**PROBLEM IDENTIFIED**

Upon the notification of an abnormal newborn screening result, the Minnesota Department of Health Newborn Screening Program faces both a provider and family fact sheet to the child’s primary care provider (PCP). However, we are unaware if the child’s PCP actually receives or uses the fact sheets. Additionally, when the fact sheets were first created, assumptions were made regarding what information providers and families would find useful.

**GOAL**

We sought to better understand PCP usage of the fact sheets and the content they found important, with the goal of revising these fact sheets to better serve the needs of our PCPs.

**METHOD**

We conducted an electronic survey to email to PCPs. Providers who had a patient with a positive newborn screening result in the past six months were invited to participate in the survey. These PCPs consisted of MDs, DOs, and NPs. Provider emails were obtained from the Minnesota Board of Medical Practice and Board of Nursing. As a reminder to the survey participants, the survey included examples of our current provider and family fact sheets. We chose to use our cystic fibrosis fact sheet since it accounted for the majority of the results these providers had experienced. The survey was opened on June 10, 2016 and closed on July 15, 2016.

**QUICK FACTS**

The survey was emailed to 103 primary care providers and 20 completed the survey (19.4% response rate). Respondents had been practicing for a median of 16 years.

15 respondents recalled receiving the provider fact sheet and 100% found it useful overall.

For the family fact sheet, 17 respondents recalled receiving it, 8 actually provided it to the family, 2 did not provide it, and 7 could not recall.

18 respondents preferred to receive the fact sheets by fax (even when offered the option of integration into their EHR system).

When asked if they’d prefer the American College of Medical Genetics’ A1Ctive (ACT) Sheets, 15 indicated they were unfamiliar with them.

In addition to this change, we restruductured the fact sheets in a more meaningful way. The biggest change was switching the title of the fact sheet from disorder-based to analyte-based. Having an analyte-based fact sheet allows for a discussion of potential differentials and in turn reinforces the fact that this is a screening result and not diagnostic.

Last, while rewriting the content for the family fact sheet, we were mindful to use plain language as much as possible for ease of understanding.

**WHAT DID WE LEARN?**

Very Important or Important  Somewhat Not Important

**BEYOND THE SURVEY**

While revising the fact sheets, MDH genetic counselors identified other opportunities for change detailed below and included those in the revisions. Historically, we did not have a fact sheet for every possible result; only the most common ones. Some of our fact sheets were multi-purpose, for example, a sickle cell disease fact sheet was used anytime S hemoglobin was present in a disease state.

Another example of this is a positive cystic fibrosis result, the same fact sheet was utilized even when the number of mutations and follow-up timeline were not the same. In reality, the follow-up on a one mutation result is very different than a two mutation result. Additionally, the implications of a one mutation result can be very different depending on the immunoreactive trypsinogen level. Thus, we developed fact sheets that better suited the result and the message conveyed to the provider with regards to clinical expectations and how quickly to follow-up on the result.

**NEXT STEPS**

assess what content the families want

ensure provider receipt & family provision

translate into other languages