(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.

Multidisciplinary care is a team approach to the provision of healthcare by all relevant medical and allied health disciplines. In 1995 a House of Representatives inquiry recommended multidisciplinary care as a means of achieving best practice: “through their combined understanding …, all members of the team liaise and cooperate together and with the patient to diagnose, treat and manage the condition…to the highest possible standard of care”

Multidisciplinary teams of all relevant specialists on a cancer site specific basis should provide advice on initial treatment and on management of recurrent or metastatic disease. This model is a significant change in clinical management than currently occurs in some areas of cancer care, since decisions by the team are collective rather than those of the individual doctor alone. It is utilised most often in the treatment of breast cancer but is by no means consistent practice there either. For multidisciplinary teams to work effectively, it is essential that all patients are evaluated by the team before a decision on treatment is taken and that members of the team have a balanced view of the strengths and weaknesses of their own and others’ treatment modalities. It is also important that the teams include all relevant health professionals (not only the medical specialities) including, nursing, social work, psychology.
For women with breast cancer, there is evidence that multidisciplinary care has the potential to reduce mortality, improve quality of life and reduce health care costs. Recent significant documents dedicated to reform in the delivery of cancer services including *Optimising Cancer Care* and the *National Service Improvement Framework*, have clearly stated the importance of the multidisciplinary approach.

The multidisciplinary approach to care has advantages both for patients and doctors. For patients, it is reassuring that a number of specialists have reviewed the case and different treatment options have been carefully considered. It is also more likely that a greater number of treatment possibilities have been explored and that psychosocial issues are addressed in comparison to the traditional model of care. For doctors, the corporate nature of the decision (which should be documented) gives added weight, particularly in complex cases. It may also help to protect the individual physician against litigation and encourage adherence to evidence based protocols of management. The open nature of process enables a level of ongoing peer review that is consistent with the demands of good clinical governance.

One of the difficulties associated with conducting multidisciplinary treatment meetings is the time associated with the process and its attendant cost. This can be addressed in a number of ways depending upon the situation – eg the use of technology to bring the team together in rural and remote areas; in the public sector encouraging attractive full-time or maximum part-time contracts to address the problem of time pressure caused by competing institutional responsibilities, in the private sector enabling Medicare payments for attending multidisciplinary meetings and clinics. Administrative support to conduct effective multidisciplinary meetings is also crucial.

The structure of the multidisciplinary approach may vary depending upon the incidence of the disease and its complexity. For example in lung cancer – a high volume cancer - we know that outcomes are poor and treatment regimens are highly variable. Adherence to treatment protocols and clinical trial participation would most likely lead to better patient care and outcomes. To enable this to occur there is need for more multidisciplinary discussions and agreement amongst clinicians about protocols. This would result in appropriate multidisciplinary management models for selected cases while others would simply be protocol driven.

In low volume cancers with similar poor outcomes – e.g., cancers of the upper gastrointestinal tract (pancreas, oesophagus, stomach) there is good evidence that these cancers should be treated in high volume treatment centres. By design, all these patients would probably be seen by a multidisciplinary team at that centre.

In colorectal cancer we know that difficulties arise in the treatment of low rectal cancers and WACOG/TCCWA feel that these cancers should be referred to specialist colorectal surgeons. We do not know if appropriate numbers of colorectal cancer patients are receiving adjuvant therapies. We need more audit data and patterns of care studies to best determine the value of centralisation for difficult cancers. The medical colleges have an important responsibility in ensuring culture change to determine the practicality of multidisciplinary models.

We also feel that the value of multidisciplinary approaches to the treatment of urological and neurological malignancies needs to be promoted in Australia urgently.
Finally we refer the committee to a separate submission to this inquiry by Dr Timothy Threlfall calling for the routine collection of cancer staging data for cancers treated in Australian centres.

(ii) The role and desirability of case managers/coordinators to assist patients and/or their primary care givers

The concept of a case manager/coordinator is not new in health care settings particularly when clients needs are complex and they are required to traverse departments and/or community services in order to obtain a package of care that is tailored to their needs drawing upon the input of more than one clinical area (eg mental health and organ transplantation services).

The benefits from a patient and family perspective are multiple including timely access to advocacy and one-to-one support in relation to information, explanation and early identification of problems and problem resolution.

The benefits from the service providers perspective relate to the achievement of seamless and consumer focused care delivery resulting in minimisation of complaints and communication inefficiencies.

We support the view that it is reasonable to generalise the existing evidence of the value of breast care nurse models (i.e. reduction in psychosocial morbidity associated with cancer and it’s treatments, enhanced early recognition of support needs and provision of continuity of care) to other high volume cancers such as colorectal, lung, gynaecological and urological cancers.

The current evidence from NSW gleaned from efforts to implement cancer care coordination roles in some health service areas, indicate that two important functions are served by such roles. These relate both to classic patient care coordination and the administrative organisation for the conduct of the multidisciplinary team meetings. Much of what follows below is cited from the South West Sydney Cancer Service experience.

A key finding from the NSW experience is that these roles provide a link across clinical services thereby reducing the fragmentation of services and providing the patients and carers with a clear pathway. In this model the roles of care coordinators are non-clinical. The model has been developed under the Health Services Managers Award as these positions are considered to be essentially management and can be filled with candidates from a broad health background. Alternative models consider that the position needs to be filled by a Nurse (preferably an Oncology Nurse) who would have the expertise to provide the patient and their family with clinical information when required.

The breakdown of activities in the NSW model are:

60-70% Direct Patient Care

0-30% Organisation of the weekly Multi-Disciplinary Team (MDT) tasks are: reminders, minutes, recording of team’s opinion, ensuring imaging and pathology are available. The NHS has a detailed specification for a generic specialist MDT as well as specific MDT

10% Management/secretarial support for the Tumour Program business meeting. The coordinator would document and audit agreed pathways developed by the Tumour Program. To be truly effective the coordinator position must be able to influence practice. By holding this strategic role in the Tumour Program the main causes of poor quality and system inefficiencies can be addressed.

Regardless of whether the cancer care coordinator is a nurse, allied health professional, or has another background, it is important that they be provided with appropriate training and that the Government addresses the need to provide education initiatives, so that there will be adequate numbers of coordinators in the future.

We also urge the Australian Government to introduce the concept of ‘rehabilitation’ into the cancer treatment and survival arena. That is, both physical and social particularly in relation to occupational rehabilitation. This is a standard of care in the area of injury management and cardiovascular disease but not cancer and it should be.

(iii) Differing models and best practice for addressing psycho/social factors in patient care.

Many cancer treatment centres do not deliver mainstream health services to cancer patients and their families/carers within a holistic model with meaningful outcomes with regard to psychosocial needs. Much of the impact upon the individual and their family hinges upon the interpersonal style and approach of the senior clinician. For example a randomised control trial conducted to assess the effect of physician compassion on patients’ anxiety revealed that women who saw a 40-second ‘enhanced compassion’ videotape in which the physician acknowledged the psychological concerns of the patient, expressed partnership and support, validated her emotional state through touch and reassurance were significantly less anxious than women who saw a tape without these components of compassion.

This evidence is cited alongside a wide range of other examples gathered in a ‘smorgasbord’ of ‘how to deliver’ best-practice approaches to meeting the psychosocial needs of patients in the following publication:

‘Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer’- April 2003, prepared by the National Breast Cancer Centre and the National Cancer Control Initiative and published as part of the National Health and Medical Research Council (NHMRC).

This publication is a practical guide for clinical teams/health service strategists on how to deliver services within a holistic framework combining mainstream treatments alongside best-practice communication, information-giving, emotional/ practical support and specialist interventions including risk management for psychological and psychiatric manifestations.
Rather than repeating the information in this excellent publication, we recommend it to the committee. This comprehensive and well researched clinical practice guide should form the basis of cancer services and plans with reference to sourcing evidence on best-practice service delivery options, leading to strategies such as:

- training for senior clinicians and multi-disciplinary teams on the best-practice psychosocial strategies described in the relevant sections;
- development/enhancement of specific services such as liaison psychiatry, access to counselors by referral etc;
- making information available for patients/families delivered through a range of media;
- endorsing/supporting the provision of complementary therapies that enhance quality of life through stress management and well-being enhancement.

It is important that access to trained psychologists and counsellors for cancer patients be funded under Medicare and public hospital cancer centres be specifically funded to provide these services for cancer patients.

(iv) Differing models and best practice in delivering services and treatment options to regional Australia and Indigenous Australians

Indigenous Australians with cancer are twice as likely to die from the disease than non-Indigenous Australians. Because of this significant imbalance, in August 2004 in Darwin, The Cancer Council Australia convened a national discussion forum on the issue ‘Reducing the impact of cancer in Indigenous communities: ways forward’. Epidemiological presentations at this meeting noted that the comparatively high mortality rate is partly the result of Indigenous Australians getting ‘more than their share’ of cancers with poorer survival outcomes such as cancers of the lung, oropharynx, oesophagus, liver gallbladder and pancreas. Conversely, Indigenous Australians have lower rates of some of the more curable cancers, such as breast, prostate, bowel and skin cancers. Later diagnoses along with a reduced likelihood of completing treatment also contribute to poorer survival rates.

Relatively limited information is available and even less appears in published form that provides a profile of contemporary cancer care among Indigenous Australian populations. The abovementioned meeting highlighted that there is no national dataset from which to draw information regarding the reasons for such poorer cancer outcomes in this community.

Quality medical care has been described as delivering optimal health services with technical proficiency, and avoiding overuse, under use, or misuse of health services and technologies. Closer analysis of these variables in medical care within certain groups are often referred to as patterns of care studies and are very useful studies in indicating areas for improvement. To the best of our knowledge no such patterns of cancer care studies of Indigenous Australians have been conducted and should be - to accurately determine any disparities. It is crucial that any such work include not only objective/quantitative medical data but also social and qualitative data gathered from informed discourse with Indigenous cancer patients and their families and friends.
The issues associated with delivering services to regional Australia and Indigenous Australians are not necessarily the same even assuming commonality with regard to geography.

In Western Australia, cancer care in the rural and regional setting is somewhat fragmented and undertaken with differing models, standards and approaches. With some notable exceptions, there is generally a lack of co-ordination of care and an under-emphasis on the psychosocial aspects of patient needs. There is also a lack of consistency in the nature and quality of services patients receive. There is no one “right” model but in general there is acceptance that a tiered or ‘step down’ service delivery system is required and ideally all cancer patients, depending upon their geographical location and cancer diagnosis, should receive treatment through this system. The structure of this system is based on multiple considerations such as population size, disease incidence, level of complexity, specialisation and availability of service provider and so on. An example of such a structure is:

**Cancer Centre** - this is a facility that provides services for patients with more common cancers as well as managing patients with rare or more complex cancers. Clinician specialisation in cancer sites should be evident as well as a co-ordinated comprehensive multidisciplinary approach and evidence of clinical research and teaching. A Cancer Centre would generally be located in a major teaching hospital.

**Cancer Unit** – this is a specialist unit within a hospital facility, usually a district hospital. Cancer Units will be able to manage the more common cancers. They will not have the resources, volume of patients or specialisation to optimally manage more complex or rare cancer cases. These cases will be referred to a Cancer Centre. Each unit must have formalised linkages to a Cancer Centre.

**Cancer Outreach Program** – This program can be utilised in more geographically remote areas where there is not a closely available cancer unit or cancer centre. The specialist cancer services are be provided by a Cancer Centre and the local health care providers would have formalised links with a specified cancer centre.

What ever the model, an appropriate workforce must be planned and managed across the whole region and the same is true of equipment requirements. We feel that consumers need to be consulted in planning and monitoring cancer services. Within individual centres and units, lead cancer clinicians need to be appointed, as well as some lead cancer nurses, care coordinators and lead managers for cancer services.

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

Indigenous Australians (metro and rural) present another layer to the above considerations in terms of cultural and/or social factors that inhibit the ability of the health provider to achieve the desired health outcomes within this section of the community. In relation to addressing these complexities, it is recommended that the acknowledged navigators of this cultural/social phenomenon – the Aboriginal Health Care Workers – be further supported in their role to strengthen their capacity/ability to provide a conduit of
access to services and treatments for Indigenous Australians rather than considering a ‘new’ approach that would operate in parallel to these workers.

(v) Current barriers to the implementation of best practice in the above fields

A systematic review of 76 international studies on barriers to guideline adherence identified the following salient factors: lack of awareness, lack of familiarity with evidence, lack of agreement, lack of self-efficacy (i.e., the belief in one’s ability to perform a behaviour), low expectancy of favourable outcomes, inertia/lack of motivation, and perceived external barriers beyond control of individuals. These factors are directly relevant to the issues of implementation of a multidisciplinary approach and best practice in the psychosocial aspects of cancer care.

Australia has an international reputation for the production and dissemination of well-researched clinical practice guidelines for the management of clinical aspects of certain cancers and these guidelines address the issues of multidisciplinary care, co-ordination of care and psychosocial care... However outside of breast cancer there is a paucity of data that indicates high levels of compliance to the established guidelines for the range of cancers where guidelines do exist. Funding is rarely made available by State or Federal health jurisdictions for the actual implementation of guidelines at the local level. This is particularly so in less common and poorer prognostic cancers such as neurological and upper gastrointestinal cancers for which there are no current NHMRC guidelines.

Funding is required to enable guideline implementation to occur but to ensure that it does occur also requires the use of a regulatory framework that measures outcomes and adherence to best practice models and approaches. To this end there is a critical need for a national cancer accreditation and credentialing system. This framework will be a powerful tool to ensure adherence to standards and implementation of best practice models of care in the areas of concern to this inquiry. Some preliminary work in this area has been undertaken in the non-Government sector primarily by the Australian Cancer Network (a group established and supported by The Cancer Council Australia and the Clinical Oncological Society of Australia) but it lacks funding and “teeth”. Accreditation is also an important tool to prevent the “service packaging” that occurs currently (and increasingly) where any service provider can lay claim to having a specialised cancer centre without having to providing supporting evidence to that claim. This practice is confusing to consumers and as it is an inexpensive way of marketing negates the need for true investment in best practice.
(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,

In Australia there is very little funding available for research into less conventional therapies, despite the substantial expenditure by the Australian community on such therapies. We support funding for research in this area in particular for those therapies that are unique to Australia and/or have a high level of consumer interest or use. Given the wide range of complementary and less conventional therapies, funding should generally not be provided for those therapies where there is current research being undertaken in other countries such as the USA. An exception may be where there is a local factor which may have reasonable claim to influencing the outcome of the therapy.

We are aware that NHMRC have recently earmarked some funds for research in this area. We believe any further increases in funding should be as an extension of the overall pool of research funds available rather than simply reallocating existing research funds.

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

As a broad statement it would be reasonable to say that the evidence regarding the efficacy of the vast majority of less conventional therapies is absent. There is some evidence of specific less conventional therapies that appears to show a positive impact and others where evidence shows that the therapy is not effective or poses a serious risk. There is also good evidence that demonstrates a positive psychosocial impact of complementary therapies such as meditation, massage etc.

Despite the lack of evidence of efficacy, a systematic review of 26 studies from 13 countries reported an average prevalence of use of 31% amongst cancer patients. Recent studies have confirmed the popularity of these therapies among Australian cancer patients with 22-52% of medical oncology patients, 40% of those being treated palliatively and 46% of children with cancer reporting use of at least one complementary and alternative therapies.

Many of the most popular therapies are of psychosocial nature and include relaxation, meditation and visual imagery, and hence pose minimal risk to patients’ health. Other popular therapies include dietary therapies, antioxidants, high dose vitamins and minerals and herbal therapies, and have the potential to pose risk to patients’ physical well-being if used by patient groups who are susceptible to reacting adversely to them or because they can interfere with the effectiveness of conventional treatment. It is important to note that in the United States it has been estimated that 70% of people who attend non-medically trained complementary and alternative medicine therapists do not inform their family doctor. An Australian study found 40% of cancer patients using these therapies felt they could not discuss use with their oncologists, possibly due to fear of a negative response.
Ultimately, if patients are going to use complementary and less conventional therapies it is important that they feel they can inform their physicians, so that any interactions or complications with conventional medical treatments can be avoided. Recent Australian clinical practice guidelines highlight the need for oncologists and general practitioners to be aware of the therapies being used or considered by their patients, and to encourage patients to discuss them.

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

One of the key issues for consumers is the lack of easily accessible, comprehensive information on complementary and less conventional therapies that will enable them to make an informed choice. Currently consumers must gather information from fragmented sources many of whom either have a commercial interest in the therapy or on the opposite end of the scale are completely dismissive of any non conventional or complementary therapies. This is compounded by the fact that a number of mainstream clinicians are not receptive to patients undertaking complementary or less conventional therapies so consumers are reticent in asking their clinicians for advice or information.

The provision of comprehensive, credible and consumer accessible information on complementary and alternative therapies would be a positive and legitimate role for Government. This is particularly important as cancer patients and their families may spend large sums of money on such therapies. We suggest that there could be the formation of a special unit (perhaps housed in the proposed Cancer Australia) whose brief it is to gather, condense and disseminate up-to-date comprehensive information on alternative/complementary therapies in a language and format accessible to consumers through multiple media eg publications, a website etc. The information should address at least the following issues:

- The reported therapy and its purported use
- Evidence of effectiveness/efficacy (including psycho-social/quality of life benefits or otherwise) – this could be presented in a consumer friendly scale which would tell the consumer whether there have been any studies; what they have identified (no effect/inconclusive effect/harmful etc.)
- Is it harmful (contraindications/adverse effects/drug interactions etc) – are there particular patient groups that this can be dangerous for; will it interfere with the effectiveness of mainstream treatments etc. Consumers report to us that even in the absence of solid evidence of the effectiveness of a particular complementary or less conventional therapy they would still like to try the therapy (ies) as long as it is not harmful or will not interfere with the effectiveness of their conventional treatment.
- Cost, where it can be accessed and a comparison of this cost to other

There is an important role for the Australian Government in collaboration with the medical colleges, The Cancer Council Australia and consumer groups to release authoritative statements and or guidelines regarding the complementary and less conventional cancer treatments.
The other role that the Government could play would be to encourage, perhaps through the accreditation process, patient access to some complementary therapies within comprehensive cancer centres. The service delivery could be through partnerships with NGO’s for example there is the Brownes Cancer Support Centre at Sir Charles Gardiner Hospital which is run as a separate not-for-profit entity – a similar model could be replicated in other major hospitals providing cancer services. The Cancer Council WA also provides a range of complementary therapies through its cancer support network – this may also be provided as an inreach program into cancer centres or simply accessed through a referral arrangement. The key would be in overcoming clinician resistance and the tool to do this may be through accreditation.

It is also important that Governments actively promote and regulate standards relating to manufacture and quality assurance of products such as vitamins. Governments must also ensure that advertising of complementary therapies does not make excessive claims to prevent exploitation of vulnerable patients and their families.
Comments received from a recently held CONSUMERS FORUM

(a) (iii) differing models and best practice for addressing psycho/social factors in patient care

- A reassessment of priorities with more appreciation of the impact of cancer on self and family matters.
- Good guidance and care the entire time. Being very frail and vulnerable at the time, it was especially valuable. The surgeon kept an eye on my emotional state and when I needed help, referred me for counselling. The counselling in turn helped me to get my priorities sorted. Down the track I went back to counselling to deal with issues that I hadn't dealt with. I did a course in CBT, which benefited me immensely and continues to do so.
- I cannot praise too highly the invaluable support I received from the TCCWA nurse in the hills. She rang and introduced herself shortly after I had paid a visit to Crawford Lodge (to look in the wig library) where I had seen someone from the Helpline who registered me with the TCCWA. When she rang and introduced herself and came around to visit me at home, she was my first real contact with someone I could really talk to about my situation for the first time since I was diagnosed. This nurse became to me the “face” of the TCCWA and the more help and support I received from her and through the TCCWA literature, the more I trusted both.
- A card was given to me after my surgery for a visit to the Specialist Breast Cancer Psychologist at Royal Perth Hospital. I found it absolutely crucial to my wellbeing to be able to talk to her about my anger, fears, depression and how to get on with my life as a cancer survivor. I went to see the psychologist for almost 3 years until I really felt I was OK and I could never have done this if there had been any cost involved. If there had been any cost at all I would have felt I could not justify spending money on something that wasn't actually a life and death essential thing, especially after all the money we had already spent on my surgery and treatment.
- TCCWA phone buddy. The first phone call came out of the blue so I was pleasantly surprised by it. My buddy continued to ring me throughout my treatments and I was able to talk to someone who had gone through the things I had gone through and come out the other end without having to go to a support group. This was especially great for me because I couldn't face support groups as it was just too confronting and as I worked all through my treatments I couldn't take more time off to attend many of the self help type courses that were run during work hours.
Key Points:
- Counselling is of high importance. Helps if it is free.
- Having a support person.
- Alternative support structures as one type doesn’t suit all. Eg support groups, counsellor, phone buddy
- Health professionals can’t solely focus on treatment. They do need to take in consideration the psychosocial factors.
- Community education for patients for example on chemotherapy, radiotherapy. Should be in various forms like written publications and public seminars.

(b) (i) the extent to which less conventional and complementary treatments are researched or are supported by research

- Information should be filtered through a reliable source. eg the Cancer Council/Dept of Health. There is a plethora of unconventional approaches available, advertised in newspapers/magazines etc. There are many charlatans taking advantage of people at a vulnerable time by promising false hope.
- The best ways to get information on alternative/complementary treatments, which were 7 years ago, were the Cancer Support Association Newsletter and naturopathy magazines like Nova. In addition to these now there are many research reports in the Virtual Cancer Centre, The Supporter from the Brownes Centre and CCWA brochures.
- More funding needs to be allocated for studies in this area at reputed research centers in prominent hospitals to have a real impact. This has been an area where a lot of catching up is called for, especially as pharmaceutical companies have also neglected to do so.

Key Points:
- Information from a reliable source. This can be the Cancer Council, Department of Health or an accredited organisation.

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

- I found the TCCWA a terrific one-stop-shop for complementary therapies as is the Brown's Dairy Support Centre at Charles Gairdner. I just didn't feel well enough or have the energy to search out complimentary therapies, wonder if I was getting a good practitioner or if there were other therapies that could help which I didn't know about. I believe they are very important in offering best practice therapies, keeping you up to date with new therapies and making you feel better and more able to cope both physically and mentally. It was really important to me to be able to access all these through the TCCWA, an organisation I could trust.

Key Points:
- One stop shop for enquiries about complimentary therapies was essential.
(iii) the legitimate role of government in the field of less conventional cancer treatment.

- Information needs to be screened by people who understand “good research”. Eg representative test population/potential for bias/minimum required for statistical tests/awareness of risks/comparison of study groups and controls.
- After having had cancer, I believe I would be worried about getting the right information because the medical profession would always advocate conventional treatment and alternative treatments would be advocated by organisations that would stand to benefit by treating you. I would therefore want to have an unbiased view of my particular situation by an independent organisation in order to feel confident about my decision.
- I believe the Government will need to commission more research into alternative treatments so that different treatments undergo a scientific study that will enable a patient to measure the risks and benefits of all types of treatment. Having scientific evidence will also mean that independent organisations will carry information relating to all types of treatments rather than the position now where to be credible, independent organisations find it difficult to suggest non-proven treatments. Having all types of treatments researched can only benefit the patient and there is a possibility in the long run that if some alternative therapies are proven to be effective, this will save lives and millions of dollars.

Key Points:
- National Review Body to determine appropriate and best practice therapies. This would be made up of various stakeholders including consumers and health professionals. Information can be disseminated to various state organisations.
- Government to promote less conventional treatment methods with various Colleges of Health Professions.
- More research into alternative treatments.
- Information on treatments available by a ‘neutral’ organisation.