The Children & Young People's Cancer Association

NHS England

Whole genome sequencing (WGS) test for children

An information guide for parents, carers and families

The purpose of this guide is to give information about a whole genome sequencing (WGS) test which is being offered to your child as part of diagnosis for cancer, suspected cancer and non-cancerous (benign) tumours.

Information in this guide should be used to supplement professional advice specific to your circumstances. If you have any questions, it is important to ask your child's medical team.

What is a genome?

Our bodies are made up of cells. Each cell contains genetic information that makes us all unique, and this is written in a code called DNA. This works like a computer programme that tells each cell in your body what to do and how to do it. Your genome is a complete set of these instructions.

Science has now developed enough for us to be able to read this DNA information to help our understanding of tumours and cancer.

Most tumours and cancer are caused by changes in the DNA coding within a person's genome or individual cells. These changes can happen when a baby is first growing in the womb or later in life. Sometimes they can be inherited and passed down through family members. These changes can mean a person has a greater risk of developing cancer.

What is whole genome sequencing (WGS)?

Whole genome sequencing (WGS) is a way of looking at your child's background DNA information (known as **germline**) and comparing it with that of their tumour or cancer cells (known as **somatic**). These can be different and can help us to understand more about your child's specific diagnosis and treatment.

The whole genome sequencing (WGS) test is offered to all children and young people in England up to the age of 25 years, who have or may have cancer, suspected cancer, or non-cancerous tumours. This test is not yet routinely available in Wales, Scotland and Northern Ireland.



Why consider a WGS test?

Results from a WGS test may help us to understand:

- what type of tumour or cancer your child has
- whether your child is on the correct treatment plan and how likely the tumour or cancer is to respond to the treatment
- whether your child might benefit from a specific treatment, drug or clinical trial
- why your child has developed their tumour or cancer
- whether your child has a gene which might increase their risk of developing other cancers in the future
- whether other family members may have a greater risk of developing cancer

Your child's healthcare professional will explain what happens and you will be able to ask questions before you decide whether or not you want to go ahead.

By using a WGS test, this extra information may help doctors when they are considering the treatment plan for your child. WGS is a new service and the impact it may have on treatment plans is still being explored. Whether or not your child has a whole genome sequencing test, your child will continue to get the best possible treatment and care.

What happens in a WGS test?

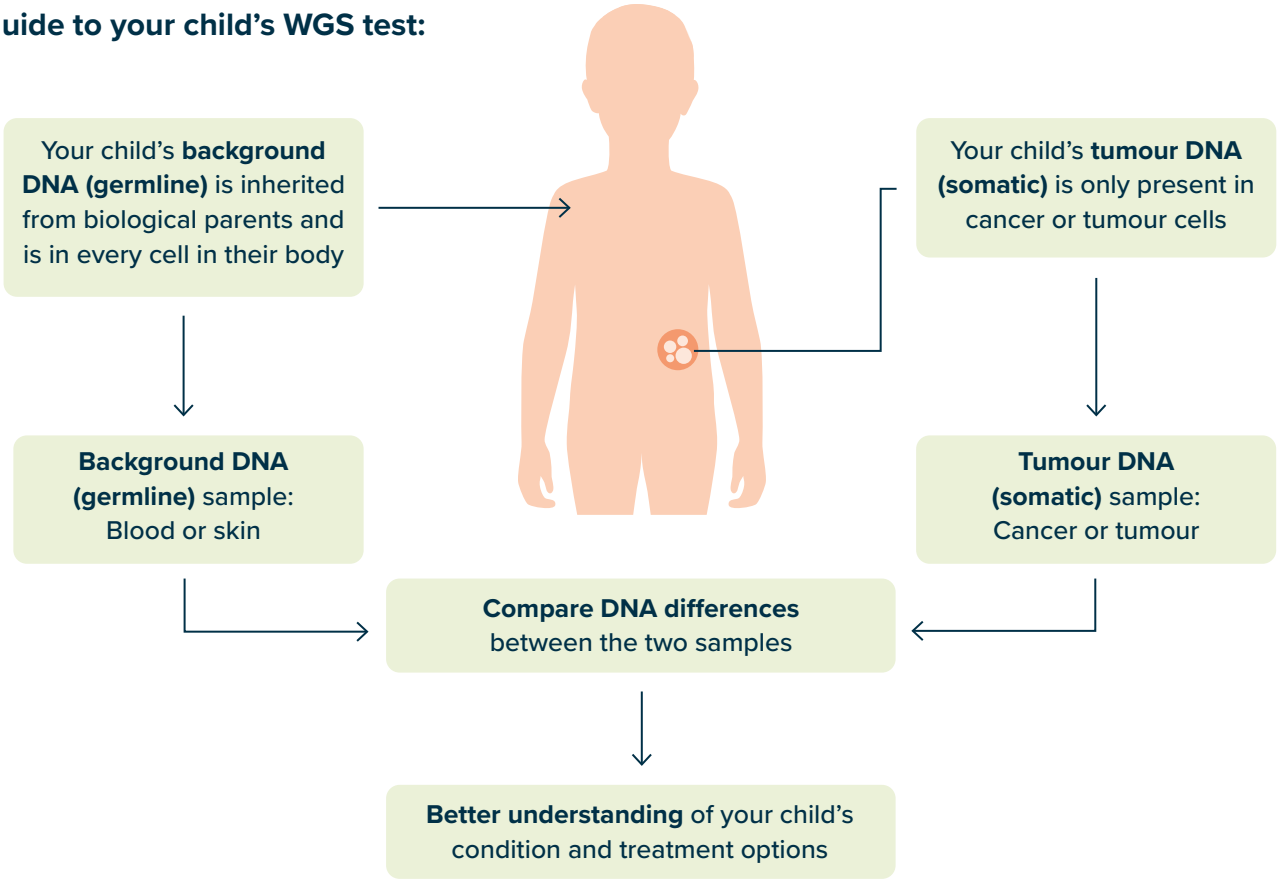
To do a WGS test, a doctor will take the following two samples from your child:

- **Blood** or **skin sample** – this sample shows DNA information inherited from parents. This is called a 'germline' sample.
- A **small piece of cancer or tumour tissue** (or bone marrow in leukaemia patients) – this sample shows DNA information of the tumour or cancer, which may be different to the background or inherited DNA information. This is called a 'somatic' sample.

Whenever possible, samples are used from tests that are already being carried out as part of your child's diagnosis. If additional tests are required, these will be discussed with you before you decide whether to go ahead.

Both samples are collected and sent to a genetic laboratory for testing. Scientists will compare the two samples and look for any differences in DNA. This comparison may give more information about your child's particular condition.

A guide to your child's WGS test:



Your child's WGS results

Once your child's DNA has been looked at, the results are returned to your child's healthcare professional who will share the results with you. This may take a few weeks. The result may give more information about your child's condition and treatment.

This test is about identifying your child's cancer or tumour type and linked genes, so will not look for other unlinked cancer types that could occur in the future. It does not look for changes in DNA that may cause other health conditions.

There is a small chance it may also show whether your child has a higher risk of getting further cancers and if these risks may affect other family members.

In this case, you will be given the opportunity to discuss your results with a genetics specialist who will talk to you about your child's results and how to manage any risks there may be for other family members. They will also help you to think about how to talk to your family members about your child's result.

Important information about your child's data

All data is kept securely and confidentially. Your child's 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

Your child's 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. Only clinical, laboratory and healthcare staff linked to your child's care and who have been authorised to do so can see this data. You may withdraw your consent for your child's data to be used or for you to be contacted at any point at:
www.genomicsengland.co.uk/patients-participants/taking-part/resources

Data use for insurance purposes

Insurance companies will not be given access to information about any predictive genetic test without explicit consent. When applying for an insurance policy, insurance companies may ask for medical and family history information. The information that is shared with insurance companies is regulated by a voluntary government code called the Code on Genetic Testing and Insurance which can be found at:
www.gov.uk/government/publications/code-on-genetic-testing-and-insurance

Data use for research purposes

Health data donated by millions of other NHS patients has helped develop our understanding of diseases, new medicines and treatments. You will be given the option to contribute your child's genomic and health data to a secure Research Library managed by Genomics England, so that approved researchers may access that data in a form that does not identify your child. If you choose to do this, you may be contacted in the future by someone in your child's clinical team (or occasionally by Genomics England) to give you more information if anything has been found which might be relevant to your child's health or that of your family, or if researchers identify a study that might be relevant to your child's cancer. Data may be used to find new discoveries or to identify areas for new drug development.

Re-consent

Once your child reaches 16 years of age, and if you said yes to their data being added to the Research Library, they will be asked if they are happy for their data to continue to be used for research.

Further information

Find out more about whole genome sequencing here:
www.nhs.uk/conditions/genetic-and-genomic-testing

To find out more about how your child's data can help research please visit the Genomics England website:
www.genomicsengland.co.uk

CCLG: The Children & Young People's Cancer Association publishes free resources on a variety of topics related to children and young people's cancer. Order or download at: **www.cclg.org.uk/publications**

Scan to order or download this factsheet or any other CCLG publications FREE of charge.

Young Lives vs Cancer provides practical support and advice for children and young people affected by cancer and their families.
www.younglivesvscancer.org.uk

Macmillan Cancer Support offers support and advice to those affected by cancer.
www.macmillan.org.uk

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This factsheet was reviewed by Sarah Haywood and Amanda Skinner, Genomics Nurse Practitioners (South West Peninsula Genomics Hub), Ruth Bagg, Service Delivery Project Manager (South West Peninsula Genomics Hub), Ana Juett, Programme Manager (South West Genomic Medicine Service Alliance), Amanda Pichini, Consultant Genetics Counsellor (Genomics England), Dr Aditi Vedi, Consultant Paediatric Oncologist, Cambridge and Dr Madeleine Adams, Consultant Paediatric Oncologist, Cardiff in conjunction with the CCLG Information Advisory Group, comprising multi-professional experts in the field of children and young people's cancer. Thanks also to parents and patients feedback through South West Genomics Hub and CCLG.

We are CCLG: The Children & Young People's Cancer Association, a charity dedicated to creating a brighter future for children and young people with cancer. Powered by expertise, we unite the children and young people's cancer community, driving collective action and progress.

We fund and lead pioneering research, provide trusted information and guidance for children and young people with cancer and their families, and bring together professionals to improve treatment, care and outcomes.

Our expert information helps children and young people, and everyone supporting them, to navigate the challenges of cancer and its impact, offering reassurance and clarity when it's needed most.

We make every effort to ensure that this information is accurate and up to date at the time of printing. Information in this publication should be used to supplement appropriate professional or other advice specific to your circumstances.

Our work is funded by donations. If you would like to help, visit **www.cclg.org.uk/donate** or text '**CCLG**' to **70085** to donate **£3.** You may be charged for one text message at your network's standard or charity rate. CCLG will receive 100% of your donation.

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