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Children's Hospital

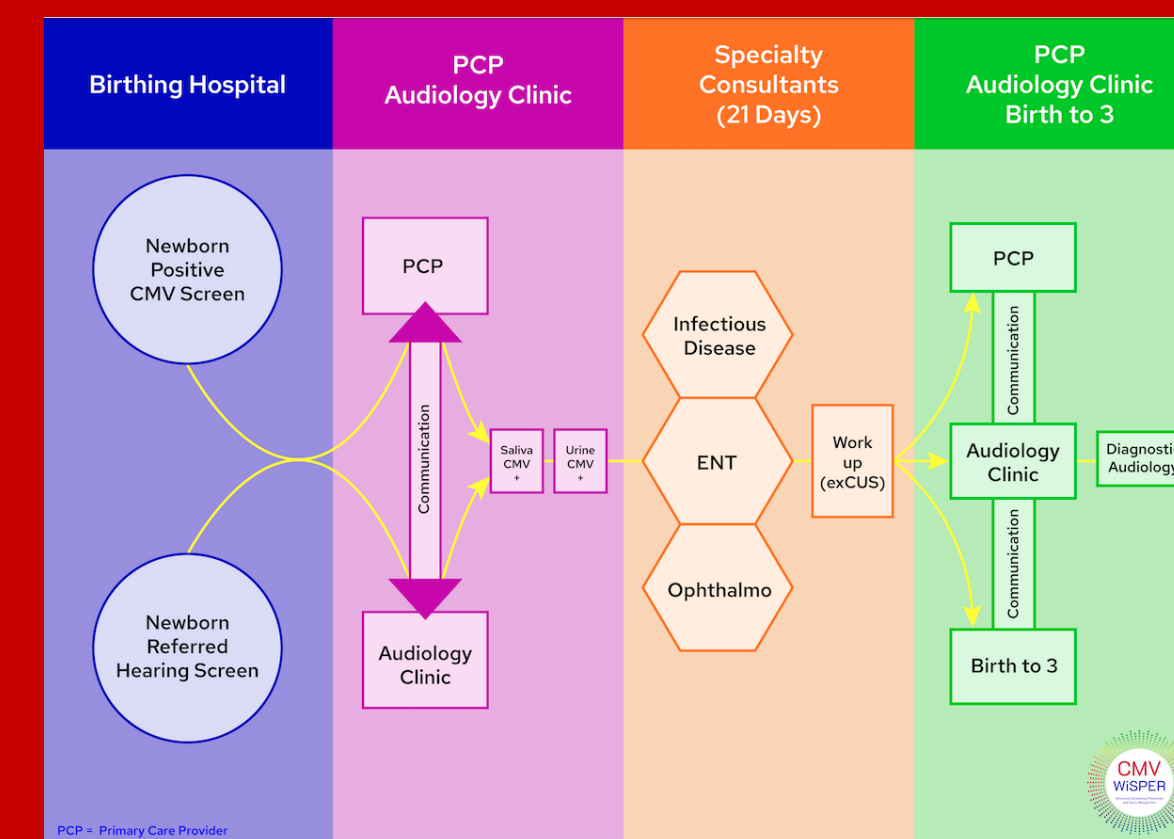


Department of Pediatrics
UNIVERSITY OF WISCONSIN
SCHOOL OF MEDICINE AND PUBLIC HEALTH

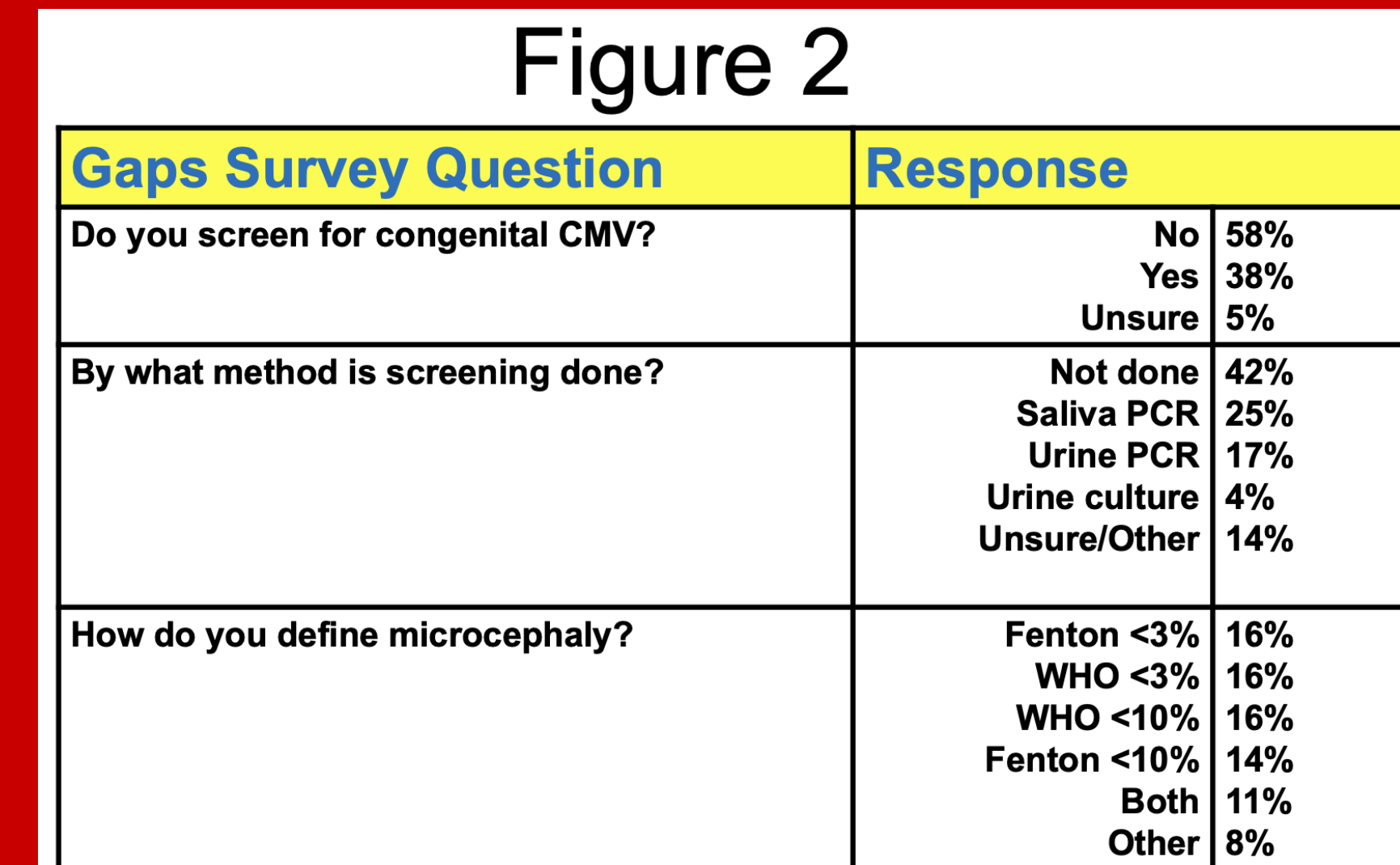
Departments of Pediatrics¹ University of Wisconsin-Madison, Madison, Wisconsin and Wisconsin
Department of Health Services.²

- The lack of a national consensus statement for congenital cytomegalovirus (cCMV) screening has led to wide variations in statewide screening practices.
- Wisconsin currently has no standard practice around cCMV screening, diagnosis and follow-up.
- The number of Wisconsin infants screened by saliva or urine PCR or diagnosed by retroactive NBS testing is largely unknown.
- A 2023 survey of Wisconsin birthing centers showed that 41% screened newborns for cCMV and only 15% had a written policy.

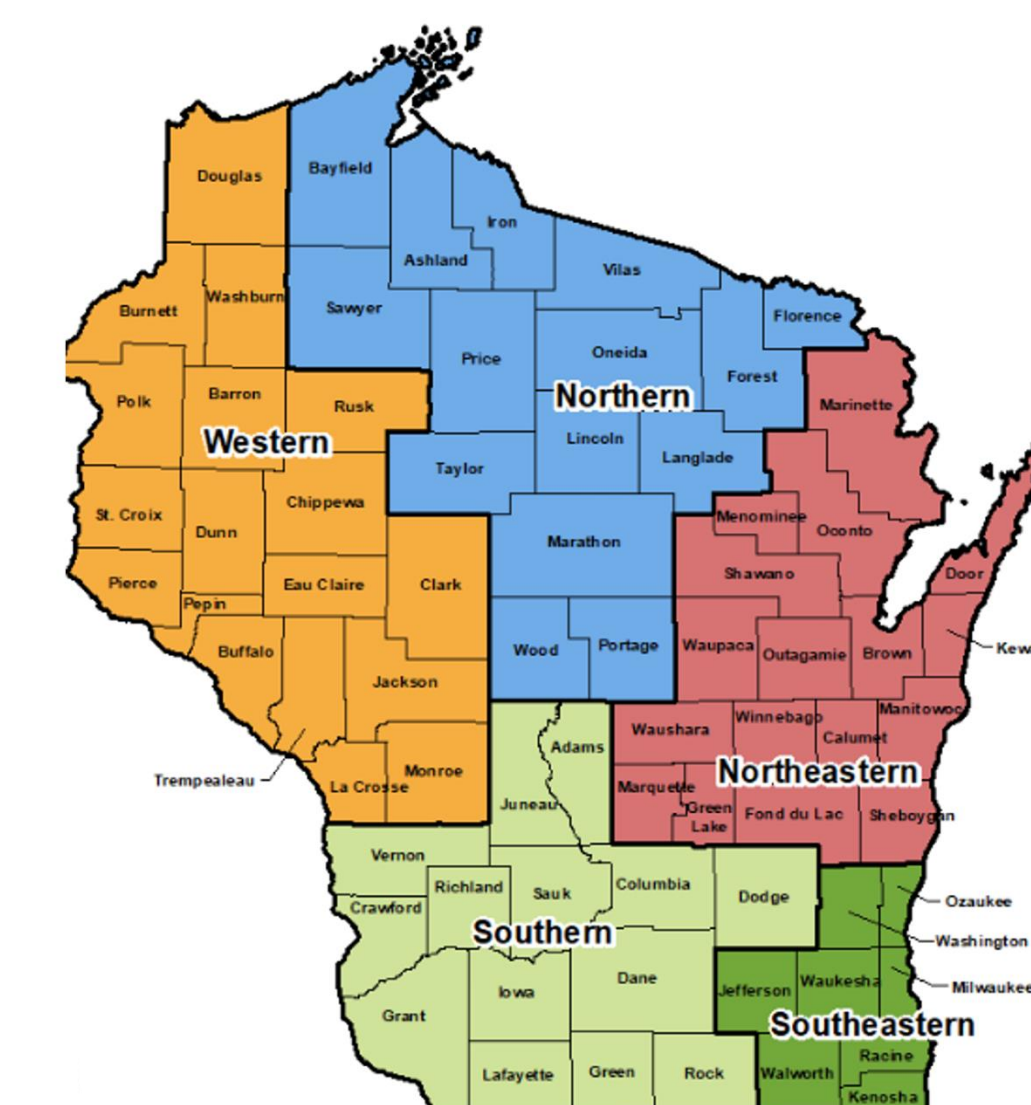
- The Wisconsin Department of Health Services (DHS) provided a grant to establish a statewide taskforce to identify gaps in care and develop cCMV screening recommendations.
- The **CMV WiSPER (Wisconsin Screening, Prevention and Early Recognition)** task force was led by staff in the DHS Birth Defects Prevention and Surveillance Program and co-investigators in the Dept of Pediatrics at UW Madison SMPH.
- In July 2024, **CMV WiSPER** recruited a statewide coalition of perinatal providers, audiologists, pediatric specialists (ENT and ID) and families with lived experience.
- From Nov 2024 to Jan 2025, birthing centers were surveyed to identify gaps in cCMV screening.
 - A Qualtrics survey was sent by email with follow-up calls to non-responders.
- Starting Jan 2025, audiology clinics are being surveyed to identify gaps in hearing follow-up.
- Families were engaged in all sessions.
- **CMV WiSPER** is conducting family focus groups to identify themes in family lived experience.




- The stakeholder group was multidisciplinary (Figure 1) with representation from the 5 regions in Wisconsin.
- “State-of-the-Art” talks on cCMV were done in 4/5 Wisconsin regions.
 - Talks were hybrid with **CMV WISPER** leaders visiting on site.
- Birthing Center Gaps Survey response rate was 70% (55/79) using email and follow-up calls.
 - Increased from 50% in 2023 (email only)
- Most birthing centers were small with level one nurseries.
- Primary respondents were nurse managers.
- Birthing Center Gaps Survey included 30 questions.
 - Figure 2 - selected responses
- Survey results and family lived experience will be used to inform development of statewide tools.
 - Sample draft of audiology workflow tool shown in Figure 3



Challenges	Lessons Learned
Scheduling	"Do No Doodles" – Leaders set meeting dates in advance- people will come
No central data base for cMNV screening results and QI studies	Explore options in birth defects and infectious disease reporting
Institutional restrictions on sharing guidelines/protocols	Limited access of protocols to leaders/workgroups for consensus development
Back to basics	For hearing-targeted screening, how many screens before referral to audiology?
Common language	In extended-screening such as microcephaly, how is it defined (growth curve and %)




Lived Experience in Families Affected by Congenital Cytomegalovirus Infection



**Tuesday, September 24
3-4 PM**

**Aspirus Wausau Hospital
Room 40-720-02
Birthing Center Classroom**

Webex seminar link:
<https://wiscnhs.zoom.us/j/92906550513?pwd=ZmVkdzRlZWpScUJMcUo0dDZkdjBldz09>



**Presented by the Wisconsin
Congenital CMV Stakeholder
group with support from the
Wisconsin Department of Human
Services**

- In 2024, less than half of Wisconsin birthing centers currently screen for cCMV.
- Grant funding was pivotal for project momentum.
 - Masters of Public Health (MPH) students (\$30/hr)
 - Family-lived experience (\$30/hr)
- What worked well.....
 - Stakeholders valued families-first orientation.
 - First regional meeting was family lived experience.
 - Inclusive stakeholder meetings led to engaging and insightful discussions.
 - Surveys were sent by email with follow-up calls by MPH student.
 - Three workgroups focused on making statewide tools/workflow diagrams.
 - Family and Education
 - Birthing Hospital/Newborn Screening
 - Audiology
- Challenges and lessons learned (Figure 4) may vary from state-to-state.
- The **CMV WISPER** stakeholder group is a model of an action plan and tools for other states seeking to identify state-specific gaps in cCMV screening.

- Year 1
 - Audiology Gaps Survey
 - Family focus groups
 - Theme-based, structured group interviews
 - Statewide public facing website for tools
 - Educational materials
 - Hearing-targeted screening tool
 - Retroactive NBS testing tool
 - Audiology follow-up workflow
 - Education and media for June national CMV month
- Year 2
 - Develop QI options to track cCMV screening.
 - Focus on provider and family education
 - Roll out American Academy of Pediatrics recommendations on extended cCMV screening (in publication)
 - Increase prenatal education
 - Obstetrics, family medicine and maternal/fetal medicine specialists

