Australian Government

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Australian Government response to the Senate Community Affairs References Committee report:

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

April 2025

Acknowledgment of Country

The Australian Government acknowledges and pays respects to all Aboriginal and Torres Strait Islander people across Australia, who are the custodians of the land and of the oldest continuous living culture on Earth. We honour Aboriginal and Torres Strait Islander peoples' ongoing connection to sea, waterways and Country. We pay respects to Elders past and present.

Overview

On 14 June 2023, the Senate referred the issue of equitable access to diagnosis and treatment for individuals with rare and less common cancers, including neuroendocrine cancer, to the Senate Community Affairs References Committee (Committee) for inquiry and report. The Australian Government welcomes the final report and thanks the Committee for its work.

The Government acknowledges the challenges experienced by individuals with rare and less common cancers and thanks all the patients, families, advocates, health care providers and researchers who shared their experiences with the Committee.

Cancer is responsible for Australia's largest disease burden and is a leading cause of death.[1] The Government acknowledges that while only a small number of people are diagnosed with rare and less common cancer every year, rare and less common cancers account for approximately 33 per cent of all cancer deaths.[1] Improving outcomes for people with the poorest cancer experiences and developing measures that achieve equity for all Australians with cancer is critical to the Government.

It is with this ambition that the Government released the first national Australian Cancer Plan (ACP) in November 2023 following an extensive consultation period with state and territory governments, First Nations communities, clinicians, researchers, people affected by cancer and support organisations. The ACP represents a once in a generation reform opportunity that aims to deliver world-class cancer outcomes and experiences for all Australians affected by cancer, irrespective of their tumour type, background or location.

While the Government provides national leadership on cancer policy and research, improving outcomes for Australians affected by cancer is a shared responsibility. To achieve this, coordinated action is needed across the cancer control system, including at all levels of government, non-government organisations, and the health and research sectors. Eight recommendations fall within areas of state and territory responsibility or require collaboration between the Australian and state and territory governments. The Government has written to the state and territory health ministers seeking their consideration and action

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[1] Australian Institute of Health and Welfare. Cancer Data in Australia 2024. Cat. No. CAN 122. Canberra

on these recommendations. The Department of Health and Aged Care will also engage and collaborate with the jurisdictions through the Cancer and Population Screening (CAPS) Committee to respond to the recommendations.

Some of the recommendations are complex and require rolling implementation to address. While the Government response addresses work already underway, several recommendations will be considered when making future policy decisions. The Government also acknowledges the recommendations relate to a number of other key reviews and reforms, including the Health Technology Assessment (HTA) Review and the National Disability Insurance Scheme (NDIS) Review.

In this context, the Government response supports (or supports in-principle) 31 of the 41 recommendations, while noting the remaining recommendations.

Recommendation 1

The Committee recommends that the Australian Government further develop clinical guidelines and local pathways for rare and less common cancers and ensure that they are accessible and available for general practitioners at the point-of-care.

The Australian Government **supports in-principle** this recommendation.

Optimal Care Pathways (OCPs) are embedded into the Australian Cancer Plan as national standards of consistent, safe, high-quality, and evidence-based care, including cancer-specific and population-specific OCPs.

32 OCPs have been developed to date, with 30 for specific cancer types and 3for specific population groups. A number of the cancer type specific OCPs are for rare and less common cancers. These include cervical cancer, cancer with an unknown primary site, several types of blood and lymphatic system cancers, neuroendocrine cancer and head and neck cancer. OCPs are available online, ensuring they are easily accessible to health care providers, patients and their families.

Cancer Australia has developed a *National Optimal Care Pathways Framework* to standardise the development, evaluation, and integration of OCPs into cancer care, support health professionals and ensure accessibility for people affected by cancer.

Recommendation 2

The Committee recommends that the Department of Health and Aged Care investigate the feasibility of a two-week urgent referral system for suspected cancer, such as the model offered in the United Kingdom.

The Australian Government **notes** this recommendation.

In the Australian context, the Optimal Care Pathways (OCPs) outline each step of the patient journey, including the best practice timelines to referral processes between treating medical practitioners as patients progress through early detection, diagnosis and treatment. Referral processes and timelines may vary between cancer types, including for rare cancers, and is subject to the treating medical practitioner’s clinical decision and an individual’s preference.

The Government recognises the importance of timely referral processes in healthcare and is exploring how technology can support this. The department is establishing digital standards to support referrals and electronic Requesting (eRequesting) to enable timely and consistent workforces to connect patients and their treating medical practitioners. In the 2023-24 Budget, the Government invested $5.8 million over two years for the Department of Health and Aged Care to collaborate with key sector stakeholders on the design of a national eRequesting capability. A further $5.9 million was provided in the 2024-25 Budget to continue the development of this capability.

Recommendations 3 and 4

The Committee recommends that the Australian Government undertake a review of Medicare reimbursement settings for diagnostic tests and services, with a view of ensuring patients with, or with suspected rare or less common cancer, receive prompt, appropriate and affordable diagnostic testing.

The Committee recommends that the Australian Government enable increased reimbursements for MRI, PET and CT services throughout the diagnosis, surveillance and restaging of rare cancers.

The Australian Government **supports in-principle** recommendation 3 and **notes** recommendation 4.

The Government recognises access to diagnostics tests and surveillance is crucial to improving outcomes for patients with rare and less common cancers. The Department of Health and Aged Care has been working closely with the Medical Services Advisory Committee (MSAC) and expert working groups to explore ways to streamline health technology assessment for diagnostic services relating to rare cancers.

This has successfully resulted in the listing of several Medicare Benefits Schedule (MBS) items for rare cancers in recent years, including:

- 1 November 2022: PET for rare and uncommon cancers for initial staging (MBS item 61612)
- 1 March 2023: Whole body MRI for the detection of cancer in individuals with germline pathogenic TP53 variants (MBS item 63564)
- 1 November 2023: genetic variant testing in patients suspected of having either a myeloid or lymphoid haematological malignancy (MBS items 73445, 73446, 73447, 73448)
- 1 January 2024: genetic testing for patients with ovarian, fallopian tube or primary peritoneal cancer to determine eligibility for access to PBS olaparib (MBS item 73307)
- 1 July 2024: Abdominal MRI for rare genetic conditions (MBS items 63539 and 63540)
- 1 July 2024: testing for the detection of measurable residual disease in patients with acute lymphoblastic leukaemia (MBS items 73316, 73313)
- 1 November 2024: PET for treatment response and recurrence for rare and uncommon cancers (MBS item 61614).
- From 1 July 2025, MBS items 61612 and 61614 will be amended to expand access to all cancers that meet the criteria for a whole body fluorodeoxyglucose (FDG) PET study for initial staging and evaluation of suspected residual, metastatic or recurrent cancer for a patient who is undergoing or is suitable for active therapy. The expansion of these items to include all FDG-avid cancers will benefit patients with rare and less common cancers.

As part of the 2024-25 Budget, the Government committed $69.8 million to remove barriers to access Medicare eligible MRI machines over two stages. This will enable all MRI equipment to provide Medicare funded services, starting on 1 July 2025 at practices that have a current licence, followed by all remaining practices on 1 July 2027.

Also, $92.8 million has been committed to boost funding for nuclear medicine services through the reintroduction of annual indexation, which will include all PET services from 1 July 2027.

Additionally, from 1 November 2025, a new MBS item will be listed for ^{177}Lutetium-DOTA-octreotate treatment for advanced neuroendocrine tumours with high somatostatin receptor (H-SSTR) expression, eligibility for which will be determined through a new MBS item for a diagnostic whole body ^{68}Ga-DOTA-octreotate PET scan.

Under the MBS, the Government provides access to rebates for a broad range of services, including over 500 pathology tests. The Pathology Services Table of the Medicare Benefits Schedule (MBS) lists the pathology tests for which Medicare benefits are available, their Schedule fees and conditions for use. From 1 July 2025, Medicare fees for MBS pathology groups Haematology, Immunology, Tissue Pathology, Cytology, and Infertility and Pregnancy will be indexed alongside other MBS categories. Indexation of these groups will support a high rate of bulk-billed diagnostic services to ensure that Australians continue to have access to high quality and affordable healthcare.

The Department continues to work with MSAC to develop reliable methodologies to assess diagnostic services for rare and less common cancers. The *Health Technology Assessment Policy and Methods Review* was published on 10 September 2024. It includes recommendations relevant to evidentiary requirements for health technology assessments. The Government has committed to the establishment of an Implementation Advisory Group to guide the development of a response to this review and health technology assessment reforms.

The Government relies on the advice of the independent expert MSAC and other groups of independent clinical experts, such as the MBS Review Advisory Committee, to inform its decisions about the appropriate rebates for health services on the MBS. This ensures that the Government achieves value for public money. The Government notes the Committee’s recommendation that reimbursements for particular services should be increased, but will continue to seek independent expert advice when making decisions on these matters through Budget processes.

Since 1 July 2024, the Minister for Health has authority to approve recommendations for new and amended MBS services following a positive MSAC recommendation, when the services are under a certain expenditure threshold, without going through the full Budget process. This is assisting to reduce the time taken for Government approval to list eligible new and amended MBS items. Where an MSAC application relates to a diagnostic imaging service for a rare or uncommon cancer and the service meets the expenditure requirements, the Minister’s delegation will support the MBS item being made available to patients sooner.

Recommendation 5

The Committee recommends that the Australian Government, in partnership with state and territory governments, undertake a review of the distribution and availability of MRI, PET and CT services and infrastructure across jurisdictions, with a view of ensuring more equitable access to these services going forward.

The Australian Government **supports in-principle** this recommendation.

The Government recognises the importance of access to MRI, PET and CT services for many patients with rare and less common cancers throughout their cancer journey. As part of the feasibility assessment for a lung cancer screening program, an assessment of the existing CT infrastructure was conducted by Cancer Australia. This found the spread of CT machines across Australian states and territories closely reflects the distribution of the Australian population. To further supplement existing CT infrastructure, the National Lung Cancer Screening Program will partner with Heart of Australia to provide 5 mobile CT screening trucks to service rural and remote Australia.

The Government will explore additional opportunities to work with state and territory governments to review the distribution and availability of MRI, PET and CT services and infrastructure across jurisdictions to ensure equitable access.

The Government has written to the state and territory health ministers seeking their consideration and action on this recommendation.

Recommendation 6

The Committee recommends that, as a matter of priority, the Australian Government legislate a complete ban on genetic discrimination in life insurance.

The Australian Government **supports** the recommendation.

The Government recognises the importance of genetic and genomic health information and therapies. They are reshaping clinical practice and changing the way medical practitioners prevent, diagnose, treat, and monitor a range of heritable conditions, cancer predisposition syndromes and cancers. Individuals should not be dissuaded from potentially life-saving testing, out of fear of discrimination when purchasing life insurance.

In September 2024, the Government announced its intention to legislate a total ban on the use of adverse genetic testing results in life insurance. This ban will restrict the ability of life insurers to request, or utilise, adverse predictive genetic testing results in their underwriting. Under the ban, applicants will still be required to disclose any confirmed diagnoses (regardless of whether these resulted directly or indirectly from genetic testing), as well as any relevant family medical history. The Australian Securities and Investments Commission will be assigned regulatory responsibility for overseeing the ban, and the regime will be subject to 5 yearly reviews.

Recommendation 7

The Committee recommends that the Australian Government investigate opportunities to increase equitable uptake and access to genomic screening and profiling for Australians.

The Australian Government **supports** this recommendation.

The Government is committed to increasing equitable uptake and access to genomics and is funding a number of activities to achieve this.

On 15 November 2024 the Minister for Health and Aged Care, the Hon Mark Butler MP, announced the establishment of a new national body, Genomics Australia, to provide leadership, coordination and expertise so all Australians can reap the benefits of genomic research and technologies. The Government has committed ongoing funding for Genomics Australia, including over $30 million for its first four years of operation.

In April 2023, the Health Technology and Genomics Collaboration (the Collaboration) was established as an intergovernmental forum to drive the development of a nationally consistent approach for implementing genomics into the Australian health system as one of its key functions. The Collaboration's current work plan includes a project to update the National Health Genomics Policy Framework, which will investigate factors that influence the uptake and access of genomic health technologies and what action may be needed at a national level to improve equity. A key focus for Genomics Australia, once established, will be supporting national objectives as articulated in the updated National Health Genomics Policy Framework.

Cancer Australia has developed a National Framework for Genomics in Cancer Control (Framework) as one of the Australian Cancer Plan’s five-year goals under the strategic objective *Maximising Cancer Prevention and Early Detection*. The Framework will span the care continuum including personalised prevention, risk-stratified screening, diagnosis and treatment, supportive care, and foundations for an agile system specific to cancer care.

The Government established the Genomic Health Futures Mission (GHFM) which will invest $500.1 million over 10 years in genomics research under the Medical Research Future Fund (MRFF). It will improve testing, diagnosis and treatment for genetic diseases, guide prevention and help personalise treatment options to better target and improve health outcomes and reduce unnecessary interventions and associated health costs for all Australians. The GHFM will also advance precision medicine for all Australians while keeping a focus on improving overall healthcare for Aboriginal and/or Torres Strait Islander people. This will be accomplished in partnership with Aboriginal and/or Torres Strait Islander people to deliver genomics research that is scientifically sound, culturally safe and competent to address inequity in research participation and outcomes.

The Government has also provided $114 million in funding for infrastructure to support precision medicine research and manufacturing including:

- $80 million to create the Centre of Excellence in Cellular Immunotherapy at Melbourne’s Peter MacCallum Cancer Centre.

- $15 million to help establish an innovative cancer genomics laboratory in South Australia, which aims to improve treatment options for Australians with cancer.
- $19 million to the Western Australian government to expand the use of comprehensive genomic profiling for Western Australian cancer patients.

The Government currently funds many Medicare Benefits Schedule (MBS) items which may be used in the diagnosis and management of cancer. This includes MBS pathology items for specific gene variants for cancer diagnosis and management and determining eligibility for funding cancer treatment under the Pharmaceutical Benefits Scheme. It also includes cascade testing of family members for identified genes predisposing them to cancer.

Additionally, the Government is providing additional investment into key precision oncology programs in Australia. This includes $112.6 million over three years from 2025-26 to support the extension and expansion of the ZERO Childhood Cancer Program, and $30.8 million over two years from 2025-26 for the continuation of the Precision Oncology Screening Platform Enabling Clinical Trials (PrOSPeCT) Program. This investment will ensure that more children and young people with cancer can access precision medicine that may increase their quality of life and survival rate, and builds on previous Government funding.

The Government has also committed $6.7 million over four years from 2025-26 to continue the Australian Rare Cancers Portal (the ARC Portal), allowing individuals with rare and less common cancers to access guidance on genomic profiling, and expert advice, regardless of where they live.

Recommendation 8

The Committee recommends that the Australian Government closely monitor the outcomes of the DNA Screen study, and the implications of the study for the future development of population wide, preventive genomic screening programs.

The Australian Government **supports in-principle** this recommendation.

The Government is committed to monitoring the outcomes of the DNA Screen study and other relevant research and clinical trials.

Recommendation 9

The Committee recommends that the Australian Government, through the Medical Research Future Fund, extend funding for the ZERO Childhood Cancer Program beyond June 2025.

The Australian Government supports this recommendation.

On 6 March 2025, The Australian Government announced that it was investing a further $112.6 million over three years from 2025-26 for the ZERO Childhood Cancer program (ZERO) to ensure that all Australian children aged 0 to 18 years with cancer can continue to benefit from genomic profiling. This investment also includes an expansion of the program to include young people aged 19 to 25 with certain cancers.

Recommendations 10 and 11

The Committee recommends that the Australian Government utilise the Health Technology Assessment Policy and Methods Review to provide Australian rare and less common cancer patients with timely and affordable access to novel medicines.

The Committee recommends that the Australian Government ensure that the Managed Access Program is more widely accessed where appropriate.

The Australian Government **notes** these two recommendations.

The Government is committed to seeking better outcomes for those affected by rare cancers. The Government is addressing rare diseases at a national level through the National Strategic Action Plan for Rare Diseases and provides direct support for health and medical research through the Medical Research Future Fund and the National Health and Medical Research Council, with several funding schemes available to support research into rare cancers.

The Health Technology Assessment Policy and Methods Review was published on 10 September 2024 and includes recommendations relevant to rare diseases and Managed Access Programs (also known as Managed Entry Agreements) as a potential mechanism to facilitate earlier access to innovative medicines.

The Government has established of an Implementation Advisory Group (IAG) to guide health technology assessment reforms.

Recommendation 12

The Committee recommends that the Australian Government adjust regulatory processes to broaden indication coverage for medicines that treat rare and less common cancers, including neuroendocrine cancer.

The Australian Government **notes** this recommendation.

The Government notes that indication coverage is impacted by both Therapeutic Goods Administration approval and subsidy through its health technology funding programs.

When recommending medicines for listing, health technology funding programs accept that products have adequate safety and efficacy to allow marketing in Australia for the specific therapeutic indications for which they are registered with the Therapeutic Goods Administration. Generally, a health technology funding program will not recommend listing a product for indications beyond those approved by the TGA.

The Health Technology Assessment Policy and Methods Review was published on 10 September 2024 and includes recommendations relevant to broadening indication coverage, particularly for paediatric patients.

The Government has committed to the establishment of an Implementation Advisory Group to guide health technology assessment reforms.

Recommendation 13

The Committee recommends that the Australian Government work with state and territory governments to ensure the families of paediatric cancer patients are not financially disadvantaged for hospital stays.

The Australian Government **supports in-principle** this recommendation.

The Government recognises the impact of hospitals stays on paediatric cancer patients and their families.

The planning and delivery of Australian public hospital services is undertaken by states and territories in their role as system managers. The Government provides significant funding through the National Health Reform Agreement (NHRA) to assist states and territories with the costs of delivering public hospital services, including for paediatric cancer patients on an activity basis.

Facilitated by the Medicare Principles in the NHRA, states and territories have agreed to provide all Medicare-eligible persons with the choice to receive public hospital services free-of-charge, on the basis of clinical need and within a clinically appropriate period. The NHRA also requires states and territories to ensure arrangements are in place to ensure equitable access to public hospital services, regardless of geographical location.

The Government has written to the state and territory health ministers seeking their consideration and action on this recommendation and the Department of Health and Aged Care will engage with health representatives from the states and territories through the Cancer and Population Screening (CAPS) Committee.

Recommendation 14

The Committee recommends that the Australian Government work with state and territory governments to identify the barriers faced by cancer patients requiring rehabilitation, prosthetics and implants as a result of their treatment, with a view to ensuring they have financial support for those services.

The Australian Government **supports in-principle** this recommendation.

The Government recognises the importance of access to rehabilitation, prosthetics and implants for many patients with rare and less common cancers.

The Government provides Medicare benefits (rebates) for privately provided services listed on the Medicare Benefits Schedule (MBS). There are a range of items listed on the MBS that provide a rebate for surgical facial reconstruction for patients, including for head and neck cancer surgery, when performed by a medical practitioner.

On 1 July 2023, following extensive consultation, changes to a range of plastic and reconstructive surgery items, including oral and maxillofacial surgery items, were implemented. These changes were a result of recommendations from the MBS Review

Taskforce that considered how items on the MBS can be aligned with contemporary clinical evidence and practice and improve health outcomes for patients.

For a new medical service to be funded through the MBS, an assessment by the Medical Services Advisory Committee (MSAC) is required. The MSAC is an independent, expert advisory group which provides advice to the Government based on an assessment of the comparative safety, clinical effectiveness, and cost effectiveness of procedures.

The MBS funds privately provided medical services, but does not fund products or devices such as prostheses.

The Prescribed List (PL) requires private health insurers to pay a minimum benefit for patients with private health insurance cover for surgical implants received as part of an MBS funded episode of hospital or hospital-substitute treatment. Currently there are a range of implant products listed on the PL under the Plastic and Reconstructive Category.

For patients receiving public hospital services as a public patient, implants are provided and funded by states and territories in accordance with NHRA arrangements discussed in the response to recommendation 13 above.

The Government will explore opportunities to work with state and territory governments to better financially support cancer patients and their families. The Government has written to the state and territory health ministers seeking their consideration and action on this recommendation and the Department of Health and Aged Care will engage with health representatives from the states and territories through the Cancer and Population Screening (CAPS) Committee.

Outside of hospital services, the Government funds external prostheses for people with breast cancer through the National External Breast Prostheses Reimbursement Program.

The Department of Health and Aged Care has engaged a service provider to lead an independent review of cancer prostheses equity in Australia. The review will examine the availability of Commonwealth, state and territory prostheses programs, current challenges for cancer patients to access prostheses, develop strategies to address identified gaps and barriers and help find appropriate funding options. This review is expected to be finalised in the second half of 2025.

Recommendation 15

The Committee recommends that the Australian Government review the eligibility criteria of the Medical Treatment Overseas Program, with a particular focus on access to clinical trials and treatments for rare and less common cancer.

The Australian Government **notes** this recommendation.

The Medical Treatment Overseas Program (MTOP) provides financial assistance to approved Australians and permanent residents with life-threatening medical conditions to access medical treatment overseas where the proposed treatment is accepted by the Australian medical profession as a standard form of treatment, but it is not available in Australia.

The MTOP has Guidelines that outline the administrative and clinical criteria that must be met by each application. As outlined in the Guidelines, applications that are seeking financial assistance for participation in a clinical trial or experimental treatment cannot be assessed by the MTOP. Experimental treatments and clinical trials conducted internationally are not subject to Australian regulatory, legal and ethical frameworks, which exposes patients and the Australian Government to significant risk. The Government supports clinical trials through other avenues, including the National One Stop Shop platform (recommendation 16) and the Clinical Trials Activity Initiative (recommendation 17).

The MTOP Program Guidelines state that the MTOP must ensure that taxpayer funded financial assistance is being provided for life-extending, safe, effective treatment, supported by proven medical evidence. This means treatments being proposed for overseas delivery require evidence comparable to that assessed by Australian health services and funding bodies considering implementing a treatment in this country.

Recommendation 16

The Committee recommends that the Australian Government work with state and territory governments to implement the One Stop Shop and National Clinical Trials Front Door platform as a matter of priority.

The Australian Government **supports** this recommendation.

The Government is committed to implementing the National One Stop Shop to harmonise and streamline the regulatory and operating environment for health and medical research in Australia. The Government announced funding of $18.8 million in the 2024-25 Budget to advance the National One Stop Shop ICT solution. On 16 September 2024, a Request for Expression of Interest (REI) for delivering the National One Stop Shop ICT Solution was published on AusTender.

The Government continues to work in collaboration with state and territory governments through the Inter-Governmental Policy Reform Group (IGPRG) to deliver the National One Stop Shop and related initiatives including but not limited to, implementation of the National Clinical Trials Governance Framework and development of a quality standard and accreditation scheme for Human Research Ethics Committees (HRECs).

Recommendation 17

The Committee recommends that the Australian Government ensure the Clinical Trials Activity initiative has an appropriate focus on funding clinical trials and research for people with cancer, including children, young people, and patients diagnosed with rare and less common cancers.

The Australian Government **supports** this recommendation.

The Government is committed to ensuring research on rare cancers, rare diseases and unmet need remains a priority area for funding under the Clinical Trials Activity Initiative. The 2023 Clinical Trials Activity Initiative grant opportunity closed in May 2024, and seeks to award up to $65 million of funding across four research streams, which includes rare cancers, rare disease and unmet need. The 2024 Clinical Trials Activity grant opportunity also opened in September 2024 and seeks to award up to $63 million in funding across the same research streams. This funding is reflected in the $6.5 billion Medical Research Future Fund (MRFF) 3rd 10-year Investment Plan, announced in the 2024-25 Budget. Additionally, the MRFF will provide $150 million over 10 years for the Low Survival Cancers Mission into research to improve care and health outcomes for people with cancer with a survival rate of less than 50%, many of which are rare and less common cancers, starting from 2027-28.

Recommendation 18

The Committee recommends that the Australian Government provide appropriate funding to key cancer advocacy organisations supporting patients with rare and less common cancers by providing informative resources and support services that:

- increase health literacy;
- empower patients to make informed decisions regarding their health; and
- are culturally appropriate and accessible in a variety of languages.

The Australian Government **supports** this recommendation.

The Government recognises the important role non-government organisations (NGOs) play in supporting patients with rare and less common cancers. In November 2023, the Government announced $166 million for the establishment of a new Australian Cancer Nursing and Navigation Program (the Program). The Program is a national reform to deliver improved cancer outcomes, ensuring people effected by cancer have access to high quality and culturally safe care, irrespective of their cancer type, stage of diagnosis or where they live. The Program provides funding to a number of cancer NGOs, including Rare Cancers Australia, Head and Neck Cancer Australia and Neuroendocrine Cancer Australia, to deliver specialist support services (including telehealth)

The Government is also providing $16.5 million for a Cancer Patient Support Program. This Grant Program funds initiatives that will build equity across the cancer control spectrum by providing opportunities to organisations that specifically focus on increasing equity across tumour types, and/or priority population groups. It will ensure a diverse range of evidence-based projects are funded that assist in addressing gaps in the system, ensuring that any investment through this opportunity is complementary, and not duplicative to existing Government funded programs. Seventeen organisations have received funding in the first and second round of grants, including:

- Deakin University ($495,000) to develop an optimal care pathway and quick reference guide for people in rural and remote areas living with cancer.
- Little Big Steps ($688,000) to develop e-resources to support physical activity for paediatric cancer patients and survivors.
- BEAT Bladder Cancer Australia ($420,000) to undertake awareness, prevention, education and support activities for bladder cancer patients.

- Pancare Foundation ($641,456) to develop a digital hub to provide diet information for people impacted by upper gastrointestinal cancer.
- The Lift Cancer Care Foundation ($831,600) to develop RACGP accredited resources focused on cancer survivorship care.
- Victorian Comprehensive Cancer Centre Alliance ($874,797) to develop a national regional workforce education support strategy to support regional health care professionals.
- ASHM Health ($454,231) to develop an optimal care pathway and associated resources for LGBTIQA+ people with cancer.
- Australian New Zealand Children's Haematology Oncology Group ($499,000) to develop information and resources to ensure adolescents and young adults can make informed decisions about participating in clinical trials.
- Cancer Council Queensland ($924,000) to develop an Australian Cancer Care Workplace Initiative to enhance employer capabilities and workplaces to better support employees and their families affected by cancer.
- Cancer Nurses Society of Australia ($996,182) to develop a Cancer Nursing Education Portal that will facilitate access to evidence-based cancer specific education for nurses.
- Community Broadcasting Association Australia ($416,120) to develop an awareness raising campaign targeting hard to reach priority populations from CALD backgrounds through community service announcements.
- Gather My Crew ($441,000) for the development of a module to be available through the Gather My Crew app, aimed at improving support for rural, regional and remote cancer patients.
- Myeloma Australia ($800,000) for the development of a digital platform offering tailored content to both myeloma patients and health care professionals.
- Palliative Care Australia (924,870) to improve medical specialist's referral to palliative care for patients with advanced cancer.
- Rare Cancers Australia ($999,592) for the development of resources to create equity and access to information for CALD patients with rare and less common cancers.
- So Brave ($1,000,000) to develop education for health care professionals and development of resources to support women with pregnancy and postpartum associated cancers.
- Sydney University ($996,502) for upskilling the cancer workforce in detecting and managing sexual function and intimacy concerns for individuals with cancer.

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Additionally, the Government has procured the Sax Institute, in partnership with the Sydney Health Literacy Lab, to develop a National Health Literacy Strategy (NHLS) to improve the health literacy environment in Australia as well as individuals' self-care capabilities. Public consultation on the draft NHLS is expected to commence in late-2024.

Recommendation 19

The Committee recommends that the Australian Government provide sufficient funding and resources to ensure that the supportive care aspirations of the Australian Cancer Plan are delivered on for all Australians, including for those affected by rare and less common cancers.

The Australian Government **supports** this recommendation.

The Australian Cancer Plan (Plan) is a 10-year reform agenda for the whole Australian cancer community. Implementation of the ACP requires leadership and collaboration across the entire cancer control sector. The Plan's launch was supported by a record investment of nearly $750 million in cancer care in the 2023-24 Budget, including the introduction of the National Lung Cancer Screening Program, the Australian Cancer Nursing and Navigation program, and initiatives to improve First Nations cancer outcomes. This was followed by an additional $71 million investment in the 2024-25 Budget, building on the Government's commitment to improve outcomes for all Australians affected by cancer.

The Plan identifies the five-year goal of building networked high-quality comprehensive cancer care systems to deliver optimal cancer care and better outcomes. This includes integrating Optimal Care Pathways into routine care, establishing the Australian Comprehensive Cancer Network and improving equitable access to evidence-based innovative models of care. These actions will support all Australians affected by cancer including people with rare and less common cancers.

Since 2005, the Government has contributed over $12 million towards 142 community grants through Cancer Australia's *Supporting people with cancer* grant initiative. The grant initiative provides funding to community organisations to develop evidence-based projects, which support people affected by cancer. Going forward, the initiative will be guided by the Plan's strategic objectives, with grants required to support at least one or more of the priority population groups identified in the Plan and/or demonstrate direct improvements for people whose cancer outcomes are inequitable. Grants awarded under this program in recent years have included projects which support people with rare and less common cancers.

Recommendation 20

The Committee recommends that the Department of Health and Aged Care monitor and report on progress for the delivery of the all-cancer nurse service.

The Australian Government **supports** this recommendation.

The Australian Government has committed $166 million to establish a new Australian Cancer Nursing and Navigation Program (ACNNP). The program will ensure all people with cancer have access to high quality and culturally safe care, irrespective of their cancer type or location. A key component of the ACNNP is the all-cancer nurse service led by the McGrath Foundation in partnership with the cancer sector to deliver around 250 Commonwealth-funded cancer nurses in health and hospital services across Australia to deliver support to Australians with all types of cancers.

In January 2025, as part of the all-cancer nurse service, the Australian Government announced an additional $2.3 million for the McGrath Foundation to expand their 'Find-A-Nurse' online tool to support patients in finding cancer nurses near them.

In consultation with the sector and an external evaluator, the Department of Health and Aged Care is planning a comprehensive evaluation to inform future program and policy decisions by evaluating the efficacy and sustainability of the ACNNP. The evaluation will include regular monitoring and mid-point progress reports.

Recommendation 21

The Committee recommends that the Australian Government explore the provision of at least one specialised neuroendocrine tumour nurse, and paediatric cancer nurse, in each Australian jurisdiction.

The Australian Government **notes** this recommendation.

Whilst the Australian Government provides funding for the Australian Cancer Nursing and Navigation Program (ACNNP), nurses are typically funded by the states and territories. Jurisdictions may choose to fund specialised neuroendocrine tumour or paediatric cancer nurses where there is a need.

The ACNNP adopts a tumour-inclusive approach with funding provided for an all-cancer nurse service that ensures all people with cancer are supported, irrespective of cancer type.

The tumour-inclusive approach aligns with the Australian Cancer Plan and will implement one of its key recommendations to develop and implement an integrated and multidisciplinary navigation model. The ACNNP will improve equitable access to high quality, culturally safe cancer nursing and navigation services for all people with cancer, including paediatric cancer patients and people with neuroendocrine cancer.

Additionally, the Specialist Support Service stream of the ACNNP will fund cancer NGOs to ensure tailored support is available to meet the unique needs of people with specific cancer types, including people with neuroendocrine cancer. This includes $4.4 million over 4 years to Rare Cancers Australia and $2.4 million over 4 years to Neuroendocrine Cancer Australia to deliver specialist support services.

Paediatric cancer patients can access support through the Child and Youth Cancer Hub. Canteen, in collaboration with Camp Quality and Redkite, will receive $9.4 million to continue the delivery of the Child and Youth Cancer Hub, providing tailored cancer navigation services for young people with cancer aged 0 to 25 and their families.

In addition, the Australian Government has committed $2.1 million to support Canteen Connect. Collectively these initiatives aim to help families impacted by cancer access the practical and emotional support they need, when they need it.

The Government will also provide $24.5 million over 4 years for Youth Cancer Services to continue to provide specialist, age-appropriate treatment and support for young cancer patients aged 15 to 25. Each hospital-based service has a multidisciplinary specialist team of health professionals, including nurses who are experienced in treating and caring for young people with a range of different cancers.

Recommendation 22

The Committee recommends that the Australian Government ensure that general practitioners are appropriately incentivised and remunerated for patient care coordination and longer-term management of complex and chronic diseases, including rare and less common cancers.

The Australian Government **supports in-principle** this recommendation.

The Government recognises the important role that multidisciplinary primary care health teams play in supporting patients with complex and chronic conditions.

The Government commissioned several reviews following the report of the Strengthening Medicare Taskforce to examine reforms to ensure multidisciplinary teams are better supported to assist patients with complex and chronic conditions.

In late 2024, the Department of Health and Aged Care published final reports from four major reviews which make recommendations to strengthen primary care and the health workforce:

- Review of General Practice Incentives (8 October 2024)
- After Hours Review (8 October 2024)
- Working Better for Medicare Review (8 October 2024)
- Unleashing the Potential of our Health Workforce: Scope of Practice Review (5 November 2024).

In January 2025, the department established a taskforce to work with stakeholders to design and coordinate advice to Government on options to respond to the reviews, including the National Regulation and Accreditation Scheme Complexity Review that is underway. The taskforce will bring together consolidated advice to government on an integrated primary care reform agenda covering recommendations from all four reviews. Key stakeholders will be engaged to develop advice to government, including through the establishment of an Expert Panel comprised of representatives and individuals from across the primary care sector.

MBS fee-for-service items are also reviewed by experts to ensure that they continue to support high-quality care. The MBS Review Advisory Committee (MRAC) has commenced a review of time-tiered items for primary care. This review process will include consultation with stakeholders. The review is expected to be finalised and advice provided to Government at the end of 2025.

On 1 March 2025, the Government introduced two new MBS items, face to face and video, for consultation of at least 60 minutes with a nurse practitioner. Providing access to a long consultation will support nurse practitioners in managing the health of people with complex and chronic health conditions.

Announced in the 2023-24 Budget, MBS chronic conditions management items will be streamlined and simplified from 1 July 2025. The items will incentivise the regular review of chronic disease management plans and strengthen continuity of care. This is in addition to existing MBS items that are available for undertaking multidisciplinary case conferences, including items specific for cancer care.

The introduction of MyMedicare, a voluntary patient registration model, in 2023 will also assist patients with complex and chronic conditions by encouraging continuity of primary care.

Recommendation 23

The Committee recommends that the Australian Government consider further investment to ensure the timely and affordable provision of psychological services to support patients and their families acutely impacted by rare and less common cancers.

The Australian Government **supports** this recommendation.

The Government is committed to reforming the mental health and suicide prevention systems to ensure all Australians can access the care they need, regardless of where they live or how much they earn. The Government is investing in complementary models to more fairly and efficiently deliver better care to those who need it, including to those with rare cancers, and their families.

Mental health support is available under the Better Access to Psychiatrists, Psychologists and General Practitioners through the MBS (Better Access) initiative. Under Better Access, Medicare benefits are available to eligible patients for up to a maximum of 10 individual and 10 group psychological services per calendar year provided by appropriately trained general practitioners, psychologists (clinical and registered), eligible social workers and occupational therapists. People with relevant plans under the Chronic Disease Management framework may also be able to access Medicare benefits for five allied health services, such as dietetics and exercise physiology services, per calendar year in addition to the 10 individual and 10 group treatment sessions available under Better Access.

Through the 2024-25 Budget, the Government is investing $361 million in the mental health and suicide prevention system which will ensure Australians get the right care for their level of need. This investment shifts away from the one-size-fits-all approach and will relieve pressure on the Better Access initiative.

The Government is also rolling out a national network of 61 Medicare Mental Health Centres (building on the existing Head to Health centres) to provide free community-based services for people with moderate to complex needs. While not intended to provide ongoing care, the number of sessions provided to consumers are not capped. A further $29.9 million over four years from 2024-25 will be provided to strengthen the clinical capacity of centres to appropriately support consumers with severe and complex needs. Medicare Mental Health Centres will have strengthened clinical support through free telehealth access to psychologists and psychiatrists as part of a multidisciplinary team.

The Government has committed $164 million over four years for a new National Early Intervention Service providing low intensity mental health support. The national early intervention service will expand support for people at risk of, or experiencing, mild mental illness or transient distress. From 1 January 2026, the service will provide free low-intensity cognitive behavioural therapy, delivered by skilled and trained professionals, via phone or video. Services will be free and accessible without a diagnosis or referral from a GP. The service will also provide a curated set of free, evidence-based online tools and resources for people able and willing to try self-guided support.

The Australian Cancer Nursing and Navigation Program (ACNNP) will also provide access to psychosocial supports for cancer patients. Rare Cancers Australia and Neuroendocrine Cancer Australia are planning to deliver tele-psychosocial supports as part of the Specialist Support Services stream.

Young people with cancer aged 0 to 25 and their families can access psychosocial supports through the Child and Youth Cancer Hub. The Cancer Hub provides practical and emotional support for young people with cancer and their families, including access to specialist counsellors and dedicated cancer navigators.

Additionally, the Support for Cancer Clinical Trials (SCCT) program provides funding to the Psycho-oncology Co-operative Research Group (PoCoG), among Australia’s 14 Multisite Collaborative Cancer Clinical Trials Groups (CTGs) to develop investigator-initiated and industry-independent cancer clinical trial protocols. PoCoG develops and conducts clinical trials to test new treatments for cancer patients and their carers, to improve the psychological care of people affected by cancer.

Recommendation 24

The Committee recommends that the Australian Government work with state and territory governments, and palliative care services to support:

- improved understanding amongst patients, families and clinicians of the potential benefits, and timely delivery of palliative care;
- increased awareness that palliative care is not just an end-of-life service;
- increased availability of tailored and appropriate palliative care services, for a range of population groups; and
- where appropriate, greater dialogue upon diagnosis, or throughout treatment, between patients, families and clinicians on palliative care options.

The Australian Government **supports** this recommendation.

The Government currently funds a number of programs and projects that aim to improve the provision of high-quality palliative care in Australia through workforce development, quality improvement, data development and advance care planning. These programs focus on increasing access to palliative care for all people with a life-limiting illness including those diagnosed with a rare or less common cancer.

The National Palliative Care Strategy (2018) represents the commitment of the Australian Government and all state and territory governments to ensuring the highest possible quality of palliative care is available to all people. The Implementation Plan for the Strategy articulates a shared direction for the continual improvement of palliative care in Australia, including improving access to palliative care.

The Government has also invested in the development of the Paediatric Palliative Care National Action Plan that provides a roadmap for a national approach to common goals for paediatric palliative care.

The Government has invested approximately $198.4million from 2023-24 to 2026-27 to strengthen access to quality palliative care, improve understanding and increase awareness of palliative care as beneficial from a diagnosis of a life-limiting illness, and increase education and training of the health and aged care workforces. The current reviews and reforms of the national funding and governance arrangements for the health and disability systems, that is the National Health Reform Agreement (NHRA) and the National Disability Insurance Scheme (NDIS), provide an opportunity for the Government to continue working at a national level to clarify supports people with a life limiting illness can expect to receive from the health and disability systems. The Independent Review of the NDIS identifies the interface between palliative care and the NDIS as a critical priority area when reviewing arrangements between the NDIS and other service systems. The Government is currently considering its response to the recommendations made by the NDIS Review.

Delivering high quality palliative care is an essential part of the Australian Cancer Plan, demonstrated by the two-year action to develop and refine integrated care models to maximise access to high-quality, timely and evidence-based palliative and end-of-life care. The Australian Cancer Nursing and Navigation Program (ACNNP) will ensure people are empowered with education, resources and the support to better navigate the health system, including palliative care.

The Government will identify opportunities to engage with state and territory governments to progress these initiatives where appropriate.

Recommendation 25

The Committee recommends that the Australian Government consider a review of the eligibility criteria and adequacy of the Carer Payment and Carer Allowance with a view of ensuring that people caring for cancer patients have access to appropriate support.

The Australian Government **notes** this recommendation.

Pensions, including the Carer Payment are generally paid at the highest legislated rate of income support payments in the Australian social security system. Base pensions are indexed in March and September each year. Payment rates will next be updated on 1 January 2025.

Qualification for the Carer Payment and Carer Allowance is not determined based on the medical condition or disability of the care receiver. Government policy is for each individual to be assessed based on the care provided to determine their eligibility. This does not mean the carer cannot qualify for the Carer Payment or Carer Allowance if the care receiver has cancer. Qualification is dependent on an appropriate assessment of the severity of the condition and the level of care provided. The assessment process for the Carer Payment and Carer Allowance considers the amount of help a person requires to undertake activities of daily living – such as communication, showering, toileting, grooming, dressing, feeding, mobility and a range of cognitive and behavioural activities.

In 2025, the Government is making changes to the 25 hour participation limit for Carer Payment, changing it to 100 hours over a 4 week period, to allow more flexibility in the hours carers work. In addition to the change to the 25 hour rule, this proposal seeks to deliver a range of other improvements for carers, by improving participation rules for Carer Payment recipients:

- Suspension of CP for up to 6 months where a carer exceeds the participation hours limit, exceeds the income limit, or Temporary Cessation of Care (TCC) days, rather than cancellation;
- Allowing use of single TCC days for one-off or occasional instances where carers need greater flexibility in the number of participation hours they use (currently a minimum of 7 TCC days may be taken); and
- Removing travel time, education and volunteering activities from the participation limit.

Recommendation 26

The Committee recommends that state and territory governments reform patient assisted travel schemes with a view to:

- create more consistency in scheme offerings across all jurisdictions;
- increase financial assistance; and
- expand schemes to include travel and accommodation costs for clinical trial participants.

The Australian Government **notes** this recommendation as this is the responsibility of state and territory governments.

The Government has written to the state and territory health ministers seeking their consideration and action on this recommendation and the Department of Health and Aged Care will engage with health representatives from the states and territories through the Cancer and Population Screening (CAPS) Committee.

Recommendation 27

The Committee recommends that Australian health services continue to invest in, and extend the use of telehealth and teletrial technology and infrastructure, to ensure adequate and timely delivery of diagnostic, treatment and support services, particularly for people living outside metropolitan areas.

The Australian Government **supports** this recommendation.

The Government is committed to ensuring equitable access to healthcare for people living outside metropolitan areas and recognises technology plays an important role in achieving this.

Medicare Benefits Schedule (MBS) telehealth services are available nationally as part of a consistent and demand-driven program which provides patient rebates in relation to their private healthcare costs. The final report from the independent clinician-led review of MBS Telehealth by the MBS Review Advisory Committee includes 10 principles and 10 recommendations intended to inform telehealth policy and relevant amendments to the MBS. The Government is currently considering the report.

All Australian governments are collaborating on a broad program of work to improve the operating environment for health and medical services in Australia. As part of this, the National Teletrials Compendium has been developed and agreed. It is designed to support a consistent national approach to implementation of teletrials in Australia and is reviewed regularly.

Specialist telehealth support services will also be provided as part of the Australian Cancer Nursing and Navigation Program (ACNNP). Funding will be provided to a number of cancer NGOs, including Rare Cancers Australia and Neuroendocrine Cancer Australia, to deliver the telehealth support services.

The Australian Comprehensive Cancer Network will aim to improve patient outcomes and address disparities by improving connectivity between cancer services. The integrated national network connects cancer services across Australia to enable cancer expertise to be accessed from more places, ensuring patients can receive care as close to home as possible, particularly in rural and regional areas.

Recommendation 28

The Committee recommends that the Australian Government prioritise and monitor the implementation of the recommendations from the National Medical Workforce Strategy 2021–2031, and ensure it addresses the needs of rare and less common cancer patients, including neuroendocrine cancer patients.

The Australian Government **supports in-principle** this recommendation.

The National Medical Workforce Strategy 2021-2031 (NMWS) has been agreed by all Australian Health Ministers and is guiding long-term collaborative medical workforce planning across Australia. It identifies achievable, practical actions to build a sustainable, highly trained medical workforce. The NMWS aims to rebalance the supply and distribution of the medical workforce, including improving the geographic distribution of the medical workforce and increasing generalist capability of the medical workforce, shifting the balance away from highly specialised medical practitioners. Implementation is underway with governments and sector stakeholders to facilitate successful delivery of the NMWS.

The Australian Government established the Medical Workforce Advisory Collaboration (MWAC) in 2024. The MWAC's role is to advise Commonwealth, state and territory health ministers, through the Health Workforce Taskforce, on medical workforce priorities including supply and demand and distribution. The MWAC oversees the ongoing implementation and evaluation of the National Medical Workforce Strategy 2021–2031.

The Department of Health and Aged Care is leading work to implement a range of actions to forecast future supply needs in all medical specialties. Part of this work will occur through improved data collection, sharing and analysis for medical workforce planning, reforming medical training and accreditation which includes encouraging junior doctors to take up specialty training in areas of need, and improving the professional and geographic distribution of the medical workforce.

Recommendation 29

The Committee recommends that the Australian Government, in partnership with state and territory governments and the higher education sector, review the emerging educational and workforce skill needs in relation to precision oncology, genomics, molecular curation and theranostics.

The Australian Government **supports in-principle** this recommendation.

The Government recognises that there are emerging educational and workforce skill needs relating to ongoing advancements in genomics, molecular curation and theranostics in cancer care.

In response to the Australian Universities Accord, the Government has committed to establish an Australian Tertiary Education Commission (ATEC) and to introduce a new Managed Growth Funding system. The ATEC will play a key role in ensuring our national skills needs are met, informed by analysis from Jobs and Skills Australia. It is proposed that the ATEC's function would include a potential role in implementing a new Managed Growth Funding System, which will support the long-term growth in enrolments to reach the Government's attainment targets as well as meet community expectations and industry skills needs.

The Commonwealth is leading a review and update of the National Health Genomics Policy Framework in collaboration with states and territories. The review and update will provide opportunity to identify intergovernmental agreed actions in relation to genomics workforce capability and capacity.

Genomics Australia will undertake activities that support the national objectives articulated in the Framework and Implementation Plan.

Cancer Australia has developed a National Framework for Genomics in Cancer Control as one of the Australian Cancer Plan's five-year actions under the strategic objective Maximising Cancer Prevention and Early Detection. The Framework will span the care continuum including workforce, personalised prevention, risk-stratified screening, diagnosis and treatment, supportive care, and foundations for an agile system specific to cancer care (models of care, research and data, quality and safety and funding considerations).

The Government will explore opportunities to work with states and territories to review the emerging educational and workforce skill needs in relation to precision oncology, genomics, molecular curation and theranostics. A key focus of this work will be how to provide complex information to a range of generalist health professionals on a just in time basis through digital and AI driven tools, to assist with patient diagnosis and management. This will become an increasingly important education strategy, particularly if we are to achieve the goal of genomics becoming embedded in the health system. We will not be able to limit the use of these skills to specially trained health workers, or specific new health workforces.

Recommendation 30

The Committee recommends that state and territory governments provide sustained funding and participation incentives for staffing positions and training opportunities for medical professionals and researchers interested in specialising in rare and less common cancers, including neuroendocrine cancers.

The Australian Government **notes** this recommendation as this is the responsibility of state and territory governments.

The Government has written to the state and territory health ministers seeking their consideration and action on this recommendation and the Department of Health and Aged Care will engage with health representatives from the states and territories through the Cancer and Population Screening (CAPS) Committee.

Recommendation 31

The Committee recommends that the Australian Government continue to engage with and support Aboriginal Community Controlled Health Organisations to ensure the ongoing and expanded delivery of culturally safe and appropriate health and supportive care for First Nations people.

The Australian Government **supports** this recommendation.

The Government is committed to ensuring First Nations people have access to culturally safe and appropriate health and supportive care and is funding a number of activities to achieve this.

In October 2023, a dedicated Aboriginal and Torres Strait Islander Cancer Plan (Plan) was launched. The Plan was developed and owned by the National Aboriginal Community Controlled Health Organisation (NACCHO) and funded by the Government. The Plan provides a comprehensive footprint for cancer reform.

The Government provided $197.9 million to NACCHO to support the Aboriginal Community Controlled Health Organisation (ACCHO) sector to respond to cancer inequities and improve cancer outcomes for First Nations people across the cancer care journey. Funding will deliver practical programs in prevention and screening, treatment and navigation, with a focus on remote and outer regional locations. This will enable First Nations people to exercise choice and receive holistic care and support within their communities and will support the implementation of the Aboriginal and Torres Strait Islander Cancer Plan. An additional $12.5 million was provided to NACCHO for the co-design of the National Lung Cancer Screening Program with First Nations Australians and ACCHO partnerships.

In addition, the Government has established a new grant program through Cancer Australia to enhance the delivery of culturally safe and accessible care for Aboriginal and Torres Strait Islander people receiving services in mainstream health services, in partnership with local ACCHOs. The Partnerships for culturally safe cancer care grant program opened in July 2024, providing up to $19.9 million over the next three years.

This was part of the $38.6 million provided to Cancer Australia through the 2023-24 Improving First Nations Cancer Outcomes budget measure to ensure mainstream health services are culturally safe and accessible for Aboriginal and Torres Strait Islander people. Other funded activities included:

- The First Nations Cancer Scholarships program ($5.9 million over 2023-27), which provides financial, academic and wellbeing support to Aboriginal and Torres Strait Islander postgraduate students in cancer-related fields.
- The Partnerships for Cancer Research grants program ($12.3 million over 2023-27).
- A Refresh of the Optimal Care Pathway for Aboriginal and Torres Strait Islander people with cancer ($0.2 million over 2023-24).

The Government is committed to continuing to work closely with NACCHO on improving First Nations cancer outcomes.

Recommendation 32

The Committee recommends that the Australian Government, in collaboration with Aboriginal Community Controlled Health Organisations, develop initiatives to increase participation rates of First Nations people in cancer screening, research and clinical trials.

The Australian Government **supports** this recommendation.

The Government is committed to increase the participation of First Nations peoples in cancer screening, research and clinical trials in line with the Aboriginal and Torres Strait Islander Cancer Plan and funds a number of activities to achieve this. This includes $12.5 million to the National Aboriginal Community Controlled Health Organisation (NACCHO) to lead the co-design of the National Lung Cancer Screening Program. The Department of Health and Aged Care and Cancer Australia are working in partnership with NACCHO to co-design and implement the Program to ensure it is culturally safe and accessible for First Nations people.

Additionally, the Government has provided $12.7 million to NACCHO to work with the community-controlled sector to improve health care access for First Nations peoples, including point-of-care cervical screening testing. The Government also provided $5.9 million to the Australian Centre for the Prevention of Cervical Cancer for point of care cervical screening testing for First Nations women and people with a cervix.

The Government has funded a $10.2 million national cervical screening campaign to be delivered in 2024-25. The primary target audiences for this campaign are First Nations and multicultural women and people with a cervix. As part of this campaign, NACCHO has been contracted and funded $500,000 to provide advice and expertise on the messaging in the campaign, as well as undertake community engagement and localised grants for smaller community organisations. NACCHO will also work directly with ACCHOs and AMHS to engage healthcare workers on the campaign and cervical screening self-collection.

The BreastScreen Australia (BSA) National Policy and Funding Review will develop evidence-based recommendations to improve the BSA program, including increasing First Nations' participation in breast cancer screening. A final report and the recommendations are expected by early 2025.

The 2024-26 Australian Medical Research and Innovation Priorities has identified Aboriginal and Torres Strait Islander health as a priority area. As a result, many Medical Research Future Fund (MRFF) grant opportunities include funding streams specifically targeted to address issues related to Aboriginal and Torres Strait Islander health.

In particular, the MRFF's Indigenous Health Research Fund is investing $160 million over 11 years in Aboriginal and Torres Strait Islander-led research to tackle health issues facing Aboriginal and Torres Strait Islander people.

The MRFF has allocated $150 million over 10 years for the Reducing Health Inequities Mission, from 2027-28. This Mission will fund research to address inequities in health outcomes by improving access to quality health services by priority populations, which may include Aboriginal and Torres Strait Islander people.

The National Health and Medical Research Council (NHMRC) invested $10 million to fund a National Network for Aboriginal and Torres Strait Islander health researchers as part of responding to NHMRC's Road Map 3: A strategic framework for improving Aboriginal and Torres Strait Islander health through research. The National Network was established in December 2020 and is funded over 5 years. It aims to increase the number and capabilities of Aboriginal and Torres Strait Islander health researchers.

The NHMRC priorities for the current triennium (1 July 2021–30 June 2024) include improving the health of Aboriginal and Torres Strait Islander people through research that addresses health inequities. An associated activity with this priority is ensuring that at least 5% of NHMRC funding is directed towards research focussed on Indigenous health. This priority will be retained for the next triennium.

Recommendation 33

The Committee recommends that the Australian Government partner with organisations representing culturally and linguistically diverse communities to develop initiatives to increase participation rates in cancer screening, research, and clinical trials.

The Australian Government **supports** this recommendation.

The Government is committed to increasing participation in cancer screening, research and clinical trials for culturally and linguistically diverse (CALD) communities and funds a number of activities to achieve this. The March 2022-23 Budget committed $10.6 million (2022-23 to 2023-24) to support the Enhanced Communications for CALD Communities – Prevention and Management of Chronic Conditions Campaign measure, a targeted initiative delivering on the National Preventive Health Strategy 2021-2030.

A community-led campaign was co-designed with the Department of Health and Aged Care's Culturally and Linguistically Diverse Communities (CALD) Health Advisory Group and the Preventive Health Communications and Engagement Working Group. The campaign focused on increasing uptake of bowel, breast and cervical screening among multicultural communities where data shows rates are lower than the general population. Campaign activities were delivered nationally through four peak multicultural organisations from February 2024 to October 2024, using a range of approaches that included education sessions, digital and traditional media. Campaign activities are being evaluated to provide evidence for an informed, tailored public health communications strategy for multicultural communities.

The 2024-26 Australian Medical Research and Innovation Priorities has identified individuals from culturally and linguistically diverse communities as a priority population. As a result, many Medical Research Future Fund (MRFF) grant opportunities include funding streams specifically targeted to improving the health and wellbeing of individuals from culturally and linguistically diverse communities. Further, applicants must articulate in their project plans how the views and preferences of people from culturally and linguistically diverse communities are addressed in the design and conduct of their research.

The MRFF has allocated $150 million over 10 years, from 2027-28 for the Reducing Health Inequities Mission. This Mission will fund research to address inequities in health outcomes by improving access to quality health services by priority populations, which may include people of culturally and linguistically diverse backgrounds.

The National Health and Medical Research Council (NHMRC) offers partnering opportunities to individuals, philanthropic trusts and foundations, government agencies and other funders to effectively and efficiently direct funds by drawing on NHMRC's expertise and services. The research topics for these partnerships is dependent on the interests and objectives of the partner.

Recommendation 34

The Committee recommends that the Australian Government ensure continued funding for rare and less common cancer projects to reduce existing research and clinical trial disparities.

The Australian Government **supports** this recommendation.

Under the Medical Research Future Fund (MRFF), the Government has committed $750 million over 10 years from 2024-25 under the Clinical Trials Activity Initiative to increase clinical trial activity in Australia. Under this Initiative, a priority area for funding is clinical trials research that investigates new drugs, devices or treatments for rare cancers/diseases or for areas of unmet medical need. Additionally, the MRFF will provide $150 million over 10 years, for the Low Survival Cancers Mission into research to improve care and health outcomes for people with cancer with a survival rate of less than 50%, many of which are rare and less common cancers, starting from 2027-28.

Between 2018 and 2022, National Health and Medical Research Council (NHMRC) committed approximately $221.6 million for 186 new research grants relevant to rare and/or less common cancers. This equates to approximately 5.0% of total NHMRC commitments across the same time period.

The Australian Government has announced a further $150.1 million from 2025-26 for the continuation of key precision oncology programs, including the ZERO Childhood Cancer Program, The Precision Oncology Platform Enabling Clinical Trials (PrOSPeCT) Program, and the Australian Rare Cancers Portal (ARC Portal).

Recommendation 35

The Committee recommends that the Australian Government fund biobanking initiatives to ensure the availability of quality cancer samples for research.

The Australian Government **supports in-principle** this recommendation.

The Government recognises the important role biobanks play in supporting cancer research. Under the Medical Research Future Fund (MRFF), the Government has committed $600 million over 10 years from 2024–25 under the National Critical Research and Infrastructure Initiative for infrastructure that will be used to conduct world-class health and medical research. This includes funding for biobanks for development and/or expansion of biobanks.

Additionally, under the Research Data Infrastructure Initiative the MRFF will invest $100 million over 10 years from 2024-25 to support the creation or extension of national research data infrastructure including a focus on biobanks.

Around $8.1 million has been allocated to the Commonwealth Scientific and Industrial Research Organisation (CSIRO) for establishment of the Australian Health Biobank (AHB) including the collection and storage of samples.

Additionally, the National Health and Medical Research Council (NHMRC) Direct Research Guidelines allow for NHMRC grant funds to be used to access biospecimen and data collections, and to prospectively support new biobanking initiatives.

Recommendation 36

The Committee recommends that the Australian Government explore options to provide incentives to expand genomic research in Australia.

The Australian Government **supports** this recommendation.

The Government recognises the potential for genomic research to improve outcomes for people with rare and less common cancers. The Medical Research Future Fund's (MRFF) Genomics Health Futures Mission is investing $500.1 million in genomic research over 10 years from 2018-19 to 2027-28.

The MRFF also provided $150 million over 10 years, for the Low Survival Cancers Mission in the 2024-25 Budget. Starting from 2027-28, the Low Survival Cancers Mission invests in research to improve care and health outcomes for people with cancer with a survival rate of less than 50%, many of which are rare and less common cancers.

Recommendation 37

The Committee recommends that the Australian Government consider new mechanisms to encourage greater private sector investment in rare and less common cancer related research and clinical trial sponsorship in Australia.

The Government **supports in-principle** this recommendation.

The Government recognises the importance of research and clinical trials in improving outcomes for people with rare and less common cancers. The Government, through the Department of Industry, Science and Resources has previously invested $61.2 million towards Omico's Precision Oncology Screening Platform enabling Clinical Trials (PrOSPeCT).

On 6 March 2025, the Government announced a further $30.8 million across two years from 2025-26 for the continuation of this program, which is dual funded with the private sector. PrOSPeCT provides free genomic profiling to Australians with advanced or incurable cancers to match them with Australian clinical trials for new targeted therapies.

The Government will consider additional opportunities to encourage greater private sector investment.

Recommendation 38

The Committee recommends that the Australian Government review its evidentiary standards specifically for rare and less common cancer clinical trials to consider accepting real-world evidence and greater uncertainty in data where appropriate.

The Australian Government **supports in-principle** this recommendation.

The Government has established an Implementation Advisory Group (IAG) to guide health technology assessment reforms. The IAG is considering the recommendations from the Health Technology Assessment Policy and Methods Review. This includes recommendations to enhance real-world data and real-world evidence for HTA.

Recommendation 39

The Committee recommends that the Australian Government ensure the timely delivery of the national cancer data framework and minimum dataset, as per the timeframes set out in the Australian Cancer Plan.

The Australian Government **supports** this recommendation.

Cancer Australia is developing the National Cancer Data Framework and considering a minimum cancer dataset in partnership with the Australian Institute of Health and Welfare and Cancer Council Australia, consistent with the timeframes set out in the Australian Cancer Plan. The Framework and dataset will address gaps in a consistent way, including stage at diagnosis, ensuring accessible and timely data for patients, clinicians and researchers.

Recommendation 40

The Committee recommends that the Australian Government, in consultation with the cancer control sector, address the following key data-related issues in its delivery of the national cancer data framework and minimum dataset, under the Australian Cancer Plan:

- ensure that data is collected and reported in a way that includes information on both tumour location and body part, as well as molecular level information on cancer type and subtype;
- ensure that information on the stage of cancer at diagnosis is consistently captured;
- where appropriate, ensure that researchers and academics have access to such data in an accessible and timely way; and
- ensure that patient privacy and consent is upheld throughout this work and in any future reforms.

The Australian Government **supports in-principle** this recommendation.

The National Cancer Data Framework is intended to be whole of sector strategic approach to improving cancer data. The Framework is being developed in consultation with the cancer control sector and will consider the key data-related issues identified by the committee. The Framework and dataset will uphold privacy and consent principles and align with the Closing the Gap Priority Reform Four to be addressed by the Indigenous Data Sovereignty principles. The Government will explore the feasibility of collecting molecular level information in line with the Framework once developed.

The Government has also provided $1.5 million in funding to establish the Australian Cancer Data Alliance and boost the capability of jurisdictional population-based cancer registries to collect cancer stage and recurrence data. The Improving stage at diagnosis and metastatic cancer data project will facilitate the collation, standardisation and publication of stage at diagnosis and metastatic cancer data, including the development of a national minimum dataset, by supporting jurisdictional population-based cancer registries.

Additionally, the Government is undertaking broader work to improve data sharing. The Intergovernmental Agreement on Data Sharing commits all jurisdictions to share public sector data as a default position, where it can be done securely, safely, lawfully and ethically. The agreement came into effect in July 2021, and sets out agreed principles for data sharing.

The National Clinical Quality Registry and Virtual Registry Strategy 2020-2030 seeks to build best practice capacity and capability across the clinical quality register (CQR) sector, and gradually integrate CQR data with Australia’s healthcare datasets and infrastructure.

Recommendation 41

The Committee recommends that any existing or future reforms to health and cancer data must prioritise and align with the National Agreement on Closing the Gap Priority Reform Four to ensure:

- commitment to the best practice collection, handling, and reporting of Aboriginal and Torres Strait Islander data; and
- that such information and data is available to Aboriginal and Torres Strait Islander people in a timely and accessible way.

The Australian Government **supports in-principle** this recommendation.

The development of the National Cancer Data Framework will be in line with principles of the National Agreement of Closing the Gap Priority Reform Four to improve and share access to data and information to enable Aboriginal and Torres Strait Islander communities make informed decisions. Cancer Australia commissioned Indigenous-led consultations which included two roundtables in May and July 2024 and a series of one-on-one interviews. The consultations have ensured Indigenous Data Sovereignty principles are embedded into the Data Framework and the key data gaps impacting improvements to Aboriginal and Torres Strait Islander cancer control are captured.

In May 2024, The National Indigenous Australians Agency (NIAA) released the Framework for Governance of Indigenous Data. The Framework provides guidance to the APS in improving governance practices for data related to Aboriginal and Torres Strait Islander people, ensuring that Aboriginal and Torres Strait have an equal position at the decision-making table on matters affecting them.

Cancer Australia has commissioned the National Centre for Aboriginal and Torres Strait Islander Wellbeing at the Australian National University to undertake the Kulay Kalingka Study. This study is Aboriginal and Torres Strait Islander designed and led and will investigate Aboriginal and Torres Strait Islander people’s understanding of cancer, participation in health promotion and cancer screening programs, exposure to risk factors, and patient and carer experiences of cancer, including cancer treatment and participation in clinical trials. The Kulay Kalingka study will collect data to report on indicators identified on the National Cancer Control Indicators website that currently have no data.

Additionally, $8.1 million over four years will be invested for timely access to accurate data on cervical cancer incidence, treatment and mortality to better target elimination efforts and enable reporting of vaccination and screening coverage. This will include improvements in collation, handling, reporting and accessibility of Aboriginal and Torres Strait Islander peoples' data in the National Cervical Screening Register.

Acronyms

ACCHO – Aboriginal Community Controlled Health Organisation

ACNNP – Australian Cancer Nursing and Navigation Program

ACP – Australian Cancer Plan

AHB – Australian Health Biobank

ATEC – Australian Tertiary Education Commission

BSA – BreastScreen Australia

CALD – Culturally and Linguistically Diverse

CAPS Committee – Cancer and Population Screening Committee

CQR- Clinical Quality Register

CSIRO – Commonwealth Scientific and Industrial Organisation

CT – Computed Tomography

CTG – Clinical Trials Group

DNA – Deoxyribonucleic Acid

EAG – Expert Advisory Group

HTA – Health Technology Assessment

MBS – Medicare Benefits Schedule

MRFF – Medical Research Futures Fund

MRI – Magnetic Resonance Imaging

MSAC – Medical Services Advisory Committee

MTOP – Medical Treatment Overseas Program

NACCHO – National Aboriginal Community Controlled Health Organisation

NDIS – National Disability Insurance Scheme

NGO – Non-government Organisation

NHLS – National Health Literacy StrategyNHMRC – National Health and Medical Research Council

NHRA – National Health Reform Agreement

NMWS – National Medical Workforce Strategy

NPCP – National Palliative Care Projects

OCP – Optimal Care Pathway

PBS – Pharmaceutical Benefits Scheme

PET – Positron Emission Tomography

PoCoG – Psycho-oncology Co-operative Research Group

PL – Prescribed List

PrOSPeCT – Precision Oncology Screening Platform enabling Clinical Trials

SCCT – Support for Cancer Clinical Trials Program

TCC – Temporary Cessation of Care

ZERO – Zero Childhood Cancer Program