

NEXT STEPS



LEARNING FROM YOUR GENERATION



SALIVA SAMPLE – THINGS TO KNOW



NEXTSTEPSSTUDY.ORG.UK

GIVING A SALIVA SAMPLE FOR GENETIC RESEARCH

Towards the end of your interview we will ask your permission to provide you with a saliva collection kit and instructions, so if you agree you can provide a saliva sample for genetic research.

We wish to extract your DNA from this sample for research purposes only.

WHAT IS DNA?

GENETICS RESEARCH IS THE STUDY OF GENES. YOUR GENES DETERMINE YOUR GROWTH AND DEVELOPMENT. DNA IS THE CHEMICAL CODE YOUR GENES ARE WRITTEN IN.

FIND OUT WHAT GIVING A SALIVA SAMPLE INVOLVES BY WATCHING OUR VIDEO:

EXPLAINMYPROCEDURE.COM/NEXTSTEPS



WHY DO WE WANT A DNA SAMPLE?

We will ask for your permission to extract, analyse and store DNA from your saliva sample **for research purposes only**.

Research shows that an increasing number of illnesses have a genetic component. Genetic researchers can identify genes linked to certain conditions by combining information about your DNA with all the other information we have collected about your health and lifestyle.

This will help with understanding who is most at risk of certain illnesses and conditions, which may in turn lead to improved diagnosis, treatment and disease prevention.



WHAT WILL THE STORED DNA SAMPLES BE USED FOR?

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

Any future analysis will be done at the specialist storage facility or at another laboratory, which may be outside the UK. This could include research by the commercial sector.

We will not sell or make any profit from the samples you donate. However, if researchers need samples to be sent to another laboratory then a charge may be made to cover the cost of transportation.

Researchers who want to use your DNA will have to apply for permission to the Centre for Longitudinal Studies (CLS), which oversees Next Steps and access to the samples and resulting data.

Permission to use the samples and resulting data is only given to genuine researchers who can explain the potential impact of the research and its wider value for society; to research which meets ethical guidelines.

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



DO YOU HAVE TO GIVE A SAMPLE?

No, like all parts of the survey, it's completely voluntary.



CAN YOU FIND OUT THE RESULTS?

We will not routinely feed back any results from genetic analysis. The tests that will be done on your DNA are for research purposes. These tests are not the same as clinical genetic tests and cannot be used for individual diagnosis.

If, however, through the course of the research we find something that we think could indicate a preventable medical issue, we would attempt to contact you and advise you to consult with a medical professional.



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.

