CHAPTER 5

OTHER ISSUES RAISED IN THE INQUIRY

5.1 Improving cancer outcomes is a multifactorial field that extends far beyond the scope of this inquiry. While the Committee's investigations were necessarily focussed by the terms of reference, a number of specific issues relating to cancer treatment and care were raised in submissions and at the hearings. These are briefly discussed in this chapter.

Early detection through screening programs

Access to free mammograms

5.2 The issue of providing free mammograms for women outside the target ages, through the national breast cancer screening program, was raised.

5.3 The Department of Health and Ageing advised that BreastScreen Australia actively targets women aged 50-69 years, but women aged 40-49 and over 70 years are also eligible to attend.

5.4 This policy is in line with international evidence which demonstrates that breast cancer screening is most effective in the 50-69 year age group. BreastScreen Australia is a joint Commonwealth, State and Territory funded program. Funding is provided by the Commonwealth through the Public Health Outcome Funding Agreements. The Agreements are bilateral funding agreements between the Commonwealth and each State and Territory Government. The agreements provide State and Territory Governments with broadbanded (pooled) funding linked to the achievement of outcomes in a range of public health programs including breast cancer screening.

5.5 An article in the March 2002 edition of the *Medical Journal of Australia* reports on outcomes of a systematic review of screening mammography in women 70 years and over. The review concludes that:

- Age is the strongest risk factor for breast cancer, as indicated by the increasing number of cancers detected across age groups - however, because older women at a higher risk of death from other causes, they may only experience the downsides of screening, and not live long enough to experience the benefits; and
- Women aged 70 years and over, in consultation with their doctor, may want to decide for themselves whether to continue mammographic screening.[1]

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[1] Alexandra L Barratt, Les M Irwig, Paul P Glasziou, Glenn P Salkeld and Nehmat Houssami, Benefits, harms and costs of screening mammography in women 70 years and over: a systematic review, *The Medical Journal of Australia*, 2002, 176, 266-271.

5.6 This is consistent with current BreastScreen Australia policy, although individual States and Territories have different practices in relation to service provision for women over 70 years of age. All women over the age of 70 years can make an appointment and attend any BreastScreen Australia service across Australia.

5.7 All eligible women aged 50-69 years who already attend BreastScreen Australia services are reinvited to attend for breast cancer screening every two years. However, there are differences between jurisdictions as to when women are no longer invited to attend for breast cancer screening. Where States and Territories do cease to reinvite after women have reached an upper age limit, letters are sent to women affected outlining the reasons why they will not be reinvited in the future but that they are free to call and make an appointment for a two-yearly mammogram if they wish.[2]

Access to free mammograms once diagnosed with breast cancer

5.8 Witnesses raised the issue of their ability to access breast cancer screening through BreastScreen Australia following a diagnosis of breast cancer.[3]

> My breast cancer was detected by BreastScreen and I found they provided an efficient service of the highest professional standard. So I was understandably surprised when I was advised that my follow up mammograms would not occur at Breastscreen, but on a referral from my surgeon to a private Radiologist...
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> When I made my appointment with this private radiologist, I was informed that the mammogram and ultrasound would cost $314-00, payable at the time of service. Fortunately at the time, I was in a position to meet such a financial demand, but I know of many women who would find an up front payment difficult under any circumstances. The benefit I received from Medicare for this service was $164-60, leaving my family out of pocket $149-40. This is obviously a huge burden for many women on low or no incomes; it is a pressing social issue for women who have no direct access to money, which is not uncommon when many women are forced to take long periods off work to undergo cancer treatment plans.[4]

5.9 The BreastScreen Australia Program, as a population screening program, is aimed at well women, without symptoms. BreastScreen Australia services recommend that women who have had breast cancer in the past and have had surgery to remove a lump or for a mastectomy continue to visit their breast specialist for their regular mammograms. Reasons for this include:

- If a woman has had breast cancer and surgery to remove a lump, special techniques and procedures may be required, such as detailed pictures of the treated part of the breast. These special procedures are not offered at a

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[2] *Submission* 87, p.15 (DoHA).

[3] *Committee Hansard* 19.4.05, p.33 (Ms Crossing).

[4] *Submission* 101, pp.1-2 (Ms Catherine Green).

screening visit as BreastScreen Australia is set up to provide mammograms to detect the apparent early signs of breast cancer in women with no symptoms.

- If a woman has breast cancer, regular check-ups should involve a thorough clinical examination by a doctor, annual mammograms and any other test that may be required. BreastScreen Australia only provides screening mammograms.

5.10 State and Territory BreastScreen Programs are responsible for determining their own policies for making services available for women who have been diagnosed with and treated for breast cancer. Some States take women who have had treatment for breast cancer back into the screening program after a specified period of time, others take such women back if they have a letter from their treating surgeon indicating that it is appropriate for that woman to return to biennial mammographic screening.

5.11 The Committee is also aware that the Cancer Funding Reform Project, reporting through the Health Reform Agenda Working Group to Australian Health Ministers is examining a range of strategic funding issues associated with the provision of cancer care. The project will investigate the current funding arrangements for cancer treatment in the Australian health system across the public and private sectors.

Recommendation 30

5.12 The Committee recommends that the target age groups for BreastScreen Australia and the National Cervical Screening Program should be reviewed regularly, given the increasing trends in life expectancy for Australian women. In addition, a review should be conducted of how women outside the age limits are made aware of their cancer risk.

Access to breast prostheses and lymphoedema sleeves

5.13 Issues relating to access to breast prostheses and lymphoedema sleeves were raised in evidence.[5]

5.14 Ms Crossing explained that if a women has a mastectomy they need a breast prosthesis so their spinal alignment does not become compromised and cause other health problems. She reported that access to breast prostheses after a mastectomy is not consistent between States. The same difficulties apply regarding access to lymphoedema sleeves which are necessary to treat 'painful swelling of the arm'.[6]

5.15 The Department of Health and Ageing advised that the Medicare Benefits arrangements are designed to provide assistance to people who incur medical

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[5] *Submission* 24, p.3 (Breast Cancer Action Group NSW).

[6] *Committee Hansard* 19.4.05, p.33 (Ms Crossing).

expenses in respect of clinically relevant professional services that are contained in the Medicare Benefits Schedule, and rendered by or on behalf of qualified medical practitioners. Therefore Medicare benefits are not payable for the costs of aids and appliances, including breast prostheses and lymphoedema sleeves.

5.16 However, the Commonwealth does provide funding for the surgical implantation procedure, under the Medicare Benefits Schedule for privately insured patients (excluding those seeking implantation for purely cosmetic purposes) and for public patients (including the prostheses) through the Australian Health Care Agreements.

5.17 The Plastic and Reconstructive Subgroup of the Medicare Benefits Schedule contains a number of services which provide for the surgical implantation, removal and/or replacement of breast prostheses as well as breast reconstruction procedures for women who have undergone mastectomy.

5.18 In addition, private health insurance funds are currently required under the Surgically Implanted Prostheses, Human Tissue Items and Other Medical Devices (Schedule 5) of the National Health Act 1953 to fully fund prostheses items that are provided as part of an episode of hospital care, such as breast implants.

5.19 The funding for breast implants listed in Schedule 5 is limited to patients who have undergone specific Medicare Benefits Schedule procedures; it does not cover the prostheses provided for cosmetic procedures such as breast enlargement. The range of surgically implanted breast prostheses listed on the Prostheses Schedule includes both saline and silicone-gel filled prostheses. The Commonwealth has had no role in the funding of products currently listed on Schedule 5. This has been a matter between the health funds and the supplier of the product.

5.20 For external prostheses (not surgically implanted) like breast prostheses and lymphoedema sleeves, private health insurance funds may be able to provide a rebate for the cost of the prostheses as part of their ancillary cover.

5.21 If the person does not have private health insurance, help may be available from State/Territory governments, such as the Program for Aids for Disabled People in New South Wales.

Access to PET scans for people with recurrent or advanced breast cancer

5.22 The issue of access to Positron Emission Tomography (PET) scans for people with recurrent or advanced breast cancer was raised.[7] Ms Crossing noted that although Positron Emission Tomography scans for most cancers are funded by the Commonwealth, they are not funded for breast cancer even though a great deal of evidence shows it is an important tool for following and staging the course of advanced breast cancer. Cost implications for the patient are significant with

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[7] *Submission* 24, p.3 (Breast Cancer Action Group NSW).

Ms Crossing indicating that 'it is $900 out of your pocket and that is a huge sum of money for most women faced with this particular situation'.[8]

5.23 The Department of Health and Ageing advised that there are currently 13 PET scanners in Australia. Nine scanners receive Commonwealth funding in eight facilities and all eight facilities are participating in an evaluation of PET clinical and cost effectiveness. Results from this program are expected to become available from mid 2006 and will inform the decisions about future PET funding.

5.24 The Department also advised that the average Medicare Benefits Schedule fee for a PET scan is around $950 and that conditions of Commonwealth funding specify that scans are performed at no or minimal out of pocket cost to the patient. PET effectiveness and cost effectiveness in the management of breast cancer would need to be considered by the Medical Services Advisory Committee before any decisions about public funding could be made. The role of the Medicare Service Advisory Committee is to advise the Federal Minister for Health and Ageing on the evidence relating to the safety, effectiveness and cost effectiveness of new medical technologies and procedures.[9]

Adolescent cancer care

5.25 The provision of appropriate cancer care services for adolescents and for young adults with cancer, an age group for whom the incidence of cancer is increasing, was raised in evidence by a number of people including witnesses from CanTeen and the Centre for Children's Cancer and Blood Disorders at Sydney Children's Hospital:

> Published Australian data, which mirrors overseas data, indicates that during the past decade alone cancer incidence has increased by 30 per cent in young people aged between 10 and 24 years. This increased incidence of cancer in adolescents and young adults is higher than in any other age group.[10]

5.26 The Committee was advised that there is also growing concern internationally for the adolescent and young adult cancer population and mounting evidence for targeting improvements for this patient group.[11]

5.27 While cure rates both for younger children and older adults with cancer have improved, the same is not true for adolescent cancer patients as shown in Figure 5.1.

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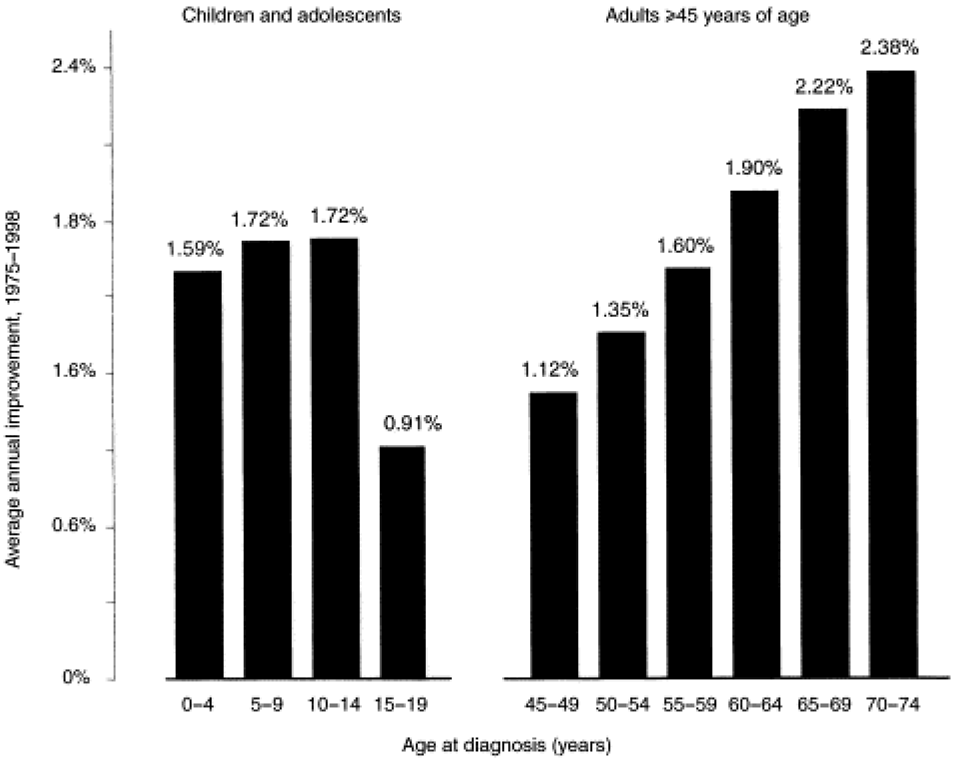
[8] *Committee Hansard* 19.4.05, p.33 (Ms Crossing).

[9] *Submission* 87, supplementary information, (DoHA).

[10] *Committee Hansard* 19.4.05, p.57, (Dr O'Brien).

[11] *Submission* 69, p.2 (Ms Ewing).

Figure 5.1: Management of cancer in adolescents



Source: Albritton K and Bleyer WA, 'The management of cancer in the older adolescent', *European Journal of Cancer* vol.39 2003, pp.2584-2599.

5.28 Issues for adolescents as described for the Committee include firstly, that access to clinical trials for adolescents with cancer is very poor which means they are less likely to have access to state-of-the-art treatment. Secondly, they are less likely to be treated in specialised multidisciplinary cancer care units where the best results are achieved. There are no guidelines for the referral of adolescents and young adults with cancer to specialist care which means they are randomly referred to either paediatric or adult cancer physicians. Dr O'Brien indicated that:

> Survival rates for children with leukaemia or cancer are higher when treatment is supervised by a tertiary paediatric cancer centre, where treatment is planned and supervised by a multidisciplinary team comprising both medical, surgical and radiation oncological disciplines, and where treatment utilises active trials conducted by international paediatric cooperative groups.[12]

5.29 A recent Victorian study was quoted as demonstrating that treating adolescents with a particular type of bone tumour in a paediatric regime improved survival rates by 50 per cent.[13] Other evidence based on studies by McTiernan in the

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[12] *Submission* 99, p.2 (Westmead Hospital, Sydney and The Children's Hospital at Westmead Sydney).

[13] Mitchell, A, E et al, *Medical Journal of Australia* 2004: 180 (2): 59-62.

UK and referred to by witnesses reported that international studies have shown significant improvements in outcomes for adolescents and young adults treated on clinical trials. The review by McTiernan confirmed that adolescents with acute lymphocytic leukaemia, non-hodgkins lymphoma, nephroblastoma and rhabdomysarcoma as well as medulloblastoma have all shown a significant survival advantage when treated on trial protocols within specialist centres, compared to those that are not.[14]

Recommendation 31

5.30 The Committee recommends that Cancer Australia consider the development of appropriate referral pathways that take account of the particular difficulties confronted by adolescents with cancer.

Damien's story – The needs of adolescents

In April 1999 I was diagnosed with a bone cancer called Osteosarcoma, in my left knee. At the time I was 15 years old and was treated at the Royal Children's Hospital in Melbourne for 9 months.

When I was diagnosed I was a typical 15 year old. I was very fit and healthy and had no history of cancer in my family. I didn't know anything about cancer or any of the treatments for it. It was something I had never come across before.

From the time 'something showed up on the x-ray' until the time I finished my treatment I wasn't at school. This meant that I didn't get the opportunity to spend time with my friends like a 'normal' teenager would. Even outside of school my friends didn't come and visit me. I assume because they didn't know what to say. This meant that I didn't have anyone who was my age that I could talk to about what was happening to me. Even within the hospital there were very few teenagers of my age due to that fact, I was being treated at a children's hospital…

Soon after I finished my treatment, I attended a camp for Patient Members of CanTeen. This was the first opportunity I had had to talk to people my age about what had happened in the last 9 months of my life and how it would effect the rest of my life. I got to meet people who had 'been there and done that' and see how they had continued with their lives…

I believe it is hard enough for a young person to grow up and cope with the normal changes that happen in their life. Throw in a diagnosis of cancer, and it throws the young person out of their normal life, and into hospital. Being able to talk to people my age that had been through similar experiences was able to bring back some kind of 'normalness' into my life.

Submission 51, p.14 (CanTeen Australia).

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[14] McTiernan. A, Issues Surrounding the participation of adolescents with cancer in clinical trials in the UK, *European Journal of Cancer Care*, 12 (3), 233-9, September, 2003.

5.31 CanTeen, the organisation that supports young people living with cancer, indicated that 12-24 year olds undergoing treatment were not surviving as well, or being supported as well, as were children between the ages of 1-12.[15]

5.32 The psychosocial care needs of adolescents with cancer differ from those of an adult or a child and are not being addressed. Witnesses, including young patients, emphasised that when you are a teenage patient, being treated in a children's environment adds to the frustrations in terms of the physical facilities and the support services. These frustrations are similar if the adolescents were treated in a ward with very sick adults. The personal experience of a teenage cancer patient being treated in a children's hospital was described by Ms Michels:

> The women's and children's hospital has a toy room, a great resource for little kids. The walls are painted with huge bright murals of clowns, fairies and under-the-seas themes, all directed at small children. The prints in the rooms are of kittens and Peter Rabbit, and the video collection had much to be desired. Once you have sifted through the Wiggles and stories like that, you might get to view something like Toy Story. I wanted a couch to sit on and play music that I like listening to. I found myself spending a lot of time in the 'quiet room', which is a room with two couches and no bright paintings or anything. The small children did not go in there as it was not exciting.[16]

Ms Michels then described her experience when treated in an adult hospital a few years later:

> I met a lot of lovely people and their families but I struggled a lot because of the age gap. I did not feel like we could talk about the stuff that teenagers talk about in front of adults. It was hard for my friends to stay positive around me as I was surrounded by sick and older people lying in beds.[17]

5.33 Witnesses told the Committee there appeared to be inflexibility in decisions and policies as to where adolescents are treated which could impact on outcomes. One example was given for NSW: 'if you are aged 15 and 11 months then you can go to a children's hospital. If you are 16 then you cannot be admitted to a children's hospital for a new diagnosis of cancer'.[18] Ms Ewing noted that the Cancer Control Network:

> acknowledges that adolescents with cancer "present a challenge that is not adequately addressed by current systems or models of care in Australia". [White 2002]. This situation is likely to have occurred because the care of adolescent patients is often seen as neither the preserve of paediatric or

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[15] *Submission* 51 p.2 (CanTeen).

[16] *Committee Hansard* 19.4.05, p.61 (Ms Michels).

[17] *Committee Hansard* 19.4.05, p.63 (Ms Michels).

[18] *Committee Hansard* 19.4.05, p.70 (Ms Senner).

> adult services [Leonard et al 1995], and consequently these people fall into the void between.[19]

5.34 It was suggested to the Committee that the way to address this issue is for the establishment of specialised teenage cancer units where there could be collaboration between both paediatric and adult cancer specialists. Such a unit would utilise a multidisciplinary team to deliver appropriate medical and psychosocial care.[20]

The needs of adolescents

The needs of adolescents are different to those of both children and adults, as there is this middle ground. We are not dependent, like children are on their parents, but we do not have people dependent on us. We have all different issues. By having adolescent wards you would be surrounded by people where you fit in, you feel like you belong and you are not alone. You could have the same interests. Friendships would naturally form and support would be given. Adolescents would be surrounded by others that are dealing with similar situations in and out of hospital. They can relate to what is going on, as they are going through the same things. There would be a positive environment with others who they can feel comfortable and relaxed amongst. We can share, listen, have fun, joke, be ourselves, relax, learn, heal and grow throughout this. Talking is a great healer for cancer patients because it releases disturbing thoughts bottled up inside. It is proven beyond a doubt that the mind can help heal the body when you are thinking positively. Cancer patients and other young people living with cancer have a genuine understanding of each other’s situation and what we are going through.

Committee Hansard 19.4.05, p.63 (Miss Lauren Michels).

5.35 The Committee concluded that it was very important that information was provided as soon as possible about the current treatment profile in Australia for this age group, how it compares with other countries and how many clinical trials are available and being accessed. In terms of the environments in which these young people are being treated, often for long periods of time, it was important to ask the State and Territory health departments how they are addressing the issue.

Recommendation 32

5.36 The Committee recommends that State and Territory Governments recognise the difficulties experienced by adolescent cancer patients being placed with inappropriate age groups and examine the feasibility of establishing specialised adolescent cancer care units in public hospitals.

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[19] *Submission* 69, p.2 (Ms Ewing).

[20] *Committee Hansard* 19.4.05, p.58 (Dr O'Brien).

Research

5.37 The Committee noted that cancer research in Australia is funded by a number of bodies including the Commonwealth, through the NHMRC, as well as State and Territory governments, Cancer Councils and charities and others.

5.38 The Commonwealth Government announced as part of the 2005-06 Budget that funding will be provided over four years for a dedicated cancer research budget and that seed funding is to be provided to establish a National Research Centre for Asbestos Related Diseases.

5.39 The Committee was advised that the Cancer Institute New South Wales has a major research program and has invested research fellowships, infrastructure that enables researchers to access equipment and expertise, and translational (bench to bedside) research.[21]

5.40 The Victorian Department of Human Services has established a Cancer Research Working Group. The group provides advice on the better integration, coordination and development of cancer research and promotes communication between research centres and health services to facilitate the translation of cancer research into clinical practice.[22]

5.41 The Cancer Institute New South Wales has recommended that the Commonwealth government consider a more strategic focus for cancer research.[23] The Institute suggested that, in addition to the traditional areas funded by the NHMRC, further research should be directed towards translational research, health services research, screening and early detection, and clinical trials.

Clinical Trials

5.42 Clinical trials are fundamental to establishing whether there is benefit in new treatments. Participation in clinical trials needs to be encouraged as there is evidence that people receive better care and have longer survival if enrolled in trials, though there is a considerable disparity between the numbers enrolled.[24]

5.43 Witnesses expressed concern at the relatively low enrolment of people in clinical trials, with the enrolment of adults being around two to three per cent though 20 to 30 per cent are eligible.[25] This contrasts with children, where every child is considered for a trial and over 50 per cent are entered.

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[21] *Submission* 53, pp.2, 6 (Cancer Institute NSW).

[22] *Submission* 66, p.5 (Victorian Department of Human Services).

[23] *Submission* 53, p.6 (Cancer Institute NSW).

[24] *National Service Improvement Framework for Cancer,* p 42.

[25] *National Service Improvement Framework for Cancer,* p 42.

5.44 The Cancer Institute New South Wales stated that national cancer clinical trials are poorly funded and operate on grants from philanthropy. The Institute called for the provision of support to these groups from governments throughout Australia.[26]

5.45 The Committee noted that in response to the low enrolments in clinical trials, the Cancer Institute New South Wales established The Clinical Trials Program which has four main aims, to:

- Introduce and study new cancer treatments;
- Increase participation rates in cancer clinical trials;
- Promote a culture of research and innovation in our cancer service programs; and
- Connect cancer clinical trials in New South Wales to key national and international trials.

5.46 A Clinical Trials Office has been established to assist the Cancer Institute New South Wales in achieving the above listed aims. The Clinical Trials Office will endeavour to provide high quality cancer clinical trial infrastructure for New South Wales, managing the initiatives identified as a result of workshops and discussions with key stakeholders and groups.[27]

5.47 The Committee also noted that the Commonwealth is committing significant funding over the next four years to provide infrastructure grants for cancer clinical trials through the Strengthening Cancer Care Initiative.[28]

Data

5.48 Many witnesses identified gaps in cancer data, which if addressed could lead to improvements to both service planning and treatment for cancer patients.

5.49 The Australian Institute of Health and Welfare identified three major gaps in national data on services and treatment options.

5.50 The first related to the lack of national data on hospital outpatient services for cancer. The AIHW indicated that from July 2005 a collection of hospital outpatient occasions of service delivery for chemotherapy and radiation oncology would commence for the principal referral and other major hospitals in each State.

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[26] *Submission* 53, p.6 (Cancer Institute NSW).

[27] Cancer Institute NSW Clinical Trials Program, accessed at http://www.health.nsw.gov.au/cancer_inst/research/trials.html on 26 May 2005.

[28] DOHA Health Fact Sheet 1, Investing in Australia’s health: Strengthening Cancer Care, accessed at: http://www.health.gov.au/internet/budget/publishing.nsf/Content/health-budget2005-hbudget-hfact1.htm on 26 May 2005.

5.51 The second area is data on the stage of cancer, a pre-requisite to interpreting changes in survival and to analysing the effects of changes in treatment and services. The need for staging data was also strongly supported by Dr Threlfall, Manager and Principal Medical Officer, Western Australia Cancer Registry.[29] The AIHW has acknowledged that some work was occurring in the area of staging data. For example:

- The National Cancer Control Initiative has developed a national clinical cancer core data set. The data set has been endorsed by the National Health Data Committee of the Australian Health Ministers Advisory Committee. The National Cancer Control Initiative has also undertaken some pilot work in Western Australia and the Northern Territory on the feasibility of collecting staging data.[30]
- The Cancer Institute New South Wales has commenced a program for the collection of a minimum data set of 45 items on every cancer patient in New South Wales. The minimum data set is targeted at the patient's journey and is expected to be rolled out within a 12 month period.[31]
- The Victorian Department of Human Services has established a Data/Information Working Group that is promoting the collection of the National Cancer Control Initiative's Minimum Data Set.[32]

5.52 The AIHW acknowledged that the standardisation of staging data across States and Territories would take some time and that the coding from the detailed to the aggregated data set would be very costly.[33]

5.53 The third gap relates to the lack of linkage between existing data sets. There are a number of individual data sets from the Medicare Benefits Schedule and Pharmaceutical Benefits Scheme, the Health Insurance Commission data bases, and hospital records, where there is little linkage of these data bases. Commonwealth statisticians and the ABS are working on protocols on how the ethical linkage of data can be undertaken, taking into account relevant privacy legislation.[34]

5.54 The Committee heard that there was a major gap in the collection of data on cancer staging. Data on the stage of cancer is a pre-requisite to interpreting changes in survival and to analysing the effects of changes in treatment and services. The AIHW acknowledged that while work is being undertaken in this area, the standardisation of staging data across States and Territories would take some time and would be costly.

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[29] *Committee Hansard* 19.04.05, p.10 (Dr Threlfall).

[30] *Committee Hansard* 31.03.05, p.9 (Dr Threlfall).

[31] *Committee Hansard* 19.04.05, p.50 (Prof Bishop).

[32] *Submission* 66, p.5 (Victorian Department of Human Services).

[33] *Committee Hansard* 20.04.05, p.79 (Dr Choi).

[34] *Submission* 3, p.5 (AIHW).

Given the importance of cancer staging data, the Committee makes the following recommendation.

Recommendation 33

5.55 The Committee recommends that Cancer Australia, in consultation with State and Territory Governments and the Australian Institute of Health and Welfare, take a leadership role in coordinating the development of a national approach to the collection of cancer staging data.

Palliative care

5.56 Palliative care was raised by a number of witnesses as an area requiring greater attention due to the increasing incidence of cancer. As stated by Professor Kricker 'the fact that 36 000 die is not reflected in the state of development of the palliative care services. It is a crying need'.[35]

5.57 Palliative care is a relatively new discipline in Australia's health care system and aims to improve the quality of life of people with life-limiting conditions.[36] To a great extent, hospice palliative care in Australia has been driven by community demand through non-government organisations led by doctors, nurses, other committed health professionals and members of the public.

5.58 The provision of good palliative care is not just for the benefit of the terminally ill patient. Providing good palliative care at the end of a cancer patient's journey has measurable health outcomes in terms of the unpaid carers. Professor Currow stated:

> I would like to reflect on the fact that good palliative care is not a black hole into which we pour money; it is something with measurable health outcomes that are felt long after the death of a person. The care giver impact is positively affected by the involvement of palliative services and that effect has hangover, if you will, that lasts for many years after the death of the person who has had a life-limiting illness. The very small investment that we make in palliative care has an enormous benefit for the health of the whole community when measured in those sorts of parameters.[37]

5.59 It is evident from the growth in the demand for domiciliary palliative care throughout Australia that patients in the final stage of the cancer journey appreciate the option of being able to die at home or, at least, spend as much time as possible there. Dr Helen Manion reported that a World Health Organisation survey showed that

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[35] *Committee Hansard* 19.4.05, p.24 (Professor Kricker).

[36] *Submission* 8, p.4 (Dr Beverley McNamara and Dr Lorna Rosenwax).

[37] *Committee Hansard* 19.4.05, p.6 (Professor Currow).

80 per cent of people have the wish to be able to remain in their own homes to die but the reality is that the majority of cancer patients die in an institution.[38]

5.60 Despite improvements in survival rates, Professor Currow stated that 'one in two people diagnosed with a solid cancer will still have their life substantially shortened by that in 2005. So we need excellent support and end of life care'. Currently the majority of patients (greater than 80 percent in most cases) referred to palliative care services in Australia have cancer.[39] Given the increasing numbers of people with cancer, without recognition of this resource need, the planning of future cancer services across the country will continue to be ad hoc. Professor Currow stated that 'unless we start to plan for the future in a very proactive way and ensure that every position has the flow-on effects of all the allied health, nursing and medical needs – and equalling that with the challenge of ensuring that we are providing infrastructure across the continuum of care; so in the community, in in-patient settings and in out-patient settings – we are going to have problems in the future'.[40]

5.61 Professor Currow mentioned the variation across Australia in metropolitan, rural, regional and remote Australia in accessing specialised palliative care services.[41] This disparity was highlighted by investigators at the University of Western Australia who conducted research which found that one third of people who died of cancer had not receive specialist palliative care. They found that people were less likely to receive specialist palliative care services if they were aged 84 years or over; female; Aboriginal; living in remote areas; or socioeconomically disadvantaged. Their research also found that use of specialist palliative care services reduced the likelihood of dying in a hospital or in a residential aged care facility, suggesting that the use of specialist palliative care services potentially reduces the demand on other hospital beds.[42]

5.62 Submissions suggested that the use of care coordinators is important to ensure that all patients are referred to a specialist palliative care service.[43]

5.63 The role of the carer of a terminally ill patient has been recognised by the Australian government. Some carers qualify for financial entitlements through Centrelink with the Carer Payment for those who are not able to work due to their

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[38] *Submission* 1, pp.1-2 (Home Hospice Inc).

[39] *Submission* 70, p.1 (Australian and New Zealand Society of Palliative Medicine); *Committee Hansard* 19.4.05, p.16 (Professor Currow).

[40] *Committee Hansard* 19.4.05, p.16 (Professor Currow).

[41] *Committee Hansard* 19.4.05, p.17 (Professor Currow).

[42] *Submission* 8, pp.5-6 (Dr Beverley McNamara and Dr Lorna Rosenwax).

[43] *Submission* 70, p.2 (Australian and New Zealand Society of Palliative Medicine).

caring responsibilities and the Carer Allowance, which helps parents or carers to care for adults with a disability at home.[44]

5.64 The Commonwealth is 'providing $201.2m throughout the five years of the Australian Health Care Agreements (2003-08) for palliative care. Of this, $188m is broadly allocated on a per capita basis to States and Territories for continued service provision, and $13.2m for the Australian Government to implement a national program of initiatives. In the 2002 Federal Budget, the Australian Government announced a further $55m over four years (2002-06) for national activity to improve the standard to palliative care offered in local communities'.[45]

5.65 To meet the demand for palliative care in the home, witnesses raised concerns over the availability and supply of some drugs.[46] Drugs that are available in a hospital are not automatically available for a patient being looked after at home. The Pharmacy Guild recommended that 'the range of medication used in palliative care listed in the PBS be broadened to assist in providing wider access to medication at an affordable price for patients who wish to remain in the community during the terminal phases of their lives'. The Guild acknowledged that there have been recent listings of several medications but is concerned that preparations currently listed are not adequate, citing Midazolam and Ketalar as examples. They explained that 'there is little incentive for manufacturers to apply for PBS listings for these drugs for innovative uses such as in palliative care' and recommended that the dual listing of medications used in palliative care should be investigated.[47]

5.66 The Committee questioned the Department of Health and Ageing about why a drug that has gone through an approval process for a specific reason, and when it may then need to be used in a different dose or in a different treatment, needs to go through the process again as it is very expensive and there is marginal, if any, profit for the manufacturer to do it.

5.67 In response to this issue about drugs on the palliative care list, Dr Lopert from the Department of Health and Ageing, advised that they are 'aware that there is concern over availability of some medications on the palliative care list, but their lack of availability of the palliative care list reflects that fact that they do not have marketing approval for the indications that are relevant to the palliative care setting'. Dr Lopert stated that the process is a safeguard as 'the broader issue from the PBS point of view as opposed to the registration point of view is that it is inappropriate to provide reimbursement for drugs for an indication outside that for which it is approved for marketing in Australia – that is one of the principles underlying the

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[44] Accessed at http://www.centrelink.gov.au/internet.nsf/payments/carer_allow_adult.htm and http://www.centrelink.gov.au/internet.nsf/payments/carer.htm on 10.6.05.

[45] *Submission* 87, p.27 (DoHA).

[46] *Committee Hansard* 20.4.05, p.59 (Mr Cuthill).

[47] *Committee Hansard* 20.4.05, p.60 (Mr Cuthill).

PBS…The issue of approval for indications other than those for which it is registered is an issue for the TGA rather than the pharmaceutical benefits branch'. When questioned specifically about Midazolam, Dr Lopert stated 'the approved indication is actually quite narrow. It is not approved for an indication that could be conceivably appropriate for use in a palliative care setting – it talks about use as an adjunct in anaesthesia for a surgical procedure'.[48]

5.68 The Committee noted there was some confusion about the authority process for palliative prescriptions, particularly for the first dose. The Department of Health and Ageing provided the following advice:

> Requirements for prescriptions for palliative care medicines to be authorised by the Health Insurance Commission were put in place to minimise use outside the intended population whilst ensuring access to patients with the greatest need. It would be impractical to not require authorisation of the 'initial' supply, whilst requiring authorisation for continuing supply. First, without the authority mechanism it would not be possible to monitor where an initial supply has occurred. Second, it is most likely that medical practitioners would continue to prescribe under the 'initial' supply arrangement without ever seeking authority to prescribe a continuing supply.[49]

5.69 The Department also advised that the work of the Palliative Care Medications Working Group continues, with a further medication, Paracetamol Sustained Release, included on the palliative care section of the PBS in April 2005. A further list of 10 medications have now been prioritised by the Palliative Care Medications Working Group, and will be progressed for listing in coming months. For example, Flinders University of South Australia has now been engaged to support the generation of evidence and data to support registration and listing of these medications under the Scheme. In addition to the above, the Working Group is working on a number of strategies to: support quality use of medications through education and support for GPs and other primary health care workers, in the management and care of palliative care patients in the community; and increase the awareness of health professionals and the broader community on medications currently available and how they can be accessed.

5.70 Dr Page raised the issue of access to palliative care in regional and rural areas. She stated that 'palliative care and pain management is becoming an increasingly specialised field which, again, translates very poorly into rural and remote areas. I am very distressed to say that the worst palliative care services are often for children's cancers'. Dr Page also stated that 'palliative care is something which should be available in every country town' and highlighted 'there are a vast number of GPs out there with palliative care skills and advanced level pain management skills'.[50]

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[48] *Committee Hansard* 20.4.05, p.84 (Dr Lopert).

[49] *Submission* 87, Additional information, p 1 (DoHA).

[50] *Committee Hansard* 19.4.05, p.84 (Dr Page).

5.71 Palliative Care Australia, the peak national organisation representing palliative care in Australia released a detailed set of standards for providing quality palliative care for all Australians on 23 May 2005. Workshops to promote and explain the new standards are currently underway throughout the country.

5.72 The Committee noted that as the Australian population ages and the incidence of cancer increases, the community's need for quality, long-term palliative care will grow. It is essential that the health care system (including public, private and not-for-profit) is well equipped to provide quality palliative care services that meet new national standards.