

100,000 Genomes Project

Opt in to receive additional findings

Information sheet for 100,000 Genomes Project

This sheet tells you how to 'opt in' (or choose) to receive additional findings. Please read it carefully. Opting in 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 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 want to receive additional findings in the 100,000 Genomes Project.
- You want to receive carrier-test results in the 100,000 Genomes Project.
- You want your child to receive childhood-onset additional findings.
- You are a consultee for a participant and think that they want to receive any additional findings.

You don't have to give a reason for your decision. If you opt in and then change your mind later, you can opt out again using the 'opt-out form'. This is available from hospital staff running the project or from our website.

If you opt in

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

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 opting in.

We may invite you to take part in future research. This could include your views on additional findings or why you decided to opt in to receive 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 being a participant in the 100,000 Genomes Project, please ask the hospital team for a 'withdrawal form'.

If you are opting in 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 to receive additional findings. Please use a separate form for each child.

To opt in to receive additional findings for yourself, 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-in form

1 I have read and understood the Opt-in information.

Initial here to show you agree.

2 Adult participant

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

Additional findings:

Initial if you want to receive additional findings results.

Carrier test results:

Initial if you want to receive carrier test results.

Your full name (BLOCK CAPITALS):

Date of birth:

(DD/MM/YY)

Signature:

Date:

(DD/MM/YY)

3 Child participant

I give 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 the 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 wants to receive additional findings.

Initial here to show you agree.

Your full name (BLOCK CAPITALS):

**I confirm that I am a consultee for:
(Their full name in BLOCK CAPITALS)**

**Please state either 'personal'
or 'nominated' to show the
category of consultee you are:**

Your signature:

Date:

(DD/MM/YY)

Please return this opt-in 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

