

# 100,000 Genomes Project

## Opt out of receiving additional findings

### Information sheet for 100,000 Genomes Project

This sheet tells you how to opt out of receiving (any further) 'additional' findings. Please read it carefully. Opting out of receiving additional findings does not affect any other aspect of taking part in the project.

There are more details about additional findings below and in the information sheet for the project. This is available on our website ([www.genomicsengland.co.uk](http://www.genomicsengland.co.uk)) or you can get a copy from hospital staff running the project.

Please discuss your decision with family and friends and ask the hospital team any questions you have.

### Information about additional findings

- Participants can choose if they want certain other conditions that might affect them to be looked for in their samples ('additional findings').
- These conditions are not connected to a participant's rare disease or cancer.
- All the conditions can potentially be treated or prevented.
- Results might also be important to other members of a participant's family.
- Even if the results seem to show that a participant doesn't have one of the conditions, they could still get it in the future.
- We may add to or change which conditions we look for. This means a participant might get other results in the future.

## Information about carrier testing (only relevant to adult participants)

- Adults can decide to be tested to see if they 'carry' a risk of passing on serious genetic conditions to future children or grandchildren.
- These conditions may or may not be able to be cured, made less severe or prevented using standard NHS treatment.
- Someone may still have a child with one of the conditions, even if the result doesn't identify the condition in their genome data.
- We will regularly update the conditions we look for. So a participant could get further reports about different conditions in the future.

### If someone's partner is part of this project and they also agree to carrier testing:

- we will look for other conditions if a future child would only be affected if both a participant and their partner are carriers; and
- If a participant has children with a different partner in the future, that test result will not be helpful, because a new partner will not have been studied at the same time.

## Fill in this form if any of the following apply

- You no longer want to receive (any further) additional findings in the 100,000 Genomes Project.
- You no longer want to receive (any further) carrier-test results in the 100,000 Genomes Project.
- You no longer want your child to receive (any further) childhood-onset additional findings.
- You are a consultee for a participant, and think that they no longer want to receive (any further) additional findings.

You don't have to give a reason for your decision. If you opt out and then change your mind later, you can opt in again using the 'opt-in form'. You can get this from the hospital staff running the project or on our [website](#).

## If you opt out

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

Additional findings which have been found, but not yet been returned to you or your clinical team, will stay on our databases. They will still be accessible for approved purposes.

The original permission (consent) you gave for you, your child or a person who lacks capacity to join the 100,000 Genomes Project is not affected by you opting out.

We may invite you to take part in future research. This could include your views on additional findings or why you decided to opt out of receiving them. You do not have to take part in this research if you don't want to.

If you want to withdraw yourself, your child or the person who lacks capacity from taking part in the 100,000 Genomes Project, please ask the hospital team for a 'withdrawal form'.

## If you are opting out on behalf of a child

- You need to have legal parental responsibility for the child. Ask the hospital team if you need more information about this.
- You don't have to be a participant in the project yourself.
- You can only use this form for one child from receiving additional findings. Please use a separate form for each child.

To opt out of receiving additional findings for you, your child, or a person who lacks capacity, please fill in this form.

- Initial the options that apply.
- Sign your name and fill in the boxes.

## Opt-out form

**1** I have read and understood the Opt-out information.

**Initial** here to show you agree.

**2** Adult participant

I want to withdraw my permission to receive additional findings or carrier test results (or both).

Additional findings:

**Initial** if you no longer want to receive additional findings results.

Carrier test results:

**Initial** if you no longer want to receive carrier test results.

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

**Date of birth:**

(DD/MM/YY)

**Your signature:**

**Date:**

(DD/MM/YY)

### 3 Child participant

I want to withdraw permission for my child to receive additional findings.

**Initial** here to show you agree.

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

**I confirm that I have legal responsibility for (Put your child's full name in BLOCK CAPITALS):**

**Your relationship to the child (BLOCK CAPITALS):**

**Your child's date of birth:**

(DD/MM/YY)

**Your signature:**

**Date:**

(DD/MM/YY)

## 4 Adult who lacks capacity

I believe the adult who lacks capacity no longer wants to receive additional findings.

<b>Initial</b> here to show you agree.	
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<b>Your full name (BLOCK CAPITALS):</b>	
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<b>I confirm that I am a consultee for (Put their full name in BLOCK CAPITALS):</b>	
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<b>Their date of birth:</b>	(DD/MM/YY)
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<b>Please state either 'personal' or 'nominated' to show the category of consultee you are:</b>	
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<b>Your signature</b>	
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<b>Date:</b>	(DD/MM/YY)
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Please return this opt-out form to the person who gave it to you or your clinical care team or send it to:

Genomics England  
Queen Mary University of London  
Dawson Hall  
Charterhouse Square  
London  
EC1M 6BQ

