

BE PART OF RESEARCH ABOUT GENES

Your guide to giving a saliva sample

Adding information about your and your baby's genes

We would like to add genetic information about you and your baby to help understand how genes influence people's lives, and how genes and the environments people experience work together. Collecting genetic information at the start of the study will enable new scientific insights into children's health and development in the early years.

We will ask biological parents to provide a saliva sample and to take a saliva swab from their baby's mouth which will be used to extract DNA. As a thank you, we will provide an additional £5 voucher for your sample and another £5 for your baby's sample.

What are genes and DNA? Why is it important to study them?

DNA is the genetic information inside the body's cells that helps make people who they are. Genes are made up of sections of DNA, and are the biological way that children inherit characteristics from their parents.

Scientists have used genetic information collected later in life in similar studies to develop new treatments for common conditions like diabetes, psychological disorders and inflammatory diseases.

Why is it important to add information about both your genes and your baby's genes?

Adding genetic information from biological mothers and fathers, as well as their babies, will allow researchers to understand which genes are passed from parent to child, and how parents' genes influence their children's lives as well as their own.

Do you and your baby have to give a saliva sample?

It's completely up to you whether to give these samples, and if you don't wish to do this you can still take part in the study.

We will ask the parent who does the longer interview to give permission for their baby's sample. You may wish to discuss this decision with your child's other parent.

How are the saliva samples given?

We'll ask you to take your baby's saliva sample by brushing a special mouth swab on their gums. It's simple to do, does not hurt, and typically takes under a minute.

Your own sample is given by spitting into a small tube.

The interviewer will explain the process and provide the saliva collection kits with instructions. Ideally, we'd like you to collect the samples while the interviewer is present. Otherwise, it can be left with you to do another time.

You should not eat, drink, smoke or chew gum in the 30 minutes before giving the sample. The whole process will take around 5 minutes for each sample.

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Scan QR code below or go to gnestudy.info/saliva to find out more about giving your sample.



What will happen to the saliva samples?

The saliva samples will be sent to the University of Bristol research laboratory which is licensed by the Human Tissue Authority. **Your family's name and address will not be attached to the saliva samples.** A sample of DNA will be extracted and stored securely and anonymously for research about genes in the future. The saliva samples will be destroyed once the DNA sample has been extracted.

What will the DNA samples be used for?

The DNA samples will be used for research purposes only. Qualified researchers will need permission from a special committee with expertise in genetics and in overseeing and safeguarding access to the samples. They'll only be given permission if their research will benefit the public. Researchers from commercial organisations will usually partner with public organisations (e.g. the NHS or universities) except under circumstances of exceptional potential public benefit.

The DNA samples will be treated in strict confidence in accordance with the General Data Protection Regulation (GDPR), and any researchers using the samples will not have access to your family's name, address or any other personal details that could directly identify individuals in the study.

The DNA samples will never be used for paternity testing or human cloning. Your DNA will never be given to lawyers or insurance companies. We will not sell or make any profit from the samples you give.

We won't feed back any genetic information individually to you as the tests done on the samples are for research and cannot be used to diagnose medical conditions. If you have any concerns about genetic conditions, we'd advise you to speak to a medical professional.

You can change your mind about allowing the use of your or your child's DNA at any time without giving any reasons. When your child is an adult, they can also choose to withdraw their permission.

To change your permissions after the interview, write to us at **Freepost GENERATION NEW ERA** or gnestudy@ucl.ac.uk.

Have a question about giving a saliva sample?

More information can be found in the main study booklet and on the study website www.gnestudy.info/saliva.

You can also email or call the Generation New Era team: gnestudy@ipsos.com or Freephone 0800 151 0610.