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Participant Information Sheet (FAQs)

Study of Cognition, Adolescents and Mobile Phones (SCAMP) Wave 2 (IRAS number: 150360)

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 9 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. Our findings also indicate a surge in the prevalence of clinical depression and anxiety during the COVID-19 pandemic, especially among girls and those with high mobile phone use and sleep problems.

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. 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.

What's involved?

One or two online surveys (35-45 minutes per survey) – you will be asked to complete one survey if you joined the study before Sept 2022 and two surveys if you joined the study after Sept 2022. 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 independently in a quiet environment. All information that you give in these surveys is confidential, so we won't tell other people what you say. Therefore, it's really important to answer the questions as honestly and as accurately as possible.

What are the benefits to you?

- You will earn a **£20** Amazon Voucher for each completed survey 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 England. If you give permission, we will send your name, gender, date of birth, and address to NHS England 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

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birth records) to us. Updated contact details will be used to help maintain contact with participants. Information on illnesses and treatments 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?

A range of tests on your urine and saliva samples for approved health research are undergoing if you have provided samples. This includes measuring the levels of molecules that can tell us about your environment or health (biomarkers). The saliva sample you provided is being 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 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, 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 (if you participate in the Activity Tracker Study) 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?

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?

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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 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). 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
- Samaritans; telephone: **116 123**; www.samaritans.org
- Shout; text: **85258**; 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 Research Ethics Committee.

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/, by sending an email to scamp@imperial.ac.uk, or by filling in the contact form on our website at [Contact us – SCAMP \(scampstudy.org\)](http://Contact us – SCAMP (scampstudy.org)) .

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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 online contact form indicated above.