

# Early intervention referral and enrollment among Utah's cCMV cases

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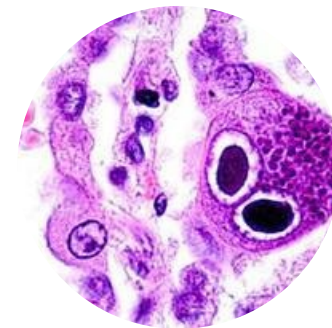
# Learning objectives

1. Describe referral and enrollment statistics for early intervention services among Utah's cCMV cases
2. Explain the breakdown of early intervention enrollment and referrals among each cCMV case classification category
3. List the primary indications for referral among cCMV cases, as well as reasons cases did not enroll in early intervention services

# Overview: Utah EHDI programs



Early Hearing Detection and  
Intervention (EHDI)



**Congenital Cytomegalovirus  
(CMV) Public Health Initiative**



Children's Hearing Aid Program  
(CHAP)

# Utah's CMV testing

- Hearing targeted



- High-risk targeted



# Hearing targeted

## Utah CMV legislation

- 26B-7-105 UCA, “Cytomegalovirus (CMV) Public Education and Testing” (effective 7/1/2013)
  - If a newborn **fails the newborn hearing screening test(s)**... medical practitioner shall test the infant for **CMV before 21 days of age**
- R398-4, “Cytomegalovirus Public Health Initiative”
  - CMV testing if... infant fails **both** initial and follow-up hearing screen
  - Or, initial screen is failed after **14 days** of age
  - Or, fail initial screen and no repeat screen before **14 days** of age
  - Practitioners must report results to DHHS within **10 days** of receiving them
- R386-702, “Communicable Disease Rule” (effective 2015)
  - **All laboratory results** for... CMV in infants less than or equal to **12 months of age** must be reported electronically to DHHS

# High-risk targeted

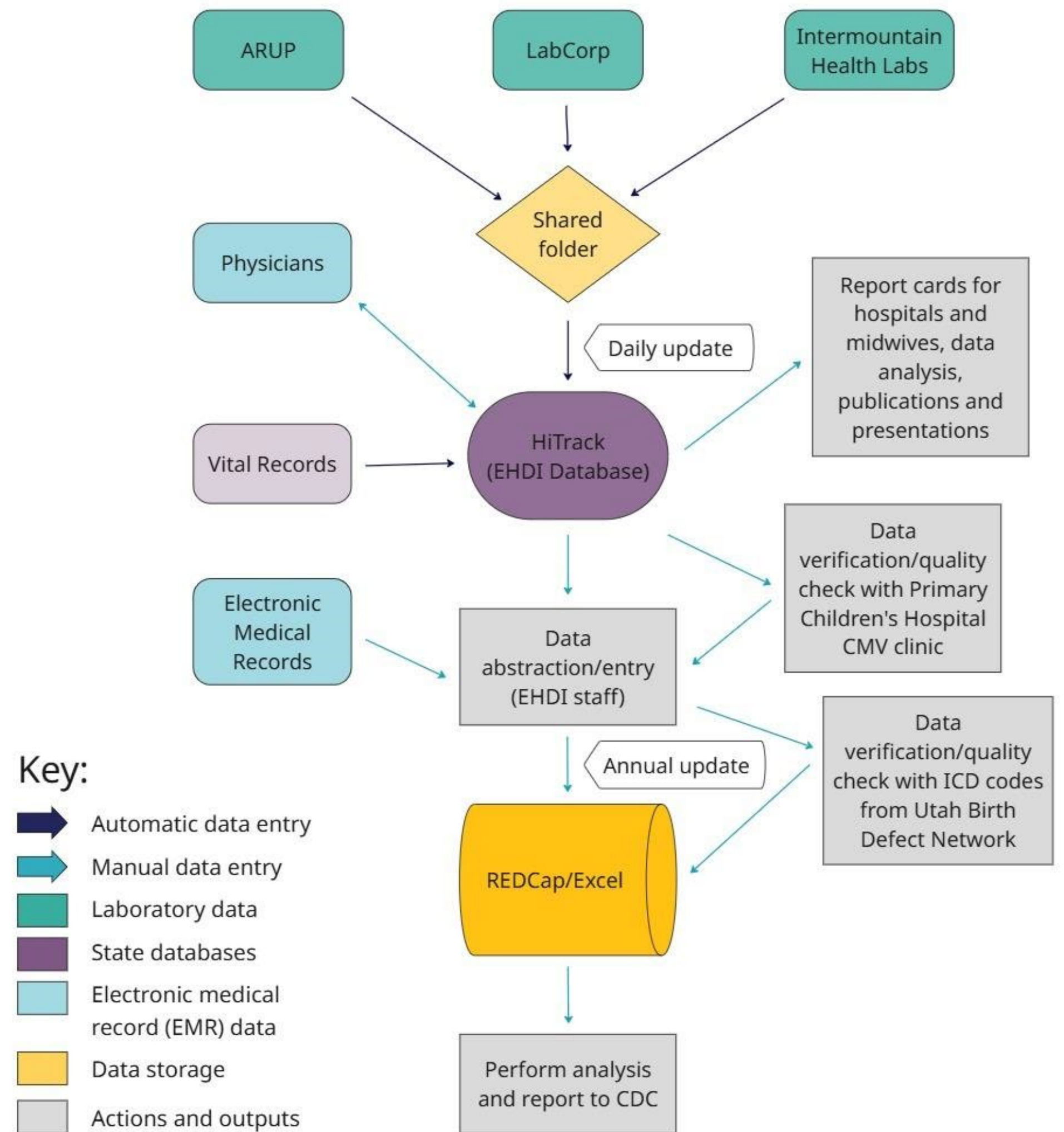
Intermountain Health hospitals adopted high-risk testing protocol in 2019

## If any of the following present:

- 1) Mother positive for CMV infection during pregnancy
- 2) Abnormal head size (OFC <10<sup>th</sup> %ile OR >90<sup>th</sup> %ile at birth)
- 3) Intrauterine growth restriction (weight <10<sup>th</sup> %ile for gestational age)
- 4) Unexplained hydrops
- 5) Intracranial OR intraabdominal calcifications on first imaging exam
- 6) Unexplained hepatomegaly OR splenomegaly (>1 cm below the right or left costal margin)
- 7) AST or ALT >100 U/L OR unexplained direct bilirubin >1.0 mg/dL
- 8) Petechial rash or blueberry muffin rash at any time
- 9) Leukomalacia, polymicrogyria, lissencephaly, pachygyria, schizencephaly
- 10) Unexplained persistent thrombocytopenia (platelets < 100k/mm<sup>3</sup>)
- 11) Failed hearing screen

**Send urine CMV PCR**  
(obtain by 21 days of life when possible)

# Case ascertainment/ abstraction process



# Council for State and Territorial Epidemiologists (CSTE)

## cCMV classification: clinical criteria

Present during neonatal period:

- Hepatomegaly
- Splenomegaly
- Petechial rash or purpura



Present in child aged 6 years or younger:

- Microcephaly
- Brain imaging abnormalities
- Sensorineural hearing loss
- Seizures
- Cerebral palsy
- Chorioretinitis
- Vision impairment

# CSTE cCMV classification: laboratory criteria

## Confirmatory laboratory evidence:

- Positive CMV result on urine, whole blood, or CSF within 21 days
- Positive amniotic fluid specimen, autopsy specimen








## Presumptive laboratory evidence:

- Positive CMV result on urine, whole blood, or CSF within 22-42 days
- Positive saliva result within 42 days

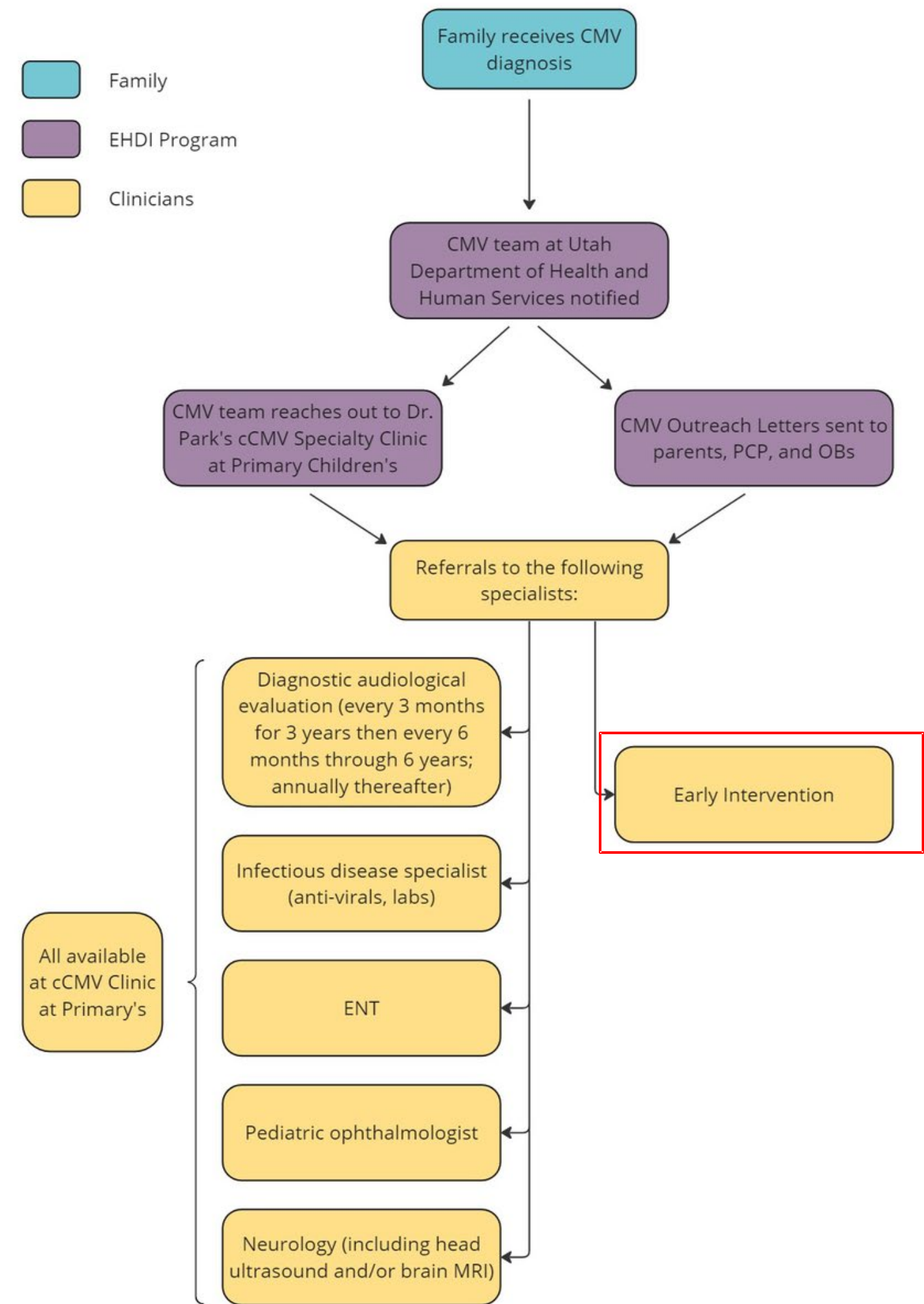


Absence of a negative urine result collected within 21 days of life

# CSTE cCMV case classification

Laboratory evidence	Clinical criteria	Classification
Confirmatory laboratory evidence 	<u>No</u> clinical evidence	Confirmed <u>infection</u>
Confirmatory laboratory evidence 	<u>Clinical</u> evidence 	Confirmed <u>disease</u>
Presumptive laboratory evidence 	<u>Clinical</u> evidence 	Probable <u>disease</u>

# Clinical side/referral process



# Early intervention



# Partnering with early intervention (EI) services

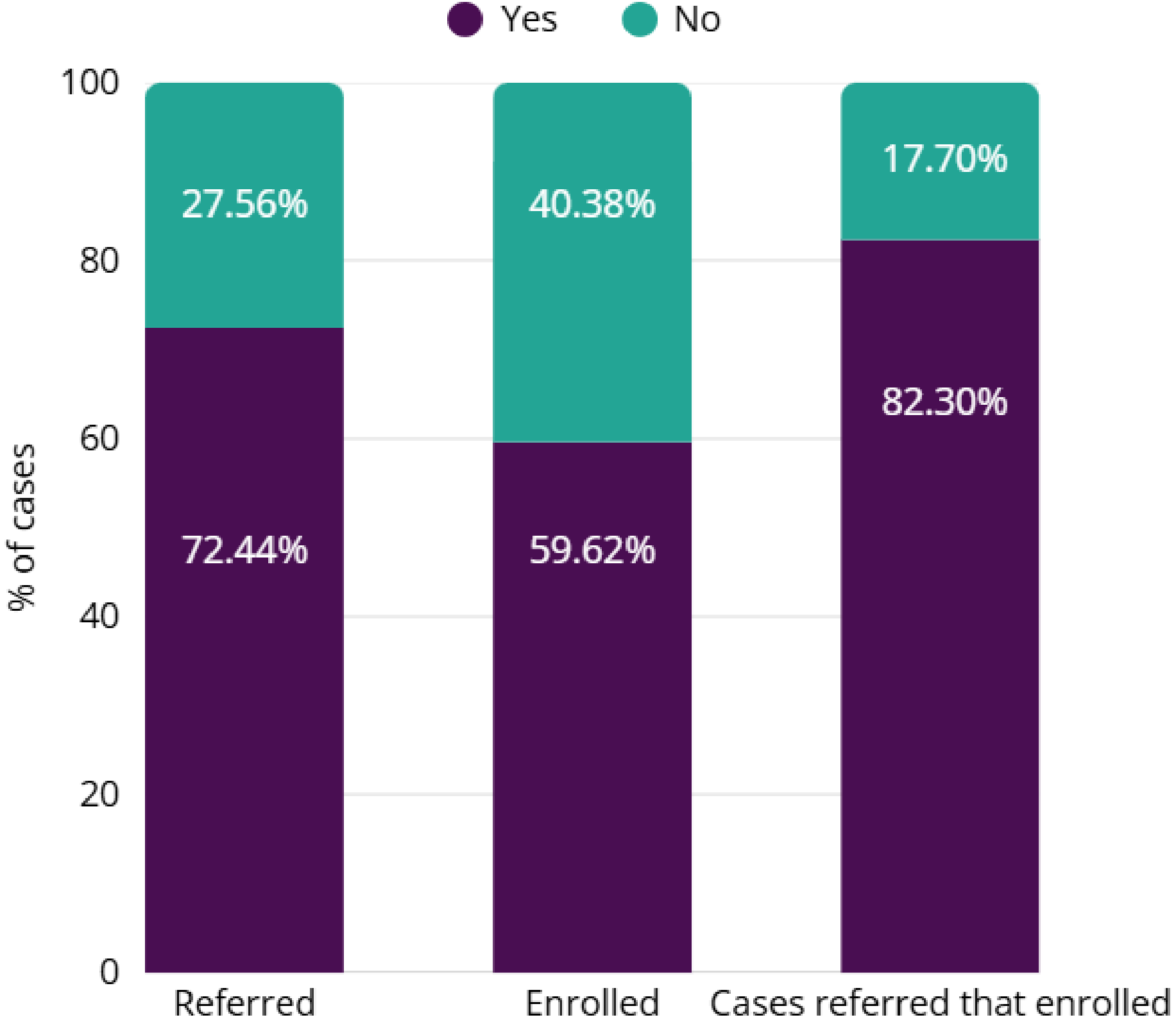
- Utah EHDI partnered with the state's Part C of IDEA early intervention lead agency, **Baby Watch Early Intervention Program (BWEIP)**
- Made cCMV a **qualifying diagnosis** for EI services shortly after CMV legislation was passed
- Utah EHDI has a data sharing agreement with BWEIP to collect EI data on cCMV cases



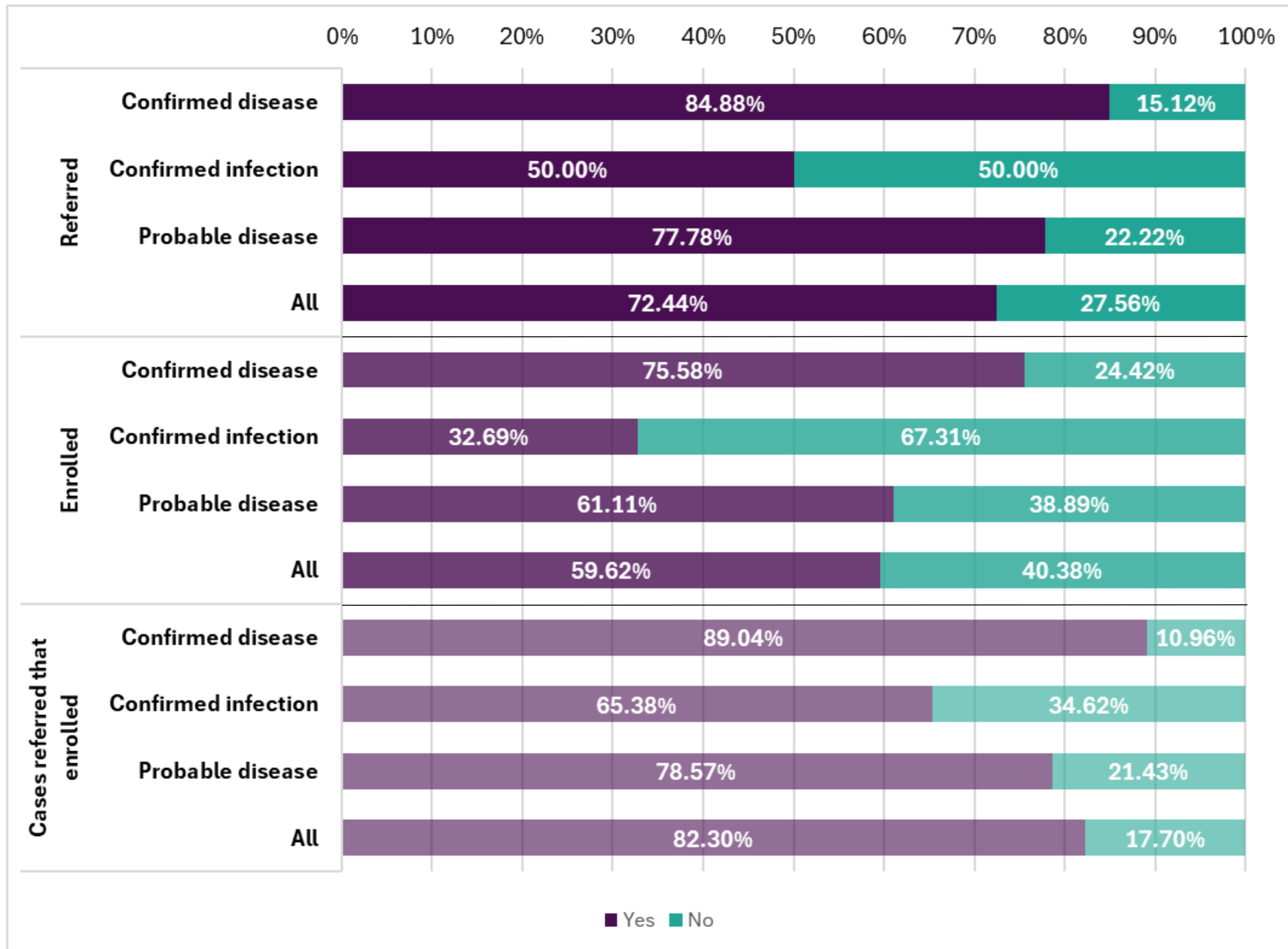
# Cases referred to and enrolled in EI



# # of all cCMV cases referred to and enrolled in EI



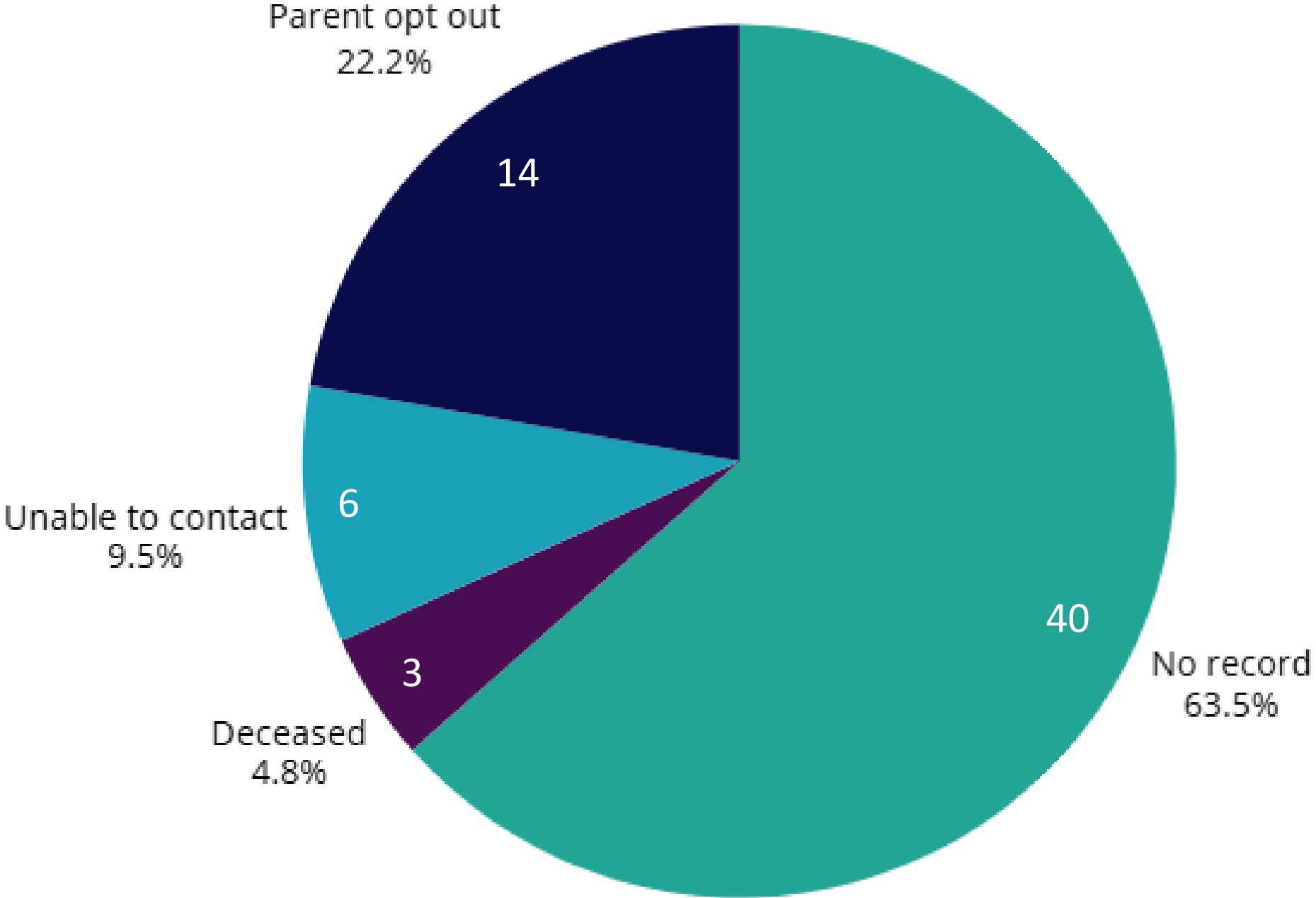
# % of all cases referred to and enrolled in EI, by case classification



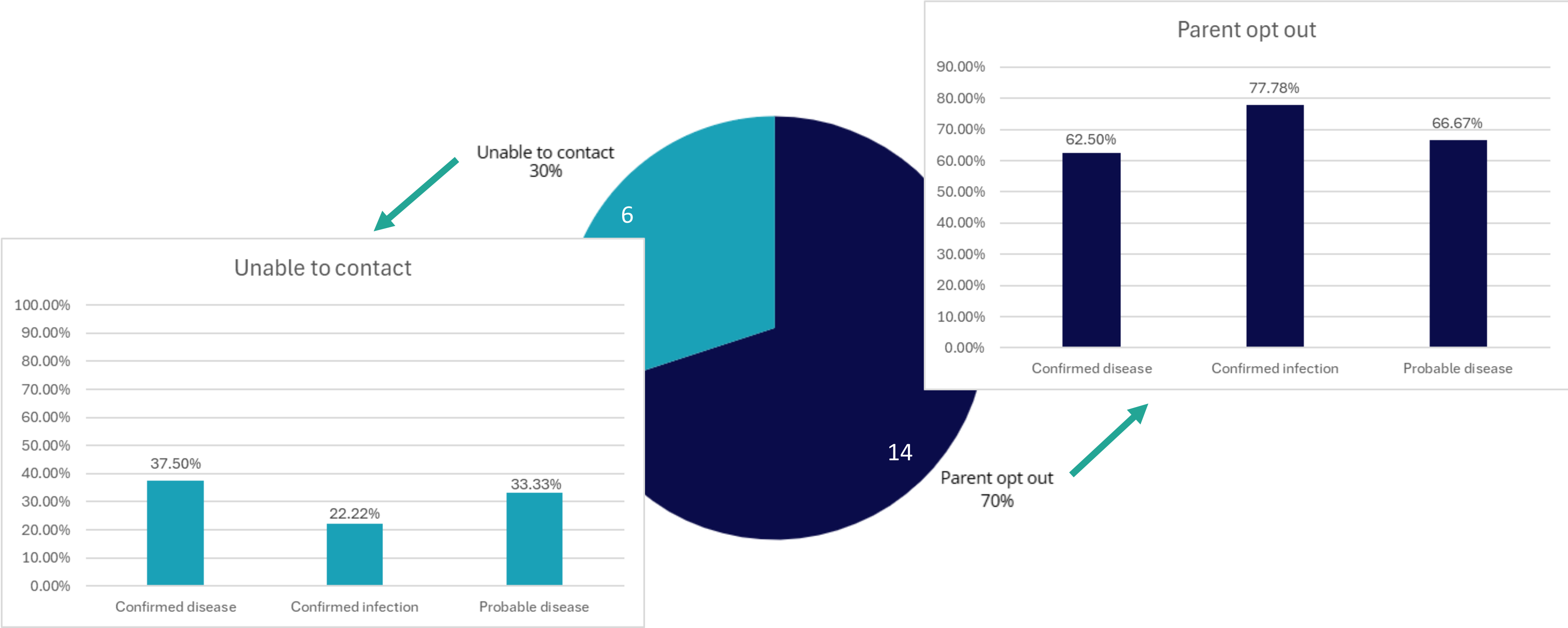
# Cases that did not enroll



# Reasons among **all** cases for not enrolling in EI (July 2013 - end of 2024)



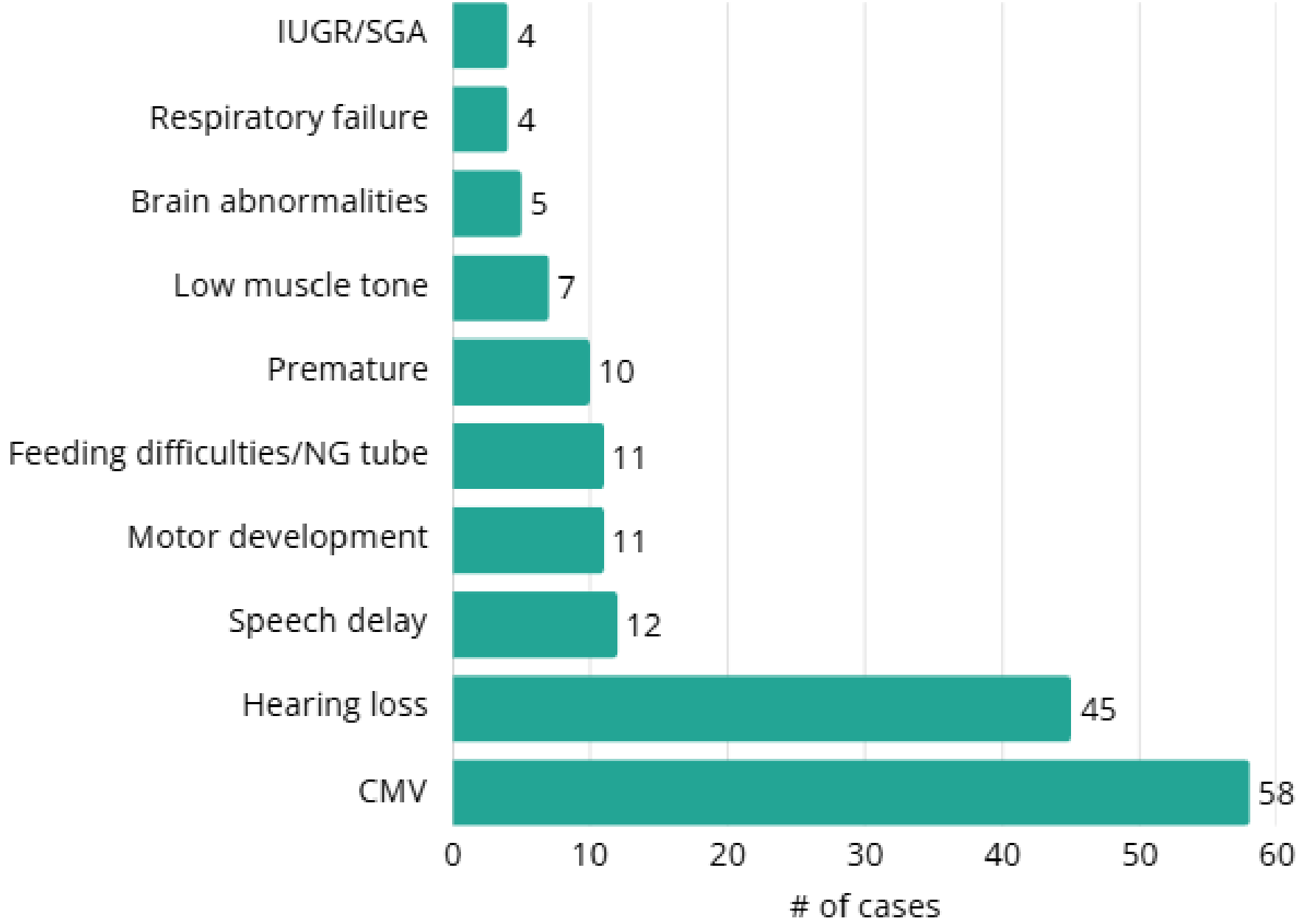
# Reason for not enrolling among those referred (July 2013 - end of 2024)



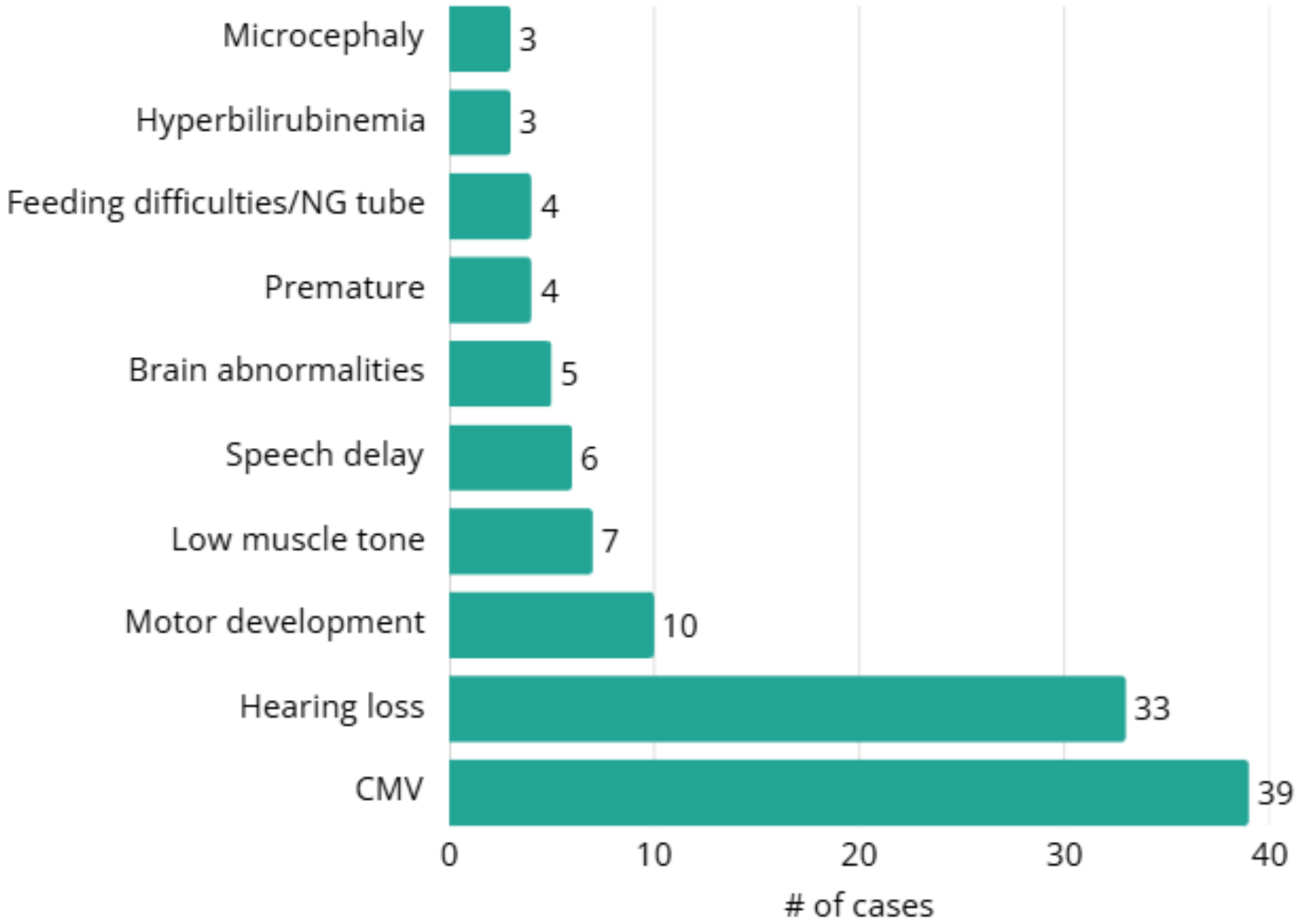
# Reason for referrals



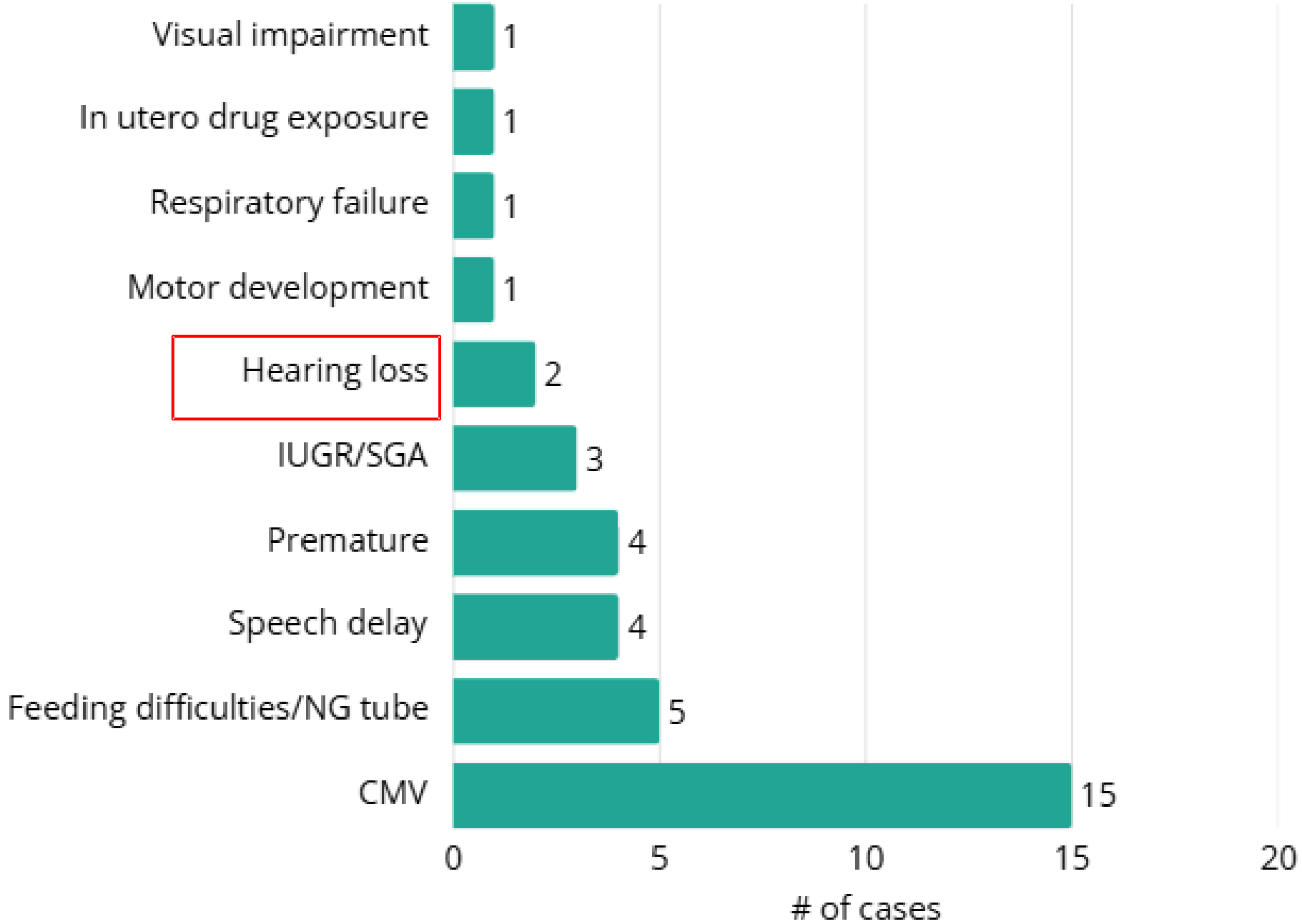
# Reasons for referral among **all** cases (July 2013 - end of 2024)



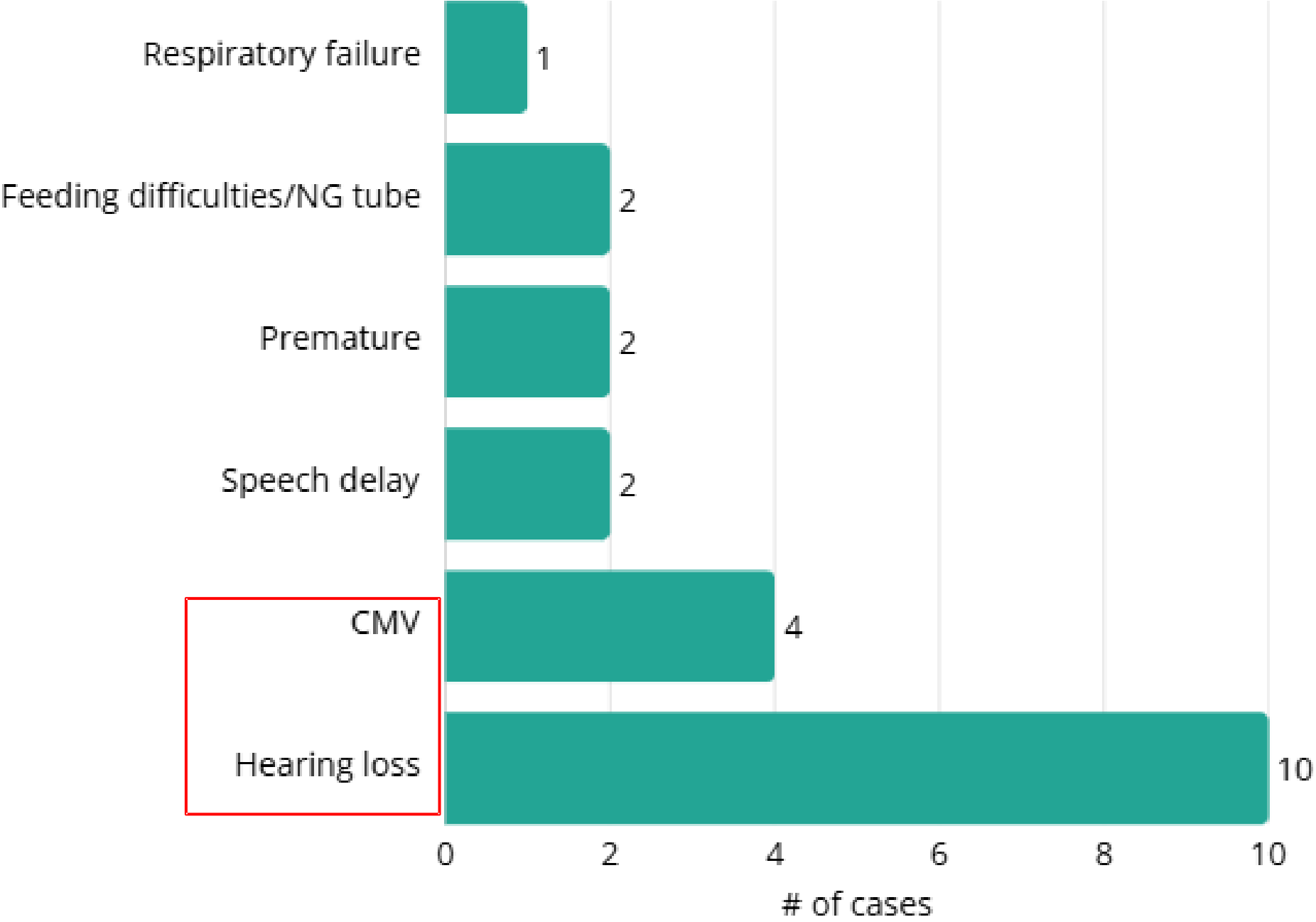
# Reasons for referral among confirmed disease cases (July 2013 - end of 2024)



# Reasons for referral among confirmed infection cases (July 2013 - end of 2024)



# Reasons for referral among probable disease cases (July 2013 - end of 2024)



# Of cases referred, % that mention CMV as a reason for referral (July 2013 - end of 2024)

All cases	51.33%
Confirmed disease	53.42%
Confirmed infection	57.69%
Probable disease	28.57%

# Of cases referred, % that were **only** referred because of CMV (July 2013 - end of 2024)

All cases	14.16%
Confirmed disease	16.44%
Confirmed infection	15.38%
Probable disease	0.00%

# Takeaways



# Takeaways

- Disease cases are referred and enrolling in EI at **greater** percentages than infection cases
  - Infection cases still at risk for developing symptoms
- Among those referred, **parents opting out** is the most common reason for not enrolling
  - More research is needed to understand why parents are opting out
- With CMV as a qualifying diagnosis, it is used **~50% of the time** as a reason for referral

# Thank you!

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