

Cancer among Black and African American Iowans

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A report of University of Iowa
Health Care Holden Comprehensive
Cancer Center's Community
Outreach and Engagement Team

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Executive Summary

The Community Outreach and Engagement team at Holden Comprehensive Cancer Center sought to understand data on cancer and related risk and protective factors among Iowa's Black and African American population. The [2021 Cancer in Iowa report](#) showed that Black Iowans have substantially higher incidence of and mortality from cancer than their non-Hispanic white counterparts in all but the oldest age groups.¹ The team conducted a mixed methods needs assessment, incorporating quantitative data from a variety of publicly available sources and qualitative data from key informant interviews.

Quantitative data showed that Black Iowans have higher cancer rates than non-Hispanic white counterparts for prostate, lung, colorectal, liver, stomach and laryngeal cancers, as well as myeloma (Figure 1). Mortality rates were higher among Black Iowans (compared to non-Hispanic white) for lung, prostate, breast, colorectal, pancreatic, liver, uterine, and stomach cancers, as well as myeloma (Figure 2). Lung cancer is the leading cause of cancer death among Black Iowans, followed by prostate, female breast, colorectal, and liver cancers (Figure 2). According to data from [CDC Wonder](#), in 2018, Black Iowans had higher cancer mortality than their counterparts in every other state in the country.² Indeed, in 2018, mortality rates for Black people throughout the Midwest (Iowa: 226.9, Wisconsin: 216.0, Missouri: 201.6, Kansas: 199.5, Illinois: 196.4, Ohio: 187.5, Indiana: 186.8, Nebraska: 186.3, Michigan: 183.3, Minnesota: 178.1; age-adjusted rates per 100,000) were among the highest in the country.²

Interviews conducted by the team highlighted several needs, including the need for greater visibility of culturally specific community resources and greater cultural sensitivity in service provision. Population strengths were also identified, including psychological resiliencies such as adaptive coping strategies and self-efficacy in advocating for personal and family needs. Needs differed between Black immigrant and African American populations.³

Iowa is a segregated state, and many Black Iowans live in poverty and without health insurance. There are likely multiple contributing causes of the differences in incidence and mortality rates between Iowa's non-Hispanic Black and non-Hispanic white populations.⁴ This report summarizes the mixed methods needs assessment the team conducted to more deeply understand and contextualize the findings of the 2021 Cancer in Iowa report. It also delineates the community-identified needs, barriers, and solutions to cancer disparities in Iowa.

Describing Iowa's Black Population: Sociodemographic Characteristics and Social Drivers of Health

Approximately 121,447 Black people (inclusive of African Americans and Black immigrants) call Iowa home, accounting for approximately 4% of the state's population.⁵ The proportion of Black Iowans varies by county, ranging from 0 to 9.6% Black, with the 10 counties having the highest proportion of Black residents shown in Table 1.

[Social determinants of health](#) are the conditions in which people are born, grow, live, and age.⁶ They can include a wide range of factors, such as access to nutritious and affordable food, availability of broadband internet, and free or affordable early childhood education. They contribute to a person's health, wellbeing, and quality of life. We looked at several social drivers—including poverty rates, lack of health insurance, and racial segregation—to understand the disparities in Iowa's cancer rates.

Among the Iowa counties that reported data, 11 have 100% of the Black population living below the poverty line.⁷ Among the 10 counties with the highest percentage of the Black population without health insurance, the numbers ranged from 74.1% without to 18.6% without.⁸ This can be compared to an average of 6.8% of all Iowans without health insurance.⁸

The Racial Segregation Index was used to examine segregation in Iowa. A higher score means that one group is more concentrated in an area compared to others.⁹ The racial segregation index for Iowa is 0.63, which is about the same as the national average.¹⁰ This means that Iowa has a noticeable amount of racial segregation, like the rest of the country. Among Iowa counties, 10 had a racial segregation index of more than 0.95, meaning they are almost entirely made up of one racial group with very little racial diversity.¹⁰ Buena Vista County was the lowest in the state at 0.53, making it one of the most racially diverse counties in Iowa.¹⁰

Redlining is the practice of denying services to residents of certain areas based on their race/ethnicity. Redlining is a known predictor of health outcomes, including cancer.^{11,12} Many Iowa cities have a history of redlining.¹³ Future research may use newly developed redlining and related indices to investigate the relationship between redlining and cancer outcomes among different race/ethnicity groups. For more data, please see <https://dsl.richmond.edu/panorama/redlining/>.

TABLE 1. CHARACTERISTICS OF THE BLACK POPULATION IN TOP 10 IOWA COUNTIES WITH THE HIGHEST PROPORTION OF BLACK RESIDENTS.

County	# Black Residents	% Black residents	% of Black Population Living Below Poverty	% of Black Population Without Health Insurance	Racial segregation index
United States	41,288,572	12.5%	17.5%	8.7%	0.63
State of Iowa	120,619	3.8%	32.5%	6.8%	0.63
Black Hawk County	12,800	9.6%	29.5%	4.4%	0.70
Johnson County	11,355	7.3%	22.9%	14.8%	0.69
Polk County	35,994	7.1%	28.0%	6.7%	0.68
Scott County	12,261	6.9%	33.8%	14.4%	0.71
Linn County	13,388	5.7%	23.6%	11.4%	0.78
Des Moines County	2,043	5.2%	46.5%	6.1%	0.80
Jefferson County	761	4.8%	7.4%	18.4%	0.78
Woodbury County	4,491	4.2%	28.3%	9.0%	0.65
Emmet County	340	3.5%	35.6%	0.4%	0.80
Webster County	1,256	3.4%	33.1%	14.8%	0.82

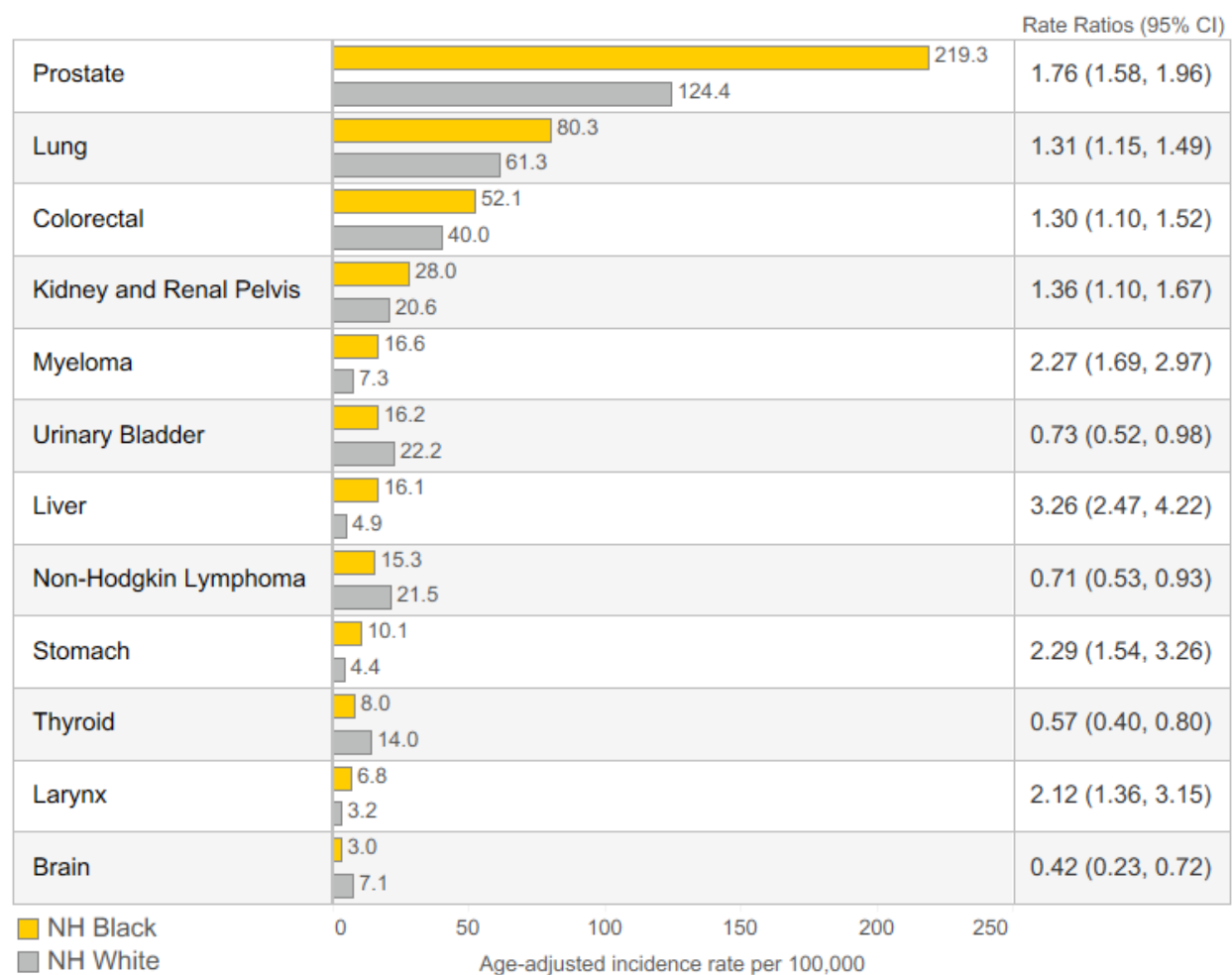
Source: American Community Survey 5-year Estimates, 2018-2022 retrieved from [Cancer InFocus Iowa](#)

Cancer Burden Among Iowa's Black Population

Leading cancers, disparities affecting Iowa's Black and African American population

Iowa's Black population shoulders an undue burden of cancer relative to other racial and/or ethnic groups, as shown in the figures below. Figure 1 shows the cancers for which significant differences in incidence rates were observed between non-Hispanic Black and non-Hispanic White populations.¹⁴ The table to the right of the graph shows the rate ratios comparing the incidence rates of non-Hispanic Black rates to non-Hispanic white rates. If the rate ratio is greater than 1 it indicates that the rate is higher among non-Hispanic Black compared to non-Hispanic white; whereas a rate ratio below 1 indicates the rate is lower among non-Hispanic Black than non-Hispanic white. Significant differences were determined by comparing the rate ratio between the two groups with differences being statistically significant at $P < 0.05$. In several cancer types, notably prostate, lung, colon and rectum, myeloma, and liver cancers, the occurrence is significantly higher in the non-Hispanic Black population.

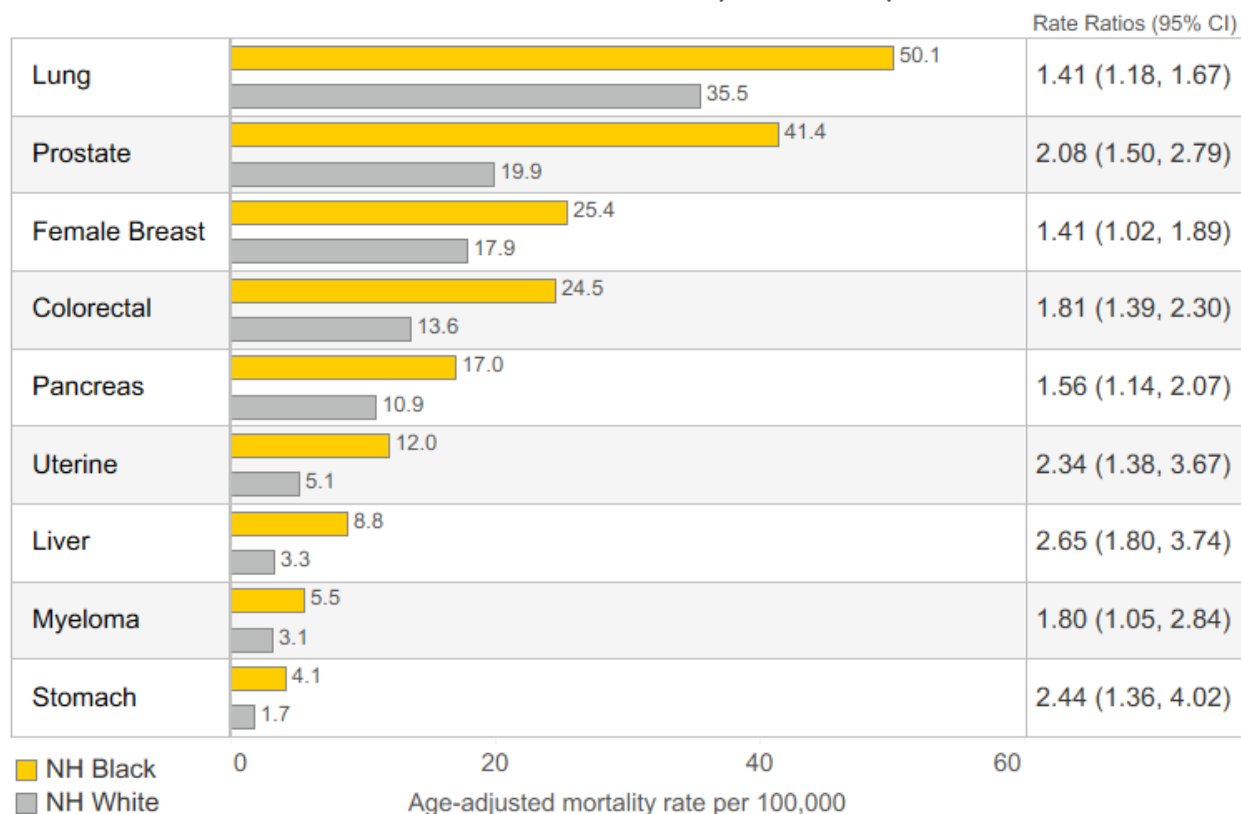
FIGURE 1. CANCER SITES WHERE NON-HISPANIC BLACK INCIDENCE RATES ARE SIGNIFICANTLY DIFFERENT FROM NON-HISPANIC WHITE INCIDENCE RATES, 2017-2021, IOWA



Source: SEER databases

Figure 2 shows the cancers for which we observed a significant difference between non-Hispanic Black mortality rates compared to non-Hispanic white mortality rates.¹⁵

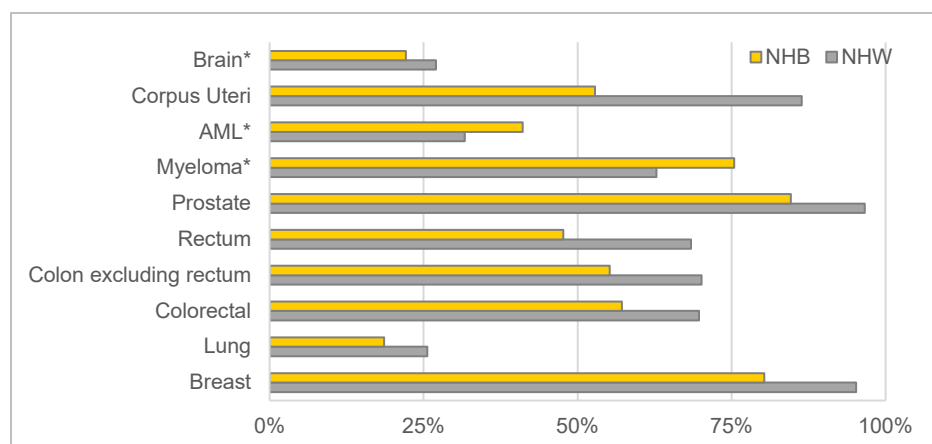
FIGURE 2. CANCER SITES WHERE NON-HISPANIC BLACK MORTALITY RATES ARE SIGNIFICANTLY DIFFERENT FROM NON-HISPANIC WHITE MORTALITY RATES, 2018-2022, IOWA



Source: SEER databases

For most cancer sites, survival rates for white Iowans are better than those of Black Iowans, with the exceptions of acute myeloid leukemia (AML) and myeloma. Figure 3 shows differences in five-year age standardized relative survival.¹⁴

FIGURE 3. FIVE-YEAR RELATIVE SURVIVAL, NON-HISPANIC WHITE VERSUS NON-HISPANIC BLACK, IOWA, 2015-2019



Source: SEER databases

Geographic Variations in Cancer Burden

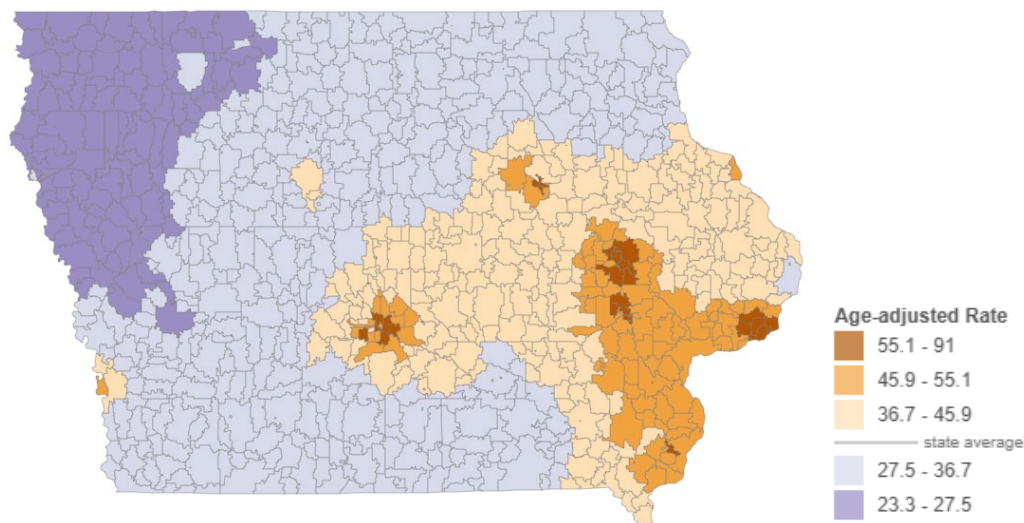
Studying cancer in small populations comes with challenges. If a population, such as Iowa's Black population, is small enough to warrant concern for confidentiality, then data is often withheld so that private health information is not accidentally revealed. To address this issue, statisticians from the University of Iowa College of Public Health developed CAMSA: Cancer Analytics and Maps for Small Areas. This tool provides ZIP-code tabulation area (ZCTA) and county-level estimates of different cancer rates without risking privacy.

The maps below show areas in the state where age-adjusted incidence rates of leading cancers are high among the Black population. In areas with fewer Black residents, there is less data available for the estimates, causing these areas to look more like the statewide average and perhaps providing a less accurate estimate of cancer in Black populations.

Colorectal cancer:

Colorectal cancer among Iowa's Black population is highest in Waterloo, Cedar Rapids, Marion, Bettendorf, Davenport, and the greater Des Moines area. Rates are the lowest in the west of the state.

FIGURE 4. NON-HISPANIC BLACK AGE-ADJUSTED COLORECTAL CANCER INCIDENCE RATES, 2016-2020

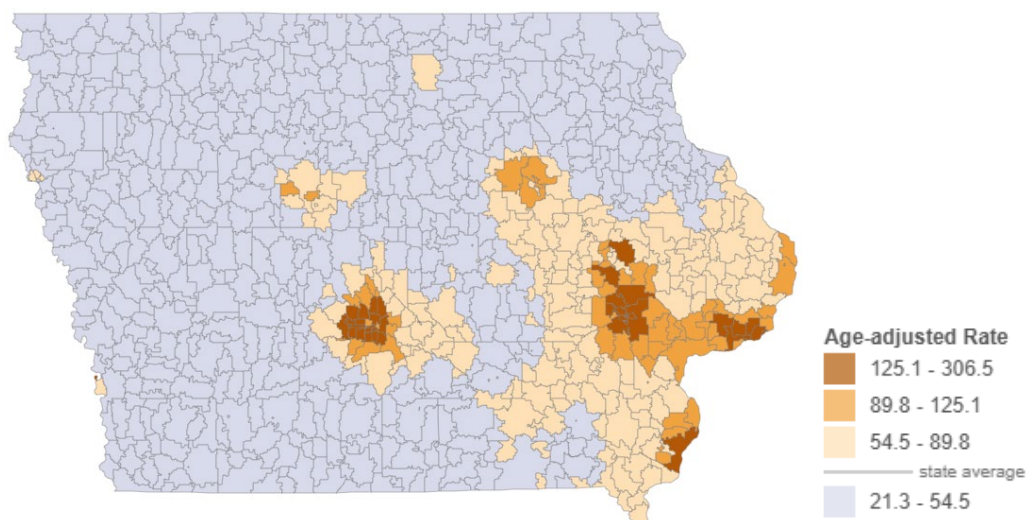


Source: Cancer Analytics & Maps for Small Areas, The College of Public Health, The University of Iowa

Female breast cancer:

Breast cancer rates are highest in Waterloo, Cedar Rapids, Marion, Bettendorf, Davenport, Sioux City, and the greater Des Moines area.

FIGURE 5. NON-HISPANIC BLACK AGE-ADJUSTED FEMALE BREAST CANCER INCIDENCE RATES, 2016-2020

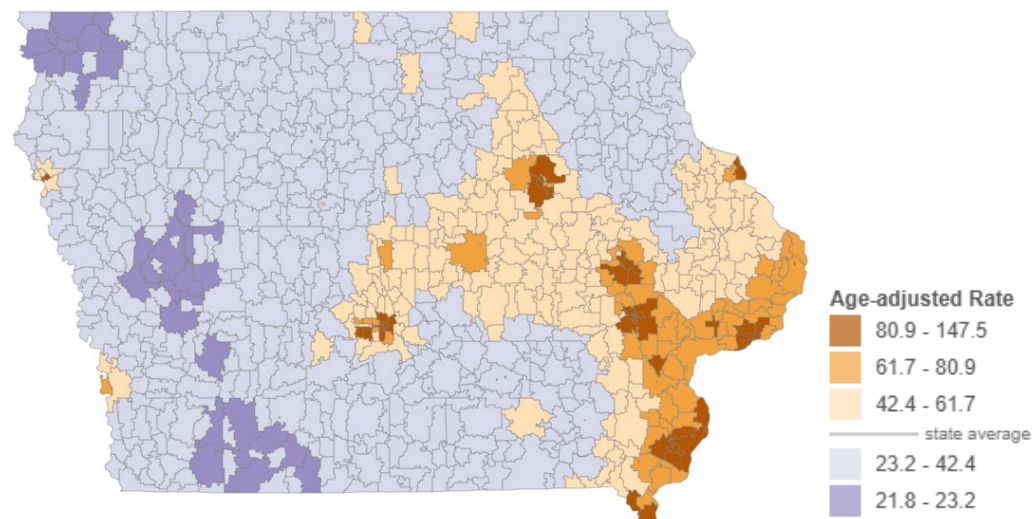


Source: Cancer Analytics & Maps for Small Areas, The College of Public Health, The University of Iowa

Lung cancer:

Lung cancer is highest in Waterloo, Cedar Rapids, Marion, Davenport, the greater Des Moines area, and the greater Burlington area.

FIGURE 6. NON-HISPANIC BLACK AGE-ADJUSTED LUNG CANCER INCIDENCE RATES, 2016-2020

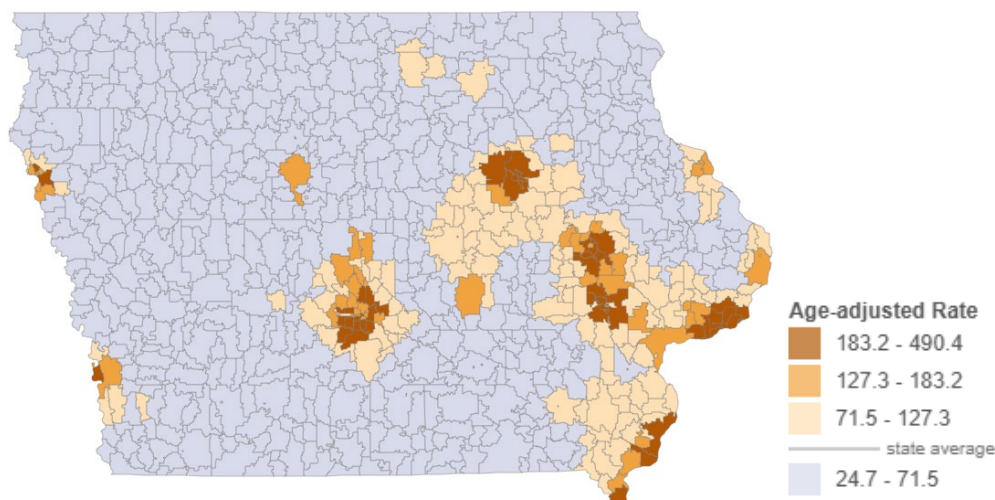


Source: Cancer Analytics & Maps for Small Areas, The College of Public Health, The University of Iowa

Prostate cancer:

Prostate cancer is highest in Waterloo, Cedar Rapids, Marion, Davenport, Bettendorf, the greater Quad Cities area, the greater Des Moines area, the area surrounding Burlington and Keokuk, and in Council Bluffs.

FIGURE 7. NON-HISPANIC BLACK AGE-ADJUSTED PROSTATE CANCER INCIDENCE RATES, 2016-2020

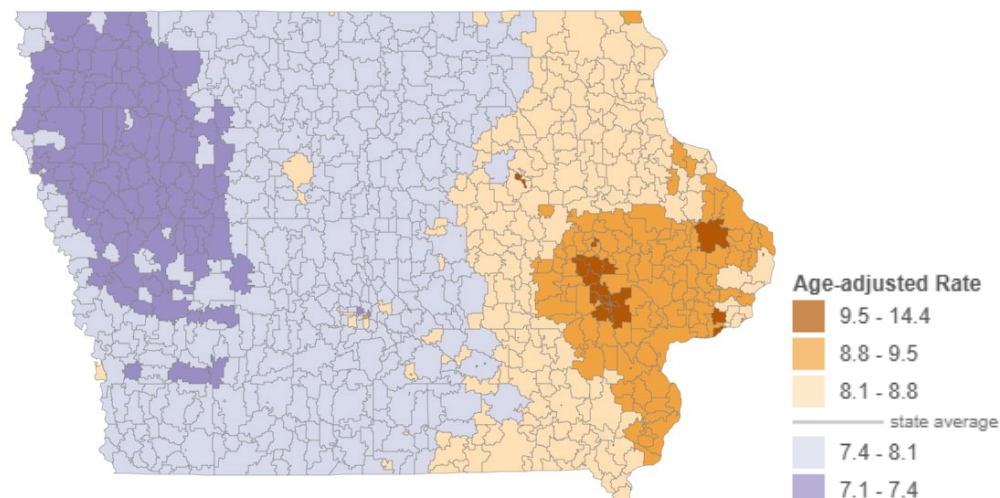


Source: Cancer Analytics & Maps for Small Areas, The College of Public Health, The University of Iowa

Cervical cancer:

Hotspots for cervical cancer among Black Iowans were found in the Cedar Rapids area, the greater Burlington area, and the Fort Dodge area. Counties in Western Iowa have lower age-adjusted cervical cancer rates among Black residents.

FIGURE 8. NON-HISPANIC BLACK AGE-ADJUSTED CERVICAL CANCER INCIDENCE RATES, 2016-2020



Source: Cancer Analytics & Maps for Small Areas, The College of Public Health, The University of Iowa

Cancer Risk and Protective Factors among Iowa's Black and African American Population

Several health-related behaviors are known to impact cancer burden, including diet, alcohol use, physical activity, and access to healthcare.¹⁶ Data for many of these behaviors are collected by the Behavioral Risk Factor Surveillance System Survey, a survey conducted by the Centers for Disease Control and Prevention. One issue with this survey, particularly among Iowans, is that small populations often suffer from small sample sizes. For this reason, we are only able to present information for Iowa's Black population at the state level.

Alcohol consumption:¹⁷

Approximately half (50.3%) of Iowa's Black population reported any alcohol consumption in the last 30 days. This is lower than non-Hispanic whites but higher than non-Hispanic Asian and Hispanic Iowans. Prevalence of binge drinking was similar across racial/ethnic categories.

Fruit and vegetable consumption:¹⁸

Fruit and vegetable consumption among Iowa's Black population is similar to other racial/ethnic groups.

Exercise:¹⁷

Approximately one-third (30.7%) of Iowa's Black population report meeting U.S. physical activity guidelines, which is similar to other race/ethnicity groups reported. The groups were also similar when looking at any physical activity participation (Figure 9).

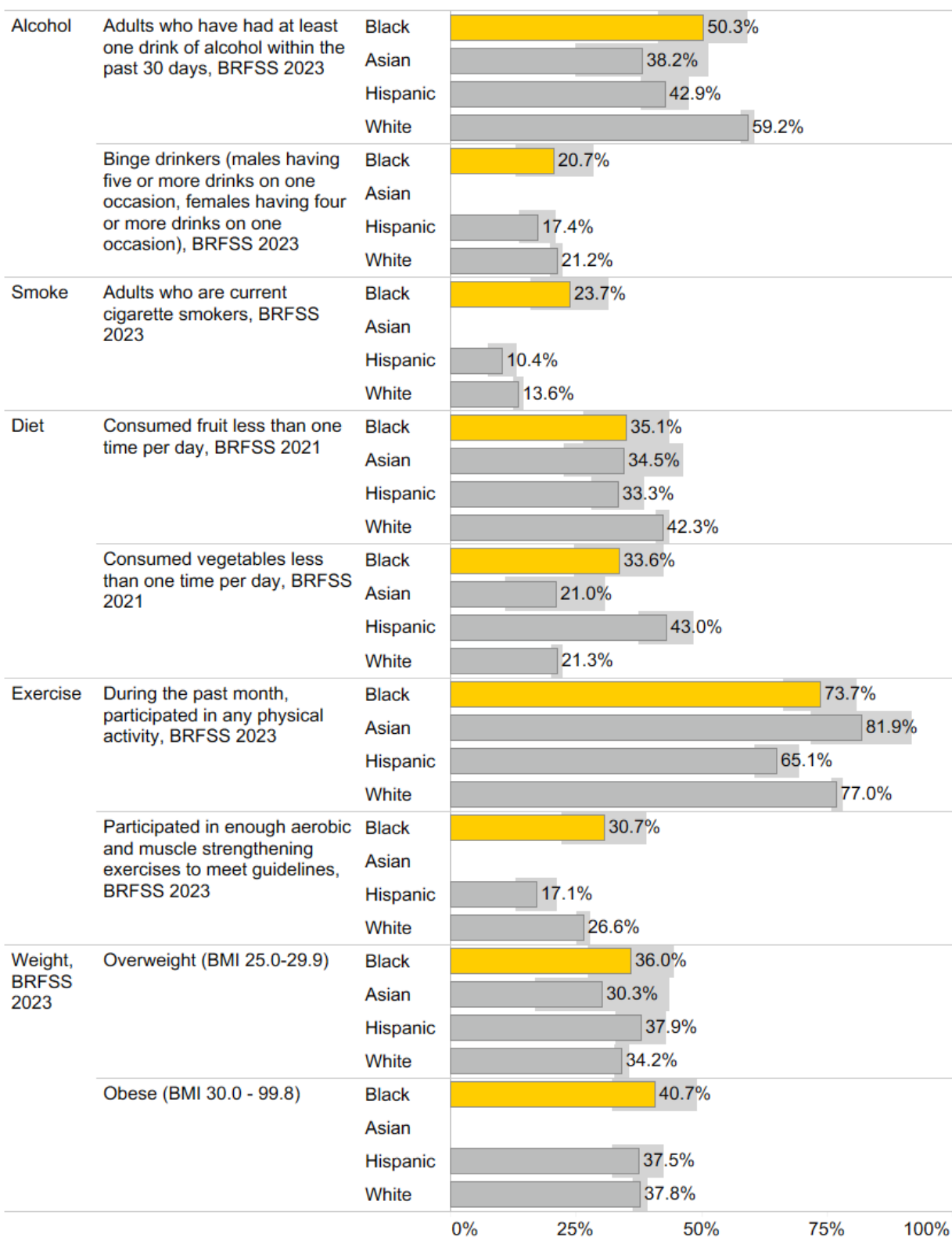
Tobacco use:¹⁷

A larger proportion of Iowa's Black population reports being current tobacco smokers than other race/ethnicity groups (23.7% vs 10.4%-13.6%).

Obesity:¹⁷

A greater proportion of Iowa's Black population reports having a body mass index (BMI) that would classify them as "overweight" or "obese" than other racial and ethnic groups (obese: 40.7% vs 38%; overweight: 36% vs 30%-38%). It is important to note that the American Medical Association [recently advised](#) against using BMI alone when evaluating patients' health; BMI is especially problematic for Black patients as the cutoffs were designed based on white bodies.¹⁹

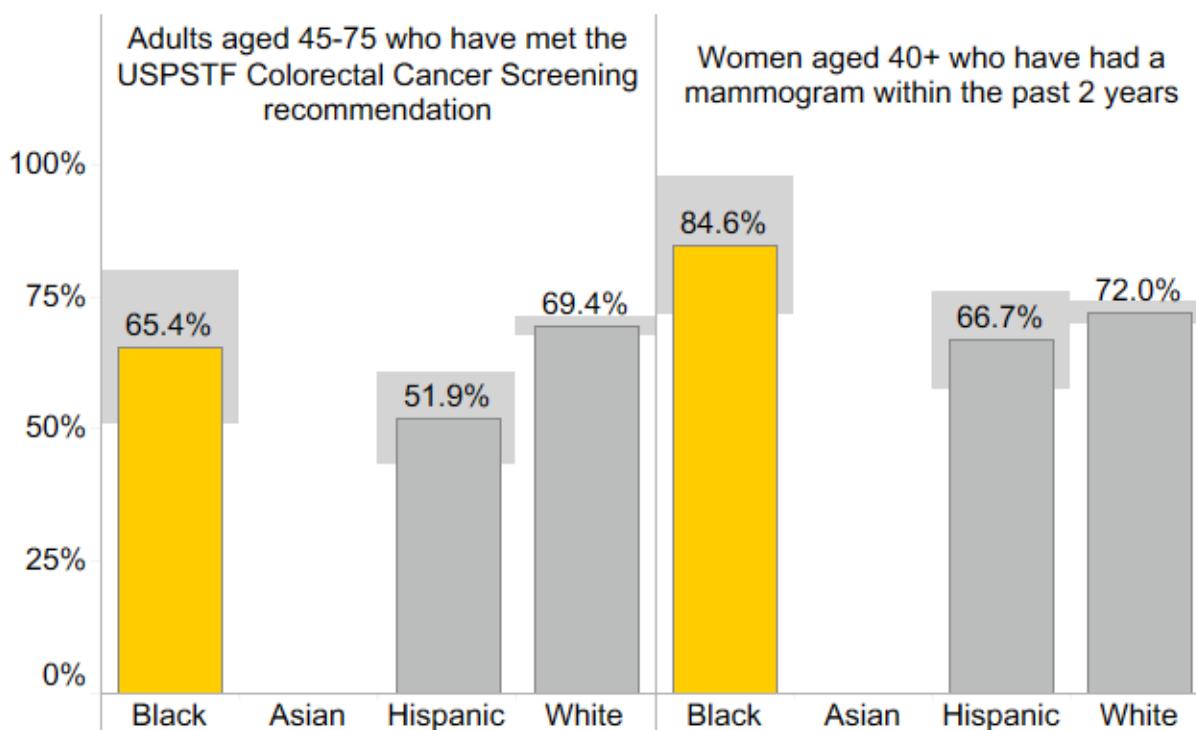
FIGURE 9. HEALTH BEHAVIORS BY RACE, IOWA



Cancer screening:²⁰

There are only two cancer screenings for which there are available data regarding racial/ethnic differences in Iowa—colorectal cancer and breast cancer. Black and non-Hispanic white Iowans had very comparable rates for being up to date with colorectal cancer screenings. Black Iowa women over the age of 40 have a higher prevalence of receiving mammograms than white Iowa women—85% compared to 72%.

FIGURE 10. CANCER SCREENING BY RACE, IOWA, BRFSS 2022



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Qualitative Interviews

We conducted interviews with 20 individuals to more thoroughly understand Black Iowan's needs, as well as community-reported barriers and facilitators to accessing cancer care. Methods are described in more detail in Appendices 1 and 2.

Fourteen of the interviewees identified as Black Iowans (either African American or immigrants), six identified as Black African immigrants, and one identified as both. Seventy percent of the interviewees were female. All interviewees were Iowa residents who either held professional roles working directly with one of the groups of interest or occupied positions within community-based organizations representing these groups. The purpose of the interviews was to understand:

- (1) What specific needs or priorities does the community encounter in accessing cancer care?
- (2) What specific barriers impede access to cancer care within the community?
- (3) What existing support systems are available to the community across the cancer care continuum, from screening through survivorship?
- (4) Does mistrust toward healthcare providers or the healthcare system constitute concern within the community?

The full interview guide, mapped to these four research questions, is in Appendix 2.

Results

The full qualitative analysis of these interviews can be found in an accompanying manuscript.³ Below, we summarize answers to the four original research questions. All points below were raised by community members within interviews, unless stated otherwise.

(1) What specific needs or priorities does the community encounter in accessing cancer care?

Interviewees offered the following ideas to improve how the community engages with cancer care and address the disconnect between health care centers and the patients they serve. Respondents emphasized the importance of building trust through consistent and culturally aware engagement from health institutions. Generally, responses suggested strategies like hiring more diverse staff, providing health education to the community in community spaces, and engaging in ways for the health organizations to have a more visible presence at local events.

Specific suggestions included:

- Holding educational meetings for the community in publicly accessible spaces (although others suggested attendance is an issue at these types of events)
- Offering free cancer screenings in community settings
- Working with schools on cancer education

- Working with local cancer centers on education, services, and culturally appropriate care
- Ensuring that providers communicate with their patients, give them time, and are available to answer questions
- Providing better insurance options
- Partnering across institutions (academic, state, CBOs, faith-based organizations) to address cancer in the community
- Specific education on nutrition and physical activity
- Support navigating the healthcare system
- Implementing culturally responsive communication and empathy-centered training for healthcare providers

(2) What specific barriers impede access to cancer care within the community?

- **Health literacy:** Interviewees described a lack of knowledge about cancer and limited access to accurate and straightforward health-related information. They report that insufficient knowledge can become a barrier to cancer prevention efforts, early detection, and understanding treatment options.
- **Cultural barriers:** Many interviewees shared that cancer is often seen as a “death sentence,” and fear makes people reluctant to discuss cancer within families and communities. As a result, they avoid cancer screenings and information about preventative measures. Some respondents indicated that cultural barriers were linked to lack of knowledge.
- **Structural barriers:** Reported barriers included limited access to care and financial and economic impediments. Interviewees said day-to-day realities, such as work hours, family obligations, and transportation barriers, may make it difficult to access quality cancer-related care. They also expressed challenges in seeking healthcare services due to the high costs associated with care delivery. Several interviewees shared that their unfamiliarity with navigating the healthcare system and/or insurance made it difficult to access.
- **Social and interpersonal barriers:** Reported barriers included absence of racial representation in the healthcare setting, racism, culturally inappropriate care, and poor communication. Many interviewees emphasized the need for greater diversity in racial representation among healthcare staff. They said that interacting with people who share similar backgrounds provides a sense of belonging, safety, and trust. Language barriers and a shortage of culturally sensitive interactions also contributed to misunderstandings and dissatisfaction of care.

(3) What existing support systems are available to the community across the cancer care continuum, from screening through survivorship?

- **Family and community members** are reported sources of emotional, logistic, and informational support during a cancer diagnosis. Whether it is practical support in the form of childcare or transportation, or information about the importance of cancer screening, interviewees noted that community support is a great source of strength during and after a cancer diagnosis. Connections were also described as critical in encouraging health-seeking behaviors (e.g., going to the doctor, getting screened, eating healthily, etc.). Finally, family and community members were seen as playing a critical role in overcoming barriers in accessing and using cancer-related and other medical care.
- **Community based organizations:** Several community-based organizations provide both cancer prevention (e.g., exercise) and cancer support to individuals within the community. There was a desire expressed for more organizations, educational opportunities, etc., since these organizations are often local and/or do not serve the entire state.

(4) Does mistrust toward healthcare providers or the healthcare system constitute concern within the community?

- Responses indicated that trust plays a nuanced role in shaping healthcare experiences within the community. Some individuals noted that historical trauma, including generational mistreatment, also influences whether individuals felt safe in healthcare spaces. Some also noted that generational changes are occurring, whereby younger generations may not hold those same views.
- Mistrust easily spreads within the community. If one person has a bad experience with a doctor or facility, this may be shared with others and impact their health-related behaviors.
- Provider communication was considered key to trust. Interviewees talked about providers not taking their time with patients, giving the impression of lack of care (e.g., prioritization of profits over people) and/or not having experience treating Black patients. Cultural communication differences were noted as contributors to lack of trust.
- Interviewees suggested several ways to improve trust including cultural humility and awareness training for providers and health-related education and literacy building.

In addition to these findings, we noted differences between African American and Black immigrant responses in the following areas:

Trust:

African American interviewees frequently referenced a deep-rooted historical mistrust of the U.S. healthcare system, shaped by generational narratives and past injustices. These historical

experiences may have a chilling effect across generations. As each generation learns about these historical contexts, this shapes the health seeking behavior of that individual. In contrast, Black African immigrant respondents may not subconsciously consider the historical experiences and instead described mistrust from a general unfamiliarity with how the U.S. healthcare system operates. Limited orientation and adaptation to the system may contribute to feelings of uncertainty and hesitation.

Health Literacy and System Navigation:

Black African immigrants expressed the need for basic information and greater health literacy on issues such as accessing and utilizing preventative care and the insurance system. In contrast, African Americans may already understand the health sector and be more focused on interpersonal challenges, such as communication differences and generational mistrust.

Cultural Beliefs and Stigma:

Black African immigrants may carry culturally rooted beliefs that may perpetuate misinformation regarding cancer. Respondents described how these cultural roots have obstructed open discussion about the disease within communities. Additionally, there may be the belief that by disclosing one's struggles, such as cancer, others in their community may treat them differently. In contrast, among African Americans, there is a fear that one's disease will become a burden to family members, which can result in avoidance and silence within the family.

Role of Family and Community:

Black African immigrants often emphasize having tight-knit communities and being close to their families. However, many lack extended support networks in the U.S. The effect of this barrier is greater among those who are recent migrants to the U.S. In contrast, African Americans reported having local and extended family and community networks on which they can rely on when needed.

Perceived Discrimination:

The perception of discrimination varies among both groups. African Americans are more likely to refer to racism and bias as the source of perceived poor healthcare treatment. In contrast, Black African immigrants may be more likely to focus on language barriers, including accents or lack of medical terminology, as contributing to poor patient-provider communication.

Appendix 1: Methods Used in the Qualitative Portion of this Needs Assessment

Ethics

This qualitative needs assessment was considered not human subjects research by the University of Iowa IRB.

Eligibility and Recruitment

The eligibility criteria for this study included any adults (18+ years old) who self-identified as Black and or Black immigrant of African descent who lived in Iowa, and who have knowledge of cancer care in their community. Preference was given to individuals who act as representatives (leaders) for their community or that provide services to the community and thus may have a higher-level systems perspective on the needs of each group of interest. Participants were recruited using a combination of convenience and snowball sampling to facilitate broader representation within the study sample. Initial contacts were identified through the cancer center community advisory board, and other community partnerships. We aimed to recruit at least ten interviewees that could talk on the African American experience, and ten who could talk on the Black immigrant experience. We offered \$50 to compensate each participant for their time.

Interview Procedures

Prior to scheduling an interview, eligibility and information regarding the needs assessment was relayed electronically via email. All interviews were conducted virtually using Zoom, in which meeting transcription as well as recording was completed within the software. All interviews were conducted by one team member (GW) with another (HH) acting as secondary notetaker for some interviews. The interviews lasted between 30 minutes to 60 minutes. After each interview, transcription was edited to remove all identifying data prior to analysis.

Data Analysis

We used a hybrid thematic analysis approach, combining both inductive and deductive coding, supported by iterative study team meetings. Inductive coding was first performed independently by two coders (GW, SN). The initial codebook was guided by prior literature and the health equity framework. Additional emergent codes identified during the initial review of ten transcripts (GW, SN) were defined and incorporated into the codebook, which was then finalized. The coding team met weekly in order to create a detailed audit trail, as well as enhance reflexivity at each step to ensure credibility and improve trustworthiness of the data. Through an iterative process, transcripts were coded and re-coded with (GW) doing the initial coding, and (SN) reviewing, coding and flagging codes for discussion where there were disagreements. Through a collaborative process, coding discrepancies were addressed until consensus was reached. All qualitative analysis was conducted using software Dedoose version 9.2.22.

Themes were developed through an iterative process of data visualization and reduction (GW, SN), which involved first consolidating overlapping codes and eliminating unused codes. Subsequently, all codes were systematically reviewed to identify patterns of co-occurrence and opportunities for further data refinement.

Appendix 2: Interview Questions Used in this Needs Assessment

Interview process/questions:

Start with introductions, small talk to get interviewee relaxed with the process.

*Have interviewee introduce themselves and their role in the community

Ask interviewee if it's ok to record – explain that recording is so that we can have access to the conversation after the fact to make sure that our transcripts are complete and that we're not missing any of their thoughts or recommendations. Intro question: Do you hear a lot about cancer in your community? What do you hear? [or similar]

[Determine if interviewee represents Black and/or African American community]

1: What are the specific needs or priorities your community faces in accessing cancer care?

[RQ1] *High Focus*

What are needs specific to cancer screening?

What are needs specific to cancer treatment?

What are needs specific to survivorship care?

2: What are the specific barriers your community faces in accessing cancer care? [RQ2]

What are barriers specific to cancer screening?

What are barriers specific to cancer treatment?

What are barriers specific to survivorship care?

3: What supports your community to get cancer care, from screening to survivorship? [RQ3]

What resources are there in your community to help an individual to access cancer care?

4: We've heard a lot about trust, and lack thereof. Is mistrust of healthcare a concern for your local Black/African American community? What are the consequences of mistrust, if it exists? [RQ4]

Do you think your community is willing to seek healthcare?

Who would you say that they do trust?

Are there specific facilities (doctors, hospitals) that individuals do or do not go to for health or cancer care? Why?

5: What would the community like to see from local healthcare facilities, systems, and/or providers to improve trust from the community? [RQ5]

6: Is there anyone else that you think we should talk to to understand your community's cancer-related needs?

(And how do you think we can get people into screening)

End: Thank interviewee for their time; remind them we can offer \$50 as a thank you for their time, they will need to provide the w9, if one isn't already on file.