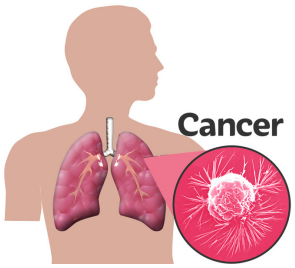
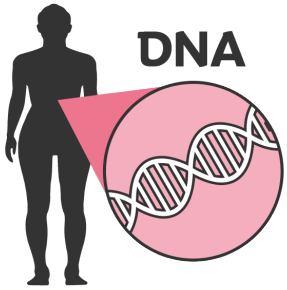


Information about whole genome sequencing for if you think you have cancer

This leaflet is for patients who are offered a whole genome sequencing test for cancer and their family members.



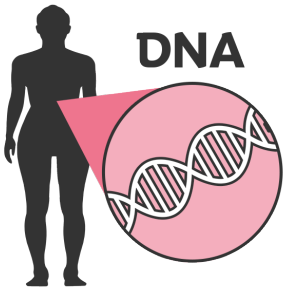
Whole Genome Sequencing is when all the information that is needed to build and maintain your body is collected by a specialist doctor.

Whole Genome Sequencing is available on the NHS for certain types of cancer where it offers better patient care.

The test can provide extra information about your diagnosis and treatment.

Your healthcare professional will talk with you and you will be able to ask questions before you decide whether to have the test.

What is your genome?

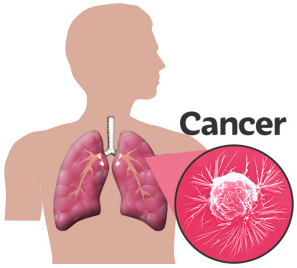


Your genome is the information needed to build the human body and keep it healthy.

It is written in a code called **DNA**. Your genome is made up of pieces of DNA, called **genes**.

NHS Genomic Medicine Service, Whole Genome Sequencing for Cancer, July 2020, v2.0 to be used for Whole Genome Sequencing go-live. This document is subject to version control and is regularly updated.

Please confirm you are using the current version by contacting your local Genomic Laboratory Hub.

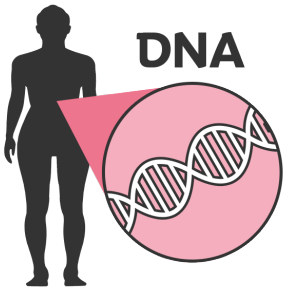


Most cancers are caused by unusual changes to a person's genome. This happens because of their lifestyle or because of their environment.

Sometimes some changes can be passed down through a person's genes.

This can mean a person has a bigger risk of having cancer.

What can a Whole Genome Sequencing test tell you?



Even though the Whole Genome Sequencing test looks at your whole genome, the test focuses on changes in genes related to cancer; it is not looking for changes in genes that cause other conditions.

A Whole Genome Sequencing test for cancer may help to understand:

- Why you developed the cancer
- The type of cancer you have
- Which treatments may work best for your cancer
- If you are at risk of developing other cancers
- Whether your family members may have a bigger risk of developing cancer

If you decide to have a Whole Genome Sequencing test, your healthcare professional will discuss this with you.

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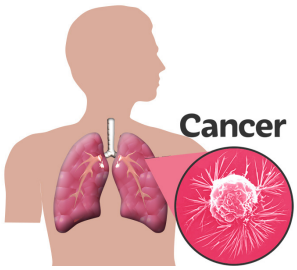
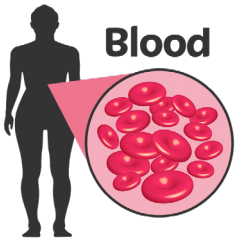
What happens in a Whole Genome Sequencing test?



1. Tumour sample collected (blood or bone marrow sample if the Whole Genome Sequencing test is for blood cancer)
2. Blood, saliva or skin sample collected (if the Whole Genome Sequence test is for blood cancer, a skin or saliva sample will be taken)
3. Samples sent to genetic testing laboratory for analysis
4. Results returned to your healthcare professional (see 'Getting your results').

Whole Genome Sequence testing for cancer involves getting information about the tumour and a sample of your blood, saliva or skin.



This gets information to support diagnosis or decide the best treatment.

If you are offered a Whole Genome Sequencing test for blood cancer, your blood or bone marrow sample will be the tumour sample.

The test will be carried out on a sample of the tumour that has been removed as part of your treatment.

You may need to have another appointment to collect your blood, saliva or skin sample.

results

The samples are then sent to a lab to be checked.

If you decide **not** to have a Whole Genome Sequencing test you will still get the best possible health care.

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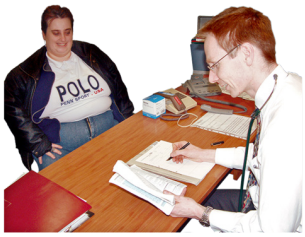
Getting your results



Once a sample has been taken it will be looked at and the result sent to your healthcare professional.

The result may provide information about your cancer and treatment options.

The result from the tumour sample is compared with that of the blood, saliva or skin sample.

The test result may show whether you have a higher risk of getting other cancers and if these risks may affect your family members.

In this case you may meet a specialist who will talk to you about your results and can discuss how to manage your risk of cancer.

This will help you think how to talk to your family members about the result.

Data About Your Genes

All data is kept securely and confidentially. Your data is used in line with UK law and NHS policy.
More information can be found at:
https://www.england.nhs.uk/contact-us/privacy-notice/

Your test data and results are stored in a secure database for the NHS Genomic Medicine Service – the part of the NHS that oversees Whole Genome Sequencing.

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Only staff who have been approved can see your data.

Data use for insurance purposes

Data won't be shared with insurance companies without your agreeing.

Insurance companies may ask you to provide medical information about you and your family.

Data use for research purposes

Health data donated by millions of other NHS patients has helped develop new medicines and treatments.

All patients have the option to give their data to a Library so that approved researchers may use that data.

If you choose to do this then your data will help researchers to develop new treatments.

To find out more about how your data can help research, please see the Genomics England website: http://www.genomicsengland.co.uk.

Further information

Find out more about Whole Genome Sequencing from these organisations: http://www.nhs.uk/conditions/genetic-and-genomic-testing

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