



UCL

Participant Information Sheet –

UCL Research Ethics Committee Approval ID Number: 8227/003

Add-on to You-COPE: Youth COVID Response Personal Experience: Tracking health and wellbeing amongst 16-24 year olds in the UK during and after the COVID-19 pandemic using an app

Name and Contact Details of the Researcher:

Tayla McCloud, PhD student, Division of Psychiatry youcope@ucl.ac.uk

Name and contact details of the Principal Researcher:

Professor Russell Viner, UCL Institute of Child Health (r.viner@ucl.ac.uk)

1. Why am I being contacted?

We are contacting you by e-mail because when you took part in the You-Cope online study you gave us permission to contact you about additional research. We are now adding in an add-on to the study which uses an app on your phone to collect information on wellbeing and also how the effects of COVID-19 has affected 1) your physical activity levels 2) amount you sleep and 3) how much you are using screens. Understanding how physical and mental health have been affected in young people throughout the national 'lockdown' and beyond will be important to inform national health and education policy during this pandemic and in the future.

2. What will happen to me if I take part?

We invite you to download the app **onto your phone** which is available for iPhones and Android. Instructions on how to download the app are in the e-mail we sent you. Once you have downloaded it we will ask you to give consent for taking part in the app component of the study. The app will ask you each day to answer questions and also collect information on your physical activity, screen time and sleep.

1. **Each day** We will collect 3 pieces of information that are normally collected on your phone – step count per day (number of steps per day), amount of total screen time per day (hours per day) and sleep time (hours per day). We will use the information that you

phone measures automatically and you can see on the health apps on your phone. **We will not be looking at what you spend time looking at on your phone (so we won't know what apps or websites you have been using), or where you have been, just amount of time using your phone, activity levels and sleep.** With your permission, we will also collect the same data stored on your phone for the past 6 months. This will allow us to measure activity during lock-down and just before.

2. **Each day** we will ask if the area where you live is in lockdown.
3. **Each day** We will ask some questions about your thoughts and feelings on that day.
4. **Every two weeks** we will also ask some additional questions about your thoughts and feelings in the past 2 weeks and we will ask you to if you have had COVID-19 (coronavirus infection) or had a test which showed you had a virus. We will not be reporting any of this to anyone.

3. Do I have to take part?

It is completely up to you whether you take part in this add-on study. If you do decide to take part, we will ask you to indicate this consent in an additional consent form when you download the app. You are free to withdraw at any time without giving a reason, without this impacting you negatively in any way. You can stop taking part at any time. If you miss days you can still give responses on future days. It doesn't matter how many days you have missed. If at any time you would like to request that the data you have inputted so far be deleted, you can email the study researchers and this will be done for you.

4. What are the possible disadvantages and risks of taking part?

We do not believe that any of the included questions will be unduly distressing. However, it is possible that you may feel discomfort or distress as a result of being asked questions about your feelings and related factors. You can exit the survey at any time. If you are feeling distressed, we would encourage you to contact one of the following sources of support:

- *Samaritans*: a free, 24-hour confidential listening and support service for people experiencing feelings of distress (call 116 123).
- *Nightline*: a confidential listening, support and practical information service for students by students, open 6pm to 8am every night of term (call 0207 631 0101, text 07717 989 900, or email listening@nightline.org.uk).
- *Papyrus Hopeline*: Provides information and support for anyone under 35 who is struggling with suicidal feelings, or anyone concerned about a young person who might be struggling, open weekdays 10am-10pm and weekends 2pm-10pm (call 0800 068 4141 or text 07786 209 697).
- *NHS*: If you feel like you need support with your mental health you can discuss this with your GP. If you feel at risk of harming yourself, please discuss this with your GP, call NHS 111 or go to a hospital A&E department.

5. What are the possible benefits of taking part?

This work will contribute to knowledge in this important area, adding to our understanding of how young people are being affected by the current Coronavirus pandemic and the related

public health measures. This has the potential to inform national health and education policy during this pandemic and in the future. There is no direct compensation for taking part.

6. What if something goes wrong?

Any complaints or serious adverse events should be reported to the Principal Researcher, Lee Hudson l.hudson@ucl.ac.uk

If participants feel their complaint has not been handled to their satisfaction, they can contact the Chair of the UCL Research Ethics Committee by email (ethics@ucl.ac.uk).

7. Will my taking part in this project be kept confidential? What will happen to my data?

All of the information you provide during the course of this research will be kept strictly confidential, regardless of what you tell us. We will store your information we collect on a secure database at UCL which will only have your e-mail address and age as an identifier. All information will be transferred from the app to the secure database encrypted and securely. Individuals will not be able to be identified in any resulting reports or publications.

All data will be collected and stored in accordance with the General Data Protection Regulation (GDPR), 2018. You can request that any of your data be deleted up to 24 hours after it has been entered by contacting the study researchers.

Email addresses will be destroyed at the end of the study at which point the data will be completely anonymous and cannot be traced back to you in any way.

Completely anonymous data (separated from email address and any identifiable information provided) will be made publicly available for additional research by other researchers, in accordance with Open Science. This anonymised dataset will be hosted on an open science repository indefinitely. It is mandatory to consent to this as part of your participation in the study. This will help to improve the quality of scientific research and our understanding of this area, by making our process more transparent and encouraging collaboration, and will allow the government and other interested parties use our data in more effect ways to inform policy decisions.

8. What will happen to the findings of the research project?

We are working with various third sector and government departments. This will ensure that the findings of this study inform governmental policy decisions going forward. We will also spread the word about our findings through links with other organisations such as Student Minds to help inform support for young people.

Our findings will also be disseminated through published articles and presentations. Participants will be able to obtain copies of any publications which are produced as part of this project by emailing the researchers. It will not be possible to identify any individuals from any of these reports or publications, as only summary data will be presented.

9. Local Data Protection Privacy Notice

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk. This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses

participant information can be found in our 'general' privacy notice. For participants in health and care research studies, click [here](#). The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices. The lawful basis that will be used to process your personal data are: 'Public task' for personal data and 'Research purposes' for special category data. Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible. If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at data-protection@ucl.ac.uk.

Thank you for reading this information and for considering to take part in this research study. You will be able to request a copy of this Information Sheet at any time by emailing us on youcope@ucl.ac.uk. Contact information is also available in the drop down on the left of the app.