

**EUROlinkCAT Work Package 5 Education**

**Summary of the protocol for submission for ethics approval**

***Who are we?***

EUROlinkCAT is a project funded by the European Union Horizon 2020 research and innovation programme. It will last for five years (2017-2021) and will bring together different sources of information about the lives of children born with congenital anomalies (also known as birth defects).

***What are we trying to do?***

This part of the EUROlinkCAT project seeks to find out how children with a congenital anomaly are getting on at school and if they have any unmet educational needs. Currently, we do not know much about the education of children born with a range of congenital anomalies. We are also going to explore if there is an association between educational achievements and clinical and/or sociodemographic factors and if there are any geographical differences in Europe.

***How are we going to find the answers?***

This project will analyse the school achievements of children with a range of different congenital anomalies up to and including the school year when the child turns 16 years and whether the child has any special education needs. We will link data from European registries of congenital anomalies that are part of the European Surveillance of Congenital Anomalies (EUROCAT) network, to data on education from each of the participating regions. This study will also use some other information collected for the EUROlinkCAT project, for example, on factors such as stays in hospital, days in intensive care, surgery. Educational data for children with congenital anomalies will be compared with that for children of similar age and geographical area born without congenital anomalies (controls).

***Who will take part?***

Eleven registries [Finland, Denmark: Odense, Norway, two Italian registries (Tuscany and Emilia Romagna), five English registries and Wales] plan to take part in this study.

***What have we done?***

We have prepared a detailed research protocol that each registry will use for their ethics application. We have described what is currently known from previous studies, what we plan to do, what data we will use and how the data will be analysed. We have 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 is released.

***What happens next?***

The registries will now seek approval to link the education 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. A detailed analysis plan and the detailed instructions for the local analyses will be prepared for the registries. Only combined data and the summarised results will be sent to the research team for further analyses of combined data. No information on individual children will be released.

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

Information about how children with specific congenital anomalies get on at school will be published. These results will increase knowledge on the educational achievements and needs of these children. We will work with the EUROlinkCAT Action Advisory Panel to ensure that the best ways to implement relevant findings and translate them into policy across Europe are found.