

# Participant Notification Sheet

In response to the coronavirus pandemic, six National Core Studies have been set up for COVID-19 research. This has been initiated by the UK Government and Chief Scientific Adviser, Sir Patrick Vallance.

One of these is the 'COVID-19 Longitudinal Health and Wellbeing National Core Study'. This is a very important study and the work is considered a national priority. This study is funded by the Medical Research Council. As part of this National Core Study, the University of Bristol and the University of Edinburgh are establishing the UK Longitudinal Linkage Collaboration (UK LLC). This is a new research infrastructure designed to support the secure analysis of COVID-19 data.

The UK LLC will bring together information from longitudinal study volunteers with their routine records in a secure way to help researchers work to improve health and wellbeing throughout and beyond COVID-19. Access to study participants' health records will help researchers track which participants have had COVID-19, when (or if) participants had a vaccination, and any other relevant health related information. The research will also consider the wider impacts of COVID-19 – and particularly lockdown and the disruption of the normal functioning of the economy and government services – on health and wellbeing. This information may help us determine the effects of lockdown on physical and mental health and wellbeing matters such as education and employment now and in years to come.

**This document has been created to inform longitudinal study volunteers, sometimes also referred to as study participants, how collaborating studies will work with the UK LLC. It intends to be clear about the process your information goes through to become de-personalised by the time it reaches the UK LLC secure research database. It also intends to clearly communicate your rights to withdraw consent and how to do this.**

## **What to expect as a participant in a collaborating study**

Your study remains the owner and Data Controller of the study data and has ultimate control of how your data is used in the UK LLC. Your study continues to control which participants' data is uploaded to the UK LLC, what data is provided or linked to, and who can use which data for what purposes.

### **Is my data being held and used in the UK LLC?**

We cannot tell whose data is in the UK LLC as all data is de-personalised, meaning we cannot confirm if your data is included or not. You will need to contact your study to confirm if your data has been included or not.

### **How you can withdraw consent for the UK LLC to hold your data**

You need to contact your study to let them know you wish to withdraw consent. Your study will then notify the UK LLC with this information and your data will be withdrawn at the following quarterly update. Your study is responsible for your consent preferences.

### **How the design of the UK LLC ensures the confidentiality of your data**

Data from collaborating studies is processed before reaching the UK LLC secure research database to de-personalise the data. 'De-personalised data' is information that does not identify an individual, as people's identifiers such as name and address will have been removed and other potentially identifiable information (such as job title) changed so it is less specific. This type of information still requires a level of protection and careful handling as there is a theoretical possibility that an individual could be re-identified by bringing together information from different sources. In addition to health data, the UK LLC links to data about the area where study participants live to provide further context for research (but does not hold volunteers address information).

In contrast to a 'lending library' where books are allowed to be taken away, the UK LLC is designed to act as a 'reading library' for researchers. If they have had their request to enter the 'reading library' approved, researchers will be allowed to access selections of data inside the UK LLC secure research database. They won't have access to all of the data - only the data which is relevant to their research.

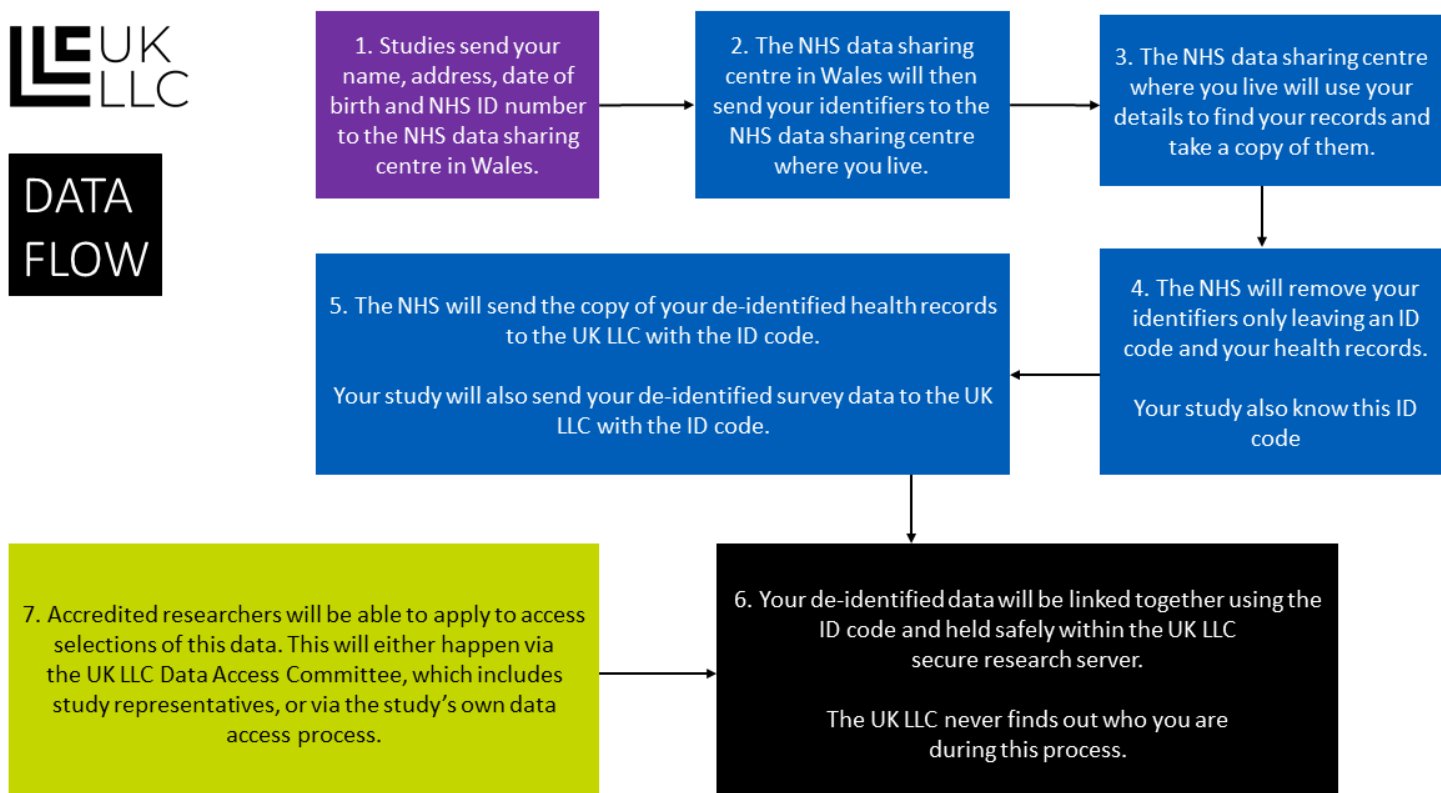
To summarise the process using the ‘reading library’ analogy - researchers request to enter the library, read their pre-selected choice of ‘books’ when in the library, then leave without taking their books home. Researchers can take away a summary of their research findings, which is checked by UK LLC staff as an additional layer of security to make sure individuals aren’t able to be identified.

Commercial companies can request access to selections of data held within the UK LLC. This will only be approved where the company can demonstrate to the UK LLC Data Access Committee and the studies who have contributed data that the research will be of public benefit. The data cannot be used for any profit making purposes. Studies that have not agreed to share their data with commercial companies will not have their data included in any potential data selection from such an organisation.

**This diagram outlines the process study data takes to end up within the UK LLC:**



**DATA  
FLOW**



## **Who controls the use of your data**

The UK LLC is part of the University of Bristol, which is the Data Controller for the information placed in the UK LLC secure research database. The University can be contacted at:

Data Protection Officer, University of Bristol, Beacon House, Queens Road, Bristol, BS8 1QU, UK

Email: [data-protection@bristol.ac.uk](mailto:data-protection@bristol.ac.uk)

## **The legal basis we have for holding your personal data:**

There are two distinct channels that studies may use to contribute your information to enable this:

### A) In England and Wales

Our legal basis for linking study information with NHS records and providing these into the UK LLC is through using the emergency data sharing powers of the Control of Patient Information Regulations 2002. These are specifically designed to allow data to be used effectively in emergencies such as the COVID-19 pandemic. We are working with your study and the NHS to move to using the established mechanism used by your study. If you have told your study or the NHS that you don't want your health records used in research, then we respect this and have asked studies not to provide your data for linkage to health records.

### B) Our legal basis for using your information, under UK GDPR and the Data Protection Act 2018, is:

- 1) performance of a task carried out in the public interest and, where sensitive personal information is involved.
- 2) scientific or historical research purposes or statistical purposes.

The GDPR defines 'sensitive personal information' as information that reveals a person's racial or ethnic origin, political opinions, religious or philosophical beliefs, trade union membership; and the processing of genetic data or biometric data for the purpose of uniquely identifying a person; data concerning health or data concerning sex life or sexual orientation.

Studies which contribute data to the UK LLC also have their own legal basis for collecting, processing and sharing their participants' data for research purposes. This can generally be found in the privacy notice on the study's website or in their participant information sheets.



## **Where your data is stored**

The data will be stored on secure servers controlled by the University of Bristol and located at the University of Swansea who have built the secure research system the UK LLC uses.

The University of Swansea are data processors working under contract to the University of Bristol for the UK LLC. This system is tried and tested for this purpose – it already hosts many secure databases, including hosting the NHS records of the all the people living in Wales.

## **How your data is being used**

We will provide a full list of who is using UK LLC data, who they are employed by, what purpose they have, which data they are using and what the outcomes of their research investigations are. We are developing a web site to show this, but in the meantime you can request this by emailing [project-infoukllc@bristol.ac.uk](mailto:project-infoukllc@bristol.ac.uk)

## **Your rights**

The UK LLC aims to meet the highest standards when collecting and using personal information. We encourage people to tell us if they think that our collection or use of information is unfair, misleading or inappropriate. We would also welcome any suggestions for improving the way we handle your personal details.

The General Data Protection Regulation (GDPR) and the UK Data Protection Act 2018 provides individuals with rights over how their data are used. The UK LLC supports these rights.

Those who use the UK LLC or those accessing our website have a right to access their personal information, to object to the processing of their personal information, to rectify, to erase, to restrict and to port their personal information. Please visit the University of Bristol website pages on fair processing for further information in relation to your rights.

If you have any questions about the content within this document and would like to contact a team member at the UK LLC you can email [project-infoukllc@bristol.ac.uk](mailto:project-infoukllc@bristol.ac.uk)



If you would like to complain about our handling of your data, contact the University's Information Rights Officer via email at [data-protection@bristol.ac.uk](mailto:data-protection@bristol.ac.uk)

Or by post to:

Data Protection Officer

University of Bristol

Beacon House

Queens Road

Bristol BS8 1QU, UK

If you remain dissatisfied, it is your right to complain directly to the Information Commissioner for a decision. The Information Commissioner can be contacted at:

Information Commissioner's Office

Wycliffe House

Water Lane

Wilmslow

Cheshire

SK9 5AF

[www.ico.org.uk](http://www.ico.org.uk)

This Participant Notification Sheet is intended to be clear and concise. We recommend that you also read our full privacy notice for more detailed information.

This Participant Notification Sheet was last updated on 12 May 2021.