

# General Data Protection Regulation (GDPR) Participant Information

## ChILD-EU

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 (or your child) have participated on this clinical research study. The information below details what data is held about you (or your child) and who holds or stores this.

The University of Edinburgh and NHS Lothian are the co-sponsors 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 co-sponsors will keep identifiable information about you for at least 3 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 NHS Hospital Trust where you or your child took part in the trial will use your or your child's name, NHS or Community Health Index (CHI) number and contact details to contact you about the research study, and make sure that relevant information about the study is recorded for your or your child's care, and to oversee the quality of the study. Individuals from NHS Lothian and the University of Edinburgh and regulatory organisations may look at your or your child's medical and research records to check the accuracy of the research study. The NHS Hospital Trust where you or your child took part in the trial will pass these details to NHS Lothian and the University of Edinburgh along with the information collected from you and your medical records or from your child and your child's medical records. The only people in the University of Edinburgh and NHS Lothian who will have access to information that identifies you or your child will be people who need to contact you or your child to inform you or your child about research or tests available for interstitial lung disease, people who manage the database where the trial data is stored or people who audit the data collection process. The people who analyse the information will not be able to identify you or your child and will not be able to find out your or your child's name, NHS or CHI number, or contact details.

The University of Edinburgh and NHS Lothian will keep identifiable information about you or your child from this study for at least 3 years after the study has finished.

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

The co-sponsors (University of Edinburgh and NHS Lothian) will collect information about you or your child for research from your or your child's medical records. This information will include your or your child's name,

NHS or CHI number, contact details, date of birth and health information, which is regarded as a special category of information. We will use this information to audit the data collection process. Date of birth will be used in the study analysis. The NHS or CHI number will be used by the co-sponsor organisation (University of Edinburgh and NHS Lothian) or the Kids Lung Foundation to periodically ask central NHS registers to provide information on your health status.

### Use of data for future research

When you agree to take part in a research study, the information about your or your child's 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 or your child's 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 or your child's information could be used for research in any aspect of health or care, and could be combined with information about you or your child from other sources held by researchers, the NHS or government.

Where this information could identify you or your child, 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 or your child, such as insurance.

Where there is a risk that you or your child can be identified your data or your child's 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](http://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](mailto:dpo@ed.ac.uk)

**NHS Lothian**

Data Protection Officer  
NHS Lothian  
Waverley Gate  
2-4 Waterloo Place  
Edinburgh  
EH1 3EG  
Tel: 0131 465 5444  
[Lothian.DPO@nhs.net](mailto:Lothian.DPO@nhs.net)