

Whole genome sequencing for suspected cancer

Information for patients
and family members



**Genomic
Medicine Service**

This booklet is for patients and their family members who may be offered a whole genome sequencing test for cancer.

Through the NHS Genomic Medicine Service, whole genome sequencing is now available for certain conditions where the scientific evidence shows it can help improve patient care. Your healthcare professional will provide further information 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 chemical code called DNA. Your genome is made up of segments of DNA, called genes. Cancers are caused by cells with unusual changes in their genome.

These changes often happen during a person's life.

Some changes can be passed down through your genes. These can give a person 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 is focused 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 you and your healthcare professional to understand:

- Why you developed the cancer
- The type of cancer you may have and how it may behave
- Which treatments may be most effective for your cancer
- If you are at risk of developing other cancers in the future
- Whether your family members may be at a higher risk of developing cancer.

If you decide to have a whole genome sequencing test, your healthcare professional will discuss the process with you and how long it will take to get a result.



What happens in a whole genome sequencing test?

- Tumour sample collected (blood or bone marrow sample if the whole genome sequence test is for blood cancer)
- Blood or skin sample collected (if the whole genome sequence test is for blood cancer, a blood, saliva or skin sample will be taken)
- Samples sent to genetic testing laboratory for analysis
- Results returned to your healthcare professional (see 'Getting your results').

Whole genome sequence testing for cancer involves sequencing the whole genome of the tumour and a sample of your blood, saliva or skin. The sequence of the tumour is compared to that of the blood, saliva or skin to provide information to support diagnosis or help you and your healthcare professional to decide the most appropriate treatment options.

If you are offered a whole genome sequencing test for blood cancer, your blood or bone marrow sample will count as the tumour sample. In this case the whole genome sequence of your blood sample will be compared to a saliva or skin sample.

The whole genome sequencing test will be carried out on a sample of the tumour that has already been removed as part of your treatment. You may need to have a further appointment to collect your blood, saliva or skin sample. The samples are then sent to a genetic testing laboratory to be analysed.

You will have an opportunity to discuss the whole genome sequencing test with your healthcare professional and ask any questions that you have before you decide whether you want to have the test.

If you decide not to have a whole genome sequencing test you will continue to receive the best possible care and support from healthcare professionals.



Getting your results

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

The result from the tumour sample may provide information about your cancer and the most appropriate treatment options.

By comparing the result from the tumour sample with that of the blood, saliva or skin sample, the whole genome sequencing test result may show whether you have a higher risk of developing further cancers that may be inherited and have implications for your family members.

In this case you may be referred to a Clinical Genetics Service to discuss your options and how to manage your risk of cancer.

Your consultation with Clinical Genetics will also help you think through how to talk to your family members about the result.



Genomic data and data protection

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 www.england.nhs.uk/contact-us/privacy-notice

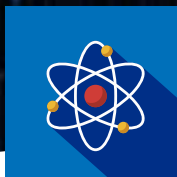
The data from your genomic test is entered into a secure national database for the NHS Genomic Medicine Service. This system will store data about your test and the results. Only staff with approved access can see your data.

Data use for insurance purposes

Insurance companies will not be given access to information about any predictive genetic test that you have had without your explicit consent.

When applying for an insurance policy, insurance companies may ask you to provide medical information about you and your family. The information that you need to share with an insurance company is regulated by a voluntary government code called the Code on Genetic Testing and Insurance:

www.gov.uk/government/publications/code-on-genetic-testing-and-insurance



Data use for research purposes

Research is a vital part of healthcare and health data donated by millions of other NHS patients has helped develop the medicines and treatments that patients receive today.

As part of the NHS Genomic Medicine Service all patients will be given the option to contribute their genomic data to a secure library so that approved researchers may access that data in a form that does not identify them.

If you choose to do this then your data will be helping researchers and scientists to develop the treatments of tomorrow.

To find out more about how your genomic data can help research please see the Genomics England website:

www.genomicsengland.co.uk

If you choose to contribute to this research library, you may also be contacted in the future by someone in your clinical team (or occasionally by Genomics England) to give you more information if anything has been found which might be relevant to your health or that of your family, or if researchers identify a study that might be relevant to you and your condition. We would then explain the study and you would be able to say whether or not you would be prepared to take part.

Further information

You can find out more about whole genome sequencing from the following organisations:

www.nhs.uk/conditions/genetic-and-genomic-testing