The Parent Experience:

Facilitators and challenges to follow-up after identification with cCMV by universal newborn screening in Minnesota

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Objectives

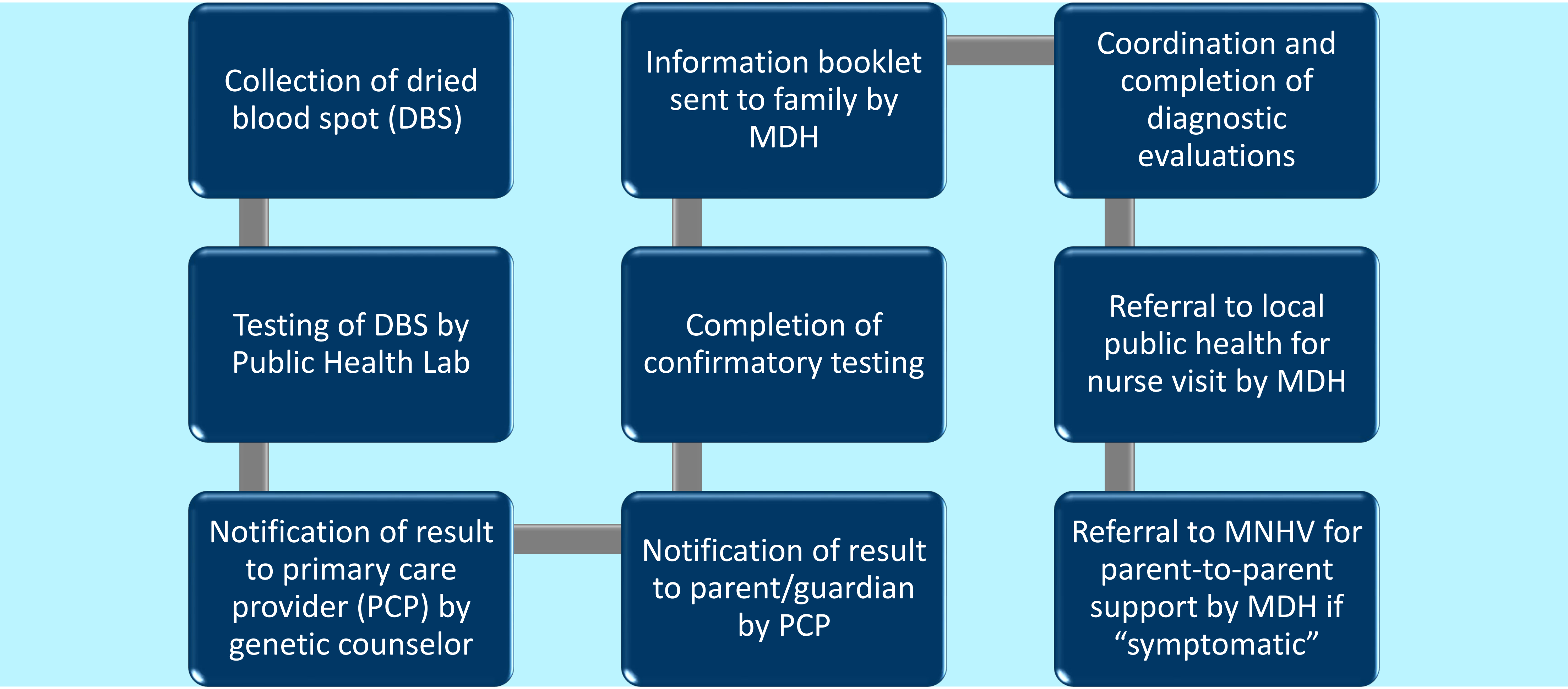
- Describe three factors that facilitate a positive experience for parents after their child is identified with congenital cytomegalovirus (cCMV) though universal newborn screening (NBS).
- Identify three challenges that parents experience after their child is identified with cCMV through universal NBS.
- List three interventions to help improve the experience of parents after their child is identified with cCMV through universal NBS.

Background

HRSA Newborn Screening Propel

- In July 2023, the Health Resources and Service Administration (HRSA) awarded grants to 28 states and territories under the State NBS Systems Priorities Program (NBS Propel)
  - Project was funded under focus area two
    - Activities related to improving short-term to long-term follow-up
  - Includes collecting feedback from parents, specialists, primary care providers, and LPH nurses
- Project goals
    - Better understand the experiences of families with children identified with cCMV by NBS and the professionals interacting with them
    - Identify one area for improvement in the NBS system
    - Use results to develop a replicable process for engaging with families and other partners to assess their experiences with the NBS system
- Funding expected to last 5 years (2023-2028)
- Contracted with an outside vendor to help with Phase 1

Universal cCMV screening process flow-Minnesota



Collection of dried blood spot (DBS)

Testing of DBS by Public Health Lab

Notification of result to primary care provider (PCP) by genetic counselor

Notification of result to parent/guardian by PCP

Completion of confirmatory testing

Information booklet sent to family by MDH

Coordination and completion of diagnostic evaluations

Referral to local public health for nurse visit by MDH

Referral to MNHV for parent-to-parent support by MDH if “symptomatic”

Methods

Family focus groups

Recruitment (October – November 2024)

Letter

Online interest form

Scheduled for a focus group session

Online focus groups (December 2024-January 2025)

Used moderator guides for structure

Grouped families, when possible

Post-survey

Gift card incentive for participation

Evaluation questions

Evaluation question 1:
What facilitators and barriers have families experienced in navigating short-term follow-up for congenital CMV?

Evaluation question 2:
What facilitators and barriers have families experienced in navigating longitudinal follow-up for congenital CMV?

Evaluation question 3:
What are the differences across families, if any, in how they experience short-term and longitudinal follow-up?

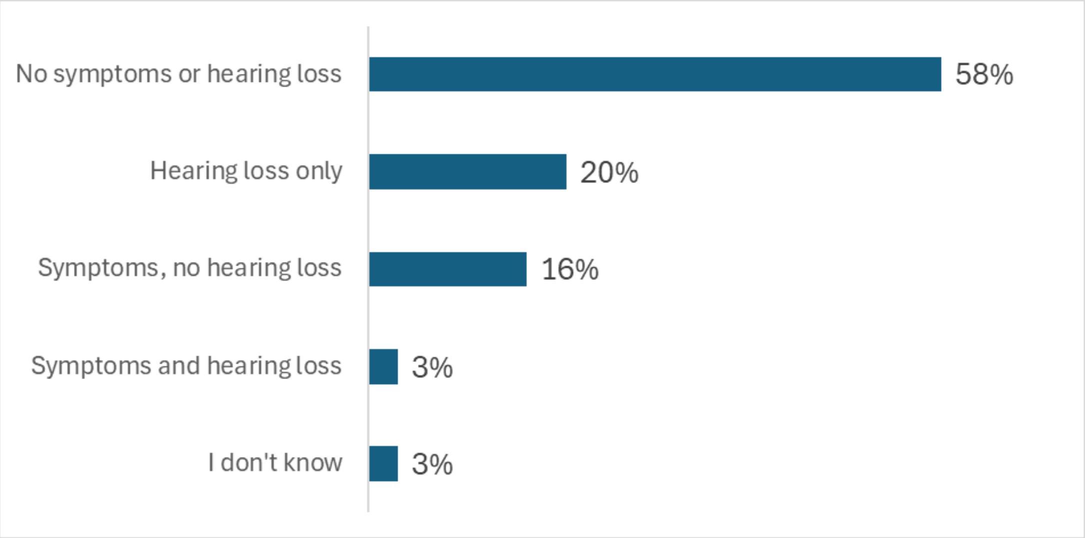
Data analysis

- Rapid qualitative analysis by four analysts
- Developed a summary template with section headings represented key interview domains
- Focus group transcripts were used to create a summary of content related to the domains of interest
- Analytic matrix was used to summarize data across all participants to identify themes
- Illustrative quotes were extracted from the transcripts

Results

Focus group demographics

- 6 parent focus groups conducted
- 30 parents participated
- Majority were white, non-Hispanic
- Over 55% employed full time
- 81% reported having private health insurance
- Average age of child with cCMV was 12 months (range: 3 to 21 months)



Overall challenges

Receiving the initial NBS result did not go well.

Difficulty adhering to monitoring schedule.

Limited provider knowledge among some primary care providers and specialists.

Sense of urgency and anxiety with the burden of scheduling and care coordination.

Lack of clear information when families need it the most.

> I don't really talk about her having CMV. … Friends and family, they don't know how to support me. It's kind of just, like, all new experience overall. And so, it kind of feels a little alone, because there's not, like, other people other than her doctor to talk to about this.

Focus group participant

“I feel like…my child is the experiment, and the data is coming from my child…”

“…And they're like,’ we haven't tested enough kids to fully know what the true risks are, you know.’”

“‘I think the most helpful thing that we got told by our infectious disease doctor, like right away when we first met her, was that my baby is one of the ‘guinea pig babies,’ which I really hate.”

Focus group participants

Facilitators

Knowledgeable and proactive providers.

Help with care coordination.

Balanced delivery of information.

Access to trusted information.

Learning the benefits of monitoring appointments.

> My panic set in because I got the phone call from my pediatrician… And then she set me at ease right away, and just said, ‘here’s what's going on. Don't panic. Do not go on the Internet.’ She gave me one website, the Department of Health. She's like, ‘you're allowed to go on this website. Otherwise, you're not. Don't spiral.’ …I feel like that's maybe an ideal way [to deliver results].

Focus group participant

Suggestions for implementation - providers

- Provide “talking points” for delivering results and include guidance to make sure families are aware of vetted resources
- Provide standardized information to pediatricians to relay to families about next steps.
- Develop a referral network for specialists to help families coordinate follow-up appointments.
- Work with specialists on workflow changes to accommodate volume of appointments.

Suggestions for implementation - families

"I mean, I read all the way through it [information booklet from MDH]… And then otherwise, I've held onto it. I know it's there. I just kind of hold on to it. And I was like, you know, right now, there's nothing that we really need to do so. We don't need those additional resources. So, I'll just hold on to it. And if we do, then I know that that's there."
– Focus group participant

- Deliver trusted information to families as soon as possible after diagnosis.
- Share data and statistics on long term outcomes with families.
- Develop and share a timeline with families for how long monitoring will continue and what the purpose is.
- Provide resources to help cope with uncertainty and anxiety.
- Increase awareness of CMV in the community.

Conclusion and next steps

Next steps

- Ongoing survey with larger group of parents
- Main survey themes:
  - Return of results
  - Confirmatory testing and follow up exams
  - Information and resources
  - Treating or watching for symptoms
- Analyze provider interviews
- Use all feedback to select opportunities for quality improvement in the NBS system

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Questions?

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