Special Commission of Inquiry into Healthcare Funding

Statement of Professor Tracey O'Brien, AM

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1. This statement made by me accurately sets out the evidence that I would be prepared, if necessary, to give to the Special Commission of Inquiry into Healthcare Funding as a witness. The statement is true to the best of my knowledge and belief.

2. This statement is provided in response to a letter of 24 October 2024 issued to the Crown Solicitor's Office and addresses the topics set out in that letter relevant to my role.

A. INTRODUCTION

3. I am the NSW Chief Cancer Officer and Chief Executive of the Cancer Institute NSW (**the Cancer Institute**). I was appointed to this role in July 2022. I have worked for NSW Health for over 27 years. I am a paediatric oncologist, haematologist and transplant medicine specialist. I have a clinical appointment at the Kids Cancer Centre, Sydney Children's Hospital. I am a Conjoint Professor in Clinical Medicine at the University of New South Wales, Conjoint Honorary Professor in the School of Medicine at Western Sydney University and Honorary Professor at the Centre of Applied Artificial Intelligence, Faculty of Science and Engineering, Macquarie University. Before my appointment at the Cancer Institute, I was the Director of the Kids Cancer Centre at Sydney Children's Hospital, Randwick, for seven years and Director of the Transplant and Cellular Therapy Program for 18 years. A copy of my curriculum vitae is exhibited.

4. In my role as NSW Chief Cancer Officer and Chief Executive, Cancer Institute NSW, I provide strategic leadership, direction and management of the Cancer Institute. I am responsible for the strategic and operational focus of the organisation and overseeing and directing the Government's investment in cancer research funding and cancer control programs within NSW to maximise local benefits and leverage local, national and international efforts to drive cancer control. I also am responsible for ensuring appropriate governance, so the Cancer Institute fulfils its statutory operating and reporting requirements, meets its obligations within an agreed budget, and meets specified performance standards and strategic objectives set out in the *Cancer Institute (NSW) Act 2003* (**the Act**).

B. BACKGROUND

5. Cancer is one of the most significant 21st-century global health challenges, and is the leading cause of death in NSW, responsible for one-in-three deaths.[1] [2] Despite significant survival improvements, the burden is growing due to our increasing and ageing population. The number of people diagnosed with cancer each year in NSW has grown by more than 75% since 2000 and is projected to grow by almost another 20% by 2036.[3] More people with cancer are living longer, care is more complex, and health needs for cancer survivors are rapidly increasing causing significant pressures on health systems.

6. Cancer ranks among the top disease groups in terms of health system expenditure in Australia, with over $12.08 billion spent in 2019-2020, with costs projected to grow exponentially from 2020 to 2050.[4] [5]

7. The Cancer Institute, established under the Act, is the NSW Government's dedicated cancer control agency. Its objectives, as set out in the Act, include increasing the survival rate for cancer patients, reducing cancer incidence in the community, improving the quality of life of cancer patients and their careers, and operating as a source of expertise on cancer control for various stakeholders, including the government, health service providers, medical researchers, and the general community. The Act also sets out guiding principles for exercising the functions of the Cancer Institute (section 6) and the Cancer Institute's functions (section 12).

8. "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.

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[1] The global challenge of cancer. (2020). Nature cancer, 1(1), 1–2, available online at https://doi.org/10.1038/s43018-019-0023-9.

[2] Retrieved from: https://www.healthstats.nsw.gov.au/.

[3] Data from NSW Cancer Registry, with projected population data sourced from NSW Department of Planning and Environment

[4] Australian Institute of Health and Welfare. (2022). Disease expenditure in Australia 2019–20, available online at https://www.aihw.gov.au/reports/health-welfare-expenditure/disease-expenditure-in-australia-2019-20.

[5] 'Estimates and projections of the global economic cost of 29 cancers in 204 Countries and Territories from 2020 to 2050', JAMA Oncology 2023, 9(4), 465-472.

9. The Act provides that there is to be a Chief Cancer Officer. The Chief Cancer Officer provides state-wide stewardship of all cancer control initiatives in NSW, including that of a trusted expert and public voice for cancer control in NSW.

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

11. The Cancer Institute leads and implements the state-wide Cancer Plan. Now in its fifth iteration, the *NSW Cancer Plan 2022-2027* (**Cancer Plan**) drives the state's vision for cancer control, building upon past achievements.[6]

12. The Cancer Plan is developed in consultation with the stakeholders across health, cancer control and community sectors, as well as people with lived experience of cancer. More than 800 representatives contributed to the development of the latest Cancer Plan.

13. The Cancer Institute serves as the Cancer Plan's custodian and is responsible for the governance and coordination of over 80 partner organisations working to execute the Cancer Plan. This partnership-based approach enhances efficiency, minimises duplication and eliminates wastage while setting and achieving cancer control objectives.

14. The Cancer Plan is based on principles of equity, collaboration and person-centredness. It recognises the need to reduce cancer disparities for vulnerable populations, including Aboriginal people, regional and rural communities, multicultural communities, people with higher socio-economic disadvantage, LGBTQ+ people, older Australians and people engaged in the justice system.

15. The Cancer Institute is also working with the Aboriginal Health and Medical Research Council of NSW and relevant health and community stakeholders to co-develop a dedicated NSW Aboriginal Cancer Strategy.

16. The Cancer Institute spans pillars of cancer control: primary prevention, screening and early detection (secondary prevention), optimal care, research and innovation. This positions it to lead a coordinated, strategic approach to continued improvement. Fragmenting these elements across separate agencies, funds, or MOH branches would dilute this focus, as optimal cancer outcomes require a unified approach across the entire

[6] Available online https://www.cancer.nsw.gov.au/getmedia/e53d5875-78c9-432e-a4d9-5c08935c3a48/CINSW-NSW-Cancer-Plan-Dec2022-FINAL-WR.pdf

continuum. This integrated approach - called cancer control - has proven transformative, with jurisdictions adopting better outcomes for people and communities.[7]

C. THE CURRENT FUNDING MODEL

Funding allocation

17. The Cancer Institute had an annual operating expense budget of $187 million for the 2023-24 financial year. This included a base budget of ~$183 million that was then supplemented by an additional $4 million from Federation Funding Agreement Schedule (**FFA**) for additional prevention activities.

18. The model used to derive the annual budget is largely based on historic budget allocations and is determined by MOH. Whilst the budget is published within the annual Performance Agreement, there is minimal clarity on the methodology used to determine the budget. For example, the fixed, variable or performance-based / criteria-driven components.

19. The budget allocation is annual, and all funding must be utilised in-year. Broadly, there is a risk that annual variation in budget could impact the ability to deliver services or functions. There is no advanced visibility of funding for future years nor a mechanism to understand any potential future variations and develop mitigation plans.

20. The annual allocation model limits more strategic medium- and/or long-term investment decisions, particularly in prevention and research activities, which typically benefit from longer-term investment commitments and often have longer time horizons for returns.

21. From its annual budget, the Cancer Institute delivers a suite of statewide clinical services and programs, including smoking cessation (Quitline), public behaviour-change campaigns, health promotion and information to improve cancer literacy and ease navigation of services. Key centralised programs, such as Reporting for Better Cancer Outcomes (**RBCO**), Patient Reported Measures (**PRMs**) and eviQ, are led by the Cancer Institute in collaboration with cancer services across public, private, and primary care. These are examples of centralised programs led by the Cancer Institute, in partnership with cancer services across public, private and primary care; they leverage evidence,

[7] Morris, M., Seguin, M., Landon, S., McKee, M., Nolte, E. (2022). 'Exploring the Role of Leadership in Facilitating Change to Improve Cancer Survival: An Analysis of Experiences in Seven High Income Countries in the International Cancer Benchmarking Partnership (ICBP)', International Journal of Health Policy and Management, 11(9), pp. 1756-1766. doi: 10.34172/ijhpm.2021.84

data, clinical insights, and lived experiences to drive continuous improvements in cancer care and outcomes for the people of NSW.

22. Funding for some prevention activities are shared through State and Commonwealth funding sources. Australia has three national cancer screening programs – breast, bowel and cervical, with a national lung cancer program to commence from July 2025. The role the Cancer Institute plays in each of these differs depending on the design of the national program and each are supported by different cost share arrangements.

23. BreastScreen Australia is the national breast screening program, with each state and territory operating its own BreastScreen service. The Cancer Institute is responsible for the BreastScreen NSW service, funded through a 50/50 cost-sharing model between the Commonwealth and NSW governments. The Commonwealth is responsible for policy, quality standards and accreditation, sharing delivery costs with states and territories. In NSW, the BreastScreen NSW State Coordination Unit (**SCU**) within the Cancer Institute manages program governance, funding allocation, service quality, and delivery, including return of results, reminders and registry. The SCU partners with nine local health districts (**LHDs**), known as Screening and Assessment Services (**SAS**), which deliver the day-to-day screening activities. BreastScreen NSW operates 52 fixed sites and 16 mobile vans across the state – servicing over 250 locations.

24. Funding received from the Commonwealth for BreastScreen NSW is delivered via the National Health Reform Agreement (NHRA). No details about the quantum of BreastScreen funding are available in the NHRA. The Breast Screen Australia National Policy and Funding Review is currently underway, and recommendations are expected in early 2025.

25. The Cancer Institute allocates funding to the nine LHDs operating SASs. Annual funding is negotiated with the LHDs, using the prior year's activity as a baseline with a small Consumer Price Index (CPI) adjustment. Neither state nor federal funding sources have been adjusted to account for the growing eligible population due to an aging demographic.

26. The Cancer Institute does not receive capital funding to maintain or replace mammography machines and mobile vans, or to expand services. Business cases from LHDs for equipment replacement, new sites or service expansion are considered by the Cancer Institute (via the BreastScreen NSW SCU) and must be funded with the Cancer Institute's relatively static annual operating budget. This is further complicated by yearly

budget cycles, while effective service and equipment planning require a 5 to 10-year outlook.

27. Despite inadequate funding to meet demand, the Cancer Institute's centralised responsibility for purchasing all clinical equipment used by the SASs to deliver BreastScreen services is beneficial. This approach secures the best pricing, maximises service agreements, minimises contract administration, and standardises equipment to ensure consistent safety and quality standards across all BreastScreen NSW sites. All purchased assets are transferred to the respective LHD at the end of the year. A decentralised purchasing model would raise overall equipment costs by reducing economies of scale, increasing contract administration, and potentially compromising safety and quality standards.

28. The Cancer Institute's role in the National Bowel Screening Program is to manage the NSW Patient Follow-up Function (**PFUF**), funded by the Commonwealth. In the 2023-24 financial year, the Cancer Institute received $2.63 million for PFUF. This Function provides a telephony service to assist NSW participants who receive a positive test in connecting with primary care for follow-up diagnostic testing, typically colonoscopy. Commonwealth funding is provided on a 2-year fixed-term block basis, with actual funding adjusted according to activity.

29. The Cancer Institute also implements various initiatives to boost bowel screening participation, including raising awareness with participants and primary care providers, removing diagnostic service barriers and delivering mass media behaviour change campaigns and public health engagement activities. The Commonwealth provides kits, results, screening register and reminders.

30. Fixed-term Commonwealth funding is usually provided for time-limited services or specific initiatives. An example of funding for a specific initiative is the enhancement of smoking cessation and quit services. This Commonwealth funding is provided over three years and depends on achieving KPIs and milestones. The funding is provided to the MOH and is paid to the Cancer Institute as supplementary funding. Challenges with this funding model include the timeliness of payments from the Commonwealth, little real negotiation opportunity, and the fact that the multi-year allocation of funding does not align with real costs.

31. Like BreastScreen, the cervical screening program is also a joint program between states, territories, and the Commonwealth. NSW is currently negotiating a $6.8 million

three-year fixed-term FFA with the Commonwealth for funding to support initiatives against the 2023 National Cervical Cancer Elimination Strategy. Over the next three years, the Cancer Institute will deliver a range of prevention activities to improve screening participation, which is currently lower than the national average.

32. Over the last five years, the Cancer Institute has delivered its strategic priorities with a minimal average annual increase of 0.9 per cent to its operating budget – this would broadly equate to ~$12 million to $15 million variation over the last five years. This limited growth is insufficient to account for the increasing burden of cancer and, combined with aggressive savings targets applied by MOH (relative to the size of the organisation), has meant a reduction in prevention and other activities. For example, no bowel cancer screening campaign was run in the 2023-24 financial year, and limited funds were available for media spending on tobacco, breast and skin prevention campaigns despite the development of campaign assets. This adversely affects return on investment for campaigns but, moreover, results in higher longer-term health and system costs with fewer cases of cancer diagnosed at an earlier stage when positive health outcomes are highest and treatments most cost-effective.

33. A minimal increase in the allocated budget has also limited the ability to embrace new technology and upgrade or replace critical applications. For example, eviQ, considered a crucial asset across cancer services (see paragraphs 96 - 100 below), operates on old digital technology, compromising safety and limiting automation and analytics that would enhance clinical benefit.

34. Through its annual budget allocation, the Cancer Institute supports cancer research across universities, medical research institutes and healthcare services through clinical trial funding and research grants. The minimal increase in budget, together with savings targets, has limited available investment in cancer research in recent years. Cancer research takes time, even decades, and the continuity of research progress is interrupted by the ongoing need to secure future funding. Basic science and translational research grants are often funded for 3 to 5 years, as shorter durations are insufficient to maximise outputs and impact. The annual cycle of budget allocation limits medium to longer-term strategic planning. In the 2023-24 financial year, no new grants were awarded due to the need to meet savings and efficiency targets

35. Clinical trial funding is provided to clinical trial units across LHDs annually to support infrastructure and increase trial participation for cancer patients. The annual cycle of budget allocation perpetuates a cycle of staff turnover and inability to recruit, as staff do

not have the security of permanent employment. Many staff have left publicly funded trial units to work at private sector clinical trial units.

36. Notwithstanding limitations relating to budget constraints and annual funding cycles, research remains an essential pillar of cancer control and a priority within the state Cancer Plan. Cancer research funding is best directed by the Cancer Institute to ensure alignment with statewide cancer control vision and priorities. Fragmenting cancer research investment and activities across other agencies, MOH branches or funds would weaken focus and an integrated cancer control approach, proven to return the best outcomes.

37. From the annual budget allocation, the Cancer Institute also provides block funding to LHDs and Specialty Health Networks to support the workforce for local cancer services, including supporting cancer directors and managers, coordination of care and psycho-oncology services.

Seeking Supplementary Funding from NSW Health

38. Under the current funding mechanisms, there are limited means for enhancement to the overall budget commensurate with an overall increase in the burden of cancer, both in terms of complexity and volume. The exception is if it is tied to a specific program and is time-limited. A business case can be submitted to MOH for consideration. Recent examples include successful supplementary funding for BreastScreen over two financial years to support recovery from the COVID-19 pandemic closures and time-limited funding for developing public campaigns and quit support services to address vaping in young people.

D. THE ROLE OF THE CANCER INSTITUTE

Connecting to maximise impact

39. Cancer has one of the most complex stakeholder landscapes in medicine. The Cancer Institute works in partnership with primary and aged care, public and private tertiary healthcare, academic and research institutions, and non-government and advocacy organisations (**NGOs**), with links stretching from local and statewide to national and international organisations.

40. Cancer control is inherently complex, spanning over 200 distinct diseases that impact nearly every organ of the body, requiring expertise from a vast network of medical,

surgical, and nursing sub-specialists and multidisciplinary allied health staff. Cancer also relies on ICU, emergency, radiology, laboratory and diagnostics services – all of which must function well for a cancer patient to receive the best care. Individual cancer care often straddles public and private sectors across inpatient and outpatient settings, requiring effective coordination to ensure patients receive consistent, high-quality care at every stage of their journey.

41. The Cancer Institute's role as the lynchpin in the NSW cancer control ecosystem is to build and share connections and intelligence that help drive improvements across the cancer continuum from prevention and early detection, through to treatment and care, to end-of-life, or supporting people to live well with and beyond cancer. This connected approach allows for a more significant collective impact than the sum of its parts.
42. The Cancer Institute has a crucial role in research and innovation, supporting researchers and clinicians across clinical and academic environments to generate, implement, and scale new evidence and improvements across the cancer continuum while advancing efforts to achieve equitable cancer outcomes.

A source of expertise and information

43. The Cancer Institute acts as a source of expertise for consumers and clinicians, with our suite of websites garnering 21,304,265 views from 3,704,775 active users over the past 12 months.

44. The Cancer Institute supports individuals with information to reduce their cancer risk, access screening and navigate their cancer care. The Cancer Institute offers information and resources across more than 46 community languages.

45. The Cancer Institute works to deliver vital health information to communities via both traditional and social media. Over the past 12 months, the Cancer Institute has driven more than 1000 stories across print, online, radio and television in NSW, with a potential cumulative audience reach of more than 17.5 million. The NSW Government's monitoring service estimates that this coverage would have cost more than $5.5 million in paid advertising. Across the same period, the Cancer Institute's health messaging was viewed more than 16 million times through our social media channels and was shared by stakeholders, partners and individuals, further maximising its reach.

46. The Cancer Institute also partners with healthcare workers to deliver health information to communities. This includes developing educational materials and training programs for workers, consumer resources, and educational tools.

47. Last financial year, we delivered this training to 25 bilingual community educators and cultural support workers. In addition to this, we supported 92 community education sessions via our multicultural grants.

48. The Cancer Institute's Helping Mob Live Healthy and Prevent Cancer Toolkit online resource was co-created with Aboriginal people and provides cancer screening and prevention information for anyone working to improve the health of Aboriginal clients or communities. This year, the Helping Mob Live Healthy and Prevent Cancer toolkit webpage had over 9,000 views, and almost 850 fact sheets and resources were downloaded.

49. Our ability to deliver broader health information to communities outside of our major behaviour change campaigns is limited by budget allocations and restrictions on NSW Government advertising. For example, campaign activity to empower cancer patients to be part of shared decision-making has ceased.

50. The Cancer Institute is vital in building connections across the cancer continuum, linking clinicians and system planners with researchers, community organisations, patient advocates, consumer advocates and people with a lived cancer experience. This fosters dialogue, builds capacity and capability, shares knowledge and supports the translation, innovation and scaling of innovations in cancer control. These goals are advanced through our program of events and webinars, including the NSW Cancer Innovations Conference and Cancer Conversations series.

51. The Cancer Innovations Conference 2023 brought together more than 450 stakeholders, including clinicians, NGOs and those with lived experiences, to discuss challenges and opportunities in cancer control, such as addressing equity, the emergence of AI and innovations in practice.

52. Due to budget constraints, the Cancer Institute could not run the conference in 2024, limiting learning and development opportunities and stakeholder engagement for the sector.

Addressing disparities and driving equity

53. A priority of the Cancer Institute is to address disparities in cancer risk, access, experiences and outcomes for NSW people. The burden of cancer is not evenly shared. The Cancer Institute leads equity-focused strategies in cancer control, aiming to benefit those facing the greatest need.

54. The Cancer Plan has a focus on improving cancer outcomes for Aboriginal People, culturally and linguistically diverse communities, older people, regional and remote communities, sexuality and gender diverse and intersex people, people with a mental health condition, people from lower socioeconomic backgrounds and people engaged in the justice system.

55. There are focused work programs with priority populations across prevention, screening, treatment, and clinical trials in partnership with external stakeholders and government and non-government organisations.

E. DRIVING POSITIVE HEALTH OUTCOMES AND SYSTEM SUSTAINABILITY THROUGH PREVENTION

Prevention is a vital and cost-effective approach

56. Australian policy highlights the need to enhance investment in prevention and is recognised by the World Health Organization as the most cost-effective strategy for effective cancer control. Australia spends less than 2% of health expenditure on prevention, far less than other comparable countries.[8]

57. Effective prevention requires sustained long-term planning and investment, with 'short-termism' a known barrier to impactful prevention initiatives. Annual funding allocations, savings targets, and funding uncertainty each year undermine prevention programs.[9]

58. Meaningful prevention requires a sustained commitment from the health system, broader government, non-government and community services. In a fiscally constrained environment, investment in prevention is often overlooked in favour of more political or immediate health system issues. Without long-term dedication to prevention, the burden on the healthcare system to treat preventable cancers will continue to grow.

59. An accurate figure of the costs of cancer in NSW is not available, making it challenging to assess the optimum investment in cancer prevention initiatives.

60. The Cancer Institute develops and implements initiatives targeting both primary prevention, aimed at preventing cancers from occurring, and secondary prevention, focussed on reducing the impact of cancers through screening and early detection.

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[8] *National Preventive Health Strategy 2021-2030* (**SCI.0001.0027.0001**).

[9] Gratten Institute Report No 2023-03. Feb 2023, *The Australian Centre for Disease Control (ACDC); Highway to health*.

Addressing behavioural risk factors to reduce cancer burden

61. A substantial body of evidence links risk factors such as tobacco smoking, overweight and obesity, alcohol, physical inactivity and sun exposure to a wide range of cancers. Almost half (42%) of the cancer burden in Australia is attributable to personal and behavioural risk factors.[10]

62. Prevention is most effective when a suite of complementing strategies are employed, including regulatory and pricing interventions, communication, education and behaviour change programs, and programmatic interventions such as smoking cessation assistance.

63. Public education campaigns are among the most cost-effective investments to reduce cancer incidence, morbidity, mortality and economic burden.

64. The Cancer Institute leads programmatic interventions, behaviour change programs for primary and secondary cancer prevention, public education and community engagement initiatives to address cancer risk factors. It works closely with MOH and the Commonwealth Government to ensure these initiatives align with and complement regulatory interventions.

65. Since 2006, the Cancer Institute has delivered successful behaviour change campaigns covering primary prevention – targeting smoking, vaping and overexposure to harmful UV radiation; and secondary prevention, aimed at reducing the cancer burden by increasing participation in cancer screening. Due to their effectiveness and impact, many campaigns have been licensed by other Australian states and several countries internationally.

66. All behaviour campaigns follow a best-practice public health development process supported by the Department of Customer Service (DCS), typically taking about 18 months to complete. Each campaign is evidence-based, beginning with problem identification and analysis, followed by formative research, development and design and multiple rounds of testing with the target audience, alongside strategy development.. Once launched, campaigns are monitored for performance and optimised as needed, with all campaigns undergoing formal evaluation. This rigorous approach ensures effectiveness across populations, culturally and linguistically diverse groups and First

[10] Australian Institute of Health and Welfare, *Cancer in Australia 2021, Summary - Australian Institute of Health and Welfare*, available online: https://www.aihw.gov.au/reports/cancer/cancer-in-australia-2021/summary

Nations people. Campaign creative can generally remain effective for up to three years, maximising return on the initial development costs.

67. The Cancer Institute's campaigns show significant benefits and return on investment to the community, health system and broader economy. Recently developed campaigns have been independently evaluated to provide a return ranging from $4.50 to $33.20 for every dollar invested due to a combination of health system savings and the economic benefit of keeping people well. The total investment in delivering these campaigns has been $21.16 million (expended over multiple years due to an 18-month development cycle) with a return of over $281 million to NSW. Below is an outline of the campaigns delivered in the last several years.

68. Tobacco is the leading preventable cause of ill health and death in Australia and is linked to 16 different types of cancer, and accounts for 22% of the cancer burden in Australia. UV exposure is responsible for 95% of melanomas and 99% of non-melanoma skin cancers and 8% of cancer health expenditure in Australia.

69. Tobacco campaigns in NSW have delivered substantial benefits. An external evaluation following the '2022/23 Tobacco Control Campaign' showed that it encouraged an additional 23,719 people aged 18 years and older to attempt to quit smoking, with 593 people permanently stopping because of the campaign. The cost-benefit analysis projected that the campaign saved over 3,813 life years and generated $24.90 for every dollar invested, totalling $4,126 million in potential economic benefit for NSW.

70. The Cancer Institute has also targeted vaping cessation, addressing a growing health challenge particularly affecting young people aged 16-24. Vaping poses significant health risks, leads to nicotine addiction and can act as a gateway to tobacco smoking among young people, jeopardising decades of progress in tobacco control. The Cancer Institute's 2023-24 Anti-Vaping campaign 'Every vape is a hit to your health' contributed to nearly 20,000 people (14-24 years in NSW) attempting to quit vaping. For every dollar invested, $8.20 was returned to the NSW economy, totalling $35.3 million for the people of NSW.

71. External evaluation of the 2023-24 'If You Could See UV' campaign found that it motivated over 75% of young people who saw the campaign to improve their sun protection behaviours. Cost-benefit analysis estimated that the campaign helped to avert over 2,200 skins cancer, returning $17.10 to the NSW economy for every dollar invested, and generating a potential benefit of over $21 million for NSW.

72. To achieve meaningful behaviour change, social marketing initiatives must be delivered both at scale, tailored to reach diverse populations, adjusted for demographics and regional variations and sustained over the long term. Behaviour change assets should remain in market for the maximum time and be deployed across multiple media channels. To maximise reach, campaigns need to be amplified through local community engagement and collaboration with other key stakeholders. The 'Slip, Slop, Slap' UV campaign of the early 1980's is widely credited as playing a key role in the dramatic shift in sun protection attitudes and behaviour over the past two decades. Despite this success, Australia still has one of the highest rates of melanoma in the world underscoring the need for sustained prevention activity for the long term.

73. The longer-term planning and execution to market that is required for prevention campaigns is challenged by current annual funding cycles which often means administrative burden and costs are increased. An example of this is renewing or renegotiating short-term contracts with agencies with specialist technical or target audience expertise. In addition, Cabinet approval is required every year for all proposed expenditure.

74. The NSW Government's commitment to reduce government advertising expenditure each year has presented recent challenges as cancer prevention campaigns have been included in these blunt savings initiatives, despite proven return on investment. Cuts to advertising budgets significantly impact on effectiveness and return on investment of these campaigns. For example, in the 2023-24 financial year, the Cancer Institute was required to reduce the budget for the anti-tobacco campaign (referred to in paragraph 69) by $2.14 million to comply with advertising caps. Independent economic modelling estimates this cut would lead to a 51% reduction in both quit attempts and people who quit permanently and a $106.1 million reduction in benefits for people of NSW.

F. INCREASING EARLY DETECTION TO DRIVE IMPROVED OUTCOMES AND REDUCE SYSTEM BURDEN

75. Cancer screening is the best way to detect cancers in their earliest stages when they are most treatable. Screening is a form of secondary prevention. The Cancer Institute promotes increased participation of eligible NSW citizens in the available national population-based cancer screening programs, with emphasis on priority populations where screening rates are known to be lower. The Cancer Institute also supports effective transition from screening into diagnostic and care services.

76. In 2023-24, BreastScreen NSW delivered the highest number of screens in the history of the service (372,000 women). This was achieved through significant investment in a social marketing campaign, engagement activities and capital investment to increase capacity. This level of activity was achieved due to fixed term funding allocated to address recovery post COVID closures. Despite this number of screens, participation remains at just 51.7% meaning almost half of the eligible population is not screening. Funding is required for prevention activities, but also to address increased participation and population growth.

77. An external evaluation of the 2024-25 BreastScreen NSW Campaign Program projects an additional 9,770 screenings beyond the baseline levels, driven by anticipated increases in the number of women screened during 2024-25, with continued benefits from high rescreen rates in subsequent years. The campaign's primary benefit is reduced mortality through earlier detection of breast cancer, which improves survival rates. For every dollar invested, a return of $15.30 is expected, with a total return of over $42.2 million for NSW. Notably, recent campaign activity during October 2024 for Breast Cancer Awareness Month saw a 21% increase in bookings compared with the previous month.

78. Of the three national cancer screening programs, screening for bowel cancer is the most cost-effective due to the ability to diagnose at an early stage of cancer or pre-cancerous lesions. This is called stage shift, as earlier stage disease has less treatment requirements and has better survival rates.

79. Bowel cancer screening participation in NSW is 39.5%, the second lowest of all states and territories. NSW needs to invest in a targeted and sustained approach to increasing screening participation and removing barriers to early diagnosis and treatment.

80. An external evaluation of the 2021-22 Bowel Cancer Screening Campaign showed the campaign prompted an additional 16,780 people in NSW to participate in bowel cancer screening, preventing 379 years of life lost. Cost-benefit analysis in 2023 predicted that for every $1 invested in bowel cancer screening campaigns, $13.50 would be returned to the NSW economy, with a total return of $43.1 million for NSW.

81. A planned 2023/34 bowel screening campaign was cancelled due to the NSW Government's advertising expenditure caps referred to at paragraph 74 above.

82. The Direct Access to Colonoscopy (**DAC**) is an example of a quality improvement initiative led by the Cancer Institute, part of NSW Health Leading Better Value Care

(LBVC) Program, to improve access to colonoscopy for participants needing further investigation following a positive screening test. Since the 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. Economic and outcome evaluation is underway.

83. 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 the presence of the HPV virus which causes the majority of cervical cancers, therefore providing the opportunity for monitoring and treatment before cervical cancer develops.

84. Participation in the Cervical Screening program is NSW is currently 59.7%. This is one of the lowest participation rates in Australia. Participation rates declined during the COVID pandemic and have continued to decline.

85. In 2023, the Commonwealth Government released the National Strategy for the Elimination of Cervical Cancer in Australia.[11] This provides a plan to achieve elimination of cervical cancer by 2035.

86. To address the low and declining participation rates for cervical screening, the Cancer Institute works with Primary Health Networks (**PHNs**), women's health services and non-government and community agencies to support the delivery of the cervical screening program, which primarily occurs in a primary care setting. The Cancer Institute promotes the uptake of cervical screening through training and provision of resources for health professionals and raises awareness across the screening population (25-75 years).

G. ENABLING QUALITY, HIGH-VALUE CARE

Data informed continuous improvement in cancer care

87. The Cancer Institute has comprehensive data assets including linked data and longitudinal data. This is critical in understanding the evidence for improvement, reducing unwarranted variations in care and in addressing inequity.

[11] Available online https://www.health.gov.au/sites/default/files/2023-11/national-strategy-for-the-elimination-of-cervical-cancer-in-australia.pdf

88. The Cancer Institute leads the RBCO program which publishes annual reports on cancer control indicators across prevention, screening, treatment and research. Data is available (reported publicly on the Cancer Institute's website) at a LHD level and private hospitals level, enabling quality improvement and identifying areas of unwarranted variation. The RBCO program has engaged over 770 clinical experts to interpret data, and to develop over 200 agreed cancer control indicators to use as benchmarks for comparing outcomes. In 2023, 187 reports were issued, with insights shared across 48 formal CEO meetings promoting bidirectional knowledge sharing and identifying opportunities for improvement.

89. The program engages all levels of the health system – from clinicians to managers, executive and chief executives across LHDs and PHNs. It highlights and seeks to understand variations in cancer control across geographic areas and population groups, and supports evidence-based best practice and continuous quality improvement to maximise the impact in reducing the burden of cancer.

90. The program is built on collaboration, combining centralised, clinically informed data and intelligence with the LHDs understanding of the needs of their communities to support improved local decision making.

91. The RBCO program provides contextualised insights to the support care delivery and quality improvement across the range of cancer services. It sources and links cancer data, analyses with clinical input, co-designs information and solutions and ensures ongoing monitoring to drive sustained improvement. Each LHD receives an annual, system wide view of how their care compares with other LHDs across both public and private.

92. Access to a comprehensive, system-wide view reveals issues that only emerge through state or facility comparisons - enabled by the centralised RBCO program and trusted partnership between the Cancer Institute and clinical experts across LHDs. This approach has driven real system changes, such as improved surgical mortality, reduced variation in types of surgical procedures that prioritise patient choice, the establishment of statewide networks and the consolidation of complex cancer surgery to fewer locations. This consolidation builds critical expertise, leading to enhanced care quality and opportunities to reduce costs as procedural proficiency grows.

93. A comprehensive system-wide view also enables identification of areas for capacity building and cost avoidance, supporting future sustainability. For instance, recognising

significant variation across the state in the uptake of hypofractionated radiotherapy (fewer radiotherapy sessions) for early-stage breast cancer revealed an opportunity to build service capacity, reduce costs and improve patient outcomes. Collaborative efforts to address barriers to change led to an accelerated adoption of guideline-aligned practices, enhancing patient care by reducing treatment time and potentially saving $540,000 in out-of-pocket expenses for patients across NSW. The estimated benefit to the system included expanded capacity, enabling treatment of an additional 1,660 women from 2021 to 2030, and $6.8 million of costs savings for NSW Heath by eliminating low-value care. This change model relied on delivering accurate, system-level clinical data to services in a timely trusted manner.

94. The RBCO program also focuses on using data to better understand disparities in access to and utilisation of cancer care, as well as outcomes for vulnerable populations at both state and LHD level. The Cancer Institute's rich linked data assets enable a better understanding of the impacts of the social determinants on cancer outcomes. The RBCO program's reporting in 2024 highlights the increased risk of death at 2 years across the top 5 cancers when people have 1 or more degrees of disadvantage in social determinants of health, laying the groundwork for deeper insights. The Cancer Institute is using this knowledge to design initiatives to improve equity in cancer care.

Ensuring safe, high value care

95. With evidence around cancer and new treatments proliferating so rapidly, no individual service or LHD would be able to keep pace. The Cancer Institute delivers centralised tools, information and training to ensure local care aligns with the latest evidence.

96. The eviQ program, established over 20 years ago, supports the delivery of safe and effective, evidence-based cancer treatments. eviQ consists of two complementary resources: eviQ Cancer Treatments and eviQ Education. Content is clinician-led, with over 500 clinical experts across 20 expert reference committees, ensuring multidisciplinary expertise in treatment protocols, rigor in evidence review and consensus recommendations.

97. Central coordination and infrastructure at the Cancer Institute saves clinicians time, reduces duplicated efforts and minimises unwarranted variations in care. Due to financial constraints, eviQ reference committees have shifted online, discontinuing in-person sessions where clinical experts collaborate, regarded as the preferred method for

stakeholder engagement and forum for nuanced and robust conversations to achieve protocol consensus.

98. eviQ contains over 1100 cancer treatment protocols and is used in all cancer services in NSW, across Australia, and globally in over 200 countries with 2.2 million sessions annually. Feedback from over 500 clinical users show 93% agree that the eviQ information supports evidence-based treatment and care standardisation.[12]

99. At the point of care, eviQ provides clinicians with essential safety information for cancer treatments, including information on drug doses and schedules, drug interactions, and identifying and managing toxicities. This enables clinicians to provide consistent, high-quality education to patients, helping them manage any toxicities after discharge.

100. eviQ Education resources support training and education in cancer treatment services and multidisciplinary care teams. The Antineoplastic Drug Administration Course (ADAC) education modules are embedded nationally as the minimum standard for all nurses and pharmacists working in cancer care, with over 49,000 users across the country. Evaluation by 14,700 clinical staff show a 94-96% satisfaction rate and 87% reporting increased knowledge that improves their practice and patient care. The rapid learning material and eviQ information is used across many cancer education activities and within university training programs (pharmacy, nursing and medical training).

Patient Reported Measures supporting person centred and high value care

101. With an estimated half of patient's symptoms being missed during medical consultations, a PRMs tool was introduced to elevate the patient voice and enhance the commitment to patient centred care. NSW has led the nation in embedding a patient-reported outcomes tool across cancer units state-wide. This point-of-care tool gathers insights on what matters most to patients, giving clinicians real time data to support effective management during consultations. Available in 11 languages plus an Aboriginal Wellbeing self-reported tool, it has facilitated over 24,000 personalised assessments for over 11,000 patients.

102. The PRMs tool was centrally developed and co-designed with 50 stakeholders across LHDs, ensuring local input and decision making through a statewide lens. This approach

[12] Shingleton JV, Stapleton BW, Kelly AP, Ward RL, Lean CL, Rushton SA, O'Brien TA. eviQ Cancer Treatments Online: Providing evidence-based information to improve cancer patient outcomes. Asia Pac J Clin Oncol. 2024 Aug;20(4):491-496. doi: 10.1111/ajco.14067. Epub 2024 Apr 17. PubMed PMID: 38629178. Available online https://pubmed.ncbi.nlm.nih.gov/38629178/

fostered local ownership and created a simple, robust tool adaptable to each LHD service workflows – key to its successful implementation and sustainability, unmatched in any other state.

103. Almost 50% of patients have requested further support information, and early evidence shows a 33% reduction in unplanned emergency department admissions from one LHD using PRMs. The program has received positive feedback with a range of benefits including practical and financial patient support, earlier management of toxicities, faster referrals to allied health, and reduced levels of patient distress.

H. RESEARCH TO IMPROVE CANCER OUTCOMES

104. Through strategic capacity building, the Cancer Institute has positioned NSW as leading hub for cancer research, attracting additional investment and establishing the state as a preferred location for clinical trials.

105. Investment in research accelerates improvement in cancer outcomes. It is conservatively estimated that for every dollar invested in cancer research, $3.43 in economic returns are gained.[13]

106. Cancer research projects funded by the Cancer Institute span the entire cancer continuum, including pre-clinical and discovery research, prevention, early detection, treatment and survivorship. The Cancer Institute is committed to building research and translating research into practice. This is achieved by investing in the next generation of research leaders, supporting research and clinical trials infrastructure, providing funding for major translational research programs and fostering collaboration across research and clinical sectors.

107. The Cancer Institute's research grants are awarded via a competitive, independent grant process and in accordance with the *Grants Administration Guide* (**SCI.0001.0049.0001**). Grants agreements include milestones and deliverables, including annual and final reports and financial acquittal statements. An external Grants Review Committee reviews annual and final reports of the translational research program to assess progress and potential risks.

[13] Glass, P, Pezzullo ML, Culter HG, Yates KA, Tracey EA, Welberry H, Catazariti A, and Bishop JF. The Health Returns on Investment in Cancer Research. Cancer Institute NSW Monograph, May 2008. Available online https://www.cancer.nsw.gov.au/getattachment/69f39b11-ab7e-487a-8851-a3f096c7d95e/rm-2008-3_health-returns-on-investment.pdf

108. The Cancer Institute has strategically focussed on expanding research capacity since its establishment in 2003, with significant impact. A key indicator of success is the ability to attract additional competitive grant funding. Cancer Australia's analysis of funding trends from 2003 to 2020 highlights indirectly Cancer Institute effectiveness. In the early years, from 2003 to 2005, NSW secured 25% of the country's competitive cancer research funding, totally $72.6 million while Victoria received 39% or $114M. However in the latest reported period, 2018-2020, NSW saw consistent year on year growth, attracting over $400 million, or 43% of funding, more than any other state, including Victoria, which secured 36% ($332 million). This sustained increase reflects NSW's strengthen research pipeline and strategic position in cancer research. Over the study period, the Australian Government provided the largest share of cancer research funding (58%), with smaller contributions from states and territory governments (12%), cancer councils (11%), medical research institutes, hospital and foundations (5%) and universities (2%).[14]

109. Research funding is allocated from the annual Cancer Institute budget. Annual funding cycles limit longer term strategic research investment and in fiscally challenging times, spending on research, where return is often years later, is often reduced or suspended for more urgent clinical need. In the 2023-24 financial year, no new research grants were given by the Cancer Institute to meet savings and budget targets.

110. The Cancer Institute provides investment in clinical trials supporting infrastructure, equipment, staff and educational activities. There were 795 cancer clinical trials available in NSW at over 80 clinical trial units; 2,571 people with cancer in NSW were enrolled into a clinical trial in the 2023-24 financial year.

111. The Cancer Institute provides benchmarking data on clinical trial activity to LHDs. This data supports LHDs to monitor their progress against other clinical trial units across the state, identify gaps and inefficiencies and provide opportunities for areas of improvement. It also maps flow of patients in and out of the LHD to access clinical trials.

112. The Cancer Institute is leading work in partnership with LHDs and community groups to addressing barriers to access clinical trials for priority populations including adequate in-language resources, education and training for clinical staff, community advocacy groups

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[14] Cancer Research in Australia An overview of funding for cancer research projects and programs in Australia 2012 to 2020, available online https://www.canceraustralia.gov.au/sites/default/files/publications/cancer-research-australia-overview-funding-cancer-research-projects-and-programs-australia-2012-2020/pdf/cancer_of_funding_for_cancer_research_projects_and_programs_in_australia_2012_to_2020_final.pdf

and heath care interpreters. In the 2023-24 financial year, reported data indicated a 125% increase in Aboriginal participation in clinical trials.

113. The Cancer Institute supports the state's NHMRC-accredited Research Translation Centre (Advanced Health Research and Translation Centres and Centre for Innovation in Regional Health) through its Translational Cancer Research Capacity Building Grants. These are designed to 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.

114. The Cancer Institute's Research Equipment Grants scheme supports researchers to access to equipment and related infrastructure enabling a more rapid progress down the translational pathway. This has been particularly relevant in the adaption of multi-omics which is the pathway to precision medicine.

115. Effective cancer research requires a sustainable expert workforce. The research sector faces ongoing workforce challenges due to short term contracts and grants-based funding. The Cancer Institute has focused on building a pipeline of future research leaders through its program of early and mid-career fellowships. Evidence shows that research fellowships offer a significant return on investment.

116. 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.

Professor Tracey O'Brien	Witness: Sarah Crosby
	
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