# Chapter 5

# Classification and Coding

# Table Contents

# Appendices

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http://www.nbdpn.org/bdsurveillance.html

# 5.1  Introduction

The National Birth Defects Prevention Network (NBDPN) promotes the use of coded information that is comparable across birth defects programs and methods of case ascertainment, especially for conditions that are reported annually to NBDPN. The proper and accurate coding of diagnostic information is an essential aspect of birth defects surveillance.

A disease classification system plays an important role in the ability of surveillance systems to collect, code, retrieve, and translate information regarding diagnoses and procedures. These activities depend on the ability to assign specific codes to medical information, based on a standardized classification scheme. There are two important ways that classification systems and the coding of birth defects within those systems are central to the surveillance process. Classification and coding rely on a standardized set of rules and procedures for case ascertainment based on medical information, as well as on a standardized way of describing and organizing "cases" based on their clinical conditions.

Coded medical information has become an important part of the health care delivery system. Coding rules, guidelines, and standards have evolved for practically every type of health service encounter. Surveillance systems should understand the various factors that affect the quality of the coding of birth defects and should implement procedures to improve the utility of coding.

In this chapter we discuss disease classification systems (Section 5.2), classification issues that affect surveillance systems (Section 5.3), guidelines for effective coding (Section 5.4), quality issues related to coded data (Section 5.5), and tips and hints to assist with the classification and coding aspects of managing a surveillance system (Section 5.6). References cited in this chapter may be found in Section 5.7.

The two appendices to this document may be viewed or downloaded from the NBDPN website at http://www.nbdpn.org/bdsurveillance.html. Appendix 5.1 is the Texas Disease Index and Appendix 5.2 is the listing of CDC 6-digit codes.

## 5.2  Disease Classification Systems

Over time, a number of systems for classifying pathology, diseases, injuries, and clinical procedures have been developed. This has led to a classification system known as the International Classification of Diseases (ICD). At present, the World Health Organization (WHO) and 10 international centers coordinate classification efforts and promote a standardized classification system for organizing coded data for storage, retrieval, and analysis. Using a standardized system, disease information that is collected by various medical professionals can be compared, grouped, and tabulated for statistical purposes. Definitive information about disease classification in the United States is available from the National Center for Health Statistics (NCHS) of the Centers for Disease Control and Prevention (CDC) (see http://www.cdc.gov/nchs/icd9.htm).

The ninth revision of the International Classification of Diseases (ICD-9) was in use from 1979 to 1998. The United States uses the standard ICD version for coding deaths and in 1979 developed a 'clinical modification' for use in hospitals (i.e., ICD-9-CM). The clinical modification of the ICD-9 expanded the general categories, permitted greater detail and description, and included codes for clinical procedures. A large body of ICD-CM coding guidelines and rules was also developed. Since most of the information about birth defects comes from clinical records, the discussion below refers primarily to ICD-9-CM. However, comments regarding structure and organization are applicable to ICD-9 codes as well.

In 1999, the tenth revision (ICD-10) became operational for coding causes of death on death certificates. Although the classification structure is basically unchanged, ICD-10 reflects a significant revision from ICD-9. The codes are alphanumeric instead of numeric (as was the case in ICD-9), there are more general categories, and the codes are described in greater detail than in earlier versions. As of 2002, NCHS is developing the clinical modification ICD-10-CM. (This reference manual will not discuss ICD-10-CM until it is implemented).

Of importance to birth defects surveillance is the fact that, although ICD-9-CM is an acknowledged standard for coding medical information, it is not optimal for the level of detail required for coding many birth defects.

In 1979 the British Paediatric Association (BPA) developed a classification of diseases by modifying ICD-9-CM (British). In 1983, staff in CDC's birth defects branch modified the BPA coding system and developed a classification system specific to birth defects coding. The 6-digit CDC code is a classification system that allows coding of more detailed descriptions of birth defects and related conditions (see Appendix 5.2 for a complete listing of the 6-digit CDC codes).

## 5.2.1  Description and Format

The ICD-9-CM and the 6-digit CDC coding systems are divided into general categories that include body systems, medical conditions, and other health-related issues. The codes are hierarchical and expand to reflect specific conditions within a general category. Each code category is populated with specific diseases and related conditions. In ICD-9-CM the majority of the codes used in birth defects programs is between the code categories 740 and 759, which come under the general heading of 'congenital anomalies'. The ICD-9-CM and the 6-digit CDC coding systems utilize a similar format for categorizing disease. ICD-9-CM utilizes up to five digits, while the CDC coding system utilizes six.

## 5.2.2  ICD-9-CM and the 6-digit CDC Code – A Comparison

In most cases, the first four digits of the 6-digit CDC code are identical to the first four digits of the ICD-9-CM code. This enables birth defects programs to utilize the coded data collected from hospital data sets, while at the same enhancing the level of coding detail for birth defects program use. Since, the 6-digit CDC code usually collapses into the ICD-9-CM at the fourth-digit level, programs that use ICD-9-CM codes have data that are comparable between states.

The most significant difference between ICD-9-CM and the 6-digit CDC code is reflected in the level of detail indicated by the sixth digit. The sixth digit can be used to indicate one of three aspects of the defect:

➢  *Laterality of the defect*
    .001  Left side only
    .002  Right side only
    .003  Unilateral, unknown which side
    .004  Bilateral; both sides

➢  *Greater specificity for a particular defect*
    .005  Example: 756.615 Diaphragmatic hernia (Bochdalek)
    .006  Example: 756.616 Diaphragmatic hernia (Morgagni)
    .007  Example: 756.617 Hemidiaphragm

➢  *Incomplete confirmation of a defect (includes possible or probable or only diagnosed prenatally)*
    .008  Example: 745.498 Probable Ventricular Septal Defect (VSD)

# 5.3 Classification Issues That Affect Surveillance Systems

It is important to recognize that there are advantages and disadvantages associated with both the ICD-9-CM and 6-digit CDC coding systems. Programs need to be aware of the ways in which these may affect data quality and other surveillance activities.

➢ *Any coding system is limited to the number of literal descriptions assigned to a code in the system*. In other words, there may be synonyms for one birth defect, or many related birth defects may be assigned to one code. The disease index provided in Appendix 5.1 is a tool that can be used to assist with coding. This alphabetic cross-linked index of birth defects and corresponding 6-digit CDC codes was developed by the Texas Birth Defects Monitoring Program. The cross-linked index is an expansion of the ICD-9-CM Congenital Anomalies category 740-759.9 and includes multiple disease descriptions, synonyms, and other descriptive terms that are used to describe birth defects.

➢ *Classification systems provide a framework for coding but often do not provide compatible definitions of diagnoses*. Clinical case definitions and case definitions used for public health surveillance are not always the same. Surveillance systems must specify how clinical documentation should be used to determine the appropriate disease code. See Chapter 3 on Case Definition for a discussion of ways to determine how birth defects should be coded.

➢ *Diagnostic categories are not consistent in the amount of detail they provide, nor are they always clear.* For instance, the chromosomal anomaly category (758) is very general. The musculoskeletal system (754-756) is not well-defined. Additionally, all birth defects are not identified with an explicit code, so there can be questions about how to code a particular defect or whether it should be coded at all.

➢ *A single ICD-9-CM code may be used to describe several different defects*. This may make it difficult to use the code to recover specific information. For example, codes such as those listed below present challenges because of the potential heterogeneity of the defects included under a given code:

- 742.2 Reduction deformities of brain (includes holoprosencephaly and absent corpus callosum)

- 747.21 Anomalies of aortic arch (includes overriding aorta and double aortic arch)

- 753.0 Renal agenesis and dysgenesis (includes absent kidney and hypoplasia of kidney)

- 756.0 Anomalies of skull and face bones (includes hypertelorism and craniosynostosis)

- 756.79 Other congenital anomalies of abdominal wall (includes gastroschisis and omphalocele)

➢ *ICD-9-CM codes do not reflect the status of the diagnosis*. For example, a condition may be possible or probable. This is problematic when birth defects are reported to the surveillance system in coded format, or when programs use the hospital disease index in case finding.

➢ *How information is coded in an administrative database (e.g., hospital disease index, hospital discharge data, Medicaid data) is determined by the methods used to assign codes and by the objectives of those who maintain the database*. In other words, code use is defined by the "business operations" of the facility or organization doing the coding. For example, the ICD-9-CM classification system is used primarily in hospitals and other care settings to comply with federal financial justification for payment. Coding decisions made by someone with that goal in mind could be different

from those made by someone coding for a surveillance system.

➢ *Professional disease coding training and courses for ICD-9-CM are beneficial in providing a good foundation for training staff regardless of the surveillance approach being used (i.e., active or passive case ascertainment).* Information on such courses is available from the American Health Information Management Association (http://www.ahima.org).

# 5.4 Guidelines for Effective Coding

As noted earlier, the primary goal in coding information is to provide accurate, consistent, and concise representation of that information. Coded diagnostic information is easier to analyze, compare, retrieve, and store. All of these attributes promote the use and dissemination of information between systems. The use of computer technology and the development of particularly large databases have accelerated the demand for coded information. The standardization of information that is translated into a code or discrete data element is one of the objectives of the Health Insurance Portability and Accountability Act of 1996 (HIPAA). For a thorough discussion of birth defects coding, see Rasmussen and Moore (2001).

Programs should:

➢ **Develop** well-defined surveillance case definitions. This includes identifying the characteristics of eligibility (e.g., demographics, pregnancy outcome, gestational age), and specific birth defects or diagnosis. These issues are discussed in Chapter 3 on Case Definition.

➢ **Understand** that the disease classification system and associated coding guidelines are developed to standardize results and assist in decision-making. The coding rules for ICD-9-CM as used by hospitals are established at the federal level through a set of guidelines administered, maintained, and updated by NCHS. To comply with these federal standards, a hospital coder may be required to use codes that differ from those used by a surveillance system coder. The 6-digit CDC code is supported by a body of guidelines and procedures that specifically address issues in assigning codes to birth defects. Coding rules for the 6-digit CDC code are detailed and have many exceptions. For example, when using the 6-digit CDC code, there may be exceptions in the laterality rule (i.e., does not apply to all diagnoses).

➢ **Adapt** surveillance procedures and the database to disease code changes as they occur. ICD-9-CM codes and code definitions are subject to rule changes, additions, deletions, and edits. ICD-9-CM changes are usually timed to coincide with the beginning of the federal fiscal year. It is essential for programs that use administrative databases to be aware of these code changes.

➢ **Track** disease code changes. Consider adding a date field to each disease code listed in the database. Disease codes are added, deleted, or edited by the authoritative agency, usually on an annual basis. Any code assignment change may affect statistical analysis or other evaluation activities. Tracking disease code changes will be an essential task when ICD-10-CM replaces ICD-9-CM.

➢ **Assign** a disease code to each diagnosis that is reportable to the program. This facilitates building a database of eligible disease codes (conditions), which can be incorporated into abstracting software (e.g., drop-down windows) and used to develop queries and generate lists.

➢ **Identify** the disease classification system that is to be used. Some programs may use more than one disease classification system.

    Examples:

    • An active case ascertainment system might only use the 6-digit CDC code.

- • A passive case ascertainment system might only use the ICD-9-CM classification system.

- • A passive case ascertainment system might use the 6-digit CDC code if the program receives case reports in a descriptive or literal format and if surveillance staff assign codes.

- • A passive case ascertainment system might use ICD-9-CM for case reports that are submitted to the program, but might use the 6-digit CDC code when staff actively review medical charts or for special projects.

➢ **Promote** the use of the 6-digit CDC code where possible. Because the CDC code conveys greater detail, surveillance systems should ideally incorporate this coding system into regular program operations. This may be easier for active ascertainment systems, as passive case ascertainment systems are often limited to the standard classification system in use at hospitals (i.e., ICD-9-CM). However, in order to promote consistency, accuracy, completeness, and comparability across birth defects programs, passive case ascertainment should use the 6-digit CDC code whenever possible.

➢ **Use** the NBDPN Abstractor's Instructions cited in Chapter 3 on Case Definition. This tool should be used as a reference for the birth defects that are central to the NBDPN. It describes the diagnosis and identifies the appropriate disease code.

➢ **Use** technical reference materials. For example, *The International System for Human Cytogenetic Nomanclature (ISCN)* is the definitive guide to understanding the classification system used in cytogenetics (Mitelman, 1995). The text provides information on definitions, on how to read and understand karyotypes, and on other technologies used in laboratory analysis. Surveillance systems can use the *ISCN* as a tool to assist in assigning a disease code to a case with a chromosomal anomaly.

➢ **Use** clinicians for advice on understanding medical conditions and for providing guidance on assignment of disease codes.

➢ **Develop** coding procedures for abstractors, especially as relates to standardized methods for translating medical information into a disease code. Document decision items that result from coding discussions through the use of a decision log or similar record-keeping system. Surveillance systems that are research based may require a different set of procedures than a surveillance system that is focused on providing services. The NBDPN Abstractor's Instructions cited in Chapter 3 on Case Definition provide a good foundation.

# 5.5 Coded Data Quality Issues

Many factors can affect the quality of coded data. As mentioned earlier, any disease coding system has limitations. Additionally, the translation of a medical diagnosis into a disease code requires interpretation and judgment. Programs can improve the quality of coded data by considering the following recommendations.

Programs should:

➢ **Promote** coding to the highest degree of accuracy, completeness, and consistency as required by the surveillance system and as recommended by the NBDPN.

➢ **Develop** methods to identify situations that may result in inconclusive or incomplete diagnoses. This is particularly important for programs that work with or receive diagnosis information in coded format. Programs can use length-of-stay patterns, type of diagnosis, and type of data source (e.g., prenatal diagnosis center) to determine whether follow-up is necessary. For example, a chromosomal anomaly diagnosed during the newborn period may be a 'suspect' condition at discharge, pending receipt of laboratory results.

➢ **Code** all individual defects associated with a chromosomal anomaly, syndrome, or association, unless a coding rule or the NBDPN Abstractor's Instructions cited in Chapter 3 on Case Definition specify otherwise (see next recommendation). Code the major chromosomal anomaly or syndrome as well. Some of the most frequently diagnosed syndromes are listed in the category 759.8 in the 6-digit CDC code (see Appendix 5.2).

  - Chromosomal anomalies should be coded to the highest degree of detail that is provided by the karyotype.

  - Birth defects that are components of syndromes identified by 759.8x should be coded separately.

➢ **Identify** those birth defects that are exceptions to the 'code all defects' rule outlined above. For some diagnoses, all birth defects related to the condition may not need to be coded. Refer to the NBDPN Abstractor's Instructions cited in Chapter 3 on Case Definition for a listing and description of these conditions. Develop methods to query the database to find potentially "extra" disease codes. This often occurs with passive case ascertainment using multiple data sources. Some sources may report the major birth defect, while others may report each defect within the major diagnosis.

➢ **Code** at the most specific level possible. For example, if the specific heart defect is known, it is essential to list the specific defect rather than a more general description such as 'congenital heart disease'. Passive case ascertainment systems may find it useful to develop data quality audits to identify diagnoses that frequently are assigned general or non-specific codes and that may merit follow-up.

➢ **Develop** computer edit checks to identify problems with code use. For example, some conditions should be combined under a single code. These include spina bifida and hydrocephalus, imperforate anus and anal fistula, esophageal atresia and tracheoesophageal fistula, tetralogy of fallot, and cleft lip and palate. Edit checks can also be developed for gender-specific conditions and for conditions that may also be acquired (e.g., hydrocephalus, skeletal deformations). Edit checks can further be used to identify codes for defects that should not be counted due to gestational age, birth weight, or other established eligibility criteria.

➢ **Develop** methods for identifying general or non-specific codes, miscodes, inappropriate or redundant codes, or unusual combinations of coded data in a case abstract or case record.

➢ **Evaluate** the accuracy and consistency of code assignment. Conduct evaluations to determine the level of agreement in code assignment among program staff, as well as between staff and acute care coders in hospitals. This is particularly effective in identifying differences that result due to federal ICD-9-CM coding guidelines. Identify problem areas and implement quality control procedures as necessary.

➢ **Develop** coding procedures documentation especially regarding decision items, discussion points, or code assignments. Identify implementation dates.

# 5.6 Tips and Hints

➢ *Coded data can be used to enhance surveillance capability, as they are easily manipulated and queried in a database.* For example:

- Birth defects case records that have multiple disease codes can be identified and investigated further to determine whether an underlying condition or syndrome is present.

- Birth defects codes that are included or excluded due to specific criteria can be identified and flagged.

➢ *Administrative databases, especially hospital discharge data, use the ICD-9-CM coding system.* Discharge data can be used for specific screening purposes. For example:

- Maternal pregnancy disease codes may identify potential birth defects cases, especially if the pregnancy results in a fetal demise.

- Possible cases of birth defects can be queried using disease codes for prematurity, low birth weight, stillbirths, etc.

➢ *Some programs may find it helpful to retain the complete descriptive text of the birth defect.* As previously stated, disease coding systems have limitations. While birth defects are translated to the most accurate disease code, the code may not be precise enough in describing the birth defect.

➢ *Patterns of disease code assignment for particular birth defects may vary between hospital disease coders.* During case finding and abstracting and when reviewing medical records, it is helpful to be observant of coding patterns and inclinations. In many instances, disease codes are listed in the medical records, which helps with these informal assessments.

# 5.7  References

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