



Vision for Change

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to help beat cancer**

Aboriginal population, both Aboriginal and Torres Strait Islander People, are referred to in this document as 'Aboriginal' in recognition of the fact that Aboriginal people are the original inhabitants of NSW.

Messages to the Premier and other quotes in this document reference the author's electorate rather than suburb

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Government efforts to reduce the number of people who hear the words ‘you’ve got cancer’ must continue. The NSW Government knows that we face a future where more people in NSW will be getting cancer, and living longer with it. Decisions need to be made now to ensure that people with cancer and their families get quality cancer care, wherever they live.

This means being free of worrying about chemotherapy co-payments; getting coordinated cancer care wherever they go in the healthcare system; and having specialist palliative care if they need it, wherever they choose to die. We also need to ensure that action is taken to reduce the chances of more people being diagnosed with cancer. Government action to reduce the availability of tobacco, by reforming how it is sold, will help with this.

There is also an opportunity for the NSW Government to show leadership in Aboriginal cancer control. Aboriginal elders and community members have told us that having more Aboriginal staff in cancer services across the state will make a difference to closing the gap in cancer outcomes between Aboriginal and non-Aboriginal people...and we need to listen.

About 61,000 Australian lives have been saved by improvements in cancer prevention, screening and treatment over the past 20 years. Continued advances in these areas can help see that this number increases; and the NSW Government has the opportunity to contribute to these advancements.

The five issues in this document have been chosen because action now will see an immediate improvement, and will continue to impact in the future. The actions are achievable and within the power of the State. A government that takes these actions will demonstrate its commitment to reducing the impact of the burden of cancer. Cancer Council staff, advocates and volunteers share this vision for change.

TOBACCO RETAIL REFORM

More than 5,000 people die every year in NSW from smoking-related causes and the costs to the individual, their family and the State are high. Despite their danger, the availability of tobacco products ‘anywhere, anytime’ undermines the NSW Government’s tobacco control initiatives. There is strong support for tobacco retail reform among the NSW community and the Government has the responsibility to make it happen.

Cancer Council NSW recommends that the NSW Government:

Introduce targeted reforms to support people trying to quit smoking and reduce the likelihood of young people taking up smoking. These reforms should take into account the harms caused to public health, and the impact of retail availability on smoking; and they need to include controls on the number, type, distribution and location of retail outlets selling tobacco. A positive licensing scheme may be one way to manage the retailing of tobacco.

Our vision for change is for a NSW Government that addresses the selling of tobacco to support people who are trying to quit, and encourage young people to live smoke free.



INCREASING THE ABORIGINAL WORKFORCE IN CANCER SERVICES

Lack of access to culturally appropriate health care services is a barrier to closing the gap in cancer outcomes between Aboriginal and non-Aboriginal people. Currently there isn't a strategic approach to recruiting and supporting an Aboriginal workforce in cancer services across NSW. The NSW Government has targets for Aboriginal representation across the whole health workforce, and cancer services need particular attention.

Cancer Council NSW recommends that the NSW Government:

- Map the Aboriginal health workforce in NSW cancer services by occupation, salary level, location and classification, to establish a baseline.
- Develop an Aboriginal health workforce plan specifically for cancer services, which ensures that workforce distribution matches Aboriginal community cancer need and ensures cultural safety for employees.
- Implement strategies to increase the Aboriginal health workforce in cancer services to 2.6% of the total health workforce in line with the aim of the NSW Health Aboriginal Workforce Strategic Framework 2011-2015.

Our vision for change is for a NSW where Aboriginal people who go to a cancer service will be cared for by an Aboriginal person.

NO CHEMOTHERAPY CO-PAYMENTS

In NSW, people with cancer who are public hospital patients may be charged a co-payment for their chemotherapy medicines which can add to the financial and emotional burden of cancer. This is inequitable as this is not a requirement in other states. Even within NSW some patients may have the fee waived by the hospital. The chemotherapy co-payment may be up to \$180 for the first round of chemotherapy with additional costs if medicines are changed.

Cancer Council NSW recommends that the NSW Government:

Restructure funding and administrative arrangements so that no public patient is charged for injectable and infusible chemotherapy when they attend a NSW public hospital.

Our vision for change is that cancer patients who have their chemotherapy in a public hospital get it for free.

COORDINATED CANCER CARE

The patient journey for people diagnosed with cancer, their carers and families is often complex. Patients can find coordinating appointments and keeping up with the amount of information distressing, especially at a time when they may feel unwell and vulnerable. The effectiveness of coordinated cancer care varies and it is unclear what is happening to manage it systematically across the state. These problems are worse for Aboriginal people who are more likely to live in rural and remote NSW, be diagnosed later and have complex needs.

Cancer Council NSW recommends that the NSW Government:

- Develop key performance indicators for coordinated cancer care and require regular public reporting on achievements in each Local Health District.
- Fund a model of coordinated cancer care that meets the needs of Aboriginal cancer patients, their carers and families.

Our vision for change is that people with cancer, and their families, get the cancer care they need in a logical, connected and timely manner no matter where they live in NSW.



MORE PALLIATIVE CARE SERVICES

Many people in NSW who need specialist palliative care don't get it, particularly if they are people with cancer who live in rural or remote NSW and/or are Aboriginal.

In NSW the number of specialist palliative care physicians needed to provide specialist palliative care across the state remains unacceptably low in comparison to the minimum requirement of 1.0 full time equivalent (FTE) positions per 100,000 head of population recommended by the Australian and New Zealand Society of Palliative Medicine. NSW also has too few specialist palliative care nurses, which has significant implications for specialist palliative care services in rural and remote NSW.

Cancer Council NSW recommends that the NSW Government:

- Fund specialist palliative care services across NSW to a level that ensures a specialist palliative care physician ratio of at least 1.0 FTE position per 100,000 head of population, which is an extra 34 FTE positions.
- Fund extra positions for specialist palliative care nurses across the state to achieve parity with Victoria.

- Fund culturally appropriate palliative care services for Aboriginal people, as outlined in The NSW Government plan to increase access to palliative care 2012-2016.
- Undertake a rigorous evaluation of the Palliative Care Home Support Program and make the report publicly available.
- Provide adequate funding to complete all other actions included in The NSW Government plan to increase access to palliative care 2012-2016.

Our vision for change is that every person who is dying from cancer has the best quality of life and if needed, a specialist palliative care team, to care for them.

The NSW Government's Cancer Plan 2011-2015 will soon come to an end and a new cancer plan, to take NSW beyond 2015, is needed. The Government's current commitment to people with cancer must continue and a new vision for a patient-centred cancer care system developed; with particular attention to Aboriginal people, people from culturally and linguistically diverse backgrounds and people in rural and remote NSW.

Overview of cancer in NSW

Every year over 13,000 people die of cancer in NSW accounting for over 25% of all deaths; for people aged between 35 and 84 years cancer is the leading cause of death.¹

Each year there is an estimated increase of approximately 1,000 new cancer cases, resulting in a rise from more than 35,000 new cases in 2006 to an estimated 51,000 by 2021: an increase of 44%.² This increase reflects the growth in the NSW population, particularly those over the age of 65 years.

The rise in incidence rate, together with improved survival, means that more people are living longer with the disease. Consequently, the number of people in NSW who may need support because of their experience with cancer in the short and longer term is growing. This includes the carers and families, as well as the person with cancer.

However, the experience of cancer is not the same for all groups of people across NSW. Aboriginal people have higher cancer incidence and mortality rates, and significantly lower rates of survival.³⁻⁵ Of particular concern, lung cancer incidence and mortality is substantially higher across Aboriginal people 40 years and over.⁴ Aboriginal people also have lower rates of access to investigations and procedures, and a lower likelihood of being treated for cancer.⁴

Other minority and under-served groups, including people from culturally and linguistically diverse backgrounds and those from lower socioeconomic backgrounds, have higher incidence and mortality rates.⁶ People living in rural and remote NSW are also further disadvantaged in their access to cancer services.^{7,8}

MESSAGE TO THE PREMIER:

'In order to consign this terrible disease to the history books, State Government must play a much larger role. Funding is needed to assist those who are experiencing cancer. State Government needs to face up to its responsibility of ensuring the welfare of its constituents.'

71 YEAR OLD, CONCERNED COMMUNITY MEMBER, BLACKTOWN

Progress and Challenges

Over the last 20 years, around 61,000 Australian lives have been saved by improvement in cancer prevention, screening and treatment.⁹ The benefit of action taken in these areas is clear.

Decisions made by various governments mean that in NSW, over the last decade there have been many positive changes in cancer control. NSW now has smoke free pubs and clubs, no tobacco displays in shops, better sun protection for children when they are at school, and an end to commercial solariums. There have also been positive developments in providing services to people with cancer and making their access to care a little easier. New regional cancer centres, improvements in the Isolated Patients Travel and Accommodation Assistance Scheme and increased support to people who want to spend their last days of life at home are just a few examples.

Yet governments have acknowledged the need for further action to reduce the impact and incidence of cancer. The NSW Government's Cancer Plan 2011-2015 identifies strategies to reduce the incidence of cancer and improve survival rates.⁶ The Plan focuses on responding to the needs of people with cancer in a patient-centred way, with particular attention to Aboriginal people, people from culturally and linguistically diverse backgrounds and people in rural and remote NSW.⁶ Other government policies, such as the NSW Tobacco Strategy 2012-2017,¹⁰ the NSW Government plan to increase access to palliative care 2012-2016,¹¹ and the NSW Aboriginal Health Plan 2013-2023,¹²

include goals which have the potential to prevent cancer or benefit people living with cancer.

However, it is clear that the burden posed by cancer will continue to increase and that the NSW Government needs to prepare for this.² While efforts to reduce the incidence of cancer should continue, a strong emphasis is needed on improving the quality of life of those living longer with the disease, including long term follow up after treatment and improved rehabilitation and palliative care.⁶ Addressing cancer prevention and treatment in NSW will continue to be key areas requiring the concerted effort of all involved in cancer control for the foreseeable future.



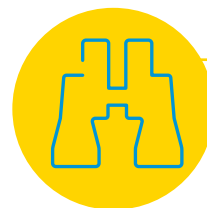
Our Community's Vision for Change

To develop *Saving Life 2015: Vision for Change*, Cancer Council gathered evidence about cancer-related issues in NSW, focusing on those where action from government would make the biggest difference.

Support for addressing the retail supply of tobacco is strong. Its availability 'anywhere, anytime' thwarts people's attempts to quit smoking and makes it harder to reduce the smoking rates in NSW. Therefore, tobacco retail reform continues to be a focus area leading up to, and beyond, March 2015.

Cancer Council is strongly committed to addressing the disparity in cancer outcomes between Aboriginal and non-Aboriginal people. As there are many areas of inequity, we had to identify which action may have the greatest impact in Aboriginal cancer control. To do this we searched the literature, including research from the Aboriginal Patterns of Cancer Care Project, which is investigating the cancer experiences of Aboriginal people in NSW. As a partner in the Aboriginal Cancer Partnership Project, we received input from Aboriginal community members and Aboriginal people who work across the health system, including in cancer services. The feedback received emphasised that the NSW Government needs to focus on increasing the Aboriginal workforce in cancer services.¹³

Advocates and volunteers who are directly engaged in the work of Cancer Council participated in the process via an online questionnaire. Over 850 people helped to prioritise three areas for NSW Government action in addition to increasing the Aboriginal cancer workforce and reducing the retail availability of tobacco. They ranked abolishing chemotherapy co-payments, coordinated cancer care and palliative care, as the most important. People provided stories about their experience of having cancer or caring for someone with cancer. These are included in *Saving Life 2015: Vision for Change* to provide a glimpse of the day to day lives of those who are affected most by government decisions. Participants also provided messages for the Premier, and a snapshot of these has been included.



Tobacco Retail Reform

PROBLEM

More than 5,000 people die every year in NSW from smoking-related causes.¹⁴ With 900,000 smokers in NSW¹⁵ the tangible costs of smoking to NSW society, including health care costs and lost labour, are estimated at \$2.9 billion annually.¹⁶

Despite the known impact of tobacco use, NSW still has almost 10,000 retail outlets selling cigarettes.¹⁷ The NSW Government has a strong record of implementing initiatives to reduce demand for tobacco, including public education campaigns, retail display bans and smoke-free outdoor areas. However, the widespread retailing of cigarettes undermines the Government's tobacco control initiatives.

In NSW, there are no legal limits on where tobacco can be sold, who can sell it and when, aside from a ban on mobile sellers and market stalls. There is also no cap on the total number of outlets selling tobacco. This is in contrast to other products that are legal but potentially harmful, such as alcohol and prescription medicines. Currently, no licence is needed to sell tobacco, instead NSW retailers are only required to notify the NSW Ministry of Health via the online Retailer Notification Scheme.¹⁸ The aim of the scheme is to capture data about the number and location of tobacco retailers and to allow for enforcement of retail laws.

Research literature shows a link between tobacco retailing and smoking, such as:

- High-density and widespread distribution of tobacco retailers contribute to smoking^{19:20}
- Retail outlet density is higher in disadvantaged communities²¹
- Retailers near schools contribute to increased smoking rates and cigarette purchases among adolescents²²
- People not intending to smoke, such as people trying to quit and those who don't have an entrenched smoking habit, are more likely to make unplanned purchases in convenience, route and impulse retailers. This includes petrol stations and licensed venues^{19:23}
- Consuming alcohol, especially in social settings like bars and clubs where tobacco is commonly sold, increases smoking and undermines quit attempts²⁴
- People trying to quit are more likely to relapse if they can buy cigarettes close to home²⁵
- For some smokers, the sight of a retail outlet prompts thoughts about smoking or buying cigarettes, even though tobacco must now be out of sight in stores.²⁶

MESSAGE TO THE PREMIER:

'As a young person, I am aware of the negative cultural association between cigarettes and alcohol within my age group. Consumption of alcohol is often paired with cigarette smoking, and many young people I know will buy cigarettes and alcohol together in preparation for a social night out. Friends of mine have often said that they only smoke when they drink or only get a craving for a cigarette after having had a few drinks. I believe that to dissuade this behaviour, cigarettes should be banned from being sold at liquor retail outlets.'

23 YEAR OLD, FAMILY MEMBER/FRIEND OF SOMEONE WITH CANCER, PITTWATER



'When my son was under-age, the local milk bar was giving him credit to buy cigarettes, keeping his watch for security. Made me believe we need licensing of retailers.'

60 YEAR OLD, FAMILY MEMBER/FRIEND OF SOMEONE WITH CANCER, NORTH SHORE

'I don't want my grandchildren to ever start to smoke. I don't want them to have access to cigarettes as a part of their way of life.'

57 YEAR OLD, FAMILY MEMBER/FRIEND OF SOMEONE WITH CANCER, ORANGE

In 2012, Cancer Council NSW conducted an audit of 1,739 tobacco outlets across NSW to observe compliance with existing retail laws and record the price of a standard brand of cigarettes.

The audit found that:¹⁷

- On average, there are 17.7 tobacco outlets per postal area
- There is one pharmacy for every five tobacco retailers
- Convenience, route and impulse retailers make up almost 80% of tobacco outlets. These outlets are known to tempt people not intending to smoke
- About one in three outlets (34%) are premises licensed to sell alcohol
- More than one in four retailers did not comply with retailing laws, either because they are not listed under the Retailer Notification Scheme or because, at the time of the audit, they failed to meet in-store requirements, or both. One unlisted retailer was found per approximately 13 listed retailers, and unlisted retailers were more likely to break in-store retailing laws
- The Retailer Notification Scheme does not provide accurate information about tobacco retailers in NSW. Some retailers were not listed and many were listed multiple times or their records were out-of-date.

SOLUTION

Tobacco retail reform that aims to reduce the supply of tobacco has the potential to help the NSW Government achieve its smoking reduction targets, without making it unreasonably difficult for smokers to buy cigarettes if they do not want to quit. Tobacco retail reform will help the NSW Government achieve its goals to reduce the impact of smoking related illnesses.¹⁰ This includes lower smoking rates by 3% for non-Aboriginal people and 4% for Aboriginal people by 2015.²⁷ It will also support the Government's aim to reduce the incidence of cancer (through improving modifiable risk factors) and improve the cancer outcomes for Aboriginal people, rural and remote populations and people who are socioeconomically disadvantaged.⁶

The majority of smokers want to quit²⁸ but quitting is difficult, and new ways must be found to make it easier. It is expected that the biggest gains from tobacco retail reform would be achieved by preventing young people from taking up smoking, helping current smokers to quit, reducing smoking among disadvantaged people, and stopping 'tipping point' smokers (who may describe themselves as 'light smokers' or 'social smokers') from developing an entrenched smoking habit.

If tobacco retail reform was to achieve even a small reduction in smoking rates over current tobacco control activities, it would have a strong social and economic impact. It would also send a strong message that cigarettes are a dangerous product, and further contribute to the de-normalisation of smoking.

Recent survey results show strong community support for tobacco retail reform. 91% of respondents to the 2009 NSW Smoking and Health Survey support policies requiring retailers to have a licence to sell tobacco products. Even among smokers, 88% of respondents supported such regulation.²⁸

ACTION

Cancer Council NSW recommends that the NSW Government introduce targeted reforms to the retail sector to support people trying to quit smoking and reduce the likelihood of young people taking up smoking. These reforms should take into account the harms caused to public health, and the impact of retail availability on smoking, and they need to include controls on the number, type, distribution and location of retail outlets selling tobacco. A positive licensing scheme may be one way to manage the retailing of tobacco.

Increased Aboriginal Workforce in Cancer Services

PROBLEM

Aboriginal people have higher cancer incidence and mortality rates, and significantly lower rates of survival, compared to non-Aboriginal people. They are also less likely to initiate or complete cancer treatment.⁴

Lack of, and more limited access to, culturally appropriate health care services has been identified as a significant barrier to closing the gap in cancer outcomes between Aboriginal and non-Aboriginal people. One reason may be that care providers in cancer services are likely to have pre-conceived ideas about cultural difference and the design and delivery of Aboriginal cancer care; and some ideas may possibly serve to exclude Aboriginal people.²⁹ However the problem is likely to relate to a lack of Aboriginal workers in the cancer patient journey which in turn contributes to late diagnosis, inadequate treatment and care, and poorer long term outcomes.^{30;31}

The problem is also more complex than a lack of Aboriginal workers. To fulfil their role, Aboriginal Health Workers employed in NSW Health need to overcome significant barriers such as, lack of recognition and support, career development opportunities, training and development and resources,

as well as competing demands.³²

This suggests that there are problems with the systems and processes in use to recruit, retain and develop the workforce of Aboriginal Health Workers.

NSW Ministry of Health aims to meet and exceed the NSW Government's target of 2.6% representation of Aboriginal people in the health workforce by 2015.³³ However, only 1.9% of the total NSW Health workforce is Aboriginal, and the necessary growth per annum to achieve the target is not being reached.³³ No information about Aboriginal people working in cancer care services is available.

Currently, the highest number of Aboriginal people employed in NSW Health is in the 50-54 year age group, which means that a significant number will leave over the next ten years. Also, females represent three-quarters of the total Aboriginal workforce in NSW Health, a gender imbalance which has implications for future workforce planning.³⁴

SOLUTION

The NSW Cancer Plan 2011-15 recognises the need for culturally appropriate cancer services and programs for Aboriginal people, developed in partnership with Aboriginal communities and peak bodies.⁶

The Government also understands that strengthening the Aboriginal workforce in the health system is critical to improving services,¹² and that increasing the representation of Aboriginal people across all health professions will help to close the gap in health outcomes between Aboriginal and non-Aboriginal people.³⁵

One way to increase the health system's responsiveness to the needs of Aboriginal people with cancer, their carers, and their communities is to focus specifically on the Aboriginal workforce in cancer services. Where they do exist within cancer services, Aboriginal Health Workers or Liaison Officers are considered invaluable by the Aboriginal community.³⁶

A training needs analysis, undertaken by the Aboriginal Health and Medical Research Council of NSW (AHMRC), highlighted the importance of increasing the Aboriginal workforce across cancer services.³⁶ Recently this was reinforced at the NSW Aboriginal Cancer Partnership forum. At this gathering, Aboriginal community members and Aboriginal staff from general, and cancer specific, health



services provided input into the development of Cancer Council's *Saving Life 2015: Vision for Change*. Participants agreed that increasing the Aboriginal workforce is the most effective option for reducing the gap in cancer outcomes for Aboriginal people. It was generally considered that having dedicated Aboriginal workers in cancer services may solve many cancer-related health issues for Aboriginal people.¹³

Aboriginal employment strategies may include traineeships and mentoring programs;³⁶ scholarships to increase the recruitment of Aboriginal nurses; strategies to increase the number of male Aboriginal Health Workers; employing Aboriginal people to provide cancer information and support and engaging with high schools to encourage young Aboriginal people to think about a career in Aboriginal cancer services.¹³

A multi-disciplinary team approach that includes Aboriginal Health Workers, cancer care coordinators and Aboriginal cancer support workers may also contribute to the development of a culturally appropriate model of care for Aboriginal cancer patients and their families. Examples of Aboriginal cancer workforce models currently being funded in other states may be useful references. In South Australia for example, two dedicated Aboriginal Cancer Care Coordinators work together across several major public hospitals.³⁷

It is important that consideration be given to how to ensure cultural safety of the workforce through improved recruitment, retention, and education and training

systems.¹² A more visible Aboriginal workforce in the health system may assist in decreasing the impact of workplace racism. This may improve retention rates, while simultaneously enhancing cultural understanding and educating non-Aboriginal staff about the value of the Aboriginal workforce to the health system.¹²

A partnership approach with Aboriginal elders, community members, Aboriginal Community Controlled Health Services and other relevant stakeholders will be essential in planning, implementing and evaluating an Aboriginal workforce strategy for cancer services. This will ensure that the process is holistic and guided by the principles of self-determination, equal partnership and mutual respect.

ACTION

Cancer Council NSW recommends that the NSW Government:

- Map the Aboriginal health workforce in NSW cancer services by occupation, salary level, location and classification, to establish a baseline
- Develop an Aboriginal health workforce plan specifically for cancer services, which ensures that workforce distribution matches Aboriginal community cancer need and ensures cultural safety for employees
- Implement strategies to increase the Aboriginal health workforce in cancer services to 2.6% of the total health workforce in line with the aim of the NSW Health Aboriginal Workforce Strategic Framework 2011-2015.

'We have to do something NOW.... For the sake of the future for my people, my culture and our survival as a people, and for our generations to come. We have to do it now!'

44 YEAR OLD, PRIMARY CARER, LISMORE

'I have had several members pass away from cancer ... specific funding should go into campaigns targeted at Aboriginal people.'

30 YEAR OLD, FAMILY MEMBER/ FRIEND WITH CANCER, BARWON

No Chemotherapy Co-payments

PROBLEM

In NSW, people with cancer who are public hospital patients may be charged a co-payment for their chemotherapy medicines. This can add to the financial and emotional burden of cancer. It is also inequitable as some patients may have the fee waived by their hospital, while others do not. The situation in NSW is different to other states, which can add to the confusion.

The Pharmaceutical Benefits Scheme (PBS) is managed by the federal government. Under the PBS, a co-payment may be charged for every drug that requires a script from a doctor. In 2012 the federal government revised the arrangements for chemotherapy medicines that are administered through intravenous infusion or injection.³⁸ Under these new arrangements a co-payment is required from the federal government for each new chemotherapy drug but not for repeat prescriptions of the same drug.³⁸

This co-payment is not paid by cancer patients receiving chemotherapy treatment in other states. For example, in Victoria patients requiring chemotherapy are admitted to the hospital for the day.³⁹ Inpatients, including cancer patients who are admitted as day patients to have their chemotherapy, are not required to pay a PBS co-payment.³⁹ However, the NSW Government opts to provide chemotherapy to almost all (97%) of chemotherapy patients on a 'non-admitted' basis.⁴⁰ The impact of this decision is that, in most situations, patients are expected to pay the co-payment.

As of 1 January 2014, the PBS co-payment is \$36.90 for general patients and \$6.00 for concession card holders.⁴¹ In NSW this is charged for each chemotherapy medicine that is injected or infused via a drip during a chemotherapy treatment. It is common for patients to have to pay four or five co-payments (approximately \$180 in total) for their first chemotherapy treatment, as often several different drugs are used at the same time. If the oncologist changes the chemotherapy regime, the patient pays another co-payment for every new prescription. This is in addition to the co-payments made for other drugs, such as take-home medications, which may be prescribed to relieve the side effects caused by chemotherapy, such as nausea and vomiting.

Already many people, particularly low-income individuals and families, struggle to meet the out-of-pocket costs for medical, pharmaceutical and allied health services.⁴² Co-payments may also impact on patients' ability to afford other essential medicines. While the co-payment for people with a health care card is less, they may still decide to not take other essential medicines as a result.⁴³ Given that almost half of all public



cancer outpatients (45%) have a household income under \$30,000 after tax,⁴⁴ a large number of patients who need chemotherapy, are likely to have difficulty meeting the cost of co-payments. This situation is expected to worsen with the federal government's proposed increase in the cost of prescriptions.

The relationship between co-payments, use of health care services, and health outcomes is complex, so the precise impact on different people is unknown. However, there is good evidence to show that, overall, co-payments reduce access to necessary care but there is no evidence that they reduce health care costs.⁴⁵

Some public hospitals have chosen to waive the co-payment and others provide exemptions on recommendation from a social worker. This situation is inequitable as cancer patients may be reluctant to speak up about financial difficulties and may pay the bill at the expense of other care items or daily living costs. Also, public hospitals do not routinely assess a patient's need for practical and financial support, so the hardship often goes unnoticed.

SOLUTION

Ensuring that no public hospital patient pays a co-payment for their injected or infused chemotherapy will make the situation equitable across NSW and with other states such as Victoria.

Most importantly, it may improve the quality of life for cancer patients and their families by lessening the financial and emotional burden and freeing up some extra dollars to spend on the other costs they face during their cancer treatment.

ACTION

Cancer Council NSW recommends that the NSW Government:

- restructures funding and administrative arrangements so that no patient is charged for injectable and infusible chemotherapy when they attend a public hospital.

'During my husband's 18 weeks of unsuccessful treatment, we paid.... we also lived very close to a budget and the medical costs hurt. It's not just the chemotherapy, it's the total medications like anti-nausea, anti-reflux, creams for rashes etc.'

45 YEAR OLD, PRIMARY CARER, RIVERSTONE

'The cost of my own chemotherapy was \$300 per month and not to mention other costs that came in to the overall treatments. It did put considerable strain on the family ..my wife took the burden and hid these costs from me to not worry me at the time. That was an added issue that didn't have to be there when emotions were already very high.'

53 YEAR OLD, HAS/HAD CANCER, MIRANDA

Coordinated Cancer Care

PROBLEM

The patient journey for people diagnosed with cancer, their carers and families is often complex. It may involve appointments with numerous health professionals and attending several treatment facilities across multiple (and often distant) locations. Patients can find coordinating appointments and keeping up with complex information distressing, especially at a time when they may feel unwell and vulnerable.

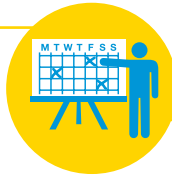
Poor coordination of cancer care can lead to a break-down in communication between service providers, which can compromise a patient's care, and add more costs to the health system.

For Aboriginal people, problems with coordination of cancer care are even more pronounced. They are more likely to be diagnosed at a more advanced stage of cancer and have higher levels of comorbidity.⁴ As a result, appointments, medications and information and support needs are often complex.

Cancer care in the public health system is provided by a multi-disciplinary cancer care team, which brings together a group of health professionals, such as doctors, nurses and allied health professionals, to discuss treatment options and develop individualised treatment plans.⁴⁶ Some multidisciplinary teams are supported by a cancer care coordinator but not all. Research shows that where cancer care coordinators are available, patients report being twice as satisfied with communication and information coming from the multidisciplinary team meeting as those that had no one responsible for coordinating their care (86% compared to 43% satisfaction rate).⁴⁷

However, the effectiveness of the current system varies. Some cancer care coordinators report that the multidisciplinary team meeting is not an effective mechanism for discussing the patient's supportive care needs, and that extra meetings with psycho-oncology support staff are often required to discuss patients' support care and develop an action plan.⁴⁷

Currently, Local Health Districts (LHDs) fund approximately 30 FTE Cancer Care Coordinator positions across NSW. A further 50 FTE positions were funded by Cancer Institute NSW through the Cancer Services Infrastructure Support Program but funding ceased in June 2014 despite some positive outcomes.⁴⁷ LHDs now receive block funding to manage coordinated cancer care, and key performance indicators are being developed by the Cancer Institute NSW. However it is unclear how coordinated cancer care is currently managed in each LHD.



SOLUTION

Cancer care needs to be delivered in a logical, connected and timely manner so that the medical and personal needs of cancer patients are met, regardless of where they live in NSW. The development of new ways of providing coordinated cancer care in NSW needs to ensure that the elements previously described by patients and their families as effective are maintained. This includes having a point of contact for information, support to understand the outcomes of the multi-disciplinary team meetings, and help organising their care when they had to use multiple services and facilities across the health sector.⁴⁷

Culturally safe coordinated cancer care for Aboriginal people with cancer is needed and further research into what works for Aboriginal people with cancer is required to guide its development.⁴⁸

ACTION

Cancer Council NSW recommends that the NSW Government:

- Develop key performance indicators for coordinated cancer care and require regular public reporting on achievements in each LHD.
- Fund a model of coordinated cancer care that meets the needs of Aboriginal cancer patients, their carers and families.

'It is absolutely vital that every cancer patient, be they in hospital, hospice, nursing home, rehabilitation centre, or at home need a single point of contact ... In times of severe stress one point of contact is often all that is able to be accessed through the fog of emotions.'

72 YEAR OLD, HAS/HAD CANCER, COFFS HARBOUR

'I personally found the 'cancer care system' lacking. I was left to work things out myself and seek some help when desperate, but many a day went by when I was confused and would have loved some help from a professional.'

65 YR OLD, HAS/HAD CANCER, TAMWORTH

More Palliative Care Services

PROBLEM

In high income countries, such as Australia, over two-thirds of people who die, from whatever cause, need palliative care.⁴⁹ In NSW, cancer is responsible for over 25% of all deaths.¹ With a projected increase in deaths from cancer over the next seven years,² this means that many people who are dying from cancer will need palliative care.

While some people with life-limiting cancer may find support from their primary health care provider (such as a GP), others will have complex problems needing the services of a specialist palliative care provider.

Unfortunately, many people in NSW who need specialist palliative care don't have access to it. People in rural and regional NSW are particularly disadvantaged.¹¹ Beyond the metropolitan areas there are few specialist palliative care services, and those that are available may be one palliative nurse working alone on a part-time basis to provide services to a large area. Where palliative care medical specialist support is available in rural and regional NSW, it is usually on a fly-in/fly-out basis only.⁵⁰ After-hours access to specialist palliative care services is non-existent outside metropolitan areas.

Aboriginal communities in NSW are further disadvantaged. Aboriginal people are more likely than non-Aboriginal people to live in remote areas of Australia⁵¹ where specialist palliative care services are limited.⁵² Aboriginal carers may also have their own significant health problems, which can limit their ability to provide the care required. Culturally appropriate palliative care

services for Aboriginal people has been recognised as an area of need by the NSW Government.¹¹

There is a significant difference between where people say they'd prefer to die and where they actually do die. It is generally estimated that 70% of Australians say they want to die at home, but only 16% are able to do so.¹¹ For people in NSW, this may be related to the limits in available community-based specialist palliative care services.

Funding of one million dollars for palliative care volunteers has been recently announced by the NSW Government.⁵² This is in addition to enhancement funding in 2013 for end-of-life support packages of up to four days of home-based care for the dying patient and their family. People who receive the packages have support from community workers who are trained to provide personal and domestic care.⁵³

However, there are limitations to the packages. It is difficult to predict how long the dying process will take, so a maximum of four days of care may not be enough. Additionally, packages are not available in all parts of a Local Health District so people in some communities, particularly in rural and regional areas, will continue to be disadvantaged.

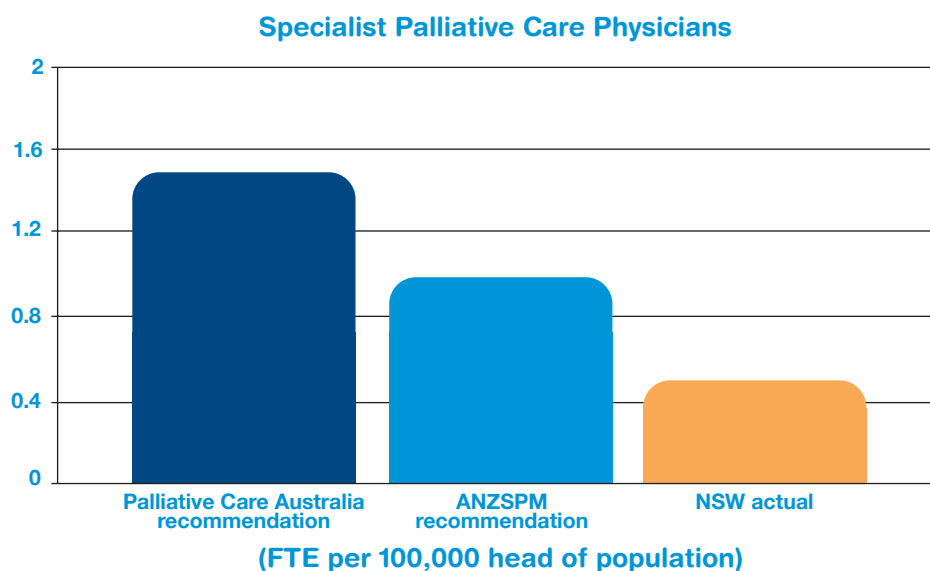
Areas such as Port Macquarie, Dubbo, Tweed Heads and Maitland remain without services. The community workers employed to provide the home-based support require input from the specialist palliative care teams who, in many areas are already overstretched. While the packages make it possible for some people who are dying, and their families, to get vital home help and support, the need for accessible clinical care from community-based specialist palliative care staff remains a priority.⁵⁴

In NSW the number of specialist palliative care physicians, and nurses, needed to provide specialist palliative care across the state remain low. The Australian and New Zealand Society of Palliative Medicine (ANZSPM) recommend one full time equivalent (FTE) specialist palliative care physician per 100,000 head of population as the minimum required for an adequate service.⁵⁵ When taking into account additional training positions to ensure the ongoing development of the specialty, Palliative Care Australia estimates that 1.5 FTE per 100,000 head of population is a more realistic requirement.⁵⁶





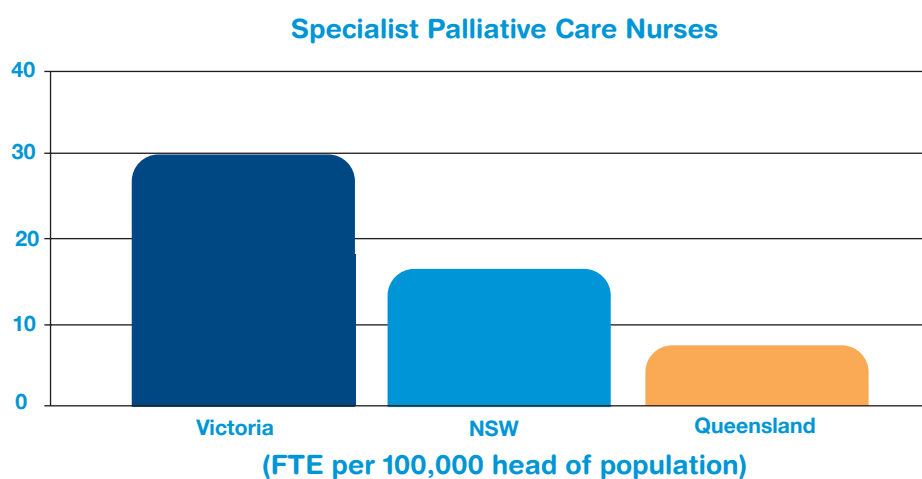
However, the latest figures from the Australian Institute of Health and Welfare (AIHW) show that in 2011, NSW had only 40 FTE specialist palliative care physicians, which equates to 0.5 FTE physicians per 100,000 head of population.⁵⁷



Adjusting for the projected increases in population to 2013,⁵⁸ we estimate that NSW needs 74 to 111 palliative care physicians to bring the numbers up to those suggested by the ANZSPM and Palliative Care Australia respectively. Based on this, we estimate a current shortfall of between 34 to 71 palliative care physicians. In 2012-13 the NSW Government provided funding for two new palliative care specialist training positions,³³ however this is not enough.

Based on the more conservative figure proposed by the ANZSPM we suggest an additional 34 FTE palliative care physicians are required to achieve the minimum number of specialists needed to adequately service the NSW population.

Across Australia the staffing levels of specialist palliative care nurses range from 7.9 FTE per 100,000 head of population in Queensland to 30.3 FTE per 100,000 head of population in Victoria. Within this national range, NSW has the second lowest ratio with 17.4 FTE per 100,000 head of population.⁵⁹ Despite the positive addition of 30 new clinical nurse specialists and educators announced by the NSW Government in September 2013, there is still a shortage of clinical specialist palliative care nurses to focus on planning end of life programs and this has significant implications for specialist palliative care services, particularly in rural and regional NSW.





SOLUTION

Accessing the community-based specialist palliative care team early can improve a patient's quality of life throughout the dying process.⁶⁰ Palliative Care NSW, the peak body for palliative care in NSW, has highlighted that the cost of community-based palliative care services can be up to 300% less expensive than care in an acute bed or intensive care bed. They suggest that an increased investment in palliative care services will result in budgetary efficiencies by avoiding inappropriate and preventable admissions to emergency and acute services, and by minimising or avoiding investigations, treatments and procedures that offer no improvement to a patient's quality of life.⁵⁰

The NSW Government plan to increase access to palliative care 2012-2016¹¹ includes a goal to expand community-based specialist palliative care services, especially in rural areas and for special needs populations, so additional funding will help achieve this goal.

An appropriately resourced system of community-based specialist palliative care across NSW will provide the right care, at the right time, in the right setting, to patients and families as the patient's illness progresses and their service needs change... regardless of where they live in NSW.

ACTIONS

Cancer Council NSW recommends that the NSW Government:

- Fund specialist palliative care services across NSW to a level that ensures a specialist palliative care physician ratio of at least one FTE position per 100,000 head of population, which is an extra 34 FTE positions.
- Fund extra positions for specialist palliative care nurses across the state to achieve parity with Victoria.
- Fund culturally appropriate palliative care services for Aboriginal people, as outlined in the NSW Government plan to increase access to palliative care 2012-2016.¹¹
- Undertake a rigorous evaluation of the Palliative Care Home Support Program and make the report publicly available.
- Provide adequate funding to complete all other actions included in The NSW Government plan to increase access to palliative care 2012-2016.

'Many Aboriginal and Torres Strait Islander people don't understand what palliative care really means....so many of my people miss out on a better quality of life they could have because of misinformation and the fear it creates.'

44 YEAR OLD, PRIMARY CARER, LISMORE

'My family and I found ourselves at the bedside of my husband's final battle with oesophageal cancer...a very dramatic event but thankfully we had the palliative care team near. It is something that I hoped I never had to experience, however I was so relieved to receive their expertise... they then took us through the process of saying goodbye. They even took my young son and answered his questions.'

45 YEAR OLD, FAMILY MEMBER/FRIEND OF SOMEONE WITH CANCER, RIVERSTONE

Conclusion

A VISION FOR CHANGE IN NSW

Our vision is that cancer will be beaten and that those currently living with the disease will have access to patient-centred services when they need them, wherever they live in NSW.

This vision includes having a community where the high burden of disease and poorer health outcomes from cancer do not impact Aboriginal people any more than they do non-Aboriginal people. This provides an imperative for all to commit to improving the responsiveness of the health system and to 'closing the gap' in cancer outcomes between Aboriginal people and non-Aboriginal people.

The actions outlined in this document all help move towards this vision. The next State Government can act to make sure that no cancer patient needs to pay for chemotherapy; that patients have well-coordinated care throughout the cancer journey; and that those who need it, can access specialist palliative care service wherever they choose to die. These actions will improve the lives of people with cancer and their families. Improvements in these areas will benefit Aboriginal people, people from culturally and linguistically diverse backgrounds and people living in rural and remote NSW. Government action to increase the Aboriginal health workforce in cancer services will also help close the gap in cancer outcomes between Aboriginal people and non-Aboriginal people.

In addition, continuing our efforts to reduce the supply of tobacco will make it easier for the Government to achieve its aim of lower smoking rates in NSW.

Every person with cancer and their carers and families, advocates, policy-makers and the wider NSW community stand to benefit from improving the cancer care system. United in our desire to improve cancer control for the whole of the NSW community, and in particular for those most disadvantaged, Cancer Council staff, volunteers and advocates will continue to work closely with the next NSW Government to make this happen.

MESSAGE TO THE PREMIER:

'We are a community of thousands of local people looking forward to working with you to reduce cancer rates and improve outcomes for people living with cancer and their carers and family members.'

39 YEAR OLD, FAMILY MEMBER/FRIEND OF SOMEONE WITH CANCER, HEFFRON

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