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.

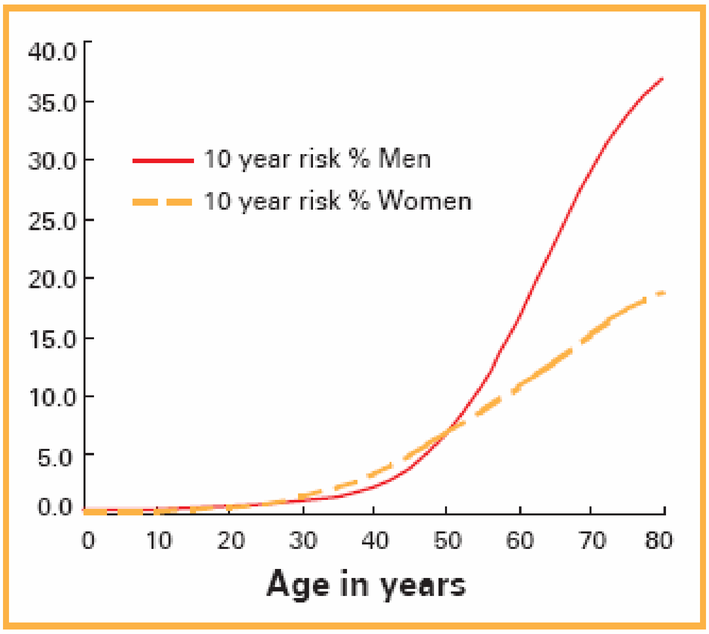
[8] *Deaths, Australia*, 3302.0 Australian Bureau of Statistics, 15 December 2004, p.3.

[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).