

Investigating differences in gender mortality for children admitted to UK critical care units

Privacy Notice

This research is part of a Doctoral Research Fellowship at the Population Policy and Practice programme, at the University College London (UCL) Great Ormond Street Institute of Child Health (ICH). It uses information collected from administrative sources to conduct research in order to understand the impact of critical illness on children.

This project is a collaboration between ICH, Great Ormond Street Hospital, St Mary's Hospital London Paediatric Critical Care Unit, and Paediatric Intensive Care Audit Network (PICANet).

It is led by Mrs Ofran Almosawi and funded by the National Institute of Health Research.

1.1 What is this Privacy Notice about?

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

Every year more than 20,000 children are admitted to PICUs in the UK. Previous small studies have showed that baby girls may have higher mortality rates than baby boys in PICU. In 2017 we completed an analysis of all babies (0-12 months old) who were admitted to PICUs over an 11-year period. We obtained anonymous records for 68,000 babies and compared the rates of death between girls and boys during their admission to PICU. We discovered that girls had higher death rates than boys. This is different to what is seen in the general population where boys have higher death rates than girls for children of all ages. We carefully examined whether this difference could be due to differences in age, disease severity, infections, and a number of other factors. None of the factors could explain why girls died more than boys in PICU. We now want to examine these findings in greater detail as this could have implications for the care of critically ill children generally.

1.3 What is the lawful basis for using this information?

The lawful basis for using information collected routinely for administrative purposes for research is the 'public task'. This is part of the University's commitment to 'integrate research and innovation for the long-term benefit of humanity'.

The public task basis may be found in Article 6(1)(e) of the General Data Protection Regulation, which states:

"Processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller"

The processing also falls under Article 9(2)(j), which states:

"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 not be collecting any new information, just used routinely collected data. We will select all children who were admitted to a Paediatric Critical Care Unit (PICU) in the UK between 01 January 2010 and 31 December 2019. PICU data is collected for any child admitted to PICU nationally as part of the PICANet project. We will also use hospital data for mothers and babies that are collected by the National Health Service for births, and information on deaths, collected by the Office for National Statistics for the same period.

PICU admissions are available from PICANet and include the following personal data:

- Reason for admission, length of stay in PICU, severity of illness on admission, any treatments received during the course of admission

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

- For mothers: Clinical/Management information such as birth type if emergency/planned, length of time spent in hospital, any complications at birth, any medical condition during pregnancy or complications during the course of pregnancy, mother's age, baby's birth weight, gestational age
- For children: reason for admission to PICU, length of stay in PICU, for any deaths in PICU – cause of death
- Geographical information such as hospital, local authority.

Hospital, PICANet and mortality data will be de-identified before it is transferred to the research team. This means that personal identifiers will be removed. We will use date of death, as it is important to take deaths into account as an important outcome measure within these analyses. It will not be possible to identify any individual within the data.

1.5. How will the information be used?

We will use electronic records that are routinely collected as part of health services to compare the risk of mortality between girls and boys. We will look at a range of health outcomes for children and their mothers to identify any reasons for differences in mortality in PICU. Researchers will only access anonymised data and will not be able to identify any individuals from the data.

Finding out whether what causes the differences in mortality between girls and boys will help improve targeting of resources and highlight groups in need of alternative support. Findings from the study will help policy-makers decide whether a risk of death scoring based on gender will help improve outcomes for children who are admitted to PICU. Evidence generated by this study will support commissioners in providing improved services for children who could benefit most, and lead to increased efficiency through more effective targeting of resources. It could potentially identify risk factors for mothers that impact on a child's outcome in PICU.

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 disseminated to healthcare professionals, NHS managers, commissioners and policy makers.

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?

The study data will be transferred to the University research team in an encrypted form ('scrambled'), where it will be securely stored in the UCL Data Safe Haven. The UCL Data Safe Haven, is a registered data processor under the terms of the Data Protection Act 1998 (ICO Data Protection Registration: Z6364106. See link: Information Commissioners <https://ico.org.uk/ESDWebPages/Entry/Z6364106>).

The research team will request permission through the ethics committee to keep the data until December 2023. It 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.

1.7 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 'opting out'. Please visit NHS Digital's website for further details: <https://digital.nhs.uk/about-nhs-digital/our-work/keeping-patient-data-safe/how-we-look-after-your-health-and-care-information/your-information-choices/opting-out-of-sharing-your-confidential-patient-information>

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 Ofran Almassawi or the data controller Dr Katie Harron:

Ofran Almassawi, PhD student
UCL Great Ormond Street Institute of Child Health
30 Guilford Street
London. WC1N 1EH
Email: o.almossawi@ucl.ac.uk
Telephone:

Dr Katie Harron (Data Controller, and PhD Supervisor)
UCL Great Ormond Street Institute of Child Health
30 Guilford Street
London. WC1N 1EH
Email: k.harron@ucl.ac.uk
Telephone: 02079052101

You may also contact the UCL Data Protection Officer:
Lee Shailer
Data Protection and Freedom of Information (FOI) Officer
University College London
Legal Services
6th Floor
1-19 Torrington Place
Email: l.shailer@ucl.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>

PICANet
<https://www.picanet.org.uk/>