

**Please take the time to read this information sheet.**

### **About the study**

The Study of Cognition, Adolescents and Mobile Phones (SCAMP) has been following up several thousand London teenagers (including you) for over 6 years. Together, the commitment of SCAMP participants and scientists has resulted in publication of important study findings such as: using screen-based media at night (especially in the dark) is associated with getting too little sleep and having poor sleep quality; using social network sites for more than 5 hours per day is associated with emotional and behavioural problems; using mobile phones or video gaming for more than 3 hours per day is associated with obesity; and having more access to natural green space (e.g. grassland and woodland) is associated with better thinking and memory skills, and better mental health.

SCAMP is continuing to investigate why mental illness commonly emerges during adolescence. We (the SCAMP research team) are trying to find out whether factors such as use of mobile phones/social media, how your brain processes information (cognition), physical activity, and sleep, have an impact on your mental health. If your school has been part of SCAMP since Year 7, **YOUR CONTINUING HELP** is extremely valuable to the science. If you are new to SCAMP, you can make a really valuable contribution too, as we are excited to take the study into a new phase (ages 17 to 22, i.e. the next 5 years), as young people move into higher education or get their first job. Studies like SCAMP need to keep following **the same people** (i.e. including you) for a long time – that is what will really help us to work out whether these factors have short-term or long-lasting impacts on your mental health, which is really important for promoting throughout your whole life. Your contribution to this study can benefit all young people, including you. An opportunity like this is unlikely to arise again.

### **Why are we using an app?**

- As you are at/nearing school leaving age, we can no longer ask you to do a computerised assessment in school, so we have designed a new app to collect information instead.
- Mostly we will ask for the same type of information (i.e. your health, cognition, lifestyle, mobile phone use), and link and store it, in the same way as before.
- We will still ask you to report some information via surveys/cognitive tasks using the app, and we will still ask you for permission to access your health records, as before.
- But with an app you can provide the information about your mobile phone use, physical activity and sleep in a much easier way: automatically from your phone (in the background) – it requires no effort from you, and gives more accurate information.

### **What's involved?**

#### **For NEW participants joining our cohort (Sept 2022 onwards)**

1. **An online survey** (30-40 minutes) – you will be asked to answer questions (about your physical and mental health and your behaviour), and to complete a few short cognitive tasks (which are a bit like computer games). Please carry out the survey in exam conditions, which means being quiet, doing your own work, and putting your hand up if you have a question. All information that you give today is confidential, so we won't tell your parents and teachers what you say. Therefore, it's really important to answer the questions as honestly and as accurately as possible.
2. **A Bio-Zone session** (15-20 minutes)- We will ask you to provide non-invasive biological samples (urine and saliva), and discretely measure your height, weight and waist circumference. This tells us more about your health and development than survey alone.

**For ALL participants in the cohort: Download our SCAMP Study app and sign up.**

The app is available from Apple App Store and Google Play Store. The app doesn't take up lots of storage space and won't run your battery down. To sign up, you will need to provide information about yourself including name, date of birth, email, and phone number. Once you have signed up in the app, there are lots of ways to contribute to the science, and you will earn reward points for each of these. You can choose to:

- **Complete surveys regularly** - the app will notify you to answer questions about your lifestyle and mental health, and to complete cognitive tasks (which are a bit like computer games). On average this will take 5 min per week. If more convenient you can complete multiple surveys in one go, each survey will be available for 2 months.
- **Give permission for collection of information about your mobile phone use, physical activity, and sleep** – if you give permission, the app will collect frequency and duration of calls and messaging (for Android phones only), time spent on different apps; amount of data usage; when the phone is turned on and off; and information about physical activity (e.g. daily steps, walking/running distance) and sleep from Apple HealthKit or Google Fit on your phone (depending on your mobile phone operating system). The information collected will **not** include any details identifying phone numbers/people that you contact or who contact you, nor the content of any messages, chats or social media posts, nor your browsing history. You can turn off this background information collection at any time via Settings in the app.
- **Give permission to access your routine health data** - we need to know about any illnesses or treatment you may have had and how your health is in future. The easiest way to collect this information without bothering you is to access your health data kept by organisations such as NHS Digital, if you give permission.
- **Wear an activity tracker** – If you agree, we will post an activity tracker (e.g. Fitbit) for you to wear for 2 months to collect information on your physical activity and sleep, and then return it. This is the easiest and most accurate way to assess your exercise and sleep habits. Over that time you will get an insight into your fitness, activity and sleep patterns!
- **Provide a urine and saliva sample** – If you agree, we will post a collection kit to you, with instructions on how to provide samples and send them back to us. Samples provide important information that you cannot tell us via a survey. For example, we can look at genes which make some people more susceptible to disease, and biomarkers related to stress, mental illness and cognition.

We understand this is a lot of information to ask for. However, combining information about your genes, lifestyle and health allows us to unravel the complex interaction between nature (genes) and nurture (lifestyle, including your mobile phone use, physical activity, and sleep) in causing mental illness.

### **What are the benefits to you?**

- You will earn rewards points which can be redeemed (e.g. **coffee, vouchers, gift packs**) as a thank you for your contributions to the research.
- You will be contributing to vital medical research into mental health, that will help all young people, including you.
- Be informed about opportunities to steer the research via the SCAMP Young People's Advisory Group.

### **Do I have to take part?**

No, taking part is voluntary. You can change your mind at any time without giving a reason.

## **Why do we need to access your routine health records?**

Lots of information about you and your physical and mental health is already collected by the NHS. We don't want to waste your time by asking you to report this in surveys, so we ask for your permission to access this important past and future information from NHS Digital. If you give permission, we will send your name, gender, date of birth, and address to NHS Digital who will then link the information on our behalf to your NHS number, update your contact details and return the updated details and health data (such as hospital in-patient admissions, outpatient attendance and birth records) to us. Updated contact details will be used to help maintain contact with participants. Information on illnesses and treatment you may have had will be used to answer scientific questions about how lifestyle and genes influence mental health.

## **How will you use my urine and saliva samples, and will I get to see my sample test results?**

Over the coming years, a range of tests may be done on your urine and saliva samples for approved health research. This will include measuring the levels of molecules that can tell us about your environment or health (biomarkers). The saliva sample you provide will be processed in laboratories to extract DNA and analyse differences in the DNA sequence. The information about biomarkers, and differences in DNA (genetic data) will be combined with other information (lifestyle, health) so that researchers can analyse the interactions between genes and environment in relation to mental health. Laboratory staff and researchers will not see your personal details associated with your urine or saliva sample, extracted DNA, genetic data or biomarker data – at each stage personal details will be replaced with a code number. The results of any biomarker or genetic laboratory tests undertaken on samples you donate to SCAMP or results of any analyses on your biomarker or genetic data will not be sent to you, your doctors or anyone else. This is because urine and saliva samples will not be analysed immediately, and are being collected for research purposes only, not for clinical diagnosis of disease, so most of the biomarker and genetic information generated will have no relevance to any individual.

## **How will we use information about you?**

We will need to use information from you for this research project. This information will include your name, date of birth, and contact details, held by Imperial College London. We will link your past and future SCAMP assessment data with routine data that you authorise access to, and any additional information you provide, and biomarker and genetic data. People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

Imperial College London is the sponsor for 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 your personal data for 25 years after the study has completed in relation to data subject consent and primary research data. More information can be found in our Privacy Notice (<https://www.scampstudy.org/privacy-notice/>). Your data collected by the activity tracker will be gathered and stored by both Fitbit Inc (Fitbit) and Small Steps Labs LLC (Fitabase) and Fitbit will be the controller for the data they collect. Please read their privacy policies (<https://www.fitbit.com/global/uk/legal/privacy-policy>) to understand how they will use your data.

## **How is information about you kept confidential?**

# Imperial College London

Your confidentiality, and the appropriate use and protection of your data are top priority. Imperial College ensures this research complies fully with General Data Protection Regulation (GDPR) and the Data Protection Act 2018. All individually identifiable data are dealt with in the strictest confidence. 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, including mailing out packages (such as urine and saliva sample collection kits and fitness trackers) and other official SCAMP correspondence. These service providers must by law follow non-disclosure agreements and strict data security requirements. They will only be able to use your data for the purposes of the SCAMP study. Your personal data are stored long-term on a secure computer network at ICL. Your identifiable information is stored separately from other information about you, e.g. your health, educational records, biomarker and genetic information, and behaviours, to preserve confidentiality.

## **Who can access and use your information?**

Where appropriate, your data will always be analysed by the research team in a de-identified form. Access to your identifiable information is strictly limited to key members of the research team, who are required to sign strict non-disclosure agreements. This is an agreement we must stick to by law which means we will not tell anyone else your information. Your other personal information may be shared with other researchers to support research in the future, but only in a form that does not identify you.

## **How will the results of the study be made available?**

Study findings (based on group-level data) will be published in scientific journals but no data individually identifying you, your family or your school will ever be published. We will share these study findings with you via the app, social media and the SCAMP study website. Feedback on individual participants will not be available.

## **What if something goes wrong?**

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been treated during the course of this study then you should immediately inform the Investigator (Professor Mireille Toledano; [m.toledano@imperial.ac.uk](mailto:m.toledano@imperial.ac.uk)). The normal National Health Service complaints mechanisms are also available to you.

## **What are the possible disadvantages and risks of taking part?**

Some people find that thinking about their own mental health can cause negative feelings. If you are feeling distressed, talking about it with someone may help. For information about accessing Child and Young People's Mental Health Services (CYPMHS), please see: <https://www.nhs.uk/mental-health/nhs-voluntary-charity-services/nhs-services/children-young-people-mental-health-services-cypmhs/>. You can also access the information on NHS Mental Health Services at <https://www.nhs.uk/mental-health/>

Mental health charities, which offer helpline services, are also available:

- Childline; telephone: **0800 111**; [www.childline.org.uk](http://www.childline.org.uk)
- Samaritans; telephone: **116 123**; [www.samaritans.org](http://www.samaritans.org)
- Shout; text: **85258**; [www.giveusashout.org](http://www.giveusashout.org)

## **Who is organising and funding the research?**

The study is being organised by Imperial College London and funded by the Medical Research Council.

## **Who has reviewed the study?**

This study has been given a favourable ethical opinion for conduct by the North-West Haydock

## **What Phone Settings permission do I need to give to allow SCAMP Study App to collect information on mobile phone use in the background?**

If you are an Apple phone user, you will be automatically prompted to **install a VPN**. If you are an Android phone user, you will be displayed a message “You are missing required permission” and prompted to click “Resolve” to give us permission to collect information on phone call and SMS. You will also be displayed a message “You are required to grant Usage Access Settings” and prompted to click “Resolve” and turn on “Allow usage tracking” for the SCAMP Study App to give us permission to collect information on time spent on different apps.

## **What happens if I delete the app?**

You can delete the app at any time, but we will keep information about you that we already have. Deletion of the app does not mean you stop being part of the SCAMP study.

## **What are your choices about how your information is used?**

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have. If you choose to stop taking part in the study, we would like to continue collecting information about your health from central NHS records. If you do not want this to happen, tell us and we will stop. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

## **Where can you find out more about how your information is used?**

You can find out more about how we use your information at [www.hra.nhs.uk/information-about-patients/](http://www.hra.nhs.uk/information-about-patients/), by asking one of the research team, by sending an email to [scamp@imperial.ac.uk](mailto:scamp@imperial.ac.uk), or by ringing us on (0)20 7594 1892.

**Contact for Further Information:** If you have any other questions or concerns about the study, its purpose or procedures, or if you want to stop taking part in the study, please contact the SCAMP team via the email or telephone number above.