**Information about the project for parents and carers**

**Project title: Children & young people with Long Covid (CLoCk) study**

**Invitation and brief summary**

We work at Public Health England and the UCL Great Ormond Street Institute of Child Health. You are being contacted because your child was tested for Covid. We want to understand more about the long-term impact of Covid in children and young people that tested positive compared to those that tested negative.

**Purpose of the research**

It seems that some children and young people (CYP) remain ill for a long time after infection with 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.

**How we will do the research**

We are approaching children and young people who had a Covid test to see whether they have health problems at 3, 6,12 and 24 months after the infection. We will compare any problems of those who had a positive COVID test with those who didn’t test positive. We can then agree on what is a medical diagnosis of long COVID and how we might treat it.

**What would taking part involve?**

We would ask you and your child to go onto our website and fill out some information and sign a consent form. We would then ask your child to complete questionnaires online two or three times over the next 24 months. Each time would take about 20 minutes. The questions do not need to be completed all in one go. We will contact you when your child is due to complete the next set of questionnaires. The questionnaires ask about physical and mental health. After completing the final questionnaire, your child will receive a £25 voucher.

**Benefits to taking part**

We all want to better understand Covid so that we can help people who are having symptoms get the help they need early. Your child’s participation will help us do this. We will provide information about where you can get help for your child’s health problems if you need that.

**Possible disadvantages and risks of taking part?**

Answering questions about health can be difficult for some children and young people but there are no specific risks from taking part in the study. Children and young people will not be deprived of any treatment that they should receive as a result of taking part in this 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 information from the questionnaires you complete for this research project. This information will include your child’s name, contact details and details about your child’s health and wellbeing. We will use this information to do the research. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that your child took part in the study. We are also asking for consent for your child’s data to be used in future research.

**What are your choices about how your information is used?**

You and your child can stop being part of the study at any time, without giving a reason, but we would like to keep information about your child that we already have.

**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/](about:blank) and [www.hra.nhs.uk/patientdataandresearch](about:blank)
* 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 or your child tells us something that makes us think that you or someone else could be harmed, then we will need to break this confidentiality to safeguard you and/or your child.

**What will happen if my child doesn’t want to carry on with the study?**

You and your child are free to withdraw from the study at any time. Your care and your child’s care will not be affected.

If you and your child do withdraw from the study, we would like to still use the information from the questionnaires that your child has completed up to that point. If you prefer for these not to be used, please let the researcher know and we will not use them.

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

We will write to you and your child to let you know the overall findings of the study. We hope to publish the findings of the study. No names or other identifiable information will be used in any reports or publications.

**Who has approved the research?**

This project has been checked by the x Research Ethics Committee. It has been funded by the National Institute of Health Research for England and the research has been designed with young people and members of the public. The study has been reviewed by experts in health and research.

**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 and your child can contact the following places:

1) Your doctor

2) ChildLine - [www.childline.org.uk](about:blank), 0800 1111

3) NHS 111; https://111.nhs.uk4) Text Shout to 85258

**What if there is a problem?**

If you have a concern about any aspect of this study, you 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 can do this by contacting UCL-ICH Manager, referencing 20PP47: [research-incidents@ucl.ac.uk](about:blank)