Data Quality Indicators (DQI) in EUROCAT

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, which serve to highlight the strengths and weaknesses of the data. The DQIs help to focus the attention of registries on areas needing improvement, and they are useful to data users for the interpretation of 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. DQIs have been published on the EUROCAT website each year since 2005 and are discussed at annual EUROCAT meetings.

However, the clinical background for collecting data changes over time and prevalence of specific anomalies may change. The DQIs have to follow changes over time and revision will be necessary.

Revision of the DQI is part of Workpackage 5 in the Joint Action 2011-2013. A report on the DQI status has been written in 2011 with proposals for changes. The report showed major improvements in the data quality since the first set of DQI (1999-2003) in many local registries. The report has been discussed at the PMC meeting in November 2011. This document presents the revised set of DQI for use from 2012. The first set of the revised DQI for the years 2005-2009 will be available for the local registries at the Registry Leaders Meeting in Budapest in June 2012.

For inclusion in the DQIs:

- Registries with full member status at the time of the DQI analysis
- 1+ years of data in the central database for the birth years covered in the analysis

DQIs usually run in April. . 5 years of data covered. 2005-2009 run in April 2012, 2006-2010 will be run in April 2013 etc

List of Data Quality Indicators (DQI)

Ascertainment:

Total number of cases

Total congenital anomaly prevalence – >200 per 10,000 births expected

Prevalence of subgroup "anencephalus" – compare to the EUROCAT average

Prevalence of subgroup "severe cardiac defects" – compare to the EUROCAT average

Prevalence of selected congenital anomalies often diagnosed after the neonatal period – compare to the EUROCAT average

Includes codes for corpus callosum anomalies (Q040), cataract (Q120), coarctation of aorta (Q251), Hirschprung (Q431) and craniosynostosis (Q750).

Prevalence of subgroup "Genetic syndromes and microdeletions" – compare to the EUROCAT average

Prevalence of malformed fetal deaths – compare to the EUROCAT average

Down syndrome: Observed/Expected ratio by maternal age – compare to the EUROCAT average

Accuracy of diagnosis:

% potential multipleanomalies - compare to the EUROCAT average

% fetal deaths with postmortem examination carried out – compare to the EUROCAT average

% TOPFA (GA ≥ 15 weeks) with post-mortem carried out – compare to the EUROCAT average

% chromosomal cases (except trisomy 13, 18 and 21) with karyotype text – compare to the EUROCAT average

% potential multiple anomalies with known karyotype – compare to the EUROCAT average

Prevalence of selected 4-digit Q-BPA codes – compare to the EUROCAT average

Selected exact Q-BPA codes = Q00.00, Q00.20, Q04.00, Q04.35, Q21.10, Q21.21, Q25.10, Q25.11, Q26.20, Q33.80, Q39.11, Q44.20, Q61.41, Q64.20, Q71.31, Q89.80

Prevalence of selected unspecified Q codes – compare to the EUROCAT average

Selected unspecified codes = Q04.9, Q05.9, Q24.9, Q33.9, Q43.9, Q54.9, Q63.9, Q74.9, Q79.9, Q89.9, Q99.9

% livebirths with ASD, VSD, hydronephrosis, hypospadia or club foot with known data on surgery – compare to the EUROCAT average

Completeness of information:

Number of core variables 90% complete - compare to total number of core variables

11 variables: Sex, Nbrbaby, Nbrmalf, Type, Weight, Gestlength, Survival,Whendisc, Agedisc, Agemo, Civreg

Number of non-core variables 80% complete – compare to total number of non-core variables

26 variables: Death_date, Condisc, Karyo, PM, Datemo, Residmo, Totpreg, Occupmo, Assconcept, Illbef1, Illdur1, Drugs1, Consang, Prevsib, Sib1, Sibanom, Moanom, Faanom, Firstpre, Surgery, Folic, Matedu, Socm, Socf, Migrant, Aetiology

% TOPFA with civil registration known – compare to the EUROCAT average

% livebirths with one week survival known – compare to the EUROCAT average

Medication exposure recorded using 7 digit ATC codes – yes or no

% of ATC codes with 7 digits and in correct format – compare to the EUROCAT average

% genetic syndromes + microdeletions with syndrome text complete – compare to the EUROCAT average

% malformation1 text complete – compare to the EUROCAT average

Number of unresolved data edits (excluding free text fields) – compare to the EUROCAT average

(If Central Registry changes information in the central database, CR staff will request that the change be made in the local registry data also. If the change is not made and data are re-submitted to CR, this will be flagged as an 'unresolved data edit'. This is a new feature of the central database.)

Timeliness:

Timeliness for February deadline – yes or no

Denominator Information:

Years with 80% maternal age denominators

Years with monthly denominators