



Early Outcomes from a National Support Service for People Living with Inherited Cancer

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Setting the scene: Inherited Cancers



- Most cancers are sporadic BUT 5-10% of cancers are inherited
- For thousands of Australians every year, a cancer diagnosis may signal risk for an entire family.
- The implications of living with inherited cancer risk are unique, nuanced and often poorly understood by the wider community and healthcare system.
- **Inherited Cancers Australia (ICA)** is the **only national organisation in Australia dedicated exclusively to inherited cancer risk**, providing free support, education, peer connection and advocacy for families navigating hereditary cancer.



Inherited Cancers Australia: the traditional support model

Peer mentorship

Social media: ~55K followers, private
FB support pages ~3K members).

Education/support resources

Information & Support Days

Fundraising and networking events



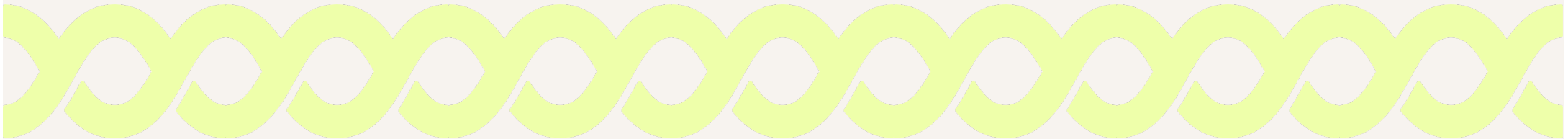
A new model of community-based hereditary cancer support

The challenges:

- With expanded access to genetic testing, and increased community awareness and education:
 - Increased enquiries outside the team's expertise
 - Increased reports of poor experiences with GPs when seeking referrals for testing
 - Previous ad hoc clinical support arrangements became less sufficient

Enhanced model:

- March 2025: 6-month Support Service pilot funded by Gilead
- Continuation of the traditional support model PLUS an embedded genetic counsellor.





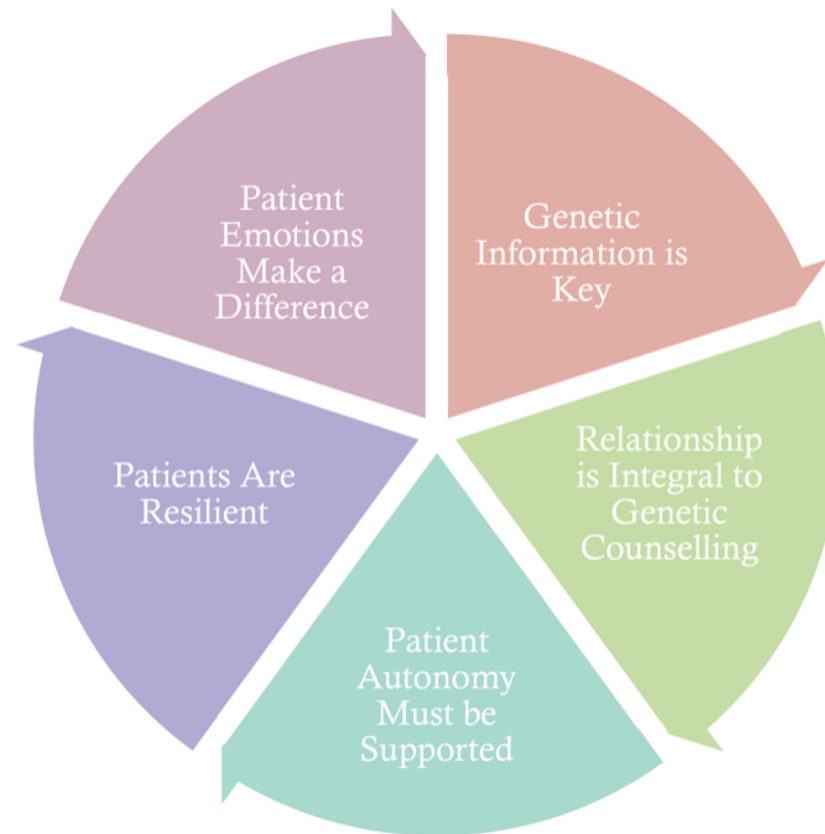
What is a genetic counsellor?!

“Genetic counselling is a communication process, which aims to help individuals, couples and families understand and adapt to the medical, psychological, familial and reproductive implications of the genetic contribution to specific health conditions.”

Australasian Society of Genetic Counsellors

THE RECIPROCAL ENGAGEMENT MODEL (REM) OF GENETIC COUNSELLING

VEACH, P. M., BARTELS,
D. M., & LEROY, B. S.
(2007). COMING FULL
CIRCLE: A RECIPROCAL-
ENGAGEMENT MODEL
OF GENETIC
COUNSELING PRACTICE.
J GENET COUNS, 16(6),
713-728.



In the current era of genomic medicine, whilst we are called to adapt and extend our skillset, the same core tenets and competencies hold true.

THE LANDSCAPE OF GENETIC COUNSELLING



XX inherited

Who we are Inherited Cancers ▾ Be supported Events Lived experiences Get involved Shop

You can connect with our specialist.

Inherited Cancer Support Service

Navigating hereditary cancer can feel overwhelming, but you don't have to do it alone. Our **free** Inherited Cancer Support Service provides expert guidance to help you understand your risks, access care, and make informed decisions about your health.

The **ICA team** includes a **certified genetic counsellor** who is available to speak with you **free of charge** via phone, email or video call.

Our expert care:

- Connect you with **local healthcare services** and specialists
- Provide **personalised information** on genetic testing, screening, and risk management
- Help you explore **treatment options** and pathways for inherited cancer
- Break down **complex medical information** into clear, actionable steps

Connecting with a **genetic counsellor** can be beneficial if you have questions or concerns about inherited cancer risk. Genetic counsellors are trained to assess your family history and genetic information to determine your risk of developing certain cancers and the implications for your family members. They provide support and **personalised guidance** on preventive measures, early detection strategies, and potential genetic testing options.

By understanding your genetic risk, you can make informed decisions about your health and take **proactive steps** to manage your cancer risk effectively.

[I'd like support](#)



Genetic counselling through ICA

Free, confidential genetic counselling for community members: any gene, any stage of life, any topic*

Nation-wide

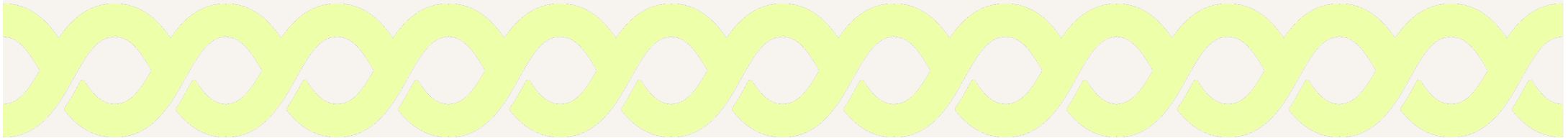
Phone/email/Zoom

An introduction to, or a continuation of, the conversation in the clinic, acknowledging the limited capacity of the clinical system

*It's NOT: medical advice, facilitation of testing, formal referrals

Evaluation

- Describe the implementation and early outcomes of embedding a GC into the ICA Support Service
- Initial pilot period: March - August 2025
- Extended: September 2025 – June 2026
- 0.2 FTE in 2025 > 0.3 FTE in 2026

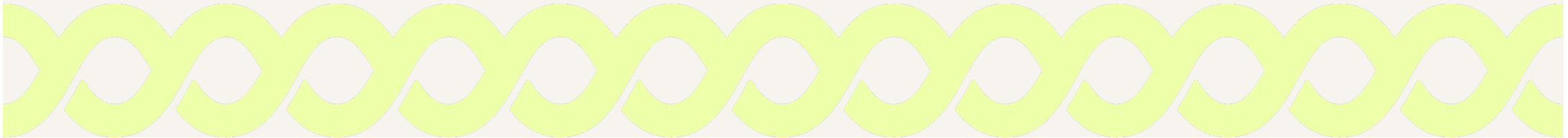


How outcomes were assessed

- **Retrospectively recorded:**

- Service utilisation
- Consultation/event type
- Hereditary cancer syndromes represented
- Themes of support needed

(+ some preliminary evaluation survey data...)



Early implementation outcomes

Contacted ICA via: Support Service Form, website query, phone

GC interactions = 103

- 62 Zoom/phone consultation (~60 minutes each)*

- 33 email interaction (~2-4 exchanges each)

- (5 recent; appointment pending)

- 3 genetic counsellors

At least 6 returning 2-3 times 3-18 months after initial consultation

~96% AFAB

Representing: NSW, QLD, SA, Vic, WA (incl. metro, regional, remote)





Breast & ovarian: *BRCA1/2, PALB2, ATM, CHEK2*

Familial adenomatous polyposis (FAP): *APC*

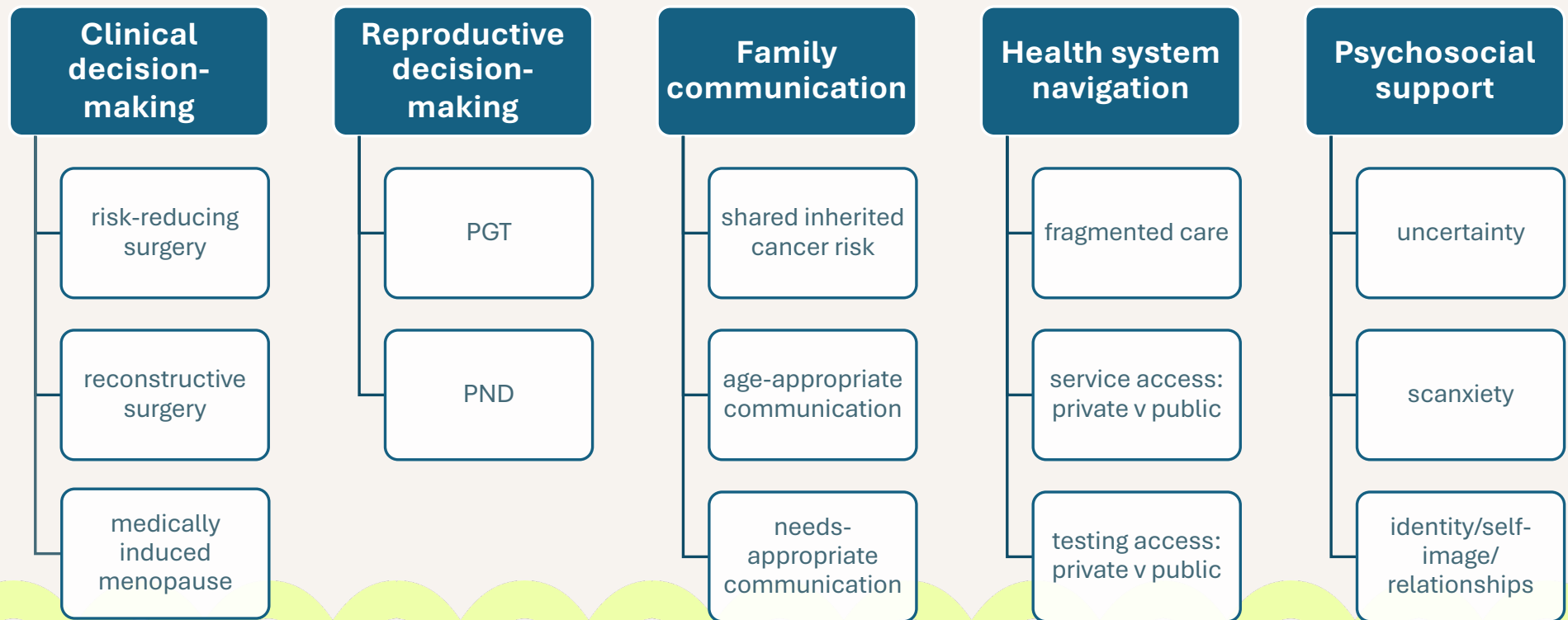
Lynch syndrome: *MLH1, MSH5*

Li Fraumeni: *TP53*

Cowden: *PTEN*

Significant, non-specific family history

The complexity of support needs



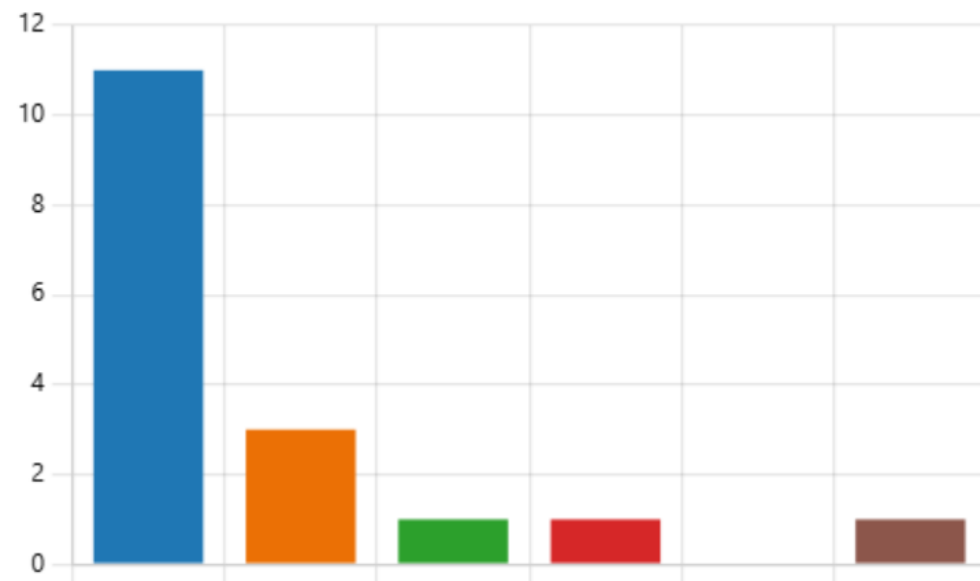
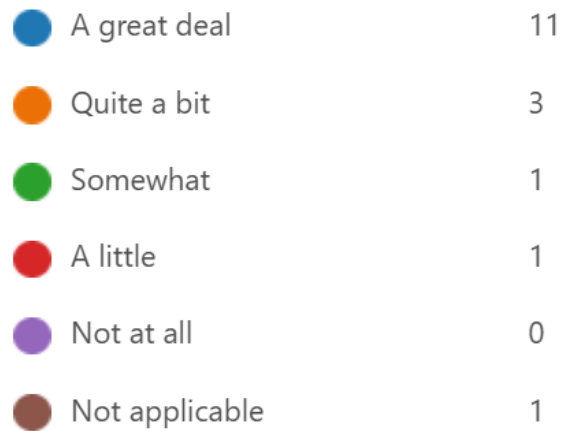
Some quick and dirty data from a recent evaluation survey (n=17)...

3. After using the service, how confident did you feel about what to do next regarding your inherited cancer concerns?

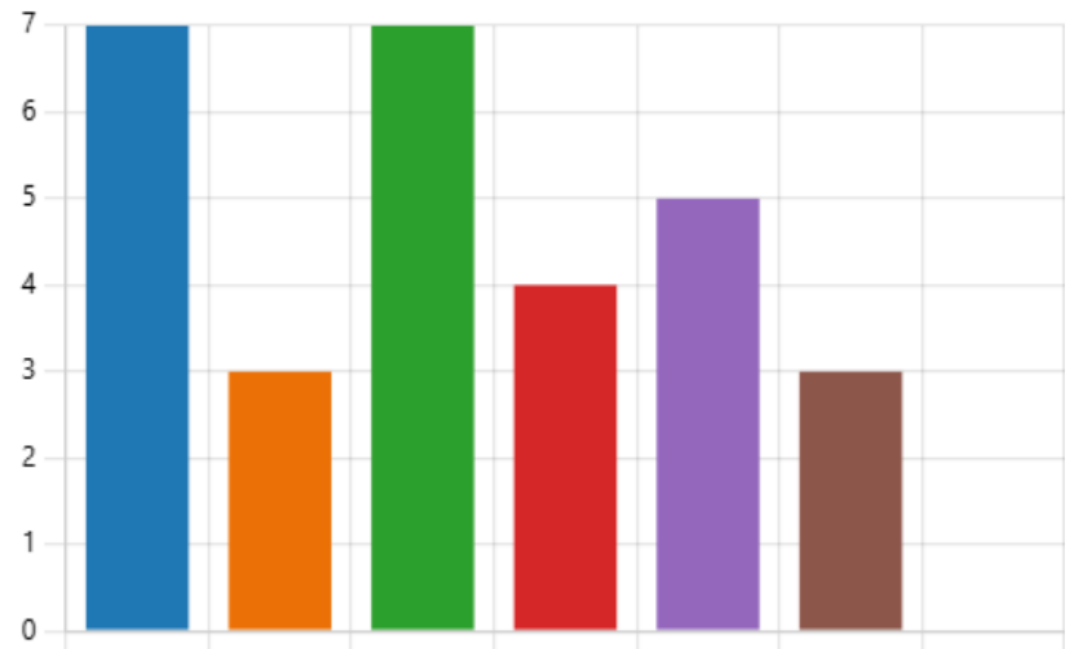
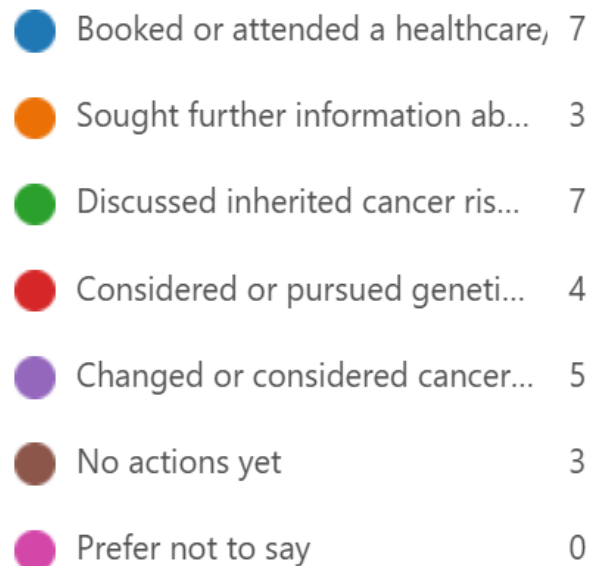
● Much more confident	14
● Somewhat more confident	2
● No change	1
● Less confident	0
● I was already confident	0



4. To what extent did speaking with the genetic counsellor help reduce uncertainty, worry, or confusion about inherited cancer risk?



5. Since speaking with the genetic counsellor, have you done or plan to do any of the following?
(Select all that apply)



"Without ICA you wouldn't get the human side of things - everything else is really clinical"

"... you have exactly the expertise I am looking for." (member is a Dr)



"I have also recommended you to a good friend of mine who has a very strong history of cancer in her family, but who has never been tested or had any relatives who have been tested. I hope she reaches out."

"Thanks again for all your support, it's been so wonderful for me as a parent to be able to talk with you about how to support (children's and husband's name)"

"... I felt as though I could take a deep breath again"

"Speaking to you I felt comfortable, safe, heard & treated like a whole person who had the right to be open & honest about my concerns & admit while I want to manage my cancer risk, I also want to manage other risks that come with surgery & that's ok. I haven't always felt my concerns were understood or treated with respect & empathy so really appreciate the way you acknowledged those concerns & also provided me with evidenced-based advice & information to inform my decision making. "

"Thank you so much Gabby, (I) greatly appreciated your time and response, will definitely catch up with you again...Sometimes all is needed is someone with an understanding to help with the plan ahead."



“... I felt as though I could take a deep breath again”



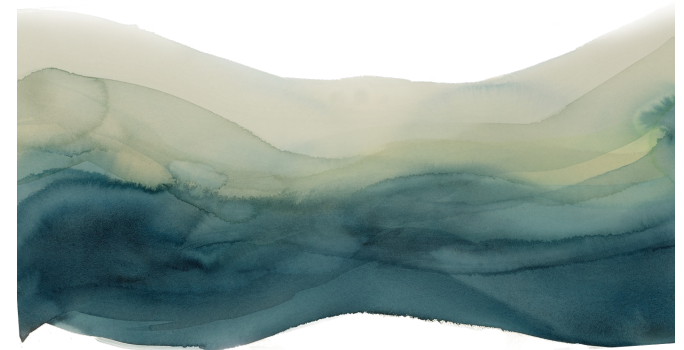
Next steps

- Refine the model of care
- Evaluate outcomes more systematically (e.g. post-session evaluation survey)
- Explore opportunities for scale-up
- Advocate for translation across other charity support organisations

Implications for supportive cancer care



- Embedding genetic counselling expertise within a national hereditary cancer support organisation is feasible, valued, and addresses an important unmet need across informational, psychosocial, and care-navigation domains
- Complements existing clinical genetics services
- Opportunity to strengthen genetics capability within the nursing workforce





THANK YOU
Questions?

Contact me:
support@inheritedcancers.or.au