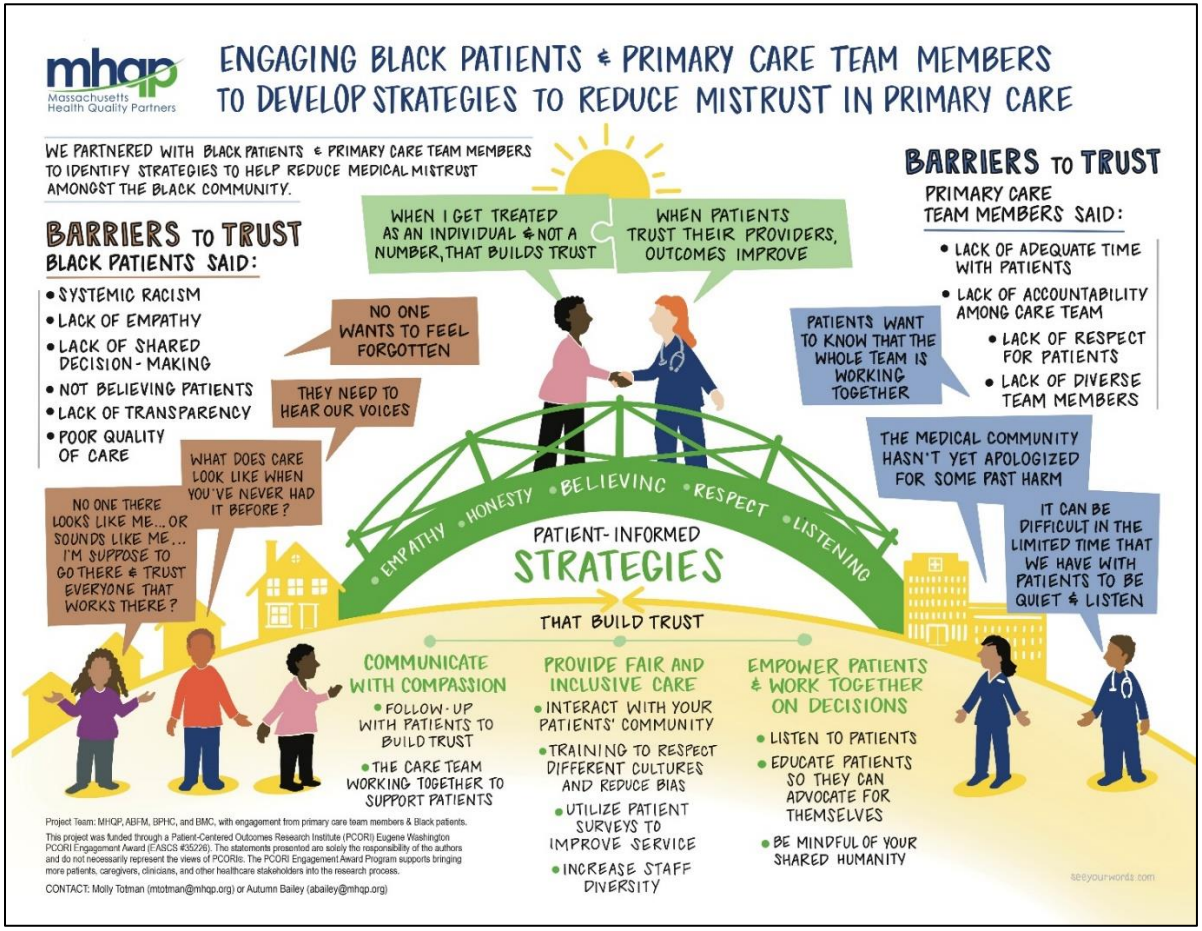
ENGAGING BLACK PATIENTS AND PRIMARY CARE TEAM MEMBERS IN PCOR/CER TO REDUCE MISTRUST IN HEALTHCARE

Massachusetts Health Quality Partners

Summary Illustration

This illustration brings to life the key findings of our project, offering a powerful tool for the healthcare and research community to better understand the perspectives and priorities of both patients and primary care teams in addressing medical mistrust. We hope this illustration will be widely shared and utilized to help identify the most effective community-identified solutions and drive sustained efforts toward rebuilding trust and improving care for Black patients.



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Executive Summary

Trust is the foundation of high-quality healthcare, shaping the patient-provider relationship and influencing health outcomes. As the gateway to the healthcare system, primary care plays a vital role in building trust and ensuring equitable care. In 2021, Massachusetts Health Quality Partners (MHQP) began to measure patients' trust in their primary care clinicians in its statewide commercial Patient Experience survey. For four consecutive years, primary care patients who identify as Black/African American have reported significantly lower trust scores compared to White patients. To address this critical issue, MHQP partnered with the American Board of Family Medicine (ABFM), Boston Medical Center (BMC), and the Boston Public Health Commission (BPHC) to develop a Roadmap for recommending methods to reduce medical mistrust among Black patients.

The project team engaged Black patients and primary care team members—including physicians, physician assistants, nurses, patient navigators, and clinical support staff—through two focus groups and a multi-stakeholder convening. Black patients' experiences highlighted the profound impact of systemic racism on medical mistrust. Factors such as past medical harm, historical injustices (e.g., the Tuskegee Study, Henrietta Lacks), lack of diverse representation among medical staff, and insufficient organizational accountability for addressing past harm all contributed significantly to mistrust within Black communities.

> *"It's just things we go through that makes us look at 'Should I do I believe in this doctor?' or if something come up again, 'what do I do…how do I live through this?' …**It's just a matter of life and death with some of us.**" (Black/African American Patient)*

Participants explored both interpersonal and systemic factors that influence trust in healthcare. At the individual level, primary care team attributes such as empathy, honesty, clear communication, and believing patients were identified as key drivers of trust among Black patients. Systemic factors such as integrated multidisciplinary care settings, organizational accountability, and support for patients navigating the healthcare system were also seen as critical facilitators of trust. Based on focus group insights, the project team identified 13 key topic areas for participants to rank by priority, guiding the development of targeted strategies. The top priorities selected included: Communicate with Compassion, Work Together on Decisions/Support Patient Agency Through Education and Tools, and Foster Equitable and Inclusive Care.

During the multi-stakeholder convening, participants proposed nine strategies for future research addressing mistrust:

Communicate with Compassion	• Implement patient-centered check-ins • Implement systems that support effective and timely patient care and follow-up • Establish routine training for all primary care staff on team communication and active listening • Strengthen interpersonal relationships between patients and primary care teams • Support opportunities for patients and primary care teams to interact in and outside the clinical setting
Work Together on Decisions/ Support Patient Agency Through Education & Tools	• Utilize collaborative tools that enhance mutual decision making between the patient and the primary care team
Foster Equitable & Inclusive Care	• Educate and train all primary care staff to respect different cultures and incorporate anti-racism into patient care. • Ensure that the primary care practice highlights and incorporates diversity and inclusion in all aspects of their clinic • Evaluate and establish practices that deliver care tailored to the needs (health-related or social) of patients and their community

Acknowledging the challenges of addressing medical mistrust, this Roadmap provides a foundation for future research. Researchers are urged to collaborate with Black community members to develop and test patient-centered comparative effectiveness research (CER) questions that align with stakeholder priorities and center the experiences of Black patients.

*"**We need to hear [patient's stories] so that we can be a voice in the wilderness**, crying out to make the pathway straight, that which is crooked by systemic racism, **and [so] we can [have] proper healthcare**." (Black/African American Patient)*

***"It goes back generations** as to why **we don't trust the medical care profession**." (Black/African American Patient)*

*"**[Trust is] a two-way fold**. The doctor also has to trust the patient and the only way we can do that is by sharing our humanity**. Take off the white [coat], take off the degrees**." (Black/African American Patient)*

*[There's] still a lot of things that **we have to own as a whole medical community and apologize for and be accountable** to the roles we played knowingly or not knowingly." (Family Medicine Physician)*

About This Roadmap

Massachusetts Health Quality Partners (MHQP), the American Board of Family Medicine (ABFM), the Boston Public Health Commission (BPHC), and Boston Medical Center (BMC) collaborated to develop this Roadmap, which offers stakeholder-identified insights to inform research aimed at reducing medical mistrust amongst in the Black community. Through two focus groups and a multi-stakeholder convening of patients who identified as Black/African American and members of the primary care team (MDs, PAs, PharmDs, nurses, patient navigators, and clinical support staff) participants emphasized the need for increased research, support, and organized advocacy to engage Black community members and rebuild trust in healthcare. The following participant quotes highlight the significance of trust in healthcare:

"I needed to know...how we build trust with one another and how we can extend that out to the medical profession. [Because] when we think about it, they're just people too. So how do we share humanity with them so that we get that in return, which we so richly deserve."(Black/African American Patient)

"Healthcare should really be a partnership …and you can be super limited in your ability to care for a patient or care for a community if there is no trust." (Family Medicine Physician)

"We just want to be treated like we're human. We want to be cared for, we want to be heard. We want to know that we matter. It's stressful just thinking about all the things that we do every day and then on top of this...we have physicians who aren't listening to us." (Black/African American Patient)

"We all have to be pulling the same weight. My patients can't love me but hate my front desk staff...[or] not like going to our lab on site. That trust has to come all the way through at every touch point and studies have shown that those are the some of the gaps [we] miss when we try to do this work." (Family Medicine Physician)

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This project was reviewed and classified as exempt by Solutions Institutional Review Board, IRB protocol no. 0617.

Project Background, Methods, and Literature

Medical mistrust among the Black community is rooted in historical and ongoing unequal treatment, has implications for the health and well-being of Black individuals, and is associated with racial disparities in poor health outcomes.[1] Within the Black community, mistrust stems from everyday racism, structural oppression, and a legacy of discriminatory health care practices, including the exploitation of Black individuals in medical research.[2] In addition, medical mistrust is higher among those identifying as Black American compared to those identifying as White American.[3,4]

In 2021, MHQP began incorporating the Wake Forest Physician Trust Scale[5] into its annual statewide Patient Experience Survey of commercially insured primary care patients. Across four consecutive years, adults identifying as Black or African American reported statistically significant lower levels of trust than their White counterparts (see Table 1 below). The primary care relationship between health care providers and patients holds a pivotal role in establishing trust, ultimately contributing to enhanced health outcomes and the mitigation of health disparities.[6,7]

Despite the critical role that the primary care relationship plays in establishing and fostering trust, there is a noticeable gap in patient-centered comparative effectiveness research (CER) addressing mistrust in the Black community. In response to survey findings and the identified lack of patient-centered CER, MHQP partnered with BPHC, ABFM, and BMC to further our understanding of medical mistrust within the Black community and collaboratively shape a future research agenda.

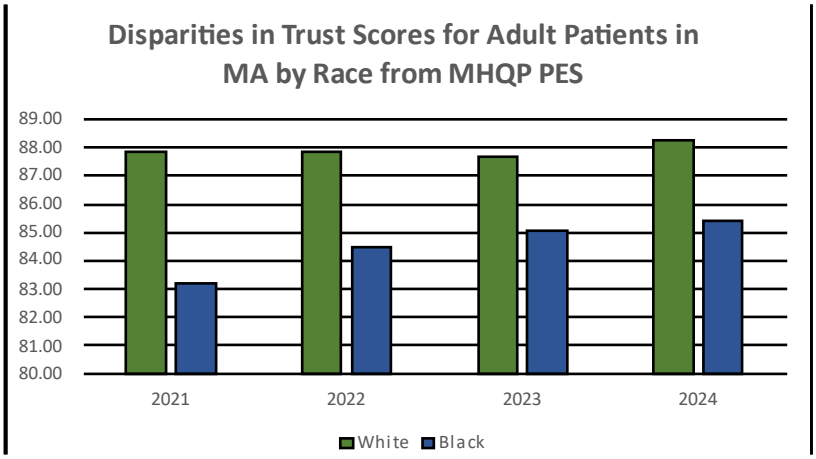

Table 1: Trust Scores from MHQP's Commercial Statewide Patient Experience Survey by Race. Note that these disparities are statistically significant.

Project Goal and Methods

The goal of this Roadmap is to provide strategies and measurable outcomes for potential future patient-centered CER aimed at reducing mistrust in healthcare based on the lived experiences of Black patients, and the outcomes important to them.

The project team implemented the following methods to ultimately create this Roadmap:

- ✓ *Collaboration and Engagement:* This project was structured as a collaborative effort with team members from partner organizations BMC, BPHC, and ABFM. In addition, the team partnered with two patients (identifying as Black/African American) and two primary care team member co-creators, who provided feedback and guidance on project materials.

- ✓ *Literature Review:* The project team reviewed the existing literature on mistrust in healthcare among Black patients. Findings and gaps identified in the literature guided the development of focus group discussion questions.

- ✓ *Focus Groups and Prioritization Survey:* To explore lived experiences of mistrust and identify factors that drive mistrust and trust, the project team hosted two focus groups in the Fall of 2024. The patient and primary care team focus groups were held separately to create a safe space that would allow for honest and transparent conversations. The first group included 10 patients who identified as Black and/or African American, ranging in age from 18 to 75. The second group included 10 primary care team members, including clinicians (MDs, PAs, Nurses), patient navigators, and clinical support staff. Both focus groups were facilitated by Dionne Grayson—an author and owner of Building Your Dreams LLC. Following the focus groups, the project team synthesized the discussions and identified key focus areas to address mistrust. These focus areas were then ranked by each group through an electronic survey.

- ✓ *Muli-stakeholder Convening & Confirming Priority Research Directions:* The project team hosted a multi-stakeholder convening in January of 2025. Facilitated by Ms. Grayson, the multi-stakeholder convening was joined by 20 focus group participants, including 10 patients and 10 primary care team members. Together, they developed eight strategies with measurable outcomes to assess effectiveness based on the highest-ranked topics from the focus groups. The project team confirmed the findings and surveyed participants to prioritize directions for future research.

Key Knowledge from Literature

Mistrust in healthcare among Black patients varies by several sociodemographic factors. Black women diagnosed with breast cancer and who also have publicly funded insurance (e.g. Medicare, Medicaid) are more likely to have higher mistrust than those who have private insurance.[8] Older Black patients tend to be more skeptical of healthcare providers and Black men are more likely to report higher levels of mistrust than Black women.[9]

Patients who experience discrimination and structural racism, especially within a healthcare setting, are also more likely to have higher levels of mistrust. Issues like access to care and experiencing implicit bias can erode trust and confidence in the healthcare system.[4,9,10] Poor patient-provider communication is also a driver of mistrust; when patients feel as if their doctor is not providing them with accurate or complete information, their trust in the relationship is eroded. [8]

The 2020 COVID-19 pandemic deepened medical mistrust within the Black community. Inconsistent messaging from health departments and governmental agencies fueled mistrust in minority communities, contributing to lower COVID-19 vaccination rates within the Black community.[11]Black Americans' COVID-19 vaccine hesitancy was rooted in historical injustices including the Tuskegee study and medical experimentation, mistrust of physicians and the healthcare system, mistrust of pharmaceutical companies, and lack of cultural competency and sensitivity among healthcare providers.[12,13] *Note that current gaps in research can be found in Appendix C.

Focus Group Findings: Understanding the Context of Mistrust

Importance of Understanding and Improving Trust

Participants cited various motivations for joining the project, such as advocacy, professional roles, and research interests. Despite their diverse backgrounds, all shared a common commitment to reducing medical mistrust:

> *"This is a learning experience [for me] to be able to voice my opinion for once and to speak up on the things that I didn't like [within] the healthcare system [and advocate] for other people's family members as well." (Black/African American Patient)*

> *"Knowledge is power. When you don't have that trust you can't impart that knowledge to your patients and they're not receptive to it....I think we as healthcare professionals have the power to change this discourse and change that level of trust our community has." (Family Medicine Physician)*

> *"I'm here to...educate myself so that I can at some point go out in the community- [I] do a lot of outreach and networking- to update men, women, and people of color [on] why it's important that we need to have a little more trust." (Black/African-American Patient)*

> *"If someone doesn't trust you or what you're saying, they're not going to comply in what you're recommending. That's a huge barrier in underserved patient populations. I want to continue to add to the research and add to the discourse and engage in conversations like this to be a part of the solution." (Clinical Pharmacist)*

Reaching a Common Understanding: What Does Trust Mean to Patients?

During the patient focus group, the facilitator led the participants in a discussion about experiences, perspectives, and priorities regarding medical mistrust. To begin the conversation, the facilitator asked the patient participants, *"What does trust mean to you?"* Figure 1 below shows the responses:

Figure 1: A word cloud representing patient responses to the question, "What does trust mean to you?"

Reaching a Common Understanding: How Do Primary Care Team Members Know When a Patient Trusts Them?

Similarly, in the primary care team focus group, the facilitator asked the participants to share their thoughts on how they know when a patient or caregiver trusts them. The quotes below showcase their responses:

> *"I'm every patient's friend, meaning that the way that I welcome makes them feel very warm around me...Also the fact that I've been [in the practice] so long." (Clinical Support Staff)*

> *"One of the happiest moments for me [is] is when [a patient] wants me to see their family members. Especially if I have a parent in the clinic room with me and they say, like, 'can you see my kids?' That is always a very important moment for me that tells me that they trust me." (Family Medicine Physician)*

> *"I know the patients trust me when they continually ask to speak to me or for me to help them with things that other people can help them with." (Family Medicine Triage Nurse)*

> *"Patients will come back and tell you about the behavior of the [specialty providers]....which shows me a level of comfort that they can be candid." (Physician Associate)*

Understanding Factors Influencing Trust and Mistrust in Healthcare

Focus group discussions with Black patients and primary care team members identified key factors contributing to medical mistrust across multiple levels.

Racism as a Persistent and Foundational Challenge to Reducing Mistrust in Healthcare

The focus group conversations underscored the unique challenges that Black individuals face due to systemic racism and the historical mistreatment (e.g., Tuskegee Experiment, Henrietta Lacks) of Black patients by the healthcare system. Several patients shared that they were treated poorly and overlooked by medical professionals who held biases and harmful racial stereotypes. These experiences of discrimination and disrespect operate both at the interpersonal level—through direct interactions with the primary care team—and at the system level, reinforcing structural inequities that contribute to medical mistrust. Below are quotes about the systemic injustices that framed the conversations:

"…How can I navigate this system that is… systematically racist...but with my daughter…I had to really be calm and try to navigate. I told the doctor…'Act like this is your child laying on here on this bed, strapped down, don't know what's going on.'" *(Black/African American Patient)*

"I met patients who [say], 'Well, is it because I have [Medicaid] that my providers [is] treating me this way?'...'Would I get better care if I had [private health insurance]?' So, there's a lot that plays into this [mistrust], there's a lot of trauma [within] the Black community." (Clinical Support Staff)

"I realized just by looking around me in the [hospital] waiting room that somehow I didn't look like the rest of the people that were waiting to be seen. Not only the fact that when I did see the doctor, I was made to feel less than." *(Black/African American Patient)*

"In the predominantly Black neighborhood they would schedule [multiple] patients in blocks...[We] knew that wasn't right...but as our primary provider in a predominantly African-American community it didn't make a difference to us...For us, it was a system level factor that led to mistrust about the care that we received." (Patient Navigator)

Interpersonal and System-Level Factors Impacting Trust and Mistrust

Patients and primary care team members discussed various **factors that can build or erode trust** in healthcare among patients identifying as Black. For example, participants shared that empathetic communication from a clinician (e.g., eye-contact, a warm demeanor) could help build trust, whereas the absence of empathetic communication (e.g., dismissive or lack of eye contact), could hinder or erode trust.

Interpersonal Factors

- Compassionate, empathetic, and transparent communication with patients
- Supportive care team relationships
- Shared decision-making between patients and care teams
- Validation and belief of patient experiences
- Unconditional regard for patients by care team
- Shared humanity between patients and clinicians
- Clinician acknowledgment of past clinical errors and uncertainty
- Delivery of culturally competent care tailored to patient needs
- Treatment of patients with dignity and respect
- High-quality, evidence-based patient care focused on patient outcomes

[The doctor] said I'm going to prescribe you some medication that's for high blood pressure because you're an African American man, you're at the age of 45 and I see you ain't on no medication.' I said well, you didn't check my blood pressure.' ***How you gonna put me on something you don't even check my blood pressure?"*** *(Black/African American Patient)*

"I think it's very important to have ***unconditional regard*** *.... being able to...just approach [patients] openly and...[say] 'what could I do for you today?' and just show that and model that. I think it goes a long way to* ***building that trust*** *because I feel like* ***Black patients are used to being judged****. We're used to* ***being stereotyped****." (Family Medicine Physician)*

"...there was nothing else that told me that this man [doctor] could care for me any way, shape, form or fashion unless I dressed up, did the dance for him and performed the way that he felt that I deserved his care. ...I was ***looked at as less than because of the color of my skin****. That was the only* ***reason why I was treated so bad****." (Black/African American Patient)*

"I'm trying to give ***[patients] independence****...Particularly* ***with Black patients, we have this relationship*** *because we do have* ***something in common****...we're* ***both Black****...I think it's very important to let all patients know whatever color they are that* ***I'm here for you as much as I can be****... there's some things that you can do to be able to* ***help yourself and to help me help you****." (Patient Navigator)*

System-Level Factors

- Patient barriers to scheduling and receiving care
- Reliable patient follow-up on test results, referrals, questions
- Sufficient appointment availability and time with clinicians
- Patient education and tools to manage health
- Healthcare workforce reflecting the racial, ethnic, and linguistic diversity of the community
- Equitable and inclusive patient care across settings
- Effective, team-based care where roles are clearly defined
- Longitudinal continuity with a primary care clinician
- Effective care coordination between providers
- System accountability (e.g. surveys, standards)
- Payment models that incentivize high-quality, patient-centered care

"I'm like shaking the tree, writing emails. I'm doing the same for my Black patient on Medicaid, ***there's no access****. But the experience of that…for my patients who are Black…* ***'is this because I'm Black?'*** *There are reasons for that… there's that interplay of when the quality of the care itself at the individual level is not what it needs to be.* ***It feels racist****." (Internal Medicine Physician)*

"I have ***a relationship with [my health center].*** *I've participated in many of their groups…learning how to* ***eat better or their exercise class****…they had everything there, the* ***dentist office****…. I also had a* ***great relationship with the other staff****… there…" (Black/African American Patient)*

"I had a ***heart attack*** *while I was in the hospital* ***because of the stress*** *[that] they had put on me. You talk about* ***mistrust****, [it] that took my entire family to say,* ***'this just isn't what care looks like'.*** *But then how do you,* ***as a Black person, sit back and say, what does care look like when you've never had it before?"*** *(Black/African American Patient)*

"We all know the medical field can't be trusted. ***It's a billion-dollar business****." (Black/African American Patient)*

*"[My doctor] said [if] you stop going to see a doctor, I won't like that…****come and see me and far as [the finances], we'll figure it out.' That really [touched] my heart****." (Black/African American Patient)*

Potential Strategies and Outcomes to Consider for Patient-Centered CER

Ranking Focus Areas

The project team analyzed the focus group discussions and developed 13 preliminary high-level topics to focus on during the multi-stakeholder convening. The patient and primary care team participants ranked the following topics via an online survey as priority areas to discuss and develop future patient-centered CER, the bolded topics signify what the patient and primary care teams ranked as highest priority areas (see Appendix A for additional descriptions and quotes):

Patient Identified and Ranked Focus Areas	Primary Care Team Identified and Ranked Focus Areas
1. Communicate with Compassion	**1. Communicate with Compassion**
2. Agency through Education and Tools	**2. Work Together on Decisions**
3. Equitable and Inclusive Care	**3. Equitable and Inclusive Care**
4. Work Together on Decisions	**4.** Honesty and Transparency
5. Honesty and Transparency	**5.** Personalized, Whole-Person Care
6. Personalized, Whole-Person Care	**6.** Respect and Validation of Patients
7. Respect and Validation of Patients	**7.** Safe, High-Quality Care
8. Safe, High-Quality Care	**8.** Support Patients' Care Navigation
9. Support Patients' Care Navigation	**9.** Accountability
10. Accountability	**10.** Team-Based Care reflecting Community
11. Know the Patient's History	**11.** Primary Care Payment Models
12. Make Care Easier to Access	**12.** Longitudinal Continuity with Primary Care Clinician
13. Encourage Patient Advocacy	**13.** Care Coordination across Settings

Multi-Stakeholder Convening: Selected Priority Areas for Developing Patient-Centered Comparative Effectiveness Research

Participants rated the following focus areas as priorities for developing strategies for future patient-centered CER to reduce medical mistrust among Black patients: 1) Communicate with Compassion; 2) Work Together on Decisions 3) Support Patient Agency through Education and Tools; and 4) Equitable and Inclusive Care (highlighted below). Based on the prioritized topics, the patients and primary care team participants discussed strategies that researchers should consider for future patient-centered CER aimed at reducing medical mistrust amongst Black patients. Below are the strategies for consideration, along with a description and illustrative quotes for each strategy (See Appendix B for more detail):

Communicate with Compassion

- **Check in, Listen, Validate**: Implement patient-centered check-ins during primary care visits by asking empathetic, open-ended questions.
- **Consistently Follow-Through**: Implement systems for patient outreach supporting effective and timely patient care and follow-up (e.g., communicating test-results, responding to patient portal questions).
- **Train for Supportive Communication:** Establish routine, structured training for all primary care staff on communication, and active listening.

"Everyone that is involved in the patient's care [should be trained]. Starting from who checks them in to the providers... [medical assistants]...nursing staff, everyone who has a hand in that patient care, it's very important because that can set the tone for the whole patient's experience." (Clinical Pharmacist)

"When my doctor says right off the bat, 'How's everything going since our last visit? Is medication working?' It shows me they're invested in my care." (Black/African American Patient)

"The pressure to see more patients in less time often means we're not always fully present in the moment with our patients. It's about listening and giving them the space to speak. That's how we build trust and equity." (Pediatrician)

"Elements of follow up [are] very important to patients. No one wants to feel forgotten...they know I'm dealing with a specific crisis, for example, is there anyone reaching out to close that circle?"(Black/African American Patient)

Communicate with Compassion Continued

- **Strengthen Meaningful Human Connection:** Strengthen interpersonal relationships between patients and the primary care team emphasizing meaningful human connection.
- **Connect with the Community, Relate, Build Trust:** Support opportunities for patients and primary care teams to interact in and outside the clinical setting through activities (e.g., patient and family advisory groups, hosting community health fairs).

"When a patient says, 'How are you?' and they mean it, it really makes a huge difference. I thank them for asking because it shows their care and helps me feel human." (Internal Medicine Physician)

"[Trust is] a two-way fold. The doctor also has to trust the patient and the only way we can do that is by sharing our humanity. Take off the white [coat], take off the degrees." (Black/African American Patient)

"… if [our community] [wants to] do a health fair or a lunch, dine with the doc... they know our clinic is right there….they know I got residents, and we do a lot of community service...I think, just those interactions in the community to show that you're just not just the doctor in the office, but you care...you know what's going on in your community." (Family Medicine Physician)

"Sometimes, we have to offer incentives like a lunch or gift cards to get Black community members to participate. But once they come together, they start sharing their stories and that builds trust." (Black/African American Patient)

Work Together on Decisions & Support Patient Agency through Education and Tools

- **Collaborate, Support, and Empower:** Use collaborative tools and resources that enhance mutual decision making between the patient and the primary care team and ensure individuals are aware of their rights as patients.

"What I have [my mother] do to help her deal with that anxiety is write down any of her questions and concerns before she even comes into a visit. That seems to have really helped in keeping her on point with her healthcare. I think that's something that would work for all of us." (Black/African American Patient)

"…in addition to training, really giving more power back to patients…something like a Bill of Rights… where people can come knowing what they can expect and what they can request." (Family Medicine Physician)

"If we as African American men and women don't take charge [of our health], then that [poor treatment] is the outcome that we get." (Black/African American Patient)

"The big picture I always want to leave my clients with is that their actions help [primary care staff] help them get better…hopefully…[the patients] trust that I am on your side. I'm not here just to throw things at you and say you better do it. [I] just to let [patients] know that ….I am working with you, not against you." (Patient Navigator)

Foster Equitable and Inclusive Care

- **Educate and Train on Cultural Humility and Anti-Racism**: Educate and train all primary care staff—including front desk personnel and medical assistants—to respect different cultures and incorporate anti-racism into patient care.
- **Embrace Diversity, Cultural Awareness, and Center Belonging:** Ensure the primary care practice highlights and incorporates diversity and inclusion in all aspects of the clinic (e.g. signage, team meetings, patient-staff interactions).
- **Identify and Address Patient Health-related Social Needs**: Evaluate and establish practices that deliver care tailored to the needs (health-related or social) of patients and their community.

"When [a] clinic started asking [patients] about their experiences of racism in their care, it was actually the staff [who] started telling their own stories about their experiences of racism in their own care, which may or may not have been at the same clinic. But I think there's something about creating a culture among the staff." (Internal Medicine Physician)

"[Organizational] culture should be… open, welcoming, secure, trusting and all inclusive. …the culture of the organization…really matters and reinforcing that culture, assuring patients that yes, we do care, and we not only care today, but… are here for you tomorrow." (Black/African American Patient)

"I noticed that patients become really sick [due to] lack of needs. Stuff that they can't afford…they're very stressed [with] higher rents and high electricity bills…Is there a way we can build some sort of relationship with the outside world? I know that we're a hospital and our job is to care for the sick, but really there's a lot of things that makes patients sick…it's all about problems. How can we help with that small portion?" (Clinical Support Staff)

"Perhaps some cultural sensitivity training. Especially when you have people of color, and maybe the health care that they're receiving is in an area where [providers are] not accustomed to dealing with people from different cultures, but I feel that training could help reduce unconscious bias." (Black/African American Patient)

Patient-Centered Outcomes

Based on the focus areas and strategies described by participants, several patient-centered outcomes to measure the effectiveness of identified strategies to reduce medical mistrust were identified. Note that outcomes should be stratified by race to measure and monitor disparities in care and experiences.

Identified-Outcomes

- **Patient-reported outcomes** (e.g., patient experience, patient satisfaction, complaints, reviews, quality of life)
- **Primary Care Team Self-Evaluations** (self-efficacy)
- **Administrative Outcomes** (e.g. Number of missed/kept appointments, patient referral of family and friends)
- **Clinical Outcomes** (e.g. vaccine uptake, blood sugar levels, blood pressure control)

*"**Surveys** are very important because this is the **chance [to challenge]** the individual that we saw… that PA or that doctor is still **getting away with the mistreatment and the mistrust** that comes along with that." (Black/African American Patient)*

*"…[at] the end of [an] appointment…maybe they'll have [a] very **short one-on-one [survey]**, 'Have I answered all your questions? Do you have any additional questions? Is there **something you need today, long term**?' Maybe a couple questions at the end of every single appointment where we…**collect data.**" (Black/African American Patient)*

*"…providers need to **look within themselves** to say, '**what am I really doing this for?**' But they can **evaluate themselves**. I think that they should, **before** they put it **on to a patient through a survey**, what do you think we're doing and **how can we do it better**?" (Black/African American Patient)*

*"… I think checking to see [if] people coming in [for] their annual visits. **Are they coming back?** Are they not coming back?" (Black/African American Patient)*

*"…if the doctor [says to a patient] 'go and have a mammogram' or 'go and have a COVID shot because you're in a high-risk group'…and the **patient [is] following through** with what the primary care [team] is saying to them. [We] will be able to **measure [improved patient trust].**" (Black/African American Patient)*

Prioritized Directions for Future Patient-Centered CER

Following the discussions, the project team sent out a survey to participants and additional patients and primary care team members to gather perspectives regarding the identified priorities for future research. Both primary care team and patient participants (n=26) ranked the following as the most important area for future research:

1. Check in, Listen, Validate	*Implement patient-centered check-ins during primary care visits by asking empathetic, open-ended questions.*

Participants also ranked the following as the second prioritity for future research:

Patients	Primary Care Team Members
2. Embrace Diversity, Cultural Awareness, and Center Belonging: *Ensure the primary care practice highlights and incorporates diversity and inclusion in all aspects of the clinic (e.g. signage, team meetings, patient-staff interactions).*	**3. Strengthen Meaningful Human Connection:** *Strengthen interpersonal relationships between patients and the primary care team, emphasizing meaningful human connection.*

How Might Researchers Utilize These Findings to Develop Patient-Centered CER Questions?

To reduce medical mistrust and promote health equity, researchers must engage Black patients and primary care teams as equal partners in all phases of patient-centered CER. This report provides a foundation of community-identified priorities and strategies that researchers can use to ensure their work is responsive, culturally relevant, and actionable. Based on the lessons learned from this project and findings shared in this Roadmap, researchers should consider the following strategies:

1) Engage Black patients, community partners, and primary care team members in the design, implementation, and evaluation of any potential research studies.
2) Use the context, barriers, and facilitators of mistrust identified in this Roadmap to guide an in-depth understanding of the specific factors driving mistrust within the community or setting where research may take place.
3) Incorporate the priority focus areas and strategies to reduce mistrust identified in this Roadmap to compare two or more evidence-based health care services or practices.
4) Incorporate and tailor the patient-centered outcomes identified in this Roadmap to evaluate the effectiveness and impact of your research on the outcomes that matter most to stakeholders.

Example Patient-Centered CER Questions:

What is the effectiveness of tailored follow up communication strategies on Black primary care patient experience trust scores compared to standard communication protocols?
What is the effectiveness of clinical care with and without tailored shared decision-making on preventive care screening rates (e.g. breast cancer, colorectal cancer, etc.) among Black primary care patients?
What is the effectiveness of training clinical support staff with and without an anti-racism module on the primary care team's self-efficacy for delivering equitable care?
How do trust-centered interventions, compared to standard of care impact chronic disease management outcomes among Black primary care patients?

Closing Remarks

The findings of this project underscore the ongoing need for meaningful efforts to reduce medical mistrust. We hope this Roadmap serves as a valuable resource for healthcare organizations, community organizations and healthcare researchers working to build trust with Black patients. Trust is the foundation of strong, lasting patient-provider relationships. Recognizing the importance of mutual trust in improving care experiences and health outcomes, patients and primary care teams shared their experiences of what it feels like to have a trusting healthcare relationship (see Figure 2).

Figure 2: A word cloud representing patient and primary care team responses to the question, *"What does it feel like to have a trusting patient-provider relationship?"*

If you have any questions about the research Roadmap, please contact Molly Totman (mtotman@mhqp.org) or Autumn Bailey (abailey@mhqp.org).

Appendices

Appendix A: Barriers & Facilitators of Trust Identified by Participants

Topic	Description	Quotes from Participants
Communicate with Compassion	Patients and primary care team members emphasized the importance of empathy in building trust through communication. Using open-ended questions and centering the patient's needs fosters genuine patient-provider interactions.	"[My doctor] made direct eye contact with me and said to me, 'How can I help you today?' The only reason why she was there was to help me. It wasn't any 'Tell me about what had happened, what you felt, what did you…'. [it was] tell me how I can help you right now." (Black/African American Patient) "I had lost my dad…I dropped down to like 99 lbs. I was not eating, and my health wasn't great…When [my doctor] saw me, she came in, she shook her head and she just started crying…cause she's never seen me look that bad and… she was like, 'what do I need to do to get you better?'…that showed me like, you know, she's not just a doctor, like, she's a real person with a heart." (Black/African American Patient) "I think it's very important to have unconditional regard especially if you have difficult patients. I don't like the label patients as difficult…. just approach [patients] openly and say 'what could I do for you today?' and just show that and model that. I think it goes a long way to building that trust because I feel like Black patients are used to being judged. We're used to being stereotyped." (Family Medicine Physician)

Supporting Patient Agency & Working Together on Decisions	Shared decision-making strengthens trust by engaging patients and families in their care. Patients and primary care team members emphasized self-advocacy, shared responsibility, and supporting Black patients to feel empowered to make informed health decisions.	"…Always [include] your family in whatever decision because doctors don't like that, because they feel that if they say something in front of others, there's no way for them to say, 'well, you misunderstood me.' Which they're famous for saying." (Black/African American Patient) "My daughter [will] question everything. Don't tell her, she want[s] to know why, you got to explain it, show it, and then she going to research. [My daughter will go] and research what the doctor said, and she'll come back and tell [them] 'I ain't taking that.' So we got to do a lot of research for ourselves." (Black/African American Patient) "I'm trying to empower [patients], I'm trying to give them independence…Particularly with Black patients, we have this relationship because we do have something in common, [we're] both Black…I think it's important to let all patients know whatever color they are that I'm here for you as much as I can be, but at the same time, there's some things that you can do to be able to help yourself and to help me help you." (Patient Navigator) "If we as African American men and in women don't take charge [of our health], then that [poor treatment] is the outcome that we get." (Black/African American Patient) "But [healthcare providers] will misdiagnose if we don't be an advocate for our families [and] our community." (Black/African American Patient)

Equitable and Inclusive Care	Patients emphasized the need for culturally competent care. Experiences of racism and discrimination erode trust, while primary care team members who acknowledge these challenges, empathize, and treat Black patients with dignity help create a more inclusive and equitable care experience.	"…There was nothing else that told me that this man could care for me any way shape form or fashion unless I dressed up, did the dance for him…I realized that I was looked at as less than because of the color of my skin. That was the only reason why I was treated so bad." (Black/African American Patient) "…How can I navigate this system that is… systematically racist and disproportionate to the black folks, but with my daughter…I had to really be calm and try to navigate. I told the doctor… 'if I'm a Black doctor and this is your child, a white child to come to me, you would want the best healthcare that I could provide and that's what I want from you. Act like this is your child laying on here on this bed, strapped down, don't know what's going on." (Black/African American Patient) "I had a trusting relationship with one of my Black patients …She was upset about [George Floyd's murder] and she….[talked about] how hard it was interacting with people around those topics…[The] fact that she wanted to talk about that in her annual appointment with me, felt like a relationship of trust, actually talking about racism with somebody who was white in the system."(Internal Medicine Physician)

Honesty & Transparency	Participants shared that transparency, including acknowledging mistakes and limitations, helps primary care team members build trust with patients.	"…For the [healthcare professional] to have the integrity to say, 'I don't know, I don't have the answer' and do the right thing; I have found to be part of why I respect the care that I get and value it." (Black/African American Patient) "I know one thing I'd appreciate is if a doctor would just say, 'I don't know'. Let me refer you to someone else, and I've only experienced that one time in my life where they said, 'I don't know.'" (Black/African American Patient) "I confused [my patient] with another female patient… I could tell something was off in the interaction and later in the day, I was like 'I think I got my wires crossed.'… [My patient] came in and I was like, 'you know, I want to apologize because I think I made a mistake'… and she accepted my apology. So, I can tell she trusts me and that's how it came about." (Internal Medicine Physician) "[Patients] may be not being fully transparent with us because they feel in doing so, they might be judged, or they might get in trouble…[if] they tell us the truth and that's not really the case." (Clinical Pharmacist)

Personalized, Whole-person Care	Participants emphasized the importance of individualized care that recognizes and values the diverse experiences of Black patients. When care feels impersonal, it can contribute to mistrust.	"I was aging and they just looked at me as another older Black woman, so they just checked off boxes." (Black/African American Patient) "We just want to be treated like we're human. We want to be cared for, we want to be heard. We want to know that we matter. It's stressful just thinking about all the things that we do every day and then on top of this, you know, we have physicians who aren't listening to us." (Black/African American Patient) "Black people are not a monolith… When we ask questions about race or ethnicity, it is not as specific as it should be. When we see Black patients or African American patients, we do consider Tuskegee… We do consider Henrietta Lacks, but that is a very Americanized outlook on that and we don't necessarily take into consideration patients from Africa or immigrants into this country and what their experience is." (Clinical Pharmacist)
Safe, High-Quality Care	Patients shared that the dismissal of symptoms, medical gaslighting, and overlooked health concerns greatly contributed to medical mistrust. They emphasized the need for thorough, attentive, and respectful care to ensure safety and restore confidence in medical treatment.	"[My provider] was supposed to do a surgery, and I was still having complications after and he was looking at me as if I'm hallucinating. I'm at the ER, I'm in pain, I went and got a second opinion… [The provider said] I had tumors…he was supposed to remove the tumors, but he left one behind. But he told me, like as if 'oh it wasn't there when I did the surgery' and it was like he didn't thoroughly check." (Black/African American Patient) "I had to have back surgery and what happened was I went, they did the back surgery…I'm complaining because the pain was unbearable…The doctor said to me, which really infuriated me, 'No amount of pain medication is going to help this' which said to me that he felt like I was just asking for more medication." (Black/African American Patient)

		"I had a heart attack while I was in the hospital because of all of the stress and pressure that they had put on me in my heart. You talk about mistrust, [it] that took my entire family to say 'this just isn't what care looks like'. But then how do you, as a Black person, sit back and say, what does care look like when you've never had it before?" (Black/African American Patient)
Support Patients' Care Navigation	Participants emphasized the importance of guiding and supporting patients through the healthcare system. Primary care team members who went the extra mile helped build trust.	"I had an experience with my daughter… she needed to have her gallbladder removed…Before I made the decision in my mind, I was going to get a second opinion. Her pediatrician's office called me, and the doctor spoke with me personally and begged me to get a second opinion before we proceeded with surgery. I already had a good level of trust with them, but that took it to another level." (Black/African American Patient) "[I told the patient], 'I'm going to call the pharmacy with you on the phone.' So, I did that… It was time for me to leave so I explained to [the patient] that I would try again prior to me leaving and call him back to give him an update on what was going on. … The next day I came in … I followed back up with him…it was just that extra [effort of] contacting the pharmacy with him on the phone and …the follow through." (Family Medicine Triage Nurse)

Accountability	Failure to acknowledge past and present harm in medicine has contributed to mistrust among Black patients. Patients and primary care team members emphasized the need for individual and organizational accountability to rebuild trust.	"My son was a hemophiliac, and he got to be 22 years old…He went to [hospital name] just for his first physical. He ended up losing his life because the doctors wasn't up to par. The doctor [kept] telling me he knew what he was doing. [The doctor] gave [my son] a different medication, which made him sick. He fell off the bed and he died. So, I didn't trust [the hospital] for 10 years" (Black/African American Patient) "Mistrust is definitely there from day one, and having been at this eight years, it does take two or three visits with a Black patient before I really feel like they know that I'm accountable to them…It's a large burden to place on a provider to be accountable to a lot of the demands that [a] patient has but being willing to be accountable and help engender trust. I think a lot of the lack of accountability previously has led to a lot of [the current mistrust]." (Physician Associate) "I think the other thing is something that we have not owned well is race based medicine…You have to be willing to sit down and have a conversation [with your patients] and really be honest about we were wrong, and we all bought into the [kidney filtration rate race calculations] and that's what we learned in medical school. I think there's still a lot of things that we have to own as a whole medical community and apologize for and be accountable to the roles we played knowingly or not knowingly." (Family Medicine Physician)

Accessible Care	Participants highlighted the challenges of accessing timely care, particularly for Black patients. Systemic barriers, such as limited clinical hours and restricted treatment availability, contributed to frustration and mistrust.	"My son suffers from chronic croup, and we have had to jump through all types of hurdles to get proper treatment because it sometimes happens during the hours where the physician's office is closed, then we have to rely on urgent care or...the emergency room. As a parent and you have a child that's struggling to breathe, you don't have time to really build a rapport, your child needs help." (Black/African American Patient) "I'm like shaking the tree, writing emails. I'm doing the same for my Black patient on Medicaid, there's no access. But the experience of that at the individual level for my patients who are black... 'is this because I'm Black?' There are reasons for that...In addition to the individuals experience, there's that interplay of when the quality of the care itself at the individual level is not what it needs to be. It feels racist." (Internal Medicine Physician)
Team-based Care	Participants emphasized that trust is built through coordinated, patient-centered care. Every primary care team member plays a role in shaping the patient experience, and strong team relationships help foster trust.	"It's also important from every touch point in the system, we all have to be pulling the same weight. My patients can't love me but hate my front desk staff. They can't have a great experience with me but then not like going to our lab on site." (Family Medicine Physician) "I think trust is built... when [patients] see that we have really good team-based relationships. If [a patient navigator] ...is in the community, is trusted and knows me well and trust me, I think that that goes a long way to building [patient's] trust with the healthcare system and with recommendations" (Internal Medicine Physician)

Primary Care Payment Systems	Participants highlighted how current payment structures in primary care can hinder trust-building by prioritizing efficiency over meaningful patient interactions. They emphasized the need for payment models that allow for longer visits, and patient-centered care.	"There are really good [patient evaluation tools] and trust can be part of them, but it's not part of what's driving [payment] incentives for health care systems… if you're actually aligning incentives and you can provide more time…People don't have to be on a hamster wheel with 20 minute visits, and you can actually have more time to connect about..[and] really ensure that you've answered everybody's questions." (Family Medicine Physician) "Some of the pressures of medicine right now [are] the pressures to see more patients in less time…[It] makes you want to be like…'This is what this appointment is scheduled for [so] I'm going to hit that point and I'm going to move on.' Whereas what [the appointment] was scheduled for might not be the reason why the patient came." (Pediatrician) "Unfortunately, in our healthcare system in America, that's guided by the insurance companies, there are some situations where say for example you want your blood work done in advance your visit, but the insurance company has this protocol that the lab is part of the visit… In the case of the gentleman, you could explore with him and hopefully he trusts that he would say, 'look, I can't afford to pay to come there twice, right?'" (Patient Navigator)
Continuity of Care	Participants highlighted the importance of continuity in primary care to build trust. Smooth transitions can help patients feel supported and prevent disruptions in care.	"I went to see [my doctor] … and she said, 'hey, I'm retiring, here's the date but I want you to see this new provider, this is the person I want you to see from now on.' I thought that was terrific because I've been passed along in the health system so many times when my PCP might retire, you just find out they're no longer here and you need to select the new one with no guidance, with no help." (Black/African American Patient)

		"[My doctor] said [if] you stop going to see a doctor, I won't like that…come and see me and far as [the finances], we'll figure it out.' That really [touched] my heart." (Black/African American Patient)
Care Coordination	Participants highlighted the value of integrated care, where multiple services are available within the same health center. Access to coordinated medical, dental, and wellness resources, along with strong patient-provider relationships, fostered trust.	"I have a relationship with [my health center]. I've participated in many of their groups, nutrition, learning how to eat better or their exercise class, learning how to stay healthy and strengthen and move forward as I got older. Also, they had everything there for me the dentist office and everything was there. I also had a great relationship with the other staff that was there." (Black/African American Patient)

Encourage Patient Advocacy	Participants emphasized the need for Black patients to advocate for their health and challenge dismissive care. Speaking up, seeking alternatives, and finding primary care team members who listen were key strategies for ensuring better treatment.	"I understand more and more that we as black folks have become so intimidated by somebody that we think knows more than we do about us or our bodies that we just sort of sit there, take it, go somewhere quietly and suffer. That's what they want us to do. We need to stop." (Black/African American Patient) "But [my mother] had gone to her physician and explained… these [medication] side effects, which weren't pleasant and was letting her [provider] know that [she is] not going to take this medication. We need to come up with another alternative and this doctor refused to listen to her. Once I got my mother to calm down, I just explained to her, you know, you don't have to take this and it's time for you to see someone else." (Black/African American Patient) "If you want to talk about how BIPOC communities begin to build trust with the medical profession, how can you do that without hearing their voices? How can you do that without including everyone to say this is what we feel." (Black/African American Patient)
Knowledge of Patient's History	Participants discussed the importance of primary care team members reviewing and considering their medical history before making treatment decisions. Trust was strengthened when primary care team members demonstrated familiarity with patients' records rather than making assumptions.	"[The doctor] said 'I'm going to prescribe you some medication that's for high blood pressure because you're an African American man, you're at the age of 45 and I see you ain't on no medication.' I said 'well, you didn't check my blood pressure. How you gonna put me on something you don't even check my blood pressure?'" (Black/African American Patient) "Most of the time, the doctors will open the chart up right in front of you, go through your history… I asked [the doctor] 'Yo, can you pull my chart up? Because I don't want to talk to you until you put my chart up because I've been coming here for a very long time, so it ain't like you don't have a record.'" (Black/African American Patient)

Appendix B: Strategies to Reduce Medical Mistrust

Communicate with Compassion		
Theme	**Description**	**Quotes from the Multi-Stakeholder Convening**
Check in, Listen, Validate	Implement patient-centered check-ins with patients throughout primary care visits by asking empathetic, open-ended questions.	"I love to just stop what I'm doing and ask them [patients]… how they're feeling. I'll literally just say, 'how are you feeling right now?' or 'what are your thoughts right now?' and give them that open-ended opportunity to share whatever might be on their mind." (Family Medicine Physician) "When my doctor says right off the bat, 'How's everything going since our last visit? Is medication working?' It shows me they're invested in my care." (Black/African American Patient) "The pressure to see more patients in less time often means we're not always fully present in the moment with our patients. It's about listening and giving them the space to speak. That's how we build trust and equity." (Pediatrician)
Consistently Follow-Through	Implement systems for patient outreach that support effective and timely patient care and follow-up (e.g., communicating test-results, responding to patient portal questions or phone calls).	"Patients are often calling, saying, 'I've been waiting for my lab results.' Following through with clear communication and follow-up is so important in building that trust." (Family Medicine Triage Nurse) "We make sure that if a patient misses an appointment, we follow up and see what we can do to accommodate them. The follow-up makes a difference in how they feel about their care." (Patient Navigator) "…Elements of follow up I think is very important to patients. No one wants to feel forgotten or 'gee if they really cared, I just got out of the hospital…no one's calling to see how I'm doing.' Or they know I'm dealing with a specific crisis, for example, is there anyone reaching out to close that circle?" (Black/African American Patient)

Train for Supportive Communication	Establish routine, structured training for all primary care staff—including front desk personnel and medical assistants—on team-based communication, and active listening.	"[Patients] want reassurance, and they want to know that the whole team is working together, not the MA…saying 'well, they're running behind again,' it's more that feeling of we're all supporting this patient. I think that's what compassion could look like to people." (Family Medicine Physician) "I would say everyone that is involved in the patient's care [should be trained]. So, starting from who checks them in to the providers… [medical assistants] …[and] nursing staff, everyone who has a hand in that patient care, it's very important because that can set the tone for the whole patient's experience." (Clinical Pharmacist) "…hopefully we all have some sort of huddle or… regular staff meeting where everyone can…give their input…. It's easy to… [not] look at… all the things with registration this person has to go through and… how does that affect their communication with the patients." (Family Medicine Physician)
Strengthen Meaningful Human Connection	Strengthen interpersonal relationships between patients and the primary care team that emphasizes meaningful human connection.	"Once we share our humanity, that's when we can get through everything else together. If the doctor trusts me and I trust them, that's when we build a relationship." (Black/African American Patient) "[Trust is] a two-way fold. The doctor also has to trust the patient and the only way we can do that is by sharing our humanity. Take off the white [coat], take off the degrees." (Black/African American Patient) "When a patient says, 'How are you?' and they mean it, it really makes a huge difference. I thank them for asking because it shows their care and helps me feel human." (Black/African American Patient)

Connect with the Community, Relate, Build Trust	Support opportunities for patients and primary care teams to interact in and outside the clinical setting through activities like establishing patient and family advisory groups, hosting community health fairs, wellness workshops, and patient-provider storytelling events.	"Something I was…thinking about is…your [clinic's] presence in the community. … if [our community] [wants to] do a health fair or a lunch, dine with the doc or any kind of thing they know our clinic is right there…they know I got residents, and we do a lot of community service and we're gonna be there. I think, just those little interactions in the community to show that you're just not just the doctor in the office, but you care, you come out, you know what's going on in your community." (Family Medicine Physician) "Sometimes, we have to offer incentives like a lunch or gift cards to get Black community members to participate. But once they come together, they start sharing their stories and that builds trust." (Black/African American Patient) "Often times…we…the people on the ground would have to deliver [management] decisions, but it didn't come from the people on the ground. It didn't come from the constituents, the demographic or the people that we work with, but the decision always came from [higher management]. …so we need these people [from higher management] to come down and meet these [patients] down here and really show their face." (Black/African American Patient)

Work Together on Decisions, Support Patient Agency through Education and Tools		
Theme	Description	**Quotes from Multi-Stakeholder Convening**
Collaborate, Support, and Empower	Use collaborative tools and resources that enhance mutual decision making between the patient and the primary care team and ensure individuals are aware of their rights as patients.	"...you [can] use... a simple [tool] like [P.O.P.] ...Find the problem, 'P' ... the patient can initiate the problem that they want addressed. You can look at some of the different options ["O"] that you see together...that will meet both peoples [needs]...medically what might be helpful but what meets their social and personal needs. Pick one ["P"] ... can we do a quick intervention together to make sure that we're getting to the root of what you're asking?" (Pediatrician) "...in addition to training, giving more power back to patients...something like a Bill of Rights... where people can come knowing what they can expect and what they can request." (Family Medicine Physician) "What I have [my mother] do to help her deal with that anxiety is write down any of her questions and concerns before she even comes into a visit. That seems to have really helped in keeping her on point with her healthcare. I think that's something that would work for all of us...before the appointment, whatever [issues] that you need to address with your PCP and then make sure they're covered before you leave." (Black/African American Patient) "But the big picture I...want to leave my clients with is that their actions help [primary care staff] help them get better...hopefully... [the patients] trust that I am on your side. I'm not here just to throw things at you and say you better do it. [I]... let [patients] know that ... I am working with you, not against you." (Patient Navigator)

Foster Equitable and Inclusive Care		
Theme	**Description**	**Quotes from Multi Stakeholder Convening**
Educate and Train on Cultural Humility and Anti-Racism	Educate and train all primary care staff—including front desk personnel and medical assistants—to respect different cultures as well as incorporate anti-racism into patient care.	"…I wanted to mention perhaps some cultural sensitivity training. Especially when you have people of color, and maybe the health care that they're receiving is in an area where they're just not accustomed to dealing with people from different cultures… that training could help reduce unconscious bias." (Black/African American Patient) "Sometimes we, as African Americans, feel that we don't matter in healthcare. When I get treated as an individual and not a number, that builds trust." (Black/African American Patient) "Being required to show up ready to be a person first in staff meetings…When [a] clinic started asking [patients] about their experiences of racism in their care, it was actually the staff [who] started telling their own stories about their experiences of racism in their own care, which may or may not have been at the same clinic. But I think there's something about creating a culture among the staff." (Internal Medicine Physician)

Embrace Diversity, Cultural Awareness, and Center Belonging	Ensure that the primary care practice highlights and incorporates diversity and inclusion in all aspects of their clinic (e.g. signage, team meetings, patient-staff interactions).	"You have to look at your [patient] demographics and you need to figure out…what is the need of that group. Then you need to look for ways to meet those needs and be inclusive…Maybe that's in signage or your advertising or your hiring more of a diverse staff that reflects the community that you're working in. I think all of those things help play a role in showing that you understand that you have some commonality with the patients you're serving…." (Family Medicine Physician) "[Organizational] culture should be… open and welcoming and secure, trusting and all inclusive. …the culture of the organization…really matters and reinforcing that culture, assuring patients that yes, we do care, and we not only care today, but… [we] are here for you tomorrow." (Black/African American Patient) "In my practice, when we start with acknowledging each other's humanity, that builds the culture we need for inclusive care. We talk about the humanity in our staff meetings, and that extends to how we treat patients." (Family Medicine Triage Nurse)

Identify and Address Patient Health-related Social Needs	Evaluate and establish practices that deliver care tailored to the needs (health-related or social) of patients and their community.	"…I noticed that patients become really sick because of lack of needs. Stuff that they can't afford…they're very stressed [with] higher rents and high electricity bills…Is there a way we can build some sort of relationship with the outside world? I know that we're a hospital and our job is to care for the sick, but really there's a lot of things that makes patients sick…it's all about problems. How can we help with that small portion?" (Clinical Support Staff) "[In an ideal scenario], you have a wonderful clinic that has a social worker and a case manager, and you can fix those social determinants of health needs right there on site. Maybe you have a pantry, and you can write prescriptions for food…I can dream up a lot, but it really comes down to resources…and being able to have as many as possible for that community." (Family Medicine Physician) "We've started offering walk-in clinics and Saturday appointments because many of our patients are hourly workers without sick leave. They shouldn't have to choose between missing work and getting healthcare." (Patient Navigator)

Appendix C: Outcomes to Measure the Effectiveness of Strategies to Reduce Medical Mistrust

Outcome Type	Quotes from Participants
Patient-reported outcomes (e.g., patient experience, patient satisfaction, complaints, quality of life)	"[Asking patients] how much you felt…your concerns were heard, and… was there something during the visit that help to move you into feeling like your relationship was more human or more trusting? And also, the opposite, was there something that happened in the visit that that made you feel less trusting, and like they didn't see you?" (Pediatrician) "Regular satisfaction data that you get, you might be able to see some positive trends in your patient satisfaction data." (Family Medicine Physician) "As a part of the end of [the] appointment a person has, maybe they'll have [a] very short one-on-one [survey]; 'Have I answered all your questions? Do you have any additional questions? Is there something you need today, long term?' (Black/African American Patient) "Surveys are very important because this is the chance that we [get to] challenge the individual that we saw… that PA or that doctor is still getting away with the mistreatment and the mistrust that comes along with that." (Black/African American Patient)
Primary Care Team Self-Evaluations	"…providers need to look within themselves to say, what am I really doing this for? They can evaluate themselves. I think that…before they put it on to a patient through a survey, what do you think we're doing and how can we do it better?" (Black/African American Patient)
Administrative Outcomes (e.g. missed/kept appointments, patient referral of family and friends)	"…Patients will probably invite more families to come and get their care. Friends, if it's good for them, I'm sure they'll refer more people." (Administrative Support Staff) "…checking to see are people coming in their annual visits? Are they coming back? Are they not coming back?" (Black/African American Patient)
Clinical Outcomes	"… [With increased patient trust], outcomes would start to improve. For your primary care or your health center locally, you'll notice improvement in blood pressures, improvement in A1c levels [blood glucose control], you would notice clinical improvements as that trust improves." (Clinical Pharmacist) "…if the doctor [says to a patient] 'go and have a mammogram' or 'go and have a COVID shot because you're in a high-risk group'…and the patient [is] following through with what the primary care [team] is saying to them. [We] will be able to measure [improved patient trust]" (Black/African American Patient)

Appendix D: Gaps in Current Research: Improving Trust and/or Reducing Mistrust in Healthcare in the Black Community

- **Historical Context and Ongoing Impact:** More research is needed on how historical events like the Tuskegee Syphilis Study and the case of Henrietta Lacks continue to shape mistrust among Black communities today.
- **Intersectional Experiences:** Studies often overlook how intersecting identities (e.g., race, gender, socioeconomic status) influence mistrust.
- **Structural Changes:** Research should explore structural solutions such as accountability policies, race-stratified public reporting, DEI initiatives, anti-racism training, digital health equity efforts, and community-based partnerships.
- **Process Changes:** There's a need to test process-level changes, including equity-informed clinical protocols, tailored communication, expanded access, and equity-driven patient experience improvement.
- **Co-Creation of Solutions by Clinicians:** Research should examine how healthcare clinicians understand and can address their role in building or eroding trust.
- **Co-Creation of Solutions by Black Patients:** Approaches must actively partner with Black patients in the co-creation and testing of trust-building strategies.

References

1. Murray TM. Trust in African Americans' healthcare experiences. Nursing Forum. 2015;50(4):285-292. doi:10.1111/nuf.12120
2. Washington HA. Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present. 1st ed. Doubleday; 2006.
3. Williamson LD, Tarfa A. Examining the relationships between trust in providers and information, mistrust, and COVID-19 vaccine concerns, necessity, and intentions. BMC Public Health. 2022;22(1). doi:10.1186/s12889-021-12372-6
4. Armstrong K, Putt M, Halbert CH, et al. Prior experiences of racial discrimination and racial differences in health care system distrust. Med Care. 2013;51(2):144-150. doi:10.1097/MLR.0b013e31827310a1
5. Dugan E, Trachtenberg F, Hall MA. Development of abbreviated measures to assess patient trust in a physician, a health insurer, and the medical profession. BMC Health Serv Res. 2005;5:64. doi:10.1186/1472-6963-5-64
6. Starfield B. Primary Care: Concept, Evaluation, and Policy. Oxford University Press; 1992.
7. Phillips KE, Haft H, Rauner B. The key to improving population health and reducing disparities: Primary care investment. Health Aff Forefront. 2022. https://www.healthaffairs.org/content/forefront/primary-care-investment-key-improving-population-health-and-reducing-disparities
8. Sutton AL, He J, Edmonds MC, Sheppard VB. Medical mistrust in Black breast cancer patients: Acknowledging the roles of the trustor and the trustee. J Cancer Educ. 2019;34(3):600-607. doi:10.1007/s13187-018-1347-3
9. Hammond WP. Psychosocial correlates of medical mistrust among African American men. Am J Community Psychol. 2010;45(1-2):87-106. doi:10.1007/s10464-009-9280-6
10. Hall OT, Jordan A, Teater J, et al. Experiences of racial discrimination in the medical setting and associations with medical mistrust and expectations of care among Black patients seeking addiction treatment. J Subst Abuse Treat. 2022;133:108551. doi:10.1016/j.jsat.2021.108551
11. Best AL, Fletcher FE, Kadono M, Warren RC. Institutional distrust among African Americans and building trustworthiness in the COVID-19 response: Implications for ethical public health practice. J Health Care Poor Underserved. 2021;32(1):90-98. doi:10.1353/hpu.2021.0010
12. Dong L, Bogart LM, Gandhi P, et al. A qualitative study of COVID-19 vaccine intentions and mistrust in Black Americans: Recommendations for vaccine dissemination and uptake. PLoS One. 2022;17(5):e0268020. doi:10.1371/journal.pone.0268020
13. Nguyen TC, Gathecha E, Kauffman R, Wright S, Harris CM. Healthcare distrust among hospitalised Black patients during the COVID-19 pandemic. Postgrad Med J. 2022;98(1161):539-543. doi:10.1136/postgradmedj-2021-140824