

**NBDPN Standards for Birth Defects Surveillance
Data Quality Assessment Tool**

Version 1.1 (V1.1), 2016

Purpose: Performance standards for birth defects surveillance are intended to improve and standardize operations, outcomes, and surveillance functions across state programs, thereby making data more consistent and useful for a variety of purposes at local, state, multi-state, and national levels.

Format: This Assessment Tool lists performance indicators and associated measurements for data quality. Each line item measurement identifies the level of standards performance as (1) (2) or (3). Performance indicators are organized into completeness, timeliness and accuracy categories.

Definitions - explanations: Each performance indicator is followed by a definition that provides clarification of how to interpret the indicator and the reason/explanation for the specific performance indicator.

NBDPN Guidelines: These standards (i.e. performance indicator (and measurements)) will be linked directly back to the NBDPN Birth Defects Surveillance Guidelines and Standards Manual so that programs will understand how the guidelines and standards fit together (<http://www.nbdpn.org/guidelines.php>). Chapters of the Manual that relate to each indicator are specified after the definition. Each performance measure references one or more chapters from the NBDPN Birth Defects Surveillance Guidelines and Standards. The applicable chapters include:

- Chapter 3: Case Definition
- Chapter 4: Data Elements
- Chapter 5: Classification and Coding
- Chapter 6: Case Ascertainment Methods
- Chapter 7: Data Quality Management
- Chapter 9: Data Management and Security
- Chapter 12: Inclusion of Prenatal Diagnoses in Birth Defects Surveillance

Instructions: This is designed as a self-assessment tool for a birth defects surveillance system. Three performance levels are associated with each indicator:

- Level 1: Rudimentary level of performance by a surveillance program
- Level 2: Essential level of performance by a surveillance program
- Level 3: Optimal level of performance by a surveillance program

Before completing each indicator, be sure to read all performance options.

For each indicator, please check the highest performance level that applies for your birth defects surveillance system.

Before you start, please complete the identification box below.

State	
Name of person completing tool	
Title	
Email	
Date	

Table of Contents

DQ1: Completeness	3
DQ1.1 Types of data sources used systematically and routinely to identify potential cases at a population-based level.....	3
DQ1.2 Birth defects included using standard NBDPN case definitions	4
DQ1.3 Pregnancy outcomes included.....	4
DQ1.4 Systematic and routine identification of cases during ascertainment period (age of diagnosis)	5
DQ1.5 Data elements collected	5
DQ2: Timeliness	6
DQ2.1 Time of case data completion for NBDPN "core" list	6
DQ2.2 Time of case data completion for NBDPN "recommended" list.....	6
DQ3: Accuracy.....	7
DQ3.1 Data quality procedures for verification of case diagnosis	7
DQ3.2 Scope of birth defects verified.....	8
DQ3.3 Level of expertise for individuals who perform case diagnosis verification.....	8
DQ3.4 Database quality assurance process.....	9

DQ1: Completeness

Completeness is the extent to which data are all-inclusive and comprehensive. For example, are all of the cases of birth defects that occur within the target population, within a specified time period, identified by the surveillance system? (Reference: Chapter 7)

		Level 1	Level 2	Level 3
Completeness DQ1.1	<p>DQ1.1 Types of data sources used systematically and routinely to identify potential cases at a population-based level</p> <p>This indicator is measuring the completeness of case ascertainment, and to some extent, accuracy of the program's surveillance data. The ultimate goal is to cast a wide net to ascertain as many cases as possible.</p> <p>Reference: Chapters 6 and 12</p> <p>Please check the highest performance level that applies.</p>			
	<p>None or Unable to achieve level 1 (Please explain in comment box)</p>			
	<p>Level 1</p> <p>Each of the following sources:</p> <ul style="list-style-type: none"> • Vital record data (e.g. birth and death certificates, fetal death certificate/report) • Additional source for case identification (e.g. hospital discharge, disease index) 			
	<p>Level 2</p> <p>The data sources in level 1 and any additional sources of natal or postnatal data</p> <p>Examples include:</p> <ul style="list-style-type: none"> • Insurance/Payer (Medicaid, All Payer Claims Database, CHIP, HMO, etc.) • Birth defects-specific reports submitted regularly by catchment area hospitals • Public Health Program (Newborn Metabolic Screening; Newborn Hearing Screening; Maternal Child Health, such as CSHCN, WIC, etc.) • Laboratories for natal or postnatal case identification and confirmation • Clinics (Pediatrics General, Cardiology, CNS-Neurology, Developmental, Genetics Clinic, Musculoskeletal, Orofacial, Orthopedics, Urology, etc.) • Pathology (Anatomical autopsy, Surgical, Tissue, etc.) • Providers (Pediatrician, Genetic Counselor, etc.) 			
	<p>Level 3</p> <p>The data sources in level 1, any of the additional data sources in level 2 and routine reporting from any of the following data sources for systematic specialized ascertainment of prenatally diagnosed defects (assessment of prenatal laboratory results is not sufficient for level 3)</p> <p>Examples include:</p> <ul style="list-style-type: none"> • Maternal Fetal Medicine Clinics • Other prenatal diagnostic facilities (e.g. standalone radiology center) • Outpatient prenatal care clinics and offices 			
Comments:				

Completeness DQ1.2	DQ1.2 Birth defects included using standard NBDPN case definitions	Level 1	Level 2	Level 3	
	This indicator reflects the scope of medical conditions in the surveillance database				
	Reference: Chapter 3				
	Please check the highest performance level that applies.				
	None or Unable to achieve level 1 (Please explain in comment box)				
	Level 1 All of the NBDPN "core" birth defects				
	Level 2 All of the NBDPN "recommended" birth defects				
Level 3 All conditions on the NBDPN list including "core", "recommended" and "extended", plus birth defects beyond the list.					
Comments:					

Completeness DQ1.3	DQ1.3 Pregnancy outcomes included	Level 1	Level 2	Level 3	
	This indicator identifies the types of pregnancy outcome categories in the surveillance data base, regardless of data sources.				
	Reference: Chapters 3 and 12				
	Please check the highest performance level that applies.				
	None or Unable to achieve level 1 (Please explain in comment box)				
	Level 1 Live births				
Level 2 Live births, stillbirths ¹ (fetal deaths at ≥20 weeks EGA ² OR >350 grams if EGA is not available)					
Level 3 Live births, stillbirths ¹ (fetal deaths at ≥20 weeks EGA ² OR >350 grams if EGA is not available), and other pregnancy loss, e.g. induced terminations					
Comments:					
¹ Programs may identify stillbirths from a variety of data sources, e.g. death certificates, hospital reports, pathology reports, etc. ² EGA = estimated gestational age. Gestational age may be derived in various ways (including last menstrual period, physician prenatal estimate, postnatal exam, etc.). The NBDPN Birth Defects Surveillance Guidelines and Standards Chapter 3 gives a hierarchy of the accuracy of these methods. Programs should employ this hierarchy to use the most accurate method for including EGA in surveillance data.					

Completeness DQ1.4	<p>DQ1.4 Systematic and routine identification of cases during ascertainment period (age of diagnosis)</p> <p>This is an indication of what is actually done (systematic and routine), not just the capacity/authority to do it.</p> <p>Reference: Chapter 3</p>	Level 1	Level 2	Level 3
	<p>Please check the highest performance level that applies.</p>			
	<p>None or Unable to achieve level 1 (Please explain in comment box)</p>			
	<p>Level 1 Identification of cases diagnosed through 1 month of age</p>			
	<p>Level 2 Identification of cases diagnosed through 1 year of age</p>			
	<p>Level 3 Identification of cases diagnosed beyond 1 year of age</p>			
	<p>Comments:</p>			

Completeness DQ1.5	<p>DQ1.5 Data elements collected</p> <p>A surveillance program should collect those items needed to fulfill its stated objectives. The value of the data is increased based on the extent to which data elements use clear definitions and are collected in a standardized way.</p> <p>Reference: Chapter 4</p>	Level 1	Level 2	Level 3
	<p>Please check the highest performance level that applies.</p>			
	<p>None or Unable to achieve level 1 (Please explain in comment box)</p>			
	<p>Level 1 All level 1 data elements</p>			
	<p>Level 2 All levels 1 and 2 data elements</p>			
	<p>Level 3 All level 1, 2 & 3 data elements and additional elements beyond the NBDPN list</p>			
	<p>Comments:</p>			

DQ2: Timeliness

Timeliness is the extent to which data are rapid, prompt, and responsive. For example, a birth defect case should be ascertained or reported to the program shortly after diagnosis. With rapid case identification the program is able to provide timely prevention and intervention services, respond quickly to investigations, and monitor trends. (Reference: Chapter 7)

Timeliness DQ2.1	DQ2.1 Time of case data completion for NBDPN "core" list	Level 1	Level 2	Level 3
	Case identification to completion ¹ , based on delivery year. Reflects when program regards data as "final", and when the NBDPN could use these data in the annual report or a central data repository.			
	Reference: Chapters 3 and 7			
	Please check the highest performance level that applies.			
	None or Unable to achieve level 1 (Please explain in comment box)			
	Level 1 ≥75% of all "core" NBDPN birth defects list reported cases complete within 2 years of delivery.			
Level 2 ≥95% of all "core" NBDPN Birth defects list-reported cases complete within 2 years of delivery.				
Level 3 ≥99% of all "core" NBDPN Birth defects list-reported cases complete within 2 years of delivery.				
Comments:				
¹ "Complete" means the data are available for analysis/use and no further case investigation is required.				

Timeliness DQ2.2	DQ2.2 Time of case data completion for NBDPN "recommended" list	Level 1	Level 2	Level 3
	Case identification to completion ¹ , based on delivery year. Reflects when program regards data as "final", and when the NBDPN could use these data in the annual report or a central data repository.			
	Reference: Chapters 3 and 7			
	Please check the highest performance level that applies.			
	None or Unable to achieve level 1 (Please explain in comment box)			
	Level 1 ≥75% of all "recommended" NBDPN birth defects list-reported cases complete within 2 years of delivery.			
Level 2 ≥95% of all "recommended" NBDPN Birth defects list-reported cases complete within 2 years of delivery.				
Level 3 ≥99% of a "recommended" NBDPN Birth defects list-reported cases complete within 2 years of delivery.				
Comments:				
¹ "Complete" means the data are available for analysis/use and no further case investigation is required.				

DQ3: Accuracy

Accuracy is the extent to which data are exact, correct and valid. For example, accurate diagnostic data affect a program's ability to provide reliable disease rates and to maintain data comparable to those from other programs. Diagnostic accuracy reflects the program's conformance with agreed-upon definitions and requirements. (Reference: Chapter 7)

		Level 1	Level 2	Level 3
Accuracy DQ3.1	<p>DQ3.1 Data quality procedures for verification of cases diagnosis</p> <p>This indicator includes ongoing data quality procedures for accuracy and completeness of the case diagnosis.</p> <p>Verification of case diagnosis is an important quality assurance procedure. Quality assurance procedures should be conducted as specified in the guidelines manual.</p> <p>Reference: Chapter 7</p> <p>Please check the highest performance level that applies.</p>			
	None or Unable to achieve level 1 (Please explain in comment box)			
	<p>Level 1</p> <p>Minimal data quality procedure for case verification, majority of cases accepted as reported</p>			
	<p>Level 2</p> <p>Verification using "some" method, e.g. clinical case report from a specialty clinic, agreement across multiple data sources, agreement between procedure and diagnostic codes, laboratory reports</p>			
	<p>Level 3</p> <p>Verification using method beyond level 2, e.g. medical records</p>			
	Comments:			

		Level 1	Level 2	Level 3
Accuracy DQ3.2	<p>DQ3.2 Scope of birth defects verified</p> <p>This indicator includes ongoing data quality procedures for accuracy and completeness of the case diagnosis.</p> <p>Reference: Chapter 7</p> <p>Please check the highest performance level that applies.</p>			
	None or Unable to achieve level 1 (Please explain in comment box)			
	<p>Level 1</p> <p>Special projects, selected diagnoses, or samples only</p>			
	<p>Level 2</p> <p>Verification for all "core" birth defects</p>			
	<p>Level 3</p> <p>Verification for all "recommended" birth defects</p>			
	Comments:			

Accuracy DQ3.3	<p>DQ3.3 Level of expertise for individuals who perform case diagnosis verification</p> <p>This will determine the extent to which a program has the capacity to determine diagnosis. Program staff should maintain a level of expertise, through on-going training.</p> <p>Reference: Chapters 5, 6 and 7</p> <p>Please check the highest performance level that applies.</p>	Level 1	Level 2	Level 3
	<p>None or Unable to achieve level 1 (Please explain in comment box)</p>			
	<p>Level 1 Staff with no or minimal disease coding or clinical expertise perform routine case reviews</p>			
	<p>Level 2 Staff with expertise in disease coding or clinical training (e.g. RN or genetic counselor) perform routine case reviews</p>			
	<p>Level 3 Clinical geneticist, dysmorphologist or other high level expert depending on defect (i.e. pediatric cardiologist for heart defects) routinely performs case reviews</p>			
	<p>Comments:</p>			

Accuracy DQ3.4	DQ3.4 Database quality assurance process The quality of the registry database can be enhanced significantly through use of quality assurance steps during data collection and processing. Procedures to screen the data for potential error at the field level, the record level and across records for an individual can enable isolating and resolving problems with the data. Standardization of data elements is an important quality assurance procedure. Quality assurance procedures for each data element should be conducted as specified in the guidelines manual. Reference: Chapters 4, 7 and 9 Please check the highest performance level that applies.	Level 1	Level 2	Level 3
	None or Unable to achieve level 1 (Please explain in comment box)			
	Level 1 Quality checks are performed for "core" data elements			
	Level 2 Quality checks are performed for "recommended" data elements			
	Level 3 Quality checks are performed for "extended" NBDPN data elements			
	Comments:			

Summary

[Note that you do not need to complete the following table. These scores will be generated automatically.]

Performance Measure	None	Level 1	Level 2	Level 3
DQ1: Completeness				
DQ1.1 Types of data sources used systematically and routinely to identify potential cases at a population-based level				
DQ1.2 Birth defects included using standard NBDPN case definitions				
DQ1.3 Pregnancy outcomes included				
DQ1.4 Systematic and routine identification of cases during ascertainment period (age of diagnosis)				
DQ1.5 Data elements collected				
DQ2: Timeliness				
DQ2.1 Time of case data completion for NBDPN "core" list				
DQ2.2 Time of case data completion for NBDPN "recommended" list				
DQ3: Accuracy				
DQ3.1 Data quality procedures for verification of cases diagnosis				
DQ3.2 Scope of birth defects verified				
DQ3.3 Level of expertise for individuals who perform case diagnosis verification				
DQ3.4 Database quality assurance process				