

# 100,000 Genomes Project

## Information on how to withdraw from the project

This document gives you details of how to withdraw from the 100,000 Genomes Project. Please read it carefully. To withdraw from the project, please fill in the form that follows.

You can also use this form to withdraw your child from the project. You don't have to be taking part yourself to withdraw your child. You can only withdraw one child using this form. Please use a separate form for each child you want to withdraw.

You don't have to give us a reason for your decision. Please ask your clinical team if you have any questions about withdrawing from the project.

Withdrawing from this project will not affect your participation in any other research project you are part of.

We will begin acting on your wishes as soon as we have received and processed this form.

There are two options if you want to withdraw.

### Option 1 – partial withdrawal: 'no further contact'

We at Genomics England would no longer contact you directly.

- Your healthcare professional will still get your initial report about your rare condition or cancer. They will ask you if you want to receive this. Your healthcare professional will not get any further reports relevant to your healthcare.
- Any samples already collected can still be used as part of the project.
- We will continue to update and store information from your health and other records for use in approved research.

## Option 2 – full withdrawal: ‘no further use’

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You or your child would no longer be a participant in the 100,000 Genomes Project.

We at Genomics England will no longer:

- contact you or your child directly;
- collect or store anything further from you or your child’s health records or other records;
- allow research access to any samples including DNA (we will destroy these); or
- allow research access to information that we hold about you or your child. This information will be put beyond all further use. We will keep a minimum amount of information for auditing. See below for details of this.

Your healthcare professional will still get your initial report about your rare condition or cancer. They will ask you if you want to receive this. Your healthcare professional will not get any further reports relevant to your healthcare. Even if you choose option 2 – full withdrawal, it is not possible to:

- remove your data or samples from research that is underway or has already been done (any leftover sample is destroyed after the research is completed); or
- remove all records of you from our databases. We need to keep an audit record to say that you or your child were once part of the project and then withdrew. This includes your surname, first name, date of birth, address and contact details.

To withdraw you or your child, please fill in this form. Initial the boxes that apply to you, and fill in your details. Please then return this form to your or your child's clinical team.



## Withdrawal form

### 1 I have read and understood the withdrawal information.

**Initial** here to show you agree.

### 2 For adult participants

I want to withdraw from the 100,000 Genomes Project.

**Initial** your choice.

i. Option 1 – Partial withdrawal

ii. Option 2 – Full withdrawal

You:

**Your full name (BLOCK CAPITALS):**

**Date of birth:**

(DD/MM/YY)

**Signature:**

**Date:**

(DD/MM/YY)

### 3 Parent on behalf of your child:

I want to withdraw my child from the project.

**Initial** your choice.

i. Option 1 – Partial withdrawal

ii. Option 2 – Full withdrawal

You:

Your child's full name  
(BLOCK CAPITALS):

Your relationship to the child  
(BLOCK CAPITALS):

Your child's date of birth:

(DD/MM/YY)

Your name:

Your signature:

Date:

(DD/MM/YY)

**When you have filled in this form:**

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

**For GMC Staff use only (if this applies):**

<b>Person receiving this form:</b>	
<b>Signature:</b>	
<b>Date:</b>	(DD/MM/YY)
<b>Name of interpreter if used (BLOCK CAPITALS):</b>	
<b>Signature:</b>	
<b>Date:</b>	(DD/MM/YY)
<b>Adult participant NHS number:</b>	
<b>Child participant NHS number:</b>	

