Rules Advisory Committee Meeting
House Bill 2685
Meeting Minutes

Date: Wednesday, October 1, 2025
Time: 9:00 AM – 11:00 AM
Location: Virtual - Zoom OHA Public Health Division

Meeting Started: 9:05 AM

Meeting Recorded

Committee Members Present: Anna Agnew, Justine Clark, Annette Cole, Kate Dillon, Sheevaun Khaki, Chad Ludwig, Cynthia Luxford, Emilia Allen Smith, David Stein, Louise Vaz, Shelley Weise, Mariah Wharton, Willa Woodard Ervin, Heather Durham

Absent: Laura Erickson, Michael Gilbert, Leonard Machado, Zilmullia Pittman

OHA Staff & **Consultants to OHA**: Shelby Atwill, Mellony Bernal, Gianna Bortoli, Sarah Kowalski, Sadie Morrissey, Megan Sanders, Cate Wilcox

Public Attendees: Diana Kincaid

Total Attendees: 22

Summary of Meeting

Agenda Item: Introductions & Housekeeping

Summary of Discussion: Meetings are recorded for note-taking purposes. Reviewed agenda. Welcome to the Rules Advisory Committee meeting for HB2685. This is our 2nd meeting of the committee. Reviewed RAC meeting guidelines. Meeting was recorded.

Agenda Item: Reviewed Protocol Development Process

Summary of Discussion: Two distinct protocols must be created—one for Expanded Targeted Screening for CMV and another for Diagnostic Testing and Care following a positive CMV result.

- These protocols must follow medical guidance and best practices and will be reviewed and approved by medical experts in a process separate from the RAC sessions.
- Expanded Targeted Screening for CMV is not universal testing—all newborns are screened, but only certain children meeting criteria will receive the CMV test. Screening

and any follow-up testing must be completed before hospital discharge and within 14 days of birth.

Agenda Item: Questions for the RAC: Rule organization

Summary of Discussion: After the last RAC meeting, there was discussion about how to best organize the new CMV rule requirements for facilities.

- The question is whether these rules should be placed within the existing screening rules or in a separate division. Having a separate division would only serve organizational purposes and would not change the substance of the rules. Input is requested on which option would make the rules easier to read and reference. RAC members did not provide feedback. A decision was made that the CMV rules will remain embedded in the EHDI rules as drafted.
- A RAC member raised concern about whether the rule language should specify that educational information be provided within 48 hours. It was noted that this suggestion came up at the last RAC meeting, but concerns remain about the use of mandatory terms like “shall,” since they could create enforcement issues. The team will review whether that language can appropriately be included.

Agenda Item: Review of Statement of Need and Fiscal Impact

Summary of Discussion: RAC participants raised concerns about the variability of CMV testing costs and how they impact facilities, especially birth centers.

- A RAC member noted their facility’s send-out lab costs of around $250 per test, with urine PCR at $213 and saliva at $275. Others confirmed that most hospitals use send-out labs, with turnaround times of up to five days, which complicates the required 14-day confirmation window. A RAC member emphasized that even $50 per test could be financially significant for birth centers operating on tight budgets.
- Questions were raised about whether “existing staff and resources” would include care coordination and tracking of results. It was clarified that program staff (e.g., EHDI) would support implementation, but follow-up would depend on facilities and primary care providers, with more detail to come in final protocols.
- There was extensive discussion about testing methods. RAC members noted that saliva often requires urine confirmation, which can delay results, especially in rural areas. Some suggested starting directly with urine testing to avoid turnaround issues. Concerns were also raised about using outdated cost references (2016), with calls for more current, Oregon-specific data.
- RAC participants highlighted the need for more comprehensive information in the rules about follow-up requirements, staffing, costs beyond the test itself, and alignment with

clinical protocols.

Agenda Item: Review Statement of Need and Fiscal Impact

Summary of Discussion: Summary of Reporting and Compliance Discussion

- The RAC members discussed the absence of a state-level reporting requirement for CMV test results in Oregon. Currently, positive results are not reported back to the state program, leaving responsibility for follow-up and referrals with individual facilities. Questions were raised about what “compliance errors” in the draft rules referred to, and it was clarified that this language relates to general compliance requirements (such as HIPAA, hospital licensing, and management obligations), not CMV-specific reporting.
- A RAC member asked why CMV was treated differently from other newborn screenings that do have reporting requirements to public health. OHA staff explained that the difference stems from the legislation. A RAC member involved in drafting the legislation mentioned that an earlier version of the bill did include reporting requirements, but they were removed due to cost concerns. They further added that a reporting mandate would have required significant system upgrades, and eliminating this provision was considered a necessary step to ensure the bill passed.
- Concerns were raised about the follow-up responsibilities for infants who test positive for congenital CMV in the absence of state-level monitoring. A RAC member questioned whether the rules underestimate the true cost impact, noting that follow-up will likely fall on primary care providers and birthing centers, requiring significant time and coordination that may not be reimbursed.
- A RAC member confirmed that birthing centers often provide postpartum follow-up for up to six weeks, seeing mothers and babies frequently during that period. They noted that many families in their region choose not to see pediatricians, which means birthing centers may end up coordinating care for positive CMV cases beyond their typical scope. They emphasized that this additional burden—especially in rural areas with limited access to care—will require considerable time and effort in care coordination, patient support, and referral management.
- OHA asked for additional comments regarding the statement of fiscal need and impact. It was acknowledged that the draft document may need reorganization and updates, particularly around cost estimates. While some references used were from prior years, the team attempted to update costs where possible. However, feedback from facilities indicates that actual costs may be significantly higher than those listed. The facilitator encouraged facilities to share their own current cost data so that this information can be incorporated into revised estimates.

Agenda Item: Review Example Protocols

Summary of Discussion: The group began reviewing sample CMV protocols from Colorado, Utah, and OHSU to help guide Oregon's development.

- Members emphasized the importance of clarifying definitions and risk factors. A RAC member noted that Colorado's protocol blends risk factors with clinical signs and stressed that small-for-gestational-age (SGA) is not always a reliable indicator unless accompanied by reduced head size. A RAC member added that growth chart variations complicate interpretation and argued that premature birth or low birth weight alone may not be strong risk factors. Both emphasized the need for flexibility in protocols, especially for preterm infants.
- A RAC member from Salem Hospital described their experience since implementing CMV testing, highlighting challenges such as delayed discharges due to waiting for urine samples. They developed take-home urine kits for families, which helped maintain timelines. Others, including a RAC member from a birth center, stressed that community midwives rarely encounter conditions like SGA and would generally refer more complex cases to higher-level care. They requested clearer language around responsibilities for birthing center staff to avoid confusion.
- The discussion then turned to testing methods. Most facilities preferred urine as the standard test, with saliva only used as backup when urine could not be collected. A RAC member suggested framing urine collection as "prolonging hospitalization" rather than "delaying discharge", since it is part of necessary newborn care. State data indicate around 1,500 infants annually are referred for further evaluation after newborn hearing screening, which could represent a substantial testing population.
- Follow-up protocols from Utah and Colorado were also reviewed. They included audiology, infectious disease, neurology, ophthalmology, and early intervention referrals, as well as family handouts and checklists. RAC members agreed that Oregon would benefit from a standardized form or checklist to guide providers through the steps, since CMV is not encountered often in practice. Members supported this idea, noting it would reduce confusion and support care coordination.
- Concerns were raised about access to specialty care. A RAC member pointed out that only a few pediatric infectious disease providers in Oregon currently manage CMV, raising risks of bottlenecks and delays. Others highlighted challenges in scheduling ophthalmology and audiology appointments, particularly outside the Portland metro area. A RAC member emphasized that rural birth centers may lack access to specialists altogether, and families who birth outside hospitals often do not follow up even when referrals are made. Several participants stressed that these gaps could create inequities in care.
- RAC members discussed the need for centralized coordination, noting that individual small facilities cannot realistically manage all aspects of follow-up. Some suggested state-level or centralized case management to ensure timely evaluation and treatment. A RAC member underscored the importance of confirmatory hearing tests and timely antiviral treatment, since treatment pathways differ depending on the severity of disease and should be started as early as possible.

- RAC members raised questions about timelines for newborn hearing screening, especially for preterm infants, and whether Oregon's protocols should allow flexibility. OHA mentioned that timelines regarding cCMV screening are in statute but timelines around hearing screenings are not as defined. A RAC member asked if this will cause changes to the birthing center rules and OHA noted that freestanding birthing center rules already went out for comment, and permanent rules are expected to be filed within the next few weeks. This rulemaking includes amending those rules to include CMV testing requirements.

Agenda Item: Public Comment

Summary of Discussion: A parent expressed gratitude and encouragement for the RAC's work, noting that while CMV implementation will add workload for providers without additional state resources, strong advocacy for state support is essential. The speaker emphasized the importance of including preventative education materials early in pregnancy within the rules and highlighted the critical role of providers—especially midwives—in sharing education and ensuring referrals and follow-up care.

- OHA facilitator confirmed that prenatal health care providers would be prioritized in the updated rule language, reflecting earlier feedback, and thanked participants for their patience as those changes are finalized.
- A RAC member echoed the parent's comments, stating they were encouraged to see CMV education moving toward becoming a standard of care in Oregon, as it already is in some other states. They noted that midwives are already leading in educating families.

Agenda Item: Closing and Next Steps

Summary of Discussion: A RAC member emphasized the importance of ensuring CMV protocols address more than just newborn hearing screen failures, stressing that small-for-gestational-age and other symptoms must also be included in screening criteria. The facilitator confirmed that the forthcoming protocol will reflect the expanded targeted screening approach outlined in legislation and informed by RAC input.

- A RAC member raised questions about timelines, noting the need for systems to prepare before the January implementation date. OHA explained that a draft protocol is expected by mid-October, with submission to the rules coordinator by November 6. The draft will then be posted for public comment, and RAC members will also have the opportunity to review and provide feedback.
- A RAC member asked about representation on the expert committee developing the protocols. OHA confirmed there is statewide and multi-system participation and committed to sending the committee list by email, with invitations extended as needed to ensure broad expertise, including NICU representation.

Meeting Adjourned: 10:57 AM