

## Services and treatment options for persons with cancer Joint submission to Senate Inquiry

Clinical Oncological Society of Australia

The Cancer Council Australia

National Cancer Control Initiative

The National Aboriginal Community Controlled Health Organisation

The Clinical Oncological Society of Australia is the peak multidisciplinary society for health professionals working in cancer research or the treatment, rehabilitation or palliation of cancer patients.



The Cancer Council Australia is Australia's peak non-government national cancer control organisation. Its member bodies are the eight state and territory cancer councils, whose views and priorities it represents on a national level.



The National Cancer Control Initiative is a partnership between The Cancer Council Australia and the Department of Health and Ageing. Its role is to provide expert advice to the Australian Government and other key groups on all issues related to cancer control as well as manage a range of cancer related projects.



The National Aboriginal Community Controlled Health Organisation is the peak body in Aboriginal health representing over 130 Aboriginal Community Controlled Health Services across Australia.



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## Introduction

Every Australian is likely to be affected by cancer, either through personal experience or the diagnosis of a loved one. The latest evidence shows that one in three Australian men and one in four women will develop a malignant cancer by the age of 75.<sup>1</sup>

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.<sup>1</sup> 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 wellbeing, relationships, work and plans for the future.

Each cancer patient should be seen as a valued individual who deserves the best possible treatment and support centred on their specific needs. Moreover, care should focus on the person, not the disease, and should include emotional support and foster hope.

## Cancer in Australia

Cancer kills more Australians than any other single cause,<sup>2</sup> and opinion polls have found cancer to be the nation's greatest individual disease concern.<sup>3</sup>

The burden of cancer in Australia is rising, with 88,398 new cases (excluding non-melanoma skin cancers) and 36,319 cancer deaths in 2001, compared with 65,966 new cases and 30,928 deaths in 1991. Cancer currently accounts for 31 per cent of male deaths and 26 per cent of female deaths in Australia and the loss of an estimated 257,000 potential life years.<sup>1</sup>

More than 267,000 Australians are living with cancer, many with persistent and incurable forms.<sup>2</sup>

## Translating evidence into action

We commend the Senate for conducting this Inquiry. The Hon Senator Peter Cook in particular is thanked for his personal commitment to focusing on all aspects of an individual patient's needs.

On behalf of the 267,000 Australians with cancer and the many thousands newly diagnosed each year, it is our hope that this Inquiry helps to promote an evidence-based view of how the system should be reformed.

## The future

There is great potential for reforming cancer services in Australia to better meet the needs of the individual patient, their carer and family. The draft *National service improvement framework*<sup>4</sup> provides an appropriate policy context; the forthcoming establishment of the Federal Government's new national cancer agency,<sup>5</sup> Cancer Australia, could provide an authority for its implementation; and existing clinical practice guidelines,<sup>6</sup> if adopted nationally, provide best practice protocols.

Converting these tools into action will require financial investment. In considering this, it is important to note that despite killing more Australians than any other cause and imposing an enormous direct and indirect financial burden, cancer accounts for only 5.7 per cent of the nation's health budget.<sup>1</sup>

As Australia's population ages<sup>7</sup> and treatment advances continue to take effect, there will be increasing numbers of cancer patients surviving for longer periods but with relatively fewer taxpayers to support them.

Investment in enhanced cancer care has the potential to provide significantly high returns: improved patient outcomes could reduce hospital stays and relieve pressures elsewhere on the health system and better enable patients, their carers and families to continue contributing to the economy. Improved coordination of existing services could also provide substantial cost-benefit offsets.

## Recommendations

This submission addresses the terms of reference in the context of the current position and the available evidence. Barriers to best practice are set out on page 25. Recommendations for addressing these barriers, according to the evidence and the views of cancer healthcare professionals, are set out on page 41 and are also summarised on the following page.

## Recommendations for a national cancer system that aims to provide optimal treatment and support to every person with cancer

### General

- In consultation with all key stakeholders, Cancer Australia to develop and introduce standard models of multidisciplinary care based on the *National service improvement framework*. Flexibilities should be built into the system to facilitate different models in different environments.
- In consultation with all key stakeholders, Cancer Australia to establish a national system for accreditation of cancer centres and credentialing of individual practitioners based on clinical practice guidelines.
- Invest in building the cancer workforce, including the recommendations of Australian Medical Workforce Advisory Committee (AMWAC, attached). Design training programs on projected future patient load and anticipated changes in technology.
- Improve cancer-awareness among all medical practitioners by introducing an improved cancer curriculum and a cancer-specific exit exam for all medical graduates.
- Invest in improved delivery and coordination of outpatient-based services in all settings.
- Streamline procedures for assessing and approving pharmaceuticals for treating cancer patients.
- Expand MBS items 801–805 to include all specialists involved in a multidisciplinary team, including surgeons, medical and radiation oncologists and pathologists.
- Build cancer accreditation into the Medicare schedule, for example by offering a higher rebate to all credentialed practitioners.
- Add subspecialties such as psychosocial care to the Medicare schedule.

### Regional communities

- Adopt the recommendations outlined in The Cancer Council Australia's position statement (Appendix C) on travel and accommodation schemes.
- Establish cancer centres in large regional centres, with the capacity to employ oncologists, care coordinators, oncology social workers and psychologists; attract metropolitan practitioners; and provide outreach services within their region. Such centres could have formal links to urban centres for mentoring, continuing medical education, care coordination of complex/rare cases and conjoint appointments.

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- Explore the application in remote areas of effective models of support, such as the Cancer Council Helpline and incorporating psychosocial support into telemedicine conferencing.
- Pilot the specialist breast nurse model with a focus on psychosocial support, operating from the nearest regional centre of sufficient size.

#### Indigenous communities

- Recognise cancer affecting Aboriginal peoples and Torres Strait Islanders as a priority and foster networks between government, community and representative Aboriginal and Torres Strait Islander organisations to develop a national response to the prevention and treatment of cancer.

#### Less conventional and complementary treatments

- Implement clinical practice guidelines to help ensure that a person with cancer can discuss their possible interest in less conventional and complementary therapies with healthcare professionals in an open and non-judgemental way.
- Subject commonly used but unproven treatments to rigorous clinical testing so that those which demonstrate efficacy can be recommended as appropriate.
- Support the Therapeutic Goods Administration in its role of assessing the safety of complementary and less conventional therapies and determining emerging research priorities.

## Addressing the terms of reference...

(a) The delivery of services and options for treatment for persons diagnosed with cancer, with particular reference to:

i) the efficacy of a multidisciplinary approach to cancer treatment,

## Definitions

In terms of cancer management in Australia, there are two distinct models of care. The traditional model is one where a general practitioner refers a patient to a specialist, usually a surgeon, who conducts the primary intervention, usually removal of a tumour. Patients may then see other cancer specialists in an ad hoc way (depending on the level of involvement and coordination provided via the GP or surgeon) for opinions and treatment before – but more often after – the primary intervention.<sup>8</sup>

The multidisciplinary model describes an integrated team approach by all healthcare professionals involved in the patient's care. Team members first agree on the precise diagnosis and staging of the disease, then confer on the most efficacious plan for the patient's care. The patient and 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.<sup>8</sup> (See following section.)

## Why a multidisciplinary approach is more efficacious

### Caring for the person

Optimal cancer treatment should mean not just treating the disease, but also caring for and supporting the individual patient, their carer and family. To do so efficaciously may involve health care professionals from a number of disciplines, including the general practitioner who makes the referral; surgeons, medical and radiation oncologists; oncology and palliative care nurses; social workers, psychologists, occupational therapists and physiotherapists; pharmacists, dieticians and palliative care physicians.<sup>8</sup>

Establishing a multidisciplinary team means consensus is reached by a range of professionals on the diagnosis and stage of the disease and the optimal management of the individual patient.<sup>8</sup>

### Avoiding overlaps and gaps in service

A coordinated, team approach should mean the provision of care is planned and integrated, with individual treatments provided when they are most beneficial in relation to other services.<sup>8,9</sup>

Unnecessary duplication of and potential gaps in service provision can therefore be reduced.<sup>8</sup>

### Team skills, individual approach

A team approach should help to ensure that the patient can make fully informed decisions about their treatment on the basis of advice from a range of disciplines. A team approach also eliminates the risk of an individual professional making recommendations based on personal experience, professional bias or self-interest.<sup>8</sup>

Moreover, the multidisciplinary approach should help to ensure that patients have access to the full range of services required for their care.<sup>8</sup>

### Continuity, coordination

Employed effectively, multidisciplinary care should facilitate patients moving from one treatment modality to the next as though they are part of one service. For example, patients should experience the provision of surgery, radiation and medical oncology services as integrated components.<sup>8</sup>

Communication strategies should also be in place to ensure that GPs and other community care providers are fully informed about the diagnosis, treatment and supportive care for each person with cancer in their care. People with cancer should receive information about care and referral pathways so they understand what will happen throughout their journey.<sup>8,9</sup> (See following section, Care coordination.)

### Best practice, based on evidence

A standard, best-practice approach to multidisciplinary care should ensure that treatment and care are based on agreed national clinical practice guidelines, or the best available evidence in the absence of guidelines.<sup>8,9</sup>

It is also important to note that while national standards are pivotal to best practice, flexibility is also required within a national framework. Different models of multidisciplinary care will need to be applied in different circumstance, depending on the individual patient's needs and the setting in which they are treated.



Standards that should be built into a flexible, national, multidisciplinary model should include:<sup>4</sup>

- Case-conferencing for agreement on options for treating each patient.
- Audit systems for collecting information about the care of people with cancer, ensuring care is based on evidence and protocols. Results could be used to develop continuous quality improvement programs.
- Pathways for patients to be invited to participate in clinical trials.
- Protocols for exchange of information among all team members, including general practitioners.
- Opportunities for patients to provide feedback about the care received from all team members.
- People with cancer having the opportunity to contribute to the planning of cancer services.
- Protocols to ensure patients can discuss their concerns openly with their treatment team or individual team members.
- Access to an individualised written treatment and follow-up plan.
- Provision of culturally appropriate care (See Psychosocial support, Indigenous cancer sections).
- Access to supportive care services including psychologists, psychiatrists and social workers, if needed.

#### Limitations of the traditional approach

The flaws in the traditional approach to cancer treatment are in direct contrast to the strengths of a multidisciplinary model. The traditional model is not structured to respond to the patient's and their families' overall needs and is likely to focus on the disease more than the person.<sup>8</sup>

Under the traditional approach, patients may rely on the opinion of an individual professional, making patients feel vulnerable and less in control of their situation. The risk that a healthcare professional lacks an up-to-date, evidence-based view or may make a decision out of professional bias or self-interest is also greater with the traditional approach.<sup>8</sup>

When additional treatments and support services are required, they may be delivered less efficiently under the traditional model, with the risk of patients being passed from one clinician or professional to the next without continuity of care.<sup>8,9</sup>

### The evidence

Numerous articles in the scientific literature provide information on the multidisciplinary care of cancer patients, yet only a limited number of studies have evaluated the effects of a multidisciplinary approach on cancer care. However, several studies indicate that multidisciplinary care has the potential to improve outcomes for patients with some cancers and increased patient satisfaction (see Appendix A).

Multidisciplinary teams may include specialised clinicians or clinicians with high-volume caseloads. Similarly, multidisciplinary care may be practised in hospitals or specialist cancer centres with a high volume of cancer patients. Studies have suggested an association between high-volume hospitals and improved short-term outcomes in initial cancer treatment. In addition, improved outcomes have also been associated with surgeon specialisation and surgery undertaken for some cancers.<sup>8</sup>

There is also evidence suggesting that a multidisciplinary approach leads to improved patient access to clinical trials,<sup>10</sup> increased patient satisfaction, alleviation of pain in advanced cancer patients and cost-savings to taxpayers.<sup>8</sup>

Appendix A provides a summary of a literature review undertaken in 2003 that provides medical evidence of the efficacy of multidisciplinary care.

### Current position

It is understood that multidisciplinary care is recommended as best practice by the majority of healthcare professionals, patients, their families and carers throughout Australia and endorsed as best practice in NHMRC clinical guidelines.<sup>6,8,9</sup> It is supported in-principle by the federal Coalition and the ALP, and featured prominently in the cancer control policies announced by both during the 2004 federal election campaign.<sup>5,11</sup>

However, there are no national standards, system of accreditation for cancer centres nor credentialing of healthcare professionals to facilitate best practice in multidisciplinary care Australia-wide.<sup>8</sup>

At present, credentialing is being driven by the Australian Council for Safety and Quality in Health Care. For example, in some areas of care there are arrangements for audit as part of a credentialing process.

The issue of accreditation is not being addressed at the national level in any capacity, although the feasibility of accreditation and credentialing is being explored by the Australian Cancer Network in conjunction with other cancer organisations. The US, however, has introduced a set of national guidelines for accrediting cancer centres, aimed at helping cancer patients make a more informed choice about the centre for their care.<sup>12</sup>

While we believe that most of the major cancer centres in the larger capitals use a non-standard multidisciplinary care model with varying degrees of success, the application of multidisciplinary care in the private sector is severely restricted due to Medicare not supporting attendance in multidisciplinary care team meetings (see section on barriers to implementation of best practice).<sup>8</sup>

The National Breast Cancer Centre has commissioned the Pam McLean Cancer Communications Centre to develop a training module for cancer teams designed to improve communication and teamwork.<sup>9</sup> However, no funding has been made available to implement the module.

Multidisciplinary care is also very limited in regional areas, due to infrastructure problems common to the provision of medical services in rural and remote Australia.<sup>13</sup>

#### Workforce and training

Multidisciplinary care is supported as best practice, but the effectiveness of any model of care depends on the availability of healthcare professionals to provide optimal services.

Shortage in the cancer workforce are outlined in Appendix B, a summary of the findings and recommendations of the Australian Medical Workforce Advisory Committee report.<sup>35</sup>

(a) The delivery of services and options for treatment for persons diagnosed with cancer, with particular reference to:

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

## Overview

It is noted that “care coordinator” and “case manager” are grouped in these terms of reference. However, in a cancer context, care coordination should refer to the integration of a patient’s overall needs from across all disciplines;<sup>14</sup> case-management usually applies to the specific management of an associated need, such as a patient’s psychosocial needs. We address this criterion in the context of care coordination and the desirability of a care coordinator.

There is evidence that the designation of a care coordinator can play a valuable role in helping to ensure continuity of care and to deliver the full benefits of a multidisciplinary model stated throughout this submission.<sup>14,15</sup>

It is important to note, however, that care coordination is no substitute for adequate service provision. While care coordination has been shown to help achieve optimal results,<sup>16</sup> it is essential that all Australians have access to models of care that include the full range of evidence-based treatment and support services. Service pathways must first be in place before they can be effectively coordinated.

## Role of a care coordinator

Care coordination evolved from efforts to reduce fragmentation of services for patients with complex care needs. While no precise definition appears in the medical literature,<sup>17</sup> the *Clinical practice guidelines for the psychosocial care of adults with cancer* recommend that specialist oncology nurses, in both inpatient and outpatient settings, take responsibility for coordinating services provided by the multidisciplinary team and monitoring the patient’s progress.<sup>9</sup> The guidelines also suggest that GPs can help ensure continuity of care, because of their knowledge of a patient’s social and medical background, especially in relation to follow-up and the management of co-morbidities.<sup>9</sup>

The draft *National service improvement framework for cancer* also recommends that patients have a designated coordinator of care who knows about all aspects of their disease, treatment and support.<sup>4</sup>

The care coordinator should help patients move between treatment modalities, ensure they have access to information and support and that the treatment team is fully aware of a person's preferences and psychosocial situation. The care coordinator might be an oncology nurse, GP, 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.<sup>4</sup>

Standardised care protocols, such as care maps, pathways and guidelines, have also been identified as an important mechanism for achieving coordinated and continuous care.<sup>4,14</sup>

### Desirability of a care coordinator

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.<sup>18</sup> 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.

While an individual care coordinator is desirable to usher the patient through this maze, all team members should have a role in ensuring continuity of care.<sup>8,9</sup> Service limitations in some settings and the need for flexibilities to help address them mean care coordination, where a designated coordinator is not feasible, should still be a priority.

### The evidence

The limited evidence available shows significant benefits for cancer patients and their families where treatment has been coordinated by a case manager or care coordinator.

The National Institute of Clinical Excellence in the UK undertook a systematic review of the literature published between 1966 and March 2003 to determine the state of evidence on interventions to improve cancer service models for supportive and palliative care.<sup>19</sup> Thirteen studies were identified that evaluated interventions including appointment of nurse coordinators, multidisciplinary team interventions, and introduction of standardised guidelines, protocols and methods for improved communication. The evidence showed that effective care coordination enabled services to complement each other and provide more effective supportive care services.<sup>19</sup>

The *Clinical practice guidelines for psychosocial care for adults with cancer* in Australia similarly present evidence supporting the efficacy of designating a care coordinator.<sup>9</sup>

A recent review concluded there was level 2 evidence (involving at least one randomised control trial) to suggest that specialist breast nurses in a care coordination role provided improved continuity of care and improved patients' understanding of their care program.<sup>9</sup>

### The experience of breast cancer

The incidence of breast cancer (11,791 cases diagnosed in 2001)<sup>1</sup> and the targeted work of the Commonwealth-funded National Breast Cancer Centre (NBCC) provides a unique insight into the efficacy of care coordination in that patient group. As the first centre of its kind to operate on a national level, the NBCC has been well placed to develop and pilot a number of the recommendations for best practice in care coordination.

The NBCC's specialist breast nurse project found that a specialist breast nurse with a care-coordination role contributed a range of benefits, including: improved team functioning and appropriate use of each professional's skills and resources; care being delivered more smoothly, including referrals; other health professionals having improved information about patients and breast cancer issues; and women being prepared for each treatment stage.<sup>20</sup>

A recent report on the NBCC's multidisciplinary care demonstration projects reinforced the view that specialist oncology nurses acting as care coordinators facilitated more effective communications among the team and with patients.<sup>21</sup>

Studies from overseas also demonstrate improved patient outcomes where specialist nurses have played a care coordinating role, not only in breast cancer but also in cancers of the lung, prostate and bladder.<sup>22,23</sup>

### Current position

A number of states have moved towards formally introducing cancer care coordinators as a way to improve patient outcomes.<sup>17</sup>

In Queensland, cancer coordination positions have been established in a number of Health Service Districts in the Southern and Central Zone of the state. These were initially established to scope patterns of care and referral pathways, and to define a model that is consistent state-wide while able to meet local needs.<sup>24</sup>

To support its Cancer Clinical Service Framework, the NSW Health Department plans to recruit up to 50 cancer nurse coordinators. They will work through Lead Clinicians and Directors of Area Cancer Services to support oncology team meetings, develop care pathways and protocols, and provide a direct source of contact for patients and primary care physicians accessing cancer services.<sup>25</sup>

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A training program for care coordinators is also planned in NSW under the auspices of the NSW Cancer Institute. There is no current funding for the provision of such training outside NSW.<sup>25</sup>

In Victoria, program coordinators and regional nurse coordinators have been introduced as part of the Breast Services Enhancement Program.<sup>26</sup> Individual institutions have also established nurse coordinator roles for specific cancers.<sup>26</sup>

Currently in Australia there are no national standards or credentialing system to support the broad implementation of cancer care coordination.<sup>8</sup> However, both the draft *National service improvement framework* and the *Clinical practice guidelines for the psychosocial care of adults with cancer* provide best-practice advice in a national policy context.<sup>4,9</sup>

(a) The delivery of services and options for treatment for persons diagnosed with cancer, with particular reference to:

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

## Overview

Many people diagnosed with cancer face practical, emotional and psychological demands in addition to their physical treatment. These psychosocial needs are significant, and frequently go undetected and unmet.<sup>9</sup>

The extent to which a cancer diagnosis impacts on the psychosocial needs of a patient, their carer and family may vary according to other factors. For example, the elderly, young families with a parent with cancer or young adults may display a particularly high level of psychosocial need due to a complex number of interacting factors.<sup>8,9</sup> Such groups of patients can experience increased distress which can contribute to sub-optimal care.<sup>8,9</sup>

### Models for delivering psychosocial care

The potential for psychosocial needs to vary widely underlines the importance of a multidisciplinary approach centred around each patient's specific needs. Effective communication and care coordination are pivotal to the delivery of adequate psychosocial support.<sup>9</sup>

Adoption as national best practice of the *Clinical practice guidelines for the psychosocial care of adults with cancer* would help to ensure that a patient's psychosocial needs are considered by all members of the care team.<sup>8,9</sup>

The guidelines are thoroughly researched and contain evidence-based information on the emotional, social, psychological and practical impact of cancer on patients and their families, and how these can be addressed by healthcare professionals involved in the patient's care. Key points in the guidelines follow.

### Psychosocial care throughout cancer journey

The psychosocial care of a person with cancer should begin from diagnosis and proceed through treatment, recovery and survival, or through the move from curative to non-curative aims of treatment, palliative care, death and bereavement. It should involve all members of the treatment team, the person's GP and carer, family and friends.



### Cultural and personal issues

Social and cultural sensitivity must be observed in assessing a patient's psychosocial support needs, establishing the care setting and delivering services. Sensitivity to the particular needs of each patient is required, with an awareness of issues of gender, age, culture, education and socio-economic status.

### Communication

Good communication involves more than a mere facility with words; it requires both a willingness to engage with others emotionally, and appropriate and sensitive use of physical touch. The ability of healthcare professionals to communicate with patients, their families and friends, and with each other, lies at the core of optimal patient care. The guidelines provide evidence-based, best practice communications advice in all situations, such as discussing initial diagnosis, prognosis and treatment options, potentially life-threatening procedures, palliation, and bereavement.

The development of clinic-based protocols can be beneficial in ensuring effective communication between members of the treatment team and the patient, and the delivery of quality supportive care.

### Assessment and monitoring

All health professionals involved in the care of cancer patients should be aware of the risks for adverse emotional outcomes, and actively assess adjustment and mood during the course of treatment and follow-up.

While the emotional and psychological care of the patient may be the responsibility of their treating health professional, clinicians should recognise their own level of training and skill in this area, and refer patients whose problems are complex or beyond their training and expertise to specialised services.

It is also recommended that people considered at risk of psychological problems are referred to specialised psychological services early in their treatment, as this may minimise the likelihood of their developing related disorders.

### Referrals

Establishing optimal methods for referring patients to professional help is vital in ensuring good psychosocial care. All health professionals need to develop their own referral networks for supportive and psychological care of their patients.

These networks would optimally comprise psychiatrists, clinical psychologists, oncology social workers and occupational therapists with expertise in cancer issues and with whom the health professional can communicate about their patients.

Comprehensive care of the individual may also require the involvement of other specialists, such as physiotherapists, speech pathologists, dentists, endocrinologists, nutritionists, reconstructive surgeons and fertility specialists.

It should be noted that local circumstances and the availability of resources may limit referral options and the referral networks that can be developed.

### Established models

Current models for assisting patients with significant psychological problems include cognitive behavioural therapy, psychotherapy, group therapy, family and/or couple therapy, telephone counselling, and complementary therapies.<sup>9</sup>

Features common to all psychological interventions should include empathetic manner, listening, affirmation, reassurance and support. The most appropriate psychological therapy will depend on the patient, the issues at hand and the training and skills of the therapist. Therapies may be delivered individually, or via a group or family model and may be face-to-face or remote.<sup>9</sup>

While some people will be more comfortable with individual counselling, others will benefit from group counselling where they can gain from sharing the commonality of their experience.<sup>9</sup>

Other models that offer both a psycho-educational and psychosocial benefit are the Living with Cancer Program (believed to be available in Victoria, Queensland, NSW and South Australia), Home Care Program and Cancer Survival Toolbox.

The likelihood of patients gaining access to these forms of assistance will depend on whether their psychosocial needs are given due consideration – which in turn may depend on whether they are treated under a flexible multidisciplinary model.<sup>8</sup>

Cancer Helplines, run by Cancer Councils in each state and territory, are a key source of psychosocial support for patients, their carers and families, receiving around 160,000 calls nationally each year. This Helpline service provides information and support about cancer and referral to appropriate services, both within Cancer Councils and in acute and community-based settings. Another model for psychosocial is peer support, either through self-help groups or one-on-one peer relationships. Pastoral care is also an established form of support.

### The evidence

Up to 66 per cent of people with cancer experience long term psychological distress, up to 30 per cent experience clinically significant anxiety problems and prevalence rates for depression range from 20-35 per cent.<sup>9</sup>

Many people also report inadequate information to guide decision-making, and others are disadvantaged because of a lack of knowledge about practical support,

even when such services are available. The psychosocial impact on the families of those with cancer is considerable.<sup>9</sup>

According to a report by the National Breast Cancer Centre, breast cancer nurses identified psychological distress in up to 72 per cent of women diagnosed with breast cancer.<sup>28</sup> There are numerous other examples.<sup>9</sup>

Psychosocial interventions such as cognitive behavioural therapy are shown to reduce psychosocial morbidity in the acute phase of cancer, while longer-term supportive psychotherapies are effective in people with advanced cancer.<sup>29</sup>

Despite these benefits, there is evidence that patients feel their psychosocial needs are not being met under current arrangements.<sup>9</sup> For example, a recent outpatient pilot program undertaken by the Alfred Hospital, Melbourne, demonstrated a high need for improved psychosocial support and, where psychosocial care was adequately resourced, improved continuity of general care.<sup>30</sup>

#### Current position

The *Clinical practice guidelines for the psychosocial care of adults with cancer* provide clear recommendations on evidence-based best practice in psychosocial care.<sup>9</sup> However, these recommendations have not been implemented in all treatment centres due to the absence of national cancer care standards, accreditation and credentialing.<sup>8</sup>

Under current arrangements, there is no standard approach to assessing a cancer patient's psychosocial needs and referring them for specialised care. Nor is there a standard approach to monitoring a patient's mental and emotional wellbeing and ensuring that support is provided according to their changing needs.<sup>8</sup>

Some GPs and specialists have been trained to focus on a patient's psychosocial needs, many have not.<sup>8</sup> Whether or not a patient is referred to a health professional trained to deal with their psychosocial needs is an example of the cancer care "lottery".

While it is understood that specialised psychosocial care is often accessible to cancer patients through inpatient services in metropolitan hospitals, outpatient and community psychosocial services are poorly resourced and often too costly for patients.<sup>8,21</sup> Psychiatric services are refundable under the Medicare scheme, but ongoing psychosocial support is not refunded. In addition, there is no Medicare rebate for psychologists who see cancer patients in the private sector.<sup>31</sup>

Oncology social workers have unofficially observed and reported staff reductions in their discipline over the past 10 years. It is understood that cuts to this workforce increase the risk of sub-optimal psycho-oncology services being provided across the system.

(a) The delivery of services and options for treatment for persons diagnosed with cancer, with particular reference to:

iv) differing models and best practice for delivering services and treatment options to regional Australia and Indigenous Australians,

## Overview

People in regional communities and Aboriginal peoples and Torres Strait Islanders face a range of barriers to optimal cancer care, and recent reports show higher relative cancer mortality rates among these groups.<sup>32,33,38</sup> While the two distinct population groups may share geographic barriers to treatment and support, there are a number of problems unique to each. We therefore address these under separate headings.

### Regional communities

People diagnosed with cancer need access to specialised treatment that is often only available in metropolitan hospitals. For people in rural and remote regions, this means significant travel costs compounding the expense of treatment and loss of income. It may also mean losing the companionship of loved ones who are unable to travel hundreds of kilometres to the nearest treatment centre in addition to being in an unfamiliar environment at a time of great distress.

### Models

#### Travel and accommodation

While models for treating people in regional areas are being explored (see following), the reality is that distance will always impose barriers to accessing the full range of services; travel will always be required for treating complex cancers in remote patients.

Assistance has been available since 1978, through the Isolated Patients' Travel and Accommodation Assistance Scheme, to subsidise travel and accommodation costs for people in rural and remote areas requiring specialist medical treatment not available locally. The scheme was initially administered at the federal level but responsibility was transferred to the states and territories in 1987.

Serious concerns associated with access and equity have arisen since devolution to the states and territories and it has been identified that schemes are not working as well as they could for people affected by cancer.<sup>1,13,14</sup>

### Telemedicine

Telemedicine uses telecommunications to give out-posted clinicians access to practitioners in other disciplines and to enable case-conferencing by phone or video hook-up. Telemedicine can therefore support some elements of the multidisciplinary team approach across vast distances.<sup>13</sup>

Telemedicine may have a role in managing selected cases, for example very remote or very complex cases; it may also have a role in linking regional providers into metropolitan multidisciplinary teams in areas where there is not a critical mass of providers to setup a local multidisciplinary team. However, telemedicine can be time-consuming, constrained by technical limitations and unable to support the high numbers of cancer patients in regional areas.<sup>13</sup> It is also unsupported by Medicare.

### Outreach services

Outreach services involve transporting city-based specialists to remote locations to treat people living in those communities and to provide advice to regional physicians.<sup>13</sup> The Federal Government's commitment to a mentoring program, linking metropolitan teaching hospitals to regional centres and promoting multidisciplinary care,<sup>5</sup> is commended.

As with most models for supporting regional patients, the effectiveness of outreach services is limited due to short consultation times, poor continuity of care, responsibilities of visiting versus local clinicians not being clearly delineated, and the need to train local health professionals.<sup>13</sup> Most importantly, there is a shortage of metropolitan clinicians able to participate in outreach services, with many clinicians already having a higher caseload than the accepted international recommended benchmark (see Appendix B, summary of the Australian Medical Workforce Advisory Committee report).<sup>35</sup>

### Regional cancer centres

More comprehensive cancer services 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. Some regional providers have formal linkages/conjoint appointments with metropolitan centres.

One example is the centre at Albury-Wodonga, a former outreach facility that now features five resident oncologists, a clinical trials unit, oncology pharmacist and a two-machine radiotherapy service. Outreach clinics are performed within the region from Albury-Wodonga. Reported benefits include an increase in the number of new patients able to be treated locally from 150 to 750 a year, an eight-fold increase in chemotherapy day treatments performed locally, the establishment of

multidisciplinary clinics and more than 10 per cent of new patients treated through a clinical trial.<sup>13</sup>

Regional cancer centres are also known to exist in Ballarat, Bendigo, Wagga Wagga, Port Macquarie, Lismore and Townsville.

Barriers to their development include the lack of coordination and support between national and state funding agencies, and difficulty in attracting metropolitan-trained health professionals and their families to regional areas.<sup>13</sup>

### The evidence

Around 30 per cent of Australia's population live outside the metropolitan centres, placing them at risk of being unable to access optimal cancer services.<sup>4</sup>

All state and territory cancer registries report higher relative mortality and morbidity rates in cancer patients based outside the major urban centres.<sup>36</sup> This is supported by a range of research articles.

Among the most compelling studies, a 2004 report published in the *Medical Journal of Australia* showed that people with cancer in regional areas of NSW were 35 per cent more likely to die of the disease within five years of diagnosis than people in cities.<sup>32</sup> The study also showed that mortality rates increased as the distance between the patient's location and the nearest urban centre grew. In some cases, remote patients are up to 300 per cent more likely to die within five years of diagnosis.<sup>32</sup>

The evidence also shows that people in regional areas report higher levels of distress associated with their diagnosis and lower satisfaction with the availability of treatment and support.<sup>9</sup>

Access to support is limited by a lack of information on what is available. For example, a study of rural women travelling to the city for breast cancer treatment found that only 39 per cent received financial assistance and 19 per cent of these had trouble claiming money for which they were eligible.<sup>37</sup>

## Indigenous Australians

### Current position

Aboriginal peoples and Torres Strait Islanders with cancer are twice as likely to die from the disease as non-Indigenous Australians with cancer, according to evidence gathered in the Northern Territory and South Australia.<sup>38-40</sup>

The appalling differential in outcomes can be explained by a range of factors, including poorer access to prevention programs; later-stage diagnosis; relatively higher rates of deadlier cancers; coexisting disease; and reduced likelihood of

completing a treatment program. However, when these differences are accounted for, Aboriginal peoples and Torres Strait Islanders continue to have higher cancer mortality rates for reasons unknown, underscoring the lack of cancer research involving these populations.<sup>38-40</sup>

It is understood that Aboriginal peoples and Torres Strait Islanders in regional areas share geographic barriers to service access with other non-urban communities, which are compounded by language and cultural barriers, poverty, dispossession, institutionalised racism, and poor understanding of available support services.<sup>38-40,33</sup>

Aboriginal peoples and Torres Strait Islanders in urban areas share barriers to service provision faced by people in the same locality with lower socioeconomic status, severely exacerbated by the problems of ethnicity outlined above.<sup>33</sup>

Despite the unacceptable imbalance in cancer survival rates, cancer involving Aboriginal peoples and Torres Strait Islanders has often been overlooked, partly because it has been considered a lower priority when compared with the numerous other health problems than consign Indigenous Australians to a health status commensurate with people in some of the world's poorest nations.<sup>33</sup>

In 1989, the National Aboriginal Health Strategy made only one reference to cancer – in relation to the need for greater awareness among Aboriginal and Torres Strait Islander communities of breast self-examination and Pap smears.<sup>41</sup> Fifteen years later, Aboriginal and Torres Strait Islander women have more than double the risk of developing cervical cancer than non-Indigenous women, and are four times as likely to die from the disease.<sup>42</sup> This statistic reflects the poorer access to all aspects of prevention, screening and treatment that characterises cancer in Aboriginal and Torres Strait Islander communities.

### Treatment models

There are no known cancer-specific treatment models for Aboriginal peoples and Torres Strait Islanders in Australia. Some public hospitals in urban centres employ Aboriginal liaison officers to interface between patients and healthcare providers. Aboriginal and Torres Strait Islander peoples are also represented in the caseloads of outreach clinicians, where staff from Aboriginal Community Controlled Health Services plays an important role in facilitating transport, language, financial, emotional and other supporting roles.<sup>33</sup>

In the main, however, Aboriginal Community Controlled Health Services are so poorly resourced that significant time and money are required to explore ways to address the imbalance in treatment outcomes between Indigenous and non-Indigenous peoples.

### The evidence

At present there is no national dataset on cancer affecting Aboriginal peoples and Torres Strait Islanders, and only the Northern Territory, Western Australian and South Australia cancer registries record Indigenous-specific data.<sup>38</sup>

Studies on bowel, lung, breast and cervical cancer, and non-Hodgkin lymphoma, show the Aboriginal peoples and Torres Strait Islanders are diagnosed at a later stage, have reduced access to treatment, are more likely to decline treatment, and have lower survival rates over a five-year period.<sup>38-40</sup>

A national discussion forum on cancer in Indigenous Australians convened by The Cancer Council Australia in August 2004 produced anecdotal evidence from a range of individuals supporting the view that cultural and socioeconomic issues unique to Aboriginal and Torres Strait Islander communities contributed to poor patient outcomes.<sup>33</sup>



(a) The delivery of services and options for treatment for persons diagnosed with cancer, with particular reference to:

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

## Current barriers to implementing best practice in multidisciplinary care

### Care standards

Although it is understood that most major metropolitan hospitals take a multidisciplinary approach to cancer treatment, there are no standard care models, no accreditation system and no formal incentives to ensure adherence to best practice.<sup>8</sup>

The absence of structures to initiate and sustain best practice means that the cancer “lottery” can apply even in care settings that are nominally multidisciplinary.

### Practical barriers

The multidisciplinary model can pose practical problems for clinicians, particularly in the absence of an accreditation system, incentives or adequate Medicare support (see following section).

Commonly reported barriers in this context include the time spent in team meetings, despite not all team members having a role at all times; difficulties in running an multidisciplinary approach in the private sector due to lack of remuneration in a non-salaried environment and lack of funding for specialised ancillary care; insufficient resources required to convene, conduct and record meeting outcomes; delays caused by infrequency of team meetings; and disproportionate burden on some team members.<sup>8</sup>

### Medicare

Medicare does not provide a flexible means of delivering cancer care through a team of highly trained professionals. For example, subspecialisation is essential to effective multidisciplinary care, yet it is not recognised by the Medicare schedule.

While there is limited recognition of physicians in a multidisciplinary team by Medicare (MBS items 801–805), other disciplines are not recognised at all, reducing their incentive to participate.<sup>8</sup>

The absence of subspecialty MBS items also creates problems in the private sector, where there is already little or no funding for specialised ancillary support for the various clinicians, psychologists and counsellors required to deliver optimal care.<sup>8</sup>

### Pharmaceuticals

An evidence-based approach to treating most cancers (excluding non-melanoma skin cancer) will include the use of chemotherapy and other supporting medications. A major problem for cancer patients in Australia is the time such evidence-based treatments take to become available through the Pharmaceutical Benefits Scheme.<sup>8</sup>

A study conducted by the Peter MacCallum Cancer Centre in Melbourne showed that it took the Therapeutic Goods Administration on average 44 months to approve new cancer pharmaceuticals, compared with 13 months to approve pharmaceuticals to treat HIV/AIDS. This is despite the fact that 39,000 Australians died from cancer in 2001, while a total of 91 died from AIDS in 2002 (the most respective recent national death figures).<sup>1,44</sup>

In considering the need to expedite PBS availability of cancer drugs, it is also important to note that, while cancer is the cause of most deaths in Australia overall, drugs for treating cancer did not appear on the list of the 17 costliest drug groups published by the PBS in 2003-04.<sup>45</sup>

### Workforce issues

Central to the provision of multidisciplinary care is the availability of adequate numbers of cancer professionals to staff the team. Staff shortages have been well documented and are outlined in the attached summary from the AMWAC report.<sup>35</sup>

### Education

A review of cancer knowledge among recent medical graduates has revealed major deficiencies in the knowledge, skills and attitudes to cancer of graduating students, especially in the area of cancer communication. The review also indicates that students' exposure to cancer in medical curricula is lower than it was 10 years ago.<sup>46</sup>

The Cancer Council Australia's Oncology Education Committee has developed an Ideal Oncology Curriculum, endorsed by the International Union Against Cancer, but its uptake by Australian universities has been limited.<sup>46</sup>

## Current barriers to implementing best practice in care coordination

### Care standards

In the absence of standardised models of care, the involvement of a care coordinator may depend on the protocols used by individual treatment centres and may vary widely.<sup>9</sup> Outcomes for patients are likely to vary as a consequence, contributing again to the cancer care “lottery”.

For example, a study of the practices of 153 breast care nurses in Victoria found that their liaison role with other health professionals was varied; that joint consultations were not always a routine part of practice; and that referral rates by breast care nurses to some professional groups was limited.<sup>47</sup> This study is an important reminder that care coordinator roles have enormous potential, but careful consideration needs to be given to how such roles are designed and implemented to ensure they adhere to best practice.

### Conflict with other team members

A key challenge to efficient care coordination is ensuring that the involvement of the care coordinator does not inadvertently generate some of the problems their role is designed to avoid – overlaps, unnecessary duplication of effort, fragmentation of services, and a sense of intrusion into the field of other professionals.

Despite some concerns in this area, the NBCC specialist breast nurse project found that the presence of a coordinator helped to eliminate these problems and allayed the concerns of initially sceptical clinicians.<sup>20</sup>

### Insufficient research

While the limited evidence available shows that care coordination can improve patient outcomes,<sup>19-23,9</sup> more research is required to inform the development of flexible models of coordinated care.

### Resources

Care coordinators in under-resourced settings, particularly regional areas, are often faced with unreasonable workloads and expectations. For example, oncology nurses in remote communities may be required to provide services beyond their formal role, and report having to also manage the frustrations of distressed patients whose needs are not being met locally.<sup>13</sup>

## Current barriers to implementing best practice in psychosocial support

### Recognition and resources

In the absence of national standards, an accreditation and credentialing system and the adoption of clinical practice guidelines, a patient's psychological and emotional support needs are at risk of being overlooked.<sup>8,9</sup> These risks are heightened when patients are treated under the traditional model, with attendance to their psychosocial needs at the discretion of an individual clinician.<sup>8</sup>

Under-resourced care settings also place patients at significantly higher risk of receiving limited or no psychosocial support, particularly people in regional and/or Indigenous communities (see below).<sup>8,33</sup> This may be exacerbated by the absence of Medicare rebates for psychosocial care.

### Current barriers to implementing best practice in regional areas

While a number of models for supporting regional cancer patients are discussed in the previous section, the problems of distance will always leave many people in these areas at serious risk of receiving sub-optimal treatment and care.<sup>8,35</sup>

Most significantly, workforce limitations are always felt most acutely in regional areas.<sup>8,13,35</sup> It is understood that the most effective way to support cancer patients is for services to either be in or as close to their local area as feasible. In the absence of sufficient numbers of cancer clinics in regional centres, patients in these areas continue to receive sub-optimal care, although telemedicine and outreach services are having some success.<sup>13</sup>

### Poor use of travel and accommodation support

Absence of specialists in remote areas and the immobile nature of some diagnostic and therapeutic equipment mean travel and accommodation will always be required for some patients outside urban centres.

Government support for travel and accommodation is therefore essential to ensuring that patients do not miss out on treatment and support because of location. However, existing state and territory travel and accommodations schemes are not meeting the needs of individual patients in rural areas.<sup>34,13,8</sup>

### Psychosocial support in regional areas

The further a patient lives from a major city, the less likely they are to have access to a range of support services for their psychological and emotional needs. This may be compounded by the many other problems of distance from the benefits of urban infrastructure.<sup>9</sup>

## Current barriers to implementing best practice in Indigenous communities

### Recognition and understanding of the problem

Aboriginal and Torres Strait Islander cancer patients' mortality rates compared with non-Indigenous cancer patients are so high and their capacity to access services so low that talk of "best practice" in this context is utterly incongruous.<sup>38-40,33</sup> The first step towards addressing this disparity in treatment outcomes is recognising the problem in a holistic sense and identifying it as a priority.<sup>33</sup>

### Health care inequity

The extent of poverty and poor health in Indigenous communities is well-documented.<sup>48</sup> The inherent links between poverty and cancer are increasingly being established.<sup>33</sup> Evidence shows one reason for the higher relative cancer mortality rates among Aboriginal peoples and Torres Strait Islanders is the prevalence of deadlier cancers – cancers of the lung, oropharynx, oesophagus, liver, gallbladder and pancreas.<sup>49</sup> These are linked to a variety of factors including viral hepatitis, particularly in childhood, smoking, alcohol abuse and poor nutrition,<sup>38</sup> which in turn are associated with low socioeconomic status. Many of these antecedents to cancer can be prevented.<sup>50</sup>

Aboriginal peoples and Torres Strait Islanders are faced with a double-burden of disease: communicable diseases prevalent in the poorest developing countries compounded by illnesses associated with obesity, tobacco and alcohol use, characteristic of developed countries.<sup>48</sup>

One barrier to cancer and other services highlighted by Indigenous health professionals is "institutionalised racism".<sup>33</sup> Many other barriers to preventive health services have been identified and these impact directly on cancer prevention, including lower uptake rates of Pap smear screening and inequities in access to the Australian Government Cervical Cancer Prevention Program<sup>42</sup> and Practice Incentive Program for general practice, which has been recently evaluated.<sup>51</sup> For example, in the 2001-02 Federal Budget, \$71.9 million over four years was allocated to increase GP participation rates in the National Cervical Screening program. However, the National Aboriginal Community Controlled Health Organisation report that little of this allocation was accessible to Aboriginal Community Controlled Health Services, nurses and Aboriginal Health Workers, who provide many of the Pap tests to Aboriginal women.

Jurisdictional Public Health Outcome Funding Agreement reports confirm that BreastScreen programs have much lower relative participation rates by Aboriginal women in every state and territory.

There are inequities in access to nicotine replacement therapy, even though the therapy has been shown to be effective.<sup>52</sup> For example, in the Northern Territory the provision of free nicotine patches to Indigenous clients led to a 15 per cent quit

rate after six months, compared with 1 per cent quit rate for those receiving brief intervention. There is also evidence that mainstream programs (eg Quitlines, group therapy) are not suitable for most of the Aboriginal population, necessitating specific programs.<sup>53</sup>

### Liver cancer

In Western Australia, Indigenous Australians are four times more likely to die of liver cancer than the general population.<sup>54</sup> Age-standardised death rates for liver cancer for Indigenous males in the Northern Territory approach that for lung cancer in non-indigenous males generally (1987-97).<sup>38</sup> Liver cancer death rates have almost tripled in Aboriginal Australians over the past decade.<sup>38</sup>

Rates of hepatitis B infection in Aboriginal Australians were very high prior to vaccination in the 1990s, with, for example, positive testing of 46 per cent of children in remote communities in the Northern Territory. New cases are still occurring in Aboriginal adolescents aged over 15, at rates four times higher than the general population.<sup>55</sup>

Treatment for viral hepatitis in Aboriginal chronic hepatitis B carriers is likely to be suboptimal, including within prisons, and this has implications for workforce training and custodial care. The Federal Government's response to the Review of the National Hepatitis C Strategy was that "... health services in prisons are a matter for state/territories".<sup>55,56</sup>

There is a lack of national screening protocols for hepatitis B and C for Indigenous Australians and no clear screening protocol for liver cancer. Therefore, the large hepatitis B and C-positive Aboriginal population has poor access to early treatment and continuing exposure to risk factors such as alcohol consumption.

Unless the problems set out above are addressed, we may be seeing the tip of the iceberg in a future hepatocellular cancer epidemic affecting Aboriginal peoples and Torres Strait Islanders.

While this inquiry focuses on treatment, the circumstances around the doubling of relative mortality rates for Indigenous cancer patients demonstrate the need for a comprehensive approach to addressing cancer affecting Aboriginal peoples and Torres Strait Islanders.

See *Recommendations*, on page 41 for addressing the barriers to best practice set out in this section.

**(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.

## Definitions

### Complementary therapies

Complementary therapies are used together with evidence-based conventional treatments. They do not cure cancer but may help to relieve symptoms or side-effects and improve well-being. Examples include acupuncture, aromatherapy, art therapy, massage therapy, meditation, visualisation and yoga.<sup>57</sup>

### Conventional therapies

Conventional therapies are evidence-based treatments that have been tested following a strict set of scientific guidelines and shown to be safe and effective at curing cancer, slowing its growth or providing relief from symptoms. The main conventional therapies are surgery, radiotherapy, chemotherapy and immunotherapy. Conventional therapies are sometimes referred to as mainstream, medical or orthodox treatments.

### Alternative therapies

It is noted that the terms of this inquiry do not refer directly to “alternative therapies”. However, it is possible that the term “less conventional treatments” could apply to “alternative therapies”. These should therefore be discussed because of their potential to cause significant harm to the patient.

By definition, alternative therapies are used *instead* of conventional therapies to treat cancer. Most of these have not been scientifically tested or have little evidence supporting their safety and effectiveness. Examples include shark cartilage, special diets and herbal treatments.<sup>57</sup> Alternative therapies are sometimes called unproven or “disproven” treatments.

Alternative therapies often cease to be widely used over time. Recent examples include krebiozen (a popular treatment in the 1950s, derived from horse blood, disproven and now banned in many countries); the secret remedy of Milan Brych (an unqualified practitioner in Queensland in the 1970s, later jailed in the US for

medical fraud); and laetrile (a cyanide-based extract of stone-fruit pips, popular in the 1970s but disproven in US studies).<sup>58</sup>

An important observation about alternative therapies is that they are seldom offered for conditions that are well understood by conventional science, such as pneumonia, bone fractures and venous thrombosis.<sup>58</sup> It could be argued that elements of the alternative therapies industry are only viable where illnesses are incurable or not fully understood by conventional science.

### Supporting evidence-based medicine

COSA, The Cancer Council Australia, the NCCI and NACCHO are evidence-based organisations, fundamentally supporting treatments that are shown to be effective through standardised, rigorous testing.<sup>61</sup> If treatments currently considered unconventional were later shown to be efficacious, these would be adopted and endorsed by evidence-based organisations. Equally, therapies shown to be unsafe would be discouraged.

Clinical evidence is obtained through a rigorous, standardised process,<sup>61</sup> involving different methods for different levels of evidence (meta-analyses; randomised controlled trials; cohort studies; consensus of expert opinion). Support for treatments outside this framework is often based on anecdotes, biased media coverage and the opinions of individual authority figures, none of which is reliable in a scientific context.<sup>58</sup>

### Existing research

The vast majority of research exploring the use of complementary and alternative medicines by cancer patients has been conducted in the United States, and there is little information about their use among Australian cancer patients. An important shortcoming of the literature is that most studies fail to distinguish between "complementary" and "alternative" medicines, despite the important distinctions noted here.

A systematic review of the literature suggests that between 7 and 64 per cent of adult cancer patients use some form of non-conventional treatment.<sup>64</sup> The complementary and alternative medicines most commonly used are special diets or food supplements and mind-body techniques such as meditation and relaxation. Studies generally indicate that cancer patients who use complementary and alternative medicines tend to be younger, female, better-educated and those with more advanced disease.<sup>62-65</sup>

In the largest Australian study published to date, 22 per cent of 319 cancer patients reported using non-conventional therapies, with meditation/relaxation, diet and megavitamins the most prevalent. Furthermore, three quarters of patients reported using more than one non-conventional therapy.<sup>62</sup> A more recent study found that 52 per cent of 156 cancer patients at one Australian hospital reported using at least



one non-conventional therapy since their cancer diagnosis and more than one quarter used three or more. Meditation/relaxation, change in diet and multivitamins were the most commonly used therapies.<sup>65</sup>

#### Future research

The only difference between therapies that are supported by conventional practitioners and those that are not is evidence. Acquiring the level of evidence needed to show efficacy is time-consuming and resource-intensive, and should be done on the basis of demonstrated interest and clear guidelines.

Conventional practitioners should nonetheless welcome open discussion about non-conventional therapies.

Given the high level of community interest, it is recommended that the National Health and Medical Research Council fund well-designed scientific studies examining the safety and effectiveness of promising and commonly used complementary and alternative cancer medicines. This could enable people with cancer and healthcare providers to differentiate between treatments that are dangerous and those that may be helpful.

#### Targeting of funds

Study criteria should ensure that much-needed research funds are not allocated to testing treatments where the limited evidence already available suggests a negligible likelihood of efficacy.

The Therapeutic Goods Administration has a legitimate role in helping to identify which emerging therapies might best be prioritised for clinical testing (see response to b [iii]).

An example of funds being ineffectively used is the US study of laetrile in the late 1970s. The Food and Drug Administration's 1970 agreement to trial laetrile in humans was withdrawn after preclinical studies in animals showed it had no likely effect as an anticancer agent.<sup>66</sup> This fuelled claims among laetrile advocates of a government conspiracy to suppress an important breakthrough in cancer treatment. Courts in a number of states successfully challenged the federal government's authority to decide which drugs should be available to cancer patients, and laetrile was legalised in more than 20 states.<sup>67</sup>

The US National Cancer Institute was thereby forced to spend millions of dollars studying laetrile. Only 92 patients of 70,000 who had reportedly used laetrile came forward, of whom six showed some benefit. While there was no evidence of efficacy, laetrile was shown to cause cyanide poisoning, and was subsequently banned.<sup>68</sup>

### Patient-based research

A person with cancer should be encouraged to understand their illness and directed to as much information as they desire to assist them in making decisions and coming to terms with their diagnosis. The *Clinical practice guidelines for the psychosocial care of adults with cancer* contain detailed advice for clinicians on how to refer patients to information from a range of sources, including support groups, literature, multimedia CDs and the Internet.<sup>9</sup>

### The Internet

The internet has the potential to be an excellent tool for facilitating patient-based research and networking patients with their peers and other sources of support. However, there are no controls over the veracity of information on the Internet.

It is understood that the Internet is the main source of information on alternative cancer treatments and can be used to present misinformation, speculation and anecdotes as evidence. Patients should be warned of the dangers of following advice obtained from the Internet or of assuming data published on the Internet is reliable. The key is effective communications between the patient and their multidisciplinary team, based on an empathetic attitude from the care professionals.<sup>9</sup>

**(b) How less conventional and complementary cancer treatments can be assessed and judged, with particular reference to:**

**ii) the efficacy of common but less conventional approaches either as primary treatments or as adjuvant/complementary therapies**

### Evidence of efficacy

The only scientifically valid way to “assess” or “judge” the efficacy of any therapy as a form of primary treatment for cancer is to subject it to rigorous testing.<sup>61</sup> Complementary or alternative treatments that are shown to be efficacious in clinical trials would be welcomed as conventional medicine and incorporated into the mix of other proven treatments according to the needs of the individual patient.

There are already some evidence-based benefits associated with the use of complementary therapies (but not alternative therapies). Underscoring these may be a sense that the patient is taking more control of their circumstances. It is therefore essential that mainstream professionals are receptive to patient interests in this area and that they encourage patients to be proactive in self-care,<sup>9</sup> while recommending complementary therapies that are shown to be effective and warning against those that may be unsafe.

### Established evidence

Patient-reported psychological benefits of complementary medicines include feeling calmer, emotionally stronger, more able to cope with the demands of the illness and feeling more hopeful about the future. Physical benefits can include increased energy and reduced feelings of nausea.<sup>63,65</sup>

Evidence is also mounting in support of the efficacy of some complementary medicines. For example, systematic reviews of the literature have found acupuncture effective in reducing nausea, vomiting and pain and relaxation therapy effective in reducing anxiety and pain.<sup>64,69</sup>

As the evidence-base expands, complementary therapies should increasingly be integrated into conventional cancer care centres. Notably, complementary therapies that are shown to be beneficial have been incorporated into treatment at the Peter MacCallum (Melbourne) and Charles Gairdner Hospital (Perth) cancer centres.

### World Health Organisation recommendations

Given that much of the information promoted to the public about complementary and alternative medicines is not evidence-based and may be unreliable or incorrect, the World Health Organisation recommends consumers use the following checklist to facilitate informed use of complementary and alternative medicines:<sup>70</sup>

- Is the therapy suitable for treating the condition?
- Does the therapy have the potential to prevent, alleviate and/or cure symptoms or in other ways contribute to improved health and well-being?
- Is the therapy or herbal medicines provided by a qualified (preferably registered and certified) practitioner with adequate training background, skills and knowledge?
- Are the products or materials of assured quality and what are the contraindications and precautions?
- Are the therapies or herbal medicinal products available at a competitive price?

### Primary intervention

Current medical evidence demonstrates that best patient outcomes are produced by conventional therapies, and that these are delivered in an optimal way through an integrated, team approach.<sup>8</sup> These conventional treatments are surgery, radiotherapy, chemotherapy and immunotherapy, and are usually best supported by the involvement of other disciplines, including the referring GP, nurses, counsellors and dieticians (distinct from diet as a form of therapy per se; see subheading below).

The evidence does not support the efficacy of alternative therapies as a primary form of treatment.<sup>58,71</sup>

### Adjuvant/complementary therapies

As emphasised throughout this submission, the patient and their needs should be the focus of an individualised care plan, and patients should be encouraged to take control of their circumstances.<sup>9</sup> This means discussing all aspects of their care with the team and care coordinator where appropriate.

People with cancer who are considering using non-conventional medicines should question the efficacy of the treatment, the risks and contraindications, and the qualifications and experience of complementary and alternative medicine practitioners.

Importantly, patients should also ensure that their care team and coordinator are fully aware of any complementary or alternative medicines they may use. This will minimise the serious risk of such treatments undermining evidence-based treatments or causing dangerous side-effects. US research shows that a significant number of patients are afraid or embarrassed to discuss their use of complementary or alternative therapies with their doctors.<sup>9,58</sup>

A person with cancer has a right to investigate all possible options for improving their treatment outcome and quality of life. An understanding attitude from healthcare professionals should ensure that the use of complementary and alternative medicines can be discussed in an open and non-judgemental manner.

### Dangerous misconceptions

It is understood that a common misconception regarding complementary and alternative therapies is that, unlike conventional therapies, these are “organic”, natural and therefore safe. This overlooks the fact that many conventional medicines, such as aspirin, morphine or paclitaxel – all derived from plant products – are natural.

These, however, are not marketed as herbal or alternative medicines, because their efficacy has been demonstrated and they have therefore been adopted as evidence-based, conventional medicines.

Conversely, many “herbal” medicines are shown to be unsafe. For example, unregulated complementary or alternative medicines, including those obtained through the Internet, may be contaminated with pharmaceutical substances such as non-steroid anti-inflammatory drugs or steroids, or with toxic heavy metals like lead, mercury and arsenic.<sup>72</sup>

Complementary medicines may also interact with prescription medicines. For example, St John's wort may lead to reduction in plasma concentrations of a number of medicines, including cyclosporin and oral contraceptives, and may cause serotonin syndrome when used with tramadol. A large number of herbs, including garlic (*Allium sativum*), Korean ginseng (*Panax ginseng*), and *Ginkgo biloba* have interactions with warfarin, and there is some evidence that glucosamine and cranberry juice (*Vaccinium* species) might increase the activity of warfarin.<sup>73,74</sup>

Vitamin E and beta carotene are antioxidants whose use may be expected to reduce cancer in predisposed individuals. However, controlled trials in heavy smokers showed that the combination of smoking and vitamin E/beta carotene increased the risk of developing lung cancer.<sup>75</sup>

### Diet

Another common belief is that special diets have a potentially curative effect. These diets (such as the Gerson diet) usually involve exclusive consumption of specific fruits and vegetables or their juices,<sup>57</sup> on the disproven premise that the body of a person with cancer requires “cleansing”. In reality, such diets are likely to cause weight loss and greater debility as a result.<sup>58</sup>

Appropriate nutrition and physical activity are essential to optimal health and wellbeing at all times<sup>50</sup> and may be particularly relevant to a person with cancer, during and after their treatment.<sup>76</sup> A multidisciplinary approach to care should include the provision of professional dietary advice designed to reduce treatment side-effects, build immunity and maintain a healthy weight.<sup>8</sup>

### Costs to patient

The understandable desperation to “try anything” for a cure may leave cancer patients at risk of spending money on treatments with a very low probability of success, at a time when they are already financially stretched by loss of income and mounting medical costs.

Patients should be encouraged to weigh up all the evidence in the context of their individual circumstances before making decisions on potentially expensive, yet unproven, treatments. The pursuit of improbable treatments, particularly those that may be promoted out of the self-interest of the merchandiser, can also lead to false hope and disappointment.

**(b) How less conventional and complementary cancer treatments can be assessed and judged, with particular reference to:**

iii) the legitimate role of government in the field of less conventional cancer treatment.

### National care standards

A key role of government should be the introduction of national care standards and an accreditation and credentialing system, driven by the policy set out in the draft *National service improvement framework for cancer* and established clinical practice guidelines.<sup>4,6,8</sup>

The *Clinical practice guidelines for the psychosocial support of adults with cancer* promote a patient's right to consider the use of less conventional and complementary cancer treatments, and contain guidelines on how to discuss these issues in a sensitive and productive way.<sup>9</sup>

### Research

The Federal Government has a legitimate role in funding research into the efficacy of emerging treatments, including less conventional and complementary therapies. See research recommendation in response to criterion (b) i.

### Safety

The Therapeutic Goods Administration (TGA) has a legitimate role in assessing the safety and efficacy of medicines, including complementary and alternative medicines.

It is noted that the TGA has adopted the recommendations of a recent report calling for increased quality assurance in complementary and alternative medicines and a focus on determining emerging research priorities in the sector.<sup>77</sup>

This is welcome and applauded, particularly the commitment to ensure that consumers and healthcare professionals have access to reliable information about complementary medicines and the skills to make informed decisions.<sup>77</sup> This commitment will require adequate recurrent funding for policy to translate to ongoing results.

Senate inquiry into services and treatment options for persons with cancer – joint submission  
COSA, The Cancer Council Australia, NCCI, NACCHO

### UK position

In an international context, it is noted that the United Kingdom has responded to the groundswell of interest in this area by appointing Professor Edzard Ernst as the nation's first professor of complementary medicine, operating from Exeter University.

Professor Ernst is a medical doctor who has also practised acupuncture, autogenic training, herbalism, homoeopathy, massage therapy and spinal manipulation. In a recent review he concluded that the only way to determine the efficacy of complementary and alternative therapies was to subject them to the same rigorous testing as conventional therapies.<sup>71,78</sup>



## Recommendations for a national cancer system that aims to provide optimal treatment and support to every person with cancer

### General

- In consultation with all key stakeholders, Cancer Australia to develop and introduce standard models of multidisciplinary care based on the *National service improvement framework*. Flexibilities should be built into the system to facilitate different models in different environments.
- In consultation with all key stakeholders, Cancer Australia to establish a national system for accreditation of cancer centres and credentialing of individual practitioners based on clinical practice guidelines.
- Invest in building the cancer workforce, including the recommendations of Australian Medical Workforce Advisory Committee (AMWAC, attached). Design training programs on projected future patient load and anticipated changes in technology.
- Improve cancer-awareness among all medical practitioners by introducing an improved cancer curriculum and a cancer-specific exit exam for all medical graduates.
- Invest in improved delivery and coordination of outpatient-based services in all settings.
- Streamline procedures for assessing and approving pharmaceuticals for treating cancer patients.
- Expand MBS items 801–805 to include all specialists involved in a multidisciplinary team, including surgeons, medical and radiation oncologists and pathologists.
- Build cancer accreditation into the Medicare schedule, for example by offering a higher rebate to all credentialed practitioners.
- Add subspecialties such as psychosocial care to the Medicare schedule.

### Regional communities

- Adopt the recommendations outlined in The Cancer Council Australia's position statement (Appendix C) on travel and accommodation schemes.
- Establish cancer centres in large regional centres, with the capacity to employ oncologists, care coordinators, oncology social workers and psychologists; attract metropolitan practitioners; and provide outreach services within their region. Such centres could have formal links to urban centres for mentoring, continuing medical education, care coordination of complex/rare cases and conjoint appointments.

- Explore the application in remote areas of effective models of support, such as the Cancer Council Helpline and incorporating psychosocial support into telemedicine conferencing.
- Pilot the specialist breast nurse model with a focus on psychosocial support, operating from the nearest regional centre of sufficient size.

#### Indigenous communities

- Recognise cancer affecting Aboriginal peoples and Torres Strait Islanders as a priority and foster networks between government, community and representative Aboriginal and Torres Strait Islander organisations to develop a national response to the prevention and treatment of cancer.

#### Less conventional and complementary treatments

- Implement clinical practice guidelines to help ensure that a person with cancer can discuss their possible interest in less conventional and complementary therapies with healthcare professionals in an open and non-judgemental way.
- Subject commonly used but unproven treatments to rigorous clinical testing so that those which demonstrate efficacy can be recommended as appropriate.
- Support the Therapeutic Goods Administration in its role of assessing the safety of complementary and less conventional therapies and determining emerging research priorities.

## Conclusion

As Australia's No.1 killer and major disease concern, cancer should be a top priority for all tiers of government and the broader community.

Australia's relatively good statistical record in cancer treatment reflects the quality of services that can potentially be accessed. However, not everyone is receiving optimal care, and too many patients report that their individual needs are not being met. Patients talk of inequities in the system; that receiving optimal care is a matter of chance rather than certainty; and of being lost in a maze of options at a time when they may be at their most vulnerable.

Australia clearly needs to do more to support and care for people with cancer.

We already have a draft policy framework and clinical practice guidelines to inform the establishment of a national system based on best-practice, and government commitment to establishing a national agency that may be able to put it all in place. Rather than a major overhaul of the system, successful reform could be based on integrating existing and emerging resources to deliver optimal results.

## Appendix A – review of literature on multidisciplinary care

*Extracted from Optimising Cancer Care (COSA, The Cancer Council Australia, NCCI 2003); prepared by Karen Pedersen, Senior Project Officer, National Cancer Control Initiative.*

### Summary

This report was undertaken to examine evidence evaluating multidisciplinary care in cancer. Evidence relating to multidisciplinary care in cancer was identified from a search of published literature (Medline database), supplemented by the identification of additional papers from major articles. The literature search revealed that numerous articles provided information on the multidisciplinary care of cancer patients, however, only a limited number were identified that provided information on the evaluation of a multidisciplinary approach to cancer care. Available evidence indicates that multidisciplinary care has the potential to improve outcomes for patients with some cancers and increase patient satisfaction. It has been suggested that multidisciplinary care may also improve recruitment to clinical trials and reduce health care costs. Much of the identified evidence relating to the evaluation of a multidisciplinary approach in cancer care comes from retrospective, descriptive or comparative non-randomised studies. Issues that arose in considering the identified studies included potential difficulties in separating benefits of care delivered by a multidisciplinary team from those of multimodality treatment, lack of clarity as to what constitutes a multidisciplinary team in different settings and the uncertainty as to the applicability of findings to the Australian setting.

### Multidisciplinary care in cancer

A major report into cancer services in England and Wales published in 1995 (the 'Calman-Hine report') recommended changes in professional practice to increase team-working among those providing cancer treatment and care (EAGC 1995). A more recent report on cancer care in England and Wales published in December 2001 has found that although multidisciplinary teams are increasingly common there is still considerable progress to be made in arrangements in many hospitals and for many cancers (CHI 2001). The report comments that:

- there is evidence that being cared for by a multidisciplinary team may improve outcomes;
- although there is no research evidence on their cost-effectiveness, it has been suggested that multidisciplinary teams might result in savings by reducing the length of hospital stays or the need for readmission.

## Literature search

To identify evidence evaluating multidisciplinary care in cancer a search was undertaken of the Medline database for articles relating to multidisciplinary care and cancer. The search strategy used is detailed below. This was supplemented by the identification of additional papers from major articles. The literature search identified over one thousand articles published in the last ten years that included multidisciplinary care and cancer as search terms. Review of the identified abstracts indicated that while numerous articles provided information on the multidisciplinary care of cancer patients, few provided information on the evaluation of a multidisciplinary approach to cancer care.

## Search strategy and selection criteria

Information was obtained from the Medline database, supplemented by the identification of additional references from major articles. Search terms used were 'multidisciplinary care', 'multi-disciplinary care', 'integrated care', 'cancer', 'neoplasm(s)', 'survival', 'outcome', 'evaluation', 'readmission', 'hospitali(s/z)ation', 'length of stay', 'quality of life' and combinations of these. The search strategy was limited to papers published in the period 1992 to 2002 and there were no restrictions placed on language or type of publication.

## Evidence for multidisciplinary care in cancer

### Outcomes

A number of studies have reported on variations in breast cancer care and outcome for women with the disease (Sainsbury et al. 1995; Gillis & Hole 1996; Richards, Sainsbury & Kerr 1997; Purushotham et al. 2001).

Improved survival for women with breast cancer in the United Kingdom (UK) has been reported for patients whose surgeons had higher rates of usage of chemotherapy and hormone therapy (Sainsbury et al. 1995), as well as patients cared for by specialist surgeons (Gillis & Hole 1996) or surgeons with a high caseload (Sainsbury et al. 1995; Richards, Sainsbury & Kerr 1997).

Gillis and Hole studied specialist care and survival in 3786 breast cancer patients operated on in the west of Scotland between 1980 and 1988 (Gillis & Hole 1996). They found that the five-year and ten-year survival rates for patients cared for by specialist surgeons were 9% and 8% higher, respectively, compared with women cared for by non-specialist surgeons. For patients treated by specialist surgeons there was a 16% reduction in the risk of death (relative hazard ratio=0.84), after adjustment for age, tumour size, socioeconomic status and nodal involvement. Indicators of specialist interest were the establishment of a dedicated breast clinic, a defined association with pathologists and oncologists, organising and facilitating clinical trials and maintaining a separate record of patients with breast cancer in their care.

Review of cancer registry data from 12,861 patients with breast cancer treated in Yorkshire between 1979 and 1988 found that patients of surgeons with higher rates of usage of chemotherapy and hormone therapy had prolonged survival (Sainsbury et al. 1995). The study authors determined that while there was considerable variation in survival of patients between surgeons, rate of use of chemotherapy and hormone therapy explained about 26% of this survival variation. It was estimated that had the practice of the surgeons with the better outcomes been used by all treating clinicians, five-year survival would have been increased by around 4–5%.

Five-year survival for women with early breast cancer also appears to be greater in women who are treated by surgeons with a high caseload (defined as more than thirty to fifty new cases per year) (Richards, Sainsbury & Kerr 1997). It was suggested that this may relate to the increased likelihood that such patients are treated by a multidisciplinary team and receive adjuvant therapy.

There is evidence that some women with breast cancer may not be receiving the full treatment options. In one US study, the initial treatment recommendations received by women subsequently examined in a multidisciplinary breast cancer centre were compared with a second opinion provided by a multidisciplinary panel (Chang et al. 2001). For 43% of the women (32 of 75), the multidisciplinary panel would have recommended a different treatment, in accord with guideline recommendations, from that recommended by the outside clinicians (this being most frequently breast-conserving treatment instead of mastectomy).

Management by a multidisciplinary team may improve survival for women with ovarian cancer (Junor, Hole & Gillis 1994). A retrospective study of all 533 cases of ovarian cancer registered in Scotland in 1987 addressed the value of multidisciplinary teams in the treatment of women with the disease. The study found that after adjustment for age, stage, pathology, degree of differentiation and presence of ascites, survival improved when patients were (1) first seen by a gynaecologist, (2) were operated on by a gynaecologist, (3) had residual disease of less than 2 cm post-operatively, (4) were prescribed platinum chemotherapy and (5) were referred to a joint clinic. The improved survival from management by a multidisciplinary team at a joint clinic was not solely due to the prescription of platinum chemotherapy (Junor, Hole & Gillis 1994). Altered diagnosis and management of women with gynaecologic malignancies following a pathology review was reported in one Canadian study. The retrospective review by a consultant pathologist altered diagnosis for 33% of specimens and management for 12% of patients (Chafe et al. 2000).

A significant improvement in three-year disease-free survival and local control has been reported for patients (n=134) with soft tissue sarcomas treated by a multidisciplinary group at a hospital in Finland (Wiklund et al. 1996). Outcomes for patients referred to the multidisciplinary group between 1987 and 1993 were compared with previously published results from the hospital in which the group

was established and population-based Finish material. A retrospective audit of the management of thyroid cancer patients (n=205) in a large teaching hospital in the UK found that inadequate surgery and failure to administer radioiodine were less common in patients managed in a specialist clinic setting than in patients managed by clinicians outside the setting (Kumar et al. 2001). The specialist clinic involved joint management of patients by specialists (including surgeons, endocrinologists and oncologists) with an interest in the disease.

A survey of the opinions of non-radiologist clinicians regarding the active participation by abdominal radiologists in a multidisciplinary gastrointestinal cancer clinic in the US revealed that radiologist participation was highly regarded (Silverman et al. 1998). Specific benefits cited in the survey included improved interpretation, more efficient use of non-radiologist clinician time and improved rapport between radiologists and non-radiologists. Non-radiologist clinicians believed that patient care was improved.

### Clinical trials

There is some evidence suggesting that management of patients by multidisciplinary teams may increase recruitment into clinical trials (Twelves et al. 1998; Sateren et al. 2002). In one study from Scotland, women with breast cancer seen by a specialist surgeon and those referred to an oncologist were significantly more likely to enter clinical trials. Women seen by surgeons with a high caseload or referred to an oncologist were approximately seven times and three times, respectively, more likely to enter a clinical trial (Twelves et al. 1998). The area of Scotland (Health Board) where the women were first treated also influenced study entry. In the US, investigation of patient accrual into National Cancer Institute-sponsored cancer treatment trials found that the number of oncologists and the presence of a hospital with an approved cancer program were both significantly associated with increased patient accrual into clinical trials (Sateren et al. 2002). Approval of cancer programs by the American College of Surgeons Commission on Cancer requires, among other things, hospitals to have a multidisciplinary cancer committee.

### Patient satisfaction

Multidisciplinary care may increase patient satisfaction (Frost et al. 1999; Gabel, Hilton & Nathanson 1997). Positive benefits of a multidisciplinary team approach have been reported for women with newly diagnosed breast cancer in terms of their satisfaction with health and healthcare and physical and psychosocial adjustment (Frost et al. 1999). In this US study, women who received their medical oncology consultation as part of a multidisciplinary outpatient clinic (n=66) reported significantly higher levels of physical function and satisfaction with their health, physician and nursing care compared with women who received their medical oncology consultation in the hospital (n=55). In the outpatient clinic setting a concerted effort was placed on providing information and psychological support. In a separate study, instigation of a multidisciplinary breast cancer clinic within a hospital in the US was found to increase patient satisfaction by

encouraging support group involvement (involvement of patient's families and friends) and by helping patients make treatment decisions (Gabel, Hilton & Nathanson 1997). A significant decrease in the time between diagnosis and initiation of treatment was also observed. The study compared all patients seen during the first year of the multidisciplinary clinic's operation (n=177), with all patients diagnosed with breast cancer at the hospital in the year prior to the clinic's inception (n=162).

High levels of patient satisfaction have been demonstrated for women attending a multidisciplinary one-stop diagnostic clinic for investigation of symptomatic breast lesions in the UK (Berry et al. 1998). High levels of patient satisfaction have also been reported for advanced cancer patients attending a half-day multidisciplinary symptom control clinic in a cancer centre in the US (Bruera et al. 2001). In these advanced cancer patients, significant improvements were reported in overall symptom distress, depression, anxiety and sensation of well being from the first (n=166) to the second (n=110) clinic visit, with further significant improvements recorded at two-week (n=64) and four-week (n=38) week telephone follow-up assessments.

#### Palliative care

Studies in the UK and Ireland involving the prospective collection of data on pain prevalence and severity have demonstrated that multidisciplinary palliative care teams are effective in alleviating pain in advanced cancer patients (Higginson & Hearn 1997). A systematic review has examined studies investigating the effects of home care intervention programs on the quality of life or readmission time to hospital for patients with incurable cancer (Smeenk et al. 1998a). The authors concluded that while the effectiveness of home care programs remains unclear, enabling team members to visit patients at home and holding regular multidisciplinary team meetings seem to be important elements for obtaining positive results. Limited evidence from the Netherlands has examined a program aiming to optimise cooperation, coordination and communication among the professional caregivers for patients with terminal cancer. The main objective of the program was to offer care to patients that was specifically tailored to meet their needs and offered by professional caregivers from primary and hospital teams. An intervention group (n=79) was compared with a control group (n=37) who received standard community care. Published results indicate that the intervention program improves quality of life for both the patients (Smeenk et al. 1998b) and their caregivers (Smeenk et al. 1998c) and results in less rehospitalisation during the terminal phase of illness (Smeenk et al. 1998b).

#### Health care costs

A cost-outcomes analysis of care for melanoma patients at a multidisciplinary melanoma clinic in the US has suggested that multidisciplinary care may reduce health care costs (Fader et al. 1998). The analysis evaluated whether coordinated multidisciplinary melanoma care that follows evidence-based, consensus-



approved clinical practice guidelines in a large academic medical centre could provide a more efficient alternative to traditional community-based strategies with clinical outcomes that were at least equivalent. Costs incurred by a third-party payer for the diagnosis and initial management of patients with local disease were compared for a consecutive sample of 104 patients treated in the Michigan community with 104 blindly selected patients treated at the University of Michigan Multidisciplinary Melanoma Clinic, during an identical time period. Patients were matched for Breslow depth and melanoma body site. The study found that patients treated in the multidisciplinary clinic would save a third-party payer approximately US\$1600 per patient when compared with a similar group treated in the community. Surgical morbidity, length of hospitalisation and long-term survival of the multidisciplinary clinic patients were similar to those reported in the literature. The study authors indicated that differences in the usage pattern of health care resources explained the cost discrepancy (Fader et al. 1998).

### Australia

In Australia, the NBCC is conducting a study to profile the provision of multidisciplinary care for women with breast cancer in a representative sample of hospitals from all states and territories (Luxford & Rainbird 2001). The NBCC has also coordinated a National Multidisciplinary Care Demonstration Project to investigate the cost, acceptability, feasibility and impact on patterns of care of the multidisciplinary approach in three demonstration sites (Luxford & Rainbird 2001). A recent report on the project demonstrated that specialist oncology nurses play an important role as a coordinator of care and facilitator of effective communication among the multidisciplinary team and with patients (Observational Study of Multidisciplinary Care, NSW National Breast Cancer Centre, 2004).

## Appendix B

### Australian Medical Workforce Advisory Committee Specialist Medical and Haematological Workforce in Australia Supply, requirements and projections, 2001-2011

#### Summary of findings and recommendations

This report describes the current specialist medical and haematological oncology workforce, assesses the adequacy of that workforce, and projects workforce supply and requirements to the year 2011.

The report concludes that the supply of specialist medical and haematological oncologists is deficient, particularly in rural regional centres. Moderate deficiencies are also evident in some metropolitan locations. Workforce shortages are particularly evident in Queensland, Western Australia, Tasmania and the Northern Territory. The Working Party considered that the current shortfall of medical and haematological oncologists was not less than 40. This figure was derived from expert State/Territory based knowledge and by calculating the number of oncologists required to move from 1.4 to 1.6 FTE medical and haematological oncologists per 100,000 persons nationally.

As a result, it is recommended that:

- the Royal Australasian College of Physicians (RACP) should progressively increase the number of first year advanced trainees in medical oncology over the period 2002 to 2007 from 13 per year to between 15 and 18; and
- the RACP and the Royal College of Pathologists of Australasia (RCPA) should progressively increase the number of first year advanced trainees in the Joint Specialist Advisory Committee (JSAC) in Haematology training program from 14 to between 17 and 20. This assumes that 75% of trainees will choose to practise in oncology.

#### Description of the Current Medical and Haematological Oncology Workforce *Number of practising medical and haematological oncologists*

- In 2000, there were approximately 338 medical and haematological oncologists in active practice in Australia (180 medical oncologists and 158 haematological oncologists). This estimate was derived from a rationalisation process using data from MOG, HSAZ and RACP;
- In total, 71% (158/220) of clinical haematologists spend some of their clinical work time in oncology practice. The AMWAC/MOG/HSAZ 2000 survey found that, on average, haematological oncologists spent 61.4% of their total work time in oncology practice;

- Medical and haematological oncology is a relatively small specialty, representing approximately 2% of all medical specialists;
- Over the last five years, the medical oncology workforce is estimated to have grown by 2.7% per annum, and the clinical haematological workforce by 0.5% per annum;
- Between 1995 and 2000, the per annum increase in the Australian population was 1.1% with an above average increase in Queensland (2.1%).

#### *Medical and haematological oncologists to population*

- In 2001, reconciled data from MOG/HSANZ indicated that there were 1.4 medical and haematological oncologists per 100,000 population, with an SPR of 1:69,874. This estimate takes into account the average total work time (61.4%) that haematological oncologists spend working in oncology. It therefore provides an indication of the number of full-time-equivalent haematological oncologists;
- By subspecialty, there were 0.9 medical oncologists per 100,000 persons (1:107,805) and 0.5 FTE haematological oncologists (1:122,134);
- Relatively well supplied States/Territories, as indicated by population share were, New South Wales, Victoria, South Australia and the Australian Capital Territory. The Northern Territory, Queensland and Western Australia were relatively poorly supplied.

#### *Geographic distribution*

- Based on reconciled MOG/HSANZ 2001 data, the majority (65.9%) of medical and haematological oncologists were located in New South Wales and Victoria and predominantly in the capital cities of these two States. Between them, these two States account for 58.7% of the Australian population. In total, 6% of the workforce had their main practice in a rural location, while 32.7% of metropolitan oncologists provided outreach services to rural areas. On average, these metropolitan specialists provided two days of face-to-face visiting services per month and 5.9 hours of non face-to-face services.

#### *Age profile*

- The average age of medical and haematological oncologists in 2000 was 45 years, with the majority (78.7%) aged between 35-54 years. Only 1.3% were aged 65 years and over and 12.4% were aged 55-64 years.

#### *Gender profile*

- In total, 20.3% of the workforce are women. This representation is expected to increase given that 54% and 26.7%, respectively, of advanced trainees in medical oncology and advanced haematology trainees are women, and the

cohort of medical and haematological oncologists aged 55 years and over is predominantly male.

#### *Hours worked*

- The AMWAC/MOG/HSANZ 2000 survey indicated that nationally, medical and haematological oncologists work an average of 55 hours per week, with variation among States. Notably, oncologists in Queensland work longer hours, on average, 61 hours per week;
- On average, medical oncologists work 56.8 hours per week and haematological oncologists 53 hours per week;
- On average, male medical and haematological oncologists work 56.4 hours per week and the comparative figure for female oncologists is 49.1 hours.

#### *Work setting*

- In total, 84.8% of medical and haematological oncologists work some of their time in a salaried position and 68.8% work some of their time in private practice; with 64% of total workforce time spent in a salaried position and 33.9% of time in private practice;
- Of specialists in a salaried position, 88% of salary was received from a public health care service facility;
- Of specialists in private practice, 57.1% also had a paid public hospital appointment.
- Patient care activities accounted for 62.8% of total workforce time; with 36% of time spent in the public sector and 26.8% in the private sector;
- Of time spent in the public sector, 21.9% was spent in outpatient care and 14.1% on in-patient care;
- Teaching and research accounted for 15.6% of workforce time, administration for 8.9% and multidisciplinary team activities for 6.9%.

#### *Type of medical and haematological oncology practice*

- Of total workforce time, 73.4% was spent in three clinical areas, viz., the management of 'other haematological malignancies', 'solid tumour-advanced disease' and 'solid tumour-adjuvant management'. Medical oncologists spent more time in the management of solid tumour-advanced disease, solid tumour-adjuvant management and solid tumour-palliative care, while haematological oncologists spent more time in the management of other haematological malignancies and acute leukemia.

### *Services provided*

- The patient pathway to consult a medical and haematological oncologist is via referral from a general practitioner (GP), general surgeon or some other specialist;
- Important triggers for a GP referral are lack of experience within the practice regarding the condition and/or its treatment, condition unresponsive to treatment and severity of the condition;
- The most important trigger for a general surgeon to refer a patient to a medical or haematological oncologist is for adjuvant therapy (ie chemotherapy and/or immunotherapy);
- During the past five years, the number of Medicare services provided by medical and haematological oncologists has increased by 32.9%, with a compound average annual increase of 7.4%;
- In total, 30.4% of metropolitan based medical and haematological oncologists provided rural outreach services, with wide variation in this activity by State. For example, 75% of metropolitan specialists in Queensland provided rural outreach services, while only 20% of specialists in Victoria were similarly involved.

### Training Arrangements for Medical and Haematological Oncologists

#### *Medical oncologists*

- In February 2001, there were 36 RACP medical oncology advanced trainees with 71% of trainees located in New South Wales and Victoria;
- The average age of medical oncology trainees was 32 years;
- Between 1996 and 2000, there was a 4.6% average annual increase in the number of trainees graduating from the RACP Training Program in Medical Oncology with an average of 13.6 graduates per year.

#### *Haematological oncologists*

- In 2000, there were 41 advanced trainees in the JSAC in Haematology training program with 57.8% located in New South Wales and Victoria;
- The average age of advanced haematology trainees was 31 years;
- Between 1997 and 2000, 29 trainees graduated from the JSAC in Haematology training program. This is an average of 7 per year;

- Over the next three years 40 trainees are expected to graduate from the JSAC in Haematology, on average, 13 per year. The AMWAC/HSANZ 2000 survey of trainees found that in the longer term, 30 trainees (75%) expect to spend 40% of their work time in haematological oncology practice. The Working Party considered that once in the workforce, the amount of work time spent in oncology practice was likely to be greater than 40% because of an evident decline in demand for laboratory haematology and an increase in demand for oncology haematology.

#### Adequacy of the Current Specialist Medical and Haematological Oncology Workforce

##### *Specialist to population benchmarks*

- The AMWAC/MOG/HSANZ 2000 survey found that the population required to sustain a resident rural practice in medical oncology and in haematological oncology was the same (viz a population catchment of 100,000). This estimate assumes access to required infrastructure, support services and other specialist services. This size population is consistent with large rural centres. Across geographic regions there were 2 FTE medical and haematological oncologists per 100,000 persons in capital cities, 1.4 in other urban areas, 0.8 in large rural centres and 0.2 in other rural and remote areas;
- Based on the benchmark of the American Society of Clinical Oncology (viz., 1.8 oncologists per 1,00,000 persons), there is a national undersupply of oncologists (1.4 per FTE per 100,000 persons), but particularly in Queensland (1.0/100,000), Western Australia (1.2/100,000), the Northern Territory (0.5/100,000) and Tasmania (1.3/100,000).

##### *Consumer assessment*

- Survey responses from five of eight State/Territory member organisations of the Australian Cancer Society indicated that opinion varied with respect to access to public sector and private sector medical oncology services according to State/Territory and geographic location. For example, more visiting services were required in the Northern Territory, while Queensland was perceived to have a definite shortage and a serious maldistribution problem, with most services located in the south-eastern corner of the State. Waiting times in Tasmania and the Australian Capital Territory were perceived to be problematic.

#### *General surgeon assessment*

- In total, 69.7% of general surgeons considered that the supply of medical oncologists was about right, 25% considered they were either in short supply or totally inadequate and 5.3% perceived there to be an oversupply;
- A higher proportion (44%) of rural surgeons considered the supply of medical oncologists to be inadequate and more rural surgeons (40.4%) than metropolitan surgeons (11.9%) reported having to modify their management of cancer patients either occasionally or frequently because of the lack of specialist oncologists.

#### *General practitioner and health service assessment*

- In total, 64.6% of Divisions of General Practice considered access to medical oncology services to be inadequate, while 33.9% thought it was about right. As with general surgeons, rural Divisions perceived a greater need for additional medical oncologists than did urban Divisions.

#### *State/Territory health departments*

- The survey of State/Territory health departments confirmed the shortage of medical and haematological oncologists in many rural areas and indicated that some metropolitan areas also have shortages. Furthermore, demand for services was said to be increasing.

#### *Consultation waiting times*

- The average waiting time for a public patient presenting to a public sector service with a clinically urgent condition to see a medical and haematological oncologist was 2.9 days. Comparative figures to see an oncologist in his/her private rooms was 2.1 days and in a private facility 1.3 days;
- Among State/Territories there was wide variation in the amount of time patients had to wait to see a medical oncologist and a haematological oncologist. For example, for a standard first consultation, public patients presenting to a public health service, in the Australian Capital Territory and Queensland wait above average times, respectively, 26.6 days and 22.1 days, compared with a national average of 12.3 days.

#### *Workloads*

- In total, 35.4% of medical and haematological oncologists were dissatisfied with the amount of work they did, 41.6% were satisfied and 22.9% were neither dissatisfied or satisfied. This is a relatively high level of professional dissatisfaction with workload. Oncologists aged 45-54 years were less satisfied than younger or older oncologists. Oncologists in the Australian Capital Territory and New South Wales were less satisfied and oncologists in large rural centres were less satisfied than oncologists in other locations;

- Of oncologists dissatisfied with their workload, 83.7% were also dissatisfied with the hours they worked.

#### *Access to support from other service providers*

- The AMWAC/MOG/HSANZ 2000 survey found that 20.5% of oncologists were dissatisfied with the availability of similar consultants, 18.7% were dissatisfied with the availability of skilled nursing staff and 17.3% were similarly dissatisfied with availability of allied health personnel;
- In total, 43% of medical and haematological oncologists considered there was a shortage of skilled nurses in their area and 26.6% indicated a shortage of allied health practitioners.

#### Projections of Requirements

- Requirements for the services provided by medical and haematological oncologists are expected to increase as a result of:
  - growth in consumer demand associated with population growth, population ageing and growth in the incidence of cancer;
  - changes in patients expectations and demands;
  - demand for equitable geographical access;
  - change in indication for treatment; and
  - advances in medical technology.
- The Working Party considered that workforce requirements were not likely to be below 1.7% (ABS projected growth in the adult population combined with the impact of ageing on requirements for medical services) or above 3.5% (projected growth in cancer incidence for the Australian population aged 20 years and over). The Working Party decided to use 2.6% as the growth indicator (ie the average of the high and low estimates). The figure of 2.6% was considered by the Working Party to be a conservative estimate on which to base workforce requirements because it does not:
  - take into account changes in patient's expectations and demands;
  - allow for changes in treatment indications which may increase requirements;
  - take into account the increase in survival of patients with cancer and the attendant necessity for more consultations per patient;
  - allow for the trend towards more complex cancer treatment, including multi-modality treatment (eg radiation and chemotherapy); or
  - account for the possibility of greater workforce attrition in the future due to burnout.

#### Projections of Supply

##### *Entrants into the workforce*

- Over the next two years 23 (12 per year) new medical oncologists are expected to enter the workforce;



- Over the next three years 40 (13 per year) new clinical haematologists are expected to enter the medical workforce, of whom, approximately 28 (9 per year) are expected to spend some of their work time practising in oncology.

#### *Overseas trained doctors*

- The number of overseas trained specialists entering the workforce was estimated to be small (approximately 2 per year) and was considered to be off-set by the number of Australian oncologists migrating overseas.

#### *Retirements*

- In total, 6 medical oncologists and 14 haematological oncologists indicated that they intended to retire in the next five years (ie four per year) and a further 21 and 20, respectively, in the next ten years;
- The average age of expected retirement for medical and haematological oncologists was 63 years.

#### *Representation of women*

- The representation of women in the workforce is expected to increase from 20% in 2001 to 24.5% in 2011 based on the age and gender profile of current trainees (39% female) and the current workforce (viz., 36% of oncologists under the age of 40 years are female, compared with 5% of oncologists aged 50 years and over).

#### *Potential for substitution*

- Data from Medicare indicated a wide range of medical specialists, in addition to medical and haematological oncologists, were involved in the provision of specialist oncology services (ie as defined by three selected Medicare items associated with the administration of cytotoxic chemotherapy). These disciplines included general and specialist surgeons, radiation oncologists, anaesthetists, obstetricians and gynaecologists, physicians (internal medicine, general medicine, neurology, paediatrics and thoracic medicine) and general practice. However, the trend is toward the selected Medicare items being provided by medical and haematological oncologists.

#### **Balancing Projected Supply with Projected Requirements**

- The Working Party estimated that requirements for medical and haematological oncologists would increase by a minimum of 2.6% per annum over the period 2001 to 2011;
- The Working Party understands workforce requirements may occur more in one specialty area than the other (ie haematology or medical oncology). The current flexibility and overlap in the RACP Training Program in Medical

Oncology and the JSAC in Haematology Training Program and in work practice allows for this contingency and is supported by the Working Party;

- A balance in supply to match estimated growth rate in requirements of at least 2.6% per annum can be achieved by increasing the number of Fellows graduating from the RACP Training Program in Medical Oncology per year to 16 from 2004 and from the JSAC in Haematology Training Program from 2006 to 18. This latter figure is based on the assumption that 75% (14) of new haematology workforce entrants will choose to work some of the time (approximately 61%) in oncology;
- To achieve an average annual output of 16 graduates in medical oncology it is estimated that the RACP advanced training program will need to have an intake of year 1 commencing trainees of approximately 18 from 2002 (ie 5 additional commencing trainees on the number commencing in 2000). This represents a reasonably large increase in trainee numbers in a year and is unlikely to be practical. Therefore, the Working Party recommends a staged increase of 15 commencing trainees in 2002, 16 in 2003 and 18 in 2004;
- To achieve an average annual output of 14 new clinical haematologists practising in oncology it is estimated that the JSAC in haematology advanced training program will need to have an intake of year 1 commencing trainees of 19 to 20 from 2002. As with medical oncology, the Working Party recommends a staged increase of 17 commencing trainees in 2002, 18 in 2003 and 20 in 2004;
- Ideally, training positions should be increased proportionately less in the comparatively well supplied States (as indicated by specialist-to-population ratios) of Victoria, South Australia and New South Wales and kept roughly in line with population shares in 2006. In particular, consideration needs to be given to addressing distributional problems by improving service provision in Queensland, Western Australia, Tasmania and the Northern Territory and in regional rural centres within States/Territories;
- A complicating factor is that new training positions require appropriate infrastructure to ensure that trainees gain adequate supervision, experience and support;
- Training positions also need to be attractive to applicants. The perception that medical and haematological oncologists work long hours in a physically and emotionally demanding environment is thought to contribute to the current shortage of trainees.

## RECOMMENDATIONS

The following recommendations should be considered in the context of the identified shortfall of medical and haematological oncologists and the current workforce maldistribution among and within States/Territories. The Working Party recommends:

1. To achieve an appropriate supply of medical and haematological oncology specialists, State/Territory health departments, in consultation with:
  - the Royal Australasian College of Physicians (RACP) should progressively increase the number of first year advanced trainees in medical oncology over the period 2002 to 2007 from 13 per year to between 15 and 18;
  - the RACP and the Royal College of Pathologists of Australasia (RCPA) should progressively increase the number of first year advanced trainees in the JSAC in Haematology training program from 14 to between 17 and 20. This assumes that 75% of trainees will choose to practise in oncology.

The aim of maintaining first year advanced trainee intakes within the above ranges is to match workforce supply with an expected future growth in medical and haematological oncology requirements, over the projection period (2001 to 2011), of 2.6% per annum. A suggested distribution of the new commencing medical oncology trainees is shown in the following table and for haematological oncology trainees is shown in subsequent table.

Recommended distribution of RACP Medical Oncology Advanced Training  
 Program trainee intake, by State/Territory, 2002-2004

State/Terr	2002	2003	2004	2004 share of commenc -ing trainees	2008 population share
NSW	6	6	5	27.8	33.3
Victoria	4	4	4	22.2	24.1
Queensla nd	3	3	4	22.2	19.8
South Aust.	-	1	1	5.6	7.5
West. Aust.	1	1	2	11.1	10.3
Tasmania	-	-	1	5.6	2.3
North. Terr.	-	-	-	-	1.2
ACT	1	1	1	5.6	1.5
Australia	15	16	18	100.0	100.0

Source: AMWAC, ABS

Recommended distribution of JSAC in Haematology advanced training  
 program trainee intake, by State/Territory, 2002-2004

State/Terr	2002	2003	2004	2004 share of commenc ing trainees	2008 population share
NSW	7	6	6	30.0	33.3
Victoria	3	3	4	20.0	24.1
Queensla nd	4	4	5	25.0	19.8
South Aust.	-	1	1	5.0	7.5
West. Aust.	1	1	2	10.0	10.3
Tasmania	-	1	1	5.0	2.3
North. Terr.	-	-	-	-	1.2
ACT	1	-	1	5.0	1.5
Australia	16	17	20	100.0	100.0

Source: AMWAC, ABS

2. That if necessary, the coordination of the adjustments to trainee intake in both training programs (ie RACP Medical Oncology Advanced Training Program and JSAC in Haematology Advanced Training Program) be overseen by State/Territory based medical and haematological oncology working groups, comprising representatives from the RACP, MOG, RCPA, HSANZ and State/Territory health departments.
3. The Working Party has identified a current shortage of specialist medical and haematological oncologists in some States/Territories. Addressing this problem may require the establishment of additional funded specialist positions in areas of acknowledged shortage. The Working Party recommends that these issues be considered by State/Territory based medical and haematological oncology working groups proposed in Recommendation 2 above.

4. The Working Party encourages the RACP, MOG and HSANZ, together with Commonwealth, State and Territory governments, to further develop strategies to encourage improvement in the provision of medical and haematological oncology services to rural areas.
5. That medical and haematological oncology workforce distribution and requirements and supply projections be monitored regularly so that amendments can be made if new trends emerge; this monitoring be coordinated by RACP, MOG, HSANZ and AMWAC and the results be incorporated into the AMWAC annual report to AHMAC.
6. That a full update of this review of the medical and haematological oncology workforce be undertaken in 2005.



## Appendix C – The Cancer Council Australia position statement, State and territory travel and accommodation schemes

### Summary statement

People with cancer living in rural and remote areas are more likely to experience greater problems and concerns associated with travel for treatment and follow up care than their peers who reside in urban or regional cities.<sup>1</sup> Across Australia, these problems are compounded by access and equity issues associated with travel and accommodation subsidy schemes.<sup>2,3,4</sup> People will have ways of coping with the inconvenience and practical hardship that travelling for treatment causes. The role then of government and non-government providers alike is to build on these strengths, and provide effective emotional, informational and practical assistance so that adjustment, functioning and quality of life can be improved.<sup>1</sup>

#### **Recommendations:**

The Cancer Council Australia supports the immediate establishment of a Commonwealth-funded Task Force to address the identified problems associated with travel and accommodation subsidy schemes for people from rural and remote areas. The focus will be to:

1. Establish the feasibility of a cooperative approach to standardised eligibility criteria between the Commonwealth and states and territories.
2. Specifically consider the needs of individuals at increased risk of psychosocial problems and populations experiencing disproportionate difficulties with access to schemes, such as Australian aboriginals.
3. Assess mechanisms to improve the current financial assistance provided for a person with cancer and their carer/ escort.
4. Consider assistance for accessing the treatment and treating physician of a person's choice and accessing a second opinion on treatment options.
5. Develop an awareness campaign for health care workers and people from rural and remote areas travelling for cancer treatment. This would include the availability of the schemes and eligibility criteria and how to access these and other financial assistance programs (for example with social work assistance)<sup>2,3,4</sup>
6. Develop recommendations in response to 1–5.

## Background

The impact of travel on peoples' experiences of cancer treatment have consistently been described as inconvenient and a practical hardship.<sup>5</sup> In Australia, assistance has been available since 1978 to help subsidise the costs of travel and accommodation of people living in rural and remote areas who require specialist medical treatment not available locally. Initially the scheme was administered by the Commonwealth but responsibility was transferred to the states and territories in 1987. On the whole, financial assistance for travel and accommodation is valuable. However, serious concerns associated with access and equity have arisen since devolution to the states and territories and it has been identified that schemes are not working as well as they could for people affected by cancer.<sup>2,3,4</sup>

Australia's population is highly dispersed and it is estimated that approximately 30% of all people with cancer live outside a major population centre.<sup>5</sup> At the same time, cancer treatment is complex and can involve different modes of delivery, multiple specialists and the need for highly specialised equipment. These two factors combined mean that it is unlikely that people treated in rural and remote areas will ever be able to access all the services they require locally and therefore there will be an ongoing need for travel for some components of cancer care.<sup>5</sup>

## Lack of information

People with cancer report they are often given insufficient information about financial assistance schemes. A study of eighty rural women travelling to the city for breast cancer treatment found that only 39% of them received financial assistance and 19% of these had trouble claiming money for which they were eligible.<sup>6</sup> Similarly, the *Draft National Service Improvement Framework for Cancer*<sup>5</sup> refers to a study of 192 people with haematological malignancies who travelled for treatment, with one quarter of those surveyed identifying that they had never heard of the local assistance scheme. Scheme awareness was also identified as a major impediment to access in the *Radiation Oncology Jurisdictional Implementation Group Final Report*<sup>1,2</sup>.

## Inequity

The *Living with Cancer Conference*<sup>2</sup> identified as a priority the need to address inequities in the application of travel and accommodation schemes across state and territory jurisdictions. *Optimising Cancer Care in Australia*<sup>4</sup> goes one step further, stating that "There is variation between and within jurisdictions, in the rules that apply and the manner in which they are applied." Further significant difficulties occur around the issue of a carer/ escort to accompany a person travelling for treatment. Assessment is often based on medical grounds rather than consideration being given to psychosocial need. The evidence associated with the distress caused by being away from home, family and friends for extended periods of time supports the view of some health care workers that the need for an escort should be at the discretion of the person undergoing treatment.



This is an important issue for all people; however, for groups such as Aboriginal peoples and Torres Strait Islanders or those from culturally and linguistically diverse backgrounds, the disadvantage is compounded.<sup>4</sup>

#### Financial issues

Out-of-pocket-expenses associated with travel and accommodation can add significantly to the overall expenses of people who need to travel greater distances for treatment. Often two households are needing to be maintained with all of the associated costs. The estimated expenses highlighted in the National Breast Cancer Centre report *Out-of-pocket-expenses incurred by women for diagnosis and treatment of breast cancer in Australia*<sup>7</sup> provide evidence of the extent of outlay incurred even when a government-funded scheme is taken into account. Financial difficulties associated with the need to travel are further compounded by circumstances such as a loss of income due to treatment or for people who are of limited means prior to diagnosis. Up-front payments required by some jurisdictions also have significant impact.

#### Special considerations

Consideration also needs to be given to the needs of people living just within the limit of assistance. People with cancer who reside within 90kms of a treatment centre are likely to have the same levels of need as a person living in a rural and remote area (as designated by a 100km zone). The question of access to a second opinion, and choice of specialist and treatment centre also warrant consideration, particularly where clinical and consumer guidelines provide evidence that these strategies represent best practice.<sup>8,9,10</sup>

#### The solution

The Cancer Council Australia's goal is to lead the development and promotion of national cancer control policy in Australia, in order to prevent cancer and reduce the illness, disability and death caused by cancer. It does this by working together with its eight member state and territory cancer organisations. Among other cancer-control activity, The Cancer Council Australia advocates on behalf of people affected by cancer to ensure that issues related to cancer care get the attention, legislative action and funding they deserve.<sup>11</sup>

The problems outlined above have emerged time and time again from numerous journal articles, reports and papers. The *Living with Cancer*<sup>2</sup>, *Cancer in the Bush*<sup>3</sup> and *Optimising Cancer Care*<sup>4</sup> reports record the collective views of consumers, practitioners, researchers and organisations involved in cancer care from across Australia, and they are unanimous in their call for action.

The Cancer Council Australia endorses these comments and calls for the immediate establishment of a Task Force to address the identified problems associated with travel and accommodation subsidy schemes for people from rural and remote areas. Such a group should be funded through the Commonwealth, chaired by The Cancer Council Australia and have membership of people with practical and professional experience and expertise in the areas of rural and remote travel and accommodation schemes, policy development, problem-solving and cancer care. The scope of the Task Force will be to:

1. Establish the feasibility of a cooperative approach to standardised eligibility criteria between the Commonwealth and states and territories.
2. Specifically consider the needs of individuals at increased risk of psychosocial problems and populations experiencing disproportionate difficulties with access to schemes, such as Australian aboriginals.
3. Assess mechanisms to improve the current financial assistance provided for a person with cancer and their carer/ escort.
4. Consider assistance for accessing the treatment and treating physician of a person's choice and accessing a second opinion on treatment options.
5. Develop an awareness campaign for health care workers and people from rural and remote areas travelling for cancer treatment. This would include the availability of the schemes and eligibility criteria and how to access these and other financial assistance programs (for example with social work assistance) <sup>2,3,4</sup>
6. Develop recommendations in response to 1–5.

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