

Participant Notification Sheet

This document has been created for longitudinal study participants who are existing participants in the studies taking part in the UK Longitudinal Linkage Collaboration (UK LLC). Its purpose is to tell you how the UK LLC will work to make sure your data is only used in the ways you agreed. A list of the studies taking part in the UK LLC is available on our website [About us | UK Longitudinal Linkage Collaboration \(ukllc.ac.uk\)](#)

We will tell you about the process your data goes through to reach the UK LLC Trusted Research Environment. A Trusted Research Environment (TRE) is a secure computer system where approved researchers can access and study data. We will make sure you know about your right to opt out and how to do this.

As a result of the coronavirus pandemic, six National Core Studies are working to support COVID-19 research. These have been set up by the UK Government and Chief Scientific Adviser, Sir Patrick Vallance. These studies are considered a national priority.

If you are interested in reading about these studies, you can click this link to the UK Government website: <https://www.gov.uk/government/publications/the-national-core-studies-programme>

One of these is the COVID-19 Longitudinal Health and Wellbeing National Core Study. As part of this study the UK Longitudinal Linkage Collaboration (UK LLC) has been set up.

The UK LLC will bring together information from longitudinal study participants with their health and administrative records eg. NHS COVID-19 data, education data, occupation data. This will be done to help researchers improve health and wellbeing as we continue to live through the coronavirus pandemic.

Longitudinal studies work by selecting a group of individuals or properties and then repeatedly collecting data on these people (or the people living in the properties) over time – often over a period of many years and sometimes decades.

Being able to study health records will help researchers investigate a number of different things. For example, which occupations may increase the risk of catching COVID-19, why some people with COVID-19 end up more poorly than others, COVID-19 related health issues such as Long-COVID, if or when participants took up the invitation to be vaccinated, and other similar health related information.

The research will also consider the wider impacts of the coronavirus pandemic. In particular, the lockdowns and the disruption of the day-to-day running of the country on peoples' health and wellbeing.

All of this information may help us show the impact of the effects of COVID-19 and lockdown on many aspects of health, education and employment now, in the years that follow and into the future.

Who runs the UK LLC?

The UK LLC is run by two teams of staff based across the Universities of Bristol and Edinburgh. We work closely with your study to make sure we store, handle, process and destroy the data in the right way. The terms of this are set out in a contract. Through this contract, 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.**

The UK LLC also involves IT experts from the University of Swansea, environmental science experts at the University of Leicester, the NHS and the Office for National Statistics. The UK LLC involves members of the public across its governance who provide a supportive and influential role. Only a small number of staff teams from the University of Bristol and the University of Swansea can access the linked data. Researchers wishing to access parts of the data must apply and be approved before there are granted access. The data and the processing of the data is not outsourced to a commercial company.

How does the UK LLC ensure that you won't be identified by your data?

Data from the studies taking part is de-personalised before reaching the UK LLC Trusted Research Environment. 'De-personalised data' is information that does not identify an individual, as details such as name and address have been removed and other potentially identifiable information (such as job title) changed so it is less specific. In addition to health and administrative data, the UK LLC links to data about the place where study participants live to provide further context for research – for example air pollution data or access to broadband (but does not hold participants' address or postcode 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 access the 'reading library' approved, researchers will be allowed to access selections of data inside the UK LLC Trusted Research Environment. They won't have access to all of the data - only the data which is relevant to their research. They cannot download data from the system. 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.

What should I expect as a participant in a collaborating study?

All communication about the UK LLC will come from your study. The UK LLC is designed to make the most of existing data. If your study collects new data from you, de-personalised copies of this may also be shared with the UK LLC. This will be for research purposes approved by your study only.

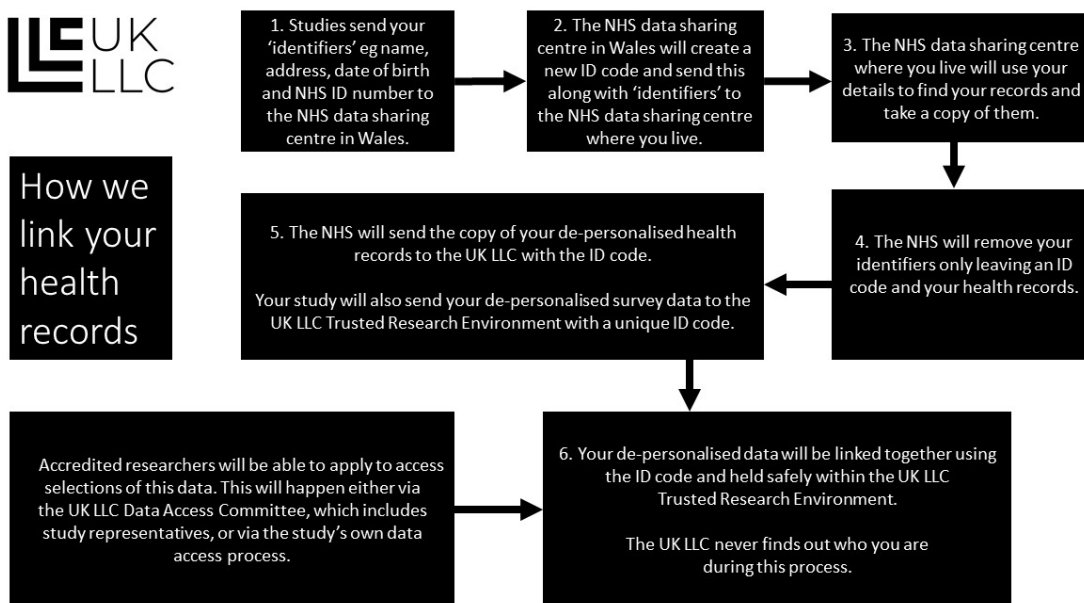
Is my data being held and used in the UK LLC?

As all data in the UK LLC is de-personalised, we cannot identify any individual and therefore cannot confirm whose data is included. You will need to contact your study to check this. All the studies in the UK LLC are listed on our website <https://ukllc.ac.uk/about/>

Can you opt out so your data is not used in the UK LLC?

All study participants from any of the studies taking part who wish to opt out, either for themselves, or on behalf of a child, can do so. You should contact your study directly and let them know. You have the right to opt out at any time without needing to provide a reason. However, it is not possible to stop using your data which is part of active research investigations. Once you have opted out no new research will be started using your data. **If you choose to opt-out your study will manage this process according to their standard policies and procedures.**

This diagram outlines how data moves from the study to the UK LLC Trusted Research Environment:



There is more detail about how this works in our privacy policy - <https://ukllc.ac.uk/privacy-policy/>

Who can access the data in the UK LLC?

A small team of experts from the University of Bristol Medical School manage the data. University based IT system experts manage the security of the Trusted Research Environment. All researchers requesting to access the data in the UK LLC need to be accredited research professionals working for an organisation with the resources and skills to conduct research. Requests to access data will go to the UK LLC Data Access Committee and/or go through the study's own data access process. All must be Office for National Statistics Accredited Researchers – this is the main national scheme which makes sure researchers are legitimate and know how to use data in a safe way. All researchers must be UK-based.

Where is the data stored?

The data will be stored on secure servers controlled by the University of Bristol and physically located at the University of Swansea who have built the UK LLC Trusted Research Environment. 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.

How is my data being used?

We will provide a full list of who is using UK LLC data, who they are employed by, for what purpose they are using the data, what data they are using and the outcomes of their research investigations. We are developing a page on our website to show this, but in the meantime you can request this by emailing info@ukllc.ac.uk.

Who will these researchers work for?

Most researchers will work for UK Universities. Some may work within the NHS or other government departments. Some may work for charities.

Commercial companies can request access to data within the UK LLC. These must be companies where their purpose, or part of their purpose, is to conduct high quality research. These requests 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.**

Some studies have opted-out of sharing data with commercial companies. The study always remains in control of who has access to their data. The UK LLC is committed to working with your study to uphold your rights and responsibilities around data sharing and research in your study.

LEGAL & GDPR INFORMATION

Who controls the use of your data?

The University of Bristol is the 'Data Controller' (legally responsible for data protection) of the UK LLC and can therefore determine how the data is processed for the UK LLC. The organisation running your study (a University or part of the NHS) remains the owner and Data Controller of the study data for all other purposes. 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

Our legal basis: Data Protection (Data Protection Act 2018, UK GDPR)

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.

For using confidential health (NHS) information

- 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 coronavirus pandemic. We are working with your study and the NHS to move to using the established legal basis 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.

- In Scotland and Northern Ireland

We are in discussions with the NHS in Scotland and Northern Ireland to establish a legal basis for using NHS Scotland and Health and Social Care Northern Ireland records.

For using confidential administrative information

The UK LLC will use the research provisions of the Digital Economy Act 2017 to link to administrative records (such as those held by HM Revenue and Customs, the Department for Work and Pensions, and the Department for Education and its devolved equivalents). We will access existing de-personalised data from these sources from the UK's statistical authorities and agencies. The Digital Economy Act provides a legal basis for the transfer of confidential information by public authorities for research purposes in a way that does not breach any duty of confidentiality owed to the individual by the public authority.

The legal basis for the UK LLC under UK GDPR and the Data Protection Act 2018:

1. Performance of a task carried out in the public interest (Article 6(1)(e) in the GDPR); and, where sensitive personal information is involved;
2. Scientific or historical research purposes or statistical purposes (Article 9(2)(j) in accordance with Article 89(1)). 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.

This legal basis within UK GDPR and the Data Protection Act 2018 is separate to, and in addition to, the actions and legal basis of the collaborating studies which establishes the basis for your data to be collected, processed and shared for research purposes.

For using study data

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.

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. You can email us at info@ukllc.ac.uk

The General Data Protection Regulation (GDPR) and the UK Data Protection Act 2018 provides individuals with rights over how their data is 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:

<http://www.bristol.ac.uk/secretary/data-protection/gdpr/rights-of-data-subjects/>

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 info@ukllc.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

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

This Participant Notification Sheet is intended to be clear and concise. We recommend that you also read our privacy policy for more detailed information - <https://ukllc.ac.uk/privacy-policy/>

This Participant Notification Sheet was last updated on 30 September 2021. This document will be reviewed in February 2022.