IHC

I HAVE BOWEL CANCER

WHAT HAPPENS NEXT?

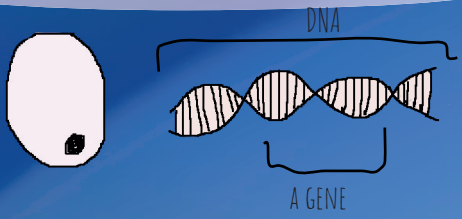
We want to find out whether your cancer was caused by chance, or if it could have been inherited (passed down in families). To understand this, we need to do some genetic testing.

In the next few pages, we will try to help you understand what is happening, why it is happening, and what the next steps are.

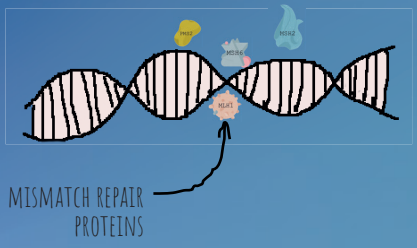
INHERITED CANCER & GENES

Some cancers are inherited, which means they can be passed down from parent to child through genes.

A gene is a section of the DNA found inside a cell. DNA are instructions that tell the cell what to do.



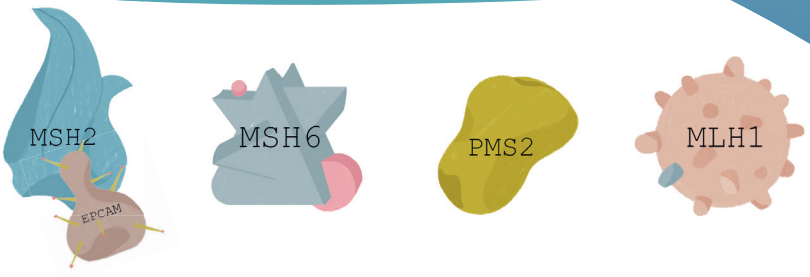
MISMATCH REPAIR GENE



The job of the Mismatch Repair (MMR) genes are to make proteins that repair any error in the DNA. Errors occur when DNA is replicated, in other words, when a cell makes a copy of itself.

Cells need to make copies of themselves all the time, to replace old and damaged ones.

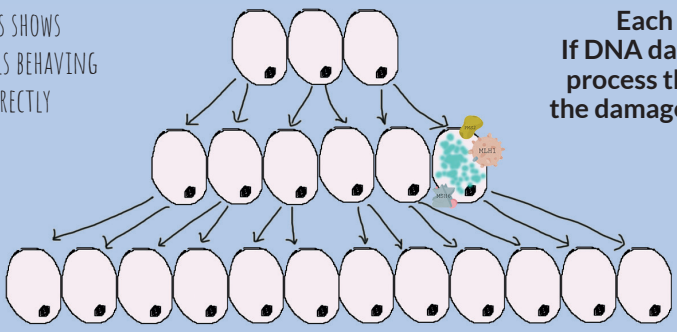
There are 4 MMR genes, and one gene called EPCAM (this gene works together with MSH2) we need to know about. This is because they can cause inherited cancer.



What is Lynch syndrome?

Lynch syndrome is when a copy of the MMR genes does not work properly. In people with Lynch syndrome, the proteins that MMR genes make do not function properly, so are less protected if cells become damaged and need repairing.

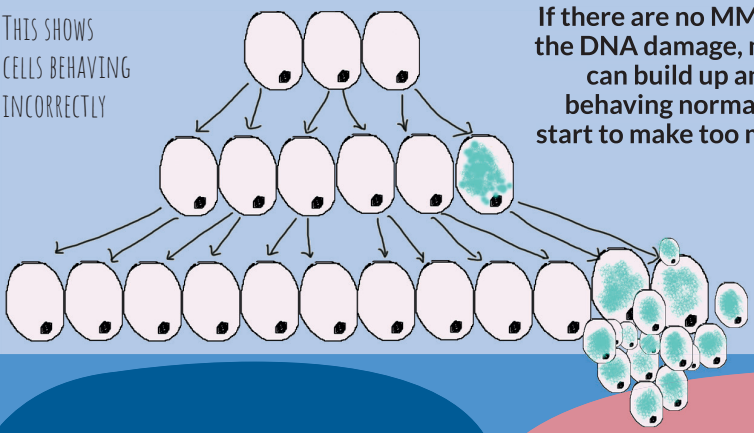
This shows cells behaving correctly



Each cell splits into two cells. If DNA damage occurs during this process the MMR proteins repair the damage, and the cell carries on behaving as normal.

Cancer is a disease that occurs because the DNA inside the cell becomes damaged and the cell is no longer controlled in the usual way.

This shows cells behaving incorrectly



If there are no MMR proteins to repair the DNA damage, mistakes in the DNA can build up and this can stop cells behaving normally. Sometimes, cells start to make too many copies of itself.

This can become a cancer tumour

IIf your MMR proteins do not work properly, and errors occur in your DNA, this means you have a higher risk of getting cancer.

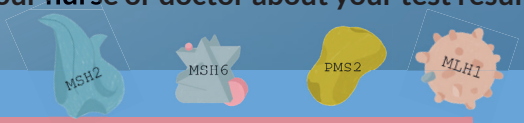
Remember: Having altered MMR genes does not mean a person will definitely get cancer, they are at a higher risk compared to someone whose MMR genes work properly.

Lynch Syndrome is inherited which means other people in your family may be affected, and at risk.

THE NEXT STEPS: TESTING

Your cancer cells are checked using a test called Immunohistochemistry (or IHC). This is a standard routine test that looks for MMR proteins.

The results of the IHC test will determine what needs to happen next. Ask your nurse or doctor about your test result.



RESULT 1

ALL MISMATCH REPAIR PROTEINS ARE PRESENT

You are unlikely to have Lynch Syndrome, and your cancer is unlikely to be inherited.

If there is a strong family history of cancer, or you are 40 years old or younger, you need to tell your team. You might be offered genetic testing

RESULT 2

MLH1 PROTEIN MISSING (CAN HAVE OTHER MISMATCH REPAIR PROTEINS MISSING TOO)

Your cancer cells will be sent for another test. Your team will choose whether to use BRAF or Methylation. This test gives more detail but doesn't confirm Lynch Syndrome.

If you have MLH1 missing & evidence of BRAF or Methylation you are unlikely to have Lynch Syndrome. You will not be offered further genetic testing. Please tell your team if you have a family history of cancer

RESULT 3

MLH1 PROTEIN IS PRESENT, BUT OTHER MISMATCH REPAIR PROTEINS ARE MISSING

You will be referred to clinical genetics for a blood test. Here the genes can be looked at in much more depth. Lynch Syndrome can be confirmed.

Sometimes your cancer team can discuss genetic testing and request this test

How long will this take?

IHC up to 7 days → **BRAF or Methylation** up to 3 months → **Clinical Genetics** up to 6 months

Diagnosed with bowel cancer

More support:

www.lynch-syndrome-uk.org

This resource was with thanks to support from Imperial College Healthcare NHS Trust, and St Mark's Hospital Centre for Familial Intestinal Cancer. Designed by Fruit Fly Collective.