

Study of hospital admissions in early-years of life (maternity-baby data study)

Privacy Notice

This research is part of the Population Policy and Practice programme, at the University College London (UCL) Great Ormond Street Institute of Child Health (ICH), in collaboration with the Clinical Effectiveness Unit and the Royal College of Surgeons of England (RCS). It uses information collected from administrative sources to conduct research in order to understand the health of children and their families.

It is led by Dr Katie Harron and funded by Wellcome Trust.

1.1 What is this Privacy Notice about?

This privacy notice outlines the purpose of the research and explains how we will collect and use the data for this study. It also describes how to get further information and what to do if you (or your child) do not want to be part of the study.

You have the right to access any personal information held about you, to have your information processed fairly and lawfully and the right to privacy. These rights are upheld by law and outlined in the [Data Protection Act 1998](#).

1.2 What is this study about?

We are using NHS hospital data to describe the use of hospital services by young children and how this might be linked to the health of a child's mother during and prior to pregnancy. The study aims to provide a better understanding of how the health of the mother and child are inter-related, and help inform improvements to maternity services and child health. We have some understanding about how a child's health is linked to the circumstances of the mother during pregnancy. For example, mothers who smoke during pregnancy are more likely to give birth to smaller babies. These circumstances may also influence how often children are admitted to hospital. This study is looking at this issue using hospital data that are routinely collected within the NHS. This avoids the time and cost involved with collecting new data on large numbers of people. It also allows information on maternal and baby healthcare records to be brought together. At present, healthcare information for mothers and babies is not routinely linked and there is a lack of information on which maternal factors are most important.

1.3 What is the lawful basis for using this information?

The legal basis for this study falls under Article 6(1)(f) of the GDPR, i.e. the "legitimate interests" of healthcare research. This is because the data processing described here is to support scientific and statistical research. The processing also falls under Article 9(2)(j):

"processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes".

1.4. What information will we collect about you (or your child) for the study?

We will use hospital data for mothers and babies that are collected by the National Health Service for births between 01 April 2001 and 31 March 2013. We will also use information on deaths, collected by the Office for National Statistics.

NHS Hospital Episode Statistics are made available by NHS Digital, and include the following personal data:

- Clinical/Management information such as the type of hospital admission – planned/unplanned, speciality of treatment, length of time spent in hospital, the reason for hospital admission (diagnosis);
- Geographical information such as hospital, local authority.

Hospital and mortality data will be de-identified before it is transferred to the research team. This means that personal identifiers will be removed. However, we will use some personal sensitive data. We will use baby's date of birth, so that length of stay in hospital after birth, and time to subsequent readmission can be calculated. We will also use date of death, as it is important to take deaths into account as an important outcome measure within these analyses. Once these variables have been derived, date of birth and date of death will be deleted from the data. It will not be possible to identify any individual within the data.

Detailed lists of the management information collected in hospital may be found [here](#) (See 'Data elements').

1.5. How will the information be used?

We are using NHS hospital data to describe the use of hospital services by young children and how this might be linked to the health of a child's mother during and prior to pregnancy. The study aims to provide a better understanding of how the health of the mother and child are inter-related, and help inform improvements to maternity services and child health.

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To date, we have published three papers for this study:

1. Harron K, Gilbert R, Cromwell D, et al. Linking data for mothers and babies in de-identified electronic health data. *PLoS One* 2016;11:e0164667.
2. Harron K, Gilbert R, Cromwell D, et al. International comparison of emergency hospital use for infants: data linkage cohort study in Canada and England. *BMJ Qual Saf* 2018;27:31–9.
3. Harron K, Gilbert R, Cromwell D, et al. (2017) Newborn length of stay and risk of readmission. *Paediatr Perinat Epidemiol* 31:221–32.

Further outputs of the analysis, in the form of aggregate data with small numbers suppressed, will be submitted for publication in peer-review journals and presented at national and international conferences. Results will be disseminated to healthcare professionals, NHS managers, commissioners and policy makers. The study team is also closely linked with ongoing maternity service evaluation conducted by the Royal College of Obstetricians (RCOG). The RCOG set standards for clinical practice, publish clinical guidelines and patient information leaflets, contribute to policy development, and advise the government and other public bodies on healthcare matters.

Data in this study will not be used for marketing purposes, shared with or transferred to any third parties. The data provided to the team for research will not be transferred to other countries.

1.6. Where will the data be stored and how long will it be retained?

Data will be stored on the secure server at the Royal College of Surgeons (RCS). The RCS is a registered data processor under the terms of the Data Protection Act 1998 (ICO Data Protection Registration: Z5948910. See link: [Information Commissioners Office](#)).

The research team have permission to keep the data until December 2019

1.7 Access to your (or your child's) information in the study?

It will not be possible to access your study data from the research team data because all the personal information will be removed. Due to this, the right to request access to and rectification or erasure of your personal data, or restriction of processing of personal data, and the right to data portability, is restricted.

1.8 What if I do not want my data (or child's data) to be used in this study?

The research team will not be able to identify you and cannot remove your records from the study directly at your request.

You have the right to tell NHS Digital if you do not want the information you provide to the NHS to be used beyond the purpose of providing healthcare. This is known as a 'patient objection'. Please visit NHS Digital's website for further details: <https://www.nhs.uk/your-nhs-data-matters/manage-your-choice/>.

Your choice will not affect the health care you receive.

1.9 How do I contact the Research team (or Data Controller)?

If you have questions or concerns about the study please contact Dr Katie Harron:

Dr Katie Harron
UCL Great Ormond Street Institute of Child Health
30 Guilford Street
London. WC1N 1EH
Email: k.harron@ucl.ac.uk
Telephone: 02079052101

RCS is the Data Controller for this study, and the clinical effectiveness unit can be contacted at ceu@rsceng.ac.uk. If you have any questions about how RCS uses personal data, you can contact their Data Protection Officer: dpo@rsceng.ac.uk.

You also have the right to complain directly to the [Information Commissioner's Office](#), which is an independent regulatory authority set up to uphold information rights.

Additional information/links:

Information Commissioner's Office www.ico.gov.uk

Hospital Episode Statistics <http://content.digital.nhs.uk/hes>