

**Lay summary**

**WP5 Survey Report on Availability of Education Data in European Regions**

***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 needs. Currently we do not know much about this for many congenital anomalies.

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

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. Before we start linking this data, we needed to find out in which regions information on education for children with a congenital anomaly is available and how this data can be accessed by surveying all 21 registries taking part in EUROlinkCAT. This survey asked a number of questions on the type of education data collected and whether the data could be used for research.

***What are the results of the survey?***

The registry leaders from all the 21 registries\* completed the survey.

The registries reported that children start school from 4-5 years (UK) to 7 years (Finland) of age, and this is also the case for children with a congenital anomaly.

The timing for children to take first official tests or exams varied in the different European regions, from 6-7 years (UK, Spain: Valencia) to 18 years for a high school diploma (Finland, Croatia: Zagreb).

Children with a congenital anomaly also have to take the exams if they attend mainstream school.

Ten registries (two Italian registries (Tuscany and Emilia Romagna), Finland, Denmark: Odense, five English registries and Wales) are able to take part in the study which will link the data.

***What happens next?***

We will now seek approval to link the education data from the ten registries.

***What will we do with the linked data?***

No information on individual children will be released – information about how groups of children with specific anomalies get on at school will be published. These results should increase knowledge on the educational achievements and needs of children with specific congenital anomalies. 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.