SENATE COMMUNITY AFFAIRS REFERENCE COMMITTEE

Inquiry into services and treatment options for persons with cancer

A SUBMISSION FROM THE

CANCER INSTITUTE NSW

Introduction

The Cancer Institute NSW was established by the NSW Parliament through the Cancer Institute NSW Act 2003. It has as its objectives to improve cancer survival, reduce cancer incidence, improve the quality of life of cancer patients and provide expert advice to government, the public and key stakeholders.

It has developed the NSW Cancer Plan 2004-2006 as a high level, comprehensive strategic plan for all involved in cancer control in NSW. It provides enhancement funding throughout NSW in clinical services, research, information and registries, prevention and screening and in cancer education.

The Cancer Institute NSW and the NSW Department of Health work collaboratively as the key agencies for cancer control by the NSW Government. Programs are implemented by Area Health Services, hospitals, research institutes and non-government organisations.

Major programs of the Cancer Institute NSW include:

- Clinical enhancements:
  Cancer nurse coordinators, lead clinicians, psycho-oncology support and state-wide cancer streams.
- Research program:
  Research fellowships, infrastructure and "bench to bedside" translational research grants.
- Information program
  Clinical cancer data analysis, standard treatment protocols.
- Area Health Services – Cancer Services stream
  Directors of Cancer Services and development officers in all Area Health Services.

NSW Health has implemented a Cancer Services Framework in all Area Health Services in NSW. This framework was further supported by the Cancer Institute NSW with NSW Cancer Plan and in subsequent funded programs of the Institute.

The Cancer Institute NSW has offered to work constructively with all Australian Government agencies and other stakeholders to improve cancer outcomes. Cancer developments within state jurisdictions in general are appropriate collaborators to assist the Australian Government with the implementation of programs and to provide advice on the development of cancer policy.

While the barriers listed below are many, similar barriers occur in all comparable countries. Thus, directly addressing the issues listed will enable Australia to stay at the forefront of cancer control. Currently, cancer results are good compared to other similar countries. However, results in some cancers are unsatisfactory worldwide as they are in Australia.

Section (a)

1. Summary of the barriers and opportunities to be addressed for effective cancer control in Australia

1.1 Increasing burden of cancer in Australia

Cancer represents approximately 19% of the disease burden (number of disability life years) in Australia. In NSW, approximately 32% of all deaths are due to cancer and while cancer death rates are going down, cancer incidence is increasing.

The Cancer Institute NSW has projected that the numbers of cancer patients in NSW will increase substantially over the next decade. This provides a strong rationale for a greater focus on cancer control by all jurisdictions and interested parties.

1.2 Prevention, early detection and screening

From the above, greater emphasis could be placed on prevention, early detection and screening. Such an emphasis may reduce the expected impact of increased numbers of cancer patients.

Tobacco remains the most important cause of preventable disease and cancer in Australia. The Australian Government should consider matching state expenditure on tobacco control. Such a commitment would have immediate and longer term positive impact on the nation’s health and reduce the burden of tobacco related disease on the health care system.

Early introduction of universal bowel cancer screening for the Australian population will prevent bowel cancer and provide for early detection of bowel cancer. The current timetable for the introduction of bowel screening could be accelerated.

The Australian Government could assist the Cancer Institute NSW to ready NSW for bowel cancer screening.

New research on new screening methods for prostate cancer, melanoma and lung cancer needs to be supported. Joint approaches between the Commonwealth and the Cancer Institute NSW could be considered.

1.3 Efficient models of care delivery

General practice involvement in the diagnosis, referral and subsequent management of cancer is an important element of cancer care. In addition, increasingly general practitioners are pivotal in identifying those at risk for screening or for lifestyle intervention. Such interventions and support will reduce the burden on public hospitals and improve the health outcomes.

The Cancer Institute NSW will be expanding its GP liaison programs in NSW. The Australian Government could match the NSW contribution to cancer programs in general practice initiated by the Cancer Institute NSW.

Multidisciplinary care will be encouraged in NSW hospitals and clinics through the development of cancer specific teams in each Area Health Service. Such a program will result in peer review, peer support and more up to date standardised care applied more routinely.

Multidisciplinary care in NSW will be supported by state-wide cancer specific streams established by the Cancer Institute NSW. This activity could be supported by the Commonwealth by providing a fee for specialists involved in such peer review processes (see below)

With increasing numbers of cancer patients expected over the next 10 years, more efficient methods to provide ambulatory care need to be developed. The Cancer Institute NSW will investigate these more efficient methods.

1.4 Better coordination of care

Patients, carers of patients and consumer groups in cancer have all expressed their concern that cancer care in Australia is not adequately coordinated. On an individual patient level, it often remains the patient's responsibility to sequence appointments, deal with a multitude of specialists and health professionals and obtain tests and results. A professional approach to care coordination is required so that timely therapy occurs in the right sequence with greater support for the patient in that process.

The Cancer Institute NSW has introduced a new role in NSW hospitals for care coordinators where patients will be increasingly supported. The Australian Government could review such coordination of care with the Cancer Institute NSW to identify its applicability more widely.

Care coordination for cancer also requires better integration between cancer treatment centres and general practice. A GP liaison program between the NSW Divisions of General Practice and the Cancer Institute NSW offers an opportunity to improve this coordination.

The Cancer Australia initiative by the Australian Government offers opportunity for better coordination between Commonwealth and State based initiatives in cancer control. The Cancer Institute NSW would favour a model which involves states in the development of national policy.

1.5 Psycho-oncology support

The need for more routine emotional and practical support has been identified by the Cancer Institute NSW based on input from patients, carers and consumers.

The broad application across Australia of NHMRC Guidelines on psycho-oncology support is important in achieving this support. This practical application is being supported by the Cancer Institute NSW with the development of a practical guide for psycho-oncology support. In addition, support teams in NSW Hospitals will be supported by an additional staffing, supported by the Cancer Institute NSW.

1.6 Strategic cancer workforce development

The cancer workforce in Australia needs to be better identified and its development linked to cancer projections and the distribution of cancer patients.

There is a need for the development of cancer subspecialisation especially within multidisciplinary teams. In rural or outer metropolitan population growth areas, maintaining and promoting specialist skills could be achieved through education.

The Cancer Institute NSW is developing training for professional skills and competencies for cancer health professionals. In working in professional workforce development, the Commonwealth and state jurisdictions will need to take a collaborative approach with learned colleges, health sector unions, special craft groups and employers.

The Cancer Institute NSW will support the professional development year for radiotherapists in partnership with others, establish new academic posts in the radiation sciences and provide specialist trainee positions. Skills in a number of other cancer disciplines will be enhanced through professional education programs of the Cancer Institute NSW.

The Cancer Institute NSW and the NSW Department of Health are collaborating with AHWOC and RORIC to support an integrated approach nationally to workforce projection analyses and strategy development. This coordinated approach offers the best opportunity for development of appropriate responses to the workforce requirements of the future.

1.7 Cancer information

Cancer patients, carers and the public need timely, credible and accurate advice tailored to their specific needs. These needs change and so should the information. At diagnosis this information includes prognostic information and proposed treatment plans and their side-effects. At other times, they may need more detailed information on radiotherapy, clinical trials or on palliative care.

Health professionals need to access current information, need information on standard therapy or treatment protocols.

The public needs clear messages on cancer risk reduction, identification of their own cancer risk, screening messages and how to obtain other credible information.

The Cancer Institute NSW will develop a well maintained cancer services directory for NSW so that patients, carers and health professionals can identify where key cancer services are located and their depth.

The Cancer Institute NSW will provide a standard treatment protocols website. This will provide one site where the most up to date treatment can be reviewed, with the evidence that support its use.

Such standard approaches will reduce unorthodox practice while identifying new treatments in common use and the evidence that shows its value.

To improve the standards of care, when evidence shows clear benefit, high cost cancer drugs should be readily available. The Australian government could consider methods to fast track cancer drug approvals provided the evidence supports their use.

1.8 Research to drive practice improvement

To improve cancer outcomes, cancer research should be encouraged in hospitals, research institutions and universities. Such research will add to the enhancement of a research culture in these institutions leading to review, critical analyses of results and improvement in practice.

A review by the National Cancer Control Initiative (NCCI) has revealed that over recent years, most NHMRC funding for cancer research has gone to biomedical science. This review is critical of the relative lack of funding for clinical research, such as clinical trials, epidemiology and public health and health service research. Overall, the ability to translate biomedical discoveries into clinical practice and programs remains a major challenge.

National cancer clinical trials groups are poorly funded and operate on small grants and funding from philanthropy. These important national resources need support from governments throughout Australia.

There may be the need to review a more strategic approach to cancer research in Australia, to review the health outcome improvement such research produces and to provide more balance in the type of cancer research supported.

The Cancer Institute NSW has taken a strategic approach to cancer research funding in NSW. This program will build the research workforce and thus its human capacity in high quality research in NSW. It will support areas of existing strength but encourage a high degree of scientific connection between groups. It will support infrastructure that enables researchers to access equipment and expertise more readily. The Cancer Institute NSW has invested in translational research to encourage research discoveries to directly benefit patients and clinical practice.

The Australian Government could consider a more strategic focus for cancer research in Australia. Such an approach could be directed to translational research, health service research, screening and early detection and clinical trials research as well as traditional areas funded by the NHMRC.

2. Establishment of Cancer Care Funding Reform

In relation to cancer care, the 2002 report to the Australian Health Ministers Conference of the Australian Health Care Agreement Reference Group, convened to examine the interaction between hospital funding and private health insurance, found that “several barriers exist in relation to the movement away from traditional cancer care and the development and implementation of a “new” approach to cancer care and control. These include unsatisfactory current funding arrangements that tend to undermine current clinical practice, inequities in access to treatment and infrastructure issues particularly relating to high cost machinery and the availability of workforce.”

The Reference Group recommended that Ministers should consider committing to reform current funding arrangements that inhibit the provision of multidisciplinary and coordinated cancer care including:

- the introduction of flexible funding arrangements to promote substitution and coordination across difference modalities that provide for integrated cancer care; are supportive of an enhanced role for General Practitioners; reflect a level playing field between the public and private sectors in terms of appropriate technology.
- Allow private health insurance funds to offer coverage for non-admitted or ambulatory patient service for cancer patients to ensure integrated care
- Reform of payment arrangements under the Medicare Benefits Schedule to promote multidisciplinary cancer care services

As a consequence of this Report, Health Ministers, through the Health Ministers Reform Agenda, are sponsoring the Cancer Funding Reform Project. Options for cancer funding reform are to be provided to Ministers by the end of 2005. The draft aims of the project are to make recommendations, based on available evidence, about specific alternative funding arrangements and implementation options to improve access to coordinated best practice treatment for cancer.

Key Issues for the NSW Health

A key issue for NSW Health is that although models of cancer care have changed considerably over the last few years (for example a shift from admitted to non-admitted hospital care for chemotherapy), funding models have remained rigid and are based on historical arrangements. These inflexible funding arrangements act as a barrier to the implementation of best practice cancer care.

The two key issues for NSW Health relate to the need to enhance current arrangements for multidisciplinary care and the role of private health insurance and the private sector in funding and providing cancer care. These issues are examined below.

Multidisciplinary Care

The current structure of the Medical Benefits Schedule (MBS) does not fund clinicians providing treatment to private patients to participate in multidisciplinary care (MDC) meetings. This is a barrier to best practice cancer care.

The National Service Improvement Framework for Cancer (NHPAC, 2004) and The Optimising Cancer Care in Australia Report (Clinical Oncology Society of Australia and the Cancer Council Australia, National Cancer Control Initiative, 2003) acknowledges as a priority the need to support multidisciplinary care through MBS reimbursement for participation in multidisciplinary meetings and processes. Particular issues are outlined below.

The MBS does not facilitate coordinated, integrated and multidisciplinary care by encouraging the participation of the broad range of clinicians that need to be involved in the provision of multidisciplinary cancer care. Currently only two clinical areas have access to MBS rebates for MDC – General Practitioners and Physicians (this could include medical and radiation oncologists). The remainder of clinicians have no access to MDC. This means there is no incentive for the entire cancer team which usually include a broader base of clinicians (including pathologists, radiologists, surgeons, medical oncologists, radiation oncologists, general practitioners, specialist nurses, other allied health and palliative care service providers) to provide MDC. This can lead to fragmentation of care.

Private medical, surgical medical and radiation oncologists can each claim a relevant MBS item only if they review a patient together when the patient is present. This does not reflect current best practice in which clinicians may attend multidisciplinary meetings where several patients are discussed, only one of whom may be their patient or in cases where due to the technical aspects of the discussion, it is often not appropriate for the patient to be in attendance.

Clinicians treating private patients are not funded throughout the MBS to attend multidisciplinary meetings. There is therefore little incentive for private patient clinicians to participate in multidisciplinary care.

Private Health Insurance and the role of Private Hospitals

The key aim of Medicare is to provide free access to public hospital services and affordable access to medical services. While this aim is still relevant today, since Medicare was introduced in 1984, there have been significant changes in clinical practice and in the organisation and delivery of health services. For example, the relative roles of the public and private sector in providing and funding health care have shifted considerably. There has also been a major shift in hospital-based care from an inpatient, admitted setting to the provision of care on a non-admitted or same-day basis. For example at NSW public hospitals over 90% of chemotherapy and radiotherapy services are delivered on a non-inpatient basis.

Current private health insurance arrangements (PHI) reflect older models of care where most patients would receive treatment on an admitted in-patient basis. Cancer treatment modalities have now evolved to the extent that much of the hospital-based treatment for cancer (for example radiotherapy and chemotherapy) occur on a non-admitted basis. However, private health insurance arrangements only fund services at hospitals where the patient is admitted. There is currently no ability to insure for hospital based non-admitted care.

There are also differences in the public and private hospital billing arrangements that force patients to make decision about their care based on financial considerations. For example in many instances, staff specialist providing non-admitted radiotherapy services to private patients in public hospitals are limited to charging the MBS schedule fee (ie, patients are bulk billed). However in the private sector, the ‘gap payments for these non-admitted services can be substantial which places the patients at a significant financial disadvantage. This leads to increased pressure on the public hospital system and forces patients to make treatment location decisions based on financial rather than clinical considerations.

The above two examples illustrate instances where historical structural funding arrangements are adversely affecting best practice cancer care. Although these issues are being addressed through the current Australian Health Ministers Reform Agenda processes the NSW Government is keen to ensure that there is support from all levels of government in developing and implementing funding arrangements that promote best practice coordinated cancer care.

Section (b)

Assessment of conventional and complimentary approaches to cancer therapy.

The NSW Cancer Plan Goal 20 states the need to provide credible information about the benefits and risks of complementary approaches.

Broad Aims of the Cancer Institute NSW in complementary approaches
To develop a plan for the Cancer Institute NSW to specifically focus on making Complementary Therapies Information available to people with cancer, their families, carers and health professionals.

Introduction
Studies have shown that the proportion of people with cancer who choose to use complementary therapies varies widely from 7-83.3% (Verdoef, 1999; Richardson et al, 2000). Complementary therapy use by the Australian general population has also been found to be increasing from 48.5% to 52.1% in a South Australian population over a seven year period (MacLennan et al, 1996; Rao, 2004).

It was reported that by 1993 Australians were spending $621 million per year on complementary medicines, almost twice what was spent on pharmaceuticals, and spending a further $309 million visiting complementary practitioners (Bensoussan, 1999). In 1996 the international market was estimated to be $20 billion and expanding annually by more than 15%. The complementary therapy industry is important to the general population, the economy and also very important to people with cancer.

Many health professionals are not familiar with the complementary therapies and therefore do not feel comfortable discussing their use with their patients. With an emphasis on evidence-based approaches, it is important for appropriately designed studies to be conducted to evaluate their effectiveness so people with cancer and their health professionals have the information required to make an informed choice (Bensoussan, 1999; Lewith, 2000).

In order to determine what the Cancer Institute NSW can do to support this process it is important to understand what complementary therapies people with cancer choose to use.

Definition of Complementary therapies
It is important to clearly define the term complementary therapies however proposed definitions generally fall short (Bensoussan 1999). The treatments vary regionally influenced by cultural and historical factors and have been defined and reported differently in the literature by various research groups (Traunt & Bottorff, 1999; Verdoff et al, 1999; Lewith, 2000; Ponholzer et al, 2003).

In Australia the proposed **Therapeutic Goods Administration (TGA)** definition of complementary medicines ('traditional' or 'alternative') is:

- *any plant; plant material, alga, bacterium, fungus or non human animal material (eg cartilage or bone) or synthetically produced substitute*
- *any substance obtained by extraction, distillation, purification or traditional preparation of the above list*
- *vitamins (provitamins or synthetic equivalent of substances with an Australian or New Zealand recommended daily intake)*
- *amino acids (or synthetic equivalent)*
- *minerals (including salts)*
- *microorganism, whole or extracted, except for a vaccine*
- *homoeopathic medicine*

The definition proposed by the **National Centre for Complementary and Alternative Medicine (NCCAM)** at the US National Institute of Health (2005) is used by the National Cancer Institute and reported in the scientific literature (Traunt & Bottorff, 1999; Verdoef et al, 1999; NCI, 2004; Rao 2004, Molassiotis et al, 2005).

'Complementary and alternative medicine is a group of diverse medical and health care systems, practices, and products that are used to diagnose, treat and/ or prevent illness and are not used in conventional medicine. The term complementary represents those taken in addition to generally accepted practice, while alternative therapies are those undertaken instead of conventional medicine' (NCCAM, 2005).

There are over 600 complementary therapies listed and the following major groups are used when discussing them:

1. Biological based practices: herbal medicines, diet and nutritional including urinology and macrobiotic diet and biological products including shark cartilage and chelation therapy etc
2. Mind-body medicine: including meditation, imagery, spiritual healing and hypnosis;
3. Manipulative and body-based practices: including massage, acupuncture, chiropractic and therapeutic touch;
4. Energy medicine: electrical, sound, light therapies and reiki, qi gong etc
5. Whole medical systems: including natropathy, ayurveda, traditional Chinese medicine and homeopathy.

The **Cancer Support UK** is part of the NHS, based at the Royal Marsden Hospital and funded by the Diana, Princess of Wales Memorial Fund. Complementary Therapies are defined as *'a range of therapies based on holistic treatment, eg aromatherapy, homeopathy, massage etc.* Complementary therapies usually treat the cause of the problem rather than the symptoms.' They also state 'Complementary therapies cannot cure cancer, and they should not be seen as an alternative to conventional treatments. However, some people say they help in living with cancer and in coping with the effects of medical treatment. Many people say that using complementary therapies gives them a sense of control as they are doing something positive.'

The groupings used on the site are:
Holistic approaches: acupuncture, healing (therapist channeling energy eg Reiki), herbal medicine, homeopathy
Nutritional approaches: Nutritional therapists
Physical approaches: aromatherapy, massage, reflexology
Psychological approaches: art therapy, meditation, relaxation, visualisation

They relate closely to the groups proposed by the NCCAM except that they do not have a separate group for energy interventions.

The **British Columbia Cancer Agency** website (2005) describes separates the supportive therapies (complementary or coping) programs that are used to help patients who are using conventional therapies and include art and music therapy, patient and family counselling, vocational counselling, relaxation therapy, prayer, meditation, support groups and therapeutic touch (called healing in UK). The alternative therapies (unconventional) are those that have not undergone scientific testing. There are 46 listed on the site however they are not grouped and they are those most enquired about at the agency including Vitamins, Teas, Coenzyme Q, Comfrey, Ginseng, Minerals, Macrobiotic Diets, Mushroom Therapies, Oxygen Therapies, Psychic Surgery, Pycnogenol and Shark Cartilage.

Recommendations for the committee on definitions

- Accept the TGA definition as a description of complementary medicines
- Adapt the NCCAM definition of complementary and alternative medicine
- Accept the groupings of complementary therapies by the NCCAM

References:

British Columbia Cancer Agency
http://www.bccancer.bc.ca/PPI/UnconventionalTherapies/default.htm Accessed 7th February 2004

National Centre for Complementary and Alternative Medicine (NCCAM)
http://nccam.nih.gov/health/whatiscam/ Accessed 24th January 2005

Therapeutic Goods Administration http://www.tga.gov.au/docs/html/meddef.htm#cmed Accessed 24th January 2005

UK Cancer Support
http://www.cancersupportuk.nhs.uk/main/default.asp?cancer_network=0&lang=en&page=5_home.html Accessed 7th February 2005

Appropriate Website links

British Columbia Cancer Agency This site has a database of information detailing specific therapies. http://www.bccancer.bc.ca/PPI/UnconventionalTherapies/default.htm

Memorial Sloan-Kettering Cancer Centre
About Herbs, Botanicals and Other Products database with details of specific therapies.
http://www.mskcc.org/mskcc/html/11570.cfm

National Cancer Institute provides information on Complementary and Alternate Medicine (US) http://cis.nci.nih.gov/fact/9_14.htm

The Cancer Council NSW complementary therapies decision tree
http://www.cancercouncil.com.au/canceranswers/answers.asp?pageid=1673

The Theraputic Goods Administration in Australia is defining complementary medicines
http://www.tga.gov.au/docs/html/meddef.htm#cmed

A review of the literature on complementary therapies in cancer

Introduction to the literature review by the Cancer Institute NSW

Studies have shown that the proportion of people with cancer who choose to use complementary therapies varies widely from 7-83.3% (Verdoef, 1999; Richardson et al, 2000). Complementary therapy use by the Australian general population has also been found to be increasing from 48.5% to 52.1% in a South Australian population over a seven year period (MacLennan et al, 1996; Rao, 2004). It was reported that by 1993 Australians were spending $621 million per year on complementary medicines, almost twice what was spent on pharmaceuticals, and spending a further $309 million visiting complementary practitioners (Bensoussan, 1999). In 1996 the international market was estimated to be $20 billion and expanding annually by more than 15%. The complementary therapy industry is important to the general population, the economy and also very important to people with cancer.

Many health professionals are not familiar with the complementary therapies and therefore do not feel comfortable discussing their use with their patients. With an emphasis on evidence-based approaches, it is important for appropriately designed studies to be conducted to evaluate their effectiveness so people with cancer and their health professionals have the information required to make an informed choice (Bensoussan, 1999; Lewith, 2000).

In order to determine what the Cancer Institute NSW can do to support this process it is important to understand what complementary therapies people with cancer choose to use. In order to aid this a review of the literature was conducted. The electronic databases Medline, Cinahl, Cochrane and Embase were searched and articles that identified cancer specific populations relevant to Australia were included. Only articles available in English and able to be accessed through the Cancer Institute NSW library system were included in this review. One non cancer specific study was included as it contained a cancer population and was completed in Western Sydney in early 2004.

What complementary therapies do people with cancer use?

Australian data:

An Australian cross-sectional study of 507 people attending an oncologist outpatient clinic in either a large metropolitan hospital in Sydney or a smaller regional service in Port Macquarie were assessed for their use of complementary therapies (Begbie et al, 1996). The study population was asked to complete a self-administered questionnaire and 335 people responded resulting in a 66% response rate (n=271 in Sydney and n=64 in Port Macquarie). Of these 319 were complete enough for inclusion in the analysis (62%). The study was designed to determine the expectations of and satisfaction with conventional and complementary therapies. The majority of study participants were aged 51-70 years, female, married, had private health insurance, a secondary education and were not working which may reflect the socio-economic status of the population.

The study found 21.9% of participants (n=70) had used complementary therapies, most commonly relaxation/massage interventions (58.6%) and dietary (57%, n=40). The other therapies that were asked on the questionnaire were megavitamins (52.9%, n=37), positive imagery (44.3%, n=31), faith/spiritual healing (30%, n=21), homoeopathy (15.6%, n=11), naturopathy (27.1%, n=19), immune therapy (17.1%, n=12), acupuncture (11.4%, n=8) and any others (1.4%, n=1). 75% of a people who had tried complementary therapies used more than one therapy.

A cross-sectional survey of inpatients in the Nepean, Springwood and Blue Mountains Hospitals and outpatients of the Nepean Cancer Care Centre was undertaken in early 2004 (Snape, 2004).

This was conducted in the general hospital population and although the Cancer Centre was included it is not possible to differentiate people with cancer from the rest of the population. 41% (n=234) of people participated in the survey with 33% declining and 26% of people unable to participate. 53% of people surveyed had used in the past 5 years, were using or intended to use complementary therapies. There were 40 people who were currently using complementary therapies of which 27.5% were males, 70% females and 2.5% did not specify their gender. Of this the majority used complementary medicines, vitamins and minerals (72.5%, n=29), herbs (37.5%, n=15), food supplements (15%, n=6), homeopathy (10%, n=4), essential oils (10%, n=4), flower essence (5%, n=2), probiotics (5%, n=2) and other (colloidal silver and antioxidants – 5%, n=2). The complementary therapies currently used were massage (5%, n=2), meditation (5%, n=2), reflexology (5%, n=2), acupressure (2.5%, n=1) and reiki (2.5%, n=1). Although the population was not cancer specific it is included in this review because of the limited cancer specific information from Australia.

International data:

A European cross-sectional study of 956 people with cancer on their use of complementary therapies was released in early 2004 (Molassiotis et al, 2005). The data collected from Spain, Israel, Turkey, Scotland, Greece, Switzerland, Sweden, Italy, Czech Republic, Serbia, Denmark, Belgium, Iceland and England, via a descriptive survey completed in the waiting rooms of outpatient clinics. 591 females and 365 males participated in the study with a mean age of 55.7 yrs. The most frequent cancer diagnosis was breast (30.8%), colorectal (16.1%) and lung cancer (12.1%). There were 58 therapies were reported with only 38 being used prior to their cancer diagnosis. The therapies most commonly being used by the participants at the time of the survey were homeopathy (3.8%), herbs (12.1%), medicinal teas (4.5%), spiritual healing (3.1%) and relaxation therapy (3.7%). The study also explored the reasons people use complementary therapies.

In an American cross-sectional survey 1935 randomly selected people with cancer from a central cancer registry were asked them about their use of complementary therapies, what they hoped to gain and if they informed their medical practitioner (Morris et al, 2000). 617 people responded, 288 with breast cancer and 329 with other primary cancers. Their age ranged from 18-75 years. In this group of 249 people (74%) reported the use of complementary therapies 63% nutrition, 53% massage, 44% herbal remedies, 39% relaxation, 31% chiropractor and 31% acupuncture. No statistical analysis is reported indicating is if there was a difference between the two groups. No further statistical analysis of the use of therapies was reported to determine if the frequency of use of specific complementary therapies differed between people with breast cancer and those people with other types of cancer. Methodologically this is a limitation of the study.

In a US cross-sectional study to determine the prevalence and predictors of complementary therapy use English-speaking adults answered a self-administered questionnaire (Richardson et al, 2000). Of the 453 people who completed the study (response rate of 51.4%), 83.3% had used at least one complementary therapy however when religious and spiritual practices were excluded the only 68.7% of the population had used complementary therapies. A wide range of cancer types were represented including breast (n=60), skin (n=56), lymphoma (n=57), gynaecological (n=56), gastrointestinal (n=58), genitourinary (n=114) and head and neck cancer (n=52) with all other demographics being normally distributed across the groups. The majority used religious and spiritual practices (80.5%). 62.2% used nutritional supplements and herbs, the supplements included melatonin (20.3%), shark or bovine cartilage (25.3%), and homeopathic remedies (17.6%) and the herbs used included essiac tea, mistletoe, ayurveda and folk remedies. 59.2% used movement and physical therapies including massage (33%), chiropractic or osteopathic treatments (22.9%) and regular exercise (57.5%).

A UK study based at a London hospital conducted a postal survey of people with cancer and interviewed those who had used complementary therapies (Downer et al, 1994). 600 surveys were sent out, 415 (69%) were returned of which 16% had used complementary therapies. 74% of people using complementary therapies participated in semi-structured interviews. 75% used two or more therapies and most were used for the perceived anti cancer effect. The most common complementary therapies used were healing (65%), relaxation (35%), visualisation (34%), dietary (26%), homeopathy (25%), vitamins (20%) and herbs (20%) were used although specific details were not given. A number of other complementary therapies were also used to a smaller extent including acupuncture (14%), meditation (14%), bach flowers (12%), hypnotherapy (9%), aromatherapy (8%), naturopathy (8%), reflexology (6%) and osteopathy (5%). Generally respondents were dissatisfied with the dietary and herbal therapies as they had difficulty adhering to these interventions that were considered unpalatable.

A subgroup of 200 people was asked to complete the hospital anxiety and depression scale and the cancer locus of control questionnaire (Downer et al, 1994). 68% completed these and those using complementary therapies were significantly more anxious than those in the conventional treatment group (8 vs 6, $p<0.01$). There was not significant difference in their depression scores. The scores for locus of control indicated that those who were taking complementary therapies were more likely to have a higher internal control over the origin or course of their illness as expressed by a lower score (20.5 vs 27, $p<0.006$) indicating they feel they had more control of the development of their condition. However there was no difference between the two groups on factors influencing the course of their illness. There is no measure of the severity or stage of the disease and therefore patient groups may be expected to have differing outcomes dependant upon their diagnosis (Downer et al, 1994).

Table 1: Types of complementary therapies used by people with cancer

Study Detail	Cancer Type	Characteristics of Users	Complementary Therapy	% Use
Begbie, 1996 **Adults – Australia (n=319)** **21.9% use CT** **Self-administered survey**	**Breast; lung; genitourinary; gastrointestinal; haematological; other; unknown**	Young Married	Relaxation	59
			Diet	57
			Megavitamins	53
			Positive imagery	44
			Faith healing	30
			Naturopathy	27
			Immune therapy	17
			Homoeopathy	16
			Acupuncture	11
			Other (not reported)	1
Boon, 2000 **Adult women – Canada (n=422)** **62 % use CT** **Postal survey**	**Breast**	Younger More educated Higher income Used support groups Chemotherapy Internal locus of control	Vitamins/minerals	49.6
			Herbal remedies	24.6
			Green tea	17.3
			Special foods/diet	15.3
			Essiac (a herbal tea)	14.8
			Bodywork eg. Reiki, massage, therapeutic touch	14.1
			Meditation	10.2
			Shark cartilage	5.4
			Homeopathy	3.9
			Faith healing	3.4
Downer, 1994 **Adults – UK (n=415)** **16% use CT** **Postal survey, subgroup interview**	**Breast; gastrointestinal; gynaecology; other; lymphoma**	<50 years Higher SES class Female Lymphatic cancer	Healing	65
			Relaxation	35
			Visualisation	34
			Diet	26
			Homoeopathy	25
			Vitamins	20
			Herbs	20
			Acupuncture	14
			Meditation	14
			Bach flowers	12
			Hypnotherapy	9
			Aromatherapy	8
			Naturopathy	8
			Reflexology	6
			Osteopathy	5

Study Detail	Cancer Type	Characteristics of Users	Complementary Therapy	% Use

Hall, 2003 **Adult men – US (n=351)** **37% use CT** **Postal Survey**	**Prostate cancer**		Vitamins Herbal medications Dietary change Vitamin E Multivitamins Lycopene Saw palmento	35 12 12 22.3 21.8 3.8 3.8
Morris, 2000 **Adults – US (n=617)** **74% use CT** **Self-administered survey**	**Breast cancer vs other non-specified cancers**	Breast cancer Younger (45-54 yrs)	Nutrition Massage Herbal remedies Relaxation Chiropractor Acupuncture	63 53 44 39 31 31
Molassiotis, 2005 **Adults – Europe (n=956)** **35.8% use CT** **(varied from 14.8% in Greece to 58.8% in Czech Republic)** **Self administered survey**	**Breast, colorectal, lung, head & neck, gynaecological, haematological, genitourinary, stomach, prostate, bone/spine, pancreatic, liver, malignant melanoma, brain tumours**	Not clearly defined however the highest prevalence of use was in pancreatic (56.3%), liver (55.6%), bone/spinal (54.5%), brain (50%) and breast (44.7%) cancers	Homeopathy Acupuncture Aryurveda Naturopathy Herbs Medicinal teas Vitamins/minerals Other dietary supplements Other biological therapies Spiritual and healing Relaxation therapy Visualisation Other mind-body therapies Energy therapies Massage Other body based therapies	3.8 1.9 0.4 0.4 12.1 4.5 5.1 1.9 1.3 3.1 3.7 2.3 4.2 1.5 2.3 1.9
Ponholzer, 2003 **Adult men – Austria (n=245)** **29.8% use CT** **Self-administered survey**	**Prostate**	Primary therapy Disease progression Less satisfied Lower QoL	Reduced fat diet Selenium Vitamin E	13.3 10.8 9.3
Richardson, 2000 **Adults – US (n=453)** **83.3% use CT** **Religion excluded: 68.7%** **Self-administered survey**	**Breast; head & neck; gastrointestinal; urology; prostate; skin; gynaecology; lymphoma**	All: <55 years Female Received surgery Religion excluded: Female Higher education Received chemotherapy	Religious and spiritual practices Nutritional and supplemental Movement and physical	80.5 62.2 59.2

In a Canadian cross-sectional study, 557 women with breast cancer from the Ontario Cancer Registry were mailed a questionnaire about their use of complementary therapies (Boon et al, 2000). The questionnaire was compiled from a mix of questions from validated questionnaires and adapted to the local population and trialled by focus groups. 411 questionnaires were returned and able to be used, a response rate of 76.3%. The average age of the population was 58 years, the average time since diagnosis was 34.9 months, 71.6% were married while 15% were widowed, 51.6% were North American and 30.4% were European. 49.2% had higher than a high school education and 49.7% had a household income of Can $40 0000 or greater. 62% of women reported using complementary therapies (the median was two) and with 39.4% visiting a complementary therapy practitioner at least once in their life, therefore it is not clear if this was to treat their cancer and this is a limitation of the study. The top 10 therapies reported were vitamins/minerals (49.6%), herbal remedies (24.6%), green tea (17.3%), special foods/diet (15.3%), essiac tea (14.8%), bodywork eg. Reiki, massage, therapeutic touch (14.1%), meditation (10.2%), shark cartilage (5.4%), homeopathy (3.9%) and faith healing (3.4%).

Hall and colleagues (2003) determined what the motivations were for people with prostate cancer being treated with curative intent to use complementary therapies. A cross-sectional postal survey of 351 men who had finished treatment was conducted and 238 men returned the survey (67.8% response rate). 37% were using complementary therapies, which were not influenced by the type of treatment they were given. Those complementary therapies used were Vitamins (35%) with 22.3% taking Vitamin E and 21.8% taking multivitamins, herbal medications (12%) with lycopene and saw palmento the most popular, both being taken by 3.8% of all respondents and with dietary change of any sort being tried by 12% of respondents.

Ponholzer and colleagues (2003) conducted a cross-sectional study of men with prostate cancer in Austria to determine the use of complementary and alternative medicine in this population. The 822 men consecutively attending routine follow-up completed an anonymous self-administrated questionnaire. The average age of those who completed the survey was 69.8 ± 6.5 years (range 45-95yrs) completed the survey. There was a mean time between diagnosis and evaluation of 3.9 ± 3.1 yrs. 245 men (29.8%) indicated that they used at least one complementary or alternative medicine. There was no significant difference between those who did use complementary medicine and those who did not in age, PSA level or time interval from diagnosis and follow-up. There was a difference according to the primary therapy (radical prostectomy, 23.3%; radiotherapy, 31.6%; endocrine therapy 38.8%, $p<0.01$). The most frequent were a reduced fat diet (13.3%), selenium (10.8%), Vitamin E (9.3%). Self reported health status and quality of life were lower in those using complementary therapies compared to those who were not ($p<0.01$ for both). The study specified type of herb and dietary change in a manor quite different to other studies and it may be that the products chosen may differ as it is a European population, exclusively male and prostate cancer.

A summary of the numbers of people (and proportions) within each study using each therapy is displayed in Table 2.

Table 2: Most popular complementary therapies used by people with cancer

Complementary Therapy Category	Studies Total number using complementary therapies	Complementary therapy	Number using specific complementary therapies
Biological based practices: herbs, nutrition, diet and biological			
Herbal medicines	Downer, 1994	Bach flowers	8 (12%)
	Boon, 2000	Herbal remedies	65 (24.6%)
	Downer, 1994		13 (20%)
	Hall, 2003	Lycopene n=8 (3.4%) Saw palmento n=8 (3.4%)	29 (12%)
	Morris, 2000		110 (44%)
	Molassiotis, 2005		118 (12.1)
	Boon, 2000	Essiac (a herbal tea)	39 (14.8%)
	Boon, 2000	Green tea	45 (17.3%)
	Molassiotis, 2005	Medicinal teas	43 (4.5%)
	Downer, 1994	Aromatherapy	5 (8%)
Diet and nutritional changes (eg urinology and macrobiotic diet),	Begbie, 1996	Diet	40 (57%)
	Boon, 2000		40 (15.3%)
	Downer, 1994		17 (26%)
	Hall, 2003		29 (12%)
	Morris, 2000		47 (63%)
	Ponholzer, 2003		33 (13.3%)
	Molassiotis, 2005	Other dietary supplements	19 (1.9%)
	Begbie, 1996	Megavitamins	37 (53%)
	Downer, 1994		13 (20%)
	Hall, 2003	Multivitamins	52 (21.8%)
		Vitamin E	53 (22.3%)
	Ponholzer, 2003	Vitamin E	23 (9.3%)
	Boon, 2000	Vitamins/minerals	130 (49.6%)
	Molassiotis, 2005		49 (5.1%)
	Ponholzer, 2003	Selenium	26 (10%)
	Richardson, 2000	Nutritional and supplemental	234 (62.2%)
Biological (eg. shark cartilage & chelation therapy)	Boon, 2000	Shark cartilage	14 (5.4%)
		Other biological therapies	13 (1.3%)
Mind-body medicine			
Mind-body techniques eg meditation, imagery and hypnosis	Begbie, 1996	Relaxation/meditation	41 (58%)
	Downer, 1994		23 (35%)
	Morris, 2000		29 (39%)
	Molassiotis, 2005		35 (37%)
	Begbie, 1996	Positive imagery (Visualisation)	31 (44%)
	Downer, 1994		22 (34%)
	Molassiotis, 2005		22 (2.3%)
	Begbie, 1996	Faith healing	21 (30%)
	Boon, 2000		9 (3.4%)
	Richardson, 2000	Religious and spiritual practices	304 (80.5%)
	Molassiotis, 2005	Spiritual and healing	30 (3.1%)
	Boon, 2000	Meditation alone	27 (10.2%)
	Downer, 1994		9 (14%)
	Downer, 1994	Hypnotherapy	6 (9%)
	Molassiotis, 2005	Other mind-body therapies	40 (4.2%)

Manipulative and body-based practices:			
Complementary Therapy Category	**Studies Total number using complementary therapies**	**Complementary therapy**	**Number using complementary therapies**
Manual healing eg massage, chiropractic	Begbie, 1996	Acupuncture	8 (11%)
	Downer, 1994		9 (14%)
	Morris, 2000		23 (31%)
	Molassiotis, 2005		18 (1.9%)
	Downer, 1994	Reflexology	4 (6%)
	Morris, 2000	Massage	40 (53%)
	Molassiotis, 2005		22 (2.3%)
	Morris, 2000	Chiropractor	23 (31%)
	Richardson, 2000	Movement and physical	200 (59.2%)
	Molassiotis, 2005	Other body based therapies	18 (1.9%)
Energy medicine:			
Electrical, sound, light therapies and reiki, qi gong	Boon, 2000	Bodywork eg. Reiki, massage, therapeutic touch	38 (14.1%)
	Downer, 1994	Healing	42 (65%)
	Molassiotis, 2005	Energy therapies	1.5
Whole medical systems			
Alternative systems of medical practice (eg ayurveda, naturopathy, traditional Chinese medicine and homeopathy)	Begbie, 1996	Homoeopathy	11 (16%)
	Downer, 1994		16 (25%)
	Boon, 2000		10 (3.9%)
	Molassiotis, 2005		36 (3.8%)
	Begbie, 1996	Naturopathy	19 (27%)
	Downer, 1994		5 (8%)
	Molassiotis, 2005		4 (0.4%)
	Downer, 1994	Osteopathy	3 (5%)
	Molassiotis, 2005	Aryurveda	4 (0.4%)

Summary: What complementary therapies do people with cancer use?

The only Australian study reported relaxation (58%), diet (57%), vitamins (53%), positive imagery (44%) and faith healing (30%)as the five most popular therapies (Begbie et al, 1996). A smaller proportion of people with cancer used naturopathy, immune therapy, homoeopathy and acupuncture. The proportions differ to the other studies possibly due to the cultural differences in the study population or the categories participants were able to choose from when answering the study survey.

The numbers of people consuming each therapy are detailed on table 2. Although the studies differ with the way the complementary therapies are classified it can be seen from Table 2 that religious and spiritual practices tend to be the most commonly reported (80.5%, Richardson et al, 2000). Healing (65%, Downer et al, 1994), nutritional and supplemental therapies (62.2%, Richardson et al, 2000) and physical movement (59.2%, Richardson et al, 2000) were the next commonly reported. Some of the categories are not exclusive such as nutritional and supplemental practices as reported by Richardson et al (2000) as this includes dietary, general nutrition and biological supplements. When religious and spiritual practices were excluded similar results were found in studies from in the US, Canada and UK (Downer et al, 1994; Boon et al, 2000; Morris et al, 2000; Richardson et al, 2000). Details of the studies reviewed can be found in Table 1.

In these studies ethnicity was not well described (Boon et al, 2000), and as it has been proposed there may be regional differences in complementary therapy use and because of the cultural diversity of the Australian population these studies should be applied with caution to Australia. All these studies are of cross-sectional design of self-administered surveys with two being postal surveys (Downer et al, 1994; Boon et al, 2000) so only associations can be drawn from the data. There are limitations of being able to compare the results of different studies as they tend to use slightly different definitions of complementary therapies.

In those studies where information was reported on the non participants those who chose to participate in a cross-sectional study on the use of complementary therapies were more likely to be younger (Richardson et al, 2000), female (Begbie et al, 1996) have a higher income (Begbie et al, 1996; Boon et al, 2000) have private health insurance (Begbie et al, 1996; Richardson et al, 2000), a secondary education (Begbie et al, 1996; Boon et al, 2000) be not working (Begbie et al, 1996) and more likely to have breast cancer (Richardson et al, 2000).

Generally the predictors of using complementary therapies were being younger (Downer et al, 1994; Begbie et al, 1996; Boon et al, 2000; Morris et al, 2000; Richardson et al, 2000), more highly educated (Downer et al, 1994; Boon et al, 2000; Richardson et al, 2000), being female (Downer et al, 1994; Richardson et al, 2000), and using chemotherapy (Boon et al, 2000; Richardson et al, 2000).

The approach of the Cancer Institute NSW to provide objective information on complementary medicine to the public should be supported. Lack of knowledge about these approaches or their possible interactions with conventional therapy should be noted. There is a real need for more research to obtain further objective information on the value or harm of these approaches.

Key recommendations:

Section (a)

1. Cancer Australia and other Australian Government programs are developed collaboratively with State Government cancer programs.
2. The Australian Government consider early introduction of universal bowel cancer screening and matching state expenditure on tobacco control.
3. More efficient methods to provide ambulatory cancer care are considered. In particular the Australian Government consider reform of the funding models for ambulatory care.
4. Care is better coordinated between general practice and specialists and within specialist centres. Multidisciplinary care is encouraged by consideration of a fee for this activity.
5. Emotional and practical patient support is considered a basic service increasingly available to all cancer patients.
6. Workforce development include identification of future trends in cancer incidence and includes upgrading skills of health professionals currently in practice.
7. Information available to cancer patients, carers and health professionals better target their needs. Health professionals have access to the best evidence that their treatments are of value.
8. Cancer research include clinical trials, health service research and psycho-oncology research as well as biomedical research. Research be used to drive improvement and assessed on its likely clinical impact as well as other criteria.

Section (b)

9. The definitions of complementary treatment be uniform for Australia based on the TGA definition.
10. Credible and accurate information about complementary medicine be accessible to cancer patients, carers and health professionals. This information be based on the same evidence based criteria as conventional therapy where available. Where such information does not exist this gap in knowledge is acknowledged.
11. Where gaps in knowledge exist, research provide information on interactions with conventional agents and evidence for value to the patient. For pharmaceutical agents, they should be assessed for both benefits and harm.
12. Where quality of life may be improved by complementary approaches, methods to make such therapy more accessible be considered.

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