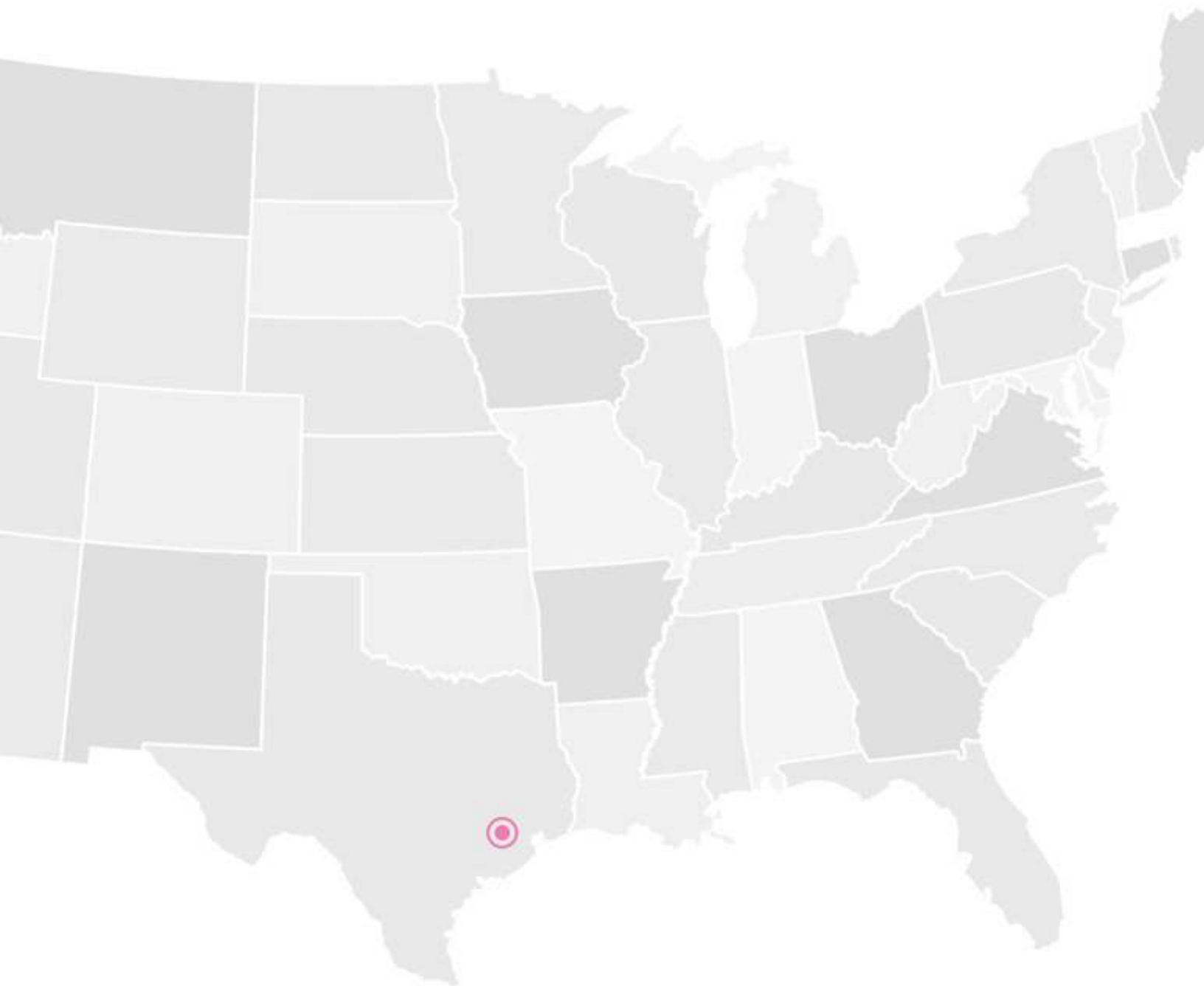


Closing the Breast Cancer Gap: A Roadmap to Save the Lives of Black Women in America

2021

HOUSTON



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

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

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Executive Summary

About Susan G. Komen

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

Background and Purpose

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

Research shows that despite recent scientific advancements, there are widespread disparities in breast cancer statistics between Black and white women. Breast cancer mortality is about 40 percent higher in Black women than in white women.

About This Report

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

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

The methods involve a literature scan, compiled quantitative data, reviewed federal and state policies and collected qualitative data from community members and providers to prepare a landscape analysis report for each of the 10 MTAs.

This study does not attempt to establish causality between underlying risk factors and breast cancer outcomes.

Rather, the analysis aims to:

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

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

Key Findings

- Incidence rates are comparable across counties and to the state average and lower than the national average. However, there are *noteworthy differences in incidence rates comparing Black to white women*. For example, in Harris County, the incidence rate is higher among Black women at 121.2 new cases per 100,000 individuals per year as compared to white women at 112.2 new cases per 100,000 individuals per year. The trends are similar in Galveston County, the incidence rate is higher for Black women compared to white women (117.3 versus 113.5), and the five-year incidence rate trend is rising for Black women while it is stable for white women.
- The late-stage breast cancer incidence rates are comparable to the state rate of 37.7 cases per 100,000 individuals and lower than the national rate of 42.3 cases per 100,000 individuals. Harris County is the exception, it is the only county in the metro that reports a late-stage incidence rate above the national rate (45.4). Importantly, in three out of five counties (Fort Bend, Galveston and Harris counties) that comprise the Houston MTA, the late-stage breast cancer incidence rate is higher among Black women compared to white women. Black women in Harris county had the highest average count of cases that are late-stage (n=214) as compared to Black women and white women residing in other Houston counties.
- On average, the overall screening mammography rates, not disaggregated by race, in most counties in the Houston MTA are higher than the overall state average at 65 percent but well below the national average at 73 percent. Fort Bend is the only exception; it has the highest screening mammography rate among all women in the Houston MTA at 77 percent.
- In terms of access to screening, several focus group participants noted *free and convenient breast cancer screening availability in their communities*. According to participants, opportunities for free mammograms at work and churches are convenient and facilitate women getting their first and annual mammograms.
- Despite access to screening through non-health care setting as noted above, several focus group participants noted barriers in the form of restrictive work policies, and the fear of losing their jobs if they tried to take time off work to have mammograms.
- Others expressed some confusion around screening guidelines, particularly what is the right age to receive a screening mammogram. The focus groups data revealed that self-examination is a common practice.
- Insights from qualitative data collected among community members suggests that *access to and utilization of diagnostic procedures may be more limited in the Houston MTA and may be associated with delayed diagnosis*. The high costs of diagnostic procedures for women, who are insured and uninsured alike was reported as a challenge.
- Age-adjusted breast cancer mortality rates are comparable with state and national rates. Across the Houston MTA, however, there are notable differences by race. *In four out of five counties, the breast cancer mortality rate is higher among Black women as compared to white women*. Harris County reports both the highest mortality rate (32.2 deaths per 100,000 deaths) in the

metro for Black women as well as the greatest disparity between Blacks and whites (20.7 for white women versus 32.2 for Black women). Galveston follows closely in both respects: it has the second highest mortality rate (31.8) and the second greatest disparity between white women and Black women (22.2 for white women versus 31.8 for Black women).

- Based on the focus group findings, *the high out of pocket costs and fear of debt were some of the common reasons Black women may decide not to pursue treatment*. Some participants described receiving *differential treatment largely due their race*. They explained that *having insurance, being financially stable, and being educated did not necessarily translate into a high quality and pleasant health care experience*.
- *Survivors listed social support as a critical facilitator for Black women to seek and continue treatment*. Some survivors shared having multiple sources of support including family, friends, coworkers and faith-based organizations. Focus group participants in Harris County described the importance of having access to Black support groups.
- The data collected and reviewed for this report suggest breast health inequities among Black women in the Houston MTA could be explained by: 1) economic vulnerability driven by institutionalized racism, 2) large percentage of uninsured and underinsured community members, and 3) lower quality of health care due to the structural racism and personally-mediated racism. How the health system functions may be significantly contributing to the underlying inequities in breast cancer outcomes in the Houston area.

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 Houston MTA (full details provided in the recommendations section of this report). The recommendations follow a systems framework:

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

Micro-Level Strategies

- Support Quality Improvement (QI) initiatives along the breast cancer continuum of care.
- Improve service delivery through enhanced linkages with culturally competent patient navigators, peer support/educators and other system facilitators.
- Increase education about family health history in the community to identify high-risk families and offer genetic counseling and testing and breast cancer screening to meet the need.
- Implement a culturally relevant health promotion campaign intended to increase knowledge of current screening guidelines.

Mezzo-Level Strategies

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

- Create avenues for social support and community connection and strengthen networks of culturally responsive patient navigators.
- Invest in Black led CBOs providing non-medical services.

Macro-Level Strategies

- Analyze current health care insurance policies to ensure equitable access to services through Medicaid expansion and financial assistance programs.
- Advocate to expand Medicaid eligibility and to remove burdensome restrictions that would limit access to Medicaid.
- Support Financial Assistance Programs.
- Cultivate and engage leadership and governance at all levels to support racial equity and reduce breast cancer disparities.
- Ensure that planning of local metro initiatives are inclusive of and collaboratively driven by Black women and their advocacy organizations.
- Fund Collective Impact initiatives at the community level to address root causes of breast cancer disparities.

While the recommendations speak to the Houston metro area, it is strongly advised that more focused attention is placed on the high-need counties of Harris and Galveston. Both counties have worse breast cancer measures, are food insecure, economically vulnerable and worse off on a range of social determinants of health compared to other counties in the Houston MTA.

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

About Susan G. Komen

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

Introduction

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

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

Through the African American Health Equity Initiative (AAHEI), Komen seeks to improve breast health equity by reducing late-stage diagnosis and mortality for Blacks in the 10 U.S. metropolitan areas (referred to throughout this report as MTAs or metro) where Black breast cancer disparities are the greatest. These MTAs include Atlanta, GA; Chicago, IL; Dallas-Fort Worth, TX; Houston, TX; Los Angeles, CA; Memphis, TN; Philadelphia, PA; St. Louis, MO; Virginia Beach, VA; and Washington, D.C. As part of the AAHEI, Komen engaged JSI, a public health research and consulting organization, to conduct a landscape analysis in each MTA to better understand the underlying causes of breast cancer inequities across the care continuum among Black women. Findings from each landscape analysis report serve to inform the design and implementation of Komen’s long-term and cross-sector collaborative efforts as well as serve as a call to action for all community-based organizations, policymakers, hospitals,

health care providers, faith-based organizations, civic leaders and citizens to engage in evidence-informed strategies to reduce breast cancer disparities among Blacks.

Project Objectives

The specific objectives of the landscape analysis are:

To understand breast cancer disease burden in each MTA by describing breast cancer measures (incidence, in situ incidence, late-stage diagnosis and mortality) and other key health metrics (such as life expectancy and age-adjusted mortality), comparing Black women to white women, per data availability.¹

To describe systemic barriers, including adverse SDOH, and other socioeconomic and contextual factors that may contribute to breast cancer inequities, comparing counties within each MTA.

To explore community members' perspectives regarding their experiences with breast cancer screening and treatment, and their perceptions regarding barriers/facilitators to obtaining care, factors contributing to breast cancer inequities and suggestions for advancing breast health equity.

To explore health care provider perspectives regarding individual, community and health systems factors contributing to breast cancer inequity, along with their recommendations for system-level change.

To identify PSE-level strategies that may help to mitigate breast cancer inequities and achieve Komen's goals of improving breast health equity.

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

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

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

These recommendations are intended to be a call to action for all community-based organizations,

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

policymakers, hospitals, health care providers, faith-based organizations, civic leaders and citizens. The recommendations are offered as evidence-informed interventions to reduce breast cancer disparities among Blacks.

Methods

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

This study defines the Houston MTA in accordance with the US Office of Management and Budget’s 2015 definition of the “central counties” surrounding the city of Houston. This designation encompasses most of the city of Houston and comprises the counties of Brazoria, Chambers, Galveston, Fort Bend and Harris. Data are unavailable at this unit of geographic specificity, so researchers collected and analyzed data at the county-level for most indicators. State- and national-level data were collected for measures related to breast cancer disease burden to provide additional points of comparison (Office of Management and Budget, 2010; U.S. Census Bureau).

TABLE 1: HOUSTON DATA METHODS AND SOURCES

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

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

Social Determinants of Health

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

racism	Number of Fair Housing Act Cases Filed with a Race Basis	Fair Housing Act Cases dataset (US Department of Housing and Urban Development, Office of Fair Housing and Equal Opportunity)
racism	Number of Blacks Killed by Police	The Counted Database (The Guardian)

Health and Wellness

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

Health Systems

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

Breast Cancer Disease Burden

Subcategory	Indicator	Source
prevalence	Prevalence	2017 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
incidence	Age-Adjusted Incidence Rate	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
incidence	5-year Incidence Rate Trend Direction	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
incidence	Age-Adjusted Incidence Rate for White Women	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
incidence	5-year Incidence Rate Trend Direction for White Women	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
incidence	Age-Adjusted Incidence Rate for Black Women	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
incidence	5-year Incidence Rate Trend Direction for Black Women	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
in situ incidence	Age-Adjusted In Situ Incidence Rate	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
in situ incidence	5-year In Situ Incidence Rate Trend Direction	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
in situ incidence	Age-Adjusted In Situ Incidence Rate for White Women	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
in situ incidence	5-year In Situ Incidence Rate Trend Direction for White Women	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
in situ incidence	Age-Adjusted In Situ Incidence Rate for Black Women	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
in situ incidence	5-year In Situ Incidence Rate Trend Direction for Black Women	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
late-stage incidence	Age-Adjusted Late-Stage Incidence Rate	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
late-stage incidence	Average Count of Cases that are Late-Stage	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
late-stage incidence	Age-Adjusted Late-Stage Incidence Rate for White Women	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
late-stage incidence	Average Count of Cases that are Late-Stage for White Women	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
late-stage incidence	Age-Adjusted Late-Stage Incidence Rate for Black Women	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
late-stage incidence	Average Count of Cases that are Late-Stage for Black Women	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
mortality	Age-Adjusted Mortality Rate	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
mortality	5-year Mortality Rate Trend Direction	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
mortality	Age-Adjusted Mortality Rate for White Women	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
mortality	5-year Mortality Rate Trend Direction for White Women	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
mortality	Age-Adjusted Mortality Rate for Black Women	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
mortality	5-year Mortality Rate Trend Direction for Black Women	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
screening mammography	Percent of Women Getting Mammograms	2017 County Level Modeled Estimate Combining BRFSS and NHIS (US Centers for Disease Control and Prevention; State Cancer Profiles; National Institutes of Health)

Qualitative Data

In the Houston MTA, a total of nine focus groups were conducted among 82 community members. Two of the nine focus groups were among community health workers and/or patient navigators in Harris and Galveston counties, and included 18 participants. In addition, two provider interviews were conducted.

Table 2 summarizes the demographic characteristics of 64 focus group participants, representing both breast cancer survivors and the undiagnosed. Among breast cancer survivors, the majority were above 55 years of age, did not have insurance (48 percent) and had been diagnosed with stage 1 breast cancer (42 percent). Undiagnosed women were younger, mostly in the 35-54 age group, with the majority reporting access to private insurance (58 percent). Non-provider participants were Black. Demographics were not collected for community health navigators, patient navigators or clinical providers.

TABLE 2. HOUSTON METRO AREA QUALITATIVE DATA COLLECTION

Variable Name	Breast Cancer Survivors (n=21)	Undiagnosed Women (n=43)
Age		
18-24 years	0%	2.3%
25- 34 years	0%	7%
35-44 years	4.8%	11.6%
45-54 years	4.8%	16.3%
55-64 years	47.6%	3.2%
65-74 years	23.8%	2.9%
75 and above	19%	11.6%
Zip codes		
	Breast Cancer Survivors (n=21)	Undiagnosed Women (n=43)
77004	5%	4.8%
77016	0%	2.4%
77021	0%	7.1%
77033	0%	2.4%
77034	0%	2.4%
77045	10%	4.8%
77047	0%	4.8%
77048	5%	0.0%
77049	0%	2.4%
77051	10%	0.0%
77053	5%	2.4%
77083	5%	0.0%
77459	5%	9.5%
77061	0%	2.4%
77477	0%	2.4%
77478	5%	0.0%
77479	0%	4.8%

77083	0%	2.4%
77087	0%	2.4%
77489	15%	11.9%
77498	0%	2.4%
77518	5%	0.0%
77532	5%	0.0%
77539	5%	0.0%
77545	10%	7.1%
77550	0%	2.4%
77551	5%	0.0%
77568	0%	2.4%
77583	0%	2.4%
77590	0%	4.8%
77591	5%	9.5%

Insurance Status	Breast Cancer Survivors (n=21)	Undiagnosed Women (n=43)
I don't have health insurance	48%	9.3%
Medicaid	28.6%	14%
Medicare	48%	34.9%
Military Health care	0%	0%
Private Insurance	38%	58.1%
Through my parents	0%	0%
Not sure	4.8%	2.3%

Ever been screened for breast cancer	All Women
Yes	88.4%
No	11.6%

Type of breast cancer screening or assessment	Screened Women
Clinical breast exam	30%
Mammogram	82.5%
3D Mammogram	35%
Breast self-exam	25%
Other	0%

Stage of breast cancer at diagnosis	Breast Cancer Survivors (n=21)	Undiagnosed Women (n=43)
Stage 0	5.3%	N/A
Stage 1	42.1%	N/A
Stage 2	26.3%	N/A

Stage 3	10.5%	N/A
Stage 4	15.8%	N/A

Policy Data

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

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

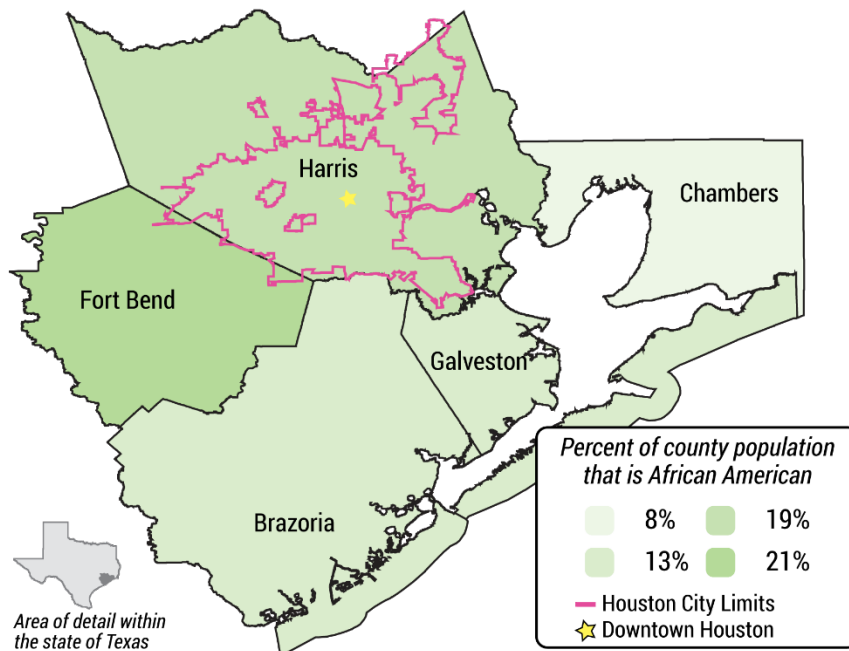
Section 1 Findings: Burden of Breast Cancer

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

Demographics

The Houston MTA is a five-county region in eastern Texas that is home to 6 million people. More than 75 percent of these individuals (4.5 million) reside in Harris County, with the city of Houston being located almost entirely in this county (refer to Map 1). The other four counties in the region are Brazoria, Chambers, Fort Bend and Galveston.

MAP 1: BLACKS IN THE HOUSTON METROPOLITAN AREA



The Houston MTA is a majority-white metro: 64 percent of its 6 million residents are white (see table 3), and 18 percent are Black. While Fort Bend County has the largest proportion of Black residents (21 percent), given that the population of Harris County is about six times greater that of Fort Bend County, Harris County has the highest number of Blacks in the county (154,618). Refer to table 3 for a demographic breakdown of the MTA as a whole and to table 4 for county-level demographics. The number of Black women over the age of 45 is noted for each county because this census-

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

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: HOUSTON METRO AREA DEMOGRAPHICS

Gender	
Male	50%
Female	50%
Age	
Under Age 18	27%
Age 18-64	63%
Over Age 65	10%
Race/Ethnicity	
White	64%
Black	18%
Asian	8%
American Indian or Alaska Native	0%
Native Hawaiian or Other Pacific Islander	0%
Some Other Race	7%
Two or More Races	2%
Hispanic/Latino	38%
White Not Hispanic	34%
Minority Race	36%
Number of Black Women Over Age 45	199,737
Total Population	5,943,402

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

TABLE 4: HOUSTON METRO AREA COUNTY DEMOGRAPHICS

County	Total Population	Percent of Total Population That Is Female	Percent of Total Population That Is African American	Number of African American Women Over Age 45
Brazoria	345,995	49%	13%	7,258
Chambers	39,283	50%	8%	663
Fort Bend	711,421	51%	21%	28,417
Galveston	321,184	51%	13%	8,781
Harris	4,525,519	50%	19%	154,618

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

Breast Cancer Disease Burden in the Houston MTA

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

A helpful measure for breast cancer disease burden is prevalence, or the proportion of the population that has the disease at a given time. Prevalence is measured in multiple ways depending on the time period of interest. This report uses age-adjusted complete prevalence, which represents the proportion of people alive on a certain day who have been diagnosed with breast cancer, regardless of when the diagnosis was made (National Cancer Institute, 2020). Prevalence statistics are only available at the state

level. The complete age-adjusted prevalence for Texas is 1.53 percent. This is lower than the national percentage of 1.69 percent. In fact, only six states in the nation report a lower breast cancer prevalence than Texas (National Cancer Institute).

Breast cancer indicators for other measures are available at the county level. Tables 5-9 describe the breast cancer disease burden in the Houston 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 7, are represented as percentage of women over the age of 40 that have had a screening mammogram in the last two years.

TABLE 5: HOUSTON METRO AREA BREAST CANCER INCIDENCE RATE (PER 100,000)

	Age-Adjusted Incidence Rate	5-Year Incidence Rate Trend Direction	Age-Adjusted Incidence Rate for White Women	5-Year Incidence Rate Trend Direction for White Women	Age-Adjusted Incidence Rate for Black Women	5-Year Incidence Rate Trend Direction for Black Women
Brazoria	111.2	Stable	112.2	stable	119.9	stable
Chambers	116.1	Stable	119.2	stable	*	*
Fort Bend	114.4	Stable	120.0	stable	121.7	stable
Galveston	113.0	Stable	113.5	stable	117.3	rising
Harris	111.9	Stable	112.2	stable	121.2	stable
Texas	111.9	stable	112.6	stable	118.4	falling
National	125.2	stable	126.1	stable	124	Stable

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

Overall breast cancer incidence rates are comparable across counties and comparable to the state average (see table 5). Although the incidence rates in the Houston MTA are relatively lower than the national rate, there are noteworthy differences in incidence rates comparing Black to white women. For example, in Harris County, the incidence rate is higher among Black women at 121.2 new cases per 100,000 individuals per year as compared to white women at 112.2 new cases per 100,000 individuals per year. The trends are similar in Galveston County, the incidence rate is higher for Black women compared to white women (117.3 versus 113.5), and the five-year incidence rate trend is rising for Black women while it is stable for white women.

TABLE 6: HOUSTON METRO AREA BREAST CANCER IN-SITU INCIDENCE RATE (PER 100,000)

	Age-Adjusted In Situ Incidence Rate	5-Year In Situ Incidence Rate Trend Direction	Age-Adjusted In Situ Incidence Rate for White Women	5-Year In Situ Incidence Rate Trend Direction for White Women	Age-Adjusted In Situ Incidence Rate for Black Women	5-Year In Situ Incidence Rate Trend Direction for Black Women
Brazoria	23.7	stable	22.2	stable	28.2	Stable
Chambers	17.8	*	20.1	*	*	*
Fort Bend	27.5	stable	27.5	stable	26.3	stable
Galveston	26.2	stable	27.0	stable	22.2	stable
Harris	26.4	stable	25.5	stable	30.2	stable
Texas	22.6	stable	21.9	stable	26.9	stable
National	30.1	stable	29.7	stable	31.8	stable

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

Similarly, the in-situ incidence rates among women for every county in the Houston MTA are below the national average, but there are differences in rates by race (see table 6). In two counties – Brazoria and Harris – the in-situ incidence rates are higher among Black women as compared to white women, while in Fort Bend and Galveston the reverse is true; rates among white women are higher than among Black women.

Screening mammography rates that were publicly available, and therefore used in this report, are not disaggregated by race. Table 7 shows that screening mammography rates in the Houston MTA vary by county. Except for Chambers County, the rates in each county are higher than the state average of 65 percent. However, rates for all counties are below the national average of 73 percent (see table 7). Fort Bend is the only exception; it has the highest screening mammography rate in the Houston MTA at 77 percent, which is higher than the national average of 73 percent. Chambers County, which has the smallest proportion of Blacks relative to other Houston MTA counties, reports the lowest screening mammography rate in the metro at 62 percent.

TABLE 7: HOUSTON METRO AREA SCREENING MAMMOGRAPHY RATES AMONG WOMEN OVER 40

	Percent of Women Getting Mammograms
Brazoria	65%
Chambers	62%
Fort Bend	77%
Galveston	68%
Harris	69%
Texas	65%
National	73%

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

Research suggests that incidence rates are positively correlated with screening mammography screening rates. Since screening mammography rates not disaggregated by race at the county level, it is not possible to discern whether rates are comparable across races per county (Harding et al., 2015). However, screening mammography rates disaggregated by race are available at the state level and such some differences. According to the Centers for Disease Control, the rates are higher among Black women compared to white women although not statistically significant (69.6 percent versus 67.1 percent) (Centers for Disease Control and Prevention). Further, Texas' state affiliate of the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) provides screening mammogram data by race and ethnicity. The NBCCEDP, described in the Policy Context section, is a "payer of last resort" for uninsured and underinsured women. The distribution of women receiving mammograms from July 2013 - June 2018 is reported by race/ethnicity. The group accounting for the largest share of NBCCEDP mammograms in Texas is Hispanic women (68.5 percent), followed by white women (15.9 percent), African American women (10.9 percent), and Asian/Pacific Islander women (3.1 percent) (Centers for Disease Control and Prevention, 2019). Some studies suggest it is possible that the racial disparity in mammograms has been closed or reversed (Fazeli Dehkordy et al., 2019).

MAP 2: LATE-STAGE BREAST CANCER IN THE HOUSTON MTA

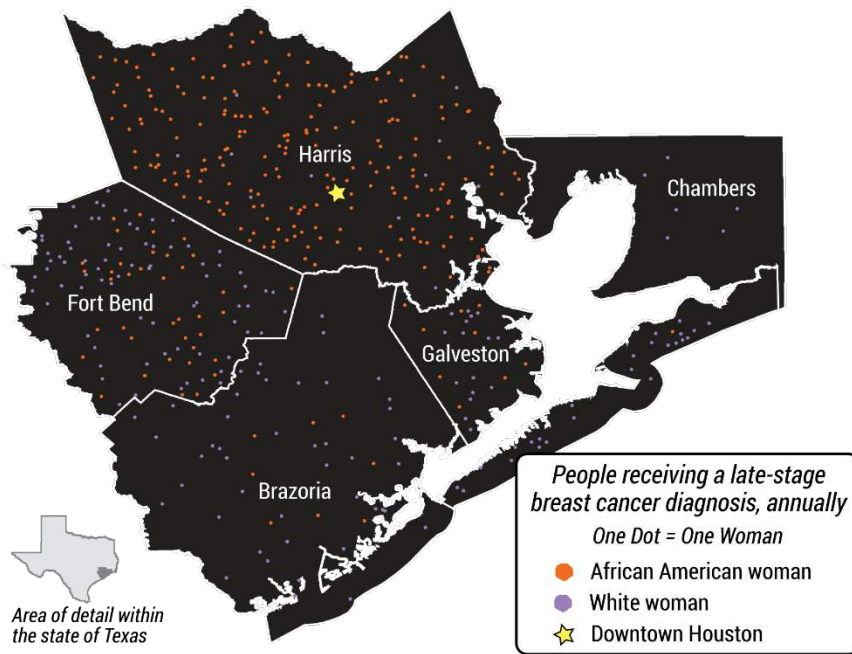


Table 8 and Map 2 depict late-stage breast cancer incidence rates in the Houston MTA. The rates range from 30.5 to 45.4 late-stage cases per 100,000 individuals per year, with most rates being comparable to the state rate of 37.7 and lower than the national rate of 42.3. Harris County is the exception as the only county in the metro that reports a late-stage incidence rate above the national rate (45.4 for all races in Harris County compared to 42.3 for all races nationally).

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

TABLE 8: HOUSTON METRO AREA BREAST CANCER LATE-STAGE INCIDENCE RATE (PER 100,000)

	Age-Adjusted Late-Stage Incidence Rate	Average Count of Cases That Are Late-Stage	Age-Adjusted Late-Stage Incidence Rate for White Women	Average Count of Cases That Are Late-Stage for White Women	Age-Adjusted Late-Stage Incidence Rate for Black Women	Average Count of Cases That Are Late-Stage for Black Women
Brazoria	33.4	56.0	34.4	45.0	33.8	8.0
Chambers	30.5	6.0	32.1	5.0	*	*
Fort Bend	38.0	132.0	38.8	77.0	48.0	37.0
Galveston	33.3	53.0	32.1	41.0	45.0	10.0
Harris	45.4	15.0	44.0	11.0	45.6	214.0
Texas	37.7	5251.0	37.0	4261.0	47.5	790.0
National	42.3	78906.0	41.4	62991.0	51.0	11514.0

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

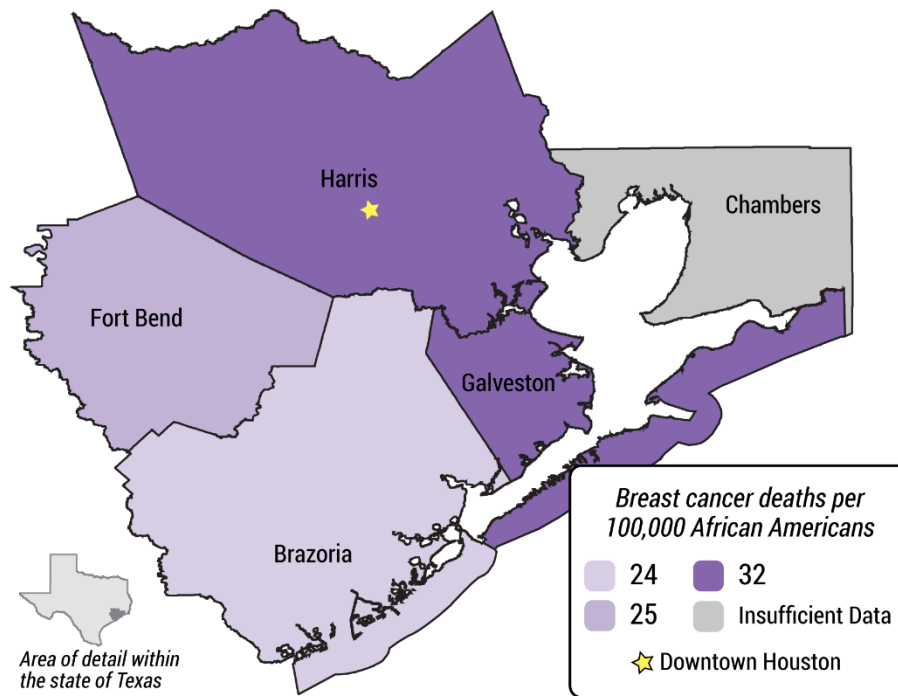
Importantly, in three out of five counties that comprise the Houston MTA, Black women are more likely to receive a late-stage breast cancer diagnosis compared to white women. The late-stage incidence rate for Black women is greatest in Fort Bend County (48), but the disparity in rates comparing Black to white women is greatest in Galveston, where the rate is 45 for African American women compared to only 32.1 for white women. The highest number of women receiving a late-stage diagnosis reside in Harris County (see Map 2 and table 8).

TABLE 9: HOUSTON METRO AREA BREAST CANCER MORTALITY RATE (PER 100,000)

	Age-Adjusted Mortality Rate	5-Year Mortality Rate Trend Direction	Age-Adjusted Mortality Rate for White Women	5-Year Mortality Rate Trend Direction for White Women	Age-Adjusted Mortality Rate for Black Women	5-Year Mortality Rate Trend Direction for Black Women
Brazoria	19.7	falling	20.0	falling	23.8	rising
Chambers	18.0	*	*	*	*	*
Fort Bend	18.6	falling	20.0	falling	25.3	stable
Galveston	22.7	falling	22.2	falling	31.8	stable
Harris	22.3	falling	20.7	falling	32.2	falling
Texas	20.1	falling	19.4	falling	29.1	falling
National	20.6	falling	20.1	falling	28.1	Falling

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

As seen in Table 9, age-adjusted breast cancer mortality rates range from 18 to 22.7 per 100,000 and are comparable with state and national rates. Across the Houston MTA, however, there are notable Black women as compared to white women. Harris County reports both the highest mortality rate in the metro for African American women as well as the greatest disparity between Blacks and whites (20.7 for white women versus 32.2 for Black women). Galveston follows closely in both of these respects: it has the second largest mortality rate (31.8) and the second greatest disparity between white women and Black women (9.6). Mortality rates in Galveston and Harris are higher than in Fort Bend and Brazoria (see Map 3).

MAP 3: BREAST CANCER MORTALITY RATE IN HOUSTON MTA

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

women in three out of five counties being more likely to receive a late-stage breast cancer diagnosis as compared to their white counterparts, and in four out of five counties Blacks reporting a greater breast cancer mortality compared to their white counterparts.

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

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 Houston MTA. Based on a review of the quantitative findings, priority counties for qualitative data collection in the Houston MTA were identified: Fort Bend, Harris and Galveston counties. Fort Bend and Harris have the highest breast cancer burden, while Harris and Galveston County have the highest social determinants of health burden and score poorly on other health measures as well.

Taken together, the data on breast cancer disease burden comparing and contrasting counties to one another, to state and national rates, and by race suggests that breast cancer inequity may be greatest for Black women residing in Harris, Galveston and Fort Bend counties. In these three counties, screening mammography rates are lower than the national average. Incidence rates though lower than the national rate, point to growing racial differences. Importantly, data clearly point to disparities in late-stage incidence and mortality, with Black

Screening.

There are different screening guidelines for those at average risk and for those at higher risk. Recommendations for those at higher risk also vary from one organization or professional society to another. There is some inconsistency for screening recommendations among organizations for those at higher risk (Komen 2021a). Screening mammography rates for all counties are below the national average except for Fort Bend. These data are not disaggregated by race, however the information shared by focus group participants gives some indication of the experiences of Black women seeking and obtaining breast cancer screening.

Access. In terms of access to screening, several focus group participants noted free and convenient breast cancer screening availability in their communities. According to participants, opportunities for free mammograms at work and churches are convenient and facilitate women getting their first and annual mammograms.

“First of all, I had never taken a screening mammogram and a girlfriend of mine said, ‘They’re giving free mammograms. Come on, let’s go’. I had no idea what a screening mammogram was. And two days later she called me and told me I had a mass on my left breast, which I had no idea what that was. But I am truly blessed to be here.” – Galveston County Survivor

Social Support. In addition to having access to convenient screening, focus group participants emphasized the important role that their family members and friends played in their decision to be screened. Focus group participants shared stories of family, co-workers and friends encouraging them to participate in screening opportunities within the community, providing health education and helping them to remember and attend screening appointments.

“I ask my coworkers for help. My supervisor pushed me to get a screening mammogram, she said: ‘Wait.... You work for the state, so I know you have insurance, and you’ve never gone to have a screening mammogram? It’s free now with Blue Cross, Blue Shield. Just make an appointment’. And another co-worker, She said, ‘You know, I’ve never had one.’ She’s 47. ‘Well, sister, you need to have one.’ So every year when I get ready to make my appointment, I send out a message to my coworkers...” - Fort Bend County Undiagnosed

Time. Despite access to screening through non-health care settings as noted above, several focus group participants noted barriers in the form of restrictive work policies, and the fear of losing their jobs if they tried to take time off of work to have mammograms.

“Maybe they have insurance that will pay for a portion of a screening mammogram or a screening or a whatever it is, but they can’t get off work. If they get off work, they’re not going to get paid. They’re not going to get paid, how are they going to pay their bills?” - Fort Bend County Undiagnosed

Screening mammography Screening Guidelines. When discussing breast cancer screening the majority of focus groups discussed experiences receiving mammograms. Some expressed some confusion around screening mammography screening guidelines, particularly regarding what the right age is to receive a screening mammogram. One Harris County focus group participant without a family history of breast cancer described being diagnosed at 28 and at Stage 4. She reflected on whether more variation was needed in screening mammography screening guidelines, and whether this would have helped her identify her breast cancer at a less progressive stage. Another Galveston County undiagnosed participant described her daughter's death from breast cancer at 29.

"I read somewhere they want women to get screening at 40, but I think they should be earlier... my daughter was 29. Okay, she's gone. She died at 29, never had a screening mammogram and all those things." - Galveston County Undiagnosed

An undiagnosed Harris County participant echoed this concern as she described her peer group between the age of 30 – 35, not prioritizing breast cancer screening mammography screening until after age 45. One patient navigator spoke with her Chief Cancer Control Officer about the possibility of putting Black women without a family history of breast cancer into the "high-risk" category so that they can receive screening mammography earlier.

"I asked our Chief Cancer Control Officer and he said, they were considering putting African American women in a high-risk category, so that they would fit with a high-risk guideline. But we never did that." - Harris County Patient Navigator

Types of Screening. The focus groups data revealed that self-examination is a common practice, and this messaging is being shared in churches and amongst family members. Four participants diagnosed with breast cancer from Fort Bend, four from Harris, and one from Galveston found lumps in their breast while conducting a self-examination. One undiagnosed participant from Fort Bend shared that many women in her circle are under the impression that as long as they conduct self-exams, they do not need to have mammograms, and that mammograms are only necessary if a lump is found. Many focus group participants expressed a preference for 3D mammograms (also called digital breast tomosynthesis or digital screening mammogram) and considered them to be better quality than a traditional screening mammogram. A 3D screening mammogram takes images of the breast to create a 3D rather than a 2D image (Mayo Clinic Staff, 2018). This is aligned with perceptions reported in the research literature that digital screening mammography is of higher quality than traditional screening mammography (Ansell et al., 2009). However, there is debate in the clinical field as to whether 3D mammograms are truly more effective, particularly for women with "dense breasts" or breasts with more glandular than fatty tissue. The United States Prevention Services Task Force (USPSTF) has concluded that currently, there is insufficient evidence to assess the benefits and harms of using 3D mammograms or digital breast tomosynthesis as a primary screening method for breast cancer (U.S. Preventive Services Task Force, 2019).

The majority of focus group participants reported that they did not receive genetic testing and/or timely tests even after requesting them. This finding is consistent with the literature that shows that Black

women with a family history of breast or ovarian cancer are less likely than white women with a similar family history to receive genetic counseling with white women having nearly five times greater odds of receiving genetic counseling (Armstrong, Micco, Carney, Stopfer, & Putt, 2005).

Diagnosis

While screening may be available within the Houston MTA, focus group findings suggest that access to and use of diagnostic procedures may be more limited. This in turn may be associated with delayed diagnosis, influencing the late-stage diagnosis rates documented earlier in the report.

High costs. The predominant challenges with this phase of the breast cancer continuum of care appear to be the high costs of the diagnostic procedures for women, who are insured and uninsured alike, who fear being diagnosed with breast cancer and what those diagnoses will entail in terms of cost and life changes. Patient navigators reported instances of clients cancelling diagnostic appointments due to out-of-pocket costs, which could often be as high as \$2000.

“I call patients and schedule biopsies, and they are canceled because they cost \$2,000. They’ll say my diagnostic was covered and I have to explain this is the amount they have to pay after insurance is applied. They can’t do it. The billing department says, ‘Well she can pay half and be billed.’ Well who can come up with \$500? Then they say, ‘if I have cancer, how much is radiation’s going to cost?’ I don’t have an answer for them.”
Galveston County Patient Navigator

“I was part-time on that job for eight years. When I was diagnosed with the cancer I was at a time in my life where if you worked twenty hours you were able to apply for several different insurances. And on my job they never actually explained to us what the different insurance required. I didn’t apply...So when I was diagnosed, I ended up getting FMLA...I lived through the experience of not getting paid, having cancer treatment, and living on \$324 a month for six months.” – Galveston County Survivor

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

“I’m seeing more women who’ve told me that, not only do they have fear, but there’s so much cancer in their families, friends, and people that they know. One lady told me, ‘you’re just talking in vain because if it’s there, I just don’t want to know. I can’t deal with knowing, so, let’s not find out.’ So, there is a lot of fear.” Harris County Patient Navigator

Personally-mediated racism. For the participants that did follow-up on their diagnostic procedures, it is at this phase of the care continuum that experiences of racial discrimination began to occur. One

participant described an unpleasant experience during a biopsy and cancer diagnosis of feeling invisible because of her race.

“The nurse and the doctor were talking to each other and they couldn't find it and then I'm there wondering, ‘Well do I have it? Is it there?’ I finally said to them I need a second opinion so they went and got the head doctor to come and he found it. That was horrible. And then when she called me, after the biopsy got the results, she didn't show any compassion at all. ‘Well you got cancer.’” - Harris County Survivor

Mental strain. One final, important finding within the diagnosis phase of the breast cancer continuum of care is the mental strain on newly diagnosed women. Comments from focus group participants and patient navigators speak to the overall need to address the mental health needs of women who have been diagnosed with breast cancer. The weight of a breast cancer diagnosis is not to be overlooked as participants noted it can mean the difference between someone seeking treatment immediately or delaying.

“I know a couple of women that have actually been diagnosed, they did absolutely nothing about it. I have a friend, she got diagnosed, and I'm like, ‘So what are you going to do?’ She said ‘I'm not doing a damn thing, I'm going to drink everyday. I don't care what my children say’.” - Galveston County Undiagnosed

“I felt so emotional when I was diagnosed. All I needed was just to know who's out there. My mom died, she wasn't there. My sister had to move. So it's like I really had nobody I could just talk to just to. I find that people who thought that I had so much that they never offered me anything. I needed to lean on a sister. I needed somebody to love on, somebody to love me back.” - Harris County Survivor

“They say the chemo gets you depressed. With everything you don't think straight, so how are you going to get your insurance paperwork done? Patients need a family member, somebody that's going to help them walk through this, because if they're not, it is so easy to get lost.” - Galveston County Patient Navigator

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 Houston MTA focus group participants.

High costs and fear of debt. Economic security may be unattainable for many in the Houston MTA given the high percentages of the population that is uninsured and below 200 percent of the FPL. Harris and Galveston Counties have the highest percentages of the population that earns below 200 percent of the FPL, almost 40 percent and 30 percent respectively. Some participants said that one of the biggest

reasons insured and uninsured Black women may decide not to pursue treatment was fear of going into debt.

“I will tell you this, it’s expensive. Even with my insurance, if you could see what I owe now. Every time I go to the doctor for an injection, for a check up... you are talking \$1500 out of my pocket. And sometimes that alone can make you say what the heck?” – Fort Bend County Survivor

“So, when I was first diagnosed, I wound up losing my full-time benefits because I was on 10-hour work shifts and unable to work 10 hours. I was paying Cobra insurance when I got diagnosed. My doctor suggested looking into Medicaid. I did my research myself. I went online and then went to a clinic listed on the Medicaid page, they knew nothing and had to call other organizations to learn how to begin the process for me to get Medicaid. They told me I had to end Cobra to start Medicaid and I did. Being between two insurances, I ended up missing a treatment.” – Harris County Survivor

Patient navigators’ perspectives aligned with survivors’ views on barriers to treatment. Like the diagnostic phase in the care continuum, patient navigators described how health care was out of reach for many Harris and Galveston County residents. They reported instances of clients missing surgery appointments due to high costs or being lost to follow-up due to their inability to meet day-to-day living needs. They further emphasized that women often must prioritize day-to-day living needs over their health. Some patient navigators further explained that the Medicaid application process can be lengthy and burdensome. For example, they shared that the Fort Bend Medicaid application was a hefty 23 pages long. Focus group participants expressed a related sentiment that the onus was always on them - the patients - to determine what was and was not covered by insurance.

“They say it’s free, but it’s the details and all the guidelines that they put you through, that make you feel like, “Man, I wouldn’t have come here.” They want to know your income, what your mom do, what your dad do, what you pay on this bill. It’s just a demeaning process.” – Fort Bend County Undiagnosed

Unless you're probably homeless and crawling on the street you're not going to qualify for financial assistance. You have to be destitute. One of the biggest issues in Harris County are patients that are uninsured and under-insured. Now it's getting worse because the county used to be 200 percent poverty level now it dropped down to 150 percent. So if you over 150 percent, you still have to pay, if you don't qualify for the Harris Health Financial assistance. I pulled up the Fort Bend indigent health care program, the application is 23 pages long. And I said, what if I was sick, and I needed help and I pulled up this application up, I'm going to stay sick. - Harris County Patient

Patient navigators further explained that a large proportion of uninsured women do not qualify for

Medicaid, nor can they afford to purchase private insurance. In response, the Harris County health system offers a financial assistance program to help community members in this situation. Patient navigators explained that women who live outside Harris County will often use a family member's address to get the "Gold Card," or the Harris Health Financial Assistance Program. While this program is not considered insurance, the requirements appear to be less stringent, easing the process of accessing some form of financial relief.

Concerns regarding insurance costs were also shared by providers. A Harris County breast oncologist explained how insurance does not ensure access, especially when patients have a plan with exorbitant out-of-pocket costs. The provider went on to say that their patients might be "better off" not having insurance than having insurance they cannot afford to use.

"People opt for these high deductible, low monthly plans, and then you get a diagnosis of something like cancer, and it's bankruptcy versus if they'd just been paying a little bit more every month, they just took the cheapest option, and I think a lot of these people that pick these plans are uneducated or they can't afford more. Sometimes it's actually better to be uninsured than to have crappy insurance for some of these patients." – Harris County Breast Oncologist

Personally mediated racism. Perceptions of being discriminated against based on race begins at the diagnosis stage and continue into treatment experiences. The majority of focus group participants expressed that Black women who exercised decision-making within the health care setting were largely ignored or met with disapproval. Some participants shared experiences of not being listened to by their providers, which, in turn, may have led to misdiagnosis, delays in treatment and deepening mistrust. This finding is consistent with existing literature that has demonstrated how perceived racism and discrimination in the patient-provider relationship affects communication, care and treatment (Masi & Gehlert, 2009; Sutton et al., 2019). Several studies have examined perceptions of trust and respect in patient-provider relationships and shown both qualitatively and quantitatively how deeply rooted mistrust and fear adversely affect quality of care and treatment-seeking behaviors. One study showed how higher levels of mistrust were associated with lower levels of communication, specifically for breast cancer radiation therapy (Sutton et al., 2019).

"I somehow got missed. I went to the doctor because I was having problems. They just said okay but did not pass the information on. After getting married, I transferred insurance companies and was with a new group of insurance and good doctors. I went in [again] and said "Hey listen, my breast is hurting and I found a lump. So, he checked me and yeah there's a lump but the screening mammogram didn't pick it up. A whole year went by, and another. And, I said, 'Now listen something is going on.' Got another screening mammogram and it did pick up fibroid cysts. Finally, I said, 'Listen this breast is aching all day and all night' and he said to me 'well cancer doesn't hurt.' I said, Listen, 'I don't care what it does, or not let's find out what is going on' So he immediately called a surgeon and scheduled a biopsy." - Harris County Survivor

Some participants described receiving differential treatment largely due their race. They explained that

having insurance, being financially stable, and being educated did not necessarily translate into a high-quality and pleasant health care experience. They described situations where health care providers made assumptions about them and appeared to be subscribing to stereotypes that Black women are uninsured, uneducated, uninformed, aggressive, non-compliant and not interested in their own health. Many participants reported that such treatment perpetuates mistrust and trauma stemming from historical injustices inflicted by the health care system. As a result, participants indicated that patient-provider communication is rooted in a lack of trust – the implications of mistrust, provider bias and historical injustices can be life threatening.

“I worked at Memorial Hermann and used to accompany African American women into their discussion with the doctor after they’ve had their screening mammogram. I had this situation where this African American lady, she was probably around 57 and the doctor, says well I got your readings back and it looks like you’re going to need a biopsy. And then, the doctor asked her, ‘do you understand what I’m saying? You’ll need to set up a follow up appointment.’ The patient looked at me and she said, ‘is she trying to talk to me about cancer.... the devil is a lie, if you’re trying to talk to me about cancer.’ The doctor rushed out of the room and called the patient’s primary care doctor to complain about non-compliance.” - Harris County Patient Navigator

“I don’t want to say it’s about access or resources. I’ve seen how individuals are basically treated when they go through the door. They don’t know if we have insurance. We may have everything... they don’t ask, its just how we are being treated.” – Galveston County Survivor

Poor quality care experiences. Many participants shared experiences of not receiving quality health care and having providers who did not implement a patient-centered approach to care. For instance, participants described providers who did not ask important medical history questions, such as asking about current medications.

“I was taking this estrogen, so when I go back the second time, the lump had got bigger. They said, ‘Well are you taking anything?’ I said, ‘Yeah, I’m taking estrogen because I had a hysterectomy.’ They never told me to stop taking it. Then I go back when the lump gets even bigger. They say ‘Oh my God, please stop taking that [estrogen] immediately.’ I was like, are you serious? Why would you let me walk out of here the first time without asking?” - Fort Bend County Survivor

Social support. Survivors listed social support as a critical facilitator for Black women to seek and continue treatment. Some survivors shared having multiple sources of support including family, friends, coworkers and faith-based organizations. A Fort Bend County survivor described a friend who attended her diagnostic appointment, a supervisor who adjusted her work schedule so she could make her appointments, a nephew who cut her hair for her during treatment and supportive health care providers.

Several participants also mentioned the church as a valuable source of social support, especially for older Black women. The church's role for breast cancer survivors who do not have family or do not trust the health care system cannot be overstated. The majority of the breast cancer survivors in the focus groups were between 55-65 years old and lived alone. These women shared the importance of the church in their treatment experiences.

"When one of our church members was sick, the Pastor called up people to have them go sit with her. You know? She didn't trust the medical staff. So Pastor assigned 31 of us to go every day to visit there until her family came to stay at our place." - Fort Bend County Undiagnosed

"It was very important that we support each other, especially when you get older. Myself, I don't have family here. My children live in different states. And this is new for me to be retired and have no one that I can call on, you know? And it's really hard. But this church, the family, the church family, it's very important to me. And when I come here, when I see her face, I feel so at home..." - Galveston Undiagnosed

Patient navigators emphasized the need for social support to manage the complexities of insurance options, especially when a survivor is physically, emotionally and mentally strained, as a result of treatment. One patient navigator shared the need for support with paperwork to manage and maintain insurance.

"They say in chemo you get depressed and you're losing your hair and everything and you don't think straight... how do you get your insurance paperwork in order [in such circumstances]? That's one of the biggest things needed, they need to make sure somebody knows- a family member, somebody that's going to help you walk through this, because it is not so easy." - Galveston Patient Navigator

High quality of care experiences. Some participants had better breast cancer treatment experiences and noted how a high-quality experience was a key facilitator to treatment adherence. When asked to describe the ideal care situation, survivors consistently described high-quality care as meeting two key characteristics: 1) having providers that are kind and take the time to thoroughly explain the treatment options and address fears, and 2) having a care team that collaborates among themselves and with the patient and emphasizes shared decision-making. Participants' articulation of quality care aligns with the definitions of patient-centered cancer care that focuses on patient preferences and needs to inform clinical decision-making (Nardi et al., 2018).

Overwhelmingly, undiagnosed and survivor focus group participants considered MD Anderson health care facilities to be of high quality and the best place to go in the Houston MTA to survive breast cancer. Participants described how MD Anderson emphasizes team care, and when first diagnosed, a person is assigned to a care team. While MD Anderson is considered the premier breast cancer treatment facility in the Houston MTA by many focus group participants, some shared their disappointment in not being

able to receive care at the MD Anderson facilities due to insurance barriers but recounted pleasant experiences in other facilities like Baylor St. Luke's Dan L Duncan Comprehensive Cancer Center.

"I was diagnosed at stage three, triple negative and people didn't give you very much hope. I tried for months and months to get into MD Anderson. I said I'm giving up. I've got to find somebody. I was diagnosed in April, this was August, and I still had not been treated yet. In the meantime, this lump is growing and growing. I called Baylor, and I'll never forget, and they said, "Okay, we'll get your records." She called every doctor until she got my records. I called her Monday and on Friday I was seeing the doctor" - Galveston County Survivor

Survivorship

Support services. Some survivors, particularly from Fort Bend and Harris County, expressed much gratitude for the American Cancer Society (ACS) support services during treatment. For instance, they recollected support received with wigs, prosthetics, and make up – all offered in a professional and kind manner. They described ACS as providing linkages to other survivors, who, in turn, helped these women with post-surgery rehabilitation and strategies to get through chemotherapy.

Mental strain. While support groups are essential elements of breast cancer survivorship, many participants shared their reluctance to join. A Harris County patient navigator who is also a survivor described the sadness and anxiety around support group members passing away.

A lot of times you don't want to get involved because of the close-knit relationship you develop with others. It's stressful for you because when you develop these relationships with these women then you think about yourself. I've lost a good 12 friends myself and it's not easy, it's hard. – Harris County Patient Navigator

Black organizations. Focus group participants in Harris County described the importance of having access to Black support groups. Harris County survivors lamented the loss of funding of the Sister's Network, a Black breast cancer survivorship organization. One Galveston patient navigator referenced *Reconstruction of a Survivor* as one of the only survivorship organizations in the area.

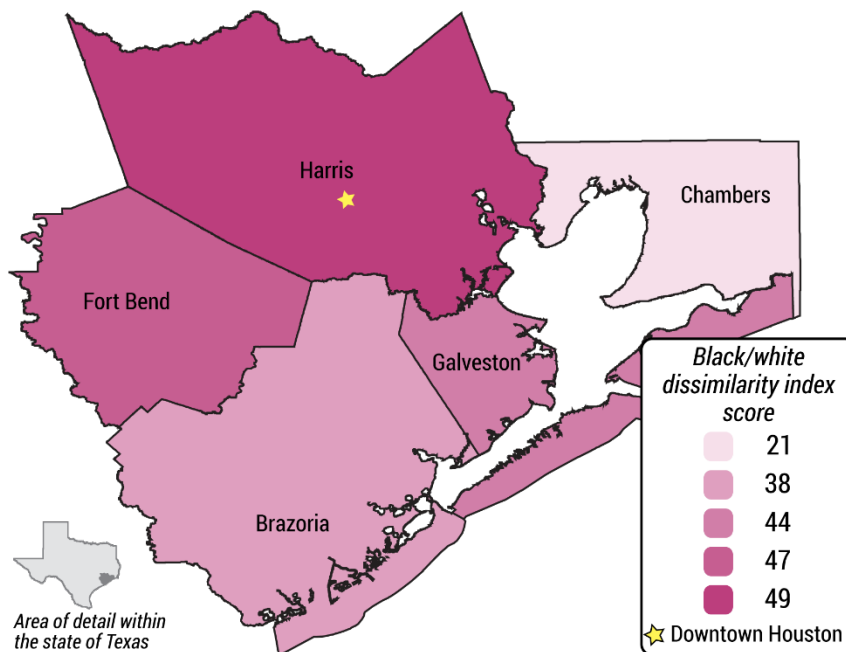
Section 2 Findings: Systemic and Social Determinants of Health

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 and SDOH—were informed by consultations with the Komen AAHEI team, academic experts (see Acknowledgements for details), findings from the literature scan and principles in the guiding frameworks.

Residential Segregation and Redlining Practices

In the Houston MTA, the majority of Blacks and whites reside in racially homogenous neighborhoods. The degree of residential segregation can be measured using the black-white dissimilarity index, which ranges from 0 to 100. A county’s score on this index corresponds to the percentage of people within a racial group who would need to relocate in order for the county to achieve integration. Zero indicates complete integration of the two races and 100 indicates complete segregation of the two races. For example, a score of 35 means that 35 percent of whites living in a particular county would need to move to a different neighborhood within that same county in order to achieve racial integration.

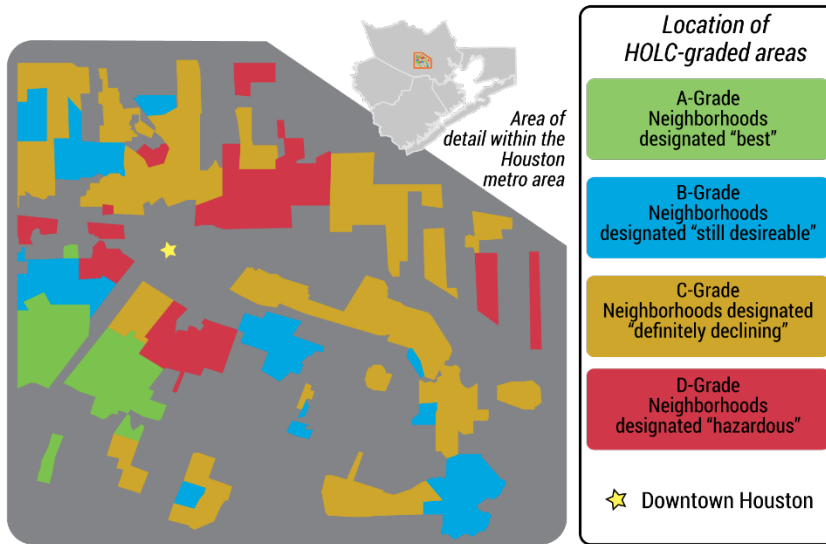
MAP 4: RESIDENTIAL SEGREGATION IN THE HOUSTON METRO AREA



In the Houston MTA, Harris and Fort Bend (the two counties with the largest numbers and highest percentages of Black residents – see table 4 above) are the most racially segregated, with scores of 49 and 47, respectively (refer to map 4). Galveston County’s score (44) is close behind. This indicates that nearly half of all white people living in each of these places would need to relocate to new neighborhoods within the county in order to achieve racial integration.

Source: 2019 County Health Rankings (County Health Rankings)

MAP 5: REDLINING IN THE HOUSTON METROPOLITAN AREA



Source: 2019 Mapping Inequality Project (University of Richmond)

Harris County’s high score on the black-white dissimilarity index was likely influenced by the fact that portions of the county were redlined in the 1930s (see map 5). Redlining – the practice of identifying and systematically discriminating against certain neighborhoods based on their racial makeup – is an example of structural racism (also referred to as institutionalized racism per Dr. Camara Jones’ framework). Between 1933 and 1954, Home Owners’ Loan Corporation (HOLC) field agents with the federal government assigned grades

to neighborhoods ranging from A to D, best to hazardous respectively. The practice is commonly called redlining because designated hazardous areas assigned a D grade were marked in red. Government officials in Houston declared a number of neighborhoods in Harris County “hazardous” because of their large Black populations. This structural practice excluded individuals and entire communities from investment and resources over generations. Areas of advantage (where whites lived) became more advantaged and more white while areas of disadvantage (where people of color lived) became more disadvantaged and less white (Rothstein, 2017). For this reason, the level of segregation that currently exists between Blacks and whites in Harris County can be traced – at least in part – to redlining.

Experience of racism in everyday life

In addition to practices of structural racism, as defined above, Blacks in the Houston MTA likely experience several forms of personally mediated racism that can be examined by looking at a range of measures (U.S. Department of Housing and Urban Development, 2019; U.S. Department of Justice Federal Bureau of Investigation, 2017). One example is data on hate crimes. In 2017, the number of hate crimes committed with a racial bias motivation was highest in Fort Bend and Galveston counties: both counties reported six such crimes (see table 10).

TABLE 10: HOUSTON METRO AREA RACISM

County	Number of Hate Crimes Committed With a Race/ Ethnicity/ Ancestry Bias Motivation	Number of Fair Housing Act Cases Filed With a Race Basis	Number of Blacks Killed by Police
Brazoria	2	23	1

Chambers	0	1	0
Fort Bend	6	47	1
Galveston	6	41	0
Harris	5	651	13

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)

Another measure is the Fair Housing act cases filed with a race basis. As seen in table 10, over 85 percent (651) of the Fair Housing Act cases filed with a race basis in the Houston MTA between 2006 and 2019 were filed in Harris County. This number is almost 14 times greater than in the county with the next largest number of cases (47 in Fort Bend). Finally, between 2015 and 2016, more Blacks were killed by police in Harris County than in any other county in the Houston MTA. The rate in Harris County is more than six times higher than the combined rate across the rest of the metro. Of the 13 Blacks who lost their lives at the hands of police in Harris County during that two-year period, nearly 25 percent (four) were unarmed.

Overall, these data suggest that Harris County may be a place where Blacks are likely to face discrimination based on their race. Harris County reported one fewer race-based hate crime in 2017, but along other measures of racism it appears to be doing far worse than Galveston and Fort Bend.

The experiences of community members from the Houston MTA provide additional insights about experiences of personally mediated racism that Blacks experience. As noted above (see Findings I), focus group participants reported receiving poorer quality care and differential treatment at the diagnosis and treatment stages in the breast cancer continuum. For instance, many expressed the sentiment that Black women who exercised decision-making within the health care setting were largely ignored or met with disapproval. Many noted how providers embraced stereotypes about Blacks being uneducated, aggressive and non-compliant. Others explained that irrespective of insurance and education, Blacks receive differential treatment due to their race.

The majority of focus groups engaged across counties reported encountering racial discrimination while shopping and in the workplace. There were several stories of women not being asked if they needed assistance, ignored and mistreated in grocery and retail settings. Additionally, many women shared their struggles in the workplace with white supervisors, enduring daily microaggressions and some blatant, racially motivated professional and personal attacks.

“I was a retail store manager for Cracker Barrel, just recently. I had a district manager who was a white woman. I was the only Black manager she had in the district. She gave me hell. There was nothing that me and my team could do right. Instead of coming to me and discussing stuff with me, she would go to the other manager - they were all white. So she got rid of me, so she could bring in someone else.” - Galveston Undiagnosed

“Just recently, I was in the shoe department. I love shoes. So, I’m walking around looking for shoes. No one but me and a sales person. She never came over to ask, ‘May I help you?’ Two white ladies came in, and she immediately went to them and asked, ‘May I help you?’” -Harris County Survivor

Other Health Measures and Disparities

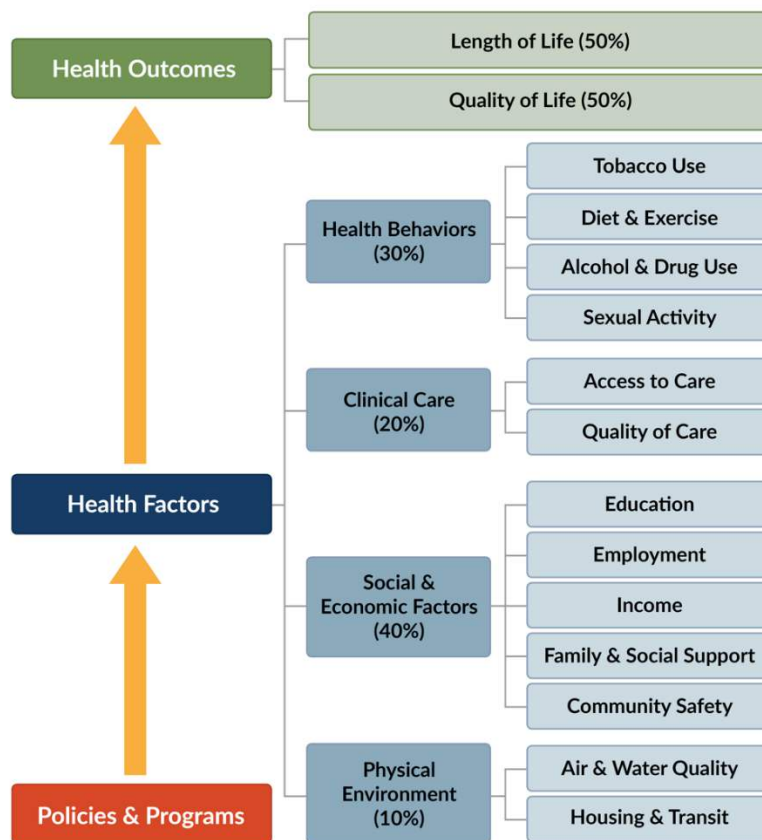
Data suggest that there are disparities in the Houston MTA in terms of overall health and wellbeing. Life expectancy is considered a good metric of overall health and wellbeing. Life expectancy for Blacks in the Houston MTA varies widely, from 73 years in Galveston County to 81 years in Fort Bend County (see table 11). In most counties, whites outlive Blacks by an average of two years. The disparity is greatest in Harris and Galveston counties; the average Black person will die more than four years before the average white resident.

TABLE 11: HOUSTON METRO AREA LIFE EXPECTANCY IN YEARS

County	Life Expectancy	Life Expectancy for Whites	Life Expectancy for Blacks
Brazoria	79	78	79
Chambers	77	77	75
Fort Bend	83	81	81
Galveston	78	77	73
Harris	80	79	75

Source: 2019 County Health Rankings (County Health Rankings)

FIGURE 2. COUNTY HEALTH RANKINGS MODEL



County Health Rankings model © 2014 UWPHI

County Health Rankings (CHR) provide a reliable picture of the health of a county relative to other counties and uses local data and evidence to help communities identify their opportunities for improving health. CHR are derived from over 30 measures of health outcomes and health factors to give an overall ranking of health in the county as compared to other counties in the same state (See Figure 1). Lower scores are considered to be better. On this metric, Fort Bend and Brazoria stand out as being ‘healthier’ counties with CHRs of 2 percent and 7 percent respectively (see table 12 below). The rest ranges from 20 percent to approximately 40 percent.

TABLE 12: HOUSTON METRO AREA HEALTH AND WELLBEING

County	County Health Rankings Percentile	Percent of Adults Reporting "Fair" or "Poor" Health	Average Number of Poor Physical Health Days per Month	Average Number of Poor Mental Health Days per Month
Brazoria	7%	16%	3.3	3.2
Chambers	28%	15%	3.4	3.5
Fort Bend	2%	14%	2.9	3.0
Galveston	38%	18%	3.7	3.5
Harris	21%	18%	3.6	3.6

Source: 2019 County Health Rankings (County Health Rankings)

Galveston and Harris, the two counties with the lowest life expectancy for Blacks, also report worse on other health and wellbeing indicators for all races relative to other counties in the MTA (see table 12). For example, in both counties, nearly one in five adults report that their health is “fair” or “poor”, higher than other counties. The average number of poor mental and physical health days were comparable across counties.

The patterns are similar for another commonly studied health metric: age-adjusted premature mortality rate, which is measured as the number of deaths among residents under the age of 75 per 100,000 population. Premature age-adjusted mortality ranges from 217 in Fort Bend to 402 in Galveston County (see table 13). There are notable differences comparing rates among whites and Blacks. In Harris County, for example, although the overall premature age-adjusted mortality rate is lower than in Galveston, the age-adjusted premature mortality rate for Blacks is nearly 200 points higher than it is for whites (527 versus 342). In Galveston County, the disparity is even more dramatic: 631 for Blacks compared to 407 for whites. Health behaviors such as rates of drinking, physical activity, and obesity are fairly similar across counties (see table 14).

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

County	Premature Age-Adjusted Mortality	Premature Age-Adjusted Mortality for Whites	Premature Age-Adjusted Mortality for Blacks
Brazoria	332	387	333
Chambers	399	404	619
Fort Bend	217	244	283
Galveston	402	407	631
Harris	331	342	527

Source: 2019 County Health Rankings (County Health Rankings)

On the range of health disparities included in this report, Fort Bend stands out as a unique case. Among all Houston MTA counties, Fort Bend county has the best life expectancy for Blacks, the highest CHR score of any county in the metro and one of the best in the entire state (it is ranked fifth out of the 254 counties in Texas), has a lower average number of poor physical and mental health days, and the lowest premature age-adjusted mortality. Community members validated these findings – the majority of Fort Bend focus group participants described a high quality of life in the county that is characterized by a good school system and a community that has everything they need (doctors, restaurants, shopping) within a short distance.

TABLE 14: HOUSTON METRO AREA HEALTH BEHAVIORS

County	Percent of Adults Who Are Obese	Percent of Adults Who Drink Excessively	Percent of Adults Who Are Physically Inactive
Brazoria	30%	19%	21%
Chambers	28%	21%	28%
Fort Bend	29%	18%	19%
Galveston	32%	19%	24%
Harris	27%	18%	22%

Source: 2019 County Health Rankings (County Health Rankings)

Access to Health Services

Although not disaggregated by race, data on health services suggest that access to health services is a challenged for many residents in the Houston MTA. Data suggest that there are limited breast cancer resources in the Houston MTA. Galveston is the only county to offer mobile screening mammography, and there are only three cancer coalitions in the entire metro region (see table 15).

TABLE 15: HOUSTON METRO AREA BREAST CANCER RESOURCES

County	Number of Mobile Screening mammography Centers	Number of Cancer Coalitions	Number of Survivor/Support Groups
Brazoria	0	0	2
Chambers	0	1	0
Fort Bend	0	0	0
Galveston	2	1	1
Harris	0	1	3

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

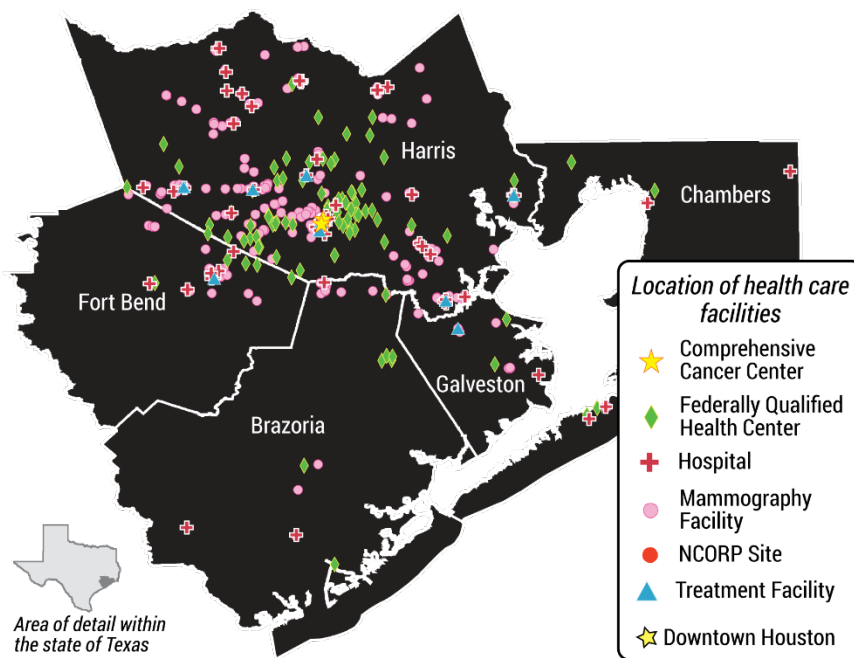
Other health systems in the Houston MTA also appear to be limited. All counties in the Houston MTA report that some percentage of their population is medically underserved (ranging from 11 percent in Galveston to 100 percent in Chambers) (see table 16). According to the Health Resources and Services 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. All of Chambers County's mostly white and very small population is considered medically underserved because it is a rural county and has the lowest number of PCPs, other PCPs, and oncologists. However, even in urban counties, such as Harris and Fort Bend, one in four residents is medically underserved. The rate is particularly alarming in Harris County, as its rate of 26 percent means that nearly 1.2 million of its residents are medically underserved. Harris County's high person-per-primary-care-provider ratio reflects this issue for the population. Even though Harris County has the largest number of health systems resources, including federally qualified health centers, treatment facilities and both comprehensive cancer centers in the MTA (see map 6 health systems), it appears to be a place of high need in terms of health systems (see table 15).

TABLE 16: HOUSTON METRO AREA HEALTH SYSTEMS

County	Percent of Total Population That Is Medically Underserved	Number of PCPs	Persons per PCP	Number of "Other" PCPs	Persons per "Other" PCP	Number of Private PCPs	Number of Private Oncologists
Brazoria	12%	225	1,574	50	1,981	210	8
Chambers	100%	4	9,975	48	2,072	0	0
Fort Bend	25%	627	1,182	59	1,700	524	4
Galveston	11%	236	1,396	82	1,214	100	9
Harris	26%	2,665	1,722	79	1,269	578	5

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

MAP 6: HEALTH SYSTEMS IN THE HOUSTON METROPOLITAN AREA



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

Economic Vulnerabilities

Data compiled on multiple measures suggest that several counties in the Houston MTA are economically vulnerable. Residents of Harris and Galveston counties face particular difficulties. In Harris County,

almost 40 percent of the population earns below 200 percent of the FPL (see table 17). This is the highest rate in the metro. The next highest rate is in Galveston, where almost 30 percent of the population live below 200 percent of the FPL. Poverty rates among Black women in particular are also high, with the rate being highest in Galveston County (23 percent). Black women in Fort Bend appear to fair better relative to the other counties.

Of the estimated 200,000 Black women over the age of 45 who live in the Houston metro area, 82 percent (more than 163,000) reside in Harris and Galveston counties, indicating that, between the two counties, around 30,000 Black women over age 45 live below the poverty line (see table 17 Houston MTA Economic Security and table 4 County Demographics). Disparities in percentage of uninsured populations follow similar trends, with Fort Bend as the lowest at 10 percent uninsured and Harris County as the highest at 20 percent uninsured.

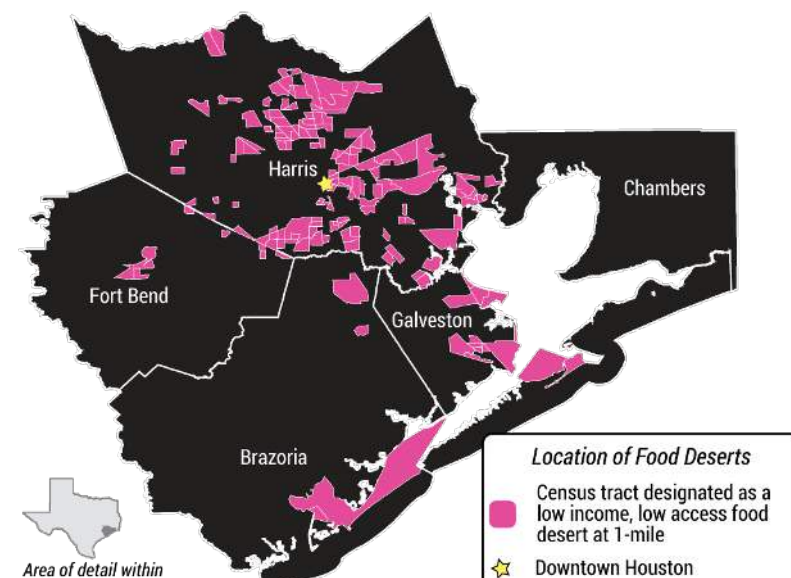
TABLE 17: HOUSTON METRO AREA ECONOMIC SECURITY

County	Percent of Population That Is Uninsured	Percent of Population Below 200% FPL	Percent of Black Women Over Age 45 Who Live Below Poverty Level
Brazoria	12%	24%	8%
Chambers	14%	28%	19%
Fort Bend	10%	20%	8%
Galveston	14%	29%	23%
Harris	20%	38%	17%

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

Food insecurities are also prevalent. In every county in the metro, at least 15 percent of the population is considered food insecure (see table 18 below). Galveston and Harris counties have the highest rate, where 17 percent of the total population in each county is considered food insecure.

MAP 7: FOOD DESERTS IN THE HOUSTON METROPOLITAN AREA



Area of detail within 2019 Food Research Atlas (US Department of Agriculture, Economic Research Service)

Food deserts in the MTA are concentrated in Harris and Galveston, making up approximately 20 percent of the land area in both counties (see map 7). Blacks living in these two counties are more likely to receive federal food assistance as compared to other counties in the metro: 27 percent of Black families in Galveston and 22 percent in Harris are enrolled in the federal government’s supplemental nutrition assistance program (SNAP/EBT).

TABLE 18: HOUSTON METRO AREA FOOD SECURITY

County	Percent of Population That Is Food Insecure	Percent of Total Population With Limited Access to Healthy Foods	Percent of Black Households Receiving SNAP/EBT
Brazoria	15%	7%	11%
Chambers	15%	5%	15%
Fort Bend	15%	7%	12%
Galveston	17%	8%	27%
Harris	17%	6%	22%

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

Consistent with these secondary data findings, as noted earlier in the report (see Findings I), focus group participants described economic challenges. Many of the community members and patient navigators described how large proportions of the population are uninsured; they described the high costs of breast cancer diagnosis and treatment, and, as a consequence, the need to choose between their day-to-day living needs and health care costs.

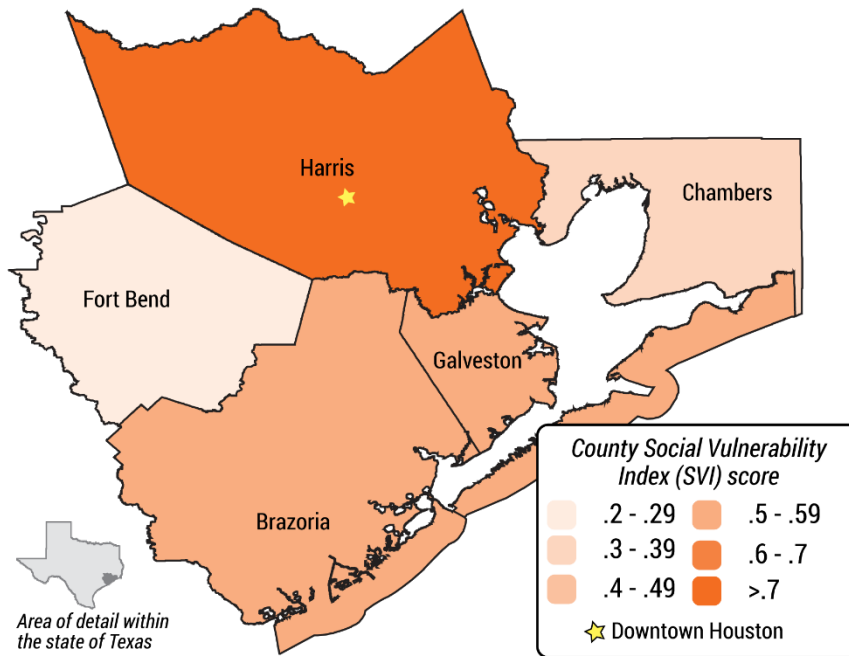
Research suggests that women experiencing economic vulnerability or lower socioeconomic status (SES) of every race and ethnicity tend to have worse breast cancer outcomes than women of higher SES (Newman, 2017). Disparities in breast cancer survival related to SES have been found to be associated with differences in disease stage at presentation and differences in treatment. However, there is also increasing evidence about how Black women compared to white women of the same SES experience persistent disadvantages. Studies are using different methods of measuring SES (e.g., household income, composite measures of SES, employment) (D. R. Williams et al., 2016). Different measures of SES, while a valuable contribution to scholarship, decrease the ability to rigorously compare and contrast findings across studies. Additionally, many of the existing measures do not account for accumulated wealth or assets where there are stark racial disparities (D. R. Williams et al., 2016).

Social and Economic Vulnerability

SDOH affect health outcomes – such as breast cancer – for individuals and communities. These play out not just across individual lifetimes, but generationally. Disadvantages compound in certain communities, which exacerbate and cement a wide range of negative outcomes and existing burdens, including with regard to health (Cozier et al., 2009; Institute of Medicine of the National Academies, 2011).

This report examines SDOH related to housing, education and transportation. While several of these measures are not available disaggregated by race, they still illustrate the vulnerability and challenges in the county as a whole. Across a number of different measures, Harris County appears to face the greatest SDOH burden with Galveston County following in a close second.

MAP 8: SOCIAL VULNERABILITY IN THE HOUSTON METROPOLITAN AREA

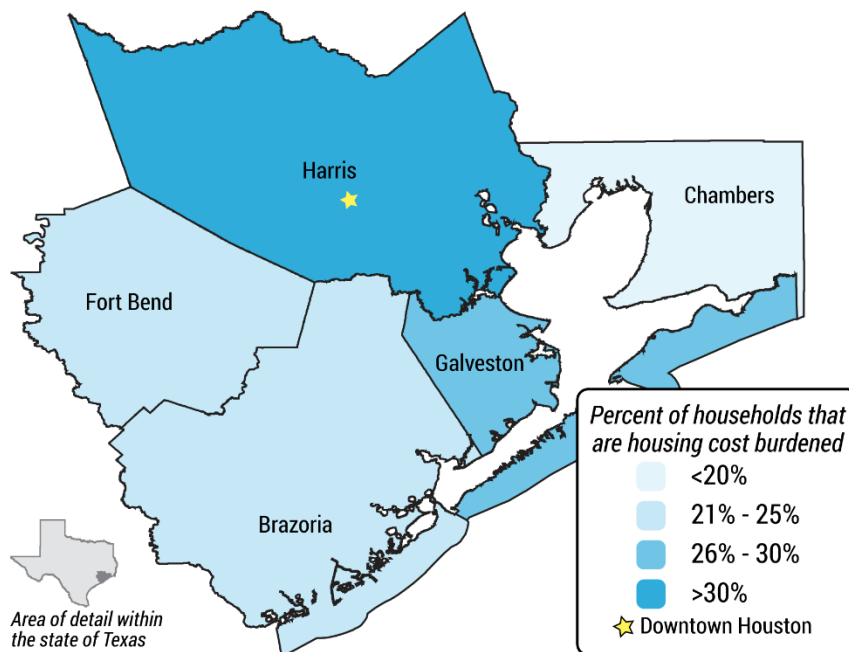


One of the most comprehensive measures of SDOH burden is a county’s social vulnerability index (SVI) score. SVI scores (which range from zero to one, with one representing high social vulnerability) are calculated by the CDC and measure the exposure of a population to social vulnerabilities that limit their ability to withstand adverse impacts from multiple stressors to which they are exposed. As seen on map 8, Harris has the highest SVI score in the Houston metro (.7), followed by Galveston (.57). These rates are significantly higher than

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

the metro average (.47), and Harris County’s SVI score is more than 2.5 times greater than the best score in the metro (Fort Bend at .27).

MAP 9: HOUSING COST BURDEN IN THE HOUSTON METROPOLITAN AREA



Housing insecurity appears to be one of several key factors affecting Harris County’s high SVI score. In Harris, one in three households is considered housing-cost burdened, a measure calculated by the US Department of Housing and Urban Development to assess the proportion of renters and homeowners that spend 30 percent or more of their total income on housing. Harris County reports the highest housing-cost burden rate in the Houston MTA (see map 9), with Galveston County as a close second with 27% of its population being housing-cost burdened.

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

The majority of the population in the Houston MTA has a high school degree, but Harris County reports the lowest rate of educational attainment: in Harris County, nearly one in every five people over the age of 25 lacks a high school degree. When considering the educational attainment of Black women, specifically, Galveston stands out as the place where these women are the least likely to have earned a high school degree (see table 19). Post-secondary educational attainment rates vary widely across the Houston MTA, with Fort Bend reporting the highest percentage of the population with a Bachelor’s Degree (46 percent) and Chambers reporting the lowest percentage (21 percent).

Gentrification is another measure connected to educational attainment. All counties except Galveston appear to be gentrifying as depicted by proportional change in population with a bachelor’s degree or higher. Most counties are also reporting a change in median income (table 20).

TABLE 19: HOUSTON METRO AREA EDUCATION

County	Percent of Population Over Age 25 That Has a High School Degree or Higher	Percent of Population Over Age 25 That Has a Bachelor's Degree or Higher	Percent of Black Women Over Age 25 Without a High School Degree
Brazoria	88%	30%	5%
Chambers	86%	21%	8%
Fort Bend	90%	46%	6%
Galveston	88%	30%	13%
Harris	81%	31%	10%

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

TABLE 20: HOUSTON METRO AREA GENTRIFICATION

County	Proportional Change in Population With a Bachelor's Degree or Higher	Percent Change in Median Household Income
Brazoria	3%	12%
Chambers	4%	-1%
Fort Bend	5%	11%
Galveston	1%	7%
Harris	3%	9%

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

Per Table 21, transportation could be a barrier to timely access of services. Public transit utilization is low across the metro. At 3 percent, Harris – the most-urban county – reports the highest percentage of transit users. Many households lack a vehicle in Harris and Galveston counties (6 percent). Perhaps unsurprisingly, a higher percentage of people engage in active transportation (e.g., walking or riding a bike) in these places (3 percent and 4 percent, respectively). Residents of Galveston County face unique transportation challenges due to the physical geography of the area. The southeastern portion of Galveston County – where the city of Galveston and the majority of the county’s population is located – is an island. For this reason, residents of Galveston are physically cut off from many resources.

As seen in map 6, the vast majority of hospitals, treatment centers, and clinics are located on the mainland, in Harris County. A roundtrip visit to either of the Comprehensive Cancer Centers in

downtown Houston would take a resident of Galveston over two hours if they have a personal vehicle. If they do not have a personal vehicle (as is the case for about one in 15 Galvestonians), the trip takes over seven hours on public transit (see table 21). Galveston patient navigators emphasized this transportation challenge and described women walking to medical appointments in uncomfortable weather conditions with their children.

TABLE 21: HOUSTON METRO AREA TRANSPORTATION

County	Percent of Households Without a Vehicle	Percent of Total Population That Commutes More Than 45 Minutes to Work	Percent of Total Population That Commutes to Work Using Public Transit	Percent of Total Population That Commutes to Work by Foot/Bike/Other
Brazoria	3%	25%	0%	2%
Chambers	4%	19%	0%	2%
Fort Bend	2%	29%	2%	2%
Galveston	6%	20%	1%	4%
Harris	6%	21%	3%	3%

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

“We don’t have the vast transportation system. We have city transportation, but they only stop at certain locations. If those clinics aren’t at any of those locations, that means patients have to walk. We have seen many women walk to their appointments, drenched in sweat.” - Galveston Patient Navigator

The 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 care 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 exempt grandfathered plans or policies, a very minor share of plans in existence prior to the passage of the ACA 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 USPSTF and Health Resources and Services Administration (HRSA). In accordance with these guidelines, plans must provide coverage for mammograms beginning at age 40 without cost sharing. For women at high risk of breast cancer, plans must also cover genetic screening and preventive medication for breast cancer (The Henry J. Kaiser Family Foundation, 2015).

Pre-Existing Conditions Protections

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

Medicaid Expansion

Under the ACA, states have the option to expand their Medicaid program to individuals with incomes of up to 138 percent of the FPL. Texas has not elected to expand eligibility for its Medicaid program. This leaves people in what is called a “coverage gap” where their incomes are too high to qualify for Medicaid but not high enough to afford health insurance otherwise; thus, they remain uninsured. One-third of all people in the coverage gap in the U.S. live in Texas and 92 percent of all adults in the coverage gap are located in the Southern U.S. (Garfield, Orgera, & Damico, 2020). If Texas were to expand eligibility for its Medicaid program, an estimated 1.55 million additional Texans would be able to enroll in Medicaid coverage (Garfield et al., 2020). One study estimated the number of deaths related to the coverage gap due to poor or no access to health care. The study estimated that 730 people in Texas die each year because of the coverage gap and failure to expand the state’s Medicaid program (Miller & Wherry).

Secondary data indicate that, on average, the percentage of insured in the Houston MTA is lower than the national average of 92 percent (Berchick, Barnett, & Upton, 2019). Even in Fort Bend, which has the highest insured rate in the MTA, 10 percent of its population is uninsured (see table 9). The worst rate in

the metro is in Harris County, where one in every five residents is uninsured; this rate is higher than the national average. Recent research indicates that the national 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 (Buchmueller & Levy, 2020). Regarding screening, research suggests that states that expanded eligibility for their Medicaid program have improved cancer screening rates compared to states that did not (like Texas), and that early adoption of Medicaid expansion is associated with greater improvements in screening (Fedewa et al., 2019; Swift, 2019).

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

In Texas, the program is called the Breast and Cervical Cancer Services Program (BCCS); women living in Texas, who are 50 to 64 years old, at or below 200 percent of the FPL, and uninsured are eligible for this program (Texas Health and Human Services, 2020).

Women who do have access to screening services but who do not have coverage for diagnostic services are considered “underinsured” and are eligible for services through BCCS.(Texas Health and Human Services Commission - Women's Health Services Division, 2017). States have the leeway to identify “priority populations” for their screening program, and Texas has prioritized women 50-64.

In Texas, the BCCS guidelines for reimbursement and frequency of screening mammography differ by age. For age groups below age 50, the guidelines also take into account whether the woman has experienced symptoms of breast cancer or is considered high risk (see table 22). At minimum, breast cancer screening through BCCS includes a clinical breast exam, review of the client’s breast health history, a screening mammogram, client education, an assessment of tobacco use, and if appropriate, a referral to a tobacco Quit Line (Texas Health and Human Services Commission - Women's Health Services Division, 2017). If a woman shows symptoms of breast cancer, BCCS covers a range of detection services, including a diagnostic screening mammogram, breast ultrasound, and breast biopsy.

TABLE 22: GUIDELINES AND REIMBURSABLE COVERAGE FOR SCREENING MAMMOGRAPHY BY AGE IN THE TEXAS BREAST AND CERVICAL CANCER SERVICES PROGRAM

Age Group	Guidelines for Screening
Ages 50 and above	Annual screening
Ages 40-49	Asymptomatic: Screening every two years High Risk*: Up to annual screening
Ages under 40	Asymptomatic: Without History of Breast Cancer: Not eligible for breast cancer screening services

Source: Fiscal Year 2017 Policy and Procedure Manual, Breast and Cervical Cancer Services, Texas Health and Human Services Commission.

**High risk determined by “established breast cancer risk assessment tools” such as the Gail Model National Cancer Institute risk calculator.*

In Texas, from the five-year period of January 2013 to December 2017, the NBCCEDP served 121,317 women for both breast and cervical cancer screening and detection services. Specific to breast cancer,

50,292 women received a screening mammography over this five-year period, and 88,730 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 a woman’s access to services (e.g., eligible regardless of screening location or provider) or can impede a woman’s access to services (e.g., requirements that NBCCEDP fund screening costs).

In Texas, the program is called the Medicaid for Breast and Cervical Cancer Program (MBCC). Women who have been diagnosed with breast or cervical cancer or certain “pre- cancer conditions” are eligible for “full regular Medicaid benefits” (Texas Health and Human Services Commission, 2017). As of 2017, MBCC is delivered via Medicaid managed care plans, specifically through STAR+PLUS plans for people with chronic medical conditions and disabilities (Texas Health and Human Services Commission). An individual is no longer eligible for MBCC if any of the following occur: no longer receiving “active treatment” for breast or cervical cancer, becomes 65, acquires another source of creditable coverage,, or moves out of Texas (Texas Health and Human Services Commission, 2017).

TABLE 23: OVERVIEW OF SCREENING AND TREATMENT SERVICES

	Breast and Cervical Cancer Services (Screening Focus)	Medicaid for Breast and Cervical Cancer (Treatment Focus)
Age	All women 50 - 64, eligibility for women 40-49 and under 40 varies by symptoms and risk (see Table 19)	18 - 64
Resident	Texas resident	Texas resident
Insurance status	Uninsured or underinsured (e.g., without access to diagnostic services), without access to services otherwise	Uninsured and not otherwise eligible for Medicaid, without access to services otherwise
Program Services	Screening and diagnostic services (including clinical breast exam, screening mammogram, ultrasound, biopsy)	All Medicaid services (including visits to the doctor, hospital stays, emergency care, medication, transport)

Sources: Part X, Medicaid for Breast and Cervical Cancer (MBCC), Fiscal Year 2017: Policy and Procedure Manual, Breast and Cervical Cancer Services, Texas Health and Human Services Commission.

Texas State Cancer Plan

The Texas Cancer Plan is a "statewide blueprint for cancer research, prevention and control." In the most recent Texas State Cancer Plan (2018), the goal related to breast cancer is to "Increase screening and early detection to increase the number of cancers diagnosed at an early stage and reduce deaths from breast cancer." The plan includes strategic actions related to policy, communication, programs, and systems improvement. Although these broader strategic actions could create some positive impacts on the experiences of Black breast cancer patients and survivors, the strategic actions do not address

racial inequities in breast cancer specifically (Garcia & Magid, 2018).

State Laws Impacting the Breast Cancer Community

- **Diagnostic Imaging.** The preventive services mandate requires that almost all private health insurance plans cover certain preventive services without patient cost sharing.
- **Metastatic Step Therapy.**
- **Oral Parity.**
- **Diagnostic Imaging.** Texas has passed legislation that eliminates the out-of-pocket costs for medically necessary diagnostic mammograms.
- **Metastatic Step Therapy.** Texas has passed legislation that prohibits the use of step therapy or “fail-first” protocols for advanced, metastatic cancer treatments and its associated conditions.
- **Oral Parity.** Texas 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

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

Breast Cancer Disease Burden

The data on breast cancer disease burden comparing and contrasting counties to one another, to state and national averages, and by race indicate that breast cancer inequity may be greatest for Black women residing in Harris, Galveston and Fort Bend counties. Screening mammography rates are lower than the national average. Incidence rates, though lower than the national average, point to growing racial inequities especially in Harris and Galveston counties. Moreover, the disparities in late-stage incidence and mortality are clear, with Black women in three out of five counties being more likely to receive a late-stage breast cancer diagnosis compared to their white counterparts, and Black women in four out of five counties reporting a higher breast cancer mortality compared to their white counterparts.

Quality of Care

One area where the quantitative and qualitative data slightly diverge is with respect to screening mammography rates. Although screening mammography rates in the Houston MTA are higher than the state average, they are well below the national average. Qualitative findings suggest that mammograms are freely available within various community institutions, including the workplaces and places of worship. Inconsistent screening guidance and mistrust for providers and the health system at large could delay health care seeking behaviors and ultimately result in late diagnosis. This is a common issue for women pursuing breast cancer screening, given the shifting and evolving guidelines, particularly as it relates to patient age and whether to pursue a screening mammogram.

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

The USPSTF, a panel of experts that influences which preventive services must be covered without cost sharing in accordance with the Affordable Care Act, has ratings for different preventive services. The USPSTF recommends biennial screening mammograms for women ages 50-74. However, there is not a similar blanket recommendation from the USPSTF for women younger than 50. The USPSTF recommends that beginning biennial mammograms before 50 should take individual patient factors into account such as family history and genetic susceptibility (U.S. Preventive Services Task Force, 2018). Conversely, the American College of Obstetricians and Gynecologists recommends that regular annual screening mammography begin at age 40 in women of average risk for breast cancer (Committee on

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

The ability of Black women to access diagnostic procedures within Houston metro is more limited. Qualitative findings indicate that late diagnosis can be attributed to the high cost of diagnostic procedures for both insured and uninsured women. There are little to no financial assistance programs available to support breast cancer diagnosis according to Houston metro patient navigators. Additionally, transportation barriers could be contributing to women’s inability to access timely diagnosis procedures.

Data show that (see table 21) public transit utilization is low across most of the metro (<2 percent), with only a marginally higher percentage of transit users in Harris (the most-urban County). Many households lack a vehicle in Harris and Galveston counties (6 percent), and a higher percentage of people engage in active transportation in these places (3 percent and 4 percent, respectively). Residents of Galveston County face unique transportation challenges due to the physical geography of the area. The southeastern portion of Galveston County – where the city of Galveston and the majority of the County’s population is located – is an island. For this reason, residents of Galveston are physically cut off from many resources. As seen in map 6, the vast majority of hospitals, treatment centers, and clinics are located on the mainland, in Harris County. A roundtrip visit to the Comprehensive Cancer Centers in downtown Houston will take a resident of Galveston over two hours in a personal vehicle. If they do not have a personal vehicle (as is the case for about one in fifteen Galvestonians), the trip takes over seven hours on public transit (see table 13). Galveston patient navigators emphasized this challenge and described women walking to appointments in uncomfortable weather conditions with their children.

Social Determinants of Health

Data on systemic and SDOH along with qualitative data collected from community members suggest that breast health inequities among Black women in the Houston MTA could largely be explained by three factors: 1) a large percentage uninsured and underinsured populations, 2) economic vulnerability stemming in large part from practices of structural racism, such as redlining, and 3) lower quality of health care in part due to personally-mediated racism.

Texas’s decision not to expand eligibility for its Medicaid program under the ACA, leaves people with an insurance “coverage gap”. Data showed that 21 percent of Harris County’s population is uninsured. Close to half of the breast cancer survivors who participated in focus groups from three priority counties (Harris included) reported not having insurance (48 percent). Participants consistently described the high costs of breast cancer diagnosis and treatment and poor or limited insurance as being their biggest barriers. Participating community members and providers alike often cited the fear of debt as a reason for not following up with care. 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). Studies have estimated deaths related to the coverage gap due to poor or no access to health care, with one study

estimating that 730 people in Texas die each year because of the coverage gap and failure to expand the state's Medicaid program (Miller & Wherry). The opposite has also been shown: states that expanded eligibility for their Medicaid program improved cancer screening rates compared to states that did not, and early adoption of expansion is associated with greater improvements in screening (Fedewa et al., 2019; Swift, 2019).

Another important finding was how focus group participants explained that access to insurance alone was not enough to overcome breast cancer inequities. The type of insurance influenced the quality of care received as well as the range of health options available. Those enrolled in Medicaid reported feeling that they received poorer quality care. This finding is consistent with the literature showing that among Black breast cancer patients, a woman's insurance type was a significant predictor of mistrust of the medical establishment. Women with Medicaid expressed greater mistrust and suspicion compared to women with private insurance or private insurance and Medicare (Sutton 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).

Findings show that Houston MTA community members are often faced with having to choose between day-to-day living needs or costly health care. Housing costs, particularly in Harris and Galveston counties, also contribute to financial strain, with one in three households considered housing-cost burdened. Further, findings show that nearly one in every five adults in Harris County lack a high school degree – the highest rate in the metro. In Galveston County, Black women are the least likely to finish high school and it is well established that lack of or poor quality education impact future employment and income opportunities (OECD, 2012).

Residents of Harris and Galveston counties also face particular economic difficulties. In Harris County, almost 40 percent of the population earns below 200 percent of the federal poverty line (see table 9). Food deserts in the MTA are also concentrated in Harris and Galveston, making up approximately 20 percent of the land area in both counties. Of the estimated 200,000 Black women over the age of 45 who live in the Houston MTA, 82 percent (> 163,000) reside in Harris and Galveston counties, indicating that, between the two counties, around 30,000 Black women over the age of 45 live below the poverty line.

Some of these economic vulnerabilities can be explained by practices of structural racism. Harris and Fort Bend counties (the two counties with the largest numbers and highest percentages of Black residents) are also the most racially segregated, with black-white dissimilarity index scores of 49 and 47, respectively and Galveston County at 44 is closely behind. This indicates that nearly half of all white people living in each of these places would need to relocate to new neighborhoods within the county in order to achieve racial integration. Harris County's high score on the black-white dissimilarity index was likely influenced by the fact that portions of the county were redlined in the 1930s.

Relatedly, the qualitative data suggest that personally mediated racism severely impacts the quality of health care Black women receive, regardless of insurance status and income. Black women are likely to encounter health care staff with discriminatory attitudes and behaviors. This can lead to misdiagnosis, delays in treatment, and deepens mistrust of providers and the health care system at large. 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 experience a longer duration from the time of first symptoms to diagnostic resolution for breast cancer as compared to white women

(Hoffman et al., 2011). Other evidence shows that commercially insured Black breast cancer patients were diagnosed at a later stage and had a higher mortality rate when compared with their white counterparts with the same insurance status (Daly & Olopade, 2015).

Surprisingly, there was little-to-no mention of Komen as a support or resource for Black breast cancer survivors. Participants across several focus groups conducted with Fort Bend and Harris County survivors mentioned the American Cancer Society (ACS) support services after diagnosis as being beneficial. This may be indicative of the general perceptions of Komen as primarily serving white women.

Breast cancer inequities across the care continuum in the Houston MTA persist due to economic vulnerability and relatedly the lack of insurance, the high cost of health care especially diagnostic services, variation in messaging about screening guidelines and experiences of personally mediated racism. Taken together, these factors severely reduce the quality of care that Black women receive across the cancer care continuum. Particular aspects of the breast cancer continuum that warrant further investigation and intervention include diagnosis and the quality of breast cancer treatment.

Recommendations

Komen’s AAHEI is a substantial undertaking to dismantle the systems that perpetuate the growing breast cancer inequities experienced by Black women. Findings from the Houston 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 reflects 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 African American 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 a collaborative approach to advance breast health equity for Blacks. This provides a mechanism for community/stakeholder engagement and recognizes the informal and formal systems and networks of social support that are accessed by Black women.

These recommendations represent actionable strategies as the bridge between social determinants of health and the breast cancer care experience of Black women and are intended to be a call to action for all community-based organizations, policymakers, hospitals, health care providers, faith-based organizations, civic leaders, and citizens. The recommendations are offered as evidence-informed strategies to reduce breast cancer disparities among Blacks.

Systems thinking and systems frameworks help to shed light on the multi-dimensionality of the health care system, its ever-changing nature, and how it has the potential to facilitate or impede population health improvements. For most, the lasting impression of the health care system begins at the micro-level – where providers and patients interact. As Black women progress along the breast cancer continuum of care, the complexity of their experience increases as their care ushers in other microsystems – additional clinical teams for diagnosis and treatment, coordination to address potential co-morbidities and referrals to community services for supports not found within clinical systems. Availability of all of these components, at a high level of quality, is often lacking, and when present must interact and relate in a functional manner that places the needs of Black women front and center. When multiple microsystems come together, the mezzo-system is formed and the health care experience can become more complicated, particularly if there is no assistance to navigate these systems and no

coordination of needed care. How systems function at the micro-and mezzo-levels are directed by policies and resources within and beyond the organization - the macro-level.

The following recommendations apply this systems framework given the complexity of the root causes of breast cancer disparities and among them, racism. Racism is a social disease. It is far reaching and as described in the literature review, touching essential social institutions – education, government and health care – at multiple systems levels. Accordingly, recommendations address both general and specific changes, strategies or interventions at the micro-, mezzo- and macro-level and 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, coordination of suggested strategies and interventions should be done so in collaboration with communities across traditional silos. This coordination with communities is in keeping with Komen’s use of collective impact which 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. Lastly, while these recommendations speak to the Houston metro area, data analyzed suggest a need for more focused attention on the high-need counties of Harris and Galveston is strongly advised. 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

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 African American women. Komen and partners may want to support QI initiatives in the major health systems in the Chicago MTA, especially in counties that are largely African American. These efforts have been helping improve the quality of care, often perceived by community residents, and confirmed by providers, as varying across health systems and of worse quality among institutions that serve under-insured or Medicaid populations. Komen and partners could consider ways to support QI initiatives in non-hospital and non-health system care settings (in addition to hospital and health system settings), such as federally qualified health centers that are more accessible to priority populations.

Improve service delivery through enhanced linkages with culturally competent patient navigators, peer support/educators, and other system facilitators.

The breast cancer community can consider various ways to support patient navigators, such as funding culturally competent patient navigator trainings, and funding patient navigator services to increase breast cancer patients' access to these invaluable services. This includes increasing the number of navigators and assuring they are geographically accessible. These service providers can help African American women navigate the fragmented health care system and connect to non-medical support resources. Additionally, providing capacity building assistance to a CBO to serve as a resource to local patient navigators as they work to enhance skills and knowledge may facilitate further expansion of a corps of patient navigators as well as create another linkage between community and health care system. 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).

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 African American, 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 African American women may further translate into reduced rates of referring these women to genetic counseling.

In Georgia, the screening mammography rate for African American women over the age of 40 is 79.4%, compared to 72% of white women in the same age range. While African American women are getting screened at high rates, the breast cancer mortality rate is higher for African American 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 African American 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 health care; to educate about the role genetic testing and counseling can play in overall health care; 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 African American women and their families around these programs and contribute to the growing body of research evidence about the genetic drivers of breast cancer in Black women.

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

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

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

Mezzo-Level Strategies

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

Particular aspects of the breast cancer continuum that warrant further investigation and intervention include the availability of accessible, high-quality screening, low cost or free diagnostic mechanisms and various treatment options for Black women. This can also include exploring partnerships with FQHCs. The integration of oncological, primary care and mental health services is valuable. Overweight and obese women are represented among the increased incidence rate for breast cancer after menopause. Reducing a woman's risk for breast cancer through routine primary care and help improve weight-related risk. Additionally, the breast cancer experience is characterized by an increased toll on mental health. Poor mental health also increases stress, a risk factor for breast cancer. Therefore, the integration of mental health services along the breast cancer care continuum is also important.

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

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

Invest in Blacks led CBOs providing non-medical services.

The breast cancer community should consider supporting existing community-based organization (CBO) grass-roots efforts related to SDOH (e.g., improving food security, transportation access), and

improving access to health care services (e.g., assistance in completing burdensome and lengthy Medicaid application processes). The services offered by these CBOs in turn become referral sources for hospital social workers, patient navigators, care coordinators, etc. working to address identified social needs of survivors and undiagnosed women alike. The systematic discrimination many communities across the Houston metro experience has resulted in the depletion of investment and resources. This includes funding for local, Black-led organizations serving their communities and supporting them with food, and other basic day-to-day needs. Komen and partners may identify community-based, Black-led organizations that were or are providing essential non-medical services to the community. Organizations that provide these services may benefit from financial support and technical assistance to ensure sustainability. Relatedly, AAHEI may want to consider supporting the expansion of Black-specific support groups in the Houston metro. This could take the form of partnering with existing Black-led organizations.

Macro-Level Strategies

Analyze current health care insurance policies to ensure equitable access to services through Medicaid expansion and financial assistance programs.

Patient and household out-of-pocket costs for health care services and the percentage of people and households covered by health insurance are key indicators of this building block (World Health Organization, 2010). The ACA is an example of a national health financing measure that aims to ensure the health care funds are available to cover the health needs and set the financial incentives to providers, to ensure that all individuals have access to health care (World Health Organization, 2010). While the ACA has generally strengthened this essential systems building block, there is much room for improvement as a large proportion of uninsured women in the Houston MTA do not qualify for Medicaid nor can they afford to purchase private insurance. Not strengthening the health finance building through Medicaid expansion hinders Houston MTA residents' ability to seek health care services without the risk of severe financial hardship. Additionally, the breast cancer community could support legislation that removes or lessens cost barriers for diagnostic services for breast cancer, such as the federal Access to Breast Cancer Diagnosis Act which would remove out-of-pocket costs for medically-necessary diagnostic imaging (Susan G. Komen, 2020b). In Texas, Komen has sponsored successful Texas state legislation to eliminate out-of-pocket costs for diagnostic mammograms (Women's Health Texas).

Advocate to expand Medicaid eligibility and to remove burdensome restrictions that would limit access to Medicaid.

Another opportunity is the option to expand Medicaid eligibility in Texas. Secondary data indicate that, on average, the percentage of insured in the Houston MTA is lower than the national average of 92% (Berchick et al., 2019). Even in Fort Bend, which has the highest insured rate in the MTA, 10% of its population is uninsured (see table 9). The worst rate in the metro is in Harris County, where one in every five residents is uninsured; this rate is higher than the national average. An eligibility expansion would ensure that more women receive timely screening and breast cancer care services. The breast cancer community can build on advocacy relationships in the state and examine partnerships to advocate for Medicaid expansion in the state. To have its greatest reach, advocacy efforts engage all levels of the system – micro, mezzo, macro – patients, providers, CBOs and policy makers, to clearly illustrate how and whom will be positively affected by policy changes.

Support Financial Assistance Programs.

The breast cancer community can engage with other health systems, counties and/or county partners to advocate for additional financial assistance programs in the other counties of the Houston area. There may be many opportunities to address the financial burden that women experience. One opportunity Komen could prioritize is advocating for other health system financial assistance programs to meet deductibles for high-deductible health plans or cost sharing for underinsured women, particularly in Galveston County. The Galveston County patient navigators spoke at length of the high costs at the diagnostic and treatment phase of the breast cancer continuum of care. 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 (Community Benefit Connect).

Cultivate and engage leadership and governance at all levels to support racial equity and reduce breast cancer disparities.

The sixth systems building block, leadership and governance, is essential if comprehensive systems change is going to take place and produce a positive impact on population health and reduce disparities. “Leadership and governance in building a health system involve ensuring that strategic policy frameworks exist and are combined with effective oversight, coalition-building, regulation, attention to system design and accountability” (World Health Organization, 2010). Leadership and governance need to affect and take place across all levels – micro, mezzo, and macro - of the system, as well as within community systems, to achieve lasting systems change and systems coordination. Komen is in the position to cultivate leaders at the community level working in collaboration with CBOs as well as working with health care organizations, health plans and state and federal government agencies.

The job of leaders is to inspire collective efforts and devise smart strategies for the future (Seaman & Smith, 2012). Systems building, in particular, requires a team approach whereby partners collaborate and cooperate to achieve shared goals known as collective impact. Successful leadership “bridges disciplines, programs, and jurisdictions to reduce fragmentation and foster continuity; clarifies roles and ensures accountability; develops and supports appropriate incentives; and, has the capacity to manage change” (Committee on Integrating Primary Care and Public Health, Board on Population Health and Public Health Practice, & Institute of Medicine, 2012). Ideally, these characteristics and the work required is that of multiple leaders, not just a single organization, in order to provide adequate stability and longevity. This configuration also allows for work at multiple levels of a system so that connections can be made, horizontally and vertically thus enabling greater reach and depth for stakeholder and community engagement.

Engaging health insurers, legislators, and hospital CEOs, for example, would help facilitate meaningful impact. Komen’s AAHEI presents an opportunity for a racial equity lens to be applied across all aspects of its initiatives, organizational processes, grantmaking, community-based partnerships, and policy advocacy. The findings of the Komen African American Health Equity Initiative Landscape Analysis underlie the importance of this intentional approach and leadership. As applied locally, regionally, and nationally, intersectional strategies may begin to effectively redress long standing historical and persistent systems of structural racism.

Ensure that planning of local metro initiatives are inclusive of and collaboratively driven by Black women and their advocacy organizations.

Across the micro, mezzo, and macro level strategies, the leadership of Black women themselves must be at the forefront. Paramount in the breast cancer community's efforts will be calling on, supporting and enhancing the vast assets of Black women and Black-led institutions. From peer-led health and equity advocacy organizations to faith-based organizations and Black hospitals, each need to be mobilized and supported, turning around centuries of having been undermined. Applying a culture of continuous learning that is multi-directional, where the knowledge and lived experience of Black residents, breast cancer survivors and institutions are validated, promises to enrich such efforts. Also necessary are means of ensuring that organizations and initiatives are accountable in attaining concrete measures that advance racial equity. Supported by the observations of those who generously participated in the landscape analysis and by decades of racial equity and social justice research, such elements will ensure that the Komen African American Health Equity Initiative is appropriately crafted and optimally effective in achieving its aims.

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

Collaborative approaches promise to leverage more of the significant resources needed to attain ambitious goals that lie beyond the capacity of individual institutions or foundations. Such collaborations must extend beyond traditional silos. The intersectional issues that weave together to create the SDOH in any community require full engagement of not only medical and public health sectors, but social services, housing and urban planning, economic development, environmental and occupational protections, systems of education, transportation infrastructure, and healthy eating and active living initiatives. These, among other sectors, collectively foster the requisite conditions that promote health. Komen offers great leadership in its ability to act as a convener of diverse stakeholders and as a funder that leverages contributions from public and private sectors. Komen advances training that builds skills and self-advocacy of individuals, competencies of providers, and strength of institutions. Komen is a policy leader at all levels of government and within health systems.

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

Appendix A. Map Measures

TABLE 24: HOUSTON METRO AREA MAPS

	Map 4: Percent of Population That Is Black	Map 8: Social Vulnerability Index Score	Map 9: Percent of Households That Are Housing Cost Burdened	Map 4: Residential Segregation Score
Brazoria	13%	0.52	21%	38
Chambers	8%	0.29	19%	21
Fort Bend	21%	0.27	25%	47
Galveston	13%	0.57	27%	44
Harris	19%	0.7	33%	49

Appendix B. Abbreviations & Glossary

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

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

Black/white dissimilarity index: A measure of residential segregation that illustrates the evenness with which two mutually exclusive groups (in this case, Blacks and whites) are distributed across the geographic units (in this case, census tracts) that make up a larger geographic entity (in this case, counties). Calculated by County Health Rankings (CHR) using the Index of Dissimilarity formula and data from American Community Survey (ACS) 5-year. Scores range from 0-100 with scores closer to 100 indicating 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 mammogram or clinical breast exam using two or more views of the breast.

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

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

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

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

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

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

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

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

Development and Research (PD&R), 2019).

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

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 CDC and SEER, and the following formula: the number of individuals in an area who were diagnosed with breast cancer during a one-year period (numerator) divided by the total number of individuals living in that area (denominator). Incidence rates are expressed in terms of number of cases per 100,000 individuals per year (National Cancer Institute).

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

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

Jim Crow: Jim Crow refers to a set of laws enacted by 21 states in the southern U.S. and the District of Columbia to enforce and uphold racial segregation. These laws were in place following the civil war and banned by the US Civil Rights Act in 1964 (Krieger, Jahn, & Waterman, 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 African American women in the study (not white women) with the strongest effect observed for African American women born prior to 1965 (Krieger et al., 2017).

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

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

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

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

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

individuals per year (National Cancer Institute).

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Appendix C. Focus Group Guides

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

Step 1: Introduction of project and confidentiality

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

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

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

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

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

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

How data will be used, privacy and confidentiality

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

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

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

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

PROBES TO USE AS NECESSARY:

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

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

PROBES TO USE AS NECESSARY:

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

12. *Financial cost and time of follow-up testing and diagnosis*
13. *Financial cost of treatment and time for treatment*
14. *Quality of screening and diagnosis for Black women*
15. *Racism, bias, segregation and the inability to get the care they need*

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

PROBES TO USE AS NECESSARY:

- a. *What screening recommendations do you give to your Black patients? How often do you share screening guidelines?*
- b. *How does it differ, if at all, from other types of patients?*
- c. *Do you routinely have conversations with your patients about risk factors for breast cancer? With younger, Black patients? If so, does this information influence your recommendations for screening?*

5. What factors promote (or encourage) regular screening among Black women?

PROBES TO USE AS NECESSARY:

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

6. What are the barriers or factors that may prevent Black women from getting screened regularly?

PROBES TO USE AS NECESSARY:

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

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

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

PROBES TO USE AS NECESSARY:

- a. *Do you refer to a specialist? How do you support second opinions? ASK ONLY IF PCP*
- b. *How do you engage the patient in the decision-making process?*
- c. *How do they handle/address questions from the patient and/or family about treatment options?*
- d. *Do you consider the cost of various treatment options in your decision? If yes, does that include a conversation with the patient/family about the options and costs?*
- e. *How do you approach the topic of clinical trials?*

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

PROBES TO USE AS NECESSARY:

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

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

PROBES TO USE AS NECESSARY:

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

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

PROBES TO USE AS NECESSARY:

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

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

PROBES TO USE AS NECESSARY:

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

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

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

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

Step 1: Introduction of project and confidentiality

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

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

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

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

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

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

How data will be used, privacy and confidentiality

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

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

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

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

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

Does anyone object to being recorded?

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

Step 3: Answer Questions from Participants

Step 4: Confirm Consent to Participate

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

Step 5: Answer Questions (if needed)

Step 6: Turn on the Recorder

Step 7: Begin Discussion with Questions Below

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

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

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

PROBES TO USE AS NECESSARY:

- a. *Where have you faced discrimination because of your race?*
 1. *Health care system*
 2. *Transportation*
 3. *Work*
 4. *Housing*
 5. *Education/School*
 6. *General profiling (e.g., grocery store, mall, police, etc.)*
- b. *Have you ever been prevented from moving into a neighborhood because the landlord/realtor refused to sell or rent you a house or apartment? If yes, please tell me more.*
- c. *Have you ever moved into a neighborhood where neighbors made life difficult for you or your family? If yes, please tell me more.*
- d. *Have you ever been fired from a job because of your race? If yes, please tell me more.*
- e. *Have you ever been denied a promotion because of your race? If yes, please tell me more.*
- f. *Have you ever not been hired for a job because of your race?*
- g. *While seeing a doctor, has there been a time you felt that assumptions were made about you? Tell me more. What made you feel this was happening?*
- h. *Is there anything that happens in the doctor office's that makes you feel different- the doctor or staff's behavior, things they say or do, or how they look at you?*

3. How has discrimination or racism affected your health?

PROBES TO USE AS NECESSARY:

- a. *Prevented you from getting health care or treatment?*
- b. *Affected the quality of care you received?*
- c. *Has discrimination affected the timeliness of the care you received?*

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

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

PROBES TO USE AS NECESSARY

- a. *Explore factors behind screening (family history, following guidelines, provider's advice, community outreach programs, the experience of other women in their social network) and awareness that early screening can catch breast cancer when it might be easier to treat.*
- b. *Do you feel you were aware of the signs and symptoms that one might have breast cancer? Why or why not? What factors led to this awareness? [Note: there often aren't signs as well as the common signs of unusual discharge or a lump]*

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

PROBES TO USE AS NECESSARY

- a. *What options were offered to you?*
- b. *How did you feel throughout the process?*
 - 1. *Were there times you felt uncomfortable or unable to access screening?*
 - 2. *Did you feel you had enough time to ask questions and/or absorb information?*
 - 3. *Did you feel you were treated with less courtesy or respect than other people?*
 - 4. *Did you feel you received poorer service than other patients?*
 - 5. *Did you feel the provider or the staff acted as if they think you are not smart?*
 - 6. *Did you feel the provider or staff acted as if they are afraid of you?*
 - 7. *Did you feel threatened or harassed?*
- c. *How old were you the first time you were screened? How often did you go after your first time?*
- d. *Explore the influence of*
 - 1. *Providers, staff: temperament, cultural competency, kind, respectful*
 - 2. *Process and systems: forms, wait time, referrals, timely, follow-up*
 - 3. *Overall environment: location, privacy, welcoming, feels safe*
 - 4. *Accessibility: easy to reach, timely*
- e. *Assess comprehensives and quality of care.*

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

PROBES TO USE AS NECESSARY

- a. *How was your breast cancer found?*
 - b. *What diagnostic procedures did you have/were you offered?*
 - c. *As best you can remember, how long did it take to get a diagnosis? What were the challenges?*
 - d. *How did you select a provider/care team?*
 - e. *Were you referred to a breast oncologist? Breast surgeon? Who provided your treatment?*
 - f. *For those who wanted a second opinion, what was that experience like?*
 - g. *Tell us about how a care and treatment plan was developed?*
 1. *To what extent were you offered choices and provided opportunities to discuss these options with your providers?*
 2. *Did you feel comfortable to ask questions?*
 - h. *What type of counseling and support was offered? [Include navigation to treatment services]*
 1. *Were the associated costs, insurance coverage, co-pays, etc. discussed with you? Were you offered or referred to a financial assistant? If so, when (at what stage of the process)?*
 - i. *How did you feel throughout the process?*
 1. *Did you feel you had enough time to ask questions and/or absorb information?*
 2. *Did you feel you were treated with less courtesy or respect than other people?*
 3. *Did you feel you received poorer service than other patients?*
 4. *Did you feel the provider or the staff acted as if they think you are not smart?*
 5. *Did you feel the provider or staff acted as if they are afraid of you?*
 6. *Did you feel threatened or harassed?*
- 7. Was hormonal therapy (e.g. Tamoxifen, Arimidex, Femara, Aromasin) part of your treatment?**
If so, was five years or ten years prescribed?

- a. *PROBE: Were you able to stay on hormonal therapy for the recommended length of time? Why or why not? (they may still be on it)*
 - b. *PROBE: Did you ever skip a dose or cut the pills in half? If so, why or why not?*
 - c. *PROBE: What were the challenges?*
- 8. Please share some of the factors in the decision to start treatment based on your personal experience or the experience of other Black women, you know.**

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

PROBES TO USE AS NECESSARY

- a. *Who was involved in the decision to start treatment?*
 1. *Partner*
 2. *Family*
 3. *Friends*
 4. *Pastor /Clergy*
 - b. *Was the decision-making process different for different types of treatment (chemotherapy, surgery, radiation)?*
 - c. *What may make it difficult for a Black woman in your area to start and continue the full course of breast cancer treatment if they need it?*
 - d. *What would facilitate the completion of the full course of treatment (for example, a full course of chemotherapy)?*
 1. *Family considerations:* *Caretaking responsibilities, spousal support*
 2. *Personal/life:* *Scheduling, time off from work, meeting family responsibilities*
 3. *Fears:* *Concerns about the procedure, concerns about side effects of treatment*
 4. *Faith Practices:* *Spiritual/religious beliefs*
 5. *Accessibility:* *Insurance, easy to reach, distance, affordable costs/co-pays, time off from work*
 6. *Process and systems:* *Forms, wait time, referrals, timely, follow-up*
 7. *Providers and staff:* *Temperament, cultural competency, kind, respectful, perceived racism, perceived trust and respect, bias, provider hostility, mistrust about the health system, no relationships with providers*
 8. *Overall environment:* *Location, privacy, welcoming, feels safe*
- 9. What factors may lead to delays in starting treatment or not completing treatment even if someone has access?**

PROBES TO USE AS NECESSARY

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

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

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

PROBES TO USE AS NECESSARY

- a. *If used, were these options used to complement traditional cancer treatment, or instead of?*
- b. *If used, were these options recommended? If so, by whom?*
- c. *If used, how were the services beneficial?*
- d. *If they were not beneficial, why not?*

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

PROBES TO USE AS NECESSARY

- a. *How did you decide where to seek treatment? What were your options?*
- b. *Did your provider/care team specialize in breast cancer, or did they treat all kinds of cancers?*
- c. *What have you heard or yourself experienced about Black patients' experiences within the health care system?*
- d. *Have you received access to a full team of providers (i.e. including a PCP, radiation oncologist, medical oncologist, surgeon/surgical oncologist, plastic surgeon (reconstruction), dietitian, social worker, receptionist/scheduler/front desk staff, chaplain/other religious contact, new patient coordinator, Program RN, patient navigator)?*
 1. *Which members of your cancer team did you feel most comfortable seeing?*
 2. *What is it about that provider that makes you feel comfortable?*
 3. *Did you have any uncomfortable experiences? What made you uncomfortable?*

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

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

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

Survivorship

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

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

PROBES TO USE AS NECESSARY

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

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

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

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

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

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

PROBES TO USE AS NECESSARY

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

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

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

b. Do women have access to a full complement of holistic approaches to cancer treatment and survivorship such as acupuncture, reiki, nutrition support, mindfulness-based stress reduction, meditation, therapist, etc.?

1. If used, how were the services beneficial?

2. If they were not beneficial, why not?

- c. *Were there times when you felt challenged or unable to access the support, information, or resources you felt you needed? Why?*
1. *Would it be useful to have learned about these resources sooner than you did?*
 2. *At what point would the services have been more useful?*
 3. *Was there a cost/fee to access any of the resources/information?*
14. **What else might be helpful to you or other Black women cancer survivors and their families?**

Step 8: Thank you for your participation.

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