

FLORIDA DEPARTMENT OF HEALTH

Florida's Early Experience Implementing Targeted Congenital Cytomegalovirus (cCMV) Screening



Florida
HEALTH

CMV Public Health and Policy Conference
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TOPICS

- Legislative requirements
- Implementation approach and activities
- Early implementation experience
- Lessons learned
- Next steps

Legislative Requirements

cCMV SCREENING

- Section 383.145, Florida Statutes, was amended to require cCMV screening beginning January 1, 2023, for infants who do not pass the newborn hearing screen.
- Legislation requires:
 - Point-of-care cCMV screening for hospital births.
 - Expedited hearing screening referrals for birthing center and home births.
 - Primary health care provider (PCP) referrals for outpatient cCMV testing.
 - cCMV screening reported to the Department of Health within seven days.

Implementation Approach and Activities

IMPLEMENTATION APPROACH

Phased implementation approach:

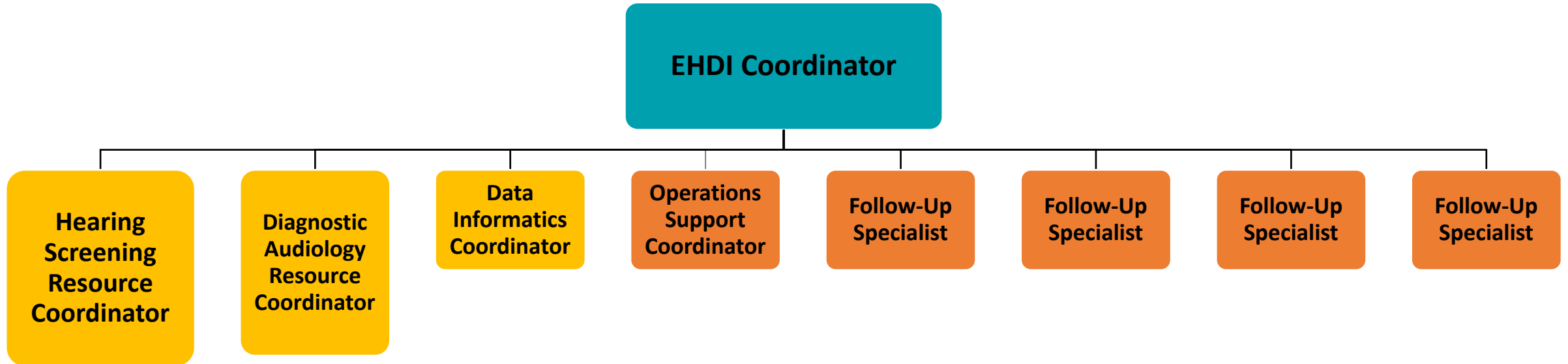
- Phase I (July to December 2022): Build capacity for screening, electronic reporting, and specialized follow-up.
- Phase II (January to June 2023): Implement specialized follow-up, develop resources, and build capacity for data analysis.
- Phase III (July 2023 to present): Analyze data and implement system refinements.

IMPLEMENTATION APPROACH

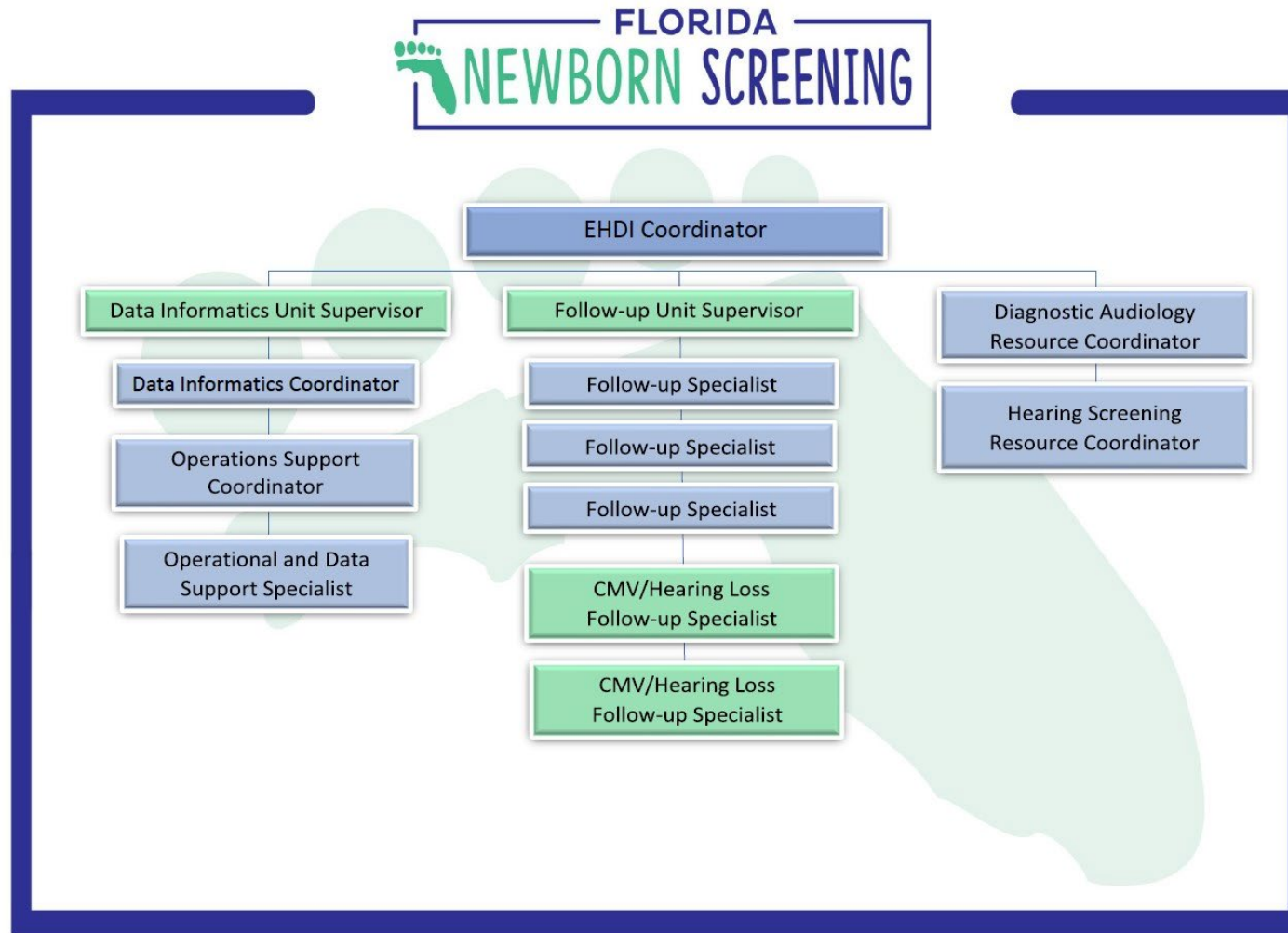
Phase I activities included:

- Developing cCMV stakeholder education and training resources.
 - <https://floridanewbornscreening.com/conditions/hearing-2/congenital-cytomegalovirus-ccmv/>
- Restructuring the EHDI Program to support specialized follow-up.
- Developing follow-up procedures and workflows.

IMPLEMENTATION APPROACH



IMPLEMENTATION APPROACH



IMPLEMENTATION APPROACH

Phase II activities include:

- Develop and implement cCMV referred hearing data system workflow.
- Draft standard operating procedures for follow-up.
- Manually analyze data to provide targeted training and technical assistance.
- Update frequently asked questions based on early implementation experience.

IMPLEMENTATION APPROACH

Phase III activities include:

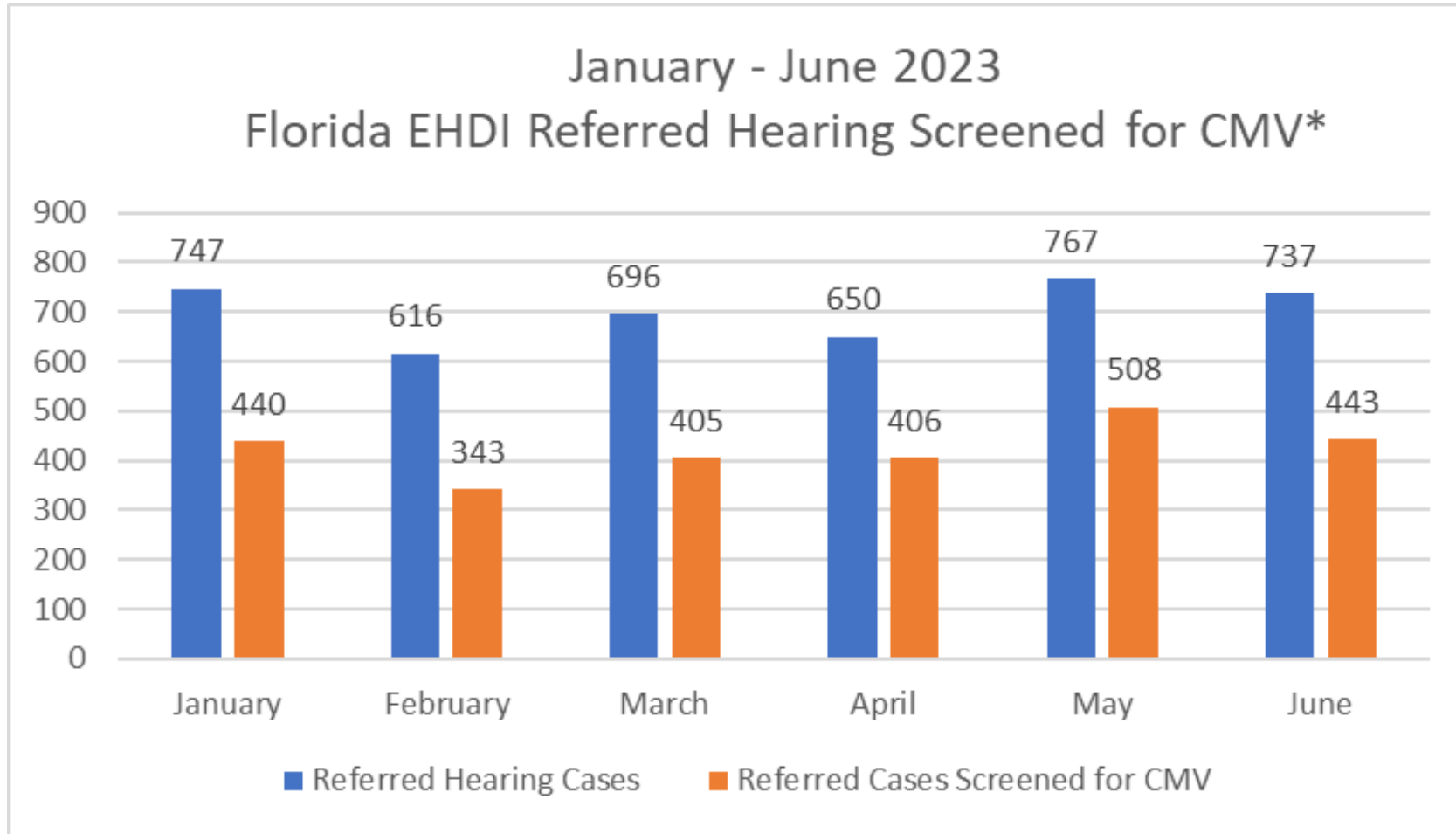
- Update existing automated data reports and develop new reports.
- Regularly analyze data to conduct continuous quality improvement activities.
- Disseminate performance data to stakeholders.

Early Implementation Experience

SCREENING AND REPORTING

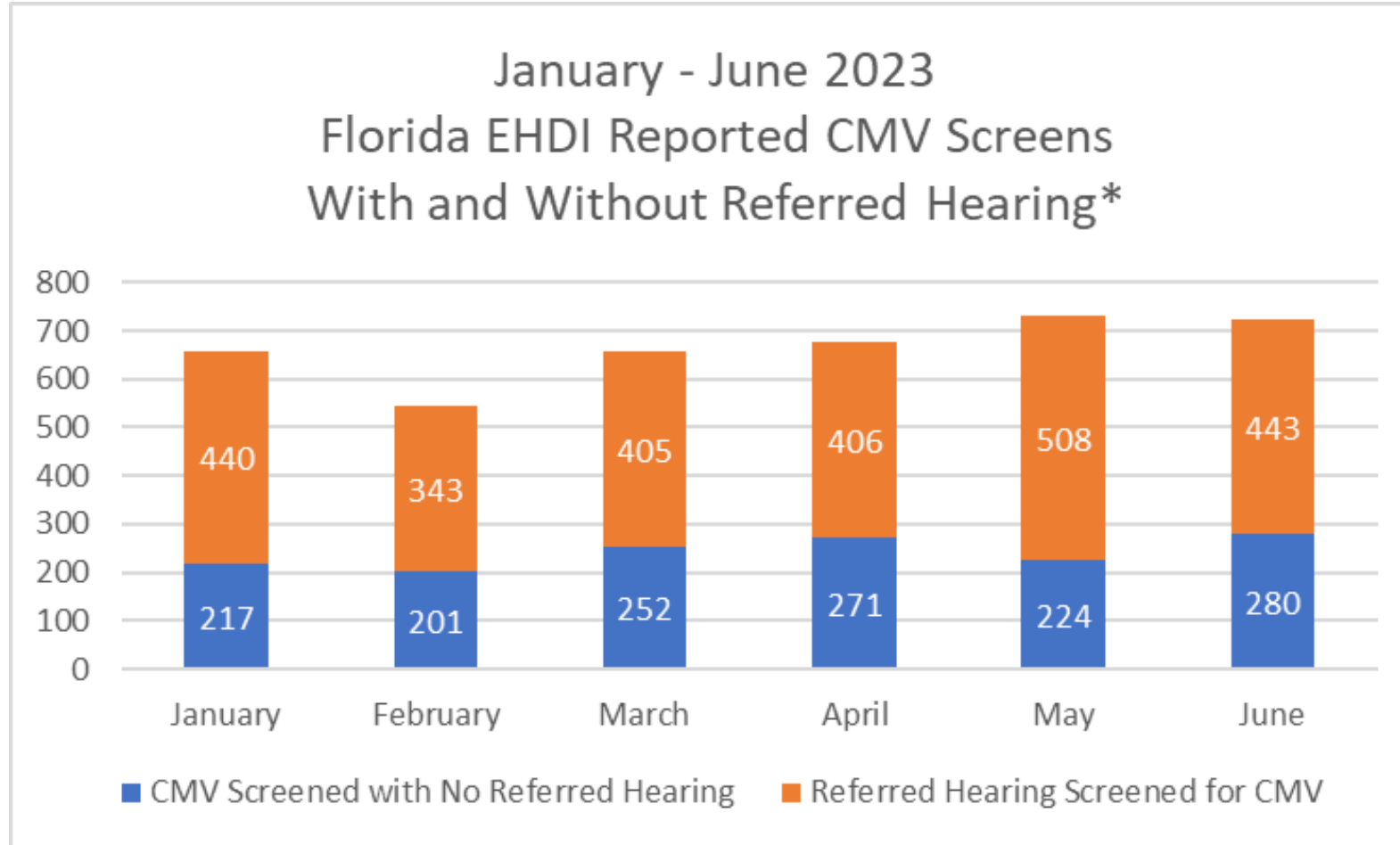
- Hospitals conduct cCMV screens prior to discharge or before 21 days of age for newborns who fail the hearing screen, whichever is earlier.
- Birthing centers and home birth providers refer newborns for a hearing screen within seven days of birth.
 - For birthing center and home births, PCPs refer newborns for cCMV screens following a failed outpatient hearing screen.
- cCMV screening results are reported by hospitals and PCPs through eReports™ CMV Module.

SCREENING AND REPORTING



*Provisional Data

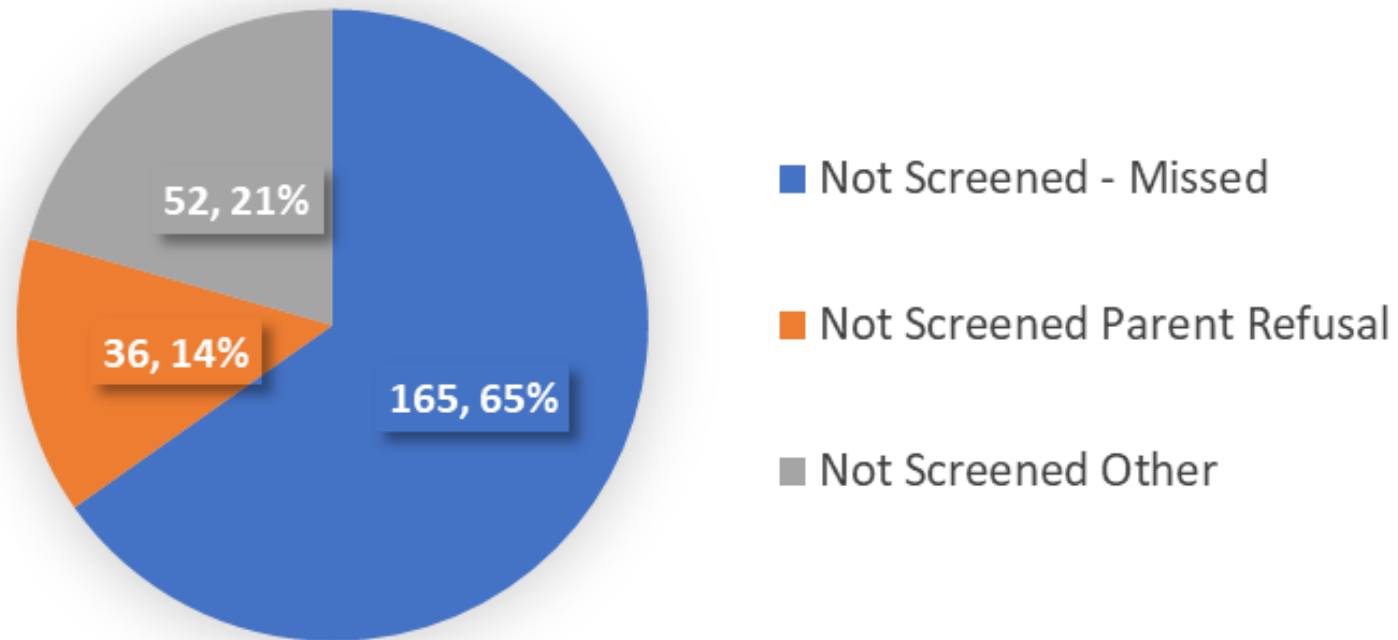
SCREENING AND REPORTING



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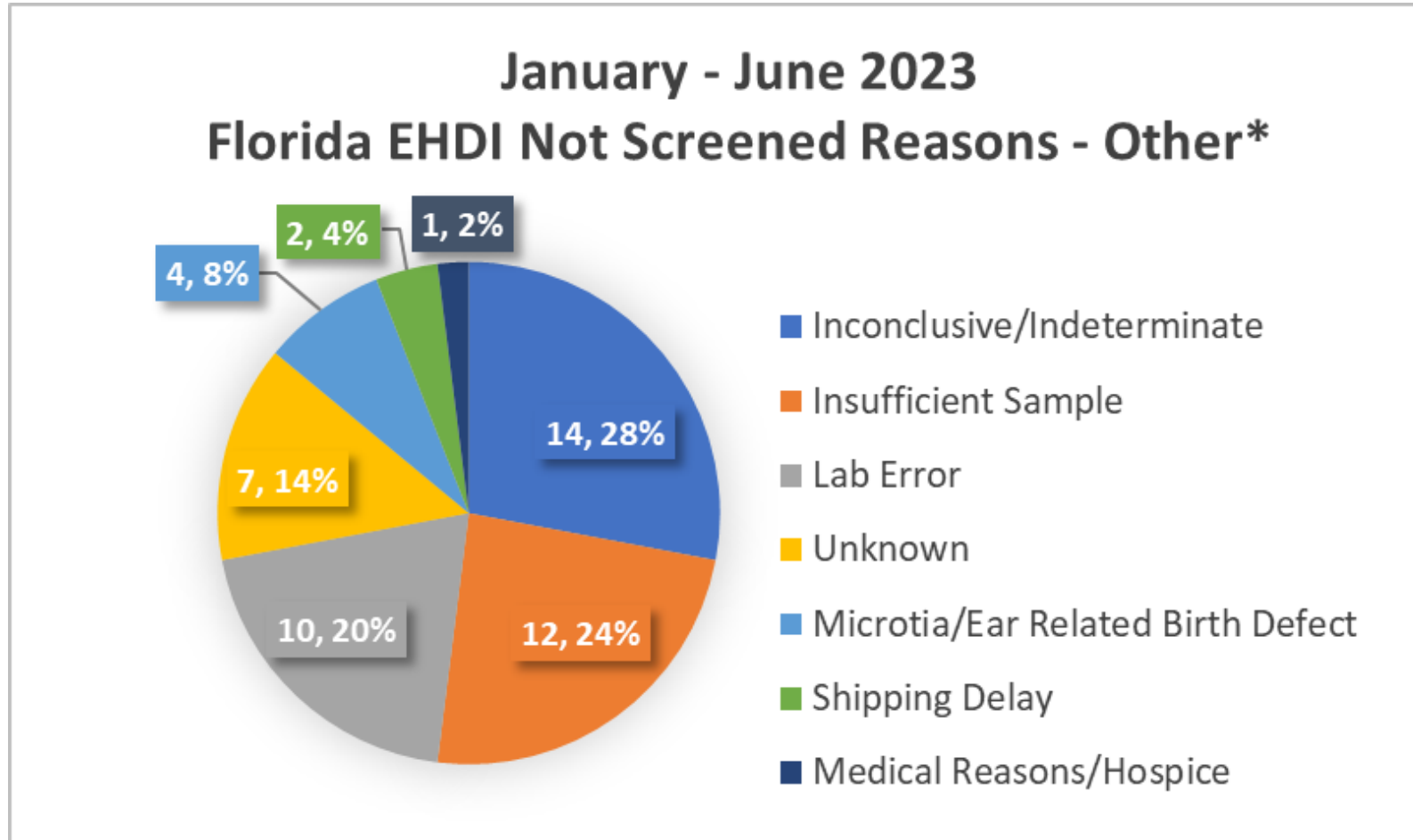
SCREENING AND REPORTING

January - June 2023 Florida EHDI Not Screened Reasons*



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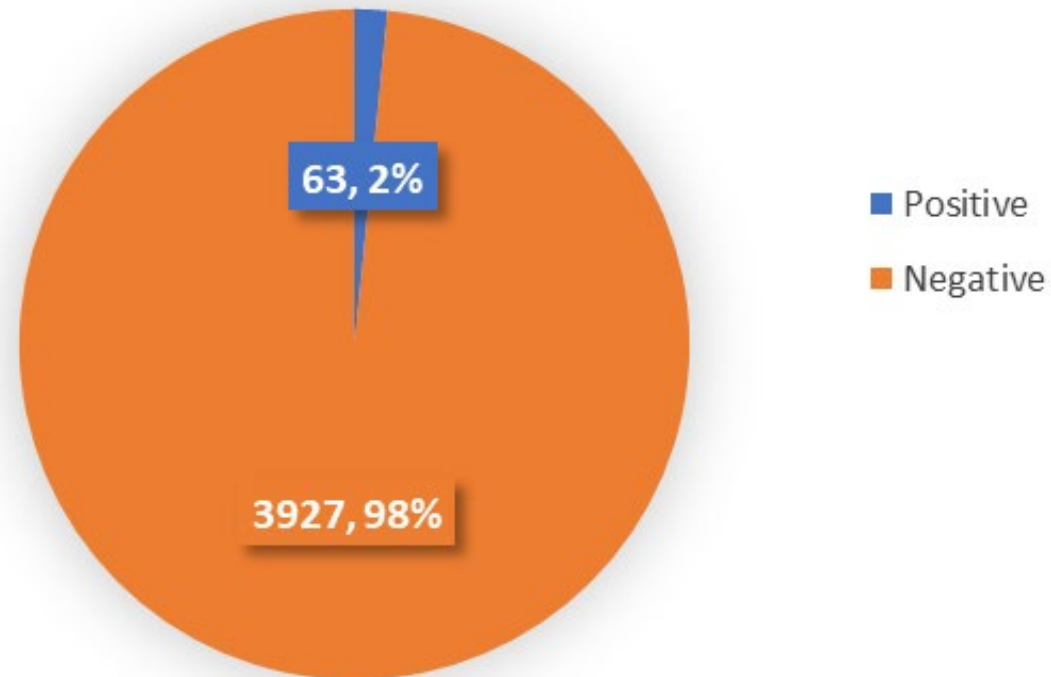
SCREENING AND REPORTING



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SCREENING AND REPORTING

January - June 2023
Florida EHDl CMV Positive vs. Negative Results*



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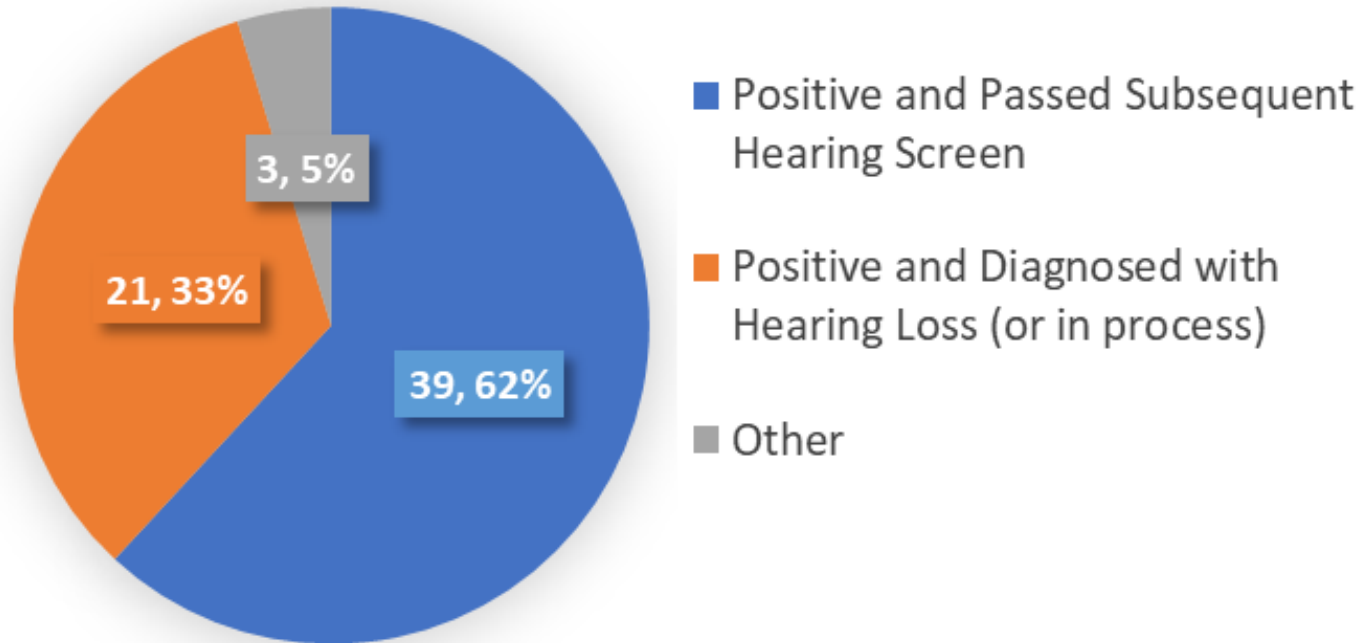
FOLLOW-UP

Follow-up procedures for positive cCMV screens include:

- EHDI staff contact the neonatal intensive care unit or the newborn's PCP.
- EHDI staff refer newborns diagnosed with cCMV to the Early Steps program.
- EHDI staff continue follow-up for infants who do not pass their hearing screens through diagnosis.

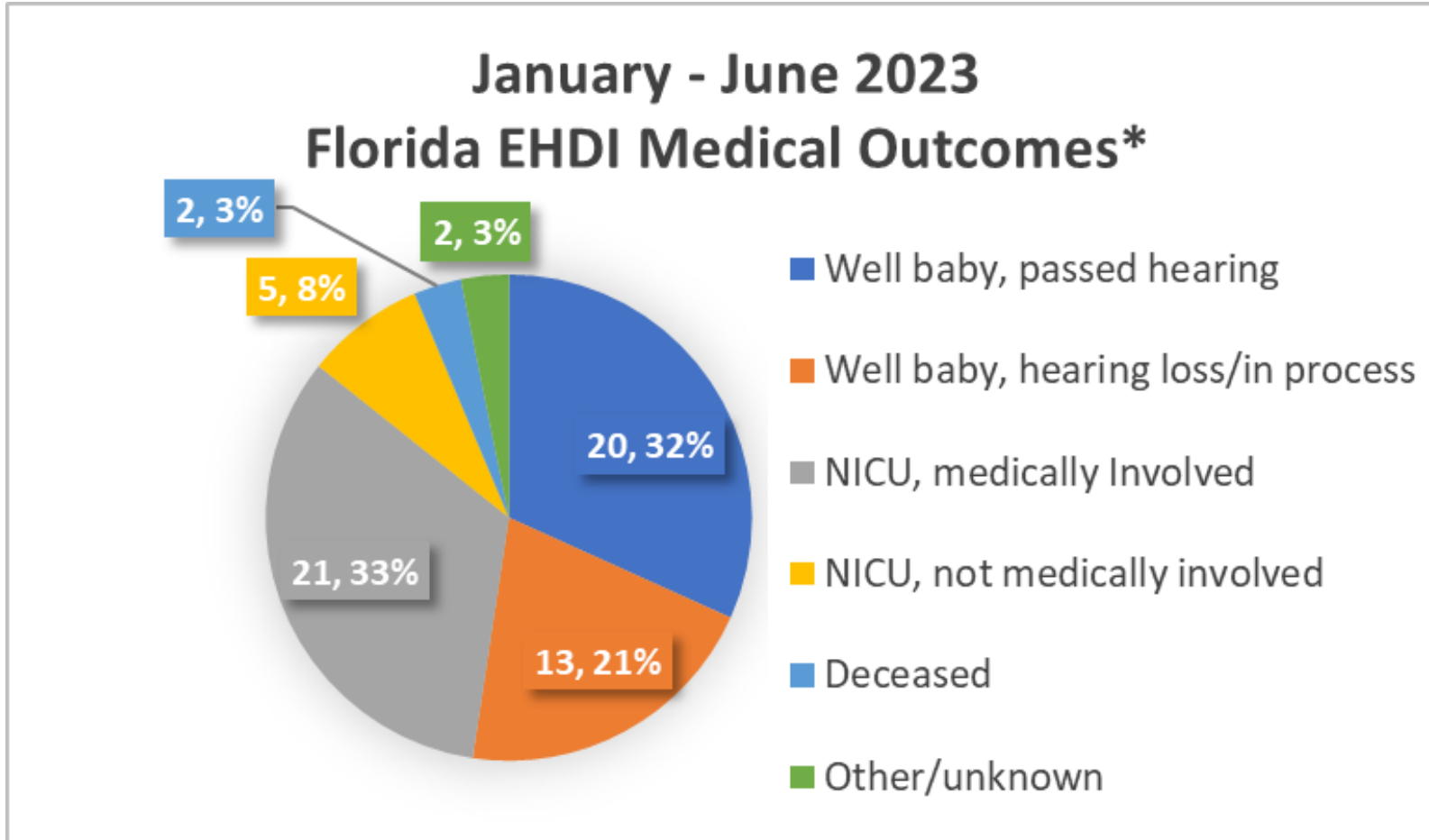
FOLLOW-UP

January - June 2023 Florida EHDl CMV Hearing Outcomes*



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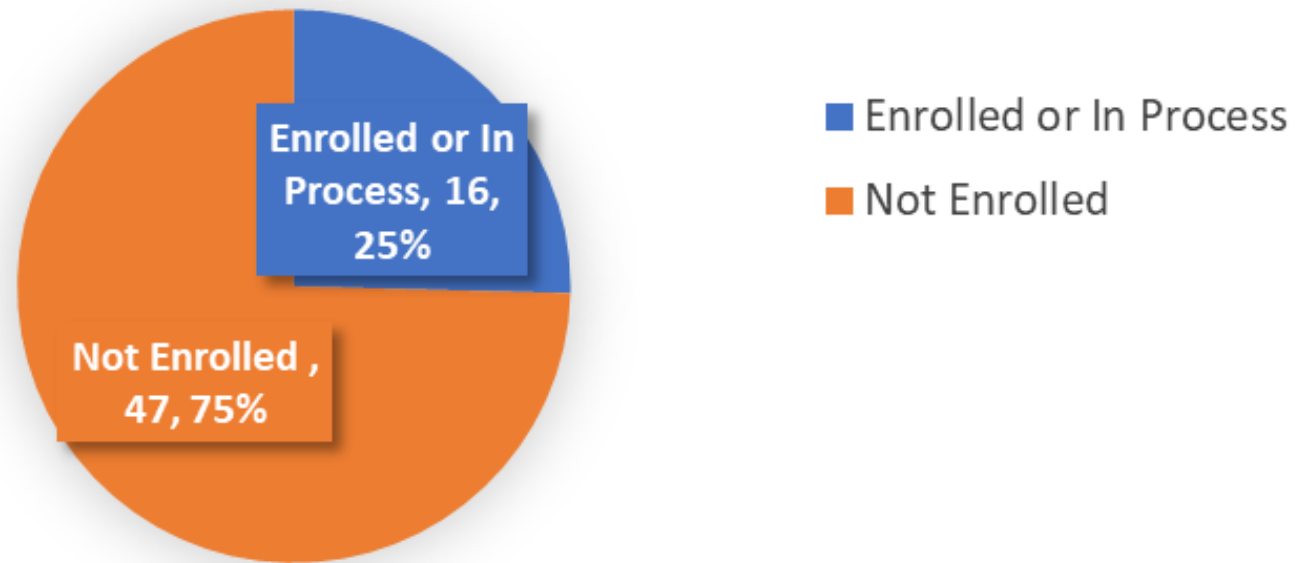
FOLLOW-UP



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FOLLOW-UP

January - June 2023 Florida EHDI CMV Positive Early Intervention Enrollment*



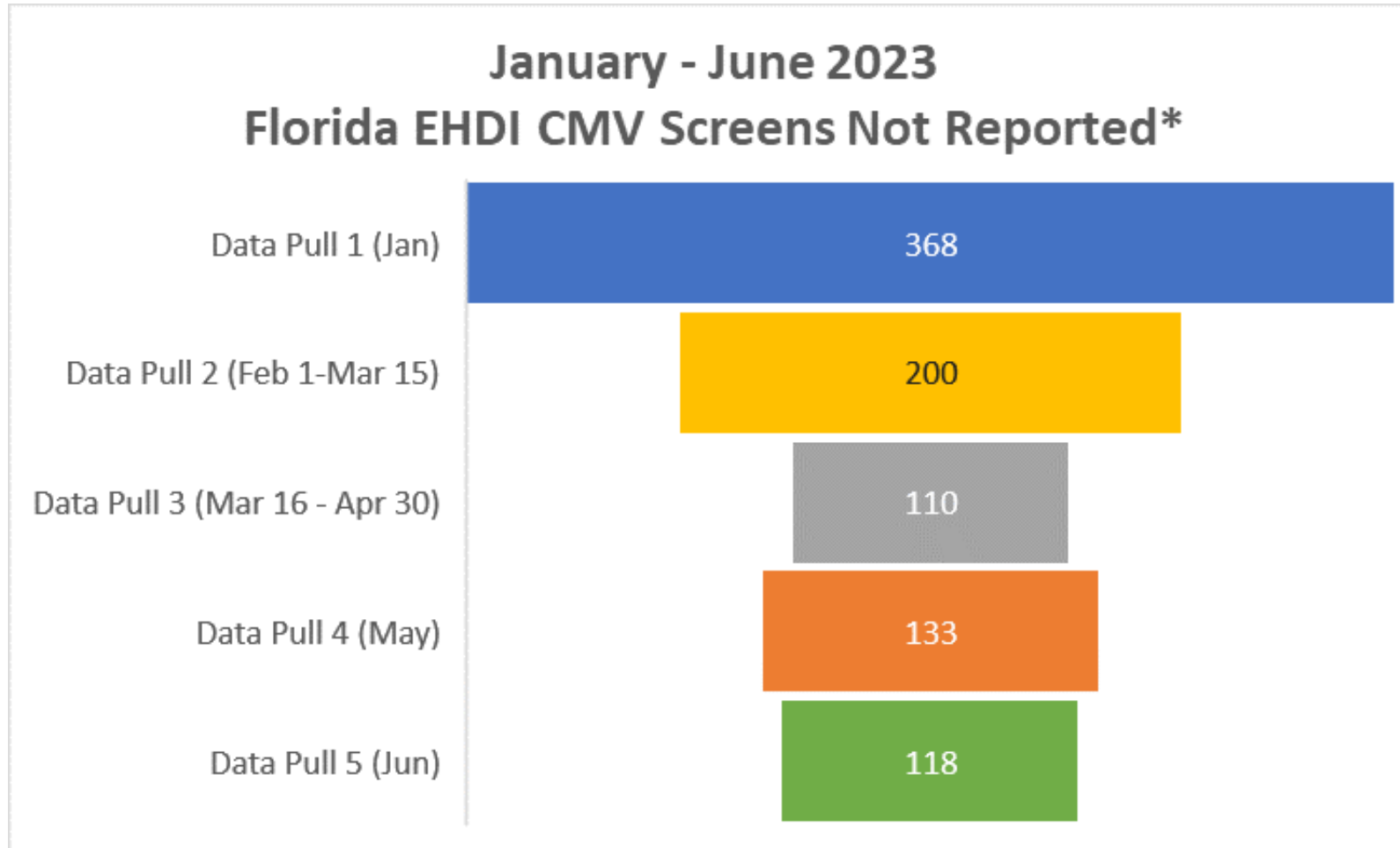
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TRAINING AND TECHNICAL ASSISTANCE

Training and technical assistance activities include:

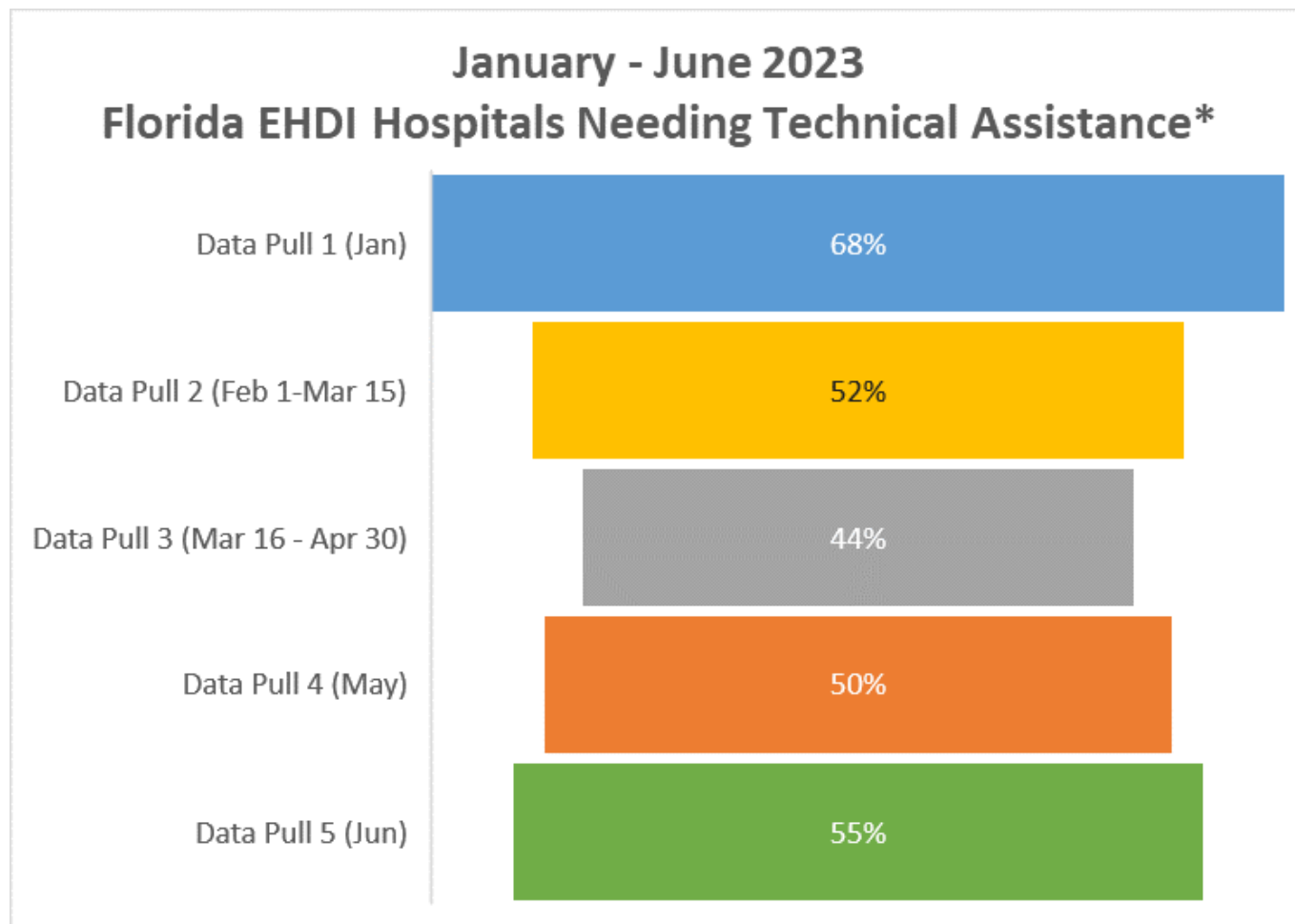
- Provision of individualized training and technical assistance.
 - Email
 - Virtual and in-person site visits
- Regular review of reported data.
 - Outreach for cases not reported
- Updates to available website resources.
 - Frequently asked questions
 - eReports CMV Reporting Module

TRAINING AND TECHNICAL ASSISTANCE



*Provisional Data

TRAINING AND TECHNICAL ASSISTANCE



*Provisional Data

Lessons Learned

LESSONS LEARNED

- Engage the state-level Newborn Screening Program during planning.
 - Follow-up approach differs from EHDI follow-up.
 - Has established emergency contacts for NICUs and large PCP offices.
- Disseminate universal resources in the just-in-time style.
- Compile written copies of local stakeholder cCMV screening and reporting protocols to assist with data analysis after screening launch.
- Educate and engage audiologists on:
 - Need for timely outpatient hearing screens to facilitate cCMV screening.
 - Recommendations for ongoing evaluation for cCMV positive infants.
 - Access to view cCMV screening results for infants in their care.

LESSONS LEARNED

- Consider how hearing screening data reporting will impact the expected number of cCMV screens.
- Create data entry fields and selections for:
 - Inconclusive/indeterminate results
 - Insufficient samples
 - Lab errors
 - Shipping delays
 - Hospice
- Provide clear definitions for data entry fields to ensure valid and reliable reporting.
- Make reporting module registration available prior to launch.
 - Plan for a surge of registrations after launch.

LESSONS LEARNED

- Create staffing capacity to address surge of stakeholder needs just prior to and directly after launch.
- Ensure adequate sustained staffing for key cCMV related functions:
 - Training and technical assistance for cCMV screening and reporting
 - Follow-up for positive newborns
 - Data analysis and continuous quality improvement
- Create internal resources to support consistent messaging at the state level.
 - Frequently asked questions document
 - Bank of previous email responses

LESSONS LEARNED

- Prepare to provide varying levels of ongoing training and support for stakeholder groups.
 - Innovators
 - Early adopters
 - Early majority
 - Late majority
 - Laggards
- Prepare to provide PCP education about cCMV screening, confirmatory testing, and available resources.
 - [https://www.nationalcmv.org/resources/educational-downloads/downloads/cm-v-newborn-roadmap-\(1\).aspx?ext=.pdf](https://www.nationalcmv.org/resources/educational-downloads/downloads/cm-v-newborn-roadmap-(1).aspx?ext=.pdf)

LESSONS LEARNED

- Consider how to facilitate continuity of care for hearing follow-up for cCMV positive infants.
 - Give audiologists view-only rights for cCMV screening and most recent hearing evaluation results.
- Stay within your program scope and expertise.
 - Leave facility decisions up to the facility.
 - Identify available experts willing to consult.
 - Engage the EHDI Advisory Committee.

Next Steps

NEXT STEPS

- Automate and formalize the cCMV screening data validation process.
- Refine and expand cCMV data searches.
- Continue to provide virtual and in-person targeted training and technical assistance for late adopters.
- Update available resources based on stakeholder feedback.
 - Frequently asked questions
 - cCMV virtual training

QUESTIONS?

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www.floridanewbornscreening.com

