What we can learn from Electronic Reporting and Birth Defect Registry Matching for CCHD Newborn Screening

Amy Gaviglio MS LCGC | Genetic Counselor/Follow-Up Coordinator
• Results of the screening must be reported to the Department of Health (DOH)

• The DOH shall establish the mechanism of the required data collection and reporting of screening and follow-up diagnostic results to the DOH according to the DOH’s recommendations

• Develop and implement policies for intervention services and post-diagnostic follow-up
Hypotheses

• Clinical Decision Support and Electronic Reporting would...
  • Increase MDH’s ability to track eligible newborns who were not screened
  • Allow for more robust individual-level data collection
  • Decrease incorrect interpretations of the algorithm

• Collaboration and Data Sharing with the Birth Defects program would...
  • Allow for quicker outcome collection after a failed pulse ox screen
  • Allow for greater understanding of CCHDs missed by pulse ox screening
Telepathy CCHD™ Overview

• Designed to be used WHILE performing the screen
**Individual-Level Data Obtained by MDH**

**CCHD Screening Results**

<table>
<thead>
<tr>
<th>Sc #</th>
<th>Age at Scrn</th>
<th>Test Time</th>
<th>Hand</th>
<th>Foot</th>
<th>Diff</th>
<th>Result</th>
<th>Suggested</th>
<th>In</th>
<th>Ov</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>24 h 27 m</td>
<td>12/06/2017 01:23:56 PM</td>
<td>92</td>
<td>94</td>
<td>2</td>
<td>Rescreen Required</td>
<td>Rescreen Required</td>
<td>D</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>25 h 39 m</td>
<td>12/06/2017 02:35:22 PM</td>
<td>93</td>
<td>96</td>
<td>3</td>
<td>Rescreen Required</td>
<td>Rescreen Required</td>
<td>D</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>27 h 1 m</td>
<td>12/06/2017 03:57:39 PM</td>
<td>92</td>
<td>95</td>
<td>3</td>
<td>Fail</td>
<td>Fail</td>
<td>D</td>
<td></td>
</tr>
</tbody>
</table>

**Reported to MDH on 2/18 at 06:53:56 PM**

**Screening Details**

- Date/Time of Screen: 02/18/2018 06:51:52 PM
- Screening Facility: FAIRVIEW - SOUTHDALE HOSPITAL
- Screener: Thotthil, Ancy
- Screening Result: Pass
- Suggested Result: Pass
# Program – Level Follow-Up of CCHD Data

<table>
<thead>
<tr>
<th>RESULTS</th>
<th>FOLLOW-UP PERFORMED</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unreported CCHD screening</td>
<td>• Run biweekly query and inform hospital of seemingly unscreened infants</td>
</tr>
<tr>
<td></td>
<td>• Ask units to enter that an Echo was done rather than screening</td>
</tr>
<tr>
<td></td>
<td>• Added new functions to allow end-user entry of Reasons for Not Screening</td>
</tr>
<tr>
<td>Misinterpretation of screening algorithm</td>
<td>• Run biweekly query to pull cases where the suggested outcome and chosen outcome don’t match and inform hospital</td>
</tr>
<tr>
<td>Screening algorithm not completed</td>
<td>• Run biweekly query to pull cases where the final result was ‘Rescreen Required,’ but no further screen or action was reported</td>
</tr>
<tr>
<td>Failed pulse oximetry screens</td>
<td>• Will discuss shortly...</td>
</tr>
</tbody>
</table>
By the Numbers

- 67,704 MN patients in MNScreen with 2017 DOB (*including out-of-hospital births*)
  - 215 refused CCHD screening (78% of refusals are out-of-hospital births)
  - 301 died prior to screening
- 96.2% eligible (non refused/non deceased) infants screened
  - 2.1% no screen on record with no known reason
  - 1.7% unscreened due to clinical reasons (e.g., prenatal dx/clinical sx)
- 219 cases (0.34%) had interpretative discrepancies with the algorithm
Hypotheses

• Electronic Reporting and Clinical Decision Support would...

  Allow for more robust individual-level data collection

  Increase MDH’s ability to perform Quality Assurance and Quality Improvement activities

  Decrease incorrect interpretations of the algorithm
We Give the Answer... and Yet...

219 w/ wrong outcome chosen

216 should have been Rescreened

- 139 Rescreen, but marked as Pass
- 77 Rescreen, but marked as Fail

3 should have been Failed, but marked as passed

- 2 Rescreened with Passing Results
- 1 Determined to Be Entry Error and actually Passed
... A Closer Look at those Marked as ‘Failed’...

77 Rescreen, but marked as Fail

16 to Echo

11 Normal
5 Non-critical CHD

61 Rescreened

57 cases followed algorithm appropriately, despite choosing wrong outcome
...And Those Marked as ‘Passed’...

139 Rescreen, but marked as Pass

- 105 had no Rescreen
- 34 Rescreened
  - 30 cases followed algorithm appropriately, despite choosing wrong outcome
Why are we still seeing incorrect screening outcomes?

• **Choosing the ‘Wrong’ Answer is Too Easy**
  - Changed warning in system
  - Changed default to NOT accept discrepant interpretation

• **Confusion between Rescreen and Fail results**

• **Confusion about >3% difference**

HOWEVER, despite wrong selections, 87 out of 219 actually had appropriate follow-up (FINAL = 0.2% with inappropriate (Echo) or no appropriate follow-up)
Newborn Screening and Birth Defects Connection

Failed Pulse Ox Screen Case Determination

- Failed Pulse Ox Reported via MNScreen
  - Query Run Weekly to pull Failed Pulse Ox Cases
- Suspected Case entered into Birth Defects (BD) Queue
- BD Abstractor Reviews Case in Facility EMR
- Findings from BD abstraction entered into MNScreen
- NBS Staff Notified of Outcome
- CHD case reported to Birth Defects Program

Undetected/Unscreened Case Reporting

- = NBS
- = Birth Defects
What Did We Detect?

- 5 Cases (~1 in 13,000 infants)

<table>
<thead>
<tr>
<th>Case</th>
<th>Sat Values</th>
<th>Age at Screen</th>
<th>Hospital Location</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>CCHD1</td>
<td>100/93 – sent to Echo</td>
<td>25 hours</td>
<td>Rural</td>
<td>Tetralogy of Fallot</td>
</tr>
<tr>
<td>CCHD2</td>
<td>94/93 – discharged</td>
<td>29 hours</td>
<td>Rural</td>
<td>TAPVR</td>
</tr>
<tr>
<td></td>
<td>inappropriately</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CCHD3</td>
<td>88/90 90/90 91/92 92/92</td>
<td>23 hrs 36 min</td>
<td>Rural</td>
<td>Tetralogy of Fallot</td>
</tr>
<tr>
<td></td>
<td></td>
<td>23 hrs 51 min</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>27 hrs 49 min</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>47 hrs 11 min</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CCHD4</td>
<td>Not Provided</td>
<td>Not Provided</td>
<td>Urban</td>
<td>Tetralogy of Fallot</td>
</tr>
<tr>
<td>CCHD5</td>
<td>94/92</td>
<td>32 hrs 47 min</td>
<td>Homebirth</td>
<td>Tetralogy of Fallot w/ Pulmonary Atresia</td>
</tr>
</tbody>
</table>
What aren’t we detecting?

CCHD Cases with Passing Pulse Ox Results

- Tetralogy of Fallot = 5
- Coarctation of the Aorta = 16
- Double Outlet Right Ventricle = 2
- Transposition of Great Arteries = 1
- Ebstein's = 1
- DORV/TOF = 1

- 59% Coarctation of the Aorta
- 18% Tetralogy of Fallot
- 12% Double Outlet Right Ventricle
- 4% Transposition of Great Arteries
- 4% Ebstein's
- 3% DORV/TOF
Mode of Detection of CCHD Cases (N = 128)

- Prenatal Dx: 34%
- Clinical Sx: 22%
- Presented Post Screen: 19%
- Pulse Ox: 4%
- Deceased: 11%
- Unknown: 10%
Hypotheses

• Collaboration and Data Sharing with the Birth Defects program would...

  Allow for quicker outcome collection after a failed pulse ox screen

  Allow for greater understanding of CCHDs missed by pulse ox screening
Conclusions

• Electronic reporting of point-of-care results provides an opportunity for more timely QA/QI efforts

• Robust individual-level data allows for assessment of algorithm effectiveness, but may not direct outcomes
  • Consideration of removing second re-screen recommendation
  • Can perfusion index or other measurements help improve detection?

• Routine collaboration and data sharing with Birth Defects programs is necessary to understand program impact
  • Integration can be beneficial for both programs

• Impact of Pulse Ox Screening is likely context-dependent – may be more beneficial in resource-limited areas
Acknowledgements

• Heather Pint, RN PHN
• Amy Dahle, MPH
• Sook Ja Cho, MPH
• Barbara Frohnert, MPH
• Jamie Lohr, MD
• Minnesota Birth Facilities and Midwives