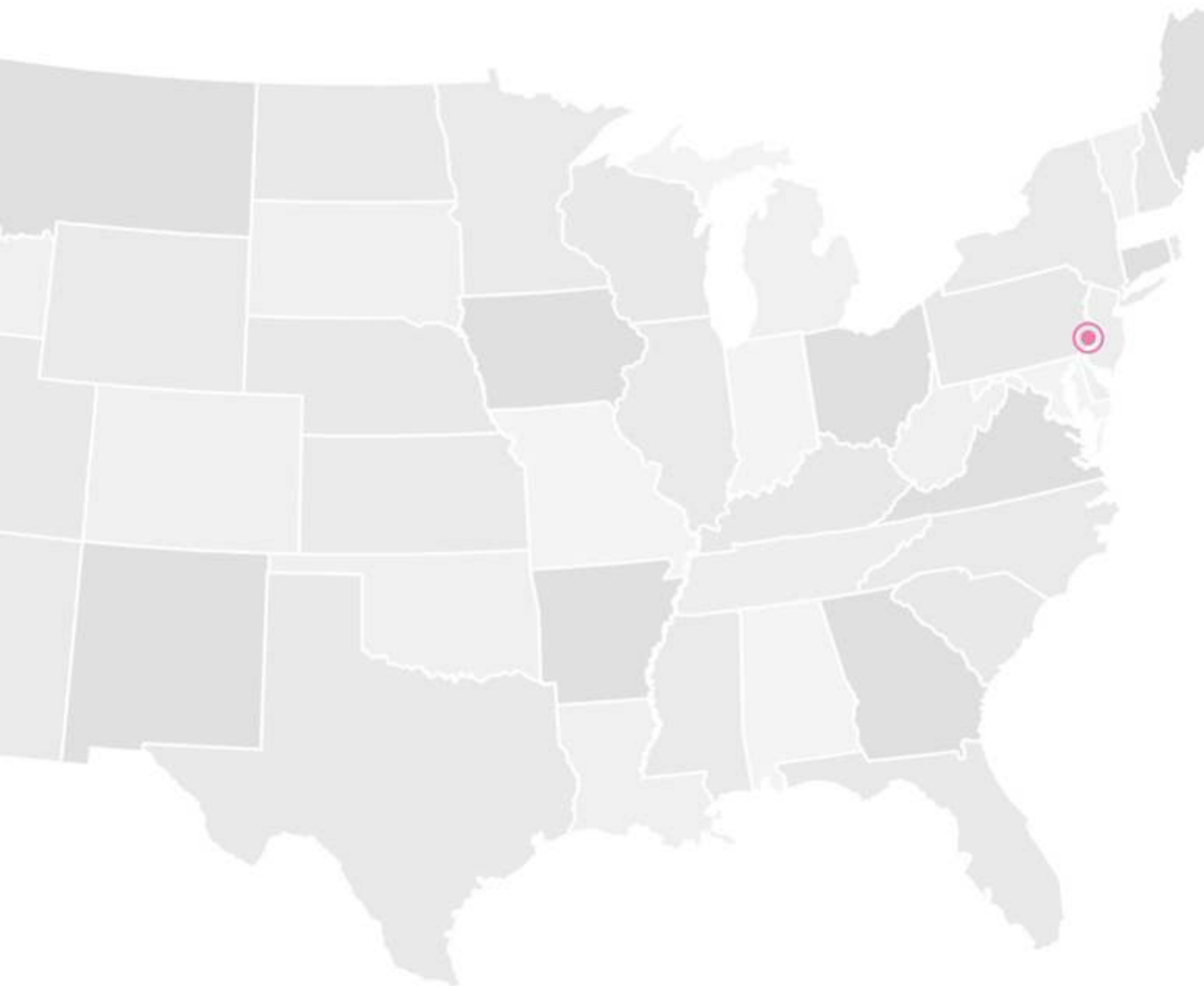


Closing the Breast Cancer Gap:
A Roadmap to Save the Lives
of Black Women in America

2021

PHILADELPHIA



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

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



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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 US 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 African American Health Equity Initiative (AAHEI), now known as Stand for H.E.R. – a Health Equity Revolution, to improve breast health equity for Blacks. The 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, D.C.

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

- Throughout the Philadelphia MTA, Black women are more likely to die from breast cancer than their white counterparts.
- A pattern of lower breast cancer incidence rates but higher mortality rates among Blacks is evident in seven out of the MTA's eleven counties.
- Research and data on screening mammography rates indicate that Black women receive screening mammograms at a higher rate than white women. However, the lack of awareness around free screening programs in the Philadelphia MTA was also noteworthy.
- The data suggest that there is no uniform trend in terms of late-stage incidence rates comparing Black to white women. In some counties, the late-stage incidence rates are higher among white women, while in other counties, the reverse is true.
- The highest overall late-stage incidence rate is in Bucks County, PA, at 57.4 per 100,000 women. Salem and Cecil counties are noteworthy because their incidence rates for Black women are the highest in the MTA, but absent disaggregated mortality data for these counties warrants further investigation.
- Decades of discriminatory practices have led to striking segregation in the Philadelphia MTA. The Philadelphia MTA is segregated across a number of dimensions, including race and socioeconomic factors, creating stark contrasts by geography. In addition to the 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 data illuminate the resulting inequities across a number of metrics, including mortality rates, with Philadelphia and Camden counties being areas of concentrated disadvantage.
- The stories of Black women, breast cancer survivors and undiagnosed, convey their experience of poor-quality care, racism, microaggressions and health care discrimination. While this is not a new finding, it was particularly salient in this study.
- Finally, the challenge of retaining patients in the continuum of care with a history of or active psychiatric and behavioral health issues emerged as a more novel finding in the study from our qualitative data.
- Overall, the data suggest breast health inequities among Black women in the Philadelphia 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 Philadelphia 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 responsive patient navigators.
- Implement implicit bias trainings for providers, administrators, and health care staff.
- Increase education about family health history in the community to identify high-risk families and offer genetic counseling and testing and breast cancer screening to meet the need.
- Expand financial assistance programs for Black women diagnosed with breast cancer.
- Implement a culturally relevant health promotion campaign intended to increase knowledge of current screening guidelines.
- Implement a culturally relevant health promotion campaign intended to increase awareness of free screening.

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.
- Support a community-based participatory applied research project to explore how to retain breast cancer patients with substance use/mental health issues.
- Identify and implement strategies for survivorship planning.
- Conduct broader outreach to Black women.

Macro-Level Strategies

- Conduct a root cause analysis relating to healthcare quality.
- Support efforts to develop guidelines and policies that address disproportionate breast cancer mortality among Black women, including increased genetic counseling and testing services.
- Advocate for expansion of eligibility requirements for free screening programs to improve access.

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 Blacks.

About Susan G. Komen

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

Introduction

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

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

Black women are, on average, 40 percent more likely to die of the disease as compared to white women (Howlader et al., 2018). The five-year breast cancer survival rate for Black women is 83 percent as compared to 92 percent for white women (Howlader et al., 2020). However, overall, breast cancer incidence among Black women is lower than among white women. However, from 2013-2017 for women younger than 40, incidence is higher among non-Hispanic Black women than non-Hispanic white women (Noone et al., 2017). The incidence rates are higher among Black women under age 40 (where incidence is the number of new cases that develop in a specific time period) (American Cancer Society, 2020). Black women are also more likely than white women to be diagnosed with aggressive breast cancers, such as Triple Negative Breast Cancer (TNBC) and inflammatory breast cancer and are more likely to be diagnosed at a later stage, when treatments are limited, costly and the prognosis is poor (American Cancer Society, 2019; Williams et al., 2016).

Through the African American Health Equity Initiative (AAHEI), 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, D.C

As part of the AAHEI, 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, health care 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 women 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 inequities and suggestions for advancing breast health equity.
- To explore health care provider perspectives regarding individual, community and health systems factors contributing to breast cancer 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 Philadelphia MTA. 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.

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).

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.

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

Methods

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

This study defines the Philadelphia MTA in accordance with the US Office of Management and Budget's 2015 definition of the Philadelphia-Camden-Wilmington metropolitan statistical area (MSA), which encompasses the city of Philadelphia and comprises Philadelphia, Bucks, Chester, Montgomery and Delaware counties in Pennsylvania; Burlington, Camden, Gloucester, and Salem counties in New Jersey; New Castle County in Delaware; and Cecil County in Maryland (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. PHILADELPHIA 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 Philadelphia MTA, a total of four out of six focus groups were conducted among 29 community members. Two of the six focus groups were conducted among patient navigators in Philadelphia, Delaware, and Camden Counties, and included nine participants. In addition, two individual interviews were held with patient navigators, and five provider interviews were conducted.

Table 2 summarizes the demographic characteristics of 29 focus group participants, representing both breast cancer survivors and the undiagnosed. Among breast cancer survivors, the majority were above 55 years of age, had insurance (100 percent), and had been diagnosed with stage 1 breast cancer (42 percent). Undiagnosed women were younger, mostly in the 25-54 age group, with the majority reporting access to public insurance – Medicaid or Medicare (59 percent). Non-provider participants were Black. Demographics were not collected for community health navigators, patient navigators, or clinical providers.

TABLE 2. PHILADELPHIA METRO AREA QUALITATIVE DATA COLLECTION

Variable Name	Breast Cancer Survivors (n=12)	Undiagnosed Women (n=17)
Age		
18-24 years	0.0%	0.0%
25- 34 years	0.0%	11.8%
35-44 years	8.3%	17.6%
45-54 years	33.3%	29.4%
55-64 years	50.0%	41.2%
65-74 years	8.3%	0.0%
75 and above	0.0%	0.0%
Zip Codes		
	Breast Cancer Survivors (n=12)	Undiagnosed Women (n=17)
08107	8.3%	0.0%
08109	8.3%	0.0%
08110	25.0%	0.0%
08081	8.3%	0.0%
08094	8.3%	0.0%
19038	8.3%	0.0%
19720	25.0%	0.0%
19153	8.3%	0.0%
19032	0.0%	5.9%
19050	0.0%	5.9%
19107	0.0%	5.9%
19114	0.0%	5.9%
19120	0.0%	5.9%
19121	0.0%	5.9%

19124	0.0%	5.9%
19132	0.0%	11.8%
19139	0.0%	11.8%
19141	0.0%	11.8%
19143	0.0%	5.9%
19145	0.0%	5.9%
19146	0.0%	11.8%

Insurance Status	Breast Cancer Survivors (n=12)	Undiagnosed Women (n=17)
I don't have health insurance	0.0%	5.9%
Medicaid	33.3%	23.5%
Medicare	8.3%	35.3%
Military Health care	0.0%	0.0%
Private Insurance	58.3%	17.6%
Through my parents	0.0%	0.0%
Not sure	0.0%	23.5%

Ever Been Screened for Breast Cancer	Breast Cancer Survivors (n=12)	Undiagnosed Women (n=17)
Yes	N/A	82.4%
No	N/A	17.6%

Type of Breast Cancer Screening or Assessment	Breast Cancer Survivors (n=12)	Undiagnosed Women (n=17)
Clinical breast exam	N/A	30.8%
Mammogram	N/A	30.8%
3D Mammogram	N/A	30.8%
Breast self-exam	N/A	15.4%
Other	N/A	0.0%

Stage of Breast Cancer at Diagnosis	Breast Cancer Survivors (n=12)	Undiagnosed Women (n=17)
Stage 0	8.3%	N/A
Stage 1	41.7%	N/A
Stage 2	33.3%	N/A
Stage 3	8.3%	N/A
Stage 4	8.3%	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 Philadelphia MTA using secondary data, as well as relevant findings from the qualitative data.

Demographics

The Philadelphia MTA is an 11-county region spanning parts of southeastern Pennsylvania, southwestern New Jersey, northern Delaware and northeastern Maryland. The region is home to 6 million people, 67 percent of whom are white and 21 percent of whom are Black. There are 266,789 Black women over the age of 45 living in the Philadelphia MTA (see Table 3). This number 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).

Philadelphia County is the most populous county in the Philadelphia MTA, home to approximately 25 percent of the total population (see Table 4). Philadelphia County also has the highest Black population, both in terms of percentage (43 percent Black) and in terms of absolute number (approximately 675,000 residents of the county are Black) (see Table 4). The other 10 counties in the region are Bucks, Chester, Delaware and Montgomery in Pennsylvania; Burlington, Camden, Gloucester and Salem in New Jersey; Cecil County in Maryland; and New Castle County in Delaware. Refer to Table 4 for demographic information specific to each county within the MTA.

TABLE 3. PHILADALPHIA METRO AREA DEMOGRAPHICS

Gender	
Male	48%
Female	52%
Age	
Under Age 18	22%
Age 18-64	63%
Over Age 65	15%
Race/Ethnicity	
White	67%
Black	21%
Asian	6%
American Indian or Alaska Native	0%
Native Hawaiian or Other Pacific Islander	0%
Some Other Race	3%
Two or More Races	3%
Hispanic/Latino	9%
White not Hispanic	63%
Minority Race	33%
Number of Black Women Over Age 45	266,789
Total Population	6,065,644

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

TABLE 4. PHILADALPHIA 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
New Castle County, DE	555,036	52%	25%	28,455
Cecil County, MD	102,416	50%	7%	1,203
Burlington County, NJ	449,192	51%	16%	15,775
Camden County, NJ	510,996	52%	19%	20,090
Gloucester County, NJ	291,372	51%	10%	6,479
Salem County, NJ	63,776	51%	13%	1,971
Bucks County, PA	626,486	51%	4%	4,620
Chester County, PA	514,652	51%	6%	5,770
Delaware County, PA	563,384	52%	21%	21,954
Montgomery County, PA	818,677	51%	9%	15,369
Philadelphia County, PA	1,569,657	53%	43%	145,103

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

Breast Cancer Disease Burden in the Philadelphia MTA

Breast cancer disease burden in the Philadelphia 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 Philadelphia MTA, the likelihood of receiving a breast cancer diagnosis, the stage of diagnosis and the likelihood of death from the disease vary along geographic and racial lines.

A helpful measure for breast cancer disease burden is prevalence, or the proportion of the population that has the disease at a given time. It is important to note that prevalence is measured in multiple ways depending on the time period of interest, and this report uses age-adjusted complete prevalence, which represents the proportion of people alive on a certain day who have been diagnosed with breast cancer, regardless of when the diagnosis was made (National Cancer Institute, 2020). Prevalence statistics are only available at the state level. In Pennsylvania, where five counties in the Philadelphia MTA are located, the complete prevalence age-adjusted percentage is 1.68. This is very close to the national percentage of 1.69. In New Jersey, Maryland, and Delaware, the complete prevalence age-adjusted percentages are 1.67, 1.90, and 1.73 respectively.

Breast cancer indicators for other measures are available at the county level. Tables 5-9 describe the breast cancer disease burden in the Philadelphia 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. Race disaggregated data are not available for Cecil County, MD, Salem County, NJ, or Bucks County, PA, as too few Black women live in these places to calculate the rates.

TABLE 5. PHILADELPHIA 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
New Castle County, DE	138.6	stable	139.7	stable	137.1	stable
Cecil County, MD	128.1	stable	125.1	stable	200.4	stable
Burlington County, NJ	143.1	stable	145.1	stable	148.6	stable
Camden County, NJ	138.0	stable	139.8	stable	137.0	stable
Gloucester County, NJ	145.9	stable	146.4	stable	147.7	stable
Salem County, NJ	132.5	stable	127.3	stable	163.7	stable

Bucks County, PA	138.5	stable	141.7	stable	120.4	stable
Chester County, PA	142.2	stable	144.2	stable	110.0	stable
Delaware County, PA	138.8	stable	144.8	stable	121.8	stable
Montgomery County, PA	142.9	stable	146.4	stable	128.8	stable
Philadelphia County, PA	123.9	stable	128.3	stable	126.0	stable
Delaware	136.1	stable	136.1	stable	134.1	stable
Maryland	131.5	stable	132.2	stable	131.9	stable
New Jersey	134.3	rising	137.7	stable	125.4	stable
Pennsylvania	131.9	stable	133.2	stable	126.5	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 Philadelphia MTA range from 123.9 new cases per 100,000 individuals per year in Philadelphia County, PA, to 145.9 in Gloucester County, NJ (see Table 5). By and large, most counties have similar age-adjusted breast cancer incidence rates comparing whites to Blacks. Incidence rates are higher among white women as compared to Black women in Bucks County, PA, Chester County, PA, Delaware County, PA, and Montgomery County, PA. Two counties in the MTA are the exception, with substantially higher rates among Black woman as compared to white women: in Salem County, NJ, the incidence rate 163.7 for Black women compared to 127.3 for white women; and in Cecil County, MD, the incidence rate is 200.4 for Black women compared to 125.1 for white women. Except for Cecil and Salem Counties, the breast cancer incidence rates among Black women are similar to or slightly lower than state and national averages.

TABLE 6. PHILADELPHIA 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
New Castle County, DE	43.1	stable	44.1	stable	44.6	stable
Cecil County, MD	26.8	stable	27.7	stable	*	*
Burlington County, NJ	38.5	stable	38.2	stable	37.9	rising

Camden County, NJ	47.8	rising	46.4	stable	46.5	rising
Gloucester County, NJ	46.1	rising	45.2	stable	41.7	*
Salem County, NJ	31.7	stable	34.1	stable	*	*
Bucks County, PA	31.6	stable	32.3	stable	37.3	stable
Chester County, PA	41.6	stable	42.0	stable	38.6	stable
Delaware County, PA	36.7	stable	37.9	stable	33.9	rising
Montgomery County, PA	39.1	stable	39.4	stable	40.7	stable
Philadelphia County, PA	36.5	stable	33.9	stable	40.2	stable
Delaware	39.3	stable	39.3	stable	43.2	stable
Maryland	33.2	stable	32.2	stable	36.1	stable
New Jersey	41.3	stable	42.3	stable	33.9	rising
Pennsylvania	34.5	stable	34.0	stable	38.4	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)

Almost all in situ breast cancer incidence rates (overall, white, and Black women) are higher in Philadelphia MTA counties than the national rates. However, there are no notable disparities between rates among white and Black women: rates are higher for white women in some counties and higher for Black women in others. The largest disparity exists in Philadelphia County, PA, which reports an in-situ incidence rate of 33.9 for white women compared to 40.2 for Black women (Table 6).

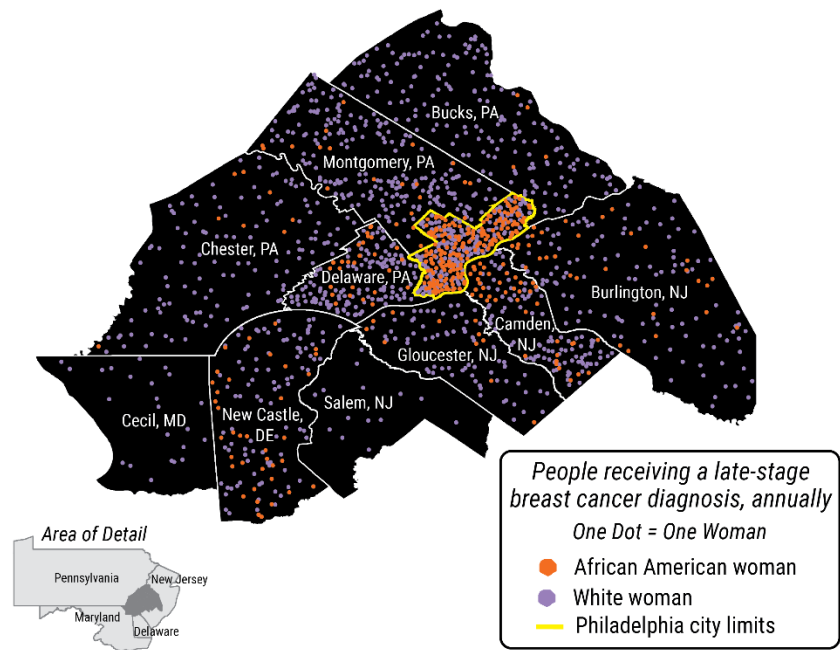
TABLE 7. PHILADELPHIA METRO AREA LATE-STAGE BREAST CANCER INCIDENCE RATE (PER 100,000)

	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
New Castle County, DE	49.1	140.0	49.9	96.0	50.4	38.0
Cecil County, MD	48.6	25.0	48.8	23.0	*	*
Burlington County, NJ	48.4	140.0	47.7	109.0	59.1	27.0
Camden County, NJ	45.4	143.0	42.3	99.0	59.8	37.0
Gloucester County, NJ	44.8	80.0	42.9	67.0	58.8	10.0
Salem County, NJ	41.7	17.0	40.0	14.0	*	*
Bucks County, PA	57.4	183.0	60.1	173.0	35.2	5.0
Chester County, PA	52.0	135.0	53.6	122.0	43.0	8.0
Delaware County, PA	55.6	163.0	60.5	126.0	47.0	31.0
Montgomery County, PA	55.7	234.0	57.8	199.0	54.3	23.0
Philadelphia County, PA	49.1	405.0	51.3	187.0	51.3	200.0
Delaware	53.0	256.0	54.8	188.0	51.0	59.0
Maryland	53.1	1633.0	53.1	981.0	55.8	556.0
New Jersey	44.3	2430.0	43.9	1866.0	51.5	389.0
Pennsylvania	55.7	3637.0	57.8	3154.0	49.0	401.0
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, as with in situ incidence rates, there is no uniform trend in terms of late-stage incidence rates comparing Black women to white women. In some counties the late-stage incidence rates are higher among white women, while in other counties, the reverse is true. The highest overall late-stage incidence rate is in Bucks County, PA, at 57.4 per 100,000.

MAP 1. PHILADELPHIA METRO AREA LATE-STAGE BREAST CANCER CASES



Map 1 shows the concentration of women who receive late-stage breast cancer diagnoses annually in the Philadelphia MTA. Observed patterns align with population trends. The density of diagnoses increases closer to the center of the MTA, with the highest concentration in Philadelphia County, PA, where Black women comprise the majority of late-stage diagnoses. Delaware County, PA, and Camden County, NJ, have the next highest concentrations of late-stage diagnoses. However, the data indicate that there are more cases among white

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

women as compared to Black women. 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 Cecil County, MD, and Salem County, NJ, as too few Black women live in these places to report the number.

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

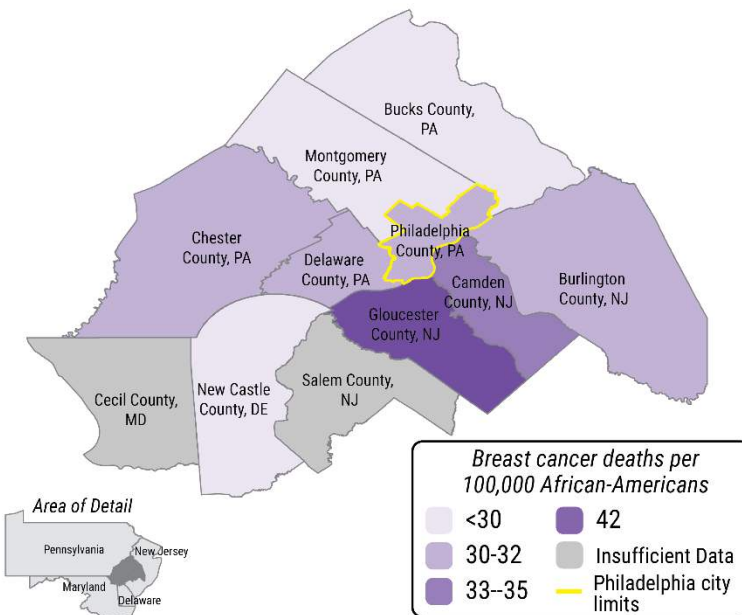
	Age-Adjusted Mortality Rate	5-Year Mortality Rate Trend Direction	Age-Adjusted Mortality Rate for White Women	5-Year Mortality Rate Trend Direction for White Women	Age-Adjusted Mortality Rate for Black Women	5-Year Mortality Rate Trend Direction for Black Women
New Castle County, DE	19.5	falling	19.1	Falling	23.6	falling
Cecil County, MD	19.3	falling	19.5	Falling	*	*
Burlington County, NJ	24.2	falling	23.9	falling	30.2	stable
Camden County, NJ	25.2	falling	23.5	falling	34.4	falling
Gloucester County, NJ	23.3	falling	22.1	falling	41.5	stable
Salem County, NJ	27.8	stable	27.9	stable	*	*

Bucks County, PA	22.4	falling	22.7	falling	28.2	*
Chester County, PA	22.2	falling	22.1	falling	31.9	falling
Delaware County, PA	22.1	falling	20.6	falling	30.2	stable
Montgomery County, PA	21.1	falling	20.9	falling	27.2	stable
Philadelphia County, PA	25.3	falling	22.1	falling	30.4	falling
Delaware	21.4	falling	21.2	falling	25.0	falling
Maryland	22.1	falling	20.6	falling	27.6	falling
New Jersey	21.7	falling	21.3	falling	29.2	falling
Pennsylvania	21.6	falling	20.9	falling	30.3	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)

In every county in the Philadelphia MTA where disaggregated data are available, the breast cancer mortality rate among Black women is higher than the rate among white women (see Table 8). Data are unavailable for Black women in Cecil County, MD, and Salem County, NJ, the two places where incidence rates for Black women are highest, potentially due to fewer Blacks living in those counties. The racial disparity in breast cancer mortality rates is greatest in Gloucester County, NJ, where the age-adjusted mortality rate for white women is 22.1 compared to 41.5 for Black women. As displayed in Table 8, the lowest overall mortality rates are 19.5 and 19.3 in New Castle County, DE, and Cecil County, MD. Notably, despite having the highest incidence rate among Black women, Cecil County, MD, reports the lowest overall mortality rate from the disease. It is not possible to determine whether the mortality rate among Black women in Cecil County is similarly low, as these data are not available. Salem County, NJ, reports the highest overall mortality rate at 27.8 deaths per 100,000 women, which aligns with its high incidence rate. As with Cecil County, MD, racially disaggregated mortality data are unavailable for Salem County, NJ.

MAP 2. PHILADELPHIA METRO AREA AFRICAN AMERICAN BREAST CANCER MORTALITY RATES



As seen in Map 2, Gloucester County, NJ, the highest breast cancer mortality rate for Black women at 41.5 deaths per 100,000 (see Table 8). Camden County, NJ, has the next highest with a reported rate of 34.4 per 100,000. The lowest rate is reported in New Castle County, DE, at 23.6 per 100,000. In Cecil County, MD, and Salem County, NJ, these rates are not reported due to insufficient data.

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

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

	Percent of Women Getting Mammograms
New Castle County, DE	70%
Cecil County, MD	71%
Burlington County, NJ	81%
Camden County, NJ	76%
Gloucester County, NJ	74%
Salem County, NJ	72%
Bucks County, PA	78%
Chester County, PA	76%
Delaware County, PA	80%
Montgomery County, PA	78%
Philadelphia County, PA	74%
Delaware	80%
Maryland	78%
New Jersey	83%
Pennsylvania	76%

National	73%
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Source: 2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)

Burlington County, NJ, and Delaware County, PA, report the highest percentages of women getting screening mammograms at 81 percent and 80 percent (Table 9). Notably, despite this high rate of preventative care, the overall mortality rates in these counties are mid-range for the MTA (see Table 8, 24.2 in Burlington County and 22.1 in Delaware County). New Castle County, DE, and Cecil County, MD, report the lowest percentage of women getting screening mammograms (70 percent and 71 percent). Given that these same counties report the lowest overall age-adjusted mortality rates (see Table 8), it appears that screening mammography rates alone are not a good predictor of breast cancer mortality in the Philadelphia MTA.

Overall, a study of breast cancer disease burden measures suggests that throughout the Philadelphia MTA, Black women are more likely to die from breast cancer than their white counterparts, even though they are diagnosed with the disease at lower rates. This pattern is evident in Bucks County, PA, Chester County, PA, Delaware County, PA, Montgomery County, PA, Philadelphia County, PA, Camden County, NJ, and New Castle County, DE. In all of these places, the breast cancer incidence rate is lower among Black women than it is among white women, but the breast cancer mortality rate is higher among Blacks than among whites. This pattern has been noted in the literature. A study in South Carolina, for example, found that while the breast cancer incidence rate was higher for European American or Caucasian women compared to Black women (124 versus 118.5 per 100,000 women), the breast cancer mortality rate was higher for Black women (29.8 versus 21.3 per 100,000 women) (Samson et al., 2016). A potential explanation could be that Black women do not receive screening mammograms as regularly as white women and therefore are diagnosed with breast cancer at a later (more lethal) stage. Additionally, research and data on screening mammography rates indicate that Black women receive screening mammograms at a higher rate than do white women.

Although racially disaggregated data are not available at the county level, these data are available at the state level. Racial differences in screening mammography screening reported in Pennsylvania, New Jersey, Maryland and Delaware - the four states that comprise the Philadelphia MTA - show that Black women are screened for the disease at a higher rate than white women. In Pennsylvania, the screening mammography rate for Black women over the age of 40 is 76.2 percent compared to 69.9 percent of white women in the same demographic. In New Jersey, the screening mammography rate for Black women over age 40 is 82.5 percent compared to 73.2 percent for white women. The Maryland screening mammography rate for women over age 40 is 84.1 percent for Black women compared to 75 percent for their white counterparts. Lastly, the Delaware screening mammography rate for women over age 40 is 86.9 percent for Black women compared to 76.8 percent for their white counterparts. In all cases, Black women receive screening mammograms at a higher rate than white women.

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.

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 Philadelphia MTA. Based on a review of the quantitative findings, priority counties for qualitative data collection in the Philadelphia MTA were identified: Philadelphia County, PA, Delaware County, PA, Salem County, NJ, and Camden County, NJ. Philadelphia County and Camden County have the highest breast cancer burden, while Philadelphia County and Salem County have the highest SDOH burden and score poorly on other health measures as well. The themes shared below represent the perspectives of community members from these priority counties, not the entire Philadelphia MTA.

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). Black women receive screening mammograms at a higher rate than white women in all states that constitute the Philadelphia MTA. Focus group participants' perspectives give some indication of the experiences of Black women seeking and obtaining breast cancer screening.

Screening Guidelines. Overall, community members were aware of the screening guidelines from the American Cancer Society indicating that screening mammograms begin at 40. However, they indicated they were not aware of the guidelines for women 35-39 years of age, and the movement away from annual screening for women over 40 years of age. There was a sentiment that the guidelines need to be different for Black women due to survivors' own experiences with early-age onset of disease and a perception that Black women are more likely to get aggressive cancers including triple negative breast cancers of which some primary care providers are still unaware.

“Well, the literature tells us that these women are getting diagnosed at younger ages, and that they're also, unfortunately, have more aggressive disease that's less responsive to treatment... If they're getting diagnosed at younger ages, we need to consider earlier screening for certain women and certain populations.” - Navigator

“Young women that were ignored, felt something, or had to fight to get a screening mammogram, fight to get an ultrasound, because of their age, and eventually end up being diagnosed.” - Navigator

Screening access. Patient navigators and survivors noted that free screening programs are widely available. However, there is a lack of awareness of the existence of these programs. Survivors and navigators noted that the lack of awareness around screening programs and the perception of a high cost being associated with getting a screening mammogram can present a barrier.

“We need more general education for women that by law up here, you can walk in and get your screening mammogram. You don't need a referral from your doctor to get a

screening mammogram. But they don't know that. People aren't educating them for that. We need more public service to make people aware.” – Navigator

“There needs to be funds made available for those people who fall outside of the poverty guidelines for the national breast screening program [the National Breast and Cervical Cancer Early Detection Program], but still are underserved. They're not getting their screening mammograms because maybe they're not thought to be in poverty, but they still have competing needs that prevent them from getting screened.” - Navigator

Fear. All participants described how fear, denial and stigma led to irregular screening and unwillingness to get treatment once cancer was found. In contrast, providers interviewed for this research alluded to a lack of information being the primary reasons why Black women irregularly screen and don't optimally use primary care rather than fear.

“The fear that I hear from other women is, ‘I feel fine and I don't want to be told I have cancer. I'm afraid they're going to operate on me.’ A lot of fear that is not that logical, but it's a lot of fear...that's the kind of stuff I'm hearing.” – Provider

“Coming up as a kid it was the unspoken word. You never mentioned cancer, then when people died in the family, you don't know what they died of, because it was hushed. If a person had it, you weren't allowed to touch them either, because you'll catch it.” -Survivor

Insurance barriers. Findings from focus groups also support national findings, indicating that no insurance and underinsurance adversely impact timely screening and treatment. Providers reported that many women experience life changes (e.g., job loss and insurance) and do not get routine screening while they are uninsured.

“The most common thing that I see, is somebody has lost a job, lost their insurance, and therefore didn't get health care for a couple of years until they were re-employed. And when I see them, I'm always surprised because there are a lot of places in the city where you can get a free screening mammogram when you don't have health insurance, but they weren't aware of that.” – Provider

Diagnosis

While screening is readily available within the Philadelphia MTA, focus group findings suggest that community members experience poor-quality care and barriers at the diagnosis stage of the breast cancer continuum of care. Many survivors characterized the care that they received at this stage as being inefficient, inaccessible, and not patient-centered, resulting in significant mental strain. Another survivor noted that the steps involved from screening to formal diagnosis could have been more streamlined. This, in turn, may be associated with delayed diagnosis, influencing the breast cancer mortality rates documented earlier in the report. Furthermore, some providers noted that some practices do not accept Medicaid and that Medicaid does not cover all the diagnostic testing required for patients.

Difficulty getting a diagnosis. Community members reported women finding lumps or noticing abnormalities and having their symptoms treated as if they weren't urgent in nature.

"I went one week and had one screening mammogram, got called back to receive the second screening mammogram, and then a week later I was called back for a biopsy. The lump is there, we could have done multiple things in that one visit, versus three weeks out to finally get a biopsy." - Survivor

"When I realized something was not right in terms of the look of the breast, and I called my OBGYN, I couldn't get an appointment until a month later. One of my best friends is a nurse, when I explained to her what had happened, she said, 'Call them back and tell them this is an emergency'. When I did that I was able to get an appointment the next week." – Survivor

"People who come late with tumors do so for a variety of different reasons. Sometimes it's often that they didn't have health insurance, and therefore they didn't know where to go or how to get care, don't know about (free) programs, and were concerned about the cost. So they delay in coming for those reasons. - Provider

Mental strain. The diagnosis phase of the breast cancer continuum of care can be extremely stressful for patients. This stress is often compounded for Black women whose breast cancer journey is frequently coupled with a need to self-advocate within the health care system. Survivor and patient navigators' description of the mental strain on newly diagnosed women was poignant. Their comments speak to the overall need to address the mental health needs of women who have been diagnosed with breast cancer such as anxiety, stress and depression. The weight of a breast cancer diagnosis is significant, and community members noted it can mean the difference between someone seeking treatment immediately or delaying.

"I believe that stress played a lot in my diagnosis, which is why I'm a stress educator now, because people don't realize how big stress is, and what it can do, in terms of leading to chronic health conditions, such as breast cancer... going through a diagnosis is stressful enough, and now you got to fight. We don't need that, that's not helping us at all. It's working against me." – Survivor

"I think comorbid conditions like the under-assessed role of chronic stress plays a role...but kind of this chronic toxic stress, the role of women generally, that you still have to maintain as close to full time employment as you can. You're still mainly a primary caregiver for either elders or children. When you could be resting, or kind of having the time to process through clinical trials you'll be eligible for or looking at the research." - Navigator

"Finding providers to provide emotional support and counseling for patients in the treatment is a huge barrier. It's hard to find people. Sometimes you have to wait months

to get an appointment and by then the patient is either in crisis or it's no longer needed.”
- Navigator

Treatment

Focus group participants characterized the transition from diagnosis to treatment as multifaceted and dynamic. All participants reported that women are generally afraid of how terrible chemotherapy will be based on poor responses to treatment that they have seen among friends and family. Below is a description of the barriers and facilitators to breast cancer treatment as described by the Philadelphia MTA focus group participants.

Provider approach. Providers with very strong navigation programs, empathic skills in their bedside manner, who explain cancer treatment thoroughly, honestly, and in non-technical language while being respectful of their patients’ religious beliefs, were more likely to report compliance and retention in treatment plans among their Black patients. Overall, provider approach appears to correlate with patient behavior.

“I tell them that I am invested with them for the long haul, and I expect to be seeing them in follow-up for years down the road. When you have your surgery, we'll do these telehealth visits where we talk to them a couple of days out. I tell them I've got a 90-day global period after surgery where you're going to see me and in that 90-day global period, you don't have a co-pay. I'm invested. You're not paying to see me. I want to make sure that you are following up. When you let someone know that you care about them, they're more likely to be invested in the home care, invest in themselves. That's important. You cannot underestimate that because you're talking about a group of people who are traditionally, historically disenfranchised, given less treatment, worse treatment...the reality is that every experience they've had up until that point in their lives would lead them to believe that they're not going to get the best treatment.” - Provider

“What I've learned is that as you're processing the disease, meaning how the treatment is going, it's important to have your doctor say, ‘I know it's difficult. We're going to work through it.’” - Patient navigator

Lack of patient-centered care. Survivors rated the quality of care they received throughout their cancer journey on a scale of 1-10, highlighting why they gave that rating and what would have made them give a higher rating. Below are illustrative quotes reflecting the kinds of issues like poor management of side effects and treatment delays that survivors experienced. Undiagnosed Black women also shared stories of dismissal of their complications related to endometriosis and pregnancy.

“I said a four. That was only attributed to my assistant surgeon not really paying attention to my port, basically I got an infection. I saw my assistant surgeon three times. That led me to being in the hospital for seven days, because my port got infected. I came back in with a 104 fever to see my surgeon, my assistant surgeon still said, ‘You're fine.’ My surgeon came in finally this time and said, ‘Your port is infected. We're taking it out

right now'. Her being there saved my life, because my assistant surgeon wanted to send me home a fourth time with a 104 degree fever, barely walking, and letting me know that my port was okay." – Survivor

"The radiation doctor came in and what she said to me really bothered me, because first of all, this is my life we're talking about here, she said, 'Oh, don't worry about it, you're going to be fine. He [the surgeon] needs to go on vacation'. And I'm thinking, how dare you. I just got some more devastating news. I want this cancer out of me, what do you mean he's going on vacation for two weeks? I just got news that it spread to another part of my body, when she left the room I said, '[Patient navigator name] I don't care what she just said, get a hold of that doctor please, make something happen'." - Survivor

Retention challenges among substance use/mental health patients. Findings from provider interviews and navigator focus groups indicate that providers and navigators tended to have high attrition rates among patients who had active substance use issues or a history of psychiatric issues. Providers shared that if they did lose patients to follow-up it was often these patients who really struggled to understand what a cancer diagnosis meant. It was apparent that the current team-based approach to providing a cancer diagnosis, even when it included patient navigation was still not enough to address the unique challenges surrounding patients with substance use or mental health issues.

"A patient that has a PTSD history or a history of hospitalization for psych things or has a limited understanding. Like when you meet them, you're just like, 'This person really just doesn't have a great understanding of what this diagnosis means about what the steps are going to be needed to take care of it, etcetera'. Those are the most difficult ones where you're just like, 'You know what? If they leave this office right now, I may never see them again'." - Provider

Social support and patient navigation. Providers, navigators, undiagnosed women and survivors all noted the importance of social capital and support for outreach, education and successful treatment. Several navigators noted the importance of social support groups for Black women including cancer support groups, navigators, cancer buddy programs, church and community centers. These support groups were highlighted as being crucial for retention in the face of treatment weariness. Some navigators reported having resources to do more than what a typical navigator program does, including providing resources to patients who need help getting bills paid. Many survivors rely on short/long-term disability. When this coverage expires, they often cannot afford COBRA payments, underscoring the value of financial support offered through navigation programs. Others noted that navigators who connected patients to a faith community or linked them to a medical home were more likely to have fewer issues losing patients to follow-up. All study participant groups noted that a lack of support led to a sense of isolation and hopelessness among survivors. In a health care system that is challenging at best to navigate, the need for identifying supportive advocates on behalf of Black women is essential.

"I think mostly African Americans are participants in our support group...they probably utilize that service more than the Caucasian group". – Navigator

“The best thing I ever did was... join the support group...at first, you think it's a death sentence, but then you realize, no, it's just a journey God is taking you through. Then when you see these other women who are going through it two, three, four times, you think, ‘Okay, if they can do it, I can do it’.” – Survivor

“My navigator was the one, they said two weeks for the surgery, but God, she made it happen in two days. So, I was the advocate for myself a lot, but if it wasn't for her just pushing...” – Survivor

“I just kept it to myself where if I had possibly shared it with my family, and friends, I would have been able to get better direction, or just having a sounding board about those things.” - Survivor

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

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

“There are valid reasons sometimes that patients develop, and families develop a mistrust of their medical team. They're not given accurate information... their diagnosis was delayed not necessarily to any fault of their own, rather than saying, ‘You should trust the medical system. We wouldn't hurt you.’ because that's not necessarily people's lived experience.” - Provider

“I called the MD Anderson Cooper, and then I spoke to somebody, I knew she was a Black woman, so I said, ‘Help me out, is there any Black doctors that I can see, it was important to me because I don't think white people listen to us.’” – Survivor

“But, I'm at the point where I don't trust any of them now, because of the fact, they all told me, do this, and this and, this. I did everything they said. But you didn't tell me that

the radiation is not going to heal... I had stage two, so to me they leave out stuff because they're looking at the money.” – Survivor

“She was 33 and got diagnosed with metastatic disease, in a lot of pain. Because of the community she lived in and it was a reputable hospital, her doctors specifically said to her, ‘I will not give you any pain medication because I’m not going to fuel your drug habit.’” - Navigator

Self-advocacy. While self-advocacy and involvement in one’s health care is important, Black women reported having to “fight” for adequate treatment and coverage that they needed while contending with racial discrimination in the health care setting. They also reported having to do their own research to get more information about their condition. They reported having to stand up for themselves and demand to have their medical concerns heard and addressed.

“I was fighting for my life, but I was fighting for treatment. I had to fight for everything. I knew for a fact that wasn't happening to every patient.” - Survivor

“It's just the fact that if I didn't open up and express the fact that I did not like being treated that way. If I did not stand up for myself basically, I wonder how the relationship would have ended.” - Survivor

Survivorship

Most survivors reported feeling like there wasn’t a clear survivorship plan that was a part of their exit strategy once they were done with intensive treatment. Survivors reported feeling like they needed to do their own research or connect with other organizations outside of their treatment facility to define what their survivorship plan should be. Survivors shared that while emotional and mental health support was available from both family and community groups, they needed more support from their care team. This finding is not supported by quantitative data but is still significant to note. Providers described routine follow-up visits and scans as being key components of their survivorship programs with patients.

“It was like, ‘I'm done. Now what?’... I stay very involved in the cancer community, so I know about the survivorship plan, and things like that. Those are things that I found out on my own at the time they weren't a part of your exit strategy, when you finished that last chemo treatment.” – Survivor

“The education part, the compassionate part, the concern just disappeared once survivorship made its way into the program. Once you ring that bell. Once you've moved on, even now to the follow up appointment, they didn't seem to be as concerned.” - Survivor

Survivor Support Resources. Community members, patient navigators and providers noted the critical role that financial, educational and support resources play along the breast cancer continuum of care. Community members reported that they were connected to survivor groups with predominantly Black women. They shared that these groups really meet their holistic needs, including their spiritual needs.

To promote screening and education, providers shared that they collaborated with federally qualified health centers and community-based organizations, particularly churches, as part of their strategy.

“I would say that if you're not connected to a church, then you don't have a community center. I mean, out in West Philly it's not like people are going and working out at the local community center, or they're not going to health fairs in the West Philly XYZ because there isn't a West Philly XYZ. There's a lot of churches and there's definitely a Haitian Community Center and a West African Community Center and there's some Asian things... but for just the average English speaking third or seventh or ninth generation Philadelphian who doesn't go to church, I don't know what your community center is. If it exists, we haven't found it and we haven't done any outreach there.” – Provider

“It's the type of support group. You don't want it to be a pity party, if it's a place where they're coming to encourage each other. It really makes a difference and I've had that experience in the women that come to my support group saying, when they went other places that they came out feeling worse than when they went in. The biggest thing that makes Sister Will You Help Me so successful is that we are a safe space for spiritual women...when it comes to African American and our spirituality, that's a huge component. We understand that prayer and spirituality is a huge component in African American community.” - Navigator

Section 2 Findings: Systemic and Social Determinants of Health

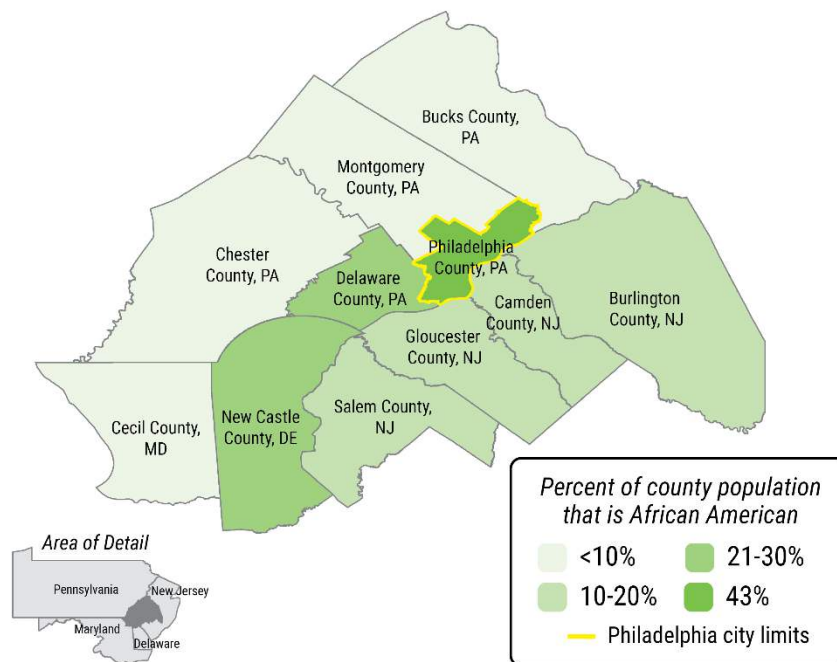
Section 2 explores the systemic and SDOH that may drive breast cancer inequities. The set of factors explored in this section—residential segregation, economic vulnerability, experiences of racism, SDOH—were informed by consultations with Komen’s AAHEI team, academic experts (see Acknowledgements for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

Residential Segregation

The Philadelphia MTA is segregated along racial and socioeconomic lines, creating stark contrasts by geography. Approximately 2 million people of color live in the Philadelphia MTA, comprising 33 percent of the region’s total population (see “Minority Race” in Table 3). More than half of the approximately 1.2 million Blacks who live in the Philadelphia MTA reside in Philadelphia County (see Tables 3 and 4).

Other counties with higher percentages and numbers of Blacks include Delaware County, PA, and New Castle County, DE, where Blacks account for 21 percent and 25 percent of the total population (see Map 3). In counties on the western side of the Philadelphia MTA, including Cecil County, MD, Chester County, PA, Montgomery County, PA, and Bucks County, PA, a smaller percentage of the population is African American (see Table 4 and Map 3).

MAP 3. AFRICAN AMERICAN POPULATION IN THE PHILADELPHIA METRO AREA

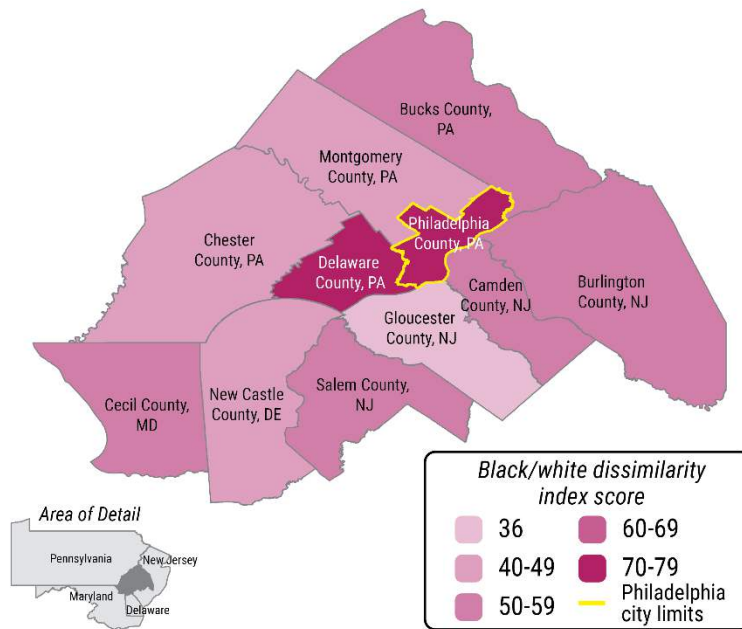


In addition to the MTA as a whole being racially segregated (with most people of color living in just a few of the counties - see Map 3), many of the counties in the MTA are also internally racially segregated. Counties’ internal segregation can be measured using the Black/white dissimilarity index to 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

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

complete integration of the two races and 100 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 PHILADELPHIA MTA



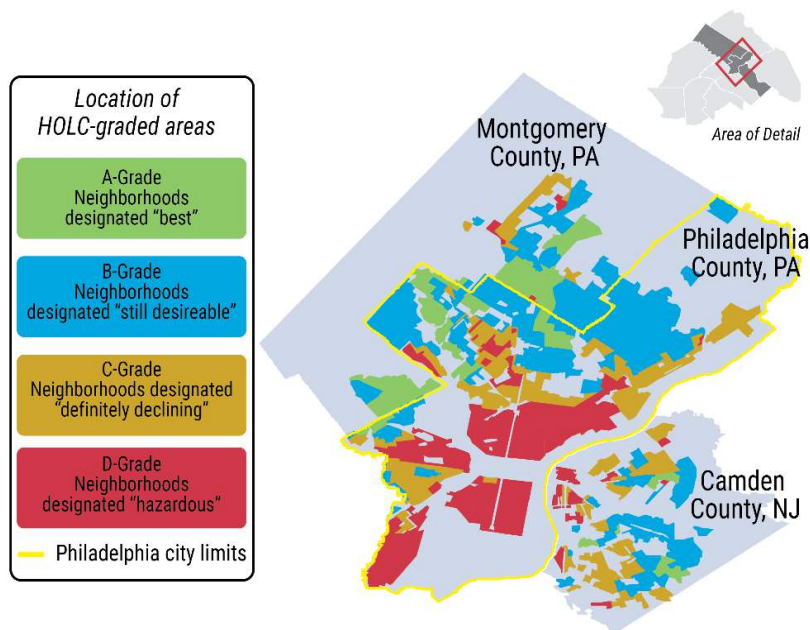
Source: 2019 County Health Rankings (County Health Rankings)

As seen in Map 4, Delaware County, PA, and Philadelphia County, PA, have the highest residential segregation scores in the Philadelphia MTA, reported at 72 and 70, indicating that people living in those counties are more segregated than people living in the other counties of the MTA. Five counties report moderate segregation scores: Bucks County, PA (53), Cecil County, MD (51), Salem County, NJ (52), Camden County, NJ (56), and Burlington County, NJ (51). Gloucester County, NJ, has the lowest index score at 36.

The patterns of residential segregation that are visible today across the Philadelphia MTA are

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

MAP 5. REDLINING IN THE PHILADELPHIA 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. Banks and other mortgage lenders used these grades to inform their lending practices and policies throughout the Philadelphia

MTA. Map 5 shows areas within the Philadelphia MTA that were included in the “residential security” maps created by HOLC agents in the first half of the twentieth century. Portions of Philadelphia and Montgomery Counties in Pennsylvania appear on the 1937 map of the city of Philadelphia. Camden County, NJ, appears on the map of the city of Camden, also produced in 1937.

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

Personally Mediated Racism

Data suggest that in addition to institutionalized racism, Blacks in the Philadelphia 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, Philadelphia County, PA, reports the highest number of race-based incidents, including the highest numbers of Fair Housing Act cases and highest number of Blacks killed by police by a significant margin at 125 cases and 8 people. With regard to hate crimes, Burlington County, NJ, and Gloucester County, NJ, report the highest numbers at 28 and 29 crimes within the reporting period.

TABLE 10. PHILADELPHIA 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
New Castle County, DE	9	66	1
Cecil County, MD	0	8	1
Burlington County, NJ	28	33	0
Camden County, NJ	9	53	0
Gloucester County, NJ	29	24	0
Salem County, NJ	1	3	0
Bucks County, PA	0	31	0
Chester County, PA	1	26	1
Delaware County, PA	0	40	3
Montgomery County, PA	0	69	0
Philadelphia County, PA	19	125	8

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 experiences of community members from the Philadelphia MTA provide additional insights about experiences of personally mediated racism that Blacks experience. As noted above (see Findings I), focus group participants reported receiving poorer quality care and differential treatment at the diagnosis and treatment stages in the breast cancer continuum. The majority of focus group participants reported encountering racial discrimination in health care and retail settings. Two participants (a survivor and an undiagnosed woman) described their personal experiences with personally mediated racism noting how their gynecological and pregnancy complications were ignored and assumptions made about their ability to deliver a healthy child.

“I was pregnant. I went to the emergency room feeling pain, explaining to them what was going on. And I honestly sat in that emergency room for hours, and I bled on the floor. No one came to my assistance... it was in the whiter part of the County [Delaware].” - Undiagnosed woman

“The doctor, white doctor trying to get me out of there, was like, ‘It’s okay hun, you just have a UTI.’ And this was after being there for hours in pain, throwing up, I was just really a mess” – Survivor

“So, when I grew up, I felt being Black was a problem. I went through it with that era for a long time. I was born in '56, I'm 63 years old, so it bothered me because it happened every year. Every year, the racism. God, I know those white women are in hell today, because of how they disrespected and discriminated against me, and I was a young little girl. They looked at me with evilness.” - Survivor

Health Disparities

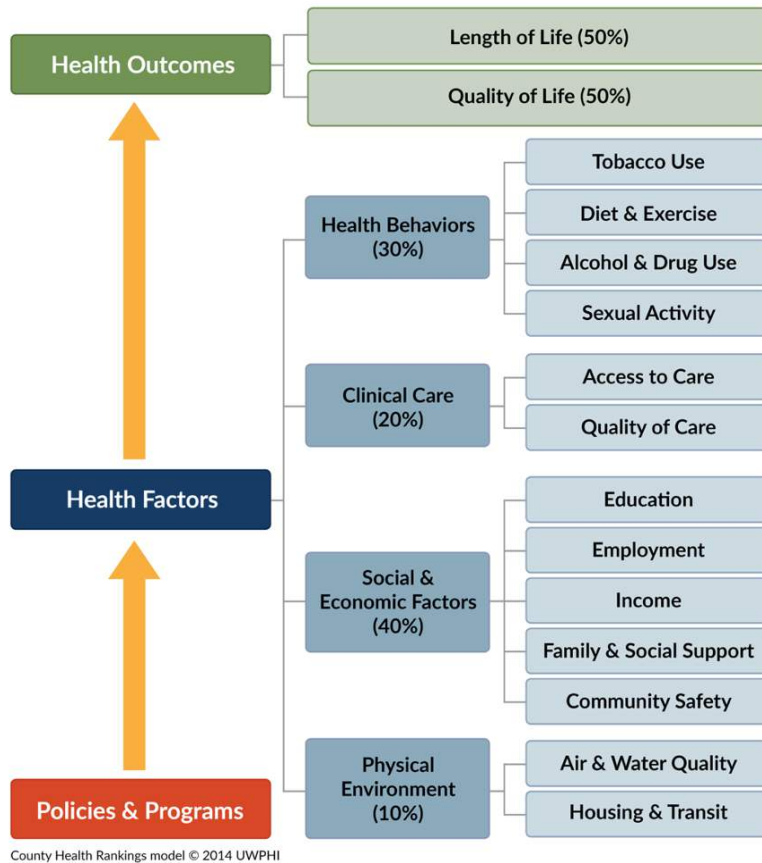
Data suggest that there are significant disparities in the Philadelphia MTA in terms of overall health and wellbeing. Philadelphia County, PA, overall has the poorest health outcomes in the Philadelphia MTA including the highest percentage of adults reporting “fair or poor” health at 20 percent and the highest average numbers of poor physical and mental health days per month at 4.5 and 4.6 days (Table 11).

TABLE 11. PHILADELPHIA 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
New Castle County, DE	33%	15%	3.3	3.8
Cecil County, MD	75%	14%	3.4	4.2
Burlington County, NJ	48%	13%	3.4	3.3
Camden County, NJ	95%	18%	4.0	4.2
Gloucester County, NJ	76%	16%	3.8	4.3
Salem County, NJ	90%	18%	4.1	4.0
Bucks County, PA	9%	12%	3.2	3.7
Chester County, PA	4%	11%	3.0	3.5
Delaware County, PA	70%	14%	3.7	4.2
Montgomery County, PA	6%	12%	3.1	3.4
Philadelphia County, PA	100%	20%	4.5	4.6

Source: 2019 County Health Rankings (County Health Rankings)

FIGURE 2. COUNTY HEALTH RANKINGS MODEL



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

Three counties in the Philadelphia MTA (all in the state of Pennsylvania, which has 67 counties) rank in the top 10 percent by CHR: Bucks (9 percent), Chester (4 percent), and Montgomery (6 percent). However, the other two Pennsylvania counties in the MTA rank poorly with Delaware County at 70 percent and Philadelphia County at 100 percent, indicating that it has the lowest CHR in the state.

In terms of health behaviors, Salem County, NJ, and Cecil County, MD,

report the highest rates in two of the three metrics: obesity and physical inactivity. Obesity rates are reported at 32 percent in Cecil County and 34 percent in Salem County, and physical inactivity rates are reported at 28 percent in both. The highest rate of excessive drinking lies in Chester County, PA, at 24 percent. However, Chester County also holds the lowest reported rates of obesity and physical inactivity.

TABLE 12. PHILADELPHIA METRO AREA HEALTH BEHAVIORS

County	Percent of Adults Who Are Obese	Percent of Adults Who Drink Excessively	Percent of Adults Who Are Physically Inactive
New Castle County, DE	29%	19%	23%
Cecil County, MD	32%	18%	28%
Burlington County, NJ	28%	18%	22%
Camden County, NJ	29%	17%	27%
Gloucester County, NJ	31%	20%	26%

Salem County, NJ	34%	17%	28%
Bucks County, PA	28%	21%	19%
Chester County, PA	22%	24%	16%
Delaware County, PA	26%	19%	20%
Montgomery County, PA	26%	19%	17%
Philadelphia County, PA	29%	22%	24%

Source: 2019 County Health Rankings (County Health Rankings)

TABLE 13. PHILADELPHIA METRO AREA LIFE EXPECTANCY

County	Life Expectancy	Life Expectancy for Whites	Life Expectancy for Blacks
New Castle County, DE	79	79	76
Cecil County, MD	76	76	76
Burlington County, NJ	80	79	78
Camden County, NJ	78	78	74
Gloucester County, NJ	78	78	76
Salem County, NJ	77	78	70
Bucks County, PA	80	80	78
Chester County, PA	81	80	76
Delaware County, PA	78	79	76
Montgomery County, PA	81	81	78
Philadelphia County, PA	76	77	74

Source: 2019 County Health Rankings (County Health Rankings)

Overall life expectancy in the Philadelphia MTA is lowest in Philadelphia County, PA, at 76 years and highest in Chester County, PA, and Montgomery County, PA, at 81 years (see Table 13). In every county, life expectancy is equivalent or lower for Blacks than whites. The largest racial disparity in life expectancy between whites and Blacks is in Salem County, NJ, where whites live an average of eight years longer than their Black counterparts (78 years versus 70 years).

TABLE 14. PHILADELPHIA 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
New Castle County, DE	349	345	445
Cecil County, MD	436	436	627
Burlington County, NJ	310	319	371
Camden County, NJ	381	359	556
Gloucester County, NJ	344	345	437
Salem County, NJ	425	397	661
Bucks County, PA	290	300	374
Chester County, PA	243	243	417
Delaware County, PA	352	339	449
Montgomery County, PA	266	266	406
Philadelphia County, PA	472	436	576

Source: 2019 County Health Rankings (County Health Rankings)

Premature age-adjusted mortality (Table 14) measures the number of deaths of people under the age of 75 per 100,000. Philadelphia County, PA, reports the highest overall premature age-adjusted mortality rate at 472 deaths per 100,000 while Chester County, PA, has the lowest at 243. Across all counties, premature age-adjusted mortality is higher for Blacks than for whites. The largest disparity between whites and Blacks is reported in Salem County, NJ, where the rate is 397 premature deaths per 100,000 white residents versus 661 premature deaths per 100,000 Black residents. Salem County's premature age-adjusted mortality rate among Blacks is the highest in the Philadelphia MTA. The next highest rate is in Cecil County, MD, which reports 627 premature deaths per 100,000 Blacks.

Access to Health Services

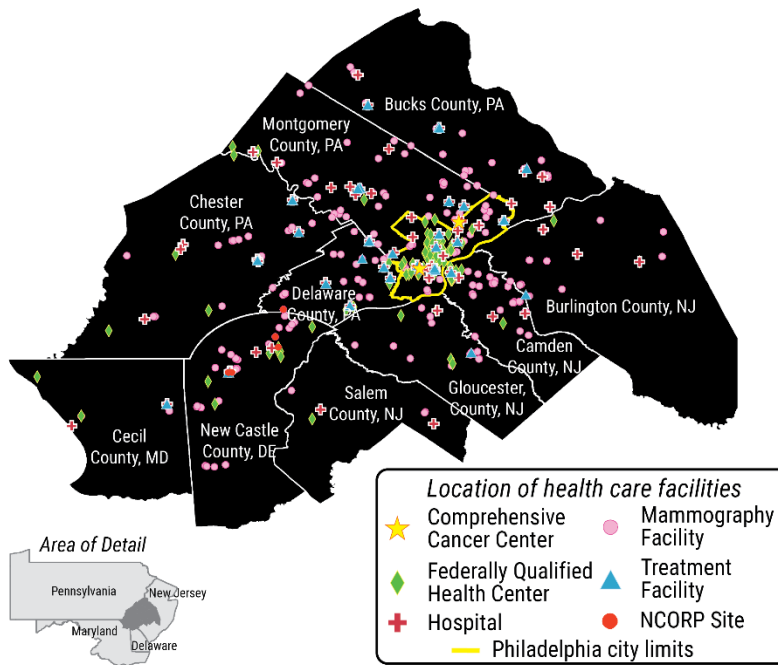
Data suggest that there are significant disparities in the health system in the Philadelphia MTA, including in health care facilities and the proportion of the population that is medically underserved. According to the Health Resources and Services Administration (HRSA), Medically Underserved Areas/Populations are areas or populations designated by HRSA as having too few primary care providers, high infant mortality, high poverty or a high elderly population. Table 15 demonstrates these wide disparities in adequate health service coverage across the MTA. In Bucks County, PA, 95 percent of the population is considered medically underserved. Philadelphia County, PA, and New Castle County, DE, report the next highest percentages at 51 percent and 45 percent. Four counties report that 5 percent or less of their populations are medically underserved: Burlington County, NJ (5 percent), Salem County, NJ (4 percent), Delaware County, PA (4 percent), and Montgomery County, PA (3 percent).

TABLE 15. PHILADELPHIA 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
New Castle County, DE	45%	464	1,200	144	695	349	6
Cecil County, MD	9%	39	2,631	52	1,939	3	8
Burlington County, NJ	5%	541	1,158	58	1,721	29	21
Camden County, NJ	10%	373	1,205	55	1,809	25	23
Gloucester County, NJ	11%	513	944	84	1,185	60	11
Salem County, NJ	4%	158	1,850	47	2,133	18	4
Bucks County, PA	95%	23	2,758	27	3,694	0	15
Chester County, PA	11%	445	1,160	79	1,270	20	13
Delaware County, PA	4%	612	921	74	1,351	119	2
Montgomery County, PA	3%	1,164	706	86	1,159	156	2
Philadelphia County, PA	51%	1,058	1,482	128	781	327	21

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 PHILADELPHIA MTA



The health systems map (Map 6) shows the concentration of health care facilities in the Philadelphia MTA, and generally reflects population density across the metro. The highest concentration of centers in Philadelphia County, PA, including both of the comprehensive cancer centers and most of the federally qualified health centers. Treatment facilities are also concentrated in the counties closer to the center of the metro. Hospitals and screening mammography facilities are available across all counties with some higher concentrations again near the center of the metro. All NCI National Community Oncology Research Program (NCORP) sites are either in Delaware County, PA, or New Castle County, DE. Cecil County, MD, has the lowest

Source: HRSA Data Warehouse, 2019 dataset (US Department of Health and Human Services, Health Resources & Services Administration); Comprehensive Cancer Centers and 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)

number of health care facilities available.

In focus groups, community members did not explicitly note a lack of access to facilities in the areas. However, one provider noted regional differences in quality of care within Philadelphia County.

“There’s definitely less availability per capita in those areas (focus areas of the study), and that would be correct... South-West Philly and West Philly have like a crappy hospital, an okay hospital, and then two Penn hospitals that are really good. So, you could argue that depending on which hospital you chose to go to your outcomes or your access to good screening would be different, and you might be right.” - Provider

TABLE 16. PHILADELPHIA METRO AREA BREAST CANCER RESOURCES

County	Number of Mobile Screening mammography Centers	Number of Cancer Coalitions	Number of Survivor/Support Groups
New Castle County, DE	1	1	3
Cecil County, MD	1	0	1

Burlington County, NJ	0	1	4
Camden County, NJ	0	1	9
Gloucester County, NJ	2	1	12
Salem County, NJ	0	1	3
Bucks County, PA	0	1	0
Chester County, PA	1	1	2
Delaware County, PA	0	1	8
Montgomery County, PA	2	1	2
Philadelphia County, PA	3	1	36

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

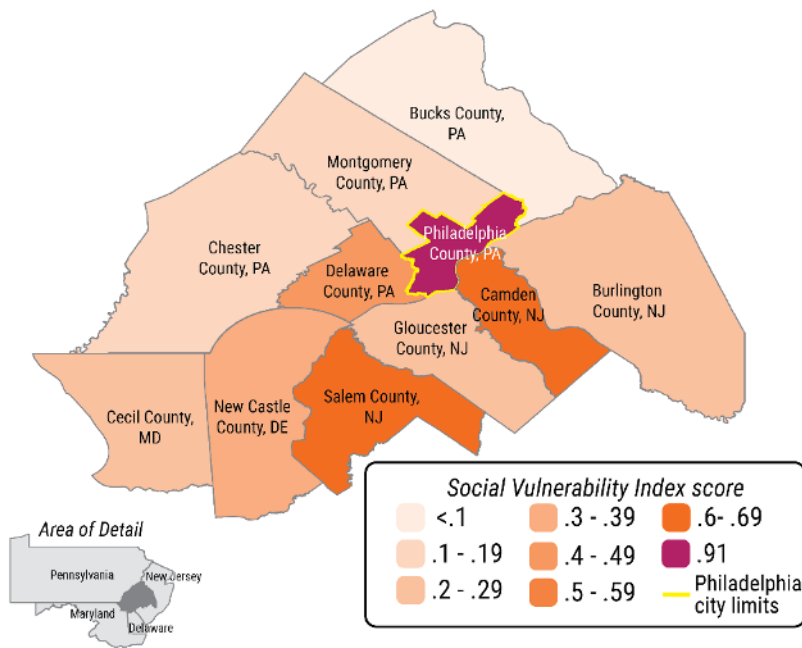
Like health care facilities, breast cancer resources are also concentrated in Philadelphia County, PA, particularly in the form of breast cancer support groups (36 groups are located in Philadelphia) (see Table 16). Philadelphia County also has the most mobile screening mammography centers, with three. Gloucester County, NJ, has the next highest number of resources available with 12 support groups, two mobile screening mammography centers and one cancer coalition. Bucks County, PA, has the fewest number of resources with only one cancer coalition.

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

Social and Economic Vulnerability

Social determinants affect health outcomes – such as breast cancer – for individuals and communities. These play out not just across individual lifetimes, but generationally. Disadvantages compound in certain communities, which exacerbates and cements a wide range of negative outcomes and existing burdens, including with regard to health (Cozier et al., 2009; Institute of Medicine of the National Academies, 2011). The Social Vulnerability Index (SVI) of each county can be seen in (Map 7). The SVI is calculated by the CDC, and a county’s score “refers to the resilience of communities when confronted by external stresses on human health, stresses such as natural or human-caused disasters, or disease outbreaks” (e.g., such as hurricanes, fires, and COVID-19). Scores range from 0.0 to 1.0, with scores closer to 1.0 indicating greater vulnerability. Map 7 demonstrates the SVI for each county in the Philadelphia MTA. Philadelphia County, PA, has the highest SVI score in the metro at 0.92 with Camden County, NJ, and Salem County, NJ, also demonstrating a moderate-high score with both at 0.61. Bucks County, PA, has the lowest score at 0.08. Individual factors influencing a county’s SVI can be parsed by looking at specific indicators.

MAP 7. PHILADELPHIA METRO AREA SOCIAL VULNERABILITY



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

As suggested by its high SVI score, Philadelphia County, PA, appears to be a place of economic insecurity as compared to other counties in the MTA. Philadelphia County, PA, reports that 10 percent of its population is uninsured, the highest percentage in the MTA (see Table 17). Additionally, 25 percent of Black women over the age of 45 who reside in Philadelphia County, PA, live below the federal poverty level (FPL). Philadelphia County, PA, reports a lower percentage than many other places in the MTA in terms of the percent of the population below 200 percent FPL (17 percent). New Castle County, DE, similarly stands out as a place of high need, as 47 percent of its population lives below 200 percent FPL.

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

“Usually, Black women are the primary breadwinner...during these times they usually don't have a flash fund, or a rich husband to rely on to sit back and take care of all the bills. If you're telling them that they have to take time off, and they're not able to work because of cancer treatment or even radiation or anything like that, that's going to cause disruption to the household... on top of childcare, transportation, lack of PTO time, lack of having those types of investments. All the little things that our white counterparts take for granted.” – Survivor

“It's unfortunately a deeper systemic issue where poverty is overwhelming. Poverty is overwhelming...There's so many other things that they're trying to do that getting that screening mammogram just doesn't come up.” - Provider

“...areas like West Philly, when you look down on a zip code basis, you've got areas up there with average income that's below the poverty line. So, when you've got the average household having an income of \$22,000, you're in a situation where people are presenting late.” - Provider

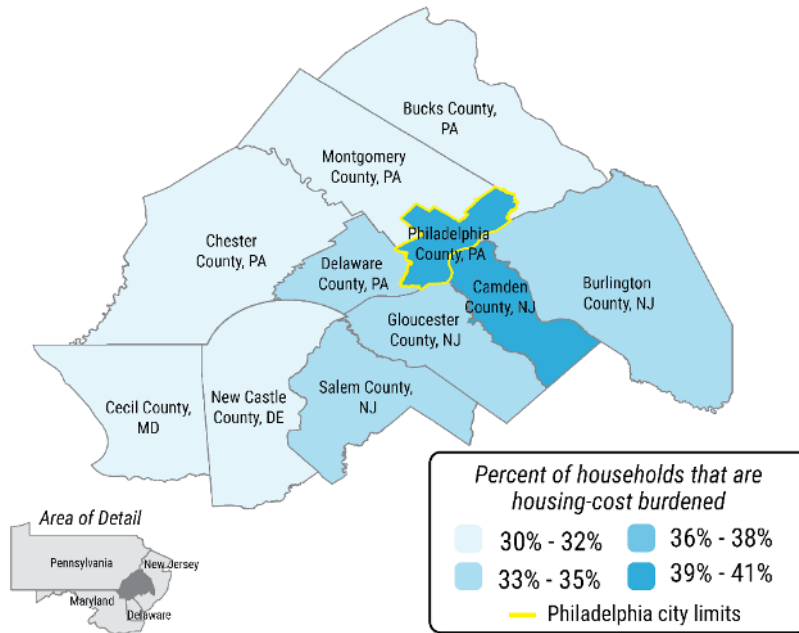
TABLE 17. PHILADELPHIA METRO AREA ECONOMIC SECURITY

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
New Castle County, DE	5%	47%	17%
Cecil County, MD	5%	28%	16%
Burlington County, NJ	4%	24%	7%
Camden County, NJ	8%	18%	15%
Gloucester County, NJ	5%	16%	9%
Salem County, NJ	7%	25%	20%
Bucks County, PA	4%	16%	14%
Chester County, PA	6%	17%	14%
Delaware County, PA	5%	28%	16%
Montgomery County, PA	4%	24%	10%

Philadelphia County, PA	10%	17%	25%
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Source: American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)

MAP 8. HOUSING-COST BURDEN IN THE NATIONAL CAPITAL METRO AREA



As displayed in Map 8, Philadelphia County, PA, and Camden County, NJ, report the highest percentages of households that are housing-cost burdened at 40 percent and 39 percent respectively. Three counties report the lowest rate in the MTA at 30 percent: New Castle County, DE, Chester County, PA, and Montgomery County, PA.

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

TABLE 18. PHILADELPHIA 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
New Castle County, DE	12%	5%	20%
Cecil County, MD	9%	7%	24%
Burlington County, NJ	10%	6%	12%
Camden County, NJ	12%	5%	23%
Gloucester County, NJ	10%	9%	21%
Salem County, NJ	13%	3%	33%
Bucks County, PA	8%	4%	16%

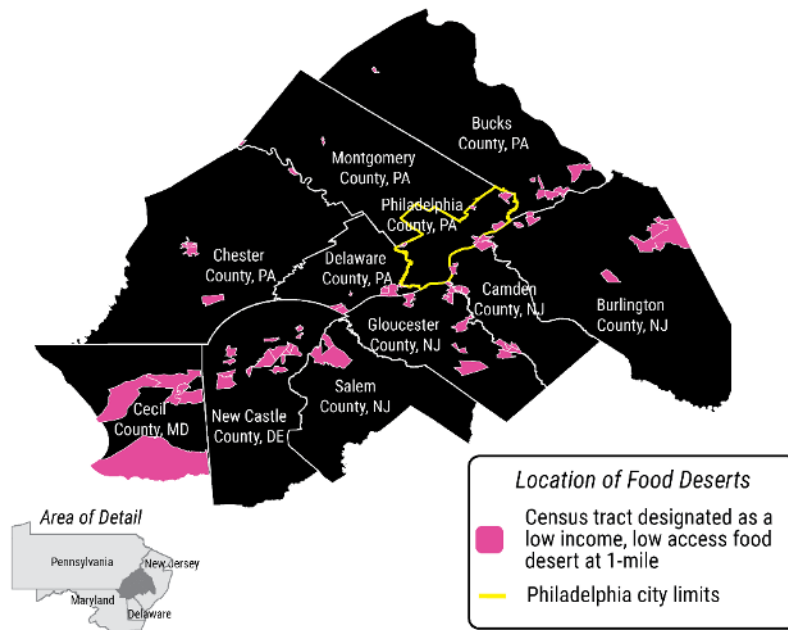
Chester County, PA	8%	6%	21%
Delaware County, PA	13%	2%	27%
Montgomery County, PA	10%	4%	19%
Philadelphia County, PA	21%	0%	34%

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

Philadelphia County, PA, reports the highest rate of food insecurity in the MTA, with 21 percent of its population classified as food insecure (see Table 18). It also reports the highest proportion of African American households receiving SNAP/EBT benefits, at 34 percent. Even though Philadelphia County, PA, reports the highest access to healthy food (zero percent of its population is defined as having limited access to healthy foods), these data show that food access does not equate to food security. Other counties reporting higher rates of food insecurity include Delaware County, PA, and Salem County, NJ, both at 13 percent insecure. Additionally, 27 percent and 33 percent of Black households receive SNAP/EBT benefits in Delaware County, PA, and Salem County, NJ.

“We did a needs assessment of our Medicaid and Medicare patients here in Camden to see what was needed for them to continue with their treatment, we looked at over 50 patients... Over a third was food insecurity. There's one story of a woman who needed to get special food, but she unfortunately had only limited funds with her SNAP dollars. She was trying to figure out how to use those SNAP dollars to buy things like Ensure that she needed, while at the same time being able to provide for her family. Food insecurity, I think having a third of people having issues with food insecurity is pretty high” - Patient Navigator

MAP 9. FOOD DESERTS IN THE PHILADELPHIA METRO AREA



Map 9 illustrates the location of food deserts throughout the Philadelphia MTA. Food deserts are census tracts designated by the USDA as low-income areas with low access to food within one mile. Most of the food deserts in the Philadelphia MTA are concentrated along the southern strip of the region, with Cecil County having the largest proportion of its area classified as food deserts. Larger food deserts are also present in New Castle County, DE, Salem County, NJ, Gloucester County, NJ, and Burlington County, NJ. Philadelphia County is among the counties with the fewest food deserts, along with Montgomery County, PA, and Delaware County, PA.

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

TABLE 19. PHILADELPHIA 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
New Castle County, DE	7%	14%	4%	4%
Cecil County, MD	5%	21%	1%	3%
Burlington County, NJ	5%	22%	4%	2%
Camden County, NJ	12%	20%	7%	3%
Gloucester County, NJ	6%	24%	2%	2%
Salem County, NJ	8%	16%	1%	4%
Bucks County, PA	5%	23%	3%	3%
Chester County, PA	5%	20%	3%	4%

Delaware County, PA	11%	21%	11%	5%
Montgomery County, PA	6%	22%	5%	3%
Philadelphia County, PA	31%	27%	25%	12%

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

Philadelphia County, PA, is the most urban county in the Philadelphia MTA, and it reports the highest rates across all four transportation metrics displayed in Table 19: 31 percent of its households do not have a vehicle, 27 percent of its population commutes more than 45 minutes to work, 25 percent of its population commutes to work using public transportation, and 12 percent of its population commutes via foot, bike, or other means. Camden County, NJ, and Delaware County, PA, report the next highest percentages of households without a vehicle at 12 percent and 11 percent. Delaware County, PA, also reports the next highest percentage of its population that commutes to work via public transportation at 11 percent.

“So depending on how far your hospital is from your home, if you don't drive, or if you can't drive, that's true for a lot of people, getting someone to take you back and forth can be a huge problem.” – Provider

“We did a needs assessment of our Medicaid and Medicare patients here in Camden, and when we looked at over 50 patients that we screened, more than 50% of them, the biggest need was transportation for them to continue to proceed with their treatment, that was a barrier.” - Navigator

TABLE 20. PHILADELPHIA 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
New Castle County, DE	91%	36%	9%
Cecil County, MD	89%	23%	5%
Burlington County, NJ	93%	37%	7%
Camden County, NJ	88%	31%	12%
Gloucester County, NJ	93%	31%	8%

Salem County, NJ	87%	21%	16%
Bucks County, PA	94%	39%	9%
Chester County, PA	93%	51%	10%
Delaware County, PA	93%	38%	10%
Montgomery County, PA	94%	48%	8%
Philadelphia County, PA	83%	27%	16%

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

Philadelphia County, PA, reports the lowest educational attainment in the Philadelphia MTA (see Table 20). Eighty three percent of the population over the age of 25 has a high school diploma, while only 27 percent of the population over the age of 25 has a bachelor’s degree. Philadelphia County, PA, also has among the highest percentage of Black women living in the MTA without a high school degree (16 percent). This situation is true for Salem County, NJ, as well. Camden County, NJ, and Salem County, NJ, also exhibit poorer levels of education across all three metrics. Montgomery County, PA, and Chester County, PA, report the highest overall educational attainment rates with 94 percent and 93 percent of their populations having a high school diploma. Bucks County, PA, residents report high levels of high school graduation but moderate levels of bachelor’s degree attainment at 39 percent. At 5 percent, Cecil County, MD, reports the lowest percentage of Black women residents without a high school diploma. Focus group participants’ views on how a patient’s level of education affects their experience and breast cancer outcomes varied, with one provider noting that it was a very important driver of poor outcomes and a navigator noting that it wasn’t important at all.

“I think that's what you see in this area [Philadelphia county], tremendous disparities in income, tremendous disparities in education...I think the number one thing is low income, 1b is low general education, which education as you know, empowers people so that they can stay on top of their health and get a better income. And then you compound that with the fact that this group for reasons that are just really not fully appreciated have an increased risk of early-onset and aggressive types of breast cancer.”
 - Provider

“I really think it's priorities. I don't know so much that it's lack of awareness or lack of education. When I did my program last year and specifically asked about the barriers to care, it was those simple things. It was transportation. It was language for Latinas. For African American women, it was not being able to get away from work. It was fear.” – Navigator

TABLE 21. PHILADELPHIA METRO AREA GENTRIFICATION

County	Proportional Change in Population With a Bachelor's Degree or Higher	Percent Change in Median Household Income
New Castle County, DE	4%	10%
Cecil County, MD	2%	8%
Burlington County, NJ	3%	9%
Camden County, NJ	3%	9%
Gloucester County, NJ	3%	7%
Salem County, NJ	2%	6%
Bucks County, PA	4%	7%
Chester County, PA	3%	6%
Delaware County, PA	2%	4%
Montgomery County, PA	2%	7%
Philadelphia County, PA	3%	7%

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

Table 21 measures gentrification rates across two metrics: the proportional change of the population with a bachelor's degree or higher and the proportional change in median household income. By these metrics, New Castle County, DE, can be classified as the most gentrified county in the MTA with a 4 percent change in its population with a bachelor's degree and a 10 percent change in its median household income. Delaware County, PA, can be classified as the least gentrified with a 2 percent change in its college educated population and a 4 percent change in median household income. Philadelphia County, PA, performs moderately in both metrics with a 3 percent change in its college-educated population and a 7 percent change in median household income.

Policy Context

This section examines key policies relating to access to 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 screening 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, 2015b).
- **Pre-Existing Conditions Protections.** Per the ACA and effective as of 2014, health insurers cannot deny coverage to an individual or charge more for coverage due to a pre-existing condition. For example, insurers cannot discriminate based on a previous or current breast cancer diagnosis or other health condition. Additionally, health insurers cannot refuse to provide coverage for treatment and other services related to a pre-existing condition (U.S. Department of Health & Human Services, 2017).
- **Medicaid Expansion.** Under the ACA, states have the option to expand their Medicaid program to individuals with incomes of up to 138 percent FPL. More than 1 in 6 Pennsylvania residents are enrolled in the state's Medicaid program, known as Medical Assistance (MA) with managed care programs under the name of HealthChoices (Pennsylvania Department of Human Services, 2020a, 2020b; The Henry J. Kaiser Family Foundation, 2019). Pennsylvania adopted an expanded Medicaid program effective January 1, 2015 (The Henry J. Kaiser Family Foundation, 2015a), and the program is available to:
 - Adults of documented status with incomes up to 138 percent FPL. New Jersey, Maryland, and Delaware each also expanded coverage, effective on January 1, 2014 for all three states. (The Henry J. Kaiser Family Foundation, 2020b) Eligibility criteria for adults is listed in the table below:

TABLE 22. MEDICAID ELIGIBILITY IN THE PHILADELPHIA METRO AREA

State	Eligibility
Pennsylvania	Adults of documented status with incomes up to 138% of the federal poverty line (FPL)
New Jersey	Adults with incomes up to 138% of the FPL and pregnant women up to 200%
Maryland	Adults with incomes up to 138% of FPL, pregnant women up to 259% FPL, and certain aged, blind, and disabled (ABD) individuals meeting income requirements

Source: healthinsurance.org

As of October 2019 there were an estimated 800,900 adults in the expansion population in Pennsylvania (The Henry J. Kaiser Family Foundation, 2019). From 2013 to 2017, the uninsured rate in Pennsylvania decreased from 12 percent to 7 percent (compared to a national drop from 17 percent to 10 percent over the same time period. For nonelderly Black residents in Pennsylvania, the uninsured rate decreased from 17 percent in 2013 to 8 percent in 2017 (The Henry J. Kaiser Family Foundation, 2018). Comparatively, the uninsured rate for non-elderly white residents in Pennsylvania decreased from 10 percent in 2013 to 6 percent in 2017. As displayed in Table 17, the five-year American Community Survey estimates the average uninsured rate in the Philadelphia MTA at 6 percent (with a low of 4 percent in Burlington, Bucks, and Montgomery Counties and a high of 10 percent in Philadelphia County).

New Jersey, Maryland, and Delaware each also saw similar drops in uninsured rates. As of October 2019, New Jersey had 580,200 adults in the expansion group, Maryland had 306,700, and Delaware 62,500. From 2013 to 2017, the uninsured rate in New Jersey decreased from 15 percent to 9 percent and from 12 percent to 7 percent in Maryland and Delaware, compared to the national drop from 17 percent to 10 percent (The Henry J. Kaiser Family Foundation, 2020a).

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

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

In Pennsylvania, the screening program is known as the Pennsylvania Breast & Cervical Cancer Early Detection Program (PA-BCCEDP). Women living in Pennsylvania, who are 40-64 years of age, at or below 250 percent of the FPL, and uninsured or underinsured are eligible for this program (Pennsylvania Department of Health, 2020). In New Jersey, the program is called the New Jersey Cancer Education and Early Detection Program (NJCEED); women living in New Jersey, 40 to 64 years old, at or below 250 percent of the FPL, and uninsured or underinsured are eligible for this program (New Jersey Department of Health, 2020). In Delaware, the program is called the Delaware Screening for Life Program; women living in Delaware, 40 to 64 years old, at or below 250 percent of the FPL, and uninsured or underinsured are eligible for this program (Delaware Department of Health, 2020).

In Pennsylvania, from the five-year period of July 2014 to June 2019, the NBCCEDP served 28,500 women for both breast and cervical cancer screening and detection services. Specific to breast cancer, 20,778 women received a screening mammogram over this five-year period, and 25,897 women received breast cancer screening and diagnostic services (note that each category provides a unique count of women receiving services, but women may be counted in multiple categories. Thus, the distinct category figures listed are not unduplicated women receiving services) (Centers for Disease Control and Prevention, 2019).

In New Jersey, from the five-year period of July 2014 to June 2019, the NBCCEDP served 39,813 women for both breast and cervical cancer screening and detection services. Specific to breast cancer, 27,575 women received a screening mammogram over this five-year period, and 24,981 women received breast cancer screening and diagnostic services (note that each category provides a unique count of women receiving services, but women may be counted in multiple categories. Thus, the distinct category figures listed are not unduplicated women receiving services) (Centers for Disease Control and Prevention, 2019).

In Delaware, from the five-year period of July 2014 to June 2019, the NBCCEDP served 3,508 women for both breast and cervical cancer screening and detection services. Specific to breast cancer, 1,619 women received a screening mammogram over this five-year period, and 2,754 women received breast cancer screening and diagnostic services (note that each category provides a unique count of women receiving services, but women may be counted in multiple categories. Thus, the distinct category figures listed are not unduplicated women receiving services) (Centers for Disease Control and Prevention, 2019).

In Pennsylvania, women who are diagnosed (either through the PA-BCCEDP or through another means) may be eligible for treatment through the Department of Human Services- Breast and Cervical Prevention and Treatment Program if they meet certain requirements. In New Jersey, women who are diagnosed through the NJCEED program may be eligible for treatment through the Medicaid program. In Delaware, women who are diagnosed through the Delaware Screening for Life Program may be eligible for treatment through the Delaware Cancer Treatment program.

THE VARYING LEVELS OF ELIGIBILITY FOR BCCTP CAN FACILITATE WOMEN’S ACCESS TO SERVICES (E.G. ELIGIBLE REGARDLESS OF SCREENING LOCATION OR PROVIDER) OR CAN IMPEDE A WOMAN’S ACCESS TO SERVICES (E.G. REQUIREMENTS THAT NBCCEDP FUND SCREENING COSTS).

TABLE 23. OVERVIEW OF SCREENING AND TREATMENT SERVICES IN THE PHILADELPHIA METRO AREA

State	Age Eligibility and Screening Guidance	Insurance Status	Program Services
Pennsylvania <i>Healthy Woman Program</i>	40-64 years old <i>Mammograms may begin screening mammograms at 40, should begin annual screening mammograms at 45 (can switch to every other year at 55 or continue annually)</i>	Uninsured or underinsured	Mammograms, Pap and HPV tests, pelvic exams, follow-up diagnostics tests for abnormal screening results
New Jersey - <i>New Jersey Cancer Education and Early Detection (NJCEED)</i>	40 - 64 or younger if symptomatic for breast cancer <i>Mammograms may begin screening mammograms at 40, should begin annual screening mammograms at 45</i>	Uninsured or underinsured	Education, outreach, screening, case management, tracking, follow-up, and facilitation into treatment
Maryland - <i>Maryland Breast and Cervical Cancer Program</i>	40-64 years old for breast cancer screening <i>Annual screening mammogram starting at 40</i>	Have no health insurance or health insurance that does not completely pay for needed services, or have health insurance, but have not been able to get screened or get needed follow-up testing	Clinical breast exam (CBE) , screening mammograms (screening and diagnostic), breast ultrasound, surgical consultation, breast biopsy, pap test, HPV test, colposcopy and cervical biopsy, patient navigation, case management, linkage to treatment as needed
Delaware - <i>Screening for Life</i>	Age 18-64 and ineligible for Medicaid Age 65+ and ineligible for Medicare <i>“Regular screening mammograms” for women age 40 and older as recommended by their health care provider</i>	Uninsured or underinsured	Office visits, screening mammograms and clinical breast exams, pap tests, other cancer screening tests (prostate, colorectal, and lung cancers), health education, and help with coordinating associated care

Sources: [Pennsylvania Breast & Cervical Cancer Early Detection Program](#); [New Jersey Cancer Education and Early Detection \(NJCEED\)](#); [Delaware Screening for Life](#), [Maryland Breast and Cervical Cancer Program](#), [Sussex County New Jersey Cancer Education and Early Detection](#), [Bergen County Cancer Education and Early Detection](#).

TABLE 24. MEDICAID FOR BREAST AND CERVICAL CANCER IN THE PHILADELPHIA METRO AREA

State	Age	Insurance Status	Program Services
Pennsylvania	Under age 65	Be uninsured or have insurance coverage that does not include breast or cervical cancer treatment	Full Medicaid benefits including doctor or clinical visits, lab tests and x-rays, prescriptions, hospital visits (including surgery), home health agency visits, medical supplies and equipment, and emergency care
New Jersey	Under age 65	Be uninsured	Full Medicaid benefits to uninsured women diagnosed with breast and/or cervical cancer, and in need of treatment
Maryland	N/A	Be uninsured or underinsured, have Medicare, or have health insurance other than Medicare in which the deductible has not been met, there is a copay or coinsurance, or the needed services are not covered by insurance	Diagnostic screening mammograms, surgical consultations, breast ultrasound, breast biopsies, colposcopies, cervical biopsies, surgery, chemotherapy and radiation therapy, home health, pharmacy, medical equipment and supplies), physical therapy, occupational therapy
Delaware	Over 18	Be uninsured	Cancer treatment services for up to 24 months after cancer treatment is initiated, when services are provided by a Delaware Medical Assistance Provider

Sources: [Pennsylvania's Breast & Cervical Cancer Prevention and Treatment Program \(BCCPT\)](#); [Breast and Cervical Cancer Program Update](#), [Delaware Cancer Treatment Program](#).

Flexibility in the Medicaid Program via Medicaid Waivers

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

The Trump administration has promoted work requirements through Medicaid waivers, which have previously not been approved (Brooks, Roygardner, & Artiga, 2019). Several states have applied to enact work requirements, meaning that Medicaid eligible enrollees would have to report working a certain number of hours or involvement in a volunteer role, in school, or in time spent looking for a job. Their Medicaid coverage would be contingent on meeting these requirements. Enrollees can also be exempt from these requirements for other reasons including being pregnant, medically frail, being a full-time student and other reasons (and they must renew their exemptions annually).

Work requirements in Medicaid are a widely criticized strategy that constrict access to Medicaid coverage, do not reach their purported goal of increasing work among Medicaid enrollees, and likely harm health by limiting access to insurance coverage (Cauley Narain & Zimmerman, 2019). In all four states in the Philadelphia MTA, there are no work requirements for Medicaid eligibility (The Commonwealth Fund, 2020). Furthermore, most adults enrolled in Medicaid are already working; in Pennsylvania, 60 percent of adults on Medicaid are working full- or part-time, 58 percent in New Jersey, 70 percent in Maryland, and 56 percent in Delaware (Garfield, Rudowitz, Orgera, & Damico, 2019). Among adult Medicaid enrollees who work full-time, most of them work in low-paying jobs and in sectors that do not tend to offer employer-sponsored insurance.

Cancer Plan for Pennsylvania

The Pennsylvania Cancer Control Plan 2013-2018 was strategized by stakeholders from a number of industries and expertise groups including academic institutions, cancer institutes, foundations, health systems and patient advocacy, amongst others. The five-year plan outlines five broad goals to improve cancer outcomes:

- Advocate for state and federal policies, practices and reform - and community-based systems that promote consumer access to affordable and quality health care
- Reduce cancer health disparities, defined as populations disproportionately burdened by disease and its contributing factors
- Promote evidence-based health provider practices across the cancer care delivery continuum, including reform-based transformation models
- Develop and expand community support system linkages to improve cancer control, while addressing the impacts of social, economic and physical health determinants
- Build capacity for sustainable cancer control programs, research and stakeholder engagement

Breast cancer is the third leading cause of cancer-related death in Pennsylvania, after lung and colon/rectum cancers. Under Goal 2, the plan intends to specifically improve rates for key cancer surveillance indicators and measures for high-burden, CDC-priority cancers, including breast cancer.

While there is no specific mention of addressing disease burdens in Black populations in Pennsylvania within the plan, it outlines intentions to reduce the barrier to availability and access to care through outreach to underserved populations and on “focusing resources on the disproportionate cancer burden in vulnerable populations including factors such as race/ethnicity,” demonstrating commitment to addressing racial health disparity.

Cancer Plan for Maryland

The Maryland Cancer Plan was written by representatives from the Maryland Department of Health and Mental Hygiene, Maryland Cancer Collaborative, the Maryland State Council on Cancer Control, cancer survivors and other experts in the state. The five-year plan does not focus on individual types of cancer, but instead discusses, 1) preventive factors for cancer, 2) topics that cut across prioritized cancer types (such as patient navigation services), and 3) cancer survivorship and palliative care.

The Maryland Cigarette Restitution Fund (CRF) Cancer Prevention, Education, Screening, and Treatment Program targeted seven cancers for public health intervention in Maryland, the first of which is breast cancer. Breast cancer had the highest incidence of all cancers in Maryland between 2008 and 2012, making up 15.8 percent of all cancer diagnoses. Three initiatives that the plan specifically recommends reducing breast cancer incidence are initiatives to increase breastfeeding, increase physical activity and decrease alcohol consumption. They are also working to increase the number of women receiving screening mammograms through more rigorous screening policies.

The state cancer plan also acknowledges care discrepancies between Black and white women. While they do not have the data to show discrepancies in breast cancer incidences, they show that the breast cancer mortality rate for Black women is 30.4 percent, while it is 21.8 percent for white women. However, 89.9 percent of Black women ages 50-75 received a screening mammogram in Maryland in the past two years, while only 82.4 percent of white women did the same.

The plan highlights three strategies that have particular significance to the Black community. The first is patient navigation services, which they show can be helpful for breast cancer screening adherence among Medicare beneficiaries. They also recommend one-on-one education about ways to overcome barriers to cancer screening. By offering services such as patient navigation and education, health systems can mitigate some of the inequities in care by ensuring that Black women receive the needed resources and enhanced access to care. Thirdly, they suggest reducing structural barriers by eliminating administrative obstacles. Reducing structural barriers is essential to promoting equity during breast cancer diagnosis and treatment for Black women. However, “reducing structural barriers” is relatively vague, and it is unclear what steps the plan recommends to achieve this goal.

Cancer Plan for Delaware

The Delaware “Next Five-Year Plan” for cancer was developed by the Delaware Cancer Consortium (Delaware Cancer Consortium, 2017). The Consortium was originally formed as the Delaware Advisory Council on Cancer Incidence and Mortality in March 2001 to advise the Delaware governor and legislature on the causes of cancer incidence and mortality, and potential methods for reducing both. The Consortium is made up of several committees including an advisory council, appointed by the state governor to advise the governor and legislature, the Early Detection & Prevention Committee, the Cancer Risk Reduction Committee, the Delaware Cancer Registry Advisory Committee, and the Healthy

Lifestyles Subcommittee. Moving forward, the Consortium intends to prioritize physical activity and nutrition as a means of preventing cancers related to obesity, including postmenopausal breast cancer, and tobacco prevention as a means of reducing lung cancer rates (Healthy Delaware, 2020).

The plan outlines a number of goals and objectives aimed at addressing breast cancer in Delaware, particularly through increased screening efforts, including:

- Decreasing the number of late-stage breast cancer diagnoses by 50 percent
- Reimbursing screening for Delawareans who meet age and income eligibility guidelines
- Providing breast cancer screening services to rarely/never-screened women through expansion of mobile screening services and targeted health education services
- Collaborating with breast cancer screening programs to ensure use of the National Program of Cancer Registries (NPCR) data for public health and surveillance research purposes

While the plan does not outline strategies to specifically address cancer burdens among Black women, the plan outlines a goal to identify barriers to obtaining cancer screening and develop programs and services to assist in eliminating these barriers in at-risk and underserved populations. Although the methods used to identify these barriers are unclear and the “underserved communities” are undefined, this goal may demonstrate some degree of commitment to addressing racial health inequities.

Cancer Plan for New Jersey

The New Jersey Comprehensive Cancer Control Plan is authored by the New Jersey Department of Health. The most recent New Jersey plan covered the time period of 2013 to 2018 (New Jersey Department of Health). At the date of publication of this report, an updated cancer plan has not yet been released. Within the Comprehensive Cancer Control Plan, the breast cancer work group focused on improving public awareness and education for those at higher risk of breast cancer. The most recent cancer plan included the following goals

- Reduce the female breast cancer death rate to 23.5 per 100,000 population
- Reduce the incidence rate of late-stage female breast cancer to 43.7 per 100,000 population
- Increase the proportion of women (ages 50 to 74) who receive a breast cancer screening based on guidelines (New Jersey Department of Health)

The New Jersey state plan did not include specific strategies to address breast cancer among Black women in the state.

State Laws Impacting the Breast Cancer Community

- **Metastatic Step Therapy.** Pennsylvania and Delaware have passed legislation that prohibits the use of step therapy or “fail-first” protocols for advanced, metastatic cancer treatments.
- **Oral Parity.** Pennsylvania, New Jersey and Delaware have passed legislation that ensures patient cost-sharing for oral chemotherapy treatments are no less favorable than the patient cost-sharing for intravenous chemotherapy treatments.

Discussion and Conclusion

The landscape analysis sought to understand the underlying causes for breast cancer inequities across the care continuum among Black women in the Philadelphia MTA, with a focus on systemic issues and SDOH.

Breast Cancer Disease Burden

The data on breast cancer disease burden comparing and contrasting counties to one another, and by race, indicate that breast cancer inequity may be greatest for Black women residing in Philadelphia and Camden Counties.

Camden County is one of three counties reporting high late-stage incidence rates among Black women as well as higher mortality rates compared to white women. In Philadelphia County the racial disparity in mortality rates is amplified because it is home to the majority of Black women over age 45 in the MTA (145,000 of the estimated 266,000 Black women over age 45 (see Table 4). Salem and Cecil Counties stand out because their incidence rates for Black women (163.4 and 200.4) are the highest in the MTA: not only among Black women, but across all demographic groups, irrespective of racial disaggregation. Data are not available on the late-stage incidence rates and mortality rates among Black women in Salem and Cecil because relatively few Black women live in these counties (see Table 5). Salem County also has a lower life expectancy and higher premature age-adjusted mortality. We cannot make the leap to say higher incidence in Salem suggests higher late-stage diagnosis and higher mortality in the absence of disaggregated race data. These data suggest that the condition of Black women in these counties warrants further study, particularly around the linkage to care and treatment stage of the breast cancer continuum of care. Although there is no clear disparity in late-stage incidence, between Black and white women, the disparity in breast cancer mortality becomes abundantly clear, with Black women reporting higher rates than their white counterparts across all counties in the MTA where data is available (see Table 6). This trend holds even in Bucks, Chester, and Delaware Counties, where the breast cancer incidence rates, in situ incidence rates, and late-stage incidence rates are higher among white women than they are for Black women. Even in these places, Black women die from the disease at higher rates than their white counterparts.

Quality of Care

Survivor and undiagnosed Black women's stories convey their experience of poor-quality care, racism, microaggressions and health care discrimination, an already-established and still-pervasive finding in this study. Surprisingly, the lack of awareness about free screening programs was a key finding expressed by women, patient navigators and providers alike. Finally, the challenge of retaining patients with a history of or current psychiatric and behavioral health issues emerged as a more novel finding in the qualitative data portion of this study that warrants further investigation.

Fear of painful screening mammograms, being diagnosed with what many women perceive to be a death sentence, and chemotherapy were found to influence screening, treatment and care seeking. Many survivors interviewed noted being in denial or in shock after first receiving their diagnosis. This is consistent with the literature. For example, Daly and Olopade (2015) noted that the research literature has found a link between fears of a potential cancer diagnosis and delayed follow-up diagnosis and care

(Daly & Olopade, 2015). A systematic review by Jones et al. (2014) found that factors contributing to delays in breast cancer diagnosis and care among Black women include a fear of cancer treatments, fear of being abandoned by one's partner, taboo and stigma (C. E. Jones et al., 2014). While the study was conducted by researchers in the UK, most research included in the review was performed in the U.S.

One observation was that survivors who experienced personally mediated racism and racial microaggressions during their care were more likely to mistrust their providers and not adhere to recommended treatment plans. This was exacerbated among women experiencing care that was inefficient, inaccessible, or not patient-centered (i.e. where they were not being listened to nor their concerns being treated with a level of urgency). Research shows that race likely plays an important role in worse outcomes among Black women, and 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 more treatment delays compared to white women, with Black women experiencing a longer duration from the first symptoms to diagnostic resolution for breast cancer (Hoffman et al., 2011).

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).

Findings from the policy review and qualitative data indicate incongruence between recommendations for screening mammography from national organizations and implementation guidelines in state cancer plans and Breast and Cervical Programs. Further, inconsistent screening guidance, fear, and mistrust of providers and the health system at large could also delay health care seeking, ultimately resulting in late diagnosis. This is a common issue for women pursuing breast cancer screening, given the shifting and evolving guidelines, particularly as these guidelines relate to patient age and whether to pursue a screening mammogram. The USPSTF, a panel of experts that influences which preventive services must be covered without cost sharing in accordance with the Affordable Care Act, has ratings for different preventive services. The USPSTF recommends biennial screening mammograms for women ages 50-74. However, there is not a similar blanket recommendation from the USPSTF for women younger than 50. The USPSTF recommends that beginning biennial screening mammograms before 50 should take individual patient factors into account, such as family history and genetic susceptibility (U.S. Preventive Services Task Force, 2018). Conversely, the American College of Obstetricians and Gynecologists recommends that routine, annual screening mammography begin at age 40 in women of average risk for breast cancer (Committee on Practice Bulletins - Gynecology, Pearlman, Jeudy, & Chelmow, 2017).

Data from the qualitative study are consistent with the notion that these differences in recommendations make it difficult to have consistent messaging across the MTA. Community members and providers shared that they have some familiarity with the guidelines, but the guidelines have recently changed and community members are uncertain of some of the nuance of the guidelines. In particular, the recommendation to screen up to 10 years early when familial risk is identified is hard to comply with because cancer history is not always shared among family members.

In addition to screening guidelines from important national task forces and professional academies, variation at state levels can add to the confusion among patients, community members and providers. For example, the state-level National Breast and Cervical Cancer Early Detection Program and Breast and Cervical Cancer Treatment Programs also vary in their screening mammogram recommendations by age, eligibility and program details, which may lead to confusion among patients and/or providers. This could contribute to a lack of clarity among women about screening guidelines and for which services they may receive coverage. This in turn may impact trust or mistrust of their providers and the healthcare system, particularly if women are frequently crossing state borders or receiving health care information from friends and family in nearby states.

Social Determinants of Health

Data on systemic issues and SDOH along with qualitative data collected from community members suggest that breast health inequities among Black women in the Philadelphia MTA could largely be explained by five factors: 1) fear, denial and economic vulnerabilities, which together influence care seeking and adherence, 2) poor quality care at every stage of the continuum of care that was reported to be inefficient, inaccessible and not patient-centered, 3) a lack of empathic providers with very strong navigation programs who influence treatment adherence among patients, 4) social support and faith beliefs that influence treatment adherence, and 5) personally mediated racism, microaggressions and health care discrimination being correlated with a lack of trust in the health care system and providers deepening retention issues.

Findings from this study around barriers to retention in care also confirm existing research literature on these factors including having no insurance or being underinsured. In the Philadelphia MTA, Black populations have low uninsured rates, suggesting that having insurance alone is not enough to overcome breast cancer inequities. The counties with the highest uninsured rates are in Philadelphia County (10 percent), which is also the county with the largest Black population (43 percent). Focus group participants explained that the type of insurance they had influenced the quality of care received. Overall, these findings largely align with findings from the recent literature. Studies have shown that the insurance type (e.g., private insurance, Medicaid, Medicare) and benefit design structure (i.e., the way the benefits are structured and available to an enrollee) are barriers to timely breast cancer-related services and quality of care (Wharam et al., 2018). Furthermore, the literature shows that among Black breast cancer patients, a woman's insurance type was a significant predictor of mistrust of the medical establishment. Women with Medicaid expressed greater mistrust and suspicion compared to women with private insurance or private insurance and Medicare (Sutton et al., 2019). A study in Chicago found qualitatively 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).

Another finding from this study that confirms existing literature around barriers to retention in care was the undue burden women bear juggling financial and care-giving roles while working at inflexible jobs, making it impossible to successfully engage in optimal care and treatment plans that would require taking time off work. This is aligned with other research in the field (Blinder, Eberle, Patil, Gany, & Bradley, 2017; Nonzee et al., 2015).

Breast cancer inequities across the care continuum in the Philadelphia MTA persist due to irregular screening, poor quality care, experiencing personally mediated racism in health care settings, as well as insufficient patient navigation programs, inadequate strategies to combat paralyzing fear related to a

cancer diagnosis and lack of social support. Taken together, these factors severely reduce the quality of care Black women receive across the cancer care continuum. This study confirms the existence of many well-understood barriers across the care continuum facing Black women. Many of these factors have existing dedicated resources supporting the mitigation of these barriers. However, this study also highlights novel barriers and adds nuance to existing barriers across the care continuum that warrant further research, intervention and new policies that Komen can support. These issues uncovered in Philadelphia, Delaware and Camden counties include: 1) lack of information around unique breast cancer risk factors faced by Black women, 2) lack of awareness of free screening programs, 3) need for culturally competent patient navigator support, 4) tendency to lose patients to follow-up who have current substance use issues or a history of psychiatric issues, 5) patient-provider communication issues, and 6) lack of robust survivorship planning.

Recommendations

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

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

The following recommendations apply this systems framework and address specific changes, strategies, or interventions at the micro, mezzo and macro levels. These recommendations are intended to work in concert and not as discrete changes. Recommendations acknowledge that the systems and their components are relational, non-linear and dynamic. Thus, suggested strategies and interventions should be coordinated with communities, in keeping with Komen's collaborative approach to advance breast health equity for Blacks. This provides a mechanism for community/stakeholder engagement and recognizes the informal and formal systems and networks of social support that are accessed by Black women. These recommendations represent actionable strategies as the bridge between social determinants of health and the breast cancer care experience of Black women.

Micro-Level Strategies

Increase access to culturally responsive patient navigators.

Given the importance of patient-provider communication and the ability of providers to exercise cultural sensitivity, the role of patient navigators as “translators” during health care visits and as a “support system” after the visit is essential. Patient navigators are important members of the clinical care team. They offer expertise in navigating the health care system; and can offer resources to help integrate clinical care with mental health and related support. According to focus group participants, Black patient navigators were highlighted as particularly valued resources. Black patient navigators, more likely to reflect the lived experience of Black breast cancer patients, may serve as a key conduit between patients and their providers. Navigators offer crucial perspectives and enable more culturally relevant care.

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

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

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

Data suggest that in addition to institutionalized racism, Blacks in the Philadelphia 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, Philadelphia County, PA, reports the highest number of race-based incidents, including the highest numbers of Fair Housing Act cases and highest number of Blacks killed by police by a significant margin at 125 cases and eight people. Qualitative findings from this study indicate that historic distrust of the health care system, as well as family and personal experiences of implicit bias, racism and discrimination, both generally and in the health care system impact quality of care received as well as retention in treatment for Black women.

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

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

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

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

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

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

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

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

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

Implement a culturally relevant health promotion campaign intended to increase awareness of free screening.

The breast cancer community may to support a health promotion campaign that is intended to ensure Black women know that free screening mammograms are available, particularly in Philadelphia, Delaware and Camden Counties and how to access them. This campaign should be rigorously evaluated, and if done effectively should demonstrate significant increases in awareness among undiagnosed Black women around these programs. Furthermore, we recommend that AAHEI encourage major treatment centers in the aforementioned counties provide a clinical visit for free so that women can access screening mammograms, as our findings indicate that sometimes having even a small copay can create a barrier to getting screened.

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. The AAHEI project may want to support QI initiatives in the major health systems in the MTA, especially in cities that have large African American 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.

Support a community-based participatory applied research project to explore how to retain breast cancer patients with substance use/mental health issues.

The breast cancer community can support a community-based participatory applied research project that seeks to identify the kind of infrastructure that needs to be built to ensure that cancer treatment systems are equipped to deal with unique challenges presented by patients who have current substance use issues or a history of psychiatric issues. Findings from this study indicate high attrition rates among patients who have current substance use issues or a history of psychiatric issues. CBPR focuses on social, structural and physical environmental inequities through active involvement of community members, organizational representatives and researchers in all aspects of the research process. Therefore, the recommended CBPR project should be an interdisciplinary research team composed of cancer research specialists, behavioral health specialists, patients, navigators and select community service providers. According to Holkup et. al, the strength of this research approach is that partners contribute their expertise to enhance understanding of a given phenomenon and integrate the knowledge gained with

action to benefit the community involved (Holkup, Tripp-Reimer, Salois, & Weinert, 2004). Furthermore, this research framework empowers people by considering them agents who can investigate their own situations. The community input makes the project credible, enhancing its usefulness by aligning it with what the community perceives as social and health goals, and in so doing helps dismantle the lack of trust communities may have in relation to research.

Identify and implement strategies for survivorship planning.

Findings from this study indicate that there is a lack of robust survivorship planning for breast cancer survivors through hospitals. Many survivors reported finding information about survivorship planning through breast cancer support groups. Most breast cancer resources in the MTA are concentrated in Philadelphia County, PA, particularly in the form of breast cancer support groups (36 groups are located in Philadelphia) (see Table 16). Gloucester County, NJ, has the next highest number of resources available with 12 support groups and one cancer coalition. Bucks County, PA, has the fewest number of resources with only one cancer coalition.

Therefore, the breast cancer community may partner with a few major treatment cancer centers in Philadelphia, Camden and Delaware Counties to collaborate with community stakeholders, including cancer research specialists, survivors, navigators and select community service providers to gather their perspectives and actionable insights.

Conduct broader outreach to Black women.

Findings from this study indicate that Black women who aren't connected to churches, sororities, or community-based organizations may not be receiving the outreach and education that they need. Therefore, the AAHEI should support broader outreach to Black women that goes beyond churches, sororities and community-based organizations that serve Black women to reach women who are not engaged in these supportive spaces. Komen encourages the breast cancer community to support innovative outreach education and awareness campaigns with community stakeholders in places that reach a wider audience like supermarkets and other less frequently used avenues.

Macro-Level Strategies

Conduct a root cause analysis relating to healthcare quality.

In Philadelphia County, where the majority of the Black women in the MTA reside, Black-white disparity in mortality rates is noteworthy when examined alongside with qualitative data findings in this study, underscoring that Black women experience diagnosis delays as well as poor quality treatment care (see Tables 6 and 8). This points to some failures in the diagnosis and treatment phases of the breast cancer continuum of care. For these reasons, Komen's AAHEI project may want to invest in a root cause analysis (RCA) process to identify the contributing factors and underlying causes of diagnosis delays and sub-optimal care, as well as the key leverage points where intervention would have a significant impact on reducing breast cancer inequities. By conducting an RCA, stakeholders, including non-health stakeholders, can begin to understand the complexity of this issue in their community. The breast cancer community may want to invite breast cancer survivors, community-led efforts (e.g. workers' unions, non-profits, food banks, community health centers, women's organizations, environmental justice organization etc.), and research centers with long-standing academic-community partnerships to participate in the RCA process. The RCA includes an action planning process to determine how to intervene on key leverage points identified through the RCA. Additionally, the RCA process can spur innovative ideas and strategies guided by best practices for addressing the factors and underlying causes that impact breast cancer mortality inequities in Philadelphia County. Once complete, AAHEI may want to engage in partnerships with the RCA stakeholders and provide grants to implement the RCA action plan among these organizations' respective members and networks.

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

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

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

As an example, breast cancer risk is one area that warrants further investigation, particularly with regard to differences in risk factors by race/ethnicity, that could inform more personalized strategies for breast cancer screening and treatment. In March 2018, the American College of Radiology (ACR) and the Society of Breast Imaging (SBI) recommended that all women, especially Black women (and those of Ashkenazi Jewish descent), have a breast cancer risk assessment no later than age 30 so those at higher

risk can be identified and their screenings and breast health care be appropriately modified. The societies also made recommendations for modifications to the screening approach for women with specific risk factors and/or at higher risk of developing breast cancer; modifications included changes to the age at which screening should start, as well as the frequency and modality (mammography, ultrasound, MRI, etc.) of screening.

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

Advocate for expansion of eligibility requirements for free screening programs to improve access.

Evidence from the policy data and qualitative findings indicate that the screening mammography free screening programs are still not accessible to many who need it. As noted previously in this report, national estimates indicate that NBCCEDP serves about 11 percent of women eligible for the program, indicating demand for services may exceed the availability of services through the program. (The Henry J. Kaiser Family Foundation, 2015b). The breast cancer community may support lobbying to advocate for the expansion of this program so that these free screenings are more accessible and available outside of traditional poverty lines. In addition, these programs need to have extended hours so that women who can't easily take time off of work to get screened can do so outside of normal business hours. Komen could provide an important and influential voice to expand the reach of early screening and detection services in the Philadelphia MTA by leading advocacy efforts, phone campaigns, letter writing campaigns, lobbying days with state lawmakers, etc. Komen AAHEI could engage local community members and local community partners for these advocacy efforts.

This landscape analysis report conveys comprehensive issues facing Blacks in the AAHEI MTAs. The JSI and Komen AAHEI teams led the methodology, analysis and recommendations development. However, these recommendations are intended to be a call to action for all community-based organizations, policymakers, hospitals, health care 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 25. PHILADELPHIA 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
New Castle County, DE	25%	45	0.39	30%
Cecil County, MD	7%	51	0.22	31%
Burlington County, NJ	16%	51	0.20	34%
Camden County, NJ	19%	56	0.61	39%
Gloucester County, NJ	10%	36	0.20	34%
Salem County, NJ	13%	52	0.61	34%
Bucks County, PA	4%	53	0.08	32%
Chester County, PA	6%	46	0.13	30%
Delaware County, PA	21%	72	0.40	34%
Montgomery County, PA	9%	50	0.15	30%
Philadelphia County, PA	43%	70	0.92	40%

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

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

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

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

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

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

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

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

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

Housing-cost burden: A measure to indicate the proportion of renters and homeowners that spend 30 percent or more of their total income on housing. Calculated by the 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 percent or more of their total income on housing (numerator) divided by the total number of households (denominator) (Office of Policy Development and Research (PD&R), 2019).

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

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

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

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

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

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

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

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

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

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

Mortality rate: A measure of death calculated by the National Cancer Institute using SEER and National Vital Statistics System (NVSS) data. Calculated by SCP using the following formula: the number of

individuals in an area who died during a one-year period (numerator) divided by the total number of individuals living in that area (denominator). Expressed in terms of number of deaths per 100,000 individuals per year (National Cancer Institute).

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Appendix C. Focus Group Guides

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

Step 1: Introduction of project and confidentiality

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

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

JSI is working with Susan G. Komen®, a leading breast cancer foundation, to understand the reasons behind the differences in breast cancer [late-stage] diagnosis and mortality among Black women across 11 US metropolitan areas. Research has found that Black women are less likely to be diagnosed early, when breast cancer is more treatable, as compared to white women and other races. Black 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 Black 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 to reduce late-stage breast cancer diagnosis and mortality in the Black 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 Black 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?

a. 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?

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

PROBES TO USE AS NECESSARY:

2. *Explore the influence of:*
 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 Black women*
 15. *Racism, bias, segregation and the inability to get the care they need*

4. What do you think is driving higher rates of breast cancer deaths among Black women in [insert name of metro]? Does this information surprise you?

PROBES TO USE AS NECESSARY:

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

5. *Trust/mistrust of the medical system*
6. *Historical, institutional racism*
7. *Access to care, including specialists*
6. *Financial cost and time of follow-up testing and diagnosis*
 - a. *Financial cost of treatment and time for treatment*
1. *Quality of screening and diagnosis for Black women*
2. *Racism, bias, segregation and the inability to get the care they need*

3. Which screening guidelines do you use with your patients?

PROBES TO USE AS NECESSARY:

4. *What screening recommendations do you give to your Black patients? How often do you share screening guidelines?*
 5. *How does it differ, if at all, from other types of patients?*
 6. *Do you routinely have conversations with your patients about risk factors for breast cancer? With younger, Black patients? If so, does this information influence your recommendations for screening?*
7. What factors promote (or encourage) regular screening among Black women?

PROBES TO USE AS NECESSARY:

8. *Explore the influence of:*
 - i. *Providers, staff: temperament, cultural competency, kind, respectful*
 - ii. *Special programs and services that are culturally competent*
 7. *Services meeting women where they are/mobile services*
 - a. *Process and systems: forms, wait time, referrals, timely, follow-up*
 - b. *Overall environment: location, privacy, welcoming, feels safe*
 - c. *Accessibility: easy to reach, timely*
 - d. *Other factors in the community*
- e. What are the barriers or factors that may prevent Black women from getting screened regularly?

PROBES TO USE AS NECESSARY:

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

5. *Competing priorities*
6. *Social determinants of health*
7. *Racism, bias, segregation*
 8. *Can you tell me a little more about the relationship between the Black and your hospital/practice?*
 9. *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?*

10. Please describe your process and strategies for getting Black women who have been diagnosed with breast cancer linked to and retained in treatment?

PROBES TO USE AS NECESSARY:

11. *Do you refer to a specialist? How do you support second opinions? ASK ONLY IF PCP*
9. *How do you engage the patient in the decision-making process?*
 - a. *How do they handle/address questions from the patient and/or family about treatment options?*
 1. *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?*
 2. *How do you approach the topic of clinical trials?*
3. *What are the factors that make it easier for Black patients to be connected to and retained in treatment?*

PROBES TO USE AS NECESSARY:

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

2. *Financial Cost of Treatment and Time for Treatment*

3. What are the barriers that hinder Black women from being connected to and retained in treatment?

PROBES TO USE AS NECESSARY:

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

12. What may make Black women choose not to seek treatment even if they have health insurance and available providers?

PROBES TO USE AS NECESSARY:

13. *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,*
 - a. *Overall environment: location, privacy, welcoming, feels safe*
 1. *Accessibility: easy to reach, timely*
 2. *Comprehensives: are they receiving the basics + cutting edge*
 3. *Social Determinants of Health*
 4. *Faith practices*
 5. *Family dynamics (getting at spousal and familial support)*
 6. *Trust/mistrust of the medical system*
 - b. *Fear of pain, losing hair, etc*
 - c. *Access to care, including specialists*
 - d. *Financial Cost of Treatment and Time for Treatment*

e. What types of support services, if any, are Black women breast cancer survivors directly referred to?

PROBES TO USE AS NECESSARY:

- f. *How adequate are the levels of support and services?*
 - g. *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.?*
 - h. What are the existing resources in place to leverage and reduce breast cancer disparities among Black women in [insert name of metro]?
3. 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 Black women across 11 US metropolitan areas. Research has found that Black women are less likely to be diagnosed early, when breast cancer is more treatable, as compared to white women and other races. Black 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 Black 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 Black community. These discussions allow us to gather information from different groups to better understand what steps can be taken so that Black 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*

- a. 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 Black 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 Black women.

- b. 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:

- c. *Where have you faced discrimination because of your race?*

4. *Healthcare system*

a. *Transportation*

b. *Work*

5. *Housing*

a. *Education/School*

b. *General profiling (e.g., grocery store, mall, police, etc.)*

1. *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.*

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

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

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

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

6. *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?*

7. *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?*

- c. How has discrimination or racism affected your health?

PROBES TO USE AS NECESSARY:

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

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

2. *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.

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

PROBES TO USE AS NECESSARY

4. *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.*
- e. *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]*
6. *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?*
- c. *Were there times you felt uncomfortable or unable to access screening?*
- d. *Did you feel you had enough time to ask questions and/or absorb information?*
- e. *Did you feel you were treated with less courtesy or respect than other people?*
- f. *Did you feel you received poorer service than other patients?*
- g. *Did you feel the provider or the staff acted as if they think you are not smart?*
 1. *Did you feel the provider or staff acted as if they are afraid of you?*
 2. *Did you feel threatened or harassed?*
- h. *How old were you the first time you were screened? How often did you go after your first time?*
 1. *Explore the influence of*

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

5. 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

- 6. *How was your breast cancer found?*
- 7. *What diagnostic procedures did you have/were you offered?*
 - a. *As best you can remember, how long did it take to get a diagnosis? What were the challenges?*
 - b. *How did you select a provider/care team?*
 - c. *Were you referred to a breast oncologist? Breast surgeon? Who provided your treatment?*
- 8. *For those who wanted a second opinion, what was that experience like?*
 - a. *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?*
 - 3. *What type of counseling and support was offered? [Include navigation to treatment services]*
 - 4. *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)?*
 - b. *How did you feel throughout the process?*
 - c. *Did you feel you had enough time to ask questions and/or absorb information?*
 - d. *Did you feel you were treated with less courtesy or respect than other people?*

1. *Did you feel you received poorer service than other patients?*
 2. *Did you feel the provider or the staff acted as if they think you are not smart?*
 3. *Did you feel the provider or staff acted as if they are afraid of you?*
 4. *Did you feel threatened or harassed?*
5. Was hormonal therapy (e.g. Tamoxifen, Arimidex, Femara, Aromasin) part of your treatment? If so, was five years or ten years prescribed?
6. *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)*
 7. *PROBE: Did you ever skip a dose or cut the pills in half? If so, why or why not?*
 8. *PROBE: What were the challenges?*
9. Please share some of the factors in the decision to start treatment based on your personal experience or the experience of other Black 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*
5. *Was the decision-making process different for different types of treatment (chemotherapy, surgery, radiation)?*
6. *What may make it difficult for a Black woman in your area to start and continue the full course of breast cancer treatment if they need it?*
7. *What would facilitate the completion of the full course of treatment (for example, a full course of chemotherapy)?*
 8. *Family considerations: Caretaking responsibilities, spousal support*
 10. *Personal/life: Scheduling, time off from work, meeting family responsibilities*
 - a. *Fears: Concerns about the procedure, concerns about side effects of treatment*
 - b. *Faith Practices: Spiritual/religious beliefs*
 - c. *Accessibility: Insurance, easy to reach, distance, affordable costs/co-pays, time off from work*
 - d. *Process and systems: Forms, wait time, referrals, timely, follow-up*
 11. *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*

- a. Overall environment: Location, privacy, welcoming, feels safe
- b. What factors may lead to delays in starting treatment or not completing treatment even if someone has access?

PROBES TO USE AS NECESSARY

- c. *What factors may contribute to a delay in starting treatment? Ending treatment early/discontinuing treatment?*
- d. Family considerations: Caretaking responsibilities, spousal support
1. Personal/life: Scheduling, time off from work, meeting family responsibilities
 2. Fears: Concerns about the procedure, concerns about side effects of treatment
 3. Faith Practices: Spiritual/religious beliefs
 4. Accessibility: Insurance, easy to reach, distance, affordable costs/co-pays, time off from work
 5. Process and systems: Forms, wait time, referrals, timely, follow-up
- e. 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
12. Overall environment: Location, privacy, welcoming, feels safe
- a. Were you offered complementary or integrative medicine options to help with treatment, such as acupuncture, Reiki, nutritional support, etc.?

PROBES TO USE AS NECESSARY

- b. *If used, were these options used to complement traditional cancer treatment, or instead of?*
- c. *If used, were these options recommended? If so, by whom?*
- d. *If used, how were the services beneficial?*
- e. *If they were not beneficial, why not?*
13. 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?*
1. *Did your provider/care team specialize in breast cancer, or did they treat all kinds of cancers?*
 2. *What have you heard or yourself experienced about Black patients' experiences within the healthcare system?*

b. *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?*

c. *Did you have any uncomfortable experiences? What made you uncomfortable?*

1. *Which members do you wish you could have had greater interaction with and why?*

2. *Did you feel you had enough time to ask questions and/or absorb information?*

3. *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.

14. *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

1. *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?*

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

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

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

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

3. *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

4. *What type of resources were available to you (e.g., financial, stress management/healthy living, emotional, spiritual resources)?*
 5. *How did you come to know about these? Did you have to ask?*
 6. *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.?*
 - c. *If used, how were the services beneficial?*
 - d. *If they were not beneficial, why not?*
- e. *Were there times when you felt challenged or unable to access the support, information, or resources you felt you needed? Why?*
 - f. *Would it be useful to have learned about these resources sooner than you did?*
 - g. *At what point would the services have been more useful?*
 - h. *Was there a cost/fee to access any of the resources/information?*
3. What else might be helpful to you or other Black women cancer survivors and their families?

Step 8: Thank you for your participation.

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