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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 Codebreaker Study**

#### **What is the purpose of this study?**

This TEDS study aims to understand more about a variety of cognitive abilities such as memory, and verbal and spatial abilities. It will allow us to build on over 20 years of prior data collection. A fuller understanding of genetic and environmental influences, and how they interact with early life factors to affect midlife cognitive functioning, may contribute to improved cognitive health as well as to better health, education and services.

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.

#### **What am I being asked to do?**

Taking part will involve completing a series of online tasks. These tasks will assess your memory, verbal and spatial abilities. The study will take about 25-30 minutes. You can complete the study in multiple sessions (e.g., log out or close your browser, then log in again later) if you need to. However, it would be best to pause only *between* tasks, if possible, rather than in the middle of a task. If you would like to see your scores for the initial tasks, click on the link to *Your Results* when it appears at the top right corner of the screen.

We would be grateful if you would complete the study as soon as possible.

The website requires an up-to-date web browser, such as the latest versions of Firefox, Chrome, Edge or Safari. One of the tasks, towards the end of the study, can only be completed using a **desktop or laptop computer**, not a mobile device (phone or tablet). You might find it easier to complete the whole study on a desktop/laptop, so that you can go through everything together.

#### **Rewards**

If you decide to take part in this study, you will receive a £10 Love2Shop voucher code to thank you for your time. We will also hold a prize draw for all participants. The prizes are 2 x iPad minis and 50 £20 Love2Shop voucher codes. You will double your chances of winning if both you and your twin take part.

#### **Do I have to take part?**

It is entirely up to you whether or not to participate. 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 you will be asked to complete a consent form at the start of the web activity, 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 UK GDPR (the Data Protection Act 2018, as modified by the Data Protection, Privacy and Electronic Communications Regulations 2019). 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* <http://www.forepsyte.com/> and *The Many Brains Project* to implement the activities and run them on their web servers, which are based in the UK. King's College London (KCL), represented by the TEDS study, is the **data controller**, while *Quodit* and *The Many Brains Project* are the **data processors**, under GDPR definitions. There is a legal contract between KCL, *Quodit* and *The Many Brains Project* to guarantee that, for example, *Quodit* and *The Many Brains Project* will keep your data secure during collection, will not share your personal data with any third party, and at the end of data collection will transfer all the data to KCL.

### **Where will my data be stored?**

For the duration of data collection, your activity data will be stored securely on the web servers run by *Quodit* and *The Many Brains Project*. The data collected on *The Many Brains Project* server will be automatically copied to the *Quodit* server. Immediately after data collection, the entire set of activity data will be transferred from *Quodit* 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.

Another copy of your data from the activities on *The Many Brains Project* server will also be converted into scores and made fully anonymous by the removal of all identifying information. This anonymous copy of the data will then be retained permanently by *The Many Brains Project* in a data archive.

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.

The data retained by *The Many Brains Project*, archived for their academic research purposes, will be fully anonymised, and cannot be linked to any personally identifiable information.

### **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.

The anonymous data retained by *The Many Brains Project* will be retained indefinitely in their archive.

### **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>

### **Are there any risks in my taking part?**

The final activity, called Spatial Spy, has been known to cause feelings of motion sickness in a small number of participants in other studies. Other than this, we have no reason to think that taking part in this study will confer any risks. However, we are legally required to say that if this study has harmed you in any way you can contact KCL as described below.

**Any questions?**

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

If this study has harmed you in any way or 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](mailto: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. 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.**