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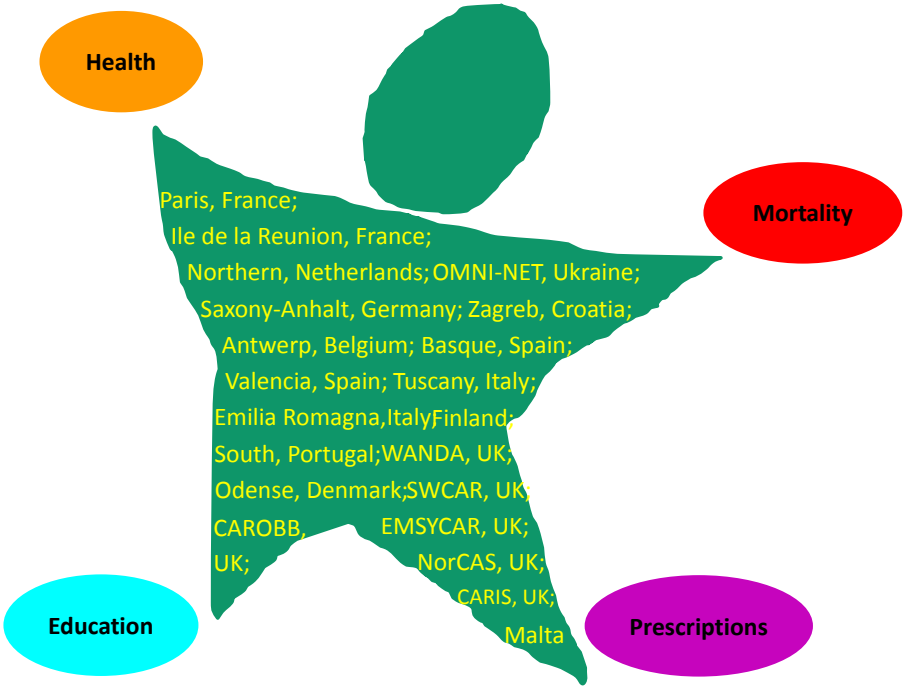
Establishing a linked European Cohort of Children with Congenital Anomalies



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Background:

- Congenital anomalies (or birth defects) 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.
- EUROlinkCAT will use the existing EUROCAT infrastructure to support 21 registries in 13 European countries to link their congenital anomaly data to mortality, hospital discharge, prescription and educational databases.

Aims:

- To investigate the health and educational outcomes of children with congenital anomalies for the first 10 years of their lives.
- To facilitate the development of a more reciprocal relationship between families with children with congenital anomalies, health and social care professionals and researchers using "ConnectEpeople".

Objectives:

- To establish a European network of standardised datasets containing information on the mortality, health, educational achievements and needs of children up to 10 years of age with congenital anomalies born from 1995-2014.
- To provide an e-platform "Connect**E**people" for public and professional engagement in setting and disseminating relevant reseach priorities and their outcomes, focusing on four specific anomalies:
  - Severe Heart Anomalies
  - Orofacial clefts
  - Spina Bifida
  - Down syndrome
- To expand the knowledge on the survival, health, disease determinants and clinical course of children according to their specific anomaly.

- To investigate socio-economic health inequalities.
- To evaluate the costs of hospitalisation during the first five years of life for children with a congenital anomaly.
- To expand the knowledge on the educational achievements and needs of children with specific congenital anomalies.
- To evaluate the accuracy of existing electronic health care databases and make recommendations on their use and on improving their accuracy.
- To engage with the relevant international/national/regional health authorities by establishing an Action Advisory Panel to ensure that relevant findings are implemented and translated into health policy.
- To enable the established infrastructure and methodology for this unique research platform to be available for local research and future European wide analyses beyond the end of the project.

Strengths of EUROlinkCAT:

- Creating a standardised dataset for each of 21 EUROCAT registries in 13 European countries containing a total of around 200,000 births will
  - Enable reliable information on rare syndromes to be obtained.
  - Enable results to be generalizable across Europe.
  - Establish a method of standardisation across Europe available for future research.
  - Demonstrate that pan European analysis of sensitive information can be performed safely.
- Establishing the e-forum, “ConnectEpeople” will
  - Enable improved provision of the information families of children with congenital anomalies want.
  - Have the potential to be self-sufficient and continue after the project funding stops.

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