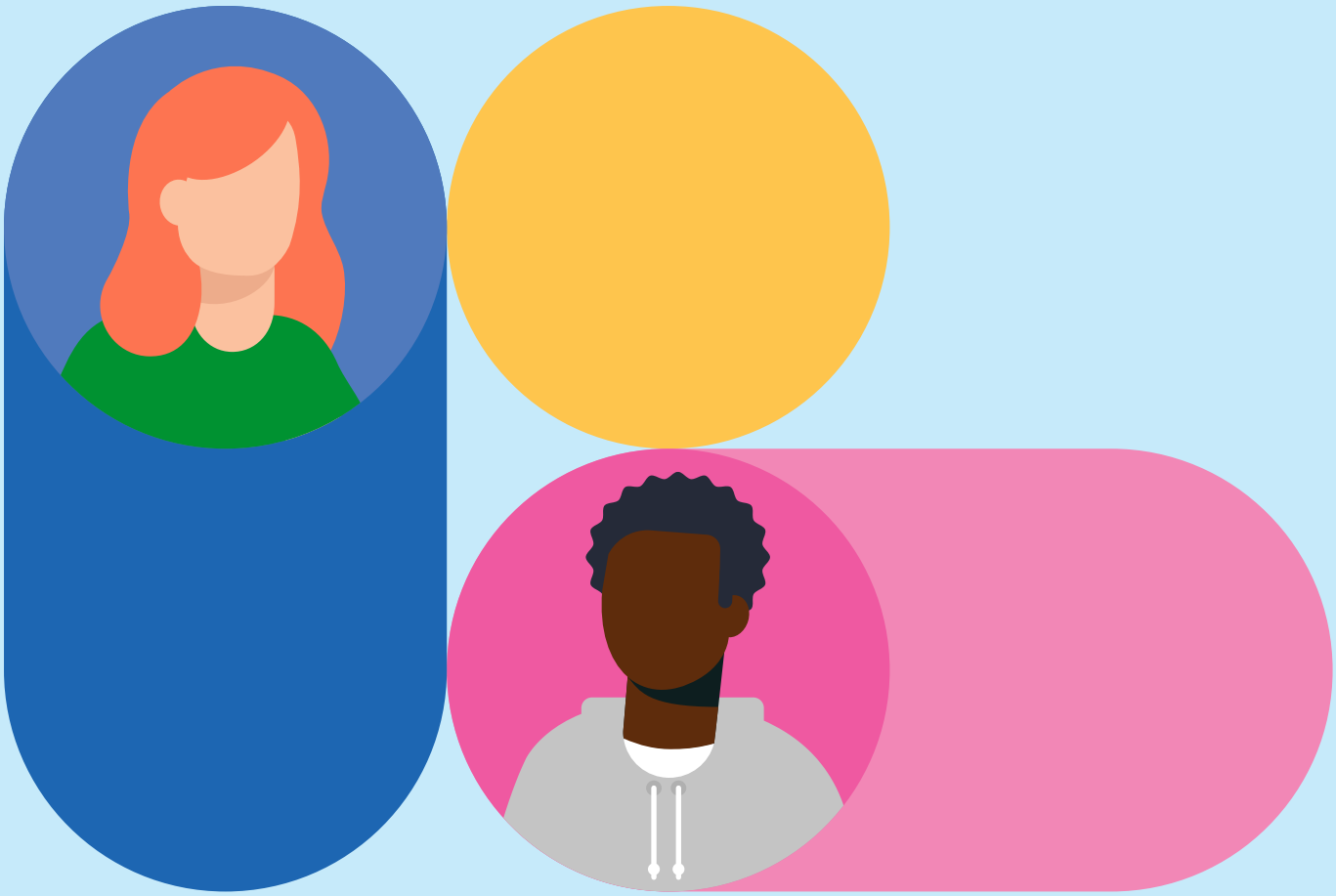
Genomics England

Continuing in the 100,000 Genomes Project



Why are you contacting me?

We are contacting to ask if you want to carry on being part of the 100,000 Genomes Project.

When you joined the Project, your parent or guardian gave their permission for you to be part of it. This is because you were a child at the time.

But now, it's up to you. You can decide to continue in the Project, or you can stop taking part.

Your choice will be recorded on a form. You will get a copy of this form for your record. You can also change your mind later – it's your choice.

This sheet has information to help you decide. You may also want to talk about this decision with your family or people involved in your health care.

You can also read this at:
www.genomicsengland.co.uk

What is the 100,000 Genomes Project?

The 100,000 Genomes Project is run by Genomics England, a company set up and owned by the UK Department of Health and Social Care. We partnered with the NHS to do this.

This Project collected 100,000 genomes from people affected by either rare conditions or cancer. A genome is a person's entire genetic sequence – their body's instruction manual. Genomes are made of a chemical called DNA, and contain thousands of genes. Genes tell our bodies how to grow and develop.

Looking at someone's genome could tell us information about their condition. To study someone's genome, we take a DNA sample. Most people donated a small blood sample or saliva sample when they joined the Project. People with cancer also donated a sample of their cancer, such as a small piece of their tumour. We sequenced the genome of each person in the Project, meaning the DNA was 'read' letter by letter. Results were shared with the healthcare professional who referred each person to the Project.

We at Genomics England look after your samples, genome sequence and health data, and continue to keep it secure. The place where your genome and health data are held is called the National Genomics Research Library.

Why is studying genomes important?

Thousands of people have agreed to put their genome and health information into the National Genomic Research Library. Bringing all this data together in one place gives researchers a better opportunity to learn about conditions like yours. It can also help them understand more about how conditions can be diagnosed and treated, or to develop new tests that could predict or prevent diseases.

What are the benefits for me?

Some participants have received a diagnosis or a genetic cause for their condition. Some people have been able to benefit from better treatment for their condition.

This isn't the case for everyone in the Project because there is still so much that we don't understand about the genome. But every participant has contributed knowledge which will help people in the future – people like them, and people with a range of other conditions.

If you choose to continue in the Project, a genetic cause could be found for your condition if this hasn't been found already. Research could help you and your family learn more about your condition, or it might mean you could become part of a trial of a new medicine or treatment. In these situations, we and/or a member of your health care team would get in touch with you.

Your data will also continue to support research that could benefit future generations. This could help to find out more information for others, like helping them to be diagnosed more quickly when they become ill.

What do you do with my data?

It is our legal and ethical duty to take care of data and samples for everyone in the Project.

At Genomics England, we hold information that could personally identify you, but we do not share this with anyone except people involved in your health care.

Your data in the National Genomic Research Library includes your genome sequence and electronic health records from the NHS and other organisations. Before we put your data into the Library, we remove information that could personally identify you and replace it with a unique code number. These health records would continue to be collected across your lifetime and beyond, unless you choose to withdraw.

Only approved healthcare researchers can access your data. They use this to find new diagnoses or treatments, or learn more about genes and health. These researchers could come from hospitals, universities, charities, or healthcare companies like pharmaceutical companies – who could use the data to develop new treatments. They could be based in the UK or in other countries around the world. Their research could help you or others, now or in the future.

Your data will never be used by insurers or for marketing purposes.

How do you keep my data safe?

The Library is held in a secure data centre in the UK. Data stays within a digital database where all research activity is continually monitored.

New research proposals are approved by an independent Access Review Committee. This committee includes clinical experts, scientists, and NHS patients already in the Library. Every researcher signs a code of good practice, and completes data protection training.

We take steps to make it as hard as possible for researchers to find out who the data belongs to, and have strict penalties for anyone who tries to identify or misuse the data.

More information about your data and research in the Library can be found at:
www.genomicsengland.co.uk/patients-participants/data

You have the right to see what data we hold about you. Please read our Privacy Notice to learn more:
www.genomicsengland.co.uk/privacy-policy

What about additional findings?

As part of the Project, your parent or guardian chose if they wanted us to look for changes in genes that may increase the risk of developing certain health conditions. We call these 'additional findings' as they are usually unrelated to the reason why someone had their genome sequenced in the first place.

These conditions could be serious but the NHS can already treat them or use screening to pick them up at the earliest stage possible. For participants who were under 16, we only looked for conditions that could affect people in childhood.

We worked with the NHS to return these findings to participants who had asked for them, and finished this in 2023. We are gathering information to understand whether and how to continue to offer this to participants in the future. We don't yet know whether this will happen. If and when further additional findings could be looked for, we will contact you and the other Project participants with more information.

In the meantime, you can choose whether you would like to receive these types of findings, should we be able to look for additional findings in the future. You can change your mind about receiving additional findings at any time.

More information at:
www.genomicsengland.co.uk/initiatives/100000-genomes-project/additional-findings

What if I don't want to take part anymore?

You can choose not to continue in the Project. And if you do choose to continue now, you can change your mind at any time in the future. You don't have to give a reason and your decision will not affect your healthcare.

There are two ways you can withdraw from the study:

1. **Partial Withdrawal**
   This means you are happy for your data and samples to continue to be in the National Genomic Research Library and used for further research, but you don't want any further contact from us.

2. **Full Withdrawal**
   This means you don't want any further contact, and you no longer want your data and samples to be in the National Genomic Research Library. We would not be able to remove data from research that has already started or been completed in the Library. But no one can start new research on your data, and no more healthcare information is collected. We would also destroy any leftover samples.

What happens if I don't confirm my choice?

Every participant must be given the opportunity to choose if they want to continue to be part of the 100,000 Genomes Project. This would usually be when they are around 16 years old. Your healthcare team or the NHS teams involved in delivering the Project will aim to get in contact with you, usually by letter or by phone.

If we are unable to get in contact with you, or if we don't hear back from you with confirmation of your choice:

- Your health data that was collected up to age 16 will remain in the National Genomic Research Library. This is because researchers may identify a diagnosis or finding that may be relevant for your clinical care, which could then be fed back to you by your NHS healthcare team.

- From age 16, we will stop collecting new health data about you. We will not contact you about future research opportunities such as clinical trials.

If you were enrolled in the Project with other family members such as your parents, their data will continue to be collected and analysed, unless they choose to withdraw from the Project.

Thank you for being part of the 100,000 Genomes Project.

If you would like to find out more information about what happens after you give consent or withdraw, or what happens if we do not receive a reply from you, please visit:

You can also read this at:
www.genomicsengland.co.uk