

Transparency Statement

Information about how your data is processed in light of GDPR updates, for patients recruited to research study:

An Investigation into the molecular pathogenesis of lung disease: IRAS 235499

For participants recruited to the study listed above prior to October 2018

- Please find the below updates to clarify the way in which any data has been collected from you as part of your involvement in this study.
- If you were recruited after October 2018 the patient information leaflet (PIS) that you were provided with on recruitment to the study would have had the information as below.

UCL is the sponsor of this study based in the United Kingdom and acts as the 'data controller'. As part of your recruitment to this study you would have consented to information from your medical notes being recorded. UCL is responsible for looking after this information and using it properly. UCL will keep identifiable information about you for 10 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 as possible.

At the time of your recruitment and sample collection

UCL will have collected information from you and/or your medical records for this research study in accordance with our instructions. UCL may have used your name, NHS number 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 UCL and regulatory organisations may look at your medical and research records to check the accuracy of the research study. The hospital will pass these details to UCL along with the information collected from you and/or your medical records. The only people in UCL who will have access to information that identifies you will be people who need to contact you to check information 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, NHS number or contact details.

You can find out more about how we use your information by contacting Sam Janes at s.janes@ucl.ac.uk or at <https://www.ucl.ac.uk/legal-services/privacy/participants-health-and-care-research-privacy-notice>

Understanding how your sample/information are used.

When you agreed to take part in this study, you consented to your sample being regarded as a donation/gift which may be used in the future for investigations into the molecular changes underlying lung disease.

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 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.

Any new research will be reviewed by a research ethics committee but consent for future studies may only be required if the committee considers that the study is likely to substantially affect the subjects' interests.