Sickle cell disease (SCD) affects approximately 100,000 Americans, predominantly those of African descent. The inherited blood disorder may cause acute pain episodes, infection and other serious health problems that can affect every organ in the body.

To optimize health outcomes, national guidelines recommend routine follow-up appointments every six months, and more frequently for patients on specific therapies or experiencing complications. Yet, a recent national study showed that a majority of patients, both children and adults, reported missing a clinic appointment. This means that a majority of patients with SCD may miss out on therapies that have the potential to improve their health and quality of life.

To better understand what's behind the high rate of missed appointments, NICHQ conducted a series of interviews with patients and providers. Now, we're inviting all SCD stakeholders—health professionals, service providers, patients, and families—to join NICHQ for a live-webinar where we'll share our findings and facilitate a discussion on change strategies.

Webinar objectives:

- Share key takeaways from the national study on appointment attendance among patients with SCD
- Share findings from the stakeholder interviews, including common reasons behind missed appointments and suggestions for increasing appointment attendance
- Facilitate an interactive discussion on systems-, hospital- and individual-level opportunities to increase appointment attendance
When: March 23, 2020, 3-4 pm ET

About the speakers

- Suzette Oyeku, MD, MPH, Professor of Pediatrics at the Albert Einstein College of Medicine
- TaLana Hughes, MPH, Executive Director of the Sickle Cell Disease Association of Illinois
- Judith Gooding, NICHQ Chief Operating Officer and Project Director for Disseminating Results: Missed Sickle Cell Disease Clinic Appointments and the Health Belief Model

This webinar is part of the initiative, Disseminating Results: Missed Sickle Cell Disease Clinic Appointments and the Health Belief Model, which is funded through a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award (EADI-14446).