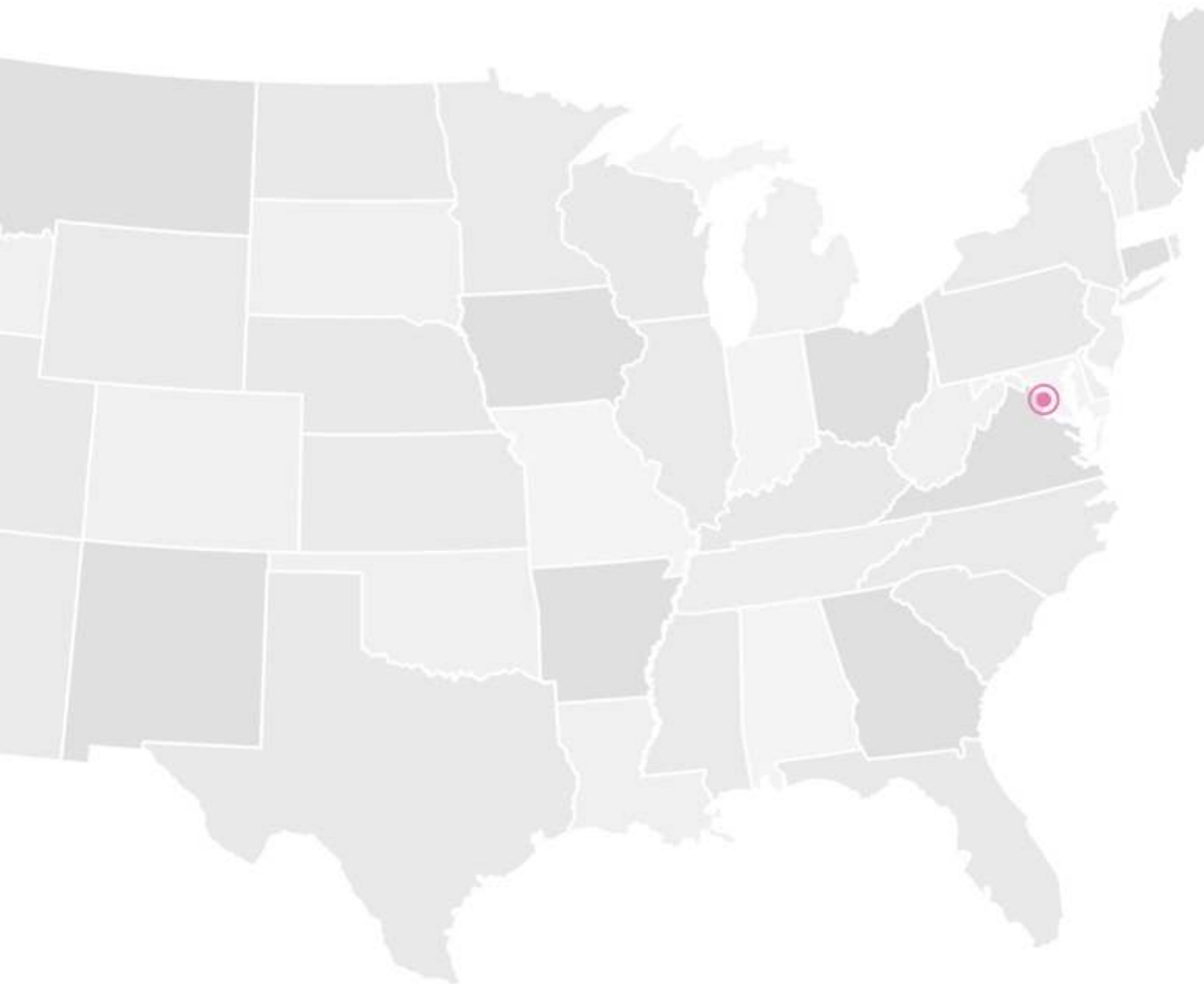


Closing the Breast Cancer Gap:  
A Roadmap to Save the Lives  
of Black Women in America

2021

WASHINGTON, D.C.



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

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



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

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# Executive Summary

## About Susan G. Komen

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

## Background and Purpose

Breast cancer is the most common cancer diagnosed among 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 women and white women. Breast cancer mortality is about 40 percent higher in Black women than in white women.

## 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. – Health Equity Revolution - to improve breast health equity for Black women. Stand for H.E.R. aims to reduce breast cancer disparities in Black women starting in the 10 U.S. metropolitan areas (referred to throughout this report as MTAs or metro) where the inequities are greatest: Atlanta, GA; Chicago, IL; Dallas-Fort Worth, TX; Houston, TX; Los Angeles, CA; Memphis, TN; Philadelphia, PA; St. Louis, MO; Virginia Beach, VA; and Washington, 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 involve a literature scan, compiled quantitative data, reviewed federal and state policies and collected qualitative data from community members and providers to prepare a landscape analysis report for each of the 10 MTAs.

This study does not attempt to establish causality between underlying risk factors and breast cancer outcomes. Rather, the analysis aims to:

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

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

## Key Findings

- Black women in the MTA are consistently more likely to die from the disease compared to white women.
- As with breast cancer mortality, there is a clear racial disparity for late-stage diagnosis. The late-stage breast cancer incidence rate among Black women in the MTA is higher than the rates for white women in five of the nine counties in the MTA, and highest in Prince George’s County, MD and Washington, D.C., where over 50 percent of Black women live.
- Arlington County stands out as unique with the highest breast cancer mortality rates among Black women compared to white women. Overall, the data on breast cancer disease burden, comparing and contrasting across counties and by race suggests that the disease is most fatal for Black women who live in Arlington County, VA, Washington, D.C. and Prince George’s County, MD and least fatal for white women living in Arlington County, VA.
- This is despite the fact that Black women are more likely to have had a screening mammogram or clinical breast exam compared to white women in both locations. In Washington, D.C. and Prince George’s County, MD, where the majority of Black women over 45 reside in the MTA, Black women are more likely to be diagnosed with breast cancer, at later stages and are more likely to die than their white counterparts.
- Decades of discriminatory practices have led to striking segregation in the National Capital MTA. The National Capital MTA is segregated across a number of dimensions, including race and socioeconomic factors, creating stark contrasts by geography.
- In addition to the MTA as a whole 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, with Washington, D.C. being an area of concentrated disadvantage. The data suggest breast health inequities among Black women in the National Capital 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 National Capital Area 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.
- Fund Black-specific support groups, particularly in Prince George's County, MD.
- Increase education about family health history in the community to identify high-risk families and offer genetic counseling and testing and breast cancer screening to meet the need.
- To implement a culturally relevant health promotion campaign intended to increase knowledge of current screening guidelines.

#### Mezzo-Level Strategies

- Increase access to integrated care, including mental health services, to improve the breast cancer care experience.
- Support Quality Improvement (QI) initiatives along the breast cancer continuum of care.
- Conduct a root cause analysis relating to delays in breast cancer diagnosis.

#### Macro-Level Strategies

- Advocate against requirements for a primary care physician referral for screening mammograms.
- Influence the state cancer plans to address structural barriers.
- Advocate for financial compensation for community health workers.
- Support financial assistance programs.
- Ensure a racial-equity lens in the collection and dissemination of core breast health measures.
- Fund collective impact initiatives at the community level to address root causes of breast cancer disparities.

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

## About Susan G. Komen

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

## Introduction

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

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

Black women are, on average, 40 percent more likely to die of the disease as compared to white women (Howlader et al., 2018). The five-year breast cancer survival rate for Black women is 83 percent as compared to 92 percent for white women (Howlader et al., 2020). However, while overall breast cancer incidence among Black women is lower than among white women, 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 Stand for H.E.R., Komen seeks to improve breast health equity by reducing late-stage diagnosis and mortality for Black women in the 10 U.S. metropolitan areas (referred to throughout this report as MTAs or metro) where Black women 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 Stand for H.E.R., Komen engaged JSI, a public health research and consulting organization, to conduct a landscape analysis in each MTA to better understand the underlying causes of breast cancer inequities across the care continuum among Black women. Findings from each landscape analysis report serve to inform the design and implementation of Komen’s long-term and cross-sector collaborative efforts as well as serve as a call to action for all community-based organizations, policymakers, hospitals, healthcare providers, faith-based organizations, civic leaders and citizens to engage in evidence-informed strategies to reduce breast cancer disparities among Black women.

## Project Objectives

The specific objectives of the landscape analysis are:

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

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

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

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

- 1) elevate key findings regarding the underlying causes for breast cancer inequities across the care continuum among Black women, and
- 2) offer insights that can inform strategic discussions about strengths, gaps, challenges and opportunities to promote breast health equity and create community- and systems- level change.

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

# Methods

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

This study defines the National Capital MTA in accordance with the U.S. Office of Management and Budget’s 2015 definition of the “central counties” surrounding the city of Washington, D.C. In addition to Washington, D.C., this area comprises Montgomery and Prince George’s counties in Maryland; Arlington, Fairfax, Fauquier, Loudoun, Prince William and Stafford counties in Virginia; and the cities of Alexandria, Fairfax, Falls Church, Manassas and Manassas Park in Virginia. Data are unavailable at this unit of geographic specificity, so researchers collected and analyzed data at the county- and county-equivalent-level for most indicators. State- and national-level data were collected for measures related to breast cancer disease burden to provide additional points of comparison (Office of Management and Budget, 2010; U.S. Census Bureau).

**TABLE 1. NATIONAL CAPITAL METRO AREA DATA METHODS AND SOURCES**

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

target population	Number of African American Women over age 45	<a href="#">American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)</a>
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### Social Determinants of Health

Subcategory	Indicator	Source
social vulnerability	Social Vulnerability Index Score	<a href="#">2016 Social Vulnerability Index (US Centers for Disease Control and Prevention)</a>
economic security	Percent of Population that is Uninsured	<a href="#">American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)</a>
economic security	Percent of Population Below 200% FPL	<a href="#">American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)</a>
economic security	Percent of Black Women over age 45 who live Below Poverty Level	<a href="#">American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)</a>
food security	Location of Food Deserts	<a href="#">2019 Food Access Research Atlas (US Department of Agriculture, Economic Research Service)</a>
food security	Percent of Population that is Food Insecure	<a href="#">2019 County Health Rankings (County Health Rankings)</a>
food security	Percent of Total Population with Limited Access to Healthy Foods	<a href="#">2019 County Health Rankings (County Health Rankings)</a>
food security	Percent of Black Households Receiving SNAP/EBT	<a href="#">American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)</a>
education	Percent of Population over age 25 that has High School Degree or Higher	<a href="#">American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)</a>
education	Percent of Population over age 25 that has Bachelor's Degree or Higher	<a href="#">American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)</a>
education	Percent of Black Women over age 25 without a High School Degree	<a href="#">American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)</a>
transportation	Percent of Households without a Vehicle	<a href="#">American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)</a>
transportation	Percent of Total Population Commuting more than 45 Minutes to Work	<a href="#">American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)</a>
transportation	Percent of Total Population that Commutes to Work using Public Transportation	<a href="#">American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)</a>
transportation	Percent of Population Commuting to Work by Foot/Bike/Other	<a href="#">American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)</a>
housing stability	Percent of Households that are Housing-Cost Burdened	<a href="#">2016 Comprehensive Housing Affordability Strategy dataset (US Department of Housing and Urban Development)</a>
housing stability	Proportional Change in Population with a Bachelor's Degree or Higher	<a href="#">American Community Survey 2013-2017 5-Year Estimates (US Census Bureau); American Community Survey 2008-2012 5-Year Estimates (US Census Bureau)</a>
housing stability	Percent Change in Median Household Income	<a href="#">American Community Survey 2013-2017 5-Year Estimates (US Census Bureau); American Community Survey 2008-2012 5-Year Estimates (US Census Bureau)</a>
segregation	Black/White Dissimilarity Index Score	<a href="#">2019 County Health Rankings (County Health Rankings)</a>
racism	Number of Hate Crimes Committed with a Race/Ethnicity/Ancestry Bias Motivation	<a href="#">2017 Hate Crime Statistics (Federal Bureau of Investigation, Uniform Crime Reporting)</a>
racism	Number of Fair Housing Act Cases Filed with a Race Basis	<a href="#">Fair Housing Act Cases dataset (US Department of Housing and Urban Development, Office of Fair Housing and Equal Opportunity)</a>
racism	Number of Blacks Killed by Police	<a href="#">The Counted Database (The Guardian)</a>

### Health and Wellness

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

### Health Systems

Subcategory	Indicator	Source
primary care	Percent of Total Population that is Medically Underserved	<a href="#">HRSA Data Warehouse (US Department of Health and Human Services, Health Resources &amp; Services Administration)</a>
primary care	Number of PCPs	<a href="#">2019 County Health Rankings (County Health Rankings)</a>
primary care	Persons per PCP	<a href="#">2019 County Health Rankings (County Health Rankings)</a>
primary care	Number of "Other" PCPs	<a href="#">2019 County Health Rankings (County Health Rankings)</a>
primary care	Persons per "Other" PCP	<a href="#">2019 County Health Rankings (County Health Rankings)</a>
primary care	Number of Private PCPs	<a href="#">HRSA Data Warehouse (US Department of Health and Human Services, Health Resources &amp; Services Administration)</a>
primary care	Location of FQHCs	<a href="#">HRSA Data Warehouse (US Department of Health and Human Services, Health Resources &amp; Services Administration)</a>
primary care	Location of Hospitals	<a href="#">HRSA Data Warehouse (US Department of Health and Human Services, Health Resources &amp; Services Administration)</a>
cancer care	Location of Comprehensive Cancer Centers	<a href="#">National Cancer Institute</a>
cancer care	Location of Screening mammography Facilities	<a href="#">American College of Radiology</a>
cancer care	Location of Treatment Facilities	American College of Surgeons; Association of Community Cancer Centers
cancer care	Location of NCORP Sites	<a href="#">National Cancer Institute</a>
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	<a href="#">2017 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</a>
incidence	Age-Adjusted Incidence Rate	<a href="#">2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</a>
incidence	5-year Incidence Rate Trend Direction	<a href="#">2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</a>
incidence	Age-Adjusted Incidence Rate for White Women	<a href="#">2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</a>
incidence	5-year Incidence Rate Trend Direction for White Women	<a href="#">2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</a>
incidence	Age-Adjusted Incidence Rate for Black Women	<a href="#">2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</a>
incidence	5-year Incidence Rate Trend Direction for Black Women	<a href="#">2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</a>
in situ incidence	Age-Adjusted In Situ Incidence Rate	<a href="#">2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</a>
in situ incidence	5-year In Situ Incidence Rate Trend Direction	<a href="#">2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</a>
in situ incidence	Age-Adjusted In Situ Incidence Rate for White Women	<a href="#">2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</a>
in situ incidence	5-year In Situ Incidence Rate Trend Direction for White Women	<a href="#">2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</a>
in situ incidence	Age-Adjusted In Situ Incidence Rate for Black Women	<a href="#">2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</a>
in situ incidence	5-year In Situ Incidence Rate Trend Direction for Black Women	<a href="#">2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</a>
late-stage incidence	Age-Adjusted Late-Stage Incidence Rate	<a href="#">2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</a>
late-stage incidence	Average Count of Cases that are Late-Stage	<a href="#">2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</a>
late-stage incidence	Age-Adjusted Late-Stage Incidence Rate for White Women	<a href="#">2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</a>
late-stage incidence	Average Count of Cases that are Late-Stage for White Women	<a href="#">2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</a>
late-stage incidence	Age-Adjusted Late-Stage Incidence Rate for Black Women	<a href="#">2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</a>
late-stage incidence	Average Count of Cases that are Late-Stage for Black Women	<a href="#">2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</a>
mortality	Age-Adjusted Mortality Rate	<a href="#">2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</a>
mortality	5-year Mortality Rate Trend Direction	<a href="#">2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</a>
mortality	Age-Adjusted Mortality Rate for White Women	<a href="#">2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</a>
mortality	5-year Mortality Rate Trend Direction for White Women	<a href="#">2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</a>
mortality	Age-Adjusted Mortality Rate for Black Women	<a href="#">2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</a>
mortality	5-year Mortality Rate Trend Direction for Black Women	<a href="#">2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</a>
screening mammography	Percent of Women Getting Mammograms	<a href="#">2017 County Level Modeled Estimate Combining BRFSS and NHIS (US Centers for Disease Control and Prevention; State Cancer Profiles; National Institutes of Health)</a>

## Qualitative Data

In the National Capital MTA, a total of eight focus groups were conducted with 50 community members participating. One of the eight focus groups were with six community health workers and/or patient navigators in Washington, D.C. and Prince George’s County. In addition, two provider interviews were conducted.

Table 2 summarizes the demographic characteristics of 50 focus group participants, representing both breast cancer survivors and the undiagnosed. Among breast cancer survivors, the majority were above 55 years of age with private insurance (72.4%) and had been diagnosed with stage 1 breast cancer (48.3%). Undiagnosed women were younger, mostly in the 35-54 age group, with the majority reporting access to private insurance (66.7%). Non-provider participants were Black. Demographics were not collected for community health workers, patient navigators or clinical providers.

**TABLE 2. NATIONAL CAPITAL METRO AREA QUALITATIVE DATA COLLECTION**

Variable Name	Breast Cancer Survivors (n=29)	Undiagnosed Women (n=21)
<b>Age</b>		
18-24 years	0.0%	0.0%
25- 34 years	0.0%	19.0%
35-44 years	3.4%	28.6%
45-54 years	13.8%	38.1%
55-64 years	51.7%	9.5%
65-74 years	24.1%	0.0%
75 and above	6.9%	4.8%
<b>Zip codes</b>		
	Breast Cancer Survivors (n=29)	Undiagnosed Women (n=21)
20002	N/A	9.5%
20012	N/A	4.8%
20018	N/A	9.5%
20707	N/A	9.5%
20737	N/A	4.8%
20815	N/A	9.5%
20874	N/A	4.8%
20877	N/A	4.8%
21229	N/A	4.8%
22025	N/A	4.8%
20011	10.7%	9.5%
20019	3.6%	4.8%
20774	3.6%	4.8%
20748	3.6%	4.8%
20772	7.1%	4.8%
20720	7.1%	4.8%

20017	3.6%	N/A
20001	3.6%	N/A
20005	3.6%	N/A
20009	3.6%	N/A
20020	3.6%	N/A
20021	3.6%	N/A
20024	3.6%	N/A
20504	3.6%	N/A
20721	3.6%	N/A
20740	3.6%	N/A
20746	3.6%	N/A
20769	3.6%	N/A
20784	3.6%	N/A
20904	3.6%	N/A
20906	3.6%	N/A
20910	3.6%	N/A
21403	3.6%	N/A
22193	3.6%	N/A

<b>Insurance Status</b>	<b>Breast Cancer Survivors (n=29)</b>	<b>Undiagnosed Women (n=21)</b>
I don't have health insurance	0.0%	0.0%
Medicaid	13.8%	19.0%
Medicare	31.0%	9.5%
Military Healthcare	0.0%	4.8%
Private Insurance	72.4%	66.7%
Through my parents	0.0%	0.0%
Not sure	0.0%	0.0%

<b>Ever been screened for breast cancer</b>	<b>Breast Cancer Survivors (n=29)</b>	<b>Undiagnosed Women (n=21)</b>
Yes	N/A	71.4%
No	N/A	28.6%

<b>Type of breast cancer screening or assessment</b>	<b>Breast Cancer Survivors (n=29)</b>	<b>Undiagnosed Women (n=21)</b>
Clinical breast exam	81.5%	25.0%
Mammogram	92.6%	56.3%
3D Mammogram	66.7%	43.8%
Breast self-exam	70.4%	37.5%

Other	18.5%	0.0%
<b>Stage of breast cancer at diagnosis</b>	<b>Breast Cancer Survivors (n=29)</b>	<b>Undiagnosed Women (n=21)</b>
Stage 0	10.3%	N/A
Stage 1	48.3%	N/A
Stage 2	27.6%	N/A
Stage 3	17.2%	N/A
Stage 4	6.9%	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 National Capital MTA using secondary data, as well as relevant findings from the qualitative data.

## Demographics

The National Capital MTA is a fourteen-county region in the Mid-Atlantic that is centered around Washington, D.C., the capital of the United States. The MTA spans two states and one federal district and is home to 5.3 million people. Its population is 52 percent white and 27 percent Black (see Table 3).

More than 20 percent of all residents of the National Capital MTA (1.1 million people) live in Fairfax County, Virginia (VA) (see Table 4), with another 20 percent of the region's population (1 million people) residing in Montgomery County, Maryland (MD). The 670,000 residents of Washington, D.C. represent 13 percent of the MTA's total population. The other 47 percent of the region's population is spread across 11 other counties and county-equivalents in the MTA: Prince George's County, MD, Alexandria City, VA, Arlington County, VA, Fairfax City, VA, Falls Church City, VA, Fauquier County, VA, Loudoun County, VA, Manassas City, VA, Manassas Park City, VA, Prince William County, VA and Stafford County, VA. Refer to Table 4 for demographic information specific to each county and county-equivalent within the MTA. The number of Black women over age 45 is noted for each county and county-equivalent 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). Almost two-thirds of all Blacks who live in the MTA (approximately 893,000 Blacks) live in Prince George's County, MD, and Washington, D.C.

**TABLE 3. NATIONAL CAPITAL METRO AREA DEMOGRAPHICS**

<b>Gender</b>	
Male	49%
Female	51%
<b>Age</b>	
Under Age 18	23%
Age 18-64	65%
Over Age 65	12%
<b>Race/Ethnicity</b>	
White	52%
Black	27%
Asian	11%
American Indian or Alaska Native	0%
Native Hawaiian or Other Pacific Islander	0%
Some Other Race	6%
Two or More Races	4%
Hispanic/Latino	17%
White not Hispanic	43%
Minority Race	48%
<b>Number of Black Women Over Age 45</b>	306,293
<b>Total Population</b>	5,272,803

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

**TABLE 4. NATIONAL CAPITAL 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
Washington, D.C.	672,391	53%	48%	74,818
Montgomery County, MD	1,039,198	52%	18%	37,675
Prince George's County, MD	905,161	52%	63%	134,391
Alexandria City, VA	154,710	52%	22%	6,043
Arlington County, VA	229,534	50%	9%	3,894
Fairfax City, VA	23,580	51%	5%	175
Fairfax County, VA	1,142,004	50%	10%	20,808
Falls Church City, VA	13,843	51%	5%	239
Fauquier County, VA	68,406	51%	8%	1,253
Loudoun County, VA	374,558	50%	8%	4,983
Manassas City, VA	41,379	50%	13%	963
Manassas Park City, VA	16,117	47%	14%	350
Prince William County, VA	450,763	50%	21%	16,449
Stafford County, VA	141,159	50%	17%	4,252

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

## Breast Cancer Disease Burden in the National Capital MTA

Breast cancer disease burden in the National Capital MTA is 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 this MTA, the likelihood of receiving a breast cancer diagnosis, the stage of diagnosis and the likelihood of death from the disease appear to 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 Maryland, where two of the 14 counties in the MTA are located, the complete prevalence age-adjusted percent is 1.90 percent. In Virginia, where 11 counties in the MTA are located, the complete prevalence age-adjusted percent is 1.86 percent. Prevalence data is also available for Washington, D.C., even though it is not a state. In Washington, D.C., the age-adjusted complete prevalence percentage is 1.97 percent. In all three of these locations, the prevalence percentages are notably higher than the national prevalence of 1.69 percent.

Breast cancer indicators for other measures are available at the county and county-equivalent level. Tables 5-9 describe the breast cancer disease burden in the MTA. Data on breast cancer incidence rates, in situ incidence rates, late-stage incidence rates and mortality rates are all expressed in terms of number of new cases or number of deaths annually per 100,000 individuals. Screening mammography rates, shown in Table 7, 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 Fairfax City, VA, Falls Church City, VA, Fauquier County, VA, Loudoun County, VA, Manassas City, VA, Manassas Park City, VA, or Stafford County, VA, given the small number of Black women residing in these counties.

Breast cancer incidence rates in the MTA range from 89.9 new cases per 100,000 individuals per year in Manassas Park, VA, to 138.1 in Fairfax County, VA (see Table 5). Washington, D.C., has a similarly high incidence rate of 134.6 new cases per 100,000 individuals. Throughout the MTA, breast cancer incidence rates for both Black women and white women are similar to national and state rates. In some counties, the incidence rates are higher among white women as compared to Black women, while the reverse is true in other counties. However, in the places where the majority of the MTA's Blacks reside (Washington, D.C., and Prince George's County), incidence rates are higher among Black women compared to white women. Manassas City, VA, also has a particularly high incidence rate for Black women at 196.3, compared to 114.2 for white women and 120.6 overall. This is notable because Manassas City, VA, has a smaller overall population compared to other counties (~41,000 compared to other counties in the 100s of thousands) and a relatively smaller proportion of their population is Black (14% compared to 48% and 63% in Washington, D.C., and Prince George's County, respectively).

**TABLE 5. NATIONAL CAPITAL 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
Washington, D.C.	134.6	stable	128.4	falling	133.6	stable
Montgomery County, MD	127.4	stable	128.8	stable	129.1	stable
Prince George's County, MD	128.8	stable	106.6	stable	134.0	stable
Alexandria City, VA	115.9	stable	120.2	stable	98.4	stable

Arlington County, VA	131.9	stable	139.0	falling	117.0	stable
Fairfax City, VA	138.1	stable	150.3	stable	*	*
Fairfax County, VA	124.3	stable	132.4	stable	112.8	stable
Falls Church City, VA	124.1	stable	138.7	stable	*	*
Fauquier County, VA	117.0	stable	116.9	stable	118.4	stable
Loudoun County, VA	130.5	stable	133.9	stable	105.4	rising
Manassas City, VA	120.6	stable	114.2	stable	196.3	stable
Manassas Park City, VA	89.9	stable	78.2	stable	*	*
Prince William County, VA	115.6	stable	118.2	stable	102.6	stable
Stafford County, VA	131.6	stable	126.8	stable	139.0	stable
Maryland	131.5	stable	132.2	stable	131.9	stable
Virginia	128.3	stable	128.3	stable	133.1	stable
National	124.2	stable	126.1	stable	124.0	stable

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

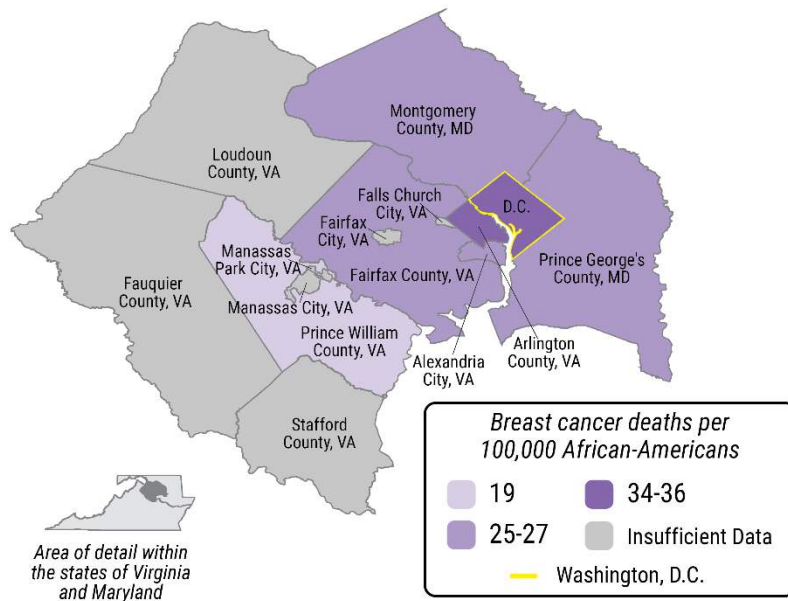
The breast cancer mortality rates are higher for Black women compared to white women in every place in the MTA where data are available (ten counties and county-equivalents). The disparity between Black women and white women is widest in Arlington County, VA, where the mortality rate for white women is 16.0, compared to 36.1 breast cancer deaths per 100,000 Black women. The next largest racial disparity is in Washington, D.C., where the mortality rate for Black women is 33.9, compared to a mortality rate of 19.3 among white women. The lowest overall mortality rates (non-racially-disaggregated) in the MTA are in Loudoun County, VA, and Fairfax County, VA, at 16.6 and 17.1 breast cancer deaths per 100,000 individuals, respectively. Fairfax City, VA, which has the highest incidence of breast cancer in the MTA (138.1) also reports the highest mortality rate in the MTA at 35.0 (see Table 5 Incidence and Table 6 Mortality).

**TABLE 6. NATIONAL CAPITAL 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
Washington, D.C.	27.9	falling	19.3	falling	33.9	stable
Montgomery County, MD	18.2	falling	18.4	falling	25.1	falling
Prince George's County, MD	25.2	falling	21.0	falling	26.6	falling
Alexandria City, VA	22.9	stable	21.6	stable	26.0	stable
Arlington County, VA	18.1	falling	16.0	falling	36.1	stable
Fairfax City, VA	35.0	stable	36.3	*	*	*
Fairfax County, VA	17.1	falling	18.2	falling	26.1	stable
Falls Church City, VA	*	*	*	*	*	*
Fauquier County, VA	23.4	falling	24.0	falling	*	*
Loudoun County, VA	16.6	falling	18.2	falling	*	*
Manassas City, VA	23.0	stable	23.5	*	*	*
Manassas Park City, VA	*	*	*	*	*	*
Prince William County, VA	18.1	falling	18.6	falling	19.3	*
Stafford County, VA	23.0	stable	23.7	stable	*	*
Maryland	22.1	falling	20.6	falling	27.6	stable
Virginia	21.4	falling	20.4	falling	28.8	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)

### MAP 1: NATIONAL CAPITAL METRO AREA BLACK BREAST CANCER MORTALITY RATES



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

As seen in Map 1 (Black Breast Cancer Mortality Rates) and Table 6 (Mortality Rate), the Black breast cancer mortality rate is highest in Arlington County, VA, at 36.1 deaths per 100,000 Blacks, with Washington, D.C., coming close behind at 33.9 deaths per 100,000 Blacks. This is striking, given the relatively moderate breast cancer incidence rate among Blacks in Arlington County (see Table 5) and the county's relatively high screening mammography rate (see Table 7).

These data suggest that even though Black women in Arlington are less likely to be diagnosed with breast cancer than their white counterparts, those who are diagnosed are more likely to die. This pattern has been noted in the literature. A study in South Carolina, for example, found that while the breast cancer incidence rate was higher for European-American or Caucasian women compared to Black women (124 versus 118.5 per 100,000 women), the breast cancer mortality rate was higher for Black women (29.8 versus 21.3 per 100,000 women) (Samson, Porter et al., 2016). The study further reported that Black women were even more likely to have had a screening mammogram or clinical breast exam compared to white women (81.9% of Blacks versus 74% of whites) and more likely to have late-stage breast cancer at the time of diagnosis (47% of Blacks versus 35% of whites).

### TABLE 7. NATIONAL CAPITAL METRO AREA SCREENING MAMMOGRAPHY RATES (WOMEN OVER AGE 40)

	Percent of Women Getting Mammograms
Washington, D.C.	73%
Montgomery County, MD	82%
Prince George's County, MD	74%
Alexandria City, VA	77%
Arlington County, VA	82%
Fairfax City, VA	85%
Fairfax County, VA	80%
Falls Church City, VA	95%
Fauquier County, VA	78%

Loudoun County, VA	85%
Manassas City, VA	79%
Manassas Park City, VA	62%
Prince William County, VA	67%
Stafford County, VA	79%
Maryland	74%
Virginia	82%
National	73%

*Source: 2017 County Level Modeled Estimate Combining BRFSS and NHIS (US Centers for Disease Control and Prevention; State Cancer Profiles; National Institutes of Health); State level directly estimated 2018 BRFSS data (US Centers for Disease Control and Prevention; State Cancer Profiles; National Institutes of Health)*

Racially disaggregated data on screening mammography rates are only available at the state but not county and county-equivalent level. In Maryland, where two of the MTA's counties are located, 84 percent of Black women over age 40 received a screening mammogram in the last two years compared to 75 percent of white women. In Virginia, where 11 of the MTA's counties and county-equivalents are located (including Arlington), 85 percent of Black women over age 40 received a screening mammogram in the last two years compared to 75 percent of white women. In Washington, D.C., 76 percent of Black Women over age 40 received a screening mammogram in the last two years compared to 69 percent of white women. In all three states, Black women over the age of 40 are more likely to have had a screening mammogram in the last two years compared to white women in the same age group. At a county level, the percentage of women receiving a screening mammogram varies greatly throughout the MTA, from 62 percent in Manassas Park City, VA, to 95 percent in Falls Church City, VA (see Table 7). In 12 of the 14 counties, the screening mammography rate meets or exceeds the national average of 73 percent.

**TABLE 8. NATIONAL CAPITAL METRO AREA LATE-STAGE INCIDENCE (PER 100,000)**

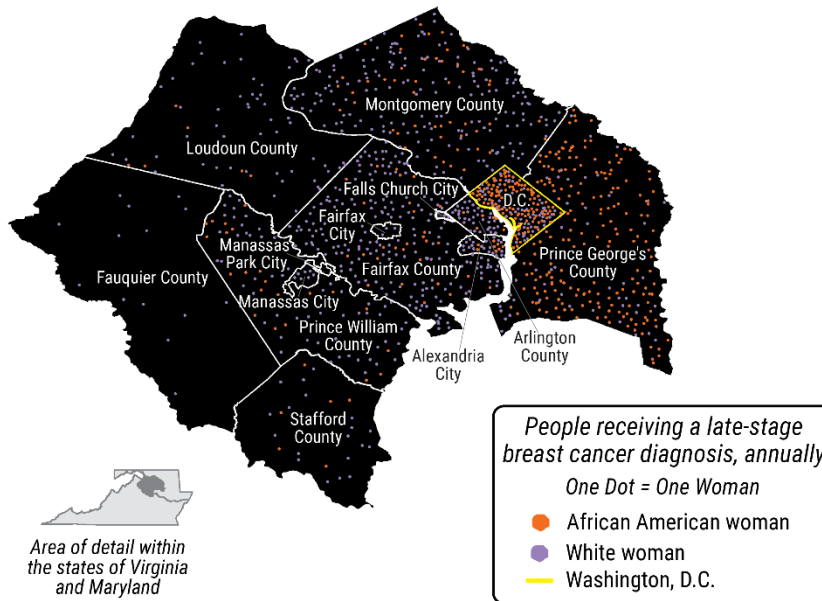
	Age-Adjusted Late-Stage Incidence Rate	Average Count of Cases That Are Late-Stage	Age-Adjusted Late-Stage Incidence Rate for White Women	Average Count of Cases That Are Late-Stage for White Women	Age-Adjusted Late-Stage Incidence Rate for Black Women	Average Count of Cases That Are Late-Stage for Black Women
Washington, D.C.	51.5	179.0	37.6	55.0	62.7	114.0
Montgomery County, MD	49.8	265.0	52.1	174.0	46.0	50.0
Prince George's County, MD	53.0	247.0	38.9	45.0	58.3	189.0
Alexandria City, VA	38.6	30.0	38.7	21.0	42.5	8.0
Arlington County, VA	37.4	43.0	39.4	35.0	46.5	5.0
Fairfax City, VA	35.7	4.0	42.8	4.0	*	*

Fairfax County, VA	43.5	250.0	46.6	181.0	44.4	27.0
Falls Church City, VA	52.3	4.0	56.1	3.0	*	*
Fauquier County, VA	50.2	17.0	47.3	14.0	*	*
Loudoun County, VA	39.8	73.0	40.6	54.0	39.5	6.0
Manassas City, VA	48.7	10.0	46.6	7.0	*	*
Manassas Park City, VA	*	*	*	*	*	*
Prince William County, VA	36.5	81.0	36.2	53.0	40.6	21.0
Stafford County, VA	43.8	30.0	40.8	21.0	52.5	7.0
Maryland	53.1	1633.0	53.1	981.0	55.8	556.0
Virginia	49.2	2080.0	49.1	1478.0	55.1	490.0
National	41.0	78641.0	41.4	62240.0	51.0	11590.0

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

The age-adjusted, late-stage breast cancer incidence rate among all women is highest in Prince George's County, MD, at 53.0, with Washington, D.C., a close second with a rate of 51.5 (see Table 8). Eight of the 14 counties have late-stage incidence rates that fall below both Maryland and Virginia's late-stage incidence rates (53.1 and 49.2, respectively), but only five fall below the national average rate of 41.0. Of the nine places where data are available for both Black and white women, late-stage incidence rates are higher for Black women than for white women in five counties (Washington, D.C., Prince George's County, MD, Alexandria City, VA, Arlington County, VA, Stafford County, VA). There is a large disparity between the average count of cases that are late-stage for Black and white women in Washington, D.C., and Prince George's County, MD. In Washington, D.C., an average of 114.0 cases are late-stage among Black women, while only an average of 55.0 cases are late-stage among white women. In Prince George's County, MD, a very high average of 189.0 cases are late-stage among Black women, while only an average of 45.0 cases are late-stage among white women.

**MAP 2: NATIONAL CAPITAL METRO AREA LATE-STAGE BREAST CANCER CASES**



Map 2 shows the concentration of women who receive a late-stage breast cancer diagnosis annually. Washington, D.C., has a high concentration of late-stage diagnoses, with the majority of the cases being Black women. Arlington County, VA, and Alexandria City, VA, also have a high concentration of late-stage diagnoses, the majority of which are among white women. The counties and county-equivalents surrounding Washington, D.C., have moderate concentrations of late-stage diagnoses, while places farther away from Washington, D.C., have

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

much lower concentrations of late-stage diagnoses, reflecting the region’s population density.

**TABLE 9. NATIONAL CAPITAL METRO AREA BREAST CANCER IN SITU INCIDENCE (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
Washington, D.C.	42.1	falling	45.2	stable	37.9	stable
Montgomery County, MD	35.4	stable	36.7	stable	30.8	rising
Prince George's County, MD	29.8	falling	23.2	falling	31.8	stable
Alexandria City, VA	33.5	stable	33.9	stable	30.3	stable
Arlington County, VA	40.2	stable	40.7	falling	34.9	stable
Fairfax City, VA	30.6	stable	34.5	*	*	*
Fairfax County, VA	42.9	stable	44.6	stable	36.1	stable

Falls Church City, VA	80.5	stable	93.9	stable	*	*
Fauquier County, VA	26.5	stable	27.7	stable	*	*
Loudoun County, VA	41.1	stable	43.8	stable	30.9	stable
Manassas City, VA	22.8	falling	24.3	*	*	*
Manassas Park City, VA	*	*	*	*	*	*
Prince William County, VA	31.3	stable	30.8	stable	30.5	stable
Stafford County, VA	39.6	stable	39	stable	47.2	stable
Maryland	33.2	stable	32.2	stable	36.1	stable
Virginia	35.7	stable	34.9	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)*

In situ incidence rates among women for most counties across the MTA are higher compared to the state and national average -- 33.2 for Maryland, 35.7 for Virginia and 28.3 nationally (See Table 9 In Situ Incidence). Falls Church City, VA, has particularly high in situ incidence rates, at 80.5 overall and 93.9 for white women. There is no data available for in situ incidence rates for Black women in Falls Church due to its small Black population. In the nine counties where data are available for both Black and white women, in situ incidence rates are higher for white women in seven of the counties. The greatest racial disparity is in Loudoun County, VA, where in situ incidence rates are 43.8 for white women and 30.9 for Black women.

When multiple measures of breast cancer are examined together, the data underscore how race is associated with breast cancer disease burden. Take the case of Arlington County, VA where Black women appear more likely to receive a screening mammogram after 40 years of age compared to their white counterparts, report a lower incidence compared to their white counterparts, but report a higher late-stage incidence rate and are twice as likely to die from breast cancer. Moreover, comparing breast cancer disease burden data across places and races in the National Capital MTA suggests that the disease is most fatal for Black women who live in Arlington County, VA, and Washington, D.C., while white women living in these same two places face lower mortality rates. In fact, at 16.0 deaths/100,000 white women, Arlington County has the lowest breast cancer mortality rate in the MTA.

A recent analysis at Washington Hospital Center in Washington, D.C., found that Black women were presenting with advanced breast cancer at rates almost double the national average; many of these women also had health insurance coverage (MedStar Washington Hospital Center Blog Team, 2016; Sun, 2014). Research from other parts of the country may shed light on why the observed patterns exist. Tammemagi et al, for example, examined a cohort from a large health system in Detroit, Michigan, for

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

## Community Member Perspectives across the Breast Cancer Care Continuum

This section summarizes perspectives from community members and health care providers collected through focus group discussions and interviews, which provide additional insights at each phase of the breast cancer continuum of care in the National Capital MTA. Based on a review of the quantitative findings, priority counties for qualitative data collection in the National Capital MTA were identified as: Washington, D.C. and Prince George's County, MD. These locations have the highest breast cancer disease burden, high social determinants of health burden and score poorly on other health measures. Further, these locations have the highest proportion of Blacks in the county. The themes shared below represent the perspectives of community members from these two locations, not the entire National Capital 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). Screening mammography rates in the MTA are above the national average in all but two counties in the MTA, both of which are in Virginia. Although the data are not disaggregated by race, focus group participants' perspectives gives some indication of the experiences of Black women seeking and obtaining breast cancer screening.

**Screening guidelines.** Overall, community members were aware of the screening guidelines from the American Cancer Society indicating that 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.

*"People are confused, and I think it's because there's been so many mixed messages sent out there. I mean, a couple of years ago they were saying wait until age 50, and then wait every other year. I think it's been so all over the map that I think all patients are confused." -Provider*

*"I'm not sure if the standards are actually right for Black women. I think breast cancer [among Black women] is actually different than breast cancer [among White women] and that we should have different standards. We have different physiology and I don't think we know enough about our Black physiology to do the right thing by us and the doctors are giving us information that works on white women because that's where the research has been done." -Survivor*

**Referrals.** Patient navigators and health care providers noted that changes to the referral process act as a barrier to getting mammograms. Local radiology facilities are now requiring referrals for mammograms, which requires a visit to a primary care physician (PCP). This results in more time and additional costs for those who have a PCP and poses a barrier for those who do not.

*“Then, now, you've got to make an appointment with your primary care doctor. Who knows when that will be, if it's a busy provider to get the order. Then, to take time out again to go and get the screening mammogram. I just think those are barriers. Our center just implemented that, and I really fought them on it.” - Provider*

*“I'm dealing with a young lady who started a new job, who doesn't have insurance, or it doesn't kick in until 90 days or whatever it is. I made an appointment for her to see a PCP. She doesn't even have a primary care physician and she wanted to know why she couldn't get screened right away. You first have to have a primary care physician to refer you to get a screening mammogram.” -Patient Navigator*

**Family History.** Komen encourages knowing what's normal for you and paying close attention to any changes to report to your PCP. In the focus groups, several participants indicated that they screened early due to knowledge of familial breast cancer history. However, others noted how this is only possible if an individual is aware of their family history. African immigrants indicated that family medical history is frequently unknown because the cause of death is seldom discussed among family members, or because autopsies are not performed in their home countries. Other Black participants noted that cancer is not openly discussed, family members did not disclose their cancer diagnosis, and, as such, the next generation of women were often unaware of their risk for breast cancer.

*“I got screened simply because there's a history of cancer in my family. My grandmother was diagnosed with breast cancer in her early thirties, my mother in her early thirties, and they both died before they were 50. So, growing up with that dynamic, you know to do your self-examinations and you learn early on a lot about cancer, whether you want to or not.” - Survivor*

*“A lot of us don't know our family history because some of our parents died and grandparents and great grandparents died from cancer. But you don't know that if you don't have any family history because they didn't talk about it and they didn't tell you.” - Survivor*

**Screening for women under 40.** Among the three states that comprise the National Capital MTA, the differences in guidance for those 35-39 years of age could possibly contribute to confusion among both providers and patients. Even women with familial risk factors reported encountering barriers when seeking screenings. Several participants indicated that they sought out services prior to the recommended screening age because they detected a lump or had other symptoms, but they were turned away. The data suggest that medical staff do not see the connections between history and risk, contributing to delays in diagnosis.

*"I've in fact, just today, had a 30-year-old woman who came in today after feeling a lump. Now her father had breast cancer, so when a man has breast cancer, the risk of a BRCA mutation is significantly higher. She said, when she first asked for the screening mammogram, they told her no. Well, she's been diagnosed with breast cancer."-Provider*

*"I was diagnosed at 36, and I went to my OBGYN for my checkup. And, he told me that he doesn't know how he missed conducting a screening mammogram at 35. He does a baseline screening mammogram for all his patients at age 35. He said because he's realized that a lot of women are coming in at age 40, already with breast cancer." - Survivor*

**Fear.** Community members and patient navigators described how fear is a barrier for Black women who should begin getting their screening mammography. Navigators described cases in which the patient, their family and their community circle had been so impacted by cancer over the years that they were reluctant to follow up about an abnormal screening. Survivors described not wanting to share their diagnosis for fear it would disrupt their family lives. Withholding health information from family members may delay when and if women seek treatment, and whether the next generation of women will pay attention to their breast health.

*"I have another friend of mine, she doesn't have breast cancer, but it runs rampant in her family; especially, feminine cancers. She doesn't want to go, she doesn't want to know; I mean, anything medical, she just puts a stop to it and it doesn't make any sense." – Survivor*

*"I was coaching this young woman and she was 32 and had three kids. She was volunteering in the hospital. She had triple negative. She was diagnosed at stage one. We had to convince her even to get that first screening mammogram. About five women had to convince her of that, because she found a lump and shared it with us, but wouldn't even want to get the treatment." - Patient Navigator*

*"What discouraged me from getting my first screening mammogram was everything that every other woman before me said. It hurts. They squeeze your [breast] in that thing. It's gonna mash your breast all down. I was like, 'Oh, I don't want to get my breasts all mashed down. With a metal plate.' That was my fear. That's what instilled the fear in me of getting a screening mammogram. Once I got it, I mean it was mashed, but it wasn't as scary as everybody made it out to be." - Undiagnosed*

## Diagnosis

While screening may be readily available within the National Capital MTA, focus group findings suggest that community members face barriers within the health care system at the diagnosis stage of the

breast cancer continuum of care. Community members reported having to advocate for themselves to get the care that they need.

Community members indicated they experienced barriers with getting a diagnosis after a positive or abnormal screening or seeking a diagnosis when presenting with symptoms. Although mammograms are available for free or at low cost, the costs of diagnostic procedures such as biopsies and scans present a barrier for some women in the MTA. In addition, community members shared that the experience of receiving a cancer diagnosis was not always done in a supportive manner. This, in turn, may be associated with delayed diagnosis, influencing the late-stage diagnosis rates documented earlier in the report.

**Difficulty getting a diagnosis.** Community members and health care providers reported women finding lumps or experiencing other symptoms and seeking breast cancer care. During their care-seeking journey, their symptoms were dismissed or not seen as urgent in nature.

*“Two years ago, I started experiencing my breasts inverting and having pain. I went back and forth to the doctor and I got glowing letters from the radiologist saying that it was just dense tissue, Black women have dense tissue. Finally, in February of last year I said, ‘This is too much. I’m experiencing pain, breasts aren’t supposed to invert. There’s something wrong.’ So I went back, the radiologist had a fit. ‘You were just here two weeks ago. You can’t have another X-ray.’ I said, ‘I don’t care what it is. We’re going to find out what’s wrong with me.’ And so they ordered a biopsy and at that time that’s when it came out that I was stage four breast cancer.” -Living with metastatic breast cancer*

*“I called the number, and they said to me... this was in, probably, June/July. And she said, ‘Well, we can see you in about November.’ And I said, ‘I’m sorry, November’s unacceptable.’ I said, ‘I’ve got this lump, and you need to get me in right away.’ And she said, ‘Oh okay.’ So they finally got me in, and come to find out, after all of that, weeks later, I was diagnosed at Stage Two.” -Survivor*

**High Cost.** Another challenge during this phase of the breast cancer continuum of care appears to be the high costs of the diagnostic procedures. Women who were insured and uninsured alike feared being diagnosed with breast cancer and what that diagnosis would entail in terms of cost and life changes.

*“I got a free screening mammogram, because I have Obamacare. The radiologist came in and said, ‘You have a funky screening mammogram. You have to come back tomorrow to get more diagnostic testing, whether it’s a sonogram, an MRI... a CAT scan or whatever.’ And guess what, the copay is \$2,000. So, the fact that I got the screening mammogram for free, or my insurance covered it, but then it doesn’t cover the diagnostic testing. So, what do I do? I let it go, because I have to feed my kids.” – Survivor*

*“Seventy-seven point three percent (77.3%) of Black women... Black moms are single. Add breast cancer to that equation, what do you have? Can I miss a day at work? Do I*

*have to feed my kids? Who am I taking care of? And all of those factors fall into, 'How am I going to care for myself?' And if I can't get diagnostic testing today, because I got to feed my kids, it's going to get put on the back burner." -Patient Navigator*

*"If someone is diagnosed and they need treatment, Medicaid patients don't have out of pocket costs. I think the working class, middle class people say, 'Oh they have insurance.' Well, yeah they do. But they've got higher copays, higher deductibles. It's the people who have insurance now who have these financial challenges with having to cover their medical costs." -Provider*

**Communication of diagnostic results.** The diagnosis phase of the breast cancer continuum of care includes the communication of diagnostic results. Some health care systems have patient portals where patients have access to their test results within 24 hours. Others have to wait up to a week, and sometimes patients have to follow up on their own because they don't receive any communication. After receiving the results, the women are not always clear on what the results mean and if follow-up steps are necessary. For those who receive a cancer diagnosis, the call often comes at an inopportune time and when social support is not present.

*"I got the results back in the same day, because I'm with Kaiser, and now Kaiser gives you everything online, so you are able to go online and your test results are there. And I did like the follow-up, because they did see something. So, I liked the fact that they saw it, and I was informed on the same day." -Undiagnosed*

*"I went for another screening mammogram. And a week after the screening mammogram, I didn't get my result. So, I called to say, 'I was there a week ago. I've not received my results. Can I get my results?' They said, 'We sent your results to your doctor's office. Call your doctor's office.' So, I told them, 'My doctor is on vacation. I need to know what the results are.' And they said, 'Well, there's nothing we can do. You have to wait for your doctor.' So, I told the lady, I said, 'If you don't give me the results, I'll be in your office in 10 minutes. And you don't want me to come over there.' And she said, 'Hold on.' She went somewhere, came back to the phone and said, 'It looks like you need to come in for your follow-up.' I said, 'I need to come in for a follow-up, and I'm forcing you to give me my results?' -Survivor*

*"That Monday I got a call on my job and I'm thinking that they're calling me to check on me to see how I'm doing following the biopsy because I was in so much pain. So, the doctor said, 'I'm just calling you to let you know that your biopsy came back that you do have cancer.' Now I'm at work and I felt like I should have been called into the office and maybe bring a family member with me, my daughter or whatever for support." -Survivor*

## Treatment

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

**Income and Insurance Barriers.** In 11 of the 14 counties in the MTA, the uninsured rate is below 10 percent. Notably, Washington, D.C., has a very low rate of uninsured people, however, it has the highest percentage of people living under 200 percent of the federal poverty level in the MTA. That dichotomy may make it difficult to have the resources to cover out-of-pocket expenses for medical care. Community members and patient navigators said that women have competing priorities and will often choose more immediate needs, like rent and food, over health care expenses. As one of the survivors explained, those who have employer-sponsored insurance when they are diagnosed may lose their insurance in the course of their cancer treatment because they are no longer able to work.

*“How am I going to pay for it? So, all these things are going through my head, giving me excuses not to [start treatment]. Then I have these brick walls too that I'm running into. So that's my concern and why I became a patient navigator was because that's one of the things I wanted to address is to see, to make sure that we get those people that are similar to me or, that might have the same issues in being uninsured and underinsured.”*  
-Patient Navigator

*“I was fortunate. My job still kept me, I'd been gone a year this time, but only because we had a new HR person who understood and moved me from FMLA to American Disability Act to keep me where I'm still employed, so I'm still protected.”* -Survivor

**Poor management of side effects.** Several survivors shared stories of their treatment experiences. Within the course of their care, some explained that they experienced side effects that they later learned could have been prevented. The preventive measures became clear during discussions with their white counterparts in support groups. They cited not being prepared for their treatment journey. In addition, they missed the opportunity to consult with dental and fertility professionals about quality of life issues.

*“Then my mouth had a lot of blisters in my mouth. And I'm like, I mean my mouth was so sore, and I'm asking the nurse, I'm saying, ‘Why are these blisters in my mouth?’ And she said, ‘Well, that's from the chemo and you have to eat ice.’ And I said, ‘Well, no one told me this.’ And I mean blisters were all in my mouth.”* – Survivor

*“I was 36, wanted to have kids, but I didn't ask anything about that because I didn't know that there was something that could be done. After I had gone through treatment and everything and had met other people that are still in my breast cancer circle now, both Black and white, I'm hearing from the white females how they were talked to about having their eggs frozen, all of that stuff, whether they were in their 20s or their 30s. I never got that conversation.”* -Survivor

**Self-advocacy.** Survivors who have experienced breast cancer more than once reported that they learned that they needed to do their own research and advocate for the treatment plan that was best for them. During their first experience, they trusted their doctor’s recommendations because they lacked knowledge of their options and didn’t know what questions to ask. Others expressed how information was withheld from them and alluded to how personally mediated racism and bias may be influencing these experiences.

*“I really had to fight. And then even after that experience, when I finally got the diagnosis, the first set of doctors I had, I told them I wanted to have a bilateral mastectomy, because I had lost my older sister to breast cancer. And they told me, ‘Oh, that’s not necessary. You’re being [unnecessarily], aggressive.’ I had to change physicians.” - Survivor*

*“If you don’t have the support, if you don’t know, you know this, the first time around, I just went in and trusted. So, I did whatever they told me, I went with what they told me because you’re the doctor. You wouldn’t do anything that was crazy. You know what to do. This time I couldn’t do that. Now, they say, ‘You don’t need blood work’, I said, ‘No, we’re going to do blood work.’ I said, ‘I don’t trust you all for us not to do blood work.’ So now we come in, I’ve had to learn, I’ve got to look and see where my bilirubin is and this and that and look at the trends.” - Survivor*

*“But yet, it happens to where we don’t get told all the information, we don’t get asked the pertinent questions that our white counterparts do. It needs to stop. And it’s not even an age thing. It doesn’t matter the age of the doctor, whatever, they’re set in their ways to where they don’t, they just don’t. And that’s even with research. If there’s a new drug coming out that could possibly help you with your particular type of breast cancer, I was triple negative both times, with your particular type of breast cancer, you’ll see it on TV way before your doctor even brought it to you, because it could be something that could help you. Then you have to go to your doctor, ‘Why didn’t you tell me about so and so and so and so?’” -Survivor*

**Team-based care approach.** Participants commented on the notable differences of breast cancer treatment quality when the approach centered on having a provider team. Some survivors commented on being overwhelmed when their providers did not work as a team. Those who received care under a team-based model reported positive experiences.

*“Using the whole team approach. The medical oncologist, we have a team meeting every week where we discuss the issues. The navigator chimes in with her information that may help us to get modify treatment plans or figure out where the patient is coming from. So, then as the patient kind of moves through our system, we’re all aware of what her challenges may be, so that we’re all working together.” -Provider*

*“At MD Anderson, the whole team, they meet every Wednesday morning at like six or seven o'clock. That is the oncologist, the surgeons, the nursing staff, the radiologist and they go over everyone's case and they talk about it and discuss, ‘Well, here's where we are. Here's what we think, here's ...’ And they all agree. And, so, when you have that, and then they come back and they talk to you from the nurses, to the oncologist, to the surgeons and they're all saying the same thing, it's just a different experience.” -Survivor*

*“Cancer care has changed so much over the years. Because we didn't have those teams when I was diagnosed 27 years ago. You talked to this one, you talked to that one and you hope that they were talking to one another, but there were times and they weren't. So, you'd have to say, ‘Well, so and so told me ... This doctor, so and so told me this. So, what do you think about that?’ Well, I was like, ‘Well, can you call him and find out what's going on?’ But then I had a mastectomy in 2014 and it was a lot different. And when I had the mastectomy followed by a DIEP flap, my doctors were there when I woke up.” -Survivor*

**Patient Navigation.** When discussing facilitators that would help Black women stay in breast cancer treatment, patient navigators were suggested as a resource. During treatment, women are looking for a point person within their health system to help make decisions. While navigation services are available, the scope of practice seems to vary across the system from primarily appointment setting to helping remove barriers to care.

*“They're different at [Washington] Hospital Center. Your navigator does everything for you at Kaiser. [At Washington Hospital Center] your navigator just schedules your appointment. So, if I need to know something, I still go back to the Kaiser [patient navigator], who just happened to be a friend of mine, but there's no real navigation.”— Survivor*

*“So, the navigator takes that role on, and the benefit of that is she's able to get those appointments sooner than if someone were just to call on their own. And then the navigator also assesses the patient to find out what other barriers she may have. Are there childcare issues, are there issues with her job? Are there some domestic issues, transportation issues? Trying to find out what those barriers will be and getting her into treatment. And if we find the patient is starting to kind of veer off path and not show up for appointments, she reaches directly out to them to try and find out what's going on.” - Provider*

*“If I only had one person that I could sit down and explain what I'm feeling and what I'm thinking and then tell me why and why am I taking all this chemo? Why am I taking radiation...But like she said there's no one there, it's just a whole lot of someone's there, but no one person that can sort of like pull you together, so you can make those*

*decisions. You probably do make the right decisions, but it would be nice to have someone there who knows you're afraid of maybe the chemo.” -Survivor*

**Personally mediated racism.** When discussing their treatment experiences some participants described how they were treated differently than their white counterparts in all aspects of quality of care, right from the provider’s tone, to how information was shared, to how patients were engaged and attempts to make patients comfortable.

*“We're treated different because we're female and they think that we are crazy already, and then you're female and you're Black. I said, 'I need to get some hair.' But they kept saying, 'Well you're Medicaid', I said, 'I don't have Medicaid. Why?’, 'Because Medicaid doesn't cover this.' 'But I'm not on Medicaid. I have private insurance.' So yes, Medicaid may not cover this, but I've got regular insurance so why are we at this conversation, telling me about Medicaid when I have Kaiser, and not Medicaid Kaiser.” – Survivor*

*“When I went to [Washington] Hospital Center they said that they had only one pillow per person, because I needed another pillow. And I said, 'Can I get a pillow?' And they said, 'Well we only have one pillow per person.' So, my white neighbor comes up to the [hospital] and said, 'What's wrong?' And I said, 'My back is uncomfortable and they only will give me one pillow because they said they only have one pillow per person.' So, my white neighbor goes to the counter and says, 'Excuse me. I need to get an extra pillow for my friend.' And they said, 'How many do you need?' Now they just told me, they only give you one per person and he's able to go up there and get four or five, however many you need, they give it to him. And then when I complained, they told me I was hysterical.”–Survivor*

*“Yeah. I actually had my white oncologist refuse to take my port out after my treatment and three years had gone by and she said, 'Well, you're going to die anyway, so you should keep it. You're going to need it again.' Again, another lack of understanding of triple negative and what it really means. So, I had to go to a Black doctor to get my port taken out.” -Survivor*

## Survivorship

**Transitioning out of specialty care.** Providers noted that survivorship is an area that needs improvement. Patients develop close relationships with their oncologist, and it is hard for both the provider and patient to break that bond when the time comes for the patient to leave care.

*“I would say we don't have very good support for those patients. It's also one of those things where at some point we have to send them back with their primary care doctor. There is some reluctance both on the primary care side and the patient side. They always want to be linked with my oncologist.” -Provider*

**Social Support.** Survivors shared that while emotional and mental health support is available from both family and community groups, they want more resources that are specific to Black survivors and those currently in treatment. This includes support groups designed to address the unique needs of Black women as well as community health workers.

*“There's no calling your primary doctor at 12 o'clock. It'd be nice if you had somebody who was with you other than your kids, maybe in your family, somebody professional who can help you. I thought that would be great for me. I don't know. Maybe someone else would, but that's nice to have, to tell you that you won't look like this, one boob won't be up the other one's down.” –Survivor*

## Section 2 Findings: Systemic and Social Determinants of Health

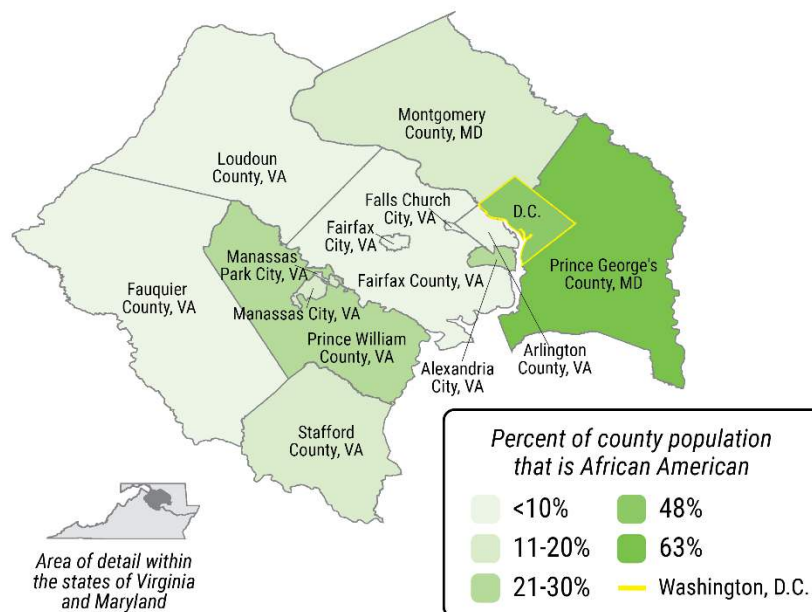
Section 2 explores the systemic and SDOH that may be driving breast cancer inequities. The set of factors explored in this section—residential segregation, economic vulnerability, experiences of racism, social determinants of health—were informed by consultations with Komen’s Stand for H.E.R. team, academic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

### Residential Segregation

The Nation Capital Area MTA is segregated across several dimensions, including race and socioeconomic factors, creating stark contrasts by geography.

On the Eastern side of the MTA, Prince George’s County, MD, has the highest percentage (63%) of Black residents. Washington, D.C., has a population that is 48 percent Black, and Prince William County, VA, has a population that is 21 percent Black (see Map 3 – Percent Blacks and Table 24 in the Appendix. Most other counties in the MTA have populations that are less than 21 percent Black.

#### MAP 3: BLACK POPULATION IN THE NATIONAL CAPITAL METRO AREA

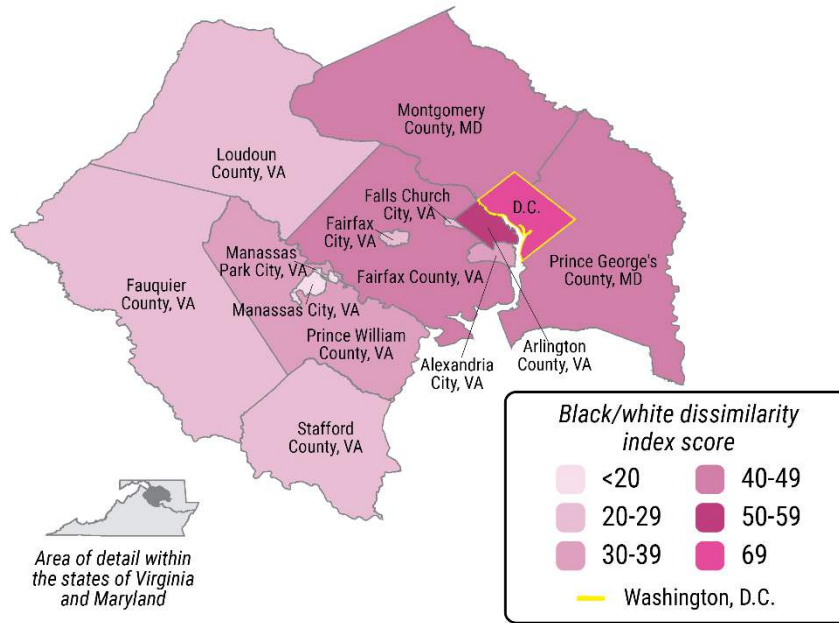


Source: American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)

In addition to the MTA as a whole being racially segregated (with most people of color living predominantly in a few of the counties on 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 (Map 4). Index scores range from 0 to 100 and correspond to the percentage of people within a racial group who would need to relocate in order for a county to achieve integration. Zero indicates complete

integration of the two races and 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 NATIONAL CAPITAL MTA**



As seen in Map 4, Washington, D.C., has the highest score (69), indicating that it is the most segregated place in the MTA. Arlington County, VA, has the next highest score at 54. Counties' scores decrease the further one moves away from the Washington, D.C. epicenter, with Loudoun County, VA, Fauquier County, VA and Stafford County, VA, having the lowest scores for residential segregation, indicating that the racial distribution of residents in these locations is more even.

Source: 2019 County Health Rankings (County Health Rankings)

**Experiences of Racism in Everyday Life**

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 National Capital MTA.

Data suggest that Blacks in the MTA experience several forms of personally-mediated racism (U.S. Department of Housing and Urban Development, 2019; U.S. Department of Justice Federal Bureau of Investigation, 2017). As seen in Table 10, Washington, D.C., reports the highest level of racism when compared to the other counties in the MTA. In 2016 and 2017, twelve Blacks were killed by the police (See Table 10 Racism). Further, in Washington, D.C., there were 108 hate crimes committed with a racial bias motivation in 2015 and 107 Fair Housing Act cases with a racial basis have been filed since 2006. While other counties and county-equivalents in the region experience similarly high Fair Housing Act cases filed with a racial bias, no other counties in the MTA come close to experiencing the same number of police killings and racial bias hate crimes as Washington, D.C.

**TABLE 10. NATIONAL CAPITAL METRO AREA 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
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Washington, D.C.	12	108	107
Montgomery County, MD	0	2	93
Prince George's County, MD	5	5	53
Alexandria City, VA	0	1	7
Arlington County, VA	0	2	17
Fairfax City, VA	1	0	0
Fairfax County, VA	0	17	90
Falls Church City, VA	0	0	2
Fauquier County, VA	0	3	1
Loudoun County, VA	0	7	11
Manassas City, VA	0	1	3
Manassas Park City, VA	0	1	1
Prince William County, VA	0	2	16
Stafford County, VA	0	4	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 National Capital 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 while shopping and in the workplace. There were several stories of women not being asked if they needed assistance and being ignored and mistreated in retail settings. Additionally, many women shared their struggles in the workplace with enduring daily microaggressions and some blatant, racially motivated professional and personal attacks.

*“A friend of mine, he's from Bangladesh, we went shopping together, and we went into a very, very expensive store, and while we were in the store, people just assumed that we weren't together. And so, I went to one section of the store, he went to another section of the store. He's getting all kinds of help, and I'm just getting followed. And so, we get to meet back up, and he was like, ‘What are you getting?’ And you could tell the salesperson was kind of like, what are you asking her what she's getting for? And we made a statement. I came in the store looking like money, and he came in the store*

*looking like thrift, no lie, and I'm like, how discriminative. I look like I belong here, like I'm supposed to be shopping here, and I'm ashamed to be in the streets with him because I'm like, what you got on?" –Undiagnosed Community Member*

*"I worked as a cashier at [local university] and this customer came and it was time for him to pay and put his money on the counter; and so I said, 'Okay.' So, I got the money, gave him his change, and when I went to go hand him the change back, he said, 'Put it on the counter.' He didn't want to interact, he didn't want to associate; a white guy, and that was my very first time ever experiencing racism." - Undiagnosed Community Member*

## Other Health Measures & Disparities

Data suggest that there are disparities in the National Capital MTA in terms of overall health and wellbeing. In Manassas Park City, VA, nearly 20 percent of adults report that their health is “fair” or “poor” (Table 11). In Loudoun County, VA, on the other hand, only 12 percent of adults report that they have “fair” or “poor” health. All places in the MTA report that their residents have between 2.4 and 3.6 poor physical health days per month, with Montgomery County, MD, reporting the fewest days and Manassas Park City, VA, reporting the most days. In terms of mental health, residents of Montgomery County, MD, and Loudoun County, VA, report the fewest number of poor mental health days per month (2.8 days in both counties). Residents of Washington, D.C., report an average of 3.5 poor mental health days every month, the most of any place in the MTA.

**TABLE 11: NATIONAL CAPITAL METRO AREA HEALTH AND WELLBEING**

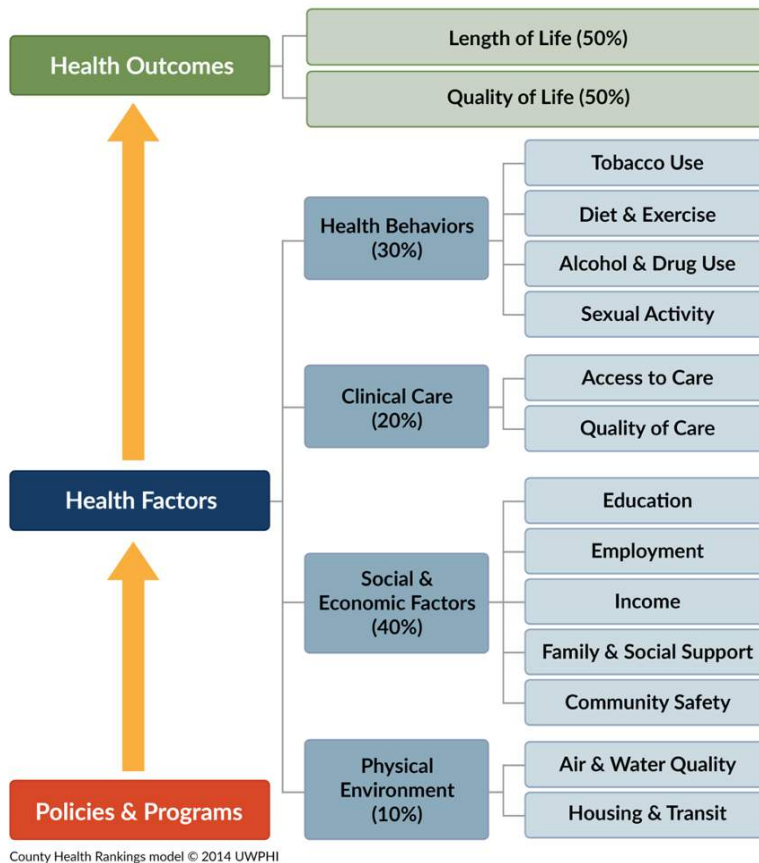
County	County Health Rankings Percentile	Percent of Adults Reporting "Fair" or "Poor" Health	Average Number of Poor Physical Health Days per Month	Average Number of Poor Mental Health Days per Month
Washington, D.C.	*	13%	3.0	3.5
Montgomery County, MD	4%	10%	2.4	2.8
Prince George's County, MD	46%	15%	3.0	3.1
Alexandria City, VA	5%	13%	3.2	3.2
Arlington County, VA	2%	12%	2.7	3.1
Fairfax City, VA	12%	13%	2.8	3.0
Fairfax County, VA	2%	11%	3.0	3.1
Falls Church City, VA	3%	11%	2.7	3.1

Fauquier County, VA	14%	13%	3.1	3.4
Loudoun County, VA	1%	12%	2.6	2.8
Manassas City, VA	20%	17%	3.3	3.3
Manassas Park City, VA	44%	19%	3.6	3.4
Prince William County, VA	7%	15%	3.0	3.3
Stafford County, VA	11%	14%	3.1	3.2

*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). Six of the 11 Virginia counties in the MTA rank in the top 5 percent of all counties in Virginia (which is composed of 95 counties). Loudoun County's CHR is in the top 1 percent of all Virginia counties. Manassas Park City, VA, however, has poorer health outcomes than many of the other counties in the state. Its CHR percentile (44%) indicates that it is worse off than the majority of other Virginia counties in the MTA.



Montgomery County, MD, is one of the two Maryland counties in the MTA that ranks in the top 4 percent of all counties in Maryland (which is composed of 23 counties). Prince George's County, MD, however, ranks at 46 percent of all counties (see Table 11).

In terms of health behaviors, Prince George's County, MD, reports the highest rate of obesity in the MTA, with 36 percent of adults reporting that they are obese (Table 12). By contrast, Washington, D.C., reports one of the lowest obesity rates in the MTA: only 23 percent of adults living in the District report that they are obese. Only Alexandria City, VA, Montgomery County, MD, and Arlington County, VA, report lower percentages of adult obesity (at 22%, 21% and 20%, respectively) (Table 1). Unsurprisingly, obesity

trends in the MTA are reflected in the region's physical inactivity rates. Adults in Prince George's County, MD, report the highest level of physical inactivity (22%), the same rate reported by adults in Fauquier County, VA, and Manassas Park City, VA. Physical inactivity is lowest among adults in Alexandria City, VA (14%), Arlington County, VA (15%) and Montgomery County, MD (15%). With regard to alcohol consumption, 28 percent of adults in Washington, D.C., report that they engage in excessive drinking - the highest rate in the MTA. Only Arlington County, VA, comes close to this percentage, where 26 percent of adults report that they drink excessively. In ten out of the 14 places in the MTA, less than 20 percent of adults report that they drink excessively. The lowest rates of excessive drinking are reported by adults living in Prince George's County, MD (15%), Montgomery County, MD (15%) and Loudoun County, VA (17%).

**TABLE 12 NATIONAL CAPITAL METRO AREA HEALTH BEHAVIORS**

<b>County</b>	<b>Percent of Adults Who Are Obese</b>	<b>Percent of Adults Who Drink Excessively</b>	<b>Percent of Adults Who Are Physically Inactive</b>
Washington, D.C.	23%	28%	17%
Montgomery County, MD	21%	15%	15%
Prince George's County, MD	36%	15%	22%
Alexandria City, VA	22%	21%	14%
Arlington County, VA	20%	26%	15%
Fairfax City, VA	23%	18%	18%
Fairfax County, VA	23%	17%	16%
Falls Church City, VA	28%	20%	20%
Fauquier County, VA	26%	19%	22%
Loudoun County, VA	23%	17%	16%
Manassas City, VA	31%	18%	21%
Manassas Park City, VA	33%	17%	22%
Prince William County, VA	30%	18%	18%
Stafford County, VA	32%	19%	19%

*Source: 2019 County Health Rankings (County Health Rankings)*

Life expectancy in the MTA is lowest in Washington, D.C., at 78 years (Table 13 Life Expectancy). Notably, the life expectancy for white people in Washington, D.C., is considerably higher (87 years) than it is for Blacks (73 years). Washington, D.C.'s life expectancy for Black people is the lowest in the MTA and the disparity between whites and Blacks (14 years) is the greatest. The highest overall life expectancy (not disaggregated by race) is in Manassas Park City, VA, at 91 years. However, there is a large disparity between life expectancy for white and Blacks in Manassas Park City, with the life expectancy as 91 years for white people and 79 years for Black people. The county with the highest life expectancy for Blacks is Loudoun County, VA, where Blacks live an average of 84 years.

**TABLE 13: NATIONAL CAPITAL METRO AREA LIFE EXPECTANCY**

County	Life Expectancy	Life Expectancy for Whites	Life Expectancy for Blacks
Washington, D.C.	78	87	73
Montgomery County, MD	84	84	82
Prince George's County, MD	80	79	78
Alexandria City, VA	84	84	81
Arlington County, VA	85	85	79
Fairfax City, VA	79	79	*
Fairfax County, VA	85	84	83
Falls Church City, VA	82	*	*
Fauquier County, VA	80	80	76
Loudoun County, VA	84	83	84
Manassas City, VA	79	78	77
Manassas Park City, VA	91	91	79
Prince William County, VA	82	81	82
Stafford County, VA	81	80	81

*Source: 2019 County Health Rankings (County Health Rankings)*

Premature age-adjusted mortality measures the number of deaths per 100,000 among people under age 75. Washington, D.C., has the highest premature age-adjusted mortality rate, at 415 (Table 14 Age-

Adjusted Premature Mortality). Again, the disparity between whites (149) and Blacks (644) is by far the greatest in Washington, D.C. The age adjusted premature mortality rate is lowest in Manassas Park City, VA, at 164, but these data are not disaggregated by race as there are too few Blacks who live in Manassas Park. Looking only at the 12 counties where disaggregated data are available, the county with the lowest racial disparity between whites and Blacks is Prince William County, VA, where the premature age-adjusted mortality is 284 for whites and 269 for Blacks. Prince William County, VA, is also the only county where the rates are higher for whites as compared to Blacks.

**TABLE 14. AGE-ADJUSTED PREMATURE MORTALITY**

County	Premature Age-Adjusted Mortality	Premature Age-Adjusted Mortality for Whites	Premature Age-Adjusted Mortality for Blacks
Washington, D.C.	415	149	644
Montgomery County, MD	193	199	289
Prince George's County, MD	332	350	366
Alexandria City, VA	201	176	328
Arlington County, VA	170	159	341
Fairfax City, VA	313	329	686
Fairfax County, VA	167	178	254
Falls Church City, VA	208	*	*
Fauquier County, VA	310	308	511
Loudoun County, VA	170	186	231
Manassas City, VA	311	364	418
Manassas Park City, VA	164	*	*
Prince William County, VA	230	248	284
Stafford County, VA	264	284	269

Source: 2019 County Health Rankings (County Health Rankings)

## Access to Health Services

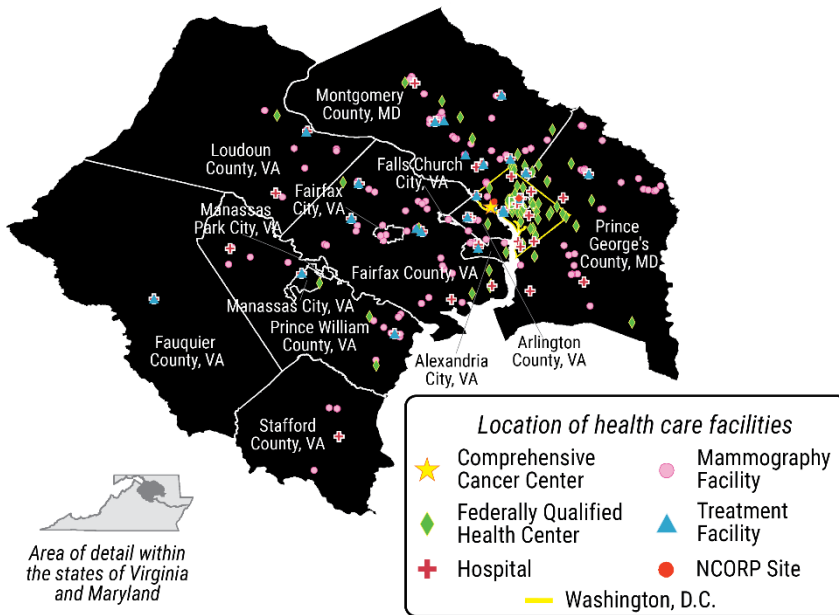
Data suggest that there are significant disparities in the health system in the MTA, including in health care facilities and the proportion of the population that is medically underserved. According to the Health Resources and Services Administration (HRSA), Medically Underserved Areas/Populations are areas or populations designated by HRSA as having too few primary care providers, high infant mortality, high poverty or a high elderly population. For example, in Manassas City, VA, Manassas Park City, VA and Stafford County, VA, 100 percent of the population is medically underserved. Washington, D.C., is close behind, with 79 percent of the population qualifying as medically underserved (Table 15). In Falls Church City, VA, and Fairfax City, VA, none of the population is medically underserved.

**TABLE 15. NATIONAL CAPITAL 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
Washington, D.C.	79%	802	849	166	601	435	9
Montgomery County, MD	12%	1,408	741	79	1,270	140	5
Prince George's County, MD	30%	486	1,868	55	1,833	75	4
Alexandria City, VA	5%	105	1,484	63	1,585	11	0
Arlington County, VA	2%	178	1,292	59	1,703	31	23
Fairfax City, VA	0%	2	12,082	145	688	0	10
Fairfax County, VA	5%	1,218	935	80	1,243	114	10
Falls Church City, VA	0%	45	311	199	503	1	14
Fauquier County, VA	42%	35	1,973	53	1,877	4	1
Loudoun County, VA	9%	309	1,249	59	1,687	12	3
Manassas City, VA	100%	45	922	159	629	1	8
Manassas Park City, VA	100%	*	*	*	*	0	12
Prince William County, VA	27%	206	2,210	46	2,184	5	1
Stafford County, VA	100%	46	3,138	33	2,993	0	2

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

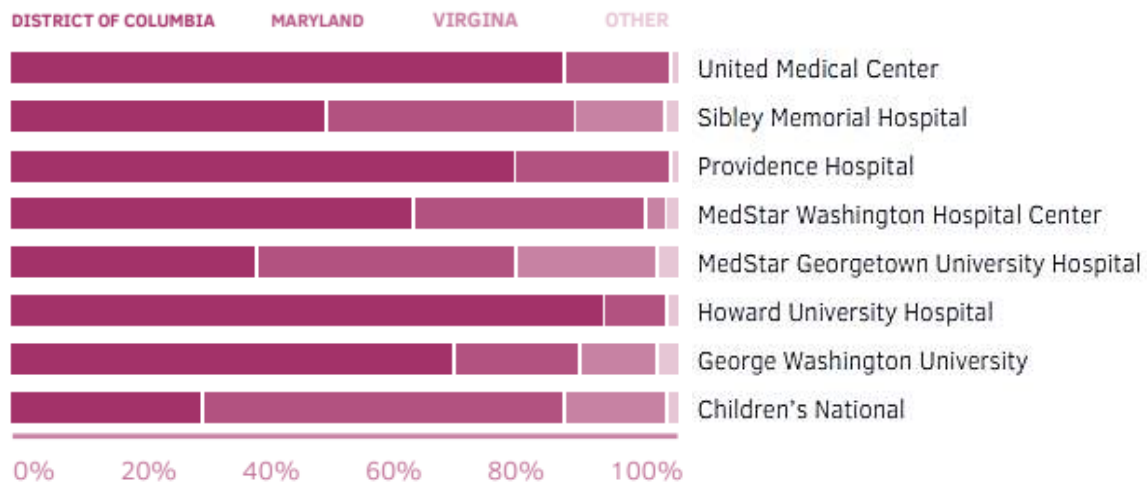
**MAP 5: HEALTH SYSTEMS IN THE NATIONAL CAPITAL MTA**



The health systems map (Map 5) shows the concentration of health care facilities across the MTA. Most resources are centered around Washington, D.C. Specifically, most of the Federally Qualified Health Centers (FQHCs) and hospitals are in Washington, D.C., as is the only comprehensive cancer center.

It is also important to note that the counties in which people reside are not necessarily the same as the counties in which people receive care. Due to migratory patterns, including where residents are employed and how far

they are willing to travel to receive quality care, people may travel to other counties to access health services. Figure 3 below shows the residential origin of patients who receive care in eight major hospitals in Washington, D.C.

**FIGURE 3. PERCENT OF DC HOSPITAL PATIENT ORIGINS BY STATE, 2014**

*Inpatient Discharge Database, DC Hospital Association.*

*Source: District of Columbia Health Systems Plan (Government of the District of Columbia Department of Health, 2017)*

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

In contrast to the quantitative data compiled and reviewed above, in focus groups, community members did not explicitly note a lack of access to facilities in the areas. Instead, they noted that overall quality of care and how Black women are treated varied across facilities in the MTA. In addition, they noted how perceptions of a patient's insurance coverage impacts their quality of care. When patients have Medicaid or are without insurance, women are more likely to receive treatment at Howard Hospital, United Medical Center, or Prince George's Community Hospital, which are all perceived to provide a lower quality of care.

*“Howard University, Washington Hospital Center, George Washington, Georgetown, Sibley and Suburban, as long as you got the right insurance I don't care what color you are, they'll treat you well. But if you go to certain inner city hospitals in the emergency room they have to kind of assess you; figure you out first before they treat you well or they just put you on the side.” –Undiagnosed Community Member*

*“So, if you have Medicaid, Trusted, AmeriHealth, etc, those are the insurances in the city that are given to those who don't have any money or limited or whatever. And I think they get a lot of assumptions when they walk in; people assume certain things, and it could be because of how they present because I can be guilty too as a nurse.” – Undiagnosed Community Member.*

*“We had a patient that we had to refer to another site and the patient didn't want to go. There may be perceptions among patients of how they're going to be treated elsewhere. People may not feel that they're welcome in other environments, and they honestly may not.” -Provider*

**TABLE 16. NATIONAL CAPITAL METRO AREA BREAST CANCER RESOURCES**

<b>County</b>	<b>Number of Mobile Screening mammography Centers</b>	<b>Number of Cancer Coalitions</b>	<b>Number of Survivor/ Support Groups</b>
Washington, D.C.	2	2	8
Montgomery County, MD	1	0	3
Prince George's County, MD	1	0	2
Alexandria City, VA	2	1	2
Arlington County, VA	2	1	1
Fairfax City, VA	3	1	1
Fairfax County, VA	4	0	1
Falls Church City, VA	1	0	2
Fauquier County, VA	3	1	2
Loudoun County, VA	4	0	2

Manassas City, VA	2	0	3
Manassas Park City, VA	1	0	1
Prince William County, VA	5	0	3
Stafford County, VA	5	0	2

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

Many of the breast cancer resources are in Washington, D.C., as well. The county has two mobile screening mammography centers, two cancer coalitions and eight survivor support groups, the latter of which is significantly higher than any other place in the MTA (Table 16). Manassas Park City, VA, has the fewest absolute resources of any county, with only one mobile screening mammography center, one survivor support group and no cancer coalitions.

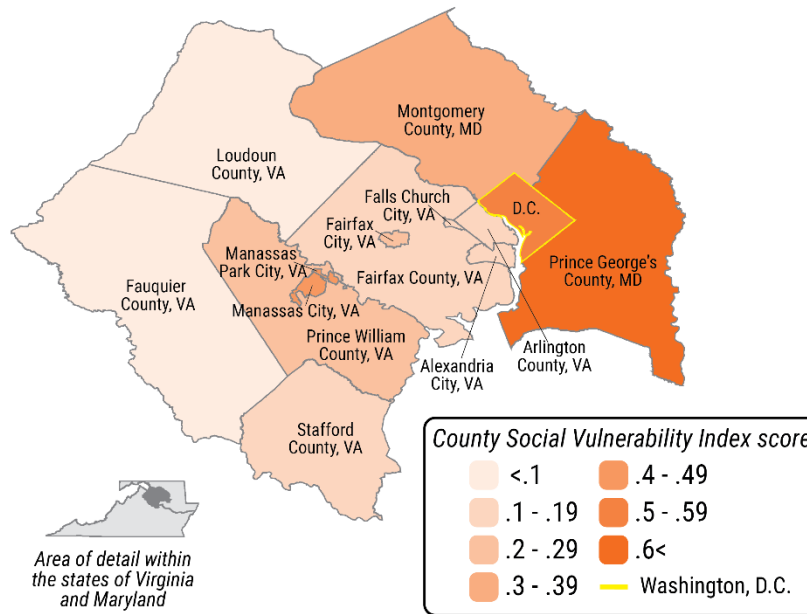
Community members, patient navigators and providers noted the critical role that financial, educational and support resources play along the breast cancer continuum of care. Community members reported using the State Breast and Cervical Program and charitable organizations to fill financial gaps that were barriers to receiving care. Most of the survivors we spoke with were connected to two Black survivor groups but had previous experience with groups that were not race specific. They shared that groups that are not race specific do not meet their needs, and Black women often have a “meeting after the meeting”. To address lifestyle risk factors and to promote screening behaviors, providers shared that they have to collaborate with more than cancer programs and include primary care and community-based organizations in their strategy.

*“I didn't really have much at the time. So, I went to church one Sunday, and I decided to talk to the priest at the church. So, I went to him, I was talking to him while crying, and he's the one who now referred to the Catholic Charities. They are the ones that started out helping.” –Survivor*

*“We rely on the external resources in our community to be able to provide those preventive strategies, diet, exercise, nutrition, smoking cessation, alcohol limitation, et cetera. We educate about it, but to get to scale, no one cancer program can do it. I don't even think cancer programs are the right way to do it.”-Provider*

## Social and Economic Vulnerability

**MAP 6: NATIONAL CAPITAL METRO AREA SOCIAL VULNERABILITY**



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

Social determinants affect health outcomes – such as breast cancer – for individuals and communities. These play out not just across individual lifetimes, but generationally. Disadvantages compound in certain communities, which exacerbate and cement a wide range of negative outcomes and existing burdens, including with regard to 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 6. 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.

Washington, D.C., reports the highest percentage of the population below 200 percent of the FPL in the MTA, at 31 percent, which is about 208,000 people. (Table 17). Washington, D.C., also has the highest percentage of Black women over age 45 who live below the FPL, at 22 percent.

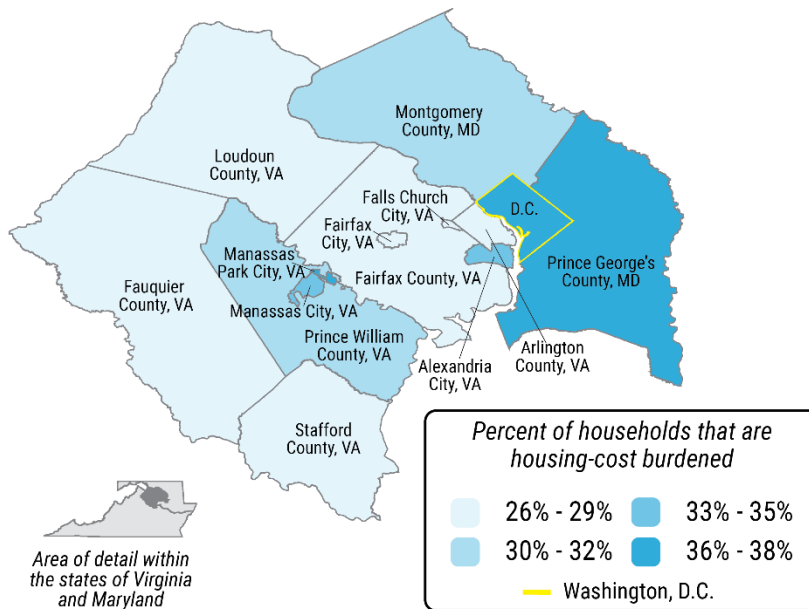
**TABLE 17. NATIONAL CAPITAL METRO AREA ECONOMIC SECURITY**

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
Washington, D.C.	4%	31%	22%
Montgomery County, MD	7%	18%	9%
Prince George's County, MD	10%	24%	7%
Alexandria City, VA	12%	23%	17%
Arlington County, VA	6%	16%	20%
Fairfax City, VA	10%	17%	13%

Fairfax County, VA	8%	15%	9%
Falls Church City, VA	3%	9%	0%
Fauquier County, VA	7%	15%	7%
Loudoun County, VA	5%	11%	4%
Manassas City, VA	14%	27%	7%
Manassas Park City, VA	19%	27%	0%
Prince William County, VA	10%	19%	7%
Stafford County, VA	6%	15%	5%

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

**MAP 7: HOUSING-COST BURDEN IN THE NATIONAL CAPITAL METRO AREA**



The measure illustrated in Map 7 indicates the percentage of renters and homeowners that spend 30 percent or more of their total income on housing. Prince George’s County, MD, and Manassas Park City, MD, each report 38 percent of households as housing-cost burdened, while Washington, D.C., reports 36 percent of households as housing-cost burdened.

With regard to food security in the Washington, D.C., MTA, Washington, D.C., has the highest percent of Black households receiving SNAP/EBT at 29 percent (Table 18). However, only 1

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

percent of the county’s total population has limited access to healthy foods. In all counties except one, less than 4 percent of the population has limited access to healthy foods. Contrastingly, in Manassas Park City, VA, 11 percent of the population has limited access to healthy foods. In the same county, 2

percent of Blacks households receive SNAP/EBT benefits and 4 percent of the population is food insecure.

**TABLE 18. NATIONAL CAPITAL 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
Washington, D.C.	12%	1%	29%
Montgomery County, MD	6%	2%	13%
Prince George's County, MD	14%	4%	12%
Alexandria City, VA	10%	*	10%
Arlington County, VA	8%	0%	14%
Fairfax City, VA	4%	0%	14%
Fairfax County, VA	5%	2%	9%
Falls Church City, VA	5%	*	18%
Fauquier County, VA	6%	1%	15%
Loudoun County, VA	4%	1%	7%
Manassas City, VA	5%	1%	16%
Manassas Park City, VA	4%	11%	2%
Prince William County, VA	6%	3%	9%
Stafford County, VA	7%	3%	8%

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

Food deserts are low income, low access food desert designated by the census tract. Most of the food deserts in the MTA are located in Prince George’s County, MD, where they are also the largest compared to the other food deserts in the MTA. There are no food deserts in Arlington County, VA, Fauquier County, VA, or Manassas City, VA. Community members from the Prince George’s county area expressed that access to high-quality grocery stores were only present in the most affluent areas of the county.

*“There’s also, like she said MOM’s, and I was thinking of Whole Foods, Wegmans, the more upscale stores. I used to live in Largo and Upper Marlboro, and I now live in Suitland [in Prince George’s County, MD]. But because I’ve lived in these other areas, I’m in the habit of knowing better. I’ve chosen to stay in Suitland and eventually I believe those things will come, but I got to travel. And luckily, I have a car, so I can do that.” –  
Undiagnosed Community Member*

Washington, D.C., as the most urban place in the MTA, has by far the highest percentage of households without a vehicle (36%), as well as the highest percent of the population that commutes to work using public transportation (35%) or by foot/bike/other (19%) (Table 19). Many of the counties farther from Washington, D.C., such as Fauquier County, VA, Loudoun County, VA, Manassas City, VA, Prince William County, VA and Stafford County, VA, have much lower percentages of households without a vehicle (2%-5%) and much higher percentages of the total population that commute more than 45 minutes to work (34%-42%).

**TABLE 19. NATIONAL CAPITAL 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
Washington, D.C.	36%	20%	35%	19%
Montgomery County, MD	8%	32%	15%	4%
Prince George's County, MD	9%	36%	16%	3%
Alexandria City, VA	10%	26%	22%	6%
Arlington County, VA	12%	18%	26%	8%
Fairfax City, VA	6%	26%	10%	6%
Fairfax County, VA	4%	27%	10%	3%
Falls Church City, VA	6%	24%	20%	5%
Fauquier County, VA	3%	41%	1%	3%

Loudoun County, VA	2%	30%	4%	3%
Manassas City, VA	4%	34%	4%	2%
Manassas Park City, VA	5%	39%	6%	1%
Prince William County, VA	3%	42%	5%	3%
Stafford County, VA	2%	42%	4%	2%

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

In Falls Church City, VA, 98 percent of the population over age 25 has a high school degree or higher (Table 20). However, in this same county, 14 percent of Black women over age 25 do not have a high school degree. Falls Church County, VA, and Arlington County, VA, have the highest percentage of the population over age 25 with a bachelor's degree or higher (78% and 74%, respectively). Contrastingly, they also have relatively high percentages of Black women over age 25 without a high school degree (14% and 13%, respectively).

**TABLE 20. NATIONAL CAPITAL 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
Washington, D.C.	90%	57%	14%
Montgomery County, MD	91%	58%	7%
Prince George's County, MD	86%	32%	6%
Alexandria City, VA	91%	62%	14%
Arlington County, VA	94%	74%	13%
Fairfax City, VA	92%	57%	3%
Fairfax County, VA	92%	61%	8%
Falls Church City, VA	98%	78%	14%
Fauquier County, VA	91%	35%	19%
Loudoun County, VA	94%	60%	7%

Manassas City, VA	81%	30%	5%
Manassas Park City, VA	82%	31%	0%
Prince William County, VA	89%	40%	6%
Stafford County, VA	94%	39%	7%

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

Gentrification is another measure connected to educational attainment. The percent change in median household income is greatest in Washington, D.C., at 21 percent change (Table 21). It is the lowest in Falls Church City, VA, where the percent change in median household income is -7 percent, the only county to have a negative percent change. All counties in the MTA have a positive proportional change in the population with a bachelor's degree or higher, with Manassas Park City, VA, having the highest proportional change at 9 percent. Washington, D.C., community members shared experiences of being long-term residents and observing the gentrification taking place in the city.

*“In my neighborhood we are experiencing heavy gentrification, and it's a battle over parking between the churches and the residents. It's walking out of my door and folks looking shocked or looking at me like I'm breaking into my own house, and I know you've experienced it.” –Undiagnosed Community Member*

## Policy Context

This section examines key policies relating to access and coverage for breast cancer screening, diagnosis and treatment. The main relevant policies and programs 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).

Table 21 below provides a broad context of health insurance coverage by type in Washington, D.C., Maryland and Virginia (analysis by the Kaiser Family Foundation of American Community Survey data). Notably, in 2018, Virginia had the highest uninsured rate of the three states (9%) with the lowest rate in Washington, D.C. (3%). Of the three locales, Washington, D.C. had the highest percentage in Medicaid (28%) compared to 19% in Maryland and 12% in Virginia.

**TABLE 21. HEALTH INSURANCE COVERAGE BY TYPE IN WASHINGTON, D.C., MARYLAND AND VIRGINIA IN 2018 (ANALYSIS BY THE KAISER FAMILY FOUNDATION)**

Location	Employer	Non-Group	Medicaid	Medicare	Military	Uninsured	Total
Washington, D.C.	53%	7%	28%	8%	1%	3%	100%
Maryland	56%	5%	19%	13%	2%	6%	100%
Virginia	54%	6%	12%	14%	4%	9%	100%

*Source: Health Insurance Coverage of the Total Population, Kaiser Family Foundation analysis of American Community Survey data, 2018.*

## 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 Medicaid eligibility.

- **Preventive Services Mandate.** The preventive services mandate requires that almost all private health insurance plans cover certain preventive services without patient cost sharing. This mandate does not apply to grandfathered plans or policies, a very minor share of plans in existence prior to the passage of the Affordable Care Act on March 23, 2010, that have not undergone major changes to benefits. These preventive services are determined by guidelines from expert clinical entities, including the US Preventive Services Task Force (USPSTF) and the Health Resources and Services Administration (HRSA). In accordance with these guidelines, plans must provide coverage for mammograms beginning at age 40 without cost sharing. For women at high risk of breast cancer, plans must also cover genetic screening and preventive medication for breast cancer (The Henry J. Kaiser Family Foundation, 2015).
- **Pre-Existing Conditions Protections.** Per the ACA and effective as of 2014, health insurers cannot deny coverage to an individual or charge more for coverage due to a pre-existing

condition. For example, insurers cannot discriminate based on a previous or current breast cancer diagnosis or other health condition. Additionally, health insurers cannot refuse to provide coverage for treatment and other services related to a pre-existing condition (U.S. Department of Health & Human Services, 2017).

- **Medicaid Expansion.** Under the ACA, states have the option to expand their Medicaid program to individuals with incomes of up to 138 percent of the FPL. More than one in four Washington, D.C., residents are enrolled in the city's Medicaid program. Washington, D.C., opted to expand its Medicaid program shortly after the Affordable Care Act was signed into law, with the expansion criteria going into effect on January 1, 2014. The expanded Medicaid program is available to (Norris, 2018):

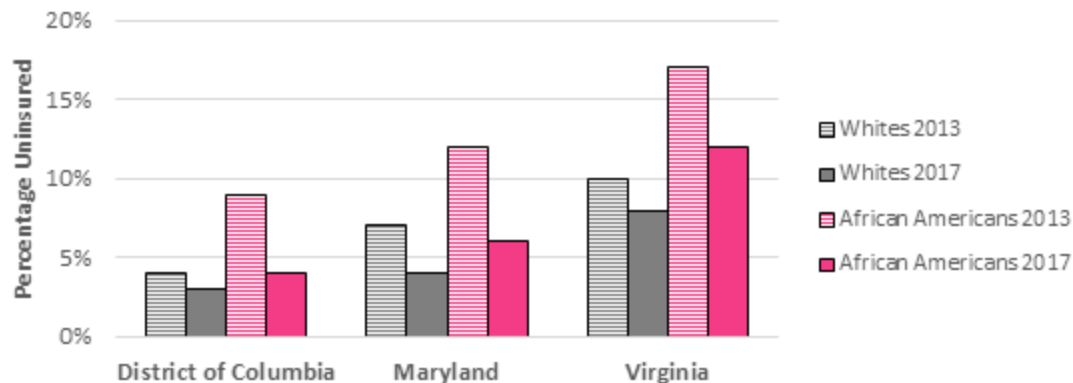
- Adults with dependent children with incomes up to 216 percent of the FPL
- Adults without dependent children with incomes up to 210 percent of the FPL

Maryland and Virginia both expanded their Medicaid program as well, with Maryland's going into effect on January 1, 2014 and Virginia's beginning on January 1, 2019. Both states' expansion criteria are the following:

- Adults with or without children with incomes up to 138 percent of the FPL

The expansion of Medicaid has predictably increased the number of people who have health coverage. The percentage of uninsured, nonelderly residents in Washington, D.C., Maryland and Virginia decreased from 2013 to 2017 among whites and Blacks. However, in 2013 and 2017, in Washington, D.C., Maryland and Virginia, the uninsured rate remained higher for Blacks (Figure 4 below).

**FIGURE 4. PERCENTAGE OF NONELDERLY WHITES AND BLACKS UNINSURED IN 2013 AND 2017**



Source: JSI analysis of the Kaiser Family Foundation data.

As displayed in Table 17, the five-year American Community Survey estimates the average uninsured rate in the Washington, D.C., MTA to be at 4 percent (with a high of 19% in Manassas Park City, VA, and a low of 3% in Falls Church City, VA).

As of October 2019, there were an estimated 109,700 adults in the expansion population in Washington, D.C. (The Henry J. Kaiser Family Foundation, 2019). There were 306,700 adults in the expansion population in Maryland. The data is not available for Virginia's expansion

population because the state's expansion went into effect in 2019. From 2013 to 2017, the uninsured rate in Washington, D.C., decreased from 7 percent to 4 percent, the uninsured rate in Maryland decreased from 12 percent to 7 percent and the uninsured rate in Virginia decreased from 14 percent to 10 percent. These numbers can be compared to the national uninsured rate drop from 17 percent to 10 percent over the same time period (The Henry J. Kaiser Family Foundation, 2019).

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

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

In Washington D.C., the screening program is known as the Project Women Into Staying Health (WISH). Women living in Washington, D.C., who are between the ages of 21 and 64 and are uninsured or underinsured are eligible for this program (DC Health, 2020). In Maryland, the program is called the Maryland Breast and Cervical Cancer Program (BCCP); women living in Maryland, 40 to 64 years old, at or below 250 percent of the FPL and uninsured or underinsured are eligible for this program (Maryland Department of Health, 2020). In Virginia, the program is called Every Woman's Life Program (EWL); women living in Virginia, who are 50 to 64 years old, at or below 250 percent of the FPL and are uninsured or underinsured are eligible for this program (Virginia Department of Public Health, 2020).

During the five-year period of July 2014 to June 2019, the NBCCEDP served 2,610 women in Washington, D.C., for both breast and cervical cancer screening and detection services. In Washington, D.C., 3,575 women received a screening mammogram over this five-year period, and 2,553 women received breast cancer screening and diagnostic services. In Maryland, over the same time period, the NBCCEDP served 10,659 women for both breast and cervical cancer screening and detection services. Specific to breast cancer, 17,470 women received a screening mammogram over this five-year period, and 8,451 women received breast cancer screening and diagnostic services. In Virginia, the NBCCEDP served 18,542 women for both breast and cervical cancer screening and detection services. Specific to breast cancer, 29,849 women received a screening mammogram over this five-year period, and 18,417 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).

**TABLE 22. GUIDELINES AND REIMBURSABLE COVERAGE FOR SCREENING MAMMOGRAPHY BY AGE IN THE BREAST AND CERVICAL CANCER SERVICES PROGRAMS**

Age Group	Guidelines for screening frequency in Washington, D.C.	Guidelines for screening frequency in MD	Guidelines for screening frequency in VA
Ages 50 and above	Screening every 1-2 years	Annual screening	Annual screening
Ages 40-49	Screening every 1-2 years once benefits/harms discussed with PCP	Screening every two years	Screening every two years
Ages 35-39	(25-40 years): Clinical breast exam every 1-3 years	Baseline screening mammogram	Baseline screening mammogram (one screening total)

*Source: Breast Cancer Screening, The GW Medical Faculty Associates; Breast Cancer Risk Assessment and Screening in Average-Risk Women American College of Obstetrics and Gynecology.*

The varying levels of eligibility for BCCTP can facilitate women’s access to services (e.g., eligible regardless of screening location or provider) or can impede a woman’s access to services (e.g., requirements that NBCCEDP fund screening costs). If a woman is diagnosed with breast or cervical cancer, she is then eligible to receive Medicaid services.

In Washington, D.C., women who are diagnosed through WISH may be eligible for treatment through the Medicaid program if they meet certain requirements. In Maryland, women who are diagnosed through BCCP may be eligible for treatment through the Breast and Cervical Cancer Diagnosis and Treatment Program if they meet certain requirements. In Virginia, women who are diagnosed through EWL may be eligible for treatment through the Medicaid program if they meet certain requirements.

**TABLE 23. OVERVIEW OF SCREENING AND TREATMENT SERVICES**

<b>Breast and Cervical Cancer Services (Screening Focus)</b>			
<b>Resident</b>	<b>Age</b>	<b>Insurance status</b>	<b>Program Services</b>
<b>Washington, D.C.</b>	Every 1-2 years for women age 40 and above (see Table 22)	Uninsured or underinsured	Free breast and cervical cancer screening and diagnostic follow-up, and patient navigation, transportation assistance and cancer education
<b>Maryland</b>	Annually for women 50 and above, biannually for women 40-49 and once for women 35-39 (see Table 22)	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) , mammograms (screening and diagnostic), breast ultrasound, surgical consultation, breast biopsy, pap test, HPV test, colposcopy and cervical biopsy, patient navigation (services such as help scheduling appointments and follow-up, finding transportation, interpretation services and more), case management and linkage to treatment as needed
<b>Virginia</b>	Annually for women 50 and above, biannually for women 40-49 and once for women 35-39 (see Table 22)	Uninsured or underinsured	Clinical breast exam, screening mammogram, pelvic exam and Pap test.

<b>Medicaid for Breast and Cervical Cancer (Treatment Focus)</b>			
<b>Resident</b>	<b>Age</b>	<b>Insurance status</b>	
Washington, D.C.	18 - 64	Uninsured and not otherwise eligible for Medicaid, without access to services otherwise	
Maryland	Not Listed	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	
Virginia	18-64	Cannot have creditable health insurance that covers the treatment of breast or cervical cancer, including Medicare.	

## 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 CMS) (National Conference of State Legislatures, 2018). Traditionally, these waivers have been used to pilot improvements to delivery system reform in the Medicaid program.

However, the Trump administration has promoted requirements that enrollees work a certain amount of hours to maintain Medicaid coverage; a type of Medicaid waivers which have previously not been approved (Brooks, Roygardner et al., 2019). Several states have applied to enact work requirements with some of these attempts challenged and overturned in court.

In Washington, D.C., Maryland and Virginia, there are no work requirements around Medicaid eligibility. Virginia had requested permission from CMS to implement work requirements in Medicaid; however, once Democrats in Virginia took control of the State House and Senate, Governor Northam stopped such plans from moving forward (Vozzella, 2019).

## Cancer Plan for Washington, D.C., Maryland and Virginia

### Washington, D.C. Cancer Control Plan

Previously, the DC Cancer Consortium, a local advocacy organization, authored the District's Cancer Control Plan. However, the DC Cancer Consortium was funded with one-time funding and was not able to remain financially solvent (Montague, 2019). The last published cancer control plan covered the time period of 2013-2018; the DC Cancer Consortium has not published a subsequent cancer control plan, although a plan was expected to be released for the 2019-2023 period.

Although no longer current, the overarching goal in the 2013-2018 DC Cancer Control plan was to reduce Washington, D.C.'s breast cancer mortality via four objectives (DC Cancer Consortium, 2013):

- Objective 1: Increase the percentage of women (40 years and older) who have received a screening mammogram within the past two years (from 81.6% to 90%).
- Objective 2: Increase early detection and prevention by enhancing health care providers' roles in ensuring access to appropriate care, including risk reduction and clinical breast examination.
- Objective 3: Decrease (to no more than 30 days) the time from abnormal breast cancer screening to definitive cancer diagnosis for all racial and income groups.
- Objective 4: Decrease (to no more than 30 days) the time from diagnosis of breast cancer to treatment for all racial and income groups.

### Maryland Cancer Plan

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 to reduce 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 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. The second recommendation is 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.

### **Virginia Cancer Plan**

The Virginia Comprehensive Cancer Control Program (VACCCP) is a part of the Virginia Department of Health. In partnership with the Cancer Action Coalition of Virginia (CACV), the VACCCP authors the Virginia Cancer Plan. VACCCP’s mission is “to reduce the incidence, morbidity and mortality of all cancers through prevention, early detection, treatment and rehabilitation.” The current Virginia Cancer plan covers the time period of 2018-2022 and notes that breast cancer is the most commonly diagnosed cancer in the state. The main objective specific to breast cancer in the current plan is to, “Increase the percentage of women aged 40-74 who received a screening mammogram in the past two years” (from 80.4% to a 2022 target of 84.4%) (Cancer Action Coalition of Virginia, 2018). The Virginia Cancer Plan proposes meeting this target through the following strategies:

- Provide education to physicians, other health care providers and the public about current national breast cancer screening guidelines;
- Provide education to physicians and other health care providers regarding breast cancer screening in the LGBTQ community; and
- Provide education to physicians, other health care providers and patients related to the benefits of 3D mammograms for women with dense breasts (Cancer Action Coalition of Virginia, 2018).

The Virginia State Cancer Plan does acknowledge the national difference in the five-year survival rate for breast cancer, which is lower for Black women compared to non-Hispanic white women (Cancer Action Coalition of Virginia, 2018). However, the above objective and described strategies do not describe specific strategies for Black women. Still, these strategies could have positive effects on Black women and receipt of screening mammogram services in the state by improving provider and public awareness of screening guidelines (and thus, increasing the possibility of screening that meets the standard of care), improving care for Black LGBTQ women and potentially improving awareness of the benefits of 3D mammograms for Black women, who are more likely to have dense breasts than white women (McCarthy, Keller et al., 2016).

### **State Laws Impacting the Breast Cancer Community**

- **Oral Parity.** Maryland and Virginia have passed legislation that ensures patient cost-sharing for oral chemotherapy treatments are no less favorable than the patient cost-sharing for intravenous chemotherapy treatments.

## Discussion and Conclusion

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

### Breast Cancer Disease Burden

The data present a compelling story about breast cancer in the National Capital MTA: as compared to white women in the National Capital MTA, Black women are diagnosed at later stages and die from the disease at higher rates, a pattern that may indicate deep and persistent inequities in access to and/or quality of treatment. Although there is no consistent trend in incidence rates, comparing Black women to white women (see Table 5) across the different counties in the National Capital MTA, Black women are consistently more likely to die from the disease compared to white women (see Table 6). Furthermore, screening mammography rates suggest that Black women are likely getting mammograms at a similar - if not higher - rates than white women in the National Capital MTA (see Table 7). (Note: Even though the preventative screening data in Table 7 are not disaggregated by race, we are making this inference based on state level data.)

The demographic data establish that the 80 percent of Black women 45 and over living in the National Capital MTA are residents of either one of three places -- Washington, D.C. (24%), Prince George's County, MD (44%), or Montgomery County, MD (12%) (see Tables 3 and 4), which are clustered in the eastern portion of MTA. In Washington, D.C., and Prince George's County, MD, where most Black women over 45 live, are more likely to have late-stage diagnosis than white women. Regardless of where they reside in the MTA, Black women are more likely to have a late-stage diagnosis and die of breast cancer than white women in those same areas (see Table 8). Further on other measures, unlike Washington, D.C., Prince George's County doesn't show a Black-white racial disparity in overall life expectancy and premature mortality (see Tables 13 and 14).

It is not clear why the late-stage incidence is higher for Black women in the MTA given suspected higher rates of screening mammography. A potential explanation for this finding could relate to delays in follow up diagnostics after screening due to higher out-of-pocket costs for those services and delays in getting those services, either self-induced or because of systemic barriers. Further, inconsistent screening guidance 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 U.S. Preventive Task Force (USPSTF), a panel of experts that influence 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 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 regular annual screening mammography begin at age 40 in women of average risk for breast cancer (Committee on Practice Bulletins - Gynecology, Pearlman, Jeudy, & Chelmow, 2017). Guidelines for clinical breast exams prior to

age 40 differ depending on the organization in question. For example, the American College of Obstetricians and Gynecologists and the National Comprehensive Cancer Network recommend offering clinical breast exams every three years for women aged 25-39. The USPSTF's current guidance indicates there is insufficient evidence to make a recommendation for or against clinical breast exam use for women 25-39, and the American Cancer Society recommends against clinical breast exams for women age 25-39 (Committee on Practice Bulletins - Gynecology et al., 2017).

## Quality of Care

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.

There are two places where consistency in state-level breast cancer screening policy and programs would be beneficial to women in the MTA. Both Maryland and Virginia include a baseline screening mammogram for women 35-39. Whereas Washington, D.C. does not have this guideline which may be most beneficial for Black women. While all three NBCCEDPs relevant for the National Capital MTA have different criteria, the Virginia program has limited services for people under 50. Given that Black women tend to have earlier onset of breast cancer, access to early screening through Virginia's NBCCEDP Every Woman's Life Program would be beneficial.

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

This was most apparent in the qualitative discussions about the diagnosis phase of the breast cancer continuum of care. Black women present with symptoms that are ignored or dismissed. It causes both mental and physical strain to live with symptoms for a year or more before getting a cancer diagnosis. In particular, they reported that women under 40 had a harder time getting screened and/or referred for diagnostic procedures, including one case where there was clearly familial risk.

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

## Social Determinants of Health

The National Capital MTA is so highly segregated - both within and across areas - the question can be considered through two geographic lenses: an inter-county comparison across the entire metro and a comparison of groups living in the MTA's two most populous counties Washington, D.C., and Prince George's County, MD.

From a resources standpoint, two of the three counties in the MTA that are 100 percent medically underserved have private oncologist numbers similar to counties closer to Washington, D.C., that are less than 5 percent medically underserved. These counties also have higher numbers of mobile screening mammography when compared to Washington, D.C., and Prince George's County, MD, where most Blacks in the MTA live. Research shows that the pattern of resources clustered in predominantly white areas impacts a women's cancer journey. Ansell et al. found that in Chicago, facilities that served predominantly "minority" women were less likely to have dedicated breast imaging specialists reading results as compared to those facilities that served predominantly white women (Ansell et al., 2009). Studies have also found racial differences in time to breast cancer diagnosis (Hoffman et al., 2011), time to breast cancer treatment (Halpern & Holden, 2012; Ko, Andreopoulou, & Moo, 2016; Nurgalieva et al., 2013), type of breast cancer treatment (Curtis, Quale, Haggstrom, & Smith-Bindman, 2008) and completion of breast cancer treatment (Green et al., 2018; Ko et al., 2016).

In the National Capital MTA, areas with large Black populations have some of the lowest uninsured rates, suggesting that having insurance alone is not enough to overcome breast cancer inequities. The counties with the highest uninsured rates are all in Virginia, which may be due to the state not having Medicaid expansion during the period reflected in this table. In 2019, Virginia joined Washington, D.C., and Maryland in adopting Medicaid expansion.

Focus group participants explained that the type of insurance they were perceived to have influenced the quality of care received. They reported feeling that those enrolled in Medicaid received poorer quality care within the major hospitals in Washington, D.C. Focus group participants with private insurance who had experienced their insurance type being mistaken for Medicaid also reported poorer treatment until the health care staff were aware of their actual insurance provider and plan. Relatedly, the type of health insurance impacts where a patient receives care. Medicaid recipients or those without insurance are likely to receive treatment at safety net hospitals such as Howard Hospital, United Medical Center, or Prince George's Community Hospital, which were all perceived by focus group participants to provide a lower quality of care.

These data are consistent with the literature showing that among Black breast cancer patients, a woman's insurance type was a significant predictor of mistrust of the medical establishment. Women with Medicaid expressed greater mistrust and suspicion compared to women with private insurance or private insurance and Medicare (Sutton, He, Edmonds, & Sheppard, 2019). A 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).

Additionally, the qualitative data expose that personally mediated racism leads to a poorer experience for Black women in the MTA. Participants reported that they were not given adequate instruction to mitigate known side effects. Nor were they told to prepare for quality of life issues such as infertility and tooth loss. It is only in conversations with white women, usually at support groups, that they find out

they are being treated differently. Although Washington, D.C., has eight support groups, participants didn't feel they met the needs of Black women and that they need Black only support groups.

Given that the research supports the experience reported in the focus groups and interviews, it is possible that Black women in the National Capital MTA are provided with a lower quality of care as compared to white women, and that this racial disparity in care provision directly contributes to the breast health inequities in the region.

Data further indicate that Blacks from Washington, D.C., and Prince George's County, MD, are heavily burdened by SDOH. A high percentage of Black populations in these two locations are medically underserved, below the 200 percent FPL and food insecure. These data suggest that even if an Black woman in either of these places is physically proximate to a treatment facility, she may be unable to access care due to economic barriers or other burdens related to SDOH. Washington D.C., also reports the highest number of Black killed by police, number of hate crimes committed with a race/ethnicity bias and number of housing act cases filed with a race bias. There is a strong and growing body of evidence on the negative health effects of such experiences on entire families and communities (Novak, Geronimus, & Martinez-Cardoso, 2017; Parker, Parker, Philbin, & Hirsch, 2018). Research on HDHPs and their impact on breast cancer care tend to stratify by income level, but not by race and ethnicity. Overall, HDHPs appear to exacerbate delays across the breast cancer continuum of care for multiple socio-demographic groups with low-income women experiencing the longest delays (Wharam et al., 2019).

Breast cancer inequities across the care continuum in the National Capital MTA persist due to systemic policies and practices, economic vulnerability, incongruence between guidelines and implementation, variation in messaging about screening guidelines and experiences of personally mediated racism. Taken together, these factors severely reduce the timeliness and quality of care that Black women receive across the cancer care continuum. Particular aspects of the breast cancer continuum that warrant further investigation and intervention include diagnosis and the variation in quality of breast cancer treatment across the various health and hospital systems.

## Recommendations

Komen’s Stand for H.E.R. is a substantial undertaking to dismantle the systems that perpetuate growing breast cancer inequities experienced by Black women. Findings from the National Capital Area MTA landscape analysis suggest that the work ahead requires interventions across multiple levels of the system:

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

This framework reveals that the health system is multidimensional, ever-changing and has the potential to facilitate or impede population health.

For most, the lasting impression of the health system begins at the **micro level** – where providers and patients interact. As Black women progress along the breast cancer continuum of care, they encounter other micro systems and the complexity of their experience increases. Access to and quality of these micro systems vary, and there is a need for these systems to interact and relate in a manner that centers the experiences of Black women.

When multiple micro systems intersect, the **mezzo system** is formed and the health experience becomes more complicated, particularly in the absence of navigation assistance or care coordination.

System functionality at the micro and mezzo levels is directed by policies and resources within and beyond the organization – **the macro level**.

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

## Micro-Level Strategies

### Increase access to culturally responsive patient navigators.

It is particularly important to have a person on the clinical team who is more frequently available than the oncologist to help women reduce barriers to care and address quality of life issues along their breast cancer journey. Supporting culturally responsive, trained patient navigators is needed, such as funding cultural competence patient navigator trainings, as is funding patient navigator services to increase breast cancer patients' access to these invaluable services. Navigators offer expertise in navigating the health care system; and can offer resources to help integrate clinical care with mental health and related support.

One organization that is already doing this work locally is the George Washington University Cancer Institute. They developed a comprehensive competency-based training for Oncology Patient Navigators. Trained navigators can help Black women navigate the fragmented health care system and connect to non-medical support resources. For example, by helping women transition from screening to diagnosis and treatment, where providers, payment and coverage may vary. Increasing access includes improving the number of navigators and assuring they are geographically accessible. This could be particularly important for working-class middle-class women that encounter financial barriers due to cost sharing.

### Fund Black-specific support groups, particularly in Prince George's County, MD.

The qualitative data indicate that Black women desire more support groups specific to their unique needs. Furthermore, Prince George's County, MD, has a dearth of support groups given its high burden of breast cancer. Focus group participants suggested that having social support can combat myths, misinformation and fear and is more helpful than the family and friends who have not experienced breast cancer. Women in the area mentioned that they have participated in non-traditional support avenues such as Dragon Boat races and a basketball class for survivors but they are usually the only Black women present.

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

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

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

In Georgia, the screening mammography rate for Black women over the age of 40 is 79.4 percent, compared to 72 percent of white women in the same age range. While Black women are getting

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

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

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

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

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

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

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

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

## Mezzo-Level Strategies

### **Increase access to integrated care, including mental health services, 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.

These efforts may help improve the quality of care, often noted by participants as varying across health systems and hospitals and perceived to be of worse quality among institutions that serve Medicaid populations. Consideration should be given to ways to support QI initiatives in non-hospital and non-health system care settings (in addition to hospital and health system settings), including through convening partners including clinics, health centers, public health and others.

Engagement could include with some of these organizations to build on or begin QI initiatives along the breast cancer continuum of care: the American Society of Clinical Oncology, Virginia Community Healthcare Association, Mid-Atlantic Association of Community Health Centers, DC Metropolitan Radiological Society and the hospital associations in Washington, D.C., Maryland and Virginia.

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

The breast cancer community may want to invest in a root cause analysis (RCA) process to identify the contributing factors and underlying causes of late-stage incidence, as well as the key leverage points where intervention would have a significant impact on breast cancer inequities strengths and areas of opportunity. By conducting an RCA, stakeholders, including non-health stakeholders, can begin to understand the complexity of late-stage incidence in their community.

Breast cancer survivors, community-led efforts (e.g., workers' unions, non-profits, food banks, community health centers, women's organizations, etc.) and research centers with long-standing academic-community partnerships can be invited to participate in the RCA process. The RCA includes an

action planning process to determine how to move forward 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 late-stage incidence in Washington, D.C. and Prince George's County. Once complete, the recommended next step is to engage in partnerships with the RCA stakeholders and provide grants to implement the RCA action plan among these organizations' respective members and networks.

## Macro-Level Strategies

### **Advocate against requirements for a primary care physician referral for screening mammograms.**

As stated in the policy context, Washington, D.C. has a relatively low uninsured rate at 3 percent. Additionally, Washington, D.C., Maryland and Virginia have all chosen to expand eligibility for their Medicaid programs. However, as described elsewhere in this report, insurance access alone is necessary but not sufficient to address the inequities Black women experience in the continuum of care. The qualitative data suggest that requirements for PCP referral for screening mammograms creates both time and cost barriers that can result in diagnostic delays. Research also shows that Black women experience a longer duration from the first symptoms to diagnostic resolution for breast cancer (Hoffman et al., 2011).

The breast cancer community can convene area health plans to discuss the barriers the referral policies create for Blacks and advocate for the removal of barriers to seamless and timeless breast cancer care. Specifically, the assessment can include whether local Black women are receiving breast cancer screening, diagnosis and treatment services according to quality guidelines and without delays. If they are not, area health plans, community advocates, community members and health care providers could assess potential solutions.

### **Influence the state cancer plans to address structural barriers.**

The Washington, D.C. cancer plan expired in 2018, and a subsequent cancer control plan has not yet been released. The delay may in part be caused by a funding lapse to the organization that was responsible for the plan. The previous plan's goals were in alignment with many of the recommendations in this report. The plan recommended that the time from abnormal screening to definitive diagnosis and from diagnosis to treatment be no more than 30 days each. Funding the development of the DC Cancer Control plan or advocacy for its development is needed.

The Maryland cancer plan acknowledges care discrepancies between Black and white women and highlights three strategies that have particular significance to the Black community. They recommend: 1) patient navigation services, 2) health education and 3) reducing structural barriers by eliminating administrative obstacles. Reducing structural barriers is relatively vague, and it is unclear what steps the plan recommends achieving this goal. Thought leadership to the Maryland Cancer Collaborative is needed in identifying concrete steps to reducing structural barriers in the state.

The Virginia State Cancer Plan does acknowledge the national difference in the five-year survival rate for breast cancer, which is lower for Black women compared to non-Hispanic, white women (Cancer Action Coalition of Virginia, 2018). However, the plan does not specify strategies for improving care for Black women, and thought leadership is needed to identify other concrete steps to reducing breast cancer racial inequities in Virginia.

**Advocate for financial compensation for community health workers.**

Community health workers (CHWs) can help women navigate the complex health care system and connect them to valuable and necessary services. CHWs are typically employed in community-based settings, whereas patient navigators typically work in clinical settings where their services are reimbursable. CHWs also work at all stages of the breast cancer continuum including educating people who are not seeking services. Culturally competent CHWs can help Black women navigate services and relationships with providers. In addition to increasing the quality and availability of these services, advocating for CHWs creates employment opportunities in the community. The [Institute of Public Health Innovation](#) is one of the region's leading partners in the development, coordination and evaluation of CHW initiatives, and could serve as a leader in this effort.

The Virginia Cancer Control Plan also advocates for a CHW model as a promising approach to improve care across the continuum of cancer. Payment for CHWs and direct service in the short term by providing funding for such training and services.

Over the longer-term, examination is needed on whether the ACA rule change (2014), allowing Medicaid reimbursement for preventive services delivered by non-licensed providers, could serve as a funding stream for CHW services focused on breast cancer prevention (Association of State and Territorial Health Officials). To take advantage of this option, states must request and receive approval for a state plan amendment from CMS. States can pass state plan amendments through state legislation. Through this avenue, legislation could be sponsored to recognize CHWs as non-licensed reimbursable providers in the Medicaid program for cancer prevention services, which would then require CMS approval (Association of State and Territorial Health Officials).

**Support financial assistance programs.**

As indicated in the findings sections, residents of Washington, D.C. and Prince George's county face economic vulnerability. Although Washington, D.C. has low rates of uninsured people, residents may still have issues meeting the high out of pocket costs for breast cancer diagnosis and treatment. Financial assistance programs are needed to overcome these barriers.

Non-profit health systems could examine whether offering financial assistance programs would qualify under Community Benefit, the Internal Revenue Service Requirement that nonprofit 501(c)(3) hospitals provide services or support activities that promote health in their communities to maintain tax-exempt status.

**Ensure a racial-equity lens in the collection and dissemination of core breast health measures.**

Collecting and providing access to racially disaggregated, geographically-specific breast cancer data (e.g., screening mammography rates among white women as compared to Black women at the county or census tract level) will help researchers, program officers and policy makers address racial disparities more effectively. This type of data collection enables the development and evaluation of more targeted interventions. Education of organizations already engaged in such data collection is needed to request they disaggregate their data by race and to report these data at a greater level of geographic specificity.

**Fund collective impact initiatives at the community level to address root causes of breast cancer disparities.**

Collaborative approaches promise to leverage more of the significant resources needed to attain ambitious goals that lie beyond the capacity of individual institutions or foundations. Such collaborations must extend beyond traditional silos. The intersectional issues that weave together to create the SDOH in any community require full engagement of not only medical and public health sectors, but social services, housing and urban planning, economic development, environmental and occupational protections, systems of education, transportation infrastructure and healthy-eating and active-living initiatives. These, among other sectors, collectively foster the requisite conditions that promote health.

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

## Appendix A. Map Measures

**TABLE 24. NATIONAL CAPITAL METRO AREA TABLE MAPS**

	<b>Map 3: Percent of Population that is Black</b>	<b>Map 6: Social Vulnerability Index Score</b>	<b>Map 7: Percent of Households that are Housing-Cost Burdened</b>	<b>Map 4: Residential Segregation Score</b>
Washington, D.C	48%	0.59	36%	69
Montgomery County, MD	18%	0.31	32%	44
Prince George's County, MD	63%	0.62	38%	49
Alexandria City, VA	22%	0.19	33%	39
Arlington County, VA	9%	0.12	29%	54
Fairfax City, VA	5%	0.20	27%	24
Fairfax County, VA	10%	0.16	28%	40
Falls Church City, VA	5%	0.13	29%	25
Fauquier County, VA	8%	0.03	26%	21
Loudoun County, VA	8%	0.09	27%	26
Manassas City, VA	13%	0.43	33%	19
Manassas Park City, VA	14%	0.43	38%	16

Prince William County, VA	21%	0.28	31%	34
Stafford County, VA	17%	0.14	28%	25

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

## Appendix C. Focus Group Guides

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

#### **Step 1: Introduction of project and confidentiality**

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

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

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

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

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

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

#### **How data will be used, privacy and confidentiality**

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

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

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

**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 African-American 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 African-American 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 African-American 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 African-American 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 African-American 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, African-American patients? If so, does this information influence your recommendations for screening?*
- ### 7. What factors promote (or encourage) regular screening among African-American 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 African-American 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 African-American community 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 African-American 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 African-American 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 African-American 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 African-American 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 African-American 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 African-American 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 African-American women across 11 US metropolitan areas. Research has found that African-American women are less likely to be diagnosed early, when breast cancer is more treatable, as compared to white women and other races. African-American women may also be less likely than other women with breast cancer to survive the disease. This is true across the country, and the gap is highest in these 11 major metropolitan areas -- [insert name of metro] is among them.*

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

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

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

**How data will be used, privacy and confidentiality**

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

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

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

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

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

Does anyone object to being recorded?

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

**Step 3: Answer Questions from Participants****Step 4: Confirm Consent to Participate**

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

**Step 5: Answer Questions (if needed)****Step 6: Turn on the Recorder****Step 7: Begin Discussion with Questions Below**

- 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 African-American women. An important aspect for us to discuss is your experiences with racism in your community and workplace and how racial discrimination affects the health of African-American women.*

- 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 African-American women, you know.**

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

**PROBES TO USE AS NECESSARY**

- a. *Who was involved in the decision to start treatment?*
  1. *Partner*
  2. *Family*
  3. *Friends*
  4. *Pastor /Clergy*
5. *Was the decision-making process different for different types of treatment (chemotherapy, surgery, radiation)?*
6. *What may make it difficult for an African-American woman in your area to start and continue the full course of breast cancer treatment if they need it?*
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*
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  - 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 African-American 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 African-American women cancer survivors and their families?**

***Step 8: Thank you for your participation.***

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

### **Step 1: Introduction of project and confidentiality**

*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.]*

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### **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.*

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*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?**[Text Wrapping Break]

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

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 African-American women, you know.**

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

**PROBES TO USE AS NECESSARY**

- a. *Who was involved in the decision to start treatment?*
  1. *Partner*
  2. *Family*
  3. *Friends*
  4. *Pastor /Clergy*
  
5. *Was the decision-making process different for different types of treatment (chemotherapy, surgery, radiation)?*
  
6. *What may make it difficult for an African-American woman in your area to start and continue the full course of breast cancer treatment if they need it?*
  
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 African-American 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

3. *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?*
- c. *Have you had adequate support to address your emotional/social, health and economic needs as a cancer survivor?*
2. *What support has your family needed? When? At diagnosis? After treatment?*
3. *Have you made any lifestyle changes as a result of your experience as a cancer survivor?*
- d. *Have you sought additional support from fellow survivors (i.e., support groups)?*

- 2. 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

3. *What type of resources were available to you (e.g., financial, stress management/healthy living, emotional, spiritual resources)?*
  4. *How did you come to know about these? Did you have to ask?*
  15. *Did you access these resources or have adequate support for doing so?*
1. *Do women have access to a full complement of holistic approaches to cancer treatment and survivorship such as acupuncture, reiki, nutrition support, mindfulness-based stress reduction, meditation, therapist, etc.?*
  1. *If used, how were the services beneficial?*
  1. *If they were not beneficial, why not?*
1. *Were there times when you felt challenged or unable to access the support, information, or resources you felt you needed? Why?*
  1. *Would it be useful to have learned about these resources sooner than you did?*
  1. *At what point would the services have been more useful?*
  1. *Was there a cost/fee to access any of the resources/information?*

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

***Step 8: Thank you for your participation.***

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