

TNSPMP MEETING AGENDA AND NOTES



TNSPMP PROJECT TEAM MEETING

RADISSON CONFERENCE ROOM

FRIDAY – NOVEMBER 21ST, 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 Tivana</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>	√

NATIONAL NEWBORN SCREENING SURVEY RESULTS

Simran Tiwana, MBA, discussed results from the performance measure national survey conducted in October 2008.

PERFORMANCE MEASURES FEASIBILITY MATRIX

Mirsa Douglass presented the approach that will be used by DSHS to review feasibility of evidence-based performance measures.

Presentation background:

- *Much work has been accomplished to identify candidate performance measures to pilot in year 3. The candidate list will be documented in a report titled, Identification of Evidence-Based Performance Measures: Exploring Time to Treatment February 2009. Evidence with supporting literature is the primary selection tool for identifying candidate performance measures. Performance measures with weak or no supporting evidence will be eliminated from consideration and will not be listed in the report unless a compelling argument is made.*
- *The performance measures on the candidate list will be defined and reviewed for feasibility of implementation and potential impact on the newborn screening program and system. The presentation given outlines the process of determining the feasibility of each measure. By going through this process, we will identify informational and implementation needs. If significant flaws make implementation difficult, measures will not be considered for further development or testing.*
- *DSHS team members request that system stakeholders provide input on the definitions of the candidate performance measures.*
- *Year 2 will involve assessing and improving feasibility for piloting measures having the greatest impact in year 3.*

Group discussion points:

- Likert scales used to rate feasibility should go from 1 to 5 instead of 1 to 10
 - Use the word “unacceptable” instead of “unfavorable” in the definition of unsatisfactory condition
 - Suggestions on the elements to assess impact include:
 - Health outcome of the infant (clinical, education)
 - Quality and quantity of the evidence (For example, maple syrup urine disease shows evidence for time to treatment that varies considerably.)
 - Evidence or measure as primary or surrogate
 - Support from a practice guideline (surrogate markers)
 - Extent of the gap or deficiency
 - Cascading effect of the performance measure
 - Impact on the efficiency of the system
 - Infants served
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PROPOSED PERFORMANCE MEASURES FOR CONGENITAL HYPOTHYROIDISM

Simran Timana, MBA, presented evidence-based performance measures for Congenital Hypothyroidism 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 treat along with appropriate dosage of L-Thyroxine*
- *Normalized T4, FT4 and TSH levels within one month of treatment*
- *Evaluation for transient/permanent CH at the age of three years*
- *Number of patients receiving assessment of co-morbidities*

Group discussion points:

- Developmental evaluation should be standardized for better results from performance measures
 - False positive rates – could be normal developmental levels because you have small babies
 - Develop statistics for frequency of testing done compared to when testing should have been completed. Need to also consider capturing a measure that provides information on when metabolic levels are out of control.
 - Consider data collection for a years worth of data where DSHS extracts the information for doctor's offices
 - The development of a performance measure goal for time to treatment may be difficult considering there is a wide variable in the number of days shown
 - Follow up time is variable
 - Consider a measure that monitors the time it takes for the endocrinologist to become involved
 - Normalized levels of T4 and TSH should be broken out
 - 3 year evaluations will be hard to get, one year evaluations will be easier
 - Identify number of patients with co-morbidities
 - Identify number of transient cases
 - Track endocrinologist consultation with babies who have been released with CH
 - Time to endocrinologist involvement in care (PCP contact or face-to-face) may be better marker than time to treatment
 - Need to tie hearing screening data into NBS data to evaluate co-morbidities.
 - Normalize level within 1 month
 - Levels fluctuate daily due to daily activities
 - Normalize TS FT4 in 2 weeks
 - Normalize TSH in 1 month
 - Obtain levels every 2 weeks
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- Ultrasound / imaging studies should be performed at the time of diagnosis
 - Difficult to collect data for evaluation at 3 years to differentiate transient patients
- Low feasibility of co-morbidity assessment

PROPOSED PERFORMANCE MEASURES FOR PKU

Simran Timana, MBA, presented evidence-based performance measures for Phenylketonuria (PKU) 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*
- *Frequency of phenylalanine monitoring*
- *Average phenylalanine levels (metabolic control)*
- *Compliance of patient/family with diet*
- *Percent that received genetic counseling*
- *Percent of patients who have consulted with a metabolic nutritionist*
- *Cognitive outcome at a particular age*

Group discussion points:

- PKU can be controlled by diet low in phenylalanine and high in tyrosine
 - Could utilize PKU monitoring data produced in laboratory since DSHS does ~90% of the dietary monitoring
 - A marker could be non-compliance identified as not having a PKU level within an identified range
 - Family education is important
 - What is the optimal time to treatment and frequency of monitoring?
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**OVERALL NEXT STEPS**

- Document TNSPMP Quarterly Meeting Notes
- Complete Performance Measures Impact Assessment Matrix
- Complete Identification of Evidence-Based Performance Measures: Exploring Time To Treatment February 2009
- Formulate Definitions of Evidence-Based Performance Measures

TNSPMP QUARTERLY MEETING NOTES TIMELINE

- 12/05/08 Distribute TNSPMP November Quarterly Meeting notes for system stakeholder review
- 12/12/08 Deadline for system stakeholders to provide feedback and suggested edits for quarterly meeting notes.
- 12/31/08 Posting deadline of quarterly meeting notes on TNSPMP website

PERFORMANCE MEASURES IMPACT ASSESSMENT MATRIX

- 12/12/08 Deadline for system stakeholders to provide suggestions on parameters to incorporate when assessing impact of evidence-based performance measures
- 01/16/09 Distribute draft matrix tool to assess impact of performance measures for system stakeholder review
- 01/23/09 Deadline for system stakeholders to provide feedback on matrix tool
- 02/19/09 Presentation of final matrix tool at quarterly meeting

IDENTIFICATION OF EVIDENCE-BASED PERFORMANCE MEASURES: EXPLORING TIME TO TREATMENT FEBRUARY 2009 TIMELINE

- 01/30/09 Distribute draft of February 2009 report which will identify evidence-based performance measures
- 02/06/09 Deadline for system stakeholders to provide feedback on report
- 02/27/09 Deadline to finalize report

FORMULATE DEFINITIONS OF EVIDENCE-BASED PERFORMANCE MEASURES

- 01/02/09 DSHS will begin formulating definitions of performance measures.
- 02/19/09 Present definitions at TNSPMP Quarterly Meeting
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TNSPMP QUARTERLY MEETING DATES

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

Too cold in building
Noisy group in room next door

POSITIVE FEEDBACK

Being in same location as meetings
Round table set up was effective
Content in agenda was good
Historical tidbits
Organizers did fantastic job
Flexibility
Good humor
Commitment
CDC representative was present
Presentations easy to understand
Hand-held smile on a stick