Presenter: North Dakota
Topic: Implementing Newborn Screening Long-Term Follow-Up Program in MAVEN

Stakeholders: Newborn Screen Program, North Dakota Health Information Network, MAVEN Program Members, Iowa State Hygienic Laboratory

Key Questions:

1. Suggestions for receiving data or pulling data hidden in a text field instead of relying on manual data entry
2. Any other barriers to using dual systems by different agencies that need the same information?
3. Suggestions for evaluating data in SHL system compared to MAVEN and frequency of evaluation?
4. Any advice on receiving newborn screening via ELR?

Diagnostic Questions:

Colorado: What kind of case burden do you have with these babies? Where the confirmatory testing is performed?

60% percent positivity, 106 cases per year including trait reporting. Confirmatory testing done at the facility within North Dakota or a reference facility.

Tennessee: What kind of indicators exist within the SHL system to indicate if the case is closed or not?

The entry in the database will remain as an open record until confirmatory results are received. Event will be completed on the laboratory website. Will note the test and lab values within the database/notes section.

Kentucky: Where does office of vital statistics come into play, if at all?

Working with vital records to work on birth match. Occurs about every 2 weeks. Ensure each baby has screening, as mandated by state. Have information on newborn screening card.

Indiana: Can you currently receive these confirmatory tests within MAVEN?

It will be important to know what questions to be asked/imported within MAVEN. Initial problem is time and buy-in from stakeholders. Integration will not be feasible within at least a year. What can we do in the meantime to ensure data quality in the short term?

There could be a potential with utilizing HIN as a means of identifying confirmatory results, as the nurse struggles sometimes with contacting these facilities.

Colorado – What is contained within the notes section that are able to be parsed?

Information within this section includes the type of test recommended (SWEAT testing, etc), if genetic counseling is indicated, and patient/parent contact information. Some of the information is similar to a voicemail our conversation that the contract nurse in Iowa would have with the primary care provider and parents. This section also can include patient history and any other details related to patient case.

North Dakota currently screens for at least 49 different disorders, each with different confirmatory tests.

Colorado – Why isn't the nurse from Iowa directly entering results within MAVEN?

We currently don't have an interface/module within MAVEN to monitor this. This is the overall goal for this project.

Iowa did not want to abandon their system, as they spent time and money with developing a new one.

Diagnostic Brainstorming

- What type of computer language will the new laboratory system use to communicate data? It will be essential to develop an interface between the two systems. May be important to have SHL sit down with their vendor to ensure that this is able to be accomplished, and meet their needs.
- North Dakota should try to have an active involvement with the development of the new system that Iowa is creating.
- Look into establish a formal status code that will, on completion and confirmation of the case, trigger the message to be sent to MAVEN for long term follow-up.
- It will be beneficial to understand the workflow for how the data is transmitted, to ensure that the correct data points are being collected.
- Evaluation of the current information to identify points where you can streamline the process. Ex: Information you want to keep, eliminate, add on to current structure.
- Managing dual systems: the biggest issue is how to manage human error, as you rely largely on this. Other issues include who owns both the system(s) and the data that is collected.
- Need to consider the leadership within both states, and develop a means to formalize a data exchange agreement.
- Incorporate a form of decision support within the ELR process in MAVEN to identify positive vs negative results and screening items.

- Identify SHL is also working with the Iowa newborn screening program and how they are reporting data to them.

- How long will it take to receive the data that SHL would send you? It will be important to identify factors that would potentially impact the timeliness of this information.

- ND has outsourced newborn screening out to Iowa, primarily due to the cost including extra staffing and laboratory tools used. One of the only laboratories open for newborn screenings 365 days out of the year which is crucial to this screening program.

Action Step Brainstorming

- Identifying other states that are actively surveilling newborn screening electronically and incorporating long term follow-up.

- Tennessee state labs are currently reporting data through HL7 messaging. Would be beneficial if the SHL would be able to produce this standard and each of the states submitting to them were able to actively consume this information.

- Ensuring demographic information is streamlined within both systems, standards for entering this data manually, and methods of identifying duplicate patient records.

- Develop template with all possible fields that you would like to collect data on so that you would be able to communicate to Iowa and ensure that at least some of these variables would be incorporated into the new laboratory system.

- Reach out to other states that are using Iowa labs for newborn screening to see if they have approached the electronic sharing of information and if they have run into any issues.

- Develop a standardized testing period to of this new system, including time that it will take to troubleshoot issues.

Case Presenter Reflections

- Unique situation and process for newborn screening. At times it is hard to identify a specific negative or positive, depending on the condition.
- A lot of this information we have brainstormed, including common fields we want to include and obtaining feedback from other states.
- Wanting to better understand the amount of time it takes to implement this system from a business process perspective.
- Important to develop a good quality testing plan to ensure accurate flow of electronic data within each system.
- Also key to ensure the correct transmission of demographic information, similar to issues that North Dakota's immunization system has run into.
- Important to understand the connection between MRN with the mother and the patient and a way to standardize it all between hospitals in North Dakota.