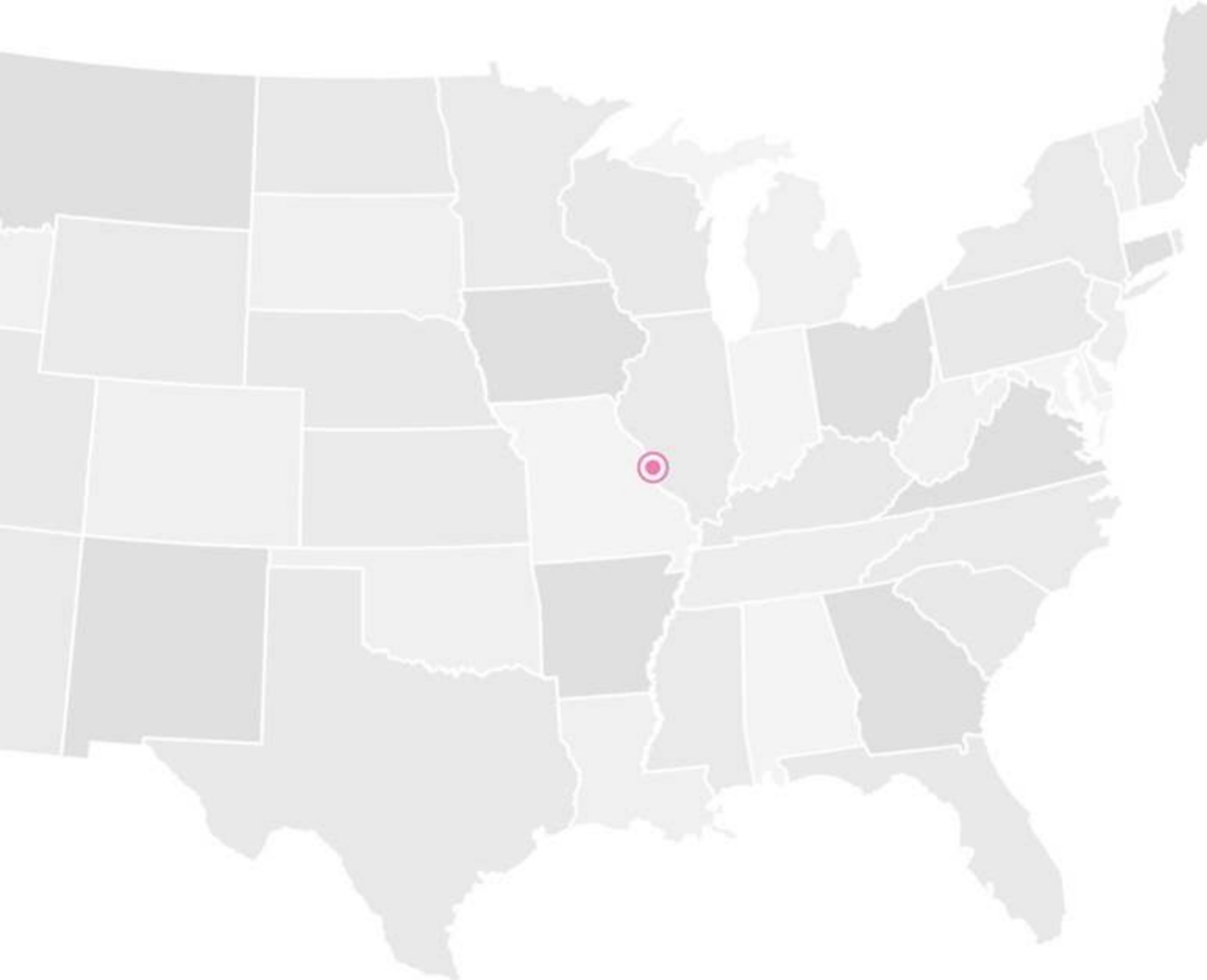
Closing the Breast Cancer Gap:

A Roadmap to Save the Lives of Black Women in America

2021

ST. LOUIS



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

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

susan G. Komen.

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Komen expresses 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.

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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, 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 outcomes 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 Black Health Equity Initiative (AAHEI), no known as Stand for H.E.R., a Health Equity Revolution, to improve breast health equity for Blacks. Stand for H.E.R. aims to reduce breast cancer disparities in Blacks 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.

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 involved a literature scan, compiling quantitative data, reviewing federal and state policies and collecting 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

- Although there is no consistent trend in local incidence rates, comparing Black women to white women across the different counties in the St. Louis MTA, Black women are consistently more likely to die from the disease compared to white women.
- St. Louis County stands out with breast cancer mortality rates among Black women that are almost twice that compared to white women.
- Late-stage diagnoses are higher for Black women versus white women in St. Louis City, MO, yet are not as apparent in other counties in the MTA.
- The rates of screening mammography screening are lower than state rates in Madison County and St. Clair County, Ill. and in Jefferson County, Mo. At the same time, disparities in mortality rates exist in St. Louis City and St. Louis County, Mo., that have similar or higher rates than the state of the percentage of women who get a screening mammogram.
- Decades of discriminatory practices have led to striking segregation in the St. Louis MTA. The St. Louis MTA is segregated across several dimensions, including race and socioeconomic factors, creating stark contrasts by geography. In addition to the entire MTA being racially segregated (with most people of color living predominantly in a few of the counties), many of the counties in the MTA are also internally racially segregated.
- The four counties with the largest Black populations, St. Louis City and County in Missouri as well as St. Clair and Madison County in Illinois, tend to have the greatest percent of those who are medically underserved, below 200 percent federal poverty line (FPL), and food insecure.
- The data suggest breast health inequities among Black women in the St. Louis MTA could be explained by economic vulnerability driven by institutionalized racism and disparities in access and quality of care.

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 St. Louis 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

- Increase access to culturally competent patient navigators and community health workers (CHWs).
- 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.
- 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.
- Fund Black-specific support groups across the MTA, particularly those that are taking leadership roles in building collaborations and strengthening advocacy.
- Encourage health institutions (health care systems and payers) to invest in high-need areas.

Macro-Level Strategies

- Implement a health promotion campaign intended to increase awareness of breast cancer inequities among Black women.
- Support expeditious implementation of Medicaid Expansion in Missouri.
- Conduct a root cause analysis relating to delays in breast cancer diagnosis.
- Support financial assistance programs.
- Fund collaborative initiatives at the community level to address root causes of breast cancer disparities.

This landscape analysis report conveys comprehensive issues facing Blacks 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 Black women.

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 US 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. 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). 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 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 analyses 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 social determinants of health (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 inequity, and suggestions for advancing breast health equity.
- To explore health care provider perspectives regarding individual, community and health systems factors contributing to breast cancer inequities, 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 landscape analysis conducted for the St. Louis. The report details 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.

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

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[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 "in place," and in the context of breast cancer means a condition where abnormal cells are found in the milk ducts or lobules of the breast, but not in the surrounding breast tissue. 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).

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, compiled quantitative data, reviewed federal and state policies, and collected qualitative data from community members and healthcare providers to prepare this landscape analysis report.

This study defines the St. Louis MTA in accordance with the US Office of Management and Budget's 2015 definition of the central counties in the St. Louis-St. Charles-Farmington metropolitan statistical area (MSA). This area encompasses the city of St. Louis and comprises St. Louis, St. Charles, and Jefferson counties in Missouri; and Madison, St. Clair, and Monroe counties in Illinois (Office of Management and Budget, 2010; U.S. Census Bureau). Data are generally unavailable at the MSA-level of geographic specificity, so researchers collected and analyzed data at the county-level (a sub-MSA unit) for most indicators. State- and national-level data (both super-MSA units of measure) were collected for measures related to breast cancer disease burden to provide additional points of comparison.

TABLE 1. ST. LOUIS 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)
ethnicity	Percent of Population that is Hispanic/Latino	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)
ethnicity	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 St. Louis MTA, a total of seven focus groups were conducted with 47 participating community members. Two of the focus groups were with six community health workers and/or patient navigators in St. Clair County, IL, and St. Louis City, IL. In addition, two provider interviews were conducted, and a provider was also among the members of one of the community focus groups.

Table 2 summarizes the demographic characteristics of 47 focus group participants, representing both breast cancer survivors and the undiagnosed. Among breast cancer survivors, the majority were above 55 years of age with Medicare, followed by private insurance or Medicaid and the plurality had been diagnosed with stage 1 breast cancer (42.1%). Undiagnosed women were younger, mostly in the 35-54 age group, with the majority reporting access to private insurance (58.1%). Non-provider participants were Black. Demographics were not collected for CHWs, patient navigators, or clinical providers.

TABLE 2. ST. LOUIS METRO AREA QUALITATIVE DATA COLLECTION

Variable Name	Breast Cancer Survivors (n=24)	Undiagnosed Women (n=23)
Age		
18-24 years	0.0%	0.0%
25- 34 years	4.2%	8.7%
35-44 years	0.0%	8.7%
45-54 years	12.5%	47.8%
55-64 years	25.0%	17.4%
65-74 years	50.0%	17.4%
75 and above	8.3%	0.0%

Zip Codes	Breast Cancer Survivors (n=24)	Undiagnosed Women (n=23)
63033	4.2%	N/A
63034	8.3%	N/A
63044	4.2%	N/A
63108	8.4%	N/A
63109	4.2%	N/A
63110	4.2%	N/A
63111	4.2%	N/A
63112	8.3%	N/A
63130	4.2%	N/A
63146	4.2%	N/A
63121	4.2%	4.3%
63131	4.2%	4.3%
63136	4.2%	17.4%
63138	4.2%	4.3%
62226	4.2%	8.7%

63031	4.2%	4.3%
62205	4.2%	8.7%
63042	N/A	4.3%
62040	N/A	4.3%
62221	N/A	4.3%
62269	N/A	13.0%
63117	N/A	4.3%
63133	N/A	8.7%
63134	N/A	4.3%
63137	N/A	4.3%

Insurance Status	**Breast Cancer Survivors** (n=24)	**Undiagnosed Women** (n=23)
I don't have health insurance	48.0%	9.3%
Medicaid	28.6%	14.0%
Medicare	47.6%	34.9%
Military Healthcare	0.0%	0.0%
Private Insurance	38.1%	58.1%
Through my parents	0.0%	0.0%
Not sure	4.8%	2.3%

Ever Been Screened for Breast Cancer	**Breast Cancer Survivors** (n=24)	**Undiagnosed Women** (n=23)
Yes	N/A	87.0%
No	N/A	8.7%

Type of Breast Cancer Screening or Assessment	**Breast Cancer Survivors** (n=24)	**Undiagnosed Women** (n=23)
Clinical breast exam	60.9%	52.6%
Mammogram	69.6%	89.5%
3D Mammogram	56.5%	31.6%
Breast self-exam	47.8%	42.1%
Other	4.3%	10.6%

Stage of Breast Cancer at Diagnosis	**Breast Cancer Survivors** (n=24)	**Undiagnosed Women** (n=23)
Stage 0	5.3%	N/A
Stage 1	42.1%	N/A
Stage 2	26.3%	N/A
Stage 3	10.5%	N/A
Stage 4	15.8%	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 St. Louis MTA using secondary data, as well as relevant findings from the qualitative data.

Demographics

The St. Louis MTA is a seven-county region in the Mid-Atlantic that is centered around St. Louis, Missouri (MO). The MTA spans two states, Missouri and Illinois, and is home to almost 2.5 million people. Its population is 74 percent white and 20 percent Black (see Table 3). 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).

About 40 percent of all residents of the St. Louis MTA (1 million people) live in St. Louis County, Mo. (see Table 4). The 315,000 residents of St. Louis City, Mo., represent 13 percent of the MTA's total population. The other 47 percent of the region's population is spread across five other counties in the MTA: Madison County, Ill., Monroe County, Ill., St. Clair County, Ill., Jefferson County, Mo., and St. Charles County, Mo. Refer to Table 4 for demographic information specific to each county within the MTA.

TABLE 3. ST. LOUIS METRO AREA DEMOGRAPHICS

Gender	
Male	48%
Female	52%
Age	
Under Age 18	23%
Age 18-64	62%
Over Age 65	15%
Race/Ethnicity	
White	74%
Black	20%
Asian	3%
American Indian or Alaska Native	0%
Native Hawaiian or Other Pacific Islander	0%
Some Other Race	1%
Two or More Races	2%
Hispanic/Latino	3%
White not Hispanic	72%
Minority Race	26%
Number of Black Women Over Age 45	104,351
Total Population	2,486,485

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

TABLE 4. ST. LOUIS 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
Madison County, IL	266,153	51%	9%	3,754
Monroe County, IL	33,739	51%	0%	94
St. Clair County, IL	264,433	52%	30%	16,018
Jefferson County, MO	222,639	50%	1%	275
St. Charles County, MO	385,115	51%	4%	2,841
St. Louis City, MO	314,867	52%	48%	31,780
St. Louis County, MO	999,539	53%	24%	49,589

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

Breast Cancer Disease Burden in the St. Louis MTA

Breast cancer disease burden in the St. Louis 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 St. Louis MTA, the most striking disparity is that the likelihood of death from the disease (mortality) varies along geographic and racial lines, with Blacks having mortality rate that range from 24 percent higher in St. Louis City, Mo., to 86 percent higher in St. Louis County, Mo.

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. In Missouri, where four of the seven counties in the MTA are located, the complete prevalence age-adjusted percent is 1.66 percent. In Illinois, where three counties are located, the complete prevalence age-adjusted percent is 1.70 percent. The prevalence in both Missouri and Illinois is comparable to the national percentage of 1.69 percent.

Breast cancer indicators for other measures are available at the county level. Tables 5-9 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 Monroe County, Ill., Jefferson County, Mo., and St. Charles County, Mo., as too few Black women live in these places to calculate the rates.

TABLE 5. ST. LOUIS 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
Madison County, IL	134.7	rising	135.0	stable	138.3	stable
Monroe County, IL	132.5	stable	133.2	stable	*	*
St. Clair County, IL	134.2	stable	138.1	stable	126.6	stable
Jefferson County, MO	131.1	stable	131.7	stable	*	*
St. Charles County, MO	135.0	stable	136.1	stable	128.5	stable
St. Louis City, MO	125.2	stable	122.0	stable	129.0	stable

St. Louis County, MO	148.3	stable	149.6	stable	143.8	stable
Illinois	131.9	stable	133.1	stable	133.5	stable
Missouri	129.2	stable	128.7	stable	133.1	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 125.2 new cases per 100,000 individuals per year in St. Louis City, MO, to 148.3 in St. Louis County, Mo., (see Table 5). 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 counties and higher for Black women in others. Incidence rates throughout the state of Missouri (129.2) and Illinois (131.9) are higher than national rates (124.2). Both states have higher incidence rates among Black women (133.5 IL, 133.1 MO) than among white women (133.1 IL, 128.7 MO). Nationally, white women tend to have somewhat higher incidence rates (126.1) than Black women (124).

TABLE 6. ST. LOUIS 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
Madison County, IL	30.3	stable	30.2	stable	34.8	stable
Monroe County, IL	34.2	stable	34.6	stable	*	*
St. Clair County, IL	37.6	stable	35.1	stable	41.9	stable
Jefferson County, MO	27.5	stable	27.8	stable	*	*
St. Charles County, MO	30.4	falling	30.6	stable	*	*
St. Louis City, MO	35.3	stable	38.3	stable	33.1	stable
St. Louis County, MO	37.2	stable	38.3	stable	33.5	stable
Illinois	33.8	stable	33.4	stable	36.6	stable
Missouri	28.3	stable	27.7	stable	33.2	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)

St. Louis County, Mo., and St. Clair County, Ill., both have particularly high in situ incidence rates among women, at 37.2 and 37.6 overall (see Table 6), especially when compared to the state and national rates of 33.8 for Illinois, 28.3 for Missouri, and 30.1 nationally. St. Clair County, Ill., also has a large disparity between Black and white women, with the in situ incidence rate at 41.9 for Black women and 35.1 for white women. Conversely, St. Louis County, MO, has a higher in situ incidence rate for white women, at 38.3, compared to Black women at 33.5 (Table 6).

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

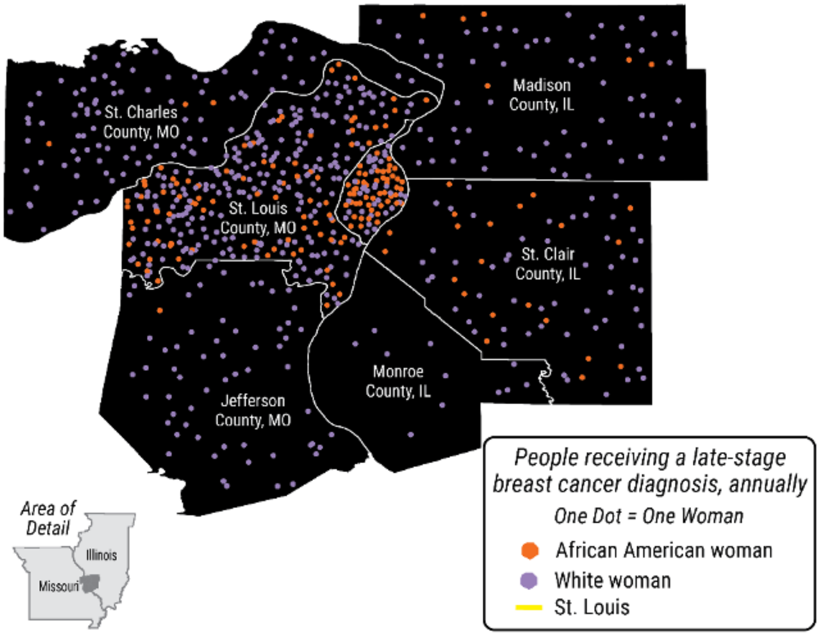
	Age-Adjusted Late-Stage Incidence Rate	Average Count of Cases That Are Late-Stage	Age-Adjusted Late-Stage Incidence Rate for White Women	Average Count of Cases That Are Late-Stage for White Women	Age-Adjusted Late-Stage Incidence Rate for Black Women	Average Count of Cases That Are Late-Stage for Black Women
Madison County, IL	52.3	71.0	53.1	65.0	50.5	6.0
Monroe County, IL	66.2	11.0	66.0	11.0	*	*
St. Clair County, IL	55.0	76.0	60.5	54.0	46.9	21.0
Jefferson County, MO	52.9	59.0	53.4	58.0	*	*
St. Charles County, MO	49.2	95.0	51.2	91.0	35.0	3.0
St. Louis City, MO	50.9	83.0	43.7	32.0	59.2	50.0
St. Louis County, MO	63.5	334.0	65.3	239.0	63.1	86.0
Illinois	52.7	3451.0	53.1	2708.0	56.5	588.0
Missouri	54.3	1675.0	54.8	1426.0	55.2	2018.0
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)

As shown in Table 7, the age-adjusted, late-stage incidence rate of breast cancer among all women is highest in Monroe County, Ill., at 66.2, with St. Louis County, Mo., coming in a close second at 63.5 (see Table 7), the late-stage incidence rates across most of the counties are comparable to the late-stage incidence rates in Illinois and Missouri (52.7 and 54.3, respectively), but all counties' rates are higher than the national late-stage incidence rate of 42.3. In the five counties where data is available for both Black and white women, late-stage incidence rates are higher for white women than Black women in four of the counties (Madison County, Ill., St. Clair County, Ill., St. Charles County, Mo., and St. Louis

County, Mo.). The reverse is true for St. Louis City, Mo. (59.2 among Black women as compared to 43.7 among white women).

MAP 1. ST. LOUIS 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 1 shows the concentration of women who receive a late-stage breast cancer diagnosis annually in the St. Louis MTA. Observed patterns align with population trends. The density of diagnoses increases closer to the center of the MTA, with the highest concentration in St. Louis City, Mo., where Blacks comprise the majority of late-stage diagnoses (average annual count of 50 among Black vs 32 among white women). The greatest count of late-stage diagnoses cases is in St. Louis County, with average counts of 86 among Black and 239 among white women. St. Charles County has the next highest count at 95, with a greater number among white women who comprise most of that county's population. The remaining counties have lower overall numbers of late-stage diagnoses, the majority of which are white. Data are not available for Black women in Monroe County, Ill. nor Jefferson County, Mo., as too few Black women live in these places to report the number.

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

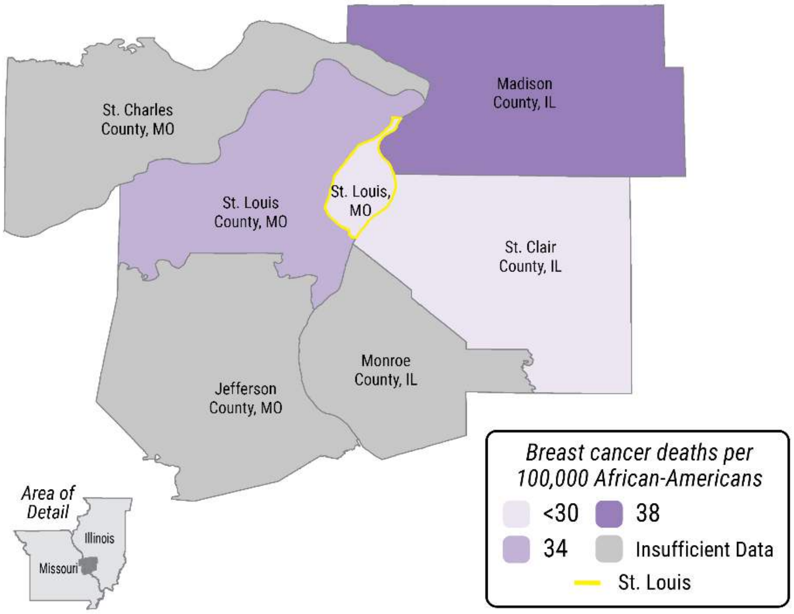
	Age-Adjusted Mortality Rate	5-Year Mortality Rate Trend Direction	Age-Adjusted Mortality Rate for White Women	5-Year Mortality Rate Trend Direction for White Women	Age-Adjusted Mortality Rate for Black Women	5-Year Mortality Rate Trend Direction for Black Women
Madison County, IL	21.5	falling	20.6	falling	37.8	*
Monroe County, IL	24.6	stable	24.9	stable	*	*
St. Clair County, IL	20.9	falling	19.5	falling	25.6	falling
Jefferson County, MO	19.3	falling	19.5	falling	*	*
St. Charles County, MO	19.8	falling	19.9	falling	*	*

St. Louis City, MO	24.3	falling	22.2	falling	27.6	Falling
St. Louis County, MO	21.7	falling	18.5	falling	34.4	Stable
Illinois	21.8	stable	20.9	falling	30.7	Falling
Missouri	21.7	falling	20.8	falling	31.1	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 breast cancer mortality rate is higher for Black women than white women in every county in the MTA where data is available for both demographics (see Table 8). Data are unavailable for Black women in Jefferson County, Ill., and St. Charles and Monroe Counties, Mo., potentially due to fewer Blacks living in those counties. The racial disparity in breast cancer mortality rates is most striking in both Madison County, Ill., and St. Louis County, Mo., where the age-adjusted mortality rates for white women are 20.6 and 18.5 compared to 37.8 and 34.4 among Black women. As displayed in Table 8, these two counties, Madison County, Ill., and St. Louis City, Mo., report the highest overall mortality rates at 24.6 and 24.3 deaths respectively per 100,000. The lowest overall mortality rates are in Jefferson County, Ill., and St. Charles and Monroe Counties, Mo.. These rates do not align with the ranking of incidence rates by county.

MAP 2. ST. LOUIS 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 2 and Table 8, the number of Black breast cancer deaths is highest in Madison County, Ill., at 37.4 deaths per 100,000 Blacks, followed by St. Louis County at 34.4 per 100,000. St. Louis County has more total deaths among Black women due to breast cancer because they have a higher population of Black women. There is insufficient data for breast cancer deaths among Blacks in St. Charles County, Mo., Jefferson County, Mo., and Monroe County, Ill..

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

	Percent of Women Getting Mammograms
Madison County, IL	63%
Monroe County, IL	72%
St. Clair County, IL	68%
Jefferson County, MO	66%
St. Charles County, MO	72%
St. Louis City, MO	76%
St. Louis County, MO	74%
Illinois	73%
Missouri	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 throughout the MTA, from 63 percent of women receiving a screening mammogram in Madison County, Ill., to 76 percent in St. Louis City, Mo. (see Table 9). The screening mammography rates around the MTA are similar to the state and national averages of 73 percent for Illinois, 74 percent for Missouri and 73 percent nationally. Racially disaggregated screening mammography rates are not available at the county level, but these data are available at the state level. In Illinois, where three of the MTA's counties are located, 79.9 percent of Black women over age 40 received a screening mammogram in the last two years compared to 72.6 percent of white women. In Missouri, where four of the MTA's counties are located, 76.9 percent of Black women over age 40 received a screening mammogram in the last two years compared to 70.1 percent of white women.

Overall, the data on breast cancer disease burden compared and contrasted across counties and by race suggest that the disease is most fatal for Black women who live in Madison County, Ill., (37.8; yet with few cases) and St. Louis County, Mo. (34.4) and least fatal for white women living in St. Louis County, Mo. (18.5) and St. Clair County, Ill. (19.5). While breast cancer incidence rates in the MTA are higher for white women in some counties and higher for Black women in other counties, in every county where data are available and disaggregated by race, mortality rates are higher among Black women than white women. The relatively high survival rates for white residents and low survival rates for Black residents of St. Louis County stands out. Availability of screening mammography does not appear to be a factor. At 74 percent, St. Louis County had one of the highest rates of screening mammography screening in the MTA for both race groups. Black women have somewhat lower rates of breast cancer incidence (143.8) compared to white women (149.6) in St. Louis County. At the same time, Black women in St. Louis County, Mo., have consistently higher incidence rates as compared to Black women in all other counties. Higher rates of in situ cancer observed in St. Louis County may indicate greater access to early diagnoses, which would improve survival rates. Yet St. Louis County was also observed to have higher rates of late-stage diagnoses. The data suggest that regardless of screening and diagnoses rates, those Black women who are diagnosed are more likely to die of the disease. 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, Porter et al., 2016).

Rates of mammograms, in situ cancer and late-stage diagnoses are all similar for white and Black women in the county. Taken together, these data suggest that the poorer survival among Black women in St. Louis County does not appear to be attributable to general lack of access to screening mammography. More research is needed to determine whether late-stage diagnoses among Blacks could be attributed to early age of onset prior to recommended screening ages. At the same time, premature mortality for all causes among Blacks (565) is roughly twice the rate of whites (287) in St. Louis County. Overall life expectancy is also lower for Blacks (73) than white residents (80).

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, Michigan, 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% 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 St. Louis MTA. Based on a review of the quantitative findings, priority counties for qualitative data collection in the St. Louis MTA were identified as: St. Louis City and St. Louis County, Missouri, and St. Clair County, Illinois. These locations have the highest breast cancer disease burden, high SDOH burden and score poorly on other health measures. Further, these locations have the highest proportion of Blacks in the MTA and, as such, have sample availability for qualitative data collection.

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 mammography rates in the MTA are similar to the national average in all but two counties in the MTA, both of which are in Illinois. Although the data are not disaggregated by race, focus group participants' perspectives gives some indication of the experiences of Black women seeking and obtaining breast cancer screening.

Institutionalized racism. Participants discussed avoiding the health care system due to experiences they, family members, or the Black community have had. The mistrust of the health care system was described by two physicians as still persisting, one tracing it back to the Tuskegee experiments.

> *"I did HIV clinical trials. So, I knew how hard it was to get Blacks to trust you, to sign on to a clinical trial [even as an Black clinician recruiting]. They [may be too young to remember but] just have heard of Tuskegee [dangerous experiments on Blacks]." – Provider*

Participants referenced both the benefits of Komen support and how a transformation to address racial equity would be welcome, in terms of the evolution of Komen:

> *"I mean, discrimination has been around for years and it's always going to be around. It's different levels of discrimination...but even with Susan G. Komen, when she [sic] first started out and I was part of writing a grant for inner city women for breast screening [it existed]. It's just been the last maybe six or seven years that you see more women of color even being involved with Susan G. Komen. So, I don't know what the premise was on why it started out like that, but so many women lost the advantage of getting screenings, getting education about breast health." – Provider*

Survivors mentioned finding this effort a positive change in commitment towards women of color by Komen. One mentioned that those she knew were hesitant to participate in focus groups for this Health Equity Initiative, citing, "We've had community members that are reluctant to participate because they feel like Komen has ignored black women for so long."

> *"Let me ask you this, because Komen has been around for a long time and I remember years and years ago going to the races [for the cure prior to] having cancer and volunteering. Now they seem to be super interested in women of color, Black women specifically. What you're doing is, as you go about collecting the information and what have you, they're changing. They're changing this." – Survivor*
>
> *"This is a shift for them [Komen]. Thank you so much." – Survivor*

> *"But this is exciting because if Komen is going to take a look at breast cancer, we'll start there, and then it might just trickle down. You know what I mean, with all disparities in African American women ended. This could really be big." – Undiagnosed*

Screening guidelines. Changing guidelines around when to get breast cancer screening were said to feed into misconceptions and add to barriers to proactively screen. Participants observed that there are mixed messages across providers, including how often to get a screening mammogram. The removal of recommendations for breast self-exam were viewed as problematic, preventing women from both keeping breast health a priority and becoming familiar with their breasts to note changes.

> *"We in health care are trying to get them to be more observant of doing breast exams, and it doesn't help when you've got the Cancer Society saying, 'don't do breast exams.' So, after you finally get a woman comfortable enough to touch her breasts, because you'd be surprised the ones that don't, they don't want to touch their breast. So now we're saying, 'Don't touch them. Just wait until you [are older]' ... and then they're telling us, 'Well annual breast exam, it's not that important.' So, it's too many mixed messages." – Patient Navigator*

Screening guidelines that emphasize starting annual screening mammography at a later age was a potential barrier for the Black women who are diagnosed before the age of 45. A few participants mentioned younger women who do not have a family history not being able to get screened as providers were reticent without falling under the age guidelines and with limited insurance coverage as leading to their late-stage diagnosis. Patient navigators noted that they, along with providers on their teams, just recently learned that younger women, starting at age 35, who are otherwise eligible, may receive screening under The Missouri Show Me Healthy Women program. This program provides breast and cervical cancer screening and diagnostic services to low-income women and women who are uninsured or underinsured.

One young, Black woman's story exemplifies the fortitude and persistence required to obtain screening despite their age.

> *"I wasn't offered any [screening] because of my age. I was 28 when I got diagnosed. They just told me. I had a two-year-old; he's three now. They told me maybe it's a clogged milk duct, or maybe it's a cyst. I wasn't offered any screening. They just told me to monitor. That was the first doctor I went to. I went to two other ones after that. The last one is the one that actually offered to do an ultrasound. Even when I went to the radiologist, he said, maybe it's just a fibroadenoma, a benign tumor. Not until I had my surgery to remove it did they find out it was cancer. Even before I had my ultrasound, they said it wasn't." – Survivor*

Genetic testing that may identify high-risk Black women is limited in the St. Louis MTA. Few women participants with family histories mentioned having gotten genetic testing. Genetic counselors were said to be in short supply for all patients, according to a provider interviewed: "That is an absolute need so that not just the person who is recently diagnosed, but their families can have a better understanding of the risk." At the same time, this was not viewed as a high priority for their population which needs insurance and access to basic health care and cancer screening for people.

> *"So, when I think about genetic counselors, we do have them, and I would love in a real ideal world that they be a part of almost every consultation that we feel we should do genetic testing on a patient. However, we're just trying to get people screened." – Provider*

Community Outreach and Engagement. Participants wanted to see major initiatives that would steep the Black community in awareness of breast cancer inequities, including late-stage diagnoses, aggressive disease progression, and higher mortality among Black women. They also wanted information about risk factors and protective factors for breast cancer.

> *"I did not hear about breast cancer until almost the time I had it. It wasn't talked about at my house. It wasn't talked about at church. I didn't hear about it at school, I didn't hear about it in the streets. I did not know anything about breast cancer." – Survivor*

The most highly recommended channels of communication were family members, churches, hair salons and bringing mobile health vans into underserved neighborhoods. Family sharing of information was thought to be vital, yet uncommon. A promising local model to promote family-based education was discussed. The Tell Your Mom Campaign, said to have been very successfully launched at a pilot school in North Side St. Louis City, educates high school students about the statistics while encouraging them to "[talk] to your mothers, talk to your sisters, talk to your grandmas." Pervasive, community-wide outreach through mailings, advertisements, media and postings were recommended.

> *"It does not just need to be talked about when it's breast cancer month, or breast cancer week, or we fixin' to do this walk for breast cancer. The knowledge of it needs to be out there at all times, just don't bring it about when it's October and we want to wear some pink... [There] should be literature everywhere about it, because that's something that has affected our Black community, with our Black women." – Survivor*

Participants noted that Black women also need information on where to go for screening, and if needed, treatment.

> *"I see this way, way too much, where there is an extreme delay [in seeking screening and treatment] because people don't know where to go, what to do, and they're very fearful." – Provider*

Health providers, in turn, were said to need to learn from Black women about the needs, assets, and strategies that are appropriate to safeguarding Black women's health and wellbeing. The importance of educating and engaging faith-based organizations was frequently raised. There were those who expressed skepticism that churches were willing to do all the outreach that they could for fear of scaring and driving away congregants.

> *"You've got to educate the clergy...If somebody bring it [a breast cancer program] to them, then they'll be willing to do it. But if they don't get the information, they thinking*

> *'What can I do to draw more people in the church?... Stop saying things to make people leave the church that might want to join the church.' " – Survivor*

Other participants shared great progress in forging collaborations with churches. Pastors, bishops and clergy from St. Louis City, St. Louis County, Mo., and St. Clair, Ill., were planning to share breast cancer information with their congregation. Religious participants believed that fellow-church members need to be reminded that "God created every man for a purpose, and he put doctors on this earth to help us."

> *"Send them to the churches...people go to their church. We don't go to community health groups. If you're going to have the screening mammogram wagon in a certain community, make sure that the community knows [through the Black churches]." – Survivor/Peer Navigator*

The Breakfast Club, in partnership with providers, introduced an innovative initiative being planned to hold open houses at diagnostic centers to help women overcome their fear of screening mammography equipment as being dangerous and painful. During these open houses, women will be introduced to the machines, hear from others who have had procedures and learn about the full range of evolving screening and treatment options.

Limited access. Community members, patient navigators and providers discussed that there are portions of each county with limited access to breast cancer screening services. The Illinois Breast and Cervical Cancer Screening Program was described as an important source of information and support resources in St. Clair County, yet one that has diminished over time. St. Clair County has two health departments, an East Side Health District and the St. Clair County Health Department. East Side serves the four townships in St. Clair County that are primarily Black. Participants noted that there used to be a consortium agency for the Illinois Breast and Cervical Program at East Side that offered a Well Woman Program. About three years ago, they stopped offering the program due to inadequate support. The St. Clair County Health Department then took up the responsibility for this program across the entire county, working to maintain the services and access to the trusted Black Patient Navigator program in East County.

Screening mammography vans were seen as an important resource when parked at accessible and culturally familiar sites where women congregate such as work, churches and cultural fairs. Community members from St. Louis County described that such mobile services were too few to cover the entirety of St. Louis North County. Mobile screening mammography vans were said to be even less available in St. Clair County in general and when they are in St. Clair were observed to be more likely to be near expensive neighborhoods rather than in areas of higher need. Across counties, patient navigator and peer navigator participants, echoed by a provider who was interviewed, identified a need to promote these screenings to residents and dedicate a van to serve more broadly defined areas of need, rather than a specific workplace or random site.

> *"A dedicated mobile van should hold screenings' not just once or twice a month but on a more frequent basis where we can actually look at what are the best neighborhoods and community organizations and churches to partner with to be available routinely...and not just during the day, but during the evening, knowing many women can't take advantage of the van in the middle of the day, and on weekends... We really have not developed those types of programs that I think would resonate in the community, so we know that people are working, sometimes one to two jobs, can't just be at a church on*

> *Thursday at noon... They need to take it down to East St. Louis, Washington Park, Cahokia, where people [are] who don't have transportation." – Provider*

Diagnosis

Focus group findings suggest that community members may experience poor-quality care and barriers within the health care system when needing a diagnosis after a positive or abnormal screening or when seeking a diagnosis when presenting with symptoms. Community members reported having to advocate for themselves to get the care that they need. For those able to receive mammograms for free, or at low cost, the insurance barriers and costs of diagnostic procedures such as biopsies and scans present a barrier for some women in the MTA. In addition, many survivors characterized that the care and advice they received at this stage was inappropriate. For example, several being told to wait for long periods and not worry prior to an eventual positive diagnosis. These factors may be associated with delayed diagnosis, influencing the late-stage diagnosis rates documented earlier in the report.

Delays and difficulty getting a diagnosis. State and MTA wide data indicate elevated rates of late-stage breast cancer diagnosis, with racial disparities among Black women vs. white women evident in St. Louis City, Mo. A provider interviewed discussed potential factors involved in North St. Louis County, Mo.:

> *"A portion of that risk [of late-stage and triple negative diagnosis in the North St. Louis area] could be driven by a family history/hereditary profile. There's a question about is it related to stress, is it related to poverty, is it related to other drivers that we don't quite understand that are leading to increased risk...I believe people are getting mammograms, [if] there's an abnormality they may get a biopsy and then they have a diagnosis, and... that we have [tremendous] delays in people getting their definitive surgery and delays in chemotherapy, if they get it at all, and delays in starting their radiation. " – Provider/Researcher*

Among Black focus group participants, insurance was viewed as a key barrier. Even those with what they described as "good insurance" encountered life-threatening barriers to reimbursement for proper diagnosis. For example, a focus group participant was almost turned away from getting additional testing, despite having symptoms, because since she had already had a negative screening mammogram; her insurance would not cover any more tests. Yet her committed care team fortunately proceeded without insurance.

> *"It sounds like [the inequities are] based on insurance, more than racism because I have good insurance, at Grayfield Clinic. But I had a screening mammogram done and the screening mammogram of course was negative, but something was going on with my breast...I told my primary that I was having breast pain and so she wanted to get some more tests run and the insurance said, 'You just had a screening mammogram and the screening mammogram was negative and they didn't see anything.' So, by divine intervention, [the health team] decided to go on and do an ultrasound and biopsy and… the breast had the cancer. [They didn't] see it on the screening mammogram." – Survivor*

Other near tragedies were shared by peer patient navigators related to misdiagnosis and lack of adequate follow-up on possible tumors. A survivor shared that, despite yearly mammograms, two tumors were missed that she ended up feeling by hand.

> *"I was just laying in the bed and it rolled in position where I could feel it and it scared me. That's when I called the hospital and asked them, could I come right in...They said, it's just a little cyst and it's been there for years. The doctor say, 'Since I got you here,...I'm going to send you down for an ultrasound.' That's when they found the two tumors. I had two of them. It's kind of scary when you think, if you go every year and you get a screening mammogram and then you find out that you've got stage three cancer." – Survivor*

Unfortunately, her experience was not unique. Other women who had regular mammograms that found abnormalities were told to wait and not worry, then they were eventually diagnosed with late-stage breast cancer.

> *"Every year they have the screening mammogram van [at work]. I was there every year at least for the 11 years that I was there. They always told me something about my left breast. Something was going on but it's nothing to worry about. I would do the screening mammogram. Unfortunately, it didn't pick up on it. They just thought it was a growth and we're just going to watch it to make sure it doesn't get bigger. I moved to Atlanta in 2014 and that's when I was diagnosed with bilateral [breast cancer]... She said I had 10 knots here under my right lymph nodes and three here under the left." – Survivor*

Some attributed the lack of strong follow-up of an abnormality found during screening to personally mediated racism.

> *"In your mind you wonder, if you had been a white woman and walked in there, it would have been, 'It's just a cyst, but maybe we can do a biopsy on it.'...You become trusting and you shouldn't, because I think more should be done and if you know what the rate [of early onset, late-stage breast cancer is high for] Black women, it should be more than, 'it's just a cyst.' " – Survivor*

Participants described having to overcome stereotypes before getting properly diagnosed for a range of health conditions. St. Louis County participants noted that the first issues doctors try to identify are high blood pressure and diabetes and attributed the constant tests for these diseases to racism. These women attributed their high blood pressure, measured during clinical exams, to the anticipation and fear of getting diagnosed with an illness and having to go to the hospital.

> *"Once they basically check your vitals and they see that you have hypertension, they ignore what's going on with you and just deal with your hypertension, high blood pressure. Which you can leave the hospital and they done took care of the high blood pressure, but you still have leg pain due to the simple fact of the high blood pressure." – Undiagnosed*

Support after diagnosis. Several survivors in St. Louis City responded that they were not offered support services by their hospital, health care organization or community organization. They appeared to have largely found one-another and vital support networks through informal channels. The Breakfast Club is one example of a peer network that operates in St. Louis City and St. Louis County, and was started locally by Black women breast cancer survivors in 1997 with no other form of support group. The Breakfast Club offers extensive networking, advocacy and neighborhood outreach. The Breakfast Club Buddy Program links survivors to those who have been newly diagnosed.

> *"The only way I found out is I was not afraid to tell anyone about what was going on with me. I was at church and I was talking to a young lady who used to come to the Breakfast Club. She tells me… 'I'm going to put you in touch with the Breakfast Club'... It was the best thing that could have ever happened because... when I had the lumpectomy and she was able to explain it to myself and my husband. That helped. Other than that… [all you get from doctors is] a little letter in the mail." – Survivor.*

> *"I found out about this group, believe it or not, my white boss. When they found out, I finally had to break down and tell them I had breast cancer and I was going to be out. He came in my office and he handed me a card from the Breakfast Club." – Survivor*

Even for women with their own social capital and support, a peer network offered invaluable information and support as fellow survivors.

> *"At the time my mom and my sister and my daughters were around, and I said [when referred to the support group], 'I've got plenty of support.' I did not have the knowledge. I did not have people who had been through that; they could explain things to me, but I had support. That was wonderful. But once I got involved with the Breakfast Club and there was so much knowledge." – Survivor*

Treatment

Women raised issues surrounding treatment. During interviews and focus groups, we learned of a number of Black women who experienced long and unnecessary delays in getting treatment, almost to the point of presenting back with metastatic disease because they missed their window of care. Participants discussed the quality of care and their experiences during treatment. Below are the major themes that arose.

Insurance barriers. Overall, focus group participants highlighted that lack of insurance and the poor quality of available and affordable insurance programs were principle contributing factors to treatment inequities. Affordable insurance programs often limit coverage and/or have very high annual deductibles and copays. Focus group participants in St. Louis County noted having to choose between health and covering day-to-day needs. Women noted if you have insurance, you also must pay a copay, and physicians will not see you if you cannot pay for the copay. An interviewed provider concurred that insurance was a primary driver of inequities in breast cancer health outcomes along with Missouri not having expanded Medicaid (at the time) and the closure of the local public hospital. They lamented hundreds of thousands of people who lacked coverage, observing that many of those people are in the same areas with the highest mortality rates.

> *"So, there's no confusion that having no insurance or being underinsured is a large contributing factor to the inability of a woman to get screening routinely and in treatment, efficiently, if they have a problem. Some of the highest breast cancer mortality rates that we see are in the inner North County, on our cancer profile. And the inner North County [of St. Louis County] also has many zip codes where one in four households are uninsured. So not having insurance along with the higher poverty index are positively correlated. So, I would say that is a significant factor...I think probably the biggest issue is we need a systemic solution to our uninsured population. Again, you*

> *can't have lack of Medicaid expansion, not embracing The Affordable Care Act, and then also have a weak public health infrastructure with no city hospital." – Provider*

Insurance was described as a major factor in stopping treatment. Women may have insurance that affords quality-care access, but if they lose it, they stop receiving quality health care services. One mentioned, for example, having a pool of health care funding via her work that ran out over the course of her illness. Even when insurance is reinstated, treatment was described by patient navigators as taking a long time to start again. We were also told of a woman whose insurance refused to cover chemotherapy after radiation, giving as the only reason that she was already at stage 4 and presumably not treatable.

> *"We take them to some of the clinics that are around, and when that happens, case in point, we took one of our community members to [a clinic], of course she couldn't get service...maybe didn't have the $28 for the initial fee...This was in a clinic and we expected them to help but what happened was she was frozen out; told okay you don't have the money we can't see you. ...Our [support] group... provided the funds and she was put back in line, [but] by the time the end of the day came, she had been passed by, passed by other people to be seen. That's all the time she could get was that day. She had a job to do, she had to work. That was the only day, and we were advocating to try and get her in to be seen, but they wouldn't see her." – Peer Navigator*

> *"I had to have a test done and the test was like $2,000, my copay. So, the lady was like, 'Well, you've got to pay for this now, or you can't have the test done.'...When you have insurance, but it's not the best insurance, you still get treated [poorly] and you keep on being pushed toward Medicaid. 'Well, you need to apply for Medicaid.' But you cannot get Medicaid if you have insurance... So the racist part is when you're sitting there and you're seeing everybody else being told that they owe stuff way better than what you're being told, and they [women who aren't Black] can still do things without having the copays... So, yes. I believe there was a lot of racism, as well." – Survivor*

A survivor shared that her mother recently died of cancer and that she suspects the cancer may have progressed more rapidly because her insurance ran out. They moved her mother to an area "in the back" and changed her treatment plan to a less effective chemotherapy option explicitly because of insurance. The family contributed what they could – $2,000– to even afford the medications she did receive. A provider emphasized the need, from the very beginning of their cancer journey, to show people a pathway to getting treated successfully and without financial ruin, while offering them the support of peers to see that they can get through this.

Personally Mediated Racism. While there was some hesitancy to describe experiences as "discrimination" ("I haven't been discriminated. I've just been misjudged"), others called out racist incidents when seeking health care.

> *"When you are going through a scare, the last thing you need is someone to be biased towards you, someone who is not going to be there for you, someone who is putting you on a backburner. If you don't want the job, don't take it. People need to know someone is there for them. People are very racist right here in this hospital. I witnessed it." – Survivor*

Women emphasized the need to advocate for themselves. Yet, they also acknowledged how racism and other power imbalances stood in their way. This conversation among undiagnosed focus group participants was telling:

> *"I feel like people do not have the wherewithal to advocate for themselves, or have the ability to articulate it in such a way to where it grabs hold of someone's attention that is [in] a position that can make things happen. You can be left floundering." – Undiagnosed*

> *"You cannot advocate for yourself. Matter of fact, you're viewed as a 'problematic patient.' With an attitude. They have coding for that; problematic patient, patient they don't want to see." – Undiagnosed*

> *"Or they'll use other language, 'not adhering to treatment.' " – Undiagnosed*

> *"'Non-compliant,' they use all kinds of pretty words to describe you. So that's where the disparity, when it starts." – Undiagnosed*

A Black health care professional who participated in an undiagnosed focus group noted that her own experience is poor when she goes for treatment as an Black woman in a health care setting. The treatment she receives is different when she is not wearing her white coat. Doctors don't say hello or acknowledge her presence, aren't cordial and don't follow customary principles of hospital culture in interacting with patients/visitors, etc.

> *"I was very ignored until finally the doctor came into the room and started asking me very specific questions. The way that I answered the questions made the doctor stop, and she said to me, 'What is your background?' I said, 'Why does that matter?' She said, 'Do you work in the health care field?' I said, 'More or less.'... She stopped, and she said, 'Oh, so what's your title?' I said, 'It's Dr. XX,' and within 30 minutes I was upstairs in a room. What really ticked me off was, until you knew that I know, you treated me like I was just a common ordinary, so if I get treated this way then what do other people go through? So, I wrote an extremely long letter, a major complaint, and from that moment until I was discharged nurses were on me like white on rice... But prior to that I really felt like I was just another Black face, until you understood that this Black face came with a level of influence and authority." – Undiagnosed*

Patient navigators varied regarding health care discrimination they have witnessed. For example, one said they had not observed differences along racial lines in the treatment offered by the many private providers contracted by the St. Clair Health Department, while another relayed that they often heard mistrust voiced by patients due to recent treatment they, their families or their acquaintances faced.

> *"A lot of people have had some bad blood [with these institutions). Just, it's the truth... they'll say 'I'm not going there because my grandma/somebody went to the emergency room, and my grandmother died. I'm not going to that institution.'... Or [they were] treated like they weren't a part of the human race. You know?" – Patient Navigator*

Indeed, participants noted avoiding health care in attempts to avoid discrimination.

> *"I think that's what stopped me for a long time for even going to the doctor because of living out there and thinking that I'm going to be treated differently or not treated at all because I was so used to it happening." – Undiagnosed*

Quality of Care. Some participants mentioned very positive experiences with health care providers and patient navigators. For example, a young woman who had a complex history, including multiple cancer experiences, described how her Black female oncologist was a partner on her cancer journey.

> *"They've been fantastic. I have had no problems. I always felt like I could ask questions. They spend time with you to explain stuff. I know some doctors you go to and they're rushing you and there's a ton of people sitting out there. They're very busy. But I've never felt that way there." – Survivor*

Other survivors described the many challenges and the mental strain entailed when providers did not adopt a respectful, shared decision-making approach. These two women describe being patronized rather than provided with information and consulted on decisions about their own health.

> *"When I found out, I felt like just pounding me, pounding me with different things is going on and I wasn't really prepared... At the time I was also planning my wedding and the doctor was like, 'Well, I don't want you to be losing your hair. I don't want you to be looking different on your wedding then what you're going to be looking like in the future or what you look like now?' ...She just stopped giving me options and said, 'We're going to do this, this and that,' and that's how it went. And I was like, 'Okay, then how do I know if this is going to work?'... She didn't really answer all my questions thoroughly until maybe the second treatment...and that's when I had to sit her down and just talk to her and tell her, 'I don't understand what's going on and I need answers.' So, I felt like I was pressured to get started without all the information that I needed. That's what I felt." – Survivor*

> *"It becomes a lack of education/information for our community, for women of color...We get a little information, because they give us the little tags and tell you what to do, the exam and all like that. That's as far as it goes. They don't like you going to Google stuff...Then it's like, 'Don't worry about that. We're going to take care of that.' Then when they don't take care of it, then they put your life in jeopardy. They put your life in jeopardy." – Survivor*

Participants also called out the lack of provider knowledge regarding the best treatment options for Black women. Especially for triple negative breast cancers, a factor being the lack of clinical trials tailored to Black women.

> *"We are behind in really understanding the best way to care for triple negative breast cancers, and I think part of the reason is because the major population group with triple negative [breast cancer] is not adequately represented in our clinical trials." – Provider/Researcher*

A provider at a Community Health Center discussed tragically losing a patient who had to wait to get care at an area hospital due to the conflict between a patient's desire for privacy and the hospital's admittance policies.

> *"And it took us, I kid you not, eight months just to get her, her first chemo. And the reason being is because we referred her to St. Mary's. She would not give the information for her child support so she couldn't get a medical card. And we kept explaining to her, this is important. St. Mary's gave her a couple rounds of chemo free because they knew how bad her cancer was already stage four. And she ended up I think eight months into her diagnosis, starting her real chemo and radiation. And this was what, two years ago last summer, I called to check on her and her mom told me she had passed. And then I got my report and she had metastasized everywhere. Liver, everywhere." – Provider*

Integrated mental health and complementary therapies. Tending to mental health was discussed as being an essential support, rarely offered to Black women. When it was offered, there was stigma needlessly attached due to the assessment and referral process. Participants recommended that mental health services be offered as an integral part of breast cancer treatment from the first point of diagnosis, attention to which can help women get through the stress and facilitate staying in treatment. Focus group participants pointed out that mental health services should be offered to all patients, and not solely based on a mental health assessment. The multiple stressors of daily discriminations on top of financial instability and family responsibilities of Black women, alongside paucity of support, were pointed out to be compounded by the greater likelihood of breast cancer being diagnosed at a later stage, with poorer prognosis.

> *"The mental health component should be adapted into the message regarding Black women in breast cancer, period, and dealing with a life changing event, such as cancer." – Patient Navigator*

> *"Well, your mental health provider should... already be part of your team, because that will absolutely help to get you through that...because we know that Black women, oftentimes... it does tend to be later stage, right... and it definitely becomes scarier... then depending on the type–whether it's very aggressive or not. But mental health should definitely be part of your treatment team, not an afterthought...I think it definitely needs to be as soon as you get that diagnosis, 'Here are ... providers we strongly encourage.' At that point a person may or may not decide to take advantage of it, but at least make it so that... you normalize it so then it doesn't become, now on top of everything they actually think I'm crazy. Like, no, it's just a part of your treatment." – Patient Navigator*

Survivorship

Transitioning out of specialty care. Health care policies also affected availability of post-treatment services. One survivor discussed wanting to see an oncologist five years post-diagnosis and being "pushed away" as no longer being considered to be a cancer patient.

> *"I went back, even though I've been passed the five years. I was trying to still see if I could get some more of that treatment. But no, after five years it's almost like they let you go... I called the oncologist to see if I could come in and get an appointment [because of not feeling well] and they say, well you be going to the doctor in a year to Dr. ____. So, I said, okay. Can I wait that long? Do I have to wait that long?" – Survivor*

Another issue raised by a provider was the lack of awareness of the need for continued breast cancer screening after a double mastectomy.

> *"They don't realize. Like I tell them, even if you had double mastectomy, you still have to be screened. And they don't realize that because it's just so many messages out there." – Provider*

Ongoing peer support and advocacy across communities. The robust peer support and effective advocacy of groups, such as the Breakfast Club, were described as remaining vital to survivors and, through their advocacy and ability to engage both provider institutions and community members, to helping reduce underlying root causes of breast cancer inequities. While such support groups were mentioned and relied upon in St. Louis City and St. Louis County, there was a greater need that existed. Lack of available support groups and survivorship programs were presented as an issue even more frequently among survivors in St. Clair County and Madison County, Ill. Breast cancer survivors affiliated with the Breakfast Club noted that it expanded to have a branch, Native Circle, run by Native American women that also offers culturally appropriate and tailored support. They explained that Native Americans in the St. Louis MTA are frequently of mixed ancestry, often with Black heritage.

> *"We are not medical navigators; we are community members. And that involves medical navigating, but also social work. It also involves teaching. It involves everything from taking someone to dialysis, picking them up from medical treatments, making appointments, going with people to their radiation and chemotherapy sessions, advocating all of that." – Peer Navigator*

Section 2 Findings: Systemic and Social Determinants of Health

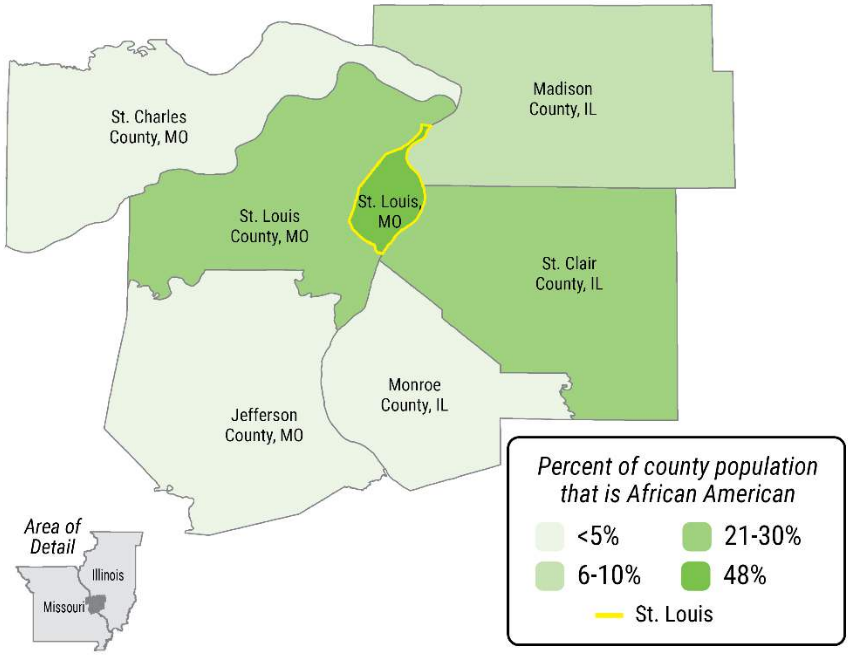
Section 2 explores the systemic and social determinants of health that may be driving breast cancer inequities. The set of factors explored in this section—residential segregation, economic vulnerability, experiences of racism and social determinants of health—were informed by consultations with Komen's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

Residential Segregation

The St. Louis MTA is segregated across a number of dimensions, including race and socioeconomic factors, creating stark contrasts by geography.

In the center of the MTA, St. Louis, Mo., has the highest percentage (48%) of Black residents (see Map 3 and Table 25 in the Appendix). St. Clair County, Ill. and St. Louis County, Mo., have the next highest percentages of Black residents, at 30 percent and 24 percent respectively. The additional counties have populations that are less than 10% Black. In fact, Monroe County, Ill., has a population that is 0 percent Black.

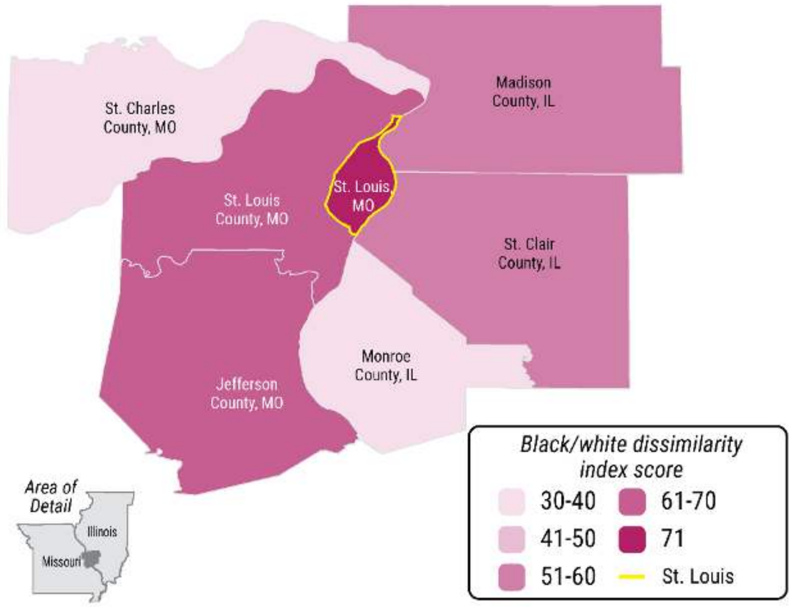
MAP 3. BLACK POPULATION IN THE ST. LOUIS METRO AREA



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

In addition to the MTA as a whole being racially segregated with most Blacks living in just a few of the counties, comprising 48 percent of the population in St. Louis City, Mo., 30 percent in St. Clair, Ill., and 24 percent in St. Louis County, Mo., (see Map 3), many of 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). 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.

MAP 4. RESIDENTIAL SEGREGATION IN THE ST. LOUIS MTA

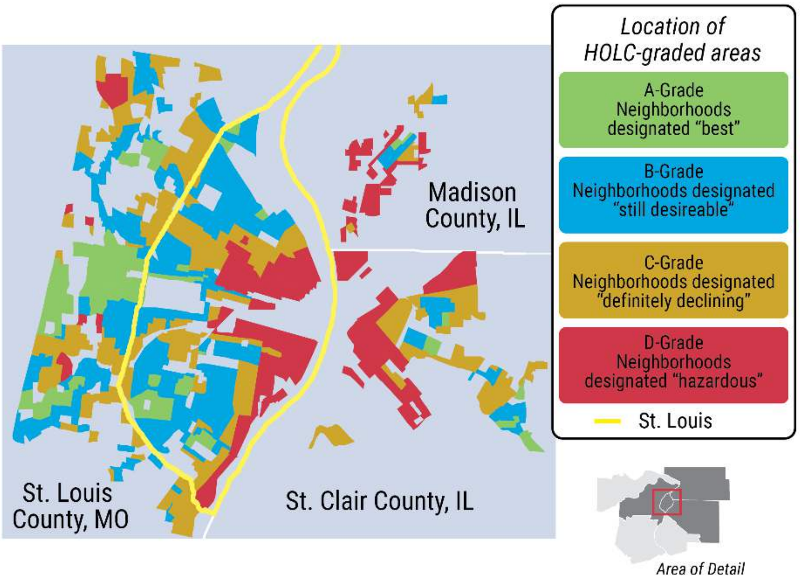


Source: 2019 County Health Rankings (County Health Rankings)

As seen in Map 4, St. Louis City, Mo., has the highest score (71), indicating that it is the most segregated place in the MTA. St. Louis County, MO, and Jefferson County, MO, have the next highest scores at 64 and 67. These data align with findings of Washington University in their report, Segregation in St. Louis-Dismantling the Divide. Counties' scores are significantly lower in St. Charles County, Mo., and Monroe County, I, indicating that the racial distribution of residents in these locations is more even. This is likely due to the limited number of Black people living in these counties.

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 St. Louis MTA.

MAP 5. REDLINING IN THE ST. LOUIS MTA



Source: 2019 Mapping Inequality Project (University of Richmond)

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. Map 5 shows areas within the St. Louis MTA that were included in the "residential security" maps created by HOLC agents in the first half of the twentieth century. In addition to the city of St. Louis, portions of St. Louis County, Mo., Madison County, Ill., and St. Clair County, Ill., appear on the redlining maps of St. Louis from 1937 and 1940.

Banks and other mortgage lenders used these grades to inform their lending practices and policies throughout the St. Louis MTA. Redlining was widely employed by government agencies in St. Louis, with officials declaring many neighborhoods in the city of St. Louis "hazardous" because of their large Black populations. 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 the city of St. Louis (see racial segregation section above) can be traced-–at least in part--to redlining.

During interviews and focus groups, both providers and residents called out the many ways that neighborhoods segregated by race and income have affected overall health outcomes.

> *"You take African American women, put them over there. Just put them over there for a minute. And everybody else is going along with their life. And the mortality rate is different. Okay? No matter what level of education, where they're living, but it's still occurring. Does it have to do with environment? Does it have something to do more genealogically what's inside of us that causes some of those emotional and social determinants? I mean, I know social determinants is something that occurs, but is it something that is offsetting that as well?" – Patient Navigator*

> *"Those of us who are low income, North Side, African American–Those of us who have been disregarded for so long, and have become aware now...of the pollution that's occurring on that side of the city and the environmental rates and going on, there's a high rate of asthma and bronchial infections...lead poisoning…[T]here has been history of racism in the area that's pretty predominant and overlays a lot of things so that feeling of powerlessness and helplessness is pretty prevalent." – Survivor/Peer Navigator*

The survivors who volunteer to help other women navigate their breast cancer journey also discussed hazardous conditions and shifting demographics affecting Northern St. Louis County.

> *"One of the things that I noticed [is] the numbers of diagnoses of breast cancer...in North St. Louis, it went up, and a lot of people are going, well, part of it's environmental. We have Cold Water Creek, which is not a healthy place…Radioactive material that they buried in the ground is now permeating the water systems, the air, the entire environment out there…And then further down in North County is a landfill that has radioactive things buried in it, so there are environmental factors there. But the other part of it is that, as people get better and earn more money, they're moving out of the city because, no offense, there's some places there that aren't safe. You don't want your child going to school there. So as these women are moving to North County, that's where they're being diagnosed. They're the same ladies that were in the city that we were missing but now they're in the county." – Survivor/Peer Navigator*

While some residents found the conditions in their neighborhoods difficult to bear, others described the assets of where they live, feeling strongly connected to their Black communities. Many participants tended to have lived in the area for a long time; particularly in St. Clair County, Ill.. Some had been born there. Several moved there or returned because of the need to support family, their mother or ill siblings, or be near them. What they appreciated was being with family, the people in general and support they give to one another, the Southern lifestyle/pace of living and being in a small, close community that is near city amenities. While a few participants said they would prefer not to live in their county if they had a choice, others expressed a civic pride strengthened by a strong culture of service and bonds, as recounted:

> *"I've been in St. Clair County for almost 65 years. And I love it here because somebody in this place has to be the one to not be the hero but be the solution to all the problems. And I feel I can help some because I did accomplish something today in my neighborhood. So, I love it here and I wouldn't tell people to move out because they don't know that St. Clair County is a gold mine. And I can live anywhere. Could have lived anywhere, but I chose to stay right here." – Survivor*

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, St. Louis City, Mo., reports the highest level of racism when compared to the other counties in the MTA, with St. Louis County, Mo., close behind. In 2016 and 2017, police in St. Louis City, Mo., killed 13 Blacks (see Table 10). Further, there were 220 hate crimes committed with a racial bias motivation in 2015, and eight Fair Housing Act cases have been filed with a racial basis since 2006. In St. Louis County, Mo., two Blacks were killed by the police in 2016 and 2017 and 322 hate crimes were committed with a racial bias motivation in 2015. It should also be noted that Ferguson, Mo., a town in St. Louis County, is where Michael Brown, a young Black teenager, was killed by a white police officer in 2014. Brown's death was the impetus for many nationwide protests that called for police abolition.

TABLE 10. ST. LOUIS 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
Madison County, IL	0	25	0
Monroe County, IL	0	1	0
St. Clair County, IL	0	45	4
Jefferson County, MO	0	22	0
St. Charles County, MO	0	81	0

St. Louis City, MO	13	220	8
St. Louis County, MO	2	322	2

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)

The history of racism was still felt deeply, permeating the focus group participants’ lives.

> *“There has been a history of racism in the area that's pretty predominant and overlays a lot of things so that feeling of powerlessness and helplessness is pretty prevalent.”*
> *– Patient Navigator*

> *"It's a lot of when you talk about the African American population, it's a lot that we still are affected from back in the slavery times. And I hate saying that because it's not that you use this as a crutch but when you look at other people's attitudes towards you, their attitudes build up on that too." – Survivor*

Racism and discrimination in the workplace were among the persistent experiences of racism that participants directly encountered. Many focus group participants in St. Louis County, Mo., shared examples of Blacks having been looked over for positions they have been qualified for but weren’t given. Participants mentioned covering the work of white colleagues and then such colleagues spreading rumors about their poor performance to employers. Some hiring managers were said to only share a job within their social networks, greatly reducing the likelihood of Black women being considered for certain positions. In some cases, companies are required to post a job for a certain period of time due to federal mandates, but by the time these jobs are posted, these positions are already filled.

> *“When I first came here, I had 10 years of service with Bell Telephone. When I got to St. Louis, I could not get a job. They would not accept my transfer...I tried, and I tried, and I tried, and I went downtown, and I took their little test. I had worked for Southern Bell and South Central Bell. Southern Bell is the way Deep South. I would have thought that I would have had a problem there. I didn't. But then I came here to the Midwest and I could not [get employed].” – Survivor*

> *“When I told him [a coworker at a 911 dispatch who would not do his share of the work] to take his feet down off of the console and stay in the cube [as required], well he looked at me, he said ‘I'm going to get you.’ And I smiled. I said, ‘Do what you got to do.’...He didn't care because he was a good friend of somebody that got him the job. So, he got me fired.” – Survivor*

Health Disparities

Data suggest that there are significant disparities in the St. Louis MTA in terms of overall health and wellbeing. In St. Louis City, Mo., nearly one in four adults report that their health is “fair” or “poor” (Table 11). In Monroe County, Ill., only 11 percent of adults report that they have “fair” or “poor” health. Monroe County, Ill., reports that residents have the fewest poor physical health days and poor mental health days per month, at 3.1 days each. St. Louis City, Mo., on the other hand reports that residents have the most poor physical mental health days per month, at 5.0 days each.

Focus group participants discussed multiple health conditions —comorbidities that brought complications, tremendous stress, additional economic hardship, and the need for multiple medications —many with serious side effects. They relied on their own knowledge of their complex conditions, yet were often not listened to when they tried to relay their needs to providers. This was also true in advocating for family members. Patient navigators said not all physicians keep track of comorbidities.

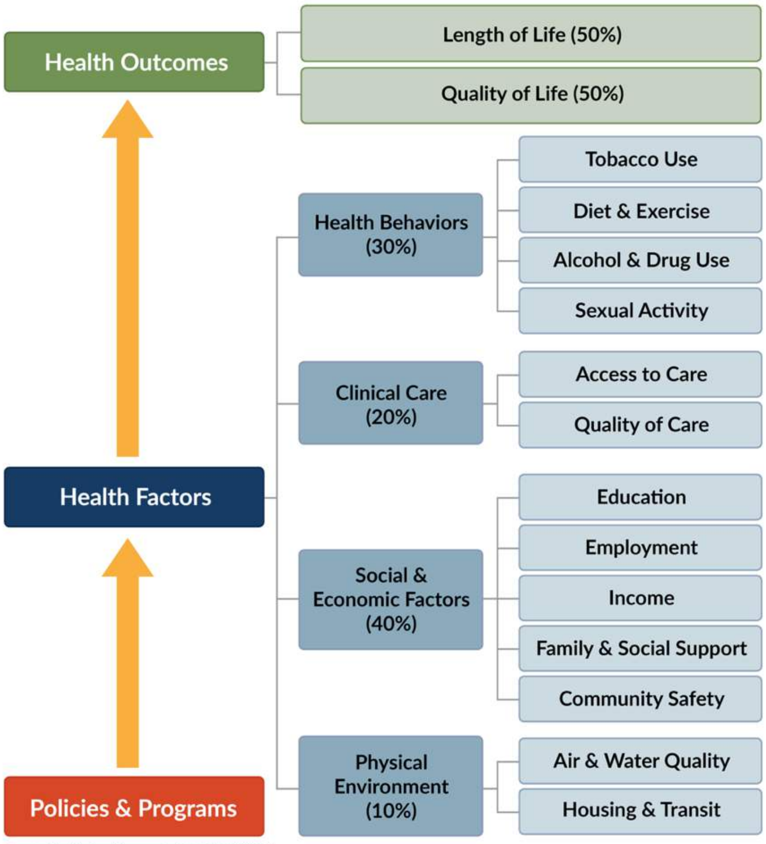
> *“The providers sometimes aren't as... proactive as they should be, meaning that you have a physician that might have seen a patient ongoing for 10 years. But [the patient has] diabetes, maybe some other comorbidity situation is going on, and that never reaches the top of their radar until the woman presents with an issue.” – Patient Navigator*

TABLE 11. ST. LOUIS 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
Madison County, IL	75%	16%	4.0	3.7
Monroe County, IL	1%	11%	3.1	3.1
St. Clair County, IL	92%	18%	4.2	3.9
Jefferson County, MO	21%	15%	4.0	4.2
St. Charles County, MO	1%	12%	3.5	3.8
St. Louis City, MO	12%	24%	5.0	5.0
St. Louis County, MO	72%	15%	3.6	3.8

Source: 2019 County Health Rankings (County Health Rankings)

FIGURE 2. COUNTY HEALTH RANKINGS MODEL



County Health Rankings model © 2014 UWPHI

The County Health Rankings (CHR) similarly highlight county-level differences in health and wellbeing across the 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).

The CHR for Monroe County, Ill., is in the top 1 percent of all Illinois counties, of which there are 102. Madison County, Ill., and St. Clair County, Ill., however, are in the 75th and 92nd percentiles, meaning that they have poorer health outcomes than many of the other counties in the state. In Missouri, St. Charles County is in the top 1 percent of all Missouri counties, of which there are 114. St. Louis County, on the other hand, is in the 72nd percentile of all Missouri counties (see Table 11).

There are not significant differences in health behaviors throughout the counties in the St. Louis MTA. The greatest disparity exists between Madison County, Ill., which has an obesity rate of 36 percent, and St. Charles County, Mo., which has an obesity rate of 28 percent (see Table 12). All of the counties have similar rates of adults who drink excessively (between 19 percent in St. Clair County, Ill., and 23 percentin Monroe County, Ill.), as well as adults who are physically inactive (between 19 percent in Jefferson County, Mo., and 26 percent in St. Clair County, Ill.).

TABLE 12. ST. LOUIS METRO AREA HEALTH BEHAVIORS

County	Percent of Adults Who Are Obese	Percent of Adults Who Drink Excessively	Percent of Adults Who Are Physically Inactive
Madison County, IL	36%	21%	25%
Monroe County, IL	33%	23%	22%
St. Clair County, IL	33%	19%	26%
Jefferson County, MO	32%	21%	19%
St. Charles County, MO	28%	22%	24%

St. Louis City, MO	35%	21%	25%
St. Louis County, MO	29%	20%	22%

Source: 2019 County Health Rankings (County Health Rankings)

Focus group participants described the several measures they took to stay healthy, whether as undiagnosed women or as survivors. Support from patient and peer navigators, area breast cancer organizations, fitness programs such as the YMCA, faith-based organizations and providers were each described as being helpful for fitness and nutrition. Partnerships among these anchor supports were both long-established and expanding.

Peer volunteers engaged in The Breakfast Club peer breast cancer support group described that they partner locally to offer a healthy eating program as well as swimming and exercise programs in partnership with the YMCA. The YMCA (and some insurances) also offers "Silver Sneaker," which is free exercise for women above a certain age.

> *"I started eating healthier. I got to a gym, so I'm working out more. We have an instructor. If you have the Silver Sneakers, you got it free. So, I go there as many times that I can a week and make sure that I walk every day. – Survivor*

Participants discussed safety as a significant barrier to healthy behaviors.

> *"I mean, come on, let's be real. So, when you talk about safety, so you're talking about community safety, can you walk? Do you have paths that you can walk?...Where you can exercise, where you can get out and walk, and you can jog and not be accosted, right?" – Undiagnosed*

TABLE 13. ST. LOUIS METRO AREA LIFE EXPECTANCY

County	Life Expectancy	Life Expectancy for Whites	Life Expectancy for Blacks
Madison County, IL	77	77	71
Monroe County, IL	82	*	*
St. Clair County, IL	77	78	73
Jefferson County, MO	76	76	73
St. Charles County, MO	80	80	79
St. Louis City, MO	74	77	70
St. Louis County, MO	79	80	73

Source: 2019 County Health Rankings (County Health Rankings)

Life expectancy in the MTA is highest in Monroe County, Ill., at 82 years across demographics (Table 13). Monroe County, Ill., however, does not have enough Black residents to have racially disaggregated data for life expectancy. Every county that does have racially disaggregated data reports having higher life expectancies for white people than Black people. Notably, the disparity in both St. Louis City, Mo., and St. Louis County, Mo., is the greatest, with white people living an average seven years longer than Black people in both countries. Overall life expectancy is lowest in St. Louis City, Mo., at 74 years.

TABLE 14. ST. LOUIS 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
Madison County, IL	404	397	622
Monroe County, IL	226	*	*
St. Clair County, IL	424	370	592
Jefferson County, MO	412	415	639
St. Charles County, MO	274	277	307
St. Louis City, MO	562	423	757
St. Louis County, MO	341	287	565

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. St. Louis City, Mo., has the highest premature age-adjusted mortality rate, at 562 (Table 14). Again, the disparity between white people (423) and Black people (757) is also by far the greatest in St. Louis City, Mo., with a disparity of 334 deaths. The age-adjusted premature mortality rate is lowest in Monroe County, Ill., at 226, but these data are not disaggregated by race as there are too few Blacks who live in Monroe County, Ill. Looking only at counties with disaggregated data available (six total), all counties have higher premature age-adjusted mortality rates for Blacks than for whites.

Access to Health Services

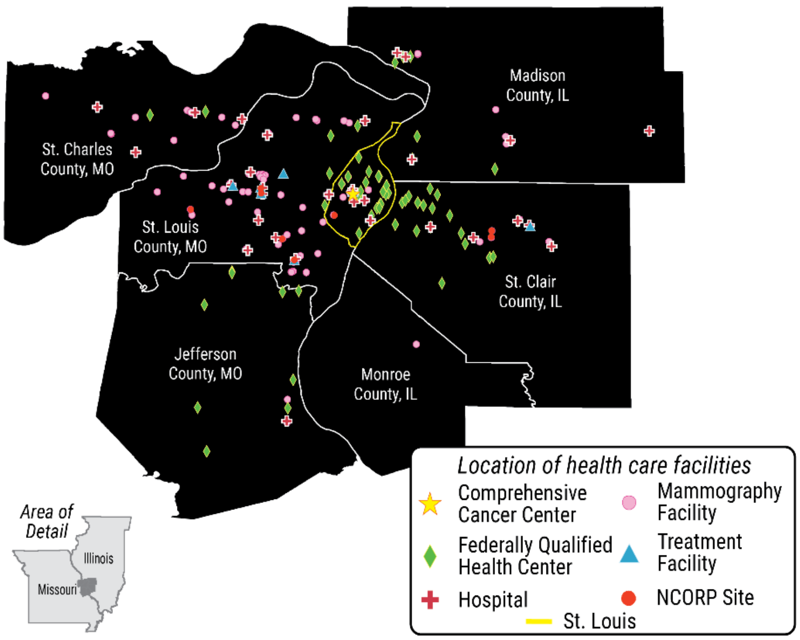
Data suggest that there are significant disparities in the health system in the MTA, including in health care facilities and the proportion of the population that is medically underserved. According to the Health Resources and Services Administration (HRSA), Medically Underserved Areas/Populations are areas or populations designated by HRSA as having too few primary care providers, high infant mortality, high poverty or a high elderly population. For example, in St. Clair County, Ill., 60 percent of the population is medically underserved, while in Jefferson County, Mo., and St. Louis County, Mo., only 3 percent of the population is medically underserved (Table 15).

TABLE 15. ST. LOUIS 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
Madison County, IL	24%	120	2,215	62	1,609	4	8
Monroe County, IL	14%	11	3,097	53	1,894	1	0
St. Clair County, IL	60%	153	1,717	82	1,215	33	10
Jefferson County, MO	3%	52	4,312	35	2,869	0	0
St. Charles County, MO	13%	170	2,300	45	2,247	8	12
St. Louis City, MO	36%	272	1,145	208	481	249	10
St. Louis County, MO	3%	1,228	813	85	1,171	183	10

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 ST. LOUIS MTA



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)

The health systems map (Map 6) shows the concentration of health care facilities across the MTA. Most resources are centered around St. Louis City, Mo.. Specifically, the only comprehensive cancer center is in St. Louis City, Mo., and most of the Federally Qualified Health Centers (FQHCs) are in St. Louis City, Mo., and St. Clair County, Ill. The majority of the screening mammogram facilities and treatment facilities are located nearby in St. Louis County, Mo.

Given the area's high levels of segregation, health care disparities in the St. Louis MTA should be examined through the lens of residential segregation and its systemic and long-term adverse impacts on the breast cancer continuum of care. A research study, using national data, examined whether racial and ethnic health care disparities were associated with residential segregation. The authors concluded that disparities in health care use are related both to a person's racial and ethnic identity and their community's racial and ethnic composition. Thus, the authors suggest that both individual and community-level strategies are required to address health care disparities (Gaskin, Dinwiddie et al., 2012). Other studies have shown how systematic disinvestment in communities makes it harder to attract health care systems, providers and specialists (Andrasfay, Himmelstein et al., 2019; White, Haas et al., 2012). Further, research in other parts of the country have shown how facilities serving racial and ethnic minority populations tend to have poorer quality of care as compared to facilities predominantly serving white women (Ansell et al., 2009; Curtis et al., 2008; Daly & Olopade, 2015; Nurgalieva et al., 2013). This includes having fewer dedicated breast imaging specialists and/or other specialists who are more likely to provide detailed information on risk and risk reductions options, as compared to primary care practitioners. Reduced quality of care also includes facility and staffing limitations that result in Black women receiving inadequate screening mammography screening and delays in initiation of chemotherapy, radiation and surgery.

Focus group participants lamented loss of health care facilities over time. Access to health care in St. Clair County, Ill., was described as problematic for several reasons. The quality and accessibility across hospitals was said by patient navigators to vary dramatically. They elaborated that women with poor insurance are turned away and sent to other hospitals. Grave concern was voiced that several of the major hospitals that Black women depend on, St. Elizabeth's and Memorial Hospital, are moving all of their diagnostic services out of the primarily Black neighborhoods to locations that they worry will be more inaccessible (in Shiloh or O'Fallon). Women often refuse to go to the new hospital because it is hard to reach and/or they perceive it as having poor quality. Participants were said to have to travel back and forth across the river to hospitals where they could receive more comprehensive services than Touchette can offer.

> *"Touchette does provide screening mammography services, and they also provide biopsies and things of that nature. But Memorial and St. Elizabeth, both of those organizations have services that Touchette can't provide. For one is they don't have a stereotactic machine, so anybody that have any type of calcifications automatically would have to be referred to either Memorial or St. Elizabeth or the surgeon would then have to do an open biopsy. And you know, that's almost barbaric now, especially since we have all this other modern technology that they can do opposed to getting an open biopsy." – Patient Navigator*

> *"Centreville to Alorton, we've got more sick people in that area than we have in Belleville, Cahokia, East St. Louis, Fairview Heights, O'Fallon [where there are low-income health care services], but there's nothing down there." – Patient Navigator*

North St. Louis was described as a "health care desert; especially for those with inadequate insurance."

> *"North County is a big area and that area does not have nearly as many hospitals or federally qualified health centers as they should have, or imaging centers where people can go and get screened. So then, that means that people have to know where they can go to get care when they feel as though they can't afford it, whether that means, again, they're uninsured or underinsured, and there's just no known easy mechanism for people to seize. Oh, this is where we go to get care, to get health care when we don't have insurance.*
>
> *So, if you have 300,000 people in a community, and 300,000 people are in North County, but you have one hospital at one end of the county, another hospital at the other end of the county, and maybe two other imaging centers, and that's it. That's truly not enough for that population whereas St. Louis city also has 300,000 people ... access to imaging centers, particularly imaging centers that are also available for people who are uninsured and underinsured, that's just not the case." – Provider*

Changes to the health care infrastructure in St. Louis have further marginalized access to quality care. A historically Black-operated hospital, Homer G. Phillips on the North Side, closed in 1979 and the absence remains. Among a trend of closing Black hospitals across the nation, this was described as a major shift that undermined health care access. The network of community health centers intended to fill gaps of hospital closures and to improve access was viewed as insufficient for the many women who need referrals to larger facilities with specialty care services (Wesley, 2010).

> *"St. Louis is so racially polarized and even having worked at Homer [G. Phillips in the Ville neighborhood] Hospital, which I'm sure everybody's heard, they closed it, they had the accreditation and gave them accreditation to the other city hospital on the South side. And then... the federally qualified clinics started to come in and they were called the overseers of those people who did not have insurance... [women] had to come to one of the clinics to get referrals [to a hospital, and then had far to travel]. And they may be...on a waiting list because you got to go through the case manager and get the appointment and all of that, and that still exists today. North St. Louis is literally a health*

> *care desert. They have clinics, but they're scattered around. Whereas I come North of the South of Delmar, I can probably find a doctor or clinic on every other corner." – Survivor/Peer Navigator*

> *"Well also in the past, those doctors came from the community and that's not the case now. You don't have a doctor living down the street from you when you live in North Side St. Louis." – Survivor/Peer Navigator*

TABLE 16. ST. LOUIS METRO AREA BREAST CANCER RESOURCES

County	Number of Mobile Screening mammography Centers	Number of Cancer Coalitions	Number of Survivor/ Support Groups
Madison County, IL	2	0	3
Monroe County, IL	1	1	1
St. Clair County, IL	2	0	16
Jefferson County, MO	1	0	3
St. Charles County, MO	1	0	16
St. Louis City, MO	4	2	8
St. Louis County, MO	5	1	16

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

Many of the breast cancer resources are in St. Louis County, Mo., and St. Louis City, Mo., with five and four mobile screening mammography centers (Table 16). A St. Louis provider described that Mercy Hospital, Missouri Baptist Medical Center (Missouri Baptist) and BJH health care's Siteman Cancer Center (Siteman) operate mobile screenings. They partner with businesses to provide screenings to their employees to make it easy for women. Yet they, and patient navigators, shared that the mobile screening mammography services are not adequate to reach across any of the three counties--St. Clair County, Ill., St. Charles County, Mo. or St. Louis County, Mo.

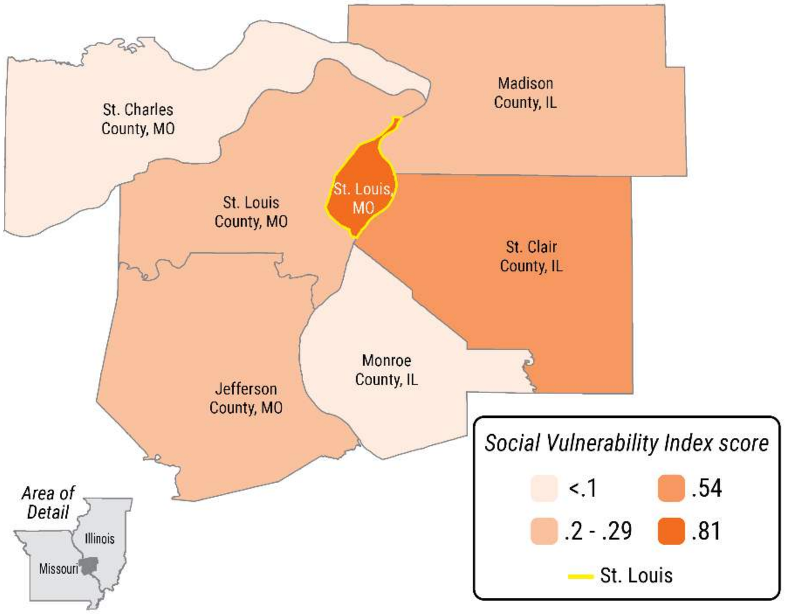
St. Louis City has the most cancer coalitions, with two. St. Clair County, Ill., St. Charles County, Mo. and St. Louis County, Mo., each have 16 survivor/support groups, which is a significantly greater amount than the other counties.

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 exacerbate and cement a wide range of negative outcomes and existing burdens, including with regard to . 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. St. Louis City, Mo., has the highest SVI score by a wide margin at 0.81. St. Clair County, Ill., has the next highest SVI score at 0.54. St. Charles County, Mo., and Monroe County, Ill., have the lowest SVI scores, at 0.04 and 0.00 respectively. Individual factors influencing a county's SVI can be parsed by looking at specific indicators.

MAP 7. ST. LOUIS METRO AREA SOCIAL VULNERABILITY



Source: 2016 Social Vulnerability Index (US Centers for Disease Control and Prevention)

St. Louis City, Mo., reports the highest percentage of the population below 200 percent FPL in the MTA, at 46 percent, which is about 145,000 people (see Table 17). Jefferson County, Mo., has the highest percentage of Black women over age 45 who live below the FPL, at 29 percent, with St. Louis City, Mo., coming in close behind at 28 percent. Both Jefferson County, Mo., and St. Louis City, Mo., also have the highest percentages of the population that is uninsured, at 9 percent and 13 percent, respectively. Monroe County, Ill., has particularly high economic security: 15 percent of their population falls below the FPL, 3 percent are uninsured and 0 percent of the Black women in the county fall below the FPL. This is likely because there are only 94 Black women over age 45 in the entire county (see Table 3).

TABLE 17. ST. LOUIS 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
Madison County, IL	5%	29%	26%
Monroe County, IL	3%	15%	0%
St. Clair County, IL	8%	34%	24%
Jefferson County, MO	9%	27%	29%
St. Charles County, MO	5%	15%	8%
St. Louis City, MO	13%	46%	28%

St. Louis County, MO	7%	24%	13%

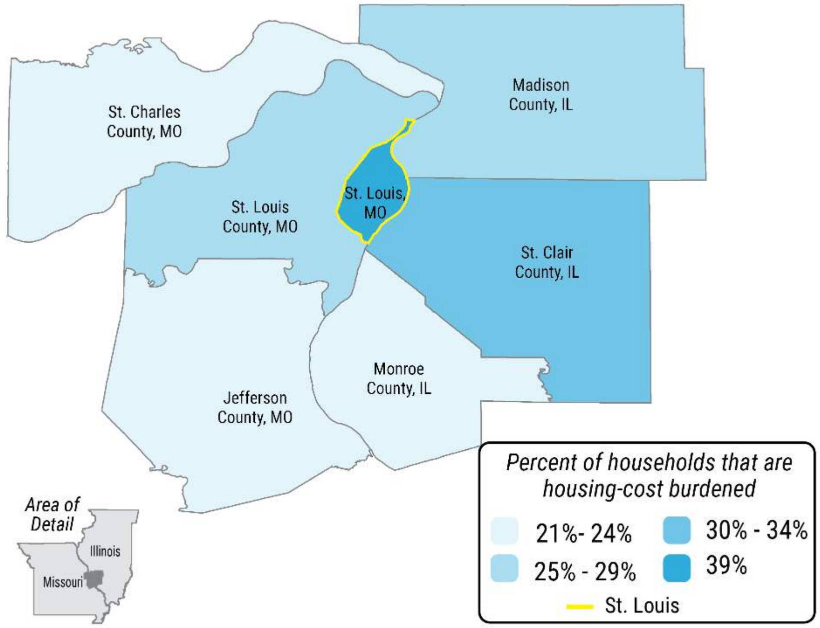
Source: American Community Survey 2013-2017 5-Year Estimates (US Census Bureau):

Stress arose from economic vulnerabilities. Focus group participants described the need to choose between health and day-to-day needs. Economic factors included the need to overwork to support families and still the inability to obtain or afford necessities, especially health insurance, remains. Work demands were said to put stresses on entire families, even without a breast cancer diagnosis. Inability to be allowed or to afford to take time off from work and the demands of caring for family were among factors attributed to not following up on treatment.

> *"When a physician is telling you, you need surgery, and it'll probably take a couple of days of work, and you also may need chemotherapy, and you need more days off from work, I think all of that is playing into whether people return back or whether they decide to do an alternative therapy or just pray for deliverance from the problem. So, I think sometimes it's rooted in the very real possibility of how do I continue my life without a normal and usual source of income?" – Provider*

> *"I was the only Black [woman] working there as a 911 dispatcher on a shift that calls for 12 hours, and I worked the city eight years but I was doing 106 hours because nobody wanted to work. Well I got three boys, and everybody wants to be off. So, I had to explain to my children what I was doing. The baby boy did not like it." – Survivor*

MAP 8. HOUSING-COST BURDEN IN THE ST. LOUIS METRO AREA



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

St. Louis City, Mo., St. Louis County, Mo., and St. Clair County, Ill., have the highest percentages of households that are housing-cost burdened in the MTA. The measure illustrated in Map 8 indicates the percentage of renters and homeowners that spend 30 percent or more of their total income on housing. St. Louis City, Mo., reports 39 percent of households as housing-cost burdened, St. Clair County, Ill., reports 30 percent of households as housing-cost burdened, and St. Louis County, MO, reports 27 percent of households as housing-cost burdened (Map 8).

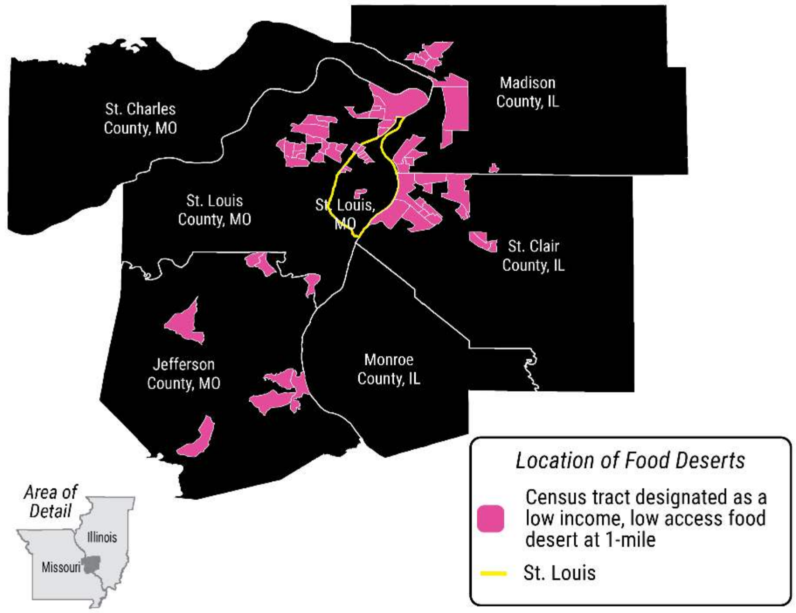
TABLE 18. ST. LOUIS METRO AREA FOOD SECURITY

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
Madison County, IL	12%	12%	36%
Monroe County, IL	7%	5%	17%
St. Clair County, IL	17%	12%	36%
Jefferson County, MO	11%	8%	25%
St. Charles County, MO	10%	5%	10%
St. Louis City, MO	25%	3%	39%
St. Louis County, MO	15%	6%	25%

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 St. Louis MTA, St. Louis City, Mo., has the highest percent of Black households receiving SNAP/EBT at 39 percent (Table 18). St. Louis City, Mo., also has the highest percentage of the population that is food insecure, at 25 percent. However, only 3 percent of the county's total population has limited access to healthy foods.

MAP 9. FOOD DESERTS IN THE ST. LOUIS METRO AREA



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

Most of the food deserts in the MTA are located in St. Louis County, Mo., Madison County, Ill., St. Clair County, Ill., and Jefferson County, MO. The food deserts in the former three counties are all centered around northeast St. Louis City, Mo. Map 9 defines food deserts as low-income, low access food desert designated by the census tract. There are no food deserts in St. Charles County, Mo., or Monroe County, Ill.

Focus group participants in St. Louis County, Mo., identified the cost of healthy foods as a barrier to eating healthily. Indeed, money to buy groceries and ideal time management were listed as factors that promote healthy eating and exercise. St. Clair County, Ill., was described as having food deserts, and while jobs were said to be available, remaining financial stressors served as barriers to buying fresh vegetables. Some see the lack of safety as a major obstacle to shopping for healthy food. Food quality in stores was described as poor. Liquor stores are prevalent —participants viewed that fact as demonstrating that their health is not a priority.

> *"Well if you live in a place where there are food deserts...there have been issues to where grocery stores in certain neighbors, the quality of meat was poor. Fruits and vegetables were spoiled and rotten... So, one of the risk factors, is to minimize your alcohol consumption, or to stay away from it all, but on every corner is a liquor store, so that's what's being promoted. So, your health is not necessarily ... being promoted depending on where you live. On the other hand, if you live in a certain part of St. Clair County, where all the money is being shipped into, you get all of the messages of health. You have numerous grocery stores that have all kinds of fruits and vegetables, including exotic [produce that is not that expensive]." – Undiagnosed*

St. Louis City, Mo., as the most urban place in the MTA, has by far the highest percentage of households without a vehicle (21 percent), as well as the highest percent of the population that commutes to work using public transportation (9 percent) or by foot/bike/other (6 percent) (Table 19). In Monroe County, Ill., Jefferson County, Mo., and St. Charles County, Mo., 0 percent of the population commutes to work using public transit. In those same counties, 0-2 percent of the population commute to work by foot/bike/other. In Jefferson County, Mo., only 4 percent of households do not have a vehicle, but 25 percent of the population commutes more than 45 minutes to work.

TABLE 19. ST. LOUIS 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
Madison County, IL	6%	15%	2%	2%
Monroe County, IL	4%	23%	0%	2%
St. Clair County, IL	10%	16%	4%	3%
Jefferson County, MO	4%	25%	0%	1%
St. Charles County, MO	3%	13%	0%	2%
St. Louis City, MO	21%	11%	9%	6%
St. Louis County, MO	7%	10%	3%	2%

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

Providers, patient navigators and residents in St. Louis County and St. Louis City, Mo., and in St. Clair, Ill., described transportation as challenging in reaching health facilities that are often far from patients' homes or work. St. Louis County focus group participants specifically mentioned the cost of transportation as a barrier to screening, noting that the cost of traveling from St. Louis County to the South side of St. Louis is $10. Patient navigators and a provider in these counties highlighted poor transportation options as being a major barrier to health care access.

> *"If you're saying, 'What are some of the reasons that we may see a disparity...' first I would point to is the lack of expansion of Medicaid [means there] are unnecessarily high rates of uninsured men and women in our community. And then, the actual access to readily available health care in people's community coupled with a poor transportation infrastructure."* – *Provider*

> *"There's nothing in Centreville or Alorton to help these people that have to be transported 35, 40 miles away from home to get dialysis...or to get chemo." – Patient Navigator*

TABLE 20. ST. LOUIS 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
Madison County, IL	92%	26%	10%
Monroe County, IL	95%	31%	15%
St. Clair County, IL	91%	27%	13%
Jefferson County, MO	88%	20%	8%
St. Charles County, MO	95%	37%	5%
St. Louis City, MO	86%	34%	19%
St. Louis County, MO	93%	43%	10%

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

In Monroe County, Ill., and St. Charles County, Mo., 95 percent of the population over age 25 has a high school degree or higher (Table 20). However, in the same St. Charles County, Mo., 15 percent of Black women over age 25 do not have a high school degree. St. Louis County, Mo., has the highest percentage of the population over age 25 with a bachelor's degree or higher (43 percent).

TABLE 21. ST. LOUIS METRO AREA GENTRIFICATION

County	Proportional Change in Population With a Bachelor's Degree or Higher	Percent Change in Median Household Income
Madison County, IL	3%	7%
Monroe County, IL	5%	5%
St. Clair County, IL	2%	1%
Jefferson County, MO	3%	9%
St. Charles County, MO	2%	10%
St. Louis City, MO	6%	12%
St. Louis County, MO	3%	8%

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. The percent change in median household income is greatest in St. Louis City, Mo., at 12 change change (Table 21). It is the lowest in St. Clair County, Ill., where the percent change in median household income is 1 percent. All counties in the MTA have a positive proportional change in the population with a bachelor's degree or higher, with St. Louis City, Mo., having the highest proportional change at 6 percent.

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.

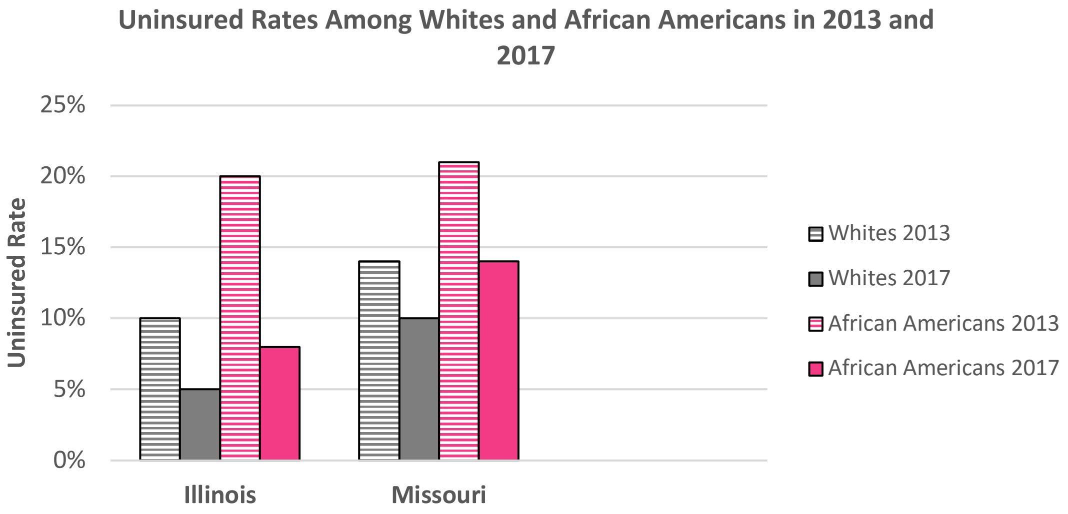
- **Preventive Services Mandate.** The preventive services mandate requires that almost all private health insurance plans cover certain preventive services without patient cost sharing. This mandate does not apply to grandfathered plans or policies, a very minor share of plans in existence prior to 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% FPL. Missouri has not elected to expand eligibility for its Medicaid program. This leaves people in what is called a “coverage gap” where their incomes are too high to qualify for Medicaid but not high enough to afford health insurance otherwise; thus, they remain uninsured. In Missouri, as of 2018, there are an estimated 113,000 people in the coverage gap, meaning their incomes are below 100% FPL, and another 92,000 people who may have been eligible for coverage on the marketplace, meaning their incomes are between 100-138% FPL, creating an estimated total of 205,000 uninsured people who would have been eligible for insurance under expansion (Garfield, Orgera et al., 2020). In the state’s August 2020 election, Missouri voters approved a ballot measure for a constitutional amendment to adopt Medicaid expansion. The constitutional amendment specified that Missouri may not implement additional eligibility or enrollment restrictions for the population eligible for expansion. The ballot specified a timeline of necessary information submitted by the state to the Centers for Medicare and Medicaid Services by March 1, 2021, with coverage expansion to go into effect by July 1, 2021 (The Henry J. Kaiser Foundation, 2020b). At the time of this report publication, the

Medicaid expansion is therefore approved but not yet implemented in Missouri. Illinois, the second state in the Komen AAHEI St. Louis MTA, has elected to expand its Medicaid program.

Recent research indicates that the uninsured rate among non-elderly adults has decreased for all racial/ethnic groups with larger decreases among non- Hispanic Black and Hispanic groups compared to non-Hispanic whites. See Figure 3 below for trends of uninsured rates for the nonelderly in Missouri and Illinois (2013-2018) comparing rates among Black and white residents in each state. There is an overall downward trend of uninsured rates for both Blacks and whites in Missouri and Illinois, but an inequity in uninsured rates remains between the groups.

The coverage disparities have narrowed compared to before the ACA, but disparities in coverage by race and ethnicity remain (Artiga, Orgera 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, Yabroff 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).

FIGURE 3. TRENDS OF UNINSURED RATES FOR THE NONELDERLY IN MISSOURI AND ILLINOIS



Source: JSI analysis of Kaiser Family Foundation data (The Henry J. Kaiser Family Foundation, 2018).

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

In Missouri, the NBCCEDP program is known as the Show Me Healthy Women Program (SMHW). Women living in Missouri, who are 50 to 64 years old, and are uninsured are eligible for this program. In Illinois, the NBCCEDP program is known as the Illinois Breast and Cervical Cancer Program. Women living in Illinois, who 35 to 64 years old, and are without insurance are eligible for this program.

> From July 2014 to June 2019, 25,771 mammograms were provided in Missouri through the NBCCEDP (Centers for Disease Control and Prevention, 2020). From July 2014 to June 2019, 51,191 mammograms were provided in Illinois through the NBCCEDP (Centers for Disease Control and Prevention, 2020).

> In Missouri, women who are diagnosed through the SMHW program may be eligible for treatment through the Breast or Cervical Cancer Treatment MO HealthNext Program. In Illinois, women who are diagnosed (either through the ICCBP or through another means) may be eligible for treatment through the ICCBP Medicaid if they meet certain requirements.

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). In Missouri, providers are available in 85 counties plus St. Louis and there are 182 provider locations throughout the state, including local public health agencies, FQHCs, hospitals, private physician offices, and not-for-profit health centers. If a woman is diagnosed with breast or cervical cancer, she is then eligible to receive Medicaid services.

TABLE 22. OVERVIEW OF SCREENING SERVICES IN THE ST. LOUIS METRO AREA

State	Age	Insurance Status	Program Services
Missouri Show Me Healthy Women	35-64 (and older if they do not receive Medicare Part B)	No insurance to cover program services	Screening: clinical breast exams, screening mammograms for women age 50-64 (target population), screening mammograms for women 40-49 using alternate funds (if available), pap tests, pelvic exams Diagnostic: specialist consultations (breast and cervical), diagnostic mammograms, ultrasound, breast biopsies, fine needle aspiration, conization (cold knife, laser, loop electrosurgical excision procedure), colposcopy (with or without biopsy)
Illinois Illinois Breast and Cervical Cancer Program (IBCCP)	35 to 64 years old	Without insurance	Screening: Free mammograms, breast exams, pelvic exams and Pap tests

Sources: Show Me Healthy Women (Missouri Department of Health and Senior Services, 2017), IL Breast & Cervical Cancer Program (IBCCP) (Illinois Department of Public Health, 2020)

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

State	Age	Insurance Status
Missouri	Under age 65	Uninsured or have health coverage that does not cover breast or cervical cancer treatment
Illinois	35 to 64 years old	Without insurance

Source: Breast or Cervical Cancer Treatment MO HealthNet Program (Missouri Department of Social Services), IL Breast & Cervical Cancer Program (IBCCP) (Department of Public Health, 2020)

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 et al., 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. Neither Missouri nor Illinois have implemented any work requirements for their Medicaid programs (The Fund, 2020; the Henry J. Kaiser Foundation, 2020a).

Cancer Plan for Missouri

The Missouri Cancer Action Plan is developed and published every five years by the Missouri Comprehensive Cancer Control Program (CCCP) (Missouri Cancer Consortium, 2016). The CCCP is funded by the CDC and provides leadership for and coordination of Missouri's comprehensive cancer control efforts. The cancer plan is focused around four broad goals:

- Goal #1: Reduce the incidence of cancer by promoting healthy lifestyles and reducing environmental hazards
- Goal #2: Increase the early detection of cancer by promoting the use of evidence-based screening guidelines
- Goal #3: Increase access to evidence-based treatment of cancer
- Goal #4: Assure the highest quality of life possible for cancer survivors and their families, including end-of-life transitions

Goals 2 and 3 have a particular focus on breast cancer with intentions to increase the percentage of women who receive regular breast cancer screening and increase the percentage of cancer patients (including patients of in situ and invasive breast cancer) who receive evidence-based treatment.

Other goals have created specific targeted intervention for Blacks in Missouri, particularly Goal 1 with objectives to reduce smoking and obesity rates for Blacks. Goal 4 also outlines strategies to make tools and resources available to identified disparate populations, including those of minority race or ethnic status, and to increase information and awareness about the service needs of diverse populations, including diverse racial and ethnic backgrounds. However, the plan makes no specific mention about targeting breast cancer rates in Black women in the state.

Illinois Comprehensive Cancer Control Plan

The Illinois Comprehensive Cancer Control Plan is developed by the Illinois Cancer Partnership (ICP), a partnership involving public sector, private, and nonprofit partners. The most recent plan covers the time period of 2016-2021 (Department of Public Health, 2016).

In the plan, the specific goal related to breast cancer is to increase the proportion of women 40 and older who receive a screening mammogram through promotion of the Illinois BCP and faith-based, community-based partners. Not specific to breast cancer but relevant to breast cancer survivors, the Illinois Comprehensive Cancer Control Plan also includes a strategy to educate health care providers and patients to increase the awareness of issues relevant to cancer survivors (such as a communications campaign on improving survivorship, faith-based survivorship programs, etc.). While the plan describes breast cancer inequities by race, the state plan does not provide specific recommendations to address breast cancer inequities.

State Laws Impacting the Breast Cancer Community

- **Diagnostic Imaging.** Illinois has passed legislation that eliminates the out-of-pocket costs for medically necessary diagnostic mammograms, breast ultrasound and breast MRI.
- **Metastatic Step Therapy.** Illinois has passed legislation that prohibits the use of step therapy or "fail-first" protocols for advanced, metastatic cancer patients.
- **Oral Parity.** Missouri and Illinois 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

This landscape analysis sought to understand the underlying causes of breast cancer inequities across the care continuum among Black women in the St. Louis MTA, with a focus on systemic racism and SDOH. Examining multiple measures of disease burden together underscores how race is strongly influencing breast cancer disease burden.

Breast Cancer Disease Burden

The review of data presents a compelling story about breast cancer in the St. Louis MTA deserving of further research. As compared to white women in the St. Louis MTA, Black women die from the disease at higher rates, a pattern that may indicate deep and persistent inequities in access to and/or quality of treatment.

Missouri and Illinois are among states in which incidence of breast cancer among Black women has exceeded the incidence among white women. Although there is no consistent trend in incidence rates within the St. Louis MTA, comparing Black women to white women (see Table 5) across the five different counties in the St. Louis MTA that disaggregate data by race, Black women have greater incidence of breast cancer in St. Louis City, Mo., and Madison County, Ill. A strong trend is seen in mortality in the four areas in the St. Louis MTA that disaggregate those statistics by race. Across these counties, Black women are consistently more likely to die from the disease compared to white women (see Table 8), at rates that are from 24 percent higher in St. Louis City, Mo., to 86 percent higher in St. Louis County, Mo. Late-stage diagnoses are elevated for Black women versus white women in the St. Louis City, Mo. area, where it is a striking 18.5 percent higher rate.

Screening mammography rates are not likely to explain all of the reasons for higher mortality among Black residents. State data on screening mammography rates suggest that Black women are likely getting mammograms at similar rates as white women in the St. Louis MTA. The percent of women of any race getting mammograms is reported to be 63 percent(Madison County, Iii.) to 76 percent (St. Louis City, Mo.) within the St. Louis MTA. While the areas on the higher end are comparable to state rates of 74 percent in Missouri and 73 percent in Illinois, rates in Jefferson County, Mo., St. Clair County, Ill., and Madison County, Ill., are 5-10 percent below their respective state average (see Table 9). As approximately a quarter to a third of residents over age 45 have not had a screening mammography, these rates could be improved upon, however are not likely to explain the inequity in mortality.

Quality of Care

It is not clear why the late-stage incidence is higher for Black women in St. Louis City. Inconsistent screening guidance and mistrust of providers and the health system at large could delay health care seeking, ultimately resulting in late diagnosis. Patient navigators observed that this is a common issue for women in the MTA given the shifting and evolving guidelines, particularly as these guidelines relate to patient age and whether to pursue a screening mammogram. Several survivors also shared experiences of annual mammograms having not detected breast cancer that had progressed to a late stage, and there were those whose diagnoses had been delayed after screening found an abnormality when providers told them to just watch and wait. This raises the specter of poor equipment, lack of availability of well-trained technicians, poor adherence to guideline concordant care or other potential issues surrounding quality of care.

Inequities might lie in delays between diagnosis and treatment, access to treatment and the quality of treatment available to Black women versus white women in St. Louis County, Mo. St. Louis County has the lowest percentage of medically underserved populations (3 percent); yet the data are not available by race. During interviews and focus groups, participants shared that Black women experienced long and unnecessary delays in getting treatment, even to the point of presenting back with metastatic disease due to a missed window of care.

Research also shows that race likely plays an important role in poorer outcomes among Black women, as breast cancer disparities for Black women can persist regardless of insurance status. A study by Hoffman et al., for example, showed that both publicly and privately insured Black women experienced a longer duration from the time of first symptoms to diagnostic resolution for breast cancer as compared to white women (Hoffman et al., 2011). Other evidence shows that commercially insured Black breast cancer patients were diagnosed at a later stage and had a higher mortality rate when compared with their white counterparts with the same insurance status (Daly & Olopade, 2015). Also, Black women are likely to encounter health care staff with discriminatory attitudes and behaviors. This can lead to misdiagnosis and delays in treatment and deepens mistrust of providers and the health care system at large.

This was most apparent in the qualitative discussions about the diagnostic phase of the breast cancer continuum of care. While examples of providers offering high quality, respectful services to Black women were abundant, others described presenting with symptoms or even with abnormalities found during screening mammography that were ignored or dismissed. It causes both mental strain and reduces the chances of survival to live with symptoms for a long period before getting a cancer diagnosis. In particular, they reported that women under 40 had a harder time getting screened and/or referred for diagnostic procedures, including one case where the patient had to seek out three different physicians before receiving the appropriate diagnostic tests. Additionally, the qualitative data expose that personally mediated racism leads to a poorer experience for Black women in the MTA. Several survivors reported that they were not listened to when they asked for screening nor included in shared decision making to shape their treatment plans.

Women told of facing such discrimination with grace and resilience. They confronted situations, but focused on their strength, character and self-worth rather than victimhood. They found means of self-advocating and gaining greater strength by joining together.

It is often only in conversations with other survivors, usually at support groups or through peer navigation programs, that they find out they are being treated differently or learn information that is critical. Cancer coalitions and support groups were mentioned and relied upon on St. Louis City and St. Louis County, yet there was a greater need that existed. While St. Clair had a high number of support groups (16) catalogued by the Komen Affiliate in 2015, cuts to the Illinois Breast and Cervical Cancer Program have diminished resources, especially in East St. Clair where more of the Black neighborhoods are located. Monroe County and Madison County, Ill., and Jefferson County, Mo., have the fewest support groups. The longstanding efforts of women of color to operate their own peer networks, including The Breakfast Club, was noteworthy, and participants felt they met the needs of Black women more fully while also helping to create community change through their networking and advocacy.

Given that the research supports the experiences reported in the focus groups and interviews, it is possible that Black women in the St. Louis MTA are provided with a lower quality of care by some providers at some institutions as compared to white women, and that this racial inequity in care provision directly contributes to the breast health disparities in the region.

Inequities might lie in access to treatment, delays between diagnosis and treatment and the quality of treatment available to Black women versus white women in St. Louis County, Mo. St. Louis County has the lowest percentage of medically underserved populations (3 percent), yet we did not have information by race.

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).

Providers conveyed that quality of care was not equal and that practices rooted in historic and systemic racism, as well as unconscious bias, affected their own training and work experience. They strongly asserted that while the vision was there to end disparities, they were still far from equity. While some were in active coalitions, others found it hard to discuss racial equity among peers.

Tied to disparate care, was disparate research. Only recently has cancer among Black women been researched in clinical trials, which was said to have hampered the state of knowledge regarding incidence and the best treatment options for triple negative breast cancers, their increase and their predilection for recurrence within two years (Jiao et al., 2014). Furthermore, Black women may have less access to improvements in treatments (Yedjou et al., 2017).

Social Determinants of Health

The St. Louis MTA exhibits high rankings of segregation —both within and across areas. Within St. Louis City are clusters of Black households and lower-income neighborhoods interspersed with neighborhoods experiencing gentrification and the concurrent rise in housing prices. Community members spoke of jobs, transportation options, availability of nutritious and affordable foods, exposures to pollutants and walkable streets varying along such lines. Of likely consequence to health inequities, in each of the priority counties within the St. Louis MTA, St. Clair, Ill., and St. Louis City and St. Louis County, Mo., access to health care services, particularly high-quality cancer diagnostic and treatment facilities, tended to be farther away from underserved Black neighborhoods. While FQHCs may be available, with a few exceptions, these were not described as offering the same level of access to high-quality breast cancer services.

The demographic data establish that the areas of the St. Louis MTA with higher proportions of Black residents are St. Louis City, Mo. (48 percent), St. Clair County, Ill. (30 percent) or St. Louis County, Mo. (24 percent, which has a larger actual number of Black women over 45) (see Table 4). These areas show a Black-white racial disparity in overall life expectancy and premature mortality (see Tables 13 and 14).

From a resource standpoint, the two counties in the MTA that have the greatest percentage of medically underserved people are St. Clair County, Ill.(60 percent) and St. Louis City, Mo. (36 percent). These same counties have the greatest proportion of Blacks in the MTA, with Blacks comprising 30 percent of St. Clair County, Ill., and 48 percent St. Louis City, Mo. While each county in the MTA had at least one mobile screening mammography center, participants indicated that mobile vans were not consistently available in the highest need Black neighborhoods. Research shows that the pattern of resources clustered in predominantly white areas impacts a women's cancer journey. Ansell et al. found that in Chicago, facilities that served predominantly "minority" women were less likely to have dedicated breast imaging specialists reading results as compared to those facilities that served predominantly white women (Ansell et al., 2009). Studies have also found racial differences in time to breast cancer diagnosis (Hoffman et al., 2011), time to breast cancer treatment (Halpern & Holden, 2012; Ko, Andreopoulou, & Moo, 2016; Nurgalieva et al., 2013), type of breast cancer treatment (Curtis, Quale, Haggstrom, & Smith-Bindman, 2008) and completion of breast cancer treatment (Green et al., 2018; Ko et al., 2016).

In the St. Louis MTA, areas with large Black populations have some of the highest uninsured rates, suggesting that not having insurance may be among factors contributing to breast cancer inequities. The uninsured rates may, in part, be related to the state not having adopted an expanded Medicaid program. The rates of uninsured tended to be lower in Illinois than in Missouri counties. During the period reflected in Table 17, Illinois had expanded Medicaid, while Missouri had not (Update: Medicaid Expansion in Missouri was recently approved by ballot initiative in August 2020).

Focus group participants explained that the type of insurance they were perceived to have influenced the quality of care received. They reported feeling that those enrolled in Medicaid received poorer quality care and were turned away from services at some facilities. Focus group participants with limited, private insurance with poor coverage had similar, if not worse, experiences. Health professionals who were Black also reported poorer treatment until the health care staff were aware that they were physicians themselves. Along similar lines, the type of health insurance impacts where a patient receives care. Medicaid recipients, or those without insurance, are likely to receive treatment at an FQHC or at hospitals, which were perceived by focus group participants and interviewed providers as providing a lower quality of cancer care.

Across those offering their experiences and perspectives, emphasis was placed on insurance as a key factor. Many Black women in this MTA were described as not having adequate or any insurance to cover needed care. Those without adequate insurance may not be able to access treatment and were claimed to be viewed as undesirable. They are "pushed out" of care. Insurance was also described as a major factor in stopping treatment because of the cost of copays or facilities not accepting all policies. These data are consistent with the literature showing 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, He, Edmonds, & Sheppard, 2019). A qualitative study in Chicago found that Black breast cancer patients often expressed concern that the type of health insurance impacts the quality of breast cancer care received (Masi & Gehlert, 2009).

Data further indicate that Blacks from St. Louis City and County in Missouri as well as St. Clair and Madison County in Illinois, are heavily burdened by SDOH. A high percentage of Black populations in these four locations are medically underserved, below the 200% FPL, and food insecure. These data suggest that even if an Black woman in any of these places is physically proximate to a treatment facility, she may be unable to access care due to economic barriers or other burdens related to SDOH.

St Louis City also reports the highest number of Blacks killed by police, number of hate crimes committed with a race/ethnicity bias and number of housing act cases filed with a race bias within the MTA. There is a strong and growing body of evidence on the negative health effects of such experiences on entire families and communities (Novak, Geronimus, & Martinez-Cardoso, 2017; Parker, Parker, Philbin, & Hirsch, 2018). Participants in St. Louis City and St. Clair mentioned neighborhood safety as a factor that affects healthy behaviors (walking and exercising, accessing food stores) and travel to health care and support programs, including not being able to attend our focus group sessions at night.

Timeliness of care is a key concern. Research on HDHPs and their impact on breast cancer care tend to stratify by income level, but not by race and ethnicity. Overall, HDHPs appear to exacerbate delays across the breast cancer continuum of care for multiple socio-demographic groups with low-income women experiencing the longest delays (Wharam et al., 2019).

Despite these many challenges the landscape analysis also identified innumerable opportunities to advance racial equity. Partnerships that link health care organizations, community-based organizations, and local government were strong. The assets Black women themselves bring are abundant and many have organized themselves into advocacy and peer-support networks. Participants clearly voiced that Komen's leadership and resources could make a pivotal contribution to helping the St. Louis MTA advance community-driven, collaborative initiatives to foster needed change. Breast cancer inequities across the care continuum in the St. Louis MTA persist due to systemic policies and practices, economic vulnerability, incongruence between guidelines and implementation, variation in messaging about screening guidelines and experiences of personally mediated racism. Taken together, these factors severely reduce the timeliness and quality of care that Black women receive across the cancer care continuum. Particular aspects of the breast cancer continuum that warrant further investigation and intervention include the availability of accessible, high-quality screening and diagnostic mechanisms and treatment options for Black women. Opportunities to expand upon growing clinical/community partnerships present themselves. Such collaborations can enhance not only education and outreach for residents and providers, but hold promise in strengthening policies, systems and environments. Resulting improvements in economic, physical and social conditions are among determinants that can lead to healthier Black neighborhoods.

Recommendations

Komen's AAHEI is a substantial undertaking to dismantle the systems that perpetuate growing breast cancer inequities experienced by Black women. Findings from the St Louis MTA landscape analysis suggest that the work ahead requires interventions across 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 micro systems and the complexity of their experience increases. Access to and quality of these micro systems vary, and there is a need for these systems to interact and relate in a manner that centers the experiences of Black women. When multiple micro systems intersect, the mezzo system is formed and the health experience becomes more complicated, particularly in the absence of 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

Increase access to culturally competent patient navigators and community health workers (CHWs).
The breast cancer community should consider various ways to support culturally competent, trained patient navigators and CHWs, such as serving on patient navigation and CHW advisory boards, funding culturally competent patient navigator/CHW trainings, and funding patient navigator/CHW services to increase breast cancer patients' access to these invaluable services. This includes increasing the number of navigators and assuring they are geographically accessible. Komen Missouri already engages patient navigators as local partners in supporting women and advancing their local programming. Interventions that expand patient navigators/CHWs and survivors as peer lay navigators into underserved areas have been among the focus areas for these collaborators. Efforts could build upon CHW reimbursement that Missouri HealthNet (the state Medicaid program) piloted in their Primary Care Health Home Program. The pilot was conducted in Southwest MO (2015-2017) and the state found it to be effective at cost-effectively improving health outcomes for clients with complex chronic conditions while addressing the social determinants of health (Missouri Department of Social Services, 2017).

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. This 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. Stand for H.E.R. 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.

Fund Black-specific support groups across the MTA, particularly those that are taking leadership roles in building collaborations and strengthening advocacy.

The breast cancer community may want to fund support groups specifically for, and led by, Black women. Support for and expansion of the Breakfast Club is highly recommended. Formed and run by Black breast cancer survivors in St. Louis City and St. Louis County, Mo., this powerful model offers extensive peer networking, a buddy system of support (including at health appointments), advocacy and extensive neighborhood outreach. Promising new initiatives are being driven by the leadership of these Black survivors as partners within clinical/community/faith collaborations. Expansion in Missouri, and replication in St. Clair County, Ill., would build not only needed support, but the advocacy and leadership that can drive effective strategies designed and led by Black women themselves.

Encourage health institutions (health care systems and payers) to invest in high-need areas.

The breast cancer community may favorably influence health systems and payers to 'give back' to historically disenfranchised communities by: 1) incentivizing health systems and payers to invest in Black communities; 2) requiring grantees from major health institutions to invest in community benefits to provide breast health services in community health centers; and 3) partnering with non-profits to fund standalone breast clinics that could replace the breast health services that were previously available at now-closed hospitals. An example is continued expansion of screening mammography services within FQHCs in North St. Louis and ensuring that NCI Community Oncology Research Programs are broadened within the MTA and located in areas of greatest need. Additionally, focus group participants noted the value of free mobile screening mammogram programs and shared that expanding this approach and better targeting their placement and partnerships with CBOs and resident leaders would both increase awareness of and access to mammograms. Eased referral and transportation to specialty care is needed. It is a vital time to assure continuity of services in Belleville and other predominantly Black communities in St. Clair County, Ill., as hospitals and specialty clinics affiliated with them relocate and/or change services. These strategies will help to improve access to high-quality care while ensuring that over time there is commensurate scientific advancement in breast cancer treatment options for Blacks.

Macro-Level Strategies

Implement a health promotion campaign intended to increase awareness of breast cancer inequities among Black women.

The breast cancer community may initiate a campaign that could include outreach to community leaders (e.g., faith leaders and employers) and be integrated with enhanced mobile screening mammography services within the most underserved Black neighborhoods where screening rates are lowest and delays to treatment highest. This campaign should be rigorously evaluated and, if done effectively, should demonstrate significant increases in awareness of these programs among undiagnosed Black women. Furthermore, we recommend that Stand for H.E.R. encourage major treatment centers in both the Missouri and St. Louis counties to provide a free clinical visit so that women can access mammograms, as our findings indicate that sometimes having even a small copay can create a barrier to getting screened. Piloted “open houses” reflect clinical/community efforts in the St. Louis MTA to reduce fear and familiarize women with screening mammography and other screening equipment and treatment practices. These programs should be reviewed, and if found successful, replicated.

Support expeditious implementation of Medicaid Expansion in Missouri.

A significant opportunity presents itself with the recent passage by ballot initiative on August 4, 2020, of Medicaid expansion in Missouri, extending coverage to 217,000 low-income residents. Not strengthening the health finance building though Medicaid expansion has hindered the MTA residents’ ability to seek health care services without the risk of severe financial hardship. Stand for H.E.R. can add their voice in assuring that such expansion is implemented in a timely fashion. There are potential barriers ahead given experiences of other states and considering budget concerns and opposition to expansion expressed by the Governor. Stand for H.E.R. could also foresee and strongly advocate against any potential future proposal to limit access to Medicaid, such as through harmful waivers entailing work requirements. Secondary data indicate that St. Louis City has the lowest percentage of the population that is uninsured, however, at 13 percent the rate of uninsured is 5 percent higher than the national average of 8 percent. The eligibility expansion should ensure that more women receive timely screening and breast cancer care services. Stand for H.E.R. should continue to build on advocacy relationships in the state and examine partnerships to advocate for implementation of Medicaid expansion in the state. To have its greatest reach, advocacy efforts should engage those across all levels of the system: patients, providers, CBOs and policy makers, to clearly illustrate how and who will be positively affected by policy changes.

Participants noted that Susan G. Komen has played an important role in this effort, and renewed support would help maintain such progress. An Illinois survivor noted that her hospital offered her a screening mammogram, and since it was free due to a recent major Komen grant, she accepted. At the same time, a provider in Missouri relayed that Komen funds had been vital but had not been as available.

Conduct a root cause analysis relating to delays in breast cancer diagnosis.

The breast cancer community may invest in a root cause analysis (RCA) process to identify the contributing factors and underlying causes of late-stage incidence, as well as the key leverage points where intervention would have a significant impact on breast cancer inequities, strengths and areas of opportunity. By conducting a RCA, stakeholders, including non-health stakeholders, can begin to understand the complexity of late-stage incidence in their community. Participants of a RCA process should include breast cancer survivors, community-led efforts (e.g., workers' unions, non-profits, food banks, community health centers, women's organizations, housing alliances, etc.) and research centers with long-standing academic-community partnerships. The RCA includes an action planning process to determine how to maximize key leverage points to address root causes. Additionally, the RCA process can spur innovative ideas and strategies guided by best practices for addressing the factors and underlying causes that impact late-stage incidence in the St. Louis MTA. The RCA can build upon analyses conducted by area researchers and their collaborators, such as those within the Program for the Elimination of Cancer Disparities and the St. Louis Integrated Health Network. 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 financial assistance programs.

As indicated in the findings' sections, residents of the St. Louis MTA face economic vulnerability. In St. Louis City, Jefferson County, Mo., and St. Clair County, Ill., where many residents are also uninsured, Black women may still have issues meeting the high out-of-pocket costs for breast cancer diagnosis and treatment. The breast cancer community can prioritize advocating for health system financial assistance programs to meet deductibles for high-deductible health plans or cost sharing for underinsured women. Nonprofit health systems offer such financial assistance programs through grant funding and other mechanisms. These funds could be leveraged for further reach. In addition to working with hospitals, Komen could collaborate with CBOs that offer financial assistance to women, reducing financial distress and empowering women to access affordable care, such as Gateway to Hope and the Thelma D. Jones Breast Cancer Fund. For example, Gateway to Hope, a local 501c3, provides financial assistance to people diagnosed with breast cancer living at, or below, 450% of the federal poverty level. Their assistance is paired with ongoing, evidence-based navigation for the duration of treatment and uses a person-centered approach. Gateway to Hope's program gives people the opportunity to meet their most pressing financial needs, including living and medical expenses – ultimately removing financial barriers to care that so often extend beyond medical bills themselves. Yet despite their value, charitable programs in the St. Louis MTA were said to require yearly eligibility applications that are hard to navigate in the midst of cancer care; especially for those with limited literacy and competing demands for their time due to family and work. If bolstered, the application processes should be eased and tailored to more fully relieve the financial burden that women experience.

Fund collaborative initiatives at the community level to address root causes of breast cancer disparities.

Collaborative approaches promise to leverage more of the significant resources needed to attain ambitious goals that lie beyond the capacity of individual institutions or foundations. Such collaborations must extend beyond traditional silos. The intersectional issues that weave together to create the SDOH in any community require full engagement of not only medical and public health sectors, but social services, housing and urban planning, economic development, environmental and occupational protections, educational systems, transportation infrastructure and healthy eating and active living initiatives. Each of these arenas arose as deserving improvement based on county-level data, indicating that Blacks from St. Louis City and County in Missouri and St. Clair and Madison County in Illinois, are heavily burdened by SDOH. A high percentage of Black populations in these four locations are medically underserved, below the 200% FPL, and food insecure. These data suggest that even if an Black woman in any of these places is physically proximate to a treatment facility, she may be unable to access care due to economic barriers or other burdens related to SDOH. Participant observations called out conditions that were particularly distressed in North St Louis City, Mo., the North side of St. Louis County, Mo., and the Black neighborhoods of St. Clair County, Ill. Fostering the requisite conditions that promote health demands collective action. The robust collaborations that exist in the St. Louis MTA are available to build upon. These include the Program for Elimination of Cancer Disparities and the St. Louis Integrated Health Network.

This landscape analysis report conveys comprehensive issues facing Blacks in the metro areas. The 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 start reducing breast cancer disparities among Blacks.

Appendix A. Map Measures

TABLE 24. ST. LOUIS METRO AREA TABLE MAPS

	Map 3: Percent of Population that is Black	Map 4: Residential Segregation Score	Map 7: Social Vulnerability Index Score	Map 8: Percent of Households that are Housing-Cost Burdened
Madison County, IL	9%	53	0.22	25%
Monroe County, IL	0%	34	0.00	23%
St. Clair County, IL	30%	57	0.54	30%
Jefferson County, MO	1%	67	0.22	23%
St. Charles County, MO	4%	31	0.04	21%
St. Louis City, MO	48%	71	0.81	39%
St. Louis County, MO	24%	64	0.28	27%

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% 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% or more of their total income on housing. Calculated by the US 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% 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 (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) (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 [<u>insert name of metro</u>]? 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 [<u>insert name of metro</u>]? 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 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. *<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*
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8. *<u>Overall environment:</u> 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 <u>where</u> 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.
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.*

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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 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. *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*
   4. *Faith Practices: Spiritual/religious beliefs*
   5. *Accessibility: Insurance, easy to reach, distance, affordable costs/co-pays, time off from work*
   6. *Process and systems: 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*

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*
   4. *Faith Practices: Spiritual/religious beliefs*
   5. *Accessibility: Insurance, easy to reach, distance, affordable costs/co-pays, time off from work*
   6. *Process and systems: 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.

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