

The Draft NSW Cancer Plan

**A plan for NSW to lessen the impact of
cancers**

DRAFT

2022-2026

11 March 2021

You are invited to comment on the next NSW Cancer Plan

Welcome to the draft NSW Cancer Plan (the Plan). This document provides initial content that will form the basis of the Plan, which will guide cancer control in NSW between 2022 and 2026.

The Plan has been developed following extensive consultations commencing June 2020 with more than 600 people including those with experience of cancer, their families and carers; clinicians; national and international experts; representatives from government agencies and non-governmental organisations; and other key stakeholders. I would like to take this opportunity to thank all those who have given their time and expertise to date.

This document includes:

- The proposed vision.
- Four proposed goals.
- Three overarching principles.
- Four proposed priorities and associated strategic actions.
- Six system enablers.

This document also includes placeholders for sections of the Plan that are still under consideration – such as collaborating partners, key indicators and measures of progress. These will be included in the final Plan.

The Plan places the experiences of those at risk of and affected by cancer at its centre. It includes direct quotes and statements of success from the perspective of people at risk of or affected by cancer, their families, and carers.

It is my pleasure to invite you to provide your comments on this draft Plan. This will be a Plan for all of NSW, outlining how we can work together to end cancers as we know them, so it is important that we all have the opportunity to shape the vision, goals, priorities and actions that will guide our work in the coming years.

Comments on the draft Plan can be provided through the NSW Government [Have Your Say](#) website.

How to navigate this document

You are invited to comment on the next NSW Cancer Plan	2
Welcome to the NSW Cancer Plan	4
The NSW Cancer Plan on a page	5
Cancers in NSW	6
Vision and Goals	9
Guiding Principles	10
Priority 1: Prevention of cancers	12
Priority 2: Screening and early detection of cancers	14
Priority 3: Optimal cancer treatment, care and support	17
Priority 4: Cancer research	20
System enablers	23
Implementation and measuring progress	26
References	27
Appendix 1: Glossary	28
Appendix 2: Key terms and acronyms	35

Please note that a [Glossary](#) and list of [Key terms and acronyms](#) are provided in the Appendices.

Welcome to the NSW Cancer Plan

This NSW Cancer Plan (the Plan) sets the vision, goals and priorities for how we, as a NSW community, can end cancers as we know them. The Plan sets an ambitious direction for the NSW cancer, health and broader communities to address challenges and leverage new opportunities in all areas of cancer control, from prevention through to survivorship and end-of-life care.

First and foremost, this is a plan centred on people. It is grounded in an understanding of what's most important to people at risk of or who have experienced cancer, their families and carers. These experiences are incorporated throughout the Plan as quotes and stories, and the Plan considers what success looks like from their perspective.

It is also an overarching plan that provides guidance and direction for all of NSW – not just those parts that might traditionally be considered part of the cancer or health sectors. Cancer is not just a health issue. It is well known that factors such as level of education, socioeconomic status, cultural background, and place of residence impact the risk of experiencing cancer, access to cancer care, treatment and support and cancer outcomes. Success of this plan requires an active commitment from all parts of the NSW community – including individuals and local communities, government agencies, non-government and community organisations, and the private sector.

NSW and Australia are recognised as global leaders in cancer. One and five-year survival rates for most cancers are the highest in the world.¹ The Plan also recognises, celebrates, and builds upon these existing strengths. To know more about key achievements under the current NSW Cancer Plan, visit the [Cancer Institute NSW website](#).

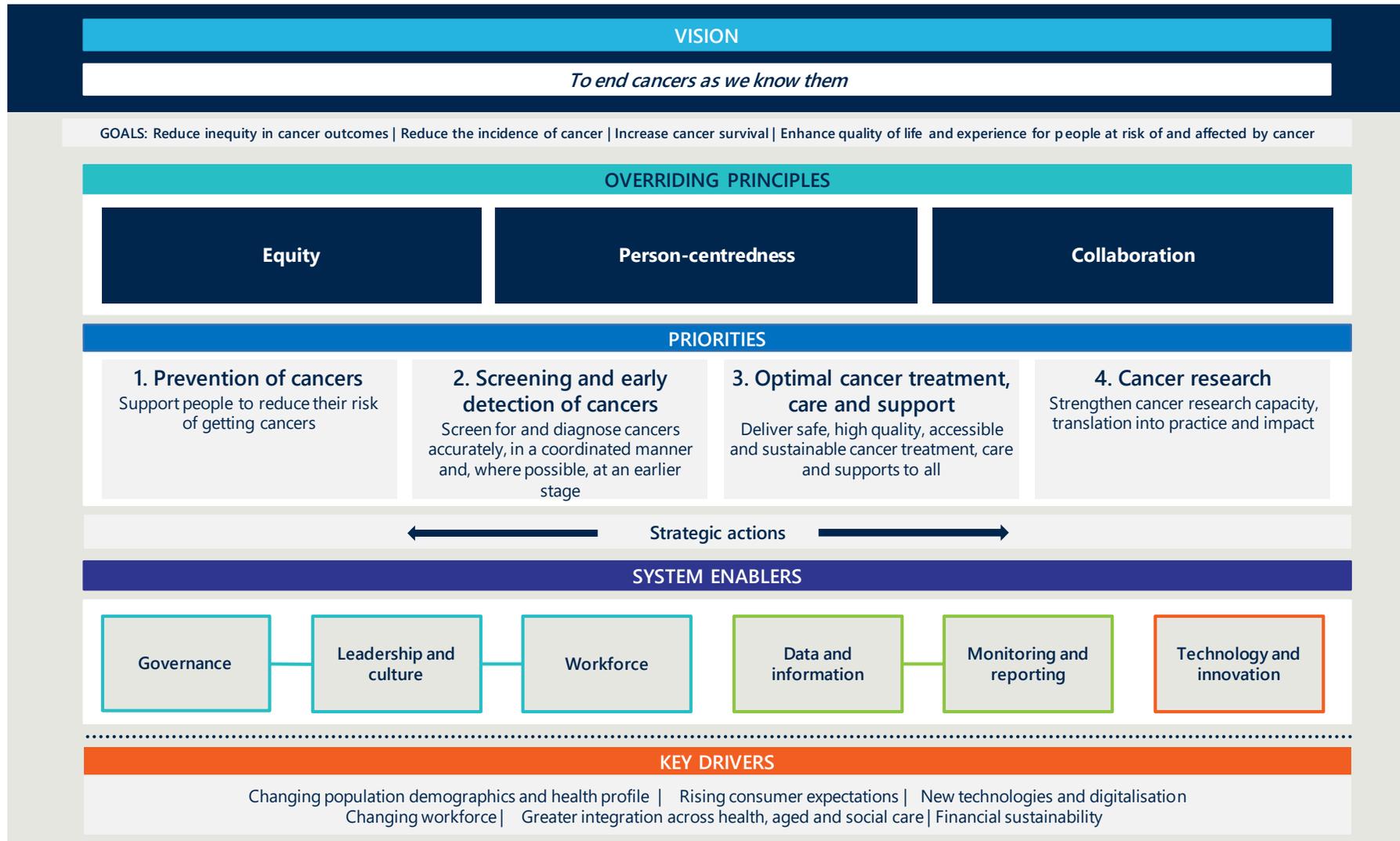
However, there are still inequities and unwarranted variation. Some parts of the NSW community – including Aboriginal communities,² multicultural communities, LGBTIQI+ communities, and people living in regional, rural and remote areas – are less likely to access prevention or screening services, are often diagnosed at a later stage, have fewer options for cancer care, and have poorer outcomes.³ This Plan has a specific focus on accelerating progress in addressing these remaining inequities.

¹ Arnold, M. Rutherford MJ. Bardot A. et. al. (2019). Progress in cancer survival, mortality, and incidence in seven high-income countries 1995-2014 (ICBP SURVMARK-2): a population based-study. *The Lancet Oncology*. 20(11) pp. 1493-1505. doi: [https://doi.org/10.1016/S1470-2045\(19\)30456-5](https://doi.org/10.1016/S1470-2045(19)30456-5)

² Note that the Plan uses the term 'Aboriginal' rather than 'Aboriginal and Torres Strait Islander', recognising Aboriginal people are the original inhabitants of NSW.

³ Cancer Institute NSW. (Undated). *Cancer type summaries for NSW*. Available from: <https://www.cancer.nsw.gov.au/research-and-data/cancer-data-and-statistics/cancer-type-summaries-for-nsw> accessed: 1 Feb 2021.

The NSW Cancer Plan on a page



An explanation of what's in the Plan:

A vision	The vision details what we, as a system, are collectively trying to achieve.
Four goals	The goals set clear outcomes that will help us to achieve the vision.
Three overriding principles	The principles cut-across and direct all the priorities and strategic actions
Four priorities	The priorities outline our collective focus areas for the next five years and include the high-level actions required.
Six system enablers	The system enablers are the key factors that will support achievement of the priorities. The system enablers are broader than the NSW cancer system and require system collaboration and partnerships.

The vision, goals, principles and priorities are intended to help organisations to identify and plan their activities over the coming years, so that all parts of the system are working collaboratively, either independently or in partnerships, towards a common end.

Cancers in NSW

NSW is a global leader in cancer outcomes, although cancer remains a significant and growing burden of disease

Cancer contributes the largest burden of disease in Australia.⁴ Although cancer survival rates have increased, and cancer mortality rates continue to decline, cancer still accounts for approximately three of every ten deaths.⁵

Whilst NSW is recognised as a global leader in cancer care, cancer continues to have a significant impact on the people of NSW. In 2020, approximately 16,000 people died from cancer, and around 49,000 people are estimated to have been diagnosed with cancer.⁶ The most common cancers – prostate, bowel, breast, melanoma and lung –

⁴ Australian Institute of Health and Welfare. 2019. [Australian Burden of Disease Study: impact and causes of illness and death in Australia 2015](#). Australian Burden of Disease series no. 19. Cat. no., BOD 22. Canberra: AIHW

⁵ Australian Institute of Health and Welfare. 2019. [Cancer in Australia 2019](#). Cancer Series no.119. Cat. no. CAN 123. Canberra: AIHW

⁶ Cancer Institute NSW. 2020. [Cancer Control in NSW: Statewide Report 2019](#).

account for 59 per cent of all new cases. It is estimated that one in two people in NSW will be diagnosed with cancer by the age of 85.⁷

In NSW, there remains variation in access to a range of cancer services and in cancer outcomes. For example, men are 1.3 times more likely to be diagnosed with cancer than women. Some groups of people within the population are more affected by cancer proportionately than others, including:

- Aboriginal communities
- multicultural communities
- rural and regional communities
- LGBTQI+ communities
- those with long-term mental health conditions
- those incarcerated or engaged with the justice system
- people from lower socio-economic backgrounds.⁸

Success requires many people and organisations across NSW working together

Effective and equitable cancer services relies on a significant and diverse group of people and organisations across health, human services and other sectors, as noted below. Each has a role to play in contributing to the success of this Plan, through undertaking activities in line with some or all of the agreed priorities and actions, and all should see themselves as part of this Plan.

- **The NSW Ministry of Health**, which provides overall direction, management and oversight of NSW Health.
- **The Cancer Institute NSW**, which sets the direction and leads efforts on cancer care in NSW and measures and reports upon progress.
- **Cancer-specific publicly-funded health services**, which provide specialist cancer services.
- **The wider public health system**, for example, emergency and acute care services, as well as allied health, psychosocial or palliative care.

⁷ Cancer Institute NSW. (Undated). *Cancer type summaries for NSW*. Available from: <https://www.cancer.nsw.gov.au/research-and-data/cancer-data-and-statistics/cancer-type-summaries-for-nsw> accessed: 1 Feb 2021.

⁸ Cancer Institute NSW. 2020a. *ibid*

- **Primary care**, including General Practitioners and Aboriginal Community Controlled Organisations.
- **The private sector**, which provides cancer-specific care and treatment services.
- **Not-for-profit organisations**, which deliver a range of health promotion activities, patient information, care and support, including patient advocacy.
- **The research community and academia**, which drive forward advancements in prevention, screening, treatment, follow-up and survivorship care.
- **The broader NSW and Australian governments**, which provide the enabling environment for cancer screening, care, treatment and support

Vision and Goals

The vision of the NSW Cancer Plan outlines what we, as a system, are collectively trying to achieve.

Vision	To end cancers as we know them
---------------	--------------------------------

The goals set clear outcomes that will help us to achieve the vision.

Goals	Reduce inequity in cancer outcomes
	Reduce the incidence of cancer
	Increase cancer survival
	Enhance the quality of life and experience for people at risk of and affected by cancer

Guiding Principles

Three overriding principles guide the direction of the NSW Cancer Plan. The principles cut across and direct all priorities and strategic actions.

Equity

Ongoing advances in knowledge, research and treatments will continue to improve cancer outcomes for the population as a whole. To accelerate improvements in overall cancer outcomes, we will need to focus on opportunities to address remaining inequities, so everyone can achieve their best health.

Equity means:

- Taking an equity / “focus populations-first” lens to decision making, investment and monitoring. Focus populations for this Plan include groups such as Aboriginal communities, multicultural communities, rural and remote communities, older people, those incarcerated and engaged with the justice system, and the LGBTIQI+ community.
- Empowering and partnering with focus populations such as through community-based organisations (CBOs) to ensure that prevention messages are appropriately targeted, and that cancer screening, treatment care and support services meet their needs and preferences and are provided in culturally safe ways and spaces.
- Ensuring that the workforce reflects the diversity of the NSW population, and has the skills to deliver care that is culturally safe, particularly for Aboriginal people.
- Building a strong and impactful voice for focus populations at the system level including through co-design, leadership roles and governance structures.
- Engaging the community about value-based cancer care, including factors such as the need to balance the increasing demand for and cost of expensive treatments, therapies and/or devices for the few and/or providing marginal benefit, with ensuring that everyone receives a standard level of cancer care which is their right.

Person-centredness

World class clinical outcomes will be supported and enhanced by exceptional experiences of people at risk of and who have experienced cancer, their families and carers.

Person-centredness means:

- Ensuring that prevention and screening, treatment services, care and support are centred on patient, family and carers experience and are responsive to individuals needs and preferences – including ensuring that services are culturally safe and appropriate.

- Empowering patients, their families and carers to make informed decisions and be full partners in their care.
- Building a system that is easier for patients, families and carers to understand and navigate, and strengthen ways to coordinate their care.
- Ensuring cancer services meet the holistic needs of patients, families and carers including access to supportive care, including psychosocial and allied health services and non-clinical supports.

Collaboration

Collaboration at the system, service and care team levels with clarity of roles and accountabilities and effective governance will achieve optimal cancer outcomes for the people of NSW.

Collaboration means:

- Strengthening 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, the Aboriginal Health and Medical Research Council (AH&MRC) and non-governmental organisations (NGOs).
- Partnering effectively with primary health care to support prevention, screening and early detection efforts, to support people as they transition from primary care to secondary and tertiary services, and to assist with coordination of care.
- Partnering effectively across government – including education, planning and communities and justice – to ensure that prevention and responses to cancer are considered in major strategies, framework and plans.
- Formalising 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.
- Strengthen engagement between the Cancer Institute NSW, cancer services and the health and human services sector, so that activities related to cancer prevention, screening, treatment and follow up are considered as part of the delivery of broader public health services.

Priority 1: Prevention of cancers

What success looks like	All people in NSW 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.

Preventing cancer is one of the most effective ways to achieve our vision of ending cancers as we know them and to address inequities. At least 1 in 3 cases of cancer can be prevented. In Australia approximately 16,700 cancer deaths and 41,200 cancer cases each year could be prevented.⁹

A number of actions for a healthier lifestyle can lower the risk of getting cancer. This includes avoiding or stopping smoking, healthier diets, increasing physical activity, reducing sun exposure, and reducing consumption of alcohol at harmful levels. These behaviours are influenced by the social determinants of health - that is, the conditions in which people are born, educated, work, live and age. Therefore, a public health approach to cancer prevention is essential to make the greatest impact.

Many risk factors for cancer are also shared with other chronic diseases such as heart disease, type 2 diabetes, and respiratory diseases, making a strong case for the inclusion of cancer in broader chronic disease partnerships.

Putting the principles into practice. Examples include:

- **For equity**, enabling community leaders to deliver cancer prevention information and support within their own communities, for examples, Aboriginal Health Workers.
- **For person-centredness**, supporting the use of wearable technologies and health apps to empower individuals to make healthier decisions, based on their own health information.
- **For collaboration**, working with the education sector to include cancer-prevention messages into education curricula and learning.

⁹ Wilson et al. (2018). How many cancer cases and deaths are potentially preventable? Estimates for Australia in 2013. *International Journal of Cancer*. 142(4):691-701

“ Our communities are really fearful of cancer...we think its 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 representative

Our actions for the next five-years

Note: Collaborating partners are still to be confirmed and will be included in the final Plan.

Four actions sit under this priority:

Action

- 1 Engaging and communicating effectively with the NSW community to build awareness of cancer and ‘change the cancer narrative’, including with focus populations
- 2 Targeting evidence based prevention efforts in areas with the greatest demonstrated impact, including helping people not take up smoking, and smoking cessation
- 3 Accelerating the uptake of new technologies and innovations to support people to change their behaviours and reduce their risk of cancer
- 4 Strengthening broad population health prevention collaborations and partnerships at all levels across public, private and non-governmental sectors

How we will know if we are successful

Note: Key indicators of success are in development and will be included in the final Plan.

Priority 2: Screening and early detection of cancers

<p>What success looks like</p>	<p>People at risk of cancer are directed to and supported to access cancer screening and diagnostic services, so that potential cancers are diagnosed as early as possible.</p>
<p>For people at risk of or affected by cancer, their families, and carers</p>	<p>It is easy for me to check for cancer. I know what I can do myself, and I have access to cancer screening programs.</p> <p>Services and community-based organisations help to direct me to cancer screening programs and provide advice if I need it.</p> <p>My GP or primary care doctor knows the early signs and symptoms of potential cancer and will send me for screening if it is appropriate.</p> <p>If I do have cancer, it is diagnosed early so I can have the best outcomes.</p>

Cancer screening means checking the body for signs of cancer before symptoms appear. Screening can be done by an individual – for example breast or testicular self-exams – or through the health system – for example routine mammograms offered through BreastScreen. Early detection of cancer is enabled through initiatives such as national cancer screening programs, opportunistic testing, risk recognition and symptom recognition.

Early detection of cancer can significantly improve outcomes for patients. According to an analysis conducted by the Australian Institute of Health and Welfare:¹⁰

- People with cancers diagnosed through the National Bowel Cancer Screening Program had a 40% lower risk of dying than those who had not been involved.
- 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 Pap test.

¹⁰ Australian Institute of Health and Welfare. (2018). [Analysis of cancer outcomes and screening behaviour for national cancer screening programs in Australia](#). Cancer series no. 111. Cat. no. CAN 115. (Canberra: AIHW)

Efforts are needed to enhance screening rates and support early detection. As of 2018:

- Six out of ten 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.

Putting the principles into practice. Examples include:

- **For equity**, 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 to understand information to all people who have suspected cancer about next steps, care pathways and support services available.
- **For collaboration**, working across government and community sectors to align screening and early detection strategies and messaging, particularly for focus populations.

“ To be honest, I don't think my doctor believed me when I first told him I was in pain. I had to push and push for a referral to a specialist – and finally after 18-months I got one. When I saw the specialist they told me my cancer was already quite advanced...imagine if I'd been referred earlier and they'd caught it sooner ”

Multicultural community representative

“ My GP was really good, even though I had no obvious signs of cancer. She sent me for a CT scan and that showed spots on my liver. Then she immediately put me in contact with a specialist team and I saw them really quickly. I actually feel very lucky. ”

Person who has experienced cancer

Our actions for the next five-years

Note: Collaborating partners are still to be confirmed and will be included in the final Plan.

Six actions sit under this priority:

Action

- 1 Promoting primary care provider endorsement of the established national cancer screening programs to enhance uptake of these programs
- 2 Focusing efforts so that NSW is the national leader in participation in screening and early detection programs
- 3 Increasing opportunistic screening for cancers across the NSW health system
- 4 Targeting early detection efforts on those localities or population groups with the highest potential for impact
- 5 Continuing to build the cancer knowledge of primary care providers and supporting them to proactively identify and effectively manage people who have or may have cancer, including increasing the tools available
- 6 Embedding consistent and coordinated pathways from primary care to the establishment of a plan for and commencement of cancer treatment and care

How we will know if we are successful

Note: Key indicators of success are in development and will be included in the final Plan.

Priority 3: Optimal cancer treatment, care and support

<p>What success looks like</p>	<p>People affected by cancer, their families and carers receive safe, high-quality and seamless cancer treatment care and support that meets their holistic needs.</p>
<p>For people at risk of or affected by cancer, their families, and carers</p>	<p>Once I am diagnosed with cancer, I quickly start treatment and I receive the best treatment possible.</p> <p>It is easy for me to access all the services that I need. This includes cancer treatment, but also things like allied health, psychosocial support, and non-clinical support such as financial planning advice.</p> <p>There is good communication between everyone involved in my care. I don't have to repeat my story each time I see someone.</p>

Effective cancer treatment means ensuring that people living with cancer receive comprehensive assessment, multidisciplinary treatment and care planning, and safe, high-quality and person-centred treatment. Evidence indicates that a team approach to cancer care, where health professionals together consider all options and develop an individual treatment plan, can reduce mortality and improve 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.
- Patient overall health.
- Patient choices and preferences.

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

An important part of delivering optimal cancer treatment, care and support is collecting and responding to patient feedback. There is a strong body of evidence linking patient

¹¹ Cancer Australia. (2021). [Multidisciplinary care](https://www.canceraustralia.gov.au/clinical-best-practice/multidisciplinary-care). Available from: <https://www.canceraustralia.gov.au/clinical-best-practice/multidisciplinary-care> accessed: 2 February 2021.

experience and person-centred care to improved clinical effectiveness, patient safety, healthy behaviours and better patient outcomes.¹²

Putting the principles into practice. Examples include:

- **For equity**, continuing to expand access to culturally safe supportive care and services, for example through ensuring diversity in recruitment practices and cultural safety training for cancer care staff.
- **For person-centredness**, co-designing with people who experience cancer, their families and carers, patient-reported measures that reflect what matters most to them.
- **For collaboration**, strengthening linkages between all providers of cancer treatment, care and support – including public, private and non-governmental providers – so that people who experience cancer, their families and carers have a seamless experience.

“

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

”

“

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

”

¹² Doyle C, Lennox L, Bell DA, 2013, Systematic review of evidence on the links between patient experience and clinical safety and effectiveness [BMJ Open](https://doi.org/10.1136/bmjopen-2012-001570) 3:e001570. doi: 10.1136/bmjopen-2012-001570

Our actions for the next five-years

Note: Collaborating partners are still to be confirmed and will be included in the final Plan.

Seven actions sit under this priority:

Action

- 1 Supporting best practice and value-based cancer care
- 2 Strengthening the provision of cancer care that is coordinated, easy to access and navigate
- 3 Ensuring 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 planning advice
- 4 Providing patients with timely access to relevant, credible and easily understandable information, for shared decision making at all stages of the pathway
- 5 Building better integration and communication across services and providers, including between primary, secondary and tertiary services and across the public and private systems
- 6 Ensuring high-quality and accurate information is available to system stakeholders to support evidence-informed decision making and quality improvement initiatives
- 7 Ensuring patient reported measures are routinely used for service planning, delivery, and quality improvement

How we will know if we are successful

Note: Key indicators of success are in development and will be included in the final Plan.

Priority 4: Cancer research

<p>What success looks like</p>	<p>The people of NSW have access to cancer services underpinned by world-class research that is routinely translated into clinical practice.</p>
<p>For people at risk of or affected by cancer, their families, and carers</p>	<p>I am confident that all parts of the NSW cancer system – from prevention to survivorship and palliative care – is based on the best possible evidence.</p> <p>If I am diagnosed with cancer, I am able to access world-class treatment, including clinical trials if these are appropriate for me. I feel confident to participate in cancer research.</p>

High-quality cancer research is critical for evidence-based practice, particularly to inform practice improvements. 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 needs to be routinely translated into clinical practice and guidelines.

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

For some people experiencing cancer, clinical trials offer the best option for effective care, treatment and support. However, access to trials remains difficult and unwarranted variation remains:

- For every 100 people diagnosed with cancer in NSW, there were nine enrolments in a cancer clinical trial in 2018-19.
- In 2018-19, there were differences in the number of cancer clinical trials open for recruitment between different NSW local health districts (LHDs) and specialty health networks (SHNs). 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.¹³

¹³ Cancer Institute NSW, 2020. [Cancer Control in NSW: Statewide Report 2019](#).

Putting the principles into practice. Examples include:

- **For equity**, 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 that is provided to those who experience cancer, their families and carers is clear and easy to understand.
- **For collaboration**, building greater links between researchers within NSW, across Australia and internationally to ensure that the people of NSW have access to cutting-edge clinical trials and best practice cancer treatment, care and support.

“ 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

Our actions for the next five-years

Note: Collaborating partners are still to be confirmed and will be included in the final Plan.

Five actions sit under this priority:

Action

- 1 Investing in cancer research infrastructure including through collaboration inter-state and beyond
- 2 Enhancing access to and participation in cancer clinical trials, including for focus populations
- 3 Providing easy to understand information to people experiencing cancer, their families and carers that supports their involvement in cancer research
- 4 Empowering primary care providers to support participation in clinical trials by those at risk of or affected by cancer
- 5 Further enhancing access and availability of high-quality linked data to support and enhance cancer control through research across NSW

How we will know if we are successful

Note: Key indicators of success are in development and will be included in the final Plan.

System enablers

Priorities and strategic actions in this Plan will be supported by six system enablers. System enablers are those factors that underpin and support the implementation and success of the Plan (see Figure 1). Many of these enablers are broader than just the NSW cancer system and require collaboration and partnerships.

These enablers should be seen collectively. However, some have particularly strong linkages between them and have been grouped together.

Figure 1 | System enablers



Governance	<p>Effective governance structures are a cornerstone for safe, high-quality, person-centred care and accountability.</p> <p>Opportunities to enhance governance within the health and cancer care system include:</p> <ul style="list-style-type: none"> • Ensuring that patients, their families and carers, including representatives of focus populations, are represented on relevant governance committees within LHDs/SHNs and in cancer services. • Building a voice for focus populations at the system level, such as through the creation of executive-level positions focused on equity and equality. • Strengthening governance of the NSW Cancer Plan such as through stronger alignment to NSW Health governance structures, the establishment of an enduring and cross sector Steering Committee to monitor progress.
Leadership and culture	<p>Strong leadership and supportive workplace cultures provide an environment in which safe and high-quality care can be delivered. There are opportunities to continue to build positive leadership and culture in cancer care delivery including:</p>

	<ul style="list-style-type: none"> • Leadership demonstrating and championing the importance of person-centred care and a focus on delivering exceptional experience, including for cancer services. • Continuing work to build positive workplace cultures, built on collaboration and trust, to lead enhanced patient and staff experience and better clinical outcomes.
Workforce	<p>A health and cancer workforce with the right skills, capabilities and experience is essential to the delivery of high-quality, safe and person-centred cancer care, including:</p> <ul style="list-style-type: none"> • Ensuring that there are enough staff within cancer services and in areas of need to deliver high-quality, person-centred care (including addressing any regional disparities). • Ensuring that the workforce is representative of the NSW population and has the skills to deliver care that is culturally safe and appropriate. • Ensuring that every staff member receives regular, effective training in customer service, effective communication and person-centred care. • Identifying and supporting new roles to enhance the delivery of prevention, care, treatment and support. This could include supporting the workforce to work at the top of their scope of practice, and extending the scope of practice for some roles as appropriate.
Data and information	<p>Success of the next Cancer Plan will be built on continuing to improve communication and sharing of information between primary, secondary and tertiary settings and across the public and private settings, including:</p> <ul style="list-style-type: none"> • Continuing to focus on data linkages, integration and interoperability of clinical information systems between primary, secondary and tertiary care; between cancer services and other services within LHDs/SHNs; and between the public and private sectors so that all clinicians have access to information to support coordinated care delivery. • Enhancing the availability, quality and use of longitudinal data.

	<ul style="list-style-type: none"> • Continuing to support linkages with data sets that sit outside the public health domain. • Continuing to address ongoing challenges around data privacy and security, and data sovereignty for data related to Aboriginal communities.
<p>Monitoring and reporting</p>	<p>Systems for monitoring and reporting support ongoing accountability and continuous quality improvement. Opportunities for enhancing monitoring and reporting including:</p> <ul style="list-style-type: none"> • Continuing to build partnerships and engage with providers of cancer care and clinical champions, supporting them with access to clinical and outcomes data and to information and benchmarks where appropriate. • Improving the type, collection and real-time use of patient reported measures to improve service delivery. • Providing greater transparency around data to enable identification and understanding of variation, and support accountability for variation and decision making.
<p>Technology and innovation</p>	<p>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 patients. Opportunities include:</p> <ul style="list-style-type: none"> • Co-designing with consumers new models of prevention, diagnosis, cancer care treatment, support and follow up. • Leveraging new technologies to deliver cancer treatment closer to home for those patient’s where this is their preference, such as through virtual care models. • Incorporating technological advancements and innovations such as genomics, personalised medicine and artificial intelligence to support better cancer care and improve access and outcomes.

Implementation and measuring progress

Governance of the NSW Cancer Plan

Clear governance structures are important to support effective, coordinated and collaborative implementation of the Plan.

While the Cancer Institute NSW is the custodian of the Plan, a number of collaborating partners will be identified in the Plan with responsibilities for progressing key initiatives, within each priority and strategic action.

Overall governance of the Plan is provided by the multi-stakeholder NSW Cancer Plan Governance Committee. The purpose of the Governance Committee is to:

- Provide oversight and advice on implementation, monitoring and reporting for the NSW Cancer Plan to ensure achievements of the objectives.
- Promote and facilitate engagement and communication between all stakeholders involved in implementing the NSW Cancer Plan.
- Provide oversight and advice for evaluations of the NSW Cancer Plan.
- Provide oversight and advice through the development and implementation of subsequent cancer plans for NSW.

Monitoring and reporting on progress

Monitoring and reporting on success is vital to understand whether we have been successful in achieving the vision and goals and to inform adaptations that will be required over the life of the Plan. The Plan will outline a selection of high-level indicators that will be used to track progress across the system.

A key part of this will be done through the [Cancer Plan Performance Index](#). This uses a number of measures to indicate progress against the goals we are working towards.

It is anticipated that individual organisations will also develop their own measures of success, aligned with their specific activities, and that these will be used to track and report on progress within each organisation.

References

Arnold, M. Rutherford MJ. Bardot A. et. al. (2019). Progress in cancer survival, mortality, and incidence in seven high-income countries 1995-2014 (ICBP SURVMARK-2): a population based-study. The Lancet Oncology. 20(11) pp. 1493-1505. doi: [https://doi.org/10.1016/S1470-2045\(19\)30456-5](https://doi.org/10.1016/S1470-2045(19)30456-5)

Australian Institute of Health and Welfare. (2018). Analysis of cancer outcomes and screening behaviour for national cancer screening programs in Australia. Cancer series no. 111. Cat. no. CAN 115. (Canberra: AIHW)

Australian Institute of Health and Welfare. (2019). Cancer in Australia 2019. Cancer Series no.119. Cat. no. CAN 123. Canberra: AIHW

Australian Institute of Health and Welfare. 2019. Australian Burden of Disease Study: impact and causes of illness and death in Australia 2015. Australian Burden of Disease series no. 19. Cat. no.,. BOD 22. Canberra: AIHW

Cancer Australia. (2021). Multidisciplinary care. Available from: <https://www.canceraustralia.gov.au/clinical-best-practice/multidisciplinary-care> accessed: 2 February 2021.

Cancer Institute NSW. (2020). Cancer Control in NSW: Statewide Report 2019. Available from: <https://www.cancer.nsw.gov.au/what-we-do/supporting-cancer-care/reporting-for-better-cancer-outcomes-program/cancer-control-in-nsw-statewide-report-2019>.

Cancer Institute NSW. (Undated). Cancer type summaries for NSW. Available from: <https://www.cancer.nsw.gov.au/research-and-data/cancer-data-and-statistics/cancer-type-summaries-for-nsw> accessed: 1 Feb 2021.

Doyle C, Lennox L, Bell DA. (2013). Systematic review of evidence on the links between patient experience and clinical safety and effectiveness. BMJ Open 3:e001570. doi: 10.1136/bmjopen-2012-001570

Kukutai, T. Taylor, J. (Ed.). (2016). Indigenous data sovereignty: toward an agenda. Canberra: ANU Press.

Wilson et al. (2018). How many cancer cases and deaths are potentially preventable? Estimates for Australia in 2013. International Journal of Cancer. 142(4):691-701

Appendix 1: Glossary

Term	Definition
Allied health	<p>The Allied Health Workforce in NSW Health is a diverse group of individual professions, in most instances university qualified professionals, who work in a health-care team to support a person's medical care.</p> <p>In NSW Health, more than 20 professions fall within the scope of allied health, including counselling, exercise physiology, genetic counselling, nutrition and dietetics, occupational therapy, radiation therapy, pharmacy and radiography.</p> <p>Further information can be found on the NSW Health Website.</p>
Cancer control	<p>A whole of population approach that aims to reduce cancer incidence, morbidity and mortality of cancer. This involves evidence based interventions and services from prevention, to screening, detection, treatment and survivorship and/or palliative care.</p>
Cancer services	<p>Health services within NSW that provide treatment, care and support to people affected by cancer, their families and carers. These may be public services (i.e. part of an LHD or SHN), private services, or public-private partnerships.</p>
Cancer system	<p>All services and organisation that contribute to cancer control in NSW, along the continuum from prevention to survivorship and/or palliative care.</p> <p>The cancer system includes government, non-governmental organisations and private providers.</p>
Clinical champions	<p>Competent and trustworthy professionals who are able to influence and lead others to adopt new and useful practices. These may be formal or informal roles.</p>
Co-design	<p>A way of bringing people at risk of or who have experienced cancer, their families and carers, and health workers together to improve services. Co-design creates an equal and reciprocal relationship between those involved in design, enabling them to design and deliver services in partnership with each other.</p>

	Further information on co-design can be found in the ACI Guide to Build Co-design Capability .
Collaborating partners	Those organisations identified to actively contribute to the success of strategic actions in the plan.
Community-based organisations	Non-profit organisations that work at the local level to improve life for their communities, including specific focus populations.
Culturally safe and appropriate care	<p>Care that is delivered in a way that respects and responds to the diverse needs of people from different backgrounds including traditions, history, values and family systems.</p> <p>Culturally safe and appropriate care takes into account factors such as language and other communication difficulties, treatment preferences, and preferences of who provides care and in what location.</p>
Data sovereignty	Data sovereignty, as it related to Aboriginal communities, is "the right 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
Equity/equitable	<p>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.</p> <p>Equity in the context of this Plan means that 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.</p> <p>Equity is different to equality. Equality has to do with giving all groups the exact same resources and support, where</p>

¹⁴ Kukutai, T. Taylor, J. (Ed.). (2016). *Indigenous data sovereignty: toward an agenda*. Canberra: ANU Press.

	<p>equity involves distributing resources and support based on the needs of specific groups.</p> <p>This Plan acknowledges that to achieve equity, some groups within NSW need additional and targeted focus and support.</p> <p>Further information on equity can be found on the NHMRC website.</p>
Focus population/s	<p>Those groups within the NSW community where we will place additional emphasis and effort in order to reduce inequity.</p> <p>Focus populations may include Aboriginal communities, multicultural communities, older people, people in regional, rural and remote areas, and the LGBTIQI+ community.</p> <p>The Plan does not explicitly name specific focus populations, acknowledging that different organisations may focus on different groups.</p>
Governance	<p>For NSW Health, governance refers to the processes and behaviours that ensure an organisation performs by achieving its intended purpose and confirms by complying with relevant laws, codes and directions and meets community expectations of probity, accountability and transparency.</p>
Health services	<p>All services within NSW that provide health care, treatment and support. This includes both public, private and non-governmental services.</p> <p>In this Plan, health services is a broader term than cancer services.</p>
Health system	<p>The organisation of people, institutions and resources that deliver health services to meet the health needs of the people of NSW.</p> <p>In this Plan, the health system refers to all groups including the NSW Ministry of Health, LHDs/SHNs, the primary health care system, private and non-governmental providers, and prevention services.</p>

Holistic needs of patients, families and carers	<p>Holistic care is care that meets all the needs of a person, including physical, psychosocial, spiritual and non-clinical.</p> <p>Non-clinical supports that may be provided could include financial planning advice, transportation support, and carer respite.</p>
LGBTQI+	An umbrella term that embraces a mix of sexual preferences and orientations, including lesbian, gay, bisexual, trans, queer, intersex, agenda and asexual.
Lived experience	<p>Refers to people who have first-hand experience as someone at risk of or affected by cancer, their families and carers.</p> <p>Lived experience is used to differentiate from others who may have experience working within the cancer system, but who have not personally had cancer or been a patient, family member or carer interacting with the cancer system.</p>
Multidisciplinary team/multidisciplinary care	A multidisciplinary team involves 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 cancer screening programs	<p>There are currently 3 population-based cancer screening programs in Australia:</p> <ul style="list-style-type: none"> • BreastScreen Australia Program • National Bowel Cancer Screening Program • National Cervical Screening Program
Non-clinical support	Support that a person who is experiencing cancer, their family or carer, may need that is not directly related to clinical treatment, care and support. This may include financial planning advice, transportation support, and carer respite.
Opportunistic screening	Occurs when a doctor or health professional offers a cancer screening check to people who are being examined for other reasons, or as part of a routine medical check-up.
Palliative care	Aims to improve the quality of life of people as they head towards the end of life, and their families and carers. It can include the prevention and relief from pain and other

	<p>distressing symptoms through early identification, assessment and treatment. Palliative care addresses needs that may be physical, psychosocial or spiritual.</p> <p>Further information on palliative care can be found on the NSW Health website.</p>
Patient reported measures	<p>Aim to allow patients to provide direct, timely feedback about their health-related outcomes and experiences to improve care and clinical interactions.</p> <p>Further information on patient reported measures can be found on the on the Cancer Institute NSW website.</p>
People at risk of or who have experienced cancer, their families and carers	<p>An umbrella term to encompass people who engage with the cancer control system.</p> <p>In its broadest sense, the term encompasses all the people of NSW, as everyone is at risk of cancer.</p>
Person-centred / person-centredness	<p>Person-centred care is widely recognised as a foundation to safe, high-quality healthcare. It is care that is respectful or, and responsive to, the preferences, needs and values of the individual.</p> <p>It involves seeking out and understanding what is important to the patient, fostering trust, establishing mutual respect and working together to share decisions and plan care.</p>
Primary health care / primary care providers	<p>Generally, the first contact a person has with the health care system. Primary care relates to the treatment of patients who are not admitted to hospital.</p> <p>Whilst 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, dentists, and Aboriginal Health Workers.</p> <p>Further information on primary care can be found on the Australian Government Department of Health website.</p>
Psychosocial support	<p>Can include mental health counselling, education, spiritual support, group support, and other services. Services are usually provided by mental health professionals such as</p>

	psychologists, social workers, counsellors and specialised nurses.
Public health approach	<p>A public health approach seeks to reduce the incidence of cancer through addressing the factors that increase the likelihood that a person will be diagnosed with cancer. These factors can include socioeconomic status, cultural background, and place of residence.</p> <p>A public health approach looks at the health and wellbeing of populations or communities as a whole through changes to prevention, policy interventions and advocacy.</p>
Secondary services	Services or facilities that provide specialist care, following referral from primary care.
Service-level collaboration	For the purposes of this Plan, service-level collaboration refers to collaboration between different facilities and care teams within a distinct health service, for example within an LHD.
Social determinants of health	The non-medical factors that influence health outcomes. These include factors such as socio-economic status, employment, educational attainment, and cultural background.
System enablers	Those factors that underpin and support the implementation and success of the Plan. Many of these enablers are broader than just the NSW cancer system and require collaboration and partnership.
System-level collaboration	For the purposes of this Plan, system-level collaboration refers to collaboration between different parts of the NSW cancer system, such as between government and non-governmental organisations, between different parts of government, or between the Ministry of Health and LHDs/SHNs
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.
Unwarranted variation	Whilst some variation in access to care and outcomes is normal and expected, some variation cannot be explained by illness or patient preferences.

Value-based care	<p>Value based care means continually striving to deliver care that improves:</p> <ul style="list-style-type: none">• Health outcomes that matter to patients.• Experiences of receiving care.• Experiences of providing care.• Effectiveness and efficiency of care. <p>Further information on value-based care can be found on the NSW Health website.</p>
-------------------------	---

Appendix 2: Key terms and acronyms

Term/Acronym	
ACCHO	Aboriginal Community Controlled Health Organisation
ACI	Agency for Clinical Innovation
AHMRC	Aboriginal Health and Medical Research Council
BHI	Bureau of Health Information
CBO	Community-based organisation
CEC	Clinical Excellence Commission
HETI	Health Education and Training Institute
LHD	Local Health District
MDT	Multidisciplinary team
NGO	Non-governmental organisation
NHMRC	National Health and Medical Research Council
PHN	Primary Health Network
SHN	Specialty Health Network
The Plan	The NSW Cancer Plan 2022-2026