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NBDPN

Surveillance Guidelines and Standards

Prenatal Diagnosis Chapter

Janet D. Cragan, MD, MPH

Centers for Disease Control and Prevention

National Center on Birth Defects
and Developmental Disabilities



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Prenatal Diagnosis Subcommittee

- Russ Kirby (AL)
- Mary Jo Campodonica (CA)
- Elizabeth Harris (CA)
- Ruth Merz (HI)
- Mark Canfield (TX)
- Marcia Feldkamp (UT)
- Lowell Sever (WA)
- Jan Cragan (CDC)



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Survey of Program Directors

- How to focus the chapter
- Rank specific topics 1 to 5
- Comments and suggestions

- 33 out of 52 responded (63%)



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Focus of Chapter

- Ascertainment of defects among pregnancies electively terminated after prenatal diagnosis (14.7%)
 - Start with pregnancy outcome
 - Identify defects that led to termination
 - Identifies pregnancies likely missed by traditional surveillance
 - Avoids need to collect identifiers
 - May not address quality of prenatal dx



Focus of Chapter

- Ascertainment of prenatally diagnosed defects regardless of the pregnancy outcome (85.3%)
 - Start with prenatal diagnosis
 - Identify the pregnancy outcome (LB, SB, AB)
 - Casts wide net for prenatal dxs
 - Predictive value of different prenatal dxs
 - Requires identifiers for all outcomes



Specific Topics

- Top choices
 - Sources of prenatal case ascertainment (32%)
 - Accuracy of prenatal diagnosis for different defects (26%)
 - Calculation of prevalence estimates including prenatally diagnosed defects (24%)



Specific Topics

- Last choices
 - Sensitivity of ascertaining defects among elective terminations (44%)
 - Prenatal screening, distinguished from prenatal diagnosis (38%)



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Comments and Suggestions

- Quality and scope of prenatal dx surveillance
 - Passive or active
 - State-wide or selected areas
 - Include all or selected diagnoses
 - Availability of resources
 - Pilot testing and evaluating feasibility of prenatal surveillance in population



Comments and Suggestions

- Case ascertainment
 - Maternal conditions that warrant a prenatal record review; usefulness of prenatal risk factor data
 - Partnerships with private labs and clinics where prenatal diagnoses made
 - Methods for linking prenatal diagnoses to other data sources
 - Postnatal confirmation of diagnoses



Comments and Suggestions

- Ethical, privacy, and IRB issues
 - Collecting information about terminations
 - Contacting women who terminated a pregnancy
 - Following up prenatal dxs for which pregnancy outcome is unknown
 - Intervening after a spontaneous loss or elective termination to prevent defects in future pregnancies



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Comments and Suggestions

- Provide standard terminology to facilitate discussion of prenatal dx surveillance
 - Distinguish between ascertainment of prenatal diagnoses and inclusion of elective terminations
- Utility of prenatal screening procedures



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Discussion

- Do the results of the survey accurately reflect the needs of surveillance programs ?
- Are there topics or issues relative to the prenatal dx chapter that have been left out?
- Do you have additional suggestions or concerns regarding this chapter?

