

NEXT STEPS



LEARNING FROM YOUR GENERATION



£10

**VOUCHER WHEN
WE RECEIVE YOUR
SAMPLE**

**WHY SHOULD I GIVE
A SALIVA SAMPLE?**



NEXTSTEPSSTUDY.ORG.UK

HELP DISCOVER HOW GENES INFLUENCE OUR LIVES

As part of the Age 32 Survey, we will ask if you would provide a saliva sample so we can analyse your DNA for research.

DNA is the set of instructions for how our bodies are put together. Our DNA can determine whether we develop certain health conditions, but our behaviour, housing, finances and other factors matter too. Combining all these different things in one study can help reveal what's driven by our genes, what isn't, and how our genes and environment work together.

WHY DOES NEXT STEPS NEED MY DNA?

There are few studies in the world like Next Steps, that collect a broad range of information over time to try and understand the whole person. DNA is an important piece of this puzzle. By combining information about genes with the answers to the survey questions, Next Steps can paint a fuller picture of your generation.

WHAT WILL WE ASK?

During the survey, we will ask if you would be willing to provide a saliva sample, and give your permission to extract, analyse and store DNA from your sample. This will be done **anonymously** and **securely**, and for research purposes only.

If you don't want to do this, you don't have to.



HELPING TREAT COMMON DISEASES

Studies like Next Steps have already helped improve the care given to people with common diseases.

One of the other studies we manage, which is following people born in 1958, collected DNA from its study members in 2002-2004. Their contribution has led to historic scientific discoveries, and has been part of the evidence base for new treatments for common conditions like diabetes, bipolar disorder, and inflammatory diseases.



HOW WILL MY DNA BE ACCESSED AND STORED?

The stored DNA samples will only be used by researchers. They cannot be accessed by lawyers or insurance companies. They will also not be used for cloning.

Your samples will be stored securely and anonymously at a specialist storage facility at the University of Bristol. Researchers who want to use your DNA or the resulting data will need to apply for permission to the Centre for Longitudinal Studies (CLS) which oversees Next Steps.

We have a strict data access policy for your samples, and only give permission to researchers who can demonstrate that their work is ethical and of scientific and societal benefit. We may grant approval to research by the commercial sector, for example a healthcare organisation testing new treatments, but we will not sell or make any profit from the samples you donate.

Researchers will only be allowed to use the samples at the specialist storage facility or at another similar laboratory, which may be outside the UK. If researchers need us to send samples to another laboratory, we may charge them for the cost of transportation.

The anonymised samples will be treated in strict confidence in accordance with the General Data Protection Regulations (GDPR).



WHAT'S INVOLVED?

We'll send you a saliva collection kit with instructions. You'll be asked to spit in a small tube. The whole process, from reading the instructions to putting the sample in the package, will take less than 10 minutes. Watch this video for step-by-step instructions: [explainmyprocedure.com/nextsteps](https://www.explainmyprocedure.com/nextsteps).

CAN I FIND OUT THE RESULTS?

The tests that will be done on your DNA are for research purposes, and are not the same as clinical genetic tests. The results cannot be used for individual diagnosis. As such, we will not routinely feed back your individual results, but we will share the broader findings from the research with all study members, in our regular mailings and on our website.

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WHAT WILL HAPPEN TO YOUR SAMPLE?

DNA will be extracted and stored securely at a laboratory at the University of Bristol.

Your sample will be labelled with a unique ID number so that results of any testing can be linked with the other information we hold about you.

The laboratory will not have access to your name and address or any other information the study holds about you.



WHAT IF YOU CHANGE YOUR MIND AFTER YOU HAVE GIVEN A SAMPLE?

You can withdraw your consent for your DNA to be stored at any time, without giving a reason, by writing to us at:

**Centre for Longitudinal Studies
UCL Social Research Institute
20 Bedford Way
London WC1H 0AL**

Or by email at: nextsteps@ucl.ac.uk

We will inform the laboratory and any remaining stocks of your DNA will be destroyed.

