

## PARTICIPANT PRIVACY INFORMATION

**Research Study Title:** COSMOS cohort study of mobile phone use and health

**IRAS 145713**

Imperial College London is the sponsor for this study based in the United Kingdom. We will be using information from you and your medical records 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 identifiable information about you for:

- 30 years after the study has finished in relation to data subject consent forms.
- 30 years after the study has completed in relation to primary research data.

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/secretariat/information-governance/data-protection/> but this is the notice most applicable to the information provided by participants and therefore takes precedence for all purposes described hereunder.

### **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.

### **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 must 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.

### **ACCESS TO AND USE OF DATA**

We may transfer your data to third parties where this is necessary to operate the study efficiently or to carry out data analysis leading to the publication of research results. This includes transfers to private companies delivering services on behalf of the study universities and other research institutions that are working with us to carry out data analysis and publish research results; public-sector organisations such as the NHS that supply us with extracts from your NHS medical record. We will manage these data transfers to ensure the same level of security as if processed within the College.

## INTERNATIONAL TRANSFERS

There may be a requirement to transfer your data to countries outside the European Economic Area (for example, to a research partner). 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.

## YOUR RIGHT TO WITHDRAW

Every COSMOS participant has the right to withdraw at any time, without providing a reason. If you are considering withdrawing from the study, please contact us on 020 7594 1892 (Monday - Friday 9:00am - 5:00pm, excluding Bank Holidays) or by email at [ukcosmos@imperial.ac.uk](mailto:ukcosmos@imperial.ac.uk).

If you decide to withdraw, please choose one of the following options concerning future contact and use of information.

1. **No Further Contact** – this means that COSMOS would no longer contact you directly but would still have your permission to retain and use information provided previously and to obtain and use further information from your health records.
2. **No Further Access** – this means that COSMOS would no longer contact you or obtain further information from your health records in the future but would still have your permission to use the information provided previously.

Should you withdraw from the study without specifying an option for future contact and use of data, we will assume that “No Further Contact” is intended.

You are free to withdraw your voluntary consent at any point, and doing so will not affect your healthcare, healthcare rights or your relationship with your mobile network operator.

## AUTOMATED DECISION MAKING

We will not use your data as part of any automated decision-making or profiling process that will affect you in any way.

## 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](mailto: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.

## HRA Transparency Statement

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- 30 years after the study has completed in relation to primary research data.

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.

You can find out more about how we use your information at [www.ukcosmos.org](http://www.ukcosmos.org) or by contacting the COSMOS research team at [ukcosmos@imperial.ac.uk](mailto:ukcosmos@imperial.ac.uk)

Imperial College London will collect information about you for this research study from NHS Digital, ONS, NHS Scotland, NHS Wales, Public Health England and Northern Ireland Public Health Agency as well as mobile phone operators. This information will include your name, NHS number, contact details, mobile phone usage, and health information, which are regarded as a special category of information. We will use this information to investigate the possible health effects related to long-term mobile phone use.

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/>).

Your information could be used for research in any aspect of health or care, and could be combined with information about you from other sources held by researchers, the NHS or government.

Where this information could identify you, we will hold the information securely with strict arrangements about who can access it. The information will be used only for the purpose of health and care research, or to contact you about future opportunities to participate in research. We will not use the information to make decisions about future services available to you, such as insurance.

Where there is a risk that you can be identified your data will only be used in research that has been independently reviewed by an ethics committee.