

General Data Protection Regulation (GDPR) Participant Information

UNDERSTANDING CAUDA EQUINA SYNDROME (UCES)

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 information as you are currently a participant on this clinical research study. The information below details what data is held about you and who holds or stores this.

NHS Lothian is the sponsor for this study based in the United Kingdom. We will use information from you and 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 5 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.

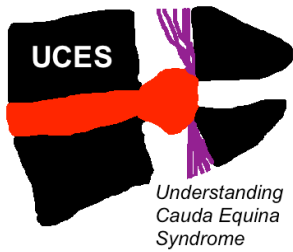
Providing personal data directly (contact details on the consent form)

If you answer the questionnaires by email, the NHS organisation treating you will keep your name and contact details confidential and will not pass this information to NHS Lothian. The NHS organisation treating you will use this information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Certain individuals from NHS Lothian and regulatory organisations may look at your medical and research records to check the accuracy of the research study. NHS Lothian will only receive information without any identifying information. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details. The NHS site treating you will keep identifiable information about you from this study for 5 years after the study has finished.

If you choose to answer the questionnaires by telephone or post, NHS Lothian will use your name and contact details to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Individuals from NHS Lothian and regulatory organisations may look at your medical and research records to check the accuracy of the research study. The NHS site treating you will pass your name and contact details to NHS Lothian. The only people in NHS Lothian who will have access to information that identifies you will be people who need to contact you to complete the questionnaires or audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details. NHS Lothian will keep identifiable information about you from this study for 5 years after the study has finished.

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Providing personal data indirectly (from your medical records)

NHS Lothian will collect information about you for this research study from your medical notes. The NHS site treating you will not provide any identifying information about you to NHS Lothian. We will use this information to conduct the research study.

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](#).

This information will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for the purpose of health and care research, and cannot be used to contact you or to affect your care. It will not be used to make decisions about future services available to you, such as insurance.

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:

NHS Lothian
Data Protection Officer
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