**Participant Notification: Virus Watch**

**Who are we?**

We are researchers at University College London (UCL). UCL is the data controller for this project.

**What is this project about?**

The Coronavirus (COVID-19) Pandemic has caused large numbers of deaths and severe societal disruption worldwide. To respond and support the NHS and public health decision makers, we need to know how many people become infected with the virus, how many of them become ill, what their symptoms are, how many seek health care, how commonly they transmit the illness to household contacts, what proportion need hospitalisation and what proportion die.

We also need to understand how the population responds e.g. hand washing behaviours during and after coughing, sneezing or nose wiping, and whether people restrict their movements and social contacts, how well the vaccines are working and how that affects people’s behaviour. Since many of those infected will have relatively mild symptoms and not seek medical advice the only way to accurately obtain this information is to conduct large scale community studies.

We will follow up members of the public using regular online surveys of symptoms and behaviours, to build a detailed picture of how the virus spreads and the population responds.

**The data used in this project**

If you have consented to take part in this project, the data that will be used in this project will come from different sources:

1. Household surveys

A lead person in your household (whom the household will nominate) will be asked to provide the following information:

* 1. A brief baseline questionnaire about your household, and general health
  2. Weekly illness questionnaire- Data on whether the lead householder or anyone else in the family has been ill and their symptoms, including temperature, and time off work.
  3. Monthly questionnaire- Information about online health information seeking, social distancing questions, contacts, activities, places visited and hand & respiratory hygiene.

2. Routinely collected medical records and laboratory test data

These are data that are routinely collected through the NHS or are recorded as part of vital statistics registration. The data include vaccinations,hospital visits, tests or treatments and any deaths in the family during the course of the study. NHS Digital holds the data on hospital admissions (called Hospital Episode Statistics data) and deaths. We will also hold virological testing data routinely collected by Public Health England and the NHS Test and Trace Service.

3. Virological and blood testing data

If your household has been randomly selected to be part of a smaller group of Virus Watch participants that we study to find out whether you have been infected with COVID-19 (or a different kind of respiratory infection) when you experience a respiratory illness, we will have data from you on tests results from nasal and throat swabs and blood samples collected as part of the study. You may also be part of the vaccine evaluation study providing finger prick blood samples monthly or every other month.

4. Geotracking data

If you have downloaded the movement tracking App called “Tracker for ARCGIS” onto your phone, and are participating in the geotracking study, we will hold movement data about you.

**Data controller/processors**

UCL as study sponsor will be data controller for all data generated by the study (Survey data, Geolocation data and Laboratory data tested at the Francis Crick /UCLH and Thriva). UCL are processors of the linked NHS Digital and Public Health England COVID-19 testing and vaccination datasets for this study.

**Confidentiality**

All survey data will be undertaken using RedCap Survey Software and securely stored in the UCL data safe haven. All laboratory test results and routinely collected hospital data and deaths data will be stored on highly secure servers at UCL and can only be accessed by a small number of accredited individuals. The survey data will be securely downloaded to the UCL secure server for analysis. Movement tracking data will be stored on the secure ArcGIS EU Amazon server.

**Patient Notification/Fair Processing Notice**

The identifying information (such as NHS numbers and names) are kept in a separate database, away from the data about your health, virological 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.

**Where to find the results**

Our results will be published in open access journals so that they can be read online and downloaded for free. We will announce these publications and provide lay summaries of our results on our website: <https://ucl-virus-watch.net/> Publications will also be released to the press via the UCL Media Engagement Office.

**Legal and ethical permissions**

The legal basis for processing personal data for this purpose data at UCL falls under Article 6(1)(e) of the General Data Protection Regulations (GDPR), i.e. *“processing is necessary for the performance of a task carried out in the public interest”*. It also falls under Article 9(2)(j), “*processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purpose*”.

Ethical approval for this research was granted by the London - Hampstead Research Ethics Committee reference: 20/HRA/2320

**Data storage and retention**

In accordance with the Medical Research Council guidelines, the survey data and test results collected in this study will be securely stored for a minimum of 10 years. For the health data supplied by NHS Digital, the data retention period will be [*end date of DSA*.] in the first instance. Retention of data is necessary to ensure that analyses can be checked and to adhere to guidelines on reproducibility of research.

**Your options**

If you would like to know more about the project and how we using your data, please contact us at viruswatch@ucl.ac.uk . You may also contact the principal investigator, Professor Andrew Hayward, by phone or post, via the UCL Institute of Epidemiology and Health Care. Contact details are available here: <https://www.ucl.ac.uk/epidemiology-health-care/>

You are entitled to object to your data, or your child’s data (if you are their legal guardian), being used for this research. If you do not want us to use your or your child’s data, please get in touch using the contact details above.

You have the right to tell NHS Digital if you do not want the information you provide to them to be used beyond the purpose of providing healthcare. This is known as an "opt-out". Please visit NHS Digital’s website for further details: <https://www.nhs.uk/your-nhs-data-matters/manage-your-choice/>. Your choice will not affect the health care you receive.

University College London is the Data Controller for this study. If you have any questions about how UCL uses personal data, you can contact the Data Protection Officer: [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk).

You also have the right to complain directly to the [Information Commissioner’s Office](https://ico.org.uk/about-the-ico/who-we-are/), which is an independent regulatory authority set up to uphold information rights.