

TNSPMP MEETING AGENDA AND NOTES



TNSPMP PROJECT TEAM MEETING

RADISSON CONFERENCE ROOM

THURSDAY – NOVEMBER 20TH, 2008

TNSPMP FACILITATOR: ROBIN SCOTT

MEETING NOTES

ATTENDEES:

<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>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>Colleen Buechner</i>	√
<i>Becky Roberson</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>Other Visiting Guests:</i>	
<i>Kayan Lewis</i>	
<i>Sandhya Sanghi</i>	√
<i>Claudia Wood</i>	√
<i>Jimi Ripley-Black</i>	√
<i>Patty R Hunt</i>	√
<i>Johnnie Baldwin</i>	√

TNSPMP STATUS UPDATE

Mirsa Douglass provided a progress update with an overview of the three phases of the project and year two scope of activities.

- TNSPMP Objectives
 - To identify gaps or deficiencies in pre and post analytical phases of the Texas Newborn Screening System. (Year 1- Completed)
 - To develop and identify evidence-based performance measures and determine their effectiveness. (Year 2)
 - To document specific interventions for which there is a likelihood of improving performance/quality in areas with noted deficiencies. (Year 3)
 - TNSPMP Project changes since September meeting
 - Texas Performance Evaluation and Assessment Toolkit (TxPEAT) is no longer a project deliverable. The term “toolkit” is vague and too broad creating confusion among team members. Rather terms specific to the development activities of performance measures will be used.
 - The project scope has been limited to reviewing disorders with documented recommendations for timeliness of medical treatment
 - Congenital Adrenal Hyperplasia (CAH)
 - Galactosemia (GALT)
 - Medium Chain acyl CoA Dehydrogenase (MCAD)
 - Congenital Hypothyroidism (CH)
 - Maple Syrup Urine Disease (MSUD)
 - Phenylketonuria (PKU)
 - Sickle Cell Disease (HgSS)
 - TNSPMP Year Two Activities
 - Complete the identification process of candidate performance measures for disorders of interest and other measures related to timeliness of medical treatment
 - Complete feasibility and impact assessment for each candidate performance measure
 - Implement infrastructure and processes to pilot performance measures in year 3
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PROPOSED PERFORMANCE MEASURES FOR MSUD

Simran Timana presented evidence-based performance measures for Maple Syrup Urine Disease (MSUD) which was followed by round table and plenary discussion. The following are suggestions and input provided on performance measurement development.

Suggested performance measures include:

- *Time to treatment*
- *Time to reduce plasma leucine concentration levels*
- *Long term metabolic control*

Group discussion points:

- Consider changing the performance measure from “reduce leucine levels” to “normalize leucine levels”
 - Would need to quantify length of time that leucine levels must stay normalized
 - Leucine tolerance could be useful information to stratify severity as classical, severe, etc.
 - Data on time to reduce plasma levels is difficult to collect
 - The two most important measures are diagnosis and treatment less than x number of days, with an emphasis on time to treatment
 - Frequency of leucine measurements should be easy to do though expertise on how to evaluate and use leucine levels would be necessary
 - Frequency of clinic visits could be tied to frequency of leucine measurements
 - Feedback from metabolic community is needed on the frequency of monitoring infants for leucine levels
 - It is difficult to obtain data on long-term metabolic control
 - What is the feasibility of any intervention changing the outcome
 - The mild form is not being identified until symptomatic because levels can be in normal range
 - Time to treatment should be associated with the form/severity; classical, severe, moderate, mild
 - Need to exclude special populations such as Mennonites
 - Is there any literature that supports achieving lower levels without monitoring, that patients that maintain the lower levels has the same outcome as those that are monitored. Is there value in decreasing the levels if the levels jump back up?
 - Measurement can include:
 - The frequency of leucine measurements
 - How often a metabolic specialist is seen so someone knows what to do with the lab data
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CONGENITAL HYPOTHYROIDISM

Dr. Don Wilson gave a presentation on Congenital Hypothyroidism followed by a question and answer session.

PROPOSED PERFORMANCE MEASURES FOR SICKLE CELL

Simran Timana presented evidence-based performance measures for Sickle Cell which was followed by round table and plenary discussion. The following are suggestions and input provided on performance measurement development.

Suggested performance measures include:

- *Age of initiation of penicillin prophylaxis*
- *Age at time of first Prevnar (or other appropriate) immunization*
- *Compliance with twice daily prophylaxis penicillin regimen*
- *Parent education on identifying enlarged spleen in their child*
- *Genetic counseling (may be universal)*
- *Time to diagnosis*
- *Time to treatment*
- *Time to referral to a hematologist*

Group discussion points:

- In Texas, parents with Sickle Cell trait receive letters from DSHS
 - The ethics in reproductive options for affected patients is not a DSHS NBS responsibility
 - We need more evidence and data for age at introduction of penicillin treatment, age at first symptoms (onset), and age of first Prevnar treatment
 - What does the literature say about the effect of data at age of symptom onset?
 - It will be difficult to collect data on spleen enlargement, when and if parent education was received and whether the parents contacted other specialists
 - Only one study discussed parents following spleen size
 - The goal for time to treatment should be less than one month
 - Compliance with treatment will be difficult to monitor especially since data is dependent on responses from hematologists
 - Can't assume compliance with penicillin treatment based on prescriptions but can monitor prescription behavior.
 - Often parents/infant are not referred to a hematologist because the primary care physician feels that he/she can provide the needed medical care
 - Educate parents regarding signs and symptoms of infection and fever – comprehensive education
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- Could possibly use ImmTrac to obtain information on when pneumococcal vaccine was administered
- Measures can include:
 - Age of initial penicillin treatment
 - Age at time of initial pneumococcal vaccination
 - Compliance with pneumococcal vaccine schedule (medical records or ImmTrac)