National Standards for Birth Defects Surveillance

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For the SGSC Standards Work Group

NBDPN Annual Meeting
October 19, 2015
Surveillance Guidelines and Standards Committee
Standards Work Group

- AR: Bridget Mosley
- CDC: Cara Mai, Richard Olney, Jennifer Isenburg
- CO: Russel Rickard, Carol Stanton
- FL: Russell Kirby
- IA: Paul Romitti
- MA: Marlene Anderka (Chair)
- MI: Glenn Copeland
- TX: Mark Canfield
- UT: Marcia Feldkamp, Sergey Krikov
Standards will:

• Demonstrate the **value** of birth defects surveillance systems

• Help states **advocate** for additional resources to improve their systems

• Allow for better **national estimates and meaningful comparisons** across areas

• Facilitate **state collaborations**

• Prepare us for the **future** (e.g. EHR)
Standards Work Group
2015/2016 Agenda

- Assessment of Data Quality Standards
- Begin Drafting Standards on Data Utility
- Revision of the BD Surveillance Manual
Newly published article on NBDPN data quality standards in BMC Public Health

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Development and implementation of the first national data quality standards for population-based birth defects surveillance programs in the United States

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Second year of data quality assessment results were collected from programs as part of the annual NBDPN call for data.

Referenced updated lists of birth defects and data elements.
Appendix 3.1

Birth Defects Descriptions

for NBDPN Core, Recommended, and Extended Conditions

Updated March 2015

Participating members of the Birth Defects Definitions Group:

Lorenzo Botto (UT)
John Carey (UT)
Cynthia Cassell (CDC)
Tiffany Colarusso (CDC)
Janet Cragan (CDC)
Marcia Feldkamp (UT)
Jamie Frias (CDC)
Angela Lin (MA)
Cara Mai (CDC)
Richard Olney (CDC)
Carol Stanton (CO)
Csaba Siffel (GA)
Updates & Changes to NBDPN Birth Defects List

- List of birth defects updated (conditions added, dropped, merged and separated)
- ICD10 codes added
- Each birth defect designated as Core, Recommended or Extended
- Detailed descriptions of birth defects were updated and enhanced
Descriptions of NBDPN Data Elements
for Population-based Birth Defects Surveillance

Updated March 2015

Participating members of the NBDPN Data Elements Subgroup:

Glenn Copeland (MI)
Mary Ethen (TX)
Jane Fornoff (IL)
Sergey Krikov (UT)
Rebecca Liberman (MA)
Cara Mai (CDC)
Brennan Martin (VT)
Russel Rickard (TX)
Sherry Spence (CO)
Updates & Changes to NBDPN Data Elements List

* Summary list of data elements updated
* Each data element designated as standard level 1, 2 or 3
* Quality assurance check(s) provided for each data element
* Detailed descriptions of data elements were updated and enhanced
• 47 population-based birth defects surveillance programs (44 states, CDC, DOD, Puerto Rico)

• 47 completed tools were collected (2 excluded - DQ 1.1 has to meet at least a level 1 and program must achieve at least an average score of 1 across all measures)

• 17: active case-finding; 28: passive case-finding
2015 Results:
All Performance Measures

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<th>DQ1.2</th>
<th>DQ1.3</th>
<th>DQ1.4</th>
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<th>DQ2.1</th>
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</table>

Legend:
- Level 3
- Level 2
- Level 1
- None
Data Quality Products

BIRTH DEFECTS SURVEILLANCE SYSTEMS
NBDPN DATA QUALITY ASSESSMENT REPORT SUMMARY 2015

Data Quality Assessment for Population-based Birth Defects Surveillance System
Performance standards for birth defects surveillance are intended to improve and standardize operations, outcomes and surveillance functions across state programs, thereby making data more consistent and useful for a variety of purposes at the state, multi-state and national levels. The eleven indicators of data quality were developed around completeness, timeliness and accuracy of data (see Appendix 1). Three performance levels were associated with each indicator:

1. Level 1: Rudimentary level of performance by a surveillance program
2. Level 2: Essential level of performance by a surveillance program
3. Level 3: Optimal level of performance by a surveillance program

The expectation is that the majority of sites would be able to achieve a Level 2 on all measures.

Performance Measure Score
Aggregate program self-reported performance measure scores are shown in the bar graph. The percent of programs by standard level is calculated for all programs in the U.S. (45 programs) that reported levels 1-3 for that measure. The calculation by standard level excludes those programs who could not meet level 1 for DQ1.1 or an overall average score all measures of at least one (n=3).
What are the key factors and attributes that we need to be similar across programs?
Data Utility Standards

EARLY DRAFT OUTLINE

1. Core Monitoring
   * 1.1 Birth Defect Database
   * 1.2 Data Sharing, Collaboration, and Reporting

2. Public Health Practice
   * 2.1 Referral to Service
   * 2.2 Education, Outreach and Prevention

3. Research
Support for development, production, and distribution of these guidelines was provided by the Birth Defects State Research Partnerships Team, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention.
Goals for Manual Revision

- Combine guidelines and standards
- Have a new structure with a more logical flow
- Be more web-friendly
- Be easier to navigate (with essential in chapters and additional details in appendices)
NBDPN Standards Data Quality Tools - Data Quality Performance Measures

- Results of the 2015 NBDPN Data Quality Assessment
- Assessing the Quality of Data from the FL Birth Defects Registry: Completeness, Accuracy, Timeliness
- Implementing a Quality Improvement Approach to Enhance Birth Defects Surveillance in MA