## Research Governance and Integrity Team



### **Participant Information Sheet**

# Study of Cognition, Adolescents and Mobile Phones (SCAMP) Screentime Validation Study (SVS)

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish.

### Do I have to take part?

It is up to you to decide whether to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign an online consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you are receiving, now or in the future.

### What is the purpose of the study?

The Study of Cognition, Adolescents and Mobile Phones (SCAMP) has been following up several thousand London teenagers 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. If you are new to SCAMP, you can make a really valuable contribution too, as we are excited to launch a new SCAMP sub-study, to understand how young people use their phones in daily life. Studies like SCAMP need to keep following **the same people** 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 have I been chosen?

You have been invited to take part because you are a young person aged 16 to 18 attending one of our SCAMP collaborating schools. These schools are contributing to research that aims to answer

## Research Governance and Integrity Team



important questions about young people's cognition and mental health in relation to mobile phone and digital device use.

### What will happen to me if I take part?

You will be asked to complete one online survey (20-30 minutes). You will be asked to answer questions (about your health, lifestyles and mobile phone use), upload screenshots from your smartphone showing your daily screen usage (about total screen time and time spent on social media). 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 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: <a href="https://www.nhs.uk/mental-health/nhs-voluntary-charity-services/nhs-services/children-young-people-mental-health-services-cypmhs/">https://www.nhs.uk/mental-health/</a>
Services at <a href="https://www.nhs.uk/mental-health/">https://www.nhs.uk/mental-health/</a>

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

Childline; telephone: 0800 111; <u>www.childline.org.uk</u>

• Samaritans; telephone: 116 123; www.samaritans.org

Shout; text: 85258; www.giveusashout.org

### What are the possible benefits of taking part?

- You will earn a £30 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.

#### 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; <a href="mailto:m.toledano@imperial.ac.uk">m.toledano@imperial.ac.uk</a>). The normal National Health Service complaints mechanisms are also available to you.

## Research Governance and Integrity Team



### How will we use information about you?

Imperial College London is the sponsor for this study and will act as the Data Controller for this study. Being a Data Controller means that we are responsible for looking after your information and using it appropriately plus are responsible for explaining this to you. Imperial College London will keep your personal data for:

- 25 years after the study has finished in relation to data subject consent forms.
- 25 years after the study has completed in relation to primary research data.

The study data will then be fully anonymised and securely archived or destroyed. The study is expected to finish in 12 / 2025. For more information / confirmation regarding the end date please contact the study team, see 'WHERE CAN YOU FIND OUT MORE ABOUT HOW YOUR INFORMATION IS USED' for contact information

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. People within the College and study team (see section sharing your information with others) will use this information to do the research or to check your records to make sure that research is being done properly and the information held (such as contact details) is accurate. 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. Imperial College London is the sponsor of this research, and is responsible for looking after information. We will keep all information about you safe 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.

As a university we use personally-identifiable information to conduct research to improve health care and services. As a publicly-funded organisation, we have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study. Our legal basis for using your information under the General Data Protection Regulation (GDPR) and the Data Protection Act 2018, is as follows:

Imperial College London - "performance of a task carried out in the public interest"; Health and care research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. We do this by following the <a href="UK Policy">UK Policy</a> Framework for Health and Social Care Research.

Where special category personal information is involved (most commonly health data, biometric data i.e. finger prints or facial recognition and genetic data, racial and ethnic data etc.), Imperial College London relies on "scientific or historical research data or statistical data".

### **International Transfers**

We may share data about you outside the UK for research related purposes to where necessary to provide access to a data processor / service provider who will utilise your personal data as instructed by us. If this happens, we will only share the data that is needed. We will also make sure you can't be identified from the data that is shared where possible. This may not be possible under certain

## Research Governance and Integrity Team



circumstances – for instance, if you have a rare illness, it may still be possible to identify you. We will make sure your data is protected. Anyone who accesses your data outside the UK must do what we tell them so that your data has a similar level of protection as it does under UK law.

### **Sharing your information with others**

We will only share your personal data with certain third parties for the purposes referred to in this participant information sheet and by relying on the legal basis for processing your data as set out above. Other Imperial College London employees (including staff involved directly with the research study or as part of certain secondary activities which may include support functions, internal audits, ensuring accuracy of contact details etc.), Imperial College London agents, contractors and service providers (for example, suppliers of printing and mailing services, email communication services or web services, or suppliers who help us carry out any of the activities described above). Our third party service providers are required to enter into data processing agreements with us. We only permit them to process your personal data for specified purposes and in accordance with our policies.

#### Potential use of study data for future research

When you agree to take part in a research study, the information collected either as part of the study or in preparation for the study (such as contact details) may, if you consent, be provided to researchers running other research studies at Imperial College London and in other organisations which may be universities or organisations involved in research in this country or abroad. Your information will only be used to conduct research in accordance with legislation including the GDPR and the <a href="UK Policy Framework for Health and Social Care Research">UK Policy Framework for Health and Social Care Research</a>. This information will not identify you and will not be combined with other information in a way that could identify you, used against you or used to make decisions about you.

#### 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.
- You have the right to ask us to access, remove, change or delete data we hold about you for the purposes of the study. You can also object to our processing of your data. We might not always be able to do this if it means we cannot use your data to do the research. If so, we will tell you why we cannot do this.
- 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.

#### 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/
- in our Privacy Notice at https://scampstudy.org/privacy-notice/
- by asking one of the research team
- by sending an email to scamp@imperial.ac.uk, or

## Research Governance and Integrity Team



by filling in the contact form on our website at <u>Contact us – SCAMP (scampstudy.org)</u>.

### **Complaint**

If you wish to raise a complaint about how we have handled your personal data, please contact the research team first by sending an email to <a href="mailto:scamp@imperial.ac.uk">scamp@imperial.ac.uk</a>, or by filling in the contact form on our website at Contact us – SCAMP (scampstudy.org).

Following our response, if you are not satisfied please contact Imperial College London's Data Protection Officer via email at <a href="mailto:dpo@imperial.ac.uk">dpo@imperial.ac.uk</a> / <a href="mailto:imperial.dpo@nhs.net">imperial.dpo@nhs.net</a> via telephone on 020 7594 3502 / 020331304001 and/or via post at Imperial College London, Data Protection Officer, Faculty Building Level 4, London SW7 2AZ./8<sup>th</sup> Floor of Salton House, ICT Division, St Mary's Hospital, Praed Street, London, W2 1NY

If you remain unsatisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO)-via <a href="https://www.ico.org.uk">www.ico.org.uk</a>. Please note the ICO does recommend that you seek to resolve matters with the data controller (us) first before involving them.

### What will happen to the results of the research study?

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.

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

SCAMP study is being organised by Imperial College London and funded by the Medical Research Council. This sub-study, the Screentime Validation study within SCAMP, is specifically funded by the Huo Family Foundation.

#### Who has reviewed the study?

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

#### **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, or if you would like a copy of your signed online informed consent form, please contact the SCAMP team via the email or online contact form indicated above.

Thank you for reading the information sheet!