

# Surveillance of CCHD Screening: Data interpretation The New Jersey Experience

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# New Jersey's CCHD Screening Legislation

*Each birthing facility licensed by the Department of Health and Senior Services to perform a pulse oximetry screening for congenital birth defects (CHDs), **a minimum of 24** hours after birth, on **every newborn in its care.***

P.L.2011, CHAPTER 74, *approved June 2, 2011*  
Assembly, No. 3744

# Evaluating New Jersey's mandate

## Screening coverage rate:

- Proportion of live-births screened as per legislation

## Number and characteristics of failed screens:

- Fails reported to New Jersey Birth Defects Registry (NJ BDR)
- CCHDs without a failed pulse ox screen registered

# Screening Coverage

- **Aggregate screening data**
  - # live-births
  - # live-births screened
  - # fails
  - Discrepancies
- **Template provided**
- **Request on a quarterly basis**
- **First 2 + years of data (8/31/2011-12/31/2013)**



**New Jersey Department of Health Critical Congenital Heart Defects Screening Program  
Aggregate Report**

<b>Current Reporting Period (CRP): January 1-March 31, 2014</b>	
<b>Hospital Name: Happyreport Hospital</b>	<b>TOTAL</b>
<b>1. Number of live-births born at birthing facility during CRP</b>	
<b>2. Number of live-births screened with pulse oximetry during CRP</b>	
<b>3. Number of failed screens</b>	■

**EXPLANATION OF LIVE-BIRTHS SCREENED AND NOT SCREENED IN CRP**

**SCREENED**

<b>Live-births who were SCREENED at your birthing facility in CRP</b>	
a. Number born and screened at your birthing facility in CRP	
b. Number born at your birthing facility in ANY previous reporting period, but screened in CRP	
c. Number not born at your birthing facility, but transferred into your facility and screened in CRP	
d. Other explanation(s), provide number of infants for each explanation:	

**NOT SCREENED**

<b>Live-births BORN at your birthing facility during CRP, who were NOT SCREENED in CRP</b>	
e. Number of expirations	
f. Number born at birthing facility, but <24 hours of age at end of CRP	
g. Number transferred out of your birthing facility at <24 hours	
-Name(s) of hospital(s) transferred to and number of infants transferred	
h. Number not CURRENTLY medically appropriate to screen (to be screened at later time)	
i. Other explanation(s), provide number of infants for each explanation:	
<b>Live-births NOT BORN at your birthing facility during CRP, who were NOT SCREENED in CRP</b>	
j. Number not born and not screened during reporting period	



# Screening Coverage

Number of live-births:

**Discrepancy categories:**

Expirations

Not medically appropriate\*

Less than 24 hours at end of period\*

Transferred out < or >24 hours\*

Number of live-births **eligible** to be screened:

\* Should be screened in subsequent reporting periods if in NJ birthing facility.

# Screening Coverage

August 31, 2011- December 31<sup>st</sup>, 2013 (53 birthing facilities)

Number of live-births:	237,304
Number of live-births eligible to be screened:	230,654
Number of live-births screened:	229,681
Proportion of eligible live-births screened:	99.6 %

**Number of fails reported on aggregate data: 137**

# New Jersey Birth Defects Registry (NJ BDR)

- **Diagnosis option added to NJ BDR to capture failed pulse oximetry registrations.**
- **Module added to BDR for failed screens only:**
  - **individual level screening results,**
  - **diagnoses (discharge and prenatal, if any),**
  - **signs before and at time of screen,**
  - **echo date/time,**
  - **transfer date/time**

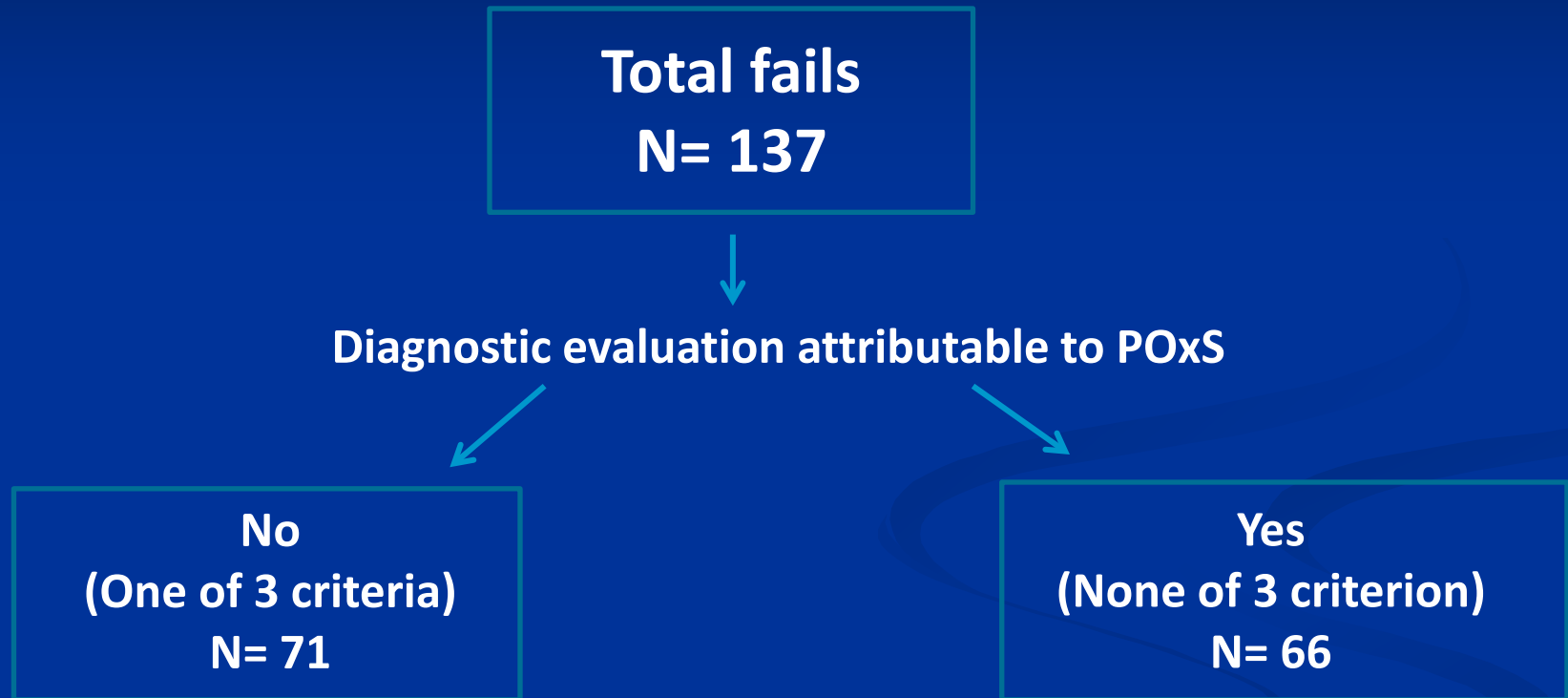


# Key indicators to evaluate the unique contribution of CCHD screening

- Prenatal diagnosis of congenital heart defect
- Pulse oximetry measurement at the time of the screen unrelated to screen.
- An echocardiogram or cardiac consultation planned prior to the screening.

# Failed Screens Registered to NJ BDR

August 31, 2011- December 31<sup>st</sup>, 2013



## One of 3 Criteria

- Prenatal diagnosis of CCHD
- Signs/symptoms at the time of the screen *or*
- Cardiac consult or echocardiogram planned prior to the screen

# Failed Screens Registered to NJBDR

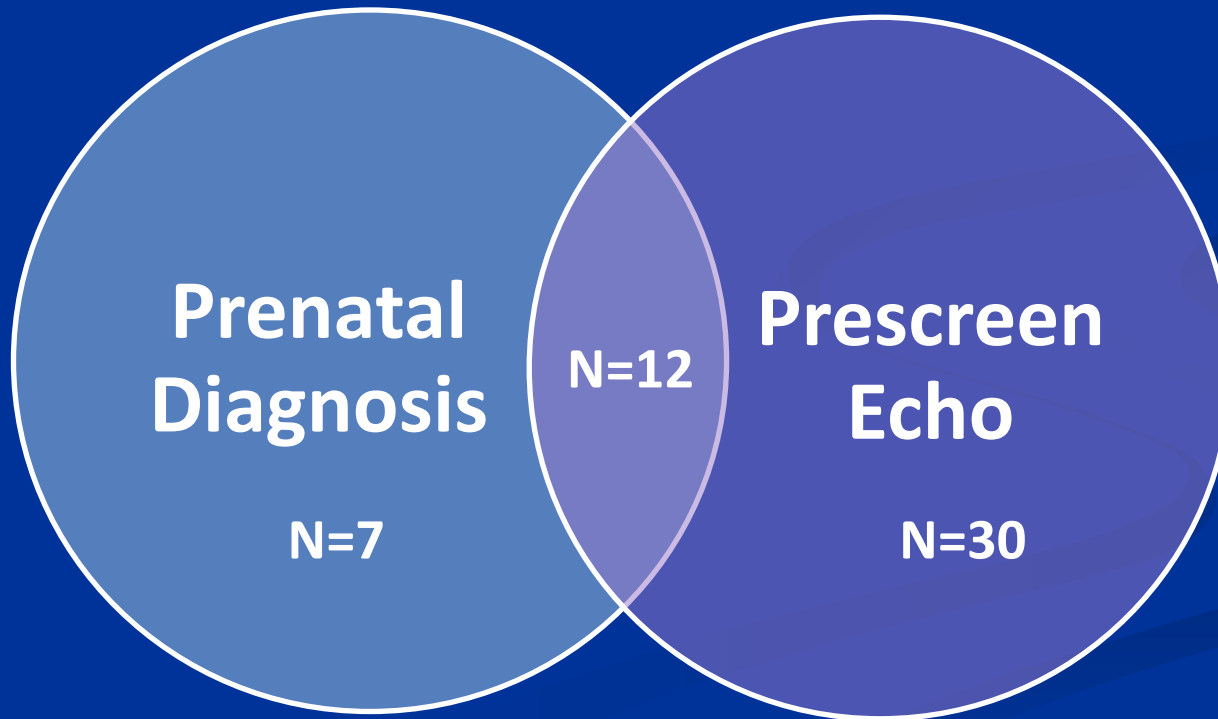
## Diagnostic evaluation attributable to POxS (n=66)

- 9 - CCHD
- 7 - CHD
- 5 - Other significant medical conditions
- 19 - PDA or PFO as only finding
- 26 - No known reason for failed POxS

# Characteristics of Failed Screens

Of the 71 infants whose diagnostic evaluation was not attributable to failed POxS

69% (n=49) had either a prenatal diagnosis or echo prior to screen



# Characteristics of Failed Screens

CASE	AGE AT SCREEN	PRE-DUCTAL	POST-DUCTAL	NUMBER OF SCREENS	FOLLOWED NJ PROTOCOL	FAILED ON NATIONAL PROTOCOL	FINAL DIAGNOSIS
1	2 DAYS	97	84	1	Y	Y	COARCTATION OF AORTA
2	3 DAYS	94	86	1	Y	Y	COARCTATION OF AORTA
3	2 DAYS	99	88	1	Y	Y	COARCTATION OF AORTA*
4	2 DAYS	43	39	1	Y	Y	D-TGA
5	2 DAYS	87	84	1	Y	Y	TAPVR
6	2 DAYS	92	93	2	N	Y	TAPVR
7	2 DAYS	72	72	3	N	Y	TAPVR
8	2 DAYS	91	92	1	N	Y	TRICUSPID ATRESIA
9	2 DAYS	95	92	3	Y	N	EPSTEIN ANOMALY

# CCHD registration without an accompanied reported failed screen

- NJ BDR identified 159 infants with CCHD who did not have a failed pulse ox screen registered as well.

## Scenarios

- Passed mandated screen
- Failed, but not registered
- Not screened
  - Prenatal diagnosis of CCHD, incorrectly thought screen not needed
  - Transferred after 24 hours on oxygen, didn't need to screen.
  - Missed

# New Jersey's Lessons Learned: Aggregate Screening Data

## Pros:

- Quick method to assess screening coverage statewide
- No existing or new infrastructure necessary
- Provides guidance to hospitals for monitoring compliance
- QC for NJ BDR on failed screen registrations

## Cons:

- Burden on hospital staff (moderate, MMWR, 2012)
- Inability to:
  - Unduplicate transfers (small number)
  - Identify aggregate fails

# New Jersey's Lessons Learned: NJBDR

## Pros:

- Ability for rapid implementation
- Utilized existing infrastructure
- Detailed information on all failed screens to address wide range of questions
- Ability to link to birth certificate for supplemental information.

## Cons:

- Internal NJ DOH maintenance for case review and technical assistance
- Training necessary and ongoing QC
- Inability to readily evaluate false negatives



# New Jersey's Future for Ongoing CCHD Surveillance

- Continue aggregate data collection
- Continue use of NJ BDR for failed screens
  - Analytic potential:
    - Cut-offs among fails registered
    - Burden of echos and transfers
- Roll-out of new electronic birth certificate
  - Screening results , prenatal diagnosis on all live-births
    - Ability to evaluate screening cut-offs, proportion with prenatal CHD diagnosis, account for transfers for screening coverage

# Acknowledgements



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