

**Submission
No 49**

**THE IMPLEMENTATION OF PORTFOLIO COMMITTEE No. 2
RECOMMENDATIONS RELATING TO THE DELIVERY OF SPECIFIC HEALTH
SERVICES AND SPECIALIST CARE IN REMOTE, RURAL AND REGIONAL NSW**

Organisation: Cancer Council NSW

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Submission to the Select Committee on Remote, Rural and Regional Health's Inquiry

**Implementation of Portfolio Committee No. 2
recommendations relating to the delivery of specific health
services and specialist care in remote, rural and regional NSW.**

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About Cancer Council NSW

Cancer Council NSW is the leading cancer charity in NSW dedicated to reducing the impact of cancer and ensuring programs and services reach communities throughout NSW. Cancer Council NSW is the only non-government organisation in Australia that works across every cancer in research, prevention, support, and advocacy. To achieve a cancer free future, Cancer Council NSW:

- supports people affected by cancer by providing emotional and practical support programs, as well as evidence-based information about cancer.
- enables the community to reduce their cancer risk through programs, information and policy efforts in skin cancer prevention, nutrition, alcohol, tobacco control and cancer screening.
- advocates and speaks up to achieve better cancer outcomes.
- conducts and funds world-class research to reduce the impact of cancer.

We rely on the generosity of the community to conduct our work – 94% of our revenue comes to us from the community. In 2022/23, our revenue was \$90 million – with \$4.2 million in funding from governments, most in the form of competitive research grants.

Cancer Council NSW is a committed partner in delivering the NSW Cancer Plan 2022–2027 and working in collaboration with all health system and community stakeholders to achieve the best possible cancer outcomes for people in NSW.

This submission was prepared by Cancer Council NSW in consultation with people affected by cancer and health professionals, including members of Cancer Council NSW's Health Services Advisory Group.

Executive Summary

Cancer Council NSW welcomes the opportunity to provide input into the Select Committee on Remote, Rural and Regional Health's inquiry into the implementation of Portfolio Committee No. 2 recommendations relating to the delivery of specific health services and specialist care in remote, rural, and regional New South Wales (NSW).

In this submission, Cancer Council NSW make recommendations for continued work (Table 1) and call attention to the:

- ongoing challenges people with cancer face when accessing transport.
- financial toxicity people experience when they undergo treatment for cancer.
- need for cancer services to have their processes integrated into statewide virtual care strategies and technology.
- opportunity to embed Cancer Council NSW's supportive care services in referral pathways.

Table 1. Cancer Council NSW's recommendations for continued work

Terms of Reference	Cancer Council NSW's Recommendations
<p>B. Patient transport and paramedicine</p> <p>- Recommendation 3</p>	<ul style="list-style-type: none"> • NSW Government works with Transport for NSW, Local Health Districts and community transport providers to create publicly accessible guidelines for community transport fees and set pricing benchmarks. • NSW Government reviews the Community Transport NGO Partnership Grants Program, to broaden eligibility and ensure funding is sufficient to enable more equitable and affordable for patients in remote, rural and regional areas. • NSW Health and rural and regional Local Health Districts include not-for-profit community transport providers, like Cancer Council NSW, through working groups to jointly plan and coordinate transport services. • NSW Health works with stakeholders, including NGO providers of non-emergency health transport, like Cancer Council NSW, to review the Transport for Health Policy.
<p>F. Cancer and oncology</p> <p>- Recommendation 21</p>	<ul style="list-style-type: none"> • NSW Government considers conducting a stocktake of regional cancer centres to understand the breadth of the issue with regards to public patients accessing private-public services for treatment. • NSW Health embeds Cancer Council Australia's Standard for Informed Financial Consent by developing and implementing a procedure in care and referral pathways that will assist healthcare professionals explain the likely costs associated with a comprehensive treatment plan to people affected by cancer.

Terms of Reference	Cancer Council NSW's Recommendations
<p>F. Cancer and oncology</p> <p>- Recommendation 30</p>	<ul style="list-style-type: none"> • Cancer Institute NSW continues to support cancer services to integrate their processes into statewide virtual care strategies and technology.
<p>G. Other specialist care and allied health services</p> <p>- Recommendation 5</p>	<ul style="list-style-type: none"> • Rural and regional cancer services, Cancer Institute NSW and Cancer Council NSW continue to engage regularly to better understand unmet needs and embed Cancer Council NSW's supportive care services in referral pathways.

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Introduction

On current trends, around 1.52 million people across the state will be diagnosed with cancer between 2020 and 2044, and around 500,000 people will die of cancer.¹ Cancer outcomes are among the best in the world in NSW, yet for people living in remote, rural, and regional areas, cancer outcomes remain poor. The 5-year survival for all cancers combined was lower in regional and remote areas compared to people living in a major city meaning people in regional and remote areas have poorer survival from cancer.² In addition, the age-standardised incidence rate of all cancers combined was higher in regional areas compared to major cities in 2012-16.² The age-standardised incidence rate was slightly lower in remote and very remote areas; however, the rates were impacted by lower participation in population screening programs, delayed diagnosis of cancer, and lower life expectancy in remote areas.²

People with cancer in remote, rural, and regional areas face greater challenges in accessing high-quality cancer care. The challenges they face include travelling to larger regional centres and/or metropolitan areas and related arrangements, financial stress, and a lack of knowledge regarding available support services.³

Cancer Council NSW is a committed partner in delivering the *NSW Cancer Plan 2022-2027* and working in collaboration with all health system and community stakeholders to achieve the best possible outcomes for people in NSW. Cancer Council NSW is a lead or partner in 14 out of 37 actions identified in the NSW Cancer Plan.

In 2020, Cancer Council NSW responded to the Inquiry into health outcomes and access to health and hospital services in rural, regional, and remote NSW. In the response, Cancer Council NSW made recommendations related to patient transport, out-of-pocket costs for public patients accessing private-public services, adopting the Australasian Teletrial Model and integrating supportive care services in referral pathways. While we are pleased the NSW Government acted upon several recommendations, including reviewing and improving the Isolated Patient Travel and Accommodation Assistance Scheme (IPTAAS), there are still challenges faced by people with cancer.

In this submission, Cancer Council NSW make recommendations for continued work and call attention to the:

- ongoing challenges people with cancer face when accessing transport.
- financial toxicity people experience when they undergo treatment for cancer.
- need for cancer services to have their processes integrated into statewide virtual care strategies and technology.
- opportunity to embed Cancer Council NSW's supportive care services in referral pathways.

Response to the Inquiry

B. Patient transport and paramedicine

Legislative Council Portfolio Committee No. 2 recommendations include recommendation 3, 28 and 29. Our reflections and recommendations relate to the progress made on recommendation 3.

Recommendation 3: That NSW Health, the rural and regional Local Health Districts and Transport for NSW work collaboratively to ensure, where feasible, more frequent and appropriately timed affordable transport services are available to support people to attend medical appointments in rural, regional and remote areas.

Progress since recommendation

Transport is a critical factor that enables people to access cancer care. However, for many people, especially in regional, rural, and remote areas, transport can be a barrier that prevents people from receiving the best quality cancer care. There are fewer cancer services in remote, rural, and regional areas and people often travel vast distances and make multiple trips for treatment. For instance, people receiving regular treatments for radiotherapy will usually need it for one to eight weeks. Additionally, cancer and its treatment may affect people's ability to drive safely, and they are often advised against driving. Hence, they rely on limited or alternative transport options.

Cancer Council NSW commends the NSW Government for acting upon recommendations to review and improve the Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS). Clients who have used the scheme, have reported to Cancer Council NSW that they have fewer financial worries due to the improved subsidy rates. Therefore, Cancer Council NSW recommends that IPTAAS is continuously funded. Additionally, Cancer Council NSW is pleased to participate in the Ministry of Health's IPTAAS community of practice and will work alongside the NSW Government to continuously review and improve the eligibility for the scheme and ensure the web-based forms are user-friendly.

Cancer Council NSW acknowledges the complexities of funding non-emergency health related transport and the range of Commonwealth programs (e.g., My Aged Care and NDIS) and state government initiatives that needs to be considered. However, it's important to note that incomes are generally lower for people in regional, rural, and remote areas.⁴ Therefore, the copayment required to be paid by patients to access community transport providers may not be as affordable in remote, rural and regional areas as it is in a major city, where people have higher incomes.

We know affordability of transport has an impact on people's ability to access treatment, especially if they need to access treatment over multiple days or weeks and traveling long distances to treatment is the main barrier people with cancer face when accessing community transport providers. Cancer Council NSW hears from and assists people with cancer in rural and regional areas who cannot afford the community transport co-payments and as such are not offered services.

The copayments for accessing non-emergency health related transport, including community transport, can be a substantial barrier for people with cancer. The NSW Government should work with Commonwealth Government and stakeholders to ensure there is adequate funding for the community transport sector, so people affected by cancer are not faced with escalating copayments. Cancer Council NSW recommends the NSW Government work with

Transport for NSW, Local Health Districts and community transport providers to create publicly accessible guidelines for community transport fees and set pricing benchmarks across NSW. Pricing benchmarks are a reference point for pricing so that patients are charged a similar copayment no matter which community transport provider they access.

Cancer Council NSW recommends the NSW Government reviews the Community Transport NGO Partnership Grants Program to ensure funding is sufficient to enable equitable access to non-emergency health related transport across NSW. The grant should allow community transport providers to be funded at a higher rate or a similar rate to IPTAAS if the person being transported is from a remote, rural, or regional area and would otherwise meet the IPTAAS criteria. Expanding the Community Transport NGO Partnership Grants Program is particularly important to assist people with cancer, who cannot access Commonwealth programs (e.g., My Aged Care and NDIS), so they do not face unaffordable copayments.

Cancer Council NSW has chosen to highlight the following instances that demonstrate the need to improve affordability of non-emergency health related transport:

- Cancer Council NSW is aware from social workers in a regional cancer centre that there are a number of patients who forgo treatment because they could not afford the cost to travel.
- A person with cancer in Griffith mentioned, “I have cancer, but I am also a carer for my wife and to use community transport, it would cost me \$45 a return trip. I have treatment 5 days a week for 6 weeks. It would be too expensive for me to use community transport”.
- A patient on the Mid North Coast was quoted \$230 for a return trip. If the patient was eligible for My Aged Care this would have been subsidised and delivered for \$66 per return trip.
- Another patient in Dondingalong in the Kempsey Shire with metastatic cancer, was advised that they needed to travel to the Mid North Coast Cancer Institute, which was about a two-hour return trip. A community transport provider quoted \$90 a return trip, and this was unaffordable. The client then became eligible for Cancer Council NSW’s Transport to Treatment Service and has since requested to use the service 22 times. This would have cost the client \$1,980 if they didn’t have access to Cancer Council NSW’s Transport to Treatment Service.

Cancer Council NSW’s Transport to Treatment is a free service for people who cannot access community transport providers or have other transport barriers. The service supports mainly people in rural and regional areas, where there is a lack of public transport, ride sharing and community transport, and people are disadvantaged by distance to access treatment. Transport to Treatment was designed to complement existing community transport providers, but people with cancer rely heavily on Transport to Treatment when they can’t afford the copayment charged by community transport providers.

In 2022-23, Cancer Council NSW’s Transport to Treatment volunteers dedicated more than 25,000 hours to transport over 1,600 clients to cancer treatment and other cancer-related appointments. There were 19,847 trips made in 2022-23. In the current financial year, Cancer Council NSW has had to introduce more restrictive eligibility criteria that prioritises people in greatest need of assistance to ensure the service is sustainable. Consequently, there have been fewer trips than in previous years with 7,701 trips made year to date and volunteers have dedicated 9,358 hours so far.

Cancer Council NSW believes that more work needs to be done to improve coordination within the non-emergency health related transport system. Closer partnerships between Local Health Districts and transport stakeholders, including Cancer Council NSW, would enable a more systematic approach to planning and delivering transport solutions for a given

population. Despite providing significant transport services for people in rural and regional areas and being identified in the *NSW Cancer Plan* as the lead organisation for delivering practical support for people affected by cancer, Cancer Council NSW is not routinely involved in transport planning and mechanisms at a policy or delivery level.

Recommendations for continued work

- NSW Government works with Transport for NSW, Local Health Districts, and community transport providers to create publicly accessible guidelines for community transport fees and set pricing benchmarks.
- NSW Government reviews the Community Transport NGO Partnership Grants Program, to ensure funding is sufficient to enable more equitable and affordable transport for patients in remote, rural, and regional areas.
- NSW Health and rural and regional Local Health Districts include not-for-profit community transport providers, like Cancer Council NSW, through working groups to jointly plan and coordinate transport services.
- NSW Health works with stakeholders, including NGO providers of non-emergency health transport, like Cancer Council NSW, to review the Transport for Health Policy.

E. Aged care and palliative care

Legislative Council Portfolio Committee No. 2 recommendations include recommendation 18, 23 and 24. While we cannot comment on the progress made on these specific recommendations, Cancer Council NSW would like to reiterate the importance of accessible and well-funded palliative care services for people with cancer in remote, rural, and regional areas.

A terminal or life limiting illness is a distressing time for patients, carers, and families. Many have experienced the challenges and distress when palliative care has not been well resourced and supported. Provision of palliative care can be inconsistent in rural and regional areas, where services are limited. Cancer Council NSW supports the efforts to further these recommendations and supports the continuous funding of palliative care services.

F. Cancer and oncology

Legislative Council Portfolio Committee No. 2 recommendations include recommendation 21 and 30. Our reflections and recommendations relate to the progress made on both recommendations.

Recommendation 21: That NSW Health working with the Commonwealth and all relevant service providers investigate strategies to ensure public patients being treated in regional cancer centres can access private-public services while reducing out-of-pocket costs.

Progress since recommendation

People living in remote, rural and regional areas are more likely to experience greater out-of-pocket costs⁵. People with cancer should be adequately supported to make informed choices about their cancer care. Financial toxicity refers to the negative impacts of a cancer diagnosis on a person's financial wellbeing. It is the combined impact of direct out-of-pocket costs for medical treatment, indirect costs, such as accommodation and travel, and the changing financial circumstances of an individual and their household following a cancer diagnosis. Those who experience financial toxicity often struggle to afford necessities and skip treatment.⁶ This leads to poorer cancer outcomes, higher psychological distress, and reduced quality of life.⁷ A recent analysis in Victoria showed that the proportions of people with out-of-pocket costs, who were not fully informed in advance, were 42% for surgery, 36% for radiotherapy, and 50% for chemotherapy.⁸ Embedding the Standard for Informed Financial Consent will guarantee that patients are informed of the likely out-of-pocket costs in advance, so that they can better prepare for the financial impact. This will involve developing and implementing a procedure in care and referral pathways that will assist healthcare professionals explain the likely costs associated with a comprehensive treatment plan to people affected by cancer.

Cancer Council NSW is pleased to see recent progress to address out-of-pocket costs for public patients undergoing cancer treatment in Wagga Wagga. While Cancer Council NSW has heard of instances of public patients being charged differing amounts for the same treatment in regional cancer centres, we are not aware of widespread issues. As a starting point, the NSW Government could consider conducting a stocktake of regional cancer centres to identify the number of regional cancer centres in the state and whether the centres are set up to allow public patients to be treated in private-public services without out-of-pocket costs.

In addition, financial counselling is an important tool to limit the impact of financial hardship, however, existing services are stretched. Cancer Council NSW provides a Financial Counselling Service that is free for users and provides guidance to people with cancer around the unique cost of cancer and supports people with budgets and debt management through advocacy with creditors. In 2022-23, there was a 19% increase in the number of clients accessing Cancer Council NSW's Financial Counselling Service compared with the previous year. Cancer Council NSW's ability to meet growing demand is limited by the fact that the organisation receives no funding for these services. Delays in access to financial counselling reduces people's chances of having financial stresses resolved, which can negatively impact their cancer outcomes and quality of life and can deter people from receiving treatment^{6, 7, 9}.

In the lead up to the 2023 NSW Election, the former Premier promised to increase funding for financial counselling by \$9.6 million. To date, Cancer Council NSW is not aware whether this promise has been matched by the current NSW Government. One of the actions in the NSW Cancer Plan 2022-27 is to "*ensure people who experience cancer, their families and carers are actively linked with supportive care and services such as psychosocial care, allied health care and financial counselling*"¹⁰. In the NSW Cancer Plan Implementation Plan 2024-25, Cancer Council NSW is a lead in delivering financial assistance and financial counselling¹¹. While, in the 2023 NSW Ministry of Health Independent Review Rural Health Inquiry, Cancer Council NSW is noted as delivering measures to reduce the out-of-pocket costs for people with cancer, it should be noted that our organisation is only able to progress this work within our resources, which government does not contribute to. The increase in clients accessing our Financial Counselling Service suggests an ongoing need and gap in service delivery.

Recommendations for continued work

- NSW Government considers conducting a stocktake of regional cancer centres to understand the breadth of the issue with regards to public patients accessing private-public services for treatment.
- NSW Health embeds Cancer Council Australia's Standard for Informed Financial Consent by developing and implementing a procedure in care and referral pathways that will assist healthcare professionals explain the likely costs associated with a comprehensive treatment plan to people affected by cancer.

Recommendation 30: That NSW Health:

- *commit to providing continuity of quality care with the aim of a regular on-site doctor in rural, regional and remote communities*
- *commit to a model of care under which virtual care technology is used to supplement, rather than replace, face-to-face services*
- *where virtual models of medical care are operating, roster additional suitably trained nursing staff to assist in the provision of the physical care usually attended to by the medical officer*
- *provide staff members with training on how to effectively use telehealth and other virtual models of care*
- *create a public information campaign specifically targeted to rural, regional and remote communities in order to assist patients to effectively engage with virtual care, including factsheets and checklists to set expectations and support positive interactions*
- *ensure that the use of virtual care, if required, is undertaken in consultation with community members, health providers and local governments in rural, regional and remote areas*
- *investigate telehealth cancer care models to improve access to cancer treatment and care including the Australasian Tele-trial model to boost clinical trial participation in regional areas.*

Progress since recommendation

Virtual models of care act as a bridge between specialist hospital services and community care. Virtual models of care enhance patient-centricity without compromising safety and quality. It's important to note that virtual models of care, such as telehealth, should be an option for appropriate consultations, rather than a replacement for all face-to-face visits.

According to the Bureau of Health Information's Outpatient Cancer Clinics Survey 2023, 94% of patients who responded said that virtual care was very good or good and 86% would use virtual care again or in some circumstances.¹² Respondents mentioned virtual care was convenient, saved time, saved money and respondents felt they received the right care at the right time.¹² Participation in clinical trials supports the development of new cancer treatments and allows people with cancer to access advanced therapies and expand treatment options. However, participation in a clinical trial usually requires frequent visits to specialists in major cities. All other states and territories aside from NSW and the ACT are participating in the Australian Teletrial Program, which is funded for 5 years (2021 to 2026) to bring clinical trials close to home for patients in rural and remote areas.¹³

Cancer Council NSW understands that the Cancer Institute NSW is working closely to support cancer services, including clinical trials, to integrate with existing statewide virtual

care strategies and technology. The NSW Cancer Plan Implementation Plan 2024-25 refers to this and Cancer Council NSW recommends continuing with the implementation of this activity and ensuring people in remote, rural and regional areas can access clinical trials as well.¹¹

Recommendations for continued work

- Cancer Institute NSW continues to support cancer services to integrate their processes into statewide virtual care strategies and technology.

G. Other specialist care and allied health services

Legislative Council Portfolio Committee No. 2 recommendations include recommendation 5, 10, 30, 42, 43 and 44. Our reflections and recommendations relate to the progress made on recommendation 5.

Recommendation 21: That NSW Health and the rural and regional Local Health Districts actively engage with local community groups and charities to understand the services and resources they provide, and to ensure that where possible and appropriate, service gaps are filled by government.

Progress since recommendation

The Cancer Institute NSW partnered with multiple cancer services to deliver the patient-reported measures program (PRMs).¹¹ Routine collection of PRMs fosters communication between healthcare professionals and patients by allowing issues to be raised and reviewed. PRMs assists healthcare professionals and patients identify supportive care needs. Cancer Council NSW defines supportive care as all forms of care and support that aims to improve the quality of life of people with cancer, cancer survivors and their loved ones. Supportive care is a core, evidence-based component of integrated and patient-centred cancer care, comprising the services necessary for people affected by cancer to manage the demands of the disease and treatment, into survivorship¹⁴. This includes services to meet the informational, emotional, social, and practical needs of people affected by cancer.

Most commonly reported problems from respondents across all patients and cancer types, September 2019–August 2023

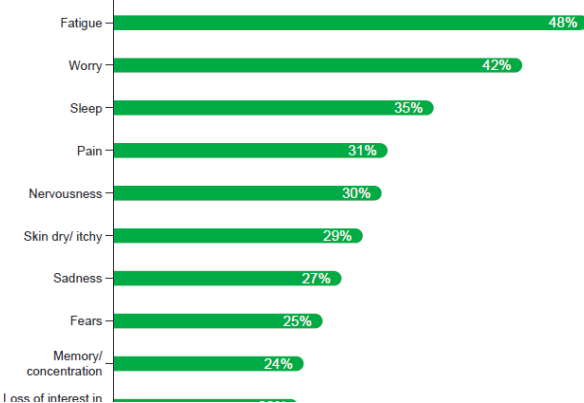


Figure 1: Most commonly reported problems from respondents across all patients and cancer types in NSW, September 2019- August 2023. ¹⁵

Cancer Council NSW's Supportive Care Needs 2022 survey found the most common unmet needs amongst survey participants (n = 527) were uncertainty about the future, tiredness, help with doing usual things, fear about cancer spreading, feeling down and anxiety. Support needs also varied by geographical location, with more people with cancer from regional areas expressing a need for accommodation and financial assistance to help pay for travel, treatment, and equipment expenses.

There is an opportunity for Cancer Council NSW to further support the Cancer Institute NSW and rural and regional cancer services to understand local PRMs data, identify unmet needs and establish referral pathways to Cancer Council NSW's supportive care services. This would allow more patients to be supported by Cancer Council NSW. In this financial year, 3,650 clients have accessed Cancer Council NSW's financial assistance, financial counselling, pro bono program, Transport to Treatment Service, counselling, home help and accommodation to date. Over half of those clients (58%) live in regional, rural, and remote areas.

Cancer Council NSW is investing significantly in survivorship research in a new joint venture with a university. It is the aim of this work to fill a critical gap and establish what survivorship care could and should look like for people with cancer in NSW, including for people living in regional and rural areas.

Cancer Council NSW would like to reiterate the importance of engaging and consulting community members, local community groups and charities in service planning and delivery. This is particularly important to ensure that services are sustainable and meet the local needs of communities. For example, Cancer Council NSW is not involved in discussions around transport planning as mentioned under Terms of Reference B. However, people who cannot access community transport providers or have other transport barriers, use Cancer Council NSW's Transport to Treatment Service, which does not receive government funding and relies heavily on volunteer drivers.

Recommendations for continued work

- Rural and regional cancer services, Cancer Institute NSW and Cancer Council NSW continue to engage regularly to better understand unmet needs and embed Cancer Council NSW's supportive care services in referral pathways.

Conclusion

Cancer Council NSW welcomes the Select Committee on Remote, Rural and Regional Health's inquiry into the implementation of Portfolio Committee No. 2 recommendations relating to the delivery of specific health services and specialist care in remote, rural and regional NSW. While Cancer Council NSW are pleased to see progress on some of the recommendations, more action is required so that people with cancer can have equitable access to cancer care.

The fact is cancer survival is poorer for people living in remote, rural and regional areas compared to those in a major city. Travelling to a larger regional centre and/or metropolitan area and related arrangements, financial stress, and a lack of knowledge regarding available support services were some of the major challenges people faced. In consultation with people affected by cancer and health professionals, Cancer Council NSW have made recommendations for continued work and called attention to ongoing challenges. For instance, the copayments to access community transport is a major barrier for people with cancer, who need to access treatment over multiple days or weeks.

Cancer Council NSW commends the Select Committee on Remote, Rural and Regional Health on inquiring into the implementation of Portfolio Committee No. 2 recommendations. The organisation is keen to respond to future inquiries to identify progress and gaps on these recommendations. Cancer Council NSW stands ready to grow and further support people affected by cancer in regional NSW along with the Government's support.

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