

# 100,000 Genomes Project

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If you want to stop being a consultee, please let the clinical team know. You can stop being a consultee without withdrawing someone from the project.

## Information on how to withdraw a person you are a consultee for from the project

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Following discussion, we feel that at the moment, your relative, friend, patient or client who you are a consultee for (we refer to them as 'the person') cannot decide for themselves whether to leave the 100,000 Genomes Project.

This document tells you how to advise us that you believe the person would no longer want to take part in the 100,000 Genomes Project. Please read it carefully.

We ask you to advise us based on what you know of their wishes and feelings, and to consider their interests only.

Please let us know about any advance decisions the person may have already made about taking part in research. These should take priority.

If the person is withdrawn, they will still receive the best available care. Withdrawing from this project will not affect the person's participation in any other research project they are part of.

If you have any questions about withdrawing someone from the project, please ask the hospital staff running the project.

The consultee declaration form below is similar to the withdrawal form which we would have given to the person, had they been able to make their own decision about this.

We have edited this form to address it to you as their 'consultee'.

There are two options to withdraw the person from the project.

## Option 1 – partial withdrawal: ‘no further contact’

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We at Genomics England would no longer contact you directly as a consultee.

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

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

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The person would no longer be a participant in the 100,000 Genomes Project.

The 100,000 Genomes Project will no longer:

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

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

- remove their 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 the person from our databases. We need to keep an audit record to say that they were once part of the project and then withdrew. This includes their surname, first name, date of birth, address and contact details.



## Consultee declaration of advice on withdrawing an adult participant from the 100,000 Genomes Project

To give us your advice, please fill in this form. Initial the boxes that apply, and fill in your details. Please then return this form to the hospital staff running the project.

1. Your name:

I want to advise you about withdrawing

2. The person's name:

from the 100,000 Genomes Project.

I have had the opportunity to ask questions. I understand what is involved. I understand that you will always follow my advice about withdrawing the person.

In my opinion they would want to stop taking part in the project. My advice is that they should be withdrawn.

**Initial** your advice.

i. Option 1 – Partial withdrawal

ii. Option 2 – Full withdrawal

Your signature:

Date:

(DD/MM/YY)

Relationship to participant  
(Please state if you are a 'personal'  
or 'nominated' consultee):

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

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

**Staff use only:**

<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>	