

Ad Hoc Literature Review Determination Workgroup Meeting

April 24, 2008 –THURSDAY
Conf. Rm: L-202 or Remote Call-In
Dial In 866-633-3380, Room Code *882 99 76*
3:00 p.m. – 4:00 p.m.

Agenda

1) Welcome and Introductions (Mirsa, 5m)

Attendees make introductions.

2) Purpose of Meeting (Susan, 5m)

To review proposed research questions, prioritize questions, and identify the highest priority.

3) Ground Rules (Donna, 5m)

Review courtesy rules such that all attendees have an opportunity to contribute and participate.

4) Review Tool to Prioritize Questions (Susan, 5m)

Discuss the tool that will be considered in ranking the questions before the group reviews each question.

The following criteria questions were used to rank research questions.

- a. Where does the topic rank in priority for Texas Newborn Screening?
- b. The question is not too general in that it would be too large of a project given the timeframe or not too narrow?
- c. Does the question have the potential to inform about multiple gaps and/or weaknesses in the newborn screening process?
- d. With current knowledge, is it likely that the question is researchable, meaning are we able to collect evidence that would answer the question and is the evidence of good quality? *(Note – It was decided during prioritization to remove this criteria from consideration as this will be discovered during the literature search processes.)*
- e. Will the timeframe for completion of grant activities allow for a comprehensive review of the literature on the topic—including current best practices—and sufficient recommendations for future directions?

5) State and Review Proposed Questions (Mirsa, Team, 20m)

State each question, in turn, and allow a maximum of 5 minutes of discussion among the group for each question.

Questions that were related to laboratory testing were eliminated from the panel of questions to review. Questions reviewed were:

- a. Using a multidimensional scorecard approach, how well do the pre and post analytical aspects of the Texas Newborn Screening Program serve the children of Texas?
- b. What is known about tracking mobile families of clients with identified abnormalities?
- c. What is known about education of providers/parents on newborn screening disorders?
- d. What is the best time to treatment for disorders that consistently manifest symptoms in affected newborns shortly after birth? OR What is the optimum time to treatment for disorders that have the potential to cause severe complications in affected newborns shortly after birth?
 - How can the Texas Newborn Screening Program improve the timely submission of specimen cards to the State Laboratory?
 - What are the best methods for expediting confirmatory testing?

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- What methods are used to expedite specimen collection, specimen transport, and result delivery throughout the NBS process across the system for rapid treatment of affected infants?
- What are the negative effects of unsatisfactory specimens on time to treatment?

6) Prioritize Proposed Questions (Susan, Team 15m)

Group will rank proposed questions and identify the highest priority question.

The team ranked research question, “What is the best time to treatment for disorders that consistently manifest symptoms in affected newborns shortly after birth?” as the highest question.

It was agreed that literature research will also explore educational aspects so that performance measures can be considered for development with respect to education.

Also, the team agreed that Dr. Robert Crumb’s suggested scorecard approach, condensed version shown below, will be a useful tool and a framework to develop performance measures for this project.

For Pre and Post Analytical Phases of Texas Newborn Screening Program:

For Structure, Process, and Outcome Measures:

Texas vs. other states

Quantitative

Qualitative

Texas vs. national standard

Quantitative

Qualitative

Texas vs. “ideal”

Quantitative

Qualitative

7) Next Steps (Mirsa, Team, 5m)

Distribute meeting notes. (Mirsa)

Explore possible students who may want to assist with literature review.

(Alice Gong, Charleta Guillory)

Team Attendance			
√	Susan Tanksley	√	Alice Gong
√	Donna Williams	√	Charleta Guillory
√	Mirsa Douglass	√	Sandra Billings
√	Susan Snyder		George Buchanan
	Lisa Kalman	√	Robert Crumb
√	Kayan Lewis	√	Abrienne Patta
√	Colleen Shaw	√	Malika Washington
√	Pamela Thompson		