

Frequently Asked Questions

Our Patient and Public Representatives have created a list of questions they had about the UK Longitudinal Linkage Collaboration (UK LLC). They're listed here, along with our replies. If you have any questions that aren't answered here, you can contact us via email at info@ukllc.ac.uk. This is Version 1 of this set of frequently asked questions. Further versions will be produced and made publicly available as our work continues.

1. What is the UK LLC?

The UK Longitudinal Linkage Collaboration (UK LLC) has been set up to bring together de-personalised study data from more than twenty of the UK's top longitudinal studies with de-personalised copies of study participants NHS COVID-19 data, education data, occupation data and information related to where people live. This collaboration will create a powerful research resource. The linked study data will be held in a trusted research environment providing a rich source of longitudinal data which will be kept updated as time goes on.

2. How will this data be used for COVID-19 research?

Researchers will apply to access our resource through the Health Data Research UK Gateway. Researchers will be able to submit an application to access this data for COVID-19 research. Requests will be reviewed and either approved or declined.

All researchers will need to be trained and approved by the Office for National Statistics before they are allowed to access data. All researchers will be bound by contract which includes clauses to maintain confidentiality and security of the data.

3. My study is taking part in the UK LLC, can I opt-out?

Yes. 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. They should contact their study directly and let them know. Study participants have the right to opt-out at any time.

4. What will the findings be used for?

The findings established by projects using this resource will be used by/for:

- The UK Scientific Advisory Group for Emergencies (SAGE). This is a committee of UK academics and NHS staff trying to understand COVID-19
- NHS and government planners who are developing strategies for how to manage the pandemic
- Scientific publications on COVID-related issues.

5. Who decides if a research project is relevant?

Our Data Access Committee and the data access committees of the studies taking part will decide whether or not the research project will be of public benefit and if data should be made available to the researcher in our trusted research environment. All of these committees have both lay and expert members.

6. Who controls the data?

We're part of the University of Bristol. They are the Data Controller for the information placed in our secure research database. Our full privacy document can be found here: <https://ukllc.ac.uk/privacy-policy/> and we have a Participant Notification Sheet for study participants available to read and download here: <https://ukllc.ac.uk/about/>

7. Can I be identified?

No, it is not likely that anyone will be identified from this.

All the data in the UK LLC is de-personalised. This means information such as name, address and NHS ID have been removed and replaced by a code ID number. Each study and the NHS will make sure that the data they provide is de-personalised before they send it. This will include checking and removing rare events which may accidentally identify someone.

Our data staff are trained specialists, bound by professional conduct and contractual obligation. They will manage the handling and protection of the data. Data will never leave the trusted research environment. Your data will always stay in the UK and be covered by UK data protection law.

In the very unlikely event that a research study volunteer is accidentally identified then we have policies to deal with this – the researcher will be legally bound to maintain your privacy in the same way as a doctor is for their patient.

8. Do you have access to everyone's data in the UK?

No. We only have access to COVID-19 relevant data connected to the study participants in the studies taking part in this project. If you're not a study participant of a study taking part, we will not have any data related to you.

9. Will this change study participants' health records and will GP's or doctors be informed about this?

No. This will not change anyone's health records or change any care they're receiving. GP's or doctors will not learn anything new about study participants. Findings established by projects using this resource will improve standards of care and contribute to future public health strategy.

10. What is 'administrative data' and why are you using it?

Administrative data are the records generated by government service providers as part of everyone's daily life – such as education, employment and tax and benefits records.

Some of this is very important to our COVID-19 research, as we know the pandemic has impacted on people's lives in very different ways. Being able to access data like this will allow us to answer questions such as:

- * do some types of jobs put certain people at greater risk of getting COVID-19 or not?
- * is the furlough scheme helping people financially during the pandemic and is it also helping with mental health?
- * what is the status of children's mental health as they return to school?

11. Is anyone making money out of this?

No. We're funded by the Medical Research Council as part of the COVID-19 Longitudinal Health & Wellbeing National Core Study. The Medical Research Council is funded by UK Government which is ultimately funded by taxpayers, as such we will always be transparent about who uses the data. No data used within our trusted research environment may be used for profit-making purposes.

12. Can commercial companies access the data and use it in scientific research?

In some cases, yes. Commercial companies can request access to data held within the UK LLC trusted research environment. The UK LLC Data Access Committee and the study's own data access committees will only approve requests where the company can demonstrate their research will be used for public benefit and not for profit making.

The commercial company will have to make commitments to publish their findings into the public domain as quickly as possible – so their findings can be used by anyone.

For those studies that don't currently provide data to commercial companies, taking part in the UK LLC will not change this (we will make sure this data is not used).

13. How will this work improve public health?

Researchers will be able find out more about the impact of the COVID-19 pandemic than was ever possible before. Longitudinal studies have lots of detailed information about study participants' lives before and following the pandemic. Having a 'before and after' picture will allow researchers to examine the broader impact on health and wellbeing due to lockdown measures and the disruption to our health, financial and social systems. Researchers' findings will provide insights and guidance for policy makers and support meaningful changes to public health practice.

14. Can data be accessed from researchers from other countries?

No. Data can only be accessed by researchers based within the UK.

15. Can anyone take part?

People can't sign up directly. We provide a research resource that brings together existing data to facilitate and enhance research possibilities, rather than a standalone study. A list of studies taking part is available here: <https://ukllc.ac.uk/about/>

16. Why are you collecting mental health data?

Mental health data is as important as physical health data, and both have been gathered together as part of the studies' COVID-19 questionnaires. The COVID-19 pandemic has had an influence on many aspects of peoples' lives, and it's vital to capture as much of the picture as possible.

17. What happens if you identify a study participant is at risk of cancer or an inherited genetic disease?

As the data we hold within our trusted research environment is de-personalised, it cannot be linked back to any individual. This means it's not possible to identify or report any such individual level detail back to any study participants.

18. What is a longitudinal study?

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. These groups of people are typically chosen due to a common factor, such as groups of pregnant women or people living in a particular area or a specific age range. This data can discover new information to improve and save lives.

19. What are you doing with address data?

We're using address data to give more context to the data for researchers studying COVID-19. For example, researchers will be able to study health data alongside environmental data about the area where people live and the local services they have available. This will include information such as whether people have access to parks and open spaces, air pollution levels and availability of broadband. Having this extra layer of data may point to how where people live has resulted in changes to their health and wellbeing compared to those in a different part of the country.

This data is all de-personalised and coded with an ID number to make sure no individual participants' addresses can be identified.

20. Will you be telling study participants how their data has helped research and about any findings that come out of this work?

Yes. We'll send regular updates to all the studies taking part in the project. We will send the latest information we have on how their data has been used and any research findings that are discovered. The studies will then include this news in their own communications eg newsletters, emails, social media accounts. We will also make this information available on the UK LLC website <https://ukllc.ac.uk> and on our Twitter and LinkedIn accounts.