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# PALB2 Predictive Testing

## Information for patients

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

**If you do not carry the gene change**, your risk of developing cancer may be similar to other people in the general population, and your children would not be at risk of inheriting the gene change.

**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. There are a number of ways you can manage your increased risk, including screening and risk reducing surgery.

*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
<input type="checkbox"/>	You have decided to proceed with testing; We have made the following arrangements for you to receive the results.	
<input type="checkbox"/>	You have decided to get back in touch when you feel ready to proceed with testing.	

Following testing, results are usually available within 6 weeks. Results are confirmed in writing to you and copied to your referring clinician/GP.

You were seen by:	Genetic Counsellor	Patient Label
Date:		

**Our knowledge regarding PALB2 is rapidly increasing, and advice could change over time.** The management options overleaf are available if you have inherited the PALB2 gene change. Some of these *may* also be appropriate to consider should you decide not to proceed with genetic testing.

## Cancer risks and management options for PALB2

Exact lifetime cancer risks for individuals with a PALB2 gene change are not fully understood, but more specific information will become available with ongoing research.

**Female breast cancer:** Studies estimate the lifetime risk of developing breast cancer to be between 40%-60% (compared to population risk of around 12%). However, an individual's actual risk is thought to be dependent on how many breast cancers there are in their immediate family.

**Breast Screening:** The following screening is suggested:

From age 30-49	MRI and mammography every year
From 50-69 years	Mammograms every year
70 years+	mammograms every 3 years (through National Breast Screening Programme)

**Risk reducing breast surgery:** At the moment there is not enough long term data on the breast cancer risks to know whether preventative mastectomy should be considered. It may be appropriate, particularly if there is a strong family history of breast cancer, but caution is advised. Having your breasts removed reduces risks by over 90%. There are many surgical options available that include reconstruction surgery.

**Be breast aware:** We would encourage you to be breast aware and seek advice from your GP if you notice any changes in your breasts. An additional information leaflet has been supplied.

**Ovarian cancer:** There is a small increased risk of ovarian cancer (around 5% lifetime risk compared to population risk of 1.5-2%). There is no effective screening for ovarian cancer however risk reducing surgery can be considered.

**Pancreatic cancer:** There is a small increased risk of pancreatic cancer for both men and women (2-3% lifetime risk compared to population risk of 1%). There is not clear evidence of whether surveillance for pancreatic cancer is effective and until more data is available, we do not recommend it outside of a clinical study. Specific advice usually depends on the family history.

**Male breast cancer:** There may be an increased risk of breast cancer, but the chance is relatively low and not at high enough risk to need extra screening.

**Prostate cancer:** there is no evidence to suggest that the risk of prostate cancer is significantly increased, but studies have been small so far. If you have any symptoms you were concerned about you should go to your GP and ask their advice.

## Additional information

**Preimplantation Genetic Testing (PGT):** Some PALB2 carriers (female and male) might consider the option of Preimplantation Genetic Testing (PGT) to avoid passing on the PALB2 gene 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, unless their position changes.

**PALB2 Interest Group:** The PALB2 gene has only been linked to cancer predisposition recently. Research is being conducted to gather more information and help future generations. To find out more and consider participating, please look at:

[www.palb2.org](http://www.palb2.org)

The group has also produced a comprehensive information leaflet which can be located on the Resource Section of their website.

