

CASE CLASSIFICATION BY NBDPN REGISTRIES

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GOALS

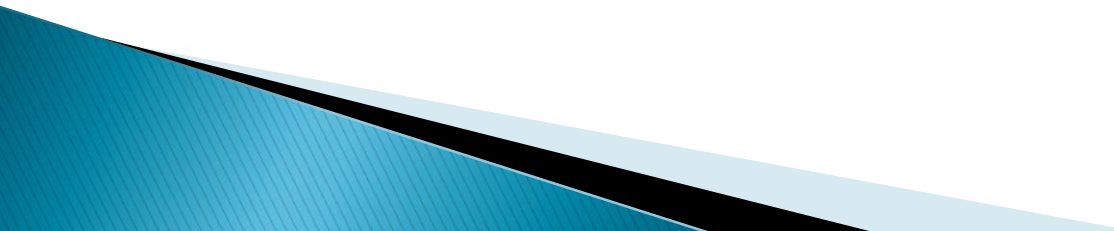
- ▶ Review previous activities
- ▶ See if we can find a simple, practical way to go forward

BACKGROUND

OPERATIONAL DEFINITION

- ▶ Classifying children/fetuses with birth defects into isolated, multiple, etc.

MOTIVATION

- ▶ Makes groups more homogeneous
 - ▶ Thus (perhaps) easier to see patterns (e.g. of association with etiologic factors, outcomes)
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BACKGROUND

COMMON CATEGORIES:

- ▶ Isolated
 - ▶ Multiple
 - ▶ Syndromic
 - ▶ Chromosomal
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- ▶ Categories may differ with different studies or data uses
 - ▶ May be at different levels (e.g. child, heart)
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- ▶ MAY BE DONE BY: clinicians, other humans, computer algorithms, combination

BACKGROUND: NBDPN SURVEY ON CONGENITAL HEART DEFECTS

METHODS

- ▶ Sent out in 2010
- ▶ 36 BD surveillance systems responded

SOME RESULTS

- ▶ 43% currently classify cases
- ▶ Which defects are classified?
 - 19% All
 - 22% Selected

BACKGROUND: NBDPN SURVEY ON CONGENITAL HEART DEFECTS

- ▶ When are cases classified?
 - 24% Routinely
 - 14% Only if needed for a project/analysis
 - 5% Other

- ▶ Who performs the classification?
 - 14% Clinical geneticist
 - 30% Other classifier

BACKGROUND: NBDPN Work Group

- ▶ Led by Russel Rickard in 2012–2013
- ▶ Goal: Develop computer algorithm to classify cases (children/fetuses) into:
 - Isolated:
 - One birth defect code (BPA or ICD–9)
 - If more than one code, only one code for a major defect and all others for minor defect
 - Multiple
 - All remaining children
- ▶ Problem: Agreeing on minor defects

WHAT CAN WE DO NOW?

- ▶ GOAL: See if we can find a simple, practical way to go forward
 - ▶ Note: Optional for NBDPN registries
- ▶ What is the simplest thing we can do now to get something in place?
 - To be most efficient, should probably use computer or computer/human combo
- ▶ Does anyone have an existing SAS (or other) program they are willing to share?

WHAT CAN WE DO NOW?

- ▶ OTHER IDEAS?

Thanks

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