



## Information Booklet

This information booklet gives details of the COSMOS Study which started in the UK in 2009. COSMOS is monitoring a large group of people in order to investigate if there are any health issues linked to long term mobile phone use.

This is independent research supported by the Department of Health. Please take the time to read this information leaflet. If there is anything that is not clear, or if you would like more information, please use the contact details on the back of this document.



## About the Study

### What is COSMOS?

COSMOS is an international cohort study investigating possible health effects from long term use of mobile phones and other wireless technologies.

### What is a cohort study?

In a cohort study, the health of people who form the cohort is followed over a period of time. For this study, the cohort is a large group of people who are using mobile phones in their daily lives.

### How large is the COSMOS cohort?

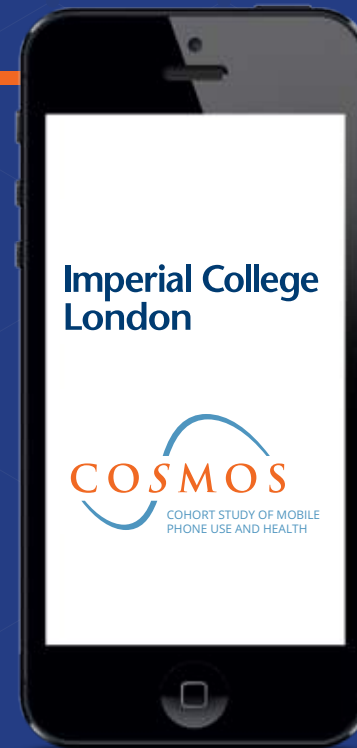
The UK cohort consists of approximately 105,000 adult mobile phone users, recruited from across the UK between 2009 and 2012. The international cohort is made up of approximately 340,000 European mobile phone users.

### What is the purpose of COSMOS?

To carry out long term (for 20-30 years) health monitoring of a large group of people so that we can identify if there are any possible health issues linked to using mobile phones and other wireless technologies over a long period of time.

### What health outcomes are we investigating?

We are looking at a large number of health outcomes including any changes in the frequency of specific symptoms over time, e.g. headaches and sleep disorders, and the risks of cancers, benign tumours, neurological and cerebrovascular diseases. We are also investigating possible effects upon reproductive health and fertility, and the potential impacts of social mobile phone use upon well-being and mental health.



### Who is conducting this study?

In the UK, this research is being carried out by Imperial College London. COSMOS is an international study being conducted in six European countries.

### Who is funding this study?

The study in the UK is funded by the Department of Health. The study was formerly funded by the MTHR, an independent programme of research into mobile phones and health that was jointly supported by the Department of Health and industry - <http://www.mthr.org.uk/>.

## Why is this research important?

Today there are over 4.5 billion mobile phone users worldwide, and more than 32 million smartphones are purchased every year in the UK. Population exposure to radiofrequency electromagnetic fields (RF-EMF) from mobile phones and other wireless technologies has become ubiquitous.

RF-EMFs were classified as possibly carcinogenic to humans by the International Agency for Research on Cancer (IARC) in 2011. Many reviews have concluded that there is no convincing evidence to date that mobile phones are harmful to health in the short term.

*To address uncertainties about possible long term health effects related to RF-EMFs, however, it is important we monitor the health of a large group of mobile phone users over a long period of time.*

This research has been endorsed as a priority by agencies worldwide, including the Department of Health, Public Health England (PHE), the UK Advisory Group on Non-Ionising Radiation (AGNIR), the European Union's Scientific Committee on Emerging and Newly Identified Health Risks (SCENHIR), and the World Health Organisation (WHO).

Following the publication of the Stewart report by the Independent Expert Group on Mobile Phones in 2000, an independent research programme, the Mobile Telecommunications and Health Research Programme (MTHR), was set up in the UK to look into the possible health impacts of mobile telecommunications.

over  
**4.5**  
**BILLION**  
mobile phones users

## Whilst research on mobile phones and health is now managed by The Department of Health, seminal reports by the MTHR have concluded that:

"COSMOS...has the potential to help resolve many of the remaining uncertainties relating to the health risks of mobile phone use. This is necessarily a long-term study that is expected to continue for many years."

"The Committee is convinced that the best way to address these uncertainties is to carry out a large cohort study of mobile phone users, an approach that has also been rated as a high priority by the World Health Organisation."



## Where can I find more information?

Government information on mobile phone use and health is provided on the following websites:

<https://www.gov.uk/government/publications/radiofrequency-electromagnetic-fields-health-effects>

<http://www.nhs.uk/conditions/Mobile-phone-safety/Pages/Introduction.aspx>

# Information Needed

As part of our ongoing research, we need to collect up-to-date information about you and your life. We are doing this in various ways:

## Follow-up Questionnaire

The follow-up questionnaire is one way for you to provide us with important information on:

**Your use of mobile phones and other wireless technologies** – the questionnaire covers your past and current use of mobile phones and other wireless technologies.

**Your health and medical history** – the questionnaire covers aspects of your past and current health, including reproductive health.

**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.



## Medical and Health-Related Records

If you gave consent, the information you provide about your health through the questionnaires is being supplemented directly by follow-up of your health through routine medical and other health-related records, e.g. cancer registrations, using your NHS number, linked to your name, address, and date of birth over the study period.

## 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). For example, data on the frequency and duration of your mobile phone use, both for your contract subscription and pay-as-you-go phones.

**This information will not include any details identifying phone numbers that you call or those of people who call you, or any content of messages or addresses of websites visited etc.**

To continue to obtain mobile phone records from your network operator(s) over the study follow-up period, it is important for us to know if you have changed to a different network operator or changed phone number. You can keep us informed of changes through [www.ukcosmos.org](http://www.ukcosmos.org), by email, or by Freephone (see last page for details). Alternatively, if you gave consent, we will obtain this information from network operators.



## Phone Usage App

In order to collect additional mobile phone data and enhance the accuracy of the mobile phone usage you report in the follow-up questionnaire, we are also launching a usage app as part of our study.

The app is for Android smart phones e.g. Samsung, Moto, LG etc., and runs in the background to collect important usage information, especially information we cannot obtain from network operators. For example, use of speaker phone or other hands-free kits, which side of the head voice calls are made on, and the amount of data uploaded or downloaded, including whether this occurs over the mobile phone network or over a WiFi network.

**The app does not collect any personally identifiable information** such as phone numbers, the content of calls or messages, websites visited or any other personal information. The app does not reduce battery life and, **only when WiFi connection is available**, it will upload data to a secure server at Imperial College.



## Why did you need my consent?

When you joined the study a few years ago you gave us your consent. We needed your consent to comply with Data Protection laws and observe the common law duty of confidentiality owed to patients.

This gives Imperial College your permission to hold and use information that identifies you. It also allows us to follow up on any changes to your health and obtain information from your mobile network operator(s) on your mobile phone use.

## 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 0800 0270270 or email us at - [ukcosmos@imperial.ac.uk](mailto:ukcosmos@imperial.ac.uk).

If you do decide to withdraw, you will have the following options concerning future contact and use of your data:

**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.

**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.

**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.

# Data Protection

## 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 and has sought advice from the Information Commissioner to ensure it does.

All individually identifiable data (such as name and address) will be dealt with in the strictest confidence. Your individually identifiable data will be stored separately from health and mobile phone use information to preserve confidentiality. In the short-term, your data may be held by service providers contracted by Imperial College, but these service providers will be legally bound by non-disclosure agreements and strict data security requirements. All your data will be stored long-term 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 members of the international COSMOS consortium in other countries across Europe or with other researchers. **However, no individually identifying data will ever be passed to international COSMOS partners or any other researchers.**

Imperial College may share with contracted service providers limited data e.g. name, address, sex as required. 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.

## Next Steps

### What am I being asked to do now?

Your continued participation is voluntary. We are asking all participants to complete this follow-up questionnaire and, if they have an android smartphone e.g. Samsung, Moto, LG etc., to download an app onto their phone for a short period to collect phone usage information.

### Part I Follow-up Questionnaire

Please complete the questionnaire online by visiting [www.ukcosmos.org](http://www.ukcosmos.org). We are grateful to all our participants for their time spent contributing to an important piece of research which will benefit the health of current and future generations.

### Part II Phone Usage App

If you have an Android phone and would like to help us further, please visit our website at [www.ukcosmos.org](http://www.ukcosmos.org) for more information and instructions on how to download the phone usage app. Participants are asked to keep the app installed on their phone for at least 2 weeks (and every week beyond this will help the study further).



## Next Steps



Average  
**45-50  
MINUTES**

### **How long will the follow-up questionnaire take to complete?**

The follow-up questionnaire is split into clear modules and should take 45-50 minutes in total. Progress is saved so that you can complete the questionnaire in multiple visits if more convenient. You can use a personal computer, tablet or mobile phone to complete the questionnaire, however, we recommend a personal computer or tablet for the best user experience.

### **How can I update my details regularly?**

If you are participating in the study and have moved home, changed your name, email address or phone number, we ask that you keep us informed and update your details on our website. You will also have the chance to make any changes when you complete the follow-up questionnaire.

### **What happens if I move out of the UK?**

Even if you choose to leave the country, your data remain valuable to our study. We ask that you continue to keep your details up to date.





## Contact Details

Should you have any other concerns or queries we would be pleased to provide you with further information:

Use the contact form on the **UK COSMOS** website: [www.ukcosmos.org](http://www.ukcosmos.org)



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