Recommendations at a Glance

The National Birth Defects Prevention Network (NBDPN) ***Recommendations*** denote specific guidance that NBDPN strongly suggests incorporating into every birth defects surveillance program to ensure timely, accurate, and complete data.

The NBDPN Recommendations are summarized here, with numbering corresponding to the chapter and section where each Recommendation can be found throughout the *Guidelines for Conducting Birth Defects Surveillance*.

Recommendation 1.0.0: NBDPN strongly recommends that birth defects surveillance programs strive to conduct all Core activities defined by the Surveillance Guideline Standards and achieve minimum data quality standards prior to expanding into Enhanced and/or Extended practices.

Recommendation 1.1.0: When establishing or updating a birth defects surveillance program, staff should engage in discussions with the public health agency's institutional leadership, legal advisors, pertinent IT staff, data reporting sources, partners, and key collaborators in order to ensure alignment with the program's mission and objectives.

Recommendation 1.2.0: Birth defects surveillance programs should work with their agency and/or health department to propose, amend, or add legislation or authorizing regulations that will shape and enable surveillance operations.

Recommendation 1.4.0: The information technology (IT) platform should use IT standards to support the requirements of the birth defects surveillance program.

Recommendation 1.4.4: Birth defects surveillance programs should utilize record linkage procedures to facilitate matching all reports to the correct case record, and for other surveillance functions.

Recommendation 2.1.1: Birth defects surveillance programs must define the geographic boundaries (i.e., catchment area) of the source population for case identification.

Recommendation 2.1.2a: Birth defects surveillance programs must define the programmatic case inclusion criteria for residency.

Recommendation 2.1.2b: For surveillance purposes, birth defects surveillance programs should use the address on the vital record (when available) to determine whether the residence meets the programmatic case inclusion criteria for residency.

Recommendation 2.1.3: Birth defects surveillance programs must define the set of pregnancy outcomes to be included as a component of programmatic case inclusion criteria.

Recommendation 2.1.4: When multiple estimates of gestational age are ascertained for an individual case, the NBDPN suggests using the most accurate method available in the records to determine the case status.

Recommendation 2.1.5: Birth defects surveillance programs must define the maximum age by which a birth defect must have been diagnosed for it to meet the programmatic case inclusion criteria for age-at-diagnosis.

Recommendation 2.2.1a: Birth defects surveillance programs should meet data quality standards for Core defects before expanding to include Enhanced or Extended conditions.

Recommendation 2.2.1b: For any defect under surveillance, birth defects surveillance programs should use the NBDPN birth defects case definition criteria in **Appendix 2A** when determining whether to report the case to NBDPN.

Recommendation 3.0.0: To support estimating prevalence and monitoring trends, birth defects surveillance programs should collect the set of data elements developed by NBDPN, as detailed in **Appendix 3A**.

Recommendation 3.1.0: Birth defects surveillance programs should collect and store data elements in accordance with national standards to promote interoperability and data sharing, whenever possible.

Recommendation 3.2.0a: Quality assurance steps should be an integral part of data collection.

Recommendation 3.2.0b: Birth defects surveillance programs should use data elements identified from preferred data sources, as defined in **Appendix 3A**. If a data element is not available or there is a suspected error from the preferred data source, additional sources may be used.

Recommendation 3.2.0c: Birth defects surveillance programs are encouraged to automate data collection and data entry to minimize abstraction errors, whenever possible.

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.

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.

Recommendation 4.2.3b: Birth defects surveillance programs must use the NBDPN Birth Defect Case Definition Codes when reporting birth defects surveillance data to NBDPN.

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.

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.

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.

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 in **Appendix 2A**.

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.

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.

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.