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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 breast cancer journeys, and the countless Black lives lost to pervasive structural racism.

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Executive Summary

About Susan G. Komen

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

Background and Purpose

Breast cancer is the most common cancer diagnosed among women in the U.S. 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% from 1989 through 2018 (American Cancer Society, 2019a). However, these trends vary by race and ethnicity.

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

About This Report

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

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

The methods involved a literature scan, compiling quantitative data, reviewing federal and state policies, and collecting qualitative data from community members and providers to prepare a landscape analysis report for each of the 10 MTAs.

This study does not attempt to establish causality between underlying risk factors and breast cancer outcomes. Rather, the analysis aims to elevate key findings regarding the underlying causes for breast cancer inequities across the care continuum among Black women and 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

- The breast cancer disease burden in the Tidewater MTA is largely influenced by two factors, where a person lives and their race. The data illuminate inequities across a number of metrics, including late-stage incidence and mortality rates, with Chesapeake and Suffolk Cities being areas of concentrated disadvantage.

- Suffolk City and Chesapeake City stand out because their incidence rates (166.9 and 153.9), late-stage incidence rates (72.2 and 63.4) are all the highest or among the highest in the MTA for Black women. They also show the highest discrepancies between Black and white women across all breast cancer burden measures.

- A pattern of lower breast cancer incidence rates but higher mortality rates among Black women is evident in four out of the MTA’s eight cities/counties for which there was data. In about half of the cities of the MTA, white women have higher late-stage incidence rates than Black women (Hampton City, Newport News City, Portsmouth City). The two counties that are part of the MTA and Poquoson City did not have enough Black women to calculate late-stage incidence.

- In the remaining four cities (Chesapeake City, Norfolk City, Suffolk City, and Virginia Beach City), Black women have higher late-stage incidence rates than their white counterparts.

- Throughout the metropolitan area, Black women are more likely to die from breast cancer than their white counterparts who live in the same place.

- Suffolk City and Chesapeake City mortality rates (42.8 and 33.7) are all the highest or among the highest in the MTA for Black women.

- Black women have either the same or higher rates of screening mammography screening and lower incidence of breast cancer in half of the cities/counties examined for this analysis.

- Further investigation may be warranted to better understand why the screening rates are relatively high with relatively no discrepancies between Black women and their white counterparts, yet across the board, breast cancer mortality is higher for Black women in all cities/counties for which there was data.

- Decades of discriminatory practices have led to striking segregation in the Tidewater MTA. The Tidewater MTA is segregated across a number of dimensions, including race and socioeconomic factors, creating stark contrasts by geography. Many of the cities/counties in the MTA are also internally racially segregated.

- The stories of Black women, breast cancer survivors and undiagnosed, convey their experience of poor-quality care, racism, microaggressions, and health care discrimination. While this is not a new finding, it was particularly salient in this study.

- Overall, the data suggest breast health inequities among Black women in the Tidewater 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 Tidewater 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.
- Support financial assistance programs.
- Implement implicit bias trainings for providers, administrators, and health care staff.
- Increase education about family health history in the community to identify high-risk families and offer genetic counseling and testing and breast cancer screening to meet the need.
- Implement a culturally relevant health promotion campaign intended to increase knowledge of current screening guidelines.
- Identify and implement strategies for survivorship planning.

**Mezzo-Level Strategies**

- Increase access to integrated care to improve the breast cancer care experience.
- Support Quality Improvement initiatives along the breast cancer continuum of care.
- Invest in high-need areas by health institutions, systems, and payers.
- Support a community-based participatory research project to uncover the drivers of late-stage diagnosis rates.
- Conduct broader outreach to Black women.

**Macro-Level Strategies**

- Influence the State Cancer Plan to address structural barriers.
- Conduct a root cause analysis (RCA) relating to delays in breast cancer diagnosis and healthcare quality.

*This landscape analysis report conveys comprehensive issues facing Black women in this MTA. These recommendations are intended to be a call to action for all community-based organizations, policymakers, hospitals, healthcare providers, faith-based organizations, civic leaders, and citizens. The recommendations are offered as evidence-informed strategies to reduce breast cancer disparities among 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 women in the United States 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 U.S. declined by 41% since 1989 (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% 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% compared to 92% for white women (Howlader et al., 2020). While overall, breast cancer incidence among Black women is lower than among white women, incidence is higher among non-Hispanic Black women younger than 40 than non-Hispanic white women of the same age group (Noone et al., 2017). Black women are also more likely than white women to be diagnosed with aggressive breast cancers, such as Triple Negative Breast Cancer (TNBC) and inflammatory breast cancer and are more likely to be diagnosed at a later stage, when treatments are limited, costly, and the prognosis is poor (American Cancer Society, 2019; Williams et al., 2016).

Through its African American Health Equity Initiative (AAHEI), now known as Stand for H.E.R. – a Health Equity Revolution, Komen seeks to improve breast health equity by reducing late-stage diagnosis and mortality for Black women starting in the 10 U.S. metropolitan areas (referred to throughout this report as MTAs or metro) where Black breast cancer disparities are the greatest. These MTAs include Atlanta, GA; Chicago, IL; Dallas-Fort Worth, TX; Houston, TX; Los Angeles, CA; Memphis, TN; Philadelphia, PA; St. Louis, MO; Tidewater, VA; and Washington, DC.

As part of this initiative, 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 analyses are:

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

This report summarizes findings from the landscape analysis conducted for the Tidewater, Virginia MTA. The report details key findings pertaining to the project objectives as stated above. Findings are organized into two sections: Section 1 describes the breast cancer disease burden in the MTA through secondary data and community member perspectives. Section 2 explores the systemic barriers and underlying root causes, including experiences of racism and adverse SDOH that may be driving breast cancer inequities. The final section includes recommendations to reduce breast cancer disparities and advance breast health equity.

Given the goals and methods traditionally used in a landscape analysis project, the intent is not to provide conclusive evidence or to establish causality between particular factors and breast cancer outcomes among Black women. Rather, the analysis aims to elevate key findings regarding the underlying causes for breast cancer inequities across the care continuum among Black women and offer

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¹ As defined in the Abbreviations & Glossary, these terms are defined as follows: Incidence is defined as the number of new cases of a disease that develop in a specific time period; in situ means “in place,” and in the context of breast cancer means a condition where abnormal cells are found in the milk ducts or lobules of the breast, but not in the surrounding breast tissue. Late-stage diagnosis indicates that breast cancer has spread beyond the breast to lymph nodes, surrounding tissue or other organs in the body (most often the bones, lungs, liver or brain).
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 used to prepare this landscape analysis include a literature scan, compiled quantitative data, reviewed federal and state policies, and collected qualitative data from community members and healthcare providers.

This study defines the Tidewater MTA in accordance with the U.S. Office of Management and Budget’s 2015 definition of the “central counties” in the Virginia Beach-Norfolk-Newport News metropolitan statistical area (MSA). This area is entirely located in the state of Virginia, and comprises Gloucester County and York County, and the cities of Chesapeake, Hampton, Newport News, Norfolk, Poquoson, Portsmouth, Suffolk, and Virginia Beach. Data are unavailable at this unit of geographic specificity, so researchers collected and analyzed data at the county- and county-equivalent- (city-) 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). We refer to this MTA as “Tidewater” because that is the name used and recognized locally for the region.

**TABLE 1. TIDEWATER METRO AREA DATA METHODS AND SOURCES**

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<thead>
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<th>Subcategory</th>
<th>Indicator</th>
<th>Source</th>
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<tbody>
<tr>
<td>sex</td>
<td>Percent of Population that is Male</td>
<td>American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)</td>
<td></td>
</tr>
<tr>
<td>sex</td>
<td>Percent of Population that is Female</td>
<td>American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)</td>
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<tr>
<td>age</td>
<td>Percent of Population that is Under Age 18</td>
<td>American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)</td>
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<tr>
<td>age</td>
<td>Percent of Population that is Age 18-64</td>
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<td>age</td>
<td>Percent of Population that is Over Age 65</td>
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<td>race</td>
<td>Percent of Population that is White</td>
<td>American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)</td>
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<tr>
<td>race</td>
<td>Percent of Population that is Black</td>
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<tr>
<td>race</td>
<td>Percent of Population that is Asian</td>
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<tr>
<td>Race</td>
<td>Percent of Population that is</td>
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<tr>
<td></td>
<td>American Indian or Alaska</td>
<td>American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)</td>
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<td>Native</td>
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<td>Native Hawaiian or Other</td>
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<td>Pacific Islander</td>
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<tr>
<td></td>
<td>Some Other Race</td>
<td>American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)</td>
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<tr>
<td></td>
<td>Two or more Races</td>
<td>American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)</td>
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<td>Hispanic/Latino</td>
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<td>White not Hispanic</td>
<td>American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)</td>
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<td>Minority Race</td>
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<td>Target Population</td>
<td>Number of Black Women over age 45</td>
<td>American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)</td>
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### Social Determinants of Health

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<td>Social Vulnerability</td>
<td>Social Vulnerability Index Score</td>
<td>2016 Social Vulnerability Index (US Centers for Disease Control and Prevention)</td>
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<td>Food Security</td>
<td>Location of Food Deserts</td>
<td>2019 Food Access Research Atlas (US Department of Agriculture, Economic Research Service)</td>
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<td>Food Security</td>
<td>Percent of Population that is Food Insecure</td>
<td>2019 County Health Rankings (County Health Rankings)</td>
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<td>Food Security</td>
<td>Percent of Total Population with Limited Access to Healthy Foods</td>
<td>2019 County Health Rankings (County Health Rankings)</td>
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<td>Education</td>
<td>Percent of Population over age 25 that has High School Degree or Higher</td>
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</tr>
<tr>
<td>Education</td>
<td>Percent of Population over age 25 that has Bachelor's Degree or Higher</td>
<td>American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)</td>
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### Transportation

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<td>transportation</td>
<td>Percent of Total Population Commuting more than 45 Minutes to Work</td>
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<td>Percent of Total Population that Commutes to Work using Public Transportation</td>
<td>American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)</td>
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<td>Percent of Population Commuting to Work by Foot/Bike/Other</td>
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<td>Percent of Households that are Housing-Cost Burdened</td>
<td>2016 Comprehensive Housing Affordability Strategy dataset (US Department of Housing and Urban Development)</td>
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<td>Proportional Change in Population with a Bachelor's Degree or Higher</td>
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<td>Percent Change in Median Household Income</td>
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<td>Location of Redlining</td>
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<td>2017 Hate Crime Statistics (Federal Bureau of Investigation, Uniform Crime Reporting)</td>
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<td>Fair Housing Act Cases dataset (US Department of Housing and Urban Development, Office of Fair Housing and Equal Opportunity)</td>
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<td>Number of Black people Killed by Police</td>
<td>The Counted Database (The Guardian)</td>
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### Health and Wellness

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<td>County Health Rankings Percentile</td>
<td>2019 County Health Rankings (County Health Rankings)</td>
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<td>Percent of Adults Reporting &quot;Fair&quot; or &quot;Poor&quot; Health</td>
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<td>quality of life</td>
<td>Average Number of Poor Physical Health Days</td>
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<td>Premature Age-Adjusted Mortality</td>
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<td>Percent of Adults who are Obese</td>
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<td>health behaviors</td>
<td>Percent of Adults who Drink Excessively</td>
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<tr>
<td>health behaviors</td>
<td>Percent of Adults who are Physically Inactive</td>
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### Health Systems

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<tr>
<td>primary care</td>
<td>Percent of Total Population that is Medically Underserved</td>
<td>HRSA Data Warehouse (US Department of Health and Human Services, Health Resources &amp; Services Administration)</td>
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<tr>
<td>primary care</td>
<td>Number of PCPs</td>
<td>2019 County Health Rankings (County Health Rankings)</td>
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<td>primary care</td>
<td>Persons per PCP</td>
<td>2019 County Health Rankings (County Health Rankings)</td>
</tr>
<tr>
<td>primary care</td>
<td>Number of &quot;Other&quot; PCPs</td>
<td>2019 County Health Rankings (County Health Rankings)</td>
</tr>
<tr>
<td>primary care</td>
<td>Persons per &quot;Other&quot; PCP</td>
<td>2019 County Health Rankings (County Health Rankings)</td>
</tr>
<tr>
<td>primary care</td>
<td>Number of Private PCPs</td>
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<td>primary care</td>
<td>Location of FQHCs</td>
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<tr>
<td>primary care</td>
<td>Location of Hospitals</td>
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<tr>
<td>cancer care</td>
<td>Location of Comprehensive Cancer Centers</td>
<td>National Cancer Institute</td>
</tr>
<tr>
<td>cancer care</td>
<td>Location of Screening mammography Facilities</td>
<td>American College of Radiology</td>
</tr>
<tr>
<td>cancer care</td>
<td>Location of Treatment Facilities</td>
<td>American College of Surgeons; Association of Community Cancer Centers</td>
</tr>
<tr>
<td>cancer care</td>
<td>Location of NCORP Sites</td>
<td>National Cancer Institute</td>
</tr>
<tr>
<td>cancer care</td>
<td>Number of Mobile Screening mammography Centers</td>
<td>Google search</td>
</tr>
<tr>
<td>cancer care</td>
<td>Number of Private Oncologists</td>
<td>Docstop and Healthgrades</td>
</tr>
<tr>
<td>cancer support</td>
<td>Number of Cancer Coalitions</td>
<td>2015 Affiliate profile files and Google search</td>
</tr>
<tr>
<td>cancer support</td>
<td>Number of Survivor/Support Groups</td>
<td>2015 Affiliate profile files and Google search</td>
</tr>
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### Breast Cancer Disease Burden

<table>
<thead>
<tr>
<th>Subcategory</th>
<th>Indicator</th>
<th>Source</th>
</tr>
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<tbody>
<tr>
<td>prevalence</td>
<td>Prevalence</td>
<td>2017 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</td>
</tr>
<tr>
<td>Metric</td>
<td>Description</td>
<td>Source</td>
</tr>
<tr>
<td>--------</td>
<td>-------------</td>
<td>--------</td>
</tr>
<tr>
<td>incidence</td>
<td>Age-Adjusted Incidence Rate</td>
<td>2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</td>
</tr>
<tr>
<td>incidence</td>
<td>5-year Incidence Rate Trend Direction</td>
<td>2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</td>
</tr>
<tr>
<td>incidence</td>
<td>Age-Adjusted Incidence Rate for White Women</td>
<td>2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</td>
</tr>
<tr>
<td>incidence</td>
<td>5-year Incidence Rate Trend Direction for White Women</td>
<td>2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</td>
</tr>
<tr>
<td>incidence</td>
<td>Age-Adjusted Incidence Rate for Black Women</td>
<td>2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</td>
</tr>
<tr>
<td>in situ incidence</td>
<td>Age-Adjusted In Situ Incidence Rate</td>
<td>2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</td>
</tr>
<tr>
<td>in situ incidence</td>
<td>5-year In Situ Incidence Rate Trend Direction</td>
<td>2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</td>
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<tr>
<td>in situ incidence</td>
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<td>2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</td>
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<tr>
<td>in situ incidence</td>
<td>5-year In Situ Incidence Rate Trend Direction for White Women</td>
<td>2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</td>
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<td>in situ incidence</td>
<td>Age-Adjusted In Situ Incidence Rate for Black Women</td>
<td>2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</td>
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<tr>
<td>in situ incidence</td>
<td>5-year In Situ Incidence Rate Trend Direction for Black Women</td>
<td>2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</td>
</tr>
<tr>
<td>late-stage incidence</td>
<td>Age-Adjusted Late-Stage Incidence Rate</td>
<td>2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</td>
</tr>
<tr>
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<td>Average Count of Cases that are Late-Stage</td>
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</tr>
<tr>
<td>late-stage incidence</td>
<td>Age-Adjusted Late-Stage Incidence Rate for White Women</td>
<td>2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</td>
</tr>
<tr>
<td>late-stage incidence</td>
<td>Average Count of Cases that are Late-Stage for White Women</td>
<td>2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</td>
</tr>
<tr>
<td>late-stage incidence</td>
<td>Age-Adjusted Late-Stage Incidence Rate for Black Women</td>
<td>2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</td>
</tr>
<tr>
<td>late-stage incidence</td>
<td>Average Count of Cases that are Late-Stage for Black Women</td>
<td>2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</td>
</tr>
<tr>
<td>mortality</td>
<td>Age-Adjusted Mortality Rate</td>
<td>2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</td>
</tr>
<tr>
<td>mortality</td>
<td>5-year Mortality Rate Trend Direction</td>
<td>2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</td>
</tr>
<tr>
<td>mortality</td>
<td>Age-Adjusted Mortality Rate for White Women</td>
<td>2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</td>
</tr>
<tr>
<td>mortality</td>
<td>5-year Mortality Rate Trend Direction for White Women</td>
<td>2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</td>
</tr>
<tr>
<td>mortality</td>
<td>Age-Adjusted Mortality Rate for Black Women</td>
<td>2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)</td>
</tr>
</tbody>
</table>
Qualitative Data

In the Tidewater MTA, a total of five focus groups were conducted among 53 community members. In addition, one individual interview was held with a patient navigator and two provider interviews were conducted.

Table 2 summarizes the demographic characteristics of 53 focus group participants, representing both breast cancer survivors and the undiagnosed. Among breast cancer survivors, the majority were above 55 years of age, had insurance (100%), and had been diagnosed with stage 1 breast cancer (42%). Undiagnosed women were younger, mostly in the 25-54 age group, with the majority reporting access to public insurance – Medicaid or Medicare (59%). Non-provider participants were Black. Demographics were not collected for community health navigators, patient navigators, or clinical providers.

<p>| TABLE 2. TIDewater Metro Area Qualitative Data Collection |
|-------------|-----------------|-----------------|
| Variable Name | Breast Cancer Survivors (n=20) | Undiagnosed Women (n=31) |
| Age | | |
| 18-24 years | 0% | 6.5% |
| 25-34 years | 10% | 0% |
| 35-44 years | 10.0% | 22.6% |
| 45-54 years | 15.0% | 12.9% |
| 55-64 years | 35.0% | 29.0% |
| 65-74 years | 15.0% | 22.6% |
| 75 and above | 15% | 6.5% |
| Zip Codes | | |
| 23224 | 0% | 3.2% |
| 23230 | 5% | 0% |
| 23320 | 5% | 3.2% |
| 23322 | 0% | 6.5% |
| 23323 | 0% | 6.5% |
| 23325 | 5% | 0% |
| 23435 | 5% | 0% |
| 23501 | 0% | 3.2% |
| 23501 | 0% | 3.2% |
| 23502 | 0% | 3.2% |</p>
<table>
<thead>
<tr>
<th></th>
<th>Breast Cancer Survivors (n=20)</th>
<th>Undiagnosed Women (n=31)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Insurance Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I don't have health insurance</td>
<td>0%</td>
<td>3.3%</td>
</tr>
<tr>
<td>Medicaid</td>
<td>10%</td>
<td>10%</td>
</tr>
<tr>
<td>Medicare</td>
<td>40%</td>
<td>23.3%</td>
</tr>
<tr>
<td>Military Healthcare</td>
<td>10%</td>
<td>7%</td>
</tr>
<tr>
<td>Private Insurance</td>
<td>40%</td>
<td>56.7%</td>
</tr>
<tr>
<td>Through my parents</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Not sure</td>
<td>0.0%</td>
<td>0%</td>
</tr>
<tr>
<td>Ever Been Screened for Breast Cancer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>N/A</td>
<td>87.1%</td>
</tr>
<tr>
<td>No</td>
<td>N/A</td>
<td>12.9%</td>
</tr>
<tr>
<td>Type of Breast Cancer Screening or Assessment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinical breast exam</td>
<td>N/A</td>
<td>11.1%</td>
</tr>
<tr>
<td>Mammogram</td>
<td>N/A</td>
<td>77.8%</td>
</tr>
<tr>
<td>3D Mammogram</td>
<td>N/A</td>
<td>7.4%</td>
</tr>
<tr>
<td>Breast self-exam</td>
<td>N/A</td>
<td>3.7%</td>
</tr>
<tr>
<td>Other</td>
<td>N/A</td>
<td>0%</td>
</tr>
<tr>
<td>Stage of Breast Cancer at Diagnosis</td>
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<td></td>
</tr>
<tr>
<td>Stage 0</td>
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</tr>
<tr>
<td>Stage 1</td>
<td>45%</td>
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</tr>
<tr>
<td>Stage 2</td>
<td>20%</td>
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</tr>
<tr>
<td>Stage 3</td>
<td>15%</td>
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</tr>
<tr>
<td>--------</td>
<td>-----</td>
<td>-----</td>
</tr>
<tr>
<td>Stage 4</td>
<td>15%</td>
<td>N/A</td>
</tr>
</tbody>
</table>
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.

JSI 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. 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 Tidewater MTA using secondary data, as well as relevant findings from the qualitative data.

Demographics

The Tidewater MTA is a region in the North Atlantic coastal plain that falls within Eastern Virginia. The region includes communities along the Chesapeake Bay and its tributaries. The MTA is home to approximately one and a half million people. Its population is 58% white and 32% Black (see Table 3). The number of Black women over age 45 is noted for each city 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).

TABLE 3. TIDEWATER METRO AREA DEMOGRAPHICS

<table>
<thead>
<tr>
<th>Gender</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>49%</td>
</tr>
<tr>
<td>Female</td>
<td>51%</td>
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</table>

<table>
<thead>
<tr>
<th>Age</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Under Age 18</td>
<td>23%</td>
</tr>
<tr>
<td>Age 18-64</td>
<td>65%</td>
</tr>
<tr>
<td>Over Age 65</td>
<td>13%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>58%</td>
</tr>
<tr>
<td>Black</td>
<td>32%</td>
</tr>
<tr>
<td>Asian</td>
<td>4%</td>
</tr>
<tr>
<td>American Indian or Alaska Native</td>
<td>0%</td>
</tr>
<tr>
<td>Native Hawaiian or Other Pacific Islander</td>
<td>0%</td>
</tr>
<tr>
<td>Some Other Race</td>
<td>2%</td>
</tr>
<tr>
<td>Two or More Races</td>
<td>4%</td>
</tr>
<tr>
<td>Hispanic/Latino</td>
<td>7%</td>
</tr>
<tr>
<td>White not Hispanic</td>
<td>54%</td>
</tr>
<tr>
<td>Minority Race</td>
<td>43%</td>
</tr>
</tbody>
</table>

| Number of Black Women Over Age 45 | 98,785 |
| Total Population                  | 1,548,095 |

Source: American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)
The region’s population is spread across eight cities and two counties in the MTA: Chesapeake City, Hampton City, Newport News City, Poquoson City, Portsmouth City, Suffolk City, Virginia Beach City, Gloucester County, and York County. The sizes of cities and counties in the MTA range from an approximate 12,000 in Poquoson City to 450,000 in Virginia Beach City. The percent of total population that is Black range from 1% in Poquoson City to 53% in Portsmouth City. Refer to Table 4 for demographic information specific to each city and county within the MTA.

Breast Cancer Disease Burden in the Tidewater MTA

Breast cancer disease burden in the Tidewater 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 Virginia, the complete prevalence age-adjusted percentage is 1.86, higher than the national percentage of 1.69.

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 per 100,000 individuals per year. Screening mammography rates, shown in Table 9, are represented as the percentage of women over the age of 40 that have had a screening mammogram in the last two years. Some racially disaggregated rates are unavailable for Gloucester County, York County, and Poquoson City, as too few Black women live in these places to calculate the rates.
## Table 5. Tidewater Metro Area Breast Cancer Incidence Rate (Per 100,000)

<table>
<thead>
<tr>
<th></th>
<th>Age-Adjusted Incidence Rate</th>
<th>5-Year Incidence Rate Trend Direction</th>
<th>Age-Adjusted Incidence Rate for White Women</th>
<th>5-Year Incidence Rate Trend Direction for White Women</th>
<th>Age-Adjusted Incidence Rate for Black Women</th>
<th>5-Year Incidence Rate Trend Direction for Black Women</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chesapeake City</td>
<td>148.1</td>
<td>stable</td>
<td>148.1</td>
<td>stable</td>
<td>153.9</td>
<td>stable</td>
</tr>
<tr>
<td>Gloucester County</td>
<td>128.6</td>
<td>stable</td>
<td>131.2</td>
<td>stable</td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>Hampton City</td>
<td>145.3</td>
<td>stable</td>
<td>152.9</td>
<td>stable</td>
<td>142.2</td>
<td>rising</td>
</tr>
<tr>
<td>Newport News City</td>
<td>139.6</td>
<td>stable</td>
<td>141.9</td>
<td>stable</td>
<td>142.6</td>
<td>stable</td>
</tr>
<tr>
<td>Norfolk City</td>
<td>134.8</td>
<td>stable</td>
<td>130.9</td>
<td>stable</td>
<td>144.6</td>
<td>stable</td>
</tr>
<tr>
<td>Poquoson City</td>
<td>155.0</td>
<td>stable</td>
<td>153.0</td>
<td>stable</td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>Portsmouth City</td>
<td>140.1</td>
<td>stable</td>
<td>142.1</td>
<td>stable</td>
<td>135.4</td>
<td>stable</td>
</tr>
<tr>
<td>Suffolk City</td>
<td>152.4</td>
<td>stable</td>
<td>140.0</td>
<td>rising</td>
<td>166.9</td>
<td>stable</td>
</tr>
<tr>
<td>Virginia Beach City</td>
<td>146.5</td>
<td>stable</td>
<td>150.6</td>
<td>stable</td>
<td>149.7</td>
<td>stable</td>
</tr>
<tr>
<td>York County</td>
<td>137.4</td>
<td>stable</td>
<td>144.8</td>
<td>stable</td>
<td>134.3</td>
<td>stable</td>
</tr>
<tr>
<td>Virginia</td>
<td>128.3</td>
<td>*</td>
<td>128.3</td>
<td>*</td>
<td>133.1</td>
<td>*</td>
</tr>
<tr>
<td>National</td>
<td>124.2</td>
<td>stable</td>
<td>126.1</td>
<td>stable</td>
<td>124.0</td>
<td>stable</td>
</tr>
</tbody>
</table>

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

Breast cancer incidence rates in the MTA range from 128.6 new cases per 100,000 individuals per year in Gloucester County to 155.0 in Poquoson City (see Table 5). There are no significant trends among incidence rates for white women versus Black women, as the incidence rates are higher among white women in some places and higher for Black women in others. Incidence rates throughout the state of Virginia (128.3) are higher than national rates (124.2). The state has higher incidence rates among Black women (133.1) than among white women (128.3).

## Table 6. Tidewater Metro Area Breast Cancer In Situ Incidence Rate (Per 100,000)

<table>
<thead>
<tr>
<th></th>
<th>Age-Adjusted In Situ Incidence Rate</th>
<th>5-Year In Situ Incidence Rate Trend Direction</th>
<th>Age-Adjusted In Situ Incidence Rate for White Women</th>
<th>5-Year In Situ Incidence Rate Trend Direction for White Women</th>
<th>Age-Adjusted In Situ Incidence Rate for Black Women</th>
<th>5-Year In Situ Incidence Rate Trend Direction for Black Women</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chesapeake City</td>
<td>46.8</td>
<td>stable</td>
<td>45.1</td>
<td>stable</td>
<td>52.0</td>
<td>stable</td>
</tr>
<tr>
<td>Gloucester County</td>
<td>38.8</td>
<td>stable</td>
<td>42.6</td>
<td>*</td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>Hampton City</td>
<td>41.0</td>
<td>stable</td>
<td>37.3</td>
<td>stable</td>
<td>44.7</td>
<td>stable</td>
</tr>
<tr>
<td>Newport News City</td>
<td>40.5</td>
<td>stable</td>
<td>37.7</td>
<td>stable</td>
<td>47.1</td>
<td>stable</td>
</tr>
<tr>
<td>Norfolk City</td>
<td>40.8</td>
<td>stable</td>
<td>39.1</td>
<td>stable</td>
<td>46.5</td>
<td>stable</td>
</tr>
<tr>
<td>Poquoson City</td>
<td>44.5</td>
<td>stable</td>
<td>41.9</td>
<td>*</td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>Portsmouth City</td>
<td>48.9</td>
<td>stable</td>
<td>46.3</td>
<td>falling</td>
<td>52.0</td>
<td>stable</td>
</tr>
<tr>
<td>Suffolk City</td>
<td>47.4</td>
<td>stable</td>
<td>42.6</td>
<td>stable</td>
<td>57.1</td>
<td>stable</td>
</tr>
<tr>
<td>Virginia Beach City</td>
<td>41.3</td>
<td>stable</td>
<td>41.8</td>
<td>stable</td>
<td>42.0</td>
<td>stable</td>
</tr>
<tr>
<td>York County</td>
<td>42.4</td>
<td>stable</td>
<td>44.2</td>
<td>*</td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>Virginia</td>
<td>35.7</td>
<td>*</td>
<td>34.9</td>
<td>*</td>
<td>38.4</td>
<td>*</td>
</tr>
<tr>
<td>National</td>
<td>28.3</td>
<td>stable</td>
<td>29.7</td>
<td>stable</td>
<td>31.8</td>
<td>stable</td>
</tr>
</tbody>
</table>

Source: 2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
High rates of in situ breast cancer may indicate greater trend in incidence yet are more likely to be indicators that women are being screened in a timely fashion to catch this early pre-invasive stage of disease when it can be treated most successfully. In situ breast cancer incidence rates among women (overall total for all races) are higher in Tidewater MTA cities/counties than the national rate of 28.3 and the Virginia state rate of 35.7. (See table 6 - in situ). The lowest overall rates of in situ breast cancer are found in Gloucester County, Newport News, Norfolk, at 38.8, 40.5, and 40.8, respectively. In situ incidence rates are higher among Black women than among white women in every city and county in the MTA where data are available for both Black and white women.

| TABLE 7. TIDEWATER METRO AREA LATE-STAGE BREAST CANCER INCIDENCE RATE (PER 100,000) |
|----------------------------------|----------------------------------|----------------------------------|----------------------------------|
| Age-Adjusted Late-Stage Incidence Rate | Average Count of Cases that are Late-Stage | Age-Adjusted Late-Stage Incidence Rate for White Women | Average Count of Cases that are Late-Stage for White Women |
| Chesapeake City | 52.9 | 63.0 | 49.1 | 37.0 | National | 41.0 | 78641.0 | 41.4 | 62240.0 |
| Gloucester County | 67.4 | 13.0 | 66.0 | 11.0 | National | 41.0 | 78641.0 | 41.4 | 62240.0 |
| Hampton City | 55.1 | 39.0 | 56.8 | 17.0 | National | 41.0 | 78641.0 | 41.4 | 62240.0 |
| Newport News City | 53.4 | 50.0 | 56.2 | 26.0 | National | 41.0 | 78641.0 | 41.4 | 62240.0 |
| Norfolk City | 49.9 | 59.0 | 47.0 | 26.0 | National | 41.0 | 78641.0 | 41.4 | 62240.0 |
| Poquoson City | 55.9 | 3.0 | 55.1 | 3.0 | National | 41.0 | 78641.0 | 41.4 | 62240.0 |
| Portsmouth City | 57.0 | 28.0 | 65.0 | 13.0 | National | 41.0 | 78641.0 | 41.4 | 62240.0 |
| Suffolk City | 63.1 | 28.0 | 54.1 | 13.0 | 72.2 | 15.0 |
| Virginia Beach City | 51.2 | 117.0 | 52.9 | 84.0 | 53.9 | 27.0 |
| York County | 50.1 | 17.0 | 56.9 | 15.0 | National | 41.0 | 78641.0 | 41.4 | 62240.0 |
| Virginia | 49.2 | 2080.0 | 49.1 | 1478.0 | National | 41.0 | 78641.0 | 41.4 | 62240.0 |
| National | 41.0 | 78641.0 | 41.4 | 62240.0 | National | 41.0 | 78641.0 | 41.4 | 62240.0 |

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

As shown in Table 7, the age-adjusted, late-stage incidence rate of breast cancer among all women is highest in Gloucester County, at 67.4, with Suffolk City coming in second at 63.1 (see Table 7), the late-stage incidence rates across all the cities/counties are higher than the late-stage incidence rates in Virginia (49.2) and the national rate of 41.0. In the seven cities/counties where data is available for both Black and white women, late-stage incidence rates are higher for white women than Black women in three of the cities (Newport News, Portsmouth, and Hampton). The reverse is true for the remaining four cities. The largest disparity is in Suffolk City (72.2 among Black women as compared to 54.1 among white women) followed by Chesapeake City (63.4 Black versus 49.1 white women).
Map 1 shows the concentration of women who receive a late-stage breast cancer diagnosis annually in the Tidewater MTA. Newport News, Norfolk, Hampton, and Portsmouth cities show high concentrations of late-stage diagnoses, with most cases being Black women. Virginia Beach also shows high concentrations of diagnoses. However, most of those cases are in white women. The places farther from the center of the MTA have much lower concentration of diagnoses, reflecting the region’s population density.

### TABLE 8. TIDEWATER

<table>
<thead>
<tr>
<th></th>
<th>Age-Adjusted Mortality Rate</th>
<th>5-Year Mortality Rate Trend Direction</th>
<th>Age-Adjusted Mortality Rate for White Women</th>
<th>5-Year Mortality Rate Trend Direction for White Women</th>
<th>Age-Adjusted Mortality Rate for Black Women</th>
<th>5-Year Mortality Rate Trend Direction for Black Women</th>
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<tbody>
<tr>
<td>Chesapeake City</td>
<td>22.5</td>
<td>falling</td>
<td>18.9</td>
<td>falling</td>
<td>33.7</td>
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</tr>
<tr>
<td>Gloucester County</td>
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<td>*</td>
<td>21.6</td>
<td>*</td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>Hampton City</td>
<td>23.8</td>
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<td>16.9</td>
<td>falling</td>
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<td>30.7</td>
<td>stable</td>
</tr>
<tr>
<td>Norfolk City</td>
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<td>falling</td>
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<td>falling</td>
</tr>
<tr>
<td>Poquoson City</td>
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<td>*</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>Portsmouth City</td>
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<td>stable</td>
<td>23.8</td>
<td>stable</td>
<td>32.2</td>
<td>stable</td>
</tr>
<tr>
<td>Suffolk City</td>
<td>26.8</td>
<td>falling</td>
<td>16.2</td>
<td>falling</td>
<td>42.8</td>
<td>stable</td>
</tr>
<tr>
<td>Virginia Beach City</td>
<td>22.1</td>
<td>falling</td>
<td>22.3</td>
<td>falling</td>
<td>27.5</td>
<td>falling</td>
</tr>
<tr>
<td>York County</td>
<td>18.8</td>
<td>falling</td>
<td>19.1</td>
<td>falling</td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>Virginia</td>
<td>21.4</td>
<td>*</td>
<td>20.4</td>
<td>*</td>
<td>28.8</td>
<td>*</td>
</tr>
<tr>
<td>National</td>
<td>20.6</td>
<td>falling</td>
<td>20.1</td>
<td>falling</td>
<td>28.1</td>
<td>falling</td>
</tr>
</tbody>
</table>

Sources: 2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health); 2017 County Level Modeled Estimate Combining BRFSS and NHIS (US Centers for Disease Control and Prevention; State Cancer Profiles; National Institutes of Health)
The lowest overall mortality rates in the Tidewater MTA are reported in York County at 18.8 per 100,000 (see Table 8). Norfolk City reports the highest overall, age-adjusted mortality at 28.7. The highest mortality rate for Black women is reported in Suffolk City (42.8), which also reports the highest difference in rates between Black and white women with the mortality rate for white women at 16.2. Mortality rates for Black women are not available in Gloucester County, Poquoson City, and York County due to low Black populations (see Map 2). Importantly, for all counties where data are available, mortality rates are higher among Black women as compared to white women.

**MAP 2. TIDEWATER METRO AREA BLACK BREAST CANCER MORTALITY RATES**

Map 2 shows breast cancer mortality for the Tidewater MTA. Again, the mortality rate is higher for Black women than white women in all counties and cities where data is available. Map 2 highlights that Suffolk City has the highest Black breast cancer mortality, followed by Norfolk City. Chesapeake City, Newport News, and Portsmouth city also show mortality rates higher than the Black mortality rate for the state and nation, which is much higher than the overall mortality rates for white women.

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

<table>
<thead>
<tr>
<th>Location</th>
<th>Percent of Women Getting Mammograms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chesapeake City</td>
<td>75%</td>
</tr>
<tr>
<td>Gloucester County</td>
<td>68%</td>
</tr>
<tr>
<td>Hampton City</td>
<td>80%</td>
</tr>
<tr>
<td>Newport News City</td>
<td>72%</td>
</tr>
<tr>
<td>Norfolk City</td>
<td>74%</td>
</tr>
<tr>
<td>Poquoson City</td>
<td>81%</td>
</tr>
<tr>
<td>Portsmouth City</td>
<td>75%</td>
</tr>
<tr>
<td>Suffolk City</td>
<td>73%</td>
</tr>
<tr>
<td>Virginia Beach City</td>
<td>74%</td>
</tr>
<tr>
<td>York County</td>
<td>84%</td>
</tr>
<tr>
<td>Virginia</td>
<td>83%</td>
</tr>
<tr>
<td>National</td>
<td>73%</td>
</tr>
</tbody>
</table>

*Source: 2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)*
The percentage of women receiving a screening mammogram varies from 68% in Gloucester County to 84% in York County. Gloucester County (68%) and Newport News City (72%) are the only city/counties where the screening mammography rate does not meet or exceed the national rate of 73%. The rate meets or exceeds the state rate in Virginia of 83% in York County (84%). Although racially disaggregated data are not available at the county level, these data are available at the state level. In Virginia, 85% of Black women over age 40 received a screening mammogram in the last two years compared to 75% of white women.

Throughout the Tidewater MTA, Black women are more likely to die from breast cancer than their white counterparts, even though they are more likely to receive a screening mammogram and are not more likely to be diagnosed with the disease. The late-stage incidence rate is higher among Black than white women in some counties, but the reverse trend was seen in others. Patterns noted in the literature have not found clear relationships between disparities in Black women breast cancer mortality and rates of incidence or of screening mammography. A study in South Carolina, for example, found that while the breast cancer incidence rate was higher for European-American or Caucasian women compared to Black women (124 versus 118.5 per 100,000 women), the breast cancer mortality rate was higher for Black women (29.8 versus 21.3 per 100,000 women) (Samson et al., 2016). The study further reported that Black women were even more likely to have had a screening mammogram or clinical breast exam compared to white women (81.9% of Black women versus 74% of whites) and more likely to have late-stage breast cancer at the time of diagnosis (47% of Black women versus 35% of whites).

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

Research from other parts of the country may shed light on why the observed patterns exist. Tammemagi et al, for example, examined a cohort from a large health system in Detroit, Michigan, for 10 years (n=906, with 264 Black women and 642 white women) (Tammemagi et al., 2005). The authors found that Black breast cancer patients experienced more recurrence of their cancer, more cancer progression, and worse all-cause breast cancer and competing-causes survival. Compared to white women, Black women had shorter overall survival (Hazard Ratio=1.34, 95% CI: 1.11, 1.62).

**Community Member Perspectives across the Breast Cancer Care Continuum**

This section summarizes perspectives from community members and health care providers collected through focus group discussions and interviews, which provide additional insights at each phase of the breast cancer continuum of care in the Tidewater MTA. Based on a review of the quantitative findings, priority cities for qualitative data collection in the Tidewater MTA were identified: Newport News, Norfolk, and Portsmouth, as well as neighboring Chesapeake and Hampton. Breast cancer disease burden appears highest in Chesapeake, Newport News, and Norfolk. Portsmouth, Norfolk, Newport
News, and Hampton have the greatest SDOH burden, and score poorly on other health measures as well.

The themes shared below represent the perspectives of community members from these priority counties, not the entire Tidewater MTA.

**Breast Cancer 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). Although racially disaggregated data are not available at the city or county level, in Virginia, 85% of Black women over age 40 received a screening mammogram in the last two years compared to 75% of white women. The qualitative data indicate that people believe there are still barriers to breast cancer screening. Focus group participants’ perspectives give some indication of the experiences of Black women seeking and obtaining breast cancer screening in general and in the Tidewater area specifically.

**Family History.** Community members noted that knowing their family history related to breast cancer influences their screening and prevention behavior. Several people cited lack of awareness of breast cancer history in their families until after they were diagnosed. They believe that knowing this history would have allowed them to share this with their providers and they may have begun screening earlier. Also, if they knew their family history and shared that with their provider, the doctors initiated conversations on when to screen.

> “Because of the fact that mom had it and [my husband’s] mother, when I took [my daughters] to the doctor, they refused to do the test on them because they said they were too young and insurance would not cover it. Well, my husband and I made the decision that insurance doesn’t have to cover it.” – Newport News Survivor

> “My grandma had breast cancer, but she didn’t pass away from breast cancer. She had later got bone cancer, so she passed away. And I’m 25 so I thought, they said my mom never had it or anything, it wasn’t generational. So, I’m thinking that because I’m 25, I just need to wait till I’m 30, I didn’t know that I should go get checked. So, I have a twin sister, so now that I had breast cancer, all my sisters, I got three more. Now they’re young so they all got checked.” – Norfolk Survivor

> “When you, or someone you love or someone close to you has had breast cancer, because for me my aunt and my great aunt, both on my mom’s side had breast cancer. So, because of that when I had discussions with my doctor, I was saying, ‘Okay, when do I need to start having these screenings? And he told me, I needed to have them earlier because of that, because I knew in my family that it was there, I was more aware.” – Newport News Undiagnosed
Screening Access. Providers, undiagnosed women, and survivors noted that there are free screening programs available through the Health Department and other sources. However, focus group participants noted there is a lack of awareness of the existence of these programs and transportation issues may make it difficult to access the service. They noted that the lack of awareness around screening programs and the perception of a high cost being associated with getting a screening mammogram can present barriers to screening.

“Does not surprise me, being part of the community, why this a hot spot. People are not aware of resources. They don’t know what is available if they do not have insurance, they don’t know how to apply or that support exists.” – Provider

“I moved from another city and it took me two years to get screened because I didn’t have insurance. I tried everything. I finally got one of those mobile truck things and they were willing to help, I had to go through the health department, and she pushed for me to get women’s all over wellness.” – Norfolk Survivor

“The city of Portsmouth has over five zip codes. In 2012 I was wondering ‘why is Portsmouth ranked number one and two of Black women dying from breast cancer’? I did a follow up to see where the information was going out of these five zip codes, the information was only getting into one zip code and that was in the affluent area of Portsmouth. So then when you get to the less affluent area and you start asking, ‘Do you understand what a screening mammogram is?’ and you find out that the education isn’t there. They’re not going to get these mammograms because they’re thinking that a screening mammogram is automatically removing their breasts. So, you know that that’s some of the systematic stuff. You got five zip codes, but my information only goes to one of those zip codes. And it’s ironic that the zip code where the information isn’t going is the zip code where the women are dying.” – Portsmouth Undiagnosed

Fear. Although screening mammography rates for Black women are higher than white women, in all focus groups, participants described how the discomfort of screening mammography and the fear of finding cancer stopped women from accurately following breast cancer screening guidelines.

“They don't like the fear, they hate it. One of my friends had seven sisters, three had died from breast cancer. So her sister had a fear. She knew for years that she had a lump in her breast. Not until it started oozing did she go to the doctor, and then somebody had to push her.” – Portsmouth Undiagnosed

“My mother didn’t get her first screening mammogram until she was almost 65. And she has two sisters that were diagnosed with breast cancer, and so I got on her so hard I said, ‘Look lady, you going.’” – Norfolk Survivor
"If I know, I can’t deal with it. If I don’t know, what am I going to do about it? If I’m going to die... because at one time breast cancer is like a death sentence and especially to the African American.” – Norfolk Survivor

“I was on the phone with the lady, and she was like, “You sound young,” on the phone. She said, “Honey, I don’t know if you’re old enough to have your [breast] examined, but they take your [breast], and I mean they smash your [breast]. I didn’t even know a [breast] could get so flat.” She’s just going on, and inside, I’m cringing because I’m scared like, ‘Oh my God, I have to get this done, and this lady is freaking me out on the phone’. “ – Norfolk Undiagnosed

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

“In general, I mean you’re not going to go to the doctor and spend money on a co-pay that may take away from something else you have to do in your household that depends on your financial situation. You may not even go to the doctor until you get some symptoms, something’s leaking or oozing.” – Norfolk Undiagnosed

“If you go in on a free screening mammogram and they say you have breast cancer, where do you go from there if you got the exam free, but you don’t have the insurance to cover everything else? And sometimes, it’s the fear of just knowing that you may have it and you don’t have the resources after the diagnosis.” – Portsmouth Undiagnosed

Diagnosis
While screening is readily available within the Tidewater MTA, focus group findings suggest that community members experience barriers at the diagnosis stage of the breast cancer continuum of care. Many survivors characterized the care that they received at this stage as being inefficient, inaccessible, and not patient-centered, resulting in significant mental strain. For example, one survivor noted that the steps involved from screening to formal diagnosis could have been more streamlined. This, in turn, may be associated with delayed diagnosis, influencing the breast cancer mortality rates documented earlier in the report.

Difficulty Getting Diagnosed. Community members reported women finding lumps or noticing abnormalities and having their symptoms treated as if they weren’t urgent in nature. Women had to “push” their providers to follow-up and schedule further testing.
“I had to push to even get to the diagnosis. I was like, something is wrong. And so, they weren’t hearing, they were like, “Uh.” And then when I took charge of my own care and I was like, no, this is not what you’re going to do. This is what you’re going to do. They wanted to, like we talked before about proving our intelligence. They wanted me to be dumb and just do whatever they said. And I was like, no, I am 32 years old.” – Newport News Survivor

“Even going to the doctor and going by myself, because I’m not a person where [I share things]. And, I have to get out of that, not putting my things on other people. It’s like this is me. I’m going to deal [with] it. Not knowing from getting three mammograms to you still telling me you don’t know yet. Ultrasounds. And, my next step is a biopsy. I’m scared. I don’t know. I don’t even want to even tell my mother. That’s been the hardest.” – Norfolk Undiagnosed

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

“I couldn’t like, that fear sets in. That fear is like, what am I going to do? And the first thing, Lord, I’m getting ready to die and leave those kids with that man, with those kids and he relies on me, and you know. Okay, so right here and there, I have to make decisions. Okay? I cried and it was short lived. That cry, that fear was short lived, because right now they’re making appointments.” – Newport News Survivor

“Just that scare of waiting a week from the biopsies ... to get the results. I remember the day of the results, my mother was cleaning up the wounds from the biopsy, and I just burst into tears. I think it just hit me that it was possible that I could have breast cancer. I’ve had that same scare on three different occasions now.” – Newport News Undiagnosed

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 Tidewater MTA focus group participants.

Insurance Barriers. Community members shared that insurance coverage factors into the decisions to begin and complete treatment. Survivors noted that they observed providers making treatment
decisions based on the type of insurance a patient has. They shared that type of insurance should not keep women from receiving the best possible care. Others shared that women make treatment decisions based on their perceived ability to pay.

“Insurance is a big factor. Afterwards, as far as medications were concerned because I had to change medication one, two, three after I had my breast cancer surgery [after an emergency hysterectomy]. I used to be in so much pain when walking, and I used to be at work crying. So finally, we were like, okay, change the medication. [The provider] is like, okay, I don’t care if you’re in pain, but this is what your insurance can afford. Okay? And the nurse said, well if you can afford it, that's fine. Don't worry about if I can afford it, but if this medication is going to relieve me from that pain, not being able to walk, not being able to get out of the bed, not being able to care for my household. And she told me before she would write the prescription and said, well, I’m going to need you to call your insurance company to see if it’s covered because the medication is 1,200 dollars a month. Okay? And she looked, she said, oh, you have government insurance. You should be good. Where do you work? None of your business.” – Newport News Survivor

“Most are Black who don't follow-up. I think it is because of not understanding their rights for coverage. They didn’t know that reconstruction is their right.” – Provider

Provider Approach. Women diagnosed with breast cancer want strong navigation programs and providers with empathic skills in their bedside manner, who explain cancer treatment thoroughly, honestly, and in non-technical language while being respectful of their patients.

“He’s got to be sensitive to our needs, and he’s got to be willing to take the time to listen, cause a lot of them don’t.” – Newport News Survivor

“Surgeons are more compassionate about breast cancer than they used to be. How women are treated was historically brutal. One client had an experience that was deforming. The surgeon cut off her breasts. She was mangled; they didn’t remove excess skin. The surgeon laughed at the patient when asked and said, 'Be happy you don’t have breast cancer’.” – Provider

“My provider was really great. She listened to me. Being a good listener, very empathetic and at that point in time, when I started back in 2014, I was just really interested in clean eating and everything was clean. It had to be clean and I guess during, because of the nature of my special case of cancer. Then she was just open to it, we talked about acupuncture as an idea of alternative medicine, you know.” – Newport News Survivor
Lack of Patient-centered Care. Survivors shared that they made treatment decisions without full knowledge of possible options and side effects. Some survivors pushed to get more information while others just went with the doctor’s recommendation. Below are illustrative quotes reflecting issues like poor communication that survivors experienced.

“Well, I was so upset, and I just went with what they suggested. They suggested that I have the lumpectomy. They didn't tell me what stage it was. They just said it was early, so they did the lumpectomy, and they recommended chemo and radiation.” – Newport News Survivor

“They suggested mastectomy because I was stage three, and I didn't even know anything about reconstruction. And when they thought about reconstruction, I didn't want an implant. So, the doctor said, the surgeon said, well, we'll send you to the plastic surgeon. I'm like a plastic surgeon?” – Newport News Survivor

“Because my doctor told me, well even that they literally told me, they were like, well this is what you're choosing, but you know it's going to come back. It's not a matter of if, it's when. They were really upset with me that I decided not to have a mastectomy, like really upset. And so, they pushed me in a mastectomy as hard as they could.” – Newport News Survivor

“And so, I pushed my doctor and what they decided, because they thought I didn't know any better. I went to medical school briefly, so I knew a little bit. And they thought I didn't understand the language. So, they decided, "Well, we're just going to remove the whole breast." There are several other options before we get there. Several other options.” – Newport News Survivor

Social support. Undiagnosed women and survivors all noted the importance of social capital and support for successful treatment. However, some survivors shared that they didn’t share their diagnosis because they didn’t want to burden their family members and others in their networks.

“I've had two close friends go through breast cancer. I've had one who had a double mastectomy. I've had one who had the surgery that wasn't the mastectomy and she still had to go back and get more removed. Still had to have the radiation and all the treatment. I think it did make a difference for them that they had their core group of friends, and Black women, supporting them and saying, "You're going to get through this. We got you. We're behind you." We weren't going through it.” – Newport News Undiagnosed
"At the time, I was living with my mother and she didn’t know when I went in to have that lumpectomy. I call an Uber to have my lumpectomy and everything, and come back home, and she’s like, why you not at work? I said, I don't feel good. I took some days. I told nobody. I went through the entire process by myself. If she hadn’t asked me, she would have never known." – Newport News Survivor

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

“If you don’t seek out the right doctors, you’re not going to get the same treatment. And sometimes that can be a struggle depending on who your primary is, and how open they are. But it’s up to us to take that step to say, “Oh no, no, no, no, no.” And then you got to do your research, and then you got to go and ask them questions. You have to seek out somebody.” – Newport News Survivor

“And I just did chemotherapy and chemotherapy. It causes extra problems, and I didn’t know that. So, I feel like going in as black women we have to do our own research. You need to do your own research because I remember a lot I was depending on these doctors. You have to make sure you have these good doctors. Doctors could be good but just because you’re [an] African American woman they not taking extra care.” – Norfolk Survivor

**Survivorship**
Survivors shared that emotional and mental health support was needed as they experienced depression and loneliness as a survivor. Undiagnosed women also observed that breast cancer survivors they know experienced depression.

“Theyir relationships fell apart because their spouses or significant others couldn’t deal with it. And they didn’t have any moral support, they didn't have any friends or sisters that they could talk to because they were the same way, they were afraid, they were fearful.” – Norfolk Survivor

“My sister didn’t come around; she lives out of town. When she came to town, she didn’t come see me. It’s like I was already dead. My best friend of 50 years can’t come around me.” – Norfolk Survivor
“I know two women who are more than five-year survivors, but they still go through depression because they are afraid of it coming back and all. So, they’ve been a survivor over five years, but they go through periods of depression because they are afraid of it coming back and then there’s that thing when it comes back, it comes back with a vengeance. That’s a phrase out there. They fear tomorrow rather than living in today because they worry about it coming back, of what they’ve gone through, rather than being excited about having gone through and being here today.” – Portsmouth Undiagnosed
Section 2 Findings: Systemic and Social Determinants of Health

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

Residential Segregation

The Tidewater MTA is segregated along racial and socioeconomic lines, creating stark contrasts by geography. Higher concentrations of Black people live around the center of the MTA (Map 3), with the highest percentage (53%) reported in Portsmouth City (see Table 4). Hampton City has the next highest concentration at 50% followed by Norfolk City (42%), Suffolk City (42%), and Newport News City (41%). Poquoson City has the lowest concentration, with Black people accounting for just 1% of its total population.

In addition to the MTA as a whole being racially segregated (with most people of color living in just a few of the places - see Table 4), many places in the MTA are also internally racially segregated. Internal segregation can be measured using the Black/white dissimilarity index to assess the extent to which there may be residential segregation (see Map 4). Index scores range from 0 to 100 and correspond to the percentage of people within a racial group who would need to relocate for a place 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% of whites within a particular place would need to move to a different neighborhood within the county or city to achieve racial integration.

Source: American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)
As seen in Map 4, Norfolk City and Portsmouth City have the highest scores (53 and 55, respectively), indicating that people living in those county-equivalents are more segregated than people living in the other cities/counties of the MTA. The next highest score is in Poquoson City, at 47. The lowest scores are reported in Gloucester County at 22, indicating that the racial distribution of residents in this location is more even.

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

“At that time where I lived, there was ‘the front of the hospital and the back of the hospital’. So, if you lived in front of the hospital, that was primarily African Americans, but on the other side of the hospital was a white community. White people were very clear about keeping it “white and right” back there.” – Newport News Undiagnosed

Examples of institutionalized racism are the local, state, and federal housing policies that generated and perpetuate residential segregation in the U.S. They include exclusionary zoning laws, racially-restrictive covenants, and redlining – the practice of identifying and systematically discriminating against neighborhoods based on their racial makeup. Between 1933 and 1954, the Federal Housing Administration along with the Home Owners’ Loan Corporation (HOLC) a federally-funded program to help homeowners refinance their mortgages, introduced redlining policies in over 200 cities.
Field agents with the federal government assigned grades to neighborhoods ranging from A/best to D/hazardous. These color-coded “residential security maps” were used by government agencies, mortgage lenders, appraisers and other real estate professionals to inform their lending and real estate practices and policies. Officials declared sections of these cities as “hazardous” because Black peoples lived in these neighborhoods, making it difficult for people of color to obtain mortgages and become homeowners. In so doing, the government excluded these individuals and communities from investment and resources. Areas of advantage (where whites lived) became more advantaged and areas of disadvantage (where people of color lived) became more disadvantaged (Rothstein, 2017). Redlining set up feedback loops, as the more advantaged white population moved into white areas, thereby making them even more advantaged and whiter. For this reason, the high level of segregation that currently exists between Blacks and whites in these cities (see racial segregation section above) can be traced – at least in part – to redlining.

Map 5 shows areas within the Tidewater MTA that were included in the “residential security” maps created by HOLC agents in the first half of the twentieth century. Portions of Newport News City, Hampton City, Norfolk City, Portsmouth City, Chesapeake City, and Virginia Beach City appear on the 1937 map of Greater Norfolk, Virginia.

**Personally Mediated Racism**

Data suggest that in addition to institutionalized racism, Black people in the Tidewater 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, Norfolk City reports the highest number of Black people killed by police at three, Chesapeake City reports the highest number of hate crimes at six, and Virginia Beach City reports the highest number of Fair Housing Act cases (by a significant margin) at 29.

<table>
<thead>
<tr>
<th>County</th>
<th>Number of Black People Killed by Police</th>
<th>Number of Hate Crimes Committed with a Race/Ethnicity/Ancestry Bias Motivation</th>
<th>Number of Fair Housing Act Cases Filed with a Race Basis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chesapeake City</td>
<td>2</td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td>Gloucester County</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Hampton City</td>
<td>0</td>
<td>3</td>
<td>12</td>
</tr>
<tr>
<td>Newport News City</td>
<td>1</td>
<td>2</td>
<td>9</td>
</tr>
<tr>
<td>Norfolk City</td>
<td>3</td>
<td>1</td>
<td>15</td>
</tr>
<tr>
<td>Poquoson City</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Portsmouth City</td>
<td>2</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td>Suffolk City</td>
<td>0</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Virginia Beach City</td>
<td>2</td>
<td>5</td>
<td>29</td>
</tr>
<tr>
<td>York County</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
</tbody>
</table>

Sources: 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)
To date, most of the research on racism and health has focused on the relationships between personally mediated racism and health, and interpersonal racism and health. A growing body of research demonstrates how personally mediated racism has long-term and adverse effects on psychological wellbeing, mental health, and other healthy-living practices (such as alcohol and drug use, sleep disturbance, and eating patterns) (Bailey et al., 2017; Kwate et al., 2003). The research also points to the links between personally mediated racism and biomarkers of disease, including allostatic load (Williams & Mohammed, 2013).

The experiences of community members from the Tidewater MTA provide additional insights about experiences of personally mediated racism that Black people experience.

“I think you are always on edge. You are not at rest; you are always thinking. So, your body is always in this tense place and I could feel it in my shoulders, you just feel the weight and you drag.” – Norfolk Survivor

Health Disparities

Data suggest that there are disparities in the Tidewater MTA in terms of overall health and wellbeing. Overall, Poquoson City reports the best health metrics with the fewest percent of adults reporting “fair” or “poor” health at 11%, fewest average number of poor physical health days per month at 2.9, and the fewest average number of poor mental health days per month at 3.2. Hampton City reports among the poorest health measures across all three metrics with 19% of adults reporting “fair” or “poor” health, 3.8 average poor physical health days per month, and 3.7 average poor mental health days per month.

<table>
<thead>
<tr>
<th>County</th>
<th>County Health Rankings Percentile</th>
<th>Percent of Adults Reporting &quot;Fair&quot; or &quot;Poor&quot; Health</th>
<th>Average Number of Poor Physical Health Days per Month</th>
<th>Average Number of Poor Mental Health Days per Month</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chesapeake City</td>
<td>28%</td>
<td>14%</td>
<td>3.2</td>
<td>3.3</td>
</tr>
<tr>
<td>Gloucester County</td>
<td>37%</td>
<td>12%</td>
<td>3.0</td>
<td>3.3</td>
</tr>
<tr>
<td>Hampton City</td>
<td>67%</td>
<td>19%</td>
<td>3.8</td>
<td>3.7</td>
</tr>
<tr>
<td>Newport News City</td>
<td>65%</td>
<td>19%</td>
<td>3.6</td>
<td>3.8</td>
</tr>
<tr>
<td>Norfolk City</td>
<td>71%</td>
<td>17%</td>
<td>3.9</td>
<td>3.8</td>
</tr>
<tr>
<td>Poquoson City</td>
<td>6%</td>
<td>11%</td>
<td>2.9</td>
<td>3.2</td>
</tr>
<tr>
<td>Portsmouth City</td>
<td>91%</td>
<td>21%</td>
<td>3.8</td>
<td>3.9</td>
</tr>
<tr>
<td>Suffolk City</td>
<td>32%</td>
<td>16%</td>
<td>3.3</td>
<td>3.4</td>
</tr>
<tr>
<td>Virginia Beach City</td>
<td>17%</td>
<td>13%</td>
<td>3.2</td>
<td>3.4</td>
</tr>
<tr>
<td>York County</td>
<td>5%</td>
<td>11%</td>
<td>3.0</td>
<td>3.4</td>
</tr>
</tbody>
</table>

Source: 2019 County Health Rankings (County Health Rankings)
The County Health Rankings (CHR) similarly highlight county-level differences in health and wellbeing across the Tidewater MTA. CHR are derived from over 30 measures of health-related outcomes and factors to give an overall health ranking of a county or county-equivalent compared to other counties and county-equivalents in the same state (See Figure 2). York County and Poquoson City in the Tidewater MTA rank in the top 5% and 6% respectively of all places in Virginia. Portsmouth City has the poorest health outcomes in the MTA with 91% as its CHR percentile score.

In terms of health behaviors, 43% of adults are obese in Poquoson City - the highest rate of obesity in the MTA. Portsmouth City has the highest rate of adults who are physically inactive at 28% (Table 12). Virginia Beach City has the highest rate of excessive drinking at 22%, followed by Norfolk City at 21%. York County and Virginia Beach City have the lowest rates of obesity at 29%. York County also has the lowest rate of physical inactivity at 19%. Portsmouth City and Newport News report the lowest rates of excessive drinking in the MTA, both at 16%.

### TABLE 12. TIDEWATER METRO AREA HEALTH BEHAVIORS

<table>
<thead>
<tr>
<th>County</th>
<th>Percent of Adults who are Obese</th>
<th>Percent of Adults who Drink Excessively</th>
<th>Percent of Adults who are Physically Inactive</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chesapeake City</td>
<td>34%</td>
<td>17%</td>
<td>23%</td>
</tr>
<tr>
<td>Gloucester County</td>
<td>32%</td>
<td>18%</td>
<td>23%</td>
</tr>
<tr>
<td>Hampton City</td>
<td>38%</td>
<td>18%</td>
<td>22%</td>
</tr>
<tr>
<td>Newport News City</td>
<td>32%</td>
<td>16%</td>
<td>22%</td>
</tr>
<tr>
<td>Norfolk City</td>
<td>32%</td>
<td>21%</td>
<td>23%</td>
</tr>
<tr>
<td>Poquoson City</td>
<td>43%</td>
<td>19%</td>
<td>22%</td>
</tr>
<tr>
<td>Portsmouth City</td>
<td>30%</td>
<td>16%</td>
<td>28%</td>
</tr>
<tr>
<td>Suffolk City</td>
<td>34%</td>
<td>17%</td>
<td>26%</td>
</tr>
<tr>
<td>Virginia Beach City</td>
<td>29%</td>
<td>22%</td>
<td>22%</td>
</tr>
<tr>
<td>York County</td>
<td>29%</td>
<td>18%</td>
<td>19%</td>
</tr>
</tbody>
</table>

*Source: 2019 County Health Rankings (County Health Rankings)*
Overall life expectancy in the Tidewater MTA is lowest in Portsmouth City at 74 years and highest in York County at 83 (Table 13). Disparities tend to exist between white and Black people across the MTA with all but one place (Gloucester County) reporting higher life expectancies for whites than Black people. The largest disparities are reported in Norfolk City and Newport News City, where whites live an average of four years longer than their Black counterparts (77 years versus 73 years in Norfolk City, 78 years versus 74 years in Newport News).

Premature age-adjusted mortality measures the number of deaths per 100,000 among people under age 75. Portsmouth City has the highest premature age-adjusted mortality rate at 559 (Table 14). Similar to life expectancy, racial disparities that show higher premature mortality for Black people versus whites exist for every county-equivalent, except for Gloucester County where the rate for Black people is 377 and for whites is 425. The largest disparity exists in Norfolk City, where the age-adjusted premature mortality rate is 409 for whites and 627 for Black people. The second-largest disparity exists in Portsmouth City where the rate is 506 for whites and 634 for Black people.
Access to Health Services

Data suggest that there are significant disparities in the health system in the Tidewater 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 Suffolk City, 100% of the population is medically underserved. Norfolk City (38%), Gloucester County (35%), Newport News (34%), and Hampton City (32%) each have approximately one third of their population medically underserved. A quarter of the population (25%) is medically underserved in Portsmouth City. Meanwhile, Poquoson City reports 0% of their population designated as medically underserved, Virginia Beach 4%, York County 11%, and Chesapeake City 12%.

### TABLE 15. TIDEWATER METRO AREA HEALTH SYSTEMS

<table>
<thead>
<tr>
<th>County</th>
<th>Percent of Total Population that is Medically Underserved</th>
<th>Number of PCPs</th>
<th>Persons per PCP</th>
<th>Number of &quot;Other&quot; PCPs</th>
<th>Persons per &quot;Other&quot; PCP</th>
<th>Number of Private PCPs</th>
<th>Number of Private Oncologists</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chesapeake City</td>
<td>12%</td>
<td>191</td>
<td>1,246</td>
<td>458</td>
<td>218</td>
<td>4</td>
<td>7</td>
</tr>
<tr>
<td>Gloucester County</td>
<td>35%</td>
<td>22</td>
<td>1,692</td>
<td>54</td>
<td>1,865</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Hampton City</td>
<td>32%</td>
<td>58</td>
<td>2,335</td>
<td>81</td>
<td>1,235</td>
<td>5</td>
<td>9</td>
</tr>
<tr>
<td>Newport News City</td>
<td>34%</td>
<td>102</td>
<td>1,783</td>
<td>125</td>
<td>797</td>
<td>12</td>
<td>5</td>
</tr>
<tr>
<td>Norfolk City</td>
<td>38%</td>
<td>237</td>
<td>1,034</td>
<td>168</td>
<td>594</td>
<td>126</td>
<td>2</td>
</tr>
<tr>
<td>Poquoson City</td>
<td>0%</td>
<td>6</td>
<td>2,003</td>
<td>0</td>
<td>*</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Portsmouth City</td>
<td>25%</td>
<td>49</td>
<td>1,944</td>
<td>128</td>
<td>782</td>
<td>7</td>
<td>4</td>
</tr>
<tr>
<td>Suffolk City</td>
<td>100%</td>
<td>87</td>
<td>1,026</td>
<td>101</td>
<td>992</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Virginia Beach City</td>
<td>4%</td>
<td>338</td>
<td>1,339</td>
<td>87</td>
<td>1,143</td>
<td>16</td>
<td>3</td>
</tr>
<tr>
<td>York County</td>
<td>11%</td>
<td>82</td>
<td>829</td>
<td>61</td>
<td>1,652</td>
<td>7</td>
<td>5</td>
</tr>
</tbody>
</table>

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
The health systems map (Map 6) shows the concentration of health care facilities in the Tidewater MTA, and generally reflects population density across the metro. Most Federally Qualified Health Centers (FQHCs) and hospitals are in Newport News City, Hampton City, and Portsmouth City. Most of the screening mammogram facilities and NCI National Community Oncology Research Program (NCORP) sites are located in the county-equivalents in the center of the MTA with the largest concentrations in Virginia Beach and clusters in Newport News City and Hampton City. The fewest facilities exist in Poquoson City which has no facilities listed and few if any facilities lie in the outskirts of Suffolk City, Chesapeake City, Virginia Beach, and Gloucester County. The MTA lists 3 NCORP sites, all close to the center of the MTA and no comprehensive cancer centers.
TABLE 16. TIDEWATER METRO AREA BREAST CANCER RESOURCES

<table>
<thead>
<tr>
<th>County</th>
<th>Number of Mobile Screening mammography Centers</th>
<th>Number of Cancer Coalitions</th>
<th>Number of Survivor/Support Groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chesapeake City</td>
<td>2</td>
<td>1</td>
<td>20</td>
</tr>
<tr>
<td>Gloucester County</td>
<td>0</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Hampton City</td>
<td>1</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Newport News City</td>
<td>0</td>
<td>1</td>
<td>25</td>
</tr>
<tr>
<td>Norfolk City</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Poquoson City</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Portsmouth City</td>
<td>0</td>
<td>1</td>
<td>15</td>
</tr>
<tr>
<td>Suffolk City</td>
<td>0</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Virginia Beach City</td>
<td>0</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>York County</td>
<td>0</td>
<td>1</td>
<td>3</td>
</tr>
</tbody>
</table>

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

Availability of breast cancer resources vary across the MTA. Chesapeake City, with two, and Hampton City, with one, are the places with mobile screening mammography centers. Chesapeake City is also among areas with a sizable number of survivor support groups (20). Newport News has 25 and Portsmouth City 15 survivor support groups, while other cities/counties range from four to having none in Poquoson City. All the cities/counties have one to two cancer coalitions, with a total of 14 listed in the MTA.

It is important to note that the cities/counties in which people reside are not necessarily the same as those where 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 cities/counties to access health services. There are also many government complexes in the Tidewater MTA, that include the Langley Air Force base in Hampton City, naval and air stations in Norfolk City, and a US Coast guard stations in Portsmouth as well as other complexes that may offer unique health care services.

Social and Economic Vulnerability

Social determinants affect health outcomes – such as breast cancer – for individuals and communities. These play out not just across individual lifetimes, but generationally. Disadvantages compound in certain communities, which exacerbates and cements a wide range of negative outcomes and existing burdens, including with regard to health (Cozier et al., 2009; Institute of Medicine of the National Academies, 2011). The Social Vulnerability Index (SVI) of each county can be seen in (Map 7). The SVI is calculated by the CDC, and a county’s score “refers to the resilience of communities when confronted by external stresses on human health, stresses such as natural or human-caused disasters, or disease outbreaks” (e.g., such as hurricanes, fires, and COVID-19). Scores range from 0.0 to 1.0, with scores closer to 1.0 indicating greater vulnerability. Portsmouth City has the highest SVI score at 0.80. Other county-equivalents with particularly high SVI scores are: Norfolk City at 0.77, Newport News City at 0.76, and Hampton City at 0.68. Poquoson City and Gloucester County report the lowest SVI scores at 0.0 and 0.03. Individual factors influencing a county’s SVI score can be parsed by looking at specific indicators.
Across the Tidewater MTA there are places experiencing economic insecurity. Norfolk City reports the highest percentage of the population below 200% FPL in the MTA, at 41% and the highest percentage of the population that is uninsured at 13% (Table 17). Gloucester County reports the highest percentage of Black women over the age of 45 who live under the poverty line at 28%, followed by Norfolk City at 25%. Poquoson City reports the lowest percentages across all three metrics with 3% uninsured, 14% of the population below 200% FPL, and 0% of Black women over 45 living under the poverty line.

Source: 2016 Social Vulnerability Index (US Centers for Disease Control and Prevention)
### TABLE 17. TIDEWATER METRO AREA ECONOMIC SECURITY

<table>
<thead>
<tr>
<th>County</th>
<th>Percent of Population that is Uninsured</th>
<th>Percent of Population Below 200% FPL</th>
<th>Percent of Black Women Over Age 45 who Live Below Poverty Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chesapeake City</td>
<td>7%</td>
<td>22%</td>
<td>10%</td>
</tr>
<tr>
<td>Gloucester County</td>
<td>8%</td>
<td>22%</td>
<td>28%</td>
</tr>
<tr>
<td>Hampton City</td>
<td>10%</td>
<td>34%</td>
<td>14%</td>
</tr>
<tr>
<td>Newport News City</td>
<td>11%</td>
<td>36%</td>
<td>17%</td>
</tr>
<tr>
<td>Norfolk City</td>
<td>13%</td>
<td>41%</td>
<td>25%</td>
</tr>
<tr>
<td>Poquoson City</td>
<td>3%</td>
<td>14%</td>
<td>0%</td>
</tr>
<tr>
<td>Portsmouth City</td>
<td>11%</td>
<td>38%</td>
<td>19%</td>
</tr>
<tr>
<td>Suffolk City</td>
<td>7%</td>
<td>25%</td>
<td>17%</td>
</tr>
<tr>
<td>Virginia Beach City</td>
<td>8%</td>
<td>23%</td>
<td>9%</td>
</tr>
<tr>
<td>York County</td>
<td>5%</td>
<td>16%</td>
<td>7%</td>
</tr>
</tbody>
</table>

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

### MAP 8. TIDEWATER METRO AREA HOUSING-COST BURDEN

Source: 2016 Comprehensive Housing Affordability Strategy dataset (US Department of Housing and Urban Development)
The measure illustrated in Map 8 indicates the percentage of renters and homeowners that spend 30% or more of their total income on housing. Norfolk City has the highest percentage of households that are housing-cost burdened in the metro area at 44%. Portsmouth City and Hampton City fall close behind at 41% and 40%, respectively. Housing costs are a burden across the MTA with the lowest percentage in Poquoson City where a quarter of the population is housing-cost burdened.

### TABLE 18. TIDEWATER METRO AREA FOOD SECURITY

<table>
<thead>
<tr>
<th>County</th>
<th>Percent of Population that is Food Insecure</th>
<th>Percent of Total Population with Limited Access to Healthy Foods</th>
<th>Percent of Black Households Receiving SNAP/EBT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chesapeake City</td>
<td>11%</td>
<td>5%</td>
<td>15%</td>
</tr>
<tr>
<td>Gloucester County</td>
<td>8%</td>
<td>3%</td>
<td>12%</td>
</tr>
<tr>
<td>Hampton City</td>
<td>18%</td>
<td>10%</td>
<td>17%</td>
</tr>
<tr>
<td>Newport News City</td>
<td>17%</td>
<td>6%</td>
<td>24%</td>
</tr>
<tr>
<td>Norfolk City</td>
<td>19%</td>
<td>8%</td>
<td>29%</td>
</tr>
<tr>
<td>Poquoson City</td>
<td>5%</td>
<td>5%</td>
<td>0%</td>
</tr>
<tr>
<td>Portsmouth City</td>
<td>20%</td>
<td>4%</td>
<td>22%</td>
</tr>
<tr>
<td>Suffolk City</td>
<td>14%</td>
<td>6%</td>
<td>23%</td>
</tr>
<tr>
<td>Virginia Beach City</td>
<td>10%</td>
<td>3%</td>
<td>15%</td>
</tr>
<tr>
<td>York County</td>
<td>8%</td>
<td>4%</td>
<td>11%</td>
</tr>
</tbody>
</table>

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

As reflected in many other socioeconomic indicators, Poquoson City reports the lowest percentage of the population as food insecure at 5%, and Portsmouth City reports the highest at 20% (see Table 18). Hampton City and Norfolk City report the highest percentages of their respective populations with limited access to healthy foods at 10% and 8%. Regarding food security in the Tidewater MTA, Norfolk City has the highest percent of Black households receiving SNAP/EBT at 29% and Poquoson City has the lowest at 0%.
Map 9 illustrates the location of food deserts throughout the Newport MTA. Food deserts are census tracts designated by the USDA as low-income areas with low access to food within one mile. Most of the food deserts in the MTA are in Hampton City, Norfolk City, Newport News City, Chesapeake City, Virginia Beach City, and Suffolk City. Notably, there are no food deserts in Poquoson City, York County, and Gloucester County.

“I worked with a lot of clients around the city and one particular day I remember I was going to a client’s home, and she asked if I could stop and get her baby some milk. And I said, okay. And I stopped at all the stores near her neighborhood, little convenience stores. None of the stores that were within walking distance from her house had milk. They didn’t have any milk, they only had soda and juice and things of that nature. And so, I finally went to get her some milk, which was a lot further. But when I went to her house, I told her, I said, "Well, now I know why you can’t walk to the store." She said, "Yeah, I can’t walk to the store with this baby on my hip and I’m pregnant now and it’s no way." – Portsmouth Undiagnosed
Transportation can be a challenge in the Tidewater MTA due to the many areas that are separated by water necessitating bridges and tunnels, many of which have tolls and are not walkable. Statistics in Table 19 indicate the places with the highest percentage of households without a vehicle are Norfolk City (13%), Portsmouth City (11%), and Newport News City (10%). Five county-equals report that 5% or less of their households lack a vehicle. Chesapeake City and Suffolk City report the highest percentage of the total population that commutes more than 45 minutes to work at 19%, with the remaining county-equals reporting between 13%-8%. Few commute to work via public transportation, that may reflect lack of access to public transportation with all county-equals below 5% and five county-equals reporting 0%. The highest percentage of people that commute to work by foot/bike/other is 11% in Norfolk City, while other county-equals report 6% or less.

### TABLE 19. TIDEWATER METRO AREA TRANSPORTATION

<table>
<thead>
<tr>
<th>County</th>
<th>Percent of Households Without a Vehicle</th>
<th>Percent of Total Population that Commutes more than 45 Minutes to Work</th>
<th>Percent of Total Population that Commutes to Work Using Public Transit</th>
<th>Percent of Total Population that Commutes to Work by Foot/Bike/Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chesapeake City</td>
<td>4%</td>
<td>31%</td>
<td>0%</td>
<td>2%</td>
</tr>
<tr>
<td>Gloucester County</td>
<td>4%</td>
<td>13%</td>
<td>0%</td>
<td>3%</td>
</tr>
<tr>
<td>Hampton City</td>
<td>8%</td>
<td>11%</td>
<td>2%</td>
<td>4%</td>
</tr>
<tr>
<td>Newport News City</td>
<td>10%</td>
<td>12%</td>
<td>3%</td>
<td>6%</td>
</tr>
<tr>
<td>Norfolk City</td>
<td>13%</td>
<td>8%</td>
<td>4%</td>
<td>11%</td>
</tr>
<tr>
<td>Poquoson City</td>
<td>4%</td>
<td>13%</td>
<td>0%</td>
<td>2%</td>
</tr>
<tr>
<td>Portsmouth City</td>
<td>11%</td>
<td>11%</td>
<td>2%</td>
<td>6%</td>
</tr>
<tr>
<td>Suffolk City</td>
<td>7%</td>
<td>20%</td>
<td>0%</td>
<td>2%</td>
</tr>
<tr>
<td>Virginia Beach City</td>
<td>4%</td>
<td>10%</td>
<td>1%</td>
<td>5%</td>
</tr>
<tr>
<td>York County</td>
<td>2%</td>
<td>9%</td>
<td>0%</td>
<td>3%</td>
</tr>
</tbody>
</table>

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

“A lot of women I worked with, they won’t go to the doctor because they don’t have transportation to get to the doctor, and so a lot of times the health insurance companies, they will offer safer, what we call Medicaid rides. However, it is still very hard, when they have kids and they have to be dropped off and picked back up from Medicaid yet, but they don’t always come back, or they don’t show up on time for their appointment. And so, they would rather just not go.” – Portsmouth Undiagnosed
TABLE 20. TIDEWATER METRO AREA EDUCATION

<table>
<thead>
<tr>
<th>County</th>
<th>Percent of Population Over Age 25 That Has a High School Degree or Higher</th>
<th>Percent of Population Over Age 25 That has a bachelor’s degree or Higher</th>
<th>Percent of Black Women Over Age 25 without a High School Degree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chesapeake City</td>
<td>92%</td>
<td>32%</td>
<td>10%</td>
</tr>
<tr>
<td>Gloucester County</td>
<td>90%</td>
<td>23%</td>
<td>10%</td>
</tr>
<tr>
<td>Hampton City</td>
<td>91%</td>
<td>26%</td>
<td>9%</td>
</tr>
<tr>
<td>Newport News City</td>
<td>89%</td>
<td>25%</td>
<td>13%</td>
</tr>
<tr>
<td>Norfolk City</td>
<td>88%</td>
<td>27%</td>
<td>18%</td>
</tr>
<tr>
<td>Poquoson City</td>
<td>96%</td>
<td>42%</td>
<td>0%</td>
</tr>
<tr>
<td>Portsmouth City</td>
<td>86%</td>
<td>22%</td>
<td>18%</td>
</tr>
<tr>
<td>Suffolk City</td>
<td>89%</td>
<td>27%</td>
<td>17%</td>
</tr>
<tr>
<td>Virginia Beach City</td>
<td>93%</td>
<td>35%</td>
<td>9%</td>
</tr>
<tr>
<td>York County</td>
<td>94%</td>
<td>44%</td>
<td>10%</td>
</tr>
</tbody>
</table>

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

Poquoson City reports the highest educational attainment rates in the Tidewater MTA (Table 20) with 96% of their population over age 25 having a high school diploma or higher. Additionally, 42% of their population over age 25 has a bachelor’s degree or higher, and 0% of Black women over the age of 25 lack a high school diploma. Portsmouth City reports the lowest education rates and ranks the poorest among all counties in the MTA across all three criteria: 86% of people over age 25 have at least a high school diploma, 22% have at least a bachelor’s degree, and 18% of Black women over age 25 do not have a high school diploma.

TABLE 21. TIDEWATER METRO AREA GENTRIFICATION

<table>
<thead>
<tr>
<th>County</th>
<th>Proportional Change in Population with a bachelor’s degree or Higher</th>
<th>Percent Change in Median Household Income</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chesapeake City</td>
<td>3%</td>
<td>3%</td>
</tr>
<tr>
<td>Gloucester County</td>
<td>2%</td>
<td>5%</td>
</tr>
<tr>
<td>Hampton City</td>
<td>3%</td>
<td>1%</td>
</tr>
<tr>
<td>Newport News City</td>
<td>1%</td>
<td>1%</td>
</tr>
<tr>
<td>Norfolk City</td>
<td>2%</td>
<td>7%</td>
</tr>
<tr>
<td>Poquoson City</td>
<td>6%</td>
<td>4%</td>
</tr>
<tr>
<td>Portsmouth City</td>
<td>3%</td>
<td>5%</td>
</tr>
<tr>
<td>Suffolk City</td>
<td>2%</td>
<td>2%</td>
</tr>
<tr>
<td>Virginia Beach City</td>
<td>3%</td>
<td>7%</td>
</tr>
<tr>
<td>York County</td>
<td>3%</td>
<td>5%</td>
</tr>
</tbody>
</table>

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

Gentrification is another measure connected to educational attainment. Table 21 measures gentrification rates across two metrics: the proportional change of the population with a bachelor’s degree or higher and the proportional change in median household income. By these metrics, Norfolk
City appears to be the most gentrified at 7% (Table 21). The rate is lowest in Newport News City and Hampton City, which are both at 1%. All counties in the MTA have a positive proportional change in the population with a bachelor’s degree or higher, with Poquoson City having the highest proportional change at 6%.

“And so not just housing segregation historically, where certain populations are put in certain areas, but then also you have other places that they're trying to, again, gentrify. And so that it puts people more into other places they can't afford. They're pushing people out.” – Norfolk Undiagnosed
Policy Context

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

The Patient Protection and Affordable Care Act (ACA)

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

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

- Pre-Existing Conditions Protections. Per the ACA and effective as of 2014, health insurers cannot deny coverage to an individual or charge more for coverage due to a pre-existing condition. For example, insurers cannot discriminate based on a previous or current breast cancer diagnosis or other health condition. Additionally, health insurers cannot refuse to provide coverage for treatment and other services related to a pre-existing condition (U.S. Department of Health & Human Services, 2017).

- Medicaid Expansion. Under the ACA, states have the option to expand their Medicaid program to individuals with incomes of up to 138% FPL. More than 1 in 14 Virginia residents are enrolled in the state’s Medicaid program. Virginia adopted an expanded Medicaid program effective January 1, 2019. The expanded Medicaid program is available to:

  - Adults with or without children with incomes of up to 138% of the FPL.
  - Because of Virginia’s relatively recent Medicaid expansion in 2019, data is not available for Virginia’s expansion population. However, between 2013 and 2017 the uninsured rate in Virginia decreased from 14% to 10%. These numbers can be compared to the national uninsured rate drop from 17% to 10% over the same time period (The Henry J. Kaiser Family Foundation, 2019). Over that same time period, the uninsured rate for nonelderly Black people remained higher than that for whites (see Figure 3).
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, & Damico, 2020). Regarding screening, research suggests that states that expanded their Medicaid program eligibility standards have improved cancer screening rates compared to states that did not, and that early adoption of the Medicaid expansion is associated with greater improvements in screening (Fedewa et al., 2019; Swift, 2019). Some studies suggest it is possible that the racial disparity in 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)**

During the five-year period of July 2014 to June 2019, the NBCCEDP served 18,542 women in Virginia 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).

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 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). Women who are diagnosed through EWL may be eligible for treatment through the Medicaid program if they meet certain requirements.

**TABLE 23. GUIDELINES & REIMBURSABLE COVERAGE FOR SCREENING MAMMOGRAPHY BY AGE IN THE BREAST & CERVICAL CANCER SERVICES PROGRAM**

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Guidelines for screening frequency in VA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ages 50 and above</td>
<td>Annual screening</td>
</tr>
<tr>
<td>Ages 40-49</td>
<td>Screening every two years</td>
</tr>
<tr>
<td>Ages 35-39</td>
<td>Baseline screening mammogram (one screening total)</td>
</tr>
</tbody>
</table>

*Source: Breast Cancer Risk Assessment and Screening in Average-Risk Women (Committee on Practice Bulletins - Gynecology, Pearlman, Jeudy, & Chelmow, 2017).*

**TABLE 24. OVERVIEW OF SCREENING & TREATMENT SERVICES FOR VIRGINIA RESIDENTS**

<table>
<thead>
<tr>
<th>Program</th>
<th>Breast &amp; Cervical Cancer Services (Screening focus)</th>
<th>Medicaid for Breast &amp; Cervical Cancer (Treatment focus)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>Annually for women 50 and above, biannually for women 40-49, and once for women 35-39 (see Table XX)</td>
<td>18-64</td>
</tr>
<tr>
<td>Insurance status</td>
<td>Uninsured or underinsured</td>
<td>Cannot have creditable health insurance that covers the treatment of breast or cervical cancer, including Medicare.</td>
</tr>
<tr>
<td>Program Services</td>
<td>Clinical breast exam, screening mammogram, pelvic exam, and Pap test.</td>
<td>Breast cancer treatment services</td>
</tr>
</tbody>
</table>

*Source: Virginia Department of Health*

**Flexibility in the Medicaid Program via Medicaid Waivers**

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

The Trump administration has promoted work requirements through Medicaid waivers, which have previously not been approved (Brooks, Roygardner, & Artiga, 2019). Several states have applied to enact work requirements, meaning that Medicaid eligible enrollees would have to report working a certain number of hours or involvement in a volunteer role, in school, or in time spent looking for a job. Their Medicaid coverage would be contingent on meeting these requirements. Enrollees can also be exempt from these requirements for other reasons including being pregnant, medically frail, being a full-time student, and other reasons (and they must renew their exemptions annually).
Work requirements in Medicaid are a widely criticized strategy that constrict access to Medicaid coverage, do not reach their purported goal of increasing work among Medicaid enrollees, and likely harm health by limiting access to insurance coverage (Cauley Narain & Zimmerman, 2019). In Virginia, there are no work requirements for Medicaid eligibility (The Commonwealth Fund, 2020). The state 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 Virginia

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 et al., 2016).

State Laws Impacting the Breast Cancer Community

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

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

Breast Cancer Disease Burden

Most Black women living within the Tidewater MTA seem to be spread fairly equally among six cities (Chesapeake City, Hampton City, Newport News City, Norfolk City, Portsmouth City, and Virginia Beach City), with Portsmouth City having the highest percentage of the total population that is Black (53%) and Norfolk City having the largest number of Black women living there (18,162) (see Table 4). Suffolk City and Chesapeake City stand out because their incidence rates (166.9 and 153.9), late-stage incidence rates (72.2 and 63.4), and mortality rates (42.8 and 33.7) are all the highest or among the highest in the MTA for Black women. They also show the highest discrepancies between Black and white women across all breast cancer burden measures.

These data suggest that the condition of Black women in these cities warrants further study, particularly around the linkage to care and treatment stage of the breast cancer continuum of care. The disparity in breast cancer mortality is abundantly clear, with Black women reporting higher rates than their white counterparts across all counties in the MTA where data is available (see Table 6). This trend holds even in the cities and counties where the breast cancer incidence rates, in situ incidence rates, and late-stage incidence rates are higher among white women than they are for Black women. Even in these places, Black women die from the disease at higher rates than their white counterparts.

Quality of Care

Survivor and undiagnosed Black women’s stories convey their experience of poor-quality care, racism, microaggressions, and health care discrimination, an already-established and still-pervasive finding in this study.

Another important finding was the importance of social support to their successful treatment. This included support from family, church, and health care providers who were honest, empathetic, and had strong patient navigation systems providing crucial wrap-around services. One observation was that survivors who experienced personally mediated racism and racial microaggressions during their care were more likely to mistrust their providers and not adhere to recommended treatment plans. This was exacerbated among women experiencing care that was inefficient, inaccessible, or not patient-centered (i.e., where they were not being listened to nor their concerns being treated with a level of urgency).

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 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. Black people 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).
Research shows that race likely plays an important role in worse outcomes among Black women, and breast cancer disparities for Black women can persist regardless of insurance status. A study by Hoffman et al., for example, showed that both publicly- and privately-insured Black women experienced more treatment delays compared to white women, with Black women experiencing a longer duration from the first symptoms to diagnostic resolution for breast cancer (Hoffman et al., 2011).

Additionally, fear of painful screening mammograms, being diagnosed with what many women perceive to be a death sentence, and chemotherapy were found to influence screening, treatment, and care seeking. Many survivors interviewed noted being in denial or in shock after first receiving their diagnosis. This is consistent with the literature. For example, Daly and Olopade (2015) noted that the research literature has found a link between fears of a potential cancer diagnosis and delayed follow-up diagnosis and care (Daly & Olopade, 2015). A systematic review by Jones et al. (2014) found that factors contributing to delays in breast cancer diagnosis and care among Black women include a fear of cancer treatments, fear of being abandoned by one’s partner, taboo, and stigma (C. E. Jones et al., 2014). While the study was conducted by researchers in the UK, most research included in the review was performed in the US.

**Social Determinants of Health (SDOH)**

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

Findings from the Hoffman (2011) study around barriers to retention in care also confirm existing research literature on these factors including having no insurance or being underinsured. Focus group participants explained that the type of insurance they had influenced the quality of care received. They reported feeling that those enrolled in Medicaid received poorer quality care within the major hospitals in the MTA. Overall, these findings largely align with findings from the recent literature. Studies have shown that the insurance type (e.g., private insurance, Medicaid, Medicare) and benefit design structure (i.e., the way the benefits are structured and available to an enrollee) are barriers to timely breast cancer-related services and quality of care (Wharam et al., 2018). Furthermore, the literature shows that among Black breast cancer patients, a woman’s insurance type was a significant predictor of mistrust of the medical establishment. Women with Medicaid expressed greater mistrust and suspicion compared to women with private insurance or private insurance and Medicare (Sutton et al., 2019). A study in Chicago found qualitatively that Black breast cancer patients often expressed concern that the type of health insurance impacts the quality of breast cancer care received (Masi & Gehlert, 2009).

Another finding from this study that confirms existing literature around barriers to retention in care was the undue burden women bear juggling financial and care-giving roles while working at inflexible jobs, making it impossible to successfully engage in optimal care and treatment plans that would require taking time off work. This is aligned with other research in the field (Blinder, Eberle, Patil, Gany, & Bradley, 2017; Nonzee et al., 2015).
Breast cancer inequities across the care continuum in the Tidewater MTA persist due to poor quality care, experiencing personally mediated racism in health care settings, as well as insufficient patient navigation programs, inadequate strategies to combat paralyzing fear related to a cancer diagnosis, and lack of social support. Taken together, these factors severely reduce the quality of care Black women receive across the cancer care continuum. This study confirms the existence of many well-understood barriers across the care continuum facing Black women. Many of these factors have existing dedicated resources supporting the mitigation of these barriers. However, this study also highlights novel barriers and adds nuance to existing barriers across the care continuum that warrant further research, intervention, and new policies that can be supported. These issues uncovered in Gloucester and York Counties and the eight cities included in this Tidewater MTA analysis include: 1) lack of information around unique breast cancer risk factors faced by Black women, 2) need for more patient navigator support, 3) patient-provider communication issues, and 4) lack of robust survivorship planning.
Recommendations

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

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

The following recommendations apply this systems framework and address specific changes, strategies, or interventions at the micro, mezzo, and macro levels. These recommendations are intended to work in concert and not as discrete changes. Recommendations acknowledge that the systems and their components are relational, non-linear, and dynamic. Thus, suggested strategies and interventions should be coordinated with communities, in keeping with Komen’s collaborative approach to advance breast health equity for Black women. 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.**

The disparity in breast cancer mortality between Black women and their white counterparts in the Tidewater MTA is abundantly clear, with Black women reporting higher mortality rates than their white counterparts across all cities/counties in the MTA where data is available (see Table 6).

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

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

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

**Support financial assistance programs.**

As indicated in the Findings sections, residents of the Tidewater MTA face economic vulnerability. One opportunity the breast cancer community could prioritize is advocating for health system financial assistance programs to meet deductibles for high-deductible health plans or cost sharing for underinsured women. 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.
Implement implicit bias trainings for providers, administrators, and health care staff.

Data suggest that in addition to institutionalized racism, the Black community in the Tidewater 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, Virginia Beach City, reports the highest number of race-based incidents, including the highest numbers of Fair Housing Act. Qualitative findings from this study indicate that historic distrust of the health care system, as well as family and personal experiences of implicit bias, racism, and discrimination both generally and in the health care system impact quality of care received as well as retention in treatment for Black women.

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

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

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

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

In Georgia, the screening mammography rate for Black women over the age of 40 is 79.4%, compared to 72% 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.

**Identify and implement strategies for survivorship planning.**

Findings from this study indicate that there is a lack of robust survivorship planning for breast cancer survivors through hospitals. Many survivors reported finding information about survivorship planning through breast cancer support groups. Most breast cancer resources in the MTA are concentrated in just a few cities (Chesapeake City, Newport News City, and Portsmouth City), particularly in the form of breast cancer support groups (see Table 16). Therefore, the breast cancer community can partner with a few major treatment cancer centers within the Tidewater MTA to collaborate with community
stakeholders, including cancer research specialists, survivors, navigators, and select community service providers to gather their perspectives and actionable insights.

**Mezzo-Level Strategies**

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

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; and specific transportation needs should be considered to ensure physical access. 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.

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

**Invest in high-need areas by health institutions, systems, and payers.**

There may be opportunities to favorably influence health systems and payers to ‘give back’ to historically disenfranchised communities. For example, by: 1) incentivizing health systems and payers to invest in Black communities; 2) by aligning research grants with Stand for H.E.R. priorities, such as requiring grantees from major health institutions to invest in community benefits, to provide services in community health centers, and to conduct clinical trials that prioritize Black women and their unique breast health issues; and 3) by partnering with non-profits to fund standalone breast clinics that could replace the breast health services that were previously available at the now closed hospitals. These strategies will help to improve access to high quality care while ensuring that over time there is commensurate scientific advancement in breast cancer treatment options for Black women.
Support a community-based participatory research project to uncover the drivers of late-stage diagnosis rates.

The breast cancer community can support a community-based participatory research (CBPR) project that seeks to identify potential system gaps between the screening and diagnosis phase of the breast cancer continuum for Black women in the Tidewater MTA. CBPR focuses on social, structural, and physical environmental inequities through active involvement of community members, organizational representatives, and researchers in all aspects of the research process. Therefore, the recommended CBPR project should be a multidisciplinary research team composed of cancer research specialists, behavioral health specialists, patients, navigators, and select community service providers. According to Holkup et al., the strength of this research approach is that partners contribute their expertise to enhance the understanding of a given phenomenon and integrate the knowledge gained with action to benefit the community involved (Holkup, Tripp-Reimer et al., 2004). Furthermore, this research framework empowers people by considering them agents who can investigate their own situations. The community input makes the project credible, enhancing its usefulness by aligning it with what the community perceives as social and health goals, and in doing so helps dismantle the lack of trust communities may have about research.

Conduct broader outreach to Black women.

Findings from this study indicate that Black women who aren’t connected to churches, sororities, or community-based organizations may not be receiving the outreach and education that they need in the Tidewater MTA. Therefore, broader outreach to Black women is needed that goes beyond churches, sororities, and community-based organizations that serve Black women to reach women who are not engaged in these supportive spaces.

Macro-Level Strategies

Influence the State Cancer Plan to Address Structural Barriers.

While the current objectives of the state cancer plan are undoubtedly important, a clearer delineation and stronger support of specific strategies for Black women is needed to move the needle. The breast cancer community could encourage the Virginia Comprehensive Cancer Control Program and the Cancer Action Coalition of Virginia to clarify concrete ways to reduce structural barriers related to the cancer care continuum for Black women in Virginia.

Conduct a root cause analysis (RCA) relating to delays in breast cancer diagnosis and healthcare quality.

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

This landscape analysis report conveys comprehensive issues facing Black women in the metro areas. 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 Black women.
## Appendix A. Map Measures

### TABLE 25. TIDEWATER METRO AREA TABLE MAPS

<table>
<thead>
<tr>
<th>Location</th>
<th>Map 3: Percent of Population that is Black</th>
<th>Map 7: Social Vulnerability Index Score</th>
<th>Map 8: Percent of Households that are Housing-Cost Burdened</th>
<th>Map 4: Residential Segregation Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chesapeake City</td>
<td>30%</td>
<td>0.24</td>
<td>34%</td>
<td>41</td>
</tr>
<tr>
<td>Gloucester County</td>
<td>8%</td>
<td>0.03</td>
<td>26%</td>
<td>22</td>
</tr>
<tr>
<td>Hampton City</td>
<td>50%</td>
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<td>40%</td>
<td>36</td>
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<tr>
<td>Newport News City</td>
<td>41%</td>
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<td>37%</td>
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<tr>
<td>Norfolk City</td>
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<td>44%</td>
<td>53</td>
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<tr>
<td>Poquoson City</td>
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<td>Portsmouth City</td>
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<td>55</td>
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<td>Suffolk City</td>
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<td>Virginia Beach City</td>
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<td>34</td>
</tr>
<tr>
<td>York County</td>
<td>13%</td>
<td>0.11</td>
<td>27%</td>
<td>32</td>
</tr>
</tbody>
</table>

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, Black people 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 by JSI 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 screening mammogram or clinical breast exam using two or more views of the breast.

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

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

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

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

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

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

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

**Housing-cost burden:** A measure to indicate the proportion of renters and homeowners that spend 30% or more of their total income on housing. Calculated by the US Department of Housing and Urban Development using the Consolidated Housing Affordability Strategy dataset and the following formula: number of renters and homeowners who spend 30% or more of their total income on housing
(numerator) divided by the total number of households (denominator) (Office of Policy Development and Research (PD&R), 2019).

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

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

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

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

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

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

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

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

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

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

**Mortality rate:** A measure of death calculated by the National Cancer Institute using SEER and National Vital Statistics System (NVSS) data. Calculated by SCP using the following formula: the number of individuals in an area who died during a one-year period (numerator) divided by the total number of
individuals living in that area (denominator). Expressed in terms of number of deaths per 100,000 individuals per year (National Cancer Institute).

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

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

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

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

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

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

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

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

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

**Structural racism:** The system in which policies, institutional practices, and cultural representations work together, often in reinforcing ways to create and perpetuate racial inequity. Structural racism manifests as differential access to goods, services, conditions, opportunities, and access to power.
Social Vulnerability Index (SVI): A measure of the exposure of a population to social vulnerabilities that limit their ability to withstand adverse impacts from multiple stressors to which they are exposed. The SVI is calculated by the CDC using the ACS 5-year report data for 15 social factors (e.g., lack of vehicle access, crowded housing). Scores range from 0.0 to 1.0, with scores closer to 1.0 indicating greater vulnerability (Agency for Toxic Substances and Disease Registry, 2018).

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

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

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

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

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

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

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

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

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

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

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

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

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

Your participation in this interview/ focus group is completely voluntary and all information you share will be kept confidential and will not be associated to you by name. At no time should you feel you have to answer a question. We will be taking notes and, with your permission, we will be recording this interview so we can engage in a conversation with you and not miss any of the details. These notes and
the recording will be kept in a secure location in our offices and only the project team will have access to these materials. The information will be aggregated, analyzed, and reported to Susan G. Komen.

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

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
   12. 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)
   13. 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 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

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?
   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
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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
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Breast Cancer Survivor Focus Group Guide

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Step 3: Answer Questions from Participants

Step 4: Confirm Consent to Participate

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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 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


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?
   b. 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

b. 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?

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

c. 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

d. What type of resources were available to you (e.g., financial, stress management/healthy living, emotional, spiritual resources)?

2. How did you come to know about these? Did you have to ask?

3. Did you access these resources or have adequate support for doing so?

4. 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.?

15. 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.*
References


Racial and Ethnic Disparities in Health Care. Washington (DC): National Academies Press (US) Copyright 2002 by the National Academy of Sciences. All rights reserved.


