

HELP SICKLE CELL DISEASE PATIENTS ACCESS THE CARE THEY NEED

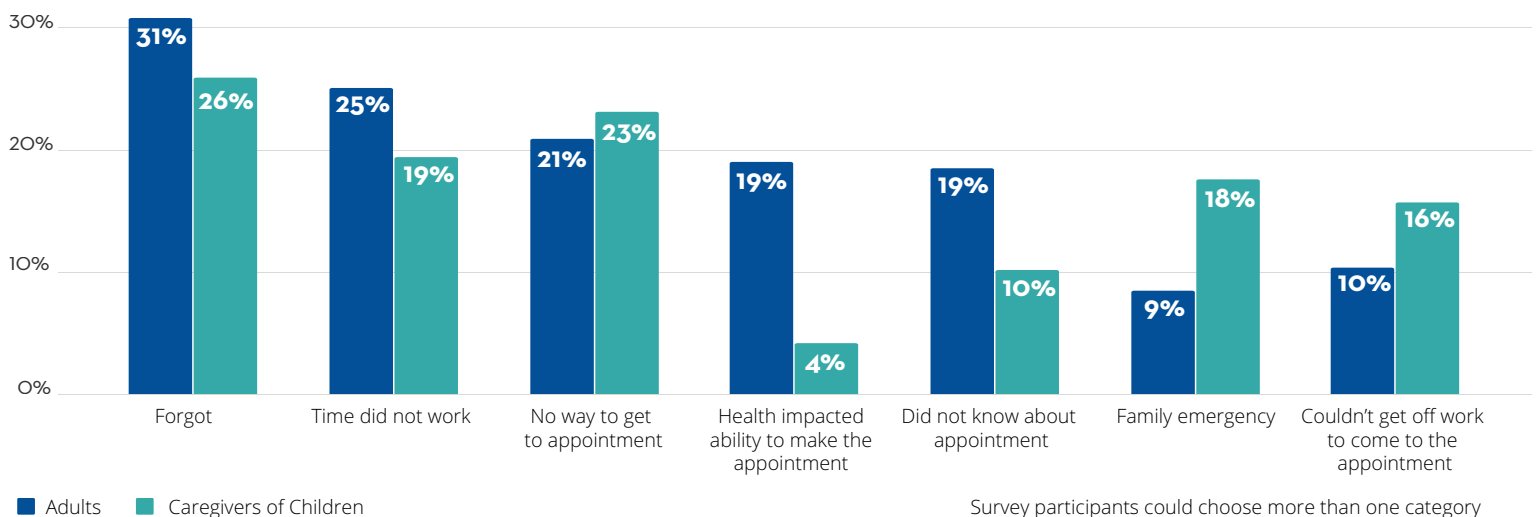
Join a Network to Drive Change

Sickle cell disease affects approximately 100,000 Americans, predominantly those of African descent. Those with the inherited blood disorder may experience unpredictable levels of pain, infection and other serious health problems that can affect every organ in the body. Medical advancements and improvements in care have contributed to a dramatic increase in life expectancy. To benefit from these advances, **national guidelines recommend routine follow-up appointments every six months**, and more frequently for patients on specific therapies or experiencing complications.

Challenge:

Despite national guidelines, a multiyear national study¹ showed that the majority of adults (87 percent) and caregivers of children (65 percent) reported missing a clinic appointment. This means that a majority of sickle cell disease patients may miss out on therapies that have the potential to improve health outcomes.

The Top Reasons Patients Miss Appointments



What Can Be Done?

Findings from the national study show that the Health Belief Model—a widely used, theoretical model for explaining and predicting healthy behaviors—can provide a valuable framework for helping stakeholders, including health professionals, service providers, and patients and families, develop effective strategies to increase appointment attendance by:

- Addressing potential barriers
- Providing cues to action, such as personalized reminders
- Increasing self-efficacy

BECOME PART OF THE SOLUTION

Sign up to join our network of sickle cell disease stakeholders where your voice and your story will play a key role in driving change. During a series of web-facilitated discussions, we will take a deep dive into the study's findings and explore how health professionals, community partners, families and all stakeholders can help increase appointment attendance.

[Sign Up to Join the Network](#)

or visit <https://link.nichq.org/missedSCDappointments>
Questions? Email: Disseminate4SCD@nichq.org

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¹Robert M. Cronin, Jane S. Hankins, Jeannie Byrd, Brandi M. Pernel, Adetola Kassim, Patricia Adams-Graves, Alexis A. Thompson, Karen Kalinyak, Michael R. DeBaun & Marsha Treadwell (2018) Modifying factors of the health belief model associated with missed clinic appointments among individuals with sickle cell disease, *Hematology*, 23:9, 683-691.