



YOUNGMINDS
fighting for young people's mental health

NHS
South London
and Maudsley
NHS Foundation Trust

KING'S
College
LONDON

INFORMATION SHEET FOR YOUNG PEOPLE AGED 16 YEARS AND ABOVE

Ethical Clearance Reference Number: 20/LO/1187

Study title

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

You are invited to take part in a research study

Before you decide if you want to take part, it is important you understand why we are doing this study and what it will involve. Please take time to read this information sheet carefully. 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 listed on page 7.

Please note, we are not able to offer you 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 this technology is useful, there is concern about its effect 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 is funded by the Medical Research Foundation and the Medical Research Council.

Why have I been invited to take part in this study?

You are invited to take part because when you were seen at a mental health service in South London and Maudsley NHS Foundation Trust, you agreed researchers could contact you about relevant studies to find out if you would be interested in taking part. You are 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.

Do I have to take part?

No! It is entirely up to you. You should only take part if you want to and choosing not to take part will not affect you in any way.

What would taking part involve?

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

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

What information will be collected?

(1) Questionnaires

You will be given a link to install our study app on to your smartphone.

You will be asked to complete a confidential questionnaire about your mental health and wellbeing via our app. Or if you prefer, we can give you a link to complete it online. It will take about 15 minutes to complete. You can complete it at a time that suits you. There are no right or wrong answers.

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

(2) Use of a smartphone

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

(3) Use of social media

You will be asked to give us permission to collect information over the next 6 months on your 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 "likes" and posts on social media and the content of your posts on social media. We would like to collect this information from any accounts you may have on Facebook, Instagram, Twitter and YouTube. We may contact you during the study to ask if you would be happy to add other social media platforms that become popular among young people. You will be able to choose which, if any, of your 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, which includes notes made by healthcare professionals. We would like your permission to collect relevant information from your 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 the information, we will need to share your name, date of birth and NHS number with the Trust so they can identify your records. We will not provide the Trust with any of the information you have given the study. We will look at your 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.

Is there anything I need to be worried about if I take part?

There may be some questions that you find difficult or upsetting. If you are not comfortable answering any of the questions, you can skip them and move on. You can also take a break and come back to it or stop completing it if you want to.

Please note, we are not able to offer you 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 you need support.

If you think you need support, you should speak to your GP or other healthcare provider, or call NHS 111, as soon as possible. If you need urgent medical care, please go to a local hospital Emergency Department or call 999. You will also find details for other organisations that you might find helpful on our website:

<https://3syp.co.uk/useful-contacts.html>.

We will be collecting information about your use of your smartphone and social media, which may cause you concerns about data privacy and confidentiality. Please contact us if you have any concerns or want more information.

What if I change my mind?

If you do decide to take part, you can change your mind about taking part at any time during the study without giving a reason. Just let us know if you no longer want to take part. Stopping taking part will not affect you in any way. Information collected up until that time will still be used unless you ask us not to.

Will the study help me?

No, but you may find it helpful to anonymously disclose your experiences and feelings. You may like taking part in a study that will help us understand how to help other young people in the future.

Payment

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

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

No. Your decision to take part or not take part will not affect your 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.

How will we use information about you?

- 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 information is stored and used properly. King's College London will keep identifiable information about you for 10 years after the study has finished.
- We will need to use information from your 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 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 information will have a code number instead.
- We will keep all your information strictly confidential. The only time we may need to break confidentiality is if we are aware of a serious risk to you or to someone else, in which case we may need to share this information with the relevant authorities. But we would contact you 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 you 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 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 still like to obtain relevant information from your health records, as described in this information sheet. If you do not want this to happen, tell us and we will not do this.
- We need to manage your records in specific ways for the research to be reliable. This means that we will not 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 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 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 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 you are 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 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.

Alternatively, you can contact the Chief Investigator for the study, Dr Rina Dutta at rina.dutta@kcl.ac.uk.

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