

**EUROlinkCAT – a Horizon2020 study 2017-2021**

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**Introduction:** Congenital anomalies (CA or birth defects ) whilst often rare diseases, are a major cause of infant mortality, childhood morbidity and long-term disability. Over 130,000 children born in Europe every year have a congenital anomaly of whom a third will have a congenital heart defect (CHD) and a fourth of these children will have an isolated CHD.

**Methods:** EUROCAT is an established European network of population-based registries for the epidemiologic surveillance of CAs. The Horizon2020 funded EUROlinkCAT project will use the EUROCAT infrastructure to support 21 EUROCAT registries in 13 European countries to link their data on children with CA to mortality, hospital discharge, prescription and educational databases. Each registry will send standard aggregate tables and analysis results to a Central Results Repository (CRR) thus respecting data security issues surrounding sensitive data. The CRR will contain standardised summary data and analyses on an estimated 200,000 children with a CA born 1995-2014 up to age 10, enabling hypotheses on their treatment, health and education to be investigated at the EU level. Information on prognosis and outcome at the European level will be published and geographical differences in morbidity and mortality will be investigated. This enhanced information will allow optimisation of personalised care and treatment decisions for children with rare CAs including all types of CHD.

Registries will be supported in using social media platforms to connect with parents of children with CAs in their regions including parents of children with severe CHDs. A novel sustainable e-forum, "ConnectEpeople", will link these families with local/national and international registries and information resources. ConnectEpeople will involve these families ensuring a meaningful dissemination of results.

**Results:** Findings will provide evidence to develop national treatment guidelines, such as concerning screening programs, to optimise diagnosis, prevention and treatment for these children and reduce health inequalities in Europe. An economic evaluation of the hospitalisation costs associated with CA will be provided.

**Conclusion:** The CRR and associated documentation, including linkage and standardisation procedures and "ConnectEpeople" forum will be available post-EUROlinkCAT facilitating future local and EU level analyses to improve healthcare for children with CA and in particular with CHD.