

# Introduction and Methods

*Update: February 2020*

## About Eurocat

Eurocat registers congenital anomalies in the Northern Netherlands region since 1981. The Eurocat database constitutes an accurate and reliable source of data for the purpose of monitoring and research of congenital anomalies. Thus, the registry contributes to the promotion of healthy pregnancies. Eurocat is part of the department of Genetics of the University Medical Center Groningen. The Dutch Ministry of Health, Welfare and Sport (VWS) has commissioned the institution of Eurocat and provides the financial means for its operation. Eurocat participates in the European network of registries of congenital anomalies (EUROCAT) and the worldwide network of the International Clearinghouse for Birth Defects Surveillance and Research (ICBDSR).

## Data collection

The birth of a child with a congenital anomaly is reported to Eurocat by healthcare professionals, like doctors, with informed consent from the parents. The initial information regarding pregnancy and the anomaly is supplemented with data from a questionnaire sent to the parents, pharmacy records and additional information from clinical records. The questionnaire for the parents covers the period before and during the pregnancy, e.g. with respect to folic acid use, exposure to harmful substances, and chronic illnesses. If parents do not respond to repeated requests to participate, they are marked as non-responders and only very limited data regarding diagnosis and pregnancy outcome are registered. The parents are informed about this procedure in the corresponding letter for participation. This procedure has been initiated in 2010, to allow a more complete registration for prevalence data. Parents are informed in writing, in compliance with applicable guidelines ('Gedragscode Gezondheidsonderzoek', Chapter 6).

## Coding of diagnoses

Anomalies are coded according to the International Classification of Diseases (ICD) with an extension based on the British Paediatric Association Classification of Diseases. For births prior to 2002, coding was done using ICD-9. From 2002 onwards the ICD-10 was used.

## Inclusion criteria

- For this report the reference date is February 19, 2020. All children with a congenital anomaly (including pregnancy terminations and miscarriages), reported before this date and who were born before January 1<sup>st</sup>, 2019, were included. The report is limited to this period because cases born in 2019 are still in the registration process and data is not yet complete. Registration is an ongoing process; children can be registered until 10 years after birth.
- At the time of birth, the mother lived in one of the three Northern provinces Groningen, Friesland or Drenthe
- The child was diagnosed with at least one major congenital anomaly, according to international criteria
- The parents gave written informed consent to register their child with Eurocat
- Children born in 2010 or later, whose parents were non-responders (see for definition under Data collection).

It should be noted that changes in numbers of reported anomalies can be due to changes in quality management or new information. For instance, in recent years a better distinction could be made between minor and major anomalies due to changes of the registry software. Minor anomalies are not included in the prevalence estimates. In addition, anomalies such as metabolic and hematologic disorders have been excluded from registration since 2011 because they did not contribute to the goals of Eurocat.

## **Acknowledgements**

We are thankful to all doctors, midwives and other professionals who assist us in completing our registry. But above all, we are deeply indebted to the parents of all registered children.

## **Eurocat Northern Netherlands**

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Groningen 2020

This report can be cited using the following reference:

‘Eurocat Update: Short report congenital anomalies Northern Netherlands 1981-2018’

Available at: [www.eurocat.umcg.nl](http://www.eurocat.umcg.nl)