



Special Commission of Inquiry into Healthcare Funding

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Submission for Special Commission of Inquiry into Healthcare Funding

Cancer Institute NSW

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Executive Summary

The Cancer Institute NSW welcomes the opportunity to submit its response to the Special Commission of Inquiry into healthcare funding in NSW. The Cancer Institute is eager to underscore its value across multiple tiers of the NSW Health system and express its dedication to enhancing healthcare sustainability. This submission sheds light on the Cancer Institute's vital role and presents four recommendations.

The Cancer Institute NSW: A dedicated cancer control agency

The Cancer Institute NSW, established under the Cancer Institute (NSW) Act 2003, plays a pivotal role in cancer control in the state. Its primary objectives encompass increasing the survival rate of cancer patients, reducing cancer incidence, improving the quality of life for individuals living with cancer and their caregivers, and serving as an authoritative source of expertise on cancer control for various stakeholders, including government, health service providers, medical researchers and the general community.

The uniqueness of the Cancer Institute NSW

NSW has been at the forefront of recognising the unique challenges posed by cancer and has established a dedicated agency for cancer control. This forward-thinking model has earned the admiration of other jurisdictions, and research shows that jurisdictions with a dedicated cancer control model have better outcomes for their citizens. The Cancer Institute, as a central and specialist agency, operates in recognition of the complexity and exceptional burden of cancer on individuals and the health system. Its governance structure allows it to transcend boundaries, working with experts and consumers to ensure equitable access to timely, patient-centered care. Legislative objectives and principles set in the Cancer Institute (NSW) Act 2003 remain highly relevant, echoing the themes outlined in the Inquiry's terms of reference.

The Cancer Institute NSW is the lynchpin in the broader complex cancer ecosystem, facilitating collaboration among health, research, not-for-profit, and community partners. Its role is to coordinate statewide programs benefiting those affected by cancer, ensure high-quality, evidence-based, equitable care, and implement preventive initiatives to reduce cancer burden on individuals and the healthcare system.

Efficient budget management and focused funding allocation

The Cancer Institute efficiently manages its budget, with over 87 per cent directed towards critical health initiatives. A rigorous funding model ensures most funds go directly to frontline care, community service and cancer research. Despite increasing demand for cancer services, the Cancer Institute has maintained consistent delivery with only a marginal 0.5 per cent annual budget increase over the last five years, emphasising sustainable budget management.

Leadership in prevention and early detection

The Cancer Institute NSW is dedicated to driving prevention, early detection and coordination in cancer control. These initiatives lead to improved patient care and have far-reaching implications for healthcare sustainability and long-term cost reduction. The Cancer Institute's comprehensive, evidence-based approach to prevention and screening is a shining example of leadership in public health.

Innovation in data and AI

The Cancer Institute's innovative programs, such as eviQ, eviQ Education and the Reporting for Better Cancer Outcomes program, combined with its leadership in data and artificial intelligence, exemplify the power of using data for healthcare improvement. By empowering healthcare districts, advancing clinical protocols, and fostering research excellence, the Cancer Institute continues to profoundly impact cancer care, serving as a model for healthcare transformation, innovation and patient outcomes.

Enabling research to improve cancer outcomes

The Cancer Institute delivers on its legislative remit to conduct, sponsor or support cancer-related research through a central focus in the NSW Cancer Plan 2022-2027. This requires robust partnerships with clinician-researchers, universities, medical research institutes, NGOs and industry. Cancer research is critical in enhancing patient care and the healthcare system, attracting substantial state, national, philanthropic and private sector funding. Over the years, NSW's strategic approach has significantly increased research funding and yielded remarkable economic returns. The Cancer Institute has facilitated numerous research grants, clinical trials, and translational efforts, positively impacting cancer care and producing many noteworthy outcomes.

Centralised education and accreditation for cancer clinicians.

The Cancer Institute NSW leads an innovative, centralised and sustainable model of education and accreditation for cancer clinicians, taking significant pressure off frontline clinicians. Its expertise and collaborative efforts with partners across the healthcare system guide healthcare professionals and ensure optimal patient outcomes.

Supported by the evidence in the submission, the Cancer Institute NSW makes the following four recommendations to the Inquiry:

- **Recommendation 1 - Sustain and strengthen the governance framework**

The Cancer Institute continues to operate under its existing governance framework, ensuring its continued success in leading and coordinating cancer control initiatives in NSW.

- **Recommendation 2 - Expand cancer prevention initiatives**

The Cancer Institute be supported to intensify its efforts in delivering evidence-based prevention programs to reduce cancer risk factors and reduce the incidence of preventable cancers. These programs should focus on educating the public about risk behaviours and the benefits of early cancer detection through screening programs.

- **Recommendation 3 - Invest in data, research and innovation**

The Cancer Institute continues to expand its commitment to harnessing data, advancing digital and AI capabilities, and supporting innovation and research to enhance patient outcomes. By accelerating access to novel therapies through clinical trials and fostering innovation, the Cancer Institute can continue positioning NSW as a national and international leader in cancer to benefit its population.

- **Recommendation 4 - Maintain focus on equity and patient-centred care**

The Cancer Institute upholds its commitment to providing equitable, evidence-based and patient-centred care. To achieve this, it should continue engaging with diverse communities, tailoring its services to meet their unique needs and priorities. Ensuring the patient's voice is central to decision-making will also improve care.

In conclusion, the Cancer Institute NSW welcomes its ongoing contribution to a stronger, sustainable healthcare system and serving the NSW population. Given the burden of cancer on individuals and the health system, a continued robust, dedicated cancer control system is vital for NSW.

Response to Terms of Reference A:

The growing complexity and urgency of cancer, along with the system and societal and economic impact, underscores the need for a dedicated cancer control agency to ensure equitable care, optimise resources and enhance the health and well-being of NSW residents.

The Cancer Institute's work is guided by the legislative objectives, principles and functions set by the Cancer Institute (NSW) ACT 2003. These remain relevant and fit for purpose now and into the future and echo many of the themes in the Inquiry's terms of reference.

Governance and Functions of the Cancer Institute NSW

The Cancer Institute NSW was Australia's first dedicated cancer control agency. It was established under the [Cancer Institute \(NSW\) Act 2003](#) in response to recognition of the devastating impact cancer has on society. Research shows that jurisdictions with this dedicated cancer control model have better survival¹.

In 2013, the Cancer Institute NSW became a pillar of the NSW Ministry of Health. The Institute is governed under the Cancer Institute (NSW) Act 2003 (the Act), the Health Services Act 1997 and the NSW Public Sector Governance and Accountability Framework.

“Cancer control” is defined in the Act to include any cancer-related activity in the field of human health, such as research, the practical application of research, innovation, treatment and care (including palliative care, supportive care and complementary health therapies), prevention, screening, diagnosis, provision of information, training and education. As part of the Act, the Chief Cancer Officer is legislated to provide state-wide stewardship of all cancer control initiatives in NSW, including that of a trusted expert and public voice for cancer control in NSW.

The legislation clearly defines the objectives (section 5), principles (section 6) and functions (section 12) by which the Cancer Institute NSW operates.

The objectives include acting as a source of expertise on cancer control for government, health service providers, medical researchers and the general community, increasing cancer survival rates, reducing cancer incidence and enhancing the quality of life for people affected by cancer and their caregivers.

The guiding principles underscore the need for effective collaboration between public private sectors and the community for cancer control; efficient resource allocation to maximise benefits; a patient-centred, evidence-based, equitable approach to cancer care; and timely, high-quality, coordinated, and accessible care for all cancer patients.

¹ Nolte, E., Morris, M., Landon, S., McKee, M., Seguin, M., Butler, J., & Lawler, M. (2022). Exploring the link between cancer policies and cancer survival: a comparison of International Cancer Benchmarking Partnership countries. *The Lancet. Oncology*, 23(11), e502–e514. [https://doi.org/10.1016/S1470-2045\(22\)00450-8](https://doi.org/10.1016/S1470-2045(22)00450-8)

The functions of the Cancer Institute NSW include research, collaboration, public awareness and health prevention and promotion, program evaluation and information dissemination for the public's benefit of cancer control.

“There are many different types of cancer and every one of them is a very complex problem requiring extensive work on prevention, early detection, diagnosis and treatment. NSW has outstanding expertise across all of these disciplines and has many organisations including hospitals, universities and medical research institutes involved in research and clinical care that are focused on different pieces of this difficult puzzle.

“The Cancer Institute NSW plays an indispensable role in coordinating all of these efforts, providing overall strategic planning, monitoring progress towards the goals of steadily improving outcomes for patients in NSW, and using funding judiciously to remove financial barriers to collaboration and thus ensure that the whole endeavour is much greater than the sum of its parts.

“What the Cancer Institute NSW has achieved is the envy of many jurisdictions in Australia and beyond, but there is so much more that needs to be done. The investments that have been made so far have built a very strong foundation on which further progress can be made, and the technologies that are available now are extraordinary.

“If NSW stays the course, it can be expected with a high level of confidence that the next decade will see major advances in all aspects of cancer control.”

**Professor Roger Redell AO,
Executive Director, Children's Medical Research Institute
Lorimer Dods Professor, University of Sydney**

The challenge and complexity of cancer is unique, underscoring the need for a strategic approach to cancer control.

When it comes to healthcare, few challenges rival the complexity and urgency of cancer. Cancer is not a single disease but rather a constellation of hundreds of types of cancer, and no single cancer type will affect two people in the same way. Cancer is a group of diseases on the rise, one that affects all ages and cuts through all communities, causing physical, psychological and financial suffering at scale. While all people of NSW are affected by cancer, not all people are affected equally, with disparities in access and outcomes for many population groups.

Cancer is recognised as one of the most significant 21st-century global health challenges². Across Australia, cancer diagnoses have increased by 88 per cent over the last 20 years³,

² The global challenge of cancer. (2020). *Nature cancer*, 1(1), 1–2. <https://doi.org/10.1038/s43018-019-0023-9>.

³ Australian Institute of Health and Welfare. (2023). *Cancer data in Australia*. Retrieved from <https://www.aihw.gov.au/reports/cancer/cancer-data-in-australia>.

with all cancers combined as the leading cause of death in Australia⁴ and globally⁵. With an aging population, projections see a further increase of 21 per cent by 2033³.

In 2023, it is expected that, on average, someone in NSW is diagnosed with cancer every 10 minutes, and every half an hour, a person dies of the disease. This equates to an estimated 53,229 diagnoses and 15,825 expected deaths from cancer in 2023⁶.

Cancer causes the most significant burden of disease in Australia, ahead of musculoskeletal, cardiovascular and mental health disorders. Around one in every five years of healthy life lost in Australia is lost to cancer⁷.

Cancer ranks among the top disease groups in terms of health system expenditure in Australia, with over 12.08 billion dollars spent in 2019/2020⁸, with costs growing yearly.

In addition to direct health care costs, significant economic costs to individuals and society include out-of-pocket care costs, lost productivity, income and tax revenue, disability and premature mortality, and caregiver costs^{5,8}.

Cancer care is also complex because it straddles primary and aged care, local health districts, private facilities and community services. Across the continuum from prevention, screening, and early detection to treatment, support and end-of-life care or survivorship, many systems, organisations and people have a role.

By fostering inter- and intra-health collaborations, driving innovation and thought leadership, and embracing the power of evidence-based practices, the Cancer Institute encourages dialogue, research, and meaningful advancements that continue to influence the future of cancer control across NSW and its many and varied settings.

As the dedicated state cancer control agency, the Cancer Institute is leading a united and coordinated approach to reduce the burden of cancer for all people in NSW. Helping reduce cancer's immediate and long-lasting emotional, psychosocial and financial impacts on individuals, families, and communities is at the heart of the Cancer Institute's work.

Partnering extensively with the health system, clinicians, consumers, non-government organisations, community groups and researchers, the Cancer Institute puts consumers' and patients' needs at the front and centre of decision-making. The Cancer Institute aims to take the burden off individual cancer services and frontline clinicians where possible.

⁴ Australian Bureau of Statistics. (2022). *Causes of Death, Australia*. ABS. <https://www.abs.gov.au/statistics/health/causes-death/causes-death-australia/latest-release>.

⁵ WHO report on cancer: *setting priorities, investing wisely and providing care for all*. (n.d.). [Www.who.int. https://www.who.int/publications/i/item/9789240001299](https://www.who.int/publications/i/item/9789240001299).

⁶ Cancer Institute NSW: Cancer incidence and mortality projections, based on NSW cancer incidence and mortality data set, 2018. Population data are sourced from SAPHaRI (Centre for Epidemiology and Evidence, NSW Ministry of Health) and projected population data are sourced from NSW Department of Planning and Environment.

⁷ Australian Burden of Disease Study: Impact and causes of illness and death in Australia 2018. Canberra: AIHW.

⁸ Australian Institute of Health and Welfare. (2022). Disease expenditure in Australia 2019–20. Retrieved from <https://www.aihw.gov.au/reports/health-welfare-expenditure/disease-expenditure-in-australia-2019-20>

Efficient budget management and focused funding allocation

Funding dedicated to the operating costs of the Cancer Institute is managed under a lean model, comprising just over 13 per cent of its overall annual budget – with the remaining 87 per cent allocated to health initiatives for cancer.

Utilising its understanding and expertise for what is needed to drive the critical outcomes of the Cancer Plan, the Cancer Institute provides a structured administrative operating model for the distribution of funds through initiatives and programs. This structured funding allocation model sees most funds allocated to the Cancer Institute delivered directly into patient, research or community services. Examples include Breastscreen NSW, coordinated funding for cancer staff across local health districts, local site clinical trial infrastructure, research grants, community grants, and public behaviour change campaigns and health promotion.

This coordinated funding model is integral to directing the proper funding to where it is most needed across the cancer control continuum – towards the identified gaps and areas where it will have the highest health impacts across communities. In this regard, the Cancer Institute takes a strategic view towards addressing opportunities for further increasing sustainable outcomes across the health sector, promoting a more substantial return on investment through the appropriate allocation of funding for cancer outcomes, and reducing disparities.

While cancer expenditure and demand across the health system continue to escalate, the Cancer Institute has demonstrated consistent and sustained delivery with only a marginal growth in its annual funding allocation. Over the last five years, the Cancer Institute delivered its strategic priorities with a minimal average annual increase of only 0.5 per cent to its operating budget across this period. The Cancer Institute consistently manages its operating expenditure sustainably – it has delivered with a minimal favourable variance reported against the annual budget received over the past five years.

Response to Terms of Reference B:

The Cancer Institute's governance and accountability structure allows for a dedicated yet broad cancer control remit. This gives the Cancer Institute a unique ability to cross boundaries, working in partnership with experts and consumers at every point in the cancer ecosystem. It takes the lead in developing a coordinated, cohesive and collaborative approach to ensuring equitable access to timely, high-quality, patient-centred care to lessen the overwhelming burden of cancer on our communities, health system and economy.

The Cancer Institute's commitment to providing accessible information and fostering community partnerships not only empowers consumers but also exemplifies its role as a trusted, collaborative organisation, driving inclusive and responsive cancer control initiatives that cater to the diverse needs of NSW's communities.

Planning for success: balancing system and statewide goals, local and community cancer priorities

“Since 2003, NSW has been in the unique position of having a centralised body responsible for the delivery of cancer services to the people of NSW. Cancer Voices NSW has been involved with the Institute since it began including contributing to all five cancer plans.

“The current plan is testament to the power of the collective, reflecting the engagement of many individuals, organisations, services and agencies partnering and collaborating to develop and then deliver on this plan which has people affected by cancer, and equity always at the fore front. We are proud of our continuing involvement.”

Elisabeth Kochman
Chairperson, Cancer Voices NSW

The NSW Government has been widely espoused as forward-thinking in establishing the Cancer Institute NSW.

The Cancer Institute is responsible for leading and implementing the state-wide Cancer Plan, which serves as the foundation for a comprehensive strategy to enhance cancer outcomes and reduce the impact of cancer on individuals, communities, and the health care system. Now in its fifth iteration, the [NSW Cancer Plan \(2022-2027\)](#) continues to drive the state's vision for cancer control, building upon past achievements. A vital aspect of this plan is active engagement with local communities, with more than 800 representatives contributing to its development.

The Cancer Institute serves as the plan's custodian and is responsible for the governance and coordination of efforts of over 80 partner organisations working to execute the NSW

Cancer Plan (2022-2027). This partnership-based approach enhances efficiency, minimises duplication and eliminates wastage while setting and achieving cancer control objectives. Continuous monitoring and reporting ensure the plan's effectiveness and adaptability.

Furthermore, the Cancer Institute leads numerous national program groups related to cancer screening and cancer-related programs, facilitating the exchange of best practices and policy reform within the NSW cancer sector and allowing the state to influence the national policy agenda for cancer control. The Australian Government is currently finalising its inaugural national Cancer Plan, aiming to replicate many of the strengths of the NSW Cancer Plan, including robust governance, a collaborative model, data-informed and with a focus on equity and reducing disparities in cancer outcomes.

Achieving impact through equity and patient-centredness

Cancer impacts every resident of NSW, yet the burden is not evenly shared, leading to significant disparities in access and outcomes among various population groups.

The Cancer Institute is recognised for its leadership in prioritising equity-focused strategies in cancer control, aiming to maximise health, social and systemic benefits for those facing the greatest need. This is a primary focus of the NSW Cancer Plan 2022-2027.

Aboriginal communities bear a disproportionate cancer burden. Aboriginal people in NSW are two to three times more likely to be diagnosed with cancer, face higher mortality from cancer than non-Aboriginal people and tend to get cancers at a younger age. Nationally, life expectancy for Aboriginal people remains around eight years less than for other Australians, and cancer is the leading cause of death⁹. As a priority, the Cancer Institute will partner with the Aboriginal Health and Medical Research Council (AH&MRC) to deliver the first NSW Aboriginal Cancer Strategy in 2024.

“The Aboriginal Health and Medical Research Council (AHMRC) are thrilled to partner with the Cancer Institute NSW to create a dedicated NSW Aboriginal Cancer Strategy. Addressing the disproportionate cancer burden in Aboriginal communities is pivotal. This partnership signifies the importance of our efforts. We're committed to making a real impact in our communities' fight against cancer.

“Our close collaboration with ACCHO and NSW Health ensures comprehensive, culturally sensitive healthcare solutions for Aboriginal communities, enhancing health outcomes and resilience.”

***Shana Quayle,
CEO, Aboriginal Health and Medical Research Council***

⁹ AIHW, Cancer Australia. (2013). Cancer in Aboriginal and Torres Strait Islander peoples of Australia: an overview. Canberra: AIHW

In addition to Aboriginal communities, the NSW Cancer Plan 2022-2027 highlights other communities that are disproportionately affected by cancer.

Regional and remote communities also face disproportionate cancer burden. When compared with major cities, cancer incidence rates are significantly higher in regional and remote areas of NSW, with cancer mortality increasing with remoteness¹⁰.

Socioeconomic status also impacts cancer risk and outcomes. In NSW, cancer incidence rates are significantly higher in the two most disadvantaged socioeconomic quintiles. Like remoteness, cancer mortality increases steadily with socioeconomic disadvantage¹⁰.

Cancer incidence and mortality also increase significantly with age¹⁰, making older people a focus of the plan. Other communities prioritised under the NSW Cancer Plan include culturally and linguistically diverse (CALD) communities, sexuality and gender diverse people, intersex people, people with a mental health condition and people engaged with the justice system.

To date, extensive partnership and collaboration has delivered several key equity achievements, including:

- implementation of a dedicated NSW Health Care Interpreting Service program to upskill interpreters' capacity to translate complex information on cancer clinical trials – to help improve clinical trial participation rates in multicultural communities
- tailored eLearning on inclusive practice for BreastScreen NSW, NSW Quitline and Cancer Institute NSW staff, which was adapted for cancer service workers across Australia and is available for free through the Institute's eviQ Education program. In the 2022/23 financial year, close to 1,000 people working in cancer across NSW and beyond have completed this tailored eLearning to help improve the experience of LGBTQI+ people with cancer
- development of targeted breast, cervical and bowel cancer screening and smoking cessation campaigns for Aboriginal, CALD and LGBTQI+ communities – to ensure communities are educated and supported to access screening programs in a way that best aligns with their beliefs, culture and personal priorities
- annual multicultural grant support to community groups – to help reach multicultural communities and improve screening and survival rates in this at-risk population.

¹⁰ Cancer Institute NSW: Data sourced from the NSW Cancer Registry. Population data are sourced from SAPHaRI (Centre for Epidemiology and Evidence, NSW Ministry of Health) and the Australian Bureau of Statistics (ABS).

“The focus, expertise and cross sectoral engagement the Cancer Institute NSW brings to its work is influencing outcomes. They are one of very few agencies that work across such a wide spectrum of influence – and it is their direct engagement with communities on the basis of equity that is incredibly impressive”.

Karen Price
Deputy CEO, ACON

Leading the way in delivering patient-centred care

Patient-centeredness is a foundational principle within the Institute’s safety and quality healthcare ethos. It is a central tenet of the Institute-led NSW Cancer Plan 2022-2027, emphasising a comprehensive, person-centred approach to cancer control. This approach spans prevention, screening, treatment, care and support services, all informed by individual experiences and preferences. It empowers individuals, families and caregivers to be active participants in their care, promotes culturally sensitive and accessible communication, enhances care coordination, and acknowledges the vital role of family and community in overall well-being. It seeks to ensure positive experiences and outcomes are tailored to each person.

The Institute’s distinct position in actively engaging and collaborating with all partners throughout the cancer ecosystem allows it to take a person-centred approach, seeing the end-to-end experience of the people served by NSW cancer services through a lens of deep cancer expertise and national and international expertise.

Patient-centred care is the cornerstone of robust and world-class health care. The collaborative efforts of the Cancer Institute NSW, working together with staff on the frontline of care, are helping deliver consistent, compassionate and supportive health care to the people of NSW.

NSW cancer patients have highly rated the cancer services available in NSW through the Bureau of Health Information’s annual Outpatient Cancer Clinics Survey. The 2023 results have again shown almost all (98 per cent) surveyed cancer patients rated their overall care as ‘very good’ or ‘good’. Nearly all (96 per cent) rated the staff who treated them as kind and caring towards them, and 97 per cent believed they were always treated with respect and dignity. Results were equally positive for patients in rural and urban facilities.

Continuous learning from patient experience

The Institute enhances patient-centred cancer care by leading a statewide program that collects real-time electronic feedback on patients’ reported experiences (PREMS) and outcomes (PROMS). No other state in Australia has achieved this coordination and scale across cancer services. In collaboration with 24 participating cancer centres across 10 LHDs, the Cancer Institute has provided over 15,700 opportunities for patient-reported measures to inform cancer care directly.

Surveys are made available in eight community languages to better support populations facing disparities and provide language-specific support. An Aboriginal well-being measure designed for and by Aboriginal people, “What Matters 2 Adults” (WMSA), is also being piloted, which accommodates the language, customs and culture-specific needs of Aboriginal people with cancer.

The Cancer Institute’s pioneering statewide point-of-care Patient Reported Measures Program, collecting real-time patient care needs and feedback and promoting inclusivity, sets a high standard for patient-centred care, ensuring equitable support for all communities.

Providing information to consumers and elevating the community voice

The Cancer Institute is a source of expertise for consumers and clinicians, with our suite of websites garnering 18,548,752 views from 3,124,408 active users over the past 12 months. The Cancer Institute has earned a reputation as a trusted and collaborative organisation. Its strong partnerships with community members and community-led organisations are pivotal in designing and delivering equitable, culturally sensitive, and responsive cancer control initiatives that align with the needs and priorities of the people of NSW. This collaborative approach entails actively engaging and closely working with a broad spectrum of stakeholders, which includes but is not limited to the following:

- Aboriginal Health & Medical Research Council (AH&MRC)
- Aboriginal Community Controlled Health Services, Aboriginal Health Workers, Aboriginal Community Controlled Organisations and Aboriginal community members
- patient advocacy groups such as Cancer Voices and people with lived experience of cancer.
- NSW Multicultural Health Communications Service, multicultural community groups, such as Pink Sari, CoAsIt and Can Revive, multicultural health teams in local health districts, multicultural community members, and refugee health services.
- ACON and gender and sexuality diverse community members, Intersex Rights Australia
- Justice Health NSW
- cancer advocacy groups, including Cancer Council NSW, Breast Cancer Network Australia and Lung Foundation Australia.

Response to Terms of Reference D:

The Cancer Institute's dedication to driving prevention, early detection, and coordination in cancer control improves patient outcomes and has far-reaching implications for the health system's sustainability and long-term cost reduction. The comprehensive, evidence-based approach to prevention and screening is an example of national leadership in public health.

Driving health system sustainability through prevention

Promoting health system sustainability through prevention initiatives is the most cost-effective strategy for controlling cancer, endorsed by the World Health Organization. [The National Preventative Health Strategy 2021-2030](#) highlights the need to enhance investment in prevention to strike a better balance treatment-prevention.

The Cancer Institute NSW leads in evidence-based prevention programs, addressing risk factors like tobacco and UV exposure to reduce the health system's burden.

Preventable Disease Impact:

- One in three cancer cases and deaths can be prevented through healthy living, such as drinking less alcohol, quitting smoking, protecting the skin from ultraviolet (UV) radiation and eating healthily.
- In NSW, around 16,000 cancer cases and 5,000 deaths yearly are preventable.
- 27 per cent of cancer-related health expenditure is due to preventable factors¹¹.
- Australia spends less than 2 per cent on prevention, far less than other comparable countries¹².

To maximise impact, the Cancer Institute NSW targets priority risk factors, demonstrating significant gains in improving the health of NSW residents and reducing system impact.

Tobacco

- Smoking is the most significant risk factor for lung cancer and the leading preventable cause of ill health and death in Australia.
- Smoking costs are estimated at \$136.9 billion, contributing to 22 per cent of the cancer burden in Australia⁷.
- The Cancer Institute's efforts have contributed reduced smoking rates from 18.4 per cent in 2003 to 8.2 per cent in 2020¹³.

¹¹ Australian Institute of Health and Welfare. (2021). Health system expenditure on cancer and other neoplasms in Australia, 2015–16. Canberra: AIHW.

¹² Calder, R.V., Dunkin, R., Rochford, C., & Nichols, T. (2019). Australian health services: too complex to navigate: a review of the national reviews of Australia's health service arrangements.

¹³ NSW Population Health Survey (SAPHaRI). Centre for Epidemiology and Evidence, NSW Ministry of Health.

- Efforts have concentrated on those communities with high smoking rates, addressing disparities.
- Despite an 11 percentage-point drop in the Aboriginal smoking rate in NSW over the past twenty years, almost 30 per cent of Aboriginal people in NSW still smoke, with nearly 22 per cent smoking daily¹³.
- The Cancer Institute collaborates with the Ministry of Health and LHDs to deliver the priorities of the NSW Tobacco Strategy.

Vaping

- Vaping is a growing public health concern.
- It poses significant health risks and may lead to nicotine addiction.
- The Cancer Institute collaborates with the Ministry, taking accountability for research, behaviour change campaigns, and cessation tools.

UV Exposure

- Australia has the highest melanoma rate globally due to UV exposure.
- Melanoma is a common cancer in younger people.
- Around 8 per cent of cancer health expenditure is linked to UV exposure.
- Prevention is most effective when initiated early in life.
- More efforts are needed to reduce melanoma incidence.

In summary, prioritising prevention is essential for long-term health system sustainability and reducing the burden of preventable disease.

Investing in prevention to reduce health system costs

The Cancer Institute has built a coordinated, collaborative, evidence-based program to tackle cancer prevention, working without boundaries across primary and secondary non-government organisations and cross-governmental partners and stakeholders. This ensures that impactful initiatives are targeted to populations of the highest need and are measured and evaluated to ensure effectiveness.

The benefit of prevention extends beyond the reduction of cancer incidence and reduced pressure on the health system; but increases workforce participation and productivity and improves the health of future generations.

The impact of prevention initiatives and investment is not immediate, and this year's investment will take time to translate into demonstrably improved cancer outcomes, with benefits realised over the longer term. Delays in addressing or deprioritising public health issues such as smoking, alcohol consumption, obesity and lack of physical activity compound the burgeoning burden of disease on future generations.

Success in prevention does not occur organically; it requires sustained long-term commitment of the health system, broader government, non-government and community sectors.

The Cancer Institute has a crucial role in leadership, collaboration and coordination of preventive cancer control measures.

World-leading public health and behaviour change campaigns

The Cancer Institute excels at best-practice social marketing campaigns to address preventable risk factors. These campaigns provide a return on investment of up to \$33.20 for every dollar invested due to a combination of health system savings and the economic benefit of keeping people well.

Distinct from traditional advertising, social marketing is an approach to develop activities to change people's behaviour to benefit individuals and society. The Cancer Institute NSW's expertise in social marketing is well recognised, with its campaigns being licensed across several Australian states and by many international jurisdictions.

Supporting people to make positive change

The Cancer Institute offers two cessation services: I Can Quit and Quitline. I Can Quit provides online resources, including a peer forum, for quitting smoking and vaping. Quitline offers phone counselling for individuals who smoke or vape, as well as information for caregivers and healthcare providers.

These services are available in English, Arabic, Cantonese, Mandarin and Vietnamese and First Nations counsellors deliver a specific Aboriginal service. The program has received positive evaluations, with continued quality improvements, such as enhanced features, tailored content and improved personalisation to enhance the client experience and engagement.

Working in partnership to address risk factors

Embedding smoking cessation in health services: The Cancer Institute developed the Smoking Cessation Framework for NSW Health Services and has worked across the health system on implementation. Key system-enabling activities have included improving the electronic medical record systems to facilitate delivery and documentation of brief smoking and vaping cessation interventions, e-referral to Quit services, developing smoking and vaping cessation training competency standards and delivering a training plan to design and build smoking and vaping cessation training for health professionals.

Partnering across government: The Cancer Institute is responsible for developing and stewarding the NSW Skin Cancer Prevention Strategy, with the third Strategy due for release in November 2023. Through the Strategy, the Cancer Institute collaborates across government, private sector and community to ensure people in NSW are protected from the harms of UV. This includes working with:

- local and regional councils to drive strategic planning and policy development. This ensures new and existing built environments incorporate sun and environmentally safe designs and that an appropriate level of shade is incorporated into community settings and landscapes
- public, private and independent education sectors to ensure young people are supported with skin cancer prevention education and protection from UV while at school

- collaborating with the Cancer Council NSW and the Australian Institute of Landscape Architecture (AILA) to increase shade provisions in future planning
- other government departments, such as Safe Work NSW and the Office of Sport, protect people where they are at particular risk through improved policies and adequate shade provisions.

The importance of primary care

The primary care sector is vital to keeping communities healthy. They help support people to access life-saving screening programs and provide care and support to people living with or impacted by cancer. Working in partnership with the primary care sector is vital, which is why the Institute developed the NSW Primary Health Care Cancer Framework in collaboration with primary care partners. The Framework aims to enhance integration between the primary and secondary sectors to improve the care and experience of people with cancer by enabling a seamless pathway through improving systems and communication. The Institute has a unique role in the ability to view the whole cancer pathway and facilitate support engagement and partnerships, undertake and provide data evaluation and research, prompt equitable and accessible services where needed, and assist with training, educational resources and provision information.

The Institute's Reporting for Better Cancer Outcomes (RBCO) program is a crucial engagement tool with Primary care, with annual reports provided to all Primary Health Networks (PHNs) and the Aboriginal Health and Medical Research Council (AH&MRC), generating significant discussion and action in improving cancer-related activity across the state. The RBCO report provides details on each region's cancer profile and burden and enables PHNs to partner with LHDs and other relevant agencies to address areas of variation.

Increasing early detection to reduce costs

The Cancer Institute plays a pivotal role in promoting early cancer detection and effective screening programs for various cancers, improving outcomes for people of NSW and in reducing the health system burden. Efforts include driving participation in bowel, bowel, and cervical programs for various cancers and supporting innovative models for colonoscopy access.

The Cancer Institute also promotes cervical screening among vulnerable populations. It will have a crucial role in implementing the upcoming National Lung Cancer Screening Program, ensuring efficient and coordinated delivery and support for participants throughout their screening and treatment pathways.

The earlier detection of cancer has significant benefits not only on patients' outcomes and experience but also on health budgets and the workforce.

Finding certain cancers early gives people the best chance of long-term survival. The early detection of cancers can also lead to less invasive treatment and less chance of long-term health complications.

Cancer screening is the best way to detect breast, bowel and cervical cancers in their earliest stages when they are most treatable. With breast cancer, for example, which affects one in seven women in NSW, if detected in its earliest stages, a woman's five-year breast cancer survival rate is 98 per cent. This drops to 43.9 per cent if detected later, when it has spread to other organs.

The more people who participate in national cancer screening programs for breast, bowel and cervical cancer, the greater the benefit to the community, the system and the economy more broadly.

The Cancer Institute drives participation in cancer screening across the three national screening programs for bowel, breast and cervical cancers:

- developing and implementing public health behaviour-change campaigns for screening
- supporting health care professionals by providing accurate, up-to-date information, data and resources
- partnering with the community to develop and deliver targeted education and engagement programs to address barriers to screening for priority populations, such as Aboriginal, CALD and sexuality and gender-diverse and Intersex communities.

In addition, the Cancer Institute delivers several state-specific services to support the national programs and their effectiveness in the NSW health system.

BreastScreen NSW

The Cancer Institute is responsible for the program management of the national breast screen program in NSW (BreastScreen NSW). The service is free to participants and delivered across the state in 51 fixed locations and over 180 mobile screening sites.

The Cancer Institute is responsible for the program's funding (clinical and capital), governance, establishing and monitoring operating procedures, quality improvement and innovation, provision of real-time operational and clinical data, and facilitation of the national accreditation process of the service. It also represents NSW on the National Program Management Committee and is currently the chair of this group.

The Cancer Institute NSW is responsible for the governance and management of the single standardised clinical and administrative record (BreastScreen Information System (BIS)), which contains records for over 2.1 million women. This system provides immediate real-time data for day-to-day operational management by services, provides historical and forecast data to plan service delivery, and delivers insights into screening behaviours of the population - enabling bespoke targeting of service delivery, public health messaging and community engagement activity.

In 2022/23, BreastScreen NSW delivered the **highest screening numbers in the program's history**, with nearly 372,000 eligible women having a breast screen.

Bowel Cancer Screening

The bowel screening test detects microscopic traces of blood, which indicate the risk of cancer and signal a need for a colonoscopy to confirm or rule out cancer. While the program is managed nationally, follow-up colonoscopies are a state responsibility.

The Cancer Institute delivers the Patient Follow-up Function for the National Bowel Cancer Screening Program in NSW. This expert team follows all people in NSW who return a positive screening test result to ensure they access a follow-up diagnostic test, typically a colonoscopy, to determine if they have bowel cancer. Waiting times for public colonoscopies are lengthy, and access to private colonoscopy services requires out-of-pocket costs, which creates inequity of access and delayed time to diagnosis, both of which can lead to a more advanced cancer diagnosis, more complex treatment options and poorer outcomes.

In response to these issues, the Cancer Institute initiated a quality improvement service model change, working in collaboration with the local health districts and other pillar agencies, to introduce the 'Direct Access to Colonoscopy' (DAC) model of care. This has been delivered under the NSW Health Leading Better Value Care (LBVC) Program. **The DAC model removes unnecessary barriers to expediting people with positive screening results to colonoscopy.** The new model improves referral practices from primary care, introduces nurse triage (increases the scope of practice for nurses), removes unnecessary specialist appointments (reduces cost and creates specialists' capacity for more complex work), and improves pre-op education (leading to better procedural outcomes).

Since the LBVC initiative commenced, 19 DAC clinics have been established across the state, facilitating rapid access to colonoscopy. Wait times from a positive screening test to referral and onto colonoscopy have been reduced in regions where DAC has been implemented.

The Cancer Institute, through data analysis of the clinics, has also been able to establish variation in the number of same-day colonoscopy/gastroscopy procedures performed, suggesting unwarranted clinical overservicing and waste. This data has been provided to local health districts for review and action.

State-wide clinical guidelines to support this model of care have been developed through the formation of clinical advisory groups and clinical expertise facilitated by the Cancer Institute.

The Commonwealth has recognised this model as an innovative model to improve access to diagnostic tests and ultimately improve the outcome of screening. NSW has been asked to share the model and findings nationally.

Cervical Screening

Cervical cancer is highly preventable, with incidence and mortality rates halving since the introduction of the screening program in 1991. A new screening test, introduced in 2017, can detect pre-cancerous changes and provides the opportunity for treatment before cervical cancer develops.

Thanks to the success of the program, Australia is on track to eliminate cervical cancer by the mid 2030's. As with other screening programs, the benefits of routine screening include earlier diagnosis and improved survival outcomes. Just over 60 per cent of women and people with a cervix in NSW, aged 25 to 74, have had their five-yearly cervical screen¹⁴.

Historically, cervical screening has been delivered in primary care by GPs and practice nurses until July 2022, when self-collection (where an individual can collect their own sample under the supervision of a health professional) was introduced. Self-collection as an alternative option to the test is expected to increase participation in the screening program as it removes significant access barriers (shame, fear, embarrassment, pain and stigma) for several women and people with a cervix. Since its introduction, rates of self-collection have risen to 16 per cent in NSW, below the national rate of 20 per cent¹⁵.

The Cancer Institute has a crucial role in promoting the uptake of cervical screening and self-collection through training and provision of resources for health professionals and public health education. Understanding the demographics of under-screened populations through data linkage and analysis enables the Cancer Institute to target regions and populations with the lowest screening participation. This is predominantly achieved through close relationships with primary health networks, women's health services and non-government and community agencies. For example, women arriving in NSW through a migrant or refugee pathway are considered high risk due to low screening rates, lack of HPV vaccination and trauma-related histories. The Cancer Institute works directly with refugee centres to provide necessary education and resources to support this vulnerable population, highlighting the Cancer Institute's unique ability to cross boundaries and use data to identify at-risk populations.

The Cancer Institute regularly explores screening and prevention behaviours through formative research. The data indicates Aboriginal women in NSW are twice as likely to develop and nearly four times more likely to die from cervical cancer than non-Aboriginal women due to lower screening rates (around 31 per cent participation), later presentation and more advanced disease at diagnosis. Research undertaken by the Institute found that Aboriginal women showed limited awareness of the renewed cervical screening program and the role of cervical screening or self-collection in cervical cancer prevention (publication in development).

This research highlighted the need for targeted communications and engagement with Aboriginal women and educational and professional development opportunities for care providers. The Cancer Institute has been able to respond directly with a statewide response, with the development of a Community of Practice group involving primary care and local health district staff, the development of specific Aboriginal educational resources, training for Aboriginal health workers and women's health nurses, and quality improvement measures for primary health networks.

¹⁴ Australian Government Department of Health and Aged Care. (2021, December 7). National Preventive Health Strategy 2021–2030. Australian Government Department of Health and Aged Care.

<https://www.health.gov.au/resources/publications/national-preventive-health-strategy-2021-2030?language=en>

¹⁵ NSW Population Health Survey (SAPHaRI). Centre for Epidemiology and Evidence, NSW Ministry of Health.

Lung Cancer Screening

This year, the Australian Government announced the introduction of a National Lung Cancer Screening Program commencing July 2025. This is the first national cancer screening program to be introduced in nearly 20 years. The program aims to detect lung cancer early to increase the likelihood of successful treatment and improve lung cancer outcomes. This is the first organised screening program offered to individuals based on risk factors, smoking history and age. Screening will be delivered by a low-dose CT scan.

This new program is anticipated to significantly impact the demand for access to public radiology and respiratory and cancer services.

The Cancer Institute has a crucial role in leading NSW's successful implementation of the screening program, ensuring it is delivered in the most efficient and coordinated way and that eligible participants are identified and supported through the screening pathway onto treatment or back to surveillance as required.

The success of the program relies on identifying those who are at high risk of lung cancer, facilitating their access to screening services, and ensuring they proceed on the appropriate pathway for their personal health needs. Compared to a population-based program, a risk-based program has significant failure points where participants can 'fall through the cracks'. The Cancer Institute has a vital role in facilitating coordination and collaboration with service providers along the pathway, through primary care, private screening providers, secondary services (private and public) and back to primary care for surveillance, ensuring data is collected in the national register.

The Cancer Institute has a central function in communication and education for the eligible population and state-based providers of the program, working with key stakeholders such as Aboriginal and multicultural agencies to ensure the program is culturally appropriate and accessible, support for LHD's developing models of care to respond to the increasing demand on the workforce education to assess access issues, supporting access to screening, and that people successfully progress along the pathway and their screening and treatment outcomes are collected.

The Cancer Institute is strategically placed to coordinate the successful implementation of this program as it supports the whole cancer pathway across the NSW health system. The ability to draw together the expertise and apply influence from primary care, screening providers (public and private), community groups and non-government organisations, and diagnostic and treatment services allows the Cancer Institute to facilitate a coordinated, person-centred approach to introducing the lung cancer screening program. Experience in collecting, analysing and translating cancer data will enable the Cancer Institute to identify areas of high need, evaluate and monitor the program's success locally, and provide informative data to the national program.

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The Cancer Institute's innovative programs, such as eviQ, eviQ Education and the Reporting for Better Outcomes program, combined with leadership in data and artificial intelligence, demonstrate the power of government-held data for healthcare improvement. By empowering health districts, advancing clinical protocols and fostering research excellence, the Cancer Institute continues to profoundly impact cancer care, serving as a model for healthcare transformation, innovation and patient outcomes.

Harnessing data insights combined with clinical expertise to lead system-wide changes and reduce variation in cancer care

The Australian Productivity Commission advocates utilising government-held data for benchmarking purposes, and the Cancer Institute NSW innovatively achieves this through the [Reporting for Better Cancer Outcomes \(RBCO\) program](#). While data is a critical driver of healthcare innovation and quality improvement, its intrinsic value is unlocked when collected, analysed and acted upon. The RBCO comprehensive data and quality improvement program continues to demonstrate iterative improvements at scale and is the envy of other jurisdictions. The Agency of Clinical Innovation (ACI) plans to adopt and use the successful cancer model in other diseases.

As custodians of all cancer data in NSW, the Cancer Institute transforms local data into actionable insights by applying clinical best practices and shares these insights with all LHDs and PHNs through the RBCO program. Clinical evidence and indicators are informed by clinical advisory groups (CAGS) of multidisciplinary clinician experts across NSW. In the 2022/23 fiscal year, the Cancer Institute delivered 86 targeted reports to health districts and services, offering independent analysis of their cancer care performance relative to other centres, data they wouldn't otherwise have access to. Reports range across topics such as surgical outcomes, radiation, clinical trials, prevention and screening, aboriginal cancer, patient-reported measures, disease-specific pathways and the impact of COVID-19 on cancer.

By facilitating the analysis and open discussion of local performance against key cancer control indicators, the Cancer Institute empowers districts to pinpoint and address clinical variations while identifying avenues for improvement and innovation. This approach ensures that individuals have equitable access to safe, high-quality, timely patient-centred care across metro, regional and rural NSW. Moreover, it enables health districts to harmonise their understanding of local priorities and patient needs with a broader system, relieving frontline services of data analysis and issue identification responsibility.

The RBCO program has had a profound impact on cancer care in NSW, with 2022 being the first year no NSW public or private facility had surgical outcomes that were outside the NSW average across the 23 cancer types reported within the program. Other examples of health system improvement include:

- Supporting Southwestern Sydney Local Health District to establish processes to identify variations in chemotherapy prescribing. This work has been shared and implemented across other districts.
- Reduction in low-volume complex surgeries for some cancers, where published literature demonstrates safe care is best delivered in specialist higher volume sites, e.g. lung, oesophageal and brain cancer. Local health districts have used RBCO's analysis to streamline service offerings. Where services are not offered, patients are linked to multidisciplinary teams and referral pathways are established for higher volume services for patient treatment.
- Improvement in lung cancer outcomes at a large local health district, following RBCO data insights, indicated higher 90-day mortality after complex lung surgery when compared with the NSW standard. Following an improvement program supported by the Cancer Institute, this local health district's surgical outcomes align with expected benchmarks.

The RBCO program continues to evolve with an increasing focus on equity and evaluating disease-specific pathways.

Embedding clinical tools to guide cancer treatment protocols

The landscape of cancer treatment has increasingly grown in volume and complexity with the surge of new drugs and therapies. Notably, advances in targeted drugs and the explosion of immunotherapies continue to change the landscape of treatment options. Keeping abreast of these developments is a formidable challenge for cancer clinicians, cancer services, hospitals and health districts.

To alleviate this burden and ensure equitable access to safe, consistent and evidence-based care for all cancer patients, the Cancer Institute NSW plays a leadership role through its globally recognised [eviQ program](#). This is distinct from its recent spin-off sister program, eviQ Education, which focuses on continuing education and accreditation.

eviQ consists of over 1,100 free, evidence-based cancer treatment protocols and is a trusted online resource visited more than 100,000 times monthly by healthcare professionals across 218 countries. The Cancer Institute was recognised in 2023 by the Union for International Cancer Control (UICC) at the World Cancer Leaders Forum as one of three finalist member organisations for this cancer control program.

The eviQ system is endorsed nationally as the primary source of evidence-based cancer treatment information, and eviQ is deeply integrated into clinical practice in most cancer units (public and private) across NSW and Australia. Every jurisdiction makes a small financial contribution, finding the resource invaluable and incentivising the inclusion of their clinicians. Its success hinges on collaborating with multidisciplinary clinical experts who contribute their expertise to develop and review treatment protocols, consensus guidelines and patient resources. These resources help to ensure all cancer patients, regardless of their treatment location, receive consistent and best-practice care. Simultaneously, the broader healthcare system benefits from a more efficient and centralised collection of continually updated, evidence-based, precise, clinician-endorsed protocols.

The Cancer Institute recently demonstrated international leadership by publishing the first-ever *International Consensus Guideline for Anti-cancer Drug Dosing in Kidney Dysfunction (ADDIKD)* in October 2022. The guideline is a supportive decision-making tool for clinicians, providing a transparent, standardised approach to managing dosing in a complex patient population. Anti-cancer drugs, such as chemotherapy, can impact patients' kidney function. This innovation will improve the safety and quality of care for people with kidney dysfunction who are receiving cancer treatment. Historically, anti-cancer drug dosing recommendations in kidney dysfunction were empirical and non-standardised. There were inconsistencies in assessing and defining kidney function, a lack of definitive guidance on which kidney function estimation tool to use, variations in dosing adjustment approaches, and limited evidence on older drugs in kidney dysfunction.

Leadership in Data and Artificial Intelligence (AI) to transform knowledge, workforce and accelerate outcomes

The Cancer Institute NSW Data Strategy (2021-2023) encompasses Data Engineering, Data Reporting, and Advanced Analytics (including AI and Machine Learning). The Cancer Institute has embedded best practices across all parts of its data lifecycle through this strategy. It has created a vibrant community of practice, engaging stakeholders from across NSW Health and external researchers and analysts.

The Cancer Institute has long been an early adopter of innovation. In 2023, it began migrating its data operations to the eHealth Data Lake to continue to scale its operations and further develop its AI capabilities.

The Cancer Institute is the first organisation in health to utilise the Data Lake Infrastructure to manage end-to-end data pipelines (from raw data ingestion of system data to reporting and insights and AI). It is developing a rich set of resources to allow other agencies across health to leverage the most out of this technology and be part of a shared community of practice.

The Cancer Institute provides researchers access to linked data for cancer research through the Enduring Cancer Data Linkage (CanDLe) program. Through a novel governance model, CanDLe aims to advance the pace, quantity and quality of population-wide cancer research aligned with the goals of the NSW Cancer Plan.

Using Artificial Intelligence to address workforce issues and cancer screening programs: Machine Reading Trial in BreastScreen NSW

BreastScreen NSW is at the forefront of clinical and technological advances in breast screening, most recently being the first jurisdiction in Australia to introduce tomosynthesis into assessment (3D mammography). This is now widely embedded across the country and helps provide a more detailed image of a woman's breast, increasing the accuracy of cancer detection.

Breast Screen NSW is a radiology-based service and requires a sizeable contingent of specialist radiographers and radiologists to deliver the service. Multiple radiologists assess all images taken during a person's mammographic screen to meet program standards.

There is a global shortage of radiologists, including radiologists specialising in breast mammography within NSW. At the end of 2020, the Cancer Institute began exploring using Artificial Intelligence to address future demand and mitigate crucial workforce challenges.

An internationally developed product was selected for a retrospective study, comparing machine-read (AI) results with the results of radiologists (and the known screen results and outcomes).

While others in Australia and internationally are looking at the utility of AI in medical imaging, NSW is the first jurisdiction to undertake a retrospective study using over 650,000 women's mammographic images to compare machine reading with radiologists. This is likely the most extensive evaluation of this technology on real-world population screening data. Currently underway, the study is combining the strengths of a large retrospective design with the benefit of prospective data collection in clinical workflow. This will provide a real-world test of this technology without risk to screening program participants or the need to wait for long-term follow-up data.

Early results are extremely promising, with sensitivity and specificity as good as the average human reader. Another six to 12 months of evaluation is planned, but it is hoped that soon, AI will be able to support the reading of images. This cutting-edge use of technology has the potential to mitigate workforce issues, improve wait times for results, and reduce workforce costs. The Cancer Institute is uniquely placed with statewide governance and accountability to undertake this large-scale research and hopes NSW will lead the way to a change in national policy.

Fostering innovation through research excellence

Section 12 of the Cancer Institute Act (NSW) tasked the Cancer Institute to undertake, commission or sponsor cancer-related research and development. Building and supporting cancer research is one of the four main priorities of the NSW Cancer Plan 2022-2027 and is fundamental to improving patient outcomes.

NSW has a large and complex research ecosystem that spans many organisations, including local health districts, universities, medical research institutions, clinical trial networks, and three National Health and Medical Research Council (NHMRC) accredited Research Translational Centres. The Cancer Institute partners with all in the ecosystem, enabling and catalysing collaboration for maximum return on research.

Cancer research is vital for:

- developing and delivering better treatments and interventions for patients
- improving the delivery of cancer services in the health system; and
- delivering better outcomes for individuals and the population more broadly.

“Garvan is an internationally regarded medical research institute with strength in cancer, genomics and immunology.

“We place enormous store in the role NSW Health plays in stewarding the State’s research ecosystem. For us, the Cancer Institute NSW, plays a vital role in supporting, guiding and enabling research at Garvan and across the State.

“Whether it be administrative or grant support, data collection and data linkage, or statewide coordination of major research opportunities, Garvan strongly believes that the State government enabling structures are critical to the continuing growth of research and research-informed healthcare in NSW.”

Professor Benjamin Kile
Executive Director, Garvan Institute of Medical Research

NSW cancer research attracts significant state, commonwealth, philanthropic and private sector funding

In 2012-2020, NSW received the highest proportion of direct funding to cancer research projects and programs nationally, with \$841 million (40 per cent of total funding) for 1,525 cancer research projects and programs¹⁶. The Australian government is the largest investor in research through funding schemes, including the NHMRC and Medical Research Futures Fund (MRFF), ahead of state government and philanthropy.

Investment in medical research, of which cancer research makes a substantive proportion, delivers an outstanding return for the Australian economy. It is estimated that for every \$1 invested, \$3.90 in economic returns are gained - higher than other government investments. From 1990 to 2004, medical research delivered net present gains of \$78b. \$52b in health gains and a further \$26b wider economic gains¹⁷.

A strategic approach to capacity building has resulted in a substantial return on investment and impact since the establishment of the Cancer Institute in 2003. When it was first created, from 2003 to 2005, NSW secured 25 per cent of cancer research funding, equivalent to \$72.6 million across 379 per cent. This was second to Victoria, which received 39 per cent of the funding, amounting to \$114 million distributed across 413 projects. However, data from the most recent three-year period, from 2018-2020, demonstrates significant and consistent year-on-year acceleration in NSW’s efforts. During this period, NSW attracted over \$400 million in funding for cancer research, surpassing all other states, with Victoria receiving 36 per cent of the funding, totalling \$332 million for 756 projects¹⁶.

Over the last ten years, the Cancer Institute has supported 348 research grants across many cancer types. This research has had an international impact with over 9,200 published

¹⁶ Cancer Australia 2023, Cancer Research in Australia: An overview of funding for research projects and programs in Australia, 2012-2020, Cancer Australia, Surry Hills, NSW.

¹⁷ [KPMG Report: Australian medical research delivers outstanding returns on investment – AAMRI](#)

research papers, four first-in-human clinical trials, and successful translation of scientific from the bench to the bedside.

Over the past five years, the Cancer Institute has awarded \$69.8 million to 141 early and mid-career researchers, who have collectively reported over 2010 publications, 460 international presentations, 500 national presentations and 350 international collaborations.

Improving access to cutting-edge care through coordinated clinical trials

“The NSW government investment in cancer research has been central to fostering a collaborative environment that is unique in Australia where medical research institutes, academia, health services, and community work together towards improved outcomes for patients with cancer.

“Cancer Institute funding has fostered the development of the next generation of research leaders, while infrastructure funding has been pivotal at enabling the purchase of state-of-the-art equipment to accelerate our research discoveries.”

**Professor Maria Kavallaris,
Head of Translational Cancer Nanomedicine Theme
Head, Research Engagement
Group Leader, Tumour Biology and Targeting
Children's Cancer Institute**

The Cancer Institute helps drive and support cancer clinical trials in the state by providing infrastructure and enabling support to cancer centres. Accelerating access to novel therapies is critical to helping improve cancer outcomes.

Clinical trials represent the best tier of research and development for preventing and treating cancer. Clinical trials study new cancer treatments and new ways of delivering existing therapies to improve survival and quality of life. They are an integral part of the cancer treatment pathway and the innovation process in healthcare.

There are 78 cancer clinical trial units in NSW, of which 63 are co-located in public settings.

Cancer Institute NSW invests more than \$5 million annually in local health districts, specialty networks and private/non-government institutions conducting cancer clinical trials.

- In the 2021-2022 financial year, 697 unique cancer clinical trials were open for recruitment across NSW, including many at multiple hospitals. In the same period, 2,272 cancer patients were enrolled into a cancer clinical trial.
- The Cancer Institute has developed language resources for CALD communities to address knowledge gaps and stigma about clinical trials and runs frequent workshops for healthcare interpreters.

- The Cancer Institute also supports over 150 clinical research staff to attend continuing education forums, boosting their professional and ethical standards and enhancing the ability to conduct cancer clinical trials in NSW.
- The Cancer Institute has developed a clinical trial feasibility tool, SiTe cCapacity Repository Tool (START), to guide clinical trial units in centralising the extensive information collected during the feasibility process, with the aim that START will result in a faster and more efficient feasibility process.

Over the past five years, the Cancer Institute has supported more than 11,000 people to enrol in potentially life-saving cancer clinical trials.

Investing in translational research

The Cancer Institute NSW supports NSW's three Research Translation Centres through Translational Cancer Research Capacity Building Grants totalling \$21 million. These grants help strengthen translational cancer research capacity in NSW and foster a collaborative culture to drive improvements in cancer care and outcomes for people living with cancer across the state. These translation centres are instrumental in increasing NSW's cancer research capacity through the provision of funding and coordination of programs in NSW.

Most importantly, cancer research supported by the Cancer Institute has led to innovation and life-changing results for the people of NSW – helping keep the brightest minds in NSW. Recent examples of research enabled by the Cancer Institute include:

- Professors Aaron Sverdlov, recipient of the Cancer Institute's 2023 Accelerated Research Implementation Grant, and his team, co-led by Professor Doan Ngo, lead the only cardio-oncology program in Australia. This spans research in mechanistic science to clinical service and models of care involving both oncology and cardiovascular clinicians. In recognition of their international standing and performance, their program was awarded the highest level of certification, the Gold Tier Centre of Excellence, by the International Cardio-Oncology Society. This is currently the only program in Australia with this designation
- Professor Paul Keall, recipient of a 2019 Translational Program Grant, led a team that invented and pioneered computed tomography (CT) ventilation imaging, which it made commercially available in 2022. The new imaging modality uses CT scans in a new way to add a ventilation image, showing how the lungs are functioning. This is expected to spare eight per cent of patients from experiencing radiation-induced injury and related side effects
- research by Professor Lisa Horvath, recipient of the 2018 Translational Program Grant, has contributed to approving new prostate cancer health services. In July 2022, the NSW Government announced that two new Medicare Benefits Schedule (MBS) items would be introduced for a prostate-specific membrane antigen (PSMA) positron emission tomography (PET) study for patients with prostate cancer. The PSMA PET will allow for better initial staging of intermediate- to high-risk patients with prostate cancer and for the restaging of patients with recurrent prostate cancer. This will help ensure that men with prostate cancer receive the most appropriate treatment pathway.

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The Cancer Institute NSW leads an innovative, centralised and sustainable model of education and accreditation for cancer clinicians.

Delivering better patient outcomes through clinician education and accreditation programs

Cancer clinicians face the formidable challenge of staying up to date with the latest evidence and advances in therapeutics to deliver excellence in care. The exponential growth in biomedical publications, doubling every 73 days, and 75 per cent of pharmaceutical research and development centres are on oncology make this challenging¹⁸.

The Cancer Institute's eviQ Education program offers hundreds of crucial evidence-based cancer eLearning resources and accreditation for cancer clinicians, serving over 130,000 users in the last 12 months alone. These resources are pivotal in keeping the clinical cancer workforce up to date and ensuring the delivery of safe, evidence-based cancer care. The program facilitates the rapid integration of emerging evidence and clinical practice.

The eviQ Education program has been recognised for its exceptional education programs, winning three awards (the Diamond Award for Industry Specific eLearning Project, the Platinum Award for Health and Safety Training and the Diamond Award for eLearning Model) at the last LearnX awards a prestigious industry education awards program.

An example is the Anti-Cancer Drug Administration Course (ADAC). This peer-reviewed, evidenced-based program establishes the minimum safety standards for administering anti-cancer drugs and handling hazardous drugs and waste. ADAC is widely integrated into paediatric and adult cancer centres across Australia and New Zealand, often as a mandatory training requirement, providing a centralised approach that eases the burden on individual centres for quality assurance monitoring and maintenance. This approach significantly strengthens workforce training and accreditation support.

Similarly, the Radiation Oncology Nursing Knowledge and Skills (RONKAS) framework supports nurses in developing a standardised level of knowledge and clinical skills relating to the safe care of patients receiving radiotherapy. This framework was developed in partnership with the Cancer Institute, Liverpool and Macarthur Cancer Centres, Icon Cancer Centre and the Cancer Nurses Society of Australia. An introductory and advanced education module, both earning continuous professional development points and competency assessment tools, is widely used across radiation units in Australia.

¹⁸ Ref The Oncology Pipeline Overview: recent approvals and near-term drugs. Am. Health Drug Benefits 2021 Dec 14(4) 154-155

Conclusions

The Cancer Institute NSW, a NSW Health pillar, is a pioneering, internationally applauded, dedicated cancer control agency established under the Cancer Institute (NSW) Act 2003. It operates under a framework that defines its objectives, principles and functions to address the complexity, burden and urgency of cancer. This framework has served well in delivering value to the NSW public and is very relevant looking forward. The Institute has consistently demonstrated efficient budget management and focussed funding allocation with majority directed towards frontline critical health initiatives.

With an aging population and cancer diagnoses on the rise, affecting diverse population groups, the Cancer Institute is best placed to provide strategic leadership, aiming to enhance patient experiences, reduce disparities, and optimise healthcare resources. This collaborative and person-centred approach seeks to ensure that all residents of NSW receive equitable and effective cancer care while addressing the unique and evolving needs of various communities. Through comprehensive planning, active community engagement, and continuous learning from patient experiences, the Cancer Institute aims to reduce the burden of cancer and promote the health and well-being of the people of NSW.

The Cancer Institute is a leader in delivering evidence-based prevention programs to reduce cancer risk factors. Cancer prevention is a recognised, cost-effective, long-term strategy for cancer control. The Cancer Institute plays a leadership role in its continued commitment and collaboration across various sectors to achieve long-term health benefits for NSW people. The Cancer Institute is critical in delivering important public health campaigns to change risk behaviours and demonstrate early cancer detection's benefits through screening programs. The Cancer Institute promotes participation in breast, bowel and cervical screening programs and is gearing up to implement a new National Lung Cancer Screening Program in 2025.

Through innovative programs like eviQ, eviQ Education and the Reporting for Better Cancer Outcomes program, the Cancer Institute empowers clinicians, ensures the adoption of evidence-based practices, and facilitates benchmarking to improve patient outcomes. The Cancer Institute's commitment to harnessing data, advancing AI capabilities and supporting ground-breaking research underscores its dedication to improving patient outcomes.

The continued strategic investment in cancer research by the Cancer Institute has yielded substantial returns, fostered innovation and produced life-changing results for the people of NSW. The Cancer Institute accelerates access to novel therapies through cancer clinical trials, providing hope and improved outcomes.

The Cancer Institute's comprehensive approach to cancer control positions NSW as a national leader in cancer, with a mission to continuously enhance the quality of care and outcomes for NSW people with cancer. As we look ahead, it is evident the Cancer Institute's unwavering commitment to advancing cancer care will continue to make a significant and positive impact on the lives of NSW with cancer.

In conclusion, this submission underscores the pivotal role of the Cancer Institute NSW in driving excellence and equity in cancer care across the state.

Recommendations

Based on the above information provided, the Cancer Institute makes the below four recommendations to the Inquiry:

- **Recommendation 1 - Sustain and strengthen the governance framework**
The Cancer Institute continues to operate under its existing governance framework, ensuring its continued success in leading and coordinating cancer control initiatives in NSW.
- **Recommendation 2 - Expand cancer prevention initiatives**
The Cancer Institute be supported to intensify its efforts in delivering evidence-based prevention programs to reduce cancer risk factors and reduce the incidence of preventable cancers. These programs should focus on educating the public about risk behaviours and the benefits of early cancer detection through screening programs.
- **Recommendation 3 - Invest in data, research and innovation**
The Cancer Institute continues to expand its commitment to harnessing data, advancing digital and AI capabilities, and supporting innovation and research to enhance patient outcomes. By accelerating access to novel therapies through clinical trials and fostering innovation, the Cancer Institute can continue positioning NSW as a national and international leader in cancer care and research to benefit its population.
- **Recommendation 4 - Maintain focus on equity and patient-centred care**
The Cancer Institute upholds its commitment to providing equitable, evidence-based, patient-centred care. To achieve this, it should continue engaging with diverse communities, tailoring its services to meet their unique needs and priorities. Ensuring the patient's voice is central to decision-making will also improve care.

These recommendations emphasise the importance of a dedicated and holistic cancer control vehicle for NSW and the importance of sustaining effective governance, intensifying prevention efforts, investing in research and innovation and maintaining a focus on equity, evidence-based and patient-centred care to enhance further the Cancer Institute's impact on cancer care and the health and wellbeing for the people of NSW.

Appendix A: Letter of endorsement from Cancer Institute NSW Board

Sensitive: NSW Government

Cancer Institute NSW



30 October 2023

Mr Richard Beasley SC
Commissioner
Special Commission of Inquiry into Healthcare Funding
submissions.hfi@specialcommission.nsw.gov.au

Re: Submission to Special Commission of Inquiry into Healthcare Funding

Dear Mr Beasley

I write on behalf of the Cancer Institute NSW Board. The Board thanks you for the opportunity to recognise the value of the legislated remit and function of the Cancer Institute NSW, its integral role as part of the NSW health system, its role in working collectively and in a unified way with local health districts, the research community and engaging directly with local communities.

The Cancer Institute NSW is unique in its ability to bring together partners across the health, government, not-for-profit, and community sectors to coordinate the delivery of statewide programs that will benefit people with cancer. It also implements programs of work that will prevent cancers, reduce its impact on people with cancer and their families and reduce the NSW health system and the population.

Yours sincerely,

Adjunct Associate Professor Christine Giles
Chairperson
Cancer Institute NSW Board

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