

Information Sheet for Participants

Ethical Clearance has been received from King's College London Research Ethics Committee (Reference Number: PNM/09/10 – 104)

PLEASE SAVE A COPY OF THIS INFORMATION SHEET FOR YOUR RECORDS.

TEDS – Parent DNA Study

We would like to invite you to participate in this research study which forms part of the Twins Early Development Study (TEDS). Before you decide whether to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please feel free to contact the TEDS team using the details at the head of this document if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

Genes are like recipes written in tiny strands of DNA, and they provide information to help make us who we are. We all have thousands of genes, and each of us has our own complex set of genes. Genes have a major influence on what we look like, the colour of our eyes and our hair, how tall we are, and so on. Genes also have a partial influence on many other aspects of development, usually making little differences and sometimes causing problems. Genes certainly don't explain everything - but they are important to look at when trying to understand the interaction of genetic and environmental influences on development.

Having DNA data for both parents and twins in TEDS will enable us to explore the influence of genes and environments on traits and behaviours between two generations. The DNA will be genotyped, and the genetic data will be analysed to help us learn more about the genetic factors that play a part in the development of human language, thought and behaviour.

Why have I been asked to take part?

You have been asked to take part because you are the parent of a TEDS twin who has previously provided us with DNA.

What will happen if I take part?

Enclosed is a DNA collection pack. It is very quick and just needs you to provide a saliva sample by spitting into a small plastic tube. It doesn't hurt at all and will take between 2 and 5 minutes to complete. The enclosed DNA kit contains instructions on exactly how to do this and a freepost envelope has been provided for you to return the sample.

Your DNA (i.e. genetic material) will be extracted from the saliva for use in research. Your saliva sample will then be destroyed, and your DNA will be frozen for storage. Eventually your DNA will be genotyped (the extraction of genetic data) for use in statistical research.

If you have any questions or concerns, please contact us, using the contact details at the head of this document.

Do I have to take part?

It is entirely up to you whether or not to take part in this study. If you choose not to, it will not affect your future participation in TEDS studies. Once you have read the information sheet, please contact us if you have any questions that will help you make a decision about taking part.

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If you decide to take part in this study, you will be asked to complete a consent form in order to confirm that you have read this information sheet and that you agree to us using your data in the ways stated.

What are the possible benefits of taking part?

If you participate, you will help us learn more about the genetic factors that play a part in the development of human language, thought and behaviour.

Rewards: To thank you for taking the time to participate, upon return of the saliva sample we will email you a £10 Love2Shop flexecode. Please make sure that you provide us with your email address on the consent form.

Are there any risks in my taking part?

There are no foreseeable risks in participating in the study. The main disadvantage to taking part in the study is that you will be donating about 2 to 5 minutes of your time to complete the task.

How will my data be protected?

Your data will be processed under the terms of UK data protection law (including the UK General Data Protection Regulation (UK GDPR) and the Data Protection Act 2018). The legal basis under which TEDS processes your data is the performance of a task in the public interest, namely scientific and statistical research purposes. Full details of our legal basis are provided in the TEDS Privacy Policy at <http://www.teds.ac.uk/about-teds/privacy>.

Where will my data be stored?

DNA will be extracted from the saliva samples and stored in freezers until it is processed for genotyping (the extraction of genetic data). After genotyping, DNA will be retained in the freezers, either for repeated genotyping in the event of error, or for future sequencing. No names will be on the test tubes we freeze, only identification numbers.

The genotypic data will be stored within secure file storage facilities provided by King's College London and any administrative data (including names and contact details) are stored in a secure database system within the KCL network. The system can only be accessed by authorised members of the TEDS admin team. The administrative data are stored separately from the other research data, in order to minimise any risk of linking confidential research data back to participants.

Will my data be shared?

Genetic data from this activity, along with other data you have previously provided, will be shared with researchers for the purposes of statistical analysis in their research. However, they will only be shared in a form in which all personally identifiable information is removed, so that you and other individual participants cannot be identified. No DNA samples will be shared outside of King's College London.

What will happen to the results of the research study?

The findings of this study will be published in scientific journals, and also summarised on our website after the completion of the study. It is anticipated that the new data will then be used in future research alongside data collected in other TEDS studies.

How long will you keep my data?

As TEDS is an ongoing longitudinal study, the research data will be kept for the duration of the study. When TEDS eventually ends, the research data (including DNA samples) will be archived for future research purposes, but in an

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anonymous form whereby participants are not identifiable. Administrative data such as names and contact details will be deleted when TEDS ends.

Data Protection Statement If you would like more information about how your data will be processed under the terms of UK data protection laws, please visit the link below:

<https://www.kcl.ac.uk/research/support/research-ethics/kings-college-london-statement-on-use-of-personal-data-in-research>

What if I change my mind about taking part?

You have the right to ask us to destroy your DNA sample if you have any objection to us using your DNA for further research in the future. However, once the DNA is genotyped, it will not be possible to remove these genetic data. You will be able to request that we withdraw your sample up to **1 month** after you return your saliva kit before it is genotyped. After this time, you will no longer be able to withdraw your data.

If you wish to withdraw permanently from TEDS, you may do so, without having to give a reason, by contacting us using the details at the head of this document. If you choose to withdraw from the project, your contact details will be deleted from the database. However, TEDS reserves the right to keep any previously collected data, including genotype data, for future analyses.

How is the project being funded?

The study is funded and regulated by the Medical Research Council independent of any commercial interest and is concerned with research only.

Will my taking part be kept confidential?

All information is confidential and the data from the DNA is used anonymously. We are not allowed to pass any information to outsiders such as police, doctors or insurance companies. At the end of the study, the remaining DNA might be used in future research that is ethically approved.

Will I be informed of genotyping?

As a research study we are not allowed to pass on individual results. We will however tell you about our research progress through our newsletters.

Any questions?

If you have any questions, please do not hesitate to contact TEDS by email using the details at the head of this document.

If this study has harmed you in any way or if you wish to make a complaint about the conduct of the study you can contact King's College London using the details below for further advice and information:

The Chair, Mr. Chris Webb, rec@kcl.ac.uk

You can also contact the KCL Data Protection Officer, whose contact details are given at the bottom of the KCL privacy notice (<https://www.kcl.ac.uk/terms/privacy>). If you are not satisfied with the response given by the KCL Data Protection Officer, then you are entitled to complain to the Information Commissioner's Office (<https://ico.org.uk/global/contact-us/>).

Thank you for reading this information sheet and for considering taking part in this research.