



Special Commission of Inquiry into Healthcare Funding

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Submission to the Special Commission of Inquiry into Healthcare Funding in NSW

Cancer Council NSW

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Executive summary

Cancer Council NSW welcomes the opportunity to respond to the Special Commission of Inquiry into Healthcare Funding. We are Australia's leading cancer charity dedicated to reducing the impact of cancer. Thanks to the generosity of the NSW community, 94% of our \$90M in revenue last year was community funded. Together, our vision is for a cancer free future.

Almost 1 in 2 Australians will be affected by cancer by the age of 85¹. If we can understand the future of cancer in Australia, we can plan how to curb its impact. Our research shows that the overall rate of people dying of cancer will fall by around 20% across the next 25 years². But the total number of people who will be diagnosed with or die of cancer in this period will be far greater than the previous 25 years².

Cancer Council NSW recognises the vision of the NSW *Future Health* strategy³, which is for a sustainable health system that delivers outcomes that matter most to patients and the community, is personalised, invests in wellness and is digitally enabled. Making this vision a reality must be a priority if we are to truly make inroads in reducing the impact of cancer across our community.

We predict that over the next 20–25 years, about 1.52 million people in NSW will be diagnosed with cancer and about half a million people in the state will die of cancer². This means cancer will remain a major public health challenge in the coming decades. It will place a significant burden on our health system, our communities and will continue to do so unless rapid government action is taken to rethink how the system responds to the prevention and management of cancer.

Thanks to improvements in treatment and early detection, cancer survival has improved greatly over the past 30 years⁴. However, inequities in outcomes by cancer type and population group continue to grow⁴. There is a need to improve the way our health system is structured, funded and held accountable for the delivery of timely, accessible, high-quality patient-centred care for cancer.

High levels of cancer risk factors in our community, such as smoking, overweight and obesity, alcohol and sun exposure, continue to contribute to cancer cases that could have been avoided through greater government investment in primary prevention. Addressing these risk factors will also reduce the burden of other chronic diseases, such as heart disease, diabetes and stroke. Keeping our communities healthy and out of hospital will reduce the burden on our health system.

This Inquiry presents a significant opportunity for the NSW Government to lead the path to a cancer free future by taking the necessary steps to support strategies we know work to prevent, detect and treat cancers. Cancer Council NSW is committed to changing the path of cancer and ensuring no one walks alone. Our recommendations are built on emerging evidence and the strong cancer control foundations in our health system. We have prioritised recommendations that can reduce the impact of cancer across the population, support the best outcomes for cancer patients and deliver the best value for the healthcare system.

Cancer Council NSW also takes the opportunity to recognise the dedication and tireless efforts of our frontline health workers, those supporting people affected by cancer, those working across the wider acute care hospital system, those working with community to help people stay well, and our public health workforce dedicated to keeping people living healthy lives and out of hospital.

Summary of recommendations

Recommendations for the Special Commission of Inquiry	Terms of Reference
<ul style="list-style-type: none"> • Fundamental change in the funding of NSW cancer services is required to meet future cancer burden and reduce inequities. • Regular auditing of NSW cancer services performance and expenditure is needed to improve transparency, accountability and inform funding decisions. • Cancer services funding should be allocated according to current and projected need. This should include supportive care services and culturally appropriate services for priority populations. • The NSW Government should work with the Australian Government, as well as the private and primary care sectors, to ensure all health services report on cancer outcomes and quality of cancer care against benchmarks outlined in Optimal Care Pathways and relevant clinical guidelines. 	<p>A. The funding of health services provided in NSW and how the funding can most effectively support the safe delivery of high quality, timely, equitable and accessible patient-centred care and health services to the people of NSW, now and into the future</p>
<ul style="list-style-type: none"> • The NSW Government should work with the Australian Government to establish an integrated approach to cancer care with joint accountability and governance, and a focus on reducing inequities, addressing cancer burden and preventing cost-shifting. • Improved transparency and accountability are essential, with NSW cancer services required to report on cancer outcomes and safety and quality of cancer care against benchmarks outlined in Optimal Care Pathways and relevant clinical guidelines. • Service agreements between NSW Health and local health entities must include targets on cancer outcomes and benchmarks of safety and quality of cancer care. • The involvement of consumers, community groups and community-based organisations in the planning, delivery and evaluation of cancer care services must be strengthened through new and existing mechanisms and with expectations clearly outlined in service agreements. 	<p>B. The existing governance and accountability structure of NSW Health</p>
<ul style="list-style-type: none"> • NSW Government spending on prevention must increase to at least 5% of the total health budget, with an increased focus on the primary prevention of chronic disease. 	<p>C. The way NSW Health funds health services delivered in public hospitals and community settings, and the extent to which this allocation of resources</p>

- Funding for prevention should be ring-fenced to allow preventative health programs and services to be fully implemented and evaluated.
- There needs to be greater transparency of health system performance against preventative health targets, including calculation of spend and public reporting against key metrics.
- Integration and coordination of preventative health services in and outside the NSW system must improve, including through better leveraging of partnerships and long-term funding agreements with community-based and non-government organisations.

supports or obstructs access to preventative and community health initiatives and overall optimal health outcomes for all people across NSW

- There needs to be improved transparency and accountability, with NSW cancer services required to report on cancer outcomes and safety and quality of cancer care against benchmarks outlined in Optimal Care Pathways and relevant clinical guidelines.
- Cancer Institute NSW should work with local communities and consumers to ensure public reporting of cancer outcomes and care is accessible, consumer-friendly and relevant to local needs.
- NSW Health should implement a workable single patient health record that can be easily accessed by healthcare providers across primary and secondary care.
- NSW Health should conduct regular audits of low value care procedures and explore strategies to de-implement low value care in relevant health services.
- NSW Health should increase efforts and resourcing to ensure PROMs are routinely used to guide real-time patient care and integrate data into quality improvement programs.
- The NSW Tobacco Retailer Notification Scheme should be amended to require an annual fee to be paid by tobacco retailers.

- D. Strategies available to NSW Health to address escalating costs, limit wastage, minimise overservicing and identify gaps or areas of improvement in financial management and proposed recommendations to enhance accountability and efficiency

- Structural reforms, short-, medium- and long-term planning, and innovation are required to prepare for an increase in cancer burden and inequities in NSW.
- The NSW Health Workforce Plan 2022–2032 should be adapted to the development of a cancer workforce strategy in consultation with the Australian

- F. The current capacity and capability of the NSW Health workforce to meet the current needs of patients and staff, and its sustainability to meet future demands and deliver efficient, equitable and effective health services

Government, with the aim of coordinating education (tertiary and postgraduate), training, recruitment and career development to meet demonstrated future need.

- Benchmarks for patient-to-healthcare professional numbers should be set according to benchmarks set in frameworks such as the Optimal Care Pathways for cancer.
- The cancer workforce strategy needs to include increased allied health workforce planning and placements in healthcare settings to support a significantly growing cancer population.
- Exploring changes to the scope of practice of non-medical specialties to deliver cancer care, provided any policy change is supported by evidence of best practice and provision of professional development/supervision/support.

- Innovative models of care need to be implemented to meet the needs of a growing number of people living with and beyond a cancer diagnosis in NSW.
- State and federal governments should improve access to virtual care including telehealth.
- Value-based funding models should be implemented to incentivise providers to improve care quality and cancer outcomes.

- H. New models of care and technical and clinical innovations to improve health outcomes for the people of NSW, including but not limited to technical and clinical innovation, changes to scope of practice, workforce innovation, and funding innovation

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. We are the only non-government organisation in Australia that works across every cancer, including research, prevention, support and advocacy.

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, mostly in the form of competitive research grants.

To achieve our vision of a cancer free future, we work alongside local communities to:

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

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. Cancer Council NSW is a lead or partner in 14 out of 37 actions identified within the *NSW Cancer Plan 2022-2027*.

Cancer information and support

Cancer Council NSW is a trusted source of cancer information across every cancer and all aspects, from prevention and screening to diagnosis, treatment and managing the physical, emotional and practical impacts of cancer. In 2022, Cancer Council NSW distributed more than 100,000 patient information booklets to NSW hospitals and treatment centres, and had more than 2 million visits to the information pages on our website.

Our flagship 13 11 20 Cancer Information and Support Line provides a critical cancer service, helping 6394 people affected by cancer to access trusted information and support in 2022.

Cancer Council NSW offers a suite of support services to meet the complex needs of people affected by cancer, including:

- emotional support through professional counselling and peer support
- Cancer Council Liaisons based in cancer treatment centres who help people with cancer navigate the health system and access support
- Pro Bono legal, financial, small business and workplace referral services
- financial assistance, including financial counselling, emergency financial assistance and home help
- Transport to Treatment, a specialised free transport service for people living in rural and regional communities facing barriers to access treatment
- accommodation at reduced rates near treatment centres, and community-based accommodation.

Prevention in the community

We work alongside local communities across NSW to increase community awareness of how they can reduce their cancer risk, encourage those eligible to participate in cancer screening

programs, and advocate to governments for initiatives and cancer control policies to improve cancer outcomes for communities across NSW.

Our widely recognised SunSmart program has helped generations to learn skin cancer prevention from an early age. Together with the community, we successfully advocated for the removal of solar beds, which had been exposing users to elevated levels of UV and increased risk of skin cancer.

Through our Tackling Tobacco programs, Cancer Council NSW works with community organisations to support their staff and clients to quit.

Cancer Council NSW partners with the Cancer Institute NSW and community organisations to raise participation in cancer screening in communities with lower participation rates.

Our reach in many communities across the state gives Cancer Council NSW the unique opportunity to be a voice for change, to reduce the risk of cancer in our community and to improve access to cancer screening, treatment and support.

Advocacy

Our advocacy is making cancer history. Working with our community, partners and stakeholders, we advocate to governments to change policies to reduce cancer risks and improve cancer care. We act to define best practice diagnosis, treatment and survivorship, and seek to ensure we can improve cancer outcomes for everyone.

We have long advocated for action to ensure that everyone in NSW has the same opportunities to access the care they need – regardless of where they live. In 2022, we celebrated a major Cancer Council NSW advocacy win with the NSW Government allocating an extra \$149.5m to improve financial support for people in regional and rural NSW who need to travel for health care.

Screening

Our world-class research in cancer screening is changing the way we prevent and detect cancers. We know that if we can detect cancers earlier, we can deliver better outcomes and increase cancer survival. Thanks to advances in cancer research such as ours, and successful vaccination and screening programs, Australia is on track to be the first country to eliminate cervical cancer by as early as 2028.

As a community-based organisation we're there to meet community where they need us. We deliver evidence-based community-facing information and support to improve screening program awareness and participation with a focus on equity. Last year we delivered 96 community screening education sessions, bringing our total to 324 since 2019. Our focus is reaching under-screened communities, with a focus on culturally and linguistically diverse communities and Aboriginal and Torres Strait Islander communities.

Research

Cancer Council is the largest non-government funder of cancer research. In addition to conducting our own world-class research, Cancer Council funds extramural research. Our research spans across investigations into new and more effective treatments, cancer prevention and patient needs in cancer care and support. Over the past 5 years, we have invested \$86 million into world-class research.

Independent Cancer Council research integrated with community advocacy has been factored into major changes in cancer control policy and practice in Australia and NSW. This includes the development and promotion of Optimal Care Pathways for cancer, cancer

screening programs, clinical practice guidelines, and support for people affected by cancer, such as concession payments and patient travel and accommodation assistance.

The extent to which independent research and published evidence translates into improved and more equitable cancer outcomes is mixed and relies heavily on the funding arrangements, structures and accountabilities at the heart of this inquiry.

How we prepared this submission

The recommendations proposed in this submission are grounded in evidence and are based on insights from peer-reviewed literature, epidemiological data, and stakeholder consultation with people affected by cancer and health professionals, including members of Cancer Council NSW's independent and multidisciplinary Health Services Advisory Group. The organisations and individuals who contributed to this submission are listed in the **Appendix**.

Introduction

Published projections by The Daffodil Centre estimate that between 2020 and 2044, around 1.5 million people will be diagnosed with cancer in NSW and more than 480,000 people in the state will die of cancer². While NSW has some of the best survival outcomes in the world, cancer continues to place an enormous burden on our health system. In 2015–2016 healthcare expenditure on cancer in Australia was \$10.1 billion, including at least \$2.7 billion attributable to health risk factors⁵. High rates of cancer risk factors, suboptimal participation in population screening programs, and inequitable access to high-quality cancer care contribute to this burden and remain significant issues in NSW.

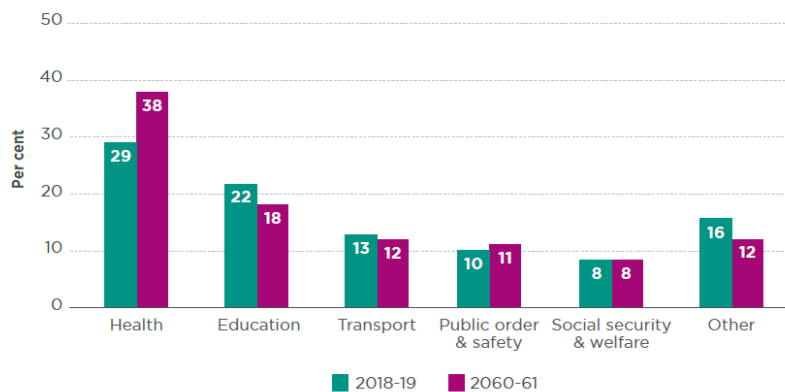
Inequities in cancer outcomes continue to persist and are widening among certain groups. Aboriginal and Torres Strait Islander peoples and those living in disadvantaged areas report higher cancer incidence and mortality, and lower survival than other Australians⁶. Possible reasons for these disparities include lower participation rates in population screening programs and poorer access to services and optimal cancer treatment and lower health literacy⁶.

Fundamental changes to the funding, structure, governance and delivery of health services in NSW will be essential to reducing the projected numbers of cancer deaths and cases and improving the lives of the millions of people in NSW affected by cancer.

Unprecedented cancer disease burden

Strain on the NSW health system in relation to meeting current disease burden and community needs across all health conditions is well documented³. Stresses on the system are likely to have a greater impact on patient and population groups, which already face systemic inequities.

NSW Treasury's *2021–22 Intergenerational Report* mentioned that the health portfolio is expected to remain the largest category of recurrent state spending, rising at an annual rate of 5.4% on average and growing from 29% of total expenses in 2018–19 to 38% by 2060–61 (as shown in Figure 1)⁷.



Source: NSW Treasury.

Figure 1. Recurrent expenses by service area as a share of total recurrent expenses⁷

The NSW *Future Health* strategy identifies that spending is largely concentrated in hospitals, with 85% of spending on outpatient, ambulatory, emergency, inpatient and sub-acute/rehabilitation care³.

Extrapolations from national data estimate that the number of cancers diagnosed in NSW in 20–25 years will be just over 50% higher than the 49,000 cases diagnosed in 2022².

NSW Health estimates that by 2032, cancer will account for 17% of the projected scale of activity within the NSW Health system³. On current trends, about 500,000 people in NSW will die of cancer over the next 20–25 years with the death burden growing disproportionately within that patient population, depending on²:

- cancer risk factors
- cancer type
- stage at diagnosis
- socioeconomic status
- cultural/Indigenous status
- place of residence
- inequitable access to services
- unexplained variations in clinical outcomes.

It is vital that the NSW Government invests in sustainable strategies to enable the health system to cope with the rising demand from chronic diseases such as cancer. We explore these strategies throughout this submission as they relate to the Terms of Reference (ToR).

1. The funding of health services provided in NSW

Terms of Reference A

The funding of health services provided in NSW and how the funding can most effectively support the safe delivery of high quality, timely, equitable and accessible patient-centred care and health services to the people of NSW, now and into the future

Recommendations for the Special Commission of Inquiry:

- Fundamental change in the funding of NSW cancer services is required to meet future cancer burden and reduce inequities.
- Regular auditing of NSW cancer services performance and expenditure is needed to improve transparency, accountability and inform funding decisions.
- Cancer services funding should be allocated according to current and projected need. This should include supportive care services and culturally appropriate services for priority populations.
- The NSW Government should work with the Australian Government, as well as the private and primary care sectors, to ensure all health services report on cancer outcomes and quality of cancer care against benchmarks outlined in Optimal Care Pathways and relevant clinical guidelines.

Summary of key insights and rationale

In 2022, cancer was the leading cause of disease burden, accounting for 17% of the total disease burden⁸. Fundamental change to the funding and delivery of cancer services in NSW is essential to improve outcomes, meet projected growth in the patient population, and reduce inequities. Without this change, all available indicators show that NSW will not be able to maintain service delivery for the growing cancer patient population nor target services to meet specific needs.

The NSW Government can work towards improving cancer outcomes by:

- ensuring cancer services are funded according to current and projected need
- increasing investment in prevention, including primary, secondary and tertiary prevention of cancer
- improving the transparency of NSW healthcare funding to better inform future planning.

Funding of cancer services according to current and projected need

As previously mentioned, the number of cancer cases diagnosed in NSW over the next 20–25 years will be much higher than the previous 25 years, placing an increasing burden on our health system. It is important that our health system is prepared for this increase and that the funding of health services is allocated according to current and projected need.

Cancer care is predominately delivered in the outpatient setting and funding decisions should ensure outpatient departments are appropriately resourced. Funding decisions should include consideration for alternative models of care to support the physical and psychosocial needs of people living with cancer. We elaborate on alternative models of care further under Terms of Reference H.

Funding for improvements in cancer prevention

As explored in section 3 of this submission, cancer prevention and prevention more broadly are among the most cost-effective investments in health available to governments, yet they are consistently underfunded in a system currently geared to treating sickness rather than promoting health. It is estimated that for every \$1 invested in prevention, a median \$14 returned to the wider health and social care economy⁹.

As discussed in greater detail in section 3, effective cancer prevention can be funded in a range of ways to deliver benefits that can be measured against all the indicators in ToR A. It is imperative that a system shift towards improved prevention as part of health services funding is recognised as an overarching driver of meeting the objectives of this inquiry. This system shift must extend to better leveraging community partnerships with community-based organisations outside the health system.

Earlier detection is key

Age-standardised mortality (death rates) is a strong indicator of trends in cancer outcomes, as it counts the number of people of a specified age who die of a specified cancer per 100,000 people in a defined population.

Although the NSW patient population is set to grow exponentially due to a combination of population growth and population ageing, cancer death rates in NSW (on national trends) are expected to fall by more than 20% over the next 20–25 years².

On current trends, a key driver of reduced death rates and health system savings will be earlier diagnosis, measured in stage-shift (i.e., more cancers diagnosed at earlier stage, when they are easier to treat).

However, these benefits will not be equitably shared, and for some cancers and populations, outcomes will remain stable or worsen^{2, 10}. Based on data available, there are stark inequities in the timing of cancer diagnosis, depending on cancer type, access to health services and patient demographic¹¹.

Rapid referral from primary to secondary and tertiary care, systematic uptake of clinical guidelines and improved tertiary prevention (see responses to ToR C) will be key to improving outcomes. Related innovations in areas such as improved state/federal cooperation, referral pathways, symptom management clinics and joint reporting against Optimal Care Pathways and population-level cancer burden are explored throughout this submission.

The Optimal Care Pathways are a set of guides that outline safe, high-quality, and evidence-based care for people with cancer¹². They map what an ideal patient-centred pathway for cancer care looks like for each step of the patient journey from prevention through to survivorship and end of life care.

They are endorsed by Cancer Australia, all states and territories and Cancer Council Australia. Research shows that people who receive care that meets the standards in the Optimal Care Pathways have a higher chance of surviving cancer than those who do not¹³.

It is crucial that the Optimal Care Pathways are also recognised as fundamental to informing state- and local-level funding for cancer services that are high quality, timely, equitable,

accessible and patient-centred – now and into the future as the patient population significantly grows.

Evidence and transparency of healthcare funding

Improved data collection and its publication will be key to improved health outcomes in NSW. While data collection and access are addressed throughout this submission, they are fundamental to ToR A.

A problem must be understood by all stakeholders for it to be solved. The only way for NSW to meet future patient need and reduce inequities is through improved collaboration across the government and non-government sectors, working together to support the funding of more effective, efficient and fairer cancer services.

Yet currently there is no public information about the funding and delivery of cancer services in NSW nor about how funding will be prioritised to meet growing patient population needs and inequities.

Available data shows cancer outcomes are significantly poorer in some Local Health Districts (LHD) compared with others¹⁴, yet there is limited public reporting on funding and few indications that funding is allocated on the basis of current or future community needs.

While auditing of government cancer services is required, information is not systematically collected and published against benchmarks for care outcomes enshrined in the Optimal Care Pathways. While the Optimal Care Pathways for cancer were endorsed in principle by all Australian state/territory governments in 2017, there is no implementation planning, targeted funding or related reporting against benchmarks in NSW. For example, there is currently no public reporting of wait times to access cancer specialist appointments, tests and treatments, meaning people with cancer have no idea whether they are waiting too long to get care.

Even less is understood about cancer outcomes in the private health system and breakdowns of performance benchmarks in settings with a mix of public and privately funded services.

Publishing data on the funding of cancer services will allow independent analysis of trends in cancer disease burden and enable collaborative planning to meet future cancer care needs in NSW.

Greater transparency and accountability embedded into the system should also be supported in relation to health services funding for other disease groups, to inform improved management of comorbidities and long-term planning.

2. The existing governance and accountability structure of NSW Health

Terms of Reference B

The existing governance and accountability structure of NSW Health;

i. the balance between central oversight and locally devolved decision making (including the current operating model of Local Health Districts);

ii. the engagement and involvement of local communities in health service development and delivery;

iii. how governance structures can support efficient implementation of state-wide reform programs and a balance of system and local level needs and priorities

v. how governance structures can support a sustainable workforce and delivery of high quality, timely, equitable and accessible patient-centered care to improve the health of the NSW population;

Recommendations for the Special Commission of Inquiry

- The NSW Government should work with the Australian Government to establish an integrated approach to cancer care with joint accountability and governance, and a focus on reducing inequities, addressing cancer burden and preventing cost-shifting.
- Improved transparency and accountability are essential, with NSW cancer services required to report on cancer outcomes and safety and quality of cancer care against benchmarks outlined in Optimal Care Pathways and relevant clinical guidelines.
- Service agreements between NSW Health and local health entities must include targets on cancer outcomes and benchmarks of safety and quality of cancer care.
- The involvement of consumers, community groups and community-based organisations in the planning, delivery and evaluation of cancer care services must be strengthened through new and existing mechanisms and with expectations clearly outlined in service agreements.

Summary of key insights and rationale

Holding the health system accountable for the quality, safety and cost of care is necessary to achieve good outcomes for people affected by cancer. However, with a cancer care system fragmented across primary, secondary and tertiary care, and with a mix of federal, state and private payers, establishing accountability is not straightforward.

“I keep getting referred to see private specialists and do tests that have high cost. The costs are not clear, and I don’t get a chance to ask about it and it’s becoming unaffordable.” Person with cancer

Even within the NSW health system, accountability for cancer care is complicated and it is – especially for people outside the system – not clear who or what entity ultimately bears responsibility for safe and high-quality care and whether they are receiving it.

However, accountability and governance are crucial for maintaining public trust in the health system. Governance structures and funding mechanisms in NSW need to change to allow joint service planning and delivery of seamless cancer care.

The NSW Government can improve accountability and governance of the cancer care system by:

- adopting new intergovernmental models with joint responsibility for planning, funding and reporting on cancer care across primary, acute and community settings
- collecting and publicly reporting on outcomes and cost data
- building partnerships between cancer systems and the communities they serve.

Collective accountability for cancer outcomes

In NSW, there should be greater joint accountability for health system performance, as well as cancer and population health outcomes.

Cancer care in Australia is complex and fragmented across multiple settings and providers with responsibility spread between state and federal governments and private organisations.

However, seamless cancer care that is patient-centred and results in good outcomes requires all parts of the health system to work together and be held jointly accountable.

At a statewide level, the *NSW Cancer Plan 2022–2027* sets out the priorities in NSW with respect to cancer control and outlines where objectives are shared across the health system, agencies, primary care and NGOs¹⁵.

However, the plan and its accompanying performance index have no measurable targets, are high level and do not clearly articulate who or what entity is held accountable for delivering safe and high-quality cancer care. Currently, LHDs are responsible for planning and delivering cancer services to meet the needs of the local community. LHD cancer plans sit alongside the NSW Cancer Plan and outline the priorities, services and activities to be delivered. However, while these plans are based on the needs of the community, funding for cancer services is decided through other mechanisms with limited connection to these plans.

While NSW Health does recognise the value of shared accountability and a ‘one-health’ system in its *Future Health* strategy, structures and funding arrangements that enable the joint planning, delivery and reporting on cancer care over the entire pathway of care are limited³. NSW Health should lead efforts to facilitate formalised collaboration and strategic alignment between cancer care providers in the NSW health system and primary care, community care and private hospitals.

The NSW Health *Integrating care for people with diabetes* initiative is an encouraging model that could be applied to care for people with cancer¹⁶.

Collect data and report on health system performance

An important way to promote accountability in the health system is to collect and report on the quality and effectiveness of cancer services. The previous section presents the case for improved data collection and reporting on cancer outcomes, as well as benchmarks of safety and quality, to ensure funding is directed where it is needed most.

It needs to be reiterated that public trust would be greatly strengthened through transparent and open reporting on cancer outcomes, safety and quality of cancer care, and costs. Key Performance Indicators need to reflect outcomes and benchmarks included in the Optimal Care Pathways.

Service agreements between NSW Health and LHDs do not include performance targets in relation to cancer outcomes. There is also no public transparency or reporting of LHD performance against the benchmarks outlined in service agreements. Publishing of cancer service safety and quality performance data should be a priority, along with efforts to make the reporting easily accessible to the public.

The Cancer Institute NSW's *Reporting for Better Cancer Outcomes* program collects and reports on performance of cancer services¹⁴. The purpose of the program is to support quality improvement in cancer control across NSW by providing LHDs with insights on cancer service performance. A statewide report is published each year that reports on a series of measures across cancer prevention, screening, treatment and care by LHD. While Cancer Council NSW applauds transparency within these reports, the focus and indicators included in these public reports need to shift toward the outcomes and measures of quality and safety that are of ultimate importance to the public.

There should be greater involvement of NGOs, community groups and consumers in the design, reporting and dissemination of performance reporting. In addition to the services they provide, community organisations, like Cancer Council NSW, can play an important role in ensuring that the public understand, trust and are involved in the health system.

Better leveraging of community partnerships across the health system

Where NGOs or community groups provide vital health and community services for people, Cancer Council NSW believes that these organisations should be both funded and actively involved in health system planning and decision-making. In the same way, NSW Health recognises that connecting with partners to deliver integrated care services is critical in the delivery of safe care across all settings. A failure to integrate the work of community-based organisations can result in inconsistent access to and fragmented care and duplication of services.

Cancer Council NSW is listed as the lead or partner organisation for the delivery of key activities across the *NSW Cancer Plan 2022–2027*¹⁷. Cancer Council NSW is the lead organisation in NSW for ensuring “people who experience cancer, their families and carers are actively linked with supportive care and services such as psychosocial care, allied health and financial counselling”. Overall, Cancer Council NSW is a lead or partner in 14 out of 37 actions identified within NSW Cancer Plan/Implementation Plan. Despite being 94% community funded, Cancer Council NSW partners with the NSW Government in good faith to deliver the best possible outcomes for the community we serve.

“There’s no roadmap for someone who’s going through cancer. It’s almost like you just navigate yourself.” Person with cancer

However, the ability of NGOs such as Cancer Council NSW to achieve objectives outlined in statewide government strategies and bridge the gap between acute and community care to deliver a ‘one system approach’, is compromised by a lack of service funding from the NSW Government. This is a risk to the ability to deliver against the government’s commitments and means the government is relying on the generosity of community donations to sustain joint, ongoing service delivery to our communities.

It has been Cancer Council NSW’s experience that where its services are integrated into the health system and care pathways, it is through local level relationships and not system-wide planning decisions. These services are accessed by thousands of people with cancer in NSW each year and relied upon by NSW health staff.

Without system-wide planning, access for people with cancer to the support and wraparound services provided by Cancer Council NSW will continue to vary significantly depending on the cancer service and hospital.

Build partnerships with local communities

In NSW, there is a need to improve how well communities are engaged and involved in the planning, delivery and evaluation of cancer services. While community partnership is a

requirement of LHDs and hospitals to meet the National Safety and Quality in Health Care Standards, community participation in health system decision-making is not widespread.

NSW Government strategies, including its *Future Health* strategy and *Elevating the Human Experience* strategy, outline the importance of partnering with patients and carers to achieve patient-centred care^{3, 18}. However, efforts to involve community groups and members at the LHD level are often described by people with cancer as tokenistic and transactional. It is not clear that LHDs are accountable for ensuring that communities are adequately engaged in the planning, delivery and evaluation of cancer services.

Closer partnerships with communities can help build trust between health services and the communities they serve. Evidence suggests that where community members are viewed as equal and integral members of health services, outcomes and experiences for those affected by cancer are improved^{19, 20}.

A 2015 literature review conducted by the Consumers Health Forum of Australia concluded that there is a substantial body of research supporting the involvement of community members in health decision-making, and consumer engagement can add value to the healthcare system by improving quality of care, efficiency of resource use, and community support for programs or services²¹.

There is a need in NSW to go beyond the current expectation that LHDs engage with consumers. New models of involving communities in the planning, delivery and evaluation of cancer services must be investigated, trialled and funded. Non-government organisations, such as Cancer Council NSW, should also be consulted on the planning, delivery and evaluation of services to ensure they are tailored to the needs of target populations and address existing service gaps.

The responsibility for community engagement and involvement in health system decision-making should be reflected in any service agreements between local health services and the NSW Government.

Statement of support from Cancer Voices NSW

Cancer Voices NSW supports the strong and diverse involvement of consumers through collaboration and partnering across all facets of cancer care and services delivered in this state. Crucially, this is underpinned by the comprehensive collection and reporting of data that is easy to access, navigate and filter to ensure gaps in care and services can be identified and addressed. Cancer Council NSW and Cancer Voices NSW are two of many collaborating partners in this process.

3. NSW Health funding of health services delivered in public hospitals and community settings

Terms of Reference C

The way NSW Health funds health services delivered in public hospitals and community settings, and the extent to which this allocation of resources supports or obstructs access to preventative and community health initiatives and overall optimal health outcomes for all people across NSW.

Recommendations for the Special Commission of Inquiry

- NSW Government spending on prevention must increase to at least 5% of the total health budget, with an increased focus on the primary prevention of chronic disease.
- Funding for prevention should be ring-fenced to allow preventative health programs and services to be fully implemented and evaluated.
- There needs to be greater transparency of health system performance against preventative health targets, including calculation of spend and public reporting against key metrics.
- Integration and coordination of preventative health services in and outside the NSW system must improve, including through better leveraging of partnerships and long-term funding agreements with community-based and non-government organisations.

Summary of key insights and rationale

NSW Treasury in their *2021–22 Intergenerational Report* recognises that to keep health spending sustainable, reduce demand for hospital care and improve health outcomes, there is a need to keep people healthy and effectively manage chronic conditions⁷.

Keeping people healthy supports their ability to engage in community as well as contribute to the NSW economy through education, workforce, sport, the arts and leisure. Spending on health is understood to be the largest single driver of projected growth in NSW Government recurrent spending. Health as a portfolio is also projected to grow faster than any other, at an average rate of 5.4% per year⁷.

With the growing burden of chronic disease, our health system has unfortunately become increasingly focused on crisis management, and government spending on disease prevention has fallen behind.

***“Our health system is built for sickness not wellness.”* Member of Cancer Council NSW’s Health Services Advisory Group**

Cancer Council NSW acknowledges the strengths of NSW Health in policy and the delivery of statewide preventative health programs and believes these strengths should be preserved. This includes the NSW public health workforce.

However, total NSW Government funding for preventative health is not enough to meet the rising challenge of chronic disease. Equally, funding for preventative programs can be uncertain and tends to be delivered in short cycles, leaving insufficient time and resourcing to appropriately plan, deliver and evaluate new services and interventions.

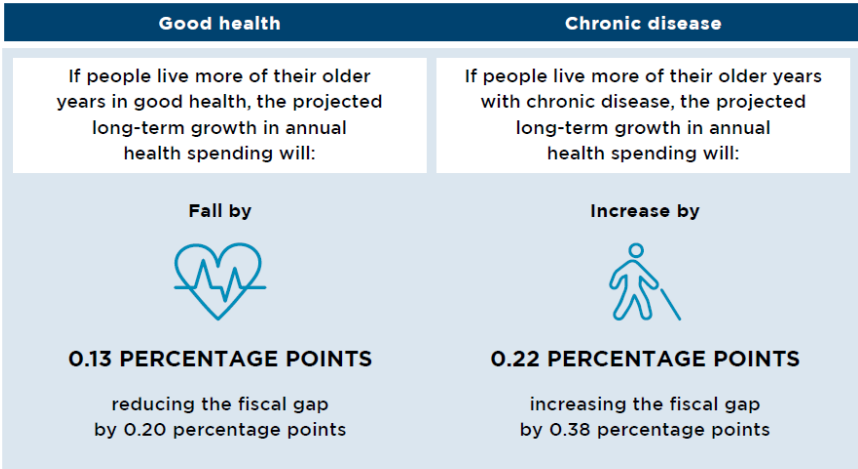
It is our view that ring-fenced funding for preventative health is necessary to allow the full implementation and evaluation of programs and services. Likewise, NSW Health should look to extend the impact of its programs and services, especially in vulnerable populations,

through partnerships and long-term funding arrangements with community-based and non-government organisations outside the health system.

The NSW Government could learn from the way that Victoria’s VicHealth health promotion agency works to bridge the gap between government and community organisations involved in sport, arts and health promotion to fund initiatives inside and outside of government.

The National Preventative Health Strategy recommends government investment in prevention should increase to 5% of the total health expenditure by 2030²². However, the way in which spend on “prevention” is calculated and reported in the public domain varies significantly and is unreliable. The Australian Government reports spending only 2% of total health expenditure on prevention. This is significantly lower than other countries with similar health systems such as Canada (over 6%) and the UK (over 5%)²³. The NSW *Future Health* strategy reports that current expenditure on prevention and promotion in NSW is 10% of total health expenditure. However, it’s unclear exactly how much of this expenditure is for primary prevention of chronic disease, and the percentage is likely to be inflated due to increased government spending on the COVID-19 pandemic.

Without significant changes to the way the NSW Government funds and ensures system accountability for preventative health, the increasing number of people diagnosed with cancer and other preventable chronic conditions will continue to place a significant burden on our health system and communities. Preventative health is relatively low cost and can deliver long-term savings by reducing the incidence and severity of many diseases including diabetes and heart disease. Effective chronic disease prevention can improve care quality and reduce inequities, and can also support a more efficient health system by increasing capacity to meet the rising demand in healthcare services⁷.



Source: NSW Treasury modelling.⁵¹

Figure 2. Healthy ageing can ease pressure on the state budget⁷

The NSW Government can reduce the burden of cancer on our health system by:

- increasing investment in the primary prevention of chronic disease, including risk factors such as overweight and obesity, smoking, physical inactivity, alcohol, and sun exposure
- increasing statewide participation in national cancer screening programs to ensure cancers are diagnosed as early as possible to ensure the best chance of survival
- ensuring people living with or beyond a cancer diagnosis have access to multidisciplinary care to manage and reduce their risk of comorbidities and secondary cancers.

Chronic disease prevention

On national trends, about one-third of cancers diagnosed in Australia could be attributable to modifiable risk factors (tobacco smoke, UV exposure, the separate and interacting effects of poor nutrition, high body mass and physical inactivity, alcohol consumption, cancer-causing viruses and occupational exposures)²⁴.

On current trends, health system expenditure for cancer in NSW will total more than \$4 billion in 2023–24, with total costs increasing in recent years by around 3%⁵. Although one-third of all cancer cases in NSW are associated with preventable risk factors, the costs to the system of preventable cancers are considerably higher²⁵. This is because several of the cancers in NSW most strongly associated with established preventable risk factors (e.g., non-melanoma skin cancer and melanoma, bowel cancer, kidney cancer, lung cancer) are among the costliest for the health system and contribute significantly to public hospital costs, which represent the leading cost borne by state government²⁵.

Levels of cancer risk factors such as obesity, tobacco and alcohol in NSW are worryingly high. Geographic disparities of these risk factors also contribute to cancer risk and mortality gaps across NSW.

Tobacco remains the leading cause of preventable death and disease

Tobacco use remains the leading cause of preventable death and disease in NSW. In 2020, more than 6000 people in NSW died from causes directly attributable to tobacco use, with about 3500 dying from cancers^{26, 27}. Tobacco smoking also led to more than 60,000 hospitalisations in NSW in the same year²⁶. A 2022 landmark study predicts that over the next 25 years more than 250,000 Australians will die from cancers directly caused by tobacco use, in addition to tobacco-related deaths from other causes². In 2022, 11.4% of NSW adults were current (daily or occasional) smokers²⁶. In 2019, 72% of people who smoked and attended an outpatient cancer clinic in NSW reported being advised by a health professional to quit smoking and/or offered a referral to Quitline, nicotine replacement therapy or other help to quit smoking²⁸.

Alcohol and risky drinking

The social and economic cost of alcohol use in Australia in 2017–18 was estimated to be \$66.8 billion, which includes \$2.8 billion in healthcare costs attributable to alcohol-caused conditions²⁹. Alcohol was associated with close to 3500 cancer cases (or 2.8% of all cancers) in Australia in 2013³⁰. Concerningly, over a third of adults in NSW drink alcohol at levels that put them at risk of long-term harm, and these levels have increased since 2016^{14, 31}.

Besides increasing the risk of cancer, alcohol causes a significant burden of disease in Australia. In fact, 4.5% of the total burden of disease (including chronic diseases, accidents, mental health conditions and alcohol use disorders) in Australia could be prevented by reducing alcohol use by the population³².

Alarming and persisting rates of overweight and obesity

In 2008, the economic cost of obesity in Australia was estimated to be \$58.2 billion, with a cost of \$19 billion in NSW³³. About 13% of total hospital admissions in adults aged 45–79 were attributed to overweight and obesity, accounting for nearly \$1 in every \$6 spent on hospital costs in Australia³⁴. In Australia, the rate of obesity-related cancers almost quadrupled between 1983 and 2017, and 190,000 overweight/obesity-related cancers are projected between 2013 and 2037^{34, 35}.

In NSW, almost one in four children are overweight or obese^{26, 36}. Many of those children will go on to carry that excess weight into adulthood, increasing their risk of developing chronic health conditions, including type 2 diabetes, heart disease and many cancers³⁷.

Secondary prevention

Early detection of cancer not only offers patients the best chance of survival, it also enables more efficient treatment and can significantly reduce healthcare costs³⁸. Despite the presence of population screening programs, the number of cancer cases diagnosed via emergency presentation in NSW is high. A 2022 report revealed that around 31% of patients with cancer are diagnosed in the emergency department in NSW, which is considerably higher than Victoria (24%)³⁹. For some cancers, such as liver cancer, the percentage of patients diagnosed in emergency departments in NSW is as high as 75%³⁹. This report found that advanced stage diagnosis of cancer was associated with increased emergency presentations for cancer, highlighting the need for increased government investment in early detection of cancers in the community.

Early detection in bowel cancer screening

Bowel cancer is the most expensive cancer to treat in Australia, with the majority of state government expenditure for this cancer going on public hospital treatment. Research by The Daffodil Centre shows the average health costs for a bowel (colorectal) cancer case in the first year of treatment was between \$50,000 and \$60,000, with costs more than double for late stage disease compared with localised disease⁴⁰. Evidence shows that survival for bowel cancer depends on the stage of cancer at diagnosis. For example, the 5-year relative survival rate for stage 1 bowel cancer is as high as 98.6%⁴¹. For stage 4 (late stage) bowel cancer, outcomes look very different, with a survival rate of just 13.4%⁴¹.

Regardless, participation rates in the National Bowel Cancer Screening Program (NBCSP) in NSW remain among the lowest in the country, with participation in those aged 50–74 years in 2020–21 stalled at 39.5% compared to 44.4% in South Australia and Tasmania⁴². Further to this, people who participate in the NBCSP and receive a positive result from bowel cancer screening are waiting too long for a follow-up colonoscopy, with only 12% of people receiving a colonoscopy within the recommended 30 days in NSW⁴². The impact of this becomes evident when you look more closely at the number of patients diagnosed with bowel cancer via the emergency department – 33% of patients with colon cancer and 39% with rectal cancer are diagnosed via emergency presentation in NSW³⁹. Research shows that raising participation in the NBSCP to 60% could save up to 28,000 lives in NSW over the next 25 years, as well as reduce the pressure on colonoscopy services and hospitals⁴³.

Lung cancer screening

Lung cancer is the most common cause of cancer death in NSW. In 2023, around 2994 deaths are expected from lung cancer⁴⁴. Most lung cancer cases in Australia are diagnosed at an advanced stage, with less than 20% of cases diagnosed early⁴⁵. In NSW, 74% of lung cancer cases are diagnosed via presentation to the emergency department. This calls for increased early detection efforts to improve chances of survival³⁹. On 2 May 2023, the Federal Minister for Health and Aged Care announced Australian Government investment of \$263.8 million from 2023–24 to implement a National Lung Cancer Screening Program in Australia commencing July 2025. The program is expected to prevent over 500 cancer deaths in Australia each year. To ensure the implementation of the lung cancer screening program is as successful and impactful as possible in NSW, assessment and planning of healthcare infrastructure will be essential. As discussed in section 5 (NSW workforce capacity and capability to meet the needs of people living in NSW), state and federal governments should prioritise building workforce capacity and capability to appropriately

support the implementation of the program and the increase in demand on our health services. Assessment of CT scanner capacity and capability will also be required, along with data reporting to support ongoing monitoring and evaluation of the program.

Prevention for people living with or after cancer

In addition to the risk of cancer recurrence and secondary cancers, people living with or after cancer have an increased risk of comorbidities, including cardiovascular disease, type 2 diabetes, metabolic syndrome and osteoporosis, which are often overlooked by patients and clinicians during treatment⁴⁶. Comorbidities are particularly common in populations with worse health outcomes overall, including Aboriginal and Torres Strait Islander peoples and lower socioeconomic communities⁴⁷.

A 2014 report on emergency department utilisation in NSW between 2006 and 2009 found that 40% of people with cancer visited an emergency department in the year after diagnosis⁴⁸. About 36% of emergency department visits from cancer patients were for comorbidities associated with circulatory, respiratory and digestive systems⁴⁸.

Evidence-based strategies can support people living with or after cancer to reduce their risk of comorbidities and improve other cancer outcomes through the adoption of healthy behaviours, such as healthy eating, physical activity and smoking cessation. These are key components of care and have proven benefits in terms of improving cancer and non-cancer outcomes⁴⁶. For example, smoking cessation after a cancer diagnosis is linked to a 45% median reduction in mortality⁴⁹. It also reduces the risk for many adverse health effects, including reproductive health outcomes, cardiovascular diseases and chronic obstructive pulmonary disease (COPD)⁴⁹.

To support the adoption of healthy behaviours, it's important that cancer patients have access to evidence-based community programs as well as integrated care, with recognition that primary care may be best placed to provide preventative care and management of comorbidities⁴⁶. Activity-based funding, which is the predominant model of funding in our health system, does little to incentivise providers to keep people healthy and out of hospital. Towards the end of our submission, we discuss the need for a shift in funding models, as well as alternative models of care, to focus improvements on patient outcomes.

4. Strategies to improve health system efficiency

Terms of Reference D

Strategies available to NSW Health to address escalating costs, limit wastage, minimise overservicing and identify gaps or areas of improvement in financial management and proposed recommendations to enhance accountability and efficiency

Recommendations for the Special Commission of Inquiry

- There needs to be improved transparency and accountability, with NSW cancer services required to report on cancer outcomes and safety and quality of cancer care against benchmarks outlined in Optimal Care Pathways and relevant clinical guidelines.
- Cancer Institute NSW should work with local communities and consumers to ensure public reporting of cancer outcomes and care is accessible, consumer-friendly and relevant to local needs.
- NSW Health should implement a workable single patient health record that can be easily accessed by healthcare providers across primary and secondary care.
- NSW Health should conduct regular audits of low value care procedures and explore strategies to de-implement low value care in relevant health services.
- NSW Health should increase efforts and resourcing to ensure PROMs are routinely used to guide real-time patient care and integrate data into quality improvement programs.
- The NSW Tobacco Retailer Notification Scheme should be amended to require an annual fee to be paid by tobacco retailers.

Summary of key insights and rationale

The treatment and care of people with cancer is a significant area of expenditure. Cancer is a complex disease that often requires multi-modal treatments from multiple providers over a long period of time. Complex treatments, coupled with the increasing cancer burden and co-morbid diseases, will likely result in significant increase in expenditure on cancer in the future.

However, there are opportunities for the NSW Government to improve the provision of clinically and cost-effective cancer care and prevent overservicing and unnecessary care. These opportunities include:

- better use of linked health records to improve care coordination and prevent overservicing
- public reporting of health system performance to help consumers and providers make better informed choices
- regular auditing of low value care procedures in NSW health services and exploration of strategies to de-implement low value care
- collecting and routinely using patient reported outcome measures (PROMs) to guide real-time patient care and inform quality improvement activities.

Linked health records

Cancer care in NSW is still fragmented across primary, hospital, outpatient, diagnostic, allied health and supportive care – and across public and private sectors. People with cancer will have numerous healthcare providers in multiple settings responsible for their care, which can lead to poor communication and experiences of poor and fragmented care.

Poor communication can lead to poor experiences of the health system, as one carer of a person with cancer told Cancer Council NSW: *“there were times when we were travelling five 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”*.

Anecdotal evidence suggests that the uptake of MyHealth Record across primary and hospital care in NSW has been patchy. Incomplete records of care are a potential cause of duplication and overservicing. As GP and Associate Professor Joel Rhee on Cancer Council NSW’s Health Services Advisory Committee highlighted: *“It’s a shame because we do all the investigations, but the patient ends up in the emergency department because something happens overnight and then we don’t know what’s happened. Then they end up replicating everything and it’s really frustrating.”*

The implementation of NSW’s Single Digital Patient Record will significantly improve coordination of care, patient experience and prevent unnecessary duplication of treatments and tests.

It is imperative that the Single Digital Patient Record is readily accessible to consumers and its uptake is supported across primary and hospital care providers, as well as in the private system and other providers of support services. People with cancer living in areas on the Queensland and Victorian borders, who often experience care in multiple health systems, must also not fall through the cracks.

Public reporting of health system performance

Information on the performance of the NSW cancer system is needed for the provision of safe, effective and quality care. In this submission, the sections addressing ToRs A and B cover the value of data on the quality and safety of care in NSW as a tool to help inform prioritisation of funding and drive quality improvement.

However, transparency and public reporting on health system performance is also an important enabler for involving the public in the shift towards value-based care. Public reporting is a necessary first step on a path toward a multi-stakeholder approach involving local communities to improve outcomes⁵⁰.

In NSW, there is significant variation in cancer care delivery and outcomes across the state and even between cancer services within one LHD¹⁴. However, there is no way for a person with cancer to know whether the cancer service – public or private – they have been referred to provides care that meets the highest standards.

The Cancer Institute NSW’s *Reporting for Better Cancer Outcomes* program collects and reports on performance of cancer care in NSW to assist LHDs conduct quality improvement. It primarily provides a mechanism for engagement within the health system and cancer services. However, there is an opportunity for the program – working alongside local communities – to provide translated consumer-friendly information to the NSW public on quality and safety of cancer care across NSW.

Regular auditing of low value care in health services

The scale of low value care provided in the NSW health system is difficult to measure. However, one study found that up to 20% of all procedures performed in a NSW hospital were low value⁵¹. The Choosing Wisely and Royal Australasian College of Physicians Evolve campaigns list several low value care procedures across a range of conditions. Reducing low value care is key to improving patient outcomes and reducing healthcare costs⁵⁰. Reducing the amount of low value care in our health system also has positive impacts on the environment and can help contribute to a more sustainable healthcare system⁵².

To reduce low value care in the health system, it is important to understand the extent of low value care in health services, where it occurs and why. Measurement of low value care procedures in health services can help inform quality improvement strategies⁵⁰.

Investment in bowel cancer screening can help minimise low value colonoscopy use and associated healthcare costs

The National Bowel Cancer Screening Program (NBCSP) is a government-funded program that invites eligible participants to complete an at-home immunochemical faecal occult blood test (iFOBT). Those who return a positive iFOBT test require a colonoscopy for further investigation. Clinical guidelines recommend two-yearly iFOBT from 50 to 75 years of age.

The iFOBT used in the NBCSP is an effective test in ruling out bowel cancer. The NHMRC approved guidelines and the Australian Commission on Quality and Safety in Healthcare's Colonoscopy Standard both strongly recommend iFOBT as first-line screening, and that colonoscopy should be prioritised only as a follow-up diagnostic tool. However, data from 2011 suggests that 13% of people aged 50 to 75 were over-screened using colonoscopy⁵³. A recent study also found that only 12% of colonoscopies were conducted in people testing positive for iFOBT, highlighting the inefficient overuse of low-yield colonoscopies for people who should first be screened by iFOBT⁵⁴. Boosting NSW participation in the NBCSP is not only important to save lives from bowel cancer, but can also reduce the use of unnecessary colonoscopies as a first-line screening tool that places a huge burden on our healthcare system.

Patient-reported outcome measures

Patient-reported outcome measures (PROMs) are an important contribution to the provision of patient-centred care. PROMs are standardised questionnaires that help healthcare providers understand health outcomes from the patient's perspective.

At a clinical level, routine collection and use of PROMs can help improve communication between providers and patients – and facilitate better identification and management of symptoms and concerns. Research has shown that the use of PROMs in cancer care can reduce emergency department admissions and hospitalisations⁵⁵, and improve survival^{56, 57}.

People with cancer often report struggling to communicate with their healthcare team and downplay symptoms or concerns that they might perceive as being low priority. Research has also found that healthcare providers often miss or underestimate symptoms of cancer treatment and their severity⁵⁸. PROMs have been demonstrated to improve the experience of care for people with cancer, as well as their communication with health professionals⁵⁹.

At a health system level, collecting and using PROMs is a useful way for health services to identify areas of care that need addressing.

Capturing population-level PROMs data can also improve the safety and quality of healthcare delivery. For example, the data can be used to monitor and identify gaps in performance, benchmark patient outcomes against other services, and guide policy and procedures related to service delivery⁶⁰.

Crucially, PROMs can help reduce overservicing and provision of low value care by directing funding and care to where it is needed most.

“PROMs can reduce overservicing issues by directing care to where it's needed most. Collecting and reporting on PROMs allows us to separate care which is urgently required vs not.” Professor Geoff Delaney, Radiation Oncologist, Liverpool, NSW

In NSW, the rollout of PROMs has been the responsibility of the Agency of Clinical Innovation and, for cancer services, the Cancer Institute NSW.

Consultation with NSW healthcare providers has found that some believe that PROMs have not been sufficiently implemented across NSW cancer services.

“Collecting and acting on PROMs reduces healthcare costs such as unnecessary acute hospital admissions. However, systematic resourcing to permit the routine collection of PROMs is currently lacking.” Professor Geoff Delaney, Radiation Oncologist, Liverpool, NSW

Tobacco retailer notification scheme

Nearly all states and territories across Australia require retailers to pay a fee to sell tobacco, with the exception of NSW and Victoria. NSW has a Tobacco Retailer Notification Scheme, which requires retailers to notify Service NSW of their intent to sell, with no fees attached.

Tobacco retailer licensing can be used to reduce the number of outlets selling tobacco, helping to reduce tobacco availability. A tobacco retailer fee was introduced in South Australia in January 2007. This move saw the annual cost of retail tobacco licences rise 15-fold from \$12.90 to \$200⁶¹. This initial fee increase led to an almost 24% decrease in the number of tobacco retailers within two years⁶¹. Tobacco licences declined by 33% overall by 2020, by which time the fee was \$303⁶¹. The reductions in licences have been seen mostly across food service venues (65.2%) and hotels (37.2%)⁶¹.

NSW has approximately 16,000 retail outlets selling tobacco products, and evidence suggests that very few retailers leave the market⁶². Having such a deadly product so widely available normalises use, puts young people at risk of taking up smoking, and undermines the efforts of those who are trying to quit. Retailers that profit from selling tobacco products, which cost the NSW community \$8.4 billion a year⁶³, should help fund the administration costs associated with the right to sell tobacco.

We strongly recommend the Tobacco Retailer Notification Scheme is amended to require an annual fee. A fee will not only prompt new business to reconsider entering the market and prompt existing businesses to reconsider selling tobacco, but also has the potential to generate a new source of revenue for the NSW Government. Tasmania currently sets an annual tobacco retailer fee of \$1219. If NSW were to introduce an annual fee of \$5000 per annum, it has the potential to generate \$50M annually to reinvest in preventative healthcare spending.

5. NSW workforce capacity and capability to meet the needs of people living in NSW

Terms of Reference F

The current capacity and capability of the NSW Health workforce to meet the current needs of patients and staff, and its sustainability to meet future demands and deliver efficient, equitable and effective health services.

Recommendations for the Special Commission of Inquiry

- Structural reforms, short-, medium- and long-term planning, and innovation are required to prepare for an increase in cancer burden and inequities in NSW.
- The NSW Health Workforce Plan 2022–2032 should be adapted to the development of a cancer workforce strategy in consultation with the Australian Government, with the aim of coordinating education (tertiary and postgraduate), training, recruitment and career development to meet demonstrated future need.
- Benchmarks for patient-to-healthcare professional numbers should be set according to benchmarks set in frameworks such as the Optimal Care Pathways for cancer.
- The cancer workforce strategy needs to include increased allied health workforce planning and placements in healthcare settings to support a significantly growing cancer population.
- Exploring changes to the scope of practice of non-medical specialties to deliver cancer care, provided any policy change is supported by evidence of best practice and provision of professional development/supervision/support.

Unprecedented cancer disease burden

While published analyses indicate that clinician-to-patient numbers are just above international benchmarks, there is evidence that the health workforce in NSW is not distributed and accessible according to cancer patient needs and disparities⁶⁴.

Meeting the needs of a 50% increase in cancer patient numbers will only be possible through changes in how healthcare professionals are trained, recruited, placed and supported throughout their careers, now and over the longer term.

Intergovernmental planning and development based on need

General policies underpinning health workforce in NSW have been subject to a series of state and federal reviews and mechanisms. Over the past 15 years, these include the Rudd/Gillard government Health Workforce Australia agency, the Mason review, a National Medical Workforce Strategy (2019) and the current NSW Health Workforce Plan (2022–2032)⁶⁵⁻⁶⁸.

We appreciate that these mechanisms are high-level and not designed to inform health funding policy and practice in relation to specific disease groups and trends, including inequities caused by systemic problems and socioeconomic disadvantage.

On our interpretation of the evidence, it is nonetheless vital that governments (state and federal) and governing and advisory bodies (intergovernmental, state and local/district) recognise the urgent need for workforce planning and development aligned to current and future need, continuous improvement and closing gaps in clinical outcomes.

As noted throughout this submission, while cost-shifting between state and federal governments and mixed public/private service models may serve a purpose for public officials focused on internal accountabilities, fragmentation of the system leads to suboptimal patient outcomes.

In 2010, Australian governments sought to address some of the perennial and growing problems caused by fragmentation, at least in relation to care standards, by establishing the National Registration and Accreditation Scheme (NRAS)⁶⁹.

However, like many similar mechanisms, the NRAS appears to be utilised only when there are complaints lodged rather than as a tool to ensure national standards are factored into workforce planning and funding.

Many players, no unified team

Funding for the NSW health workforce is provided by both the federal and state governments. In addition, private sector and non-government entities, such as universities, vocational education and training providers, medical colleges and employer groups can significantly influence the training and employment pathways of health professionals.

Efforts to improve pathways and ensure the workforce can respond to evolving needs must be advanced at an intergovernmental and intersectoral level if NSW is to improve cancer care standards and outcomes while meeting the needs of an exponentially increasing patient population.

Building on the work to improve national standards, healthcare planning and funding in NSW should include a focus on ensuring the cancer workforce can support the delivery of optimal care as standard care in NSW. Achieving this will require integration of all the key recommendations in this submission, including service audits and tying funding to demonstrated population need and equity.

Flexibility within an evidence-based framework

The promotion of tailored approaches and adaptations of the health workforce to areas of growing need will be crucial to improving outcomes and efficient use of limited resources.

Current and future examples include:

- the use of Rapid Access Colonoscopy in NSW within the NBCSP – avoiding the costs and delays of unnecessary steps in clinical pathways while adhering to national standards (e.g., the Colonoscopy Clinical Care Standard)^{70, 71}
- the management of patients with suspicious lung nodules when lung cancer screening commences in NSW from July 2025
- services that meet the complex needs of about 200,000 new breast cancer cases in NSW over the next 20–25 years, as screening, diagnostic and treatment technologies rapidly evolve.

There are many other examples, and concerns throughout the cancer care sector that the current and future workforce required to apply new technologies will not be able to cope with demand, in both advantaged and disadvantaged areas.

Fundamental shifts in workforce planning and funding are required and should be supported by the Inquiry. These changes must be informed by rigorous evidence review to deliver parity in clinical outcomes with no risk to patient safety.

6. New models of care to improve health outcomes for the people of NSW

Terms of Reference H

New models of care and technical and clinical innovations to improve health outcomes for the people of NSW, including but not limited to technical and clinical innovation, changes to scope of practice, workforce innovation, and funding innovation.

Recommendations for the Special Commission of Inquiry

- Innovative models of care need to be implemented to meet the needs of a growing number of people living with and beyond a cancer diagnosis in NSW.
 - State and federal governments should improve access to virtual care including telehealth.
- Value-based funding models should be implemented to incentivise providers to improve care quality and cancer outcomes.

Summary of key insights and rationale

The NSW *Future Health* strategy outlines that if current models of care are relied upon to address the rising burden of chronic disease, future demand could drive 1.7 times more activity in the health system by 2032³.

With significant improvements in cancer survival over the last 20 years, the number of people living with or beyond a cancer diagnosis has grown substantially¹⁰. Current models of care, which are mostly specialist led, are unsustainable and insufficient to meet the various needs of a growing population of people living with and beyond a cancer diagnosis in NSW.

For the most part, today's funding models incentivise providers based on activity. This shifts the focus away from quality care and improving patient outcomes, meaning that various needs of patients often go unmet. There are opportunities for the state and federal governments to explore more sustainable models of care and improve cancer outcomes including:

- implementing alternative models of care to meet the needs of people living with and beyond a cancer diagnosis (survivorship)
- improving access to virtual models of care, including telehealth services, to reduce geographic disparities in care access
- exploring alternative funding models that incentivise providers to deliver high-quality care with a greater focus on improving patient outcomes and addressing unmet needs.

Implementing alternative models of care to meet the needs of people living with and beyond a cancer diagnosis.

People living with and beyond a cancer diagnosis often experience long-term consequences of their cancer and associated treatment. Long-term physical symptoms, such as pain, fatigue and sleep disturbances, are frequently reported, as are psychological consequences, such as anxiety, depression and fear of cancer recurrence⁴⁶. In addition to the risk of cancer

recurrence and secondary cancers, people living with or beyond a cancer diagnosis often have comorbidities including cardiovascular disease, type 2 diabetes, metabolic syndrome and osteoporosis⁴⁶. As such, it is important that patients have access to timely, well-coordinated cancer care that improves their quality of life, functional outcomes, management of comorbidities, and risk of cancer recurrence.

Several alternative models of care have been evaluated and shown to be as effective as specialist-led care. These include models led by primary care, shared care between oncology specialists and primary-care providers, and care led by oncology nurses⁷². Alternative models of care have a number of demonstrated benefits to the healthcare system. For example, Nurse Practitioner led models of care have demonstrated improved symptom management for cancer patients, as well as reduced emergency department workload and presentation rates⁷³. This also means patients can receive care outside acute care settings and closer to home.

A medical oncologist on our Health Services Advisory Group noted: *“There are programs, frameworks and shared care models that we need to enact and enable to stop cancer survivors getting another cancer.”*

The most appropriate model of care will depend on several factors, including patient-level and system-level factors⁷². By trialling and testing different models of care in areas of greatest need, the NSW Government can determine the effectiveness and applicability of alternative care models to better meet the needs of cancer survivors across the state.

Governments should collaborate with healthcare providers, local communities, NGOs such as Cancer Council NSW, and research institutions on the design, implementation, and evaluation of new care models, to ensure the needs of cancer survivors are appropriately addressed and measured.

Shared care models for early breast cancer

Shared care between primary care and specialist is an innovative model of care that has been used to support the provision of holistic follow-up and survivorship care for patients with early breast cancer⁷⁴. Evaluation of shared care models for early breast cancer by Cancer Australia has shown shared care models to be as effective and acceptable as specialist-led care⁷⁴. Economic evaluation has also shown shared care to be more cost effective than traditional specialist care, with the potential to free up the time of specialists⁷⁴.

Symptom and Urgent Review Clinic (SURC) initiative, an example of an innovative nurse-led model of care in Victoria

Symptom and Urgent Review Clinics (SURC) are an example of an innovative nurse-led model of care, which supports management of patients who experience symptoms from their cancer or treatment⁷⁵. SURC clinics have been implemented across regional and metropolitan hospitals in Victoria to recognise and manage symptoms early and avoid the need for presentations to the emergency department⁷⁵. The clinics are located in oncology and chemotherapy day units and led by oncology nurses, who provide patients with a point of contact for telephone consultation and physical review when required. Evaluation of SURC has shown a reduction in emergency department presentations and improved patient satisfaction throughout treatment⁷⁵. The implementation of these clinics also demonstrated a positive return on investment with a return of \$1.73 for every dollar invested in the new service⁷⁶.

A patient with cancer told us that he preferred seeing his GP outside of his appointments with the oncologist: *“I saw the GP and he listened and was able to help me with the side effects of my cancer. Appointments with the oncologist were often rushed. There was not enough time to ask the oncologist questions, and when I did, I was often dismissed.”*

Virtual models of care

Telehealth offers benefits regarding choice, convenience and safety for both the patient and clinician, and has the potential to reduce geographic disparities in cancer. Telehealth also facilitates improved quality of care by allowing services in regional areas to link to tertiary metropolitan centres for multidisciplinary team discussions and access to clinical trials. However, last year the Australian Government announced that it would cut back on a range of telehealth services that were made available at the start of the pandemic.

Around 83% (n=289) of people surveyed in our Regional Communities Survey stated that it was important to have telehealth available as an option to consult with health professionals⁷⁷. Virtual care models have also been established to act as a bridge between specialist hospital services and community care. Established as the first virtual hospital in NSW, RPA Virtual Hospital was launched in early 2020 as a sustainable solution to increasing demand for healthcare in Sydney⁷⁸. As evidence of safety, quality and cost-effectiveness emerges, these innovative models should be scaled up across NSW.

Innovative models of care that leverage technology offer a means to enhance patient-centricity without compromising safety and quality and should be adapted to the needs of local communities. It's important to note that virtual models of care such as telehealth should be an option for appropriate consultations, rather than a replacement of all face-to-face visits.

Value-based funding focused on improving patient outcomes

To achieve higher quality, equitable, patient-centred care, there is a need for funding models to shift from an activity-based approach to a more values-based approach that incentivises health services to deliver care based on performance and improvements in patient outcomes. Activity-based funding models are useful in the hospital setting but less effective for funding the prevention and management of chronic conditions such as cancer, where care requirements are multifaceted and often occur outside the acute setting⁷⁹. Innovative funding models should enable a multidisciplinary approach to patient-centred care by incentivising providers to delegate care to nurses and allied health, which will reduce the need for more costly specialist referrals and hospitalisations. Consideration should also be given to pooled funding arrangements between LHDs and Primary Health Networks to enable more integrated and coordinated approaches to chronic disease prevention and management.

As mentioned earlier in this submission, the routine collection and reporting of Patient Reported Outcomes Measures (PROMs) is key to informing the planning, delivery and evaluation of services and ensuring they deliver value and address the outcomes that matter most to patients. Using PROMs to plan and deliver value-based care models can also reduce system wastage and overservicing by ensuring care is delivered in the areas of greatest need.

NSW is already leading the way to values-based healthcare with its Leading Better Value Care program, established by the NSW Ministry of Health in 2012⁸⁰. The program includes the implementation of innovative models of care across a range of chronic conditions, including cancer.

The Direct Access Colonoscopy Service (DACS) has been implemented under the Leading Better Value Care program. DACS is an innovative nurse-led clinic that fast tracks people with a positive iFOBT, who meet set clinical criteria, through to colonoscopy, thus avoiding the wait time to see a gastroenterologist. Evaluation of a DACS in Newcastle has shown a reduction in colonoscopy wait times and an increased proportion of patients undergoing colonoscopy in a timely manner compared to a normal colonoscopy service^{81, 82}. DACS has also been shown to deliver significant cost savings, for both patients and the health system^{81, 82}.

Conclusion

Cancer outcomes have improved greatly in NSW. This is thanks to the dedication and hard work of our healthcare professionals who strive to deliver high-quality health care to the people of NSW every day. However, it is evident that there are several cracks in our system. Unless serious action is taken by the NSW Government to fix these cracks through much needed reform, our future healthcare system could look very different from what we see today.

Without government action, health inequities will continue to widen, and the increasing burden from preventable disease will lead to poorer care quality and disease outcomes as the system struggles to keep up with the increasing demand. Our recommendations not only provide the solutions to enable higher quality, more equitable and accessible cancer care, but can also be applied to the prevention and management of a range of chronic conditions to improve patient outcomes and deliver better value for the healthcare system.

Appendix

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- Ms Carolyn Heise, Registered Nurse, Cancer Council NSW Board member
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- Associate Professor Joel Rhee, General Practitioner, Cancer Council NSW Health Services Advisory Group member
- Cancer Nurses Society of Australia
- Cancer Voices NSW

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