



# Submission to the Senate Inquiry into equitable access to diagnosis and treatment for individuals with rare and less common cancers, including neuroendocrine cancer

## 1 Introduction

Rare Cancers Australia (RCA) is a charity whose purpose is to improve the lives and health outcomes of Australians living with rare, less common (RLC) cancers. Since our establishment in 2012, RCA has provided personalised clinical, emotional, financial, and practical support to patients with rare and less common cancers throughout their diagnosis, treatment and beyond. We have also taken a lead role in raising awareness of rare cancers and bringing people together to drive meaningful policy change in access, affordability, and quality of care. As such, we are delighted to have the opportunity to respond to this Senate Inquiry and look forward to working with the Committee as they form recommendations to improve equity of care for Australians with rare and less common cancers, including those with neuroendocrine cancer.

## 2 Understanding rare and less common cancers

The Australian Institute of Health and Welfare (AIHW) estimates that there were 162,000 people diagnosed with cancer, and 50,000 people who died from cancer, in 2022.<sup>1</sup> Based on current definitions, a rare cancer is defined as an incidence of less than six per 100,000, and a less common cancer is an incidence between six and twelve per 100,000 of the population. Although each RLC cancer impacts a small number of people, approximately 52,000 Australians are diagnosed with a RLC cancer each year, making up 30% of all cancers diagnosed in Australia, and accounting for 42% of all cancer deaths.<sup>2</sup> Despite these high numbers, people with RLC cancers simply don't receive the same

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<sup>1</sup> Australian Institute of Health and Welfare. Cancer data in Australia, <https://www.aihw.gov.au/reports/cancer/cancer-data-in-australia/contents/cancer-rankings-data-visualisation> (2022, accessed 03/07/2023).

<sup>2</sup> Australian Institute of Health and Welfare. *Cancer in Australia 2021*. 2021. Canberra: AIHW.

level of support, or have access to the same treatment options, as those with more common cancers, and they pay for that inequity with their lives.

Until recently, the term 'rare cancer' encompassed hundreds of different cancers, determined by the tumour location. However, our knowledge of cancer has increased significantly over the last 50 years. Cancers that were previously considered common are becoming increasingly rare through the discovery of multiple rare sub-types linked to the discovery of genetic mutations. People with lung cancer, for example, previously understood to be a common cancer, used to be diagnosed as one of two possibilities – small cell or non-small cell lung cancer. Now, we understand there are over 30 different sub-types associated with lung cancer – many of which are rare. So, while the issues of inequitable access to care and treatment have typically been seen in people with RLC cancers, they increasingly affect every person with a cancer diagnosis.

As a result of our improved understanding of genomics in cancer, we now need to expand what we think about when we say 'rare and less common cancers'. As an organisation, under this umbrella term, we now include both the RLC cancers based on the cancer location and the rare molecular sub-types of common cancers. It is important to note that these rare molecular sub-types of common cancers are not yet included in the statistics collated by the AIHW and, as a result, estimates for the proportion of all cancer cases in Australia that are RLC (as above) are significantly underestimated.

People with RLC cancers do not have equitable access to diagnostics, treatments or support, because of small patient numbers and lack of funding availability. Added to this, the Australian healthcare system has not kept pace with advances in genomics and precision oncology. The continued reliance on large volume randomised control trials is both impractical and discriminatory to those Australians living with a rare cancer. Therefore, we must all work together to adapt existing frameworks and funding mechanisms to better support people living with rare cancers, and help drive change in diagnosis, treatment, access, affordability, and quality of care. RCA maintains that it is the fundamental right of every Australian with a RLC cancer to have timely access to the best treatment and medical technologies, at an affordable price.

With one in two people diagnosed with cancer before the age of 85, almost every Australian will be impacted by cancer at some stage in their life, whether it be through their own experience, or that of a close family member or friend. And as more rare sub-types of common cancers are being identified, Australians are increasingly likely to personally know someone with a rare cancer.

### **3 Terms of Reference a and b: barriers to screening, diagnosis and treatment, and support for Australians with rare and less common cancers**

#### **Key points:**

- Rare cancers are often complicated by a late diagnosis, making the cancer more difficult to treat, resulting in poorer outcomes.
- People diagnosed with RLC cancers frequently experience more challenges throughout a cancer journey, and so do their families.
- Access to treatment for RLC cancer patients remains a major challenge in Australia due to a range of factors, including geographic location as well as small patient numbers, lack of research funding, and clinical trial design resulting in fewer subsidised treatments.

- Recent research advances in areas such as genomics and immunotherapy have led to innovative treatments that are increasingly complicated to evaluate and fund. The current models for drug discovery, development and access approvals are not designed in a way that delivers the best outcomes or experience for people with RLC cancers.

A cancer diagnosis can have a devastating impact on individuals and their loved ones. When a person is diagnosed, their GP will usually give them information about their cancer and support services, send them for further testing, and write a referral to a specialist. But if they are diagnosed with a RLC cancer, the standard treatment pathway may not yet exist. It may be more difficult for them to find information specific to their cancer type, which can add to the distress of a diagnosis and there may not be a specific medical team or specialist with expertise in treating the type of cancer. And the only scans, testing, and therapies that may improve survival or quality of life may not yet be covered by Medicare or the Pharmaceutical Benefits Scheme (PBS). It is a terrifying and isolating position to be in as a patient, and one that many Australians with RLC cancers face every day.

Through our work over the past decade, RCA is acutely aware of the unique needs of people with RLC cancers, and the many issues they face in accessing diagnosis, treatment and support services. Over the last 20 years, many significant advances in cancer treatment and care have occurred, including through early detection, genomic technology, and immunotherapies. There are now a number of innovative, targeted treatments available for patients with common cancers that could be life-extending for people living with rare cancers, but there are issues around equity of access that must be addressed.

### 3.1 Early diagnosis

As outlined earlier in this submission, based on current definitions, RLC cancers have significantly lower survival rates than common cancers, and although comprising approximately 30% of cancer cases, they account for a disproportionate 42% of cancer deaths. Early diagnosis is critical for improving survival outcomes for cancer patients and reducing the burden on the Australian community; late diagnosis significantly increases the cost to the healthcare system, as health care expenditure is highest in the last six months of life.<sup>3</sup>

There are currently no screening programs in Australia to detect rare cancers early, so they are often complicated by a late diagnosis – making the cancer more difficult to treat. It can also be very difficult for doctors to estimate a prognosis because there is so little data available to inform their judgement. There are also issues in terms of accessing appropriate diagnostic imaging tests. For rural and regional patients, there may not be a diagnostic imaging practice nearby, requiring travel to a metropolitan centre. And if a diagnostic imaging service does not have a Medicare Benefits Schedule (MBS) item number, it can be an out-of-pocket cost of up to \$1,000 for the patient for just one imaging service. As a result, clinicians may under-utilise these services for that may incur significant out-of-pocket costs for patients.

RCA's submission to a previous Senate Inquiry into the Availability and Accessibility of Diagnostic Imaging Equipment around Australia provides further information on the challenges associated with diagnosis for RLC cancer patients (see appendix).

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<sup>3</sup> Reeve, R., Srasuebku, P., Langton, J.M. et al. Health care use and costs at the end of life: a comparison of elderly Australian decedents with and without a cancer history. *BMC Palliat Care* 17, 1 (2018). <https://doi.org/10.1186/s12904-017-0213-0>

## 3.2 Clinical trials

Clinical trials have become the new standard of care for many people with RLC cancers who have exhausted other options, or for whom no effective treatments are available. Clinical trials provide a means for patients to have early access to potentially lifesaving treatments at no cost (in Australia) and provide healthcare professionals valuable experience with the new treatments. However, access to clinical trials and research programs – which at times can represent the last or only treatment option – is often limited, given:

- Rare cancers attract less clinical trial funding due to the relatively fewer people diagnosed.
- The small populations of people with RLC cancers make it difficult to conduct large-scale randomised clinical trials. In addition, it is generally difficult for companies to develop a profitable product considering the development costs and relatively small market size.
- A lack of local clinical trial recruitment and infrastructure.
- High out-of-pocket costs associated with patient travel from rural and regional areas to metropolitan centres, where the majority of clinical trials are held.
- The high level of health literacy required of RLC cancer patients to locate clinical trials relevant to them.
- Strict clinical trial inclusion criteria, which makes it harder for people with RLC cancers to participate and access novel treatments.

The Garvan Institute has previously noted that the 'two key barriers to improved outcomes for less common cancers' are lack of access to clinical trials, and lack of access to the best available treatments, which are 'inextricably linked', because:

*As governments use information gained from trials when deciding if they will fund a new drug, it is critical that patients with less common cancers have access to clinical trials, and that government, academics, clinicians and the pharmaceutical industry work together to develop trials for these cancers, as well as the more common cancers. Currently, there is a real disconnect between the identification of a new treatment by researchers and, where relevant, access to these treatment options.<sup>4</sup>*

Greater and ongoing investment in local clinical trial recruitment and infrastructure is needed and broader clinical trials inclusion criteria should be considered in a way that maintains the integrity of the clinical trial but enables more rare disease patients to access treatments.

RCA's 2017 report *Rare Solutions: A Time to Act* provides additional information about the challenges regarding clinical trial funding and structure, and recommendations for improvement (see appendix).

## 3.3 Market entry (TGA) and affordable access (PBS)

Despite the rapid emergence of transformative cancer treatments, the timeframe for people to access treatments is lengthening. This is of particular concern for people with RLC cancers and advanced disease, who may only have a short time to live. In Australia, as with many other countries around the world, we use health technology assessment (HTA) to inform our decisions about which health

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<sup>4</sup> Garvan Institute of Medical Research, Senate Submission regarding the impact of health research funding models on the availability of funding for research into cancers with low survival rates <https://www.garvan.org.au/research/genomic-cancer-medicine-program/files/garvan-senate-submission-17-march-2017.pdf> (2017, accessed 05/08/23)

technologies can be sold in Australia, and which ones qualify for subsidies from the Australian Government.

HTA provides a pathway to achieving subsidised access to a new medical technology, but it is a time-consuming process. For cancer treatments, the time between submission to the TGA for regulatory approval, which makes a drug available to people in Australia, and PBS listing, which makes it subsidised by the public healthcare system, may be long, and some medicines may take several attempts to achieve a successful listing.

Recent research advances in areas such as genomics have led to innovative treatments that are increasingly complicated to evaluate and fund. This includes radiopharmaceuticals that deliver radiation therapy directly and specifically to cancer cells, new service models like healthcare in the home and the introduction of immunotherapy, which harnesses the body's immune system to fight cancer. In particular, cell and gene therapies such as CAR-T (which uses genetically engineered T-cells to recognise and kill cancer cells), and cancer vaccines, have been recently introduced into the Australian market, but the time to achieving subsidised access has been drawn out.

There is, therefore, a growing number of people in Australia unable to access innovative cancer technologies, therapies and services compared with abroad. Australia is one of the five worst countries in terms of 'indication coverage' for cancer medicines – intended as the number of indications covered by the public healthcare system – that do achieve subsidised access.

For RLC cancers, the inherent lack of clinical trial data creates a barrier to registration for companies and, where data does exist, delays in registration from the TGA often occur. There are no TGA application fees for orphan designated drugs, however companies must invest significant resources to prepare large applications for RLC cancers. They may be unwilling to do this if a subsequent PBS listing is unlikely due to paucity or quality of data, or if the patient population sizes are very small.

PBS listing of medicines for RLC cancers provides subsidised and affordable access to otherwise very costly medicines for Australians. By law, new medications need to be assessed for effectiveness and costs compared to existing therapies to ensure medicines listed on the PBS represent value for money. With the limited clinical trial information available it is difficult to prove cost effectiveness under the standard assessment guidelines. Pharmaceutical companies may be deterred from seeking PBS listing due to the limited evidence, high potential for rejection and the resources needed to prepare a submission for a relatively small return on investment.

TGA registration is typically required for a medicine to be listed on the PBS. Medicines are TGA registered and PBS listed based on specific cancer indications (or specific medical conditions). This means that a new registration and PBS listing is needed for each indication where a cancer medication could be relevant. By law, medicines can be prescribed for a second indication by a doctor, once a drug has been approved for a first indication (off-label use), but this results in extreme inequity of care, as only a small number of people could afford the huge monthly costs of new medicines (many thousands of dollars).

The challenge for Australia (and the rest of the world) is how to assess and fund high-cost precision therapies and technologies across a range of cancer types. Under the current structure of the health system, small patient populations make traditional assessment regimes impossible.

Through the HTA Review, currently underway, we need to seize the opportunity to adapt our HTA system to consider different levels of evidence, as well as novel trial designs, such as basket trials or umbrella trials, that consider multiple targeted therapies across multiple cancers. There is an increasing number of precision oncology therapies that are coming to market with phase II data, and as such, a greater reliance on real world evidence for ongoing evaluation is needed. We need to act and ensure systems are put in place to make this the norm, not the exception. The health system must

develop and adapt so that evidence-based knowledge can be translated quickly and seamlessly into the real-world clinical setting, and so that all Australians, not just the wealthy, have swift and affordable access.

These issues are explored in detail our 2022 *Counting the cost: The true value of investing in cancer treatment* report (see appendix).

### 3.4 Geography

For many cancer patients in Australia, including those with RLC cancers, location and proximity to services is one of the major barriers to accessing timely diagnosis and treatment. It is recognised globally that rural patients do not always have access to services or resources that are appropriate to their needs, and that fragmentation of healthcare leads to poorer patient outcomes.<sup>5</sup>

About a third of Australia's population resides in regional and remote areas. The geography of Australia, with its highly concentrated populations and large land mass, raises particular problems for both the government in providing, and the regional population in accessing the full range of healthcare services.<sup>4</sup>

For almost 20 years, poorer cancer survival with increasing rurality has been well documented<sup>6,7</sup> Over the decade to 2010, the disparity in cancer outcomes between rural and urban patients remained unchanged with 7% higher mortality, equating to almost 9,000 additional rural deaths during this period.<sup>2</sup> The disparity was greatest with oesophageal cancer and melanoma (where tertiary care is essential to maximise cure), with no evident gap in breast cancer mortality rates. In Queensland, rectal cancer mortality increases by 6% for every 100 km that patients reside from the closest radiotherapy centre. In rural New South Wales, early breast cancer patients are more likely to receive sub-optimal curative therapies, with an 84% higher breast cancer mortality.<sup>5</sup>

Numerous studies have suggested that cancer care in rural and regional Australia is fragmented and that rural and regional patients have less access to services. The social and economic disadvantages in regional locations are often linked to insufficient resources and infrastructures to support cancer care and treatment.<sup>4</sup>

A 2010 study of patient perspectives in regional Western Australia found that patients who had the involvement of a cancer nurse coordinator and cancer support workers had better experiences and more streamlined care than those who had to navigate the journey alone. The study endorsed the role of cancer nurse coordinators and cancer support workers in providing better coordination of care in rural and regional cancer patients.<sup>1</sup> Patients who had the involvement of coordinating professionals experienced better outcomes with coordination of care, understanding or education concerning their specific cancer and/or treatment, and psychosocial support.<sup>4</sup>

Ideally, all cancer patients should have access to uniformly high standards of care with health professions in the community regardless of their location or cancer type. However, regional and remote Australia is often found to be associated with social and economic disadvantages, leading to poorer outcomes for cancer patients.<sup>4</sup> In addition to the social displacement, traveling to major cities

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<sup>5</sup> Drury VB and Inma C. Exploring Patient Experiences of Cancer Services in Regional Australia. *Cancer Nursing* 2010; 33: E25-E31. DOI: <https://doi.org/10.1097/NCC.0b013e3181af5675>.

<sup>6</sup> Fox P and Boyce A. Cancer health inequality persists in regional and remote Australia. *Medical Journal of Australia* 2014; 201: 445-446. DOI: <https://doi.org/10.5694/mja14.01217>.

<sup>7</sup> Tervonen HE, Aranda S, Roder D, et al. Cancer survival disparities worsening by socio-economic disadvantage over the last 3 decades in new South Wales, Australia. *BMC Public Health* 2017; 17: 691. DOI: <https://doi.org/10.1186/s12889-017-4692-y>.

for cancer care also imposes an economic burden on rural patients who have to self-fund transportation and accommodation.<sup>8</sup>

### 3.5 High out-of-pocket costs

While Medicare, the PBS or private health insurance may cover many of the medical expenses associated with a patient's cancer treatment, there can still be significant out-of-pocket costs. This includes GP and specialist gap fees, scans not covered by Medicare, over-the-counter medications, special devices, and travel, accommodation and parking. People living with cancer may also find they are unable to work, due to high levels of pain, fatigue, side effects from medication or poor disease management. As a result, cancer patients may lose income at a time when they are also facing additional costs. In some cases, partners and family members may need to work less to take over care duties, resulting in further financial losses.

In the case of RLC cancers, the situation can be even more difficult. This is because the initial diagnosis may be protracted, requiring multiple doctor appointments, scans and biopsies. It is, of course, not unusual for people to be significantly unwell and unable to work as usual while undergoing a RLC cancer diagnosis. Medications for the cancer, where available, may not yet be funded on the PBS, resulting in enormous costs to the patient, often thousands and sometimes tens of thousands of dollars each month. Seeing several specialists, and often having to travel to do so is costly, both financially and in time.

Suitable specialist and health services may also only be available in metropolitan areas, interstate or even overseas. While travel and accommodation schemes are available in each state and territory to assist cancer patients with accessing treatment, it is important to note the schemes do not cover costs associated with participating in an investigator-led cancer clinical trial (as opposed to a sponsor-led trial, where costs to the patient are usually covered by the sponsor). And, where they are payable, they remain insufficient in meeting the actual costs incurred.

In many instances, these factors are resulting in people with RLC cancers missing out on life saving and life extending care and treatments because of affordability. Through RCA's research, we have found that one in two cancer patients are financially struggling due to the burden of paying for treatments and cancer associated costs. Anecdotally, we know that many patients are accessing their superannuation and other assets, or crowdfunding, to raise the funds needed to potentially extend their lives.

It is vital that we use the knowledge and treatments we have today to ensure that, regardless of financial position, Australians can receive the best possible treatment available.

## 4 Terms of Reference c: the adequacy of support services after diagnosis

Australians diagnosed with RLC cancers, and their families, require information to assist them in making decisions about their treatment and in understanding their disease. Due to the number of rare cancers; small patient populations and a paucity of experts in RLC cancers, there is less information and support available for them, their support networks and their clinicians. It can be difficult to find the most knowledgeable local expert or support services to help a patient with a rare cancer to best manage their illness. This brings significantly higher unmet needs in the domains of psychological well-being, the provision of reliable information and access to supportive services.

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<sup>8</sup> Drosdowsky A, Mathieson J and Milne D. Australian Indigenous Communities: Efforts to Improve Cancer Care. *Clin J Oncol Nurs* 2019; 23: 443-446. 2019/07/20. DOI: <https://doi.org/10.1188/19.Cjon.443-446>.



In recent years, RCA has seen a growing demand to support people to navigate the everyday challenges their cancer diagnosis presents, be it to access diagnostic screening tests, find multi-disciplinary care and clinicians with expertise in their RLC cancer.

In the absence of nationally available and accessible support services for people with RLC cancers, RCA has taken a lead role in creating and delivering essential services, to alleviate some of the stress, complexity and hardship experienced by patients, carers and families. We do this by:

- Providing personalised support to more than 1,000 Australians at any one time through our Specialist Cancer Navigators, who have specific expertise in complicated cancer journeys and provide each patient with access to tailored health, emotional, peer and financial support.
- Facilitating access to emergency crisis funding, for example, for transport to attend appointments, accommodation when undergoing treatment away from home, specialist medical bills, scans and day-to-day expenses associated with managing a diagnosis. These expenses are often not subsidised for those diagnosed with RLC cancers.
- Facilitating fundraising through our Patient Treatment Fund so that patients can afford to pay for cancer therapies that are not subsidised by the Government, as well as out-of-pocket costs related to the diagnosis.
- Operating a Patient Support Team phone hotline, which patients, families and carers can call between Monday and Friday, 9 am to 5 pm for health system navigation, informal counselling and information and access to support groups.
- Connecting patients with specialists around Australia and the world who have a special interest in their type of cancer.
- Developing the CAN.recall mobile app, which provides patients with a structured mechanism to communicate questions to their clinician and record answers, at a time when they are confronted with vast quantities of life changing information and under great stress.
- Developing the Rare Cancer Support Guide, which provides patients and their family and friends with comprehensive information, tools and advice for every stage of a rare cancer experience to help them manage and navigate their unique cancer experience.
- Maintaining up-to-date and comprehensive information about rare cancers through the RCA website and Rare Cancer KnowledgeBase.

As more and more people are impacted by RLC cancers, these initiatives will need to be expanded upon and further resourced, so the ever-growing needs of Australians living with cancer can continue to be met, and better experiences and outcomes can be achieved.

## **5 Terms of Reference d: Commonwealth funding for research into rare and less common cancers**

Over the past 20 years, survival rates in many RLC cancers have only improved marginally, if at all, while outcomes for common cancers have improved dramatically. It is no coincidence that government research funding into rare cancers remains disappointingly and disproportionately low, as does the money we spend on treatments for these patients through the Pharmaceutical Benefits Scheme (PBS).

There are inherent challenges in treating very small patient groups. These challenges have conspired to create an environment whereby these patients are excluded from the progress achieved for those



with more common cancer variations. As a result of limited investment in research and treatment, patients with rare cancers are, almost without exception, those most likely to have the lowest survival rates.

Australia is a leader in cancer research. The 2023 National Audit of Cancer Research Funding in Australia<sup>9</sup> reported that between 2012 and 2020, the Australian Government provided \$2.12 billion for cancer research, across 4,813 cancer research projects and programs. The report further identified 419 cancer clinical trials with a total of \$315m funding in the same period. The Australian Government (\$147m, 47%, 193 clinical trials) and State and Territory governments (\$77m, 24%, 45 clinical trials) provided the majority of funding. Of the \$2.12b in direct funding for cancer research projects, \$1.4b (66%) was for cancer research projects and programs with a specific tumour stream focus (single or multiple tumours), while \$712m (34%) was for cancer research projects and programs with no specific tumour focus.

Lack of research into RLC cancers has two direct impacts; the first is that without research, there is no likelihood of improved treatments and potentially cures; the second is that without research we will not develop the knowledge to design screening tests or early diagnosis mechanisms. As mentioned previously in this submission, early diagnosis is highly significant in improving patient survival and RCA's experience, as seen with many of our patients, is that many Australians with RLC cancers had their outcomes compromised by late diagnosis. Given the neglect of rare and less common cancer research when compared to burden of disease and mortality, we must take action to encourage the research community to increase activity related to these cancers. Research has shown that increasing the allocation of resources to research and funding treatments through the PBS positively impacts survival of cancer patients.

Despite the 2023 National Audit of Cancer Research Funding demonstrating that total funding for rare and less common cancers has increased in recent years, the total funding required to close the gap between funding and the burden of disease and mortality caused by RLC cancers compared to common cancers remains significant. Clinical trials into the effectiveness of novel, targeted therapies, in small patient populations, require collaborative trial development and research that crosses traditional boundaries of trials currently being undertaken in Australia, and the evidentiary requirements for regulators must also be made to be more flexible for rare cancers.

Given the Australian Government, through the National Health and Medical Research Council, Medical Research Future Fund and other departments is the largest funder of cancer research in this country, RCA considers the Government should take a lead role in directing funding to specifically target areas of unmet need such as RLC cancer research. By improving our investments in RLC cancer research will we be able to deliver improvements to patients and reduce mortality rates.

## 6 Conclusion

As outlined throughout this submission, the challenges around RLC cancers are multi-faceted and require diverse policy solutions, but that cannot be a barrier to action.

Given the number (and incidence) of RLC cancers will continue to grow with advances in genomic technology, it is critical that we begin to think differently about how we diagnose and treat people with cancer. As we understand more about each person's cancer, we will see an increase in the proportion of patients who have rare sub-types of previously common cancers.

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<sup>9</sup> Cancer Australia. Cancer research in Australia: an overview of funding for cancer research projects and programs in Australia 2012 to 2020. 2023. Surry Hills, NSW

We need to improve outcomes for all people living with cancer and to do so we must evolve our systems, delivery frameworks and funding mechanisms to ensure research advances and emerging therapies can be translated to the clinical setting and to patients fairly, swiftly and affordably. Specific action is required to:

- Increase funding for RLC cancer research,
- Improve AIHW data collection for RLC cancers, to include rare sub-type level information,
- Increase resourcing (including workforce) for screening, diagnostics and therapies for RLC cancers,
- Ensure all people diagnosed with cancer are able to access genomic screening as standard of care, and
- Ensure all people are able to access precision oncology therapies, when applicable.

Without action on equity, we cannot hope to have an impact on mortality or on improving RLC patient outcomes and experience in the future.

## **Appendix one – previous reports and submissions of relevance to this Inquiry**

### **Counting the cost: the true value of investing in cancer treatment**

[https://rcararecancers.blob.core.windows.net/assets/contentpage\\_htmlcontent/RCA4279%20Counting%20the%20Cost%20Report-final.pdf](https://rcararecancers.blob.core.windows.net/assets/contentpage_htmlcontent/RCA4279%20Counting%20the%20Cost%20Report-final.pdf)

### **The Rights and Roles of Australian Cancer Patients**

[https://rcararecancers.blob.core.windows.net/assets/contentpage\\_htmlcontent/RCA4059%20Patients%20Rights%20and%20Roles%20Booklet%20FA.pdf](https://rcararecancers.blob.core.windows.net/assets/contentpage_htmlcontent/RCA4059%20Patients%20Rights%20and%20Roles%20Booklet%20FA.pdf)

### **Vision 2030: Building an Australian Cancer Futures Framework**

[https://rcararecancers.blob.core.windows.net/assets/contentpage\\_htmlcontent/NOA\\_Vision20-30%20FA%20r4%20Digital.pdf](https://rcararecancers.blob.core.windows.net/assets/contentpage_htmlcontent/NOA_Vision20-30%20FA%20r4%20Digital.pdf)

### **Rare Solutions: a time to act**

[https://rcararecancers.blob.core.windows.net/assets/pages/Rare-Solutions\\_Report\\_2017.pdf](https://rcararecancers.blob.core.windows.net/assets/pages/Rare-Solutions_Report_2017.pdf)

### **RCA Submission to the Review of the National Medicines Policy**

[https://rcararecancers.blob.core.windows.net/assets/contentpage\\_htmlcontent/NMP%20Submission%20on%20behalf%20of%20Rare%20Cancers%20Australia%202021%20\(1\).pdf](https://rcararecancers.blob.core.windows.net/assets/contentpage_htmlcontent/NMP%20Submission%20on%20behalf%20of%20Rare%20Cancers%20Australia%202021%20(1).pdf)

### **RCA Submission to the Senate Inquiry into funding research into cancers with low survival rates**

[https://rcararecancers.blob.core.windows.net/assets/pages/Submission-to-Senate\\_Funding-Research\\_Low-Survival.pdf](https://rcararecancers.blob.core.windows.net/assets/pages/Submission-to-Senate_Funding-Research_Low-Survival.pdf)

### **RCA Submission to the Senate Inquiry into the Availability and Accessibility of Diagnostic Imaging Equipment around Australia**

[https://rcararecancers.blob.core.windows.net/assets/pages/Submission-to-Senate\\_Diagnostic-Imaging-Inquiry.pdf](https://rcararecancers.blob.core.windows.net/assets/pages/Submission-to-Senate_Diagnostic-Imaging-Inquiry.pdf)

In addition to the above reports, we will also be sending as a final appendix to this submission, our upcoming report on genomics in cancer. Link to be made available in due course.