



# CCHD Screening in Utah

February 27, 2014

CCHD Grantee Meeting

Washington, D.C.

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# Utah's CCHD Screening Efforts

Recruited two pilot hospitals –

- One is part of a large hospital corporation: the N to S hospital backbone for Utah
- Created initial education materials
- Obtained hospitals' IRB approval - using Kemper protocol
- **Core work group:** PH (UDOH: Newborn Screening Program, UBDP) and clinical (University Genetics and Cardiology, staff from the pilot hospitals, midwife), bioinformaticist, economist
- **Advisory committee:** wide range of stake holders: UHA, community peds, ethicist, parent advocates

# Utah's CCHD Screening Efforts

- Completed first of two 6 month pilots
  - O2 sat values and pass/fail determinations sent electronically to UBDN
  - Data analysis did not support changing oxygen saturation cut offs for 2<sup>nd</sup> pilot
- Started second 6 month pilot, February 1st
  - March 1: begin delaying start of screening from 24 to 28 hours of life at one pilot site: address the issue of delayed transition of fetal circulation

# Utah's CCHD Screening Efforts

- Division of pediatric cardiology working separately:
  - network of echo centers
  - system for cardiology consult
- Time and motion study at pilot sites; analyzing data
- NICU protocol
- Quarterly newsletters
- Utah Tool Kit (June 1<sup>st</sup>)
- planning implementation webinars
- Developing a website

# Challenges

## **Education: pilot sites' staff compliance with screening protocol**

- Cheerleader effect:
  - *If I keep checking, I can get a passing result.*
- Disbelief/lack of trust in the screen:
  - *But the baby doesn't look blue and the sats are greater than 90.*

## **Electronically downloaded O2 sat values and screening results:**

- Analysis of this data has been difficult:
  - Data entry errors
  - Data incomplete for each screen
  - Incorrect assignment of pass/fail based on entered O2 sat values
- Required many chart reviews to “correct” data.

# Utah Legislation

July 2012: Oximetry values added to UBDN reporting rule

2013 legislative session, legislation for statewide CCHD screening passed “mostly” independently

- Start date changed from 1/1/2014 to 10/1/2014
- Initial bill required reporting, with funding
  - Removed by the author to assure passage
- UDOH Pilots required was added
- Placed in the Newborn Screening Statute

# How Best to Monitor

Survey developed: calling every birthing facility

Asking:

- Aware of upcoming CCHD screening mandate
- Already screening and if so, provide us the protocol
- How are they/will they be recording screening
  - Paper vs EMR
  - Oxygen sat values vs pass/fail vs both
  - Feasibility of developing software for reporting  
(reporting not mandated)

# Monitoring Plan for Utah

Vital records: three questions being added for CCHD screening:

- Pass - Fail - Not screened
- Vital records monthly reports sent to NSP
- Inexpensive, all BFs, minimize reporting by BFs

Monitoring Pilot:

- Starting April 1, vital record clerks at BFs that are currently screening using a protocol, to record CCHD screening results (3 questions)
- Review process prior to October statewide screening



# Funding for Monitoring System

Newborn screening kit fee increased by \$0.80:

~\$42,000/year: cover a ½ FTE:

- to monitor reported data
- provide education/QI efforts to birthing facilities

Will continue to pursue improving electronic data analysis for future monitoring:

- Improve accuracy of data - Minimize need for chart review
- Maximize feasibility for electronic downloads from BF
- All BFs documenting electronically

# Lessons Learned

Need for direct access to legislator sponsoring bill: maximize the positive impact of legislation

- Start date/need for monitoring

Have a well formed argument for the need for data collection and monitoring

- Public Health mission
- To assist hospitals with implementation
- To provide QI efforts
- To determine the accuracy of screening process and monitor need for change

# CCHD Screening in Utah

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