



**Northwest Regional Newborn Bloodspot Screening
Advisory Board
Tuesday, January 30, 9:00 am-12:00 pm PST**

SUMMARY NOTES

Program Eval Site Visit / Presentation Review

Patrice Held provided updates and review of the site visit - see the attached slides and zoom recording as a resource for more detail. A completed report of the independent program evaluation will be shared with the Board when it is available. This is expected to be available in a few months time.

Questions / comments from Advisory Board members:

- Areas the board is interested in strategically working with the Program to develop?
 - Connecting with families - education, awareness and engagement
 - Sustainability of program funding that doesn't focus on fee increases (particularly for midwives and others who have patients who pay out of pocket)
 - Can we leverage partnerships who already have convening / connections that we can use to amplify the work?
 - Reboot long term funding subcommittee to figure out better model for sustainable funding.



- Action: A query will go out to gauge Board member interest in continuing the work of the Funding Subcommittee. The Program will convene this group in the Spring/early Summer.
- Do we have an equity impact analysis tool or team that can help us monitor, understand and make adaptations?

Disorder Protocol Review

The Board members reviewed and discussed edits to the disorder criteria and process for reviewing and deliberating on disorders.

- Action: OC and the Program will create an updated draft Protocol with the suggested edits and process adjustments and invite additional review/refinement prior to the next Board meeting - at which time the Board will be asked to approve the updated Protocol.
- Action: The Program will share a visual of the RUSP review process with Board members, as a reference point.

Public Comment

Representative McLain spoke with the Board about her intentions to be supportive to the Board - specifically she noted the process adjustments to bring more community voice opportunities into the disorder review were appreciated. No bills were in the short session queue, but McLain said she will continue to ask for \$500,000 to support relief on costs for out-of-pocket screens. She congratulated the Program for having the independent review.



Wrap Up/ Adjourn

The group will be polled for the next meeting in addition to the other action items listed in this summary. (**NOTE**: As of this drafting, the next Board meeting is scheduled for Wednesday, May 29 at 9am PST.)

Northwest Regional Newborn Screening Program Advisory Board Meeting

January 30, 2024

The logo for the Oregon Health Authority is centered within a light blue, curved banner. It features the word "Oregon" in a smaller, orange, serif font positioned above the "H" of the word "Health". The word "Health" is written in a large, dark blue, serif font. Below "Health", the word "Authority" is written in a smaller, orange, serif font, with a thin blue horizontal line extending from the left side of the "H" in "Health" to the start of "Authority".

Oregon
Health
Authority

NWRNBS Advisory Board Members (13)

- Person or family member of a person affected by a disorder on the Newborn Screening Panel
 - Marilyn Hartzell, Retired- Former Director of Oregon Center for Children and Youth with Special Needs
- Contracted Medical Consultant
 - Dr. Amy Yang, Clinical Geneticist, Assistant Professor and Attending Physician, Oregon Health and Sciences University
- Representative of Medicaid or insurance industry
 - Dr. Dawn Mautner, Medicaid Medical Director, Health Systems Division, Oregon Health Authority
- 2 Representatives from birthing center or hospital
 - Dr. Kara Stirling, Neonatologist, Medical Director of Newborn Services in Oregon Region of Providence Health and Services
 - Dr. Elizabeth Powers, Chief Medical Officer, Wallowa Memorial Hospital; Family Physician, Winding Waters Medical Clinic; Wallowa County Deputy Medical Examiner
- Representative of an entity that contracts with NWRNBS for newborn bloodspot screening (open)
- 3 Representatives of advocacy association regarding newborns with medical or rare disorders (1 position open)
 - Pamela Domingo, Disability Rights Oregon
 - Jill Levy-Fisch, President Save the Babies Through Screening Foundation
- Representative of a statewide association of nurses
 - Sherly Paul, Home Visiting Nurse, Health Birth Initiative, Multnomah County Health Department
- Representative of a statewide association of midwives
 - Andrea Keating, Certified Professional Midwife, Corvallis Birth & Women's Health Center
- 2 Representatives of a statewide association of pediatricians
 - Dr. Charlene Lai, Oregon Pediatric Association; Assistant Professor , Oregon Health and Science University
 - Dr. Awe Lapcharoensap, Neonatologist, Oregon Health and Sciences University and Peace Health Vancouver

NWRNBS Advisory Board

- Formed in 2019 with the objective of creating criteria for inclusion / exclusion of conditions to the Oregon NBS panel (ORS 433.299)

Additional work included:

- Identifying strategic initiatives for improving equitable testing and care:
 - Accessibility: Ensure screening and treatment are available, accessible, and not cost-prohibitive for all individuals.
 - Family-centered care: Provide care focused on social and emotional support for families, culturally appropriate education, and assistance with navigating the NBS system.
 - Timeliness: Provide timely services and results to meet United States Government Accountability Office (GAO) standards.
- Forming a long-term funding subcommittee in 2022 to look at alternatives to fee increases
- Working collaboratively with state representative to explore options for families who pay out of pocket for NBS

Oregon Health Authority

- The Oregon Health Authority (OHA) adopted the strategic goal of ending health inequities in Oregon by 2030.
- Health equity is defined by OHA as “an established health system that creates health equity when all people can reach their full potential and well-being and are not disadvantaged by their race, ethnicity, language, disability, age, gender, gender identity, sexual orientation, social class, intersections among these communities or identities, or other socially determined circumstances”.

Newborn Bloodspot Screening: A Public Health Program

Pre-analytic

Analytic

Post-analytic

Prenatal
Education

Specimen
Collection

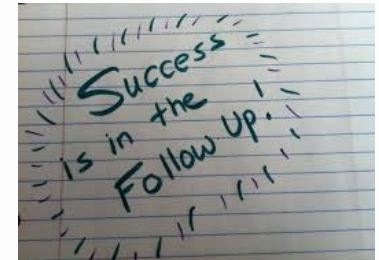
Transport

Laboratory
Testing

Short-term
Follow-up

Long-term
Follow-up

Newborn
bloodspot
screening
could save
your baby's life



Quality Improvement Projects

Newborn Bloodspot Trainings

Collection and Submission of Specimens

2023 trainings:

95 total-combination of virtual and on-site trainings

Oregon: 86 trainings

- 49 hospital trainings in 31 hospitals
- 33 clinic trainings in 29 clinics
- 4 community birth provider trainings

New Mexico: 7 trainings

- 7 trainings in 5 hospitals

Military/Navajo Nation: 2 trainings

- 2 trainings at 1 hospital

Newborn Bloodspot Collection Trainings

Out of 28 birth facilities in Oregon, 3 months after training:

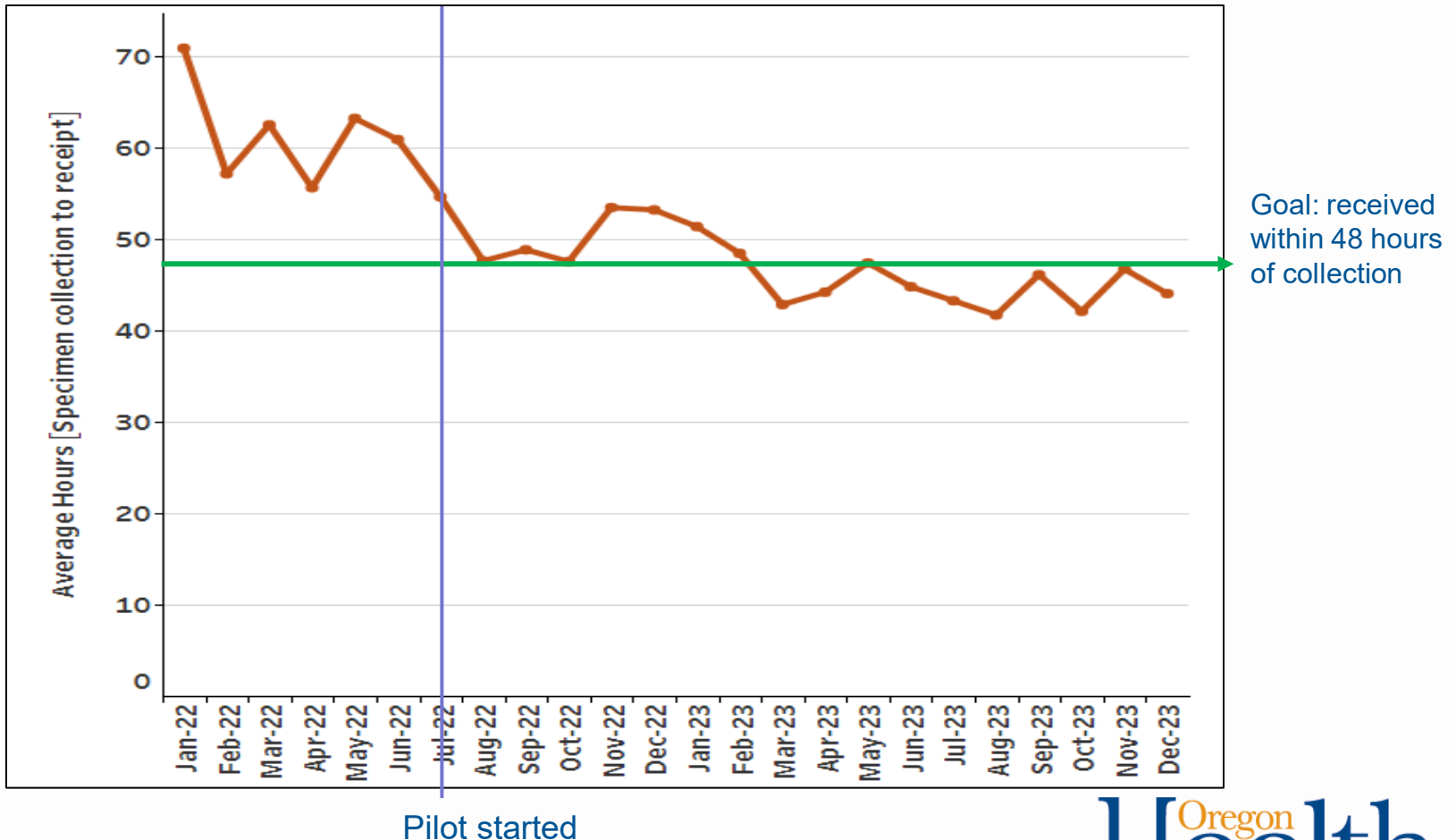
- 79% demonstrated a decrease in their unsatisfactory rate
 - 2 facilities had no change, 4 had an increased unsatisfactory rate
- 68% had at least a 50% decrease in their unsatisfactory rate
- 7 facilities had a 0% unsatisfactory rate

Out of 24 birth facilities in Oregon, 6 months after training:

- 83% demonstrated a decrease in their unsatisfactory rate
 - 2 facilities had no change, 2 facilities had an increased rate
- 3 facilities had a 0% unsatisfactory rate

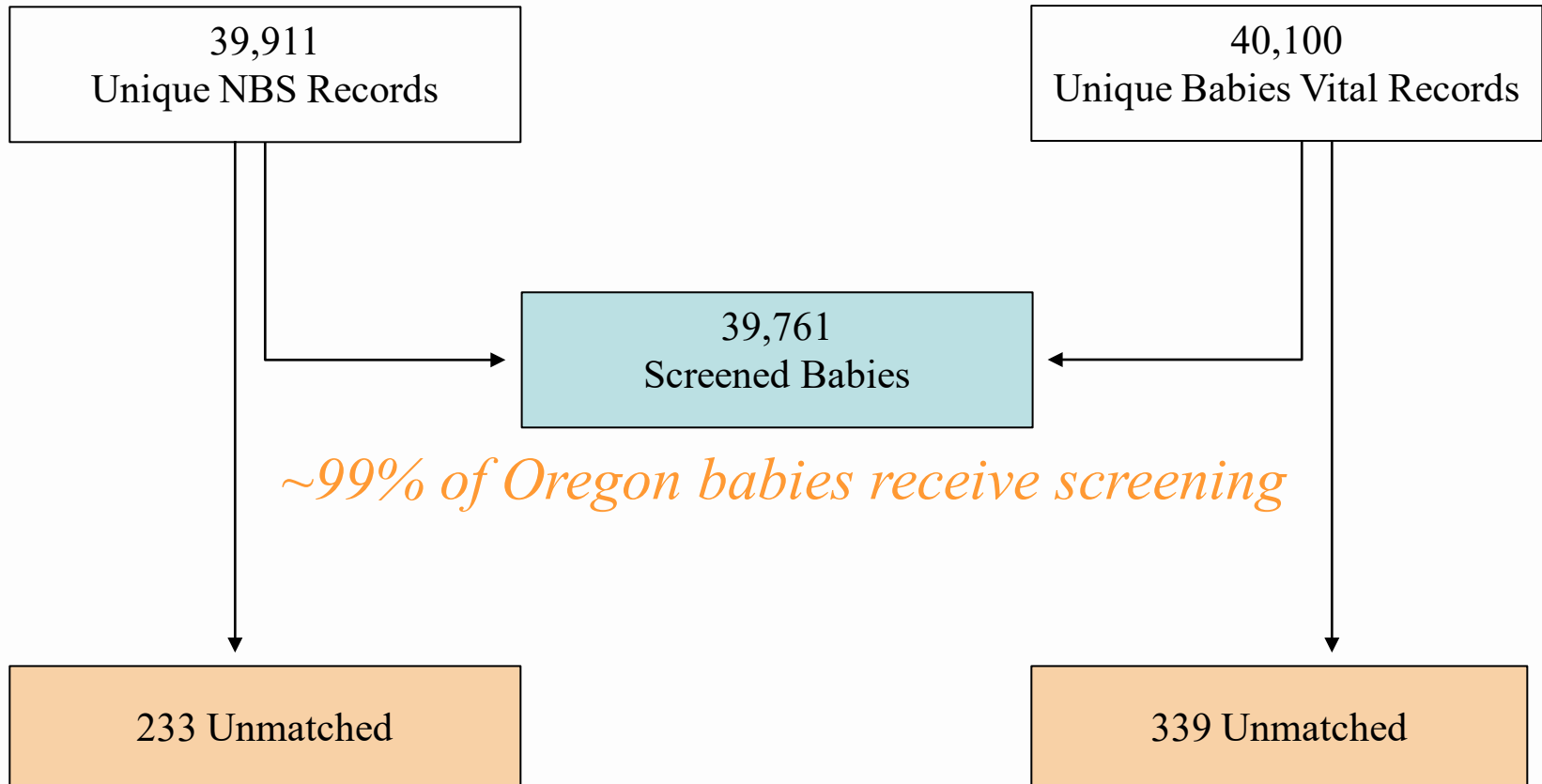
Hospital Courier Service Pilot

Average specimen collection to receipt time (hours) by month

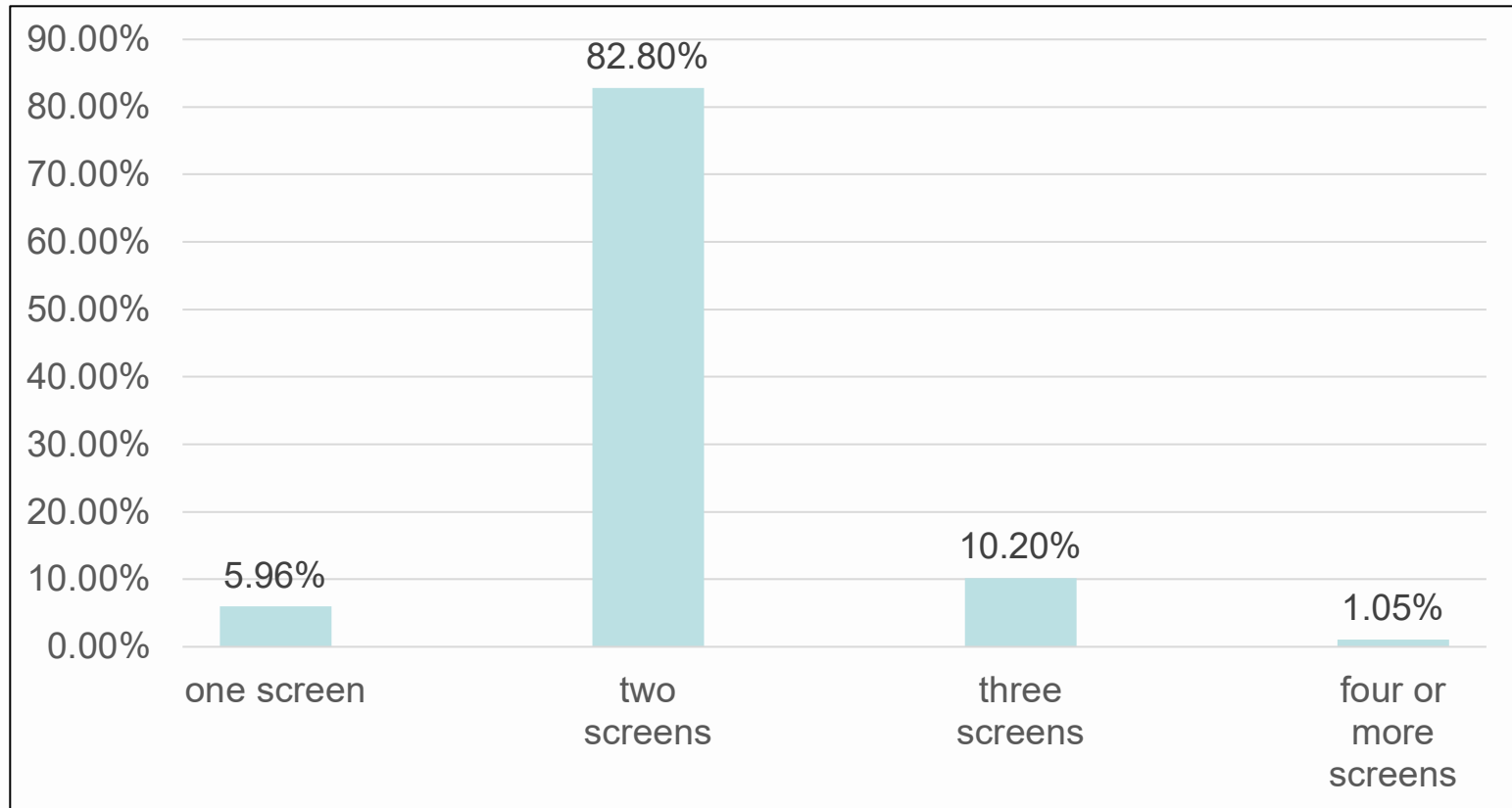


Vital Records Matching

2022 Number of Oregon Babies Screened

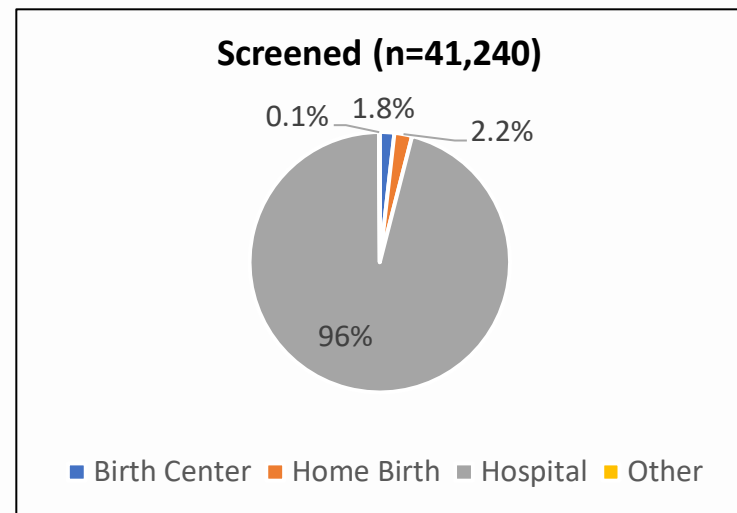
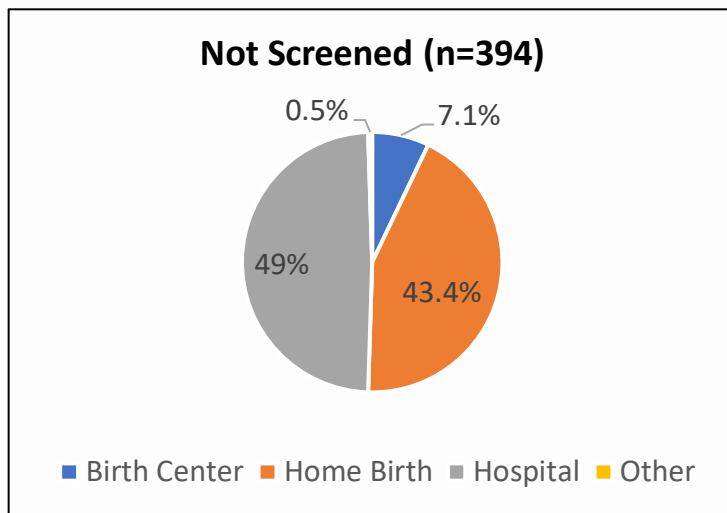
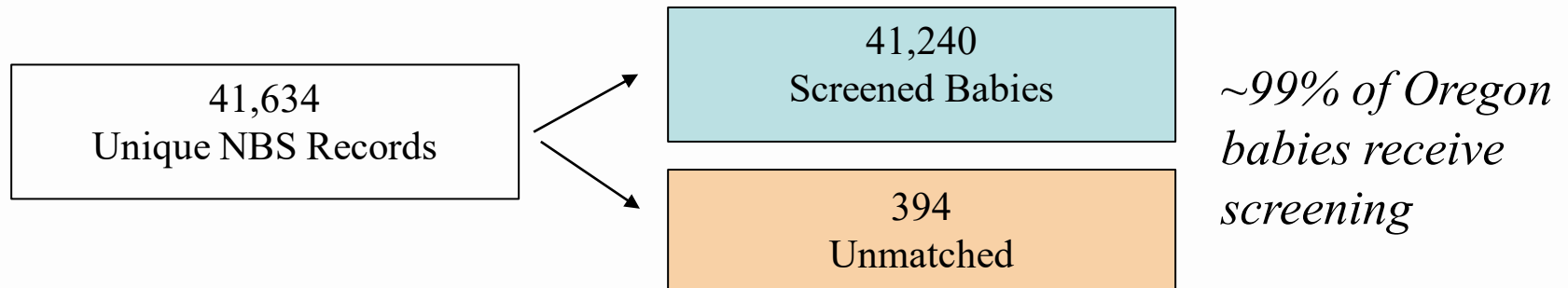


2022 Number of Screens Received Oregon Babies



94% of Oregon babies receive two or more screens

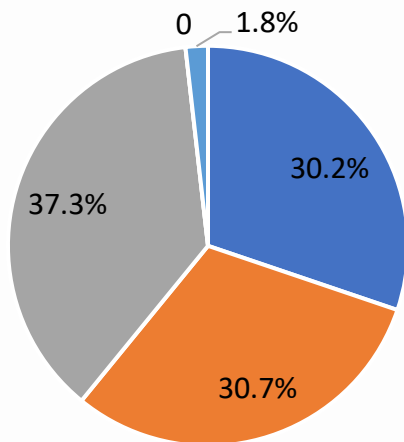
2021 Vital Records Matching



Data acquisition and analysis performed by Laurel Boyd

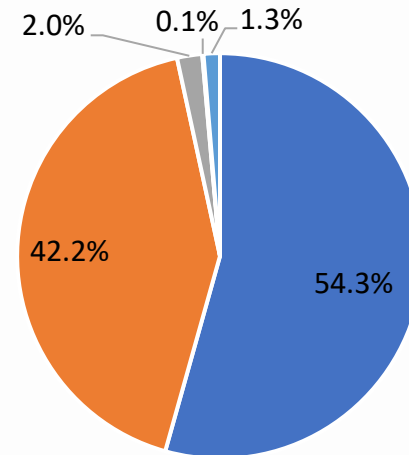
2021 Vital Records Matching

Not Screened (n=394)



- Private insurance
- Medicaid/OHP
- Self pay
- Indian Health Service
- Other

Screened (n=41,240)



- Private insurance
- Medicaid/OHP
- Self pay
- Indian Health Service
- Other

Data acquisition and analysis performed by Laurel Boyd

Workflow, Testing, & Follow-Up

Challenges and Opportunities

Newborn Bloodspot Screening: A Public Health Program

Pre-analytic

Analytic

Post-analytic

Prenatal
Education

Specimen
Collection

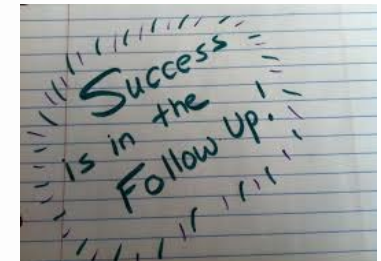
Transport

Laboratory
Testing

Short-term
Follow-up

Long-term
Follow-up

Newborn
bloodspot
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your baby's life



Challenges with Workflow



Specimen Collection

- Distribution of Kits
- Difficulties completing requested information



Transport

- Facilities using USPS



Laboratory Testing

- Error tracking
- 2 LIMS



Report Results

- Mailing Reports

Planned Solutions

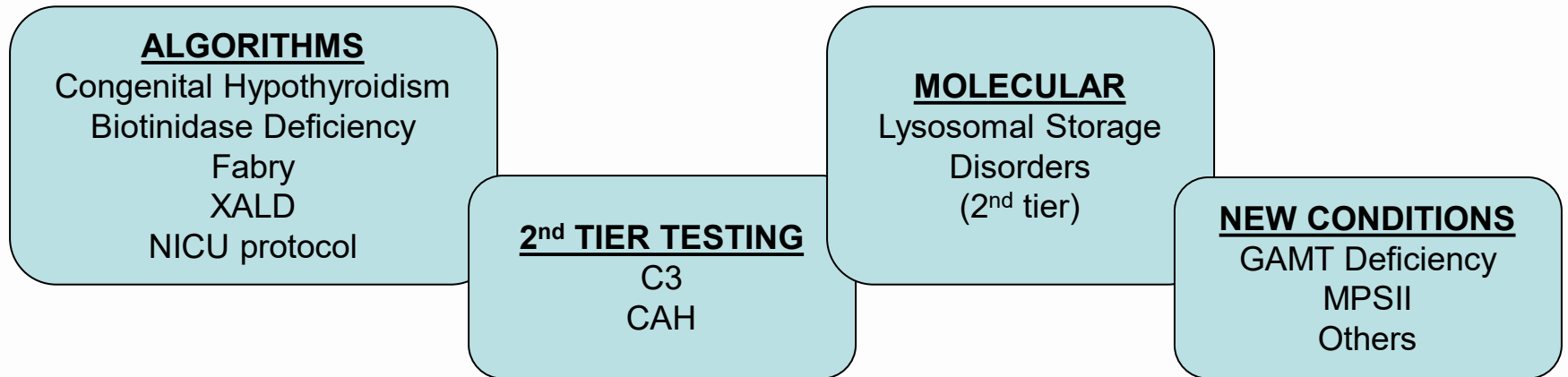
- Evaluate distribution of cards
- Redesign Cards

- Courier service for 18 hospitals (rural/frontier)
- USPS priority mailers for CBA

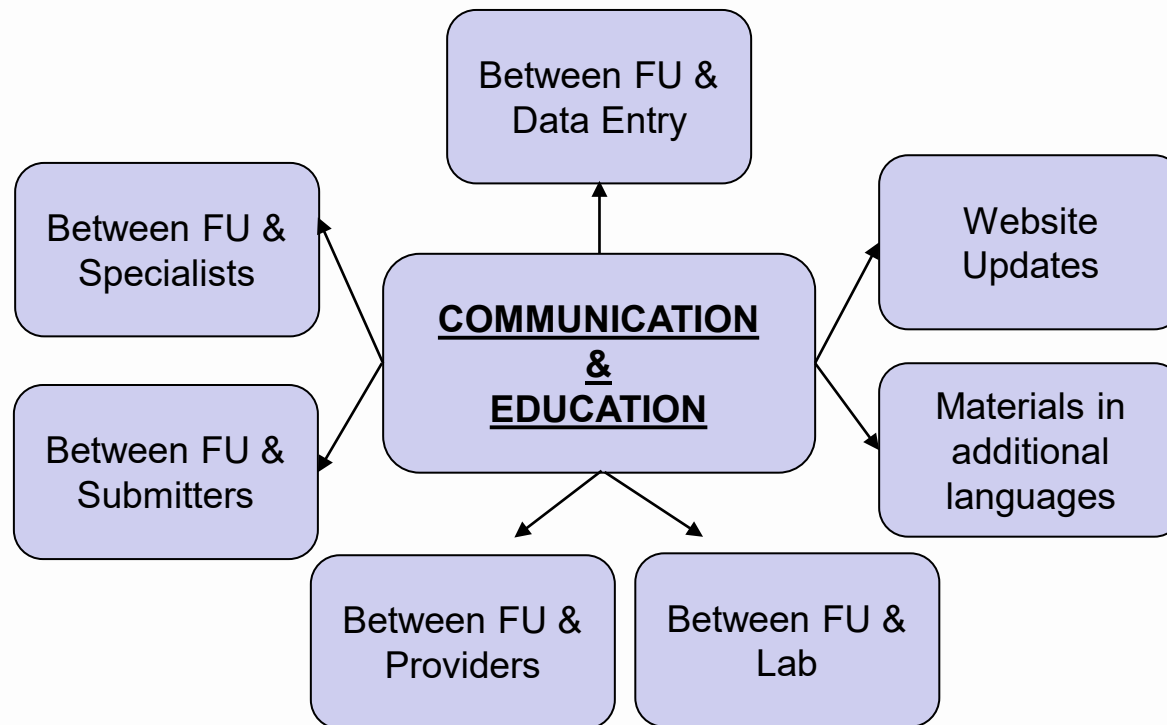
- Neometrics (iCN) upgrade
- LIMS replacement project

- Going paperless
- ETOR

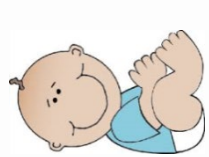
Improvements needed in Analytical Testing



Improvements needed in Communication and Education



Newborn Screening Timeline



Birth of
Baby



Specimen
Collection



Transport



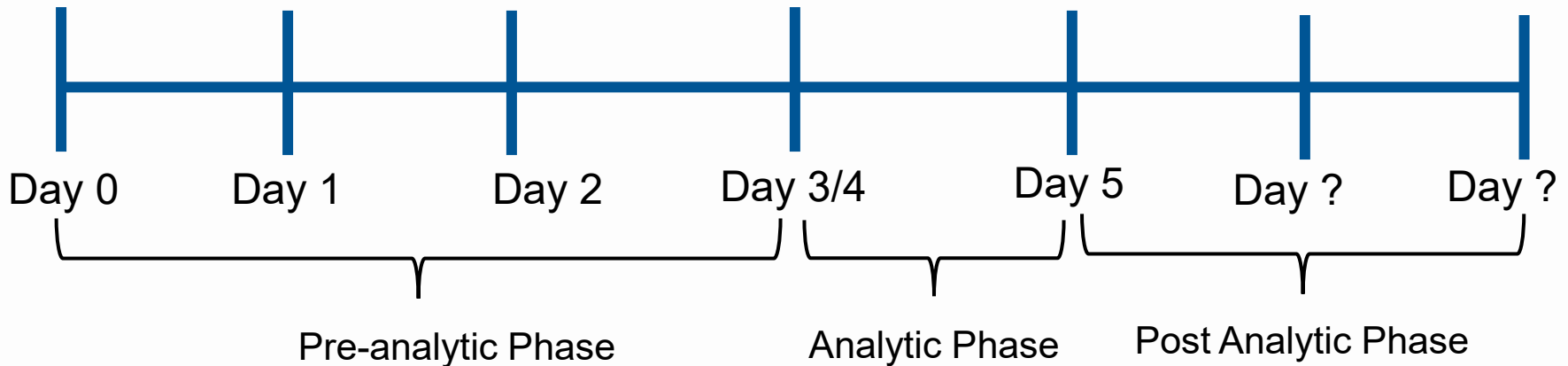
Laboratory
Testing



Report
Results*
Time critical
conditions



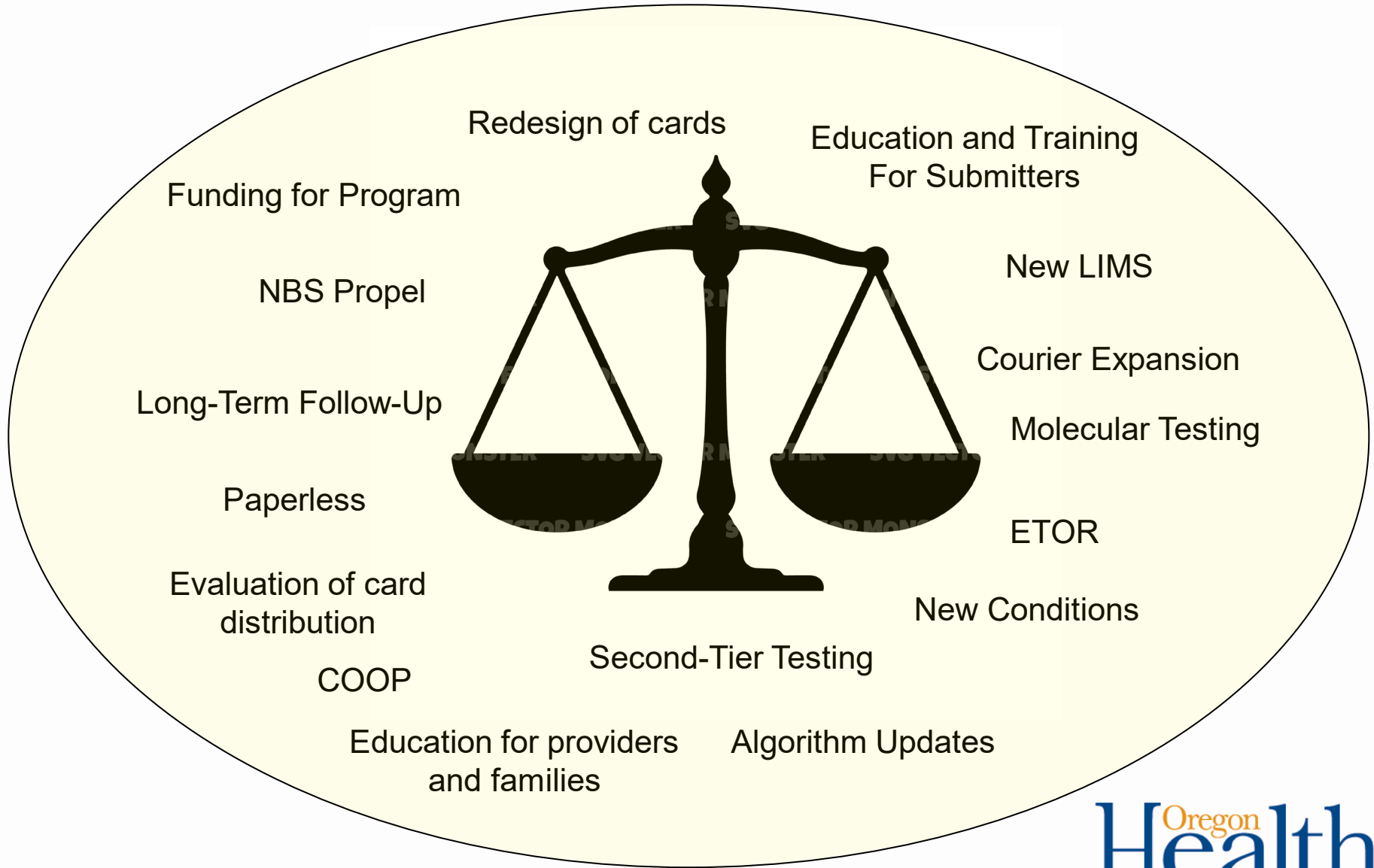
Diagnosis
Treatment



Goals and Priorities

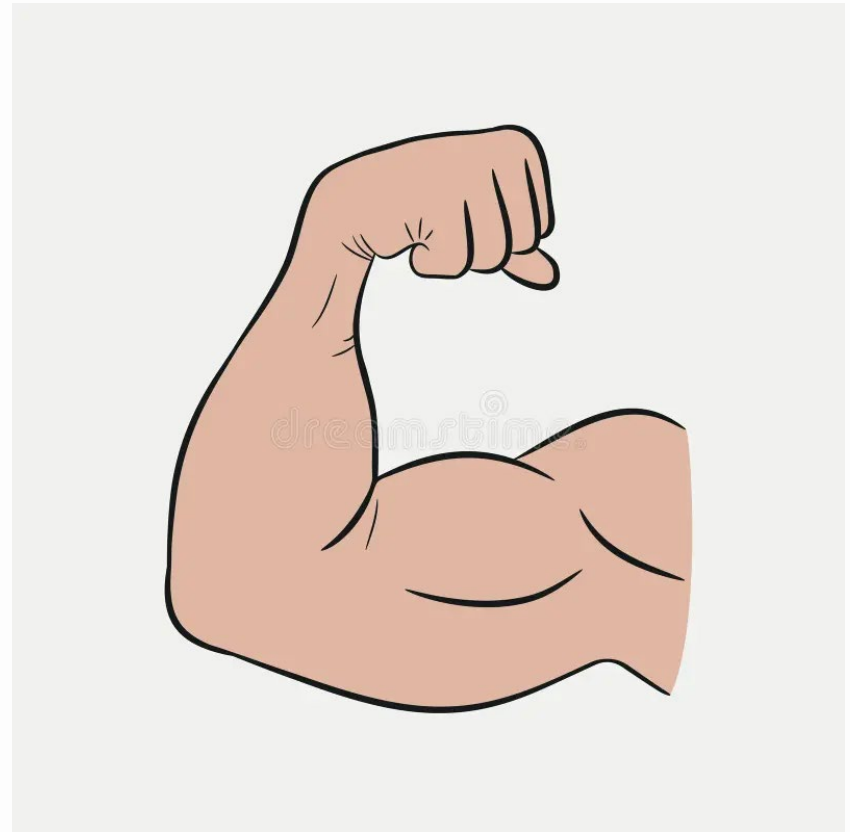
Priority Setting

Lens of Health Equity



Strengths

- ❑ OUR NBS TEAM
- ❑ OUR PARTNERS
- ❑ OUR AGENCY SUPPORT
- ❑ COMMITMENT TO HEALTH EQUITY



Disorder Evaluation Process - Oregon

Stage 1: Addition to the RUSP

Disorders that have been reviewed by the ACHDNC and have been added to the RUSP will be raised for further evaluation.

Disorder Evaluation Process - Oregon

Stage 2: NWRNBS Program Evaluation using Category One Criteria

Category One Criteria (Evaluated as Yes or No)

1. The condition is well-defined in newborns.
2. Earlier intervention results in improved outcomes compared to later identification.
3. The population level incidence and prevalence are known.
4. There is a Federal Drug Administration (FDA) approved testing method available using dried blood spots or an accurate testing method is available that meets clinical laboratory requirements for validation and testing by the laboratory using dried blood spots.
5. Diagnostic and specialty testing is available.
6. A treatment is available.
7. The contracted NWRNBS medical consultants have been consulted and appropriate specialized medical consultation is available or can be obtained by the Program.
8. The specific condition appears in the funded region of the Prioritized List as determined by the Oregon Health Evidence Review Commission.
9. The NWRNBS Program has sufficient information to perform a fiscal analysis.
10. The impact to the NWRNBS contracted partners has been assessed.

Disorder Evaluation Process - Oregon

Category Two Criteria (Evaluated using the Consensus Method)

1. The population level public health benefits of screening outweigh the risks and harms.
2. There is adequate capacity and expertise in the NWRNBS program to implement and maintain testing and reporting.
3. There is adequate capacity and expertise in the NWRNBS program to implement and maintain follow-up and education for providers and parents.
4. The NWRNBS Program has adequate fiscal resources for implementing the test, performing the test and conducting follow-up and education.
5. The population level incidence, prevalence and disease burden are significant enough to merit screening.
6. Diagnostic and specialty testing is available and accessible that allows a definitive diagnosis to be made.
7. An effective treatment that is proven to result in clinically significant benefits is available and accessible.
8. There is equitable care and treatment for the disorder.
9. Addition of the disorder is not prohibitive to NWRNBS contracted partners.

Disorder Evaluation Process – Oregon

What is missing?

- To meet OHA health equity goals, all factors impacting screening outcomes should be addressed:
 - Race, ethnicity, access to health care providers, economic status, education level, and social support
- The review process should include all partners (families, providers, and advocacy groups).
- The advisory board identified family-centered care as a priority. Direct family input is needed in the review process.
 - Families who have a child with the condition
 - Families impacted by screen positive results (either false positive or true cases)
- The first criteria (condition is on the RUSP) does not allow for Oregonians to nominate conditions to the Oregon NBS panel