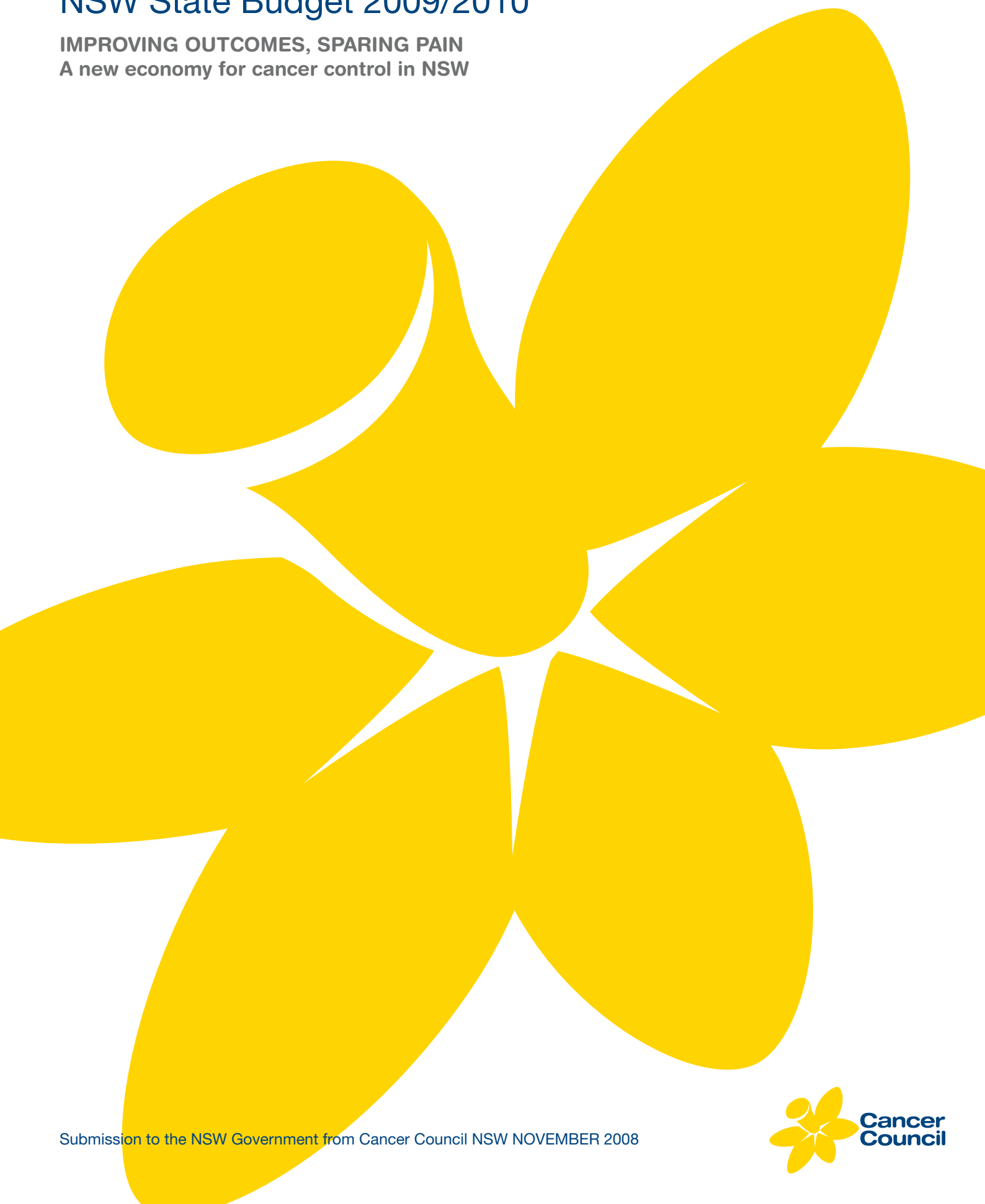


Budget Initiatives for Cancer Control

NSW State Budget 2009/2010

IMPROVING OUTCOMES, SPARING PAIN
A new economy for cancer control in NSW



Contents

Introduction	2
Executive summary	4
Improving radiotherapy services	8
Reducing bowel cancer	12
Reducing liver cancer	14
Helping people with the cost of cancer	17
Getting people to treatment	20
Smoking cessation	23
Better reporting of waiting times	25
Revenue raising option: tobacco licensing fees	28
References	29

Introduction

Cancer Council NSW is the leading cancer charity in the state. Our mission is to defeat cancer. Cancer Council envisages a future where no life is cut short nor its quality diminished by cancer.

The work of Cancer Council brings us into close and continuous contact with cancer patients and their carers, cancer consumer groups, health professionals, service providers and the community. Our strong and multifaceted connections give Cancer Council a 360 degree perspective of cancer control challenges and opportunities. Our perspective is

informed by 20,000 calls per year to Cancer Council Helpline, nine Regional Advisory Committees across the state, local community networks associated with ten regional offices, and links with 280 cancer support groups, and 350 trained advocates. Cancer Council also relies on strong partnerships with organisations such as Cancer Voices NSW, the NSW Council of Social Service (NCOSS), the Aboriginal Health and Medical Research Council (AHMRC) and leading health professionals and their representative bodies.

Although cancer survival in NSW is now amongst the highest in the world, there are many cancer patients who miss out on treatment or experience significant hardship.

Cancer has become the fifth most costly disease to Australia's health system.¹ For example, the NSW Government bears the bulk of the health care costs caused by tobacco smoking. The direct health care costs attributable to smoking as borne by the NSW Government exceed \$450 million while the total economic cost of smoking to NSW was more than \$6.5 billion when including the costs of pain and suffering.²

Cancer Council and its partners recognise that prevention and good value-for-money initiatives are an essential part of health service delivery. In this current tough economic climate, there is an opportunity

for the NSW Government to show its commitment to visionary state planning, and follow through on evidence-based policy and program developments that make a real difference to the lives of the citizens of NSW.

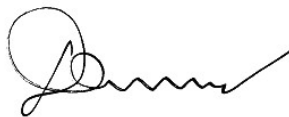
The NSW Government's *State Plan*,³ which is now integrated with the State Budget, has set ambitious targets to drive demonstrable improvements in delivery of government services for a ten year period, with a commitment to clear accounting and enhanced public reporting. Each priority in the *State Plan* has been allocated a lead Minister and a lead departmental CEO, with ultimate responsibility resting with the Premier.

The initiatives outlined in *Budget Initiatives for Cancer Control*, which are intended to inform the State Budget 2009/10, do not represent an exhaustive list of all cancer spending priorities. They are evidence-based solutions to address the top seven issues identified by the cancer community and our stakeholders. The measures outlined in this budget submission are mostly intended as additional spending to improve existing programs, and are aligned directly with the priorities of the *State Plan*. Many of the initiatives outlined in this document will save the lives of cancer patients, and will be cost-effective for the NSW economy. This package of initiatives will ensure that all people in NSW have the

best possible access to cancer control measures no matter where they live, their cultural background, or their income.

Cancer Council would like to take this opportunity to congratulate the NSW Government for the *Public Health (Tobacco) Bill 2008*, which will implement a raft of measures to protect children and our community from tobacco. Although the provisions outlined in the Bill still require some fine-tuning, this legislation will have far-reaching impacts and will significantly reduce health costs due to cancer.

Finally, the NSW Government now has a unique opportunity to raise considerable revenue by implementing a licensing system that imposes a fee on all tobacco retailers. As we outline further in this document, this measure could potentially raise \$200 million each year in revenue for the NSW Government.



Andrew Penman
CEO
November 2008

Executive summary

Cancer Council is the leading cancer charity in the state. Our mission is to defeat cancer.

Cancer Council envisages a future where no life is cut short nor its quality diminished by cancer. To achieve this, we present a package of costed proposals which requires an additional commitment of \$603 million over a five year period. We also propose that the government raise \$200 million per year by charging a fee for tobacco licences. This package of initiatives will ensure that all people in NSW have the best possible access to cancer control measures, no matter where they live, their cultural background, or their income.

1. Improving radiotherapy services

Thousands of people each year miss out on radiotherapy treatment in NSW. International and Australian benchmarks have established that 52% of all cancer patients should receive radiotherapy treatment. The main reason for not achieving the benchmark treatment rate in NSW is the lack of capital equipment. Ongoing shortages in the radiotherapy workforce are also a factor. At least 75 linear accelerators will be needed across NSW by 2015 to meet demand.

2. Reducing bowel cancer through the National Bowel Cancer Screening Program

The NSW Government needs to ensure the timely roll-out of the National Bowel Cancer Screening Program by facilitating the participation of all population groups and reducing colonoscopy waiting times. Ensuring adequate follow-up, plus expansion of the National Bowel Screening Program to include all people aged over 50 years of age would deliver mortality reductions of between 13-17% for patients with bowel cancer.

3. Reducing liver cancer through screening for hepatitis B

People from migrant Asian communities are at higher risk of hepatitis-related liver cancer than the general population. NSW has the highest number of hepatitis B infections in Australia. A targeted hepatitis B screening and surveillance program for the Greater Sydney area will halve the number of people developing liver cancer or severe liver disease and save 1,200 lives in the long-term while providing significant cost-savings to the health system.

4. Helping people with the cost of cancer

Households affected by cancer face an average of \$47,000 in out-of-pocket costs and lost income. For families on low incomes, the financial costs associated with cancer can cause lifelong hardship. Increasing the eligibility criteria and the types of items available under the Program of Appliances for Disabled People will increase the quality of life of many cancer patients. This will also ensure people with cancer are able to remain at home for as long as possible.

5. Getting people to treatment

Community transport providers in NSW refuse an estimated 90,000 requests for transport to health facilities each year; this occurs in both metropolitan and non-metropolitan regions. The Isolated Patients Travel Accommodation and Assistance Scheme cannot adequately assist people who have to travel more than 100km for medical treatment. Expansion of these health-related transport schemes will provide necessary financial relief to cancer patients and increase the number of people able to access transport to medical treatment.

6. Smoking cessation help for those most in need

People in low income or other disadvantaged groups have higher rates of cigarette smoking. Targeted interventions including the provision of free nicotine-replacement therapy via community services could increase quitting among vulnerable groups including at-risk young people, Indigenous people and people with mental illness.

7. Better reporting of waiting times

Countries such as Canada and the United Kingdom publicly report waiting times for a range of cancer services, including surgery, chemotherapy and radiotherapy. Although the NSW Government has an on-line database of surgery waiting lists, there is no user-friendly, on-line database which includes waiting times for surgery, chemotherapy and radiotherapy broken down by rural, regional and metropolitan treatment centres. This would help patients and their doctors determine the most suitable treatment centre as well as demonstrate government accountability for these services.

Summary of initiatives

Revenue	
Tobacco licensing fees	
Expenditure	
1. Improving radiotherapy services	
	Capital costs
	Recurrent costs
2. Reducing bowel cancer	
	Recurrent costs
3. Reducing liver cancer	
	Recurrent costs
4. Helping with the cost of cancer	
	Recurrent costs
5. Getting people to treatment	
	Recurrent costs
6. Smoking cessation	
	Recurrent costs
7. Better reporting of waiting times	
	Recurrent costs
Total capital expenditure	
Total recurrent expenditure	
TOTAL	
NET SURPLUS	

*These figures do not include an allowance for inflation or discounting.

Additional expenditure 1st year (\$million)	Additional expenditure 5 years* (\$million)
200	1,000
30	170
20	160
9.3	50.5
1	6
33.8	169
7.3	36.5
2	10
0.15	0.75
30	170
73.1	433
103.1	603
96.9	396

1. Improving radiotherapy services

Objective

To ensure that 52% of NSW cancer patients receive radiotherapy as per the treatment benchmark.

Background

Radiotherapy* is the use of ionising radiation for the treatment of cancer. The aim of radiotherapy is to deliver as high a dose of radiation as possible to the cancerous tumour, whilst sparing the surrounding normal tissues. Radiotherapy is an essential component of cancer treatment, and is part of the treatment of 40% of cancer patients who are cured.⁴ Radiotherapy is also used for palliation and symptom control in cases of advanced cancer. Despite the high establishment costs, radiotherapy is a cost effective therapy^{5,6} especially when compared to other cancer treatments such as chemotherapy.⁷

Benchmarks for the rate of radiotherapy have been established for various types of cancers in Europe⁸ and Australia,⁹ with the overall appropriate radiotherapy treatment rate established as **52% of all cancer patients**. Sweden¹⁰ and Canada¹¹ have reported attaining close to the benchmark rate for radiotherapy treatment. Canada has also instituted a “wait times” website so all citizens can monitor the provision of cancer services.¹¹ The United Kingdom has audited their radiotherapy services and have been advised to procure an additional 90 linear accelerators (linacs) by 2016 in order to meet projected demand.¹²

Historically radiotherapy has been provided at large regional or metropolitan cancer centres. However, a recent study from Victoria has shown that smaller satellite centres can provide safe, effective radiotherapy on par with that of the larger centres.¹³

Elizabeth’s story

I am a sole parent who had recurrent cancer in 2004. I was referred to the Gosford radiotherapy unit by my oncologist and specialist. My initial consultation with the specialist at the facility was certainly an eye opener. After carefully outlining my treatment plan the doctor proceeded to tell me the quote for my treatment. I was absolutely stunned when he told me the cost was \$8,000. I couldn’t speak. The doctor went on to tell me when the treatment would start, with tears in my eyes I told him that there was no way I had that amount of money. He was concerned and told me to speak to the practice manager who would see to an arrangement being made for a payment plan. I couldn’t see for watery eyes and just wanted to get out of there and go home. I was mortified.

There were others in the waiting room and I overheard the receptionist taking money for other people’s treatment plans. The diagnosis of cancer had been scary but knowing that treatment was out of reach made the situation seem hopeless. I knew I wasn’t alone. There were others in that room then that had to face the same reality. At no time was I made aware that there was another option of free radiotherapy at the Royal North Shore Hospital.

No one should have to make a decision to opt out of treatment because of cost or inaccessibility. I had children to consider as well as my own health. When you have not had to deal with cancer you don’t know that the treatments for cancer have huge costs involved. This should never become an issue for any patient.

* Also called radiation therapy.

Radiotherapy in NSW

Although cancer survival rates in NSW are now on average among the highest in the world,¹⁴ many people are missing out on life-saving radiotherapy treatment. Over fifty inquiries into radiotherapy have so far taken place in Australia; however at last count, less than 40% of cancer patients received radiotherapy in NSW. For example, a study into colorectal cancer found that more than half of eligible patients missed out on pre-operative radiotherapy as recommended in clinical guidelines.¹⁵ Overall, we estimate that at least 5,000 cancer patients miss out on radiotherapy each year.

The main reasons for not achieving the benchmark treatment rate in NSW is the lack of capital equipment and ongoing shortages in the radiotherapy workforce. Currently, there are 42 linacs operating at 18 sites in NSW. The majority of public facilities (70%) are located in metropolitan Sydney. Although there have been reports of improvements in productivity at radiotherapy facilities due to changes in business practices,¹⁶ even if the existing linacs are operating at optimal capacity with the full complement of staff, they cannot physically deliver enough radiotherapy fractions to meet current demand.

In many areas, geographical distance creates additional problems for people living in rural and regional areas. Due to our unique geography, Australia requires more linacs per head of population than more centralised populations, such as in Europe.⁸ Cancer Council has welcomed the establishment of new linacs in Coffs Harbour and Port Macquarie, although these projects were delayed for several years. The facilities planned for Orange and Lismore have also been delayed and are not expected to be completed by their planned deadlines.

Several cancer patients have reported to Cancer Council that although they were able to receive treatment at the private facilities in Wagga Wagga or Gosford, they faced personal costs of thousands of dollars, either in gap fees for the radiotherapy treatment itself or in consultancy fees. Public patients referred for treatment must either pay the fees or must travel to one of the sites in Sydney or Newcastle for an extended period of time, which typically ranges

from three to six weeks. There are no public radiation therapy facilities in the Central Coast, Greater Western or the Greater Southern Area Health Service regions. The facility which has been announced for Orange will be provided as a public/private partnership.¹⁷ There are no immediate plans to provide a public facility in Gosford, despite public demand for this service.¹⁷

Radiotherapy planning and reporting

Since the release of the *Radiation Oncology Inquiry* in 2002,¹⁸ the NSW Government has compiled several five-year radiotherapy plans designed to address the low rates of treatment in NSW, although the latest plan is now overdue. Workforce issues such as staff shortages and attrition have been tackled, with the establishment of academic fellowships and 108 new professional development year training positions for radiation oncology graduates and a business improvement program.¹⁶ However, despite these measures, cancer patients are reporting waiting times of several months at public radiotherapy facilities such as St George Hospital, apparently due to staffing problems.

The waiting times for radiotherapy are not collected centrally by NSW Health nor publicly reported, creating monitoring problems for health authorities, as well as referral difficulties for patients and their doctors.

An estimated 40,000 people will be diagnosed with cancer in 2011.¹⁹ It is unknown whether government planning for future radiotherapy need is adequate, as the latest radiotherapy plan has not been publicly released. Adequate and equitable access to radiotherapy must be a health care goal for the NSW Government. To meet future demands, adequate planning and forecasting in consultation with industry experts and stakeholders needs to occur in a transparent and timely manner.

In order to attain the recognised benchmark of radiotherapy treatment, as an interim step at least 66 linacs would be needed by 2011, 24 more

than currently exist.* At least 75 linacs would then be required in total by 2015 to meet projected demand. Cancer Council understands that the NSW Government has approved or is considering 12 linacs at various sites, 8 of which have been proposed by the private sector. We understand that funding has already been set aside for linacs at Lismore, Orange, Royal Prince Alfred Hospital and Liverpool Hospital. We recommend that the government fast-tracks the facilities under consideration and establishes a further 12 linacs by 2011 as a first step in increasing radiotherapy services. An additional 9 linacs would then be required by 2015.

Actions

- Establish 24 new linacs by 2011, to be located in key population catchment areas. A variety of funding sources could be used for these facilities, including private sector funding. We estimate the NSW Government would have to fund at least **12 new linacs** and their facilities directly by 2011, as an initial first step.
- Establish more linacs in regional and rural centres to overcome the travel and social challenges for patients and their families.
- Commit to and disseminate an appropriate and timely radiotherapy plan, which includes consultation with stakeholders and experts, and ensures equitable access to radiotherapy treatment and attainment of recognised benchmarks and safety and quality standards.
- Increase the number of radiation oncologists, radiation therapists and medical physicists plus allow for additional nursing, clerical and allied health staff to meet demand by 2011.
- Establish an adequate budget for purchasing publicly-funded radiotherapy services at an agreed rate, with minimal out-of-pocket costs to the patient in regions where the only available facility is privately-funded.
- Establish a reporting system on waiting times for radiotherapy to improve medical referral processes as well as government accountability.
- Establish a body to oversee design, funding and procurement of radiotherapy services.

* Forecasts of radiotherapy requirements were based on the benchmark of 52% of all cancer patients initially requiring radiotherapy and 25% requiring re-treatment (see Delaney et al., 2003). Radiotherapy for palliation and non-cancer conditions were not included. Therefore, for every 1000 people with notifiable cancer, 654 courses of radiotherapy will be required per year. Each linac is assumed to deliver 414 courses of radiotherapy per machine per year. This utilisation rate was chosen in order to maintain professional and safety standards.

Results

- **Improved access to quality healthcare [S1].***
Increasing the number of linacs and associated workforce capacity will assist in achieving the treatment benchmark of 52% of cancer patients treated by 2011, and therefore improve access to care for people with cancer.

Costs

Radiation oncology professionals have advised Cancer Council that a typical two-machine department will cost approximately \$10 to \$12 million to establish, including cost of linacs and bunkers. To establish 12 new linacs in NSW, in addition to those already planned or under consideration, **\$170 million** will be required for infrastructure costs for the purchase of linacs and bunkers, with approximately **\$40 million** required each year in staff costs by the time the facilities are completed. As more linacs are built towards 2015, the infrastructure and staff costs will increase accordingly.

Capital costs

- \$30 million for first year
- \$170 million over five years[†]

Recurrent costs (planning, staff costs and consumables)

- \$20 million in first year, rising to \$40 million on average per year for 12 facilities. Total recurrent costs estimated at \$160 million over a five year period.

* NSW Government State Plan (2006) priority.

† The five-year costs in this document do not include an allowance for inflation and are not discounted.

2. Reducing bowel cancer through the National Bowel Cancer Screening Program

Objective

To decrease the number of avoidable deaths from bowel cancer in NSW.

Background

Bowel cancer is one of the most common forms of cancer, with more than 4,500 new cases and 1,600 deaths in NSW each year.²⁰ The lifetime risk of developing bowel cancer before the age of 75 years is around 1 in 17 for men and 1 in 26 for women.²⁰ If the cancer is detected early, the five-year survival rate is around 90% of all patients. However, if cancer is detected at a later stage, the five-year survival drops to 7%.²¹ A review of bowel cancer showed that there is greater variance in mortality rates between health areas; with the highest deaths from bowel cancer occurring in the Hunter New England AHS region, followed by the Greater Southern AHS.²²

International and Australian trials have validated the effectiveness and acceptability of faecal occult blood tests (FOBT) as a population-based bowel cancer screening tool.^{23,24} A positive FOBT is most often investigated by colonoscopy, with removal of pre-cancerous polyps or cancerous lesions if present. The National Bowel Cancer Screening Program (NBCSP),²³ currently invites 55 and 65 year olds to undergo a FOBT. The Federal Government announced in May 2008 that the entry age for screening will be dropped to include people who have turned 50 years old.²⁵ This program is expected eventually to reflect the scientific evidence that any asymptomatic, average-risk person between the ages of 50 and 74 years should undergo FOBT every two years. Expanding the NBCSP to the larger age range

would be expected to decrease mortality reductions by between 13-17% for patients with bowel cancer.²⁰

FOBT uptake by eligible people was around 45.5% in the national screening program.²⁶ Low awareness of bowel cancer and the effectiveness of the FOBT test are significant barriers to screening participation.^{27,28} Concerns were raised in the evaluation of the pilot program that certain groups are even less likely to participate in the program, for example, those from non-English-speaking backgrounds, Aboriginal and Torres Strait Islanders and people in low socioeconomic groups.²³ No targeted strategies have been identified to enhance participation amongst these groups.

In 2002, Cancer Council commissioned an economic study²⁹ which found that early detection and treatment of bowel cancer represents considerable savings compared to the costs of treating advanced cancer. Removal of a small polyp (the early stage of bowel cancer) was estimated to cost **\$1,250 per patient**, whereas treatment for established cancer with surgery and chemotherapy at a public hospital can cost over **\$23,400 per patient**.^{*} In addition, early detection enables people to maintain their health and participation in the workforce and the community. Thus the program would add \$2.9 billion to the gross domestic product over 35 years.

Although recruitment to the NBCSP is a national responsibility, the subsequent increase in demand for colonoscopies is a cost to be shared between the state public and private sector health services. The NSW Government is responsible for public sector colonoscopies, histopathology and any subsequent treatments in state hospitals. However, the Cancer Council economic modelling study identified that there was serious under-capacity in colonoscopy services in both metropolitan and regional NSW. Cancer Council consultations with cancer advocacy groups over the past year have heard that colonoscopy waiting times can be several months for non-urgent public patients, however private patients are seen promptly in some Area Health Service regions.

* In 2002 economic values.

John's story

At breakfast one bright spring morning in 1999, I felt a sudden excruciating pain in the pit of my stomach. No matter what I did, it persisted, grew even worse. My wife called an ambulance. At Royal Prince Alfred, I was put through a battery of tests. It was cancer – a colon cancer stage IIIc that had spread to at least nine adjacent lymph glands. The tumour itself had perforated, spilling its poison throughout my intestines. The first pressing issue was to survive this poison crisis.

For the next five days I was barely conscious, deeply sedated with morphine. I do remember one night hearing concerned nurses' voices whispering softly, "I think we're losing him." On the sixth day, Saturday I woke. I had survived the first crisis. But I had become an integral part of the hospital, connected to the wall behind me through a labyrinth of tubes. It was not until the stoma nurse arrived that I discovered that an opening had been left in the left side of my abdomen for a colostomy bag. The bag was to be my constant companion for the next eight months.

From early 2000, three days of every second week involved chemotherapy, as part of a trial. I had a few chemotherapy side effects, mainly tingling and pain in my fingers and feet. Seven years later I am a "survivor". The chemotherapy trial was a success, decreased my chances of dying by a significant margin and is now standard therapy. Until this year when I was considered safe, I had frequent checkups at the hospital and regular colonoscopies to ensure that the cancer has not returned.

Without question, if bowel screening had been available then, I could have been spared this journey.

Actions

- Address the significant disparities that exist in current public colonoscopy waiting lists and increase the availability of colonoscopy and other relevant services throughout NSW to adequately meet demands of the full roll-out of the National Bowel Screening Program by 2009/10.
- Publicly release the plans to commit appropriate resources to cope with the full roll-out of the program.
- Apply effective strategies to support recruitment, referral and follow-up by GPs in NSW.

Results

- **Improved survival rates and quality of life for people with potentially fatal or chronic illness through improvements in health care [S2].** Full expansion of the NBCSP would deliver mortality reductions of between 13-17% for patients with bowel cancer. To not do so will engender greater costs, both economic and psychological, in the longer term.

Cost (recurrent)

Expanding the NBCSP to include all people aged between 50 and 74 years will cost the Australian health system \$130.8 million in the first year, rising to \$169.7 million by the tenth year. These costs do not include the cost of treating the actual cancer detected by the program, other than polyp removal.²⁰ Cancer Council estimates that the costs of expanding the NBCSP to include the recommended age range would be approximately \$9.3 million in the first year, \$10.5 million in the fifth year, and \$12.2 million by the tenth year to the NSW Government.[‡]

\$9.3 million for the first year
\$50.5 million over five years

[‡] Derived from the Bishop et al. (2008) national figures by adjusting by the proportion of bowel cancer incidence in the over 50 year olds in NSW (34%) (AIHW & DoHA, 2008) and by the proportion of health care costs relating to colorectal cancer borne by the NSW Government (21%) (Access Economics, 2007).

3. Reducing liver cancer through hepatitis B screening

Objective

To reduce the avoidable incidence of liver cancer in NSW.

Background

The incidence and mortality of liver cancer has doubled over the last two decades in NSW.³⁰ Almost half of all primary liver cancers occurred in people who were born overseas, including people born in Vietnam, Hong Kong, Macau, Korea, Indonesia and China.³¹ Hepatitis B is a major cause of preventable liver cancer; people with chronic hepatitis B have a **20 to 100 times higher risk** of developing liver cancer compared to the general population.³² Nearly 40% of Australia's notified cases of hepatitis B occur in NSW,³³ where an estimated 60,000 people have a positive hepatitis B status (see Figure 1).³⁴

Most people are unaware of their hepatitis B status until diagnosed with liver cancer or other complications. By this time, cancer is often advanced and the prognosis is poor.³⁵ By contrast, timely detection and treatment of asymptomatic people who are hepatitis B positive with anti-viral treatments can substantially decrease the rate of progression to liver cancer or cirrhosis.^{36,37} This would be expected to decrease the number of people with chronic hepatitis B presenting to hospital with advanced disease and requiring liver resection and other costly interventions. However, only a small proportion of people with hepatitis B in Australia receive appropriate treatment in time to prevent cancer progression.³⁸ International studies have recommended population-based screening in high-risk groups,³⁹ and hepatitis screening programs have been successful in New Zealand.⁴⁰⁻⁴³

Cancer Council commenced a collaborative pilot project in May 2007 for hepatitis B screening and liver cancer surveillance (the *B Positive* Project) in the south west of Sydney, an area identified as having high chronic hepatitis B infection and liver cancer incidence.⁴⁴ The engagement of local government and NSW Health has assisted the pilot project development.

A component of the pilot project study included modelling the cost effectiveness for a targeted program of hepatitis B and liver cancer detection through screening on a geographical basis.³⁴ Four scenarios were investigated: the pilot project area of Fairfield-Liverpool, a larger Greater Sydney scenario, a NSW-wide scenario, and a national strategy. The model found that a comprehensive screening and treatment program of high-risk populations across NSW is both feasible and cost-effective, compared to current clinical practice. For example, if the pilot program were expanded without delay as a Greater Sydney strategy to reach 8,000 people (approximately 13% of the infected population in NSW), the program would save 1,200 lives over a fifty-year period. This compares favourably with other cancer screening programs.³⁴

The Cancer Council economic model estimated the costs incurred by different participants and funding bodies in this program. By far the largest expenses are associated with disease staging (hepatitis B viral load testing) and drug treatment (Entecavir and interferon) and therefore will be borne by the Federal Government through the PBS and PBAC schemes. According to our model, the Federal Government will bear at least 70% of the program cost in the first year, rising to 90% by the fifth year.³⁴

However, expanding the *B Positive* Project to the Greater Sydney area would lead to approximately fifteen additional GP visits a year for the target population, and a significant increase in demand for specialist assessment and treatment by liver specialists through liver clinics. This is estimated to translate into each of the existing liver clinics in the target areas needing to see an additional ten patients each week. Therefore it is imperative that follow up strategies are developed by NSW Health in collaboration with the Area Health Services and health care providers.

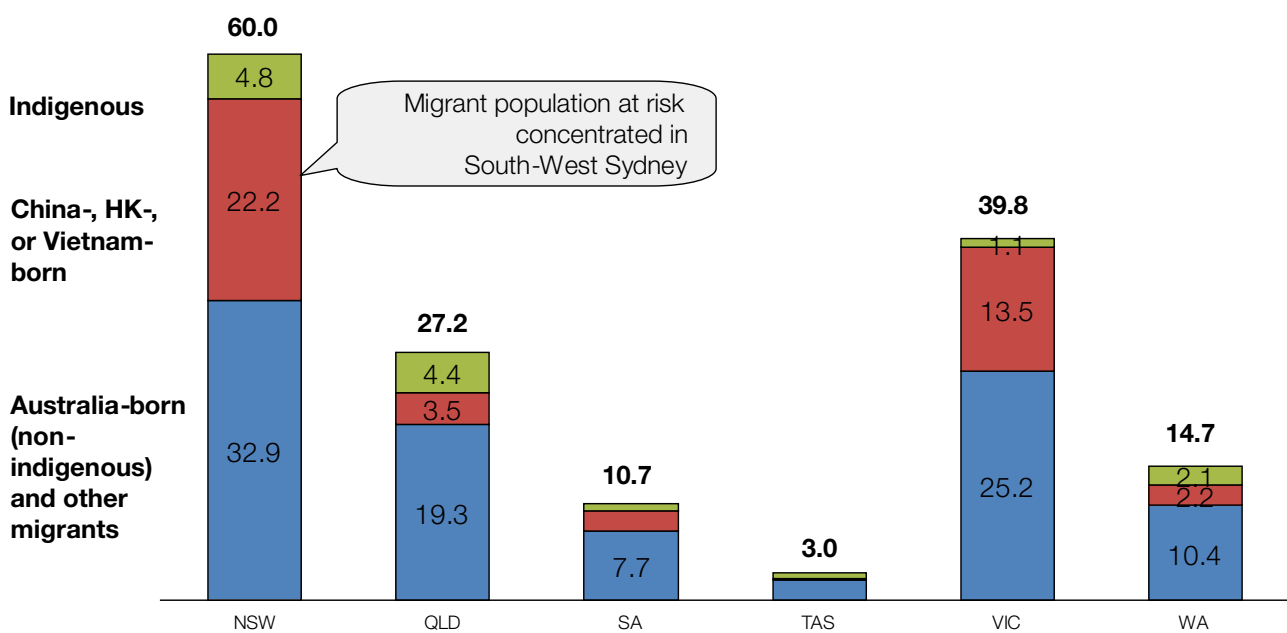
The Cancer Council has recently also collaborated with the Australasian Society for HIV Medicine to develop a new resource for primary care clinicians describing the clinical management of people with hepatitis B, which has been distributed to all primary care practitioners and many other health care professionals.⁴⁵ We also supported the listing of hepatitis B viral load assays on the Medical Benefits Schedule to enable earlier diagnosis and monitoring of treatment efficacy.

A relatively modest investment by the NSW Government can lead to significant improvement in outcomes for people with chronic hepatitis B. The *B Positive* Project represents an unparalleled opportunity for the NSW Government to lead the way in providing a comprehensive and targeted hepatitis B screening program and a liver cancer surveillance program and save thousands of lives.

Figure 1: NSW has the highest number of hepatitis B infections in Australia

Hepatitis B Infections by State and Population Group

Thousands of Hepatitis B infections



Notes: ACT and NT have together about another 5,200 cases
 Source: ABS 2006 census; Nguyen et. al. 2007; O'Sullivan et. al.; G. Dore; team analysis

A GP's story

Alan migrated from Hong Kong in 1997. Four and a half years ago his brother died of liver cancer within a year of diagnosis. Because of this, all the siblings came for check-ups at my clinic even though they had no symptoms. Alan was found to be hepatitis B positive and further investigations showed that he had a small cancer in his liver.

He was operated on in Royal Prince Alfred Hospital removing the tumour and one third of his liver. He has been well for nearly five years, playing tennis three times a week, mahjong every week and has taken many trips around the world.

Actions

We seek the NSW Government's support and political engagement to:

- Fund and support the implementation of targeted hepatitis B screening and liver cancer surveillance in the Greater Sydney area.
- Provide resources for workforce development by increasing the number of clinical, research and support staff (health interpreters, translators and multicultural health workers) to cope with increased workload.
- Support the development of a National Hepatitis B Strategy.
- Strengthen the collaboration between the State and Federal Governments to ensure that people with chronic hepatitis B receive timely diagnosis and treatment, to reduce the burden of disease related to this condition in Australia.

Results

- **Improved access to quality health care [S1]** for migrants in suburban areas where the demand for hepatitis-related services is above the State average (e.g. Sydney South West Area health Service, Sydney West Area health Service and those with high Indigenous populations).
- **Improved survival rates and quality of life for people with potentially fatal chronic hepatitis B or its sequelae, including liver cancer [S2].**
- **Reduced avoidable hospital admissions [F5]** as a direct result of preventative treatment in the home or community.

Costs (recurrent)

Costs of the roll-out of a hepatitis B program in the Greater Sydney area will be dependent on the geographic and ethnic mix of the target population, with the costs per head treated expected to be similar to the Cancer Council *B Positive* pilot program. A large proportion of the costs of this program will be borne by the federal health service. The estimated costs to the NSW government are listed below:

\$1 million in the first year
\$6 million over the first 5 years

4. Helping people with the cost of cancer

Objective

To reduce the financial burden of cancer on patients and their families by expanding eligibility and provisions of the Program of Appliances for Disabled People.

Background

The financial costs associated with cancer can cause lifelong hardship, especially for families on low incomes. An Access Economics report⁴⁶ found that households face average costs of **\$47,200** when one of its members is diagnosed with cancer. This includes approximately \$38,000 in loss-of-income as well as \$9,000 in health care and other out-of-pocket costs such as transport and specialised aids and equipment. These costs are borne at a time of great stress and illness.

In the past six months alone, over 550 people telephoned Cancer Council Helpline regarding financial issues. Over the past year, Cancer Council has provided financial assistance to 1,910 cancer patients and their carers, with small grants of \$300 (total of \$525,000) to assist with urgent bills.

The Program of Appliances for Disabled People (PADP) provides equipment, aids and appliances to people with a life-long or long-term disability in order to support them to live independently in the home.

However, a review by PriceWaterhouse-Coopers (PWC), noted that the level of government funding for the PADP meant that the program could not reliably satisfy consumer expectations. This under-funding could lead to a material decrease in the quality of life for those who miss out on necessary items.⁴⁷

Eligibility of cancer patients for the PADP

There is confusion surrounding the eligibility of cancer patients for the PADP, and especially palliative patients, as noted in the PWC review.⁴⁷ The target population for PADP is those individuals living in the community who have a disability of permanent or indefinite nature (e.g. a disability likely to last more than 12 months regardless of the cause of the disability) as defined under the *Disability Services Act 1993*.⁴⁸

However, cancer patients do not usually fall under the criteria of a permanent disability and, in many cases, the prognosis is uncertain such that medical specialists cannot always accurately predict when or if the person with cancer will recover. Cancer Council recommends that the PADP policy guidelines are altered to ensure the eligibility of cancer patients, including palliative patients, for PADP items.

Specialised equipment to help in the care of the person with cancer is a factor affecting the capacity to remain in the home and therefore prevent the patient's unnecessary transfer to a hospice or hospital. The review of the PADP noted that under-funding of the program led to long waiting lists for some items. Being placed on a waiting list is untenable for those cancer patients who are in the palliative stage or end-stage of illness. Greater awareness of the PADP amongst health professionals and cancer patients would also assist people to access the equipment they need. Cancer Council recommends that those who have been defined as in the palliative phase of illness be placed on a 'high priority' list, so that they are able to access the equipment they need in a timely manner.

Compression sleeves

Lymphoedema is the swelling of the arms and legs which can happen after the surgical removal of lymph nodes, for example as part of cancer treatment. Lymphoedema occurs in over 20% of all cancer patients who have undergone lymph node removal.⁴⁹ Although exact numbers are hard to determine, the Australian Physiotherapists Association has estimated that there are 25,000 cases of lymphoedema in Australia each year from cancer treatment and other causes.⁵⁰

The use of compression sleeves in conjunction with lymph drainage massage by a physiotherapist can reduce the symptoms of lymphoedema and improve quality of life for cancer patients.⁴⁹ This is one of the few evidence-based treatment options for this condition. The cost of a pair of compression sleeves is approximately \$600; these need replacing at least once each year. For those cancer patients for whom more than one limb is affected by lymphoedema, two or more compression sleeves will be needed at any one time. Some of the costs of lymphoedema sleeves are borne by the private health insurance industry. Patients with certain types of private health insurance cover may be able to claim some of the cost of these sleeves.

Under the proposed changes to the PADP income tiers, as outlined in the NSW Government's response to the PWC inquiry,⁵¹ only those with an income of less than \$30,000 would be eligible for compression sleeves, although they are an essential item for the physical and mental wellbeing of many cancer patients.

Home enteral nutrition

Home Enteral Nutrition (HEN) refers to food in liquid form given through a tube into the stomach or the small intestine, provided in the home setting. HEN supplies are used by people who are unable to ingest food by oral intake, such as those with head and neck cancer. An inquiry by the Greater Metropolitan Clinical Taskforce Home Enteral Nutrition Network estimated that there are at least 10,000 patients receiving HEN therapy in NSW; of which approximately 34% are cancer patients.⁵² The inquiry also found that although half of all HEN recipients are financially disadvantaged, only 20% of tube-fed HEN patients received PADP assistance. The PADP provides some subsidy towards tube-feeding equipment (feeding pump and bags), but does not include provision for the supplement formula.⁴⁸

Presently the cost of HEN formula is borne by patients, although they are now able to purchase the supplies at the lower government contract prices. For tube fed HEN, this can cost patients approximately \$300 per month, depending on the feeding apparatus involved.⁵² The GMCT report noted that HEN tube feeding equipment is sometimes re-used by patients due to its cost, which has safety implications.

Community care nurse, Sydney

Even with all other possible supports in place, the lack of access to enough, affordable and appropriate equipment for patient care can be the stumbling block to continued successful care of the palliative patient at home. Equipment is expensive to hire or purchase and the sources we have now for procuring equipment on loan do not stretch far enough. Apart from patient care, the correct equipment is key to maintaining the health and safety of both unpaid and paid carers.

Increases to PADP funding

Cancer Council supports the Greater Metropolitan Clinical Taskforce HEN Network recommendation that NSW Health expand the PADP to include HEN formula, to relieve the cost burden on cancer patients and others who rely on tube feeding for all or part of their nutritional needs. A co-payment should only be considered for the small minority of patients who rely on HEN for their total nutritional intake and have higher incomes. The GMCT have estimated that expanding the HEN nutritional assistance program to include formula, as well as consumables and equipment, would cost NSW \$17.1 million* as a fully-funded model.⁵² Currently, the PADP spends approximately \$300,300 per year on supplying new HEN equipment to its clients,⁴⁷ an amount which is woefully inadequate. Thus an additional **\$16.8 million** would be required to expand the nutritional aids program for the 2009/10 State Budget.

In order to recognise the financial difficulties faced by PADP clients including cancer patients, Cancer Council supports removing the PADP co-payment requirement for those on lower incomes or with demonstrable financial difficulty. We recommend that the cut-off income tier for this provision be increased to \$45,000 (single income); this represents approximately 75% of the national average wage.⁵³ Additional funding of **\$17 million** would be required in 2009/10 as an intermediate step to cover the increase in the income eligibility criterion - as per the calculations in the PWC review. We recommend that the total budget should then rise to \$76 million in 2014/15 to meet the eligibility criterion increase completely.

Thus implementing the above Cancer Council recommendations would require a total budget increase of **\$33.8 million** towards the PADP in the 2009/10 State Budget.

Actions

- Ensure the eligibility of cancer patients and those in the palliative stage of their illness for PADP items.
- Remove co-payments for people earning less than \$45,000 (single income) per year, as they inflict unnecessary financial hardship and may delay people applying for necessary equipment.
- Expand the program to include provision of home enteral nutrition formula, in addition to tube feeding equipment.
- Ensure that those in the palliative stage of their illness are placed on a 'high-priority' list to receive PADP items.
- Develop and implement an information strategy that increases awareness of the PADP scheme amongst health professionals and cancer patients.

Results

- **Improved survival rates and quality of life for people with potentially fatal or chronic illness through improvements in health care [S2].** Cancer patients with ongoing disability such as people with lymphoedema or needing nutritional supplementation, will have increased quality of life due to greater access to essential items. This will also assist people with cancer to remain at home for as long as possible.
- **Reduced avoidable hospital admissions [F5]** for those receiving lymphoedema sleeves and nutritional supplements.

Cost (recurrent)

\$33.8 million each year
\$169 million over five years

* Figure derived from the GMCT report (2006) and adjusted for inflation to 2008 values.

5. Getting people to treatment

Objective

To remove transport as a barrier to accessing necessary medical treatment.

Background

Transport to medical treatment is a serious issue for many cancer patients.

Cancer treatments such as chemotherapy and radiotherapy often involve intensive periods of treatments requiring hospital attendance three to five times a week for several weeks, resulting in high transport and accommodation costs for many people. Cancer patients are often very ill following treatment and may require specialised transport.

Indigenous people face considerably greater barriers in transport to treatment centres – they have fewer private transport options, are more likely to find cost of travel and accommodation a barrier, and may face extreme distances for travel if they live on geographically isolated settlements. In Indigenous communities it is not uncommon for people to walk or hitchhike long distances in order to attend medical appointments.⁵⁴

The Transport for Health (TfH) program⁵⁵ is aimed at supporting Area Health Services to be more strategic in identifying, consolidating and integrating a full range of transport services and resources to increase effectiveness and reduce duplication.* Eligibility for support under TfH is wider than for other government schemes such as Home and Community Care and

it is provided on the basis of a patient's inability to reasonably gain access to local health services by either public or private transport.⁵⁵ However, a study into community transport commissioned by Cancer Council and the Council of Social Service of NSW (NCOSS) estimated that approximately **90,000** people were refused community transport for health-related trips each year in NSW.⁵⁴ The report found that although transport is a major issue in rural areas, metropolitan areas also have significant health transport problems. This study found that community transport providers in metropolitan areas refused 1 in 6 requests for health-related transport due to lack of capacity.

The Transport for Health/Isolated Patients Travel Accommodation and Assistance Scheme (IPTAAS) is a subsidy program which assists people travelling more than 100km each way to attend an appointment with their nearest medical specialist. IPTAAS is usually used by people who are being transported by private car, or in some instances taking rail or air travel. A federal inquiry into the operation of patient assisted travel schemes such as IPTAAS found that these schemes do not adequately compensate patients and do not overcome distance as a barrier to medical treatment.⁵⁶

Although many welcome changes to transport schemes have been implemented in the past two and a half years, including expanding the eligibility and increasing the reimbursement rate for IPTAAS, there are still many problems relating to the scheme, including: the high upfront costs of the scheme, relatively high non-refundable personal contribution levels, low levels of reimbursement for accommodation costs (\$46 per night for a double and \$33 per night for a single) and fuel (15c per km), the lack of ability to elect a carer, and the intensive paperwork required for each claim. In addition IPTAAS reimbursement can take up to three months. These barriers, especially the upfront costs and complex paperwork, means that many low income and Aboriginal people will not use the scheme.

* Transport for Health includes the Isolated Patients Travel and accommodation assistance Scheme (IPTAAS); the Health Related Transport Program, Inter-facility transport (non-Ambulance); Statewide Infant Screening-Hearing Program and services funded under the former Transport For Health Program

Nancy's Story

This is a personal account of my own experiences in relation to travelling for treatment after my husband was diagnosed with oesophageal cancer. Dealing with IPTAAS was an added burden I could have done without during one of the most stressful times in my life.

My husband, Carl, had an endoscopy at Armidale Hospital in October 2003. The surgeon who did the endoscopy came to the bedside and said, "I've got a problem, it's cancer. You'll have to go to Brisbane or Sydney for treatment."

We didn't know that any form of travel assistance was available and with family where we could stay two hours north of Brisbane, we chose Brisbane. Our first trip was 7 hours drive from Armidale each way. We had to attend the Princess Alexandra Hospital (PAH) on each of three days and the Wesley Hospital on one day. This involved two hours drive each way plus \$13 each time for parking. On one day Carl was unexpectedly kept overnight and I stayed with him until 10 pm at which time, exhausted by the day's events, I went to a motel across from the hospital at a cost of about \$70. A social worker from the hospital who helped us arrange accommodation for the 5 weeks of daily radiotherapy informed us of the IPTAAS scheme and gave us the forms.

Carl was admitted to PAH with complications at different times during his radiotherapy treatment and for those times IPTAAS paid nothing, not even the \$13 per night I as a carer could normally claim, reasoning that because Carl was in the hospital, I was not caring for him - hospital staff were. Reimbursement from IPTAAS was slow. Every application would be acknowledged by a letter saying it had been received and there was currently at least an eight week delay in payment. Remember, we were in the midst of a life and death struggle with more important things and

both exhausted; I was still working in between all this. Parking availability and cost was an issue. Carl had problems and I wasn't going to leave him there alone, by the time they had admitted him and I went to move the car I'd gotten a ticket for \$75. Coming on top of everything else I just burst into tears right there in the middle of the street.

Carl died on Jan 21, 2005.

Case study

A resident of a town which is 99km from Sydney, whose carer drives them to radiotherapy treatment in Sydney every day for a period of six weeks, would face out-of-pocket petrol costs of at least \$900 and would not be eligible for any reimbursement from the government.

Actions

Although many changes are required to position transport as a core health service, Cancer Council and NCOSS recommend an immediate increase for community transport funding, via the Transport for Health program, for the next budget period. NCOSS and Cancer Council are unable to cost the IPTAAS recommendations without access to relevant NSW Health expenditure and usage data. However, funding increases to these programs should incorporate the following:

Community Transport

- Increase access to medical treatment by expanding funding for non-emergency health transport services to \$10 million per year through the Transport for Health Program (an additional \$7.3 million will be required per year).
- Improve monitoring and evaluation of the Transport for Health Program, especially of those that are refused a service, in order to determine unmet need.
- Ensure health planning includes provision of patient accommodation and transit lounges at major health facilities, access to parking for patients and their escorts and adequate discharge planning procedures to ensure patients have transport home from hospital.
- Ensure that appropriate transport services are available for cancer patients who require specialised equipment and support.
- Create health transport options for Aboriginal people by providing dedicated and flexible services to Aboriginal communities, including increasing the network of Aboriginal transport coordinators.

IPTAAS

- Eliminate the \$20 administration fee for low income clients, including Health Care Card holders, pensioners or people with demonstrable financial difficulty.
- Ensure that people undergoing block or repeated treatments such as radiotherapy need only pay the personal contribution once per treatment cycle.
- Increase the petrol allowance to 21c per kilometre for private vehicles. This would cover the cost of petrol plus minimal wear and tear to the vehicle.
- Reform payment processes so that travel and accommodation expenses can be estimated and paid in advance, or 'bulk-billed.'

- Review the rates for accommodation, especially for the Sydney metropolitan area.
- Adjust the travel and accommodation reimbursement rates on a yearly basis to match consumer price index increases.

Results

- **Improved access to quality health care [S1].** Improved transport for rural, regional and metropolitan patients would ensure an increase in access to medical treatment.
- **Improved survival rates and quality of life for people with potentially fatal or chronic illness through improvements in health care [S2].** As transport would be less of a barrier to accessing health care, patients would access health care in a more frequent and timely manner, thus significantly improving survival and quality of life.
- **Improved health for Aboriginal people [F1].** Culturally-appropriate transport is a major factor preventing Indigenous people in remote communities from receiving health care. The above reforms would facilitate increased the frequency and timeliness of attendance at medical appointments.

Cost (recurrent, community transport only)

\$7.3 million each year
\$36.5 million for five years

6. Smoking cessation help for those most in need

Objective

To decrease tobacco use amongst low-income and disadvantaged population groups in NSW.

Background

Cigarette smoking is responsible for 7.8% of the total burden of disease and injury in Australia.⁵⁷ It is a major contributor to death and illness in NSW, and caused an estimated 6,507 deaths and 55,591 hospitalisations in 2004.⁵⁸ In NSW, smoking is the leading health risk factor for males, accounting for 10% of the burden of disease. For females, smoking is the fifth highest health risk factor, accounting for 6% of the burden of disease.⁵⁸

State governments bear the majority of the health care costs caused by tobacco smoking. The direct health care costs attributable to smoking borne by the NSW Government were estimated to be \$477 million for 1998/99.² When other costs such as lost productivity due to death and absenteeism, lost household labour and the value of lost life were included, the total economic cost of smoking to NSW was more than \$6.5 billion for that year. Furthermore, NSW Government expenditure on health care costs attributable to tobacco smoking (\$477 million in 1998)² exceeds the state's revenue from GST on tobacco sales (approximately \$236 million based on 2004 tobacco expenditure figures).⁵⁹

Whilst smoking rates across the community have declined in the last decade, smoking rates for low income and disadvantaged population groups

have remained high. Amongst males, 15% of the least disadvantaged quintile smoke compared to 23% of the most disadvantaged. Among females the gap is even greater, with only 10% of the least disadvantaged smoking compared to 26% of women in the most disadvantaged quintile.⁶⁰ Smoking rates are also higher amongst a range of vulnerable and disadvantaged groups:

- 82% of Aboriginal people and 77.2% of non-Aboriginal people in custody are current smokers. The majority of the population in custody surveyed were male (82%).⁶¹
- 51% of Aboriginal women report smoking during pregnancy.⁶²
- Between 20-90% of people with a mental illness smoke (prevalence rate varies depending on diagnosed condition).⁶³

There is growing evidence that many people in such groups want to quit smoking. For example, a literature review commissioned by Cancer Council concluded that there is strong evidence that people with a mental illness want to quit.⁶³ Other reviews found significant interest in quitting among people in drug treatment programs⁶⁴ and amongst homeless smokers.⁶⁵ These studies indicate that many disadvantaged people want to quit but face obstacles associated with their disadvantage which prevent them from doing so.

Cessation interventions such as nicotine replacement therapy (NRT) and counselling can each increase the chances of quitting by one and a half to two times.⁶⁶ However, the cost of NRT is frequently cited as a barrier to use for low income and socially disadvantaged groups.⁶⁷ Currently free NRT is only available to inpatients in NSW public hospitals. Provision of free or heavily subsidised NRT is the most commonly identified strategy by staff of community service agencies to assist their clients to quit smoking.⁶⁷

Both one-to-one counselling and group counselling approximately double the chances of quitting, compared to no treatment. It is also more effective than brief advice alone.⁶⁶ Many government-funded community agencies in NSW already provide these types of counselling services to assist disadvantaged

people who have other issues, and many are in an ideal position to incorporate quitting support into their usual service delivery.

In collaboration with NCOSS, Cancer Council has been working with the community sector on tobacco control and there is now considerable interest from community sector agencies for training to allow their staff to provide these services. Staff training to make quitting support part of usual care would increase their capacity to provide effective cessation support to their clients in a sustainable way, ensuring that there is on-going support for clients through the quit attempts which lead to successful long term cessation.⁶⁸ NSW Health currently funds only one part-time tobacco cessation trainer; this is insufficient to cover current demand in the community sector.

Actions

- Employ at least one additional tobacco cessation trainer as a full-time NSW Health position to promote and implement evidence-based smoking cessation training to government-funded community service agencies. This additional position plus resources would require approximately \$100,000 per year.
- Provide free nicotine replacement therapy to clients of government-funded community service agencies who want to quit smoking. This provision would be administered through the Area Health Services with eligibility limited to those organisations that had participated in appropriate smoking cessation training. It is expected that the amount of NRT provided would increase over time as the capacity of agencies to provide cessation support increases. Approximately 7,500[§] courses of NRT (8 weeks supply for each person) would be required in the first year of the program at a total cost of \$1,900,000 per year.**

Results

- **Improved health through reduced obesity, smoking, illicit drug use and risk drinking [S3].** These strategies will make a significant contribution to the *State Plan* target of reducing smoking rates by 1% per year until 2010 and then by 0.5% per year until 2016. These actions will also help achieve the targets of Focus Area 1 of the *NSW Health Tobacco Action Plan, 2005 to 2009*,⁶⁹ identified for achievement by 2008, in particular by enhancing counselling, support and resource needs for lower socioeconomic groups, Aboriginal and Torres Strait Islander peoples and people with mental illness.

Costs (recurrent)

\$2 million per year
\$10 million over five years

[§] The number of courses available may vary from the figure provided depending on the extent to which patients would be required to undertake combined use of nicotine replacement therapies (e.g. concomitant use of patch, gum and/or lozenge).

** It is assumed the government-contract pharmaceuticals rate for NRT would apply.

7. Better reporting of waiting times

Objective

To improve patient satisfaction with health services by publicly reporting waiting times.

Background

The NSW Government has made a strong commitment to reporting and accountability in the *State Plan*. This includes reporting the total waiting times for urgent and elective surgery on the *State Plan* website.⁷⁰ The Surgery Access Line has been established to provide information and advice about waiting times to patients and general practitioners for public hospitals in NSW. Waiting times for some procedures are reported for each hospital on the *NSW Hospital Waiting Times* website.⁷¹

However, peak cancer representative groups such as Cancer Voices NSW have said that these databases are not useful to cancer patients or referring doctors. For instance, the *State Plan* website only represents waiting times for the state as a whole, rather than by areas or hospitals. The *NSW Hospital Waiting Times* database lists general procedures which are not cancer-specific. For instance, the waiting times at major hospitals for mastectomy, lumpectomy or colonoscopy were not reported this year. This website was last updated in June 2008, so is not of much practical value to patients currently scheduled for a procedure, or doctors trying to refer patients for a procedure.

Cancer representative groups have noted that surgical waiting times are only part of the story; many patients must wait several weeks before they can even attend an appointment with an oncologist. The waiting times for radiotherapy, another important

component of cancer therapy, are not publicly reported. Waiting for these appointments has caused undue stress for many patients and families, many of whom live in rural and regional areas.

Over the past two years in regional areas such as Dubbo, Tamworth and Taree, waiting times to see an oncologist have been as high as 5 months after the initial GP appointment.^{72,73} Cancer Council has heard that waiting times for radiotherapy can be up to three months, and some people never receive the recommended treatment. These waiting times are much longer than the targets outlined in the NSW Health document *A Clinical Service Framework for Optimising Cancer Care in NSW* (see box).⁷⁴ Cancer Council understands that radiotherapy waiting time data is routinely collected by NSW Health (as this would be a necessary component of service planning), but is not centrally collated or publicly reported.

Countries such as Canada and the United Kingdom have made a commitment to public reporting of cancer waiting times and have established user-friendly, on-line waiting times databases. The UK Government has a two-week waiting time target from GP referral to first specialist appointment for all patients with suspected cancer. There is also a one-month target from diagnosis to treatment for all cancer. The webpage of the UK National Health System (NHS) shows the percentage compliance with the waiting time targets, broken down by major hospitals as well as by cancer site. The collection and public reporting of such data, updated monthly, enables the UK Government to regularly monitor progress against the NHS *Cancer Plan*.⁷⁵

Canada has also implemented a public monitoring system, where "wait times" are reported on the internet to enable greater transparency and accountability. Waiting times are reported for surgery, chemotherapy and radiotherapy by province.¹¹ Representatives from Canadian medical specialist organisations took the step of forming a Wait Time Alliance, in order to determine appropriate benchmarks and to report on the government's progress in achieving benchmarks established in the strategic plan to strengthen their health care system.^{76,77}

As a result of this process, British Columbia has reported that 96.5% of its residents who required radiotherapy in 2006/07 started treatment within four weeks of being medically able to receive it.¹¹

Cancer Council has joined with cancer representative groups, such as Cancer Voices NSW, to call for an on-line waiting times database aimed at the public as well as cancer professionals, in a similar manner to that of the UK and Canada. Adopting a similar approach to public reporting of waiting times for procedures including oncology appointments, surgery and radiotherapy, would improve government accountability in NSW, as promised in the *State Plan*. However, the primary advantage is that referring doctors and their patients could more easily determine which treatment centre would be most suitable; thus improving patient satisfaction and system efficiencies.

NSW Health waiting times targets

All Area Health Services should ensure that waiting times remain within the following agreed limits for all cancer related services:

- Time between GP referral and initial specialist consultation is less than 2 weeks.
- Maximum acceptable time for results of imaging procedures is 5 days.
- Maximum acceptable time for diagnostic and therapeutic endoscopy is 2 weeks.
- For surgery, the maximum acceptable time between decision to operate and surgical procedure is 2 weeks.
- For radiotherapy, maximum acceptable time between decision to treat and commencing treatment is 3 weeks.
- For chemotherapy, maximum acceptable time between decision to treat and commencing treatment is 2 weeks.
- For palliative care, maximum acceptable time for palliative care physician consultation is 48 hours for inpatients.
- For palliative care nursing, maximum acceptable time before initial contact (eg telephone) is 24 hours, and for a home visit is 48 hours.

Source: *NSW Health. A clinical service framework for optimising cancer care in NSW*. 2003. Sydney: NSW Department of Health.

Actions

- Develop a user-friendly, publicly available database of cancer services, including waiting times for oncologists, chemotherapy, surgery and radiotherapy; listed by cancer site and by treatment centre.
- Liaise with peak cancer representative groups to determine the optimal reporting method for the database.
- Ensure the waiting times database is updated on a monthly basis.

Results

- **Improved access to quality health care [S1].**
- **Increased customer satisfaction with Government services [S8].**

Cost (recurrent)

\$150,000 each year
\$750,000 over five years.

Revenue raising option: Positive tobacco retailer licensing system

At the time of writing, the *Public Health (Tobacco) Bill 2008*⁷⁸ outlines a “negative” licensing system, under which retailers will be required to notify the Director General of Health of their intention to engage in tobacco retailing but with no associated license fee payable. The Bill proposes that retailers found guilty of breaching tobacco laws on two or more occasions will have their right to sell tobacco withdrawn for 3 to 12 months.

In keeping with community views, there are considerable public health and economic benefits to be gained from a positive, fee-based tobacco retailer-licensing scheme. While the NSW government bears direct costs in excess of \$477 million per year (in 1998/99 values)² for the health damage caused by tobacco, NSW tobacco retailers make no contribution from the considerable profits they derive from tobacco sales. A fee-based licensing scheme can be justified as an offset to the costs incurred to the government as a result of tobacco retail activity. Any increase in the cost of cigarettes – should it be passed on to consumers by some retailers – would provide the additional health benefit of further reducing smoking rates, especially among young people whose smoking is significantly price-sensitive.

A positive licensing scheme could also provide both revenue and a mechanism to ensure systematic monitoring of compliance and the collection of accurate statistics on tobacco retailing in NSW. There are a number of options for applying fees for tobacco retail licences. These are:

- A uniform fee for all points-of-sale
- A fee structure stratified by types of retail outlet
- A fee structure linked to hours of sale.

We estimate that there are approximately 20,000 retail outlets selling tobacco in NSW, although this is currently impossible for health authorities to verify due to the current lack of official data. Establishing a licensing system would cost approximately \$1.5 million each year, including costs associated with monitoring and prosecution. Depending on the size of the fee, and the licensing option (for example, a licence fee of \$10,000 plus costs), we estimate that the NSW Government could generate up to \$200 million per year through this initiative.

We believe that the wider community would support a strong fee-based licensing scheme.

Cancer Council surveys of community attitudes show that 87% of the NSW community believe that retailers should be licensed to sell cigarettes, and 81% say cigarettes are too easy to buy.⁷⁹

Tobacco control is no longer controversial, and most people welcome strong action by governments to reduce the harms associated with tobacco use. We urge the NSW Government to consider introducing licensing fees for tobacco retailers, as an adjunct to the reform package aimed at protecting children from tobacco contained in the *Public Health (Tobacco) Bill 2008*. Licensing fees have the potential to amplify the health benefits that will come from the reforms and could provide an important revenue stream for NSW.

Revenue (net)

\$200 million per year
\$1,000 million over five years

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