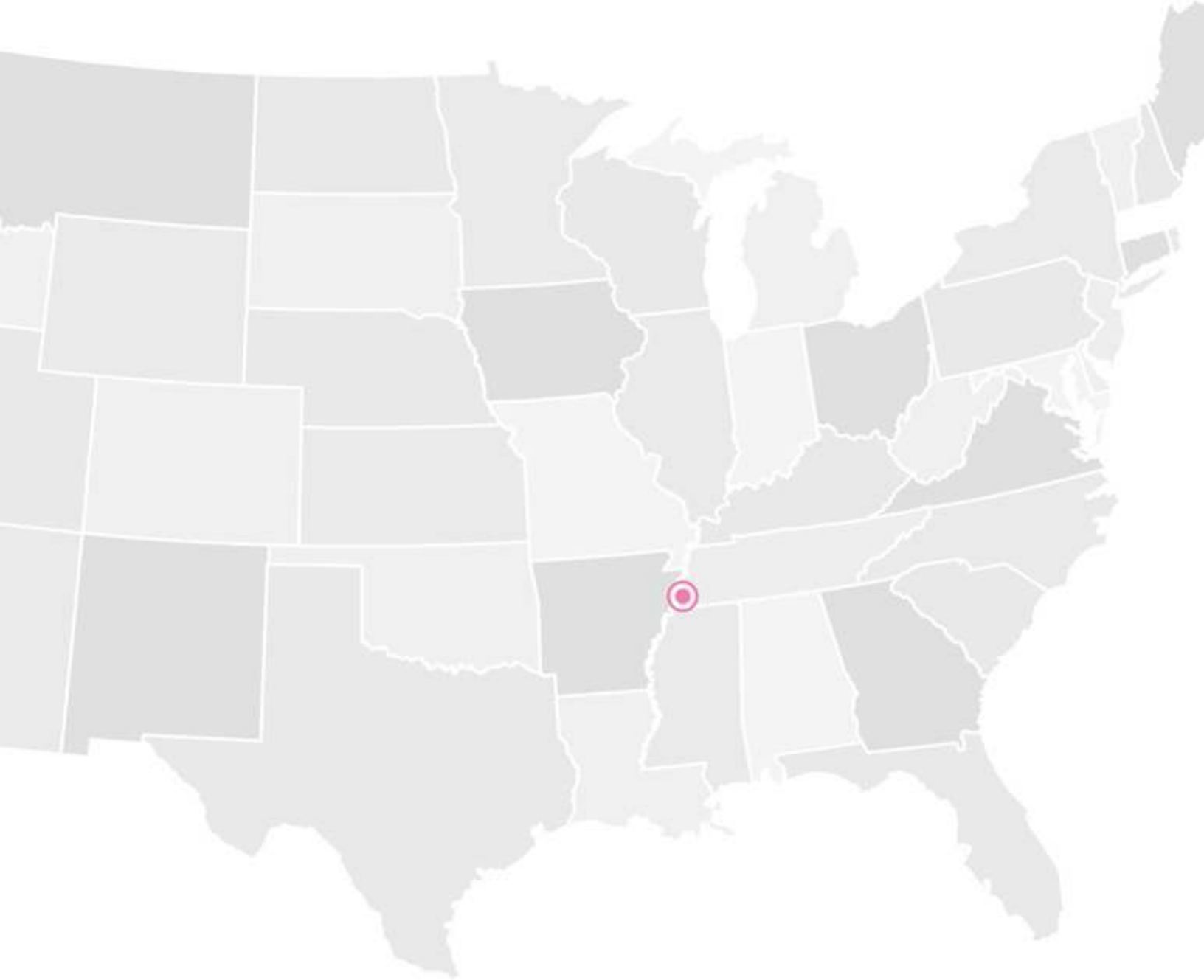
Closing the Breast Cancer Gap:

A Roadmap to Save the Lives of Black Women in America

2021

MEMPHIS



Study prepared by Susan G. Komen
with support from John Snow, Inc.

Stand For **H.E.R.**
Health Equity Revolution

susan G. komen.

Acknowledgements

This report was prepared by Susan G. Komen® (Komen) and John Snow, Inc. (JSI), a mission-driven national and international public health research and consulting organization dedicated to advancing the health of individuals and communities. The development of this report was made possible with funding from the Fund II Foundation and Merck.

Komen expressed our deepest gratitude to the resilient and powerful women who shared their journeys, their everyday experiences of racism, their trials and tribulations navigating and negotiating health systems and the simple pleasures in life from which they draw strength to keep going and care for one another. We hope the findings synthesized in this report will uplift the human stories behind breast cancer inequities and persuade decision makers to take action and lay the foundation for systems that better serve Black women. We write these findings in honor of the Black women who did not survive their cancer journeys, and the countless Black lives lost to pervasive structural racism.

We are grateful to the independent consultants, partners, community-based organizations and Komen Affiliates around the U.S. for their support in recruitment and outreach. We are also grateful to the academic experts, researchers and practitioners who provided guidance on data collection tools, data sources and frameworks for this metropolitan area. They are:

- Lucile L. Adams-Campbell, PhD, Associate Director for Minority Health and Health Disparities Research, Senior Associate Dean for Community Outreach and Engagement and Professor of Oncology at Lombardi Comprehensive Cancer Center at Georgetown University Medical Center
- Amani Allen, PhD, Executive Assistant Dean and Associate Professor of Community Health Sciences and Epidemiology, University of California Berkeley
- Raven Ballinger, Caregiver at Heart to Heart Home Care and Founder, Purple Meets Pink
- Cynthia Bradford, System Community Involvement Manager, Baptist Memorial Health Care
- Flo Brown, Coordinator of Special Events, Temple of Deliverance Church
- Elaine Hare, CEO, Susan G. Komen® Memphis-MidSouth Mississippi
- Lisa Mischke, LMSW, Grant Director, Susan G. Komen® Memphis-MidSouth Mississippi
- Aza Nedhari, Director, Mamatoto Village
- Tiana Pyles, MHA, Founder and Director, BSTARS
- Tami Sawyer, Shelby County District 7 Commissioner
- Judy Seals-Togbo, LCSW, Facilitator, Carin' and Sharin
- Karen Sock, President and CEO, Sock Enterprises Inc.
- Leilani Spence, Deputy Administrator, Community Health Bureau, Shelby County Health Department
- Britney Thornton, Founder, JUICE Orange Mound

- Ann Marie Watkins Wallace, MSPH, System Community Outreach Senior Coordinator, Baptist Memorial Health Care
- Erika T. Warner, ScD, MPH, Project Director Harvard/MGH Center on Genomics, Vulnerable Populations and Health Disparities, Assistant Professor, Harvard Medical School & Massachusetts General Hospital

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JSI Team: Tajan Braithwaite Renderos, MPH; Chanel Richmond; Karuna S. Chibber, DrPH; Naomi Clemmons, MPH; Naima Cozier, MSPH; Terry Greene, MPH; Kiely Houston, MSPH; Tracey Kirui; Aisha Moore, MPH; Oluwatunmise Olowojoba; Alison Salomon, MPH MCRP; Erin Shigekawa, MPH; and Tea Slater.

Suggested Citation:

Susan G. Komen. (2021, August 4). Closing the Breast Cancer Gap: A Roadmap to Save the Lives of Black Women in America, Memphis, TN. https://www.komen.org/wp-content/uploads/AAHEI_Memphis-Landscape-Analysis-Report.pdf

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Executive Summary

About Susan G. Komen

Susan G. Komen® (subsequently referred to as "Komen") is the world's leading nonprofit breast cancer organization, working to save lives by meeting the most critical needs in communities and investing in breakthrough research to prevent and cure breast cancer.

Background and Purpose

Breast cancer is the most common cancer diagnosed among U.S. women and is the second leading cause of death among women after lung cancer with women having a one in eight chance of developing breast cancer over the course of their lifetimes. With the increasing availability of screening mammography screening, earlier detection, and improvements in breast cancer treatment, the overall breast cancer mortality rate among women in the United States has declined by 41 percent from 1989 through 2018 (American Cancer Society, 2019a). However, these trends vary by race and ethnicity.

Research shows that despite recent scientific advancements, there are widespread disparities in breast cancer statistics between Black and white women. Among Black women, breast cancer is the most common type of cancer and the second leading cause of cancer death (American Cancer Society, 2019b). Breast cancer mortality is about 40 percent higher in Black women than in white women. Furthermore, although breast cancer survival in Black women has increased over time, survival rates remain lower than among white women (Howlander et al., 2020)

About This Report

In 2015, in partnership with Fund II Foundation, Komen launched the African American Health Equity Initiative (AAHEI), now known as Stand for H.E.R. – a Health Equity Revolution, to improve breast health equity for Black women and men. Stand for H.E.R. aims to reduce breast cancer disparities in Black women starting in the 10 U.S. metropolitan areas (referred to throughout this report as MTAs or metro) where the inequities are greatest: Atlanta, GA; Chicago, IL; Dallas-Fort Worth, TX; Houston, TX; Los Angeles, CA; Memphis, TN.; Philadelphia, PA.; St. Louis, MO.; Virginia Beach, VA.; and Washington, DC.

As part of Stand for H.E.R., Komen engaged John Snow, Inc. (JSI), a public health research and consulting organization, to conduct a landscape analysis in each MTA. The main purpose of each landscape analysis was to understand the underlying causes of breast cancer inequities across the care continuum among Black women, with a focus on systemic and social determinants of health.

The methods involve a literature scan, compiled quantitative data, reviewed federal and state policies and collected qualitative data from community members and providers to prepare a landscape analysis report for each of the 10 MTAs. This study does not attempt to establish causality between underlying risk factors and breast cancer outcomes. Rather, the analysis aims to:

1) elevate key findings regarding the underlying causes for breast cancer inequities across the care continuum among Black women, and

2) offer insights that can inform strategic discussions about strengths, gaps, challenges, and opportunities to promote breast health equity and create community- and systems-level change.

Key Findings

- In both DeSoto County, MS., and Shelby County, TN, incidence rates for Black women are lower than or equivalent to those for white women.
- In the Memphis MTA, the likelihood of receiving a breast cancer diagnosis, the stage of diagnosis and the likelihood of death from the disease vary along geographical and racial lines.
- There are no significant trends among incidence rates for white women versus Black women, as the incidence rates are higher among white women in some places and higher among Black women in others. The greatest disparity is reported in Crittenden County, AR, where the incidence rate is 78.9 for white women compared to 104.8 for Black women.
- In two of the three Memphis MTA Counties (Crittenden County, AK, and DeSoto County MS), in situ incidence rates among Black women are higher compared to white women. The disparity is greatest in DeSoto County, with the rate reported at 25.0 for white women and 33.1 for Black women.
- Almost all age adjusted late-stage rates (overall and racially disaggregated) are lower in the MTA than the corresponding state's average. The exception is Shelby County, TN, where the overall rate is on par with the state average of 49.6 and the rate reported for Black women (the highest in the MTA) is 51.1, compared with 48.9 for Black women overall in Tennessee.
- In both DeSoto County, MS, and Shelby County, TN, mortality rates are higher for Black women compared to white women (21.1 white and 32.7 Black in DeSoto, 23.3 white and 34.5 Black in Shelby).
- In the Memphis MTA, particularly in DeSoto County, MS, Black women are more likely to die from breast cancer than their white counterparts, even though they are more likely to receive a screening mammogram and are diagnosed with the disease at lower rates.
- Overall screening mammography rates, not disaggregated by race, in the Memphis MTA are lower than the state and national levels. Crittenden County, AK, however, has the lowest rate of women receiving mammograms, yet their mortality rate is 22.4, which is lower than that of Shelby County, TN (28.5). This suggests that residents who are diagnosed in Crittenden County are more likely to survive breast cancer after receiving a screening mammogram than their counterparts in Shelby County.
- Several focus group participants noted *free and convenient breast cancer screening availability in their communities, but lack of awareness surrounding these programs.* Free screening resources are not available where younger women congregate, and providers are not aware of where to refer uninsured patients for screening mammogram.
- Providers also expressed concerns about the quality of screening at facilities in areas that are low income.
- Insights from qualitative data collected among community members suggest barriers to care due to challenges for patients navigating the diagnosis systems, complicated diagnosis process and insurance barriers.

- There were numerous accounts of deductibles being too high and women foregoing care for financial reasons.
- Survivors and undiagnosed women all noted that historic distrust of the health care system, family and personal experiences of implicit bias, racism, and discrimination rather than empathy in everyday life generally and in the health care system impact quality of care and retention in treatment for Black women.
- All focus group participants also noted how Black women are vulnerable due to poverty and demanding gender roles.

Recommendations

The following strategies, research and interventions are recommended to better understand and address the complexity of the root causes of breast cancer inequities in the Memphis MTA (full details provided in the recommendations section of this report). The recommendations follow a systems framework:

- the **micro** level (the level at which patients and providers interact),
- the **mezzo** level (the level at which systems interact) and
- the **macro** level (the policy level).

Micro-Level Strategies

- Develop a diverse and culturally responsive patient navigation workforce.
- Expand financial assistance programs for Black women diagnosed with breast cancer.
- Implement implicit bias trainings for providers, administrators and health care staff.
- Increase education about family health history in the community to identify high-risk families and offer genetic counseling and testing and breast cancer screening to meet the need.
- To implement a culturally relevant health promotion campaign intended to increase knowledge of current screening guidelines.

Mezzo-Level Strategies

- Increase access to integrated care to improve the breast cancer care experience.
- Support Quality Improvement (QI) initiatives along the breast cancer continuum of care.
- Create avenues for social support and community connection and strengthen networks of culturally responsive patient navigators.

Macro-Level Strategies

- Conduct a root cause analysis relating to healthcare quality.
- Support efforts to develop guidelines and policies that address disproportionate breast cancer mortality among Black women, including increased genetic counseling and testing services.

This landscape analysis report conveys comprehensive issues facing Black women in this MTA. These recommendations are intended to be a call to action for all community-based organizations, policymakers, hospitals, healthcare providers, faith-based organizations, civic leaders and citizens. The recommendations are offered as evidence-informed strategies to reduce breast cancer disparities among Blacks.

About Susan G. Komen

Susan G. Komen® (subsequently referred to as "Komen") is the world's leading nonprofit breast cancer organization, working to save lives by meeting the most critical needs in communities and investing in breakthrough research to prevent and cure breast cancer. Komen has an unmatched, comprehensive 360-degree approach to fighting this disease across all fronts and supporting millions of people in the U.S. and in countries worldwide. Komen advocates for patients, drives research breakthroughs, improves access to high-quality care, offers direct patient support and empowers people with trustworthy information. Founded by Nancy G. Brinker, who promised her sister, Susan G. Komen, that she would end the disease that claimed Suzy's life, Komen remains committed to supporting those affected by breast cancer today, while tirelessly searching for tomorrow's cures.

Introduction

Breast cancer is the most common cancer diagnosed among U.S. women and is the second leading cause of death among women after lung cancer. Women in the U.S. have a one in eight chance of developing breast cancer over the course of their lifetimes. With the increasing availability of screening mammography screening, earlier detection, and improvements in breast cancer treatment, the overall breast cancer mortality rate among women in the United States (U.S.) declined by 41 percent over the last 30 years (American Cancer Society, 2021).

However, these trends vary by race and ethnicity. Research shows that despite recent scientific advancements, there are widespread racial health disparities in breast cancer comparing Black women to white women.

Black women are, on average, 40 percent more likely to die of the disease as compared to white women (Howlader et al., 2018). The five-year breast cancer survival rate for Black women is 83 percent as compared to 92 percent for white women (Howlader et al., 2020). However, overall, breast cancer incidence among Black women is lower than among white women. However, from 2013-2017 for women younger than 40, incidence is higher among non-Hispanic Black women than non-Hispanic white women (Noone et al., 2017). The incidence rates are higher among Black women under age 40 (where incidence is the number of new cases that develop in a specific time period) (American Cancer Society, 2020).

Black women are also more likely than white women to be diagnosed with aggressive breast cancers, such as Triple-Negative Breast Cancer (TNBC) and inflammatory breast cancer, and are more likely to be diagnosed at a later stage, when treatments are limited, costly and the prognosis is poor (American Cancer Society, 2019; Williams et al., 2016).

Through the Stand for H.E.R., Komen seeks to improve breast health equity by reducing late-stage diagnosis and mortality for Blacks starting in the 10 U.S. metropolitan areas (referred to throughout this report as MTAs or metro) where Black breast cancer disparities are the greatest.

These MTAs include Atlanta, GA; Chicago, IL; Dallas-Fort Worth, TX; Houston, TX; Los Angeles, CA; Memphis, TN; Philadelphia, PA; St. Louis, MO; Virginia Beach, VA.; and Washington, DC.

As part of Stand for H.E.R., Komen engaged JSI, a public health research and consulting organization, to conduct a landscape analysis in each MTA to better understand the underlying causes of breast cancer inequities across the care continuum among Black women.

Findings from each landscape analysis report serve to inform the design and implementation of Komen's long-term and cross-sector collaborative efforts as well as serve as a call to action for all community-based organizations, policymakers, hospitals, healthcare providers, faith-based organizations, civic leaders and citizens to engage in evidence-informed strategies to reduce breast cancer disparities among Blacks.

Project Objectives

The specific objectives of the landscape analysis are:

- To understand breast cancer disease burden in each MTA by describing breast cancer measures (incidence, in situ incidence, late-stage diagnosis and mortality) and other key health metrics (such as life expectancy and age-adjusted mortality), comparing Black to white women, per data availability.[1]
- To describe systemic barriers, including adverse SDOH, and other socioeconomic and contextual factors that may contribute to breast cancer inequities, comparing counties within each MTA.
- To explore community members' perspectives regarding their experiences with breast cancer screening and treatment, and their perceptions regarding barriers/facilitators to obtaining care, factors contributing to breast cancer inequities, and suggestions for advancing breast health equity.
- To explore health care provider perspectives regarding individual, community and health systems factors contributing to breast cancer inequity, along with their recommendations for system-level change.
- To identify policy, systems and environmental (PSE) level strategies that may help to mitigate breast cancer inequities and achieve Komen's goals of improving breast health equity.

This report summarizes findings from the analysis conducted for the Memphis MTA. The report begins with a discussion of methods used, followed by guiding frameworks and key findings from the literature scan that informed all aspects of the project. The subsequent sections review key findings pertaining to the project objectives as stated above. Findings are organized into two sections: Section 1 describes the breast cancer disease burden in the MTA through secondary data and community member perspectives. Section 2 explores the systemic barriers and underlying root causes, including experiences of racism and adverse SDOH that may be driving breast cancer inequities. The final section includes recommendations to reduce breast cancer disparities and advance breast health equity.

[1] As defined in the Abbreviations & Glossary, these terms are defined as follows: Incidence is defined as the number of new cases of a disease that develop in a specific time period; In situ means a condition where abnormal cells are found in the milk ducts or lobules of the breast, but not in the surrounding breast tissue. In situ means "in place;" Late-stage diagnosis indicates that breast cancer has spread beyond the breast to lymph nodes, surrounding tissue or other organs in the body (most often the bones, lungs, liver or brain).

Given the goals and methods traditionally used in a landscape analysis project, the study's intent is not to provide conclusive evidence or to establish causality between particular factors and breast cancer outcomes among Blacks. Rather, the study aims to:

1) elevate key findings regarding the underlying causes for breast cancer inequities across the care continuum among Black women, and

2) offer insights that can inform strategic discussions about strengths, gaps, challenges, and opportunities to promote breast health equity and create community- and systems-level change.

These recommendations are intended to be a call to action for all community-based organizations, policymakers, hospitals, healthcare providers, faith-based organizations, civic leaders, and citizens. The recommendations are offered as evidence-informed interventions to reduce breast cancer disparities among Blacks.

Methods

The methods include a literature scan, compiling quantitative data, reviewing federal and state policies and collecting qualitative data from community members and healthcare providers to prepare this landscape analysis report.

To understand and visualize geographic variability, indicators were projected spatially using ArcGIS version 10.6.1. The maps that appear in this report were created in ArcMap version 10.6.1 and processed in Adobe Illustrator version 24.1.1. Data sources for geographies of interest (e.g., food deserts and redlined areas) are identified in Table 1. Political boundaries, including county and state lines, were created using Census TIGER/Line shapefiles.

TABLE 1. MEMPHIS METRO AREA DATA METHODS AND SOURCES

Demographics		
Subcategory	**Indicator**	**Source**
population	Total Population	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)
sex	Percent of Population that is Male	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)
sex	Percent of Population that is Female	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)
age	Percent of Population that is Under Age 18	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)
age	Percent of Population that is Age 18-64	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)
age	Percent of Population that is Over Age 65	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)
race	Percent of Population that is White	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)
race	Percent of Population that is Black	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)
race	Percent of Population that is Asian	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)
race	Percent of Population that is American Indian or Alaska Native	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)
race	Percent of Population that is Native Hawaiian or Other Pacific Islander	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)
race	Percent of Population that is Some Other Race	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)
race	Percent of Population that is Two or more Races	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)
race	Percent of Population that is Hispanic/Latino	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)
race	Percent of Population that is White not Hispanic	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)

race	Percent of Population that is Minority Race	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)
target population	Number of Black Women over age 45	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)

Social Determinants of Health

Subcategory	Indicator	Source
social vulnerability	Social Vulnerability Index Score	2016 Social Vulnerability Index (US Centers for Disease Control and Prevention)
economic security	Percent of Population that is Uninsured	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)
economic security	Percent of Population Below 200% FPL	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)
economic security	Percent of Black Women over age 45 who live Below Poverty Level	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)
food security	Location of Food Deserts	2019 Food Access Research Atlas (US Department of Agriculture, Economic Research Service)
food security	Percent of Population that is Food Insecure	2019 County Health Rankings (County Health Rankings)
food security	Percent of Total Population with Limited Access to Healthy Foods	2019 County Health Rankings (County Health Rankings)
food security	Percent of Black Households Receiving SNAP/EBT	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)
education	Percent of Population over age 25 that has High School Degree or Higher	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)
education	Percent of Population over age 25 that has Bachelor's Degree or Higher	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)
education	Percent of Black Women over age 25 without a High School Degree	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)
transportation	Percent of Households without a Vehicle	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)
transportation	Percent of Total Population Commuting more than 45 Minutes to Work	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)
transportation	Percent of Total Population that Commutes to Work using Public Transportation	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)
transportation	Percent of Population Commuting to Work by Foot/Bike/Other	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)
housing stability	Percent of Households that are Housing-Cost Burdened	2016 Comprehensive Housing Affordability Strategy dataset (US Department of Housing and Urban Development)
housing stability	Proportional Change in Population with a Bachelor's Degree or Higher	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau); American Community Survey 2008-2012 5-Year Estimates (US Census Bureau

housing stability	Percent Change in Median Household Income	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau); American Community Survey 2008-2012 5-Year Estimates (US Census Bureau
segregation	Black/White Dissimilarity Index Score	2019 County Health Rankings (County Health Rankings)
racism	Location of Redlining	2019 Mapping Inequality Project (University of Richmond)
racism	Number of Hate Crimes Committed with a Race/Ethnicity/Ancestry Bias Motivation	2017 Hate Crime Statistics (Federal Bureau of Investigation, Uniform Crime Reporting)
racism	Number of Fair Housing Act Cases Filed with a Race Basis	Fair Housing Act Cases dataset (US Department of Housing and Urban Development, Office of Fair Housing and Equal Opportunity)
racism	Number of Blacks Killed by Police	The Counted Database (The Guardian)

Health and Wellness

Subcategory	Indicator	Source
quality of life	County Health Rankings Percentile	2019 County Health Rankings (County Health Rankings)
quality of life	Percent of Adults Reporting "Fair" or "Poor" Health	2019 County Health Rankings (County Health Rankings)
quality of life	Average Number of Poor Physical Health Days	2019 County Health Rankings (County Health Rankings)
quality of life	Average Number of Poor Mental Health Days	2019 County Health Rankings (County Health Rankings)
quality of life	Life Expectancy	2019 County Health Rankings (County Health Rankings)
quality of life	Life Expectancy for Whites	2019 County Health Rankings (County Health Rankings)
quality of life	Life Expectancy for Blacks	2019 County Health Rankings (County Health Rankings)
quality of life	Premature Age-Adjusted Mortality	2019 County Health Rankings (County Health Rankings)
quality of life	Premature Age-Adjusted Mortality for Whites	2019 County Health Rankings (County Health Rankings)
quality of life	Premature Age-Adjusted Mortality for Blacks	2019 County Health Rankings (County Health Rankings)
health behaviors	Percent of Adults who are Obese	2019 County Health Rankings (County Health Rankings)
health behaviors	Percent of Adults who Drink Excessively	2019 County Health Rankings (County Health Rankings)
health behaviors	Percent of Adults who are Physically Inactive	2019 County Health Rankings (County Health Rankings)

Health Systems

Subcategory	Indicator	Source
primary care	Percent of Total Population that is Medically Underserved	HRSA Data Warehouse (US Department of Health and Human Services, Health Resources & Services Administration)
primary care	Number of PCPs	2019 County Health Rankings (County Health Rankings)

primary care	Persons per PCP	2019 County Health Rankings (County Health Rankings)
primary care	Number of "Other" PCPs	2019 County Health Rankings (County Health Rankings)
primary care	Persons per "Other" PCP	2019 County Health Rankings (County Health Rankings)
primary care	Number of Private PCPs	HRSA Data Warehouse (US Department of Health and Human Services, Health Resources & Services Administration)
primary care	Location of FQHCs	HRSA Data Warehouse (US Department of Health and Human Services, Health Resources & Services Administration)
primary care	Location of Hospitals	HRSA Data Warehouse (US Department of Health and Human Services, Health Resources & Services Administration)
cancer care	Location of Comprehensive Cancer Centers	National Cancer Institute
cancer care	Location of Screening mammography Facilities	American College of Radiology
cancer care	Location of Treatment Facilities	American College of Surgeons; Association of Community Cancer Centers
cancer care	Location of NCORP Sites	National Cancer Institute
cancer care	Number of Mobile Screening mammography Centers	Google search
cancer care	Number of Private Oncologists	Docstop and Healthgrades
cancer support	Number of Cancer Coalitions	2015 Affiliate profile files and Google search
cancer support	Number of Survivor/Support Groups	2015 Affiliate profile files and Google search

Breast Cancer Disease Burden		
Subcategory	**Indicator**	**Source**
prevalence	Prevalence	2017 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
incidence	Age-Adjusted Incidence Rate	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
incidence	5-year Incidence Rate Trend Direction	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
incidence	Age-Adjusted Incidence Rate for White Women	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
incidence	5-year Incidence Rate Trend Direction for White Women	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
incidence	Age-Adjusted Incidence Rate for Black Women	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
incidence	5-year Incidence Rate Trend Direction for Black Women	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
in situ incidence	Age-Adjusted In Situ Incidence Rate	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
in situ incidence	5-year In Situ Incidence Rate Trend Direction	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
in situ incidence	Age-Adjusted In Situ Incidence Rate for White Women	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
in situ incidence	5-year In Situ Incidence Rate Trend Direction for White Women	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
in situ incidence	Age-Adjusted In Situ Incidence Rate for Black Women	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
in situ incidence	5-year In Situ Incidence Rate Trend Direction for Black Women	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
late-stage incidence	Age-Adjusted Late-Stage Incidence Rate	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
late-stage incidence	Average Count of Cases that are Late-Stage	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
late-stage incidence	Age-Adjusted Late-Stage Incidence Rate for White Women	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
late-stage incidence	Average Count of Cases that are Late-Stage for White Women	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
late-stage incidence	Age-Adjusted Late-Stage Incidence Rate for Black Women	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
late-stage incidence	Average Count of Cases that are Late-Stage for Black Women	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
mortality	Age-Adjusted Mortality Rate	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
mortality	5-year Mortality Rate Trend Direction	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)

mortality	Age-Adjusted Mortality Rate for White Women	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
mortality	5-year Mortality Rate Trend Direction for White Women	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
mortality	Age-Adjusted Mortality Rate for Black Women	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
mortality	5-year Mortality Rate Trend Direction for Black Women	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
screening mammography	Percent of Women Getting Mammograms	2017 County Level Modeled Estimate Combining BRFSS and NHIS (US Centers for Disease Control and Prevention; State Cancer Profiles; National Institutes of Health)

Qualitative Data

In the Memphis MTA, a total of five focus groups were conducted among 56 community members. Three individual interviews were held with provider interviews and one patient navigator focus group was conducted.

Table 2 summarizes the demographic characteristics of 56 focus group participants, representing both breast cancer survivors and the undiagnosed. Among breast cancer survivors, the majority were above 55 years of age, utilized Medicare for insurance (54 percent) and had been diagnosed with stage 2 breast cancer (33 percent). Undiagnosed women were older, mostly in the 55-64 age group, with the majority reporting access to private insurance (34 percent). Non-provider participants were Black. Demographics were not collected for community health navigators, patient navigators or clinical providers.

TABLE 2. MEMPHIS METRO AREA QUALITATIVE DATA COLLECTION

Variable Name	Breast Cancer Survivors (n=24)	Undiagnosed Women (n=32)
Age		
18-24 years	0.0%	3.1%
25- 34 years	0.0%	3.1%
35-44 years	0.0%	15.6%
45-54 years	12.5%	18.8%
55-64 years	41.7%	43.8%
65-74 years	25.0%	15.6%
75 and above	20.8%	0.0%

Zip Codes	Breast Cancer Survivors (n=24)	Undiagnosed Women (n=32)
38016	0.0%	9.4%
38106	16.7%	15.6%
38107	0.0%	3.1%
38108	0.0%	3.1%
38109	29.2%	9.4%
38111	0.0%	6.3%
38112	0.0%	6.3%
38114	16.7%	3.1%
38116	12.5%	3.1%
38118	0.0%	3.1%
38119	0.0%	3.1%
38122	0.0%	3.1%
38125	0.0%	3.1%
38126	0.0%	9.4%

38127	16.7%	9.4%
38128	0.0%	6.3%
38141	0.0%	3.1%
38671	4.2%	0.0%
38672	4.2%	0.0%

Insurance Status	Breast Cancer Survivors (n=24)	Undiagnosed Women (n=32)
I don't have health insurance	4.2%	21.9%
Medicaid	20.8%	12.5%
Medicare	54.2%	21.9%
Military Healthcare	0.0%	0.0%
Private Insurance	37.5%	34.4%
Through my parents	0.0%	3.1%
Not sure	0.0%	12.5%

Ever Been Screened for Breast Cancer	Breast Cancer Survivors (n=24)	Undiagnosed Women (n=32)
Yes	N/A	90.6%
No	N/A	9.4%

Type of Breast Cancer Screening or Assessment	Breast Cancer Survivors (n=24)	Undiagnosed Women (n=32)
Clinical breast exam	N/A	28.1%
Mammogram	N/A	65.6%
3D Mammogram	N/A	9.4%
Breast self-exam	N/A	18.8%
Other	N/A	3.1%

Stage of Breast Cancer at Diagnosis	Breast Cancer Survivors (n=24)	Undiagnosed Women (n=32)
Stage 0	8.3%	N/A
Stage 1	29.2%	N/A
Stage 2	33.3%	N/A
Stage 3	16.7%	N/A
Stage 4	12.5%	N/A

Policy Data

This study involved a review of federal and state policies that affect health care access, cost and utilization, as well as policies most relevant to the breast cancer clinical continuum of care, including breast cancer screening, diagnosis and treatment. A searched key policy sources such as Kaiser Family Foundation, the Centers for Disease Control and Prevention (CDC) and the American Cancer Society to identify relevant federal policies was conducted.

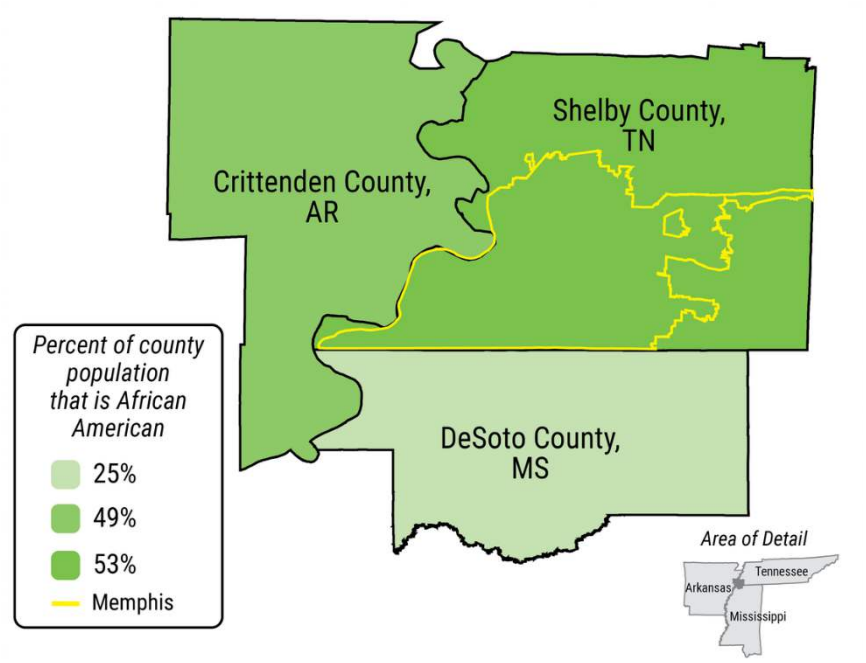
At the state level, the study examined whether the state had adopted an expanded Medicaid program, whether the state had adopted a Medicaid waiver (Section 1115 of the Social Security Act) that could restrict access to Medicaid and its services (e.g., work requirements), and any state rules related to the NBCCEDP (e.g., eligibility requirements) and the state Breast and Cervical Cancer Treatment Program (BCCTP). Additionally, the study examined state cancer plans to discern whether relevant actions or recommendations in the state cancer plan may impact breast cancer screening, detection and treatment. The main sources for this type of information included state department of health or state Medicaid resources (e.g., Medicaid eligibility, state NBCCEDP eligibility), and policy-focused organizations or think tank materials (e.g., Kaiser Family Foundation, state-level organizations).

Section 1 Findings: Burden of Breast Cancer

Section 1 describes the breast cancer disease burden in the Memphis MTA using secondary data, as well as relevant findings from the qualitative data.

Demographics

The Memphis MTA is characterized by a population that is predominantly Black in Crittenden County, Ark., and Shelby County, Tenn. DeSoto County, Miss. has the lowest percentage of Blacks (Map 1) MAP 1. Memphis metro area Black population



Source: American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)

TABLE 3 MEMPHIS METRO AREA DEMOGRAPHICS

Gender	
Male	48%
Female	52%
Age	
Under Age 18	26%
Age 18-64	62%
Over Age 65	12%
Race/Ethnicity	
White	44%
African-American	49%
Asian	2%
American Indian or Alaska Native	0%

Native Hawaiian or Other Pacific Islander	0%
Some Other Race	3%
Two or More Races	2%
Hispanic/Latino	6%
White not Hispanic	41%
Minority Race	56%
Number of African-American Women Over Age 45	107,552
Total Population	1,160,392

Source: American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)

The Memphis MTA is a tri-county region in the southeastern U.S. that is centered around Memphis, Tenn. The MTA spans three states—Arkansas, Mississippi, and Tennessee—and is home to 1.2 million people. Its population is 44 percent white and 49 percent Black (see Table 3–Memphis Metro Area Demographics).

TABLE 4 MEMPHIS METRO AREA COUNTY DEMOGRAPHICS

County	Total Population	Percent of Total Population That Is Female	Percent of Total Population That Is Black	Number of Black Women Over Age 45
Crittenden County, AR	49,278	53%	49%	4,268
DeSoto County, MS	173,267	52%	25%	6,959
Shelby County, TN	937,847	52%	53%	96,325

Source: American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)

More than 80 percent of all residents of the Memphis MTA (nearly 938,000 people) live in Shelby County, Tenn. (see Table 4 - county specific demographics). The other approximately 19 percent of the MTA's population resides in DeSoto County, Miss. and Crittenden County, Ark.). Refer to Table 4 (county specific demographics) for demographic information specific to each county within the MTA. The number of Black women over age 45 is noted for each county in the MTA because this Census-designated delineation best aligns with breast cancer metrics (e.g., percentage of women over age 40 who have received a screening mammogram in the last two years).

Breast Cancer Disease Burden in the Memphis MTA

Breast cancer disease burden in the Memphis MTA is highly dependent on two factors: where a person lives (e.g., the county in which they reside) and their race (e.g., whether they are Black or white). In the Memphis MTA, the likelihood of receiving a breast cancer diagnosis, the stage of diagnosis, and the likelihood of death from the disease vary along geographic and racial lines.

A helpful measure for breast cancer disease burden is prevalence, or the proportion of the population that has the disease at a given time. It is important to note that prevalence is measured in multiple ways depending on the time period of interest, and this report uses age-adjusted complete prevalence, which

represents the proportion of people alive on a certain day who have been diagnosed with breast cancer, regardless of when the diagnosis was made (National Cancer Institute, 2020). Prevalence statistics are only available at the state level. The three counties in the Memphis MTA are spread across three different states: Tennessee, Mississippi and Arkansas. In Tennessee, the complete prevalence age-adjusted percentage is 1.65. In Mississippi, the complete prevalence age-adjusted percentage is 1.54. Finally, in Arkansas the percentage is 1.46. In comparison, the national percentage is 1.69.

Breast cancer indicators for other measures are available at the county level. Tables 3 and 4 describe the breast cancer disease burden in the MTA. Data on breast cancer incidence rates, in situ incidence rates, late-stage incidence rates, and mortality rates are all expressed in terms of number of new cases, or number of deaths per 100,000 individuals per year. Screening mammography rates, shown in Table 9, are represented as the percentage of women over the age of 40 that have had a screening mammogram in the last two years. Some racially disaggregated rates are unavailable for Crittenden County, Ark., as too few Black women live in this county to calculate the rates.

TABLE 5. MEMPHIS METRO AREA BREAST CANCER INCIDENCE RATE (PER 100,000)

	Age-Adjusted Incidence Rate	5-Year Incidence Rate Trend Direction	Age-Adjusted Incidence Rate for White Women	5-Year Incidence Rate Trend Direction for White Women	Age-Adjusted Incidence Rate for Black Women	5-Year Incidence Rate Trend Direction for Black Women
Crittenden County, AR	97.9	stable	78.9	stable	104.8	stable
DeSoto County, MS	112.3	stable	113.4	falling	99.1	stable
Shelby County, TN	128.8	stable	128.7	falling	128.5	stable
Arkansas	125.1	stable	122.0	stable	133.5	stable
Mississippi	121.7	stable	116.5	stable	121.6	stable
Tennessee	123.2	stable	122.3	stable	123.2	stable
National	124.2	stable	126.1	stable	124.0	stable

Source: 2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)

Breast cancer incidence rates in the MTA range from 97.9 new cases per 100,000 individuals per year in Crittenden County, Ark., to 128.8 in Shelby County, Tenn. (See Table 5- Incidence). There are no significant trends among incidence rates for white women versus Black women, as the incidence rates are higher among white women in some places and higher among Black women in others. Among Black women, Shelby County reports the highest rate at 128.5. Shelby County is also the place with the

highest incidence rate among white women, at 128.7. The greatest disparity is reported in Crittenden County where the incidence rate is 78.9 for white women compared to 104.8 for Black women. Shelby County is the only county in the MTA whose rates are higher than state and national averages.

TABLE 6. MEMPHIS METRO AREA BREAST CANCER IN SITU INCIDENCE RATE (PER 100,000)

	Age-Adjusted In Situ Incidence Rate	5-Year In Situ Incidence Rate Trend Direction	Age-Adjusted In Situ Incidence Rate for White Women	5-Year In Situ Incidence Rate Trend Direction for White Women	Age-Adjusted In Situ Incidence Rate for Black Women	5-Year In Situ Incidence Rate Trend Direction for Black Women
Crittenden County, AR	26.4	stable	26.6	stable	28.8	*
DeSoto County, MS	26.1	stable	25.0	stable	33.1	stable
Shelby County, TN	31.4	stable	33.4	stable	30.1	stable
Arkansas	26.7	rising	25.9	stable	26.6	stable
Mississippi	24.7	rising	23.5	stable	27.3	rising
Tennessee	24.5	stable	24.2	stable	26.1	stable
National	28.3	stable	29.7	stable	31.8	stable

Source: 2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)

High rates of in situ breast cancer may indicate greater trend in incidence yet are more likely to be indicators that women are being screened in a timely fashion in order to catch this early pre-invasive stage of disease when it can be treated most successfully. In situ incidence rates among women for most counties across the MTA are higher compared to the state and national average: 26.7 for Arkansas, 24.7 for Mississippi, and 24.5 in Tennessee, and 28.3 nationally (See table 6 - in situ). Shelby County has the highest overall rate reported at 31.4 per 100,000. In two of the three counties, in situ incidence rates among Black women are higher rates than among white women (Crittenden County and DeSoto County). The disparity is greatest in DeSoto County, with the rate reported at 25.0 for white women and 33.1 for Black women.

TABLE 7. MEMPHIS METRO AREA LATE-STAGE BREAST CANCER INCIDENCE RATE (PER 100,000)

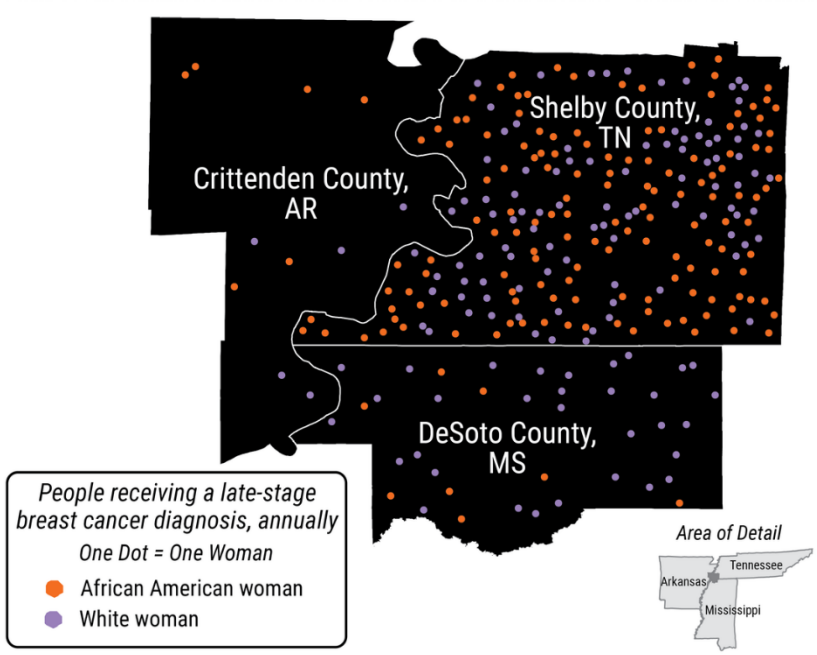
	Age-Adjusted Late-Stage Incidence Rate	Average Count of Cases That Are Late-Stage	Age-Adjusted Late-Stage Incidence Rate for White Women	Average Count of Cases That Are Late-Stage for White Women	Age-Adjusted Late-Stage Incidence Rate for Black Women	Average Count of Cases That Are Late-Stage for Black Women
Crittenden County, AR	42.2	11.0	41.3	5.0	44.0	6.0
DeSoto County, MS	44.5	39.0	48.5	31.0	34.6	8.0

Shelby County, TN	49.7	244.0	48.3	98.0	51.1	140.0
Arkansas	48.9	739.0	48.7	592.0	51.1	128.0
Mississippi	52.2	801.0	51.4	467.0	54.5	327.0
Tennessee	49.6	1662.0	50.1	1336.0	48.9	297.0
National	41.0	78641.0	41.4	62240.0	51.0	11590.0

Source: 2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)

The highest age-adjusted late-stage breast cancer incidence rate among all women is reported in Shelby County, TN (49.7) and the lowest rate is in Crittenden County, AR (42.2). Almost all rates (overall and racially disaggregated) are lower in the MTA than the corresponding state's average. The exception is Shelby County, TN, where the overall rate is on par with the state average of 49.6 and the rate reported for Black women (the highest in the MTA) is 51.1, compared with 48.9 for Black women overall in Tennessee (Table 7).

MAP 2. MEMPHIS METRO AREA LATE-STAGE BREAST CANCER CASES



Source: 2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)

Map 2 (late stage) shows the concentration of women who receive a late-stage breast cancer diagnosis annually. Shelby County has a high concentration of late-stage diagnoses, the majority of which are among Black women. DeSoto County, MS, has the second highest concentration, with most cases among white women, while Crittenden County, AR, has the lowest concentration, reflecting the region's population density.

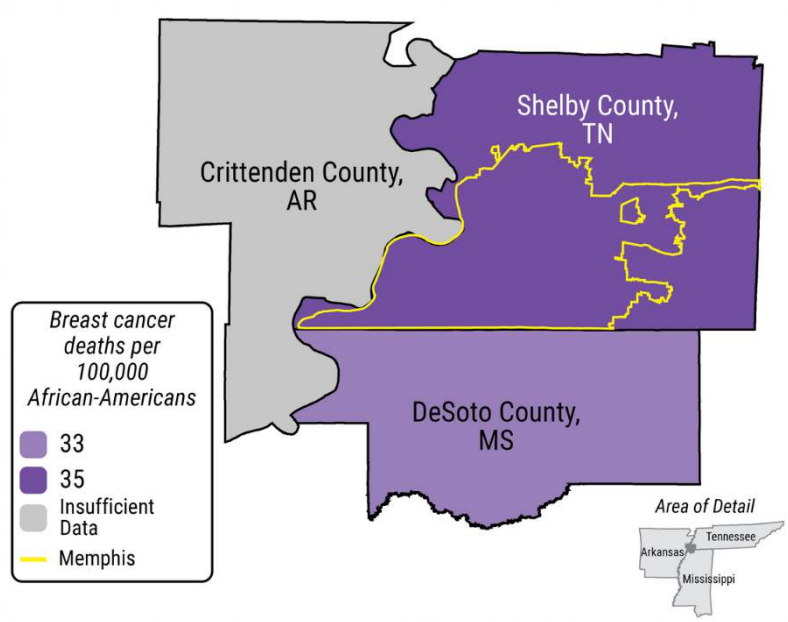
TABLE 8. MEMPHIS METRO AREA BREAST CANCER MORTALITY RATE (PER 100,000)

	Age-Adjusted Mortality Rate	5-Year Mortality Rate Trend Direction	Age-Adjusted Mortality Rate for White Women	5-Year Mortality Rate Trend Direction for White Women	Age-Adjusted Mortality Rate for Black Women	5-Year Mortality Rate Trend Direction for Black Women
Crittenden County, AR	22.4	stable	30.8	stable	*	*
DeSoto County, MS	22.3	stable	21.1	stable	32.7	*
Shelby County, TN	28.5	falling	23.3	falling	34.5	falling
Arkansas	21.6	falling	20.4	falling	29.7	falling
Mississippi	23.5	falling	19.6	falling	31.4	falling
Tennessee	22.1	falling	20.8	falling	30.4	falling
National	20.6	falling	20.1	falling	28.1	falling

Sources: 2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health); 2017 County Level Modeled Estimate Combining BRFSS and NHIS (US Centers for Disease Control and Prevention; State Cancer Profiles; National Institutes of Health)

The lowest mortality rates in the MTA are reported in DeSoto County at 22.3 deaths per 100,000 individuals overall, 21.1 for white women, and 32.7 for Black women. Data is unavailable for Black women in Crittenden County, AR. In both DeSoto County, MS and Shelby County, TN incidence rates for Black women are lower than or equivalent to those for white women. However, in both counties, mortality rates are higher for Black women compared to white women (21.1 white and 32.7 Black in DeSoto, 23.3 white and 34.5 Black in Shelby).

MAP 3. MEMPHIS METRO AREA BLACK BREAST CANCER MORTALITY RATES



Source: 2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)

As seen in Map 3 (breast cancer deaths among Blacks) and Table 8 (mortality rate), the number of Black breast cancer deaths is highest in Shelby County, TN, at 34.5 deaths per 100,000 Blacks, with DeSoto County, MS coming behind at 32.7 deaths per 100,000 Blacks. This is striking, given the relatively low breast cancer incidence rate among Blacks in DeSoto County (see Table 7-incidence) and the county's relatively high screening mammography rate (see Table 9-screening mammography).

TABLE 9. MEMPHIS METRO AREA SCREENING MAMMOGRAPHY RATES (AMONG ALL WOMEN OVER AGE 40)

	Percent of Women Getting Mammograms
Crittenden County, AR	59%
DeSoto County, MS	68%
Shelby County, TN	64%
Arkansas	71%
Mississippi	70%
Tennessee	74%
National	73%

Source: 2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)

The percentage of women receiving a screening mammogram varies from 59 percent in Crittenden County to 68 percent in DeSoto County. The rates across the metro are lower than the state and national averages (see Table 9 - screening mammography). Racially disaggregated screening mammography rates are not available at the county level. Crittenden County, however, has the lowest rate of women receiving mammograms, yet their mortality rate is 22.4, which is lower than that of Shelby County(28.5) (see Table 8 - mortality). This suggests that residents who are diagnosed in Crittenden County are more likely to survive breast cancer after receiving a screening mammogram than their counterparts in Shelby County.

Overall, a study of breast cancer disease burden measures suggest that in the Memphis MTA particularly in DeSoto County, MS, Black women are more likely to die from breast cancer than their white counterparts, even though they are more likely to receive a screening mammogram and are diagnosed with the disease at lower rates. This pattern has been noted in the literature. A study in South Carolina, for example, found that while the breast cancer incidence rate was higher for European-American or Caucasian women compared to Black women (124 versus 118.5 per 100,000 women), the breast cancer mortality rate was higher for Black women (29.8 versus 21.3 per 100,000 women) (Samson et al., 2016). The study further reported that Black women were even more likely to have had a screening mammogram or clinical breast exam compared to white women (81.9 percent of Blacks versus 74 percent of whites) and more likely to have late-stage breast cancer at the time of diagnosis (47 percent of Blacks versus 35 percent of whites).

Research has also explored additional trends in breast cancer and comorbidity outcomes. Tammemagi et al., for example, examined a cohort from a large health system in Detroit for 10 years (n=906, with 264 Black women and 642 white women) (Tammemagi, Nerenz, Neslund-Dudas, Feldkamp, & Nathanson, 2005). The authors found that Black breast cancer patients experienced more recurrence of their cancer, more cancer progression, and worse all-cause breast cancer and competing-causes survival. Compared to white women, Black women had shorter overall survival (Hazard Ratio=1.34, 95 percent CI: 1.11, 1.62). Taken together, these findings suggest effective control of comorbidities could improve life expectancy and decrease disparities in breast cancer survival.

Research from other parts of the country may shed light on why the observed patterns exist. Tammemagi et al, for example, examined a cohort from a large health system in Detroit, Michigan, for

10 years (n=906, with 264 Black women and 642 white women) (Tammemagi et al., 2005). The authors found that Black breast cancer patients experienced more recurrence of their cancer, more cancer progression, and worse all-cause breast cancer and competing-causes survival. Compared to white women, Black women had shorter overall survival (Hazard Ratio=1.34, 95% CI: 1.11, 1.62).

Community Member Perspectives across the Breast Cancer Care Continuum

This section summarizes perspectives from community members and health care providers collected through focus group discussions and interviews, which provide additional insights at each phase of the breast cancer continuum of care in the Memphis MTA. Based on a review of the quantitative findings, priority counties for qualitative data collection in the Memphis MTA were identified: Crittenden County, DeSoto County and Shelby County. DeSoto County and Shelby County have the highest breast cancer burden. Shelby County has the highest SDOH burden for Black women.

Screening

There are different screening guidelines for those at average risk and for those at higher risk. Recommendations for those at higher risk also vary from one organization or professional society to another. There is some inconsistency for screening recommendations among organizations for those at higher risk (Komen 2021a).

Screening Guidelines. Overall, community members were aware of the screening guidelines from the American Cancer Society indicating that mammograms begin at 40. There was a sentiment that the guidelines need to be different for Black women due to the perception that Black women have early-age onset of disease.

> *"They say you should get a baseline at 35, and start getting mammograms at 40, but, what about the younger women? Because where I work, that's who I see. I see women are getting diagnosed younger, and younger. They say if you have a family history, a first-degree relative, then you should maybe start early, but a lot of people don't know their family history, so how can you know to get somewhere early to detect it?" – Undiagnosed*

Screening access. Community members noted that free screening programs are widely available. However, there is a lack of awareness of the existence of these programs, this is especially true of young undiagnosed women. Free screening resources are not available where younger women congregate. Providers described their colleagues who are in private practice being unaware of where to refer uninsured patients for mammograms.

> *"The state of Tennessee provides funds for pap smears and mammograms. You have to live in Tennessee, and meet the income guidelines, but patients can receive free pap smears, mammograms, and follow-up diagnostic mammograms. Mississippi and Arkansas don't have this program." — Provider*

> *"There are a lot of resources out there. They have a lot of health fairs around the city and libraries and stuff, but you don't see a lot of youth getting the information. I guess*

> *the school system can help if you catch them early, maybe in junior high. Maybe by the time they graduate there they can start doing self-exams and talking to their doctor." – Undiagnosed*

> *"The health department will get you in touch with coordinators that can get you in screening programs. I work as one of those coordinators and it is a touchy situation for me, when I hear women don't have insurance, can't get their screening mammogram. I strictly enroll them in this program, so if you contact the health department, they can navigate you through the program." – Undiagnosed*

> *"I was in private practice in Memphis for 20 years before I started working here. If I had someone without insurance, I didn't know what to do with them. I didn't have a relationship with this TBCCEDP program. The program starts screening at age 50 and offers mammograms every two years up to age 75. Exceptions to that are if there is a strong family history, we will get a screening mammogram at a younger age. It's not like every doctor in Memphis can access this program for their patients. We have a contract with them. It's word of mouth. We've been here since 1987. But I'm sure there are plenty of people in Memphis who don't have insurance, who don't get their screening mammogram because they don't know about Church Health or, there's a couple of other clinics like the health department. When we have patients, who don't qualify for TBCCEDP we use the Susan G. Komen funding." — Provider*

> *"The Tennessee breast and cervical program is important because one-time Komen ran out of funding and they didn't know when they would get it back. Folks can just go to the breast and cervical program and get their screening mammogram. So, if one place run out of funding, it's okay, we still got other sources where you can get mammograms." — Undiagnosed*

Quality of Mammograms. While mammograms are readily available, a provider expressed concerns with the quality of these screenings at facilities in low income areas.

> *"One of the barriers that I find, at least in the screening population, is that we have a couple practices in town that are what I would consider probably subpar. They do not have the same quality for screening mammography that some of our other centers do. I feel like those are sometimes located... some of their outposts are located in our more impoverished areas. Some of the doctors in those areas preferentially send their patients to those places, so sometimes they're not getting maybe the quality imaging that they need. Which means either they're getting missed altogether as somebody who maybe should be seeing a surgeon either because they're high risk, or because of something on their imaging, or because they've got a new cancer, or they're still getting referred but now we're adding a layer of delay and cost because we're repeating that imaging because what they had in the beginning was not standard, or was not quality imaging not what you would want your care plan based on. And, that is also very difficult to explain to patients, especially if their doctor was the one that sent them there. I think that definitely affects our African American patients. That scenario I think*

> *disproportionately affects our African-American patients as opposed to our Caucasian patients." — Provider*

Self-examination. The majority of survivors described getting screened routinely but still identified the lump on their own.

> *"I was getting ready to get a new hairstyle; I just wanted a new look. I was lying in the bed and I was talking to the beautician, and I felt this lump. It was hard and I mean really hard. So, I jumped up and I told my husband, I said, "Feel this" he said, "Oh my gosh" and anyway long story short, I was at the doctor's office." – Survivor*

> *"I found my own. I was just laying down doing something. I found that it was the small lump, and I knew that it hadn't been there. So, I went and had it checked out at Baptist, and that's where I was going from my mammograms. And when they checked out, they found out it was malignant. I found it myself again, even after regular mammograms." – Survivor*

Diagnosis

Fear is a significant barrier. Providers noted fear is a major barrier within this phase of the breast cancer continuum of care.

> *"People are just afraid. The African American population has not been served well by the medical community. There is fear of loss of control, and all of that that goes along with getting a cancer diagnosis that is really prominent in the African American population." – Provider*

> *"My younger sister died from breast cancer. She was a nurse she went regularly to get a screening mammogram. She was our own medical advocate. But when she found a lump in her breast, she just panicked and would not go to the doctor. Nobody could encourage her to go, my mom, her husband, her children, none of us knew how to help." — Survivor*

> *"When they find that they got a diagnosis, they couldn't go around enjoying life, you almost want to give up. You don't have the strength or the power to fight. So, a lot of people don't want to be diagnosed." – Survivor*

> *"I think another thing in our community, a lot of older people say you just got to die of something one day. They say you got to die of something one day. And so, they just live and don't go to the doctor, and just let life progress. So, when they pass, they just pass..." – Undiagnosed*

Complicated diagnosis process. Navigating the diagnostic systems is challenging for patients.

> *"When it comes to the diagnostic tests, there are multiple tests, and each of them has a different insurance availability. We have pretty good screening rates, but the follow-up is the challenge. They just took off from work once, and now they have to do it again. Then they do an ultrasound, and now they need a biopsy. How do you fix that? It is just the nature of diagnosis." — Provider*

> *"I got diagnosed in December 2009 and in January 2010 and am still waiting on treatment because my primary care physician didn't take the time to sign off on stuff that was on her desk. When I contacted her the third time I said, "You know what? You found this, you are now my primary care physician, so you need to sign off so I can get my second opinion." That's the only way I get stuff moving because if I had to go wait on her, it'll probably have been sometime in April." - Survivor*

Treatment

Focus group participants characterized the transition from diagnosis to treatment as multifaceted and dynamic. Below is a description of the barriers and facilitators to breast cancer treatment as described by the Memphis MTA focus group participants.

Financial and Family Support. Providers emphasized the importance of having access to financial and caretaking support.

> *"What I was really struck with is how long people wait to begin treatment. In my first practice, if you had told someone they had cancer, they were scheduling their surgery the next week. Now, there are a lot of women waiting, three to four weeks, because they need to get things at their job organized before they can go ahead with their cancer operation. So, there's definitely a lot more economic pressure. I've had a number of patients who have gone into medical bankruptcy, and I've had one patient lose her home. I would say that's probably a bigger stressor in the African American community because of lower paying jobs and little to no to little medical savings. Also, I find African American patients delaying the operation because they have no time off work." – Provider*

> *"We did a retrospective chart review of our patients, and we have about 17,000 patient visits a year and we found 36 cases of breast cancer that had been diagnosed. Then we looked through the chart to see if they got the care that was appropriate for them. Out of 36 patients, nine of them did not get the care that was indicated. All nine were Black. One of them was just lost to follow-up. She just disappeared. We couldn't find her, didn't respond to any calls, letters, she just disappeared. The other eight you could see the conversation with the patient and the provider documented the chart. The reasons they didn't follow-through with treatment were social reasons. They couldn't take off work. Their family needs them. I can't be sick. So that taught me that it's not just about mammograms they are mean important, but that's not the only issue. In the Black community women are often the providers. The women are making the money and*

> *supporting the family. So, I think it's fear of what my family is going to do if I take off for four months? Who's going to pay the bills?" — Provider*

> *"I see women who do well with the treatment who have family support. Just like any other chronic devastating illness, you gotta have family support. There should be a marker for those who have a family person that is committed to their well-being because I bet that's an independent indicator of survival." — Provider*

> *"If you're a single mother, or if you're married, and you got children, and you're trying to survive the day, and you don't take the time out to take care of yourself, because you're a nurturer, and you're taking care of everyone else in your life. If you have elderly parents, you're taking care of them. You're taking care of your husband, boyfriend, your children, your grandkids. It's a lifestyle, and by the end of the day, you are so exhausted, that you haven't had the time to write, exercise, relax, meditate, or take a bath." — Undiagnosed*
>
> *"I find that many African-American women have had children a lot younger, so that actually sometimes can be good and bad, like sometimes I'll have a 40-year-old woman, and I'll ask her about childcare impacting her health decision, but her kids are grown. There's a chance that someone will be 50 and her kids are all in their twenties, so she doesn't have the impact, whereas other women who are 50 might still have a child in the house." —Provider*

Impact of Faith on Treatment. Women's religious faith was a significant factor in women's decisions not to access treatment. Additionally, many survivors characterized a positive and quality experience with a provider as one that integrated their faith.

> *"I have heard African American women with breast cancer say they are going to do holistic approaches and that God can heal them. They won't go to the doctors at all. I know a lady that needed surgery and said, "They are not gonna cut on me. I'm a woman of faith.". – Undiagnosed*

> *"My friend's mom passed away from cancer. She said that her prayer warriors were going to pray for her and pray it away. She wouldn't take the medication and it turned to stage 4 cancer. It was very hard on her family because she was sick, and she really didn't tell them, until it got really bad. They didn't have time to process her passing." – Undiagnosed*

> *"In the south, I've noticed that from all my patients living here. I do think that faith helps ground people and takes away fear. Many of my patients will listen to my*

> *recommendations, but they also look me in the eye, and say it's all in God's hands." - Provider*

> *"I do think culturally there tends to be in the African American community a little more denial and a bigger tendency to think that God's going to heal them. Some may think this is not really happening because I'm a good person." - Provider*

> *"I went to West Clinic and loved my provider. What really stood out with me is she chatted with me and asked, "Do you believe in prayer?" I said, "I sure do." She said, "Let's pray." I was sold. She could do whatever. I was good to go." - Survivor*

> *"I was just sitting there and I'm shaking, I'm nervous, I'm just terrified because I didn't know what was going on. My oncologist says to me, "Do you know God?" I said, "Yes sir. I know God." He said, "I know God, you're going to be alright." And I'm still going to this same man. He was just a good doctor." - Survivor*

Insurance barriers. Community members noted limited provider options for those who are uninsured and those with insurance find deductibles unaffordable. There are limited health system options that complicate access to care. There were numerous accounts of deductibles being too high and women foregoing care for financial reasons, including needing to organize life and work before moving forward with treatment.

> *"I had a patient who was diagnosed with breast cancer last year. She's African American in her fifties and she has adult children that depend on her. She has a child who's an alcoholic and has had drug issues. She is the only one who makes money in the family. She's still paying her breast cancer bill. This year she got diagnosed with contralateral cancer. She started crying, she was like, "I'm still paying for last year. So, like, how am I going to keep paying this?" She is employed and has commercial insurance. So, all of us are like, "Oh, well, you're insured. You have a job; you have an insurance plan." But, I mean, how wonderful is all of our commercial insurance if your deductible is $3,000 and you're only making minimum wage?" – Provider*

> *"A lot of times, I think when you go to the free clinic and places like that, they treat you differently because you don't have insurance. There is a big difference in how they will treat you if you are insured versus uninsured." – Undiagnosed*

> *"I definitely sometimes have people who ask me like, "Well, what's going to be cheaper," or, "What is this going to cost me?" I think one of the other things that's a little bit unique about Memphis maybe than some of the other markets I've lived in, is that some of the commercial insurers in town are wedded to one system or the other. People sometimes go back and forth, which I think is difficult because if your insurance changes*

> *through your employer. One year you're getting your screening mammogram in one place, the next year you're getting it at another place, so people don't always have that same continuity." - Provider*

> *"After I had my surgery, I was supposed to go back in. I was still in a lot of pain. And so, they scheduled my appointment. This white nurse called me and told me if I'm not bringing in $360, I could not come in." – Survivor*

> *"They want to know what kind of insurance you have, that's the first thing they'll ask. They're not concerned about your condition or anything like that. "What type of insurance you have?" Just recently I was supposed to get radiation. The doctor said they had to check with my insurance to see what is covered. So, I guess I was supposed to die or something if I don't have insurance to cover it." - Survivor*

> *"I can just imagine if you don't have insurance it'd be harder for you to get in to see the doctor or get treatment in a timely manner. There are times when you have insurance, the copay for some medicine is hard. So, trying to think of somebody without insurance trying to pay for their medication." - Survivor*

> *"I went for a scheduled appointment with my private doctor. I was asked for my deductible which I didn't have and was told "You cannot see the doctor unless you pay your deductible, $185." She was very rude and wouldn't let me in. and asked if I could pay $60 and I don't have that either. Then she asked how much I could pay, and I said, "$1." They asked that I make a new appointment. I said, "Why should I make another appointment, I'm already here. I've got things to do, too. My time is valuable, too."- Undiagnosed*

> *"The first question, before I even saw the doctor was insurance status. I filled out my papers and was sitting there waiting and a lady called me into the office from the insurance department. She talked about the type of insurance and my possible copayment and I'm sitting here going, "Are you for real?" I didn't even get to see that doctor because we just left. My son is a doctor, so he communicated with them. He was really angry and handled them." - Survivor*

Personally mediated racism. Survivors and undiagnosed women all noted that historic distrust of the health care system, family and personal experiences of implicit bias, racism and discrimination rather than empathy in everyday life generally and in the health care system impact quality of care and retention in treatment for Black women.

> *"When I was diagnosed with breast cancer, we decided (my family) that we would look into one of the doctors from the facility I had retired from. The first one that I went to was with a research program that was doing research for African American women with breast cancer. But the doctor's attitude when I went for the first appointment wasn't pleasant. He more or less went through everything, he talked with me, but he was kind of dismissive. The second meeting, I took my husband and my daughter with me because I was feeling uncomfortable. The doctor said that he had spoken with me in detail about my options and that the decision would be mine, but he recommended breast removal, but was not sure that is accepted in "y'all's culture." That's the term he used. By this time, my husband and my daughter, both were kind of feeling what I had already felt. Then the doctor says, "Well, I'm getting ready to go out on vacation. I'm gonna leave the information here. Y'all talk about it. If you decide what you want to do, you can call back to the office to set an appointment." My husband was really upset, we pushed him on out the door. But that really bothered me." - Survivor*

The relationship between social support and proactively seeking health care has been established in the literature. A study conducted in Dallas-Fort Worth examined how perceived neighborhood social capital (e.g., social cohesion and how "tight-knit" a neighborhood appears to be) relates to screening mammography use among Black women. The authors based their inquiry on the premise that "social relationships create a form of capital that can affect health" (Dean et al., 2014). They found that individuals' perceptions of high social capital in a neighborhood had statistically significant and positive associations with Black women's screening mammography usage in the past year. Specifically, each unit increase in a woman's perception of her neighborhood's collective efficacy was associated with a 40 percent higher likelihood of receiving a screening mammogram in the previous year (OR=1.40, CI: 1.05, 1.85) (Dean et al., 2014). The authors hypothesize that 1) living in tight-knit community may increase the chance that a woman will hear health information from neighbors and social connections, 2) living in a neighborhood with high social capital and collective efficacy may also indicate that the community may have greater access to health resources like mammograms, and that 3) in addition to access to services, a "positive community of support" could positively influence Black women's use of mammograms (Dean et al., 2014).

Quality of Care. Survivors correlated quality of care to being insured and where you accessed care. How much information a provider shared was also a determinant of how the survivors perceived the quality of care.

> *"I would have a different PCP very often. One of the things about why some of the clinics that you go to and some areas, if it's a learning facility then your providers change. I know it's three months, so I knew every July from July to July. It's a whole new group. So, you may or may not see the same person. But if you just do it and then the students are the nurse practitioners and all of them are in that learning phase. They're in rotation and they rotate through, which is how I got to even know a lot of people because I see it, they rotate it through. Care continuity is an issue, especially if you're in these learning facilities." - Survivor*

> *"I was in the midst of some doctors talking about this Tamoxifen, and this doctor said that they know that Tamoxifen can lead to ovarian and cervical cancer, but they're not*

> *concerned about the long-term effects of it. They're only concerned about how it can help you right then." - Survivor*

> *"Memphis is still racially segregated, and most African-American communities are in South Memphis where there's very little access to healthcare. My practice is in East Memphis and is a drive to get here, so it's not as convenient. Then West Memphis, Crittenden County, there's nothing there. Baptist right now is building a hospital, so hopefully that will improve, there is going to be some new facilities, but West Memphis, Crittenden County right now does not have a radiation facility, so that is a big burden for patients who live there."- Provider*

Survivorship

Survivor Support Resources. Survivors and providers noted the critical role that support resources play along the breast cancer continuum of care. Community members reported that they were connected to survivor groups that met their educational and spiritual needs.

> *"My pastor at my church immediately referred me to join a support group. He said, "I need you to go and join a support group because you're going to be around people that share the same thing that you have and you'll be able to open up and talk." - Survivor*

> *"After I'd gone through everything, I felt like I needed support. I needed to hear other women talk about their journeys and stuff like that. They were talking about stuff, I didn't know what those ladies was talking about, and I brought my pencil and pad, they educated me. I have my own support group that is more faith based, but I learned so much from those ladies." - Survivor*

Racism is Daily Life

Survivors and undiagnosed women shared personal experience of implicit bias and discrimination in their lived experiences.

> *"I retired from FedEx and I had a manager that discriminated against me. And we clashed all the time because he did not respect me as a person and he had a Caucasian employee that tried to run over me, and I wouldn't allow it. We had this conversation about how he was prejudice toward me. He would call me in this office, and he would try to talk down to me, which I did not allow. I got tired of it. I wrote a letter to the director in my department and then went all the way up and I said, I'm being discriminated against. And when you say you're discriminated against at FedEx, that's a red flag. They removed him from the department because they questioned other employees and they found out that he was doing all these things to me, and some of them they thought they'd be retaliated against. It put a lot of stress on me really. But my, my mother and father, my mother mostly say, "If you feel you're right, you don't back down and you don't let anybody talk down to you berate at any time. And I never have, and I never will." – Survivor*

> *“I remember, it's like an experience that's always stuck with me. I remember when I was about eight or nine years old, I've always been a chubby child. I've had different opinions from pediatricians; some of them were like, "Oh, it's not that big of a deal" and others made a big deal about it. One time my pediatrician recommended or referred me to a specialist, probably was an endocrinologist or something. He was an old white guy with glasses. He had a really bad attitude and was really mean. I remember I was there with my mom and she had my baby sister. The doctor came in there so quickly. You could tell he didn't want to be there. He was like huffing and puffing and had an attitude and instead of giving me any kind of meaningful advice about my weight, he just was like "Oh, well you just need to make better choices." He was talking so mean to my mom and said, “you need to be feeding her better, see what's there in that sippy cup?” My mom said, " It's Kool-Aid” and he was like, "See, that's bad. You need to stop doing that." He was awful and I just remember how he treated us.” - Undiagnosed*

> *“I think being an African American is very stressful, here in America. Watching the news is stressful. This jail in Mississippi, 13, 14 black men come up dead. Anything your mind and eyes see is recorded, so all that affects your body, and your body gives off hormones that can help you get breast cancer. It's a stressful world.” - Undiagnosed*

> *“There's just one thing, when you're in the medical field and you're the caretaker or you get called on the N word. I just smile and kept moving. I had this one man, and every time I would go in his room, "Here comes the N word. IT didn't affect me because I know who I am, and I know what I had to do eventually I won him over.” - Survivor*

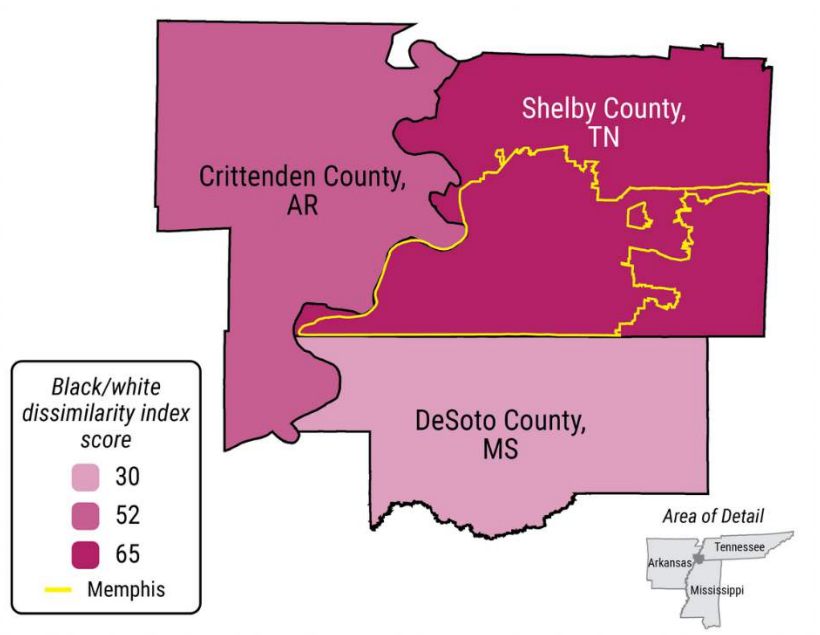
Section 2 Findings: Systemic and Social Determinants of Health

Section 2 explores the systemic and SDOH that may drive breast cancer inequities. The set of factors explored in this section—residential segregation, economic vulnerability, experiences of racism, SDOH—were informed by consultations with Komen's AAHEI team, academic experts (see Acknowledgements for details), findings from the literature scan and principles in the guiding frameworks.

Residential Segregation

The Memphis MTA is segregated along racial and socioeconomic lines, creating stark contrasts by geography. Approximately 650,000 people of color live in the Memphis MTA, comprising 56 percent of the region's total population (see "Minority Race" in Table 3). Shelby County, Tenn., has the highest percentage (53 percent) of Black residents. Crittenden County, Ark., has a population that is 49 percentBlack and DeSoto County, Miss., has a population that is 25 percent Black (see Map 1).

MAP 4. MEMPHIS METRO AREA RESIDENTIAL SEGREGATION

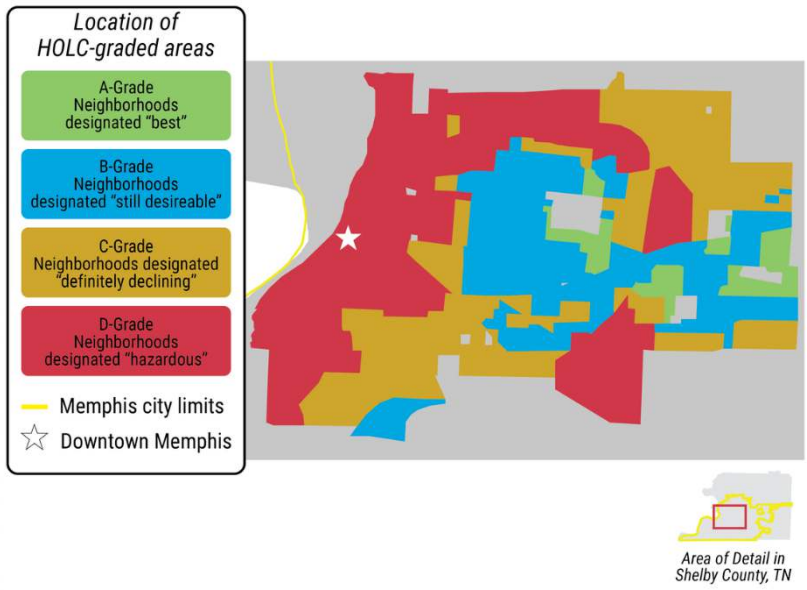


Source: 2019 County Health Rankings (County Health Rankings)

In addition to the MTA as a whole being racially segregated (with most people of color living in Shelby County and DeSoto County see Table 4- County Demos), the counties in the MTA are also internally racially segregated. Counties' internal segregation can be measured using the Black/white dissimilarity index to assess the extent to which there may be residential segregation (see Map 4- residential segregation). Index scores range from 0 to 100 and correspond to the percentage of people within a racial group who would need to relocate in order for a county to achieve integration. Zero indicates complete integration of the two races and one hundred indicates complete segregation of the two races. For example, a score of 35 means that 35 percent of whites within a particular county would need to move to a different neighborhood within the county in order to achieve racial integration.

As seen in Map 4, Shelby County has the highest score (65), indicating that it is the most segregated place in the MTA. Crittenden County, has the next highest score at 52, and DeSoto County has the lowest at 30.

The patterns of residential segregation that are visible today across the Memphis MTA are the direct result of systemic racism. As defined and discussed at the beginning of this report, racism occurs across three levels: institutionalized or structural (differential access to goods, opportunities, and power), personally mediated (prejudice about others' abilities and motives) and internalized (self-devaluation based upon race). Although measures of racism are limited, some quantitative data that can serve as a proxy for racism are available for the Memphis MTA.



Source: 2019 Mapping Inequality Project (University of Richmond)

MAP 5. MEMPHIS METRO AREA REDLINING

An example of institutionalized racism is redlining – the practice of identifying and systematically discriminating against neighborhoods based on their racial makeup. Between 1933 and 1954, Home Owners' Loan Corporation (HOLC) field agents with the federal government assigned grades to neighborhoods ranging from A to D, best to hazardous respectively. The practice is commonly called redlining because designated hazardous areas assigned a D grade were marked in red. Banks and other mortgage lenders used these grades to inform their lending practices and policies. Map 5 shows areas that were included in the "residential security" maps created by HOLC agents in the first half of the twentieth century. Portions of Shelby Countyappear on the map of the city of Memphis, produced sometime in the 1930s.

Officials declared large sections of Shelby County "hazardous" because Blacks lived in these neighborhoods. In so doing, the government excluded these individuals and communities from investment and resources. Areas of advantage (where whites lived) became more advantaged and areas of disadvantage (where people of color lived) became more disadvantaged (Rothstein, 2017). Redlining set up feedback loops, as the more advantaged white population moved into white areas, thereby making them even more advantaged and whiter. For this reason, the high level of segregation that currently exists between Blacks and whites in Shelby County (see racial segregation section above) can be traced – at least in part – to redlining.

Personally Mediated Racism

Data suggest that in addition to institutionalized racism, Blacks in the MTA experience several forms of personally mediated racism (U.S. Department of Housing and Urban Development, 2019; U.S. Department of Justice Federal Bureau of Investigation, 2017).

As seen in Table 10-racism, Shelby County appears to experience the highest level of racism when compared to the other counties in the MTA. Between 2013-2017, five Blacks were killed by the police in Shelby County (See table 10 - racism). Further, in Shelby County there were eight hate crimes committed with a racial bias motivation and 132 Fair Housing Act cases filed with a racial basis. No other counties in the MTA come close to reporting the same levels of personally mediated racism.

TABLE 10. MEMPHIS METRO AREA RACISM

County	Number of Blacks Killed by Police	Number of Hate Crimes Committed with a Race/Ethnicity/ Ancestry Bias Motivation	Number of Fair Housing Act Cases Filed with a Race Basis
Crittenden County, AR	0	0	8
DeSoto County, MS	1	0	15
Shelby County, TN	5	8	132

Source: 2017 Hate Crime Statistics (Federal Bureau of Investigation, Uniform Crime Reporting); Fair Housing Act Cases, 2009-2019 dataset (US Department of Housing and Urban Development, Office of Fair Housing and Equal Opportunity); The Counted Database, 2015-2016 dataset (The Guardian)

Other Health Measures and Disparities

TABLE 11. MEMPHIS METRO AREA LIFE EXPECTANCY

County	Life Expectancy	Life Expectancy for Whites	Life Expectancy for Blacks
Crittenden County, AR	73	75	72
DeSoto County, MS	77	76	79
Shelby County, TN	76	78	74

Source: 2019 County Health Rankings (County Health Rankings)

Overall life expectancy in the Memphis MTA is lowest in Crittenden County, at 73 years (Table 11 - life expectancy). Notably, the life expectancy in Crittenden County is higher for white people (75 years) than it is for Blacks (72 years). This trend also holds in Shelby County where whites live on average to age 78, whereas Blacks live to age 74. This gap of four years represents the greatest racial disparity in the MTA. The highest overall life expectancy (not disaggregated by race) is in DeSoto County, at 77 years. DeSoto County is also the only county in the MTA where the life expectancy for Blacks (79 years) is higher than for whites (76 years).

Data suggest that there are disparities in the Memphis MTA in terms of overall health and wellbeing. In Crittenden County, 1 in 4 adults report that their health is “fair” or “poor” (Table 12 - health and wellbeing). In DeSoto County, MS, on the other hand, only 16 percent of adults report that they have “fair” or “poor” health. All places in the MTA report that their residents have between 3.4 and 5.0 poor physical health days per month, with DeSoto County, reporting the fewest days and Crittenden County reporting the most days. In terms of mental health, residents of DeSoto County report the fewest number of poor mental health days per month (3.9 days). Residents of Crittenden County report an average of 5.0 poor mental health days every month, the most in the MTA.

TABLE 12. MEMPHIS METRO AREA HEALTH AND WELLBEING

County	County Health Rankings Percentile	Percent of Adults Reporting "Fair" or "Poor" Health	Average Number of Poor Physical Health Days per Month	Average Number of Poor Mental Health Days per Month
Crittenden County, AR	92%	25%	5.0	5.0
DeSoto County, MS	4%	16%	3.4	3.9
Shelby County, TN	57%	20%	4.4	4.5

Source: 2019 County Health Rankings (County Health Rankings)

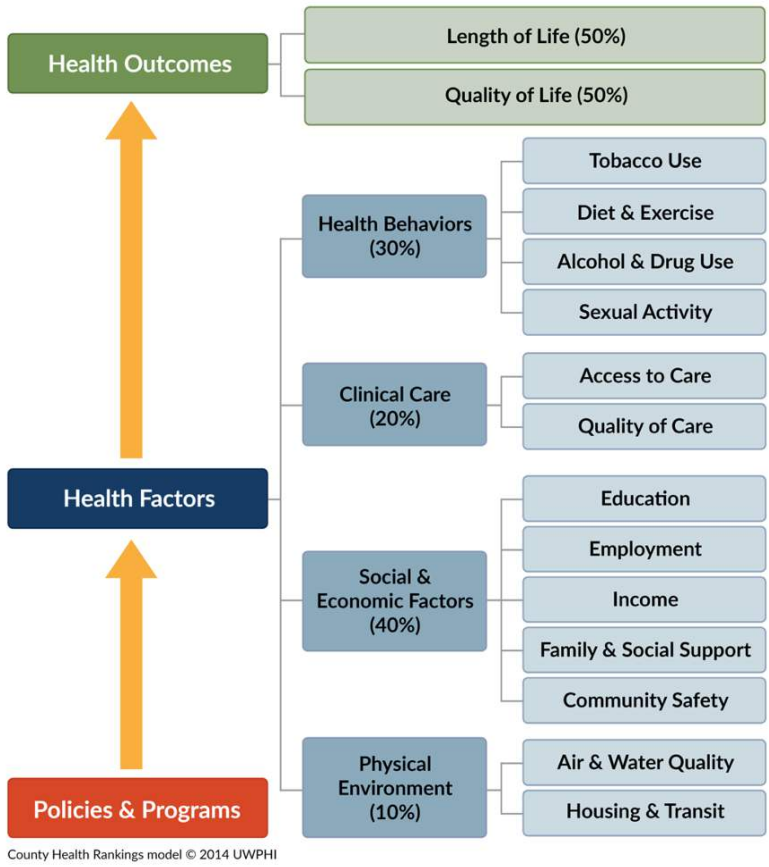


FIGURE 2. COUNTY HEALTH RANKINGS MODEL

The County Health Rankings (CHR) similarly highlight county-level differences in health and wellbeing across the Memphis MTA. CHR are derived from over 30 measures of health-related outcomes and factors to give an overall health ranking of a county compared to other counties in the same state (See Figure 2). DeSoto County, MS, ranks in the top 4 percent of all Mississippi counties. Crittenden County, AR, however, has poorer health outcomes than most of the counties in the state of Arkansas.

TABLE 13. MEMPHIS METRO AREA: AGE-ADJUSTED PREMATURE MORTALITY RATE (PER 100,000)

County	Premature Age-Adjusted Mortality	Premature Age-Adjusted Mortality for Whites	Premature Age-Adjusted Mortality for Blacks
Crittenden County, AR	588	551	644
DeSoto County, MS	398	428	352
Shelby County, TN	465	374	572

Source: 2019 County Health Rankings (County Health Rankings)

Premature age-adjusted mortality measures the number of deaths per 100,000 among people under age 75. Crittenden County, AR, has the highest premature age-adjusted mortality rate, at 588 (Table 13 - age-adjusted premature mortality). The rate is lowest in DeSoto County, MS, at 398, and DeSoto County

is also the only county in the MTA where the premature age-adjusted mortality rate is higher for whites (428) than for Blacks (352). The greatest racial disparity is in Shelby County, TN, where the rate is 374 for whites compared to 572 for Blacks.

Crittenden County, AR, has the highest rate of obesity in the Memphis MTA, with 41 percent of adults who are obese and 37 percent of adults who are physically inactive (Table 14 - health behaviors). DeSoto County, MS, has the highest rate of excessive drinking, with an estimated 16percent of its population engaging in excessive drinking. DeSoto County otherwise has the lowest rate of obesity (32 percent) and Shelby County, TN, has the lowest rate of physical inactivity (24 percent).

TABLE 14. MEMPHIS METRO AREA HEALTH BEHAVIORS

County	Percent of Adults Who Are Obese	Percent of Adults Who Drink Excessively	Percent of Adults Who Are Physically Inactive
Crittenden County, AR	41%	13%	37%
DeSoto County, MS	32%	16%	30%
Shelby County, TN	35%	13%	24%

Source: 2019 County Health Rankings (County Health Rankings)

Access to Health Services

Data suggest that there are significant disparities in the health system in the Memphis MTA, including in health care facilities and the proportion of the population that is medically underserved. According to the Health Resources and Services Administration (HRSA), Medically Underserved Areas/Populations are areas or populations designated by HRSA as having too few primary care providers, high infant mortality, high poverty or a high elderly population. In both Crittenden County, AR, and DeSoto County, MS, 100 percent of the population is medically underserved (Table 15 -- health systems). Approximately 30 percent of the population in Shelby County, TN, is designated as medically underserved, but this smaller percentage represents many more people because Shelby County's base population is much larger than the other two counties (see Table 4- County Demographics).

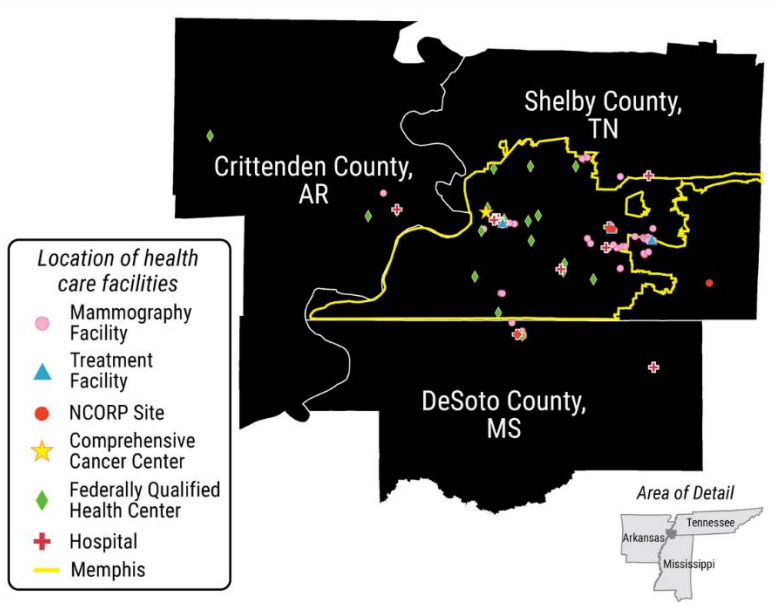
TABLE 15. MEMPHIS METRO AREA HEALTH SYSTEMS

County	Percent of Total Population That Is Medically Underserved	Number of PCPs	Persons per PCP	Number of "Other" PCPs	Persons per "Other" PCP	Number of Private PCPs	Number of Private Oncologists
Crittenden County, AR	100%	18	2,735	80	1,250	0	8

DeSoto County, MS	100%	62	2,832	57	1,770	0	9
Shelby County, TN	30%	780	1,198	122	820	214	8

Sources: 2019 County Health Rankings (County Health Rankings); HRSA Data Warehouse, 2019 dataset (US Department of Health and Human Services, Health Resources & Services Administration); 2019 Docstop web search; 2019 Healthgrades web search

MAP 6. HEALTH SYSTEMS IN THE MEMPHIS METRO AREA



The health systems map (Map 6) shows the concentration of health care facilities across the Memphis MTA. Most resources are centered within the boundaries of Memphis within Shelby County, TN, including the only comprehensive cancer center in the MTA. Crittenden County, AR, and DeSoto County, MS, have few hospitals, Federally Qualified Health Centers (FQHCs) and screening mammography facilities.

Source: HRSA Data Warehouse, 2019 dataset (US Department of Health and Human Services, Health Resources & Services Administration); Comprehensive Cancer Centers and NCI National Community Oncology Research Program (NCORP) sites, 2019 dataset (National Cancer Institute); Mammography facilities, 2019 dataset (American College of Radiology); Treatment facilities, 2019 dataset (American College of Surgeons; Association of Community Cancer Centers)

TABLE 16. MEMPHIS METRO AREA BREAST CANCER RESOURCES

County	Number of Mobile Screening mammography Centers	Number of Cancer Coalitions	Number of Survivor/ Support Groups
Crittenden	2	1	2

County, AR			
DeSoto County, MS	1	0	1
Shelby County, TN	1	1	19

Sources: 2015 Affiliate Profile Files (Komen); 2019 Google search

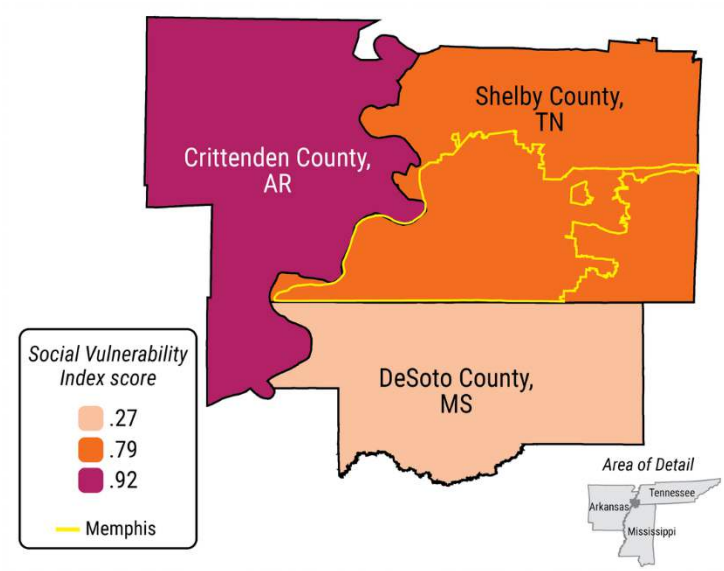
As with health care facilities, most breast cancer resources are concentrated in Shelby County, TN, which has one mobile screening mammography center, one cancer coalition, and 19 survivor/support groups. Crittenden County, AR has the next highest at two mobile screening mammography centers, two survivor/support groups and one cancer coalition. DeSoto County, MS has the fewest resources with only one mobile screening mammography center and one survivor/support group.

It is important to note that the counties in which people reside are not necessarily the same as the counties in which people receive care. Due to migratory patterns, including where residents are employed and how far they are willing to travel to receive quality care, people may travel to other counties to access health services.

Social and Economic Vulnerability

Social determinants affect health outcomes – such as breast cancer – for individuals and communities. These play out not just across individual lifetimes, but generationally. Disadvantages compound in certain communities, which exacerbates and cements a wide range of negative outcomes and existing burdens, including with regard to health (Cozier et al., 2009; Institute of Medicine of the National Academies, 2011). The Social Vulnerability Index (SVI) of each county can be seen in (Map 7). The SVI is calculated by the CDC, and a county's score "refers to the resilience of communities when confronted by external stresses on human health, stresses such as natural or human-caused disasters, or disease outbreaks" (e.g., such as hurricanes, fires, and COVID-19). Scores range from 0.0 to 1.0, with scores closer to 1.0 indicating greater vulnerability. Crittenden County, AR, has the highest SVI score at 0.92, with Shelby County, TN, coming in second at 0.79. DeSoto County, MS, has the lowest SVI score, at 0.27. Individual factors influencing a county's SVI score can be parsed by looking at specific indicators.

MAP 7. MEMPHIS METRO AREA SOCIAL VULNERABILITY



All focus group participants noted how Black women are vulnerable due to poverty and demanding gender roles. This commentary aligned with research in the field. For example, in focus groups with Black women conducted by Yan et al., focus group participants expressed the competing demands of being the head of household and primary caregiver for children and/or elders versus their own care and treatment needs for breast cancer (Yan et al., 2019). Other literature on competing demands also aligns with sentiments expressed in the focus groups. For example, Nonzee et al. described that women may delay or postpone care due to childcare or scheduling conflicts, fear of lost wages from taking time off work for medical appointments, and responsibility for elderly caregiving (Nonzee et al., 2015).

> *" African American women are holding down the family. A lot of single women are in the mother and the father position. It is a lot of stress on them, trying to take care of the children, working, and paying your bills, and not having enough money. When you see more white women are married, and their husbands have jobs, and they have two incomes. Black women over here are struggling. You're struggling to get your child through school, then you struggle to get them through high school, then you get them out of high school, then they go to college. It was just a hard struggle." - Undiagnosed*
>
> *"In general, I would say a lot of people have lower income jobs, but a lot of women will have low-income jobs like warehouse jobs. Many of them are hired without benefits or are shift workers, so if they don't come to work, they lose their job. For many of my patients, it's difficult for them to miss the work to get the screening mammogram, miss the work to get the appointment." - Provider*

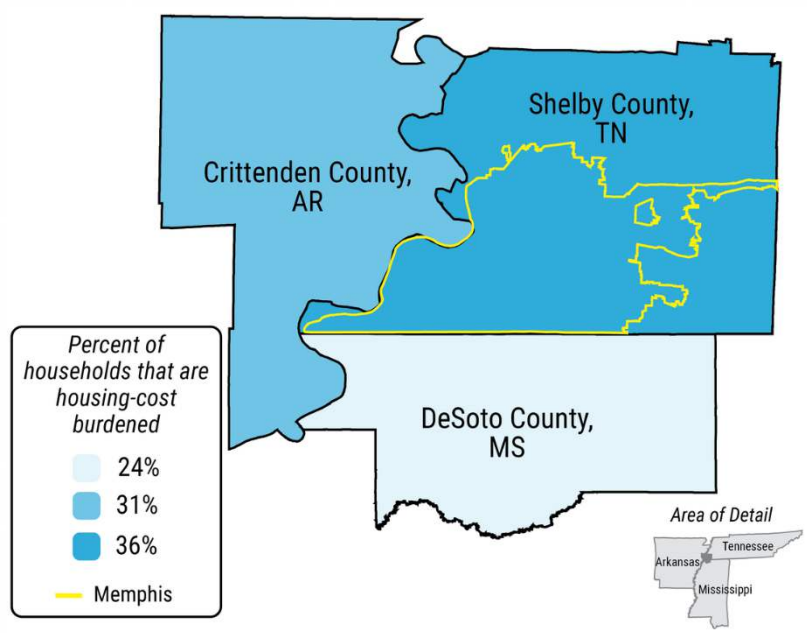
Crittenden County, AR reports the highest percentage of the population below 200 percent of the Federal Poverty Line (FPL) in the MTA, at 48 percent, which is about 24,000 people (Table 17 - economic security). Crittenden County, AR also has the highest percentage of Black women over age 45 who live below the FPL, at 23 percent. Crittenden County, AR has 11 percent of the population that is uninsured, which is higher than DeSoto County, MS (where the uninsured rate is 10 percent), but lower than Shelby County, TN (where the uninsured rate is 13 percent). DeSoto County, MS has relatively higher economic security than the other two counties in the MTA. In the county, 26 percent of the population falls below the federal poverty line, and 11 percent of Black women over age 45 live below the FPL (see Table 3 - demographics).

TABLE 17. MEMPHIS METRO AREA ECONOMIC SECURITY

County	Percent of Population That Is Uninsured	Percent of Population Below 200% FPL	Percent of Black Women Over Age 45 Who Live Below Poverty Level
Crittenden County, AR	11%	48%	23%
DeSoto County, MS	10%	26%	11%
Shelby County, TN	13%	41%	19%

Source: American Community Survey 2013-2017 5-Year Estimates (US Census Bureau):

MAP 8. MEMPHIS METRO AREA HOUSING-COST BURDEN



Source: 2016 Comprehensive Housing Affordability Strategy dataset (US Department of Housing and Urban Development)

The measure illustrated in Map 8 (housing-cost burden) indicates the percentage of renters and homeowners that spend 30 percent or more of their total income on housing. Shelby County, TN, has the highest percentage of households that are housing-cost burden in the MTA at 36 percent. Crittenden County, AR, and DeSoto County, MS, report 31 percent and 24 percent of households as housing-cost burdened, respectively.

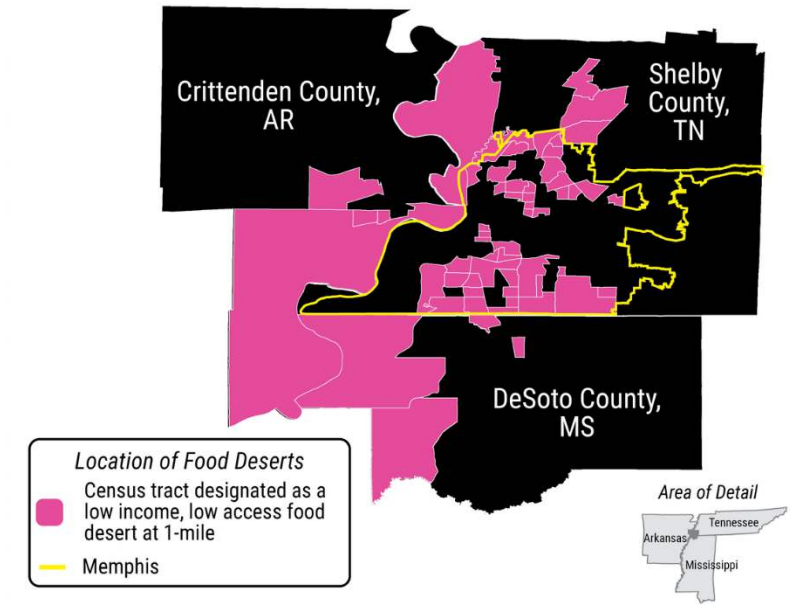
TABLE 18. MEMPHIS METRO AREA FOOD SECURITY

County	Percent of Population That Is Food Insecure	Percent of Total Population with Limited Access to Healthy Foods	Percent of Black Households Receiving SNAP/EBT
Crittenden County, AR	25%	5%	33%
DeSoto County, MS	13%	9%	17%
Shelby County, TN	21%	11%	30%

Source: 2019 County Health Rankings (County Health Rankings); American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)

With regard to food security in the Memphis MTA, Crittenden County, AR, has the highest percent of Black households receiving SNAP/EBT at 33 percent and the highest percentage of its total population that is food insecure at 25 percent (Table 18 -- Food security). However, only 5 percent of the county's total population has limited access to healthy foods. The lowest food insecurity rates across the three metrics can be considered to be in DeSoto County, MS, with 13 percentof the population reported as food insecure, 9 percent of the total population with limited access to healthy foods and 17 percent of Black households receiving SNAP/EBT.

MAP 9. FOOD DESERTS IN THE MEMPHIS METRO AREA



Source: 2019 Food Research Atlas (US Department of Agriculture, Economic Research Service)

Map 9 illustrates the location of food deserts throughout the Memphis MTA. Food deserts are census tracts designated by the USDA as low-income areas with low access to food within one mile. Food deserts are located throughout the MTA. The largest food deserts are located in DeSoto County, MS, and Crittenden County, AR. However, the highest density of food deserts is located in Shelby County, TN, primarily within the city limits of Memphis.

> *"Depending on the neighborhood, eating what you consider right, may not be what they can afford. Then a lot of households may not have transportation to get to a good grocery store. A lot of people are living in food deserts here in Memphis. This creates a barrier to try to have a good diet." - Undiagnosed*

TABLE 19. MEMPHIS METRO AREA TRANSPORTATION

County	Percent of Households Without a Vehicle	Percent of Total Population That Commutes More Than 45 Minutes to Work	Percent of Total Population That Commutes to Work Using Public Transit	Percent of Total Population That Commutes to Work by Foot/Bike/Other
Crittenden County, AR	11%	10%	0%	4%
DeSoto County, MS	3%	11%	0%	1%
Shelby County, TN	9%	8%	1%	3%

Source: American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)

Public transportation is not widely accessible or utilized in the Memphis MTA. Shelby County, TN, the most urban county, is the only county that reports that some residents commute to work using public transportation (1 percent). Notably, residents of Crittenden County, TN, a very rural county, appear to

face significant transportation barriers: 11 percent of households do not have a vehicle and 4 percent of the population commutes to work by foot/bike/other.

> *"I think patients having access to reliable transportation is a problem. It's not only can the person drive, but do they have access to a car that works. Sometimes you'll have families where maybe there's one car that's shared. I've had people cancel appointments because their car broke down on the way here. There is definitely transportation insecurity." - Provider*

TABLE 20. MEMPHIS METRO AREA EDUCATION

County	Percent of Population Over Age 25 That Has a High School Degree or Higher	Percent of Population Over Age 25 That Has a Bachelor's Degree or Higher	Percent of Black Women Over Age 25 Without a High School Degree
Crittenden County, AR	81%	17%	24%
DeSoto County, MS	89%	24%	10%
Shelby County, TN	88%	31%	13%

Source: American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)

In DeSoto County, MS, 89 percent of the population over age 25 has a high school degree or higher (Table 20- education), and 10% of Black women over age 25 do not have a high school degree (lowest rate of this metric in the MTA). Crittenden County, AR, has the lowest education rates across all three metrics: 81 percent of the population has a high school diploma or higher, 17 percent of the population has a bachelor's degree or higher, and 24 percent of Black women over age 25 do not have a high school diploma.

> *"Literacy is another challenge. We have long forms, so people who come into our office who have limited literacy, I think take a little longer to fill out the forms. We give written information, but we also do a lot of verbal education. I have not, in our practice, noticed that that's a limitation to getting through your care, but I can imagine how maybe some patients felt like they just kind of went through the care without maybe fully understanding, if they weren't able to read the materials that were provided." - Provider*

TABLE 21. MEMPHIS METRO AREA GENTRIFICATION

County	Proportional Change in Population With a Bachelor's Degree or Higher	Percent Change in Median Household Income
Crittenden County, AR	2%	6%
DeSoto County, MS	2%	6%
Shelby County, TN	2%	5%

Source: American Community Survey 2013-2017 5-Year Estimates (US Census Bureau); American Community Survey 2008-2012 5-Year Estimates (US Census Bureau)

Gentrification is another measure connected to educational attainment. Table 21 measures gentrification rates across two metrics: the proportional change of the population with a bachelor's degree or higher and the proportional change in median household income. All three counties in the MTA have the same percent change in population with a bachelor's degree or higher at 2 percent. The three counties also have very similar rates of percent change in median household income: Crittenden County, AR, and DeSoto County, MS, both report 6 percent and Shelby County, TN, reports 5 percent. By these measures, it does not appear that significant gentrification is occurring.

Policy Context

This section examines key policies relating to access and coverage for breast cancer screening, diagnosis and treatment. The main policies and programs relevant are the Patient Protection and Affordable Care Act (ACA), including Medicaid expansion, the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) and the Breast and Cervical Cancer Prevention and Treatment Act (BCCPTA).

The Patient Protection and Affordable Care Act (ACA)

The ACA was signed into law in 2010, enacting broad health reforms across the nation, most notably expanding health insurance coverage and enacting consumer protections. The provisions of the law that are most relevant to women seeking breast cancer-related services are the preventive services mandate, the provision that bars insurers from denying coverage based on pre-existing conditions (such as a previous diagnosis of breast cancer), and the state-by-state option to expand eligibility for Medicaid.

- **Preventive Services Mandate.** The preventive services mandate requires that almost all private health insurance plans cover certain preventive services without patient cost sharing. This mandate does not apply to grandfathered plans or policies, a very minor share of plans in existence prior to the passage of the Affordable Care Act on March 23, 2010, that have not undergone major changes to benefits. These preventive services are determined by guidelines from expert clinical entities, including the US Preventive Services Task Force (USPSTF) and the Health Resources and Services Administration (HRSA). In accordance with these guidelines, plans must provide coverage for mammograms beginning at age 40 without cost sharing. For women at high risk of breast cancer, plans must also cover genetic screening and preventive medication for breast cancer (The Henry J. Kaiser Family Foundation, 2015).

- **Pre-Existing Conditions Protections.** Per the ACA and effective as of 2014, health insurers cannot deny coverage to an individual or charge more for coverage due to a pre-existing condition. For example, insurers cannot discriminate based on a previous or current breast cancer diagnosis or other health condition. Additionally, health insurers cannot refuse to provide coverage for treatment and other services related to a pre-existing condition (U.S. Department of Health & Human Services, 2017).
- **Medicaid Expansion.** Under the ACA, states have the option to expand their Medicaid program to individuals with incomes of up to 138 percent of the federal poverty level (FPL). More than 1 in 7 Tennessee residents are enrolled in the state's Medicaid program, known as TennCare. Tennessee, as well as Mississippi, has not adopted Medicaid expansion.

Arkansas has expanded Medicaid coverage, effective January 1, 2014. Eligibility criteria for adults is as follows:

- Adults with incomes up to 138 percent FPL
- Pregnant women up to 214 percent FPL
- Seniors and People with disabilities up to 80 FPL

In March 2018, Arkansas' 1115 waiver (Section 1115 of the Social Security Act) was approved by CMS, effective for approximately three years. Through the waiver, Arkansas implemented work requirements and eliminated the three-month retroactive eligibility provision and replaced with a 30-day provision.

Enrollees must participate in and timely document and report 80 hours per month of community engagement activities, such as employment, education, job skills training, or community service, as a condition of continued Medicaid eligibility (Centers for Medicare & Medicaid Services, 2020). In 2019, a court overturned the Arkansas' work requirements, and in 2020, the DC Circuit upheld the district court's decision to set aside the waiver amendment.

As of October 2019, there were an estimated 113,000 adults in the coverage gap in Tennessee (Kaiser Family Foundation, 2019). From 2013 to 2017, the uninsured rate in Tennessee decreased from 16 percent to 11 percent (compared to a national drop from 17 percent to 10 percent over the same time period. For nonelderly Black residents in Tennessee, the uninsured rate decreased from 14 percent in 2013 to 12 percent in 2017 (Kaiser Family Foundation, 2020). Comparatively the uninsured rate for non-elderly white residents in Tennessee decreased from 14 percent in 2013 to 9 percent in 2017. As displayed in Table 17 (economic security), the five-year American Community Survey estimates for the average uninsured rate in the Memphis Metro Area is about 11 percent (with a low of 10 percent in DeSoto County, MS and a high of 13 percent in Shelby County, TN).

Mississippi reports similar statistics to Tennessee. As of October 2019, there were 103,000 adults in the coverage gap in Mississippi, and from 2013 to 2017, uninsured rates dropped from 20 percent to 16 percent compared to 17 percent to 10 percent nationally. Arkansas, which expanded Medicaid coverage, saw a much higher drop in uninsured rates. As of October 2019, there were 326,900 adults in the Medicaid expansion group and uninsured rates dropped from 19 percent to 10 percent between 2013 and 2017.

Recent research indicates that the uninsured rate among nonelderly adults has decreased for all racial/ethnic groups with larger decreases among non- Hispanic Black and Hispanic groups compared to non-Hispanic whites. The coverage disparities have narrowed compared to before the ACA, but disparities in coverage by race and ethnicity remain (Artiga et al., 2020). Regarding screening, research suggests that states that expanded their Medicaid program eligibility standards have improved cancer screening rates compared to states that did not, and that early adoption of the Medicaid expansion is associated with greater improvements in screening (Fedewa et al., 2019; Swift, 2019). Some studies suggest it is possible that the racial disparity in mammograms has been closed or reversed (Fazeli Dehkordy et al., 2019).

National Breast and Cervical Cancer Early Detection Program (NBCCEDP) and Breast and Cervical Cancer Treatment Program (BCCTP)

In Tennessee, the screening program is known as the Tennessee Breast & Cervical Cancer Program (TBCSP). Women living in Tennessee, who are over the age of 40, at or below 250 percent of the FPL, and without insurance or underinsured are eligible for this program (Tennessee Department of Health, 2020). In Mississippi, the program is called the Mississippi Breast and Cervical Cancer Early Detection Program (MSDH/BCCP); women living in Mississippi, 40 to 64 years old, at or below 250 percent of the FPL, and uninsured or underinsured are eligible for this program (Mississippi State Department of Health, 2020). In Arkansas, the program is called the Breast Care Program; women living in Arkansas, 40 to 64 years old, at or below 250 percent of the FPL, and uninsured or underinsured are eligible for this program (Arkansas Department of Health, 2020

In Tennessee, from the five-year period of July 2014 to June 2019, the NBCCEDP served 29,720 women for both breast and cervical cancer screening and detection services. Specific to breast cancer, 28,337 women received a screening mammogram over this five-year period, and 24,543 women received breast cancer screening and diagnostic services (note that each category provides a unique count of women receiving services, but women may be counted in multiple categories. Thus, the distinct category figures listed are not unduplicated women receiving services) (Centers for Disease Control and Prevention, 2020).

In Mississippi, from the five-year period of July 2014 to June 2019, the NBCCEDP served 14,427 women for both breast and cervical cancer screening and detection services. Specific to breast cancer, 16,423 women received a screening mammogram over this five-year period, and 14,243 women received breast cancer screening and diagnostic services (note that each category provides a unique count of women receiving services, but women may be counted in multiple categories. Thus, the distinct category figures listed are not unduplicated women receiving services) (Centers for Disease Control and Prevention, 2020).

In Arkansas, from the five-year period of July 2014 to June 2019, the NBCCEDP served 16,257 women for both breast and cervical cancer screening and detection services. Specific to breast cancer, 7,779 women received a screening mammogram over this five-year period, and 7,188 women received breast cancer screening and diagnostic services (note that each category provides a unique count of women receiving services, but women may be counted in multiple categories. Thus, the distinct category figures listed are not unduplicated women receiving services) (Centers for Disease Control and Prevention, 2020).

In Tennessee, women who are diagnosed (either through the TBCSP or through another means) may be eligible for treatment through TennCare Medicaid if they meet certain requirements. In Mississippi, women who are diagnosed through the MSDH/BCCP program may be eligible for treatment through the Medicaid program. In Arkansas, women who are diagnosed through the Breast Care Program may be eligible for treatment through the Medicaid program.

THE VARYING LEVELS OF ELIGIBILITY FOR BCCTP CAN FACILITATE WOMEN'S ACCESS TO SERVICES (E.G., ELIGIBLE REGARDLESS OF SCREENING LOCATION OR PROVIDER) OR CAN IMPEDE A WOMAN'S ACCESS TO SERVICES (E.G., REQUIREMENTS THAT NBCCEDP FUND SCREENING COSTS). IF A WOMAN IS DIAGNOSED WITH BREAST OR CERVICAL CANCER, SHE IS THEN ELIGIBLE TO RECEIVE MEDICAID SERVICES.

TABLE 23. MEDICAID FOR BREAST AND CERVICAL CANCER IN THE MEMPHIS METRO AREA

State	Age	Insurance Status	Program Services
Tennessee	Under age 65	Be uninsured or have insurance coverage that does not include breast or cervical cancer treatment	Full Medicaid benefits to uninsured women diagnosed with breast and/or cervical cancer, and in need of treatment
Mississippi	Under age 65	Be uninsured or underinsured	Full Medicaid benefits to uninsured women diagnosed with breast and/or cervical cancer, and in need of treatment
Arkansas	Under age 65	Be uninsured or underinsured	Full Medicaid benefits to uninsured women diagnosed with breast and/or cervical cancer, and in need of treatment

Sources: Tennessee Department of Health, Mississippi State Department of Health, Arkansas Department of Health.

TABLE 24. OVERVIEW OF SCREENING AND TREATMENT SERVICES IN THE MEMPHIS METRO AREA

State	Age Eligibility and Screening Guidance	Insurance Status	Program Services
Tennessee - Tennessee Breast and Cervical Cancer Early Detection Program (TBCCEDP)	Under 65 years old *Following the U.S. Preventive Services Task Force guidelines: biennial screening mammography between ages 50-74; under 50 screening based on individual risk*	Uninsured or underinsured	Breast and cervical cancer screening (office visits, clinical breast exams, screening mammograms, Pap and HPV tests, medical consultations) to eligible women and diagnostic follow up tests for those with suspicious results

Mississippi - Mississippi Breast and Cervical Cancer Early Detection Program	50 - 64 or younger when special funding is available	Uninsured or underinsured; no Medicare or Medicaid	Clinical breast exam, pelvic exam, Pap test, screening mammogram, diagnostic testing, referrals for treatment
Arkansas - BreastCare	40-64 years old for breast cancer screening *Every one to two years for age 50+; up to individual decision for ages 40-49*	Uninsured or have insurance, need diagnostic tests AND meet financial criteria	Mammograms, clinical breast exams, pelvic exams and Pap tests, follow-up testing if needed

Sources: Tennessee Department of Health, Mississippi State Department of Health, Arkansas Department of Health.

Flexibility in the Medicaid Program via Medicaid Waivers

One aspect of flexibility in the Medicaid program is a state's option to apply for Medicaid "waivers" in the state's administration of the program. These waivers allow states to "waive" some of the typical federal requirements in order to pilot new approaches (subject to approval from the Centers for Medicare and Medicaid Services [CMS]) (National Conference of State Legislatures, 2018).

The Trump administration has promoted work requirements through Medicaid waivers which have previously not been approved (Brooks, Roygardner, & Artiga, 2019). Several states have applied to enact work requirements, meaning that Medicaid eligible enrollees would have to report working a certain number of hours or involvement in a volunteer role, in school or in time spent looking for a job. Their Medicaid coverage would be contingent on meeting these requirements. The three states in the Memphis MTA have varying statuses of work requirements. Tennessee and Mississippi have submitted work requirement waivers; Tennessee for a 20 hours/week average requirement and Mississippi for a 20 hour/week requirement. Arkansas has had work requirements blocked by court ruling. Enrollees can also be exempt from these requirements for other reasons including being pregnant, medically frail, being a full-time student and other reasons (and they must renew their exemptions annually).[93]

Work requirements in Medicaid are a widely criticized strategy that constrict access to Medicaid coverage, do not reach their purported goal of increasing work among Medicaid enrollees, and likely harm health by limiting access to insurance coverage (Cauley Narain & Zimmerman, 2019). Furthermore, most adults enrolled in Medicaid are already working; in Tennessee, 59 percent of adults on Medicaid are working full or part time, 55 percent in Mississippi, and 55 percent in Arkansas. Among adult Medicaid enrollees who work full-time, most of them work in low-paying jobs and in sectors that do not tend to offer employer-sponsored insurance.

Cancer Plan for Tennessee

The State of Tennessee Cancer Plan 2018-2022 was strategized by the Tennessee Cancer Coalition which is made up of stakeholders from a number of organizations including state government agencies, hospitals, colleges/universities, faith-based organizations and insurance companies. The plan outlines goals and strategies for primary prevention, screening and early detection, treatment, palliative care, survivorship, childhood cancer and surveillance and evaluation.

Breast cancer is the most common cancer diagnosis in females in Tennessee (second-most overall) and the second-most leading cause of cancer death in females (third overall). To address this, the plan outlines a number of goals including:

- Increasing the percentage of women aged 50-74 who have had a screening mammogram within the past two years
- Increasing the percentage of residents with personal or family history of breast cancer that are offered genetic counseling or testing
- Increasing the number of health plans that have cancer genomic best practices for hereditary breast cancer
- Increasing the number of Tennessee Department of Health Breast and Cervical Screening Program providers by recruiting community-based clinics and federally qualified health centers to participate
- Creating a work group of stakeholders and interested parties to study and make recommendations regarding the feasibility and potential benefits of population-based surveillance for recurrent metastatic breast cancer

The plan acknowledges higher cancer mortality rates for Blacks and also outlines strategies to address health equity and cancer disparities including the following objectives:

- Providing data linking social determinants of health to cancer-related health disparities to cancer control advocates and the general public
- Coordinating the work of regional Tennessee Cancer Coalition partners to address social determinants of health of highest priority in each region

Cancer Plan for Mississippi

The Mississippi Comprehensive Cancer Control 2018-2022 State Plan was developed by the Mississippi Partnership for Comprehensive Cancer Control (MP3C) which will also serve as the coordinating body for the implementation of its goals and objectives. The plan is organized around four broad goals:

1. Promoting personal healthful behaviors
2. Bringing partners together to maximize existing resources and strategize how to effectively impact policy, systems, and environmental changes

3. Implementing evidence-based interventions
4. Determining resources needed to address gaps and barriers

These goals are to be implemented in fields of prevention; early detection; clinical trials; survivorship; treatment; policy, systems, and environmental changes (PSE) and evaluation and surveillance.

The plan outlines some objectives and strategies address and improve breast cancer prevalence and mortality including:

- Promoting awareness of and participation in cancer clinical trials
- Maintaining the number of surveillance data and methods for determining burden of cancer

The plan recognizes the higher burden of cancer faced by Black women in the state as well as the larger cancer disparities between whites and Blacks in Mississippi. The plan includes strategies to reach underserved and minority populations including:

- Promoting community awareness about resources for low or no cost cancer screening services for underserved men and women
- Strategizing at least one system change that will increase cancer screening, particularly for minority, underserved and under/uninsured populations
- Promoting involvement of cancer care providers in cancer clinical trials statewide with emphasis on organizations providing care to minorities and underserved to ensure adequate representation in studies

Cancer Plan for Arkansas

The Arkansas Cancer Plan (ACP) 2015-2020, titled *Cancer is Personal*, was developed by the Arkansas Cancer Coalition (ACC), the statewide comprehensive cancer control partnership. The coalition itself aims to maintain and engage the cancer-control partnership drive the state cancer-prevention strategy and implementation.

The ACP focuses efforts on seven priority cancers, including breast cancer, for which it highlights five objectives working towards one overarching goal: reduce deaths from female breast cancer in Arkansas

- Increase the proportion of women aged 40+ who have received a breast cancer screening
- Decrease the incidence of late-stage disease of female breast cancer for women of all ages who have been diagnosed with breast cancer

- Increase the number of women living in rural communities who have received breast cancer screening and diagnostic services and appropriate treatment
- Increase the proportion of breast cancer survivors who are living five years or longer after diagnosis
- Increase the number of appropriate referrals of women with breast cancer diagnosis meeting current guidelines for genetic counseling and genetic testing

The plan recognizes racial cancer disparities and names race/ethnicity as a risk factor for breast cancer and includes a strategy to develop messaging and/or targeted outreach to increase prevention and screening rates among identified disparate populations and groups that experience high mortality rates, including Black women.

State Laws Impacting the Breast Cancer Community

- **Metastatic Step Therapy.** Arkansas has passed legislation that prohibits the use of step therapy or "fail-first" protocols for advanced, metastatic cancer treatments and its associated conditions.
- **Oral Parity.** Arkansas and Mississippi have passed legislation that ensures patient cost-sharing for oral chemotherapy treatments are no less favorable than the patient cost-sharing for intravenous chemotherapy treatments.

Discussion and Conclusion

The landscape analysis sought to understand the underlying causes of breast cancer inequities across the care continuum among Black women in the Memphis MTA, with a focus on systemic issues and social determinants of health.

Breast Cancer Disease Burden

The data on breast cancer disease burden comparing and contrasting counties to one another, to state and national averages, and by race, indicate that breast cancer inequity in the Memphis MTA may be greatest for Black women residing in Shelby County. Black women are more likely to die from breast cancer than their white counterparts, even though they are more likely to receive a screening mammogram and are diagnosed with the disease at lower rates.

While there is no uniform trend in breast cancer incidence rates (see table 5), with higher rates among white women in some counties and higher rates among Black women in others, it is notable that the greatest disparity is reported in Crittenden county, AR where the incidence rate is 78.9 for white women compared to 104.8 for Black women. In both DeSoto County, MS and Shelby County, TN incidence rates for Black women are lower than or equivalent to those for white women. However, in both counties, mortality rates are higher for Black women compared to white women (21.1 white and 32.7 Black in DeSoto, 23.3 white and 34.5 Black in Shelby). Insights from focus groups facilitated with community

members suggest barriers to care due to challenges for patients navigating the diagnosis systems, complicated diagnosis process, and insurance barriers.

The qualitative data reveal that women in the diagnosis and treatment phases of the breast cancer continuum are burdened by concerns over loss of income and an inability to fulfill caretaking roles once diagnosed or starting treatment. Many survivors described working hourly jobs with no sick leave at the time of their diagnosis. Additionally, those with caretaking responsibilities had the added stress of maintaining a household during intense treatment plans. Many emphasized the importance of family who provided childcare and financial support. These barriers are consistent with research that has found that retention in care is heavily impacted by a woman's ability to manage financial and caregiving roles while working at jobs that make it difficult to take time off from work (Masi & Gehlert, 2009).

Most health care facilities and breast cancer resources are concentrated in Shelby County, including the only comprehensive cancer center in the MTA. Crittenden County and DeSoto County have few hospitals, Federally Qualified Health Centers and screening mammography facilities. In both Crittenden County, AR, and DeSoto County, MS, 100 percent of the population is medically underserved (Table 15). Public transportation is not widely accessible or utilized in the Memphis MTA. Patients having access to reliable transportation is a problem.

Quality of Care

Regardless of insurance status, Black women are likely to encounter health care staff with discriminatory attitudes and behaviors. Shelby County reports the highest level of racism when compared to the other counties in the MTA. Most focus group participants described encountering personally mediated racism at work and the health care system. Research has demonstrated the long-term and adverse effects of personally mediated racism on psychological wellbeing, mental health, and other healthy-living practices (such as alcohol and drug use, sleep disturbance, and eating patterns) (Bailey et al., 2017; Kwate et al., 2003). The research also points to the links between personally mediated racism and biomarkers of disease, including allostatic load (Williams & Mohammed, 2013).

Furthermore, there are barriers plaguing access to genetic counseling and testing services in the Black community. These services are valuable for those with a family health history of cancers to determine whether or not genetic mutations known to cause increased risk for breast and other cancers (such as mutations in BRCA1/BRCA2 genes) are present. One of the root causes of the genetic testing disparity is the lack of knowledge and communication of genetic testing in the Black community. Blacks do not participate in genetic testing at the same rate as European Americans (Huang et al. 2014). Implicit racial bias is associated with negative markers of communication among minority patients and may contribute to racial disparities in processes of care related to genetic services (Schaa et al., 2015).

Social Determinants of Health

Shelby County, TN is the most segregated place in the MTA (see Map 4), which is in turn associated with racial and ethnic health care disparities (Gaskin et al., 2012). Residential segregation is connected to redlining, which has led to many Black communities with higher concentrations of poor quality housing and limited opportunities for higher education, gainful employment, and quality health care (Kramer & Hogue, 2009; Landrine & Corral, 2009). The legacy of redlining and segregation is exemplified in one focus group participant's experience of being referred to a food pantry in her community that had lower quality options compared to those in a predominantly white community.

Shelby County, TN reports the highest percentage of the population that is uninsured at 13 percent (Table 17). Crittenden reports the highest percentage of Black women over the age of 45 who live under the poverty line at 23 percent. Consistent with the literature, focus group participants shared that the type of insurance they have influenced the quality of care received. Some survivors reported feeling that being uninsured and receiving treatment at the free clinic, did not get them access to the best quality treatment and medication and led to mistrust. The literature shows that among Black breast cancer patients, a woman's insurance type was a significant predictor of mistrust of the medical establishment. Women with Medicaid expressed greater mistrust and suspicion compared to women with private insurance or private insurance and Medicare (Sutton et al., 2019). A key finding in the Memphis MTA was also the lack of knowledge between providers and community members in regard to the free and convenient breast cancer screen availability in their community.

Breast cancer inequities across the care continuum in the Memphis MTA persist due to economic vulnerability and relatedly the lack of insurance, the high cost of health care, experiencing personally mediated racism in health care settings, inadequate strategies to combat paralyzing fear related to a cancer diagnosis, and lack of social support. Taken together, these factors severely reduce the quality of care Black women receive across the cancer care continuum. This study confirms the existence of many well-understood barriers across the care continuum facing Black women. This study also highlights novel barriers and adds nuance to existing barriers across the care continuum that warrant further research and intervention. These issues uncovered in the Memphis MTA include: 1) the need for more diverse and culturally responsive patient navigation, 2) increased awareness of free diagnostic screening, and 3) support for racial equity training for providers.

Recommendations

Komen's AAHEI is a substantial undertaking to dismantle the systems that perpetuate the growing breast cancer inequities experienced by Black women. Findings from the Memphis MTA landscape analysis suggest that the work ahead requires interventions at multiple levels of the system: the micro level (the level at which patients and providers interact), the mezzo level (the level at which systems interact), and the macro level (the policy level).

This framework reveals that the health system is multidimensional, ever-changing, and has the potential to facilitate or impede population health. For most, the lasting impression of the health system begins at the micro level – where providers and patients interact. As Black women progress along the breast cancer continuum of care, they encounter other microsystems, and the complexity of their experience increases. Access to and quality of these microsystems vary, and there is a need for these systems to interact and relate in a manner that centers on the experiences of Black women. When multiple microsystems intersect, the mezzo system is formed and the health experience becomes more complicated, particularly if there is no navigation assistance or care coordination. System functionality at the micro and mezzo levels is directed by policies and resources within and beyond the organization – the macro level.

The following recommendations apply this systems framework and address specific changes, strategies, or interventions at the micro, mezzo, and macro levels. These recommendations are intended to work in concert and not as discrete changes. Recommendations acknowledge that the systems and their components are relational, non-linear, and dynamic. Thus, suggested strategies and interventions

should be coordinated with communities, in keeping with Komen's collaborative approach to advance breast health equity for Blacks. This provides a mechanism for community/stakeholder engagement and recognizes the informal and formal systems and networks of social support that are accessed by Black women. These recommendations represent actionable strategies as the bridge between social determinants of health and the breast cancer care experience of Black women.

Micro-Level Strategies

Develop a diverse and culturally responsive patient navigation workforce.

Although there is no clear disparity in incidence, between Black and white women in the Memphis MTA, the disparity in breast cancer mortality becomes abundantly clear, with Black women reporting higher rates than their white counterparts in Shelby County, TN and DeSoto County MS.

As noted earlier in the report, Black women exercising decision-making and/or practicing self-advocacy within the health care setting were largely ignored or met with disapproval. For some women, experiences of not being listened to by their providers led to delays in treatment and deepening mistrust. Historical injustices inflicted by the health care system and continued personally mediated provider biases exacerbate barriers to care. Given the importance of patient-provider communication and the ability of providers to exercise cultural sensitivity, the role of patient navigators as "translators" during health care visits, and as "support systems" after the visit is essential. Patient navigators are important members of the clinical care team. They offer expertise in navigating the health care system; and can offer resources to help integrate clinical care with mental health and related support. According to focus group participants, Black patient navigators were highlighted as particularly valued resources. Black patient navigators, more likely to reflect the lived experience of Black breast cancer patients, may serve as a key conduit between patients and their providers. Navigators offer crucial perspectives and enable more culturally relevant care.

Evidence indicates that patient navigation can be effective in improving screening mammography screening (Baik, Gallo, & Wells, 2016; Scheitler, Shimkhada, Ko, Glenn, & Ponce, 2018). One study reported that a patient navigation program improved timely care and compliance with breast cancer treatment (Castaldi, Safadjou, Elrafei, & McNelis, 2017).

Komen's Stand for H.E.R. should continue to build and support a network of culturally responsive, trained patient navigators who represent the Black community. This includes increasing the number of navigators and assuring they are geographically accessible. This investment could also support the development of comprehensive patient resource materials that are helpful and widely available, so that patients and caregivers don't have to do extensive research or ask a friend to find needed resources. This was found to be problematic irrespective of socioeconomic and education status in this study. These navigators could also coordinate more support groups that are culturally competent and even virtually accessible for women who might not be able to meet in person.

Expand financial assistance programs for Black women diagnosed with breast cancer.

To mitigate barriers to treatment, Komen and partners should consider the expansion of existing financial assistance programs specifically for Black women in the Memphis MTA. Komen currently offers a Treatment Assistance Program (TAP), which provides financial assistance to local cancer patients unable to afford the costs associated with breast cancer treatment. This does include limited costs associated with childcare, home care and transportation. Patients must have incomes at or below 250 percent FPL. An expansion of this program's available funds specifically for Black women in the Memphis MTA would give many more women relief to the financial burden of treatment.

Implement implicit bias trainings for providers, administrators, and health care staff.

Komen and partners should support implicit bias trainings for providers. The exact focus of the training could include: 1) basics of implicit bias, 2) challenging racial/ethnic stereotypes using results from this study as stimulus for case examples and content, 3) improving empathic communication skills related to cancer diagnosis and treatment and 4) cultural humility.

Increase education about family health history to identify high-risk families and offer genetic counseling and testing to meet the need.

Individuals who have first-degree family members with a history of disease may benefit from genetic testing which may lead to early screening and early detection, implementing preventive actions, participating in research trials and even accessing interventions that could slow or prevent disease progression. However, several studies show that Black women are less likely to have genetic testing.

Various studies assessed the reasons why people of diverse ancestry take advantage of genetic testing in such small numbers. For example, a study conducted by Glenn *et al.* from 2004 to 2006 revealed that among Black, Asian and Latina women, a leading reason why these women did not undergo a *BRCA* gene test was lack of awareness of the availability of this service (Glenn *et al*., 2012). In addition, health care providers may not obtain family history information from non-White women at the same rates as White women (Murff et al. 2005). Lower rates of discussing family history of breast cancer with Black women may further translate into reduced rates of referring these women to genetic counseling.

In Georgia, the screening mammography rate for Black women over the age of 40 is 79.4 percent, compared to 72 percent of white women in the same age range. While Black women are getting screened at high rates, the breast cancer mortality rate is higher for Black women than white women in most counties in the MTA where data is available for both demographics (see Table 8). The qualitative findings indicate community uncertainty of the appropriate age for screening with some saying 50-years-old is the appropriate age for a first screening mammogram. Other community members shared concerns about Black women in their 30s receiving breast cancer diagnosis before the recommended screening ages. This underscores the value of genetic counseling and testing for those at increased hereditary risk for breast cancer.

The breast cancer community has an opportunity to support a health promotion campaign that amplifies the need to discuss family health history so that families may make decisions about their healthcare; to educate about the role genetic testing and counseling can play in overall healthcare; and to provide information on accessing trusted providers of testing and counseling services. While these services are often covered by insurance, a program is needed to provide services to the under- and

uninsured families.

This campaign should be rigorously evaluated, and if done effectively should demonstrate significant increases in awareness and uptake among Black women and their families around these programs and contribute to the growing body of research evidence about the genetic drivers of breast cancer in Black women.

Implement a culturally relevant health promotion campaign intended to increase knowledge of screening guidelines, especially among the never-screened and those at high-risk.

Although data show that many Black women are being screened, the qualitative data from the focus groups pointed to confusion about the varying screening recommendations (from the American Cancer Society, the American College of Radiology, and the United States Preventative Services Task Force). Quantitative data also showed screening rates below the national average among certain counties, which may be driven by a combination of factors beyond this confusion to include financial barriers, fear and mistrust of the healthcare system.

The breast cancer community has an opportunity to support a health promotion campaign that clarifies current screening guidelines; educates about the role family health history plays in determining risk of breast cancer and resulting recommended age at screening onset and interval; and to encourage further assessment of suspicious findings through diagnostic exams. In addition, patient education is needed about low- and no-cost options for the uninsured as well as programs to overcome barriers to care (such as vouchers for services, financial assistance for transportation or childcare) to ensure Black women know that mammograms can be accessed.

Community-based organizations can play an integral role in providing education and breast cancer services to the Black community. Partnerships with community-based organizations for community engagement in the Black community can aide in building community trust and providing culturally competent services and resources such as community education on screening and diagnostic services, referrals to screening services, linkages to culturally responsive community navigators and treatment assistance.

This campaign and partnerships should be rigorously evaluated, and if done effectively should demonstrate significant increases in awareness and uptake among never-screened and late-screened Black women around these programs as well as uncover some the root causes of late-stage diagnosis among Black women.

Mezzo-Level Strategies

Increase access to integrated care to improve the breast cancer care experience.

Particular aspects of the breast cancer continuum that warrant further investigation and intervention include the availability of accessible, high-quality screening, low cost or free diagnostic mechanisms and various treatment options for Black women. Access includes reducing barriers relating to insurance coverage. Integrated care efforts can also include exploring partnerships with FQHCs. The integration of oncological, primary care, and mental health services is valuable. Overweight and obese women are represented among the increased incidence rate for breast cancer after menopause. Reducing a

woman's risk for breast cancer through routine primary care and help improve weight-related risk. Additionally, the breast cancer experience is characterized by an increased toll on mental health. Poor mental health also increases stress, a risk factor for breast cancer. Therefore, the integration of mental health services along the breast cancer care continuum is also important.

Support Quality Improvement (QI) initiatives along the breast cancer continuum of care.

Quality improvement (QI) initiatives employ qualitative and quantitative methods to enhance the effectiveness of interventions, programs and policies. Institutionalizing a commitment to quality improvement supports continuous learning and refinement in ways that ensure limited resources are used optimally and service delivery objectives (e.g., quality care) are achieved. The AAHEI project may want to support QI initiatives in the major health systems in the MTA, especially in cities that have large Black populations.

To help combat potential system-level discriminatory practices, additional QI measures are warranted to maintain and build upon. This may include monitoring progress relating to treatment adherence, assessing care experiences, and reducing time to diagnosis among Black women. Komen and partners may want to support QI initiatives in the major health systems in the Chicago MTA, especially in counties that are largely Black. These efforts have been helping improve the quality of care, often perceived by community residents, and confirmed by providers, as varying across health systems and of worse quality among institutions that serve under-insured or Medicaid populations. Komen and partners could consider ways to support QI initiatives in non-hospital and non-health system care settings (in addition to hospital and health system settings), such as federally qualified health centers that are more accessible to priority populations.

Create avenues for social support and community connection, and strengthen networks of culturally responsive patient navigators.

Landscape analysis data indicate that social support and being connected can be key facilitators for breast cancer screening and treatment. Having a strong, coordinated, and well-connected network can be a protective factor for many women. This may be particularly relevant for women without insurance and high-quality health care. Focus group participants suggested that having social support can combat myths, misinformation, and fear and is more effective when available through multiple sources: family, friends, community (faith-based organizations or community-based organizations) and health care providers. Patient navigators reiterated this need; they emphasized how social support can help people navigate the complexities of insurance options, especially when a survivor is physically, emotionally, and mentally strained as a result of treatment. Memphis MTA focus group participants consistently articulated the need for more frequent opportunities throughout the year to engage in group discussion, similar to the focus groups. They valued the safe space that was created through focus groups to discuss each other's unique experiences of seeking breast health care as Black women. Komen and partners may want to support avenues for community connection in order to foster social connectedness as well as increase awareness and understanding of breast cancer screening and treatment options.

Macro-Level Strategies

Conduct a root cause analysis relating to healthcare quality.

The breast cancer community has an opportunity to invest in a root cause analysis (RCA) process to identify the contributing factors and underlying causes of sub-optimal care, as well as the key leverage points where intervention would have a significant impact on reducing breast cancer inequities. By conducting an RCA, stakeholders, including non-health stakeholders, can begin to understand the complexity of this issue in their community. Komen's Stand for H.E.R. may want to invite breast cancer survivors, community-led efforts (e.g., workers' unions, non-profits, food banks, community health centers, women's organizations, environmental justice organization etc.), and research centers with long-standing academic-community partnerships to participate in the RCA process. The RCA includes an action planning process to determine how to intervene on key leverage points identified through the RCA. Additionally, the RCA process can spur innovative ideas and strategies guided by best practices for addressing the factors and underlying causes that impact breast cancer mortality inequities in Memphis MTA. Once complete, Stand for H.E.R. may want to engage in partnerships with the RCA stakeholders and provide grants to implement the RCA action plan among these organizations' respective members and networks.

Support efforts to develop guidelines and policies that address disproportionate breast cancer mortality among Black women, including increased genetic counseling and testing services.

Black women experience higher rates of death from breast cancer due to a combination of factors including barriers to early diagnosis, the aggressive nature of certain breast cancers that are more prevalent in Black women (TNBC, for example) and systemic healthcare challenges.

The breast cancer community should re-examine breast cancer screening and clinical care guidelines with a racial equity lens, and develop strategies (e.g., new guidelines, policies, practices) that aim to address the multi-level influences that lead to breast health disparities. Black women are at higher risk of dying from breast cancer, which is influenced by social determinants of health, but also in part because Black women get more aggressive breast cancer at earlier ages, so in part driven by heredity. Such efforts would allow us to move beyond the "one-size-fits-all" approach to breast cancer screening, diagnosis and treatment to a more personalized approach based on individuals' risk, social inequalities and other factors that drive disparities. In collaboration with patient advocates and the community, the resulting strategies, which may include new guidelines, policies and practices would provide health care providers with a better framework for delivering patient care, may help overcome the implicit bias of some HCPs and could be used to inform and/or monitor quality improvement initiatives.

As an example, breast cancer risk is one area that warrants further investigation, particularly with regard to differences in risk factors by race/ethnicity, that could inform more personalized strategies for breast cancer screening and treatment. In March 2018, the American College of Radiology (ACR) and the Society of Breast Imaging (SBI) recommended that all women, especially Black women (and those of Ashkenazi Jewish descent), have a breast cancer risk assessment no later than age 30 so those at higher risk can be identified and their screenings and breast health care be appropriately modified. The societies also made recommendations for modifications to the screening approach for women with specific risk factors and/or at higher risk of developing breast cancer; modifications included changes to the age at which screening should start, as well as the frequency and modality (mammography, ultrasound, MRI, etc.) of screening.

Adopting a risk-based approach to breast cancer screening and treatment would benefit from additional research to better understand risk through an equity lens to inform the development of better risk assessment tools. Related strategies to consider include increasing access to genetic counseling and testing, integrated healthcare, and partnering across multiple providers to ensure personal risk for breast cancer is determined early. Additionally, public policy changes will be required to ensure evidence-based recommendations for screening and treatment will be covered by health insurance plans with little to no cost to the patient. Changes in guidelines, policies and practices could facilitate a risk-based approach to screening and treatment that could decrease the number of Black women who present with later-stage breast cancers and reduce disparities in breast cancer mortality.

This landscape analysis report conveys comprehensive issues facing Blacks in the Stand for H.E.R. MTAs. These recommendations are intended to be a call to action for all community-based organizations, policymakers, hospitals, healthcare providers, faith-based organizations, civic leaders and citizens. The recommendations for the breast cancer community are offered as evidence-informed strategies to start reducing breast cancer disparities among Blacks.

Appendix A. Map Measures

TABLE 25. MEMPHIS METRO AREA TABLE MAPS

	Map 1: Percent of Population that is Black	Map 7: Social Vulnerability Index Score	Map 8: Percent of Households that are Housing-Cost Burdened	Map 4: Residential Segregation Score
Crittenden County, AR	49%	0.92	31%	52
DeSoto County, MS	25%	0.27	24%	30
Shelby County, TN	53%	0.79	36%	65

Sources: American Community Survey 2013-2017 5-Year Estimates (US Census Bureau); 2016 Social Vulnerability Index (US Centers for Disease Control and Prevention); 2016 Comprehensive Housing Affordability Strategy dataset (US Department of Housing and Urban Development); 2019 County Health Rankings (County Health Rankings)

Appendix B. Abbreviations & Glossary

Age-adjusted rates: A weighted average of the age-specific (crude) rates, where the weights are the proportions of persons in the corresponding age groups of a standard population. The potential confounding effect of age is reduced when comparing age-adjusted rates computed using the same standard population. Rates are expressed as the number per 100,000. The age-adjusted rates that appear in this report were calculated by State Cancer Profiles (SCP) using the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program data and methods (National Cancer Institute).

Allostatic load: The "wear and tear" on the body and brain that results from chronic or repeated stress.

Black/white dissimilarity index: A measure of residential segregation that illustrates the evenness with which two mutually exclusive groups (in this case, Blacks and whites) are distributed across the geographic units (in this case, census tracts) that make up a larger geographic entity (in this case, counties). Calculated by County Health Rankings (CHR) using the Index of Dissimilarity formula and data from American Community Survey (ACS) 5-year. Scores range from 0-100 and scores closer to 100 indicate greater segregation. CHR only calculates this measure for counties with at least 100 Black residents (County Health Rankings, 2020e).

Breast cancer stage: An approach to classify and describe cancer's spread or growth in the body. There are various approaches to staging. Health care providers commonly use "TNM" to assess the stage, which stands for:

- Tumor: size and location of tumor;
- Node: whether the tumor has spread to the lymph nodes, and;
- Metastasis: whether the cancer has spread to other parts of the body and to what extent.

Clinical breast examination: A physical exam that a provider performs to check the breasts and underarms for any concerns (e.g., lumps).

Collective impact: A cross-sector approach to solving complex issues on a large scale that offers a different way of working wherein whole systems – health departments, government, businesses, CBOs and participants with lived experiences make a unified effort to collectively address the issue from multiple angles (Kania & Kramer, 2011).

Confidence Interval (CI): Statisticians use a confidence interval to express the degree of uncertainty associated with a sample statistic (e.g., mean, median or other measure). It is usually presented with a probability statement.

Continuum of Care: The clinical continuum of care for breast cancer includes all aspects of screening, detection, diagnosis, treatment, and follow-up.

County Heath Rankings (CHR) percentile: A measure calculated using the following formula: CHR (numerator) divided by the number of counties in the state (denominator). CHRs are determined through an intra-state, weighted variable process (County Health Rankings, 2016).

Diagnostic screening mammogram: A screening mammogram used to further examine breast cancer symptoms (e.g., a lump) or an abnormal result from a screening mammogram or clinical breast exam using two or more views of the breast.

Fair Housing Act cases: The Fair Housing Act (Title VIII of the 1968 Civil Rights Act) prohibits most discrimination in housing transactions based on federally recognized bases (race, religion, familial status, etc.) Individuals in the US can bring cases to the Office of Fair Housing and Equal Opportunity (FHEO) within the Department of Housing and Urban Development. If there is cause to believe discrimination occurred, the case will go through a legal adjudication process to be resolved.

Federal poverty level (FPL): A measure of income that the US Department of Health and Human Services (HHS) releases annually. The FPL is used to determine eligibility for some benefits and programs, such as Medicaid, and cost subsidies on the health insurance Marketplace. The 2020 FPL is $26,200 for a family of four, and $12,760 for an individual. The data that appear in this report were calculated by the US Census Bureau and indicate the percentage of the population whose annual income is less than twice the 2017 FPL (i.e. 200 percent FPL). In 2017, the FPL was $24,600 for a family of four and $12,060 for an individual. (Office of the Assistant Secretary for Planning and Evaluation).

Food deserts: Areas defined by the US Department of Agriculture as urban census tracts that are low income and have low access to fresh food within a one-mile radius (U.S. Department of Agriculture Economic Research Service, 2019).

Gentrification: The process whereby a neighborhood or community's characteristics change as more affluent residents and businesses move into an area and displace less affluent residents, often people of color.

Hate crime with a race/ethnicity/ancestry bias motivation: A criminal offense against a person or property that was motivated in whole or in part by the offender's bias against a person's race/ethnicity/ancestry. The FBI collects this data using self-reported data from municipalities and universities. The data included in this report are from 2017. Crimes committed in municipalities that cross county lines are counted for all of the counties in which the municipality is located (U.S. Department of Justice Federal Bureau of Investigation, 2017).

Hazard ratio: Hazard ratio: A measure of how often a health event occurs over time in one group compared to another group. Cancer research often uses hazard ratios to compare a group of patients receiving a cancer treatment to a control group (receiving another treatment or placebo). A hazard ratio of 1 signifies no difference in survival between the groups; a hazard survival less than one or greater than one signifies that survival in one of the groups was better than the other (National Cancer Institute).

Health equity: Equity is the absence of unjust or avoidable differences among groups of people, whether defined demographically, socially, economically or by some other means. Health equity means that every person has a fair opportunity to attain their highest level of health and that no individual should be disadvantaged from reaching this potential.

Housing-cost burden: A measure to indicate the proportion of renters and homeowners that spend 30 percent or more of their total income on housing. Calculated by the U.S. Department of Housing and Urban Development using the Consolidated Housing Affordability Strategy dataset and the following formula: number of renters and homeowners who spend 30 percent or more of their total income on

housing (numerator) divided by the total number of households (denominator) (Office of Policy Development and Research (PD&R), 2019).

In situ carcinoma: A condition where abnormal cells are found in the milk ducts or lobules of the breast, but not in the surrounding breast tissue. In situ means "in place" (Susan G. Komen, 2020).

Incidence: The number of new cases of a disease that develop in a specific time period. The breast cancer incidence rates that appear in this report were calculated by SCP using data from the Centers for Disease Control and Prevention (CDC) and SEER, and the following formula: the number of individuals in an area who were diagnosed with breast cancer during a one-year period (numerator) divided by the total number of individuals living in that area (denominator). Incidence rates are expressed in terms of number of cases per 100,000 individuals per year (National Cancer Institute).

Internalized racism: Refers to when members of the stigmatized race devalue themselves and their race, doubt their abilities, reject their ancestry and culture, and have a sense of hopelessness and resignation to subjugation by other races (C. P. Jones, 2000).

Invasive breast cancer: Breast cancer is considered invasive when it has spread from its original location into the surrounding breast tissue, and potentially into other parts of the body, such as the lymph nodes.

Jim Crow: Jim Crow refers to a set of laws enacted by 21 states in the southern U.S. and the District of Columbia to enforce and uphold racial segregation. These laws were in place following the civil war and banned by the US Civil Rights Act in 1964 (Krieger et al., 2017).

Jim Crow effect: In the 2017 paper by Krieger, Jahn, and Waterman, the authors describe the Jim Crow effect on breast cancer as an association with higher odds of estrogen receptor negative breast cancer only among Black women in the study (not white women) with the strongest effect observed for Black women born prior to 1965 (Krieger et al., 2017).

Late-stage diagnosis: Cancer that is diagnosed once it has spread beyond the breast to lymph nodes, surrounding tissue or other organs in the body (most often the bones, lungs, liver or brain). The late-stage diagnosis rates that appear in this report are age-adjusted and calculated by SCP as described above (see “incidence” and “age-adjusted”) (National Cancer Institute).

Magnetic resonance imaging (MRI): An imaging technique that provides detailed pictures of organs or soft tissue (including the breast). A breast MRI tends to be used for higher-risk women and may also be used during diagnosis.

Mammogram or screening mammography: An imaging technique that creates an x-ray image of the breast. Mammograms can be used in a screening phase (e.g., to check for abnormalities in otherwise healthy individuals) or to further examine abnormalities.

Medically underserved: Areas or populations designated by the Health Resources and Services Administration (HRSA) as having too few primary care providers, high infant mortality, high poverty or a high elderly population (Health Resources & Services Administration).

Mortality rate: A measure of death calculated by the National Cancer Institute using SEER and National Vital Statistics System (NVSS) data. Calculated by SCP using the following formula: the number of individuals in an area who died during a one-year period (numerator) divided by the total number of

individuals living in that area (denominator). Expressed in terms of number of deaths per 100,000 individuals per year (National Cancer Institute).

Odds Ratio (OR): A measure of association between exposure and an outcome. The OR represents the odds that an outcome will occur given a particular exposure, compared to the odds of the outcome occurring in the absence of that exposure (Gordis, 2000).

Percent of adults who are obese: A self-report measure calculated by CHR using the following formula: number of adults over age 20 whose BMI is greater than or equal to 30 (numerator) divided by the total population (denominator) (County Health Rankings, 2020a).

Percent of population that is food insecure: A measure defined by CHR as the percentage of the population "with a lack of access, at times, to enough food for an active, healthy life, or uncertain availability of nutritionally adequate foods." Calculated by CHR using the Core Food Insecurity Model (County Health Rankings, 2020b).

Percent of population with limited access to healthy foods: A measure calculated by CHR using the following formula: population that is low income and does not live within one mile of a grocery store (numerator) divided by the total population (denominator) (County Health Rankings, 2020c).

Personally mediated racism: Refers to assumptions about others' abilities, motives and intentions, resulting in intentional and/or unintentional actions taken towards others due to their race. This includes maintaining structural barriers and subscribing to harmful societal norms, and manifests as "everyday avoidance," disrespect, suspicion and dehumanization (e.g., hate crimes, police brutality) (C. P. Jones, 2000).

Premature mortality rate: A measure of premature death calculated by CHR using the following formula: the number of deaths that occurred among people under age 75 (numerator) divided by the aggregate population under age 75 (denominator). Expressed as the number of deaths under age 75 per 100,000 people. CHR uses data from the National Center for Health Statistics (NCHS) and the NVSS to calculate this measure (County Health Rankings, 2020d).

Prevalence: A measure of the proportion of the population that has a condition within a particular timeframe. The prevalence data that appear in this report are the SCP's "Complete Prevalence Age-Adjusted Percents" for each state in 2017. These statistics were calculated by SCP using estimates derived from state-specific cancer mortality and survival data using a statistical package called MIAMOD (Mortality-Incidence Analysis MODEL). Cancer survival models are derived from SEER Program data and adjusted to represent state-specific survival (National Cancer Institute).

Redlining: This unethical practice systematically restricts access to resources and services (e.g., mortgages, insurance loans, housing) based on the race or ethnicity of individuals and communities.

Social determinants of health: The conditions in the places where people live, learn, work and play that affect a wide range of health risks and outcomes. Examples include, but are not limited to, educational attainment, transportation access, housing security, income, wealth and experiences of racism.

Structural racism: The system in which policies, institutional practices, and cultural representations work together, often in reinforcing ways to create and perpetuate racial inequity. Structural racism manifests as differential access to goods, services, conditions, opportunities and access to power.

Social Vulnerability Index (SVI): A measure of the exposure of a population to social vulnerabilities that limit their ability to withstand adverse impacts from multiple stressors to which they are exposed. The SVI is calculated by the CDC using the ACS 5-year report data for 15 social factors (e.g., lack of vehicle access, crowded housing). Scores range from 0.0 to 1.0, with scores closer to 1.0 indicating greater vulnerability (Agency for Toxic Substances and Disease Registry, 2018).

Supplemental Nutrition Assistance Program/Electronic Benefit Transfer (SNAP/EBT): SNAP is a federal benefits program that provides eligible, low-income individuals and families with funds to purchase eligible food in authorized retail food stores via an Electronic Benefits Transfer card.

Triple-negative breast cancer: A type of breast cancer that is estrogen receptor-negative, progesterone receptor-negative and human epidermal growth factor receptor 2 (HER2)-negative.

Ultrasound (sonogram): A diagnostic test that creates images of tissues and organs. A breast ultrasound is typically used after an abnormal screening mammogram, clinical breast exam or breast MRI result.

White flight: The departure of white people from places (such as neighborhoods or schools) increasingly or predominantly populated by people of color (Merriam-Webster).

Appendix C. Focus Group Guides

African-American Health Equity Initiative: From Education to Impact Landscape Analysis Provider Interview Tool

Step 1: Introduction of project and confidentiality

Thank you for speaking with us today. Before we start, I am going to explain the purpose of the interview and then I can answer any questions you may have and we can start the discussion.

I am_____ and joining me is my colleague_____. We are from JSI, a mission-driven public health research and consulting organization dedicated to advancing the health of individuals and communities in the United States and globally.

JSI is working with Susan G. Komen®, a leading breast cancer foundation, to understand the reasons behind the differences in breast cancer [late-stage] diagnosis and mortality among African-American women across 11 US metropolitan areas. Research has found that African-American women are less likely to be diagnosed early, when breast cancer is more treatable, as compared to white women and other races. African-American women are also less likely than other women with breast cancer to survive the disease. This is true across the country, and the gap is highest in these 11 major metropolitan areas. [insert name of metro] is among them.

Komen wants to work to bridge this gap in access and use of high-quality breast health care for African-American women. They have launched this program to better understand why differences exist and sees this as an opportunity to take action to change these conditions, and to do so they need to learn from you.

Komen has asked JSI to help gather this information from community members and providers to better understand how understand how to reduce late-stage breast cancer diagnosis and mortality in the African-American community. These discussions allow us to gather information from different groups to better understand what steps can be taken to improve conditions in communities so that African-American women have the same ability to get the care and support they need if they do get breast cancer.

Today we hope to learn from you about your knowledge and experiences with breast cancer screening, diagnosis and treatment. We are also interested in learning what you know about the practices of providers in the metropolitan area.

How data will be used, privacy and confidentiality

Your participation in this interview/ focus group is completely voluntary and all information you share will be kept confidential and will not be associated to you by name. At no time should you feel you have to answer a question. We will be taking notes and, with your permission, we will be recording this interview so we can engage in a conversation with you and not miss any of the details. These notes and

the recording will be kept in a secure location in our offices and only the project team will have access to these materials. The information will be aggregated, analyzed, and reported to Susan G. Komen.

Is it okay to record the interview/focus group? Any questions or concerns for us before we begin?

1. **Please tell me about your practice? How long have you been in practice? Tell me about the populations you serve (race/ethnicity, age etc.)? What are your specialty areas, if any?**

2. **What do you think is driving the disproportionately high rates of late stage cancer diagnosis among African-American women in [insert name of metro]? Does this information surprise you?**

   PROBES TO USE AS NECESSARY:

   a. *Explore the influence of:*
      1. *Ethnicity and nationality*
      2. *Socio-economic status*
      3. *Social determinants of Health*
      4. *Comorbidities such as obesity, hypertension, and diabetes*
      5. *Faith practices*
      6. *Family dynamics (getting at spousal and familial support)*
      7. *Trust/mistrust of the medical system*
      8. *Historical, institutional racism*
      9. *Access to care, including specialists*
      10. *Financial cost and time of follow-up testing and diagnosis*
      11. *Financial cost of treatment and time for treatment*
      12. *Quality of screening and diagnosis for African-American women*
      13. *Racism, bias, segregation and the inability to get the care they need*

3. **What do you think is driving higher rates of breast cancer deaths among African-American women in [insert name of metro]? Does this information surprise you?**

   PROBES TO USE AS NECESSARY:

   a. *Explore the influence of:*
      1. *Factors other than late stage diagnosis*
      2. *Access to care including specialists*
      3. *Ethnicity and nationality*
      4. *Socio-economic status*
      5. *Social determinants of Health*
      6. *Comorbidities such as obesity, hypertension, and diabetes*
      7. *Faith practices*
      8. *Family dynamics (getting at spousal and familial support)*
      9. *Trust/mistrust of the medical system*

10. *Historical, institutional racism*
11. *Access to care, including specialists*
12. *Financial cost and time of follow-up testing and diagnosis*
13. *Financial cost of treatment and time for treatment*
14. *Quality of screening and diagnosis for African-American women*
15. *Racism, bias, segregation and the inability to get the care they need*

4. **Which screening guidelines do you use with your patients?**

PROBES TO USE AS NECESSARY:

a. *What screening recommendations do you give to your African-American patients? How often do you share screening guidelines?*

b. *How does it differ, if at all, from other types of patients?*

c. *Do you routinely have conversations with your patients about risk factors for breast cancer? With younger, African-American patients? If so, does this information influence your recommendations for screening?*

5. **What factors promote (or encourage) regular screening among African-American women?**

PROBES TO USE AS NECESSARY:

a. *Explore the influence of:*
   1. *Providers, staff: temperament, cultural competency, kind, respectful*
   2. *Special programs and services that are culturally competent*
   3. *Services meeting women where they are/mobile services*
   4. *Process and systems: forms, wait time, referrals, timely, follow-up*
   5. *Overall environment: location, privacy, welcoming, feels safe*
   6. *Accessibility: easy to reach, timely*
   7. *Other factors in the community*

6. **What are the barriers or factors that may prevent African-American women from getting screened regularly?**

PROBES TO USE AS NECESSARY:

a. *Explore the influence of*
   1. *Provider and staff: temperament, cultural competency, kind, respectful*
   2. *Process and systems: forms, wait time, referrals, timely, follow-up*
   3. *Overall environment: location, privacy, welcoming, feels safe*
   4. *Accessibility: easy to reach, timely*
   5. *Comprehensives: are they receiving the basics + cutting edge*
   6. *Competing priorities*
   7. *Social determinants of health*

8. *Racism, bias, segregation*
   i. *Can you tell me a little more about the relationship between the African-American community and your hospital/practice?*
   ii. *We have looked at the secondary publicly available data and we see disparities in [insert key findings for metro]. Can you help us explain these data?*

7. **Please describe your process and strategies for getting African-American women who have been diagnosed with breast cancer linked to and retained in treatment?**

PROBES TO USE AS NECESSARY:

a. *Do you refer to a specialist? How do you support second opinions? ASK ONLY IF PCP*

b. *How do you engage the patient in the decision-making process?*

c. *How do they handle/address questions from the patient and/or family about treatment options?*

d. *Do you consider the cost of various treatment options in your decision? If yes, does that include a conversation with the patient/family about the options and costs?*

e. *How do you approach the topic of clinical trials?*

8. **What are the factors that make it easier for African-American patients to be connected to and retained in treatment?**

PROBES TO USE AS NECESSARY:

a. *Explore the influence of*
   1. *Providers, staff: temperament, cultural competency, kind, respectful, bias, discrimination*
   2. *Process and systems: forms, wait time, referrals, timely, scheduling, follow-up*
   3. *Overall environment: location, privacy, welcoming, feels safe*
   4. *Accessibility: easy to reach, timely*
   5. *Comprehensives: are they receiving the basics + cutting edge*
   6. *Social Determinants of Health*
   7. *Faith practices*
   8. *Family dynamics (getting at spousal and familial support)*
   9. *Trust/mistrust of the medical system*
   10. *Access to care, including specialists*
   11. *Financial Cost of Treatment and Time for Treatment*

9. **What are the barriers that hinder African-American women from being connected to and retained in treatment?**

PROBES TO USE AS NECESSARY:

a. *Explore the influence of*
   1. *Providers, staff: temperament, cultural competency, kind, respectful, bias, discrimination*
   2. *Process and systems: forms, wait time, referrals, timely, scheduling, follow-up*
   3. *Overall environment: location, privacy, welcoming, feels safe*
   4. *Accessibility: easy to reach, timely*
   5. *Comprehensives: are they receiving the basics + cutting edge*
   6. *Social Determinants of Health*
   7. *Faith practices*
   8. *Family dynamics (getting at spousal and familial support)*
   9. *Trust/mistrust of the medical system*
   10. *Access to care, including specialists*
   11. *Financial Cost of Treatment and Time for Treatment*

10. **What may make African-American women choose not to seek treatment even if they have health insurance and available providers?**

PROBES TO USE AS NECESSARY:

a. *Explore the influence of*
   1. *Providers, staff: temperament, cultural competency, kind, respectful, bias, discrimination*
   2. *Process and systems: forms, wait time, referrals, timely, follow-up, scheduling,*
   3. *Overall environment: location, privacy, welcoming, feels safe*
   4. *Accessibility: easy to reach, timely*
   5. *Comprehensives: are they receiving the basics + cutting edge*
   6. *Social Determinants of Health*
   7. *Faith practices*
   8. *Family dynamics (getting at spousal and familial support)*
   9. *Trust/mistrust of the medical system*
   10. *Fear of pain, losing hair, etc*
   11. *Access to care, including specialists*
   12. *Financial Cost of Treatment and Time for Treatment*

11. **What types of support services, if any, are African-American women breast cancer survivors directly referred to?**

PROBES TO USE AS NECESSARY:

a. *How adequate are the levels of support and services?*

b. *What about access to a full complement of integrative approaches to cancer treatment and survivorship including Acupuncture, Reiki, nutrition support, mindfulness-based stress reduction, meditation, therapist etc.?*

12. **What are the existing resources in place to leverage and reduce breast cancer disparities among African-American women in [insert name of metro]?**

13. **Anything else you would like to share with us?**

African-American Health Equity Initiative: From Education to Impact
Landscape Analysis
Breast Cancer Survivor Focus Group Guide

Step 1: Introduction of project and confidentiality
Thank you for joining us today. Before we start, we want to point out a few things: Snacks, restrooms, and other guidelines. [Discuss guidelines for participating and point out room exit, bathroom, and snacks.]

My name is_____ and this is my colleague_____. We are from JSI, a mission-driven public health research and consulting organization dedicated to advancing the health of individuals and communities in the United States and globally. Before we begin, I am going to explain the purpose of the group discussion. I will then answer any questions you have, and then we will start the discussion. Does that sound ok?

JSI is working with Susan G. Komen, a leading breast cancer foundation, to understand the reasons behind the differences in breast cancer [late-stage] diagnosis and mortality among African-American women across 11 US metropolitan areas. Research has found that African-American women are less likely to be diagnosed early, when breast cancer is more treatable, as compared to white women and other races. African-American women may also be less likely than other women with breast cancer to survive the disease. This is true across the country, and the gap is highest in these 11 major metropolitan areas -- [insert name of metro] is among them.

Komen wants to work to bridge this gap in access and use of high-quality breast health care for African-American women. They have launched this program to understand better why differences exist. They want to hear from you about your experiences and stories from your community.

*Komen has asked JSI to help gather this information from community members to help them plan and support the programming needed to change these conditions. This project involves talking with residents and community leaders from [insert name of metro] to understand better how to reduce late-stage breast cancer diagnosis and mortality in the African-American community. These discussions allow us to gather information from different groups to better understand what steps can be taken so that African-American women have the **same** ability to get the care and support they need if they do get breast cancer.*

Today we hope to learn from you about your knowledge and experiences with breast cancer. We recognize that this is a very personal and sensitive topic and that some questions may trigger past experiences that may or may not be pleasant. We will share local support resource and the Komen helpline after the session. We intend to make you feel as comfortable as possible discussing these topics. However, if you decide you no longer want to participate at any point, you may leave at any time.
We will begin with some general questions about your life experience and cancer journey with treatment including from treatment to follow-up care, your experience at your medical facility, the resources that were/are available to you, and any challenges or barriers you may have faced in accessing these resources/services.

How data will be used, privacy and confidentiality
Your participation in this focus group is completely voluntary, and all information you share will be kept confidential. At no time should you feel you have to answer a question. We will begin with some general questions about your general knowledge of breast cancer. Then we will move to more specific questions. This discussion should last no longer than 90 minutes, about an hour and a half.

We encourage you to share your thoughts and opinions openly and freely. But, please also be respectful of other participants' opinions. There are many women in the room, and we will all have different opinions. We don't all have to agree, but we do want to hear everyone's opinions. We will do our best to make sure everyone gets a turn to voice their opinion.

We will not write down or record names. Nothing you say will be associated with you by name. Your identity will be *kept confidential at all times, and your responses will be anonymous. We will be taking notes, and, with your permission, we will be recording this interview so we can engage in a conversation with you and not miss any of the details. These notes and the recording will be kept in a secure location in our offices, and only the project team will have access to these materials.*

We also request that you do not disclose another participant's comments and/or identity outside of the focus group. We want to respect each other's privacy and confidentiality.

After the focus groups are complete, we will write up a report summarizing the main ideas and some quotes and share with Komen to support their effort to improve breast cancer prevention and treatment. Our original notes and this recording will then be deleted. No one directly involved in your care (providers, service providers, etc.) will have access to the data.

Does anyone object to being recorded?
At the end of the session, we will provide you with $30 gift cards in appreciation of the time you have taken out of your busy day to be part of this discussion. Are there any questions about what I've just said, why we're here, or what we are going to do today?

Step 3: Answer Questions from Participants

Step 4: Confirm Consent to Participate

Based on what we just shared, we want to confirm that each of you consents or agrees to participate in today's conversation. Please read and sign the consent form that is being distributed to say "YES" if you understand and wish to participate or "No" if you do not wish to participate, and you are free to leave before we begin. Are there any other questions?

Step 5: Answer Questions (if needed)

Step 6: Turn on the Recorder

Step 7: Begin Discussion with Questions Below

1. **Let us go around the room. How long have you lived in [insert name of metro], what is one favorite thing about this area?**

As we mentioned earlier, Komen wants to understand the reasons behind the differences in breast cancer diagnosis and mortality among African-American women. An important aspect for us to discuss is your experiences with racism in your community and workplace and how racial discrimination affects the health of African-American women.

2. **Please tell me about a time you have been discriminated against because of your race? Think about where you live, work, socialize, and your experiences in seeking health care?**

PROBES TO USE AS NECESSARY:

a. *Where have you faced discrimination because of your race?*
   1. *Healthcare system*
   2. *Transportation*
   3. *Work*
   4. *Housing*
   5. *Education/School*
   6. *General profiling (e.g., grocery store, mall, police, etc.*)

b. *Have you ever been prevented from moving into a neighborhood because the landlord/realtor refused to sell or rent you a house or apartment? If yes, please tell me more.*

c. *Have you ever moved into a neighborhood where neighbors made life difficult for you or your family? If yes, please tell me more.*

d. *Have you ever been fired from a job because of your race? If yes, please tell me more.*

e. *Have you ever been denied a promotion because of your race? If yes, please tell me more.*

f. *Have you ever not been hired for a job because of your race?*

g. *While seeing a doctor, has there been a time you felt that assumptions were made about you? Tell me more. What made you feel this was happening?*

h. *Is there anything that happens in the doctor office's that makes you feel different- the doctor or staff's behavior, things they say or do, or how they look at you?*

3. **How has discrimination or racism affected your health?**

PROBES TO USE AS NECESSARY:

a. *Prevented you from getting healthcare or treatment?*

b. *Affected the quality of care you received?*

c. *Has discrimination affected the timeliness of the care you received?*

Thank you for sharing these experiences. Now we will move to the section of the discussion that focuses on breast cancer.

4. **Before being diagnosed with breast cancer, had you received clinical breast exams? Screening mammography? If yes, what motivated you to get screened?**

PROBES TO USE AS NECESSARY

a. *Explore factors behind screening (family history, following guidelines, provider's advice, community outreach programs, the experience of other women in their social network) and awareness that early screening can catch breast cancer when it might be easier to treat.*

b. *Do you feel you were aware of the signs and symptoms that one might have breast cancer? Why or why not? What factors led to this awareness? [Note: there often aren't signs as well as the common signs of unusual discharge or a lump]*

5. **How was the experience of being screened for breast cancer?**

PROBES TO USE AS NECESSARY

a. *What options were offered to you?*

b. *How did you feel throughout the process?*
   1. *Were there times you felt uncomfortable or unable to access screening?*
   2. *Did you feel you had enough time to ask questions and/or absorb information?*
   3. *Did you feel you were treated with less courtesy or respect than other people?*
   4. *Did you feel you received poorer service than other patients?*
   5. *Did you feel the provider or the staff acted as if they think you are not smart?*
   6. *Did you feel the provider or staff acted as if they are afraid of you?*
   7. *Did you feel threatened or harassed?*

c. *How old were you the first time you were screened? How often did you go after your first time?*

d. *Explore the influence of*
   1. *Providers, staff: temperament, cultural competency, kind, respectful*
   2. *Process and systems: forms, wait time, referrals, timely, follow-up*
   3. *Overall environment: location, privacy, welcoming, feels safe*
   4. *Accessibility: easy to reach, timely*

e. *Assess comprehensives and quality of care.*

6. **What was the process of being diagnosed with cancer like? We would like 1 or 2 volunteers to tell us about their experience of being diagnosed, and then we will have a chance to discuss together.**

PROBES TO USE AS NECESSARY

a. *How was your breast cancer found?*

b. *What diagnostic procedures did you have/were you offered?*

c. *As best you can remember, how long did it take to get a diagnosis? What were the challenges?*

d. *How did you select a provider/care team?*

e. *Were you referred to a breast oncologist? Breast surgeon? Who provided your treatment?*

f. *For those who wanted a second opinion, what was that experience like?*

g. *Tell us about how a care and treatment plan was developed?*
   1. *To what extent were you offered choices and provided opportunities to discuss these options with your providers?*
   2. *Did you feel comfortable to ask questions?*

h. *What type of counseling and support was offered? [Include navigation to treatment services]*
   1. *Were the associated costs, insurance coverage, co-pays, etc. discussed with you? Were you offered or referred to a financial assistant? If so, when (at what stage of the process)?*

i. *How did you feel throughout the process?*
   1. *Did you feel you had enough time to ask questions and/or absorb information?*
   2. *Did you feel you were treated with less courtesy or respect than other people?*
   3. *Did you feel you received poorer service than other patients?*
   4. *Did you feel the provider or the staff acted as if they think you are not smart?*
   5. *Did you feel the provider or staff acted as if they are afraid of you?*
   6. *Did you feel threatened or harassed?*

7. **Was hormonal therapy (e.g. Tamoxifen, Arimidex, Femara, Aromasin) part of your treatment?**

If so, was five years or ten years prescribed?

a. *PROBE: Were you able to stay on hormonal therapy for the recommended length of time? Why or why not? (they may still be on it)*

b. *PROBE: Did you ever skip a dose or cut the pills in half? If so, why or why not?*

c. *PROBE: What were the challenges?*

8. **Please share some of the factors in the decision to start treatment based on your personal experience or the experience of other African-American women, you know.**

Facilitator Note: Collect information on the understanding of the different types of breast cancers, and that treatment may be different for each type.

PROBES TO USE AS NECESSARY

a. *Who was involved in the decision to start treatment?*
   1. *Partner*
   2. *Family*
   3. *Friends*
   4. *Pastor /Clergy*

b. *Was the decision-making process different for different types of treatment (chemotherapy, surgery, radiation)?*

c. *What may make it difficult for an African-American woman in your area to start and continue the full course of breast cancer treatment if they need it?*

d. *What would facilitate the completion of the full course of treatment (for example, a full course of chemotherapy)?*
   1. *<u>Family considerations:</u> Caretaking responsibilities, spousal support*
   2. *<u>Personal/life:</u> Scheduling, time off from work, meeting family responsibilities*
   3. *<u>Fears:</u> Concerns about the procedure, concerns about side effects of treatment*
   4. *<u>Faith Practices:</u> Spiritual/religious beliefs*
   5. *<u>Accessibility:</u> Insurance, easy to reach, distance, affordable costs/co-pays, time off from work*
   6. *<u>Process and systems</u>: Forms, wait time, referrals, timely, follow-up*
   7. *<u>Providers and staff:</u> Temperament, cultural competency, kind, respectful, perceived racism, perceived trust and respect, bias, provider hostility, mistrust about the health system, no relationships with providers*
   8. *<u>Overall environment:</u> Location, privacy, welcoming, feels safe*

9. **What factors may lead to delays in starting treatment or not completing treatment even if someone has access?**

PROBES TO USE AS NECESSARY

a. *What factors may contribute to a delay in starting treatment? Ending treatment early/discontinuing treatment?*

1. *Family considerations: Caretaking responsibilities, spousal support*
2. *Personal/life: Scheduling, time off from work, meeting family responsibilities*
3. *Fears: Concerns about the procedure, concerns about side effects of treatment*
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8. *Overall environment: Location, privacy, welcoming, feels safe*

10. **Were you offered complementary or integrative medicine options to help with treatment, such as acupuncture, Reiki, nutritional support, etc.?**

PROBES TO USE AS NECESSARY

a. *If used, were these options used to complement traditional cancer treatment, or instead of?*

b. *If used, were these options recommended? If so, by whom?*

c. *If used, how were the services beneficial?*

d. *If they were not beneficial, why not?*

11. **How would you rate the quality of your breast cancer treatment from one to five, one being the lowest and five the highest quality? What does five look like?**

PROBES TO USE AS NECESSARY

a. *How did you decide where to seek treatment? What were your options?*

b. *Did your provider/care team specialize in breast cancer, or did they treat all kinds of cancers?*

c. *What have you heard or yourself experienced about African-American patients' experiences within the healthcare system?*

d. *Have you received access to a full team of providers (i.e. including a PCP, radiation oncologist, medical oncologist, surgeon/surgical oncologist, plastic surgeon (reconstruction), dietitian, social worker, receptionist/scheduler/front desk staff, chaplain/other religious contact, new patient coordinator, Program RN, patient navigator)?*

1. *Which members of your cancer team did you feel most comfortable seeing?*
2. *What is it about that provider that makes you feel comfortable?*

3. *Did you have any uncomfortable experiences? What made you uncomfortable?*
4. *Which members do you wish you could have had greater interaction with and why?*
5. *Did you feel you had enough time to ask questions and/or absorb information?*

e. *Were there times when you felt challenged or unable to access the medical care you felt you needed? Why?*

Survivorship

Facilitator Note: Please be sensitive to anyone in the room who may be living with metastatic breast cancer.

12. **How would you describe your experience(s) with care for those of you who have transitioned from being a patient in treatment to post-treatment?**

PROBES TO USE AS NECESSARY

a. *How has your care been coordinated between your oncology team and your primary care provider? Did you receive a survivorship care plan? Was this helpful?*

b. *Have you had adequate support to address your emotional/social, health, and economic needs as a cancer survivor?*

c. *What support has your family needed? When? At diagnosis? After treatment?*

d. *Have you made any lifestyle changes as a result of your experience as a cancer survivor?*

e. *Have you sought additional support from fellow survivors (i.e., support groups)?*

13. **What resources were available to you and your family from your cancer treatment medical facility, another healthcare organization, or any other community organization following your treatment?**

PROBES TO USE AS NECESSARY

a. *What type of resources were available to you (e.g., financial, stress management/healthy living, emotional, spiritual resources)?*
1. *How did you come to know about these? Did you have to ask?*
2. *Did you access these resources or have adequate support for doing so?*

b. *Do women have access to a full complement of holistic approaches to cancer treatment and survivorship such as acupuncture, reiki, nutrition support, mindfulness-based stress reduction, meditation, therapist, etc.?*
1. *If used, how were the services beneficial?*

2. *If they were not beneficial, why not?*

c. *Were there times when you felt challenged or unable to access the support, information, or resources you felt you needed? Why?*

1. *Would it be useful to have learned about these resources sooner than you did?*
2. *At what point would the services have been more useful?*
3. *Was there a cost/fee to access any of the resources/information?*

14. **What else might be helpful to you or other African-American women cancer survivors and their families?**

Step 8: Thank you for your participation.

African-American Health Equity Initiative: From Education to Impact
Landscape Analysis
Breast Cancer Survivor Focus Group Guide

Step 1: Introduction of project and confidentiality

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We will begin with some general questions about your life experience and cancer journey with treatment including from treatment to follow-up care, your experience at your medical facility, the resources that were/are available to you, and any challenges or barriers you may have faced in accessing these resources/services.

How data will be used, privacy and confidentiality

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We encourage you to share your thoughts and opinions openly and freely. But, please also be respectful of other participants' opinions. There are many women in the room, and we will all have different opinions. We don't all have to agree, but we do want to hear everyone's opinions. We will do our best to make sure everyone gets a turn to voice their opinion.
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Step 3: Answer Questions from Participants

Step 4: Confirm Consent to Participate

Based on what we just shared, we want to confirm that each of you consents or agrees to participate in today's conversation. Please read and sign the consent form that is being distributed to say "YES" if you understand and wish to participate or "No" if you do not wish to participate, and you are free to leave before we begin. Are there any other questions?

Step 5: Answer Questions (if needed)

Step 6: Turn on the Recorder

Step 7: Begin Discussion with Questions Below

1. **Let us go around the room. How long have you lived in [insert name of metro], what is one favorite thing about this area?**[Text Wrapping Break]

As we mentioned earlier, Komen wants to understand the reasons behind the differences in breast cancer diagnosis and mortality among African-American women. An important aspect for us to discuss is your experiences with racism in your community and workplace and how racial discrimination affects the health of African-American women.

2. **Please tell me about a time you have been discriminated against because of your race? Think about where you live, work, socialize, and your experiences in seeking health care?**

PROBES TO USE AS NECESSARY:

a. *Where have you faced discrimination because of your race?*
   1. *Healthcare system*
   2. *Transportation*
   3. *Work*
   4. *Housing*
   5. *Education/School*
   6. *General profiling (e.g., grocery store, mall, police, etc.)*

b. *Have you ever been prevented from moving into a neighborhood because the landlord/realtor refused to sell or rent you a house or apartment? If yes, please tell me more.*

c. *Have you ever moved into a neighborhood where neighbors made life difficult for you or your family? If yes, please tell me more.*

d. *Have you ever been fired from a job because of your race? If yes, please tell me more.*

e. *Have you ever been denied a promotion because of your race? If yes, please tell me more.*

f. *Have you ever not been hired for a job because of your race?*

g. *While seeing a doctor, has there been a time you felt that assumptions were made about you? Tell me more. What made you feel this was happening?*

h. *Is there anything that happens in the doctor office's that makes you feel different- the doctor or staff's behavior, things they say or do, or how they look at you?*

3. **How has discrimination or racism affected your health?**

PROBES TO USE AS NECESSARY:

a. *Prevented you from getting healthcare or treatment?*

b. *Affected the quality of care you received?*

c. *Has discrimination affected the timeliness of the care you received?*

Thank you for sharing these experiences. Now we will move to the section of the discussion that focuses on breast cancer.

4. **Before being diagnosed with breast cancer, had you received clinical breast exams? Screening mammography? If yes, what motivated you to get screened?**

PROBES TO USE AS NECESSARY

a. *Explore factors behind screening (family history, following guidelines, provider's advice, community outreach programs, the experience of other women in their social network) and awareness that early screening can catch breast cancer when it might be easier to treat.*

b. *Do you feel you were aware of the signs and symptoms that one might have breast cancer? Why or why not? What factors led to this awareness? [Note: there often aren't signs as well as the common signs of unusual discharge or a lump]*

5. **How was the experience of being screened for breast cancer?**

PROBES TO USE AS NECESSARY

a. *What options were offered to you?*

b. *How did you feel throughout the process?*
   1. *Were there times you felt uncomfortable or unable to access screening?*
   2. *Did you feel you had enough time to ask questions and/or absorb information?*
   3. *Did you feel you were treated with less courtesy or respect than other people?*
   4. *Did you feel you received poorer service than other patients?*
   5. *Did you feel the provider or the staff acted as if they think you are not smart?*
   6. *Did you feel the provider or staff acted as if they are afraid of you?*
   7. *Did you feel threatened or harassed?*

c. *How old were you the first time you were screened? How often did you go after your first time?*

d. *Explore the influence of*
   1. *Providers, staff: temperament, cultural competency, kind, respectful*
   2. *Process and systems: forms, wait time, referrals, timely, follow-up*
   3. *Overall environment: location, privacy, welcoming, feels safe*
   4. *Accessibility: easy to reach, timely*

e. *Assess comprehensives and quality of care.*

6. **What was the process of being diagnosed with cancer like? We would like 1 or 2 volunteers to tell us about their experience of being diagnosed, and then we will have a chance to discuss together.**

PROBES TO USE AS NECESSARY

a. *How was your breast cancer found?*

b. *What diagnostic procedures did you have/were you offered?*

c. *As best you can remember, how long did it take to get a diagnosis? What were the challenges?*

d. *How did you select a provider/care team?*

e. *Were you referred to a breast oncologist? Breast surgeon? Who provided your treatment?*

f. *For those who wanted a second opinion, what was that experience like?*

g. *Tell us about how a care and treatment plan was developed?*
   1. *To what extent were you offered choices and provided opportunities to discuss these options with your providers?*
   2. *Did you feel comfortable to ask questions?*

h. *What type of counseling and support was offered? [Include navigation to treatment services]*
   1. *Were the associated costs, insurance coverage, co-pays, etc. discussed with you? Were you offered or referred to a financial assistant? If so, when (at what stage of the process)?*

i. *How did you feel throughout the process?*
   1. *Did you feel you had enough time to ask questions and/or absorb information?*
   2. *Did you feel you were treated with less courtesy or respect than other people?*
   3. *Did you feel you received poorer service than other patients?*
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   5. *Did you feel the provider or staff acted as if they are afraid of you?*
   6. *Did you feel threatened or harassed?*

7. **Was hormonal therapy (e.g. Tamoxifen, Arimidex, Femara, Aromasin) part of your treatment?**
   If so, was five years or ten years prescribed?

   a. *PROBE: Were you able to stay on hormonal therapy for the recommended length of time? Why or why not? (they may still be on it)*

   b. *PROBE: Did you ever skip a dose or cut the pills in half? If so, why or why not?*

   c. *PROBE: What were the challenges?*

8. **Please share some of the factors in the decision to start treatment based on your personal experience or the experience of other African-American women, you know.**

Facilitator Note: Collect information on the understanding of the different types of breast cancers, and that treatment may be different for each type.

PROBES TO USE AS NECESSARY

a. *Who was involved in the decision to start treatment?*
   1. *Partner*
   2. *Family*
   3. *Friends*
   4. *Pastor /Clergy*

b. *Was the decision-making process different for different types of treatment (chemotherapy, surgery, radiation)?*

c. *What may make it difficult for an African-American woman in your area to start and continue the full course of breast cancer treatment if they need it?*

d. *What would facilitate the completion of the full course of treatment (for example, a full course of chemotherapy)?*
   1. *<u>Family considerations:</u> Caretaking responsibilities, spousal support*
   2. *<u>Personal/life:</u> Scheduling, time off from work, meeting family responsibilities*
   3. *<u>Fears:</u> Concerns about the procedure, concerns about side effects of treatment*
   4. *<u>Faith Practices:</u> Spiritual/religious beliefs*
   5. *<u>Accessibility:</u> Insurance, easy to reach, distance, affordable costs/co-pays, time off from work*
   6. *<u>Process and systems</u>: Forms, wait time, referrals, timely, follow-up*
   7. *<u>Providers and staff:</u> Temperament, cultural competency, kind, respectful, perceived racism, perceived trust and respect, bias, provider hostility, mistrust about the health system, no relationships with providers*
   8. *<u>Overall environment:</u> Location, privacy, welcoming, feels safe*

9. **What factors may lead to delays in starting treatment or not completing treatment even if someone has access?**

PROBES TO USE AS NECESSARY

a. *What factors may contribute to a delay in starting treatment? Ending treatment early/discontinuing treatment?*
   1. *<u>Family considerations:</u> Caretaking responsibilities, spousal support*
   2. *<u>Personal/life:</u> Scheduling, time off from work, meeting family responsibilities*
   3. *<u>Fears:</u> Concerns about the procedure, concerns about side effects of treatment*
   4. *<u>Faith Practices:</u> Spiritual/religious beliefs*
   5. *<u>Accessibility:</u> Insurance, easy to reach, distance, affordable costs/co-pays, time off from work*
   6. *<u>Process and systems</u>: Forms, wait time, referrals, timely, follow-up*

7. *Providers and staff:* *Temperament, cultural competency, kind, respectful, perceived racism, perceived trust and respect, bias, provider hostility, mistrust about the health system, no relationships with providers*
8. *Overall environment:* *Location, privacy, welcoming, feels safe*

10. **Were you offered complementary or integrative medicine options to help with treatment, such as acupuncture, Reiki, nutritional support, etc.?**

PROBES TO USE AS NECESSARY

a. *If used, were these options used to complement traditional cancer treatment, or instead of?*

b. *If used, were these options recommended? If so, by whom?*

c. *If used, how were the services beneficial?*

d. *If they were not beneficial, why not?*

11. **How would you rate the quality of your breast cancer treatment from one to five, one being the lowest and five the highest quality? What does five look like?**

PROBES TO USE AS NECESSARY

a. *How did you decide where to seek treatment? What were your options?*

b. *Did your provider/care team specialize in breast cancer, or did they treat all kinds of cancers?*

c. *What have you heard or yourself experienced about African-American patients' experiences within the healthcare system?*

d. *Have you received access to a full team of providers (i.e. including a PCP, radiation oncologist, medical oncologist, surgeon/surgical oncologist, plastic surgeon (reconstruction), dietitian, social worker, receptionist/scheduler/front desk staff, chaplain/other religious contact, new patient coordinator, Program RN, patient navigator)?*
1. *Which members of your cancer team did you feel most comfortable seeing?*
2. *What is it about that provider that makes you feel comfortable?*
3. *Did you have any uncomfortable experiences? What made you uncomfortable?*
4. *Which members do you wish you could have had greater interaction with and why?*
5. *Did you feel you had enough time to ask questions and/or absorb information?*

e. *Were there times when you felt challenged or unable to access the medical care you felt you needed? Why?*

Survivorship

Facilitator Note: Please be sensitive to anyone in the room who may be living with metastatic breast cancer.

12. **How would you describe your experience(s) with care for those of you who have transitioned from being a patient in treatment to post-treatment?**

PROBES TO USE AS NECESSARY

a. *How has your care been coordinated between your oncology team and your primary care provider? Did you receive a survivorship care plan? Was this helpful?*

b. *Have you had adequate support to address your emotional/social, health, and economic needs as a cancer survivor?*

c. *What support has your family needed? When? At diagnosis? After treatment?*

d. *Have you made any lifestyle changes as a result of your experience as a cancer survivor?*

e. *Have you sought additional support from fellow survivors (i.e., support groups)?*

13. **What resources were available to you and your family from your cancer treatment medical facility, another healthcare organization, or any other community organization following your treatment?**

PROBES TO USE AS NECESSARY

a. *What type of resources were available to you (e.g., financial, stress management/healthy living, emotional, spiritual resources)?*
   1. *How did you come to know about these? Did you have to ask?*
   2. *Did you access these resources or have adequate support for doing so?*

b. *Do women have access to a full complement of holistic approaches to cancer treatment and survivorship such as acupuncture, reiki, nutrition support, mindfulness-based stress reduction, meditation, therapist, etc.?*
   1. *If used, how were the services beneficial?*
   2. *If they were not beneficial, why not?*

c. *Were there times when you felt challenged or unable to access the support, information, or resources you felt you needed? Why?*
   1. *Would it be useful to have learned about these resources sooner than you did?*
   2. *At what point would the services have been more useful?*
   3. *Was there a cost/fee to access any of the resources/information?*

14. **What else might be helpful to you or other African-American women cancer survivors and their families?**

Step 8: Thank you for your participation.

References

Acevedo-Garcia, D., Lochner, K. A., Osypuk, T. L., & Subramanian, S. V. (2003). Future directions in residential segregation and health research: a multilevel approach. Am J Public Health, 93(2), 215-221. doi:10.2105/ajph.93.2.215

Agency for Toxic Substances and Disease Registry. (2018). CDC's Social Vulnerability Index: What is the SVI? Retrieved from https://svi.cdc.gov/

American Cancer Society. Breast Cancer. Retrieved from https://www.cancer.org/cancer/breast-cancer.html

American Cancer Society. (2019a). Breast Cancer Facts & Figures 2019-2020. Retrieved from https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/breast-cancer-facts-and-figures/breast-cancer-facts-and-figures-2019-2020.pdf

American Cancer Society. (2019b). Cancer Facts & Figures for Blacks, 2019-2020. Retrieved from https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/cancer-facts-and-figures-for-african-americans/cancer-facts-and-figures-for-african-americans-2019-2021.pdf

American Cancer Society. (2020). Cancer Facts & Figures 2020. Retrieved from https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/annual-cancer-facts-and-figures/2020/cancer-facts-and-figures-2020.pdf

American Cancer Society. (2021). Cancer Facts and Figures 2021. Atlanta, GA: American Cancer Society.

Andrasfay, T., Himmelstein, G., & Querin, F. (2019). Medical Redlining: Demographic and local area characteristics associated with hospital closure in U.S. cities. Retrieved from http://paa2019.populationassociation.org/uploads/190116

Ansell, D., Grabler, P., Whitman, S., Ferrans, C., Burgess-Bishop, J., Murray, L. R., . . . Marcus, E. (2009). A community effort to reduce the black/white breast cancer mortality disparity in Chicago. Cancer Causes Control, 20(9), 1681-1688. doi:10.1007/s10552-009-9419-7

Artiga, S., & Hinton, E. (2018). Beyond Health Care: The Role of Social Determinants in Promoting Health and Health Equity. The Henry J. Kaiser Family Foundation. Retrieved from https://www.kff.org/disparities-policy/issue-brief/beyond-health-care-the-role-of-social-determinants-in-promoting-health-and-health-equity/

Bailey, Z. D., Krieger, N., Agénor, M., Graves, J., Linos, N., & Bassett, M. T. (2017). Structural racism and health inequities in the USA: evidence and interventions. The Lancet, 389(10077), 1453-1463. doi:10.1016/S0140-6736(17)30569-X

Bauer, M. S., Damschroder, L., Hagedorn, H., Smith, J., & Kilbourne, A. M. (2015). An introduction to implementation science for the non-specialist. BMC Psychol, 3, 32. doi:10.1186/s40359-015-0089-9

Berchick, E. R., Barnett, J. C., & Upton, R. D. (2019). Health Insurance Coverage in the United States: 2018. Retrieved from https://www.census.gov/library/publications/2019/demo/p60-267.html

Bravo, M. A., Anthopolos, R., Bell, M. L., & Miranda, M. L. (2016). Racial isolation and exposure to airborne particulate matter and ozone in understudied US populations: Environmental justice applications of downscaled numerical model output. Environ Int, 92-93, 247-255. doi:10.1016/j.envint.2016.04.008

Brooks, T., Roygardner, L., & Artiga, S. (2019). Medicaid and CHIP Eligibility, Enrollment, and Cost Sharing Policies as of January 2019: Findings from a 50-State Survey. Retrieved from http://files.kff.org/attachment/Report-Medicaid-and-CHIP-Eligibility-Enrollment-Renewal-and-Cost-Sharing-Policies-as-of-January-2019

Buchmueller, T. C., & Levy, H. G. (2020). The ACA's Impact On Racial And Ethnic Disparities In Health Insurance Coverage And Access To Care. Health Affairs (Millwood), 39(3), 395-402. doi:10.1377/hlthaff.2019.01394

Cauley Narain, K. D., & Zimmerman, F. J. (2019). Medicaid work requirements: a really bad idea for increasing employment. Journal of Epidemiology and Community Health, 73(1), 1. doi:10.1136/jech-2018-210714

Centers for Disease Control and Prevention. National Breast and Cervical Cancer Early Detection Program (NBCCEDP). Retrieved from https://www.cdc.gov/cancer/nbccedp/index.htm

Centers for Disease Control and Prevention. (2020). Georgia | Five-Year Summary: July 2014 to June 2019. National Breast and Cervical Cancer Early Detection Program (NBCCEDP). Retrieved from https://www.cdc.gov/cancer/nbccedp/data/summaries/georgia.htm

Centers for Disease Control and Prevention (2019). Social Determinants of Health. Retrieved from www.cdc.gov/nchhstp/socialdeterminants/index.html.

Centers for Medicare & Medicaid Services. 1115 Community Engagement Initiative. Retrieved from https://www.medicaid.gov/medicaid/section-1115-demonstrations/1115-community-engagement-initiative/index.html

Centers for Medicare & Medicaid Services. Affordable Care Act (ACA). Retrieved from https://www.healthcare.gov/glossary/affordable-care-act/

Centers for Medicare & Medicaid Services. High Deductible Health Plan (HDHP). Retrieved from https://www.healthcare.gov/glossary/high-deductible-health-plan/

Centers for Medicare & Medicaid Services. (2020). Georgia Pathways to Coverage. Retrieved from https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/ga/ga-pathways-to-coverage-ca.pdf

Collins, C. A., & Williams, D. R. (1999). Segregation and Mortality: The Deadly Effects of Racism? Sociological Forum, 14(3), 495-523. doi:10.1023/A:1021403820451

County Health Rankings. (2016). County Health Rankings Model. Retrieved from https://www.countyhealthrankings.org/resources/county-health-rankings-model

County Health Rankings. (2020a). Adult Obesity. Retrieved from: https://www.countyhealthrankings.org/explore-health-rankings/measures-data-sources/county-health-rankings-model/health-factors/health-behaviors/diet-exercise/adult-obesity

County Health Rankings. (2020b). Food Insecurity. Retrieved from: https://www.countyhealthrankings.org/explore-health-rankings/measures-data-sources/county-health-rankings-model/health-factors/health-behaviors/diet-exercise/food-insecurity

County Health Rankings. (2020c). Limited Access to Healthy Foods*. Retrieved from: https://www.countyhealthrankings.org/explore-health-rankings/measures-data-sources/county-health-rankings-model/health-factors/health-behaviors/diet-exercise/limited-access-to-healthy-foods

County Health Rankings. (2020d). Premature age-adjusted mortality*. Retrieved from: https://www.countyhealthrankings.org/explore-health-rankings/measures-data-sources/county-health-rankings-model/health-outcomes/length-of-life/premature-age-adjusted-mortality

County Health Rankings. (2020e). Residential Segregation - Black/White*. Retrieved from: https://www.countyhealthrankings.org/explore-health-rankings/measures-data-sources/county-health-rankings-model/health-factors/social-and-economic-factors/family-social-support/residential-segregation-blackwhite

Cozier, Y. C., Wise, L. A., Palmer, J. R., & Rosenberg, L. (2009). Perceived racism in relation to weight change in the Black Women's Health Study. Ann Epidemiol, 19(6), 379-387. doi:10.1016/j.annepidem.2009.01.008

Curtis, E., Quale, C., Haggstrom, D., & Smith-Bindman, R. (2008). Racial and ethnic differences in breast cancer survival: how much is explained by screening, tumor severity, biology, treatment, comorbidities, and demographics? Cancer, 112(1), 171-180. doi:10.1002/cncr.23131

Daly, B., & Olopade, O. I. (2015). A perfect storm: How tumor biology, genomics, and health care delivery patterns collide to create a racial survival disparity in breast cancer and proposed interventions for change. A Cancer Journal for Clinicians, 65(3), 221-238. doi:10.3322/caac.21271

Dietze, E. C., Sistrunk, C., Miranda-Carboni, G., O'Regan, R., & Seewaldt, V. L. (2015). Triple-negative breast cancer in African-American women: disparities versus biology. Nature Reviews Cancer, 15(4), 248-254. doi:10.1038/nrc3896

Elshof, LE, Schmidt, MK, Rutgers, EJT, van Leeuwen, FE, Wesseling, J, Schaapveld, M. (2017). Cause-specific mortality in a population-based cohort of 9799 women treated for ductal carcinoma in situ. Ann. Surg. 2017;267:952–958. doi: 10.1097/SLA.0000000000002239. [PMC free article] [PubMed] [CrossRef] [Google Scholar]

Fazeli Dehkordy, S., Fendrick, A. M., Bell, S., Kamdar, N., Kobernik, E., Dalton, V. K., & Carlos, R. C. (2019). Breast Screening Utilization and Cost Sharing Among Employed Insured Women Following the Affordable Care Act: Impact of Race and Income. Journal of Women's Health (Larchmont). doi:10.1089/jwh.2018.7403

Fedewa, S. A., Yabroff, K. R., Smith, R. A., Goding Sauer, A., Han, X., & Jemal, A. (2019). Changes in Breast and Colorectal Cancer Screening After Medicaid Expansion Under the Affordable Care Act. Am J Prev Med, 57(1), 3-12. doi:10.1016/j.amepre.2019.02.015

Felitti, V. J., Anda, R. F., Nordenberg, D., Williamson, D. F., Spitz, A. M., Edwards, V., . . . Marks, J. S. (1998). Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults. The Adverse Childhood Experiences (ACE) Study. Am J Prev Med, 14(4), 245-258.

Fisher, ER, Dignam, J, Tan-Chiu, E, Costantino, J, Fisher, B, Paik, S, et al. (1999). Pathologic findings from the National Surgical Adjuvant Breast Project (NSABP) eight-year update of Protocol B-17: intraductal carcinoma. Cancer. 1999;86:429–438. doi: 10.1002/(SICI)1097-0142(19990801)86:3<429::AID-CNCR11>3.0.CO;2-Y. [PubMed] [CrossRef] [Google Scholar]

Ford, D., Easton, D., Bishop, D., Narod, S., & Golgar, D. (1994). Risks of cancer in BRCA1-mutation carriers. Breast Cancer Linkage Consortium. Lancet. 1994 343:692-5. PMID: 7907678

Gallups, S. F., Connolly, M. C., Bender, C. M., & Rosenzweig, M. Q. (2018). Predictors of Adherence and Treatment Delays among Black Women Recommended to Receive Breast Cancer Chemotherapy. Womens Health Issues, 28(6), 553-558. doi:10.1016/j.whi.2018.08.001

Garfield, R., Orgera, K., & Damico, A. (2020). The Coverage Gap: Uninsured Poor Adults in States that Do Not Expand Medicaid. The Henry J. Kaiser Family Foundation. Retrieved from https://www.kff.org/medicaid/issue-brief/the-coverage-gap-uninsured-poor-adults-in-states-that-do-not-expand-medicaid/

Garfield, R., Rudowitz, R., Orgera, K., & Damico, A. (2019). Understanding the Intersection of Medicaid and Work: What Does the Data Say? Retrieved from https://www.kff.org/medicaid/issue-brief/understanding-the-intersection-of-medicaid-and-work-what-does-the-data-say/

Gaskin, D. J., Dinwiddie, G. Y., Chan, K. S., & McCleary, R. (2012). Residential segregation and disparities in health care services utilization. Med Care Res Rev, 69(2), 158-175. doi:10.1177/1077558711420263

Georgia Cancer Control Consortium. (2014). Georgia Cancer Plan 2014-2019.

Gordis, L. (2000). Epidemiology: W.B. Saunders.

Green, A. K., Aviki, E. M., Matsoukas, K., Patil, S., Korenstein, D., & Blinder, V. (2018). Racial disparities in chemotherapy administration for early-stage breast cancer: a systematic review and meta-analysis. Breast Cancer Res Treat, 172(2), 247-263. doi:10.1007/s10549-018-4909-5

Gupta, V., Haque, I., Chakraborty, J., Graff, S., Banerjee, S., & Banerjee, S. K. (2018). Racial disparity in breast cancer: can it be mattered for prognosis and therapy. J Cell Commun Signal, 12(1), 119-132. doi:10.1007/s12079-017-0416-4

Halpern, M. T., & Holden, D. J. (2012). Disparities in timeliness of care for U.S. Medicare patients diagnosed with cancer. Current Oncology, 19(6), e404-413. doi:10.3747/co.19.1073

Hawley, S. T., Fagerlin, A., Janz, N. K., & Katz, S. J. (2008). Racial/ethnic disparities in knowledge about risks and benefits of breast cancer treatment: does it matter where you go? Health Serv Res, 43(4), 1366-1387. doi:10.1111/j.1475-6773.2008.00843.x

Health Resources & Services Administration. MUA Find. Retrieved from: https://data.hrsa.gov/tools/shortage-area/mua-find

Hill, J. O., & Peters, J. C. (1998). Environmental contributions to the obesity epidemic. Science, 280(5368), 1371-1374. doi:10.1126/science.280.5368.1371

Hoffman, H. J., LaVerda, N. L., Levine, P. H., Young, H. A., Alexander, L. M., Patierno, S. R., & District of Columbia Citywide Patient Navigator Research Program Research, G. (2011). Having health insurance does not eliminate race/ethnicity-associated delays in breast cancer diagnosis in the District of Columbia. Cancer, 117(16), 3824-3832. doi:10.1002/cncr.25970

Holkup, P. A., Tripp-Reimer, T., Salois, E. M., & Weinert, C. (2004). Community-based participatory research: an approach to intervention research with a Native American community. ANS. Advances in nursing science, 27(3), 162-175. doi:10.1097/00012272-200407000-00002

Houterman, S., Janssen-Heijnen, M. L., Verheij, C. D., Louwman, W. J., Vreugdenhil, G., van der Sangen, M. J., & Coebergh, J. W. (2004). Comorbidity has negligible impact on treatment and complications but influences survival in breast cancer patients. British Journal of Cancer, 90(12), 2332-2337. doi:10.1038/sj.bjc.6601844

Howlader N, Noone AM, Krapcho M, et al. (2020). Cancer Statistics Review, 1975-2017. Table 4.13: Cancer of the female breast (invasive): 5-year relative and period survival by race, diagnosis year, age and stage at diagnosis. National Cancer Institute. Bethesda, MD. Accessed on April 27, 2020. https://seer.cancer.gov/csr/1975_2017/, 2020.

Howlader N, Noone AM, Krapcho M, Miller D, Brest A, Yu M, Ruhl J, Tatalovich Z, Mariotto A, Lewis DR, Chen HS, Feuer EJ, Cronin KA (Eds). (2020). SEER Cancer Statistics Review, 1975-2017, National Cancer Institute. Bethesda, MD, https://seer.cancer.gov/csr/1975_2017/, based on November 2019 SEER data submission, posted to the SEER web site, April 2020.

Huang, H., Apouey, B., & Andrews, J. (2014) Racial and Ethnic Disparities in Awareness of Cancer Genetic Testing Among Online Users: Internet Use, Health Knowledge, and Socio-Demographic Correlates. Journal of Consumer Health on the Internet 18:1, pages 15-30.

Institute of Medicine Committee on Prevention of Obesity in Children & Youth. (2005). The National Academies Collection: Reports funded by National Institutes of Health. In J. P. Koplan, C. T. Liverman, & V. I. Kraak (Eds.), Preventing Childhood Obesity: Health in the Balance. Washington (DC): National Academies Press (US). National Academy of Sciences.

Institute of Medicine Committee on Understanding and Eliminating Racial Ethnic Disparities in Health Care. (2003). In B. D. Smedley, A. Y. Stith, & A. R. Nelson (Eds.), Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care. Washington (DC): National Academies Press (US) Copyright 2002 by the National Academy of Sciences. All rights reserved.

Institute of Medicine of the National Academies. (2011). Breast Cancer and the Environment: A Life Course Approach. Retrieved from http://www.nationalacademies.org/hmd/~/media/Files/Report%20Files/2011/Breast-Cancer-Environment/BreastCancerReportbrief_2.pdf

Jones, C. P. (2000). Levels of racism: a theoretic framework and a gardener's tale. Am J Public Health, 90(8), 1212-1215. doi:10.2105/ajph.90.8.1212

Kania, J., & Kramer, M. (2011). Collective Impact. Stanford Social Innovation Review, 9.

King, K. E., Morenoff, J. D., & House, J. S. (2011). Neighborhood context and social disparities in cumulative biological risk factors. Psychosom Med, 73(7), 572-579. doi:10.1097/PSY.0b013e318227b062

Ko, D., Andreopoulou, E., & Moo, T.-A. (2016). Is Race a Prognostically Significant Factor in Survival Outcomes for Breast Cancer Among Caucasian and African- American Women? Clinics in Surgery, 1.

Kramer, M. R., & Hogue, C. R. (2009). Is segregation bad for your health? Epidemiol Rev, 31, 178-194. doi:10.1093/epirev/mxp001

Krieger, N. (2014). Discrimination and health inequities. Int J Health Serv, 44(4), 643-710. doi:10.2190/HS.44.4.b

Krieger, N., Jahn, J. L., & Waterman, P. D. (2017). Jim Crow and estrogen-receptor-negative breast cancer: US-born black and white non-Hispanic women, 1992-2012. Cancer Causes Control, 28(1), 49-59. doi:10.1007/s10552-016-0834-2

Krueger, R. A., & Casey, M. A. (2015). Focus groups : a practical guide for applied research.

Kumanyika, S. K., Van Horn, L., Bowen, D., Perri, M. G., Rolls, B. J., Czajkowski, S. M., & Schron, E. (2000). Maintenance of dietary behavior change. Health Psychol, 19(1s), 42-56. doi:10.1037/0278-6133.19.suppl1.42

Kwate, N. O. A., Valdimarsdottir, H. B., Guevarra, J. S., & Bovbjerg, D. H. (2003). Experiences of racist events are associated with negative health consequences for Black women. Journal of the National Medical Association, 95(6), 450-460.

Landrine, H., & Corral, I. (2009). Separate and unequal: residential segregation and black health disparities. Ethn Dis, 19(2), 179-184.

Lee, N. C., & Wolitski, R. (2016). Tools to Promote Gender Responsiveness in HIV Prevention Programs for Women and Girls. Retrieved from https://www.womenshealth.gov/blog/gender-responsiveness-hiv

Masi, C. M., & Gehlert, S. (2009). Perceptions of breast cancer treatment among African-American women and men: implications for interventions. J Gen Intern Med, 24(3), 408-414. doi:10.1007/s11606-008-0868-6

McLeroy, K. R., Bibeau, D., Steckler, A., & Glanz, K. (1988). An ecological perspective on health promotion programs. Health Educ Q, 15(4), 351-377. doi:10.1177/109019818801500401

Mendez, D. D., Hogan, V. K., & Culhane, J. F. (2014). Institutional racism, neighborhood factors, stress, and preterm birth. Ethnicity & Health, 19(5), 479-499. doi:10.1080/13557858.2013.846300

Merkin, S. S., Basurto-Davila, R., Karlamangla, A., Bird, C. E., Lurie, N., Escarce, J., & Seeman, T. (2009). Neighborhoods and cumulative biological risk profiles by race/ethnicity in a national sample of U.S. adults: NHANES III. Ann Epidemiol, 19(3), 194-201. doi:10.1016/j.annepidem.2008.12.006

Merriam-Webster. White Flight. Merriam-Webster Dictionary. Retrieved from https://www.merriam-webster.com/dictionary/white%20flight

Miller, S., & Wherry, L. R. State Level Mortality Estimates Based on Miller et al. 2019 NBER Working Paper 26081. Retrieved from http://www-personal.umich.edu/~mille/ACAMortality_ByState.pdf

Morrow M, & Katz, SJ (2015). Addressing overtreatment in DCIS: what should physicians do now? J. Natl. Cancer Inst. 2015;107:djv290. doi: 10.1093/jnci/djv290. [PubMed] [CrossRef] [Google Scholar]

Nagel, G., Wedding, U., Rohrig, B., & Katenkamp, D. (2004). The impact of comorbidity on the survival of postmenopausal women with breast cancer. J Cancer Res Clin Oncol, 130(11), 664-670. doi:10.1007/s00432-004-0594-3

National Cancer Institute (2021). BRCA gene Mutations: Cancer risk and genetic testing fact sheet. (2020, November 19). Retrieved April 16, 2021, from https://www.cancer.gov/about-cancer/causes-prevention/genetics/brca-fact-sheet#what-are-brca1-and-brca

National Cancer Institute. (2020). Measures of Cancer Prevalence. Retrieved from https://surveillance.cancer.gov/prevalence/measures.html

National Cancer Institute (2017). The Genetics of Cancer. (2017, October 12). https://www.cancer.gov/about-cancer/causes-prevention/genetics#ui-id-4

National Cancer Institute. Hazard Ratio. NCI Dictionary of Cancer Terms. Retrieved from https://www.cancer.gov/publications/dictionaries/cancer-terms/def/hazard-ratio

National Cancer Institute. SEER*Stat Tutorials: Calculating Age-adjusted Rates. Retrieved from https://seer.cancer.gov/seerstat/tutorials/aarates/definition.html

National Cancer Institute. State Cancer Profiles: Death Rates Table. Retrieved from: https://statecancerprofiles.cancer.gov/deathrates/index.php

National Cancer Institute. State Cancer Profiles: Incidence Rates Table. Retrieved from: https://statecancerprofiles.cancer.gov/incidencerates/index.php

National Cancer Institute. State Cancer Profiles: Prevalence Table. Retrieved from: https://statecancerprofiles.cancer.gov/prevalence/index.php

National Conference of State Legislatures. (2018). Medicaid Waivers in the States | Seven FAQs. Retrieved from https://www.ncsl.org/research/health/medicaid-waivers-in-the-states-seven-faqs.aspx

Newman, L. A. (2017). Breast Cancer Disparities: Socioeconomic Factors versus Biology. Ann Surg Oncol, 24(10), 2869-2875. doi:10.1245/s10434-017-5977-1

Newschaffer, C. J., Bush, T. L., & Penberthy, L. T. (1997). Comorbidity measurement in elderly female breast cancer patients with administrative and medical records data. J Clin Epidemiol, 50(6), 725-733. doi:10.1016/s0895-4356(97)00050-4

Noone AM, Howlader N, Krapcho M, et al. (editors). SEER Cancer Statistics Review, 1975-2017. Table 4.18. Cancer of the female breast (invasive): Age-adjusted rates and trends by race/ethnicity, 2013-2017. National Cancer Institute. Bethesda, MD. Accessed on April 27, 2020. http://seer.cancer.gov/csr/1975_2017/, 2020.

Nurgalieva, Z. Z., Franzini, L., Morgan, R. O., Vernon, S. W., Liu, C. C., & Du, X. L. (2013). Impact of timing of adjuvant chemotherapy initiation and completion after surgery on racial disparities in survival among women with breast cancer. Medical Oncology, 30(1), 419. doi:10.1007/s12032-012-0419-1

Office of Policy Development and Research (PD&R). (2019). Consolidated Planning/CHAS Data. Retrieved from: https://www.huduser.gov/portal/datasets/cp.html

Office of the Assistant Secretary for Planning and Evaluation. Prior HHS Poverty Guidelines and Federal Register References. Retrieved from https://aspe.hhs.gov/prior-hhs-poverty-guidelines-and-federal-register-references

Padamsee, T. J., Meadows, R., & Hils, M. (2018). Layers of information: interacting constraints on breast cancer risk-management by high-risk Black women. Ethnicity & Health, 1-24. doi:10.1080/13557858.2018.1562053

Phillips, S. P. (2005). Defining and measuring gender: A social determinant of health whose time has come. Int J Equity Health, 4(1), 11. doi:10.1186/1475-9276-4-11

Richards, L., & Morse, J. M. (2013). Readme First For a User's Guide to Qualitative Methods. Los Angeles: Sage.

Rothstein, R. (2017). The Color of Law: A Forgotten History of How Our Government Segregated America (First edition. ed.). New York ; London: Liveright Publishing Corporation, a division of W.W. Norton & Company.

Russ, S. A., Larson, K., Tullis, E., & Halfon, N. (2014). A lifecourse approach to health development: implications for the maternal and child health research agenda. Matern Child Health J, 18(2), 497-510. doi:10.1007/s10995-013-1284-z

Samson, M. E., Porter, N. G., Hurley, D. M., Adams, S. A., & Eberth, J. M. (2016). Disparities in Breast Cancer Incidence, Mortality, and Quality of Care among Black and European American Women in South Carolina. South Med J, 109(1), 24-30. doi:10.14423/smj.0000000000000396

Satariano, W. A. (1992). Comorbidity and functional status in older women with breast cancer: implications for screening, treatment, and prognosis. J Gerontol, 47 Spec No, 24-31.

Satariano, W. A. (1993). Aging, comorbidity, and breast cancer survival: an epidemiologic view. Adv Exp Med Biol, 330, 1-11. doi:10.1007/978-1-4615-2926-2_1

Satariano, W. A., & Ragland, D. R. (1994). The effect of comorbidity on 3-year survival of women with primary breast cancer. Annals of Internal Medicine, 120(2), 104-110. doi:10.7326/0003-4819-120-2-199401150-00002

Savigny, D. d., Adam, T., & Alliance for Health Policy and Systems Research, W. H. O. (2009). Systems Thinking for Health Systems Strengthening. W. H. Organization (Ed.). Retrieved from https://www.who.int/alliance-hpsr/resources/9789241563895/en/

Schaa, KL, Roter, DL, Biesecker, BB, Cooper, LA, & Erby, LH. (2015). Genetic counselors' implicit racial attitudes and their relationship to communication. Health Psychol. 2015;34(2):111-119. doi:10.1037/hea0000155

Siddharth S, Sharma D. (2018). Racial Disparity and Triple-Negative Breast Cancer in Black Women: A Multifaceted Affair between Obesity, Biology, and Socioeconomic Determinants. Cancers (Basel). 2018;10(12):514. Published 2018 Dec 14. doi:10.3390/cancers10120514

Silber, J. H., Rosenbaum, P. R., Ross, R. N., Reiter, J. G., Niknam, B. A., Hill, A. S., . . . Fox, K. R. (2018). Disparities in Breast Cancer Survival by Socioeconomic Status Despite Medicare and Medicaid Insurance. Milbank Q, 96(4), 706-754. doi:10.1111/1468-0009.12355

Strauss, A., & Corbin, J. (1998). Basics of qualitative research: Techniques and procedures for developing grounded theory, 2nd ed. Thousand Oaks, CA, US: Sage Publications, Inc.

Susan G. Komen. Expansion of Eligibility for the Breast and Cervical Cancer Prevention and Treatment Act (BCCPTA). Issues to Monitor. Retrieved from https://ww5.komen.org/Issues-to-Monitor.aspx#expansion

Susan G. Komen. (2021). Comparing breast cancer screening rates among different groups. Retrieved from https://ww5.komen.org/BreastCancer/RacialEthnicIssuesinScreening.html?ecid=social:285

Susan G. Komen (2021a). Breast cancer screening for women at higher risk. Retrieved from https://www.komen.org/breast-cancer/screening/when-to-screen/high-risk-women/

Susan G. Komen (2021b). Facts and statistics references. Retrieved from https://www.komen.org/breast-cancer/facts-statistics/references/

Susan G. Komen (2021c). Triple negative breast cancer. Retrieved from https://www.komen.org/breast-cancer/diagnosis/triple-negative/

Susan G. Komen. (2020). Breast Cancer Glossary. Retrieved from https://ww5.komen.org/BreastCancer/Glossary.html

Sutton, A. L., He, J., Edmonds, M. C., & Sheppard, V. B. (2019). Medical Mistrust in Black Breast Cancer Patients: Acknowledging the Roles of the Trustor and the Trustee. Journal of Cancer Education, 34(3), 600-607. doi:10.1007/s13187-018-1347-3

Swift, D. (2019). Cancer Screening Improved With ACA's Medicaid Expansion. Retrieved from https://www.medpagetoday.com/publichealthpolicy/publichealth/79984

Tammemagi, C. M., Nerenz, D., Neslund-Dudas, C., Feldkamp, C., & Nathanson, D. (2005). Comorbidity and survival disparities among black and white patients with breast cancer. Journal of the American Medical Association, 294(14), 1765-1772. doi:10.1001/jama.294.14.1765

Taplin, S. H., Anhang Price, R., Edwards, H. M., Foster, M. K., Breslau, E. S., Chollette, V., . . . Zapka, J. (2012). Introduction: Understanding and influencing multilevel factors across the cancer care continuum. J Natl Cancer Inst Monogr, 2012(44), 2-10. doi:10.1093/jncimonographs/lgs008

Taylor, T. R., Williams, C. D., Makambi, K. H., Mouton, C., Harrell, J. P., Cozier, Y., . . . Adams-Campbell, L. L. (2007). Racial discrimination and breast cancer incidence in US Black women: the Black Women's Health Study. Am J Epidemiol, 166(1), 46-54. doi:10.1093/aje/kwm056

The Aspen Institute. (2016). Glossary for Understanding the Dismantling Structural Racism/Promoting Racial Equity Analysis. Retrieved from https://assets.aspeninstitute.org/content/uploads/files/content/docs/rcc/RCC-Structural-Racism-Glossary.pdf

The Henry J. Kaiser Family Foundation. (2015). Preventive Services Covered by Private Health Plans under the Affordable Care Act. Retrieved from https://www.kff.org/health-reform/fact-sheet/preventive-services-covered-by-private-health-plans/

The Henry J. Kaiser Family Foundation. (2020). Status of State Medicaid Expansion Decisions: Interactive Map. Retrieved from https://www.kff.org/medicaid/issue-brief/status-of-state-medicaid-expansion-decisions-interactive-map/

Thurston, H., Bell, J. F., & Induni, M. (2018). Community-level Adverse Experiences and Emotional Regulation in Children and Adolescents. J Pediatr Nurs, 42, 25-33. doi:10.1016/j.pedn.2018.06.008

U.S. Department of Agriculture Economic Research Service. (2019). Food Access Research Analysis. Retrieved from https://www.ers.usda.gov/data-products/food-access-research-atlas/

U.S. Department of Health & Human Services. (2017). Pre-Existing Conditions. Retrieved from https://www.hhs.gov/healthcare/about-the-aca/pre-existing-conditions/index.html#

U.S. Department of Housing and Urban Development. (2019). Fair Housing Act Cases Filed by Year and State. Retrieved from: https://catalog.data.gov/dataset/fair-housing-act-cases-filed-by-year-and-state

U.S. Department of Justice Federal Bureau of Investigation. (2017). 2017 Hate Crime Statistics. Retrieved from https://ucr.fbi.gov/hate-crime/2017

Van Siejen, M., Lips, E., Thompson, A., Nik-Zainal, S., Futreal, A., Hwang, E., Verschuur, E., Lane, J., Jonkers, J., Rea, D., Wesseling, J. (2019). Ductal carcinoma in situ: to treat or not to treat, that is the question. British Journal of Cancer, 121(4), 285–292. doi: 10.1038/s41416-019-0478-6.

Wharam, J. F., Zhang, F., Lu, C. Y., Wagner, A. K., Nekhlyudov, L., Earle, C. C., . . . Ross-Degnan, D. (2018). Breast Cancer Diagnosis and Treatment After High-Deductible Insurance Enrollment. Journal of Clinical Oncology, 36(11), 1121-1127. doi:10.1200/jco.2017.75.2501

Wharam, J. F., Zhang, F., Wallace, J., Lu, C., Earle, C., Soumerai, S. B., . . . Ross-Degnan, D. (2019). Vulnerable And Less Vulnerable Women In High-Deductible Health Plans Experienced Delayed Breast Cancer Care. Health Affairs (Millwood), 38(3), 408-415. doi:10.1377/hlthaff.2018.05026

White, K., Haas, J. S., & Williams, D. R. (2012). Elucidating the role of place in health care disparities: the example of racial/ethnic residential segregation. Health Serv Res, 47(3 Pt 2), 1278-1299. doi:10.1111/j.1475-6773.2012.01410.x

Williams, D. R., & Collins, C. (2001). Racial residential segregation: a fundamental cause of racial disparities in health. Public Health Reports, 116(5), 404-416. doi:10.1093/phr/116.5.404

Williams, D. R., Lawrence, J. A., Davis, B. A., & Vu, C. (2019). Understanding how discrimination can affect health. Health Serv Res, 54, 1374-1388. doi:10.1111/1475-6773.13222

Williams, D. R., & Mohammed, S. A. (2013). Racism and Health I: Pathways and Scientific Evidence. Am Behav Sci, 57(8). doi:10.1177/0002764213487340

Williams, D. R., Mohammed, S. A., & Shields, A. E. (2016). Understanding and effectively addressing breast cancer in Black women: Unpacking the social context. Cancer, 122(14), 2138-2149. doi:10.1002/cncr.29935

World Health Organization. About Social Determinants of Health. Retrieved from https://www.who.int/social_determinants/sdh_definition/en/

Yancik, R., Wesley, M. N., Ries, L. A., Havlik, R. J., Edwards, B. K., & Yates, J. W. (2001). Effect of age and comorbidity in postmenopausal breast cancer patients aged 55 years and older. Journal of the American Medical Association, 285(7), 885-892. doi:10.1001/jama.285.7.885