



Recommendations of the EPHT Birth Defects Content Workgroup

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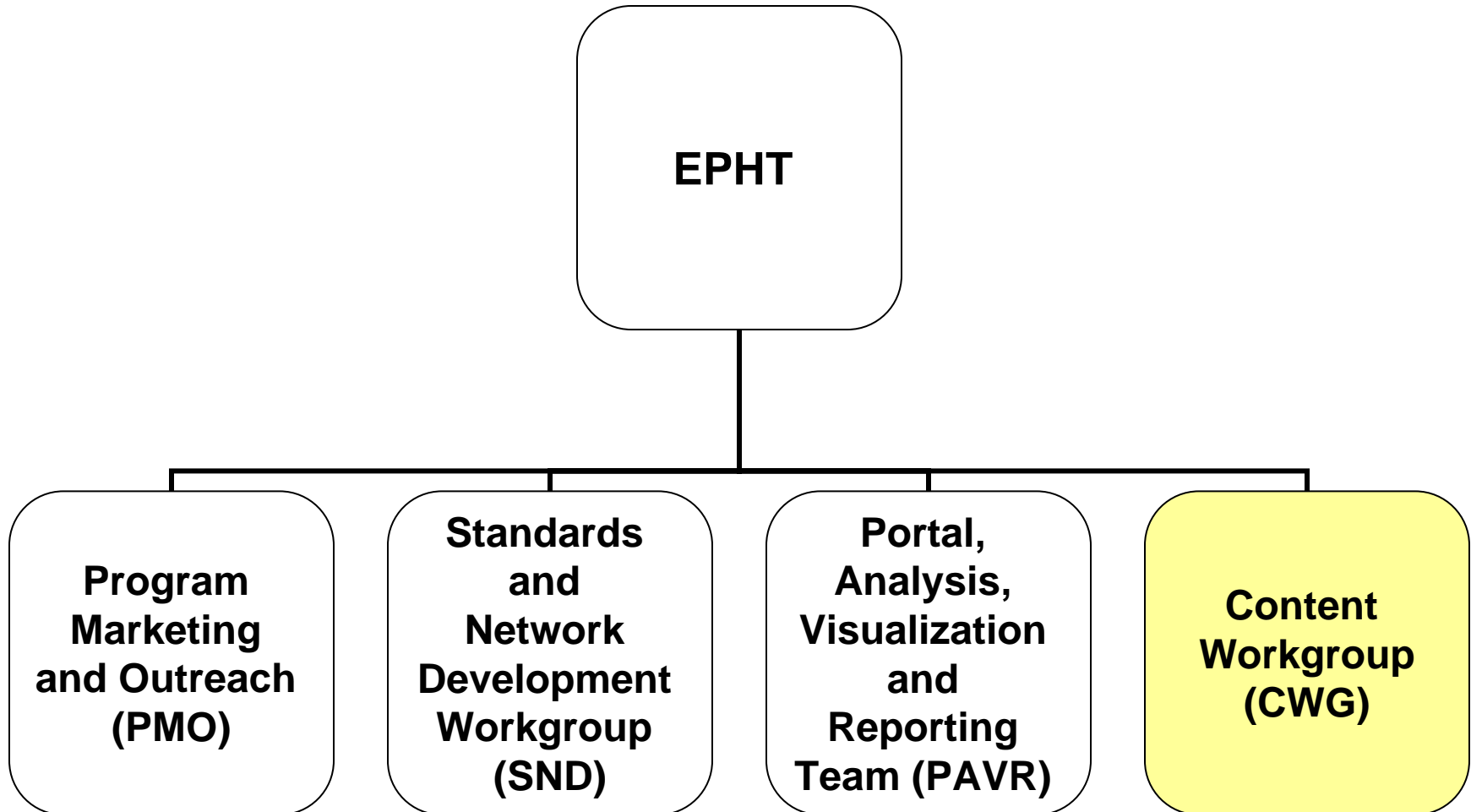
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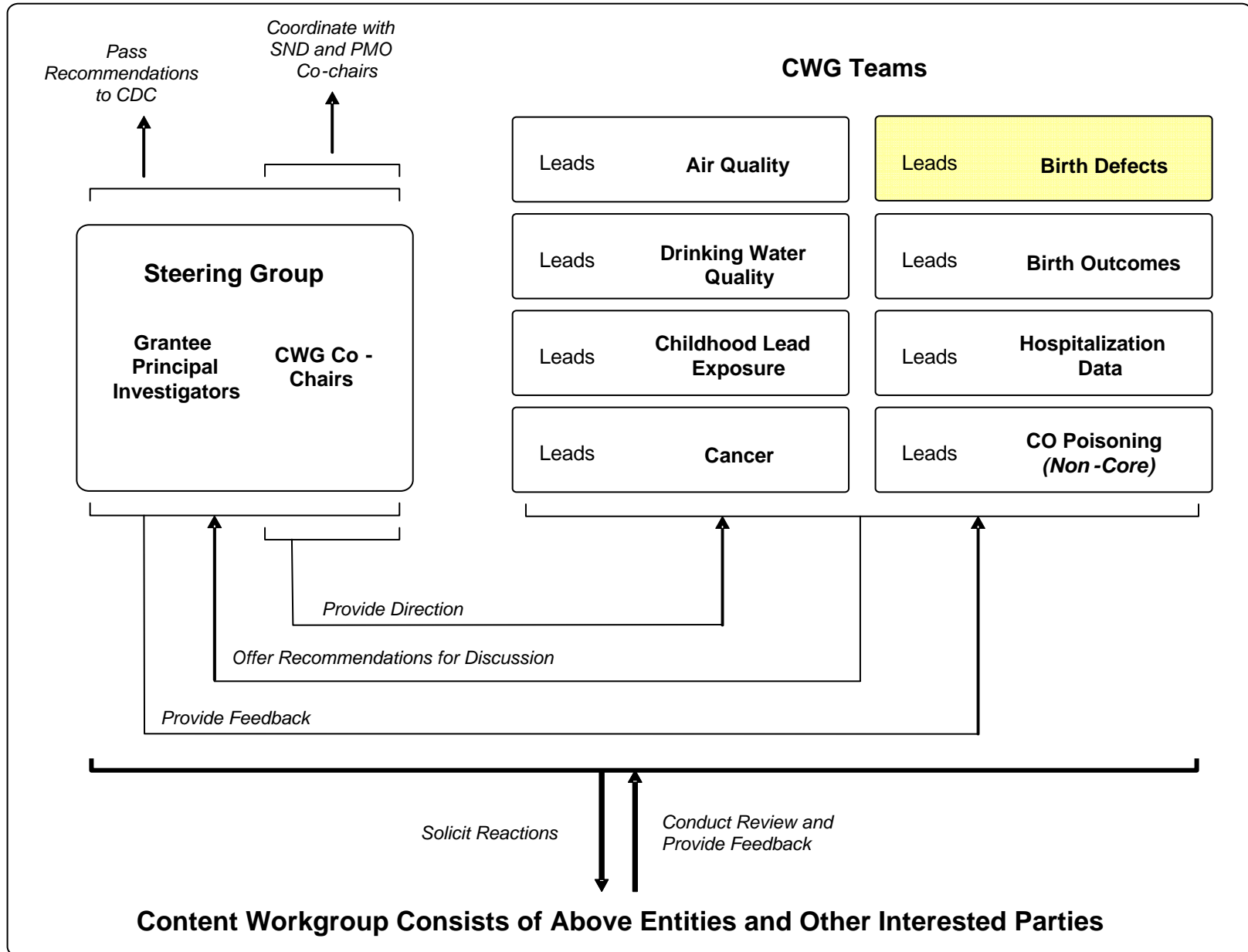
Purpose

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



Content Workgroup (CWG) Structure and Interactions



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)

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Mandy Green (OR)

Matt Strickland (CDC)

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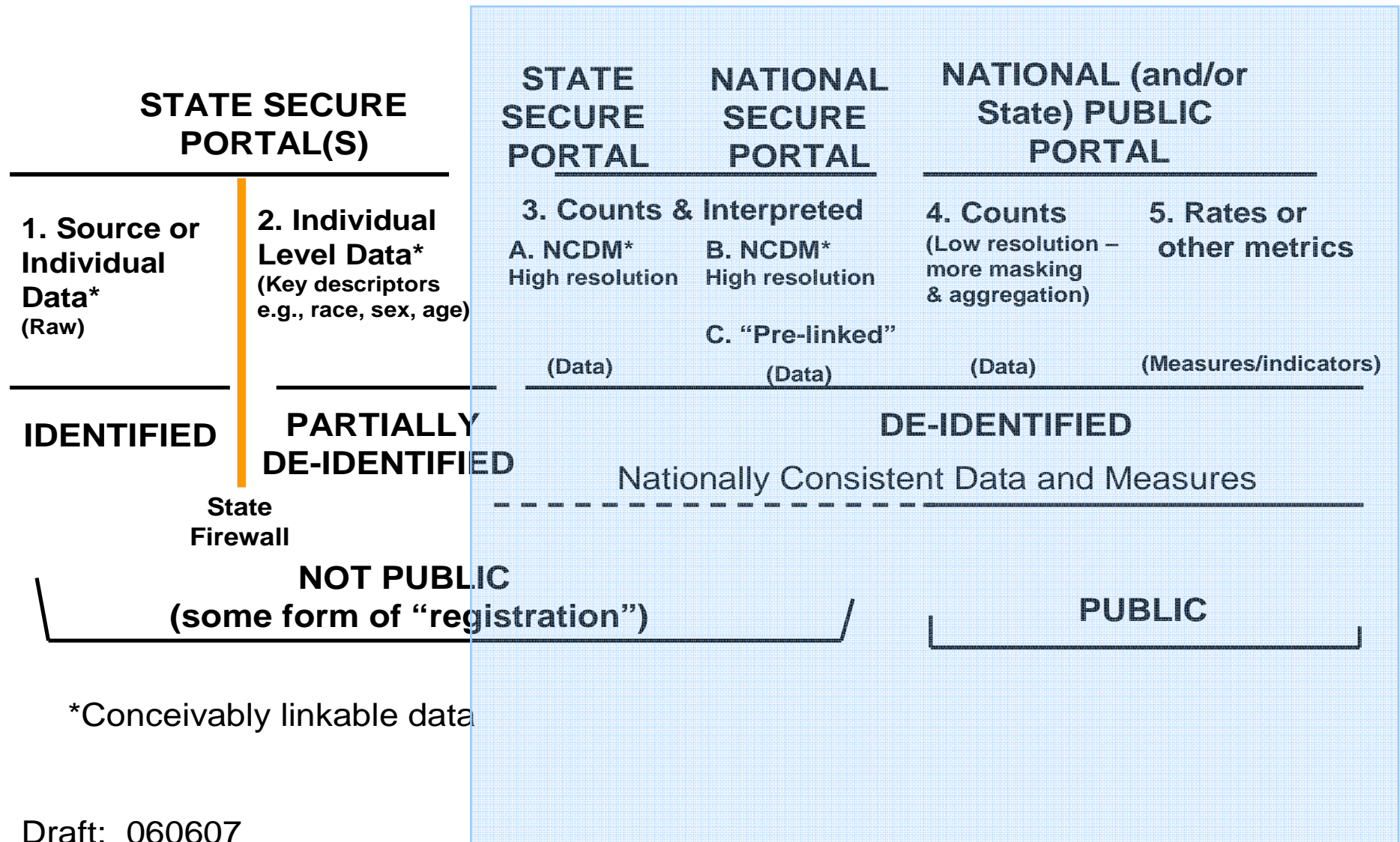
Invitation

- 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 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

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