Chapter 3: Data Elements

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3.0 Introduction

Data sources (see **Chapter 5**) can report a wide variety of information in response to the set of ***data elements*** requested by the birth defects surveillance program. Each data element may require staff time to locate, abstract, code, and evaluate, as well as computer space for storage. Since resources are finite, birth defects surveillance programs must balance comprehensiveness with efficiency to optimize the scope of data collected and the way the information is gathered, coded, and stored. As technology evolves, interoperability and automation are expected to improve efficiency.

In this chapter, we discuss several issues related to the data elements collected by a birth defects surveillance program. The reader is referred to **Appendix 3A** for the set of data elements recommended by NBDPN.

> **Recommendation 3.0.0:** To support estimating prevalence and monitoring trends, birth defects surveillance programs should collect the set of data elements developed by NBDPN, as detailed in **Appendix 3A**.

3.1 Set of Data Elements for Birth Defects Surveillance

NBDPN maintains a list of data elements that birth defects surveillance programs should collect (listed in **Table 3A** below, and detailed in **Appendix 3A**). When selecting and formatting the data elements for usage, birth defects surveillance programs should adhere to national data standards to facilitate data sharing, aggregation, and compatibility with interoperability. Refer to the US Core Data for Interoperability for information on national standards, and **Chapter 1** regarding developing or updating birth defects surveillance database platform functionality.

> **Recommendation 3.1.0:** Birth defects surveillance programs should collect and store data elements in accordance with national standards to promote interoperability and data sharing, whenever possible.

Table 3A

NBDPN Recommended Data Elements		
Core Tier		
Infant	• Age-at-Diagnosis • Birth Certificate ID • Birth Order • Birth Weight • Delivery Date • Delivery Location • Diagnosis Code(s) - NBDPN Birth Defect Case Definition Codes • Diagnosis Code(s) – Other Classification Systems	• Gestational Age • Infant Medical Record Number(s) • Name • Plurality • Pregnancy Outcome • Sex • Source of Report • Unique Case ID
Mother	• Mother's Date of Birth • Mother's Ethnicity • Mother's Medical Record Number(s)	• Mother's Name • Mother's Race • Mother's Residence at Time of Pregnancy Outcome
Enhanced Tier		
Infant	• Death – Autopsy Performed • Death – Date of Death for Live-Born Infant • Death – Death Certificate ID • Death – Fetal Death Certificate/Report ID Number • Death – Underlying Cause of Death • Diagnostic Tests and Procedures	• Method of Determining Gestational Age • Responsible Party's Address • Responsible Party's Name • Responsible Party's Telephone Number • Verbatim Description of the Birth Defect(s)
Mother	• Education Level of Mother • Gravidity • Parity • Prenatal – Date of First Prenatal Visit	• Prenatal – Date of Last Prenatal Visit • Prenatal – Month Prenatal Care Began • Prenatal – Number of Prenatal Visits

3.1.1 Criteria to Consider in Data Element Selection

The data element descriptions in **Appendix 3A** include the name and definition of each data element; justification for collecting it; source(s) from which the data element can be collected, derived, or created; how it is formatted; and how it can be checked for quality assurance. All of the NBDPN data elements were carefully selected based on the characteristics described in

Appendix 3B. In particular, the Core data elements can be collected and abstracted using a minimum number of data sources, including maternal records, infant records, and vital records (see **Chapter 5**).

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

3.1.2 Additional Data Elements

Although the data elements in **Appendix 3A** focus on surveillance for monitoring and estimating prevalence, they also provide the framework to expand and support other potential programmatic areas. Birth defects surveillance programs may consider adding data elements per their specific objectives and operational procedures to improve information management efficiencies and surveillance effectiveness (e.g., name of medical record abstractor, date of receipt of the case report). It should be noted that expansion of the list of data elements collected by a birth defects surveillance program may require additional time and resources.

Refer to the NBDPN Data Utilization Assessment Tool for additional information on ways promote and quantify the use of surveillance data elements.

3.2 Data Element Logic Checks for Quality Assurance

Birth defects surveillance programs should lay the foundation for data quality by consistently collecting the data elements that are essential for the sake of accurate surveillance (i.e., those on the NBDPN Core list in **Appendix 3A**). Within the information obtained for each case, birth defects surveillance programs should use quality assurance steps to check the completeness and accuracy of each data element and the overall data set.

> **Recommendation 3.2.0a:** Quality assurance steps should be an integral part of data collection.

Birth defects surveillance programs should prioritize data sources that enable an accurate and complete set of data elements (see **Standards Table 5.1.1** and **Appendix 5A**).

> **Recommendation 3.2.0b:** Birth defects surveillance programs should use data elements identified from preferred data sources, as defined in **Appendix 3A**. If a data element is not available or there is a suspected error from the preferred data source, additional sources may be used.

Errors and discrepancies can occur within and across data sources, during transmission, or during

abstraction. The use of technology may streamline the handling of data elements and minimize errors in data entry or abstraction.

> **Recommendation 3.2.0c:** Birth defects surveillance programs are encouraged to automate data collection and data entry to minimize abstraction errors, whenever possible.

Every data element can be subjected to quality assurance measures to identify errors needing correction. One means of identifying and correcting errors is through logic checks that ensure data are recorded within expected ranges. Many of the Core data elements in a birth defects surveillance program have a limited number of options or ranges of values (e.g., a gestational age of 75 weeks is highly unlikely to occur). Other elements may have certain logical relationships with one another (e.g., the mother's date of birth must always be before the infant's date of birth; the date of the last prenatal care visit must always be on or before the delivery date).

Specific logic checks for each of the data elements are detailed under *Quality Assurance Checks* in **Appendix 3A**. Additional guidance on quality checks through the lens of case ascertainment are discussed in **Chapter 7** [June 2004 Edition].

3.3 References

Mai CT, Gilboa SM. Surveillance for birth defects. In: Barfield WD, Besera G. Cox S, et al, eds. *From Data to Action: CDC's Public Health Surveillance for Women, Infants and Children.* 2nd ed. Centers for Disease Control and Prevention; 2020:332-351.

Olson JE, Shu XO, Ross JA, Pendergrass T, Robison LL. Medical record validation of maternally reported birth characteristics and pregnancy-related events: A report from the Children's Cancer Group. *Am J Epidemiol*. 1997;145:58-67. doi: 10.1093/oxfordjournals.aje.a009032

US Core Data for Interoperability (USCDI). Office of the National Coordinator for Health Information Technology; 2026. Updated January 29, 2026. Accessed April 28, 2026. https://isp.healthit.gov/united-states-core-data-interoperability-uscdi#draft-uscdi-v7