

The LAUNCHES QI project Study Privacy Notice

What is the LAUNCHES Study?

LAUNCHES QI (Linking AUdit and National datasets in Congenital HEart Services for Quality Improvement) is a research study. It is funded by the charity the Health Foundation (ID: 685009). The Chief Investigators are Professor Christina Pagel and Dr Sonya Crowe and the study sponsor is University College London (UCL).

The LAUNCHES Study at the Clinical Operational Research Unit (CORU), University College London respects your privacy and is committed to protecting your personal data. Please read this privacy notice carefully – it describes the de-identified data that each data source will provide to us and information about your rights.

What information is being used?

We are not collecting any new data as part of the study. We are using data already collected routinely across England and Wales to understand better the quality of services that the NHS provides to people born with Congenital Heart Disease.

The National Congenital Heart Disease Audit (NCHDA) has collected information on every heart procedure performed on children and adults with congenital heart disease in the UK since 2000. We will use the NCHDA database (source NICOR, controller HQIP) to understand better what happened to patients by seeing if there are records for NCHDA patients treated in England that appear in four other national, routinely collected, datasets:

1. The Paediatric Intensive Care Audit Network (PICANet) (contains data on children's stays in intensive care), data source PICANet, controller HQIP.
2. The Intensive Care National Audit and Research Centre Case Mix Programme (ICNARC-CMP) (contains data on adults' stays in intensive care), data source: ICNARC.
3. Hospital Episode Statistics (HES) (contains data on A&E visits, general hospitals stays and specialist outpatient appointments), data source: NHS Digital.
4. Office of National Statistics Death Registrations (ONS) (lets us know if someone has died), data source: NHS Digital.

PICANet, ICNARC and NHS Digital will receive personal identifiable data for any patients who appear in the National Congenital Heart Disease Audit (NCHDA) (i.e. people who have at least one procedure to treat congenital heart disease) and identify records relating to their treatment in their database. Each data source will destroy the personal data received by October 2019.

UCL researchers will then receive clinical data from each data source relating to matched patients with personal information stripped out and replaced with an ID number, this is known as pseudonymised data. That means that UCL researchers will not have access to names, addresses, dates of birth or treatment, or any hospital or NHS numbers. This clinical data is held at University College London's secure Data Environment, Gower Street, London WC1E 6BT. University College London are the data controller for this dataset.

Why are we using this data?

Services for congenital heart disease span a patient's lifetime, but at the moment their quality is mainly measured by 30-day survival following children's heart surgery – we urgently need a more comprehensive and meaningful picture of services so that we can continue to improve both services and the information available to patients and their families.

By linking these national datasets we will produce the first comprehensive understanding of care received by people living with CHD from birth to adulthood, whether there are variations in care across England and where there is most scope to improve care.

Please note that our study does not use automated decision profiling in any way.

How will this data be stored, for how long and who has access to it?

The data will be stored in UCL's bespoke "Safe Haven" which has been certified to meet all NHS information security and governance standards. This will prevent your personal data from being accidentally lost, used or accessed in an unauthorized way, altered or disclosed. We have established procedures to deal with any suspected personal data breach and will notify you and any applicable regulator of a breach where we are legally required to do so.

Only researchers agreed with national bodies, named on legal data sharing agreements and with a legitimate need to see it for the purpose of carrying out their job, will have access to the data. All research data will be published only in aggregated and anonymised form.

The LAUNCHES study runs until January 2021 and the research data will be stored at UCL for a further 3 years to give the researcher's time to make the overall results public, before being securely deleted.

We will not transfer any personal data outside of the European Economic Area (EEA).

What is our legal basis for using your data?

Data Protection Legislation requires that we meet certain conditions before we are allowed to use your data in the manner described in this notice. Our agreed basis is known as 'Public Task', where the use of your data is necessary for the performance of a task carried out in the public interest.

What if I don't want information about me or the child you care for to be used for the LAUNCHES study?

If you do not want information relating to you or the child you care for to be included in the LAUNCHES research data, please contact NICOR by telephone or email (details provided below) and we will ensure that your information is removed from the LAUNCHES study data (NICOR will let UCL know which data they need to delete). You are free to request this at any time and any decision request removal of your or your child's identifiers will not alter the care you receive in this or any other hospital. You also have the right to request access to and to request to rectify information held about you or the child you care for.

You can find further information about your rights in UCL's privacy notice: https://www.ucl.ac.uk/legal-services/sites/legal-services/files/ucl_general_research_participant_privacy_notice_v1.pdf

NICOR Chief Operating Officer

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Data Protection Officer University College London (Please note we will not hold your personal identifiers so we advise making contact via the information above in the first instance).

Data Protection & Freedom of Information Officer
University College London
Gower Street
London
WC1E 6BT

Data-protection@ucl.ac.uk

You also have the right to lodge a complaint with the Information Commissioner's Office (**ICO**) (the UK data protection regulator). For further information on your rights and how to complain to the ICO, please refer to the [ICO website](#).

