Electronic Birth Defects Case Reporting

Toolkit for Reporting Through an Electronic Health Records System

Improve your reporting to birth defect registries AND meet the requirements for a Meaningful Use Specialized Registry!

This Toolkit Will Help You Understand:

• Why Support Electronic Birth Defects Reporting
• Why Overall Benefits of Reporting
• What is a Birth Defect Case Report?
• Birth Defect Reporting and Meaningful Use
• What is a Reportable Birth Defect?
• What Information is in a Case Report?
• Where Can You Learn More?
Why Support Electronic Birth Defects Reporting?

One out of every 15 Michigan babies is born with a reportable birth defect. State birth defect surveillance programs act as the catalyst for prevention and treatment. The surveillance programs identify children with birth defects and facilitate their assessment and referral needs.

Surveillance teams use birth defect registries to:
- Complete birth defects incidence and mortality rates and analyze trends
- Identify and respond to potential clusters
- Formulate and test hypotheses of causation
- Plan and develop relevant programs
- Coordinate assistance for long-term care and follow-up
- Evaluate programs and services
- Further educate professionals and the community at large

The goal of reporting is to obtain more complete and reliable reporting of birth defects, while also ensuring that surveillance data sets are representative of the entire state. Most states have legislation supporting birth defect surveillance programs, and even mandate birth defect reporting. Legislation helps access in-patient and out-patient medical records on children with reportable conditions. This results in the information being population-based which is critical to research and administrative use.

**Approximately 1 in 15 Michigan babies are born with a reportable birth defect. Reporting of these birth defects will help children get the resources and services they need, while improving cost-effectiveness and timeliness of data reporting.**

Overall Benefits of Reporting

- Helps children with birth defects get the resources and support services they need
- Improves the quantity and quality of data collected, thereby enhancing the national public health capacity to monitor, understand, and prevent birth defects
- Provides the necessary information about a child’s birth defect and health status across their lifespan
- Improves public health surveillance, streamlining existing processes and procedures for case ascertainment and data collection, and improves cost-effectiveness and timeliness of data reporting
- Supports bi-directional communication, with public health eventually being able to deliver care/advice to the patient/provider directly
**Benefits to Patients**

- Provides a complete picture of medical and service needs at the statewide and community level
- Links a child with a birth defect(s), and their family, to needed services
- Enhances understanding of access to essential care and best practices
- Helps public programs identify and bridge gaps
- Informs service planning to support children and caregivers

**Benefits to Providers**

- Enables seamless “system to system” case reporting built from information already recorded in the electronic medical record
- Helps to understand the long term risks faced by children, adolescents and adults with a birth defect
- Allows for immediate follow-up of a defect report, such as or diagnostic test results or clarification of the diagnosis
- Conducts epidemiologic and outcomes research through analysis of electronic health record (EHR) data
- Supports the evaluation of patient health status, facilitates interventions for prevention and screening, and provides access to public health agencies to better care for and improve the population’s health
- Meets the Stage 2 Meaningful Use Specialized Registry Objective

**Birth Defect Reporting and Meaningful Use**

Eligible professionals enrolled in the Medicare and Medicaid Incentive Program can leverage the Meaningful Use Specialized Registry Objective to report cases to state birth defect surveillance programs, reducing the burden of paper based or electronic batch file reporting.

**What is a Reportable Birth Defect?**

For the purposes of generating and reporting birth defects surveillance data across multiple states, the National Birth Defects Prevention Network (NBDPN) established guidelines for identifying reportable conditions that will meet the requirements for reporting in most states. Reportable conditions are selected for surveillance by the states based on various factors including severity, frequency, impact, and the existence of public health prevention and intervention strategies, as well as the state of knowledge about etiology and risk factors, and other considerations.
What Information is in a Case Report?

The information collected in a case report was developed through the NBDPN to meet state reporting requirements regardless of the state where treatment occurs. The information collected includes diagnostic and demographic information, details on newborns at the time of birth, on data on parents, procedures, medications and treatments. Details on diagnostic confirmation and current health status are also included as variables in the standard case report message as well as diagnosis specific information, such as laboratory or genetic testing results.

While the overall information is quite detailed, the reports are tailored to the specific diagnosis and care setting. Each case report will include the pertinent information routinely captured within the EHR when a throughout the child’s condition history. The information available to construct the report will vary, but the case reports are designed to be very flexible, and can extract routine information as the encounter is recorded.

Where Can You Learn More?

For information on reporting using your EHR, please contact the Birth Defect Reporting Help Desk at MBDR.help@altarum.org.

For more information on birth defects surveillance in Michigan, please visit the following sites:

For statistical data:  
http://www.michigan.gov/mdhhs/0,5885,7-339-73970_2944_4670---,00.html

For reporting requirements:  
http://www.michigan.gov/mdhhs/0,5885,7-339-71551_2945_5221-16665--,00.html

For information on registering for Meaningful Use:  
https://michiganhealthit.org/public-health/birth-defects-registry/