

Information for Parents and Guardians

Loneliness in the digital world: Co-developing smartphone-based research to examine how online social experiences impact adolescent mental health

Your child is invited to take part in a research study. 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. Talk to others about the study if you wish. Contact us if there is anything that is not clear, or if you would like more information. Take time to decide whether or not you wish for your child to take part.

What is the purpose of the study?

We want to find out the impacts of online or in-person social interaction on adolescent loneliness and their mental health. We would like young people to join our smartphone-based study for two weeks and share their moment-to-moment experiences to us.

Why have they been invited to take part?

Your child is invited to take part in this study as they are aged between 12 and 15 years old and live in Scotland. As your child is a member of Generation Scotland, you have confirmed that you think your child will be able to fully understand what they would be agreeing to and what it means for them. You also agreed your child may be contacted by the Generation Scotland team to complete additional questionnaires or to invite them to participate in other health related studies.

Do they have to take part?

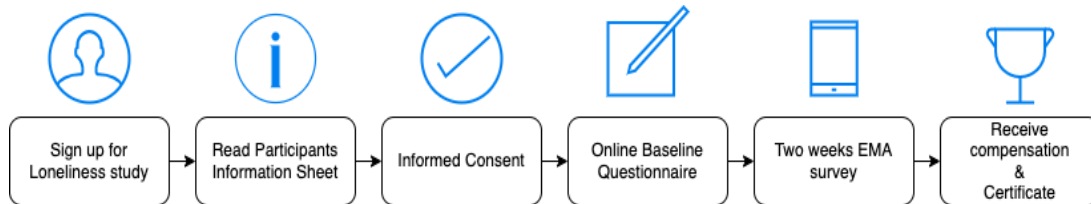
No, it is up to you and your child to decide if they want to take part. If it is decided that they will take part, you will be given this information sheet to keep, and your child will be asked to sign consent forms. Your child is still free to stop taking part at any time, without giving a reason. Deciding not to take part or choosing to stop taking part in the study will not affect your legal rights.

What will happen if they take part?

Take a look at the diagram below and read below what will happen at each stage. Starting from the participants information sheet that you are currently reading.

- If your child decides to take part, your child will complete a consent form online.
- Then your child will complete an online questionnaire about themselves, which takes approximately **10 minutes**.
- Following this, your child will participate in the smartphone-based survey of the study.
 - Your child will receive four daily questionnaires for two weeks.
 - Each of the questionnaires will comprise around 23 questions and will take less than one minute to complete.
 - The response will be anonymously recorded.

- Your child doesn't need to act on the questionnaire immediately, there is a time window (i.e., an hour) in which they can respond. Also, your child can skip a questionnaire if necessary.
- Full instructions on how to complete the smartphone-based survey will be provided by email or text once you have completed the online questionnaire.
- No identifiable data will be collected or downloaded on the App.
- At the end of the study, your child will receive a certificate of participation and a e-voucher to say thank you for taking part.



Is there anything they need to do or avoid?

By agreeing to have your child take part in this study, they need to download the 'LifeData' App on their phone and turn on notifications from this app to receive each prompt during the day. Please ensure that the 'Do Not Disturb' mode on their phone is not activated, as this will prevent them from receiving notifications from the app.

What are the possible benefits of taking part?

Your child will get a voucher as a big thank-you for being part of this study and putting in time and effort. They'll receive £5 for completing the online questionnaire, and up to £15 based on their completion rate (e.g., £15 for a 70% completion rate; £10 for 50% completion rate; £5 for 30% completion rate; £2 for under 30% completion rate). They'll also get a certificate to show they took part. The things we learn from this study will help plan future studies. Your child's involvement could really make a meaningful impact on this important area of research!

What are the possible disadvantages of taking part?

Your child might feel upset when answering questions about things that are tough for them. If they want to, they can stop at any time. If they're worried about any questions, they can talk to you, their parents.

They can also contact Samaritans for mental health support at 116 123, and learn more about them here: <https://www.samaritans.org/scotland/branches/edinburgh/>. If texting feels more comfortable, they can reach out to Shout at 85258. More info about Shout is available here: <https://giveusashout.org/>.

Every day, there are a few quick (less than 1 minute) smartphone questions, which might be time-consuming or pop up at inconvenient times. Both the baseline and shorter prompts ask some personal questions about emotions and feelings, but they don't need to answer anything that makes them uncomfortable.

What if there are any problems?

If you or your child have questions about any aspect of this study, please contact Generation Scotland Teens (genscot_teens@ed.ac.uk), or Zhuoni Xiao (zxiao@ed.ac.uk) or call us [07385 008 242] who will do their best to answer your questions. You can also find a detailed Information Sheet and Parental version on the Loneliness website <https://www.gslonelinessteens.com/>

What will happen if they don't want to carry on with the study?

Your child can choose to stop participating in the study at any time, and they don't need to give a reason. If they want to withdraw during the baseline questionnaire, they can just stop filling it out. Similarly, if they decide to withdraw during the App survey, they can stop answering the notifications they receive. If they want to remove their data from further analysis, they can email Zhuoni Xiao (zxiao@ed.ac.uk) and provide their participant ID, stating they want their data removed. It's important to know that two weeks after the study ends, we won't be able to remove your child's data from our dataset. At that point, all the data will be anonymized, so we won't be able to connect their personal data to their identity.

What will happen when the study is finished?

At the end of the study, all data will be downloaded and stored in a password-protected location on the University of Edinburgh secure computer server. These computers are safeguarded by up-to-date anti-virus software and will be automatically backed up regularly to the University of Edinburgh servers. Identifiable data (such as address, date of birth, postcode, email address) will be deleted at the study's conclusion, rendering all data anonymous. Non-identifiable data (such as your child's responses) will be retained for five years on the University of Edinburgh's secure servers. This anonymous data will be made openly available for other researchers to use in future ethically approved studies.

Will me taking part be kept confidential?

All the information we collect during the course of the research will be kept confidential and there are strict laws which safeguard your privacy at every stage.

How will we use information about you?

Personally identifiable information collected will include your child's date of birth, postcode, phone number, and email address. This information will be used by individuals conducting the research or checking records to ensure the research is conducted properly.

Individuals who do not require knowledge of their identity will not have access to your child's name or contact details. Instead, your child's data will be assigned a code number. We will ensure that all information about your child is kept safe and secure at the University of Edinburgh.

What is your choice about how your information is used?

Your child can stop participating in the study at any time without providing a reason, but we will retain the information about your child that we already have. For the research to remain reliable, we need to manage records in specific ways. This means we won't be able to allow you or your child to

view or alter the data we hold about them. If your child agrees to participate in this study, they will also have the option to permit the research team (within the sponsoring organization) to securely store their contact details and agree to be contacted about other ethically approved research studies. They will only be contacted by a member of this research team to inquire if they are interested in participating in another research study. Agreeing to be contacted does not obligate your child to participate in further studies.

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

You can find out more about how we use your information.

- at <https://www.ed.ac.uk/data-protection/privacy-notice-research>
- by asking one of the research team
- by sending an email to genscot_teens@ed.ac.uk
- by ringing us on [[07385 008242](tel:07385008242)]

What will happen to the results of the study?

With your and your child's permission, the anonymised data may be used for research or teaching purposes and might be shared with other researchers or made openly available to the scientific community, as well as publications, lay summaries, and conference presentations. Your child will not be identifiable from any published results.

Who is organising and funding the research?

This study has been organised by **Professor Heather Whalley** and Sponsored by **The University of Edinburgh**. The study is being funded by **The Medical Research Council**.

Who has reviewed the study?

The study proposal has been reviewed by the Medical Research Council. A Young Person Advisory Group have been involved in the development of the study providing feedback and coproducing study materials. A favourable ethical opinion has been obtained from the Edinburgh Medical School Research Ethics Committee.

Research Contact Details

If you have any further questions about the study, please contact Professor Heather Whalley by email: heather.whalley@ed.ac.uk

Independent Contact Details

If you would like to discuss this study with someone independent of the study, please contact Professor Stephen Lawrie by email: S.Lawrie@ed.ac.uk

Complaints

If you wish to make a complaint about the study, please contact:
The University of Edinburgh College of Medicine Research Governance Team:
resgov@accord.scot