

COSMOS STUDY

Participant Information Booklet



Thank you for your ongoing participation in the COSMOS study, the largest research project in the world investigating the possible health effects related to long-term mobile phone use. Your contribution has been valuable to this important piece of research.



About this study

What is COSMOS?

COSMOS (COhort Study of MObile phone uSe and health) is an international cohort study investigating possible health effects related to long-term use of mobile phones and other wireless technologies.



The UK cohort is made up of approximately **105,000** adult mobile phone users.

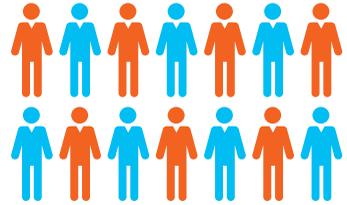
The international cohort consists of approximately **290,000** mobile phone users from five European countries.

Participants in the study will be followed up for 20 to 30 years.

More information about COSMOS is also available at www.ukcosmos.org

What is a cohort study?

In a cohort study, the health of a select group of people (the cohort) are followed over an extended period of time, often years. The aim of a cohort study is to determine whether suspected risk factors are linked to certain illnesses.



What health outcomes are we investigating?

We are investigating a large number of health outcomes including any changes in specific symptoms over time, such as headaches and sleep disturbance; and development of illnesses such as cancers, benign tumours, neurological and cerebrovascular diseases. We are also investigating possible effects on fertility, mental health and general well-being.



Who is conducting this study?

In the UK, this research is being conducted by Imperial College London. Internationally, the COSMOS study is coordinated by the international COSMOS consortium, a group of medical and university research centres across six European countries (Denmark, France, Finland, the Netherlands, the UK, and Sweden).

**Imperial College
London**

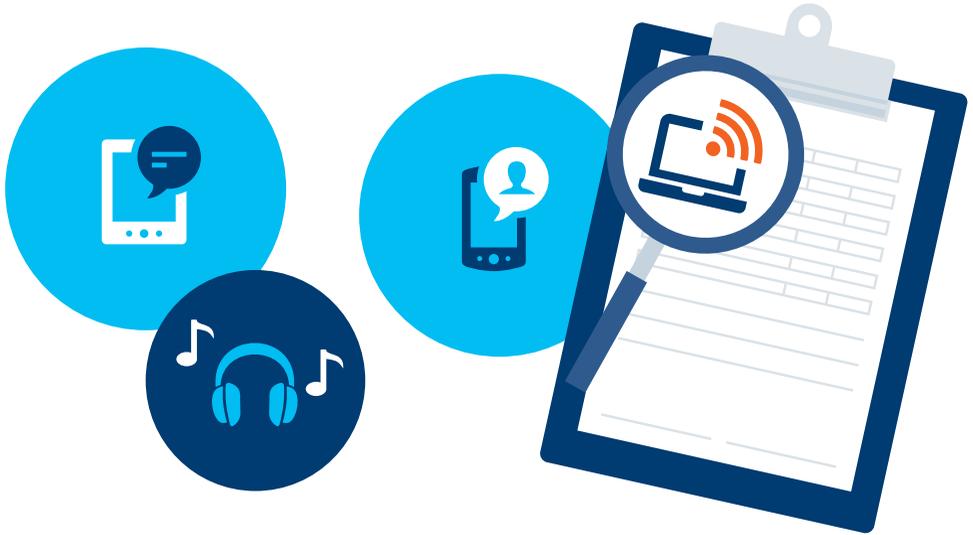
Who is funding this study?

UK COSMOS is independent research funded by the Department of Health, and formerly funded by the MTHR (an independent programme of research into mobile phones and health).



Why is this research important?

In the modern era, exposure to **radiofrequency electromagnetic fields** (RF-EMF) has become part of our daily lives, particularly as we become more reliant on sources of RF-EMF such as **mobile phones and other wireless technologies**.



In 2011, the International Agency for Research on Cancer (IARC) classified RF-EMF as possibly causing cancer in humans. However, despite a number of research studies on this topic, uncertainty remains.

The COSMOS study was designed to determine whether there are any harmful effects on health and wellbeing related to long-term mobile phone use. The study follows the health of a large cohort of people for up to 30 years, as some health effects may take many years to become apparent. This research has been endorsed as a priority by government and health agencies worldwide including the Department of Health, Public Health England (PHE) and the World Health Organisation (WHO).

Information being collected

As part of our ongoing research, up-to-date information is being continually collected about you.

A Information From You

Follow-up Questionnaires

Approximately every four years over the study period we will invite you to complete a follow-up questionnaire. These questionnaires provide us with vital up-to-date information about:

- 1 Your past and current use of mobile phones and other wireless technologies.**
- 2 Your health and medical history**
- 3 Your home environment, lifestyle and employment** – we also ask questions about your home environment, e.g. indoor air quality and noise, your lifestyle such as smoking, diet, and exercise, and your employment such as job type and shift work, as these are all relevant to your long term health.

Your contact details

We will contact you annually via email to update your contact details.



If you have moved home, changed your name, email address, phone number or network provider it is very important that you let us know - please contact us via email/Freephone to update these details. This allows us to invite you to complete questionnaires and to monitor your health and mobile phone use via routinely collected records. Even if you leave the country, your data remain valuable to the study.

B Information From Routinely Collected Records

Medical and health-related records

If you gave consent, the information you provide about your health through the questionnaires will be supplemented through NHS Digital¹ and the Office for National Statistics (ONS)¹ who will link data on: hospital inpatient admissions, outpatient appointments and A&E attendances ², cancers³, deaths ⁴, births ⁵ and NHS registration ⁶ with information you provided during the course of the study. In order to link your data, we will send your name, gender, date of birth, address and NHS number to NHS Digital¹ and ONS¹ who will then link the information on our behalf and return it to us.



Network operator data

If you gave consent, the information you provide about your phone usage through the questionnaires is being supplemented with mobile phone records from your network operator(s), including the frequency and duration of phone calls.

This information will not include any details identifying phone numbers that you contact nor those of people who contact you, nor the content of messages or addresses of websites you visit.



1. and equivalent organisations in Wales [NHS Wales Informatics Service], Scotland [NHS Scotland] or Northern Ireland as appropriate; and any successor organisations to these.
2. from the Hospital Episode Statistics (HES) dataset provided by NHS Digital for participants in England, from the Scottish Morbidity Record (SMR) Data provided by NHS Scotland for participants in Scotland and from the Inpatients and Outpatients dataset provided by NHS Wales Informatics Service for participants in Wales.
3. from Cancer Registrations Data, provided by NHS Digital for participants in England and Wales, and provided by NHS Scotland for participants in Scotland.
4. from Mortality Data, provided by NHS Digital on behalf of the Office for

5. National Statistics (ONS) for participants in England and Wales, and provided by NHS Scotland for participants in Scotland.
6. births to study participants from the ONS-NN4B-linked birth outcome data provided by the Office for National Statistics (ONS) for participants in England and Wales [supplied under s42(4) of the Statistics and Registration Service Act 2007 as amended by s287 of the Health and Social Care Act 2012], and the Scottish Morbidity Record (SMR) Data or Births Registration Data provided by NHS Scotland for participants in Scotland.
6. from NHS Registration Data, provided by NHS Digital for participants in England and Wales, and from the Community Health Index (CHI) Database provided by NHS Scotland for participants in Scotland.

Phone usage app

In order to collect additional mobile phone data that we cannot obtain from network operators, we are also launching a phone usage app called XMobiSense as part of the study.

**XMobiSense is an app for
Android smartphones.**

(e.g. Samsung, Moto, LG etc)

It runs in the background to collect important usage information.

These data include:

- use of speaker phone or other hands-free kits
- which side of the head voice calls are made on
- the volume of uploads/downloads over WiFi or mobile phone network

XMobiSense app

The XMobiSense app will periodically upload these data to a secure server at Imperial College when your phone is connected to WiFi. The app does not reduce battery life. For an average mobile phone user, the amount of data that is uploaded is minimal - in the order of 0.3Mb per day.

The app **does not collect** information identifying who you are in contact with such as phone numbers, nor the content of calls or messages, nor addresses of websites visited.

We encourage any study participants who would like to further contribute to the COSMOS study to download and keep this app running on their mobile phone for at least two weeks. Please note, however, that this is an entirely optional part of the study.



For instructions on how to download XMobiSense, please go to thecosmosproject.org/xmobisense-app

Data protection

When you joined the study a few years ago you gave us your consent.

When you joined the study a few years ago you gave us your consent. This gives Imperial College your permission to **a)** hold and use information that identifies you and **b)** follow up on any changes to your health and obtain information from your mobile network operator(s) on your mobile phone use, in compliance with Data Protection laws.



How is my information being kept confidential?

Your privacy and the appropriate use and protection of your data are paramount. Imperial College will ensure the research complies fully with the requirements of the Data Protection Act 1998.

All individually identifiable data (such as name and address) will be dealt with in the strictest confidence. Your individually identifiable data will be separated from health and mobile phone use information to preserve confidentiality. All your data will be stored on a secure computer network at Imperial College.

The results of this study will be published following independent review, but no individually identifiable data will ever be published.



Apart from Imperial College, who will be able to access my information?

Data may be shared with researchers of the international COSMOS consortium or with other university research collaborators. However, **no individually-identifying data (such as your name, address, phone number etc)** will ever be passed onto these research groups. Imperial College may share limited information (such as your name and postal address) with contracted service providers for the specific purposes related to the study, such as mailing out reminders and other official COSMOS correspondence. These service providers will be legally bound by non-disclosure agreements and strict data security requirements and will only be able to use these data for the purposes of the COSMOS Study.



How can I withdraw my consent?

You have the right to withdraw at any time, without giving a reason. If you are considering withdrawing from the study, please contact the COSMOS Freephone number on **08000 270 270** or email us at **ukcosmos@imperial.ac.uk**

If you decide to withdraw, you must choose one of the following options concerning future contact and use of your data:

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.

3 No further use – this means that, in addition to no longer contacting you or obtaining further information, COSMOS would destroy all of your information previously provided.

Should you withdraw from the study without specifying an option for future contact and use of data, **no further contact** will be enacted by default.

**Should you have any other
concerns or queries:**

Send us a message

Via the contact form at ukcosmos.org

Write to us

UK COSMOS Study
Department of Epidemiology and
Biostatistics
School of Public Health
Faculty of Medicine
Imperial College London
St Mary's Campus
Norfolk Place
London W2 1PG



Email us

ukcosmos@imperial.ac.uk

Call us

Freephone: **08000 270 270**
(Mon – Fri, 8.00am – 5.30pm,
excluding bank holidays)

