongly.

Committee Hansard 18.4.05, p.56 (Ms Barb Glaser).

> There is a tremendous interest amongst younger physicians and also amongst older physicians in recovering the heart of medicine – the psychological and spiritual reasons why they went into medical practice – and moving away from the exclusively technological and biomedical base on which medicine is taught. I offer that as an indicator that there is a hunger in the medical community for responsible, integrative approaches, which is by no means limited to cancer. I think that hunger really reflects that fact that physicians are part of the culture as a whole and that the culture as a whole has a hunger for these integrative therapies.[68]

4.63 In Europe, there has been a rich, historical tradition of herbal medicine, naturopathy and other complementary therapies, with conventional doctors working with their counterparts in the complementary therapy sector. In the USA and Europe, the benefits of complementary therapies have been acknowledged and are being actively introduced into the conventional health sector as part of what is called integrative medicine (IM).

4.64 Professor Avni Sali, a surgeon and Foundation Head of the of the Graduate School of Integrative Medicine at Swinburne Univeristy of Technology, described integrative medicine as combining the best of both worlds, the scientific aspects of conventional medicine with the scientific aspects of complementary medicine, in order for the patient to get the best result.[69] Michael Lerner also described simply that 'integrative therapies' means 'the integration of the best of both conventional and

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[68] *Committee Hansard* 12.5.05, p.4 (Mr Lerner).

[69] *Committee Hansard* 18.4.05, p.61 (Professor Sali).

complementary areas'.[70] However, in respect of the situation in Australia Professor Sali commented:

> Almost every medical faculty in the US has an integrative medicine component, and I think it is a disgrace that here in Australia more than two-thirds of the Australian public are using some form of complementary medicine and most doctors would not have a clue what their patients are doing. There really needs to be some stimulus in trying to change that culture.[71]

4.65 Courses in IM are now part of the undergraduate and post graduate medical curriculae in many parts of the world but not in Australia. An exception is that Professor Avni Sali was mainly responsible for the establishment eight years ago of the first postgraduate medical school of its kind in IM at the Swinburne University of Technology. The school is primarily focused on educating doctors about complete medicine or IM. Only a handful of Australian universities are currently offering courses in IM, naturopathy and nutritional and herbal therapies.

> Psychosocial therapies and approaches like massage, deep relaxation, exercise and healthy diet – what I call the vital quartet of spiritual, psychological, nutritional and physical approaches to cancer that intrinsically enhance health and quality of life – absolutely are very likely to emerge as tomorrow's mainstream therapies…the evidence that they are becoming mainstream is that more and more cancer centres offer them[72]

Providers of complementary therapies

> The number and type of healthcare practitioners who supply or provide advice to consumers on complementary medicines is large and varied. The group ranges from complementary healthcare practitioners such as naturopaths, TCM (Traditional Chinese Medicine) practitioners, and herbalists, to medical practitioners who may or may not provide complementary medicines to patients but who nevertheless need to be aware of the complementary and the other medicines that patients may be using.[73]

4.66 The Committee noted the variety of groups providing complementary therapies and considered that given the issues raised by the Expert Committee on complementary medicines in the Health Care system, there would be value in forming an umbrella organisation to represent the sector. This organisation would be able to progress recommendations made in the Expert Committee's report such as self-regulation.

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[70] *Committee Hansard* 12.5.05, p.5 (Mr Lerner).

[71] *Committee Hansard* 18.4.05, p.70 (Professor Sali).

[72] *Committee Hansard* 12.5.05, pp.2-3 (Mr Lerner).

[73] Expert Committee on Complementary Medicines in the Health System, Report to the Parliamentary Secretary to the Minister for Health and Ageing, *Complementary Medicines in the Australian Health System,* September 2003, p.12.

4.67 The Committee considered that complementary therapy could be better promoted if there was a more positive interaction between the different organisations in order to discuss common policies on issues such as standards and accreditation. Establishing an umbrella organisation may also lead to more positive interaction with associations representing conventional treatment and integration with their services.

4.68 The Committee saw value in a forum being held on a regular basis which professional complementary therapy bodies could attend to discuss State and Territory government initiatives and issues such as accreditation of members.

4.69 In context of the significant number of cancer patients, as well as those being treated for other conditions, who are using complementary therapies, the government has a duty of care to ensure that patients and their carers can make well informed decisions about which complementary therapies will be the best for their needs. At present complementary therapy practitioners appear to be penalised by the health care system. There are no formal interactions at a professional level between complementary therapy organisations and those representing conventional medicine and yet the numbers of patients using complementary therapies continues to grow. The Committee believes that as a first step, the government should provide a threshold for collaboration between conventional medicine and complementary therapists. Dialogue is essential and the dividends from collaboration will be of benefit to cancer patients.

Recommendation 26

4.70 The Committee recommends that complementary therapy organisations form a collaborative group with the authority to negotiate with representatives from the established medical organisations and to make recommendations to government. This body should organise a regular forum for representatives of complementary therapies to come together and discuss issues affecting their members such as regulation, research funding issues, collaboration and health and cancer initiatives at the Commonwealth, State and Territory levels.

4.71 Professor Sali expressed surprise that in general oncology there is so much resistance to looking at other possibilities, particularly in the area of complementary medicine. Oncologists were particularly mentioned as a group of medical professionals where most negative, dismissive and patronising attitudes towards complementary therapies were frequently encountered. The Committee was told that in Australia, most oncologists are very apprehensive about any type of complementary therapy being offered in an orthodox medical setting and some actively discourage people from even investigating complementary therapies. In contrast, in the USA, major cancer centres such as the Sloan-Kettering Cancer Centre in New York and many others provide complementary therapies as part of their multidisciplinary treatment.

4.72 The Committee heard evidence from Dr Barrie Cassileth of the Memorial Sloan-Kettering Cancer Centre in New York and Professor Jane Maher from the Mount Vernon Cancer Centre and the Chief Medical Officer at Macmillan Cancer

Relief in the UK, both of whom support complementary therapies and provide them within their centres. They both quoted figures that 90 per cent of cancer centres in the USA and UK offer some form of complementary therapy be it on a large scale such as Sloan-Kettering or Mt Vernon Cancer Centre or on smaller scales as resources permit. They said their centres arose from consumer demand, from patients wanting to control side-effects and promote optimum health and overall well being.

4.73 Professor Maher told the Committee that touch therapies, mind body, acupuncture, and energy therapy are well accepted in the UK and that medicinal nutritional therapies are offered but at a lower rate. She reported that over the last few years a change has been brought about by patients, and doctors have moved from being dismissive of complementary therapies to appreciating the benefits of improving quality of life and symptoms. Professor Maher said that in her centre they are very comfortable using acupuncture, homeopathy, aromatherapy, massage, reflexology, shiatsu and the Alexander technique.[74] They also provide a directory of available services and offer therapies to carers and staff. Dr Cassileth mentioned that Sloan-Kettering also offers a consultation service for leaders of hospitals and hospital systems who have come to them from all over the world to lean how to put their program in place.[75]

4.74 Dr Hassed commented on the integration of complementary therapies from a systemic perspective:

> The issue of the potential health care savings of a more holistic and integrated approach is vital, because I do not think the health care system as it currently is, with an industry that supports more intervention and more expensive intervention, is sustainable.[76]

Moving to integration - from ideas into practice

> My experience is that the only way that you make progress is actually to have complementary therapists, alternative therapists and medical scientists who have open minds, working together in reflective practice, and then you find the points of contact.[77]

4.75 The Committee asked the expert witnesses from overseas who have already travelled the path that the Australian health system is now moving along regarding complementary therapies as to what they considered would be the most effective methods to implement best practice services and overcome resistance to the use of and integration of complementary therapies. They advised the following:

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[74] *Committee Hansard* 11.5.05, p.2 (Professor Maher).

[75] *Committee Hansard* 12.5.05, p.9 (Dr Cassileth).

[76] *Committee Hansard* 18.4.05, p.70 (Dr Hassed).

[77] *Committee Hansard* 11.5.05, p.4 (Professor Maher).

1. Start small

4.76 Professor Maher suggested a step by step approach, where therapies are introduced into centres one at a time so that people get used to them and are able to see the benefits.[78]

2. Develop a shared language

4.77 Professor Maher highlighted that it is important for complementary therapists and medical practitioners to develop a shared language in order to work together, emphasising that shared language promoted a better connection between the therapist and medical practitioners.[79] She remarked that while on the Population and Behavioural Sciences Committee on Cancer Research UK, she had been involved in many discussions and debates which started as stand-offs but then gradually moved together as they found a connection.[80]

3. Use Local Champions

4.78 Dr Kohn mentioned the importance of local clinical champions, people with a very solid, orthodox background who are open minded, who are willing to get involved and be actively supportive.[81]

4. Use and adapt information from overseas

4.79 Dr Kohn referred to not just sharing information resources between countries but adapting them for local needs. She particularly mentioned the national guidelines published by the National Council for Hospice and Specialist Palliative Care Service with the Prince of Wales Foundation which deals with issues such as qualification of therapists and evidence base for therapies used.[82]

5. Location, location, location

4.80 Location of the complementary therapy services was also mentioned as important to promote use for not just the people who are more likely to access these services, namely, higher-educated women but also for men. Dr Kohn mentioned a very successful complementary therapy centre in the UK which is physically integrated within an oncology centre and she reported that they get as many men as women and also people from lower socio-economic backgrounds. She added that patients view it as part of the service, the same as any of the other oncological

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[78] *Committee Hansard* 11.5.05, p.4 (Professor Maher).

[79] *Committee Hansard* 11.5.05, p.2 (Professor Maher).

[80] *Committee Hansard* 11.5.05, p.4 (Professor Maher).

[81] *Committee Hansard* 11.5.05, p.5 (Dr Kohn).

[82] *Committee Hansard* 11.5.05, p.5 (Dr Kohn).

services.[83] Co-location of complementary therapies with conventional cancer treatment also assists with acceptance as the benefits for the patients can easily be seen by the medical practitioners.

6. Education, training and information for medical practitioners

> There seems to be a long lag between research and evidence finding its way into clinical practice and maybe this is the way doctors have been educated; maybe it is the lack of a large amount of money to promote non-patentable products for patients; maybe it has to do with a particular way of thinking about cancer which finds it difficult sometimes to think outside the square.[84]

4.81 Education and training has a very important role to play in breaking down the barriers and resistance to complementary therapies and in improving knowledge. Witnesses stressed that medical practitioners do not have to be experts in offering complementary therapies but they need to be experts in understanding its value or lack of value and able to engage in useful dialogue with their patients. Dr Cassileth commented that she had been asked to write chapters on complementary therapies for every major oncology textbook over the last few years. She also emphasised the wealth of information that is available in medical literature, on the internet on sites such as the Cochrane Collaboration and at conferences. In addition, she has just finalised a book, *Integrated Oncology: Complementary Therapies in Cancer Care* that details all the literature, research and what has been shown to be useful and not useful.

> There needs to be a standard. At a minimum, a modern, trained doctor needs to know about complementary approaches, holistic approaches and integrated approaches. There is a bare minimum, because the number of people who are using these things and not telling their doctors is a significant concern.[85]

4.82 The Committee encourages greater education of conventional medical practitioners in the role that evidence based complementary therapies can play to increase patient well being, quality of life and support their conventional treatment. In 2002, the Australian Medical Association produced a position statement on complementary and alternative medicines which recommended education in complementary medicines so that it could be incorporated into medical practices, called on educational institutions and professional colleges to provide CM education, recognised that evidence-based CM should be part of mainstream medicine and encouraged public education in CM. In 2003, the *Expert Committee on Complementary Medicines in the Health System* recommended education and training of medical practitioners in CM. In 2004, the Royal Australian College of General Practitioners and the Australasian Integrative Medicine Association established a joint

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[83] *Committee Hansard* 11.5.05, p.8 (Dr Kohn).

[84] *Committee Hansard* 18.4.05, p.58 (Dr Hassed).

[85] *Committee Hansard* 18.4.05, p.70 (Dr Hassed).

working party responsible for a number of issues to do with how aspects of CM can be introduced into general practice as well as reviewing the Australian Medical Association's Position Statement and its implications for GPs and other issues.

4.83 The Committee believes that medical practitioners treating cancer patients have an obligation to inform themselves and their patients about a wider range of approaches to cancer and know how to direct patients to find reliable information. An example of information recently released is *A Practitioners Guide to Alternative Therapies* produced by Oncology Mayne Pharma which contains 266 references, refers to information from Sloan-Kettering, the *Medical Journal of Australia* and contains useful websites.

Information for cancer patients

4.84 Many cancer patients do not tell their medical practitioners that they are using complementary therapies as they are worried about their reaction. This has the potential for unsatisfactory risk as some complementary therapies have the potential to affect orthodox treatments.

Doctors' attitude to complementary treatment

Why would I tell my doctor? They don't believe in non-hospital treatments. I don't know if it's working but I know it makes me feel better.

Submission 33, p.8 (Breast Cancer Network of Australia).

4.85 Cancer patients want credible information on complementary therapies. Witnesses said they wanted assistance to be able to find legitimate information and also to identify products and therapies for which there may be no scientific evidence.

4.86 The Expert Committee on Complementary Medicines in the Health Care System recognised the need for more information and recommended that the 'Government needs to take a more active role in ensuring that consumers have access to reliable information about complementary medicines, and the skills to interpret information and make informed decisions'.[86]

4.87 Evidence presented to the Committee identified the vast amount of information that is currently available from many sources including the NCCAM at the US National Institute of Health, the British Columbia Cancer Agency in Canada and at Cancer Support UK, which is part of the British National Health Service. This appears, to the Committee, to present an opportunity to access this information for use in Australia.

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[86] Expert Committee on Complementary Medicines in the Health System, Report to the Parliamentary Secretary to the Minister for Health and Ageing, *Complementary Medicines in the Australian Health System,* September 2003, p.22.

4.88 However, cancer patients can be vulnerable to people promoting cancer cures with no scientific evidence and at great personal cost and therefore need information from an authoritative Australian source. One witness described his experience to the Committee:

> There is no end on the internet to people trying to sell you things or promote their own therapies for whatever cancer…when you have nothing else to grab onto these things are at the end of the line…There are multilevel marketing people…he wanted me to buy $1,000 worth of supplements every month…I would ask a lot of these people 'show me the proof', and they would tell me every time that they could not afford to run clinical trials.[87]

4.89 The Committee believes that the government has a duty of care to provide this information which will contribute to informed decision making by cancer patients and those supporting them. The Committee considered the Expert Committee on Complementary Medicines in the Health System's recommendation 25 regarding a study to determine complementary medicines information and skills needs of healthcare professionals. The recommendation was accepted by the Government and the Committee considers that work can contribute to the following recommendation to better promulgate information on complementary therapies.

Recommendation 27

4.90 The Committee recommends that Cancer Australia access the information available internationally on different complementary therapies ad alternative products in order to provide up-to-date, authoritative, evidence-based information which can be regularly updated. This information should be made available in different forms and made available to cancer patients and their families as well as health professionals and other interested individuals.

Regulation of complementary therapy practitioners

4.91 In the context of the concerns expressed by health professionals about some practitioners in the complementary or less conventional sector, Dr Hassed suggested the introduction of some form of accreditation and standards.[88] A number of disciplines have already introduced accreditation and the Committee would encourage the development of regulation by professional bodies to further enhance their status and general acceptance and to protect the public from unqualified or poorly educated practitioners.

4.92 In the UK, Dr Kohn advised that only osteopathy and chiropractic practitioners are statutorily regulated but there is well advanced work underway for

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[87] *Committee Hansard* 20.4.05, p.29 (Mr Pitt).

[88] *Committee Hansard* 18.4.05, p.68 (Dr Hassed).

acupuncture and herbal medicine to be regulated and for some other therapies ultimately being self regulated.[89]

4.93 The regulation of complementary therapies provided by healthcare practitioners is not addressed in any Federal legislation.[90] The *Expert Committee of Complementary Medicines in the Health System* made recommendations to introduce nationally consistent regulations to licence practitioners of complementary medicines and self regulatory structures. In its response, the Government noted that the recommendations in these areas are State and Territory responsibilities, and indicated that the matter will be brought to the attention of the States and Territories through the Australian Health Ministers' Conference. The Expert Committee's recommendations are supported by the Committee which would caution that nationally consistent regulations do need to apply to ensure that there is uniformity between the States and Territories.

Integrative medicine as practiced in Australia

4.94 There is no integrative medicine in Australia along the lines of the USA and UK. Some models in Australia where complementary therapies are offered to patients undergoing conventional treatments include the Peter MacCallum Cancer Centre in Melbourne and the Brownes Cancer Support Centre at Sir Charles Gairdner Hospital in Perth. In these centres, complementary therapies, which have been proven to be effective, have been offered alongside conventional treatment.

4.95 The Peter MacCallum Cancer Centre supports complementary therapies aimed at relieving side-effects or improving general well being where there is evidence from appropriately conducted clinical trials.[91] The Brownes Cancer Support Centre at Sir Charles Gairdener Hospital in Perth is based on a UK model developed by Dr Jane Maher, who was a witness during the inquiry.

4.96 These centres were very well regarded by witnesses and medical practitioners the Committee spoke with but they are an add-on rather than an integral part of a comprehensive cancer service. These centres were seen by the Committee as exceptions to prove the rule. That is, there exists a basic rejection by conventional cancer centres in Australia to integrate with complementary therapies for the benefit of their patients and their carers.

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[89] *Committee Hansard* 11.5.05, p.7 (Dr Kohn).

[90] *Submission* 87, p.18 (DoHA).

[91] *Submission* 36, p.5 (Peter MacCallum Cancer Centre).

Hospital based support centres

Thirteen months ago I was the same as everyone else out on the street, just trotting along. I found a small lump in my neck. The next thing I knew, there was a diagnosis of cancer. That has turned my whole life completely upside down - in a fairly positive way in the long run but there have been some hurdles to go over along the path… When it came, I suppose the first thing that hit me was the fear of telling my children and my parents. When you think of cancer, you generally associate it with a death sentence. That is how I perceived it until about 12 months ago. So there was a big mental leap to make…. I have had quite a few visits to the [Brownes Cancer Support] centre here. The centre made a huge difference to my perception of going to the hospital. I would go not only to receive chemotherapy and other nasty things but to lie down and have a massage for an hour. At a time close after diagnosis, when I had a veneer of control but where everything underneath was turbulence, it was such an oasis. It was a wonderful place to visit.

Committee Hansard 31.3.05, p.55 (Ms Betsy Bush).

4.97 As the evidence base increases, the Committee agrees that complementary therapies should increasingly be integrated into conventional cancer care centres and the Committee encourages institutions and medical practitioners to use the steps outlined above to facilitate greater access to complementary therapies by their cancer patients.

Recommendation 28

4.98 The Committee recommends that where quality of life may be improved by complementary approaches, methods to make such therapies more accessible be discussed by State and Territory cancer services, including consumer representatives.

Complementary therapy services in the non-government sector

4.99 The majority of complementary therapy services are still funded largely through charities and by individuals.[92] In Australia, in the non-government sector, there are many organisations providing complementary therapies. Some, such as the Gawler Foundation in Victoria, have been providing a service for over 25 years. Their funding comes from fees charged for their services, including retreats, and fund raising. The Gawler Foundation has active participants from conventional medicine on the Board of Management including Dr Craig Hassed from Monash University and Professor Avni Sali. Dr Hassed and Professor Sali both referred to significant amounts of scientific evidence that complementary therapies improve quality of life and may

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[92] *Committee Hansard* 11.5.05, p.7 (Professor Maher).

extend survival time. Dr Gawler, the founder of the Gawler Foundation, noted that there is quite a body of research and their submission contains about 160 references.[93]

4.100 Dr Gawler referred to the adversarial situations they often found themselves in with some of those representing conventional medicine and institutionalised organisations. The Committee was surprised to hear that despite the Gawler Foundation's historical presence in Victoria and the large numbers of patients and carers that they cater for and successfully assisted, they had not been invited by the Victorian Department of Health to make any contribution to the planned reorganisation of the state's cancer treatment services.

4.101 Bloomhill Cancer Care in Queensland was another organisation providing complementary therapies which the Committee spoke with. It works very closely with all oncology wards in the surrounding area and has a formal partnership with BlueCare Palliative Care Service. Bloomhill provides therapies such as massage, music and art therapies, reflexology, meditation and others as well as counselling. They support not only the cancer patient but the whole family and carers, from the time of diagnosis. The Founder of Bloomhill, Margaret Gargan emphasised that they encourage people to access orthodox medical treatments but utilise complementary therapies as well. Ms Gargan said that in the Bloomhill model, once a person is assessed, they send letters to their doctors to tell them what therapies they are being offered so they are working as a team.[94]

4.102 The popular demand for the complementary therapies offered by these services is demonstrated by the large number of interstate courses run by the Gawler Foundation and Bloomhill expanding into the Blue Mountains in NSW.

4.103 Various Foundations and Associations representing different sectors of complementary therapy, as well as individuals, presented evidence to the Committee. The Committee was concerned to hear from professional complementary therapy organisations that they were not involved with the cancer initiatives being implemented at the State and Territory level. The Committee considers that such disregard of complementary services operating in the non-government sector by government bodies needs to be resolved to encourage the further development of integrative medicine in Australia.

Recommendation 29

4.104 The Committee recommends that State and Territory governments include the views of peak complementary therapy bodies in each State and Territory regarding the planning and delivery of cancer services.

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[93] *Committee Hansard* 18.4.05, p.68 (Dr Gawler).

[94] *Committee Hansard* 20.4.05, p.19 (Ms Gargan).

Conclusion

4.105 The Committee supports the recommendations made by the Expert Committee on Complementary Medicines in the Health System in their Report to the Parliamentary Secretary to the Minister for Health and Ageing in September 2003.

4.106 As noted by Dr Ian Gawler, cancer services are in the early stages of a paradigm shift fuelled by the public demanding better outcomes and better access to information on complementary therapies and medicines. The use of complementary therapies is increasing in Australia and overseas. Some patients are disillusioned with the outcomes provided by conventional medicine and turn to complementary therapies and alternative therapies to alleviate and better manage acute conditions such as cancer. This dissatisfaction can be due to the limited success with conventional outcomes; the lack of time of many medical practitioners to discuss health concerns and provide comprehensive explanations; and the shift to a more holistic view of health which looks at the whole person, including their lifestyle and emotional health and not just their symptoms.

4.107 The Committee recognises that complementary therapies are a priority for cancer patients. People want to be more active participants in their own health and due to increasing information, especially on the internet, they are better informed. Evidence has shown that there are ethical, evidence based integrative approaches to cancer care that enhance quality of life and may contribute to life extension. Patients should be able to access the level of information they require and weigh up information on proven complementary therapies so they can make informed choices about their use. The Committee believes that government has a social and ethical obligation to respond to community needs. Enhancing quality of life is a major social benefit which could be achieved at relatively low cost. As well as the government, the Committee would urge health professionals, institutions and organisations to recognise their social and ethical obligations in this area.

4.108 Evidence based research leads to informed choice and some complementary therapies are now supported by research. They are driven by progressive universities providing more graduate and postgraduate training and their use is being adopted within progressive hospitals. To date most complementary therapy research has been undertaken overseas, even though Australia has a world renowned capacity for undertaking quality research. The development of complementary therapy research in Australia requires dedicated funding along with a strategy to identify priority areas and to assist researchers competing for funding.

4.109 It is apparent from the inquiry that Australia is lagging some distance behind the USA and the UK in the development of the complementary therapy sector and the integration between mainstream and complementary therapies. After speaking to witnesses, the Committee was left with the indelible impression that, in the best interests of cancer patients in Australia, there needed to be an integrative approach based on the models in the UK, the USA and other international centres.

Lisa's story – An integrated approach

When I began my journey in February 2000, I was keen to embrace an Orthodox and Natural approach to Breast Cancer. Although a multidisciplinary tactic to my wellness was suggested in the reading material, when I inquired whom my Naturopath, Homeopath and Chinese Herbalist would be, the silence was deafening. I was soon to realise there was no methodology in place to support the delivery of my request for other modalities. There was also an observable culture of resistance, to the pursuit of legitimate objectives, by a broad range of those in positions of power in the Medical arena.

In 2004 the Cancer returned. My experience this time round was very different, but then so was the disease. The final Diagnoses: Liver, lung kidney, left breast now two lumps, an external tumor on my left side, lymph nodes, neck, right sixth rib, a moth eaten left hip lower spine and pelvic area…

This time I searched for practitioners that were willing to work together. Over the past 12 months my journey has been amazing. I was able to collaborate with 4 different practitioners. My medical heroes are:

Dr. Qi Chen, a Chinese Oncologist who has been practicing Traditional Chinese Medicine (TCM) for over twenty-three years.

Professor Martin Tattersall of RPA with 30 years experience and Australia’s first Professor of Oncology.

Michael Trembath who works on aligning both the physical structure and vibrational balance of the body.

Alistair Gray, a Practitioner in Homeopathic Medicine. A discipline committed to the seamless dynamic health of the mind, the emotions, and the physical body.

In the beginning we agreed that they were free to discuss any part of my treatment with each other. I would have regular visits with them – some weekly, some monthly, to have treatments. I was empowered with understanding, knowledge and support to make informed decisions…

Rarely does a day go past without a conversation about health. The more people I speak to the more I hear of such stories and desire for something in addition to their current treatment…We have a responsibility to share these experiences and give other patients the options, remembering we must also respect their choices. We are more than capable of combining many facets of medicine to establish a truly integrated approach and whilst we are at it, a Healthcare system that supports these modalities. This will only happen and be sustainable through continuing education.

Through the course of the past 5 years, I have come to the conclusion that there is an urgent need for a place or center where information of this nature is readily available, with an integrated approach to wellness. There must also be a program of attitudinal change.

Submission 55 (Ms Lisa Whittaker).

CHAPTER 5

OTHER ISSUES RAISED IN THE INQUIRY

5.1 Improving cancer outcomes is a multifactorial field that extends far beyond the scope of this inquiry. While the Committee's investigations were necessarily focussed by the terms of reference, a number of specific issues relating to cancer treatment and care were raised in submissions and at the hearings. These are briefly discussed in this chapter.

Early detection through screening programs

Access to free mammograms

5.2 The issue of providing free mammograms for women outside the target ages, through the national breast cancer screening program, was raised.

5.3 The Department of Health and Ageing advised that BreastScreen Australia actively targets women aged 50-69 years, but women aged 40-49 and over 70 years are also eligible to attend.

5.4 This policy is in line with international evidence which demonstrates that breast cancer screening is most effective in the 50-69 year age group. BreastScreen Australia is a joint Commonwealth, State and Territory funded program. Funding is provided by the Commonwealth through the Public Health Outcome Funding Agreements. The Agreements are bilateral funding agreements between the Commonwealth and each State and Territory Government. The agreements provide State and Territory Governments with broadbanded (pooled) funding linked to the achievement of outcomes in a range of public health programs including breast cancer screening.

5.5 An article in the March 2002 edition of the *Medical Journal of Australia* reports on outcomes of a systematic review of screening mammography in women 70 years and over. The review concludes that:

- Age is the strongest risk factor for breast cancer, as indicated by the increasing number of cancers detected across age groups - however, because older women at a higher risk of death from other causes, they may only experience the downsides of screening, and not live long enough to experience the benefits; and
- Women aged 70 years and over, in consultation with their doctor, may want to decide for themselves whether to continue mammographic screening.[1]

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[1] Alexandra L Barratt, Les M Irwig, Paul P Glasziou, Glenn P Salkeld and Nehmat Houssami, Benefits, harms and costs of screening mammography in women 70 years and over: a systematic review, *The Medical Journal of Australia,* 2002, 176, 266-271.

5.6 This is consistent with current BreastScreen Australia policy, although individual States and Territories have different practices in relation to service provision for women over 70 years of age. All women over the age of 70 years can make an appointment and attend any BreastScreen Australia service across Australia.

5.7 All eligible women aged 50-69 years who already attend BreastScreen Australia services are reinvited to attend for breast cancer screening every two years. However, there are differences between jurisdictions as to when women are no longer invited to attend for breast cancer screening. Where States and Territories do cease to reinvite after women have reached an upper age limit, letters are sent to women affected outlining the reasons why they will not be reinvited in the future but that they are free to call and make an appointment for a two-yearly mammogram if they wish.[2]

Access to free mammograms once diagnosed with breast cancer

5.8 Witnesses raised the issue of their ability to access breast cancer screening through BreastScreen Australia following a diagnosis of breast cancer.[3]

> My breast cancer was detected by BreastScreen and I found they provided an efficient service of the highest professional standard. So I was understandably surprised when I was advised that my follow up mammograms would not occur at Breastscreen, but on a referral from my surgeon to a private Radiologist...
>
> When I made my appointment with this private radiologist, I was informed that the mammogram and ultrasound would cost $314-00, payable at the time of service. Fortunately at the time, I was in a position to meet such a financial demand, but I know of many women who would find an up front payment difficult under any circumstances. The benefit I received from Medicare for this service was $164-60, leaving my family out of pocket $149-40. This is obviously a huge burden for many women on low or no incomes; it is a pressing social issue for women who have no direct access to money, which is not uncommon when many women are forced to take long periods off work to undergo cancer treatment plans.[4]

5.9 The BreastScreen Australia Program, as a population screening program, is aimed at well women, without symptoms. BreastScreen Australia services recommend that women who have had breast cancer in the past and have had surgery to remove a lump or for a mastectomy continue to visit their breast specialist for their regular mammograms. Reasons for this include:

- If a woman has had breast cancer and surgery to remove a lump, special techniques and procedures may be required, such as detailed pictures of the treated part of the breast. These special procedures are not offered at a

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[2] *Submission* 87, p.15 (DoHA).

[3] *Committee Hansard* 19.4.05, p.33 (Ms Crossing).

[4] *Submission* 101, pp.1-2 (Ms Catherine Green).

screening visit as BreastScreen Australia is set up to provide mammograms to detect the apparent early signs of breast cancer in women with no symptoms.

- If a woman has breast cancer, regular check-ups should involve a thorough clinical examination by a doctor, annual mammograms and any other test that may be required. BreastScreen Australia only provides screening mammograms.

5.10 State and Territory BreastScreen Programs are responsible for determining their own policies for making services available for women who have been diagnosed with and treated for breast cancer. Some States take women who have had treatment for breast cancer back into the screening program after a specified period of time, others take such women back if they have a letter from their treating surgeon indicating that it is appropriate for that woman to return to biennial mammographic screening.

5.11 The Committee is also aware that the Cancer Funding Reform Project, reporting through the Health Reform Agenda Working Group to Australian Health Ministers is examining a range of strategic funding issues associated with the provision of cancer care. The project will investigate the current funding arrangements for cancer treatment in the Australian health system across the public and private sectors.

Recommendation 30

5.12 The Committee recommends that the target age groups for BreastScreen Australia and the National Cervical Screening Program should be reviewed regularly, given the increasing trends in life expectancy for Australian women. In addition, a review should be conducted of how women outside the age limits are made aware of their cancer risk.

Access to breast prostheses and lymphoedema sleeves

5.13 Issues relating to access to breast prostheses and lymphoedema sleeves were raised in evidence.[5]

5.14 Ms Crossing explained that if a women has a mastectomy they need a breast prosthesis so their spinal alignment does not become compromised and cause other health problems. She reported that access to breast prostheses after a mastectomy is not consistent between States. The same difficulties apply regarding access to lymphoedema sleeves which are necessary to treat 'painful swelling of the arm'.[6]

5.15 The Department of Health and Ageing advised that the Medicare Benefits arrangements are designed to provide assistance to people who incur medical

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[5] *Submission* 24, p.3 (Breast Cancer Action Group NSW).

[6] *Committee Hansard* 19.4.05, p.33 (Ms Crossing).

expenses in respect of clinically relevant professional services that are contained in the Medicare Benefits Schedule, and rendered by or on behalf of qualified medical practitioners. Therefore Medicare benefits are not payable for the costs of aids and appliances, including breast prostheses and lymphoedema sleeves.

5.16 However, the Commonwealth does provide funding for the surgical implantation procedure, under the Medicare Benefits Schedule for privately insured patients (excluding those seeking implantation for purely cosmetic purposes) and for public patients (including the prostheses) through the Australian Health Care Agreements.

5.17 The Plastic and Reconstructive Subgroup of the Medicare Benefits Schedule contains a number of services which provide for the surgical implantation, removal and/or replacement of breast prostheses as well as breast reconstruction procedures for women who have undergone mastectomy.

5.18 In addition, private health insurance funds are currently required under the Surgically Implanted Prostheses, Human Tissue Items and Other Medical Devices (Schedule 5) of the National Health Act 1953 to fully fund prostheses items that are provided as part of an episode of hospital care, such as breast implants.

5.19 The funding for breast implants listed in Schedule 5 is limited to patients who have undergone specific Medicare Benefits Schedule procedures; it does not cover the prostheses provided for cosmetic procedures such as breast enlargement. The range of surgically implanted breast prostheses listed on the Prostheses Schedule includes both saline and silicone-gel filled prostheses. The Commonwealth has had no role in the funding of products currently listed on Schedule 5. This has been a matter between the health funds and the supplier of the product.

5.20 For external prostheses (not surgically implanted) like breast prostheses and lymphoedema sleeves, private health insurance funds may be able to provide a rebate for the cost of the prostheses as part of their ancillary cover.

5.21 If the person does not have private health insurance, help may be available from State/Territory governments, such as the Program for Aids for Disabled People in New South Wales.

Access to PET scans for people with recurrent or advanced breast cancer

5.22 The issue of access to Positron Emission Tomography (PET) scans for people with recurrent or advanced breast cancer was raised.[7] Ms Crossing noted that although Positron Emission Tomography scans for most cancers are funded by the Commonwealth, they are not funded for breast cancer even though a great deal of evidence shows it is an important tool for following and staging the course of advanced breast cancer. Cost implications for the patient are significant with

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[7] *Submission* 24, p.3 (Breast Cancer Action Group NSW).

Ms Crossing indicating that 'it is $900 out of your pocket and that is a huge sum of money for most women faced with this particular situation'.[8]

5.23 The Department of Health and Ageing advised that there are currently 13 PET scanners in Australia. Nine scanners receive Commonwealth funding in eight facilities and all eight facilities are participating in an evaluation of PET clinical and cost effectiveness. Results from this program are expected to become available from mid 2006 and will inform the decisions about future PET funding.

5.24 The Department also advised that the average Medicare Benefits Schedule fee for a PET scan is around $950 and that conditions of Commonwealth funding specify that scans are performed at no or minimal out of pocket cost to the patient. PET effectiveness and cost effectiveness in the management of breast cancer would need to be considered by the Medical Services Advisory Committee before any decisions about public funding could be made. The role of the Medicare Service Advisory Committee is to advise the Federal Minister for Health and Ageing on the evidence relating to the safety, effectiveness and cost effectiveness of new medical technologies and procedures.[9]

Adolescent cancer care

5.25 The provision of appropriate cancer care services for adolescents and for young adults with cancer, an age group for whom the incidence of cancer is increasing, was raised in evidence by a number of people including witnesses from CanTeen and the Centre for Children's Cancer and Blood Disorders at Sydney Children's Hospital:

> Published Australian data, which mirrors overseas data, indicates that during the past decade alone cancer incidence has increased by 30 per cent in young people aged between 10 and 24 years. This increased incidence of cancer in adolescents and young adults is higher than in any other age group.[10]

5.26 The Committee was advised that there is also growing concern internationally for the adolescent and young adult cancer population and mounting evidence for targeting improvements for this patient group.[11]

5.27 While cure rates both for younger children and older adults with cancer have improved, the same is not true for adolescent cancer patients as shown in Figure 5.1.

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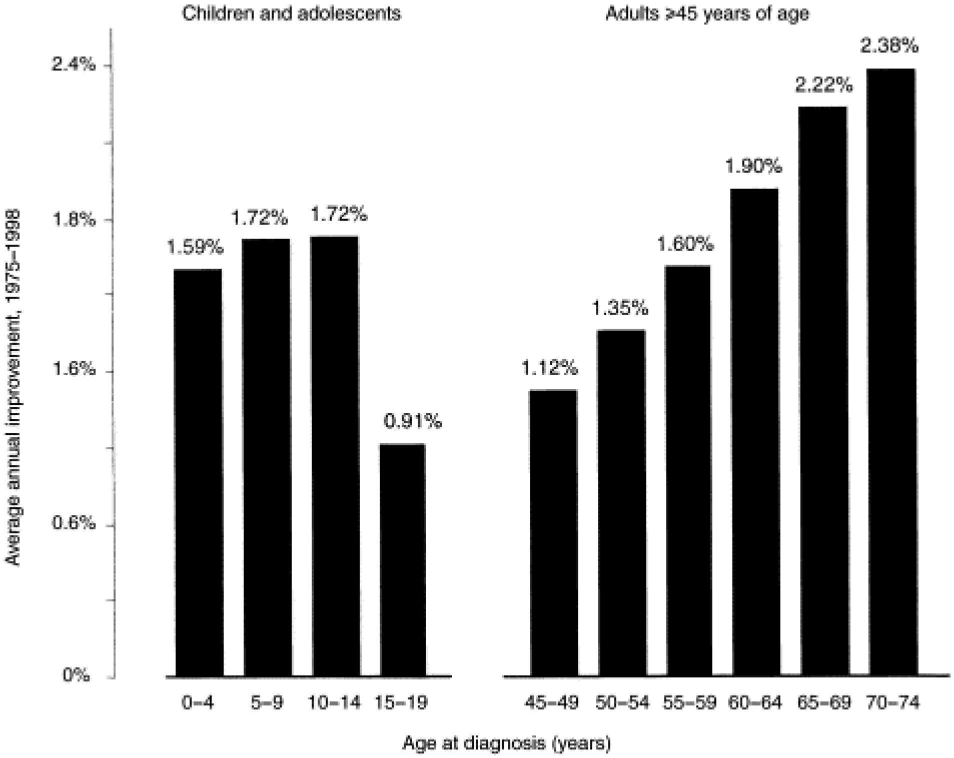
[8] *Committee Hansard* 19.4.05, p.33 (Ms Crossing).

[9] *Submission* 87, supplementary information, (DoHA).

[10] *Committee Hansard* 19.4.05, p.57, (Dr O'Brien).

[11] *Submission* 69, p.2 (Ms Ewing).

Figure 5.1: Management of cancer in adolescents



Source: Albritton K and Bleyer WA, 'The management of cancer in the older adolescent', *European Journal of Cancer* vol.39 2003, pp.2584-2599.

5.28 Issues for adolescents as described for the Committee include firstly, that access to clinical trials for adolescents with cancer is very poor which means they are less likely to have access to state-of-the-art treatment. Secondly, they are less likely to be treated in specialised multidisciplinary cancer care units where the best results are achieved. There are no guidelines for the referral of adolescents and young adults with cancer to specialist care which means they are randomly referred to either paediatric or adult cancer physicians. Dr O'Brien indicated that:

> Survival rates for children with leukaemia or cancer are higher when treatment is supervised by a tertiary paediatric cancer centre, where treatment is planned and supervised by a multidisciplinary team comprising both medical, surgical and radiation oncological disciplines, and where treatment utilises active trials conducted by international paediatric cooperative groups.[12]

5.29 A recent Victorian study was quoted as demonstrating that treating adolescents with a particular type of bone tumour in a paediatric regime improved survival rates by 50 per cent.[13] Other evidence based on studies by McTiernan in the

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[12] *Submission* 99, p.2 (Westmead Hospital, Sydney and The Children's Hospital at Westmead Sydney).

[13] Mitchell, A, E et al, *Medical Journal of Australia* 2004: 180 (2): 59-62.

UK and referred to by witnesses reported that international studies have shown significant improvements in outcomes for adolescents and young adults treated on clinical trials. The review by McTiernan confirmed that adolescents with acute lymphocytic leukaemia, non-hodgkins lymphoma, nephroblastoma and rhabdomysarcoma as well as medulloblastoma have all shown a significant survival advantage when treated on trial protocols within specialist centres, compared to those that are not.[14]

Recommendation 31

5.30 The Committee recommends that Cancer Australia consider the development of appropriate referral pathways that take account of the particular difficulties confronted by adolescents with cancer.

Damien's story – The needs of adolescents

In April 1999 I was diagnosed with a bone cancer called Osteosarcoma, in my left knee. At the time I was 15 years old and was treated at the Royal Children’s Hospital in Melbourne for 9 months.

When I was diagnosed I was a typical 15 year old. I was very fit and healthy and had no history of cancer in my family. I didn’t know anything about cancer or any of the treatments for it. It was something I had never come across before.

From the time ‘something showed up on the x-ray’ until the time I finished my treatment I wasn’t at school. This meant that I didn’t get the opportunity to spend time with my friends like a ‘normal’ teenager would. Even outside of school my friends didn’t come and visit me. I assume because they didn’t know what to say. This meant that I didn’t have anyone who was my age that I could talk to about what was happening to me. Even within the hospital there were very few teenagers of my age due to that fact, I was being treated at a children’s hospital…

Soon after I finished my treatment, I attended a camp for Patient Members of CanTeen. This was the first opportunity I had had to talk to people my age about what had happened in the last 9 months of my life and how it would effect the rest of my life. I got to meet people who had ‘been there and done that’ and see how they had continued with their lives…

I believe it is hard enough for a young person to grow up and cope with the normal changes that happen in their life. Throw in a diagnosis of cancer, and it throws the young person out of their normal life, and into hospital. Being able to talk to people my age that had been through similar experiences was able to bring back some kind of ‘normalness’ into my life.

Submission 51, p.14 (CanTeen Australia).

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[14] McTiernan. A, Issues Surrounding the participation of adolescents with cancer in clinical trials in the UK, *European Journal of Cancer Care*, 12 (3), 233-9, September, 2003.

5.31 CanTeen, the organisation that supports young people living with cancer, indicated that 12-24 year olds undergoing treatment were not surviving as well, or being supported as well, as were children between the ages of 1-12.[15]

5.32 The psychosocial care needs of adolescents with cancer differ from those of an adult or a child and are not being addressed. Witnesses, including young patients, emphasised that when you are a teenage patient, being treated in a children's environment adds to the frustrations in terms of the physical facilities and the support services. These frustrations are similar if the adolescents were treated in a ward with very sick adults. The personal experience of a teenage cancer patient being treated in a children's hospital was described by Ms Michels:

> The women's and children's hospital has a toy room, a great resource for little kids. The walls are painted with huge bright murals of clowns, fairies and under-the-seas themes, all directed at small children. The prints in the rooms are of kittens and Peter Rabbit, and the video collection had much to be desired. Once you have sifted through the Wiggles and stories like that, you might get to view something like Toy Story. I wanted a couch to sit on and play music that I like listening to. I found myself spending a lot of time in the 'quiet room', which is a room with two couches and no bright paintings or anything. The small children did not go in there as it was not exciting.[16]

Ms Michels then described her experience when treated in an adult hospital a few years later:

> I met a lot of lovely people and their families but I struggled a lot because of the age gap. I did not feel like we could talk about the stuff that teenagers talk about in front of adults. It was hard for my friends to stay positive around me as I was surrounded by sick and older people lying in beds.[17]

5.33 Witnesses told the Committee there appeared to be inflexibility in decisions and policies as to where adolescents are treated which could impact on outcomes. One example was given for NSW: 'if you are aged 15 and 11 months then you can go to a children's hospital. If you are 16 then you cannot be admitted to a children's hospital for a new diagnosis of cancer'.[18] Ms Ewing noted that the Cancer Control Network:

> acknowledges that adolescents with cancer "present a challenge that is not adequately addressed by current systems or models of care in Australia". [White 2002]. This situation is likely to have occurred because the care of adolescent patients is often seen as neither the preserve of paediatric or

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[15] *Submission* 51 p.2 (CanTeen).

[16] *Committee Hansard* 19.4.05, p.61 (Ms Michels).

[17] *Committee Hansard* 19.4.05, p.63 (Ms Michels).

[18] *Committee Hansard* 19.4.05, p.70 (Ms Senner).

> adult services [Leonard et al 1995], and consequently these people fall into the void between.[19]

5.34 It was suggested to the Committee that the way to address this issue is for the establishment of specialised teenage cancer units where there could be collaboration between both paediatric and adult cancer specialists. Such a unit would utilise a multidisciplinary team to deliver appropriate medical and psychosocial care.[20]

The needs of adolescents

The needs of adolescents are different to those of both children and adults, as there is this middle ground. We are not dependent, like children are on their parents, but we do not have people dependent on us. We have all different issues. By having adolescent wards you would be surrounded by people where you fit in, you feel like you belong and you are not alone. You could have the same interests. Friendships would naturally form and support would be given. Adolescents would be surrounded by others that are dealing with similar situations in and out of hospital. They can relate to what is going on, as they are going through the same things. There would be a positive environment with others who they can feel comfortable and relaxed amongst. We can share, listen, have fun, joke, be ourselves, relax, learn, heal and grow throughout this. Talking is a great healer for cancer patients because it releases disturbing thoughts bottled up inside. It is proven beyond a doubt that the mind can help heal the body when you are thinking positively. Cancer patients and other young people living with cancer have a genuine understanding of each other’s situation and what we are going through.

Committee Hansard 19.4.05, p.63 (Miss Lauren Michels).

5.35 The Committee concluded that it was very important that information was provided as soon as possible about the current treatment profile in Australia for this age group, how it compares with other countries and how many clinical trials are available and being accessed. In terms of the environments in which these young people are being treated, often for long periods of time, it was important to ask the State and Territory health departments how they are addressing the issue.

Recommendation 32

5.36 The Committee recommends that State and Territory Governments recognise the difficulties experienced by adolescent cancer patients being placed with inappropriate age groups and examine the feasibility of establishing specialised adolescent cancer care units in public hospitals.

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[19] *Submission* 69, p.2 (Ms Ewing).

[20] *Committee Hansard* 19.4.05, p.58 (Dr O'Brien).

Research

5.37 The Committee noted that cancer research in Australia is funded by a number of bodies including the Commonwealth, through the NHMRC, as well as State and Territory governments, Cancer Councils and charities and others.

5.38 The Commonwealth Government announced as part of the 2005-06 Budget that funding will be provided over four years for a dedicated cancer research budget and that seed funding is to be provided to establish a National Research Centre for Asbestos Related Diseases.

5.39 The Committee was advised that the Cancer Institute New South Wales has a major research program and has invested research fellowships, infrastructure that enables researchers to access equipment and expertise, and translational (bench to bedside) research.[21]

5.40 The Victorian Department of Human Services has established a Cancer Research Working Group. The group provides advice on the better integration, coordination and development of cancer research and promotes communication between research centres and health services to facilitate the translation of cancer research into clinical practice.[22]

5.41 The Cancer Institute New South Wales has recommended that the Commonwealth government consider a more strategic focus for cancer research.[23] The Institute suggested that, in addition to the traditional areas funded by the NHMRC, further research should be directed towards translational research, health services research, screening and early detection, and clinical trials.

Clinical Trials

5.42 Clinical trials are fundamental to establishing whether there is benefit in new treatments. Participation in clinical trials needs to be encouraged as there is evidence that people receive better care and have longer survival if enrolled in trials, though there is a considerable disparity between the numbers enrolled.[24]

5.43 Witnesses expressed concern at the relatively low enrolment of people in clinical trials, with the enrolment of adults being around two to three per cent though 20 to 30 per cent are eligible.[25] This contrasts with children, where every child is considered for a trial and over 50 per cent are entered.

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[21] *Submission* 53, pp.2, 6 (Cancer Institute NSW).

[22] *Submission* 66, p.5 (Victorian Department of Human Services).

[23] *Submission* 53, p.6 (Cancer Institute NSW).

[24] *National Service Improvement Framework for Cancer*, p 42.

[25] *National Service Improvement Framework for Cancer*, p 42.

5.44 The Cancer Institute New South Wales stated that national cancer clinical trials are poorly funded and operate on grants from philanthropy. The Institute called for the provision of support to these groups from governments throughout Australia.[26]

5.45 The Committee noted that in response to the low enrolments in clinical trials, the Cancer Institute New South Wales established The Clinical Trials Program which has four main aims, to:

- Introduce and study new cancer treatments;
- Increase participation rates in cancer clinical trials;
- Promote a culture of research and innovation in our cancer service programs; and
- Connect cancer clinical trials in New South Wales to key national and international trials.

5.46 A Clinical Trials Office has been established to assist the Cancer Institute New South Wales in achieving the above listed aims. The Clinical Trials Office will endeavour to provide high quality cancer clinical trial infrastructure for New South Wales, managing the initiatives identified as a result of workshops and discussions with key stakeholders and groups.[27]

5.47 The Committee also noted that the Commonwealth is committing significant funding over the next four years to provide infrastructure grants for cancer clinical trials through the Strengthening Cancer Care Initiative.[28]

Data

5.48 Many witnesses identified gaps in cancer data, which if addressed could lead to improvements to both service planning and treatment for cancer patients.

5.49 The Australian Institute of Health and Welfare identified three major gaps in national data on services and treatment options.

5.50 The first related to the lack of national data on hospital outpatient services for cancer. The AIHW indicated that from July 2005 a collection of hospital outpatient occasions of service delivery for chemotherapy and radiation oncology would commence for the principal referral and other major hospitals in each State.

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[26] *Submission* 53, p.6 (Cancer Institute NSW).

[27] Cancer Institute NSW Clinical Trials Program, accessed at http://www.health.nsw.gov.au/cancer_inst/research/trials.html on 26 May 2005.

[28] DOHA Health Fact Sheet 1, Investing in Australia's health: Strengthening Cancer Care, accessed at: http://www.health.gov.au/internet/budget/publishing.nsf/Content/health-budget2005-hbudget-hfact1.htm on 26 May 2005.

5.51 The second area is data on the stage of cancer, a pre-requisite to interpreting changes in survival and to analysing the effects of changes in treatment and services. The need for staging data was also strongly supported by Dr Threlfall, Manager and Principal Medical Officer, Western Australia Cancer Registry.[29] The AIHW has acknowledged that some work was occurring in the area of staging data. For example:

- The National Cancer Control Initiative has developed a national clinical cancer core data set. The data set has been endorsed by the National Health Data Committee of the Australian Health Ministers Advisory Committee. The National Cancer Control Initiative has also undertaken some pilot work in Western Australia and the Northern Territory on the feasibility of collecting staging data.[30]
- The Cancer Institute New South Wales has commenced a program for the collection of a minimum data set of 45 items on every cancer patient in New South Wales. The minimum data set is targeted at the patient's journey and is expected to be rolled out within a 12 month period.[31]
- The Victorian Department of Human Services has established a Data/Information Working Group that is promoting the collection of the National Cancer Control Initiative's Minimum Data Set.[32]

5.52 The AIHW acknowledged that the standardisation of staging data across States and Territories would take some time and that the coding from the detailed to the aggregated data set would be very costly.[33]

5.53 The third gap relates to the lack of linkage between existing data sets. There are a number of individual data sets from the Medicare Benefits Schedule and Pharmaceutical Benefits Scheme, the Health Insurance Commission data bases, and hospital records, where there is little linkage of these data bases. Commonwealth statisticians and the ABS are working on protocols on how the ethical linkage of data can be undertaken, taking into account relevant privacy legislation.[34]

5.54 The Committee heard that there was a major gap in the collection of data on cancer staging. Data on the stage of cancer is a pre-requisite to interpreting changes in survival and to analysing the effects of changes in treatment and services. The AIHW acknowledged that while work is being undertaken in this area, the standardisation of staging data across States and Territories would take some time and would be costly.

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[29] *Committee Hansard* 19.04.05, p.10 (Dr Threlfall).

[30] *Committee Hansard* 31.03.05, p.9 (Dr Threlfall).

[31] *Committee Hansard* 19.04.05, p.50 (Prof Bishop).

[32] *Submission* 66, p.5 (Victorian Department of Human Services).

[33] *Committee Hansard* 20.04.05, p.79 (Dr Choi).

[34] *Submission* 3, p.5 (AIHW).

Given the importance of cancer staging data, the Committee makes the following recommendation.

Recommendation 33

5.55 The Committee recommends that Cancer Australia, in consultation with State and Territory Governments and the Australian Institute of Health and Welfare, take a leadership role in coordinating the development of a national approach to the collection of cancer staging data.

Palliative care

5.56 Palliative care was raised by a number of witnesses as an area requiring greater attention due to the increasing incidence of cancer. As stated by Professor Kricker 'the fact that 36 000 die is not reflected in the state of development of the palliative care services. It is a crying need'.[35]

5.57 Palliative care is a relatively new discipline in Australia's health care system and aims to improve the quality of life of people with life-limiting conditions.[36] To a great extent, hospice palliative care in Australia has been driven by community demand through non-government organisations led by doctors, nurses, other committed health professionals and members of the public.

5.58 The provision of good palliative care is not just for the benefit of the terminally ill patient. Providing good palliative care at the end of a cancer patient's journey has measurable health outcomes in terms of the unpaid carers. Professor Currow stated:

> I would like to reflect on the fact that good palliative care is not a black hole into which we pour money; it is something with measurable health outcomes that are felt long after the death of a person. The care giver impact is positively affected by the involvement of palliative services and that effect has hangover, if you will, that lasts for many years after the death of the person who has had a life-limiting illness. The very small investment that we make in palliative care has an enormous benefit for the health of the whole community when measured in those sorts of parameters.[37]

5.59 It is evident from the growth in the demand for domiciliary palliative care throughout Australia that patients in the final stage of the cancer journey appreciate the option of being able to die at home or, at least, spend as much time as possible there. Dr Helen Manion reported that a World Health Organisation survey showed that

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[35] *Committee Hansard* 19.4.05, p.24 (Professor Kricker).

[36] *Submission* 8, p.4 (Dr Beverley McNamara and Dr Lorna Rosenwax).

[37] *Committee Hansard* 19.4.05, p.6 (Professor Currow).

80 per cent of people have the wish to be able to remain in their own homes to die but the reality is that the majority of cancer patients die in an institution.[38]

5.60 Despite improvements in survival rates, Professor Currow stated that 'one in two people diagnosed with a solid cancer will still have their life substantially shortened by that in 2005. So we need excellent support and end of life care'. Currently the majority of patients (greater than 80 percent in most cases) referred to palliative care services in Australia have cancer.[39] Given the increasing numbers of people with cancer, without recognition of this resource need, the planning of future cancer services across the country will continue to be ad hoc. Professor Currow stated that 'unless we start to plan for the future in a very proactive way and ensure that every position has the flow-on effects of all the allied health, nursing and medical needs – and equalling that with the challenge of ensuring that we are providing infrastructure across the continuum of care; so in the community, in in-patient settings and in out-patient settings – we are going to have problems in the future'.[40]

5.61 Professor Currow mentioned the variation across Australia in metropolitan, rural, regional and remote Australia in accessing specialised palliative care services.[41] This disparity was highlighted by investigators at the University of Western Australia who conducted research which found that one third of people who died of cancer had not receive specialist palliative care. They found that people were less likely to receive specialist palliative care services if they were aged 84 years or over; female; Aboriginal; living in remote areas; or socioeconomically disadvantaged. Their research also found that use of specialist palliative care services reduced the likelihood of dying in a hospital or in a residential aged care facility, suggesting that the use of specialist palliative care services potentially reduces the demand on other hospital beds.[42]

5.62 Submissions suggested that the use of care coordinators is important to ensure that all patients are referred to a specialist palliative care service.[43]

5.63 The role of the carer of a terminally ill patient has been recognised by the Australian government. Some carers qualify for financial entitlements through Centrelink with the Carer Payment for those who are not able to work due to their

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[38] *Submission* 1, pp.1-2 (Home Hospice Inc).

[39] *Submission* 70, p.1 (Australian and New Zealand Society of Palliative Medicine); *Committee Hansard* 19.4.05, p.16 (Professor Currow).

[40] *Committee Hansard* 19.4.05, p.16 (Professor Currow).

[41] *Committee Hansard* 19.4.05, p.17 (Professor Currow).

[42] *Submission* 8, pp.5-6 (Dr Beverley McNamara and Dr Lorna Rosenwax).

[43] *Submission* 70, p.2 (Australian and New Zealand Society of Palliative Medicine).

caring responsibilities and the Carer Allowance, which helps parents or carers to care for adults with a disability at home.[44]

5.64 The Commonwealth is 'providing $201.2m throughout the five years of the Australian Health Care Agreements (2003-08) for palliative care. Of this, $188m is broadly allocated on a per capita basis to States and Territories for continued service provision, and $13.2m for the Australian Government to implement a national program of initiatives. In the 2002 Federal Budget, the Australian Government announced a further $55m over four years (2002-06) for national activity to improve the standard to palliative care offered in local communities'.[45]

5.65 To meet the demand for palliative care in the home, witnesses raised concerns over the availability and supply of some drugs.[46] Drugs that are available in a hospital are not automatically available for a patient being looked after at home. The Pharmacy Guild recommended that 'the range of medication used in palliative care listed in the PBS be broadened to assist in providing wider access to medication at an affordable price for patients who wish to remain in the community during the terminal phases of their lives'. The Guild acknowledged that there have been recent listings of several medications but is concerned that preparations currently listed are not adequate, citing Midazolam and Ketalar as examples. They explained that 'there is little incentive for manufacturers to apply for PBS listings for these drugs for innovative uses such as in palliative care' and recommended that the dual listing of medications used in palliative care should be investigated.[47]

5.66 The Committee questioned the Department of Health and Ageing about why a drug that has gone through an approval process for a specific reason, and when it may then need to be used in a different dose or in a different treatment, needs to go through the process again as it is very expensive and there is marginal, if any, profit for the manufacturer to do it.

5.67 In response to this issue about drugs on the palliative care list, Dr Lopert from the Department of Health and Ageing, advised that they are 'aware that there is concern over availability of some medications on the palliative care list, but their lack of availability of the palliative care list reflects that fact that they do not have marketing approval for the indications that are relevant to the palliative care setting'. Dr Lopert stated that the process is a safeguard as 'the broader issue from the PBS point of view as opposed to the registration point of view is that it is inappropriate to provide reimbursement for drugs for an indication outside that for which it is approved for marketing in Australia – that is one of the principles underlying the

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[44] Accessed at http://www.centrelink.gov.au/internet.nsf/payments/carer_allow_adult.htm and http://www.centrelink.gov.au/internet.nsf/payments/carer.htm on 10.6.05.

[45] *Submission* 87, p.27 (DoHA).

[46] *Committee Hansard* 20.4.05, p.59 (Mr Cuthill).

[47] *Committee Hansard* 20.4.05, p.60 (Mr Cuthill).

PBS…The issue of approval for indications other than those for which it is registered is an issue for the TGA rather than the pharmaceutical benefits branch'. When questioned specifically about Midazolam, Dr Lopert stated 'the approved indication is actually quite narrow. It is not approved for an indication that could be conceivably appropriate for use in a palliative care setting – it talks about use as an adjunct in anaesthesia for a surgical procedure'.[48]

5.68 The Committee noted there was some confusion about the authority process for palliative prescriptions, particularly for the first dose. The Department of Health and Ageing provided the following advice:

> Requirements for prescriptions for palliative care medicines to be authorised by the Health Insurance Commission were put in place to minimise use outside the intended population whilst ensuring access to patients with the greatest need. It would be impractical to not require authorisation of the 'initial' supply, whilst requiring authorisation for continuing supply. First, without the authority mechanism it would not be possible to monitor where an initial supply has occurred. Second, it is most likely that medical practitioners would continue to prescribe under the 'initial' supply arrangement without ever seeking authority to prescribe a continuing supply.[49]

5.69 The Department also advised that the work of the Palliative Care Medications Working Group continues, with a further medication, Paracetamol Sustained Release, included on the palliative care section of the PBS in April 2005. A further list of 10 medications have now been prioritised by the Palliative Care Medications Working Group, and will be progressed for listing in coming months. For example, Flinders University of South Australia has now been engaged to support the generation of evidence and data to support registration and listing of these medications under the Scheme. In addition to the above, the Working Group is working on a number of strategies to: support quality use of medications through education and support for GPs and other primary health care workers, in the management and care of palliative care patients in the community; and increase the awareness of health professionals and the broader community on medications currently available and how they can be accessed.

5.70 Dr Page raised the issue of access to palliative care in regional and rural areas. She stated that 'palliative care and pain management is becoming an increasingly specialised field which, again, translates very poorly into rural and remote areas. I am very distressed to say that the worst palliative care services are often for children's cancers'. Dr Page also stated that 'palliative care is something which should be available in every country town' and highlighted 'there are a vast number of GPs out there with palliative care skills and advanced level pain management skills'.[50]

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[48] *Committee Hansard* 20.4.05, p.84 (Dr Lopert).

[49] *Submission* 87, Additional information, p 1 (DoHA).

[50] *Committee Hansard* 19.4.05, p.84 (Dr Page).

5.71 Palliative Care Australia, the peak national organisation representing palliative care in Australia released a detailed set of standards for providing quality palliative care for all Australians on 23 May 2005. Workshops to promote and explain the new standards are currently underway throughout the country.

5.72 The Committee noted that as the Australian population ages and the incidence of cancer increases, the community's need for quality, long-term palliative care will grow. It is essential that the health care system (including public, private and not-for-profit) is well equipped to provide quality palliative care services that meet new national standards.

CHAPTER 6

FUTURE DIRECTIONS FOR CANCER CARE IN AUSTRALIA

6.1 This concluding chapter summarises the major issues examined by the Inquiry as discussed in the report and reviews the actions that have been proposed to improve access to and advance best practice cancer care in Australia. The primary focus of this chapter will be on the cancer journey as it progresses through a number of stages; though there are also issues raised which apply at some or all stages of the journey, such as the need for information and support, workforce shortages, data shortfalls and access to best practice care for regional and Indigenous Australians. This chapter should be read in conjunction with the summary of recommendations.

6.2 The Committee heard that the Commonwealth, Cancer Institute NSW, Victorian Department of Human Services and the Department of Health WA are undertaking initiatives which will continue our success in providing cancer treatment in Australia. While it is apparent that institutions, organisations, practitioners, support groups and consumer advocates are doing their best to provide and promote services which realise the best outcomes for the cancer patient, there are still issues needing to be resolved.

6.3 Though acknowledging Australia's treatment record and the goodwill from all involved to improve the cancer patient's journey, the Committee was concerned at the current gap between what is known to be best practice and what is the reality for many cancer patients as told to the Committee.

6.4 The needs of cancer patients for improved information to make informed choices about conventional treatment and complementary therapies and for better access to coordinated care and psychosocial support have been well documented. Not only are these needs well known but there is evidence available to show that better outcomes accrue when these needs are addressed. The question therefore remains as to why cancer care in Australia is still described as a 'lottery' for the many people who take that journey?

6.5 As described in many reports and by witnesses, the Committee considers that Australia is at a crossroads in cancer care and the direction in which to proceed has general agreement. Indeed, many cancer patients are voting with their feet by making their own enquiries in order to find health practitioners and institutions which provide them with the care that is most appropriate to their needs. The direction is clear and it just seems to be a matter of time before the momentum of evidence and change, together with consumer advocacy, carries us there.

6.6 While Australia is doing well in cancer control across the continuum, improvements could be made through the systematic implementation of best practice treatments for people with cancer. The evidence from overseas witnesses from the

USA and UK, indicated that Australia is lagging behind current best practice especially in areas such as multidisciplinary care and integrative medicine. The Committee sought advice from these witnesses, who are all leaders in their fields, on how Australia can learn from their experience to expedite the natural evolution and overcome the barriers to best practice more quickly. As discussed through the report, this information has been combined with recommendations from Australian witnesses and findings from other reports, to provide the following plan to guide improvements to the provision and delivery of care during all stages of the cancer patient's journey. The plan needs to be read in conjunction with the Committee's summary of recommendations.

Diagnosis and referral

Referral guidelines

6.7 From the very start of the cancer journey, witnesses raised concerns that referrals were largely ad hoc. The Committee accepted that the development of referral guidelines would provide GPs with the information on who best to refer a patient to and would reassure patients that they are accessing the best possible care. The Committee considers that it is vital to ensure patients are referred in a timely manner to high quality treatment services. The Committee noted that work is underway in a number of States to develop referral pathways and recommended that Cancer Australia in conjunction with the States and Territories develop appropriate referral pathways for the management of all cancers.

Empowering cancer patients through provision of information

> An informed and empowered health consumer is critical to good outcome of care.[1]

6.8 The Committee heard that people want to be more involved in their health care and be able to make informed decisions, and that practitioners must respect the fact that people want to be involved. Witnesses told the Committee that they were concerned about the lack of information available for both the general practitioner and the cancer patient at the diagnosis and referral stage. Many patients want to be more involved in choosing their specialist and want information to enable them to engage in an informed dialogue with their GP about who would be best suited to treat them and what their treatment options are. Supporting this view, Professor Currow stated that:

> As I reflect on the cancer journey, you have raised the important issue of how do people win the lottery. At a whole-of system level, we have a couple of options: one is to change the way we deliver health care; the other, in which I believe we can invest substantially, is to have better informed patients. That is to have accessible information specific to each cancer available to people so that they can ensure that the care they are getting is genuinely interdisciplinary…is timely and is credible. We need to

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[1] *Committee Hansard* 19.4.05, p.7 (Professor Currow).

> complement any change to the health system with ensuring that health consumers themselves are adequately informed – not only the person with cancer because the effect does not finish there, but the people around them: their family and friends.[2]

6.9 This call for information has led to the publication of a directory for breast cancer treatment and services in NSW which is very well regarded. The Committee recommended Cancer Australia assist with the coordination of a directory of cancer treatment services in each State and Territory.

6.10 Witnesses told the Committee that from the outset many of them had had little exposure to the health system before they or their relative was diagnosed and they needed assistance to navigate their way through their cancer journey. The Committee considers that in conjunction with more information being made available through care co-ordinators, a common entry point for information for people with cancer was required which would include the development of a website and resource pack which consolidates and provides people with information about various cancers, treatments, support groups and advocacy groups. The Committee considers that the establishment of Cancer Australia provides an opportunity to have an authoritative body that can facilitate access to this kind of information so it is easily available and visible. The Committee therefore recommended that Cancer Australia provide access to authoritative, nationally consistent evidence based information on services, treatment options, government assistance and links to appropriate support groups which can be made available in different forms.

The need for support

6.11 Witnesses emphasised that they needed support right from the time of diagnosis. Evidence has shown that emotional distress is very common in cancer patients and that effective psychosocial support programs are associated with an enhanced quality of life and longer survival. The Committee heard that if a patient feels supported through their cancer journey they comment less negatively on every other aspect of their life and care. The Committee agreed that more options to provide psychosocial support should be pursued and this is further discussed in the section on psychosocial care below.

Improving delivery of services and treatment options

Development of multidisciplinary care

6.12 All witnesses acknowledged that a multidisciplinary approach to cancer care is best practice. There is evidence to show better patient outcomes in terms of survival and emotional well being. Despite this, evidence to the Committee indicated that it is not being widely practiced in Australia. This is due to a range of factors including the way in which services are organised and resourced in different parts of Australia. The

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[2] *Committee Hansard* 19.4.05, p.6 (Professor Currow).

Committee recognised that a range of approaches and models to multidisciplinary care are required for different parts of Australia.

6.13 The Committee noted the 1994 House of Representatives Community Affairs Committee Report on the Management and Treatment of Breast Cancer which found that the management and treatment process for women with breast cancer was fragmented and uncoordinated and recommended multidisciplinary care as best practice for women with breast cancer. In 1995 the National Breast Cancer Centre was established and has been a driving force in improving outcomes for women with breast cancer, advancing multidisciplinary care and producing clinical practice guidelines. It is argued that what was true for breast cancer in 1994, could be seen as true about other cancers in 2005 and inspires the question of why it is taking so long to apply the advances of the breast cancer model to the management of other cancers.

Measures to increase the practice of multidisciplinary care in Australia

6.14 The treatment of breast cancer provides the health system and health providers with a working model of multidisciplinary care which can be adapted for other cancers. The Committee commends the work undertaken on the *National Multidisciplinary Care Demonstration Project* which obtained information applicable to other cancers and made recommendations on the implementation of MDC, and the *Sustainability of Multidisciplinary Cancer Care Study*. There are, however, a number of systemic issues needing to be addressed to progress the practice of multidisciplinary care in Australia including those discussed below.

Multidisciplinary care needs to be better supported by the health system

6.15 Witnesses told the Committee that a multidisciplinary approach is not well supported by the health system and that practitioners have to contend with inflexible funding models. The Committee heard that the current structure of the Medical Benefits Schedule provides minimal financial incentive for clinicians to be part of a multidisciplinary approach. This is even more pronounced in the private system where some clinicians providing treatment to private patients are not funded to participate in MDC meetings. The Committee considers multidisciplinary care must be adequately and explicitly resourced by those funding health services and recommended:

- adherence to clinical guidelines be included in the accreditation process; and
- the enhancement of current MBS arrangements for relevant multidisciplinary care team members.

Accreditation of cancer services and credentialing of practitioners

6.16 It was strongly argued that two systemic changes are required if Australia's cancer treatment services are to continue to improve and meet the increasing demand of the rising incidence of cancer in the Australian community. These are accreditation of cancer services and credentialing of the health professionals who work within them. It is accepted that these systems will take time to introduce which makes it more important that their development is afforded a high priority. The Committee considers that the accreditation of cancer services and credentialing of practitioners is a fundamental priority to ensure that multidisciplinary care is incorporated as a key component of best practice care.

6.17 Work has already commenced on the development of an accreditation framework and the Committee recommended that work should commence on the development of a credentialing process as soon as possible. The Committee also recommended that the practice of multidisciplinary care be included as a criterion for assessment in an accreditation process. The Committee notes that the support of the medical Colleges is fundamental to progress both these issues and they were disappointed by the lack of input from the professional Colleges to the inquiry.

A multidisciplinary team must include non medical health providers

6.18 The issue of including non medical providers in a multidisciplinary team goes to the heart of recognising that a diagnosis of cancer provides the patient with not only physical challenges but practical and emotional issues as well. The Committee accepts that a multidisciplinary team should include not only providers of conventional medical treatment but also health professionals providing psychosocial support and services. The composition of this team would vary according to the medical and social needs of the patient at any one time.

6.19 The Committee also recognises that there are health practitioners who are able to assist cancer patients to better cope with the side effects of conventional treatment, and who can provide an improved quality of life and increase patient well being.

National adoption of clinical guidelines

6.20 Over recent years, Australia has produced a suite of clinical guidelines to support medical professionals, health practitioners and patients on the cancer journey. There is evidence to show that they are effective in improving the quality of clinical practice and the outcomes of care. The Committee considers these to be an important, evidence based resource, endorsed by the National Health and Medical Research Council and that their use should be encouraged nationally using accreditation as a vehicle. The Committee has recommended that the development of an accreditation process should include the use of clinical guidelines and encourages the professional Colleges to promote their use. Translating guidelines into clinical practice and services in both the public and private sectors was agreed by the Committee to be critically important.

Conclusion

6.21 Australia's cancer treatment record is good but services could be considerably enhanced. The introduction of well structured and well funded multidisciplinary care is of vital importance to achieving good outcomes for cancer patients in Australia. The Committee recognises that given the diversity of health care services operating throughout Australia and combined with its diverse geographical spread, it is not appropriate to encourage a fixed approach to multidisciplinary care and has recommended a flexible approach.

Improving care co-ordination

6.22 Witnesses reported experiencing fragmented care during what was often a very complex journey. Evidence demonstrated that a care coordinator has a very valuable role to play in ensuring continuity of care to deliver the full benefits of the multidisciplinary model. The Committee noted that breast care nurses provide a successful model from which to develop care coordinator positions but acknowledged that the person fulfilling the role could vary according to the location of the cancer patient and the availability of services and staff.

Improving access to psychosocial care

> There tends to be a void in the area of meeting psychosocial needs with the physical/tasks often being easier to address by healthcare providers.[3]

6.23 Cancer affects every aspect of a person's life. It affects the patient, family, friends and their physical, mental, emotional and spiritual life. Surveys have found that over 50 per cent of cancer patients feel that the practical and emotional consequences of dealing with cancer were harder than the medical issues. The Committee noted that there is a need to shift mindsets and understand that more and more individuals are going to be living with cancer for longer. There is a need to treat the individual as a whole and not just the disease.

6.24 The Committee also heard that psychosocial support is as much part of multidisciplinary care as surgery, radiotherapy or chemotherapy. Some patients will require more assistance than others, but the Committee agreed that people should be able to access support to assist them cope with issues when they need to and not only when they are in crisis. The Committee recognised that psychosocial support should be given equal priority with other aspects of care and be fully integrated with both diagnosis and treatment. As part of developing multidisciplinary care it is essential that immediate steps are taken to ensure that State and Territory health services address providing psychosocial support for cancer patients, taking into account the NHMRC approved *Clinical practice guidelines for the psychosocial care of adults with cancer*. The Committee considered that the recent changes to Medicare that allow five allied health consultations, including psychological counselling within a registered care plan, need to be promoted and evaluated.

The need for information during the cancer journey

> The most commonly mentioned unmet need is for information. The top seven of the unmet needs from a list of about 30 or so in the questionnaire, were for information and about 20 percent of people had unmet information

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[3] *Submission* 28, p.3 (ACCNS).

> needs. I think a very big message from that is that there is still a lot of work to be done in providing cancer patients with the information that they need.[4]

6.25 As noted earlier, cancer patients told the Committee that one of their biggest challenges was finding and accessing appropriate, authoritative information. In addition to the need for information to make an informed choice about their treatment and care at the commencement of their journey, cancer patients also need information further along the cancer journey about support groups, complementary therapies and other treatment options, and government assistance. The Committee considered that as a part of their role, the care coordinator should be a vital source of information for cancer patients during their cancer journey. The Committee also considered that communication skills training for health professionals was an issue that needed to be addressed at the undergraduate and postgraduate levels and through the Colleges.

The needs of regional and Indigenous Australians

6.26 Access to best practice treatment for regional and Indigenous Australians is challenging. There is little information about how to provide appropriate cancer care for Aboriginal and Torres Strait Islander people. The Committee heard many suggestions on how to provide better services, such as outreach services, developing links with centres of expertise and better access to tele and video conferencing, which they supported. The Committee understands that for logistical and other reasons not all services will be available locally for regional and Indigenous Australians. A major concern raised with the Committee was the disparity in the State and Territory travel assistance schemes. The Committee was advised of and supported the findings of other reviews that there needs to be a standardisation across jurisdictions. For Indigenous Australians the Committee noted the need for culturally appropriate care and recommended Cancer Australia, in consultation with Indigenous people, auspice work to improve access to cancer screening, diagnosis and treatment.

Complementary therapies

6.27 Evidence presented to the Committee showed that a high rate of cancer patients and Australians generally access complementary therapies, though many of them do not inform their medical practitioner as they expect scepticism and little support from them. The Committee heard many stories of this great divide between conventional and complementary medicine and therapies.

> ...the thing that sticks in my mind is the difficulty in finding help, support and wishing like crazy that the doctors and the alternative medicines could see each others values instead of being against each other. I am sure it has a lot to do with fear and lack of knowledge but for the patient it causes even more stress and anguish.[5]

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[4] *Committee Hansard* 18.4.05, p17 (Professor Hill).

[5] *Submission* 76, p.1 (Ms Sally Chambers).

6.28 Clinicians are rightly wary of therapies and products making claims to cure cancer, but medical professionals in Australia seem to be particularly wary of even evidence based complementary therapies which have been embraced overseas. Overseas witnesses told the Committee that about 90 per cent of cancer treatment centres in the USA and UK offer some form of complementary therapies, even if it is on a small scale. Numerous witnesses argued that this situation disadvantages the many cancer patients being treated in Australia.

6.29 The Committee heard from institutions such as the Peter MacCallum Cancer Centre and the Brownes Cancer Centre where complementary therapies are offered. The programs offered by these centres seem to be the exception rather than the rule and even in those settings, the offering of complementary therapies does not constitute a fully integrated service.

6.30 The Committee agrees that complementary therapies must be evidence based and adhere to the same rules as conventional medical treatments. As noted by Professor Zalcberg from the Peter MacCallum Cancer Centre:

> The important thing for people looking after patients with cancer to remember is that they are our mothers, our sisters and our wives. Like everybody else, there is nothing we do not want to give to people that we think works, but we certainly do not want people to go off and have treatments that we think are a waste of time and their money and, in fact, sometimes denies them the actual treatment that does work. So there is not any a priori reason why we do not want to move forward here, but the rules have to apply to everybody for the public's sake.[6]

6.31 However, the Committee acknowledges that there is a case for therapies which intrinsically enhance quality of life, such as meditation and massage, to be more readily accepted.

6.32 The Committee considered that a first step to greater acceptance of complementary therapies in Australia should be the clarification of the terms used to ensure that health practitioners speak the same language. The Committee suggested that complementary medicines and therapies be defined as those which are used in conjunction with conventional treatments to assist with, for example, the alleviation of side-effects. Alternative medicines and therapies are those which would be used instead of conventional treatments or whose affects are as yet unproven.

The need for more information on complementary therapies

6.33 The Committee heard that cancer patients want access to authoritative information on complementary therapies so they can discuss possible benefits with their medical practitioners and make informed decisions about their use. Given the large numbers of Australians using complementary therapies, the Committee

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[6] *Committee Hansard* 18.4.05, p.41 (Professor Zalcberg).

considers that government has a duty of care to provide such authoritative information on an ongoing basis and suggested Cancer Australia as the vehicle.

6.34 The ready availability of information internationally presents an immediate opportunity for Australia to provide patients and carers with authoritative information to help them make informed decisions about the utilisation of complementary and alternative therapies and products. This would go some way towards addressing government's duty of care and responsibilities in this sector.

6.35 The Committee noted the intense interest in the inquiry from organisations representing complementary therapies. It considers that the formation of an umbrella organisation which would be able to represent the sector to government and discuss such issues as standards and regulation is a necessary step towards greater visibility and acceptance of complementary therapies.

6.36 The Committee was concerned that, in Australia, the utilisation and wide acceptance of complementary therapies in order to achieve a better quality of life, relief from the side-effects of conventional treatments and possibly prolonged survival is demonstrably behind the situation in the USA, UK and some European countries. The Committee considers that a critical factor is the lack of authoritative information for medical professionals and cancer patients. As emphasised by witnesses, cancer patients need to use every possible resource to get the best results and it would appear that Australia's conventional treatment sector is reluctant to adopt all that is best for patients from the range of complementary therapies that are available.

Towards Integrative Medicine

6.37 The Committee heard evidence about overseas hospitals such as the Memorial Sloan-Kettering Cancer Center that are using integrative medicine which combines the best evidence based treatments from conventional medicine with the best evidence based therapies from complementary practice to treat not only the disease but the whole person. The Committee supports the following suggestions from witnesses to advance the acceptance of complementary therapies in Australia:

- Therapies should be introduced progressively to facilitate acceptance;
- Developing a shared language is important to facilitate communication between conventional and complementary therapists;
- There is a need to engage local champions with a solid orthodox background who are willing to be actively supportive;
- Australia should make greater use of and adapt information from overseas;
- Complementary services should be located near or next to conventional treatment centres; and
- Education, training and information for conventional medical practitioners has an important role to break down barriers.

The need for more investment in research into complementary therapies

6.38 Witnesses told the Committee that the vast majority of research on complementary therapies has been conducted overseas, especially in the USA with significant funding made available from government. To address the research shortfall in Australia the Committee recommended a dedicated funding stream for research into complementary therapies. The Committee also considers that there is an opportunity for Australia to access and utilise the research conducted overseas as a first step to providing greater information to consumers.

6.39 The Committee also heard about the difficulties experienced by researchers in the sector to obtain funding from the NHMRC. This was acknowledged by the NHMRC which suggested providing mentoring and advice from experienced NHMRC recipients to improve the quality of applications. The Committee agreed with this strategy and recommended that representatives who have a background in complementary therapy be involved in the assessment of research applications received by the NHMRC. The Committee agreed with the recommendation of the Expert Committee on Complementary Medicines in the Health System to establish a working group to identify research needs. The Committee further recommended that this group establish a mentoring program and develop a strategy to coordinate and prioritise research into complementary research in Australia.

Palliative care

6.40 The increasing numbers of people with cancer and who are living longer with cancer means that long term support and palliative care is an area which will require continuing attention. Witnesses noted that as this need continues to grow, planning for associated resources needs to be undertaken. The Committee recognised that the provision of good palliative care affects not only the cancer patient but the carer as well.

Conclusion

6.41 This report provides information on current practices and policies in the area of cancer care in Australia. Firstly, taking a broad perspective, the Committee heard that with the increasing numbers of cancer patients, there is a need to ensure the most efficient and effective use of scarce resources. As described by one witness:

> I get very frustrated by the fact that we could co-ordinate our few resources and our relatively few experts in this country into a more co-ordinated approach to developing and delivering information, and developing and delivering care. I think there is a lot of waste in the current situation.[7]

6.42 The Committee noted that there are many organisations in the cancer sector, some of them sustained by government funds, which appear to be either doing the

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[7] *Committee Hansard* 19.4.05, p.36 (Dr Zorbas).

same thing or competing with each other. It is recognised that this is partly caused by the different types of cancers, especially in the non government sector. However, in the best interests of efficiency and better use of funds, it is important that some re-organisation takes place and this is discussed in chapter 1.

6.43 Looking at cancer treatment and services, it is evident to the Committee that while many improvements in the area of cancer treatment have been made, resulting in better survival outcomes and more people living with cancer for longer, there are areas of cancer treatment services which can be significantly improved.

6.44 From the evidence received by the Committee it is clear that many cancer patients still face fragmented and uncoordinated care along their cancer journey. Many witnesses spoke of their distress when referred from specialist to specialist and left to navigate their own way through the health system. This is particularly an issue for cancer patients living in rural and regional areas who have problems accessing specialist services and also face higher travel costs. This problem is compounded for Indigenous Australians who not only face the difficulties of regional and rural Australians but also cultural and linguistic barriers. Improving access to multidisciplinary care and greater co-ordination of care was discussed in chapter 2.

6.45 The Committee also found that there is a great unmet need for psychosocial support for cancer patients. For those who have cancer the impact is multifaceted. There are not only physical challenges but also emotional and practical issues to be dealt with. It is therefore imperative that cancer patients receive optimal psychosocial support as they need it. Improving access to psychosocial support is discussed in chapter 2.

6.46 From evidence received by the Committee it is clear that Australia is behind best practice in the USA and UK, where integrative medicine is practiced which combines the best of evidence based conventional treatment and the best of evidence based complementary therapies. Evidence also shows that many Australians, and many with cancer, are using complementary therapies but do not discuss this with their medical practitioners. Witnesses spoke of their desire for authoritative information on complementary therapies and the Committee considers that government has a duty of care to provide this using Cancer Australia as the vehicle.

6.47 The Committee considers that more information is needed not only for cancer patients but also medical practitioners and that research conducted overseas provides an opportunity to access and adapt the information for Australia. The Committee would also like to see greater organisation of and collaboration in the sector, including the formation of a national body representing complementary therapies that can interact with government and guide development of issues such as regulation. The Committee also acknowledged the need for further research in the sector and recommended a dedicated funding stream, with more collaboration and assistance from the NHMRC.

6.48 The Committee considers it is evident that without the presence of motivated consumer groups much of what has been achieved would either not have happened or still be in a developmental phase. This is well illustrated in the treatment and support of breast cancer patients. It is important that consumers and consumer organisations continue to be empowered in order to help drive change.

6.49 The Committee believes that the recommendations and plan that it has proposed will greatly assist the delivery of services and options for the treatment for persons diagnosed with cancer as they travel the cancer journey. The successful outcome of these proposals will hopefully be a more informed population that leads to an improved quality of life and prolonged survival time for cancer patients.

Senator Gavin Marshall
Chair
June 2005

APPENDIX 1

LIST OF PUBLIC SUBMISSIONS, TABLED DOCUMENTS AND OTHER ADDITIONAL INFORMATION AUTHORISED FOR PUBLICATION BY THE COMMITTEE

1 Home Hospice Inc (NSW)

2 Davis, Professor Susan R (VIC)

3 Australian Institute of Health and Welfare (ACT)

Supplementary information

- Statistical summary provided at hearing 20.4.05
- International comparison and trend statistics provided following hearing 20.4.05

4 Deverall, Mr Clive (WA)

Supplementary information

- Information on clinical trials and other issues provided at hearing 31.3.05

5 Hall, Ms Sonja E (WA)

Supplementary information

- Powerpoint presentation provided at hearing 31.3.05

6 Brain Tumour Australia (ACT)

Supplementary information

- Additional information dated 21.4.05 provided following hearing 20.4.05

7 Queensland Institute of Clinical Research (QLD)

8 McNamara, Dr Beverley and Rosenwax, Dr Lorna (WA)

9 National Health and Medical Research Council (NHMRC) (ACT)

10 Cancer Voices NSW (NSW)

Supplementary information

- 2005 operational plan and March 2005 Newsletter provided at hearing 19.4.05

11 Cancer Patient Support Group (Illawarra) Inc (NSW)

12 Bloch, Professor, Sidney (VIC)

13 Threlfall, Dr Timothy (WA)

Supplementary information

- Summary submission provided at hearing 31.3.05

14 Allison, Dr Roger (QLD)

15 Cancer Information & Support Society (NSW)

Supplementary information

- Appendices to submission received 17.4.05, 24.4.05 and 9.5.05

16 Argall, Mr Dennis (NSW)

17 Henderson, Ms June & Mr Alastair

18 Haywood, Dr Elizabeth (VIC)

19 Name withheld (VIC)

20 Dangar, Mr Bill (NSW)

21 Bush, Ms Betsy (WA)

22 Carter, Ms Rosemary (VIC)

23 O'Brien, Dr Tracey

Senner, Ms Anne

Marshall, A/Prof Glenn - Centre for Children's Cancer & Blood Disorders (NSW)

Supplementary information

- Opening presentation slides provided at hearing 19.4.05

24 Breast Cancer Action Group (NSW) (NSW)

Supplementary information

- Directory of Breast Cancer Treatment and Services for NSW women, BCAG priorities for 2005 provided at hearing 19.4.05

25 Shepheard, Ms Diane

26 National Herbalists Association of Australia (SA)

27 Moran, Mr Alan & Mrs Gabrielle (NSW)

28 Australian Council of Community Nursing Services (ACT)

29 Cancer Council Western Australia (WA)

Supplementary information

- Statewide Supportive Care Network information provided at hearing 31.3.05

30 SCGH Brownes Cancer Support Centre (WA)

Supplementary information

- Position statement provided at hearing 31.3.05

31 Royal Australian and New Zealand College of Radiologists

Faculty of Radiation Oncology (NSW)

32 Pharmacy Guild of Australia (ACT)

Supplementary information

- Counselling Guide for Non-Prescription Medicines and info on Midazolam and Ketalar provided at hearing 20.4.05

33 Breast Cancer Network Australia (VIC)

Supplementary information

- Summary of recs from 2004 National Conference provided at hearing 18.4.05

34 Bloomhill Cancer Help (QLD)

35 Cancer Council Victoria (VIC)

Supplementary information

- Opening presentation slides, information sheet and brochures provided at hearing 18.4.05
- Additional information received following hearing dated 18.4.05

36 Peter MacCallum Cancer Centre (VIC)

37 Medical Oncology Group of Australia (NSW)

38 Australian Psychological Society (VIC)

Supplementary information

- Reference to Australian epidemiological study provided following hearing 18.4.05

39 National Breast Cancer Centre (NSW)

40 Balya Cancer Self Help & Wellness Inc (WA)

Supplementary information

- Supporting papers, letters, articles and newsletters provided at hearing 31.3.05

41 Rural Doctors Association of Australia (RDAA) (ACT)

Supplementary information

- Article 'Surgical caseload and outcomes for women with invasive breast cancer treatment in Western Australia', *The Breast* (2005) 14, 11-17 provided at hearing 19.4.05

42 Name withheld (NSW)

43 Condon, Dr John (NT)

44 Department of Health WA (WA)

45 Gawler Foundation (VIC)

46 Rogers-Clark, Dr Cath & Ellem, Ms Pammie (QLD)

47 Cancer Support Association of Western Australia (WA)

Supplementary information

- Supplementary submission provided at hearing 31.3.05

48 South Australian Massage Therapists Association Inc (SA)

49 Cancer Alliance Network (CAN Australia) (ACT)

50 Parsons, Mr Frank (VIC)

51 CANTEEN Australia (NSW)

52 Health Liberte International (QLD)

53 Cancer Institute NSW (NSW)

54 Royal College of Nursing, Australia (RCNA) (ACT)

55 Whittaker, Ms Lisa (NSW)

56 Burke Road Medical Centre (VIC)

57 Wickett, Mr John (ACT)

58 Murphy, Mr Doug

59 Oncology Social Work Australia (OSWA) (VIC)

Supplementary information

- Excellence in Psychosocial Oncology provided at hearing 18.4.05

60 Australian Natural Therapists Association (QLD)

Supplementary information

- Additional information received 7.6.05

61 National Rural Health Alliance (NRHA) (ACT)

Supplementary information

- Supplementary submission received 8.4.05

62 Health Consumers' Council (WA)

63 Name withheld

64 Australian Traditional Medicine Society (NSW)

65 Clinical Oncological Society of Australia

Cancer Council Australia

National Cancer Control Initiative

National Aboriginal Community Controlled Health Organisation (NSW)

Supplementary information

- Opening presentation and reports 'Optimising Cancer Care in Australia', Clinical practice guidelines for the psychosocial care of adults with cancer', 'Cancer priorities' provided at hearing 19.4.05

66 Victorian Department of Human Services, Programs Branch, Cancer Coordination Unit (VIC)

Supplementary information

- Additional information following hearing, dated 23.5.06

67 Australasian College of Nutritional and Environmental Medicine Inc (VIC)

Supplementary information

- Correspondence re use of vitamins provided at hearing 18.4.05
- Research articles received 23.5.05

68 Heathcote, Ms Kathy (NSW)

69 Ewing, Ms Jane (NSW)

70 Australian & New Zealand Society of Palliative Medicine (ANZSPM) (NSW)

71 Breast Cancer Action Group (VIC)

Supplementary information

- Information folder including 2004 report on experience of rural women with breast cancer and implications for provision of health services provided at hearing 18.4.05

72 Fielding, Ms Sheila (NSW)

73 Burgess, Mrs Beverley (TAS)

74 MacKenzie, Mr Alan (QLD)

75 Gaskell, Ms Brenda

76 Chambers, Ms Sally

77 McConaghy, Ms Claire (NSW)

78 Bird, Mr Neville

79 Foskett, Mr Ron

80 McCloskey, Ms Wendy (QLD)

81 Walsh, Mr John (VIC)

82 Taylor, Mr Ross (WA)
83 Bergman, Mr Robert (WA)
84 de Vries, Ms Cathy (QLD)
85 Carr, Mr Jeffrey & Ms Hazel (QLD)
86 Cancer Nurses Society of Australia (NSW)
87 Department of Health and Ageing (ACT)
88 Australian Nursing Federation (ANF) (ACT)
89 Kricker, Associate Professor William
Berry, Associate Professor Martin
Tynan, Ms Kate (NSW)

Supplementary information

- Opening presentation slides provided at hearing 19.4.05

90 Keating, Ms Anna
91 Lourensz, Mr Jarrod
92 Parker, Charles William (Bill) and Parker, Frances (NSW)
93 Shumsky, Mr Eric (NSW)
94 Cope, Mr A J (TAS)
95 McGlade, Ms Hannah
96 Brown, Mr Peter (NSW)
97 Browning, Mr Mike
98 Bates, Mrs Trish (NSW)
99 Westmead Hospital, Sydney and The Children's Hospital at Westmead, Sydney (NSW)
100 Evans, Ms Carolyn M (NSW)
101 Green, Ms Catherine (NSW)
102 EMR Safety Network-Int'l
103 Lander, Ms Mary (ACT)
104 McQueen, Mr Colin (VIC)
105 Ranieri, Mr Tony (NSW)

Additional information

Dr William Barnes – Articles from *Scientific American*, Sept 1996

Dr Barrie Cassileth, Memorial Sloan-Kettering Cancer Center – Information on Integrative Oncology

Mr Doug Ulman, Lance Armstrong Foundation – Information on the Lance Armstrong Foundation and cancer survivorship in the United States

Commissioned advice

Professor D'Arcy Holman, School of Population Health, University of Western Australia, Advice and Briefing Paper: Multidisciplinary care, dated May 2005

APPENDIX 2

WITNESSES WHO APPEARED BEFORE THE COMMITTEE AT PUBLIC HEARINGS

Thursday, 31 March 2005
Georgiana Conference Room, Mercure Hotel, 10 Irwin Street, Perth

Department of Health WA
Dr Neale Fong, Acting Director General
Professor Christobel Saunders, Chair of WA Cancer Services Taskforce
Mr Kingsley Burton, Project Director, Health Reform Implementation Taskforce
Ms Liza Houghton, Senior Project Officer, Health Reform Implementation Taskforce
Dr Tim Threlfall, Principal Medical Officer, WA Cancer Registry

Cancer Council of WA
Ms Susan Rooney, Chief Executive Officer
Mr Paul Katris, Executive Officer, Western Australian Clinical Oncology Group
Ms Amanda Leigh, Director, Cancer Services
Ms Pat Booth, Consumer
Ms Ann Revell, Consumer

Balya Cancer Self Help and Wellness Inc
Dr Jason Han, Honorary Chief Executive Officer
Dr Ivy Bullen, Honorary Chief Executive Officer

Cancer Support Association of WA
Dr Peter Daale, Chief Executive Officer

Sir Charles Gairdner Hospital, Brownes Cancer Support Centre
Mr David Oliver, Coordinator

Ms Betsy Bush

Mr Clive Deverall

Ms Sonja Hall, University of WA

Dr Lorna Rosenwax, University of WA

Dr William Barnes

Monday, 18 April 2005
St James Court Conference Centre, 12 Batman Street, Melbourne

Victorian Department of Human Services

Professor Dick Smallwood, Chair, Ministerial Taskforce for Cancer

Dr Mary Turner, Senior Medical Adviser, Metropolitan Health and Aged Care Services

Professor Bob Thomas, Director, Surgical Oncology, Peter MacCallum Cancer Centre

Ms Leonie Scott, A/Manager, Cancer Coordination Unit

Cancer Council Victoria

Professor David Hill, AM PhD, Director, The Cancer Council Victoria

Dr Raymond Snyder, Chair, Victorian Cooperative Oncology Group, The Cancer Council Victoria and Medical Oncologist, St Vincent's Hospital, Melbourne

Associate Professor Richard Bell, Snr Clinical Consultant, The Cancer Council Victoria and Medical Oncologist and Director of the Andrew Love Cancer Centre, Geelong

Ms Karen Kelly, Consumer Representative/Cancer Patient

Peter MacCallum Cancer Centre

Professor John Zalcberg, Director, Division of Haematology and Medical Oncology

Professor Sanchia Aranda, Director, Cancer Nursing Research

Breast Cancer Network Australia

Ms Lyn Swinburne, Chief Executive Officer

Ms Sue Timbs, Policy Manager

Breast Cancer Action Group

Ms Sue Lockwood, Chair

Ms Rosetta Manaszewiz, Steering Committee member

The Gawler Foundation

Dr Ian Gawler, Founder and Therapeutic Director

Dr Craig Hassed, GP and Senior Lecturer, Monash Medical School and Sessional Group Leader

Prof Avni Sali, Foundation Head of the Graduate School of Integrative Medicine, Swinburne University of Technology, Gawler Foundation board member

Ms Barb Glaser

Mr Peter McGowan

Mr Scott Stephens

Australasian College of Nutritional and Environmental Medicine

Mr Daan Spijer, Chief Executive Officer

Dr Peter Eng, Fellow and medical practitioner

Australian Psychological Society

Mr David Stokes, Manager Professional Issues

Dr Helen Lindner, School of Psychological Science, La Trobe University, Chair Australian Psychological Society Victorian State Committee and Member, National Executive, APS College of Health Psychologists

Professor Sidney Bloch, Dept of Psychiatry and Centre of Study of Health and Society, University of Melbourne

Oncology Social Work Australia

Mr Ivan Hochberg, Social Worker, The Alfred

Ms Karen Todd, Social Worker cancer services, Geelong Hospital

Ms Nicole Tokatlian, Senior Clinician/Team Leader, Haematology and Oncology Social Work Team, Royal Children's Hospital

Ms Cynthia Holland, Social worker, Gynaecology Unit, Royal Women's Hospital

Tuesday, 19 April 2005
Commonwealth Parliamentary Offices, 8th Floor Charterbridge House, 70 Phillip Street, Sydney

Clinical Oncological Society of Australia, Cancer Council Australia, National Cancer Control Initiative and National Aboriginal Community Controlled Health Organisation

Professor Alan Coates, Chief Executive Officer, Cancer Council Australia

Professor David Currow, Vice-President, Clinical Oncological Society of Australia

Professor Mark Elwood, Director, National Cancer Control Initiative

Ms Cheryl Myers

Cancer Nurses Society of Australia

Ms Tish Lancaster, Deputy Chair

Associate Professor William Kricker & Associate Professor Martin Berry

National Breast Cancer Centre

Dr Helen Zorbas, Director

Breast Cancer Action Group NSW and Cancer Voices

Ms Sally Crossing, Chair

Cancer Institute NSW

Prof Jim Bishop, Chief Cancer Officer NSW and Chief Executive Officer

Centre for Children's Cancer and Blood Disorders

Dr Tracey O'Brien, Head, Stem Cell Transplant Program

Ms Anne Senner, Clinical Nurse Consultant

CanTeen Australia

Mr Andrew Young, Chief Executive Officer

Ms Dayna Swiatek, National President

Ms Lauren Michels, Patient Member of CanTeen

Medical Oncology Group of Australia

Ms Franca Marine, Executive Officer

Rural Doctors Association of Australia

Dr Sue Page, President

Ms Susan Stratigos, Policy Advisor

Australian Traditional-Medicine Society

Mr Raymond Khoury, Head of the Herbal Medicine Department

Wednesday, 20 April 2005
Parliament House, Canberra

Royal College of Nursing Australia

Ms Elizabeth Foley, Director of Policy

Ms Laurie Grealish, Fellow

Australian Council of Community Nursing Services

Ms Margaret Dane, Clinical Nurse Consultant Palliative Care – Greater Southern Area Health Service

Bloomhill Cancer Help (via teleconference)

Mr Patrick Buick, General Manager

Ms Margaret Gargan, Founder

Mr Geoff Morton, Secretary

Ms Sarah Burns

Brain Tumour Australia

Mr Denis Strangman, Foundation Chair

Ms Clare Vivian, Executive Committee Member

Ms Susan Pitt, Executive Committee Member

Mr Matthew Pitt

Mr John Paice

Ms Sue Paice

Mr Dennis Argall

Australian Natural Therapists Association

Mr Stefan Talmatzky, Director and Natural Therapies Practitioner

National Rural Health Alliance

Mr Gordon Gregory Executive Director

Anita Phillips, Manager Policy Development

Pharmacy Guild of Australia

Mr Harvey Cuthill, National Councillor

Mr Lance Emerson, Director Professional Development

Ms Khin Win May, Policy Officer

Cancer Alliance Network

Mr Russell McGowan, Chair Cancer Alliance Network Board

Mr Don Baumber, Director

Department of Health and Ageing

Mr Philip Davies, Deputy Secretary

Professor John Horvath, Chief Medical Officer

A/Professor Rosemary Knight

Dr Leonie Hunt, A/G Principal Medical Adviser Dr Jane Cook, Senior Medical Adviser, Medicare Benefits Branch

Dr Ruth Lopert, Senior Medical Adviser, Pharmaceutical Benefits Scheme

Australian Institute of Health and Welfare

Dr Ching Choi, Head of the Health Division

Mr John Harding, Head of Health Registers and Cancer Monitoring Unit

National Health and Medical Research Council

Ms Cathy Clutton, A/g Executive Director, Centre for Health Advice Policy and Ethics

Wednesday, 11 May 2005
Parliament House, Canberra – Teleconference

Professor Jane Maher
Chief Medical Officer and consultant clinical oncologist, Mount Vernon Cancer Centre
London UK

Dr Michelle Kohn
Macmillan Cancer Relief's Complementary and Alternative Medicine adviser
London UK

Wednesday, 12 May 2005
Parliament House, Canberra – Teleconference

Mr Doug Ulman
Director of Survivorship, Lance Armstrong Foundation
Texas USA

Dr Barrie Cassileth
Chief, Integrative Medicine Service, Memorial Sloan-Kettering Cancer Centre
New York USA

Mr Michael Lerner
Author of 'Choices in Healing: Integrating the best of conventional and complementary approaches to cancer' and President Commonweal
California USA

APPENDIX 3

GOVERNMENT AND NON GOVERNMENT ORGANISATIONS INVOLVED IN CANCER TREATMENT OR SUPPORT

A list of organisations involved in cancer treatment and support was initially provided by Mr Clive Deverall at the Perth hearing. This list has been added to by Mr Deverall and through research by the Committee secretariat. It is indicative of the numbers of organisations involved and is not intended to be exhaustive.

AH Crawford Cancer Treatment Society
Austalian Medical Association Limited
Austin Research Institute
Australasian Lung Cancer Trials Group
Australasian Lymphoma and Leukemia Group
Australian and New Zealand Breast Cancer Trials Group
Australian and New Zealand Childrens Cancer Study Group
Australian and New Zealand Gynaecological Oncology Trials Group
Australian Cancer Network
Australian Cancer Research Foundation
Australian Divisions of General Practice
Australian Gastro-intestinal Trials Group
Australian Institute of Health and Welfare
Balya Cancer Self Help and Wellness Inc
Bloomhill Cancer Help
Brain Foundation
Breast Cancer Institute
Breast Cancer Network Australia
Breast Cancer Research Association
Breast Cancer Support Service
Breastscreen (8)
Camp Quality
Can Assist – Cancer Assistance Network NSW
Cancer Alliance Network
Cancer Council of Australia
Cancer Institute NSW
Cancer Research Institute
Cancer Self Help and Wellness Association

Cancer Support Association
Cancer Voices (3)
Can-Survive (Hopeline)
Canteen (7)
Childhood Cancer Association
Childrens' Leukaemia and Cancer Research Foundation Inc
Clinical Oncological Society of Australia
Coalition of Cancer Advocates
Colostomy Associations
Commonwealth, State and Territory Departments of Health (9)
Cure Cancer Australia Foundation
Gawler Foundation
Gynaecological Awareness and Interest Network
Gynaecological Cancer Society
International Breast Cancer Study Group
James Crofts Hope Foundation – [brain cancer]
Kids with Eye Cancer Association
Laryngectomy Associations (8)
Leukaemia Foundation
Life Force Foundation
Lions Cancer Institute
Ludwig Institute for Cancer Research
Make a Wish Foundation
Medical Oncology Group
Melanoma and Skin Cancer Research Institute
National Breast Cancer Centre
National Cancer Control Initiative
National Cancer Strategy Group
National Health and Medical Research Council
National Ovarian Cancer Network
NHMRC Clinical trials Centre
Ovarian Cancer Association
Ovarian Cancer Research Foundation
Palliative Care Australia (8)
Prostate Cancer Foundation of Australia
Royal Australian College of General Practitioners
Royal Australasian College of Surgeons
Royal Australian and New Zealand College of Psychiatrists
Rural Doctors Association of Australia

Sir Charles Gairdner Hospital - Brownes Cancer Support Centre
Skin and Cancer Foundation
State and Territory Cancer Councils (8)
The Cancer Information and Support Society
The Royal Australasian College of Physicians
The Royal Australian and New Zealand College of Radiologists
The Royal College of Pathologists Australasia
Trans-Tasman Radiation Oncology Group