

TNSPMP MEETING AGENDA AND NOTES



TNSPMP PROJECT TEAM MEETING

DSHS BOARD ROOM

FRIDAY – SEPTEMBER 5TH, 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>	√
<i>Kayan Lewis</i>	√

MCAD & FATTY ACID LITERATURE REVIEW

Simran Timana presented findings on MCAD and Fatty Acid Disorders as it relates to time to treatment. Following the presentation, a plenary discussion took place to suggest performance measures as it is applicable to this disorder.

The following performance measures were brainstormed during this discussion.

- Measure parent's understanding of the disorder coupled with the special care needed for the infant while awaiting diagnosis. It was recommended to use a survey for this measure within one week of notification.
 - The usefulness of the questions in the parent survey needs to be considered. For example, it may not be effective to ask a leading question such as "Are you feeding every 3 hours?" Rather the wording of questions should be structured in a non-leading way (open ended) such as "What is the longest period your baby has been without food or how long does the baby nap?"
- Measure the percent of affected infants diagnosis by three weeks of life
- Measure the timeliness for receiving presumptive positive results to a confirmed diagnosis.
- Measure the number of hospitalizations
- Measure the psychosocial stresses on families when parent is notified of a condition. Emotional support is needed.
- Measure dietary compliance: parents would need an appropriate tool or mechanism to track dietary consumption

The following general points were discussed. .

- Siblings tests
 - Need to include public health nurses and medical assistants (along with doctors) in process of notification of abnormal results
 - Per Daisy Johnson, the physician contact information is correct 40 to 50 percent of the time.
 - Physician notification to parent notification is a triangle link where a gap exists in timeliness. The time from physician notification to family contact is a rate limiting step
 - Definition of fasting needs to be considered
 - What are the set of recommendations that exist for a follow-up visit? Neurological testing follow-up should occur. Though, the definition of neurological testing follow-up needs to be considered.
 - A complacency issue exists especially if the child is doing well.
 - Although there is mixed evidence of carnitine treatment, the use of carnitine supplements as a start of treatment triggers the thought process for parents to prevent complacency. This method improves adherence to dietary treatment.
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NBS PRENATAL EDUCATION REVIEW

Simran Tiwana presented findings on prenatal education. Following the presentation, a plenary discussion took place to suggest performance measures in this area. The following performance measures were brainstormed during this discussion.

- It was recommended to look into the prenatal care curriculum being developed by the STAR-G project. Screening, Technology and Research in Genetics (STAR-G) is a collaborative project involving the genetics and newborn screening programs in Alaska, California, Hawaii, Idaho, Oregon and Washington. The effort which is being led by the Hawaii Department of Health provides useful information and resources on prenatal education. <http://www.newbornscreening.info/> (Contact is Sylvia Mann Au, MS, CGC Hawaii State Genetics Coordinator)
- Education is needed on false positives. Look into collaborative efforts, such as the Western States Genetics Services Collaborative (HRSA) involved with reducing false-positives and the effect of false positives on family trauma.
- Include a measure to determine if pre natal education is administered in the third trimester.

INTRODUCTION TO PROJECT TOOLKIT

Donna Williams reflected on the possible contents to be contained in the Texas Newborn Screening Performance Evaluation and Assessment Toolkit TX PEAT. Group gave suggestions on possible make up of TX PEAT. Many agreed to rename the TX PEAT to a title appropriate for the expected contents (performance measures) in the document..

- Resource items to include
 - March of Dimes video, links to online CD
 - Education resources for providers
 - ACT/FACT Sheets
 - Toolkit should be website driven
 - “Toolkit” may not be the best term but should include performance measures. These performance measures need to be direct with evidence for action. Consider changing the term “toolkit”.
 - Capturing specific data per disorder for comparative analysis with other cases
 - Toolkit will be designed for the state program, the newborn screening medical community, providers, and for newborn screening stakeholders in general within Texas
 - Consider two separate tools; one focusing on performance measures and another to include resources for reaching performance measures with possible interventions
 - Performance measures in the “toolkit” should link ways for effective improvements
 - Performance measure should be rectifiable by an intervention
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OVERALL NEXT STEPS

Mirsa Douglass reviewed the information to share for the next meeting held in Austin November 20th and November 21st, 2008.

- Agenda items for next meeting
 - Presentation of prioritized performance measures as suggested by the stakeholder group. Findings will include universal measures along with the measures for the disorders reviewed to date. These include Congenital Adrenal Hyperplasia, Galactosemia, and Medium chain acyl-CoA dehydrogenase deficiency.
 - Presentation of literature review for Congenital Hyperplasia and Phenylketonuria
 - Presentation of results of the NBS national survey investigating performance measures other newborn state programs utilize
 - Disorder specific breakout discussions
- Criteria and rating scale will be developed by Mirsa Douglass and Simran Tiwana to prioritize current proposed measures. Assistance will also be provided by Kayan Lewis, a research specialist with Family Health Research and Program Development.
- Suggested criteria could include available evidence based on population studies, resources to measure, viable interventions, and exclusions based on gut instincts.
- Other suggestions included the following criteria parameters: evidence-based material (30%), ease of collection (30%), cost of data collection (10%), and potential for improvement (30%) where each one is weighted as shown in parenthesis.

TIMELINE

09/10/08	Distribute TNSPMP September Quarterly Meeting notes for review and request for feedback on streamlined performance measures
09/26/08	Deadline to provide comments on TNSPMP September Quarterly Meeting notes and input on streamlined performance measures
10/17/08	Distribute prioritization tool for proposed performance measures
10/31/08	Deadline to provide comments on the prioritization of proposed performance measures

TNSPMP QUARTERLY MEETING DATES

11/20 & 11/21/08	Austin
02/19 & 02/20/09	Houston
05/07 & 05/08/09	South Texas

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08/20 & 08/21/09 West Texas



MEETING PLUS/DELTA (FEEDBACK)

Participants shared thoughts about what they liked and didn't like about the meeting

CHANGES

- Air conditioning
- Start meeting with reminder of charge and purpose
- Go back to round table format
- Include Daisy and Paula at round table
- Include two slides per page for presentation handouts
- No bats were included

POSITIVE FEEDBACK

- Good group discussion
- Facilitator
- Box lunches
- Reminder of group's process of storming and group dynamics
- Presentations
- CDC being at the table
- Project Staff
- Preparations for meeting
- Group dinner at Carrabba's restaurant