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**PARTICIPANT PRIVACY INFORMATION**

**Research Study Title:** CF-EpiNet

Imperial College Londonis the sponsor for this study based in the United Kingdom. We will be using information from 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. Imperial College London will keep this information about you until the end of the project in April 2020.

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>.

A link to Imperial College London’s data protection webpage may be found at <https://www.imperial.ac.uk/admin-services/legal-services-office/data-protection> but this is the notice most applicable to the information provided by participants and therefore takes precedence for all purposes described hereunder. This notice applies in addition to:

* the Cystic Fibrosis Registry privacy policy (<https://www.cysticfibrosis.org.uk/the-work-we-do/uk-cf-registry/uk-cf-registry-privacy-notice>)
* the College’s Data Protection Policy (<http://www.imperial.ac.uk/admin-services/legal-services-office/data-protection/our-policy>)
* and the College’s information security policy (<http://www.imperial.ac.uk/admin-services/secretariat/college-governance/charters/policies-regulations-and-codes-of-practice/information-security-/policy>).

**YOUR RIGHTS**

Your usual statutory rights to access, change or move your information are limited, because of exceptions applicable to some types of research, and also because 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. You have the right to opt out of your confidential patient information being used for research – more information can be found at <https://www.nhs.uk/your-nhs-data-matters>**. For any questions regarding the use of your data provided by the UK CF Registry, or to opt out of the Registry, please contact** [registry@cysticfibrosis.org.uk](mailto:registry@cysticfibrosis.org.uk).

**LEGAL BASIS**

As a university we use 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 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.

**CONTACT US**

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 via email at dpo@imperial.ac.uk, via telephone on 020 7594 3502 and via post at Imperial College London, Data Protection Officer, Faculty Building Level 4, London SW7 2AZ.

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 does recommend that you seek to resolve matters with the data controller (us) first before involving the regulator.

**HOW WE WILL USE YOUR INFORMATION**

Imperial College London will collect information about you for CF-EpiNet from the UK Cystic Fibrosis Registry and NHS Digital. Neither the UK Cystic Fibrosis Registry or NHS digital will provide any identifying information about you to Imperial College London. We will use this information:

* To understand the pattern of co-morbidities that develop as people with CF patients age
* To improve our current understanding of resource utilisation
* To get an overall picture of the number of people with CF in the UK, the state of their health and where they are treated
* To see if there is a difference between the health of people in different regions of the UK
* To look at the reasons for any differences and use them to make improvements to the care of people with cystic fibrosis
* To identify if new trends are emerging, for example new infections
* To monitor the safety and effectiveness of cystic fibrosis treatments

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/). All of information received from NHS Digital will be held at Imperial, and no collaborators will be able to access this data, unless they have an Imperial contract and are on site at Imperial.

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.