

Consultee declaration form

Your child, relative, or friend is being invited to continue with the 100,000 Genomes Project. You are being asked to act as a consultee on their behalf.

Your child, relative or friend may not be able to decide for themselves whether they want to continue to be part of the 100,000 Genomes Project. Someone who can't make this kind of decision for themselves is legally described as 'lacking capacity.'

The role of a consultee

A consultee is someone who will only consider the likely views and interests of their child, relative or friend. They must set aside their own personal views about participating in research and consider the person they represent.

You do not have to take on this role. And you can stop being a consultee at any time, without having to give a reason.

Who can be a consultee?

A consultee must be an adult who is prepared to be consultant on the person's behalf, such as a:

- Next of kin (parent, partner, friend, family member or carer)
- Person holding Lasting Power of Attorney for Personal welfare registered with the Public Guardian
- Deputy appointed by the Court of Protection

A consultee cannot be part of the person's NHS clinical team or anyone else acting in a professional or paid capacity (e.g. a person's solicitor).

Making a decision as a consultee



An information sheet has been provided to help people decide if they want to continue in the Project, or stop taking part. This can also be found online at www.genomicsengland.co.uk

You should consider any advance decisions your child, relative or friend may have already made about taking part in research. If you decide they would not want to take part, they will still receive the best available care.

Your advice would be recorded on a form. You would get a copy of this form for your record.

Protecting the interests of adults who lack capacity

The law protects the interests of adults who lack capacity. In England and Wales, it states that a consultee can advise about the person's likely wishes or feelings. If your child, relative or friend does not want to take part, we will respect their wishes.

The consultee agreement

By saying 'yes' to being a consultee, I understand that on behalf of my child, relative or friend:

- I must consider the aims of the research, the practicalities, risks and benefits
- I must only consider their likely views and interests
- I will inform the healthcare team of any decisions they may have already made about research
- I have been made aware and given an opportunity to get independent advice
- If I feel that they wish to be withdrawn, I will notify a healthcare professional
- I might be asked to give advice again in the future, for example if more blood or saliva samples were needed
- Hospital staff will tell me if any future changes to the research might affect them
- I can stop being a consultee at any time