

General Data Protection Regulation (GDPR) Participant Information

All information collected in this study will be kept on a secure online server in accordance with the EU General Data Protection Regulation (GDPR), along with the UK Data Protection Act. All electronic data will be stored on a password-protected computer file. Your consent information will be kept separately from your survey responses in order to minimise risk.

Message to participants from the TestEd team on behalf of the University:

We will use information from you in order to develop and to implement TestEd and the University will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Identifiable information (name, contact details) will be used to inform you of your test results and for administrative purposes only, during the study period. These details will be deleted at the end of the study. Anonymised data which will be used for research purposes will be stored for a minimum of 5 years after the study has ended. Identifiable audio recordings will also be kept securely for this period of time.

As a publicly-funded organisation, we have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, we will only use your data in the ways needed to conduct and analyse the research study.

This document explains how we will use any data that you share with us. We are legally required to tell you how we will use this information and to give you the opportunity to tell us not to use your information in that way.

Providing personal data by registering as a participant, by providing regular saliva samples, by completing questionnaires or verbally, in follow-up interviews.

To sign up to TestEd you will be asked to carefully read the study information sheet before providing your consent to participate. You will be asked to fill in a registration form, providing your name, contact details, and eligibility for the study. You will also be asked to provide some demographic details. The data collected will only be that which is appropriate and necessary for our specific research project.

The study investigators will keep your name and contact details, as well as the other information you provide, strictly confidential and will not pass this information on to third parties. We will use this information only as needed, to contact you about your test results, to make sure that information relevant to the study is properly recorded, and to ensure the quality of the study.

What happens to my data?

1. Registration form and survey

When you consent to the agreement to participate, you will enable us to access the data you provide on your registration form, the data resulting from regular tests of saliva in the samples you provide and the responses you provide through the online survey which is part of TestEd. All of this information is hosted on a secure server accessible only to the project team.

The data will serve two purposes only: first, to securely and confidentially convey your test results to you. The only members of the TestEd team with access to this data will be qualified IT professionals responsible for data protection and secure information management. Only anonymised data (which does not identify you) will be made accessible to TestEd researchers for the purpose of monitoring the progress of the project.

2. Analysis

Your anonymous survey data will be imported into quantitative data analysis software where it will be combined with others for analysis by the same research team. The survey data will be retained on our server for a minimum of 5 years after the end of the study.

3. Publication

The anonymised results of TestEd will be analysed for research purposes and may be quoted in the reports and academic publications we write. Likewise, survey responses may be used in such publications. Your name will never be used in any of these reports or publications and they will not include any personal identifiable information about you. When we publish our findings, we will upload all of the anonymised data to an online repository. When using research repositories, researchers are often required to upload their supporting or underlying data. The repositories have technical controls in place to ensure that only authorised individuals can access the information.

Certain individuals from the University of Edinburgh and regulatory organisations may examine our research records to check the accuracy of the research study, and for audit purposes. They will only be able to access de-identified (coded) and unlinked information.

Contact for further information

You can find out more about how we use your information and our legal basis for doing so in our Privacy Notice at <https://www.ed.ac.uk/data-protection/privacy-notice-research>

For further information on the use of personal data by the University of Edinburgh, please go to website: <https://www.ed.ac.uk/records-management/privacy-notice-research>

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO) at <https://ico.org.uk/>.

Data Protection Officer contact information:

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