Birth Defects Surveillance and Research in North Carolina

Nina Forestieri, MPH
Manager, Birth Defects Monitoring Branch
State Center for Health Statistics
Division of Public Health
NCDHHS
Current State-Based Birth Defect Surveillance in US

- **Active surveillance**
- **Passive w/ case confirmation**
- **Passive, no case confirmation**
- **No system or limited surveillance**

Source: NBDPN, Nov. 2017
NC Birth Defects Monitoring Program

• Statewide, population-based system (~120,000 births/year)

• Authorized in 1995 (NCGS 130A-131.16-17)

• Legislation stipulates:

  1. Hospitals/physicians must allow BDMP staff to review records.

  2. Hospitals/physicians cannot be held liable for providing data.

  3. Identifying information collected by BDMP is confidential.
NCBDMP Case Definition

- Infants with structural birth defects diagnosed within 1st year
- NC resident at birth, regardless of place of birth
- Live births (any gestational age)
- Fetal deaths (> 20 weeks gestation)
- TABs (any gestational age)
- (excl. spontaneous abortions < 20 weeks)
NCBDMP Case Ascertainment

• “Active” case finding approach:
  • Field staff systematically review and abstract clinical data from hospital medical records.
  • Cover all hospitals providing L&D and peds care in NC (90+ facilities statewide).
  • Case-finding – review hospital disease index reports, hospital discharge data, birth, fetal death, infant death certificates, prenatal dx logs to identify suspected cases.
  • Case confirmation – diagnoses verified through review of medical records of suspected cases.
NCDMP Case Ascertainment

• Data Collected:
  Maternal and infant identifiers, demographics, pregnancy outcome, clinical information (verbatim diagnoses, tests, procedures, surgical notes, cytogenetic & autopsy results)

• Birth Defect Coding:
  CDC/British Pediatric Association (BPA) coding system

• Data Collection and Analysis:
  • ~12,000 charts reviewed annually
  • ~4,500 charts abstracted
Uses of NCBDMP Surveillance Data

- Monitoring and descriptive epidemiology
- Responding to inquiries from health departments, clinicians, and the public about the occurrence of birth defects in NC
- Evaluating public health services and interventions
- Etiologic research
Centers for Birth Defects Research and Prevention
NC Center for Birth Defects Research and Prevention

- Collaboration UNC Department of Epidemiology & NCBDMP
- 2003-present
- Study region: 33 counties (PCR 2 and 4), 52,000 births
National Birth Defects Prevention Study

- Largest case-control study of birth defects risk factors
- 32,187 cases & 11,814 controls completed interviews
- Buccal cell samples from 19,065 case families & 6,211 controls
- Over 200 manuscripts published to date
Birth Defects Study to Evaluate Pregnancy Exposures

- Replaced NBDPS in 2014 (AR, CA, IA, MA, NY, NC, CDC)
- Focus on chronic medical conditions, medications
- Fewer number of phenotypes included
- Maternal phone interview
- No buccal cell collection—optional local consent for newborn dried blood spots
The NCBDMP provides complete, timely, and accurate data on birth defects in North Carolina, and collaborates with other organizations for produce high-quality research to inform local, state, and national birth defect prevention efforts.