**ICD-9 to ICD-10 Transition Guidance**

**I. Introduction**

Transition of the United States (US) healthcare system to use of the International Classification of Diseases, Clinical Modification, version 10 (ICD-10-CM), on October 1, 2015, has broad implications for use of these data for surveillance, research, and other public health purposes. It is critical that birth defects programs assess and understand the effects of this transition on their surveillance methods, the observed frequency of defects in their area, trends in defect frequency over time, referral of affected children to healthcare services, and other uses. A primary advantage of ICD-10-CM is the increased number and specificity of diagnostic codes, and updated terminology and classification that more accurately reflect current understanding. Disadvantages include the addition of alphanumeric coding, reorganization of some sections of the code, the extent of training needed for staff to gain familiarity and experience with its use, and the need to develop crosswalks or translations between ICD-9-CM and ICD-10-CM to assess defect prevalence across years. For more information about the differences between ICD-9-CM and ICD-10-CM, see the ICD-10-CM and Birth Defects page under Resources on the NBDPN website at <https://www.nbdpn.org/icd10.php>.

The transition to ICD-10-CM has implications for all birth defects surveillance programs but the specific impact will vary depending on how programs use ICD coding. Programs that receive reports of birth defects coded in ICD-10-CM may experience a change in the way some defects are defined in the new codes. It may not be possible to define defect categories using ICD-10-CM in the exact way they were defined using ICD-9-CM for monitoring and reporting purposes. Programs that receive reports coded in ICD-10-CM and then verify the diagnoses through medical record review may experience a change in the number of records for which review is required with associated changes in the resources needed to perform these reviews. Programs that use ICD-10-CM codes from administrative data for case-finding followed by medical record review may experience changes in the number and completeness of cases identified from these sources. This may vary depending on the practices and experience of coding staff at each data source. Birth defects programs are encouraged to consider how the use of ICD-10-CM may affect all stages of their surveillance methods. For more information about case ascertainment methods, see Chapter 6 of the NBDPN **Guidelines for Conducting Birth Defects Surveillance at** <https://www.nbdpn.org/guidelines.php>.

This document is intended to provide initial guidance on assessing the effect of the transition to ICD-10-CM on birth defects surveillance data and to share common practices and experience. Use of the guidance by individual programs will depend on program needs and the surveillance methods used.

**II. Assessing and Analyzing Data for Potential Issues Related to Implementation of ICD-10-CM**

A variety of approaches can be used to assess and understand the effects of the transition to ICD-10-CM coding on birth defects surveillance data. Implementation of ICD-10-CM could affect processes at multiple levels both internal and external to the program. Thus, no single approach will reveal all changes in the data that may result. The exact approach utilized will vary among programs depending on their individual needs and situations. Approaches to identifying changes in the data that resulted from the implementation of ICD-10-CM can include the following:

1. **Familiarize yourself with the anticipated changes based on known ICD-10-CM code changes**
   1. The most common type of change is the expansion of one ICD-9-CM code into multiple ICD-10-CM codes, with each ICD-10-CM code representing a subset of the conditions included in the single ICD-9-CM code
      1. This could appear as if there had been a decrease in the frequency of the condition after the transition to ICD-10-CM, when in fact each ICD-10-CM code is more specific and includes fewer of the total cases included in the single ICD-9-CM code
      2. An example is encephalocele for which there is a single ICD-9-CM code (742.0) and five ICD-10-CM codes (Q01.0, Q01.2, Q01.3, Q01.8, Q01.9), one for each of the different types
   2. Occasionally, multiple ICD-9-CM codes are lumped together into one ICD-10-CM code
      1. This could appear as if there had been an increase in the frequency of the condition after the ICD-10-CM transition, when in fact the ICD-10 code is just less specific and includes more conditions
      2. An example is congenital cataract for which there are five ICD-9-CM codes (743.30, 743.31, 743.32, 743.33, 643.34), one for each of the different types of cataract, and only one ICD-10-CM code (Q12.0)
   3. Some conditions are rearranged in ICD-10-CM such that it is impossible to recreate the exact combination represented by one or more ICD-9-CM codes
      1. An example is epispadias which is included under congenital anomalies of genital organs (752.62) in ICD-9-CM and is included under congenital malformations of the urinary system (Q64.0) in ICD-10-CM
   4. A list of anticipated changes to the prevalence of the 47 defects reported by NBDPN based on the known ICD-10-CM code changes can be found at: <https://www.nbdpn.org/icd10.php>

Anticipated changes to other defects are discussed in the webinars also available from:

<https://www.nbdpn.org/icd10.php>

* 1. In addition, each year on October 1 the National Center for Health Statistics, CDC, releases revisions and updates to the ICD-10-CM code
     1. A list of these updates to the ICD-10-CM codes for congenital malformations, deformations and chromosomal abnormalities (Q Codes, Chapter 17) by year is also available at: <https://www.nbdpn.org/icd10.php>

1. **Compare the data for a defined time period before and after the transition to ICD-10-CM**
   1. Compare the total number of case reports received, the total number of defect codes included in the data, the total number of potential defect cases that require record review, etc., across the time periods
      1. This can provide an indication of whether the ICD-10-CM data contain the same cases and conditions that are present in the ICD-9-CM data collected before the transition to ICD-10-CM
      2. If a difference in the totals is noted, consider comparing the totals for individual defects, defect categories, or organ systems to assess whether the changes are limited to certain birth defects
      3. Comparing the total number of cases with specific codes that are selected for medical record review may help identify if only certain birth defects were affected
   2. Compare the prevalence of all defects together and the prevalence of individual defects, defect categories, or organ systems across the time periods
      1. This can provide an indication of whether the differences being seen are those that were anticipated based on the changes to the ICD-10-CM code
   3. Compare the data from individual ascertainment sources across the time periods
      1. Even if the total data from all sources is similar before and after the transition, there may be variations for individual data sources that require attention
      2. This can provide an indication of issues and inconsistencies in coding practices or other methods at different ascertainment sources
      3. Different approaches may be required depending on the type of data being assessed (e.g., hospital discharge data, administrative datasets, vital records)
   4. It is important to have sufficient sample size and power to detect a change in the number of cases or in defect prevalence following the transition to ICD-10-CM and to know how large of a change can be detected
      1. The length of the time period chosen for comparison before and after the transition should include sufficient data such that random fluctuation in the numbers is not a major contributor to any differences seen
      2. The time period needed for comparison depends on the size of the hospitals or other ascertainment sources, the rarity of the defects being examined, etc.
         1. Comparisons can be made on a monthly, quarterly, yearly or even longer basis
         2. For very small ascertainment sources or very rare defects, data from several years after the transition may be needed to evaluate whether a change has occurred or to put that change in context
      3. Ideally, an equivalent time period before and after the transition should be chosen.
         1. For example, defect prevalence over the first 3 quarters of 2015 could be compared with that for the 4th quarter of 2015 and the first two quarters of 2016, or alternatively with that for the first three quarters of 2016 if there is potential variation in defect prevalence by season of the year

**III. Evaluating an Issue Further Once it is Found**

If an apparent discrepancy is found between data reported using ICD-9-CM and that using ICD-10-CM, it is important to assess whether the change is expected based on the ICD-10-CM coding scheme, results from inconsistent or inaccurate use of ICD-10-CM codes, or results from other factors either internal or external to the program. The following are factors for consideration when a difference is observed:

1. **Changes in ascertainment sources (hospitals, prenatal offices, specialty clinics, labs, etc.)**
   1. Assess whether the change in the data is confined to only certain sources or apparent in the data from all sources
   2. If the change is isolated to only certain facilities:
      1. Consider whether factors other than the ICD-10-CM transition occurred at the same time that might affect the data, such as:
         1. Acquisition of additional facilities or being acquired by another reporting source
         2. Addition of data to the reporting, such as outpatient/clinic information
         3. Change in staff responsible for generating reports for the program
         4. Change in the clinical care-giving capacity at a data source such as expansion of diagnostic services
      2. Assess whether there are facility-specific ICD-10-CM transition related factors that could contribute to the observed change in the data
         1. Incompleteness of data submission
         2. Certain ICD-10-CM codes systematically missing from reports
            1. Some facilities may not have fully updated their birth defects reporting
         3. Reports submitted with ICD-9-CM codes for discharges after October 1, 2015 instead of ICD-10-CM codes
   3. If the change is apparent in data from all sources, consider whether internal processes could affect facility reporting, such as:
      1. Implementation (or lack thereof) of changes in the codes requested, the format of files provided, the frequency with which reports are generated, filters such as the range of birth dates requested, and other reporting specifications
   4. Note that changes such as these are not necessarily related to the ICD-10-CM transition and may affect the data at any time they occur
2. **Changes in the data**
3. Assess whether the change results from changes in data from the data source that is utilized by your program
   * 1. If your program utilizes reports from vital records (birth, death, fetal death), consider whether there have been changes in the frequency with which data are received or the type of access you have (reports vs. live access)
     2. If your program utilizes reports from hospital discharge data, consider whether there have been changes in the number of hospitals included, the frequency with which data are received and reported, or the information that is included
4. **Continued monitoring**
   1. If a change in the data is noted, continue to monitor whether it persists over time
   2. A change noticed shortly after the transition to ICD-10-CM could result from lack of familiarity of staff at the data sources with the new coding scheme
      * 1. If so, the change may lessen or correct itself over time as the coding becomes more accurate and consistent with experience
   3. If the change persists, it may indicate it is more likely related to the ICD-10-CM code itself
   4. A trend in the data that was noted before the transition to ICD-10-CM and continues afterward may not be cause for concern

**IV. Tips, Suggestions and Things to Consider**

The following tips may be helpful in assessing the effects of the transition to ICD-10-CM on birth defects surveillance data:

1. **Keep notes on your coding decisions** 
   1. Have a hard copy of the ICD-10-CM code and any mapping or translation references handy
   2. Code translations from ICD-9-CM to ICD-10-CM and vice versa are available from the ICD-10-CM and Birth Defects page under Resources on the NBDPN website at <https://www.nbdpn.org/icd10.php>
2. **Be alert to changes in the documentation of case reports and medical records**
   1. Use of ICD-10-CM may force changes in terminology
3. **Note changes in surveillance data resulting from the transition to ICD-10-CM that cannot be corrected**
   1. These should be acknowledged as best as possible when disseminating data
4. **Recall that the healthcare delivery system is constantly evolving in ways that can affect surveillance data**
   1. The transition to use of electronic medical records may contribute to some of the observed changes as their use was adopted by many healthcare systems in 2015 as well

**V. Appendix**

1. For more detailed information on developing, planning, implementing, and conducting surveillance for birth defects and using the resulting data, view the **Birth Defects Surveillance Guidelines** at <https://www.nbdpn.org/guidelines.php>
2. For more information on the transition from ICD-9-CM to ICD-10-CM, including a detailed **list of anticipated changes** to the prevalence of the 47 NBDPN defects, code translations between the two systems, a timeline of updates to the ICD-10-CM made annually, and other resources, visit <https://www.nbdpn.org/icd10.php>
3. A recent study has been published examining the transition’s impact on the prevalence of birth defects using data from the Agency of Health Care Research and Quality-sponsored National Inpatient Sample. [Birth Defects Res.](https://www.ncbi.nlm.nih.gov/pubmed/31414582) 2019 Nov 1;111(18):1365-1379.
4. **Issues with Birth Defects Surveillance Data Following the Transition to ICD-10-CM Observed by Programs to Date:**
   1. Healthcare Cost and Utilization Project (HCUP) data:
      1. Clubfoot showed a decrease immediately following the ICD-10-CM transition
      2. Hypoplastic left heart syndrome showed an increase immediately following the ICD-10-CM transition
         1. Possible explanation for these results include:
            1. Hospital coders may not yet be familiar with ICD-10-CM; a longer time period may be needed to evaluate whether the increase persists
            2. The prevalence of hypoplastic left heart syndrome usually increases in October; seasonal variation in certain defects might cause an apparent increase immediately following the ICD-10-CM transition
            3. Increased prevalence in the fall of the year might also be due to the end of the government fiscal year affecting Medicaid funding for health care
   2. Medicaid data:
      1. There was a very noticeable decrease for Ventricular Septal Defect (VSD) in the 4th quarter of 2015, followed by an upward trend in the numbers in 2016
   3. State surveillance data:
      1. One state observed a drop in the total number of potential cases identified for review in 2015 compared to 2014. This was specific to certain conditions, including several cardiac conditions (e.g., Atrial Septal Defect (ASD), VSD). The decrease resolved and the numbers went back up again for 2016.
         1. A possible explanation might be that this was related to the adoption of electronic medical records by the data sources which also happened in 2015
      2. Biliary atresia showed more than a 2-fold increase in prevalence following the ICD-10-CM transition
         1. This has been observed in multiple data sets
         2. One possible explanation is that hospitals are using computer-assisted coding and that this was not set up correctly for biliary atresia in ICD-10-CM so additional conditions may be included under the biliary atresia codes
      3. One state observed an increase in the total number of potential limb defect cases with the transition to ICD-10-CM; but once the cases were reviewed, the number of a subset of confirmed limb reduction defects was actually lower than reported before the transition
      4. Other unexpected changes observed in state data include:
         1. Bladder exstrophy (increase)
         2. Small intestinal atresia (decrease)
         3. Hypospadias (decrease)
         4. Hypoplastic left heart syndrome (decrease)
         5. Cleft lip with cleft palate (decrease)
         6. Possible explanations for these unexpected results include:
            1. Some hospitals may be delayed in reporting due to the ICD-10-CM transition
            2. Hospitals may still be learning how to code in ICD-10-CM; the observed changes may be due to their lack of experience
   4. Some of the changes may result from variability due to small numbers of cases for rare defects (e.g., bladder exstrophy)
   5. Some state programs have noticed that hospital staff are coding differently in ICD-10-CM than they were in ICD-9-CM
   6. Not Otherwise Specified (NOS) codes are being used more frequently in ICD-10-CM
   7. In some instances, the increased specificity and complexity of the ICD-10-CM codes seem to have contributed to coding errors rather than improving the situation