

## ***Chapter 4: Health Information Classification Systems and Coding***

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### **Appendix**

#### **Appendix 4A: Common Health Information Classification and Coding Systems in Birth Defects Surveillance**

## Chapter 4

### Health Information Classification Systems and Coding

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#### 4.0 Introduction

The National Birth Defects Prevention Network (NBDPN) promotes the use of coded information that is comparable across birth defects surveillance programs, especially for conditions that are reported to NBDPN. In this chapter, we discuss the available major ***health information classification systems*** related to birth defects coding, considerations for how codes are selected and used, and quality assurance methods to verify the accuracy of diagnosis codes in the birth defects surveillance program database.

Classification systems provide a means of standardizing communication related to disease diagnoses, clinical and surgical procedures, test results, pharmaceuticals, devices, and other terminology. Coding of birth defects within those health information classification systems is central to the surveillance process. The demand for standardized coded medical information has been accelerated by the development of large information databases, the rise of interoperability models, and the desire to produce comparable information across states, regions, and nations.

Health information classification and coding relies on an orderly set of rules and procedures to assign specific codes to represent the medical information from a case, based on a consistent classification scheme. Health information classification systems serve important functions from the perspective of a birth defects surveillance program, but often serve *different* functions for data sources. Understanding those different motives can allow birth defects surveillance programs to make sense of the incoming data.

**Birth defects surveillance programs** use health information classification systems and codes to:

- Develop the set of diagnosis code data elements (see **Chapter 3**) related to birth defect case definition criteria (see **Chapter 2**).
- Identify ***diagnosis codes*** and ***trigger codes*** for use during case identification, case investigation, and verification (see **Chapter 5**).
- Translate narratives from the medical documentation into standardized, discrete code.
- Promote the comparability and standardization of coded data across surveillance functions and programs.

**Data sources** use their respective health information classification systems to:

- Perform a myriad of administrative and billing functions, apart from their engagement with surveillance reporting.
- Translate narratives from the medical documentation into standardized discrete diagnosis codes.
- Identify which patient information will be reported out to the birth defects surveillance program.

## 4.1 Major Health Information Classification Systems for Coding Birth Defects

Birth defects surveillance programs deal with rare medical conditions, and the clinical findings are often nuanced. Using standardized diagnosis codes with consistent definitions for birth defects is imperative, as it allows for combining data across birth defects surveillance programs. Several health information classification systems of relevance to birth defects surveillance are described in more detail below, and in **Appendix 4A**. Specific classification systems and codes for birth defects surveillance are also included with the case definitions in **Appendix 2A**. Classification and coding systems that are incorporated into *Health Level 7* (HL7) implementation guides can be used in interoperability models to facilitate the exchange of standardized health information between different health systems.

### 4.1.1 Classification and Coding Systems for Diagnoses

There are three major classification and coding systems for birth defects diagnoses (see **Appendix 4A: Table 1**):

- ***International Classification of Disease and Related Health Problems (ICD)*** is used as a global standard for codes related to mortality (cause of death), clinical care, and research in over 100 countries and 43 languages. Multinational implementation enables comparison of health status and mortality across countries. The ***ICD Clinical Modification (ICD-CM)*** is the major disease (morbidity) classification system in US health care.
  - The ICD system is incorporated into HL7 implementation, and its broad use in interoperability models (nationally and internationally), as well as the standardization of diagnosis codes, is important in birth defects surveillance.
- The ***Centers for Disease Control and Prevention/British Pediatric Association (CDC/BPA)*** codes are a set of specialized six-digit diagnosis codes specific to congenital conditions. Over time, CDC modified and added codes to represent more detailed information and specificity about the defects, including laterality, severity, or subtype.
  - The CDC/BPA codes are not incorporated into HL7 for use in interoperability models, and must be assigned by the birth defects surveillance program.
- The ***Birth Defects Study To Evaluate Pregnancy Exposures (BD-STEPS)*** and the ***National Birth Defects Prevention Study (NBDPS)*** are multi-site, population-based, case-control studies carried out as major collaborative activities by the CDC-funded Centers for Birth Defects Research and Prevention. The BD-STEPS/NBDPS codes, which reflect selected birth defects, are based on the CDC/BPA codes but were modified to provide more specificity for research purposes.
  - The BD-STEPS/NBDPS codes are not incorporated into HL7 for use in interoperability models, and must be assigned by the birth defects surveillance program.

### **4.1.2 Classification and Coding System for Terminology**

***Systematized Nomenclature of Medicine Clinical Terms (SNOMED CT)*** is the most comprehensive, multilingual glossary of clinical terms, including standardized terms for diagnoses, signs and symptoms, procedures, clinical findings, anatomical structures, pharmaceuticals, test specimens, and medical devices (see **Appendix 4A: Table 2**).

SNOMED CT codes are used to exchange health data between information systems and are incorporated into HL7 implementation guides for interoperability. As systems move toward more interoperable data exchange with electronic health records, birth defects surveillance programs should be prepared to receive SNOMED codes and understand how they relate to ICD-CM.

### **4.1.3 Classification and Coding Systems for Procedures and Test Results**

***Procedure codes*** within medical records and discharge data sets can be a valuable tool for supporting the presence of a diagnosis by providing additional information about clinical or surgical procedures that have been performed, and test results that have been obtained (i.e., screening or confirmatory labs or imaging). The four health information classification and coding systems listed below are commonly encountered by birth defects surveillance programs, and all four are incorporated into HL7 implementation guides for interoperability.

For clinical and surgical procedures (see **Appendix 4A: Table 3**):

- ***Current Procedural Terminology (CPT)***
- ***ICD Procedure Coding System (ICD-PCS)***

For information on tests and results (see **Appendix 4A: Table 4**):

- ***International System for Cytogenomic Nomenclature (ISCN)***
- ***Logical Observation Identifiers Names and Codes (LOINC)***

## **4.2 Use of Coding Systems by Birth Defects Surveillance Programs**

Birth defects surveillance programs engage with health information codes in several ways. Codes may be included in a preset list to indicate which potential cases data sources should send to surveillance programs (see ***trigger codes***, **Chapter 5: Section 5.1.3**). Codes may be present in the case records received from data reporting sources, and/or assigned by the birth defects surveillance program, or used to analyze and report out data from the birth defects surveillance program.

### **4.2.1 Considerations Related to Birth Defect Codes**

Birth defects surveillance programs should understand the structure, purpose, and limitations of the health information classification system(s) and associated diagnosis codes they use, applying these general considerations:

- The quality of verbatim descriptions associated with a code in the system may vary. For example, there may be multiple synonyms for one birth defect, each with its own code

despite applying to the same defect. Alternatively, there may be multiple related birth defects assigned together under one code that fails to capture the nuanced differences between the defects. Finally, the single code for a **syndrome** often fails to capture the case-to-case variation in the exact defects present (see **Section 5.3.3**).

- Definitions of diagnoses may be incongruent or incompatible across different health information classification systems. In particular, the case definitions used in the clinical setting are not always the same as those used for public health surveillance.
- Different diagnostic categories may vary in the amount of detail and clarity they provide (e.g., location, laterality, anatomic severity, functional/symptomatic severity). Although ICD-CM is an acknowledged standard for coding medical information, it may lack the level of detail required for coding specific birth defects in certain situations.
- Diagnosis codes were largely developed for purposes other than public health surveillance. For example, the diagnosis code rules for ICD-CM are developed and maintained by the US government to primarily support and justify health services performed, for the purpose of billing and claims management across the health insurance industry.

In summary, there are limitations within each classification system and inconsistencies when comparing between codes from different systems. The birth defect case definition criteria in **Appendix 2A** includes codes from multiple different health information classification systems (ICD-CM, CDC/BPA, and SNOMED CT) grouped together in the context of each defect diagnosis, in order to aid birth defects surveillance programs with data management and case ascertainment. The appendix also includes a newly-developed set of codes for reporting data to NBDPN (see **section 4.2.3**), to improve consistency in code assignments for the sake of data aggregation across birth defects surveillance programs.

#### **4.2.2 Responding to Changes in Classification and Coding Systems**

Birth defects surveillance programs will face periodic changes in the health information classification systems they use, and encounter updates to the diagnosis codes within those systems over time.

**Recommendation 4.2.2:** Birth defects surveillance programs must develop procedures to follow when a health information classification system changes or a diagnosis code is updated for any reason.

Birth defects surveillance programs should keep track of the frequency with which various coding systems change their structure and/or **nomenclature**, and understand the impact those changes have on program activities. Key steps include:

- Monitor the update cycle for health information classification systems and diagnosis codes relevant to the birth defects surveillance program's activities. This can be done by accessing the agency website (or the proprietor of the data set) who maintains and updates the respective systems, and becoming familiar with their update schedule.

- Develop an internal system to monitor and log updates, and retain a history of the code changes over time.
- Notify the information technology staff, database managers, and surveillance staff of changes to the diagnosis codes, instructing them to change their internal procedures as needed to incorporate the changes.
- For each diagnosis code listed in the birth defects surveillance database, consider adding a field to indicate whether a diagnosis code has been updated due to a change in the health information classification system, and when the change occurred. Any code assignment change may affect statistical analysis or other evaluation activities.
- In response to classification system changes or diagnosis code updates, adjust the birth defects surveillance program's set of data variables accordingly for each of the following:
  - Case definition
  - Trigger codes/diagnosis codes used by data sources to identify potential cases for review, or for electronic case reporting (eCR)/interoperable messaging (**Chapter 5**)
  - Translating between health information classification systems (**section 4.2.3**)
  - Data analysis purposes
  - Programmatic functions (e.g., education, outreach, referral to services, etc.)

Of note, although the National Center for Health Statistics—the center within the CDC that administers and maintains the ICD-CM system—may deactivate a diagnosis code, the surveillance system should continue to recognize deactivated codes for the point in time at which the code *was* active.

### **4.2.3 Managing Birth Defect Diagnosis Codes from Different Health Information Classification Systems**

As discussed in **section 4.2.1**, it may not always be possible to directly translate between different classification systems' codes and definitions. This results in challenges when different health information classification systems are involved in the diagnosis codes received from the data source(s), versus the diagnosis codes assigned or maintained in the birth defects surveillance program database, versus the diagnosis codes used when reporting data out.

**Recommendation 4.2.3a:** Birth defects surveillance programs must develop procedures for managing diagnosis codes from multiple different health information classification systems, especially to reconcile diagnosis codes received from the data sources and the codes preferred for use within the surveillance program itself.

Several strategies can help with managing birth defects diagnosis codes from different health information classification systems. First, it is essential that the birth defects surveillance program's operational infrastructure supports data collection and storage of different health information classification systems' codes (see **Chapter 1**).

Second, the birth defects surveillance program must understand that a specific code in one health information classification system may not translate to a specific code in another system (see **section 4.2.1**). Accurately assigning codes from multiple coding systems may require a manual process and potentially a return to review the medical records for details, and still may not result in a one-to-one match for all specific diagnoses.

Birth defects surveillance programs may consider minimizing code translation activities when resources are limited. This ensures that the timeliness of data management is not negatively impacted due to higher workloads. The value of BPA specificity (see **section 4.1.1**) may not be worth adding a year to the timeline if there is only one person reviewing cases and assigning codes within the birth defects surveillance program.

- *Example:* If the information in a case chart meets criteria to be assigned an ICD-10-CM code for congenital diaphragmatic hernia (Q79.0, Q79.1), the same case information might be used to translate to a CDC/BPA modified code in the range of 756.610 – 756.617, which includes separate codes for Bochdalek, Morgagni, hemidiaphragm, or not otherwise specified. Yet, determining exactly which code within this range would require further understanding of the nature of the hernia, and would not be a direct translation of the ICD-10-CM code to the CDC/BPA code.

Third, when developing procedures for translating a diagnosis code from one coding scheme to another, be attentive to these key considerations:

- Translating tools delineate the rules for how and by whom the interpretation will be made. For many diagnoses, an established translation can be used such that a certain code in one health information classification system always corresponds to one or more certain code(s) in another health information classification system, in order to decrease (but not necessarily eliminate) the need for manual code translation. There are several sources for such a translation, although each may have inherent biases. For example:
  - *National Center for Health Statistics (NCHS)* developed a translation when ICD-10-CM replaced ICD-9-CM. However, its objective was to assist health care facilities to adhere to federal coding guidelines for billing and reimbursement, so it is *not* tailored for public health surveillance purposes.
  - **NBDPN** developed its own translation for birth defects surveillance after ICD-10-CM replaced ICD-9-CM, and continued to update it for several years to correspond to ICD-10-CM updates.
  - The *Council of State and Territorial Epidemiologists* maintains the codes used to trigger electronic initial case reports (eICRs) for all conditions supported by electronic case reporting (eCR; see **Chapter 5**). CDC maintains a specific listing of codes used to trigger eICRs for birth defects (see [CDC website](#) on electronic case reporting).

- Identify when the code translation will occur. Code translation is typically performed at one of these two points in time:
  - **At the time the reported data is received from the data source**, an established translation is used to assign a code from the birth defects surveillance program's health information classification system of choice, based on the code received from the data source. Translation at this timepoint is often coordinated by a central information technology department that processes the incoming data. The accuracy of the assigned code will be limited by the accuracy of the translation used, and by the shortcomings related to discrepancies between what the diagnosis codes mean in their respective classification systems.
  - **After the reported data is received and reviewed** by the birth defects surveillance program's qualified staff, the staff determine the code and its translation. If the data source uses the same health information classification system as the birth defects surveillance program, the staff either accept the code as received or follow program protocols to review the case records and assign a code (see **section 5.3.2**). If the data source uses a health information classification system that differs from the birth defects surveillance program's preferred system, the staff either use an established translation or manual methods to translate the incoming code to the congruent code(s) used by their program.
- Always maintain the original case report with the diagnosis code as reported from the data source for future reference, even when codes are internally assigned by the birth defects surveillance program. Archiving the data received is an important component of the birth defects surveillance program workflow (**Chapter 1**).

The use of multiple coding schemes with different diagnosis code definitions impacts NBDPN's ability to aggregate accurate data across birth defects surveillance programs. In response, NBDPN developed a neutral code system that is directly tied to the **case definition criteria** detailed in **Appendix 2A**, and the recommendations and standards described throughout this manual.

**Recommendation 4.2.3b:** Birth defects surveillance programs must use the NBDPN case definition codes when reporting birth defects surveillance data to NBDPN.

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