

General Data Protection Regulation (GDPR) Participant Information

Genetic disorders of growth, development and the brain

20th August 2018. Version 1

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

You are receiving this as you/your child is a participant in this clinical research study. The information below details what data is held about you and who holds or stores this.

University of Edinburgh and NHS Lothian are the co-sponsors for this study based in the United Kingdom. We will use information from you/your child's 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 University of Edinburgh will keep identifiable information about you/your child for 20 years after the study has finished.

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 use your/your child's name, hospital number(s), and date of birth to contact your clinician(s) about the research study, and make sure that relevant information about the study is recorded, and to oversee the quality of the study. Individuals from the University of Edinburgh and official regulatory organisations may look at your medical and research records to check the accuracy of the research study. The only people in University of Edinburgh who will have access to information that identifies you will be members of the research team who are clinicians and/or staff members who need this information to encode (anonymise) samples received and to generate reports for your clinician(s).

Providing personal data indirectly e.g. from your medical records

The University of Edinburgh will also receive information about you for this research study from your/your child's own doctors' records. This information may include your/your child's name, address, hospital number(s) and date of birth and health information, which is regarded as a special category of information. We will use your/your child's health information in the research project.

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:

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