

TNSPMP MEETING AGENDA AND NOTES



TNSPMP QUARTERLY TEAM MEETING

TEXAS CHILDREN'S HOSPITAL - CLINICAL CARE CENTER

CONFERENCE ROOM D.0360.40 (3RD FLOOR)

6701 FANNIN STREET

HOUSTON 77030

FRIDAY – FEBRUARY 20TH, 2009

TNSPMP FACILITATOR: ROBIN SCOTT, OPEN CIRCLE CONSULTING

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>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>Jimi Ripley-Black</i>	√
<i>James W Varni</i>	√



**IMPACT ASSESSMENT INTRODUCTION AND CONSENSUS BUILDING EXERCISE**

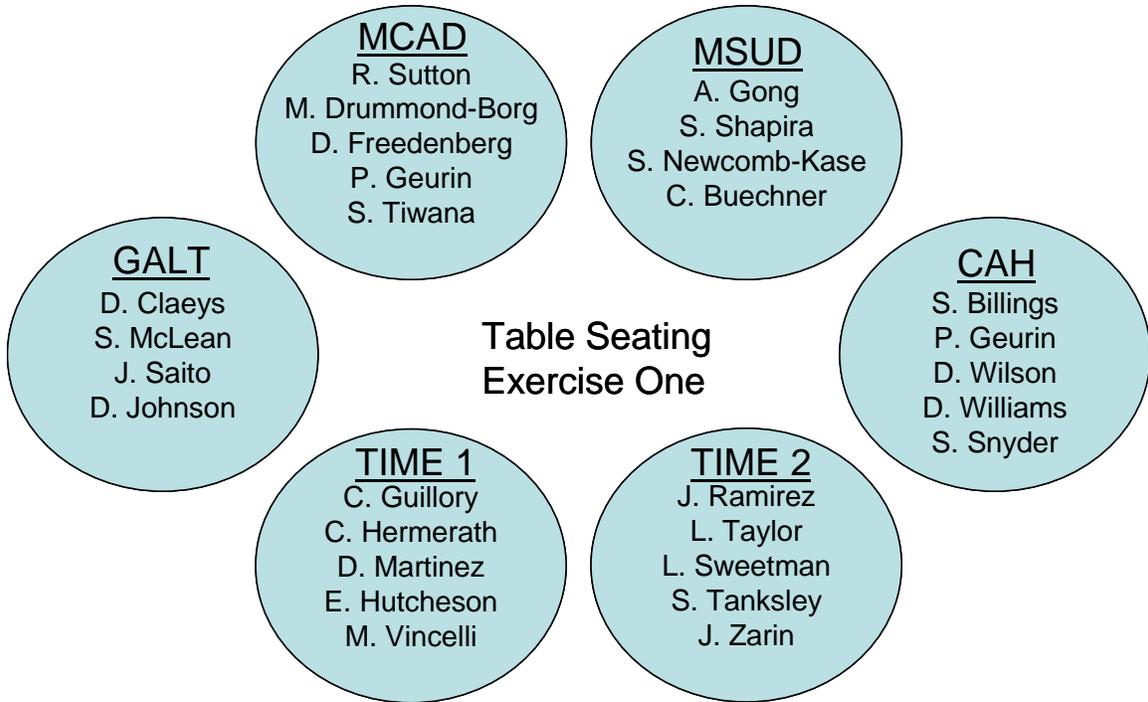
*Mirsa Douglass reviewed the design and format for the on-line survey that will be used by system stakeholders to assess impact of performance measures.*

*Following the demonstration, stakeholders divided into assessment groups to conduct an impact assessment for an assigned performance measure. After participants completed their individual assessments, results were discussed among the participant assessment groups. This was repeated another time for a second exercise.*

*The first exercise involved groups assessing the following performance measures:*

- Congenital Adrenal Hyperplasia (CAH) group – Frequency of developmental evaluations through age 18
- Galactosemia (GALT) group – Frequency of specialist center visits through age 4
- Medium Chain acyl CoA Dehydrogenase (MCAD) group – Hospitalization rate for MCAD
- Maple Syrup Urine Disease (MSUD) group – Time to reduce plasma leucine concentration levels
- Timeliness group 1 – Days from physician notification until parent notification
- Timeliness group 2 – Percent missing birth weight

*Seating arrangements as follows:*

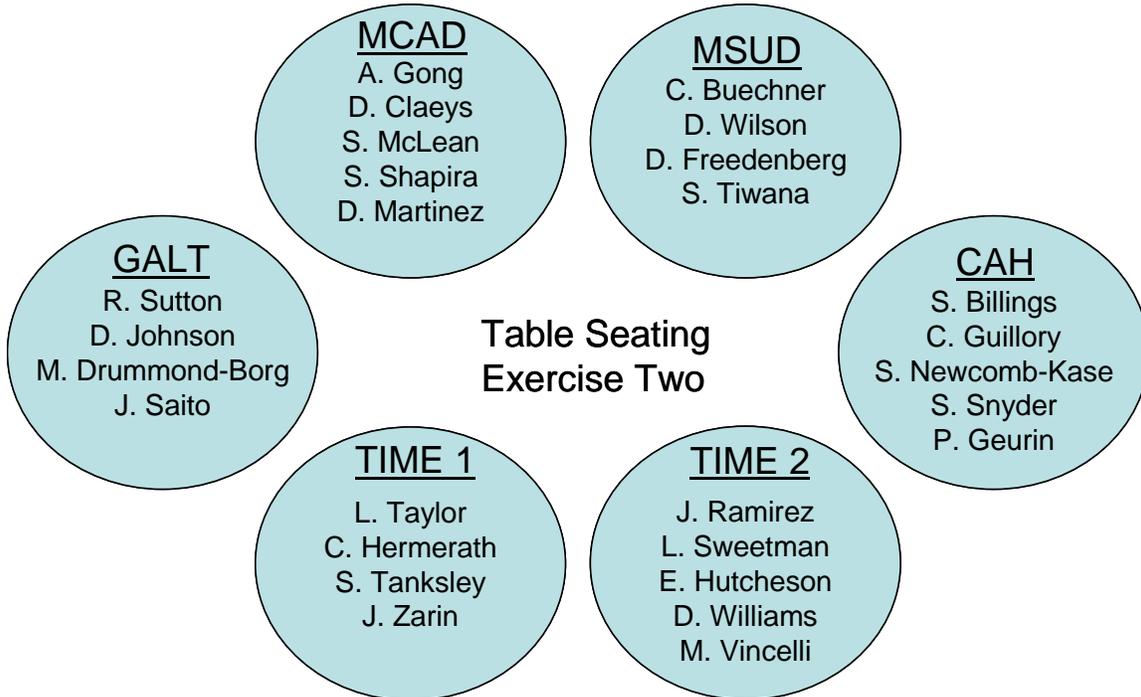




*The second exercise involved groups assessing the following performance measures:*

- Congenital Adrenal Hyperplasia (CAH) group – Time to correct gender assignment
- Galactosemia (GALT) group – Dietary compliance
- Medium Chain acyl CoA Dehydrogenase (MCAD) group – Parent understanding post physician notification
- Maple Syrup Urine Disease (MSUD) group– Frequency of laboratory monitoring for long term metabolic control
- Timeliness group 1 – Percent with incorrect PCP information
- Timeliness group 2 – Days from physician specialist visit until receipt of confirmatory testing results

*Seating arrangements as follows:*



**TOPIC: PEDSQL™: MEASURING PEDIATRIC HEALTH-RELATED QUALITY OF LIFE**

*Dr. James Varni, Professor at the Texas A&M University, gave a presentation on measuring pediatric health-related quality of life.*

**FEEDBACK ON IMPACT ASSESSMENT AND CONSENSUS BUILDING EXERCISES**

*System stakeholders shared their feedback on the approach used for impact assessment. The main points are as follows:*

- Online Survey:
    - All agreed that the current proposed format and design of the on-line survey is acceptable.
  - Feedback on performance measures:
    - When included, timeframes need to be more specific. One example is the dietary compliance performance measure for Galactosemia. “Is the performance measure over the lifetime?”  
  
Response: If the measure does not specify a period, the measure is referring to compliance during the “period” supported by the evidence review literature. This needs to be clear in the conceptual definition and will be clarified in the definition.
    - The type or form of the disorder needs to be clear. For example rather than stating “an infant with CAH”, the performance measure should specify “an infant with salt wasting CAH”.
    - The performance measures should include appropriate terminology. For example, “frequency of developmental evaluations through age 18” is a specific assessment by developmental specialists of a child's cognitive and psychomotor development, but the information in the summary evidence tables pertains to growth and ultimate adult height. A better description of this performance measure would be “frequency of medical evaluations that assess growth and development through age 18.”
    - The literature review includes information on formulating an operational definition. Without the operational definition, it is hard to assess impact based solely on the conceptual definition of the measure. It was suggested that both be formulated before moving to impact assessments.  
  
Response: Doing both for all proposed 50 measures, however, is not possible to complete within the project timeline.
    - Participants from one assessment group were able to use the evidence summary table to find better wording for the conceptual definition of the performance measure. It was suggested that groups of 2 or 3 specialists work on ensuring the proper wording of performance measures.
  - Feedback on the evidence summary tables:
    - The CAH assessment group noted that published articles that would support the performance measure provided for the exercise was missing from the evidence summary table.
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- It was suggested that medical experts review the evidence provided in the summary evidence tables and remove proposed performance measures without valid data.
- It was suggested that further review of literature was needed.
- Participants noted there were no evidence tables for performance measures related to timeliness. Examples of the measures in this assessment group are specimen collection turnaround time, specimen transit turnaround, days from abnormal screen results until physician notification, percent missing birth weight, percent missing date of birth, etc.

Evaluation criteria 6 and 7 covering explicitness and strength of evidence need to be revisited. Little or no evidence exists for timeliness of pre analytical NBS processes. Since there is a compelling argument linking their association to timeliness of treatment, they are being considered as candidate measures for this project. Also, the body of evidence for “time to treatment” for each of the specific disorders indirectly supports the performance measures in the timeliness assessment group. However, this may not be rated correctly during assessment if stakeholders do not have a dedicated “evidence summary table”

- Feedback on the evaluation criterion used for the proposed impact assessment:
  - Stakeholders would like to modify the language of the evaluation criterion so that it is customized for the needs of the newborn screening impact assessment project.
  - Performance measures are not evaluating disparity of service. This evaluation criterion doesn’t seem applicable to assessing impact.
  - Stakeholders would like to see weighting applied to the evaluation criteria.
  - It was suggested we reconsider the scoring of the Likert scale to include negative numbers.
  - It was suggested that we consider showing the Likert score rather than the descriptive level of agreement on the impact assessment survey (ex. strongly agree, strongly disagree).

### **TEXAS NBS UPDATES**

*Susan Tanksley provided a synopsis of the latest activities for the newborn screening program.*

### **TNSPMP QUARTERLY MEETING NOTES TIMELINE**

- 03/10/09**      Distribute TNSPMP February quarterly meeting notes for system stakeholder review
- 03/16/09**      Deadline for system stakeholders to provide feedback and suggested edits for quarterly meeting notes
- 03/20/09**      Deadline for posting quarterly meeting notes on TNSPMP website

### **REVIEW OF EVIDENCE SUMMARY TABLES AND CONCEPTUAL DEFINITIONS OF MEASURES**

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*It was unanimously decided that medical experts need to ensure the conceptual definitions of the performance measures coincide with the language and information presented in the evidence summary tables. The following system stakeholders were tasked with reviewing the project materials related to conceptual definitions and summary evidence tables of performance measures:*

- Dr. Don Wilson - CAH and CH assessment group (Sandra Billings offered to assist)
- Dr. Reid Sutton - MCAD assessment group
- Dr. Stuart Shapira - MSUD assessment group
- Dr. John Saito - GAL assessment group
- Dr. Debra Freedenberg - PKU assessment group
- Dr. George Buchanan - Sickle Cell Disease assessment group
- Dr. Charleta Guillory and Dr. Alice Gong - Timeliness assessment group (Sister Mary Nicholas Vincelli offered to assist)

**03/16/09** Deadline for assigned system stakeholders to review summary evidence tables and conceptual definitions of performance measures for recommended changes in language.

#### **REVIEW OF EVALUATION CRITERION USED FOR IMPACT ASSESSMENT**

*Many of the system stakeholders believe that the language used for the evaluation criterion needs to be better tailored for the newborn screening project.*

*Dr. Scott McLean volunteered to rework the wording of the evaluation criterion and consider the weighting or importance of each in assessing impact.*

**03/16/09** Deadline for finalizing evaluation criterion for the impact assessment.

#### **CONDUCTING AN IMPACT ASSESSMENT**

**03/27/09** Deadline to hold a system stakeholder Webinar to review impact assessment guidelines for completing the on-line survey.

**03/27/09** Deadline to administer the TNSPMP performance measure impact assessments for all assessment groups.

**04/24/09** Deadline to complete the TNSPMP performance measure impact assessment.

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**TNSPMP QUARTERLY MEETING DATES**

05/07 & 05/08/09 McAllen, Texas

08/20 & 08/21/09 To Be Determined

**MEETING PLUS/DELTA (FEEDBACK)**

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

**CHANGES**

Everything at Reid's house

Construction noises

No moving

Puzzle torture

**POSITIVE FEEDBACK**

Moving

Layout of the room

Cows

Fishnets

Coffee!

Cookies!

Number of attendees

Good energy

Good weather

Art gallery at Reid's house

Lunch

Great presentations

A/V setup

NICU tour

Great facilitator

B-roll