[INSERT NHS GMC LOGO]

100,000 Genomes Project

Participant consent form

If you agree to take part in the 100,000 Genomes Project, please:

- initial boxes 1, 2, 3 and 4;
- initial your choices for returning the additional findings in box 5; and
- sign your name at the end of this form.

Taking part, samples and data

1 Taking part

I have read and understood the participant information sheet 'For adults with a rare genetic condition or an adult family member' dated_____ /_____ /_____ (version_____). I have been able to ask questions and these have been answered.

I understand the following.

- **I can decide to join the project, or not.**
  My routine medical care or legal rights aren't affected if I don't take part.
- **If I join, I can withdraw at any time.**
  I do not have to give a reason why.
  If I withdraw, I understand that some research may have already taken place using my data and this can't be undone.

I agree to the following.

- You can tell my GP and other healthcare professionals that I have joined the project.
- You at Genomics England and my clinical team can contact me to:
  - ask me to provide more information for the project;
  - ask me to donate further samples if needed in the future;
  - invite me to join 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:

- a sample of blood;
- other samples, such as saliva, if needed; and
- samples already collected as part of my medical care.

My samples can be used for:

- collecting DNA for whole genome sequencing; and
- studying my blood to find out how the DNA is working.

I understand that there might be new ways of doing this in the future.

My 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 past and future health records.

- This includes personal information from all of my records from the NHS, my GP, and other organisations, including 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 NHS records, such as MRI scans, X-rays or photographs.
- The data may be used to study many different medical conditions, not just ones that affect me.
- It can be collected at any point in my life and will continue after my death, unless I have withdrawn from the project.
- Approved individuals from Genomics England, the NHS and other study monitors can look at this information at any time.

I understand the following.

- all information about me held by the project will be treated as confidential;
- my data, and information from my samples, will only be used by researchers in a form that protects my identity;
- research organisations who are accessing my data and samples may include commercial (for-profit) companies;
- researchers won't be allowed to copy or remove any of my information; and
- I will not benefit financially if research data from the project (which includes my data), leads to new treatments or medical tests.

Initial here to show you agree.	

My results

4

I agree that:

- tests can be run on my samples and health information to look for the cause of my (or my relative's) rare genetic condition and to help their medical care; and
- the results can be reported to my 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.
- I may not get a diagnosis, or information that will help with my (or my relative's) medical care now or in the future.
- Results may not be returned in time to be used in my (or my relative's) medical care.

I understand that:

- apart from my rare condition and additional findings (if I have asked for these) no other information will be looked for or reported.

Initial here to show you agree.	

Additional findings (optional)

5

I understand the following.

- I can choose if I want certain other conditions that might affect me to be looked for in my samples ('additional findings').
- These conditions are not connected to my (or my relative's) rare disease.
- All the conditions can potentially be treated or prevented.
- My results might also be important to other members of my family.
- Even if my results seem to show that I don't have one of the conditions, I could still get it in the future.
- You may add to or change which conditions you look for. This means I might get other results in the future.
- I can change my mind about receiving additional findings at any time.

Initial your choice

Yes, I want additional findings to be looked for and given to my clinical team.	

Or

No, I do not want this information to be looked for and given to my clinical team.	

Carrier testing (optional)

6

This next section is unlikely to be relevant to people who are not planning to have children in future. You can initial the box below and move to the next section.

Initial if carrier testing is not relevant for you.	

I understand that:

- I can decide to be tested to see if I 'carry' a risk of passing on serious genetic conditions to my future children or grandchildren;
- these conditions may or may not be able to be cured, made less severe, or prevented using standard NHS treatment;
- I may still have a child with one of the conditions, even if the result doesn't identify the condition in my genome data; and
- you will regularly update the conditions looked for. This means I could get further reports about different conditions in the future.
- If my partner is part of this project and they also agreed to carrier testing.
- other conditions will also be looked for, where our future child would only be affected if both myself and my partner are carriers.
- If I have children with a different partner in the future, that test result will not be helpful, because my new partner will not have been studied with me.

Initial your choice

Yes, I want this information to be looked for and given to my clinical team.	

Or

No, I do not want this information to be looked for and given to my clinical team.	

Name of participant (BLOCK CAPITALS):	
Date of birth:	(DD/MM/YY)
Signature:	
Date:	(DD/MM/YY)

Name of person receiving consent (BLOCK CAPITALS):	
Signature:	
Date:	(DD/MM/YY)

Name of interpreter if used: (BLOCK CAPITALS):	
Signature:	
Date:	(DD/MM/YY)

Additional contact details (optional)

If you are not able to receive results that are relevant to your family, is there anyone else who you would want your clinical team to try and give them to?

Name (BLOCK CAPITALS):	
Relationship to you:	
Date of birth:	(DD/MM/YY)
Address (BLOCK CAPITALS):	

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 administration use only (NHS GMC staff).

Insert local contact details here
Phone number:
Email address:
Hospital address: