

100,000 Genomes Project



Consent form

If you agree for your loved one's samples and information to be included in the 100,000 Genomes Project, please:

- initial boxes 1, 2, 3 and 4; and
- sign your name at the end of this form.

Introduction

At least one nominated representative, or person who was in a qualifying relationship (usually a family member) with the adult who has died, needs to fill in this form to agree for their samples and information to be included in the project.

If you aren't sure who was in a 'qualifying relationship' with the person who has died, a health professional can explain.

Please read the information sheet 'For the nominated representative, relative or friend of an adult who has died' and discuss this with a healthcare professional.

Only you can choose if you want your loved one's samples and information to be included. If you don't want them to be included, you don't have to say why.

Please be assured that we will always treat your loved one's samples and information with care and respect.

Taking part, samples and data

1 Taking part

I authorise this consent form on behalf of the person who has died.

Initial your choice.

I am the nominated representative of the adult who has died.

Or

I am a person who was in a qualifying relationship with the adult who has died.

I have read and understood the information sheet 'For the nominated representative, relative or friend of an adult who has died' dated ____ / ____ / ____ (version ____). I have been able to ask questions and have these answered.

I understand that:

- **only I can decide if I want my loved one's samples and information to be included in the project, or not; and**
- **if I agree for my loved one's samples and information to be included in the project, I can withdraw them at any time.**

I do not need to give a reason why.

If I withdraw, I understand that some research may have already taken place using their data and this can't be undone.

I agree to the following.

- You and the clinical team can contact me to:
 - invite me to include my loved one's samples and information in other research; and
 - send me general updates about the project.

If I am asked, I can say yes or no. It is my choice.

Initial here to show you agree.

2 Samples

I agree to donate to the project:

- my loved one's samples collected as part of their medical care; and
- samples collected after their death, if needed.

You can use the samples for:

- collecting DNA for whole genome sequencing; and
- studying their blood to find out how their DNA worked.

I understand that there might be new ways of doing this in the future.

Samples or DNA could be sent to approved organisations outside the UK for processing or analysis.

Initial here to show you agree.	
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3 Data

I agree that the project can access and collect electronic copies of my loved one's health records.

- This includes personal information from all of my loved one's records from the NHS, their GP and other organisations. This includes information about any illnesses or stays in hospital – even ones that appear unrelated to the rare condition in the family.
- The data is from different sets of records, including hospital or clinic records, medical notes, social care and local or national disease registries. It includes images from my loved one's NHS records, such as MRI scans or photographs.
- To get this data, the project will need to send some details about my loved one (for example, their NHS number and date of birth) to the organisations holding this information. This will allow them to find the health data they hold about my loved one.
- The data may be used to study many different medical conditions, not just ones that affected my loved one.
- We will continue to access any updated records for as long as their samples are in the project.
- Approved individuals from Genomics England, the NHS and other study monitors can look at this information at any time.

I understand that:

- all information about my loved one held by the project will be treated as confidential;
- the data and information from their samples will only be used by researchers in a form that protects my loved one's identity;
- research organisations accessing the data and samples may include commercial (for-profit) companies;
- researchers won't be allowed to copy or remove any of my loved one's information; and
- I will not benefit financially if research using data from the project (which includes my loved one's data) leads to new treatments or medical tests.

Initial here to show you agree.

4 Results

I agree that:

- tests can be run on my loved one's samples and health information to look for the cause of their rare genetic condition and to help the family's care; and
- the results can be reported to my loved one's clinical team for them to discuss with me.

I understand the following.

- Information generated by this project may benefit my loved one's family members, now or in the future. If relevant, the NHS will support me in sharing this with them.
- We may not get a diagnosis for my loved one's rare genetic condition.
- Results may not be returned in time to be used in the medical care of my loved one's family.

I understand that apart from my loved one's rare condition no other information will be looked for or reported.

Initial here to show you agree.

Your full name (BLOCK CAPITALS):

Your signature:

Date:

(DD/MM/YY)

Please fill in any relevant boxes below.

Full name of the adult who
has died (BLOCK CAPITALS):

Their date of birth:

(DD/MM/YY)

Their sex (BLOCK CAPITALS):

Date of their death:

(DD/MM/YY)

Any other information, for example
their religion or language:

Today's date:

(DD/MM/YY)

Name of their healthcare
professional (as appropriate)
(BLOCK CAPITALS):

Signature:

Date:

(DD/MM/YY)

Name of person receiving consent
(BLOCK CAPITALS):

Signature:

Date:

(DD/MM/YY)

Name of interpreter if used:

Signature:

Date:

(DD/MM/YY)

When you have filled this in:

- 1 (the original) will be kept in the adult participant's 100,000 Genomes Project records.
- You will keep a copy.
- We at Genomics England will keep a copy.

Staff only (if this applies). Adult participant's NHS number:	
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