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Genetic testing in the context of family, culture and community

"Genetic testing is not just a medical issue.
It is deeply shaped by culture, family, beliefs, and community."
– Sarah, BRCA2, Indian Muslim background

Genetic testing for inherited cancer risk looks for gene changes that may increase a person's chance of developing certain cancers. A gene change can be passed down in families. This means a test result may matter for other family members too.

Genetic testing can also raise questions about health, family, privacy, children, relationships, culture and the future. For some people from culturally and linguistically diverse communities, these questions may also be shaped by beliefs about illness, family, faith, fate, privacy or community expectations.

This resource draws on Sarah and Lina's experiences. Sarah has BRCA2-related inherited cancer risk and comes from an Indian Muslim background. Lina reflects on genetic testing in the context of Chinese beliefs about fate, family privacy and protecting her children's future.

Their experiences are not the same as everyone else's. They do not speak for everyone in their communities. But their stories may help you recognise questions you did not know you could ask, and what culturally safe support could look like.

Topics covered in this resource

You can read this resource from beginning to end, or jump to the section that feels most useful right now:

What culturally safe support can look like

Culturally safe support can help you understand medical information in a way that makes sense for your life, family, culture and community.

When you are exploring or going through genetic testing, this may include translated information or interpreter support. It may also include support to talk about family expectations, privacy, faith, relationships, children, or what the result could mean for other family members.

Sarah explained this clearly: *"I needed information that sat somewhere in the middle. Not too clinical. It had to be medically accurate, but also written in a way that actually speaks to people's lived realities."*

Culturally safe support does not look the same for everyone. This resource may help you recognise what support could mean for you, and what you can ask for at different points.

Before genetic testing: if family health history is hard to talk about

Before genetic testing happens, cancer may already be hard to talk about in a family or community. It may be seen as private, linked to faith or beliefs, or something people do not talk about openly.

This can make it harder to ask about family health history. You may not know who has had cancer, what type of cancer they had, how old they were, or whether anyone has died from cancer.

"In my family, illness is considered private and almost like a stigmatising thing. But at the same time, it's family-owned rather than individual."

Sarah explained that "family-owned" meant one person's illness could affect the whole family. It could shape family conversations, worries and decisions, not just the person who was unwell.

Sarah also described how care, concern and judgement could sit close together: *"We care deeply. We want you to be okay. But there's also a sort of, what did you do?"*

For Lina, illness could sit within beliefs about fate, life path and what is meant to happen. Cancer may feel like something outside a person's control. Inherited cancer risk felt different because it could be passed through family.

"Having an inherited cancer risk feels more permanent. It's 'forever'. Almost like you're meant to be malfunctioned, rather than you just have an incidental 'bad luck' [of getting cancer]."

When cancer is already a sensitive topic, family history and inherited risk can be harder to discuss.

What may help

You do not need a complete family history before asking for support. Family history can be incomplete for many reasons, including adoption, estrangement, migration, loss of family members, or because cancer has not been talked about openly.

If cancer is difficult to talk about in your family, you can tell your genetic counsellor.

You could say:

- *"Cancer is not something my family talks about openly."*
- *"I do not know all the details of my family history."*
- *"Some relatives may not want to talk about this."*
- *"Can you help me understand what information matters most?"*

Your genetic counsellor can help you work with the information you do have and think about possible next steps.

Support that may help:

- **Understanding your family history of cancer**
- **Understanding Inherited Cancers guide**
- ICA's **Inherited Cancer Support Service**

Understanding a genetic testing result

Translated information or interpreter support may help. But understanding a result is not only about language. Many people also need time to understand what the result means for their life, family and future.

Lina was offered interpreter support during specialist appointments. But even with translation, the result was still hard to understand. *"Even while speaking Chinese, we still didn't have a clue what that meant."*

At first, Lina understood that the result meant a higher chance of cancer. But she did not yet understand what it meant for her life, choices or family.

Sarah's experience was different, but it shows a similar point. She speaks fluent English, works in public health, and knew how to search for information. Even so, she received her BRCA2 result without genetic counselling. It took years to understand what it meant.

"I thought initially that genetic testing would be quite straightforward. You do a test, you get an answer, and then you can act on it medically. I didn't really fully understand the extent of it for about five years. It's not just about the results. It's about what that result means for you, for your family and for your identity."

A result is not just one piece of information. It may take time to understand what it means for your body, your family, your future and the decisions ahead.

What may help

A genetic counsellor can help explain the result and answer questions. If you would prefer to speak in your own language, you can ask for interpreter support.

You can also ask for written information to take home. Written or translated information, including **ICA's translated resources**, may help you revisit the information later or share it with family.

You do not need to understand everything at once. It is okay if understanding the result takes more than one conversation. You can ask whether you can book another genetic counselling appointment, or who to contact if more questions come up later.

Questions you may want to ask:

- "Can you explain this in plain language?"
- "What does this result mean for me?"
- "What does this mean for my family?"
- "Is there information I can take home?"
- "Who can I contact if I have more questions later?"

ICA's **Inherited Cancer Support Service** is a free service that can help you and your family understand what the result means and think through possible next steps.

Sharing genetic testing results with family

A genetic testing result may be personal, but it can also have meaning for family members. Some people may feel a strong need to share this information because it could affect their family's health or future choices. But it can help to prepare before you begin, especially if family conversations may feel sensitive.

Family dynamics, culture, privacy and beliefs can shape how people receive this information. When Sarah's cousin found out about the inherited cancer risk, she shared the information with Sarah. Sarah then had genetic testing too. As the information moved through the wider family, some relatives were upset that genetic testing had brought this risk into the open.

"It's emotionally difficult for me as well because we are the 'problem makers'. But that's not the intention here. The intention is for people to be able to make their own choices with all the information they need."

"There's a real tension between wanting to honour your family and cultural expectations and also wanting to be honest and informed about your health."

Over time, Sarah found a way to understand her role in sharing genetic information with family: *"I don't see it as creating a problem. I see it as bringing something into the open that already exists. Sharing this information is an act of care for my family."*

For Lina, sharing genetic information also raised concerns about her family's privacy: *"I'd rather not share my* BRCA *status widely. I don't want people to look at my kids differently."*

Preparing before sharing can help you think about who to tell, when to tell them, what to say, and what support you need first.

What may help

You do not have to work out what to say on your own. ICA's **Sharing genetic testing results with family: a practical guide** can help you prepare a simple message, think about who to tell first, and decide what support you may need.

There is no expectation to tell everyone immediately. You may only need to start the conversation or share one clear piece of information. Your genetic counsellor or **ICA's Inherited Cancer Support Service** may be able to help with next steps or follow-up questions.

Thinking about family, children and the future

For some people, genetic testing can raise questions that go well beyond health care. It may bring up questions about relationships, marriage, children, privacy, family responsibilities and future plans.

Sarah was trying to understand what the result meant for herself, while also thinking about family expectations and how this information might affect others in her family.

"Family dynamics are central in my community, and decisions aren't usually made in isolation. Everything about you has sort of a ripple effect on your family, especially around young girls getting married."

It also raised questions about what she may want to share with a future partner one day. *"There's also the question of disclosure. When to share, how to share, how much to share, what the response might be. Do we even share?"*

Questions about family, relationships and the future can take time to work through. Some may need attention now. Others may become clearer later.

Sarah's advice is to take things one step at a time: *"You don't have to have all of those answers immediately."*

Questions you may want support to explore

It may help to talk these questions through with your genetic counsellor, ICA's **Inherited Cancer Support Service**, or someone you trust.

If it feels right for you, this could be a family member, community leader, faith leader, or a **peer support mentor**.

You might want to explore questions such as:

- How might this information affect decisions about children or family planning?
- What, if anything, do I want to share with a partner or future partner?
- How do I balance family expectations with what feels right for me?
- What concerns do I have about privacy or disclosure?
- Which decisions need attention now?
- Which questions may take more time?

You do not need to work through all these questions at once or on your own.

Why reading experiences like Sarah and Lina's can help

Sarah and Lina's experiences do not speak for everyone. Culture, family and community can shape genetic testing in many different ways. But reading about experiences like theirs may help you find words for parts of your own experience that have been hard to explain.

For Lina, medical facts were not enough on their own. She wanted to understand what this could feel like in real life. *"All the things I heard from doctor side, it's more about percentage [of my chance of getting cancer], but what's the exact feeling?"*

For Sarah, hearing someone from a similar cultural background speak openly about inherited cancer risk helped her feel less alone.

"Representation matters. Hearing stories from your own community was so good for me. To see someone going through this just like me was really nice. It was like, oh, you know, this is not my fault."

Reading experiences like Sarah and Lina's may also help you recognise questions you did not know you could ask. You may find yourself thinking about family, culture, privacy, children, marriage or community expectations alongside questions about genetics and cancer risk.

These questions can be just as important as the medical information itself.

Ways to find support and connection

You may find it helpful to speak with someone, join a group, or read more lived experience stories.
Support that may help:

- ICA's **lived experience stories** may help you see how other people have approached similar experiences and what may help.
- ICA's **Online Support Groups** provide a safe space to connect with others navigating inherited cancer risk.
- ICA's **Peer Support Program** can connect you with a trained peer mentor.
- ICA's **Inherited Cancer Support Service** can help you make sense of your situation and work out what support may help next.