



Cancer Australia

Submission to the Senate Community Affairs References Committee inquiry into equitable access to diagnosis and treatment for individuals with rare and less common cancers, including neuroendocrine cancer

August 2023

Cancer Australia welcomes the opportunity to provide a submission to the Senate Community Affairs References Committee inquiry into equitable access to diagnosis and treatment for individuals with rare and less common cancers, including neuroendocrine cancer.

About Cancer Australia

Cancer Australia was established by the Australian Government under the *Cancer Australia Act 2006* to minimise the impact of cancer, address disparities, and improve the health outcomes of people affected by cancer in Australia by providing national leadership in cancer control.¹ Cancer Australia works collaboratively across the entire cancer control system, including with Aboriginal and Torres Strait Islander people to integrate First Nations' perspectives and co-design for improved cancer experiences and outcomes. As a respected thought leader and trusted collaborator, the agency leverages stakeholder relationships and harnesses expertise to provide world-leading advice on key issues and priorities in cancer control.

The Australian Cancer Plan

Cancer outcomes in Australia are among the best in the world, but this is not the story for all Australians. There are significant disparities in cancer outcomes among specific groups in our society, including Aboriginal and Torres Strait Islander people.

Cancer Australia has developed The Australian Cancer Plan (the Plan), a 10-year national framework that will accelerate world-class cancer outcomes, experiences, and equity across the continuum of cancer care for all cancers from screening, diagnosis, treatment, supportive care to survivorship and end-of-life care. The Plan is designed to improve cancer outcomes for all Australians, and particularly for Aboriginal and Torres Strait Islander people and those population groups whose health outcomes are poorer. Achieving equity in cancer outcomes will be a fundamental measure of success for the Plan and is central to addressing the disparity of experience and outcomes for people with rare and less common cancers.

The Plan (release pending) has six Strategic Objectives, each with an associated ten-year ambition statement, which together cover the ecosystem of cancer control:

1. Maximising Cancer Prevention and Early Detection
2. Enhanced Consumer Experience
3. World-Class Health Systems for Optimal Care
4. Strong and Dynamic Foundations
5. Workforce to Transform the Delivery of Cancer Care
6. Achieving Equity in Cancer Outcomes for Aboriginal and Torres Strait Islander people.

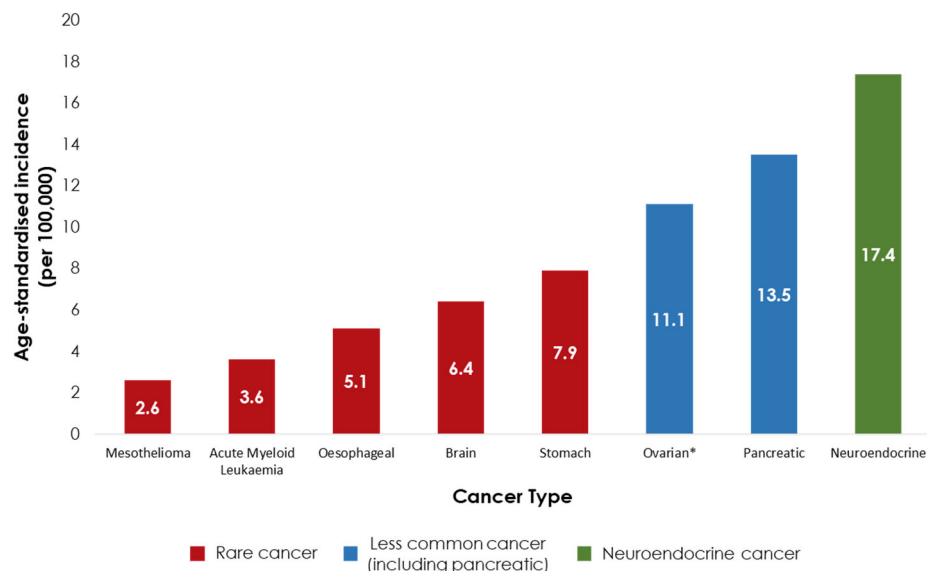
An embargoed summary of the Plan is attached.

Context

Incidence

Rare and less common cancers are a broad and diverse group of diseases, with each cancer type affecting only a small proportion of the population; however together they comprise approximately one third of all cancers diagnosed in Australia.² The Australian Institute of Health and Welfare (AIHW) and Rare Cancers Australia define 'rare cancers' as those with less than 6 age-standardised cases per 100,000 population and 'less common cancers' as between 6 to 12 age-standardised cases per 100,000 population.^{2, 3} Examples of rare and less common cancers (including neuroendocrine cancers) identified by AIHW in 2022 include, but are not limited to: mesothelioma, acute myeloid leukaemia, brain, stomach, ovarian and pancreatic cancers (**Graph 1**).

Graph 1: Age-standardised incidence rates for selected rare and less common cancers including neuroendocrine cancer estimated in Australia for 2022

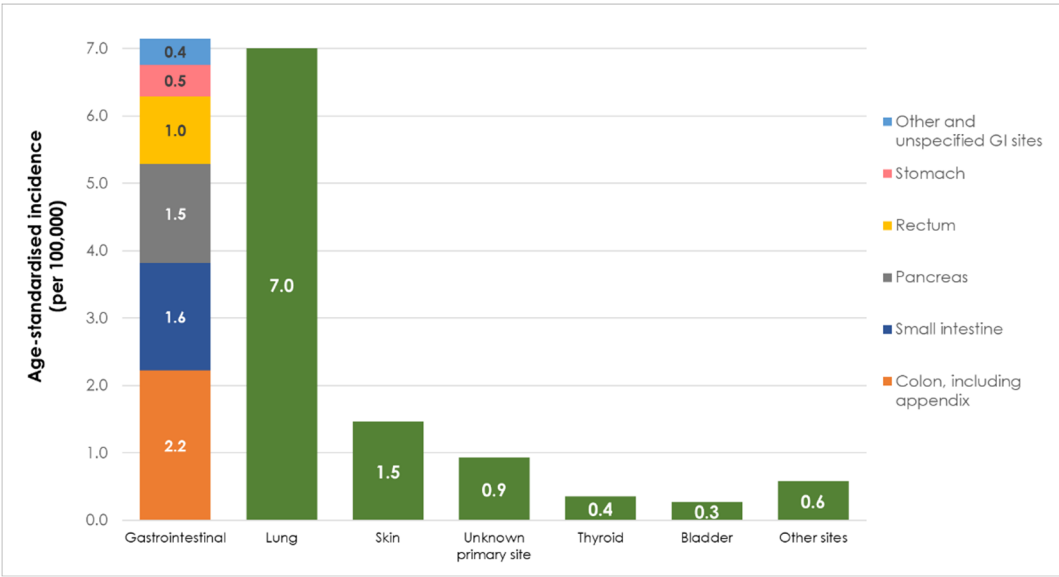


*Ovarian cancer includes serous carcinomas of the fallopian tube and rates standardised to female population

**Pancreatic cancer is included due to high mortality and low five-year survivorship, despite being on the cusp of less common cancers

Neuroendocrine cancer comprises a grouping of rare cancers (or 'sub-types') which can be found at sites throughout the body including the small and large bowel, pancreas, lung, skin, and adrenal gland.^{4, 5} Individually, the incidence rate for each neuroendocrine cancer sub-type meets the definition of rare or less common cancer (**Graph 2**), although collectively the incidence rate is above 12 age-standardised cases per 100,000 population (**Graph 1**). In 2022 it was estimated that 3.4% of all new cancer diagnoses were neuroendocrine cancers.^{6, 7}

Graph 2: Age-standardised incidence rates for neuroendocrine cancer sub-types in Australia for 2018



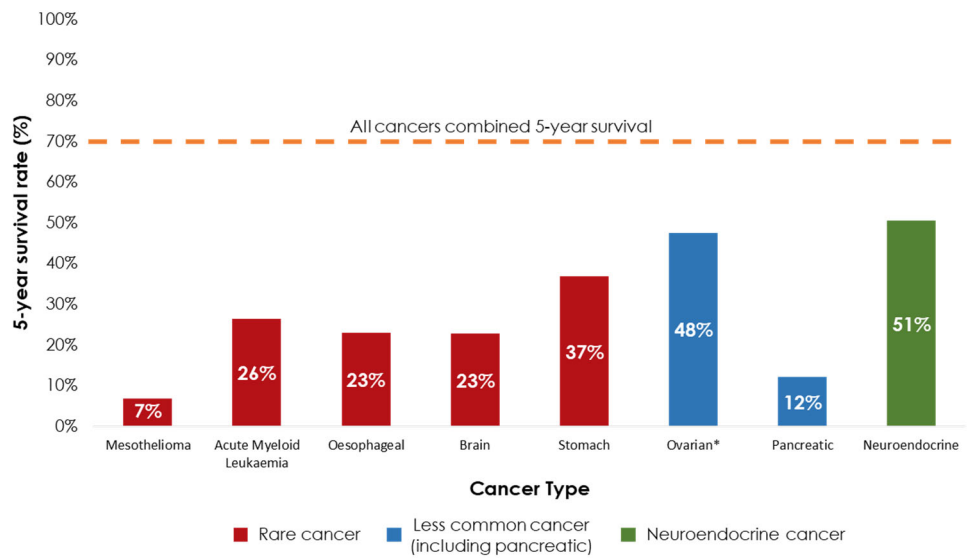
Survival

Five-year relative survival* for all cancers combined has improved over the past 30 years increasing from 52.2% in 1989-1993 to 70.1% in 2014-2018.⁸ However, improvements have not been consistent across all cancers (**Graph 3**). For some rare and less common cancers, such as mesothelioma and cancers of the lip, blood, and brain there has been little improvement in survival. For rare cancers such as eye, urethral, and bladder cancers survival may have actually decreased (**Graph 4**).⁸

Patients with rare cancers living in areas with higher socio-economic disadvantage, or rural and remote areas have been shown to have worse than average five-year survival rates (53.2% in 2007 to 2016)⁹. Additionally, patients with rare cancers living in areas of highest disadvantage had a 35% higher risk of death within five years of diagnosis compared to areas of advantage within Australia.⁹

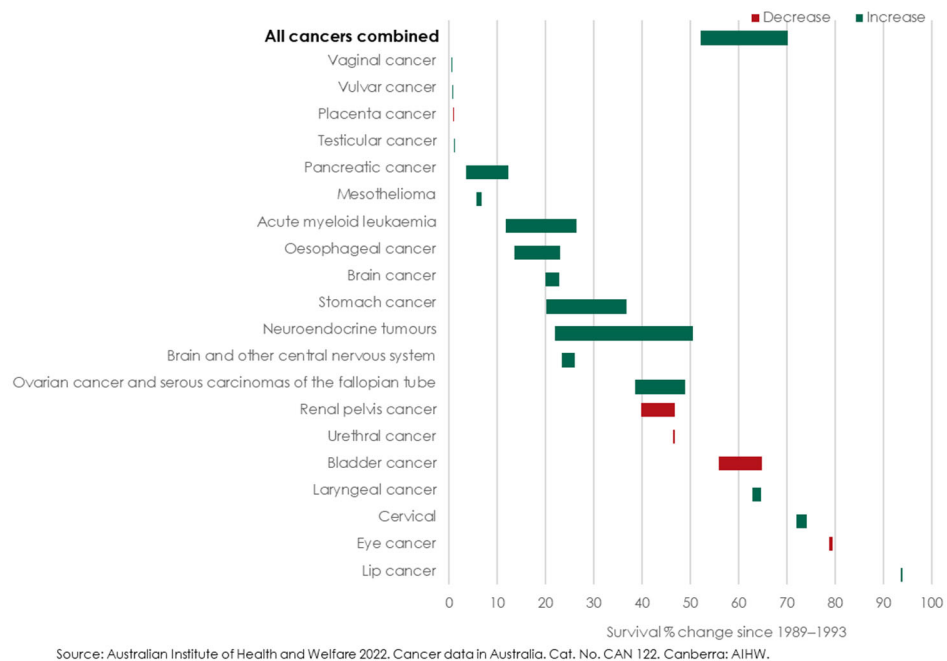
* Relative survival compares the survival of a group of people diagnosed with cancer to the expected survival of similarly aged people in the general population.

Graph 3: 5-year survival rates for selected rare and less common cancers including neuroendocrine cancer in Australia for 2014-2018



*Ovarian cancer includes serous carcinomas of the fallopian tube and rates standardised to female population

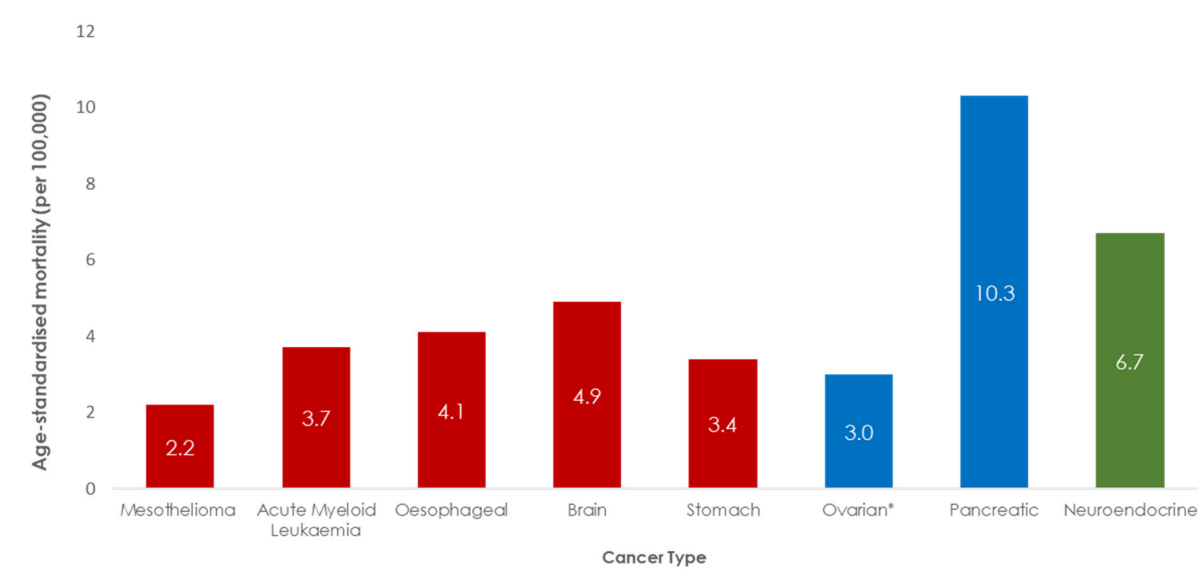
Graph 4: Percentage change in 5-year survival rates for selected rare and less common cancers including neuroendocrine cancer in Australia between 1989-1993 and 2014-2018



Mortality

Rare and less common cancers generally have higher mortality, due in part, to a lack of screening tests, delayed or incorrect diagnosis, limited options for effective treatment stemming from challenges in recruiting patients to clinical trials and geographical variations in clinical expertise¹⁰. Cancer deaths for rare and less common cancers (including neuroendocrine cancer) were responsible for 2 in 5 cancer deaths in 2022 compared to 3 in 10 deaths for all cancers combined¹¹ (Graph 5).

Graph 5: Age-standardised mortality rates for selected rare and less common cancers estimated in Australia for 2022



*Ovarian cancer includes serous carcinomas of the fallopian tube and rates standardised to female population

Priority population groups

Significant disparities in cancer outcomes exist between population groups within Australia. Disparities are strongly associated with the determinants of health, including ethnicity, language, education, age, gender, mental health, disability, health literacy, sexual orientation, location, socioeconomic group, as well as commercial influences, climate, and characteristics linked to discrimination or exposure to cancer risk factors.¹²⁻¹⁴ For patients with rare and less common cancers, who may identify across multiple population groups, there can be a compounding effect which increases the barriers to best-practice cancer care.

Further, cancer is the leading cause of death for Aboriginal and Torres Strait Islander people, and the gap between Aboriginal and Torres Strait Islander and non-Indigenous Australians is widening.^{15, 16} Aboriginal and Torres Strait Islander people have a lower relative survival rate compared to non-Indigenous Australians both overall and for specific rare and less common cancers including stomach and oesophageal cancer.^{2, 15}

People living in remote areas of Australia also have poorer cancer outcomes, are 1.3 times more likely to die from cancer and have a lower 5-year relative survival rate compared to those living in major cities.² Poorer cancer outcomes may be related to health workforce shortages in remote and very remote areas, despite having a greater need for medical services and practitioners with a broader scope of practice.^{17, 18}

Response to Terms of Reference

a) Barriers to screening and diagnosis

Australian Cancer Plan 10-year ambition

A cancer control system that seeks to eliminate racism, proactively reduces cancer risk and supports all Australians to access personalised, evidence-based cancer prevention and early detection strategies.

Screening

Cancer screening aims to detect cancers early, at an asymptomatic stage, thereby improving outcomes and reducing the burden of the disease in the community. However, for a screening program to be implemented, certain criteria need to be met to ensure that the program provides more benefit than harm to the target population.¹⁹

In Australia there are three population-based screening programs, for breast, bowel and cervical cancer, and planning is in progress for a lung cancer screening program for people at high risk. However, there are currently no screening programs available for most rare and less common cancers. This is because many rare or less common cancers either do not have an identifiable early stage at which a screening intervention is possible, or do not have an available, accurate and acceptable screening test, or do not have evidence-based, cost-effective assessment and management pathways for patients with a positive screening test.

There is an increasing interest, and growing evidence for, more risk-based, personalised approaches to population screening. Risk-stratified approaches may use a range of risk factors including lifestyle, environment and personal genomic risk information to create tailored screening advice.²⁰ In the future, this may provide an opportunity to address delays in diagnosis for people with rare and less common cancers. For example, a patient with known risk factors, such as a family history or a hereditary condition which predisposes a person to developing cancer (such as neuroendocrine cancer) could be identified by genetic screening, allowing for regular surveillance to enable early detection.

In the case of cervical cancer, Australia's success in delivering a national screening program and human papillomavirus (HPV) vaccination program has rendered it a rare cancer, on track to ultimately be eliminated (defined as less than 4 cases per 100,000).¹¹ However, the incidence rate for cervical cancer is nearly double for Aboriginal and Torres Strait Islander people compared to the national population.²¹ This disparity of outcomes illustrates that without systematically addressing inequities of access to screening and vaccination uptake, we will not achieve elimination for all Australians.

In line with the Plan's 5-year goal to improve access and participation by population groups with poorer health and cancer outcomes, a focus on under screened groups particularly those from culturally and linguistically diverse communities, people with disabilities, LGBTQIA+ people and for people in rural and remote areas is essential.²²⁻²⁴ Analysis of cancer outcomes and screening behaviour within Australia's three national screening programs showed that: participation is highest in Inner regional and outer regional areas for both breast and bowel screening, whereas it is highest in major cities and inner regional areas for

cervical screening; participation is lowest in the most disadvantaged socioeconomic group for all three cancer screening programs and is also lower for those speaking a language other than English at home for breast and bowel cancer screening.²⁵

Screening

Where appropriate, screening programs can be a powerful tool in reducing the burden of disease, however it is critically important to ensure equitable access for all Australians, such that all groups benefit equally from these programs, and that any potential intervention does not exacerbate inequity.

Diagnosis

Early detection of cancers without screening programs relies on presentation of symptoms or signs of disease. Clinicians may see very few patients with rare and less common cancers and thus be less familiar with the symptoms and signs, which can be vague and non-specific. This may potentially lead to misdiagnosis or delays in diagnosis and referral, and consequently a delay and treatment.

Neuroendocrine tumours (NETs) can be difficult to identify and diagnose as their features are non-specific⁶ and numerous other conditions may cause similar symptoms.²⁶ NETs may be misdiagnosed as: anxiety, menopause, Irritable Bowel Syndrome (IBS) or diabetes²⁷ leading to a prolonged delay in diagnosis resulting in poorer cancer outcomes.⁶ Increased awareness among health professionals is paramount to enable early diagnosis.

The Optimal Care Pathways (OCPs)²⁸ and the accompanying consumer versions, Guides to Best Cancer Care²⁹ recommend optimal timeframes within which diagnostic tests or procedures should be completed; prompt lists to support patients to understand what might happen at each step of their cancer experience and to consider what questions to ask; and provide information to help patients and carers communicate with health professionals.

Referral to an appropriate specialist within the recommended timeframes and linked to a multidisciplinary team for coordinated planning and subsequent treatment, has been demonstrated to improve outcomes and experiences for people affected by cancer.³⁰

Diagnosis

GPs have a vital role in recognising symptoms and signs in patients with possible rare or less common cancer and initiating referral to specialists for early diagnosis and care, according to timeframes in the Optimal Care Pathways.

b) Barriers to accessing appropriate treatment

Australian Cancer Plan 10-year ambition

Integrated, coordinated, data-driven, high-quality health service systems that consistently deliver optimal cancer care and excellence in outcomes.

Treatment

Best practice care for rare and less common cancers may require highly specialised expertise which is likely to be provided in limited centralised centres. It is essential that clear referral pathways exist to enable access to integrated, multidisciplinary services and evidence-based patient-centred care, in line with the OCPs.

The OCPs recommend multidisciplinary care as an integrated team approach involving health professionals discussing relevant treatment options and making joint recommendations about treatment and supportive care. This includes telehealth for shared care through a network of comprehensive cancer care to integrate primary, regional and tertiary care. These models of comprehensive cancer care integrate cancer research, clinical trials, education, and treatment, to deliver equitable care and support for consumers in all locations and across the cancer care continuum.

Cancer Australia is developing a national framework for networked, distributed comprehensive cancer care – the Australian Comprehensive Cancer Network (ACCN). The ACCN will provide strategic leadership to drive the promotion of excellence across the sector. The network will foster organisational, geographic, and service level partnerships and connectivity, and define pathways of care across the cancer care system, including Comprehensive Cancer Centres, regional hospitals, community organisations, and the primary care sector, including the Aboriginal Community Controlled Health sector. The ACCN will also drive national uptake of the OCPs as the standard of care, and enable the monitoring and reporting of system-based performance to identify and support improvements in cancer control.

Populations that may have higher health care needs, or are socio-economically disadvantaged, are spending a higher proportion of their incomes on out-of-pocket fees for healthcare.³¹ The high out-of-pocket costs associated with healthcare mean some patients may be priced out of accessing services due to high wait times for non-urgent public services.

For Aboriginal and Torres Strait Islander people, culturally safe care as close to home as possible is critical. Travel away from home, including access to appropriate accommodation for patients and carers, can be an insurmountable barrier to accessing cancer care. Alongside strengthening the Aboriginal and Torres Strait Islander health workforce, delivery of culturally safe care by the broader cancer workforce is also key to improving equity for Aboriginal and Torres Strait Islander people.

There are a limited number of health professionals with specialist expertise in rare and less common cancers, and there is an increasing pressure on the cancer workforce due to the rising number of cancer cases, our ageing population, increasing complexity of cancer care and availability of treatments, and improved survival.³²

Investment in training, recruitment, and retention of the rural and remote workforce would increase the number of accessible cancer care services delivered in these areas, and increasing telehealth services is an opportunity to increase accessible cancer care to this priority population group. Additionally, partnerships with community-based organisations should be undertaken to train the workforce in cross-cultural communication and cultural safety to ensure that the cancer care workforce delivers culturally appropriate cancer care to patients with diverse backgrounds.

Treatment

Timely referral to best practice cancer treatment and care at the right time in the right place supported by a multidisciplinary team of health professionals. Referral pathways across the ACCN are critical for a seamless transition from where people live to specialist treatment centres and referral as close to home as possible for follow up treatment and supportive care that is delivered in culturally safe services with minimum out-of-pocket costs.

c) Support services after diagnosis

Australian Cancer Plan 10-year ambition

People affected by cancer are partners in culturally safe, equitable and responsive cancer care, and health services and systems are trusted and supported for optimal experience, quality of life and cancer outcomes.

To deliver nationally equitable outcomes and experiences in cancer control, Australia's health systems must provide tailored, appropriate, and adequately resourced services to all Australians in need—when, where, and how they need them.

Patient navigation

The OCPs recommend seamless coordination as essential for patients to successfully navigate a complex health system. Patient navigation refers to the role and activities that enable people affected by cancer to overcome health care barriers and facilitate access to quality health and psychosocial care across the cancer care continuum.³³

Cancer Australia has undertaken a review of patient navigation across the cancer care continuum³³ identifying evidence to inform policy and planning. A key finding is that patient navigation is effective in improving participation in screening, reducing time from screening to diagnosis, and from diagnosis to treatment.

A priority action in the Plan is the implementation of integrated multi-channel, multidisciplined navigation models that ensure the right support at the right time for every consumer across the cancer continuum. Integrated navigation models will support patient access to the services they need including diagnosis, treatment, survivorship care, palliative care, and end-of-life care. Such models will benefit people with rare, less common, and neuroendocrine cancers to access the services they need irrespective of where they live in Australia.

Supportive care

Patient-centred, supportive care is a vital part of cancer treatment and care, covering the whole cancer care continuum to meet patient needs, including cultural, physical, psychological, social, information, and spiritual from time of diagnosis.

Cancer Australia's *Supporting People with Cancer* (SPWC) Grant initiative is an annual grants program that aims to support people affected by cancer through the provision of grants to community organisations and Aboriginal and Torres Strait Islander organisations. SPWC funds evidence-based projects to reduce the impact of cancer and better support people affected by cancer. Since its inception in 2005, 137 grants totalling \$11.55 million have been funded through this initiative, with funded projects attracting over \$9 million in co-contributions from grant recipients and served communities. These grants include 17 projects focussed on supporting people affected by rare and less common cancers to a total value of \$1.5m. One of these projects funded Cancer Council Australia to develop targeted psychosocial information for patients with less common cancers, including neuroendocrine tumours. The resources included the development of a fact sheet titled [Understanding Neuroendocrine Tumours](#).

d) Commonwealth funding for research into rare, less common and neuroendocrine cancer

Australian Cancer Plan 10-year ambition

A modern, fit for purpose cancer control infrastructure, advanced by the innovative application of technology, research and data to improve Australia's cancer outcomes

Funding

The complexity of cancer control and segmented nature of cancer care delivery creates disparities in cancer funding to different cancer types. There are specific actions in the Plan to ensure targeted and innovative research investment into areas of unmet and emerging need. Implementation considerations for these actions could include incorporating targeted funding and grants for issues that are specifically related to priority population groups to promote equity, regardless of cancer type, for example, rare and neuroendocrine cancers.

Cancer Australia Funding

Cancer Australia invests in research through the Priority-driven Collaborative Cancer Research Scheme (PdCCRS). This scheme encourages applications for research in identified priority areas which include equitable access to care, particular tumour types, including rare cancers, and populations with poor and unwarranted variations in cancer outcomes, including geographic location. Since 2007-08, Cancer Australia and its partners have provided over \$53 million to support 147 grants focussed on rare or less common cancers and neuroendocrine cancers. See Table 1 for a breakdown.

Table 1. Research funding for rare and less common cancers and neuroendocrine cancers (to 30 June 2023).

	Rare cancers and less common cancers	Neuroendocrine cancers	Total
Cancer Australia and its Funding Partners* (since 2007/08)	\$ 51.82m / 140 grants	\$1.96 million / 7 grants	\$53.79m / 147 grants

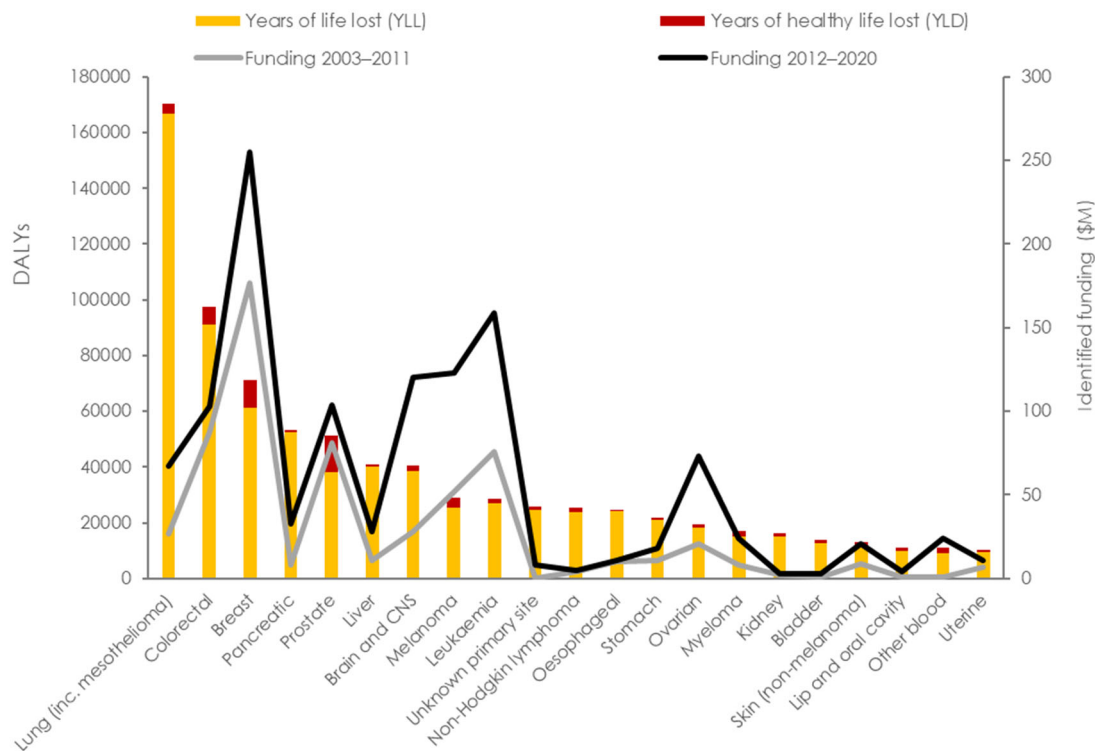
**Australia and New Zealand Sarcoma Association (formerly Australasian Sarcoma Study Group); Australian Lions Childhood Cancer Research Foundation; beyondblue; Cancer Council Australia; Cure Cancer; Leukaemia Foundation; My Room Children's Cancer Charity Ltd; National Breast Cancer Foundation; Radiation Oncology section of the Department of Health and Aged Care; The Kids' Cancer Project; World Cancer Research Fund International; Worldwide Cancer Research.*

Clinical trials are fundamental to establishing whether new cancer treatments or new ways of using existing therapies, diagnostic tests, preventative or supportive interventions are effective. Cancer Australia provides support for cancer clinical trials through the Support for Cancer Clinical Trials Program (SCCT). The SCCT Program provides funding to Australia's Multi-site Collaborative Cancer Clinical Trials Groups (CTGs) to build their capacity to undertake cancer clinical trials. Between July 2012 and Jun 2024, Cancer Australia has committed \$32.8m towards CTGs that support the development of cancer clinical trials for rare and less common cancers, as well as other related cancer types. National Technical Services to the value of \$12.6 million were procured to assist CTGs in achieving the goals of the program.

Cancer Australia also works in partnership with the Department of Health and Aged Care to deliver the Australian Brain Cancer Mission (the Mission). The aim of the Mission is to double the survival rates and improve the quality of life of patients with brain cancer over 10 years to 2027, with the longer-term aim of defeating brain cancer. The Mission brings together Government and philanthropic funding partners to coordinate investments into brain cancer research. Since its inception in 2017, \$136.66 million had been allocated to the Mission, including \$60.26 million from the Australian Government through the Medical Research Future Fund (MRFF), and \$76.4 million from philanthropy, non-government organisations and governments. To date a combined total of approximately \$124 million has been invested in initiatives under the Mission.

Funding trends for rare and less common cancers

Graph 6: Direct funding to single tumour type research projects and programs, 2003–2011 to 2012–2020, compared to cancers by DALYs in Australia, 2018



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

In the period 2003–2011 and 2012–2020, direct research funding was proportionally lower for liver, oesophageal, stomach, kidney, bladder, lip and uterine cancers, and cancers of an unknown primary site when compared to their total burden of disease, but notably proportionally higher for brain and central nervous system cancers.

Proportional funding for single tumour stream cancer research projects and programs increased between 2003–2005 and 2018–2020 for gynaecological cancers (from 5% to 8%), brain and central nervous system cancers (from 3% to 11%) and cancer of unknown primary site (from 0.1% to 1%).⁸ From 2012 to 2020, brain cancer was also in the top ten most common tumour types investigated in clinical trials, along with myeloma and endometrial (uterine) cancer.⁸

Direct funding for 2003–2011 and 2012–2020 for single tumour type research relative to burden of disease by Disability Adjusted Life Years (DALYs) in 2018 was proportionally lower for a number of cancers including cancers of the pancreas, oesophagus and stomach (**Graph 6**).

Data

There is a need for better and more comprehensive cancer data in Australia to improve patient outcomes and health system performance. The Plan provides a unique opportunity to achieve this, with the 2-year goal of the development of a National Cancer Data Framework.

Cancer Australia is leading the development of a National Cancer Data Framework (the Framework) and a minimum dataset (MDS) for the collection and reporting of comprehensive cancer data across the cancer control continuum. This work will include refreshing the National Cancer Data Strategy (2008) and seeking national agreement to a strategic vision for improving the collection and linkage of national cancer data across the continuum.

Research

Conventional, randomised clinical trials require large numbers of patients to detect statistically significant effects on health outcomes. For trials in low incidence cancers there are fewer patients available to participate, increasing unit costs per patient due to longer recruitment times, and increasing difficulty in achieving statistically significant outcomes. Furthermore, industry-led clinical trials prioritise cancers with larger populations as they produce a higher cost-benefit ratio. These factors combined lead to reduced volumes of cancer-specific research available in rare and less common cancers.

Improving patient numbers in clinical trials for rare and less common cancers requires national and international collaboration to improve the cost-benefit ratio for trials, as well statistical power. Collaborative research approaches also reduce the risk that a single patient is targeted by multiple trial groups simultaneously³⁴, further reducing patient burden. The International Rare Cancers Initiative (IRCI) was established with the aim of addressing these issues, of which the Clinical Oncology Society of Australia is a founding member.³⁵ Since 2011, the IRCI has initiated at least eight trials in very rare cancers across the nine rare cancer types which form part of their core activities to date.³⁶

Newer trial strategies that identify specific tumour molecular targets that exist across multiple cancer types, can also facilitate larger-scale clinical trials to the benefit of more patients with a broader range of cancers, including rare and less common cancers.³⁷

Key examples include:

- Precision Oncology Screening Platform Enabling Clinical Trials (PrOSPeCT) which aims to sequence the genomes of over 20,000 cancer patients including rare and less common cancers to aid in linking patients with relevant clinical trials.³⁸
- Combination Immunotherapy in Rare Cancers Under Investigation (MOST-CIRCUIT) which combines four streams of rare cancers, including neuroendocrine, together for treatment with immunotherapy³⁹ including genomic testing to guide targeted strategies.⁴⁰
- AUTO-CHECK which identifies common and rare genetic variants linked to immune-related adverse events associated for 5 cancer types, mesothelioma (rare), non-small cell lung (common), endometrial (less common), renal cell (common), and glioblastoma (less common).⁴¹
- Rare Cancers Genomics (RCG) which is performing integrative multi-omics molecular analyses to understand the molecular characteristics of rare cancers and their carcinogenesis progress, with four projects underway.^{42, 43}

Research funding and data

Targeted and innovative research investment is a key strategy to address areas of unmet and emerging need. The complexity of cancer care delivery and the low cost-benefit ratio for clinical trials in low incidence cancers creates disparities in cancer research funding. This drives inequity in treatment outcomes as clinical trials are designed to generate evidence for best-practice cancer care. Newer trial strategies that focus on common molecular targets rather than cancer type, and innovative funding models such as Cancer Australia's PdCCRS and SCCT support the development and conduct of cancer clinical trials for rare and less common cancers. A National Cancer Data Framework and minimum dataset for collection and reporting for comprehensive cancer data in Australia is needed to improve patient outcomes and health system performance.

e) Any other related matters

The use of genomics in cancer control

The rapidly expanding use of genomics in cancer control may particularly benefit patients with rare and less common cancers. There is an increasing knowledge base for genetic conditions potentially linked to rare and less common cancers including neuroendocrine cancer, and improvements in technology to allow for risk-stratified screening programs. Additionally, the use of genomic testing of tumours can inform clinical trials and treatment options for people with rare and less common cancers.

Cancer Australia is developing a National Framework for Genomics in Cancer Control across the cancer care continuum. The Framework aims to promote a common understanding of this technology, drive its safe and effective application in practice, foster collaboration and provide future direction for its integration and use within the cancer care system, for personalised, equitable cancer care, experiences and outcomes for all Australians.

Optimal Care Pathways

The OCPs aim to improve patient outcomes by setting the benchmark for quality cancer care and ensuring that all people affected by cancer receive the best care, irrespective of who they are or where they live. The OCPs²⁸ and their complementary consumer-focused Guides to Best Cancer Care²⁹ outline consistent, safe, high-quality and evidence-based care for people with cancer. The OCPs suggest that some cancers are simpler to treat, but many are more complex, however the principles for high-quality cancer care is similar for all cancers and if followed are likely to achieve the best outcomes for patients and families.

In 2021 Cancer Australia commissioned the OCP for neuroendocrine cancers, to drive best practice care for people with neuroendocrine cancers.⁶ OCPs have also been developed for rare and less common cancers including acute myeloid leukaemia⁴⁴, high grade glioma (brain cancer)⁴⁵, oesophagogastric cancer (oesophageal and stomach)⁴⁶, ovarian cancer⁴⁷, and pancreatic cancer.⁴⁸

Embedding OCPs as routine cancer care across all jurisdictions and health networks increases the likelihood of better outcomes for people with cancer. Partnering with jurisdictions to improve recognition of OCPs as the benchmark for quality cancer care ensuring their accessibility for patients and clinicians and evaluating their uptake and alignment with the care experience is key to driving integration and implementation of OCPs.

Summary

Despite Australia having significant improvements in diagnosis, treatment and survival for a number of cancer types, disparity in experience and outcomes remains for people affected by rare and less common cancer types, including neuroendocrine cancers. Similarly, some populations groups are not benefiting to the same degree, with a higher impact of cancer burden on Aboriginal and Torres Strait Islander people, people living in rural and regional Australia, people from culturally and linguistically diverse populations and people who are socioeconomically disadvantaged. A greater, practical, and more tangible focus on equity of cancer outcomes and experiences, on priority population groups and rare and less common cancers is compelling if Australia is to lift outcomes and survival, reduce disparity and improve equitable outcomes in a meaningful way for all Australians. The Australian Cancer Plan is designed to improve cancer outcomes for all Australians, and particularly for those groups whose health outcomes are poorer. The Plan sets out a national reform agenda of priorities for the next 10 years and beyond through driving improvements in outcomes, experiences, and equity across the continuum of cancer care. Implementation of the Plan is a shared responsibility requiring coordinated action across the cancer control system, including governments, non-government organisations, and the health and research sectors.

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