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Information Sheet for Participants

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

TEDS COVID-19 Study

What is the purpose of this study?

This TEDS study aims to better understand the psychological and social impact of the coronavirus pandemic. The study consists of a questionnaire, many parts of which were used in previous TEDS studies, including Waves 1, 2 and 3 of this TEDS COVID-19 study. The sections of the questionnaire have been arranged into themes such as "Relationships", "Wellbeing" and "Substance use".

We have repeated the questionnaire at several time-points to understand the ongoing effects of the coronavirus outbreak. This is the fourth wave of data collection, as summarised here:.

1. Wave 1 – first data collection, completed April-May 2020.
2. Wave 2 – short-term follow-up, completed July 2020.
3. Wave 3 – mid-term follow-up, completed October 2020.
4. Wave 4 – long-term follow-up, starting March 2021.

The findings of this study will be published in scientific journals, and also summarised on our web site 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.

All TEDS twins contactable by email were invited to participate at the start of the study.

What am I being asked to do?

Taking part will involve completing an online questionnaire (<https://www.forepsyte.com/studies/TEDScov>). The first set of questions will ask specifically about your experiences related to the outbreak of coronavirus, such as any symptoms you may have had and what your current living situation is like. The following sets of questions may be familiar because they have been included in earlier TEDS studies, including Waves 1, 2 and 3 of this study. Some of the questions are quite personal, so for privacy you might prefer to be on your own while completing the questionnaires. If you have any questions or concerns, please contact us by email at teds-project@kcl.ac.uk.

The questionnaire can be completed in around 15 minutes.

You can complete the questionnaire in multiple sessions (e.g., log out or close your browser, then log in again later) if you need to. However, your responses are only saved at specific points, so if you do need to stop, it would be best to do so **only at one of the designated 'break points'** - it will say on screen where they are. This way, you won't lose any progress when you log back in to continue.

The website requires an up-to-date web browser, such as the latest versions of Firefox, Chrome, Edge or Safari. If possible, please use a desktop, laptop or tablet to complete the questionnaire. If you use a mobile phone, the questions may be difficult to read and for best results you may find it helps to turn your phone sideways.

Rewards

Participants in wave 4 will be entered into a prize draw. The prizes will include: 20 x £100 Love2Shop vouchers, 50 x £50 Love2Shop vouchers and 100 x £20 Love2Shop vouchers. We will notify all winners of the prize draw by email shortly after Wave 4 of the study has finished.

Do I have to take part?

It is entirely up to you whether or not to participate in any or all of the four waves of this study. If you choose not to, it will not affect your future participation in TEDS studies. 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 decide to take part in this or other waves, you will be asked to complete a consent form at the start of each wave of the study, to confirm that you have read this information sheet and that you agree to us using your data in the ways stated.

How will my data be protected?

Your data will be protected in accordance with the EU General Data Protection Regulation 2016 (GDPR) and the UK Data Protection Act 2018 (DPA). 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>.

TEDS have commissioned Quodit (owners of the website www.forepsyte.com) to implement the activities and run them on their web server, which is based in the UK. King's College London (KCL), represented by the TEDS study, is the **data controller**, while Quodit is the **data processor**, under GDPR definitions. There is a legal contract between KCL and Quodit to guarantee that, for example, Quodit will keep your data secure during collection, will not share the data with any third party, and at the end of data collection will transfer all the data to KCL and then delete all data from their server.

Where will my data be stored?

For the duration of data collection, your activity data will be stored securely on Quodit's web server. Immediately after data collection, the activity data will be transferred to TEDS where they will be stored on secure file servers in the KCL network. All copies of the data held by Quodit 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 identifiable 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.

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.

Are there any risks in my taking part?

We have no reason to think that taking part in this study will confer any risks at all. However, we are legally required to say that if this study has harmed you in any way you can contact KCL as described below. Some of the questions included in this questionnaire are of a sensitive nature which may cause distress. For sensitive questions we have included a "prefer not to answer" option and links to relevant sources of help are included.

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. Please note that the TEDS office is currently closed and the freephone number is not being monitored due to the ongoing coronavirus situation. Please email us with any queries that you may have.

If you have any concerns or complaints that you do not feel have been resolved by contacting TEDS, then you may 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/>).