



# Newborn Screening Longitudinal Follow-up for Congenital CMV in Minnesota

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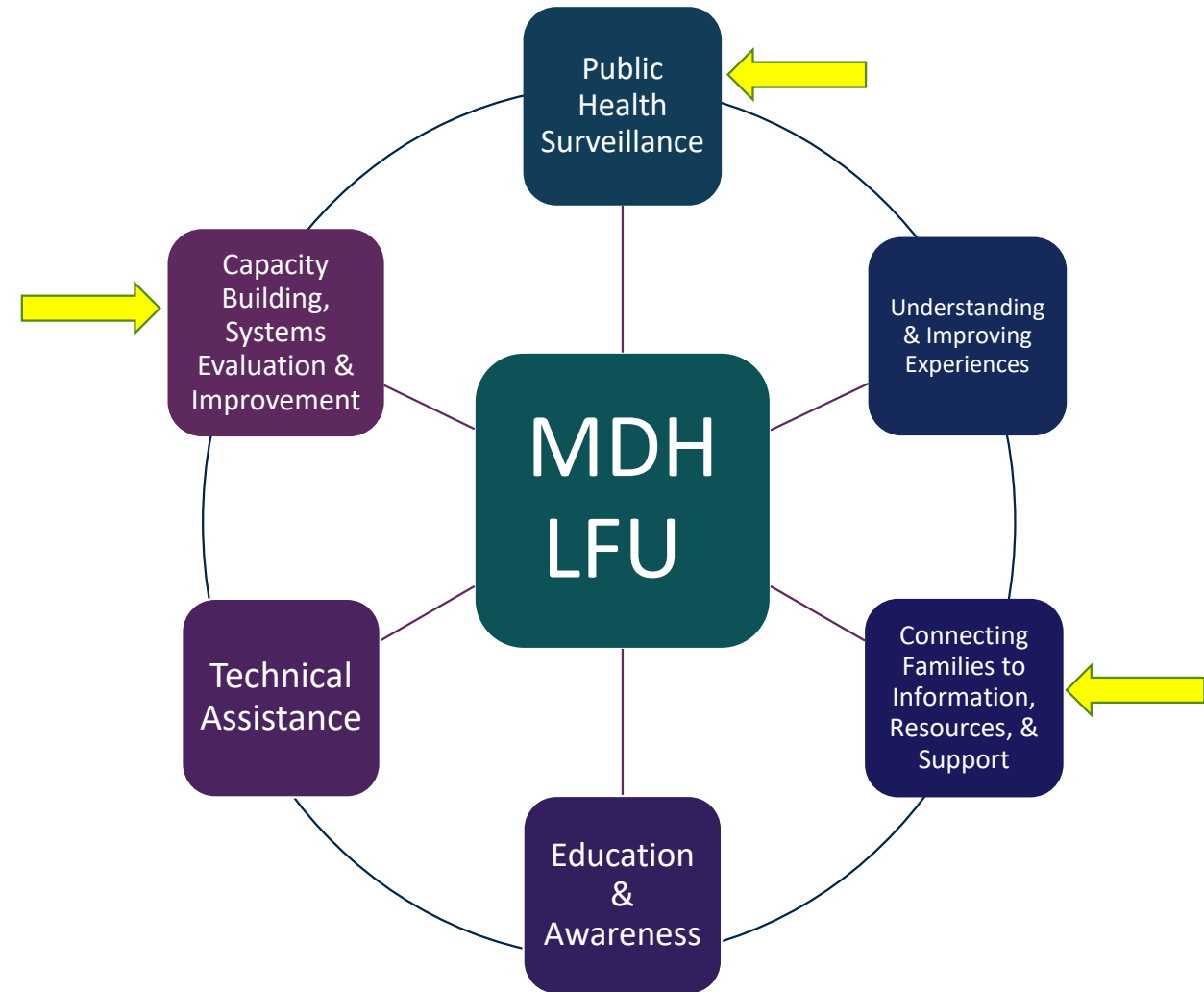
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# Learning Objectives

- Describe the goal and key components of longitudinal follow-up for newborn screening conditions in Minnesota.
- Discuss the planning and implementation of longitudinal follow-up for congenital CMV in Minnesota.
- Identify next steps for longitudinal follow-up activities including data collection.

# What is longitudinal follow-up (LFU) for NBS conditions?

- Systematic evaluation to determine how newborn screening is meeting its goal
- Focus: *after* diagnosis of a person with a condition included in newborn screening
- 6 Key Components of LFU at Minnesota Department of Health (MDH) align across all NBS conditions



# LFU Case Notification for Congenital CMV (cCMV)

- LFU is alerted of cases by short-term follow-up after confirmation of cCMV infection is received
  - Average age of child when LFU notified is 18 days
- Case details are manually entered from Natus into the Minnesota Electronic Disease Surveillance System (MEDSS).
  - MEDSS also has workflows and reporting functions that allow us to manage and track follow-up activities and analyze data



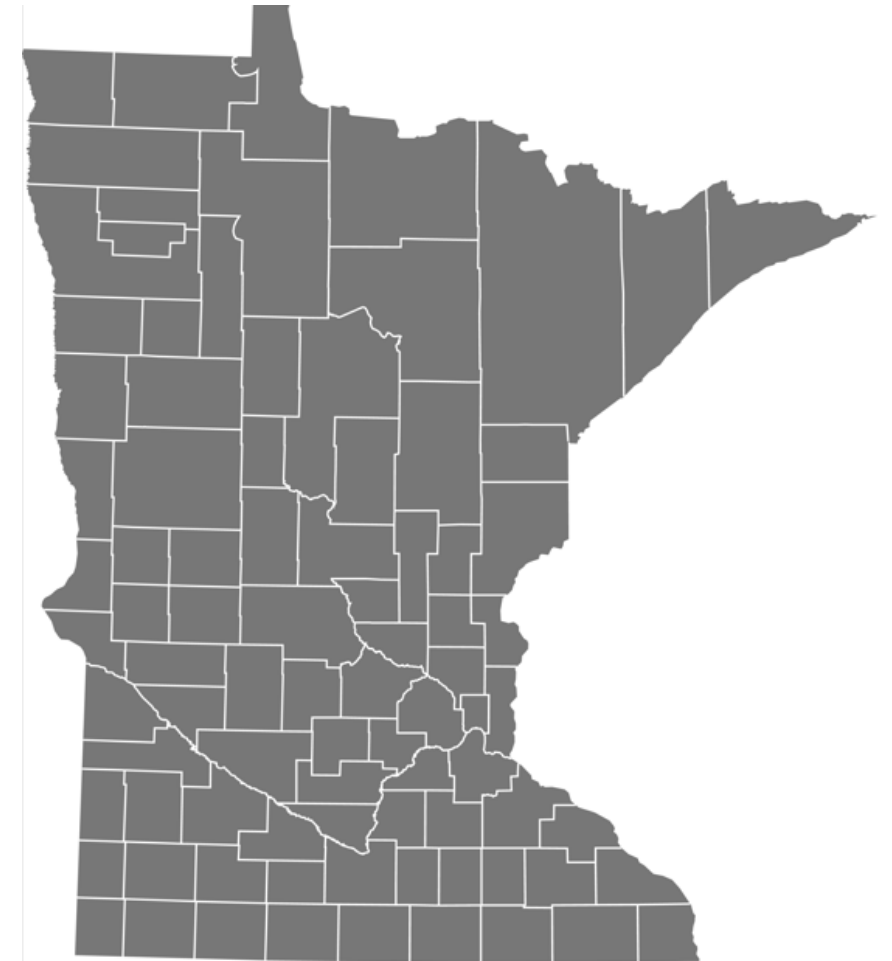
# Connections to Information, Resources, and Services

- Parent(s) or guardian(s) receive a letter and informational booklet by mail from MDH
- Information developed in collaboration with the National CMV Foundation and a workgroup of MN/ND parents of kids with cCMV
- Timing was a key consideration
  - Feedback from parents: earlier is better
  - On average, mailed 11 days after confirmatory lab resulted
- Cost to print/spiral bind is \$18/booklet
- PDF available online
- Translations available: Spanish, Somali, Hmong



# Local Public Health Referral

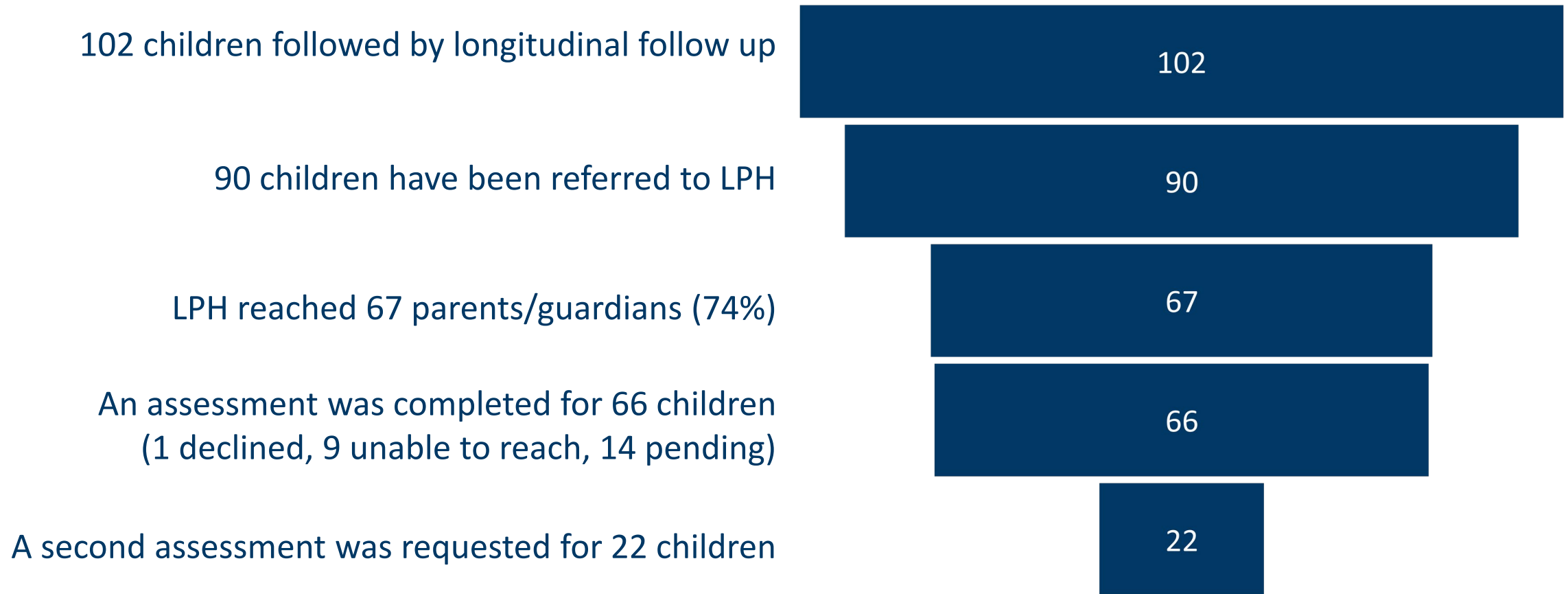
- Connection between family and Local Public Health (LPH) department for their county of residence via direct referral from MDH – utilize an electronic referral process in MEDSS
- LPH nurse contacts the family to complete a nursing assessment which includes up to 5 domains
  - Income
  - Communication with community resources
  - Caretaking/parenting
  - Growth and development
  - Health care supervision



# Local Public Health Interventions

- Link to supportive services (Family Home Visiting, WIC, teen parenting, Early Intervention)
- Facilitate connections to medical care by addressing barriers
- Communicate nursing assessment results and special concerns back to MDH via MEDSS
- Option for second visit (their discretion or MDH request)
- LPH departments are reimbursed for visits by CYSHN section

# LPH Assessment Data for cCMV





# Parent Support Pilot Project

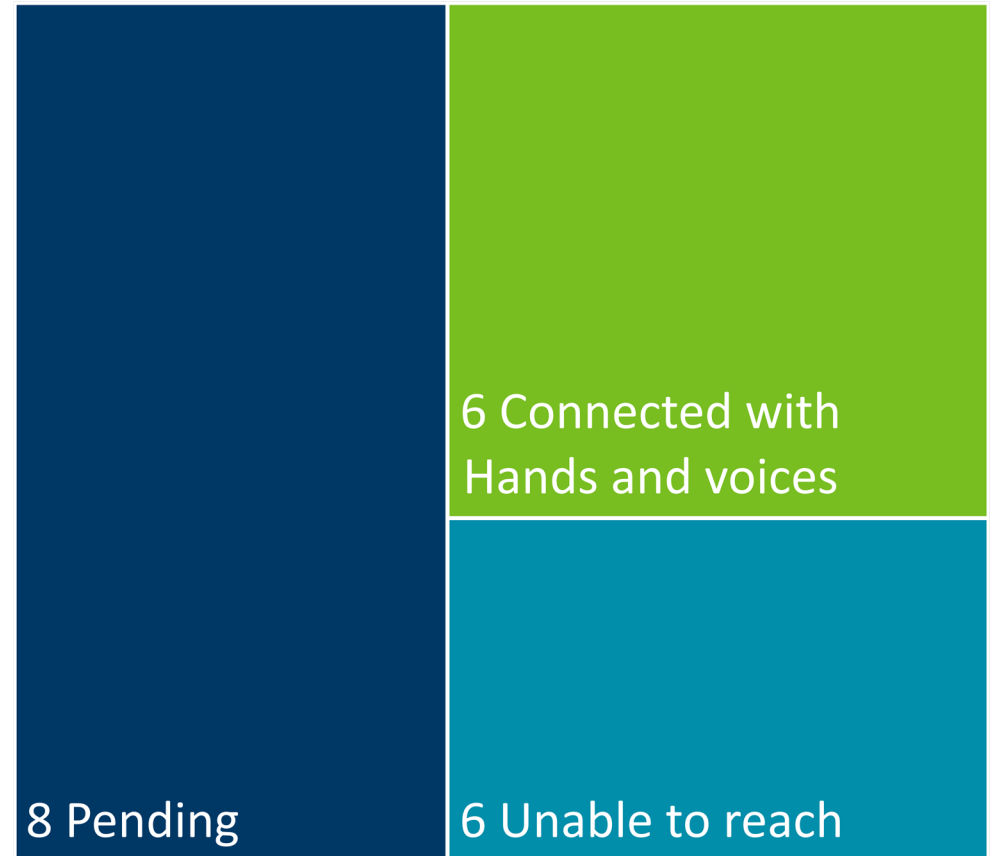
- Pilot program for parent-to-parent support in collaboration with Minnesota Hands and Voices (MNHV)
- Families included
  - Have a child classified as “symptomatic” regardless of hearing status
  - Have a child with cCMV and a permanent hearing difference
- Connection between family and MNHV is via direct referral from MDH – utilize an electronic referral process in MEDSS
- Contacted by the cCMV parent guide via phone call and are offered 1:1 support
  - Conversations are parent-led
  - List of questions available to parent guide, if needed to facilitate conversation
- Results of phone contact are documented in MEDSS



# Parent Support Pilot Project Data

- Very early in the project
- So far, most parents
  - Wonder what they can expect in the future
  - Feel angry that they didn't know about cCMV
  - Appreciate the contact
- Currently planning project evaluation

20 Referrals to MN Hands and Voices



# Capacity Building, Systems Evaluation & Improvement

- Sharing information, receiving feedback, providing updates to multiple interested partners
  - EHDI Newborn Hearing Screening Advisory Committee
  - Statewide EHDI meeting
  - Minnesota Hands & Voices
  - Educational Audiologists
  - Statewide Deaf/Hard of Hearing Advisory Committee
  - Local Public Health Nurses
  - Regional Local Public Health Association Directors
  - Follow Along Program staff
  - Statewide Interagency Early Intervention Committee
  - Early Education/Child care providers
  - MDE Part C Coordinator



# Public Health Surveillance

# cCMV Surveillance

- cCMV surveillance cases

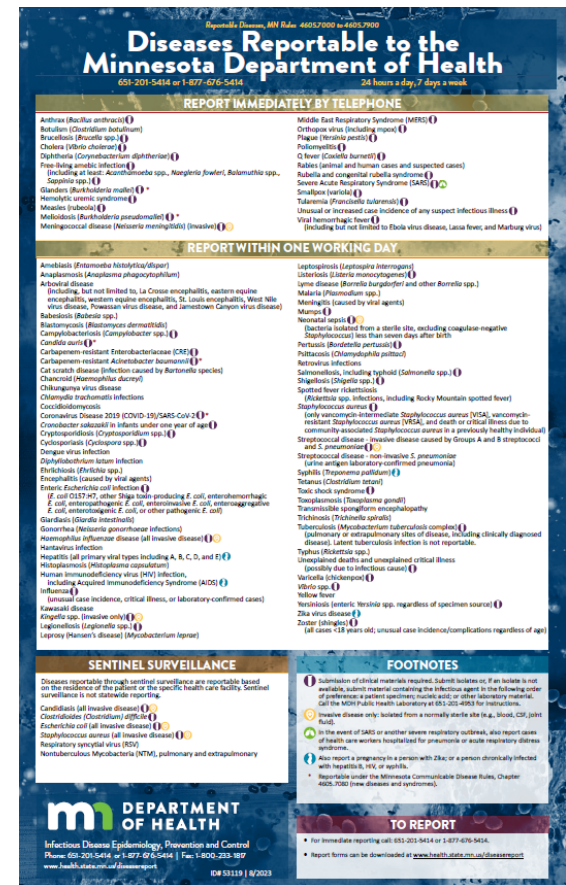
- Cases that are lab confirmed

- Positive blood, Urine, or CSF PCR (collected within 21 days of life)

- MN resident

- LFU is currently following 102 babies identified with cCMV all identified through newborn screening

- cCMV will soon be included on Minnesota's reportable communicable conditions list



- Determine time points we will be collecting data
- Determine variables we are interested in collecting
- Build database to store the data

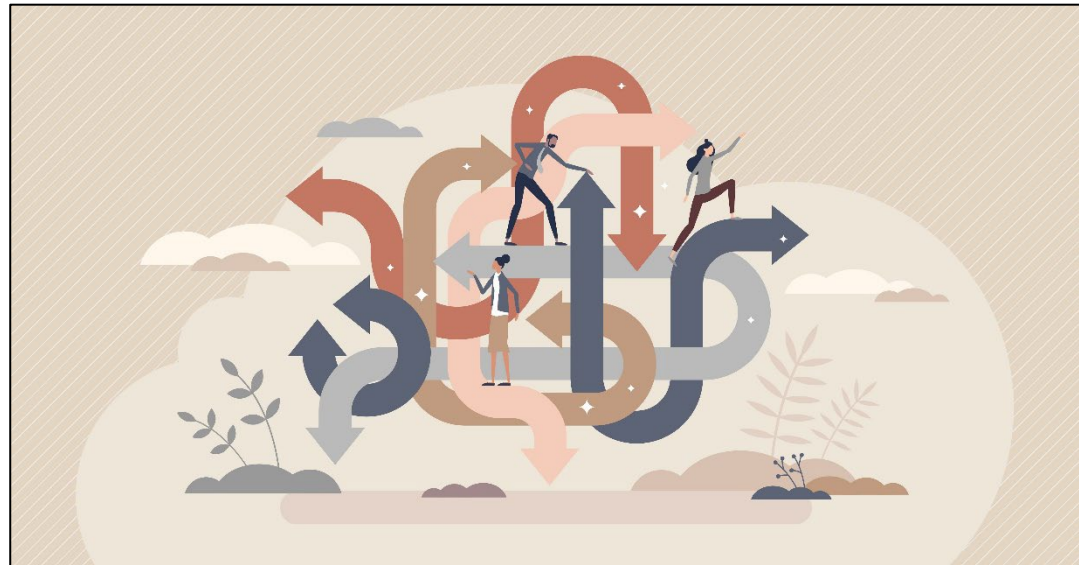


# Data collection points

- Data abstraction at 6 months – those with incomplete short term follow up
  - **20 cases – did not complete all elements of diagnostic evaluation**
  - **Only collecting data not found during short term follow up**
- Data abstraction for all cases - begin after 1 year – start March 2024
- Infant follow up time points requested by CDC SET-NET
  - 2m, 6m, 12m, 18m, 24m, 3years
  - Tentative plan – request and abstract data at 15months, 27months, and >3years



- Still finalizing data elements that we will collect
  - Will bring to cCMV consortium for input
  - CDC SET-NET contacts





# Proposed Longitudinal Data Elements

- Mortality and cause of death, if known
- Primary and/or condition-specific health care status
- Comorbidities
- Condition specific treatment measures (e.g. length of antivirals)
- Hearing status
- Vision status
- Maternal/pregnancy data

- Developmental status
- Referral for developmental delay/concerns or receiving developmental services
- Referral to early intervention
- Educational status
- Currently reviewing SET-NET data dictionary for additional elements to include

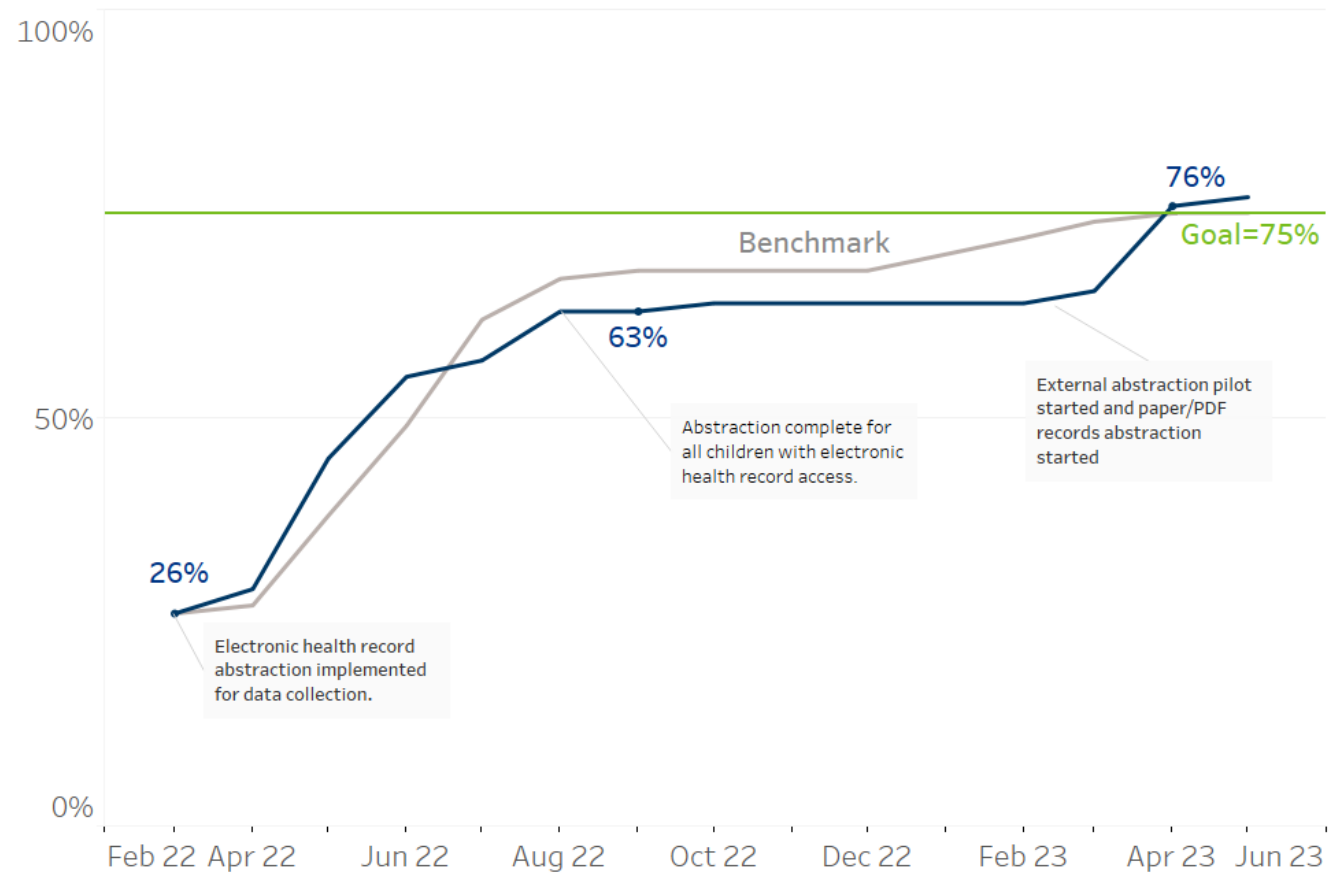
# Data Sources

- Vital Records
- Medical Records
- Exploring additional data sources
  - Case report forms
  - Family interviews
  - Educational data
  - Maternal pregnancy records



## Grant Aim: Percentage of data elements collected for children born in 2017 or with CCHD born January-June 2018

(Includes 1c, 1d, 2a, 2c, 2c.ii, & 2f)



- MDH uses MEDSS for most surveillance programs across the department
- MEDSS is a person centric disease surveillance system
  - Interoperable with newborn screening
  - Able to receive electronic lab reports from private labs throughout the state
- While starting our cCMV surveillance, will use REDCap rather than MEDSS
  - Can build quickly and make changes easily; no informatics or IT support required
  - Will have reports that can easily be imported into MEDSS
- Will eventually transition into MEDSS
  - Used by LFU surveillance/follow up, as well as most other MDH programs



Minnesota Department of Health

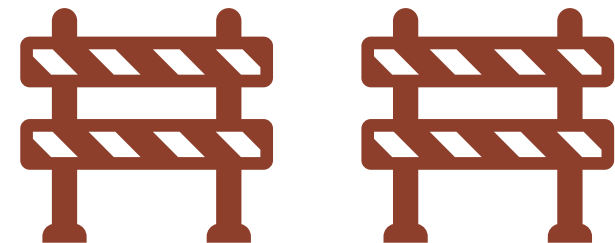
Electronic Disease Surveillance System Terms and Conditions of Use.

By logging on to the Minnesota Electronic Disease Surveillance System (MEDSS) you are acknowledging that you are an authorized representative of either the Minnesota Department of Health (MDH) or one of its stakeholders, that you are bound to comply with the agreement signed between MDH and the organization to which you belong, and that you will abide by Minnesota Statutes Chapter 13 and the Minnesota Government Data Practices Act.

If you do not agree to be bound by the terms and conditions, promptly exit this application.

# Challenges

- CSTE Case definition was just approved
- Newborn screening and surveillance case definitions are not the same
- Understanding developmental status is difficult – only source is health records
- Don't currently have access to all medical records
- Finding mom's record might be challenging
- People move, making it hard to find records



# Questions?



[health.mn.gov/CMV](https://health.mn.gov/CMV)

# Thank You

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