

Understanding Stillbirths from a Mother's Perspective



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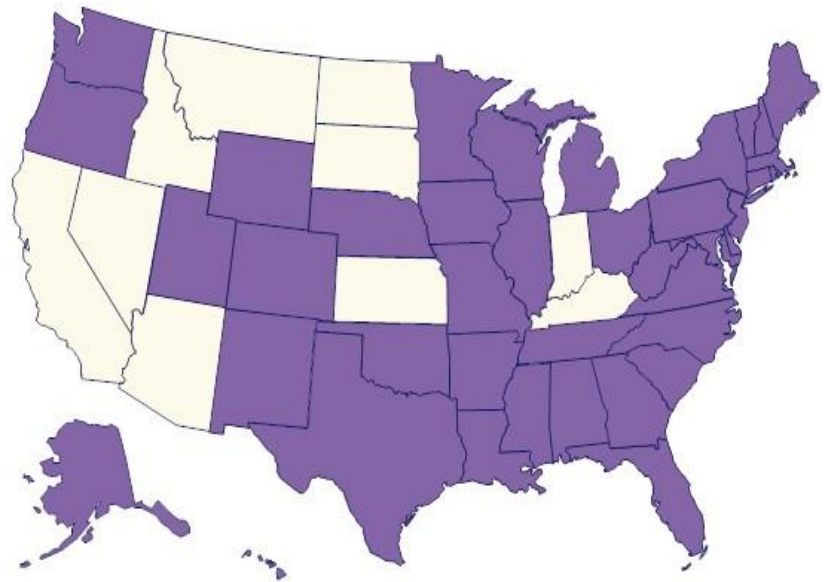
Outline

□ **Pregnancy Risk Assessment Monitoring System (PRAMS) and Stillbirth**

- Background and barriers
- Questions
- Progress
- Preliminary Results

□ **Potential Contribution to National Surveillance**

40 States and NYC Participate in PRAMS



PRAMS



- ❑ **Population-based sampling and solid infrastructure**
- ❑ **Conducted for 25 years with state health departments**
- ❑ **Among nation's best sources on behaviors and experiences before and during pregnancy among *live births***
- ❑ **Fetal mortality overlooked**
 - Overshadowed with public focused on infant mortality
 - Less is known about fetal mortality
 - Substantial variation among states in reporting requirements and completeness of reporting

Stillbirths

□ **NICHD Stillbirth Collaboration Study**

- Using questions from PRAMS, 2006 to 2008
- Identified characteristics associated with racial/ethnic disparity and interpersonal and environmental stressors, including a list of 13 significant life events
- The adjusted odds ratio for stillbirth among women reporting all 4 SLE factors (financial, emotional, traumatic, and partner-related) was 2.22 (95% confidence interval: 1.43, 3.46)

Questions

What is the level of acceptance of a PRAMS-like survey among women who recently had a stillbirth?

How soon after a loss should women be contacted to participate?

What is the best mode to conduct this survey?

PRAMS Stillbirth: Pilot Maternal Survey

- ❑ **In collaboration with Emory University**
- ❑ **Phase 1: PAL (Parent Advocacy Leaders) Interviews**
 - Identified 30 individuals/organizations through internet searches and expert referral
 - Interviewed 10 PALs
 - Support group leaders
 - Bereaved parents
 - Hospital bereavement coordinators
 - Researchers
 - Medical professionals
 - 60-90 minute semi-structured telephone interviews

PRAMS Stillbirth: Pilot Maternal Survey

□ Phase 2: Maternal Interviews

- Mothers recruited through PALs
- Interviewed 11 women who had a stillbirth Jan 2011 to Jan 2012
 - 4 in-person interviews
 - 7 telephone interviews

□ Phase 3: Expert Panel Review

- Meeting of experts in stillbirth research and advocacy (Aug 2012)
- Reviewed findings from Phases 1 and 2
 - Qualitative analysis (NVIVO) software
 - Key themes identified
 - Summary of findings prepared

Preliminary Results

□ Mothers' Response to PRAMS-like survey

Acceptability

"I think its really good because --- people actually cared for what we're going through. Like we don't get put to the side. Like you are actually trying to ... fix stuff and make sure other people don't go through what we've gone through."

When to Contact:
Right Away

"I would say within 30 days. I think ... way out ... maybe some of the details that you really want they've ... blocked out, or don't remember it the way it is."

When to Contact:
No Expiration

"I think you need to give them ample time, but ... as a mom, we will never forget any of those things that have happened to us, it's burned in our memory."

How to Conduct
the Survey
(Mail/Online)

How to
Conduct the
Survey
(In-Person
and Phone)

"I know for a lot of moms ... they will get very emotional especially when it gets to the questions about their babies and that might scare them off from sitting at a table with somebody. Like over the phone."

"If you ... physically mail them something ... it ... let them do it at their own time and ... come back and answer things as they are able."



Preliminary Results

□ Suggested Timing, PALs and Mothers

- Contact subjects ~3 months post loss
- Maintain considerations of due date for losses 20-28 weeks
- If pilot response rates are low, delay initial contact to 5-6 months post-loss



*"There is no footprint so small that it
cannot leave an imprint on this world."
-Unknown*

A Pilot Study of Stillbirth in Georgia

Next Steps

- ❑ **Pilot a State-based PRAMS stillbirths questionnaire**
 - Field test in GA and revision of the questionnaire based on mothers' feedback
 - Results will be presented June 25 at CDC/DRH Grand Rounds

- ❑ **Possible FOA in 2016**
 - Pilot implementation of reviewed PRAMS Stillbirth Survey in three states
 - If funding available

PRAMS Stillbirth: A Potential Contribution to Understanding Women who Experience Fetal Loss

- ❑ **Adds a unique perspective from women/mothers who experienced a stillbirth – population-based sampling**
- ❑ **Other added values:**
 - Learning more about the distribution of certain risk factors
 - Understanding the health care experience of these women/mothers
 - Monitoring changes over time in all of the above (e.g., access to and receipt of services)
 - Identifying new risk factors and gaps in services
 - Helping to identify and prioritize areas for prevention and research

Thank You

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The findings and conclusions of this presentation are those of the author and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

