Data Quality Indicator Form

Purpose

These data quality indicators are intended to supplement NBDPN performance standards for birth defects surveillance programs. Statistical data quality indicators can help programs to monitor their data quality over time, objectively evaluate their performance and provide direction for improving data collection, thereby facilitating data aggregation and utilization across state programs.

Format

This Indicator Form lists statistical indicators associated with the performance standards measured in the **Data Quality Assessment Tool**. Data quality indicators are organized into completeness, timeliness, and accuracy categories.

Definitions/explanations

Each data quality indicator is followed by prompts requesting the specific data elements needed for calculation, including denominators. Clarification on how to interpret specific data elements is included as well.

NBDPN Guidelines

These indicators can be linked back to the NBDPN Data Quality Assessment Tool, and the **Birth Defects Surveillance Guidelines and Standards Manual**. Specific birth defects are described and defined in Appendix 3.1 of the Manual, and data variables are described in Appendix 4.1.

Instructions

This is a self-assessment tool designed for a birth defects surveillance system. For each measure, enter the appropriate number in the blue cell. Calculations will be completed automatically as the form is completed. Calculated values will appear in the yellow cells. You may choose which year(s) of data to use for your calculations based on your program's self-assessment needs.

Comments

Utilize the comment section for each indicator to provide any additional information or to note any caveats related to your data.

For the time period: ex. 2016-2020

Form Completed by:	Date Completed:

Denominators

D1

Total # of live births

Record the total number of live births in your surveillance area

*Required

D2

of NBDPN core defect cases LIVEBORN

Record the total number of liveborn individuals (deduplicated) with any of the 14 NBDPN core defects*

*Required

D3

of NBDPN core defect cases NON-LIVEBORN

Record the total number of non-liveborn individuals (deduplicated) with any of the 14 NBDPN core defects*

*Required

*NBDPN core defects include: anencephalus, spina bifida without anencephalus, atrioventricular septal defect, common truncus, hypoplastic left heart syndrome, tetralogy of Fallot, total anomalous pulmonary venous connection, transposition of the great arteries, cleft lip with cleft palate, cleft lip alone, cleft palate alone, gastroschisis, limb deficiencies, Trisomy 21

Completeness Indicators

These indicators are designed to help assess whether a surveillance system is capturing all of the cases of birth defects that occur within the target population. While there may be true variation in birth defect prevalence over space and time, unexpected values may indicate under-ascertainment of cases or missing information from data sources including prenatal, pediatric, cytogenetic, or non-livebirth records.

DQI 1.1 Prevalence of spina bifida per 10,000 live births

1.1 # of cases with spina bifida:

Record the total number of individuals (deduplicated) both liveborn and non-liveborn with a diagnosis of spina bifida without anencephalus.

Calculation: (1.1 / D1) x 10,000

Comments:

Comment boxes are limited to 225 characters

DQI 1.2 Prevalence of gastroschisis per 10,000 live births

1.2 # of cases with gastroschisis:

Record the total number of individuals (deduplicated) both liveborn and non-liveborn with a diagnosis of gastroschisis.

Calculation: (1.2 / D1) x 10,000

Comments:

225 character limit

DQI 1.3 Spina bifida to anencephaly ratio per 10,000 live births

1.3 # of cases with anencephaly:

Record the total number of individuals (deduplicated) both liveborn and non-liveborn with a diagnosis of anencephalus.

Calculation: 1.1 / 1.3

Comments:

225 character limit

DQI 1.4 Omphalocele to gastroschisis ratio

1.4 # of cases with omphalocele:

Record the total number of individuals (deduplicated) both liveborn and non-liveborn with a diagnosis of omphalocele.

Calculation: 1.4 / 1.2

Comments:

225 character limit

DQI 1.5 Prevalence of hypoplastic left heart syndrome per 10,000 live births

1.5 # of cases with hypoplastic left heart syndrome:

Record the total number of individuals (deduplicated) both liveborn and non-liveborn with a diagnosis of hypoplastic left heart syndrome.

Calculation: (1.5 / D1) x 10,000

Comments:

225 character limit

DQI 1.6 Prevalence of dextro-transposition of the great arteries per 10,000 live births

1.6 # of cases with dextro-transposition of the great arteries:

Record the total number of individuals (deduplicated) both liveborn and non-liveborn with a diagnosis of dextro-transposition of the great arteries.

Calculation: (1.6 / D1) x 10,000

Comments:

225 character limit

DQI 1.7 Prevalence of Down syndrome per 10,000 live births

1.7 # of cases with Down syndrome:

Record the total number of individuals (deduplicated) both liveborn and non-liveborn with a diagnosis of Down syndrome.

Calculation: (1.7 / D1) x 10,000

Comments:

225 character limit

DQI 1.8 Percentage of cases missing infant sex

1.8a # of core defect cases with missing sex LIVEBORN:

Record the total number of liveborn core defect cases (totaled in D2) with undetermined, ambiguous, or no information on infant sex

Calculation: 1.8a / D2 x 100

1.8b # of core defect cases with missing sex NON-LIVEBORN:

Record the total number of non-liveborn core defect cases (totaled in D3) with undetermined (e.g., early fetal deaths or terminations for which sex was not possible to determine), ambiguous, or no information on infant sex

Calculation: 1.8b / D3 x 100

Comments:

225 character limit

DQI 1.9 Percentage of cases missing maternal age

1.9 # of core defect cases with missing maternal age:

Record the number of core defect cases (including both liveborn and non-liveborn) with missing maternal age.

Calculation: 1.9 / (D2 + D3) x 100

Comments:

225 character limit

DQI 1.10 Percentage of cases missing information on maternal race/ethnicity

1.10a # of core defect cases with missing race that are LIVEBORN:

Record the number of liveborn core defect cases (totaled in D2) missing maternal race information

Calculation: 1.10a / D2 x 100

1.10b # of core defect cases with missing race that are NON-LIVEBORN:

Record the number of non-liveborn core defect cases (totaled in D3) missing maternal race information

Calculation: 1.10b / D3 x 100

1.10c # of core defect cases with missing ethnicity that are LIVEBORN:

Record the number of liveborn core defect cases (totaled in D2) missing maternal ethnicity information

Calculation: 1.10c / D2 x 100

1.10d # of core defect cases with missing ethnicity that are NON-LIVEBORN:

Record the number of non-liveborn core defect cases (totaled in D3) missing maternal ethnicity information

Calculation: 1.10d / D3 x 100

Comments:

225 character limit

DQI 1.11 Prevalence of critical congenital heart defects (CCHDs) per 10,000 live births

1.11 # of cases with at least one CCHD:

Record the total number of individuals (deduplicated both liveborn and non-liveborn) with any of the following CCHD diagnosis: hypoplastic left heart syndrome, dextro-transposition of the great vessels, tetralogy of Fallot, coarctation of the aorta, truncus arteriosus, double outlet right ventricle, Ebstein anomaly, interrupted aortic arch, pulmonary atresia, single ventricle, total anomalous pulmonary venous connection, tricuspid atresia.

Calculation: (1.11 / D1) x 10,000

Comments:

225 character limit

DQI 1.12 Prevalence of anomalies associated with postnatal diagnosis (craniosynotosis, biliary atresia, celft palate with cleft lip) per 10,000 live births

1.12 # of cases with at least one defect associated with postnatal diagnosis regardless of when the defect was diagnosed (pre or postnatal):

Record the total number of individuals (deduplicated both live and non-liveborn) with any of the following diagnoses: craniosynostosis, biliary atresia, cleft palate without cleft lip. Include all pregnancy outcomes and all affected cases, regardless of the timing of diagnosis.

Calculation: (1.12 / D1) x 10,000

Comments:

225 character limit

DQI 1.13 Number of Level 1 data elements 90% complete (birth weight, gestational age, plurality, at least one maternal residence at delivery)

1.13a # of core defect cases with known birth weight that are LIVEBORN:

Record the number of core defect cases (totaled in D2) with known (non-missing) birthweight for liveborn

Calculation: 1.13a / D2 x 100

1.13b # of core defect cases with known gestational age that are LIVEBORN:

Record the number of core defect cases (totaled in D2) with known (non-missing) gestational age for liveborn.

Calculation: 1.13b / D2 x 100

1.13c # of core defect cases with known plurality that are LIVEBORN:

Record the number of core defect cases (totaled in D2) with known (non-missing) plurality for liveborn.

Calculation: 1.13c / D2 x 100

1.13d # of core defect cases with complete address for maternal residence at delivery that are LIVEBORN:

Record the number of core defect cases (totaled in D2) with complete address information (known street address, city, state, and zip code) for maternal residence at delivery for liveborn. Do not include with a mailing address only (i.e., PO Box with no street address).

Calculation: 1.13d / D2 x 100

1.13e # of core defect cases with known birth weight that are NON-LIVEBORN:

Record the number of core defect cases (totaled in D3) with known (non-missing) birthweight for non-liveborn.

Calculation: 1.13e / D3 x 100

1.13f # of core defect cases with known gestational age that are NON-LIVEBORN:

Record the number of core defect cases (totaled in D3) with known (non-missing) gestational age for non-liveborn.

Calculation: 1.13f / D3 x 100

1.13g # of core defect cases with known plurality that are NON-LIVEBORN:

Record the number of core defect cases (totaled in D3) with known (non-missing) plurality for non-liveborn.

Calculation: 1.13g / D3 x 100

1.13h # of core defect cases with complete address for maternal residence at delivery that are NON-LIVEBORN:

Record the number of core defect cases (totaled in D3) with complete address information (known street address, city, state and zip code) for maternal residence at delivery for non-liveborn. Do no include cases with mailing addresses only (i.e., PO Box with no street address).

Calculation: 1.13h / D3 x 100

Comments:

225 character limit

DQI 1.14 Percentage of cases that are fetal deaths and terminations

1.14a # of core defect cases that are fetal deaths ≥ 20 weeks gestation:

Record the number of core defect cases (totaled in D3) that are fetal deaths with a gestational age of 20 weeks or greater.

Calculation: 1.14a / (D2 + D3) x 100

1.14b # of core defect cases that are terminations:

Record the number of core defect cases (totaled in D3) that are terminations (any gestational age).

Calculation: 1.14b / (D2 + D3) x 100

Comments:

225 character limit

Timeliness Indicators

These indicators are designed to help assess whether a surveillance system is able to ascertain and report case information in a timely manner. Timeliness impacts a program's ability to provide prevention and intervention services, respond to investigations, and monitor trends.

DQI 2.1 NBDPN data submission submitted by the requested deadline (Y/N)

2.1 NBDPN data submission submitted by the requested timelines:

Record "Y" if your program submitted all years of data requested for the most recent NBPDN data submission by the requested deadline. Record "N" if our program was not able to submit all years of data requested by the deadline for the most recent NBDPN data submission.

Comments:

225 character limit

DQI 2.2 Percentage of CCHD cases ascertained within 6 months of delivery

2.2 # of CCHD cases identified within 6 months (or 180 days) of delivery:

Record the number of CCHD cases (totaled in DQI 1.11) that were identified by your program within 6 months (or 180 days) of delivery (including all pregnancy outcomes). Use the date that the case was first captured in your data systems even in all diagnostic information was not yet confirmed or complete.

Calculation: 2.2 / 1.11

Comments:

225 character limit

Accuracy Indicators

These indicators are designed to help assess a surveillance system's ability to provide correct and valid data. Data accuracy is important for providing reliable disease rates and maintaining comparable data across programs.

DQI 3.1 Prevalence of atrioventricular septal defect with Down syndrome per 10,000 live births

3.1 # of AVSD cases that have a Down syndrome diagnosis:

Record the number of atrioventricular septal defect (endocardial cushion defect) cases with Down syndrome (include all pregnancy outcomes).

Calculation: (3.1 / D1) x 10,000

Comments:

225 character limit

DQI 3.2 Prevalence of selected unspecified codes (small intestinal atresia/stenosis part unspecified and unspecified limb deficiency) per 10,000 live births

3.2 # of individuals with any of the following unspecified codes:

Record the number of individuals (deduplicated) with any of the following unspecified diagnosis: small intestinal atresia/stenosis part unspecified [ICD-9 751.1; CDC/BPA 751.19; ICD-10 Q41.9], or unspecified limb deficiencies (reduction defects) [ICD-9 755.20, 755.30, 755.4; CDC/BPA 755.29, 755.39, 755.49; ICD-10 Q71.9, Q72.9, Q73.8].

Calculation: (3.2 / D1) x 10,000

Comments:

225 character limit

DQI 3.3 Percentage of cases reviewed by a medical specialist (e.g., pediatric cardiologist, clinical geneticist, etc)

3.3 # of core defect cases reviewed by a medical specialist:

Record the number of core defect cases (liveborn and non-liveborn) that were reviewed by a clinical geneticist, dysmorphologist, or other high-level clinical specialist depending on defect (i.e., pediatric cardiologist for heart defects.

Calculation: 3.3 / (D2 + D3)

Comments:

225 character limit

DQI 3.4 Percentage of Down syndrome cases with karyotype results reported

3.4 # of Down syndrome cases with karyotype results reported:

Record the number of down syndrome cases with known karyotype (e.g., CDC/BPA codes 758.00, 758.010, 758.020, 758.040; or ICD code with karyotype documented in the case record).

Calculation: 3.4 / 1.7

Comments:

225 character limit