The Long term outcome by cardiac diagnosis (LTO) Study Privacy Notice

What is the LTO Study?

The Long term outcome by cardiac diagnosis (LTO) project is a research study. It is funded by the British Heart Foundation (BHF Project Grant no. PG/17/88/33401). The Chief Investigator is Dr Katherine Brown and the study sponsor is University College London (UCL).

What is the study about?

We will use the information that has been collected each time a child had a heart operation in England and Wales between 2000 and 2018, to work out how many children born with more complex heart defects survive longer term. Data are always collected as part of a quality check process when children have surgery, but up until now have only been used to assess short term mortality rates. We will work out the proportion of children with more complicated heart defects that survive until primary and secondary school ages as well as the proportion of children who have additional operations that were not planned as part of their expected treatment during childhood. We will find out whether children who are less well off or are from certain ethnic minority communities do worse than others. We will find out whether getting a defect diagnosed before birth or whether being treated at a hospital that cares for larger numbers of similar types of patient helps children do better.

What information is being used?

We are not collecting any new data as part of the study. We are using routinely collected audit data from England and Wales. This data has already been sent by hospitals treating children with heart disease, to the organization that runs the national audit.

The organization that runs the national audit called the National Congenital Heart Disease Audit (NCHDA) is the National Institute for Cardiovascular Outcomes Research (NICOR). This audit has collected information on every heart procedure performed on children and adults with congenital heart disease since 2000. As well as this audit data on heart procedures, the research team will need to use information from the Office of National Statistics (ONS) Death Registrations held by NHS Digital. This information will confirm if someone who had a heart procedure has died.

NHCDA will share patient’s personal data (including name, NHS number, date of birth) with NHS Digital in order to check this for each of the patients in the dataset. The personal data will be held for this purpose by NHS Digital and the National audit until July 2022 then it will be destroyed. The personal data will not be given to the research team.

UCL researchers will receive clinical data from the national body with personal information stripped out. That means that UCL researchers will not have access to names, addresses, dates of birth or treatment, or any hospital or NHS numbers. The researchers will not know who the patients are or the places where they were treated. The UCL researchers will receive data about any of the children who have died from NHS Digital, also with the personal identifiers stripped out. Combined together these two datasets (clinical and mortality information), neither of which contains identifiers, makes up the research dataset for this study.

Why are we using this data?

We are using this research dataset because we wish to know more about what happens to children who have had a heart operation as they grow up. Knowing more about this could help us to plan the services for these children in a better way.

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

The research dataset will be stored in UCL’s bespoke “Data Safe Haven” which has been certified to meet all NHS security and governance standards: this means that the data stored and used in the Data Safe Haven are very safe. Only a small number of trained researchers will have access to the research dataset. When any findings from the research are being shared care will be taken to ensure that no patient can be identified, for example rare conditions will be reported in groups.

The LTO study runs until July 2022 and the research dataset will be stored at UCL for a further 3 years to give the researchers time to make the overall results public, before being securely deleted. The data will at all times be held subject to the necessary data sharing agreements with the data providers.

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

What is our legal basis for using this data?

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

What if you object to your data being used for the LTO study?

We will not use any data relating to a child’s treatment if the child or their family don’t wish us to. Anyone can ask for their data to be removed from the study or for their data to be processed in a restricted way by writing us before 31st June 2020 to:

James Chal
Chief Operating Officer
National Institute for Cardiovascular Outcomes Research (NICOR)
Barts Health NHS Trust
2nd Floor, 1 St Martin’s Le Grand
LONDON EC1A 4NP

Tel: 0203 765 8539

Data Protection Officer
Derek Peacock
Barts Health NHS Trust
3rd Floor
9 Prescot Street
Aldgate
London
Post Code E1 8PR

bartshealth.nicor-generalenquiries@nhs.net

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.