

NCORE Study: Privacy Statement

Confidentiality

All information collected about you will be kept strictly confidential and stored and processed according to the Data Protection Act. We will not share any confidential information, or the result of any tests e.g. urine drug screen, with your GP or clinical team without your permission. However, should there be any concerns about risks of harm to you or anyone else, a clinical decision will be made with regard to disclosure of information and appropriate support will be discussed with you. The research data we collect from you are anonymised, so they can only be identified by a subject number. With permission, you may be contacted for follow-up studies related to this project in the future.

Who is responsible for my data?

Imperial College London is the sponsor for this UK based study. We will use information from you and your medical records in order to undertake this study and will act as the data controller. We are responsible for looking after your information and using it properly. Imperial College London will keep identifiable information about you for 10 years after the study has finished in relation to data subject consent forms and in relation to primary research data or according to your wishes on the consent form.

Further information on Imperial College London's retention periods may be found at <https://www.imperial.ac.uk/media/imperial-college/administration-and-support-services/records-and-archives/public/RetentionSchedule.pdf>.

Your rights

Your usual statutory rights to access, change or move your information are limited, as we need to manage your information in specific, lawful 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.

Legal Basis

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.

Health and care research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. We do this by following the UK Policy Framework for Health and Social Care Research.

International Transfers

There may be a requirement to transfer information to countries outside the European Economic Area (for example, to a research partner). Where this information contains your personal data, Imperial College London will ensure that it

is transferred in accordance with data protection legislation. If the data is transferred to a country which is not subject to a European Commission (EC) adequacy decision in respect of its data protection standards, Imperial College London will enter into a data sharing agreement with the recipient organisation that incorporates EC approved standard contractual clauses that safeguard how your personal data is processed.

Who will have access to my data?

Personal data: Imperial College Healthcare NHS Trust (Hammersmith Hospital) and Imperial College London will collect personal information from you for this research study in accordance with our instructions.

Individuals from regulatory organisations may look at your medical and research records to check the accuracy of the research study.

Imperial College Healthcare NHS Trust and Imperial College London 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 Imperial College London and regulatory organisations may look at your medical and research records to check the accuracy of the research study. Imperial College Healthcare NHS Trust will pass these details to Imperial College London along with the information collected from you and your medical records. The only people in Imperial College London who will have access to information that identifies you will be people who need to contact you about the research study 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.

If you wish to raise a complaint on how we have handled your personal data or if you want to find out more about how we use your information, please contact Imperial College London's Data Protection Officer Imperial College London, Data Protection Officer, Faculty Building Level 4, London SW7 2AZ, 020 7594 3502, dpo@imperial.ac.uk. 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). The ICO recommends that you seek to resolve matters with the data controller (us) first before involving the regulator.

Research data: 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 (<https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/uk-policy-framework-health-social-care-research/>).

Imperial College London

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.