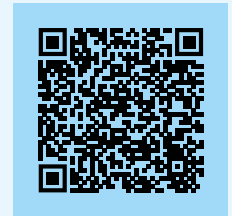


Continuation in the 100,000 Genomes Project

When you joined the Project, your parent or guardian had to give their permission for you to be part of it. This is because you were a child at the time. Now you're 16, it's up to you. You can decide to continue in the Project. You can decide to stop taking part. You can also change your mind later – it's your choice.

Before you decide, you should have been given an information sheet to review. We also recommend that you speak with your family and/or your healthcare team about your decision. Please read the statements below and feel free to ask any questions.

Find out more:



By saying 'Yes' I understand that I will continue to be in the 100,000 Genomes Project which means that:

Use of data and samples

- 1 My genome and health data, as well as my samples can continue to be stored and used for future research in the National Genomics Research Library.
- 2 Researchers accessing the Library could come from hospitals, universities, charities, or healthcare companies in the UK and other countries. To access the data, these researchers must all be approved by an independent committee of experts, including health professionals, clinical academics, and patients. There will be no access to the data by personal insurers and marketing companies.
- 3 Genomics England will continue to collect different aspects of my health data from the NHS and other organisations. The collection and analysis of my health data for research will continue across my entire lifetime and beyond.

Security

- 4 Any data or samples stored by Genomics England will always be stored securely. Genomics England will take all reasonable steps to ensure that I cannot be personally identified.

Re-contact

- 5 Genomics England and/or my clinical team can contact me if the data or samples reveals any clinical trials or other research that I might benefit from.
- 6 If something is relevant to me or my family, there is a process by which this will be shared with my clinical team.

Withdrawal

- 7 I can change my mind about taking part at any time.

Please provide confirmation of your choices

I confirm that I understand the information given to me (PIS V1.0, 28 March 2023) and had the opportunity to discuss my continued participation in the 100,000 Genomes Project. My choice is indicated below.

I agree that my data and sample may continue to contribute to the National Genomic Research Library:

Yes | No

By saying 'no' I will be withdrawn from 100,000 Genomes Project:

I would like to partially withdraw from the project

I would like to fully withdraw from the project

Optional - additional findings

As part of the Project, your parent or guardian chose if they wanted Genomics England to look for changes in genes that may increase the risk of developing certain health conditions. These are called 'additional findings,' as they are usually unrelated to the reason why someone had genome sequencing in the first place.

Genomics England and the NHS finished returning these findings to participants in early 2023. They are gathering information to understand whether and how to continue to offer this to participants in the future. If and when further additional findings' could be looked for, participants will be contacted with more information. In the meantime, you can choose whether you would like to receive these types of findings in the future, if this is offered.

8 I understand the following about additional findings:

- These conditions are not connected to the reason why I had genome sequencing in the first place.
- All the conditions can potentially be treated or prevented.
- These conditions are typically inherited, so findings could be important to other members of my family.
- I can change my mind about receiving additional findings at any time.

Additional findings

A) I want additional findings to be looked for and fed back to me **Yes** | **No**

Select if consultee or participant: <input type="checkbox"/> Consultee <input type="checkbox"/> Participant												
Name	Signature	Date										
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Complete this section with details for the participant		Ref No. (or postcode if not known)										
First name	Last name	<table border="1"> <tr> <td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td> </tr> </table>										
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Healthcare professional name	Signature	Date										
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