



INFORMATION SHEET FOR PARENTS AND CARERS OF YOUNG PEOPLE AGED 13-15 YEARS OLD

Ethical Clearance Reference Number: 20/LO/1187

Study title

Social media, Smartphone use and Self-harm in Young People (or 3S-YP for short).

Your child is invited to take part in a research study

Before you decide if your child can take part, it is important you understand why this study is being done and what it will involve. Please take time to read this information sheet carefully. Your child will have a separate information sheet for them to read. Please discuss it with them. Talk to others if you wish and ask us if there is anything that is unclear or you want more information. Our contact details are on page 7.

Please note, we are not able to offer your child any medical advice or treatment.

What is the purpose of this study?

Social media platforms (for example, Instagram) are popular among young people and many young people own a smartphone. Although there are benefits of this technology, there is concern about their effects on mental health and wellbeing. For example, studies have found that night-time use is related to poor sleep as well as mood changes. However, we don't know exactly how social media and smartphone use can impact on mental health, nor do we know how usage can change in association with changes in mental health.

In this study, we want to understand how social media and smartphone use are associated with changes in mental health and wellbeing in young people over the course of a year. Everyone is different which is why it's important for us to involve young people with a range of experiences to ensure our study best represents everyone. The information from this study will help us learn when and what type of support would be useful for young people who are experiencing difficulties.

This study is being done by researchers at King's College London in partnership with the charity YoungMinds. You can find out more about YoungMinds from their website:

www.youngminds.org.uk. This study has been funded by the Medical Research Foundation and the Medical Research Council.

Why has my child been invited to take part in this study?

Your child is invited to take part because when they were seen at a mental health service in South London and Maudsley NHS Foundation Trust, you or your child agreed researchers could contact you both about relevant studies to find out if your child would be interested in taking part. Your child is the right age to take part in this study as we want to understand the experiences of young people aged between 13-25 years old.

Does my child have to take part?

No, it is you and your child's choice. Your child should only take part if they want to and you agree. Choosing not to take part will not affect the care they receive in any way.

What would taking part involve?

If your child would like to take part and you agree, your child will need to confirm this by completing an assent form and you will need to confirm this by completing a consent form. Taking part in this study will involve us collecting the following information from your child over the next 6 months: (1) your child's answers to an initial questionnaire and then a shorter questionnaire once a month; (2) your child's use of a smartphone; (3) your child's use of social media; and (4) relevant information from your child's health records. See the details below. If your child doesn't have a smartphone or they don't use social media just let us know, they can still take part in the rest of the study.

You and your child should indicate on the consent and assent forms what information you agree for us to collect. We will only collect information that you have both agreed for us to collect. We will also ask you if we can contact you and your child in the future to tell you about other studies we are doing. You will be able to save a copy of the assent and consent forms for your records. Once you and your child have completed the consent and assent forms, your child will need to follow the steps on the screen to start taking part.

What information will be collected from my child?

(1) Questionnaires

Your child will be given a link to install our study app on to their smartphone. They will be asked to complete a confidential questionnaire about their mental health and wellbeing via our app. Or if they prefer, we can give them a link to complete it online.

It will take about 15 minutes to complete. Your child can complete it at a time that suits them. There are no right or wrong answers.

We will then send your child a reminder on the 1st of every month for the next 6 months to ask them to complete a shorter questionnaire. These will take about 5-10 minutes to complete. If your child doesn't respond to the final questionnaire, we may email or post it to them to give them another opportunity to tell us how they are doing.

(2) Use of a smartphone

You and your child will be asked to give us permission to collect information via our app over the next 6 months about how much your child uses their smartphone. This type of information is called metadata. For example, how much time your child spends on their phone per day and how much time they spend on their phone apps. We will not be collecting any information about what your child is doing in the apps. If your child is using an Android device, they may need to go to the Settings app on their phone to approve the 3S-YP app permissions.

(3) Use of social media

You and your child will be asked to give us permission to collect information over the next 6 months on your child's use of social media. We will ask you to provide a copy of your data when you join the study and again, 3 and 6 months later. We will send you the instructions on how to do this. We would collect the time of your child's "likes" and posts on social media and the content of their posts on social media. We would like to collect this information from any accounts your child may have on Facebook, Instagram, Twitter and YouTube. We may contact your child during the study to ask if they would be happy to add other social media platforms that become popular among young people. Your child will be able to choose which, if any, of their accounts we can collect information from.

Below are examples of information we would and would not collect, using a fictional participant 'Adam' and their friend 'Sam'.

Examples of information that we would collect:

- We would collect a comment by Adam on one of Sam's status updates, including the time and content of the comment, without collecting Sam's status update itself, as Sam is not taking part in the study and his account is private.
- We would collect the fact that Adam "liked" a post by Sam, including the time it took place, but we would not collect Sam's post itself, as Sam is not taking part in the study and his account is private.
- We would collect the fact that Adam "liked" a public post by the BBC, including the time it took place, but we would also collect the post that was "liked" as it is public.

Examples of information that we would not collect:

- We would not collect anything posted by Sam as he is not taking part in the study and his account is private, nor would we record that he is a friend or contact of Adam's.
- We would not collect Adam's private Facebook messages or direct Instagram or Twitter messages.
- We would not collect posts that Adam "likes", unless those posts are public, we will collect only the "like" action and the time it took place.

(4) Health records

South London and Maudsley NHS Foundation Trust maintains health records for all their patients, including notes made by healthcare professionals. We would like you and your child's permission to collect relevant information from your child's records about when and why you've used mental health services at the Trust. It will help us to understand how services are being used by the young people taking part in this study. This information is difficult to get using surveys because it is hard to remember details, like dates and times, and what therapy or treatments were used. This information will be used for research purposes only. To access this information, we will need to share your child's name, date of birth and NHS number with the Trust so they can identify their records. We will not provide the Trust with any of the information your child has given the study. We will look at your child's records at the Trust and only minimal information will be securely transferred from the system containing the information to a secure server managed by King's College London.

What are the possible disadvantages and risks of taking part?

There may be some questions in the questionnaire that your child finds difficult or upsetting. If your child is not comfortable answering any of the questions, they can skip them and move on. They can also take a break and come back to it or stop completing it if they want to.

Please note, we are not able to offer your child any medical advice or treatment.

We will not be analysing the information collected in this study until we have finished so we are unlikely to be aware if your child needs support. If you think your child needs support, you should speak to their GP or other healthcare provider, or call NHS 111, as soon as possible. If your child needs urgent medical care, please go to a local hospital Emergency Department or call 999. You will find details for other organisations that your child might find helpful on our website: <https://3syp.co.uk/useful-contacts.html>. Also, YoungMinds offers free confidential support Monday to Friday 9:30am–4pm via telephone, email and webchat for adults in need of advice about a child. Tel: 0808 802 5544. Website: www.youngminds.org.uk/find-help/for-parents/parents-helpline/.

We would like to collect information about your child's use of their smartphone and social media, which may cause you and your child concerns about data privacy and confidentiality. Please contact us if you or your child have any concerns or want more information.

What are the possible benefits of taking part?

There is no direct benefit to your child in taking part in this study. There may be some indirect benefits to your child in taking part. Your child may find it helpful to anonymously disclose their experiences and feelings. Your child may like contributing to research that will help us understand how to better help other young people in the future.

Payment

We will send your child a £10 Love2Shop voucher as a thank you when they start taking part in the study and then a £5 Love2Shop voucher as a thank you for every month that they continue to take part. At the end of the study, your child will get an additional £10 Love2Shop voucher if they have provided their social media data at 6 months. We will also send your child a Certificate of Participation as a thank you for their contribution to this research.

Will my child taking part or not taking part affect their care from the South London and Maudsley NHS Foundation Trust?

No. You and your child's decision for them to take part or not take part will not affect their care from South London and Maudsley NHS Foundation Trust. All studies have to record on a patient's health record that they have contacted the patient. No other information about the study is recorded on the health records.

What will happen if my child changes their mind about taking part?

Your child is free to stop taking part in this study at any point, without giving a reason. Withdrawing from the study will not affect your child in any way. Information collected until your child's withdrawal will still be used unless you ask us not to. Please contact us if your child wants to withdraw from the study.

How will we use information about your child?

- King's College London is the sponsor for this study based in the United Kingdom. This means that King's College London is responsible for ensuring your child's information is stored and used properly. King's College London will keep identifiable information about your child for 10 years after the study has finished.

- We will need to use information from your child's questionnaire responses, smartphone, social media accounts, and health records for this study.
- People will use this information to do the research or to check your child's records to make sure that the research is being done properly.
- People who do not need to know who your child is will not be able to see you or your child's name or contact details. Your child's information will have a code number instead.
- We will keep all your child's information strictly confidential. The only time we may need to break confidentiality is if we are aware of a serious risk to your child or to someone else, in which case we may need to share this information with the relevant authorities. But we would contact you and your child first to discuss it.
- Once we have finished the study, we will keep some of the information so we can check the results. We will write our reports on the results in a way that no-one can work out that your child took part in the study. A summary of the results will be available on the study website: www.3syp.co.uk.

What are your choices about how your child's information is used?

- Your child can stop being part of the study at any time, without giving a reason, but we will keep information about your child that we already have.
- If your child chooses to stop taking part in the study, we would still like to obtain some information from their health records, as described in this information sheet. If you or your child do not want this to happen, tell us and we will not do this.
- We need to manage your child's records in specific ways for the research to be reliable. This means that we will not be able to let you or your child see or change the data we hold about them.

Where can you find out more about how your child's information is used?

You can find out more about how we use your child's information:

- at www.hra.nhs.uk/information-about-patients/
- by contacting us on the contact details on page 7
- by contacting King's College London's Data Protection Officer, Mr Albert Chan at info-compliance@kcl.ac.uk

What if something goes wrong?

If you or your child have a concern about any part of this study, first you should contact us and we will do our best to answer your questions. If you or your child remain unhappy, you can contact the South London and Maudsley NHS Foundation Trust Patient Advice and Liaison Service using the freephone 0800 731 2864 (option 2) or by email at pals@slam.nhs.uk.

If you have a complaint, you can contact the Director of Research Quality:

Dr Gill Dale, Director of Research Quality
South London and Maudsley NHS Foundation Trust, R&D Department,
Room W1.08, Institute of Psychiatry, Psychology & Neuroscience (IoPPN),
De Crespigny Park, London SE5 8AF
Tel: 020 7848 0339

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect participants' interests. This study has been reviewed and given favourable opinion by the London - Riverside Research Ethics Committee.

Statement about insurance cover

In the event that something does go wrong and your child is harmed during the study you may have grounds for legal action for compensation against King's College London and/or South London & Maudsley NHS Foundation Trust, but you may have to pay your legal costs. The normal NHS complaints mechanisms will still be available to you (if appropriate). King's College London has obtained insurance which provides no-fault compensation i.e. for non-negligent harm, you may be entitled to make a claim for this.

Who should I contact for further information?

If you or your child have any questions or would like more information about the study, please contact the Study Coordinator, Dr Amanda Bye, by email at 3syp@kcl.ac.uk or call 07775 247 753.

Or you can contact the Chief Investigator, Dr Rina Dutta, by email at rina.dutta@kcl.ac.uk.

**Thank you for taking the time to read this – please ask us
if you have any questions**