



THE NEWBORN SCREENING PROCESS- BIRTH TO CONFIRMATION

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Up Work Group**

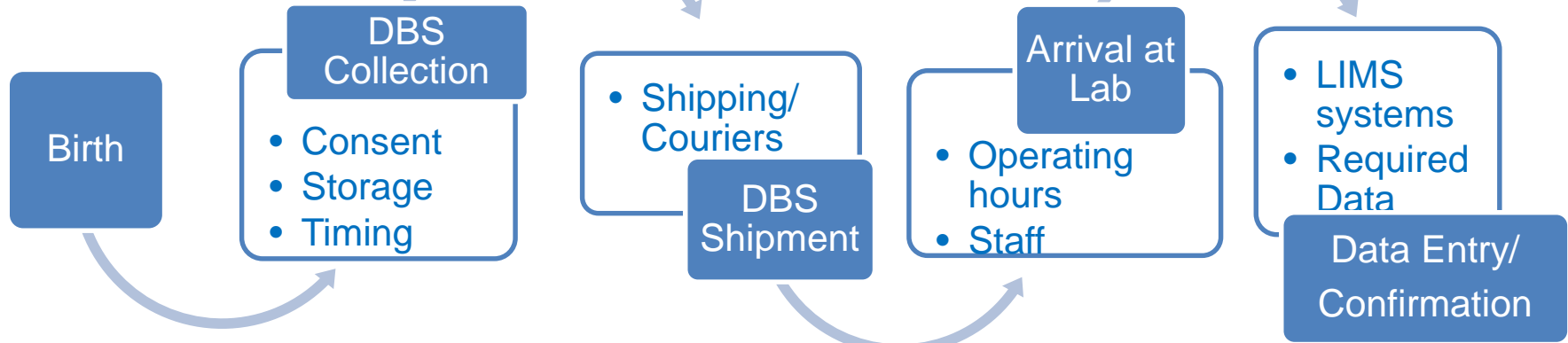
**Iowa Newborn Screening Program Follow Up
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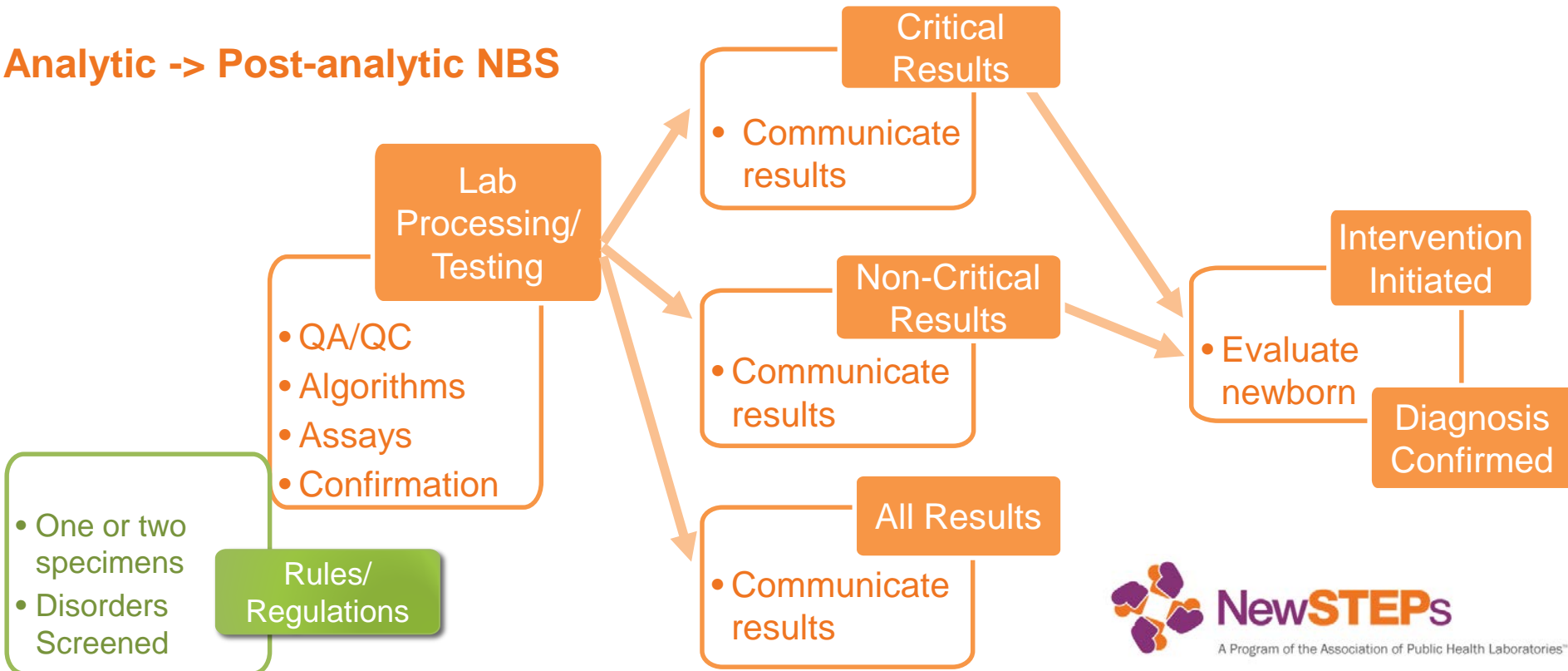
**University of Iowa
Stead Family
Children's Hospital**

NBS Process Model

Pre-analytic NBS



Analytic -> Post-analytic NBS



NewSTEPS

A Program of the Association of Public Health Laboratories™

Pre-Analytical Newborn Screening

- **Education occurs about NBS prior to birth (GOAL)**
- **Baby is born!!!**
- **Education occurs about NBS at collection**
- **Consent process completed (if required)**
- **Specimen collected between 24 - 48 hrs**
- **Specimen sent to NBS lab via courier or other shipping method the same day it's collected**
- **Specimen arrives at lab in a timely manner**
- **Data entry occurs**
- **Testing Begins**

Analytical

- **Testing occurs**
- **Tests are ran in duplicate**
- **QI activities occur throughout the testing and reporting process**
- **Information is entered into the LIMS**
- **Results are reported to follow up**
- **Final reports are released**

Post Analytical

- **Lab notifies Follow Up of any abnormalities**
- **Follow up staff reviews case details/procedures and either calls the PCP or the medical consultant**
- **PCP is given recommendations for next steps**
 - Repeat the screen
 - Do confirmatory testing
 - Refer to a specialist/CF Center
 - Hospitalization
 - Transfer to a tertiary health care center
- **PCP contacts the family**
- **Follow up continues to monitor the case until a disorder is confirmed/ruled out**

Goal of the Newborn Screening Process



Barriers/Obstacles in Newborn Screening



Overall Barriers to the NBS Process

- Lack of **UNDERSTANDING** by Physicians, Midwives, Allied Health Staff and Parents
 - Do not understand the importance of NBS
 - They are not aware of the role they play in the NBS system
 - Lack of literacy on the disorders screened for
 - Lack of genetic literacy
- Differences state to state
 - 1 screen vs 2 screen states
 - Governance
 - Budgets
 - Conditions screened for

Barriers During the Pre-analytic Phase Birthing Center/Home

- **Where birth occurs (hospital birth, home birth)**
- **Educational issues (parents, staff, midwife)**
- **Beliefs**
- **If baby leaves before 24 hrs**
- **Consent process**
- **Getting the screen collected within 24-48 hours**
- **Getting the screen to the NBS lab after collection (within 24 hrs)**
- **Staff turnover**
- **Lack of collaboration between entities within hospital**
- **Lack of collaboration between hospital/midwives/NBS programs**

Barriers – Preanalytic

Once the Card is at the Lab

- **Data Entry (staff?; manual or electronic?)**
- **Laboratory information system**
- **Missing information needed for testing (gestational age; weight)**
- **Poor quality samples**

Barriers During the Analytical Phase

- **Hours of Operation to do data entry or perform testing**
- **Appropriate staffing levels and equipment in NBS lab**
- **Assays (Kits vs Home Brew)**
- **Algorithms**
 - **Time critical disorders**
 - **2nd tier testing**

Barriers in the Post Analytical Phase (1)

- **Hours that Referral Centers/Follow Up staff work**
- **Appropriate staffing**
- **Communication of results**
 - **lab to follow up/referral center**
 - **follow up to PCP**
 - **PCP to parents**
 - **birthing center to PCP**

Barriers – Post-Analytical Phase (2)

- **Ability to correctly ID infant (use of baby girl/baby boy; mother's surname; other combinations of name)**
- **Ability to correctly ID PCP (ordering physician vs baby's PCP)**

Barriers – Post-Analytical (3)

- **Obtaining repeat screen, confirmatory testing, sweat testing**
 - **Timeliness of referral**
 - **Where referral center is located and ease of scheduling**
 - **Length of time to receive confirmatory testing to make a diagnosis**
 - **Length of Time from diagnosis to treatment**

Reminders

- **NBS is a great screening test, but it's not a diagnostic test**
- **NBS is different from state to state and country to country**
- **Many NBS disorders are rare**
- **Many PCPs have never had a baby that they've taking care of confirmed with a NBS disorder – can cause “buy in” issue or issues of “I don't want to deal with this”**
- **Parent perceptions**

This is why we do what we do



Questions?



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