EUROlinkCAT - Long term outcomes in children with congenital anomalies

Congenital anomalies are a major cause of infant mortality, childhood morbidity and long-term disability. Over 130,000 children born in Europe every year will have a congenital anomaly; a third will have a congenital heart defect.

EUROlinkCAT (Establishing a linked European Cohort of Children with Congenital Anomalies) is a five-year project funded by the EU Horizon 2020 Research and Innovation programme (grant agreement n. 821520), launched in 2017. It will use the existing EUROCAT infrastructure to support 22 registries, including the Tuscany Registry of Congenital Defects, in 14 European countries to link their congenital anomaly data to mortality, hospital discharge, prescription and educational databases. EUROlinkCAT aims to investigate survival, health, disease determinants and clinical course of children with congenital anomalies born from 1995-2014 up until 10 years of age, according to their specific anomaly.

The project also provides the unique opportunity to evaluate the accuracy of information on congenital anomalies using a range of existing health care databases. The project aims to facilitate the development of a more reciprocal relationship between families with children with congenital anomalies, health and social care professionals and researchers by conducting focus groups and a comprehensive questionnaire for parents. Another objective is to enable the established infrastructure and methodology for this research platform to be available for local research and future European wide analyses beyond the end of the project.

IFC-CNR is deputy leader for WP3-Mortality with the deliverable aiming to investigate whether there are geographic variations in survival across Europe for specific congenital anomaly subgroups.

ConcePTION - Exposure to medications during pregnancy and breastfeeding

More than 5 million women get pregnant in the EU every year and a majority takes at least one medication during pregnancy, with an average intake in the EU and USA of three medicines during pregnancy and four medicines during breastfeeding, while women with chronic illnesses take more. As few as 5% of available medications have been adequately monitored, tested and labelled with safety information for use in pregnant and breastfeeding women. The field has suffered from a lack of systematically gathered insights that could lead to more effective data generation methodologies.

ConcePTION (Continuum of Evidence from Pregnancy Exposures, Reproductive Toxicology and Breastfeeding to Improve Outcomes Now) is a five-year project funded by the Innovative Medicines Initiative (IMI) (grant agreement n. 821520), a private/public partnership aiming to establish an ecosystem for the monitoring of medicines safety in pregnancy and lactation.

The project was launched in April 2019. ConcePTION unites various networks and more than 90 organizations from 22 countries that collaboratively work towards the implementation of the ecosystem. The consortium is governed and managed by a balanced 50/50 split of public and private partners, and is jointly led by Novartis and the University Medical Center Utrecht.

IFC-CNR is involved in WP1 “Moving beyond pregnancy registries to enhance our understanding of disease-related pregnancy outcomes, medication use and safety of use during pregnancy” and WP7 “Information and data governance, ethics, technology, data catalogue and quality support”.

The first objective is to generate timely evidence about pregnancy outcomes, including perinatal and long-term effects following medication use during pregnancy, to benefit women, their babies and their families. The project will use a data science approach to transform data transparently into robust evidence that can be used for decision making.

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