

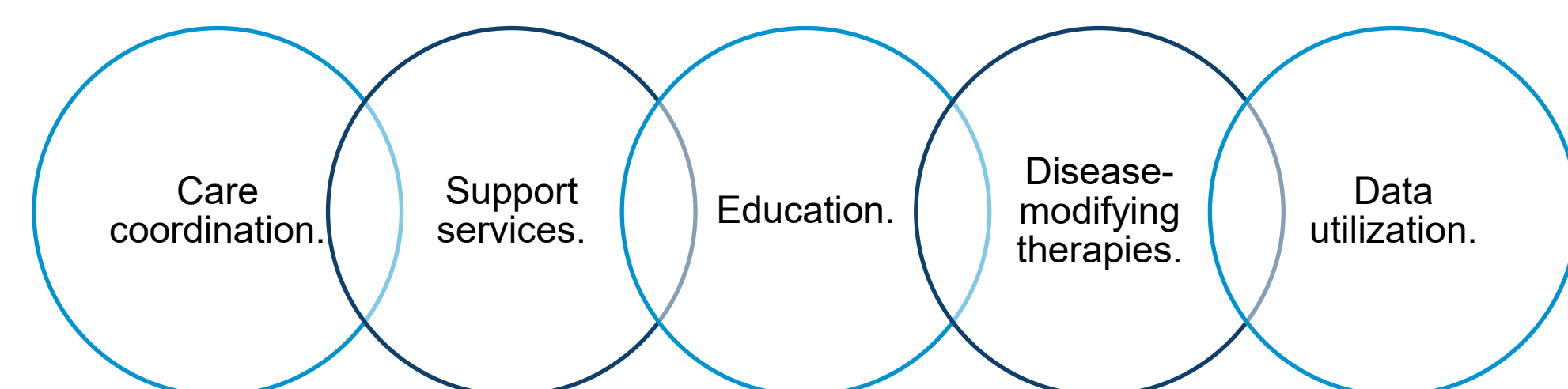
Barriers and Facilitators to Engaging Communities Affected by Sickle Cell Disease in Michigan

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Introduction

- Approximately 4,000 individuals with sickle cell disease (SCD) reside in Michigan.
- The Michigan Department of Health and Human Services (MDHHS) released its first SCD Strategic Plan in 2015.
- In response to more than a decade of progress and increased state and national attention on SCD, MDHHS began updating the plan in 2024.
- The updated plan, set for release in fall 2025, reflects the current needs of individuals living with SCD by centering their voices to increase awareness, maximize resources and carry out public health interventions focusing on:



Objective

- To explore barriers, facilitators and lessons learned when engaging with Michigan residents living with SCD, caregivers and health care providers.

Methods

- MDHHS collaborated with community partners, SCDAA-MI and MSU-IHP to host five regional focus groups with individuals living with SCD and their caregivers. An additional focus group was held with community health workers, patient advocates, social workers and clinicians.
 - Most participants were recruited through convenience sampling, in partnership with SCDAA-MI, while some were recruited directly at the clinic where they receive care.
- A provider survey was distributed via Qualtrics to practicing hematologists who care for patients with SCD.
 - Eligible providers were identified through a review of the Community Health Automated Medicaid Processing System (CHAMPS), Michigan's electronic Medicaid management system and the State of Michigan Licensing and Regulatory Affairs licensure data.
- Qualitative data were analyzed for key themes and recurring narratives, while survey data were reviewed using descriptive statistics.

Definitions, for results

The results are organized into barriers and facilitators related to engaging with communities affected by SCD. In this context, **barriers are factors that hinder public health efforts, while facilitators are factors that support or strengthen programs and interventions.**

Results

Barriers:



Focus Group:

- Inability to implement true randomized recruitment effort.
- Concerns with the accessibility of recruitment and guide materials (readability, language and digital access).
- No virtual participation was offered; transportation barriers.
- Focus group moderator burnout.
- Developing a broad yet relatable discussion guide for the complex needs of the SCD community was a significant undertaking.

Provider Survey:

- Low response rate of 10% (13/128).
 - Of the 13 responses, over 90% came from pediatric providers.
- Few validated SCD-specific survey tools available during development.
- Partner feedback, while valuable, delayed finalization and raised concerns on biases.
- Narrow provider scope; could have included more roles (advance practice providers, social workers).
- Possible outdated contact information in state registries.
- Competing provider priorities may have limited overall participation.

Facilitators:



Focus Group:

- Gift card incentives encouraged participation.
- Community-based partnerships, especially with SCDAA-MI, were instrumental in recruitment and building rapport with communities.
- Offering sessions in accessible locations during times that maximized attendance.
 - On average, eight individuals/caregivers participated per regional site (n=41), with 11 participants in the virtual advocate focus group.

Provider Survey:

- Alignment with focus group themes helped create a cohesive foundation for the strategic planning process.
- Access to state licensing registries helped group identify potential respondents.
- Collecting both quantitative and qualitative data; open-ended response options were able to capture important narratives.

“We need more doctors and nurses willing and able to care for these complex patients. Build the clinic, then educate medical students and residents and show them the care can be rewarding and effective.”

– Hematologist caring for patients with sickle cell.

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Lessons Learned

- Increase flexibility in engagement approaches by offering virtual focus groups or incorporating key informant interviews with providers.
- Obtaining consent to record focus group sessions would help ensure quotes and stories are accurately captured and represented.
- Allow more time for iterative development of guides and surveys to incorporate partner feedback.
- Use validated measures wherever possible to ensure questions are effective and appropriate.
- Focus group participation was often described as cathartic and impactful, **underscoring the importance of including individuals with SCD and their caregivers in public health planning.**

“We should do this again in a couple years. It would be nice to have the same group meet again.”

– Focus Group Participant from Lansing, MI.

Next Steps

- MDHHS will use the data from the focus groups, survey and other strategic planning activities to inform Michigan's updated SCD Strategic Plan.
- The team will apply the identified barriers, facilitators and lessons learned to strengthen future community engagement and public health planning efforts.
- The connections made through this work will **assure the SCD community remains included and that the voices most impacted will guide future efforts.**

Acknowledgements

This work was made possible by individuals with SCD, their caregivers and the providers who generously shared their lived experiences. A key takeaway is that people are eager to make an impact – incorporating their stories and needs can drive meaningful change.

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