



# eurolinkcat

– a Horizon2020 study 2017-2021



I Barisic<sup>1</sup>, JK Morris<sup>2</sup>, M Loane<sup>3</sup>, E. Garne<sup>4</sup>, J Rankin<sup>5</sup>, J Densom<sup>5</sup>, A Latos-Bielenska<sup>6</sup>, A J Neville<sup>7</sup>, A Pierini<sup>8</sup>, M Sinclair<sup>2</sup>, H de Walle<sup>9</sup>,  
(<sup>1</sup> Children's University Hospital Zagreb, Croatia <sup>2</sup> Queen Mary University of London, UK <sup>3</sup> Ulster University, Belfast, UK <sup>4</sup> Hospital Lillebaelt, Kolding, Denmark, <sup>5</sup> Newcastle University, Newcastle upon Tyne, UK, <sup>6</sup> Biomedical Computing Ltd, St Leonards on Sea, UK, <sup>7</sup> Poznan University of Medical Sciences, Poland, <sup>8</sup> Università degli Studi di Ferrara, Italy, <sup>9</sup> Consiglio Nazionale delle Ricerche - Institute of Clinical Physiology, Italy, <sup>10</sup> Universitair Medisch Centrum Groningen, Netherlands)

## Introduction

- Congenital anomalies (CA) are the leading cause of stillbirth and infant mortality and an important contributor to childhood morbidity.
- Over 130,000 children with CA are born in Europe each year
- Their physical, mental and social handicaps are a significant burden on the health care, social and educational services
- Still, comprehensive epidemiological and clinical data on morbidity, treatment, and education of these patients are lacking

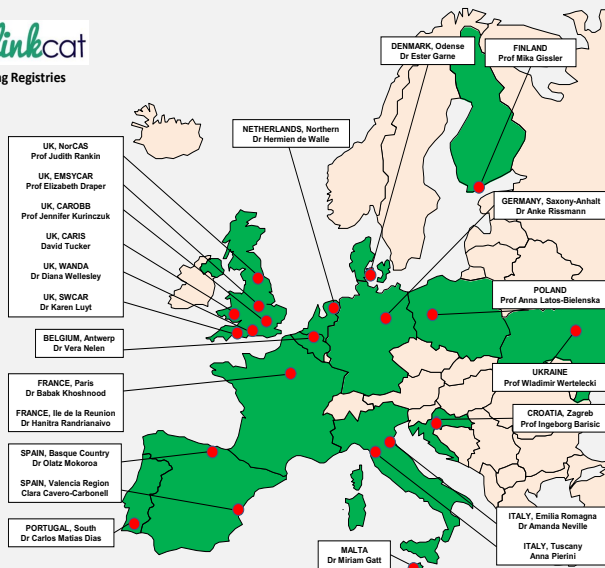
## Methods

- EUROlinkCAT will use the existing EUROCAT (European Network of Registries of Congenital Anomalies) infrastructure to support 21 registries in 13 European countries to link their congenital anomaly data to mortality, hospital discharge, prescription and educational databases
- Each registry will send standard aggregate tables and analysis results to a Central Results Repository (CRR)
- Registries will use a novel sustainable e-forum, "ConnectEpeople", to link families with local/national and international registries and information resources allowing a meaningful dissemination of project outcomes

## Objectives

- To establish a European network of standardised datasets containing information on the mortality, health, educational achievements and needs of children with congenital anomalies born from 1995-2014 up until 10 years of age
- 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 expand the knowledge on the educational achievements and needs of children with specific congenital anomalies
- To provide an e-platform "ConnectEpeople" for public and professional engagement in setting and disseminating relevant research priorities and their outcomes, focusing on four specific anomalies:
  - Children with surgery for CHD
  - Spina Bifida
  - Cleft lip
  - Down syndrome
- To evaluate the costs of hospitalisation during the first five years of life for children with a congenital anomaly
- 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

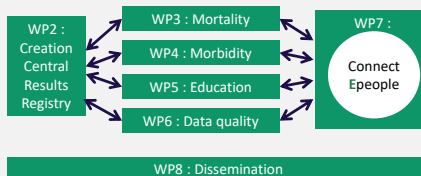
eurolinkcat  
Participating Registries



Work Package (WP) 1 : Co-ordination and management

eurolinkcat

Work Packages



## 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 anomalies and syndromes across Europe.
- Establish a method of standardisation available for future research at European level
- 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 ends

Contact Information  
enquiries@eurolinkcat.eu

<http://www.eurolinkcat.eu/>

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 733001. Jan 2017 – Dec 2021

