Understanding genetic tests for men who have a family history of breast and ovarian cancer

Information and decision aid

Centre for Genetics Education | NSW HEALTH

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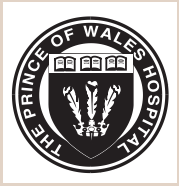


Hereditary Cancer Clinic
Prince of Wales Hospital

Macquarie University

Centre for Genetics
Education, NSW Health

Cancer Council NSW

Who is this booklet for?

This booklet is for men who are considering genetic testing because they have a family history of breast and/or ovarian cancer.

This booklet contains information about some forms of cancer in men, and genetic testing for cancer risk and its impact. At the end of the booklet there are worksheets that might assist your thinking and decisions.

The information is not a replacement for discussing genetic testing with your doctor or family cancer service. Only some sections might be useful to you.

This booklet, combined with information from health professionals, will assist you in making a decision that is right for you.

On page 46 you will find *'Some words used in this booklet'* which might assist you while reading.

What is in this booklet?

About breast cancer that runs in the family

Cancer is common in Australia.

Many families include one or more people who have had breast or ovarian or other cancers.

In some families these cancers occur in a number of generations. This is called a family history of cancer.

Why do I have a family history of cancer?

There are three reasons why you might have a family history of cancer.

Just by chance: Breast cancer is a common disease. This means that many people have several people in their family who have developed breast cancer.

Environmental factors: Many families live in similar environments. This means they often share similar diets and lifestyles. These non-inherited factors may influence the chance of developing cancer.

Inherited factors: Inherited factors include the genetic information we inherit from our parents and pass on to our children. In some families inherited genes play a role in the development of breast, ovarian and prostate cancers.

Cancer and our genes

Our genetic information provides instructions for growth and development and is in the form of many thousands of different genes including cancer protection genes, and control systems.

Some cancers occur when cells grow out of control in a particular part of the body and a lump might be the first sign of cancer.

Cancer protection genes stop cells from growing out of control.

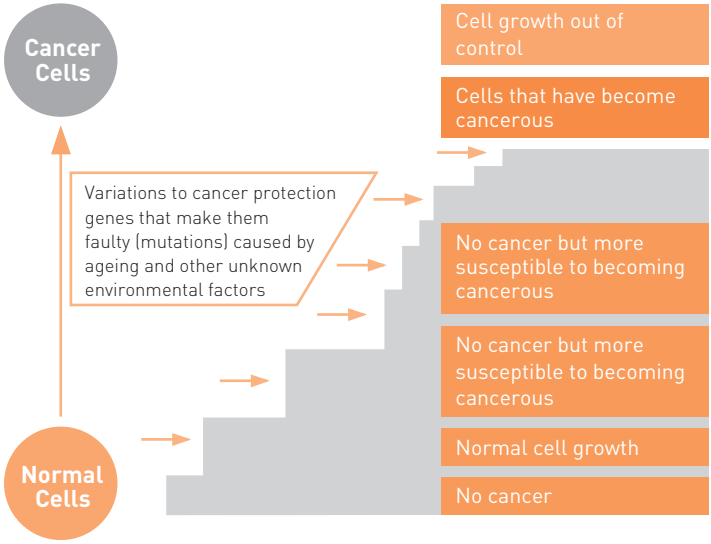
Variations in genes are common and can:

- occur when genes are copied as new cells and tissues grow
- be caused by environmental factors
- happen as we age
- be inherited from our parents

Most gene variations do not cause problems for growth and development.

However, occasionally, variations in cancer protection genes cause faults that could lead to cancer. Faults in genes are called mutations.

As shown in the diagram below, each short arrow indicates a new fault in a different cancer protection gene over time. A cell becomes cancerous when too many cancer protection genes become faulty.



It takes a long time for enough faults to build up in different cancer protection genes and cause cancer.

In fact, enough faults might never build up and cancer might never develop.

As we age, faults in cancer protection genes increase. This is why we are more susceptible to cancer later in life.

Inheriting faulty breast cancer protection genes

BRCA1 (BReast CAncer 1) and *BRCA2* (BReast CAncer 2) are known as cancer protection genes.

Faulty copies of either of these genes are known to cause breast and ovarian cancer, and sometimes prostate and other cancers.

Everyone is born with cancer protection genes *BRCA1* and *BRCA2*, but only a small number of people are born with a faulty copy of one of these genes.

Inheriting a faulty cancer protection gene

Most people are born with **two working copies** of each gene in every cell - one copy from their mother and one from their father.

Rarely, a person might be born with **a faulty copy** of a cancer protection gene inherited from either their mother or father. The working copy provides protection against cancer even though the faulty gene copy does not work properly.

Key working copy of a cancer protection gene

faulty copy of a cancer protection gene

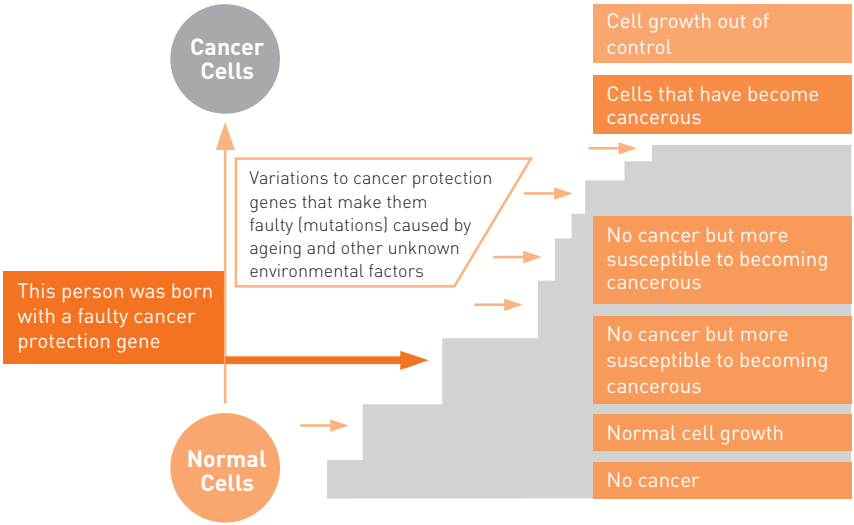
Men or women can inherit a faulty cancer protection gene. They then have a 50% chance (1 in 2) of passing it on to each of their children.

If you have inherited a faulty gene for cancer

As shown in the diagram below, if you have inherited a faulty cancer protection gene, all of your cells are at the level of the **dark orange arrow.**

The cells are already on the path that could lead to a cell becoming cancerous. This means you have a slightly increased chance of developing breast and/or prostate cancer.

Nevertheless, because faults in other cancer protection genes take time to build up, you might still never develop either of these cancers.



What does inheriting a faulty gene for breast cancer mean for you?

Men who carry a faulty copy of a *BRCA* gene have a slightly increased chance of developing breast and/or prostate cancer and some other cancers.[1]

What does it mean for your children?

The children of men with a faulty copy of a *BRCA* gene have a 50% chance (1 in 2) of inheriting the faulty gene.

Daughters who inherit the faulty gene have a much higher chance when they are adults of developing breast and/or ovarian cancer than the general population. They might also develop breast cancer at a younger age than women who do not have a faulty BRCA gene.[3]

Sons who inherit the faulty gene will also have a slightly increased chance when they are adults of developing breast and/or prostate cancer.[1,2]

Breast cancer in men

Unlike female breast cancer, breast cancer in men is rare and accounts for less than 1% of all breast cancer in Australia.[4] Around 100 men are diagnosed with breast cancer in Australia each year, compared with around 14,000 women.[5]

Many people do not know that breast cancer can occur in men. This can lead to delays in diagnosis because men sometimes don't talk to their doctor about their symptoms. However, compared with women, it is easier to detect breast cancer in men because men have less tissue in their breast area.[5]

What increases the chance of developing breast cancer in men?[4]

Age: The chance of men developing breast cancer increases with age

Having a strong family history of breast cancer and/or ovarian cancer: The more relatives a man has with breast and/or ovarian cancer, the higher is his chance of developing breast cancer

Ethnicity: Men from different ethnic communities can have a slightly increased chance of developing breast cancer. For example, it is more common in men with Jewish ancestry

Inherited factors: Having a faulty copy of a *BRCA1* or *BRCA2* gene

Is it common to inherit an increased chance of developing breast cancer?

No, most breast cancers in men are not caused by inherited factors.

While about 15% of all men who develop breast cancer have a family history of breast and/or ovarian cancer, only about 5% will have inherited a faulty gene variation in the breast cancer protection genes *BRCA1* or *BRCA2*.[1]

Quotes from men with breast cancer:[5]

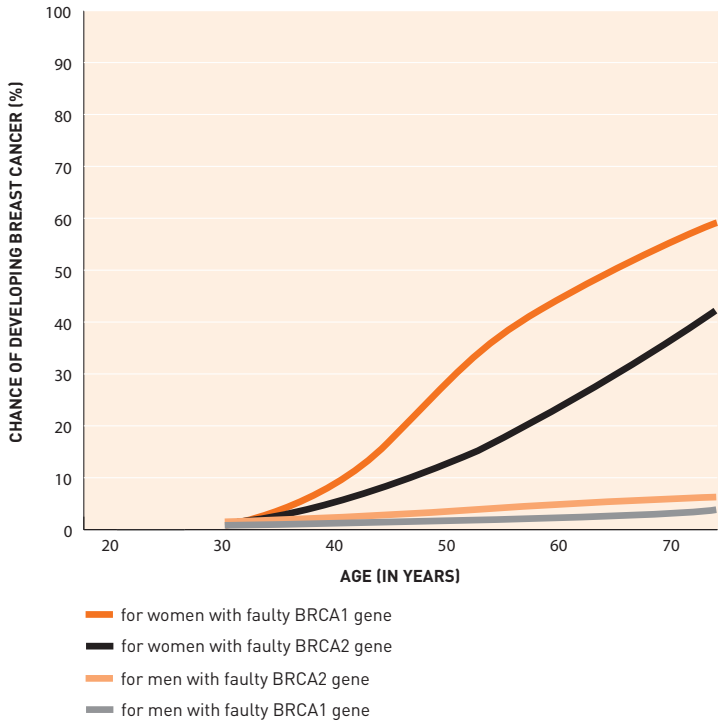
"I had quite a few men say to me 'that's a woman's disease' and I had to say, "No it's not, you could get it too".

"I was very open about having breast cancer right from the start, and that helped me deal with it".

- Cancer Australia

Chances of developing breast cancer

The graph below provides the current estimates for women and men with a faulty *BRCA1* or *BRCA2* gene developing breast cancer in a lifetime.[1]



Men who have a faulty copy of a *BRCA1* gene have a much lower chance of developing breast cancer than women.

The chance of men with a faulty copy of a *BRCA1* gene developing breast cancer in their lifetime is estimated to be between 1% and 6%.[1,6]

The chance of men with a faulty copy of a *BRCA2* gene developing breast cancer is estimated to be around 6.8%.[1]

Chances of developing prostate cancer

The chance of men with a faulty *BRCA1* or *BRCA2* gene developing breast and/or prostate cancer is only slightly higher than the general community and they might never develop one of these cancers.

The chance of developing prostate cancer for men with a faulty *BRCA1* or *BRCA2* gene is unclear.

However, the chance of men with a faulty copy of a *BRCA2* gene developing prostate cancer is estimated to be around 15% by 65 years old.

It is thought that men with a faulty copy of a *BRCA1* gene have only a slightly increased chance of developing prostate cancer by 65 years of age.

Genetic tests for men with a family history of breast and/or ovarian cancer

Two types of genetic tests are currently available.

Mutation search

A mutation search is a blood test that searches for a faulty cancer protection gene in a family. It is the first type of genetic test that is done for a family with a history of breast and/or ovarian cancer. See page 16 for Information about a mutation search.

Predictive test

A predictive test searches for the family-specific faulty gene that has been previously detected in a blood relative. See page 24 for information about predictive testing.

Mutation search. A genetic test for a faulty *BRCA1* or *BRCA2* gene

Usually, the person who undergoes a mutation search is a person who has had cancer and is part of a family with a history of breast and/or ovarian cancers.

For most men, the mutation search will have already been undertaken in their family and a mutation search will not be appropriate for them. In this case, predictive testing might be considered. See page 21.

Rarely, a man might not have breast or prostate cancer himself but has a parent and a child who has. In that case a mutation search might be considered.

Your doctor or family cancer service will be able to tell you if a mutation search is appropriate for you.

Why might I consider this type of test?

If a genetic test shows that you have inherited a faulty cancer protection gene, a result might:

- provide you with more accurate information about your future chance of developing another cancer
- influence your decisions about cancer screening, prevention and management
- help clarify who in your family has a higher chance of developing these cancers
- make it possible to offer a **predictive test to your blood relative(s)** who has not yet developed cancer. A predictive test investigates whether the relative has inherited the faulty gene that runs in your family. More information about a predictive test can be found on page 24.

Possible test results of a mutation search

There are **three** possible test results from a mutation search.

1) Inconclusive (a faulty gene was NOT found)

Many families receive this result. However, there might still be a faulty gene causing cancer in the family. If you receive this result:

- it was not possible to find a variation (mutation) in the *BRCA1* or *BRCA2* genes that makes them faulty
- you need to continue screening and management just as if you haven't had the test. See page 31. Because of your family history of cancer, you might still have an increased chance of developing cancer.

Why might you receive an 'inconclusive' result?

- your family could carry a variation in a gene that hasn't been discovered yet. At present we don't know every gene involved in cancer so we cannot test for them
- current technology cannot find all of the variations that make the *BRCA1* or *BRCA2* genes faulty
- your family history of cancer could be due to a combination of many factors (both genetic and environmental)

If you receive an inconclusive result, other members of your family cannot be offered a predictive test.

2) A faulty gene was found

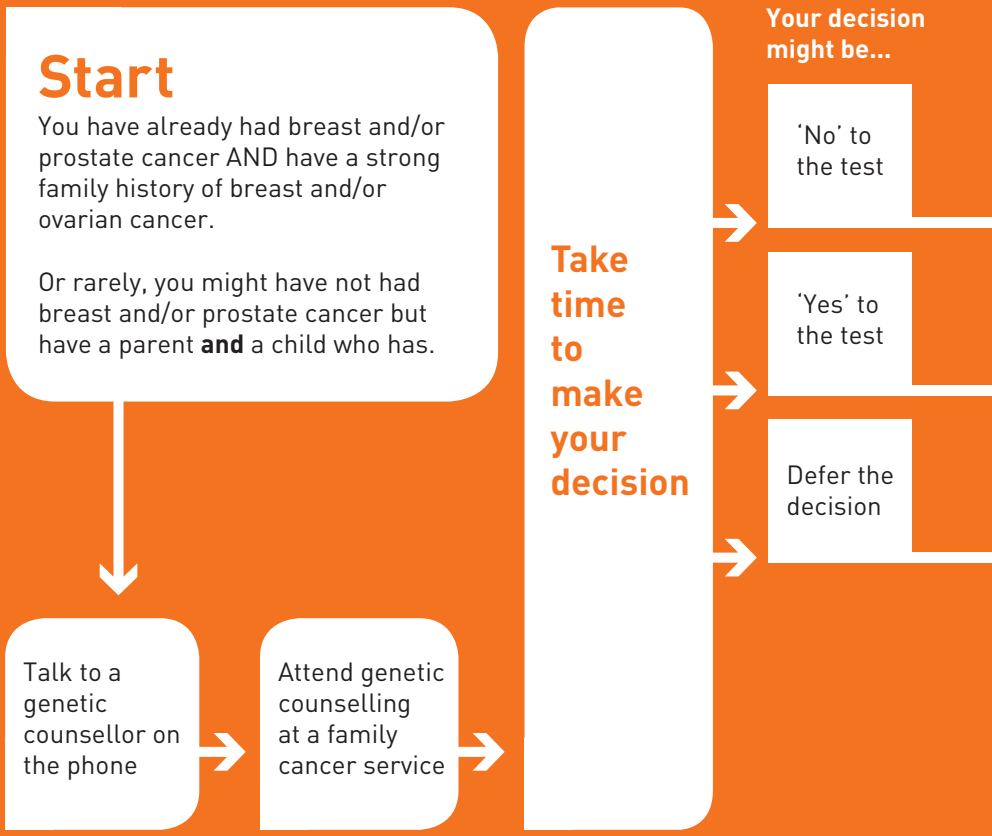
If you receive this result:

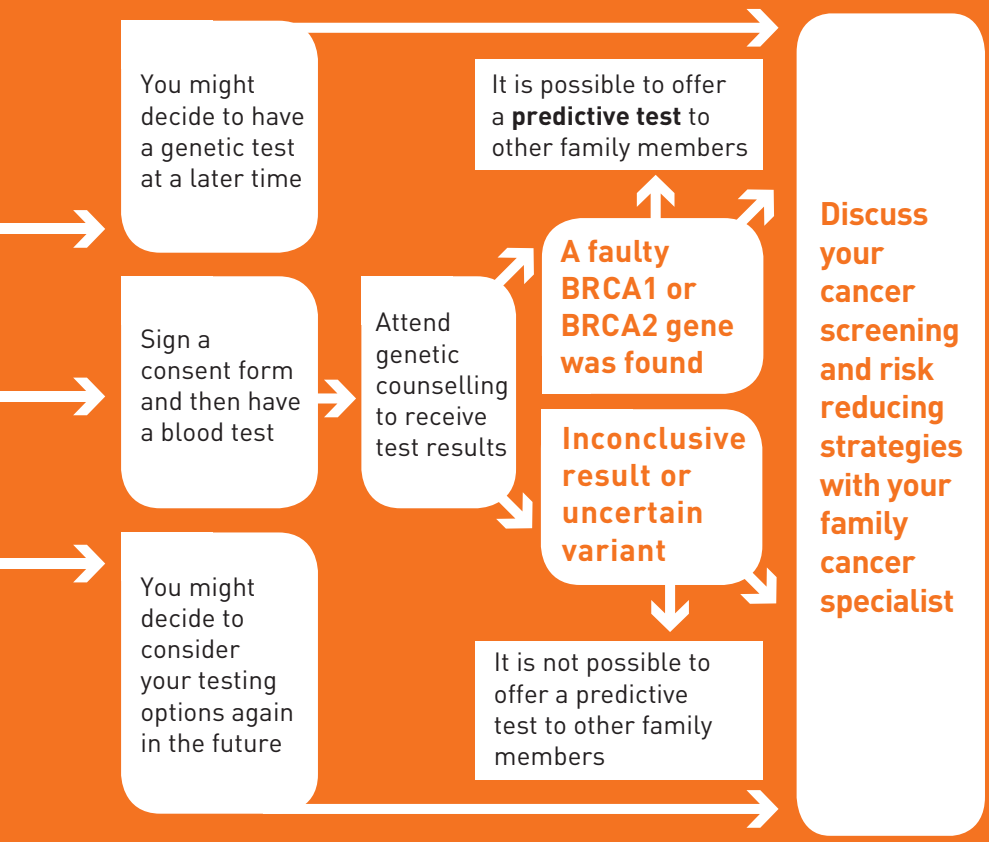
- you have inherited a faulty cancer protection gene
- you have an increased chance of developing another cancer
- other blood relatives who have not had cancer can have a **predictive test**. They will be able to find out whether or not they have inherited the same faulty gene. See page 24
- your doctors might change your screening plan to include some of the tests listed on page 34

3) Uncertain variant

If you receive this result, it means the mutation search has found a variation in the information in the *BRCA1* or *BRCA2* gene, but it is not currently clear if the variation is harmless, or if it is a variation that is making the gene faulty. This result may also be considered to be 'inconclusive'.

The mutation search process




You might decide to have a genetic test at a later time
Sign a consent form and then have a blood test
You might decide to consider your testing options again in the future
Attend genetic counselling to receive test results
It is possible to offer a **predictive test** to other family members
A faulty BRCA1 or BRCA2 gene was found
Inconclusive result or uncertain variant
It is not possible to offer a predictive test to other family members
Discuss your cancer screening and risk reducing strategies with your family cancer specialist

The impact of a mutation search on you

Waiting time

You might feel frustrated or disappointed by the length of time it takes to receive a mutation search result.

There is a lot of information in the cancer protection genes. The laboratory work can sometimes take a long time.

An inconclusive result or an uncertain variant

It can be frustrating to receive this result, generally because you do not know what has caused your family history of cancer.

You might feel some relief after this result, even though you might still have an increased chance of developing further cancer.[7,8]

This result also means other family members cannot have a predictive genetic test.

A faulty gene was found

This result could cause an increase in worry or anxiety about developing another cancer. Research has found that for people who have had genetic testing, anxiety usually lessens over about 12 months to the level that is normal for them.[7]

People often continue to feel anxiety leading up to regular screening appointments.

You might feel less anxious after this result because you understand the cause of cancer in your family and can plan future health management.

You might be glad other family members now have the option of a predictive test.

The predictive test.
A genetic test for the family-specific faulty *BRCA1* or *BRCA2* gene

A predictive genetic test is for blood relatives and looks for the previously found family-specific faulty gene.

Blood relatives may or may not have had cancer themselves. Your doctor or family cancer service will be able to tell you if a predictive test is suitable for you.

Why might I consider a predictive test?

If you learn that you have not inherited the faulty gene, your chance of developing these cancers is the same as other men of your age in the general community. You and your children could avoid extra cancer screening and anxiety.

If you learn that you have inherited the faulty gene, you can make more informed decisions about screening and cancer prevention strategies. Also, your adult offspring might wish to investigate testing.

The predictive test: possible test results

There are two possible test results from a predictive test.

1. The faulty gene was found

If you receive this result:

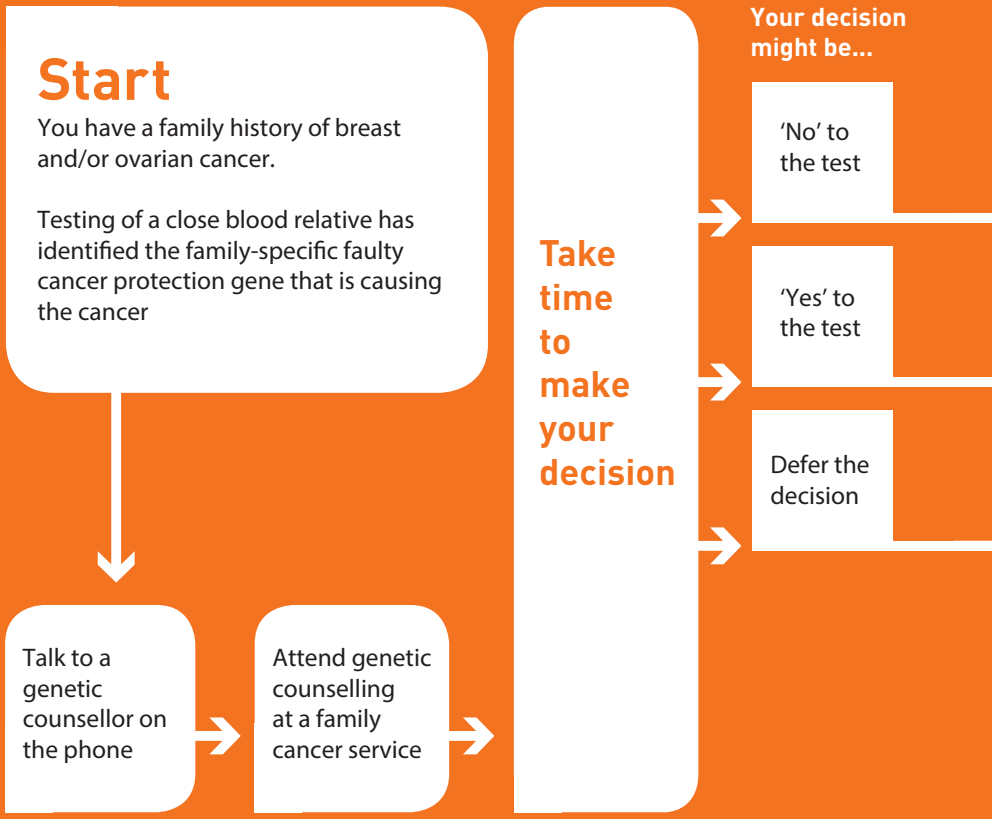
- you have inherited the faulty gene that was found in your family. You have a slightly increased chance of developing these cancers compared to other men
- men with a faulty *BRCA2* gene have a slightly increased chance of developing breast cancer and a significantly increased chance of developing prostate cancer.[1,2] Screening and other health management strategies are explained in more detail page 34
- a faulty *BRCA1* gene does not significantly increase your chance of developing breast cancer, but you may have a slightly increased chance of developing prostate cancer[1,2]
- each of your children has a 50% chance of inheriting the faulty gene (1 in 2 chance). They also have a 50% chance of inheriting your working gene (1 in 2 chance)
- women in the family who carry a faulty *BRCA1* or *BRCA2* gene have an increased chance of developing breast and/or ovarian cancer[3]

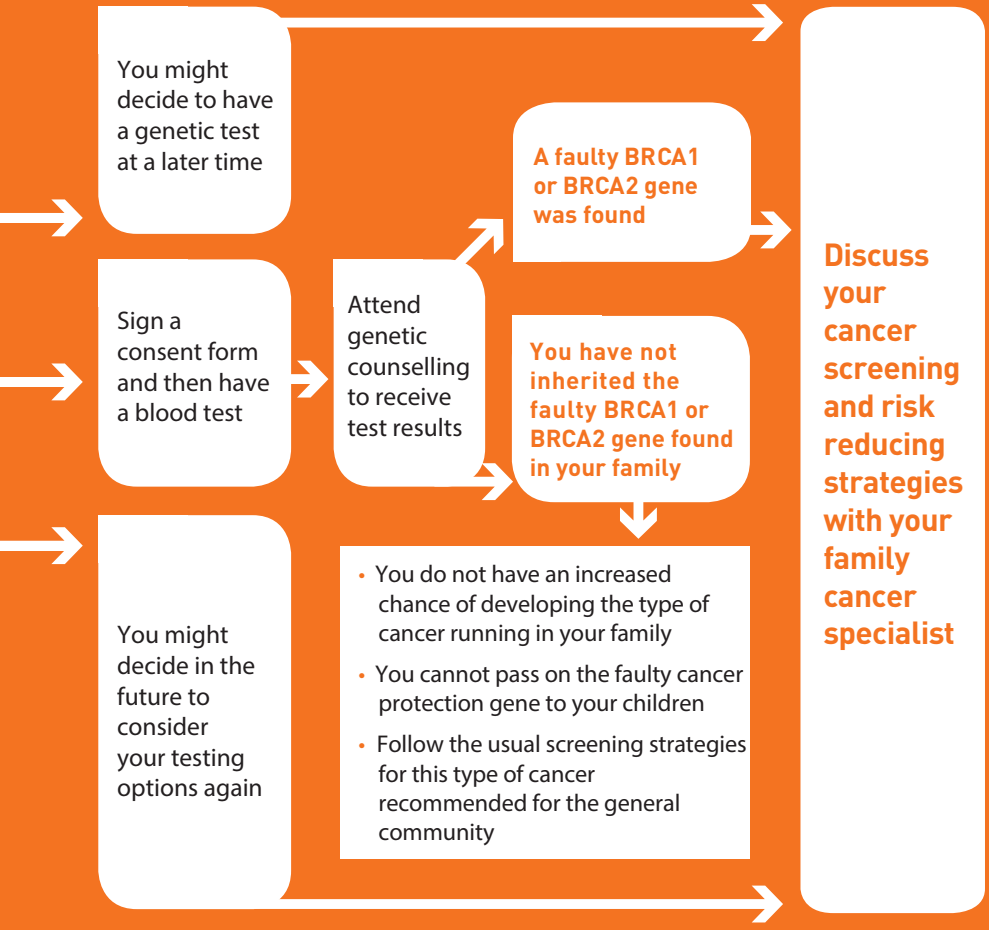
2. The family-specific faulty gene was not found

If you receive this result:

- you have **not** inherited the faulty gene known to be in your family
- you do **not** have an increased chance of developing breast and/or prostate cancer. Your chance of developing these cancers is the same as that of other men of your age in the general community
- you and your children can avoid the extra anxiety and cancer screening that is necessary for people with a family history of these cancers
- you cannot pass the faulty gene found in your family on to your children. This means your children do not have an increased chance of developing these cancers and can avoid the cancer screening recommended for people with the faulty gene

The predictive test process




You might decide to have a genetic test at a later time
Sign a consent form and then have a blood test
You might decide in the future to consider your testing options again
Attend genetic counselling to receive test results
A faulty BRCA1 or BRCA2 gene was found
You have not inherited the faulty BRCA1 or BRCA2 gene found in your family
• You do not have an increased chance of developing the type of cancer running in your family
• You cannot pass on the faulty cancer protection gene to your children
• Follow the usual screening strategies for this type of cancer recommended for the general community
Discuss your cancer screening and risk reducing strategies with your family cancer specialist

The impact of a predictive test on you

Waiting time

It takes about four to six weeks for the predictive test result to be available.

The laboratory staff will only test for the specific gene fault previously identified in the family.

Your family's faulty gene was not found in you

If you receive this result you might feel relieved that you and your children do not have an increased chance of developing breast and/or ovarian and/or prostate cancer. If you do not receive the same result as other family members, you might find it difficult because you cannot share their experiences.

Your family's faulty gene was found in you

This result could cause an increase in worry about developing cancer in the future. Research has found that for people who have had genetic testing, anxiety usually lessens over about 12 months to the level that is normal for them.[7] You might feel less anxious after you receive this result because you have a better idea of your chance of developing cancer and can plan future health management.

Other information about genetic testing

How might my result affect my family?

What about my children and future children?

How could my genetic test result affect my health management?

How could my result affect my finances?

How might my result affect my family?

Sometimes the process of having a genetic test can bring families closer together. Sometimes it can lead to disagreements.

Your genetics specialist can help you decide on how best to talk to your family about this information. It is important to remember that your genetic testing experience could give information to others in your family who could have an increased chance of developing breast, ovarian or prostate cancer.

Different results

Sometimes family members who receive the same result will feel closer to each other. Family members who receive different results may feel uncomfortable with each other and find it harder to talk to each other. This is less likely to happen if you talk about it ahead of time.

Different choices

Each person in a family has the right to make the decision that is best for them about genetic testing. However, it can be difficult for other family members to accept these decisions.

Different feelings

People considering genetic testing experience a variety of feelings. Partners of people considering genetic testing might find the process difficult too. They could feel left out because they are not blood relatives, and yet the results are important for their children.

What can I do to avoid family disagreements?

It might help to think about any potential disagreements in your family ahead of time. Then you can plan the best ways to handle this before deciding about a genetic test.

You might like to consider who, when, and how to tell other people about your genetic testing decision. You might want to choose a support person to share your thoughts and feelings with.

What about my children and future children?

If your children are already adults

You might like to think about what information you want to share with them about your family history of cancer and genetic testing.

You might suggest they visit a genetic counsellor for information regarding the condition. They can then decide whether or not they want to have a genetic test.

Even if they do not want to consider genetic testing, it is important that they are advised about when to start a screening program.

If your children are not adults

Children are not usually offered predictive genetic testing. This is because even if they have inherited the family-specific faulty cancer protection gene, they do not have an increased chance of developing cancer until they are adults.

Future children

It might be helpful to think about how your decision about genetic testing and the possible results might influence your plans for children in the future.

How could my genetic test result affect my health management?

Breast cancer in men can be treated as effectively as in women, especially if it is detected early.[10] If you have an increased chance of developing cancer, consider talking to your doctor about:

(i) Breast awareness

If you notice changes in the look or feel of your chest, for example you might feel something the size of half a grain of rice, let the treating doctor know that you may have an increased chance of developing breast cancer.

If you have a faulty copy of a *BRCA1* or *BRCA2* gene and a lump in your chest area, further tests may be needed.

(ii) Screening tests for prostate cancer*

The following tests on a yearly basis, may be beneficial to men who have a *BRCA1* or *BRCA2* mutation to detect prostate cancer at an earlier clinical stage. This may be important because prostate cancer in men with a faulty *BRCA2* gene tends to have a poorer outcome than prostate cancer that develops as a result of other causes.[2,9]

The screening tests commonly used are:

- **A rectal examination:** This involves a doctor inserting a finger in the rectum to check for lumps.
- **A prostate-specific antigen (PSA) test:** This is a blood test to measure the amount of PSA in the blood. PSA is a chemical made in the prostate. All men have PSA in the blood, but a high level of PSA can be a sign of prostate problems.

* Performing a rectal examination and a PSA test together increases the chance of finding cancer if it is present. However, it is still not certain whether prostate cancer screening reduces men's chances of dying from prostate cancer. If you want to know more about this, ask your doctor. Prospective clinical trials are currently underway to determine the effectiveness of prostate cancer screening. There are links to a few prostate cancer-related websites on page 51-52 which you may be interested in.

How could my result affect my finances?

Cost of genetic testing

Patients are not usually charged for genetic testing at public hospital family cancer services. Private pathology laboratories usually charge for genetic testing.

Health insurance

Your genetic testing decision will not affect your health insurance.

Life insurance

In Australia, life insurance includes disability and income protection insurance. Life Insurance is *'guaranteed renewable'.*

This means that if you find you have inherited a faulty cancer protection gene, the result will not affect your **current** life insurance policy.

However, if you make **changes** to an existing policy, or if you take out a **new policy**, you will have to provide:

- your genetic test result
- health information and genetic test results for any first degree relatives

Information is also available from the Centre for Genetics Education.

Visit **www.genetics.edu.au**

T (02) 9462 9599.

My worksheet.
An aid for decision making

There might be lots of reasons why genetic testing is suitable or not suitable for you. Part of making an appropriate decision is to consider all the pros and cons (positives and negatives) of genetic testing.

The worksheets on the following pages are designed to assist you to put all the facts together and consider what is important to you. You will find two examples of worksheets filled out by others on pages 40 and 42.

What's important to me?

Step 1: Clarify the decision

What is the decision I face?

"I am deciding whether or not to have a mutation search (or a predictive genetic test) for breast and/or prostate cancer."

What is your reason for making this decision?

_____

_____

_____

Step 2: Weighing the options

What I know

In the table page 44, please list the pros (*for*) and cons (*against*) for you that are associated with genetic testing.

What is important to me?

Show how important each pro and con is to you by placing one star (*) or up to five stars (*****) in the columns labelled *Personal Importance.* More stars show more importance to you. If a pro or a con is not important to you at all, then give it zero stars.

How sure do I feel?

See which column has the most stars in it. The side with the most stars is probably the right option for you. Using the scale, tick the box that most closely reflects how you're feeling about a genetic test at the moment.

Step 3: Plan the next steps

You might like to list here what you need to do before making your decision. You will find a list of helpful contacts at the end of this booklet.

Step 4: Questions to ask your doctor

You might like to write down here any questions and take them to your consultation.

The design of this worksheet is based on the Ottawa Personal Decision Guide, developed by O'Connor, Jacobsen and Stacey. 2002.

Other peoples' experiences regarding a mutation search

Andy has a family history of breast and ovarian cancer and has prostate cancer himself. He completed this worksheet to help him decide whether or not to have a **mutation search**. He listed all the pros and cons he could think of.

Personal Importance	Possible pros of having a mutation search #
***	*'I can manage my risk of developing [another] cancer.'*
***	*'I will be able to help my children to make choices regarding their risk.'*
*	*'If it is going to help the family, I have to have it done'*
**	*'To help me understand my family history'*
*	*'To help my family's awareness of cancer'*
TOTAL 10	

Edited quotes from research studies about men's reactions to genetic testing.[7]

This list does not include all the possible pros and cons of a mutation search for you.

You might think of other pros and cons that might be more important to you than the ones listed here.

Possible cons (against) of having a mutation search #	Personal Importance
'I will find out that I do have a genetic risk.'	****
'It may be worrying for some family members.'	***
'I may worry about the effect of my genetic testing decision on my children in the future.'	***
'I'd have felt so guilty. And I don't know how in reality it would have panned out'	**
'I may not want to know.'	**
	TOTAL 14

At this point in time are you leaning towards wanting to have a mutation search or not? (Please tick the box that is closest to how you feel.)

		✔
'I am leaning towards having a mutation search.'	'I am not sure yet.'	'I am leaning towards not having a mutation search.'

Other peoples' experiences regarding the predictive test

Leslie has a family history of breast and ovarian cancer but has not had cancer himself. A faulty gene causing the cancer has been identified in one of his relatives.

He completed this worksheet to help him decide whether or not to have a **predictive** test. He listed all the pros and cons he could think of.

Personal Importance	Possible pros of having a predictive test #
*****	*'I can manage my risk of developing cancer.'*
****	*'I will be able to help my children to make choices regarding their risk.'*
***	*'If it is going to help my family, I have to have it done.'*
***	*'To help my family's awareness of cancer'*
**	*' Regardless of the result, I will have greater awareness of appropriate screening.'*
**	*'I believe that the test is very important because to an extent it really eases my mind. I can know if I could have passed it on to my children.'*
TOTAL 19	

Actual quotes from people considering genetic testing for cancer risk during an Australian research project in 2006/07. [8]

This list might not include all the possible pros and cons of a predictive test for you.

You might think of other pros and cons that might be more important to you than the ones listed here.

Possible cons (against) of having a predictive test #	Personal Importance
'I am afraid I will get [breast] cancer if I have the gene fault.'	***
'It may be worrying for some family members.'	**
'I may worry about the effect of my genetic testing decision on my children in the future.'	**
'I will find out that I do have a cancer risk.'	**
'I'd have felt so guilty. And I don't know how in reality it would have panned out.'	*
'I may not want to know.'	**
	TOTAL 12

At this point in time are you leaning towards wanting to have a predictive test or not? (Please tick the box that is closest to how you feel.)

✔		
'I am leaning towards having a predictive test.'	'I am not sure yet.'	'I am leaning towards not having a predictive test.'

My worksheet

You might want to use this worksheet to help you to work through your decision about whether to have a mutation search or a predictive test.

Personal Importance	My list of pros for having a genetic test
TOTAL	

List all the pros and cons for you that you can think of and then work out how important they are to you.

My list of cons (against) having a genetic test	Personal Importance
	TOTAL

At this point in time are you leaning towards wanting to have a genetic test or not? (Please tick the box that is closest to how you feel.)

'I am leaning towards having a genetic test'	'I am not sure yet.'	'I am leaning towards not having a genetic test'

Some words used in this booklet:

A **blood relative** is someone in your family with whom you have a common ancestor but who is not related by marriage or adoption. A first degree relative is a blood relative in your immediate family such as a mother, father, child or sibling.

Cancer protection genes describe genes that, when they are working correctly, help to prevent cancer from developing.

Family history of cancer means having one or more blood relatives on the same side of the family who have had cancer. These relatives could be on either your mother's or your father's side of the family.

Genes are in every cell in our body. Genes contain the information that guides our growth, health and development.

Faulty genes are genes that are not working properly due to a mutation and so do not give the cell the correct instructions for growth and development.

Family cancer team might include a specialist doctor (clinical geneticist or oncologist) who has completed specialist training in genetics or cancer medicine after their general medical training or a genetic counsellor who has specialist training in counselling and in genetics.

Genetic testing is the process of searching genes for specific gene faults or other variations.

Mutations are variations in genes that make the gene faulty. This booklet discusses mutations in cancer protection genes that make them less able to prevent cancer developing.

Mutation search is a genetic test usually conducted first on a person who has already had cancer. This test tries to find the specific gene variation that is causing the cancer to run in a family.

Predictive genetic testing is usually only offered to people who have a relative who has been found to have a specific fault in a cancer protection gene. A predictive genetic test looks only for the family-specific gene fault that has already been found in the family.

Where to from here

Family cancer services

If you have not already visited a family cancer clinic, you might wish to contact a clinic in your area.

AUSTRALIAN CAPITAL TERRITORY

Canberra
ACT Genetics Service
The Canberra Hospital
PO Box 11 WODEN ACT 2605
Phone: (02) 6174 7630

NEW SOUTH WALES

Camperdown
Dept of Cancer Genetics
Royal Prince Alfred Hospital
CAMPERDOWN NSW 2050
Phone: (02) 9515 8780

Kogarah
Hereditary Cancer Clinic
Cancer Care Centre
St George Hospital
KOGARAH NSW 2217
Phone: (02) 9113 3815

St Leonards
Family Cancer Service
Royal North Shore Hospital
ST LEONARDS NSW 2065
Phone: (02) 9463 1554

Wollongong
Wollongong Hereditary Cancer Clinic
Illawarra Cancer Care Centre
Wollongong Hospital
Private Mail Bag 8808
South Coast Mail Centre NSW 2521
Phone: (02) 4222 5576

Newcastle and rural outreach services
Hunter Family Cancer Service
Hunter Genetics
PO Box 84, WARATAH NSW 2298
Phone: (02) 4985 3132

Randwick
Hereditary Cancer Clinic
Prince of Wales Hospital
High St RANDWICK NSW 2031
Phone: (02) 9382 2551

Darlinghurst
Family Cancer Clinic
St Vincents Hospital
DARLINGHURST NSW 2011
Phone: (02) 8382 3395

Westmead
Familial Cancer Service
Westmead Hospital
WESTMEAD NSW 2145
Phone: (02) 9845 6947

Liverpool
Department of Cancer Genetics
Liverpool Hospital
Locked Mail Bag 7103
Liverpool BC NSW 1871
Phone: (02) 8738 9746

QUEENSLAND

Brisbane
Genetic Health Queensland
Royal Brisbane and Women's Hospital
Herston Road
HERSTON QLD 4029
Phone: (07) 3636 1686

NORTHERN TERRITORY

Northern Territory Clinical Genetics Service
Royal Darwin Hospital
PO Box 41326
Casuarina NT 0911
Phone: (08) 8944 8731

SOUTH AUSTRALIA

Adelaide
Familial Cancer Unit
SA Clinical Genetics Service
Women's and Children's Hospital
NORTH ADELAIDE SA 5006
Phone: (08) 8161 6995

TASMANIA

Clinics are held regularly at
Burnie, Launceston and Hobart
Tasmanian Clinical Genetics Service
Royal Hobart Hospital
PO Box 1061
HOBART TAS 7001
Phone: (03) 6166 8296

VICTORIA

Clayton
Southern Health Familial
Cancer Centre
Special Medicine Building
246 Clayton Rd
CLAYTON VIC 3168
Phone: (03) 9594 2009

East Melbourne
Peter MacCallum Cancer Centre
Familial Cancer Centre
10 St Andrew's Place
EAST MELBOURNE VIC 3002
Phone: (03) 9656 1199

Parkville
Familial Cancer Centre
Royal Melbourne Hospital
Gratten St
PARKVILLE VIC 3050
Phone: (03) 9342 7151

Heidelberg
Austin Health Clinical Genetic Service
Austin Hospital
145 Studley Road
HEIDELBERG VIC 3084
Phone: (03) 9496 3027

WESTERN AUSTRALIA

Subiaco
Familial Cancer Program
Genetic Services of
Western Australia
King Edward Memorial Hospital
Level 3, Agnes Walsh House
374 Bagot Rd
SUBIACO WA 6008
Phone: (08) 9340 1603

Other locations in NSW

For genetic counselling services in other areas of NSW which might also provide cancer genetics services, visit our website:

www.genetics.edu.au

Other helpful organisations

These organisations can provide you with useful support and might be able to send helpful books and articles. They also have very informative websites.

The Cancer Council NSW

153 Dowling Street, Woolloomooloo NSW 2011

Ph (02) 9334 1900 or visit www.cancercouncil.com.au

Cancer Helpline

Ph 13 11 20

Cancer Helpline is a free and confidential telephone information and support service available in each state and territory.

Centre for Genetics Education

RNS Community Health Centre

Level 5, 2C Herbert St

Royal North Shore Hospital, St Leonards NSW 2065

Ph (02) 9462 9599 or visit www.genetics.edu.au

The Centre for Genetics Education, a NSW state-wide service, provides current and relevant genetics information to individuals and family members affected by genetic conditions, health professionals and the community.

Cancer Australia

Level 14, 300 Elizabeth St

Surry Hills NSW 2010

Ph (02) 9357 9400 or visit www.canceraustralia.gov.au

Cancer Australia is Australia's national authority and information source on breast and ovarian cancer. Their website provides resources for men, their families and friends.

Visit http://breastcancerinmen.canceraustralia.gov.au/home

Breast Cancer Network Australia

This is a national consumer organisation which provides advocacy, valuable information and support for people with breast cancer and their families.

www.bcna.org.au

Facing Our Risk of Cancer Empowered (FORCE)

FORCE is a website developed in the United States for members of families with a faulty copy of a *BRCA1* or *BRCA2* gene.

www.facingourrisk.org

IMPACT: Targeted Prostate Screening

IMPACT is an international study that targets men with a known genetic mutation thought to increase prostate cancer risk, and the effectiveness of prostate cancer screening. You can also learn more about prostate cancer and inherited mutations from their website.

www.impact-study.co.uk/public/home

The Prostate Cancer Foundation of Australia

The Prostate Cancer Foundation of Australia (PCFA) is the peak national body for prostate cancer in Australia. You can contact them on the Freecall number 1800 220 099 or visit www.prostate.org.au

Pink Hope

Pink Hope is a community website which offers support for young women with breast cancer and people with breast and ovarian cancer in their families.

Visit www.pinkhope.org.au

SCIENCE STUDIES MENTIONED IN THIS BOOKLET

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The information in this booklet is correct at the time of publication. However, research is ongoing, the booklet will be updated every two years.

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Further copies are available free for NSW recipients from the Centre for Genetics Education.

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Important

This information was correct at date of production. Please check with your doctor or genetic counselling service for any new information.