



State-University Partnership to Implement Public Health Surveillance for Sickle Cell Disease in Michigan



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Background

- Sickle cell disease (SCD) is a rare genetic blood disorder that primarily affects Black and Hispanic racial and ethnic groups in the United States.
- SCD can lead to multiple life-long health problems and reduced life expectancy; however, significant gaps remain in understanding progression and outcomes.
- In 2020, the CDC funded 11 states to gather population-based health information about people with SCD through the Sickle Cell Data Collection (SCDC) program (Figure 1).
- Data gathered by SCDC are used to study long-term trends in diagnosis, treatment, and healthcare access for people with SCD in the United States.
- Analysis of SCDC data can be used to inform health policy and healthcare guidelines that can improve the quality of life of individuals with SCD.

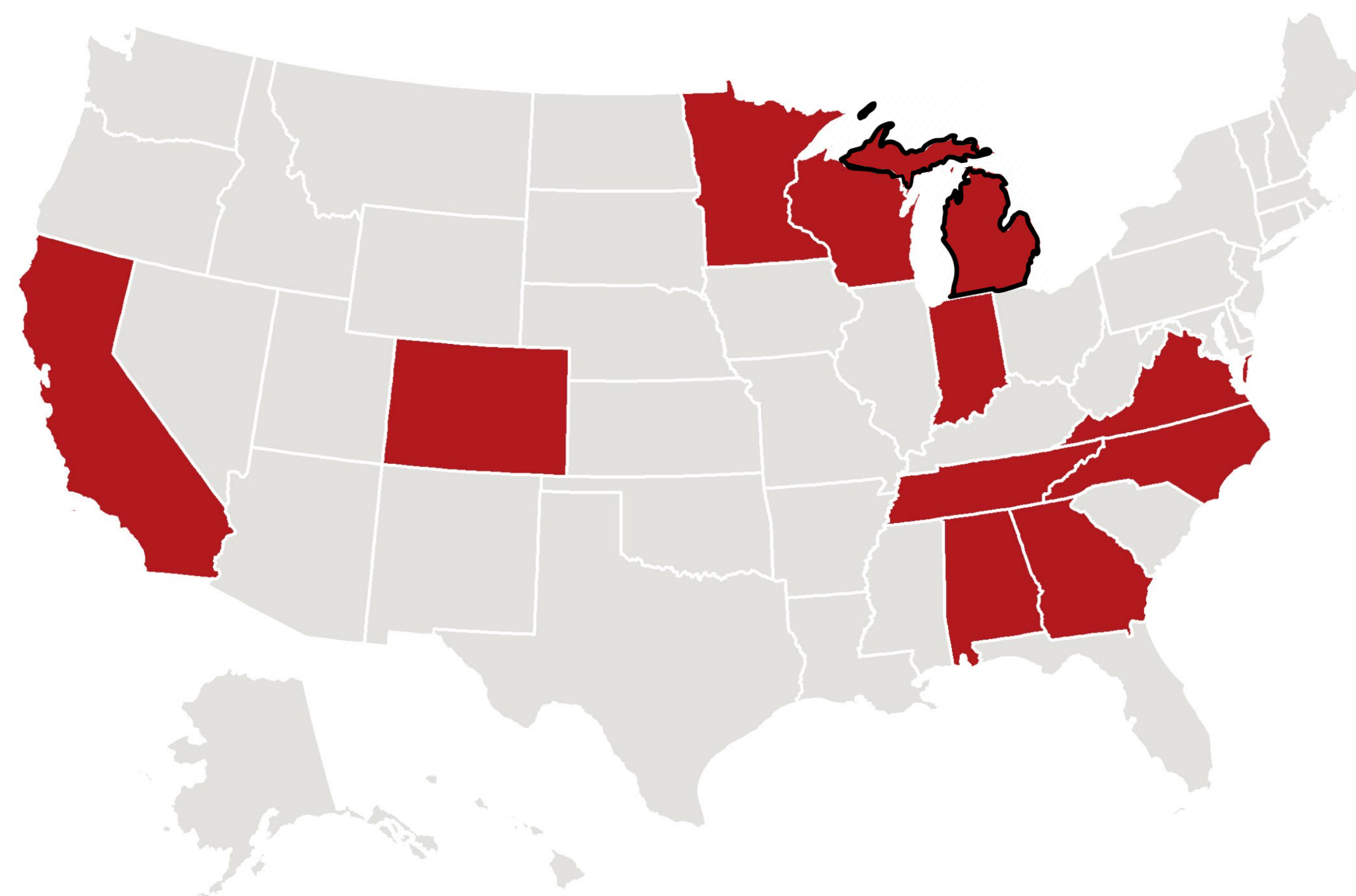


Figure 1. Map of SCDC States

Objective

Our objective was to describe the methodology to establish the CDC-funded SCDC program in Michigan.

Methods

The Michigan SCDC program (MiSCDC) is a state-university partnership between the Michigan Department of Health and Human Services (MDHHS) and the Susan B. Meister Child Health Evaluation and Research (CHEAR) Center at the University of Michigan.

To establish a public health surveillance system for SCD in Michigan, there were three main objectives:

- 1) **implement standardized methods for SCD surveillance;**
- 2) **engage stakeholders with interest in SCD; and**
- 3) **communicate findings to stakeholders in the SCD community.**

Results

To **implement standardized methods**, over a dozen sources of state-maintained and clinical data were acquired, linked, and analyzed to identify and collect health information about people with SCD in Michigan.

- Data sources include: SCD clinics in Michigan and state-maintained data such as newborn screening, Michigan Medicaid, Children's Special Health Care Services, immunization registry, vital records, and Michigan Hospital Discharge.
- Data collection was authorized by a grant of public health authority from MDHHS and data use agreements with data stewards.
- Linking and deduplicating across data sets has allowed standardized reporting of aggregate-level surveillance data to the CDC across all 11 states.

To **engage stakeholders**, MDHHS convened a multidisciplinary team comprised of patients, families, physicians, public health practitioners, and other stakeholders (Figure 2).

The team meets biannually with a mission to:

- build and maintain relationships,
- review MiSCDC data goals, and
- develop plans for using MiSCDC findings.

To **communicate results**, MDHHS developed a communication strategy to disseminate MiSCDC findings via emails, newsletters, briefs, social media, and the MiSCDC website (www.miscdc.org).

An example of this workflow is shown in Figure 3.

The MiSCDC Multidisciplinary Team has representatives from each of these areas of expertise:



Figure 2. MiSCDC Multidisciplinary Team

Conclusions

- Development of a public health surveillance system for a state-wide data collection program of a rare, chronic disease using a state-university partnership is feasible.
- A fundamental strategy for the success of this surveillance program is the permissions allowed through a grant of public health authority from MDHHS.
- The MiSCDC state-university partnership is strategically structured to leverage SCD stakeholder engagement to both conduct surveillance activities and disseminate findings to the public.
- Together, by communicating MiSCDC data and findings to stakeholders, these objectives can inform policy and system change opportunities to improve patient care and services for those living with SCD, a population impacted by racism and structural barriers to healthcare.

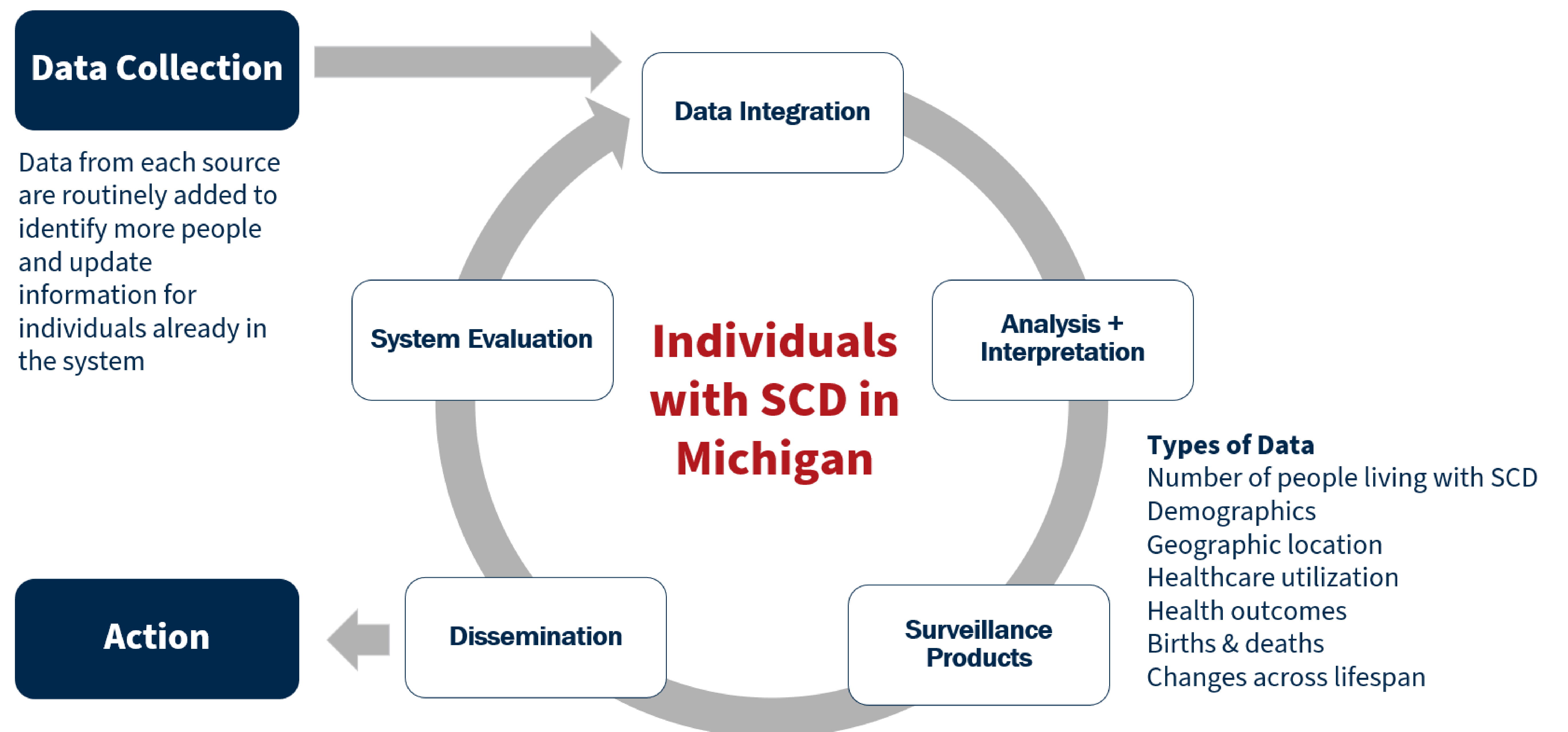


Figure 3. MiSCDC Workflow