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# Three Wishes for Sickle Cell Disease: Results from a Multi-Stakeholder Vision-Casting Project in Tennessee

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## Abstract

Although sickle cell disease (SCD) is one of the most common genetic disorders in the US, disparities in research and funding persist. To better understand stakeholder priorities, we conducted a virtual vision-casting session utilizing a graphic recorder and content analysis. Stakeholders responded to the question: "If you had three magic wishes for SCD in TN, what would they be?". Wishes for SCD centered around information and data, care and policy, and community. Better patient-centered information about treatments and modernization of data were high priorities. Stakeholders identified a need for heath equity, starting with lifetime continuity of care and access to curative treatment for all persons with SCD. Key points concerning the community included better patient inclusion in research, increased awareness, and greater public knowledge. SCD patients expressed a desire for honesty, transparency, compassion, and trust. Key areas to address in SCD include better data coordination, more influence on health policy, broader access to care and more community awareness, with the ultimate goal of improving the lives of persons with SCD. Using data to improve care and address health disparities will require researchers listening to stakeholders and understanding multiple perspectives to form unified goals.

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## Introduction

Although sickle cell disease (SCD) is one of the most common genetic disorders in the US, disparities in research and funding for SCD persist (1;2). Over 100,000 people are affected in the US, the vast majority are people of color and more than half are insured by Medicaid (3). Newborn screening for SCD has been universal for more than 30 years, yet, unlike cancer or cystic fibrosis, there is no national registry. Data, when available, are often fragmented and non-uniform across states and regions.

To address these issues, the Centers for Disease Control and Prevention is supporting efforts to establish state level surveillance programs in 9 US states through the Sickle Cell Data Collection (SCDC) program (4;5). The Tennessee (TN) statewide SCD surveillance program (TN-SCDC) began capacity-building in 2019 and the first aggregate data reports are scheduled for 2021. TN-SCDC is governed by an executive committee and a state-wide steering committee comprised of researchers, clinicians, public health practitioners, patients, patient advocates, third-party payers, and healthcare administrators (Appendix 1). As the state program moves from capacity building into data reporting, we convened a meeting of stakeholders to develop a clear vision to put data into action.

## Methods

In February 2021, the TN-SCDC steering committee conducted a virtual vision-casting session utilizing a graphic recorder and content analysis (6). Each

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stakeholder was asked to respond to the question: "If you had three magic wishes for SCD in TN, what would they be?". We shared the question with the committee 48 hours before the session. Results were shared verbally and via comments during a 90-minute session facilitated by two executive committee members. Stakeholders were encouraged to discuss verbally, but could also provide comments using the meeting chat function. Input received via email before the meeting was shared verbally by the facilitators during the discussion. Utilizing the graphic recorder, the group built consensus around the key points.

## Results

The wishes for SCD centered around three categories including disease information and data, care and policy, and community (Figure 1). Better information about treatments for patients and care providers, especially acute care providers, was desired. Modernization of data, making it more extensive, integrated, and accessible was

**Figure 1.** Three Wishes for Sickle Cell Disease in Tennessee

a high priority for stakeholders. Ideally, these data could help improve processes in a continuous feedback loop geared to identify and measure gaps in care and access and provide action plan in a "plug and play" model. Patients and patient advocates were particularly interested in ensuring all types of healthcare providers understood and utilized up-to-date information on appropriate treatment of SCD and its many complications. All stakeholders expressed a desire to have SCD as a higher priority among legislators and healthcare providers. They also identified a need for heath equity, starting with lifetime continuity of care and access to curative treatment for all persons with SCD.

Key points raised concerning the community included better patient inclusion in research, increased awareness, and greater public knowledge about SCD. Participants desire patient education with relevant information that is more specific to age in message and format, for example, focusing on the transition period from pediatric to adult care. Cutting across the three categories identified, SCD patients expressed a desire for honesty, transparency, compassion, and trust.

## Discussion

Stakeholders identified key areas to address with the TN-SCDC initiative, including better data coordination, more influence on health policy, broader access to care and more community awareness, with the ultimate goal of improving the lives of persons with SCD. Using data to improve care and address health disparities in SCD will require researchers listening to stakeholders and understanding multiple perspectives to form unified goals.

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**Appendix 1.** Tennessee Sickle Cell Data Collection Consortium 2021 Membership

SCDC

Sickle Cell Data Collection

**Tennessee Sickle Cell Data Collection Consortium**
**2021 Membership**

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