

# INFORMATION BOOKLET FOR PARTICIPANTS



It is important for you to understand why SCAMP is being undertaken and what taking part involves. Please take the time to read this information booklet.

# STUDY SUMMARY

## Key facts

- ➔ SCAMP follows several thousand secondary school pupils (including you) to investigate whether the use of mobile phones and other wireless technologies has an impact on your cognitive abilities (e.g. attention, memory), your mental health and your educational achievements.
- ➔ Data are collected using a range of cognitive tests, and questions on your digital device use, lifestyle, biosamples e.g. urine, saliva, blood, and physical and mental health.
- ➔ With your permission, SCAMP will continue to access routine records on your education and health, and link these together with your past and future SCAMP assessments.

## What will I get out of this study?

- ➔ The opportunity to take part in exciting live science that will help other people your age
- ➔ The chance to build up 'reward points' which can be banked and cashed in as a thank you for your time and contributions to the research
- ➔ Regular feedback on study findings from the SCAMP team

# ROUTINE DATA ACCESS

What information do we need?	Education records	Health records
What exactly are we interested in?	<p>Your education records such as:</p> <ul style="list-style-type: none"> <li>• Key Stage 2 &amp; 3 results</li> <li>• GCSE results</li> <li>• National Curriculum year group</li> <li>• Special Educational Needs (SEN)</li> </ul>	<p>Conditions such as:</p> <ul style="list-style-type: none"> <li>• Autism</li> <li>• Attention Deficit Hyperactivity Disorder (ADHD)</li> <li>• Migraine</li> <li>• Cancers</li> <li>• Mental health illness e.g. depression</li> <li>• Accidents</li> </ul>
Why do we need this?	To understand whether the use of wireless devices (e.g. mobile phones, tablets) affects your cognitive abilities, mental health and educational achievements	To help maintain contact and provide additional information about your mental health status that may influence your cognitive, behavioural or educational development
Where will we get this from?	English Department for Education and/or your school	NHS Digital, Office for National Statistics, or other similar bodies, who will provide data such as: hospital in-patient admissions, outpatient attendance and birth records. 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 to us
Your permissions	We would like to link your past and future SCAMP assessment data with routine data that you authorise access to, and any additional information you provide.	

# DATA PROTECTION

## 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, such as mailing out reminders and other official SCAMP correspondence. These service providers are 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 SCAMP study. All data will be stored long-term on a secure computer network at Imperial College. Your identifying information including name and address are stored separately from your health information to preserve

confidentiality. The results of this study will be published openly, but data individually identifying you or your school will always be kept confidential.

## 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, such as name and address, is strictly limited to key members of the academic research team, who are required to sign strict non-disclosure agreements. SCAMP data might be used to support other research in the future and may be shared with other researchers, but only in anonymised form.

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

Study findings will be published in scientific journals but no data individually identifying you, your family or your school will ever be published. Key findings will be shared with you, your parents, and schools via newsletters, social media and the study website. Feedback on individuals will not be available.

## What are de-identified (anonymised) data?

Data which have been processed to protect the privacy of the study participant. This is common in research. In SCAMP this means that your personal identifiers (e.g. date of birth, address, school) will be separated, encrypted (coded) and stored separately from any responses provided or information obtained from routine data. This ensures that those analysing the data for research purposes cannot identify you when they are analysing the information. These personal identifiers may only be re-linked under strict conditions and with approval from the ethical committee overseeing the research study.

## Can you withdraw from SCAMP?

If you decide now, or at a later date, that you do not wish to participate in this research, you are free to withdraw at any time without giving a reason. Deciding not to take part, or withdrawing from the study, will not affect your relationship with your school, and your medical care, legal rights, and education will not be affected.

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

1. **No further contact** – this means that SCAMP 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 routine records.
2. **No further access** – this means that SCAMP would no longer contact you or obtain further information from your records in the future, but would still have your permission to use the information provided previously.
3. **No further use** – this means that, in addition to no longer contacting you or obtaining further information, SCAMP would destroy all information previously provided about you.

# Exciting event for you!

To thank you for your participation in the SCAMP study, we would like to offer you an exciting school-to-work transition event. This event will take place at Imperial College London during 2020/2021, depending on when your school year group will be in Year 12. This day will include a variety of workshops for your future, including, but not limited to:

- ➔ Advice on University, apprenticeships and career pathways
- ➔ Interview techniques
- ➔ CV writing
- ➔ Public speaking

Travel expenses covered and free lunch provided!

As many SCAMP participants will be leaving their current school after Year 11 and starting sixth form, work or apprenticeships, we will invite you to this event with the contact details you provide the SCAMP study with.

If you didn't sign up during our school visit, please don't hesitate to contact us at [scamp@imperial.ac.uk](mailto:scamp@imperial.ac.uk) or phone us at 0800 007 5557 to register for this event.

