

Data Protection Information Sheet

Investigating the relationship between spontaneous speech features and psychology in the context of the COVID-19 pandemic and lockdown: personality, wellbeing, coping strategies and affect.

The EU General Data Protection Regulation (GDPR), along with the UK Data Protection Act, governs the processing (holding or use) of personal data in the UK.

You are receiving this as you are considering being a participant on this clinical research study. The information below details what data will be held about you and who will hold or store this.

University of Edinburgh is the sponsor for this study based in the United Kingdom. We will use information from you and/or your medical records 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. The sponsor will keep identifiable information about you for 10 years after the study has finished.

As a university, we use personally-identifiable information to conduct research to improve health, care and services. 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. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

Providing personal data directly e.g. verbally, in a questionnaire or from your care provider

The University of Edinburgh will collect information about you for this research study from your participation in it, which will exclusively be online. This information will include a recording of your voice and (if you choose to give it) your email address, both regarded as a special category of information (i.e. identifiable). We will use the recordings to study the relationship between voice features and psychological elements extracted from the questionnaires that conform the study. Voice features are numerical, and therefore, once extracted, they will be as anonymous as the results of the questionnaires, which do not include your contact details. We will only use your email address to contact you, should you agree to participate in a study follow-up; otherwise, we will not keep your email address.

Individuals from the University of Edinburgh and regulatory organisations may look at your research records to check the accuracy of the research study. The only people who will have access to information that identifies you will be those members of the research group who undertake the voice feature extraction (only if they know your voice), and people who need to contact you for a follow-up or audit the data collection process. The people who further analyse the information will not have access to your voice recordings and contact details, and therefore will not be able to identify you.





Use of data for future research

When you agree to take part in a research study, the information about your health and care may be provided to researchers running other research studies in this organisation and in other organisations. These organisations may be universities, NHS organisations or companies involved in health and care research in this country or abroad. Your information will only be used by organisations and researchers to conduct research in accordance with the UK Policy Framework for Health and Social Care Research.

Your information could be used for research in any aspect of health or care, and could be combined with information about you from other sources held by researchers, the NHS or government.

Where this information could identify you, the information will be held securely with strict arrangements about who can access the information. The information will only be used for the purpose of healthcare research, or to contact you about future opportunities to participate in research. It will not be used to make decisions about future services available to you, such as insurance.

Where there is a risk that you can be identified your data will only be used in research that has been independently reviewed by an ethics committee and/ or the sponsor.

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 www.accord.scot.

For further information on the use of personal data by NHS sites, please link to the Health Research Authority (HRA) website; https://www.hra.nhs.uk/information-about-patients/.

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:

University of Edinburgh

Data Protection Officer Governance and Strategic Planning University of Edinburgh Old College Edinburgh EH8 9YL Tel: 0131 651 4114 dpo@ed.ac.uk