Southeast of Scotland Genetic Service
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Lynch Syndrome Predictive Testing

Information for Patients

A gene change has been identified in your family that is thought to be the cause of your family history of cancer. This means that a genetic test is available for you, to see if you too have inherited the gene change and have an increased risk of developing cancer.

People with this gene change have a condition called 'Lynch Syndrome'. This confers a significantly increased risk of developing several types of cancer, particularly colon (bowel) and endometrial (uterine/womb) cancer. The specific types of cancer and level of risk is dependent on which particular gene is involved. Other cancers include ovarian cancer, urinary tract cancers, and upper gastrointestinal tract cancers, such as stomach cancer.

- ***If you carry the gene change***, your lifetime risk of cancer is significantly increased and your children or future children are at a 1 in 2 (50%) risk of inheriting the gene change.
- ***If you do not carry the gene change,*** your risk of developing cancer is similar to other people in the general population and your children would not be at risk of inheriting the gene change.

If you are found to have the gene change, there are a number of ways you can manage your increased risk. These include screening, risk reducing surgery and 'chemoprevention'.

Please see overleaf for more information on Lynch Syndrome.

A limitation of any genetic test is that just like much of medical science, we do not know with certainty all the factors that influence health. Very occasionally the current understanding of a gene change or variant may change as more information becomes available.

Plan of action going forward

Please tick as appropriate		Enter details
	You have decided to proceed with testing and we have made the following arrangements for you to receive the results:	
	A follow up appointment has been arranged on:	
	You have decided to get back in touch when you feel ready to proceed with testing.	

Following genetic testing, results are usually available within 6 weeks. Your result will be confirmed in writing to you and copied to your referring clinician/GP.

You were seen by:	Genetic Counsellor	Patient Label
Date:		

The following management options are available for you if you have inherited the gene change.

These **may** also be appropriate to consider should you decide not to proceed with genetic testing.

Colon cancer

Screening - Screening for individuals at significantly increased risk of colon cancer is by colonoscopy (a camera test to look into your bowel) every 2 years. For MLH1 and MSH2 carriers, colonoscopy is recommended from age 25 years and for MSH6 and PMS2 carriers from the age of 35 years.

Screening by colonoscopy allows the detection of polyps in the colon and the opportunity to remove them thereby potentially reducing the risk of cancer developing.

Aspirin and colon cancer risk reduction - Recent research has suggested taking aspirin regularly can half the bowel cancer risk after four years of use. The current suggestion is that daily aspirin (dose dependant on weight) may be appropriate as there is evidence that this reduces the bowel cancer risk. An ongoing study is investigating the different doses of aspirin.

Before starting aspirin, **you should consult your GP** to ensure there are no medical reasons why you should avoid taking aspirin.

Gynaecological cancers in women

The effectiveness of screening for endometrial and ovarian cancer has not been proven and we are currently not able to offer it.

We suggest that women with a gene change consider the option of having risk reducing gynaecological surgery once they have completed their family history. For MLH1, MSH2 and MSH6 gene change carriers, surgery involves removal of the ovaries, fallopian tubes, and womb. For PMS2 gene change carriers, surgery involves removal of the womb only. We will discuss this in more detail if you are shown to have inherited the gene change.

Stomach cancer

The effectiveness of screening for stomach cancer has not been proven and we are currently not able to offer it.

Helicobacter pylori testing – *H.pylori* is a bacterium commonly found in the stomach. Having *H.pylori* can slightly increase the risk of developing stomach cancer. It is therefore recommended that you are tested for the presence of *H.pylori* as it can easily be treated to eradicate it.

Additional information

Preimplantation Genetic Testing (PGT) - Some carriers (female or male) might consider the option of Preimplantation Genetic Testing (PGT) to avoid passing on the gene change to their children. PGT is a process that involves '*in vitro* fertilisation' (IVF) to create embryos from the couple in the laboratory, which are then tested at an early stage for the familial gene change.

Insurance and genetic test results – In 2018 the Association of British Insurers agreed to an open-ended moratorium which means that you will not have to disclose the results of your predictive genetic test to them when you are taking out insurance. The Moratorium will be reviewed by the Department of Health and the ABI every 3 years. For further information please see: www.abi.org.uk/data-and-resources/tools-and-resources/genetics/genetics-faqs/