Focus Groups for priority groups within the inherited cancer risk community
~ March 2025 ~

About Inherited Cancers Australia (ICA):

ICA is a national patient-focused charity supporting the 1 in 400 Australians who have inherited cancer risk (through a known gene mutation or significant family history of cancer). Our work involves supporting, educating, and advocating for these families, aiming to ensure that no individual is disadvantaged by their genes. Originally registered as a charity in 2012 as Pink Hope, we renamed to ICA in 2024 so we could expand our reach to people with other cancer risk syndromes and become more inclusive to anyone with inherited cancer risk.

We undertook this project in 2024 aiming to investigate four priority groups of people with inherited cancer risk – groups who are often underserved and who experience greater challenges with their inherited cancer risk experience, than those in the general population. This report details the findings from these focus groups.

Executive summary:

During the four focus groups, we examined the support needs and challenges of living with inherited cancer risk, across four traditionally underserved communities; people who live regionally/rurally, people of Ashkenazi Jewish heritage, people who identify as LGBTQIA+ and men. Key themes identified are listed below:

Across all groups, participants discussed the need for **more awareness in the general population of** the impact of inherited cancer risk, and considerations for families. In particular, awareness that inherited cancer risk and passing on gene mutations doesn't only affect women or people assigned female at birth, it affects all people regardless of gender.
Across all groups, participants identified the need for **more education in the primary healthcare** setting so that GPs and nurses are better equipped to identify and manage people with inherited cancer risk.
People who lived regionally and rurally experienced **challenges with access to services**, including clinical genetic services, risk reducing surgeries and high-risk screening. This group noted several barriers to accessing health services including travelling long distances, juggling family and additional costs associated in accessing private specialists due to lack of access to public services.
People of Ashkenazi Jewish heritage described challenges around the lack of **understanding of the prevalence** of BRCA gene mutations in the Jewish community and the **stigma** associated with genetic testing and inherited predispositions to cancer.
People who identified as LGBTQIA+ spoke extensively of the **importance of inclusive language** and the challenge of **understanding gender identity** and its impact in healthcare. Being able to find inclusive information, support and healthcare professionals who are knowledgeable and understand the needs of this community is also a challenge.
During the focus group for men, the common themes related to the lack of public awareness of how **inherited cancer risk affects men** and their concerns about the **impact of inherited cancer risk** on the next generation in families (i.e. men passing on this risk to their children).

Introduction:

Inherited Cancers Australia (ICA), formerly Pink Hope, has been a stand-alone recognised charity since 2012. Over this time membership (community members) has grown and as the uptake and accessibility of genetic testing continues to increase, so does the demand for support. In March 2025, there were over 2,800 members in the online support groups and a database of over 6,000 members and supporters. In Australia, the ICCon Database reports there are 29,651 people with gene mutations who are connected to a public genetic service. In 2024, over 11,000 people had publicly funded genetic testing for inherited cancer risk gene mutations. Many more people with inherited cancer risk undertake genetic testing privately, and they are not always referred to a public genetic Service after they receive their positive gene mutation result.

In late 2022, ICA undertook a national survey of members to gather insights about the needs of the community and collect demographic information from those who are engaged with us. Through this process, we identified a need to encourage more diversity within the community and the need to provide tailored support to people within traditionally underserved groups and those who face barriers accessing support. Within our online support groups, there are regular discussions about the need to diversify and be more inclusive to the broader community.

ICA identified several priority groups within the inherited cancer community where representation in our survey was lowest and populations needing further investigation and understanding. These groups are: Aboriginal and/or Torres Strait Islander peoples, those with Ashkenazi Jewish heritage, people who identify as LGBTQIA+, those from culturally and linguistically diverse backgrounds, people who live regionally or rurally, younger women and men.

While we would have liked to investigate all seven identified priority groups, we were able to hold four focus groups within the inherited cancer community to investigate and collect more in-depth data. These groups were:

- People who live regionally or rurally;
- People of Ashkenazi Jewish heritage;
- People who identify as LGBTQI+, and
- Men.

Between February and April 2024, we collected feedback and data via formal focus groups and questions via email for those who were unable to attend a focus group session.

In addition, in May 2024, ICA undertook an updated National member survey to better understand the experiences of those individuals with gene mutations related to breast, ovarian and/or prostate cancer, and those with a significant family history of these cancers, particularly their experiences with genetic testing, the healthcare system and the support provided by ICA. Over 880 full responses were received and it was noted there was a lack of culturally diverse, LGBTQIA+, men and Aboriginal and/or Torres Strait Islander people who responded to the survey. The full report from that survey can be accessed here.

This report provides a summary of the findings from the focus groups and provides key themes and ideas for providing better support to people in underserved priority groups within the ICA inherited cancer community.

Demographics

Our focus groups included 17 people, across four groups. The number of participants in each focus group is listed below:

People who live in Rural/regional areas	3
People of Ashkenazi Jewish heritage	4
People who identify as LGBTQI+	5
Men	4 (plus one woman responding on behalf of her father)

The majority of the participants (n, 13) were women (apart from the focus group for men). Participants ages ranged from 39 – 73 years old. Participants were located across all states and territories of Australia except for the Northern Territory, primarily in metropolitan areas, apart from the regional and rural group where participants were from varied regional areas across Australia.

Most participants had either BRCA1 or BRCA2 gene mutations, with a small number of participants who did not have a confirmed familial mutation but had either a significant personal or family history of cancer. As expected, the vast majority of participants had multiple family members and generations affected by cancer and cancer risk. Of those with BRCA1/2 mutations, there was a mix of those who had previously had a cancer diagnosis, and those who had not. There was a mix of people who had undertaken risk-reducing surgery and those who had not. The length of time focus group participants had known about their BRCA1 or BRCA2 mutations also varied greatly.

Structure of Focus Groups

Each of the four focus groups was approximately 90 minutes and was a semi-structured style of discussion. Participants were asked questions based on two key themes:

- Experience in the healthcare system – including identifying needs, gaps, support and opportunities; and
- Participants' personal experience – family considerations, culture/background challenges and support needs.

Each focus group opened with an anonymous survey question asking participants to use three words to describe their experience with hereditary cancer (using the Slido survey tool). In some focus groups, participants preferred to nominate these verbally.

The questions that were prepared for the focus groups were as follows. A combination of questions was used for each of the focus groups.

The health system:

- What makes the health system complex for you to navigate? Give an example.
- Have you been able to access testing, treatments, trials and support for your situation?
- Where are the gaps in tools, support and resources for inherited cancer risk patients?
- What support do you need?
- Are there tools/education opportunities for patients or clinicians that ICA could advocate for?
- What organisations are doing it well for your community?
- How does postcode affect the availability of support?
- Where do you currently find information to support you?

Your personal experience:

- Have there been any challenges with talking to family members about inherited cancer risk?
- Are there any cultural or background barriers that impact your experience with inherited cancer risk?
- Have you faced any challenges with friends/community when talking about inherited cancer risk?
- Is there anything about the way you present yourself to the healthcare system that creates barriers (bias/unconscious bias/stereotypes) e.g. sex/gender, age, cultural identity, or preferences?
- Do you believe the healthcare system has barriers?
- Did you or do you feel supported?
- Do you trust the public healthcare system to support you?
- Any other personal experiences you want to mention?

Outline of each group and justification for inclusion in this project:

ICA explored four priority groups within the inherited cancer risk community to be explored through focus groups. We know that people within these groups experience less support and increased challenges than those in the 'general' at-risk population. These groups were selected because people in these populations report being under supported, there less is data available on these groups, their health outcomes can be poorer and there are often challenges related to societal norms, culture, religion and biases. A limitation when deciding which groups to include in this project was access to participants.

Outlined below are the populations we explored through focus groups:

People who live regionally or rurally

We know that people who live regionally or rurally experience challenges in accessing healthcare services, support, screening, risk-reducing surgeries and clinical genetic services. They face additional travel, financial and family burdens and shortages of local healthcare professionals. Within ICA online support groups, there are often discussions of the frustration around these challenges and the impacts on the lives of those who live regionally and rurally. Understanding the full extent of the challenges will help us to better advocate for and support people living in these communities.

People of Ashkenazi Jewish heritage

People with an Ashkenazi Jewish heritage have a 1 in 40 risk of having a BRCA gene mutation, a rate 10 times higher than the general population. We also know that some members of this group have cultural norms and practices that do not support information sharing in families. Anecdotally, we know people of Ashkenazi Jewish heritage want more resources and information tailored to help them with managing inherited cancer risk.

People who identify as LGBTQIA+

People in the LGBTQIA+ community may face more challenges in accessing health and support services[1]. In research undertaken by La Trobe University in 2019, it was reported less than half of LGBTQIA+ people feel accepted by healthcare providers[2]. Through discussions with community members, we know that general population campaigns, resources and programs do not always resonate with people in the LGBTQIA+ community. Over the years, ICA has not provided any tailored information or support for this group and given we know many of our community identify as LGBTQIA+, it was imperative we understand more about this group.

Men

Historically, ICA has not had extensive engagement with men, nor do we properly understand the intricacies of being a male with an increased cancer risk. Medicare data shows that cascade testing rates in men are much lower than in women (30% verses 70% women). Research has also shown that men are less likely to be included in family conversations about familial cancer risk, and less likely to be informed of test results by their female relatives[3]. Men with a BRCA1 or BRCA2 gene mutation are at increased risk of developing breast cancer and prostate cancer.

Focus Group results

Describing personal experience with inherited cancer risk

As an ice breaker and a way to assess the experiences of participants, at the beginning of each focus group, participants were asked to provide three words that described their experience of living with inherited cancer risk. While some responses were collected in an anonymous online survey, other participants preferred to verbally share.

The question asked: *'List three words to describe how you felt throughout your experience of finding out you carried hereditary cancer risk'. **

*Note: no words were recorded for the LGBTQIA+ focus group, as participants did not have gene mutations so the question was not asked. However, the experiences of other members of this group were captured in written form and included below.

Scared Worried Anxious	Horrified Mortified	Certain Empowered Troubled
Lonely Frightened Worried	Empowered	Concerned Unsure Alert
Overwhelming Stressful Grateful	Overwhelmed Motivated Empowered	Surprised Challenged Sad
Surprised Lucky Over It	Distressing Overwhelming Life Changing	Protected Proactive Considered

[1] https://www.aihw.gov.au/reports-data/population-groups/lgbtiq/overview
[2] https://www.latrobe.edu.au/news/articles/2020/release/lgbtiq-adults-national-survey-published
[3] https://journals.sagepub.com/doi/10.1177/1557988317753241

The most common words used by the participants to describe how they felt upon learning they had a hereditary genetic mutation were overwhelmed, empowered, and worried, with some participants reporting feeling both overwhelming and empowered, which may reflect the dual nature of genetic information for individuals. Grouping all individual words into; positive, neutral and negative context, 58% of words were negative, 30% were positive and 12% were neutral.

Generally, the language used by participants to describe their initial feelings reflects the uncertainty, anxiety and fear of the unknown that can arise with a familial mutation discovery. Participants described being 'concerned', 'scared', 'anxious' and 'troubled' amongst others. However, some of the language used by participants also reflects their feelings of knowledge being power, such as 'empowered', 'proactive', 'motivated' and 'grateful'.

Overall themes of focus group discussions

Experiences of people who live regionally and rurally

The regional and rural focus group responses demonstrated the challenges with accessing care and the inequity in care for people who have a genetic variant that predisposes them to cancer while living regionally or rurally in Australia.

"There's just no concept of living regionally, like what that means." - Participant 3

Theme 1: Increased wait times and access to services

Participants in the regional and rural focus group noted they face the challenge of increased wait times for regional services including clinical genetic services, due to understaffed clinics. This included accessing genetic testing, wait times for prophylactic surgeries, accessing specialist medically induced menopause support, with one participant noting they were diagnosed with breast cancer while awaiting their bilateral mastectomy to reduce their cancer risk.

"I was pushed back, pushed back, pushed back. And then when I got on the list to actually have it [risk reducing surgery], yeah I found my lump." - Participant 1

"So when we had the Covid, when everything shut down, we were still getting the [breast screening] buses coming around and they wouldn't let me get on the bus because I was too young." Participant 1, who lived 5 ½ hours from Perth.

To avoid the lengthy wait times, participants noted that they tried to seek health services elsewhere, however, were unable to as they are required to access the services dedicated to their address.

"I contacted the um uh menopause centre in [another state]... and they just said it would be negligent of us to treat you by telehealth. You need to see someone on the ground in [home state]... I think I've seen everyone that will even listen to me have this conversation." - Participant 2

Another participant also noted the challenges when there is ambiguity as to which services are responsible for care in certain areas, particularly when living far from familial cancer centres.

"I just found it interesting that they said they didn't cover this area. Well, so who does cover regionally? Like obviously I won't be the only person in this region who has to access this kind of service.... They said that [metropolitan hospital] only looked after [regional town] as a favour to [regional town]. They didn't have to take people from [regional town]. They then referred me back to a specialist [from regional town] who I've seen since to get my scans done." - Participant 3

"*You're not only isolated in that people don't kind of understand what you're going through and the obvious services aren't there. But even to find a GP who understands is challenging."* Participant 2

All participants spoke of the lack of resources, information and support focused on talking to families about inherited cancer risk. They stressed that people in the general population don't understand inherited cancer risk and conversations were hard because there is little understanding in the community.

Theme 2: Travelling long distances for healthcare

Participants noted that due to living regionally or rurally, they were required to travel long distances for healthcare, particularly for ongoing monitoring and risk-reducing surgeries. Without local options, travel was the only way to access care. There were challenges around cancelled and rescheduled appointments and having to juggle many aspects of life to fit in with appointments.

"I kinda got used to going up and down the highway." - Participant 2

Participants noted the challenges that travelling long distances from home brought. This included a lack of support network in the city they were going to have care, as they were often removed from their family and friends.

"My first surgery was in Hobart – my husband came with me, but we had to go without the kids which was pretty stressful." - Participant 2

This is particularly challenging for those who have caring responsibilities, which might result in a partner unable to travel to be a support person, or the family trying to negotiate the logistics of travelling for medical care. Participants felt there is a lack of support for the families of people living regionally and rurally and in accessing care.

"I found it kind of difficult. I don't think people understand like, um, you know, the logistics of small children and travelling away. We've got no family to support us." - Participant 3

"In an ideal world, there would have been supports that we could have accessed, but there weren't any. So, you know, so my husband and sons could have been well supported. And I didn't have to be that support person." - Participant 2

Due to a lack of support and difficulties travelling for care whilst managing family responsibilities, one participant noted they changed their care team to be closer to home, but at an additional financial cost personally.

"I've got to go to a local breast surgeon, so I've got to pay for to go to the surgeons and I've got to pay for my [breast] scan now." - Participant 3

Focus Group Themes: Experiences of People with Ashkenazi Jewish Heritage

This group highlighted some of the additional challenges that can come from having a have a tenfold increase of inherited cancer risk compared to the general population, and where culture and tradition may lead to stigma within their communities.

Theme 1: Lack of understanding about the prevalence in the Jewish Community

Focus group participants highlighted the challenges, and concerns related to a lack of understanding of the prevalence of inherited cancer conditions in the Jewish community, both from within and outside of the Jewish community. There was a general desire from all participants for people with Ashkenazi Jewish heritage to have genetic testing more readily available.

"I feel that despite the fact that it is quite prevalent, BRCA is not well enough known about within the community especially the degree of its prevalence." - Participant 4

"Had I realised the prevalence, I'd have more likely tested sooner. When I chat to Ashkenazi Jewish friends and I let them know that fact, they immediately tend to want to test." - Participant 4

Participants also described experiences with healthcare professionals not understanding their increased risk and their challenges with accessing ongoing screening.

"Apparently because of my young age and because I'm under 50, I fell between the cracks and wasn't considered a person at risk although being a BRCA2 carrier at the time." - Participant 1

"I was educating my GP about what needed to be done." - Participant 1

One participant also noted they felt they had not had the same access to care as although their heritage was Jewish, they were not of Ashkenazi descent. They suggested that more information and awareness was needed for the whole Jewish community, and not just those of Ashkenazi descent.

"It's not only Ashkenazi Jews, Jewish people in general that arise in high risk to start with." - Participant 1

"Sometimes putting those tags [Ashkenazi Jewish] around it actually makes people put the stigma on people and being included or not included in the risk groups... cast the net wider might be easier than telling a specific group they need to get tested." - Participant 1

Participants also noted that overseas there are specific support organisations, and resources available to people from the Jewish community who have an increased risk of cancer. This included clinics for people with a cancer risk variant, patient advocacy groups and support groups. They noted they felt the same level of tailored support was not available in Australia for their community. One participant reflected on the healthcare system being amazing once you are finally in the 'system' but it's often hard getting to that point.

Theme 2: Stigma in the Jewish Community

Participants from this focus group also noted the impact of stigma surrounding genetic testing and having a cancer predisposition variant within the Jewish community. While the data from this report cannot be conclusive, it could be suggested that the stigma experienced in the Jewish community has contributed to a lack of understanding of the prevalence of cancer risk variants.

Participants noted that stigma in the religious community has led to a lack of communication. Which is particularly challenging when navigating the high prevalence of genetic variants and arranged marriages.

"In the religious circles, some of them don't want to talk. Some of them will not open up and it's very very hidden....there is a stigma." - Participant 3

"I know that amongst the religious communities who do have arranged marriages, the shadchan, the person who does those matches, a lot of time they're doing genetic screening amongst our communities." - Participant 3

Participants also noted concerns about the associated stigma for the younger generation, and how this impacts their ability to partner. Similar concerns were echoed in the focus group for men.

"That's a big issue especially for younger women.....It's the stigma attached to whether they'll find partners." - Participant 3

Several participants spoke about how stigma and lack of communication in their family had impacted their family's journey to genetic testing and navigating cancer, upon discovering they had a BRCA genetic variant. In some of these cases, they only found out about other members of their family having a gene mutation, after someone else was diagnosed with cancer – a cancer which could have potentially been prevented if information about the gene mutation had been shared earlier. Elderly parents were also reported as not being forthcoming with information.

"It was therefore a surprise and disappointment to learn that a cousin of my Mum's sister had indeed died of ovarian cancer and she had also had breast cancer. They had learned that they were BRCA positive years prior and never reached out to tell us." - Participant 4

When asked what could be driving the stigma within the Jewish community, one participant noted:

"There is a cultural phenomenon not uncommon in post Holocaust families of avoiding talk of negative things including ill health. We know of people who are reluctant to be open about health issues and don't even use the word cancer around their families." - Participant 4

Focus Group Themes: Experiences of people who identify as LGBTQIA+

This focus group emphasised several key challenges for people identifying as member of the LGBTQIA+ community, where language and gender stereotypical assumptions can greatly impact experiences.

Theme 1: Gender identity and health services related to cancer and cancer risk

All participants spoke of their struggles with stereotyping and healthcare professionals making assumptions about their identities. Some participants noted their healthcare professionals didn't understand or know how to have discussions about gender identity. Participants suggested healthcare professionals need to be more considerate about discussions, in particular when bringing up options about risk-reducing surgery.

"I did get the eye-roll when I sort of talked about my identity. So I thought, oh great, here we go. This is going to be interesting. But I was also prepared for it because I've advocated for others around their identity in different, different health settings in the past. The fact that I identified as anything other than woman, she didn't know what to do with that." – Participant 2

All participants experienced healthcare professionals making assumptions about their situation. From how participants presented themselves at appointments, or their preferences for family planning, to the person they brought with them to appointments. Assumptions were made with little or no consideration for their identity.

"Feeling unheard by medical professionals: Almost feeling forced into getting implants and made to feel like I had to because I am female - almost disregarding that identify as more androgynous. Getting drilled into me that I should keep my ovaries as long as possible because what if I want kids - again not being seen/heard when I explained I don't want children." – Participant 5

"The biggest thing about when you're working with people in our community is, don't make assumptions. Don't' make assumptions about someone's gender just by looking at them. Don't make assumptions the person sitting in the room is just a friend because they are the same gender." – Participant 2

Many participants spoke of experiencing gender norms and stereotyping about femininity and the impact of surgeries on body image and gender identity. Some participants noted they were not offered a flat closure after their mastectomy, it was assumed they would want to reconstruct their breasts and participants reported having to advocate for flat closure.

"I started sort of talking about Aesthetic Flat closure…..and he had no idea what I was talking about. I said I don't want that [reconstruction], I want to be flat and he sort of laughed it off saying 'in this day and age there's no reason we can't do a neat job'"- Participant 3

"My body my choice. Doesn't matter how I identify, I wasn't being heard." - Participant 2

Theme 2: Importance of language and being supported

There was ample discussion about the importance of language and feeling supported by healthcare professionals and health organisations. Participants spoke of their frustration and feeling let down by the lack of support services for people with inherited cancer risk in the LGBTQIA+ community. There is also a lack of, and difficulty in finding healthcare providers and organisations who are knowledgeable and sensitive to the specific needs of LGBTQIA+ patients.

"As far as I'm aware there are no supporting organisations or someone else to talk to who is a trans woman with BRCA1 in my area or support groups for LGBTQIA+ health." – Participant 4

Participants reported wanting more inclusive language to be used. This includes removing and replacing words like 'husband' with 'partner' or 'support person'. Improving tick boxes for gender which currently have 'male or female'. Include a tick box for how someone identifies. Some discussed the intricacies of risk reducing or breast cancer surgery and the language around breast reconstruction or top surgery. It was noted this discussion can be complex and language matters.

"I had to go to them with the information, they don't give you the information unless you ask the question….You really have to do your own research." – Participant 4

"If the surgeon was a little bit more educated about diversity of gender, then they may want to have, maybe offered that conversation about what is the difference between top surgery and flat closure." – Participant 2

"Finding allies within both the healthcare system and personal networks so LGBTQAI+ people feel seen/heard and understood." – Participant 5

When asked about health system complexities for LBGTQIA+ people, one participant reported feeling *"Out of my comfort zone - already part of a marginalised community and didn't feel like I had any "allies" when at appointments, in hospital etc."*- Participant 5

Some participants reported not having the language to talk about how they identified because they didn't fit any of the tick boxes and didn't feel included in the breast cancer community. Many reported they'd found the best information and support from online support groups.

Focus Group Themes: Experiences of Men

The focus group on the experiences of men with an inherited cancer risk highlighted the challenges that are faced due to reduced lack of awareness and understanding of how inherited cancer affects men, and the expectations and role of males in family dynamics.

Theme 1: Lack of understanding BRCA1/2 can affect men

Participants in this group noted there is a general lack of awareness and understanding of how gene mutations affect men, and the implications for their health, in general comparison to the understanding of what it means for women's health. This experience was true for both understanding from healthcare professionals and family and friends.

Some participants felt dismissed by their healthcare professionals, particularly when discussing concerns about their increased risk of prostate cancer and accessing testing. Similarly, some found that healthcare professionals were sometimes dismissive or blasé about the breast cancer risk for those with a gene mutation, with participants noting they had challenges in accessing breast screening and some feeling it was seen as "a woman's disease".

"*I'm not sure they* [healthcare professionals] *pay a lot of attention to what you're saying* [about BRCA]. *It's almost sometimes a little bit dismissive."* - Participant 2

"I had to keep on him [my GP] to say look I'm due for another PSA." - Participant 1

Participants also noted the impact of a lack of awareness and understanding in the general population about the impact of BRCA1 and BRCA2 variants for men.

"He found a lump and didn't get it investigated because he didn't know males could get breast cancer." - Participant 5, speaking about their father.

There were also concerns there is not sufficient understanding that men who have a gene variant can pass it on to male and female children.

"It's gotta be called out in that discussion, that the men have a 50% chance of passing it on and it's not just a female thing." - Participant 2

Theme 2: Concerns about family and the next generation

A strong theme echoed by all participants in the focus group on men's experiences with hereditary cancer was having huge concern for their family, particularly their children and the risk of inheriting the gene mutation.

Aside from the concern of what the health implications would be if their children were carrying a gene variant, the most prominent concern in this group was how and when to have the conversation with their children about potential inherited cancer risk and what this could mean for their future. There was particular concern from men who may pass their gene mutation onto their daughters.

"[Talking to kids] That petrifies me.... that genuinely scares me. We haven't tested our kids, my daughters." - Participant 3

"What can I do to make sure my family's safe?" - Participant 4

The timing of when to have the conversation with their kids was a common concern for the participants. Half of the participants hadn't spoken to their children about the potential of inherited cancer risk.

"Having that conversation [with kids} and so early in their lives when they've got so much to look ahead and so many to plan is a very interesting one that we haven't, we've sort of really lightly touched on it and I don't think we want to alarm them." - Participant 3

"I don't know what the right age is [to tell kids about BRCA and genetic testing], other than I think we'll probably do them both at the same time." - Participant 1

More specifically, some participants were concerned about the impact of timing on their child's future relationships, and the insurance implications related to testing.

"If my 18, or my 19 year old, suddenly found out she had this genetic mutation, what's it going to do for her insurance?" - Participant 3

While not the case for all participants in this group, some participants noted they see the stoicism of fathers, discomfort when talking about health prevention, and talking to their daughters about their health, as barriers to having conversations about gene variants. Participants also noted the impact on other family members, and concerns they may might have for their children. They spoke of guilt and the stress of watching children go through it and not knowing what they might be facing in the future.

"It has been stressful for my wife, who's a bit more of a worrier around what would happen if X does have it [a BRCA mutation]." - Participant 4

"There would be parents who would say it's better for them not to know [about BRCA]."- Participant 4

Focus group limitations

There were several limitations identified with the focus group sessions. Each focus group was quite small, due to the challenge of reaching the target demographics and identifying those who were willing to share. It was noted that people who identify as members of these demographic groups have often expressed feeling less supported and included in the ICA community than others. Due to scheduling challenges, we were unable to include everyone who self-nominated to participate, however, they were invited to provide input via email.

The focus groups were designed to create a comfortable and supportive environment for the participants, however, not all participants may have felt comfortable or been given sufficient time to express their honest thoughts and opinions during the session. This may have changed throughout the session positively or negatively, depending on their comfort levels with fellow participants. The focus groups also captured the feelings and experiences of the participants at one point in time, which may have been influenced by their current context, or by a recall bias depending on the timeframe of the experiences they were recounting, which varied for each participant.

Furthermore, this report identifies the experiences of people who have an existing relationship with ICA in some capacity. To further the impact of these focus groups, we would like to reach people who aren't engaged with ICA so we can better understand the barriers members of these communities face. It would also be valuable to expand the number of focus groups in the future to understand the experiences of other less represented members of the ICA community, such as Aboriginal and Torres Strait Islander people, people from culturally and linguistically diverse backgrounds and young people.

Conclusion

Holding focus groups to learn about the intricacies of being part of underserved priority groups within the ICA community has provided us with valuable data and insights. Learning directly from personal experiences and insights has identified opportunities for advocacy, campaigns, support and education. While each group had its unique challenges and experiences, there were three strong themes across all groups; there needs to be more general population awareness of the implications of inherited cancer risk, there is a need for tailored resources dedicated to specific aspects of each priority population, and there needs to be more education for healthcare professionals working in primary care to support people with inherited cancer risk.

Acknowledgements

We would like to sincerely thank all focus group participants for giving up their time to share their experiences so we can learn and improve outcomes for people in these communities. Hearing personal lived experiences strengthens our knowledge and enables us to better advocate for and provide support for people in these groups. We are grateful to all those who participated.

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