Report on Data Quality Indicators (DQI) in EUROCAT

Written by Ester Garne, October 2017

Background:

As part of the data quality strategy, EUROCAT developed a set of Data Quality Indicators (DQIs) in 2005. The first DQI were based on cases born in 1999-2003. These DQIs are indicators calculated on the total dataset for each registry, and serve to highlight the strengths and weaknesses of the data. The DQIs help the registries to recognize areas needing improvement, and they are useful to data users for the interpretation of the data. The DQIs cover the following areas: completeness of case ascertainment, accuracy of diagnosis, completeness of information on EUROCAT variables, timeliness of data transmission, and availability of population denominator information. For all DQI the registries can compare to the EUROCAT average for each indicator. The DQI were revised in 2012 after review of the usefulness of each indicator. DQIs have been published on the EUROCAT website each year since 2005 and up to 2014 discussed at annual EUROCAT meetings. After the transfer of the central database to JRC in Ispra, DQI documents have not been sent to registries or published on the website.
This report will compare the DQI from the years 2006-2010 to a new DQI document prepared by JRC EUROCAT for the years 2010-2014 by comparing the EUROCAT average for each DQI

Comparing EUROCAT average for 2006-2010 and 2010-2014

The DQI for 2006-2010 included 31 registries and 106206 cases in these registries. The DQI for 2010-2014 also included 31 registries and 88378 cases.

Twenty-nine registries were included in both periods. Hungary (16192 cases) and Odense (830 cases) were included in the early DQI and Auvergne (1509 cases) and Brittany (5244 cases) were included in the recent DQI. Registries may have been included with less than 5 years in each DQI, so number of cases are not completely comparable.

The EUROCAT average for each indicator and for the two time periods are compared in Table 1. Indicators related to ascertainment all show a higher prevalence in the most recent time period. Prevalence of the subgroup all anomalies has increased slightly. Prevalence of anencephalus has increased, which may be due to better ascertainment of early terminations with anencephaly. Prevalence of selected anomalies that usually are diagnosed after the neonatal period has also increased. The increased prevalence of severe CHD may be due to better ascertainment, but it may also be a true increase as suggested in recent literature.

The indicators for accuracy of diagnosis showed improvements except for % potential multiple anomalies, which may be due to over-coding of minor anomalies. It is very positive that proportion of cases with information about surgery increased from 17% to 37%.

Hungary is a large registry and is not included in the DQI from 2010-14. For most indicators the results from Hungary were below the EUROCAT average. The improvements in the recent time period may therefore partly be explained by the missing contribution of data from Hungary.

The recent time period 2010-14 includes 3 years with the Central registry in Belfast and 2 years with Central registry at JRC (births in 2013 and 2014). However, it seems fair to conclude that data quality in EUROCAT registries has been maintained during the transfer to JRC

Table 1 Comparison of the EUROCAT average for DQI in 2 time periods

	2006-2010	2010-2014	
ASCERTAINMENT			
Total congenital anomaly prevalence [95% CI)	255.8 [254.3 - 257.3]	257,1 [255,4 - 258,8]	+
Anencephaly prevalence	3.5	4.0	+
Severe cardiac defects prevalence	20.6	23.5	+
Selected postnatal diagnosis prevalence	10.5	12.6	+
Genetic syndromes and microdeletions prevalence	4.8	6.0	+
Prevalence malformed fetal deaths	4.5	4.9	+
Down syndrome: Observed/Expected ratio by maternal age	1		
ACCURACY OF DIAGNOSIS			
% Potential multiple anomalies	9.4	10.5	÷
% fetal deaths with postmortem carried out	39.5	40.2	+
% TOPFA (GA >=15 weeks) with postmortem carried out	28.8	33.9	+
% Chromosomal cases (except T13, T18 & T21) with karyotype text	66.6	75.1	+
% Potential multiple anomalies with karyotype text	19.9	25.2	+
Prevalence selected 4-digit Q-BPA codes	16.4	17.8	+
Prevalence selected unspecified Q-codes	14.7	10.5	+
% LB with ASD, VSD, Hydronephrosis, Hypospadia or club foot with surgery data	17.2	37.6	+
COMPLETENESS OF INFORMATION			
% TOPFA with civil registration known	77.1	87.9	+
% LB with one week survival known	87.3	91.2	+
% ATC codes with 7 digits and in correct format	82.8	82.1	÷
% Genetic syndromes + microdeletions with syndrome text complete	70.9	76.3	+
% Malformation 1 text complete	63.7	88.0	+
Number of unresolved data edits	0.8	0.9	÷
TIMELINESS			
Timeliness for February deadline	Total = 22	NA	