



T1D in Communities of Color:

An Initiative to Learn About Insights on Screening, Access, and Bias



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BACKGROUND

Type 1 diabetes (T1D) disproportionately impacts Black and Hispanic/Latino communities, who are more likely to experience delayed diagnosis, often presenting with diabetic ketoacidosis (DKA). Many are initially misdiagnosed with type 2 diabetes, delaying insulin therapy and increasing the risk for serious complications. Contributing factors include implicit bias, systemic barriers to care, and reduced access to diabetes management technologies like continuous glucose monitors (CGMs) and insulin pumps.

Youth of color with T1D consistently experience higher A1C levels and face challenges related to affordability, culturally responsive education, and mental health support. According to the Centers for Disease Control and Prevention (CDC), by 2050, approximately half of all U.S. youth with T1D will be from racial or ethnic minority groups.

Despite these disparities, the perspectives of people of color living with T1D remain underrepresented in research and care redesign. To address this gap, the National Minority Quality Forum's Center for Sustainable Health Care Quality and Equity (SHC) conducted national focus groups to explore lived experiences and identify strategies for equitable, person-centered diabetes care.

OBJECTIVE

To explore the lived experiences of individuals from minoritized communities affected by T1D and to identify barriers and actionable solutions to improve access, equity, and person-centered care.

METHODS

Data were collected through two national virtual focus groups held on July 10 and August 6, 2024, facilitated by the Center for Sustainable Health Care Quality and Equity (SHC). Participants included:

- Adults with T1D from minoritized communities (primarily Black and Hispanic/Latino)
- Family caregivers, clinicians, and community advocates

Each 90-minute session followed a semi-structured guide covering: diagnosis and screening, access to diabetes technology, culturally responsive Diabetes Self-Management Education and Support (DSMES), mental health, and bias in care.

Participants completed surveys and shared demographic information. Discussions were recorded and analyzed using qualitative thematic analysis to identify common themes, barriers, and recommendations for system-level improvements.

RESULTS

Participant Demographics

- **Total Participants:** 15 individuals with T1D
- **Race/Ethnicity:** Majority identified as **Black or African American, non-Hispanic**
- **Gender:** Predominantly **women**
- **Age at Diagnosis:** **12–21 years** (Mean: **17.3**)
- **Current Age:** **19–43 years** (Mean: **31.5**)

Awareness and Screening

- **T1D Awareness Prior to Diagnosis:** 80% were aware of T1D beforehand
- **Family Screening:** Most were unaware of **autoantibody testing**; all supported screening after learning its purpose, though concerns about cost and emotional burden were noted

Support Needs

Participants identified key supports:

- **Peer support groups**
- **Self-advocacy tools**
- **Resources for medication and mental health access**

Thematic Findings

1. **Delayed Diagnosis & Missed Screening**
Many experienced **DKA** at onset due to lack of early recognition and screening; strong support for preventive testing like autoantibody screening.
2. **Mental Health & Emotional Burden**
T1D was described as **exhausting and isolating**. Participants reported **minimal access to integrated mental health care**.
3. **Financial and Lifestyle Strain**
High costs for insulin, supplies, and food imposed daily burdens, often compounded by **insurance limitations** and lack of provider guidance.
4. **Implicit Bias & Technology Access**
Misdiagnoses and care delays were linked to **racial assumptions**. Participants faced inequitable access to **CGMs and insulin pumps** due to provider or payer restrictions.
5. **Gaps in DSMES**
Most had **never been offered DSMES**, or found programs **culturally misaligned**. **Community-based education** and **peer support** were preferred.



Learn more about SHC

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CONCLUSIONS

Findings emphasize the need for structural reforms and culturally tailored care strategies. Community-driven recommendations include:

- **Expand Early Screening:** Promote autoantibody screening among at-risk populations to reduce diagnostic delays and improve outcomes.
- **Integrate Mental Health Services:** Embed behavioral health into diabetes care delivery models to address emotional burnout.
- **Reduce Implicit Bias:** Implement provider training and accountability mechanisms to reduce diagnostic errors and treatment inequities.
- **Ensure Equitable Access to Diabetes Technology:** Advocate for payer and provider policies that support universal access to CGMs and pumps.
- **Enhance DSMES Availability and Cultural Relevance:** Invest in DSMES that is co-designed with and delivered by trusted community members.
- **Strengthen Community Engagement:** Leverage community-based organizations and peer networks to extend trust, education, and support.

What Do People Living with T1D Deserve?

Insights from focus group participants and community voices underscored a collective vision for **equity, access, and respect** in diabetes care:

- A **centralized, user-friendly platform** for T1D education, resources, and advocacy
- **Equitable access to technology** and clinical trials through a transparent, navigable system
- **Culturally competent care** from endocrinologists and primary care physicians
- **Collaborative providers** who partner across disciplines and with community leaders
- A **bias-free diabetes ecosystem** that ensures equitable screening, diagnosis, and treatment
- Greater recognition and **amplification of minoritized voices** in the T1D community

“People with T1D need to be heard. As clinicians, advocates, industry leaders, and family—we must listen.”

The **National Minority Quality Forum** is committed to working alongside aligned organizations to help create this future—where all individuals with T1D, particularly those from **minoritized communities**, receive the **high-quality, person-centered care they deserve**.

Access our support material and full report here



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