Use Case Scenario Summary

Use Case Scenario Name:	Newborn Screening - Critical Congenital Heart Disease
Use Case to Which Scenario Belongs:	Lab Orders-Results
Sponsor:	Michigan Department of Health and Human Services
Date:	August 18, 2016

Executive Summary

> This brief summary highlights the purpose for and value of the use case. The executive summary gives a brief description of the use case's importance while highlighting expected positive impact.

Babies with a confirmed diagnosis of critical congenital heart disease (CCHD) are at risk of serious complications within the first few days or weeks of life and often require emergency care.

Receipt of CCHD test screening results in near real-time from the state's birthing hospitals helps the state to improve beneficiary consumer health and reduce consumer healthcare costs through early detection.

Purpose of Use Case: This use case allows real-time transmission of CCHD test screening results from birthing hospitals to the state, without additional workflow steps. The newborn screening message for CCHD will first transmit information to the Michigan Department of Health and Human Services (MDHHS) Newborn Screening Registry.

Overview

> This overview goes into more details about the use case.

Currently, CCHD screening results are entered into a hospital's electronic health records (EHR) system. The MDHHS has developed a web-based application for hospitals to enter the same information into the newborn screening system via direct data entry. Since CCHD

screening may involve collection of multiple readings, this double entry has presented a burden and introduces an increased risk for data entry error.

A real-time electronic notification can send multiple-sequence test results via the health information network (HIN) from the hospital EHRs to MDHHS. This real-time notification significantly reduces the burden on hospitals and decreases the risk for error by eliminating the need for hospitals to duplicate data entry.

Persona Scenario

To explain the importance of this use case, this section follows an example from start to finish.

Persona: Tricia Lynn Franklin

In the months leading up to the birth of her first child, Tricia Franklin was looking for a permanent place to live and ended up bouncing between different doctors in the Upper Peninsula and Southern Michigan for prenatal care. As a single, soon-to-be mother, her unstable living situation and how it would affect her child was a source of great anxiety for Tricia. Even when Tricia finally located a home, she wasn't sure she would be able to find the support and care services she desired for her and her new child.

After Tricia gave birth in a small hospital in southern Michigan, her newborn received a routine screening for critical congenital heart disease (CCHD). A record of the screening and its result were logged in the hospital's electronic health record and then shared with the State of Michigan's Newborn Screening System.

When Tricia's daughter screened positive for hypoxemia, Tricia was shocked because the ultrasounds showed no complications and her daughter looked fine after birth. Tricia's mind raced with fears as her care team explained that even though prenatal ultrasounds showed no signs of CCHD, not all CCHDs are detected in an ultrasound. They quickly assured Tricia that the standardized CCHD screening helps catch the disease early enough to begin immediate intervention to reduce the severity of her daughter's condition.

Happily, Tricia's daughter responded wonderfully to the surgical intervention and was soon ready for discharge from the hospital. Tricia had been so focused on getting through her child's procedure that she hadn't had time to worry about how she was going care for a fragile newborn. Even though she had just moved, the support services were in place to help her daughter. Tricia was once again overwhelmed with relief knowing that someone was prepared to assist her new family.

Diagram

This diagram shows the information flow for this use case.

In this use case, the health information network (HIN) brokers the transport of CCHD data through the MDHHS data hub to the Michigan Newborn Screening Registry.
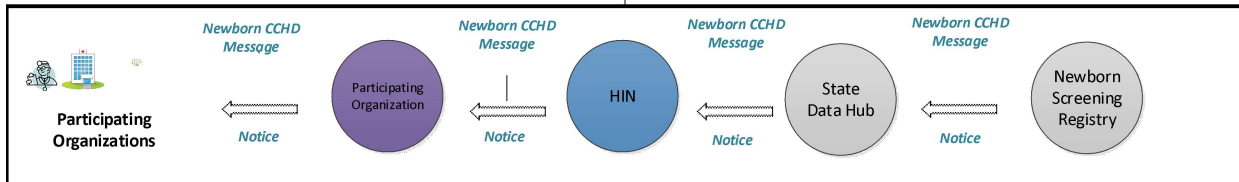

Figure 1. Workflow Between Participating Organization, HIN, and Registry

Regulation

This section describes whether this use case is being developed in response to a federal regulation, state legislation or state level administrative rule or directive.

Legislation/Administrative Rule/Directive:
☒ Yes
☐ No
☐ Unknown

Michigan Public Health Code Section 333.5431

The Michigan Public Health Code Section 333.5431 requires hospitals to screen newborns for a variety of conditions and report the results to MDHHS. In September 2013, CCHD results were added to the list of screenings to report. The effective date when CCHD screening test results were to begin being reported to MDHHS was April 1, 2014.

Meaningful Use:
☒ Yes
☐ No
☐ Unknown

Meaningful Use Stage 2 has two new public health objectives for Eligible Professionals. They have been added to the menu set, and include the capability to identify and report cancer cases to a cancer registry and specific cases to a specialized registry (other than a

cancer registry). MDHHS has classified its specialized registry to be for information submitted that is related to chronic disease management. Research is continuing to determine if this screening transmission can count towards Meaningful Use attestation for specialized registry.

Cost and Revenue

This section provides an estimate of the investment of time and money needed or currently secured for this use case.

This project's budget includes the following components:

- HL7 message development, based off the national standard
- Development of an implementation guide
- Development and deployment of a message validator at the HIN
- Technical development and maintenance at HIN, MDHHS Data Hub, and destination system
- Piloting of the new message
- Continued support for participating hospitals to use MDHHS newborn screening section

Existing infrastructure can be leveraged for implementation of this use case.

The MDHHS Data Hub has secured financing needed for development of this use case. The MDHHS newborn screening section also has financial grant support for HIE development. Both teams are contributing to staffing the project, thus project resources, including vendor development of the message validator to be deployed at HIN, have also been secured and include business and technical support resources.

Implementation Challenges

This section describes the challenges that may be faced to implement this use case.

New technical challenges are not anticipated for the implementation of this use case. Birthing hospitals that currently do not enter the CCHD screening into their EHRs will need to do so.

At MDHHS, changes will be needed to the newborn screening systems to be able to receive the HL7 message for CCHD.

Vendor Community Preparedness

This section addresses the vendor community preparedness to readily participate in the implementation of this use case.

It is MDHHS' understanding that CCHD screening results are currently entered into the hospital EHR systems, and that many state hospitals have already established their connection to the Michigan HIE platform. The HIE community of partners is already operational for the transmission of HL7 messages.

On an MDHHS newborn screening section conference call with the Michigan Birthing Hospitals on February 21, 2014, none of the hospitals expressed concern with connecting with the HIE platform via a participating organization. Many volunteered to participate in the pilot.

Support Information

This section provides known information on this support for this use case.

Support can come from multiple levels (Governor, Federal or State Legislature, Michigan HIT Commission, Michigan State Departments, CMS/ONC/CDC, MiHIN Board, Qualified Organizations, payer community, interest groups [e.g. MSMS, MHA], or citizen support).

Political Support:
☐ Governor
☐ Michigan Legislature
☐ Health Information Technology Commission
☒ Michigan Department of Health and Human Services or other State of Michigan department
☐ CMS/ONC
☐ CDC
☒ MiHIN Board

Other: In September 2013, the Michigan Legislature did not oppose the addition of CCHD to the list of reportable screenings to MDHHS, and Michigan Public Health Code Section 333.5431 requires hospitals to screen newborns and report the results to MDHHS.

The national Centers for Disease Control (CDC) is offering support for the Newborn CCHD screening project in the following ways:

- CDC is assessing states' needs for CCHD screening and reporting of screening results
  - CDC worked with New Jersey and Georgia to assess their ability to track CCHD screening
  - CDC is also helping states and hospitals to better understand how much hospitals spend for each baby screened
- CDC promotes collaboration between birth defects tracking programs and newborn screening programs for CCHD screening activities
  - State birth defects programs collect data on CCHDs and could help evaluate the effectiveness of screening by looking at false positives (babies who failed the CCHD screening but do not actually have a CCHD after further evaluation) and false negatives (babies who passed the screen suggesting there was no CCHD but actually did have a CCHD)
- CDC provides technical assistance to the Congenital Heart Public Health Consortium and to states receiving funding from the Health Resources and Services Administration (HRSA) for CCHD screening activities

Concerns/Oppositions:
None noted at this time.

Sponsor(s) of Use Case

This section lists the sponsor(s) of the use case.

- The MDHHS Newborn Screening Section
- The MDHHS Medical Service Administration Office of Medicaid Health IT/MDHHS Data Hub project team
- The Michigan Health Information Network Shared Services (MiHIN)

Metrics of Use Case

This section defines the target metrics identified to track the success of the use case.

The key metrics for this use case include:

- Number of CCHD screening results sent to state
- Percentage of overall CCHD screening results via this use case compared to all CCHD screening results received by the state
- Number of organizations and facilities sending CCHD screening results via this use case
- Percentage of organizations and facilities sending CCHD screening results via this use case compared to all facilities sending CCHD screening results to the state