NATIONAL
MINORITY QUALITY
FORUM

Center for
Sustainable Health Care
Quality and Equity

Type 1 Diabetes Focus Group Report

T1D in Communities of Color – An Initiative to Learn About Insights on Screening, Access, and Bias

T1D Focus Group Takeaways

The National Minority Quality Forum's Center for Sustainable Health Care Quality and Equity (SHC) launched virtual focus groups on July 10 and August 6, 2024, to explore the unique experiences of individuals of color with type 1 diabetes (T1D). Participants—including healthcare advocates, community leaders, and those affected by T1D—shared personal insights into the financial, emotional, and systemic barriers they face, particularly in minoritized communities. These burdens, compounded by inconsistent **access to resources and medical care, hinder effective diabetes management.** The group emphasized **addressing implicit bias, expanding DSMES access, and strengthening community engagement, stressing that targeted education, policy changes, and improved access to diabetes technology and mental health support are essential to improving outcomes for those living with T1D.**

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1. Diagnosis and Lack of Early Screening

- Most participants were diagnosed during critical health crises, such as DKA, with almost no prior screening.
- During the session, members were informed about the availability of T1D autoantibody screening.
- Participants recognized that not having the awareness and option to screen can contribute to delayed diagnoses and worsened health outcomes.

2. Emotional and Mental Burden

- Managing T1D brings a significant mental load, from counting carbs to adjusting medications.
- The constant responsibility of managing blood sugar levels is exhausting, especially for younger individuals who expressed fear, resentment, and frustration toward the lifestyle changes forced upon them and their families.

3. Lifestyle Adjustments and Challenges

- Participants discussed major lifestyle changes, including diet modifications and exercise routines.
- The high cost of specialized diets and medications, along with the strain of diabetes self-management, creates both financial and emotional burdens.

4. Gaps in Support and Access to Resources

- Financial barriers to care were a recurring theme, including difficulty affording diabetes technologies and medications.
- A lack of clear, consistent education on T1D management, particularly for newly diagnosed individuals and their families, was a significant gap.
- People are turning to social media for updates on medications and recommendations, as they are not receiving timely information from healthcare providers. There are shortages of endocrinologists, and many primary care providers (PCPs) lack sufficient knowledge about T1D, leading patients to seek advancements and lifestyle tips online.

5. Advice and Reassurance

- Many participants reflected that they would reassure their younger selves that living with T1D is manageable and that they could take control of their health.
- They emphasized the importance of educating both individuals and families, as parents need to know how to manage and support their child through the diagnosis and management journey.

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T1D in Communities of Color

Type 1 diabetes (T1D) poses severe challenges for Black and Hispanic/Latino patients, who are more frequently diagnosed with diabetic ketoacidosis (DKA) due to delayed recognition. These communities experience higher A1C levels and face barriers to **essential management technologies, like continuous glucose monitors (CGMs) and insulin pumps.** Additionally, implicit bias often leads to misdiagnoses and inappropriate treatments, further complicating care and heightening risks for complications.

Misdiagnosis Bias: Black and Hispanic/Latino patients with T1D are more likely to be initially misdiagnosed with type 2 diabetes. This bias, stemming from associations of diabetes types with certain racial and age profiles, leads to delays in proper insulin therapy. Research highlights that many young people of color with T1D receive non-insulin-based treatments initially, which are ineffective for T1D management and can increase the risk of severe complications, including DKA.

Research highlights a projected increase in type 1 diabetes (T1D) rates among youth of color in the United States over the next few decades, driven by complex interactions between genetic, socioeconomic, and environmental factors. **By 2050,** it's estimated that **about half of youths with type 1 diabetes will be of minority race/ethnic groups.**

Sources:
1. Centers for Disease Control and Prevention. (2022, December 29).
2. Hawkes, C. P., & Lipman, T. H. (2021).
3. Majidi, S., Ebekozien, O., Noor, N., et al. (2021).
4. Redondo, M. J., Libman, I., Cheng, P., Kollman, C., Tosur, M., Gal, R. L., Bacha, F., Klingensmith, G. J., & Clements, M. (2018).
5. Vajravelu, M. E., Okah, E., Bensignor, M., & Karbeah, J. (2023). Verywell Health. (n.d.). Type 1 diabetes facts.
6. American Diabetes Association. (n.d.). Statistics about diabetes.

Key Findings

Data was collected through structured discussion questions, participant surveys, and recorded dialogue with 15 individuals with type 1 diabetes, who also shared demographic information. Topics included diagnosis stories, early screening, DSMES access, and healthcare bias. Qualitative analysis identified common themes and challenges, highlighting barriers to care and potential improvements in healthcare support.

Poll Results

Demographics

The virtual focus group comprised participants living with type 1 diabetes (T1D) from a range of racial and ethnic backgrounds. **The majority were Black or African American and non-Hispanic**, with a mix of other racial backgrounds represented.

Gender:

Predominantly female

Locations represented:
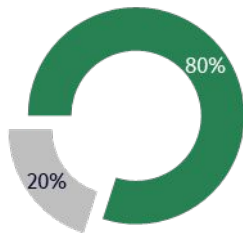
AR, DC, VA, MD, FL, CA, and more

Diagnosis Age range:

12-21 Years

17.3 Avg.

Current Age range:

19-43 Years

31.5 Avg.

Awareness of T1D Before Diagnosis:

Most participants (80%) were aware of type 1 diabetes prior to their diagnosis,

while 20% were not.

80%

20%

What kind of support and/or resources do you find most helpful?

Key support identified included:

Peer support groups

Self advocacy

Resources for medication and mental health.

T1D can be hereditary. Have you encouraged family members to be screened?

All but 2 participants were initially unaware that T1D screening existed. Once informed about the importance of autoantibody screening, **all participants agreed that family members should be encouraged to undergo screening.** There was a common undercurrent of fear surrounding the costs and responsibilities that come with a diagnosis.

Are you aware of any type 1 diabetes clinical trials, and have you participated in any?

40%

60%
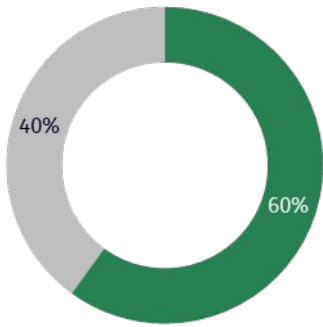
60% of participants were aware of T1D clinical trials,

but **only one had participated**. Many expressed interest if more transparency were provided, with some citing historical mistrust and concerns about private funding. **Transparency was identified as a crucial factor in building trust and increasing participation.**

Discussion Results

Diagnosis Story

Most participants were diagnosed through critical events, lacking prior T1D screening and facing worsened health outcomes.

Most participants were diagnosed with type 1 diabetes in critical situations, often experiencing severe symptoms like **Diabetic Ketoacidosis (DKA)** that required emergency hospitalization. Almost none were screened for T1D beforehand, with only **two aware of existing screening options.** This lack of early detection contributed to worsened health outcomes and complications at diagnosis.

Impact of Early Screening

Early screening could have reduced costly treatments and eased medical and financial burdens for families.

The group highlighted that early screening, as it exists today, was not available at the time of their diagnoses. They felt that such screening could have reduced both financial and medical burdens. **An earlier diagnosis might have prevented costly and invasive treatments**, such as DKA-related hospitalizations. Without early detection, families faced significant medical expenses, often compounded by limited awareness and resources for effective post-diagnosis management.

Post-Diagnosis Education and Support

Inconsistent education left many participants unprepared to manage T1D, often relying on self-learning or online communities.

After diagnosis, participants reported varying levels of education and resources. **Some received hospital-based guidance** on carb counting and insulin management, while others received little to no support. **The lack of consistent diabetes self-management education (DSMES) was a common issue,** leading many to rely on self-learning or online communities. This gap left many feeling unprepared to manage their condition, particularly early on.

Lifestyle Adjustments

The mental and emotional demands of T1D management disrupted routines and strained family relationships, creating stress and frustration.

Managing T1D involves **intense mental and emotional adjustments,** which many participants found overwhelming. The demands of carb counting, insulin adjustments, and blood sugar monitoring created a heavy mental load. Many described **feelings of fear and frustration**, especially when younger, as T1D imposed drastic changes on their lives and family routines. Strict diets, exercise requirements, and constant monitoring disrupted normalcy and strained family relationships due to the stress of disease management.

Support Gaps

Limited support and financial challenges restricted access to essential diabetes tech, with inadequate insurance forcing some to ration insulin.

A major barrier was **limited medical and social support.** Financial challenges made essential diabetes tech like CGMs and insulin pumps hard to access, and **limited information on new technologies complicated staying informed. Inadequate insurance** added financial stress, forcing some to ration insulin and risk their health.

Challenges in Diabetes Management

Financial strain and insurance hurdles limited access to essential medications, with insurers often influencing treatment decisions.

Financial and access burdens were among the most common challenges. Many struggled to afford essential medications and devices. **Navigating prior authorization for prescriptions** was a bureaucratic hurdle, and participants expressed concern that insurers, rather than doctors, often dictated their treatment decisions.

Improvements Needed in Healthcare

Participants stressed the need to address implicit bias, improve T1D care access, and enhance outreach and education in marginalized communities.

Participants agreed that healthcare systems must address **implicit bias and improve access to quality T1D care,** especially in marginalized communities. They reported **long waits for specialists and noted that PCPs often lacked diabetes expertise.** Navigating insurance and affordable care was frustrating. They called for **greater community outreach, better education, and systemic changes to improve access and affordability.**

Desired Advancements in Care

Participants emphasized the need for better access to advanced diabetes tech, financial support, and mental health care to address the emotional toll of managing T1D.

The group expressed a strong need for **better access to advanced diabetes technologies**, like CGMs and insulin pumps, along with financial assistance for these costly devices. **Insufficient insurance** coverage added to the burden. **Mental health support** was also a key concern, as participants highlighted the emotional toll of managing a chronic condition. They hoped for more **comprehensive care addressing both physical and mental health needs.**

Advice for Newly Diagnosed Individuals

Participants would reassure their younger selves that T1D becomes manageable, stressing the importance of education and family support.

Participants shared that if they could speak to their younger selves, they would **offer reassurance,** emphasizing that while T1D feels overwhelming initially, **it becomes manageable over time.** They stressed the importance of **educating both those diagnosed and their families,** as parental support is crucial, especially early on. Parents were advised to **stay informed, be supportive, and create an understanding environment, recognizing that T1D affects the whole family.**

Perceived Root Causes of Low Prescriber Attention to Up-to-Date Technology Information

Participants cited time constraints, lack of knowledge, bias, and perceived stability as reasons healthcare providers may not share the latest diabetes technologies.

Participants discussed why healthcare providers may not share the latest diabetes technologies, citing several reasons:

- **Time Constraints:** Many felt that doctors, often overwhelmed with patients, lacked time for in-depth discussions. One participant noted that lengthy consultations with their endocrinologist were rare, highlighting time pressure as a major barrier to introducing new tech.

- **Lack of Knowledge or Interest:** Some believed providers lacked awareness or interest in staying updated with T1D advancements, especially if not specialized or passionate about T1D care.

- **Bias and External Influence:** Concerns were raised about potential bias from relationships with pharmaceutical or device companies, which could influence recommendations and limit access to the best options.

- **Perception of Stability:** Some felt providers avoided new technologies if the current treatment seemed effective, resulting in missed opportunities for better management tools.

Coexisting Autoimmune Conditions

Some had other conditions with T1D, including hypothyroidism and chronic kidney disease.

Some participants mentioned having other health conditions alongside T1D. One participant was diagnosed with hypothyroidism, an autoimmune condition commonly associated with diabetes. Another had chronic kidney disease (CKD), although the cause was unclear.

What Do People Living Type 1 Diabetes Deserve?

A comprehensive, centralized platform for T1D resources and advocacy information.

Easy-to-access information about technology updates and best practices, coupled with a navigable healthcare system that allows equitable access to innovative technology and clinical trials.

Endocrinologists who provide compassionate, standard of care medicine in a culturally sensitive manner.

Primary care physicians who are more knowledgeable in T1D care and resources. Particularly as we continue to observe long wait times and lack of available endocrinologists in minoritized communities.

Collaborative healthcare provides who welcome partnerships with each other and with influencers in the space to improve education, innovation and support for T1D management.

A diabetes ecosystem that is free from disparities and that provides equitable care at all phases, including screening, diagnosis and treatment. This is especially important as we prepare for a demographic shift in which the majority of patients living with T1D will be patients of color.

People with T1D need to be heard, and as advocates, clinicians, pharmaceuticals, biotechs, family and friends, we need to listen. In the ecosystem of diabetes, the T1D community, especially those who are minorities, are not elevated enough.

National Minority Quality Forum is committed to partnering with like minded organizations to drive change and ensure that people living with T1D, especially from minoritized communities, get the high quality care that they deserve.

Special thanks to **sanofi**