CSTE cCMV Large Working Group meeting (8/8/22)
Meeting Minutes

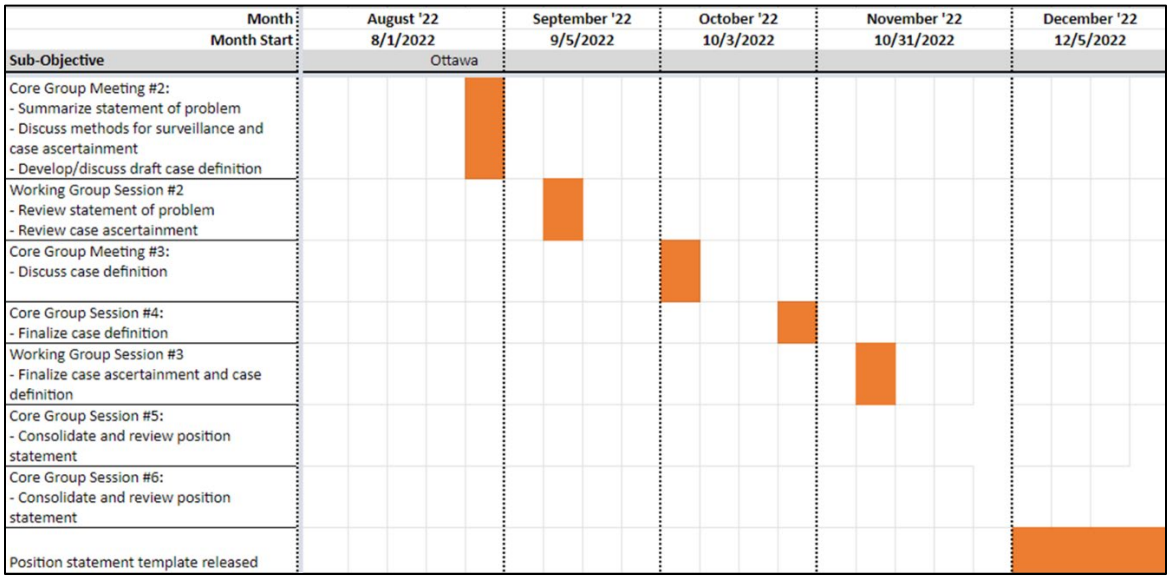
Agenda

- Brief Introductions from Utah and CDC
- Brief overview of position statement process, timelines, and group roles
- Presentation by Kelley Raines on CDC's cCMV state surveillance assessment
- Presentation by Max Sidesinger on Utah CMV surveillance
- Discussion of current jurisdiction processes for cCMV case ascertainment and reporting
- Next steps

Meeting Notes

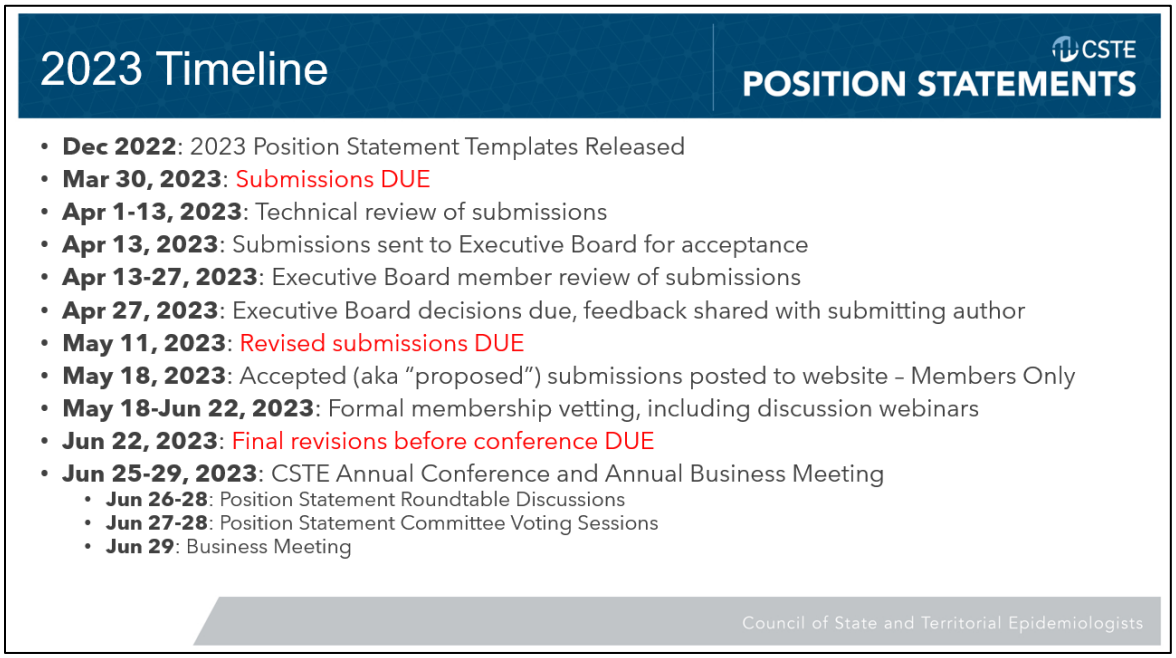
- **Goal of cCMV Position Statement**
  - Create a standardized case definition for cCMV
  - **NO** plans to make cCMV nationally reportable
- **Brief overview of position statement process, timeline, and group roles**
  - Position statement process (Council of State and Territorial Epidemiologists (cste.org)):
    - Core working group will write and develop the position statement in consultation/input from the Large Working Group
    - Position statement is submitted in late March 2023
    - Formal membership vetting in May-June 2023
    - Position statement Roundtables and Voting Sessions at CSTE meeting in late June 2023
    - Final posting of approved position statements around late August 2023
  - Group roles:
    - Core WG members: authors/co-authors of position statement
      - All authors must be CSTE members
        - Submitting and Presenting Author(s): Active Members ONLY
        - Co-authors: Active, Associate, Emeritus, or Student Members
      - All authors should follow own agency's policies for authorship or clearance
      - Co-authors should actively contribute to writing group conversations, writing content, and/or editing content
      - CSTE position statements should represent CSTE member views
    - SME members: serve in the consultant role
      - SMEs do NOT need to be CSTE members
        - SMEs listed in position statement are allowed access to any member-only discussions and during Annual CSTE Conference and Annual Business Meeting
      - SMEs advise authors on content development
    - Large WG members: serve in the reviewer role
      - Do NOT need to be CSTE members
      - Participate in Large WG meetings and provide feedback on position statement
      - Serve as first round of reviewers

- Timeline:
  - 2022 working group timeline:



Month	August '22	September '22	October '22	November '22	December '22
Month Start	8/1/2022	9/5/2022	10/3/2022	10/31/2022	12/5/2022
Sub-Objective	Ottawa				
Core Group Meeting #2: - Summarize statement of problem - Discuss methods for surveillance and case ascertainment - Develop/discuss draft case definition					
Working Group Session #2 - Review statement of problem - Review case ascertainment					
Core Group Meeting #3: - Discuss case definition					
Core Group Session #4: - Finalize case definition					
Working Group Session #3 - Finalize case ascertainment and case definition					
Core Group Session #5: - Consolidate and review position statement					
Core Group Session #6: - Consolidate and review position statement					
Position statement template released					

  - 2023 CSTE timeline:



- **Comments/Questions on Kelley's presentation:**

From Scott Grosse (CDC) to Everyone 01:16 PM: New York's targeted CMV screening law as passed and signed in 2018. (Note from presenter: Cases of cCMV identified through targeted cCMV screening are not being reported or ascertained by the NY HD; however, beginning in 2016, cCMV was added to the reporting list of the birth defects registry. The presentation focused on cCMV surveillance, so the date presented is a reflection of that.)

From Kathleen Muldoon (She/Hers) to Everyone 01:26 PM: Thank you for this report! A much needed study.

From Sondra Rosendahl (MDH) to Everyone 01:28 PM: Just to clarify, that CMV was not added by legislation [*to the MN newborn screening panel*]...it was added by our advisory committee and Commissioner approval.

From Lindsay Denson to Everyone 01:28 PM: Similar in Oklahoma (response to Sondra Rosendahl's comment)

From Caleb Lyu to Everyone 01:29 PM: May I know for the slide about expected cCMV case counts where the estimates/expected numbers came from? Is there a reference study?

From Kelley Raines to Everyone 01:32 PM: Thank you for the question, Caleb! We calculated the average annual number of expected cCMV cases based on the birth cohort for each state during 2016–2020 (National Center for Health Statistics 2022) assuming the prevalence of cCMV infection was uniformly 4.5 per 1,000 live births (Dollard et al., 2021; Fowler et al., 2018)

From David Kimberlin to Everyone 01:30 PM: This slide was the most important one from a great talk, in my view (referencing slide comparing the expected number of cCMV annual cases to reported by state).

From Tatiana Lanzieri to Everyone: As Kelley presented, at this point we only assessed surveillance activities by health departments, but we know many of you have been involved in cCMV studies, such as the cCMV registry by Baylor. One important point will be to bridge the gap and strengthen collaborations among HDs, health care providers, and academic institutions, which we hope to foster in the coming years.

- **Comments/Questions on Max's presentation:**

From Van Tong to Everyone 01:45 PM: Of babies that fail newborn screening, what % get CMV testing in time (i.e., within 21 d)?

From Max: Of those babies who fail, about 85% get tested for CMV. Of those who get tested, about 80% get it by 21 days of age

From Deepali Sanghani to Everyone 01:45 PM: Is there any follow-up being done for babies who are confirmed positive?

From Stephanie: Babies who test positive are referred to the CMV specialty clinic at Primary Children's Hospital, where they receive ENT, neurology, infectious disease, and ophthalmology exams/consultations. Even those without symptoms are monitored regularly for changes in hearing or developmental delays

- **General Discussion**

Stephanie McVicar: Question to the group – anyone opposed to the idea of developing a standardized cased definition for cCMV?

From Kristen Nichols Heitman (CDC) to Everyone 01:50 PM: A friendly reminder that we are **NOT** proposing that cCMV become a nationally notifiable condition.

From Kathleen Muldoon (She/Hers) to Everyone 01:50 PM: I think a standardized case definition is so very important.

From David Kimberlin to Everyone 01:50 PM: The only thing I can think of is the following: Why? What is the next step once a case definition is created?

Kimberly Piper (Iowa Department of Public Health): I don't foresee any opposition to a standardized case definition, but I think we need to be mindful going forward to differentiate between universal screening of newborns and universal newborn screening through the states' newborn screening programs. Universal screening of newborns for cCMV is not the same as universal newborn screening through the state newborn screening program. Newborns may be screened for cCMV at the clinical (hospital) level without going through the newborn screening program. It would be a clinical screening similar to what they would do for any other congenital infection. Standing order for hospital nurseries to do the test on all babies.

Scott Grosse (CDC): potential pitfall – people will confuse administrative prevalence with prevalence of cCMV, can't even say it is prevalence of symptomatic cCMV because symptomatic cases will be missed w/ passive surveillance.

Tatiana Lanzieri (CDC): In some states conducting cCMV surveillance, cases are reviewed and have laboratory confirmation. Whereas not all cCMV infections are identified in the absence of screening, that would not be administrative prevalence and we might discuss terminology for that. There will be a need to work on case definitions, potentially including confirmed, probable, and possible cCMV cases, and discuss what we consider birth prevalence, administrative prevalence, or reporting rates.

Pablo Sanchez (Nationwide Children's Hospital): Agrees w/ Scott – says many providers don't know how to diagnose, and a standardized case definition will help with that. Is 1 test enough? Maybe needs to be confirmed w/ a second test. We need to be cautious of what is identified. The cases identified could just be the tip of the iceberg. It is important to educate providers and the public. We need to account for false positive results)

From Mark R Schleiss to Everyone 01:58 PM: Just to follow up on my question for Scott: if there is universal screening, and it's sensitive and specific, isn't the number of cases identified by a case definition equal to the prevalence, since clinician acumen and clinical presentation (or lack thereof) is not an issue?

From Scott Grosse to Everyone 01:59 PM: @Mark -- Yes, we use NBS numbers to estimate birth prevalence of most NBS disorders. However, we know that there are missed cases for some disorders, notably hearing loss and critical congenital heart disease. See https://www.cdc.gov/mmwr/volumes/69/wr/mm6936a6.htm

From Sondra Rosendahl (MN Dept of Health Newborn Screening) to Everyone 01:59 PM: Yes, we know we will miss cases in MN. We are in the process of adding it to our Communicable Disease Rule in hopes of finding at least some of those missed cases.

From Caleb Lyu (LACDPH) to Everyone 01:59 PM: I think when we talk about prevalence, it may be misleading because even if there is universal screening, we aren't capturing cases that already have existing CMV infection, just the ones that are newly diagnosed.

Paul Romitti (University of Iowa): Might have to create a definition that's not binary – instead of yes or no, create a spectrum of case definitions with a shade of certainty.

Closing Remarks

From Jeanne Albano (KY) to Everyone 02:02 PM: Thank you all for this very informative meeting. As KY heads into targeted screening, we are attempting to gather every bit of information we can on how to identify and monitor cases and support the families.

From Karen Fowler to Everyone 02:02 PM: Passive surveillance is better than nothing for sure!

From Scott Grosse to Everyone 02:59 PM: Tatiana, Jessica, and I published an article in 2021 that discussed the challenges to the use of administrative data for cCMV surveillance.

Attendees List:

- Utah HD
    - Stephanie McVicar (Utah Department of Health and Human Services EHDI)
    - Max Sidesinger (Utah Department of Health and Human Services EHDI)
- CDC
    - Kristen Nichols Heitman
    - Tatiana Lanzieri
    - Kelley Raines
    - Jessica Leung
    - Ashrita Rau
    - David Sugerman
    - Suzanne Gilboa
    - Scott Grosse
    - Van Tong
    - Kate Woodward
    - Breanna Pennings
    - Sandy Roush
- Suresh Boppana (University of Alabama Birmingham)
- Lindsay Denson (Oklahoma Birth Defects Registry)
- Sondra Rosendahl (MN Department of Health Newborn Screening)
- Nancy Schneider (NJDOH EHDI)
- Kathleen Muldoon (Arizona EHDI)
- Karen Fowler (University of Alabama Birmingham)
- David Kimberlin (University of Alabama Birmingham)
- Paul Romitti (Iowa Center for Congenital and Inherited Disorders)
- Parker Brodsky (Virginia Newborn Screening)
- Rania Milleron (Texas)
- John Lamb (Connecticut EHDI)
- Jeanna Albano (Kentucky EHDI)

- Olivia Chapman (St. Louis County)
- Sara Bowman (South Dakota Department of Health Vaccine Preventable Diseases)
- Stephen White (Texas Department of State Health Services)
- Jane Fornoff (Illinois Birth Defects Registry)
- Caleb Lyu (LACDPH Children's Medical Services)
- Deepali Sanghani (Virginia EHDI)
- Gail Harrison (Baylor College of Medicine)
- Megan Honor Pesch (University of Michigan)
- J. Michael Bryan (GDPH MCH Epidemiology)
- Kristin Conway
- Maryrose McInerney (New Jersey EHDI)
- Kim Hicks (Delaware)
- Albert Park (University of Utah Primary Children's Hospital)
- Mark R. Schleiss (University of Minnesota)
- Kimberly Noble Piper (Iowa Center for Congenital and Inherited Disorders)
- Kirsten Coverstone (Minnesota Department of Health EHDI)
- Flor De La Garza (Oklahoma Birth Defects Registry)
- Jessica Kumar (NYS)
- Michele Herdt (NYS Birth Defects Registry)
- Jerusha Barton (GDPH MCH Epidemiology)
- Pablo Sanchez (Nationwide Children's [Ohio])