rare cancers Australia

Now it's personal

Access and equity for all

Rare Cancers Australia

Rare Cancers Australia (RCA) was founded out of the fundamental principles of equity, fairness and compassion.

We exist to redefine cancer support, so no one is left behind or feels alone. Everyone is given the best possible chance to live beyond cancer.

Our vision is that every person impacted by rare cancer will be supported from every angle, from the very beginning.

We do whatever it takes to change the story of rare cancer, through improved diagnosis, limitless support and relentless advocacy.

We stand side by side with people diagnosed with cancer, and their families, with knowledge, energy and an unwavering determination to create a better world for people diagnosed with rare cancers.

Thanks

Heartfelt thanks to Sarah Benger, Jane Weber and Oliver Holmes for their tireless work on this report, underpinned by their passion for meaningful policy reform and desire to improve lives.

Thank you to Kathryn, Jacques, Danielle and Xavier, Celestino and Michelle for so bravely sharing your experiences for the benefit of others.

Thank you also to Toni Middendorf and the team at patterntwo for layout and design and Laura Cohalan (RCA) for editorial prowess.

Sponsors

Rare Cancers Australia would like to acknowledge the following sponsors for their financial support for the development of this publication, which is given without pre-condition or editorial input:

This report is dedicated to our Co-Founders, Kate and Richard Vines, who established Rare Cancers Australia from their own lived experience. Whilst most people who are living with a rare or less common cancer won't be motivated to start a cancer organisation, there are many thousands who have benefitted from the work of one couple who did. Kate and Richard inspire all the work we do, with their relentless energy to change the story of rare.

Additionally, we dedicate this report to every person who responded to the Cancer Lived Experience Survey. We will honour your experiences.

To everyone who trusts us to support you in your darkest times, thank you, it is a great honour we take very seriously.

Contents

Acknowledgement of Country

Rare Cancers Australia acknowledges the Aboriginal and Torres Strait Islander peoples as the Traditional Custodians of the lands and waters across Australia. We pay our deepest respects to Elders past and present, and to all Aboriginal and Torres Strait Islander peoples.

We honour the strength, knowledge, and unbroken connection to Country, culture, and community that continue to thrive despite centuries of systemic injustice.

We recognise that Aboriginal and Torres Strait Islander peoples hold a holistic understanding of health—encompassing physical, emotional, cultural, and spiritual wellbeing—and that this must be respected and embedded in any conversation about access and equity in healthcare.

We also acknowledge the unacceptable disparities in cancer outcomes for Aboriginal and Torres Strait Islander peoples, who are more likely to be diagnosed at later stages, experience delayed access to treatment, and face systemic barriers to care. These inequities are further compounded by experiences of racism, cultural misunderstanding, and limited access to culturally safe and responsive health services.

The *Australian Cancer Plan* identifies Aboriginal and Torres Strait Islander peoples as a priority population and outlines the urgent need to address the cancer gap. Rare Cancers Australia supports this direction and is committed to working in partnership with First Nations communities, guided by the *National Agreement on Closing the Gap* and the *Aboriginal and Torres Strait Islander Cancer Plan*.

First Nations communities bring deep resilience, strong leadership, and enduring knowledge systems that offer valuable foundations for improving cancer care. We remain committed to listening, learning, and walking together toward equity in cancer care for all.

Foreword

Since Rare Cancers Australia was established in 2012, we have supported thousands of people living with rare and less common cancers. We have listened when no one else would, connected people with others who truly understand and can offer support, and helped to navigate pathways and funding models that weren't built for their needs. An experience that too often left our community feeling hopeless.

I see what happens when people fall through the cracks or are brushed aside as too difficult to treat. When care is delayed, fragmented, or simply not available. I share their highs and lows.

And now, for the first time, we can see that on a national scale. Almost 2,500 adults with cancer and carers have told us what it is really like to have cancer.

The insights are powerful. They give us a clearer view of what's going on: where the system is working well, and where it's falling short.

To every person who shared their cancer experience with us: thank you. We will ensure your voices are heard, counted and honoured.

It is one year since we launched the *Rare Cancer Moonshot*, a galvanising ambition to deliver equity of outcomes and experience for everyone with cancer in Australia. The groundswell of support and determination to create a better world for rare is inspiring. Patients, clinicians, researchers, developers, policy makers and others are working to turn the tide on rare cancers.

Truly personalised rare cancer care feels closer than ever. But there are major roadblocks still in the way. It's time to turn reviews and recommendations into action for people with rare cancers and their families. To harness the breakthroughs and progress made for some cancers and apply that same focus, determination and resource to reap the benefits for people with rare cancers, too.

The inequities in cancer care for all are not new. But the failure to act now, when we have the evidence, the momentum, and the tools to do better, is not an oversight. It's a choice.

Because when we know better, we *must* do better. For all of us, now it's personal.

Christine Cockburn
Chief Executive Officer, Rare Cancers Australia

Summary of Recommendations

1

Cancer Australia should work with partners to **deliver an ambitious *National Cancer Data Framework*** to ensure national collection and reporting of timely, accurate and consistent cancer data, including patient experiences and outcomes, molecular subtypes, stage at diagnosis and time taken to diagnosis – with rare cancers included for every indicator.

2

The Australian Government should **urgently review and increase subsidies for MRI, PET and CT services** for the diagnosis, surveillance and restaging of suspected and diagnosed rare and less common cancers.

Cancer Australia should lead **development of urgent suspected cancer referral guidelines** for identifying, managing and referring people with suspected rare or less common cancers, including safety netting.

3

The Australian and State and Territory Governments should accelerate the implementation of the ***National Framework for Genomics in Cancer Control* and the refreshed *National Health Genomics Framework*** to:

- deliver comprehensive and affordable genomic profiling as standard of care for patients with confirmed or suspected rare, less common and advanced cancers; and
- increase Australia's genomic infrastructure and capacity, including the development of a National Genomic Data Registry for Cancer, to support the standardised and optimised use and reuse of genomic data for cancer care and research.

4 The Australian Government should **urgently remove barriers to fast and fair access to treatments** for people with rare and less common cancers so that every person diagnosed has affordable access to the best treatment when they need it:

- subsidise access to treatments across multiple cancer types without the need for separate applications for each type ('pan-tumour' or 'multi-cancer' assessment)
- reduce the median time for a medicine to be listed on the Pharmaceutical Benefits Scheme (PBS) following Therapeutic Goods Administration (TGA) registration to 60 days
- identify areas of high unmet clinical need and prioritise increased access to medicines for this group through incentives and bridging funding
- strengthen consumer involvement and transparency in decision-making and significantly increase resources for the Pharmaceutical Benefits Advisory Committee (PBAC) and the Medical Services Advisory Committee (MSAC), enabling faster and more responsive assessment processes.

5 The Australian and State and Territory Governments should **increase and equalise financial support for people accessing treatment away from home**, including clinical trials, and raise reimbursement rates to match those set by the Australian Taxation Office.

6 The Australian Government and partners should ensure every person diagnosed with a rare or less common cancer has **access to tailored information and evidence-based supportive care, based on their personal needs**, through:

- continued delivery and evaluation of the Australian Cancer Nursing and Navigation Program
- sustained funding for established specialist patient support services
- a national cancer patient experience survey to measure whether needs are being met.

Now it's personal

In Australia, there is a 'cancer lottery'. Survival outcomes and experience vary based on factors that should not determine health outcomes: where a person lives, their age, their finances, and whether the cancer is readily detected or well understood.

People with rare and less common cancers feel this inequity deeply. They face delayed diagnoses, fewer treatment options, limited access to information and inconsistent support across the care continuum[1]. That leads to poorer survival outcomes.

While cancer outcomes in some parts of Australia, particularly for common cancers, are among the best in the world[2, 3], that is far from the whole story.

> **There are stark inequities. The three most common cancers, breast, prostate and melanoma, have five-year relative survival rates above 92%. Rare and less common cancers have far lower five-year survival rates with some cancers seeing no improvement in the last 20 years. Five-year survival drops as low as 8% for mesotheliomas[4].**

For those living in rural or remote parts of Australia, the barriers to cancer care are even greater, and their chance of survival lower[4].

Differences in survival and experience persist, despite overall improvements in cancer mortality rates across Australia over the past two decades, and a strong national focus on equitable cancer care through the *Australian Cancer Plan*[5].

But these improvements have largely bypassed rare cancers, revealing a systemic issue that extends beyond mere low incidence. The current Australian cancer care system, predominantly designed around common cancer pathways, is not adequately serving the unique and complex needs of rare cancer patients.

Now, through a national survey of nearly

2,500

people impacted by cancer, we can see that people with rare and less common cancers are more likely to report delays in diagnosis and unmet support needs than those with a common cancer[6].

For decades, cancer policy, funding, and system design in Australia have centred on the most common cancers. National screening programs, awareness campaigns, and early detection initiatives have overwhelmingly targeted high-incidence cancers such as breast, prostate, bowel, and skin cancers. Health technology assessment (HTA) and reimbursement processes, too, have been calibrated to favour conditions where large patient populations make trial recruitment easier, data more abundant, and cost-effectiveness thresholds more achievable.

This focus has led to real and measurable progress for some, but not all. Those gains are not shared equally. People with rare cancers deserve the same level of attention, innovation, urgency, and support as anyone else.

> **Equity in cancer care is not achieved by averages, it is achieved when no one is left behind.**

In 2024, the *Senate Standing Committee on Community Affairs Inquiry into Equitable Access to Diagnosis and Treatment for Individuals with Rare and Less Common Cancers, including Neuroendocrine Cancer* (hereafter referred to as the Senate inquiry), handed down 41 recommendations to drive meaningful reform by improving diagnosis, access to care, and patient outcomes. While a formal government response is pending at the time of writing, the findings have reinforced the urgent need for targeted action to improve equity and outcomes for people with rare cancers.

Addressing this inequity requires more than adapting existing systems; it demands a fundamentally different approach. One that moves beyond the principle of "the greatest good for the greatest number" and instead embraces targeted, equity-driven policy, investment, and research strategies.

That's why Rare Cancers Australia (RCA) and the rare cancer community launched the *Rare Cancer Moonshot* in 2024[7], a galvanising call for increased and unified efforts across government, healthcare, research, industry and the community to deliver:

- over 90% average five-year survival for every cancer type; and
- true equity of experience.

One year on, there have been notable shifts in the recognition and prioritisation of rare. But there is a long way to go. The development of Australia's first Optimal Care Pathway (OCP) for rare and less common cancers is a major step toward equity. Informed by clinical and lived experience, the OCP will set a national benchmark for coordinated, evidence-based care. This is supported by broader national efforts to embed OCPs across the system[8].

Rare cancers are increasingly recognised in national frameworks, including the *National Framework for Genomics in Cancer Control*[9] and the *National Cancer Data Framework*[10], and there is a clear focus on increasing access to genomic-led cancer care through the newly established Genomics Australia. Continued funding for the Zero Childhood Cancer Program[11] and the Precision Oncology Screening Program enabling Clinical Trials (PrOSPeCT)[12] means thousands more will benefit from precision oncology.

Australian Government funding for the Australian Rare Cancer (ARC) Portal[13] is a huge milestone in addressing barriers to multi-disciplinary expertise and advice for people with rare cancer, particularly those living away from major cancer centres. Investment through the *Australian Cancer Plan* is also expanding access to personalised support. The Australian Cancer Nursing and Navigation Program (ACNNP), a partnership between government and patient organisations including Rare Cancers Australia, is increasing access to specialist cancer nursing and navigation support – connecting people with the right care, information, and services when they need them[14].

Progress has been slow on desperately needed Health Technology Assessment (HTA) reform and access to new therapies. Patients are waiting too long and the pace of change is frustrating. Recommendations from *The New Frontier: delivering better health for all Australians* (2021), the *Health Technology Assessment Policy and Methods Review* (HTA Review, 2024) and the Senate inquiry (2024) have set a path for change – but there is a high risk of inertia.

To achieve true equity of outcomes and experience, it is time to turn reviews, recommendations and frameworks into tangible improvements for people with rare and less common cancers. The patient-reported insights of the Cancer Lived Experience Survey provide an understanding of the current state and a baseline to improve from, and we owe it to every person with cancer and their loved ones to accelerate progress and achieve the Rare Cancer Moonshot.

Cancer Lived Experience Survey: If it matters to you, it matters to us

Recognising that change starts with understanding, we asked people with cancer to tell us what matters. Equity of experience is an important ambition of the Rare Cancer Moonshot, but there was no baseline for measuring that. Until now.

Nearly 2,500 people impacted by cancer completed the Cancer Lived Experience Survey, sharing insights into what happened and how they felt before, during, and after their cancer diagnosis, throughout treatment and beyond, and the impact of their cancer on themselves and those close to them. Three quarters of respondents had, or cared for someone who had, a rare or less common cancer.

We are deeply grateful to every person who completed the survey and so generously shared their time, insights, and reflections. Their voices are not only heard, they are recognised. They fuel our relentless advocacy to change the story of a rare cancer diagnosis and will strengthen the support we offer.

The survey focused on the experiences of adults with rare and less common cancers and their carers. It was open between March and June 2025 for any adult living in Australia who has or has had cancer, and any adult who is caring for someone with cancer or has cared for someone who has died from cancer.

Early findings are shared in this report, alongside quotes and case studies from people with rare and less common cancers. The full findings, alongside data limitations and considerations regarding under-represented population groups, will be published later this year. Findings will be made available to inform, strengthen and improve services and support across the sector.

Given the distinct challenges facing children with cancer and the complexity of developmental, psychosocial, and family needs, the adult questionnaire would not have captured children's experiences justly. While not included in this survey, children with cancer are a vital part of the rare cancer community and their experiences and needs have shaped this policy report in other ways. We hope that a lived experience survey for children with cancer can be conducted in the future.

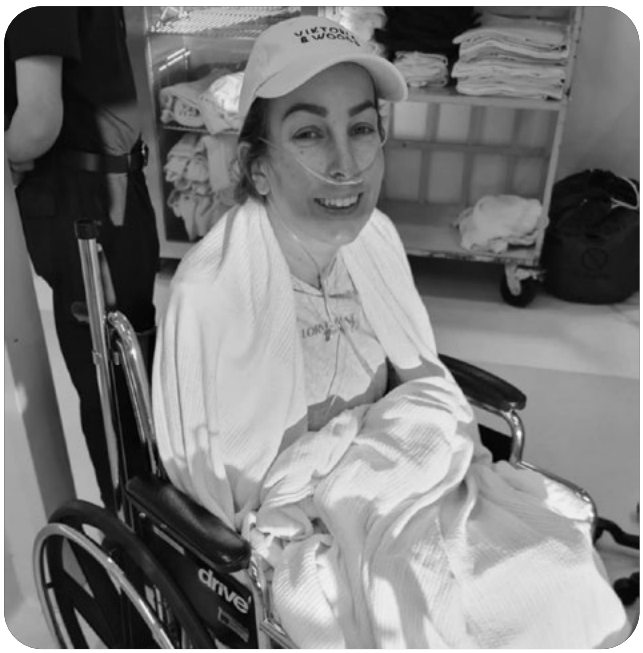
We thank So What? Research for conducting the Cancer Lived Experience Survey on our behalf and for their collaborative approach throughout the project. The survey was approved by the Human Research Ethics Committee (Reference Number: 2025-02-121).

> Thank you for the opportunity for allowing me tell my story, no one has ever been interested in my experience before.
>
> – Carer of person with cancer, Cancer Lived Experience Survey

KAT'S STORY

"Cancer is cancer – and we should all be treated equally"

At just 31, Kathryn (Kat) Berecic was living the life she dreamed of, when she was diagnosed with a rare appendix cancer. After exhausting treatment options in Australia, she's turned to options overseas to extend her life – but at an enormous cost.



"In 2021, I was living a happy, regular life with my husband. We had just married, bought a house in Melbourne's suburbs, and had started IVF. It should have been the best time of my life.

I remember I had just started taking progesterone tablets as part of the IVF process when I started getting really sick. At first they told me it was normal, but the doctor sent me for a blood test, and I was told to go to hospital because my inflammation was through the roof.

It took them two days in emergency to actually figure out what was wrong. I was complaining about tummy and back pain, so the doctor finally ordered an ultrasound, and straight away he picked something up. My appendix was twice the size it should be, and they rushed me off to have an emergency appendectomy.

I was alone in my follow-up appointment with the surgeon when he told me, "You have cancer".

I quickly discovered the gaps in the care system. I sought multiple opinions but they knew so little about my cancer. One said surgery could kill me, while another had never even seen a case like mine before.

It wasn't until we did some research ourselves online that we discovered a surgeon in Sydney with experience in appendix cancer. Meeting him felt like a huge weight off my shoulders. I finally found someone who knew what they were doing and it just put me so at ease. But it took a long time to get to that stage – and that shouldn't be the case.

So, when I found Rare Cancers Australia it was like someone had just wrapped their arms around me and said, 'We're going to take care of you and we're here for everything you need'. They've helped me navigate so many of the challenges that come with this journey. From there, I had two major surgeries in Australia, including heated chemotherapy poured into my abdomen. When the growth returned, we started looking at alternative options.

I've been on bowel cancer chemo for four years because that's the closest thing they have. But unlike bowel cancer, appendix cancer doesn't have access to PBS-funded immunotherapies. We're treated like we're the same, but we're not given the same treatment options. It's not right.

There are no clinical trials specifically for people like me. I don't fit the criteria, even though I'm otherwise treated like I have colorectal cancer. Cancer is cancer – and we should all be treated equally.

Mum started to deep dive into online research and joined support groups and learned of a person in the UK who was doing an immunotherapy in Japan. He had bowel cancer and was given about six months to live, and he was 10 years on and doing amazingly. So that's where my global search for treatment began – we got in touch with him and spoke to a few others who'd had that same treatment overseas.

> **Being a young person with cancer is very hard. There's a belief that if you're young, you can't be seriously ill. And it's so incredibly lonely when you're the only young person in the chemo ward.**

My first trip to Japan, in late 2022, kept me stable for the first time since diagnosis, for almost two years. When my disease progressed again, I returned, but the treatment wasn't as effective the second time around.

At the start of this year, I had a third major surgery in Australia. When surgeons couldn't do any more for me, I returned to the US for a histotripsy, and I'm now travelling to Germany undergoing dendritic cell therapy and transarterial chemoembolisation (TACE).

> **These treatments give me hope – but there's an enormous risk and cost associated with going overseas when you've got stage 4 cancer.**

The first trip is for six weeks, then there's back and forth between Germany and home for the next several months. I can't get travel insurance. I risk complications with every flight. I don't speak the language. If I end up in hospital tomorrow, it could cost tens of thousands. Every day feels like a gamble.

The burden of cost has been hard to bear as well. Every time I travel, I need a carer – both my parents came with me to Germany.

I'd love to be able to have these options in Australia. The expense of being overseas is just crazy because the flights are expensive, then the accommodation, then the treatment; the prices are through the roof.

Without crowdfunding, I wouldn't be able to do this. We had to sell our house and move in with my parents. My husband works around the clock to keep us afloat. I was never someone who posted about my life to social media, but I've had to share all these really personal photos because that was how I was going to get the funding. People have been incredibly kind and generous and I'm so lucky that I've had that support.

I rely on a lot of complementary therapies to support my body through the treatment. They're out-of-pocket and very expensive, but they're the things that keep my immune system functioning and have helped to keep me strong. I see an integrative practitioner and she gives me all these different IVs that I need, I also do acupuncture and take a tonne of vitamins.

I couldn't do it without my mum. She cooks for me when I don't have the energy to do it myself. Without her I'd be having toast for dinner!

Being a young person with cancer is very hard. There's a belief that if you're young, you can't be seriously ill. And it's so incredibly lonely when you're the only young person in the chemo ward. Meanwhile, my friends are having babies, building families – the life I dreamed of.

I'm still fighting for that simple life. I just want to be home, with my husband and family, doing the everyday things I used to take for granted. That's what I'm fighting for."

Counting rare

Too often, people with rare and less common cancers are invisible in data collection and reporting. Without the foundation of good data, health policy and pathways may not reflect the different needs of individuals, leaving gaps where tailored support is most needed.

Current cancer data collection in Australia does not fully reflect the complexity or impact of rare cancers. Fragmentation across jurisdictions exacerbates these issues, limiting our ability to measure outcomes, benchmark care quality, and plan services effectively. As a result, the burden and lived experience of rare cancer patients are often underrepresented in research, care planning, and health policy[1].

People with rare cancers frequently face delayed diagnoses due to inconsistent coding practices, limited integration of genomic data, and fragmented clinical pathways. A strong, standardised data approach can help overcome these barriers—ensuring the right information is available to guide timely, accurate, and personalised care[15].

Crucially, better-linked data helps us see the full picture: from the cost and quality of care to patient outcomes, experience, and opportunities for prevention. Collecting consistent data on stage at diagnosis, including for rare cancers and rare subtypes within common cancers, is especially important. It allows us to identify where delays are occurring and where earlier diagnosis can be achieved.

Equity begins with visibility.

By strengthening how we collect and use data, including patient-reported data, we can ensure every individual is seen, heard, and supported with care that is inclusive, personalised, and fair.

Rare by numbers

Although rare by incidence, rare and less common cancers account for one in four cancers diagnosed in Australia each year. That's more than 40,000 people diagnosed each year, or one person every 13 minutes.

Tragically, mortality rates are disproportionately high for these cancers, making up one in three cancer-related deaths. More than 16,000 people die from a rare or less common cancer each year[4].

And that's not the whole picture. Rarity is currently defined by incidence, with no molecular data available to show the true scale of people affected by rare subtypes of common cancers.

Over the last 20 years, on average, the five-year survival rates for common cancers have increased by 22%, compared with 19% for less common cancers, and only 13% for rare cancers. Relative five-year survival rates range from only 8% for mesothelioma to 96% for prostate cancer. Survival rates for some rare and less common cancers, including blood and brain cancer, have seen little or no improvement. While for some cancers, including bladder cancer, survival rates have decreased[4].

In Australia in 2024:

One in four
cancers diagnosed were rare or less common

One in three
cancer deaths were from a rare or less common cancer

Missing data on rare subtypes

Figure 1: Increase in average five-year survival rates between 1987–1991 and 2016–2020

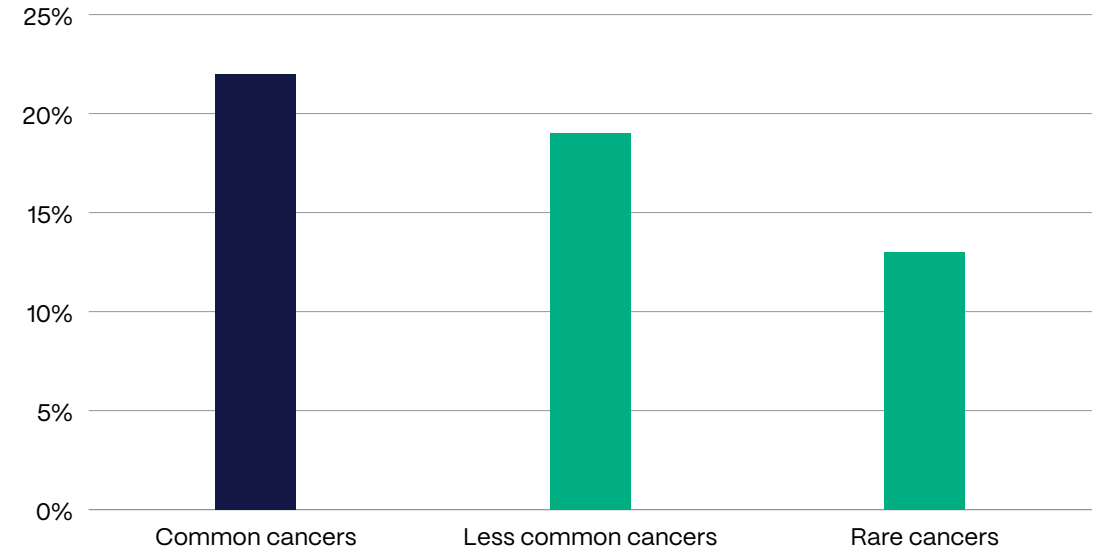


Figure reference[4]

A genomic approach: Rare cancers are not so rare

There are hundreds of different rare and less common cancers, defined as those with an incidence of fewer than 6 people (rare) or 12 people (less common) per 100,000 per year. Together, they add up, with more than 40,000 people diagnosed with a rare or less common cancer in Australia each year[4]. Yet even that is an underestimation.

Many common cancers are increasingly recognised as collections of rare subtypes distinguished by unique genomic or molecular features. These subtypes often have very different prognoses, treatment responses, and care needs, yet they remain invisible in many current datasets[16]. Each person's cancer is as unique as their fingerprint[16], because each cancer possesses distinct molecular and genetic characteristics that can be identified. However, molecular data is not consistently or routinely captured or reported, making it difficult to assess the true incidence of rare cancers.

This data gap also impacts on direct patient care. Molecular data are essential to inform precision medicine and identify candidates for emerging therapies or clinical trials. They can provide important insights into how aggressive a cancer is and potential drug-resistance, building on the traditional classification of aggressive cancers as those that spread rapidly, despite intensive treatment[17].

Including molecular subtype in national reporting ensures that cancer care is not only evidence-based, but also equitable and personalised, helping us to better serve patients whose cancers don't fit traditional categories[18]. It is an urgent priority – one that was explicitly recognised by the Senate Inquiry, which recommended that the Australian Government strengthen cancer data collection to include both tumour location and molecular-level information, as part of the *National Cancer Data Framework* under the *Australian Cancer Plan*[1].

The *National Framework for Genomics in Cancer Control* further reinforces this by outlining actions to implement nationally consistent processes for collecting, linking, and using genomic data to inform best practice care[9]. Critically, this national effort must include the collection and reporting of molecular subtype data, which is especially important for rare and less common cancers. There is a window of opportunity to develop a minimum data set so services across Australia can record and report these data consistently, enabling research and avoiding siloed data registries.

> **Classifying cancers by body part is convenient but minimally helpful… In reality, each body part has many different types of cancer that all behave quite differently. If you put them in the same bucket, it just gets murky and doesn't mean anything… While we do it, it doesn't make sense. We really need to know what is the type of cancer we're dealing with. That's the key part of information. That's more difficult but it's much more relevant.**
>
> **– Associate Professor Benjamin Loveday in oral evidence to the Senate Standing Committee on Community Affairs: Equitable access to diagnosis and treatment for individuals with rare and less common cancers, including neuroendocrine cancer, 1 February 2024[37]**

How other countries are embedding molecular-level data in cancer reporting

Australia can draw inspiration from successful international models to help establish effective, equitable measurement and reporting systems for rare and less common cancers.

United Kingdom

National Disease Registration Service (NDRS)

The NDRS, part of NHS England, collects and links data on all cancer patients in England. It includes molecular and genomic test results, often sourced from pathology labs and genomic laboratory hubs, especially for cancers where molecular testing is standard of care (e.g., EGFR and ALK in lung cancer, BRAF in melanoma, MSI in colorectal cancer)[79].

European Initiative to Understand Cancer

UNCAN.eu

The UNCAN.eu is establishing a federated data ecosystem that links clinical, molecular, and environmental data across borders. This includes integration of cancer registries with genomic sequencing, biobanks, and real-world data to enable improved diagnosis, subtype classification, and research into rare and molecularly defined cancers[19].

United States

SEER Program (Surveillance, Epidemiology, and End Results)

The SEER Program, run by the U.S. National Cancer Institute, collects cancer incidence and survival data across multiple population-based cancer registries. In recent years, the SEER program has introduced a centralised approach to integrate tumour case data from SEER registries with genomic testing results supplied by molecular laboratories[19].

These international examples show that collecting molecular subtype data is feasible and highly valuable, especially when integrated into routine registry or linked administrative systems. They serve as models for Australia to consider when advancing its cancer data maturity strategy, particularly for improving care for people with rare and less common cancers.

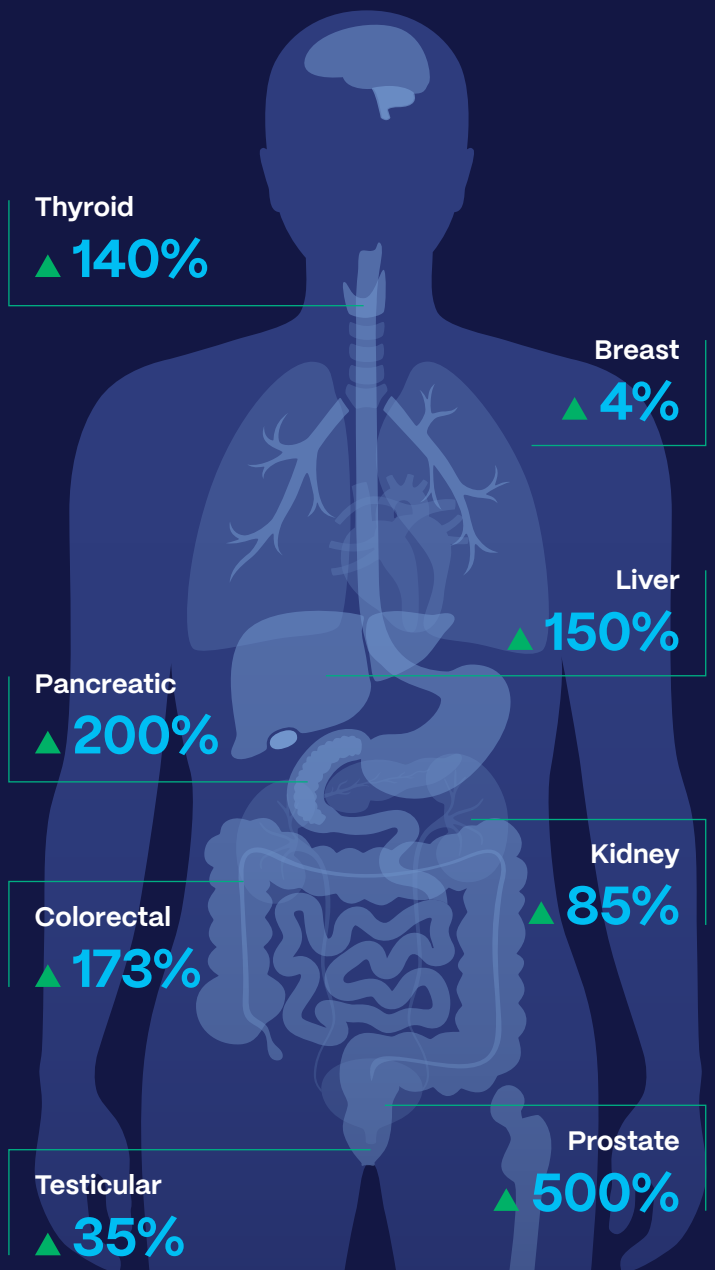
Cancer incidence is rising among young Australians

Younger Australians, who often report being otherwise fit and healthy, are increasingly being diagnosed with cancer, including rare cancers.

Recent data show a rising number of cases being diagnosed in people under 40, particularly among adolescents and young adults (AYAs) aged 15–39. Over 4,000 new cancer cases are diagnosed in AYAs each year, with rates of certain cancers showing an upward trend in this age group[20].

Between 2000 and 2024, in 30–39-year-olds, prostate cancer increased by 500%, pancreatic cancer by 200%, liver cancer by 150%, colorectal by 173% and kidney cancer by 85%[21].

While cancer incidence remains highest among older adults, this trend is alarming and demands urgent attention. As rates of early-onset cancer continue to rise, there is an urgent need to better understand the factors driving this and to develop targeted prevention, diagnostic, treatment and support strategies.



> I got really sick of people saying I was too young to have it even though I did. They weren't denying it but saying I was just a young case – that stigma needs to change and the government and people need to realise this is a cancer, not just an old people's cancer. Unfortunately this prevents the government from funding new needed treatments because stats only show mortality rates in the elderly, preventing us young ones from accessing life saving treatment and dying too young.
>
> – Person with cancer, Cancer Lived Experience Survey

Younger people can face unique challenges during diagnosis, sometimes being told they are 'too young' to have cancer before being diagnosed, as they fall outside of the average risk profile.

In our recent Cancer Lived Experience Survey, people aged 25–34 were significantly more likely to report not believing their symptoms were serious and to have delayed getting tests as a result (31% compared with 17% overall). This highlights the need for greater awareness, education and information for younger people.

There is also a need to shift service models and pathways to better meet the different needs of young adults. A diagnosis at this stage of life significantly impacts career development, family planning, and financial stability, placing considerable psychological and emotional strain on individuals and their families.

When cancer affects younger people—who are just starting to build their lives and careers—it results in substantial lost productivity, underscoring the economic and social value of early diagnosis and access to effective treatment. For every $1 spent on extending life and quality of life for younger people with non-curative cancer, there is a $3.06 return in social and economic value—and over a five-year period this could create more than $2 billion of value in Australia alone[22].

Improved data collection is an essential enabler, particularly regarding age at diagnosis, stage, genomic characteristics, and patient-reported outcomes. This is vital for improving survival and experience, and designing a healthcare system that meets the evolving needs of younger Australians facing cancer[21].

"I was otherwise young, fit and healthy, working as an operator. I was planning my wedding to my fiancée and raising my son to be the best version of himself that he could be. When I heard those three words, 'you have cancer', I felt like I'd been hit by a freight train with no signs of it slowing down. My future hopes and dreams were shattered within seconds."

– Noel, living with thymic carcinoma

National leadership, local empowerment

To improve cancer outcomes and health system performance, Australia must invest in strengthening data infrastructure. States and territories need dedicated funding, a skilled workforce, modern systems, and clear national standards to collect, link, and report cancer data consistently.

Current disparities in capability and reporting across jurisdictions are unacceptable. There is a national imperative to support all states and territories to meet the highest standards of cancer data collection and use. The ambition of the *Australian Cancer Plan* to improve outcomes for all Australians with cancer cannot be achieved without addressing these gaps.

States and territories must be supported not only to maintain and expand their cancer registries, but also to ensure that these datasets are routinely linked with a range of health and administrative datasets. This will enable benchmarking, support planning, and help identify and reduce unwarranted variations in care.

Laying the foundation: A framework for smarter cancer data

The *National Cancer Data Framework*, developed by Cancer Australia in collaboration with the AIHW and Cancer Council Australia, is set to underpin how Australia collects, manages, and uses cancer data into the future. It provides a vital opportunity to improve how data is captured and connected, particularly for priority populations and people affected by rare and less common cancers, who are often left out of traditional data systems.

The *Australian Cancer Plan* highlights the critical need to address data gaps that limit the ability to assess the delivery of optimal care at a population level, improve cancer outcomes, and meet the information needs of patients, carers, clinicians, and decision-makers across the cancer continuum[8]. Without consistent and comprehensive data, it is difficult to assess whether patients are receiving optimal care, or to identify where improvements are needed. The *National Cancer Data Framework* has the potential to drive smarter, more equitable care delivery across the system and across the care pathway through a national cancer control reporting framework aligned with Optimal Care Pathway indicators[10].

The *National Cancer Data Framework* will also play a critical role in integrating patient-reported outcome measures (PROMs) and experience measures (PREMs), supporting more meaningful measurement of care and patient wellbeing.

The *National Cancer Data Framework* is an important step, but its power lies in full implementation. States and territories need resourcing and support to realise the Framework's ambitions, which should bring everyone up to the highest capability, not draw down the average. The sooner we begin capturing this critical data, the sooner we can start implementing improvements to transform care for those who need it most.

Listening to patients is not an optional extra

Survival is a critical outcome and clinical metric, but it does not tell the full story. Traditional clinical metrics do not reflect how well people live, the impact of their cancer and its treatment, or the full effectiveness of an intervention.

When we listen to patients about their experiences and the impact of cancer and treatment on their quality of life, we can improve direct patient care, better meet their needs and more effectively evaluate the impact of treatments and services. RCA's recent *Cancer Lived Experience Survey* offers a powerful example of what's possible when we take the time to listen. Patients and carers gave generously of their time and personal stories, not only to be heard, but to contribute to meaningful change. Their willingness to participate reflects a strong desire to improve the system for others and reinforces the importance of developing a national approach to consistently capture and act on patient experience and outcome data. The insights have shed light on poorly understood parts of the cancer pathway, including how people reach a diagnosis and their information and support needs.

Patient-reported experience measures (PREMs) provide vital insight into how care is delivered and help identify what matters most to patients, and opportunities to improve how care is delivered. Systematically capturing cancer patient experience at a national level to inform improvements in cancer care services is standard practice in many other countries[23]. For example, the annual *Cancer Patient Experience Survey* and *Under 16 Cancer Patient Experience Survey* in England are well-established tools used to inform service improvement, policy development, and performance benchmarking[24].

In Australia, there is no national, standardised cancer patient experience survey currently in place. Victoria and New South Wales have implemented state-based cancer experience surveys, although approaches vary in scope and consistency. With more people travelling across state borders to access expertise and specialised treatments, it is more important than ever that we have a consistent view of how people with cancer are using and experiencing health systems across Australia.

> **It's a very good idea to have people give their experiences through a survey so that progress can be made towards better management of all areas of cancer.**
>
> **– Person with cancer, Cancer Lived Experience Survey**

The integration of Patient-reported outcome measures (PROMs) into cancer care has been shown to improve both quality of life and overall survival[25]. PROMs reflect the impact of cancer and its treatment on quality of life, symptoms, and functional status from the patient's perspective. While PROMs are well-established in clinical trials, their routine use in everyday clinical practice is still emerging. Symptom monitoring through PROMs offers a proven way to detect issues early, providing critical insights to clinicians and supporting more timely and effective care. The European Society for Medical Oncology (ESMO) *Clinical Practice Guideline* highlights the vital role of PROMs across the cancer care continuum, recommending their use to inform clinical decisions, personalise care, and improve patient outcomes[26]. Embedding PROMs into routine care—and ensuring they are accessible across service providers—helps ensure patient experiences directly shape service design, clinical care, and system-level improvements.

An example of this in practice is the Cancer Institute NSW Patient Reported Measures Program, which enables cancer services to electronically collect patient-reported health outcomes and experiences and makes the information available to the relevant healthcare teams through the cancer service's electronic medical record[27].

This approach enables clinical use in direct patient care as well as research, and has been implemented at pace across the state without considerable addition costs. The patient questionnaires are available in ten languages and local services have led on implementation within their services, responding to local needs.

The *Australian Cancer Plan* identifies the routine collection and use of patient reported measures (PRMs) as a key enabler of person-centred, high-quality cancer care[28]. The national PanCancer Initiative, co-led by Movember, Cancer Australia, and the Australian Department of Health, Disability and Ageing, has emerged as a significant national effort in this space[29]. One of the initial priorities of the initiative is the development of a core outcome set to standardise the collection of PRMs across cancer services in Australia. While this is a positive step, the next challenge is to implement it at all levels of the system and to ensure patient-reported information is accessible to the entire care team. This includes integrating PRMs into clinical workflows, linking data between service providers, including primary care and clinical trials, and using this information to ensure that patients' experiences and needs directly shape their care[30].

Embedding patient reported measures into national reporting frameworks will help ensure that the lived experience of people with cancer informs continuous improvement, service planning, and policy decisions at all levels[23, 31].

Recommendation 1

Cancer Australia should work with partners to deliver an ambitious *National Cancer Data Framework* to ensure national collection and reporting of timely, accurate and consistent cancer data, including patient experiences and outcomes, molecular subtypes, stage at diagnosis and time taken for diagnosis – with rare cancers included for every indicator.

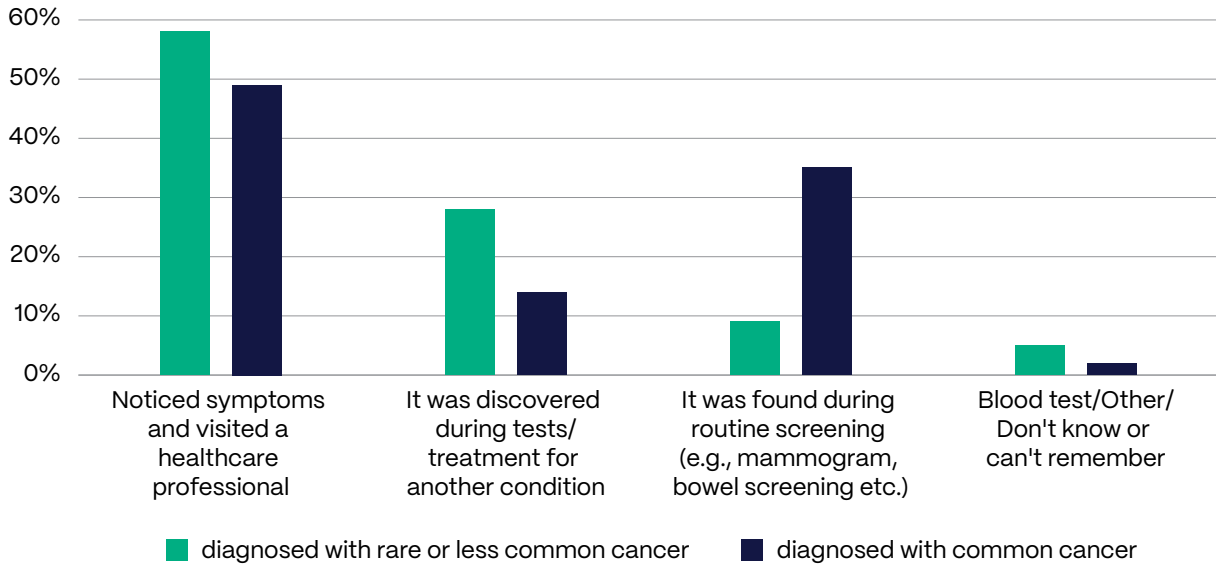
Diagnosing rare

Complex routes to diagnosis

The path to diagnosis for people with rare and less common cancers can be long and uncertain. National cancer policy initiatives to diagnose cancers earlier, including awareness campaigns and national screening programs, have largely focused on the most prevalent or preventable cancers. But that approach has left people behind.

Cancer pathways such as the Optimal Care Pathways focus on cancer diagnosis through a GP referral for symptoms or a screening program. While more than half (56%) of Cancer Lived Experience Survey respondents were diagnosed after seeing a healthcare professional about symptoms, one in four were diagnosed as an incidental finding when having tests or treatment for another condition – and this was higher for those with a rare or less common cancer.

Figure 2: Cancer Lived Experience Survey responses to 'How did you first become aware of your cancer?'



The key to early diagnosis, which gives a person the best chance of longer-term survival, is finding cancer before symptoms appear[32]. Screening programs have contributed significantly to improved outcomes for breast and bowel cancers[33, 34]. More than a third (35%) of respondents to our Cancer Lived Experience Survey said they first became aware of their common cancer through routine screening. Just 9% of respondents with a rare or less common cancer said they were diagnosed this way. Population-based screening programs have an important role – but they will not be the answer for people with rare cancers or young people who remain outside of the risk profile until minimally invasive and cost-effective testing becomes available. Instead, we need to maximise opportunities for prevention and earlier detection through targeted, risk-based screening, (particularly for people with an identified genetic risk), increased symptom awareness and recognition, strong referral pathways and safety-netting.

In Australia, we have made great strides in raising public awareness of red flag cancer symptoms, such as a lump in the breast or changes in a mole, encouraging people to seek help. However, other symptoms of cancer – sometimes called serious non-specific symptoms – such as weight loss, fatigue, loss of appetite and abdominal pain, are poorly understood. These symptoms are linked to a range of conditions and while the risk is low, they can be the sign of a rare cancer. Currently, there is low awareness, unclear guidance on suspected cancer referral pathways for GPs and no primary care safety-netting model for patients who present with these vague symptoms.

Our Cancer Lived Experience Survey highlighted barriers to diagnosis:

One in four

respondents with a rare or less common cancer said they were initially **diagnosed with another condition**.

Almost half

(46%) of people who were diagnosed with a rare or less common cancer after noticing symptoms felt that their **symptoms were overlooked or associated with another illness or condition**.

People with rare or less common cancers were also more likely to experience delays in diagnosis.

21%

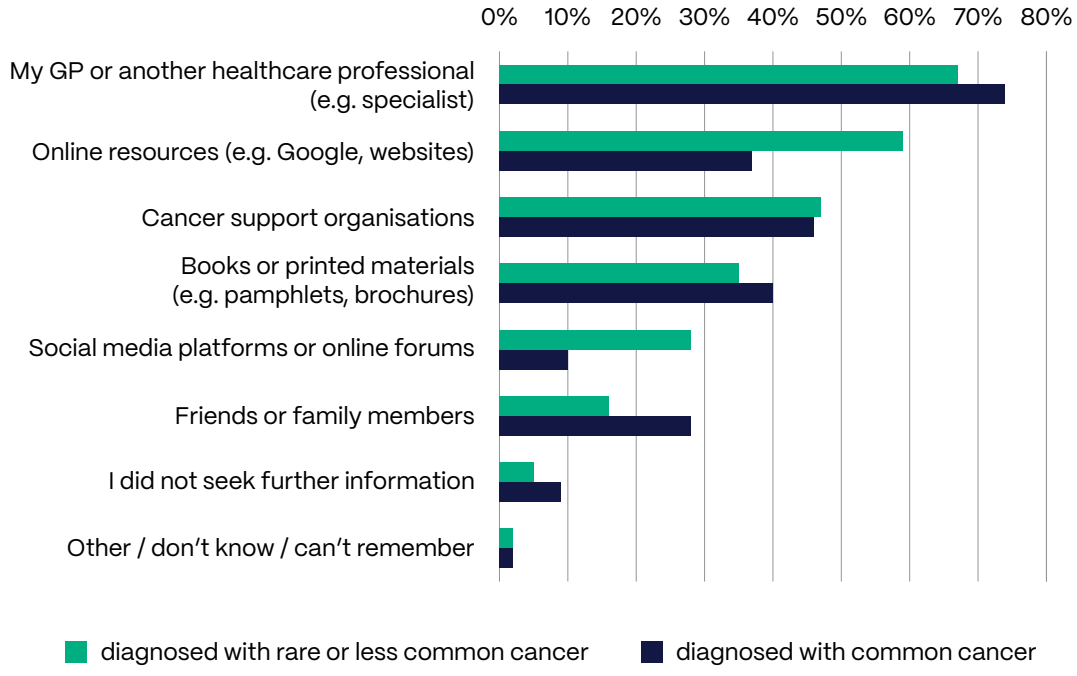
of respondents with a rare or less common cancer had to wait **more than six months** from first seeing a healthcare professional about symptoms to getting tested for cancer. **7%** reported that it took **more than three years**. **88%** of respondents diagnosed with a common cancer had tests within **three months** of seeing a healthcare professional about symptoms.

The Cancer Lived Experience Survey also highlighted gaps in information and support during the diagnostic phase:

- people diagnosed with a rare or less common cancer were **significantly less likely to understand** which tests they were having and what they would tell them.
- **19%** of people with a rare or less common cancer said they **did not know what their diagnostic tests were for**, compared with just **3%** of those with a common cancer
- people with a rare or less common cancer were **more likely to seek and use information from websites and social media** than those with common cancers.

> I would have preferred to get relevant and current information from my health professionals, but without that I reverted to Google to get a good understanding of my particular cancer, the latest research and advice on lifestyle modifications.
>
> – Person with cancer, Cancer Lived Experience Survey

Figure 3: Cancer Lived Experience Survey responses to 'Where did you find the MOST HELPFUL information after your diagnosis?'



Identifying opportunities to diagnose earlier

By better understanding people's routes to diagnosis and how long it takes, we can better target strategies for diagnosing cancers earlier and faster.

For example, a retrospective cohort study using hospital registry data and primary care records showed that sarcoma patients had increased GP clinical activity from six months pre-diagnosis, with variability in the tests they were offered[35]. That window shows opportunities to improve earlier diagnosis through increased awareness, consistency and use of investigation and referral guidelines, which could in turn improve survival and quality of life outcomes[35]. Data linkage projects have also shown the positive impact of Australia's national screening programs due to earlier stage of diagnosis and the prevention of some cancers through action on pre-cancerous lesions[33, 34].

However, our understanding of the link between different routes to diagnosis, stage of diagnosis and outcomes is still emerging and is severely limited for rare cancers. We need better data capture, reporting and linkage across all cancers, not just the most common and those with a national screening program. This should include measures of the time taken for people to receive a cancer diagnosis and their healthcare activity in the lead up to diagnosis.

> I was wrongly diagnosed with arthritis, even with a lump on my collar bone. Approximately nine months later I insisted that there was something not right. It can't be arthritis.
>
> The doctor did heaps of other tests, which revealed multiple myeloma. I was considered to be too young (50) for the doctor to be looking for myeloma.
>
> – Person with cancer, Cancer Lived Experience Survey

> Being female and having small children, along with breastfeeding, I was always dismissed and told it's normal to be tired, fatigued, low iron and in extreme pain with ovulation and menses.
>
> – Person with cancer, Cancer Lived Experience Survey

Diagnostic and surveillance tests out of reach and out-of-pocket

In its inquiry into the equitable access to diagnosis and treatment for people with rare and less common cancers, the Senate Standing Committee on Community Affairs heard evidence from patients, clinicians and expert groups about the additional barriers to diagnosis for people with rare and less common cancers.

These included symptoms being overlooked, a lack of diagnostic imaging equipment, long distances travelled to access tests, and high out-of-pocket costs for tests that are only covered by Medicare for certain cancer types. Compounding these challenges is the persistent lack of consistent and comprehensive data on rare cancers, which limits visibility of diagnostic delays and inequities, and hinders efforts to drive targeted system improvement[1].

In our Cancer Lived Experience Survey, 34% of respondents who were diagnosed with a rare or less common cancer attended four or more appointments to discuss symptoms they had noticed before receiving a cancer diagnosis, compared with 12% of those with common cancers. Those appointments are not just lost opportunities to speed up diagnosis – they can also come with out-of-pocket and travel costs, as well as disruption to work, education and caring responsibilities. A higher number of pre-diagnosis GP consultations has also been linked with patients reporting a poorer experience of their subsequent cancer care[36].

People with a suspected or confirmed cancer type that is not covered by a Medicare Benefits Schedule item face high out-of-pocket costs of up to $1,500 per scan. This financial burden is particularly acute for rural and regional patients who must often travel significant distances to access metropolitan-based imaging services, and is compounded by the fact that those payments are not included when calculating the Medicare Safety Net cap.

Poor availability of diagnostic imaging during diagnosis, treatment and surveillance is a direct barrier to optimal care for people with rare cancers. Limited, inflexible and confusing Medicare items for magnetic resonance imaging (MRI) and positron emission tomography (PET) scans and the low utilisation and sub-optimal distribution of machines are hindering access to clinically indicated scans[37].

For example, only one MRI per year is subsidised for patients with hepatocellular cancer (primary liver cancer), however these patients often have diffuse liver involvement which is difficult to assess via CT – clinical best practice would be to use MRI. There are also discrepancies in eligibility for Medicare reimbursement for PET scans based on cancer type – where patients with certain types of cancers, such as non-small cell lung cancer, are eligible for reimbursements, whilst others such as cholangiocarcinoma or uveal melanoma, are not. Where a scan is not subsidised, patients need to either self-fund or have a clinically sub-optimal test, which can impact their treatment and survival.

There has been some progress toward greater equity. Prior to November 2024, patients with rectal cancer could only access a subsided MRI scan for initial staging, when optimal clinical practice was to re-assess through MRI following pre-operative treatment. This was expanded to include restaging and follow-up, better reflecting clinical need and giving greater discretion to clinicians. However, incremental change will not right the current inequities quickly enough – we need a more flexible approach to allow clinicians to refer patients with rare cancers for the tests they need at the right time, without limitations that interfere with optimal clinical care.

In a community consultation exercise led by RCA in late 2024, 182 people with cancer told us about its financial impact.

One third

said they had delayed or declined a test or treatment because of the cost.

Diagnostic tests were the most commonly delayed or declined, followed by surveillance or follow-up tests and then genomic tests[38].

Recommendation 2

The Australian Government should urgently review and increase subsidies for MRI, PET and CT services for the diagnosis, surveillance and restaging of rare and less common cancers.

Cancer Australia should lead development of urgent suspected cancer referral guidelines for identifying, managing and referring people with suspected rare or less common cancers, including safety netting.

Precision oncology is gaining momentum

Australia is at a critical juncture, poised to move genomic-led cancer diagnosis and treatment out of research and into standard of care. This approach can open the door to new treatments and address the some of the barriers created by low incidence and high evidentiary thresholds that have prevented people with rare cancers from accessing life-saving treatments.

Comprehensive genomic profiling (CGP) is already being used in Australia and internationally, with rapidly growing evidence for its use and effectiveness[39]. Australia's two major translational research programs using CGP and precision oncology, the Zero Childhood Cancer Program (ZERO) and Omico's Cancer Screening Program (CaSP), have delivered compelling results and provide a platform for scaling up access to testing and targeted therapies[11, 12].

Over half (55 %) of children who received precision medicine guided treatment through the first phase of ZERO achieved complete or partial remission or stable disease for at least six months[40]. The two-year progression-free survival rate for children who received therapy guided by CGP was double to those who did not, and five times higher than patients whose treatments were unguided[40]. Since its launch, CaSP has identified a personalised treatment recommendation for 68% of its screened patients[12]. The Australian Government recently extended funding for these programs, including the expansion of ZERO to include 19-25-year-olds, recognising the value and potential of genomic-led cancer care[41].

In our Cancer Lived Experience Survey, people with a rare or less common cancer were more likely to report having had genomic testing as part of their diagnosis (36% for rare and less common cancer compared with 18% for common cancer) and to have had a targeted therapy or treatment informed by a genomic test (19% for rare or less common compared with 10% for common cancer). People diagnosed in the past five years were more likely to say they had genomic testing at diagnosis than those diagnosed prior to 2020. However, 17% of all respondents could not remember or did not know whether they had genomic testing at diagnosis.

The reality is that genomic-led cancer care remains out of reach for many patients. Children, young adults and adults with advanced cancers can now access testing through ZERO and PrOSPeCT, but others continue to miss out as they do not know about testing or cannot afford to pay for it.

As access to genomic testing expands, it is vital that appropriate services and support are in place. Not every person will have an actionable target. For example, 17% of survey respondents with a rare or less common cancer had genomic testing at diagnosis, but it did not affect their care plan. For those who are matched with a treatment, there can be prohibitive out-of-pocket costs, or the treatment may only be available overseas.

Progress is promising – but there is a long way to go to.

The full potential benefits of genomics may only be realised when somatic testing becomes standard of care for everyone with cancer. While that may not be possible immediately, given current cost, infrastructure, workforce and training considerations, that end goal must guide implementation. We must set up now for smooth future expansion, so as more actionable targets are identified and targeted therapies come to market, more patients can access personalised therapies early in their pathway. Precision oncology must become the standard, not a last resort.

When I was diagnosed with stage 2 colorectal cancer in 2022, I had tests to identify genetic or hereditary causes for my cancer – but no one mentioned genomic testing for the tumour itself. After surgery and 12 rounds of chemotherapy I was declared cancer free and told to go on and enjoy my life.

Eleven months later I had a recurrence, with extensive spread through my abdomen that blindsided my medical team. I had a 13–hour surgery to remove my uterus, ovaries, spleen, gallbladder, portions of abdominal lining and more small and large intestine (in addition to what was taken during my initial surgery in 2022). Then they filled my abdominal cavity with heated chemotherapy.

It was only then that my tumour sample, stored since 2022, was tested. It turned out I have a BRAF mutation and there was a targeted treatment available.

I am incredibly grateful to be living well on that targeted therapy, thanks to my medical, integrative and supportive care teams. But alongside that gratitude, I always wonder if things could have been different if we had identified the BRAF mutation earlier.

– Tenielle, living with a rare colorectal cancer

Accelerating implementation through national leadership

There is growing consensus on the compelling need for genomic-led care for people with rare cancers.

The *National Framework for Genomics in Cancer Control*[39], published in November 2024, identifies people with rare cancers as a priority group for access to genomic testing and personalised oncology. Genomics Australia, a new body within the Department of Health, Disability and Ageing, has a clear early priority to accelerate the implementation of personalised cancer care[42].

Together, Genomics Australia and Cancer Australia must provide critical leadership and collaboration with states and territories to increase testing capacity, infrastructure, data collection, workforce training and development, clinical and patient pathways and information to make personalised cancer care a reality.

The *National Framework for Genomics in Cancer Control*[9] and the refreshed *National Health Genomics Policy Framework*, currently under consultation, set the right ambitions. But now is the time to act. We must build on the work already done and harness proven research to drive change. National frameworks and policy are yet to set the detailed roadmap for embedding the use of genomics into cancer care. There are no measurable targets, implementation dates, and responsibility for complex cross-departmental delivery remains unclear. For example, reforms to Health Technology Assessment (HTA) to enable faster, fairer access to genomic technologies and targeted treatments sit within the HTA Review[43], but will require decisive leadership and support from Genomics Australia to realise the benefits of genomics for patients, providers, and the health system.

Funding also needs to be addressed. Genomics Australia has been allocated $30 million over the next four years to provide national leadership, coordination and expertise to support the better integration of genomics into the Australian health system in a person and family-centred, culturally safe, efficient, effective, ethical and equitable way[41]. That funding is a welcome start, but as delivery plans are finalised, there must be an increase in health system funding to match the scale and pace of implementation.

The overall genomic investment of other countries such as England, Canada and the United States is significantly higher than Australia's national genomic funding to date[44].

In addition to improving diagnosis and care, expanding genomic testing and data collection creates broader system value by attracting clinical trials and industry investment[9]. Access to high-quality, structured genomic data enables more effective patient matching for precision oncology trials, an increasingly important avenue for rare cancer patients who may have few standard treatment options. National initiatives such as Omico demonstrate how genomic profiling can be successfully leveraged to drive trial-based access to novel therapies and attract global pharmaceutical investment[12]. Clear national infrastructure and pathways for genomic-led care can help position Australia as a more attractive destination for global clinical trials, partnerships, and pharmaceutical investment. This not only increases access to novel therapies for patients but also strengthens Australia's research and innovation ecosystem.

Recommendation 3

The Australian and State and Territory Governments should accelerate the implementation of the National Framework for Genomics in Cancer Control and the refreshed National Health Genomics Framework to:

- **deliver comprehensive and affordable genomic profiling as standard of care for patients with confirmed or suspected rare, less common and advanced cancers; and**
- **increase Australia's genomic infrastructure and capacity, including the development of a National Genomic Data Registry for Cancer, to support the standardised and optimised use and reuse of genomic data for cancer care and research.**

Cross-sector delivery

At the end of 2024, RCA hosted a Genomics Policy Roundtable Series in partnership with Australian Genomics. Speakers and attendees discussed the wide-ranging potential of genomic-led cancer care and placed particular emphasis on the pressing need for comprehensive genomic profiling at diagnosis for people with rare cancers. To move from research into standard of care, five priority actions emerged from the discussions:

1 **Foster collaboration and coordination within and across stakeholder groups to advocate for, progress and implement a national approach to cancer genomics in Australia**

Strong leadership, cohesive planning, and multidisciplinary collaboration are essential for integrating genomic profiling into routine cancer care.

2 **Develop a national approach to standardise access to genomic profiling for cancer patients, starting with those most in need**

A national model of care should be established to ensure equitable access to genomic profiling, prioritising patients with rare or less common cancer and advanced cancers, those living rurally or remotely, and Aboriginal and Torres Strait Islander communities.

3 **Invest in genomic infrastructure and technology**

Investment is needed to increase Australia's genomic infrastructure and capacity, including the development of a National Genomic Data Registry for Cancer, to support the standardised and optimised use and reuse of genomic data for cancer care and research.

4 **Prepare the workforce for genomic medicine**

Workforce preparation is critical, with a focus on upskilling cancer healthcare professionals in the use and interpretation of genomics through training and education, and workforce development and planning, to ensure a pipeline of future genomic healthcare professionals.

5 **Implement, monitor, and evaluate for continuous improvement.**

The full summary of the Roundtable Series is available at: www.rarecancers.org.au/advocacy/reports-submissions

JACQUES' STORY

When the system fails

At 22, the world was Jacques' oyster. He had just graduated from university, landed a job in IT, and moved in with his girlfriend. Life was full of plans and possibilities – until a rare cancer diagnosis turned his world upside down. He reflects on the complexities of his experience – and the urgent need to improve how people with rare cancers access treatment.

"I had pain in my shoulder blade for a while before I visited the GP. I assumed it was from a work or sports injury, so I wasn't too worried about it. But then I felt a lump, like a swollen bruise.

Initial scans suggested it was lymphoma – a serious diagnosis, but generally treatable, and survival rates are improving.

After a biopsy, everything changed. I was told it was actually Ewing Sarcoma, a rare and aggressive cancer that affects the bone or surrounding soft tissue, mostly in young people. The tumour was already 10cm across, and the cancer had spread to my spine and pelvis.

That was the hardest moment – not just being told I had cancer, but that it was worse than they originally thought.

Jacques with his girlfriend Gin

I began high dose chemotherapy, followed by radiation therapy. My oncologist also recommended molecular profiling of my tumour. Even though standard treatment was going well, Ewing Sarcoma often comes back within 12 months.

The profiling revealed a HER2 mutation, commonly seen in breast cancer. It recommended a drug which targets exactly that mutation, and was proving to be really effective.

This was amazing news, until we found out the therapy is only funded under the Pharmaceutical Benefits Scheme (PBS) for breast cancer, not Ewing Sarcoma – even though it targets the exact same mutation.

To access it privately, it was going to cost over $120,000. I remember thinking, *how are we going to pay for this?*

We couldn't get compassionate access from the drug company, either. We'd done the right thing getting gene testing early to find the best treatment before the cancer returns – but because we were proactive, the system worked against us, and the drug wasn't covered.

I couldn't help but compare the whole experience to my work in IT. It felt like a broken user journey.

> **You're diagnosed, tested, told there's a treatment that can help – then you hit a wall. The system fails. That's the gap that needs fixing.**

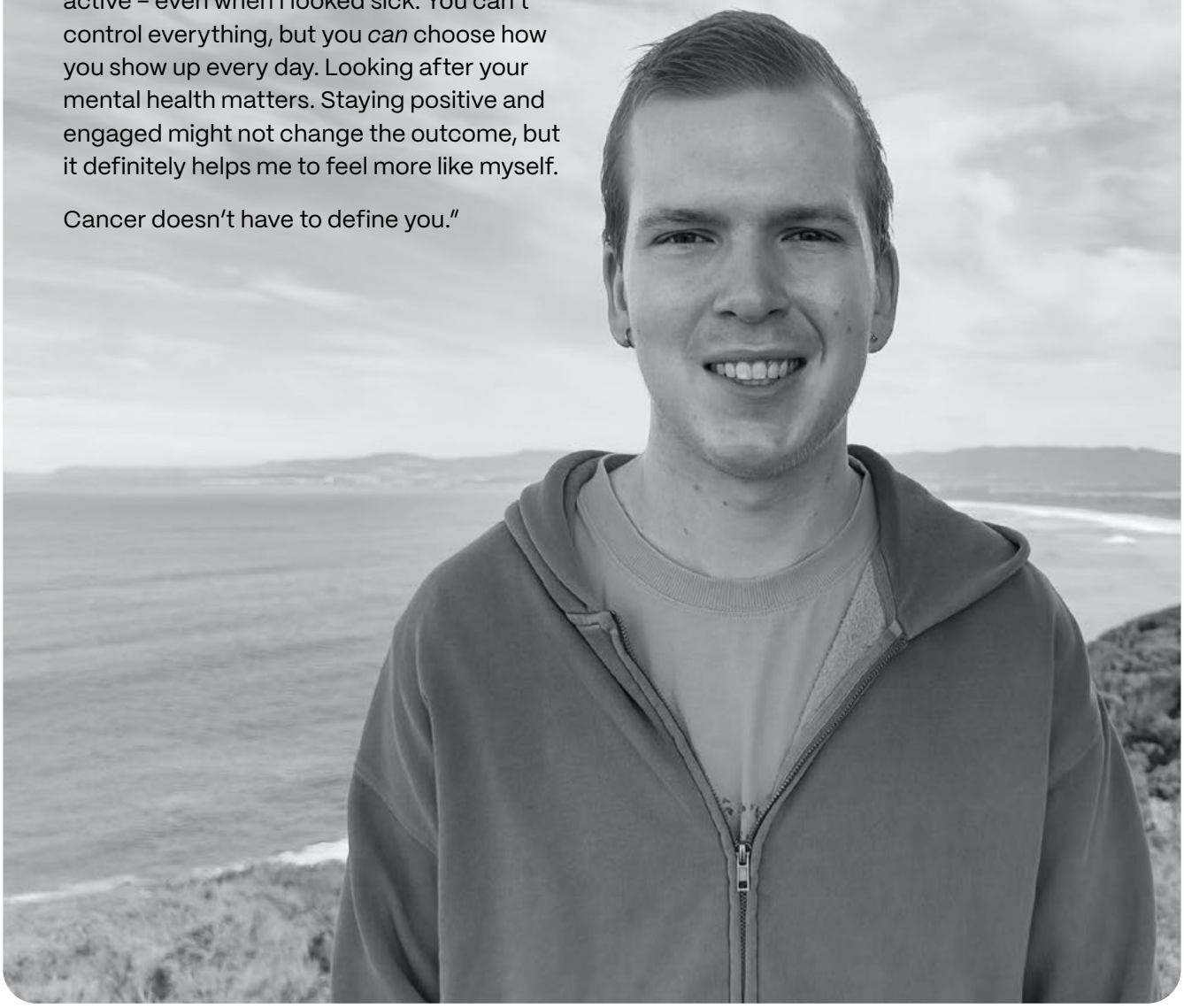
Feeling like we were out of options, we decided to raise the money ourselves. We contacted Rare Cancers Australia, who helped my dad and I set up a fundraising page. Asking for money is so uncomfortable. My dad wrote the profile – I think it's easier to ask for help for your child than for yourself.

But the support we received was incredible – family, friends, the rare cancer community and other donors – all got behind me and incredibly we reached our fundraising goal. I've now been on targeted therapy for a few months and I'm feeling good. Compared to chemo, the side effects are minimal. Now it's just about seeing how things go.

I've tried to keep things as normal as possible – working part-time, travelling, staying active – even when I looked sick. You can't control everything, but you *can* choose how you show up every day. Looking after your mental health matters. Staying positive and engaged might not change the outcome, but it definitely helps me to feel more like myself.

Cancer doesn't have to define you."

“You can't control everything, but you *can* choose how you show up every day. Looking after your mental health matters. Staying positive and engaged might not change the outcome, but it definitely helps me to feel more like myself.”



Treating rare

Delayed and inequitable access to medicines

It is widely recognised that people are waiting too long to access new medicines in Australia. Australia's HTA system is slow and outdated and has struggled to keep pace with evolving technologies and therapies.

According to the Department of Health, Disability and Ageing, the median time it takes for a medicine to be listed on the PBS after TGA registration is 670 days[73]. The *Health Technology Assessment Policy and Methods Review* (HTA Review) recommended that be shortened to just 60 days[43].

Compared with other countries within the Organisation for Economic Co-operation and Development (OECD), Australia has a relatively prolonged review time, with few interim pathways for patients to access the treatment under review whilst the assessment occurs[43].

> **While sponsors and government haggle over price and future funding, the patients of today are left without access to the medicines that could extend their life.**

Clinicians are in the unthinkable position of knowing that there is a safe and effective treatment that could save their patient, extend their life or significantly reduce their chance of relapse, but that it is out of reach.

Established over 30 years ago, Australia's TGA and PBS processes were designed to evaluate the safety, effectiveness and value of drugs and vaccines of that era, where the focus was on treatments for broad populations[43]. These processes require a level of evidence that is incompatible with the recently developed cancer specific treatments that serve a small population, such as rare cancer communities. This results in rare cancer patients being denied PBS funded treatments that have been established as safe and effective and in many cases are already in use for Australians living with other cancers.

Whilst maintaining high evidentiary standards is essential to ensure responsible use of taxpayers' money, these standards should not prevent the very taxpayers who fund the PBS from accessing treatment when they need it most. A more flexible and innovative approach is urgently needed.

This has a compounding effect, where pharmaceutical and biotech companies, knowing the odds are stacked against them, are discouraged from bringing forward applications in Australia for rare cancer treatments.

> **It's a vicious cycle that leaves patients behind, clinicians frustrated, and families burdened both emotionally and financially.**

As someone diagnosed in 2020 at the age of 35 with a late-stage and rare form of a common cancer, I quickly discovered that my treatment options were both limited and extremely costly. My experience highlighted a significant disparity in the availability and affordability of essential medications in Australia. For instance, my initial drugs were not covered by the Pharmaceutical Benefits Scheme (PBS), costing me an astonishing $6,742 a month.

The situation becomes even more disheartening when considering the cost of adding immunotherapy to my treatment plan, which would exceed $60,000 – despite being on the PBS for other mutations of bowel cancer, just not mine. If this isn't inequity, I'm not sure what is. I hope to see the day when our healthcare system doesn't discriminate against cancer types.

– Gemma, living with a rare bowel cancer

The strain on the PBAC resource is also clear. It is critical that Australia's reimbursement process has the capacity and capability to assess new technologies and medicines quickly and effectively. Last year's deferral of applications, including some for rare cancers, must not happen again.

Resource constraints also cannot excuse a lack of engagement or transparency. Strong consumer engagement and consultation is important in ensuring patient experience and patient reported outcomes, including the broader personal and social impacts of access to medicines, are part of decision-making. *The Enhance HTA Report* identifies important ways to improve and strengthen transparency and engagement, including the introduction of a system with clearer notifications and other measures to support more relevant, direct and concise input from the most valuable of information sources: consumer groups and the patients themselves[46].

The uncomfortable truth is that people are dying even though effective treatments exist.

So far, the response to this is the long-awaited HTA reform, which will be a marker of the Albanese Government's success. With a majority government and multi-partisan support for HTA reform and equitable access to medicines, this is the time to tackle the tricky questions and get to work on implementing the recommendations of the HTA Review.

The HTA Review acknowledges many of the barriers that prevent people with rare cancers from accessing the medicines they need, maintaining a clear focus on ensuring patients can access the best treatments when they need them. It represents a significant step in the path to reform. If adopted, the recommendations could have a profound impact for people with rare and less common cancers. They could:

- enable faster access to life-saving and life-improving medicines
- allow therapies to be approved across multiple cancer types in one application ('pan-tumour' assessment), meaning thousands more patients would benefit from affordable medicines that others can already access
- address some of the evidentiary challenges for small patient populations, through greater use of different trial designs, real-world evidence, patient-reported and social value measures
- amplify the patient voice in decision-making and increase transparency[46].

> I've said that if we're re-elected, implementing this review is a very serious part of a second-term agenda for health.
>
> – The Hon Mark Butler MP, Minister for Health and Ageing[45]

> The reality here is that this review was long overdue... we had the review, the findings were brought down last September, and we've seen very little since then, and we've certainly seen no improvement in Australians getting access to life-changing and life-saving medicines in a quicker timeframe.
>
> – Senator the Hon Anne Ruston, Shadow Minister for Health and Aged Care[45]

There remains a long path between the intention for reform and patients benefiting, with a risk of inertia as has been seen following other reviews, including *The New Frontier – Delivering better health for all Australians*[47]. The scale of the challenge must not further delay change. Delivery of other critical health policies including the *National Health Policy Framework* and the *National Framework for Genomics in Cancer Control* are relying on HTA reform, as are patients and their families.

When the Independent Advisory Group issues its advice regarding a roadmap for implementation in early 2026[48], there can be no more buying time. The resources and funding must be made available to deliver faster, fairer access to medicines for all Australians, with an unwavering focus on equity.

The current inequities are known and evidenced – failure to act now will intentionally leave people behind. It is time to finally level the playing field.

Personal decisions: Understanding what matters

Every patient is a person. They hold their own values, responsibilities, hopes and fears, which can influence treatment and care decisions. They should be supported to ask questions, seek information and be involved in their care in a way that meets their preferences and needs.

People don't always have the same treatment goals, underscoring the importance of working with people to identify what they want and their personal priorities. Nearly half (45%) of Cancer Lived Experience Survey respondents said achieving survival or cure was most important to them during their initial cancer treatment. Maintaining quality of life, including managing side effects, pain and physical changes, was most important for a further one in four (23%).

The majority (77%) of respondents to our Cancer Lived Experience Survey said they (or the person they cared for) were involved in decisions about which treatment/s to have for their rare or less common cancer and when to start. For one third of them (32%), only one treatment option was available. One in ten (11%) said they preferred to let their clinical team make the treatment decisions.

Cancer Lived Experience Survey respondents with a rare or less common cancer were more likely to have had chemotherapy, immunotherapy including CAR T-cell therapy, a targeted therapy and/or a stem cell or bone marrow transplant than respondents with a common cancer. They were less likely to have had surgery.

One in five (19%) survey respondents with a rare or less common cancer felt their treatment options were not presented in an understandable way when they were diagnosed. One in two (56%) were informed that their case had been reviewed by a multi-disciplinary team (compared with 42% of respondents with a common cancer).

Thirteen per cent of Cancer Lived Experience Survey respondents said they or the person they cared for had chosen not to proceed with a recommended treatment.

The most common reasons were:

51%
concerns about side effects, impact on quality of life, or physical changes

44%
the treatment not being curative or improving survival

13%
limited ability to spend time with friends

8%
the cost of the treatment

There was no significant difference between the responses of people with rare and less common cancers and those with common cancers.

Strengthening care through a new Optimal Care Pathway for people with rare and less common cancers

The development of the first Optimal Care Pathway (OCP) for People with Rare and Less Common Cancers is a national initiative under the *Australian Cancer Plan*, led by Rare Cancers Australia. It will set out a standardised, evidence-based roadmap for high-quality cancer care across the entire care continuum—from prevention and early detection, through to diagnosis, treatment, survivorship, and end-of-life care.

This OCP is critical, given rare and less common cancers often lack specific clinical guidelines and are not well recognised in mainstream cancer care. The creation of this OCP recognises that people with rare and less common cancers face unique and specific challenges and their diagnosis, treatment and care require a different approach. It will provide information and resources for clinicians who may have limited experience with a rare cancer or are not aware how to access established protocols. The OCP will help to address this gap by supporting consistent, coordinated, and equitable care regardless of where a patient lives or the rarity of their cancer.

Importantly, the OCP is being shaped through deep collaboration with patients, clinicians, and stakeholders from across the cancer sector to ensure the pathway reflects real-world experiences and needs, to deliver tangible improvements in care and outcomes.

Improving experience and outcomes

Adherence to OCPs supports earlier diagnosis, timely access to care and treatment, and ultimately, improved cancer outcomes and survival[51]. Core principles guiding OCPs include embedding supportive care throughout the pathway, and ensuring individuals are informed and actively involved in decision-making. In line with these principles, the OCP for People with Rare and Less Common Cancers will be accompanied by a consumer guide, to help patients and families understand what best-practice care should look like and empower them to advocate for their needs. Alongside clinical guidance, the OCP will put information directly in the hands of both patients and providers, transforming clinical practice and lived experience.

> **I want to see that no matter where you are, who you are, that every patient who is diagnosed with a rare or less common cancer gets the best possible care in Australia.**
>
> **– Lillian Leigh, Co-Chair, Optimal Care Pathway for Rare and Less Common Cancers Expert Working Group, living with a rare lung cancer.**

Is a new dawn finally breaking on a multi-cancer approach to medicines access?

The development of immunotherapy has brought great hope to many people diagnosed with a rare or less common cancers. But that hope remains heavily restricted by inequitable costs.

Since the initial listing of Programmed Death-Ligand 1 (PD-(L)1) inhibitors nearly a decade ago, evidence of their effectiveness and application has grown, particularly in metastatic and advanced cancers[74, 75]. This is exemplified by the significant improvements in patients with advanced melanoma, recent studies indicating PD-(L)1 inhibitors as monotherapies or in combination have extended the median overall survival to approximately 30-70 months[74, 75]. Many patients also report a lower impact on their daily function and quality of life than they experienced from chemotherapy.

However, under the current HTA system, people with rare cancers tend to miss out on subsidised access, even when there is a strong indication that the treatment would be effective for them based on the genomic profile of their cancer. This is not just a matter of how long it takes for the PBAC to evaluate, but whether the treatment is submitted for consideration for their rare indication at all, given the evidentiary requirement, small population from which to generate data, and the cost and time associated with applications.

Patients find themselves in a cruel lottery: if you're diagnosed with a common cancer, there is a good chance that your treatment will be Pharmaceutical Benefits Scheme (PBS)-listed, with a manageable co-payment of $31.60 – set to reduce to $25 in 2026[76]. Yet if your diagnosis is rare, it is unlikely that you are eligible for PBS subsidy, so you are left to pay out-of-pocket – sometimes $6-10,000 per treatment cycle. Due to the extremely high cost, many patients will miss out entirely.

There is a fairer way. By using evidence differently and assessing applications across cancer types – a 'pan-tumour or 'multi-cancer' application – people with rare cancers could have access too.

Successive Government inquiries and reviews have recognised the need for a change like this, including the 2024 Senate inquiry and the HTA Review[1, 43]. 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.

After seven years of advocacy and discussion, there is renewed hope of a way forward. In July 2025, the PBAC considered two re-submissions for the PD-(L)1 inhibitors Pembrolizumab and Nivolumab for broad listing of cancers. These submissions sought subsidised access to treatment for patients with several types of cancer in the one assessment, based on evidence from other cancer types. If recommended, these approaches could pave the way for multi-cancer approvals across other treatments. At the time of writing, the outcomes of the PBAC meeting were unpublished. People with rare cancers are eagerly awaiting the outcome and a step towards equity of access.

In a community consultation exercise led by RCA in late 2024, 182 people with cancer told us about cancer's financial impact.

One in three

people said they had been told that a test or treatment was funded for other cancer types but not theirs.
This was higher for people with a rare cancer **(38%)** than those with a common cancer **(18%)**[38].

Leading with high unmet clinical need

HTA is an imperative, quantitative process to evaluate the uncertainties, risks and costs associated with a submission to support the PBAC or MSAC to decide whether to recommend the subsidy of a new therapy. However, it is not the only factor that is considered. The committees also look at the broader potential impact of a therapy or device, recognising the differential impact for various patient communities. For example, some patient communities have access to multiple effective therapies while others have no, or very limited, available treatment options and therefore face a higher mortality and quality of life impact, meaning a new treatment would bring additional value for that group. This is the case for most rare cancers.

Identifying agreed areas of high unmet clinical need would provide reviewing committees, industry sponsors and stakeholders with a clear and shared understanding of the targets for improving equity and increasing access to treatments where they are most needed. The HTA Review Committee recognised the need to identify therapeutic areas of high unmet clinical need, recommending a process and criteria be developed to support ongoing identification (recommendation 44, HTA Review)[48]

Clarity could encourage engagement between committees and sponsors about those areas, the level of need and desired solutions to more efficiently direct resources towards submissions in these areas. A high priority clinical unmet need list and an invitation, or incentive, for sponsors to advance medicines and technologies that address those areas could proactively narrow the current gaps in access[43], rather than a system that is driven by sponsor submissions. The establishment of bridging funding to speed up access to TGA registered therapies with high added therapeutic value that address the unmet clinical needs of this group would further reduce the current inequity.

Recommendation 4

The Australian Government should urgently remove barriers to fast and fair access to treatments for people with rare and less common cancers so that every person diagnosed has affordable access to the best treatment when they need it:

- **subsidise access to treatments across multiple cancer types without the need for separate applications for each type ('pan-tumour' or 'multi-cancer' assessment)**
- **reduce the median time for a medicine to be listed on the Pharmaceutical Benefits Scheme (PBS) following Therapeutic Goods Administration (TGA) registration to 60 days**
- **identify areas of high unmet clinical need and prioritise increased access to medicines for this group through incentives and bridging funding**
- **strengthen consumer involvement and transparency in decision-making and significantly increase resources for the Pharmaceutical Benefits Advisory Committee (PBAC) and the Medical Services Advisory Committee (MSAC), enabling faster and more responsive assessment processes.**

When distance becomes a barrier

People diagnosed with rare and less common cancers face not only a life-threatening illness but a heavy financial burden[38].

To access specialist expertise, tests and treatments, many patients and their carers need to travel long distances, including interstate or abroad, and stay away from home and their support networks for extended periods of time.

For patients in regional and remote areas, the burden is even greater. Many must travel long distances or temporarily relocate to access treatment, incurring thousands in additional costs[49, 50].

Telehealth and virtual multi-disciplinary teams are important for ensuring patients can access specialist expertise regardless of where they live. Earlier this year, the Australian Government committed four years of funding for the Australian Rare Cancer Portal (ARC Portal), a platform that connects local clinical teams with Australian and international rare cancer expertise, tailored to the individual patient's case[13]. The ARC Portal plays a particularly important role in bridging the care gap for people in rural and remote areas, with 45% of its referrals in the first four years coming from outside major city centres[77]. However, there will always remain a need for people with rare cancers to travel to access highly specialised treatments and clinical trials, making financial subsidy even more important.

Access to emerging therapies such as CAR T-cell treatment remains particularly challenging. The complexity of administering CAR T therapy—limited to a small number of accredited centres in Australia—requires patients and a full-time carer to relocate and remain within close proximity of the treating service for follow-up monitoring or urgent care for months at a time. These requirements have a huge impact on people's lives, particularly those outside major centres, with the burden of travel, accommodation, time off work, and care responsibilities making access logistically and personally difficult.

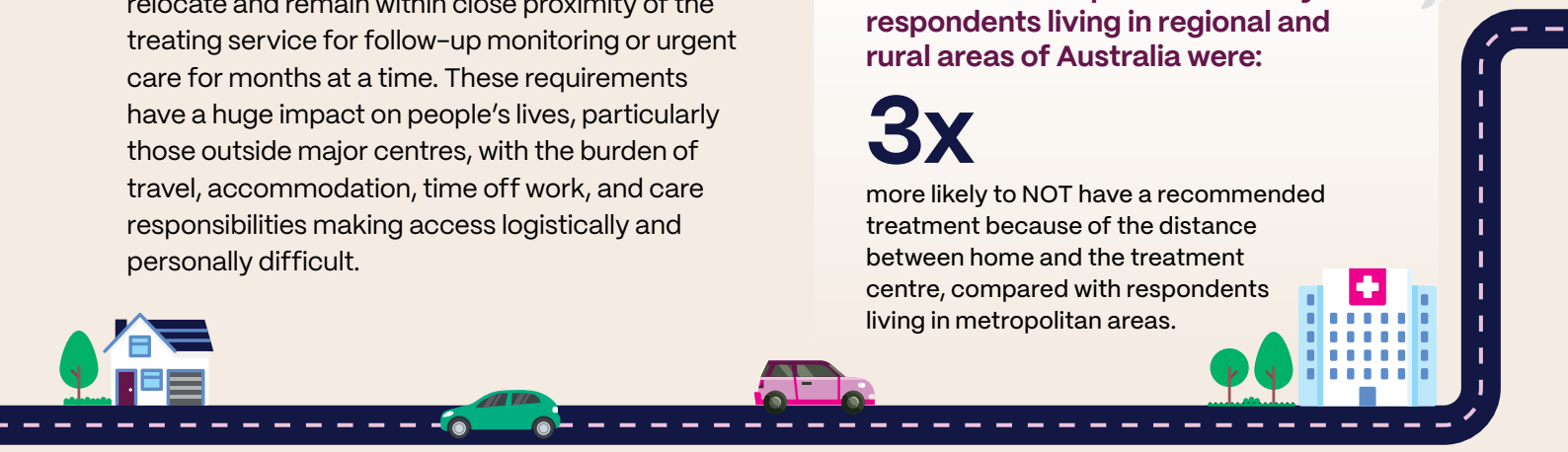
> **We have to travel to South Australia for a clinical trial to hopefully prolong my husband's life – but my son needs to attend school and we have limited family supports.**
>
> **– Gaby, carer for husband who is living with glioblastoma**

Access to treatment abroad is another major financial burden for many people with rare cancers. With some treatments such as proton beam therapy not yet available in Australia, and many emerging targeted therapies and personalised vaccines not subsidised here, patients and their families look abroad. The Medical Treatment Overseas Program was established to bridge that gap, but many people with rare cancers are denied support because their treatment is not intended to cure the disease – it may be to stabilise or slow its spread to give them important extra years with family. It is hard to access and clinicians report frustration with the criteria and inflexibility. The Program is an expensive way to fund treatment that would be cheaper to deliver in Australia, with less disruption and risk for the person having it.

Cancer Lived Experience Survey respondents living in regional and rural areas of Australia were:

3x

more likely to NOT have a recommended treatment because of the distance between home and the treatment centre, compared with respondents living in metropolitan areas.



> Trying to work, pay bills and keep food on the table while juggling tests, treatment and poor health puts incredible strain on patients and their families. It is heartbreaking hearing parents tell us that they cannot feed their children, are taking on extra shifts instead of being at the hospital with their child, or have debt collectors knocking at the door while they are managing treatment.
>
> The additional costs quickly add up and there simply isn't enough financial support available – and that becomes even harder when the person needs to travel for treatment. The financial relief available is not sufficient and for many patients it becomes another administrative hurdle when they need to focus on their treatment and spending time with loved ones.
>
> – Cathy Slattery, Head of Patient Programs, Rare Cancers Australia

State and territory-based patient travel and accommodation scheme reimbursement rates fall far short of actual expenses, leaving patients and their carers significantly out-of-pocket. Only NSW and ACT patients can access funding to travel for clinical trials or experimental treatments, and many states will not cover any costs for a carer who needs to travel with the person having treatment. For people accessing treatment outside of their home state, there is greater complexity in seeking financial assistance.

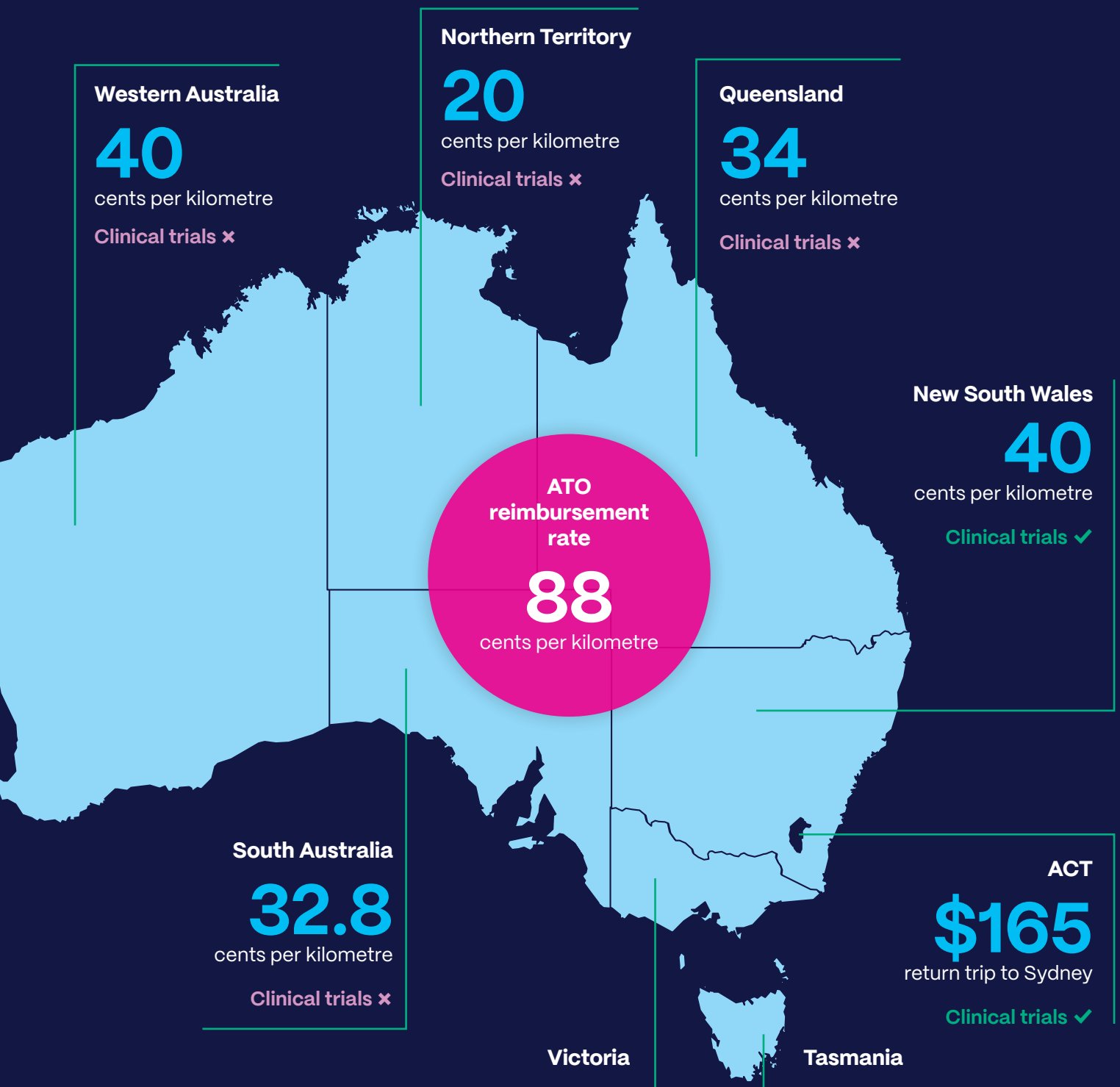
In Australia, the Australian Taxation Office (ATO) sets a standard reimbursement rate of 88 cents per kilometre for work-related car travel in the 2024–25 financial year. In contrast, patient-assisted travel schemes are less than half that rate of reimbursement for patients travelling to access medical care.

The variation in reimbursement rates across Australia and the overall lower compensation compared with the ATO's standard highlight the need for a nationally consistent and adequate patient travel subsidy scheme, as recommended in the Senate inquiry[1]. Such a scheme would aim to reduce the financial burden on patients requiring travel for medical care, ensuring equitable access to necessary health services regardless of geographic location or the greater need to travel due to the rarity or complexity of their cancer.

Recommendation 5

The Australian and State and Territory Governments should increase and equalise financial support for people accessing treatment away from home, including clinical trials, and raise reimbursement rates to match those set by the Australian Taxation Office.

Variation in patient travel scheme reimbursement rates across Australia



Western Australia
40
cents per kilometre
Clinical trials ✗

Northern Territory
20
cents per kilometre
Clinical trials ✗

Queensland
34
cents per kilometre
Clinical trials ✗

New South Wales
40
cents per kilometre
Clinical trials ✓

ATO reimbursement rate
88
cents per kilometre

South Australia
32.8
cents per kilometre
Clinical trials ✗

ACT
$165
return trip to Sydney
Clinical trials ✓

Victoria
21
cents per kilometre
Clinical trials ✗

Tasmania
24
cents per kilometre
Clinical trials ✗

FIGHTING FOR XAVIER

A family's relentless battle against neuroblastoma

When Xavier was diagnosed with stage 4 high risk Neuroblastoma in March 2021, he was just three years old. For his parents, Danielle and Andrew, it marked the beginning of an unrelenting fight to save their little boy's life – one that has taken them halfway around the world. Danielle, a devoted mother and advocate, shares their story.

"Xavier's symptoms came out of nowhere one night. He came into our room with severe abdominal pain and projectile vomited all over our bed. We initially thought he had appendicitis so immediately called an ambulance.

By the time we reached the hospital, Xavier seemed fine and happy. But days later, his pain returned, this time in his back. We saw multiple doctors, and despite blood and urine tests, we were told it was just a virus.

By the end of the week, the pain had moved to Xavier's chest; he couldn't even climb up on my bed. I called another ambulance, and we ended up at the Women's and Children's Hospital in Adelaide.

I pushed for an x-ray, and that's where they'd found a solid mass in his abdomen. An ultrasound and CT scan confirmed the worst. Xavier had a solid tumour on his right adrenal gland; it was called neuroblastoma.

Xavier with mum Danielle and with his two siblings, Isabelle and Benji

From that moment, we didn't leave the hospital. We were in the trenches. Xavier went through 18 months of intense treatment including chemotherapy, surgery, high dose chemo with stem cell treatment, radiotherapy, and immunotherapy.

Even though treatment made him incredibly sick, I wanted to give Xavier as 'normal' a life as possible. He loves swimming, so after his second round of high-dose chemo, we pushed to replace his central line with a port so he could get back in the water. It was one of the best decisions we made.

This led to me pushing very strongly for Xavier to have his treatments, where possible, conducted at home. At first, his treating team looked at me like I had four heads, but thankfully our oncologist was understanding of our needs and priorities and listened.

It has made a huge difference. Now we're in hospital for only a couple of hours a day, the rest can be done at home. We've been able to try new approaches like hyperbaric oxygen therapy, hydrogen inhalation, and selected supplements. Being able to do it all from home has given us flexibility—especially with our plumbing business to run and two other children, Isabelle (9) and Benji (3), who are still so young and need us too.

Alongside conventional treatments, I've also worked closely with an integrative GP and naturopath, with the support of Xavier's oncology team. The deal through all of this was we had to have an honest, open relationship, which it is, and it has worked well.

After finishing treatment in September 2022, Xavier was declared NED (no evidence of disease). We were so relieved. But our relief was short lived. Just six months later, scans showed two new growths. Xavier had relapsed.

His only chance of long-term survival lay overseas: a clinical trial at Memorial Sloan Kettering (MSK) Cancer Centre in New York, which would cost us upwards of half a million dollars.

We drained our savings, ran fundraisers, worked with media – anything we could do to get Xavier there. In March 2024, we flew to the US to start his treatment. We were there for over a month at a time, commuting back and forth with the kids for approximately six months. It was a lot to handle.

What we found over there though, was world-leading, child-focused care. The team at MSK were incredible. Their holistic, tailored approach to treating neuroblastoma blew us away. I learned so much and I brought back ideas to share with Xavier's team here. To their credit, they listened. Having Xavier's team in New York, but then also having our team here, has oddly ended up giving us the best of both worlds.

Just when we were settling into our new routine of treatment abroad, our world was turned upside down once more when we received the news that Xavier had relapsed again.

Our team at MSK in New York remained hopeful to continue treatment, but we had to wait until Xavier reached NED again, to recommence the vaccine trial that could be his lifeline. This will cost us a further $150,000 and we're doing everything possible to raise the funds.

I strongly believe that we as parents shouldn't have to fundraise to save our children's lives. It's so wrong. We are having to raise over half a million dollars and that's still not enough.

This is where Australia's Medical Treatment Overseas Program (MTOP) must evolve. It needs to support access to phase 2 trials and rare cancer treatments, especially when no viable alternatives exist at home. Families shouldn't be forced to choose between going broke or giving up.

In mid-2025, we were grateful to hear that the Australian Government had finally secured domestic access to a treatment called DFMO, a promising drug for patients in remission from neuroblastoma, is now publicly available. For the first time, Xavier was eligible and we were ready to start him on the medication in July.

> **There is no 'standard path' with rare cancers like his. I've seen so much change in neuroblastoma treatment pathways over the past five years or so and am hopeful more change will come.**

Xavier with mum Danielle

But before he could begin, a new focal relapse was detected. Xavier had relapsed again.

This is now his third relapse, and it highlights what many families like ours are facing: neuroblastoma must be treated not just as a one-time disease, but as a chronic illness—one that requires long-term access to treatment options, innovative drugs, and clinical trials.

We're tired and we're heartbroken. But we're still fighting.

As Xavier's mum, I will never stop. We'll keep pushing, keep researching, keep hoping. Xavier deserves a future—and so does every other child facing this cruel disease.

Supporting rare

Supportive care is not an optional extra. It is a critical pillar of comprehensive cancer care that helps people to live as well as possible with their cancer, not just survive.

Alongside the best available medical treatment, patients should have access to comprehensive supportive care that includes effective symptom management and psychological, practical, and spiritual support. Integrative cancer care brings together conventional treatments with evidence-based supportive and complementary therapies, addressing the emotional, social, informational, and spiritual needs of patients throughout their cancer[52]. This approach is particularly important for people with rare and less common cancers, who often face complex challenges that extend well beyond clinical care.

Meeting the support needs of people with cancer leads to better outcomes – improving quality of life, increasing treatment adherence, and reducing complications. National and international cancer care frameworks increasingly recognise that addressing the full spectrum of patient needs is essential to delivering effective, person-centred care[28, 53, 54].

The story of cancer has changed. People are now living for years, or decades, with advanced and 'treatable but incurable' cancers. With the right medical, integrative and supportive care, they can live well, but our services and pathways have not kept pace with their evolving needs. These needs will shift over time and may span from the uncertainty of diagnosis and treatment, through periods of active management, survivorship, or progression, to end-of-life care.

Young people diagnosed with early-onset cancer often face distinct challenges, including impacts on education, employment, fertility, and relationships, requiring tailored, age-appropriate support. Given this complexity, it is essential that the care team regularly review patient needs and adapt supportive care plans, particularly during key transition points such as changes in treatment, disease progression, or shifts in personal circumstances.

> **For incurable cancers such as mine, I needed help to find alternative therapy options. A cancer navigator was a major find to help with other recommendations such as possible overseas treatments, genomic testing and enrolling in clinical trials.**
>
> **– Person with cancer, Cancer Lived Experience Survey**

Support that's still out of reach

A responsive and person-centred supportive care system is vital to helping people navigate these complex and evolving challenges. Yet, for people with rare cancers, access to supportive care services remains inconsistent and, in many cases, inadequate.

People in regional and remote areas often experience even greater unmet support needs, facing additional challenges such as limited access to psychosocial services and survivorship care close to home[78].

Nearly half (49%) of Cancer Lived Experience Survey respondents with a rare or less common cancer (compared with 33% of respondents with a common cancer) reported that their mental health needs could be better supported during their cancer experience.

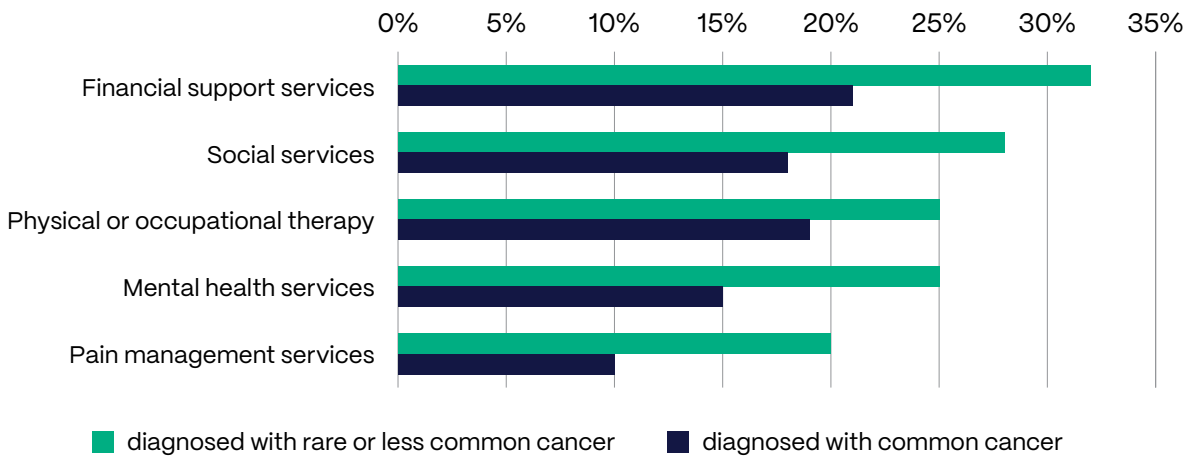
People diagnosed with rare cancers face a disproportionately high burden of psychological distress. Evidence points to significantly elevated rates of anxiety, depression, post-traumatic stress disorder, and suicide among this group, compared to both the general population and those with more common cancers[55]. These outcomes are strongly influenced by factors such as advanced disease, intensive treatment, and socioeconomic disadvantage[55].

One in four respondents to the Cancer Lived Experience Survey with a rare or less common cancer (compared with 15% of respondents with a common cancer) identified that they were not referred to mental health services but would have liked to be.

The findings reinforce the need to embed tailored psychosocial support within rare cancer care pathways and to prioritise timely needs assessment, recognition and referral for management of psychosocial issues as a critical component of care.

This must be supported by workforce training and upskilling to ensure all members of the care team are equipped to identify and respond to the unique psychosocial needs of people with rare and less common cancers.

Figure 4: Unmet support needs* identified through the Cancer Lived Experience Survey



*respondents that agreed with the statement 'I was not referred, but I would have liked to be'

63%

of survey respondents with a cancer diagnosis **relied on their family, friends and social support networks** to provide a "great deal" of support.

59%

of Cancer Lived Experience Survey respondents impacted by a rare or less common cancer reported that their **cancer experience made their household financial situation worse**.

Beyond gaps in mental health support, survey respondents with rare and less common cancers were significantly more likely to identify unmet support needs for pain management, physical and occupational therapy, financial support services, and social services. This reinforces the critical need to better integrate comprehensive supportive care into the cancer system, particularly for those facing complex, long-term challenges.

Support to exercise safely and effectively is also important. The Clinical Oncology Society of Australia (COSA) recommends that exercise be embedded as part of standard practice in cancer care and to be viewed as an adjunct therapy that helps counteract the adverse effects of cancer and its treatment[60]. Exercise has been shown to reduce treatment-related side effects, improve physical function and fatigue, enhance mental wellbeing, and may even improve survival outcomes[54, 60]. For people living with rare and less common cancers, many of whom live with their cancer for long periods, ongoing access to evidence-based exercise programs tailored to their individual needs should be embedded into supportive care planning.

The financial impacts of cancer on the rare cancer community are impossible to ignore. The cost of treatment, travel, time off work, and other care-related expenses creates significant financial toxicity[56, 57]. This burden is often higher for people with rare cancers who may also need to travel long distances to access treatment or seek out treatments that are not subsidised[38].

One in three patients contacting Rare Cancers Australia for support in the 2024–25 financial year reported financial concerns during their first contact, highlighting the depth and persistence of financial strain within this community.

Despite the higher support needs of people with rare and less common cancers, findings from the Cancer Lived Experience Survey show that many supports remain out of reach. The impact of unmet support needs on quality of life, treatment adherence, and mental health cannot be overstated[58, 59]. Addressing this gap is essential to improving the lived experience, well-being, and long-term outcomes of patients and their families.

To do this, we must ensure the experiences and needs of people with cancer are heard and acted on. Australia needs a National Cancer Lived Experience Survey, as is done in other countries, to understand and track what matters most to patients across different cancer types, locations, and population groups, and understand what cannot be seen through traditional clinical metrics. This would provide the evidence needed to guide more responsive and equitable supportive care policies, services, and investment.

> **I still don't understand how you're supposed to survive financially if you can't work because of cancer. I was diagnosed in my 40s as a renter, and my family barely had money to eat for my first year of treatment. We ended up borrowing money from family, but that resulted in a rift that hasn't been healed. I couldn't even access unemployment. Why isn't there some financial aid for cancer sufferers?**
>
> **I feel like I've lost my chance at life, and my future is futile, even if I somehow manage to survive the cancer.**
>
> **– Person with cancer, Cancer Lived Experience Survey**

Personalising supportive care

People affected by rare cancers need access to support that is flexible, responsive, and grounded in choice, particularly in terms of who provides that support.

Support needs are shaped by a person's social and cultural context, the stage of their cancer pathway, and where they live. What makes supportive care truly effective is its ability to adapt to each individual's unique experience, acknowledging that needs evolve over time and may differ across geographic, cultural, and personal circumstances[53, 58, 61].

Some people may prefer support from clinical professionals, while others may find greater comfort and understanding from peer groups, community organisations, or culturally specific services[62]. Ensuring people have meaningful choices in how and from whom they receive support is essential to providing care that is person-centred, equitable, and impactful.

The *Australian Cancer Plan* recognises this need, calling for the development and implementation of integrated, multi-channel, multi-disciplinary navigation models that ensure people receive the right support at the right time across the cancer continuum[28]. Similarly, the Senate inquiry recommended that the Australian Government provide sufficient funding and resources to realise the supportive care aspirations of the Cancer Plan for all Australians, including those affected by rare cancers[1].

60%

of Cancer Lived Experience Survey respondents diagnosed with a rare or less common cancer said they **needed or would have liked access to a supportive care navigator.** However, only **24%** were referred and attended, while **36%** were not referred but would have liked to be.

> **Listening to our patients is perhaps the most important thing we can do when it comes to mental health and quality of life for patients diagnosed with a rare or less common cancer. Having conversations that matter, talking more honestly and confidently to help those in need to access available resources and supports is imperative.**
>
> **Normal distress arises and dissipates and can often be helped with compassion and validation. Distress can also be experienced by many patients as burdensome, overwhelming, and unwanted, persisting over time and situations. Usual coping strategies are unhelpful or may make the problem worse. This distress and difficulty coping can interfere with a person's adjustment and treatment for their cancer and disrupt valued roles, commitments, goals and ultimately quality of life.**
>
> **Clinicians all have a role to respond to this distress along the continuum of cancer care. A cancer nurse coordinator or care navigator can provide a central point of contact for patients to help identify any unmet needs and support access to appropriate supportive care services.**
>
> **– Jo Keyser, Rare Cancer Clinical Nurse Consultant, Cancer Network WA**

When you're diagnosed with a rare cancer, the information is very hard to find. So trying to get my head around what it was I was dealing with was really difficult. I went looking through Facebook and found the Rare Cancers Australia webpage and then found that they also had a sarcoma group, which was just an absolute Godsend because when you get a rare cancer and you can't find anything, you feel very unseen and very isolated.

And, you know, no one's doing charity cricket matches or marathons to raise money for malignant peripheral nerve sheath tumours – it doesn't roll off the tongue very well. So to find a group that you can identify with, it was just a huge relief. To be able to speak to other people that had been through what I was going through, it really helped give back a little bit of control."

– Bronwyn, living with peripheral malignant nerve sheath tumour

Guiding the way: Why navigation matters

Navigating the healthcare system can be overwhelming and isolating, particularly when facing an unfamiliar cancer type or limited local services.

Care navigation provides patients and their families with a consistent point of contact to guide them through their cancer. It focuses on the person's experience, helping them understand their diagnosis, treatment options, and available support services[63, 64].

Navigation is deeply person-focused, empowering individuals to actively engage with their care, ask informed questions, and make decisions that align with their values, priorities and needs. When integrated with clinical care, navigation helps ensure patients and carers receive the right support, from the right person, at the right time[63, 65].

> **Rare Cancers Australia's Patient Support Program connects individuals with Specialist Cancer Navigators who provide personalised, guidance throughout their cancer experience.**

Navigators assist patients in accessing a wide range of services across the health, social services and community sectors, including financial assistance, support with treatment fundraising, peer support networks, clinical trial information, and travel arrangements—all while addressing emotional and psychological needs. Data from the program reflects this demand: the top support requests in 2024–2025 include resourcing and practical assistance (29%), financial support (23%), and connection to support groups (15%).

To ensure this care remains person-centred and responsive, in 2025 Rare Cancers Australia introduced a more structured approach to capturing patient-reported outcomes and experiences. This includes embedding distress screening and PROMs tools into our Patient Record Management System to monitor well-being and identify support needs without adding burden to the patient. In addition, patients are invited to complete PREMs questionnaires to share feedback at key points in their journey. These tools help our Navigators understand how patients feel over time and adapt care accordingly, ensuring the support we provide continues to reflect what matters most.

Navigation is a critical enabler of the Optimal Care Pathway and must be recognised as a core component of comprehensive cancer care. Embedding navigation into cancer care systems improves the lived experience of patients, enhances health equity, and supports better outcomes, especially for those with rare or complex cancers who may otherwise fall through the cracks[66].

People with rare and less common cancers often report difficulty accessing clear, timely, and relevant information about their diagnosis, treatment options, and prognosis[67]. According to the Cancer Lived Experience Survey, 35% of survey respondents with a rare or less common cancer reported that they could be better supported with access to information. This highlights the urgent need for more accessible, tailored, and patient-friendly resources to help patients and families make informed decisions and feel more supported throughout their care journey.

RCA Specialist Cancer Navigator, Rebecca Brookman

The Australian Cancer Nursing and Navigation Program (ACNNP) is a national government initiative aimed at improving access to high-quality, culturally safe, and person-centred cancer care for all Australians, regardless of cancer type or geographic location.

Central to the program is the co-design of a national framework that supports integrated, person-centred cancer care navigation. The program promotes innovation in care delivery, recognising the need for flexibility and the diverse roles played by health professionals across different settings. Importantly, navigation services under the ACNNP are aligned with Optimal Care Pathways, helping connect individuals to a range of critical supports including financial aid, psychological care, and other supportive services.

Sine 2012, Rare Cancers Australia has provided vital practical, emotional and financial support to people with rare and less common cancers, their carers and their families. Our multi-disciplinary expertise, understanding of the unique challenges faced by the rare community and strong connections across the health and care sector enable us to provide tailored information, support, and guidance to individuals and families navigating complex and often under-resourced care pathways.

As a proud partner in the ACNNP, we have been able to support more people, with thousands of new referrals each year. We are committed to ensuring that the needs of those with rare cancers are not only recognised but meaningfully addressed within the emerging national framework, working in close alignment with other patient organisations, Cancer Australia and the Department of Health, Disability and Ageing.

The *Australian Cancer Plan* calls for the evaluation, adaptation, and national scaling of integrated care navigation models across the cancer care continuum[28]. Ongoing monitoring and evaluation of the ACNNP will identify the most responsive, sustainable, and effective way to ensure every person with cancer in Australia has access to the right information and support at the right time.

Recommendation 6

The Australian Government and Australian Cancer Nursing and Navigation Program (ACNNP) partners should ensure every person diagnosed with a rare or less common cancer has access to tailored information and evidence-based supportive care, based on their personal needs, through:

- **continued delivery and evaluation of the Australian Cancer Nursing and Navigation Program**
- **sustained funding for established specialist patient support services**
- **a national cancer patient experience survey to measure whether needs are being met.**

A one-in-a-million diagnosis – twice: A family's rare cancer journey

Doctors were stunned when Celestino was diagnosed with a rare cancer while caring for his daughter Jasmine, already facing a rare cancer diagnosis of her own. Both cancers were considered 'one-in-a-million'. Now, Celestino and his wife Michelle reflect on the heartbreak, navigating a system not built for rare, and the support that got them through.

JASMINE'S STORY, AS TOLD BY HER MUM, MICHELLE

"Our daughter Jasmine was 16 when she began experiencing pelvic pain. It seemed minor at first; just a dull ache when sitting. Her GP assumed it to be muscular and we tried osteopathy, but the pain never went away. Scans were inconclusive. Then Jasmine found a lump in her breast, and everything changed.

That lump led to a biopsy, and we heard a word we'd never heard before: rhabdomyosarcoma – a rare, aggressive childhood cancer. It's diagnosed in about one in a million Australian children each year. By the time they found it, the cancer had already spread throughout her body.

Jasmine began 42 weeks of chemotherapy and six weeks of radiation. It was gruelling, but she responded well, and we were relieved when doctors said the word "remission." She continued with 18 months of maintenance chemo and radiation, and throughout it all, she finished high school and got an ATAR of 95.45. We were so proud of her strength and resilience.

Nine months after finishing treatment, the cancer returned.

> **There is no standard treatment for relapsed rhabdomyosarcoma so it's just a case of trying anything you can.**

She went through another 51 weeks of chemo and more radiation and went into remission again, only to relapse nine months later.

Jasmine found it to be deeply isolating. Most people don't know what to say, so they say nothing. And then, as if things couldn't get harder, my husband Celestino was diagnosed with a rare cancer too – adrenocortical carcinoma (ACC).

We couldn't find anyone who'd heard of it, so we reached out to Rare Cancers Australia (RCA). Finally, we found others who understood what we were going through.

Despite everything, we were all determined to keep living life. Jasmine took a break from treatment to get married. She was the most beautiful bride. But the next day she felt unwell, and was back in hospital. Her cancer had returned and had spread significantly. Regretfully, she was forced to cancel her honeymoon.

We had one last avenue: when she was first diagnosed, Jasmine had joined the Zero Childhood Cancer Program, which tests your tumour against a range of treatments. One combination—immunotherapy with chemotherapy—showed real promise for her tumour's genomic profile. This gave us such hope, but access was a major challenge.

Jasmine with her husband

JASMINE'S STORY (continued)

Because immunotherapy isn't a standard treatment for rhabdomyosarcoma, the hospital was reluctant to pursue it. Even though another young girl with the exact same disease had responded well in a clinical trial – the hospital wouldn't go ahead on ethical grounds.

We know they were just following the rules. But at the same time, Jasmine is literally sitting in front of them saying, "If you don't do this, I'm going to die. I'll sign whatever you want."

It's hard to reconcile rigid systems with a patient literally begging for a chance to survive.

We called RCA and straight away they said, "What can we do to help?" It was so reassuring to have someone willing to fight for us. Thanks to their help, we were granted compassionate access.

She had a few cycles but by then, it was just too late. Her body was exhausted after six and a half years of treatment. She made the decision to stop treatment, and in December 2024 –

> **It's hard to reconcile rigid systems with a patient literally begging for a chance to survive.**

five months after her wedding day – Jasmine passed away at the age of 22.

Although the treatment came too late, we were grateful for the chance to try. That's all she wanted; to know she'd done everything she could.

We packed a lifetime into those six-and-a-half years. She travelled, fell in love, got married, and saw the Northern Lights. She never asked, "Why me?" She simply made the most of every day.

We will honour her by helping others feel less alone, and by raising awareness of the challenges people with rare cancer face. We are so humbled by all the support we've received; no one should have to go through this alone."

CELESTINO'S STORY

I tell people there's more chance of winning Powerball than being diagnosed with a rare cancer at the same time your daughter is fighting her own.

"I was 56 when I started getting fevers, pain in my side, and was constantly running to the bathroom. Scans showed a mass on my adrenal gland. My urologist believed it was benign and decided to monitor it rather than operate. Eighteen months later, the pain returned—and the mass had doubled in size.

> **What are the odds of two people in the same family – my daughter and I – being diagnosed with two of the rarest cancers, at the same time?**

> We need a better, more compassionate system – one that values lives, not numbers. We're not statistics – we're people, with families. It makes you feel expendable.

Michelle and Celestino with their daughter Jasmine

After a risky surgery to remove it, I was diagnosed with Stage 3 adrenocortical carcinoma (ACC). I had never heard of it. As it turned out, my urologist had never had a case of ACC. We were both stunned. What are the odds of two people in the same family – my daughter and I – being diagnosed with two of the rarest cancers, at the same time?

Strangely, my first feeling wasn't fear, it was hope. When Jasmine was diagnosed with rhabdomyosarcoma, I remember thinking, *Why her? Why not me?* So when it was me, I thought maybe this was a sign she would be OK. Maybe it could be me now, not her.

With ACC, we needed help accessing information and finding an oncologist who'd even heard of it. That's when we reached out to Rare Cancers Australia (RCA).

RCA supported our family in ways I can't fully explain. They connected me with information, advice, and other people who understood what we were going through.

RCA's support groups became my lifeline. ACC is so rare – less than 1 person per million in Australia – and we're scattered all over. Without these groups, how would we ever find each other? We share treatment options, clinical trials, and questions to ask our doctors. It wasn't just support. It was survival.

My scans were clear for a while, but 12 months later, I found out the cancer had returned and spread.

A week before getting that news, Jasmine passed away. She was 22. Losing a child was the hardest thing I've ever been through.

The RCA Navigators became like family to us. They found information when we couldn't, helped us understand our options, and have been through it all with us. They are truly special people.

I became the first person in the world to trial a new Theranostics treatment for solid tumour cancers. Early results were promising, but the cancer progressed. Now, I'm on a new immunotherapy trial, and I am hopeful. I know my cancer is incurable, and survival rates are low. My doctors tell me I may only have two years, but I hope I can be here for longer.

What's frustrating is knowing that others with ACC aren't as lucky. Treatment like the one I'm on costs around $8,000 per round out of pocket. It's proven to help – but because our numbers are so small, it's not approved and likely never will be. The system isn't built for people like us.

We need a better, more compassionate system – one that values lives, not numbers. We're not statistics – we're people, with families. It makes you feel expendable.

Together, rare cancers affect tens of thousands of Australian families. There has to be a better way."

Recognising and supporting carers

Caring for someone with cancer presents unique and often intense challenges, and carers themselves need support to manage the emotional and practical demands of their role.

Due to the complex and less well-understood nature of rare cancers, carers frequently face additional burdens, from navigating fragmented health systems and searching for reliable information, to advocating for appropriate care in the absence of established pathways[68]. These demands can force carers to give up work, study, or personal pursuits, leading to emotional, physical, and financial strain[69].

More than a quarter (28%) of carers who responded to the Cancer Lived Experience Survey reported that their financial situation became worse while caring for a person with a rare or less common cancer, reflecting the broader financial toxicity that cancer can impose on entire families.

> **The rarity of the diagnosis can also mean that support networks are limited, leaving carers feeling isolated and unsupported.**

They may have to take on unfamiliar roles such as coordinating specialist appointments, managing treatments, and providing emotional support for their loved one, all while coping with the uncertainty and stress that rare cancers often bring. The intense focus on the person with cancer can make it difficult for carers to prioritise their own needs, increasing the risk of burnout[70].

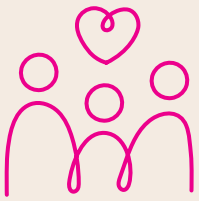
The impact of caregiving can extend across the household, affecting relationships and placing pressure on other family members, including children, partners, and siblings. For young carers supporting someone with a rare cancer, the experience can disrupt education, social life, and future opportunities[71].

Our Cancer Lived Experience Survey revealed significant gaps in support for carers. Over one third (34%) of carers of people with a rare or less common cancer said they were not referred to a carer support service but would have liked to be. 29% said they would have liked to have been referred to a supportive care navigator but were not – almost two times higher than for those caring for someone with a common cancer. There were also unmet needs for mental health, social services, financial support, respite, transportation and genetic counselling.

Almost one third (30%) of carers who responded to the Cancer Lived Experience Survey reported that they were involved in decisions about treatment options. This highlights the importance of ensuring carers have access to the information they need and are recognised as valued and visible partners in care.

The survey also showed concerning gaps in support during the end-of-life period. Over one quarter (28%) of people caring for someone with a rare or less common cancer said they did not feel very or at all supported during this time. Bereavement support was noted as especially lacking, highlighting the need for more comprehensive and compassionate services to assist carers through one of the most challenging phases of the care experience.

In a community consultation exercise led by RCA in late 2024, 182 people with cancer told us about cancer's financial impact.



One third

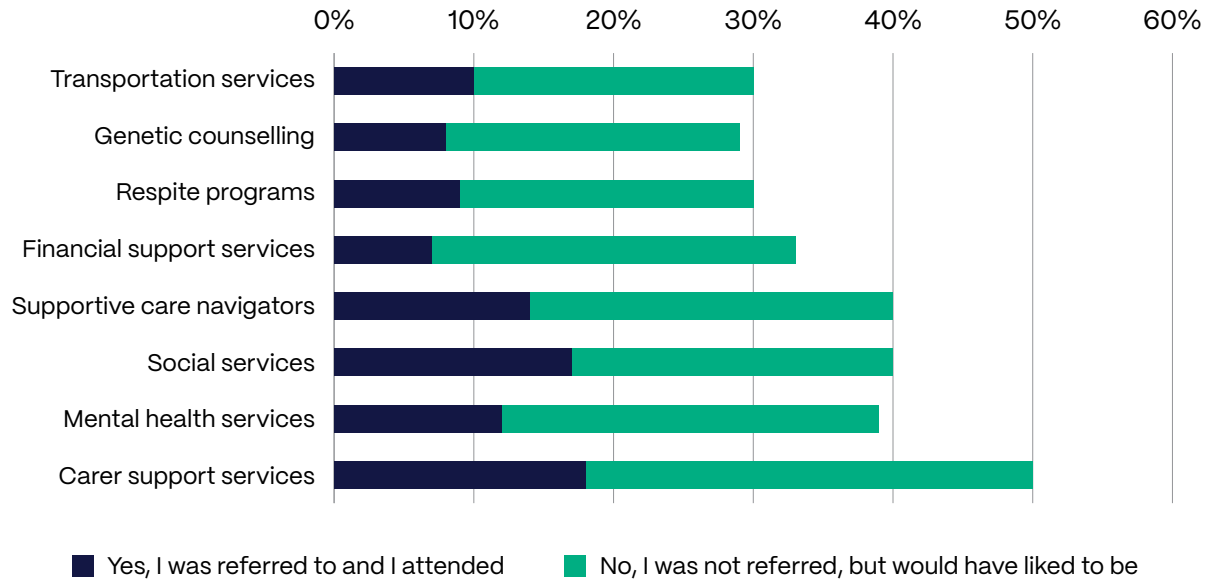
of people said they relied on receiving money from their family or friends because of the costs associated with their cancer care.

The *National Carer Strategy 2024–2034* highlights the importance of ensuring carers can access supports, services, and programs at the right time, in the right place, and in the right way[72]. This aligns with Recommendation 25 of the Senate inquiry which calls on the Australian Government to review the eligibility criteria and adequacy of the Carer Payment and Carer Allowance to ensure carers of cancer patients receive appropriate support[1].

To improve outcomes for both patients and carers, it is essential to recognise carers as key partners in cancer care, and to provide targeted, accessible support that acknowledges the specific challenges of rare cancer caregiving.

> **We are a young family, it has been a lot to go through. You have no choice but to sit back and watch it happen to the person that you love. But hearing from his doctor that there is nothing more that they can do because his cancer is rare... I won't accept that. We just keep digging, and keep fighting.**
>
> **– Cheyanne, carer for her husband, Noel, who lives with thymic carcinoma**

Figure 5: Carer support needs reported through the Cancer Lived Experience Survey*



*Responses from carers of adults diagnosed with rare, less common, and common cancers combined

Equity and access for all: It's time to deliver

Rare and less common cancers affect people of all ages, across every part of the country. Their needs are distinct and complex. For too long, they have been left behind.

Equity will not happen by chance. It requires new ways of thinking, tailored policy, deep collaboration, and unwavering national and local commitment. By personalising our approach to rare cancer care through genomics, equitable access to affordable treatments, specialist expertise, coordinated care, using data and collaboration as a foundation, we can transform outcomes and change the story of a rare cancer diagnosis.

Now is the time to truly listen to people with rare cancers and their families. To turn recognition, reviews and frameworks into action. To turn encouraging words into improved survival and experience.

Together, we can deliver the *Rare Cancer Moonshot*. We can give every person diagnosed with cancer in Australia what they deserve – the best chance to survive and live well, no matter their cancer type, finances, or postcode.

> We need to fast-track the process of bench to bedside for promising new treatments. As cancer patients we just don't have time, it is not on our side, and current healthcare models and policy must catch up with the science if we want to ensure that no patient is left behind.
>
> – Caitlin, living with ovarian cancer

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