Australian Government

Department of Health and Ageing

Submission to

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Inquiry into Services and Treatment Options

For Persons with Cancer

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CONTENTS

PART I – OVERVIEW

1.1 CANCER IN AUSTRALIA

Cancer can be a life-threatening disease with a devastating impact on patients, their families and the community. Fighting cancer requires well coordinated measures that tackle prevention, treatment, research and support for cancer patients and their families.

There is scientific knowledge about different cancers, which is rapidly expanding, however not all this knowledge results in optimal treatments. Nevertheless, cancer care is a rapidly changing field with promising new therapies, and emerging new technologies, treatments and effects, potentially extending both life expectancy and the quality of life.

Cancer is a complex and chronic set of diseases with over 100 different tumour sites. Most cancers (more than 85 percent) results from damage to genes in utero and/or after birth by environmental carcinogens (for example, tobacco smoke, asbestos, etc). A minority of cancers result from the inheritance of a damaged gene. Cancer usually presents as a solid growth or tumour, which may spread from its primary site to involve distant organs. Most deaths from cancer result from spread to vital organs like the lungs, liver and brain.

The prognosis and outcomes for cancer patients varies markedly accordingly to tumour type, stage of diagnosis and treatment options. Many people diagnosed with cancer face practical, emotional and psychological demands in addition to their physical treatment. Cancer patients report that their experience of the ‘patient journey’ is important and can be as significant as the outcome. Therefore, there are considerable challenges in providing optimal services and treatment options for all Australians.

Cancer treatment requires highly specialised and coordinated care. Care is delivered across the whole health care environment and the community by a number of health professionals and through varying modes of treatment (e.g. general practice, surgery, chemotherapy and radiotherapy). Sequential treatment and multiple medical appointments means that the cancer patient journey can be a bewildering and difficult experience for people affected by cancer.

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

Increasingly, consumers want to be able to choose how they are involved in the development of their treatment plan, and they want treatment in a multidisciplinary setting. They need treatment that is evidence-based, timely and organised in advance. They also expect evidence-based information to be routinely provided to them and to be provided with good psychosocial support.

1.2 THE BURDEN OF CANCER

Most Australians will be affected by cancer, either directly, or indirectly by being involved with someone who has cancer.

Cancer is a very common experience with one in three men and one in four women directly affected by cancer before the age of 75 years. Cancer is the commonest cause of years of life lost for Australians between the ages of 25 and 64 years – what might be regarded as the prime of life and the most economically important years.

Each year, an estimated 460,000 people are diagnosed with cancer. Approximately 374,000 of these cancers are less threatening types of skin cancer – namely non-melanocytic skin cancer. For other types of cancer, over 88,000 people will be diagnosed and approximately 36,000 people will die per year. Cancer accounts for 31 percent of male deaths and 26 percent of female deaths in Australia per annum. A copy of the Australian Institute of Health and Welfare statistical report *Cancer in Australia 2001* is at **Attachment A**.

Those cancers which represent the highest burden of disease are bowel cancer due to its high incidence and lung cancer due to its high mortality. The highest incidence of cancer in males is prostate cancer and breast cancer for females.

Cancer control is measured by success in prevention, reduction in incidence, increasing survival and improving quality of life. Australia is doing well by international comparisons. Our cancer survival rates are second only to the United States of America with deaths in Australia falling, on average, by 1.9 percent per year during the last decade alone. A copy of the Australian Institute of Health and Welfare report *Cancer Survival in Australia 2001 – Part 1* is at **Attachment B**.

Five-year survival rates are the most telling statistic of the effect of cancer services. In Australia, five-year survival rates for the most common cancers affecting men (prostate) and women (breast) are now more than 80 percent. Cancers with the lowest relative survival in both males and females were cancers of the pancreas (5.4 percent for males and 5.2 percent for females) and lung (11 percent for males and 14 percent for females).

However, this improvement in outcome is not equal across the whole community. Cancer continues to rise, with a disproportionate rate of cancers in disadvantaged groups (for example high rates of lung cancer in low socioeconomic populations) including Aboriginal and Torres Strait Island populations, those in rural and remote areas and for patient with specific tumours.

Recent trends in cancer data indicate that over the last decade from 1990 to 2000, the incidence of cancer has increased by 36 percent compared with a 12 percent increase in population over the same period. Given the ageing of the population and the fact that cancer is mainly a disease of older people, cancer incidence is expected to continue to rise in the future. Such trends will pose an ongoing challenge in the delivery of optimal cancer care.

PART 2 - ROLE OF THE AUSTRALIAN GOVERNMENT

The Australian health system is complex with multiple levels of government and shared responsibility for health care services. Cancer is the responsibility of all governments, non-government organisations and the community. The Australian Government has a national leadership role in delivering outcomes through a wide range of areas including research, policy and program implementation, and building and maintaining partnerships with stakeholders.

The Australian Government's role as a national leader has resulted in well targeted health programs.

The Australian Government and State and Territory Governments jointly fund public hospital services. The Australian Government also has specific administrative responsibility for two major national subsidy schemes, the Medicare Benefits Schedule and the Pharmaceutical Benefits Scheme. These schemes cover all Australians and subsidise patients for the costs of fee-for-service payments for private medical services and for a high proportion of prescription medications.

2.1 HEALTHCARE PROGRAMS

2.1.1 Australian Health Care Agreements

Under the 2003-08 Australian Health Care Agreements, the Australian Government provides substantial financial assistance to the States and Territories as a contribution to the cost of providing public hospital services. In addition, State and Territory Governments provide funds through their own budgets.

Under these arrangements, State and Territory Governments are responsible for ensuring the provision of public hospital services free of charge to public patients on the basis of clinical need and within clinically appropriate times.

From 1998 to 2003, the Australian Government increased its contribution to public hospitals through the Australian Health Care Agreements. The difference in funding between 1997-98 and 2002-03 amounted to a 28 percent increase in real terms. Under the 2003-08 Agreements, the Australian Government will provide funding of up to $42 billion, representing a further $10 billion, and a real increase of 17 percent over the life of the Agreements.

While there are no specific requirements on States and Territories in relation to the delivery of cancer-related services in public hospitals, the availability and quality of such services (both in an in-patient and out-patient setting) is an area of strong interest to the Australian Government and has been identified as a priority area for health reform by health ministers.

2.1.2 The Medicare Benefits Schedule

The Medicare Benefits Schedule is a major part of the national health care system and provides high quality health care that is both affordable and accessible to all Australians.

It ensures that all Australians have access to free or low-cost medical, optometrical and hospital care while being free to choose private health services, and, in special circumstances, allied health services.

Medicare ensures that Australian receive:

- free treatment as a public patient in a public hospital;
- the Medicare rebate, which pays 85 percent * of the schedule fee for a visit to a medical practitioner such as doctors (including specialists) outside hospital, participating optometrists or dentists (specified services only);
- affordable medicines through the Pharmaceutical Benefits Scheme; and
- free or subsidised Pap smears as part of the National Cervical Screening Program

* From 1 January 2005, the Medicare rebate was increased from 85 percent to 100 percent of the schedule fee for GP attendances.

2.1.3 Pharmaceutical Benefits Scheme

The Pharmaceutical Benefits Scheme aims to provide all Medicare eligible persons with access to a comprehensive range of cost-effective prescription medications that are affordable both to the individual and the community.

Drugs may only be added to the Schedule of Pharmaceutical Benefits by the Minister of Health and Ageing if they have been recommended for listing by the Pharmaceutical Benefits Advisory Committee. Under the *National Health Act 1953* the Pharmaceutical Benefits Advisory Committee is required to consider the comparative effectiveness and cost of drugs proposed for listing on the Pharmaceutical Benefit Scheme and may only recommend the listing of a drug that is significantly more costly than the therapy likely to be replaced in practice if for some patients it represents a significant increment in clinical benefit.

All new drug listings with a net annual cost to the Pharmaceutical Benefits Scheme exceeding $10 million per annum are considered by Federal Cabinet before they can be approved by the Minister for listing on the Scheme.

While the Pharmaceutical Benefits Scheme operates primarily through reimbursement to community pharmacies, it also provides access to certain high cost drugs, such as immunosuppressants used in transplantation.

In 2003/2004 direct Pharmaceutical Benefits Scheme expenditure on oncology medications amounted to $412.3M (7.3 percent of PBS expenditure), with a further $173.3M of indirect expenditure (includes drugs used for bone pain associated with malignancy, and for laxatives and analgesics, a significant proportion of which are used in the management of cancer patients). These figures do not include expenditure under the recently instituted Palliative Care Medications Program.

A number of States utilise cancer chemotherapy subsidised as pharmaceutical benefits by virtue of reform arrangements agreed to in the Australian Health Care Agreements for instance, Victoria and Queensland utilise specific arrangements developed with specialist hospital oncologists to provide cancer chemotherapy to public hospital day admitted and non-admitted patients. Other States and Territories are evaluating the Australian Government offer that includes enhanced subsidy for cancer chemotherapy. This funding provides access to high cost cancer chemotherapy drugs via administratively simple arrangements. The cost of cancer chemotherapy over the last decade has grown significantly on a per capita basis as the newer treatment protocols have developed using multi-drug therapies that aggressively treat the cancer early after diagnosis.

Outside the Pharmaceutical Benefits Scheme, the Herceptin Program, established in December 2001 and administered by the Health Insurance Commission, subsidises the cost of Herceptin for certain patients with metastatic breast cancer who have hormone receptor positive disease. Estimated expenditure in 2004-2005 is $32.7m.

2.1.4 Private Health Insurance: Hospital and Ancillary Care

Cancer patients may be treated for all or part of their therapy in the private sector. Private health insurance is structured to pay benefits for services provided either “in-hospital – admitted services” (known as hospital tables or applicable benefits arrangements) or “out-of-hospital – non-admitted services” (ancillary health benefits).

The payment of benefits from hospital tables is extensively regulated. Health funds are required to offer a product that covers all episodes of hospital treatment, and to have a “no gap” or “known gap” product. Hospital products must also include cover for palliative care, rehabilitation and psychiatric services. The Australian Government pays 75 percent of the Medicare Benefits Schedule fee for admitted patient services. Health funds pay the remaining 25 percent, and can pay more if there is a gap cover arrangement in place.

Privately insured patients will incur out-of-pocket costs for services provided on an out-of-hospital basis. Health funds are prohibited from paying benefits for out-of-hospital services where those services attract a Medicare benefit. Ancillary benefits are only payable for services that do not attract a Medicare benefit, such as physiotherapy.

Decisions about whether certain services are provided on an in-hospital or out-of-hospital basis, along with the level of cover provided by their hospital product, will determine the out-of-pocket costs for privately insured patients.

Private health insurance will cover most or all of the in-hospital services provided to a privately insured person, depending upon the level of cover provided by the particular hospital product. These services may be surgical or other aspects of cancer treatment, such as chemotherapy, as long as they are provided on an in-hospital basis.

Health funds are less regulated in relation to ancillary health benefits. They may pay ancillary benefits for as many allied health services as they choose. These benefits are usually capped at a dollar figure per service and/or a total annual dollar figure. The main restriction is that benefits cannot be paid for out-of-hospital services for which a Medicare benefit is payable, eg. general practice services.

2.2 CANCER INITIATIVES

The Australian Government has a diverse array of initiatives in cancer care and control covering the continuum of care from prevention to detection to treatment to palliative care, as well as targeting specific groups, such as indigenous people and Australians living in regional and remote areas.

2.2.1 Governance arrangements and policy advisory structures

Cancer was established as a National Health Priority Area in 1996. Eight priority cancers where significant health gains can be made through prevention, early detection and evidence-based management, were identified by all governments. These are breast cancer, cervical cancer, bowel cancer, lung cancer, melanoma, non-Hodgkins lymphoma, non-melanocytic skin cancer and prostate cancer.

National Cancer Strategies Group

The National Cancer Strategies Group was established in 1998 to provide expert advice to the Australian Government on prevention, detection, treatment and management of cancer in Australia.

The role of the National Cancer Strategies Group is to pursue strategies to improve the prevention, detection, treatment and management of cancer in Australia. Membership of the National Cancer Strategies Group includes clinicians, consumers, epidemiologists, rural general practitioners, peak cancer bodies, and Australian Government, State and Aboriginal and Torres Strait Islander representatives. The National Cancer Strategies Group was responsible for the first national cancer control plan in Australia, *Priorities for Action in Cancer Control 2001-2003* (see **Attachment C**).

The National Cancer Strategies Group is under the auspices of the National Health Priority Action Council. The National Health Priority Action Council is a sub committee of the Australian Health Ministers' Advisory Council. The National Health Priority Action Council is chaired by the Australian Government's Chief Medical Officer, and comprises representatives from each jurisdiction, as well as a consumer representative and an Aboriginal and Torres Strait Islander representative. The National Health Priority Action Council's purpose is to drive health service improvements to achieve better health outcomes for all Australians, including disadvantaged groups, for the national health priority chronic conditions.

The Australian Screening Advisory Committee

The Australian Government established the Australian Screening Advisory Committee in 2004. It is chaired by the Australian Government's Chief Medical Officer. The Committee's purpose is to provide expert advice to the Australian Health Ministers' Advisory Council and the Minister for Health and Ageing on screening issues.

To assist the Committee to achieve its objectives, a number of Working Groups have been established to develop and implement priorities for screening programs and issues. These are the:

- Aboriginal and Torres Strait Islander Women's Forum
- Policy Review and New Technologies Working Group
- Monitoring and Evaluation Working Group
- Communication and Education Working Group
- Quality Improvement and Workforce Working Group

2.2.2 National Service Improvement Framework for Cancer

In 2002, the Australian Health Ministers' Advisory Council agreed to the development of National Service Improvement Frameworks for the national health priority chronic conditions of cancer, diabetes, asthma, cardiovascular disease and stroke, and arthritis and musculoskeletal conditions, under the auspices of the National Health Priority Action Council. The Frameworks are joint initiatives of the Australian and State and Territory Governments.

The National Service Improvement Frameworks will be an integral component of a proposed National Chronic Disease Strategy, being developed by the National Health Priority Action Council under the health reform agenda.

The cancer Framework is the first developed and draws on existing international and national plans including the United Kingdom's National Cancer Plan and Australia's cancer plans and policies, including States and Territories. It also draws on a number of other recent documents developed including *Optimising Cancer Care in Australia* (see **Attachment D)**, the *Priority Actions for Cancer Control,* and the report of the Radiation Oncology Inquiry among others.

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

2.2.3 Strengthening Cancer Care

The Australian Government has committed a further $137.1 million over the next four years through its *Strengthening Cancer Care* Initiative. The Initiative has drawn from the *National Service Improvement Framework for cancer* and is targeted at ensuring better coordination of the national cancer effort, more research funding for cancer care, enhanced cancer prevention and screening programs, and better support and treatment for those living with cancer. A copy of the *Strengthening Cancer Care* policy document is at **Attachment F.**

2.2.4 National Breast Cancer Centre and National Cancer Control Initiative

The Australian Government manages several components of its cancer control program through two outsourced organisations, the National Breast Cancer Centre and the National Cancer Control Initiative.

National Breast Cancer Centre

The National Breast Cancer Centre is Australia's peak body for breast and ovarian cancer control. It was established in 1995 following the House of Representatives Inquiry into the Management and Treatment of Breast Cancer. The Australian Government provides funding of $2.85 million per year to the Centre. A copy of the National Breast Cancer Centre's Annual Report 2003-2004 is at **Attachment G**.

The National Breast Cancer Centre is recognised as a world-leading organisation in breast cancer control, fostering an evidence-based approach to the diagnosis, treatment and support of women with, or at risk of, breast cancer.

The objectives of the National Breast Cancer Centre are to:

- provide accurate information about risk factors and appropriate services for high-risk women;
- ensure that all women with breast and ovarian cancer are diagnosed as early as possible;
- ensure that all women with breast and ovarian cancer receive optimal care ; and
- ensure that all women diagnosed with breast and ovarian cancer and their families receive adequate psychosocial, physical and practical support.

The Centre has been active a number of areas, publishing over 20 sets of guidelines and recommendations for specialists and general practitioners across all aspects of breast cancer. Many resources addressing familial aspects of breast cancer, early detection, treatment and supportive care have been published for women and their families.

The National Breast Cancer Centre has trialled innovative approaches to improving care and changing policy and practice including those relating to specialist breast nurses, multidisciplinary care, audit and feedback and programs for remote practitioners.

One of the real successes of the National Breast Cancer Centre has been the introduction of communication skills training for health professionals, with improved communication skills improving the doctor-patient relationship.

The National Breast Cancer Centre has also played an important role in improving the monitoring of breast cancer control in Australia, with consistent national approaches to measuring key aspects of breast cancer control including tumour size and interval cancers. The five year survival rate for breast cancer during the period 1992-97 was 84 percent and the mortality rate declined by an average of 2.2 percent per year from 1991-2001.

In 2001 the Government expanded the remit of the National Breast Cancer Centre to include ovarian cancer. The Centre works with women, health professionals, cancer organisations, researchers and governments to reduce the number of Australian women who die from breast and ovarian cancer.

National Cancer Control Initiative
The National Cancer Control Initiative was established in 1997. The Australian Government has a funding agreement with The Cancer Council Australia for the operation of the National Cancer Control Initiative. A copy of the National Cancer Control Initiative – 1997-2002 Report is at **Attachment H.**

The National Cancer Control Initiative is a key expert reference body that provides timely advice on all issues relating to cancer control (defined as all actions that reduce the burden of cancer in the community). This encompasses the continuum of care including prevention, early detection, treatment and palliative care. The National Cancer Control Initiative provides horizon scanning advice to Government about evidence for new therapeutic options in cancer control, including treatment modalities, medications and diagnostic tests. It identifies appropriate initiatives and makes specific recommendations to the Australian Government, all supported by the best scientific evidence available and regular monitoring of cancer control outcomes.

Projects managed by the National Cancer Control Initiative are designed to demonstrate and foster evidence-based, cost-effective practices in cancer control and to have national relevance. The National Cancer Control Initiative projects involve strategic partnerships with government, cancer councils, health care professionals and consumers and recent activities have included:

- development of clinical practice guidelines (including colorectal cancer, the psychosocial care of adults with cancer and prostate cancer);
- production of a national database of cancer control initiatives;
- collection and analysis of cancer data including the development of a national clinical cancer core data set and the assessment of the feasibility of collecting cancer staging data;
- auspicing the national non-melanoma skin cancer survey;
- auspicing a randomised trial to encourage appropriate removal of pigmented skin cancer lesions;
- involvement in international reviews of cancer control;
- a survey of cancer researchers in Australia; and

- auspicing a national lung cancer workshop and prostate cancer informed decision-making workshop.

2.3 INTERNATIONAL CANCER ACTIVITIES

The Australian Government operates very much in an international environment, looking to the experiences of other countries and the work of international organisations to inform domestic policy on cancer prevention, control, treatments and care.

International Agency for Research on Cancer
Established in 1965 as an arm of the World Health Organisation, and located in Lyon, France, the International Agency for Research on Cancer's principal objective is to promote international collaboration in cancer research. Drawing on the work and resources of its 16 member states (of which Australia is one), the International Agency for Research on Cancer conducts focused research on cancer aetiology and prevention, providing evidence on global cancer prevalence and incidence, the causes of cancer and mechanisms of carcinogenesis, and the most effective strategies for cancer prevention and early detection. Australia became a member in 1965, and contributes $A1.5 million a year with representation on the Governing and Scientific Councils.

The Agency's emphasis on encouraging and facilitating international collaborations, provides opportunities for Australian scientists to participate in international research programs and for young Australian cancer researchers to gain post-doctoral experience in an international setting. There is a long history of researchers returning to Australia, having participated in the International Agency for Research on Cancer fellowship program, with improved scientific training and networks that lead to increased Australian cancer research capacity.

The Monographs Program on the Evaluation of Carcinogenic Risks to Humans assesses the risk of exposure to various chemicals and provides internationally recognised evidence for the regulation of carcinogenic exposures, including in Australia. Membership of International Agency for Research on Cancer enables our involvement in all aspects of the assessment process, including selection of the agents to be reviewed, membership of the expert review committees and provides early knowledge of the findings.

Australian case-control studies have benefited from International Agency for Research on Cancer's role in developing international standard protocols and questionnaires to enable data to be pooled for increased statistical power and permit less common exposures to be evaluated. Examples include international collaborative case-control studies of childhood and adult brain tumours, pancreatic tumours, and risk exposures associated with mobile phone use.

In the same vein, the International Agency for Research on Cancer is useful to Australian researchers in facilitating new approaches to cancer research designs and protocols by bringing together Australian scientists with other international experts. An example is the development of protocols for cancer case-control family studies.

World Health Organisation

The World Health Organisation's cancer control program promotes policy and program development, globally and in member states, focusing on:
- promotion and strengthening of comprehensive national cancer control programs;
- building international networks and partnerships for cancer control;

- promotion of organised, evidence-based interventions for early detection of cervical and breast cancer;
- development of guidelines on disease and program management;
- advocacy for a rational approach to effective treatments for potentially curable tumours; and
- support for low-cost responses to global needs for pain relief and palliative care.

Australia contributes to that work through its contribution of funds, as a member of World Health Organisation-sponsored international networks, and by the provision of data and policy information.

As a member of the World Health Organisation Executive Board, representing the Western Pacific region, Australia has co-sponsored a resolution on the need to increase the priority of cancer prevention and control by member states and the World Health Organisation. The resolution will be considered by the World Health Organisation's 192 member States at the World Health Assembly in May 2005.

Organisation for Economic Cooperation and Development
The Organisation for Economic Cooperation and Development has significantly increased its policy research on health. Australia was a major stakeholder in a three-year study to measure and analyse the performance of health systems. The study report was presented to Health Ministers in May 2004, who agreed on an on-going program of work on health.

The Australian Government is urging the Organisation for Economic Cooperation and Development, as part of that on-going program, to improve its health expenditure data and to undertake analytical projects to improve the capacity of health care systems, including in relation to cancer prevention, treatment and palliative care.

PART 3 – ROLE OF THE AUSTRALIAN GOVERNMENT IN OPTIMAL CANCER CARE

Australia is doing well in relation to both survival and quality indicators however, improvements could be made by systematically implementing best practice treatments for people with cancer from the time of diagnosis. Cancer is potentially one of the most preventable and treatable of today's common causes of death.

3.1 REDUCE THE RISK OF CANCER

The risk of developing some cancers can be reduced by modification of lifestyle or the environment. It is not yet known what causes some cancers. For others, the factors that are known to increase risk cannot be changed (e.g. genetic inheritance).

Research over the past 40 years has identified opportunities to reduce the risk of cancer in the following areas:

- Reduce smoking
- Limit alcohol intake
- Increase protection of skin from the sun
- Improving diet mainly by increasing the intake of fruit and vegetables
- Reduction in rates of overweight and obesity
- Increased physical activity
- Increased rates of safe sex
- Understanding familial risk

3.1.1 Population health programs

The Australian Government recognises the importance of reducing the risk of cancer and is engaged with the following cancer prevention activities.

Tobacco Control

The Government is actively pursing a range of strategies through the *Australian National Tobacco Strategy 2004-2009*, to discourage people from taking up smoking and to encourage those people who already smoke to stop. A new five-year National Tobacco Strategy was endorsed by the Ministerial Council on Drugs Strategy in 2004. The directional approach of the new *National Tobacco Strategy 2004-2009* builds on existing tobacco control efforts and achievements by State and Territory Governments and the Australian Government, and is further enhanced by research into effective international tobacco control strategies.

The Strategy highlights the need for a comprehensive and multifaceted approach and a national collaborative effort to improve the health of all Australians by eliminating or reducing their exposure in all its forms. These measures include ratification and implementation of the provisions of the World Health Organisation's Framework Convention on Tobacco Control; implementation of a program aimed at helping women to stop smoking during and after pregnancy; commissioning of a project to better understand the role of youth interventions in overall tobacco control strategies; a national review of smoking related issues for Aboriginal and Torres Strait Islander people; development and introduction of new graphic health warnings for all tobacco products; deregulation of nicotine replacement therapies; and providing guidelines to GPs to assist them in helping their patients to quit smoking.

Public health measures already in place such as the National QuitLine network; pricing measures; labelling tobacco products with health warnings; banning most forms of tobacco advertising, promotion and sponsorship; and education programs and campaigns have proven effective in reducing tobacco use in Australia.

Protection of skin from the sun

Each year, approximately 374,000 non-melanoma skin cancers (a less threatening form of skin cancer) and around 8,000 melanoma cases are diagnosed. Sun protection will help prevent skin cancer.

The Australian Government recognises that skin cancer has a major impact on the health of our community. Both melanoma and non-melanoma skin cancer are two of the eight priority cancers identified in the National Health Priority Area initiative.

As part of the recent *Strengthening Cancer Care* Initiative, the Australian Government in conjunction with the States and Territories will invest $5 million over three years towards skin cancer prevention campaigns commencing in 2005-06. A national survey on sun protective behaviours undertaken during over the summer of 2003-04 will assist in the development of the campaigns.

Healthy eating and active living

The national strategy, *Eat Well Australia: An Agenda for Action for Public Health Nutrition 2000–2010*, was developed by the National Public Health Partnership in recognition of the vital role food and nutrition play in the health and wellbeing of all people. *'Eat Well Australia'* includes a separate action plan for Aboriginal and Torres Strait Islander nutrition.

The strategy focuses on:

- increasing the consumption of vegetables and fruit;
- promoting healthy weight;
- promoting good nutrition for women and children; and
- promoting good nutrition for vulnerable and disadvantaged groups.

The National Health and Medical Research Council has developed dietary guidelines targeting children and adolescents, adults and older Australians.

In 2004, the Australian Government made a commitment to the *Building a Healthy, Active Australia* initiative which provides $116 million over four years, to address childhood obesity through the provision of information to families on how to make healthy eating and physical activity part of their daily lives, the establishment of physical activity programs in after school care facilities, and through grants to schools to initiate activities to promote healthy eating.

In 2004, Australian Health Ministers endorsed a range of childhood obesity initiatives. These initiatives are consistent with State and Territory plans and activities already underway. The package includes New Physical Activity recommendations for children and youth; Physical Activity guidelines for adults; a schools resource kit to promote healthy eating and physical activity in Australian schools; a national information program to promote increased consumption of fruit and vegetables; the promotion of Healthy School Canteens to ensure that canteens provide children with healthy eating choices and a review of the evidence for actions to reduce obesity in adults and older Australians.

3.2 FIND CANCER EARLY

Some cancers can be detected early using inexpensive and simple tests. Mortality can be reduced with treatments that can be more effectively applied after early detection. However, not all cancers can be detected early enough, or simply, or inexpensively and some cannot be treated effectively after detection. The challenge is to decide when it is appropriate and cost-effective to screen entire populations. For most cancers, there is simply not enough information or tools available to set up a new screening program.

The Australian Government uses World Health Organisation principles to assist in determining whether there is sufficient evidence to warrant the consideration of organised, population based screening program.

In summary, the World Health Organisation principles specify that population screening should only be considered where:

- the condition is an important health problem;
- there is a recognisable latent or early symptomatic stage;
- the natural history of the condition, including the development from latent to declared disease, is adequately understood;
- there is an accepted treatment for patients with recognised disease;
- there is a suitable test or examination (i.e. for screening purposes);
- the test is acceptable to the population;
- there is an agreed policy on whom to treat as patients;
- the cost of case finding (including diagnosis and treatment of patients diagnosed) should be economically balanced in relation to possible expenditure on medical care as a whole; and
- case finding is a continuing, and not a ‘once and for all’ project.

Before the Australian Government can consider national population screening, there must be clear indications about:

- who and when to screen;
- the likely uptake of screening;
- the most appropriate test procedures;
- program organisation, including registration and recall of people who have been screened for follow up treatment of screen-detected disease; and
- quality assurance throughout the screening pathway.

Population screening is the systematic application of a suitable screening test, to identify individuals at risk of a specific condition/disorder to warrant direct preventive action. It is undertaken amongst asymptomatic individuals. Importantly, population screening is an organised process that involves call and recall of the population to regular screening, as an aid to early detection and appropriate follow up of people requiring further treatment. As such, population screening differs significantly from dealing with symptomatic patients.

Since new information and evidence about the causes of cancer emerge daily, dedicated research and optimal horizon scanning is needed to ensure that Australia remains at the forefront of cancer screening and detection.

3.2.1 Population screening programs

Australia's population-based breast cancer and cervical screening programs, BreastScreen Australia and the National Cervical Screening Program, have been in operation since 1991. A pilot is currently underway to examine the acceptability, feasibility and cost effectiveness of bowel cancer screening in Australia.

Breast cancer screening

There is evidence from randomised control trials that mammography screening reduces deaths from breast cancer at least among women 50-69 years. The objective of BreastScreen Australia is to decrease mortality and morbidity from breast cancer through detection of small early stage invasive cancers. Early detection allows for less invasive treatment and increased survival rates.

BreastScreen Australia targets asymptomatic women aged 50-69 years but women aged 40-49 years and over 70 years are also eligible to attend. Screening and assessment services provide free biennial screening mammograms and follow-up to the point of histopathological diagnosis. Multidisciplinary assessment teams are a key component of the program.

BreastScreen Australia is cost shared between the Australian Government and State and Territory Governments. The Australian Government contribution is provided through the Public Health Outcome Funding Agreements. States and Territories are expected to implement BreastScreen Australia services consistent with national policies and in the most appropriate way to meet local needs. Each jurisdiction provides a different context for service delivery, through variables such as demographics, distance, and infrastructure. In addition, a national (and world-wide) shortage of radiographers and radiologists is a constant challenge to service provision. A copy of the *Breastscreen Australia – Monitoring Report 2001-2002* is at **Attachment I**.

Cervical screening
The National Cervical Screening Program is a joint initiative of all Australian Governments. The objective of the National Cervical Cancer Screening Program is to reduce morbidity and deaths from cervical cancer, in a cost-effective manner through an organised approach to screening.

The program policy states that routine screening with Pap smears should be carried out every two years for women between the ages of 18 (or two years after first sexual intercourse) and 69 years.

Other aspects of the National Cervical Screening Program, including the Pap Test Registers and health promotion activities, are cost-shared between the Australian Government and State and Territory Governments. The Australian Government contribution is provided through the Public Health Outcome Funding Agreements.

As part of the 2004 election policy, *Investing in Stronger Region*s, the Government committed $10.5 million over four years to provide more practice nurses in rural areas to undertake a wider range of procedures, including Pap smears.

The 2001 Federal Budget provided $71.9 million in incentives to general practice to improve the screening rates for cervical cancer and target higher risk women. A copy of *Cervical Screen in Australia 2001-2002* is at **Attachment J**.

Bowel Cancer Screening
In the 2000-01 Federal Budget, the Australian Government announced an investment of $7.2 million over four years to conduct a Bowel Cancer Screening Pilot program (the Pilot).

The Australian Government reaffirmed its commitment to reducing the impact of bowel cancer by providing a further $7.4 million over 4 years to continue work commenced in the Bowel Cancer Screening Pilot, including supporting people who may not have fully completed the screening pathway.

The primary aim of the Pilot was to provide information about the feasibility, acceptability and cost effectiveness of Faecal Occult Blood Test screening amongst the Australian population in both rural and urban areas. The final evaluation of the Pilot is nearing completion and will inform decisions about the introduction of a national bowel cancer screening program.

The Pilot invited 56,907 people to participate in bowel cancer screening between 2002 and 2004. As at the end of 2004, the overall estimated participation rate was 45.9 percent. There were 67 suspected cancer cases and 259 confirmed advanced adenomas among the 1,273 participants that had a record of a colonoscopy or pathology results for polyps.

3.3 EVIDENCE-BASED TREATMENT

The Australian Government has a commitment to the application of evidence-based treatment in cancer care. Cancer patients expect and should be confident that they will receive care that delivers a known benefit. Given the life-threatening nature of cancer, patients are always hopeful of a cure and it is important that false expectations are not given and that the treatment regimens are in accord with best practice and scientific knowledge.

Clinical practice guidelines are summaries of evidence and are often a first step in encouraging evidence based practice. There is considerable research demonstrating that evidence-based clinical practice guidelines are effective in improving the quality of clinical practice and the outcomes of care for people with cancer.

Clinical practice guidelines are used at the service level to develop protocols about the delivery of care. The audit of practice against local protocols and clinical practice guidelines assists services in understanding where care could be strengthened. The establishment of strategies to modify practice can be developed from this information.

In Australia, substantial effort has been directed at the development of clinical practice guidelines for cancer and guidelines are available, or will soon be, for most of the priority cancers including:

- Early breast cancer (National Health and Medical Research Council endorsed)
- Advanced breast cancer (National Health and Medical Research Council endorsed)
- Skin cancer and melanoma (National Health and Medical Research Council endorsed)
- Non-melanoma skin cancer (National Health and Medical Research Council endorsed)
- Bowel cancer (National Health and Medical Research Council endorsed)
- Prostate cancer (National Health and Medical Research Council endorsed)
- Familial aspects of cancer

Guidelines for the psychosocial care of people with cancer have also been endorsed by the National Health and Medical Research Council.

Guidelines for non-Hodgkin's lymphoma, lung and ovarian cancer are under development.

Consumer guides have been developed for several cancers to provide evidence based information for people with cancer in parallel to the clinical practice guidelines.

The consumer guides include evidence about treatment effectiveness. The guides appear to be judged by people with cancer as very useful. Among people with early breast cancer, between 66 percent and 90 percent report receiving a copy of the consumer guides.

3.3.1 Complementary therapies

It is recognised that many cancer patients use complementary and alternative therapies regularly.

The practice of complementary medicine may be broadly divided into 'complementary therapies' and the use of 'complementary medicines'.

'Complementary therapies' include a diverse group of health-related therapies and disciplines that are not considered to be a part of mainstream medical care in Australia. These may or may not include the use of complementary medicines. A literature review conducted by the Cancer Institute NSW focusing on complementary therapies used by people with cancer is at **Attachment K**. The literature review also provides details of appropriate website links.

'Complementary medicines' include herbal medicines, vitamin and mineral supplements, other nutritional supplements, traditional medicines such as Ayurvedic medicines and traditional Chinese medicines, homoeopathic medicines, and aromatherapy oils.

In Australia, there is a substantial gap between the extensive use of complementary medicines and the evidence to support that use. For various reasons, there is relatively little research undertaken in Australia to support the use of complementary medicines. There is however a substantial body of overseas clinical research into complementary medicine. In 2003, The Cochrane Controlled Trials Register recorded 641 clinical trials of acupuncture, 666 of herbal medicine, and 124 of homoeopathy. The field of application of complementary medicine is very diverse, and many complementary medicine trials are criticised as being methodologically weak.

Complementary Treatment

The regulation of complementary therapies provided by healthcare practitioners is not addressed in any Federal legislation. Accordingly, the Australian Government has no direct power or authority over the way in which health practitioners conduct their professional practice.

In its recent response to the recommendations of the Expert Committee on Complementary Medicines in the Health System, the Australian Government has noted a number of recommendations aimed at ensuring that providers of complementary healthcare therapies meet minimum standards of training, accreditation and practice under uniform registration programs where appropriate. The Australian Government has noted that these are State and Territory responsibilities and proposes, through the Health Ministers' Conference, to bring these matters to the attention of State and Territory Governments.

Regulation of complementary medicines

Complementary medicines are regulated under the *Therapeutic Goods Act 1989* (the Act), which is administered by the Therapeutic Goods Administration.

The Act aims to provide a national framework for the regulation of therapeutic goods in Australia and to ensure their quality, safety and efficacy. Under the Act, 'complementary medicines' that make therapeutic claims are regulated as therapeutic goods.

Australia has a risk-based system where the level of evaluation and regulatory control of a therapeutic good is based on the relative safety of the product and the seriousness of the condition for which it is intended to be used.

Generally, therapeutic goods must be either Listed or Registered in the Australian Register of Therapeutic Goods before they can be supplied in Australia. Before a product can be included in the Australian Register of Therapeutic Goods, a sponsor is required to submit an application to the Therapeutic Goods Administration, together with relevant supporting data. The Therapeutic Goods Administration is unable to compel a sponsor to submit an application if it chooses not to do so.

Whether a product is Listed or Registered in the Australian Register of Therapeutic Goods depends primarily on three matters:

a) the ingredients;
b) the dosage form of the product; and
c) the promotional or therapeutic claims made for the product.

Registered medicines are assessed as having a higher level of risk, and are subjected to a high level of scrutiny. They are individually assessed by the Therapeutic Goods Administration for quality, safety and efficacy prior to market entry.

Listed medicines are lower risk than Registered medicines and may only contain ingredients approved by the Therapeutic Goods Administration as being of low risk. Most, but not all, complementary medicines are Listed medicines.

Although Listed medicines are required to meet certain criteria in relation to safety and quality manufacture, the Therapeutic Goods Administration does not evaluate their efficacy prior to market approval. Therefore, they may not refer to serious forms of disease, disorders or conditions and, generally, must not indicate that they are for the treatment, cure, management or prevention of any disease, disorder or condition. However, sponsors of such medicines are required to hold evidence to support the claims made for their product and to make such evidence available to the Therapeutic Goods Administration if requested.

Indications/claims related to neoplastic diseases (cancers) may only be made after evaluation of the product (and the claims) through Registration of the product. Therefore, claims related to cancer may not be made for Listed medicines.

There are currently no complementary medicines Registered for indications/claims related to cancer. Therefore, the Therapeutic Goods Administration is not able to comment on the efficacy of any complementary medicines as primary treatments or as adjuvant/complementary therapies in cancer, as no efficacy data has been submitted by a complementary medicine sponsor for evaluation by the Therapeutic Goods Administration.

However, it should be noted that certain medicines do not need to be included in the Australian Register of Therapeutic Goods. This includes medicines that are dispensed, or extemporaneously compounded, for a particular person for therapeutic application to that person. This allows complementary healthcare practitioners, such as herbalists, naturopaths, and traditional Chinese medicine practitioners, to prepare medicines for individual patients that do not need to be assessed or evaluated by the Therapeutic Goods Administration for quality, safety or efficacy. The regulation of extemporaneously compounded medicines is the responsibility of State and Territory Governments.

In response to the recommendations of the Expert Committee on Complementary Medicines in the Health System, the Government has accepted the recommendation that the Therapeutic Goods Administration, in collaboration with its New Zealand counterparts, undertake a review of the regulation of raw herbs and other starting materials for the manufacture, dispensing or extemporaneous compounding of medicines to ensure that they meet appropriate standards of quality and safety.

3.4 CANCER CARE

The treatment of cancer depends upon the type of cancer and its spread at diagnosis and upon the patients needs and wishes. There are many different disciplines involved in the treatment and support of people with cancer. For many people with cancer, surgery will be the first step in treatment. This may be followed by combinations of radiotherapy, chemotherapy and other treatments and it can often be a bewildering journey for cancer patients, their families and carers.

When treatment practices are compared with evidence-based guidelines or practice in other similar countries, people with cancer in Australia are usually found to be receiving high quality treatment. Opportunities to improve treatment and support for people with cancer lie mainly in modifying the ways in which cancer care is organised and services delivered.

3.4.1 Multidisciplinary care

Optimal cancer care depends in part on the pathway of treatment. There is evidence that referral mechanisms from primary care to specialist services and between specialists, are critical to survival and quality of life.

There is evidence from overseas studies that survival is improved when treatment is provided by experts working together as a team rather than by individual clinicians seeing people with cancer sequentially. In a multidisciplinary approach to care, the treatment options and plans are considered by the team often including specialists with all of the relevant expertise. The core treatment team includes but is not limited to surgery, medical oncology, radiation oncology, pathology, radiology, nursing and supportive care.

There is also evidence that treatment recommendations made by a multidisciplinary panel are more in accord with the evidence than those by individual doctors. A recent from the United Kingdom found that multidisciplinary care improved: survival; recruitment of people with cancer into clinical trials; personal satisfaction; and mental well-being of team members.

Multidisciplinary approaches to the treatment of cancer are recommended in Australian clinical practice guidelines. The Australian Government funded the National Breast Cancer Centre to undertake substantial work in the area of multidisciplinary care. In 1999, the Australian Government contracted the National Breast Cancer Centre to undertake a trial of multidisciplinary models in a number of treatment centres following the 1996 report titled *Investigation of Multidisciplinary teams for the management of breast cancer.*

The National Multidisciplinary Care Project involved the establishment of three demonstration sites and was conducted over the period 1999 to 2003. The goals of this project were:

- Trialling international best practice in multidisciplinary care in breast cancer and enabling the development of standards for multidisciplinary care in the Australian context;
- Providing information about costs, acceptability, feasibility and impact on local patterns of care of this approach to multidisciplinary care; and
- Providing an analysis of policy and funding implications of the introduction of multidisciplinary care for breast cancer nationally.

The project found that while most clinicians recognised the desirability of multidisciplinary care, a large minority of services did not offer multidisciplinary treatment planning. The trial identified particular barriers related to communication with rural and regional specialists and general practitioners and the inadequacy of infrastructure resources, both human and technological to overcome these barriers.

The project also showed that most specialist clinicians treating women with breast cancer are aware of evidence based guidelines and that compliance is high. However, improvements in the provision of psychosocial support and information about treatment options involving the full range of therapies were demonstrated following implementation of the multidisciplinary care strategies. A copy of *Multidisciplinary Care in Australia: a National Demonstration Project in Breast Cancer* is at **Attachment L**.

A follow-up study focusing on the sustainability of multidisciplinary care has recently been completed by the National Breast Cancer Centre. A copy of *Sustainability of Multidisciplinary Cancer Care – A follow-up study to the national Multidisciplinary Care Demonstration Project* is at **Attachment M**.

The study found the factors that contributed to the sustainability of multidisciplinary care include:

- the allocation of funds and personnel to maintain, support and improve multidisciplinary strategies;
- ensuring multidisciplinary case conference meetings are held routinely;
- enlisting a ‘champion’, usually a well respected clinical opinion leader, to drive the multidisciplinary care strategies.

The National Breast Cancer Centre is now developing a practical guide for health service providers about establishing, preparing and supporting multidisciplinary meetings for breast cancer care. The final guide will be released following external review in early to mid 2005.

3.4.2 Care coordination

A common complaint of patients and people with cancer in Australia, is the apparent lack of continuity of care across treatment modalities and the private and public sector.

In one survey undertaken in 2001, women with breast cancer reported that they saw a different doctor every time they visit the hospital and that they did not clearly understand the various roles and responsibilities of those in the treatment team. However, a 2003 report of a national consumer survey of women with early breast cancer found that 94 percent of women said they understood who was coordinating their care, although 42 percent said that they would have liked to have had access to one main contact person. This study also reported that about one in five women reported access to a specialist breast nurse.

There is evidence from international studies that some strategies improve continuity of care. For example, specialist breast cancer nurses have been found to effectively function as coordinators of care and to improve continuity of care.

The *National Service Improvement Framework for cancer* developed and auspiced by the Australian Government supports the development of systems to improve the coordination of care for people with cancer including defined referral pathways and designated coordinators of care.

The *NSW Cancer Plan 2004-06* (see **Attachment N**) has also identified care coordination as a pivotal role to facilitate the optimal sequence and timeliness of care. The Cancer Institute NSW is establishing a Cancer Nurse Coordinators Program. Similarly, *The Cancer Services Framework for Victoria* (see **Attachment O**) indicates that specific care coordinators are needed to improve the efficiency of cancer care and recommends the need for multidisciplinary coordinated care, with care coordinators in individual institutions or localities.

3.4.3 Access to radiation oncology

Radiation oncology is one of the three main treatments for cancer, along with surgery and chemotherapy. It involves the use of ionising radiation (eg, from x-rays, electron beams or gamma rays) to kill tumour cells. It is used as both a curative and palliative treatment. A course of treatment can involve treatment, five days a week, for up to six weeks. It requires large teams of staff and expensive equipment costing up to $10 million for a typical facility.

The New South Wales Collaboration for Cancer Outcomes Research and Evaluation estimated that 52.3 percent of people newly diagnosed with cancer should have radiation oncology treatment. This estimate was based on a comprehensive evidence based review by The New South Wales Collaboration for Cancer Outcomes Research and Evaluation, and is widely accepted.

Radiation Oncology Inquiry
In 2001, an Inquiry into Radiation Oncology was initiated by the Australian Government in response to a growing concern regarding the capacity of the radiotherapy sector to provide radiation therapy to those cancer patients requiring it for treatment or palliative care. Previous reviews had highlighted particular shortages of workforce professionals (radiation therapists, medical physicists and radiation oncologists) and equipment resulting in poor access to radiotherapy. This is especially the case for those living outside of metropolitan centres, where most facilities are located.

The Inquiry, chaired by Professor Peter Baume AO, delivered its report *A vision for radiotherapy: Report of the Radiation Oncology Inquiry* (the 'Baume Report') in 2002 (See **Attachment P**). This report made 96 recommendations and highlighted a number of problems with the delivery of radiotherapy that required specific action. The Baume Report identified five key action areas:

- Addressing the underlying fragmentation in responsibilities for radiotherapy;
- Improving the availability of radiotherapy for regional patients;
- Addressing workforce problems;
- Ensuring appropriate quality of service; and
- Encouraging resolution of disputes over funding issues through funding reform.

Due to the complex relationships between the Baume Inquiry recommendations and multi-jurisdictional responsibilities for delivery and funding of radiotherapy, Australian Health Ministers agreed in 2002 to establish the Radiation Oncology Jurisdictional Implementation Group. The Radiation Oncology Jurisdictional Implementation Group responded to the Baume report and provided the forum for all levels of government to agree and implement a number of activities, including:

- A service development framework for radiation oncology service delivery planning;
- Improvements to patient travel assistance schemes in each jurisdiction;
- Nationally consistent quality program funded by the Australian Government;
- Workforce initiatives funded by the Australian Government; and
- Continued exploration of funding reform.

The Radiation Oncology Jurisdictional Implementation Group recommended that jurisdictions continue to work collaboratively to reform the radiotherapy sector through an ongoing radiotherapy reform mechanism. In 2003, Australian Health Ministers established the Radiation Oncology Reform Implementation Committee. The Radiation Oncology Reform Implementation Committee continues to address many of the issues raised by the Baume Inquiry, including overseeing workforce, patient access, quality and service planning initiatives. It provides the forum for States and Territories to address cross-border service provision, consider nationally consistent data collection and collaborate with the Planning Forum and the non medical radiation therapy workforce working group.

Radiation oncology major equipment, and professional (medical) services, are funded by the Australian Government through separate mechanisms.

Radiation Oncology Health Program Grants
The Radiation Oncology Health Program Grant reimburses the cost of expensive radiation oncology capital equipment such as megavoltage linear accelerators and planning computers.

Payments are made on a per service basis for radiation oncology services that are also Medicare eligible.

In 2003-04, the Australian Government expended $32.9 million on the Radiation Oncology Health Program Grant program. Currently the Radiation Oncology Health Program Grant program provides funding for approximately 110 linear accelerators and 20 brachytherapy units. Significant effort is being made to increase radiation oncology capacity and numbers of equipment will be steadily increasing over the next two years.

Approval of Radiation Oncology Health Program Grants is governed by Part IV of the Health Insurance Act 1973. Under the Act each Radiation Oncology Health Program Grant must separately be applied for and approved.

Professional services
Total Medicare benefits for radiotherapy services in 2003-04 were $77.5 million.

New/expanded facilities
The Australian Government has worked collaboratively with State and Territory Governments to commit over $50 million to improving access to radiotherapy facilities through the following initiatives:

- New South Wales - Funding of $8 million has been provided for a new facility at Lismore, and $1 million for outreach services in Dubbo.
- Victoria - includes $10 million for a new facility in Traralgon and $2 million to expand the existing radiotherapy facility in Geelong.
- Queensland - includes $8 million to establish a private radiotherapy facility in Toowoomba, and $15 million for a range of other measures to address Queensland areas of need including outreach services.
- Western Australia- an additional linear accelerator is to be provided in Perth, with priority access for regional patients, and a range of other measures to improve access to radiotherapy to patients outside of the metropolitan area ($6 million).
- Northern Territory - the Australian Government has committed $150,000 towards a feasibility study to assess the best mechanism to improve access for Northern Territory patients. This report has been finalised and the Australian and the Northern Territory Governments are considering future options.

Radiation Oncology Treatment Services Quality Program
The Australian Government has also committed $550,000 for the development of a Radiation Oncology Treatment Services Quality Program.

An amount of $60,000 has also been put towards a Level 3 Trial Dosimetry Program, which aims to test the accuracy of radiation dose of linear accelerators at 30 individual radiotherapy facilities in Australia. This Program is being undertaken at the Centre for Clinical Radiation Research, Department of Radiation Oncology at Newcastle Mater Misericordia Hospital.

3.4.4 Access to care in regional, rural and remote areas

It is estimated that some 30 percent of people with cancer live outside a major population centre. The provision of services close to the patient’s domicile is inevitably limited by the population density and the distance from major centres of population.

Some services such as radiotherapy are not available outside capital cities and a few major towns. However, many people with cancer do receive components of their care outside major treatment centres and close to their place of residence. The ongoing challenge is to provide services in regional, rural and remote areas using a multidisciplinary approach including specialist input.

The Australian Government funds a range of initiatives to support health services in regional areas of Australia. Since 1996, $4 billion has been spent on rural health initiatives nationally.

Key national initiatives in cancer that relate to regional areas include:

- The Medical Specialist Outreach Assistance Program - provides funding for an oncology service through the Rural Doctors Network at Finley. Medical Specialist Outreach Assistance Program supports Palliative Care in New South Wales, South Australia, Tasmania and Western Australia.
- The Supporting Women in Rural Areas Diagnosed with Breast Cancer Initiative – this measure was announced as part of the 2003-04 Budget and provides $4 million over four years to enable women diagnosed with breast cancer to receive supportive care and information on treatment, management and quality of life issues in their local area.
- The Mentoring for Regional Cancer Services Initiative – this measure is part of the recently announced *Strengthening Cancer Care* Initiative and will see the provision of $3 million each year over the next three years, to establish and assist hospitals, providers and support networks to develop and implement cancer care mentoring. The mentoring system will foster multidisciplinary approaches in regional areas where on the ground support is less comprehensive. This will be achieved by involving major urban teaching hospitals in each State, linked to a number of regional and bush nursing hospitals in regional centres.
- The Australian Government has contributed $200,000 to an 18-month trial being conducted by the Upper Hume Community Health Service to facilitate multidisciplinary care and care coordination arrangements for cancer patients. Funding has also been provided by the Victorian and NSW Departments of Health, the Albury Wodonga Border Hospital Integration Project and Upper Hume Community Health.
- Better Treatment for Cancer Patients - in the 2002 Budget $72.7 million was allocated to this measure which focuses on radiation oncology. These funds have been provided to improve patients in regional areas with access to radiation therapy. Funds have been allocated to a combination of new facilities in identified areas of need, and projects to help attract and retain radiation therapy professionals.

3.4.5 Cancer care and Aboriginal and Torres Strait Islander people

A review of the Australian Government's Aboriginal and Torres Strait Islander primary health care program was completed in 2003-04. This involved an independent assessment of the program, utilising six other consultancy reports specifically commissioned for the Review. One of the consultancy reports was *Cancer, Health Services & Indigenous Australians* conducted by the Co-operative Research Centre for Aboriginal and Tropical Health.

This paper looked at the performance of the Australian health system in relation to cancer control for Aboriginal and Torres Strait Islander people in the Northern Territory as one way of providing an insight into the relationship between health care (including primary health care) and a range of issues including survival rates for Aboriginal and Torres Strait Islander people. Key findings of the report included:

- Aboriginal and Torres Strait Islander survival is lower for almost all cancer sites, partly due to delayed diagnosis and accordingly lower chance of survival.

- Primary health care has had a key role in significantly improving survival for non-Aboriginal and Torres Strait Islander people.
- Similar improvements are possible for Aboriginal and Torres Strait Islanders if primary health care programs are strengthened and access improved to primary and specialist services.

Evidence from overseas and within Australia shows that access to appropriate primary health care is essential to achieving improvements in health. The Australian Government is strengthening and expanding health care infrastructure and services for Aboriginal and Torres Strait Islander people.

The Australian Government's two pronged approach to comprehensive primary health care for Aboriginal and Torres Strait Islander people aims:

- to improve the responsiveness of the mainstream health system; and
- to provide complementary action through Aboriginal and Torres Strait Islander-specific health programs.

The Australian Government has a commitment to collaboration between Aboriginal and Torres Strait Islander communities, mainstream health providers and Aboriginal Community Controlled Health Services to achieve better health outcomes. Under the changed arrangements for Aboriginal and Torres Strait Islander Affairs, collaboration across government with education, family and community services as well as with State/Territory, local government and communities is a high priority.

In the 2004-05 Federal Budget, the Australian Government recognised the need for increased funding to meet the health needs of Aboriginal and Torres Strait Islander people. Additional funding of $10 million from 2004-05, totalling an additional $40 million funding over four years, will improve Aboriginal and Torres Strait Islander people's access to health services in a number of regions which are currently under-serviced.

This funding will ensure that there will be more doctors, nurses, Aboriginal and Torres Strait Islander Health Workers and allied health professionals providing services to Aboriginal and Torres Strait Islander people. Funds will also be used to improve the quality of services and to strengthen service management where that is needed.

Funds are provided to enable more Aboriginal and Torres Strait Islander people to become qualified to work as health professionals and health service managers, through targeted scholarships and expanded training programs.

This takes the total funds that the Australian Government spends through its Aboriginal and Torres Strait Islander-specific health program to $281 million this year.

The majority of these funds are used to provide health and substance use services, specifically for Aboriginal and Torres Strait Islander people.

Funds are also used to fund the construction or refurbishment of clinics and staff housing in remote areas; for workforce development; and to support targeted health programs such as child and maternal health, chronic disease, mental health and immunisation, and for research and data development.

From 2007-08, base funding through the Australian Government's Aboriginal and Torres Strait Islander-specific grants program will have grown to $313 million per annum. This is an increase from the $115 million provided in 1995-96.

These funds are in addition to the funding provided through other mainstream programs, such as the Medicare Benefits Schedule and the Pharmaceutical Benefits Scheme, which are becoming more responsive to meeting the health needs of Aboriginal and Torres Strait Islander people.

The Government is continuing to take action to improve the way mainstream programs work. The adult health check item on the Medicare Benefits Schedule, announced in May 2004, will enable Aboriginal and Torres Strait Islander people who have higher levels of untreated illness than other Australians to have illness detected and treated earlier.

The 2004 Budget included arrangements to list medicines on the Pharmaceutical Benefits Scheme to treat conditions particular to Aboriginal and Torres Strait Islander health needs. This will include consideration of medicines not yet registered in Australia, as well as consideration by the Pharmaceutical Benefits Advisory Committee of medicines not yet subsidised under the Pharmaceutical Benefits Scheme.

Since the Government took office in 1996 it has doubled, in real terms, funding provided through Aboriginal and Torres Strait Islander-specific programs.

3.4.6 Psychosocial support

People with cancer report that there is an overwhelming need to have appropriate and timely psychosocial care and support throughout the cancer patient journey. Many patients report anecdotally that their experience of cancer is more influenced by the psychosocial support they receive, rather than the medical treatment.

A high proportion of people diagnosed with cancer experience moderate to severe psychological problems, such as anxiety and depression. These problems impair quality of life and can have an important impact on patients' families. For example, 25 to 40 percent of women with breast cancer report that they experience significant psychosocial problems following diagnosis of their cancer.

Supportive care for people affected by cancer should be given equal priority with other aspects of care and be fully integrated with diagnosis and treatment. It is not stage-of-disease dependent; people have supportive care needs from the time that the possibility of cancer is first raised.

Australian evidence has suggested that oncologists' awareness of their patients' physical and psychosocial well-being is less than optimal. A study of medical oncologists showed that clinicians tended to overestimate patients' levels of perceived supportive care needs but underestimated patients' levels of anxiety and depression.

The National Cancer Control Initiative and the National Breast Cancer Centre together have produced the *Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer* (see **Attachment Q**). The guidelines provide clinically useful information about the emotional impact of cancer, strategies to reduce this impact and treatment of problems when they occur. These guidelines are a world first, and build upon the *Psychosocial Clinical Practice Guidelines for Breast Cancer*, developed by the National Breast Cancer Centre.

In 2003, The National Cancer Control Initiative, in conjunction with the National Breast Cancer Centre, developed a dissemination and implementation strategy for these guidelines. The strategy consists of four-modules including interactive educational workshops for health professionals (module 1), health professional summary cards (module 2), consumer summary cards (module 3) and a rural and remote strategy (module 4). Modules one and two of the four-module strategy commenced during the second half of 2004.

3.5 PALLIATIVE CARE

The needs of people with cancer at the end of life are complex. Adequate care during the end of life period is fundamentally based upon the provision of supportive care and the development of effective relationships with health professionals early in the cancer journey.

For some people with cancer, these services may be provided by generalist health providers, while for others, specialist palliative care services may be needed.

The Australian Government is providing $201.2 million throughout the five years of the Australian Health Care Agreements (2003-2008) for palliative care. Of this, $188 million is broadly allocated on a per capita basis to state and territories for continued service provision, and $13.2 million for the Australian Government to implement a national program of initiatives.

In the 2002 Federal Budget, the Australian Government announced a further $55 million over four years (2002-2006) for national activity to improve the standard of palliative care offered in local communities. The combined national allocation of $68.3 million (2002-2008) comprises the National Palliative Care Program, and is being implemented across six broad priority areas:

- provision of an expanded range of medications for palliative care in the community;
- assistance for families and increased support to other care networks;
- education, training and support for the primary care workforce;
- increasing the range and reach of palliative care services;
- capacity building in the palliative care research community; and
- performance information development.

The National Palliative Care Program is addressing the six priority areas above in a variety of ways including:

- Supporting better pain and symptom management;
- Improving the quality of palliative care services;
- Supporting families and the community to better care for their loved ones, especially at home;
- Improving the skills and knowledge of health professionals in palliative care;
- Funding research so there is more evidence for palliative care practice; and
- Gathering quality data to better plan palliative care services and the treatment of patients.

Further information on the National Palliative Care Program is available from the Department of Health and Ageing's website at www.health.gov.au/palliativecare.

3.6 INFORMATION ON SERVICES AND CANCER

Evidence has consistently shown that patients who are well informed experience less anxiety and have better coping skills than those who are poorly informed. A good understanding of their choices and what may happen to them improves peoples' satisfaction with care, psychosocial well being and compliance with treatment.

There is inconsistent evidence about the extent to which people with cancer in Australia currently receive adequate information. It is likely that information is better for some cancers than others. In a population based survey of women with breast cancer, most women reported that they had enough information about all aspects of their disease and its management. However, other reports note that people with cancer are dissatisfied with the information that they received.

People can be assisted to understand their disease and its treatment through the provision of written information, their own treatment plans and through good communication with their treatment team.

There is some research about how best to provide written information for people with cancer. For example, with regard to treatment decisions, information should include evidence-based statements about the benefits and harms associated with treatment options and the quality and consistency of the empirical studies underlying these statements. Information should also be presented in a balanced way using concise, jargon-free language.

Many organisations produce well-written and appropriate information to assist people living with cancer, however few health care services carry the full range of information available to the public. However, it is not always easy for patients and their carers to gather the information together so that they can make fully informed decisions about different treatment options.

Health*Insite* (http://www.healthinsite.gov.au) is an Internet gateway designed to provide consumers with easy access to reliable, high quality and relevant information about health and wellbeing. This service has been funded by the Australian Government to assist consumers to make more informed healthcare decisions. It is freely available to anyone with an Internet connection and may also be accessed through public libraries and other organisations in the community.

Health*Insite* works by linking users to specific information on the websites of approved information partners, each of which have been independently assessed to ensure the quality, currency and relevance of information they provide. Health*Insite* links to a large number of resources about various types of cancer and includes information about diagnosis, treatment options, support services, latest research and statistical information. Health*Insite* also links to personal stories from people who have experienced the effects of cancer in their lives.

3.7 CANCER RESEARCH

There is a wide range of cancer research conducted in Australia. The program ranges from basic molecular biology through to clinical trials of drugs and therapies through to the assessment of measures that relate to quality of life.

Cancer research provides evidence that will drive improvements in cancer prevention, treatment and subsequent improvements in survival and quality of life for cancer patients. For improvement to occur quickly, research needs to be an integral component of cancer control.

Currently, cancer research in Australia is funded by a number of organisations including, the National Health and Medical Research Council, State and Territory Governments, Cancer Councils and charities and others.

The Australian Government provides substantial support for research into better treatments for cancer through the National Health and Medical Research Council. The National Health and Medical Research Council is obliged to pursue activities that will help raise the standard of individual and public health throughout Australia, and has funding processes that allow great scope for innovative research to be conducted. This is a very competitive process and only those research proposals that have the highest degree of scientific merit, as determined by a rigorous system of peer review, receive funding. In 2004, the National Health and Medical Research Council provided more than $64 million specifically for cancer research. The National Health and Medical Research Council is providing a separate submission to this Inquiry.

As announced in the *Strengthening Cancer Care* Initiative, the Australian Government is providing a further $17 million over the next three years for dedicated cancer research and to provide start-up support for a national research centre for asbestos related disorders.

Clinical Trials

There is a need to continue to develop the evidence base for improving care. Clinical trials are fundamental to establishing whether there is benefit in new treatments. There is also evidence that people with cancer enrolled in clinical trials receive better care and have longer survival. It has been estimated that around 2-3 percent of people with cancer participate in clinical trials with around 20-30 percent eligible for current trials. Among people with breast cancer, participation is somewhat higher at around 6 percent. In a recent population based survey, 12 percent of women with breast cancer reported being offered an opportunity to participate in a clinical trial with 6 percent of women agreeing.

It should be noted that the commercial development of new treatments drives increasing numbers of industry-initiated trials. Reliance on industry funding risks having insufficient evidence on the benefits of surgery, radiotherapy and other drug regimens, as well as key questions that are not of concern to industry.

The Australian Government is investing $15 million over the next three years, commencing in 2005-06, to support for clinical trials. This measure was announced as part of the *Strengthening Cancer Care* Initiative and will help build Australia’s capacity to conduct clinical trials

Clinical Trials Register

A national clinical trials register has been a topic of debate by various stakeholders (industry bodies, researchers, the general public) for several years.

A national clinical trials register is seen as beneficial by many for the following reasons:

- It goes some way to overcome the so-called “negative publication bias” that exists in medical journals, whereby research that does not detect significant differences in treatment modalities, for example, is not as readily published. This information is still a valuable contribution to medical knowledge.
- It can potentially prevent wasting of resources, as depending on its structure, a register could allow certain stakeholders to see what kinds of trials are already being carried out, preventing needless reproduction of research.
- Depending on the form the register takes, it can form an information resource useful to many as time goes on, and the trial database becomes larger.

The Therapeutic Goods Administration and National Health and Medical Research Council jointly commissioned an independent review into the avenues of access to unapproved therapeutic goods in Australia in 2003. This report included use of unapproved medicines in clinical trials, and the feasibility of a clinical trial register contained in the Terms of Reference. (“unapproved” may be considered as medicinal products not yet evaluated by the Therapeutic Goods Administration for quality, efficacy and safety for their proposed indication). The report is planned to undergo public consultation during 2005.

3.7.1 Data

The Australian Institute of Health and Welfare has a number of national datasets containing cancer data and is submitting a separate submission to the Inquiry.

3.8 WORKFORCE DEVELOPMENT

A challenge to cancer patients accessing services is the availability of a sufficient number of skilled health professionals to deliver care. The Australian Government is concerned about health workforce shortages and has recently made a considerable investment in the health workforce.

Medical Practitioners

The Australian Government has made medical workforce a major focus of its $4 billion package for Strengthening Medicare. The range of initiatives contained in Strengthening Medicare will improve our medical workforce capacity in the short term but importantly also make a major investment in the longer term education and training of Australia’s future doctors.

Initiatives that will have an impact in the short term include:

- the number of appropriately qualified overseas trained doctors practising in Australia is being significantly increased through international recruitment strategies, reduced red tape in approval processes and changes to immigration arrangements;
- the employment of nurses to assist general practitioners is being supported through practice grants and the introduction of new Medicare Benefits Schedule items; and
- refresher training courses and other support is being provided for doctors no longer practising medicine to help them return to the medical workforce.

It is expected that these wide ranging initiatives will increase the number of full-time equivalent doctors by more than 1,500 by 2007.

As part of Strengthening Medicare, there are also two major investments being made in the education and training of the medical workforce:

- 246 new publicly funded undergraduate medical school places are being made available each year; and
- 150 new general practice vocational training places are being provided each year, an increase of one third.

The Australian Government has expanded the number of publicly funded medical school places across the tertiary sector by more than 25 percent since 2000. Five new medical schools have been established since that time, and three further new medical schools are being established over the next few years. These initiatives will expand the number of publicly funded students completing university medical studies from approximately 1300 in 2005 to approximately 1900 in 2010, an increase of over 45 percent.

Other Health Professionals
The Baume Inquiry into Radiation Oncology found that the shortage of radiation therapists and medical physicists was a major limiting factor in the number of radiotherapy services which could be provided.

The Australian Government has spent over $13 million on a range of workforce initiatives designed to increase the number of radiation therapists and medical physicists. This has included $3.2 million to increase the number of radiation therapy students by 50 per cent for the 2002 to 2004 university intakes. Other activities have included:

- Development of a graduate-entry program for radiation therapists at Monash University, and support for trainees in Western Australia studying under the program;
- Piloting a return to work program in NSW for radiation therapists who wish to return to the profession after an absence of a number of years;
- $1.12 million to fund an additional 30 radiation therapy places for students starting in 2004, at Newcastle University and the Royal Melbourne Institute of Technology;
- $720,000 for the introduction of clinical tutors in Western Australia; and
- Development of a radiation oncology medical physics training program, to allow medical physicists to complete the required post graduate education requirements and improve the quality of training opportunities.

As part of the Australian Government's Higher Education Reforms, the Minister for Education, Science and Training announced in July 2004 the creation of 4,000 new publicly funded university places to study nursing over the period 2005-2008. Additional funding of $40.4 million over four years has also been provided towards the costs associated with clinical placements for nurses.

The Minister for Education, Science and Training also announced at the same time the establishment of additional publicly funded university places in a range of other health disciplines including radiography, medical science, physiotherapy and social work.

As part of the *Strengthening Cancer Care* Initiative, the Australian Government is also providing funding of $25 million over the next three years to support cancer health professionals. The funding will go towards more radiation therapy undergraduate places and professional training packages for nurses, cancer professionals, counsellors and general practitioners.

PART 4 - CONCLUSION

Australia has one of the best systems of cancer care in the world. Our cancer survival rates are second only to the United States of America by international comparisons despite the increasing incidence. Cancer deaths in Australia have fallen on average by 1.9 per cent per annum during the past ten years.

The Australian Government has recognised the burden of disease that cancer creates in the community and has a strong track record of substantial investment with a diverse set of initiatives over a number of years designed to improve cancer control. Cancer is a National Health Priority Area and the Australian Government commits substantial funding to cancer control.

While Australia is doing very well in cancer control across the whole spectrum from research and prevention, to detection to treatment and palliation, improvements could be made through the systematic implementation of best practice treatments for people with cancer from the time of diagnosis.

The Australian Government in conjunction with State and Territory governments has developed the *National Service Improvement Framework for cancer*. This Framework positions patients at the centre of cancer care. It focuses on improvement in the 'patient journey' for people at risk of or living with cancer. These improvements will ensure access and best practice care for all Australians regardless of their geographic location, social economic status or tumour type.

The Australian Government has also reaffirmed its commitment to reducing the burden of cancer by announcing the *Strengthening Cancer Care* Initiative. This Initiative will ensure better coordination of our national cancer effort, provide more research funding for cancer care; enhance cancer prevention and screening programs; and better support and treat those living with cancer and the professionals who care for them.

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