# Breaking the cycle

## Insights from the Inherited Cancers Australia community.

inherited CANCERS AUSTRALIA | evohealth

September 2024

# Contents.

# About this report

## Background

*Breaking the cycle: Insights from the Inherited Cancers Australia community* has been developed based on insights gathered from a community survey of individuals with hereditary cancer risk. This report highlights the unique needs of these individuals and their families, the impact of the support provided by Inherited Cancers Australia (formerly Pink Hope) and the urgent need for government funding to continue this work.

## Approach

The report has been informed by:

- A community survey of the needs and health experiences of Australians with an increased risk of hereditary cancer; and
- Case studies and testimonials from individuals and families living with hereditary cancer risk.

## Acknowledgements

We would like to acknowledge the ongoing support from the individuals and organisations who contributed to this project, namely the community survey participants. Their insights and experiences were invaluable in shaping this report and highlighting the critical need for continued support for those at risk of inherited cancers.

## Survey and report

The report was developed by Evohealth, a health advisory firm based in Canberra. Evohealth designed the survey, with support from Inherited Cancers Australia including distribution and administration. The output of the survey was then analysed by Evohealth for inclusion in this report.

Funding for the survey and independent report was provided by Gilead Australia.

# Executive Summary

## Cancer is a killer

Cancer affects thousands of Australians each year and is collectively one of our biggest killers. [1]

An estimated **626** cases of cancer **diagnosed per 100,000 Australians** in 2023. [1]

An estimated **51,000**, or approximately **3 in 10, deaths** from cancer in 2023. [1]

## Hereditary cancer – a cycle that needs to be broken

Hereditary cancer is cancer that cuts across generations. Cancer is a devastating diagnosis for anyone to receive, yet hereditary cancer strikes even deeper, casting a shadow over entire families and forcing multiple generations into the fight of their lives. When cancer runs in the family, the stakes and the emotional toll are even higher.

It's estimated that **~5%** of all cancers are hereditary in nature. [2-4]

When a hereditary cancer gene is identified, the individual risk of developing cancer increases dramatically compared to the rest of the population. For example, women with a breast cancer gene (BRCA) mutation have a 72 per cent lifetime risk of developing breast cancer, including more aggressive forms that are resistant to the best treatments available. [5-7] This stark reality is also true for other cancers, such as ovarian and prostate, that have also been identified to have a hereditary link.

**Lifetime risk** of ovarian cancer **~2%** in general population versus **40%** for those with BRCA1 or **18%** for those with BRCA2 mutations. [8]

**5x increase** in the risk of **developing prostate cancer** for those with **2+ male family members** who have been diagnosed. [9]

**Estimated ~10-12%** of men with more advanced and harder to treat metastatic castration-resistant prostate cancer carry inherited BRCA1 or 2 mutations. [9]

## **Taking action –** prevention is better than a diagnosis

Following confirmation of an elevated cancer risk, people often need to make the difficult decision to engage in preventive measures that are costly and have life-changing effects. For example, prophylactic mastectomy reduces the risk of breast cancer by at least 95 per cent in women who have a BRCA gene mutation and strong family history of breast cancer. However, this life-altering procedure carries surgical risks and can significantly impact an individual's sense of identity and body image. Surgical removal of ovaries to reduce cancer risk can induce early menopause, which in addition to the decision to undertake preventive action, can increase distress and anxiety further. [10]

The impact extends beyond the individual, with family members potentially subject to the same fear and need to make difficult decisions. For every person identified as a gene mutation carrier, 3.3 family members undergo genetic testing to understand their own risk. [11] This ripple effect heightens the emotional and financial strain on families.

**Hereditary cancer risk is a ticking time bomb that devastates families, forcing life-altering decisions, such as surgical removal of breasts or ovaries.**

# Knowledge is power, but so is community and support

Families with an inherited cancer risk need information to ensure they can make informed decisions about their own and their family's future. In this situation, two old adages hold true- prevention is better than cure, AND knowledge is power. There is no greater truth than this, for these Australians and their families.

Inherited Cancers Australia is dedicated to supporting the growing community of people at high risk of hereditary cancer. We know from 15 years of experience in supporting people, that their needs are not always met by our current health system.

In 2024, we sought to understand the challenges of the inherited cancer community, by conducting a comprehensive survey, asking each respondent about their personal experience and what support and challenges they have encountered on the way.

The survey findings reveal that while many people at risk of inherited cancer are eager to take preventive action—critical for saving lives and likely reducing long-term costs, this decision is met with significant barriers. Our work to date has helped reduce these barriers:

**77.5%** of survey respondents sought information to investigate options to reduce individual cancer risk

**More than 70%** of people found Inherited Cancers Australia's online information and resources helpful in supporting their risk reduction decision

It is clear that people have turned to our organisation, when the broader Australian health system has left them short. Stories shared in our survey highlight the challenges of our health system, specifically providing inconsistent information, inadequate support, and heightened struggles for those in rural areas.

For some people, this information has supported their decision to prevent a future cancer diagnosis, including lifesaving preventive surgery. Alarmingly, despite being in the most productive years of their lives and earning above-average income, many of our survey respondents still bear significant out-of-pocket expenses to take measures that are lifesaving. Our survey data reveals that out-of-pocket costs for cancer related care for respondents were:

**54%** of people spent more than **$5,000**

**26%** of people spent over **$15,000**

**55%** of survey respondents have had risk reducing surgery

Some people reported costs of over **$50,000**

**48%** of survey respondents have had a cancer diagnosis

# More and more Australians

With more and more Australians undergoing genetic testing each year, this community is rapidly expanding. This places considerable pressure on our resources.

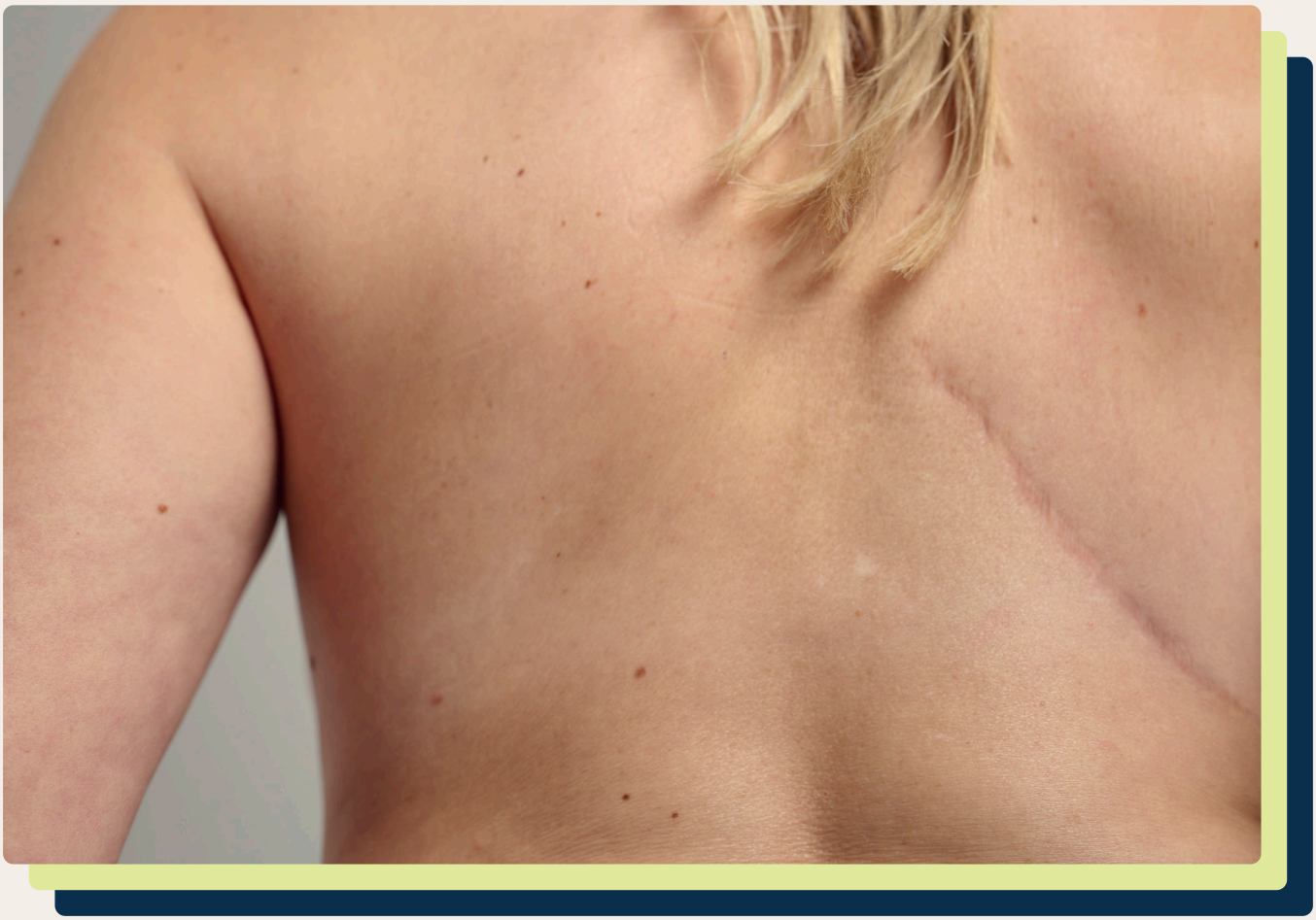
Inherited cancer risk knows no bounds, affecting all genders and cultural backgrounds. Our survey highlights that we have had less impact in some critical groups, namely men, people who identify as Aboriginal and/or Torres Strait Islander people, and those from culturally and linguistically diverse (CALD) backgrounds.

This underscores the need for targeted support and information to empower all individuals to make informed decisions about their health.

**96.3%** of respondents female versus 50.7% of the Australian population [12]

**1.8%** of respondents identify as Aboriginal and/or Torres Strait Islander versus 3.8% of the Australian population [13]

**98.6%** of respondents indicated English as their language of choice versus 77.7% of the Australian population [14]



# **Breaking the cycle –** recommendations for a better future

With many more Australians predicted to need support, including those from vulnerable communities, in the coming years we need the Australian Government to:

1. **Develop a national prevention strategy and roadmap to reduce the impact of inherited cancer in the Australian community.**

2. **Conduct a full economic analysis to understand the cost-effectiveness of risk reduction interventions compared to the treatment of diagnosed cases.**

3. **Provide ongoing funding to patient groups to deliver tailored, accurate information and support to those at risk of inherited cancer, including targeted outreach to Aboriginal and Torres Strait Islander people, CALD communities, and men.**

**Inherited Cancers Australia is poised to be the beacon of hope for those at risk of inherited cancer, but sustained funding and strategic action are crucial to ensure that no one is left behind.**

# Hereditary cancer community insights

**96.3%** of respondents identify as female versus 50.7% of the Australian population [12]

**98.6%** respondents indicated English as their language of choice versus 77.7% of the Australian population [14]

**55%** of survey respondents have had risk reducing surgery

**1.8%** of respondents identify as Aboriginal and/or Torres Strait Islander versus 3.8% of the Australian population [13]

**54%** of survey respondents indicated they spent more than $5,000 out of pocket for cancer related care with some people reporting costs of over $50,000

**77.5%** of survey respondents sought information and support to investigate options to reduce individual cancer risk

**More than 70%**

of people found the online information and resources from Inherited Cancers Australia helpful in supporting their risk reduction decision.

## Hereditary cancer

Cancer that runs in families is known as hereditary cancer. [15]

**Estimated ~5%**

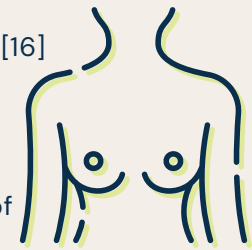
of all cancers are thought to be hereditary in nature. [2-4]

For every **1 person identified** as a gene mutation carrier **3.3 family members will undertake genetic testing** to understand their own risk. [11]

## Hereditary breast cancer

**Estimated ~5-10%**

of breast cancers are hereditary. [16]



Women with BRCA mutations are more likely to develop cancer earlier in life and have a more aggressive, harder to treat type of breast cancer. [5-7]

**Up to 72%**

risk of developing breast cancer in their lifetime with BRCA1 or 2 mutations [5]

## Hereditary ovarian cancer

**Estimated ~20-25%**

of Australian women with an ovarian cancer diagnosis are thought to have a hereditary predisposition for the disease. [17]

**Estimated ~20%**

of ovarian cancers thought to be caused by variants in the BRCA1 and BRCA2 genes. [8, 18]

Lifetime risk of ovarian cancer **~2%** in general population versus **40%** for those with BRCA1 or **18%** for those with BRCA2 mutations. [8]

## Hereditary prostate cancer

**Estimated ~5-10%**

of prostate cancer cases are thought to be caused by inherited genetic risk factors. [9, 19]

**Estimated ~10-12%**

of men with more advanced and harder to treat metastatic castration-resistant prostate cancer carry inherited BRCA1 or 2 mutations. [9]

**5x increase** in the risk of developing prostate cancer for those with 2+ male family members who have been diagnosed previously. [9]

# Cancer needs no introduction

Cancer touches every corner of our society, impacting citizens from all backgrounds and across all stages of life. Cancer affects thousands of Australians each year and is collectively one of our biggest killers. [1]

An estimated **626 cases** of cancer **diagnosed per 100,000 Australians** in 2023. [1]

An estimated **51,000**, or approximately **3 in 10, deaths** from cancer in 2023. [1]

As a society we understand that a cancer diagnosis can be devastating for the individual and their loved ones. The immediate response to such news is often a mix of fear, uncertainty, and determination to regain health. Gruelling cancer treatment can include surgery, chemotherapy, radiation, and other treatment. It is also fraught with side effects and complications which can have lifelong impact.

A cancer experience takes a huge emotional, physical and financial toll on the individual and their family. [20-22] The uncertainty of prognosis and the stress of ongoing treatments can contribute to mental health challenges. Studies show that cancer survivors experience mental health disorders, such as anxiety and depression at double the rate of the general population. [21] This increased emotional distress extends beyond the patients themselves, often impacting their families and caregivers who share the struggle.

Cancer survivors experience **mental health disorders** (e.g. anxiety, depression) at **double the rate** of the general population. [21]

# Cancer is costly

Financially, the burden of cancer is staggering. In 2015-16, Australia spent $10.1 billion on diagnosing and treating cancer. [20] This figure includes costs associated with hospital admissions, outpatient services, pharmaceuticals, and other medical interventions.

For individual patients, the financial strain can be overwhelming. In New South Wales, for example, 1 in 10 people with cancer were found to spend over $10,000 out of pocket in the first year following diagnosis. [22] These expenses cover a range of needs, from medical bills and travel for treatment, to lost income due to inability to work.

There is no denying that cancer is a devastating disease with profound effects on both individuals and their families.

In **2015-16, $10.1 billion** was spent on **diagnosing and treating cancers** in Australia. [20]

**1 in 10** people with cancer in New South Wales found to spend **over $10,000 out of pocket** in the first year following diagnosis. [22]

# Cancer can lurk in the shadow of your family tree

For some individuals the cancer diagnosis of a family member is even more devastating, as it could also indicate that they themselves are at extremely high risk of a similar fate. [23] Cancer that runs in families is known as hereditary cancer. [15]

> *"The only survivor after a cancer diagnosis on my mother's side is me..."*
>
> **-Inherited Cancers Australia community member**

**Cancer that runs in families is known as hereditary cancer. [15]**

Hereditary cancer is caused by inherited gene mutations (e.g. germline pathogenic variants) that can be passed down from parents to their children. These mutations are present in every cell of the body from birth and significantly increase the risk of developing specific types of cancer. Individuals with hereditary cancer often have a family history of the same or related cancers, and these cancers tend to occur at a younger age compared to sporadic cancers. [15, 23, 24] (Figure 1).

Comparatively, sporadic cancer occurs due to gene mutations (e.g. somatic mutations in oncogenes and suppressor genes) that arise randomly during a person's lifetime. These mutations are typically caused by environmental factors such as exposure to radiation, chemicals, smoking, diet, or simply the aging process. Most cancer cases are sporadic, with no clear pattern of inheritance within families. [15, 23, 24]

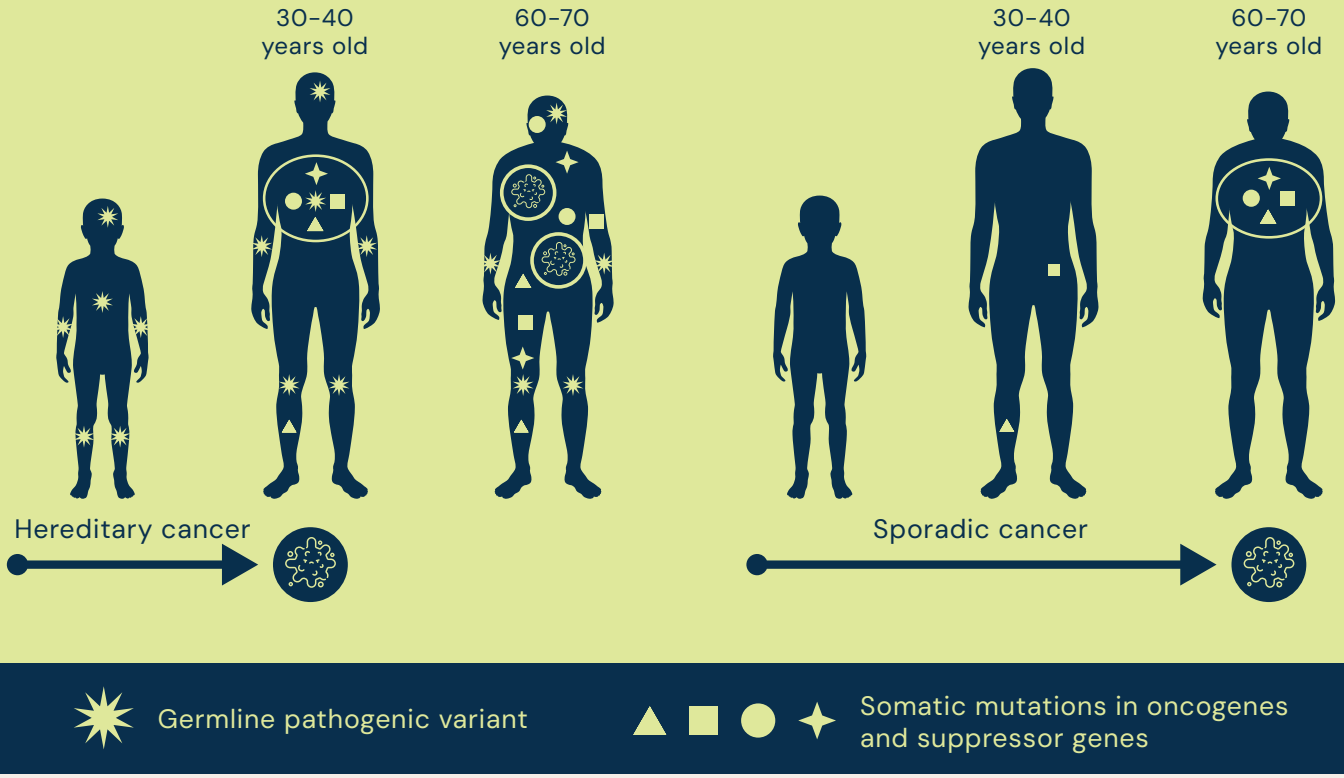
*Figure 1. Mechanisms of sporadic cancer versus hereditary cancer*

## Hereditary cancers

**Hereditary cancer** arises from gene mutations passed down through generations, significantly increasing an individual's risk of developing specific types of cancer. [15]

## Sporadic cancers

**Sporadic cancers** occur due to environmental factors or random mutations. [15]




*Source: Adapted from multiple sources [15, 23, 24]*

Genetic abnormalities can be detected through testing, and coupled with a detailed family cancer history, can indicate that a hereditary cancer risk may exist. [15, 23] Common cancers such as breast, ovarian and prostate cancer can have a hereditary link. [15, 23] However, the number of all cancer diagnoses that may have a hereditary link is unknown and highly debated, with best estimates suggesting it could be around 5 per cent of all cancers. [2-4]

**~5%** of all **cancers** are thought to be **hereditary** in nature. [2-4]

*"7 from 11 people who were tested in my family have a gene mutation that puts us at risk of cancer."*

**- Inherited Cancers Australia community member**

The diagnosis of a hereditary cancer predisposition carries profound implications, not only for the individual but also for their entire family. Psychological distress, anxiety, and fear of developing cancer are common among those with a hereditary cancer risk.

*"My grandma had breast cancer, my mum had ovarian cancer, and my cousin had breast cancer. I thought the cancer would stop in my generation, but it didn't."*

**- Inherited Cancers Australia community member**

Early detection and management of hereditary cancer risks are crucial for affected individuals and their families, offering the possibility of timely interventions and tailored preventive strategies that can reduce morbidity and mortality from cancer. [25] Yet, many people find the decision to take preventive measures, such as prophylactic surgery or regular screening, overwhelming.

*"I have been shocked by the complexity of the decision-making process. I have seen multiple specialists, but because they are specialists in their particular area only, no-one has an overview of my health or is guiding me in making decisions. I have received conflicting, sometimes contradictory information and advice from almost every doctor. I am not the only woman with BRCA1 and I have been baffled by the fact that almost every doctor I speak with tells me to do something different and cites different medical "facts." It is confusing, stressful, and difficult to navigate. I spoke with a genetic counsellor, but I felt the need for emotional counselling. I don't want to see a random psychologist through my GP because I don't have a mental health struggle per se, it's a normal human response to feel distressed when one learns one has these mutations and has to face major surgery, and what I wanted was not cognitive behavioural therapy from a psychologist, but an informed person to debrief with about the huge volume of often conflicting medical information..."*

**- Inherited Cancers Australia community member**

Individuals with hereditary cancer risk face unique challenges, as they live under the shadow of a potential diagnosis without having cancer. Unlike those with a definitive diagnosis, these individuals must navigate through life with the knowledge that they have a significantly higher chance of developing cancer.

*"I could not live with myself if I didn't do *everything* possible to reduce my risk of cancer. Our family has forever been impacted by cancer trauma and I need to be here for my babies for much longer yet. There was no choice to be made. The idea of six-monthly scan-xiety was also unpalatable."*

**- Inherited Cancers Australia community member**

These Australians need support to make informed decisions, including how to prevent the cancer occurring in the first place. They want to reduce the uncertainty of their future. Unfortunately, our health system currently favours cancer treatment over prevention.

*"I wasn't really given much support at all in my BRCA1 journey. I paid for scans I didn't think I had to; I was lost in the public system. I had a near four year wait, for a mastectomy reconstruction."*

**- Survey respondent**

**Due to the constant uncertainty and high risk of developing cancer without an actual diagnosis, individuals at risk of hereditary cancer have unique support needs to understand their risk and make informed decisions about prevention.**

# **Inherited Cancers Australia** – a lifeline for people at high risk

Inherited Cancers Australia is a beacon of hope, support and empowerment for individuals and families facing hereditary cancer risk.

Our mission is to 'Empower Australians to understand and manage their hereditary cancer risk through education, advocacy and support.'

We were founded 15 years ago on the principles of education, support, and advocacy, and have provided vital resources and a sense of community to those at high risk of hereditary breast and ovarian cancer ever since. Over this time our community has grown, and as it became clear that more people needed our help, beyond those with inherited breast and ovarian cancer risk, we recently changed our name to signal that all those at risk of hereditary cancer are welcome in our community.

As a patient focused organisation, Inherited Cancers Australia is dedicated to breaking the cycle and reducing the risk of all inherited cancers. Through various modalities and platforms, we help patients and families understand their risk, make informed decisions, and advocate for change on their behalf with government and other key policymakers.

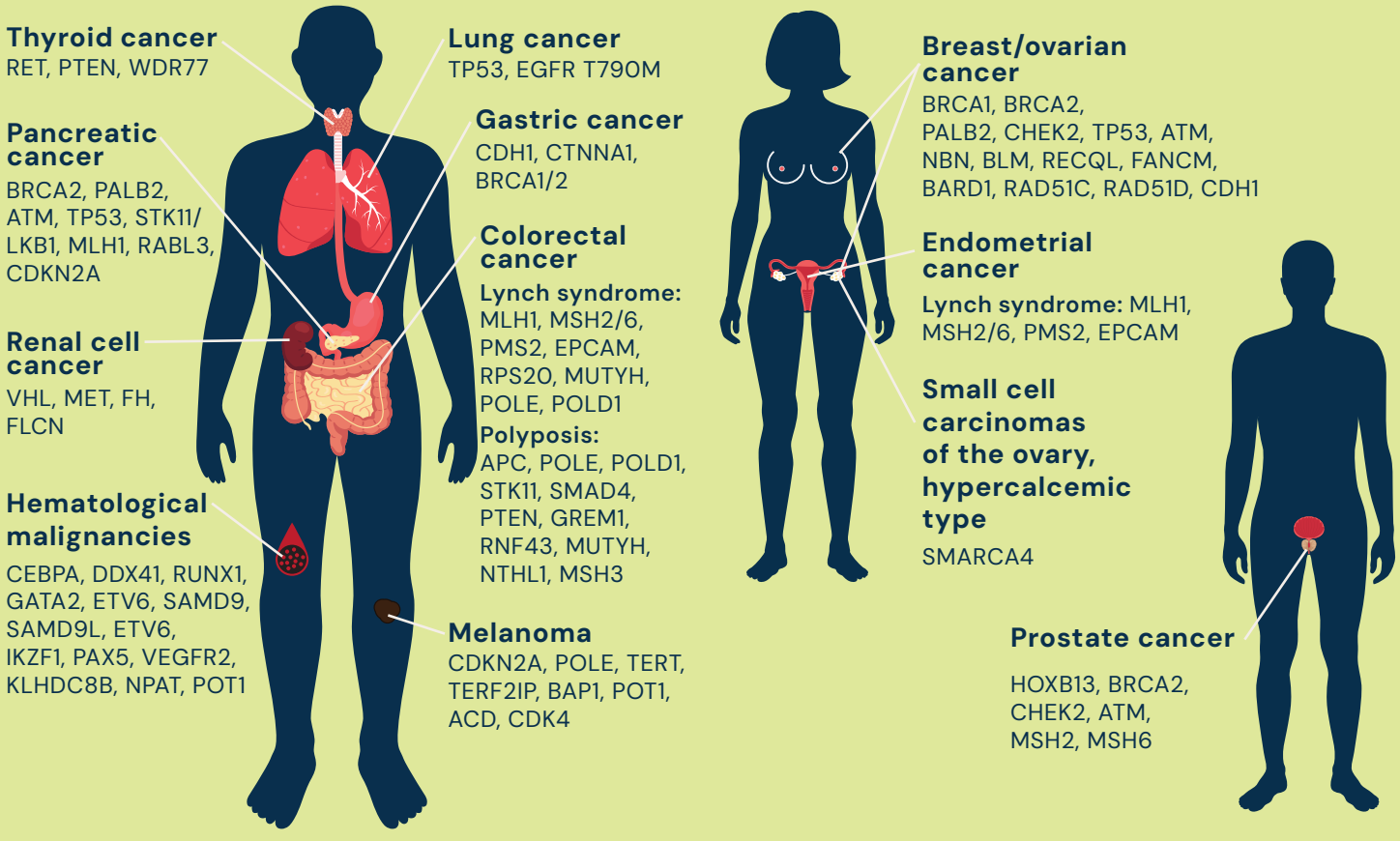
## Our mission

**Empower Australians to understand and manage their hereditary cancer risk through education, advocacy and support**

# Hereditary cancer – a family affair

Genetic links have been found in many cancers, with each changing the risk profile for the individual's chance of developing cancer and in some cases the severity of the cancer. Figure 2 highlights many of the known gene mutations linked to different types of cancer. Alarmingly, gene mutations for hereditary cancers includes cancers that affect men, women and children. [24]

*Figure 2. Main hereditary cancer genes and organs at risk* *Source: Adapted from [24]*



# We can't escape our DNA

In addition to the presence of gene mutations, family history plays a crucial role in diagnosing hereditary cancers. Individuals with a significant family history of breast, ovarian, or prostate cancer are often encouraged to undergo genetic testing to identify potential mutations. The presence of gene mutations, such as BRCA1 (Breast Cancer gene 1), BRCA2 (Breast Cancer gene 2), and others, can confirm a hereditary predisposition, guiding decisions about preventive measures and early detection strategies. [26] Identifying these more prevalent mutations not only impacts the individual's management plan but also has implications for other family members who may be at risk. It's been shown that for every person identified as a gene mutation carrier 3.3 family members will undertake genetic testing to understand their own risk. [11] This is an additional 3 people that may also require support and management into the future.

# Common cancers can be hereditary

For some of our most diagnosed and well-known cancers including breast, ovarian, and prostate cancers, specific genetic abnormalities, such as mutations in the BRCA1 and BRCA2 genes, play a crucial role in determining an individual's lifetime risk of developing cancer, the severity of the cancer and the age of cancer onset/diagnosis.

## Breast cancer

In Australia, breast cancer is the most diagnosed cancer among women, with around 20,000 cases diagnosed each year. [1] It accounts for around 28 per cent of cancer diagnosed in Australian women annually. [1] It is estimated that around 5-10 per cent of breast cancers are hereditary. [16] Meaning that 1 in 10 Australian women with a breast cancer diagnosis could have inherited it from family and/or have passed it on to their own children. The BRCA1 and BRCA2 mutations increase both women and men's overall lifetime risk for developing breast cancer. [16] These mutations also often lead to earlier onset cancers. [7]

Women with **BRCA1 or 2 or both** have up to **72% risk** of developing breast cancer in their lifetime. [5]

Men with a **BRCA2** mutation have **8% risk** of breast cancer by the time they are 80 years of age. [5]

These BRCA mutation positive women are also at increased risk of triple negative breast cancer and early onset of metastatic breast cancer that is notoriously more aggressive, harder to treat and has a higher rate of recurrence than other breast cancer types. [5, 6]

# Ovarian cancer

Ovarian cancer is often diagnosed at a later stage and is estimated to affect approximately 1,700 women annually in Australia. [1] The five-year survival rate for ovarian cancer was 47.6 per cent for 2015-19. [1] It is thought that 20-25 per cent of Australian women with an ovarian cancer diagnosis have a hereditary predisposition for the disease. [17] Variants in the BRCA1 and BRCA2 gene are responsible for almost 20 per cent of ovarian cancers and have been found to increase a woman's lifetime risk of developing ovarian cancer 9-20-fold. [8, 18]

**Lifetime risk** of ovarian cancer **~2%** in general population **versus 40%** for those with BRCA1 or **18%** for those with BRCA2 mutations. [8]

# Prostate cancer

Prostate cancer is the most common cancer in men in Australia, with over 20,000 new cases diagnosed annually. [1] It accounts for almost a third of cancer diagnoses in men annually. [1] Fortunately, survival rates for prostate cancer have improved with the introduction of screening programs that enable earlier diagnosis. [1] It is estimated that 5-10 per cent of these prostate cancer cases are caused by inherited genetic risk. [9, 19] If two or more close family members have had prostate cancer diagnoses or a family history of breast and ovarian cancer is present, then the risk of developing prostate cancer is substantially increased for an individual. [9]

A **five-fold increase** in the risk of **developing prostate cancer** for those with **2+ male family members** who have been diagnosed. [9]

It's estimated 10-12 per cent of men with more advanced and harder to treat metastatic castration-resistant prostate cancer carry inherited BRCA1 or 2 mutations.[9]

This only highlights some of the gene mutations that can cause hereditary cancer, yet we know that there are many, many more (Figure 2). Ultimately, we know these mutations increase cancer risk substantially and affect whole families, not just individuals. We must ensure that those at risk are supported to make informed decisions on their health to manage this risk.

**A hereditary cancer predisposition puts the individual at higher lifetime risk of developing cancer and in some cases earlier, more aggressive, more advanced and less treatable cancers.**

# From Understanding to Action: Reducing Hereditary Cancer Risk

The exact number of individuals at high risk of hereditary cancer is unknown. However, with the identification of an increasing number of gene mutations, hereditary cancer risk will touch many Australians. Once a person knows that they have a hereditary cancer mutation, the path forward can be emotional and daunting. [25]

> *"I was terrified of getting cancer and seeing what the cancer treatments do to your body. I've watched family members die from cancer, even after receiving treatment."*
>
> **– Inherited Cancers Australia community member**

Unlike a cancer diagnosis that typically leads to a known treatment pathway or management plan, identification of high-risk status and next steps is less well defined. High risk individuals can choose several pathways forward and must weigh the risks and benefits of each:

**Do nothing.**

**Watch and wait (e.g. monitoring).**

**Undertake preventive measures. [25]**

Adding to the uncertainty are preventive measures specific to each gene mutation, that are not without their own risks or challenges (Table 1). [25]

*Table 1. Preventive measure and challenges in accessing health support needs by cancer type*

| Cancer Type | Monitoring and preventive measures | Challenges |
|---|---|---|
| **Breast cancer** | • Prophylactic mastectomy<br>• Regular screening (yearly from late 20s) mammograms and magnetic resonance imaging (MRI)<br>• Initiate chemoprevention (e.g. tamoxifen or raloxifene) | • Surgery wait times<br>• Invasive nature, loss of normal breast function and body image issues from prophylactic mastectomy<br>• High cost and accessibility of regular screening<br>• Potential side effects of chemoprevention<br>• Costs of medicines for chemoprevention |
| **Prostate cancer** | • Annual serum Prostate Specific Antigen (PSA) screening from age 40<br>• Prophylactic surgery (e.g. prostatectomy) | • PSA screening may lead to overdiagnosis and overtreatment<br>• Significant side effects and impact on quality of life from prophylactic surgery |
| **Ovarian cancer** | • No reliable or recommended screening<br>• Prophylactic oophorectomy and salpingectomy<br>• Initiate chemoprevention (e.g. oral contraceptives) | • Surgical menopause and associated health risks and impacts from prophylactic oophorectomy<br>• Limited effectiveness of regular screening methods<br>• Potential side effects and long-term use concerns of chemoprevention<br>• Costs of medicines for chemoprevention or surgical menopause |

*Source: Developed by Evohealth from multiple sources [10, 27-33]*

# Preventive measures reduce risk and save lives

It is well understood that preventive surgeries can reduce the risk of some cancers to near zero. Prophylactic mastectomy, removing breasts for risk reduction, has been shown to reduce the risk of breast cancer by at least 95 per cent in women who have a BRCA gene mutation and strong family history of breast cancer. [10] Further, prophylactic prostatectomy has been shown to reduce the risk of prostate cancer to nearly zero because the entire prostate gland is removed, although it is an extremely rare procedure due to the potential significant side effects. [27] Bilateral salpingo-oophorectomy (BSO), surgical removal of ovaries, has become the standard of care for risk reduction in women at hereditary risk of ovarian cancer, with ovarian cancer risk found to decrease by more than 80 per cent. [28] Removing the ovaries however, results in immediate surgical menopause, often much earlier than the general population.

For some of our community, taking preventive action is an easy decision. But for many it is an emotional experience fraught with fear and uncertainty.

*"I was having surveillance on my ovaries and had an elevated CA125 blood test and had to wait 1 month to repeat the test. Even though the following test was normal, I had been in extreme distress waiting for results, so decided to have an oophorectomy."*

**- Inherited Cancers Australia community member**

*"Watching two women in my family suffer from breast cancer at the same time and unfortunately losing one of them made me want to do it (risk reducing surgery) pretty quickly. I didn't want my children and husband to have to watch me go through all of that and potentially lose my own life."*

**- Survey respondent**

*"After watching my mother go through cancer treatments and surgery, I was keen to do anything preventive that I could."*

**- Inherited Cancers Australia community member**

# Risk carried across generations

Unfortunately, despite preventing their own cancer, the risk doesn't end with the individual. Current and future family members may have the same risk, and so on and so on. [25] Sadly, hereditary cancer has, and will continue to have, a substantial impact beyond the initial cancer diagnosis, making it a truly horrible family affair. The support these families need to navigate a health system based on diagnosis and treatment, with little room for prevention, is unique and needs to be better understood in Australia.

**For those with hereditary cancer risk, decisions on risk-reduction and further family risk assessment go beyond the individual and can be very difficult to navigate.**

# Reducing risk saves lives

## Supporting those with hereditary cancer risk to make informed decisions

We know that taking preventive action to reduce hereditary cancer risk saves lives. This requires specialised and targeted support to make an informed decision. In our 15 years of experience helping people make these life changing decisions, we have learnt that there is not a one size fits all approach.

To guide us, as we move to the next stage at Inherited Cancers Australia, we went directly to the source and asked our community to share their experiences, needs and challenges via a comprehensive survey.

This survey provides valuable, firsthand data on the emotional and practical support required, as well as identifying gaps in existing services to ensure that support strategies are tailored to the real-world needs of the community. By capturing the voices of those directly affected, we can advocate more effectively for targeted resources and policy changes, ultimately enhancing the support provided to individuals and families at risk.

## Understanding what the community needs

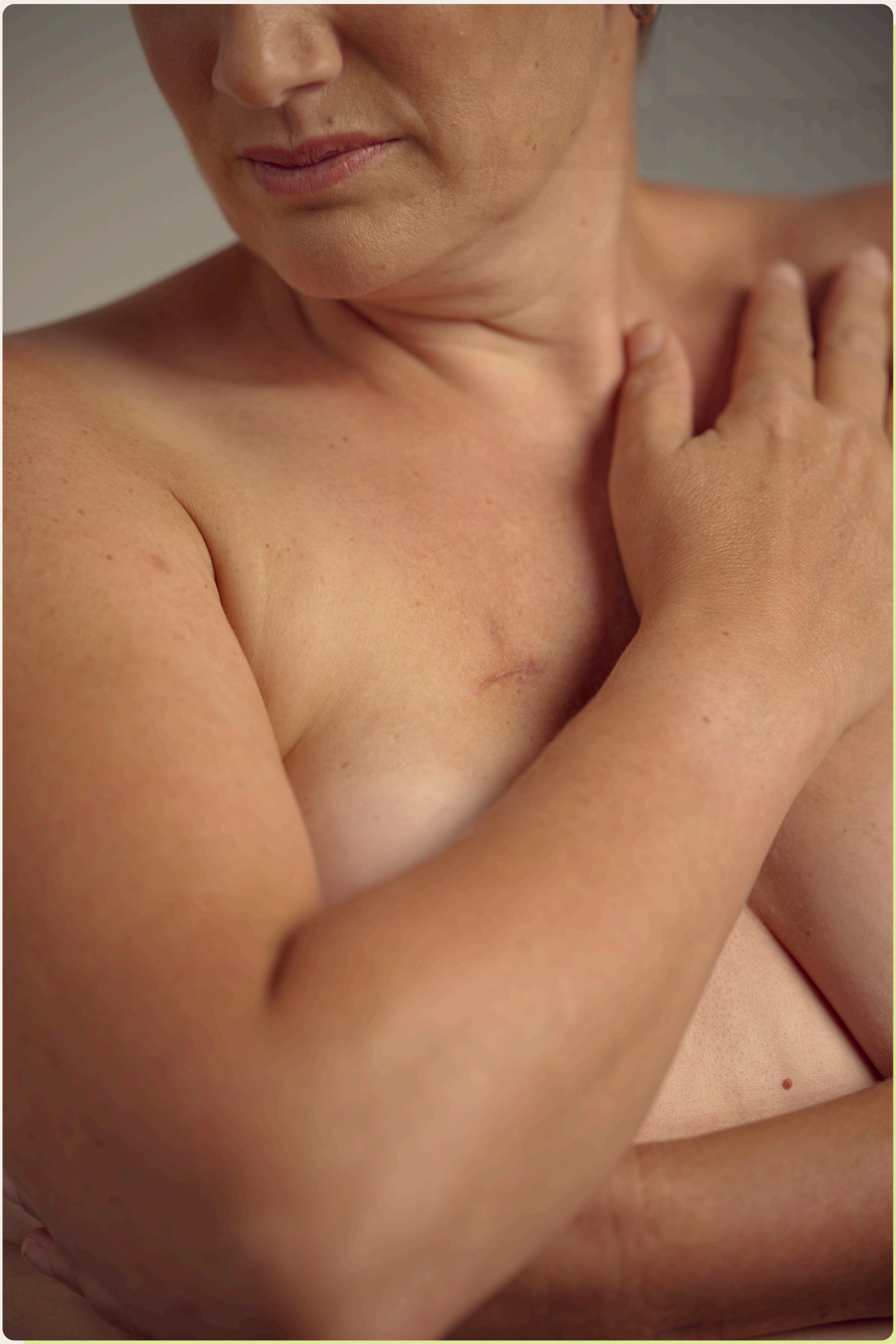
Our survey was designed to understand the support needs and health experiences of Australians with an increased risk of hereditary cancer, with a focus on breast, ovarian and prostate cancer, in alignment with our broader inherited cancer focus.

The link to the online survey was widely distributed across Australia via email to our community and healthcare professional database, shared across social media channels and our website, shared via posters at family cancer centres and genetic services, emailed to relevant organisations and not-for-profits working in cancer and genomics, and via a feature story in The Age.

The survey was live between 14th May to 6th June 2024.

Once the survey data was collected, it was cleansed and analysed to identify key insights, challenges, and needs of the high-risk hereditary cancer community.

The following sections of this report highlight the results of this survey, supplemented by individual insights to describe the challenges that those with hereditary cancer risk face in Australia and, critically, what more can be done to support these individuals.



# Voice for the vulnerable – community insights from those at risk of hereditary cancer

To understand the key insights from our community survey it's important to understand the backgrounds and experiences of the people who took part. We are so grateful for everyone who shared their experiences and stories with us. A summary of those who contributed is described below.

We received 1,023 responses to the survey and included 884 in our analysis.[1] Of these, most reported as English-speaking, female respondents in the 35–54-year age group, living in a major city. This cohort largely aligned with our previous focus on female hereditary cancers (breast and ovarian). As we evolve to Inherited Cancers Australia, we will endeavour to broaden our focus and better serve all those at risk. A full breakdown of survey respondent demographic characteristics can be found In Appendix A.

## Respondent cancer diagnosis and risk profile

| | |
|---|---|
| Are at increased risk of cancer, and their genetic testing result was reported as a Variant of Unknown Significance (VUS), inconclusive, or they did not have a gene mutation for cancer | 5.5% |
| Have a gene mutation(s) that puts them at high risk of cancer and have had a cancer diagnosis | 28.3% |
| Have a gene mutation(s) that puts them at high risk of cancer and have NOT had a cancer diagnosis | 41.3% |
| Had a significant family history of cancer and have had a cancer diagnosis but don't have a gene mutation | 8.0% |
| Had a significant family history of cancer, but didn't know if they carried a gene mutation | 16.6% |
| No response | 0.2% |

[1] Responses were included in the analysis if the respondent had completed more than the initial demographics questions.

# Survey respondent characteristics

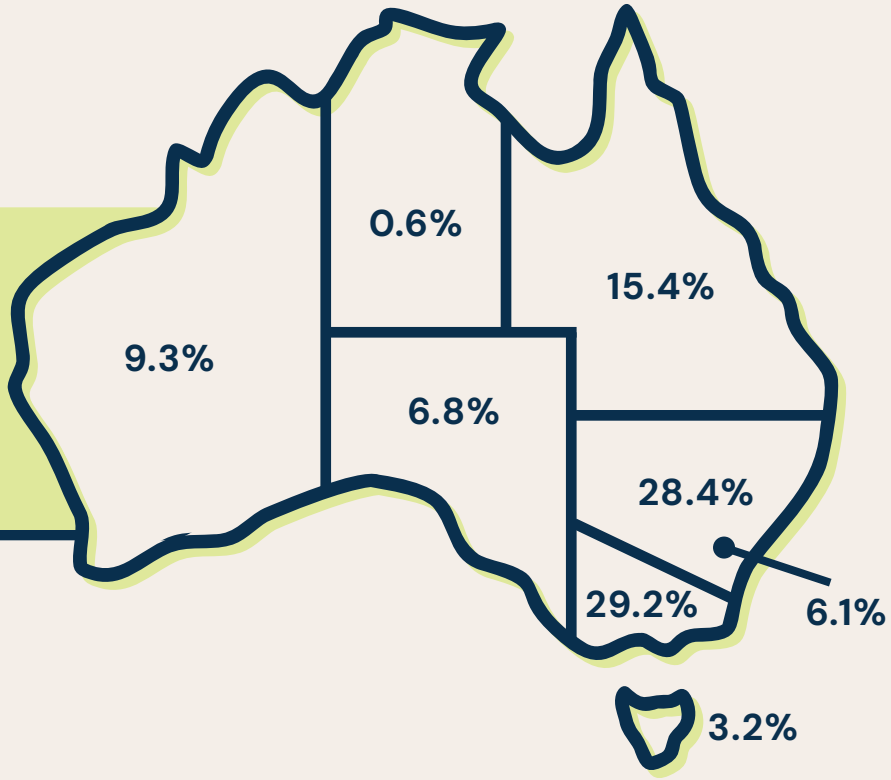
**96.3%** female vs **3.1%** male

**98.6%** indicated English as their language of choice

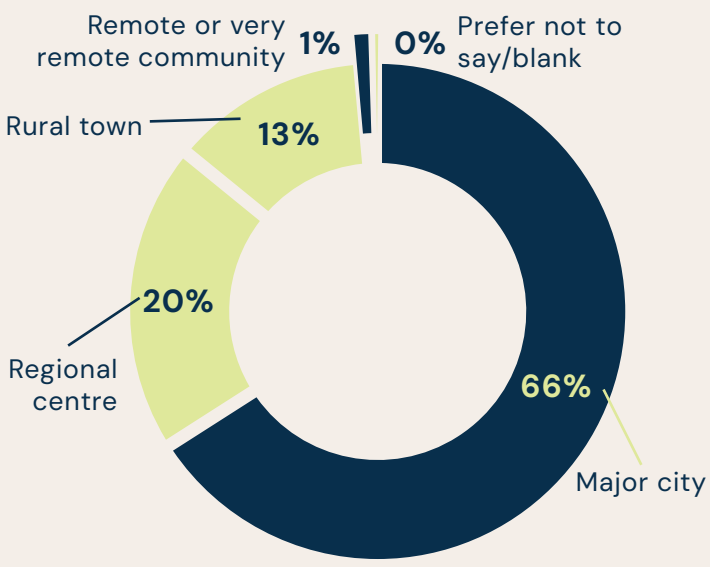
median salary in the range of **$75,000 to $99,999**, which is above the national median of **$67,600**

**1.8%** identify as Aboriginal and/or Torres Strait Islander

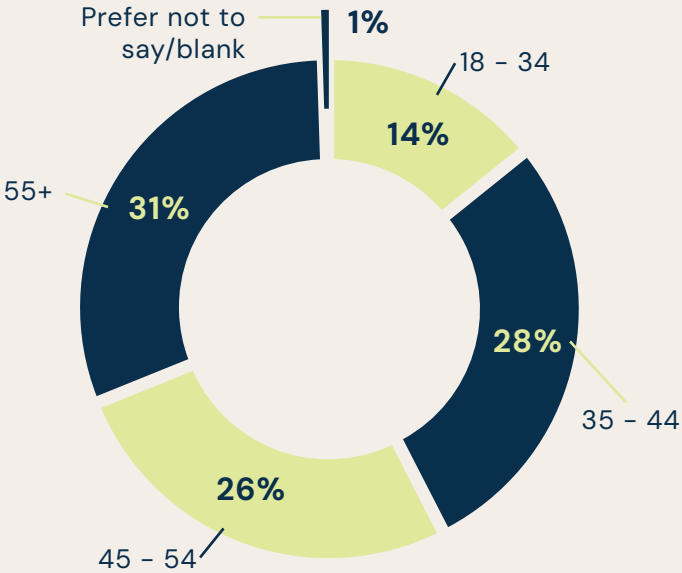
## Survey respondent geographical distribution




## Survey respondent regionality distribution




## Survey respondent age distribution



# Knowledge is power

It is clear from the survey that our community is actively seeking support to take preventive action and reduce the impact of their inherited gene mutation and avoid a cancer diagnosis for them and their family. The gaps in individual support needs and our understanding of them are discussed in the following sections and analysed against current government priorities.

> *"I have not felt so comfortable and empowered around my BRCA1 carrier status since I found out about having the flawed gene 4 years ago. Meeting others who just get what it's like has made me feel less alone, and the info from the day was invaluable."*
>
> **– Survey respondent**

## 1 Prevention of hereditary cancer saves lives.

Cancer Screening is one of the pillars of the Australian Cancer Plan. [34] In the Plan, "adoption of targeted or personalised screening strategies that may involve the application of new technologies and assessment of genomic risk" is highlighted, as well as established cancer screening programs, such as cervical and breast, as risk reduction strategies. [34]

Prioritising the assessment of genomic risk is welcome news for individuals and families with a known cancer risk. Understanding hereditary cancer risk saves lives.

> *"I was … the first in my family and it was how we discovered both the BRCA1 mutation in 11+ family members and one case of ovarian cancer (cousin) and one of prostate cancer (uncle), saving both lives. Doctors here in Australia have openly told me I would not have been tested here."*
>
> **- Survey respondent**

A lack of information and support regarding the risks associated with hereditary cancer, will lead to more diagnoses, healthcare utilisation and unfortunately, more lives lost.

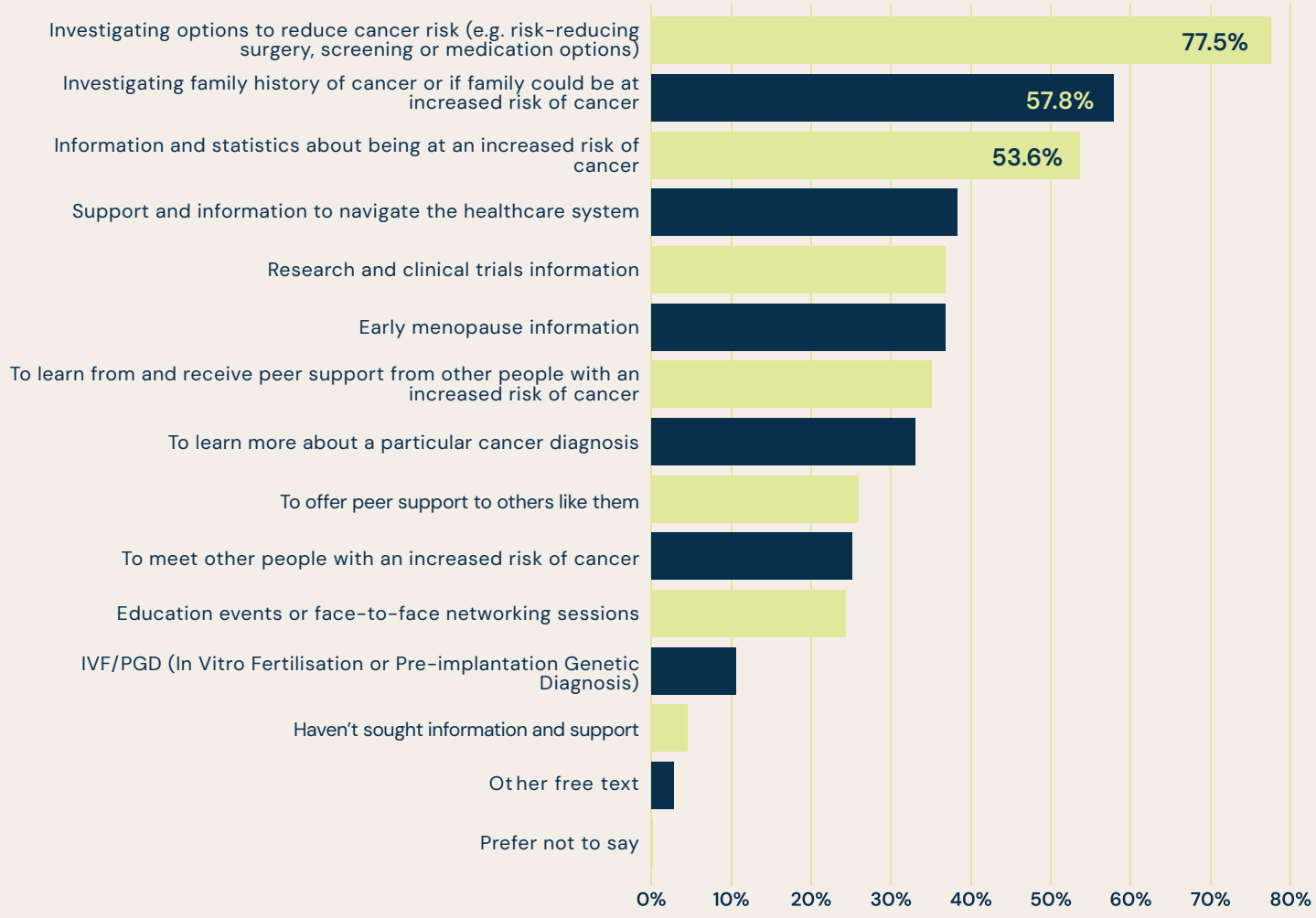
> *"There has been a general lack of encouragement or support to seek information or to support my desire to have surgery to remove the risk of ovarian cancer, in general doctors seem preoccupied with stopping me from making myself infertile, despite having had kids and now being more concerned with being around to see them grow up…"*
>
> **- Survey respondent**

Our organisation is filling the void. We offer a range of support services for people with hereditary cancer risk, including information available through online resources, support groups, education events, information and support days, as well as a genetic counsellor service. Some survey respondents were unaware of our work, or only accessed the services following a cancer diagnosis, or risk-reducing surgery. We know that more work needs to be done to increase awareness of hereditary cancer, enhance information and support to allow earlier engagement and conversations around risk. This can't be left to small organisations alone to carry the burden.

> *"I really like that it is Australian. A lot of information and support services out there on the internet are US-centric."*
>
> **- Inherited Cancers Australia community member**

Investigating options to reduce individual cancer risk was the most common reason for seeking information, with many others wanting to understand family risk (Figure 3). It is often said that knowledge is power, and the survey data revealed this to be true for those with hereditary cancer risk.

*Figure 3. Reasons for seeking information and support from Inherited Cancers Australia*




*Source: Inherited Cancers Australia survey*

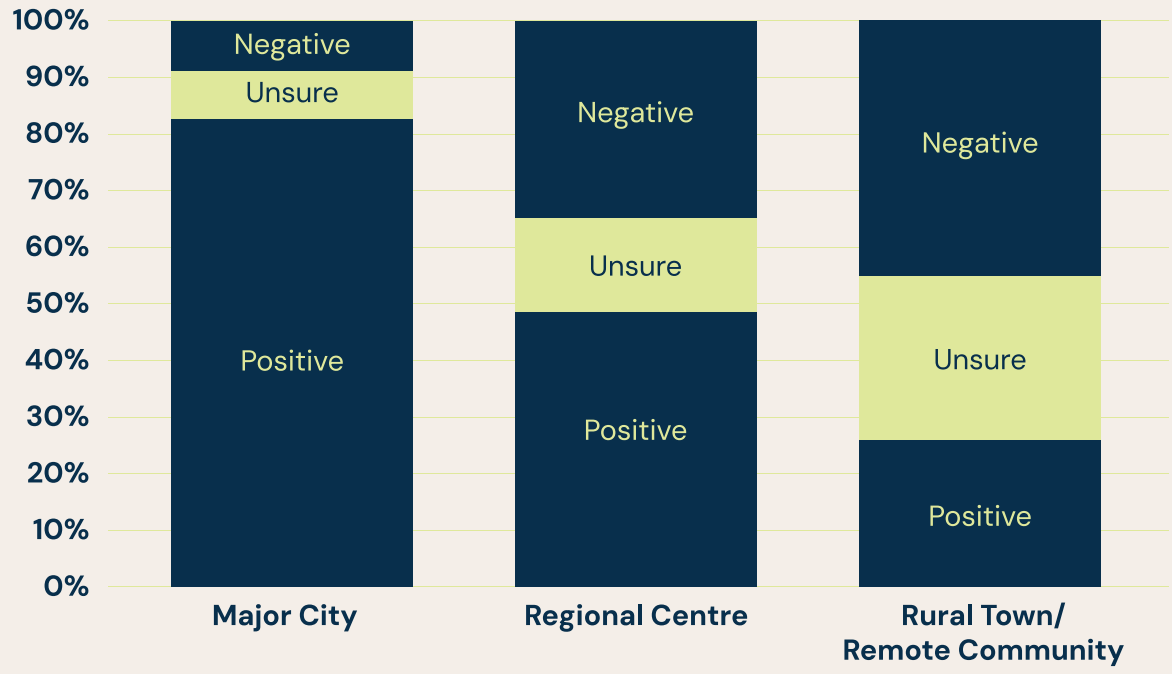
There are known inequalities in cancer survival among people living in rural, regional and remote areas of Australia. These disparities in cancer treatment contribute to overall poorer health outcomes. [35] Survey respondents described how their access to cancer related healthcare was impacted by where they lived, with more positive interaction for people in major cities than rural areas (Figure 4). This is consistent with broader access to the health system for most health conditions in Australia.

> *"Due to family history I have to travel to Perth if I want to continue getting breast ultrasounds, it is a 650km round trip and then payment of ultrasound on top of trip. We can only access very basic health services. Mammogram breast screen does come to town sometimes however I am not eligible to go there."*
>
> **- Survey respondent**

A national approach to reducing the risk of hereditary cancer must include equitable access for those in regional and rural Australia. By actively reducing this risk, the future burden on the health system would likely be reduced.

Whilst 5 per cent of all cancers are believed to be due to inherited risk, [2-4] some have significantly greater hereditary risk than others, for example, ovarian cancer. [8, 17]

*Figure 4. Relationship between where you live and impact on healthcare access*




*Source: Inherited Cancers Australia survey*

Action 1.5.4 of the Australian Cancer Plan to "Develop a policy framework for genomics cancer control across the cancer continuum" is progressing, with a roundtable of key stakeholders planned for the end of 2024. [34] The hope is that this policy framework will identify and provide direction for the incorporation of genomic testing technologies, amongst other supports, into the broader cancer care system. [34]

While we will support this crucial work and represent our hereditary cancer community in these discussions, it's important that we consider the impact and consequences that these technologies may have on our community. More testing means more people are aware of their potential cancer risk, requiring more support from organisations such as ours.

We cannot do this alone. These Australians need national leadership, including a national strategy and roadmap to reduce the risk of hereditary cancer, to complement the national policy framework for genomics.

# Recommendation 1

**Develop a national prevention strategy and roadmap to reduce the impact of inherited cancer in the Australian community.**

## 2 Understanding the economics of reducing hereditary cancer risk

Cancer costs lives and places considerable strain on individuals, families and our health system. The cost of treating cancer in Australia is significant, both in lives lost, emotional impact and healthcare budgets, both at a Federal and State/Territory level. In 2016, it was estimated that health system expenditure on cancer was over $10 billion. [20] Cancer is our leading cause of death when considered as a single category. [1, 20]

For those at risk of a hereditary cancer, accurate information to reduce their individual risk helps protect their future and that of their loved ones. In fact, access to information or online resources provided was rated the most highly valued support service offered by Inherited Cancers Australia.

*"When I was looking into surgical options for prophylactic mastectomy and later when I wanted more info on my Mum's triple negative breast cancer, I stumbled across some online videos of expert speakers that I found very informative and shared with the family who also found it useful."*

**- Survey respondent**

*"Online resources helped me decide to take proactive preventive surgeries."*

**- Survey respondent**

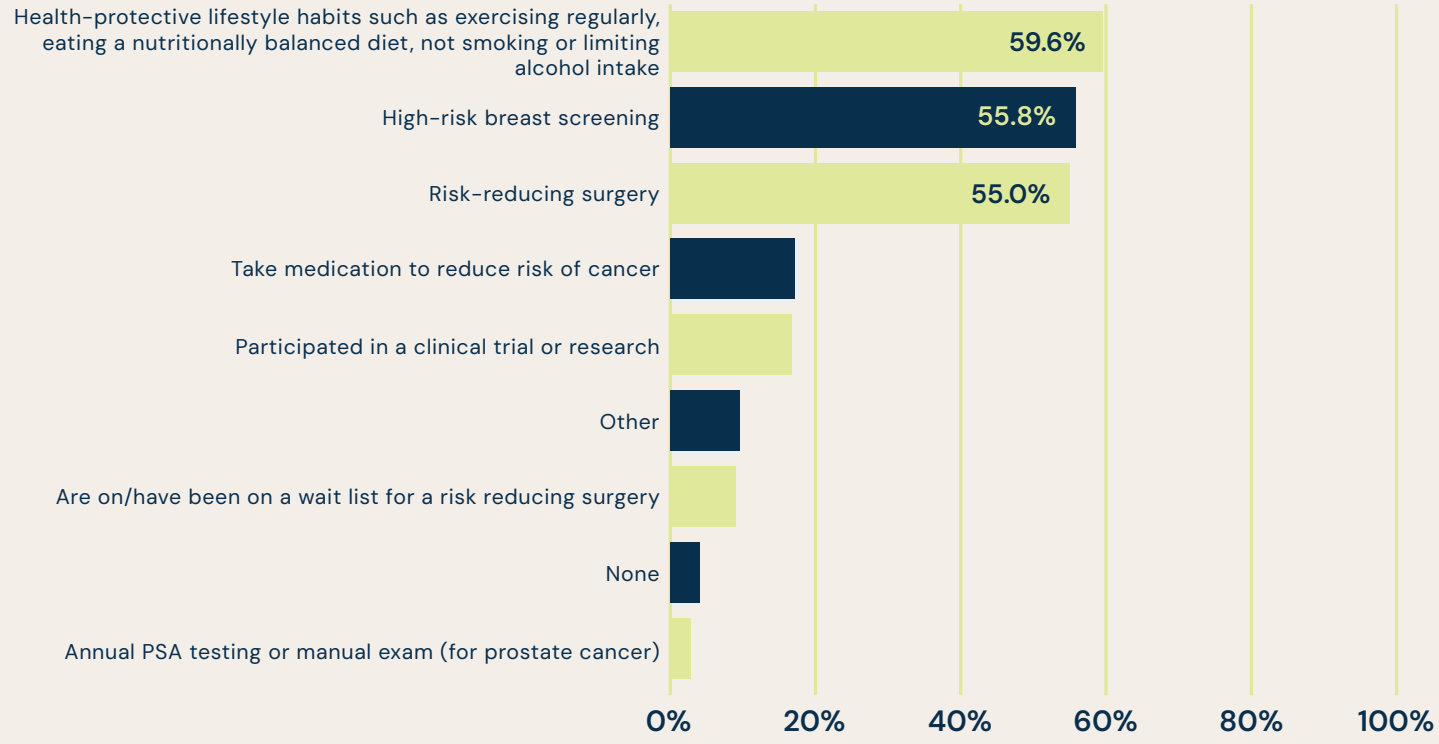
Managing risk and preventing a cancer diagnosis with this information is a priority for people with a hereditary cancer genetic profile.

How risk is mitigated and monitored varies following confirmation of genetic testing. Options include active monitoring of cancer risk, known colloquially as 'watch and wait', or where possible, active intervention such as surgery.

> *"I find the online communities really helpful to hear from real people and online interviews with specialists in the field."*
>
> **- Survey respondent**

In our survey, the most common health intervention reported was risk-reducing surgery at 55 per cent, which is not surprising given Inherited Cancers Australia's focus to date on breast and ovarian cancers. Across the survey pool, 17.1 and 16.7 per cent of people took medication or participated in a clinical trial or research, respectively, to seek to reduce risk (Figure 5). This, in addition to a range of other preventive strategies, such as lifestyle changes and high-risk breast screening, demonstrates that individuals are keen to prevent a future cancer diagnosis.

*Figure 5. Managing cancer risk*




*Source: Inherited Cancers Australia survey*

For prostate cancer, only 2.8 per cent of men surveyed sought screening via annual PSA testing or manual exam. Given that only 3.1 per cent of respondents identified as male, these results should be interpreted with caution. It does, however, reveal that men with a hereditary risk of prostate cancer may not be seeking information as readily as women, and this may lead to increased risk.

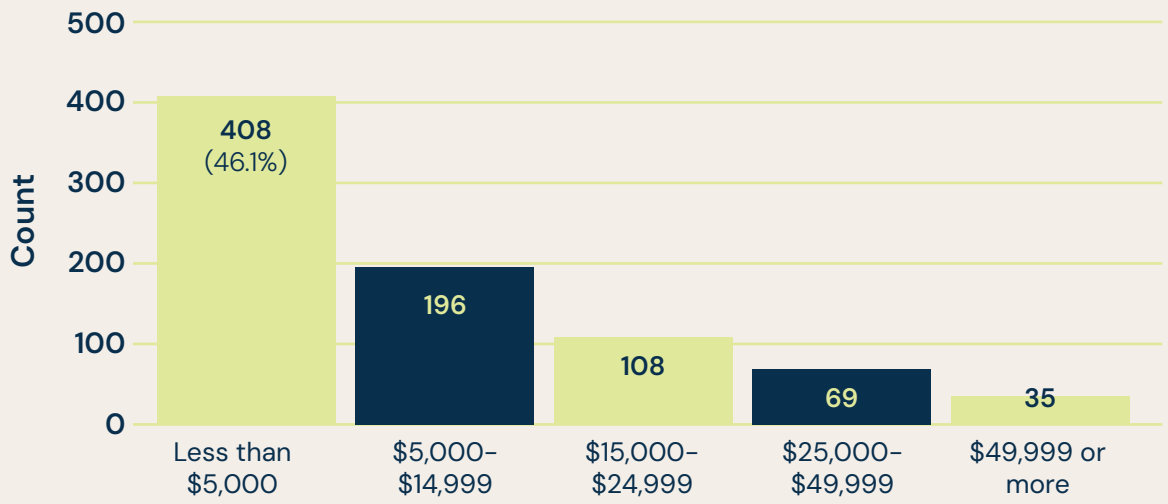
# Hitting the hip pocket of Australians

Despite Australia's universal health system, many people continue to pay out of pocket costs for obtaining preventive care or treatment.

Our survey reveals that many survey respondents paid significant out of pocket costs to manage their risk of cancer and/or cancer diagnosis. This included surgery, medication, allied health services, tests, biopsies and other direct healthcare costs. Over half of respondents (53.9 per cent) paid more than $5,000 out of pocket, 11.5 per cent spending over $25,000 and some people reporting costs of over $50,000 (Figure 6). These costs are prohibitive for many Australians, particularly those in marginalised and vulnerable communities.

> *"I accessed my super to cover a portion of my fees for mastectomy and reconstruction— $13,400. The ATO then taxed me an additional $3,400 out of my super for accessing my super early. The rest I paid for up front with what savings I had."*
>
> **- Survey respondent**

*Figure 6. Out of pocket costs for cancer related healthcare*

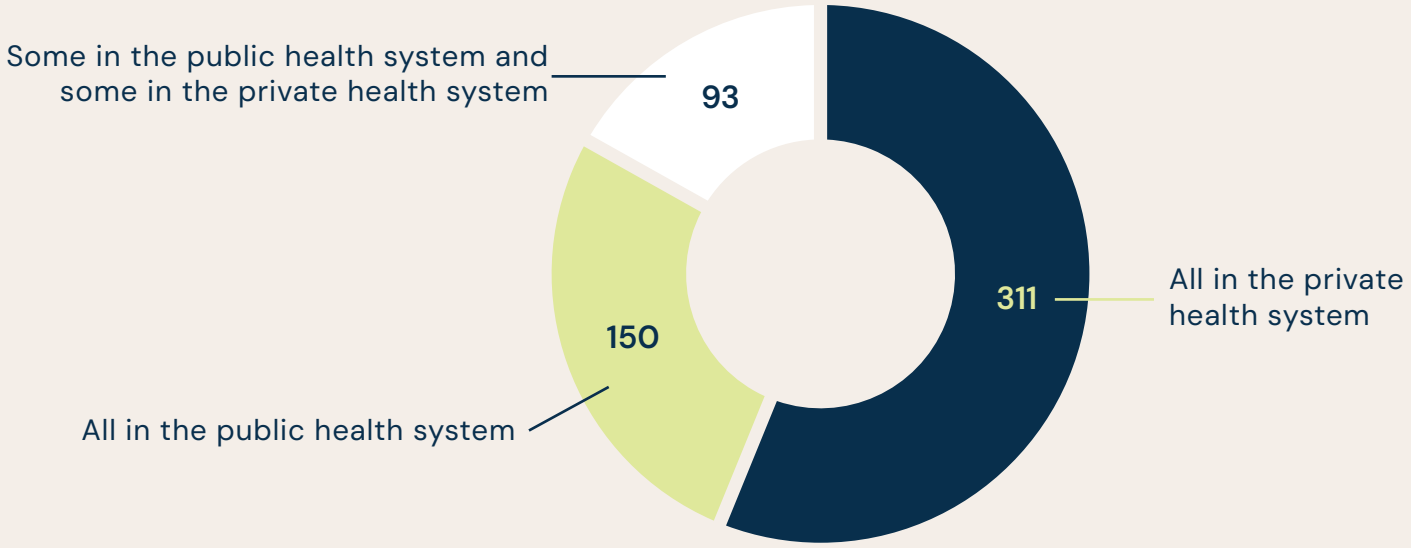



*Source: Inherited Cancers Australia survey*

It also appears that the private health system, a system under considerable pressure, is providing the bulk of the risk reduction surgery, with twice the number of respondents accessing only the private health system care, versus public (Figure 7).

This important preliminary finding needs further analysis to understand if access to public or private surgery impacts on the wait times of those seeking to reduce future cancer risk.

*Figure 7. Private and public hospital utilisation for risk reduction surgery*




*Source: Inherited Cancers Australia survey*

Cancer survivors experience mental health disorders, such as anxiety and depression, at double the rate of the general population. [21] The impact of a cancer diagnosis or understanding that you have a greater risk, takes an emotional toll on individuals and their families. This mental health burden on patients or carers may not be factored into the reported out of pocket costs.

## Prevention pays

Australia currently has three government-funded, population-based cancer screening programs: the National Breast Cancer Screening Program, the National Cervical Screening Program, and the National Bowel Cancer Screening Program. [36] Comprehensive analyses of the cost-effectiveness of these programs, which consider early diagnosis and treatment resulting from screening, have been conducted. These analyses have found that the benefits to harms of these programs are favourable, meaning that the advantages of early cancer detection and treatment outweigh the potential risks, such as false positives, overdiagnosis and associated anxiety. [36]

These programs are considered cost-effective, which means that it is more beneficial to screen for cancer early than to wait for symptoms to appear and then treat the disease. Early detection through screening allows for less aggressive treatment options, better patient outcomes, and reduced healthcare costs in the long run. [36] For instance, it is estimated that cervical cancer screening costs around $17,000 per life-year saved, bowel cancer screening costs approximately $3,000 per life-year saved, and breast cancer screening costs about $40,000 per life-year saved. [36]

Other economic analyses have also focused on the number of cancers, deaths, and other health outcomes prevented by screening. For instance, one study evaluated offering genomic screening to all young adults in Australia to detect high-risk hereditary breast and ovarian cancer, Lynch syndrome, and familial hypercholesterolemia. [37] The study estimated that genomic screening for every 100,000 people could prevent 63 cancers, 31 cases of heart disease, and 97 deaths, resulting in an increase of 747 quality-adjusted life years (QALYs). [37] For the entire young adult population of Australia, this would mean preventing 2,612 cancers, 542 heart disease cases, and 4,047 deaths, resulting

in over 31,000 additional QALYs. [37] Assuming a 50 per cent uptake in the population of the testing, the study found their proposed screening program to be cost effective at AU$23,926 per QALY gained, with authors suggesting under some circumstances the screening may save the system money. [37]

## Good for the economy

Our survey reveals that around 87 per cent of respondents are in their most productive years, aged between 25 and 65 years (Table 2). With a median salary in the range of $75,000 to $99,999, which is above the national median of $67,600 [38], any loss of productivity resulting from cancer diagnosis could significantly impact on the wellbeing of the individual, their family and the broader economy. Given that many of these individuals are still young and contributing economically, maintaining their health through early detection and prevention is not only beneficial to them personally but also helps ensure their continued ability to contribute productively to their families, communities and Australia.

*Table 2. Salary range of respondents, count and percentage*

| Salary Range | Count | Percentage |
|---|---|---|
| Less than $10,000 | 42 | 4.8% |
| $10,000 – $24,999 | 51 | 5.8% |
| $25,000 - $49,999 | 104 | 11.8% |
| $50,000 -$74,999 | 148 | 16.7% |
| **$75,000 - $99,999** | 122 | 13.8% |
| $100,000 - $124,999 | 129 | 14.6% |
| $125,000 - 149,999 | 55 | 6.2% |
| $150,000 - $174,999 | 23 | 2.6% |
| Over $175,000 | 50 | 5.7% |
| Prefer not to say / blank | 160 | 18.1% |
| Total | 884 | 100% |

*Source: Inherited Cancers Australia survey*

Where possible, preventing a cancer diagnosis from occurring may in fact be cost-effective when compared to treating the disease. Understanding this requires government investment to conduct a full cost-effectiveness evaluation of prevention via risk reduction compared to treatment, at both an individual and population level.

# Recommendation 2

**Conduct a full economic analysis to understand the cost-effectiveness of risk reduction interventions compared to the treatment of diagnosed cases.**

## 3 At risk individuals and families need information to make informed decisions.

We know that for every person diagnosed with a hereditary cancer, around 3 family members will seek testing to understand their risk. [11] More than 3 out of 4 respondents who accessed information from Inherited Cancers Australia, did so to seek information on how to reduce their, or their families, risk of developing cancer. With more testing, comes more people who need this information and support – creating more pressure on the health system.

People reported valuing our community support at Inherited Cancers Australia, with respondents grateful to meet and support members with the same gene mutation, as well as having up to date information that is written for the Australian setting.

## 3 out of 4 people access Inherited Cancers Australia to seek information to reduce their risk of cancer.

# Insights from our community

*"Being able to connect with others/ask questions with same gene mutation as there isn't a lot of info available for this variant."*

*"I don't have a great amount of comparison but do note how positive the community are. They all have different experiences etc (perhaps more varied than a cancer support group community) and the organisation are sensitive to this. The tone is so uplifting (versus depressing, which I've seen on other websites, including US hereditary cancer websites)."*

*"Thank you for the very welcoming, friendly, safe, informative event today. The guest speakers were a wealth of knowledge and their openness to answer our questions was very appreciated. I really enjoyed meeting and speaking with other people in this community."*

*"My daughter and I gained a lot of information from attending an event where health professionals and cancer patients spoke about treatments etc."*

*"The ever-evolving scope of data that's relevant to decision making, the need to be at the forefront of research as well as policy."*

*"The information day was everything I needed, and more! As a young mother who is high risk and eagerly awaiting the results of my BRCA testing it covered all the questions I had. It has helped me create more targeted questions that I will ask when I meet my specialist in the future. It also helped answer questions I had as I navigate my mum's journey as an ovarian cancer patient and BRCA2 mutation warrior. Thank you, thank you, thank you."*

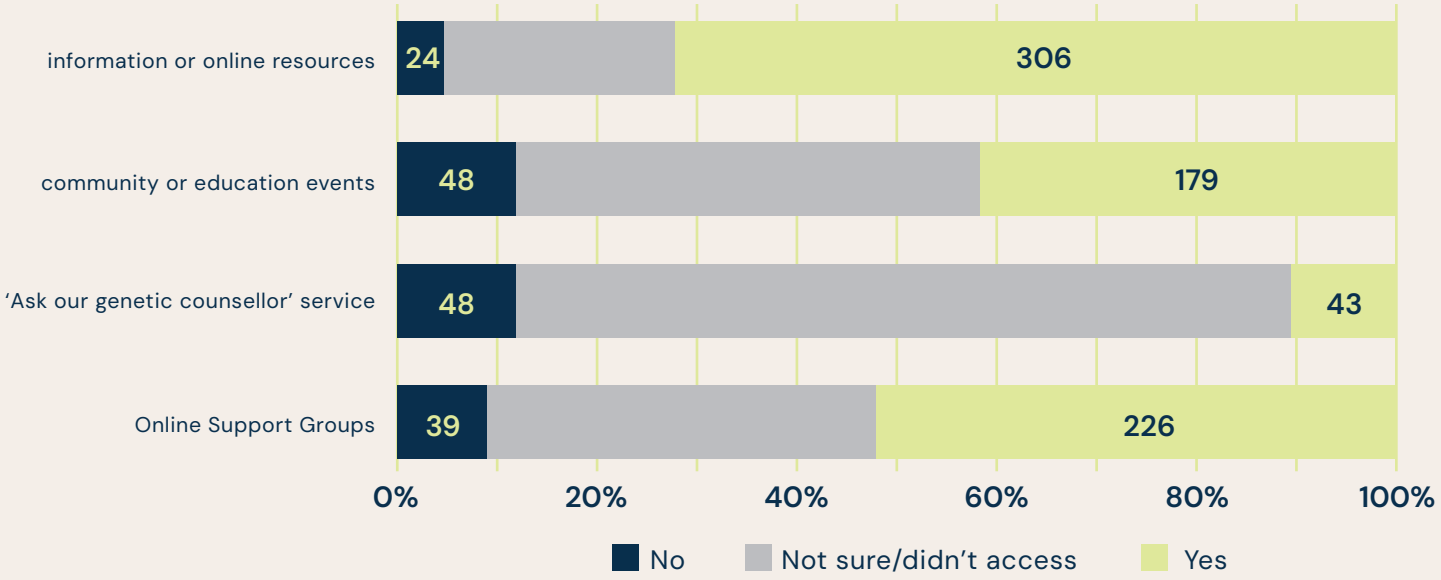
# Making informed decisions

Beyond the community support, however, is the importance of seeking accurate information to inform how an individual will reduce their cancer risk and/or diagnosis. Over 70 per cent of people found the online information and resources helpful in supporting their risk reduction decision (Figure 8).

This, along with support groups and education events, allowed people to make informed decisions.

Organisations such as ours are filling a critical information gap for people at risk of hereditary cancer.

*Figure 8. Helpfulness of Inherited Cancers Australia resources and making an informed choice*




*Source: Inherited Cancers Australia survey*

# The community is growing

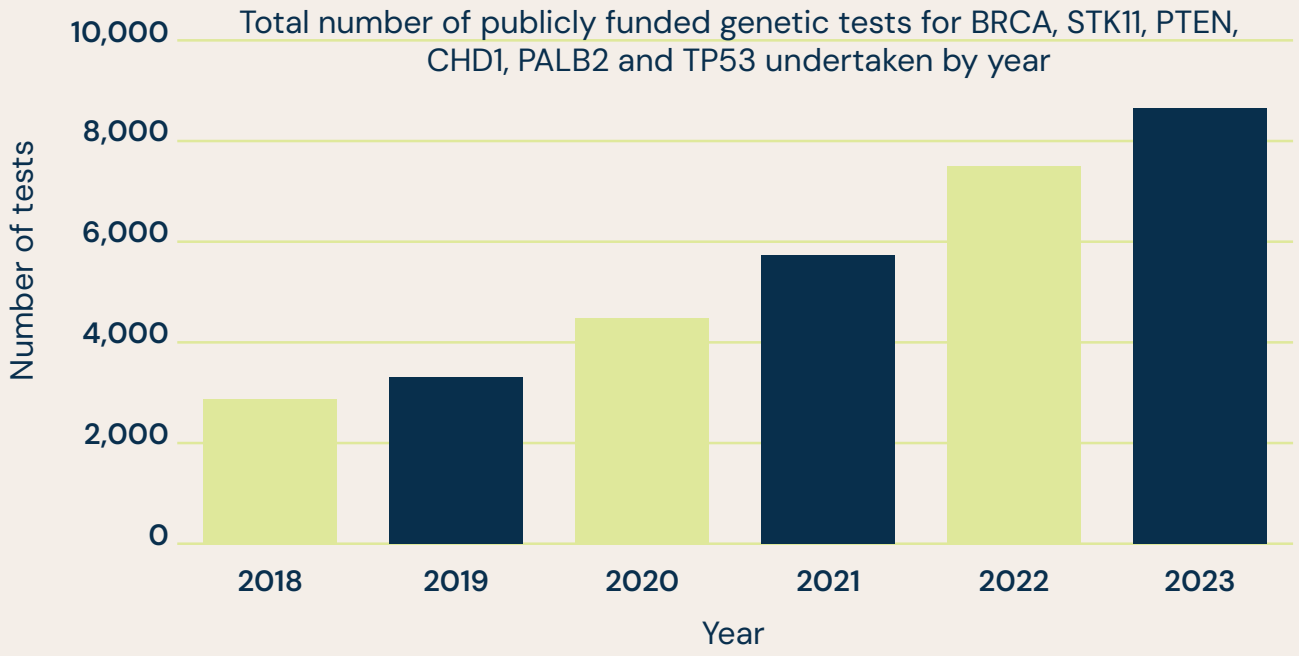
Not accounting for those who undertake private genetic testing, since 2017 over 36,000 people[2] have undertaken publicly funded genetic testing for BRCA and other high risk hereditary mutations. A number that continues to grow and with it, the population of individuals who are aware they are at hereditary cancer risk. This can be seen in the year-on-year growth in uptake of publicly funded genetic testing (Figure 9).

This increase is fuelled by advancements in testing uptake and knowledge due to research programs and government initiatives expanding access to related treatments and services. For example:

- Listing of medicines, such as Olaparib, on the Pharmaceutical Benefits Scheme (PBS) for treatment of cancers that require confirmation of BRCA1 or 2 mutation prior to treatment initiation. [40]
- Addition of Medicare Benefits Schedule (MBS) item for testing Homologous Recombination Deficiency (HRD) status, that includes BRCA1 or 2 status in certain ovarian cancer patients. [41]
- Government funding of TRACEBACK, a program that identifies the BRCA status of deceased ovarian cancer patients who were not previously tested (diagnosed from 2001 - 16) to provide their families with critical information on their own potential risk status. [42]

[2] Analysis of MBS items 73296, 73297, 73295, 73303 and 73304 from Services Australia data [39]

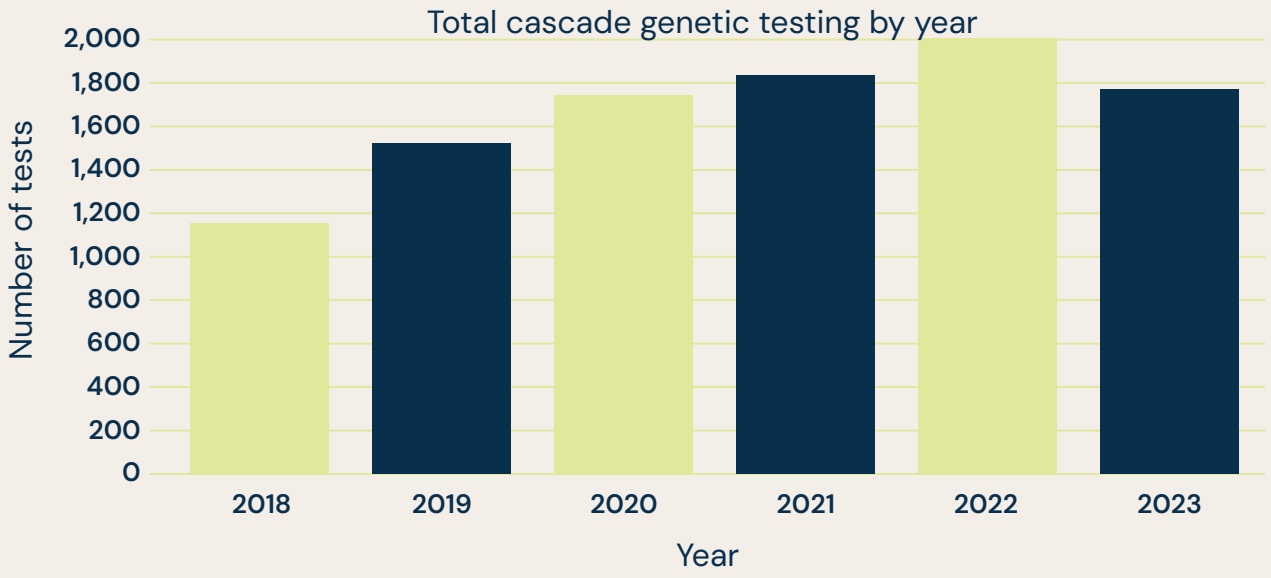
*Figure 9. Total number of publicly funded genetic tests for BRCA, STK11, PTEN, CHD1, PALB2 and TP53 undertaken by year*




*Source: Inherited Cancers Australia Analysis of MBS items 73296, 73297, 73295, 73303 and 73304 from Services Australia data [39]*

Confirmation of the mutation in any of the above circumstances may trigger further testing to identify if the person is a carrier, then if they are found to be a carrier, family testing (i.e. cascade testing) may occur. Since 2017 11,000 people[3] have undertaken cascade genetic testing after identification of a relative who carriers a gene mutation, these numbers are increasing year on year (Figure 10).

*Figure 10. Total cascade genetic testing by year*




*Source: Inherited Cancers Australia Analysis of MBS item 73297 from Services Australia data [39]*

As a result, the number of individuals who know they have a hereditary cancer risk is increasing, underscoring the need for expanded support services and preventive measures.

[3]Analysis of MBS item counts for item 73297

# Not all people are represented

Information to make an informed choice must be tailored to individuals and accessible across multiple modalities. The survey itself provided interesting preliminary insights into who may, and importantly, who may not be accessing critical information and services.

Almost half of all the survey respondents (47.9 per cent) did not access the information or services provided by Inherited Cancers Australia. This could be due to a lack of need, or awareness around the services provided, or potential barriers to accessing the information itself, such as language barriers, delivery method or not tailored to their individual preferences.

Whilst caution must be exercised in interpretation, a critical insight is that amongst survey respondents, some important vulnerable communities were not represented in the data. Table 3 below compares the survey response information with accepted national datasets.

*Table 3. Comparison of survey and national data for vulnerable groups*

| | **Survey** | **National** [13, 14, 43] |
|---|---|---|
| **Aboriginal and/or Torres Strait Islander people** | 1.8% | 3.8% |
| **LGBTQI+** | 3.6% | 3.9% |
| **English not preferred language** | 0.8% | 22.3% |

*Source: Inherited Cancers Australia survey and the following sources [13, 14, 43]*

As mentioned, the survey highlighted that Australians with higher than the national median wage were accessing our information, resources, events and community. Similar to the concerns noted above, we need to ensure that those people with lower health literacy or from a challenging socioeconomic background have equitable access to the same information to make informed decisions as those we currently serve.

It is not surprising that with our previous focus on female centred hereditary cancers, such as breast and ovarian, that 96.3 per cent of respondents identified as female. However, there is an equally critical need for men with hereditary cancer risk to access information and make informed decisions. Our new mission, and name change to Inherited Cancers Australia, will help support this.

## So much to do, so little funding

With so many people seeking our services and resources and taking the time to complete our survey – we can see that there is much to be done. More and more people will need our help as the health system facilitates greater testing. Organisations, such as ours, are filling a critical gap and helping to reduce risk, and therefore cancer prevalence into the future. Yet only so much can be achieved with limited funding.

# Recommendation 3

**Provide ongoing funding to patient groups to deliver tailored, accurate information and support to those at risk of inherited cancer, including targeted outreach to Aboriginal and Torres Strait Islander people, CALD communities, and men.**

# Recommendations

We are proud of the impact that we have made on the lives of many Australians in the past 15 years. As we evolve to continue our mission to empower Australians to understand and manage their hereditary cancer risk, our organisation and others like us, need support from the Australian Government.

Our survey has highlighted critical gaps for many people who have, through no fault of their own, a greater risk of cancer. We firmly believe that preventing this cancer from occurring makes not only rational sense from an individual perspective, but is ultimately better for the health system and our economy.

In order to achieve this, we are calling on the Australian Government to:

## 1 Develop a national prevention strategy and roadmap to reduce the impact of inherited cancer in the Australian community.

The launch of the Australian Cancer Plan was a pivotal moment. For Inherited Cancers Australia, including the role of genomic risk acknowledged our community.

In order to realise the benefits that we believe will accrue from reducing risk at an individual and population level, Australia needs a national prevention strategy and roadmap for inherited cancer. This strategy, aligned with the Australia Cancer Plan, can bring to life elements of the Plan for the future for many Australian citizens.

From testing through to risk reduction care, this strategy will provide the national leadership that is currently missing.

## 2 Conduct a full economic analysis to understand the cost-effectiveness of risk reduction interventions compared to the treatment of diagnosed cases.

Australia is proud of the robust approach to Health Technology Assessment (HTA) over the past 20 years. This has provided access to safe, efficacious and cost-effective care for millions of Australians. Whilst individual screening programs have been evaluated, there has not been a government funded analysis of the effectiveness of preventive care for those with hereditary risk of cancer, versus treatment of a cancer diagnosis.

Our hypothesis, supported by studies discussed earlier, is that any such intervention will be cost-effective at both the individual and population level.

# 3 Provide ongoing funding to patient groups to deliver tailored, accurate information and support to those at risk of inherited cancer, including targeted outreach to Aboriginal and Torres Strait Islander people, CALD communities, and men.

Our survey highlighted, that when accessed, information provided by Inherited Cancers Australia supported our community to make informed decisions regarding risk reduction. Yet we know that we haven't even begun to reach the many, many Australians either currently, or yet to receive, a hereditary cancer risk confirmation.

There are also many people who are from vulnerable groups who cannot access the information we provide because of language, digital or other barriers.

We need help to communicate accurate information to every single Australian at risk. This needs to be delivered in multiple languages, and across a range of modalities. Inherited Cancers Australia stands ready to fill this gap, yet we need funding to do so.

These **three simple and actionable recommendations** call on the Australian Government to provide much needed and cost-effective support for Australians with a hereditary cancer burden that wish to live long, healthy lives and continue to contribute to their communities and the economy.

We are only getting started at Inherited Cancers Australia. We remain committed to empowering those at risk of hereditary cancer, but we recognise how much more we can achieve with national leadership, solid economic evidence, adequate funding and government support.

# Abbreviations

| Abbreviation | Description |
|---|---|
| **BRCA1** | Breast cancer gene 1 |
| **BRCA2** | Breast cancer gene 2 |
| **CALD** | Culturally and Linguistically Diverse |
| **HRD** | Homologous Recombination Deficiency |
| **HTA** | Health Technology Assessment |
| **MBS** | Medicare Benefits Schedule |
| **PBS** | Pharmaceutical Benefits Scheme |
| **PSA** | Prostate Specific Antigen |
| **QALY** | Quality adjusted life-year |

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# Appendix A – Survey respondent demographics

*Table 1. Respondents by age group, count and percentage*

| Age Group | Count | Percentage |
|---|---|---|
| 18 - 24 | 14 | 1.6% |
| 25 - 34 | 111 | 12.6% |
| 35 - 44 | 250 | 28.3% |
| 45 - 54 | 233 | 26.4% |
| 55 - 64 | 170 | 19.2% |
| 65+ | 102 | 11.5% |
| Prefer not to say / blank | 4 | 0.5% |
| Grand Total | 884 | 100.0% |

*Table 2. Respondents by gender, count and percentage*

| Gender | Count | Percentage |
|---|---|---|
| Female | 851 | 96.3% |
| Male | 27 | 3.1% |
| Prefer not to say / blank | 6 | 0.7% |
| Grand Total | 884 | 100.0% |

*Table 3. Respondents by jurisdiction, count and percentage*

| Jurisdiction | Count | Percentage | Australian Population Percentage |
|---|---|---|---|
| NSW | 251 | 28.4% | 31.3% |
| VIC | 258 | 29.2% | 25.6% |
| QLD | 136 | 15.4% | 20.5% |
| SA | 60 | 6.8% | 6.9% |
| WA | 82 | 9.3% | 10.9% |
| TAS | 28 | 3.2% | 2.1% |
| NT | 5 | 0.6% | 0.9% |
| ACT | 54 | 6.1% | 1.7% |
| Prefer not to say / blank | 10 | 1.1% | N/A |
| Grand Total | 884 | 100.0% | 100.0% |

*Table 4. Respondents by regionality, count and percentage*

| Regionality | Count | Percentage |
|---|---|---|
| Major City | 583 | 66.0% |
| Regional Centre | 177 | 20.0% |
| Rural Town | 112 | 12.7% |
| Remote or Very Remote Community | 8 | 0.9% |
| Prefer not to say / blank | 4 | 0.5% |
| Grand Total | 884 | 100.0% |

*Table 5. Respondents by categories provided, count and percentage*

| Category | Count | Percentage |
|---|---|---|
| Aboriginal and Torres Strait Islander | 16 | 1.8% |
| Ashkenazi Jewish | 40 | 4.5% |
| LGBTQIA+ | 32 | 3.6% |
| Prefer not to say | 7 | 0.8% |
| None of the above | 790 | 89.4% |
| Grand Total | 884 | 100.0% |

*Table 6. English preferred language, count and percentage*

| English preferred language | Count | Percentage |
|---|---|---|
| Yes | 872 | 98.6% |
| No, please share further details below if you are comfortable | 7 | 0.8% |
| Prefer not to say / blankblank+ | 5 | 0.6% |
| Grand Total | 884 | 100% |

*Table 7. Respondents by salary range, count and percentage*

| Salary Range | Count | Percentage |
|---|---|---|
| Less than $10,000 | 42 | 4.8% |
| $10,000 – $24,999 | 51 | 5.8% |
| $25,000 - $49,999 | 104 | 11.8% |
| $50,000 -$74,999 | 148 | 16.7% |
| $75,000 - $99,999 | 122 | 13.8% |
| $100,000 - $124,999 | 129 | 14.6% |
| $125,000 - 149,999 | 55 | 6.2% |
| $150,000 - $174,999 | 23 | 2.6% |
| Over $175,000 | 50 | 5.7% |
| Prefer not to say / blank | 160 | 18.1% |
| Grand Total | 884 | 100.0% |

# DISCLAIMER

This Report has been prepared by **Evohealth** Pty Ltd (Evohealth) on behalf of **Inherited Cancers Australia**, with funding provided by Gilead (Australia) Pty Ltd.

This project has been commissioned by Inherited Cancers Australia, with funding from Gilead Australia to develop a community survey and report of outcomes.

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