**Finding out more about Children and Young People aged 11-15 with Long COVID (the CLoCk study)**

**Summary**

It seems that some children and young people remain ill for a long time after catching the COVID virus. They are said to have ‘long COVID’. Doctors don’t know how to diagnose long COVID, how common it is or how long it goes on for. There is no simple test for long COVID. We need to know more about it if we want to treat it.



We work at an organisation called Public Health England and at University College London and Great Ormond Street Hospital. We are contacting you because you were tested for COVID and you might be able to help us. It doesn’t matter if you were found to have COVID or not, we are still interested in finding out more about how you are feeling now.

**How will we do this research?**

We are contacting children and young people from all over the country who had a COVID test to see how they are feeling months afterwards. We will compare any problems of those who had a positive COVID test, showing that they were definitely infected, with those who were not infected. This will tell us what kind of problems carry on for a long time in young people who have had COVID and help us decide what is ‘long COVID’. Knowing these things could help with coming up with treatments.

**What would taking part involve?**

We would ask you to go to our website and fill in a form saying you agree to take part. We would then ask you to answer some questions online about how you are feeling three or four times over two years, a few months apart. Each time would take about 20 minutes. You would not have to complete the questions all in one go. We will contact you when you are due to complete the next set of questions. The questions are all about your health. At the end, you will receive a £25 voucher.

**What’s good about taking part?**

We all want to better understand COVID so that we can help young people who are still having problems months after being infected get the care they need. You can help us do this. We will let you know where you can get help if you need it.

**Are there any risks to taking part?**

Answering questions about health can sometimes be difficult for some young people but there are no risks from taking part in the study.

**Do I have to take part and what happens to my information?**

No, you do not need to take part. Participation is voluntary and you can stop being part of the study at any time, without giving a reason, but we would like to keep information about you that we already have. We will need to use your answers from the questions you complete for this research project. This information will include your name, contact details and details about your health. We will only use this information to find out about long COVID. Only the computer which sends out the reminders to you to complete the questions needs to know your name and email address. No person needs to see your name or contact details. Your answers will have a code number instead. We will keep all information about you safe and private. When we have completed this research, we will write our reports in a way that no-one can work out that you took part in the study.

**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 would like to keep information about you that we already have. You can tell us if you don’t want this.

**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/ and www.hra.nhs.uk/patientdataandresearch
* Our leaflet available from [X]
* By asking one of the research team
* By sending an email to [email], or
* By ringing us on [phone number]

**How will my information be kept confidential?**

All your information will be kept on secure computer systems at Public Health England and UCL (Data SafeHaven). The Data Safe Haven has been certified to the ISO27001 information security standard and conforms to NHS Digital's Information Governance Toolkit. Only the researchers will have access to the information. If you tell us something that makes us think that you or someone else could be harmed, then we will need to tell someone who can help to protect you and/or the other person.

**What will happen if you don’t want to carry on with the research?**

You can stop taking part in the study at any time. If you are seeing your local doctor or hospital, that will not be affected in any way.

**What will happen to the results of the research?**

We will write to you to let you know the results of the research. No names will be used in any reports of this research, so you won’t be able to be identified.

**Who has approved the research?**

This project has been checked given the go ahead by a group of experts who are not connected to us or the research in any way (a Research Ethics Committee). It has designed with young people and members of the public who are closely involved in the study.

**Who do I speak to if I have more questions or worries?**

If you would like further information, please contact:

Contact: Professor Roz Shafran

Address: UCL Great Ormond Street Institute of Child Health, 30 Guilford Street, London, WC1N 1EH

Email: Clock@phe.gov.uk

Telephone: 02084953240

**Where can I get help if needed?**

This study can’t offer you help if you need it but you or your parents can contact the following places:

1) Your doctor

2) ChildLine - www.childline.org.uk, 0800 1111

3) NHS 111; https://111.nhs.uk
4) Text Shout to 85258

**What if there is a problem?**

If you have a concern about any part of this research, you or your carer should ask to speak to the researchers, who will do their best to answer your questions. If you remain unhappy and wish to complain, you or your carer can do this by emailing University College London at research-incidents@ucl.ac.uk and giving reference number 20PP47.