



An agenda for cancer control—  
2011 and beyond

**Saving  
life**

*why wouldn't you?*





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# Executive summary

## Cancer challenge for NSW

Every year over 13,000 families lose a loved one to cancer in NSW and not surprisingly community concern about cancer is high. Cancer places a significant burden on patients, their families, the health system and the broader community but we have made progress. In the past decade we have seen a decrease in the number of cancer deaths as well as positive policy and legislative changes. However, it is possible to further reduce both the impact and incidence of cancer through astute public policy interventions.

## Challenges for the future – looking towards 2021

Cancer is predominantly a disease of ageing. As the ageing population grows, so will the number of new cancer cases. By 2021, NSW will see a 14% increase in the number of cancer deaths compared with 2007 levels. These projections clearly highlight the need for governments to address cancer prevention and treatment in NSW as a key priority over the next decade.

## A 10-year vision – beating cancer together

Cancer Council NSW invites all interested parties to take the required action to ensure that, by 2021, NSW will be a place where:

1. fewer people are diagnosed with preventable cancers
2. more people take measures to reduce their own cancer risk
3. people are protected from involuntary exposure to known carcinogens
4. everyone lives in an environment that enables healthier choices
5. cancer information and support is received when and where it is needed
6. cancer patients receive treatment in line with established international and national guidelines and benchmarks, at a cost they can afford
7. cancer patients who need to travel for treatment receive more financial and practical support
8. no cancer patient experiences financial hardship or goes without essentials in order to meet the costs of treatment
9. there are fewer differences in cancer rates and outcomes due to poverty, country of birth, Aboriginality or place of residence
10. strong government investment in the research sector places NSW as the premier state for cancer research.

*“The Government should come to the party a bit more, there are people who can’t afford to have any type of [cancer] treatment.” Rex\**

\*Name changed

# Executive summary

## Creating a better state of cancer control

This document outlines immediate opportunities for the NSW Government to reduce the impact and incidence of cancer, through funding and provision of health care services, public health initiatives, and regulatory mechanisms.

## More radiotherapy services across NSW

Health authorities agree that radiotherapy is needed for at least 50% of cancer patients, however a lack of resources means that only 36% of patients receive the treatment in NSW. Cancer Council NSW recommends that the NSW Government ensures optimal and equitable access to radiotherapy services for cancer patients across NSW by:

- funding new radiotherapy centres and machines
- purchasing services from private radiotherapy centres so that patients are not required to pay a 'gap fee'.

**This investment would overcome the current gap in radiotherapy service provision and ensure that patients requiring radiotherapy in NSW have access to affordable, timely treatment, regardless of where they live.**

## Burden-free transport and accommodation for patients

Cancer patients who need to travel for treatment should receive financial and practical support to reduce the cost, stress and hardship of travel and living away from home. Cancer Council NSW recommends that the NSW Government supports burden-free travel and accommodation for cancer patients across NSW by:

- improving access to and reimbursement rates provided under the Isolated Patients Travel Accommodation and Assistance Scheme
- increasing funding for community transport services
- requiring all Area Health Services to implement policies to provide parking spaces for cancer patients, close to treatment.

**These changes would substantially reduce the financial, physical, practical and psychological stressors on patients and carers. These changes would also help address inequities in access to treatment for people from rural and regional areas, and those on lower incomes.**

## Optimal cancer care for all

Optimal cancer care for all patients in NSW can be achieved, in part, by the systematic adoption of best practice standards.

The groundwork for such standards was completed in 2003 with the publication of the *NSW Clinical Services Framework for Optimising Cancer Care*. Cancer Council NSW recommends that the NSW Government establishes mechanisms to improve the quality of cancer care provided to all cancer patients by:

- re-issuing the *NSW Clinical Services Framework for Optimising Cancer Care*, including processes for monitoring and reporting
- establishing two centres for quality improvement in cancer care, in a rural and a metropolitan area.

**These actions would provide the basis for ongoing systematic improvements in cancer care for patients across NSW, and help close the gap between evidence and practice.**

### Smoke-free dining and drinking

While smoking is banned in nearly all 'enclosed' public places in NSW, it is still permitted in many partly enclosed areas. Cancer Council NSW recommends that the NSW Government provides for smoke-free public places to protect people from exposure to second-hand smoke by:

- legislating requirements for specific public areas and workplaces to be smoke-free, including those that are partially or entirely outdoors, with priority given to banning smoking in areas where food or drink is provided as part of a business
- developing legislation in a way that enables the Government to easily declare new public places to be smoke free, in line with rapidly changing community standards and expectations and emerging evidence.

**These low-cost changes would provide healthier environments for all to enjoy, with benefits in reduced ill health and, over the longer term, reduced smoking rates.**

### Stronger safeguards on selling tobacco

Despite their danger, tobacco products remain more widely available than any other consumer product in NSW. This ready availability of tobacco reinforces smoking and makes it harder for those trying to quit. State governments have the power and responsibility to regulate the sale, supply and availability of harmful products consistent with community interests and protection of public health. Cancer Council NSW recommends that the NSW Government ensures that selling of tobacco is regulated in proportion to the harmfulness of the product by:

- requiring that all retailers selling tobacco hold a licence to do so
- designing a licensing scheme that requires prior approval to sell tobacco, imposes conditions on holding a licence, and provides for the withdrawal of the licence if conditions are breached
- instituting a fee for a tobacco retail licence that, at minimum, covers the cost of administering and enforcing the scheme, and reflects the social cost and harm of the product.

**These actions would provide the state with a mechanism to shape the conditions of sale, supply and availability of tobacco, which could be used to boost its efforts to reduce smoking in NSW.**

### Emerging priorities

There are also two emerging priorities that require future Government consideration and planning:

#### Expanded specialist services for chronic hepatitis B

The incidence of liver cancer in NSW has increased over the past two decades, particularly in south-western Sydney, where there are high rates of chronic hepatitis B infection, a significant cause of liver cancer. Cancer Council NSW recommends that the NSW Government expands specialist diagnostic and disease-management services for people with chronic hepatitis B in south-western Sydney, to match the expected increased need.

#### Expanded colonoscopy services

The National Bowel Cancer Screening Program involves a faecal occult blood test which may be followed by a colonoscopy. Cancer Council NSW recommends that the NSW Government conducts a NSW system-wide review of colonoscopy services capacity including:

- an investigation of private sector capacity, current workforce and facilities and a computerised referral system
- an estimate of future funding needs for reporting of waiting times in NSW.

**If adopted, the recommendations would enable NSW to continue its advances in the battle against cancer, for the benefit of all its people.**



# 1. Cancer challenge for NSW

**Almost 100 people are diagnosed with cancer every day in NSW.**

**Cancer affects one in two men and one in three women by the age of 85.**

**Every year over 13,000 families lose a loved one to cancer in our state.<sup>1</sup>**

## Introduction

Cancer is a complex set of diseases whose diagnosis and treatment places a significant burden on patients, their families, the health system and the broader community.

In 2007, cancer was the leading cause of death in NSW with over 36,000 people diagnosed.<sup>1,2</sup> The most common cancer deaths and cases were lung, bowel, prostate, melanoma or breast cancers.<sup>1</sup> Men were one-and-a-half times more likely than women to be diagnosed with cancer.<sup>1</sup>

Cancer is the second most common cause of death among Aboriginal people in NSW.<sup>3</sup> Cancer death rates are 66% higher in Aboriginal men and 59% higher in Aboriginal women compared with non-Aboriginal people (based on NSW Central Cancer Registry data for 1994–2002).<sup>1,4</sup>

On 31 December 2004, there were 221,602 persons in NSW (106,519 males and 115,083 females), who had been diagnosed with at least one cancer between 1980 and 2004. This was 3.3% of the NSW population.<sup>1</sup>

Not surprisingly, community concern about cancer is high, with cancer burden and issues rated as the most important health issues for both prevention and research across the country.<sup>5</sup>

## Achievements so far

Over the past decade, many improvements have been made in cancer control in NSW. This includes a decrease in cancer deaths of 13% in men and 6% in women (1998–2007).<sup>1</sup>

Positive policy changes in NSW over the past decade have included legislative changes designed to reduce smoking and tobacco exposure; expansion of the radiotherapy workforce; information support for clinicians; and a major boost to cancer research in cancer treatment centres. Recognition of the importance of a multidisciplinary approach to cancer diagnosis and treatment has been a further positive development.

## 2. Challenges for the future - looking towards 2021

**It is predicted that in the 10 years between 2011 and 2021, over 425,000 people in NSW will be diagnosed with cancer and over 140,000 people will die of the disease.**

Although future cancer projections seem overwhelming, it is possible to reduce both the impact and incidence of cancer through astute public policy interventions. If governments act now, it is possible for NSW to be well prepared for the health care challenges we will face over the next 10 years. By 2021, NSW cancer treatment services, including radiotherapy, will face the challenge of caring for an ageing population that has grown to approximately eight million people.<sup>6</sup> The population growth in NSW will be seen mainly in coastal areas and in Sydney, where the population is predicted to grow from 4.5 million in 2011 to approximately 5.1 million in 2021.<sup>6</sup>

Population ageing is a worldwide phenomenon. From 2011 onwards, the impact of the baby boomer generation turning 65 years of age will be felt across the country.<sup>7</sup> In NSW, by 2021, the number of residents aged 85 years and over will have almost doubled compared with the number in 2004.<sup>6</sup> Median age will have jumped from 37 years to 41 years of age as a result of fewer births and increased life expectancy.

Cancer is predominantly a disease of ageing. As the ageing population grows, so will the number of new cancer cases. There were 36,041 new cases of cancer in 2007, and in 2021 the estimated number of new cases is expected to be 50,967 (28,789 males and 22,178 females), an increase of 42 per cent between 2007 and 2021.<sup>1</sup> The number of new cases of cancer is expected to increase by 5,000 every five years, resulting in 50,000 new cases by 2021.<sup>1</sup>

By 2021, it is predicted that the most common cancers in NSW will be prostate cancer (9,846), bowel cancer (6,696), breast cancer (5,393), melanoma of the skin (5,699) and lung cancer (4,081).<sup>1</sup>

It is expected that by 2021, NSW will see a 14% increase in the number of cancer deaths compared with 2007 levels.<sup>1</sup> Variations in the number of cancer deaths are a combination of higher death rates and increases in the projected population.<sup>1</sup> Between 2011 and 2021, the number of cancer deaths is predicted to increase from 13,782 (7,661 in men and 6,121 in women) to 15,190 (8,244 in men and 6,946 in women).<sup>1</sup>

These projections clearly highlight the need for governments to address cancer prevention and treatment in NSW as a key priority over the next decade.





### 3. Beating cancer together – a 10-year vision

**Cancer Council NSW believes that cancer can be beaten, and that there will come a time when lives are not cut short, nor quality of life diminished.**

Cancer Council NSW, together with health and research bodies, the Government, community groups, businesses and committed individuals, share a common interest in ensuring that in NSW, fewer people get cancer. Those who do have cancer must receive the information, support and treatment they need, when and where they can best avail themselves of it.

Cancer Council NSW invites all interested parties to take the required action to ensure that, by 2021, NSW will be a place where:

1. fewer people are diagnosed with preventable cancers
2. more people take measures to reduce their own cancer risk, by following guidelines for sun protection, not smoking, healthy eating, physical activity, responsible consumption of alcohol and cancer screening
3. people are protected from involuntary exposure to known carcinogens, particularly tobacco and second-hand smoke, at work, in public or at home
4. everyone lives in an environment that enables healthier choices rather than prompting unhealthy choices
5. cancer patients, families and carers receive information and support when and where they need it, so they can make informed choices and be relieved of avoidable burden
6. cancer patients receive treatment in line with established international and national guidelines and benchmarks, at a cost they can afford
7. cancer patients who need to travel for treatment receive more financial and practical support to reduce the cost, stress and hardship of travel and living away from home
8. no cancer patient experiences financial hardship or goes without essentials in order to meet the costs of treatment
9. there are fewer differences in cancer rates and outcomes due to poverty, country of birth, Aboriginality or place of residence
10. strong government investment in the research sector places NSW as the premier state for cancer research.

## 4. Creating a better state of cancer control

Given the challenges of the coming decade, it is clear that future governments will be forced to tackle the growing burden of cancer. Key priorities include the need for more action to:

- ensure that all cancer patients who need radiotherapy in NSW receive this treatment
- reduce the financial and other physical and emotional burdens faced by patients when accessing treatment
- limit the burdens associated with travelling to treatment and living away from home during treatment
- improve cancer patients' experiences during treatment and ensure equity of access to care and treatment for cancer patients living in rural and remote areas
- protect residents from exposure to tobacco smoke and the influence of poorly regulated sales of tobacco.

All of the actions outlined in this section provide immediate opportunities for the NSW Government to reduce the impact and incidence of cancer, through funding and provision of health care services, public health initiatives and regulatory mechanisms. Two emerging priorities that will require future Government consideration and planning are also presented.

### 4.2 Burden-free transport and accommodation for patients

### 4.1 More radiotherapy services across NSW



**4.4 Smoke-free dining  
and drinking**

**4.5 Stronger safeguards  
on selling tobacco**

**4.3 Optimal cancer  
care for all**

## 4.1 More radiotherapy services across NSW

*why wouldn't you?*

**Each year, thousands of people miss out on radiotherapy treatment because of service gaps.**

**The NSW Government can fix this by funding new services in priority areas.**

*“The health system is not set up for people living in places like Boggabri – all the specialist services are too far away and there is extensive travel involved ... [and] extensive coordination to minimise additional trips or spending all day waiting for various appointments.” Rex\**

### Problem

Radiotherapy is an important and cost-effective arm of cancer treatment.<sup>8,9</sup> However, access to radiotherapy treatment is currently limited in certain areas of NSW.

Health authorities around the world accept that radiotherapy is needed for at least 50% of cancer patients during their illness.<sup>10-14</sup> In NSW between 1996 and 2006, lack of facilities and resources meant that only 36% of cancer patients received radiotherapy.<sup>15</sup> It has been estimated that, as a result, almost 51,000 eligible cancer patients did not receive radiotherapy and nearly 40,000 years of additional life were lost over this 10-year period.<sup>16</sup>

These findings are supported by the Audit Office of NSW, which found that radiotherapy treatment rates for NSW residents, in both the public and the private sector, are considerably lower than appropriate targets.<sup>17</sup>

As of late 2009, NSW had 42 linear accelerators (the machines used to deliver radiotherapy treatment) at 18 sites. Cancer Council NSW supports plans that have been announced for new services for the Central Coast, Central West and Far North Coast of NSW. However, even after these are established, some parts of the state will still only have private radiotherapy facilities, some will have no services at all and some will have inadequate numbers of machines to meet needs.

It has been estimated that in some areas of NSW, 80% of patients requiring radiotherapy live more than 120 kilometres from the nearest facility.<sup>18</sup> Such patients have to travel long distances for treatment and stay away from home for extended periods, pay the additional costs of treatment as a private patient, or receive suboptimal treatment.<sup>13,19</sup>

The financial, physical and emotional burdens reported by patients living in regional and rural areas of NSW highlight the need for urgent, substantial and sustained improvements to radiotherapy services in the state.<sup>13,16</sup>

## Solution

The problem of cancer patients missing out on essential radiotherapy treatment can be solved by the Government planning and investing in expanded radiotherapy services. Conservative estimates of future radiotherapy demand (based on expected new cancer cases and annual capacity per machine per year) show that NSW will need 69 linear accelerators by 2012 and 81 by 2017.<sup>16</sup>

In addition to funding new facilities and machines, the NSW Government has the power to establish cooperative arrangements with private radiotherapy providers to provide affordable treatment for patients living in areas with only private services. This would also relieve pressure and alleviate waiting times at public radiotherapy centres.

The Audit Office of NSW noted that NSW Health should identify a range of funding sources for radiotherapy services, and recommended the development of a funding strategy taking into account the role of the Commonwealth and the private sector.<sup>17</sup>

## Action

Cancer Council NSW recommends that the NSW Government ensures optimal and equitable access to radiotherapy services for cancer patients across NSW by:

- funding new radiotherapy centres and machines with priority focus on areas at a distance from existing services
- purchasing services from private radiotherapy centres so that patients are not required to pay a 'gap fee'.

If the recommended investment in radiotherapy infrastructure is made, NSW would have the chance to overcome the current gap in radiotherapy service provision and ensure that patients requiring radiotherapy in NSW have access to affordable, timely treatment, regardless of where they live.

*"My husband was diagnosed [with cancer] and died very soon after. We had to travel 600km to radiotherapy treatment and sadly this took most of his remaining time ... if the centre was closer we could have returned home [to] our family." Fiona\**

## 4.2 Burden-free transport and accommodation for patients

*why wouldn't you?*

**Transport, accommodation and parking are unnecessarily expensive and problematic for cancer patients.**

**The NSW Government can fix this by improving transport assistance and services, and providing more accommodation and affordable parking at treatment centres.**

*"I claimed costs through IPTAAS and only received \$16 back. This was to cover all my accommodation and petrol costs." Max\**

### Problem

Many patients from regional and rural areas of NSW need to travel long distances for treatment and find accommodation while away from home. This places substantial financial, physical and emotional burdens on the patients and their families.<sup>13,19-24</sup> This burden can be greater for Aboriginal patients, who often have few private transport options and longer distances to travel.<sup>21,25</sup>

While some treatment centres have accommodation nearby, others lack appropriate accommodation. A recent review highlighted a shortfall in facilities in Central Sydney, North Sydney and Newcastle and found that most regional base hospitals require additional beds.<sup>23</sup> Of particular concern is the fact that although demand for accommodation beds is increasing, the number of available beds is shrinking, with a loss of over 280 beds across the state over the past seven years.<sup>26</sup>

The Isolated Patients Travel Accommodation and Assistance Scheme (IPTAAS) exists to assist people in isolated and rural communities to gain access to specialist medical treatment not available in their own area. However, the scheme has many limitations including:

- high upfront costs for patients
- relatively high non-refundable personal contribution levels
- low reimbursement for accommodation (\$33 per night for a single room) and fuel (15 cents per kilometre)
- complex and onerous paperwork (10-page forms)
- inconsistent application administration
- payment delays (up to three months).

A recent federal inquiry found that schemes of this type do not adequately compensate patients and do not overcome distance as a barrier to medical treatment.<sup>22</sup>

Community transport programs are available in some areas of the state but are often stretched beyond capacity. It has been estimated that 90,000 people per year are currently refused health-related trips on community transport due to lack of capacity.<sup>21</sup> Demand for these services will only increase as the population ages.

Cancer patients and carers report problems with parking at treatment centres, including lack of spaces, the cost of the parking and the distance of the parking from cancer treatment centres. Although these issues may be problems for many people attending hospital, they pose exceptional challenges for cancer patients because:

- treatment, such as radiotherapy, requires attending a hospital up to five days per week for six weeks
- the side effects of treatment leave patients feeling unwell immediately afterwards, making long walks to car parking physically difficult and uncomfortable
- it adds stress, particularly when a patient is left to arrive at treatment on their own whilst a carer or a supportive friend attempts to find parking
- the cost impact is cumulative, over the many days and weeks of treatment
- street parking surrounding the hospital is generally metered with time limits shorter than the time taken for treatment appointments.

## Solution

The burden on patients with cancer who are accessing specialist medical treatment could be reduced by ensuring easy access to transport support and facilities, such as parking and accommodation.

The existing IPTAAS that provides financial assistance to country patients travelling for specialist treatment is not effective. Travel and accommodation burdens on cancer patients could be eased by a reform of IPTAAS to ensure that country patients are adequately compensated, thereby reducing additional financial burdens related to one's distance from cancer treatment.

Reimbursement benefits under IPTAAS need to be substantially increased, and adjusted by the Consumer Price Index each year to reflect any increases in costs charged to patients travelling to treatment. Guidelines provided by the Australian Taxation Office relating to 'reasonable amounts' for travel and accommodation allowances, and those provided by various awards, provide benchmarks for the actual amounts of reimbursement, as well as for recognising higher costs of staying in capital cities and some regional centres.

Additional Government investment in community transport programs and accommodation facilities would address current state-wide gaps in these services. For patients regularly attending hospital for treatment, hospitals need to provide parking or alternative transport solutions so that this does not add to the stress of treatment.

## Action

Equitable access to cancer treatment in NSW is an imperative that requires current gaps in transport and accommodation to be addressed. Cancer patients who need to travel for treatment should receive financial and practical support to reduce the cost, stress and hardship of travel and living away from home.

Cancer Council NSW recommends that the NSW Government supports burden-free travel and accommodation for cancer patients across NSW by:

- improving access to and reimbursement rates provided under the Isolated Patients Travel Accommodation and Assistance Scheme
- increasing funding for community transport services to meet the need for health-related trips
- funding accommodation facilities in priority areas, at an affordable price
- introducing a requirement that all Area Health Services implement policies to provide free or subsidised designated car parking spaces for cancer patients, close to treatment.

If implemented, these changes would substantially reduce the financial, physical, practical and psychological stressors currently placed on patients and carers, particularly those who need to travel for treatment. These changes would help address any inequities in access to treatment for people from rural and regional areas, and those on lower incomes.

*"I arranged to stay at a unit in the grounds of the hospital. I had to pay upfront with an offer from Isolated Patients Travel Accommodation and Assistance Scheme that they would reimburse me for part of the cost. ... It took five months of constant phoning before any reimbursement was received." Carole\**

## 4.3 Optimal cancer care for all

*why wouldn't you?*

**Cancer care can be fragmented and complicated, and there are variations in quality and patterns of care. More needs to be done to make sure the cancer system provides optimal care for all.**

**The NSW Government can fix this by establishing a systematic approach to improving the quality of cancer services.**

*“My aunt has slipped through the system, she was diagnosed in September 2008 and no-one told her that her radiotherapy was to start in February 2009 ... She has not been given any guidance or support ... No-one is assisting her with information or support; we just didn't know what we were meant to do.” Sharon\**

### Problem

In NSW, people with cancer have to navigate a complex system of medical and support services to obtain the care and treatment that they need. Cancer care is delivered by a range of public, private and community organisations in hospitals, cancer care centres, doctors' rooms, general practice, community health centres and within the home environment.

Where there are insufficient or inadequate links between service providers, the coordination, continuity, convenience and cost-effectiveness of a patient's care is compromised.

Inadequate coordination of care and lack of systematic record keeping can result in patients repeating their medical history every time they see a new health care provider or having tests repeated because results from other service providers are unavailable. Patients may also experience difficulties in accessing relevant and reliable information when they need it.

The existence of evidence-based clinical guidelines does not automatically result in the provision of quality care to all patients. Studies demonstrating variations in quality and patterns of care highlight the challenges of introducing system-wide quality improvement in cancer care.<sup>27,28</sup> Some of the challenges include the wide span of the 'organisation' providing cancer care, the many complex interconnected procedures, the diverse clinical and non-clinical workforce, and the dispersed geography of those involved in providing treatment and care to each patient.<sup>29</sup>

Improvements in the provision and coordination of services for people with cancer are needed to ensure that all NSW residents have access to consistently high standards of cancer care and evidence-based best practice, regardless of geographical, socio-economic or cultural considerations.

## Solution

Optimal cancer care for all patients in NSW can be achieved, in part, by the systematic adoption of, monitoring of and reporting on, best practice standards. The groundwork for such standards was completed in 2003 with the publication of the *NSW Clinical Services Framework for Optimising Cancer Care*.<sup>30</sup> This document remains highly relevant, providing:

- clinical and organisational standards of care for patients with cancer
- an optimal structure for a cancer service to ensure equity in access to best practice care
- milestones, goals and performance indicators against which progress within agreed timeframes can be measured
- practical tools to support implementation and monitor progress.<sup>30</sup>

The document has not been reviewed for some time, but provides a strong basis for promoting high quality care for all patients. If reviewed to ensure continued relevance, and adopted uniformly, these standards would reduce the current variability in practice across cancer treatment centres. It would also provide clear information to cancer patients and carers as to the standard of care they can legitimately expect.

Previous work in NSW on quality management and improvement in cancer care highlighted the need to reposition service quality as an organisational goal, and that efforts to improve the quality of care and treatment require a focus on organisational, policy and professional factors. The authors concluded that quality improvement needs a structured process to organise and manage care, and routinely measuring and reviewing care outcomes in order to demonstrate not only what worked and why, but also how further improvements can be achieved.<sup>29</sup>

Another step towards optimal cancer care for all NSW cancer patients would be the establishment of two centres for quality improvement, in a rural and a metropolitan area. These centres would provide the capacity to develop, pilot, evaluate and disseminate quality improvement initiatives and technologies in cancer care, to improve state-wide capacity in providing quality care. They would provide a central point from which to explore strategies to improve linkages between cancer services, ensure consistency in access to treatment and care within Area Health Services and improve quality improvement mechanisms for rural and regional settings.

## Action

Cancer Council NSW recommends that the NSW Government establishes mechanisms to improve the quality of cancer care provided to all cancer patients by:

- reviewing and re-issuing the *NSW Clinical Services Framework for Optimising Cancer Care*, including processes for monitoring and reporting
- establishing two centres for quality improvement in cancer care, in a rural and a metropolitan area.

Cancer Council estimates that the cost of establishing two centres for quality improvement would be approximately \$600,000 over three years. If implemented, these actions would provide the basis for ongoing systematic improvements in cancer care to patients across NSW, and help close the gap between evidence and practice.

*“I slipped through the cracks and had no support throughout my radiation treatment. The only person there was the specialist. On the last day of treatment, the social worker came and wanted to give me support but I was ready to leave everything behind.” Lenore\**

## 4.4 Smoke-free dining and drinking

*why wouldn't you?*

**Despite legislation to ban smoking in enclosed public spaces, there are still many outdoor or partially enclosed settings where the community and workers are exposed to dangerous levels of second-hand smoke.**

**The NSW Government can fix this by introducing legislation to make specific public areas smoke free, including outdoor and partially enclosed settings.**

*"No one, myself and my kids included, should have to breathe in smoke with their dinner. It would be nice to have the freedom to dine alfresco with my kids, but I just don't think to go alfresco because the smokers are inescapable when they are all sitting outside." Kim\**

### Problem

Smoking is responsible for almost 8% of the total burden of disease and injury in Australia; more than any other single lifestyle factor.<sup>31</sup> Studies show that exposure to second-hand smoke increases the risk of lung cancer and heart disease, as well as sore throats, nasal symptoms, asthma, chest infections and eye irritation.<sup>32,33</sup> In children, it increases the risk of middle ear infections, croup, bronchitis and asthma.<sup>32,33</sup> The evidence shows that exposure in some outdoor settings is substantial enough to cause harm, and in 2006, the US Surgeon-General determined that there is no risk-free level of exposure to second-hand smoke.<sup>32,33</sup>

Smoking is banned in nearly all 'enclosed' public places under the Smoke-free Environment Act 2000 and related amendments that came into force in July 2007.<sup>34,35</sup> However, the definition of 'enclosed' means that smoking is permitted in many partly enclosed areas; and the legislation does not deal with smoking in outdoor areas.

There are many outdoor settings where large numbers of people spend long periods of time close together, including places where people meet to eat and drink and where children may be present. These include alfresco dining areas, beer gardens, sporting grounds and stadiums, and outdoor recreation areas, such as markets, swimming pools and children's playgrounds. Many of these areas are workplaces as well as public places, so exposure to second-hand smoke poses health risks to workers as well as members of the public.

Evidence of the harm from exposure to second-hand smoke in these settings is increasing.

1. A study of air quality in NSW pubs and clubs found that partially enclosed smoking areas had significant levels of second-hand smoke, sometimes in excess of World Health Organisation recommended limits.<sup>68</sup>
2. Someone next to a smoker in outdoor settings can inhale tobacco constituents many times above background air pollution levels.<sup>36</sup>
3. A study of air quality in five Californian locations next to outdoor smoking areas found substantial levels of second-hand smoke even in areas that are completely outdoors.<sup>37</sup>
4. Modelling has shown that a worker spending over six hours at an outdoor bar is exposed to as much nicotine as someone living in a smoking household.<sup>38</sup>

Growing awareness of the health risk of second-hand smoke, changing community attitudes about smoking, and increasing sensitivities to the immediate discomfort of second-hand smoke exposure, have led to strong community support for smoke-free public places.

In 2009, a survey by the Cancer Institute NSW found that 94% of adults agreed that playgrounds should be smoke free, 86% supported smoke-free sports stadiums and 74% supported smoke-free beaches.<sup>39</sup> Community support for smoke-free outdoor areas has increased over the past few years, particularly in relation to children's playgrounds, beaches and sports stadiums.<sup>39,40</sup> When asked about dining and drinking areas, 69% of respondents to a 2006 telephone survey supported smoke-free outdoor dining.<sup>41</sup> In the same study, when asked if smoking should be banned in rooms where only one side is open to the outdoors, 70% agreed it should be, increasing to 97% if the area in question was a dining area.<sup>41</sup> In the same survey, 65% of respondents reported that they avoided places where they would be exposed to second-hand smoke.<sup>42</sup>

## Solution

Local Councils across NSW have responded to changing community standards about second-hand smoke, with 66 Councils and Shires passing policies for smoke-free outdoor areas as at March 2010. One Council has surveyed relevant businesses and found that 61% reported that it was easy/relatively easy to implement the smoking ban and almost 67% reported no effect on their business.<sup>43</sup>

Although it is encouraging that local government has shown such leadership in creating smoke-free outdoor policies for public areas within their control, local policies alone cannot provide the required population level of protection from exposure to second-hand smoke. It would be far more effective for the state to create uniformity in smoke-free provisions for outdoor settings by introducing legislative provisions governing smoking in public places.

Other Australian States and Territories have legislated for smoke-free outdoor public places. Queensland prohibits smoking in outdoor eating and drinking areas with strong conditions on Designated Outdoor Smoking Areas.<sup>44</sup> Tasmania has established 'smoke-free areas' in at least 50% of outdoor dining areas.<sup>45</sup> The ACT has banned smoking in outdoor dining and drinking areas from December 2010 and has limited outdoor smoking areas in pubs and clubs to no more than 50% of outdoor space.<sup>46</sup> In 2009, Western Australia amended its Tobacco Products Control Act to prohibit smoking in outdoor eating areas, except in designated smoking zones, from September 2010.<sup>47</sup>

In the above jurisdictions, legislation also bans smoking in other outdoor public areas where people congregate, such as outdoor sporting or cultural venues, children's playgrounds, patrolled beaches, and near the entrances of non-residential buildings.

Increasing the number of smoke-free public settings also benefits smokers, particularly those trying to quit.<sup>48</sup> Increasing smoke-free environments changes social norms relating to tobacco and its use, which will help reduce smoking uptake and increase quit rates.<sup>49</sup>

As noted by a Commonwealth Government-commissioned economic study, there is great potential for reducing smoking-related mortality with cost-effective policies, and even moderate action could ensure substantial health gains.<sup>50</sup>

## Action

Cancer Council NSW recommends that the NSW Government provides for smoke-free public places to protect people from exposure to second-hand smoke by:

- legislating requirements for specific public areas and workplaces to be smoke free, including those that are partially or entirely outdoors, with priority given to banning smoking in areas where food or drink is provided as part of a business
- developing legislation in a way that enables the government to easily declare new public places to be smoke free, in line with rapidly changing community standards and expectations and emerging evidence.

If implemented, these low-cost changes would provide healthier environments for all to enjoy, with benefits in reduced ill-health and, over the longer term, reduced smoking rates.

*"My family and I love the outdoors and when we go to a restaurant or café, we like to choose to dine on the deck or veranda or in the garden. But we are denied that choice – we want to be able to dine outside and enjoy the fresh air without breathing in cigarette smoke. With non-smokers such as myself making up 80% of the population, why should I be forced to sit indoors?" Wendy\**

\*Name changed

## 4.5 Stronger safeguards on selling tobacco

*why wouldn't you?*

**In spite of its harmfulness, tobacco is widely available in the community, and the sale of tobacco products remains largely unregulated.**

**The NSW Government can fix this by regulating the sale, supply and availability of tobacco, as it does with other harmful products.**

*"I can teach my two children not to smoke, I can make sure they can't get any cigarettes when they are around me, but how do I know that when I'm not around, that the many people out there selling cigarettes will be so vigilant? Maybe they would be if they had to comply to licensing agreements? The government is accountable to us, the community, we can do our part, but they need to do their part in protecting our children; and licensing retailers is another way to do this." Kim\**

### **Problem**

Tobacco is an inherently harmful product that has no safe level of use and is the single greatest cause of preventable death and illness.<sup>31,51-53</sup> In NSW in 2006, the total social cost of smoking was \$6.6 billion; and the NSW Government bears direct costs in excess of \$477 million per year (1998/99 values) for the health damage caused by tobacco use.<sup>54</sup>

Recognising the need to control the retail environment in order to reduce the harm of tobacco, the state has introduced changes, including banning displays of tobacco products in shops. However, despite their danger, tobacco products remain more widely available than any other consumer product. There are no restrictions on the type, number or density of retail outlets selling tobacco in NSW, and these products remain commonly available from supermarkets, tobacconists, petrol stations, convenience stores, hotels, clubs and liquor stores.

The ready availability of tobacco reinforces smoking and makes it harder for those trying to quit. Cancer Council research has shown that 87% of smokers come within walking distance of a tobacco outlet in the course of their usual daily activities and that 8% would quit and 20% would cut down on smoking if cigarettes were no longer available within walking distance.<sup>55</sup> In this study, over 40% of smokers, particularly young people and women, reported that the availability of cigarettes at pubs, clubs and restaurants increased the amount they smoke.

The research also found that cigarettes were often purchased on impulse, including by smokers trying to quit (45%). Smokers who purchased cigarettes at a service station or convenience store were more likely to be young, male, single and have made a quit attempt in the previous two years.

Under recent changes to the law, tobacco retailers in NSW are required to notify the Director General of the NSW Health Department if they are selling or intending to sell tobacco. However, this notification scheme treats the selling of tobacco as a 'right' rather than an act that is otherwise prohibited, and does not place conditions on retailers.

## Solution

State governments have the power and responsibility to regulate the sale, supply and availability of harmful products consistent with community interests and protection of public health. This power can be exercised by direct regulation, or through licensing schemes. Licensing will add flexibility and rigour to the existing regulations relating to tobacco retailing, such as prohibiting sales to minors. Licensing is already widely used to control the sale of products such as alcohol, poisons and firearms. Licensing is an appropriate regulatory response to situations where there are adverse effects from consumption or use. Tobacco products clearly fit into this category, with high social and financial costs of tobacco use imposed on third parties such as family and the health care system.

Introducing a licensing scheme for tobacco would provide both immediate and longer-term benefits.

In the short term, a licensing scheme would assist the state in enforcing existing tobacco retailing regulations, especially if non-compliance was penalised by suspending or revoking a licence. Licensing of retailers would also demonstrate NSW's determination to combat the harm caused by tobacco and add impetus to other tobacco-control investments, such as social-marketing campaigns and the ban on tobacco displays in retail outlets.

Over the medium to longer term, a licensing scheme would provide a platform to place conditions on the right to sell tobacco, including supplying regular sales data, mandatory staff training, and providing quitting information and sale of quitting aids alongside tobacco. The advantage of a licensing scheme over direct regulation is the ability to tailor and impose conditions as part of the license to meet different circumstances.

It is reasonable to hypothesise that a licensing scheme would, over time, lead to a reduction in the number of retail outlets selling tobacco. Given the link between the ready availability of the product and purchasing behaviour, any reduction in availability would have a positive impact on reducing smoking rates and improving quitting success in NSW.

There is strong community support for greater regulation of tobacco retailers. In 2009, a random telephone survey of over 1,500 NSW residents undertaken by the Cancer Institute NSW found that 91% of respondents agreed that regulation should be introduced to require retailers to have a licence to sell tobacco products, in the same way that retailers need a licence to sell alcohol.<sup>39</sup>

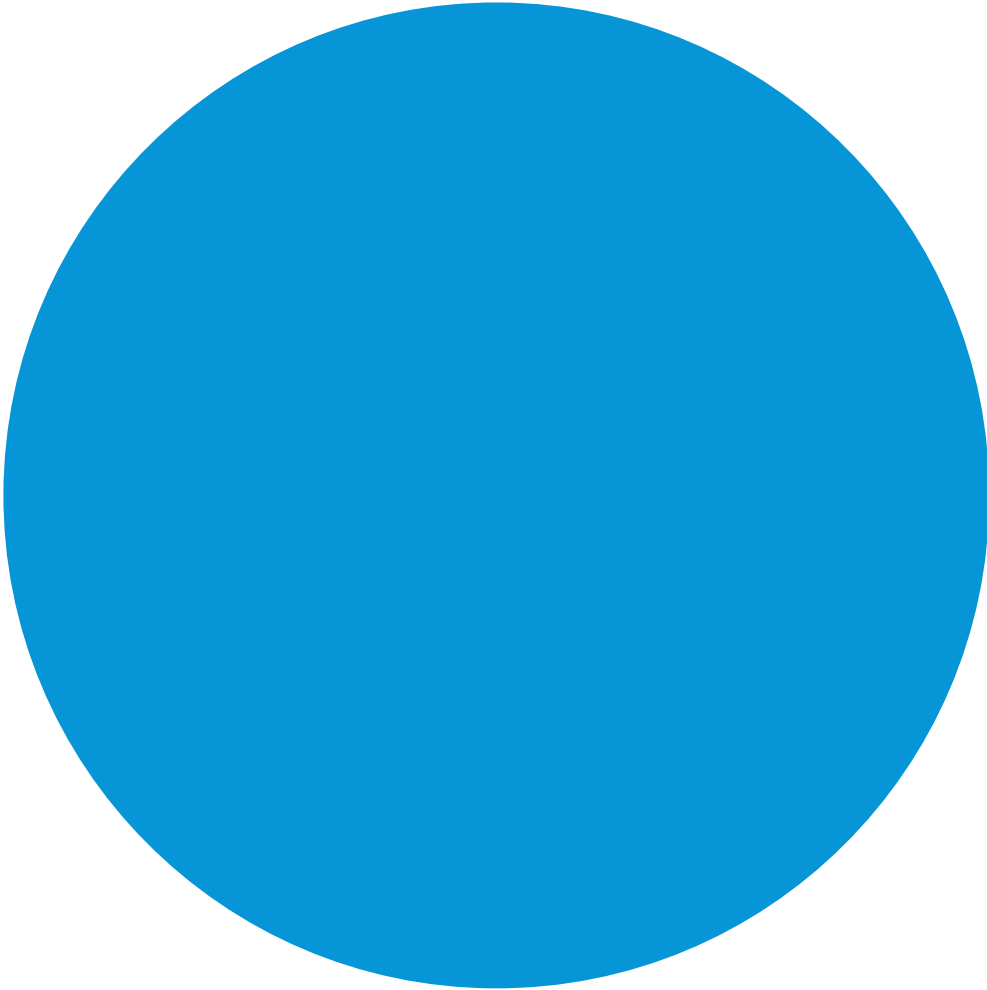
## Actions

Cancer Council NSW recommends that the NSW Government ensures that selling of tobacco is regulated in proportion to the harmfulness of the product by:

- requiring that all retailers selling tobacco hold a licence to do so
- designing a licensing scheme that requires prior approval to sell tobacco, imposes conditions on holding a licence, and provides for the withdrawal of the licence if conditions are breached
- instituting a fee for a tobacco retail licence that, at minimum, covers the cost of administering and enforcing the scheme, and reflects the social cost and harm of the product.

If implemented, these actions would provide the state with a mechanism to shape the conditions of sale, supply and availability of tobacco, which could be used to boost its efforts to reduce smoking in NSW.

*“Why indeed do we continue to have tobacco, a product proven beyond all doubt to induce death and harm so easily, at any convenience store, every service station and every retail outlet, ever accessible, 24 hours a day? We license alcohol sellers and we license drivers to safeguard society. Tobacco licensing would discourage sellers, and reduce accessibility. We need to do everything we can to reduce the burden on the health budget from smoking.” Heather\**



## 5. Emerging priorities

### Expanded specialist services for chronic hepatitis B

The incidence of liver cancer in NSW has increased over the past two decades. In 2005, liver cancer accounted for over 400 new cancer cases and nearly 300 deaths.<sup>56</sup> A significant cause of liver cancer is chronic hepatitis B virus infection; and individuals born in hepatitis B-endemic countries are 6 to 12 times more likely to develop liver cancer than Australian-born people. NSW has the highest number of chronic hepatitis B infections in Australia and the highest rates of liver cancer in NSW are in south-western Sydney.<sup>1</sup>

In response to this problem, Cancer Council NSW is piloting the 'B Positive' Project in the Fairfield and Liverpool Local Government Areas of south-western Sydney. This Project tests the feasibility, acceptability, and cost effectiveness of a targeted hepatitis B screening and surveillance program in individuals with chronic hepatitis B infection, who are at increased risk of developing liver cancer. Economic modelling from the project has demonstrated that a targeted hepatitis B screening and surveillance program for the Greater Sydney area could 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.<sup>56,57</sup>

While a targeted hepatitis B screening and surveillance program is not expected to greatly impact on the volume of GP consultations in the local area, it will lead to a significant increase in demand for specialist services. As an immediate response to the growing rates of liver cancer, Cancer Council NSW recommends that the NSW Government expands specialist diagnostic and disease-management services for people with chronic hepatitis B in south-western Sydney, to match the expected increased need.

### Expanded colonoscopy services

Bowel cancer is one of the most common forms of cancer, with almost 5,000 new cases and 1,700 deaths in NSW each year.<sup>1</sup> If detected early, five-year relative survival is 87% for all patients, however, if detected at a later stage, five-year survival drops to 12%.<sup>58</sup>

Screening for bowel cancer using a faecal occult blood test (FOBT) can reduce deaths associated with bowel cancer.<sup>59-61</sup> A positive FOBT result is most often investigated by colonoscopy. Research indicates that for people aged 50–75 years, a colonoscopy following a positive FOBT yields one cancer diagnosis per 20 colonoscopies.<sup>62</sup> The National Bowel Cancer Screening Program currently invites Australians turning 50, 55 and 65 years before 2010 to undergo a faecal occult blood test.<sup>63</sup>

Although funding and management for the National Bowel Cancer Screening Program is a federal responsibility, the subsequent increase in demand for colonoscopies is a cost to be shared between state public and private sector health services. The NSW Government is responsible for funding colonoscopies in the public sector, as well as paying for histopathology examinations and any subsequent treatments in state hospitals. According to the National Bowel Cancer Screening Program register, currently only 11% of positive faecal occult blood test results are followed up by colonoscopy.<sup>64</sup> Colonoscopy services in both metropolitan and regional areas of NSW are under resourced, resulting in waiting lists of up to 12 weeks for urgent colonoscopy in some hospitals and up to 18 months for non-urgent public patients.<sup>65,66</sup>

While the NSW Government has ensured that better information is available on health services via the *NSW Hospital Waiting Times* website, available data cover only public hospital inpatient services.<sup>67</sup> Therefore, information about procedures undertaken in the private sector and those performed on an outpatient basis in the public sector are not available.

Moreover, no relevant data on colonoscopies are included in the NSW Health performance reporting system. This information is collected by the Australian Institute of Health and Welfare but is subject to reporting and other delays.<sup>66</sup>

Due to the absence of a state-wide electronic data system, the total number of colonoscopies performed in NSW is unknown.

Cancer Council NSW recommends that the NSW Government conducts a NSW system-wide review of colonoscopy services capacity, including waiting times. This review should include:

- an investigation of private sector capacity, current workforce and facilities and a computerised referral system
- an estimate of future funding needs for reporting of waiting times in NSW.

We also recommend that the NSW Government works with clinical groups to develop and implement guidelines for the appropriate use of colonoscopy.

The ultimate goal of this work should be identifying capacity and distribution of colonoscopy services to service the demand created by the National Bowel Cancer Screening Program, and to establish service agreements procedures and guidelines for reliably assessing and managing people who have a positive screening test.

## 6. Conclusion

Although there has been much progress in cancer control in NSW over the past decade, the projected increase in people being diagnosed with cancer and the increase in people dying from cancer, will place significant pressure on the health system and the community.

The specific recommendations in this document, if implemented early, can prepare NSW for the challenges ahead.

Expanding radiotherapy services and establishing a systematic approach to quality improvement in cancer care will be critical to ensuring our health care system can meet the needs of cancer patients.

Improving transport, accommodation and parking assistance for cancer patients will reduce unnecessary additional stress on cancer patients and their families.

Legislating for smoke-free dining and drinking and creating stronger safeguards on the selling of tobacco both build on existing efforts to reduce smoking rates in NSW – critical to beating cancer since tobacco is responsible for around one-fifth of cancer deaths in Australia.

All the recommendations in this document are within the power of a State Government to implement, all are based on sound evidence, and all serve the public interest. All recommended actions help move NSW towards being a place where fewer people get cancer and those who do are able to receive treatment and support they need, when and where they can best avail themselves of it, and without undue financial hardship.

If adopted, the recommendations would enable NSW to continue its advances in the battle against cancer, for the benefit of all its citizens.

The NSW government represents the interests of approximately seven million people and has both the responsibility and the power to reduce the impact of cancer on our lives. Cancer Council NSW has identified five priority issues for State Government action if we are to achieve our shared goal of beating cancer. It's all about better treatment for cancer patients and better living for us all.

**If adopted, the recommendations would enable NSW to continue its advances in the battle against cancer, for the benefit of all its people.**

[www.savinglife.com.au](http://www.savinglife.com.au)





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# Notes





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