The NSW Cancer Plan

A plan for NSW to lessen the impact of cancers



2022-2027



Publisher

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We are particularly grateful to the individuals affected by cancer who contributed their own story and experiences, which form the heart of this plan.

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Acknowledgement of Country

We acknowledge the traditional custodians of the lands on which we work and live, and recognise their continuing connection to land, water and community. We pay our respect to Elders past and present.

Artwork by Dennis Golding (2016)

The artwork in this document reflects the Cancer Institute NSW, and how it collaborates and shares values with other networks to foster greater knowledge, awareness and success of health services for Aboriginal communities.



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Foreword from the Minister for Health

The Hon. Brad Hazzard, Minister for Health

Most of us will be touched by cancer at some point in our lifetime – through a personal diagnosis, diagnosis of someone close to us, providing care or by searching for better treatments and cures.

Despite incredible advances, cancer remains one of our biggest public health challenges, with our population ageing and living longer than ever before. There are also communities who continue to experience poorer cancer outcomes, including Aboriginal communities, multicultural communities, people from lower socioeconomic backgrounds, regional, rural and remote communities, older people, sexuality and gender diverse and intersex people, people with a mental health condition and people who are engaged with the justice system. The NSW Government, through the work of the Cancer Institute NSW, remains committed to achieving equitable cancer outcomes for all people in NSW.

People in NSW have access to a world-class health system, that aims to continually improve to deliver the best possible outcomes for everyone, no matter who they are or where they live. This NSW Cancer Plan sets the vision, goals and priorities for how we can achieve this. It provides a clear and ambitious direction across all areas of cancer control – from prevention, screening, early detection and treatment through to palliative care.

It recognises that cancer is not just a health issue. It is influenced by the cultural and social determinants of health such as people's level of education, socioeconomic status, cultural background and place of residence all affect their risk of developing cancer, access to care and survival.

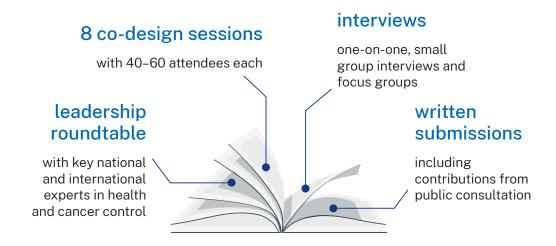
The Cancer Institute NSW, as a pillar of NSW Health and our state's cancer control agency, is the custodian of this plan. Since its establishment in 2003, the Institute has demonstrated strong national and international leadership in cancer control, particularly in its work to prevent cancer and drive better outcomes through information, research and education.

However, the success of this plan requires commitment beyond NSW Health – there must be effective and sustained collaboration across all parts of our community, including individuals, government agencies, non-government and community organisations, and the private sector.

This plan builds on the work that has already been done in creating one of the best cancer care systems in the world, which is driven by our exceptional health workers, clinicians and researchers, who are working around the clock to serve their local communities.

Guided by this plan, we can save more lives from cancer.

This plan was designed with stakeholders who provided their thoughts, comments and expertise.





Introduction from the Cancer Institute NSW

Professor Tracey O'Brien
NSW Chief Cancer Officer and CEO, Cancer Institute NSW

I am pleased to present the fifth NSW Cancer Plan, which sets an ambitious direction for cancer control in NSW over the years ahead.

People affected by cancer are at the heart of this plan. It is grounded in an understanding of what's most important to them. Their voices are woven throughout the document, and most importantly, the plan considers what success looks like from their perspective. I thank everyone who has contributed to this plan, but especially those who have shared stories about their personal experience of cancer.

Three overriding principles guide the direction of the NSW Cancer Plan: equity of outcomes, a focus on people affected by cancer (person-centredness) and collaboration. These principles inform how individuals, organisations and government will work together to develop and deliver initiatives across all aspects of cancer care, research and experience.

Although we have seen cancer survival rates increase and mortality rates decrease since the first statewide Cancer Plan in 2004, some communities continue to bear the burden of cancers more than others.

This plan takes an equity-led approach to cancer control. It seeks to ensure every person affected by cancer is seen at the right time, in the right place, for the right care. It acknowledges the unfair burden of cancer on specific communities, and seeks to address inequities and variations in access to care and outcomes they experience.

In particular, the plan acknowledges the importance of achieving health equity for Aboriginal* peoples in NSW and delivering services designed and developed with the community that respond to the needs and aspirations of Aboriginal peoples.

If we take the knowledge of cancer prevention, treatment and care we have today, and apply it equitably across the community, we can make significant improvements to cancer outcomes for all. This plan focuses our efforts to do just that.

To deliver person-centred care and improve the experiences of people affected by cancer, the work guided by this plan will aim to empower people to make informed decisions about their care, and ensure they are treated with kindness and respect in a culturally safe and responsive environment.

Collaboration is vital to achieve improvements for the future of cancer control in NSW. We must take a united approach to reduce the burden of cancer by coordinating our priorities, resources and efforts.

The plan itself is a testament to the power of collaboration. It is the product of more than 800 people from across the state coming together to contribute their experiences, expertise and hopes for a future without cancer.

I am confident the direction set by this statewide plan will have a positive impact on the health of NSW and help us continue to work towards realising our vision: to end cancers as we know them.

The NSW Cancer Plan 2022–2027

^{*} The NSW Cancer Plan uses the term 'Aboriginal' rather than 'Aboriginal and Torres Strait Islander', recognising Aboriginal people are the original inhabitants of NSW. This is informed by Communicating Positively: A Guide to Appropriate Aboriginal Terminology.¹



NSW Cancer Plan

Vision: To end cancers as we know them



Goals

Reduce inequity in cancer outcomes

Reduce the incidence of cancer

Increase cancer survival

Enhance quality of life and experience for people at risk of and affected by cancer

Overriding principles



Equity of outcomes

Improve cancer outcomes in communities that continue to have poorer outcomes to help everyone achieve their best health.

Focus on achieving equitable cancer outcomes for Aboriginal communities.

Person-centredness

Focus on the experiences of people with cancer and those accessing screening and prevention services, to ensure they achieve outcomes that are meaningful to them.



Collaboration

Work together at the system, service and care team levels with clear roles, accountabilities and governance, to achieve the best cancer outcomes.

Priorities

1. Prevention of cancers



2. Screening and early detection of cancers



3. Optimal cancer treatment, care and support



4. Cancer research



Strategic actions

System enablers

Staff are engaged and well supported

- Leadership and culture
- Workforce



Innovation and digital advances inform service delivery

- Data and information
- Technology and innovation



The system is managed sustainably

- Governance
- Monitoring, evaluation and reporting



Target outcomes

Achieve equitable cancer outcomes for all NSW residents.

Reduce the risk of preventable cancers for people in NSW.

Increase one- and fiveyear survival of NSW residents with cancer.

Increase the collection and use of people's reported experience and outcomes to improve care and services.

Our actions

Over the next five years, the following high-level actions will address our four priority focus areas. These actions will inform detailed implementations plans.



Priority 1

Prevention of cancers

Action

- 1.1 Improve people's ability to understand and engage with prevention, screening and cancer care services and information, and reduce cancer-related fear, stigma and shame among Aboriginal and multicultural communities.
- 1.2 Prioritise evidence-based prevention efforts in areas with the greatest need and demonstrated impact, including helping people to not take up smoking or vaping, quit smoking and vaping, protect their skin from ultraviolet radiation and reduce alcohol consumption.
- 1.3 Use new technologies and innovations, such as digital services, to support people to adopt healthy lifestyle behaviours and reduce their risk of cancer.
- 1.4 Strengthen broad public health prevention collaborations and partnerships at all levels across public, private and nongovernment sectors.



Priority 2

Screening and early detection of cancers

Action

- 2.1 Engage primary care providers and Aboriginal Community Controlled Health Services, including GPs, practice nurses and Aboriginal Health Workers/Practitioners, to increase participation in the national cancer screening programs.
- 2.2 Maximise participation in screening and early detection programs, particularly for people at higher risk, and make NSW a national leader in early detection of cancers.
- 2.3 Promote opportunities for people who are already engaged with the health system to participate in cancer screening and enable key community organisations to support cancer screening, particularly for Aboriginal communities and other focus populations.
- 2.4 Prioritise early detection efforts in communities with the greatest need and the highest potential for improved outcomes, through the delivery of culturally safe and responsive services for Aboriginal communities and other focus populations.
- 2.5 Continue to support primary care providers to proactively identify and effectively care for people who have, or may have, cancer.
- 2.6 Create and deliver consistent, coordinated and timely pathways to ensure people with cancer are referred appropriately from primary care to treatment and care.



Priority 3

Optimal cancer treatment, care and support

Action

- 3.1 Support best practice and value-based cancer care to ensure people are seen at the right time, in the right place, for the right care.
- 3.2 Provide care that is patient led, culturally safe and responsive, coordinated, as close to home as possible, easy to access and navigate, given by multidisciplinary teams (teams of cancer specialists with expertise in different areas of cancer care) and affordable for the person being treated.
- 3.3 Ensure people who experience cancer, their families and carers are actively linked with supportive care and services such as psychosocial care, allied health care and financial counselling.
- 3.4 Provide patients, families and carers with timely access to relevant, credible and understandable information that helps them to play an active and informed role in making decisions about their treatment and care.
- 3.5 Improve integration and communication across services and providers, between local health districts (LHDs) and specialty networks (SNs), and across the public, private and primary care settings, including Aboriginal Community Controlled Health Services.
- 3.6 Ensure high quality and accurate information is available to those working in the health system to support them to make decisions and develop quality improvement initiatives that are informed by the best available evidence.
- 3.7 Ensure feedback from patients about their experiences and outcomes is routinely used for care delivery, service planning and quality improvement.



Priority 4

Cancer research

Action

- 4.1 Invest in cancer research infrastructure in NSW and promote national and international collaboration.
- 4.2 Enhance access to and participation in cancer clinical trials, with a focus on communities that experience poorer cancer outcomes, such as Aboriginal communities, and people from regional, rural and remote communities and other focus populations.
- 4.3 Provide easy-to-understand and culturally safe and responsive information to people experiencing cancer, their families and carers to support their involvement in cancer research.
- 4.4 Support primary care providers to encourage people to participate in cancer clinical trials and other research.
- 4.5 Build the capability of the cancer control workforce to engage and participate in cancer research, including clinical research.
- 4.6 Improve the ability to link databases to support cancer control research and better understand people's overall health.

The NSW Cancer Plan 2022–2027

Cancers in NSW

While NSW is recognised as a global leader in cancer care, with one of the highest one-and five-year survival rates for most cancers in the world,² cancer continues to have a significant impact on the people of NSW.

Cancer contributes to the largest burden of disease in Australia.³ The social determinants of health continue to have a negative impact on the provision of cancer services and in cancer outcomes in NSW.

While cancer survival for Aboriginal people continues to improve, there is still a disproportionate gap in cancer outcomes.

Closing the gap in cancer outcomes for Aboriginal communities is a key priority of the NSW Cancer Plan.

Other groups of people within NSW that are disproportionately affected by cancer include:

- multicultural communities
- people from lower socioeconomic backgrounds

- regional, rural and remote communities
- · older people
- sexuality and gender diverse people (lesbian, gay, bisexual, transgender and queer people, known as LGBTQ+ communities)
- people with innate variations of sex characteristics (intersex people)
- · people with a mental health condition
- people who are engaged with the justice system.⁴

Together with Aboriginal people, these communities are 'focus populations' of this Cancer Plan.



Although NSW remains a global leader in cancer outcomes, cancer remains a leading cause of illness and premature death.



3 in 10

deaths will be caused by cancer³

1 in 2

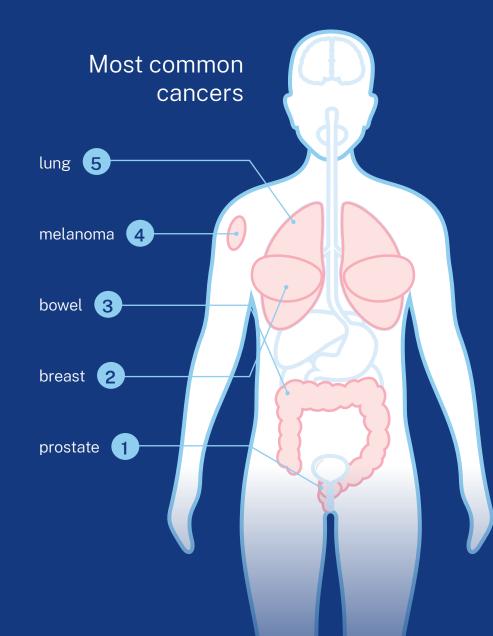
will be diagnosed with cancer by the age of 85⁴

16,700+

people will die from cancer⁴

• 51,000+

people will be diagnosed with cancer⁶



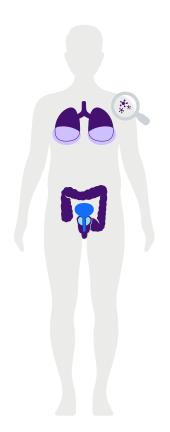
*The figures on this page are projections for 2022. Projections of incidence and mortality are not precise predictions of the future. Models are based on projected populations and the assumption that historical trends will continue into the future. The accuracy of projections becomes less certain over time.

The NSW Cancer Plan 2022–2027

Cancer in Aboriginal people in NSW

The NSW Cancer Plan recognises Aboriginal peoples as the first peoples of Australia and the traditional custodians of the lands in NSW. This plan recognises Aboriginal communities as a priority.

Aboriginal people are more likely to be diagnosed with cancer, are likely to be younger when they are diagnosed and are more likely to die of cancer than non-Aboriginal people.





Lung cancer is the **second most** common cancer for both Aboriginal men and women and the **number one** cause of cancer death for Aboriginal people.



Breast cancer is the **most common** diagnosed cancer and **second most** common cause of cancer death for Aboriginal women.



Prostate cancer is the **most common** diagnosed cancer and **second most** common cause of cancer death for Aboriginal men.



Bowel cancer is the **third most common** diagnosed cancer and cause of cancer death for Aboriginal men and women.



Melanoma is the **fourth most common** diagnosed cancer for Aboriginal women and **fifth most common** diagnosed cancer for Aboriginal men.

Cancer incidence and mortality in Aboriginal people in NSW⁶

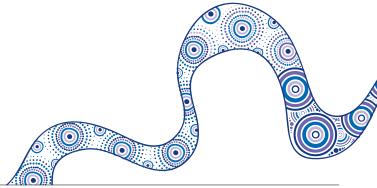
The reason for inequities in cancer outcomes for Aboriginal people are multiple and complex.

The trauma of colonisation and continuing impact of past health policies combined with ongoing experiences of racism and discrimination has led to feelings of mistrust and fear. Fear and capacity issues around leaving community or country for treatment and lack of culturally safe and responsive care are also major barriers for Aboriginal people to access health services.

Fear and stigma about cancer, due to a lack of understanding about the disease, can prevent Aboriginal people from participating in cancer screening or having symptoms checked. This can lead to later diagnosis causing poorer outcomes.

Aboriginal people and communities are also often dealing with complex personal and familial issues and lower levels of health literacy, which impact their health seeking behaviours.

These barriers can also contribute to higher prevalence of certain lifestyle behaviours, such as tobacco use and alcohol consumption which can contribute towards higher cancer incidence.



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Culturally safe and responsive care is delivered in a way that respects and responds to the diverse needs of people from different cultural and language backgrounds, personal traditions, history, values and family systems. Cultural safety also accounts for factors such as the cultural and social determinants of health, treatment preferences, and preferences for who provides care and in what location. Access to culturally safe and responsive cancer prevention, screening, diagnostic and treatment services and care is key to improving cancer outcomes for Aboriginal people.

The NSW Cancer Plan is aligned with Target One of the National Agreement on Closing the Gap⁷, to 'ensure that Aboriginal and Torres Strait Islander people enjoy long and healthy lives'.

This plan will provide a strengths-based approach to address the impact of cancer in Aboriginal communities. This will be done through strong partnerships with the Aboriginal Health and Medical Research Council of NSW (AH&MRC), Aboriginal Community Controlled Health Services, Aboriginal Health Workers, Aboriginal Community Controlled Organisations and Aboriginal community members in co-designing strategies to achieve equitable cancer outcomes.



Overriding principles

Three overriding principles guide the direction of the NSW Cancer Plan. These principles inform how individuals, organisations and governments involved in cancer control will work together to develop and deliver initiatives to improve cancer outcomes.



Equity of outcomes

Improve cancer outcomes in communities that continue to have poorer outcomes to help everyone achieve their best health.

- Take an equity-first lens to decision making, investment and monitoring. This means prioritising and enabling community driven services for Aboriginal communities and other focus populations that have poorer cancer outcomes.
- Recognise the individual, social, cultural and environmental factors that are important to prevent cancers and create supportive environments for healthier decisions and behaviours.
- Empower and partner with Aboriginal communities and other focus populations through community-led organisations, such as Aboriginal Community Controlled Organisations, multicultural organisations and other community-led groups, to create supportive environments, and invest in initiatives and services that are culturally safe and responsive to meet community needs and preferences for service delivery.
- Ensure the workforce reflects the diversity and needs of the NSW population, and has the skills to deliver care that is culturally safe and responsive, particularly for Aboriginal people.
- Build a strong voice for Aboriginal communities and other focus populations at the system level through co-design, leadership roles and governance structures.
- Deliver effective, efficient and affordable treatments that improve cancer outcomes for all.



Person-centredness

Focus on the experiences of people with cancer and those accessing screening and prevention services, to ensure they achieve outcomes that are meaningful to them.

- Ensure prevention, screening, treatment, care and support services are informed by people's experiences, and are responsive to their needs and preferences – including ensuring services are culturally safe and responsive and appropriate.
- Ensure care is patient led, empowering people at risk of or affected by cancer, their families and carers to make informed decisions and be full partners in their care.
- Ensure information and communication is accessible, culturally safe and responsive and tailored for each individual, to support informed decision making.
- Build a system that is easier for people in the community to understand and navigate, and strengthen ways to coordinate care.

- Ensure cancer services meet all the needs of patients, families and carers, including access to supportive care, such as psychosocial and allied health services and non-clinical supports.
- Acknowledge the important role of family and community in the care of cancer patients. This is particularly important for Aboriginal communities so people feel empowered to make informed decisions about their care based on their values, beliefs and experiences.
- Ensure people at risk of or affected by cancer and carers have positive experiences and outcomes that matter to them.





Collaboration

Work together at the system, service and care team levels with clear roles, accountabilities and governance, to achieve the best cancer outcomes.

- Strengthen partnerships with primary health care
 to support prevention, screening and early detection
 efforts, help people through all stages of care,
 and assist with the coordination of care.
- Partner effectively across government including the education, planning and communities and justice sectors – to ensure cancer is considered in major strategies, frameworks and plans and to increase the resources and infrastructure available to the community.
- Formalise governance systems and frameworks, so those working within cancer can partner effectively and be held accountable to meet the vision, goals and priorities of the NSW Cancer Plan.
- Work with partners to ensure activities related to cancer prevention, screening, treatment and follow-up are integrated into the delivery of other health services.
- Strengthen alignment with existing strategies, frameworks and plans developed by the NSW Ministry of Health, NSW Health pillars, the Australian Government Department of Health, Cancer Australia and other non-government organisations.

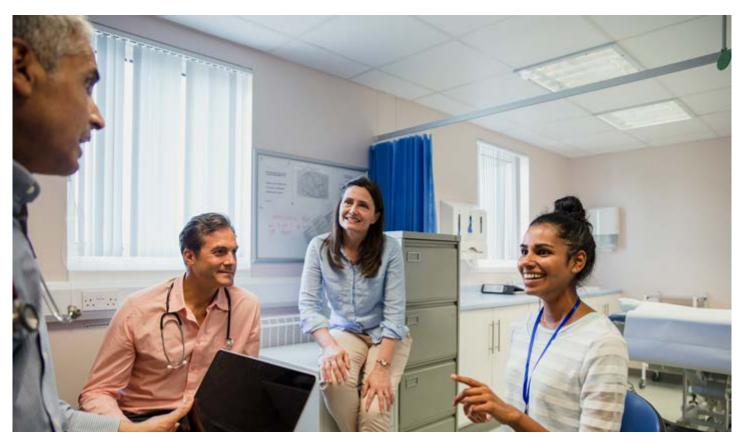
 Create and support strong partnerships with the Aboriginal Health and Medical Research Council of NSW (AH&MRC), Aboriginal Community Controlled Health Services, Aboriginal Health Workers, Aboriginal Community Controlled Organisations to ensure cancer control initiatives are co-designed, culturally safe and responsive and provide continuity across the cancer care pathway.

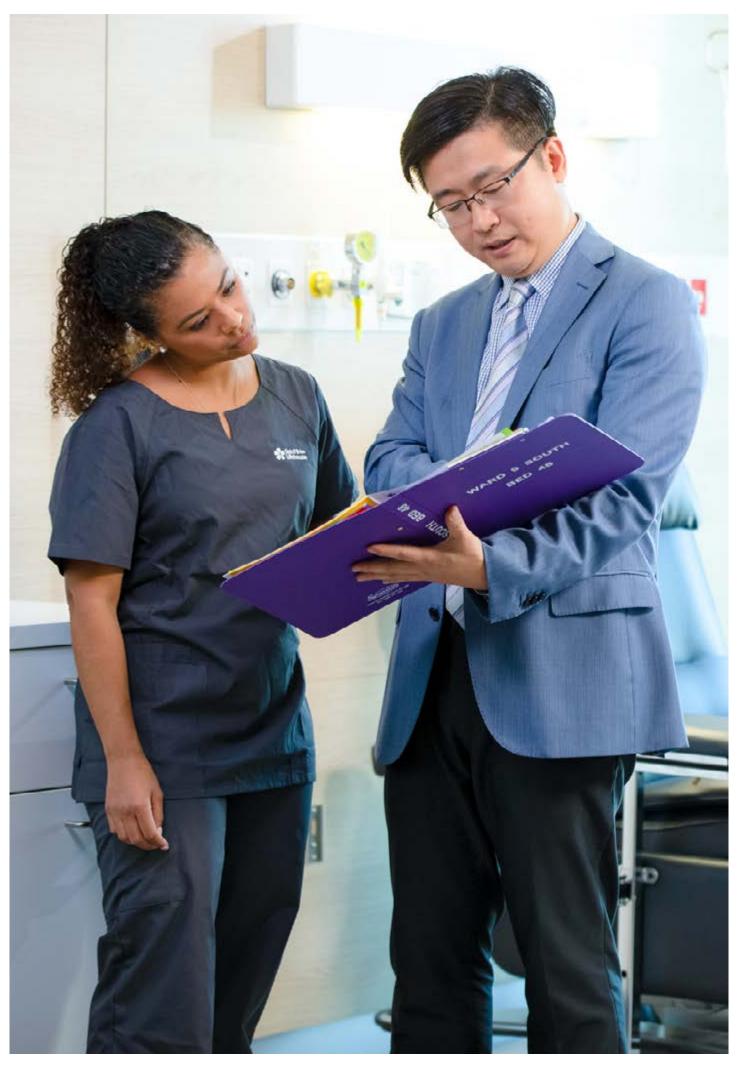
Putting the principles into practice

These principles will be put into practice under each priority throughout this plan.

The *Implementation Plan* that supports this *NSW Cancer Plan* provides further detail on how the overriding principles will be embedded into the work of key stakeholders.

The actions in the *Implementation Plan* intend to contribute to driving progress under each of the principles – for example, action for Aboriginal communities and other focus populations; actions that enhance access in regional, rural and remote areas; or actions that bring together groups to develop coordinated and collaborative approaches.





Priorities



Priority 1

Prevention of cancers

Support people to reduce their cancer risk

Our actions for the next five years

Action

- 1.1 Improve people's ability to understand and engage with prevention, screening and cancer care services and information, and reduce cancer-related fear, stigma and shame among Aboriginal and multicultural communities.
- 1.2 Prioritise evidence-based prevention efforts in areas with the greatest need and demonstrated impact, including helping people to not take up smoking or vaping, quit smoking and vaping, protect their skin from ultraviolet radiation and reduce alcohol consumption.
- 1.3 Use new technologies and innovations, such as digital services, to support people to adopt healthy lifestyle behaviours and reduce their risk of cancer.
- 1.4 Strengthen broad public health prevention collaborations and partnerships at all levels across public, private and nongovernment sectors.

"Our communities are really fearful of cancer ... we think it's going to take us overnight – you get diagnosed and that's it. What we need is better education about cancer in the community, so that people know what it is, what you can do to reduce your chance of getting it, and how important it is to have those conversations with your doctor."

Aboriginal community member





Preventing cancer is one of the most effective ways to address inequities and achieve our vision of ending cancers as we know them. At least one in three cases of cancer can be prevented. In Australia, approximately 16,700 cancer deaths and 41,200 cancer cases each year could be prevented through lifestyle changes.8

A number of healthy lifestyle behaviours can lower the risk of getting cancer. These include avoiding or stopping smoking, reducing alcohol consumption, reducing sun exposure, eating healthy food and increasing physical activity. Some cancers that are linked with viruses like human papillomavirus (HPV) or hepatitis B can also be prevented through vaccination.

Behaviours are influenced by the social and cultural determinants of health-that is, the conditions in which people are born, educated, work, live and age as well as their cultural beliefs and practices. Therefore, a public health approach to cancer prevention, thinking about individuals and the environments that they live in, is essential to make the greatest impact.

Many risk factors for cancer are also linked to other chronic diseases, such as heart disease, type 2 diabetes and respiratory diseases, making a strong case for including cancer in broader chronic disease partnerships.

Prevention also includes secondary prevention of cancers. This is detecting and treating cancers as soon as possible through screening and regular tests, and encouraging personal strategies to reduce the impact of cancers and prevent recurrence.

Putting the principles into practice

Examples may include:

For equity of outcomes, enabling community leaders, such as Directors of Aboriginal Health, specialised Aboriginal Health Workers and Practitioners and bilingual community educators, to deliver cancer prevention information and support their own communities.

For person-centredness, providing support services that deliver tailored information and support to help people improve their health.

For collaboration, working with the education sector to include cancer prevention messages into education curricula and learning.

What success looks like

For the health system

All people in NSW live in healthy environments and are supported and empowered to make evidence-informed decisions and behaviour changes that reduce their risk of cancers.

For people at risk of or affected by cancer, their families and carers

I know what I can do to reduce my chance of getting cancer, and I know where I can go and who I can talk to if I have questions.

I believe I have the knowledge, and culturally appropriate resources, and support within my community to make positive changes for my own health and the health of my Mob.

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Priority 2

Screening and early detection of cancers

Screen for and diagnose or detect cancers accurately, in a coordinated manner and, where possible, at an earlier stage

Our actions for the next five years

Action

- 2.1 Engage primary care providers and Aboriginal Community Controlled Health Services, including GPs, practice nurses and Aboriginal Health Workers/Practitioners, to increase participation in the national cancer screening programs.
- 2.2 Maximise participation in screening and early detection programs, particularly for people at higher risk, and make NSW a national leader in early detection of cancers.
- 2.3 Promote opportunities for people who are already engaged with the health system to participate in cancer screening and enable key community organisations to support cancer screening, particularly for Aboriginal communities and other focus populations.
- 2.4 Prioritise early detection efforts in communities with the greatest need and the highest potential for improved outcomes, by delivering culturally safe and responsive services for Aboriginal communities and other focus populations.
- 2.5 Continue to support primary care providers to proactively identify and effectively care for people who have, or may have, cancer.
- 2.6 Create and deliver consistent, coordinated and timely pathways to ensure people with cancer are referred appropriately from primary care to treatment and care.

Early detection of cancer can significantly improve outcomes for patients. This is enabled through cancer screening, which means checking the body for signs of cancer before symptoms appear, opportunistic testing (offering screening linked to other occasions of care), risk recognition and symptom awareness.

There are three national screening programs for breast, bowel and cervical cancers. According to the Australian Institute of Health and Welfare (AIHW):⁹

- people with cancers diagnosed through the National Bowel Cancer Screening Program had a 40% lower risk of dying than those who had not been screened
- women with cancers diagnosed by BreastScreen had a 42% lower risk of dying than women with cancer who had never been screened*
- women with cancers diagnosed through cervical screening had an 87% lower risk of dying than women with cancers who had never had a Cervical Screening Test.

Efforts are needed to increase screening rates and support early detection, with the AIHW analysis showing:9

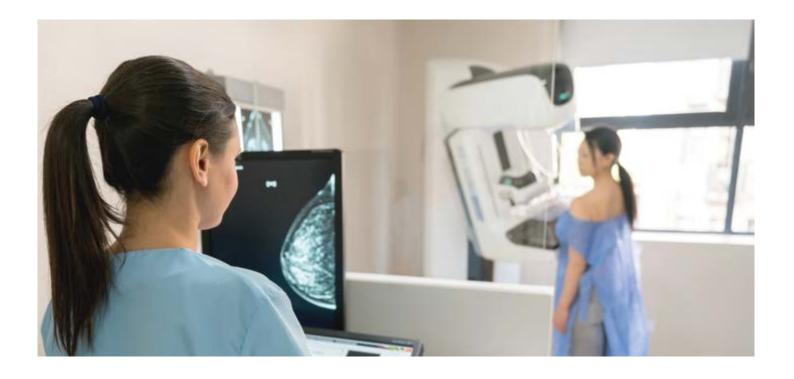
- six out of 10 eligible people were not participating in the National Bowel Cancer Screening program
- 40% of eligible women were overdue for a screening mammogram
- people from Aboriginal and Torres Strait Islander or culturally and linguistically diverse backgrounds were less likely to participate in bowel, breast and cervical screening
- four out of 10 eligible women were overdue for cervical screening.

"I received my bowel cancer screening kit in the mail and put it away in my bedroom, thinking I would do it some other time. My husband encouraged me to just get it over with. After a positive result, I had a colonoscopy and found out I had cancer. It's worthwhile doing the kit straight away, that's what I tell everyone now."

Multicultural community representative

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^{*} While data presented in this section specifically refers to cisgender women (i.e. women whose sense of personal identity and gender corresponds with their birth sex), not everyone with a cervix and/or breasts is a woman, and cervical and breast cancer screening is important for everyone with a cervix and/or breasts including transgender and non-binary people.



Putting the principles into practice

Examples may include:

- For equity of outcomes, continuing to improve access to cancer screening in regional, rural and remote NSW through mobile screening services, for example BreastScreen NSW mobile vans.
- For person-centredness, providing easy-tounderstand information to all people who may have cancer about next steps, care pathways and support services available.
- For collaboration, working with the Aboriginal Health and Medical Research Council of NSW (AH&MRC), Aboriginal Community Controlled Health Services, and Aboriginal community Elders and representatives to co-design culturally safe and responsive screening and early detection strategies and messaging campaigns that are relevant and meaningful.

"I was very much guided by my GP [general practitioner], who I have a strong and longstanding relationship with, and my specialists. I know there's a lot of rubbish information out there on the internet, so I'm glad they were able to give me the information that I needed."

Person who has experienced cancer



What success looks like

For the health system

High-quality cancer screening services are available, accessible and acceptable to all eligible people and meet the needs of diverse communities through the lens of equity and cultural safety and responsiveness.

People at risk of cancer or with suspected cancer can access diagnostic services, to confirm a diagnosis as early as possible.

For people at risk of or affected by cancer, their families and carers

We have conversations in the community about cancer, how to prevent it and the importance of finding it early.

I have any changes in my general health checked by my GP or Aboriginal Community Controlled Health Service.

I am supported to undertake my free Aboriginal-specific 715 health check every nine months.

I have access to cancer screening that is culturally safe and responsive and supportive.

Services and community-based organisations help to direct me to cancer screening programs and provide advice if I need it.

My GP or primary care provider knows the early signs and symptoms of potential cancer and will send me for testing if it is needed.

If I have cancer, it is diagnosed early and I am referred for appropriate care guided by either the Optimal Care Pathway for Aboriginal and Torres Strait Islander people with cancer¹⁰ or mainstream health pathways.



Priority 3

Optimal cancer treatment, care and support

Deliver safe, high-quality, accessible and sustainable cancer treatment, care and supports to all

Our actions for the next five years

Action

- 3.1 Support best practice and value-based cancer care to ensure people are seen at the right time, in the right place, for the right care.
- 3.2 Provide care that is patient led, culturally safe and responsive, coordinated, as close to home as possible, easy to access and navigate, given by multidisciplinary teams (teams of cancer specialists with expertise in different areas of cancer care) and affordable for the person being treated.
- 3.3 Ensure people who experience cancer, their families and carers are actively linked with supportive care and services such as psychosocial care, allied health care and financial counselling.
- 3.4 Provide patients, families and carers with timely access to relevant, credible and understandable information that helps them to play an active and informed role in making decisions about their treatment and care.
- 3.5 Improve integration and communication across services and providers, between local health districts (LHDs) and specialty networks (SNs), and across the public, private and primary care settings, including Aboriginal Community Controlled Health Services.
- 3.6 Ensure high quality and accurate information is available to those working in the health system to support them to make decisions and develop quality improvement initiatives that are informed by the best available evidence.
- 3.7 Ensure feedback from patients about their experiences and outcomes is routinely used for care delivery, service planning and quality improvement.

Quality cancer treatment means ensuring people living with cancer receive comprehensive assessment, treatment and care overseen by a multidisciplinary team of cancer and allied health specialists. It also means delivering safe, high-quality and person-centred treatment at all stages of the cancer care pathway, including survivorship and palliative care.

"I feel so fortunate to have this multidisciplinary team around me who support and coordinate my care. But even with this team things fall through the cracks. You have to be a self advocate and remind them, 'Oh I've had this scan' or 'These were my results last time'. Often communication between doctors and between hospitals isn't great."

Person who has experienced cancer

Evidence indicates a team approach to cancer care, where health professionals together consider all options and develop an individual treatment plan, can improve survival and quality of life.¹¹

There are many forms of treatment, used alone or in combination to treat cancer. The best treatment for individuals depends on a variety of factors including:

- type of cancer
- stage and grade of cancer
- the patient's overall health
- the patient's choices and preferences.

Effective cancer support also includes allied health, psychosocial support, palliative care, non-clinical support, fertility services, support for cancer survivors, and support for families and carers.

Ensuring cancer care and care settings are culturally safe and responsive and supportive is vital in improving outcomes and experiences of Aboriginal people.

An important part of delivering the best cancer treatment, care and support is collecting and responding to patient input, feedback and advice at all stages (planning, implementation, review and evaluation). Strong evidence links patient experience and person-centred care to improved clinical effectiveness, patient safety, healthy behaviours and better patient outcomes.¹²



Putting the principles into practice

Examples may include:

- For equity of outcomes, continuing to expand access to culturally safe and responsive services for Aboriginal people and other cultural groups, for example through ensuring diversity in recruitment practices and cultural competency training for all cancer care staff.
- For person-centredness, co-designing patient feedback systems with people who experience cancer, their families and carers to capture what matters most to them.
- For collaboration, strengthening links between all providers of cancer treatment, care and support so that people who experience cancer, their families and carers have a seamless experience.

"It would be nice if the whole process was a little bit more clear, or a little easier to understand. I remember after my diagnosis someone gave me a list of 20 or so specialists and told me to pick one ... that's not very helpful. At the beginning, you're really just going through the motions and it's frightening and confusing."

Person who has experienced cancer



For the health system

People affected by cancer, their families and carers receive safe, high-quality and seamless cancer treatment, care and support that meets all their needs.

For people at risk of or affected by cancer, their families and carers

Once I am diagnosed with cancer, I quickly start treatment and I receive the most appropriate treatment.

A clinician, other healthcare worker or Aboriginal cancer health worker supports me and my family to understand and navigate the cancer (health) system, support my health literacy and assist me in making informed decisions.

It is easy for me to access all the services that I need. This includes cancer treatment, but also things such as allied health, psychosocial support and non-clinical support like financial counselling advice.

There is good communication between everyone involved in my care. I don't have to repeat my story each time I see someone.

I feel the care provided is culturally safe and responsive and have a supportive and trusting relationship with my care team.



Priority 4

Cancer research

Strengthen cancer research capacity and translation into practice and impact, and improve patient, family and carer experience

Our actions for the next five years

Action

- 4.1 Invest in cancer research infrastructure in NSW and promote national and international collaboration.
- 4.2 Enhance access to and participation in cancer clinical trials, with a focus on communities that experience poorer cancer outcomes, such as Aboriginal communities, and people from regional, rural and remote communities and other focus populations.
- 4.3 Provide easy-to-understand and culturally safe and responsive information to people experiencing cancer, their families and carers to support their involvement in cancer research.
- 4.4 Support primary care providers to encourage people to participate in cancer clinical trials and other research.
- 4.5 Build the capability of the cancer control workforce to engage and participate in cancer research, including clinical research.
- 4.6 Improve the ability to link databases to support cancer control research and better understand people's overall health.

"My specialists tried for ages to get me on a clinical trial but it's not easy. You have to be sick, but not too sick. You have to have the right cancer. You have to be in the right location. Eventually I got on one and honestly it saved my life. I don't think I would be here without that."

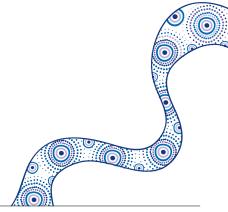
Person who has experienced cancer

High-quality cancer research is vital to ensure the health system, in particular system improvements, are based on the best available evidence. This is supported by trained and motivated staff who are actively engaged in research projects when appropriate. To have the most impact, the results of cancer research need to be routinely and rapidly translated into clinical practice and guidelines.

Research is key across all parts of cancer care – for example, to support best practice approaches to prevention, to identify ways to enhance participation in screening programs, or to make sure people with cancer receive the best possible treatment, care and support.

For some people with cancer, clinical trials offer the best option for effective care, treatment and support. However, improvements are needed in access to and participation in clinical trials:

- For every 100 people diagnosed with cancer in NSW, there were six enrolments in a cancer clinical trial in 2019–20.4
- In 2019–20, there were differences in the number of cancer clinical trials open for recruitment between different NSW local health districts (LHDs) and specialty networks (SNs). Metropolitan LHDs tended to have more cancer clinical trials open for recruitment than regional, rural and remote LHDs.⁴
- There is lower participation in cancer clinical trials among Aboriginal communities and other focus populations, including multicultural communities and those living in regional, rural and remote areas.





Putting the principles into practice

Examples may include:

- For equity of outcomes, providing opportunities to participate in clinical trials for those living in regional and rural areas, for example through telemedicine or virtual care.
- For person-centredness, ensuring all information about participation in clinical trials is supportive, culturally safe and responsive and easy to understand.
- For collaboration, building greater links between researchers within NSW, across Australia and internationally to ensure the people of NSW have access to cutting-edge clinical trials and best practice cancer treatment, care and support.



✓ What success looks like

For the health system

The people of NSW have access to cancer services underpinned by world-class research that is routinely translated into clinical practice.

For people at risk of or affected by cancer, their families and carers

I know there is investment in research that is improving the cancer system – from prevention, diagnosis and treatment to survivorship and palliative care.

If I am diagnosed with cancer, I can access information about clinical trials that is culturally safe and responsive and easy to understand, and I feel confident to discuss these options with my cancer care team, GP or Aboriginal health team.

I can access world-class treatment, including clinical trials if these are appropriate for me. I feel confident to participate in cancer research.



System enablers

Priorities and strategic actions in this *NSW Cancer Plan* will be supported by three groups of system enablers.

System enablers underpin and support the implementation and success of the *NSW Cancer Plan*. Many of these enablers are broader than just the NSW cancer system and require collaboration and partnerships.



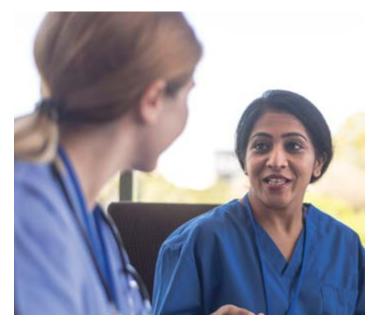
Staff are engaged and well supported

- Leadership and culture
- Workforce

Leadership and culture

Strong leadership and supportive workplace cultures provide an environment for delivering safe and high-quality care. There are opportunities to continue to build positive leadership and culture in cancer care delivery which may include:

- championing the importance of person-centred care with a focus on delivering exceptional experience through shared decision making
- building positive workplace cultures with a foundation of collaboration and trust, to enhance patient and staff experience and improve clinical outcomes
- creating culturally safe and responsive environments within health and cancer services to support better care and experiences for Aboriginal people at risk of or affected by cancer.



Workforce

A workforce with the right skills, capabilities and experience is essential to deliver high-quality, safe and person-centred cancer care. This may include:

- ensuring the workforce is representative of the diversity of the NSW population and has the skills to deliver care that is culturally safe and responsive
- ensuring all staff members receive regular, effective training in communication, personcentred care and customer service
- identifying and supporting new roles to enhance the delivery of prevention, care, treatment and support. This could include supporting the workforce to extend their scope of practice for some roles, proactively building the capability of staff to take on new roles, and building the capacity of the Aboriginal health workforce across the health system
- creating networked models of care to improve access to specialist services, for example through virtual care.





Innovation and digital advances inform service delivery

- Data and information
- Technology and innovation

Data and information

Success of the NSW Cancer Plan is built on continuing to improve communication and sharing of information across all care settings (both public and private). This may include:

- focusing on linking data across the health system and the integration and interoperability of clinical information systems so that all clinicians have access to information to support coordinated care delivery
- ensuring data for Aboriginal people and other focus populations is accessible to support timely research, planning and service decision making
- addressing ongoing challenges around data privacy, security and sovereignty (the right to maintain, control, protect and develop intellectual property) for data related to Aboriginal communities
- enhancing the availability, quality and use of data and information
- supporting linkages with data sets outside the public health domain, such as Census data.

Technology and innovation

Enhancements in technology and innovation can lead to better communication, sharing of information, and development of new models of care that meet the needs and preferences of people who have (or are at risk of) cancer. Opportunities may include:

- co-designing new models of prevention, diagnosis, cancer treatment, care, support and follow-up with consumers, clinicians and other key stakeholders
- using new technologies to deliver cancer treatment closer to home for patients who would prefer this, such as through virtual care models
- incorporating technological advances and innovations such as genomics, personalised medicine and artificial intelligence to support better care.





The system is managed sustainably

- Governance
- Monitoring, evaluation and reporting

Governance

Governance means there are established structures and processes to direct and oversee cancer control initiatives.

Effective governance is vital for safe, high-quality, person-centred care and accountability.

Opportunities to enhance governance may include:

- ensuring patients, their families and carers are represented on governance committees
- enabling the voices of Aboriginal Elders and leaders to drive community-led decision making and service delivery
- ensuring focus populations are represented on governance committees and at the system level, such as through executive-level staff positions focused on equity
- strengthening alignment with NSW Health governance structures
- strengthening legal and policy environments, and having strong governance structures for the use of technology.

Monitoring, evaluation and reporting

Systems for monitoring, evaluation and reporting ensure ongoing accountability and continuous quality improvement.

Opportunities for enhancing monitoring, evaluation and reporting may include:

- continuing to build partnerships and engage with cancer care providers, including supporting them with access to clinical and outcomes data and information
- identifying competent and trustworthy professionals who are able to champion best practice and influence and lead others
- improving the type, collection and real-time use of patient-reported measures, so feedback on people's experiences and outcomes can be used to improve service delivery
- providing greater transparency around data to identify and understand any variation in cancer treatment and outcomes
- ensuring there are clear systems for evaluating the NSW Cancer Plan, including process and outcome evaluations of related activities and initiatives.

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Working together

Success requires many people and organisations in NSW working together.

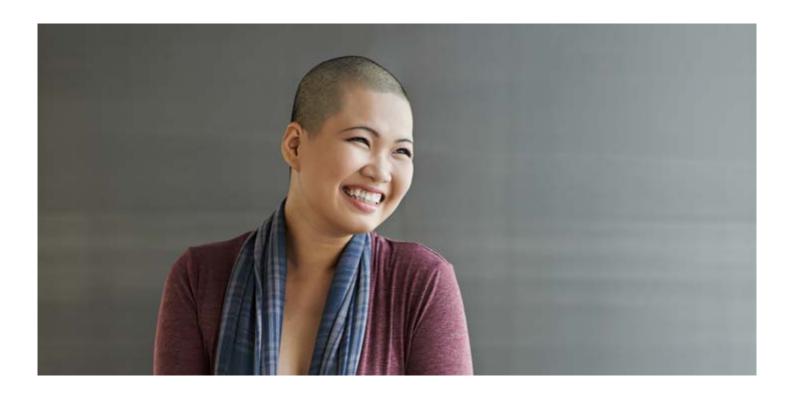


The following organisations, agencies and services each play a role in contributing to the success of this *NSW Cancer Plan*, through undertaking activities in line with some or all of the agreed priorities and actions:

- The NSW Ministry of Health provides overall direction, management and oversight of NSW Health.
- The Cancer Institute NSW, a pillar organisation of NSW Health, sets the direction for cancer control across the state in collaboration with other stakeholders, leads efforts on cancer care in NSW, and measures and reports progress.
- Other pillar organisations of NSW Health provide specialised support to the health system (i.e. the Agency for Clinical Innovation (ACI), Bureau of Health Information (BHI), Clinical Excellence Commission (CEC) and the Health Education and Training Institute (HETI)).
- The broader NSW and Australian governments provide the enabling environment for prevention, cancer screening, care, treatment and support.
- Cancer-specific publicly-funded health services are provided by specialist cancer services in local health districts (LHDs) and specialty networks (SNs).

- The wider public health system including emergency and acute care services, preventative health, allied health, psychosocial and palliative care and the Multicultural Health Communications Service (MCHS) support people's holistic health needs.
- Primary care is provided by Primary Health Networks (PHNs), general practitioners (GPs) and Aboriginal Community Controlled Health Services (ACCHSs).
- Organisations including the Centre for Aboriginal Health at the NSW Ministry of Health, the Aboriginal Health and Medical Research Council (AH&MRC), Aboriginal Community Controlled Health Services (ACCHSs) and Aboriginal Community Controlled Organisations work for and with Aboriginal communities
- The private sector, which, along with the public health system, provides diagnostics, cancer-specific care and treatment services, and manufactures pharmaceuticals.
- Not-for-profit organisations deliver a range of health promotion activities, patient information, care and support, including patient advocacy (e.g. the Cancer Council NSW and Cancer Voices NSW).
- The research community, professional bodies and academia drive advances in prevention, screening, treatment, follow-up, survivorship and palliative care.

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Related strategies

The NSW Cancer Plan is influenced by, and operates alongside, a number of statewide strategies.

It is guided by the Premier's Priorities and aligns with Future Health: Guiding the next decade of care in NSW 2022–2032, which provides the strategic framework and priorities for the whole health system over the next decade.

Other key strategies

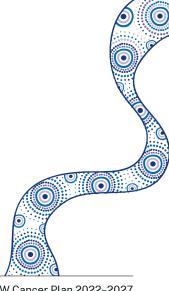
Other key strategies that have informed or enabled the development of the NSW Cancer Plan include:

Informing

- Elevating the Human Experience
- National Agreement on Closing the Gap
- National Preventive Health Strategy 2021–2030
- NSW Aboriginal Health Plan 2013–23
- NSW Plan for Healthy Culturally and Linguistically Diverse Communities: 2019-2023
- NSW Refugee Health Plan
- NSW LGBTQI+ Health Strategy
- Rural Health Plan

Enabling

- Health Professionals Workforce Plan 2012–22
- NSW Health Aboriginal Workforce Strategic Framework Good Health Great Jobs
- Respecting the Difference: An Aboriginal Cultural Training Framework
- NSW Health Strategic Framework for Integrated Care
- NSW Primary Health Care Cancer Framework
- End of life and Palliative Care Framework 2019–24
- NSW Health Genomics Strategy
- NSW Tobacco Strategy 2012-21
- NSW Skin Cancer Prevention Strategy
- NSW Healthy Eating and Active Living Strategy 2013-18
- NSW Hepatitis B and C Strategies 2014–20.



Implementation and measuring progress

Governance of the NSW Cancer Plan

Clear governance structures will support effective, coordinated and collaborative implementation of the NSW Cancer Plan.

While the Cancer Institute NSW is the custodian of the NSW Cancer Plan, overall governance of the plan is provided by the multi-stakeholder NSW Cancer Plan Governance Committee. The Governance Committee:

- provides oversight and advice on implementation, monitoring and reporting for the NSW Cancer Plan to ensure goals are achieved
- promotes and facilitates engagement and communication between all stakeholders involved in implementing the NSW Cancer Plan
- provides oversight and advice for evaluations of the NSW Cancer Plan
- provides oversight and advice through the development and implementation of subsequent cancer plans for NSW
- reflects the diversity of the community in NSW.

Implementation of the NSW Cancer Plan

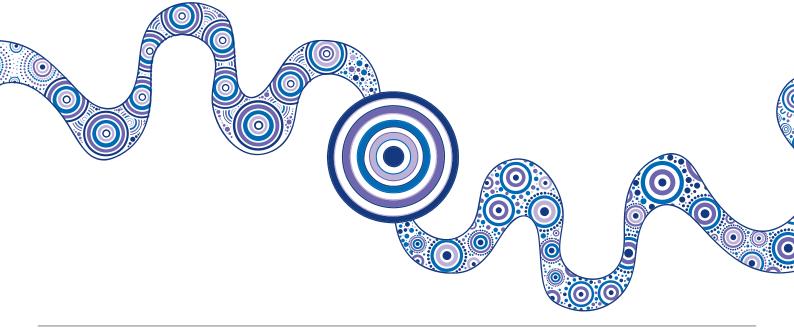
The purpose of the NSW Cancer Plan is to provide the overarching direction for cancer control in NSW. How we will address the strategic priorities and achieve the goals will be determined in a supporting implementation plan, which will be developed with collaborators and stakeholders.

The implementation plan will detail the activities and initiatives, the responsible collaborators and stakeholders, and the timeframes for delivering these within the life of this NSW Cancer Plan. The implementation plan will be reviewed and refreshed annually with partners, collaborators and key stakeholders.

Monitoring, evaluation and reporting on progress

Monitoring, evaluation and reporting on success is vital to understand if we have achieved the goals of the plan and to inform changes over the life of the *NSW Cancer Plan*. The implementation plan will also be a key part of how we will measure and track progress against the *NSW Cancer Plan*.

We will continue to measure and track our progress against the goals of the NSW Cancer Plan through the NSW Cancer Plan Performance Index, which includes a selection of high-level system indicators.



Glossary

| Term | Definition |
|---|--|
| Allied health | A diverse group of individual professions, in most instances university qualified professionals, who work in a healthcare team to support a person's medical care. |
| | In NSW Health, more than 20 professions fall within the scope of allied health. Further information can be found on the <u>NSW Health website</u> . |
| Cancer care pathway | The stages of a person's cancer and interactions with the cancer system, from prevention to screening, detection, treatment, follow-up, survivorship and palliative care. |
| Cancer control | A whole-of-population approach that aims to reduce cancer incidence, morbidity and mortality. This involves evidence-based interventions and services from prevention, to screening, detection, treatment and survivorship and palliative care. |
| Cancer system | All services and organisations that contribute to cancer control in NSW, along the continuum from prevention to survivorship and palliative care. The cancer system includes government, non-governmental organisations and private providers. |
| Co-design | A way of bringing together people at risk of or who have experienced cancer, their families and carers, health workers, and other key stakeholders to improve services. Co-design creates an equal and reciprocal relationship between those involved in development, enabling them to design and deliver services in partnership with each other. Further information on co-design can be found in the <u>ACI Guide to Build Co-design Capability</u> . |
| Cultural determinants of health | 'The cultural determinants of health originate from and promote a strength-based perspective, acknowledging that stronger connections to culture and country build stronger individual and collective identities, a sense of self-esteem, resilience, and improved outcomes across the other determinants of health including education, economic stability and community safety.' ¹³ |
| Culturally safe and responsive care | Care that is delivered in a way that respects and responds to the diverse needs of people from different cultural and language backgrounds, including personal traditions, history, values, family systems and experiences. Cultural safety is not defined by the health professional but is defined by the health consumer's experience – the individual's experience of care they are given, ability to access services and to raise concerns. |
| Data sovereignty | In this context, "the right [for Aboriginal communities] to maintain, control, protect and develop the cultural heritage, traditional knowledge and traditional cultural expressions, as well as their right to maintain, control, protect and develop the intellectual property over these." ¹⁴ |

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| Term | Definition |
|--------------------------------|---|
| Equity/equitable | Health equity is defined as differences in health that are avoidable and also considered unfair or unjust. Issues of equity can impact on health in a number of ways, including socially or economically disadvantaged groups who experience different prevalence of disease or poorer health outcomes; groups who have different levels of access to health interventions due to geography, economic barriers or discrimination; and groups who may respond differently to interventions such as children. |
| | Equity in the context of this <i>NSW Cancer Plan</i> means all groups of people in NSW, regardless of factors such as where they were born or live, their cultural background, their gender or sexual identify, should have the same opportunity to access cancer services and the same outcomes. |
| | Equity is different to equality. Equality would be giving all groups the exact same resources and support; equity would be distributing resources and support based on the needs of specific groups. |
| | This NSW Cancer Plan acknowledges that to achieve equity, some groups within NSW need additional and prioritised focus and support. Further information on equity can be found on the National Health and Medical Research Council website. |
| Health pathways | An agreement between primary and specialist services on how people with specific health conditions are managed in the local context. In particular, they provide guidance in the initial assessment, management and referral of patients from primary care to specialist services. |
| Health services | All services within NSW that provide health care, treatment and support. This includes public, private and non-government services. In this <i>NSW Cancer Plan</i> , this term is a broader term than 'cancer services'. |
| Health system | The organisation of people, institutions and resources that deliver health services to meet the health needs of the people of NSW. |
| | In this <i>NSW Cancer Plan</i> , the health system refers to all groups including the NSW Ministry of Health, local health districts (LHDs)/specialty networks (SNs), the primary healthcare system, private and non-government providers, and prevention services. |
| Intersex | Describes people who have innate sex characteristics that don't fit medical and social norms for female or male bodies, and that create risks or experiences of stigma, discrimination and harm. Intersex is about an individual's body and is not related to sexuality or gender. |
| LGBTQ+ | An umbrella term that embraces sexuality and gender diverse identities including lesbian, gay, bisexual, transgender and queer people. |
| Multidisciplinary team/care | A team involving a range of health professionals from different disciplines, from one or more organisations, working together to deliver comprehensive patient care that addresses as many of the patient's needs as possible. |
| National screening programs | The three population-based cancer screening programs in Australia: BreastScreen Australia, the National Bowel Cancer Screening Program and the National Cervical Screening Program. |
| Palliative care | Aims to improve quality of life for people nearing end of life, their families and carers. It can include the prevention and relief from pain and other distressing symptoms through early identification, assessment and treatment. Palliative care addresses needs that may be physical, psychosocial or spiritual. |

| Term | Definition |
|--|---|
| Person-centred | Person-centred care is widely recognised as a foundation to safe, high-quality health care. It is respectful of, and responsive to, the preferences, needs and values of the individual and the community as a whole. |
| | It is about a focus on the patient. This involves: seeking out and understanding what is important to the patient, their family and carers, and what is important to the community as a whole; fostering trust; establishing mutual respect; and working together to share decisions and plan care. |
| Primary health care/primary health care providers | Generally, the first contact a person has with the healthcare system. Primary care relates to the treatment of patients who are not admitted to hospital. |
| | While general practitioners (GPs) are the basis for primary care in Australia, primary care can also be provided through nurses (such as general practice nurses, community nurses and nurse practitioners), allied health professionals, midwives, pharmacists and dentists. |
| | Aboriginal Community Controlled Health Services are health organisations that provide culturally safe and responsive primary care for Aboriginal people. |
| | Further information on primary care can be found on the <u>Australian Government Department of Health website</u> . |
| Primary health networks | Were established with the key objectives of increasing the efficiency and effectiveness of medical services for patients, particularly those at risk of poor health outcomes, and improving coordination of care to ensure patients receive the right care in the right place at the right time. |
| | Further information on PHNs can be found on the <u>Australian Government Department of Health website</u> . |
| Psychosocial support | Care including mental health counselling, education, spiritual support, group support and other services. Services are usually provided by mental health professionals such as psychologists, social workers, counsellors and specialised nurses. |
| Secondary services | Services or facilities that provide specialist care, following referral from primary care. |
| Social determinants of health | The non-medical factors that influence health outcomes. These include factors such as socioeconomic status, employment, educational attainment and cultural background. |
| Survivor/ survivorship | The process of living with, through and beyond cancer. By this definition, cancer survivorship begins at diagnosis. It includes people who continue to have treatment to either reduce risk of recurrence or to manage chronic disease and includes the longer-term impacts of cancer treatment on people affected by cancer. |
| System enablers | Those factors that underpin and support the implementation and success of the <i>NSW Cancer Plan</i> . Many of these enablers are broader than just the NSW cancer system and require collaboration and partnership. |
| Tertiary services | Services that provide a higher level of specialised health care, usually in hospital and on referral from a primary or secondary health professional, that has staff and facilities for advanced medical investigation and treatment. |
| Value-based care | Continually striving to deliver care that improves: • health outcomes that matter to patients • experiences of receiving care • experiences of providing care • effectiveness and efficiency of care. Further information on value-based care can be found on the NSW Health website. |

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