Chapter 5: Case Ascertainment Methods

Contents

Appendices

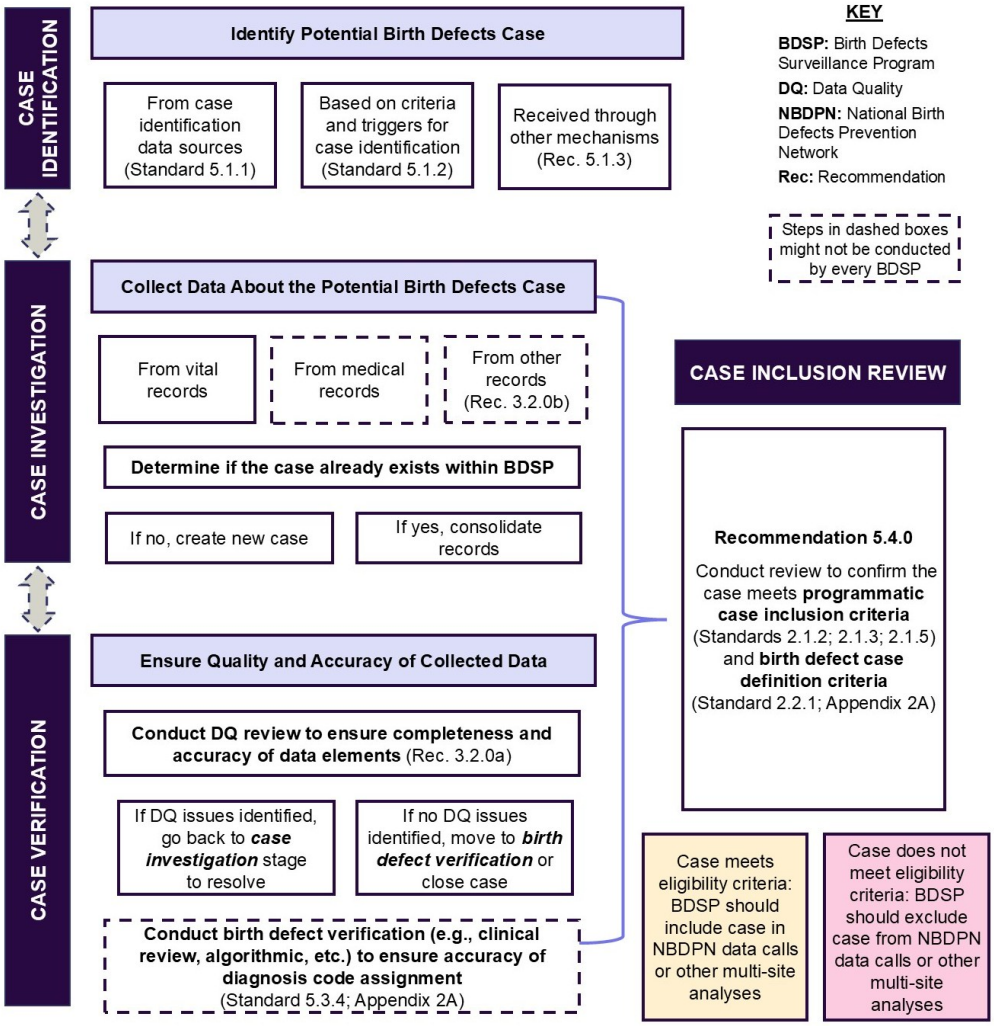
Chapter 5
Case Ascertainment Methods

5.0 Introduction

The National Birth Defects Prevention Network (NBDPN) supports a systematic approach to case ascertainment that involves a four-part process:

1) Identifying potential birth defects cases.
2) Investigating potential cases through data collection.
3) Verifying the completeness and accuracy of collected data, including the diagnosis/diagnoses assigned to the case.
4) Assuring that cases meet the programmatic case inclusion criteria (**Chapter 2**) and the NBDPN birth defect case definition criteria (**Appendix 2A**).

The schematic below shows the basic framework of program case ascertainment activities.



Although the schematic is shown as an overview of the course of action, processes may vary across birth defects surveillance programs (e.g., the order in which steps occur may differ, proceeding concurrently or as a circular process) based on their individual program goals, resources, and protocols.

Boxes with a solid outline in the diagram denote activities that NBDPN recommends all birth defects surveillance programs conduct. Boxes with a dotted outline denote Enhanced or Extended activities that birth defects surveillance programs might or might not conduct.

5.1 Case Identification

Birth defects surveillance programs use a set of processes and procedures to identify possible cases that might meet their ***programmatic case inclusion criteria*** and ***birth defect case definition criteria*** (see **Chapter 2**). The methods used to identify potential cases directly impact the surveillance program's calculated birth defect rates. The fundamental set of case identification strategies should include these functions:

- Establish strategic relationships with case identification data sources.
- Define the criteria and/or triggers that should prompt a data source to report to the birth defects surveillance program, and specify the data elements to be reported.
- Establish mechanisms by which the birth defects surveillance program will receive case identification data.

Recommendation 5.1.0: NBDPN recommends that birth defects surveillance programs aim to *identify* 95% of birth defects cases by 6 months past the date of delivery.

5.1.1 Case Identification Data Sources

In general, birth defects surveillance programs benefit from strategically utilizing multiple data reporting and information sources to notify them about potential cases. Please see **Appendix 5A** for more details on potential data sources for case identification.

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)

At a minimum, birth defects surveillance programs should identify cases through birth hospitals and facilities, pediatric hospitals, and tertiary care hospitals within their catchment area. Each of these data sources plays a distinct role in helping birth defects surveillance programs identify as many birth defects cases as possible within their area while limiting the resources needed.

- **Birthing facilities** (hospital labor & delivery units, and other birthing centers) perform a substantial proportion of deliveries and are thus positioned to provide the initial identification of a potential birth defect. However, birthing facilities are not the ideal case identification source for cases that are electively terminated, or for subtle birth defects that miss detection at the time of delivery.
- **Transfer hospitals, pediatric hospitals, and other tertiary hospitals** are often the best data source for cases in which detection of the birth defect was delayed (e.g., after discharge from the original birthing facility), or the infant was transferred soon after

delivery for additional specialty care. For subtle defects, these sites may be the location where the defect was first identified. For obvious or critical defects, they may provide more comprehensive records than the birthing facility. They may also be the best source for a final diagnosis, as assigned birth defects diagnoses can evolve over time in response to diagnostic tests and procedures.

To optimize resources, birth defects surveillance programs should evaluate other data sources for their value added in identifying potential birth defects cases per program objectives. For example, birth certificates do not have high sensitivity to capture birth defects overall but may be used to identify cases that were not otherwise reported to the birth defects surveillance program. Maternal-fetal medicine centers and diagnostic sites are important sources for prenatal data collection, particularly for case identification of non-live birth outcomes.

Recommendation 5.1.1: Birth defects surveillance programs should be selective about their data sources for case identification and investigation, choosing those which support the birth defects surveillance program's need for accurate, complete, consistent, and timely data. Each source should fill a specific data need.

Appendix 5B is a useful tool to assess the strengths of a data source for case identification, as well as case investigation and verification.

5.1.2 Criteria and Triggers for Case Identification

Birth defects surveillance programs must give their data and information sources a set of specific criteria to guide which potential cases the birth defects surveillance program does or does not wish to receive information about for the purpose of case identification.

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.

5.1.3 Mechanisms for Receiving Case Notification

Streamlining available technology to receive notifications and case reports from data sources should be implemented with the goal of improving the birth defects surveillance program's quantifiable data outputs in terms of accuracy, completeness, and timeliness.

Recommendation 5.1.3: Birth defects surveillance programs should strive to automate the process of requesting, receiving, and uploading cases that meet their case identification criteria, and become familiar with the different modes for receiving notifications and case reports.

Notifications and receipt of case reports from data sources can occur through several different mechanisms and formats, and often include various combinations depending on the source. Birth defects surveillance programs should be aware of their agency-wide procedures regarding electronic transactions with external data sources.

- ***Interoperability models*** provide the framework for the exchange of data in a highly automated and ongoing manner resulting in very timely data for case identification. If the data source and birth defects surveillance program are both set up to utilize ***Health Level 7 (HL7)*** messaging (often through an intermediary such as a centralized informatics or surveillance program support office), they can set certain ***trigger codes***—diagnostic codes, procedure codes, and key words or phrases related to birth defects—such that every time the data source encounters any case meeting the birth defects surveillance program's designated criteria, a standard set of information about the case will be sent to the birth defects surveillance program to notify them of the potential case. See **Chapter 4** and **Appendix 4A** for details on health information classification systems that use HL7 messaging.
    - Interoperability models include ***electronic case reporting (eCR)***, and other non-eCR HL7 reporting such as Clinical Document Architecture (CDA) and the Fast Healthcare Interoperability Resources (FHIR). The ***Public Health Informatics Institute (PHII)*** provides information on resources specific to birth defects surveillance programs.
- Automated modes for receiving notification or case reports via secured portal access or other type of electronic transmission are varied and depend on the capabilities of the data source and the type of information that is being requested, submitted, and/or accessed by the birth defects surveillance program. To establish an automated mode, the birth defects surveillance program must develop the list of reporting criteria including the set of diagnosis codes to serve as a standing request to the data source, and coordinate other logistics (e.g., a schedule for access or case reporting, and the format and mechanism of electronic transmission for case reports).

  The general types of automated modes for notifications include:
    - Open access to the electronic medical record, electronic health record, and/or direct receipt of potential birth defects cases, through fillable-web-based forms.
    - File downloads or file access. This mode is often utilized by large administrative and clinical-information data sets such as hospital indices, hospital discharge datasets, Medicaid datasets, vital records, and other public health programs (e.g., early hearing detection and intervention programs).

- Other variations of lists or individual reports via fax, e-file fax, postal mail, and encrypted email may be received. These mechanisms should be used as minimally as possible to reduce resources required.

5.2 Case Investigation

Case investigation entails gathering, abstracting, and consolidating data on a potential case. The key focus should be on collecting the data elements that support the primary goals of birth defects surveillance programs: monitoring and estimating prevalence. At a minimum, birth defects surveillance programs should ensure the NBDPN Core data elements (as defined in **Appendix 3A**) are completed during the case investigation (see **Recommendation 3.0.0**, and **Standard 3.1.1**).

5.2.1 Data Collection Sources

The data sources used by a birth defects surveillance program for case investigation are often the same as those used for case identification (see **Standard 5.1.1**). In some cases, the information reported from the data and information source at the time of case identification may be sufficient to rely upon for case investigation. However, additional information is often needed—either from the initial source or from one or more supplementary sources—to complete the case details and enable accurate investigation.

Certain data sources—including vital, medical, and other related records—are best situated to provide specific data elements. **Appendix 3A** lists the data source(s) for each data element, ranked in order of preference. **Appendix 3B.4** provides guidance on which data source takes precedence for various purposes (e.g., vital records are often the preferred source for demographic information). For the case investigation process, birth defects surveillance programs should identify data sources that are uniquely tailored to meet focused needs and then customize the list of data elements requested from each source. For example:

- Pediatric and other tertiary hospitals are ideal for providing details on inpatient follow-up care, the diagnostic process, and specialty evaluations.
- Clinic-based data sources (e.g., genetics clinics, specialty outpatient clinics) are well-suited to provide details on outpatient follow-up care, testing, and more precise diagnoses based on subspecialty evaluations or second opinions.
- Diagnostic centers and laboratories (e.g., cytogenetics, pathology, serology) provide results from prenatal and postnatal screening or confirmatory testing.

5.2.2 Record Consolidation

When multiple reports are received on the same case, differences can be expected in some of the information across reports. Consolidating the case information across reports into a single summary record can enhance the case information and help identify discrepancies between reports. Considerations include:

- **Demographics:** Most demographic items are constants that do not change with the age of the child (e.g., date of birth, race or ethnicity, mother's date of birth). Updating missing data fields using demographic data from subsequent reports is generally appropriate. Conflicts across reports for these fields can be resolved by prioritizing data from specific files or facilities over others. (**Appendix 3A** lists the preferred data source for each data element under *Data Source.*)
- **Identifiers:** In contrast to demographics, identifiers (e.g., name, parents' names, address) may be expected to change over time. (**Appendix 3A** includes guidance for managing changes to identifiers under *Additional Considerations.*)
- **Diagnostics:** Redundancy may arise when multiple reports are received for a child. This is simple to manage when the same diagnoses are repeatedly reported for the same case. However, if diagnostic data changes across reports, the birth defects surveillance program should determine the cause for the change and properly manage the documentation as follows:

    1. *Additional newly-diagnosed birth defects:* Newly diagnosed relevant conditions must be added to the documentation in the surveillance database for each case.
    2. *Previously diagnosed conditions reported with greater or lesser specificity:* Reports may differ on the diagnosis code due to improvement in level of detail (e.g., through additional clinical testing or results beyond initial diagnosis). The surveillance database should be updated with the most specific diagnosis code possible (see **Recommendation 5.3.3a**).
    3. *Actual changes to a previous diagnosis:* Changing a diagnosis can reflect a revision based on better information, or merely a proposed alternative diagnosis. Such changes need to differentiate the initial diagnosis from a new diagnosis. Having an effective mechanism in place for facilities to report corrections to diagnostic information can help reduce confusion in interpreting subsequent reports. When a change to a diagnosis is reported, programs should generally give preference to the diagnosis received from more specialized health care sources (e.g., pediatric/tertiary hospitals, specialty clinics, laboratory data; see **Appendix 3B.4**) and codes received at a later gestational age or older infant/child age. Some birth defects surveillance programs may prefer not to change original information, but rather flag it as inaccurate or no longer valid. This approach is especially useful when comparing reported information with the results of medical records review by surveillance staff.
    4. *Surgical repair of a condition may affect how a diagnosis is later reported:* Phased surgical repair may reflect the current status of the medical condition (e.g., complex cardiac cases with phased repair; repair of cleft palate and cleft lip at different times). Revision or corrective surgeries also impact how a diagnosis may be reported. When a surgical procedure improved the understanding of the defect type or level of severity, the surveillance database should be updated with the most specific diagnosis code possible. When a surgical procedure lessened the severity of a defect by partially or fully correcting it, the most specific diagnosis code reflecting the original severity should be maintained in the surveillance database. (For example: If a cleft lip has been repaired, the original cleft lip diagnosis does not get removed from the case.)

- **Procedures:** Redundancy can be expected in data reported for procedures since it is common for a child to have some treatments repeated, or corrective procedures performed multiple times or in stages.
    - If the *same procedure* is reported to have occurred on *multiple separate dates*, treat them as multiple separate procedure events and record each date.
    - If the *same procedure* is reported to have occurred multiple times on the *same date*, treat it as a single procedure event and record it once.
    - If *different procedures* are reported to have occurred on the *same date*, treat each procedure as a separate event and record each one.

Discrepancies in information across two seemingly similar records require a closer look at one or both records. Birth defects surveillance programs should implement methods to ensure case records are not inadvertently merged due to partial overlap across multiple case records. Common inconsistencies include:

- **Medical record numbers:** Both records from the same data source contain the same medical record number, but one has an additional medical record number from the same data source.
- **Hospital admission dates:** Both records have identical dates and diagnoses, but one has additional (and sometimes conflicting/overlapping) admission dates with the same or different diagnosis.
- **Multiple gestations:** Case records for multiple gestations may contain the same or similar demographics, diagnoses, and procedures. Birth defects surveillance programs should ensure data elements for plurality and birth order (see **Appendix 3A**) are recorded. These data elements can be used to ensure similar case records for multiple gestations are not inadvertently flagged as duplicate records and merged.

5.2.3 Medical Record Abstraction

Many birth defects surveillance programs perform ***medical record abstraction***, in which staff trained to identify birth defects through medical records gather information about the fetus/infant/child and the mother (when possible). The staff member formats the information in a standardized manner (i.e., case abstract) for use by the birth defects surveillance program. Medical record abstraction for some or all of the cases received by a birth defects surveillance program can aid with case investigation and support the case verification process.

NBDPN's birth defect case definition criteria (**Appendix 2A**) are the established national guidance for birth defects surveillance programs. Birth defects surveillance programs should develop their abstracting procedures to include the NBDPN case definition criteria to ensure quality information goes into the abstract. The review of medical records includes:

1. Applying birth defect case definitions and inclusion criteria (**Appendix 2A**).
2. Completing all required data elements (**Appendix 3A**).

3. Collecting other pertinent information.
4. Entering data into the database.

Birth defects surveillance programs rely on the medical information obtained from data sources to build the case record abstract. Despite having little control over the quality of the information the data sources report out, birth defects surveillance programs bear responsibility for assuring the quality of the coded medical information in their own database. Gathering additional supporting information from tests, results, or procedures can help improve the level of detail of the information a birth defects surveillance program collects, and the accuracy of the final diagnosis codes it assigns. Additional guidance on quality assurance is detailed in **Chapter 7** [June 2004 Edition].

Birth defects surveillance programs that collect medical information beyond what is listed in these Guidelines should also incorporate abstracting instructions for any additional topics to meet their individual programmatic objectives.

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.

5.3 Case Verification

Case verification is the process of ensuring the completeness and accuracy of data collected during the case identification and investigation processes.

5.3.1 Completeness of Data Elements

Birth defects surveillance programs should review case data elements for completeness and accuracy, particularly ensuring high quality data for NBDPN core data elements (see **Appendix 3A** for recommended data element quality checks). If critical information is missing or an error is identified, birth defects surveillance programs should return to the case investigation process.

5.3.2 Accepting or Assigning Birth Defect Codes

The birth defects surveillance program needs to determine appropriate diagnosis codes in response to the compiled or abstracted medical documentation, and indicate the level of certainty about the diagnosis code(s) for the case. In general, there are four approaches birth defects surveillance programs take to arrive at the diagnosis code that is entered or maintained in the surveillance database. Each approach has its own considerations:

- **Accept the diagnosis code as reported** by the data source. The level of detail of the reported diagnosis code will be dependent on the health information classification system used by the data source, and its accuracy will depend on the coding procedures utilized by the data source. The extra steps that a birth defects surveillance program takes to verify the certainty of a reported diagnosis code depend on available resources and program objectives. See **Appendix 2A** under *NBDPN Case Definition: Tier 2 Surveillance* for criteria to assist with determining the certainty of diagnosis codes accepted as-reported.
- **Manual coding based on abstraction and record reviews** involves qualified birth defects surveillance program staff examining information from the medical record(s) and manually assigning the appropriate birth defects diagnosis code(s) based on that information. This approach gives birth defects surveillance programs more control over how codes are used, how diagnoses are verified, and the types and number of medical records that are reviewed to determine the final diagnosis code assignment for each case. However, medical record abstraction is time-consuming, requires some level of clinical expertise, and the accuracy of the final code assignment for the case ultimately depends on what is documented in the patient records from the data source(s) and the proficiency of the abstractor and/or clinical reviewer. See **Appendix 2A** under *NBDPN Case Definition: Tier 1 Surveillance* for criteria to assist with determining the certainty of diagnosis codes assigned after abstraction +/- clinical review.
- ***Natural Language Processing (NLP)*** is a type of machine language scanning that uses specially developed software to "read" information and extract key data. Custom-designed software is increasingly used in public health to detect, analyze, extract, compile, and interpret text from a medical record or health data repository and suggest results and interpretations. Some public health NLP software programs propose diagnosis codes. Birth defects surveillance programs may utilize NLP to support the assignment of a diagnosis code as part of abstracting and clinical review procedures.
- **A combination of approaches** described above is used by many birth defects surveillance programs to balance the efficient use of resources versus the accuracy of the code assignments in the birth defects surveillance program database.

Regardless of the approach(es) taken to arrive at a diagnosis code, the birth defects surveillance program should take care to consider the level of certainty of the diagnosis, using the case definition criteria in the **Appendix 2A**.

Recommendation 5.3.2: Birth defects surveillance programs should designate whether a diagnosis is *Accepted* versus *Confirmed*, with guidance from the NBDPN case definition criteria.

5.3.3 Assigning the Most Specific Code Possible

Health information classification systems contain broad diagnosis code categories, with a set of more specific diagnosis codes to choose from within the code category.

> **Recommendation 5.3.3a:** Birth defects surveillance programs should strive to assign or maintain the most specific code possible, given the information available in the records associated with the case.

For example, if the specific heart defect is known, it is essential to assign a code for the specific defect rather than a more general description such as "congenital heart disease."

Take a thoughtful approach to situations in which a less specific code assignment may occur:

- "**Other specified**" code indicates that the patient's condition falls within a broad diagnosis code category but is not consistent with any of the more specific codes available. Clinicians or coders might use an "other specified" code when the clinical evaluation is complete (i.e., *sufficient* clinical data), but the defect's particular characteristics are truly distinct from any of the more specific codes. For example, ICD-10-CM contains a code for other specified congenital malformations of the circulatory system (Q28.8), applicable to congenital aneurysms and other spinal vessel anomalies.
- "**Unspecified**" code indicates that a diagnosis is present without providing specifics about its nature. Clinicians or coders might use an "unspecified" code when the clinical evaluation is incomplete or when the medical record lacks the documentation necessary to assign a more specific code (i.e., *insufficient* clinical data). For example, ICD-10-CM contains a code for an unspecified congenital malformation of the esophagus (Q39.9). Sometimes, an "unspecified" code is used when a fetal loss, infant death, or transfer to another facility occurred prior to the final clinical diagnosis.
- **Syndromes, Sequences, and Associations** represent groupings of multiple major defects in a single case that are related to each other.
    - Chromosomal anomalies should be coded to the highest degree of detail that is provided by the karyotype.
    - Birth defects surveillance programs should become familiar with groupings of defects that are often found together in ***syndromes***, ***sequences***, and ***associations***. For example, when Trisomy 21 is present, congenital heart defects are often also seen—especially atrioventricular septal defects (AV canal). Some such groupings of commonly co-occurring defects are detailed in the *Additional Information* section of the birth defects case definitions in **Appendix 2A**.

Recommendation 5.3.3b: Birth defects surveillance programs should strive to ensure that all defects are coded. If reported codes suggest *other specified*, *unspecified,* or a defect commonly grouped into a *syndrome, sequence, or association,* birth defects surveillance programs should request and review the medical records to better understand the actual diagnosis, search for information that may support a more specific code assignment, ensure all defects are included in cases, and verify whether a confirmed diagnosis or grouping designation has been made.

- **"Possible" or "probable"** diagnoses may be listed in the medical records for a case, coupled with a diagnosis of a syndrome, sequence, or association. Mention of possible or probable diagnoses, or a list of differential diagnoses, does not indicate that the presence of these conditions has been confirmed. NBDPN recommends using the criteria in the *Tier 1 Surveillance* and *Tier 2 Surveillance* sections of the birth defects case definitions in **Appendix 2A** to guide the approach to determining the level of certainty of the diagnosis for such cases.

5.3.4 Accuracy of Data

Clinical Case Review: Some birth defects surveillance programs have an expert in the field of medical diagnosis who reviews the completed case abstract and evaluates it for accuracy of the medical information, which could impact the certainty of the diagnosis and the assignment of a diagnosis code (**Appendix 2A**). Clinical case review is particularly important for birth defects surveillance as studies have found low ***positive predictive value*** for some birth defects codes. Review by trained subject matter experts can change the original defect classification(s) and improve the accuracy of assigned diagnoses.

Clinical reviews can sometimes result in further classification as part of a syndrome, sequence, or association (see **Section 5.3.3**).

Clinical reviews may be performed for some or all cases as part of the case verification process, depending on the birth defects surveillance program's goals, objectives, and resources.

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.

Other Verification Methods: Although many birth defects surveillance programs use clinical reviews to verify birth defects and check the accuracy of data collected, other methodologies

may be employed. Examples include accepting diagnoses reported by high-quality data sources that submit verified diagnoses (e.g., cytogenetic labs, clinical specialty clinics, etc.), utilizing algorithmic reviews, artificial intelligence methods (e.g., natural language processing, machine learning), or accepting the diagnosis code when it is reported consistently across multiple data sources.

5.4 Case Inclusion Review

As information is gathered and reviewed during case identification, investigation, and verification, a birth defects surveillance program may find that a case does not meet the programmatic case inclusion criteria (**Chapter 2**) or birth defect case definition criteria (**Appendix 2A**).

> **Recommendation 5.4.0:** Birth defects surveillance programs should review cases to ensure that they meet both their programmatic case inclusion criteria and the NBDPN birth defect case definition criteria.

Case inclusion review may occur at any point along the case ascertainment process. Examples are given below:

- During case identification, a logic edit or a manual review may determine that the identified individual does not meet the programmatic case inclusion criteria or the birth defect case definition criteria. Examples of the former include determining that the case is a resident of another jurisdiction, or the pregnancy resulted in a fetal loss at < 20 weeks gestation.

  During case investigation or case verification, review of medical documentation may reveal that the reported diagnosis is actually not a birth defect. For example, the condition is acquired and not congenital, or a previously reported diagnosis is ruled out following a new diagnosis that is not a congenital anomaly. Such a change in diagnosis or etiology often happens with additional consultations, especially genetic consultations and cytogenetic lab reports.

5.6 References

Lynberg MC, Edmonds LD. Surveillance of birth defects. In: Halperin W, Baker EL Jr., eds. *Public Health Surveillance*. New York, NY: Van Nostrand Reinhold; 1992:157-171.

Mai CT, Kirby RS, Correa A, Rosenberg D, Petros M, Fagen MC. Public health practice of population-based birth defects surveillance programs in the United States. *J Public Health Manag Pract*. 2016;22(3):E1-8. doi: 10.1097/PHH.0000000000000221

Mburia-Mwalili A, Yang W. Birth defects surveillance in the United States: Challenges and implications of International Classification of Diseases, 10th revision, Clinical Modification implementation. *Int Sch Res Notices*. 2014;2014:212874. doi: 10.1155/2014/212874