

Virus Watch

Participant Information Sheet

Children aged 10-17 years V1

11.08.21

COVID-19 has changed all of our lives since March 2020. Schools have been closing on and off across the country and many people switched to working from home and not going out. Others were not able to work. This is all to try to stop the virus from spreading and making people ill.

We are inviting you to take part in a research study together with your household so that we can learn more about this virus. This will help scientists to work out how we can stop the virus from doing so much harm. Please read this information (Parts 1 and 2), discuss it with an adult, and then decide if you want to take part.

What is the study about?

This research study is about COVID-19. COVID is a new type of coronavirus, so there are some things we know but lots of things we don't know.

WHAT DO WE ALREADY KNOW ABOUT COVID-19	WHAT DON'T WE KNOW AND HOPE VIRUS WATCH WILL FIND OUT
✓ We know that grown-ups often get a cough and a high temperature when they get COVID.	✗ We don't know whether children have different symptoms like tummy ache, diarrhoea or feeling sick.
✓ We know that COVID has made some adults very ill but that children are extremely unlikely to get very ill with COVID.	✗ We don't know how many people just get a mild illness a bit like a cold or if children can catch COVID without getting ill at all.
✓ We know that our bodies remember some infections so they can fight them off in future.	✗ We don't know if getting COVID once will stop you from getting it again.
✓ We know that COVID can spread very easily.	✗ We don't know how often children spread COVID.

<p>✓ We know the government has given us lots of advice to stop COVID from spreading.</p>	<p>✗ We don't know how much people are able to follow this advice.</p>
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Why do you want me to take part?

The Virus Watch study needs everybody in each household to take part so it is very important that we include children and young people as well as grown-ups.

We need to know how many children and young people get COVID and whether they spread infection to others in the house. This means we would like everyone in your household to take part.

This will help us understand how useful it is to close schools, how long they need to close for and when this should happen.

Do I have to take part?

No. It is up to you to decide whether to take part or not. You can leave the study at any time and you don't have to give us a reason.

What will I need to do?

At the start of the study, an adult in your household will answer some questions about you. We want to know how old you are and whether you have any medical conditions like asthma.

The study has two parts; these are:

1) Online illness reporting study - Whenever anyone in your house is ill with coughs and colds and symptoms that could be COVID they will need to write down their symptoms every day that they are ill. Your family can help you with this. Each week an adult in your house will get an e-mail asking them to say whether or not anyone was ill and to record their symptoms on an online survey.

We would like to understand how people respond to government advice about COVID-19 and how this advice is affecting their lives. Once a month, we will ask your household a series of questions about this including what questions about COVID-19 are important to them and we will do our very best to answer them.

2) We would like to examine your medical records to record any doctor or hospital visits related to respiratory infections, any positive swab test results and details of any COVID-19 vaccinations you may have received. We may do this for up to 5 years after the end of the study. This is because we expect this virus to come back each winter.

How long will this study go for?

This study will run until June 2022.

What if I have more questions?

If you have any more questions you can ask an adult to send us an email to: viruswatch@ucl.ac.uk

Thank you for reading Part 1.

The next section outlines how information about you may be used.

Children's Participant Information Sheet Part 2

- **Will my taking part in the study be kept confidential?**

Yes. All the information that your lead householder enters into our surveys will go directly into secure computers at UCL (Data Safe Haven). Access to personal data that could be used to identify you will be strictly limited to a small number of trained researchers at UCL. The identifying information (such as NHS numbers and names) are kept in a separate database, away from the data about your health, test results, or any other information collected via the survey. All staff working on this project have a legal duty of confidentiality to protect personal information about individuals. All staff working with the data have had special training in keeping data confidential and secure.

All information will be collected and stored in accordance with data protection legislation. UCL policy is to store data for a minimum of 10 years.

We will need to share some information about you with organisations NHS Digital, Office for National Statistics (ONS) and Public Health England (PHE) in order to link to your medical records. We will share your name, date of birth, sex, home addresses, and, where available, NHS number. NHS Digital, ONS and/or PHE will return information to us from your medical records including details of any hospital visits and COVID-19 vaccinations you may have received. We will also receive any positive results arising from the Test and Trace programme, and we may organise further genetic tests on the type of virus you were infected with from these positive swab samples. These data will be used for research purposes only and researchers analysing the information will not be able to identify you.

The Office for National Statistics may provide access to data shared with them to accredited researchers for accredited research purposes via accredited processing environments, where it is lawful and ethical to do so, and where the research is

considered to be in the public good. It will not be possible to identify individuals from this data. Data will only be used for statistical research and analysis purposes and will not be shared with anyone else (other than access by accredited researchers).

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 dataprotection@ucl.ac.uk. Further information on how UCL uses participant information for participants in health and care research studies, click <https://www.ucl.ac.uk/legal-services/privacy/ucl-general-privacy-notice-participants-and-researchers-health-and-care-research-studies>

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 legal basis for processing personal data for this study at UCL falls under Article 6(1)(e) "public task" and Article 9(2)j "processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes". Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudo-anonymise 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. If you remain unsatisfied, you may wish to contact the Information Commissioner's Office (ICO) (<https://ico.org.uk/concerns/handling/>).

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 like to continue collecting information about your health from central NHS records. If you do not want this to happen, tell us and we will stop.
- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.
- If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study.

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/

- our study website www.ucl-virus-watch.net
- by sending an email to the study manager viruswatch@ucl.ac.uk

- **What if I am unhappy about the way the study is conducted?** We have tried to make the study as easy as possible for those taking part, if you have any complaint about the way you have been dealt with this will be addressed. If you wish to complain about the conduct of the study please ask an adult in your household to contact the study manager, at UCL Department of Epidemiology & Public Health, 1-19 Torrington Pl, Fitzrovia, London WC1E 7HB or email viruswatch@ucl.ac.uk. If you remain unhappy you can take up your complaint through the UCL Ethics Committee at: ethics@ucl.ac.uk and copy in the research-incidents@ucl.ac.uk .

- **Harm:** In the unlikely event that you are injured by taking part, compensation may be available but you may have to pay your legal costs. If you suspect that the injury is the result of the Sponsor's (University College London) negligence, then you may be able to claim compensation. Please ask an adult in your household to make the claim in writing to Professor Andrew Hayward who is the Chief Investigator for the clinical trial/ study and is based at UCL 1-19 Torrington Place. The Chief Investigator will then pass the claim to the Sponsor and on to Sponsor's Insurers. Also, the normal National Health Service complaints mechanisms will still be available to you (if appropriate).

Thank you for reading Part 2