

Identifying and supporting patients with inherited cancer risk

This webinar will start shortly.



Identifying and supporting patients with inherited cancer risk

Zoom webinar – Tuesday 25th February 2025

Acknowledgement of traditional owners

We acknowledge the Tasmanian Aboriginal people as the traditional owners and ongoing custodians of the land on which we are meeting today. We pay our respects to Elders past and present.

We would also like to acknowledge Aboriginal people who are joining us today.

Learning outcomes

- Describe the guidelines and criteria for referral for a genetic assessment
- Outline the circumstances when it is appropriate to refer for a genetic assessment
- Outline the information required on a referral for genetic assessment
- Discuss the implications of genetic testing for a gene mutation related to breast, ovarian and/or prostate cancer
- Describe the role patient support organisations play for patients who carry gene mutations that predispose them to cancer
- Outline where to access the most appropriate evidence-based information about cancer genetics.

Some housekeeping

- Tonight's webinar is being recorded
- Please use the Zoom Q&A feature to ask questions
- At the end of the webinar your browser will automatically open an evaluation survey. We appreciate you taking the time to complete this to help us improve our events programme

Presenters



Rachel Pope-Couston
Senior Genetic Counsellor
Tasmanian Clinical Genetics Service

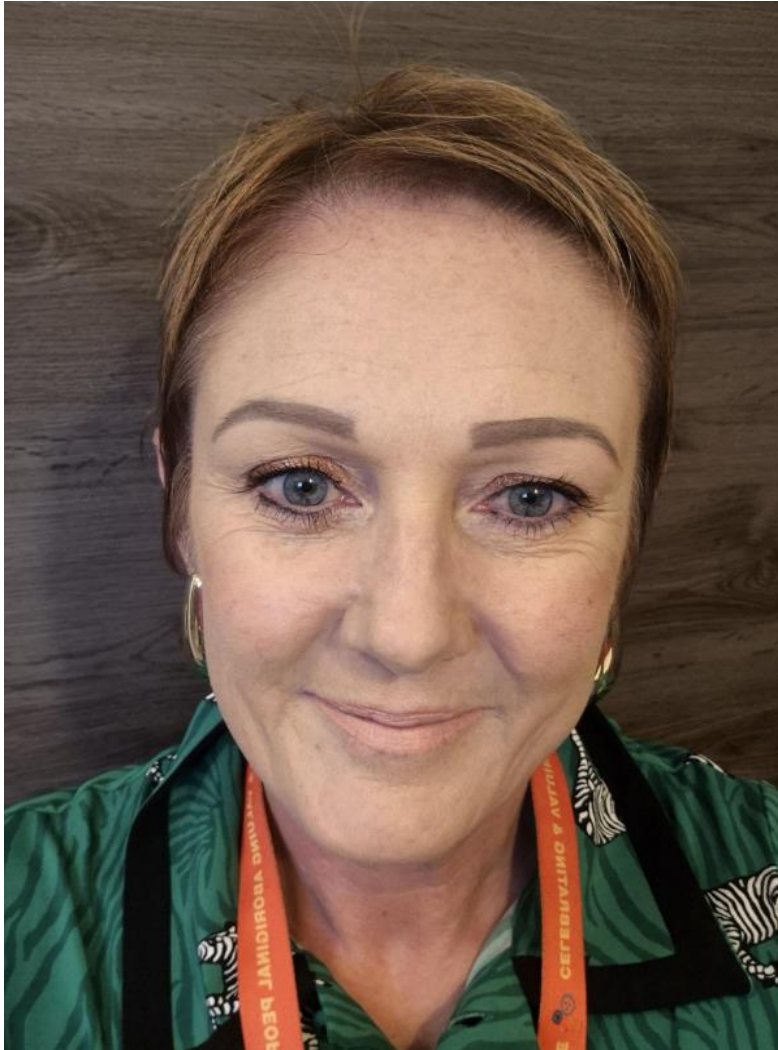
Presenters



Robyn Smith

Programs and Advocacy Manager
Inherited Cancers Australia

Presenters



Lindi Bell
BRCA2 “previvor”



TASMANIAN
HEALTH
SERVICE



Supporting and identifying people with inherited cancer risk in primary care

Presented by

Rachel Pope-Couston
Manager/Senior Genetic Counsellor
Tasmanian Clinical Genetics Service

Robyn Smith
Programs & Advocacy Manager
Inherited Cancers Australia

Lindi-Jane Bell
Lived experience with inherited cancer risk

Session Goals



- Identify and support patients with hereditary cancer risk, related to breast, ovarian and/or prostate cancer.
- Ensure patients are educated so they can make informed decisions about managing their cancer risk
- Enable early detection and prevention to improve outcomes for 'high-risk for cancer' people

Learning objectives



- Describe how to find the guidelines and criteria for referral for a genetic assessment
- Outline the circumstances when it is appropriate to refer for a genetic assessment
- Outline the information required on a referral for genetic assessment
- Discuss the implications of genetic testing for a pathogenic variant (gene mutation, gene change, likely pathogenic variant) related to breast, ovarian and/or prostate cancer
- Describe the role patient support organisations play for patients who carry gene mutations that predispose them to cancer.
- Outline where to access the most appropriate evidence-based information about cancer genetics

Causes of cancer



Environmental

Lifestyle and environmental exposures make a significant contribution to cancer risk in the general population.

Polygenic risk

A series of genetic variations which together can increase or decrease the risk of developing a certain type of cancer.

Single-gene pathogenic variants (inherited cancer predisposition syndromes)

A genetic change in a critical cancer pathway gene which increases the chance for developing associated cancers e.g. BRCA1, BRCA2, MLH1

Role of the GP and other primary carers in cancer genetics



Risk categorisation

- Risk Stratification of patients either as near-population or above population risk is crucial to appropriate management including referral to a genetics service for further assessment and advice
- It can be difficult to know what is a population risk personal/family history vs increased risk (moderate risk) vs high risk
- Breast cancer occurs in 1 in 8 women in Australia so most family trees will contain diagnoses of breast cancer
- So what are you looking out for?

Picking up on genetic *red flags* in your patient's personal or family history



These can include:

- Young (or unexpected) age of diagnoses
- Unexpected pattern e.g. male breast cancer
- Bilateral diagnoses (breast cancer)
- Diagnoses in multiple blood relatives
- Linked malignancies e.g.
 - breast, ovarian and prostate
 - ovarian and bowel
 - breast and stomach



Start the conversation



- Listen for the red flags
- Where possible, collect full names, age of onset, type of cancer
- Note which side of the family the cancers are on and whether the two sides of the family are related by blood
- Encourage discussion about extended family
- Some people will want to talk and some will not
- Hereditary cancer risk spans throughout the family
- Talk about both men and women (be aware of myths surrounding inheritance and who may be affected)
- Discuss a referral for a “genetic assessment”

When and where to refer



- If you think the personal and/or family history may be above population risk based on
 - Red flags
 - EviQ referral guidelines
 - iPrevent assessment
 - Known pathogenic variant in a related person
- Referral to local clinical genetics service
 - The HGSA website lists public and private services and providers
 - The Tasmanian Clinical Genetics Service in TAS
- If the personal and/or family history is not suggestive of increased risk, but the person wants to explore risk assessment and/or genetic testing
 - Consider referral to a private genetics option
 - Utilise iPrevent for unaffected females

The screenshot displays the HGSA website. At the top, the logo for the Human Genetics Society of Australasia is visible, with the tagline "... making sense of your genes". Below the logo is a navigation bar with links for "About", "Education and Training", and "Consumer Resources". The main heading is "Clinical Genetics Services", followed by a brief description: "The HGSA provides a list of clinical genetics services in each jurisdiction, right." Below this is a purple header for the "eviQ" platform, with the NSW logo on the left and navigation icons on the right. The page title is "General practitioner referral guidelines for cancer genetics assessment". Below the title, it shows "ID: 1147 v.8" and "Endorsed". A blue box contains a disclaimer: "In this document the terms 'male' and 'female' refer to sex assigned at birth. For more information about providing individualised care refer to Resources to assist in the care of transgender individuals referred to a clinical genetics service or familial cancer centre". A purple box labeled "Guideline" contains the text: "Referral to a clinical genetics service or familial cancer centre¹² for assessment should be considered for all people meeting the categories below:".



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Victoria Australia

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iPrevent

iPrevent™ is a breast cancer risk assessment and risk management decision support tool designed to facilitate prevention and screening discussions between women and their doctors

[Home](#) > [Patients and carers](#) > [Health services](#) > [Cancer prevention](#) > [iPrevent](#)



Accepted
clinical
resource



RACGP



Tasmanian Clinical Genetics Service



Statewide public service through THS and TAS DoH

- See all ages, stages and conditions
- Based in Hobart with outreach clinics to Launceston and North West
- Offer in person, telehealth and phone appointments

Service includes:

- Genetic counsellors: AHPs with post-grad clinical MGC, focus on decision-making support including diagnostic and predictive cancer genetic testing
- Clinical geneticists: Medically trained, previous speciality, additional training in genetics. Focus on diagnostic assessments for general conditions.
- Administration, Research Co-ordinator, Research Officer

Tasmanian Clinical Genetics Service



- Some States have separate Familial Cancer Services and general clinical genetics services
- Sometimes other services also separated e.g. antenatal genetics services
- Tasmania has one public genetics service that sees everything with some specialised staff members and MDT clinics and meetings e.g. paediatric cancer, neurogenetics, paediatric hearing loss, prenatal genetic counselling
- Clinical Genetics Services are not genetic testing services or laboratories
- Perform clinical assessment and offer relevant genetic testing based on clinical utility and other case by case considerations
- Some clinical services have associated laboratories like PeterMac and MCRI/VCGS but the clinical service is always a distinct entity

Referring to the TCGS



- Prefer eReferral, will accept email, fax and paper
- eReferral allows direct communication with referrer
- More detailed referral = more likely the patient is accurately triaged
- Detail the family history of cancer (full names/ DOB/type/age of onset)
- List any psychological concerns

Things to consider:

- Does the patient have a personal history of cancer?
 - If not, are affected relatives still living? Could they be referred for assessment instead? (very helpful information)
- Has genetic testing been undertaken in the family?
- Does the patient have a relative letter/documentation from a family member?

Wait times vary depending on location and triage category

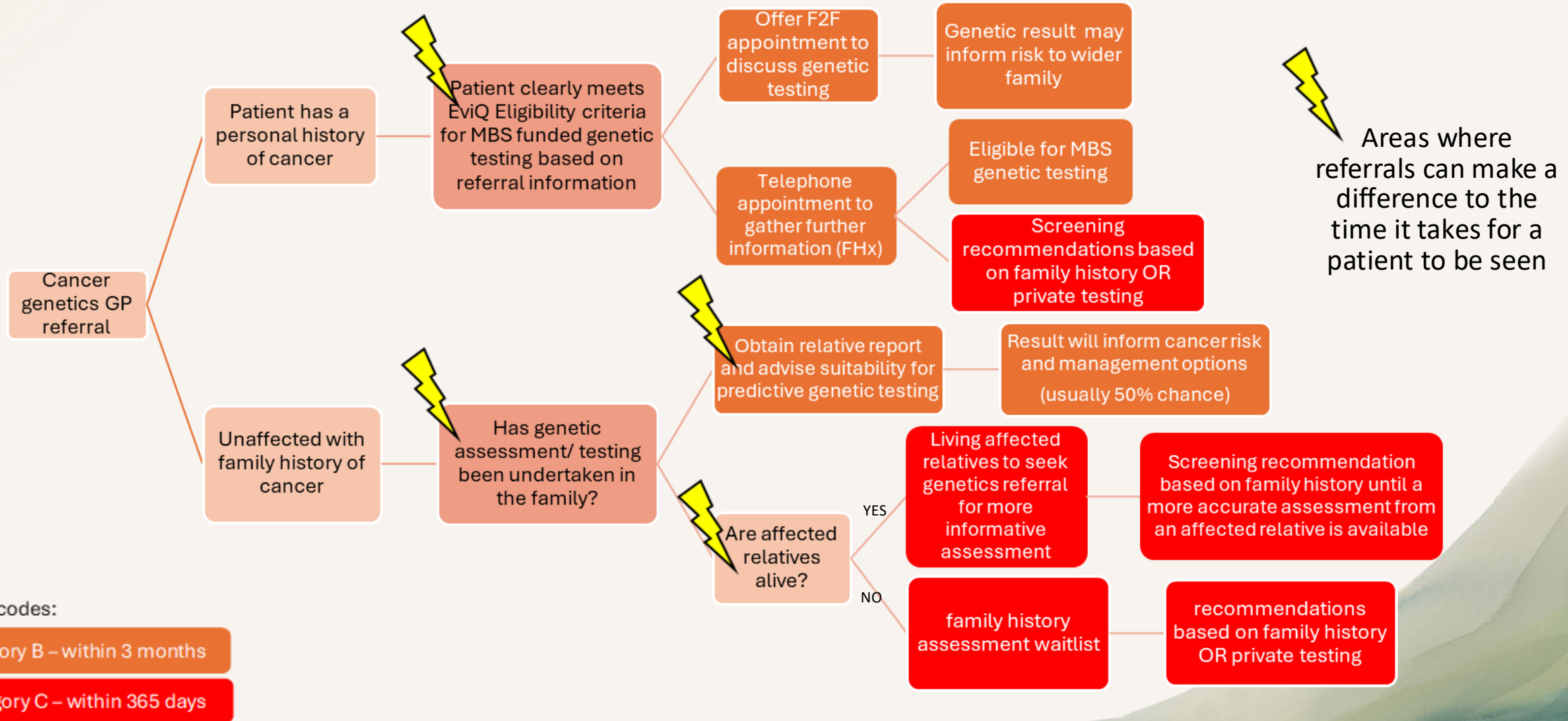
Why do details matter?



Identifying affected/gene positive or negative relatives is important for:


- Triage codes - how quickly we will see patients
- **No relative report = no predictive testing** (theoretically). Relative details help us to locate reports more quickly
- Help to avoid unnecessary testing, helping to reduce cancer risk-related anxiety
- Help to communicate effectively with other genetics services
- Accuracy is key in genetics to facilitate accurate risk/screening advice


Why do details matter?



Why do details matter?



 Tasmanian Health Service
TASMANIAN CLINICAL GENETICS SERVICE
ROYAL HOBART HOSPITAL
GPO Box 1061, HOBART TAS 7001,
Phone: 03 6166 8296 Fax: 03 6173 0328



Genetic File No. T0000

23 March 2024

Dear Relative

A member of your family has been found to carry a genetic change (also known as a pathogenic variant or a mutation) in a gene called *BRCA2*. The *BRC2* gene is one of several genes involved in the prevention of breast cancer. Pathogenic variants in *BRC2* cause an increased risk of developing breast and ovarian cancer in women and breast and prostate cancer in men. This pre-disposition to cancer can be passed down from parent to child.

Genetic testing is available to members of your family who would like to find out if they carry this gene change or not. For those who are found to carry the *BRCA2* gene change, there are strategies that can be put in place to reduce the risk of cancer occurring and to facilitate the early detection of cancer.

Of course, there are many issues to consider when contemplating a genetic test, and we would encourage you to contact your nearest genetics service to discuss these issues before deciding whether or not to be tested. Genetic clinics can provide cancer risk assessment, genetic testing, counselling and medical advice regarding cancer surveillance. These services are provided free of charge, as is the genetic test.

If you live in Tasmania, please contact our service directly on (03) 6166 8296 to arrange an appointment. If you live outside of Tasmania, you should make an appointment with your GP to arrange a referral to your nearest familial cancer genetics service and provide them with the information in this letter including the Genetic File No. at the top left side of this page.

Relative letters or ‘To whom it may concern’ (TWIMC) letters are given to patients if a genetic cause has been identified in them. This helps to:

- Anonymously inform relatives of inherited cancer
- Educate relatives about what has been found
- Advise them on next steps
- Facilitate referral of at-risk family members
- contains a unique Genetic file number which helps identify families in genetic records of service
- Ask patients about relative letters. If they do not have one their relative can request one

Types of genetic testing

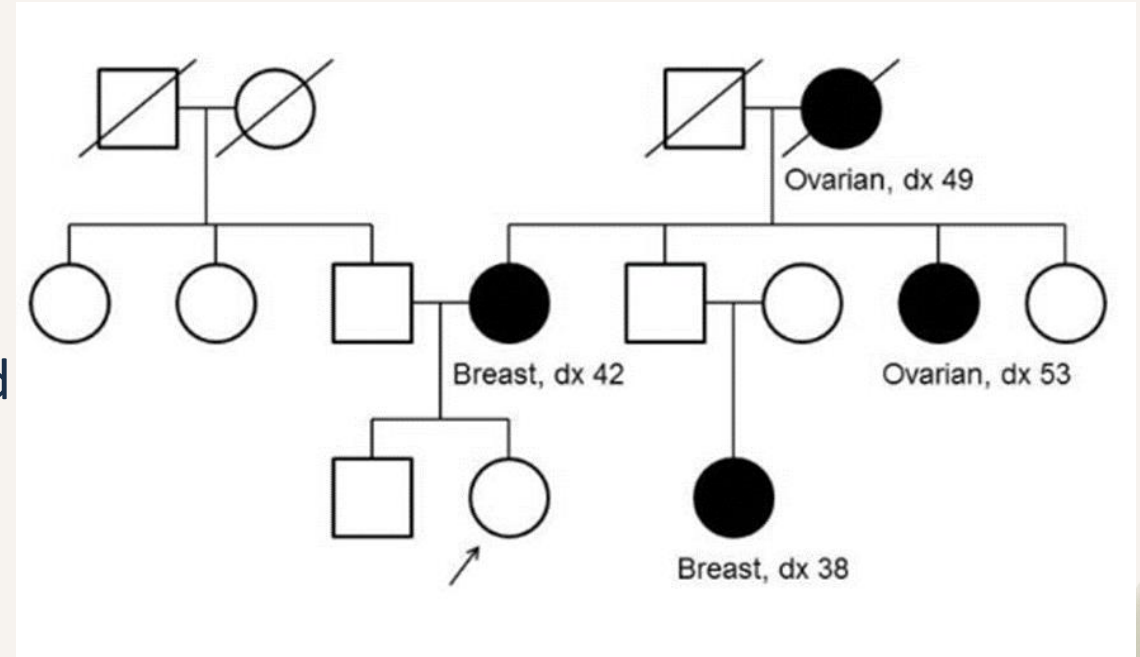


- **Diagnostic genetic testing**
 - Identifying the causative genetic variant in a person affected by cancer.
 - A variant search is often performed on a group of selected genes (known as a panel) related to the types of cancer present in the person and family.
- **Predictive genetic testing**
 - If a pathogenic variant is identified, testing may be arranged in other family members to work out if they have inherited the same variant and the associated increased risk for cancer
- **Somatic (tumour) testing**
 - Used to find variants that exist in cancer cells which may alter treatment and management.
 - Performed on tissue or sometimes fluid from people with cancer.

Diagnostic testing approach



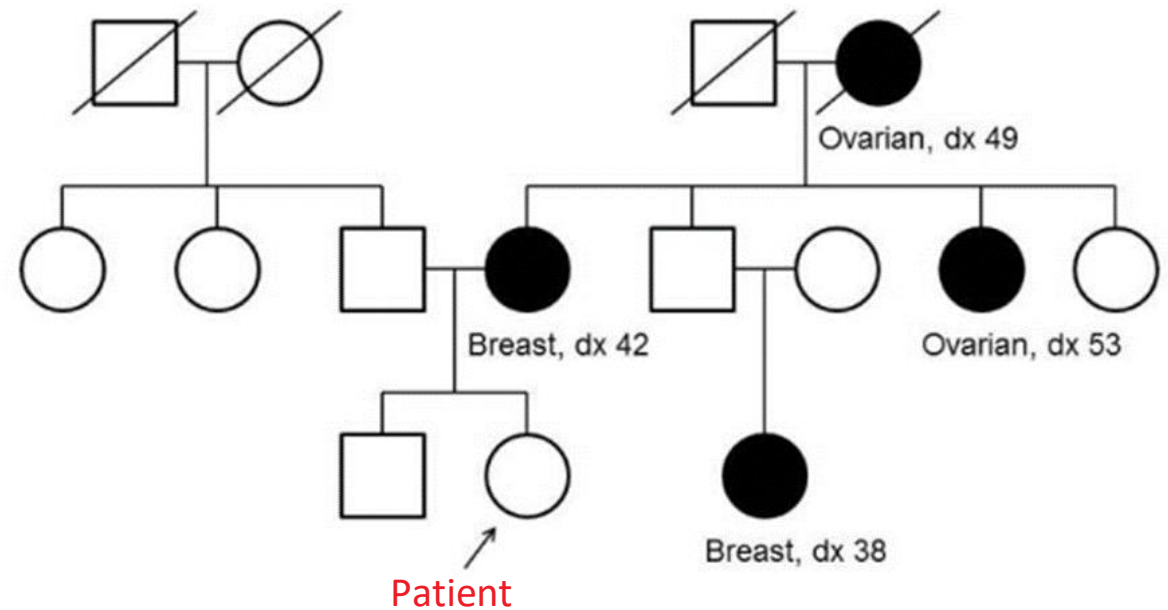
- Diagnostic genetic testing is most informative for the family when it is undertaken in an affected relative
- Why?
- Unlikely that a public genetics service would offer diagnostic genetic testing to an unaffected individual if there are living affected relatives available and willing to consent to testing



Case study



1. Who should be referred to Genetics first (ideally) in this family?
2. What would be the limitations/considerations of undertaking a diagnostic test in the patient referred?
3. What are the possible outcomes of a test if it performed?

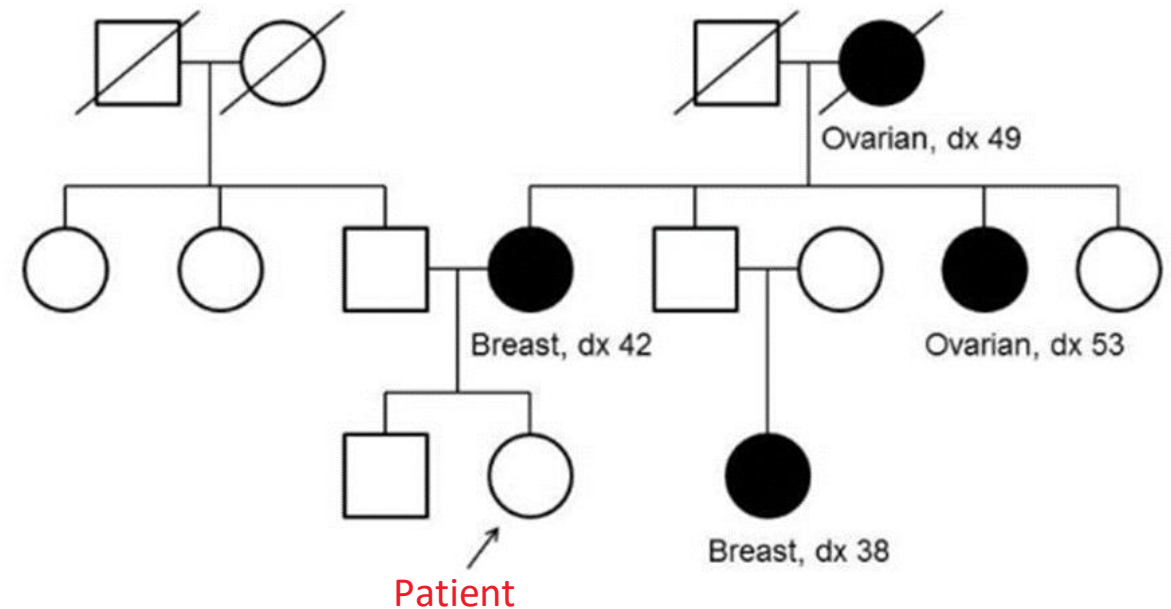


Case study



1. Who should be referred to Genetics first (ideally) in this family?
2. What would be the limitations/considerations of undertaking a diagnostic test in the patient referred?
3. What are the possible outcomes of a test if it performed?

- A result *may not inform* the risk for other family members
- Finding a genetic cause may *reveal the genetic status of untested relatives* - psychosocial/consent/insurance implications
- *Uncertain findings (VUS)* are even *harder to interpret* in unaffected individuals



Genetic counselling and genetic testing



- Genetic testing should ideally only be performed after genetic counselling
- Genetic counselling is an activity and a profession
- Genetic counselling can be performed by relevant specialist with knowledge of implications and ability to discuss these with the patient e.g. Mainstreaming for germline and somatic testing in people affected by cancer
- Genetic Counsellors are highly trained genetic healthcare professionals with professional regulation and certification pathway
- Genetic Counsellors specialise in helping people adapt to personal and family genetic risk or conditions in order to make personalised decisions

Genetic counselling/psych support



- Important aspect of genetic testing
- Collect data about family history
- Explains process
- Calculates potential risk
- Explores psychosocial issues
- Counsel around options for screening/management
- Good for patients to be encouraged to see a psych if they carry hereditary cancer risk.
- Can explain uncertain and uninformative results such as a VUS (Variant of Uncertain Significance)
- [Find Genetic Services in Australia](#)

Implications of genetic testing



- Impact on individual and family
- Access to personalised treatment such as PARPi for cancer patients
- Different surgical options ie mastectomy
- Predictive/Cascade testing of family members
- Risk reduction/management recommendations:
 - High-risk breast screening program (mammogram/ultrasound/MRI)
 - BRCA1 - mastectomy and tubes/ovaries removed from 35
 - BRCA2 - mastectomy and tubes/ovaries removed from 40, prostate screening at 40
 - Bowel screening for those with lynch syndrome
 - PALB2 - consider removing ovaries at 50 and/or mastectomy
- Life insurance implications - >\$500k
- Early, surgically induced menopause can be an implication of risk management surgery

Inherited cancer risk



- Up to 18% of ovarian cancers have an inherited link
- 5 - 10% of breast cancers have an inherited link
- 5 - 10 % of prostate cancers have an inherited link
- 5 - 10% of pancreatic cancers have an inherited link
- Up to 30% of all bowel cancers have an inherited link
- 1 - 2% of melanomas have an inherited link

There is a **large burden** in high risk for cancer families (financial and emotional).

These families experience **poorer health outcomes** (younger diagnosis, more aggressive cancers, throughout multiple generations).

Increased demand



- More gene mutation carriers are being identified through research and increased access to treatments

11% of Traceback patients have gene mutations. 6,000 more to test



Family members of children with germline mutations are testing

Journal of Clinical Oncology
An American Society of Clinical Oncology Journal

OPEN ACCESS | ORIGINAL REPORTS | © | March 09, 2022

TRACEBACK: Testing of Historical Tubo-Ovarian Cancer Patients for Hereditary Risk Genes as a Cancer Prevention Strategy in Family Members

Authors: Rachel Delahanty, MD, Linh Nguyen, PhD, Stuart Craig, BSc(Hons), Belinda Creighton, GDir, Dinuka Ariyaratne, BSc(Hons), Dale W. Garsed, PhD, Elizabeth Christie, PhD, ... SHOW ALL - on behalf of The Australian Ovarian Cancer Study, Ovarian Cancer Prognosis and Lifestyle Study and the TRACEBACK Study | AUTHORS INFO & AFFILIATIONS

Publication: Journal of Clinical Oncology • Volume 40, Number 18 • <https://doi.org/10.1200/JCO.21.02108>

Identified 89 BRCA 21 PABL2 and ATM in 2023

DNA Screen – Secure DNA testing for your future health

DNA testing can save lives by helping to take preventative action against disease risk. DNA Screen, led by Monash University, is offering secure, free DNA testing to identify risk of cancer and heart disease that can be prevented or treated early.

Register

Broader testing for ovarian cancer patients

About Ovarian Cancer Find Support

MSAC recommend funding of two HRD tests



1 in 12 Omico participants have a germline mutation



Ministers Department of Health and Aged Care

Home Media centre Mark Butler Anika Wells Ged Kearney Emma McBride Kate Thwaites

Home > The Hon Mark Butler MP > Minister Butler's media

New and expanded PBS Listings for breast and prostate cancer

Australians with prostate and breast cancer now have affordable access to affordable new and expanded medicines under the Pharmaceutical Benefits Scheme (PBS).

The Hon Mark Butler MP Minister for Health and Aged Care

More PBS listings for BRCA breast cancer patients

Media event date: 2 January 2025

Mark Butler MP Minister for Health and Aged Care

1 Jul, 2024

NEW AND EXPANDED PBS LISTINGS FOR BREAST CANCER, LEUKAEMIA AND LUPUS TREATMENTS

Australians with early breast cancer, leukaemia, and types of lupus, and insomnia, will now have access to new and expanded treatment options under the Pharmaceutical Benefits Scheme (PBS).

Olaparib (Lynparza®) has been expanded for use for patients with human epidermal growth factor receptor 2 negative (HER2-negative) high-risk early breast cancer with specific gene mutations.

In Australia, breast cancer is the most common type of cancer among women, with more than two thirds of all patients diagnosed with HER2-negative.

MBS guidelines for genetic testing



Can be arranged by appropriate specialist:

- For cancer patient to access PARPi (73295):
 - Advanced (FIGO III-IV) high-grade serous or high-grade epithelial, fallopian tubes or primary peritoneal cancer
 - breast cancer (recently expanded criteria)
- Somatic testing of cancer sample in people with prostate cancer

Should only be arranged following formal genetic counselling appointment

- For a relative, predictive/cascade (73297):
 - Person who has a biological relative who has a pathogenic or likely pathogenic gene variant (eg BRCA1, BRCA2, STK11, PTEN, CDH1, PALB2 or TP53)

Genetic testing for BRCA under MBS



Since 2017, over 41,850 people have undertaken publicly funded genetic testing related to cancer risk or treatment (10,224 in 2024)

Diagnostic testing

- 73296 - Germline testing for breast/ovarian/prostate patients with a greater than 10% chance of mutation or where result can inform treatment options
- 73295 - Germline testing for ovarian cancer patients (whose tumour did not permit testing) and for HER2-, early high-risk BC (including TNBC), mBC, for access to PARPi (diagnostic testing)

Predictive testing

- 73297 - Germline predictive/cascade testing for relatives
- For every 1 diagnostic genetic result, 3.3 members of a [family will be tested](#)

Somatic testing

- 73301/2/3 - Tumour testing for BRCA for OC and prostate cancer patients for access to PARPi

Private Genetic Testing



- Many people do not meet the guidelines for publicly funded genetic testing. Eg adopted, relative(s) not living
- Some people may want to access earlier appointment
- Can be assessed +/- testing privately
- Appropriate private service can vary depending on whether person has had cancer, family history and risk assessment e.g.
 - proactive cancer risk panel testing in unaffected individual with close to population risk
 - private appointment with qualified genetic counsellor/clinical geneticist if affected or increased risk
 - HGSA website

Important advice

- Ensure the private lab/service provides suitable pre- and post- genetic test genetic counselling
- Ensure testing is undertaken in a NATA accredited laboratory



We are Australia's leading charity supporting those with inherited cancer risk

Our vision is that every Australian is informed and supported to manage their risk of hereditary cancer.



History



- Founded in 2009, registered National charity in 2012
- Rebranded and rename in August 2024, formerly Pink Hope
- 3 pillars: Support, educate and advocate for individuals with hereditary cancer risk and those diagnosed.
- 5 Staff in VIC, NSW and the ACT, plus many local volunteers
- Mission: Empower all Australians to understand and act upon hereditary cancer risk, through evidence-based education and support.



Our community



- Majority women
- 70% have an identified gene mutation (mostly BRCA, PALB2, CHEK2)
- 30% strong family history of cancer
- 36% have had a cancer diagnosis (majority breast and ovarian)
- Our community are younger than other cancer charities:
 - 43% under 45yrs,
 - 69% under 55 yrs
- Database of 6,000 people (includes family and supporters)
- Over 2,800 engaged in our online support groups
- Instagram followers - 22k, facebook followers - 32K
- At least 1 question per day in the support group, 18% growth
- Community can access support via PM, DM, linkedin, phone, email or a form on our website

Our community



- 73% of respondents had 1 or more cancer diagnosis in immediate family
- 56% of respondents had 2 or more 2nd deg family with a cancer diagnosis
- 37% of people waited over 3 months to see a genetic counsellor
- 20% of people undertook genetic testing privately
- Regional centre ~ <50% had a positive experience accessing healthcare, compared with >80% in major city
- 26% of respondents spent over \$15,000 managing their risk/cancer
- Only 27% of respondents undertook RR surgery wholly in the public system
- 3 from 4 people accessed ICA to seek info about risk reduction

Cancer and risk runs in the family



2 of my sisters were diagnosed with breast cancer a short time after I was identified as carrying the BRCA 1 .

One of my sisters was diagnosed with breast cancer so I decided on the surgery but 5 years later the same sister was diagnosed with breast cancer again. A paternal 1st cousin has had breast cancer twice as well.

My aunt, grandma and mother all died of bilateral breast cancer in their 40s.

In reality it ran on my Dads side and his mother had died at 34yrs. It was passed on only to him and my uncle and not my aunt.

I have had breast cancer and both my father and my brother have/had prostate cancer.

My sister died from ovarian cancer so I didn't want to take any risks.

- 73% (n = 645) had 1 or more 1st degree family members with a **cancer diagnosis**
- 56% (n = 495) had 2 or more 2nd degree family members with a **cancer diagnosis**

My younger cousin died of Ovarian Cancer at a young age. My great grandmother died of ovarian cancer. My aunt died of ovarian cancer.

The deaths of my sister (ovarian cancer), mother (ovarian cancer) and grandmother (breast cancer).

Both my sister and I have had breast cancer before 40.

I am the only sibling of 4 and my mother, who are not diagnosed with breast cancer. I lost my 1 sister 3 years ago to this disease. My brother was diagnosed with breast cancer last year as was my middle sister a few years ago. My mother was diagnosed over 30 years ago.

I have a family history of prostate cancer (grandfather died with it, father received treatment for it but recovered and died with lung cancer)

Most talked about topics

Menopause

“Hi can anyone tell me what the recommendations on HRT is for perimenopause in BRCA 2”

Keep or take the uterus?

“I was given the choice of having my uterus out too”

When to have surgery

“I honestly don’t know where/how to start the process.”

Wait times for surgery and genetic testing

“Is anyone else experiencing ridiculous waiting times for appointments to get results back?”

PGT/IVF

“I don’t know how I would cope knowing my future kids may have to go through what I’m going through.”

Surgery and scan anxiety

“I am completely out of my depth and haven’t had much notice of the surgery date”.



Costs

“I was so overwhelmed with the out of pocket cost that was quoted to me.”

Surgical complications

“The left my nipple is facing more towards the outside of my body and it’s a different shape to my right.”

ICCon database

- 29,651 individuals with gene mutations across Australia who are linked to Genetic Services.
- 10,244 people had publicly funded genetic testing related to BRCA, STK11, PTEN, CHD1, PALB2, TP53 and lynch syndrome in 2024.
- There are many more who access testing privately.



A thirty-year retrospect of the detection of cancer predisposition in Australia: an overview of carrier data submitted to the Inherited Cancer Connect (ICCon) Database

EJ Cops¹, RL Austin², A Campbell³, J Duffy⁴, M Field⁵, M Fine⁶, A Goodwin^{7,8}, MT Harris^{9,10}, EL Ip^{11,12}, L Lynagh¹³, C Michael¹, MW Millward¹, MJ Monnik⁴, CB Nichols¹⁴, NS Pachter^{14,15}, NK Poplawski¹⁶, A Ragunathan¹⁷, L Rocciano¹, A Spiegelman¹⁸, RD Susman¹, L Thrupp¹, KM Tucker^{19,20}, MJ Wallis^{21,22}, L Warwick²³, RA Williams^{19,20}, KHC Wu^{24,25,26}, The ICCon Partnership, and PA James^{1,26}

¹Parkville Familial Cancer Centre, Peter MacCallum Cancer Centre & Royal Melbourne Hospital, ²Genetic Health Queensland, Royal Brisbane and Women's Hospital, ³Austin Health Clinical Genetics Service, Austin Health, ⁴Hereditary Cancer Clinic, Westmead Hospital, ⁵Hereditary Cancer Service, Royal North Shore Hospital, ⁶King's Cancer Link, Royal Adelaide Hospital, ⁷Cancer Genetics Department, Royal Prince Alfred Hospital, ⁸Faculty of Medicine and Health, University of Sydney, ⁹Monash Health Familial Cancer Centre, Monash Health, ¹⁰Faculty of Medicine, Nursing and Health Sciences, Monash University, ¹¹Cancer Genetics, Liverpool Hospital, ¹²School of Medicine, Western Sydney University, ¹³Clinical Genetics and the Sydney Cancer Centre, St Vincent's Hospital, Sydney, ¹⁴Faculty of Medicine, Nursing and Health Sciences, Monash University, ¹⁵Cancer Genetics, Liverpool Hospital, ¹⁶School of Medicine, Western Sydney University, ¹⁷Faculty of Health and Medical Sciences, University of Western Australia, ¹⁸Acelaide Medical School, Faculty of Health and Medical Sciences, University of Adelaide, ¹⁹Familial Cancer Services, The Crown Prince of Wales Cancer Centre, Westmead Hospital, ²⁰Wander Family Cancer Service, Hunter Cancer Genetics, ²¹Hereditary Cancer Centre, Prince of Wales Hospital, ²²Prince of Wales Clinical School, The University of New South Wales, ²³Hereditary Cancer Service, Royal North Shore Hospital, ²⁴School of Medicine and Menzies Institute for Medical Research, University of Tasmania, ²⁵ACT Genetic Service, Canberra Hospital, ²⁶St Vincent's Clinical School, The University of New South Wales.

Data submitted to the ICCon Database

Contributing Cancer Genetics Services:

- VIC: Parkville FCC, Peter MacCallum Cancer Centre & Royal Melbourne Hospital, Austin Health, Monash Health
- NSW/ACT: Liverpool Hospital, Prince of Wales Hospital, Royal North Shore Hospital, Royal Prince Alfred Hospital, St George Hospital, St Vincent's Hospital Sydney, Westmead Hospital, Hunter Cancer Genetics, Otagung Hospital, ACT Genetic Service
- WA: Genetic Health Western Australia
- QLD: Genetic Health Queensland
- SA: Adair Genetic Unit, Royal Adelaide Hospital
- TAS: Tasmanian Clinical Genetics Service

29,651 individuals submitted to the ICCon Database

Date of last data submission: VIC: June 2022-June 2023, depending on site; NSW/ACT: June 2023, except Hunter Genetics: August 2018; QLD: October 2022; WA: June 2023; SA: June 2022; TAS: March 2017. PV = pathogenic or likely pathogenic variant; carrier numbers = total number of carriers. An additional 827 carriers submitted by NSW/ACT are excluded from these analyses as the minimal dataset is still to be confirmed.

Most frequently observed cancer predisposition genes with clinically relevant variants in each state

Detection of cancer predisposition in the Australian population over the past 30 years

Mutation Detection: 21%

Predictive Testing: 79%

Gene-cancer correlations & cancer status at the time of genetic testing

Cancer status at the time of predictive testing:
Unaffected: 10,244 | Affected: 2,081

What we do



- Provide evidence-based information, tools and resources
- Promote open discussion about family cancer history - across generations
- Work collaboratively with healthcare professionals and other health organisations
- Advocate for high-risk families
- Promote preventive health practices and campaigns
- Ensure all individuals at high-risk for cancer are supported and empowered to make informed decisions about managing their cancer risk
- Contribute to research, genomics working groups and support the HTA process

For patients



IG Live: Expert Q&A

Expert Q&A: BRCA-P Explained
Everything women with BRCA1 gene mutations need to know about the BRCA-P Clinical Trial

Guest: Prof Geoffery Lindeman
BRCA-P Study Chair, medical oncologist
Cancer Centre & Royal Melbourne Hospital

Tue 1 Oct 8pm

[Set a reminder](#)



Support for Women/Assigned Females At Birth - Inherited Cancers Australia

This group supports:

- Women facing an inherited cancer diagnosis
- Women with a strong family history of cancer
- Women at increased risk of cancer due to known gene mutations

Group by Inherited Cancers Australia

Support for Women/Assigned Females at Birth - Inherited Cancers Australia

Private group · 1.7K members

Manage, Invite, Chats, Featured, About, Photos, Events

Inherited Cancers Australia
September 18 at 11:23 AM

Thank you **WIN News Canberra**, for featuring the story of our community member Amy. Her \$1,000 annual cost to manage her inherited cancer risk reflects an important finding from our inherited cancer survey report: 54% of respondents face out-of-pocket expenses exceeding \$5,000 for inherited cancer care, with 1 in 4 paying over \$15,000, and some even surpassing \$50,000. These financial burdens, coupled with lengthy wait times and limited resources, especially in regional areas... See more

of took a lot of time to
AMY K PROSSER BRCA2 GENE HOLDER
we've been doing
WINNEWS

WIN News Canberra
September 13 at 3:38 PM

Regional Aussies with a higher genetic risk of cancer are being left behind when it comes to preventive health care.

#WINNews | Channel 8 & 80 (HD)
Weeknights from 5:30pm

Breaking the cycle of inherited cancers in Australian families.

Inherited Cancers Australia
@inheritedcancersaus · 1K subscribers · 9 videos
Inherited Cancers Australia (formerly Pink Hope) is committed to breaking the cycle of...
inheritedcancers.org.au

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- Triple-negative breast cancer: hit me like a freight train! · 59K views · 7 months ago



The Empowered Patient Project
Inherited Cancers Australia

No rating · Education · Health · Science

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Pillars of health

This week we chatted to Kathryn Elliott about lifestyle factors and how changing them can positively impact a breast cancer...

10 May 2023 · 29 min.

Information & Support Day

Adelaide Information & Support Day
Sun 10 November 9:00am-1:30pm
\$25 per person (includes morning tea & lunch)

if you are at high-risk for cancer because you carry a gene mutation such as BRCA, PALB2, CHEK2, ATM or Lynch syndrome, or you have a strong family history of cancer, this day is for you!

Hear from experts as we discuss cancer genetics, options for managing your risk of cancer, screening programs, mental health, menopause, IVF/PGT, research and hear from community members sharing their personal stories.

We'll have genetic counsellors, psychologists, menopause specialists, fertility specialists, gynaecologists, menopause specialists, breast surgeons and other experts presenting the most up to date information relevant to the high-risk community.

There will be plenty of time for socialising and you are welcome to bring family, friends or a support person.

For further information or questions, please contact our team at
info@inheritedcancers.org.au (02) 9084 2288



Our support service



This free service allows you to submit questions about being high risk. Healthcare professionals or consumers can submit questions and these will be triaged and forwarded on to experts for a response.

A free peer support program where those wanting support are matched with a mentor.

www.inheritedcancers.org.au/be-supported

Join our peer support program

Our trained Peer Support Mentors provide tailored support by sharing evidence-based information, resources, practical tips, and personal insights without offering medical advice to help you confidently navigate your high-risk experience. With the support of our mentors, you can face the complexities of inherited cancer without feeling scared, isolated or overwhelmed.

[I'd like to sign up](#)

XX **inherited**
cancers

Who we are

Inherited Cancers ▾

Be supported

Events

Lived experiences

Get involved

You can connect with our specialists.

Specialist nurse navigator

Our free Specialist Nurse Service will help you understand how to manage your risk of hereditary cancer. Our expert can:

- assist you in accessing healthcare services in your area
- answer questions you have about the treatment options for inherited cancer
- connect you with support services
- help translate complex medical information.

Our expert can help you feel confident to make informed evidence-based decisions about your hereditary cancer experience and future.

[Email us for nurse support](#)

Ask a genetic testing question

This service can help you understand if you are at-risk of inherited cancer for free. Our trained specialist can:

- determine if you should investigate genetic testing
- provide general information relating to your situation
- suggest questions to ask your doctor about your specific situation.

[Ask a genetic testing question](#)

Continued connection



We support many generations in families, an example:

- Support through Mum with ovarian cancer
- Support with genetic testing/counselling
- Info about screening and risk reduction
- Info about PGT and family planning
- Info about research I could be part of pre surgery
- Support with cousin with breast cancer
- Info/support with risk reducing surgeries
- Info about talking to children

Real life implications of inherited cancer risk



- Family experiences shape decisions for risk reducing surgery - not everyone will follow the guidelines
- Guilt of potentially passing on gene mutations
- Guilt of not having a gene mutation when other family members do
- Worry about the cancers you can't screen for
- Cancer risk looms - every lump or bump needs to be investigated which means anxiety and financial pressure
- General population doesn't get it - people with gene mutations need connection
- Conflicting information from healthcare professionals

Added complications for priority populations



From our Focus Groups we heard:

- In some cultures there is a stigma around gene mutations - people don't talk about it. Some people know and don't reach out to family.
- Some health care providers were seen as blasé about the risks for men or told people they were too young for cancer.
- People worry about insurance discrimination and the next generation
- Impacts family members differently - some worry, some don't
- There are access/staff challenges in rural/regional areas
- LGBTQI+ people faced assumptions and gender stereotypes within the healthcare system
- Talking to kids and guilt was a challenge for men

Our community & challenges



- Financial toxicity over generations
- Emotional trauma from generations of cancer and risk
- Many women experiencing menopause for double the general population
- Many waiting for years on public waitlists for prophylactic surgery
- Data on prophylactic surgeries not collected
- Data for people who have gene mutations held by S&Ts
- People having risk reducing surgeries during a time in life when they are highly active in work and family life
- More research and more funded drugs and testing = more demand for us
- ICA is not Federally funded and our capacity to support is capped by the funding we can access.

BRCA Research and trials

- Elevated Risk of Ovarian Cancer biobank

www.gynecancerresearch.org/the-eroc-biobank

- Menopause and brainfog study -

e: maprc-earlymenopauseandcognition@monash.edu

- PRIMO trial

www.petermac.org/research/clinical-research/clinical-research-by-centre/familial-cancer-research-centre/primo-trial

- BRCA-P trial

www.breastcancertrials.org.au/trials/brca-p/

- TUBA-WISP II study

www.tuba-wisp.org/p-start-en

Helpful links



- [Centre for Genetics Education - NSW](#)
- [Genomics in General Practice](#)
- [Breast cancer – referring to genetics](#)
- [Colorectal cancer or polyposis – referring to genetics](#)
- [iPrevent Breast Cancer Risk Assessment Tool \(PeterMac\)](#)
- [General practitioner referral guidelines for cancer genetics assessment](#)
- [EviQ Cancer Genetics consumer information](#)
- [Nursing Australia podcast \(18:52\)](#)
- [Inherited Cancers Australia webpage for healthcare professionals](#)
- Can contact info@inheritedcancers.org.au or robyn@inheritedcancers.org.au

Person experience











Q&A time

Upcoming events



Cardiology at the interface of primary and secondary care – A vision for contemporary cardiac rehabilitation

Topic: A vision for contemporary cardiac rehabilitation

Facilitated by: Primary Health Tasmania

Speaker: Paul McIntyre
Anna Seth – GP clinical editor, Tasmanian HealthPathways

Date and time: Wednesday 12 March - 6:30pm to 8:00pm

Location: Online via Zoom

Audience: General practitioners working in Tasmania

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Starting 10th March 2025, HealthPathways will introduce personalised accounts. All users will be logged out that morning. To log back in, register for a new account or use your usual login. [Learn more](#)

Tasmania HEALTHPATHWAYS

CPD Events









- 19 February
[Early stage care for people with Parkinson's disease](#)
- 25 February
[Identifying and supporting patients with inherited cancer risk](#)
- 06 March
[Managing medications for people living with dementia](#)
- [View more events...](#)

Latest News

- 5 December
 [Background and benefits of HealthPathways, and tips to support decision making](#)
 For the background and benefits of HealthPathways, and tips to support decision making in the consulting room, see [AJGP – How to Use Community HealthPathways: Practical Tips to Support Decision Making in the Consulting Room](#)

Pathway Updates

- Updated – 21 February*
[Ambulance Transfer from General Practice and Residential Facilities](#)
- Updated – 17 February*
[Undescended Testes](#)
- Updated – 17 February*
[Hypothyroidism](#)
- Updated – 14 February*
[Scrotal Pain or Swelling in Children and Young People](#)
- Updated – 13 February*
[Hypercalcaemia](#)
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Some final words

- After this webinar end, your browser will open a link to an evaluation survey.
- Statements of attendance will be emailed to participants.
- For event queries, please contact events@primaryhealthtas.com.au

Thank you



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