

First name	NHS number (or postcode if not known)
Last name	Date of birth
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05-NGIS-OPT (v2.02)

The National Genomic Research Library

The NHS invites you to contribute to the National Genomic Research Library, managed by Genomics England.

Genomics England was set up in 2013 by the Department of Health and Social Care to work with the NHS to build a library of human genomes for researchers to study. Combining data from many different patients helps researchers to better understand disease and spot patterns in the data.

By agreeing to share your data you might get results which could lead to your own diagnosis, a new treatment, or offers to take part in clinical trials. Your taking part could enable diagnoses for people who don't have one.

Please read the following statements. Feel free to ask any questions before making a decision.

By saying 'yes' to research, I understand the following:

The National Genomic Research Library

1. NHS England, on behalf of the Trusts that provided your genomic test, will allow Genomics England to access my personal data, including my genomic record.

Security

2. Any samples and data stored by Genomics England and the NHS will always be stored securely. Genomics England will take all reasonable steps to ensure that I cannot be personally identified.

Re-contact

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

Data and sample usage

5. Researchers may include national or international scientists, healthcare companies and NHS staff. 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.

Data storage

6. Genomics England will collect different aspects of my health data from the NHS and other data from organisations listed at <https://www.genomicsengland.co.uk/privacy-policy/>. The collection and analysis of my health data for research will continue across my entire lifetime and beyond.

Withdrawal

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

More information regarding research in the National Genomic Research Library can be found at www.genomicsengland.co.uk
For any further questions, my healthcare professional can provide information.

Please use page two to indicate your research choices.

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Confirmation of your research choices

My research choice is indicated below.

- A. I have discussed taking part in the National Genomic Research Library YES | NO
If your answer to A is NO then please ignore B and sign directly below
- B. I agree that my data and remainder sample may contribute to the National Genomic Research Library YES | NO

Patient name	Signature	Date										
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If you are signing this form on behalf of someone else (children, adults without capacity or deceased patients) then please sign below.

Parent Guardian Consultee name*	Signature	Date										
<p><i>* please amend as appropriate</i></p> <p>.....</p>	<p>.....</p>	<table border="1"> <tr> <td>d</td><td>d</td><td>/</td><td>m</td><td>m</td><td>/</td><td>y</td><td>y</td><td>y</td><td>y</td> </tr> </table>	d	d	/	m	m	/	y	y	y	y
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Healthcare professional use only

To be completed by the healthcare professional recording the patient's choices.

Healthcare professional name	Signature	Date										
<p>Consent obtained remotely, no patient signature</p> <p>.....</p>	<p>.....</p>	<table border="1"> <tr> <td>d</td><td>d</td><td>/</td><td>m</td><td>m</td><td>/</td><td>y</td><td>y</td><td>y</td><td>y</td> </tr> </table>	d	d	/	m	m	/	y	y	y	y
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