TNSPMP QUARTERLY TEAM MEETING

RADISSON AUSTIN NORTH HOTEL

ELM CONFERENCE ROOM

THURSDAY – AUGUST 20TH, 2009

TNSPMP FACILITATOR: DONNA WILLIAMS, PROGRAM SPECIALIST

MEETING NOTES

ATTENDEES:

Sandra Billings	√
George R. Buchanan	√
Colleen Buechner	
Kari Casas	√
Donna Claeys	√
Robert Crumb	√
Margaret Drummond-Borg	√
Alice Gong	√
Jose L. Gonzalez	√
Charleta Guillory	√
Cheryl Hermerath	√
Scott D. McLean	√
Javier Ramirez	√
Becky Roberson	
John Saito	√
Stuart K. Shapira	
Eileen Sheridan-Shayeb	
Reid Sutton	√
Lois Taylor	
Brad Therrell	√
Sister Mary Nicholas Vincelli	√

Morgan Walthall-Sanders	√
Don P. Wilson	√
Erika Wright	√
Jerald L. Zarin	√
Margaret Bruch	
Sherry Clay	
Mirsa Douglass	√
Debra Freedenberg	√
Paula Guerin	√
Eldridge Hutcheson	√
Daisy Johnson	√
David R. Martinez	√
Jann Melton-Kissel	
Susan Neill	
Sharon Newcomb-Kase	√
Susan Tanksley	√
Donna Williams	√
Susan Snyder	√
Lisa Kalman	
Kayan Lewis	
John Hogge	√
Cheryl Burcham	√

WELCOME

Susan Tanksley welcomed the group and announced the receipt of appropriations to start a courier service. The service will be established beginning in metropolitan areas with a goal of expanding it statewide

TNSPMP STATUS UPDATE

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

- TNSPMP Evidence-Based Approach
  - Task at hand included proposal, identification and selection of performance metrics to be piloted in the third year of the project.
  - Utilized Performance Evaluation and Assessment Scheme (PEAS), existing performance measures and a national survey.
  - Produced Evidence Summary Report in May 2009.
- TNSPMP Year Two Activities
  - Conducted focus groups in four performance measure areas; endocrine, metabolic, hemoglobinopathy and universal.
  - Focus groups allowed for insight into further development of measures, definitions, terminology and comprehensibility.
  - NuStats provided top-line reports for each performance measurement area which were discussed in detail.
  - Performance measures were assessed for feasibility and impact.
  - Infrastructure and process needs are being identified to pilot performance measures in the third year of the project.
  - Document each of the performance measure's significance, standard, conceptual and operational definitions, terminology and other definitions, data reporting, data collection methods and other considerations. The operational definitions include elements of the numerator, inclusion/exclusion criteria and the denominator.
- TNSPMP Year Three Activities
  - Develop pilot project plans for each of the selected performance measures (to be completed by the November stakeholder meeting).
  - Investigate intervention models and produce a report on recommended interventions to improve performance in measurement areas.

HIGHLIGHT OF FOCUS GROUP RESULTS

Mirsa Douglass presented the results from the focus group meetings. General notes, individual discussion points are noted below.

- The following focus groups were held. The purpose of the focus groups was to gain insight into the development of the performance measures, definitions and terminology to be used, comprehensibility, validity of the measures and potential issues with reliability. The focus group process was not designed to be a consensus building exercise.
  - Two focus groups were held on 7/9/09 for the endocrine-related measures.
  - Two focus groups were held on 7/23/09 for the metabolic-related measures.
  - One focus group was held on 8/7/09 for the hemoglobinopathy-related measures.
  - One focus group was held on 8/14/09 for the universal-related measures (post screening).

Focus group results were shared with the stakeholders by performance measure area. Results included information on the standard, goal, numerator, denominator, definitions, data collection, data reporting and other considerations. Top line reports which summarize the focus group results were also provided.

Universal Focus Group - 35 participants were invited, 35 responded, 7 attended (100% response rate, 20% attendance rate).

- The following are discussion points made by the stakeholders for the focus group covering universal timeliness measures.
  - Performance Measure: From Abnormal Result to Physician Notification
    - Notification of Physician "same day as result" is challenging and needs to be clarified.
    - Look at other options including fax and e-mail to notify.
  - Performance Measure: From Parent Notification Until Physician/Specialist Visit for Confirmatory Testing
    - Both the physician and specialist can order confirmatory testing. It is not always done exclusively by the specialist.
  - Performance Measure: From Receipt of Confirmatory Test Until Treatment Initiation
    - Midwives sometimes draw specimens for confirmatory testing; it is not always done by the physicians or specialists.
- General Discussion
  - Not all of the definitions were fleshed out by the focus group process. This may require another session to obtain better definitions. It is valuable to understand that the focus groups have not gone through the whole process to define everything.
  - Consider using the term "submitting healthcare provider" to incorporate non-physicians.
  - "Critical" should be defined as anything outside the standard time causing potential for harm.
  - If information is sent by emails or fax and going to be seen by someone in the office, we should establish values for critical abnormals and make them an NBS Program standard.

Endocrine Focus Group - 51 participants were invited, 13 responded, 8 attended (25% response rate, 16% attendance rate). Participants were from the University of Texas Southwestern Medical Center (Dallas), University of Texas Hermann Hospital (Houston), University of Texas Health Science Center at San Antonio, University of Texas Medical Branch at Galveston, Texas Health and Human Services Commission, Texas Tech University Health Sciences Center, and The Children's Hospital at Scott and White Texas A&M College of Medicine (Temple).

- The following are discussion points made by the stakeholders for the Endocrine Focus Group.
  - Without a definition for all parameters, it is hard for us to move forward.
  - For the denominator population, consider including affected infants detected outside of the newborn screening (ex. infants born out of state, false negatives, etc.).
  - Performance Measure: Time to Initiate Treatment Salt Wasting Congenital Adrenal Hyperplasia (SW CAH)
    - Nurse/midwives also draw specimens not always physicians.
- General Discussion
  - Consider capturing the success of how we share family risk with parents since it is a benefit.
  - Incentives for providing the data to calculate performance measurement data (ex. submission of follow up forms) was not brought up as a topic for discussion in the focus groups.

Hematology Focus Group - 51 participants were invited, 18 responded, 8 attended (35% response rate, 16% attendance rate).

- The following are discussion points made by the stakeholders for the Hematology Focus Group.
  - Performance Measure: Time to Initiate Treatment Hemoglobin Sickle Cell Anemia Disease (HbSS)
    - The focus group included "any type of hemoglobin" in the denominator but should only include critical hemoglobinopathies.
  - Performance Measure: Age at First Prevnar® Vaccination Hemoglobin Sickle Cell Anemia Disease (HbSS)
    - Use the generic name for pneumo-vaccine rather than use the brand name Prevnar®.
  - Performance Measure: Parent Education on Assessing Enlarged Spleen and Monitoring Episodes of Fever
    - Distributing performance measure reports to the emergency room doctors is not practical, it is best to provide family education sheets to the doctor treating the child.

Metabolic Focus Group - 22 participants were invited, 21 responded, 15 attended (95% response rate, 68% attendance rate).

- The following are discussion points made by the stakeholders for the Metabolic Focus Group.
  - A stakeholder asked about "women with Phenylketonuria (PKU) who become pregnant" but this was deemed out of scope for the performance measures under development.
  - Performance Measure: Time to Reduce Plasma Leucine – Maple Syrup Urine Disease (MSUD)
    - Goal in compliance states "5 to 7 days to treatment" which means that if it took 4 days to reduce plasma leucine levels, it would not meet the standard specified. Consider re-wording this goal.
  - Performance Measure: Screening/Diagnosis of At-Risk Family

- Including at-risk family members in the denominator for the performance measure would skew the data.

FEASIBILITY FINDINGS AND DEVELOPMENT

Mirsa Douglass presented the results from the online feasibility assessment process used to determine whether or not a performance measure can be measured.

- Methodology Approach to Assessments
  - Feasibility of performance measures was assessed by the Department of State Health Services (DSHS) Newborn Screening (NBS) program. Evaluation criteria that were intended to be assessed included overall data needs, available human resources, needed infrastructure, needed processes, cost/time to start up the pilot, and the cost/time to implement the pilot.
- For the purposes of time and scope, only the following evaluation criteria were assessed: data elements identified, data collection methods, and the ease of data collection.
  - Data elements identified
    - Are the data elements identified and clear?
  - Data collection methods
    - Is there a collection method in place for all of the data elements?
  - Ease of data collection
    - Will this be easy or difficult to collect and therefore report?
- From Qualitative to Quantitative
  - Maximum possible score for a performance measure was 15 for each individual rater.
  - With 6 raters, the maximum possible total score was 90 for each measure.
  - Raters subtotal divided by maximum possible score x 100 provided the final assessment score.
- Results of the Impact and Feasibility Assessments
  - Performance Measures rating was based on an altered approach include:
    - Normalization of serum Thyroid Stimulating Hormone (TSH), Thyroxine (T4) and Free Thyroxine (FT4) concentration within one month of treatment
    - Monitoring the number of newborns with congenital hypothyroidism whose thyroid stimulating hormone (TSH) falls below 10 within one month of treatment makes this performance measure feasible. Monitoring serum levels to a normal range for infant's age makes this performance measure unfeasible.
    - Frequency of growth assessments for congenital adrenal hyperplasia (CAH) for the first year of life using DSHS frequency schedule. – Measuring for growth and evaluation (height, weight, body mass index (BMI), and Tanner staging) on a frequency standard of four times a year for first year of life. Restricting the pilot to first year of life makes this performance measure feasible.

- Impact and feasibility results for the performance areas are shown below.

Endocrine	Impact	Feasibility
CH		
Time to Initiate Treatment	87	88
Initial Dosage of L-Thyroxine†	79	78
Normalization of Serum TSH, T4 and FT4 Concentrations†	77	68
CAH		
Time to Initiate Treatment for SW CAH	88	88
Time to Initiate Treatment for SW & SV CAH: By Gender	86	86
Frequency of Medical Evaluations that Assess Growth	81	64

Hemoglobinopathy	Impact	Feasibility
Time to Initiate Penicillin Treatment (HbSS)	87	89
Compliance with Oral Prophylactic Prescription of Penicillin (HbSS)	85	73
Age of First Prevnar® Vaccination (PCV-7) (Sickle Cell Disease)	81	79
Parent Education on Assessing Enlarged Spleen/Monitoring Episodes of Fever (Sickle Cell Disease)	80	46

Universal	Impact	Feasibility
(t1) Specimen Collection Time	88	97
(t2) Specimen Transit Turnaround	85	98
(t3) Time from Abnormal Screen Resulting to Case Management Notification	85	88
(t4) Time from Abnormal Result to Physician Notification	88	88
(t4a) Time from Birth until Physician Notification	88	88
(t5) Time from Physician Notification to Parent Notification	87	51
(t6) Time from Parent Notification until Physician/Specialist Visit for Confirmatory Testing	85	60
(t6a)Time from Abnormal Screen Result to Time Infant is seen by Physician/Specialist for Confirmatory Testing	84	81
(t8) Time from Receipt of Confirmatory Testing Results to Treatment Initiation	83	66
Unsatisfactory Specimen Rate	87	98
Percent Missing Birth Weight†	77	93
Percent Missing Date of Birth	80	97
Percent Missing Date of Collection	81	94
Percent Missing PCP Information	85	92
Percent with Incorrect PCP Information	82	76

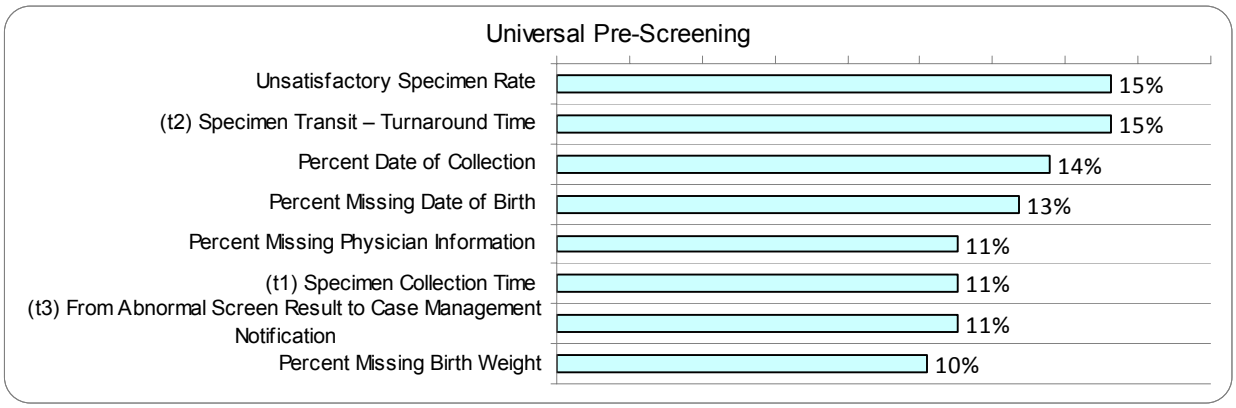
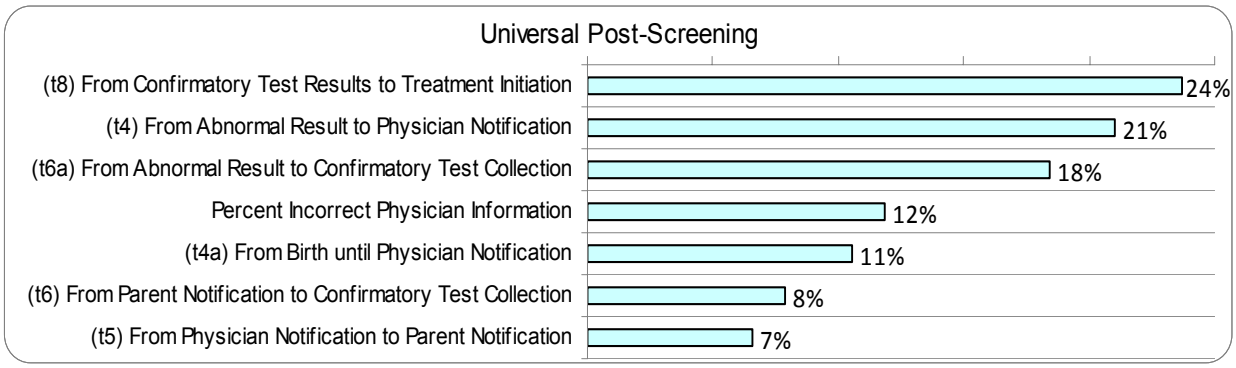
† Measure that didn't meet impact assessment criteria thresholds but was "voted in" by TNSPMP stakeholders.

Metabolic	Impact	Feasibility
MSUD		
Time to Initiate Treatment	86	82
Time to Reduce Plasma Leucine Concentration Levels	80	86
MCADD		
Time to Confirmed Diagnosis†	78	90
Adherence to Dietary Treatment (Avoid Fasting) †	76	71
Screening/Diagnosis of At-Risk Family Members	82	43
PKU		
Time to Initiate Treatment	84	93
Phenylalanine Levels for Metabolic Control	83	92
Galactosemia		
Time to Initiate Treatment	88	92

Discussion and First Draft Priorities by Performance Measure Area (Affinity Exercise)

The stakeholders participated in an affinity exercise where they were given an opportunity to "vote" on the measures. For each performance measure area (universal timeliness, endocrine, hematology, metabolic), stakeholders were given a specific number of sticky dots to distribute on those measures they felt should have a higher priority. The results are noted below.

Universal Related Measures Pre-Screening – 20 participants (6 votes each)



Universal Related Measures Post-Screening – 19 participants, 4 votes each)