



Data Protection Information Sheet

Testing and Trust: Public perceptions, expectations and experiences of COVID-19 testing in Lothian, Scotland.

Testing and Trust is the short study name that refers to the above named project. It is a research study funded by the Chief Scientist's Office's Rapid Research in COVID-19 (RARC-19) programme, and run by The University of Edinburgh. The University is the 'data controller' as defined in the Data Protection Act. Testing Trust complies with the requirements of the European Union's General Data Protection Regulations (GDPR) and the UK Data Protection Act (2018) with regard to the collection, processing, storage and disclosure of personal information.

The University of Edinburgh is the sponsor for this study based in Lothian, Scotland. Testing and Trust gathers information about participants from online survey forms and in-depth qualitative interviews. The study investigators process these data to remove the risk that any person may be identified from the data and analyses them for research purposes.

We will use information from you in order to undertake this study and 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 for administrative purposes only during the study period and will be deleted at the end of the study. Anonymised research data will be stored for a minimum of 5 years after the study has finished. 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 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 give you the opportunity to tell us not to use your information in that way.

Providing personal data directly e.g. verbally, or in an online survey

To sign up to the Testing and Trust study you will need to read the study information before consenting to participating in the study. You will register for the study via a short online survey. At the end of the survey you will be asked whether you are willing to be contacted for a follow-up interview by email and be given the option of providing your name and email address for this purpose. If you **do not** choose to take part in an interview the survey data may include your gender, age, online and location identifiers. It may also include sensitive (special category) data, such as your ethnicity, sexual orientation, gender identity, etc. The data collected will only be that which is appropriate and necessary for our specific research project. If you **do** choose to take part in an interview then the survey data will additionally include your name and contact details.

The study investigators will keep your name and contact details confidential and will not pass this information on to third parties. We will use this information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded, and to oversee the quality of the study.



What happens to my data?

1. Survey form

When you consent to the agreement to participate and submit your survey form, we will be able to access the data you provide in your responses. This is hosted on a secure online server accessible only to the research team. Your data will then be exported. If you choose to participate in a follow-up interview and enter your name and contact details, this personal information will be removed from the survey data and saved in a separate location on a secure online server. This information will be used by study investigators to contact you to arrange an interview. The rest of the information you provide will be anonymised and used in our analysis.

2. Interview

Your interview can be conducted over the telephone or using a secure online teleconferencing platform, such as Microsoft Teams, according to your preference. In both instances, an audio recording of the interview will be taken. The audio file will be saved on our secure online server and deleted from any recording devices as soon as possible. Your name will not be attached to the audio file.

3. Transcription

The file will be transferred to Frances Armstrong of Armstrong Transcriptions, who has signed a data agreement with the study investigators in order to produce a transcript of your interview. The transcript of your interview will be saved on our online server and will contain no identifying information about you.

4. 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. Your anonymised interview data, in the form of a transcript, will be imported into qualitative data analysis software where it will be combined with others for analysis by the same research team. The survey data, as well as the audio file and transcript from your interview will be retained on our server for a minimum of 5 years after the end of the study.

5. Publication

Some of what you tell us in your interview may be quoted in the reports and academic publications we write. Your name will not be attached to any quotes we use and they will not include any personal identifiable information about you. When we publish our findings, we will upload all of the anonymised transcripts 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 look at your research records to check the accuracy of the research study. They will only receive information without any identifying information. No one except the research investigators



analysing the information will be able to identify you and will not be able to find out your name or contact details.

The study investigators will keep identifiable information about you from this study for a minimum of 5 years after the study has finished.

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 blogs.ed.ac.uk/testingtrust/privacy-notice.

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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