

## Background Information

Between 2019 and 2023, the Minnesota Department of Health (MDH) conducted a longitudinal follow-up quality improvement (QI) project aimed to improve the MN Newborn Screening (NBS) System by expanding and aligning longitudinal follow-up (LFU) data collection across MDH blood spot, critical congenital heart disease (CCHD) and Early Hearing Detection and Intervention (EHDI) follow-up. Standardized, acceptable, and effective processes were developed for collecting and reporting a set of common data elements, information about well-child visits and condition-specific care for a defined cohort of children between 3 and 4 years old.

There are no national standards for longitudinal follow up common data elements.

## Objectives

1. Describe QI steps to align common data elements across NBS conditions
2. List barriers to successful electronic health records abstraction
3. Describe data completeness

## Population Identified

429 children were born in 2017 across all NBS conditions. More than 40% (n = 182) were identified as deaf or hard of hearing (DHH) through Minnesota newborn hearing screening.

## Common Data Elements

### Obtained by Data Sharing with Vital Records

- Percentage of LFU records for children age at least 4.0 years with known **mortality status**.
- Percentage of LFU records for children age at least 4.0 years who are deceased with **known cause of death**.

Mortality status & known cause of death were found for 100% of applicable records.

### Obtained by Health Record Abstraction

- Percentage of LFU records for children age at least 4.0 years with **condition-specific health care** between 3.0-<4.0 years (or with no recommended condition-specific health care between 3.0-<4.0 years).
- Percentage of LFU records for children age at least 4.0 years with a **well-child visit** between 3.0-<4.0 years.

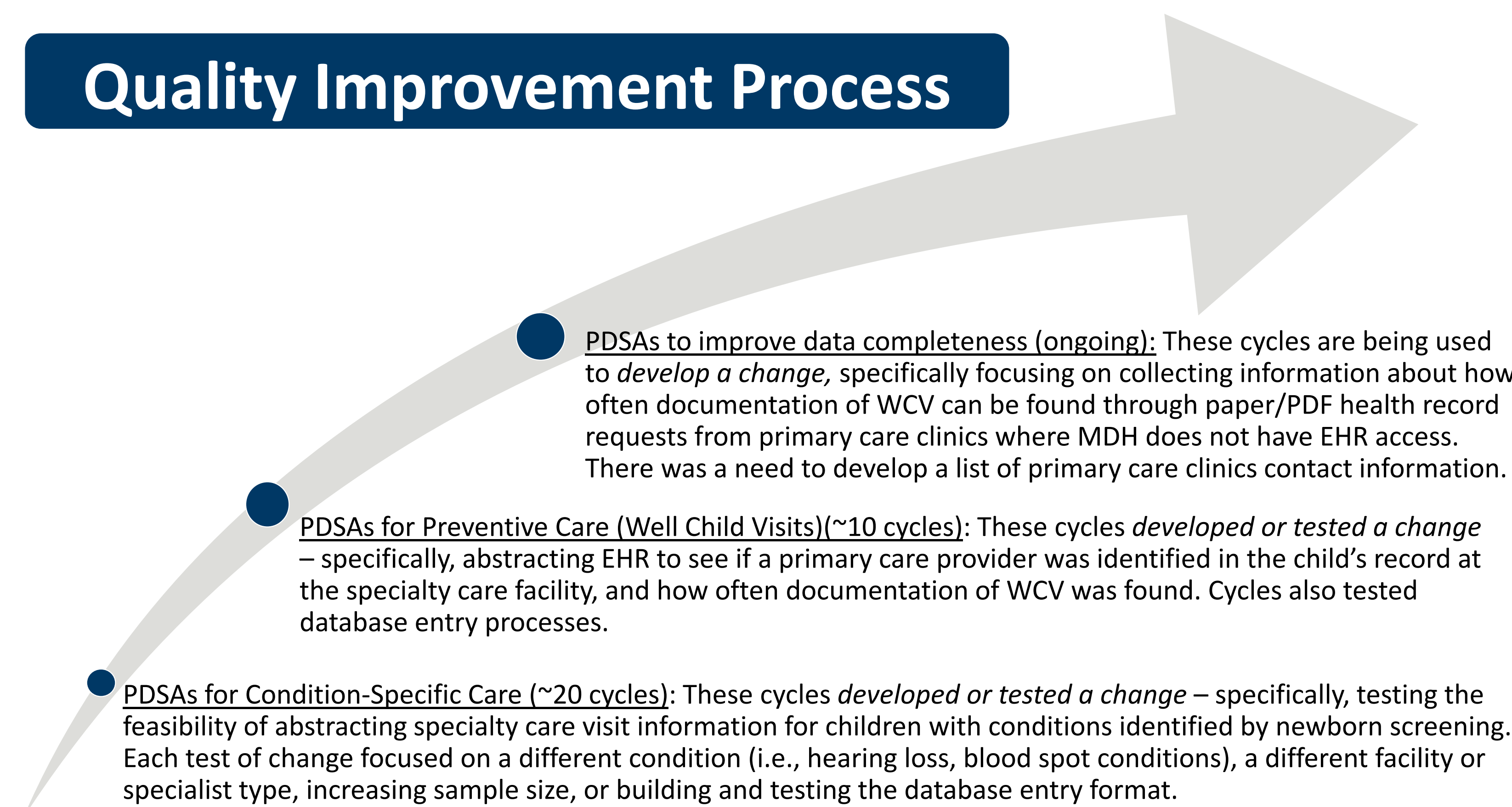
### Resources

American Academy of Pediatrics (AAP). Recommendations for Preventive Pediatric Health Care (2022). [https://downloads.aap.org/AAP/PDF/periodicity\\_schedule.pdf](https://downloads.aap.org/AAP/PDF/periodicity_schedule.pdf)

## What's the Issue & Why It's Important

- Regular primary and hearing care visits are important for maintaining health and identifying changes in health for children who are deaf or hard of hearing (DHH).
- The American Academy of Pediatrics recommends that all children have well-child visits (WCV) at least annually beginning at age 3 (and more frequently before age 3).
- For children who use hearing technology, regular hearing care is necessary to ensure the technology is working well and appropriate for their current hearing levels. For this project, condition-specific hearing care included audiology, otolaryngology, or speech-language pathology (i.e. aural habilitation) visit types.

## Quality Improvement Process



The team used a Plan-Do-Study-Act (PDSA) QI tool, abstracting records from children born in 2017. The team completed more than 40 PDSAs. Through these learning cycles, the abstractors honed the best ways to search different facilities that used different EHR software systems (i.e., specific keywords, media, visit types/filters). The team built and tested a database and wrote a detailed job aid to ensure data quality across multiple abstractors, then implemented some of the proposed changes to complete abstractions on the cohort of children in their 4<sup>th</sup> year of life.

## What we Learned

- EHR abstraction, in addition to our current processes, increased our knowledge of attended or completed well-child and hearing-specific care in the 4<sup>th</sup> year of life and improved data quality.
- Data obtained through data sharing agreements was significantly more complete than data obtained through health record abstraction.
- Data completeness was affected by lack of access to smaller health systems and independent pediatric and audiology clinics. Most of the incomplete abstractions were due to lack of EHR abstraction access for primary care.

### Acknowledgements

Members of MDH Quality Improvement Team and external Quality Improvement Steering Team, with special thanks to Kristi Bentler for team leadership and Melinda Marsolek for initial data analysis.

This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number UG8MC31893 to the Association of Public Health Laboratories (APHL) for the Newborn Screening Data Repository and Technical Assistance Center which provided \$100,000 during the fiscal year. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS, the U.S. Government or APHL.

## EHR Abstraction

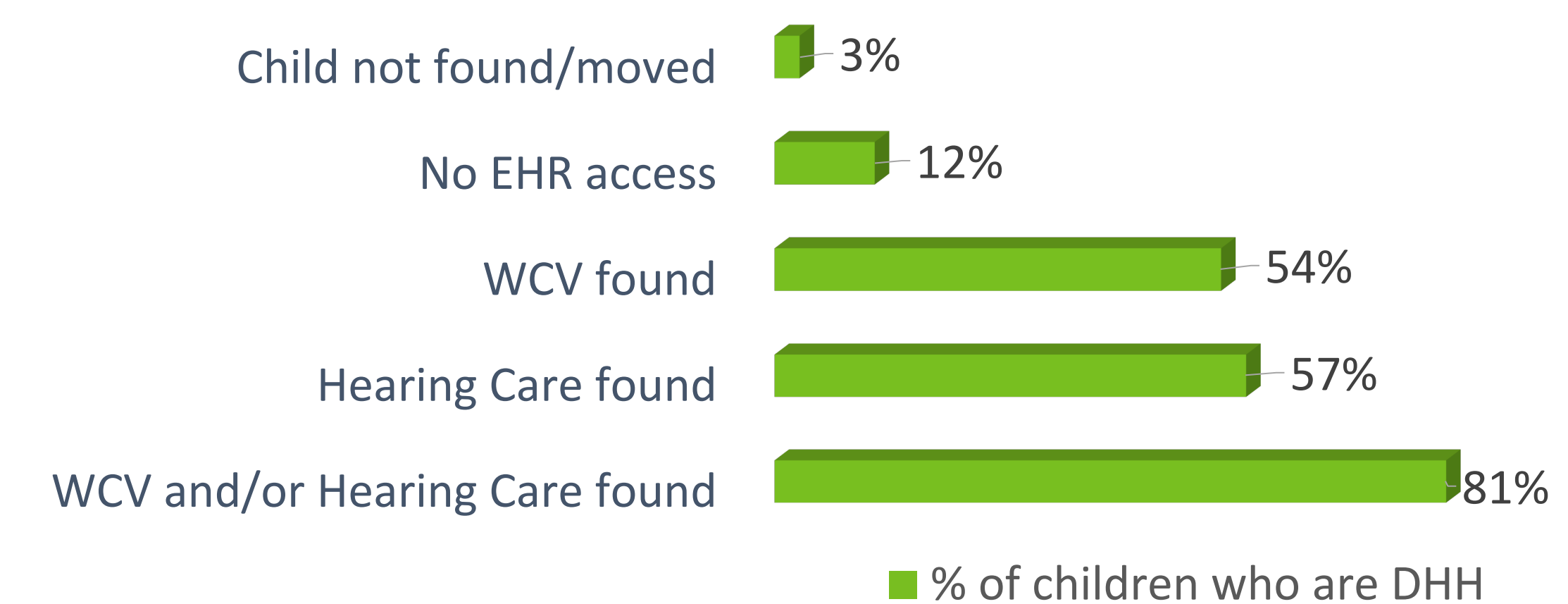
### Barriers to Abstraction

1. Unknown primary care provider contact information.
2. Ongoing need for database changes to store data from abstraction & track new abstraction attempts.
3. Facilities that changed EHR access requirements for abstractors through the project.
4. Receiving incomplete paper / PDF records.

### Keys to Successful Abstraction

1. Ability to build upon existing solid database structure and workflows.
2. Internal ability to update database structures as needed.
3. Successful collaboration with large health center to utilize their internal abstraction team.
4. EHR software that allowed for search functions.
5. Clear Job Aid to ensure data quality across multiple abstractors.

## EHR Abstraction Outcomes



Abstraction took between 4 – 10 minutes per record for an experienced abstractor; more time was needed if searches in multiple facilities were required.

## Next Steps and Questions

- Future quality improvement efforts will focus on obtaining more complete data through attempting to expand EHR access to additional clinics, exploring the feasibility of using medical records requests to supplement data obtained through EHR abstraction, and assessing inequities in health care utilization.
- What are the reasons for families disconnecting from hearing or well child care?
- What data sharing agreements are still needed in order to gather complete data?
- How can we continue to improve data quality (i.e. collaborations with state birth defect surveillance team)?
- How can we assess inequities in health care utilization?