

***Equitable access to diagnosis and  
treatment for individuals with rare and less  
common cancers, including neuroendocrine  
cancer***

Submission from the Department of Health and Aged Care  
to the Senate Standing Committees on Community Affairs

August 2023

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### List of acronyms

ACP	Australian Cancer Plan
AIHW	Australian Institute of Health and Welfare
BSA	BreastScreen Australia Program
CCC	Comprehensive Cancer Centre
GI	Gastrointestinal
MBS	Medicare Benefits Schedule
MRFF	Medical Research Future Fund
MSAC	Medical Services Advisory Committee
NBCSP	National Bowel Cancer Screening Program
NCSP	National Cervical Screening Program
NDF	National Data Framework
NECA	Neuroendocrine Cancer Australia
NHRA	National Health Reform Agreement
NLCSP	National Lung Cancer Screening Program
PBS	Pharmaceutical Benefits Scheme
RVA	Rare Voices Australia

## Introduction

The Department of Health and Aged Care (department) welcomes the opportunity to make a submission to the Senate Standing Committees on Community Affairs inquiry into Equitable access to diagnosis and treatment for individuals with rare and less common cancers, including neuroendocrine cancer.

In making this submission, the department recognises that cancer is responsible for Australia's largest disease burden and is a leading cause of death. There are over one million people alive in Australia who are currently living with or have lived with cancer. In 2022, it is estimated around 160,000 people will be diagnosed with cancer, and over 50,000 people will die from cancer.<sup>1</sup> While cancer mortality rates in Australia have been steadily decreasing, incidence rates for all cancers, including rare and less common cancers, has been increasing. The reduction in mortality rates is partly due to increasing investment and participation in screening programs and changes to personal and behavioural risk factors.<sup>2</sup>

The Australian Institute of Health and Welfare (AIHW) defines rare cancers as those with less than six incidents per 100,000 people per year, and less common cancers as between six and 12 incidents per 100,000 people per year. Examples include gallbladder cancer (3 cases per 100,000 people per year), soft tissue sarcoma (6 incidents per 100,000 people per year) and penile cancer (0.38 incidents per 100,000 people per year). This is compared with common cancers, like lung (44 incidents per 100,000 people per year) or breast (67 incidents per 100,000 people per year).

The department acknowledges that rare and less common cancers are a broad group of diseases, with only a small number of people diagnosed with each type every year. While one in three people diagnosed with cancer in Australia will have a rare or less common cancer, rare and less common cancers account for approximately 42 per cent of all cancer deaths.<sup>3</sup>

The Government is determined to improve outcomes for people with the poorest cancer experiences and is exploring initiatives that will achieve equity in access for all Australians with cancer, regardless of cancer type. It is with this ambition that the Australian Government commissioned Cancer Australia in 2021 to develop the first national Australian Cancer Plan (ACP), which will soon be released by Government. The ACP has been shaped by significant consultation with the cancer control sector and will represent a once in a generation reform opportunity that aims to deliver world class cancer outcomes and experience for all Australians affected by cancer irrespective of their background or location. It is anticipated the ACP will be launched before the Committee provides its final report in February 2024.

The department notes that the barriers for screening for rare and less common cancers differ to the barriers for diagnosis and treatment. As such, this submission will address the inquiry's Terms of Reference as follows:

- The Australian Government's role in cancer control.
- Screening for rare and less common cancers.
- Diagnosing and treating rare and less common cancers.
- Support services after diagnosis.

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<sup>1</sup> Australian Institute of Health and Welfare 2022. Cancer. Canberra: AIHW  
<https://www.aihw.gov.au/reports/australias-health/cancer>

<sup>2</sup> Australian Institute of Health and Welfare 2021. Cancer in Australia 2021. Cancer series no. 133. Cat. no. CAN 144. Canberra: AIHW  
<https://www.aihw.gov.au/getmedia/0ea708eb-dd6e-4499-9080-1cc7b5990e64/aihw-can-144.pdf.aspx?inline=true>

<sup>3</sup> Ibid.

- Health and medical research.

The department also notes separate submissions have, or will be made, to the Committee from Cancer Australia and the National Health and Medical Research Council. These submissions should be read in conjunction with this submission to ensure a complete picture of the Government's approach to supporting Australians living with cancer.

### [The Australian Government's role in cancer control](#)

The Government provides national leadership on cancer policy and research and recognises that improving outcomes for Australians living with cancer is a shared responsibility requiring coordinated action across the cancer control system, including all levels of governments, non-government organisations, and the health and research sectors.

Between 2013-14 and 2022-23, total Commonwealth expenditure for cancer control activities is estimated to be more than \$32.0 billion. This includes funding for cancer related item numbers under Medicare and the Pharmaceutical Benefits Scheme, cancer prevention, detection and support programs, health infrastructure, health and medical research, the provision of some cancer treatment.

The Government also provides funding to states and territories through the National Health Reform Agreement (NHRA) to assist with the cost of delivering public health and hospital services. States and territories are responsible for making decisions about the provision and delivery of these services within their health systems, to meet community needs. The Government's expenditure under the NHRA has grown substantially – from \$13.3 billion in 2012-13 to \$24.1 billion in 2021-22, an increase of 81 percent. Between 2022-23 and 2026-27, the Government's contribution to states and territories is estimated to grow from \$25.6 billion in 2022-23 to \$34.3 billion in 2026-27. This will ensure patients will continue to have access to the highest quality hospital services and care, in line with local need.

In 2020, all Australian governments signed the 2020-2025 Addendum to the NHRA. A key reform outlined in the Addendum is reducing the burden of long-term chronic conditions, including cancer, to improve people's quality of life. The Addendum also specifies that proactive planning is required to access innovative and emerging technologies, such as those that treat rare and less common cancers. The mid-term Review of the NHRA (Review) is currently underway, which is examining whether the objectives of the 2020-2025 Addendum to the NHRA are being met. In particular, the Review is considering whether the Addendum's health funding, planning and governance is fit-for-purpose. The Review's final report is due to Health Ministers in October 2023.

The Government's investment in cancer control aligns with its broader health reform priorities, including those set out in the National Preventive Health Strategy 2021-30, the National Medical Workforce Strategy and the National Agreement on Closing the Gap. The Government has also funded the development of the Aboriginal and Torres Strait Islander Cancer Plan, anticipated to be released later in 2023. In particular, the Government's investment for Australians living with rare and less common cancers is guided by the 2020 National Strategic Action Plan for Rare Diseases (Action Plan).

The Action Plan recognises that, while statistically rare, many Australians are impacted by rare diseases, and provides a blueprint for a nationally coordinated effort to address rare diseases.

The Action Plan was developed by an extensive multi-stakeholder consultation process led by Rare Voices Australia (RVA). The Government has funded \$4.0 million in grant projects to support implementation of the Action Plan, including:

- \$1.0 million over three years for RVA to deliver the Rare Awareness Rare Education Project. This project is developing and delivering rare disease awareness, information and education activities including a national rare disease digital platform.
- \$3.0 million for organisations to develop and deliver new education resources for health professionals, and to provide new support for people living with a rare disease. Part of this funding is supporting the University of New South Wales to deliver the Rare Disease Awareness, Education, Support and Training Project, which aims to increase awareness, education, support and training for rare diseases among health professionals and within the rare disease community.

In May 2023, RVA conducted a scan of activities aligning with the thematic goals in the Action Plan, which was developed, by the rare disease sector, for the rare disease sector, as descriptive indicators of progress. The activity scan highlights the importance of the Action Plan as a framework for mobilising nationally coordinated effort to address rare diseases in Australia. The department looks forward to working with RVA and the sector to realise its objectives in line with actions specified in the forthcoming ACP.

### Screening for rare and less common cancers

Screening is one of the most effective ways to detect the early signs of cancer and is actively working on innovative ways to increase participation rates in existing national cancer screening programs.

The Government's screening policy is informed by the Population Based Screening Framework (Framework). The Framework provides guidance for decision makers on issues to consider when introducing screening programs in Australia. It was developed by the Screening Subcommittee of the Australian Population Health Development Principal Committee and endorsed by the Australian Health Ministers' Advisory Council in 2008, and then updated in 2018.

Under the Framework, the department considers the following when deciding if a screening program should be introduced:

- the condition has a pre-symptomatic stage that can be found by screening,
- there is a suitable test to identify the condition,
- there is a suitable treatment for people who are diagnosed through screening,
- there are facilities available for testing and treatment.

The department is undertaking an environment scan to understand how emerging technologies can be considered in the context of population-based screening. This is being undertaken in consultation with the Cancer and Population Screening Committee, which is responsible for ensuring the Framework remains up to date and fit for purpose.

The department recognises that there are no national population-based screening programs for rare and less common cancers, but notes screening is a secondary prevention strategy. Screening aims to identify disease at an earlier stage or identify a disease risk marker, which will enable earlier management and treatment and result in better health outcomes. To identify a screening test, there

needs to be a very clear understanding of the natural history of the disease and identification of a recognisable latent stage. The screening test is designed to target this latent stage before symptoms of disease develop. Evidence on the natural history of most rare and less common cancers is limited as there are fewer cases to inform significant research outcomes – this includes identification of suitable screening tests.

The Framework specifies that a screening program must be cost-effective to justify the expenditure of Government funds. Given the small number of people diagnosed with rare and less common cancers in Australia each year, it is unlikely the introduction of national screening programs for each unique type of rare and less common cancer will demonstrate allocative efficiency.

While there have been no advancements in identifying suitable screening tests for rare and less common cancers, in the future, it is likely genomics offers the potential to better understand the risk of rare cancers without the need for understanding the natural history of the disease.

Genomics can be used to help doctors identify and diagnose genetic disorders and rare diseases, develop prevention strategies, and tailor a patient's treatment. Genomic medicine is already allowing clinicians to diagnose diseases more precisely, tailor treatments to an individual and better identify those at high genetic risk of inherited disease and a range of common chronic conditions. Patients affected by rare and less common cancers and other complex conditions are likely to be the major beneficiaries of future developments.

For example, \$61.3 million has been invested through the Medical Research Future Fund (MRFF) in the Childhood Cancer National Precision Medicine Program (ZERO), which offers genomic screening of cancers to help clinicians identify the most effective treatment for children with high-risk or rare cancer. This funding will:

- Expand the program to all Australian children, adolescents and young adults with medium to very-high risk cancers
- Evaluate ZERO's effectiveness in improving health outcomes through genomic biomarker-driven matching of patients to optimal treatments and novel therapeutic clinical trials.
- Develop a companion clinical trial to the Zero Childhood Cancer program, which will test new combinations of targeted drugs, to treat high risk childhood cancers based on each child's individual tumour profile.

More recently, \$61.2 million was provided to Omico for the Precision Oncology Screening Platform Enabling Clinical Trials program, which will support comprehensive genomic profiling of over 20,000 Australian patients with advanced and incurable cancers, many of which will be rare and less common. Patients will be recruited nationally, including rural, regional, and remote. Where possible, they will be matched to clinical trials for innovative biomarker-dependent cancer treatments and other therapy options. The program is expected to increase clinical trials activity in Australia by identifying cohorts of patients with advanced or incurable disease across a range of cancers who may otherwise not have the opportunity to enter a clinical trial.

Policy reform in genomics will be informed by the National Framework for Genomics in Cancer Control, currently under development by Cancer Australia which will guide best practice in genomics across the cancer care continuum. This Framework will recognise that the use of genomics in cancer

screening, diagnosis and treatment is expanding rapidly, with significant implications for cancer care, service delivery, workforce, research and data, and policy across the cancer care continuum. It is anticipated a draft Framework will be released for consultation in 2024 and the final Framework delivered to Government in late 2024.

The department is also working to establish Genomics Australia which will guide the future of genomic health and medicine and support integration of genomic medicine as a standard of healthcare in Australia. The Government will also continue to invest in research, including clinical trials, to build the evidence base for the most effective diagnosis and treatment mechanisms.

### **National Lung Cancer Screening Program**

The National Lung Cancer Screening Program (NLCSP), funded under the 2023-23 Budget, will maximise prevention and early detection of lung cancer and achieve equity in cancer outcomes for vulnerable groups. The program is expected to prevent over 500 lung cancer deaths each year and is expected to be operational by July 2025. The NLCSP will be co-designed from the outset with First Nations Australians to ensure it is culturally safe and effective.

### **National Bowel Cancer Screening Program**

The National Bowel Cancer Screening Program (NBCSP) aims to reduce deaths from bowel cancer by detecting early signs of the disease. The NBCSP has been rolled out across two innovative models to maximise participation – kits are mailed-out directly to eligible Australians over 50 years, or can be issued by participating healthcare providers.

In 2019, the Government, through Cancer Council Australia, delivered a national campaign to increase participation in the NBCSP. The campaign ran again in 2022 and 2023, targeting under screened groups including 50 to 59-year-old men, culturally and linguistically diverse communities and First Nations Australians.

The 2019 campaign is estimated to have resulted in the return of more than 93,000 additional NBCSP test kits. The 2022 campaign is estimated to have generated the return of an additional 100,000 NBCSP test kits. The 2023 campaign is live and has already exceeded key campaign performance indicators.

### **National Cervical Screening Program**

The National Cervical Screening Program (NCSP) aims to prevent cervical cancer through an organised population-based screening pathway to detect cervical abnormalities in asymptomatic women and people with a cervix, through a Cervical Screening Test.

In 2022, the Government made changes to the NCSP, so all women and people with a cervix aged 25 to 74 can choose to participate via self-collection, or collection by a healthcare provider. Self-collection is expected to improve participation, particularly for under-screened groups.

### **BreastScreen Australia Program**

The BreastScreen Australia program (BSA) is jointly funded by Australian and state and territory governments. It aims to reduce morbidity and mortality from breast cancer by providing free screening mammograms every two years for women aged 40 to 74 years.



The BSA program operates screening units at more than 750 locations nationally – this includes clinics, specialist busses, and four-wheel drives to increase accessibility and promote uptake. It also publishes information resources in several languages to increase accessibility for culturally and linguistically diverse communities.

### Diagnosing and treating rare and less common cancers

Rare and less common cancers are often difficult to diagnose and are typically diagnosed at a later stage than more common cancer types. This often makes them more difficult to treat.<sup>4</sup> However, the department recognises that there are also societal and structural barriers to accessing diagnostic services and treatment for people with rare and less common cancers.

### Cost as a barrier to diagnosis and treatment

Cost to diagnose and treat rare and less common cancers can be significant, and for many, a barrier to seeking care.

### *Medicare Benefits Schedule and Pharmaceutical Benefits Schedule reform*

The Government supports access to cancer testing, diagnosis and treatment through Medicare and the Medicare Benefits Schedule (MBS), which provides patients with financial assistance towards the costs of medical services. New and amended listings on the MBS, in line with recommendations from the Medical Services Advisory Committee (MSAC), are improving access to health care for Australians living with rare and less common cancers. MSAC is an independent scientific committee with expertise in clinical medicine, health administration, health economics and consumer matters. MSAC advises the Minister for Health and Aged Care as to whether a medical service should be publicly funded based on an assessment of its safety, effectiveness and cost effectiveness, using the best available evidence.

The Government continues to support recommendations from MSAC for the inclusion of new MBS items to assist in the diagnosis and management of patients with rare and less common cancers. Over the last decade, the number of genetic and genomic tests for cancer and inherited diseases covered by MBS has more than doubled in response to recommendations from the MSAC. For example:

- Since 1 July 2023, funding has been made available through the MBS for somatic gene panel testing for the initial diagnosis of patients with morphological features of glioma, glioneuronal tumours or glioblastoma.
- As part of the May Budget 2023-24, next generation sequencing panel testing for genetic variants in patients suspected of having either a myeloid or lymphoid haematological malignancy. These items will assist patients with both common and rare haematological malignancies and will be available on the MBS from 1 November 2023.

The Government is also responsible for the Pharmaceutical Benefits Scheme (PBS), which covers all or part of the cost of many prescription medicines for people affected by cancer with a current Medicare card, including medicines which treat rare and less common cancers. For example, as part of the 2022-23 October Budget, the Government invested \$459.1 million to extend the listing of

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<sup>4</sup> Cancer Council Australia 2021. Understanding Rare and Less Common Cancers: A guide for people with cancer, their families and friends.

<https://www.cancer.org.au/assets/pdf/understanding-rare-and-less-common-cancers>

nivolumab (Opdivo®) on the PBS to support approximately 1,450 patients with advanced or metastatic gastro-oesophageal cancers – a less common cancer more commonly diagnosed in older men. Without this listing, these patients could pay over \$92,000 per course of treatment.

#### *Other treatment options*

The Government also funds the Medical Treatment Overseas Program to assist eligible Australians with a life-threatening medical condition to access life-saving medical treatment overseas where treatment is not available in Australia. This program covers the cost of hospital accommodation, services related to the approved medical treatment and travel and accommodation.

Through the Life Saving Drugs Program, the Government provides fully subsidised access to expensive essential medicines for eligible patients with ultra-rare life-threatening diseases, separate to the PBS. While there are currently no listings for rare and less common cancers under this program, pharmaceutical companies can apply to list relevant medicines if their PBS application has been rejected.

#### **Geographic location as a barrier to diagnosis and treatment**

People in rural and regional areas are more likely to be diagnosed with a rare and less common cancer and have lower chance of survival, than other Australians.<sup>5</sup> They also face additional barriers to accessing diagnostic services and treatment. This may be attributed to:

- reduced access to hospitals with the specialist equipment required to diagnose and treat rare cancers.
- limited availability of health and medical practitioners with the expertise required to diagnose and treat rare cancers.
- higher participation in or exposure to modifiable risk factors and occupational hazards which are linked with some rare and less common cancers.

A centrepiece of the Government's 2023-24 Budget is the strong commitment to preventing cancer, and detecting and treating it earlier, with a focus equitable access to support across all cancer types, regardless of location. This includes \$197.9 million for the Aboriginal Community-Controlled Health Organisation sector to enhance community led care, from prevention through to early diagnosis and treatment. Alongside a \$38.5 million investment to improve culturally safe mainstream care, this will support holistically focused services for First Nations cancer patients and their families, irrespective of their cancer type.

The 2023-24 Budget also included \$79.4 million to strengthen the role of Primary Health Networks in commissioning allied health and nursing services to improve access to affordable multidisciplinary teams. This measure will improve increase patient access to care in the community, improve the affordability of multidisciplinary health care teams and the management of chronic conditions and reduce avoidable hospitalisations in underserved communities. Multidisciplinary team-based care is considered best practice in the treatment planning and care for patients with all cancer types, including rare and less common cancers.

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<sup>5</sup> Dasgupta, P. Cameron, J. Cramb, S. Trevithick, R. Aitken, J. Mengersen, K. Baade, P 2022. Geographical and spatial disparities in the incidence and survival of rare cancers in Australia. *International Journal of Cancer*. Vol. 152, issue 8, pp. 1601-1612

The 2022-23 October Budget provided \$452.0 million for two new Comprehensive Cancer Centres (CCCs) in Queensland and South Australia. This builds on the \$375.6 million in the 2022-23 May Budget for a centre in Western Australia. The CCCs will play an important role in Australia's health system, combining research, innovative treatment options, clinical trials and other multidisciplinary resources for people affected by cancer and their families.

These CCCs, along with the Victorian CCC at the Peter MacCallum Cancer Centre in Melbourne, Chris O'Brien Lifehouse, and the Children's Comprehensive Cancer Centre under construction in Sydney, will soon form part of the Australian Comprehensive Cancer Centre Network (Network).

The Network will enable connectivity and sharing of expertise between CCCs, other cancer services, rural and regional hospitals, and community and primary care by:

- driving uptake of Optimal Care Pathways as the standard of care
- promoting collaboration and knowledge-sharing across the cancer control sector, and
- providing strategic leadership to the sector

The Network will support rural and remote health service staff to provide patient-centred care closer to home. Allowing patients to receive care in their community within social networks reduces the financial and social burdens often placed on people with cancer in rural and regional areas, and is likely to improve cancer outcomes.

#### **Availability of treating practitioners as a barrier to diagnosis and treatment**

The supply of the cancer workforce is facing several challenges, including ageing workers and uneven distribution across jurisdictions. This creates additional barriers to accessing cancer care, particularly for people with rare and less common cancers which require practitioners with specialist expertise.

The Government is investing in the education and training of Australia's future health medical workforce through a suite of programs for undergraduate medical students, junior doctors, general practitioners, and rural generalist registrars, and non-GP specialist trainees – including those who are qualified to diagnose and treat rare and less common cancers. Through funding totalling approximately \$810 million per year, the programs aim to alleviate current workforce shortages ensure the sustainability of the workforce to meet the long-term needs of the Australian community.

The 2023-24 Budget also provides funding to introduce MyMedicare, a new voluntary patient registration model that will strengthen the relationship between patients, their general practice and practitioner, and primary care teams, to provide greater continuity of care. Practices will receive incentive payments to deliver wraparound, tailored care to provide support to patients with complex, chronic disease. From 1 November 2023, patients registered with MyMedicare will be able to access long GP consultations by phone if clinically appropriate. This will provide more flexibility for patients, which will be particularly valuable for people with multiple and more complex health conditions, such as rare and less common cancers.

The 2023-24 Budget provided \$3.0 million over two years from 2023-24 to conduct review into the barriers and incentives for all health professionals to be able to work to their full scope of practice. That is, enabling health professionals to work to the extent of their profession's recognised skill base and/or regulatory guidelines. The review will be underpinned by extensive stakeholder engagement

and collaboration with states and territories, with findings expected to be provided to government in the second half of 2024.

### **Cultural and language barriers to diagnosis and treatment**

Patients from culturally and linguistically diverse backgrounds can face challenges such as discrimination, stigma and difficulties in communication, in accessing cancer diagnosis services and treatment. These barriers are likely exacerbated for people with rare and less common cancers given their complexity. Information is often not available in all languages, and cultural norms around health and support can vary significantly. Further, some rare and less common cancers, including liver and stomach cancer, are more prevalent in people from certain migrant backgrounds.<sup>6</sup>

The Government provides the Free Interpreting Services which aims to provide equitable access to primary services for people with limited or no English language proficiency. Registered eligible medical practitioners and some allied health professionals can engage a credentialed interpreter to communicate complex or technical information to patients, which can help ensure accuracy of communication and reduce confusion. This is particularly important for people who have been diagnosed with rare and less common cancers given their complexity and risk.

Cancer Australia and Cancer Council Australia have also published resources, including guidelines, reports and fact-sheets, in multiple languages to support people with limited or no English language proficiency.

### **Support for people diagnosed with rare and less common cancers**

#### **Survivorship**

Historically, follow-up care has focused on monitoring for cancer recurrence and second primary cancers.<sup>7</sup> However, as people live longer following their cancer diagnosis, care following active cancer treatment is becoming a fundamental part of the cancer control continuum.

In Australia, there are several organisations that provide survivorship services and programs, which are predominantly run by state and territory health departments via metropolitan public hospitals. These programs focus on:

- Education and online resources for survivors, their families, and carers
- Events, public forums, support sessions
- Development of a Survivorship Care Plan
- Nutritional and exercise programs and advice
- Directory of community organisations
- Education and training for healthcare professionals

The Government continues working with states and territories to ensure all people diagnosed with cancer, regardless of their cancer type, have access to survivorship care.

#### **Information and advocacy**

The Government has made targeted investments to provide patients with rare and less common cancers information and resources. This includes:

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<sup>6</sup> Yu, X. Feletto, E. Smith, M. Yuill, S. Baade, P (2022). Cancer incidence in migrants in Australia: Patterns of three infection-related cancers. *Cancer Epidemiology Biomarkers and Prevention*, vol. 31, no. 7, pp. 1394-1401.

<sup>7</sup> Economou, D., & Corcoran, S. (2016). Incorporating a Survivorship Clinic Into Practice. *Journal of the Advanced Practitioner in Oncology*, 7(3), 343–346.

- \$0.6 million to Neuroendocrine Cancer Australia (NECA) to deliver several cancer support and awareness activities. The activities aim to provide an immediate impact to neuroendocrine cancer patients through a national awareness campaign and an expansion of NECA's resources, including translation to other languages to ensure inclusivity. An awareness campaign targeting healthcare practitioners and promoting the recently endorsed neuroendocrine tumour Optimal Care Pathway will also be undertaken.
- \$0.87 million to Pancare Australia for activities that increase survivorship for Australians living with Upper Gastrointestinal (GI) cancers. This includes a media campaign to raise awareness of upper GI cancers and developing an education program to promote the signs and symptoms of upper GI cancers among medical providers to increase the likelihood of early detection.
- \$0.4 million to Head and Neck Cancer Australia to develop an accredited learning resource for GPs and dentists, develop a support video for people who have been newly diagnosed with head and neck cancer and improve access pathways to existing resources.

Since 2008, the Government has also supported Canteen to establish and deliver the Youth Cancer Service program for young people with cancer, recognising that cancers affecting children and teenagers are considered rare. This provides patients with services, social and emotional support, access to clinical trials and developing and implementing national and local strategies to support the delivery of high-quality youth cancer services. The Government provided Canteen \$22.0 million over four years from 2020-21 to support this activity, which is available to all young people with cancer.

While not funded by Government, Rare Cancers Australia was established for people affected by rare and less common cancers, and provides patient communities, advocacy and fundraising activities, support programs, and invests research into and treatment for rare and less common cancers.

Similarly, Cancer Council Australia provides information factsheets and resources for specific cancer types, including rare and less common cancers. Cancer Council Australia, via each state and territory Cancer Council, also operates a free, confidential information and support service and offers online support groups and forums for all people affected by cancer.

### **Emotional and wellbeing support**

In July 2022, the Government launched the Cancer Hub, a digital platform providing online immediate, consolidated, and tailored cancer navigation, counselling and support service for people under 25 years and their parents. The Cancer Hub will help more than 70,000 Australians navigate the cancer journey and help a further 20,000 with mental health support. The department notes that all cancer diagnosed in children and teenagers is classified as rare, despite falling outside of AIHW's description.<sup>8</sup>

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<sup>8</sup> Cancer Council Australia 2021. Understanding Rare and Less Common Cancers: A guide for people with cancer, their families and friends.  
<https://www.cancer.org.au/assets/pdf/understanding-rare-and-less-common-cancers>

In 2022-23, an estimated \$7.1 billion was invested across the Health and Aged Care portfolio for mental health and suicide prevention. This includes \$1.5 billion for department mental health and suicide prevention programs, such as:

- Beyond Blue, which provides a telephone, email and web chat service for individuals to access mental health information and referrals, suicide prevention and aftercare activities, and mental health programs for school-aged children and their families.
- Lifeline, which provide a telephone and online crisis service, including a specific service for First Nations people.
- ReachOut, a free, online mental health information and support service for Australian young people and their carers.
- Head to Health, a hotline providing guidance and advice, and free clinics around Australia providing support and information.

People with rare and less common cancers may also be able to access up to 10 Medicare-subsidised mental health services per calendar year under the Better Access initiative.

### **Cancer care navigation and coordination**

The cancer control system is complex and can be difficult to navigate. As such, the Government has invested approximately \$194.0 million from 2007-08 to 2025-26 to support tumour-specific nurses for people diagnosed with breast, prostate, lung, ovarian cancer and melanoma. These nurses work as part of the multidisciplinary team to coordinate and provide care continuity for patients throughout their cancer treatment and management.

In line with the tumour inclusive approach of the forthcoming ACP, the Government is considering future approaches to the delivery of cancer care in Australia that will provide equitable access to culturally safe and high-quality cancer nursing and navigation services throughout the continuum of care, irrespective of a patient's cancer type or geographic location.

### **Health and medical research**

Proportional funding for research and clinical trials for many cancers is low compared with their burden on the Australian population.<sup>9</sup> In respect of medical research, from its inception in 2015 to 31 July 2023, the Medical Research Future Fund has invested \$2.78 billion in 1145 health and medical research grants. This includes \$454.70 million in 189 cancer-specific research grants, and \$37.9 million in 25 research grants that focus on rare cancers. This includes the 2021 Rare Cancers, Rare Diseases and Unmet Need grant opportunity, which awarded \$2.3 million to Flinders University for the 'Implementing a Nurse-Enabled, Shared-Care Model to Address Unmet Needs of People with Neuroendocrine Tumours: the AUS-NET Trial'. This project aims to improve the quality of life and reduce unmet needs of people with neuroendocrine tumours, with cost-effectiveness and implementation learnings to inform future research translation.

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<sup>9</sup> Cancer Australia 2023. Cancer Research in Australia: An overview of funding for cancer research projects and programs in Australia 2012 to 2020.  
[https://www.canceraustralia.gov.au/sites/default/files/publications/cancer-research-australia-overview-funding-cancer-research-projects-and-programs-australia-2012-2020/pdf/cancer\\_of\\_funding\\_for\\_cancer\\_research\\_projects\\_and\\_programs\\_in\\_australia\\_2012\\_to\\_2020\\_final.pdf](https://www.canceraustralia.gov.au/sites/default/files/publications/cancer-research-australia-overview-funding-cancer-research-projects-and-programs-australia-2012-2020/pdf/cancer_of_funding_for_cancer_research_projects_and_programs_in_australia_2012_to_2020_final.pdf)

The Government has committed \$750 million over 10 years from 2022-23 under the MRFF Clinical Trials Activity Initiative (initiative) to increase clinical trial activity in Australia in order to improve the evidence base supporting clinical care and to help patients access trials relevant to their health circumstances, and enable researchers to bring international trials to Australian patients. From its inception in 2015 to 31 July 2023, the MRFF has invested \$25.53 million in 14 grants with a research focus on rare cancer under the initiative.

In addition, a priority area for action under the forthcoming ACP is the development and implementation of the National Data Framework (NDF) and minimum dataset. Cancer Australia will lead the development of the NDF, in partnership with the department, Australian Institute of Health and Welfare, state and territory governments, and the cancer control sector. The NDF will provide a pathway for improving the collection and reporting of comprehensive data collection across the cancer control continuum. Improving cancer data will provide insight into patterns and trends of diagnoses, allowing policy makers to better target initiatives and improve outcomes for people affected by cancer, including those with rare and less common cancer types.

## References

Australian Institute of Health and Welfare 2022. Cancer. Canberra: AIHW

<https://www.aihw.gov.au/reports/australias-health/cancer>

Australian Institute of Health and Welfare 2021. Cancer in Australia 2021. Cancer series no. 133. Cat. no. CAN 144. Canberra: AIHW

<https://www.aihw.gov.au/getmedia/0ea708eb-dd6e-4499-9080-1cc7b5990e64/aihw-can-144.pdf.aspx?inline=true>

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

[https://www.canceraustralia.gov.au/sites/default/files/publications/cancer-research-australia-overview-funding-cancer-research-projects-and-programs-australia-2012-2020/pdf/cancer\\_of\\_funding\\_for\\_cancer\\_research\\_projects\\_and\\_programs\\_in\\_australia\\_2012\\_to\\_2020\\_final.pdf](https://www.canceraustralia.gov.au/sites/default/files/publications/cancer-research-australia-overview-funding-cancer-research-projects-and-programs-australia-2012-2020/pdf/cancer_of_funding_for_cancer_research_projects_and_programs_in_australia_2012_to_2020_final.pdf)

Cancer Council Australia 2021. Understanding Rare and Less Common Cancers: A guide for people with cancer, their families and friends.

<https://www.cancer.org.au/assets/pdf/understanding-rare-and-less-common-cancers>

Dasgupta, P. Cameron, J. Cramb, S. Trevithick, R. Aitken, J. Mengersen, K. Baade, P 2022.

Geographical and spatial disparities in the incidence and survival of rare cancers in Australia.

*International Journal of Cancer*. Vol. 152, issue 8, pp. 1601-1612

Economou, D., & Corcoran, S. (2016). Incorporating a Survivorship Clinic Into Practice. *Journal of the Advanced Practitioner in Oncology*, 7(3), 343–346.

Yu, X. Feletto, E. Smith, M. Yuill, S. Baade, P (2022). Cancer incidence in migrants in Australia: Patterns of three infection-related cancers. *Cancer Epidemiology Biomarkers and Prevention*, vol. 31, no. 7, pp. 1394-1401.