Genetic testing – a guide for people with a family history of breast cancer

Including: Genetic testing ● Information and support for family members ● Insurance and genetic test results ● Regional genetics centres

ABOUT THIS BOOKLET
This content is from a larger guide called “The best treatment: Your guide to UK services for people with a family history of breast cancer”, Edition 1, Breakthrough Breast Cancer.

Other booklets in this series:
- Finding out about your family history of breast cancer
- Genetics testing – a guide for people with a family history of breast cancer
- Early detection and risk factors – a guide for women with a family history of breast cancer
- Risk-reducing surgery – a guide for women at high risk of developing breast cancer
- More support and information – a guide for women with a family history of breast cancer

BREAKTHROUGH’S HEALTH INFORMATION
Breakthrough Breast Cancer is dedicated to improving and saving lives through breast cancer prevention, early diagnosis, more targeted treatments and better services for everyone affected by breast cancer. Our health information is based on the latest research and reviewed by clinicians, scientists and people affected by breast cancer.

Breakthrough Breast Cancer’s other health information materials include:
- ‘Touch. Look. Check.’ Our breast awareness leaflets and posters
- Breast Cancer Risk Factors: The Facts booklet
- A4 fact sheets summarising the research for specific breast cancer risk factors: Alcohol, Breastfeeding, Deodorants and antiperspirants, Hormone replacement therapy (HRT), Obesity, Puberty and menopause, The pill, Pregnancy, and Soya and phyto-oestrogens.
- The best treatment: Your guide to breast cancer treatment in England and Wales

All of our publications are available free of charge within the UK. Please order online at breakthrough.org.uk or call our freephone Information Line on 08080 100 200.

Breakthrough Breast Cancer is a charity registered in England & Wales (No.1062636) and Scotland (No.SC039058)
GENETIC TESTING

The discovery of genes linked to breast cancer risk has meant that some women who have a strong family history may be able to take a genetic test.

This can help to provide information as to whether they have inherited a genetic fault that puts them and potentially their family at a higher risk of developing breast cancer.

Fewer than one in 100 of the general population are likely to have an inherited fault in a breast cancer gene, therefore genetic testing is not widely available. It is only offered to people with a strong family history of breast cancer. The majority of genetic testing looks for faults in two genes which are known to increase the risk of developing breast cancer – these are the breast cancer genes BRCA1 and BRCA2. Inherited faults in these genes lead to a high risk of developing the disease.

Inherited faults in another gene, TP53, can cause Li-Fraumeni syndrome and can give an increased risk of breast cancer. This is much rarer than faults in the BRCA genes. Families in which there are childhood sarcomas and brain tumours as well as breast cancer may be offered tests for faults in TP53.

There are some extremely rare faults in other genes known to be involved in hereditary breast cancer, however; genetic tests are not available for these faults at present.

The decision whether or not to take a genetic test should be accompanied by genetic counselling. In the counselling sessions, you will have a chance to talk through what having a genetic test means, how you may feel, what they will do with the test results and how you will cope. It is important to discuss any concerns or questions with your genetic counsellor and to explore the possible impact that any result of the test may have on you and your family.

Genetic testing does not prevent breast cancer developing, but it can give an indication of how likely breast cancer is to occur and how likely it is that family members will develop breast cancer.

WHAT THE GUIDELINES SAY:
ACCESS TO GENETIC TESTING

All high risk women should have access to information on genetic tests aimed at mutation finding.

Women from families with a 20% or greater chance of carrying a mutation such as BRCA1, BRCA2 or TP53 should have access to testing.

Familial breast cancer. The classification and care of women at risk of familial breast cancer in primary, secondary and tertiary care, National Institute for Health and Clinical Excellence, 2004
WHAT ARE THE ADVANTAGES AND DISADVANTAGES OF HAVING A GENETIC TEST?

The decision whether to have a genetic test is extremely personal, complex and often difficult. People often take the test for their own benefit – to help them make informed decisions about whether to have risk-reducing surgery, attend breast screening from an early age or enter clinical trials. The other main reason for taking a genetic test is for the benefit of the health and healthcare decisions of children and other relatives. In some cases, people decide against genetic testing as they would rather not know whether they are at increased risk, and some people can experience guilty feelings associated with passing on a genetic fault to children. The implications of a test result can be life-changing.

The advantages might include:

• Finding the gene fault (mutation) that runs in a family allows blood relatives to find out whether they have inherited the increased risk of breast cancer or not.

• Finding out if you or a family member carries a gene mutation may make future decision-making about managing your risk of breast cancer easier.

• It could reduce any stress or anxiety that comes from not knowing whether or not you carry the gene mutation, even if you find out you do have the mutation.

• You might be offered different breast screening options.

• It is thought that some treatments may work better in cancers that contain certain gene mutations. If you do develop breast cancer, then knowing the genetic reason may mean that in the future you can participate in clinical trials of these treatments.

The disadvantages might include:

• The results of some genetic tests are inconclusive because we don’t know what effect a particular gene fault may have on breast cancer risk.

• Although there is a current ban on the use of genetic information for insurance purposes, it has not yet been decided whether your genetic test results could be used when insurance premiums are set in the future (see page 65 for more information).
• Even if you decide not to take a test, the majority of management options to reduce the risk should still be available to you (see page 59).

HOW DOES GENETIC TESTING WORK?
The majority of genetic testing is a two-step procedure. A relative who has, or has had, breast cancer must be tested first, before healthy relatives can be tested to see if they might also be at risk.

DIAGNOSTIC TESTING (MUTATION SEARCHING)
The genes of an affected relative (someone in the family who has or has had breast cancer) are tested first to find out if there is a fault running in the family. An affected relative must be tested first as any gene fault that is causing disease in the family is more likely to be found in their genes. Without looking at the genes of an affected relative first, testing a healthy individual would be like reading through an entire book looking for a spelling mistake without knowing where the mistake is, or if there is a mistake at all.

It is important to remember that the results of some genetic tests are inconclusive. Diagnostic tests may not find an inherited fault in the genes currently known to increase the risk of developing breast cancer. This happens because, unfortunately, we don’t yet know about all the gene faults responsible for increased breast cancer risk in families. Your relative may not wish to be tested or may have died before they could have a genetic test. In these situations, the genetic cause of the breast cancer running in the family cannot be identified, and healthy relatives cannot be tested because the genetic fault running in the family is unknown.

PREDICTIVE TESTING
Only if a fault in a gene is found through diagnostic testing can healthy relatives be tested to see whether they have inherited this fault, and are therefore more likely to develop breast cancer. This is a personal choice that each family member makes for themselves. If predictive testing shows that a healthy relative has not inherited the fault identified in the family, then their risk of breast cancer is the same as the general population. Predictive testing is the equivalent of looking for a spelling mistake in a book when we already know what page and line number to
WHAT THE GUIDELINES SAY: HOW GENETIC TESTING SHOULD BE CARRIED OUT

The development of a genetic test for a family should usually start with the testing of an affected individual (mutation searching/screening) to try to identify a mutation in the appropriate gene (such as BRCA1, BRCA2 or TP53).

Discussion of genetic testing (predictive and mutation finding) should be undertaken by someone with appropriate training.

Familial breast cancer. The classification and care of women at risk of familial breast cancer in primary, secondary and tertiary care, National Institute for Health and Clinical Excellence, 2004

[Genetic test] results should be available to the following standards:

• within two weeks where the potential genetic mutation is already known (eg because another family member has already been tested)
• within eight weeks for unknown mutations in a large gene.

Our Inheritance, Our Future: Realising the potential of genetics in the NHS, Department of Health (2003)

The results for [diagnostic testing] are now turned around within 40 days… The results of predictive tests on subsequent family members at risk, where the gene abnormality has already been identified, are usually available within ten days.


look at. Some people of Ashkenazi Jewish descent may be offered predictive testing for specific faults that are known to cause most cases of breast cancer in that ethnic group.

WHAT DOES GENETIC TESTING INVOLVE?

If you have a strong family history of breast cancer, are eligible for genetic testing and are considering it, then you should be offered genetic counselling before any testing occurs.

Normally, at least two sessions are required to make sure that you understand:

• what the procedure and the genetic test involve
• what the results might tell you
• what the results mean for you and your family
• the possible options for care after testing
• the confidentiality of results and insurance implications

If you decide to proceed then a healthcare professional will take a blood sample. This will be sent to a laboratory where the DNA will be checked for faults or mutations that could give an increased risk of developing breast cancer.

You will get your results from a healthcare professional at your clinical genetics unit.

HOW LONG DOES IT TAKE TO RECEIVE A RESULT?

Genetic testing should be carried out within eight weeks of the laboratory receiving the sample for a diagnostic test and within two weeks for a predictive test. It may take a little longer than this before you receive your result in an appointment at the genetics clinic – check with your genetics specialist if the timetable is not clear.
FOCUS ON: DIRECT GENETIC TESTS

Direct genetic tests are not offered as part of a medical consultation. They are ‘direct’ in the sense that they can be offered directly to the public via a non-medical intermediary (e.g. a pharmacist) or directly to the consumer, where there is no intermediary between the consumer and the test provider. The testing companies provide cotton buds which are swabbed in the mouth and then returned for analysis. A risk report is then produced within four weeks.

There is little evidence that direct genetic tests can predict whether someone will develop breast cancer, and they usually do not test for faults in BRCA1 or BRCA2 but instead test for alterations in genes that may only have a small effect on the risk of breast cancer. In addition, they are not carried out alongside appropriate genetic counselling. Breakthrough does not recommend the use of direct genetic tests.

For more information see the publication Over the counter testing from Genetic Alliance UK (contact details on page 70).

WHAT DO THE RESULTS OF A GENETIC TEST MEAN?

All test results have implications for you and your family. Your healthcare professionals should discuss with you what the genetic test results mean, both to you and to your family. They will also help you to decide when to tell your family and how to explain it.

If you or your relative gets a negative or inconclusive genetic test result from diagnostic testing (mutation searching):

• It does not mean that your family’s risk of breast cancer is reduced. Any relative with a strong family history of breast cancer still has a greater chance of developing breast cancer than the general population.

• A mutation (fault) associated with an increased risk of developing breast cancer has not been found.

• The genetic cause of your breast cancer is still not understood and the results are inconclusive for your family.

• Predictive testing is not possible for other members of your family.
It is not unusual to get a negative result from diagnostic testing. At the moment the disease-causing mutation is only found in at most one in five, or 10–20%, of those who go for BRCA1 and BRCA2 mutation searching. There may be a number of reasons why this number is so low, including:

- The disease-causing mutations are hard to find. The breast cancer genes are large and not all of the possible disease-causing mutations are known yet.

- There are other genes responsible for the increased risk of breast cancer within a family which have not yet been discovered.

If you get a **positive genetic test result from diagnostic testing** (mutation searching):

- A mutation (fault) associated with an increased risk of developing breast cancer has been found.

- The genetic basis for your breast cancer and for your family’s increased risk of developing breast cancer compared to the general population is understood.

- There is a 50% or one in two chance of you passing the mutation on to each of your children (male or female).

- There is a 50% or one in two chance of each of your siblings having the mutation.

- You may want to discuss the result with other members of your family, as they can now have predictive testing to see whether they carry the mutation identified in you.

If you get a **negative (favourable) genetic test result from predictive testing**:

- The particular mutation that was found in your family that increases the risk of breast cancer has not been found in you.

- You therefore have not inherited the increased risk of developing breast cancer found in your family.

- You cannot pass the mutation on to your children (male or female).

- You do still have the same risk of developing breast cancer as the general population.
If you get a **positive (unfavourable) genetic test result from predictive testing:**

- The mutation increasing the risk of breast cancer in your family has been found in you.
- You have an increased risk of developing breast cancer and may have an increased risk of developing certain other cancers.
- The genetic basis for your increased risk of developing breast cancer compared with the general population is understood.
- There is a 50% or one in two chance of you passing the family mutation on to your children.

After diagnostic or predictive testing, your healthcare professional will discuss with you the implications of the test result and your options for managing your breast cancer risk.

Some people find it difficult to cope with receiving a genetic test result, whatever the result. Everybody reacts differently to news like this and it is important to remember that your feelings are completely normal.

You may have lots of questions straight away or you may need some time to process the news before looking at options for the future. Your genetic counsellor is there to help and support you in a way that suits you.

Some people also find it useful to join a support group for people with a family history of breast cancer to hear others’ experiences as well as to discuss their own.

**WHAT THE GUIDELINES SAY:**

**HAVING A GENETIC TEST**

High-risk women and their affected relatives should be informed about the likely informativeness of the test (the meaning of a positive and a negative test) and the likely timescale of being given the results.

Familial breast cancer: The classification and care of women at risk of familial breast cancer in primary, secondary and tertiary care, National Institute for Health and Clinical Excellence, 2004

See 70 for more information about support groups.

See 59 for more information on options available to you.
FOCUS ON: GENETIC TEST FOR PEOPLE OF ASHKENAZI JEWISH DESCENT

Several hundred different faults in the BRCA1 and BRCA2 genes can cause familial breast cancer. Therefore in most families, the genes of an affected relative need to be searched to find which of these faults is causing disease in a family. However, in people of Ashkenazi Jewish descent, most strong family histories of breast cancer are caused by one of three well-known mutations in the BRCA genes.

These three mutations (two of which are found in BRCA1 and one of which is found in BRCA2) are estimated to be present in around one in 50 of Ashkenazi Jews. Although testing an affected relative first is desirable (ie someone who has had breast cancer) to find if a particular mutation is present, an alternative genetic test which looks for the three common mutations can be offered to test healthy individuals directly.

WHAT DOES THE GENETIC TEST FOR ASHKENAZI JEWS INVOLVE?

The procedure for having a genetic test is the same as for other genetic tests. However, the BRCA genes will only be tested for the three mutations that commonly cause breast cancer in Ashkenazi Jewish descent.

Since this genetic test searches for known faults it is a form of predictive testing. It is very important to know that there are other faults that occur much less frequently in Ashkenazi Jews that will not be found by this predictive test.

As for other predictive genetic tests, it should take two weeks to get the test results.

WHAT DO THE RESULTS OF THE PREDICTIVE TEST FOR ASHKENAZI JEWS MEAN?

All test results have implications for you and your family. Your healthcare professionals will discuss with you what the genetic test results mean, both for you and for your family. They will also help you to decide when to tell your family and how to explain it.
If you have a **strong family history and get a negative (favourable) genetic test result** from predictive testing for the three common Ashkenazi Jewish mutations then:

- It does not change your risk of breast cancer. If you have a strong family history of breast cancer then you still have a greater chance of developing breast cancer than the general population.

- You do not have one of the three mutations that commonly cause hereditary breast cancer in Ashkenazi Jews.

- You may have a different fault in the BRCA genes. To test for this possibility an affected relative would need to undergo diagnostic testing (mutation searching).

However, if one of your family members has been found to have one of the three mutations and your genetic test result is negative (favourable) then you have not inherited the fault in your family and you are not at high risk.

If you get a **positive (unfavourable) genetic test result** from predictive testing for one of the three common Ashkenazi Jewish mutations then:

- One of the three mutations that commonly cause hereditary breast cancer in Ashkenazi Jews has been found.

- Your increased risk of developing breast cancer, estimated from your family history, is confirmed.

- The genetic basis for your increased risk of developing breast cancer compared to the general population is understood.

- There is a 50% or one in two chance of you passing the mutation on to each of your children.

A healthcare professional will discuss your options with you. You may want to discuss the result with other members of your family, who may also wish to consider genetic testing. Each family member who would like predictive testing will need to go to counselling before being tested.
WHAT WOMEN SAY

Getting my results was much more emotional than I thought. I wasn't prepared for my reaction or that of my family.

Breakthrough Campaigns & Advocacy Network member

See page 41 for more information on support for you and your family.

See page 59 for more information on risk-reducing surgery.

DISCUSSING YOUR TEST RESULT WITH YOUR FAMILY

All test results have implications for you and your family. Your healthcare professionals will discuss with you what the genetic test results mean, both for you and for your family. They will also help you to decide if or when to tell your family and how to explain it.

You and your relatives may react differently to hearing a genetic test result. Some people find that going through genetic testing brings them closer together as a family. In other families genetic testing may be problematic, since some relatives may rather not know whether there is a genetic fault running in the family.

Genetic testing can also uncover instances of non-paternity or adoption, which might not have been known in the family.

Some people feel guilt associated with passing on a genetic fault to their children, or having a negative (favourable) result when their sibling or another relative has a positive (unfavourable) result. It is important to remember that genes are inherited by chance and that no one is to blame for passing on a gene.

For those who have a faulty BRCA gene running in the family, a negative test result means they no longer have to worry about being at high risk of breast. For those who receive a positive result, there are healthcare implications for themselves and possibly their children and other family members.
FOCUS ON: PREIMPLANTATION GENETIC DIAGNOSIS (PGD)

Preimplantation genetic diagnosis (PGD) is an in vitro fertilisation (IVF) process used to test embryos for a specific gene fault so that only embryos free from a particular genetic condition are implanted in the womb. For PGD, parents would have IVF treatment, where the eggs are harvested and fertilised outside the body. The fertilised embryos are grown in the laboratory for a couple of days until they consist of eight cells, when an embryologist will remove one or two of the cells from each embryo and test them for the particular gene fault running in the family. Embryos without the gene fault are then implanted in the womb.

Although PGD has been available in the UK since 1990, it has only recently been licensed for use to screen embryos for BRCA mutations. Not all fertility clinics have a licence to perform PGD, however, and you will need to check with them. Depending on where you live, you may have to travel some distance to visit a clinic that offers PGD.

In order to be eligible for PGD a potential parent must have had a positive genetic test for a BRCA1 or BRCA2 fault. The decision to screen embryos to see whether they have a faulty breast cancer gene is a complex and very personal issue. What might be right for one person may not be right for another. It’s important for anyone affected to have appropriate information and support so they can make the right choice for them.

If you are considering PGD, it is recommended that you first talk to your GP about the options available. Your GP can also refer you to see a specialist at a hospital or fertility clinic.

PGD may not be available as an NHS treatment and each local area will decide individually whether or not funding can be provided. You should contact your local Patient Advice and Liaison Service (PALS) to discuss your situation.
CONFIDENTIALITY OF GENETIC TEST RESULTS

When you give a blood sample for a genetic test it is quite common for you to be asked to consider:

- Whether the blood sample can be used for research into hereditary breast cancer. You will not get any results back yourself from this research. If you do agree then your sample will be anonymised and will help scientists to understand more about breast cancer genetics. You do not have to agree to this if you do not wish to.

- Whether the results of any genetic test can be shared with your relatives. Since hereditary breast cancer runs in families, obviously it may be of interest to your relatives whether or not you have the gene, and getting your permission to share information could be very helpful to your family in the future.

Your genetic test results will be kept confidential and your doctor is not allowed to tell anyone that you have taken a genetic test or to reveal the results without your permission.

An exception to this confidentiality is that under certain circumstances your doctor may inform members of your family of the results from your genetic test. This might occur in cases where it will help those relatives understand their own genetic risk, allowing them to make decisions about their own healthcare. Before speaking to any relatives, your doctor should talk about this with you and discuss any concerns you might have.

In extremely rare circumstances the courts could also authorise police or lawyers to use the information contained in medical databases. It is, however, highly unlikely that this will happen, and even less likely that the results of genetic tests for breast cancer would be useful in a criminal investigation.

WILL I BE ASKED ABOUT MY GENETIC TEST RESULTS AT WORK?

Within the UK, there is no specific legislation that would prevent an employer from asking for BRCA test results. However, the Human Genetics Commission looked at the use of genetic tests by employers recently and found no evidence that this is happening at present.
INFORMATION AND SUPPORT FOR FAMILY MEMBERS

Family history and genetics teams are keen that you should receive as much information as you need about your family history and risk of breast cancer.

Professional guidelines emphasise that you should be given full information, both verbally and in written form, to be able to work in partnership with your healthcare professionals.

Everyone is different and you can control the amount of information you are given. However, it is sometimes difficult for health professionals to judge how much information is enough and how much is too much. If you don’t understand something you are told, ask for an explanation, and keep asking until you are sure you understand. It’s fine to ask questions and to ask for more support.

Equally, if you would prefer not to know, you should not be bombarded by information you don’t want. At a time when you are distressed and anxious, you may find it difficult to take in all the information you are given. This may mean letting the doctor or nurse know the amount of information that is right for you at this time or when you have had enough information for the moment.

People often find it difficult to think of questions to ask immediately after being given important information.

You might find it useful to:

• Ask for written information to take away and look at later.

• Tell your doctor or nurse that you would like a second appointment to discuss the information you have received.

• Take a recording device into your appointment and record your consultation.

• Take a family member or friend with you so that they can help you remember the questions you want to ask and what has been said. You might want to ask them to take notes for you during the consultation.

WHAT THE GUIDELINES SAY: INFORMATION PROVISION

Effective care involves a balanced partnership between patients and healthcare professionals. Patients should have the opportunity to make informed choices about any treatment and care and to share in decision making.

Patients should be offered individually tailored information, including information about sources of support (including local and national organisations).

Familial Breast Cancer: The classification and care of women at risk of familial breast cancer in primary, secondary and tertiary care, National Institute for Health and Clinical Excellence, 2006 update
WHAT WOMEN SAY

Make sure that you ask your family if they would like information about your family’s risk. Some people will want information but others may not.

Breakthrough Campaigns & Advocacy Network member

I was nervous of talking to my sister about it as I had to tell her we have a slight increased risk. She was fine with it though, as it means we’ll now be screened.

Breakthrough Campaigns & Advocacy Network member

WHAT THE GUIDELINES SAY: GETTING FAMILY HISTORY INFORMATION

Asking women to discuss their family history with relatives is useful in gathering the most accurate information.

Familial breast cancer: The classification and care of women at risk of familial breast cancer in primary, secondary and tertiary care, National Institute for Health and Clinical Excellence, 2004

• Write your questions down as you think of them – perhaps when you are back at home – and take them with you to your next clinic visit.

Following your consultation you will receive a letter from the clinic summarising the discussion.

DISCUSSING YOUR FAMILY HISTORY OF BREAST CANCER

Discussing your family history of breast cancer can bring up many emotional issues, both for you and your family. You may be worried about the possibility of developing cancer; or if you have had cancer in the past, finding out you may have a family history of breast cancer can bring back some of the emotions you went through at the time of your diagnosis. You may also recall the illness or death of a family member from cancer or be worried about the implications for members of your family as well as yourself.

Your concerns and information needs will change as you go through the different steps of finding out about your family history of breast cancer. It is important to realise that you may react differently to different pieces of news, and that one family member may react differently to another. Some people want lots of information about their possible risk and what this means, others may not want to know immediately, or at all.

Health professionals use the information you give them to assess your risk of developing breast cancer in the future. To get the best information about your family history you may need to talk to your relatives.

You will need to know:

• The current ages of your blood-related parents, grandparents, aunts, uncles, first cousins, nephews and nieces. This is needed for both your mother’s and your father’s side of the family.

• The ages of your brothers, sisters, sons, daughters and grandchildren.
• The ages at which any relatives died (whatever the cause).

• Whether any of your relatives described above has had cancer of any kind, and if so, both their age when diagnosed and the part of the body where the cancer developed.

• Whether anyone has had several different cancers (eg if someone has had cancer in both breasts or has had breast and ovarian cancer).

• Whether you have Ashkenazi Jewish ancestry (this is because gene changes that give an increased risk of breast cancer are more common among Ashkenazi Jews).

It can be difficult to find out the details of your relatives’ medical histories. Obtaining this information can be distressing if any relatives are not ready to think about their family history or if you haven’t spoken to them for a long time.

Your genetic counsellor will discuss these possibilities with you and help you prepare for any emotions that arise. They can support you in decisions about contacting your family and suggest the best method of contacting them and having these discussions.

The US organisation Facing Our Risk of Cancer Empowered (FORCE) has produced a worksheet to help people discuss their family history with their family. Find out more at www.facingourrisk.org/information_research/documents/sharingworksheet.pdf. Please note that the resources and legal guidelines in the worksheet are specific to the USA and may not be applicable in the UK.

If you have a confirmed genetic test result, this will have some implications for your family, which you may wish to discuss with them.
INSURANCE AND GENETIC TEST RESULTS

Until 2014, there is a moratorium (temporary ban) on insurance companies asking you for any results of predictive genetic tests on the breast cancer genes BRCA1 and BRCA2 when you take out life, critical illness or income protection insurance.

Insurers do not use information from predictive genetic test results when setting premiums for private medical insurance, travel insurance or long-term care policies. The moratorium is reviewed every three years by the Department of Health and the Association of British Insurers and is due to be reviewed in 2011. To date the moratorium has been extended each time.

Insurance companies also cannot ask you to take a predictive genetic test or for the results of any predictive test taken by a relative.

However, insurance companies can ask you about your own medical history and your family medical history. They are permitted to seek, with your consent, access to certain family medical history, diagnostic (but not predictive) genetic test results and medical reports from your GP. In some cases, insurance companies may ask you to undergo a medical examination. Insurers will usually only ask your GP for first degree family history information on their report forms. First degree relative means your mother, father, sisters, brothers and any children. In some cases, insurers can ask for wider family medical information (beyond your first degree relatives).

Any genetic test you have taken as part of a research study is not considered part of your medical care, therefore insurers agree that customers will not be required to disclose any predictive or diagnostic test results acquired as part of clinical research.

You are only required to disclose health information at the time you take out an insurance policy up until the policy starts. After your policy starts, you have no obligation to disclose any additional information, including the results of genetic tests, to your insurer unless you decide to change insurers.

For information about diagnostic and predictive genetic testing see page 31.
WHAT THE GUIDELINES SAY: GENETIC TESTS AND INSURANCE

Customers will not be required to disclose the results of predictive genetic tests for policies up to £500,000 of life insurance, or £300,000 for critical illness insurance, or paying annual benefits of £30,000 for income protection insurance.

Concordat and Moratorium on Genetics and Insurance, Department of Health and Association of British Insurers, 2005

Customers will not be asked to, nor be put under any pressure to, undergo a predictive genetic test in order to obtain insurance.

Concordat and Moratorium on Genetics and Insurance, Department of Health and Association of British Insurers, 2005

WHAT WOMEN SAY

It can be difficult to buy certain types of insurance, so although it takes time, it’s best to shop around.

Breakthrough Campaigns & Advocacy Network Member

If an insurer receives the result of a predictive genetic test, the case must be referred to the insurer’s genetics expert, who is fully trained in the rules and regulations on using this information. This expert (called the Nominated Genetic Underwriter) has access to trained medical clinicians, whom they can call on for additional expertise if needed.

Every case is considered individually and the premium you pay will depend on the type of insurance policy you are buying, how long that policy will stay in force and the likelihood that the event you are insuring yourself against will happen. Therefore, it is often useful to shop around. You can either make enquiries to various insurance companies yourself or you can use an Independent Financial Adviser (IFA). IFAs will make enquiries on your behalf and will offer you independent advice on which company offers the best policy for you.

WHAT IF MY GENETIC TEST RESULT COULD HELP REDUCE MY PREMIUM?

If you have taken a predictive test and the result was favourable (negative), insurance companies are not obliged to take this into account. This means that each insurance company will decide how to deal with this situation on an individual basis.

Similarly, if you have a family history of breast cancer and have had risk-reducing surgery, you can choose to tell your insurer about your situation. Some insurers may take this into account, but they are not obliged to.
REGIONAL GENETICS CENTRES

ENGLAND

Northern Regional Genetics Service
Covers: Cleveland, Durham, Tyne & Wear, Northumberland, Cumbria
Based: International Centre for Life, Newcastle upon Tyne
Tel: 0191 241 8600

Yorkshire Regional Genetics Service
Covers: N Yorkshire, Bradford, W Yorkshire, Leeds, Wakefield, East Riding, Grimsby, Scunthorpe
Based: Chapel Allerton Hospital, Leeds
Tel: 0113 392 4430

Manchester Regional Genetics Centre
Covers: Greater Manchester, Lancashire, Cumbria and Macclesfield
Based: St Mary’s Hospital, Manchester
Tel: 0161 276 6506

Cheshire and Merseyside Genetic Services
Covers: Liverpool, Wirral, Halton, Southport, St Helens & Knowsley, Warrington, Runcorn, Chester, Crewe, Isle of Man
Based: Liverpool Women’s NHS Foundation Trust, Liverpool
Tel: 0151 802 5000

Nottingham Centre for Medical Genetics
Covers: Nottingham, N Nottinghamshire, Lincolnshire, S & N Derbyshire
Based: City Hospital NHS Trust, Nottingham
Tel: 0115 962 7728

North Trent Clinical Genetics Service
Covers: Doncaster, Worksop, Barnsley, Chesterfield, Rotherham, Sheffield, Buxton
Based: Sheffield Children’s NHS Foundation Trust, Sheffield
Tel: 0114 271 7025
West Midlands Regional Genetics Services
Covers: Staffordshire, Shropshire, Warwickshire, Birmingham, Hereford & Worcester, W Midlands
Based: Birmingham Women’s Hospital, Birmingham
Tel: 0121 627 2630

Leicestershire Genetics Centre
Covers: Leicester, Leicestershire, Rutland
Based: Leicester Royal Infirmary, Leicester
Tel: 0116 258 5736

East Anglian Regional Genetics Service
Covers: Cambridgeshire, Norfolk, Suffolk, parts of N Essex, Hertfordshire, Lincolnshire, Bedfordshire
Based: Addenbrooke’s Hospital NHS Trust, Cambridge
Tel: 01223 216446

Oxford Regional Genetics Service
Covers: Oxfordshire, Northamptonshire, Buckinghamshire, Berkshire, Swindon
Based: The Churchill Hospital, Oxford
Tel: 01865 226 034

North East Thames Regional Genetics Services
Covers: North and East London and Essex.
Based: Great Ormond Street Hospital for Children NHS Trust, London
Tel: 020 7905 2647

North West Thames Regional Genetics Service
Covers: Hertfordshire, Bedfordshire, Barnet, Hillingdon, Brent & Harrow, Ealing, Hammersmith, Hounslow, Kensington, Chelsea, Westminster, Edgware
Based: Northwick Park & St Marks Hospitals, Harrow
Tel: 020 8869 2795

South East Thames Regional Genetics Service
Covers: Kent, E Sussex, Bromley, Greenwich, Bexley, Lambeth, Southwark, Lewisham
Based: Guy’s Hospital, London
Tel: 020 7188 1364
South West Thames Regional Genetics Service
Based: St George’s Hospital Medical School, London
Tel: 020 8725 0574

Wessex Clinical Genetics Service
Covers: Hampshire, Dorset, Isle of Wight, Salisbury
Based: Princess Anne Hospital, Southampton
Tel: 02380 796170

Bristol Clinical Genetics Service
Covers: Avon, Somerset, Gloucester, Cheltenham
Based: St Michaels Hospital, Bristol
Tel: 0117 928 5652

Peninsula Clinical Genetics Service
Covers: Devon, Cornwall
Based: Royal Devon and Exeter NHS Foundation Trust, Exeter
Tel: 01392 402910

SCOTLAND
North of Scotland Clinical Genetics Service
Covers: Grampian, Highland, Orkney & Shetland, Western Isles
Based: Medical School, Aberdeen
Tel: 01224 552120

East of Scotland Regional Genetics Service
Covers: Dundee, Perth, N Fife, Angus, Perthshire
Based: Ninewells Hospital and Medical School, Dundee
Tel: 01382 632035

South East Scotland Regional Genetics Service
Covers: Lothian, Fife, Borders
Based: Western General Hospital, Edinburgh
Tel: 0131 537 1116

West Scotland Regional Genetics Service
Covers: Greater Glasgow, Clyde, Ayrshire & Arran,
Forth Valley, Lanarkshire, Dumfries & Galloway
Based: Yorkhill Hospital, Glasgow
Tel: 0141 201 0808

WALES
All-Wales Medical Genetics Service
Covers: all of Wales
Based: University Hospital of Wales, Cardiff
Tel: 02920 744028