

TNSPMP MEETING AGENDA AND NOTES



TNSPMP QUARTERLY TEAM MEETING

EMBASSY SUITES HOTEL, FORT WORTH TEXAS

SYNERGY CONFERENCE ROOM

THURSDAY – FEBRUARY 18TH, 2010

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>Liza Creel</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>Lisa Kalman</i>	
<i>Scott D. McLean</i>	✓
<i>Javier Ramirez</i>	
<i>John Saito</i>	✓
<i>Morgan Sanders</i>	✓
<i>Stuart K. Shapira</i>	✓
<i>Eileen Sheridan-Shayeb</i>	
<i>Susan Snyder</i>	✓
<i>Reid Sutton</i>	✓
<i>Larry Sweetman</i>	✓
<i>Lois Taylor</i>	✓

<i>Brad Therrell</i>	✓
<i>Sister Mary Nicholas Vincelli</i>	✓
<i>Don P. Wilson</i>	
<i>Erika Wright</i>	✓
<i>Jerald L. Zarin</i>	✓
<i>Wendy Beathard</i>	✓
<i>Brigitte Bright</i>	✓
<i>Cheryl Burcham</i>	✓
<i>Sherry Clay</i>	
<i>Debra Freedenberg</i>	✓
<i>Paula Guerin</i>	✓
<i>Eldridge Hutcheson</i>	✓
<i>Daisy Johnson</i>	✓
<i>Marcie Kirtz</i>	✓
<i>Adriana Marin</i>	✓
<i>David R. Martinez</i>	
<i>Jann Melton-Kissel</i>	
<i>Susan Neill</i>	
<i>Sharon Newcomb-Kase</i>	
<i>Jimi Ripley-Black</i>	
<i>Susan Tanksley</i>	✓
<i>Jill Wallace</i>	✓
<i>Donna Williams</i>	✓

WELCOME

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

TNSPMP STATUS UPDATE

Cheryl Burcham provided a progress update with an overview of the project and year three scope of activities. The presentation began with an introduction to the resource table which included Year One and Two summaries, deliverables and other project documents. The resource table was available throughout the meeting.

• TNSPMP Evidence-Based Approach

- Tasks included identification and selection of performance metrics to be piloted in the third year of the project.
- Delivered NBS Gaps and Barriers Summary (May 2008). Includes gaps from PEAS assessment, NNSGRC consultative report and stakeholder observations.
- Produced the final Evidence Summary Report in May 2009.

• TNSPMP Year Two Activities

- Six 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.
- Two additional focus groups were utilized in obtaining feedback from individuals impacted by the NBS and on the uses of the pre-analytical report card.
- NuStats provided summary reports of feedback in each performance measurement area and focus group, 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. The operational definitions include elements of the numerator, inclusion/exclusion criteria and the denominator.

• TNSPMP Year Three Activities

- Produced and distributed the TNSPMP Performance Measure Selection Process and Development of Pilot Plans Report January 2010 for each of the selected performance measures (Completed).
 - Execute and report on the Pilot Performance Measures (Preview of Pre-Universals reported in February; remainder to be reported in subsequent meetings).
 - Change Request Committee meet bi-weekly to discuss progress of Performance Measure Pilots. The Committee consists of Laboratory and Case Management Leadership, TNSPMP Team, Laboratory Statistician and PerkinElmer Representative.
 - Investigate intervention models and produce a report on recommended interventions to improve performance in measurement areas (First 5 Gap topics explored in February, remaining 6 to be discussed in May).
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NBS BUDGET OVERVIEW

Susan Tanksley presented an update to the Newborn Screening Program FY2008 and FY2009 Budgets. This update was a follow-up to the estimates shared with the stakeholders in April 2008.

The workload for the two past fiscal years includes: 791,134 specimens screened in the laboratory with 16,700 cases followed up in fiscal year 2008. In fiscal year 2009, 785,453 specimens were screened in the laboratory with 16,700 cases followed up.

The Budget Expenditures:

	FY 2008	FY 2009
Laboratory	\$15.2 Million	\$16.3 Million
Case Management	\$ 2.6 Million	\$ 3.1 Million
Total	\$17.8 Million	\$19.4 Million

GUEST SPEAKER

Brad Thompson, MA, LPC, the Director of The HALI Project – a non-profit organization that provides counseling and education services for communities who care for individuals with special needs.

- Topic: The Puzzle – Mr. Thompson shared experiences about his twenty year old daughter Hali. Hali deals with multiple special needs, both physical and cognitive. He utilized puzzle pieces to symbolize the complexity of caring for a special needs child.

PILOT EVALUATION PLAN

Adriana Marin presented the Pilot Evaluation Plan to include a review of the selection process and objectives.

- Preliminary Results of the Pre Analytical Universal Performance Measures were presented for a research sample size of 406,629 (all of the specimens received in the laboratory between July and December 2009):

Performance Measure	Met Performance Standard	Outside the Performance Standard
NBS Specimen Transit Time from Collection to Receipt in the Laboratory	56%	44%
Unsatisfactory NBS Specimen Rate	99.21%	.79%
Percent NBS Specimen Missing Date of Birth	99.84%	.16%
Percent NBS Specimen Missing Time of Birth	78%	22%
Percent NBS Specimen Missing Date of Collection	99.98%	0.02%
Percent NBS Specimen Missing Time of Collection	85%	15%
Percent NBS Specimen Missing Birth Weight	94.97%	5.03%

The following are discussion points made by the stakeholders on the Pilot Evaluation Plan presentation:

- A stakeholder asked what variables will be reviewed (reference transit time) providers, size of provider, region, proportion of specimens, unsats, 1st /2nd screens and requested repeats.
- One suggestion was to coordinate with the postal service to establish routes and holiday schedules.
- A stakeholder asked if we could measure the cost effectiveness of these measures or the cost of increasing time to treatment.
- In reference to Specimen Transit Time, a suggestion was made to break out by day of week of when the infant was born.
- For “Best Practices”, compare best vs. worst.
- Recommended awarding good performers and not highlight the negative. The stakeholder stated developing countries tend to award good performers.

CYSTIC FIBROSIS UPDATES

Susan Tanksley and Marcie Kirtz provided updates related to the Implementation of Cystic Fibrosis Newborn Screening statewide on December 1, 2009.

During the first two months of Cystic Fibrosis Screening, a total of 138,615 specimens were received of which 2,457 were abnormal for IRT. As of January 31, 2010, 5 cases were diagnosed.

The Cystic Fibrosis Case Management Team is in place to include the Manager Paula Geurin, two registered nurses and two public health technicians. In addition a new educator was introduced, Wendy Beathard. Wendy’s goals are to provide NBS system participants with more extensive clinically relevant education and to provide an overview from specimen collection through long-term follow-up.

The following are discussion points made by the stakeholders on the Cystic Fibrosis Update presentation:

- A stakeholder asked to what extend are you thinking of replacing the mailings with electronics.
- A stakeholder asked if information was given to siblings and genetic counseling made available for the family.
- Has research been conducted on the location of sweat testing clinics?

NBS AND LEGISLATIVE UPDATES

Susan Tanksley provided updates related to the Newborn Screening Program and Legislature.

Implementation of HB 1795

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

- Change to Health and Safety Code, Chapter 33.
 - Adds screening for secondary targets in ACMG panel, as funding allows.
 - Adds a Newborn Screening Advisory Committee.
 - Planning on 9 member committee.
 - Applications and instructions sent to >100 stakeholders.
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- Application review in process.
- Anticipate Spring 2010 meeting.
- Effective September 1, 2009.

Implementation of HB 1672

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

- Change to Health and Safety Code, Chapter 33.
- Adds provisions:
 - Disclosures that NBS specimens can be stored and used by DSHS for other purposes.
 - Allows parents or adults to request destruction of their child's/own specimen(s).
 - Confidentiality of NBS data and specimens and defines acceptable uses.
 - Interim Legislative study of NBS focusing on disclosure/destruction/notification processes.
 - Screening for sickle cell trait.
- Effective Date: May 27, 2009.
- 13,772 valid requests have been received through 2/1/2010.
- Form has been revised to increase readability.
- Next steps are to further educate using the new forms and an interim study.

New Public Health Service Fee

- As of December 1, 2009, the fee increased to \$34.50. There are now 28 disorders screened to include Cystic Fibrosis. The increase was required to cover the additional tests and follow-up and the infrastructure for the destruction requests.

NBS Program Projects

- Severe Combined Immunodeficiency Disorder (SCID) Pilot – the Secretary Advisory Committee on Heritable Disorders in Newborns and Children voted in January to recommend addition of SCID to core panel. The initial goal is to screen 10,000 Texas infants per year. The pilot project will start in Seton 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. Investigate protocols in use in other states.
- 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. All states with 2 screens to participate. Data collection has begun. Next steps are data analysis, summarize data presented, publish and present to Secretary Advisory Committee.
- Courier Service – Frew initiative funding approved at \$2.6M per year for 4 years. Routes include Dallas, Fort Worth, Tyler, Houston, San Antonio, Brownsville, McAllen, Laredo, Del Rio, Corpus Christi, Austin, Temple, Waco, San Angelo, Midland, Odessa, El Paso, Lubbock, and Amarillo. Expected start date is April 12, 2010.

The following are discussion points made by the stakeholders on the NBS and Legislative Update presentation:

- In reference to HB 1672, a stakeholder suggested that we get parents involved in telling good stories.
 - Erica Wright – announced that this spring Colorado NBS will be linked to vital statistics.
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