Submission
No 173

INQUIRY INTO HEALTH OUTCOMES AND ACCESS TO HEALTH AND HOSPITAL SERVICES IN RURAL, REGIONAL AND REMOTE NEW SOUTH WALES

Organisation: Cancer Council NSW

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Submission to the Inquiry into health outcomes and access to health and hospital services in rural, regional and remote New South Wales

Cancer Council NSW

10 December 2020

Table of Contents

Cancer Council NSW would like to acknowledge the Traditional Custodians of the land on which we live and work. We would also like to pay respect to the Elders past, present and emerging, and extend that respect to all other Aboriginal and Torres Strait Islander peoples

Executive summary

Cancer Council NSW is the leading cancer charity of NSW, supporting local communities and working across every area of cancer. We are 97% community funded and support people affected by cancer with information and practical help, speak out on behalf of the community on cancer issues, empower people to reduce their cancer risk, and use research to better detect, treat and prevent cancer.

Cancer outcomes in NSW are among the best in the world, yet for people living in rural and remote NSW outcomes remain poor compared to people living in metropolitan areas. Evidence clearly demonstrates that the chance of dying from cancer increases with distance from major centres. People in regional areas have higher rates of cancer risk factors such as smoking and are also more likely to be diagnosed with low survival cancers.

These disparities in cancer outcomes are, in part, attributed to access. People with cancer in regional areas experience poorer access to high-quality cancer care, including clinical trials, diagnostic services, supportive care and palliative care.[1] Our Regional Communities Cancer (RCC) survey found that **more than half of all people we surveyed had to travel greater than 100km for cancer care**. When asked what the NSW Government could do to improve cancer outcomes, most of our survey respondents (54%) ranked availability of cancer treatments and specialists outside of metropolitan areas as the most important issue for them.

Equitable access must also consider more than geographic proximity of services: physical and financial means, cultural acceptability, and timeliness also play a major role. Even when services are available locally, they may not be accessible because of long wait times or they do not respond to the needs of culturally and linguistically diverse communities.

Our RCC survey found distance to care is the most significant barrier to accessing cancer care. **Without comprehensive and truly accessible local services, patients are forced to travel vast distances or even avoid seeking timely treatment and care**.

While regional infrastructure helps ease the burden of distance for some, many regional cancer centres are run as public-private partnerships, exposing many to crippling out-of-pocket costs. **More than 20% of people surveyed report skipping appointments or treatment because of cost**. For people living in regional and remote areas, a*vailability* of services does not necessarily mean equity of *access*.

Quality cancer care involves interdependent and often complex pathways across multiple healthcare providers and settings. Unfortunately, evidence demonstrates people living in regional areas often do not receive best practice care. **We know what is needed to improve outcomes and all patients, irrespective of where they live, should expect person-centred and evidence-based care**, consistent with the Optimal Care Pathways (OCPs)[I].

Consideration of practical supports, transport, accommodation, out-of-pocket costs and the psychosocial impact of cancer on families and carers is crucial, yet often overlooked. Moreover, regional cancer centres are often inadequately equipped to address the complex psychosocial needs of patients necessary to make person-centred care a reality.

Reducing the regional-metropolitan cancer gap requires a multifaceted approach that tackles access as well as the high prevalence of cancer-risk factors; improves the quality of care in line with best practice; facilitates coordinated, person-centred care; and enhances the regional experience of care. Cancer Council NSW make the following evidence-based recommendations:

[I] OCPs describe optimal cancer care across the entire patient journey to promote quality cancer care and patient experience

Recommendations

1. Implement and embed the Optimal Care Pathways to ensure people with cancer in regional NSW have equitable access to high-quality treatment and care. Specifically, we recommend:
    a. Prioritise health systems and policy research to understand the drivers of care that deviate from optimal care, and possible solutions.
    b. Developing an implementation plan across primary and specialist care to ensure wait times, treatment and care for people in regional NSW align with Optimal Care Pathways.
    c. Routine public reporting on NSW outcomes and care that deviates from Optimal Care Pathways, including wait times and access to supportive care.
    d. Developing a regional cancer services capability and workforce framework to guide Local Health Districts to deliver care in line with the Optimal Care Pathways.
2. Ensure that all regional health services provide culturally safe and responsive healthcare for Aboriginal people according to the *Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer.*
3. Integrate referral pathways to community-based supportive care services including Cancer Council's 13 11 20 Information and Support line into routine care.
4. Expand patient navigation and cancer coordination models to ensure unmet needs are met including the specific needs of Aboriginal people.
5. Implement a plan to develop, evaluate and scale-up telehealth cancer care models to improve access to cancer treatment and care
6. Adopt the Australasian Tele-trial model as standard in NSW to boost clinical trial participation in regional areas.
7. Review the Isolated Patient Travel and Accommodation Assistance Scheme (IPTAAS) to ensure that eligibility criteria are needs-based and outcome-focused. Specifically, we recommend:
    a. Relaxing the 200km cumulative eligibility criteria to allow automatic qualification if a treatment schedule dictates that a patient will accumulate 200km of travel
    b. Removing the lowest IPTAAS reimbursement rate for both non-for-profit and commercial providers to provide realistic assistance for those in need
    c. Expanding eligibility criteria to explicitly include travel for people accessing a clinical trial
    d. Promoting awareness of IPTAAS in cancer services and with health professionals.
8. Expedite a review of NSW health transport policy to ensure transport is recognised as a fundamental driver of access and an essential component in health system planning.
9. Incentivise health providers to adopt the Cancer Council Australia Standard for Informed Financial Consent to ensure people with cancer have upfront information on the costs of treatment.
10. Investigate strategies to ensure public patients being treated in regional cancer centres can access private-public services with no additional out-of-pocket costs.
11. Implement the NSW Palliative and End of Life Care Framework and track progress
12. Keep people healthy and out of hospital by prioritising funding for cancer prevention and screening efforts through LHDs and community organisations.

About Cancer Council NSW work in regional areas

Cancer Council NSW is committed to supporting people affected by cancer across regional NSW. To engage with community and deliver on our mission, we employ 41 staff who work from our offices in Orange, Wagga Wagga, Byron Bay, Tamworth, Coffs Harbour, Wollongong, Charlestown and Singleton.

Our work in regional communities across NSW includes:

- helping more than 2,600 cancer patients each year travel to hospitals for treatment
- assisting more than half a million people with information and support through our 13 11 20 Cancer Information and Support Service and Cancer Council Online communities, as well as support groups, counselling and survivorship services.
- providing access to free legal, financial, accounting and workplace advice if they cannot afford to pay for it
- providing financial assistance to over 2,800 cancer patients experiencing acute financial hardship
- providing affordable accommodation to over 2,200 people with cancer.
- helping regional people affected by cancer navigate their cancer journey through our Cancer Liaison program
- delivering programs to help people in regional NSW prevent cancer.

Introduction

Cancer Council NSW welcomes the opportunity to respond to the Portfolio Committee No. 2 – health's inquiry into health outcomes and access to health and hospital services in rural, regional and remote New South Wales.

Cancer contributes the largest burden of disease in Australia. In NSW, almost 49,000 people are expected to be diagnosed with cancer and over 15,500 people will die in 2020 – more than stroke and heart disease combined.[2, 3] It's estimated that every second person in NSW will be diagnosed with cancer by the age of 85.[2]

For people living in regional[i] NSW, cancer outcomes – including cancer survival - are worse than for people living in major cities. Little progress has been made in the past 20 years to close this gap.[4]

Alongside geographic isolation, people in regional areas face additional challenges in accessing health services including inadequate transport, higher out-of-pocket costs, lower availability of supportive services, and poor care coordination. While there are some persistently challenging issues that require further consideration of broader structural reform, Cancer Council NSW believes there are significant opportunities to build on previous successes and help reduce the gap in cancer outcomes and access for people in regional areas. More can be done within existing capacity and capability.

People love living in regional NSW. Our RCC survey found that 3 out of 4 respondents agreed that living outside of a major city is good for their health and wellbeing. Often, the solutions to complex problems can be found within the community.

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[i] In this report, the term regional areas cover all areas outside of the Major cities (inner regional, outer regional, remote and very remote)

How we prepared this submission

Our submission provides an overview of the empirical evidence that describes the extent and nature of cancer disparities between people living in regional communities compared to people living in metropolitan areas.

We are also uniquely placed to share many community stories of the lived experiences of cancer patients, their families, friends and carers and those who work, treat and support people affected by cancer. To give voice to these experiences, Cancer Council NSW:

- Surveyed people living in regional NSW who had been affected by cancer,
- Held two focus groups with Cancer Council NSW staff located in regional NSW, and
- Collected stories from people affected by cancer in regional NSW

We received 349 responses to our survey, a clear indication that people living in regional NSW see this inquiry as an important opportunity to make real progress in addressing the health disparities they experience. As the leading cancer charity in NSW, our submission focuses on the terms of reference relating to cancer care, including palliative care.

41%

OF REGIONAL & RURAL NSW
experience difficulties in accessing cancer services
BECAUSE OF WHERE THEY LIVE.

MOST PEOPLE LIVING IN REGIONAL NSW are concerned that where they live may affect

CANCER SURVIVAL 78%

QUALITY OF CARE 66%

2in3

PEOPLE AGREE GOVERNMENT NEEDS TO REDUCE THE REGIONAL & METRO HEALTHCARE GAP

54% OF RESPONDENTS RANKED DISTANCE as the most significant barrier to **ACCESSING CARE**

while **27%** OF RESPONDENTS RANKED LONG **LONG WAIT TIMES**

68% **RESPONDENTS RANK LOCAL CLINICAL CARE EXCELLENT OR VERY GOOD**

Community ranking of the most important issue for NSW to improve cancer care in regional areas (n=349).

1. Availability of cancer treatments & specialists
2. Availability of non-medical health professionals
3. Out of pocket costs; initiatives to prevent cancer
4. Access to health professionals without having to travel.
5. Palliative care

> **Whilst there is never any expectation that people living in regional and rural areas would receive the exact same type of service or level of service as people living in metro areas, I do believe there are improvements that can be made to ensure a better experience for the patient through what is a harrowing time for them and their family. – Person affected by cancer**

1. A comparison of outcomes for patients living in rural, regional and remote NSW, and metro NSW

Summary:

- The more remote the area in which a person lives, the greater their chance of dying from cancer.
- People in regional areas are more likely to be diagnosed with low survival cancers, such as lung and unknown primary site cancers.
- Cancer outcomes in regional areas are linked with socioeconomic factors, as well as access.

From Bathurst to Burke, Narooma to Narrabri, there is clear evidence of higher cancer incidence, poorer survival and unwarranted variations[i] in clinical care for people with cancer living in regional NSW.[1, 5-8]

Some of the urban–regional differences can be explained by often vast distances to treatment services, yet not entirely. Cancer outcomes are also linked with socioeconomic disadvantage; areas of which often overlap with regional areas. Studies that adjust for proximity to healthcare and socioeconomic status still demonstrate significant differences in outcomes. This suggests that other factors are at play, including workforce capacity and clinical practices, treatment barriers, availability of clinical trials and specialist follow up, and the availability of support services.[9]

1.1 Regional areas record the highest rates of cancer

Cancer incidence in regional areas is higher than metropolitan areas (513 cases versus 487 cases per 100,000 persons).[10] This is likely because people living in these regions have limited access to primary healthcare services, poorer education and employment opportunities (and therefore income potential) and higher rates of cancer risk factors (See Section 6: Prevention for more information).

Cancer inequalities in rural and remote areas are due to a variety of factors, including:

- Distance to, and availability of, health services and health professionals (primary care services, specialists, treatment, and diagnostic services)
- Social determinants of health such as income, education and employment opportunities
- Higher prevalence of cancer risk factors such as tobacco smoking and alcohol use.
- Limited availability and access to support services (accommodation, transport, emotional support and provision of practical and financial assistance)
- Delayed diagnosis due to poor community education, cancer awareness and access to information

1.2 Cancer survival and mortality is determined by postcode

People living in regional NSW also have poorer cancer survival outcomes compared with their city counterparts.[9, 10] Nationally, 5-year all-cancer survival decreases with increasing remoteness, from 62% for major cities to 55% for very remote areas.[10]

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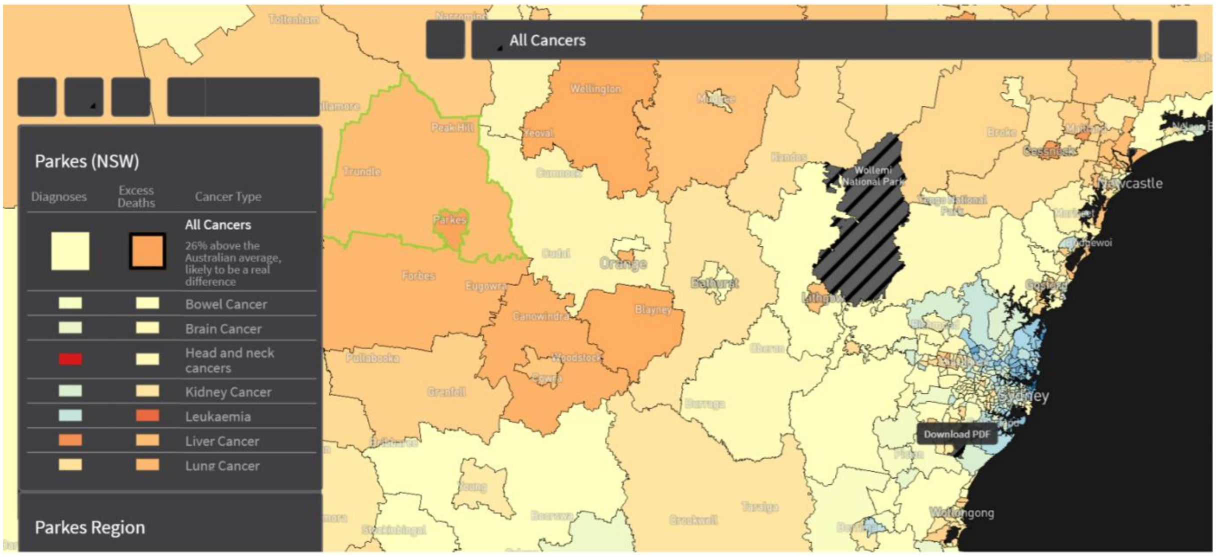
[i] variation that cannot be explained by the condition or the preference of the patient; it is variation that can only be explained by differences in health system performance

Cancer is the leading cause of death among Indigenous Australians. Indigenous people are less likely to survive cancer the further they live from urban centres.[11]

The type of cancers diagnosed also vary by area, with people in regional areas more likely to be diagnosed with low survival cancers, such as lung and unknown primary site cancers.[10]

Figure 1 demonstrates the stark disparities in cancer survival for those living outside of major cities. We can see a clear ring of disadvantage radiating outwards from metropolitan Sydney. Using Parkes as an example, people living here are 26% more likely to die within 5 years of a cancer diagnosis than the NSW average. See the Australian Cancer Atlas for more information.



Parkes (NSW)

Diagnoses	Excess Deaths	Cancer Type
🟨	🟧	**All Cancers** 26% above the Australian average, likely to be a real difference
🟨	🟨	Bowel Cancer
🟩	🟨	Brain Cancer
🟥	🟨	Head and neck cancers
🟩	🟨	Kidney Cancer
🟦	🟧	Leukaemia
🟧	🟧	Liver Cancer
🟨	🟧	Lung Cancer

Parkes Region

Figure 1. NSW snapshot of cancer survival from the National Cancer Atlas. People living in areas shaded blue are less likely to die within 5 years of diagnosis than the general population. People living in areas shaded orange are more likely to die.

Recommendations

- Implement and embed the Optimal Care Pathways to ensure people with cancer in regional NSW have equitable access to high-quality treatment and care. Specifically, we recommend:
    - Prioritise health systems and policy research to understand the drivers of care that deviate from optimal care, and possible solutions.
    - Developing an implementation plan across primary and specialist care to ensure wait times, treatment and care for people in regional NSW align with Optimal Care Pathways.
    - Routine public reporting on NSW outcomes and care that deviates from Optimal Care Pathways, including wait times and access to supportive care.

2. Access to health and hospital services in rural, regional and remote NSW

Summary

- Accessible, quality primary care is essential to prevent cancer, improve cancer outcomes and enhance quality of life. Enhancing primary care services in regional areas has positive effects on hospital utilisation and Emergency Department presentations.
- Most people surveyed (78%) were concerned about equity of access to healthcare and its impact on outcomes.

“The care that is needed should be available to whoever needs it, regardless of where you live”

\- Cancer survivor

People living in regional areas are concerned with equity of access to healthcare and the impact this has on cancer outcomes. 78% of survey respondents were concerned that living in regional areas affected their chance of cancer survival. 65% agreed that the Government needs to do more to address the gap in outcomes for people living in regional areas.

The 2018 AIHW healthcare survey of rural and remote Australians found people in more remote areas were[12]:

- more likely to report not having a GP nearby was a barrier to seeing one (**20%** compared with 3% for people in m*ajor cities*)
- more likely to indicate that not having a specialist nearby was a barrier to seeing one (**58%** compared with 6%)
- more likely to have been to an emergency department (ED) in the past 12 months because no GP was available when they needed one (**17%** compared with 10%).

2.1 Access to primary care is essential for equitable and effective cancer care

Primary care that provides access to integrated local, community-based services, produce better health outcomes and more efficient health services. This includes reduced avoidable hospital visits, improved population health, and reduces inequality.[13] However in NSW, access to primary care services (including health promotion, allied health services, community care and general practice) often depends on where one lives.

“Just yesterday I had to make a 150km round trip to visit a GP even though I do not live in a remote area.”

\- Person affected by cancer

One of the strongest sentiments that emerged from analysis of free text responses of our RCC survey was the need to strengthen primary care systems and GP access in regional areas. The limited availability of primary care services in regional areas has flow-on implications for the entire health system, including hospital budgets, where the accumulating health burden often spills to. A high proportion of people who use primary care services have elevated, preventable risk factors that increase the risk of cancer, offering an important opportunity for early intervention.[14] With prohibitive wait times or travel distances, opportunities for early intervention, monitoring and diagnosis are forgone as people dis-engage with the primary care system; only to reengage when they need more acute and complex care.

Recommendations

- Develop a regional cancer services capability and workforce framework to guide Local Health Districts to deliver care in line with the Optimal Care Pathways.

- Prioritise health systems and policy research to understand the drivers of care that deviate from optimal care, and possible solutions.
- Develop an implementation plan across primary and specialist care to ensure wait times, treatment and care for people in regional NSW align with Optimal Care Pathways
- Integrate referral pathways to community-based supportive care services including Cancer Council's 13 11 20 Information and Support line into routine care

3. Access and availability of oncology treatment in rural, regional and remote NSW

Summary

- Access to cancer care for patients in regional areas is not entirely dependent on proximity to services but also whether available care is culturally appropriate, affordable and can be accessed when needed.
- Cancer services that neglect cultural safety and responsiveness can undermine access to healthcare for Aboriginal people.
- People with cancer in regional areas have poorer access to high-quality cancer care, including clinical trials, diagnostic services and supportive care.
- More than half of survey respondents in regional areas had to travel greater than 100km for cancer care.
- Out-of-pocket costs of cancer are higher for people in regional areas. More than one in five people surveyed report skipping appointments or treatment because of cost.
- Inadequate government assistance for transport and accommodation prevents equitable access to care.

“When my son was diagnosed with leukaemia I had to move to Sydney for a year, until his death, as there is nothing in rural NSW.”

\- Mother of a child with cancer

For people living in regional NSW to access healthcare, services clearly need to be geographically available. However, other factors such as the financial means to pay for and reach the health services, cultural acceptability, private health disincentives, and long wait times can effectively prevent access, despite geographic availability. Importantly for regional communities, health services that neglect cultural safety and responsiveness undermine access for Aboriginal people.

People with cancer in regional areas experience poorer access to high-quality cancer care, contributing to the regional-metropolitan disparities in cancer outcomes.[1] There are often fewer cancer-specific healthcare professionals and infrastructure (including diagnostic services, linear accelerators, specialist surgical units and chemotherapy units) in regional compared to metropolitan areas. This is further exacerbated by sparse supportive care services and allied health staff that are an essential part of holistic cancer care.[1]

People in regional NSW need a cancer workforce and service capability to support quality cancer care and integration of services across the entire continuum of care, from prevention through to survivorship and end of life care. The Clinical Oncology Society of Australia has recommended a staffing and service mix for regional cancer centres, including medical specialists, allied health staff, oncology pharmacists, care coordinators, data managers and clinical trials coordinators. These centres should also leverage locally available community support services for comprehensive, person-centred care.

Without comprehensive local services, patients are forced to travel vast distances to receive cancer care. Alarmingly, distance can discourage some from seeking care and obtaining timely treatment altogether. When we asked what is the most significant barrier to care in our RCC survey, most people (54%) selected distance.

> "*When I'm not feeling very well, it is hard to attend appointments, but add travel and sitting in waiting rooms and it is tempting to not attend.*"
>
> - Cancer survivor

3.1 Cancer specialists are disproportionately concentrated in metropolitan areas

"In rural areas, the frustration of accessing cancer specialists and appointments adds so much stress to the person with cancer, that often they just give up"

- *Person affected by cancer*

Evidence shows that one of the most important service gaps in regional Australia is the need for more specialist oncology services.[15] 58% of survey respondents living in regional NSW reported travelling greater than 100km for cancer care. Our RCC survey also found:

- 24% of respondents report major or severe difficulty in accessing radiation therapy,
- 26% report major or severe difficulty accessing surgery, and
- 15% report major or severe difficulty accessing chemotherapy.

When asked what the NSW Government could do to improve cancer outcomes, most survey respondents (54%) ranked availability of cancer treatments and specialists outside of metropolitan areas as the most important issue for them.

The Regional Cancer Centre Initiative, established in 2010, was designed to address this need. It has focused on expanding chemotherapy and radiotherapy services into non-urban regions, engaging the private sector to fill service gaps, and developing other models of care such as shared care, regional outreach services, and telehealth services.[15] While regional cancer centres can help address some gaps in cancer care, these are often run as a public-private partnerships, which can create additional barriers to accessing quality care, especially out-of-pocket costs. For people living in regional and remote areas, a*vailability* of services does not necessarily mean equity of *access*. See Section 3.5: Cost for further information.

Cancer specialists working in rural and regional Australia may also experience unique difficulties when compared with their metropolitan counterparts. They often experience higher workloads, longer hours, and may experience professional and social isolation. These factors contribute to challenges in attracting and retaining specialists in rural and remote regions and should be considered within the context of access to specialist care.[16]

Increasing locally available treatment services has limitations with some cancers requiring complex surgery. For example, lung, rectal oesophageal and pancreatic cancer surgery, travelling to a major teaching hospital that performs these procedures often is considered best practice. Some regional centres simply cannot meet the minimum annual caseload required to achieve optimal outcomes. Patients must therefore be supported with appropriate transport and accommodation subsidies in these instances.

Recommendations

- Develop an implementation plan to ensure that wait times and cancer care for people in regional NSW align with what is recommended in the Optimal Care Pathways.
- Develop a regional cancer services capability and workforce framework to guide regional LHDs to deliver care in line with the Optimal Care Pathways
- Ensure that all regional health services provide culturally safe and responsive healthcare for Aboriginal people according to the *Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer.*

3.2 Diagnostic services: *“You should not have to delay your diagnosis because you can't get an appointment in time. Cancer doesn't wait.”*

Early detection of cancer offers patients the best chance of successful treatment. To highlight this, consider the 5-year survival of colorectal cancer diagnosed at Stage I is almost 100%, while 5-year survival for those diagnosed at Stage IV is only 13%.[10]

Because the distribution of diagnostic imaging machines in NSW is often determined by the commercial considerations of private providers, many people living in regional areas face barriers to a timely diagnosis. Diagnostic delays in cancer generally become more common with increasing rurality, due to an undersupply of medical practitioners and infrastructure.[17] Early detection is limited by fewer diagnostic facilities such as computed tomography (CT) scanning, Magnetic Resonance Imaging (MRI), nuclear imaging including Positron Emission Tomography (PET) and tissue biopsy services, resulting in increased late presentations and progressed disease.[17] Free text analysis of our RCC survey found reports of difficulties accessing PET scans because these services are usually only provided in Sydney.

> *“When my father -in -law needed help we had to travel at midnight so he could have a scan at a bigger hospital. We had to sleep in our car”*
>
> - Carer

3.3 Supportive care services are an essential component of quality cancer care

“Mum was diagnosed with pancreatic cancer on a Thursday and was only alive for 1 more week. My father asked for some counselling to deal with mums aggressive and sudden cancer diagnosis but got knocked back - there was nothing.”

- Family member of a person with cancer

Access to services that support the physical and psychological wellbeing of people affected by cancer are limited in regional areas.[15] Supportive care is an umbrella term that encompasses self-care and practical support, information, psychological support, symptom control, social support, rehabilitation, spiritual support, palliative care and bereavement care. Supportive care services are often provided by allied health practitioners (e.g. Aboriginal health workers, dietitians, exercise physiologists, occupational therapists, physiotherapists, podiatrists, psychologists, social workers) and community support organisations.

Cancer care centres are often inadequately equipped to address the complex psychosocial needs of patients and to make person-centred care a reality for people in regional areas. Our RCC survey found that despite 73% of respondents report having a cancer treatment centre in their local area, almost 60% still report having to travel over 100km for cancer care. This indicates that many people are not provided with comprehensive care that people affected by cancer need through their regional cancer centres

> *“I would like more access to support after treatment. When I go to Canberra I see notices for all sorts of classes e.g. exercise groups, stress reduction, Tai Chi - these don't seem to happen in my area.”*
>
> - Cancer survivor

The most important service gap among Australian cancer care providers are services that aim to meet the broader bio-psycho-social needs and long-term care needs of cancer survivors.[15] The failure to address the psychosocial needs of people affected by cancer in regional areas is even more stark.

Our RCC survey found that supportive care accessibility was the second most important issue that the NSW government needed to address. Almost one in four survey respondents reported major or severe difficulties accessing supportive care services.

Even when these services are available locally, they are predominantly funded by a fee-for-service arrangement and rely heavily on out-of-pocket payments from cancer survivors.[15] This creates a significant barrier for people living in regional areas.

With donor support, Cancer Council NSW fills some of these gaps in providing supportive care services. These services however must be better integrated into existing care pathways so that health professionals can routinely ask, assist and refer people with cancer who require support.

Recommendations

- Integrate referral pathways to community-based supportive care services including Cancer Council's 13 11 20 Information and Support line into routine care.
- Expand patient navigation and cancer coordination models to ensure unmet needs are met, including the specific needs of Aboriginal people.

3.4 Access to clinical trials in regional NSW is limited

"The really important thing is that, particularly for rural people, this could be the thing that makes a difference between life and death for people."

\- Cancer survivor

Clinical trials are an important way to support the development of new cancer treatments and improve cancer care, providing a gateway for accessing cutting edge therapies and expanding treatment options.[18] However, most trials demand frequent visits to specialists located in major cities. For those accessing clinical trials from regional NSW, our RCC survey found nearly half (47%) reported major or severe difficulties.

Currently, less than 5% of regional cancer patients participate in any clinical trial.[18] The bulk of cancer clinical trial enrolments are skewed towards the Sydney metropolitan LHDs.[19] As with access to specialist care, patients living outside of major metropolitan centres face many barriers accessing clinical trials – namely availability of trial sites closer to home and the significant cost and inconvenience of travel to major centres.[20] Further compounding this inequity is the ineligibility of people participating in clinical trials to access the Isolated Patients Travel and Accommodation Scheme (IPTAAS) assistance. This is a significant yet easily modified barrier that if addressed, can enhance regional trial participation. According to a former IPTAAS employee: "(regarding ineligibility for IPTAAS) … *for people in extreme financial hardship, that's a death sentence. And that is really so not fair that it should come down to financial means. When the government provides it for other medical services, why not for clinical trials?"*

> *"Of course they want to give it a shot, who wouldn't? The future of all our health is a result of trial and error and the heroics of those patients who give everything they can to living longer and finding a cure. Unfortunately, without the precious reimbursement from IPTAAS, many people had their choice taken away from them. Truthfully this was a heartbreaking situation for both patient and IPTAAS staff."*
>
> \- Kate, Northern NSW Community Programs Coordinator

Cancer Council NSW in partnership with Cancer Institute NSW are evaluating the impact of providing travel and accommodation assistance to people affected by cancer whose clinical trials would otherwise be limited through a pilot program. A report of findings will be available early 2021.

Many smaller regional centres are unlikely to acquire trial capabilities as standalone trial centres because of fewer patients and limited trial-related staff. The implications of this inequity are clear for a young woman from Northern NSW: "*Given the absence of immunotherapy options, should (or realistically when) the cancer returns, my life expectancy will depend on the availability of an immunotherapy trial and whether it is physically possible for me to get to it."*

The most efficient way to enhance trial capability in NSW is by linking these regional centres to larger centres via technology. Teletrials enable clinical trials to be conducted in regional areas using digital platforms, such as telehealth, and collaborative partnerships to establish trial participation. This reduces reduce travel, cost, social disruption to patients and provides a system-level intervention to address issues of inequity. This model of care has already been implemented in Queensland and Victoria.[18]

Recommendation

- Adopt the Australasian Tele-trial model as standard in NSW to boost clinical trial participation in regional areas.

3.5 Cost: *“I was surprised how expensive it was to have cancer.”*

Cancer treatments often involve repeated travel over extended periods of time, long length of stays and crippling out-of-pocket costs. Expenses are disproportionately higher for cancer survivors living outside metropolitan areas, those who require radiotherapy, or those with private health insurance.[21] These costs can be so great that some people forgo treatment.[14] Availability of new services and state-of-the art health infrastructure are meaningless if a patient cannot afford it.

Between 28% to 43% of cancer patients report financial distress or hardship as a result of costs associated with cancer treatment.[22] A further 21% of people with cancer report skipping care due to the cost.[23]

Consider the story of Jane[i], a mother with a rare blood cancer that cannot be treated locally:

> *“The continual out of pocket expenses and medication costs has taken all my savings and now rapidly depleting my superannuation pension. I find I am being punished for trying to prepare for my retirement. I also feel it is very unfair on my family to take unpaid leave from work to take me to Drs appointments. All my medical team advise me to move to the city where treatment assistance is available. Unfortunately because I live in a rural area I now have to make a choice of selling my home to continue treatment or stop treatment and end my life.”*

Out-of-pocket costs for specialist medical practitioners can be significant, despite MBS reimbursements.[13]. Around 70% of specialist medical services require patients to make a co-payment, and the average co-payments are about $75 per visit.[13] As cancer often demands frequent consultations, these costs add up quickly. Other significant costs experienced by people affected by cancer include private health care costs, non-Medicare subsidised services, imaging and pathology tests, medicines, parking, transport and accommodation costs to name but a few. These out-of-pocket costs are made worse by the fact that a cancer diagnosis often results in reduced capacity to work, early retirement and reduced income.[21]

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[i] Not her real name

The Isolated Patient Transport and Accommodation Scheme (IPTAAS) scheme aims to ensure equitable access to care, providing financial assistance toward travel and accommodation costs for patients needing to travel long distances for treatment. However, IPTAAS has not kept pace with changes to cancer care and the rising costs compared to its inception 30 years ago.

Government assistance through IPTAAS must be assessed according to need, rather than inflexible and arbitrary eligibility criterion. We must ensure that positive cancer outcomes are not determined by individual wealth.

> *"I had stage 4 gall bladder in 2011. Due to side effects of the chemo I was unable to work, hence not able to make mortgage payments and forced to sell my home."*
>
> - Cancer survivor

Moreover, public-private partnerships are increasingly being introduced across regional Australia to improve availability of cancer care. This brings new challenges including variations in treatment choices and additional out-of-pocket costs.[24, 25] As a survey respondent noted: *"to have cancer treatment in our local area costs more than others as the cancer centre is private, not public".* Contrary to popular belief, there is no direct link between cost and quality of care.[25]

3.5.1 Transport

"Travel and accommodation costs are often so great that many folk are financially unable to access the level of diagnosis and treatment they need."

- Cancer survivor

Travelling to cancer centres for people in regional NSW often demands great expense, time, family support and practical considerations. Our data show that "*some people simply cannot afford to travel to major cities".* Despite 75% of our survey respondents indicating they have a cancer treatment centre in their local area, 53% still report having to travel more than 100km to access cancer services. 31% of those needing transport assistance experienced severe or major difficulty accessing assistance.

> *"That people have to decide between putting food on the table or meeting the cost of travel to have treatment is appalling."*

Transport to treatment without access to a private vehicle can be challenging due to limited public transport options. If public transport is available, the limited reach of services, infrequent services, long wait times, and poor connections makes public transport a gruelling experience, if not impossible, for people who are already under significant physical and emotional strain. In some cases, such as from Nundle to Tamworth (a 60kmtrip by car), there are no public transport services. Those patients, often financially disadvantaged, are reliant on community transport options, and if none are available, they will be unable to access their

> *"George and Carol live 20 kms from Kempsey. George needed chemotherapy every 3 weeks for 6 months and was too unwell to drive himself and Carol didn't drive. George needed to attend Port Macquarie Base Hospital, approximately 60 km away but there is scarce public transport available. Even if it was available, it wasn't an option for him due to his health. The only other option was Community Transport but this costs $60.00 for the return trip and therefore added to George and Carols stress, worrying about money. Luckily Cancer Council NSW has a Transport to Treatment car at Port Macquarie and could help. However, as there is more demand for transport in the Kempsey area it wont be possible for the Port Macquarie car to meet the needs of Kempsey Local government residents and Port Macquarie needs."*
>
> - Yonit, Community Programs Coordinator, Coffs Harbour

required treatment nor qualify for IPTAAS. Where Community Transport is available, out of pocket costs are often prohibitive.

Currently, patients' need to accrue 200km of travel per week to be eligible for IPTAAS. It would be logical (and compassionate – see B*'s story below) to change the criteria to recognise that cancer treatment regimens often involve numerous trips from home to treatment each week. To truly deliver person-centred care that is respectful and responsive to individual patient needs, IPTAAS criteria should be applied according to a patient's recommended treatment schedule rather than having to physically sit in a vehicle and accumulate those kilometres each week. This would also reduce the increasing demand on increasingly pressured community transport services (where community transport is available).

3.5.2 Accommodation

Despite support from IPTAAS, the out-of-pocket costs for accommodation near major hospitals and treatment centres in NSW is a significant barrier to accessing cancer care. Our RCC survey found 37% of people needing accommodation for their cancer treatment experienced severe or major difficulties. For both not-for-profit (NFP) and commercial accommodation, the minimum reimbursement rate is a meagre $43 (patient or carer) and $60 (patient and carer) per night for the first seven nights each financial year. Many patients and families are falling through the cracks because these subsidies cannot realistically offset the cost of accommodation.

> *"We had a guest from Bendalong needing accommodation for six weeks for his daily radiation treatment for anal cancer. Unfortunately, even after putting Ben* though a tortuous weekly routine (driving from Bendalong to Nowra and back 3 times to accrue 200Kms), his IPTAAS application was rejected. The reason we were given was that "claims for accommodation are not assessed on meeting the 200km criteria". Ben needed accommodation! Ben had anal cancer. The level of discomfort Ben experienced sitting in the car driving to and from treatment is difficult to overstate. In addition, Ben needed it paid for. Ben was not working during his cancer treatment, and simply did not have sufficient savings to pay the $1355 accommodation bill."*
>
> - Jarrod, Accommodation and Support Services Coordinator, South Coast
>
> *Not his real name

Cancer Council NSW supports many patients and families in need of accommodation support. Our Accommodation Service assists cancer patients and carers across 63 Local Government Areas across 13 regions in NSW. Most of these clients seek accommodation in metropolitan areas because specialist cancer services are not commonly available locally. There is a clear and growing unmet need for accommodation as affordable hospital accommodation declines, as shown in Figure 2.

Number of accommodation nights:

2015	2016	2017	2018	2019
19,246	19,878	19,897	21,074	23,144

Figure 2. In the past four years, the number of people supported by Cancer Council NSW's Accommodation Service has more than tripled.

According to our Accommodation and Support Services Coordinators, most NFP accommodation providers in NSW agree that the reimbursement rate is too low for them to break even, so they must charge a gap or out-of-pocket cost to the patient which many people cannot afford. Where subsidised NFP accommodation is not available, patients are forced to pay higher rates through commercial providers. Many people travelling to metropolitan areas are expected to pay $120 to $150 per night for a basic room. Many cancer treatments require accommodation several weeks at a time which places those affected under a tremendous amount of financial and psychological stress.

Needing to travel and stay outside of one's own home for extended periods is usually not a choice: most people would prefer to be in the comfort of their own home given the option. Appropriate accommodation assistance is often the only means by which people affected by cancer can access their recommended treatment.

> *"When there is no alternative to traveling to a major city for diagnosis/treatment then the government needs to pay a realistic proportion of the costs incurred (travel/accommodation/ etc)."*
>
> - Cancer survivor

Recommendations

- Prioritise health systems and policy research to understand the drivers of care that deviate from optimal care, and possible solutions.
- Review the Isolated Patient Travel and Accommodation Assistance Scheme (IPTAAS) to ensure that eligibility criteria are needs-based and outcome-focused. Specifically, we recommend:
    - Relaxing the 200km cumulative eligibility criteria to allow automatic qualification if a treatment schedule dictates that a patient will accumulate 200km of travel
    - Removing the lowest IPTAAS reimbursement rate for both non-for-profit and commercial providers to provide realistic assistance for those in need
    - Expanding eligibility criteria to explicitly include travel for people accessing a clinical trial
    - Promoting awareness of IPTAAS in cancer services and with health professionals.
- Expedite a review of NSW health transport policy to ensure transport is recognised as a fundamental driver of access and an essential component in health system planning.
- Incentivise health providers to adopt the Cancer Council Australia Standard for Informed Financial Consent to ensure people with cancer have upfront information on the costs of treatment.
- Investigate strategies to ensure public patients being treated in regional cancer centres can access private-public services with no additional out-of-pocket costs.

4. Patient experience, wait-times and quality of care in rural, regional and remote NSW and how it compares to metropolitan NSW

Summary

- Treatment choices and clinical care for people in regional areas often deviate from evidence-based clinical pathways, resulting in poorer outcomes.
- Continuity of support, and access to specialists, allied health professionals and community services are major concerns for people affected by cancer living outside major cities.
- Cancer survivors living outside of major cities experience poorer quality of life and psychosocial wellbeing. Comprehensive person-centred supportive care is an essential part of quality cancer care.
- Costs of cancer are responsible for psychological distress in 41% of people surveyed
- Two-thirds of people (68%) rate their experience of care at their local cancer clinic as excellent or very good

People with cancer often face profound physical, psychological and financial challenges as a result of the disease.[10] These challenges are similarly felt by carers and families of people with cancer.

The needs of people in regional areas affected by cancer differ from, and often exceed, those living in metropolitan areas. All people affected by cancer face practical issues such as childcare, obtaining medical supplies and home help, and are often under tremendous emotional strain. These pressures are often worsened by a simultaneous loss of income if a patient is unable to work or if a family member becomes a full-time carer. For those living in regional areas, travelling long distances compounds these financial and psychological challenges.

> *"The health professionals that are here do a great job, but there aren't enough of them. For people further out west, they often just don't seek treatment due to lack of services, distance from home and cost."*
>
> \- Cancer survivor

Moreover, treatment and care that people with cancer receive can be complex and often involves multiple health providers and services. Care is often fragmented and poorly coordinated, resulting in expensive out of pocket costs while psychosocial and practical support needs often remain unmet.

Many RCC survey free text responses described a healthcare system that fails to understand the specific needs of people living in regional areas. An approach to cancer care that responds to individual patient preferences, needs and values (known as person-centred care), despite broad recognition for over 2 decades, is still yet to be embraced in routine practice. Improving the health outcomes of people with cancer requires an understanding of their current experiences and where these could be improved. As one survey respondent stated: "*Don't forget about us*".

4.1 Quality of cancer care in regional NSW is variable

> "*We want treatment that is of the same standard available in cities*"
>
> \- Cancer survivor

Care provided for people with cancer should be person-centred and evidence-based, safe, of high quality and consistent with Optimal Care Pathways. Australian researchers found that for over 10 000 people treated for colon cancer, only 44% received care in line with optimal care pathways. They also found that when care did align with best practice pathways, outcomes improved.[26] While the clinical aspects of optimal care are consistent for all people, irrespective of cultural background, optimal care also requires consideration of cultural safety and responsiveness.

For people living in regional areas, high-quality cancer care is an important issue for them: 66% of surveyed respondents are concerned that their postcode can impact on the quality of care that they receive. The Cancer Institute NSW Reporting for Better Cancer Outcomes (RBCO)[27] program reports local and state-wide cancer data to local health districts (LHDs), primary health networks, specialty health networks and participating private hospitals. This program provides a picture of quality in cancer control across NSW. While there is high overall achievement, there is clear unwarranted geographic variation in patient experience, process and outcomes.

4.1.1 Specialist oncology care

Treatment choices, clinical management and outcomes often deviate from evidence-based clinical pathways because of distance to treatment service. A meta-analysis of individuals with colorectal cancer living in regional areas of Australia showed poorer survival and experienced poorer clinical management. [7] Similarly, women with breast cancer treated outside of major cities also experience poorer survival, in part attributed to deviation from best practice recommendations.[5] These findings are likely to be moderated by a range of other factors including socioeconomic status.[5, 7]

> *"The times we were forced to use the local public health system we were disappointed, and I would go as far as saying neglected and traumatised at times."*
>
> - Cancer survivor

Funding for regional cancer centres over the past decade has provided much needed oncology support for many regional areas. Often these centres involve privately-operated services which are more likely to selectively provide high-profit services such as radiotherapy, chemotherapy and surgery, and less likely to provide comprehensive supportive care.[15] The treatment and care that a person with cancer receives depends on where they have treatment. This post-code lottery can result in unwarranted variation, including for example, higher rates of radical surgery and the associated side effects.[24]

There is also evidence of disproportionately higher out-of-pocket costs for cancer survivors accessing private healthcare in Australia that does not necessarily correlate with higher quality care.[15]

Figure 3. ***Spotlight on breast cancer*** *in non-metropolitan areas*

An Australian team systematically assessed the evidence for variations in breast cancer outcomes by residential location.[5] The review found consistent evidence for geographical variations in survival, clinical management and overall lower receipt of optimal care among women outside of metropolitan areas. They found:

- Non-metropolitan women were at least five times more likely to have a mastectomy than metropolitan women and the proportion of mastectomies progressively increased with increasing remoteness
- Non-metropolitan women were 6% less likely to undergo breast-conserving surgery, and the proportion who had breast-conserving surgery decreased progressively with increasing remoteness
- Non-metropolitan women were up to 20% less likely to receive adjuvant radiotherapy than metropolitan women
- Women residing in areas lacking radiotherapy facilities had a higher likelihood (23%) of not receiving radiotherapy than those from regions with such facilities
- Non-metropolitan women were consistently (12%–58%) less likely to undergo sentinel node biopsies (SNBs) or postmastectomy breast reconstruction
- Non-metropolitan women experienced variations in guideline-concordant care with non-metropolitan women being less likely to undergo adjuvant radiotherapy, hormonal therapy and more likely to experience longer delays in commencing adjuvant chemotherapy
- Non-metropolitan women were less likely to be referred to a radiation oncologist and were more likely to experience delays in assessment by a medical oncologist.

From the patient's perspective, our RCC survey highlights that regional cancer care staff do the best they can, with what they have. Overall, 68% of people described the care provided at their local cancer clinic as excellent or very good. People often described their care as "*excellent*" and the staff as "*wonderful but totally understaffed*". Unfortunately, good intentions do not always translate to positive experiences and outcomes. People often commented that the health system was "*not understanding of the problems*". To provide person-centred care, the health system needs to reorient around the needs and preferences of the people it serves.

> "*the team locally were stretched and tried their best but were hamstrung by no staff and little resources*"
>
> - Cancer survivor

This is of upmost importance for Aboriginal people affected by cancer. The Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer has been designed to complement the tumour-specific OCPs, focusing on the aspects of the care pathway that need to be responsive to the needs of Aboriginal and Torres Strait Islander people with cancer.

Recommendations

- Ensure that all regional health services provide culturally safe and responsive healthcare for Aboriginal people according to the *Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer.*
- Develop an implementation plan to ensure that wait times and cancer care for people in regional NSW align with what is recommended in the Optimal Care Pathways.

4.2 Wait times

Timely diagnosis and treatment are essential for the best possible cancer outcomes. Surveys show that the proportion of patients who feel they had to wait longer than was acceptable to see a GP is higher in regional areas than in cities.[13] Our RCC survey found that 61% of people agreed that wait times for specialists are longer than is acceptable. Indeed, our survey found that wait times are one of the most significant barriers to accessing cancer care, second only to distance.

> *"In 2018 my mother presented with symptoms in January yet did not start treatment to May and was dead by July. All appointments had a 2-4 week wait between. This led to anxiety and wasted time. My husband now has an enlarged oesophagus and we are waiting for a gastronomy. He is very anxious and stressed. I am trying to be positive but in the back of my mind I am worried it will be Mum all over again."*
>
> - Carer

Recommended timeframes for investigations and consultations with GPs and specialists are described in the Optimal Care Pathways.

Recommendation

- Develop an implementation plan to ensure that wait times and cancer care for people in regional NSW align with what is recommended in the Optimal Care Pathways.

4.3 Patient experience

Evidence shows that cancer survivors living outside of major cities experience poorer quality of life and psychosocial wellbeing.[28] Our survey also found that, consistent with other literature, people often value quality experiences over outcomes and place a high value on factors such as psychosocial support, affordability, timely appointments, accessibility and practical assistance.

Enhancing patient's experiences with health care is critical to improve health outcomes. Patients who have positive experiences with their doctors are more likely to maintain contact with their providers and the health system, adhere to treatment plans and achieve better health outcomes.[29]

We previously discussed the implications of cost on access to cancer care (refer to 3.5 Cost). The financial burden of cancer can also take a damaging psychological toll: "*My experience is if you are an adult who is working and has private health insurance you are going to be financially ruined. Everything is out of pocket or a large gap fee. Financially I have never recovered. After losing my husband raising two teenagers, working 3 jobs I will not be able to retire until I am 70. All our savings and other assets were sold to pay debts and living expenses*." Our survey found 41% of people have experienced psychological distress because of cancer costs.

Similarly, stressors associated with travel and accommodation often negatively affect patients experience of cancer. Kate, our Community Programs Coordinator from Northern NSW describes the situation for many Aboriginal families: "*Aboriginal families would often be very distressed and would seek family unit accommodation to accommodate their cultural needs. (*the meagre reimbursement rates*) regularly led to patients refusing to attend much needed specialist treatment, often they simply did not want to ask their family to pay such amounts and did not want to go alone".* See Section 3: access for more information on cultural safety and responsiveness.

> *"And then there's the psychological hardship which it's a little hard to understand unless you have been through it."*
>
> - *Cancer survivor*

4.3.1 Coordinated and integrated care:

“The constant need to explain, re-explain and advocate for your care or the person you care for is overwhelming.”

- Cancer survivor

To effectively navigate through a cancer journey, or prevent it in the first place, requires multiple services and providers working together, including: radiation oncologists, chemotherapy nurses, psychologists, community services, pharmacists, dieticians, nurse educators, surgeons, palliative care specialists, physiotherapists, occupation therapists, public health, financial counsellors to name but a few.

Confronted with multiple providers in multiple settings, there are many opportunities for people in regional areas to become ‘lost’ in the system – experiencing fragmented, and poor quality care.

Our RCC survey found that the health system was often not understanding of the needs of people in regional areas: hearing “*the fax hasn’t arrived yet*, *come back in a couple of days*” is simply not possible for people needing to travel vast distances. Those having to see multiple providers in multiple locations often disengage all together because of the inability of the cancer care system to coordinate.

“There were times when we were travelling 5 hours to Sydney for an appointment and the Doctor hadn’t received the scans or information from the Doctor in Wagga to review beforehand, this happened multiple times.”

- Carer

“I remember a gentleman who lost most of his nose after surgery. This patient was left with social anxiety, unable to go back to a normal daily life. One day, quite simply he was asked by a fellow patient as the reasons why he had not considered a prosthetic nose free of charge through a charitable support scheme. His heartbreaking response: “I never had knowledge of such option or service available to someone like me with limited financial means”. Can you conceive, if only this patient had been linked to an appropriate cancer care coordinator or social worker, his burden could have been lifted much sooner. How many patients are currently in his same shoes?”

- Yonit, Community Programs Co-ordinator, Northern NSW

Tragically, even where local assistance is available, many regional patients cannot access these because they do not know they’re there. As a survey respondent noted, “*in the country, people are not even aware that they are missing out on this type of support*”. Without a systematic way to coordinate comprehensive care, the health system is failing to link people with unmet needs to appropriate services. These challenges are further compounded by under-resourcing of cancer-specific social workers and care coordinators. As one survey respondent says: “*if you find the support it is awesome, but it’s hard to find*”.

There are emerging innovative workforce models that demonstrate considerable potential to support integrated, person-centred care, including care navigators.[14] In 2018 Cancer Council NSW began rolling out the Cancer Council Liaison program to improve the coordination and integration of people with information and support. We currently have Liaisons working in Albury-Wodonga and several metropolitan hospitals. Cancer Council liaisons are experienced and trained health

“Because he had different specialists in different hospitals between Wagga and Sydney there was a lot of confusion around who had what information and who was responsible for sharing information. It was like my Mum needed to be a full time administrator to keep on top of things and make sure information was sent to the right Doctors.”

- Carer

professional who works alongside treatment teams in hospitals to improve access to cancer information and practical and psychosocial support services.

"*It has been a great experience to work in collaboration with the Cancer Council liaison in supporting patients and their families. Patients and their families have been able to access additional information and resources through the support of the Cancer Council liaison*."

- Healthcare professional

Improving the coordination of comprehensive care, including community-based supportive care, is required to achieve person-based care.

4.3.2 Telehealth: *"No more long trips, no problems parking, no getting lost in a big city."*

Uptake of healthcare technologies that could lower costs and increase convenience and quality has traditionally been slow. COVID-19 has rapidly changed this, and patients rightly expect that the positive benefits of technology experienced during COVID- 19 will continue.

> *"Sometimes he had to travel 5 hours to Sydney for a 5 minute appointment."*
>
> \- Carer

Telehealth offers benefits regarding choice, convenience and safety for both the patient and clinician, and potentially can reduce geographic disparities in cancer. Telehealth also facilitates improved quality of care by allowing regional sites to link to tertiary metropolitan centres for multidisciplinary team discussion and access to clinical trials. 83% of people surveyed state that it is important to have telehealth available as an option to consult with health professionals.

Virtual care models have also been established to act as a bridge between specialist hospital services and community care. These offer tremendous potential for people in regional NSW. Established as the first virtual hospital in NSW, RPA virtual was launched in early 2020 as a sustainable solution to increasing demand for healthcare in Sydney. As evidence of safety, quality and cost-effectiveness emerges, these innovative models should be scaled up across NSW.

Telehealth does have limitations and we must continue to evaluate its continued adoption. Our survey found that telehealth is not a panacea, with people's experiences varying from "*fabulous*" and "*essential*" to "*terrible*" and "*a complete failure*". Telehealth should be an option for appropriate consultations, but not a replacement of face-to-face visits.

Our survey identified several themes for effective use of telehealth:

- Quality of IT infrastructure – sometimes the patchy nature of technology infrastructure made the telehealth experience difficult
- Comfort and familiarity with technology – for some patients who were unfamiliar with technology or preferred face-to-face interaction, telehealth was not a positive experience.
- Complexity of the appointment – patients found that not having to travel to get test results or for simple follow-up appointments was beneficial. If the consultation was more complex, many survey respondents were not confident telehealth was an appropriate option.
- Relationship between patient and healthcare provider – patients were more confident about the benefits of telehealth if they had an existing relationship.
- Preference for video – people often placed value on discussing concerns with someone they could see rather than just via telephone.

Ultimately, telehealth is most effective when led by consumers, underscoring that an authentic patient centred approach to health in regional areas is just as important infrastructure and staff. Innovative models of care that leverage technology offer a means to enhance person-centricity without compromising safety and quality and should be adapted to the needs of local communities.

Recommendations

- Implement and embed the Optimal Care Pathways to ensure people with cancer in regional NSW have equitable access to high-quality treatment and care. Specifically, we recommend:
    - Prioritise health systems and policy research to understand the drivers of care that deviate from optimal care, and possible solutions.
    - Developing an implementation plan across primary and specialist care to ensure wait times, treatment and care for people in regional NSW align with Optimal Care Pathways.
    - Routine public reporting on NSW outcomes and care that deviates from Optimal Care Pathways, including wait times and access to supportive care.
    - Developing a regional cancer services capability and workforce framework to guide Local Health Districts to deliver care in line with the Optimal Care Pathways.
- Expand patient navigation and cancer coordination models to ensure unmet needs are met including the specific needs of Aboriginal people.
- Integrate referral pathways to community-based supportive care services including Cancer Council's 13 11 20 Information and Support line into routine care.
- Ensure that all regional health services provide culturally safe and responsive healthcare for Aboriginal people according to the *Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer.*
- Implement a plan to develop, evaluate and scale-up telehealth cancer care models to improve access to cancer treatment and care

5. The access and availability of palliative care and palliative care services in rural, regional and remote NSW

Summary

- Ongoing commitment to and appropriate structures for effective implementation and monitoring of the NSW End of Life Framework is required to ensure recent funding initiatives translate to outcomes.

Access to palliative care for patients and carers in regional areas is a well-documented area of unmet need.[8] Our RCC survey found of those needing access to palliative care, 32% experienced major or severe difficulties.

Provision of palliative care is inconsistent and often shouldered by GPs, particularly regional Australia where access to specialists is limited. These clinicians are expected to have appropriate skills, knowledge and access to training and support; however, generalist staff report that they feel ill-equipped to provide palliative care to their patients.[30]

The NSW Government has made a good start to address the growing need for palliative care support. $45 million over four years was committed in the 2019-20 State Budget for 100 palliative care nurses, 64 of which have been committed for rural and regional communities. The NSW Government has also recently announced $56 million to support 5,000 palliative care home packages.

> *"Palliative care is almost non-existent, even in large regional areas."*
>
> \- Carer

Furthermore, NSW Health developed the NSW Health End of life and palliative care framework 2019-2024. We welcome this and wish to underscore the importance of robust implementation and evaluation.

Virtual palliative care models are suggested as an approach to improving access to palliative care in regional areas. However, inappropriate, inconsistent or sub-optimal delivery of virtual palliative care may negatively impact the psychosocial wellbeing of vulnerable patients and their carers. Telehealth and virtual models of care have an important role but also have notable limitations: telehealth "f*eels remote and impersonal. I felt a bit disconnected".* Careful monitoring and evaluation are required to further refine and scale up these innovative solutions.

There has been significant progress on the overarching framework to improve palliative care in NSW. An ongoing commitment to and appropriate structures for effective implementation and monitoring is required to ensure these good intentions translate to outcomes.

Recommendation

- Implement the NSW Palliative and End of Life Care Framework and track progress

6. Any other related matters

6.1 Investment in prevention delivers better health outcomes for patients and savings for our health system

Summary:

- 1 in 3 cancers are preventable. Geographic disparities in cancer risk factors including alcohol consumption, smoking, fruit and vegetable intake, and exercise contribute to cancer risk and mortality gaps.
- A shift to a population-based prevention strategy is needed to engage patients in their own care, create environments that promote healthy living and ensure equitable access to preventive health services.
- Population based health prevention is cost-effective and will have important positive implications for health service utilisation and help address disparities in outcomes.

The causes of cancer are complex but for many cancers, we know how to prevent them. Indeed, 1 out of every 3 cancers are preventable.[31] Without addressing cancer risk factors, and the social, economic and physical environments that contribute to cancer, health infrastructure and services will struggle to keep pace with the increasing cancer burden.

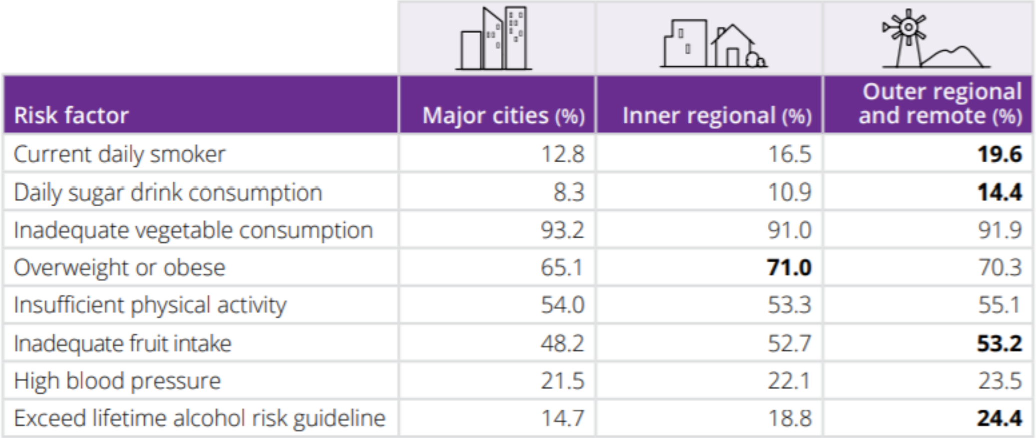
There is a complex interplay between health and socioeconomics, where social factors such as an individual's education, employment, and relationships can impact their overall health, and vice versa. Disparities in outcomes for people living in regional areas are driven in part by these upstream factors.

In 2018, people living in rural and remote areas were less likely than those in major cities to have completed Year 12 or a non-school qualification, lower proportions of people employed, and generally have lower incomes but have to pay higher prices for goods and services. Australians living outside of capital cities have, on average, 18% less household income per week compared with those living in capital cities, and 29% less mean household net worth.[1] These social determinants interact to strengthen or undermine the health of individuals and is one of main reasons for health inequalities across geographic regions.

As our health system has increasingly become locked into crisis management, prevention has become a marginal consideration as the immediate management of hospital and surgery waiting times are prioritised. The success of the NSW's health system to constrain the COVID-19 pandemic is one of prevention. Even without a vaccine, our system successfully shifted to preventing the spread of disease and strain upon our hospitals. This is an opportunity for Governments to build on this success and take a leading role in prevention by promoting healthy lifestyles and creating an environment that supports an individual's healthy choices.

6.1.1 A disproportionate burden of cancer risk factors drive disparities in cancer outcomes

The prevalence of many cancer risk factors are demonstrably higher for regional areas than for major cities (see Figure 6). Compared to people living in major cities, people in rural and remote areas have higher rates of smoking and overweight and obesity, are less likely to eat recommended serves of fruit and vegetables, more likely to consume sugar sweetened drinks and are more likely to consume alcohol at levels that put them at risk of long term harm.[1]



Risk factor	Major cities (%)	Inner regional (%)	Outer regional and remote (%)
Current daily smoker	12.8	16.5	**19.6**
Daily sugar drink consumption	8.3	10.9	**14.4**
Inadequate vegetable consumption	93.2	91.0	91.9
Overweight or obese	65.1	**71.0**	70.3
Insufficient physical activity	54.0	53.3	55.1
Inadequate fruit intake	48.2	52.7	**53.2**
High blood pressure	21.5	22.1	23.5
Exceed lifetime alcohol risk guideline	14.7	18.8	**24.4**

Figure 4. Health risk factors according to residence. Source: AIHW Australia's Health in Brief 2020

Addressing these risk factors in regional areas requires a tailored approach that acknowledges the unique characteristics of these populations. For example:

- Lung cancer is the leading cause of cancer death. People living in regional NSW are more likely to face geographic and economic barriers to accessing quit support such as face to face counselling and nicotine replacement therapy.
- Price often prevents people living outside metropolitan areas from having a healthy diet. The cost of a NSW healthy food basket and the mean cost of fruit and vegetables is highest in remote locations compared with metropolitan areas. There is need for nutrition policy actions to help shift the current diet of the population towards healthy diets.
- The burden of alcohol increases with remoteness yet access to support is limited.[32] People in remote areas travel an average of 1.5 hours or 102.7 kilometres to access treatment for alcohol or other drug dependency.[32]

Evidence-based policy that support people to make healthy choices that reduce cancer and other disease risk is central to resolving disparities in health outcomes.

6.1.2 Create environments that prevent illness and support healthy lives

Growth in health spending is the biggest element of growth in overall government spending. We know that governments face increasing financial pressure to fund a health system to meet the increasing demands of a growing and aging population. While our system is currently focused on managing hospital admissions and wait times, the role of prevention has become increasingly marginal. Preventive health is relatively low cost and can deliver long term savings by reducing the incidence of many diseases and reducing the severity of disease.[33]

RACGP recognises that preventive health care is also crucial in addressing the health disparities experienced by disadvantaged and vulnerable population groups.[14] A recent Productivity Commission review also found funding is too little focused on long-term health and prevention.[34] Prioritising funding for regional networks to use for preventative care has the benefits of tailored solutions for regional communities, better health outcomes and reduced hospitalisations.

We need to create environments that prevent illness and support people to lead healthy lives. This requires the NSW Governments to play a leading role in action to reduce the burden of cancer risk factors for people living in regional areas.

6.2 Cancer screening

Routine population screening for breast, cervical, and bowel cancer in Australia results in earlier detection and increased survival.[10] Although evidence is mixed, living in a regional location does not appear to be a major barrier to cancer screening participation for most people.[35]

Indigenous Australians are more likely to live in remote areas of Australia than non-Indigenous people and also participate in BreastScreen Australia and the National Bowel Cancer Screening Program at lower rates.[36] Unpublished evidence suggests participation in cervical cancer screening among Aboriginal women in NSW is considerably lower than the state average. This accounts for the substantially higher cervical cancer incidence and mortality in these groups. Culturally appropriate, targeted interventions co-designed with communities to increase Aboriginal screening participation, including promotion of cervical screening self-collection is needed.

Recommendation

- Keep people healthy and out of hospital by prioritising funding for cancer prevention and screening efforts through LHDs and community organisations.

Conclusion

“The government has a responsibility to provide health care to all residents, not just those that love close to the beach”

- Cancer survivor

It’s no overstatement to say that our health system is one of the best in the world – the NSW COVID-19 pandemic response serves as a timely reminder of this. However, inequities exist, diminishing the overall health of our society.

Cancer outcomes have improved greatly across NSW yet outcomes remain poor in regional NSW. Clinical advances are likely to further improve overall cancer outcomes, yet without a focus on health systems and policy, gaps between regional and metropolitan outcomes are unlikely to close. Recent infrastructure initiatives and funding has expanded regional cancer capacity but is not a panacea to ensure equitable access to cancer care.

> *“Even though my Dad is no longer with us, I have close family and friends that are experiencing the exact same problems as he did, and it is infuriating to watch someone else go through the same challenges, that can easily be fixed.”*
>
> - Carer

Closing cancer outcome gaps across geographic areas of NSW requires consideration of access as more than simply the proximity of health services. Addressing these disparities needs a multifaceted approach that tackles the high prevalence of cancer-risk factors and social determinants of health; enhancing earlier detection and optimal treatment pathways; facilitating coordinated multidisciplinary team care, including survivorship and community services; and enhancing patient’s experience of care. While there are broad, structural challenges that need to be addressed, Cancer Council NSW believes there are immediate opportunities to enhance the effectiveness of the world-class healthcare infrastructure that we have, and better leverage the network of community organisations and dedicated healthcare staff that are at the heart of regional communities.

References

1. Australian Institute of Health and Welfare. *Rural & remote health*. 2019 20/10/2020]; Available from: https://www.aihw.gov.au/reports/rural-health/rural-remote-health/contents/rural-health.
2. NSW Cancer Institute. *Cancer Statistics in NSW*. 2020 [cited 2020 07/02/2020]; Available from: https://www.cancer.nsw.gov.au/data-research/access-our-data/cancer-statistics-nsw#//.
3. Australian Institute of Health Welfare, *Australian Burden of Disease Study 2015: Interactive data on disease burden*. 2019, AIHW: Canberra.
4. Coory, M.D., T. Ho, and S.J. Jordan, *Australia is continuing to make progress against cancer, but the regional and remote disadvantage remains.* Med J Aust, 2013. **199**(9): p. 605-8.
5. Dasgupta, P., et al., *Variations in outcomes by residential location for women with breast cancer: a systematic review.* BMJ Open, 2018. **8**(4): p. e019050.
6. Diaz, A., et al., *Cancer outcomes for Aboriginal and Torres Strait Islander Australians in rural and remote areas.* Aust J Rural Health, 2015. **23**(1): p. 4-18.
7. Ireland, M.J., et al., *A systematic review of geographical differences in management and outcomes for colorectal cancer in Australia.* BMC Cancer, 2017. **17**(1): p. 95.
8. Cerni, J., J. Rhee, and H. Hosseinzadeh, *End-of-Life Cancer Care Resource Utilisation in Rural Versus Urban Settings: A Systematic Review.* Int J Environ Res Public Health, 2020. **17**(14).
9. Yu, X.Q., et al., *Geographic variation in prostate cancer survival in New South Wales.* Med J Aust, 2014. **200**(10): p. 586-90.
10. Australian Institute of Health Welfare, *Cancer in Australia 2019*. 2019, AIHW: Canberra.
11. Australian Institute of Health Welfare, *Australia's health 2020: in brief*. 2020, AIHW: Canberra.
12. Australian Institute of Health and Welfare, *Survey of Health Care: selected findings for rural and remote Australians*. 2018, AIHW: Canberra.
13. Swerissen, H., S. Duckett, and G. Moran, *Mapping primary care in Australia*. 2018, Grattan Institute.
14. Calder, R., De Courten, M., Morgan, M., Klepac Pogrmilovic, B., *Preventive Health in Primary Health Care: Scope and future development.*, Commissioned Background Paper Mitchell Institute, Editor. 2020, Victoria University: Melbourne.
15. Hunter, J., et al., *Coverage of cancer services in Australia and providers' views on service gaps: findings from a national cross-sectional survey.* BMC Cancer, 2019. **19**(1): p. 570.
16. Crawford-Williams, F., et al., *Challenges and Opportunities for Cancer Care in Regional Australia: The Health Professional´s Perspective.* Journal of Global Oncology, 2018. **4**(Supplement 2): p. 227s-227s.
17. Fox, P. and A. Boyce, *Cancer health inequality persists in regional and remote Australia.* Med J Aust, 2014. **201**(8): p. 445-6.
18. Collins, I.M., K. Burbury, and C.R. Underhill, *Teletrials: implementation of a new paradigm for clinical trials.* Med J Aust, 2020.
19. Cancer Institute NSW. *Performance index*. 2020 [cited 2020 10/02/2020]; Available from: https://www.cancer.nsw.gov.au/cancer-plan/performance-index.
20. Clinical Oncology Society of Australia, *Australasian Tele-Trial Model. Access to clinical trials closer to home through telehealth.* . 2016, COSA: Sydney.
21. Paul CL, F.E., Roach D, Baird H, *Impact of financial costs of cancer on patients - the Australian experience.* . Cancer Forum, 2017. **41**(2): p. 4-9.
22. Gordon, L.G., et al., *A Systematic Review of Financial Toxicity Among Cancer Survivors: We Can't Pay the Co-Pay.* Patient, 2017. **10**(3): p. 295-309.

23. Callander, E.J., L. Corscadden, and J.F. Levesque, *Out-of-pocket healthcare expenditure and chronic disease - do Australians forgo care because of the cost?* Aust J Prim Health, 2017. **23**(1): p. 15-22.
24. Te Marvelde, L., et al., *Differences in treatment choices for localised prostate cancer diagnosed in private and public health services.* Med J Aust, 2020.
25. Slavova-Azmanova, N.S., J.C. Newton, and C.M. Saunders, *Marked variation in out-of-pocket costs for cancer care in Western Australia.* Med J Aust, 2020. **212**(11): p. 525-526.
26. Te Marvelde, L., et al., *Alignment with Indices of A Care Pathway Is Associated with Improved Survival: An Observational Population-based Study in Colon Cancer Patients.* EClinicalMedicine, 2019. **15**: p. 42-50.
27. Cancer Institute NSW, *Cancer control in NSW: Statewide report, 2019*, Cancer Institute NSW, Editor. 2020: Sydney.
28. Butow, P.N., et al., *Psychosocial well-being and supportive care needs of cancer patients living in urban and rural/regional areas: a systematic review.* Support Care Cancer, 2012. **20**(1): p. 1-22.
29. Health, A.I.o. and Welfare, *Experiences in health care for people with chronic conditions: How GPs and other specialists communicate with their patients*. 2020, AIHW: Canberra.
30. Wenham, S., M. Cumming, and E. Saurman, *Improving palliative and end-of-life care for rural and remote Australians.* Public Health Research & Practice.
31. Wilson, L.F., et al., *How many cancer cases and deaths are potentially preventable? Estimates for Australia in 2013.* International Journal of Cancer, 2018. **142**(4): p. 691-701.
32. Australian Institute of Health and Welfare, *Alcohol and other drug use in regional and remote Australia: consumption, harms and access to treatment, 2016–17.* 2019, AIHW: Canberra.
33. Ananthapavan J, S.G., Brown V, Moodie M, Nguyen P, Barendregt J, Veerman L, Mantilla Herrera A, Lal A, Peeters A, Carter R., *Assessing Cost-Effectiveness of Obesity Prevention Policies in Australia 2018 (ACE-Obesity Policy)*. 2018: Melbourne: Deakin University.
34. Productivity Commission, *Shifting the dial: 5 year productivity review*. 2017, Australian Government Canberra.
35. Goodwin, B.C., et al., *Geographical Disparities in Screening and Cancer-Related Health Behaviour.* International journal of environmental research and public health, 2020. **17**(4): p. 1246.
36. Australian Institute of Health and Welfare. *Cancer in Aboriginal & Torres Strait Islander people of Australia*. 2018 19/12/2019]; Available from: https://www.aihw.gov.au/reports/cancer/cancer-in-indigenous-australians.

Appendix

Cancer Council NSW Regional Communities Cancer (RCC) Survey

A total of 428 people attempted the survey. 79 participants were excluded because they completed <30% of the questions or did not pass the screening questions leaving a total sample of 349.

Table 1. Regional cancer survey respondent characteristics

		Respondents (n=349)	**%**
Age	65+	189	54%
	55-64	94	27%
	45-54	46	13%
	<44	20	6%
Location	Inner regional	102	29
	Outer regional	184	53
	Remote	42	12
	Unsure	21	6
Local cancer treatment centre	Yes	254	73
	No	93	27
Travelled >100km for cancer treatment	Yes	203	58
	No	146	42

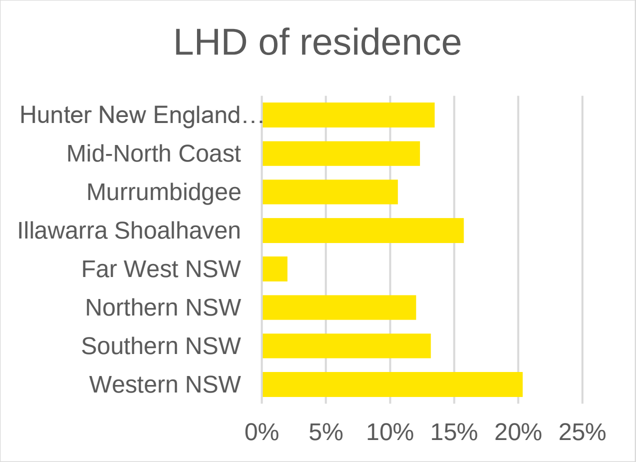


Figure 5. Local LHD of survey respondents