

INFORMATION LEAFLET

This information leaflet gives details of a long term study concerning health and use of mobile phones and other wireless technologies. This study is called COSMOS. Before you decide whether to join, it is important for you to understand why the research is being done and what is involved. 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 contact a member of the study team at:

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: ukcosmos@imperial.ac.uk Freephone: 08000 270 270 (Monday – Friday, 10.00am – 5.30pm)

Supported by the Department of Health



More information about COSMOS is also available at:

www.ukcosmos.org

ABOUT THIS 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 will the COSMOS cohort be?

The UK cohort will follow the health of approximately 90-100,000 mobile phone users (18+ years of age) for 20 to 30 years. The international cohort will follow the health of approximately 250,000 European mobile phone users.

What is the purpose of COSMOS?

To carry out long term 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 will be studied?

We will be looking at any changes in the frequency of specific symptoms over time, such as headaches and sleep disorders, and also the risks of cancers, benign tumours, neurological and cerebro-vascular diseases.

Who is conducting this study?

In the UK, Imperial College London is carrying out this research. COSMOS is an international study being conducted in a number of European countries. The study in the UK is funded by the MTHR, an independent programme of research into mobile phones and health that is jointly supported by the Department of Health and industry http://www.mthr.org.uk/.

Why is this research important?

Mobile phones and other wireless technologies have only been in widespread use for a relatively short time. It is important that we begin now to monitor the health of a large group of people over a long period of time. Through this health monitoring, we will be able to resolve current uncertainties about possible long term health effects associated with this new technology. This research has been endorsed as a priority by agencies worldwide, including the Department of Health, the UK Health Protection Agency (HPA), 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, called the Mobile Telecommunications and Health Research Programme (MTHR), was set up in the UK to look into the possible health impact of Mobile Telecommunications. The most recent report from the MTHR concluded that:

"...short term (less than ten years) exposure to mobile phone emissions is not associated with an increase in brain and nervous system cancers. However, there are still significant uncertainties that can only be resolved by monitoring the health of a large cohort of phone users over a long period of time."

"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."

http://www.mthr.org.uk/documents/MTHR_report_2007.pdf

Government information on mobile phone use and health is provided on the HPA website:

http://www.hpa.org.uk/web/HPAweb&Page&HPAwebAutoListName/ Page/1158934607786

TAKING PART

Who can take part in COSMOS?

Anyone aged 18 or over, who is a UK resident and uses a mobile phone, is eligible to take part in the study. It does not matter how often or how much you use a mobile phone, it is important that all types of mobile phone users join the study.

Why should I take part?

There are currently more than six billion users of mobile phones worldwide and in the UK there are over 70 million mobile phone devices in use. It is important for current users, and for future generations, to find out whether there are any possible long term health effects from this new and widespread technology that has become so central to our everyday lives.

Do I have to take part in COSMOS?

Taking part in this research is voluntary. Your decision will not affect your relationship with your mobile network operator.

What does taking part in COSMOS involve?

If you decide to take part, please visit the UK COSMOS website at www.ukcosmos.org and click on the 'Join Now' link to access the online questionnaire. You will be required to provide your consent and answer questions on your health, lifestyle and use of mobile phones and other wireless technologies. Completing the questionnaire will take you approximately 30-45 minutes. If for any reason you are unable to complete the questionnaire in one sitting you will be able to save your answers and come back to the questionnaire at a later time.

The initial phase of the study is five years. During this phase we will contact you approximately once a year to update your personal details, e.g. if you change mobile network operator, or to request additional information.

We will also follow your health records for at least 20 years but you will not need to do anything other than give us your initial consent.

You will be contributing to an important piece of research to benefit the health of current and future generations.

INFORMATION NEEDED

What information is needed for this study?

- For this study we need to collect information about three specific areas of your life. These are:
 - 1. Your use of mobile phones and other wireless technologies the questionnaire covers your past and current use of mobile phones and other new technologies. This will be supplemented with mobile phone records from your network operator(s), such as 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. In order 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 whether you have changed to a different network operator or changed phone number. You can keep us informed of any changes directly through the UK COSMOS website, by email, or by freephone (see below for details). Alternatively, we will obtain this information from network operators with your consent.
 - 2. Your health the questionnaire covers aspects of your past and current health. Imperial College will follow your health directly 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.
 - 3. Your lifestyle the questionnaire covers aspects of your lifestyle such as smoking, diet, and exercise as these are relevant to your long term health.

Why do you need my consent?

We need 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. If you are considering withdrawing from the study, please contact the freephone number 08000 270 270 (Monday – Friday, 10.00am – 5.30pm).

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 other 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 will information about me be kept confidential?

Your privacy and confidentiality are important to us. Imperial College has sought advice from the Information Commissioner to ensure that this research study complies fully with the requirements of the Data Protection Act 1998. All individually identifiable data will be dealt with in the strictest confidence. All data will be stored securely on a private computer network at Imperial College. The results of this study will be published following independent review but no individually-identifying data will ever be published.

Who will be able to access and use my information?

Your health and mobile phone use information will be stored securely on a private computer network at Imperial College and will be accessed by the academic research team. Your identifying information including name and address will be kept separately from your health and mobile phone use information. Access to your personal identifying information will be limited to a few members of the academic research team at Imperial College, who will be required to sign strict non-disclosure agreements. Data collected during the study may be sent to researchers in other countries who form part of the international COSMOS cohort and where the laws may not protect your privacy to the same extent as the Data Protection Act in the UK. However, Imperial College will protect your privacy by ensuring that these international researchers will only have access to anonymised information that does not identify you. No personal identifying information will ever be passed to international research teams.

NEXT STEPS

What should I do if I now want to take part?

If you would like to help by taking part, please visit the study website www.ukcosmos.org and click on the 'Join Now' link to access the online questionnaire.

What can I do if I'm unsure about taking part or have any other concerns or queries?

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

- 1. By visiting the UK COSMOS website: www.ukcosmos.org
- By writing to the following address: 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
- 3. By email: ukcosmos@imperial.ac.uk
- 4. By freephone: 08000 270 270 (Monday Friday, 10.00am 5.30pm)

Written information in this language is available on our website इस भाषा में लिखित जानकारी हमारी वेबसाइट पर उपलब्ध है 简体中文版本的书面资料可在我们的网站上找到 ਇਸ ਭਾਸ਼ਾ ਵਿੱਚ ਲਿਖਤ ਜਾਣਕਾਰੀ ਸਾਡੀ ਵੈੱਬਸਾਈਟ ਤੇ ਉਪਲਬਧ ਹੈ અમારી વેબસાઇટ પર આ ભાષામાં લેખિત માફિતી ઉપલબ્ધ છે আমাদের ওয়েবসাইটে এই ভাষায় লিখিত তথ্য পাওয়া যাবে

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