

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 data source PICANet, controller HQIP.
2. The Intensive Care National Audit and Research Centre Case Mix Programme (ICNARC-CMP) (contains data , 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 , Gower Street, London WC1E 6BT.

