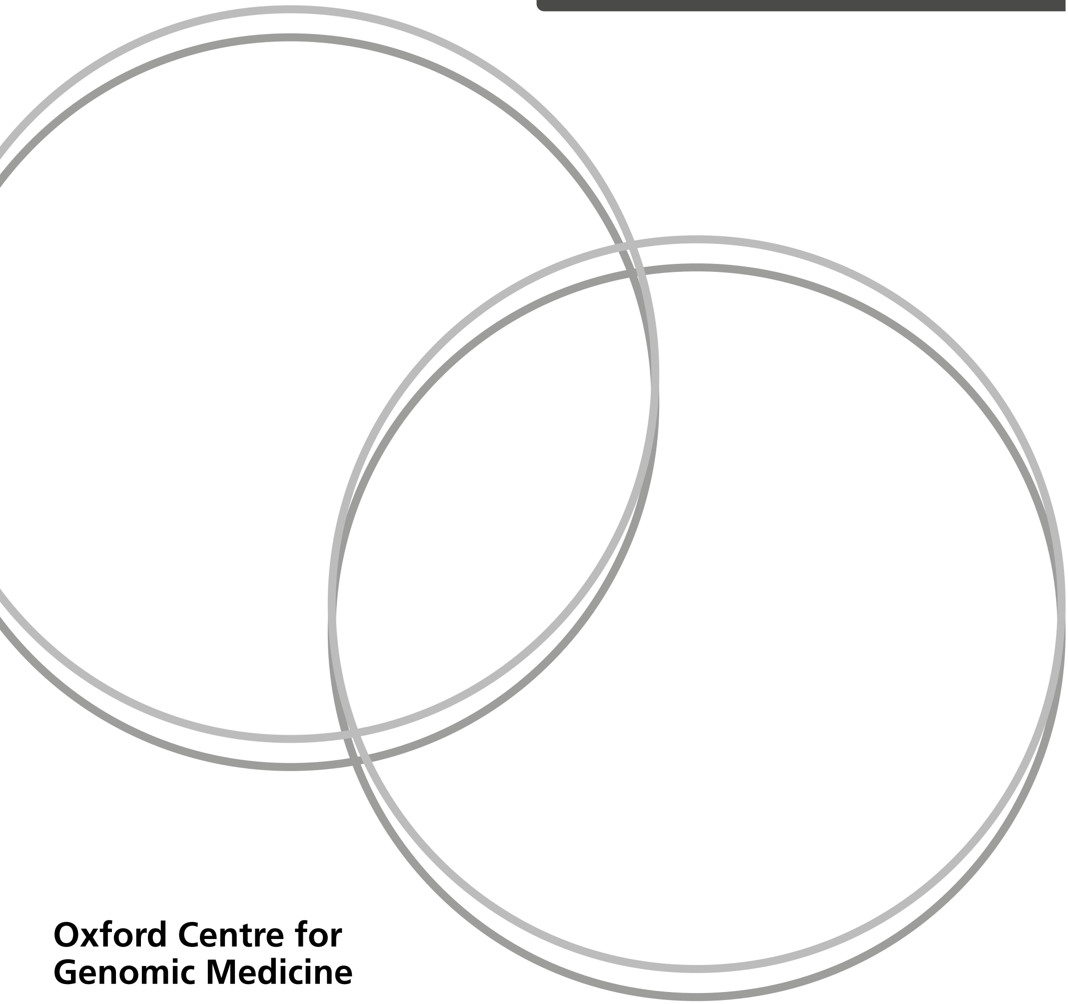
NHS

Oxford University Hospitals
NHS Foundation Trust

The Cancer Genetics Service

Information for people who have been referred to the Cancer Genetics Service



Oxford Centre for
Genomic Medicine

This leaflet contains a lot of information. You may find it helpful to keep it and refer back to the relevant sections later.

Why have I been referred?

You or some of your relatives may have had cancer. The Genetics Service can help answer some of the following questions:

- Are members of my family at an increased risk of developing cancer?
- Can we have extra cancer screening?
- Is there anything I can do to reduce my cancer risk?
- Can I have a genetic test?

What is the family history form for?

To answer these questions accurately, we need to make a full assessment of your family history. It is important for us to have as much information as possible, which is why we asked you to complete the family history form. If it was not possible to gather all the information asked for, we can still proceed, using the information you have managed to give us.

I’ve completed the form, what happens now?

We try and confirm details of your relatives’ cancers, where possible. We need permission from living relatives to look at their medical records. We will not contact your relatives directly but will send consent forms for the appropriate relatives via you, to pass on to them if you feel happy to approach them.

Once we have the information we need, we will contact you with advice or a clinic appointment. In the meantime, if you have any concerns about symptoms you should consult your GP.

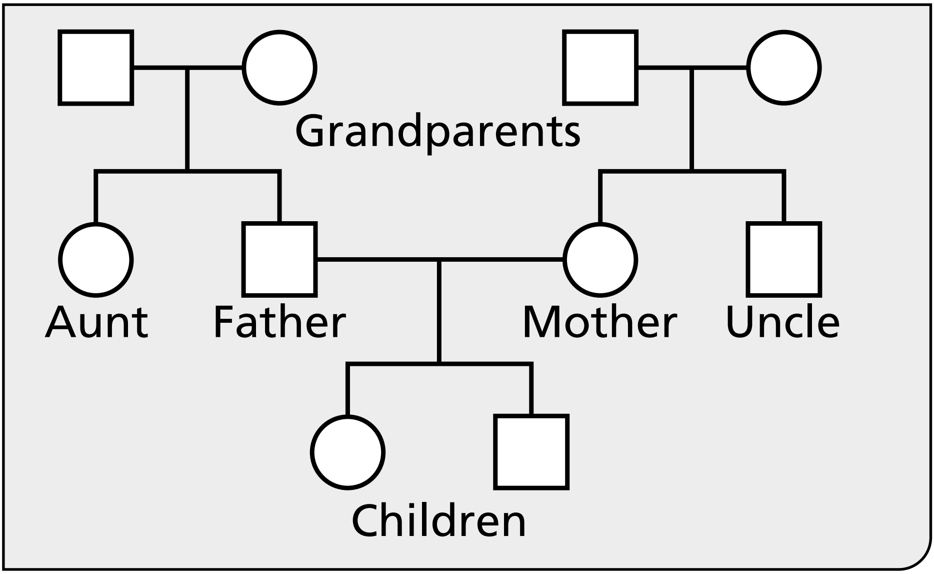
How long will all this take?

To an extent, this depends on you and your family. We really need to receive information as promptly as possible to advise you quickly and accurately. Once we have received your GP referral and family history form, we aim to contact you with screening advice or to see you in clinic within 18 weeks. This is in line with government targets.

If the consent forms are delayed, we may not be able to obtain all the information we need ready for when we prepare our advice to you. This may affect the accuracy of our advice. If you are having problems obtaining the information we require,please let us know so we can delay our advice. If the delay needs to be longer than 6 months, you may prefer to be re-referred at a more appropriate time.

How is my family history assessed?

From the form, we will draw your family tree.



Cancer is common, particularly in older people. Most of these cancers will have occurred by chance. From your family tree, we look at the types of cancer in your family and the age when they were diagnosed.

Only a small number of families have a strong inherited risk of cancer. This is more likely when we see:

- Several relatives with the same types of cancer, or cancers which are associated (e.g. breast and ovary or bowel and womb),
- Individuals with cancer at young ages,
- Individuals with more than one different cancer.

Certain cancers (e.g. lung and cervical) have recognised environmental causes and tend not to be inherited.

Will I be offered an appointment?

Not everyone is routinely offered an appointment in the Genetics clinic. Sometimes we will write back to you and your GP or consultant with information. You may also be referred on for extra cancer screening if this is appropriate. If you still have questions after receiving our letter we are happy to discuss your concerns over the telephone or to arrange an appointment for you if you wish.

What would the appointment involve?

You may be offered an appointment with one of our doctors or genetic counsellors. The appointment will usually be at one of your local hospitals. Consultations last around 45 minutes. You are welcome to bring members of your family or a friend to the clinic.

If you need an interpreter, please let us know in advance so we can make the appropriate arrangements. After the appointment we will write to you and your doctor/GP, confirming what we have discussed.

What if I cannot attend my appointment?

As only 4 or 5 families can be seen in each clinic session please let us know well in advance if you are unable to attend so that this appointment can be offered to another family. You will then be given an appointment when one is next available.

If you do not wish to continue with your referral at any stage, please let us know and we won’t send you any further appointments.

What does screening involve?

Cancer screening aims to detect cancers early when the outlook following treatment is usually good. As cancer screening can have drawbacks it is important that extra screening is only offered when the benefits to an individual outweigh the risks.

Can I have a genetic test?

In some families we are able to offer genetic testing. This involves reading the genetic code within our cells to look for a change within a ‘gene’. A gene is a short section of our inherited material (our DNA) which controls how our cells and bodies work. Where we are able to offer these tests to a family, we usually require a sample of blood from a relative who has had cancer before testing can be considered in other family members.

DNA banking

If a genetic test is not available for your family at the moment, we may offer to store a blood sample from a family member who has been diagnosed with cancer in case of future medical advances.

If a relative with cancer is terminally ill it is important for you to let us know as soon as possible. It may be possible for a blood sample to be stored from your relative. If they wish we can discuss this with them or organise for a genetic doctor or counsellor to see them. Alternatively, with their permission, we can organise for their own doctor to collect a blood sample which will be stored in the DNA lab for future testing.

If your relative is too unwell to give their consent to store a sample, please still discuss the possibility of storing a sample from them with us or their doctors. If their next of kin agree that they would have given consent had they been well enough to do so a sample may still be stored from them. In this way we can preserve the possibility of genetic testing at a later date, should that be appropriate in your family.

Research studies

We may let you know if there are approved research studies around inherited cancer in which you or your family could take part. It is your decision whether you wish to take part in these studies and it will not affect your care if you choose not to.

What about other relatives?

Relatives who are concerned about their own risk of developing cancer should ask their GP to refer them to their local Cancer Genetics Service. We can only share the information gathered regarding your family with your permission.

Where can I get further information?

Some information about cancer can be found on the following websites. You may wish to wait until after your appointment so that we can direct you to information most appropriate to you.

Website: **http://www.cancerresearchuk.org/**

Website: **http://www.macmillan.org.uk/Home.aspx**

If you need more advice please contact:

Oxford Cancer Genetics Service
Oxford Centre for Genomic Medicine
ACE building (Room 33G16)
Nuffield Orthopaedic Centre
Oxford University Hospitals NHS Foundation Trust
Windmill Road
Headington
Oxford OX3 7HE

Tel: **01865 226 034**

Email: **orh-tr.churchill-clinicalgenetics@nhs.net**

Website: **http://www.ouh.nhs.uk/clinical-genetics**

Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

This leaflet is based, with permission, on a leaflet produced by the West Midlands Regional Genetic Service.

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