Recommendations of the EPHT Birth Defects Content Workgroup

Suzanne Gilboa, PhD

National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention

Disclaimer: The findings and conclusions in this presentation have not been formally disseminated by CDC and should not be construed to represent any agency determination or policy.
Purpose

To establish a national environmental public health tracking network which will facilitate access to information on environmentally related diseases, human exposures and environmental hazards that can be used to respond to and eventually reduce the burden of environmental diseases.
EPHT Workgroups

EPHT

- Program Marketing and Outreach (PMO)
- Standards and Network Development Workgroup (SND)
- Portal, Analysis, Visualization and Reporting Team (PAVR)
- Content Workgroup (CWG)
Content Workgroup (CWG) Structure and Interactions

Steering Group
- Grantee Principal Investigators
- CWG Co-chairs

Pass Recommendations to CDC

Coordinate with SND and PMO Co-chairs

Provide Direction
- Offer Recommendations for Discussion
- Provide Feedback

CWG Teams
- Leads Air Quality
- Leads Drinking Water Quality
- Leads Childhood Lead Exposure
- Leads Cancer
- Leads Birth Defects
- Leads Birth Outcomes
- Leads Hospitalization Data
- Leads CO Poisoning (Non-Core)

Solicit Reactions
Conduct Review and Provide Feedback

Content Workgroup Consists of Above Entities and Other Interested Parties
Content Workgroup (CWG) Teams

- **Overall charge:**
  - Develop recommendations for data sets, measures/indicators and metadata in content topic areas that will be part of the national network of surveillance systems to monitor environmental health

- **Teams**
  - Air quality
  - Birth defects
  - Birth outcomes
  - Cancer
  - Carbon monoxide poisoning (non-core)
  - Childhood lead exposure
  - Drinking water quality
  - Hospitalizations (for asthma and myocardial infarction)
Birth Defects CWG Team

Co-Leads
Greg Kearney (FL)  Leslie O’Leary (CDC)  Suzanne Gilboa (CDC)

Team Members
John Braggio (MD)  Ed Fitzgerald (NY)  Miland Palmer (UT)
Gale Carlson (MO)  Cynthia Goodman (PA)  Lowell Sever (Battelle)
Jane Correia (FL)  Mandy Green (OR)  Matt Strickland (CDC)
Phil Cross (NY)  Kim Hauser (FL)  Barbara Toth (NM)
Kathy Decker (ME)  Heidi Krapfl (NM)
Jay Devasundaram (PA)  Danelle Lobdell (EPA)  CDC Tracking Support
Marcia Feldkamp (UT)  Stephanie Miller (NH)  Nick Jones
Toni Fightmaster (UT)  Asresu Misikir (PA)  Scott Kegler
Invitation

- If you are from a tracking grantee state and do not already have representation on the BD CWG Team, you are invited to join the group!
Tasks

- Task 1: Assess existing information and gaps
- Task 2: Consider surveillance goals for birth defects
- Task 3: Identify and evaluate needed data sets
- Task 4: Propose measure(s) / indicator(s) for presentation and display
- Task 5: Identify needed elements to describe data quality for metadata
# EPHTN Health Data Model

## Data Flow Diagram

<table>
<thead>
<tr>
<th>Source or Individual Data* (Raw)</th>
<th>Individual Level Data* (Key descriptors e.g., race, sex, age)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>State Secure Portal(s)</strong></td>
<td></td>
</tr>
<tr>
<td>1. Source or Individual Data*</td>
<td>2. Individual Level Data*</td>
</tr>
<tr>
<td>Identified</td>
<td>Partially Identified</td>
</tr>
<tr>
<td>De-identified</td>
<td>State Firewall</td>
</tr>
</tbody>
</table>

**Not Public**: (some form of “registration”)

*Conceivably linkable data

## Data Levels

<table>
<thead>
<tr>
<th><strong>State Secure Portal</strong></th>
<th><strong>National Secure Portal</strong></th>
<th><strong>National (and/or State) Public Portal</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>3. Counts &amp; Interpreted</td>
<td>A. NCDM* High resolution</td>
<td>4. Counts (\text{(Low resolution)}) (\text{more masking &amp; aggregation})</td>
</tr>
<tr>
<td></td>
<td>B. NCDM* High resolution</td>
<td></td>
</tr>
<tr>
<td></td>
<td>C. “Pre-linked” (Data)</td>
<td></td>
</tr>
</tbody>
</table>

**Nationally Consistent Data and Measures**

**PUBLIC**

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**Draft**: 060607
Data Source Options

- Team overwhelmingly favored use of state birth defects surveillance system data over other possible sources of birth defects data.

- Note: During approval process, Team was asked to reconsider other data sources such as vital records or hospital discharge data in order to be more “nationally consistent”
Surveillance Goal

- Surveillance goal: To monitor spatial and temporal variation in the annual prevalence of twelve major birth defects.

- Note: Why not a linkage goal?
Potential Analytic Approaches

- Comparisons within states or within groupings of states (similar to NBDPN groupings for estimation of national prevalence)
  - Prevalence of birth defects by socio-economic status (through conducting linkage at county, census tract or zip code level)
  - Prevalence of birth defects over time (moving averages)
  - Race-ethnic disparities in birth defects prevalence
    - Changes in disparities over time
Priority Birth Defects

- Twelve birth defects
  - Anencephaly
  - Spina bifida
  - Hypoplastic left heart syndrome
  - Tetralogy of Fallot
  - Transposition of the great arteries
  - Cleft lip with or without cleft palate
  - Cleft palate alone
  - Hypospadias
  - Gastroschisis
  - Upper limb deficiencies
  - Lower limb deficiencies
  - Trisomy 21

Why these 12 defects?

Why not the 21 with national estimates or the 45 reported to the NBDPN annually?
Selected Recommendations

- EPHT participants should leverage resources to support and enhance state BD surveillance systems
  - Examples include Florida and New York
  - Short → medium term, efforts should be made at the state level to geocode BD surveillance data
Selected Recommendations

- For the last five years of available data, report annual prevalence of 12 birth defects, stratified by:
  - Maternal age
  - Maternal race/ethnicity
  - Infant sex
  - Geography (county)

- States that ascertain cases among fetal deaths and/or terminations should provide two sets of prevalence estimates – one including and one excluding these other pregnancy outcomes
Selected Recommendations

- Efforts should be made at the state level to classify cases
  - Isolated
  - Multiple
  - Chromosomal/Syndrome

- Presentation of data must clarify the lack of comparability between states with different surveillance methods
Accomplishments

- Developed recommendations and how-to-guide complete with recommended SAS code for calculating stratified prevalence
- Pilot tested how-to-guide (FL, MA, NH, UT, NY)
  - Received favorable response from EPHT Steering Group (EPHT PIs)
- Developed data structure template and sample metadata with assistance of CDC, Environmental Health Tracking Branch
  - Awaiting results of evaluation by EPHT Steering Group
Next Big Tasks

- Data presentation
  - Maps?
  - Graphs?
  - Compare with ‘national prevalence’ estimates? Which state systems can/should be grouped together?

- Public health messaging
  - Coordination with PMO and those with marketing / communications expertise

- Development of metadata
- Report confidence intervals for prevalence?
Question

What linkages between birth defects surveillance data and environmental hazard data should be accomplished first through the national environmental public health tracking network?
Thank you

Suzanne Gilboa: sgilboa@cdc.gov

Leslie O’Leary: loleary@cdc.gov

Greg Kearney: greg_kearney@doh.state.fl.us