



## IHPI BRIEF

# State-University Partnership to Enhance Outreach to Adults Living with Sickle Cell Disease in Michigan



## Sickle cell disease is the most common inherited blood disorder in the U.S.

Sickle cell disease is associated with significant health complications across the life span, such as pain, stroke, and infection, as well as reduced average life expectancy of 45 years.<sup>1-2</sup> Access to consistent high-quality healthcare improves health outcomes among this population.<sup>2</sup> However, the risk for adverse outcomes is further heightened as over 90% of people with sickle cell disease in the U.S. are Black or Hispanic — racial and ethnic groups that have historically been economically and socially marginalized and often underserved in healthcare.<sup>3</sup>

There are over 4,000 individuals living with sickle cell disease in Michigan, the majority enrolled in Medicaid.<sup>4</sup> Historically, Michigan residents up to 21 years of age living with sickle cell disease were eligible to receive health coverage through Children’s Special Health Care Services (CSHCS), a program within the Michigan

Department of Health and Human Services (MDHHS) that serves children and some adults with special health care needs. The program is part of the federal Title V Maternal and Child Health Services Block Grant. It offers supplemental coverage for individuals with private or public insurance, and primary coverage for the qualifying condition for those with no other coverage. CSHCS assists with payment for medical care and treatment, including co-pays, deductibles, and transportation, and provides care coordination, case management, and other support services.

In October 2021, Michigan expanded CSHCS coverage to include people living with sickle cell disease over 21 years of age with the goal of improving health outcomes and reducing health disparities for this vulnerable population.<sup>5</sup>

In order to successfully implement this new expansion, it is important to identify as many potentially eligible people as possible. **MDHHS partnered with the Michigan Sickle Cell Data Collection (MiSCDC) program at the University of Michigan to identify adults with sickle cell disease who are potentially eligible for CSHCS coverage under the new policy.** The MiSCDC program uses multiple population-level data sources to identify people with sickle cell disease in Michigan (see page 2 for further details).<sup>6</sup>

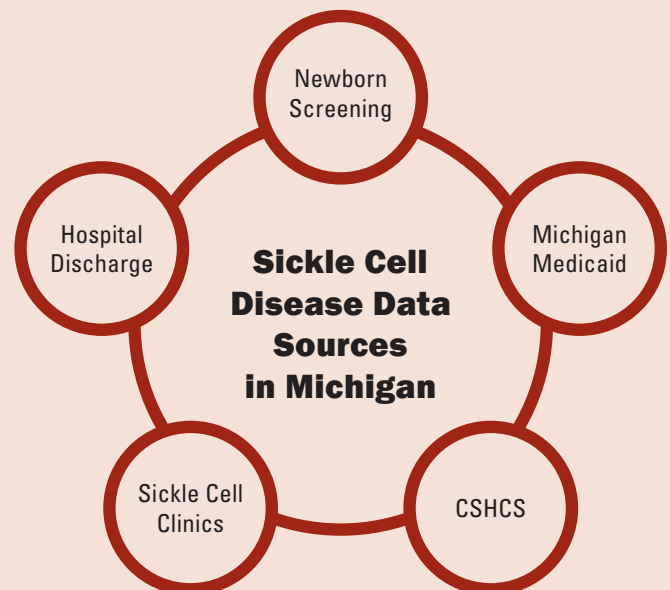
## Key outcomes of the state-university partnership

The MiSCDC program at the University of Michigan **identified 2,569 adults living with sickle cell disease in Michigan who are potentially eligible to enroll in the new CSHCS expansion.** This was enabled by the use of multi-source data from MiSCDC, which includes individuals with sickle cell disease irrespective of insurance status or engagement in care.

### Of the people identified:

**65%** were adults who had never been enrolled in CSHCS

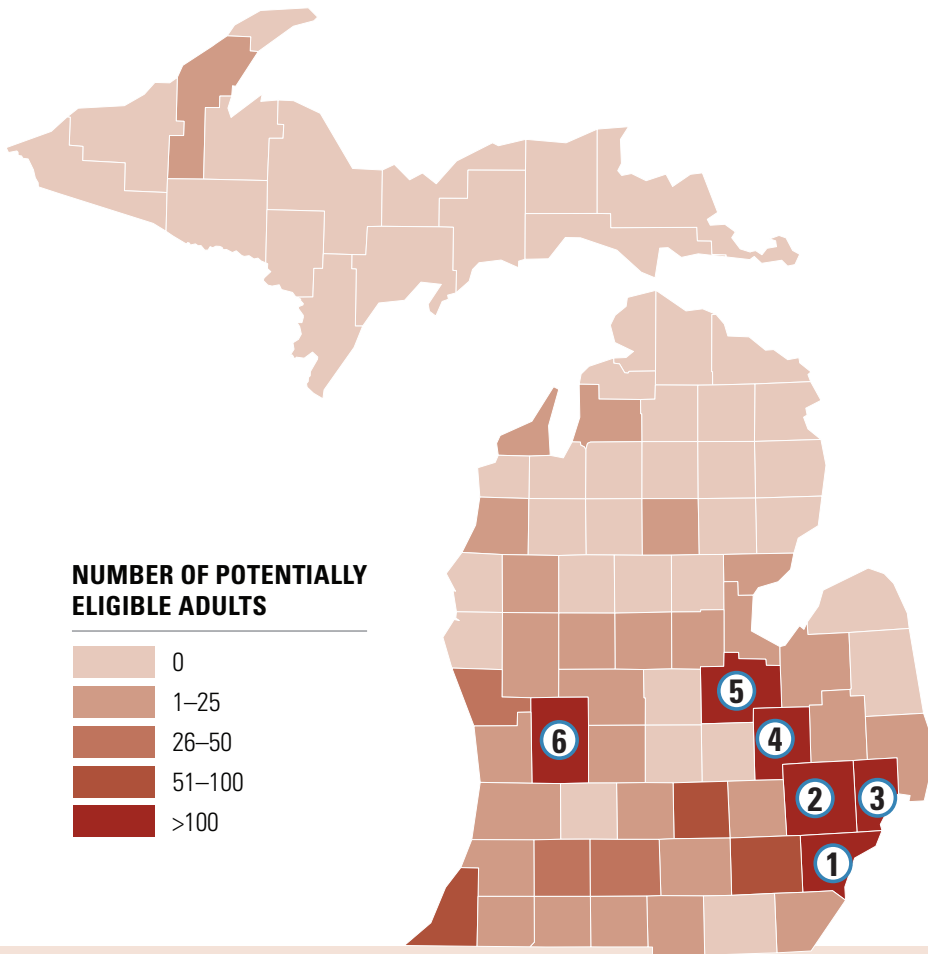
**79%** were enrolled in Michigan Medicaid at the time of the study



Half of all Michigan counties are home to adults with sickle cell disease who are potentially eligible to enroll in the CSHCS expansion, with the majority living in southeast Michigan.



MICHIGAN SICKLE CELL DATA COLLECTION



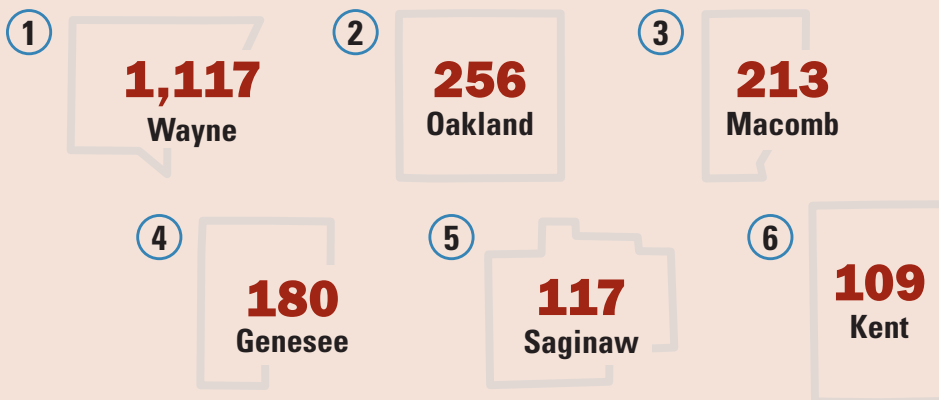
### What is the Michigan Sickle Cell Data Collection (MiSCDC) program?

MiSCDC merges numerous sources to gather population-level data to identify people living with sickle cell disease in Michigan and understand their health and healthcare over time.<sup>6</sup> The data is used to assess gaps in programs and policies related to sickle cell disease. Acquisition of data to conduct surveillance is made possible through designation of public health authority granted by MDHHS.

MiSCDC data sources include: Sickle cell disease clinics in Michigan and state-maintained data such as newborn screening, Michigan Medicaid, Children’s Special Health Care Services, immunization registry, vital records, and comprehensive all-payer databases.

MiSCDC is a collaboration led by the Susan B. Meister Child Health Evaluation and Research Center at the University of Michigan and MDHHS and is funded by the Centers for Disease Control and Prevention (CDC). There are 10 other states with CDC-funded sickle cell data collection programs like MiSCDC.<sup>7</sup>

### Counties in Michigan with >100 potentially eligible adults living with sickle cell disease



## What does this mean for health policy discussions?

To successfully implement Michigan's new policy to extend CSHCS benefits to adults with sickle cell disease, a key step is to identify potentially eligible participants.

The multi-source dataset of MiSCDC facilitated the identification of over 2,500 adults who would potentially qualify for CSHCS coverage under the new policy, as well as the proportion already covered by the state Medicaid program. This data informs the state's cost estimates for the expanded CSHCS policy and helps to target their outreach and educational efforts.

Other states, particularly those who have Sickle Cell Data Collection (SCDC) programs, could consider using similar methodologies to identify individuals with sickle cell disease—or other rare diseases—who can be connected to resources and impacted by new policies and program expansions.

Going forward, the MiSCDC team plans to continue partnering with MDHHS to evaluate enrollment and health-related outcomes of the CSHCS program expansion as well as explore strategies to identify and enroll children that are potentially eligible for CSHCS.

## References

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