

Children of the 90s & the UK Longitudinal Linkage Collaboration

Improving our knowledge and treatments for COVID-19 & Long-COVID

Information Sheet

(Version 1, 14/06/2021)

A new national project is being set up to support COVID-19 research. Data will be linked from many longitudinal population studies with health and administrative records. The purpose of this work is to support the ongoing response to the pandemic. The project is called the UK Longitudinal Linkage Collaboration. In this document we have shortened the name to UK LLC.

Many studies have agreed to take part in this project, including Children of the 90s. Children of the 90s and other studies have collected data during the pandemic. As well as COVID-19 questionnaire data, historical data will also be used in the UK LLC. This data is important to understand changes to pre-pandemic health and wellbeing as a result of the pandemic. It also allows researchers to understand how health conditions are associated with COVID-19. Some of these conditions, for example asthma or diabetes, may have been added to your health record a long time ago. The UK LLC will refresh records monthly to make sure we have the latest information. For example, on information about Long-COVID and with general health and vaccinations.

It is very helpful for researchers to see data from before the pandemic and compare it with data collected during the pandemic. This will help them understand how people have been affected in lots of different ways. And it will increase the ability to do high quality COVID-19 research. This project will provide a larger, more diverse sample of the UK population that a single study could deliver on its own. Children of the 90s researchers will benefit from being able to study this linked data which will be updated on a regular basis.

The UK LLC will link data from study participants with their health and administrative records. This will include occupation and education records. And will be done safely and securely. The data will be stored in a secure research system. A list of the studies taking part is available by emailing the UK LLC (project-infoukllc@bristol.ac.uk). It is also on the UK LLC website (www.ukllc.ac.uk).

If you do not want your data used in this way then you need to opt-out. This is described below. If you have already opted-out of Children of the 90s using your records in research then we respect that decision and will make sure your records are not used in the UK LLC either.

1. What Research Questions will it help answer?

The National Core Studies is designed to answer questions on all aspects of the COVID-19 crisis. This includes research on:

- i. the virus itself (such as why are some more likely to catch it, or be more ill than others? what symptoms do people have?);
- ii. how many people have Long COVID and what are the patterns of who has this and what form it takes?

- iii. what are the reasons people give for not getting vaccinated?
- iv. how has the pandemic has interrupted care for existing health conditions?
- v. how the pandemic has disrupted the reporting and seeking care for symptoms of new health conditions?

The research will investigate both mental and physical health. It will also investigate the associations between health, finances and housing resulting from lockdown. It will look to the future and consider how to help those whose lives have been heavily disrupted (such as school leavers and those who have lost their home during the pandemic).

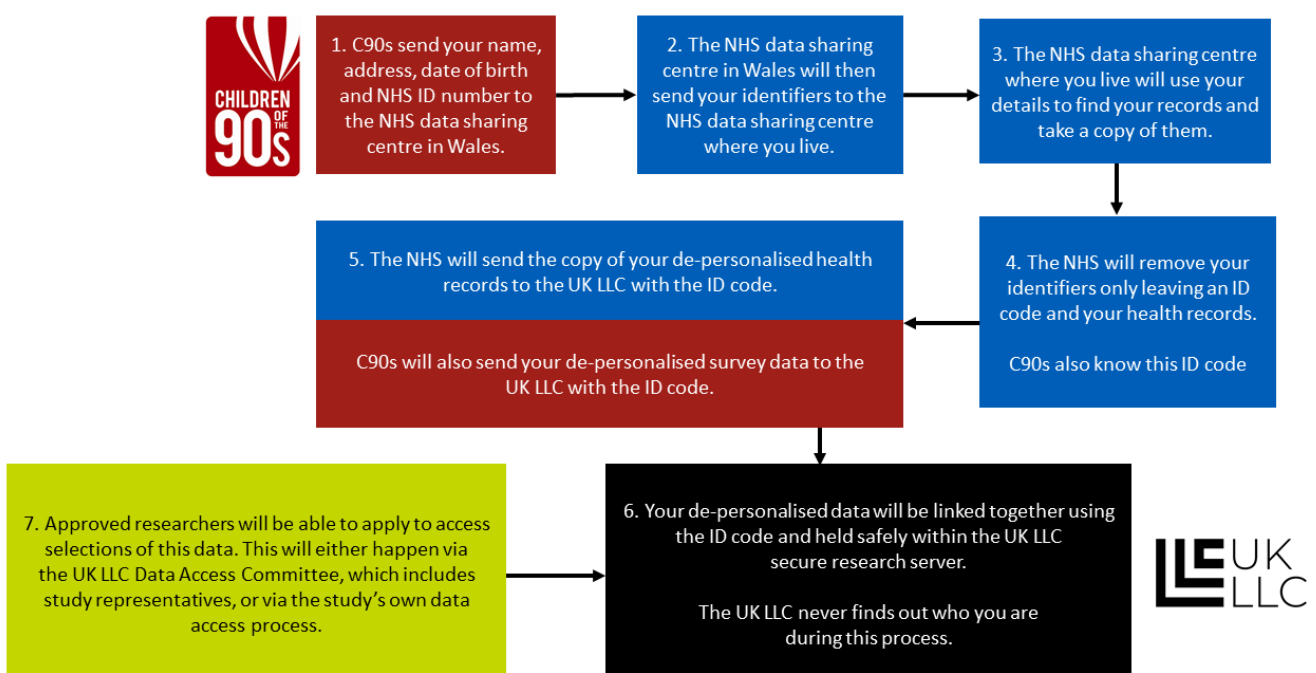
2. How will it work?

The UK LLC is run by the University of Bristol. The University of Edinburgh is a partner in the project. The University of Bristol has built and will maintain the UK LLC secure research database. The data will be safely stored in a secure research system at all times. This will be like a ‘reading library’ where approved users read the data but cannot remove or copy it.

All data will be de-personalised. This means your personal details will not be included in any data made available for research.

Research will take place within the secure research system. Only a summary of research findings are allowed to leave the system. All summaries are checked to make sure they cannot identify any one person. The risk of any individual being identified as a result of their data being part of the UK LLC is the same as the existing risk of being identified within Children of the 90s. **Your data remains in the UK at all times and is always covered by UK data protection laws and regulations and research ethics systems.**

Diagram 1 – how de-personalised Children of the 90s data is linked with de-personalised health records.



Key Points

- Your name and other identifiers are always kept separate from your data. The UK LLC never see your name and other identifiers.
- Your data will not be used for profit-making purposes. All research must be for public benefit.
- Your data remains in the UK at all times.
- Your data is always covered by UK data protection laws, regulations and research ethics systems.

3. The right to opt-out

If you do not wish your data to be included in the UK LLC **please let us know that you want to opt-out**. We will make a record of this on the Children of the 90s database. We will make sure your data is not uploaded into the UK LLC. This will not change your existing permissions for other parts of Children of the 90s. For example, where you have given consent for non-COVID-19 medical records to be used for research then this will still be the case.

4. More information about how we will use your data

What data will you be using?

Children of the 90s will select which data you have provided during the pandemic is relevant to COVID-19 research. This will include information on your health, social, economic and demographic status.

The types of information collected by Children of the 90s that will be used are:

- COVID-19 questionnaire data
- The results of COVID-19 tests collected by Children of the 90s
- Your physical and mental health status before and during the pandemic (e.g., if you had asthma, diabetes or were suffering from depression)
- Your social, economic and demographic status (e.g., your occupation, what qualifications you have, your gender and ethnicity)
- Information about your home (e.g., how many rooms there are, if you have a garden, who you share your home with)
- Your genetic information

The types of information collected from your records are:

- If you have had COVID-19 or not (from your GP records, hospital records, COVID-19 test databases), and what your symptoms are, and what treatment you received
- Data about COVID-19 vaccinations and past vaccinations
- Your physical and mental health status before and during the pandemic (e.g., if you had asthma, diabetes or were suffering from depression). Your historical records are needed as some information (e.g., if you have had a heart attack) is only recorded once at the time it happened.
- The reasons and way in which you sought help from the NHS before and during the pandemic
- Your occupation and details on employment, earnings and support during the pandemic (e.g., if you had furlough payments)

- Education records relating to exam results, attendance, special educational needs, ethnicity and language, and, support you may receive (such as free school meals)
- Information about where you live, but not your address or postcode (e.g., air and noise pollution data, what services are near you, if broadband is available)

The exact data used will depend on the priority questions being asked. These are likely to change as the pandemic continues and new challenges emerge. For example, it is likely there will be more questions about the impact of lockdown on education and schooling and children's wellbeing. These will increase the importance of using education data from Children of the 90s and linked education records. All new data will be assessed to make sure it is necessary for the research question and relates to COVID-19 research.

The Children of the 90s website will provide information on who is using Children of the 90s data in the UK LLC. The UK LLC website will also have information. This will include who researchers are employed by what is the purpose of the research which data they are using and what the outcomes of their research investigations are.

There is currently no linked data in the UK LLC secure research database as the project has not reached that point. This information will be available when linked data is ready for researchers to access. The website address is www.ukllc.ac.uk. You may request a copy of this information from project-infoukllc@bristol.ac.uk.

Will this change my health records, and will my GP or doctors find out anything about me?

No. This will not change your health records in any way. It will not change any care you are receiving. Your GP or doctors will not know you are part of Children of the 90s or learn anything new about you as a result of this.

The NHS will not gain copies of your Children of the 90s data from the UK LLC.

IMPORTANT: if you have COVID-19 or COVID-19 symptoms and are worried about this then please contact the relevant health services using the guidance given here:

<https://www.nhs.uk/conditions/coronavirus-covid-19/symptoms/>

How will the research happen?

Researchers can apply to use the data within the UK LLC secure research system. All applications to use Children of the 90s data will be reviewed by the Children of the 90s Executive in the standard way.

Researchers will be provided with a unique account and a secure working area. This is only available to the researcher and their team. The UK LLC data managers will provide researchers with the selection of data they have asked for. The researchers will carry out their work inside the UK LLC secure research system. When the researchers have their results, they will ask for these to be sent to them. This is to allow them to publish their findings. And to feed back to the NHS and government to inform health policy. The findings will show patterns across large groups of people. Your individual level data does not leave the UK LLC system unless it is being provided back to Children of the 90s.

How do you make sure this is secure?

Security is maintained in several ways:

- The data is de-personalised. De-personalised data is information that does not identify an individual. Identifiers such as name and address will have been removed and other potentially identifiable information (such as job title) changed.
- Data use and researchers are bound by legal contracts. Everyone working in the system is trained to a high professional standard.
- Only anonymous data is allowed to leave the system.
- Children of the 90s data experts and independent auditors will review the UK LLC to make sure your rights are being upheld. These auditors work for independent audit companies – such as the British Standards Institution who manage ISO27001 auditing – and also the NHS agencies who are responsible for sharing data with researchers.

Which researchers will be doing this work?

Approved UK-based researchers will be doing this work. They will be researchers from the National Core Studies for COVID-19 and from UK universities. They may also be researchers based in government departments or working for commercial companies who are conducting public benefit research which is not profit making. Researchers must be 'Approved Researchers' vetted by the Office for National Statistics. This process includes checks to ensure they are appropriately qualified. They will also receive training to understand data protection and security requirements.

What will the findings be used for?

The findings of this project 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.
- GPs and doctors wanting to understand more about COVID-19.
- Publications in scientific journals to help with COVID-19 research and planning globally.

WHAT YOU NEED TO DO NOW

Please do get in touch using the contact details below if you have questions about this process.

If **you are happy** for your de-personalised data to be used in this way then you do not need to do anything.

If **you do not want** your data used in this way then you must let us know, otherwise **we will** include your data in the UK LLC.

If **you have previously told us that you don't want** your health and administrative records used in C90s research then we will make sure your health and administrative records are not used in the UK LLC either.