Saint Mary's Hospital
Manchester Centre for Genomic Medicine

Information for Patients

Predictive testing for high risk genes that predispose to cancer

This leaflet has been designed to explain the steps involved in having a predictive test for the high risk genes that predispose to cancer.

When a specific gene fault is identified in a family, a predictive test will show whether someone has inherited the faulty copy of the gene and whether he/she has a high risk of developing specific cancers.

Predictive testing usually involves 3 appointments. It is important that you take as much time as you need before deciding to go ahead with testing. We understand that this process may seem very long, but our protocol is based on the experiences of people who have been through predictive testing in the past and the things they have found most helpful.

You do not have to convince us to test you.

It is your decision whether or not to have the test. We are here to give you information on the options available to you, to help you think through the issues before making your decision and to help you prepare for the result if you decide to be tested.

First predictive test appointment

The first appointment you receive will be with one of the members of the genetics team. This appointment is to enable us to meet you and exchange information. We welcome and encourage you to bring someone along to this appointment who can be there to help and support you.

We need to know about your family history of cancer so that we can ensure we are testing for the right condition. This appointment also gives us the opportunity to explain the cancer risks associated with the condition, how it is passed on in families, and your chance of having inherited the faulty copy of the gene.

We will explain how the test works and what its limitations are. We will also talk about the effect a 'good news' or 'bad news' result might have on you and your family. The issues we consider are practical things like the impact of having the test on your working life or if there are financial implications of

having the test. We will also talk about your options for screening and/or about risk reducing surgery. You will also have the opportunity to discuss the emotional impact of having the test and to consider the way a result might affect family relationships and how having a test might affect the way you feel about the future.

Following this appointment, we wait for you to contact us before arranging to see you again.

No testing will be done at your first appointment.

Second predictive test appointment

This appointment is arranged once you have been back in touch with us to confirm that you want to go ahead with a predictive test. It gives you the chance to talk through any matters that may have changed or arisen since your last appointment.

If you wish to go ahead with testing, a blood sample can be taken at this appointment. We arrange your appointment to come back for your result when the blood sample is taken.
We usually receive results within 4 weeks and so the results appointment will be arranged for between 4-6 weeks after your blood sample is taken.

The results appointment

This appointment is to give you the results of the test in person. We ask that you bring someone with you when you come for your result. Further appointments will be made depending on the result of the test.

For more information

If you need more advice about any aspect of testing for high risk genes that predispose to cancer, you are welcome to contact:

Manchester Centre for Genomic Medicine
Sixth Floor
Saint Mary's Hospital
Oxford Road
Manchester M13 9WL

Telephone: (0161) 276 6506 (Reception)
Facsimile: (0161) 276 6145

Department staffed Monday - Friday, 9.00 am to 5.00 pm.

Please let us know if you would like this leaflet in another format (e.g. large print, Braille, audio).

We would like to acknowledge our Clinical Genetics colleagues at Guy's and St Thomas' Hospital NHS Trust who originally designed and wrote this leaflet.

Seen in clinic by (doctor): _____

And (Genetic Counsellor): _____

Telephone number: _____

Family reference number: _____