Pre-Budget Submission

2025-26

January 2025

Executive Summary

While Australia has made significant progress in cancer care and outcomes, rare and less common cancers represent a major yet under-addressed health challenge. They account for a **quarter of cancer diagnoses and a third of cancer deaths**. Despite advances in treatment, survival rates for these cancers lag significantly behind more common cancers. People with a rare cancer diagnosis face **delayed diagnoses, limited treatment options, inequitable access to care, and a fragmented health system ill-equipped to support their needs**.

To transform survival outcomes and experience for people with rare and less common cancers, the Government should invest in three critical areas:

1. Equitable and affordable access to genomic testing and precision oncology – by expanding subsidised genomic testing, committing to fund the Zero Childhood Cancer National Precision Medicine Program, and establishment of a Precision Oncology Health System Incubator to increase patient access and rapidly generate data.

2. Equitable and affordable access to cancer treatments - by increasing Pharmaceutical Benefits Advisory Committee (PBAC) resources, funding the implementation of the Health Technology Assessment (HTA) Review recommendations, and conducting a comprehensive audit of diagnostic imaging availability and funding for rare and less common cancers.

3. Nationwide access to rare cancer specialist expertise - by funding the Australian Rare Cancers (ARC) Portal to connect patients and clinicians with expert guidance, ensuring timely, equitable and accurate treatment guidance.

These strategic investments will remove systemic barriers, reduce inequities, and deliver on key recommendations from the Senate Inquiry into *Equitable access to diagnosis and treatment for individuals with rare and less common cancers, including neuroendocrine cancer*.

Beyond improving survival, investing in improving the quality of life for people with incurable cancers can generate **$3.17 billion in social value**.[1] More importantly, these initiatives will ensure that no one is left behind simply because their cancer is rare.

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[1] Rare Cancers Australia. Counting the cost: The true value of investing in cancer treatment, https://rcararecancers.blob.core.windows.net/assets/contentpage_htmlcontent/RCA4279%20Counting%20the%20Cost%20Report-final.pdf (2022)

About Rare Cancers Australia (RCA)

At Rare Cancers Australia (RCA), our mission is to improve the lives and health outcomes of people affected by rare, less common and complex cancers. We redefine cancer support, so no one is left behind or feels alone.

We go beyond traditional cancer support, offering unparalleled personalised assistance to those facing some of the most challenging diagnoses. In 2024 along, we provided tailored support to over 1,200 new patients, while continuing our support for hundreds more. Our comprehensive support model spans emotional, practical, and financial assistance, helping people access the latest treatments, navigate the healthcare system, and connect with others so they feel less alone.

Our commitment extends beyond individual support to driving systemic change in access, affordability, and quality of care. We work tirelessly to ensure better outcomes for patients today and tomorrow through evidence-based advocacy, policy reform, and stakeholder engagement.

In 2024, we launched an ambitious '*Rare Cancer Moonshot: Equity for Everyone with Cancer'* to transform cancer outcomes in Australia. Our vision is that more than 90% of people diagnosed with cancer will survive at least five years after diagnosis, regardless of their cancer type, and there will be true equity of experience for everyone with cancer by 2035. This bold vision drives our work to address the systemic barriers and inequities that mean people with rare and less common cancers face poorer survival and experience outcomes and a higher financial cost than those with more common cancers.

Through strategic partnerships with government, healthcare providers, researchers, and industry, we are committed to creating a future where everyone, regardless of the rarity of their diagnosis, is given the best possible chance to live beyond cancer.

Background

Senate Inquiry into equitable access to diagnosis and treatment for rare and less common cancers in Australia, including neuroendocrine cancer (Senate Inquiry)

In May 2024, the Senate Community Affairs References Committee released a landmark report on equitable access to diagnosis and treatment for rare and less common cancers in Australia, including neuroendocrine cancer.

The report was informed by evidence from 149 submissions and five public hearings held across the country. Contributors included medical professionals, researchers, advocacy organisations, and individuals with lived experience of rare and less common cancers. It outlined 41 specific recommendations aimed at improving patient outcomes through enhanced access to diagnosis, treatment, support services, and research opportunities.

The Senate Inquiry confirmed many of the issues RCA has shone a light on over the past 13 years. While cancer outcomes in Australia are among the best globally, there are significant disparities between cancer types and those affected by rare and less common cancers face poorer outcomes and experience. The report called for systemic changes to address these inequities and ensure better diagnosis, treatment, care for everyone with cancer in Australia.

'Accelerating Access to the Best Medicines for Australians Now and into the Future' - A review of Australia's Health Technology Assessment policies and methods for the Australian Government (the HTA Review)

In September 2024, the Australian Department of Health and Aged Care released a report examining Australia's approach to HTA to determine what works well and what needs to improve to meet future challenges. The aim was to ensure Australians can access effective, safe and affordable health technologies in an equitable and timely way.

The HTA Review was a key commitment in the 2022–2027 Strategic Agreement between the Commonwealth Government and Medicines Australia. Led by a Reference Committee appointed by the Minister for Health and Aged Care, the Review spanned October 2022 to May 2024 and proposed 50 recommendations to improve access, equity, and the capacity to assess complex and emerging health technologies.

RCA welcomed the publication of the Review recommendations, in particular the focus on developing ways to assess 'pan-tumour' and cell and gene therapies, greater use of real-world evidence and social value measures, increasing consumer involvement, and introducing bridging funding.

The Case for Investment

Cancer remains Australia's leading cause of death, with rare and less common cancers representing a disproportionate one third of cancer deaths each year. In 2024 alone, more than 16,000 Australians are expected to have died from a rare or less common cancer[2] - deaths that might have been prevented through strategic investment in research, equitable access to new treatments, and networked highly specialised care.

A Collective Public Health Challenge

'Rare cancers' affect fewer than six in 100,000 people and include cancers of the gallbladder, tongue, testicle, eye, bone, and many others. **'Less common cancers'** affect between six and 12 in 100,000 people, such as cancers of the liver, brain, stomach, ovary, and oesophagus.

While each rare cancer affects relatively few people, collectively rare and less common cancers have an enormous impact. More than 40,000 people will receive a rare or less common cancer diagnosis in Australia this year – one quarter of all cancers diagnosed. A diagnosis that will change their life, and their family's life, as they navigate a path of limited information, sparse treatment options, uncertainty and isolation.

Despite improvements in overall cancer survival rates, there are stark inequities in access, experience and outcomes for people with rare and less common cancers in Australia:

- An average **5-year survival rate of only 45% for less common cancers and 62% for rare cancers**, compared with 77% for common cancers. While survival rates for common cancers have increased by 22 percentage points over the past two decades, rare and less common cancers have seen smaller gains of only 13 percentage points and19 percentage points, respectively.
- Two patients receiving the same therapy targeting the same genetic biomarker face **drastically different costs** - $31.60 for one and up to $10,000 for the other, per treatment cycle.
- Australians wait an average of **466 days** from medicine registration to subsidy,[3] and many will never receive subsidy due to the rarity of their cancer type.
- **One in three cancer patients** who contact Rare Cancers Australia's cancer navigators report significant financial stress due to their diagnosis in their first call.

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[2] Australian Institute of Health and Welfare. *Cancer data in Australia*. 2024 17/12/2024]; Available from: https://www.aihw.gov.au/reports/cancer/cancer-data-in-australia/contents/about.

[3] Medicines Australia. *Medicines Matter - Australia's Access to Medicines 2016-2021*. 2022 12/06/2024]; Available from: https://www.medicinesaustralia.com.au/wp-content/uploads/sites/65/2023/04/Medicines-Matter-2022-FINAL.pdf

- **Geographic inequities** further exacerbate access issues, with patients in rural and remote areas disproportionately affected.[4] 5-year observed survival rates are around 12% lower, and mortality rates over 40% higher, for people in the most disadvantaged areas compared with those in the least disadvantaged areas.[5]

Why Now? A Transformative Moment in Cancer Care

We are at a pivotal moment in cancer care. Cancer is fundamentally a genetic disease, driven by alterations in the DNA that regulate cell growth, division, and survival. A rapid expansion in our understanding of this has ushered in the era of **precision oncology**, where cancers can be diagnosed more accurately, and treatment strategies can be tailored to the unique genomic profile of an individual's cancer.

The **Zero Childhood Cancer Program** has demonstrated that precision-guided treatment doubles two-year progression-free survival in children compared to standard approaches.[6] Similarly, **Omico** has shown that genomic-driven care significantly improves survival and treatment outcomes in adults.[7] These findings underscore the **transformational impact of precision medicine** and reinforce the urgency of integrating it into mainstream cancer care.

Australia must continue to lead this shift in cancer care, offering a future where patients benefit from more accurate diagnoses, highly effective treatments, fewer side effects, and reduced exposure to unnecessary therapies.

Beyond improving patient outcomes, precision oncology holds the potential to alleviate some of the economic burden of cancer by reducing productivity losses, optimising healthcare resources, and lowering the costs associated with ineffective treatments.

Advances in genomic research and the technology driving precision oncology are poised to transform the Australian economy. Currently, 91% of all new cancer treatments are developed with molecular tumour profiling at their core.[8] Strategic investment in innovative research and development not only promises to enhance patient outcomes but also strengthens Australia's position as a global leader in cutting-edge trials and therapies, delivering significant economic and health benefits.

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[4] Rana, R.H., et al., *Predictors of health care use in Australian cancer patients.* Cancer Manag Res, 2019. **11**: p. 6941-6957.
[5] Australian Institute of Health and Welfare (AIHW) – Cancer report, Release Date 02 Jul 2024; available from: https://www.aihw.gov.au/reports/australias-health/cancer
[6] Zero Childhood Cancers. *World-first study into precision medicine for high-risk childhood cancer yields extraordinary results.* Published 07 Jun 2024
Available from: https://www.zerochildhoodcancer.org.au/blog/world-first-study-into-precision-medicine-for-high-risk-childhood-cancer-yields-extraordinary-results
[7] *Outsmarting cancer, together*. Omico Annual Report 2022. Available from https://www.omico.com.au/wp-content/uploads/2022/10/Omico_Annual-Report_2022_final_small.pdf
[8] Global Oncology Trends 2023: Outlook to 2027 IQVIA https://www.iqvia.com/insights/the-iqvia-institute/reports-and-publications/reports/global-oncology-trends-2023

To deliver equitable, sustainable, and world-class health outcomes for all Australians affected by cancer, we must ensure that precision oncology technologies are not only developed but also effectively integrated into our healthcare system.

Economic Impact

Investment in new technologies, therapies, and services to extend the length and quality of life of people with incurable cancers can return $3.17 billion of social value.[9] This represents an opportunity to not only save lives but create significant economic and social benefits for Australia.

This situation demands urgent attention and strategic investment. Without targeted intervention, thousands of Australians will continue to face poorer outcomes simply because their cancer is rare. The recommendations outlined in this submission present three investment priorities to address these inequities and transform outcomes for all Australians affected by rare and less common cancers.

[9] Rare Cancers Australia. Counting the cost: The true value of investing in cancer treatment, https://rcararecancers.blob.core.windows.net/assets/contentpage_htmlcontent/RCA4279%20Counting%20the%20Cost%20Report-final.pdf (2022)

Priority 1: Expand equitable and affordable access to genomic testing and precision oncology

Subsidise genomic testing for people with rare, less common and advanced cancers.

We are at a tipping point in cancer care. Australia has the opportunity to transform cancer outcomes, shifting from generalised, 'one size fits all' treatments to highly personalised, effective therapies that improve outcomes and minimise harm, especially for rare or less common cancers.

Comprehensive genomic profiling (CGP) is already being used in Australia and internationally, with rapidly growing evidence for its use and effectiveness. Australia has two major translational research programs using CGP that can be leveraged to accelerate its broader implementation: the Zero Childhood Cancer Program (ZERO) and Omico's Cancer Screening Program. We now need to prepare our health systems to offer and incorporate genomic testing as standard of care, starting with people with rare, less common and advanced cancers, so that patients benefit from existing and future genomic discoveries and every person is given the best chance to live beyond their cancer.

"Genomics can identify a drug target where the drug will work no matter what the label of the cancer. It means it doesn't matter if the cancer is rare anymore... And if you can apply genomics across all rare cancers, all of a sudden it opens up a whole world of possibilities for cancer patients" – *Professor David Thomas, Chief Science and Strategy Officer at Omico.*

Currently, access to genomic testing is unfair – some patients can access a research program while others are often forced to self-fund tests, creating significant barriers for those who cannot afford them and fragmentation in a person's care if accessing private and international testing options.

The establishment of Genomics Australia in June 2025 is a pivotal opportunity to address inequities in access to genomic testing and fast track widespread adoption of CGP, as is happening in other countries such as England, Sweden, Finland and Germany. Its leadership and funding will be critical in preparing our health systems for this new approach to diagnosis and care, ensuring the infrastructure, guidelines, and training are in place to integrate genomic testing into standard care. Its national leadership must ensure consistent access and quality across all states and territories, preventing a postcode lottery.

Beyond that, the Government should invest in two other critical enablers in 2025/26:

1. The creation of a National Genomic Data Registry for Cancer, as a secure way to collect, store and access clinical genomic data to inform care, service design and research. A national, centralised registry would advance the integration of genomic data into clinical care by providing insights that drive improvements in treatment and outcomes. It would also facilitate and speed up research and incentivise a higher standard of genomic data recording and reporting across the country, which is currently patchy with no national standard.

2. The introduction of subsidised comprehensive genomic profiling for everyone diagnosed with a rare, less common or advanced cancer, through the Medicare Benefits Scheme.

Fund the Zero Childhood Cancer National Precision Medicine Program for a further four years to continue vital research and transition the approach into standard clinical practice.

Since its inception in 2017, the Zero Childhood Cancer National Precision Medicine Program (ZERO) has revolutionised cancer treatment and care for children with the most challenging cancer diagnoses, showcasing the life-changing potential of precision medicine in paediatric oncology. Led by the Children's Cancer Institute and the Kids Cancer Centre at Sydney Children's Hospital, with funding from the Federal Government and the Minderoo Foundation, this program represents a beacon of hope for families facing devastating diagnoses.

"Without the Zero Childhood Cancer Program, my daughter would have continued the pattern of 'recovery' and relapse with tragic results. She was being treated for the most common type of Leukemia, and responding well, but it turned out she had a very rare sub-type and needed a different treatment approach. Everyone was shocked by the genomic test result and it saved her life." – *Laura, mother of Carys, in remission from Ph-like acute lymphoblastic leukemia.*

ZERO has already enrolled over 2,000 participants, and as of November 2023, it is open to every child diagnosed with cancer in Australia. Using advanced somatic and germline genomic profiling, ZERO identifies specific cancer drivers and delivers personalised treatment recommendations, dramatically improving clinical outcomes. For children receiving precision-guided treatment (PGT), the two-year progression-free survival rate is double that of those without it—and five times higher than for children on unguided novel treatments.

The Children's Cancer Institute and Kids Cancer Centre have submitted a funding request to sustain ZERO over the next four years and prepare for its ground-breaking approach to be embedded in standard paediatric cancer pathways. This must be a budget priority to ensure every child with cancer and their family has access to the most effective treatments and the best chance of a long, healthy life. If funding ceases in June 2025, children across Australia will miss out on the world-class care they deserve. Over 140 highly specialised research and clinical staff dedicated to this program may be lost, jeopardising Australia's position as a global leader in childhood cancer research.

"Childhood cancers represent the rarest of rare. We have shown that precision medicine, employing comprehensive genomic analysis, can improve a child's chances of survival, yet we now face our biggest challenge in moving this into routine care. Every day, clinicians are using these research results to directly inform their individual patient's care. We urgently need to come together to bridge the gap between research and real-world clinical practice." – *Associate Professor*

Vanessa (Ness) Tyrrell, Program Director, Zero Childhood Cancer and Head of Theme, Clinical Translation, Children's Cancer Institute.

At Rare Cancers Australia, we see firsthand the impact this program has on families. ZERO provides hope where traditional treatments have failed, especially for children with high-risk or previously undiagnosable cancers. Providing further funding for ZERO to complete its groundbreaking research and prepare our health systems for widespread adoption of this new approach is an investment in Australia's future.

Establish a Precision Oncology Health System Incubator (PrO-HSI)

People with rare and less common cancers face significant barriers in accessing life-changing treatments. While breakthrough therapies exist, they remain out of reach due to **limited funding pathways** and **outdated evaluation models** that fail to accommodate small patient populations. As a result, many patients are often forced to crowdfund expensive medicines or miss out on potentially life-saving care.

Omico's **Precision Oncology Health System Incubator (PrO-HSI)** is designed to change this. It will establish a structured, scalable model to test and evaluate innovative cancer treatments within the Australian healthcare system. It will provide **earlier and fairer access to new medicines** by integrating genomic testing, real-world evidence, and an outcomes-based funding approach.

At the heart of the model is a "Pay for Performance" framework, where access to new treatments is linked to measurable patient outcomes. This ensures funding decisions are driven by real-world effectiveness, rather than outdated trial measures and design that often exclude rare cancers. Companies are then incentivised to bring effective new therapies into the market while collecting real-time evidence that is fit for HTA assessment.

Omico have a proven track record, delivering impressive results through its **CaSP and PrOSPeCT** programs,[10] which have improved access to genomic-led cancer care. Building on these strong foundations, **Omico has submitted a request for funding** to take the next step with PrO-HSI, ensuring more Australians with rare and less common cancers can access cutting-edge treatments without unnecessary delays.

"We are on the cusp of a new era in cancer care. It's imperative to integrate this approach as mainstream care for all Australians." – *Professor David Thomas, Chief Science and Strategy Officer at Omico.*

PrO-HSI will play a critical role in:

- **Expanding genomic testing across the healthcare system**, particularly benefiting those with rare and less common cancers—**addressing a key Senate Inquiry recommendation**.
- **Developing funding pathways for TGA-registered targeted therapies**, which have shown response rates of **up to 40% in patients with relevant biomarkers**, improving PBS access and reducing reliance on crowdfunding.

[10] *Outsmarting cancer, together*. Omico Annual Report 2022. Available from https://www.omico.com.au/wp-content/uploads/2022/10/Omico_Annual-Report_2022_final_small.pdf

- **Generating real-world evidence** on precision oncology interventions, supporting HTA processes to ensure treatments for rare cancers are evaluated based on clinical need, rather than outdated trial paradigms.
- **Reducing financial stress for patients**, ensuring equitable access to effective targeted therapies through **innovative funding models** that remove cost barriers.

PrO-HSI offers a **transformational, structured pathway** to embed precision medicine into Australia's healthcare system—**ensuring every patient, regardless of their cancer type, can access the best possible treatments and outcomes**.

Priority 2: Increase equitable and affordable access to cancer treatments

Increase Pharmaceutical Benefits Advisory Committee (PBAC) resource to ensure timely consideration and approvals of new medicines.

In 2024, the PBAC took the unprecedented step of deferring applications from the March 2025 PBAC meeting to an extraordinary July 2025 meeting and beyond, without consultation. The Committee reported unprecedented demand and resource constraints: "This is an unprecedented number and exceeds both the current capacity of the contracted HTA workforce for evaluation, and the number the PBAC can consider in one meeting."[11]

Australian patients already wait too long to access new treatments. It takes on average, **466 days** from medicine registration to subsidy[12], and many patients will never receive subsidy due to the rarity of their cancer type. It is absolutely critical that Australia's HTA system is adequately resourced to assess new medicines quickly and effectively. Last year's deferral of applications, including some for rare cancers, must not happen again.

The Government should therefore increase resource for PBAC so that it can keep pace with the volume of applications, including those that are complex and novel. This should include resource for the PBAC to consider and contribute to implementation of the HTA Review recommendations, guided by the HTA Implementation Group, including urgent development of a framework for assessing 'pan-tumour' or multi cancer applications.

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[11] Royal Australian College of General Practitioners (RACGP) *newsGP*. 06 Nov 2024. Available from: https://www1.racgp.org.au/newsgp/clinical/unprecedented-demand-on-pbac-forces-extra-meeting

[12] Medicines Australia. *Medicines Matter - Australia's Access to Medicines 2016-2021*. 2022 12/06/2024]; Available from: https://www.medicinesaustralia.com.au/wp-content/uploads/sites/65/2023/04/Medicines-Matter-2022-FINAL.pdf

Urgently develop a framework for assessing 'pan-tumour' therapies and fund the HTA Implementation Group to prioritise and prepare for full adoption of the HTA Review recommendations.

Every day, we support patients and their families who are navigating agonising decisions about whether and how to privately fund medicines that could extend or improve their life. Medicines that are subsidised for other patients in Australia with the same genetic bio-marker, but not for them because of their rare or less common cancer type.

RCA, patients and clinicians have advocated for a solution to this since 2017, by developing a framework for assessing 'pan-tumour' or multi-cancer applications. Pan-tumour assessments are a constructive solution to a systemic inequity that leaves rare and less common cancers patients paying eye-watering costs for, or being denied access to, medicines that could extend their years and quality of life.

Successive Government inquiries and reviews have recognised the need for this change, including Senate Inquiry recommendations 10 and 12, and the recently concluded HTA Review recommendation 38. As well as enabling faster and more equitable patient access, pan-tumour assessment could streamline some of the decision-making processes that are consuming PBAC resources and potentially offer better value through bundling.

Since PBAC first considered options for pan-tumour assessment in 2018, there has been a significant increase in our scientific understanding of cancer and targeted drug development against genetic bio-markers. Australian patients with rare and less common cancers are already missing out and this will worsen as more targeted therapies become available internationally, unless we modernise our assessment processes.

The HTA Implementation Group has received initial funding through MYEFO ($4.9 million for the current fiscal year and $400,000 for 2025/26) to prioritise recommendations and develop a government response to the HTA Review. In addition, the Government should resource an expert working group to deliver recommendation 38 of the HTA Review as the first priority of the HTA Implementation plan. Patients cannot afford to wait another year for any movement on this issue.

"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" – *Senate Inquiry (Rec 10)*

*“***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.”** – *Senate Inquiry (Rec 12)*

“Support the development of further guidance on methods for assessing tumour-agnostic therapies, genomic technologies and gene therapies.” – *HTA Review (Rec 38)*

Conduct a comprehensive audit of funding and availability of diagnostic imaging for people with rare and less common cancers.

The Senate Inquiry heard from patients, clinicians and expert groups about the additional barriers to diagnosis experiences by people with rare and less common cancers including a lack of diagnostic imaging equipment, the long distances travelled by patients for test, and the high out of pocket costs for tests that are only covered by Medicare for certain cancer types.

The Government should fund a comprehensive national audit of availability and funding of diagnostic services for people with suspected rare and less common cancers, as recommended by the Senate Inquiry recommendations 3 and 4:

"The committee was concerned to hear that cost is presenting a barrier to certain diagnostic tests and services for patients and their families. Further, it was particularly concerned that this can result in practitioners being reluctant to refer patients for scans that aren't reimbursed under Medicare, which can delay diagnoses and interfere with optimal cancer care." – *Senate Inquiry (Rec 3).*

The committee believes that the Australian Government should review these settings, to ensure that all patients with suspected cancer can receive prompt, appropriate and affordable diagnostic testing." – *Senate Inquiry (Rec 4).*

The audit should examine:

1. The availability and location of diagnostic imaging services, in particular MRI, PET and CT services, with particular consideration of the patient impact of not having diagnostic capacity within close proximity.
2. Current Medicare items for diagnostic imaging, with particular attention to MRI, CT, and PET, to identify the discrepancies between eligibility for different cancer types.
3. The impact of people paying privately for tests that are not subsidised for their cancer type, as costs incurred will not contribute to their Medicare Safety Net cap resulting in further financial penalty.
4. The financial impact of diagnostic services availability on patients, with patients facing high out-of-pocket costs up to $1,000 per scan if there is no MBS item number for the known/suspected cancer type and they need to go to a private provider. This financial burden is particularly acute for rural and regional patients who must often travel significant distances to access metropolitan-based imaging services.
5. The adequacy and appropriateness of state-based travel and accommodation subsidy schemes in supporting patients who do need to travel long distances to access the right diagnostic service.

“When an item, medication or scan does not have a Medicare code, it means you can't add it to your family Medicare Safety Net - leaving families like mine to slip through the financial Safety Net. I have faced the crossroads of funding my own treatment or choosing palliative care.” – *Anonymous patient living with gastrointestinal stromal tumour (GIST).*

This audit is a crucial and urgent first step in addressing the unacceptable barriers in access to diagnostic imaging service facing people with rare and less common cancers.

The Department of Health and Aged Care should lead this audit, working in consultation with state health departments, clinical experts, and patient advocacy groups. It should set out an action plan for targeted investment in increasing diagnostic imaging capacity across the country, based on areas of highest need, and for overhauling the Medicare items to ensure fairness and reduce unintended barriers to patients receiving the right referral and right diagnostic service at the right time.

Priority 3: Improve access to rare cancer specialist expertise nationwide

Fund the Australian Rare Cancer (ARC) Portal

Accessing the latest clinical research and evidence about rare cancers can be difficult for oncologists and other health professionals as well as patients, with so many different cancer types and sub-types and a rapid expansion in our genomic understanding of cancer and its treatment.

With centres of excellence mainly in metropolitan areas, people with rare cancers living away from major cancer centres can face significant geographic barriers. Including limited access to highly specialised advice, which can impact their treatment options, ability to access clinical trials, outcomes and experience.

"Living regionally means travelling to major cities to get treatment. Doctors were not familiar with my cancer... I have had to insist on tests that local doctors didn't think were necessary. I had to google my own cancer to find out that it was much more serious than I had been told by my GP who was not familiar with it."
– Anonymous rural NSW resident, living with dedifferentiated endometroid adeno carcinoma (DEAC), a rare, aggressive type of endometrial cancer.

The Australian Rare Cancer (ARC) Portal is an innovative digital solution to bridge this critical gap in access and expand treatment options for people with rare cancers. This comprehensive platform facilitates vital connections between treating clinicians and rare cancer specialists across Australia, equipping the patient's local treating team with the latest Australian and international research, guidelines and expert support. This means they can make evidence-based treatment decisions while continuing to care for their patient locally.

A proposal for investing in the ARC Portal over the next three years to expand patient access, continue vital rare cancer research and embed the ARC Portal in routine cancer care in Australia is currently under consideration by the Department of Health and Aged Care.

Access to the latest research and treatment information is vital for every person with a rare cancer and their specialist team, but perhaps even more critical for those living regionally and remotely who traditionally have not had the same level of access. The ARC Portal is directly addressing this gap, with 45% of enrolments from outside of major cities. By leveraging digital health infrastructure, the Portal enables knowledge sharing between metropolitan centres of excellence and regional healthcare providers, ultimately working to eliminate geography as a determinant of cancer care quality and patient outcomes.

“The ARC Portal is a lifeline in providing high level cancer care in a regional setting where there are many geographical, logistic and financial challenges. It provides an extraordinary service for not only clinicians, but also patients, bridging an equity gap for our regional and First Nations patients by providing them with access, information and new treatment options.” - *Dr Michelle Harris, gynaecological oncologist, Darwin*