Inherited Cancers Australia pre- budget submission 2025-26

We are **Inherited Cancers Australia (ICA),** and our vision is to **create a future where families can manage inherited cancer risk, informed, and empowered- free from disadvantage**. We have empowered Australians to understand and manage their inherited cancer risk for 15 years, through education, evidence-based resources, and connection to a supportive community.
We are partnering with **Cancer Australia** to deliver on the goals in the **Australian Cancer Plan** focused on prevention and early detection (see appendix).

In Australia, we are the only organisation providing dedicated, tailored services to the **1 in 400** people with germline gene mutations (including ~10% of adults with a cancer diagnosis), or those with a significant family history of cancer – people who are at a much higher risk of developing cancer. The majority of these people are under 55, many with up to 80% risk of cancer. They need help accessing information, and navigating the healthcare system, as well as peer support and connection.

Challenges	Due to		ICA solutions
Psychosocial & mental health impacts	▪ Wait times for prophylactic surgery ▪ Worry about the future ▪ Generational cancer trauma ▪ Poorer outcomes, younger cancer diagnosis ▪ Barriers to access to mental health support	▪ Body image and sexuality ▪ Family planning ▪ Decision making to manage cancer risk ▪ Guilt, blame and stigma ▪ Lack of understanding from friends/family	▪ Online peer support groups ▪ Evidence-based information and resources ▪ Information and support education days with panels of experts ▪ Topic based webinars ▪ Community connection events ▪ One on one Peer Support Mentors ▪ 'Ask a genetic testing question' online form service ▪ Promotion of relevant research & trials ▪ Advocacy for policy changes, participation in genomics working groups, consultations and HTA review process ▪ Medical Advisory Committee to inform and guide our work ▪ Undertaking and supporting research and consultation
Other health impacts	▪ Medically induced menopause –increased risk of CVD, osteoporosis & impaired cognitive function ▪ Many surgeries causing changes in physical abilities		
Financial Burden	▪ Out of pocket costs for screening and investigations ▪ Long wait times for surgery in the public system so people opt for private health system ▪ Borrowing money or accessing super to fund risk reducing surgeries ▪ Many people in the same family with financial burden		
Managing risk of many cancers	▪ Many options to manage risk, all of which have other health consequences ▪ Unlike a cancer diagnosis, patients make their own decisions on how to manage cancer risk ▪ Overwhelming, life changing choices to make based on risk predictions ▪ No dedicated specialist as patients don't have a cancer diagnosis		
Health system navigation	▪ Conflicting medical opinions on how to manage risk ▪ Increased demand for genetic counselling, outweighing capacity of current workforce ▪ Knowing what support/services are available ▪ No dedicated helpline for people who don't have cancer but have a high risk of cancer		

Background

People with germline gene mutations are unique; they experience generations of cancer in their family, have large financial burdens, are at higher risk of more aggressive cancers and are much younger than the general population who seek support from cancer organisations. High-risk people report clinically relevant distress, anxiety and depression compared to the general population[1].

ICA is distinct from other cancer organisations - most of the people we support have not been diagnosed with cancer however, they have a much higher risk than the general population. Guidelines recommend early screening (from age 25) and preventative surgeries (mastectomy and oophorectomy) by age 35-40. Research shows that people with gene mutations are often diagnosed with cancer younger, with more aggressive types that are more likely to recur, hence why risk management is so important for this population.

Clinical genetic services refer their patients to ICA for support and information. Our organisation is critical in bridging the gap and improving outcomes for families who, **through no fault of their own, are disadvantaged by their genes**.

In 2024, ICA supported many Australians who are investigating and/or managing their increased risk of cancer:

Over **600** inquiries from people seeking support (phone and email)

276 people joined our online support groups now at over **2,800** people

772 people attended our online and in person support & education events

54k people visited our website with over **115k** pages accessed

Inherited Cancers Australia responds to daily requests for information and support, managing inquiries through our 'Ask our Genetic Counsellor' online form, and relies on volunteer clinicians. In 2023 alone, over 8,600 people received publicly funded genetic testing related to breast, ovarian, and prostate cancer (see appendix), with many more undergoing private testing. When faced with anxiety and the psychological burden of long waits to see a genetic counsellor or to undergo risk-reducing surgery, these individuals turn to us. They have been relying on us for over 15 years.

As **criteria for testing and treatments continue to expand**, so does the uptake of cascade testing for family members. When a person is found to have a gene mutation, research[2] shows that **3.3 family members will undertake genetic testing.** These people need support and education to make informed decisions**.**

In 2024, ICA conducted Australia's first survey[3] into the health experiences and support needs of people with inherited cancer risk. Over **880 people** responded to the survey providing robust data about the information needs and behaviour of people in our community. This survey showed that only 4% of people with inherited cancer risk accessed the Cancer Council helpline and found it helpful, over 50% of people waited more than 12 months for a risk-reducing mastectomy and many respondents had a high cancer burden in their family (see Appendix). In August 2024 we renamed to ICA (formerly Pink Hope) to include men and other niche communities, and expanded our support to those with other inherited cancer syndromes such as Lynch, Li-Fraumeni , and Hereditary Diffuse Gastric Cancer.

[1] https://pmc.ncbi.nlm.nih.gov/articles/PMC10315723/
[2] https://pubmed.ncbi.nlm.nih.gov/30254378/
[3] https://d20suj4g28m6xs.cloudfront.net/9bc637f562472ce9faa4f4be953552c5.pdf

We ask the Government to support ICA's programs in the 2025/26 budget, aligning with many of the Strategic Objectives and Goals in the Australian Cancer Plan.

1. **Implement cancer risk and genomics education programs tailored for three distinct groups:**
   Primary healthcare professionals - Including a GP online education module and rural/regional in-person training, in collaboration with Primary Health Networks. This program is in line with Strategic Objective 4 in Cancer Australia's draft Genomics framework which outlines the need for '*ongoing professional development to build competence in using genomics in cancer care*'.

   People at increased risk of cancer (gene mutation carriers) - Consumer education and information events focused on cancer risk management and screening, and clinician-reviewed digital content and resources for high risk for cancer priority populations.

   The general population - in line with Strategic Objective 4 in Cancer Australia's draft Genomic framework, we will implement a national cancer genomics awareness campaign about the inherited link of some cancers, the importance of family history, risk reduction and screening. This scalable awareness program will help the general population in understanding the impact of genomics, germline genetic testing and tumour/somatic genetic testing.

   $963,200 over 4 years

2. **Establish a free online and telephone Inherited Cancer Information and Support Service**
   Providing information, tailored support and referral services. Coordinated by a genetic counsellor, social worker or psychologist working 2 days per week, providing timely access to evidence-based information and health system navigation. This is direct patient support from a trained professional who can refer to appropriate services, information and screening. ICA is best placed to provide this specific service for people who are younger, at high risk for cancer and who must navigate complex decisions, long wait times, generational trauma and life-impacting surgeries, to manage cancer risk.

   $415,760 over 4 years

3. **Expand ICA education programs and support services - in line with the recent announcement of the expansion of BRCA genetic testing for breast cancer patients eligible for Olaparib.**

   In January 2025, the MBS guidelines were changed increasing the amount of breast cancer patients that are eligible for BRCA genetic testing. As criteria for testing and treatments continue to expand, so does the uptake of cascade/predictive testing for family members. Additionally, many Government funded research projects continue to identify more people with germline gene mutations, such as Omico/PrOSPeCT, Traceback, DNA Screen and Zero childhood cancer. These people need support to make informed decisions as they now have to manage their risk of many cancers. In line with this expansion, ICA will support the Government by scaling up services to meet an anticipated increase in demand from breast cancer patients, and their many family members who will access cascade/predictive genetic testing. Including additional peer support mentors, increased moderation of support groups, additional education events and increased management of calls/emails for help.

   $1,275,400 over 4 years

Total investment ***$2,654,360 over 4 years***

Appendix

Key insights and stats from '*Breaking the cycle: insights into the Inherited Cancers Australia Community' survey and report:*

All respondents' general stats (n, 884):

- *73% of all respondents had **1 or more immediate family members with a cancer diagnosis***
- *56% of all respondents had **2 or more 2nd degree family members with a cancer diagnosis***
- *69% of all respondents were **under 55 years old***
- *26% of all respondents **spent over $15,000** on managing cancer and cancer risk (includes surgery, medication, allied health services, tests, biopsies etc)*
- *27% of all respondents undertook risk reducing surgery wholly in the **public healthcare system***
- *67% of all respondents had undertaken **risk reducing surgery** to manage cancer risk*
- *Only 25% of all respondents accessed **mental health support** and found it helpful*
- *Only 3% of all respondents accessed **menopause support** and found it helpful*

High risk (without cancer) respondents (n, 561):

- *Only **4% of high-risk people accessed the Cancer Council helpline** and found it helpful*
- *52% of high-risk people **waited over 12 months** for a risk reducing mastectomy in the public healthcare system*
- *20% of high-risk people **spent over $15,000** to manage their cancer risk*

Respondents diagnosed with cancer (n, 321):

- *55% of people with a cancer diagnosis are under **55 years old** now – much younger than the general population age of diagnosis.*
- *Of breast cancer reported, 32% was **Triple Negative Breast Cancer** (more aggressive, harder to treat and recurs more)*
- *37% of respondents with a cancer diagnosis **spent over $15,000** on managing cancer and cancer risk.*
- *68% of ovarian cancers reported were **stage 3 or 4***
- *38% of respondents with ovarian cancer and a gene mutation were aged **under 55***
- *No men with cancer accessed **mental health support** and found it helpful.*

Access to BRCA related MBS funded genetic testing has increased each year since being listed in 2017 (includes data for 73296/7/5 and 73301/2/3/4):

Year	2018	2019	2020	2021	2022	2023	2024	Total
n tests	2,863	3,310	4,478	5,736	7,509	8,643	8,451*	41,030
% Increase	7,241%	16%	35%	28%	31%	15%	TBC	

* Figure includes data up to Nov 2024. One month of additional data should be included for 2024.

Australian Cancer Plan actions that ICA are partnering with Cancer Australia to deliver:

1.2.1: Deliver cancer prevention and health promotion activities, including healthy lifestyles, immunisation, and population screening participation, co-designed and tailored to a range of settings.
1.2.2: Strengthen cancer prevention in broader health strategies and public health partnerships.
1.2.4: Undertake ongoing assessment of the evidence for risk-based, cost-effective population cancer screening.
1.5.4: Develop a policy framework for genomics in cancer control across the cancer care continuum.
2.2.2: Improve availability of co-designed, tailored information and care for consumers to improve health literacy and reduce cancer-related stigma.
2.2.3: Support health services to provide co-designed, culturally responsive resources to enable healthcare providers to communicate respectfully with consumers.
5.5.2: Assist the sector to support all cancer care practitioners to work at the top of their scope of practice, increase retention and ensure ongoing access to continuing professional development.