Standards at a Glance

The National Birth Defects Prevention Network (NBDPN) ***Standards*** are the activities expected of a birth defects surveillance program (i.e., outputs and performance indicators). Each Standard is presented in a table which serves as a tiered rubric for birth defects surveillance program activities.

- The **Core** tier indicates the minimum criteria needed for surveillance activities to ensure a birth defects surveillance program meets an acceptable level of performance.
- The **Enhanced** tier indicates some additional activities a birth defects surveillance program might engage in based on resources available and local policies, in addition to meeting all of the criteria in the Core tier.
- The **Extended** tier (when present) indicates the archetype of what an ideal birth defects surveillance program's activities would encompass, in addition to meeting all criteria in the Core tier and some or all of the criteria in the Enhanced tier.

The NBDPN Standards are summarized here, with numbering corresponding to the chapter and section where each Standard can be found throughout the *Guidelines for Conducting Birth Defects Surveillance*.

Standard 2.1.2

Residency Status of Cases Included in Birth Defects Surveillance Program's Activities If your program is not state-level, then take "in-state" to mean "in your program's catchment area."	
Core	In-state deliveries to in-state residents.
Enhanced	*Core tier criteria plus the following:* Out-of-state deliveries to in-state residents (e.g., a resident may get care or deliver at a major medical center on the border of a neighboring state).

Standard 2.1.3

Pregnancy Outcomes Included in Birth Defects Surveillance Program's Activities	
Core	Live births
Enhanced	*Core tier criteria plus some/all of the following:* Fetal deaths delivered at a gestational age of ≥ 20 completed weeks (i.e., stillbirths) >350 grams if gestational age is unknown
Extended	*Core tier criteria, plus some/all items from Enhanced, plus some/all of the following:* Elective terminations of pregnancy at any gestational age Fetal deaths delivered at a gestational age of < 20 competed weeks (i.e., miscarriages)

Standard 2.1.5

Up to What Age-at-Diagnosis the Surveillance Program Ascertains Birth Defects Age at which the signs and symptoms brought the case to medical attention and the diagnosis was suspected. Although definitive test results for final diagnosis may have taken longer, the date of clinical findings that initiated the diagnostic process can be considered the "age-at-diagnosis."	
Core	Birth defects surveillance program ascertains cases diagnosed on or before the first birthday.
Enhanced	*Core tier criteria plus the following:* Birth defects surveillance program ascertains cases diagnosed after the first birthday. Birth defects surveillance program utilizes a later maximum age-at-diagnosis in conditions for which the diagnosis or level of severity are better understood over a longer timeline.

Standard 2.2.1

Set of Defects Included in Birth Defects Surveillance Program's Activities (see **Appendix 2A**)	
Core	Defects on the NBDPN Core list of birth defects.
Enhanced	*Core tier criteria plus the following:* Defects on the NBDPN Enhanced list of birth defects.
Extended	*Core and Enhanced tier criteria, plus some or all of the following:* Diagnoses not included on the NBDPN list but included in birth defects surveillance program activities as needed to meet jurisdictional goals.

Standard 3.1.1

Data Elements Collected (see **Appendix 3A** for details on each data element)	
Core	NBDPN Core Data Elements list
Enhanced	*Every element from the Core list, plus the following:* NBDPN Enhanced Data Elements list

Standard 5.1.1

Data Sources Utilized for Case Identification	
Core	*All of the following within the birth defects surveillance program's catchment area:* • Birth hospitals/birthing facilities • Pediatric hospitals • Tertiary care hospitals

Enhanced	*All Core tier criteria, plus some/all of the following:*
	• Prenatal diagnostic facilities
	• Maternal-fetal medicine specialists
	• Vital records
	  ○ Birth certificates
	  ○ Fetal death certificates
	  ○ Death certificates

Extended	*All Core tier criteria, plus some/all data sources in the Enhanced tier, plus some/all of the following:* • Specialty health care clinics (e.g., pediatric cardiology, genetics, ophthalmology) • Cytogenetics laboratories • Third-party payers (e.g., Medicaid databases, health maintenance organizations, Indian Health Services hospitals and clinics, all payers claim databases). • Other state programs (e.g., newborn screening, early intervention, developmental disabilities, cancer, HIV)

Standard 5.1.2

Criteria Routinely Utilized for Case Identification	
Core	*Birth defects surveillance programs routinely use the following specific indications of birth defects for case identification:* • Infant health care record contains information about a birth defect or suspected birth defect corresponding to the key terms or codes listed in the *"Diagnoses Included for Case Classification"* section of the case definitions in **Appendix 2A**. Terms and/or codes may appear within the record as a diagnosis, chief complaint, discharge code, or text description of a birth defect.
Enhanced	*Core tier, plus some/all the following specific indications of birth defects:* • Maternal health care record contains information about a pregnancy affected by birth defect or suspected birth defect in either a diagnosis, chief complaint, discharge code (e.g., ICD-10-CM O35 codes), or text description of a pregnancy affected by a birth defect. • Birth certificate with indication of a birth defect. • Fetal death certificate with indication of a birth defect. • Infant death certificate with indication of a birth defect. • Procedure code related to diagnosis or treatment of a birth defect (e.g., CPT code 49606 for repair of gastroschisis or omphalocele).
Extended	*Core tier, plus some/all the Enhanced tier, plus some/all the following nonspecific indications of birth defects:* • Infant health care record contains information that indicates the presence of a condition that can be associated with a birth defect without indication of a diagnosed or suspected birth defect (e.g., ICD-10-CM code outside Q00-Q99; such as H90.0 conductive hearing loss, bilateral). • Medical chart(s) with text that describes a finding that may suggest the presence of a possible birth defect (e.g., "abnormal facies"). • All fetal deaths and stillborn infants, whether there is an indication of a birth defect or not. • Neonatal deaths.

Standard 5.2.3

Cases in which Medical Record Abstraction is Performed	
Core	No medical record abstractions are performed.
Enhanced	Abstraction is performed in some cases selected through a criteria-based manner (e.g., all cases involving certain conditions, or by random sampling. For example, a birth defects surveillance program might perform abstraction on all critical congenital heart diseases.)
Extended	Abstraction is performed for all cases.

Standard 5.3.4

Cases in which Clinical Review is Performed	
Core	No clinical reviews are performed.
Enhanced	Clinical reviews are performed for some cases selected in a criteria-based manner (e.g., all cases involving certain conditions, or by random sampling. For example, a birth defects surveillance program might perform clinical review on all critical congenital heart disease.)
Extended	Clinical reviews are performed for all cases.

The following pages show the NBDPN Standards grouped according to tier, for an overview of the outputs and performance indicators expected for a program performing all **Core** activities, as compared to the **Enhanced** scope of activities, and the **Extended** scope of activities**.**

NBDPN Core Standards

Standard	Core Program Activities
Standard 2.1.2 Residency Status of Cases Included in Birth Defects Surveillance Program's Activities	In-state deliveries to in-state residents
Standard 2.1.3 Pregnancy Outcomes Included in Birth Defects Surveillance Program's Activities	Live births
Standard 2.1.5 Up to What Age-at-Diagnosis the Surveillance Program Ascertains Birth Defects	Cases diagnosed on or before the first birthday
Standard 2.2.1 Set of Defects Included in Birth Defects Surveillance Program's Activities	Defects on the NBDPN Core list of birth defects (see **Appendix 2A**)
Standard 3.1.1 Data Elements Collected	NBDPN Core Data Elements list (see **Appendix 3A**)
Standard 5.1.1 Data Sources Utilized for Case Identification	*All of the following within the birth defects surveillance program's catchment area:* • Birth hospitals/birthing facilities • Pediatric hospitals • Tertiary care hospitals
Standard 5.1.2 Criteria Routinely Utilized for Case Identification	*Birth defects surveillance programs routinely use the following specific indications of birth defects for case identification:* Infant health care record contains information about a birth defect or suspected birth defect corresponding to the key terms or codes listed in the *"Diagnoses Included for Case Classification"* section of the case definitions in **Appendix 2A**. Terms and/or codes may appear within the record as a diagnosis, chief complaint, discharge code, or text description of a birth defect.
Standard 5.2.3 Cases in which Medical Record Abstraction is Performed	No medical record abstractions are performed.
Standard 5.3.4 Cases in which Clinical Review is Performed	No clinical reviews are performed.

NBDPN Enhanced Standards

Standard	Enhanced Program Activities
Standard 2.1.2 Residency Status of Cases Included in Birth Defects Surveillance Program's Activities	*Core tier criteria plus the following:* Out-of-state deliveries to in-state residents (e.g., a resident may get care or deliver at a major medical center on the border of a neighboring state)
Standard 2.1.3 Pregnancy Outcomes Included in Birth Defects Surveillance Program's Activities	*Core tier criteria plus some/all of the following:* Fetal deaths delivered at a gestational age of ≥ 20 completed weeks (i.e., stillbirths) >350 grams if gestational age is unknown
Standard 2.1.5 Up to What Age-at-Diagnosis the Surveillance Program Ascertains Birth Defects	*Core tier criteria plus the following:* Birth defects surveillance program ascertains cases diagnosed after the first birthday. Birth defects surveillance program utilizes a later maximum age-at-diagnosis in conditions for which the diagnosis or level of severity are better understood over a longer timeline.
Standard 2.2.1 Set of Defects Included in Birth Defects Surveillance Program's Activities	*Core tier criteria plus the following:* Defects on the NBDPN Enhanced list of birth defects (see **Appendix 2A**)
Standard 3.1.1 Data Elements Collected	*Core tier criteria plus the following:* NBDPN Enhanced Data Elements list (see **Appendix 3A**)

Standard 5.1.1
Data Sources Utilized for Case Identification
	All Core tier criteria, plus some/all of the following:
	• Prenatal diagnostic facilities
	• Maternal-fetal medicine specialists
	• Vital records
	  ○ Birth certificates
	  ○ Fetal death certificates
	  ○ Death certificates

NBPDN Enhanced Standards are continued on the next page →

NBDPN Enhanced Standards, continued

Standard	Enhanced Program Activities
Standard 5.1.2 Criteria Routinely Utilized for Case Identification	*Core tier, plus some/all the following specific indications of birth defects:* • Maternal health care record contains information about a pregnancy affected by birth defect or suspected birth defect in either a diagnosis, chief complaint, discharge code (e.g., ICD-10-CM O35 codes), or text description of a pregnancy affected by a birth defect. • Birth certificate with indication of a birth defect. • Fetal death certificate with indication of a birth defect. • Infant death certificate with indication of a birth defect. • Procedure code related to diagnosis or treatment of a birth defect (e.g., CPT code 49606 for repair of gastroschisis or omphalocele).
Standard 5.2.3 Cases in which Medical Record Abstraction is Performed	Abstraction is performed in some cases selected through a criteria-based manner (e.g., all cases involving certain conditions, or random sampling. For example, a birth defects surveillance program might perform abstraction on all critical congenital heart diseases.)
Standard 5.3.4 Cases in which Clinical Review is Performed	Clinical reviews are performed for some cases selected in a criteria-based manner (e.g., all cases involving certain conditions, or random sampling. For example, a birth defects surveillance program might perform clinical review on all critical congenital heart disease.)

NBDPN Extended Standards

Standard	Extended Program Activities
Standard 2.1.2 Residency Status of Cases Included in Birth Defects Surveillance Program's Activities	Core + Enhanced activities suffice.
Standard 2.1.3 Pregnancy Outcomes Included in Birth Defects Surveillance Program's Activities	*Core tier criteria, plus some/all items from Enhanced, plus some/all of the following:* Elective terminations of pregnancy at any gestational age Fetal deaths delivered at a gestational age of < 20 competed weeks (i.e., miscarriages)
Standard 2.1.5 Up to What Age-at-Diagnosis the Surveillance Program Ascertains Birth Defects	Core + Enhanced activities suffice.
Standard 2.2.1 Set of Defects Included in Birth Defects Surveillance Program's Activities	*Core and Enhanced tier criteria, plus some or all of the following:* Diagnoses not included on the NBDPN list but included in birth defects surveillance program activities as needed to meet jurisdictional goals.
Standard 3.1.1 Data Elements Collected	Core + Enhanced data elements suffice.
Standard 5.1.1 Data Sources Utilized for Case Identification	*All Core tier criteria, plus some/all data sources in the Enhanced tier, plus some/all of the following:* • Specialty health care clinics (e.g., pediatric cardiology, genetics, ophthalmology) • Cytogenetics laboratories • Third-party payers (e.g., Medicaid databases, health maintenance organizations, Indian Health Services hospitals and clinics, all payers claim databases). • Other state programs (e.g., newborn screening, early intervention, developmental disabilities, cancer, HIV)

NBPDN Extended Standards are continued on the next page →

NBDPN Extended Standards, continued

Standard	Extended Program Activities
Standard 5.1.2 Criteria Routinely Utilized for Case Identification	*Core tier, plus some/all the Enhanced tier, plus some/all the following nonspecific indications of birth defects:* • Infant health care record contains information that indicates the presence of a condition that can be associated with a birth defect without indication of a diagnosed or suspected birth defect (e.g., ICD-10-CM code outside Q00-Q99; such as H90.0 conductive hearing loss, bilateral). • Medical chart(s) with text that describes a finding that may suggest the presence of a possible birth defect (e.g., "abnormal facies"). • All fetal deaths and stillborn infants, whether there is an indication of a birth defect or not. • Neonatal deaths.
Standard 5.2.3 Cases in which Medical Record Abstraction is Performed	Abstraction is performed for all cases.
Standard 5.3.4 Cases in which Clinical Review is Performed	Clinical review is performed for all cases.