

TNSPMP QUARTERLY TEAM MEETING

RADISSON AUSTIN NORTH HOTEL

ELM CONFERENCE ROOM

THURSDAY – MAY 28TH, 2009

TNSPMP FACILITATOR: ROBIN SCOTT, OPEN CIRCLE CONSULTING

MEETING NOTES

ATTENDEES:

<i>Sandra Billings</i>	√
<i>George R. Buchanan</i>	√
<i>Colleen Buechner</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>Becky Roberson</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>Sister Mary Nicholas Vincelli</i>	√
<i>Morgan Walthall</i>	
<i>Don P. Wilson</i>	
<i>Erika Wright</i>	√
<i>Jerald L. Zarin</i>	√
<i>Margaret Bruch</i>	
<i>Sherry Clay</i>	
<i>Mirsa Douglass</i>	√
<i>Debra Freedenberg</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>Donna Williams</i>	√
<i>Susan Snyder</i>	
<i>Lisa Kalman</i>	
<i>Kayan Lewis</i>	√
<i>John Hogge</i>	√

WELCOME

During introductions, participants were asked to describe TNSPMP and members of the group in one word. The following is a list of the words used.

- Fun
- Passionate
- Vintage Volvos
- Intense
- Engaged
- Collaborative
- Collegiate
- Awesome
- Agree 80% of the time
- Effective networkers
- Caring
- Opinionated
- Supportive
- Friendly
- Committed
- Accomplished
- Eclectic
- Healthy Appetite
- Dedicated

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 - In Progress)
 - To document specific interventions for which there is a likelihood of improving performance/quality in areas with noted deficiencies. (Year 3 - Not Started)
- TNSPMP Project update since November 2008 meeting
 - The project scope is limited to reviewing disorders with documented recommendations for timeliness of medical treatment and parameters related to timeliness. Performance measures, having related evidence or literature, have been identified for each of the following disorder and timeliness groups.
 - Congenital adrenal hyperplasia (CAH), galactosemia (GALT), medium chain acyl CoA dehydrogenase deficiency (MCADD), congenital hypothyroidism (CH), maple syrup urine disease (MSUD) , phenylketonuria (PKU), sickle cell disease (SCD and HgSS), and processes related to timeliness.

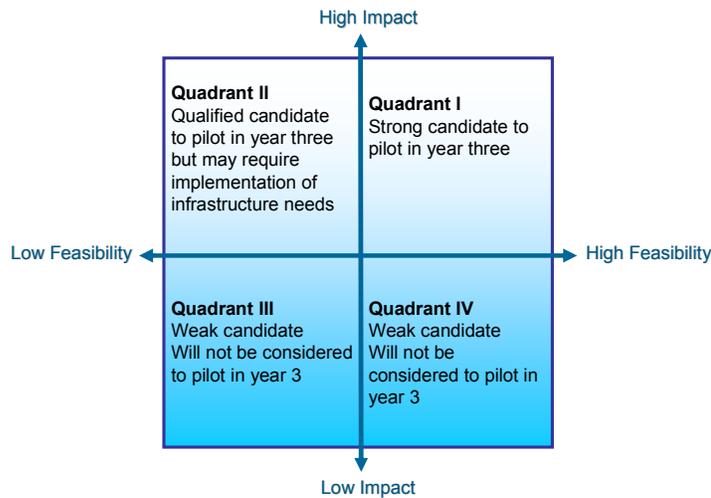
- TNSPMP Year Two Activities
 - Complete the identification process of candidate performance measures for disorders of interest and other measures related to timeliness of medical treatment. (Completed)
 - Select which performance measures will be further developed based on information from feasibility (pending) and impact assessments (completed) for candidate performance measures
 - Establish infrastructure and processes to pilot performance measures in the third year of the project

IMPACT ASSESSMENT RESULTS

Mirsa Douglass and Kayan Lewis presented the results from the online impact assessment process used to determine the relative impact of candidate measures. General notes, results from the assessment, and discussion points are noted below.

- General Background
 - Figure 1 represents a high-level guideline for how performance measures will be prioritized. As depicted, candidate performance measures assessed as having a higher relative impact will be qualified for further consideration for piloting in year three, while the performance measures with relatively less impact will be eliminated from consideration. Feasibility will also play a factor in the selection process.

Figure 1: Performance Measure Prioritization Methodology



- TNSPMP system stakeholders with special expertise for a particular performance area completed a survey to assess a relative degree of impact for associated candidate performance measures. Evaluation criteria used were modified from those suggested by the Agency Healthcare and Research of Quality (AHRQ) National Quality Measures Clearinghouse.

Figure 2: Evaluation Criterion Adapted from AHRQ

#	Evaluation Criterion	Scoring
1	This performance measure is scientifically sound.	1 -10
2	This performance measure is relevant to the stakeholders in the newborn screening system.	1 - 5
3	This performance measure can reveal health care disparities.	1 - 5
4	This performance measure has great potential for improving health care quality.	1 -10
5	This performance measure has significant health importance.	1 - 5
6	This performance measure can be used to improve the newborn screening system.	1 - 5

- As shown in the figure above, evaluation 1 was weighted greater to place more influence on the evidence-based approach of this project. Evaluation criterion 4 was also weighted greater to place more influence on the patient-centered aspect of the performance measures.
- Overall Impact Assessment Results
 - Overall stats: average = 78.8, median = 81.3, lowest score = 69.3, highest score = 88.2, and the difference = 18.9
 - 7 of the 45 candidate measures fell out of the top quartile
 - All of the “universal timeliness” measures fell in the top quartile
 - The largest variance was found with the criterion assessing scientific soundness
 - Determined action on outliers would not affect data.
- TNSPMP Stakeholder Selection Process
 - The following criteria were used as a starting point to determine the selection of candidates that would move forward for feasibility assessment.
 - Total average impact scored 80 or greater, or
 - Scientific soundness criteria scored an average of 8.5 or greater, or
 - Health care quality criteria scored an average of 8.5 or greater

The list of candidate measures that met any of the three selection criteria were presented categorically by hemoglobin disorders, metabolic disorders, endocrine disorders, and by universal timeliness processes. After presenting each group, participants decided anonymously on agreement or disagreement of the selection. Measures shown below having the indication of “In” remained on the candidate list for feasibility assessment.

Note: The voting process included a method for the team to include or exclude measures that differed from the original criteria (total average impact scored => 80, or “scientific soundness” criteria scored => 8.5, or “health care quality” criteria scored => 8.5).

Measures that did not meet the original criteria but were voted to be included are marked with an “†”. Measures that met the original criteria but were voted to be removed are marked with an “‡”.

Key	
C1	Scientific Soundness
C2	Relevance
C3	Health Care Disparity
C4	Health Care Quality
C5	Significance/Health Importance
C6	Improving NBS System

Starting Selection Criteria
Overall Score => 80
Scientific Soundness (C1) is => 8.5
Health Care Quality (C4) is => 8.5

- Hemoglobinopathy Selections

Hemoglobinopathy			C1	C2	C3	C4	C5	C6
Sickle Cell								
In	Time to Initiate Penicillin Treatment (HbSS)	86.7	8.9	4.8	4.0	8.2	4.8	4.0
In	Compliance with Oral Prophylactic Prescription of Penicillin (HbSS)	85.3	8.4	4.6	3.7	8.9	4.7	3.9
In	Age of First Prevnar® Vaccination (PCV-7)	80.8	7.1	4.6	3.8	8.7	4.4	3.8
	Parent Education on Assessing Enlarged Spleen/Monitoring Episodes of Fever (SCD)	80.0	7.3	4.3	4.1	8.2	4.4	3.6
Out	Clinical Evaluation at Age 5 for Disease Management	79.7	7.6	4.3	3.7	8.2	4.4	3.7
Out	Genetic Counseling of Parents	71.1	6.9	3.9	3.9	7.1	3.1	3.6

- Discussion points for the hemoglobin impact assessments
 - Excluded performance measures should be identified as topics for future grant/study
 - Need to be aware of overlapping efforts from other collaborative groups when deciding which measures to pilot in the third year

- Metabolic Selections

Metabolic			C1	C2	C3	C4	C5	C6
MSUD								
In	Time to Initiate Treatment	85.7	8.9	4.6	3.4	8.9	4.6	4.0
In	Time to Reduce Plasma Leucine Concentration Levels	80.4	7.4	4.1	3.7	8.9	4.1	3.9
Out	Mean Annual Leucine Levels for Long-Term Metabolic Control	72.9	7.1	3.7	3.6	7.7	4.0	3.0
MCADD								
In [†]	Time to Confirmed Diagnosis	77.5	7.7	4.1	3.9	7.4	3.9	4.0
Out	Hospitalization for Severe Episodes related to MCADD	69.3	6.6	3.9	3.9	6.6	3.9	3.0
Out [‡]	Parent Understanding Post Physician Notification	73.9	6.0	4.3	3.7	8.6	3.9	3.1
In [†]	Adherence to Dietary Treatment (Avoid Fasting)	76.4	8.3	4.0	2.7	8.0	4.4	3.1
In	Screening/Diagnosis of At-Risk Family Members	81.8	7.4	4.0	4.1	9.1	4.3	3.7
Out	Normal Developmental & Cognitive Outcome by Age 4	72.1	7.7	4.0	2.9	7.4	3.9	3.0
PKU								
In	Time to Initiate Treatment	84.1	9.0	4.6	3.8	7.5	4.5	4.3
Out	Dietary Compliance	78.8	8.0	4.3	3.9	8.0	4.0	3.4
In	Phenylalanine Levels for Metabolic Control	82.8	8.8	4.5	3.6	7.8	4.5	4.0
Out	Age-Appropriate Frequency of Phenylalanine Monitoring	77.5	7.3	4.0	3.6	8.3	4.3	3.6
Galactosemia								
In	Time to Initiate Treatment	87.5	8.8	4.6	4.3	8.5	4.6	4.3
Out	Dietary Compliance	79.1	7.5	4.3	3.9	7.8	4.3	4.0

- Discussion points for metabolic impact assessments
 - Evidence is not consistent (e.g. leucine levels for MSUD)
 - Long term considerations at system and program levels
 - “How much can we do in one year?”: Dependent on resources to pilot measures.
 - “Can we pilot more later?”: Lessons learned from the project’s upcoming pilot in year three will help with the logistics of piloting others performance measures beyond the project period. Knowledge gained in this project can be used to support grants for other measures.
 - Impact assessment is too subjective, no scientific evidence exists for some of the MCADD measures
 - The performance measures titled, “Dietary compliance for PKU patients” and “Age Appropriate Frequency for Phenylalanine Monitoring”, were not selected to move forward. However, they are related to “Time to initiate treatment for PKU” and “Monitoring Phenylalanine Levels for Metabolic Control”.

• Endocrine Selections

Endocrine			C1	C2	C3	C4	C5	C6
CH								
In	Time to Initiate Treatment	87.0	8.8	4.6	3.8	8.8	4.6	4.2
In [†]	Initial Dosage of L-Thyroxine	78.5	8.4	4.2	3.8	7.6	4.0	3.4
In [†]	Normalization of Serum TSH, T4 and FT4 Concentrations within One Month of Treatment	76.5	7.6	4.2	3.4	7.6	3.8	4.0
Out	Evaluation for Transient/Permanent CH by Age 4	75.5	7.6	4.4	3.0	7.6	3.6	4.0
CAH								
In	Time to Initiate Treatment for SW CAH	88.1	8.8	4.6	3.6	9.0	4.9	4.4
In	Time to Initiate Treatment for SW & SV CAH: By Gender	86.3	8.8	4.4	3.5	9.3	4.8	3.9
Out	Time to Gender Assignment for SW CAH	75.6	7.5	3.9	3.4	7.8	4.3	3.5
In	Frequency of Medical Evaluations that Assess Growth	81.3	8.3	4.4	3.8	8.5	4.1	3.5

- Discussion points for endocrine impact assessments
 - Both measures, “Initial Dosage of L-Thyroxine” and “Normalization of Serum TSH, T4, and FT4 Concentrations within One Month of Treatment” are interdependent.

• Universal Timeliness Selections

Universal			C1	C2	C3	C4	C5	C6
Universal								
In	(t1) Specimen Collection Time	87.9	9.1	4.6	3.5	8.8	4.5	4.7
In	(t2) Specimen Transit Turnaround	84.6	8.5	4.6	3.4	8.6	4.3	4.5
In	(t3) Time from Abnormal Screen Resulting to Case Management Notification	85.3	8.9	4.4	3.3	8.8	4.3	4.4
In	(t4) Time from Abnormal Result to Physician Notification	88.2	8.8	4.7	3.5	9.3	4.5	4.5
In	(t4a) Time from Birth until Physician Notification	87.9	8.6	4.5	3.5	9.2	4.7	4.6
In	(t5) Time from Physician Notification to Parent Notification	86.9	8.2	4.5	3.9	9.1	4.6	4.4
In	(t6) Time from Parent Notification until Physician/Specialist Visit for Confirmatory Testing	85.0	8.0	4.5	4.2	8.7	4.5	4.1
In	(t6a) Time from Abnormal Screen Result to Time Infant is seen by Physician/Specialist for Confirmatory Testing	83.5	8.5	4.4	3.7	8.5	4.2	4.1
Out	(t7) Time from Physician/Specialist Visit until Receipt of Confirmatory Testing Results	78.4	7.9	4.2	3.4	8.2	3.9	3.8
In	(t8) Time from Receipt of Confirmatory Testing Results to Treatment Initiation	82.6	8.1	4.5	3.8	8.4	4.3	4.0
In	Unsatisfactory Specimen Rate	86.5	8.9	4.6	3.3	8.7	4.4	4.7
In [†]	Percent Missing Birth Weight	76.6	8.1	3.9	2.9	7.9	3.7	4.1
In	Percent Missing Date of Birth	80.3	8.5	4.4	3.3	8.8	4.3	4.4
In	Percent Missing Date of Collection	81.2	8.7	4.2	2.9	8.2	4.1	4.4
In	Percent missing PCP Information	85.3	8.5	4.5	3.6	8.6	4.5	4.5
In	Percent with incorrect PCP Information	81.9	8.4	4.2	3.4	8.5	4.2	4.2

- Discussion points for universal timeliness impact assessments
 - Birth weight information is important for calculating newborn screening results for some disorders.

FROM CONCEPTUAL TO OPERATIONAL DEFINITIONS: FOUR TABLE GROUPS

Participants broke out into groups to work on development of a measure from one of the four categorical groups: measures related to hemoglobin disorders, metabolic disorders, endocrine disorders, and measures related to universal timeliness processes. The purpose of the exercise was to provide feedback on considerations when utilizing focus groups tasked with developing performance measures.

- Discussion points
 - Include parents in the hemoglobin focus group
 - Need well defined definitions for each term used in the operational definition
 - Where possible, provide starting definitions for focus groups to review
 - Expect arbitrary decisions in performance measure development for clinical parameters (ex. on recommended leucine levels for MSUD patients)
 - The various severity forms of the disorder will influence performance standards
 - As universal measures are developed, they may not actually be “universal”
 - Share how measures will be used with the focus group participants
 - May want to start with the definitions first and gain agreement of terms in the development process
 - Or you may want to start with the numerator and denominator first in the development process
 - Make sure the conceptual definition of the measure matches with the “title of the measure” (ex. See MCADD measures)
 - Focus group participants should be careful to adhere to developing the conceptual definition of the measure and should not change the nature of the original intent
 - Consider TN SPMP stakeholders as “resource witnesses” rather than active participants in the focus groups. Do not influence the development process of focus groups who have not participated on this project.