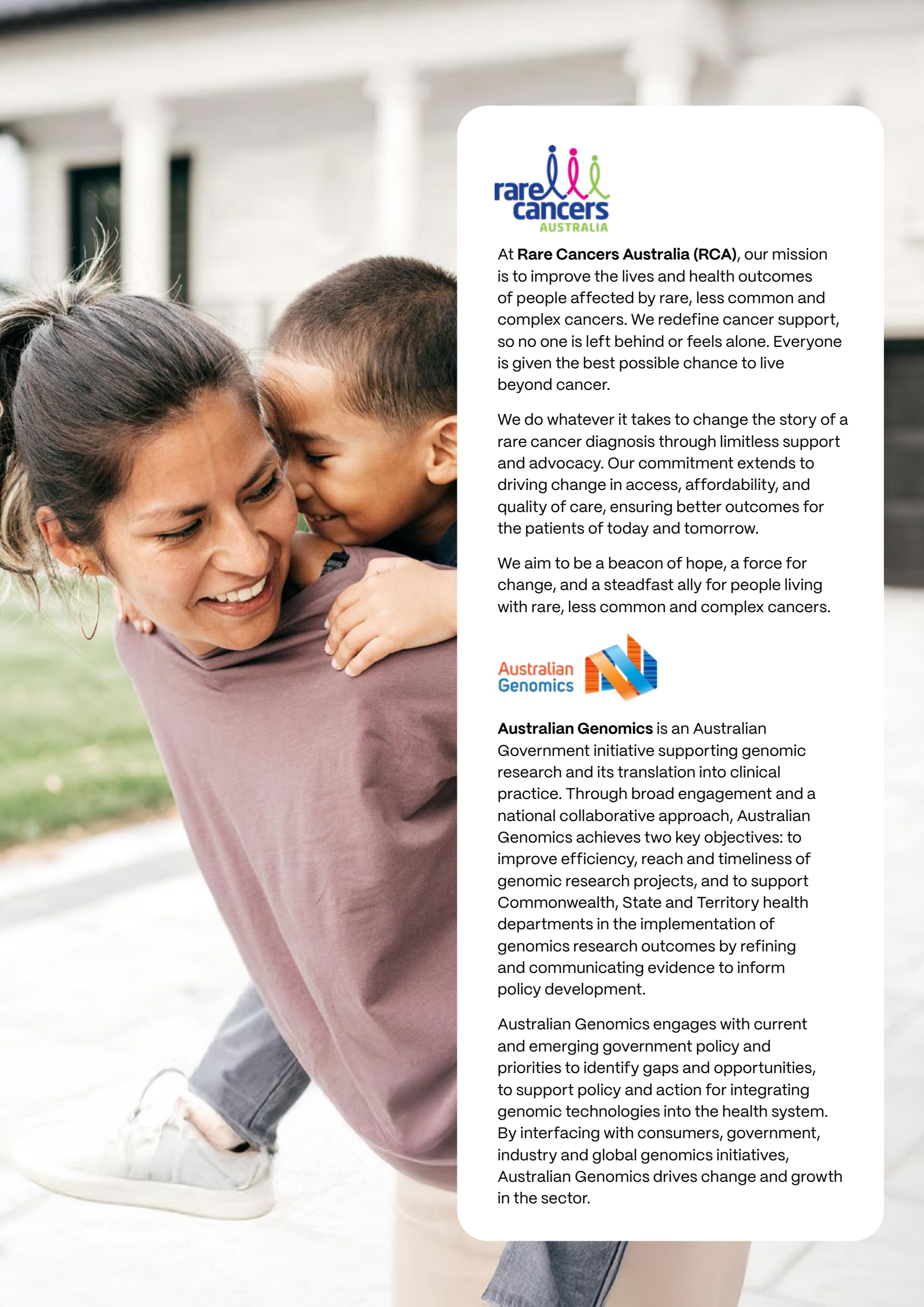
rare cancers AUSTRALIA

Advancing genomic-led cancer care in Australia

February 2025

In partnership with

Australian Genomics



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

We do whatever it takes to change the story of a rare cancer diagnosis through limitless support and advocacy. Our commitment extends to driving change in access, affordability, and quality of care, ensuring better outcomes for the patients of today and tomorrow.

We aim to be a beacon of hope, a force for change, and a steadfast ally for people living with rare, less common and complex cancers.

Australian Genomics is an Australian Government initiative supporting genomic research and its translation into clinical practice. Through broad engagement and a national collaborative approach, Australian Genomics achieves two key objectives: to improve efficiency, reach and timeliness of genomic research projects, and to support Commonwealth, State and Territory health departments in the implementation of genomics research outcomes by refining and communicating evidence to inform policy development.

Australian Genomics engages with current and emerging government policy and priorities to identify gaps and opportunities, to support policy and action for integrating genomic technologies into the health system. By interfacing with consumers, government, industry and global genomics initiatives, Australian Genomics drives change and growth in the sector.

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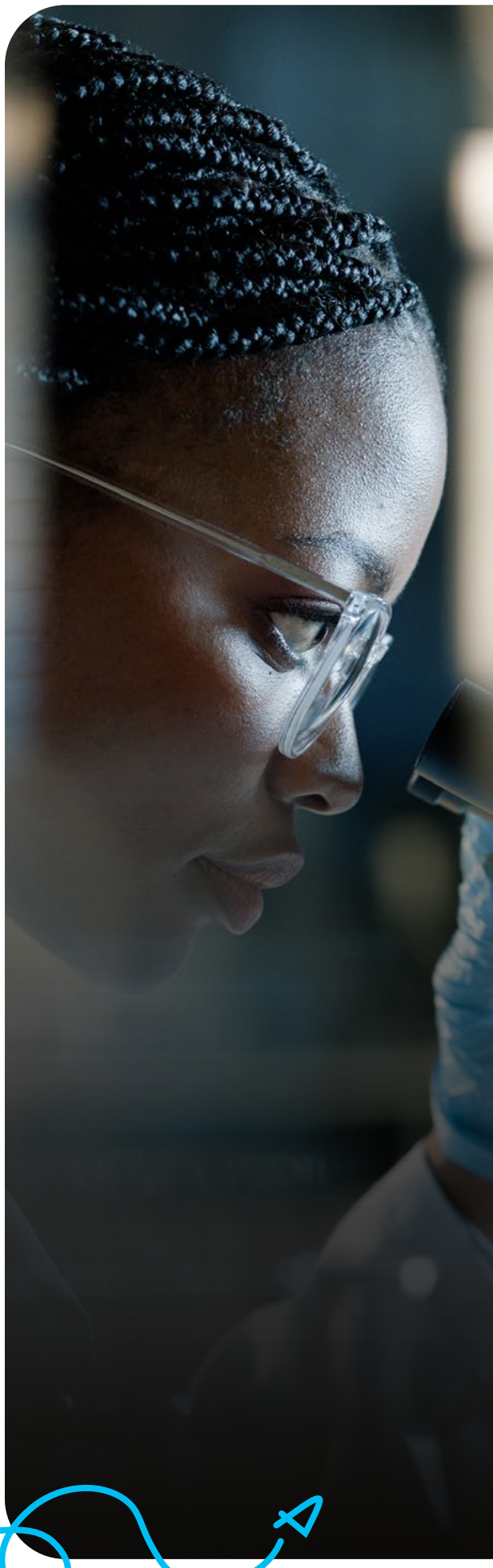
evohealth

Thank you to Renae Beardmore, Theresa Doueihi and the team at Evohealth for their excellent contribution to the Genomics Policy Roundtable Series and writing this summary report.

Executive summary



Cancer is the largest burden of disease in Australia, impacting individuals, families, and communities across physical, emotional, and financial dimensions.[1]

With over 169,000 new cases expected in 2024, cancer remains a leading cause of death.[2] Rare and less common cancers account for 24 per cent of diagnoses and 33 per cent of cancer deaths, with significantly lower five-year survival rates compared to common cancers. These disparities highlight systemic barriers, such as limited treatment options, inadequate funding, and reduced access to clinical trials.

The current 'one size fits all' approach to treatment often results in limited efficacy, significant side effects, and compromised quality of life. Many patients endure multiple rounds of ineffective therapies before finding one that works, adding emotional and financial strain to an already difficult experience.[3–5] Comprehensive genomic profiling (CGP) offers a transformative solution by personalising treatment based on a cancer's genetic makeup. This approach promises to improve treatment efficacy, reduce unnecessary side effects, and ultimately enhance quality of life and survival for patients.

Rare Cancers Australia and Australian Genomics hosted a three-part Genomics Policy Roundtable Series, bringing together key stakeholders from across the genomics and cancer care sectors. Held in Canberra on 11 September, Melbourne on 16 October, and Sydney on 8 November 2024, these roundtables explored the opportunities and challenges of advancing genomic-led cancer care in Australia.

The consensus from roundtable attendees is clear: **Australia has a unique opportunity to transform cancer care by embedding genomic profiling into routine clinical practice.** Transitioning from generalised treatment approaches to personalised therapies has the potential to significantly improve patient outcomes, extend survival, reduce the personal burden of cancer, and enhance healthcare system efficiency. This shift is particularly critical for rare and less common cancers, where genomic insights can uncover targeted treatment options that are otherwise unavailable through standard approaches.

From the Roundtable discussions, **five key steps** emerged that will help guide the integration of genomic profiling and precision oncology into Australia's cancer care system:

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. The Department of Health and Aged Care, Genomics Australia and Cancer Australia will play pivotal roles in delivering national strategy, regulation, and implementation. These efforts must ensure national alignment, engage diverse stakeholders, and foster collaboration across states and territories.

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, less common cancer and advanced cancers, those living rurally or remotely, and Aboriginal and Torres Strait Islander communities. This model will align with existing policy frameworks, including the Australian Cancer Plan and the draft National Framework for Genomics, ensuring consistency and integration across Australia's healthcare landscape.

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 implementation of genomic profiling into routine cancer care should build on existing efforts, with a focus on improving equity in access and making genomic profiling the standard of care. This process should be closely monitored and evaluated to ensure improvements in patient outcomes, reduce disparities, and enable the continuous refinement of genomic practices and policies.

Cancer patients, especially those with rare or less common cancers, deserve the opportunity to have their cancer genomically profiled, enabling the most informed treatment decisions. By taking these steps, Australia can integrate genomic profiling into routine cancer care, driving better patient outcomes, reducing disparities, and ensuring equitable access to cutting-edge, personalised therapies for all Australians.

About this report

Rare Cancers Australia, in collaboration with Australian Genomics, organised a three-part Genomics Policy Roundtable Series to explore the transformative potential of genomic-led cancer care for people with rare and less common cancers.

The roundtables, held in Canberra on 11 September, Melbourne on 16 October, and Sydney on 8 November 2024, brought together key stakeholders, including expert speakers and attendees from various sectors, to explore how integrating genomics into cancer care can enhance outcomes for people facing these challenging diagnoses.

This report summarises the discussions and insights shared at the roundtables, focusing on the application of genomic profiling in cancer care, particularly its role following diagnosis.

While genomics has the potential to impact the entire cancer continuum, from screening and prevention to diagnosis and treatment, this report emphasises its use in informing personalised treatment strategies for cancers after diagnosis.

We would like to acknowledge and thank all the speakers and attendees who contributed their expertise and insights throughout the series. Their valuable input has been instrumental in shaping the vision and next steps outlined in this report, paving the way for a future of personalised cancer care in Australia.

Roundtable themes and speaker highlights

ROUNDTABLE 1

The Australian genomic landscape and what we can learn from others.

This session delved into Australia's genomic landscape, drawing on global insights to identify opportunities for progress.

Charlotte Noble

Patient Advocate

Charlotte shared her experience with diagnosis, treatment, and genomic testing for her rare cancer. She emphasised the importance of establishing financial support, providing clear information about the necessity and role of testing, and ensuring access to well-trained healthcare providers and appropriate support services.

Louise Lyons

Senior Manager, Strategy and Policy, Indigenous Genomics, The Kids Research Institute Australia

Highlighting challenges in Indigenous genomics governance, equity, and access, Louise outlined a 10-year vision to empower Indigenous communities in genetic health services and research. Key goals include delivering benefits through a national network, developing indigenous-led policies, embedding best practices in healthcare, building workforce capacity, and ensuring access to culturally appropriate services. The vision also focuses on precision medicine and establishing a National Indigenous Genomics Institute.

Associate Professor Vanessa Tyrrell

Program Director, Zero Childhood Cancer

Vanessa discussed the journey of the Zero Childhood Cancer program, which began by focusing on high-risk paediatric cancer patients and expanded in November 2023 to include all children diagnosed with cancer in Australia. She highlighted the program's significant impact on diagnosing and treating paediatric cancers through precision medicine and the work required to move this exciting research into standard of care.

Tiffany Boughtwood

Managing Director, Australian Genomics

As roundtable co-host and presenter, Tiffany provided an overview of Australia's genomic ecosystem and the challenges in establishing a cohesive genomic cancer care system. She explored reimbursement for genomic profiling in cancer across the Asia-Pacific region and shared a case study from the National Health Service (NHS) Genomic Laboratory Hubs. The NHS offers whole genome sequencing as part of routine care, currently providing it for all children with cancer and adults with specific cancers.

Christine Cockburn

Chief Executive Officer, Rare Cancers Australia

Christine opened the Roundtable Series with insights from the rare and less common cancer community about the availability and use of genetic and genomic testing. She shared the hope that genomics has brought to many patients who had no other options and the need to push ahead to with research and translation into practice so that more people can benefit from current and future discoveries. RCA's specialist cancer support navigators support over one in four of their patients to access and navigate genomic testing.

ROUNDTABLE 2

Practical considerations and next steps for implementing genomic-led cancer care in Australia.

This session focused on identifying actionable steps and addressing challenges to embed genomics into cancer care in Australia.

Associate Professor Robyn Schofield

Patient Advocate

Robyn shared her personal cancer journey, highlighting the importance of the Oncotype Test, which informed her decision to undergo adjuvant chemotherapy. She discussed the significant barrier of the high cost of testing, stressing the need for broader access to genomic-informed care to ensure all patients can make informed, data-driven treatment decisions and avoid unnecessary toxicity where possible.

Professor David Thomas

Director, UNSW Centre for Molecular Oncology
Chief of Science and Strategy, Omico

Exploring clinical and service considerations for integrating comprehensive genomic profiling throughout the treatment pathway, David highlighted the importance of this approach for people with rare cancers. He discussed how health systems are challenged to deliver equity, certainty, and sustainability in the face of rapid scientific advancements. He also presented a structural solution, the Health System Incubator, to enable complex and transformative health innovation.

Associate Professor Ilias Goranitis

Health Economics Lead, Australian Genomics
Head, Economics of Genomics and Precision Medicine Unit, University of Melbourne

Ilias reflected on the health and economic impacts of cancer in Australia and the health economics evidence needed to prioritise and implement genomic medicine within the healthcare system. He highlighted critical gaps in the current system and shared progress on developing a cost-benefit model for genomic technologies.

Associate Professor Rachel Conyers

Group Leader, Cancer Therapies, Murdoch Children's Research Institute

Rachel provided an overview of current access to pharmacogenomics for cancer patients and the benefits of expanding access. She addressed barriers such as professionals' awareness of the latest evidence and guidelines, turnaround time, and cost-effectiveness, offering strategies to overcome these challenges and ensure equitable access to pharmacogenomic testing for all cancer patients.

Professor Clare Scott AM

Professor of Gynaecological Cancer, University of Melbourne Joint Division Head (Clinical Discovery & Translation) and Laboratory Head, Walter and Eliza Hall Institute of Medical Research Consultant Medical Oncologist, Peter MacCallum Cancer Centre, Royal Melbourne Hospital and Royal Women's Hospital

Clare shared reflections on the use of genomic testing and precision oncology in clinical practice. She discussed the role of the Australian Rare Cancer Portal, which connects local clinical teams with specialised expertise and treatment options for rare cancers and highlighted the workforce training and skills development required to support the wider use of genomics in cancer care.

ROUNDTABLE 3

Policy and system change for equitable and sustainable genomic-led cancer care.

This session delved into the systemic and policy reforms needed to make genomic-led cancer care accessible and sustainable for all.

Caitlin Delaney

Patient Advocate and Founder, CareFully

Caitlin shared her personal cancer journey, focusing on her the role of genomic testing and access to matched therapies in extending her life. She reflected on the need for equitable access to genomic-led care, stressing the importance of collaboration with all stakeholders, including patients from diverse demographics. She highlighted the need for pan-tumour approval processes, embedding genomic testing as standard of care, and educating clinicians and patients on genomics and matched therapies, so that patients do not have to fight so hard to access the information, tests and treatments that they need.

Professor Vivienne Milch

Medical Director, Cancer Australia

Vivienne provided an overview of the development and consultation of the draft National Framework for Genomics in Cancer Control, release for public consultation in November 2024. The development process included engagement with Aboriginal and Torres Strait Islander stakeholders and other priority population groups, including those with rare cancers. She shared consultation themes and findings from Cancer Australia's engagement with Aboriginal and Torres Strait Islander communities, including the importance of culture, access, self-determination, and workforce.

Renaye Lucchese

Assistant Secretary, Genomics & Health Technology Assessment Policy Branch, Department of Health and Aged Care

Presenting the Australian Government's priorities in health genomics, Renaye highlighted the role of Commonwealth and States and Territories. She provided an update on the release of the final report of the Health Technology Assessment (HTA) Review and outlined the next steps. Renaye also spoke about Genomics Australia, the national health genomics body set to commence on 1 July 2025, which will support the objectives of the National Health Genomics Policy Framework.

Elizabeth de Somer

Chief Executive Officer, Medicines Australia

Wrapping up the series, Elizabeth addressed the need for faster and more equitable access to genomic testing and matched therapies, discussing the policy changes required to improve access to genomic-led cancer care. She provided an update on the HTA review process, outlined key recommendations from the review to accelerate access to genomics, and shared the next steps for implementing the reforms, including the establishment of an implementation group to drive these reforms forward.

Transforming cancer care

Cancer is Australia's largest disease burden, significantly affecting individuals, families, and communities.[1] Its pervasive impact extends beyond physical health, influencing mental, emotional, and financial wellbeing.

For people living with cancer, the diagnosis often brings not only the challenge of managing the disease itself, but a ripple effect of changes that touch every aspect of their lives, including relationships, employment, and long-term planning.[1]

In 2024, approximately 169,000 new cancer cases are expected to be diagnosed in Australia, a figure projected to surpass 200,000 in 2034.[2] While survival rates for most cancers have improved over the past few decades, rising from a 5-year survival rate of 55 per cent between 1991 and 1995 to 71 per cent between 2016 and 2020, it remains one of the leading causes of death in Australia. In 2000, there were 36,000 deaths from cancer, and by 2024, 53,000 Australians are projected to die from the disease. These figures emphasise the ongoing and growing challenge cancer poses to Australia's healthcare system and society.

Rare and less common cancers present even greater challenges. Collectively accounting for approximately 24 per cent of cancer diagnoses and 33 per cent of cancer deaths in 2024, rare and less common cancers disproportionately affect those living with them.[2] The five-year relative survival rate for common cancers is 79 per cent, but it drops to 63 per cent for rare cancers, and just 43 per cent for less common cancers.[2] These stark disparities reflect systemic barriers, including limited treatment pathways, inadequate funding, and fewer clinical trials for rare and less common cancers.

It is not 'one size fits all'

For many people living with cancer, the journey is complex and fraught with difficulties. Many treatments, such as chemotherapy and radiotherapy, take a 'one size fits all' approach, often resulting in limited efficacy and potential toxicity for individuals. These treatments not only fail to target the specific biology of a person's cancer but may also diminish their quality of life, leaving patients to cope with debilitating symptoms such as fatigue, nausea, and cognitive impairment.[3, 4] In many cases, patients undergo multiple rounds of systemic treatment with ineffective therapies before finding one that works, instead of starting with targeted therapies tailored to their specific cancer.

The emotional toll of cancer is immense, as patients and their families navigate the uncertainty of treatment outcomes, the potential for recurrence, and the life changes imposed by the disease.[5] Financial burden further complicates the cancer journey. Many targeted treatments are prohibitively expensive, without public subsidy, leaving patients and their families to face overwhelming out-of-pocket costs. People living with cancer face the challenge of fighting for survival while managing all of this additional burden, often with little support from the healthcare system.

In 2024, rare and less common cancers are expected to account for approximately 24 per cent of all cancer diagnoses and 33 per cent of all cancer deaths in Australia.[2]

It is extremely exhausting trying to stay alive.

Cancer care is a postcode and tumour stream lottery... it is grossly unethical."

– Caitlin Delaney, patient advocate

The type of cancer a person has also shapes their treatment journey. People diagnosed with common cancers, such as breast or lung cancer, will often have access to funded or reimbursed targeted treatment options and large clinical trials, while those with rare or less common cancers face limited treatment options, with fewer clinical trials, and higher out-of-pocket costs for non-funded therapies.[6] As more subtypes of common cancers are identified, people with a rare subtype of a common cancer, such as breast or lung, are also facing these challenges.

Adding to these challenges are the systemic inequities that create barriers to accessing care. In a vast country like Australia, where you live can heavily influence your ability to receive timely and advanced care, with those in rural and remote areas often facing limited access to specialist services, clinical trials, and cutting-edge therapies. This 'postcode lottery' creates significant barriers for people living outside metropolitan areas, often delaying diagnoses and reducing treatment options.[7]

First Nations people face unique and significant challenges across every dimension of cancer care. These challenges include delayed diagnosis, delays in starting therapy, dislocation from home, and logistical issues related to language, accommodation, transport, and finance. Limited access to culturally safe and relevant care often undermines trust and access.[8] It is critically important to Aboriginal and Torres Strait Islander people that their identity is respected throughout any treatment journey.

The need for more personalised, effective approaches to cancer care has never been clearer.

Comprehensive genomic profiling (CGP) offers a transformative opportunity to address these challenges and offer better outcomes for patients. By analysing the genetic mutations driving a person's cancer, CGP enables the development of personalised treatment options tailored to the individual's specific cancer biology. This approach has the potential to improve treatment efficacy, reduce unnecessary clinical and financial toxicity, improve equity in access to care, and ultimately change the trajectory of cancer care in Australia.

To explore the potential of CGP, roundtable attendees across the series came together to discuss and exchange insights on how Australia can reap the benefits of genomics in cancer care, including how genomic profiling can be embedded in routine cancer care as a national standard accessible to all Australians.

Because, if we continue to offer a 'one size fits all' approach to cancer, Australians will not have access to the most appropriate care for their unique cancer. This is even more critical for patients with a rare or less common cancer diagnosis, who face fewer treatment options, poorer survival outcomes and higher out-of-pocket costs. By embracing genomics we can overcome many of the barriers that have prevented people with rare cancers from accessing life-saving treatments.

I would really like to see everyone have access to genomic testing, regardless of [their] financial position. Everyone should have access because it's vital for their survival to receive the correct medication."

– Charlotte Noble, patient advocate

Transforming cancer care through precision medicine

CGP involves analysing the DNA of cancer cells to identify specific genetic mutations, alterations, and variations that drive cancer growth and progression. Unlike traditional diagnostic methods, which primarily focus on tumour location and histology, CGP provides a detailed molecular map of the cancer's genetic makeup. This allows for a deeper understanding of the specific genetic factors at play in each individual case of cancer, enabling a more personalised treatment journey, which may include currently available therapies or indicate where a novel treatment option should be explored through clinical trials.

> **"To deliver precision oncology, comprehensive genomic profiling needs to be coupled with equitable access to therapies."**
>
> – Tiffany Boughtwood, Managing Director, Australian Genomics

Genomic profiling has many important uses in cancer care

Genomic profiling has broad applications across the cancer continuum, offering valuable insights to inform, personalise and improve care. During Roundtable 3, Professor Vivienne Milch highlighted how genomics shapes the delivery of cancer care at every stage (Figure 1).

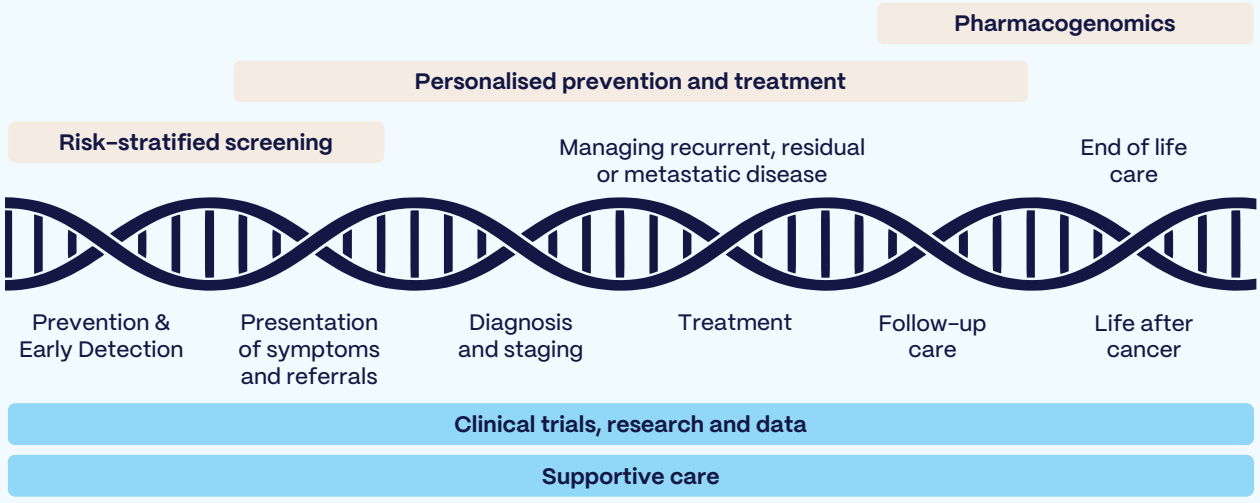


Figure 1. Genomics across the cancer continuum

Whilst genomics offers many benefits across the cancer continuum, many of which were discussed during the Roundtable Series, this report focuses on how genomic profiling can transform cancer treatment pathways, providing insight into how it can help personalise care and improve outcomes for people with cancer. This is especially important for people with rare or less common cancers, opening doors to new treatments, and was a priority for attendees.

Table 1. Applications of genomic testing

Application	Description	Potential benefits
Risk-stratified screening	Using genomic testing to tailor cancer screening based on a person's genetic profile, family history, and lifestyle, improving early detection for those at higher risk.	• Identifies individuals at high genetic risk for earlier and more frequent screenings. • Reduces over-screening and unnecessary interventions in individuals with low genetic risk. • Customises screening modalities based on genetic predisposition, enhancing early detection.[9]
Personalised prevention and treatment	Leveraging genomic information to develop tailored prevention strategies and treatment plans that improve efficacy while minimising side effects.	• Guides personalised treatment strategies for improved outcomes. • Identifies genetic mutations unique to a patient's cancer for targeted therapies. • Helps predict response to surgery or drug therapy.[10]
Pharmacogenomics	Examining how a person's genetic makeup affects their response to drugs to guide drug selection and dosing in cancer treatment.	• Optimises treatment by predicting drug efficacy and toxicity. • Improves treatment efficacy and reduces adverse events. • Provides information relevant to numerous drugs based on specific gene variants.[11]
Clinical trials, research and data	Using genomic testing to facilitate patient recruitment for clinical trials, drive the development of new therapies, and build comprehensive research databases.	• Facilitates patient recruitment for clinical trials. • Contributes to the development of new therapies and preventive strategies. • Builds databases for future research and understanding of hereditary cancer. • Enables expanded access to appropriate clinical trials.[10]
Supportive care	Using genomic insights to support shared decision-making between patients and healthcare providers, empowering patients with better choices and understanding of their condition.	• Facilitates shared decision-making between patients and healthcare providers. • Empowers patients with more treatment choices and understanding of their condition. • Supports genetic counselling for patients and families.[10]

Achieving the vision of personalised cancer care using CGP will require evolution of our health system and associated infrastructure, as well as our HTA system.

We are not, however, starting from scratch. CGP is already being used in Australia and internationally, with rapidly growing evidence for its use and effectiveness. Australia already has two major translational research programs using CGP that can be leveraged to accelerate its broader implementation: the Zero Childhood Cancer Program (ZERO) and Omico's Cancer Screening Program (see case studies on pages 20 and 22). In addition, during Roundtable 1, Tiffany Boughtwood highlighted several international programs, such as those established and reimbursed by governments in Sweden, England, Finland, and Germany, which offer valuable insights and lessons.

Throughout the series, roundtable attendees emphasised that Australia is at a pivotal moment, ready to move CGP from research into sustainable, publicly funded cancer care. Achieving this will require collaboration across governments, researchers, patient groups, providers and industry, and all attendees were eager to contribute to successful adoption.

> **Everyone's cancer is unique, much like a fingerprint."**
>
> **– Caitlin Delaney, patient advocate**

Australia stands at a pivotal moment in cancer care. The rising burden of cancer, coupled with the transformative potential of genomic profiling, presents an urgent call to action. By fostering cross sector collaboration and adopting a national approach to genomic profiling, Australia has the opportunity to transform cancer care, shifting from generalised, 'one size fits all' treatments to highly personalised, effective therapies that improve outcomes and minimise harm, especially for rare or less common cancers.

How genomics helped Carys Dawson

My name is Laura Richards, and I am the mother of Carys Dawson, an 11-year-old who was diagnosed with leukaemia, went into remission and subsequently relapsed.

In April 2020, Carys was diagnosed with pre-B ALL leukaemia. After that, she underwent about 10 months of standard treatment, which she responded to well. In fact, she became a poster child for recovery, returning to normal life after her diagnosis and treatment.

Unfortunately, in October 2023, during a routine clinic visit, we learned that Carys had relapsed. We enrolled Carys in the Zero Childhood Cancer Program, where she underwent genomic testing.

The results of the genomic testing revealed that Carys had a rare subtype of leukaemia known as ph-like ALL, something we had never heard of before. This changed everything.

With this new information, her treatment plan was reviewed, and she went on to undergo a successful bone marrow transplant in May 2024.

Carys continues to recover and has recently returned to school, a wonderful achievement for her.

Without the Zero Childhood Cancer Program, Carys would have likely continued to follow the painful cycle of "recovery" and relapse, with potentially tragic results.

Thanks to ZERO and the insights from genomic testing, Carys now has a better chance of living a long life.

Unlocking more targeted and effective cancer care

Genomic profiling has the potential to transform cancer care in Australia by providing critical information to guide the most effective treatment strategies. By revealing the unique genetic characteristics of each person's cancer, genomic profiling can inform decisions that optimise treatment response and minimise toxicity.

When embedded into routine cancer care, this approach holds significant promise for the 40,232 Australians diagnosed with a rare or less common cancer each year, enabling more precise, efficient, and manageable care.[2]

Throughout the series, roundtable attendees highlighted many current and potential future benefits that could be realised by better integrating genomic profiling into cancer care in Australia. The clinical and patient benefits were underscored during Roundtable 2, where Professor Clare Scott shared her experience and reflections from using genomic testing to inform her clinical practice for over a decade.

> **"Genomics is crucial for patients with rare cancers because it can identify a drug target that works regardless of the cancer's label. The rarity of the cancer no longer matters, what matters is its molecular profile, its molecular fingerprint."**
>
> **–Professor David Thomas, Director, UNSW Centre for Molecular Oncology and Chief of Science and Strategy, Omico**

Delivering more precise, tailored cancer treatments

By identifying specific genetic mutations and unique biomarkers, doctors can confidently tailor therapies that are more likely to be effective, allowing for targeted interventions from the outset. Some attendees noted that this approach could streamline treatment processes and reduce health service utilisation, such as hospital visits and repeat treatments, potentially minimising the need for additional biopsies and repeat testing. Some attendees recognised that currently, frontline treatments like chemotherapy are more cost-effective, however noted that this could shift as the cost of personalised medicines reduces, more personalised treatments are developed and approved, and evidence is generated on the quality of life and avoided costs associated with earlier access to personalised treatments. For patients, access to a tailored treatment journey provides a smoother, more predictable care experience, the potential to avoid the harsh toxicity of treatments that are unlikely to work for them.

> **It is unconscionable that we are allowing people to cycle through treatments that are only 20 per cent effective until they are sick enough to receive the best [available] treatment. We should give people the best treatments first. We need to turn that approach on its head."**
>
> – Elizabeth de Somer, Chief Executive Officer, Medicines Australia

Enhancing patient quality of life

The use of personalised genomic insights can improve treatment experiences and quality of life, as well as extending life. In Roundtable 2, Associate Professor Rachel Conyers discussed the importance of tailoring treatments and managing side effects by using information about the patient's unique pharmacogenes[1]. This approach is likely to reduce adverse drug reactions including fatal toxicity, reduce drug waste, and lessen the physical toll of treatment. As treatment regimens become more efficient and less invasive, patients can maintain a stronger sense of normalcy, independence, and wellbeing throughout recovery and survivorship, and we can learn more about how to reduce late and long-lasting effects of treatment.

Access to innovative treatments and clinical trials

Genomic profiling can open doors to innovative therapies and clinical trials that might otherwise be inaccessible to patients with rare or less common cancers. Roundtable attendees highlighted the potential of biomarker targeted drug development in finding treatments for cancers that have traditionally had few treatment options and limited trials. For the one in four Australians diagnosed with rare or less common cancers, participation in clinical trials can provide access to promising treatments that may not only extend life but also maintain a better quality of life while living with their cancer.

Roundtable attendees were optimistic about the opportunities and potential benefits of improved genomics integration into the Australian cancer care landscape. They emphasised that, while still in the early stages of development, the opportunities unlocked by this technology will only grow over time with the further identification of biomarkers and the development of more targeted therapeutics. This progress is especially vital for those who currently lack matched treatment options, despite access to CGP. Attendees recognised that genomic profiling could collectively unlock substantial benefits for patients, health systems, and the Australian economy in the long term, underscoring the importance of continued research to collect data in these areas.

> **Genomic profiling can be a lifesaver for rare or less common cancers when standard treatments don't work."**
>
> – Caitlin Delaney, patient advocate

As cancer continues to significantly impact individuals and communities across Australia, investing in genomic and precision medicine can improve quality of life, extend survival, and reduce the severity of side effects and adverse drug reactions.

1 Pharmacogene – genes that influence how medications work and the side effects they may cause.

Building efficiency in our health system

The integration of genomic profiling into routine cancer care offers a more sustainable and efficient approach to treatment delivery. As the number of cancer diagnoses continues to rise, genomic profiling has the potential to help alleviate the growing strain on our healthcare system.

Roundtable attendees across the series identified several ways in which genomics can enhance health system efficiency, including:

Optimising the cost-effectiveness of healthcare resources

Genomic profiling may reduce strain on healthcare resources by streamlining patient care pathways. By providing precise genomic insights early in the treatment journey, clinicians can identify effective therapies sooner, potentially reducing the need for trial-and-error approaches, unnecessary follow-ups, specialist referrals, and additional tests. Attendees noted that this could improve the cost-effectiveness of healthcare resource utilisation.

By matching patients with the most effective treatments from the outset, genomic insights may also help reduce future costs, including those associated with treating side effects from suboptimal therapies. Attendees reflected on how early genomic testing might prevent long-term complications and costs, such as organ damage, fertility issues, and lower socio-economic outcomes for children receiving non-targeted therapies. Early genomic profiling could help avoid these complications, reducing both the healthcare burden and lifetime costs; however, further data collection is needed.

In Roundtable 2, Associate Professor Ilias Goranitis highlighted that genomic profiling can be positioned as a wise investment in the nation's health by demonstrating the long-term value of precision medicine. This perspective aligns with a sustainable, forward-thinking approach to "investing" in health, which may help justify the allocation of public funds toward genomic profiling. Many attendees expressed frustration with the siloed approach to health service spending, recognising the economic savings and contributions from improving a patient's survival and quality of life are widespread and do not all fall within health. To demonstrate the long-term cost-effectiveness of targeted therapies, we need to consider the holistic benefits, for example the future economic contributions from people with cancer and their carers.

Supporting workforce productivity through streamlined care pathways

Genomic profiling has the potential to support better workforce productivity for patients, carers, and healthcare professionals through more effective treatments and streamlined patient pathways. At the patient level, roundtable attendees discussed that a successful response to matched therapies may reduce care needs and enable an earlier return to daily activities, thus supporting the economic participation of both the patient and carer. In healthcare systems, simplified and smoother patient pathways can reduce administrative complexity and facilitate better coordination of care across specialties. Attendees identified that by streamlining clinical workflows and improving need-based resource allocation, genomic profiling could also decrease strain on healthcare professionals and improve workforce efficiency.

Genomic profiling can be a transformative tool for the Australian healthcare system, with the potential to enhance efficiency, support more equitable access to personalised cancer care, and improve our understanding of cancer.

Investing in genomic medicine today is not just an investment in better cancer care; it is a commitment to building a more effective, equitable, and sustainable healthcare system for future generations.

> **Genomics offers a unique, once in a generation opportunity to reduce health inequities for Aboriginal and Torres Strait Islander peoples. If we don't lead and leverage this opportunity we will fall further behind."**
>
> – Louise Lyons, Senior Manager, Strategy and Policy, Indigenous Genomics, The Kids Research Institute Australia

Increased equity and access to personalised care

The roundtable attendees also discussed the role of genomics in promoting equitable access to personalised therapies for diverse populations. Attendees noted that integrating this technology into routine practice could reduce disparities in care quality and health equity, regardless of geography, cultural background, or socioeconomic status. For those with rare or less common cancers, genomic profiling can offer a much-needed pathway to targeted treatments, addressing the lack of standardised therapies for these patients.

In Roundtable 1, Louise Lyons discussed the importance of addressing bioethical concerns in genomic cancer care for First Nations communities. These concerns include issues such as bio-piracy, sample and data misuse, and anxieties about the familial implications of testing. These will need to be addressed to ensure that culturally safe care can be develops in a genomic-led era of cancer treatment. In Roundtable 3, Professor Vivienne Milch confirmed that Aboriginal and Torres Strait Islander communities will be a priority group for the expansion of the use of genomics in cancer care, guided by the draft National Framework for Genomics in Cancer Control, and share insights from Cancer Australia's engagement.

> **I want to see equitable access to care so that everyone can have a targeted treatment plan. This should be available to all Australians and become the standard of care."**
>
> – Associate Professor Robyn Schofield, patient advocate

Data-driven research enables long-term improvements

The expansion of genomic databases presents a valuable opportunity to advance cancer research and innovation. Attendees discussed how increased genomic data collection could inform and accelerate the development of new treatments and provide insights to refine existing therapies, and expressed frustration at the current lack of data sharing and the need for greater collaboration across industry, government, and public and private providers.

Safeguarding patient privacy through robust data sovereignty measures was identified as a critical enabler of these advancements, as well as ensuring clinical genomic data is consistently recorded and reported to allow use at patient, system and national levels.

Over time, the knowledge gained from genomic profiling could deepen the healthcare system's understanding of cancer evolution and treatment efficacy. This insight will continue to support improvements in cancer prevention, diagnosis, and treatment, reinforcing the healthcare system's ability to deliver high-quality, future-ready care.

CASE STUDY

Zero Childhood Cancer Program (ZERO) – A revolutionary approach to childhood cancer treatment through genomic profiling

Childhood cancer differs from adult cancer. Most childhood cancers have no known cause, leaving parents and carers with unanswered questions. In Australia, over 1,000 children are diagnosed with cancer each year, and cancer remains the leading cause of death by disease among children.[12]

While survival rates have improved to over 80 per cent, some types of childhood cancer remain fatal. Current treatment approaches are a 'one size fits all', which doesn't account for the unique genetic makeup of each child's cancer. Existing treatments often cause severe long-term side effects and chronic health conditions for survivors, including organ dysfunction, neurocognitive issues, and secondary cancers. These side effects affect two-thirds of childhood cancer survivors.[12]

To address the unique challenges of childhood cancer, the **Zero Childhood Cancer Program (ZERO)** was established as Australia's first national precision medicine initiative for children with cancer. Launched in 2017 and led by the Children's Cancer Institute and the Kids Cancer Centre at Sydney Children's Hospital, Randwick, ZERO uses genomic profiling to tailor treatment plans to the genetic characteristics of each child's cancer.

Initially, the program focused on high-risk cancer patients, but its success has driven significant expansion. During Roundtable 1, Associate Professor Vanessa Tyrrell highlighted ZERO's remarkable impact. From November 2023, the program broadened its scope to offer precision medicine to all children diagnosed with cancer in Australia. This expansion represents a significant milestone, with ZERO having enrolled over 2,000 patients to date and projected to reach just under 2,500 children by June 2025, ensuring nationwide access to personalised, targeted treatments.[13]

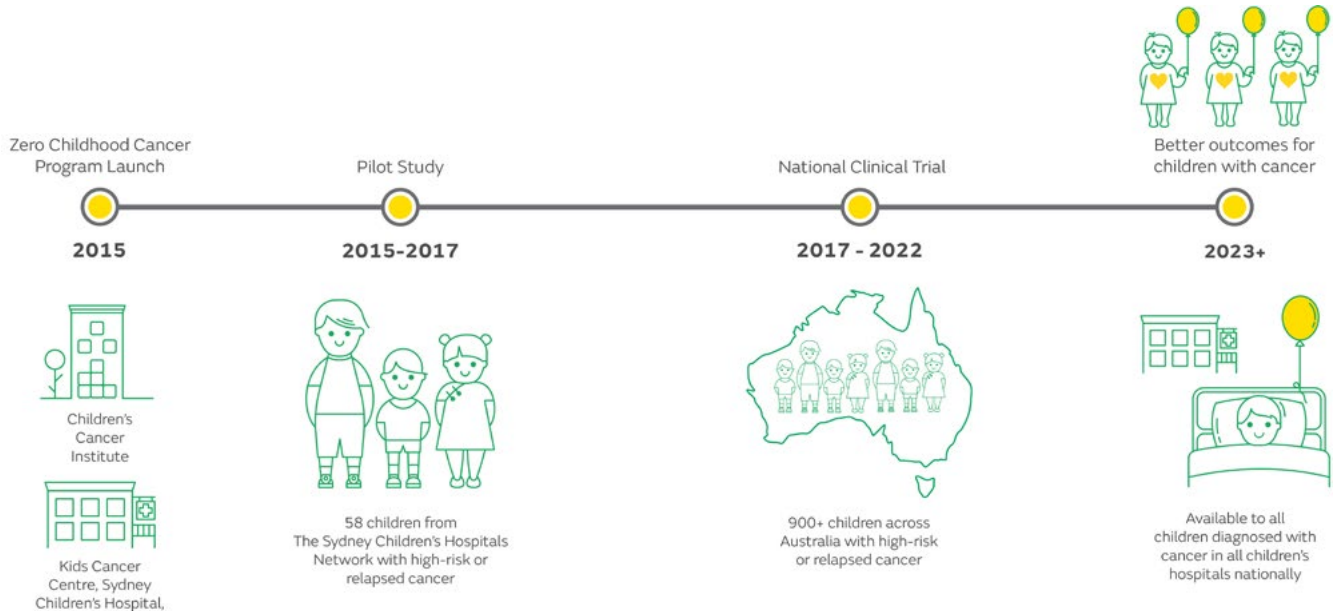


Figure 2. ZERO timeline and growth

Program outcomes and impact

Since its launch, the ZERO program has profoundly impacted childhood cancer treatment in Australia. Since the program's expansion in November 2023, an additional 1,000 patients have been enrolled.

Analysis of the first 384 high-risk/rare patients with at least 18 months of follow-up data found[14]:

- **Improved Outcomes**: Over half (55 per cent) of children who received precision medicine guided treatment (PGT) achieved complete or partial remission or stable disease for at least six months.
- **Extended Survival:** The 2-year progression-free survival rate for children receiving PGT was double that of those without it and five times higher than for children on unguided novel treatments.
- **Timely Intervention:** Children treated with PGT before disease progression had significantly better survival rates (40 per cent) compared to those treated after progression (12 per cent).

ZERO has demonstrated significantly improved outcomes for children with high-risk, rare, and aggressive cancers compared with traditional treatments. By enabling early, precision-guided therapies tailored to each child's unique genetic profile, ZERO is setting a new benchmark for personalised paediatric cancer care, offering hope and better outcomes for families across Australia.

The Zero Childhood Cancer Program is a groundbreaking advancement in childhood cancer treatment, demonstrating how genomic profiling can deliver personalised, effective, and less harmful therapies.

Roundtable attendees emphasised the need to move beyond short-term research funding and adopt sustainable healthcare models. The goal is to leverage the evidence from ZERO and other translational research programs to integrate genomic profiling into routine clinical practice, ensuring long-term, equitable access for all patients within the healthcare system.

"We are seeing children alive today who would not have survived without Zero Childhood Cancer."

– Associate Professor Vanessa Tyrrell, Program Director, Zero Childhood Cancer Program

CASE STUDY

Omico's Cancer Screening Program (CaSP) – Expanding access to precision oncology in Australia

Omico's Cancer Screening Program (CaSP) is reshaping cancer care in Australia by providing access to comprehensive genomic profiling at no cost to patients with advanced or incurable cancer.

This initiative, led by Omico through the Precision Oncology Screening Platform Enabling Clinical Trials (PrOSPeCT) program, offers new treatment avenues for patients with limited options, enabling genomic insights to guide precision treatments.[15]

Program overview: PrOSPeCT and CaSP

PrOSPeCT, Omico's flagship initiative, aims to accelerate access to precision oncology by identifying the unique genetic characteristics of each patient's cancer. The program's screening arm, CaSP, aims to provide CGP to 23,000 Australians with advanced, incurable, or poor-prognosis cancers. Its goal is to identify specific genetic mutations driving each patient's cancer and match them to clinical trials offering novel, targeted therapies.

Following CGP, each patient's results are reviewed by Omico's Molecular Oncology Board, which assesses potential precision treatment options. A report is provided to the patient's clinician, detailing recommendations for tailored therapies or suitable clinical trials that match the genetic profile of the patient's cancer. This process not only guides more personalised treatment options but also connects patients to clinical trials for cutting-edge therapies.

Outcomes and impact

Since the program's launch, the program has demonstrated significant impact:

57 per cent

of screened patients received a treatment recommendation tailored to their specific cancer profile.[16]

17 per cent

of patients who received treatment recommendations accessed a matched therapy, opening potential for better outcomes and extended survival in cases previously deemed incurable.[16]

The success of Omico's Cancer Screening Program highlights the critical need to provide genomic profiling for people with rare or less common cancers.

Roundtable attendees emphasised the importance of applying the evidence and learnings from this program to transition to sustainable delivery through the healthcare system, moving away from short-term funding models.

CASE STUDY

The NHS Genomic Medicine Service (GMS)[21]

The NHS Genomic Medicine Service (GMS) is a pioneering initiative that has transformed healthcare in England by integrating genomic technology into routine clinical care.

Launched in 2019, the GMS aims to harness the power of genomics to improve patient outcomes and advance medical research. The service has been particularly impactful in the field of rare diseases, where traditional diagnostic methods often lead to prolonged uncertainty for patients and families.

Key features of the NHS GMS:

- **Nationwide coverage:** The GMS provides consistent and equitable care across the nation.
- **Advanced testing:** It offers a single National Genomic Test Directory, covering a range of genomic technologies, from single-gene tests to whole genome sequencing. The directory covers over 200 cancers and 3,200 rare diseases, specifying eligibility criteria to ensure that all patients, regardless of location, can access advanced genomic testing when clinically indicated.[22]
- **Research integration:** The service gives patients the opportunity to participate in research, contributing to a national genomic knowledge base.

This is delivered through a national genomic testing network of seven NHS Genomic Laboratory Hubs (GLHs). These services are led by clinical geneticists and genetic counsellors who, in partnership with other healthcare professionals, diagnose genetic conditions, assess patient risks, and coordinate tailored treatment plans. They also offer emotional support and counselling to patients and their families, ensuring compassionate and comprehensive care for those affected by genetic conditions.

During Roundtable 1, Tiffany Boughtwood highlighted the success of the NHS model and shared slides and information from Dame Sue Hill, Chief Scientific Officer for England. She emphasised the importance of developing a structured, transparent system to ensure equitable access to genomic testing, ultimately improving outcomes for cancer patients.

Australia can draw important lessons from the NHS, particularly by prioritising investments in cutting-edge technology, a skilled and dedicated workforce, robust informatics systems, and comprehensive education programs. Strong national coordination and multidisciplinary leadership will be crucial to ensuring equitable access to genomic profiling and its seamless integration into routine cancer care across the country.

Next steps: Building a cohesive approach to genomic medicine

The integration of genomic profiling into cancer pathways offers a transformative opportunity to revolutionise how we treat cancer in Australia. By ensuring that every patient, particularly those with rare or less common cancers, has access to genomic profiling, we can deliver more personalised, effective, and evidence-based care aligned with the latest advances in precision medicine.

Roundtable attendees emphasised the urgency of moving from research findings to routine practice, highlighting the need for national leadership and collaboration across sectors. Programs such as PrOSPeCT and ZERO have demonstrated the potential of genomic profiling, but transitioning these initiatives into standard care requires a structured and sustainable approach. This includes the development of clinical guidelines, investment in workforce education, continuous evidence generation, and systemic infrastructure improvements.

Five key steps emerged from the discussions that will help guide the integration of genomic profiling and precision oncology into Australia's cancer care system.

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

The integration of genomic profiling into routine cancer care requires robust coordination, strategic collaboration, and cohesive planning. To date, many stakeholder groups, including researchers, clinicians, policymakers, industry representatives, and patient advocacy organisations, have advanced genomic initiatives within their respective domains. Roundtable attendees emphasised the need for these stakeholders to come together to share resources and information and move forward with a unified approach. This collaboration should leverage multidisciplinary expertise to drive innovation and improve outcomes for cancer patients, and all attendees were excited to keep working together.

During Roundtable 3, Renaye Lucchese highlighted the National Health Genomics Policy Framework, which is set for review and update by 1 July 2025, and Professor Vivienne Milch outline the newly developed draft National Framework for Genomics in Cancer Control. Roundtable attendees agreed that these frameworks provide a critical opportunity to align national efforts in genomic medicine and that there must be absolutely clarity on how these national frameworks work together and with State and Territory genomic strategies and plans, so that everyone is clear on the ambitions and actions and how to collaborate on implementation.

Key responsibilities to be addressed through cross sector stakeholder collaboration include:

- Embedding genomic profiling into routine cancer care, aligned with national standards.
- Bridging gaps between research, clinical care, and policy to foster innovation and address challenges.
- Establishing mechanisms for ongoing evaluation and adaptation based on emerging evidence.

Strong leadership and multidisciplinary collaboration will be essential to guide a national approach to embedding genomic profiling into cancer care quickly and equitably. Roundtable attendees highlighted that the Department of Health and Aged Care, Genomics Australia and Cancer Australia, will play critical roles in strategy, operations, regulation, and reimbursement.[17]

Roundtable attendees emphasised the importance of the Department of Health and Aged Care, Genomics Australia and Cancer Australia engaging widely with stakeholders, including clinicians, researchers, policymakers, patient advocates, and industry representatives, to ensure diverse perspectives are incorporated. States and territories will also play a pivotal role in operationalising the framework locally, ensuring equitable and consistent integration across the country.

Establishment of Genomics Australia[18]

On 21 March 2022, the Australian Government announced plans to establish Genomics Australia – a new national body to provide leadership, coordination and expertise so all Australians can reap the benefits of cutting-edge genomic research and technologies. In November 2024, the Government confirmed Genomics Australia will open within the Department of Health and Aged Care in July 2025, with an initial $30 million of funding for its first four years of operation.

Genomics Australia's initial priorities include enhancing access to personalised cancer care and working with states and territories to update and implement the National Health Genomics Policy Framework. As consultation for the framework concludes, Genomics Australia will shift focus to nationwide implementation.

Roundtable attendees discussed the critical role Genomics Australia will play, and how they want to see strong and forward-thinking national leadership, support and collaboration to ensure equity and efficiency as Australia expands its genomic infrastructure and services.

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 developed collaboratively by multi-disciplinary stakeholders to ensure genomic profiling becomes a routine and equitable component of cancer care across Australia. As well as addressing the specific and different needs of priority populations, this national model must align with and deliver the ambitions of the Framework for Genomics in Cancer Control and the National Health Genomics Policy Framework. It should set out the optimal way to deliver genomic-led cancer care, recognising the components that are specific to cancer and those that will be drawn from broader genomic services. Importantly, attendees highlighted the need for genomic profiling to be a part of the cancer pathway and multi-disciplinary cancer team, with information and support wrapped around the person with cancer and their carers.

Nationwide applicability with a focus on equity and priority groups

Throughout the series, attendees discussed ways to phase increased access to genomic profiling. There was consensus that groups with the highest unmet clinical need and priority populations who usually have poorer access and outcomes should be prioritised. This is reflected in the draft National Framework for Genomics in Cancer Control, which prioritises people with rare cancers as well as the priority population groups recognised in the Australian Cancer Plan.

Roundtable attendees agreed that the model must ensure no in-need group is overlooked, whether implemented in phases or simultaneously across all cancer types. Rare and less common cancers should remain a key focus due to their disproportionate burden and slower advances in treatment outcomes. Similarly, Aboriginal and Torres Strait Islander communities must be prioritised because of systemic inequities in healthcare access and outcomes. The approach should also establish a consistent, scalable model for integrating genomic profiling into clinical practice nationwide, ensuring equitable access for all.

Standardised guidelines for genomic profiling

Clear and consistent guidelines must define when and how genomic profiling is used in cancer care to ensure all patients, regardless of geographic location or cancer type, receive the same high standard of care. Standardisation will also empower clinicians to confidently and effectively incorporate genomic profiling into their treatment planning.

Equitable access to therapies remains a significant barrier. During Roundtable 3, Elizabeth de Somer noted that Australia's average time from registration to reimbursement for treatments is 466 days, compared to the OECD average of 384 days.[20] She emphasised the importance of HTA reform, highlighting the recommendations relevant to genomics.

Roundtable attendees outlined key systemic barriers to address through HTA reform, including:

- Lengthy and complex approval processes for genomic applications.
- Inconsistencies in funding pathways between federal and state governments.
- Stringent evidentiary requirements misaligned with the evolving nature of genomic technologies.
- Limited opportunities for patient engagement and representation in decision-making processes.

Despite overall improvements in cancer survival rates, significant inequities remain. The five-year relative survival rate is 63 per cent for rare cancers and 43 per cent for less common cancers, compared to 79 per cent for common cancers.[2] For certain rare and less common cancers, such as bladder, urethral, and eye cancers, survival rates have stagnated or declined.[6]

Additionally, Indigenous Australians are 1.1 times more likely to be diagnosed with cancer compared to non-Indigenous Australians. Among Indigenous populations, males (44 per cent) and females (52 per cent) have notably lower five-year crude survival rates for all cancers combined, compared to non-Indigenous males (58 per cent) and females (63 per cent).[19]

These figures highlight the urgent need for an inclusive national approach that prioritises equity in access to genomic profiling.

By streamlining these processes and ensuring transparency, HTA reform can facilitate faster and more equitable access to genomic technologies and therapies. Attendees highlighted the significance of the HTA Review and its recommendations for enabling faster assessment of genomic therapies and broader reform, in particular recommendation 38 to support the development of further guidance on methods for assessing tumour-agnostic therapies, genomic technologies and gene therapies. The HTA Review Implementation Advisory Group should progress the key recommendations2 that directly impact access to genomics and matched therapies, ensuring integration into the health system so that more patients can access subsidised personalised therapies.

Integration into clinical pathways

To maximise its impact, genomic profiling must be embedded into routine cancer care pathways. Seamless integration will enable clinicians and patients to access genomic profiling as a standard component of cancer care. This will facilitate tailored, precision therapies that improve outcomes and create consistency in care delivery across Australia.

Roundtable attendees emphasised that integration must be supported by comprehensive wrap-around care and patient support systems. This includes psychosocial support, clear communication of genomic results, and access to multidisciplinary teams to guide patients through the cancer pathway. Supporting patients and their families at every stage, from diagnosis to treatment and beyond, will enhance the effectiveness of genomic interventions and ensure equitable access to holistic cancer care.

> **“We need to ensure equity of access to genomic testing and genomics-informed treatments for all Australians. It is the future of cancer care.”**
>
> **– Professor Vivienne Milch, Medical Director, Cancer Australia**

2 Out of the 50 HTA recommendations, 18 are relevant to genomics and matched therapies, including recommendations 4, 13, 19–20, 26, 27–31, 33, 36, 38–39, and 44–47.

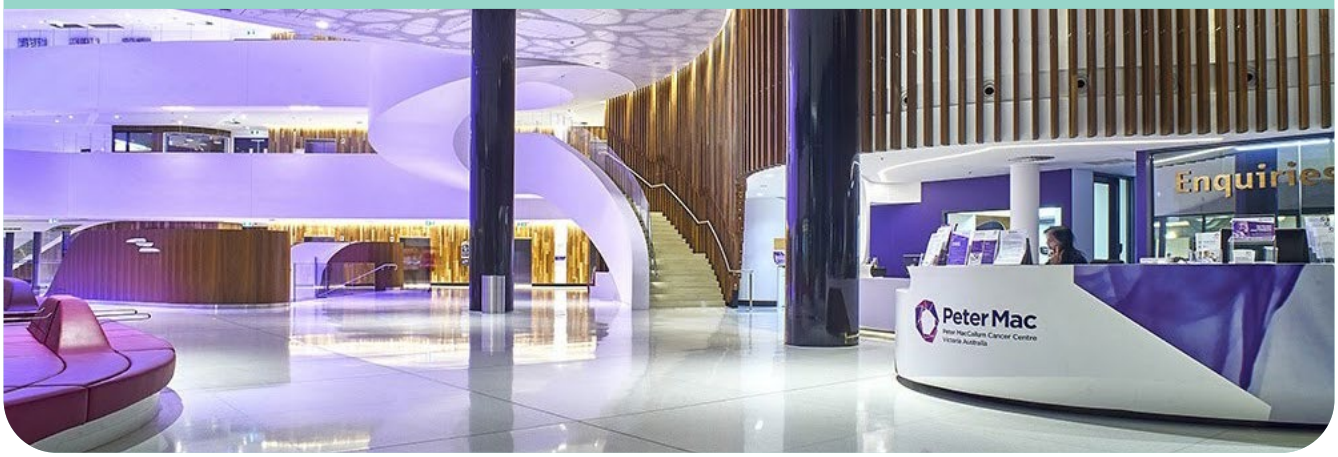
3 Invest in genomic infrastructure and technology

Integrating genomic profiling into cancer care requires a thorough review and enhancement of existing infrastructure. This includes equipping healthcare facilities with the necessary technology and systems for genomic testing, data management, and secure genomic information sharing – or ensuring that they have access to that through networked care arrangements. Reviewing current access to subsidised genomic testing and mapping existing infrastructure and testing capacity will identify gaps and the most efficient way to expand access to genomic profiling for cancer patients across Australia.

Attendees emphasised the importance of establishing a secure way to collect, store and access clinical genomic data from patients, such as a National Genomic Data Registry for Cancer. This centralised registry would securely collate genomic data from cancer patients, creating a valuable resource for researchers, clinicians, and policymakers and driving up the standard of genomic data recording and reporting across the country. Such a registry could advance the integration of genomic data into clinical care by providing insights that drive improvements in treatment and outcomes. To maximise its value, attendees noted that the effort should focus on the national collation and reporting of genomic data and its linkage with existing cancer registries, such as the Australian Cancer Database. These linkages would foster a comprehensive understanding of cancer trends, treatment efficacy, and long-term outcomes, enabling a data-driven approach to genomics-informed cancer care and research.

During Roundtable 1, Louise Lyons emphasised the critical importance of prioritising Indigenous data sovereignty, governance, and the protection of Intellectual and Cultural Property in the development of genomic infrastructure. Mechanisms must safeguard Indigenous knowledge, data sovereignty, and intellectual property in the genomic context. Key questions around data collection, management, and sharing, along with bio-specimen stewardship, including repatriation, re-testing, and appropriate storage, require careful consideration to ensure the ethical and equitable use of genomic data.

Roundtable attendees also highlighted challenges around data ownership that complicate collaboration. Restrictions imposed by pharmaceutical companies and researchers often limit access to genomic data, hindering the scalability of genomic initiatives. Establishing a shared database or registry could help overcome these barriers and accelerate research through increased cross-sector collaboration.



4 Prepare the workforce for genomic medicine

As genomic profiling becomes a routine part of cancer care, healthcare professionals must be equipped with the knowledge and skills to interpret and apply genomic data effectively, including to inform treatment decisions, and support patients who are accessing it. Roundtable attendees agreed that incorporating genomics into medical education and ongoing professional development is essential, with a particular focus on two areas:

- Training enough specialists and developing the workforce to meet future demand for genomic services (not specific to cancer – including genetic counsellors, clinical and laboratory geneticists, genomic researchers and genomic data scientists), and
- Training and developing the cancer workforce in the use, interpretation and application of genomic data and genomic-led interventions.

Greater use of genomics to inform treatment and care means everyone working with cancer patients will need some level of education and awareness of genomic-led cancer care. For example, during Roundtable 2, Associate Professor Rachel Conyers highlighted that pharmacogenomics requires continuous education to ensure healthcare professionals are better prepared to manage adverse events and drug reactions, thereby optimising treatment effectiveness. Pharmacists, in particular, are well-placed to recommend therapies tailored to specific genomic profiles, helping to minimise adverse effects and enhance patient outcomes.

Addressing workforce shortages in fields such as bioinformatics, genetic pathology, and health informatics is also critical. Professionals in these areas play a pivotal role in interpreting genomic data and delivering personalised care. Expanding training opportunities and resources in these disciplines will be key to building a robust workforce capable of supporting the integration of genomics into cancer care.

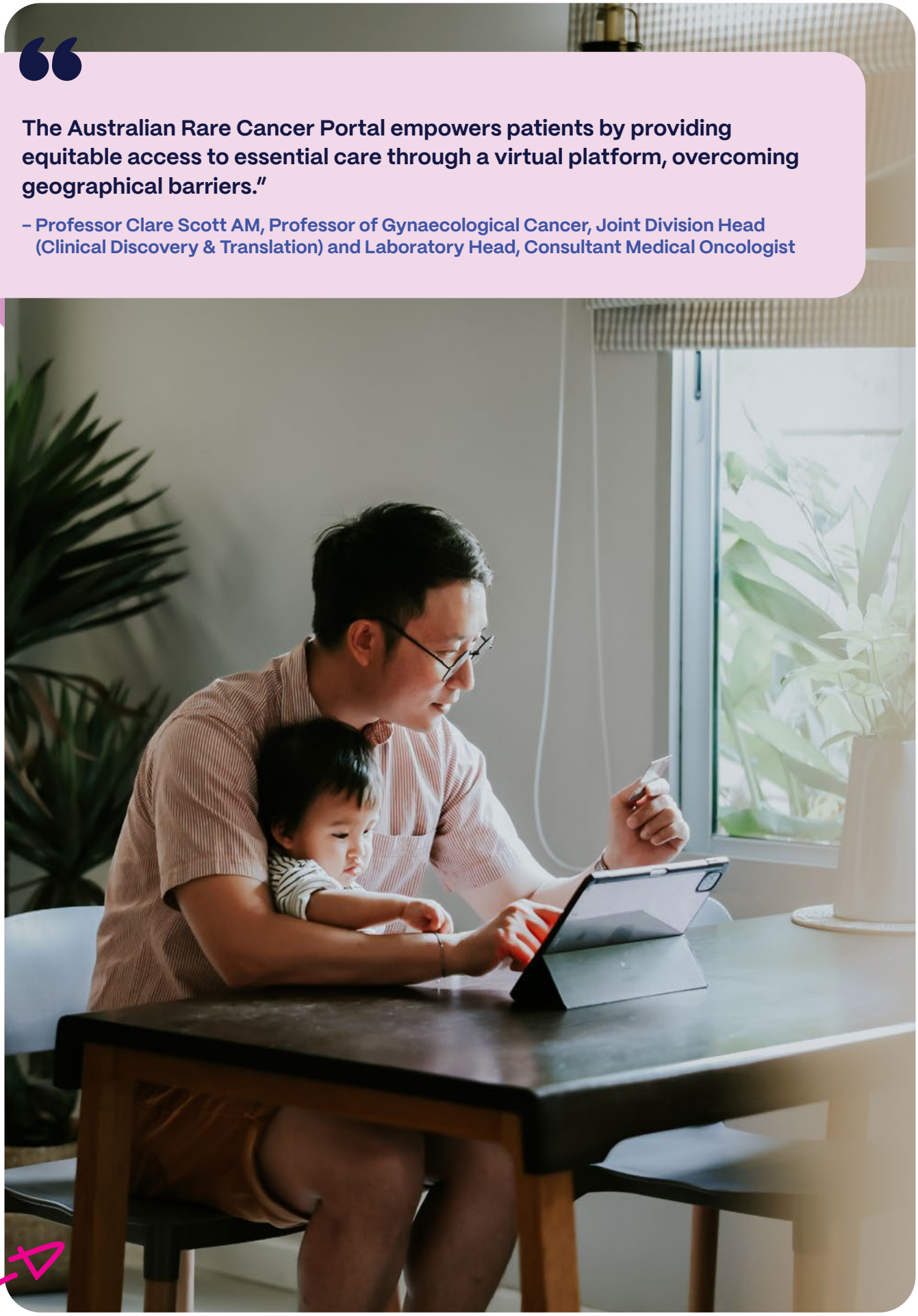
To ensure genomic medicine is culturally safe and accessible, tailored education programs must be developed for healthcare workers who support Aboriginal and Torres Strait Islander people. These initiatives should prioritise cultural safety, respect for indigenous knowledge systems, and community-driven approaches to foster trust and responsiveness in genomic care.

Roundtable attendees also noted the potential to leverage existing networks, such as the Australian Comprehensive Cancer Network (ACCN) and the Australian Rare Cancer Portal, as platforms for knowledge sharing and workforce development. These resources can provide educational materials, foster collaboration among clinicians, and facilitate the exchange of best practice in genomic medicine.

Preparing the workforce for genomic medicine extends beyond technical training. It also requires fostering a mindset that embraces genomics as a transformative tool in cancer care. Healthcare professionals must understand its potential to improve patient outcomes and feel confident integrating genomics into clinical pathways and shared decision-making.

The Australian Rare Cancer Portal empowers patients by providing equitable access to essential care through a virtual platform, overcoming geographical barriers."

– Professor Clare Scott AM, Professor of Gynaecological Cancer, Joint Division Head (Clinical Discovery & Translation) and Laboratory Head, Consultant Medical Oncologist



5 Implement, monitor, and evaluate for continuous improvement

With foundational steps in place, the roll-out of genomic profiling into cancer care must be paired with comprehensive monitoring and evaluation to drive continuous improvement. Although genomic profiling is already available to some individuals through research programs or private payment, there are significant inequities in access. Addressing these disparities is critical to ensure all patients can equally benefit from the advancements in genomic medicine and can only be achieved through nationally coordinate roll out.

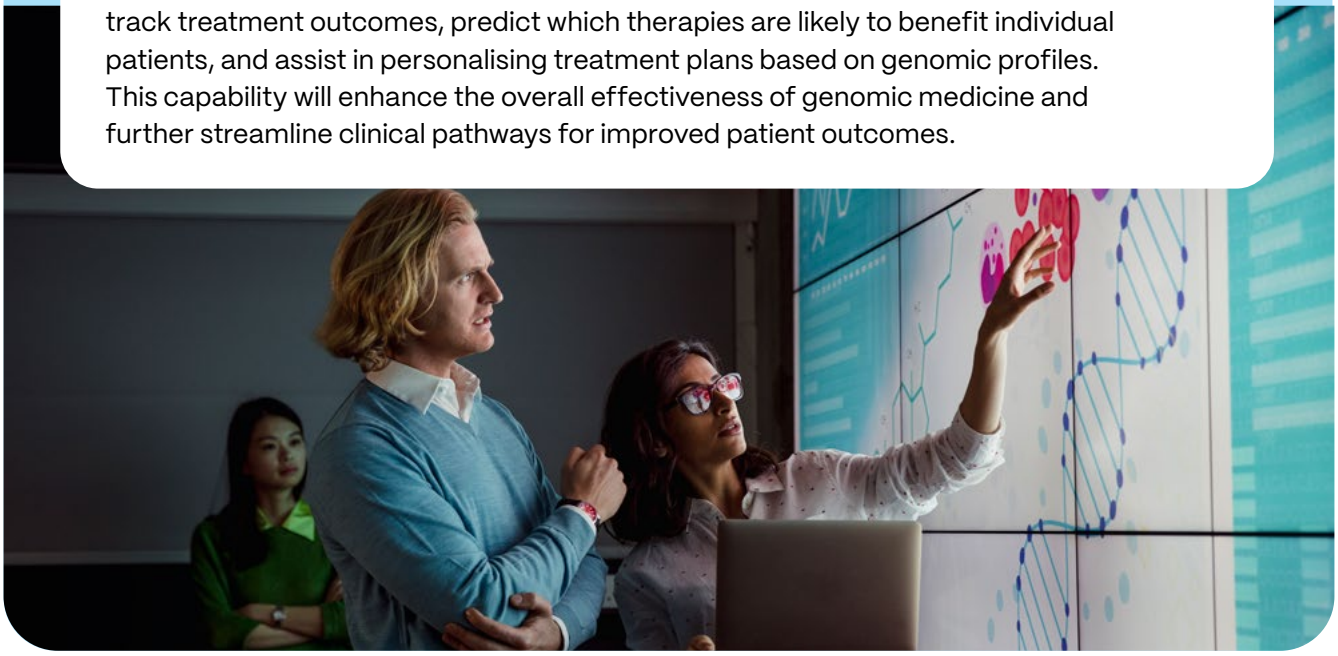
The initial stages of implementation should focus on integrating genomic profiling into clinical pathways, starting with people with highest unmet clinical need, with close monitoring to assess its impact. Regular evaluations should measure progress toward core goals, such as improving patient outcomes, reducing disparities, and ensuring equitable access to personalised treatments. This process must also identify challenges and gaps, enabling timely adjustments to enhance care quality and consistency.

Evaluations are a shared responsibility among researchers, clinicians, industry, and governments. Roundtable attendees emphasised the importance of producing, sharing, and utilising evidence to maintain momentum. Data collection should focus on key metrics, including patient outcomes such as survival rates, treatment efficacy, and quality of life, as well as the efficiency of healthcare delivery.

During Roundtable 2, Associate Professor Ilias Goranitis highlighted the need to evaluate the broader impacts of genomic profiling, such as reducing diagnostic delays, enhancing treatment planning, and improving the efficiency of care delivery. These insights are critical for refining processes, addressing barriers, and ensuring the long-term success of integrating genomics into standard cancer care.

Potential role of Artificial Intelligence (AI)

Roundtable attendees highlighted the potential role of AI in the application of genomics in cancer care. AI systems can analyse vast datasets to track treatment outcomes, predict which therapies are likely to benefit individual patients, and assist in personalising treatment plans based on genomic profiles. This capability will enhance the overall effectiveness of genomic medicine and further streamline clinical pathways for improved patient outcomes.



Time for action

People with cancer in Australia, particularly those with rare, less common or advanced cancers, deserve access to genomic profiling to ensure the most accurate information informs their treatment decisions. Genomic profiling has the potential to transform outcomes, reduce disparities, and create a healthcare system that is more precise, equitable, and patient-centred.

Achieving this vision requires collaboration across all sectors to prioritise the adoption of genomic profiling in cancer care. The roundtable series highlighted the shared commitment to a future where everyone with cancer has access to personalised medicine, ensuring that rarity is no longer a barrier to effective treatment.

The future of cancer treatment is here, and it begins with giving every patient the chance to benefit from their unique genomic insights.

Genomic-led cancer care offers hope for people with rare, less common and advanced cancers. Hope that for too long has been in short supply.

We are at a critical juncture in genomic-led cancer care in Australia. It is available to some, but not others. It completely changes treatment and outcomes for some, but not others.

That's why this Roundtable Series is so important. We all have a stake in this. It means so much to our patient community that you are here, and that you are all working in your respective roles and organisations to bring the hope of genomic-led cancer care to more patients and their families.

– Christine Cockburn, Chief Executive Officer, Rare Cancers Australia

Abbreviations

ACCN	Australian Comprehensive Cancer Network
AI	Artificial Intelligence
CaSP	Cancer Screening Program
CGP	Comprehensive genomic profiling
DNA	Deoxyribonucleic acid
GLH	Genomic Laboratory Hub
GMS	Genomic Medicine Service
HTA	Health Technology Assessment
NHS	National Health Service
OECD	Organisation for Economic Cooperation and Development
PrOSPeCT	Precision Oncology Screening Platform Enabling Clinical Trials
UK	United Kingdom
ZERO	Zero Childhood Cancer Program

Contibutors

Thank you to everyone who contributed their time, perspectives and ideas to the Genomics Policy Roundtable Series, including patient advocates and representatives from the following organisations:

Caitlin Delaney
Charlotte Noble
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Laura Richards
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Contact us

Enquiries about this report and RCA's advocacy:

policy@rarecancers.org,au

(02) 4862 2768

Support for patients and their families:

support@rarecancers.org.au

1800 257 600

Send a letter:

Rare Cancers Australia
PO Box 440
Bowral NSW 2578

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