

California Health Care Foundation

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Listening to Older Black Californians Why and How Older Black Californians Take Control of Their Health

Background

Experiencing racism in health care is harmful at any age. It is especially concerning for aging and older adults because access to and receipt of quality health care is critical for this population given its higher risk of health conditions. Historical discrimination means many older Black Americans have experienced restricted access to quality jobs, housing, education, and health care during their lifetimes that still impact them today. At the same time, aging Black Americans continue to be exposed to threatening and stressful environmental, social, and economic conditions because of their race. This combination of restrictions and exposures over the course of individuals' lives has significant implications for the health of older Black Americans and contributes to racial health disparities.

Midlife, which is generally considered to be between the ages of 45–64, is also a vulnerable period for many Black Americans as this is when evidence of accelerated aging due to race-related stress is observed. Racism damages health by triggering the release of stress hormones, starting a chain of biological events that cause premature aging. This in turn increases a person's risk for a host of

About the Study

In 2021 and 2022, Black-owned research firm EVITARUS conducted the *Listening to Black Californians* study for CHCF. In 100 individual interviews,¹ 18 focus groups, and a statewide survey of 3,325 adult Black Californians,² participants described their attitudes toward their own health and their experiences with the health care system. In 2024, The Lincoln Lab at the University of California, Irvine, led by Karen D. Lincoln, PhD, conducted new, in-depth data refinement and analyses of the survey data focused on Black older adults. Findings presented in this fact sheet are representative of middle-aged and older Black Californians.

About the Participants: Black Older Adults

The Listening to Black Californians study offers the opportunity to examine experiences of both older (age 65 or older) and middle-aged (age 45–64) adults, collectively referred to here as "aging adults" or "older adults." The study included aging adults as participants in hour-long interviews (54 participants), focus groups

(39 participants), and a statewide survey (1,752 participants). This study is notable for the large number and diversity of Black aging adults across California who participated in the qualitative and quantitative phases of the research.

This fact sheet is based on data from the study's 1,752 middle-aged and older adult survey participants; illustrative quotations come from the study's individual interviews. The study sample included 730 men (42%) and 1,022 women (58%), of whom about 62% were under age 65 and 38% were age 65 or older. Less than half (46%) had incomes under \$75,000, while 50% had a bachelor's degree or higher. Nearly all Black aging adults had health insurance coverage, with 59% having private health insurance and 38% having public health insurance (i.e., Medicare or Medi-Cal). See Appendix A for a demographic breakdown of the survey respondents.

chronic health conditions, such as diabetes, hypertension, stroke, cardiovascular disease, and dementia.³ Quality health care is crucial during this life stage as these conditions require proper diagnosis and treatment to avoid multimorbidity and premature death.

This fact sheet highlights the strengths of aging Black Californians, their strategies for taking care of their health despite experiencing racism in health care, and potential solutions to achieve equity in health care.

Aging Black Californians Take Their Health into Their Own Hands

Aging Black Californians demonstrate their resourcefulness and resilience by taking their health into their own hands. Whether they are actively engaged in the health care system or avoid seeking health care, they employ various measures to improve or maintain their health.

Black Californians were asked to respond to 12 "things that some people do because they think that these things will help them maintain or improve their health" (Figure 1). Sixty-two percent of middle-aged and older Black Californians advocated for themselves "a great deal" by "speaking up about their concerns when engaging with their health care provider when they are not asked" and "getting appropriate screenings or preventative care" (61%). More than half of aging Black Californians took health matters into their own hands by "actively trying to reduce stress" a great deal (53%). Comparatively fewer aging Black

Californians turned to exercise "a great deal" (30%), mediation or deep breathing (25%), or herbal supplements and home remedies (22%) to improve or maintain their health.

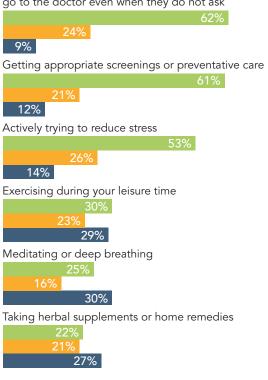
"You have to know your own body. You have to be your own advocate. And you certainly cannot trust your well-being in the hands of somebody that you met five minutes into a room. And you have to question them. And having worked with doctors, having worked in the university system, honey, people have overinflated opinions of their abilities. And that's okay. Yeah, long as they're not, you know, making some assumptions about my health care or any member of my family. I have learned to challenge because of these experiences."

– 71-year-old Black woman, Oakland

Figure 1. Actions to Improve or Maintain Personal Health, Top and Bottom Three

Q. Here are things that some people do because they think that these things will help them maintain or improve their health. For each one, please tell me how much effort, if any, you put into doing it.

Speaking up about your concerns when you go to the doctor even when they do not ask



Note: Sample includes 1,752 Black California residents age 45 or older. Source: *Listening to Black Californians*, statewide survey conducted by EVITARUS (March 5–May 8, 2022).

Quite a bit

A great deal

Aging Black Californians Have Access to Health Care, but That Care May Not Be of High Quality

Many factors contribute to whether aging Black Americans are able to access and use health care services and continue to engage with the health care system. Some of these factors include satisfaction with the care provided, experiences with the provider, and the quality of care provided. Despite relatively high access to health care — as evidenced by the 96% of middle-aged and older Black Californians who have health insurance, and the 92% who have a regular doctor or health care provider — Black Californians have negative experiences that impact their care. More than one quarter (28%) of aging Black Californians reported that they had experienced racism when accessing or receiving health care. Although the type of racism, such as interpersonal (e.g., racist comments or actions) or intrapersonal (e.g., prejudiced beliefs, internalized oppression), and the source of discrimination (e.g., doctor, nurse, staff, insurer) are not identified, discriminatory, race-based experiences within the health care system are impacting the quality of care that middle-aged and older Black Californians receive.

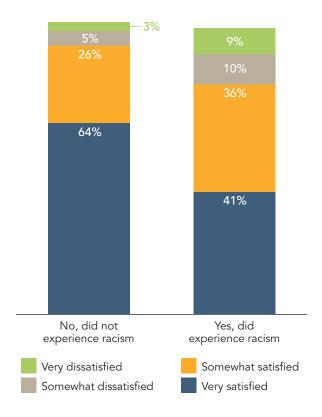
Satisfaction with Health Care is Undermined by Experiences of Racism in Health Care

Perceived experiences of racism in health care by Black Americans have been well documented. Less documented are the indirect effects of racism on the health care experiences of Black Americans and how these experiences contribute to health disparities. For Black Californians age 45 or older, lower satisfaction with health care can explain the misalignment between having access to health care (e.g., having insurance and a regular provider) and having a high risk for poor health care experiences.

Overall, aging Black Californians are fairly positive about their experiences with health care. More than half (55%) of middle-aged and older Black Californians are "very satisfied" with their main source of care, and 34% are "somewhat satisfied." At the same time, they have broad structural concerns that compromise or limit the impact of these positive attitudes on their overall health care experiences. For example, aging Black Californians who experienced racism in health care were less satisfied with their main source of care compared to those who reported no experiences of racism in health care (Figure 2). Forty-one percent of those who experienced racism in health care reported being "very satisfied" with their main source of care compared to 64% who were "very satisfied" and did not experience racism in health care.

Figure 2. Satisfaction with Main Source of Care, by Experiences of Racism in Health Care

- Q. How satisfied or dissatisfied are you with your main source for care?
- Q. Have you ever experienced racism or discrimination when accessing or receiving health care?



Notes: Sample includes 1,752 Black California residents age 45 or older. "Don't know" and "prefer not to say" responses are not shown. Figures may not sum due to rounding.

Source: Listening to Black Californians, statewide survey conducted by EVITARUS (March 5–May 8, 2022).

Insurance Type Protects Some from Poor Treatment by Providers, but Not All

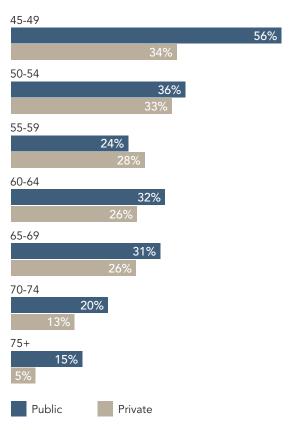
A variety of factors might contribute to lower levels of satisfaction with health care among aging Black Californians, including the perception of subpar treatment by a health care provider when accessing and receiving care. Overall, approximately 28% of aging Black Californians reported being treated poorly by a doctor, dentist, nurse, or other health care provider because of their race. This type of unfair treatment varied by age and type of insurance (Figure 3). For nearly all age groups of older adults, Black Californians with public insurance more frequently reported being treated poorly by a provider because of their race than did those with private insurance. More than half (56%) of Black Californians age 45-49 who had public health insurance coverage such as Medi-Cal or Medicare reported being treated poorly because of their race compared to 34% of their same-age counterparts who were covered by private health insurance.

For some age groups (45–49, 70–74, 75+), these differences by insurance type are larger, but for those ages 50–69, these differences are smaller. One exception was among respondents age 55–59; 24% of those covered by public health insurance reported poor treatment because of their race compared to 28% of their same-age counterparts who were covered by private health insurance. Black Californians age 70 or older with private coverage were least likely to report poor treatment by providers because of race.

Figure 3. Poor Treatment Because of Race, by Insurance Coverage and Age

Q. Have you ever been treated poorly by a doctor, dentist, nurse, or other health care provider because of your race or ethnicity?

Those Who Answered "Yes"



Note: Sample includes 1,701 Black California residents age 45 or older. Source: Listening to Black Californians, statewide survey conducted by EVITARUS (March 5–May 8, 2022).

Aging Black Californians Experience Poor Treatment by Health Care Providers, Including Being Ignored and Disrespected

For many Black Americans, a long history of unethical practices in clinical research has yielded mistrust and distrust in the health care system as well as cultural trauma that is deeply embedded in Black collective memory. That cultural trauma is reinforced in the present by negative experiences with health care providers, such as being ignored or disrespected, that maintain feelings of mistrust (i.e., general sense of suspicion) and distrust (i.e., lack of trust based on experience or reliable information) in the health care system and diminish the quality of care that aging Black Californians receive.⁴

"I must have been eight or nine years old when mother would talk to us about how the government injected Black men with syphilis and then refused to give them penicillin so that they could study the effects of the disease...she talked about involuntary sterilization of Black women and things like that. The father of gynecology, how he performed office medical operations on Black women because they didn't have any say-so, without anesthesia and stuff like that...I was very skeptical about whether or not I wanted to be vaccinated because of that latent mistrust of the White medical community that my mother had, you know, instilled in me when I was little...I went to see a Caucasian doctor, and he never even examined me, he never listened to my heart. You know, he sat across the room,...asked a couple of questions, never listened to my heart, never touched me, per se, and then prescribed medicine for whatever. And that experience did not sit well with me...I didn't go back after that because, again, that comfort level was not there."

-71-year-old Black woman, Inland Empire

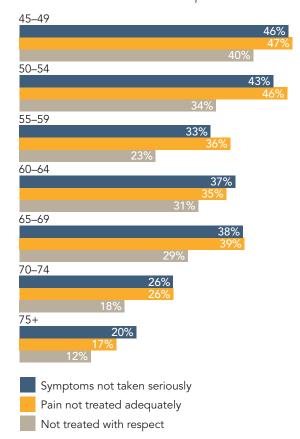
About 39% of aging Black Californians reported that their symptoms were not taken seriously by their health care provider. This rate was highest among middleaged Black Californians, with 46% of those age 45–49 and 43% of those age 50–54 reporting that their symptoms were not taken seriously. More than one-third of aging Black Californians (36%) reported that their pain was not treated adequately, and about 28% reported that they were not treated with respect. These negative experiences appear to be highest in midlife and persist over the life course, with reports of these encounters declining at advanced ages (Figure 4).

"I find that that is really racist. How can you know how I feel? You know, I'm trying to tell you and you're not listening. Like I say, it's like book sense instead of common sense. And knowing what the person really needs and wants instead of you just decide what I need and want. Can you find out why?"

-73-year-old Black woman, Central Valley

Figure 4. Negative Health Care Experiences, by Age

- Q. Has there ever been a time when your pain was not treated adequately by a health care provider?
- Q. Thinking more generally about your experiences with health care visits, have any of the following ever happened to you?
 - Your symptoms were not taken seriously.
 - You were not treated with respect.



Negative experiences in health care have significant implications for the health and well-being of aging Black Californians. One significant consequence of negative experiences is avoiding care. Avoiding care from a health care provider can lead to delayed or missed assessments of symptoms; delayed diagnoses for chronic health conditions and mental health problems; and, if left untreated, potentially longer-term and major health consequences.⁵

Middle-aged and older Black Californians were asked if they had ever avoided going to a doctor or hospital because they felt they would not be treated fairly or with respect. More than one in five aging Black Californians (22%) reported that they avoided care. Among those who reported avoiding care, 42% indicated that their pain was not treated adequately, 46% reported that their symptoms were not taken seriously, and 51% reported that they were not treated with respect (Figure 5).

"People need to be really accountable for their own. Now, that doctor came into the office and tried to make me feel like I did something wrong. He said, 'My nurse has been doing this for 22 years.' I said, 'But she...missed the mark. And give me less excuses. And blood is coming out, she evidently do something wrong. How are you approaching me like this?' He says, 'You can't say she missed the mark.' I say, 'You know what, you making a thing out of this right now?'; I could have just said, 'I'll come back a different day.' But you making me feel like I did something wrong. They need to be accountable for what they did."

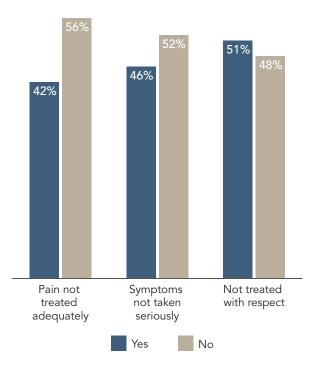
-64-year-old Black woman, Sacramento

Note: Sample includes 1,752 Black California residents age 45 or older. Source: Listening to Black Californians, statewide survey conducted by

EVITARUS (March 5-May 8, 2022).

Figure 5. Negative Treatment in Health Care Among Those Who Have Ever Avoided Care

- Q. Have you ever avoided going to a doctor or hospital because you felt you would not be treated fairly or with respect?
- Q. Has there ever been a time when your pain was not treated adequately by a health care provider?
- Q. Thinking more generally about your experiences with health care visits, have any of the following ever happened to you?
 - Your symptoms were not taken seriously.
 - You were not treated with respect.



Notes: Sample includes 1,028 Black California residents age 45 and

Source: Listening to Black Californians, statewide survey conducted by EVITARUS (March 5-May 8, 2022).

Key Areas for Action

Social determinants of health, such as income, education, and access to health insurance, offer little protection for aging Black Californians against experiencing racial discrimination when engaging with the health care system. Getting older has significant implications for the health of Black Californians, with midlife being a uniquely vulnerable period in the life course. Chronic diseases often emerge in middle age after long-term exposure to harmful environmental, social, and/or low socioeconomic conditions.6 Thus, efforts are needed to ensure that middle-aged Black Californians, in particular, are engaged with the health care system to properly diagnose, manage, and treat health conditions that are prevalent for this age group.

"Acknowledge that there are race issues among medical professionals in the medical system. Acknowledge it. And, I mean, the data is there. Like, there's actual data of doctors giving more care to a White patient than they would have a Black patient who's suffering the same issues. So, it's like, okay, we have a problem. And we need to address it collectively, together, because you have this White patient who's dealing with exactly the same thing as this Black one, but yet you're providing better care. What is that about? How do we explain that? So, it just needs to be taken head on. Because once again, it's a matter of life and death for many Black people, you know, the medical system."

-57-year-old Black man, Los Angeles

Specific actions include:

- ► Move beyond cultural competency in provider training. Training that extends beyond cultural competency is needed for health care professionals to raise awareness of discriminatory practices that fuel health disparities and unequal treatment. Requiring cultural humility training by health care providers can support active listening, which can allow patients to express concerns about their daily lives that might extend beyond their health as well as explain their motivations for and barriers to seeking care.
- "...Cultural competency needs to be a part of justice just as much as any other training that the doctors have. They need a year of ongoing cultural competency at the same time that they're receiving their training and residency or whatever. Because assumptions kill people. Assumptions really do. If you don't ask the question, a doctor is only as good as the detective that they are... How do you treat someone when you don't understand that they may have a deference to a doctor, and they're never going to question anything that you say, and they're going to be trying to please you by saying 'yes.' You need to understand that culture so that you ask things in a way that you can get an answer that can really help the patient. And we're not there. We're not there."

-71-year-old Black woman, Oakland

- ➤ Use existing tools to build trust and rapport. Health care providers can use existing tools like the social history, which is both a current part of standard care and a critical part of patient care.⁷ The social history allows health care providers to build rapport, understand the challenges and strengths that patients bring to their health care experiences, and consider supports that could be incorporated into patients' care plans. The social history and other measures of the social environment of aging Black Californians (e.g., access to green spaces, safe streets, fitness centers, etc.) are critical for encouraging preferred health behaviors and assessing the contexts that promote or prohibit personal efforts that support healthy aging. Regular review of social history categories can ensure that this tool captures the lived experiences of aging Black Californians as they evolve and that it is tailored to the needs and strengths of individual patients.
- ➤ Leverage interprofessional teams and community partners. Working with interprofessional teams, community partners, and patients can help providers maintain empathy for aging Black patients and support their ability to advocate for structural changes that could improve the overall health of patients and the health care system. Federally Qualified Health Centers (FQHCs) have better outcomes related to diabetes and

hypertension control, prenatal care, and births than the national average.⁸ FQHCs have the advantage of being deeply embedded within the communities they serve and open opportunities for patients to provide input to clinic leadership and lead their care. Health systems can partner with successful FQHCs to expand their models, reduce medical mistrust, improve culturally competent care, and raise the overall quality of care for aging adults.

Expand the Black health care workforce.

To address racism in health care, it is critical for medical education and training to include curriculum focused on the history of racism in medicine as well as contemporary practices that perpetuate inequities. The California Department of Health Care Services, medical boards, accrediting bodies, entities responsible for patient care, medical schools and other educational bodies, and providers themselves should make every effort to identify institutional policies and practices that perpetuate racism in health care. Once identified, it is essential to take steps to remove or re-engineer obstacles that undermine the ability to ensure equitable care for all.

THE TAKEAWAY

Aging Black Californians are generally satisfied with their health care and engage in a variety of health-promoting actions to maintain and improve their health. However, racism in health care impacts Black Californians across their lifespans and can lead to their disengagement with the health care system. Continued engagement by older Black Californians is crucial to support their health care needs, especially given the high prevalence of conditions associated with more advanced age, such as Alzheimer's disease and related dementias, and multimorbidity. Policies that support medical education and training, a diverse workforce, and collaboration across health systems are crucial to support the health care needs of aging Black Californians and advance health equity.

About the Author

This fact sheet was written by Karen D. Lincoln, PhD, Professor of Environmental and Occupational Health and Director of the Center for Environmental Health Disparities Research at the <u>Joe C. Wen School of Population & Public Health</u>, University of California, Irvine, and Founder and Director of <u>Advocates for African American Elders.</u> Data analysis was conducted by Hawa Mariko, PhD, and supervised by Luohua Jiang, PhD, and Karen D. Lincoln, PhD.

Endnotes

- Linda Cummings, <u>In Their Own Words: Black Californians</u>
 <u>on Racism and Health Care</u>, California Health Care
 Foundation (CHCF), January 2022.
- Linda Cummings, <u>Listening to Black Californians: How</u> the <u>Health Care System Undermines Their Pursuit of</u> <u>Good Health</u>, CHCF, October 2022.
- Sarah N. Forrester et al., "Navigating Black Aging: The Biological Consequences of Stress and Depression," The Journals of Gerontology: Series B, Psychological Sciences and Social Sciences 77, no. 11 (Nov. 2022): 2101-12.
- Karen D. Lincoln et al., "<u>Fundamental Causes of Barriers to Participation in Alzheimer's Clinical Research Among African Americans</u>," *Ethnicity & Health* 26, no. 4 (May 2021): 585-99.
- Mark É. Czeisler et al., "<u>Delay or Avoidance of Medical Care Because of COVID-19-Related Concerns United States, June 2020</u>," Morbidity and Mortality Weekly Report 69, no. 36 (Sept. 2020): 1250-7.
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- Karen McDonough, "<u>The Social History</u>," in *The Foundations of Clinical Medicine*, University of Washington Pressbooks, accessed August 2, 2024.
- "Community Health Center Chartbook 2024: Analysis of 2022 UDS Data," National Association of Community Health Centers, accessed August 2, 2024.

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Appendix A. Demographics of Aging and Older Adult Respondents (N = 1,752, age 45 or older)

	PARTICIPANTS (#)	PARTICIPANTS (%)
AGE		
45 to 49	225	14%
50 to 54	273	18%
55 to 59	260	14%
60 to 64	325	19%
65 to 69	262	13%
70 to 74	190	9%
75+	217	13%
GENDER		
Women	1022	52%
Men	730	48%
REGION		
Los Angeles County	732	42%
Inland Empire	201	11%
Orange/Imperial Counties	169	9%
San Francisco Bay Area	371	22%
Central Valley	113	8%
Central Coast	26	1%
North	126	6%
Far North	14	<1%

	PARTICIPANTS (#)	PARTICIPANTS (%)
INCOME		
Less than \$20,000	143	20%
\$20,000 to \$75,000	665	33%
\$75,000 to \$100,000	278	11%
\$100,000+	666	35%
EDUCATION		
Less than high school diploma	33	10%
High school graduate/GED	122	19%
Some college or associate's degree	727	40%
Bachelor's degree	415	19%
Graduate or professional degree	455	13%
INSURANCE TYPE		
None	51	4%
Private	1033	52%
Public	668	44%

Notes: Ns are unweighted. Percentages are weighted to represent the population of Black Californians age 45 or older.

Source: Listening to Black Californians, statewide survey conducted by EVITARUS (March 5–May 8, 2022).