

100,000 Genomes Project



Consent form

If you agree for your child'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 person with legal parental responsibility for your child 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 has 'legal parental responsibility' for your child, your healthcare professional can explain.

Please read the information sheet 'For parents of a child who has died' and discuss this with a healthcare professional.

Only you can choose if you want your child's samples and information to be included. If you don't want them to be included, you don't have to say why. If you choose not to include their samples, you and your family will still receive the best available care.

Please be assured that we will always treat your child's samples and information with care and respect. Your child's other parent can also sign this consent form if they want to, but this isn't needed.

Taking part, samples and data

1 Taking part

I have legal parental responsibility for the child named below. I agree for my child's samples and information to be included in the 100,000 Genomes Project.

I have read and understood the information sheet 'For parents of a child 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 child's samples and information to be included in the project, or not; and**
- **if I agree for my child'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 my child's clinical team can contact me to:
 - invite me to include my child'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 child's samples collected as part of their medical care; and
- samples collected after their death, if needed.

My child's samples can be used 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.

3 Data

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

- This includes personal information from all of my child'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 my 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 child's NHS records, such as MRI scans or photographs.
- To get this data, the project will need to send some details about my child (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 child.
- The data may be used to study many different medical conditions, not just ones that affected my child.
- 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 child held by the project will be treated as confidential;
- my child's data, and information from their samples will only be used by researchers in a form that protects my child's identity;
- research organisations accessing my child's data and samples may include commercial (for-profit) companies;
- researchers won't be allowed to copy or remove any of my child's information; and
- I will not benefit financially if research using data from the project (which includes my child'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 child's samples and health information to look for the cause of their rare genetic condition and to help my family's care; and
- the results can be reported to their clinical team for them to discuss with me.

I understand the following.

- Information generated by this project may benefit my 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 child's rare genetic condition.
- Results may not be returned in time to be used in my family's medical care.

I understand that apart from my child'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)

Full name of the other parent
(optional) (BLOCK CAPITALS):

Signature:

Date:

(DD/MM/YY)

Please fill in as appropriate.

Please give the following details if you miscarried or had a termination before 24 weeks.

Full name of the baby (if you gave
them a name) (BLOCK CAPITALS):

Sex of the baby (if you knew this):

Date of this miscarriage:

(DD/MM/YY)

Date of termination:	(DD/MM/YY)
-----------------------------	------------

Number of weeks into the pregnancy when the miscarriage or termination took place:	
---	--

Today's date:	(DD/MM/YY)
----------------------	------------

Please give the following details if you miscarried or had a termination after 24 weeks or if your child has died.

Full name of your child or baby (if you gave your unborn baby a name) (BLOCK CAPITALS):	
--	--

Sex (if known):	
------------------------	--

Number of weeks into the pregnancy when the miscarriage or termination took place:	
---	--

Date of birth (if relevant):	(DD/MM/YY)
-------------------------------------	------------

Date of death (if your baby was alive at birth):	(DD/MM/YY)
---	------------

Today's date:	(DD/MM/YY)
----------------------	------------

Other information for example, your religion and language:	
---	--

Health professionals will fill in this section.

Name of person receiving consent
(BLOCK CAPITALS):

Signature:

Date:

(DD/MM/YY)

Name of interpreter if used
(BLOCK CAPITALS):

Signature:

Date:

(DD/MM/YY)

Name of mother's healthcare
professional (if relevant)
(BLOCK CAPITALS):

Signature:

Date:

(DD/MM/YY)

When you have filled in this form:

- 1 (the original) will be kept in the child's 100,000 Genomes Project records.
- You will keep one copy.
- The other parent will keep a copy (if this applies).
- We at Genomics England will keep a copy.

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

