Discrimination in the Health Care System: A Qualitative Study of What People Experience and What Can be Done

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The SCAN Foundation (TSF) envisions a society where all of us can age well with purpose. We pursue this vision by igniting bold and equitable changes in how older adults age in both home and community. Our grants and impact investments prioritize communities that have been historically marginalized with an emphasis on older people of color, older adults with lower incomes, and older residents in rural communities. Learn more at www.thescanfoundation.org.

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Executive Summary

Discrimination in health care remains a persistent barrier to equitable treatment, patient trust, and timely access to care. National research indicates that up to one-third of U.S. adults report discriminatory or disrespectful treatment in medical settings, with well-documented emotional, clinical, and financial consequences. These patterns contribute to widening health disparities and undermine confidence in the health system. To better understand these experiences and identify solutions, the LeadingAge LTSS Center at UMass Boston conducted a comprehensive study with qualitative and quantitative dimensions. The current study summarizes qualitative findings and is informed by adults who self-identified as having experienced discrimination in health care.

Three virtual focus groups were held with 21 participants representing diverse racial, ethnic, gender, socioeconomic, and insurance backgrounds. Using thematic analysis of verbatim transcripts, the study explored how participants defined discriminatory treatment, how these interactions shaped trust and care-seeking behavior, and what reforms they viewed as most critical for improving respectful, inclusive, and equitable care. Participants described the circumstances surrounding discriminatory encounters, including being rushed, dismissed, judged, or ignored by providers. They attributed these experiences to factors such as insurance status, race and ethnicity, gender, body size, age, disability, and perceived socioeconomic position – patterns that mirror well-established findings in the research literature (Smedley et al., 2003; Phelan et al., 2015; Clarke et al., 2014).

This qualitative analysis complements the accompanying quantitative findings, offering deeper insight into how discrimination is experienced, the consequences that follow, and the types of reforms patients believe are most urgently needed. The following table provides a detailed description of the strategies presented and discussed.

Across groups, proposed solutions reflected patient-driven recommendations well-documented in the literature, including the need for cultural humility, structural competency, equity-focused evaluation systems, and transparent reporting mechanisms (Chapman et al., 2013; Metzl & Hansen, 2014). Together, these themes reinforce that discrimination is not merely an interpersonal issue but a systemic one requiring coordinated organizational and policy responses.

Strategies Contributing to Reduced Discrimination in Health Care

Strategy	*Description*
1. A. Provider training in cultural humility, implicit bias, and anti-discrimination	Training helps clinicians recognize and address unconscious biases, power dynamics, and discriminatory behaviors to improve communication and patient-centered care.
2. B. Clear and visible patient-facing statements on anti-discrimination policies and complaint procedures	Posting clear statements signals commitment to equitable treatment, informs patients of their rights, and explains how to report concerns through accessible complaint pathways.
3. C. Patient advocates or care navigators	Advocates support patients who feel marginalized or unheard by assisting with communication, understanding medical information, and accessing services, thereby strengthening engagement and trust.
4. D. Policies to diversify the clinical workforce	Increasing representation among clinical staff enhances cultural understanding, fosters trust, and improves communication by ensuring providers better reflect the communities they serve.
5. E. Incorporating community feedback into provider performance evaluations	Integrating patient and community input into performance assessments increases accountability and ensures care inequities are identified and addressed through continuous quality improvement.

Key Findings

- **Discriminatory encounters were common, cumulative, and deeply harmful.** Participants described repeated experiences of being dismissed, stereotyped, or treated with less respect. These were rarely isolated events; rather, they formed recognizable patterns that made bias unmistakable.
- **Discrimination eroded trust and discouraged future care-seeking.** Participants reported delaying or avoiding care, skipping preventive screenings, switching providers, or disengaging from health systems altogether. Many described hyper-vigilance, emotional exhaustion, and anticipatory stress during medical encounters.
- **These experiences had measurable health and financial consequences.** Avoidance and delayed care often led to worsening symptoms, emergency-level needs, and higher out-of-pocket costs, intensifying both health risks and financial strain.
- **Participants prioritized solutions that combine provider training with institutional accountability.** Highly valued strategies included ongoing cultural humility and implicit bias training; access to patient advocates or navigators; clearer and more responsive complaint pathways; and integrating patient feedback into provider performance systems. Participants emphasized that respectful care cannot depend on "luck of the provider" but must be reinforced through organizational systems and norms.
- **Patient experiences of discrimination point to systemic failures that extend beyond individual providers and frontline interactions and instead require policy-level solutions.** Findings highlight the need for external accountability, standardized measurement, and enforceable protections to ensure that nondiscriminatory care is treated as a core requirement of health system performance rather than an optional or inconsistently applied norm (Rosenbaum, 2016; Clark et al., 2020).

Introduction

Discrimination in health care settings remains a persistent barrier to equitable access, quality care, and patient trust.

Discrimination in health care settings remains a persistent barrier to equitable access, quality care, and patient trust. National research shows that discrimination is both widespread and consequential, with between 20% and 37% of U.S. adults reporting discriminatory treatment in a medical setting and most indicating it occurs more than once (Nong et al., 2020; Wang et al., 2024). Experiences of discrimination have been linked to delays in seeking care, poorer treatment adherence, and diminished health outcomes due to physiological stress and psychosocial strain (Lawrence et al., 2022; Rivenbark & Ichou, 2020).

This report presents qualitative findings from a study designed to examine how and why individuals perceive that they have been discriminated against by physicians, hospitals, or other health care professionals, and to identify strategies they believe could reduce such discrimination. The study sought to elevate the voices of people who have directly experienced differential treatment in clinical settings and to translate their perspectives into actionable insights for policymakers, practitioners, and health system leaders. These narratives provide important context to expand on existing quantitative evidence, which documents the prevalence of discrimination but offers limited insight into how patients interpret these experiences and how such encounters shape future health-seeking behavior (Hausmann et al., 2011; Burgess et al., 2008).

Results

Table 1 summarizes the demographic characteristics of the 21 focus group participants. The mean age of respondents was 58.9 years (SD = 4.4; range: 52-70). The sample was predominantly female (71%). A majority of participants identified as Black (62%), and 29% as Hispanic. Regarding socioeconomic characteristics, 14% of participants held a graduate or professional degree, 43% had a bachelor's degree, and 43% reported completing some college or an associate degree. Over half (52%) reported annual household income of $75,000 or higher. Most participants were married (38%), employed full- or part-time (71%), and insured (81%). Across the sample, 76% of respondents reported experiencing discrimination in a health care setting within the past two years. Specifically, 24% reported discrimination within the past six months, 28% within the past 6-12 months, and the rest one or more years prior to the study.

Table 1. Sociodemographic Characteristics of the Study Sample (N=21)

Characteristic	N	%
Age		58.9
Gender		
Male	6	29%
Female	15	71%
Race/Ethnicity		
White	4	19%
Black	13	62%
Native American	1	5%
Asian	1	5%
Other: Hispanic	2	9%
Hispanic		
Yes	6	29%
No	15	71%
Marital		
Married	8	38%
Divorced/separated	3	14%
Never been married	6	29%
Widowed	4	19%
Education		
Graduate or professional degree	3	14%
Bachelor's degree	9	43%
Some college or an associate's degree	9	43%
Income		
$75,000 and above	11	52%
Below $75,000	10	48%
Health Insurance		
Yes	17	81%
No	4	19%
Employment		
Employed full-time or part-time	15	71%
Full-time homemaker/not employed outside of home	1	5%
Retired or partially retired	2	10%
Unemployed	3	14%
Discrimination Occurrence		
Within the last 6 months	5	24%
6-12 months ago	6	28%
1-2 years ago	5	24%
More than 2 years ago	5	24%

Participant Reflections on Overall Health Care Experiences

When asked whether their experiences with doctors, hospitals, or clinics were generally positive, negative, or mixed, most participants described their encounters as *mixed* rather than consistently positive or negative. Participants emphasized that their satisfaction often depended less on the type of health care setting and more on the individual providers, the quality of interpersonal communication, and whether they felt respected during the encounter.

Several participants acknowledged receiving high-quality care at times but also described dismissive or discriminatory treatment in other instances, even within the same health system.

Positive experiences were typically linked to providers who listened attentively, demonstrated respect, and treated them as partners in care. As one participant explained, *"You can tell when they're really there to help you, and you can tell when you're just a box they have to check so they can move on."* Another participant similarly noted that their care had mainly been positive because they had built strong relationships with their physicians over time.

> *"You can tell when they're really there to help you, and you can tell when you're just a box they have to check so they can move on."*

In contrast, others recalled negative experiences characterized by rushed appointments, poor communication, or feeling ignored or judged by providers. One participant reflected, *"Sometimes I feel like I'm very clear, but they are not listening to the words that are coming out of my mouth. It's like they already decided who I am before I even sit down."* Another echoed this frustration, *"I go in and I'm talking apples, and they're talking oranges. They're not even trying to understand what I'm saying. They're just waiting to get to the next person."* Such experiences left many feeling that their concerns were not taken seriously.

Participants also discussed how their experiences and perceptions of the health care system had evolved over time. Several respondents reported a growing sense of mistrust due to repeated experiences of perceived disrespect or bias, often related to race, age, insurance status, or body size. Even those who once felt confident navigating the system reported growing wariness or disillusionment after multiple negative encounters.

Overall, while a small number of individuals described consistently positive care experiences, the prevailing theme was unpredictability. Participants emphasized that their health care interactions were deeply shaped by interpersonal dynamics, implicit bias, and structural barriers, leading many to characterize their overall experiences as "mixed" rather than clearly positive or negative.

Participants described mixed experiences with health care that they felt had worsened over time, particularly since the COVID-19 pandemic. Several noted that while they had received excellent care from individual providers in the past, the overall environment now feels more rushed, strained, and less personal. They attributed this shift to provider burnout, staffing shortages, and pressures within both insurance and clinical systems. Some participants also emphasized that the quality of care varied depending on their insurance coverage, reporting noticeable differences after transitioning from employer-sponsored plans to Medicare or disability-related coverage. Collectively, these reflections conveyed a sense of being pushed through the system, with less time for communication, less patience from providers, and increasing concern that these changes could negatively affect their health.

Experiences of Being Mistreated or Treated with Less Respect in Health Care

When asked whether they had ever felt treated unfairly, with less respect, or differently than others in a health care setting, nearly all participants described at least one experience they perceived as discriminatory. These encounters ranged from explicit forms of bias to more subtle expressions of stereotyping, dismissal, or neglect by providers and staff. Participants emphasized that such experiences were not isolated misunderstandings but reflected patterns of interaction shaped by assumptions about patients' appearance, weight, race, insurance type, or social status.

Several participants described feeling dismissed or judged based on appearance. One participant reported that emergency room staff made presumptions about him before assessing his condition, noting that *"they looked at me and treated me like I didn't belong there, like they already decided what kind of person I was before I even spoke."* Another participant recounted being evaluated through the lens of weight stigma, stating that *"One doctor said to me, 'You need to lose weight,' before I could even finish explaining why I was there. It's like they can't see past my body to treat me like a person."*

> *"They looked at me and treated me like I didn't belong there, like they already decided what kind of person I was before I even spoke."*

Others recalled instances in which their concerns were minimized or treated without urgency. One participant described waiting weeks for a follow-up after being told she might have a serious condition, explaining, *"It was like my worry didn't matter to them. They just sent me home and said, "Wait." I felt completely dismissed."* Another individual reported that her cardiologist attributed her symptoms to weight rather than ordering tests, leading her to seek care elsewhere.

Across accounts, participants expressed that these experiences not only caused emotional distress in the moment but also had lasting effects on trust and care-seeking behavior. One participant reflected on feeling devalued when the provider made no effort to engage, sharing, *"He stood in the doorway. That let me know he wasn't really interested in me. He didn't even come in to sit down or look me in the eye. That told me everything about how much he valued my time."* Others described advocating for themselves, challenging providers directly, filing complaints, or changing doctors, but acknowledged the emotional labor required to do so.

> *"It was like my worry didn't matter to them. They just sent me home and said, "Wait." I felt completely dismissed."*

Taken together, these narratives illustrate how perceived disrespect and discriminatory treatment can erode trust, discourage follow-up care, and reinforce a sense of vulnerability among patients who already feel marginalized within the health care system.

Factors Perceived to Contribute to Discriminatory Treatment

When asked what they believed contributed to their experiences of being mistreated or with less respect in health care settings, participants identified a range of perceived factors, often involving multiple aspects of their identity. Although the specific circumstances varied, most respondents attributed the differential treatment they received to visible or assumed characteristics such as race, gender, weight, insurance status, age, or socioeconomic position, as well as to implicit stereotypes held by health care providers.

Race and ethnicity were frequently cited as central factors shaping participants' experiences of discriminatory treatment. Several individuals described encounters in which they believed assumptions about their health status or behavior were made solely on the basis of racial identity. One participant recounted that a specialist immediately recommended surgery *"because people like me are always clogged up,"* despite no diagnostic testing being performed leading him to conclude that the recommendation was driven by racial stereotyping rather than clinical evidence.

Other participants described more subtle but persistent forms of racially mediated disrespect. One explained that she had not initially labeled her experiences as racism, noting that she once avoided using *"the R word"* because it often prompted defensiveness from others. She described an incident in which her pharmacy dismissed her clear and detailed request for a corrected prescription, only for her provider's nurse to later affirm that her communication had been precise. She concluded that her words were discounted *"because of the tan,"* reflecting a belief that her concerns were minimized due to her racial appearance.

Several participants cited tone, body language, and rushed interactions as additional indicators of bias. One explained that she felt her provider viewed her *"as a Black woman"* and adjusted their communication accordingly. Another stated bluntly, *"I think that race plays a part because you have some doctors that can just be racist…they rush with you, they don't want to touch you."*

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Participants also recounted more severe consequences linked to racialized treatment. One described a series of surgical complications that he believed stemmed from the way his care was handled, including a provider who severed his appendix during a procedure and offered minimal communication afterward. He noted that the surgeon spoke extensively with several other families, none of whom were his race, before his wife had to chase him down for an update.

In another case, a participant managing thyroid cancer reported being treated as if she were *"drug seeking"* when attempting to fill a necessary prescription, concluding that the suspicion was connected to *"the tan."*

Collectively, these accounts illustrate how participants perceived race and ethnicity to influence not only interpersonal interactions but also diagnostic decisions, communication quality, and the seriousness with which their concerns were addressed.

Gender-based dismissal also emerged as a recurring theme, particularly among women who felt their symptoms were minimized, stereotyped, or attributed to hormonal changes rather than fully assessed. One participant described repeatedly having her concerns *"written off as just being a woman,"* reinforcing her sense that providers were responding to her identity rather than the clinical issues she raised. Another participant explained that when she described her symptoms to new providers, they were quickly attributed to hormones or aging, noting, *"all of this doesn't have to do with aging or gender."*

Weight bias surfaced in several accounts where participants felt that providers focused disproportionately on body size rather than the health concern that brought them in, leaving them feeling blamed, dismissed, or unheard. One respondent explained that *"he didn't hear anything I said, he just kept coming back to my weight like that explained everything,"* reflecting a sense that her symptoms were not taken seriously. Others described similar experiences in which requests for guidance or referrals were minimized. One participant shared that when she asked for support in managing her weight, her provider avoided eye contact and offered only the generic advice to *"eat less and exercise more,"* dismissing her request for a referral to a dietitian. Another described seeking care for dizziness and fatigue, only to have her concerns reduced to questions about exercise and weight, despite considering herself *"a pretty average size."* She noted that as a 61-year-old woman, daily workouts were unrealistic, leaving her feeling *"not important at all"* and unsure whether her symptoms were ever fully assessed.

Participants also described **financial and insurance status** as powerful factors shaping how they were treated in health care settings. Several believed they received less time, fewer options, or poorer communication once staff learned they were covered by Medicaid – the social safety net program for low-income individuals – or had limited insurance benefits, describing this shift as immediate and noticeable. One participant noted that *"as soon as they saw what insurance I had, the tone changed,"* reinforcing her perception that she was viewed as a lower-priority patient. Another participant explained, *"When I had private insurance, I had my own room and saw a dozen doctors in a day. Now that I'm on Medicare, the doctors barely come by."*

> *"When I had private insurance, I had my own room and saw a dozen doctors in a day. Now that I'm on Medicare, the doctors barely come by."*

Others echoed this theme, describing how changes in insurance coverage directly affected the quality of care they received. One participant explained that after early retirement left her uninsured, she *"definitely noticed a difference"* in how she was treated. Another contrasted her experiences on Medicaid versus Medicare, stating that clinicians spent little time with her when she had Medicaid, but performed excessive or unnecessary procedures once she gained supplemental private insurance, which she believed was driven by billing incentives.

Participants also described stark differences in hospital experiences tied to insurance status. One individual reported receiving attentive, around-the-clock care and a private room when covered by a large employer-sponsored plan, but after transitioning to Medicare during the pandemic, she was placed in a shared room with little provider interaction. She summarized the experience by noting that clinicians *"came in like you were a stop on the way to someone or something else,"* reinforcing the perception that insurance type directly influenced the level of attention and respect she received.

Notably, many participants reported that discriminatory experiences reflected multiple, overlapping identities, such as being *Black and uninsured, a woman and overweight,* or *Latino and lower income.* These intersections shaped how participants interpreted their experiences and why they concluded the treatment was discriminatory. Several emphasized that it was not a single interaction but repeated patterns across encounters that made the bias unmistakable: *"Once it happens again and again, you know it's not random. It's something about who they think you are."*

Taken together, these accounts illustrate that perceived discrimination in health care was not experienced as a single event but as the result of cumulative and identity-based assumptions, reinforcing systemic inequities across race, gender, class, and body size.

Examples of Discriminatory Encounters and Effects on Care-Seeking Behavior

When participants were asked to describe a specific incident in which they were mistreated, with less respect, or differently than other patients, many recounted vivid experiences that had a lasting emotional and behavioral impact. One participant described an encounter with a cardiologist in which the provider focused exclusively on her weight and dismissed the symptoms she had come in to address. Rather than conducting a complete assessment or acknowledging the severity of her concerns, the physician attributed her condition to weight alone and advised her to *"just lose weight and exercise,"* without further diagnostic inquiry. The participant explained that this response made her feel *"marginalized and belittled,"* reinforcing her belief that the provider viewed her body size, not her symptoms, as the central problem.

The emotional response to this encounter was immediate and negative. The participant reported feeling *"demoralized,"* noting that the experience stood in stark contrast to previous interactions with providers who had treated her respectfully. She emphasized that the interaction not only harmed her sense of dignity but caused her to doubt whether her concerns would ever be taken seriously within that clinical system.

This encounter appeared to affect future care-seeking behavior. The participant said the experience made her reluctant to return for follow-up care and hesitant to seek help when new symptoms emerged, out of fear of being dismissed again. Although the emotional impact lessened somewhat after she found a new provider who listened attentively and treated her concerns as valid, she noted that the *"damage was already done"* and remained guarded in subsequent medical interactions. Ultimately, she chose to leave that practice and transition her care to another clinician who demonstrated empathy and took her concerns seriously.

Another participant shared a similar experience of having her health concerns minimized and delayed, with severe consequences. She recalled, *"When I went for a mammogram they said they saw a spot. When you tell somebody that you think they would be quick to follow up, well the doctor was on vacation and no one else could read the chart. I had to wait two weeks to find out if it was anything. And then when he came back, he had this really nonchalant attitude like, oh well, it's not that big of a deal, but we'll check, and lo and behold, it was breast cancer that had metastasized, and it was serious. And the annoying part was how he just kind of blew it off. Whereas when I went to another doctor, he was more conscious and said, "No, we need to take care of this now. Why are we waiting?" And he said a lot of times, that's what happens. They don't take women's issues seriously. And that's how I felt. I would never use him again."*

> *"When I went for a mammogram they said they saw a spot. When you tell somebody that you think they would be quick to follow up, well the doctor was on vacation and no one else could read the chart. I had to wait two weeks to find out if it was anything…"*

This example illustrates a recurring pattern across participants: encounters in which providers relied on stereotypes rather than clinical assessment were not only distressing in the moment, but also shaped patients' willingness to seek care, their sense of safety in medical settings, and their trust in health professionals. The experience reinforced participants' belief that respectful communication and patient-centered engagement are not simply interpersonal preferences but essential components of equitable and ethical care.

Impact of Discriminatory Experiences on Trust in Health Care

Participants overwhelmingly reported that negative or discriminatory encounters had a lasting effect on their trust in both individual providers and the broader health care system. While a few individuals described maintaining confidence in select clinicians with whom they had built strong relationships, the prevailing pattern was erosion of trust, heightened caution, and reduced willingness to seek care.

Several participants noted that their sense of trust was damaged when they felt judged, dismissed, or stereotyped based on characteristics such as weight, gender, race, or age. These encounters were described not only as emotionally distressing in the moment, but also as cumulative experiences that shaped expectations for future care. One participant explained that after repeated judgment about weight, she *"stopped going to yearly check-ups because I didn't want to put myself through that again."* Another described delaying follow-up care after a provider minimized her breast health concerns, noting that *"once they ignore something serious, it's hard to ever feel safe with them again."*

Participants also emphasized that trust, once lost, was difficult to rebuild. Some sought to rebuild confidence by changing providers, but others expressed broader skepticism toward the medical system as a whole. For example, one participant reflected that while they had eventually found a doctor they trusted, the earlier negative experience *"never really left [them]"* and continued to influence how they navigated new health encounters.

Notably, a small number of participants reported positive relationships with long-term providers, which helped counterbalance negative experiences and preserve some level of trust. One participant shared that consistent, respectful communication from a primary care physician was the only reason they continued to seek care, contrasting this with other dismissive interactions in clinical settings.

Across groups, participants expressed that rebuilding trust would require more than one-on-one provider repair; instead, they pointed to broader system-level changes, such as stronger patient advocacy, improved provider communication, and ongoing training in cultural humility and bias reduction. However, several cautioned that even with reforms, the emotional impact of past encounters continued to shape how they approached future care.

"I'm so far behind on my annuals because I'm just, I'm done. I'm so tired of going in there and feeling judged because whatever they're looking down on me for, whether it be my weight, my gender, my age, it doesn't matter. So, yeah, I'm way past overdue and I just have no desire even to go in and face him."

Participants reported that negative or discriminatory encounters had a direct and measurable influence on care-seeking behaviors, including how frequently they sought care, whether they followed medical advice, and which providers or facilities they were willing to engage with. For many, experiences of being judged, dismissed, or treated with disrespect led to delayed appointments, skipped preventive care, and intentional avoidance of certain clinicians or health systems. One participant explained, *"I'm so far behind on my annuals because I'm just, I'm done. I'm so tired of going in there and feeling judged because whatever they're looking down on me for, whether it be my weight, my gender, my age, it doesn't matter. So, yeah, I'm way past overdue and I just have no desire even to go in and face him."* Another participant echoed this reluctance, noting that being repeatedly dismissed by her provider made her *"less proactive about following up,"* even when she knew the care was medically important.

Participants also described adopting explicit avoidance strategies, such as refusing to return to a provider who had previously treated them disrespectfully or limiting engagement with the health care system unless necessary. As one participant stated, *"Once I lose confidence in a doctor, I don't go back,"* describing how this pattern gradually reduced her overall engagement with care. Others emphasized that discriminatory experiences generated heightened hesitation and distrust during future encounters, including feeling increasingly cautious after being rushed or dismissed in previous appointments.

"It kind of winds you down… I'm not pursuing health the way I should be because I just can't find anybody."

Across responses, participants highlighted that these decisions were not isolated or impulsive reactions, but cumulative responses to repeated experiences of feeling unheard, judged, or devalued. As one participant summarized, *"It kind of winds you down… I'm not pursuing health the way I should be because I just can't find anybody."* This translated into missed preventive screenings and routine care. One participant shared, *"I really don't want to go back…because I feel judged…so why even bother coming?"* Another added that she avoided multiple providers because she expected to be blamed or dismissed: *"Sometimes you won't go to the doctor because…he's just going to tell me I'm too fat or too lazy."*

Taken together, these accounts illustrate a clear linkage between perceived discrimination and reduced engagement with health care, demonstrating not only emotional harm but also tangible implications for preventive care, chronic condition management, and overall health outcomes.

In contrast, some participants described becoming more proactive as a direct result of their past negative experiences in health care. They explained that repeated instances of feeling dismissed or overlooked motivated them to take greater responsibility for monitoring their own care. As one participant shared, she now schedules appointments far in advance, prepares detailed questions on her phone, and stays vigilant about vaccinations and annual visits, emphasizing that *"you deserve to be cared for as humans"* regardless of insurance status. She acknowledged that many medical professionals are overwhelmed and exhausted but noted that this reality makes self-advocacy even more important: *"If they don't take you seriously, you have to sit up and say something…you have to advocate for yourself more and more."*

Health and Financial Consequences of Discriminatory Health Care Experiences

Participants reported that negative or discriminatory encounters in the health care system had consequences that extended beyond emotional distress, resulting in both worsening health outcomes and significant financial strain. Many explained that avoidance of care motivated by prior experiences of disrespect, judgment, or dismissal led to delays in diagnosis, unmanaged symptoms, or deterioration of existing conditions.

"I stopped scheduling my check-ups because I already knew how they were going to treat me."

One participant described postponing routine care due to feeling devalued by her provider, noting that *"I stopped scheduling my check-ups because I already knew how they were going to treat me."* She explained that this avoidance eventually contributed to a decline in her health, as conditions that could have been addressed early were allowed to progress. Another participant recounted how inadequate follow-up from a previous care team led to untreated symptoms that later became serious, stating that *"if they had actually taken me seriously when I first brought it up, it wouldn't have gotten this bad."*

Participants also described substantial financial impacts stemming from delayed or inadequate care. In some cases, worsening health interfered with their ability to work, leading to lost income and increased medical expenses. Others emphasized that when preventive or routine care is delayed, it often results in reliance on emergency, specialty, or high-cost services further increasing out-of-pocket costs and long-term financial burden.

Several participants highlighted the role of insurance systems in compounding these financial challenges. One individual described navigating a complex and costly diagnostic process after losing her job. Despite meeting her deductible, she learned that her needed procedure would cost $350 because it was performed in a surgical center not covered under her plan. She spent weeks calling multiple in-network providers, many of whom no longer offered the procedure outside of surgical centers and ultimately scheduled the test despite the cost because her symptoms continued to worsen. She explained that *"when you think you're going to be covered by insurance, you're not,"* describing the experience as both financially and emotionally draining.

Collectively, participants framed these outcomes not as isolated incidents but as systemic effects of discriminatory treatment. They emphasized that inequitable encounters not only undermine trust but also produce measurable physical, emotional, and economic harm. As one participant summarized, *"It doesn't just affect your feelings… it affects your health, your money, your whole life."*

Prioritization of Strategies to Reduce Discrimination

Participants were presented with five strategies intended to reduce discriminatory practices in health care settings and asked to rank them from most to least important. The strategies included:

1. Provider training in cultural humility, implicit bias, and anti-discrimination;
2. Clear and visible patient-facing statements outlining anti-discrimination policies and procedures for filing complaints;
3. Patient advocates or care navigators, particularly for individuals who may feel marginalized or unheard;
4. Policies to diversify the clinical workforce; and
5. Incorporating community feedback into provider performance evaluations.

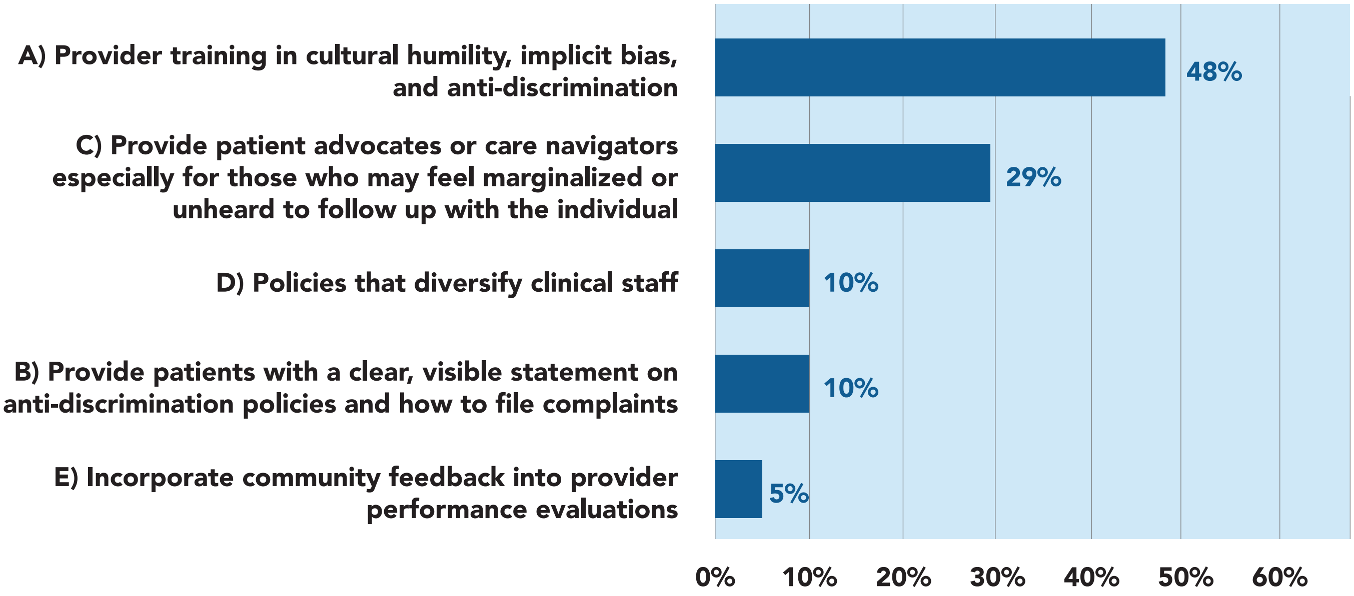
Table 2 provides a detailed description of the strategies presented and discussed.

Table 2. Strategies Contributing to Reduced Discrimination in Health Care

Strategy	***Description***
1. A. Provider training in cultural humility, implicit bias, and anti-discrimination	Training helps clinicians recognize and address unconscious biases, power dynamics, and discriminatory behaviors to improve communication and patient-centered care.
2. B. Clear and visible patient-facing statements on anti-discrimination policies and complaint procedures	Posting clear statements signals commitment to equitable treatment, informs patients of their rights, and explains how to report concerns through accessible complaint pathways.
3. C. Patient advocates or care navigators	Advocates support patients who feel marginalized or unheard by assisting with communication, understanding medical information, and accessing services, thereby strengthening engagement and trust.
4. D. Policies to diversify the clinical workforce	Increasing representation among clinical staff enhances cultural understanding, fosters trust, and improves communication by ensuring providers better reflect the communities they serve.
5. E. Incorporating community feedback into provider performance evaluations	Integrating patient and community input into performance assessments increases accountability and ensures care inequities are identified and addressed through continuous quality improvement.

A total of 21 participants ranked the strategies, and all responses were recorded and aggregated. Figure 1 illustrates the distribution of rankings across all five strategies.

Figure 1. Distribution of Top Ranked Strategy by Perceived Importance



As shown, provider training emerged as the most strongly endorsed intervention, selected as the top priority by 48% of respondents (n=10). The second-most-frequently prioritized strategy was the provision of patient advocates or care navigators, selected by 29% (n=6). Two strategies, diversifying clinical staff and providing anti-discrimination policy statements with complaint procedures, were each identified as the highest priority by 10% of participants (n=2 per strategy). The strategy selected least often as most important was incorporating community feedback into provider performance evaluations, which was ranked first by only 1 participant (5%).

Although all strategies were viewed as potentially helpful, clear patterns emerged in how participants prioritized them, reflecting a desire for both provider-level change and system-level accountability.

1. Provider training in cultural humility, implicit bias, and anti-discrimination

This strategy was ranked as the highest priority by most participants. Many emphasized that discriminatory encounters often stem from unexamined assumptions or stereotypes held by clinicians, underscoring the need for training that addresses cultural humility, implicit bias, and anti-discrimination. Participants stressed that such education must be ongoing and tied to professional standards, licensure expectations, and performance reviews, not a one-time orientation requirement. As one participant noted, implicit bias *"is something that everyone has,"* shaped by upbringing, culture, and media exposure, making continuous reflection essential. Others emphasized that onboarding should clearly communicate expectations for equitable, respectful care, explaining that early and consistent training is necessary to reinforce that *"this is how you should treat all of your patients"* and that discriminatory practices are not acceptable. Overall, participants viewed training as foundational to any broader change effort, asserting that *"education has to come first if anything is going to change."*

2. Patient advocates or care navigators for those who feel marginalized or unheard

The second-highest ranked strategy involved embedding patient navigators or advocates who can intervene when communication breaks down or when patients feel dismissed. Participants emphasized that this type of support is especially critical for individuals who lack trust in the system or who have experienced repeated bias. They noted that advocates can help ensure follow-up, clarify treatment plans, and provide reassurance in settings where providers may have limited time. As one participant described, *"having someone in the room who is on your side changes everything."* Others explained that they would have benefitted from such support during past encounters, underscoring that advocacy roles must be paired with a clinical culture that reinforces respectful communication and equity-focused training. Overall, participants viewed patient advocates as an essential complement to provider education, helping to bridge gaps in communication and reduce the risk of patients feeling overlooked or marginalized.

3. Incorporating community feedback into provider performance evaluations

Participants valued this strategy because it introduced accountability mechanisms that extend beyond internal reviews. Many emphasized that incorporating patient-reported experience data whether through public reporting, performance evaluations, or contractual incentives could encourage providers to reflect on how their communication and behavior are perceived. As one participant explained, knowing that *"real people's voices"* contribute to evaluations might prompt providers to think more carefully about how they speak to and treat patients, especially since tone and communication styles can be interpreted differently across individuals and cultural contexts. At the same time, a few participants noted that existing feedback systems (such as automated patient surveys) are often underutilized or burdensome, reducing their impact. Taken together, these reflections suggest that while community feedback is seen as a meaningful tool for accountability, its effectiveness depends on whether health systems design processes that are accessible, responsive, and genuinely used to drive improvement.

4. Policies to diversify clinical staff

While most participants agreed that representation matters for trust, comfort, and cultural understanding, this strategy was ranked lower in part because participants viewed it as necessary but insufficient on its own. Some argued that without deeper structural and cultural change, diversifying staff does not prevent discriminatory attitudes or institutional bias.

5. Visible statements on anti-discrimination policies and complaint procedures
Although participants agreed that clear signage and easily understood complaint pathways are important, this strategy was ranked lowest overall. Many noted that such statements are common in health care settings but rarely enforceable, explaining that *"a poster doesn't change anything unless action comes with it."* Others shared that while visible policies can help patients understand where to go and how to file a complaint, confidence in these processes depends on whether concerns are actually taken seriously. As one participant explained, visible guidance is useful because *"you never know who to go to or if it's going to be heard,"* whereas another emphasized that public-facing signage can create a welcoming environment and remind staff of institutional values. Still, participants stressed that statements alone are insufficient without meaningful follow-through. Overall, the rankings reflected a preference for interventions that change provider behavior and strengthen institutional accountability, rather than approaches that rely solely on policy language or symbolic gestures.

Recommendations for Institutional Responses to Discrimination Reports

Across all focus groups, participants emphasized that when a patient reports being treated unfairly, with less respect, or differently than others, health care institutions must respond in ways that are timely, transparent, and rooted in accountability rather than denial or reputational protection. Participants stressed that simply documenting complaints is insufficient; institutions must demonstrate through concrete action that such reports are taken seriously.

Participants described several components of what they viewed as a fair, credible, and supportive response:

✓ **1. Conduct a serious and confidential investigation**
Participants rejected approaches that handle complaints informally or absorb them into closed systems with no visible outcomes. They called for a structured process that includes documentation, impartial review, follow-up with the patient, and consequences if discrimination is confirmed. As one participant noted, *"Complaints shouldn't just disappear into a file. There needs to be proof something was done."*

✓ **2. Require anti-discrimination and implicit bias training for involved staff**
Many participants viewed corrective education as a necessary response, not as punishment, but as part of professional accountability. They emphasized that such training must be ongoing and triggered when an incident occurs, not limited to new-hire orientation. One participant explained, *"Training shouldn't just check a box. If something happens, there should be mandatory retraining."*

✓ **3. Acknowledge and validate the patient's experience**

Participants stressed that emotional recognition and procedural clarity are essential for rebuilding trust. They argued that institutions should formally acknowledge the complaint, apologize when appropriate, and communicate next steps. As one participant put it, *"If nobody even says sorry or admits anything happened, why would anyone trust the process?"*

✓ **4. Provide options for reassignment and patient advocacy support**

Participants strongly supported offering reassignment to a different provider or care team, particularly when trust has been compromised. They also emphasized the need for patient advocates, ombudsmen services, or navigators who can follow up with harmed patients, especially those who already feel marginalized or fear retaliation. *"You shouldn't have to go back to the same person who mistreated you,"* one participant noted.

✓ **5. Build accountability into provider performance systems**

Participants expressed that accountability must extend beyond internal discussions or quiet coaching. Some recommended public reporting of discrimination complaints or institutional dashboards, while others suggested incorporating patient feedback and complaint patterns into performance evaluations or credential renewal. As one participant summarized, *"You can put posters on the wall, but if nothing changes when people complain, it's just decoration."*

Taken together, participants advocated for a response model that links reporting, investigation, repair, and institutional learning, a shift from reactive problem handling to proactive system change. They emphasized that visible follow-through, not policy language alone, determines whether patients believe that institutions take discrimination seriously.

What Would Make Health Care More Respectful, Inclusive, and Equitable

When asked what changes would make them feel more comfortable, respected, or valued in health care settings, participants identified several key areas for improvement most of which centered on communication, provider behavior, structural supports, and accountability. Many also contrasted these desired changes with past positive encounters, noting that respectful care was not abstract, but something they had experienced when providers listened, explained decisions, and treated them as partners rather than problems to be managed.

1 **Better communication and genuine listening**

Participants consistently emphasized that effective communication and genuine listening were core components of respectful, person-centered care. Providers who took time to explain diagnoses, answer questions, and check for understanding were described as creating a sense of trust and partnership. In contrast, rushed, distracted, or dismissive interactions were often experienced as dehumanizing. As one participant explained, *"What made me feel respected wasn't anything fancy... it was just being listened to and not talked over."*

Several participants elaborated on what meaningful communication looked like in practice. One noted that *"being in communication with the patients is so important,"* emphasizing that providers' initial interactions set the tone for the entire encounter and signaled whether patients' concerns mattered. Another stressed that listening itself was a critical clinical tool, explaining that providers need to *"take it seriously,"* because identifying patterns in symptoms or concerns is impossible *"unless you look."*

2 Training in cultural competence and implicit bias

Participants stressed that comfort and respect depend not only on individual provider skill, but on whether clinicians are aware of how stereotypes, assumptions, and power imbalances shape patient interactions. They viewed training in cultural humility, anti-discrimination, and implicit bias as essential to ensuring that respect is not selectively extended based on race, weight, insurance status, gender, or age.

3 Access to patient advocates or care navigators

Several participants described how the presence of a patient advocate, someone who could help interpret information, raise concerns, or ensure follow-up would make care feel less intimidating and more equitable. This was especially important for patients who had previously felt ignored or marginalized. One respondent noted, *"Having someone in the room who is there for you changes everything."*

4 Accountability and feedback systems that lead to real change

Participants emphasized that respect is impossible without meaningful accountability. They called for formal mechanisms to document and respond to complaints, publicly track improvements, and incorporate patient experiences into provider performance evaluations. Without such systems, participants argued, respectful care remains *"optional,"* dependent on the individual provider rather than embedded within the institution.

One participant expressed a preference for public-facing accountability tools, noting that *"community report cards"* would be more effective than traditional channels such as ombudsman programs. She explained that, based on her experience working within the system, ombudsman roles often focus on resolving issues quietly rather than identifying fault, limiting their ability to drive systemic improvement. As she summarized, *"although it's better than nothing, I prefer an actual public report card for whatever entity."*

5 A visibly welcoming and inclusive environment

Participants said that the tone of a health care setting is shaped not only by providers but also by the entire clinical environment, from front desk staff to signage to follow-up processes. They described wanting to be greeted, acknowledged, and treated as individuals rather than "numbers on a chart." Small gestures, eye contact, the use of preferred names, and being asked about comfort needs were described as disproportionately meaningful.

6 Consistency in respectful care, not "hit or miss" experiences

Finally, participants noted that respectful care is often inconsistent, varying across providers, specialties, and settings. They argued that what they wanted was not *exceptional* care, but *reliable* care in which dignity, communication, and empathy were treated as standard rather than optional. Several participants used examples from positive past encounters with providers who listened, followed through, or advocated for them as models of what care *could* look like system-wide.

Together, these reflections suggest that patients do not merely want better bedside manner, they want structural reinforcement of respect, meaning systems, policies, and norms that ensure dignity is not dependent on the luck of the provider they encounter.

Implications for Policy and System Reform

Patient experiences of discrimination point to systemic failures that extend beyond individual providers and frontline interactions and instead require policy-level solutions. While training and internal process changes within health systems are necessary, participant accounts make clear that respectful, equitable care cannot depend on individual discretion or institutional goodwill alone. Rather, these findings highlight the need for external accountability, standardized measurement, and enforceable protections to ensure that nondiscriminatory care is treated as a core requirement of health system performance rather than an optional or inconsistently applied norm (Rosenbaum, 2016; Clark et al., 2020).

Policy-Relevant Insights from Patient Experiences

Patient narratives consistently framed discrimination as a quality-of-care failure with tangible consequences. Experiences of dismissal, bias, or disrespect were associated with delayed care-seeking, erosion of trust in providers, avoidable emergency department use, and worsening health conditions, outcomes that impose both human and system-level costs (Fenwick et al., 2022). Participants emphasized that when respectful care depends on the "luck of the provider," protections are inherently uneven and unreliable, particularly for individuals from marginalized groups who encounter repeated points of vulnerability within the health system.

These experiences also reveal the limits of existing legal protections as they are currently implemented. Although federal laws prohibit discrimination in federally funded health care settings, patients frequently described those protections as invisible or ineffective in practice. Many reported limited awareness of their rights, uncertainty about complaint procedures, or fear of retaliation, factors that substantially reduce the likelihood of formal reporting (Office for Civil Rights, 2016; Fenwick et al., 2022). From the patient perspective, the gap between statutory protections and lived experience reflects weak enforcement, limited transparency, and insufficient follow-through when violations occur (Rosenbaum, 2024).

Underenforcement as a System-Level Policy Failure

The underenforcement of anti-discrimination laws emerges as a central structural barrier to equity in health care. While statutes such as Title VI of the Civil Rights Act and Section 1557 of the Affordable Care Act formally prohibit discrimination in federally funded programs, enforcement remains inconsistent, largely complaint-driven, and reactive rather than proactive (Office for Civil Rights, 2016; Rosenbaum, 2016). Administrative interpretations of Section 1557 have shifted significantly across federal administrations most notably with respect to protections for LGBTQ+ individuals creating regulatory uncertainty for providers and weakening incentives for consistent compliance (Clark et al., 2020; Rosenbaum, 2024).

This enforcement gap undermines accountability in two critical ways. First, it places the burden of action on patients, many of whom lack the information, resources, or confidence to pursue formal complaints. Second, it limits the extent to which health systems face meaningful regulatory consequences for discriminatory practices, reducing incentives for sustained organizational change. As a result, civil rights protections often function as contingent or symbolic safeguards rather than enforceable standards of care (Rosenbaum, 2016; Clark et al., 2020).

Policy Recommendations Informed by These Findings

1. ***Embed Discrimination into Quality Measurement***
   Discrimination should be explicitly recognized as a quality-of-care and patient-safety issue. Policymakers can require health systems to track and report patient-reported experiences of discrimination using standardized and validated measures. Incorporating equity and respectful-care metrics into accreditation standards, licensure requirements, and value-based purchasing programs would signal that nondiscriminatory care is a measurable and enforceable dimension of quality rather than a discretionary goal (Rosenbaum, 2024). Such integration would also facilitate benchmarking across systems and support continuous quality improvement.

2. ***Tie Payment and Contracting to Equity Performance***
   Payment policy represents a powerful lever for accountability. Medicare, Medicaid, and commercial payers can link reimbursement, contracting decisions, or performance bonuses to demonstrated improvements in patient experience and reductions in discriminatory care. Aligning financial incentives with equity outcomes would move respectful care from an aspirational principle to an operational priority. In addition, reimbursement for patient advocates, care navigators, or ombudspersons, particularly for populations at heightened risk of discrimination, can help address power imbalances and improve care coordination (Fenwick et al., 2022).

3. ***Strengthen and Operationalize Civil Rights Enforcement***
   Findings underscore the need to reinforce enforcement of existing civil rights protections, particularly Section 1557 of the Affordable Care Act. Policymakers can improve transparency by requiring clearer patient-facing communication about rights, complaint procedures, timelines, and outcomes (Office for Civil Rights, 2016). Enforcement approaches should extend beyond reactive complaint resolution to include proactive compliance monitoring, clearer regulatory guidance for health care institutions, and meaningful investigation and corrective action when violations occur. Scholars emphasize that enhanced federal oversight and funding are necessary to activate Section 1557's full protective potential (Clark et al., 2020; Rosenbaum, 2024).

4. ***Support Workforce and Training Standards Through Policy***
   Although training is frequently proposed as a solution to discriminatory care, evidence suggests that voluntary or one-time efforts are insufficient. Policy can establish minimum standards for ongoing education in cultural humility, implicit bias, and anti-discrimination, tied to licensure renewal, credentialing, and institutional compliance requirements (Clark et al., 2020). Complementary workforce diversity initiatives including targeted incentives, pipeline programs, and reporting requirements can address structural contributors to discrimination by promoting representation and inclusion across clinical, administrative, and leadership roles.

5. ***Increase Transparency and Public Accountability***
   Finally, greater transparency is essential to rebuilding trust and sustaining progress. Policymakers can encourage public or community-facing reporting on discrimination complaints, enforcement actions, and system-level improvements through dashboards, audits, or annual reports (Rosenbaum, 2024). Integrating structured community and patient feedback into governance bodies, oversight boards, and performance evaluation processes can further institutionalize accountability and ensure that equity remains central to health system oversight.

Conclusion

Findings from this qualitative study highlight the significant and multi-layered impact of discriminatory and disrespectful experiences in health care settings among individuals who perceive themselves to have been treated unfairly by providers or institutions. Across all focus groups, participants described not only the emotional harm associated with being dismissed, judged, or stereotyped, but also the long-term effects on trust, care-seeking behavior, and health outcomes. Many reported delaying or avoiding needed care, switching providers, disengaging from preventive services, or approaching future health encounters with guardedness and skepticism. These patterns align with a broad body of research showing that perceived discrimination is associated with reduced utilization, poorer adherence, and increased risk of disease progression (Benjamins & Whitman, 2014; Klein & von dem Knesebeck, 2018; Jaffee et al., 2016). Participants' accounts reinforce the idea that the effects are cumulative, shaping expectations for future encounters and contributing to a sense that discrimination reflects systemic rather than isolated failures.

Although participants' accounts were varied, they consistently identified pathways for change that moved beyond symbolic statements or one-time interventions. They emphasized the need for structural accountability, respectful communication, culturally responsive care, and transparent response systems when discrimination occurs. These recommendations parallel patient-centered and policy-oriented solutions cited in the literature, including mandatory implicit bias training, structural competency, equitable reporting systems, and proactive institutional oversight (Chapman et al., 2013; Metzl & Hansen, 2014; Rosenbaum, 2024). Their perspectives make clear that equity in health care requires more than improved interpersonal behavior; it requires institutions to formally recognize harm, respond to it, and redesign processes that center patient dignity and agency.

Importantly, participants' reflections also showed that positive, respectful, and trust-building care is both possible and memorable. Many were able to name specific providers who listened, explained, affirmed, and treated them with care, underscoring that respectful practice is not an aspirational ideal but an existing model that can be scaled. Evidence supports this: patient-centered communication is associated with improved adherence, satisfaction, and clinical outcomes, suggesting that strengthening these skills can mitigate inequities (Street et al., 2009). These experiences provide a counterpoint to negative encounters and offer a foundation for designing patient-centered reforms.

Taken together, the findings point to a critical policy and practice challenge: developing health systems in which respect, trust, and equitable treatment are not dependent on individual providers but are embedded in the structure, culture, and accountability mechanisms of care delivery. Doing so will require investments in training, patient advocacy, reporting systems, and performance evaluation, as well as regulatory action to strengthen enforcement of anti-discrimination protections under laws such as Section 1557 of the Affordable Care Act (Rosenbaum, 2024). Moreover, discrimination should be understood not merely as an interpersonal problem, but as a quality-of-care and patient-safety issue with measurable public health and economic consequences, including increased health service costs and reduced system efficiency (Evans-Lacko et al., 2015).

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Appendix A: Data and Methodology

This study employed a qualitative research design using focus group discussions to examine how individuals perceive and experience discrimination in health care settings. The qualitative approach was selected to capture the depth, nuance, and contextual complexity of participants' experiences, elements that are not easily measured through survey-based or administrative data.

Participant Recruitment and Sampling

A total of 21 adults who self-identified as having experienced discrimination by physicians, hospitals, or other health care professionals were recruited through Sago, a firm specializing in participant recruitment and engagement. Purposeful sampling was used to ensure representation across multiple forms of perceived discrimination (e.g., based on insurance status, race, gender, weight). Each participant received a $185 stipend for participating in the 75-minute session to reduce the burden of participation and enhance accessibility. All sessions were conducted virtually to broaden geographic reach and accommodate individuals with mobility, transportation, or caregiving constraints.

Data Collection

Participants were distributed across three focus groups of 6–8 individuals each. All focus groups were video-recorded with consent and professionally transcribed verbatim. Field notes were taken during and immediately following each session to capture group dynamics and emergent themes. Discussions were guided by a semi-structured protocol that invited participants to:

1. Describe personal experiences of discrimination in health care settings;
2. Reflect on the factors that contributed to feeling discriminated against; and
3. Identify policies, administrative practices, or clinical strategies that could reduce discrimination and improve patient experiences.

Data Analysis

Transcripts were imported into NVivo qualitative analysis software and analyzed using an inductive thematic coding approach. The analytic process included: 1) initial open coding to identify recurring concepts and patterns; 2) axial coding to explore relationships among codes and refine thematic categories; 3) selective coding to synthesize themes that reflected shared experiences and explanatory factors underlying perceived discrimination. Coding and thematic development were iterative and interpretive, drawing on principles of constructivist grounded theory to center participants' narratives and meanings. The study was reviewed and approved by the University of Massachusetts Boston Institutional Review Board.

Appendix B: Focus Group Discussion Guide

Discrimination in the Health Care System: A Qualitative Study of What People Experience and What Can be Done

Introduction

Good afternoon. My name is [NAME], I am a researcher at the University of Massachusetts Boston, and I will be moderating today's focus group. Thank you for taking the time to join us and for your willingness to share your experiences.

Before we begin, I want to go over a few important details.
As you know, this session will be recorded. Recording allows me to focus on our discussion without needing to take extensive notes and later review the conversation to ensure your comments are accurately understood and interpreted in context.

In some cases, short audio or video clips from today's session may be used as part of a presentation to help audiences better understand how people experience discrimination in health care settings. These clips will only be used for educational or research purposes - specifically to be viewed by an audience of health policy researchers, policymakers, and academics. The recordings will not be used for marketing, commercial, or promotional purposes.

Your participation is confidential. Any information you share will be stored securely, and nothing you say will be personally identifiable in any reports or presentations.

Today's discussion is part of a study about how people experience interactions both positive and negative—with health care providers, whether in hospitals, clinics, or other settings. We're interested in hearing how these experiences have affected you, how you've interpreted them, and what you think could be done to improve care going forward.

Before we start, just a few reminders:

- There may be sometimes when you are talking and I may need to interrupt you so I want to apologize ahead of time for that. That's just because we have a limited time here today and I want to make sure I hear from everyone. So I may say thank you I understand the gist of what you're saying and there may be other times that I may ask you to elaborate.
- Your participation is voluntary and confidential.
- There are no right or wrong answers - just your perspective.
- You can skip any question you don't wish to answer.
- Please respect each other's privacy and opinions.

Thank you again for being here and for sharing your experiences. Your voice is essential to helping us understand and address how people experience care within the health system.

Icebreaker:

Let’s go around and introduce ourselves using a first name and tell us what is your favorite food.

Health Care Experiences

1. **When you think about your experiences with doctors, hospitals, or clinics, would you say these experiences were generally positive, negative, or mixed?**
    - Have these experiences changed over time? How so?

2. **Have you ever felt that you were treated unfairly, with less respect, or differently than other people in a health care setting, that is, discriminated against?**
    - What was it that made you feel you were treated unfairly or with less respect than you should have been?
    - Who was involved (e.g., doctor, nurse, front desk staff)?
    - Was this a one-time incident or part of a pattern?
    - Did you talk to anyone about it (e.g., the doctor or nurse directly, or friends, family, the facility)?
    - Did you file a complaint or take any action? Why or why not?

3. **What do you think contributed to this experience?**
    - Do you believe it was related to your race, age, gender, sexual preference, disability, religion, weight, financial status, insurance status, or something else?
    - Were multiple aspects of your identity involved (for example, gender and race)?
    - What made you conclude that the experience/interaction was discriminatory?
    - Did you feel ignored or not listened by the provider to during this experience?

4. **Was feeling ignored or not listened to one of the factors that led you to feel that you were being treated differently by the provider or was feeling unheard a result of being treated differently?**
    - In other words, was not feeling listened to part of what made a person feel discriminated against? Was being discriminated against in some way what led the person to not feeling listened to? Or was it a mix of those where it could be in either direction?

5. **Can you describe one experience that stands out where you were treated unfairly, with less respect, or differently than other people by your provider?**
    - What happened during the encounter?
    - How did it make you feel at the time?
    - Did it impact your willingness to seek future care or trust that provider? If so has that feeling ever lessened over time or has it remained?
    - Did you seek a new provider, or did you stop/reduce getting care?

6. **How did these experiences affect your trust in doctors or the health care system?**
    - Do you still feel confident in seeking care?
    - Has your trust been restored at any point?

7. Have these experiences changed how often you seek care or follow medical advice?

- Do you avoid certain doctors or facilities?
- Have you skipped or delayed appointments or treatments?

8. Do you feel that the impact of negative or discriminatory experiences with the healthcare system has led to any health and/or financial consequences?

- Have negative or discriminatory experiences affected your health? For example has your health gotten worse?

9. What are the possible ways that you think we can solve the issue of people like yourself having experiences with the health care system where they felt that treated unfairly, with less respect, or differently than other people? I am going to read some possible ways that might discourage or minimize the discriminatory practices that some people experience when they interact with their providers. Let me know if you think this would be helpful and then I am going to ask you to range these with 1 being the most important and 5 being the least important.

A. Provider training in cultural humility, implicit bias, and anti-discrimination

B. Provide patients with a clear, visible statement on anti-discrimination policies and how to file complaints

C. Provide patient advocates or care navigators especially for those who may feel marginalized or unheard to follow up with the individual

D. Policies that diversify clinical staff

E. Incorporate community feedback into provider performance evaluations

10. What should hospitals or clinics do when a patient reports feeling they felt that they were treated unfairly, with less respect, or differently than other people, that is discriminated against? For example, provide options for reassignment to a new provider or team. Require anti-discrimination or implicit bias training for involved staff. Conduct a confidential investigation. Require staff to acknowledge the complaint and validate the patient's experiences.

- What would a fair and supportive response look like?
- Should there be follow-up or accountability?
- Should there be public reporting of discrimination complaints?
- Do you support patient advocates, ombuds programs, or patient feedback councils?

11. What would it take for you to feel more comfortable or respected in a health care setting? What changes would make health care feel more inclusive or equitable?

- Have you had positive health care experiences where they felt respected and listened to? What those were like in comparison and what stood out?

12. Is there anything we haven't asked that you'd like to share?

Wrap-Up:

Thank you for your time and insights. Your voice helps shape efforts to improve health care equity.

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