

Long-term morbidity of children with specific congenital anomalies

Summary for EUROLinkCAT WP4 studies

Who are we?

EUROLinkCAT is a project funded by the European Union Horizon 2020 research and innovation programme. This project lasts five years (2017-2021) and brings together researchers from hospitals, public health institutions and universities throughout the European Union to look at the health and educational outcomes of children born with congenital anomalies.

What is meant by “long-term morbidity?”

Morbidity is a term used to describe the amount of ill health in the population. This research is looking at the occurrence of illnesses in children born with a congenital anomaly (birth defect) during the first ten years of life.

What is known and what is unknown?

We know that:

- Children born with a congenital anomaly may spend more days in hospital, may have more infections, and have more surgeries performed compared to other children.
- Improvements in health care services, treatment options, surgery, and diagnosis of congenital anomalies during pregnancy and in early life may reduce the risk of complications.
- Many children with congenital anomalies are living longer.

However, we do not know why the health outcomes of children with congenital anomalies are different between European countries and between hospitals. In some hospitals, children with congenital anomalies may have more operations, may spend more days in intensive care, and may have a higher risk of infections (measured by the use of antibiotics to treat the infections). As these children now live longer, more knowledge is needed about how being born with a congenital anomaly affects their long-term health and treatment. For instance, researchers may be able to see if there is a higher risk of developing diseases such as asthma, diabetes, epilepsy or heart disease when a child has been born with a particular congenital anomaly, by analysing the medications prescribed to these children.

What are we trying to do?

This part of the EUROLinkCAT project will look at:

- 1) The number of children (with or without a congenital anomaly) with ill health during their first 10 years of life and how it is treated

- 2) Why some children have a higher risk of ill health compared to other children
- 3) Effect of diagnosing the congenital anomaly before birth on the health and treatment options
- 4) Cost of hospitalisation
- 5) Number of prescriptions issued for asthma, diabetes, epilepsy, heart disease, and infections in children with and without congenital anomalies

How are we going to do this?

To answer these questions, 17 European congenital anomaly registries (* listed below) that are part of the European Surveillance of Congenital Anomalies (EUROCAT), will link their data on children born with congenital anomalies to their region's health care databases. Their health information (for example, the type and number of medications used or the number of days spent in the hospital) will be compared to the health information of children of the same age in the same region who do not have a congenital anomaly (known as a "control" group).

What do we need to do next?

We have proposed a detailed research protocol that each registry will use for their ethics application. In this protocol, we described our study's aim and objectives, what data the registries will need to obtain, the details of the procedure and data quality checking, and the analyses that the registers will do. We also described the procedures for the safe handling, storage and destruction of the data at the end of the project to ensure that no information on individual children will be released. The registries will now seek approval to link the health and treatment data with their registry data. When this approval is granted, the registries can go ahead with the data linkage which will provide linked data for the analysis. The results will be shared with parents and families of children with congenital anomalies and all those involved in their care and treatment.

What useful information do we expect to obtain as a result of this project?

This study will provide information for parents and families of children born with these conditions, health professionals and policy makers on the treatment and health as well as the complications. We will also investigate whether there are any inequalities in treatment or whether certain factors, such as geographical location, timing of surgery and preterm birth, influence health outcomes.

* Croatia: Zagreb; Denmark: Odense; Finland, France: Ile de la Reunion; Italy: Emilia Romagna; Italy: Tuscany; Netherlands: Northern Netherlands; Portugal: South; Spain: Basque Country; Spain: Valencia; UK: East Midlands; UK: North; UK: South West; UK: South Valley; UK: Wales; UK: Wessex; Ukraine: West. Four registries (Croatia: Zagreb; France: Ile de la Reunion; Portugal: South; Ukraine: West) will not take part in the study looking at prescriptions.