Pre-Budget Submission 2026
Inherited Cancers Australia – Submission to the Australian Government Treasury

Delivering the promise of genomics: supporting Australian families with inherited cancer risk

Genomic testing is transforming cancer prevention and treatment in Australia. However, for thousands of families, receiving a genetic test result is only the beginning. Without counselling, navigation and psychosocial support, many Australians are left to shoulder life-changing decisions alone - decisions about surgery, fertility, children, insurance, and their own cancer risk. The absence of funded post-test support limits the impact of the Commonwealth's investment in genomics and risks widening inequities.

Inherited Cancers Australia (ICA) seeks **$2.76 million over three years** to deliver a national program, ensuring every person with inherited cancer risk can access the support they need to act on their results with confidence, clarity, and care.

The Case for Investment

⇒ **Rapid expansion of genomic testing without equivalent post-test care.** Genetic testing for some inherited cancers has grown more than ten-fold in the last seven years. With cancer diagnoses rising and MBS changes expanding, eligibility for BRCA and other germline tests, demand for follow-up care is surging. Yet Australia still has no funded national model for post-test counselling, psychosocial support, or care navigation. Some families report being left to interpret complex results and navigate their next steps alone, often while distressed or recovering from cancer treatment.

⇒ **Government acknowledged gap. T**he **National Framework for Genomics in Cancer Control** (2025) recognises sustained psychosocial and navigation support as essential to equitable genomic integration. ICA currently fills this gap, but rising demand exceeds the capacity of an unfunded community charity.

⇒ **Strong alignment with national strategies.** ICA's proposal operationalises key Commonwealth strategies, including:

– **Australian Cancer Plan (2023–2033):** prevention, early detection, consumer-centred care.
– **National Preventive Health Strategy (2021–2030):** genomics-enabled prevention and health literacy.
– **National Mental Health and Suicide Prevention Plan:** early psychosocial intervention.
– **National Digital Health Strategy (2023–2028):** telehealth-enabled, digital models.
– **Genomics Australia's mandate:** equitable, sustainable, consumer-centred integration of genomics into routine healthcare.

Proposed Investment - $2.76M over three years

Cancer Risk & Genetics Education Programs ($1.15M)	Support Services ($0.96M)	Genomics Consumer Leadership & Journey Mapping ($0.65M)
A national digital hub with evidence-based information for families navigating inherited cancer risk, improving genomic literacy, reducing anxiety, and ensuring no individual is left behind. - **Fifteen in-person/hybrid national education events**. - **Twelve expert-led webinars** accessible to all Australians. - **Outreach campaigns** for Indigenous, CALD and rural/regional communities.	*This model relieves pressure on overstretched public genetics services and ensures people can act on their results safely.* - A **full-time telehealth genetic counselling service** providing up to 1,000 consultations over three years. - **Psychosocial support and navigation** to guide individuals navigating inherited cancer risk, genetic testing, and its outcome. - Strengthened **peer support networks** and moderated **community groups.**	*This ensures lived experience meaningfully shapes Australia's genomic future.* - **National consumer leadership training** for 20+ people with inherited cancer risk. - Skills development to **contribute to policy, research, HTA and system reform.** - National journey mapping to inform an inherited cancer prevention **Optimal Care Pathway.**

About ICA

Established in 2012, Inherited Cancers Australia (ICA) is the only national organisation dedicated solely to inherited cancer risk. We provide evidence-based education, psychosocial support and health system navigation for Australians born with a predisposition to cancer. Our vision is to ensure every Australian can manage their inherited cancer risk, with knowledge and confidence - free from disadvantage.

Our community is young; half are aged 25–44 and facing decisions with lifelong implications. ICA has grown from two staff members to six (4.6 FTE) in five years, in direct response to rising community demand. We operate a lean, efficient model with no physical office and deliver the majority of our work in-house, ensuring excellent value for investment. ICA also contributes to HTA processes, Government consultations, genomics working groups and research collaborations, ensuring lived experience meaningfully shapes national policy and system design. Sustaining this essential role now requires stable, long-term funding.

With mature systems, governance, and national reach, ICA is implementation-ready for scale with:

- Over 3,000 members in ICA's private online support groups (2025), increase of 25% from 2023.
- 622 direct contacts and 716 event attendees (2024,) forecast to increase >20% in 2025.
- A younger community disproportionately impacted (50% aged between 25 to 44).
- Partnerships with leading cancer centres including Peter MacCallum Cancer Centre, clinical genetic services, and the Human Genetics Society of Australasia (letters of support provided upon request).
- Governance by an experienced Board and guided by a Medical Advisory Committee.
- Over a decade of health education and outreach experience

Why Funding is Urgent

The *National Framework for Genomics in Cancer Control*[i] notes that around 10% of adults with a personal history of cancer carry a pathogenic germline variant, which amounts to approximately 17,000 Australians each year[ii]. With cancer diagnoses rising, genetic testing for inherited cancer risk continues to surge. Of benefit for breast cancer patients, policy changes have expanded access to Medicare-funded BRCA testing under MBS item 73295, first on 1st July 2024 (broadened eligibility in early breast cancer) with a further amendment from 1st January 2025 (variant detection linked to PBS-listed treatments). This has contributed to a more than ten-fold increase in utilisation of genetic testing year-on-year (Jan–Aug 2024 vs 2025)[iii]. With predicted uptake from family members, this will directly impact cascade/predictive testing rates in the months and years to come.

Capacity constraints in public genetic services mean there is still no funded pathway for ongoing post-test support[iv]. Beyond the delivery of genetic test results, families are typically left to navigate complex medical, financial, and psychosocial challenges, often relying on patient organisations for information and guidance. This gap is explicitly recognised in the *National Framework for Genomics in Cancer Control*, which calls for sustained psychosocial and navigation support following genomic results. ICA's service model currently fills this critical gap without government funding, supporting hundreds of families each year.

Cancer related genetic testing yearly increases

Year	2018	2019	2020	2021	2022	2023	2024	Projected for 2025**
Number of tests*	5,088	5,953	7,164	8,767	10,661	11,716	12,826	15,847**
Increase		17%	20%	22%	22%	10%	9%	24%

These figures represent only genetic tests claimed through Medicare and do not include privately funded or hospital-funded activity-based testing. ** Based on 2025 MBS data

With the important shift toward personalised genomics, the approach to cancer-related genetic testing has expanded significantly, and the introduction of new MBS items directly supports this more tailored model of care. The uptake of MBS-funded genetic testing continues to grow rapidly. In 2018, there were 5,088 cancer-related genetic tests undertaken, while in 2024 there were 12,826, representing a 152% total increase[v].

Beyond this, many people access cancer-related genetic testing privately or through activity-based funding in public clinical genetic services and hospitals. While we strongly support the ongoing expansion and creation of new Medicare-funded genetic tests to enable personalised cancer care, this growth will continue to increase demand for ICA programs, education and support services and will place further pressure on public health wait times. Demand is expected to rise even further with the *National Framework for Genomics in Cancer* recognising genomics as central to both diagnostic and preventive pathways, and with the *Australian Cancer Plan's* focus on prevention and early detection of cancer[vi].

Our organisation supports the government's recent efforts to expand access to genetic testing and cancer-related treatments. However, our internal funding cannot keep pace with the rapidly growing demand this expansion has created. We have identified system gaps that continue to disadvantage people with inherited cancer risk:

- Limited clinical and psychosocial services capacity creates bottlenecks that delay assessment and heighten distress, highlighting the importance of government-funded programs such as the Australian Cancer Nurse Navigation Program (ACNNP) for people with cancer.
- Long public waiting times for risk-reducing surgery, often exceeding 18 months, push families into costly private care. Our *Breaking the Cycle* report found that more than 25% of individuals spent over $15,000 out of pocket[vii].
- Access to existing cancer support programs, including the ACNNP and Cancer Council services, is generally restricted to those with a cancer diagnosis, leaving high-risk individuals without comparable support.
- Consumer voices remain underrepresented in genomics and cancer policy development, increasing the risk of inequitable service design and implementation.

These gaps illustrate the growing mismatch between expanded genomic testing and the system's capacity to support those who receive high-risk results.

The Solution

Genetic testing is only valuable when coupled with appropriate follow-up. ICA proposes a national model of lifelong support that includes:

- Specialist counselling, telehealth navigation, risk management guidance, and ongoing psychosocial support.
- Genomics consumer leadership and engagement training.
- Community and family education empowering evidence-based informed decision making.
- Increased capacity to meet the growing number of people with inherited cancer risk.
- Tailored information for a very complex and multifaceted health condition.

ICA's pilot Inherited Cancer Support Service showed strong feasibility, high consumer satisfaction, and reduced pressure on clinical genetics services. A genetic counsellor appointed at 0.2 FTE has been offering free, post-test counselling sessions to community members since March 2025, which has already been utilised by more than sixty individuals. These sessions have supported people with a wide range of inherited cancer syndromes and an equally diverse set of education, psychosocial and advocacy needs.

The model complements specialist care by supporting patients after the clinical testing phase and ensuring timely, appropriate next steps. It is designed to integrate alongside existing clinical pathways—not replace specialist genetics services. Referrals occur from familial cancer centres, clinical genetics services, oncology teams, primary care, and through our MAC. ICA provides psychosocial support, navigation, and decision support once the clinical component of testing is complete, enabling clinical services to focus on complex cases and reducing waitlist pressure.

Impacts & Benefits to the Government

We commend the Australian Government for its leadership in establishing Genomics Australia, which is driving national consistency and innovation in genomic medicine. ICA has a consumer representative (a staff member) on the Genomics Australia Advisory Council and is well placed to support the Government in realising its vision of equitable access, informed decision-making and sustainable integration of genomics into routine care. With Commonwealth investment, ICA will deliver a national model that reduces later-stage cancer diagnoses, strengthens prevention, improves equity, and maximises the return on genomic testing, delivering:

- Health-system savings through reduced hospitalisations and later-stage diagnoses (cancer is the highest spending disease group: $18.9 billion in 2022–23 AIHW)[viii].
- Improved equity in cancer and health outcomes for priority populations.
- Reduced demand on existing overstretched clinical and community GP services.
- Better mental health outcomes.
- Stronger consumer representation in genomics policy and HTA.

Program Investment Breakdown

This funding will complement existing philanthropic support and strengthen ICA's long-term sustainability. The activities proposed build on—rather than duplicate—the Cancer Patient Support Program (CPSP) grant recently awarded to ICA. Our consumer-focused education initiatives align with and complement the CPSP's healthcare provider components while enabling ICA to scale services in line with demand.

The Genomics Consumer Leadership Program is also distinct from Government-funded initiatives such as BCNA's Seat at the Table. Unlike programs focused on people diagnosed with cancer, ICA will train those at high inherited cancer risk—many without a cancer history—to ensure this younger, currently unrepresented cohort contributes to genomics policy and prevention pathways. Part of this program includes creating a Lived Experience Network (LEN) of consumers ready to support consultations and programs.

Conclusion

Genomic testing without follow-up support is incomplete care. Families deserve more than a result - they deserve guidance, compassion, and a clear pathway forward. ICA provides a proven, scalable, community-based model that delivers exactly that.

With Commonwealth investment, ICA can ensure every Australian born with inherited cancer risk has the support they need to prevent cancer - or detect it early - regardless of where they live or what they can afford.

"As someone without any living female relatives who have gone through prophylactic surgery, it has been a godsend to talk with someone with lived experience. Navigating surgical menopause at 44 has been rough and having someone to talk to has been invaluable.

[i] Cancer Australia, National Framework for Genomics in Cancer Control (2025)
[ii] Australian Institute of Health and Welfare (AIHW), *Overview of Cancer in Australia* (2025)
[iii] Services Australia MBS item reports for January to August 2024/ 2025 for 73333, 73338, 73295/6/7, 73354/7, and 73301/3/4,
[iv] Inherited Cancers Australia, *Australia's Genetic Testing Boom: Time for Collaborative Action* (2025)
[v] Services Australia MBS item reports for 2018 and 2024 for 73333, 73338, 73295/6/7, 73354/7, and 73301/3/4,
[vi] Cancer Australia, *Australian Cancer Plan* (2023)
[vii] Inherited Cancers Australia, *Breaking the Cycle – Insights from the Inherited Cancers Australia Community* (2024)
[viii] Australian Institute of Health and Welfare (AIHW), *Health System Spending on Disease and Injury in Australia 2022–23* (2024)

Proposed Funding Breakdown

Focus Area	Initiative	Deliverables	Investment
Cancer Risk & Genetics Education Programs	Digitally accessible information hub	Creation of a comprehensive inherited cancer risk digital hub: • Website redevelopment including design accessibility (WCAG 2.1 compliant) • Content creation of evidence-based articles, animations, consumer friendly resources with translation into priority languages • Consumer and healthcare professional experience design including AI driven guided search • Inclusion of resources on all inherited cancer risk syndromes including rarer and less prevalent • Digital campaigns to promote and share educational resources including 3 specifically for priority populations	$250,000 (total for project)
	National program of consumer education events	Deliver 15 (5 per FY) in-person and hybrid consumer sessions nationally (metro + regional) including • Venue/catering, travel, and logistics • Marketing, promotion materials and printed resources • Event evaluation and reporting	$120,000 ($8k per event)
	Inherited cancer risk webinar library	Utilising our Medical Advisory Committee and collaborating with HGSA, film, produce and edit 12 expert-led webinar sessions for those unable to attend in -person events including: • Accessibility features (captions and translation) • Marketing and promotion through networks of health professionals & community • Annual reviews to ensure they remain evidence-based with current guidelines	$60,000 ($5k per webinar)
		Additional 2 FTE required x 3 years	$720,000
		Subtotal – Cancer Risk & Genetics Education program	**$1,150,000**

Focus Area	Initiative	Deliverables	Investment
Support Services	Inherited Cancers Support Service (ICSS)	Grow the successful 2025 ICSS pilot program, by funding an additional 3 years, including: • Telehealth software licensing, equipment, security setup and CRM integration • Supervision, professional development & clinical governance • Program promotion, evaluation and impact reporting	$150,000 (total for project)
		Genetic Counsellor (1 FTE) to support ICSS × 3 years	$450,000
	Expansion of Community engagement and support	In line with the continued growth in germline genetic testing, increase our service capacity to support additional high-risk cancer individuals. This includes • Connections to peer support • Management of online support groups • Increasing educational campaigns and information dissemination to include a broader range of inherited cancer risk syndromes and priority populations	FTE costs only
		Additional 1 FTE required x 3 years	$360,000
		Subtotal – Support Services	**$960,000**

Focus Area	Initiative	Deliverables	Investment
Consumer Leadership Engagement & Journey Mapping	Consumer Leadership Engagement Program	Work with our community on a national engagement program supporting ICA's strategy to provide input into government consultations, research programs and working groups etc., ensuring the inherited cancer risk consumer voice is represented in all relevant discussions. • 20–25 consumer representatives across a diverse range of demographics and cancer predisposition types • Develop curriculum on research participation, policy input & presenting skills • Deliver two national training workshops and ongoing mentorship program • Collaborate and improve networks within priority populations • Provide travel grants and reimbursement for all consumers	$150,000 (total for project)
	Consumer Journey Mapping Project & Resources	Support Genomics Australia by undertaking stakeholder consultation workshops (patients, HCPs, HGSA, NFP partners and policy makers) • Consumer focus groups to gather insights and explore the many and varied inherited cancer risk pathways • Data analysis & mapping of current system gaps • Co-develop patient navigation & information tools Design and publication of the national journey map including dissemination to government and health services & peak bodies	$140,000 (total for project)
		Additional 1 FTE required x 3 years	$360,000
		Subtotal – Consumer Leadership & Engagement	**$650,000**
Total Investment – $2.76 million over 3 years			