Peer to Peer Call – ELR

North Dakota

February 28, 2018

Case Presentation – Describe the leadership challenge you face.

What is the challenge or problem you're facing? Gap you're trying to narrow?

North Dakota Department of Health's (NDDoH's) Newborn Screening program has partnered with the University of Iowa State Hygienic Laboratory (SHL) since 1992 to process all newborn screens for North Dakota. The presumptive positive screening results are posted to a secure portal site on the SHL web portal. The contracted short-term follow-up staff, who are located in Iowa, log into the web portal to retrieve laboratory reports. Upon review they then fax a letter with recommendations to the primary care providers for confirmatory testing. Currently, once confirmatory testing is done (typical length of less than one month) these infants are marked completed and no more follow up is conducted.

In 2018, the North Dakota Department of Health will be starting a long-term follow-up program, in which NDDoH staff will continue follow-up on infants who have a confirmed disorder until they reach five years in age.

Our project involves designing and implementing the new case management into North Dakota's electronic disease surveillance system, Maven. Our challenge is the issue of utilizing dual systems for case management – Iowa's web portal for short-term follow-up and North Dakota's Maven for long-term follow-up. The positive results, additional demographic information and all nurses notes located in Iowa's web portal system will need to moved/uploaded into North Dakota's Maven system somehow. The questions we have are:

- How do we do this while ensuring data quality?
- Confirmatory testing is entered into a text box in SHL's system. Is there a way we export this information and somehow electronically enter into Maven vs. having to manually enter data?
- In addition, Iowa is currently going through a system change (expected completion is Sept 2018). The question becomes: will the data stored in their system currently be different than the new system and how will this affect our case management system.

Who are the major players? What are their conflicting perspectives and interests?

The major players are the Newborn Screening program staff, Maven program staff, the SHL staff, and the contracted short-term follow-up staff. The Newborn screening program will focus on long-term follow-up, while the contracted staff follow up on short-term. The SHL has spent time and resources in developing a new system, so they are reluctant, at this time, to do their short-term follow-up using North Dakota's Maven system.

What action have you taken or are thinking about taking?

- The end goal is to have ELR and order-and-receipt between ND ordering facilities and SHL along with electronic reporting of positive cases to the NDDoH. We plan to utilize our health information network (HIN) to be the broker between the ND and IA facilities. However, this will involve time and funding resources and buy-in from multiple agencies. In the short term, we are

looking for another solution that will allow for more efficient data exchange, ensuring case follow-up, and the moving of data from the SHL web portal to Maven while maintaining data quality.

What are your stakes and interests? Any hidden issues?

- Hidden issues – so far, we are unsure how future data will be stored in the SHL's system. So while we may come up with a solution for now, we might have to revise. Are we going to be able to receive the same data in the same format?
- Because this is a new program objective, we are unsure of the amount of time needed for case follow-up, and so the case management may need be changed over the course of the first year. Maybe only have resources to follow up for three years, or maybe can extend to 10 years, does this change any of the questions and follow up in the model package?

What do you want to be advised on by your group?

- Suggestions for receiving data – can we do a roster import? Any suggestions for pulling data hidden in a text field instead of relying on manual data entry?
- Any other barriers they see to using dual systems by different agencies that need the same information that we will need to consider?
- Suggestions for evaluating data in SHL system compared to Maven and frequency of evaluation?
- Any advice on receiving newborn screening via ELR?