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

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MN Statute for CCHD Newborn Screening (144.1251)

- 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

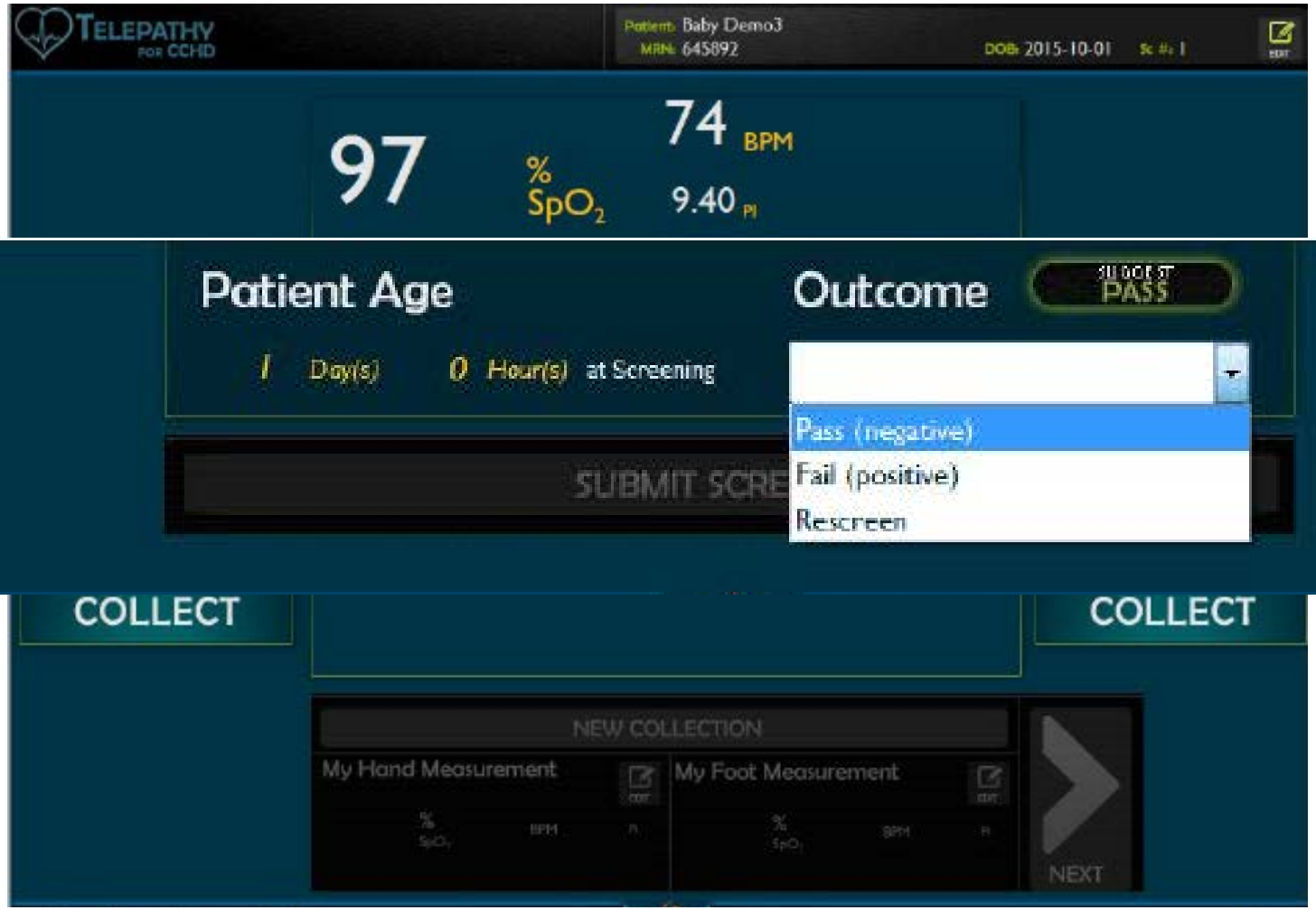
Hypotheses

- **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

Preductal

Postductal

CCHD Screening Results

Case Details

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

Enter Manual Screening Results

date/time of screen 02/18/2018 06:51:52 PM

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

screening facility: FAIRVIEW - SOUTHDALE HOSPITAL

screener: Thottiyil, Ancy

screening result: Pass

suggested result: Pass

Program – Level Follow-Up of CCHD Data

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

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

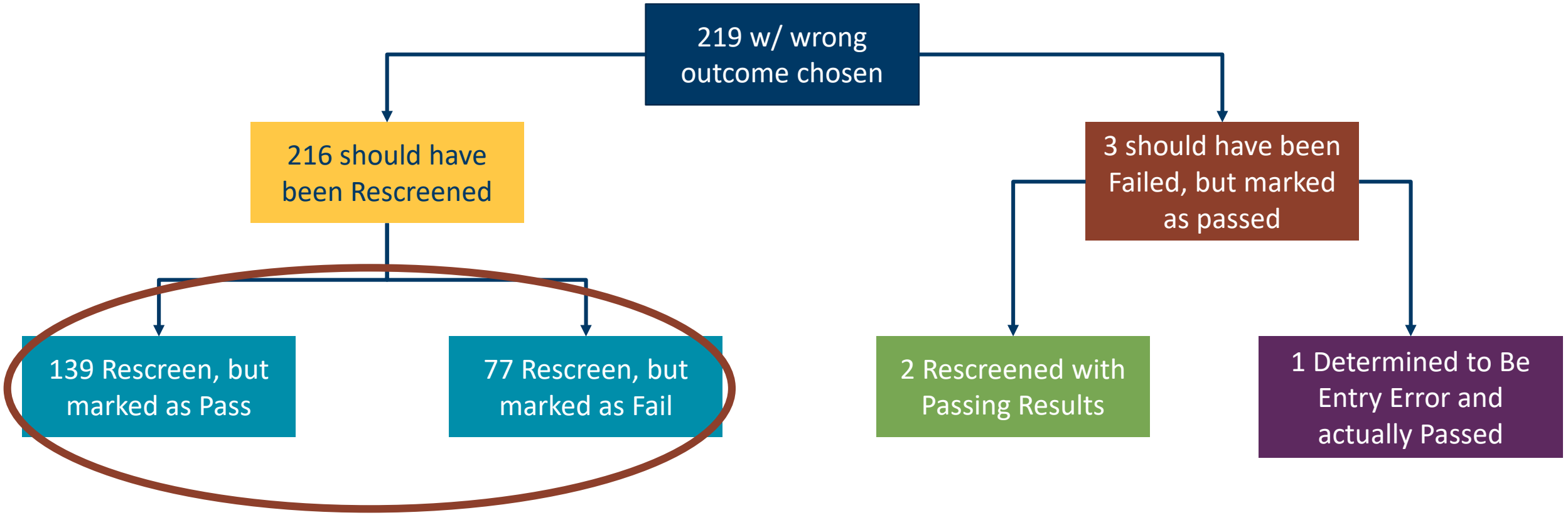
- **Electronic Reporting and Clinical Decision Support would…**

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…



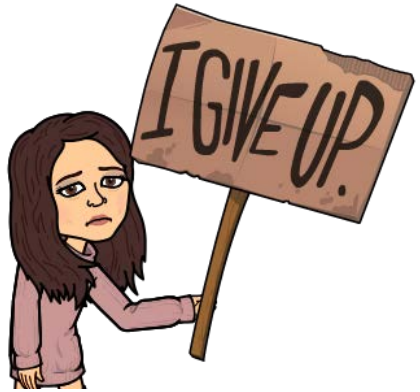
… A Closer Look at those Marked as ‘Failed’…

77 Rescreen, but marked as Fail

16 to Echo

11 Normal

5 Non-critical CHD



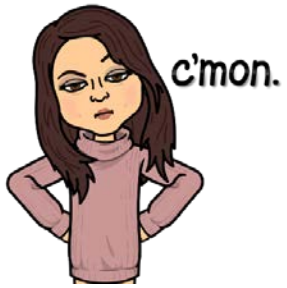
61 Rescreened

57 cases followed algorithm appropriately, despite choosing wrong outcome

…And Those Marked as 'Passed'…

139 Rescreen, but marked as Pass

105 had no Rescreen

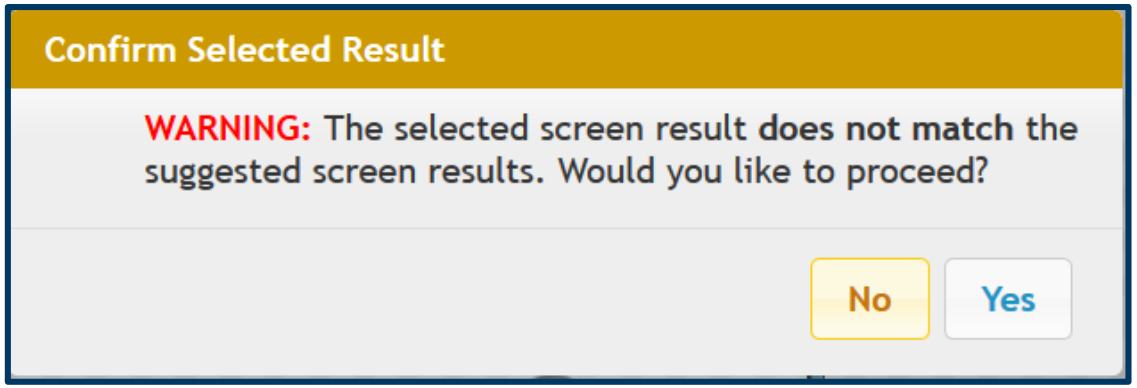


34 Rescreened

30 cases followed algorithm appropriately, despite choosing wrong outcome

Why are we still seeing incorrect screening outcomes?

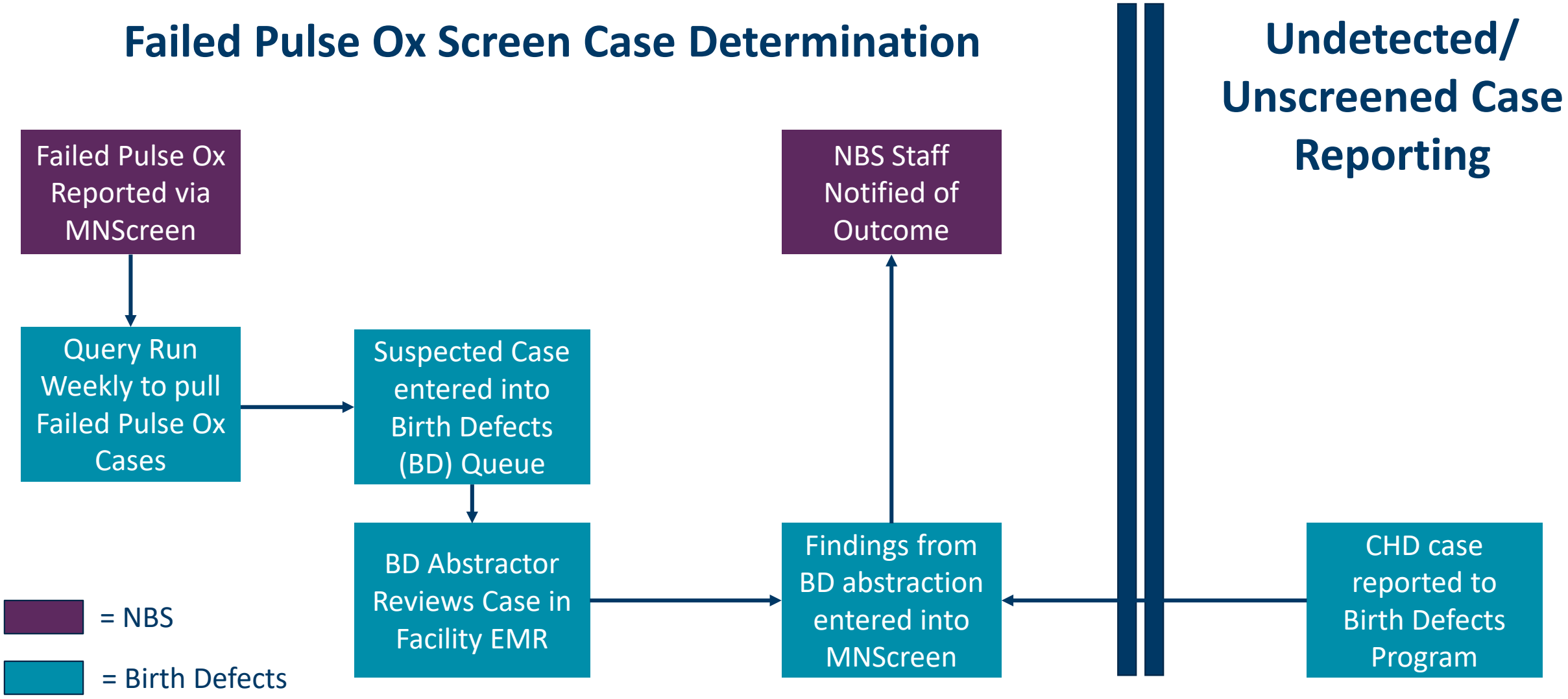
- **Choosing the 'Wrong' Answer is Too Easy**
  - Changed warning in system
  - Changed default to NOT accept discrepant interpretation



- **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



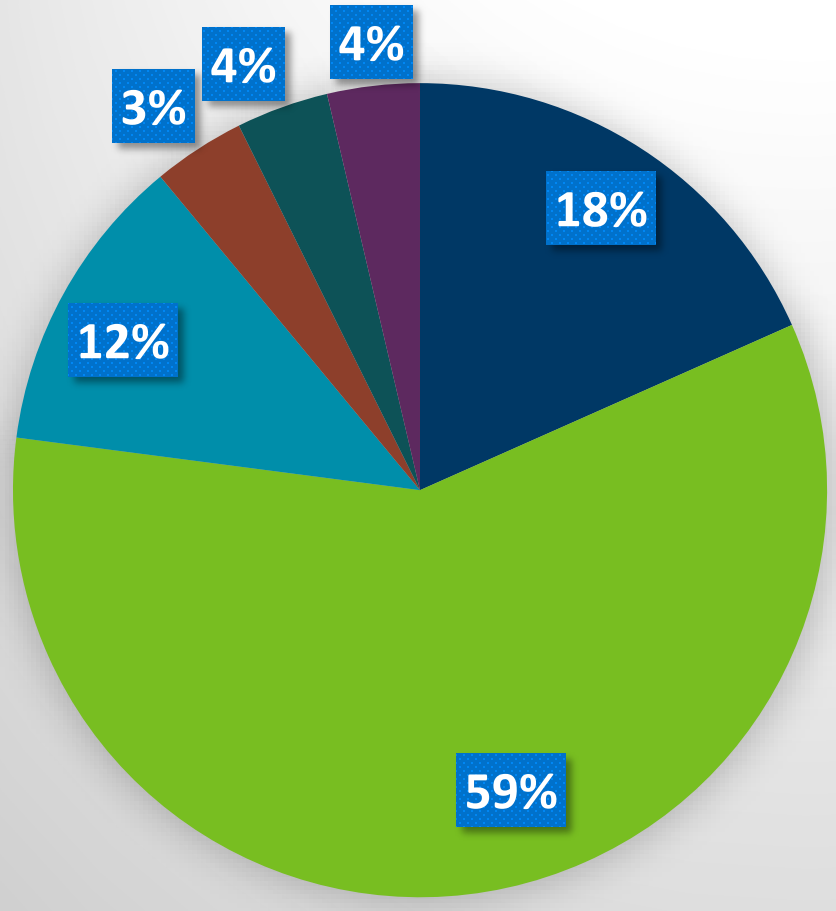
What Did We Detect?

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

Case	Sat Values	Age at Screen	Hospital Location	Outcome
CCHD1	100/93 – sent to Echo	25 hours	Rural	Tetralogy of Fallot
CCHD2	94/93 – discharged inappropriately	29 hours	Rural	TAPVR
CCHD3	88/90 90/90 91/92 92/92	23 hrs 36 min 23 hrs 51 min 27 hrs 49 min 47 hrs 11 min	Rural	Tetralogy of Fallot
CCHD4	Not Provided	Not Provided	Urban	Tetralogy of Fallot
CCHD5	94/92	32 hrs 47 min	Homebirth	Tetralogy of Fallot w/ Pulmonary Atresia

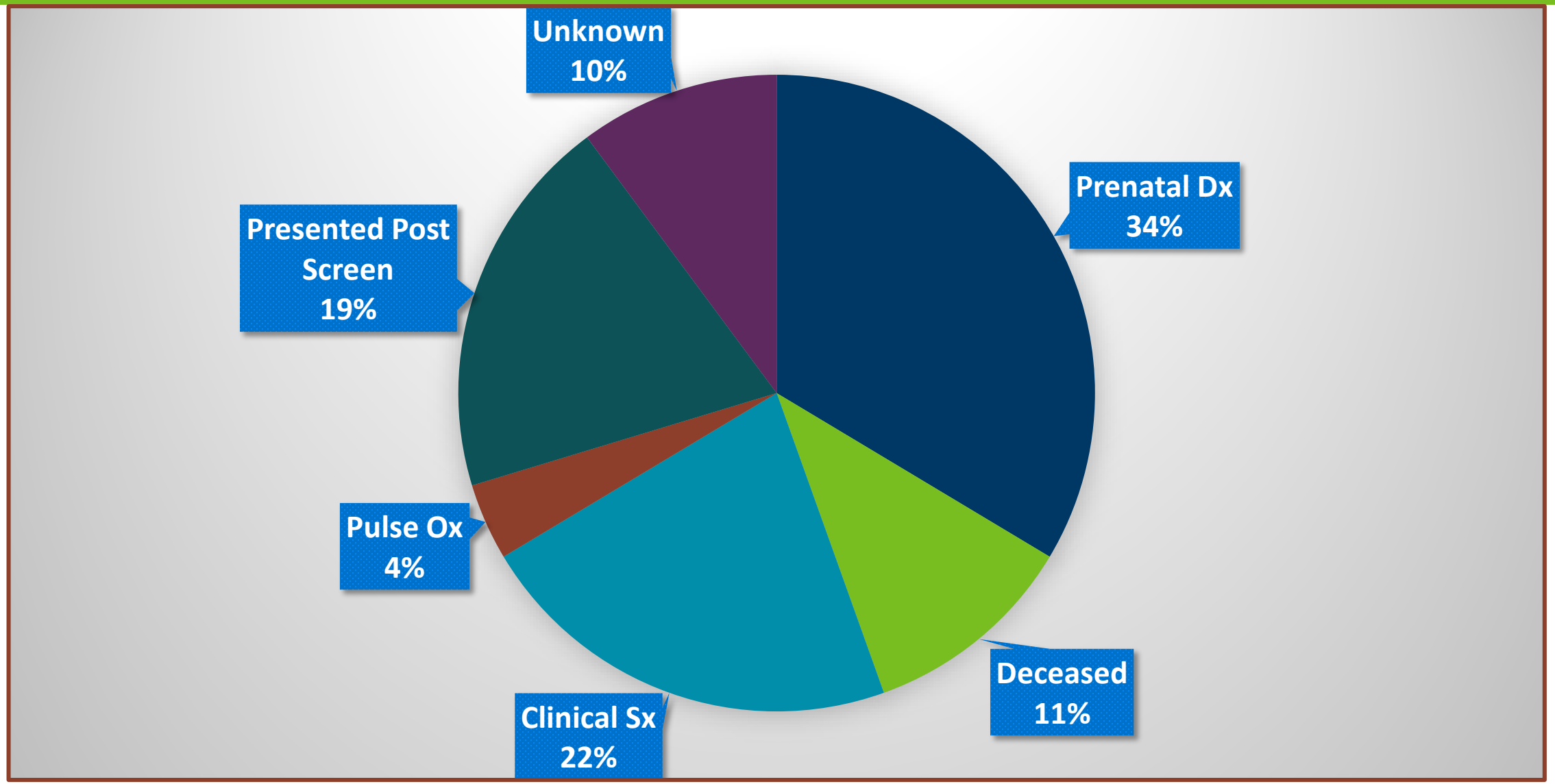
What aren’t we detecting?

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

Mode of Detection of CCHD Cases (N = 128)



Hypotheses

- **Collaboration and Data Sharing with the Birth Defects program would…**

Allow for greater understanding of CCHDs missed by pulse ox screening

Allow for quicker outcome collection after a failed pulse ox screen

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

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