NSW Cancer Plan 2022-2026

Cancer Council NSW Submission

26 April 2021

Contents

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

Executive Summary

Cancer Council NSW welcomes the opportunity to inform the draft NSW Cancer Plan 2022-26 (the draft Plan). We commend the NSW Government on the development of the draft Plan and the chance to set a clear roadmap towards a cancer free future in NSW. NSW can take pride in the tremendous improvements in cancer outcomes over the past three decades. However, these gains are not shared equally and we are pleased to see equity as a major theme within the next NSW Cancer Plan.

We know the greatest opportunity to reduce the burden of cancer is through prevention, screening and early detection. NSW can benefit by implementing effective prevention and early detection strategies, intensifying efforts and policies to ensure equitable delivery of and access to high-quality care, and integrating survivorship care into clinical practice.

Our recommendations within this submission, while ambitious and comprehensive, are also achievable, informed by evidence, and developed in consultation with community, clinicians, researchers and policy makers. To ensure the vision to end cancers as we know them is realised, we believe the final Plan and its underpinning implementation plans must be:

- **Ambitious and accountable**. Visionary goals need to be objective and measurable, while indicator targets should be used to drive coordinated efforts for each priority area.
- **Holistic and actionable**. The Plan must provide the comprehensive high-level roadmap towards the vision and must be supplemented with specific, co-designed implementation plans to coordinate state-wide collaborative action.
- **Future-focused**. The Plan must outline how its goals can be achieved considering emerging technologies, demographic changes, COVID-19 and rapidly evolving diagnostic and treatment conventions. A view beyond the five years of each Plan is needed.
- **Consumer and community centred**. The principles of meaningful consumer and community involvement outlined in the National Framework for Consumer Involvement in Cancer Control should be embedded in all implementation activities.

Cancer Council NSW is well placed and committed to working with the NSW Government and other stakeholders to support implementation of many of the initiatives outlined in this report. Our recommendations complement existing work and we look forward to working collaboratively with all stakeholders as we strive towards a cancer free future.

1. Introduction

As Australia's leading cancer charity, Cancer Council NSW welcomes the opportunity to comment on the draft Plan. Every day, we support families affected by cancer when they need it most, speak out on behalf of the community on cancer issues, empower people to reduce their cancer risk, and find new ways to better detect and treat cancer. We believe in a cancer free future.

Our 2019-2023 Strategy details how we are reducing cancer risk, increasing cancer survival, improving the quality of life for people affected by cancer and improving cancer outcomes for priority populations.

The draft Plan has a vision to "end cancers as we know them". Translating this vision into a reality requires meaningful and collaborative action across the entire cancer control system and beyond. We offer our experience, knowledge, and support to help achieve this.

The draft Plan provides a solid foundation from which NSW can continue to enhance cancer prevention and screening efforts, facilitate optimal care and treatment, and foster research that is routinely translated into policy and clinical practice.

Our submission focuses on issues that are fundamental to shifting the dial on outcomes across cancer control. Our recommendations are evidence-based and informed through widespread stakeholder engagement with experts and our communities with lived experience. Where possible, our recommendations align with and complement existing state and federal health policies.

Collective cancer control efforts from stakeholders across NSW have produced tremendous improvements in cancer outcomes. However, we know these efforts need to redouble in light of important macro-level trends: a growing and ageing population; technological advances and the shift towards personalised medicine; and the impacts of COVID-19. This rapidly evolving landscape raises important cancer control challenges for the future of NSW.

Outcomes remain unacceptably poor for many people from Aboriginal communities, culturally and linguistically diverse communities, for people living in rural and regional communities and those experiencing socioeconomic disadvantage. Cancer inequity forms a major theme of our own strategy, this submission and our recommendations are shaped through this lens.

> *"In rural areas, the frustration of accessing cancer specialists and appointments adds so much stress to the person with cancer, that often they just give up".*
>
> - *Person affected by cancer*

Cancer Council NSW is committed to collaborating with the NSW Government and other stakeholders to support implementation of many of the initiative outlined in this draft Plan.

2. Overview of cancer control in NSW in 2021

NSW has seen tremendous progress across cancer control over the past three decades [1]. Mortality rates are decreasing for most cancer types and we experience some of the highest cancer survival rates in the world [2]. Cancer Council NSW recognises that progress in cancer outcomes have been made possible because of the NSW Government's investment in and commitment to cancer control, including under previous NSW Cancer Plans. Achievements include:

- **Decreasing** smoking prevalence among Aboriginal and Torres Strait Islander Peoples Australians from 32% to 23%.
- **Increasing** proportion of adults who reported getting the recommended amount of exercise each week from 55.8% to 58.4%.
- **Increasing** proportion of the eligible NSW population participating in the National Bowel and Breast Cancer Screening Programs.
- **Increasing** the proportion of surgeries for lung, oesophageal and pancreatic cancers being undertaken at hospitals that meet the minimum caseload requirements.
- **Increasing** the ratio of enrolments in cancer clinical trials across the state from 6:100 in 2015 to 9:100 in 2017/2018.
- **Implementing** the Translational Cancer Research Centres and enhancement of collaborative research
- **Progress** in cancer data sharing and collaboration through linked data sets, including the Enduring Cancer Data Linkage initiative.

While these achievements should be celebrated, we also know progress in a number of NSW key cancer control indicators have also stalled and in some cases are worsening: declines in adult smoking rates have plateaued and rates of smoking while pregnant are increasing; obesity rates continue to rise; many sun protection behaviours remain unchanged since early 2000s [2]. Despite increasing participation in life-saving cancer screening programs, NSW is still well behind many other states and territories, national targets and participation rates seen in comparable countries [2].

Moreover, the draft Plan correctly identifies that advances in cancer control have not been shared equitably across the state. Disparities in prevention, screening, access to high-quality care, morbidity, and survival — particularly among low socioeconomic, culturally and linguistically diverse and rural populations — persist, and in some cases are widening [3].

The benefits of reducing the incidence and impact of cancer extends beyond individual health to the wellbeing of entire communities and the economic prosperity of the state [4-6]. Cancers account for almost 10% of total disease expenditure – in NSW this equates to over $2.5 billion in 2015-16 and is expected to increase [7]. Importantly, a substantial proportion of this expenditure is directly attributable to preventable risk factors associated with bowel, breast, lung, and non-melanoma and melanoma skin cancers [7].

The Plan provides a tremendous opportunity for NSW to build on the success of previous Plans and translate the wealth of cancer control research and evidence into action [8]

> *"The government has a responsibility to provide health care to all residents, not just those that live close to the beach"* - Cancer survivor

3. Goals

We welcome the goals described in the draft Plan and recognise these as crucial factors to achieving the vision. Alongside each goal we recommend an aspirational target to which all NSW cancer control collaborators can strive for and celebrate. Key indicators of objectives within each priority area should also be benchmarked against targets. While the draft Plan does not include specific, measurable targets, we hope to see this strengthened in the final Plan or included within implementation plans. Cancer Plans developed by other jurisdictions have SMART goals and targets which NSW could adapt. We know health targets can serve as a benchmark to evaluate our success and inform priorities to meet future demands.

To improve consistency and comparisons across jurisdictions, final NSW cancer control indicators should be mapped to priority area objectives, align with the National Cancer Control Indicators developed by Cancer Australia, and publicly reported on through the NSW Performance Index. We also believe it could be made clearer how each priority area and the associated actions map to the four goals.

4. Guiding Principles

4.1. Equity

We strongly support the addition of equity as both a guiding principle and goal in the draft Plan. If we are to improve equitable cancer outcomes and experiences, we must acknowledge the social, environmental, economic, cultural, biomedical and commercial factors that lead to inequity and inequality. It is these inequities that lead to the burden of disease being experienced disproportionately by some, the final Plan and implementation plans must consider these underlying factors through a collaborative and health-in-all policies approach [9,10]. Proposed and existing cancer services, interventions and programs must be tailored to the needs of particular groups through meaningful partnerships with the affected communities.

> *"When my son was diagnosed with leukaemia I had to move to Sydney for a year, until his death, as there is nothing in rural NSW."*
>
> - Mother of a child with cancer

4.2. Holistic, systems-wide and collaborative

We strongly support the addition of person-centredness and collaboration as guiding principles in the draft Plan. Creating and fostering purposeful partnerships between the NSW health system, communities, non-government organisations and private providers is required ongoing to ensure the cancer plan goals are met. We must enhance meaningful consumer and community involvement at all levels of cancer control in line with the National Framework for Consumer Involvement in Cancer Control. Consumer and community involvement extends from governance and evaluation of the Plan to implementation activities and Cancer Council NSW can play a key role here. Adopting meaningful partnerships at the regional level recognises that local individuals are best placed to understand local needs and improve health outcomes for their communities.

4.3. Policy alignment

We encourage clearer alignment between the final Plan's objectives and activities to other NSW policies and strategies (e.g., NSW Alcohol and Drug Strategy awaiting release) and federal policies (e.g., the upcoming National Preventive Health Strategy). Cancer Council NSW proposes a series of targets and indicators for consideration in alignment with existing policy in the following sections.

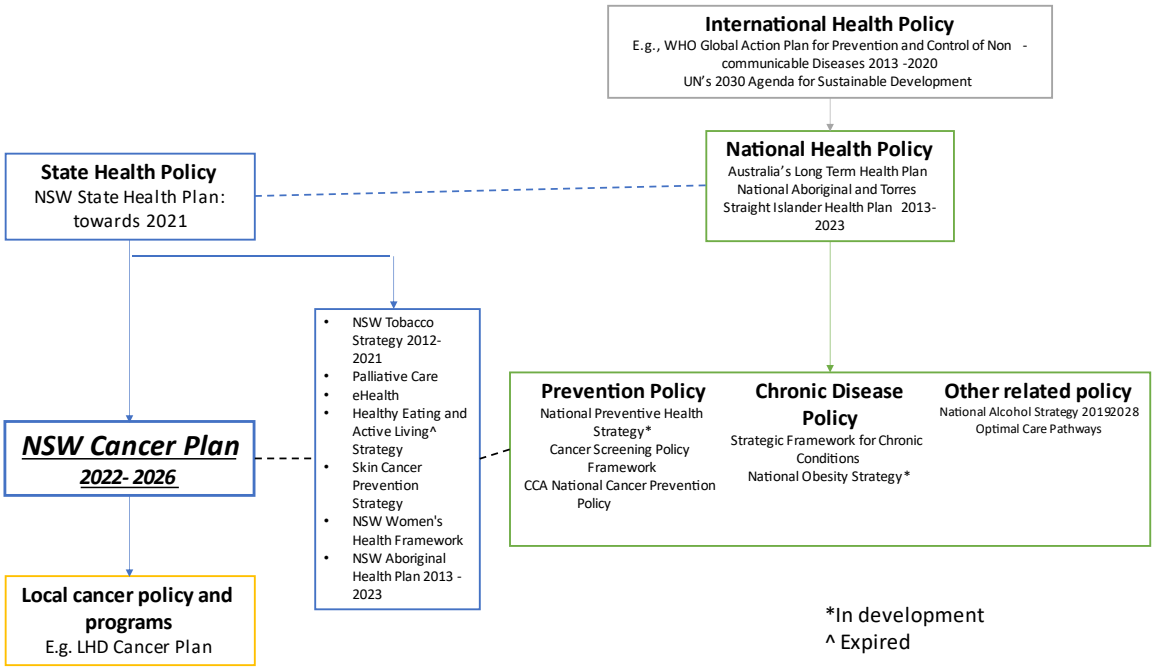


Figure 1. Relationship between the NSW Cancer Plan and other health-related policy

5. Priority areas

We acknowledge the importance of preventing cancers, screening and early detection, optimal care and research and welcome these as priority areas within the draft Plan. In this section we make recommendations for actions to support and strengthen the priorities in the Plan. These recommendations are based on the encouraging progress over the 2016-2021 NSW Cancer Plan, emerging trends, evidence and community sentiment. We also outline aspirational targets and indicators of success to ensure we deliver for the people of NSW. For a detailed description of how we tracked progress against indicators, see *Appendix 5*.

Priority 1. Prevention of cancers

We know at least 1 in 3 cancer cases can be prevented through lifestyle changes – even modest reductions in exposure to these known causes of cancer would translate to tremendous reductions in cancer burden [11, 12].

The NSW community needs an increased and sustained focus on creating environments that not only support but motivate and enable healthy living and prevent cancer. Importantly, we already know how to do this [13, 14].The opportunity is for NSW to demonstrate the leadership and courage to implement what we know works.

The development of a National Preventive Health Strategy provides an important opportunity for the NSW Government and cancer control collaborators to increase and align efforts to reduce tobacco use, improve access to and the consumption of a healthy diet, increase physical activity, reduce alcohol-related harm, improve sun protection behaviours, prevent cancer-related infections and raise awareness of modifiable risk factors that can lead to preventable cancers.

Recommendations

Cancer Council NSW supports the actions outlined in the draft Plan. In the table below we outline actions to be considered in the final Plan or implementation plans across regulation, programs, services and, mass media campaigns that can further strengthen this priority area.

Priority 1: Halve the proportion of preventable cancers diagnosed by 2040		
Strengthen regulation to prevent cancers	**Enhance primary and secondary prevention programs and services**	**Investment in evidence-based mass media campaigns**
➢ Pursue tobacco retail policy reform to reduce the availability of cigarettes. ➢ Work with the Commonwealth and states and territories to set a date for the phase-out of all retail e-cigarette sales without prescription, including those	➢ Pursue tobacco retail policy reform to reduce the availability of cigarettes. ➢ Protect children from unhealthy food and drink advertising in public spaces. ➢ Work with the Commonwealth and states and territories to strengthen	➢ Increase NSW Government investment in anti-smoking mass media campaigns to evidence-based levels. ➢ Provide recurrent funding for mass media skin cancer prevention campaigns.

Priority 1: Halve the proportion of preventable cancers diagnosed by 2040		
Strengthen regulation to prevent cancers	**Enhance primary and secondary prevention programs and services**	**Investment in evidence-based mass media campaigns**
selling nicotine-free products. ➢ Facilitate healthier food choices through mandated Health Star Ratings, strengthened nutrition and health claims regulation and restricted promotion of unhealthy foods and drinks in prominent food retail environments. ➢ Protect children from unhealthy food and drink advertising through comprehensive government regulation (including removing junk food advertising from state-owned property). ➢ Ensure public health priorities are addressed in planning regulation. ➢ Finalise and release the NSW Alcohol and Drug Strategy to provide a framework for action on alcohol. ➢ Collaborate with the Commonwealth to introduce a 20% health levy on sugar-sweetened beverages. ➢ Implement evidence-based measures addressing alcohol pricing, availability and promotion in coordination with the National Alcohol Strategy.	laws around the use of e-cigarettes and the safety of liquid nicotine products. ➢ Finalise and release the NSW Alcohol and Drug Strategy to provide a framework for action on alcohol. ➢ Implement evidence-based measures addressing alcohol pricing, availability and promotion in coordination with the National Alcohol Strategy. ➢ Develop strategies to optimise vaccination rates against cancer-causing infections. ➢ Implement healthy food provision guidelines in schools, government facilities, workplaces, sporting clubs, community facilities and events.	➢ Invest in campaigns to promote the NHMRC alcohol guidelines and Dietary Guidelines.

See *Appendix 1* for relevant indicators, interpretation, issues and challenges.

Targets

Here we provide a series of targets, aligned with established state and national policy targets, that NSW cancer collaborators could consider adopting:

- Reduce the current (daily + occasional) smoking prevalence to less than 10% by 2025 in line with the National target
- Commit to the National target of reducing smoking prevalence to less than 10% by 2025
- Halt the rise and reverse the trend in the prevalence of obesity in adults by 2030
- Reduce overweight and obesity in children aged 5-17 years by 5% by 2030
- 10% reduction in harmful alcohol consumption by Australians (≥14 years) by 2025
- Increase hepatitis B vaccine coverage in priority populations to 90% (Consistent with global target set by WHO and draft National Preventive Health Strategy)
- Maintain high and equitable HPV vaccine coverage of 80% of adolescents vaccinated by age 15, including reaching this target in Aboriginal and Torres Islander adolescents, and adolescents in remote and low-SES areas (Consistent with global target set by WHO)

Priority 2. Screening and early detection of cancers

For many cancers, diagnosing and starting treatment earlier saves lives [25]. We know that for every person with suspected cancer, shortening the wait between suspicion and exclusion or confirmation of cancer will reduce anxiety and improve the experience of care. Policies focused on minimising system level delays to cancer treatment initiation could improve population level survival outcomes.

> *"You should not have to delay your diagnosis because you can't get an appointment in time. Cancer doesn't wait."*
>
> - Carer

Recommendations

Cancer Council NSW supports the actions outlined in the plan to improve screening and early detection of cancers. In the table below we outline further actions to be considered in the final Plan or implementation plans to strengthen this priority area.

We commend initiatives such as the Cancer Institute NSW's Cancer Screening and Prevention Grants which allow community organisations like Cancer Council NSW to deliver targeted programs aimed at improving screening participation rates in under-screened communities.

Cancer Australia's inquiry into lung cancer screening recommended a national lung cancer screening program. We welcome these findings and note that implementation of a national lung cancer screening program will require meaningful collaboration with NSW. Consideration of how NSW can support implementation is a clear and pressing priority for the Cancer Institute NSW and Cancer Council NSW. Further opportunities include working with jurisdictional partners to implement recommendations from the national roadmap to improved liver cancer outcomes.

Priority 2: NSW leads Australia in cancer screening participation			
Detect cancers earlier	**Improve bowel cancer screening participation**	**Improve breast cancer screening participation**	**Improve cervical cancer screening participation**
➢ Develop and pursue ambitious 5-year targets for cancer screening participation comparable to those in similar countries. ➢ Develop KPIs for screening participation in cervical, bowel and breast programs for priority populations ➢ Prioritise targeted, co-designed and community-based interventions to increase participation for under screened populations. ➢ Provide culturally appropriate, acceptable and responsive services for all of NSW ➢ Improve data collection to capture under-screened populations ➢ Advance opportunities to detect liver cancer earlier for at-risk populations in line with the findings of the Roadmap to improved liver outcomes. ➢ Work with National and local partners to implement a National Lung Cancer Screening Program ➢ Better engage and involve primary care in the three national screening programs ➢ Include a stage of diagnosis indicator in the Performance Index	➢ Commit to ongoing investment in mass media campaigns and targeted strategies to increase participation in the National Bowel Cancer Screening Program ➢ Evaluate and scale up Direct Access Clinics to reduce wait times for colonoscopy after a positive FOBT	➢ Continue and support further research, planning and implementation of risk-based breast cancer screening strategies. ➢ Implement recommendations from Roadmap for Optimised Screening in Australia, Breast	➢ Work towards WHO cervical cancer elimination targets by implementing strategies to improve screening participation in priority populations. ➢ Fund culturally appropriate, targeted interventions to increase cervical screening participation among under-screened women, including promotion of self-collection ➢ Consider novel approaches to invitations and reminders to cervical screening, in line with the younger screening target group starting at 25 years, where a posted invitation may not be effective

See *Appendix 2* for relevant indicators, interpretation, issues and challenges.

Targets

- Eliminate cervical cancer as a public health issue by 2028.
- Increase cervical screening participation to 70% by 2028, including specifically among Aboriginal and Torres Strait Islander women, women in low-SES and remote areas (in line with comparable countries such as New Zealand)
- Increase breast cancer screening participation above 65% (consistent with the draft Australian Government National Preventive Health Strategy)
- Increase participation in the National Bowel Cancer Screening Program to 60% by 2025
- Increase self-administered cervical screening to 5% by 2023 to ensure all groups benefit from cervical screening.

Priority 3. Optimal cancer treatment, care and support

The draft Plan recognises that all people with cancer deserve timely and equitable access to best-practice care and support. By national and international standards, NSW has an excellent healthcare system. However, we also know that outcomes for people with cancer across the state show marked variation.

Cancer Council NSW commends Cancer Institute NSW's commitment to addressing disparities in cancer care through its Reporting for Better Cancer Outcomes program.

Recommendations

Cancer Council NSW supports the actions outlined in the draft Plan. However, we believe the best model for enhancing optimal cancer treatment, care and support is by improving access to treatment and care as outlined in the Optimal Care Pathways [8].

> *"Just yesterday I had to make a 150km round trip to visit a GP even though I do not live in a remote area."*
>
> - *Person affected by cancer*

Cancer Council NSW supports the commitment to collecting and using patient-reported outcomes and experience measures in the draft Plan. We strongly believe NSW treatment centres should collect the core outcome set of for national surveillance of the long-term quality of life of cancer survivors [32]. These data should be integrated into routine clinical practice to enable integrated clinical teams to respond to patient symptoms and needs in real time.

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

Creating and fostering purposeful partnerships between the NSW health system, communities, non-government organisations and private providers is essential to improve the outcomes and experiences of people with cancer and enable ongoing provision of optimal care.

We urge the NSW Government to work in partnership with communities and community organisations such as Cancer Council NSW to address root causes and implement tailored solutions to ensure that all people are able to access quality health services when and where they need them.

In the table below we outline further actions to be considered in the final Plan or implementation plans to strengthen Priority Area 3.

Priority 3: All people can access quality care when and where they need		
Accelerate adoption of person-centred and high value cancer care	**Embed Optimal Care Pathways as standard care for people affected by cancer**	**Adopt, evaluate and scale up evidence-based models of care according to implementation science**
➢ Organise, deliver and monitor cancer care in line with OCPs. ➢ Better integrate primary care and services provided by community-based organisations with hospital-based care. ➢ Prioritise outcome-focused health system policy that encourages and rewards holistic, person-centred care. ➢ Expand access to and availability of multidisciplinary supportive and psychosocial care. ➢ Develop mechanisms to support partnerships between the PHNs, LHDs and communities to facilitate joint planning, priority setting and commissioning of care. ➢ Support health services to implement the principles of consumer and community partnerships detailed in the National Framework for Consumer Involvement I Cancer Control. ➢ Embed Cancer Council Australia's Standard for Informed Financial Consent as standard practice across the health system ➢ Investigate strategies to ensure public patients being treated in regional cancer centres can access private-public services with no additional out-of-pocket costs	➢ Develop and implement a state-wide plan to embed and report on care consistent with Optimal Care Pathways. ➢ Continue to update clinical quality registries (including CINSW RBCO program) that report process and outcome measures, including wait times and patient reported experience and outcome measures that align with optimal care pathways. Alignment of these measures with optimal care pathways ensures these data are patient-centred and can: ○ Enable HPs to use PROMs to guide real-time care and enhance clinical decision making ○ Better integration of care across primary, secondary and tertiary care ➢ Partner with Aboriginal organisations to effectively implement the *Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer*	➢ Enhance methods to promote the systematic uptake of evidence-based practices into routine practice through implementation science to improve performance and delivery of health services ➢ Implement a plan to develop, evaluate and scale-up telehealth and virtual cancer care models

See *Appendix 3* for relevant indicators, interpretation, issues and challenges.

Targets

- All patients' treatment and support options are reviewed and planned by a multidisciplinary team
- All consumers have access to reliable information about their cancer care, treatment pathway and potential costs.
- Time between phases of care, such as time from referral to diagnosis, and time from diagnosis to treatment, is in line with OCPs.

> *"Mum was diagnosed with pancreatic cancer on a Thursday and was only alive for 1 more week. My father asked for some counselling to deal with mums aggressive and sudden cancer diagnosis but got knocked back - there was nothing."*
>
> - *Family member of a person with cancer*

Priority 4. Cancer research

The integration of research and innovation into the delivery of cancer services and programs is essential to ensure cancer control is underpinned by evidence.

NSW is a leader in cancer research and we recognise the work of the Cancer Institute NSW in providing researchers access to linked cancer-related data sets.

> *"The really important thing is that, particularly for rural people, this could be the thing that makes a difference between life and death for people."*
>
> - Cancer survivor discussing clinical trials

Recommendations

We support the actions outlined in the draft Plan. Research activities and investments should be linked to NSW health system priorities and actively translated into policy and practice. In the table below, we propose further actions across four key domains to be considered in the final plan or implementations plans:

Priority 4: NSW leads Australia in clinical trial participation			
Prioritise linked datasets to improve health service delivery, performance and research	**Focus on implementation research to enhance the adoption of what works**	**Adopt tele-oncology models of care to improve trial participation and enhance cancer research capacity**	**Prioritise consumers as research partners not simply participants**
➢ Continued long term commitment to access linked cancer-related data sets for researchers and health services	➢ Enhance implementation science research capacity	➢ Adopt Australasian Tele-trial Model as standard practice in NSW to enhance clinical trial participation ➢ Enhance access to clinical trials across	➢ Involve consumers along the entire research agenda in a meaningful and authentic way.

	NSW, with specific focus on Aboriginal and Torres Strait Islander people, people from Culturally and Linguistically Diverse communities, and people who live in regional, rural and remote areas

See *Appendix 4* for relevant indicators, interpretation, issues and challenges.

Targets

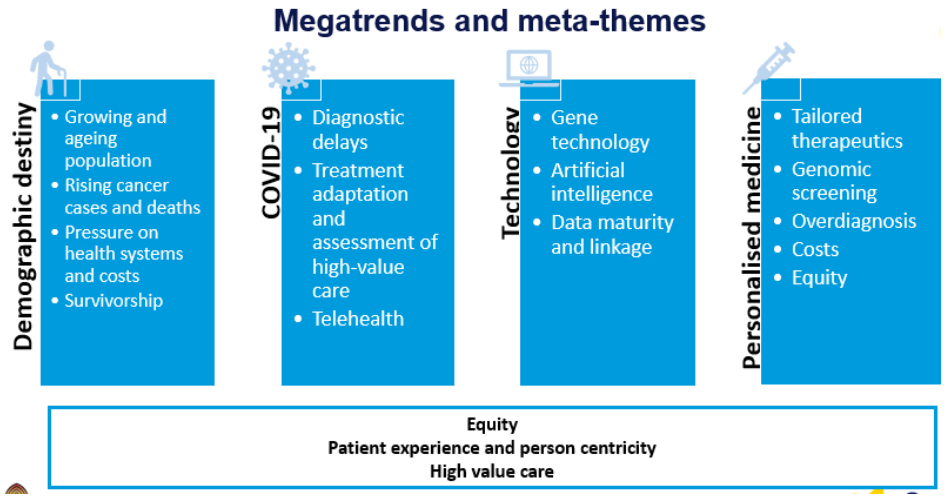
- Increase the overall number of new clinical trial enrolments in rural and regional areas by 30% (in line with the Victorian Cancer Plan)

6. System enablers

Cancer Council NSW supports and commends the strength of the identified system enablers within the draft Plan. Effectively leveraging these factors over the lifespan of this plan and beyond will help ensure NSW can meet future cancer control needs and deliver an efficient and effective cancer system.

As described in the draft Plan, a key challenge for NSW, consistent with global trends, is the increasing number of cancer cases and deaths. We know this is largely due to the growth in size and ageing of the population which is predicted to increase the demand for health services in the future [39]. This is our 'demographic destiny' according to NSW Treasury [40]. Changes in population exposure to cancer risk factors, advancements in treatment, and increased early diagnosis due to diagnostic innovations and cancer screening programs have and will continue to affect cancer incidence and mortality rates, resulting in people surviving longer and an ever increasing proportion of people who have ever been diagnosed with cancer [39]. That people with cancer are surviving longer is cause for celebration, yet these successes bring new public health challenges that must be addressed by collaborators under this NSW Cancer Plan.

Technology will revolutionise cancer care and society at large. Technologies such as genomics, precision medicine, artificial intelligence, and linked mega-data, to name a few, promise to improve quality of life and cancer outcomes yet without good systems, frameworks, regulation and guidelines, these technologies can underdeliver on benefits and overdeliver on harms.



Technology will also change consumers expectations of healthcare. Compounding these challenges is the rising cost and complexity of cancer care, which will exacerbate financial, workforce and health system pressures.

The impacts of COVID-19 will be long felt

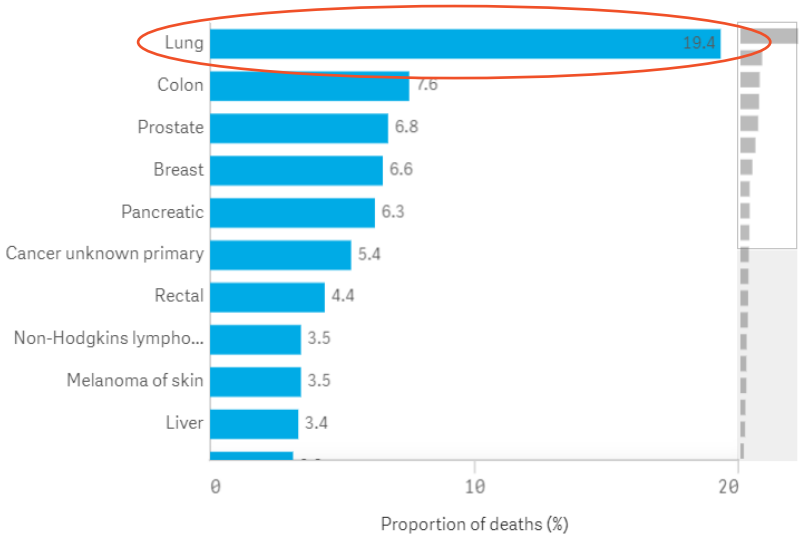
The exceptional circumstances of the COVID-19 pandemic have dramatically altered cancer care. Disruptions have been seen across all facets of cancer care, from delaying diagnoses and treatment to halting clinical trials, and diminishing access to psychosocial support [41-46]. In response to heightened vulnerability to COVID-19, cancer treatments were modified, cancer service utilisation declined and cancer screening was disrupted [47, 48]. While the long-term effects of these disruptions will not be known for some time, the psychosocial impact on patients, families, and carers is increasingly evident [42, 49]. However, not all consequences of the pandemic have been undesirable. The rapid implementation of telehealth within cancer services largely been successful and may offer permanent value in enhancing cancer care quality and access. The Plan or supporting implementation plans should consider how we can all mitigate the ill-effects and maximise the positive consequences of the pandemic.

Lung and liver cancer pose long term challenges for NSW

Lung cancer is the leading cause of cancer death by far in NSW and tobacco use is still the most important risk factor [50]. In NSW, studies show that while incidence of lung cancer among men has decreased over the past 25 years, there has been an increase in disparity across socioeconomic groups [51].

Almost half of all lung cancers are diagnosed at an advanced stage in Australia (42% of cases diagnosed at Stage 4) [20]. A significant shift in the lung cancer outcomes may therefore lie with improved early detection through lung cancer screening for those at high-risk. In late 2020, Cancer Australia released a proposal for a national lung cancer screening program to be implemented over four years. Although this is an Australian Government program, delivery will require the support and cooperation of States and Territories and will likely be implemented within the lifespan of the 2022-2026 NSW Cancer Plan.

Figure 2. Proportion of cancer deaths, NSW, 2013-2017. Source: CINSW Performance Index



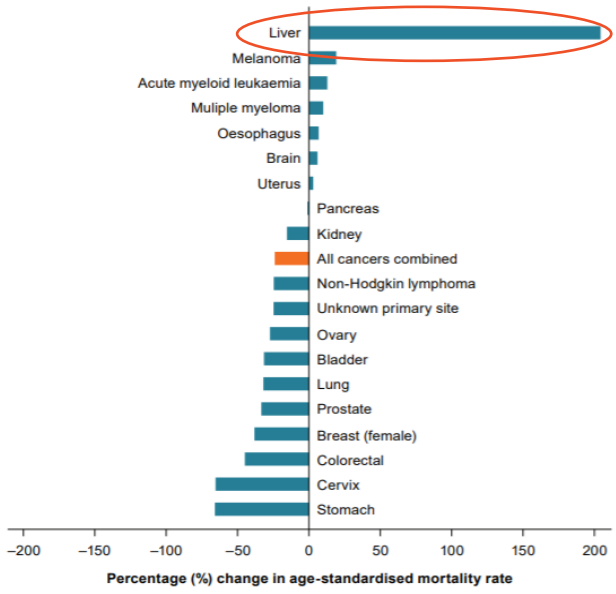


Figure 3.. Estimated percentage change in age-standardised mortality rates for selected cancers between 1982 and 2019. Source: AIHW Cancer in Australia 2019

In the context of Australian cancer prevention and care, liver cancer is an outlier, with estimated mortality rates almost three times the rate since 1982 [20]. It is the only low survival cancer that is rapidly increasing in incidence in Australia. The key drivers of increasing incidence and mortality include an ageing population, increasing prevalence of metabolic syndrome and type 2 diabetes, increased migration from hepatitis B endemic countries and hepatitis C [20]. Strategies to mitigate risk factors and improve surveillance of liver health for at-risk groups are urgently required and should be implemented in step with findings from the Roadmap to improved cancer outcomes currently in development by Cancer Council.

7. Implementation, monitoring and public reporting

Implementation

We acknowledge the importance of translating this plan into policy and practice and would welcome an ongoing opportunity for collaboration through the NSW Cancer Plan Governance Committee. To support the rollout and tracking of the Plan we further suggest:

- Partnering with non-government, consumer and community stakeholders to develop implementation plans.
- Public reporting progress against the goals and targets through the Performance Index.
- Supporting LHDs to translate the state plan into LHD-specific implementation plans.
- Establishing collaborator working groups for each priority area to better coordinate and communicate activities. These groups should include consumer and community collaborators.

Monitoring

Implementation of the Plan should be measured against clear criteria for success described in an evaluation framework. Reporting should include changes over time to assess impact, help identify investment and implementation priorities and focus action. This requires establishing a set of performance & quality indicators mapped to objectives. For example, the Victorian cancer plan monitoring and evaluation framework contains 97 measures.

These indicators allow all stakeholders to monitor and measure performance, analyse trends, compare performance to targets and benchmarks, and improve system efficiencies and quality of care. The evaluation framework should also consider measures across short, mid and long-term horizons. CCNSW welcomes the opportunity to collaborate on developing success measures.

Public reporting

We commend the Cancer Institute NSW for their efforts towards enhancing public reporting mechanisms, including development of the Performance Index. This mechanism could be further strengthened by describing trends, benchmarks and targets. The Performance Index could be reviewed to provide a more transparent line of sight between the Cancer Plan and implementation to track whether the collective actions of the sector are improving cancer outcomes over time. Enabling more granular transparency on health service performance through the Reporting for Better Cancer Outcomes Program is called for by the community. There is a clear sentiment amongst the Cancer Council NSW community that public reporting and regular updates on progress is important. We recommend:

- Cancer Institute NSW partner with Cancer Council NSW to engage with local communities to facilitate a better understanding of cancer control in their region. Most community members also request an annual update on progress towards the goals of the Cancer Plan.
- Cancer Institute NSW reorient the Performance Index and the Statewide report around the Optimal Care Pathways.
- The Performance Index should be supplemented with trend data and progress towards targets.

8. Gaps

The draft Cancer Plan effectively captures many key cancer control elements. However, we note that there are several important omissions. Collectively, these omissions account for an important contribution to the burden of cancer in NSW and include:

- Immunisation and cancer
- Overweight and obesity
- Secondary prevention for people with cancer
- Environmental and occupational cancers
- Overcoming geographical barriers to care
- Optimal Care Pathways
- Survivorship and end of life care
- Financial impact of cancer

If we are to reduce the burden of cancers in NSW, we need to systematically address the known contributors. Evidence shows that the omissions listed above have a marked impact on cancers and we recommend these be considered for inclusion in the NSW Cancer Plan and actions within the implementation plans. For a more detailed description of how these factors can be addressed, see our recommendations listed above in Section 4.

9. Appendix 1

Prevention indicators: where are we now?

Objective	Indicator	NSW[1] (%)	Target	Trend
Reduce the use of tobacco and tobacco products	Current daily smoking among adults (%)	11.2	12.4[2]	→
	Current teenage smoking (%)	6.4	NA	→
	Daily smoking among Aboriginal adults (%)	26.4	<29.9[2]	↑
	Smoking during pregnancy (%)	8.8	7.5[2]	→
Reduce over exposure to UV radiation	Adults who seek shade (%)	40.3	NA	→
	Adults who use sunscreen (%)	35.5	NA	→
	Young people prefer a tan (%)	57.6	NA	↑
	Melanoma incidence in men (per 100,000 men)	66.9	NA	↓
	Melanoma incidence in women (per 100,00 women)	41.9	NA	↓
Healthy lifestyle choices	Adults getting enough exercise (%)	61.5	61.3[3]	↑
	Adults consume alcohol within recommended levels (%)	67.2	>75[2]	↓

[1] Indicator data from HealthStats NSW and Cancer statistics NSW portal (accessed April 2021)
[2] NSW State Health Plan: towards 2021
[3] WHO Global Action Plan for Prevention and Control of Non-communicable Diseases 2013-2020

Legend: Green = Target met; Red = target not met; → = trend improving; ↓ = trend worsening; → = trend stalled

Interpretation, issues and challenges

As Table 1 shows, despite significant efforts and investment from the NSW Government and stakeholders, including Cancer Council NSW, progress towards the objectives described in the previous NSW Cancer Plan has been mixed. Lung cancer remains the leading cause of death in NSW, despite being almost entirely preventable [1]. Over the previous five years, NSW data shows that progress towards reducing the use of tobacco and tobacco products has stalled: smoking rates among adults, young adults and pregnant women all remain essentially unchanged over the past five years. This corresponds with declining trend in tobacco mass media spend in NSW since 2008 (Fig 2). Sustained investment in high intensity, effective antismoking mass media campaigns is crucial to maintaining an effective, comprehensive approach to tobacco control.[15]

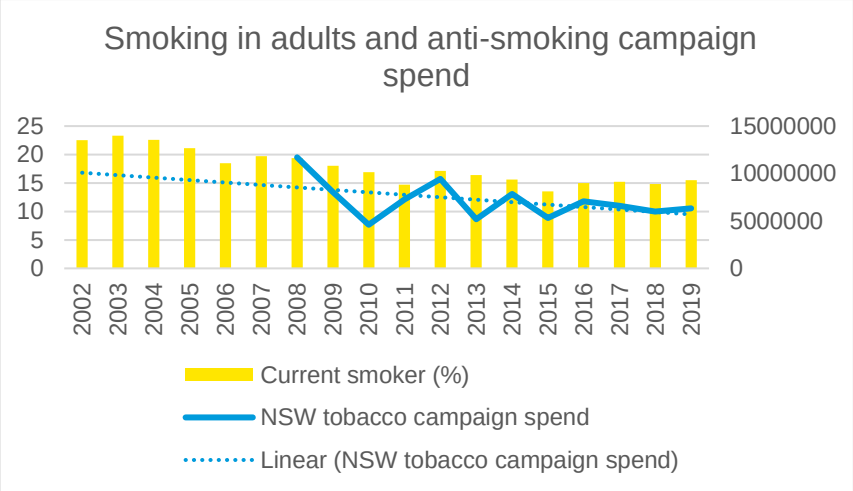


Figure 4. Current adult smoking rates and government spending on tobacco campaigns. Source https://www.opengov.nsw.gov.au/publications/18968

Sun safety messaging is also not getting through to community. In NSW, the age-standardised incidence rate of melanoma among both men and women has continued to increase since the 1970s.[2] NSW has the second highest melanoma incidence and mortality rates in Australia, second only to Queensland.[16] Skin cancers are also the most expensive cancers for the NSW healthcare system.[17, 18]There has been no statistically significant change in proportion of adults that seek shade or use sunscreen in NSW since 2007.[19] Furthermore, the 2019 CCNSW Cancer Prevention Survey identified that many park, playground, sportsground and beach goers reported inadequate shade availability.

The links between body weight, nutrition, physical activity and cancer risk are complex, interrelated and may act synergistically. Each risk factor also has an independent effect on cancer risk and collectively, are second only to tobacco as modifiable risk factors for cancer.[20] Over the past five years, the proportion of adults in NSW that meet recommended levels of physical activity has steadily increased and collaborative efforts in this area should be celebrated. However, it is disappointing to note that overweight and obesity – known to cause 13 cancer types [21] – has not been tracked as a Performance Indicator. Overweight and obesity rates have increased rapidly over the past 30 years, with 54% of adults in NSW now affected.[22]

Also of concern is that the proportion of NSW adults drinking alcohol within recommended levels has been steadily decreasing. Alcohol causes cancer yet public awareness of this link is low.[23]

A cornerstone of the draft National Preventive Health Strategy is recognising the need to "look beyond the individual". This approach recognises that there are broad contextual factors that play an integral role in determining the health of society, many of which lie outside of both the health system and the control of individuals [14, 24]. If NSW is to make meaningful gains in cancer outcomes, NSW must also actively collaborate across sectors and portfolios to consider health in all policies and to promote environments that support individuals to lead healthy lives. A renewed and long-term commitment to cancer prevention will have enormous impact on not only the burden of cancer, but many other diseases caused by the same risk factors.

10. Appendix 2

Screening and early detection indicators: where are we now?

Objective	Indicator	NSW[1]	Target	Trend
Increase early detection of breast, bowel and cervical cancers	Women participating in cervical screening (%)	55.9	>57[2]	→ *
	People participating in bowel screening (%)	39.5	>56.6[2]	↑
	Women participating in BreastScreen NSW (%)	52.8	>54[2]	↑
	Aboriginal women participating in BreastScreen NSW (%)	44	NA	↑
	CALD women participating in BreastScreen NSW (%)	42.5	NA	↑
	Eligible women never screened by BreastScreen NSW (%)	19.9	NA	→

[1] Indicator data from CINSW Performance Index (accessed August 2020)
[2] Health Portfolio Budget Statements 2019-20
* The NSW Pap Test register transitioned to the National Cervical Screening Register (NCSR) in November 2017. Participation trends over time should be interpreted cautiously

Interpretation, issues and challenges

One of the most effective actions to improve cancer survival is to increase participation in national screening programs and diagnose cancer earlier. In NSW, cancer screening participation rates are increasing but still underperforming compared to the rest of Australia – NSW has the second lowest screening participation rate in Australia for breast and bowel cancer and third lowest for cervical cancer. Importantly for cervical cancer, we have a path towards eliminating it as a public health problem and the next Plan should align with this goal.

Screening participation is not distributed equally across populations. Data are not yet published for NSW, but evidence from Queensland shows two-year cervical screening participation is more than 20 percentage points lower in Aboriginal and Torres Strait Islander women than in non-Indigenous women, and the gap widens to almost 30 percentage points over five years (50.1% vs 79.7%).[27] Unpublished NSW evidence suggests participation in cervical screening among Aboriginal and Torres Strait Islander women in NSW is also

considerably lower than the state average. Indigenous and CALD participation in breast screening, despite steady improvements, still remains significantly lower than the state average [2].

There is an increasingly important role to build on and expand community partnerships to develop culturally appropriate, acceptable and responsive interventions to enhance cancer screening participation among under-screened populations.

11. Appendix 3

Optimal treatment, care and support indicators: where are we now?

Objective	Indicator	NSW[1]	Target	Trend
Improve cancer outcomes	People having single fraction radiotherapy for bone metastases (%)	34	NA	→
	People having surgery for lung cancer in hospitals above target volume (%)	92	>80[2]	↑
	People having surgery for oesophageal cancer in hospitals above target volume (%)	81	>67[2]	↑
	People having surgery for pancreatic cancer in hospitals above target volume (%)	92	>82[2]	↑
	People having surgery for rectal cancer in hospitals above target volume (%)	84	>84[2]	↓
	People having surgery for their lung cancer (%)	19.2	21[2]	→
	People having surgery for their oesophageal cancer (%)	12.7	15[2]	→
	People having surgery for their pancreatic cancer (%)	20.4	22[2]	↑
	People having surgery for their liver cancer (%)	18.1	20[2]	→
	People with nodes examined during rectal cancer surgery (%)	81	NA	NA
Enhance the experiences of people	Outpatient rating as 'very good' (%)	85	>85[2]	→
	Hospital cancer care rating as 'very good' (%)	71	>85[2]	NA

Objective	Indicator	NSW[1]	Target	Trend
affected by cancers				

[1] Indicator data from CINSW Performance Index (accessed August 2020)
[2] 2018-19 Service Performance Agreements

Interpretation, issues and challenges

Indicators of optimal cancer treatment, care and support available through the NSW Performance Index and the NSW State-wide Report show that although overall cancer care quality is high, marked variation exists between and within services [1]. Put differently, people are missing out on the care they deserve because of where they live, their financial situation or their cultural background.

The Optimal Care Pathways (OCPs) offer a framework for achieving consistent, safe, high-quality and evidence-based multi-disciplinary care for people with cancer. They can also assist in the planning of services or programs to support access to best cancer and to evaluate whether these services or programs are achieving their intended outcomes. Despite the lifesaving benefits of OCPs, there is no dedicated plan for embedding them as standard care across the NSW health system. A plan for their implementation alongside robust data collection and public reporting is needed. The *Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer* guides delivery of culturally appropriate treatment and services and should also be implemented in partnership with Aboriginal organisations.

Timely access to care is an important component of many other Cancer Plans yet systematic measurement of wait times is not currently reported in NSW. Important measurable elements of optimal cancer care that could be prioritised include the time between phases of care, such as time from referral to diagnosis, and time from diagnosis to treatment. These should be considered for inclusion in the NSW Performance Index.

Supportive care is an essential component of cancer care highlighted in the OCPs. Studies continually demonstrate that people with cancer experience unmet supportive care needs [30]. Considering the strong body of evidence on the impact of physical, psychosocial and financial burden on quality of life and patient outcomes, survivorship must be considered a core component of cancer care and better integrated into routine practice [31].

12. Appendix 4

Research indicators: where are we now?

- For every 100 people diagnosed with cancer in NSW, there were nine enrolments in a cancer clinical trial in 2018-19.
- In 2018-19, metropolitan LHDs tended to have more cancer clinical trials open for recruitment as compared to regional, rural and remote LHDs.
- There is a lower participation rate in cancer clinical trials that are supported by the Cancer Institute NSW among patients in the most deprived areas of NSW.

Interpretation, issues and challenges

Evidence-based policy and practice is the bedrock of an effective and efficient health system. For many cancer-related challenges, there is a well-established evidence base of solutions [33]. The trouble is translating this in to practice [34]. This is in part driven by ever increasing availability of data – more than 90% of the digital data created to date across all fields was produced in the past two years, and only 1% of these data have been analysed [35]. This trend is projected to continue for the foreseeable future, creating challenges related to data quality, sharing, integration, and translation [36]. We applaud the NSW Government's commitment to enhancing the quality and accessibility of linked data-sets and strongly support actions to further enhance their availability in the draft Plan.

> "*Given the absence of immunotherapy options, should (or realistically when) the cancer returns, my life expectancy will depend on the availability of an immunotherapy trial and whether it is physically possible for me to get to it.*"
>
> - Cancer survivor

Clinical trials are an important way to enhance research capacity and support improved cancer care, providing a gateway to cutting edge therapies and technology. Nearly 32% of Australians reside outside the major capital cities, while 95% of medical specialists practise in cities [37]. Worryingly, less than 5% of regional cancer patients participate in any clinical trial [37]. Teletrials offer a path towards overcoming barriers to clinical trial participation in regional areas in NSW [1]. This reduces not only travel, cost, social disruption to patients and inequity but also improves research participation and capacity [38].

Furthermore, although consumer engagement in research is well established, there is opportunity for NSW to enhance consumer involvement to improve the relevance of research to consumers' needs, improve quality of care and health outcomes, enable more effective research translation, and improve public confidence in research. Consumer-driven health and medical research is an integral component of a high-quality, patient-centred healthcare system [36].

13. Appendix 5

The CINSW Performance Index presents the indicators used to track and report annually on progress against the Plan's objectives. We provide here an independent analysis of progress made against these indicators based upon cancer control performance for the period 2015-2020 using data publicly available from the CINSW Performance Index.

A Cancer Council NSW working group of subject matter experts from across the cancer control continuum was convened to provide input throughout the Cancer Plan consultation process. Relevant national and state policy documents were consulted for context and further information and clarification was sought from academic and clinician experts both internal and external to CCNSW when required.

We assessed NSW cancer control performance for the period 2015-2020 using data publicly available from the CINSW Performance Index. The Performance Index source data was checked to see whether more recent data was available and included in the indicator tablesif available (and referenced where appropriate). In instances where multiple data sources were available to describe trends (smoking prevalence for example can be measured using NSW Population Health Survey or the National Drug Strategy Household Survey), we used data sources consistent with those used in the NSW Cancer Plan Performance Index.

Where multiple data sources for the same measure exist (e.g. State versus National survey), we endeavoured to describe this in our contextual analysis.

Trends

Trends are described according to statistical significance if confidence intervals are known. Where confidence intervals are not known, expert judgement based upon previous years data was made and reviewed by relevant internal subject matter experts. Disagreements in trend classification were discussed until a consensus was achieved. Wherever possible, four years of data are provided. This has been assessed to determine whether the data showed:

- ↑ an improving trend (moving in the right direction)
- ↓ a worsening trend (moving in the wrong direction)
- → a stalled or unchanging trend

Traffic light rating

Each indicator has been allocated a traffic light rating (red, amber or green). These provide a snapshot of the key message about comparisons to targets. The ratings consider:

- the views and expertise of subject matter experts
- how the most recent result compares with targets or with performance in other jurisdictions if comparable with other states
- whether the result is improving over time and if so, how quickly
- any other relevant contextual information (for example, departmental policies) in place.

Green (satisfactory result)

A green rating generally describes situations where the result:

- is at or above a target, and either stable or improving over time

Red (result is of concern)

- represent a poor outcome or a high level of risk for an undesirably high proportion of the people it relates to
- be consistently deteriorating over time
- be well off target and stable or somewhat deteriorating over time.

Targets

The draft Plan does not include specific targets and only relies on qualitative terms such as increase, improve, encourage. Targets are included in this submission for context and to provide an evidence-based reference point for where each indicator could be aiming. We included representative targets drawn from a variety of sources to make clear significant gaps in NSW cancer control. Where multiple targets existed, NSW targets were given highest priority. Where NSW targets were not available, we considered national targets, followed by targets offered by leading think tank and international organisations such as the WHO.

For a full description of each indicator, see CINSW Performance Index

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