



Information Sheet for Participants

Ethical Clearance has been received from King's College London Research Ethics Committee (Reference Number: HR/DP-20/21-22060).

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

TEDS26 - Mental Health Study

We would like to invite you to participate in this research project which forms part of the Twins Early Development Study (TEDS). Before you decide whether you want 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 this study?

This phase of the TEDS study aims to better understand who is affected by mental health disorders and how best to support these individuals.

An increasing number of young adults are experiencing mental health conditions such as anxiety and depression. Over the years, TEDS has been collecting data relating to mental health from TEDS families. By adding to this wealth of data at this important stage in the lives of TEDS twins, researchers will be uniquely placed to bring greater understanding of these complex issues.

What will happen if I take part?

If you choose to take part in the study you will be asked to complete an online questionnaire. You will be able to complete this questionnaire on a smartphone, desktop browser, laptop, or tablet. If you do not have online access a paper booklet can be provided. The questionnaire takes most people around 45-60 minutes to complete, though it may take longer for those with experience of mental health difficulties. You can take a break at any point and return to the survey later. Each time that you log back in you will be able to continue from where you left off.

As a part of participation you will be asked to provide information about the stresses and strains of your life. For example, there will be questions relating to your current and past mental and physical health, events in your life, your behaviour, and substance use. Some of the questions are quite personal, so for privacy you might prefer to be on your own while completing the questionnaire.

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.

If you decide to take part in this study, you will be asked to complete a consent form at the start of the questionnaire, 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?

We believe that mental health is one of the most important issues facing young people today and we know that many of you agree that tackling mental health is really important. By taking part in this research, you are helping us to understand what contributes to mental health and what factors are linked to outcomes in individuals who have experienced these conditions. Hopefully you will also find the questionnaire interesting and will enjoy the opportunity to reflect on your feelings and behaviours.

Rewards: All participants who complete the mental health questionnaire will be sent a £10 Love2Shop voucher code. You will also be given the opportunity to return some or all of the voucher to the TEDS team to support future research if you wish. Anyone who finishes will also be entered into regular prize draws. If you are successful in the draw and your twin has also taken part, you will both receive a prize.

Are there any risks in my taking part?

Some of the questions included in this questionnaire are of a sensitive nature which may cause distress. For example, items relating to traumatic life events and experiences of self-harm. For sensitive questions we have included a "prefer not to answer" option and links to relevant sources of help are included.

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 are provided in the TEDS Privacy Policy at <http://www.teds.ac.uk/about-teds/privacy>.

You will see that the online questionnaire is hosted by the commercial service **Qualtrics**. King's College London (KCL), which includes TEDS, holds a university-wide licence with Qualtrics for hosting questionnaires. This licence is a legal agreement that covers all aspects of data protection, to ensure that your data in this questionnaire will be secure. In this agreement, KCL, represented by the TEDS study, is the **data controller**, while Qualtrics is the **data processor**. The agreement guarantees that, for example, Qualtrics will keep your data secure during collection, will not share the data with any other parties, and will allow us to delete all the data from their servers when we have finished data collection. If you would like to read more about the security and GDPR-compliance of Qualtrics, visit this link: <https://www.qualtrics.com/uk/platform/gdpr/>.

Where will my data be stored?

For the duration of data collection, your data will be stored securely on the Qualtrics web server. Immediately after data collection, your data will be transferred to TEDS where they will be stored in secure file storage facilities managed by KCL. All copies of the data stored at Qualtrics will then immediately be deleted.

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?

Your 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.

What will happen to the results of the project?

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 will be archived for future research purposes, but in an 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 will be able to withdraw your data from this specific study (TED26 - Mental Health Study) for **1 month** after you complete the questionnaire. 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 for future analyses.

How is the project being funded?

The project is funded by the Medical Research Council (MRC). You can find out more about the MRC here: <https://mrc.ukri.org/>.

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.