

# Bridging the Congenital CMV Knowledge Gap in Massachusetts



## An Interdisciplinary Approach to Clinical Resource Development

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### Background

- Each year, 1/200 babies is born with congenital cytomegalovirus (cCMV), the most common infectious cause of birth defects in U.S.<sup>1</sup>
- About 20% of babies with cCMV will develop long-term health problems such as hearing loss, developmental delays, visual impairment, and seizures<sup>2</sup>.
- cCMV care is complicated by the possibility for late onset of disease and lack of definitive treatment or prevention options.

### Knowledge gap

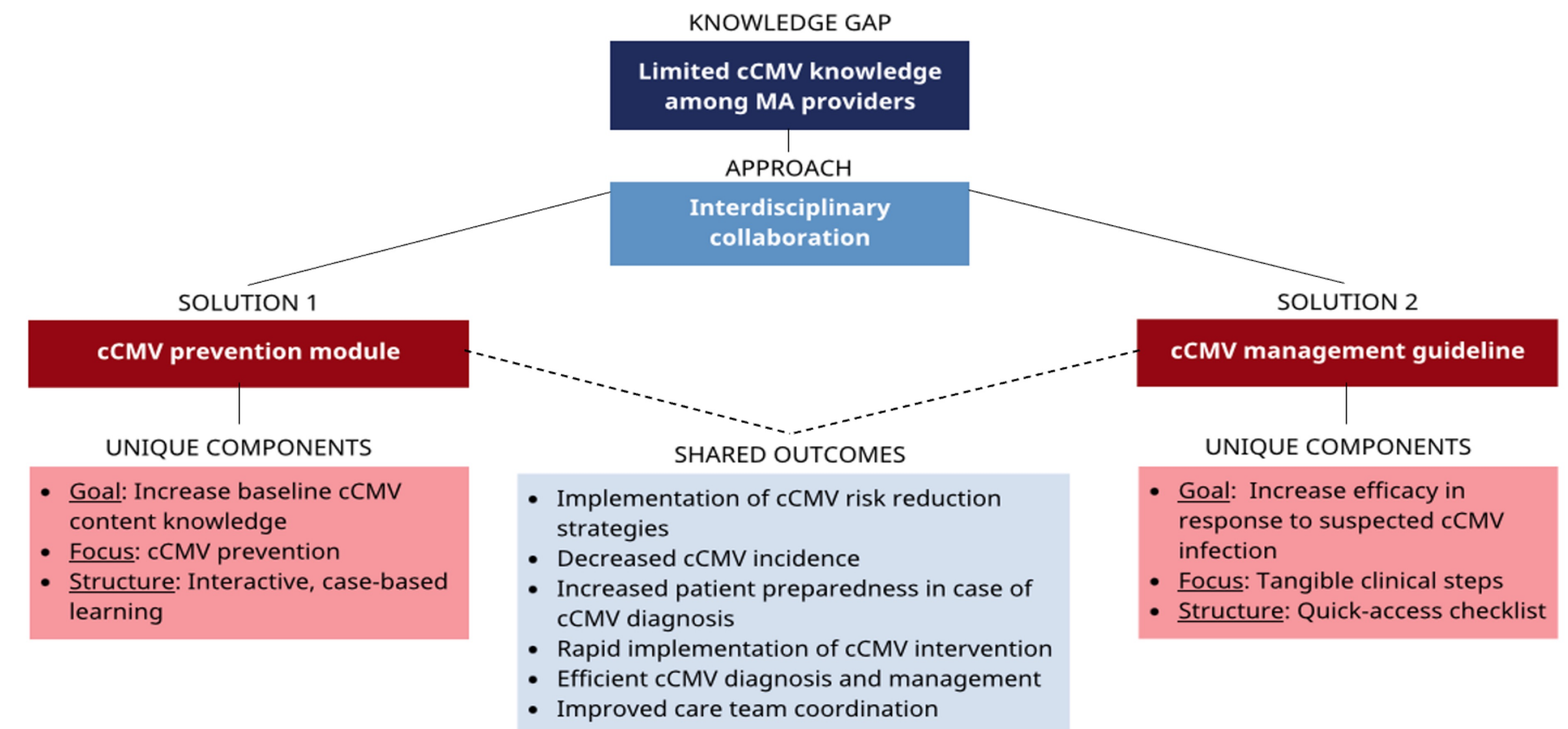
- Despite its clinical burden, 75% of women are not aware of the risks of cCMV infection during pregnancy<sup>3</sup>.
- Similarly, studies have shown that major cCMV knowledge gaps exist among healthcare providers<sup>4,5</sup>.
- With legislation pending in Massachusetts mandating prenatal education and universal newborn screening, providing information to healthcare providers about cCMV prevention and management is critical.

### Interdisciplinary Approach

- The Massachusetts Congenital CMV Coalition (MCC), an interdisciplinary team of clinicians, researchers, educators, parents, and other stakeholders, works to improve cCMV education, prevention, screening, and care in MA.
- One goal of the group is to develop educational resources that apply to a wide range of clinical learners, support decision making in real time, and holistically encompass all aspects of cCMV care.

### Clinical Resources in Development

- Resources in development feature two distinct but complementary components relevant to clinical care.



### Implementation and Next Steps

- Materials will be made available through the MCC website and distributed directly to clinicians.
- Following the distribution and use of resources, program evaluation will occur to determine the effectiveness in addressing cCMV knowledge gaps.
- Education models will be applied to complement early intervention and parent advocate resources, also developed by MCC members, to strengthen interdisciplinary connections related to cCMV care.
- Project members will continue to update materials in effort to expand partnerships between specialists.

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