

What happens if something is found on surveillance?

This depends on what is found. You may be referred to a specialist for further investigations and management.

Are there alternatives to surveillance?

An operation to reduce the risk of developing breast cancer may be discussed with women. It involves removing the healthy breast tissue and is also called a 'risk-reducing mastectomy.' Further information on risk reducing breast surgery can be found at Macmillan Cancer Support.



Will this surveillance advice change?

The surveillance recommended for you may vary from the guidance in this leaflet. Your doctor or genetic counsellor may adapt the surveillance for you based on your family history and your own medical history.

The surveillance advice suggested is based on the best available evidence at this time and the agreed opinion of experts. The guidance is reviewed and updated as evidence emerges.

I have further questions about cancer surveillance

You can discuss any specific concerns or questions about cancer surveillance with your Clinical Geneticist or Genetic Counsellor.



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The PTEN UK & Ireland Patient Group's purpose is to improve the lives of patients, parents and carers of all ages affected by PTEN genetic alterations. We aim to achieve this through providing patient support, increased awareness, earlier diagnosis, intervention and further research into treatment and prevention.

For more information, please visit our website:

www.ptenuki.org



PTEN Hamartoma Tumour Syndrome

Cancer surveillance in Adults

A guide for patients and families



Introduction

This leaflet will give you some information about why cancer surveillance is suggested in people with PTEN Hamartoma Tumour Syndrome (PHTS) and what surveillance is currently recommended.

What is 'cancer surveillance'?

This is a test or series of tests that look for early signs of cancer in people without any symptoms. The aim is to detect cancers at an earlier stage, as treatment is more likely to be successful.

Why do I need this surveillance?

The PTEN gene works to stop cells in the body from growing and dividing in an uncontrolled way. Uncontrolled cell growth is how tumours are known to develop in the body.

Genetic alterations (or spelling mistakes) in PTEN mean cell growth is not adequately controlled. As a result, people with PHTS are at risk of developing certain cancers earlier in their lifetime than the general population. We know these cancers are of the **breast**, **thyroid**, **kidney (renal)**, **bowel**, **womb lining (endometrial)** and **skin**.

For this reason, experts have suggested regular surveillance tests to try to identify these different cancers (Table 1).

Table 1: Summary of surveillance protocol in adults from the European Reference Network

Cancer	Recommended surveillance
Breast	<ul style="list-style-type: none">• From 30-50 years – Breast MRI scan every year• From 40 years - Mammogram every year
Thyroid	<ul style="list-style-type: none">• From 18 years – Ultrasound scan once a year *
Kidney	<ul style="list-style-type: none">• From 40 years – Ultrasound scan every two years
Bowel	<ul style="list-style-type: none">• From 35-40 years – baseline colonoscopy **
Skin	<ul style="list-style-type: none">• From 30 years – baseline examination of the skin **
Womb	<ul style="list-style-type: none">• No surveillance routinely offered in the United Kingdom.• Refer to Gynaecology

* The age of surveillance may vary depending on your personal or family history

** Further surveillance may be necessary depending on what is found

How likely am I to develop cancer?

Cancer is a common disease. It can occur due to a combination of factors including increasing age, lifestyle, environment, hormonal factors and some genetic contributions.

It is not possible to predict if a person with PHTS may develop cancer or what type this might be. People are affected in different ways despite having a spelling mistake in the same gene. As with most genetic conditions, this variability is not yet fully understood.

However, it would be rare for a person to develop all the cancers listed. Your doctor can advise on the signs and symptoms to be aware of. If you are worried about any new symptoms between surveillance, you should seek a medical review sooner.

Why is there no surveillance for womb (endometrial) cancer?

Surveillance is not currently recommended, as it is not proven to reliably detect womb cancer.

Your Clinical Genetics team can refer you to doctors specialising in women's health, to discuss whether removal of the womb (hysterectomy) would be appropriate for you or not.