Generations of Unmet Needs:

CRITICAL INSIGHT FROM THE 2018 SICKLE CELL DISEASE STAKEHOLDER FORUM

Prepared by the Minnesota Sickle Cell Disease Collaborative

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DEPARTMENT OF HEALTH

Sickle Cell Foundation OF MINNESOTA

"Of all forms of inequity, injustice in health care is the most shocking and inhuman."

Dr. Martin Luther King Jr.
March 25, 1966
Address before the Medical Committee for Human Rights

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The Sickle Cell Stakeholder Forum represents a first step toward understanding the challenges and disparities faced by individuals with sickle cell disease. This report will be used to generate awareness among policy makers, stakeholders, and the general public about the issues identified during the forum; to outline actions needed to address these issues; and to improve health outcomes for individuals impacted by sickle cell disease.

Acronyms

Sickle cell disease — SCD

Sickle cell trait — SCT

Newborn screening — NBS

Minnesota Department of Health — MDH

Minnesota Department of Human Services — DHS

Sickle Cell Foundation of Minnesota — SCFMN

The Centers for Disease Control and Prevention — CDC

Introduction

Over the past few years, community organizers and clinicians caring for patients with sickle cell disease (SCD) met to discuss the needs and challenges for the SCD community. This Minnesota Sickle Cell Collaborative has met twice, with more than 30 attendees, including parents of individuals with SCD, researchers, hematologists, advanced practice nurses, and public health professionals. Newborn screening programs, including the Minnesota Newborn Screening program, have been instrumental in identifying children born with SCD and ensuring that these children and their families are connected to specialists with the expertise to provide specialized care for these children. However, the 2014 legislative report, Advancing Health Equity in Minnesota[1] notes that, although MDH has allocated funds and efforts to address diseases affecting the white population, less emphasis is placed on issues primarily affecting populations of color, such as SCD. This results in significantly increased health inequities and adverse health outcomes; in the example of SCD, the most concerning is the decreased life expectancy for those living with SCD. A collaborative effort to address health disparities around SCD was identified as the type of work needed to address the issues identified in the Advancing Health Equity in Minnesota report. The Sickle Cell Disease Stakeholder Forum was an opportunity to bring together the impacted community, clinicians, and public health professionals to have an authentic conversation, identify needs, and ultimately work in partnership to move toward solutions.

Background on Sickle Cell Disease and Sickle Cell Trait

The CDC began recommending universal newborn screening for hemoglobinopathies in 1988. This was after the discovery that early intervention with penicillin prophylaxis for individuals with the most common type of hemoglobinopathy, sickle cell disease, had enormous potential to reduce infant morbidity and mortality. According to the CDC, SCD affects approximately 1 in 365 Black or African American births.[2] Or, when looking at the entire population in the United States, around 1 in 1,941 newborns will be identified to have a hemoglobinopathy, regardless of race.[3]

Sickle cell disease is an inherited disorder of hemoglobin formation. The red blood cells, which carry oxygen to the body, become hard, sticky, and abnormally shaped (like a farmer's sickle). When the hemoglobin sickles, it can block the flow of oxygen and blood in the blood vessels. Additionally these sickled cells break down at a rapid pace, compared to normal healthy hemoglobin. As a result, the individual develops a low blood count, also called anemia.

SCD is most often identified in individuals whose ancestors are from sub-Saharan Africa. It is also found in higher rates in people whose ancestors are from Spanish speaking regions (South and Central America), India, and Mediterranean countries (Turkey, Greece, Italy).[2]

Detection of SCD is the main goal of newborn screening for hemoglobinopathies. In addition, a variety of less severe hemoglobin disorders are also identified through this screening technology (hemoglobin SC disease, hemoglobin E disease, etc.). The way the screen is performed results in identification of infants who are carriers. An infant who is found to be a 'carrier' is often referred to as having 'trait.' The most common type of 'trait' is sickle cell trait (SCT). Individuals with SCT carry one copy of a gene for sickle cell disease and one normal copy of the gene. These individuals are expected to live normal lives, only experiencing symptoms under extreme circumstances. Sickle cell trait is important information for families to know when it comes to reproductive decision making. If their partner also has sickle cell trait or disease, they have an increased likelihood of having a child with sickle cell disease.

Sickle cell disease is also a disease that is uniquely impacted by racial and health disparities. The vast majority of individuals living with SCD are Black Americans and thusly, the impact of systemic racism on this community is apparent. Although SCD is the most common genetic disorder found through newborn screening, it currently (and historically) receives significantly less funding for education, outreach, and research to develop new treatments compared to other less common conditions such as cystic fibrosis (CF) that do not primarily

affect communities of color. A study conducted by Strouse et al. revealed that research funding for CF was approximately 8 to 11-fold higher than for SCD and national foundation funding was from 370 to 440-fold higher.[4] The same study noted that, between 2010 and 2013, there were five new drugs approved for CF and none for SCD, although one new drug for SCD was approved in 2017. Mortality rates are higher for individuals with SCD than for those without SCD, and although mortality among children under the age of 19 dropped by 3% from 1979-2005, mortality for adults increased 1% during that same time period with the median life expectancy for males and females being 38 years and 42 years respectively.[5]

An article published in JAMA in 2020 found additional disparities in funding. "Despite SCD being 3 times as prevalent as CF, both diseases recieved a similar amount of federal government research funding between 2009 and 2018."[6] Citing that federal funding per person with SCD was about $812, signifcantly lower that the $2807 per person with CF. The funding disparity was markedly increased when factoring in disease-specific private foundation funding." Farooq et al. continue, "...the standard of the successful CF care model is comprehensive, multidisiplinary care obtained in specialized care centers... There are more than 120 comprehensive care centers for CF in total, and 100 centers also provide adult care. In comparison, federal funding for 10 sickle cell centers ended in 2008; thus, there are no longer federally supported centers for comprehensive SCD care."

These numbers reveal that not only is there a health inequity for individuals with SCD, but that the trend in funding and health outcomes is moving in the wrong direction. In addition, while there are very effective specialty clinics and networks for CF, there are far fewer and less effective specialty clinics for SCD.[8] This is likely to be a factor in the adverse outcomes experienced by individuals with SCD.

Engaging the Community

According to the CDC Foundation, individuals with SCD experience more adverse outcomes and have access to fewer resources compared to individuals with other diseases.[7] The health outcome disparities faced by patients with SCD include a life expectancy 30 years shorter than people without SCD, a high rate of returning to the hospital after discharge, and a three times higher rate of stroke. In addition, there are few physicians trained to treat patients with SCD, especially adults, and SCD patients face longer wait times to see a doctor and to get pain medication when they are experiencing a pain crisis.[8] Understanding and addressing these disparities is a public health priority for the Minnesota Department of Health, the impacted community, and the medical providers who care for these individuals. These groups collaborated to host a community engagement event that would help to identify opportunities and develop strategies to improve the care of individuals with SCD in Minnesota. The goals of the event were to:

- increase engagement and awareness of SCD across disciplines and agencies, and partner with communities most impacted;
- gather information about challenges faced by individuals living with SCD and possible solutions by listening to affected individuals, their caregivers, and health care providers; and
- identify the resources needed for comprehensive SCD care across the lifespan.

The Sickle Cell Stakeholder Forum was held at Sanctuary Covenant Church in North Minneapolis on December 10, 2018. The forum was hosted in partnership with the Minnesota Department of Health, the Sickle Cell Foundation of Minnesota, and Children's Minnesota Hematology/Oncology. Sixty-seven individuals attended the forum representing the following stakeholder groups (participants could select multiple options):

- Individuals living with SCD (6)
- Family members/caregivers of a person living with SCD (10)
- Community members (13)
- Members of the health care system; including the University of Minnesota, Children's Minnesota, Hennepin Healthcare, HealthPartners, Neighborhood HealthSource, Essentia Health, and Memorial Blood

Centers Sickle Cell Donor Program (33)
- Researchers (8)
- Representatives from the pharmaceutical industry (3)
- Minnesota State government employees: including representatives from the Minnesota Department of Health, the Department of Human Services, and the Council for Minnesotans of African Heritage (26)
- Members of the press (2)
- Parent-to-Parent Initiative from the Sickle Cell Community Consortium (1)

The agenda for the Sickle Cell Stakeholder Forum can be found in Appendix A. The forum consisted of a series of presentations from individuals representing different stakeholder groups (see Appendix B for summaries), followed by small group discussions. All participants offered insights into the following three key questions during small group breakout discussions.

- When you reflect on the burden of SCD, what are the three most important issues impacting populations affected by this disease?
- What can we do, as a collaborative community, to improve care for adults living with SCD?
- If money were no object, what are three new services, programs, or collaborative efforts you would implement to address SCD?

Discussion among the stakeholder attendees was documented by note takers within each group.

Discussion Themes

Following the forum, notes from each of these small group discussions were assigned to themes using a consensus decision making process. Eight themes were identified within the discussions. 1) lack of comprehensive care across the lifespan, 2) transition supports, 3) race, racism, and equity, 4) policy, systems, and environmental gaps, 5) lack of support, 6) educational needs 7) research, treatment and therapy; and 8) data gaps. Themes are described below in order of frequency of theme in these group discussions, with the most discussed theme first and the least discussed theme last. Each theme contains descriptions of the elements of the discussion stakeholders had within their small groups.

Theme 1: Lack of Comprehensive Care across the Lifespan

The most discussed topic was related to the disparities faced by patients with SCD. A major reason for these disparities is the lack of comprehensive care across the entire lifespan for individuals living with SCD. Approximately 95% of children with SCD born in Minnesota receive specialized SCD care at Children's Minnesota. However, there are few resources available for adults with SCD, and older children with SCD transitioning to adult care are faced with going from a health care system that understands their comprehensive needs to one that does not (see Theme 2, Transition Supports). In addition, adult health care is more fragmented than pediatric care, with specialists and primary care providers often in different systems, making communication between providers difficult. Forum participants noted a lack of understanding of SCD by health professionals, lack of specialty care (e.g. hematology), and unwillingness of primary care providers to see SCD patients. Many of the disparities faced by SCD patients are related to emergency care for pain crises. They face long wait times and providers who do not have experience with the needs of an SCD patient in a pain crisis. SCD patients resort to keeping contact information of doctors who can advocate for them when they need emergency care for a pain crisis, but then are labeled as "troublemakers." In addition, they are frequently suspected of being drug-seekers (see Theme 3, Race, Racism, and Equity). Forum participants mentioned the need to develop specific medical guidelines, address coordination of communication between health care systems, identify specific services essential for care of SCD patients, and establish a comprehensive SCD care clinic that serves the entire lifespan. Each of these areas had significant discussion, as described below.

Medical guidelines

Guidelines and protocols in the emergency care setting were frequently mentioned as being needed. Participants noted that if emergency department guidelines and protocols existed, it would be harder for implicit bias to interfere in receiving quality care. Patients, families, and providers agreed that this would provide the medical team with the pertinent information needed to treat a SCD patient, while meeting the needs of the patients. They acknowledged that this approach would not fix the underlying problems, which are racism and lack of understanding of SCD, but that this could decrease the consequences of those problems that patients experience related to necessary medical treatment.

Coordination of health care

Participants discussed the need to improve coordination and integration of medical information across health care systems. Participants described a barrier they commonly experience when seeking emergency care: the system has no information about their diagnosis, recommended interventions, or history of treatments for medical management. This is often due to the patients not being established within the system. They felt that if medical record integration between separate health care systems was improved, it would be possible for the medical team to review the chart and information needed to individualize care to the patient's needs when care is obtained in a new health care system. They also discussed the importance of developing an emergency plan with their specialist medical team. In addition to developing that plan, it would also be important for emergency department providers to accept and honor that established plan, rather than question it. Participants also described the possibility of creating a "Sickle Cell Emergency Department Certification" training, similar to Stroke Center Certification that is already in place for facilities. This would enhance knowledge of SCD, approach to providing care, and overall patient experiences by completing specific requirements or trainings. This training should include assessment of bias and skills for addressing the identified biases.

Specific critical services were also described for improving care across the lifespan. These services identified the need for a deeper, holistic understanding of what truly creates health and well-being. Participants requested comprehensive care teams to include social services, integrative medicine, counseling, transportation services, childcare, and mental health counseling, in addition to the 'standard' medical doctor and nurse team members. Participants used words like "wrap-around care" and "comprehensive care" when describing the team of supports they believed would improve care for individuals living with SCD.

Need for a comprehensive care clinic

Many participants felt that the needs and gaps identified in these discussions would be best met through the establishment of a comprehensive care clinic that was able to meet the needs of the SCD community across the lifespan. They often described Children's Minnesota as an example of the type of comprehensive care they desired, but one without the limitations of aging-out of the system. There was specific discussion about how comprehensive care did not currently seem possible in Minnesota for adults living with SCD, because of the lack of a comprehensive adult SCD clinic option. They described an experience in which care would integrate pediatric services with adult services, and ideally, would also include primary care services. They described a "day center" in which infusions (regular transfusions are required for life following the occurrence of a stroke) were possible in addition to other services that would be able to assist a patient, prior to requiring emergency care, and possibly avoiding the need for inpatient care through early access and interventions. Participants acknowledged that new clinical partnerships have resulted in discussions about how this might be done, however providers described a number of barriers when attempting to establish these services (e.g. funding, data on SCD population, cost of SCD to health care system). There was consensus from participants that the establishment of a comprehensive care center that addressed the entire lifespan would be of benefit for this community and result in improved quality of life for individuals living with SCD.

Theme 2: Lack of Transition Support

Need for transition support

Leaving the pediatric setting and entering the world of post-pediatric health care, commonly referred to as transition, leads to gaps in health care for SCD patients. Participants described how helpful the support received in the pediatric clinic was in maintaining and managing their disease, and the difficulty in navigating their condition once the support was lost after transitioning out of pediatric care. In the absence of that support in the adult setting, patients have found the transition to adult health care a challenge. Parents of SCD patients described the need to accompany their adult children to the hospital to advocate for their needs in order to get them the proper care that they need and the necessity to call Childrens Minnesota to get their children the care they needed. Pediatric providers noted that they were hesitant to send their SCD patients into adult care knowing that they won't get the care that they need. Young adults with SCD describe being dismissed by the medical community when they attempt to articulate their needs. This experience results in a change in how the affected community accesses health care. Individuals living with SCD articulated that with the transition from the pediatric setting they began to no longer have an opportunity to focus on wellness and preventive care as those services were not available. They instead focused on crisis management, typically occurring in the emergency department setting. Discussion about the lack of transition services identified two key issues. The first was lack of an adult specialty care clinic for this patient population, where they could establish care to maintain and manage their disease effectively. The second was a lack of necessary supports to successfully transition to a new care center and style. Of great importance to the discussion were the experiences young adults recounted when seeking medical care during and following transition away from the pediatric setting. They described situations in which they seek medical care for pain crisis management and experience overt or implicit racism from the medical staff, in addition to a lack of familiarity with SCD by the staff, both of which result in negative medical interactions.

Theme 3: Race, Racism, and Equity

Although SCD is a global disorder (which can affect people of all races), in the United States of America, the vast majority of the 100,000 individuals living with SCD are Black. As such, participants discussed the impact of race, racism, and equity in relation to their experiences with SCD. This discussion spanned a variety of topics, such as how racism affects care and the historical trauma Black Americans experience with relation to the medical community. They also discussed specific examples of racism related to patient-advocacy, emergency room care, and the importance of equal trust between medical providers and patients.

The lack of familiarity of SCD, coupled with the provider's explicit or implicit bias, has resulted in very negative experiences of patients being labeled as drug-seekers rather than being treated appropriately for a SCD pain crisis. Participants described a lack of compassionate care and described repeated instances in which a pain crisis was not treated as the emergency it is. Additionally, they shared experiences in which they were attempting to advocate for themselves, or their child, as they were knowledgeable about what medical interventions may be needed or had worked well in the past. However, their advocacy resulted in being labeled a difficult patient or drug seeking by the medical team. Participants explained that this is a particularly difficult and frustrating situation, as they were taught by their medical teams to advocate for themselves and participate in shared decision-making about their care. Unfortunately, other providers and staff who are not familiar with them as a patient, or with SCD, perceive that same advocacy negatively.

Lack of cultural competency training

Participants detailed the need to address racial biases and improve cultural competency as a key part of medical training. They described the harm done to the patient and the patient-provider relationship when providers are not encouraged to become aware of their own biases and in the absence of intentional work to

address those biases. Participants shared that racism seems to be especially challenging to deal with given the 'Minnesota culture' of 'niceness.' Participants articulated they feel racism is pervasive in the experiences of Black Americans living with SCD. They described these disparities by drawing on the lack of access to care, the poor quality of treatment provided by the care team, and the lack of supports and services provided to this community when compared to other chronic diseases.

Additionally, the participants described the impact of historical trauma that Black Americans face when seeking medical care. Discussion about the historical experiences–such as the Tuskegee experiment, James Marion Sims' (known as "The Father of Modern Gynecology") shockingly unethical medical experiments on Black women without their consent; radiation experiments on Blacks between 1944 and the 1990s, the Fenfluramine experiments on young Black boys in the 1990s, forced sterilzation and contraceptive use on Black women as recent as the 2000s, just to name a few atrocities performed in the name of medicine–need to be openly taught in medical school and acknowledged by medical providers so rebuilding of trust can be possible. Some felt this rebuilding could be done through the medical community engaging with impacted communities, such as the SCD community, to rebuild trust and positive relationships.

Some discussion was more specific as to how a patient was treated by the health care provider, and that treatment was strongly influenced by the race of the individual seeking care. Patients and parents described experiences of discrimination and labeling within emergency room that results in a lack of quality care. They articulated experiences of implicit and explicit racism in the emergency room, as well as the difficultly with advocating for oneself in the face of racism.

It is important to note that the impacts of racial biases and racial discrimination are experienced not only at the individual level of provider to patient, but also at a systems level. Structural racism is embedded within health systems when the practices, policies and procedures of the institution perpetuate discriminatory behavior.

Theme 4: Policy, and Systems Gaps

Participants spent a significant amount of time detailing a number of issues encountered by SCD patients that related to policy, systems, and the impacts of SCD on their daily lives. Much of this discussion revolved around desired changes to improve the quality of life for individuals living with SCD. These changes would be needed on a number of levels, such as national or state policies, or within health care systems. In addition, participants identified specific legislation required for meaningful changes for the SCD community.

National policy gaps

Participants desired more engagement on a national level to improve the health disparities that are rampant in our communities in the United States and that uniquely affect the SCD community given it is a mostly African American population. They desired a concerted effort to expand the number of medical providers who are from communities of color. They described a need for health care for all, a living wage, equitable pharmaceutical access, and improvements in access to medical care for rural Americans as contributing to improvements for this community. They felt addressing these elements nationally would ultimately also improve outcomes for individuals living with SCD. Additionally, they described a desire for a return to the SCD Centers of Excellence model, which was a federally-funded approach to addressing the unique needs of the SCD community that is no longer financially supported by the government.

State policy gaps

Participants discussed communication of sickle cell trait by the Newborn Screening program. While participants were glad that families were now getting this information; they were surprised that development of the trait notification process was such a recent change. They discussed dissatisfaction that parents are responsible for the cost for parental testing for trait status. Additionally, participants discussed the need for

continued collaboration between the Minnesota Department of Health and trusted community leaders to continue the effort of building relationships and trust. Participants also described the need to compensate the community mentors and advisors for the time that they spend providing feedback, guidance, and advice to the Minnesota agencies and programs who rely on this critical information.

In addition to increased collaborative efforts, participants described policy or legislation changes as a possible mechanism to improve outcomes. One of the most commonly identified policies was protections around job security for those with SCD. Individuals and providers described the difficulties with keeping a steady job, or with struggling about disclosing SCD status in a job interview, due to fear of discrimination. They felt job protections would allow individuals with SCD to obtain better quality and more engaging work. They also discussed the need to increase federal and state funding to improve research opportunities and innovation for individuals living with SCD.

Need for health care system integration

Participants felt that a number of key investments would provide better service and therefore better outcomes for individuals with SCD. This included discussion of improved access and integration of electronic medical records within and between systems. They described the benefit of a patient experience 'system' that would be focused on improving patient experiences rather than protecting hospitals. They felt this could be done by capturing patient complaints, performance measures, readmissions, and other quality assurance measures to truly help understand the disorder and the issues faced by the patient, in order to make system level changes that are meaningful. They spoke about incentivizing partnerships between competing health care systems to ensure the patient is cared for across the life span, often citing the issues with transitioning out of pediatric care health systems and the lack of established adult care centers.

Theme 5: Lack of Support

Need for a community advocate

Discussions included the need for patient supports in a few key areas that extend beyond clinical services. Participants described the importance of having a community advocate; a paid professional who can support individuals and families across the state and assist with navigating the difficulties associated with a chronic disease. They felt a community advocate would also be able to teach SCD patients and families how to self-advocate in a more effective and supported way.

Need for comprehensive support services

Conversations also identified patient supports that would aid in developing the entire person, not just focusing on the medical needs. They articulated a desire for mentorship programs and social groups that focused on the whole person. They described a desire to better understand the disease on an intellectual level, not just a patient perspective. They desired an opportunity to plan and prepare for the future non-medical parts of their life where SCD would be a complicating factor, and the desire to do this with others who are knowledgeable in the impacts of SCD.

Participants described the importance of providing services that would help in supporting and creating positive mental health strategies. They often described the value of a support group. They articulated the trauma experienced by navigating this disease alone and the desire to build and participate in conversations with those who have shared experiences.

Theme 6: Educational Needs

Forum participants described the importance of education about SCD for a variety of audiences. They described the need for education on multiple levels including for the general public, the SCD community at large, medical providers, and schools.

Lack of public awareness of SCD

The current lack of awareness about SCD in the general public has resulted in exacerbation of the current social stigma faced by SCD patients and propagation of inaccurate information about SCD in the lay community. Participants felt that increased engagement on a population level would allow the community to better shape the narrative about SCD. They described that destigmatizing SCD would provide new opportunities to increase awareness and ultimately appropriately resource SCD needs by making SCD a general public concern. Increasing general public awareness would elevate the conversation to ideally change funding, research, and increase other opportunities for individuals living with SCD.

Need to change SCD community narrative

Participants expressed that the SCD community is larger than it currently identifies, and that increased conversation could bring in members who were previously unaware of their connection. They described that rather than allowing the historical narratives of SCD to remain the dominant narrative in the community, that by targeting education to this community it would create space to reshape the narrative and destigmatize SCD. They felt community engagement could lead to increased blood donations for the SCD community (which are essential and currently not meeting the needed volumes) and could result in increased partnerships with connected communities (such as immigrant and refugee communities).

Inadequate provider education

Individuals and family members impacted by SCD articulated a lack of health care provider knowledge about the disorder, which exacerbated negative health care experiences when they sought medical care. Inadequate and insensitive care in emergency department settings, due to lack of provider knowledge, was discussed by multiple groups. They described experiencing a lack of empathy from providers and staff during pain crises, and frequent experiences of being labeled as drug-seeking, rather than having their legitimate medical needs taken seriously. Participants felt that increased provider knowledge of SCD and its treatment and management, especially related to pain crisis, would allow for an easier path for patients to get the care they need in a dignified manner.

Lack of knowledge of SCD among school staff

Lastly, participants shared stories of experiences in schools that made it evident that the school staff had a lack of understanding of SCD and its possible effects on the impacted student. They described the insecurity that they experience due to people not understanding their need to be absent, and the difficulty of juggling school work while dealing with a chronic, but not readily apparent, condition. One participant described an experience where their teacher told them they did not actually have SCD, because they were “bigger than they were supposed to be.” The participants discussed the damage of such statements and described how increased awareness and knowledge about SCD among school staff would help students living with SCD manage and maintain their health, feel supported, and be successful in the school environment.

Theme 7: Research, Treatment and Therapy

Need for SCD research

Participants articulated the importance of the need to partner with the community when conducting research. They discussed the limited options available for therapy, inadequate research on health outcomes, and sparse research currently ongoing to develop new treatments for SCD. Increased research in this population, presumably, would lead to more treatment and therapy options. Additionally, it would increase the understanding of disease across the lifespan for the community. Extensive information is known about children with SCD in Minnesota because of the comprehensive care the medical teams offer for these children. Given the lack of comprehensive care in adulthood, less information is known about the impacts of this disease on the adult and aging populations. It is critical that this research is done in a way that is racially and culturally sensitive and in collaboration with the community, rather than on the community. Participants discussed collaboration as an essential component, given the trauma experienced by this community due to research practices in our nation's history, James Marion Sims' (known as "The Father of Modern Gynecology") shockingly unethical medical experiments on Black women without their consent; radiation experiments on Blacks between 1944 and the 1990s, the Fenfluramine experiments on young Black boys in the 1990s, forced sterilzation and contraceptive use on Black women as recent as the 2000s, just to name a few atrocities performed in the name of medicine, and of course, the most widely know–The Tuskegee experiment.

Theme 8: Data Gaps

Lack of data on SCD in Minnesota

Participants articulated the importance of improving data collection when considering current needs and gaps. Increasing access to and collection of data would provide better understanding of the true impact of SCD on the health care system, on the individual, and other complications of SCD in adulthood. Currently, limited data is collected about individuals living with SCD by state and federal organizations. In the absence of a registry and the inability to access and assess existing database information, we are without an accurate understanding of the true needs of the community. It is critical to ensure that the data remains humanized through the incorporation of patient stories and experiences. Without the ability collect and analyze data in Minnesota, understanding the true extent of the needs of this community will continue to be a challenge.

Conclusion

Among the dozens of conditions that are screened for in state newborn-screening programs, SCD is the most commonly detected condition, regardless of ethnicity. It is thus important to recognize SCD as a common and important medical condition among Americans, and not "just Black Americans."[9]

"Medicine is a mirror for the racial injustice in our society; it is a field riddled with racial disparities in everything from research funding to patient care to life expectancy. There may be no population of patients whose health care and outcomes are more affected by racism than those with sickle cell disease (SCD). Patients with SCD are too often marginalized and dismissed while seeking medical care when their bodies hurt and they cannot breathe."[10]

The average life expectancy for someone living with SCD is 30 years less than that of someone without SCD. For too long allocation of resources, funding, and policy decisions have been lacking. While "Minnesota is consistently ranked amount the healthiest states in the nation, it is also home to some of the greatest health disparities in the country between white residents and people of color."[11] There is a lot of work to be done to give all Minnesotans the same health outcomes and life-expectancy of white Minnesotans; it is time to prioritize the health for people of color as it is crucial to the health of the state as whole.[11]

The challenges faced by individuals with SCD and their caregivers are complex and addressing them will require identification of resources, input from multiple stakeholder groups, and development of partnerships that include the impacted community, health care providers and systems, state and federal agencies, researchers, and policy-makers. The largest take away from the Sickle Cell Disease Stakeholder Forum was that we cannot afford to wait any longer to act. Minnesotans are dying excruciating deaths decades before their peers from a condition that was first brought to the attention of the Western medical community over one hundred years ago. It is time to act and prioritize the health and care for all Minnesotans.

In the coming months, the Sickle Cell Foundation of Minnesota and the Minnesota Department of Health will be releasing a series of recommendations to improve the lives of people living with sickle cell disease in Minnesota.

Works Cited

[1] “Advancing Health Equity in Minnesota,” Minnesota Department of Health, February 2014. [Online]. Available: https://www.health.state.mn.us/communities/equity/reports/ahe_leg_report_020114.pdf. [Accessed 29 July 2019].

[2] “Data and Statistics on Sickle Cell Disease,” Centers for Disease Control and Prevention, [Online]. Available: https://www.cdc.gov/ncbddd/sicklecell/data.html. [Accessed 29 July 2019].

[3] B. Therell, M. Lloyd-Puryear, J. Eckman and M. Mann, “Newborn screening for sickle cell diseases in the United States: A review of data spanning 2 decades,” *Semin. Perinatol*., vol. 39, no. 3, pp. 238-51, 2015.

[4] J. Strouse, K. Lobner, S. Lanzkron and H. J. C. MHS, “NIH and National Foundation Expenditures for Sickle Cell Disease and Cystic Fibrosis are Associated with Pubmed Publications and FDA Approvals,” *Blood*, vol. 122, p. 1739, 2018.

[5] S. Lanzkron, C. Carroll, and C. Haywood Jr. “Mortality Rates and Age at Death from Sickle Cell Disease: U.S., 1979-2005,” *Public Health Rep,* vol. 128, p. 110, 2013.

[6] Farooq F, Mogayzel PJ, Lanzkron S, Haywood C, Strouse JJ. Comparison of US Federal and Foundation Funding of Research for Sickle Cell Disease and Cystic Fibrosis and Factors Associated with Research Productivity. *JAMA Netw Open*. 2020;3(3):e201737. doi:10.1001/jamanetworkopen.2020.1737.

[7] S. Grosse, M. Schechter, R. Kulkarni, L.-P. MA, B. Srickland and E. Trevathan, “Models of Comprehensive Multidisciplinary Care for Individuals in the United States with Genetic Disorders,” *Pediatrics*, vol. 123, p. 407, 2009.

[8] “Sickle Cell Disease Health Disparities,” CDC Foundation, [Online]. Available: https://www.cdcfoundation.org/sites/default/files/files/SickleCellDisease-HealthDisparities-FactSheet021618.pdf. [Accessed 29 July 2019].

[9] N.E. Igbineweka, N. Tshuma, and N.B. Roy. “Medical Science Must Address Health Disparities Amoungst Different Ethnic Groups.” *Nature Human Behaviour*, 5, pp 1595-1597, 2021. https://www.nature.com/articles/s41562-021-01240-3

[10] A. Power-Hays, A. McGann, and T. Patrick. “When Actions Speak Louder Than Words—Racism and Sickle Cell Disease,” *New England Journal of Medicine*. November 12, 2020. https://www.nejm.org/doi/full/10.1056/NEJMp2022125

[11] “Cultivating a Health Equity Ecosystem,” Minnesota Department of Health, Center for Health Equity. May 2020. https://www.health.state.mn.us/communities/equity/ehdi/reports/impactreport.html

Appendix A: Stakeholder Forum Agenda

Agenda

SICKLE CELL DISEASE

STAKEHOLDER FORUM

7:30 - 8:00 Breakfast

8:00 - 8:10 Welcome | Commissioner Jan Malcolm

8:10 - 8:25 Introduction: What Brings Us Together | Joanne Bartkus, Ruth Lynfield, & Ellie Garrett

8:25 - 8:45 Clinical Perspectives of Sickle Cell Disease/Issues and Barriers | Dr. Steve Nelson

8:45 - 9:05 Community Listening Sessions | Rae Blaylark

9:05 - 9:15 Questions for Speakers

9:15 - 9:25 Personal Story | James Burroughs

9:25 - 9:40 National SCD Highlight | American Society of Hematology

9:40 - 9:50 Personal Story | Isaiah Lane

9:50 - 9:55 BREAK

9:55 - 11:10 Table Discussions

11:10 - 11:20 BREAK

11:20 - 11:35 Report Out from Table Discussions | All

11:35 - 11:50 CDC Perspectives: SCD | Mary Hulihan

11:50 - 11:55 Next Steps | Joanne Bartkus

11:55 - Noon Evaluations

OUR PARTNERS

DEPARTMENT OF HEALTH | Sickle Cell Foundation of Minnesota | Children's Minnesota | STORM Sickle Treatment & Outcomes Research in the Midwest

Appendix B: Summary of Presentations

In order to frame the issues discussed at the Sickle Cell Disease Stakeholder Forum, a variety of speakers shared information, data, and personal stories about SCD. These presentations included data from the Department of Health and the Department of Human Services, information from CDC and ASH regarding current SCD efforts that are on-going, and most importantly it was framed by Dr. Nelson and Ms. Blaylark speaking about the experience of living with SCD in Minnesota, and the needs, issues, and opportunities for improvement identified by the provider and patient/family perspectives of those most impacted. *This does not include the summary of personal testimony from James Burroughs and Isaiah Lane.

Clinical Perspectives of Sickle Cell Disease/Issues and Barriers

Stephen C. Nelson, MD
Children's Minnesota

Dr. Stephen Nelson provided a presentation on clinical perspectives of SCD. The federal government mandated screening for SCD in 1986, however it was not until 2006 that all 50 states, Puerto Rico, and the US Virgin Islands were screening for SCD. Minnesota added hemoglobinopathy screening to their newborn screening panel in 1988. Health inequities exist for SCD. SCD is present in 1 in 2400 births, and while cystic fibrosis (CF) is present in 1 in 3900 births, research funding for CF was eight-times higher than for SCD in 2004, and 11-times higher than SCD in 2014. In addition, there have been five new drugs approved for CF since 2009, and only one for SCD. Mortality rates are higher for individuals with SCD, and although mortality among children under the age of 19 has dropped since 1979, mortality for adults has increased. In 1994, life expectancy for males and females with SCD was 42 years and 48 years respectively. In 2005, life expectancy for males and females was 38 years and 42 years respectively. These numbers reveal that not only is there a health inequity for individuals with SCD, but that the trend in funding and health outcomes is moving in the wrong direction.

Funding from the Health Resources and Services Administration (HRSA) supports regional collaboratives of states to address the need to improve the prevention and treatment of SCD. Minnesota is a member of the Sickle Treatment & Outcomes Research in the Midwest (STORM), which also includes North Dakota, South Dakota, Wisconsin, Michigan, Illinois, Indiana, and Ohio. A goal of STORM is to bring together the hematology and primary care communities, along with patients and families to collaborate on initiatives to improve access and delivery of care and outcomes for patients with SCD in the Midwest. To help meet this goal, the Minnesota Sickle Cell Collaborative was formed. This collaborative consists of SCD patients and their parents, researchers, social workers, registered nurses, hematologists, primary care physicians, advanced practice nurses, and others who collaborate to improve health outcomes for SCD patients. This collaborative has met twice with more than 30 participants in attendance, and they have been a collaborator in developing this stakeholder forum.

Community Listening Sessions

Rae Blaylark
Founder/CEO
Sickle Cell Foundation of Minnesota (SCFMN)

Ms. Blaylark shared information about the formation of the foundation. She discussed the foundation's primary audience: individuals and communities affected by SCD and sickle cell trait (SCT). Founded in 2015, SCFMN's mission is to improve the quality of life for individuals and communities affected by SCD and SCT. The vision of SCFMN is to act as an advocate for improved health care and services for SCD patients by educating and informing the community through outreach programs and targeted events. The foundation plans to achieve this through the values of community health, equitable access to competent care, and community-centered solutions. Ms. Blaylark shared the key strategies utilized by the foundation: patient and provider

education, community engagement, patient advocacy, and cultivating key partnerships.

SCFMN has increased their participation in national SCD activities on SCD education, advocacy, and guideline development through engagement with the Sickle Cell Disease Association of America (SCDAA), the Sickle Cell Community Consortium (SC3), and the American Society of Hematology (ASH). The foundation also engages in a number of regional community engagement efforts, such as the Sickle Cell Treatment Outcomes Research in the Midwest (STORM). She also shared local community engagement opportunities.

In 2018, SCFMN undertook an effort to directly engage with the community to introduce themselves to the community and to identify concerns and assess the needs affecting the Minnesota SCD population. This engagement effort was done through in-person interviews, surveys with both providers and patients, and community listening sessions. These conversations identified the following:

- The challenge of directly engaging with the SCD community (patients, caregivers, and medical providers) is intensified due to the lack of intentional engagement over the years with this community. Low health literacy and a need for additional education to increase both the community and medical provider capacity to understand SCD.
- A significant proportion of the adult SCD population rate their medical providers poorly or describe negative experiences and challenges related to accessing competent services.
- Emergency room protocols that were utilized and resulted in negative impacts to patients.
- The importance of support networks, effective advocates, and positive relationships with medical providers.
- The lack of a multi-disciplinary, comprehensive approach to care that improves outcomes by addressing complications of the disease prior to problems occurring.
- The experiences reported by the community have been substantiated by the reports found in the literature regarding SCD patient concerns.
- Additionally, findings specific to the medical community demonstrated providers feeling a lack of support in finance, staffing, and institutional policy to be able to address the many complex needs of the SCD population.

Ms. Blaylark provided SCFMN's recommended next steps identified through the listening sessions. The recommendations are:

- Education and awareness (community and providers)
- Advocacy and stakeholder relations
- Changes to emergency department protocols and patient experiences
- Policy and legislation
- Support and empowerment groups
- Responsible reporting and feedback mechanisms within institutions

Ms. Blaylark discussed that the recommendations would be best achieved as a joint partnership between SCFMN, the State of Minnesota Department of Health, and clinical and medical partners.

i http://sicklestorm.org/

ii https://www.cdc.gov/ncbddd/hemoglobinopathies/data-reports/2018-summer/index.html

What Brings Us Together

Ellie Garrett
Deputy Director, Office of the Medical Director
Minnesota Department of Human Services

Ms. Garrett shared data about public health care program (e.g. Medical Assistance/Medicaid) recipients and sickle cell disease. In 2017, among people covered by the state's public health care programs, 610 individuals were diagnosed or treated for SCD. Most of them were younger than 18. A substantial decrease in enrollment was evident for individual's ages 18-20 years. This may suggest either the substantial risk for death from SCD at young ages, or may be due to the criteria for qualifying for public health care programs are stricter for adults than for children.

Ruth Lynfield, MD
State Epidemiologist and Medical Director
Minnesota Department of Health

A review of vital statistics data from the Minnesota Department of Health from 2013-2017 found 28 deaths with "sickle cell" or "SC disease" included on the form filed with the State. The age range was 9-66, with a median age of 34 years. There are limitations to the data, as additional people with SCD may have died during this time, but SCD was not recorded on the form as an underlying condition. Also, in some cases, sickle cell disease may not have been the cause of death, but was listed on the death certificate.

National Sickle Cell Disease Highlights

Stephanie Kaplan
Deputy Director, Government Relations and Public Health
The American Society of Hematology

The American Society of Hematology (ASH) is a professional organization whose membership includes clinicians and scientists who focus on diagnosis, treatment, and prevention of blood diseases. ASH has recently launched an initiative to address the burden of SCD in the United States and around the world. This is the first ASH initiative in support of a single disease. Priority areas for the ASH Sickle Cell Disease Initiative include access to care, research, global issues, development of a Sickle Cell Disease Coalition, and policy development.

In 2016, ASH founded a Sickle Cell Disease Coalition, which now includes more than 65 member groups. The goal of this coalition is to "amplify the voice of the SCD stakeholder community." The SCD Coalition recently released its State of Sickle Cell Disease: 2018 Report Card,[13] which provides an assessment of progress in four areas: access to care in the U.S., provider training and education, research and clinical trials, and global issues. Since the last assessment in 2016, there has been positive change; however, there are still areas that need improvement including barriers to quality care, lack of health care providers with expertise in management of individuals with SCD, limited treatment options, and a need for further improvements in screening and treatments in the developing world.

The ASH Research Collaborative was established in 2018 to promote research to improve the lives of individuals with SCD. The collaborative has two components, a data hub to facilitate sharing of data, and a Sickle Cell Disease Clinical Trials Network. The goal of the SCD Clinical Trials Network is to develop a network of research sites to improve collaboration among researchers working to advance clinical outcomes.

In the realm of policy development, ASH works with federal agencies and the U.S. Congress to raise awareness of SCD and to promote policy initiatives to address SCD issues, including increasing funding of SCD research, training, and services, and improving reimbursement for care of individuals with SCD. They have developed an advocacy toolkit to help individuals become advocates to advance issues that impact SCD research and clinical practice.

ASH has also been actively working to update the 2014 clinical practice guidelines for Management of Acute and Chronic Complications of Sickle Cell Disease.[14] Topics addressed in these guidelines include transfusion support, cerebrovascular disease, cardiopulmonary and kidney disease, stem cell transplantation, and pain management.

CDC Perspectives: Sickle Cell Disease

Mary Hulihan
Division of Blood Disorders, National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention

The Centers for Disease Control and Prevention (CDC) is a federal agency that monitors and responds to health threats with a goal of improving public health in the United States. CDC recognizes that there are gaps in knowledge about SCD, including how many people are living with SCD in the United States, and the impact of sickle cell disease on individual health. These data gaps exist for a variety of reasons, but one reason is the lack of national data collection. To address the data gap, CDC has established a Sickle Cell Data Collection (SCDC) project with the objective of collecting, analyzing, and sharing data about SCD. Data collected as part of this project will be used to help health care providers, advocacy groups, researchers, and policy makers understand the health profile of the SCD population and track health outcomes. Ultimately, this information can be used to improve the lives of individuals with SCD by targeting efforts towards policy changes, improved health care practices, and new treatments.

The SCDC program collects information from a variety of sources, including newborn screening records, administrative datasets (such as Medicaid and those kept by hospital and emergency departments), death records, and medical charts. California and Georgia are currently the only two states involved in the SCDC program. The data is collected and maintained by state partners and represents approximately 12-15% of the United States' SCD population. However, as resources become available, the CDC plans to expand the program to build a national SCD registry to capture information from all states.

There are numerous examples of how filling data gaps with SCDC data benefits individuals with SCD. In Georgia, SCDC data was used to identify areas with higher concentrations of residents with SCD and to make health care providers aware of them. In California, SCDC data revealed that Los Angeles County had a large population of residents with SCD, but lacked access to comprehensive care. This information was used to successfully support advocacy for an adult sickle cell clinic to address this gap in health care services. SCDC data can also help pharmaceutical companies assess the need and markets for new drugs, and can help measure the impact of new drugs on health outcomes and utilization of health care services.

Communication of SCDC data is important and CDC disseminates information through publications and presentations, health education, outreach, and collaboration with partners and stakeholders. The SCDC provides educational materials to individuals with SCD and their caregivers. These are educational resources they can use to play a more active role in decisions about their care.

Detailed information about the SCDC Program and how the data can be used to improve the lives of individuals with SCD can be found in the SCDC Report: Data to Action.

iii https://www.hematology.org/

iv https://www.hematology.org/Advocacy/Sickle-Cell/

v www.scdcoalition.org

vi Contact information SCD-CTN@ashresearchcollaborative.org, datahub@ashresearchcollaborative.org

vii http://www.hematology.org/Advocacy/7644.aspx

viii https://www.cdc.gov/ncbddd/hemoglobinopathies/data-reports/2018-summer/index.html

Appendix C: Sickle Cell Disease Resources

Sickle Cell Foundation of Minnesota
Location: https://www.sicklecellmn.org/
Audience: Education, Families, Community
Description: Resources for individuals with sickle cell disease and their families

American Society of Hematology Sickle Cell Initiative
Location: https://www.hematology.org/Advocacy/Sickle-Cell/
Audience: Community, Policy Makers, Providers, Patient Resources
Description: Initiative to address the burden of SCD, both in the United States and globally

SCD Coalition
Location: http://www.scdcoalition.org/
Audience: Community, Families, Providers, Policy Makers
Description: SCD Coalition goal is to amplify the voice of the SCD stakeholder community to improve outcomes for individuals with SCD.

Centers for Disease Control and Prevention (CDC) Sickle Cell Disease
Location: https://www.cdc.gov/ncbddd/sicklecell/index.html
Audience: Community, Families, Providers, Policy Makers, General Public
Description: Information about SCD, including treatment, data and statistics, research information, and SCD management tips

Sickle Cell Disease, National Heart, Lung and Blood Institute (NHLBI)
Location: https://www.nhlbi.nih.gov/health-topics/sickle-cell-disease#Diagnosis https://www.nhlbi.nih.gov/health-topics/sickle-cell-disease/health-professional-information
Audience: General Public, Health Professionals
Description: General information about SCD, treatments and management; clinical trials and research; website also in Spanish. NHLBI Publications and Fact Sheets

Evidence-Based Management of Sickle Cell Disease: Expert Panel Report, 2014, National Heart, Lung and Blood Institute (NHLBI)
Location: https://www.nhlbi.nih.gov/health-topics/evidence-based-management-sickle-cell-disease
Audience: Providers
Description: Guidelines developed by an expert panel selected by the NHLBI's leadership composed of health care professionals provide the best science-based recommendations to guide practice decisions.

Sickle Cell Disease Association of America (SCDAA)
Location: https://www.sicklecelldisease.org/
Audience: Patients, Families, Providers, Public Health, Community
Description: National SCD organization that advocates for people affected by sickle cell conditions and empower community-based organizations to maximize quality of life and raise public consciousness while advancing the search for a universal cure.

Sickle Cell Information Center, Emory Center for Digital Scholarship
Location: http://www.scinfo.org/
Audience: Patients/Families; Health Care Providers; Community
Description: Resource with professional education, news, research updates and access to up-to-date sickle cell resources worldwide.

Baby's First Test
Location: https://www.babysfirsttest.org
Audience: Health Professionals; Patients/Families; Newborn Screening
Description: Newborn screening resources to help guide parents and health professionals

Sickle Cell School Resources, Children's Hospital of Philadelphia (CHOP)
Location: https://www.chop.edu/health-resources/sickle-cell-school-outreach
Audience: Education, Families, Community
Description: Comprehensive information on sickle cell disease and how it can affect the school life of children. Includes Sickle Cell Handbook for Schools

California Sickle Cell Resources, UCSF Benioff Children's Hospital
Location: http://casicklecell.org/
Audience: Patients, Families, Providers, Public Health, Community
Description: A wide range of patient/family resources regarding SCD treatment and management, transition, and advocacy. Also archived webinars, California data and research.

Michigan Hemoglobinopathy Quality Improvement Program, Michigan Department of Health and Human Services (MDHHS)
Location: https://www.michigan.gov/mdhhs/adult-child-serv/childrenfamilies/hereditary/genomics/rush
Audience: Public Health, Stakeholders, Community
Description: MDHHS Public Health SCD Strategic Planning resources and reports.

CDC Tips for Supporting Students with Sickle Cell Disease
Location: https://www.cdc.gov/ncbddd/sicklecell/documents/tipsheet_supporting_students_with_scd.pdf
Audience: Patients, Families, Schools, Health Professionals, Community
Description: Describes sickle cell disease (SCD) and identify roles for teachers, other school staff and parents/caregivers to support students living with SCD. Indentifies ways SCD may impact a student's daily life and describe how school staff can make accommodations (i.e., adjustments to the classroom setting or instruction) to meet the needs of children who may experience health problems associated with SCD during the school day.

The Virginia Sickle Cell Awareness Program, Virginia Department of Health
Location: http://scinfo.org/wp-content/uploads/2015/07/CounselingHandbook06.pdf
Audience: Health Professionals, Public Health/Newborn Screening
Description: A resource for those counseling individuals with sickle cell disorders as well as those providing hemoglobinopathy screening, education, and genetic counseling to individuals identified with other hemoglobin variants.

Screening Technologies and Research in Genetics (STAR-G)
Location: http://www.newbornscreening.info/Parents/otherdisorders/SCD.html
Audience: Health Professionals, Patients/Families, Newborn Screening
Description: Fact sheets on Sickle Cell Disease; Newborn Screening

Addendum: What has happened since the 2018 Stakeholder Forum?

Following the 2018 SCD Stakeholder Forum, a workgroup convened by MDH met to compile, analyze, and summarize the feedback and stories shared by stakeholders who attended the event. The workgroup included MDH staff and community partners from the Minnesota Sickle Cell Collaborative.

One of the key recommendations identified by stakeholders during the 2018 forum was to gain access to and utilize SCD data. Data was an essential need and a current gap; without data, making progress on any of the other recommended next steps would be challenging. For MDH and the Minnesota Sickle Cell Collaborative, an imperative next step that was also a recommendation from the stakeholder forum, was to seek dedicated funding to support SCD data initiatives.

In June 2019, CDC posted a notice of funding opportunity, Capacity Building for Sickle Cell Disease Surveillance (DD19-1906), to participate in a cooperative project with CDC and other grantees to build capacity and prepare to implement a state-wide data collection program. MDH, applying on behalf of Minnesota, was one of nine states awarded funding. California and Georgia – who were already working with CDC and had established Sickle Cell Data Collection (SCDC) programs in their respective states to collect population-based, comprehensive health information about people with SCD, provided technical support and leadership to the seven new grantees. The one-year planning grant helped states build the framework and roadmap to prepare to collect and link SCD data from existing sources such as vital records (birth and death records), newborn screening, hospitals, clinics, and Medicaid, to conduct in-depth analyses to better understand the needs and improve the health of people living with SCD. The Child & Family Health division at MDH led the project, with staffing support from the Health Promotion & Chronic Disease and Health Policy divisions, and collaboration with several other divisions within the health department and community partners. Work got underway in October 2019 and continued through September 2020. MDH convened a multidisciplinary team of stakeholders and collaborated with external partners including pediatric and adult hematology clinics and providers, primary care providers, the Minnesota Hospital Association, the Minnesota Department of Human Services, and the Sickle Cell Foundation of Minnesota. More information about the project is available here: DD19-1906: Helping States to Collect Sickle Cell Disease Data | CDC (https://www.cdc.gov/ncbddd/hemoglobinopathies/maps/scdc-19-1906-recipients.html)

In Spring 2020, CDC posted a new funding opportunity to provide funding to recipients for a three-year period to establish a Sickle Cell Data Collection (SCDC) Program (DD20-2003): Sickle Cell Data Collection (SCDC) Program | CDC (https://www.cdc.gov/ncbddd/hemoglobinopathies/scdc.html). Because of Minnesota's participation in the Capacity Building for SCD Surveillance project, MDH was well-positioned to apply for this funding to implement the plans for SCD data collection that were developed collaboratively with partners during the one-year planning grant. In September 2020, Minnesota was one of 11 states awarded three years of funding (through September 2023).

The purpose of the Minnesota Sickle Cell Data Collection Program (MN SCDC) is to establish a robust and sustainable SCD surveillance and epidemiologic system that is integrated within the MDH newborn screening and long-term follow-up programs. Minnesota will include data from newborn screening, vital statistics, emergency departments, hospital discharges, Medicaid and other public programs (enrollment, utilization, social drivers), MN All Payer Claims Database (public and commercial payers, Medicare), and clinics serving patients with SCD. The MN SCDC program uses a community engagement model to partner with a statewide stakeholder group, including patients and their families, health care systems (i.e., providers, medical groups, insurers), community-based organizations, and decision-makers, to develop and implement education programs, ensure coordinated holistic care, inform policymakers, address health inequities, and ultimately improve the quality of life and outcomes for individuals living with SCD and their families. Minnesota collaborates with the CDC SCDC program and other State grantees to implement a SCDC system based on standardized methods, provide aggregate data to CDC for combined summary data with other State programs,

and actively participate in collaborative epidemiologic studies.

Key SCDC program outcomes include:

- Increase standardized methods for SCD surveillance
- Increase knowledge of SCD incidence, prevalence, and mortality
- Increase understanding of SCD age, gender, race, ethnicity, cultural, socioeconomic, and geographic demographics and disparities
- Increase understanding of health care utilization patterns
- Increase the quality and availability of SCD educational, health care, and community resources available to individuals living with SCD and their families

To achieve these outcomes Minnesota will:

- Utilize a multidisciplinary team and partner with the community to design, implement, and use the data from the SCDC system
- Assure acquisition and use of relevant data sources
- Collaborate with the CDC and other State grantees to ensure a standardized implementation of the SCDC system, evaluation of the system, prioritization of analyses, and reporting of aggregate level SCD data
- Collaborate in the dissemination of the SCDC data locally, regionally, and nationally

Year Two of the project is currently underway, with the Health Promotion and Chronic Disease division at MDH leading a cross-divisional project team. The multidisciplinary team of stakeholders that was established during the capacity-building project continues to meet on a regular basis, and membership of this group has expanded to include additional partners and community stakeholders. MDH continues to partner with the Sickle Cell Foundation of Minnesota to work collaboratively with the community to establish the data collection system and expand awareness and understanding of SCD in our state. Once data are collected from various sources, data will be linked, analyzed, summarized, and shared with local, regional and national partners. These data will provide public health leaders and policy makers with quality data about the scope of SCD in Minnesota. These data will help public health, health care, and community stakeholders and decision makers know where to target activities and programs to improve health care, including ensuring better access to quality care and addressing health equity issues. In addition, the data can inform policymakers and administrators in their decision-making process related to resource allocation and assessing current health care services and what new services may be required.