

Supplementary Participant Information Sheet: Data

Children Growing Up in Liverpool Longitudinal Birth Cohort

This is a supplementary information sheet to provide more information about the data that will be used as part of the Children Growing Up in Liverpool (C-GULL) Study. Before you decide whether or not to take part it is important for you to understand what type of data we will collect and why. Please take the time to read the following information carefully and discuss it with others if you wish. A member of our research team will be happy to go through the study information with you and answer any questions you may have.

Thank you for reading this.

What types of data will this study use?

Data will be generated in the study in a number of ways. Some of these are listed below:

- C-GULL Study participants and their partners (where applicable) will be asked to complete questionnaires,
- Research Midwives will ask participants about various areas of their life, for example, your pregnancy and your child's development, and
- samples will be tested and analysed, and the results recorded.

This data will only be collected once you have agreed to take part and given full consent. This data will then be held with a unique personal identification number - which means none of your personal information (such as your name, date of birth or address) will be directly linked to it. Some members of the research team will be able to see your personal information as they will need to contact you and speak with you about the study. These individuals will have strict training to make sure that they manage your data with care and in line with your rights.

Other researchers will have access to your anonymised data so that they can use the information the C-GULL Study collects to better understand the factors that can improve the lives and health outcomes of the children (and their families) within our city. Your name and address or any other personal details will never be passed to these individuals - they will not be able to find out whose information they are using or from whom a sample has been taken. These researchers may work for a UK university, the NHS, or for commercial companies (such as those researching new treatments or diagnostic tests). All researchers will need to be approved by the C-GULL Study to ensure that the research being carried out is safe, relevant, and ethical.

The C-GULL Study **will NOT**

- sell your information to anyone,
- pass on your personal information to insurance companies or employers,
- allow access to your personal information to the police, the government, security services, relatives or lawyers (unless legally enforced to do so by the courts), or
- allow researchers to access data without C-GULL Study approval and relevant training in the secure use of data.

What is linked data and why are you using it?

Routine records are maintained by organisations such as the NHS, education and other government departments. We would like your permission to collect some of the information held in these records about you or your baby so we can understand how health and other important life events are related. This is called 'data linkage' because we link one type of information (e.g., C-GULL Study data) to another (e.g., healthcare records).

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Using linked data allows us to look for trends that will help us identify ways to improve the lives of the children (and their families) within our city. We will use the data to answer questions such as 'Why do some of our children develop asthma and others do not?' or 'What can we do to reduce the risk of babies developing food allergies in the first 12 months of life?'

If you take part in the C-GULL Study you will be asked to sign a consent form. Part of this consent form sets out the types of routine records from which we would like to request information. We will never give any of the information you provide as part of the C-GULL Study to the organisations that hold these records. We will only give them some essential personal details so we can be sure that they find the correct records to provide the information that has been requested. For the first 2 years of your child's life we will only be using NHS / healthcare linked data. However, to allow us to look for trends as the children in the study grow up, other datasets will be used in the future.

What about my child's data?

We will ask for permission to access information from your child's routine records in the same way as we ask for permission to access your information. We can only ask for information from a child's records if we have consent from a parent or legal guardian. Some examples of information from your baby's records that we would like to request are:

- Birth information (including information from any admissions to special or intensive care if your baby has needed this care),
- Child health records (which record your baby's development checks and immunisations),
- Screening test results (such as the newborn hearing test), and
- School information (once they start attending school).

Do I need to agree to Data Linkage?

We will ask you to agree to obtaining some information from your routine NHS, healthcare and birth records as without this permission we cannot, for example, find out about your baby's birth, or trace you and your baby as you both grow older. **If you do not wish to agree to this linkage, then you will not be able to take part in the C-GULL Study.**

Social care, education and economic information can help us understand more about the different things that can impact children's growth and development but these are optional. We would like to have your permission to request this information but you can still take part in the C-GULL Study if you choose not to let us use information from all the records suggested. On the consent form, you will be asked to indicate which records you will allow us to request information from.

Can I change my mind?

Yes. If you decide that you no longer want us to request some or all of the linked data about you or your child / children then you can contact us and request this. You do not need to give a reason. We will continue using your information until you tell us that you wish to withdraw your consent.

Keeping your information safe

Keeping your information safe is very important to us - we are and will continue to be extremely careful in ensuring that we keep your data safe and maintain your confidentiality.

Only members of the research team who need to contact you to manage appointments or the clinical team (Research Midwives / Practitioners) who you meet in the research centre at Liverpool Women's Hospital or one of our community centres will know your name and contact details. Linked data and samples will be stored separately from your personal

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details to protect your identity. Researchers who see linked data, samples and questionnaire results will not have access to your identity; they will not know your name or contact details.

All of your information will be stored securely. We use a number of methods, such as encryption and secure computer systems, to prevent unauthorised access to your personal information. Precautions will be taken to prevent unauthorised access and we do not expect this to ever happen. However, even in the extremely unlikely event of unauthorised access, you could not be directly identified. This is because when we collect your information or obtain further information from records we remove your personal details and replace them with a unique participant code.

Examples of Linked Data

Type of Data	Why do we need the data?	Where do we get it from?	What data do we ask for?	What sort of questions will this help C-Gull researchers answer?
Maternity & Birth	We need to be able to record the birth of your child / children in the study. We also want to understand how a child's health is affected by pregnancy and birth.	Liverpool Women's Hospital	- Maternal measurements such as blood pressure and weight - Admissions and attendance at hospital - Prescriptions and treatment. - Health status, and records of specific conditions such as diabetes - Birth time, date, weight and other measurements taken at birth	Are there any factors in pregnancy that make a child more likely to develop diabetes in early childhood?
Health	We want to be able to understand how your health and your child's health is affected by other factors and how this impacts on health and wellbeing of your child / children	Routine medical and other health records: - NHS - GPs or family doctor - Other healthcare providers such as dentists or opticians - NHS Registrations Records - Public birth and death registrations - Health related records held by the UK Department of Health - Other health related registers, such as national cancer registers	- Visits to your GP or other health professional - Admissions or attendances at hospital - Prescriptions and treatments - Health status and specific medical conditions, such as diabetes.	Does childhood exposure to Covid-19 have any impact on child development?

Do I have to agree to everything?

No. If you feel uncomfortable about answering some questions or providing a certain type of information then you do not need to do so. We do however need you to agree to us getting some information from your routine NHS and healthcare records, and to using birth and healthcare records to know when your baby is born. If you do not wish to agree to this, then you will not be able to join the C-GULL Study.

Where can I find further information?

If you have questions or want to know more about the data collected as part of the study, please talk to the C-GULL Research team at Liverpool Women's Hospital. Please contact us on cgullstudy@liverpool.ac.uk or 0151 795 6700. You can also visit our website cgullstudy.com. We're here to help and make sure you and your baby have the best experience.

Thank you for taking the time to read and consider this information sheet.