TNSPMP QUARTERLY TEAM MEETING

MAYAN RANCH BANDERA, TEXAS

CONFERENCE ROOM

THURSDAY – NOVEMBER 19TH, 2009

TNSPMP FACILITATOR: ROBIN SCOTT, OPEN CIRCLE CONSULTING

MEETING NOTES

ATTENDEES:

Sandra Billings	✓
George R. Buchanan	✓
Colleen Buechner	✓
Kari Casas	✓
Donna Claeys	✓
Liza Creel	✓
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	✓
Brigitte Bright	✓
Cheryl Burcham	✓
Sherry Clay	
Mirsa Douglass	✓
Debra Freedenberg	✓
Paula Guerin	✓
Eldridge Hutcheson	✓
Daisy Johnson	✓
Marcie Kirtz	✓
David R. Martinez	
Jann Melton-Kissel	
Susan Neill	
Sharon Newcomb-Kase	✓
Susan Tanksley	✓
Donna Williams	✓
Susan Snyder	✓
Lisa Kalman	

WELCOME

Susan Tanksley welcomed the group. Robin Scott facilitated introductions and the agenda review.

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**
  - Tasks included identification and selection of performance metrics to be piloted in the third year of the project.
  - Produced the final Evidence Summary Report in May 2009.

- **TNSPMP Year Two Activities**
  - Focus groups were utilized to obtain feedback on performance indicators in four disorder groups: endocrine, metabolic, hemoglobinopathy and universal. Their input provided insight into further development of measures, definitions, terminology and comprehensibility.
  - NuStats provided summary reports of feedback in each performance measurement area, in addition to detailed transcripts.
  - Performance measures were assessed by DSHS staff for feasibility and impact.
  - Infrastructure and process needs were identified to pilot performance measures in the third year of the project.
  - Documentation was developed on 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**
  - Complete TNSPMP Operational Framework and Pilot Project Plans for each of the selected performance measures (to be completed by December).
  - Execute and report on the Pilot Performance Measures (preliminary findings by February).
  - Investigate intervention models and produce a report on recommended interventions to improve performance in measurement areas.

CONSUMER FOCUS GROUP RESULTS

Cheryl Burcham presented the results from the focus group meeting. Results included highlights from the Draft Report provided by NuStats with the Final report to be distributed at a later date. General notes and individual discussion points are noted below.

The focus group was held on Friday September 18th at the Tammadge Research Facility in Austin, Texas. NuStats conducted a single focus group session with consumers who have experience with the State's Newborn Screening process. The target audience also included adults living with Newborn screening disorders or parents of children who have screened positive with a disorder.

Eight participants were recruited, six participated in the focus group session, and individual interviews were conducted with two who couldn't make the group session. Participants experience with the Newborn Screening Program varied. Two individuals were adult patients with Sickle Cell Disease, one young adult with CAH, four parents of young children diagnosed with a disorder

through the Texas Newborn Screening Program and one participant was a parent of children with sickle cell trait.

The discussion guide was drafted by DSHS staff and finalized by NuStats. The guide was structured so that the discussions would flow consistently in each section. The five discussion topics included: Parent Education (Prior to Screening), Specimen Collection, Parent Notification of Newborn Screening Test Results, Disorder Management Education (Post Screening) and Treatment Initiation.

Below are common themes and conclusions of the discussion topics:

- Overall, the participants were pleased with the coordination of the Newborn Screening activities.
- Parents expressed a need for more, easy-to-understand information about Newborn Screening and the types of disorders included in the screening.
- Receiving information from DSHS on a disorder and contact/follow-up was appreciated, but parents would welcome it sooner after the initial diagnosis.
- Two families with children affected by a NBS disorder strongly recommended flagging the screens of siblings when other children in the family have a diagnosed disorder.
- Disorder management is perceived to be a "family management" issue.

The following are discussion points made by the stakeholders on the Consumer Focus Group presentation:

- All agreed that educating new parents about the Newborn Screening Program is a challenge.
- A stakeholder asked if any parents discussed experience with genetic counseling. One of the parents of a CAH child discussed seeking genetic counseling because her husband is adopted.

UPDATES ON PILOT PLANS

Mirsa Douglass presented updates of the pilot performance plans. The presentation included review of plans to pilot the performance measures and discussions of considerations/limitations. General notes and individual discussion points are noted below.

Pilot Plan Components Include:

- Significance
- Performance Standard/Goal
- Conceptual/Operational Definition
- Aim of Proposed Pilot
- Pilot Scope (Data)
- Methods
- Validation/Quality Assurance
- Considerations/Limitations

The initial listing of approximately fifty (50) evidence-based performance measures under consideration for piloting was further narrowed and finalized by using results from the focus groups, impact and feasibility assessments, and priority voting by stakeholders during the August meeting. The listing now includes twenty-one (21) approved pilots to be conducted in 2010.

The following are discussion points made by the stakeholders on the Updates on Pilot Plans.

- Several discussed the timeline or scope of reviewing only four (4) months of data. This is a concern especially on those disorders with few cases. For example, will we have a statistically significant sample size to examine? Discussions included bringing in data from other states but this could add concerns with differences in protocols.
- In reference to performance measures related to missing birth weight and birth age, comments were made concerning premature infants and the appropriate time for them to receive the newborn screening.

SPECIAL RECOGNITIONS

Javier Ramirez presented hand painted Mexican artisan plates symbolizing motivation, leadership and courage to the following:

Robin Scott received El Gallo or The Rooster

Susan Tanksley received El Sol or The Sun

Mirsa Douglass received El Corazon or The Heart

GUEST SPEAKER

Amy Brower, Ph.D., of the American College of Medical Genetics (ACMG) and Scientific Advisor in Clinical Genomics and Medicine at Aurora Health Care.

- Topic: The National Coordinating Center for the Regional Genetic and Newborn Screening Service Collaborative – Providing Resources for Bridging Genetics, Primary Care and Public Health and for Bringing Genetics and NBS Services to Local Communities.

NEWBORN SCREENING UPDATES

Susan Tanksley provided updates related to the Newborn Screening Program.

Implementation of Cystic Fibrosis Screening

- DSHS held three (3) stakeholder meetings with representatives from CF Centers and medical associates.
- Currently validating reagents and equipment.
- Currently testing software specifications
- Building retrofit is 95% complete
- Staffing
  - Laboratory – filled two positions of twelve
  - Case Management – ready to offer two nurses and moving on other three positions
- Educational materials compiled
- Finalizing Cystic Fibrosis benefits package

- Grand Round Webinar on CF scheduled for December 4th
- Implementation on track for December 2009
- Fee increase scheduled for January 2010

Implementation of HB 1672
Requires parents be notified of retention of bloodspot cards after testing and given process to request destruction

- Interim Plan – began August 1, 2009.
- Long-Term Plan tentatively set for spring of 2010.
- Number of disclosure/destruction request received through November 18, 2009 = 8,288.

Implementation of HB 1795
Authorizes an NBS Advisory Committee and the addition of additional disorders to the screening panel

- The Newborn Screening Advisory Committee will have approximately nine members, who are expected to hold two meetings in FY10.
- The NBS program is developing proposals for implementation of screening for secondary targets in American College of Medical Genetics (ACMG) panel, however no funding is available at this time.

Grant Activities

- Severe Combined Immunodeficiency Disorder (SCID) Pilot – the goal is to screen 20,000 Texas infants per year. The pilot project will start in Seton and St. David's Hospital Systems. The project has received IRB approval from DSHS and Seton.
- 2nd tier CAH Assay – the goal is to dramatically cut false positive rate. Includes a two year grant of $150,000 per year.
- Second Screen Study – the purpose of the study is to gather evidence regarding the need for mandatory second screens to ensure identification of all clinically significant cases of CH and CAH.
- Courier Service – Targeted for Medicaid providers with an estimated start date of February 1, 2010.