

TNSPMP MEETING AGENDA AND NOTES



TNSPMP QUARTERLY TEAM MEETING

LAKEWAY RESORT AND SPA, AUSTIN, TEXAS

COLORADO III CONFERENCE ROOM

THURSDAY – AUGUST 19, 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>R. Michael Dulaney</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>Michael E. Speer</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>Erica Wright</i>	✓
<i>Jerald L. Zarin</i>	✓
<i>Barbara Zehnbauer</i>	
<i>Wendy Beathard</i>	✓
<i>Sue Berry</i>	✓
<i>Cheryl Burcham</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>Jill Maughan</i>	✓
<i>Carolyn Ridge</i>	✓
<i>Jimi Ripley-Black</i>	✓
<i>Robin Scott</i>	✓
<i>Susan Tanksley</i>	✓
<i>Jill Wallace</i>	✓
<i>Donna Williams</i>	✓

WELCOME

Susan Tanksley welcomed the group and introduced the new stakeholder Dr. Michael Dulaney. Robin Scott facilitated introductions and the agenda review.

TNSPMP SUMMARY OVERVIEW

Cheryl Burcham and Mirsa Douglass provided a summary overview of the TNSPMP project from current activities to the beginning of the project.

TNSPMP Year Three Highlights – New Grant Opportunity

- The Centers for Disease Control and Prevention announced a new grant opportunity for Evidence-Based Laboratory Medicine: Quality/Performance Measure Evaluation posted 5/24/10.
- The DSHS Laboratory submitted a letter of intent on 6/21/10 with the project description title of Texas Public Health Performance Measures Project (TPHPMP). The grant application was submitted on 7/6/10. The three year grant has an annual award of \$350,000.
- The goals are to link pre- and post-analytical stages of laboratory testing for blood lead, human immunodeficiency virus (HIV), and syphilis using experiences gained through the Texas Newborn Screening Performance Measures Project.

TNSPMP Year Three Highlights – Extension Request

- The request for the TNSPMP no cost extension includes the carry forward of unobligated funds from Year 2 to Year 3 for an 8 month no cost extension. The objectives of the extension include completing the pilot studies, identifying and publishing the evidence-based interventions and documenting the final project reports. The request was submitted on 6/29/10.
- The extension budget includes two stakeholder meetings, two focus groups and out of state travel expenses for one project team member to attend up to three regional or national NBS related meetings. The purpose of the out of state travel is for the project team member to share lessons learned from the TNSPMP with other groups.

As one of the project managers for the Centers for Program Coordination, Policy, and Innovation, Mirsa Douglass provided a brief overview of two of their projects (State Health Information Exchange and State Medicaid Health Information Technology Plan). Mirsa then provided a historical view of TNSPMP project through Year 2.

CDC Cooperative Agreement – Evidence-Based Laboratory Medicine: Quality/Performance Measure Evaluation – notification of award to DSHS in September 2007.

- The letter of intent was submitted on 6/18/07 and the application submitted on 7/17/07.

TNSPMP Goals

- Goal 1 – Formalized a Steering Committee to guide project.
- Goal 2 – Develop and define performance measures that may reveal gaps.
- Goal 3 – Pilot key performance measures for effectiveness.
- Goal 4 – Identify, recommend, and document evidence-based interventions.

TNSPMP Year One – TNSPMP Team and Charter

- Developed external stakeholder team representative of the NBS System.
 - Created DSHS Project Team from Lab and Follow-up.
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- Published Texas NBS Program Gaps and Barriers Summary Report in May 2008.
 - Assessed NBS System in Texas using:
 - 2005 NNSGRC review
 - NNSGRC PEAS
 - Stakeholder input

TNSPMP Year Two – Evidence-Based Performance Measures

- Investigate existing measures in the NBS community.
- Reviewed literature to identify evidence-based performance measures.
- Hosted 9 Focus Groups with healthcare professionals and consumers.
- Identified approximately 50 performance measures.
- Conducted impact, feasibility and affinity exercises to narrow the selection of candidate performance measures to pilot.
- Published Proposed Performance Measures for the NBS System Evidence Summary Report in May 2009.

TNSPMP Year Three – Pilot Performance Measures

- Pilot analysis, evaluation and report (In progress)
- Design and deploy report cards (In progress)
 - Pre-analytical Universal
 - Post-analytical Universal
 - Post-analytical Disorder Specific
- Published the TNSPMP Performance Measure Selection Process and Development of Pilot Plans Report January 2010.
- Investigate and document intervention models on recommended interventions to improve performance in measurement areas. (In progress)

STATUS OF REPORT CARD DEVELOPMENT AND DEPLOYMENT

Donna Williams provided an overview and update of the status of the performance measure report cards.

Review of the original process:

- Additional limitations to current process:
 - Labor intensive
 - Distributed quarterly to each facility that submits specimens (~2,100 via US Postal)
 - No ability to track receipt or usage
 - Cost is approximately \$1,000 for postage, paper, toner, not including staff time to manually compile the data.

Feedback and observations collected include:

- Stakeholder feedback
- Reports from other states
- Focus group feedback
 - Hospital Risk Managers
 - Hospital NBS Nurses

Next Steps:

- Working with NBS software developer to design and automate the report cards
 - Develop online accessibility for NBS submitters to view reports
 - Post with secure login and password
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GUEST SPEAKER

Sue A. Berry, MD is Professor of Pediatrics and Genetics, Cell Biology and Development at the University of Minnesota. She is the Director of the Division of Genetics and Metabolism in the Department of Pediatrics and the Institute of Human Genetics. She is the co-leader of the Region 4 Genetics Collaborative's Priority 2 (long-term follow-up) Project implementing the Inborn Errors of Metabolism Information System.

- Topic: Region 4 Genetics Collaborative Priority 2 Project: the IBEM-IS and MEMSCIS: Web-based Emergency Information.

NEWBORN SCREENING PROGRAM UPDATES

Susan Tanksley provided updates related to the Newborn Screening Program.

NBS Specimen Retention & Use

- New collection kits – began distribution in June 2010
 - Disclosure/Request to Destroy form is part of kit
 - Working on improving readability of form for next kit order.
- Valid requests received through 8/6/10 → 28, 763.
- New policy approved 8/6/10
 - Posted on NBS Laboratory website:
 - <http://www.dshs.state.tx.us/lab/nbsBloodSpotDataPolicy.pdf>
 - Defines acceptable uses and authorization/approval process
 - Notice of studies approved by commissioner must be posted on the website
- Continuing discussions in regards to potential legislative changes for 82nd Legislative Session
 - Commissioner met with Legislator on 8/18

Newborn Screening Advisory Committee

- Meetings
 - June 7, 2010 (in-person)
 - Business meeting
 - Open meetings training
 - Adopted by-laws
 - June 29, 2010 (conference call)
 - Election of officers:
 - Chair: William Morris
 - Vice-chair: Charleta Guillory
 - Next Meeting: October 18, 2010 (conference call)
 - Future topics:
 - Adding Severe Combined Deficiency (SCID) to the newborn screening panel
 - Discussion of secondary targets
 - Raising public awareness of the need for and purpose of newborn screening
 - Status of cases lost to follow-up
 - Discussion on increase in parents refusing newborn screening
 - Update on newborn hearing screening
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Secondary Targets

- No funding to implement
- IRB approval for study
- Healthy Babies EI request – 82nd Legislature

Courier Pilot Project

- Provided overview of initial courier usage statistics

Second Screen Study

- Purpose of national study - Evaluate evidence regarding use of second screens for identification of case (CH and CAH).
- Data - July 2004 to 2008.
 - 2nd Screen abnormal for CAH in TX.
 - 96/205 cases = 46.8%.
 - 2nd Screen abnormal for CH in TX.
 - 117/1012 cases = 11.6%.
- Status update - Data collection is complete!
- Data will be compiled, analyzed, discussed and presented to ACHDNC

Development of 2nd Tier Assay for CAH by LC/MS/MS

- Goal: dramatically cut false positive rate.
- Objective: Develop and refine 2nd tier assay and pilot
- 2 year grant, ~\$150,000 per year.
- Hired 1 chemist.
- Investigated and tested protocols in use in other states.
- Developing validation plan
- Next steps:
 - Validate & pilot the method
 - Order LC/MS/MS for NBS laboratory in Fall 2010.

MSGRCC Pilot of 2nd tier testing for MS/MS disorders and CAH

- ARUP Laboratories – Salt Lake City, UT.
- CDC grant funded – open to all Mountain States.
- Study approved by DSHS IRB and DSHS Commissioner.
- Staff trained at ARUP.
- Next step – start sending specimens to ARUP

SCID pilot project

- Severe combined immunodeficiency disorder (SCID)
- May 21, 2010: Sec. of HHS approved the addition of SCID to the core panel
- Pilot project with New England NBS Program
 - Requires informed consent to enroll baby.
 - Initial sites: Seton & St. David's Hospital systems- Austin.
- Study approved through DSHS/Seton/UTHSCSA IRB.
- Study approved by DSHS Commissioner.
- Training held on August 10th at St. David's (Austin).
- Training being scheduled for North Austin Medical Center.
- Houston & Dallas immunologists working on implementation plans prior to IRB submission.

MAY INTERVENTIONS REFINED

In the May Stakeholder meeting, the team brainstormed intervention ideas on the remaining six gaps and barriers. The stakeholders were asked to break into work groups. Each work group was supplied with a poster with one gap topic, a place to rate the feasibility of the idea, who would implement, and the next steps. The feasibility rating was 1 to 10 with 10 being the highest. Below are the six topics. The results of the brainstorming session will be distributed to the team at a later date.

1. Information Systems
 2. Personnel
 3. Medical Management
 4. Program Administration and Finance
 5. Program Evaluation
 6. Contingency Planning
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