

TNSPMP MEETING AGENDA AND NOTES



TNSPMP PROJECT TEAM MEETING

DSHS BOARD ROOM

THURSDAY – SEPTEMBER 4TH, 2008

TNSPMP FACILITATOR: ROBIN SCOTT

MEETING NOTES

**ATTENDEES:**

<i>Jennifer Banda</i>	√
<i>Sandra Billings</i>	√
<i>George R. Buchanan</i>	√
<i>Kari Casas</i>	
<i>Donna Claeys</i>	√
<i>Robert Crumb</i>	√
<i>Margaret Drummond-Borg</i>	√
<i>Alastair Dunnett</i>	√
<i>Alice Gong</i>	√
<i>Jose L. Gonzalez</i>	√
<i>Charleta Guillory</i>	√
<i>Cheryl Hermerath</i>	√
<i>Scott D. McLean</i>	√
<i>Javier Ramirez</i>	√
<i>John Saito</i>	
<i>Stuart K. Shapira</i>	√
<i>Eileen Sheridan-Shayeb</i>	
<i>Reid Sutton</i>	√
<i>Larry Sweetman</i>	
<i>Lois Taylor</i>	√
<i>Brad Therrell</i>	
<i>Surendra Varma</i>	
<i>Sister Mary Nicholas Vincelli</i>	√
<i>Morgan Walthall</i>	
<i>Don P. Wilson</i>	√
<i>Jerald L. Zarin</i>	√

<i>Margaret Bruch</i>	√
<i>Yvonne Caimanque</i>	√
<i>Sherry Clay</i>	√
<i>Mirsa Douglass</i>	√
<i>Paula Guerin</i>	√
<i>Eldridge Hutcheson</i>	√
<i>Daisy Johnson</i>	√
<i>David R. Martinez</i>	√
<i>Jann Melton-Kissel</i>	
<i>Susan Neill</i>	
<i>Sharon Newcomb-Kase</i>	√
<i>Susan Tanksley</i>	√
<i>Simran Tiwana</i>	√
<i>Donna Williams</i>	√
<i>Susan Snyder</i>	√
<i>Lisa Kalman</i>	√
<i>Colleen Buechner for NNSGRC</i>	
<i>Other Visiting Guests:</i>	
<i>Jill Wallace</i>	√
<i>Lynette Borgfeld</i>	√
<i>Patricia Ramos</i>	√
<i>Claudia Wood</i>	√
<i>Jimi Ripley-Black</i>	√

**TNSPMP STATUS UPDATE**

*Mirsa Douglass provided a progress update since the last quarterly meeting held in June.*

**STREAMLINED/DRAFTED DEFINITIONS OF PERFORMANCE MEASURES**

*Simran Tiwana presented concepts of performance measures development and presented streamlined performance measures from previous meetings. The following comments were discussed as possible suggestions for refinement.*

- When defining measures, do not include predisposed infants who have a family history as this would skew the numbers.
  - Contact ECI on how they can assist with ECI referral rate. Also, define measure such that a time frame involved. Example: ECI referral by month 3 of life, ECI referral by month 6 of life. Also, report on a per disorder basis and taking account only the first intervention.
  - Streamline the following performance measures further: “Percent missing one or more fields”, “Percent missing date of birth”, and “Percent missing date of collection”
  - Classify performance Measure “Access to Timely Genetic Counseling” as a universal measure (not just for Galactosemia.)
  - Feedback is requested on
    - The naming of the performance measures
    - The streamlining of performance measures
    - The definitions, conceptual and operational
    - Suggestions to capture information for information not currently in our surveys
    - Suggestions to improve response rate to surveys measuring proposed performance measures
  - Other points made about performance measures follows:
    - What is a performance measure? 1) measurable variable related to a desired outcome 2) a measure that can be compared to another either by time or situation
    - How should a performance measure be constructed? Is there a “Gold Standard”? If not, can one be constructed? Can the validity of the performance measure be tested? It must be reliable in discriminating relevant clinical outcomes. If no such data available the consistent of likelihood of such exists (stakeholder survey)
  - Gold standard is not evidence based
  - Our goal is not to test or research new ideas
  - Both performance measures and proposed interventions need to be evidence-based
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**PRELIMINARY SURVEY RESULTS FROM STATE NEWBORN SCREENING PROGRAMS**

*Mirsa Douglass reviewed performance measures provided in “report cards” for submitter feedback from state programs including Oregon, California, Nevada, Colorado, Nebraska, Tennessee, Alabama, Florida, Rhode Island, and New Hampshire. Content provided in these report cards included measures for specimen quality, specimen collection (timing), specimen transit, specimen demographics, and other miscellaneous items.*

**MCAD PRESENTATION**

*Reid Sutton, MD, presented an overview on MCAD.*