

## What would a genetic test tell you?

A genetic test would tell you whether or not you have inherited an altered HNPCC gene.

## What does it mean if you are tested and find that you have inherited an altered HNPCC gene?

This would mean that your chance of developing colorectal cancer during your lifetime would be increased (up to 80%).

If you are female, your chance of developing uterine cancer during your lifetime would be increased (up to 60%), and you would have an increased chance of developing ovarian cancer (about 10%).

Each of your children (if you have any) would have a 50/50 chance of having inherited the altered gene from you.

## What does it mean if you are tested and find that you have **NOT** inherited an altered HNPCC gene?

In this case your risk of developing HNPCC types of cancer during your lifetime would be the same as that for any other person.

Also, your children would not be at any increased risk of HNPCC types of cancer.

## What can you do to help with early detection and prevention of HNPCC types of cancer?

**Bowel awareness:** By being aware of your normal bowel habit, you are more likely to notice if there are any changes. If you are concerned, you can go along to your GP who will refer you to a specialist if necessary.

**Colonoscopy screening:** If you are at increased risk of colorectal cancer, you can be referred for colonoscopy screening.

**Uterine & ovarian screening:** Women who are at increased risk can be referred for uterine and ovarian screening.

**Risk-reducing surgery:** Some women who are at high risk consider having a hysterectomy to remove their uterus and ovaries, when they have completed their family. Surgery greatly reduces the risk of developing uterine and ovarian cancer.

### For more information:

#### Clinical Genetics Departments

Northern Scotland (main base Aberdeen)

Tel: 01224 552120 Fax: 01224 559390

(Aberdeenshire, Moray, Highland, Western & Northern Isles)

Tayside (main base Dundee)

Tel: 01382 632035 Fax: 01382 645731

(Perth & Kinross, Angus, North East Fife)

South East Scotland (main base Edinburgh)

Tel: 0131 651 1012 Fax: 0131 651 1013

(Borders, Lothian, South West Fife)

West of Scotland (main base Glasgow)

Tel: 0141 201 0808 Fax: 0141 201 0361

(Glasgow, Argyll & Bute, Ayrshire, Dumfries & Galloway, Stirling, Lanarkshire, Falkirk)

If you need more advice about cancer and support groups, please contact:

[www.maggiescentres.org](http://www.maggiescentres.org)

Maggies Highlands Tel: 01463 706302

Maggies Dundee Tel: 01382 496384

Maggies Edinburgh Tel: 0131 5373131

Maggies Glasgow Tel: 0141 330 3311

# Genetic Testing



Information for people with a family history of HNPCC who have not had cancer themselves

Seen in clinic by.....

## What can we do at the Family Cancer Clinic?

From your family history, we can estimate how likely it is that some of the people in your family have inherited an increased tendency to develop Hereditary Non-Polyposis Colorectal Cancer (HNPCC) types of cancer, (please see leaflet 'Hereditary Non-Polyposis Colorectal Cancer (HNPCC)').

We can also estimate your chance of getting these cancers during your lifetime and talk to you about your options for screening and reducing your risk. It **may** be possible for you to have a genetic test.

## Who can have a genetic test?

If there is a strong chance that some of the people in your family have an inherited susceptibility to HNPCC we will have talked to you about genetic testing.

Before we can even begin to think about testing you, we first need to look at the HNPCC genes in a blood sample from your relative who has had an HNPCC type of cancer.

A genetic test **may** be available for you, if there is a strong family history of HNPCC cancers and a relative who has had this type of cancer is willing to give a blood sample for genetic testing.

## How does genetic testing affect the family?

Having a genetic test raises many issues, both for relatives who have not had cancer and for relatives who have had cancer.

It is therefore important for anyone who is considering having a genetic test to have the opportunity to talk through the issues in order to help them to reach a decision about what they want to do.

## What needs to happen before you can have a genetic test?

You would need to approach your relative who has had an HNPCC type of cancer to see if he/she would consider giving a blood sample for genetic testing.

This is not always an easy question to ask and it is up to your relative to decide whether to give the blood or not.

We will give you a form for your relative to fill in if he/she is happy for us to have access to their medical records. On that form there will be a space for them to tell us that they are interested in talking about inherited cancer. We will then contact them and arrange to talk to them about genetic testing.

If your relative decides to give a blood sample, we can take the blood at the clinic.

The laboratory team will look for alterations in the genes that cause HNPCC in your relative's blood sample. We will contact your relative with any information as we receive it from the laboratory.

Any result will be confidential to your relative. It would be up to them to decide who they wish to tell about it.

## What would it mean for you if we **DO NOT** find an altered gene in your relative's sample?

This would mean that you could **not** be tested at that time.

Unfortunately, if we do not find an altered gene in your relative's sample, their cancer may still have been inherited. They might have an alteration in another gene that has not yet been discovered. Alternatively, we were unable to find the alteration in the genes that we tested.

This could mean that you are still at increased risk of HNPCC types of cancer. In that case it would be important for you to continue with any screening that has been set up for you.

## What would it mean for you if we **DO** find an altered gene in your relative's sample?

This would mean that **you could be tested** to see if you have inherited the same altered gene.

Before you have a genetic test we would offer you the opportunity to come back to clinic. We would then discuss what genetic testing could mean for you and how you would feel if you were found to have the altered gene.

We would ask you to take some time to think about this and to come to another appointment with the same genetic counsellor a month or so later. At the next appointment, we could take a blood sample from you if you still wish us to.

We would ask you to come back to the clinic for your result four weeks later. After the result, we will see you as often as you would like. We can also arrange further support for you.