

## TO ALL MEMBERS OF THE CF COMMUNITY,

Cystic fibrosis affects people of many different racial and ethnic backgrounds; however, for many years there has not been adequate recognition or representation of Black individuals and other people of color within the CF community.

As part of its work to [address racism and discrimination](#), the CF Foundation is working to deepen its understanding of this issue by listening to Black members of the CF community, other people of color with CF, and leading researchers who are focused on health disparities. In those conversations, sobering evidence affirms that race impacts every aspect of an individual's experience with CF.

In November 2020, we conducted a survey to better understand engagement barriers for historically marginalized individuals in the CF community. We received 75 responses from adults with CF, spouses of adults with CF, and parents or caregivers of children with CF who identified as people of color. The themes that emerged, including a lack of representation, adequate resources, and education, further illuminated the need to do better.

## NOT ONLY DO WE WANT TO DO BETTER, WE MUST DO BETTER.

One participant stated the challenge and opportunity plainly:

How will this gap between the CF Foundation and people of color be closed?  
To even get an invitation, to even get a seat ... This focus group is something  
I've been waiting on for a while.

Representation, health care provider bias, and trustworthiness emerged as key themes. Participants underscored that they are speaking up and out, which provides a roadmap for how we navigate and address inequities.

- 1. Representation:** Phrases such as “the only one” or “token” were used to describe the experiences of Black and Hispanic members of the CF community.
- 2. Health care provider bias:** Participants reported being misdiagnosed or having symptoms ignored, even when they were actively advocating for their best care.
- 3. Trustworthiness:** Participants were skeptical about the authenticity of efforts related to equity, inclusion, and justice.

The report that follows details the findings above. It is our hope that it will serve as a catalyst for conversations in the community, in care centers, in academia, and among ourselves about what it truly means to live with cystic fibrosis. These ongoing conversations rightly challenge us to ensure our community's diversity is better reflected in all aspects in making our mission—to cure cystic fibrosis and to provide all people with CF the opportunity to lead long, fulfilling lives—a reality.

We are humbled by community members who shared their unfiltered and unedited experiences to help improve how we address inequities in CF research and care and how we show up for communities of color. It is your bravery that is paving our path forward. It is not lost on us that to share such personal experiences took a substantial amount of trust that we have not earned. Thank you.

We look forward to continuing to earn your trust as we move these efforts forward, together.



# COMMUNITIES OF COLOR: FOCUS GROUPS REPORT

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## BACKGROUND

In November 2020, the CF foundation conducted early listening efforts including, interviews and a survey, to better understand the engagement barriers specific to people of color in the cystic fibrosis community. From that survey, three major themes were discovered: representation, education, and resources. To further explore these themes, focus groups were conducted on July 22 and 23, 2021 via Zoom. Participants included adults with CF, spouses of adults with CF, and parents or caregivers of children with cystic fibrosis. All participants identified as people of color and included African American/Black and Hispanic/Latinx individuals. These focus group were conducted to better understand the unique needs of people of color in the CF community, barriers to engagement, and overall perspectives of people of color in the CF community.

## METHODS

The Foundation recruited focus group members via a [call for volunteers](#) in November 2020, and also asked care team members at the Emory Adult Cystic Fibrosis Program in Atlanta to share it with their patients. Twenty individuals expressed interest in participating and all individuals that filled out the survey were invited to join the live focus groups. Eleven adults with CF and parents/caregivers participated in the live focus groups. Of those that participated, six individuals identified as Black/African American and five identified as Hispanic. The discussion questions were informed by the communities of color survey conducted in November 2020 as well as with input from stakeholders connected to the Foundation's racial justice initiatives.

# DATA COLLECTION

## Representation

### Question 1: What does representation mean to you?

When asked what representation means to them, many began with comments related to equity. Participants collectively felt the current relationship between the CF Foundation and people of color lacks equity and at times promotes tokenism. Participants expressed hesitancy engaging with the CF Foundation across many different areas due to the lack of equity related to access, treatments, and opportunities seen among people of color. Within equity, adults with CF also expressed a lack of support and visibility for established affinity groups where people of color can make connections and receive valuable information from a trusted source.

Several also described representation as visual representation, meaning seeing people of color represented visually across platforms such as the CF Foundation's website, social media platforms, as well as Foundation and care center staff.

The lack of visual representation to date has contributed to feelings of isolation and mistrust which play a major role in decisions to engage in offered opportunities. In discussing visual representation, tokenism was flagged again. Many felt that while providing visual representation, only having one person of color visually represented can be seen as tokenism and disingenuous.

Every parent except for one mentioned newborn screening in their response to this question. Parents felt the lack of representation contributed to disparities in newborn screening for people of color and those with rare and nonsense mutations. A large majority of the parents of children with CF and majority of the adults with CF had an experience with delayed diagnosis due to widespread misconceptions regarding race and CF, as well as disparities in the CF screening processes.

- "It all kind of for me begins with not seeing a little brown boy anywhere I looked on the Foundation page, or anywhere on social media pages. I just didn't see him. I didn't see myself I didn't see anything. You know, but [you see] Caucasian families and children, which makes you feel excluded like ... you don't matter."
- "I'm new to this and I've never been involved. I didn't want to because I knew there was no one that looked like me."
- "It feels like they want me as a face and for my skin color to appear inclusive."
- "Don't just have me there for a photo-op, [it] shouldn't just be that one time and then we never hear from you again. As long as it's continued involvement it won't feel like the tokenism."
- "I was diagnosed in 1995, I was two-and-a-half years old, and I almost was dead before I was diagnosed. The reason was because of my father's side and they said Hispanics can't have CF."
- "I'll do surveys because it feels like maybe my voice matters here, but I won't put my face to it."

**Question 2: When you think of CF Foundation emails or flyers you have received, invitations to events, committees, surveys, how does representation play a part in your decision to engage?**

As we explored how representation plays a part in decisions to engage, there was a great deal of variability in how participants responded. Many participants expressed past negative experiences as a barrier to participation. Negative experiences mentioned included being the only person of color on a CF Foundation committee or workgroup and feeling pressure to represent their entire community. Many described the pressure they have felt as the only person of color on a CFF committee to represent the voice of an entire community, and the discomfort of flagging disparities when no one else will.

Participants also mentioned feeling that when invited to join committees and work groups, the only reason they were invited was because of their race/ethnicity, not because of what they holistically brought to the table. Negative experiences also included past attempts at discussing the need for diversity with CF Foundation national and chapter staff which usually resulted in feeling like their voice was disregarded or not welcomed. Most adults with CF and parents also mentioned lack of access to resources and information as a barrier to engagement.

- “They didn’t want to hear from us before, why do they want to hear from us now?”
- “All I heard growing up was that it’s a Caucasian disease, I never saw anyone who wasn’t Caucasian who had it. It made me wonder if I really had CF, it made me wonder if I belonged in any of the CF groups. I just knew that our family didn’t look like that.”
- “I won’t apply to be on committees anymore because all of my experiences throughout the years have been bad, in terms of I’m the only woman of color there.”
- “I’m always on the back burner, even though I work in the medical field. I have a degree in the medical field, I have so many certifications in the medical field. It doesn’t matter because I’m not white.”
- “It is a very fine line between, you want me here or to be in the in-crowd and have diversity, but we need to see the action behind getting us involved.”

**Question 3: Do you feel representation in data is important?**

All the participants felt representation in data was important, however, many felt there is a lack of data on the impacts of race on CF. Almost all participants indicated they do not trust CF data because of CF screening and diagnosis disparities and the lack of representation in research. Adult participants also described the need for result transparency, and further explained the connection between lack of transparency in results, mistrust in data, and decisions to engage.

While there was some hesitancy in survey participation mentioned, a few participants did highlight surveys as an easier way to engage where their voice carried equal weight. Most participants also felt there was little to nothing happening in rare and nonsense research and believed this to be due to disparities mentioned earlier in the discussion. These feelings also play a significant role in decisions to engage, especially in research-related opportunities.

- “I know that we have come a long way with medications and research for specific mutations, but when is our turn? How long do we have to wait?”
- “If people are participating in these surveys, what is the point of them? Is it just for awareness, or what is actually being done? If it’s all geared towards one group of people then other groups are not going to feel important.”
- “I just saw the numbers, and I just don’t believe them. It’s assumed to be a white disease, so if it’s assumed to be a white disease and they’re not looking for it, you are either lucky to be 54 and diagnosed or you’re dead and nobody ever knows you had it.”

## Resources

### Question 4: What are the needed resources specifically for people of color with CF?

When discussing needed resources specific to people of color in the CF community there were a few themes, including post-diagnosis resources, improved cystic fibrosis basic educational resources, and improved access to resources overall. Most adults with CF described the difficulties in obtaining information regarding ongoing research and clinical trials as well as new treatments. A few even described feeling as if meaningful information was being withheld at times. Parents of children with CF indicated a major gap in the provided resources after diagnosis. Many described feelings of isolation once their child received a CF diagnosis, and felt

they had to figure it out on their own. Many also mentioned the need for additional educational resources for both parents and adults with CF to become more informed about living with cystic fibrosis and the science behind CF.

Many expressed education and awareness gaps in areas such as available treatments, vest access, nutrition, and nebulizer use and sanitation. Participants mentioned possible educational resources such as webinars and trainings specifically for the CF community to learn more about cystic fibrosis and associated disparities for people of color.

- “When my son was diagnosed, you just find out your son has a life-shortening disease, and you’re given a book and bag with papers in it. But, it’s kind of like you’re left on your own, good luck.”
- “The Foundation does not post practical things on social media, like ‘hey having trouble getting your vitamins, here is a resource you can use.’ A lot of my people had not even heard about Trikafta—they need to have more education.”
- “Financial assistance, equipment assistance, education—there should be a number I can call with questions. I can’t always reach my clinic.”
- “Some parents just know what they need for their child to survive, but they do not specifically understand the science behind it, what is going on in the child’s body, in a language they can understand. Not everyone understands certain scientific terminology or certain words.”
- “I didn’t know anything about the Wabi situation until down the road. I was boiling the equipment every time and it was very difficult. We need tips the Foundation is aware of, like teaching your child how to swallow enzymes, getting a sanitizer if you do not have a dishwasher. I had to call about settings on his machines and how to use them.”



### Question 5: What is the best way for you to receive information from CF Foundation including engagement opportunities?

Access to resources and information emerged as a theme in many areas during the focus groups. When asked how participants prefer to be contacted regarding opportunities to engage, the majority of participants highlighted care teams and simple phone calls to follow up on recent visits. Both parent and adult participants indicated care teams as a trusted source for engagement opportunities and information regarding CF research and care. A few also expressed technology-based communication such as email and social media could act as barriers for some

without internet access, and suggested using phone calls to inform community members of available resources and opportunities.

Participants also flagged the need to ensure resources and information are lay-friendly, specifically in communications meant to inform about research and clinical trials. Most participants did not view the Foundation's website as a trusted source for information due to lack of representation and access barriers.

- "The Foundation does not post practical things on social media, like 'hey having trouble getting your vitamins, here is a resource you can use.' A lot of my people had not even heard about Trikafta—they need to have more education."
- "I don't recall any of this being brought to me, I don't recall ever in clinic hearing about Community Voice or ways to be heard with the CF Foundation"
- "Resources shouldn't end when you walk out the door of the hospital. Resources and education should continue."
- "How will this gap between the CF Foundation and people of color be closed, to even get an invitation to even get a seat ... This focus group is something I've been waiting on for a while."
- "I join Facebook groups to ask other parents questions. Some people have access to things I don't have access to."
- "I've never felt like I couldn't express my concerns with my care team. I don't like having a new doctor. It's hard to build trust. My social worker creates a very open communications channel and keeps me in the loop on when there will be changes. I've always felt like I can talk with my social worker and go to her with issues."

## Education/Training

### Question 6: What education and/or training for CF Foundation program leads or care center staff do you feel is needed to create positive and successful engagement?

Many participants felt training is needed for care teams and for all CF Foundation staff in community-facing positions. Due to past negative experiences, the majority of the participants recommended cultural competency and cultural sensitivity training. Many felt that because people of color are a minority in the CF community, they are constantly educating clinical staff on how

to treat them as a patient, and in some cases feeling they need to explain and confirm their CF diagnosis. Several described being made to feel like an anomaly when in clinic, and being asked repeatedly if they are sure they have CF. There were also feelings that information and opportunities were being withheld due to misinformed staff and engrained stereotypes.

- “I had an experience where I was in clinic and one of the doctors came in with his medical students and said, “oh you have CF? You’re not white.”, I don’t want that to happen to anybody else.”
- “I had an experience this year in clinic—I was about to get a procedure and one of the doctors said, ‘Oh you have CF? Are you sure it’s CF and not something like it?’”
- “How to rewire physicians and OB-GYNs, when they’re getting trained—where is this in your medical books? That needs to be changed. You get to your OB-GYN, you’re downplayed, or ‘You’re Hispanic. Don’t worry, your child won’t have CF.’ They don’t even ask you to get the other parent tested, its downplayed because of the stereotype.”
- “We have to be at the brink of death before being diagnosed because of the persistent stereotype of it being a Caucasian disease.”
- “My child did newborn screening. What they found, they blamed on my breastfeeding. If the nurse or doctor is telling me don’t worry about it, I’m not going to worry about it. A month later, your child is dehydrated, showing all the symptoms ... I don’t know how we rewire that,”
- “When I go to events, I would see materials that explicitly say this is a Caucasian disease. And when I spoke up about this—about the resources that didn’t include Hispanics, didn’t include black women—the underlined reasoning was it’s not that important. When I spoke up, this was 2020, this was a year ago. Nobody else in the room said anything when I mentioned we should be included, nobody said a single word. That just made me so angry and sad for kids being diagnosed today.”

## CONCLUSION/REFLECTIONS

These focus groups provided a space for people of color in the CF community to be heard—some for the first time—and many expressed appreciations for that opportunity. We heard a variety of important points related to representation, including how representation impacts engagement, trust, data integrity, and more. There are many areas where representation should be considered as often as possible. As the CF Foundation works to increase representation, it is important we keep the community at the center of all we do. To this community, representation means improved newborn screening, equity, feeling seen through visual representation across all CF Foundation platforms, and having a seat at the table where they are listened to.

As listening efforts among communities of color continues, understanding where the gaps in resources are for these communities will be vital. Overall, lack of access to resources was a major theme with both adults and parents/caregivers. Many participants simply were not aware of major updates in research and care, available resources, as well as opportunities to engage and partner with the CF Foundation. Understanding where the gaps in resources are for these communities will help to inform the outreach work of the Foundation including closing gaps in health equity and increasing diversity in clinical trials. There is also a clear need to enhance the communication of essential information and opportunities between the CF Foundation and CF communities of color.

While discussing needed training for CF Foundation staff and care teams, cultural competency emerged as a top theme. Many participants shared unfortunate experiences at their care centers and chapters which included offensive and uninformed comments and behaviors. Many also expressed feeling as if they must constantly educate individuals on how to treat them as people of color with CF. These feelings and experiences have led to a lack of trust in the CF care system and overall hesitancy to engage at all levels.

As we continue to conduct listening efforts within these communities it is important to incorporate what we are hearing into this work moving forward. With increasing diversity in CF clinical trials and community-facing programs as a priority, these perspectives and voices must be included in the beginning and highlighted throughout. Participants expressed the importance of transparency, and flagged feelings of hesitation to engage due to lack of transparency and acknowledgment of disparities in the past. These individuals collectively felt a need to see continued efforts and actions, particularly in response to the feedback they have provided.