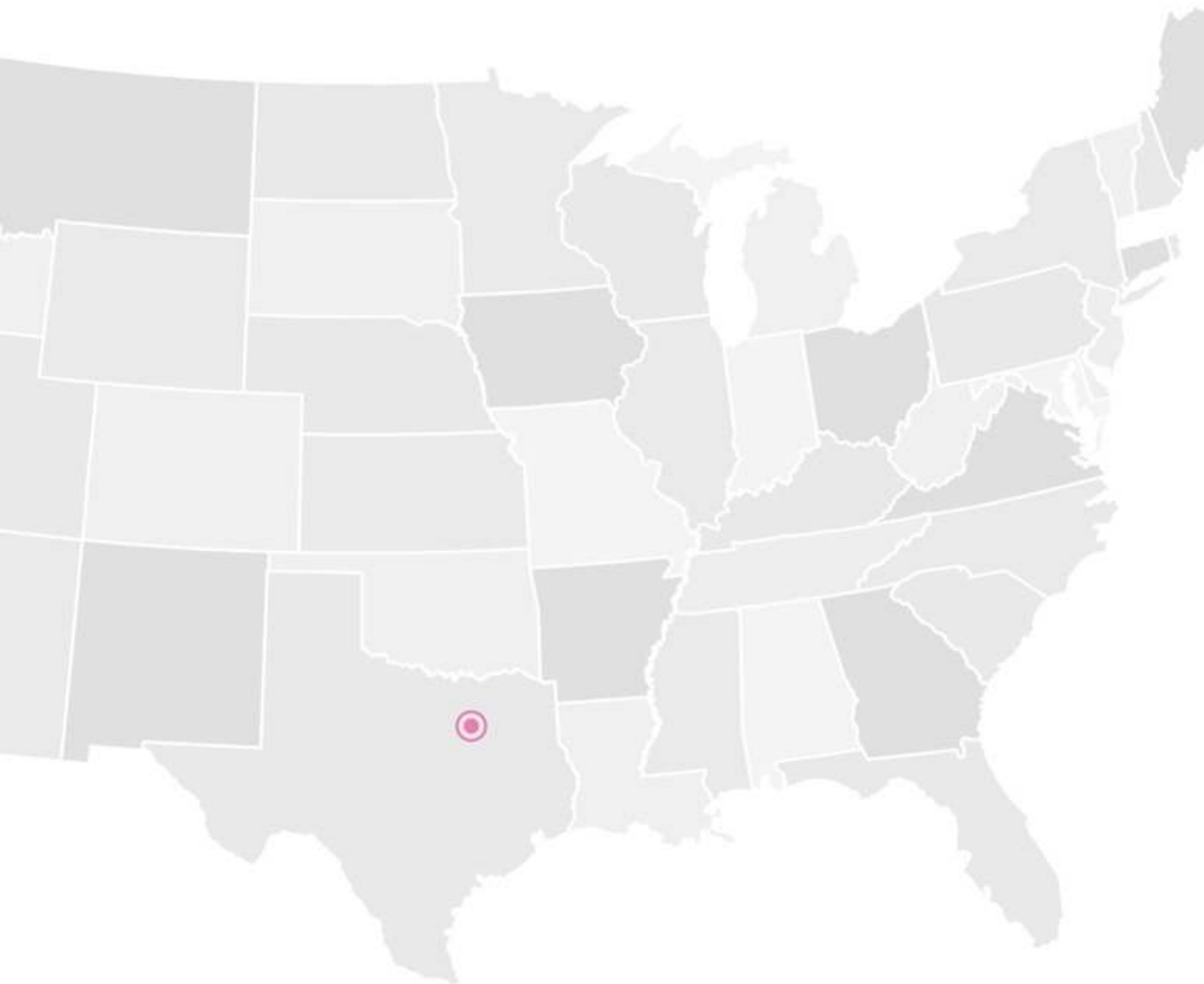


Closing the Breast Cancer Gap: A Roadmap to Save the Lives of Black Women in America

2021

DALLAS



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 women in the United States 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 women and white women. Breast cancer mortality is about 40 percent higher in Black women than in white women.

About This Report

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

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

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

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

Rather, the analysis aims to:

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

Key Findings

- Three of the four counties for which data are available by race, late-stage incidence rates among Black women are higher than they are among White women. The greatest disparity is in Ellis County, where the late-stage breast cancer incidence rate is 44.9 percent among White women and 63.6 percent among Black women. Dallas and Tarrant counties have the highest concentrations of late-stage incidence, with the majority among Black women in Dallas County and White women in Tarrant.
- In the Dallas—Fort Worth MTA, the likelihood of receiving a breast cancer diagnosis, the stage of diagnosis, and the likelihood of death from the disease vary along geographic, socioeconomic, and racial lines.
- In situ breast cancer incidence rates for most counties in the Dallas—Fort Worth MTA are higher than the state rate of (22.9%) per 100,000 but are comparable to the national rate of (28.3%). Rockwall County reports the highest age-adjusted in situ incidence rates, at 35.3 percent overall. Of the three counties in the Dallas—Fort Worth MTA that have data available by race, Dallas County’s in situ incidence rate was found to be higher among Black women, with a rate of 32.4 percent compared to among White women, with a rate of 27.2 percent.
- In every county in the Dallas—Fort Worth MTA where disaggregated data are available (three counties), the breast cancer mortality rate among Black women is higher than the rate among White women. The racial disparity in breast cancer mortality rates is greatest in Dallas County, where the age-adjusted mortality rate for White women is 18.8 percent compared to 33.2 percent per 100,000 for Black women.
- The percentage of women receiving a screening mammogram varies throughout the Dallas—Fort Worth MTA from 62 percent in Dallas County to 81 percent in Rockwall County. Racial differences in screening mammography screening reported in Texas show that Black women are screened for the disease at a higher rate than White women.
- Patient navigators noted the importance of navigation in the diagnosis phase of the breast cancer continuum.
- Medical providers specifically mentioned a need for more resources to support diagnostic mammograms.
- Patient navigators described the cost of diagnostic procedures as a significant barrier to timely diagnosis, even when the safety net hospital offers financial assistance programs for women who are uninsured.
- Texas also has not elected to expand eligibility for its Medicaid program.
- Focus group participants also elevated transportation as a significant barrier to accessing screening mammography in the Dallas—Fort Worth MTA.
- Additionally, the need for imaging centers that are in predominately Black communities and that will accept those without insurance was an identified need.

- Survivors described positive treatment experiences that involved having a choice of providers, care coordination, and increased engagement with doctors outside of in-person visits. Some community members correlated the level of care they received with the quality of their insurance.
- Providers, navigators, undiagnosed women, and survivors all noted the importance of social support for successful treatment.
- Data suggest that there are significant disparities in the health system in the Dallas MTA, including in health care facilities and the proportion of the population that is medically underserved.
- Decades of discriminatory practices have led to striking segregation in the Dallas–Fort Worth MTA. The Dallas–Fort Worth MTA is segregated across a number of dimensions, including race and socioeconomic factors, creating stark contrasts by geography.
- Overall, breast cancer disease burden measures suggest that in most counties in the Dallas–Fort Worth MTA where data are available, Black women are more likely to receive a breast cancer diagnosis, are more likely to receive a late-stage breast cancer diagnosis and are more likely to die from breast cancer than their White counterparts. These trends hold even though Black women are more likely to receive a screening mammogram.
- The data suggest breast health inequities among Black women in the Dallas—Fort Worth MTA could be explained by economic vulnerability driven by late-stage diagnoses and disparities in access to care.

Recommendations

The following strategies, research, and interventions are recommended to better understand and address the complexity of the root causes of breast cancer inequities in the Dallas—Fort Worth MTA (full details provided in the recommendations section of this report). The recommendations follow a systems framework:

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

Micro-Level Strategies

- Develop a Diverse and Culturally Responsive Patient Navigation Workforce.
- Implement implicit bias trainings for providers, administrators, and health care staff.
- Increase education about family health history in the community to identify high-risk families and offer genetic counseling and testing and breast cancer screening to meet the need.
- Implement a culturally relevant health promotion campaign intended to increase knowledge of current screening guidelines.

Mezzo-Level Strategies

- Increase access to integrated care to improve the breast cancer care experience.
- Support Quality Improvement (QI) initiatives along the breast cancer continuum of care.
- Increase awareness of free screening to promote early-stage diagnosis.
- Partner with community organizations, place-based efforts, and philanthropy organizations to address systemic barriers to equity.

Macro-Level Strategies

- Conduct a root cause analysis of risk factors for late-stage diagnoses in Dallas—Fort Worth.
- Support efforts to develop guidelines and policies that address disproportionate breast cancer mortality among Black women, including increased genetic counseling and testing services.
- Advocate to expand Medicaid eligibility and to remove burdensome restrictions that would limit access to Medicaid.
- Support Financial Assistance Programs.

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

About Susan G. Komen

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

Introduction

Breast cancer is the most common cancer diagnosed among women in the United States and is the second leading cause of death among women after lung cancer. Women in the U.S. have a one in eight chance of developing breast cancer over the course of their lifetimes. With the increasing availability of screening mammography screening, earlier detection, and improvements in breast cancer treatment, the overall breast cancer mortality rate among women in the (U.S.) declined by 41 percent since 1989 (American Cancer Society, 2021).

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

Black women are, on average, 40 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%) for white women (Howlader et al., 2020). While the overall breast cancer incidence among Black women is lower than among white women, incidence among non-Hispanic Black women younger than 40 is higher than the same age group of non-Hispanic white women from 2013-2017 (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 Stand for H.E.R., Komen seeks to improve breast health equity by reducing late stage diagnosis and mortality for Black women in the 10 U.S. metropolitan areas (referred to throughout this report as MTAs or metro) - where Black 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 this effort, Komen engaged JSI, a public health research and consulting organization, to conduct a landscape analysis in each MTA to better understand the underlying causes of breast cancer inequities across the care continuum among Black women. Findings from each landscape analysis report serve to inform the design and implementation of Komen’s long-term and cross-sector collaborative efforts, as well as serve as a call to action for all community-based organizations, policymakers, hospitals, healthcare providers, faith-based organizations, civic leaders, and citizens to engage in evidence-informed strategies to reduce breast cancer disparities among Black women.

Project Objectives

The specific objectives of the landscape analysis are:

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

This report summarizes findings from the analysis conducted for the Dallas–Fort Worth 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.

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 has spread beyond the breast to lymph nodes, surrounding tissue or other organs in the body (most often the bones, lungs, liver or brain).

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

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

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

Methods

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

This study defines the Dallas–Fort Worth MTA in accordance with the US Office of Management and Budget’s 2015 definition of central counties in the Dallas–Fort Worth–Arlington metropolitan statistical area (MSA). This area encompasses most of the city of Dallas, and comprises Collin, Ellis, Rockwall, Johnson, and Tarrant counties in Texas (Office of Management and Budget, 2010; U.S. Census Bureau). Data is generally unavailable at the MSA-level of geographic specificity, so researchers collected and analyzed data at the county-level (a sub-MSA unit) for most indicators. State- and national-level data (both super-MSA units of measure) were collected for measures related to breast cancer disease burden to provide additional points of comparison.

TABLE 1. DALLAS–FORT WORTH METRO AREA DATA METHODS AND SOURCES

Demographics		
Subcategory	Indicator	Source
population	Total Population	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)
gender	Percent of Population that is Male	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)
gender	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)

race	Percent of Population that is White not Hispanic	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)
race	Percent of Population that is Minority Race	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)
target population	Number of Black Women over age 45	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)

Social Determinants of Health

Subcategory	Indicator	Source
social vulnerability	Social Vulnerability Index Score	2016 Social Vulnerability Index (US Centers for Disease Control and Prevention)
economic security	Percent of Population that is Uninsured	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)
economic security	Percent of Population Below 200% FPL	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)
economic security	Percent of Black Women over age 45 who live Below Poverty Level	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)
food security	Location of Food Deserts	2019 Food Access Research Atlas (US Department of Agriculture, Economic Research Service)
food security	Percent of Population that is Food Insecure	2019 County Health Rankings (County Health Rankings)
food security	Percent of Total Population with Limited Access to Healthy Foods	2019 County Health Rankings (County Health Rankings)
food security	Percent of Black Households Receiving SNAP/EBT	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)
education	Percent of Population over age 25 that has High School Degree or Higher	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)
education	Percent of Population over age 25 that has Bachelor's Degree or Higher	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)
education	Percent of Black Women over age 25 without a High School Degree	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)
transportation	Percent of Households without a Vehicle	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)
transportation	Percent of Total Population Commuting more than 45 Minutes to Work	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)
transportation	Percent of Total Population that Commutes to Work using Public Transportation	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)
transportation	Percent of Population Commuting to Work by Foot/Bike/Other	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau)

housing stability	Percent of Households that are Housing-Cost Burdened	2016 Comprehensive Housing Affordability Strategy dataset (US Department of Housing and Urban Development)
housing stability	Proportional Change in Population with a Bachelor's Degree or Higher	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau); American Community Survey 2008-2012 5-Year Estimates (US Census Bureau)
housing stability	Percent Change in Median Household Income	American Community Survey 2013-2017 5-Year Estimates (US Census Bureau); American Community Survey 2008-2012 5-Year Estimates (US Census Bureau)
segregation	Black/White Dissimilarity Index Score	2019 County Health Rankings (County Health Rankings)
racism	Location of Redlining	2019 Mapping Inequality Project (University of Richmond)
racism	Number of Hate Crimes Committed with a Race/Ethnicity/Ancestry Bias Motivation	2017 Hate Crime Statistics (Federal Bureau of Investigation, Uniform Crime Reporting)
racism	Number of Fair Housing Act Cases Filed with a Race Basis	Fair Housing Act Cases dataset (US Department of Housing and Urban Development, Office of Fair Housing and Equal Opportunity)
racism	Number of Blacks Killed by Police	The Counted Database (The Guardian)

Health and Wellness

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

Health Systems

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

Breast Cancer Disease Burden

Subcategory	Indicator	Source
prevalence	Prevalence	2017 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
incidence	Age-Adjusted Incidence Rate	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
incidence	5-year Incidence Rate Trend Direction	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
incidence	Age-Adjusted Incidence Rate for White Women	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
incidence	5-year Incidence Rate Trend Direction for White Women	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)
incidence	Age-Adjusted Incidence Rate for Black Women	2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)

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

Qualitative Data

In the Dallas–Fort Worth MTA, a total of four focus groups were conducted among 25 community members. Two individual interviews were held with patient navigators, and one provider interviews were conducted. Dallas–Fort Worth Table 2 summarizes the demographic characteristics of 25 focus group participants, representing both breast cancer survivors and the undiagnosed. Among breast cancer survivors, the majority were above 45 years of age, had insurance (92%), and had been diagnosed with stage 2 breast cancer (41%). Undiagnosed women were older, mostly in the 25-54 age group, with the majority reporting access to private insurance (63%). Non-provider participants were Black. Demographics were not collected for community health navigators, patient navigators, or clinical providers.

TABLE 2. DALLAS–FORT WORTH METRO AREA QUALITATIVE DATA COLLECTION

Variable Name	Breast Cancer Survivors (n=14)	Undiagnosed Women (n=11)
Age		
18-24 years	0%	0%
25- 34 years	0%	9.1%
35-44 years	0.0%	9.1%
45-54 years	35.7%	18.2%
55-64 years	28.6%	36.4%
65-74 years	35.7%	27.3%
75 and above	0%	0%
Zip Code		
75007	7.1%	0%
75115	21.4%	27.3%
75146	0%	9.1%
75149	7.1%	0%
75154	0%	9.1%
75181	0%	9.1%
75201	7.1%	0%
75216	0%	9.1%
75217	7.1%	0%
75227	0.0%	9.1%
75232	7.1%	18.2%
75233	0%	9.1%
75237	7.1%	0%
75254	7.1%	0%
75704	7.1%	0%
76012	7.1%	0%
76017	7.1%	0%
76133	7.1%	0%

Insurance Status		
I don't have health insurance	14.3%	18.2%
Medicaid	0%	0%
Medicare	35.7%	18.2%
Military Healthcare	0%	9%
Private Insurance	57.1%	63.3%
Through my parents	0%	0%
Not sure	0%	0%
Ever been screened for breast cancer		
Yes	N/A	81.8%
No		18.2%
Type of breast cancer screening or assessment		
Clinical breast exam	N/A	44%
Mammogram	N/A	77.8%
3D Mammogram	N/A	44%
Breast self-exam	N/A	33%
Other	N/A	0%
Stage of breast cancer diagnosis		
Stage 0	8.3%	N/A
Stage 1	33.3%	
Stage 2	41.7%	N/A
Stage 3	8.3%	
Stage 4	8.3%	

Policy Data

JSI reviewed federal and state policies that affect health care access, cost, and utilization, as well as policies most relevant to the breast cancer clinical continuum of care, including breast cancer screening, diagnosis, and treatment.

JSI searched key policy sources such as Kaiser Family Foundation, the Centers for Disease Control and Prevention (CDC), and the American Cancer Society to identify relevant federal policies that were conducted. At the state level, JSI 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, JSI 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).

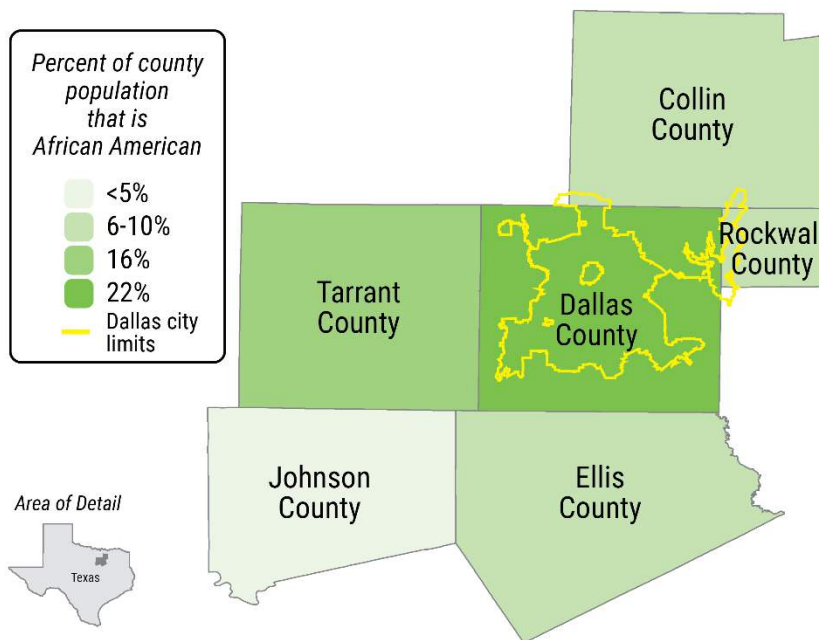
Section 1 Findings: Burden of Breast Cancer

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

Demographics

Dallas County has the highest percentage of Black residents 22 percent with Tarrant County in second at 16 percent. All remaining counties report less than 10 percent of their populations being Black (see Table 3).

MAP 1. DALLAS–FORT WORTH METRO AREA BLACK POPULATION



In addition to the MTA as a whole being racially segregated (with most people of color living in just a couple of the counties: predominantly Dallas County followed by Tarrant County - see Map 1), many of the counties in the Dallas MTA are also internally racially segregated.

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

TABLE 3. DALLAS–FORT WORTH METRO AREA DEMOGRAPHICS

Gender	
Male	49%
Female	51%
Age	
Under Age 18	22%
Age 18-64	63%
Over Age 65	15%
Race/Ethnicity	
White	67%
Black	17%
Asian	7%
American Indian or Alaska Native	0%
Native Hawaiian or Other Pacific Islander	0%
Some Other Race	6%
Two or More Races	3%
Hispanic/Latino	31%
White not Hispanic	44%
Minority Race	33%
Number of Black Women Over Age 45	181,405
Total Population	5,864,642

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

The Dallas–Fort Worth metropolitan area (MTA) is a six-county region in the southern United States. The MTA is entirely located in Texas and is home to 6.0 million people. Its population is 67 percent White, 31 percent Hispanic/Latino, and 21 percent Black (see Table 3 - demographics).

TABLE 4. DALLAS–FORT WORTH METRO AREA COUNTY DEMOGRAPHICS

County	Total Population	Percent of Total Population That Is Female	Percent of Total Population That Is Black	Number of Black Women Over Age 45
Collin	914,075	51%	9%	13,640
Dallas	2,552,213	51%	22%	110,980
Ellis	164,092	51%	9%	2,824
Johnson	160,173	50%	3%	655
Rockwall	90,414	51%	6%	736
Tarrant	1,983,675	51%	16%	52,570

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

More than 42 percent of all residents of the Dallas–Fort Worth MTA (2.5 million people) live in Dallas County (see Table 4 - county specific demographics), with another 32 percent of the region’s population

residing in Tarrant County (includes Fort Worth and surrounding areas; 1.9 million people). The other 25 percent is spread across four other counties in the MTA: Collin, Ellis, Johnson, and Rockwall. Refer to Table 4 (county specific demographics) for demographic information specific to each county within the Dallas–Fort Worth MTA. The number of Black women over age 45 is noted for each county because this Census-designated delineation best aligns with breast cancer metrics (e.g., percentage of women over age 40 who have received a screening mammogram in the last two years).

Breast Cancer Disease Burden in the Dallas–Fort Worth MTA

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

A helpful measure for breast cancer disease burden is prevalence, or the proportion of the population that has the disease at a given time. It is important to note that prevalence is measured in multiple ways depending on the time period of interest. This report uses age-adjusted complete prevalence, which represents the proportion of people alive on a certain day who have been diagnosed with breast cancer, regardless of when the diagnosis was made (National Cancer Institute, 2020). Prevalence statistics are only available at the state level. In Texas, the complete age-adjusted prevalence of breast cancer is 1.53 percent, lower than the national percentage of 1.69.

Breast cancer indicators for other measures are available at the county-level. Tables 5-9 describe the breast cancer disease burden in the MTA. Data on breast cancer incidence rates, in situ incidence rates, late-stage incidence rates, and mortality rates are all expressed in terms of number of new cases, or number of deaths per 100,000 individuals per year. Screening mammography rates, shown in Table 9, are represented as the percentage of women over the age of 40 that have had a screening mammogram in the last two years. Some racially disaggregated rates are unavailable for Ellis, Johnson, and Rockwall counties, as too few Black women live in these places to calculate the rates.

TABLE 5. DALLAS–FORT WORTH 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
Collin	124.8	stable	129.6	stable	114.8	stable
Dallas	117.2	stable	117.4	stable	125.7	stable
Ellis	116.3	stable	114.1	stable	144.7	stable
Johnson	115.9	rising	116.1	rising	*	*
Rockwall	132.2	stable	136.8	stable	*	*
Tarrant	121.7	stable	122.5	stable	129.6	stable
Texas	111.9	stable	112.6	stable	118.4	falling
National	124.2	stable	126.1	stable	124.0	stable

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

Age-adjusted incidence rates in the Dallas–Fort Worth MTA range from 115.9 new cases per 100,000 in Johnson County to 132.2 in Rockwall County (See Table 5 - Incidence). For three out of the four counties that have data available by race, Black women have higher incidence rates than White women. The largest disparity is in Ellis County, where the rate is reported at 114.1 for White women and 144.7 for Black women. The total incidence rates in counties throughout the Dallas–Fort Worth MTA (that includes all races) are greater than the state of Texas rate of 118.4 but comparable to the national rate of 124.2.

TABLE 6. DALLAS–FORT WORTH 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
Collin	27.6	stable	27.5	stable	24.8	stable
Dallas	27.9	stable	27.2	stable	32.4	stable
Ellis	23.5	stable	23.0	stable	*	*
Johnson	26.6	stable	26.6	stable	*	*
Rockwall	35.3	stable	35.4	stable	*	*
Tarrant	24.2	stable	25.1	stable	22.8	stable
Texas	22.9	stable	22.3	stable	27.3	stable
National	28.3	stable	29.7	stable	31.8	stable

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

Overall, breast cancer *in situ* incidence rates (overall total among women of each race) for most counties in the Dallas–Fort Worth MTA are higher than the state rate of 22.9 per 100,000, but are comparable to the national rate of 28.3 (See Table 6 - *in situ*). Rockwall County reports the highest age-adjusted *in situ* incidence rates among women, at 35.3 overall. Of the three counties in the Dallas–Fort Worth MTA that have data available by race, Dallas County is the only county where the *in situ* incidence rate is higher among Black women, with a rate of 32.4, than among White women, with a rate of 27.2

TABLE 7. DALLAS–FORT WORTH METRO AREA LATE-STAGE BREAST CANCER INCIDENCE RATE (PER 100,000)

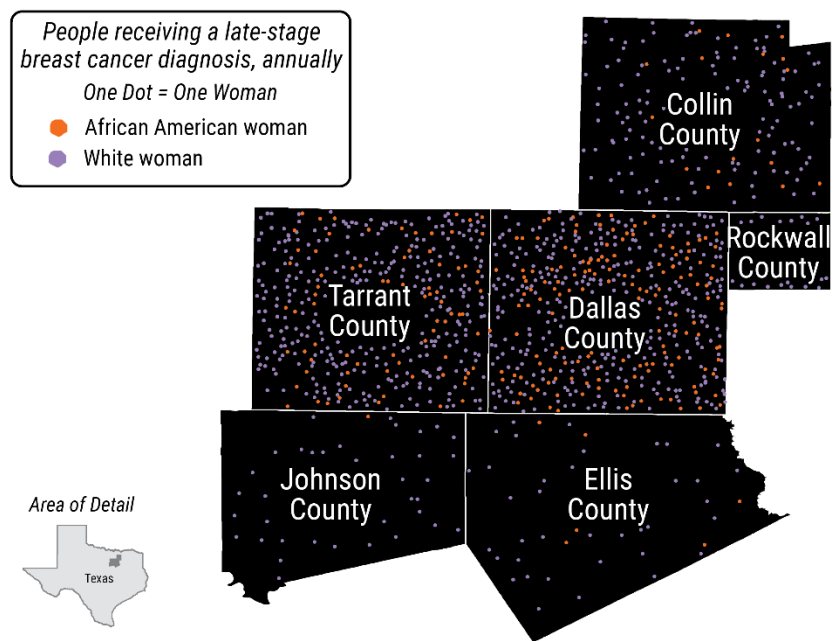
	Age-Adjusted Late-Stage Incidence Rate	Average Count of Cases That Are Late-Stage	Age-Adjusted Late-Stage Incidence Rate for White Women	Average Count of Cases That Are Late-Stage for White Women	Age-Adjusted Late-Stage Incidence Rate for Black Women	Average Count of Cases That Are Late-Stage for Black Women
Collin	36.3	164.0	38.6	131.0	37.7	18.0
Dallas	39.4	503.0	37.6	324.0	47.7	152.0
Ellis	46.4	38.0	44.9	32.0	63.6	5.0
Johnson	45.4	36.0	45.4	34.0	*	*
Rockwall	44.4	20.0	46.2	18.0	*	*
Tarrant	42.7	425.0	43.4	328.0	47.2	81.0
Texas	38.7	5251.0	38.9	4261.0	44.2	790.0

National	41.0	78641.0	41.4	62240.0	51.0	11590.0
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Source: 2012-2016 State Cancer Profiles (US Centers for Disease Control and Prevention; National Institutes of Health)

As shown in Table 7, in three of the four counties for which data are available by race, late-stage incidence rates among Black women are higher than they are among White women. The greatest disparity is in Ellis County, where the late-stage breast cancer incidence rate is 44.9 among White women and 63.6 among Black women. Ellis County reports the highest overall age-adjusted late-stage incidence rate of breast cancer, at 46.4 per 100,000. Johnson County follows in second at 45.4. In most counties in the Dallas–Fort Worth MTA, overall late-stage incidence rates are higher than overall state and national rates. Only Collin and Dallas counties (36.3 and 39.4, respectively) fall below the national average of 41.0 and only Collin County falls below the Texas state rate of 38.7.

MAP 2. DALLAS–FORT WORTH METRO AREA LATE-STAGE BREAST CANCER CASES



Map 2 – Late-stage cases shows the concentration of women who receive late-stage breast cancer diagnoses annually in the Dallas–Fort Worth MTA. Observed patterns align with population trends. Dallas and Tarrant counties have the highest concentrations of late-stage diagnoses, with the majority among Black women in Dallas County and White women in Tarrant. Rockwall and Collin counties show moderate numbers of late-stage diagnoses, the majority of which are White women. Johnson and Ellis counties both have fewer late-stage diagnoses, the majority of which are among

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

White women, reflecting the population distribution of the region.

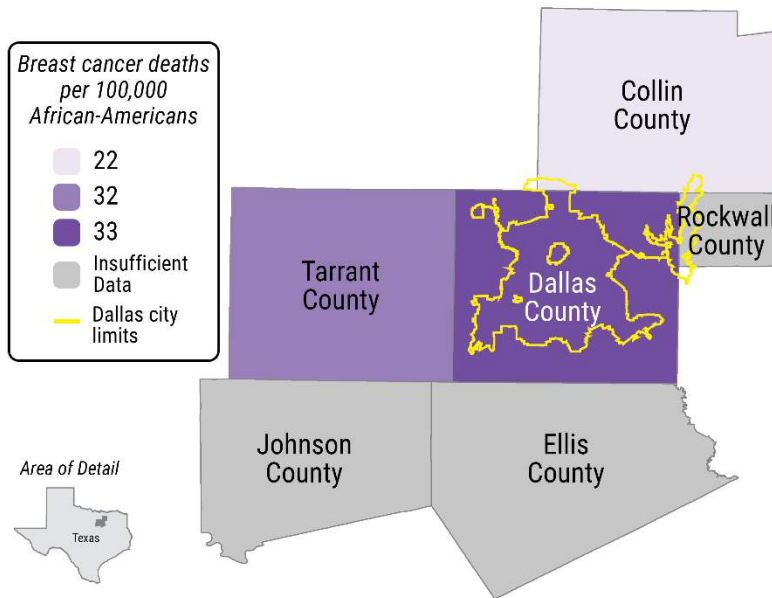
TABLE 8. DALLAS–FORT WORTH METRO AREA BREAST CANCER MORTALITY RATE (PER 100,000)

	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
Collin	16.1	falling	16.5	falling	22.0	*
Dallas	21.7	falling	18.8	falling	33.2	falling
Ellis	20.5	falling	18.7	falling	*	*
Johnson	25.6	stable	25.5	stable	*	*
Rockwall	24.2	*	24.3	*	*	*
Tarrant	20.8	falling	19.4	falling	32.4	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)

In every county in the Dallas–Fort Worth MTA where disaggregated data are available (three counties), the breast cancer mortality rate among Black women is higher than the rate among White women (see Table 8). The racial disparity in breast cancer mortality rates is greatest in Dallas County, where the age-adjusted mortality rate for White women is 18.8 compared to 33.2 per 100,000 for Black women. The disparities within the two other counties with disaggregated data show Tarrant County with a mortality rate of 19.4 for White women compared to 32.4 for Black women, and Collin County with a mortality rate of 16.5 for White women and 22 for Black women. The highest overall mortality rates in the Dallas–Fort Worth MTA are reported in Johnson and Rockwall counties at 25.6 and 24.2 per 100,000, respectively. Note that Rockwall is the county with the highest age-adjusted incidence rate (see Table 5) and both Rockwall and Johnson have elevated rates of late-stage incidence (see Table 7). With the exception of Collin county, which has the lowest overall age adjusted breast cancer mortality rate of 16.1, each of the counties in the Dallas–Fort Worth MTA have rates that are at or above state (20.1) and national (20.6) rates.

MAP 3. DALLAS–FORT WORTH METRO AREA BLACK BREAST CANCER MORTALITY RATES



As seen in Map 3, Dallas County has the highest breast cancer mortality rate for Black women at 33.2 deaths per 100,000 (see Table 8). Tarrant County has the next highest with a reported rate of 32.4 deaths per 100,000 and Collin County has a rate of 22 deaths per 100,000. In Ellis, Johnson, and Rockwall Counties these rates are not reported due to insufficient data.

TABLE 9. DALLAS–FORT WORTH METRO AREA SCREENING MAMMOGRAPHY RATES (AMONG ALL WOMEN OVER AGE 40)

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

Percent of Women Getting Mammograms	
Collin	76%
Dallas	62%
Ellis	66%
Johnson	68%
Rockwall	81%
Tarrant	71%
Texas	65%
National	73%

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

The percentage of women over age 40 receiving a screening mammogram varies throughout the Dallas–Fort Worth MTA from 62 percent in Dallas County to 81 percent in Rockwall County (see Table 9 - Screening mammography Rates). Most of the screening mammography rates in the MTA hover near or above the Texas state rate of 65 percent. In two counties, the screening mammography rate exceeds the national rate of 73 percent: Collin 76 percent and Rockwall 81 percent. Although racially disaggregated data are not available at the county level, these data are available at the state level. Racial differences in screening mammography screening reported in Texas show that Black women are screened for the disease at a higher rate than White women. In Texas, the screening mammography rate for Black women over the age of 40 is 70 percent, compared to 67 percent of White women in the same demographic.

Overall, a study of breast cancer disease burden measures suggests that in most counties in the Dallas–Fort Worth MTA where data are available, Black women are more likely to receive a breast cancer diagnosis, are more likely to receive a late-stage breast cancer diagnosis, and are more likely to die from breast cancer than their White counterparts. These trends hold even though Black women are more

likely to receive a screening mammogram. Similar patterns have been noted in the literature. A study in South Carolina, for example, found that while the breast cancer incidence rate was higher for European-American or Caucasian women compared to Black women (124 versus 118.5 per 100,000 women), the breast cancer mortality rate was higher for Black women (29.8 versus 21.3 per 100,000 women) (Samson et al., 2016). The study further reported that Black women were even more likely to have had a screening mammogram or clinical breast exam compared to White women (81.9 percent of Blacks versus 74 percent of Whites) and more likely to have late-stage breast cancer at the time of diagnosis (47 percent of Blacks versus 35 percent of Whites).

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

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 Dallas–Fort Worth MTA. Based on a review of the quantitative findings, priority counties for qualitative data collection in the Dallas–Fort Worth MTA were: Dallas county, Ellis County, and Tarrant County. Dallas County, Ellis County, and Tarrant County have the highest breast cancer burden. The themes shared below represent the perspectives of community members from these priority counties, not the entire Dallas MTA. As a result of the cancelation of data collection in the Dallas–Fort Worth MTA due to COVID-19, there were no focus group or interview data on breast cancer survivorship.

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). As mentioned, the screening mammography rate in Texas for Black women over the age of 40 is 70 percent, compared to 67 percent of White women in the same demographic. Two counties exceed the national screening mammography rate average of 73 percent: Collin (76 percent) and Rockwall (81 percent). Dallas county has the lowest rate of screening mammography at 62% in Dallas County. Although the data are not disaggregated by race, focus group participants' perspectives give some indication of the experiences of Black women seeking and obtaining breast cancer screening.

Screening Guidelines. Overall, community members were aware of the screening guidelines from the American Cancer Society indicating that mammograms begin at 40. However, there was a sentiment that the guidelines need to be different for Black women due to early age at onset of disease and a

perception that Black women are more likely to get aggressive cancers including triple negative breast cancers.

I've been getting mammograms since an early age, because I found a mass in my breast during a self-examination at home. I was 26. I think many women feel like they're too young and need to wait until a certain age for a screening mammogram, but preparation is always best. When I talk to my friends or my coworkers, I'm always pushing, you're never too young, go. – Undiagnosed

We don't know exactly why the death rate is higher in Black women, but we do know they have a higher percentage of triple negative cancers which are more aggressive cancers. Also, this population tends to get screened less and tends to have less access to care so they come in when their cancers are larger. We also know that in Black women, that the breast cancers tend to occur earlier. – Provider

One of the concerns is the Black women are presenting with late-stage disease. We see a lot of women in their 20s and it was shocking to me. We hear not enough about the women who are dying under the age of 40. If there were more people dying, or if there were more Caucasian women that were dying at 35 then I feel like there would be a different sense of urgency. But I just feel that because these are uninsured minority women, people don't care enough. I feel like they should be being screened at least at 35, for the first screening mammogram, especially if you have a first-degree relative that has had breast cancer. If they're young and they get cancer, it is aggressive cancers. – Patient Navigator

Family History. Several survivors indicated that they were not aware of their family breast cancer history until after their diagnosis, which may have changed the age they would have begun screening mammography.

As far as my screening goes, I started doing my regular mammograms. I didn't find out until after I got my diagnosis that my family did have a history of cancer. All my mother's sisters and brothers have passed, so I had no way of knowing the health history of that side of the family. I didn't find out any information on cancer on my father's side until after I was going through the diagnosis and started asking questions. – Survivor

I just knew they said after 40 you need to start your mammograms. I didn't really have any knowledge of any breast cancer in my family. I just found out that one aunt did pass away but that was because she didn't know she had it. She probably knew but just didn't get it checked out. – Survivor

Transportation and Access. Focus group participants elevated transportation as a significant barrier to accessing screening mammography in the Dallas–Fort Worth MTA, an estimated 9,200 square miles in

geographic size. Additionally, the need for imaging centers that are in predominately Black communities and that will accept those without insurance was an identified need.

I will never forget a 65-year-old Dallas patient who walked about 10 miles to get her screening mammogram in July. By the time she got to our facility she was dehydrated. We had to send her to the emergency room so she could get fluids before her screening mammogram and fortunately she was okay. She had the appointment for so long and wasn't going to miss it. – Provider

Once we get all the information and know where to go, how do we get there? There's no transportation. I was going to an imaging center here in Cedar Hill and they closed. Thank goodness I have transportation. Now, I have to go drive all the way pass through downtown to go to Baylor.– Undiagnosed

I feel that there is a lack of satellite screening mammography imaging centers for those who are most impacted by breast cancer. There are a lot of imaging places around the metroplex, and other major hospitals have imaging facilities around the DSW area but those are for folks with insurance. – Patient Navigator

Access to Screening Follow-up. While most focus group participants described the ability to access free breast cancer screening, an undiagnosed focus group participant expressed the importance of having insurance for follow-up screening.

I've always had a little deposit that would show in my screening mammogram and when I went for my first 3D screening mammogram, they saw something different. It picked up a better picture or something. But I had to go back in and do a sonogram. Then I had to do a needle biopsy and, thank the Lord, it was benign. They put some markers in there to follow up and I had to go every six months instead of every year. So, this last one I got, I've been going every year now. I did have to pay extra money, but I have insurance, but you just think about people who don't. - Undiagnosed

Diagnosis

While screening may be readily available within the Dallas–Fort Worth MTA, focus group findings suggest this phase of the breast cancer continuum can be strengthened to reduce late-stage diagnosis in the Dallas–Fort Worth MTA. Survivors who regularly and consistently screen described incidents of breast self-exam not screening mammography that led to their diagnosis. These survivors shared their concern that had they waited the full 12 months for their screening mammogram it might have led to a later diagnosis and more severe stage of cancer. Providers interviewed shared the importance of reinforcing this phase of the care continuum due to the depth of resources and time needed in this phase of the breast cancer continuum of care.

Breast self-exam Reduced Delays. Several survivors reported receiving annual screening mammography and finding lumps between screenings. There was a sentiment that self-examination is valuable and prevented them a delayed diagnosis.

I turned 40 I got regular mammograms, nothing ever showed up. I'm 52 now. Despite regular screening, the cancer just popped up and it was triple negative. I found the lump myself in September. I was watching TV, and I don't know I just felt something that didn't feel right. I normally get my mammograms in October, but that year it was scheduled in December. I'm just glad I did the self-examination because I would have waited three more months until my annual screening mammogram. I don't know how far it would have spread if I would have waited. – Survivor

At the age of 40, I started my mammograms and I've done them every year. When I found the lump, it was in May and my annual screening mammogram was scheduled in June. On the right of my breast I felt a tender spot. I got up the next morning and the holy spirit said, 'You need to go do something about that.' The next day I called for a screening mammogram. – Survivor

My grandmother passed away from breast cancer, and my mother is a nurse, so I regularly had my screening mammogram. The year that I was supposed to have received my screening mammogram, I was in a major car accident where the front car smashed into my breast. As a result, my screening mammogram was scheduled six months later than usual. I found the cancer myself before my scheduled screening mammogram. I felt something that was abnormal and called my doctor, so for me it was about being proactive, self-checking because prior I was always getting the screening mammogram. - Survivor

Diagnostic Screening mammography Resources. Patient navigators noted the importance of navigation in the diagnosis phase of the breast cancer continuum and the significant time investment in guiding patients and preventing “no-shows”. Medical providers specifically mentioned a need for more resources to support diagnostic mammograms.

Many patient navigators work hard trying to prevent no shows. I schedule a biopsy, provide instructions, and then we see, 'Okay, she no-showed. What's going on?' We call the patient about the missed appointment and asked, 'What's going on?' We have to assess the possible barriers and then offer solutions over the phone. Was it a transportation issue? Was it fear? – Patient Navigator

Many times, providers need help for diagnostic mammograms as well. Because anybody right now can, if they really wanted, they can find a way to get a screening mammogram. But after that, between the screening mammogram and the treatment stage, it's a blank and it's very difficult many times to get funded for that. - Provider

High Cost. Patient navigators described the cost of diagnostic procedures as a significant barrier to timely diagnosis, even when the safety net hospital, Parkland Hospital, offers financial assistance programs for women who are uninsured.

Parkland Hospital has the Parkland Financial Assistance program. The level of assistance depends on your income. There is a misunderstanding that care at Parkland is free. If you make a certain amount of money, a certain salary, you get a huge discount. But those patients who are caught between the low and high salaries, their copays are sometimes \$200 or \$300 when they come to Parkland for a biopsy, just depending on where they fall within their tiers. A lot of patients are shocked by this. They think this was the place to go to if they didn't have any insurance. - Patient Navigator

Treatment

Below is a description of the facilitators and barriers to breast cancer treatment as described by the Dallas MTA focus group participants.

Quality of Care. Survivors described positive treatment experiences that involved having a choice of providers, care coordination, and increased engagement with doctors outside of in-person visits. Some community members correlated the level of care they received with the quality of their insurance.

The pathologist called me to tell me I had breast cancer and I should contact my breast surgeon. I interviewed three surgeons. My thing is, if I can't get along with you then we can't move forward. I selected a very good surgeon and in fact all my doctors are very good. They work as a group, as a team. They meet and discuss your care, and everybody knows what's going on. – Survivor

It was helpful that I had a telemedicine option. I could just send an email to my doctor and describe what I was experiencing. My doctors were very good about calling me back or calling in a prescription for whatever I needed. I really liked having that aspect of feeling connected to my doctors. I still use it to this day. – Survivor

I used to work for a bank in which we had premier insurance, and it meant that I received the best health care. I would meet some of the women during a treatment who did not have access to the tests that could detect the probability of the cancer coming back. We are sharing our treatment experiences and because of insurance, that person is not going to get some extra testing that they may need to do. I just am very blessed for the extras that my insurance would pay for and at the same time felt for the other sisters who may not have all the treatment options. - Survivor

Provider Communication Skills. Patient navigators described physicians and patient encounters that are not tailored to the needs of the patient and ultimately contribute to treatment delays.

As patient navigators we are involved in the treatment consenting process and have the opportunity to listen to when the doctors are explaining the procedures. The looks on a lot of our Black women's faces are like, "What did they just say?" The language that doctors use many patients do not really understand. Black women already have a distrust for doctors, or they feel like they're experimenting, and they will decide, "I'm not doing this." We've had countless women that have said, "Nope. I don't want to do it."

and the doctor's reaction is "Well, okay. I'll give you a six-month follow-up," But they are not getting at the root of the matter. The doctors do not understand that these patients are afraid and have mistrust. She's scared. So, we have to go into depth and talk to these patients in terms they can understand. When we go back to the doctor once the patient has agreed to treatment. Then the doctor says, "Why the attitude?" - Patient Navigator

Income and Insurance Barriers. Patient navigators and a provider described cost barriers that delay treatment, competing priorities and will often choose more immediate needs, like working over healthcare. As one of the survivors explained, those who have employer-sponsored insurance when they are diagnosed may lose their insurance in the course of their cancer treatment because they are no longer able to work. Additionally, a survivor and provider echoed the sentiments of income related treatment barriers and specifically acknowledge the relationship between health outcomes and employer leave policies.

I only used my insurance prevention doctor visits. You pay all this money out, and I'm like, "Okay. Let's see what it does." I always had the highest deductible to keep the payments low, but once I was going for treatment, I regretted choosing a \$2,500 deductible plan. I was just doing it to be cheap and have less come out my check. - Survivor

The biggest barrier is financial. Our organization is able to get grants, but, most of the time, those go towards screening, diagnostics, and biopsy. But when these patients go to oncology, that's a totally different situation. We don't even really know what oncology does on that end, as far as funding if a patient can't pay for treatment, they turn them away. There are a lot of women out there who have delayed treatment because they don't have the money for oncology. One lady had to delay her surgery because she didn't have \$100. These patients literally have nothing, a lot of people are trying to decide, especially right now, spend \$80 for toilet paper or pay copays. – Patient Navigator

People who have little access or poor access to healthcare, when they are finally diagnosed with breast cancer, may not have a very smooth pathway to treatment. They may have challenges with income, childcare, transportation, all kinds of challenges, which are monumental in some cases. As a result, it may take these patients longer to arrange all the things that they have to do to get treated for breast cancer. The time to treat which providers recommend about 30 days and for these patients may be much, much longer 60 to 90 days. – Provider

Patients who have their screening mammogram one day, another day a surgical appointment, and another day a chemotherapy appointment that causes treatment delays. If patients can come one day and get all their stuff done that's much more efficient. The people who need that the most are those with the least amount of time because for most of the people in the safety net community, if they don't work, they

don't get paid and they can't afford to take multiple days off to get healthcare. – Provider

I was working in the Dallas County Sheriff's department and was around a lot of inmates. I didn't know that that was risky. I had to work. I got really sick and ended up having to retire. The amount of time that they give you to be off is not enough time for you to heal. You have your treatments and surgery you have to go through. It was just a real bad experience. - Survivor

Social support and patient navigation. Providers, navigators, undiagnosed women, and survivors all noted the importance of support for successful treatment. Several community members noted the importance of social support groups specifically for Black women. These support groups were highlighted as being crucial for retention in the face of treatment fatigue.

My church family was my support. I was diagnosed in May and I shared it with my pastor and his wife. I asked them to just let me share it when I was ready with everybody else. I had friends that took me to chemo, brought me home, and bought food/ food because I couldn't eat the food. I mean it was a comfort because I didn't have family here.

– Survivor

I had a support system from my co-workers to my family. They created a schedule for all my meals. Seven family members went to my first doctor appointment. Everyone had pencil and paper. The doctor came in as we prayed, and he joined in the prayer with us. That was when I knew, this is the doctor for me. I had a very good support system.

– Survivor

Section 2 Findings: Systemic and Social Determinants of Health

Section 2 explores the systemic and social determinants of health that may drive breast cancer inequities.

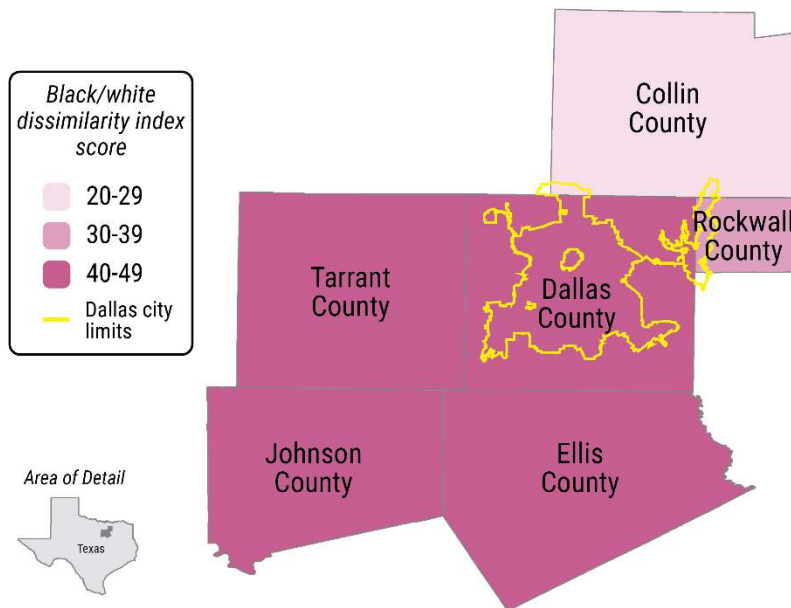
The set of factors explored in this section—residential segregation, economic vulnerability, experiences of racism—were informed by consultations with Komen’s Stand for H.E.R. team, academic experts (see Acknowledgements for details), findings from the literature scan, and principles in the guiding frameworks.

Residential Segregation

The Dallas MTA is segregated along racial and socioeconomic lines, creating stark contrasts by geography. Approximately 2 million people of color live in the Dallas MTA, comprising 33 percent of the region’s total population (see “Minority Race” in Table 3). A majority of the approximately 1.3 million Blacks who live in the Dallas MTA reside in Dallas County and Tarrant County (see Tables 3 and 4).

Counties’ internal segregation can be measured using the Black/White dissimilarity index to assess the extent to which there may be residential segregation (see Map 5). Index scores range from 0 to 100 and correspond to the percentage of people within a racial group who would need to relocate in order for a county to achieve integration. Zero indicates complete integration of the two races and 100 indicates complete segregation of the two races. For example, a score of 35 means that 35 percent of Whites within a particular county would need to move to a different neighborhood within the county in order to achieve racial integration.

MAP 4. DALLAS–FORT WORTH METRO AREA RESIDENTIAL SEGREGATION



Source: 2019 County Health Rankings (County Health Rankings)

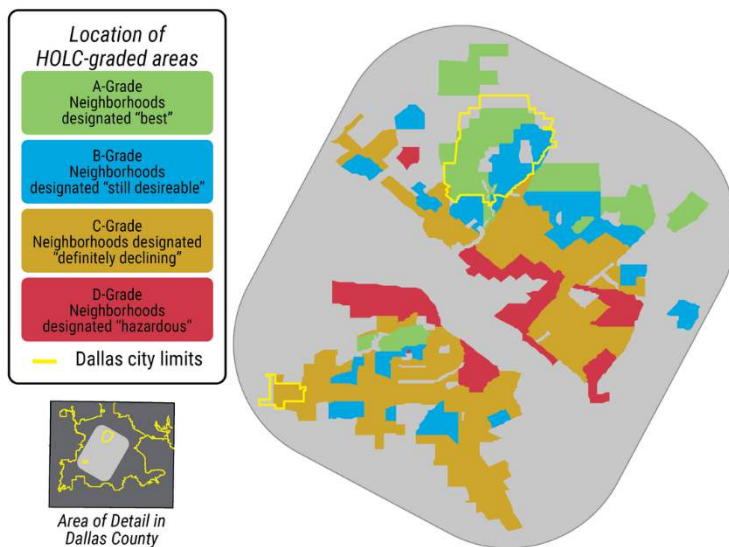
As seen in Map 4, four counties report relatively higher levels of segregation with index scores between 40-49: Ellis (40), Johnson (42), Tarrant (48), and Dallas (49). Counties’ scores decrease the further one moves away (particularly northward) from Dallas, the epicenter, with Rockwall (30) and Collin (27) counties having the lowest residential segregation scores, indicating that the racial distribution of residents in these locations is more even.

The patterns of residential segregation that are visible today across the Dallas MTA are the direct result of systemic racism.

As defined and discussed at the

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

MAP 5. DALLAS–FORT WORTH METRO AREA REDLINING



An example of institutionalized racism is redlining – the practice of identifying and systematically discriminating against neighborhoods based on their racial makeup (Map 5). Between 1933 and 1954, Home Owners’ Loan Corporation (HOLC) field agents with the federal government assigned grades to neighborhoods ranging from A to D, best to hazardous respectively. The practice is commonly called redlining because designated hazardous areas assigned a D grade were marked in red. Banks and other mortgage lenders used these grades to inform their lending practices and policies in Dallas County.

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

A noteworthy study is Krieger et al.’s analysis of data from the SEER registry to assess whether being born in an area that previously had Jim Crow laws in place was associated with higher risk of estrogen-receptor-negative (ER-) breast tumors (Krieger, Jahn, & Waterman, 2017). The study analyzed data on 47,157 US-born, non-Hispanic Black women and 348,514 US-born, non-Hispanic White women, ages 24-84, diagnosed with primary invasive breast cancer between January 1, 1992 and December 31, 2012. The authors defined Jim Crow as “legal racial discrimination practiced by 21 US states and the District of Columbia from the 1870s and 1880s until it was outlawed by the US Civil Rights Act in 1964.” The authors found that being born in an area with a legacy of Jim Crow laws was associated with increased odds of ER-negative breast cancer among non-Hispanic Black women born before 1965 as compared to White women of the same age group who did not experience a similar effect. This indicates that Black women living in an environment with discriminatory laws experienced negative impacts on health and breast cancer incidence. The authors did not observe a similar effect in Black women born after 1965. They noted that this lack of effect may be due to the smaller number of women in this younger age group diagnosed with primary invasive breast cancer. Importantly, the authors note that observing a “Jim Crow effect” on breast cancer estrogen status could occur through relevant exposures over the life course such as early life adversity, environmental and occupational exposures, and diet. Further, the authors note that while racism and discrimination exist in all states, Jim Crow states arguably had a greater burden of systemic racism and discrimination.

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

Personally Mediated Racism

Data suggest that in addition to institutionalized racism, Black people in the Dallas–Fort Worth MTA experience several forms of personally mediated racism (U.S. Department of Housing and Urban Development, 2019; U.S. Department of Justice Federal Bureau of Investigation, 2017).

As seen in Table 10-racism, Dallas and Tarrant counties report higher levels of racism than other counties in the MTA. In 2015 and 2016, 8 Blacks were killed by the police in Dallas and 4 in Tarrant (See table 10 - racism). Further, there were 14 hate crimes committed with a racial bias motivation in Tarrant County 2017 and 4 in Dallas County. In Tarrant County, there were 1186 Fair Housing Act cases filed with a racial basis since 2009 and 906 in Dallas.

TABLE 10. DALLAS–FORT WORTH 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 Residents Killed by Police
Collin	5	106	0
Dallas	4	906	8
Ellis	0	18	1
Johnson	4	9	0
Rockwall	1	7	0
Tarrant	14	1,186	4

Sources: 2017 Hate Crime Statistics (Federal Bureau of Investigation, Uniform Crime Reporting); Fair Housing Act Cases, 2009-2019 dataset (US Department of Housing and Urban Development, Office of Fair Housing and Equal Opportunity); The Counted Database, 2015-2016 dataset (The Guardian)

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

The experiences of community members from the Dallas–Fort Worth MTA provide additional insights about experiences of personally mediated racism that Blacks experience.

As a mother of black sons, even if it's not direct, what happens to your children affects you. The idea with all the different shootings of unarmed black men, just to hear my sons [talk] about it, affects me and how I feel. I can remember a couple of years back when an unarmed Black man, he was probably about 15, and he said to me, "I'm not leaving the house, I'm not leaving my room, I'm not going anywhere." In his mind it was like, I can't go anywhere and be safe. So as a mother trying to raise your children, it does affect your mental state. You're at peace when everything about you and those people who are connected with you are well. So, I can see why the White race is well, much better than we are, because they don't have to experience what we have experienced.-Undiagnosed

We just can't move ahead. We are always stressed out and hurt. You can't even go into stores without wondering why people treat you differently. You can go into a store and walk around but no one acknowledges you. Then when a White person walks in the store, they immediately ask, "May I help you?" My money is the same as hers. I worked for mine just like she did, but we're still treated differently. That's something that we probably always have to deal with. – Undiagnosed

When I was in Dallas, I worked with some judges that were really fair and liberal. I got a promotion and went to Fort Worth and that is where I experienced racism. I later found out the only reason I was promoted over there was they didn't want to promote the Hispanic [person] that was in that office. - Undiagnosed

Health Disparities

Overall life expectancy in the MTA is lowest in Johnson County at 77 years and highest in Collin County at 83 years (see Table 11 - life expectancy). Life expectancy for Whites is higher than Blacks in five of the six counties, and the largest disparities lie in Dallas and Ellis counties, where Whites live 4 years longer than their Black counterparts, on average (79 years for Whites compared to 75 years for Blacks in Dallas County; 78 years for Whites compared to 74 years for Blacks in Ellis County). Collin County has the highest life expectancy for Blacks at 81 years. In every county except Rockwall, the life expectancy for Whites is higher than for Blacks.

TABLE 11. DALLAS–FORT WORTH METRO AREA LIFE EXPECTANCY

County	Life Expectancy	Life Expectancy for Whites	Life Expectancy for Blacks
Collin	83	82	81
Dallas	79	79	75
Ellis	78	78	74
Johnson	77	81	79
Rockwall	81	76	79
Tarrant	79	79	76

Source: 2019 County Health Rankings (County Health Rankings)

Data suggest that there are some disparities in the Dallas—Fort Worth MTA in terms of overall health and wellbeing. In Dallas County, 19 percent of adults report that their health is “fair” or “poor,” compared to 13 percent in Rockwall County (Table 12 - health and wellbeing). All counties in the MTA report that their residents have between 2.9 and 3.6 poor physical health days per month, with Collin County reporting the fewest days and Tarrant County reporting the most days. In terms of mental health, residents of Johnson County report the fewest number of poor mental health days per month (3.2 days). Residents of three counties report the highest average of 3.5 poor mental health days every month: Dallas, Rockwall, and Tarrant.

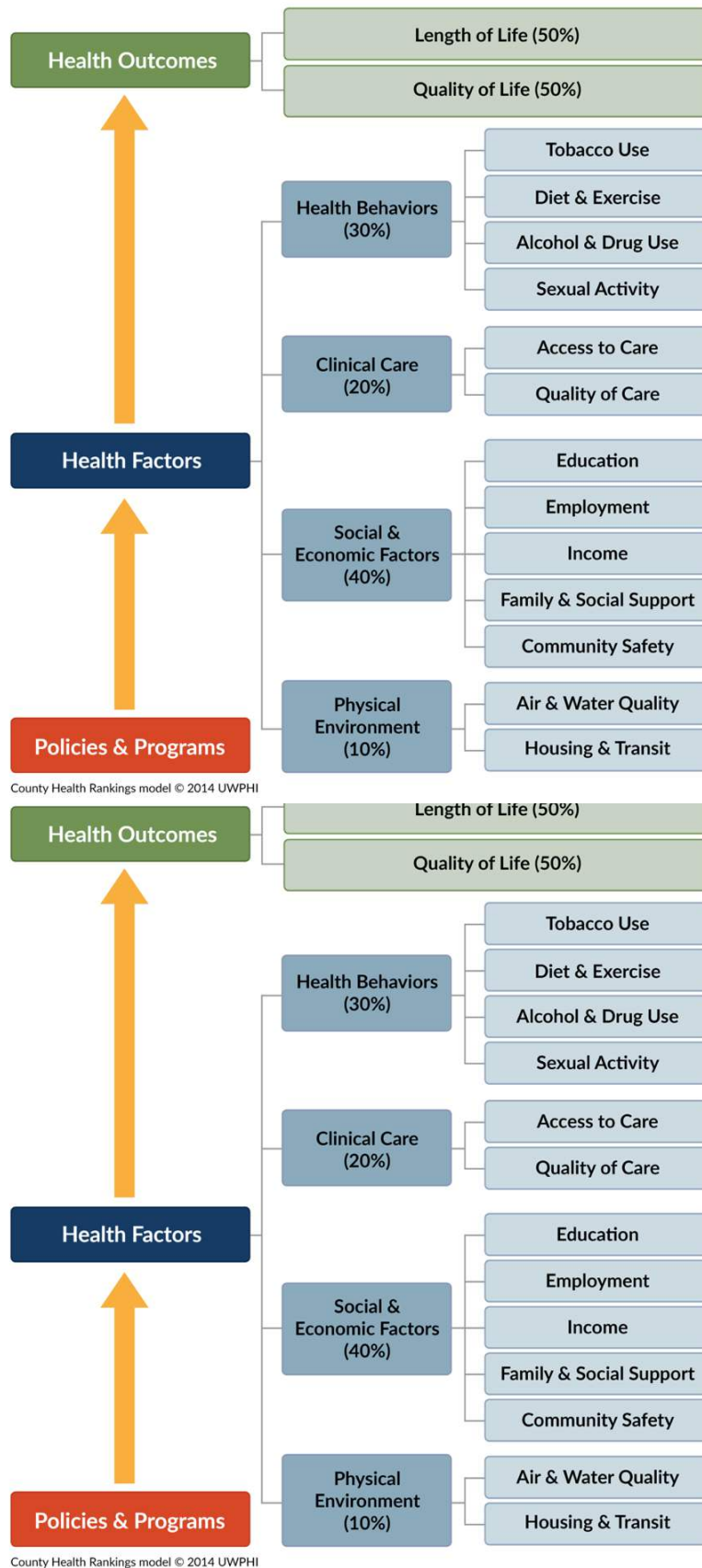
TABLE 12. DALLAS–FORT WORTH METRO AREA HEALTH AND WELLBEING

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
Collin	2%	14%	2.9	3.3
Dallas	19%	19%	3.5	3.5
Ellis	11%	17%	3.4	3.4
Johnson	14%	15%	3.0	3.2
Rockwall	2%	13%	3.4	3.5
Tarrant	13%	16%	3.6	3.5

Source: 2019 County Health Rankings (County Health Rankings)

FIGURE 2. COUNTY HEALTH RANKINGS MODEL

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



across the MTA. CHR are derived from over 30 measures of health-related outcomes and factors to give an overall health ranking of a county compared to other counties in the same state (See Figure 2).

Rockwall and Collin Counties both report the highest percentiles in the MTA at 2 percent. Dallas County reports the lowest at 19 percent (see Table 12 – health and wellbeing). In terms of health behaviors, Ellis County has the highest rate of obesity in the MTA, with 35 percent of adults who are obese and 26 percent of adults who are physically inactive (Table 12 - health behaviors). Rockwall County has the highest rate of excessive drinking, with an estimated 21 percent of its population engaging in excessive drinking.

Premature age-adjusted mortality measures the number of deaths per 100,000 among people under age 75. Johnson County reports the highest overall premature age-adjusted mortality rate (387), while Collin County reports the lowest overall rate (234) (Table 13 - age-adjusted premature mortality). All counties report higher rates among Blacks than among Whites. The disparity between Whites and Blacks is greatest in Johnson County (255 for Whites and 432 for Blacks), closely followed by Ellis County (351 for Whites and 523 for Blacks). The highest premature age-adjusted mortality rates are reported among Blacks in Ellis (523) and Dallas (515) counties.

TABLE 13. DALLAS–FORT WORTH 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
Collin	214	234	265
Dallas	344	352	515
Ellis	347	351	523
Johnson	387	255	432
Rockwall	244	417	385
Tarrant	325	343	447

Source: 2019 County Health Rankings (County Health Rankings)

TABLE 14. DALLAS–FORT WORTH METRO AREA HEALTH BEHAVIORS

County	Percent of Adults Who Are Obese	Percent of Adults Who Drink Excessively	Percent of Adults Who Are Physically Inactive
Collin	27%	19%	19%
Dallas	29%	17%	23%
Ellis	35%	18%	26%
Johnson	30%	20%	22%
Rockwall	25%	21%	25%
Tarrant	30%	18%	22%

Source: 2019 County Health Rankings (County Health Rankings)

Access to Health Services

Data suggest that there are significant disparities in the health system in the Dallas MTA, including in health care facilities and the proportion of the population that is medically underserved. According to the Health Resources and Services Administration (HRSA), Medically Underserved Areas/Populations are areas or populations designated by HRSA as having too few primary care providers, high infant mortality, high poverty or a high elderly population. For example, in Ellis County, 63 percent of the population is medically underserved (Table 15 - health systems). All remaining counties report that 20 percent or less of their population is medically underserved, with 0 percent of Rockwall County’s population designated as medically underserved.

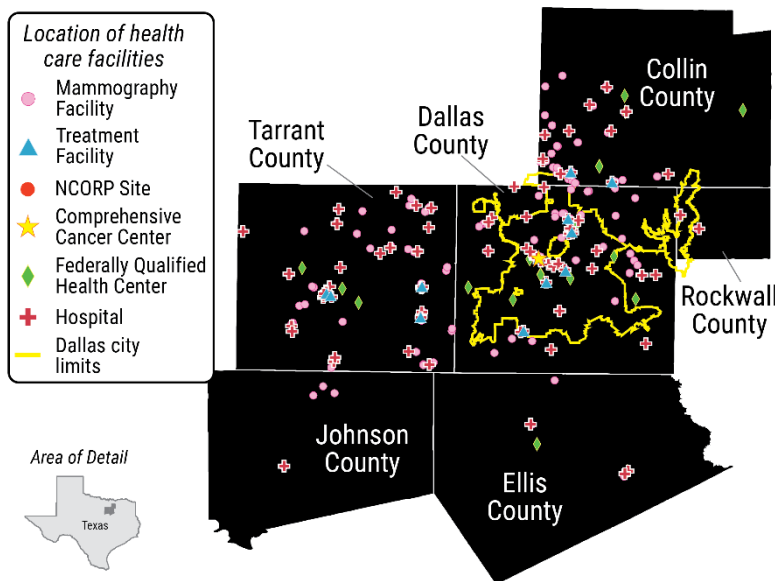
“We’ve looked at the zip codes where they’re the highest breast cancer rates in Dallas County and are trying to make sure that we provide more access like mobile units and all that stuff into those particular zip codes. We’re trying to actually build new outpatient clinics related to the safety net hospital in that area, so people are more likely to have access to healthcare in those areas.” – Provider

TABLE 15. DALLAS–FORT WORTH 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
Collin	7%	887	1,059	63	1,597	10	7
Dallas	20%	1,753	1,469	94	1,065	181	15
Ellis	63%	68	2,478	45	2,226	43	0
Johnson	17%	74	2,206	43	2,324	69	0
Rockwall	0%	71	1,324	72	1,383	39	1
Tarrant	9%	1,142	1,766	70	1,419	46	7

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 DALLAS–FORT WORTH METRO AREA



The health systems map (Map 6) shows the concentration of health care facilities across the Dallas MTA, and generally reflects population density across the metro. Most resources are centered around the city of Dallas, with additional resources in Tarrant County (around the city of Fort Worth). Most of the Federally Qualified Health Centers (FQHCs), hospitals, treatment facilities, screening mammography facilities, and the region’s only comprehensive cancer center are in Dallas County. Collin County has a fair number of health care facilities. Fewer resources are located in Johnson, Rockwall, and Ellis counties. There are no NCI National Community Oncology Research Program (NCORP) sites in the Dallas MTA.

Source: HRSA Data Warehouse, 2019 dataset (US Department of Health and Human Services, Health Resources & Services Administration); Comprehensive Cancer Centers and NCORP sites, 2019 dataset (National Cancer Institute); Mammography facilities, 2019 dataset (American College of Radiology); Treatment facilities, 2019 dataset (American College of Surgeons; Association of Community Cancer Centers)

TABLE 16. DALLAS–FORT WORTH METRO AREA BREAST CANCER RESOURCES

County	Number of Mobile Screening mammography Centers	Number of Cancer Coalitions	Number of Survivor/ Support Groups
Collin	0	0	7
Dallas	5	1	44
Ellis	0	0	0
Johnson	0	0	0
Rockwall	0	1	3
Tarrant	1	1	1

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

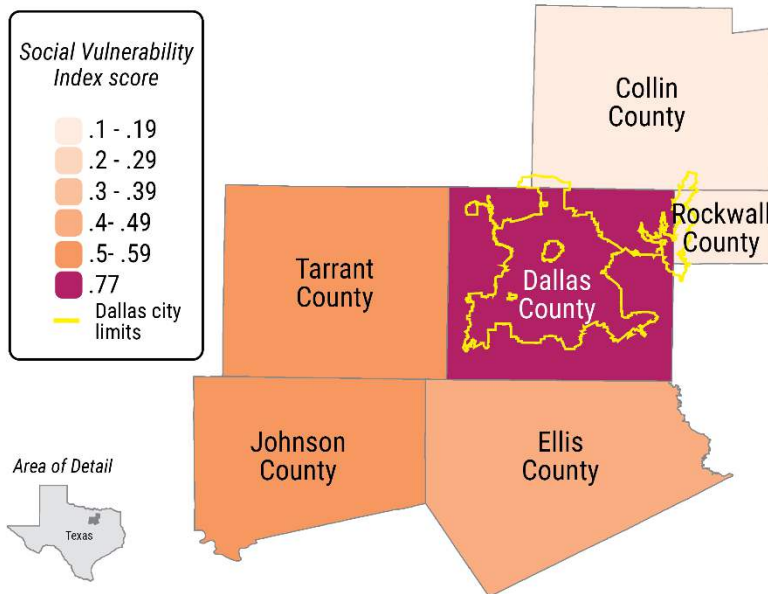
Most of the breast cancer resources are in Dallas County (see Table 16 - Breast Cancer Resources). The county has five mobile screening mammography centers, one cancer coalition, and 44 survivor support groups, the latter of which is significantly higher than any other place in the Dallas MTA. Johnson and Ellis counties do not have any mobile screening mammography centers, cancer coalitions, or survivor/support groups.

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

Social and Economic Vulnerability

Social determinants affect health outcomes – such as breast cancer – for individuals and communities. These play out not just across individual lifetimes, but generationally. Disadvantages compound in certain communities, which exacerbates and cements a wide range of negative outcomes and existing burdens, including with regard to health (Cozier et al., 2009; Institute of Medicine of the National Academies, 2011). The Social Vulnerability Index (SVI) of each county can be seen in (Map 7). The SVI is calculated by the CDC, and a county’s score “refers to the resilience of communities when confronted by external stresses on human health, stresses such as natural or human-caused disasters, or disease outbreaks” (e.g., such as hurricanes, fires, and COVID-19). Scores range from 0.0 to 1.0, with scores closer to 1.0 indicating greater vulnerability. Dallas County has the highest SVI score at 0.77. Collin and Rockwall counties report the lowest scores at 0.14 and 0.12 respectively. Individual factors influencing a county’s SVI can be parsed by looking at specific indicators.

MAP 7. DALLAS–FORT WORTH METRO AREA SOCIAL VULNERABILITY



Social determinants affect health outcomes – such as breast cancer – for individuals and communities. These play out not just across individual lifetimes, but generationally. Disadvantages compound in certain communities, which exacerbate and cement a wide range of negative outcomes and existing burdens, including with regard to health (Cozier et al., 2009; Institute of Medicine of the National Academies, 2011). The Social Vulnerability Index (SVI) of each county can be seen in Map 7. The SVI is calculated by the CDC, and a county’s score “refers to the resilience of communities when confronted by external stresses on human health, stresses such as natural or human-caused disasters, or disease outbreaks” (e.g., such as

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

hurricanes, fires, and COVID-19). Scores range from 0.0 to 1.0, with scores closer to 1.0 indicating greater vulnerability.

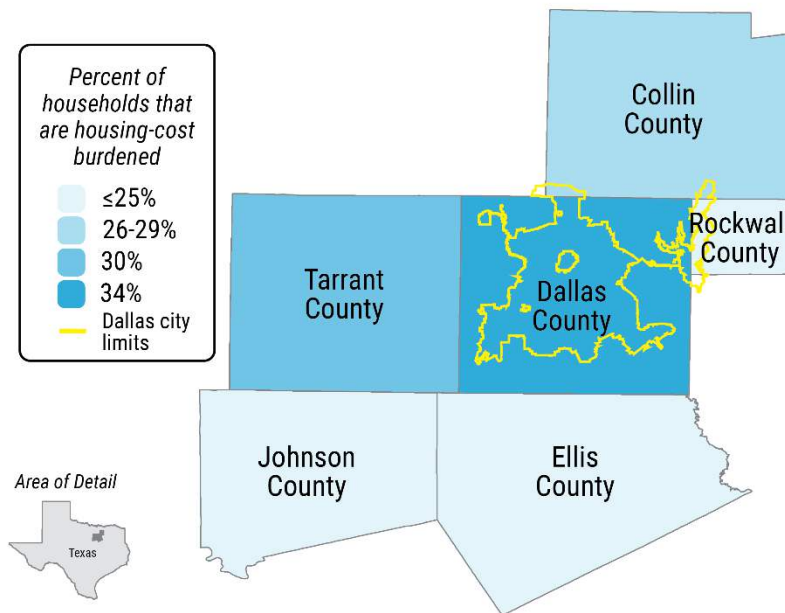
As suggested by its high SVI score, Dallas County reports the highest percentage of the population below 200 percent of the Federal Poverty Line (FPL) in the MTA, at 41 percent (Table 17 - economic security). Dallas County also has the highest percentage of Black women over age 45 who live below the FPL, at 19 percent and the highest percentage of the population that is uninsured at 21 percent. Collin County reports the greatest economic security by these metrics with the lowest rates in all three categories: 9 percent uninsured, 18 percent under 200 percent FPL, and 7 percent Black women over age 45 below FPL.

TABLE 17. DALLAS–FORT WORTH 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
Collin	9%	18%	7%
Dallas	21%	41%	19%
Ellis	15%	27%	9%
Johnson	16%	31%	18%
Rockwall	9%	18%	10%
Tarrant	16%	32%	17%

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

MAP 8. DALLAS–FORT WORTH METRO AREA HOUSING-COST BURDEN



The measure illustrated in Map 8 (housing-cost burden) indicates the percentage of renters and homeowners that spend 30 percent or more of their total income on housing. Tarrant County also reports a relatively high percentage at 30 percent. Dallas County has the highest percentage of households that are housing-cost burdened in the MTA at 34 percent, followed by Tarrant County at 30 percent.

TABLE 18. DALLAS–FORT WORTH METRO AREA FOOD SECURITY

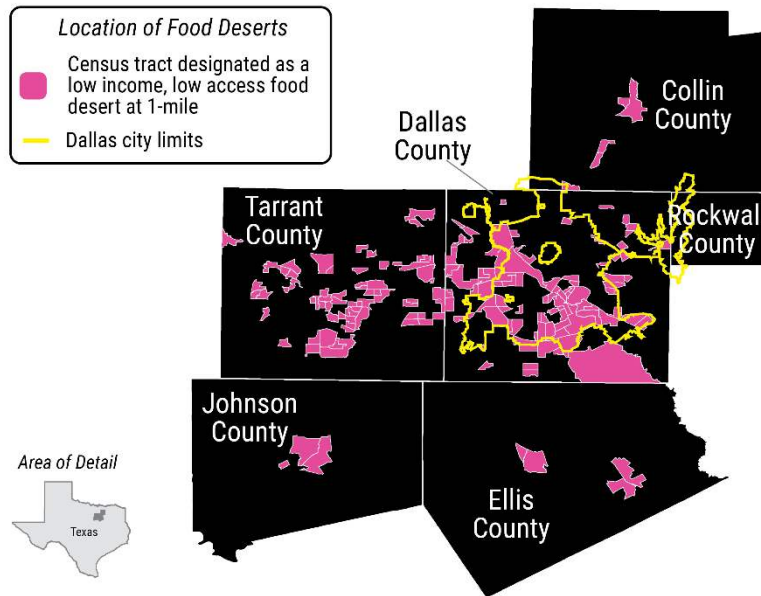
Source: 2016 Comprehensive Housing Affordability Strategy dataset (US Department of Housing and Urban Development)

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
Collin	15%	2%	9%
Dallas	18%	7%	24%
Ellis	14%	6%	20%
Johnson	15%	7%	19%
Rockwall	13%	4%	17%
Tarrant	17%	8%	22%

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

With regard to food security in the Dallas MTA, Dallas County has the highest percent of Black households receiving SNAP/EBT at 24 percent and the highest percentage of the population categorized as food insecure at 18 percent (Table 18 -- Food security). A reported 7 percent of the county’s total population has limited access to healthy foods. Rockwall County has the lowest overall rates of food insecurity 17 percent and the second-lowest percentage of the total population with limited access to food 4 percent. Collin County has the lowest rates in two of three metrics 2 percent of the population has limited access to healthy foods and 9 percent of Black households receiving SNAP/EBT) and the second-lowest rate of food insecurity – 15 percent.

MAP 9. FOOD DESERTS IN THE DALLAS–FORT WORTH METRO AREA



Map 9 illustrates the location of food deserts throughout the Dallas–Fort Worth MTA. Food deserts are census tracts designated by the USDA as low-income areas with low access to food within one mile. Almost all food deserts in the MTA are located in Dallas and Tarrant counties. Notably, there are no food deserts in Rockwall County.

TABLE 19. DALLAS–FORT WORTH METRO AREA TRANSPORTATION

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

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
Collin	3%	21%	1%	2%
Dallas	7%	17%	3%	3%
Ellis	3%	26%	0%	2%
Johnson	3%	24%	0%	2%
Rockwall	3%	33%	1%	2%
Tarrant	5%	17%	1%	2%

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

Dallas County, the most urban county in the MTA, has the highest percentage of households without a vehicle (7%), the highest percent of the population that commutes to work using public transportation (3%) or by foot/bike/other (3%), and the lowest percent of the total population that commutes more than 45 minutes to work (17% - tied with Tarrant County) (Table 19 - Transportation). In all counties, less than 5% of the population commute by public transit or foot/bike/other, and, with the exception of Dallas County, all counties report that 5 percent or less of households lack a vehicle.

TABLE 20. DALLAS–FORT WORTH 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
Collin	94%	51%	4%
Dallas	78%	30%	11%
Ellis	85%	22%	7%
Johnson	84%	19%	8%
Rockwall	92%	40%	9%
Tarrant	85%	31%	10%

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

Dallas County reports the lowest educational attainment rates in the MTA. Dallas County has the lowest percentage of the population over age 25 that has a high school degree or higher at 78 percent, and the highest percentage of Black women over the age of 25 without a high school degree (11%). Tarrant County's educational attainment is similarly low. Collin County reports the highest education rates across all three of these metrics: 94 percent with a high school degree or higher, 51 percent with a bachelor's degree or higher, and 4 percent of Black women over age 25 without a high school degree (Table 20 – Education).

TABLE 21. DALLAS–FORT WORTH METRO AREA GENTRIFICATION

County	Proportional Change in Population With a Bachelor's Degree or Higher	Percent Change in Median Household Income
Collin	2%	8%
Dallas	2%	9%
Ellis	1%	7%
Johnson	3%	6%
Rockwall	5%	13%
Tarrant	2%	10%

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

Gentrification is another measure connected to educational attainment. Table 21 measures gentrification rates across two metrics: the proportional change of the population with a bachelor's degree or higher and the proportional change in median household income. The percent change in median household income is greatest in Rockwall County, at 13 percent, and lowest in Johnson County - 6 percent. All counties in the MTA have a positive proportional change in the population with a bachelor's degree or higher, with Rockwall County having the highest proportional change at 5 percent. Rockwall appears to be gentrifying more than other places in the Dallas MTA.

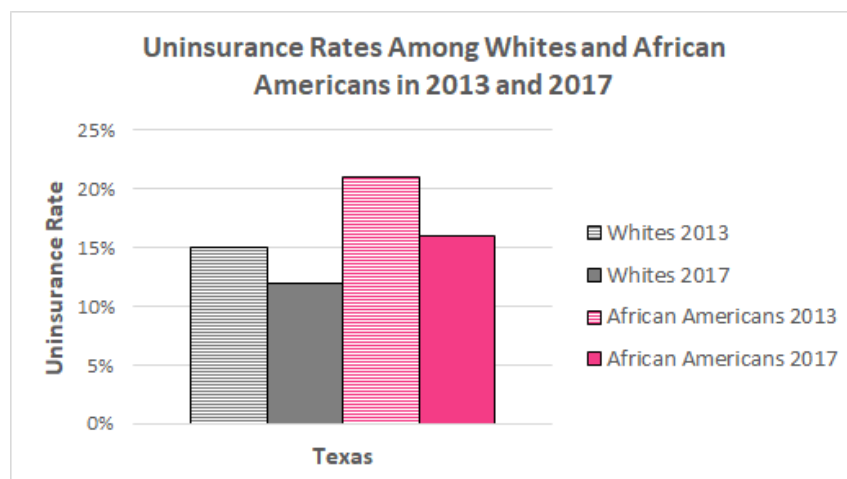
Policy Context

This section examines key policies relating to access to and coverage for breast cancer screening, diagnosis, and treatment.

Medicaid Expansion. Under the ACA, states have the option to expand their Medicaid program to individuals with incomes of up to 138% 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 US live in Texas and 92% of all adults in the coverage gap are located in the Southern US (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). 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).

See Figure 3 for trends of uninsured rates for the nonelderly in Texas (2013-2017) comparing rates among Black and White residents. There is an overall downward trend of uninsured rates for both Blacks and Whites in Texas, but an inequity in uninsured rates remains between the groups.

FIGURE 3. TRENDS OF UNINSURED RATES FOR THE NONELDERLY



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 women's access to services (e.g., eligible regardless of screening location or provider) or can impede a woman's access to services (e.g., requirements that NBCCEDP fund screening costs).

In 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). See Table 23 for an overview of screening and treatment services.

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.** 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 Dallas—Fort Worth 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 Dallas and Tarrant counties, and Johnson and Ellis counties. Racial differences in screening mammography screening reported in Texas show that Black women are screened for the disease at a higher rate than White women. Moreover, the disparities in late-stage diagnosis and mortality are clear, where Dallas and Tarrant counties have the highest concentrations of late-stage diagnoses, with the majority among Black women in Dallas County and White women in Tarrant.

Findings show that overall, community members were aware of the screening guidelines from the American Cancer Society indicating that mammograms begin at 40. However, there was a sentiment that the guidelines need to be different for Black women due to early-age onset of disease and a perception that Black women are more likely to get aggressive cancers including triple negative breast cancers.

Quality of Care

Most of the breast cancer resources are in Dallas County (see Table 16 - Breast Cancer Resources). The county has five mobile screening mammography centers, one cancer coalition, and 44 survivor support groups, the latter of which is significantly higher than any other place in the Dallas MTA. Johnson and Ellis counties do not have any mobile screening mammography centers, cancer coalitions, or survivor/support groups.

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).

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. 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 ages 25-39 (Committee on Practice Bulletins - Gynecology et al., 2017).

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 Dallas—Fort Worth MTA could largely be explained by three factors: 1) elevated rate of late-stage diagnoses, 2) economic vulnerability stemming in large part from practices of structural racism, such as redlining, and 3) lower quality of healthcare in part due to personally-mediated and structural 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 Dallas County also has the highest percentage of Black women over age 45 who live below the FPL, at 19 percent and the highest percentage of the population that is uninsured at 21 percent.

Focus group participants elevated transportation as a significant barrier to accessing screening mammography in the Dallas—Fort Worth MTA. High quality care may require an hour drive, yet public transportation is not as robust as other densely populated metropolitan areas. Additionally, the need for imaging centers that are in predominately Black communities and that will accept those without insurance was an identified need.

Patient navigators noted the importance of navigation in the diagnosis phase of the breast cancer continuum and the significant time investment in guiding patients and preventing “no-shows”. A medical provider specifically mentioned a need for more resources to support diagnostic mammograms. Patient navigators described the cost of diagnostic procedures as a significant barrier to timely diagnosis, even when the safety net hospital offers financial assistance program for women who are uninsured. 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). Furthermore, 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).

Some of the economic vulnerabilities in the Dallas—Fort Worth MTA can be explained by practices of personally-mediated and structural racism. The data show that Dallas MTA is segregated along racial and socioeconomic lines, creating stark contrasts by geography. Approximately 2 million people of color live in the Dallas MTA, comprising 33 percent of the region’s total population (see “Minority Race” in Table 3). A majority of the approximately 1.3 million Blacks who live in the Dallas MTA reside in Dallas County and Tarrant County (see Tables 3 and 4). Many of the counties in the Dallas MTA are also internally racially segregated. The data suggest that in addition to institutionalized racism, Blacks in the Dallas—Fort Worth MTA experience several forms of personally mediated racism (U.S. Department of Housing and Urban Development, 2019; U.S. Department of Justice Federal Bureau of Investigation, 2017). As seen in Table 10-racism, Dallas and Tarrant counties report higher levels of racism than other counties in the MTA.

Dallas County has the highest percentage of households that are housing-cost burden in the MTA at 34 percent, followed by Tarrant County at 30 percent. With regard to food security in the Dallas MTA, Dallas County has the highest percent of Black households receiving SNAP/EBT at 24 percent and the highest percentage of the population categorized as food insecure at 18 percent (Table 18 -- Food security). Additionally, almost all food deserts in the MTA are located in Dallas and Tarrant counties. Notably, there are no food deserts in Rockwall County. Dallas County, the most urban county in the MTA, and also has the highest percentage of households without a vehicle (7%), the highest percent of the population that commutes to work using public transportation (3%) or by foot/bike/other (3%), and the lowest percent of the total population that commutes more than 45 minutes to work (17% - tied with Tarrant County) (Table 19 - Transportation). Dallas County reports the lowest educational attainment rates in the MTA. Dallas County has the lowest percentage of the population over age 25 that has a high school degree or higher at 78 percent, and the highest percentage of Black women over the age of 25 without a high school degree (11%).

Breast cancer inequities across the care continuum in the Dallas—Fort Worth MTA persist due to economic vulnerability, lack of insurance, and personally mediated racism. Taken together, these factors severely contribute to late-stage diagnoses and affect the care experiences of Black women across the cancer care continuum. Particular aspects of the breast cancer continuum that warrant further investigation and intervention include root causes of late-stage diagnoses, development of the patient navigation workforce, and Medicaid expansion.

This study confirms the existence of many well-understood barriers across the care continuum facing Black women. Many of these factors have existing dedicated resources supporting the mitigation of these barriers. However, this study also highlights barriers at the local level, specifically within the breast cancer care context. It also describes novel barriers and adds nuance to existing barriers across the care continuum that warrant further research, intervention, and new policies that Komen Stand for H.E.R. can support.

Recommendations

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

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

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

Micro-Level Strategies

Develop a Diverse and Culturally Responsive Patient Navigation Workforce.

Komen and partners could 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. Furthermore, the field needs diverse and culturally responsive navigators who have expertise and knowledge of the Black community.

Patient navigation service providers can help Black 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 healthcare 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).

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

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

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

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

Various studies assessed the reasons why people of diverse ancestry take advantage of genetic testing in such small numbers. For example, a study conducted by Glenn *et al.* from 2004 to 2006 revealed that among Black, Asian, and Latina women, a leading reason why these women did not undergo a *BRCA* gene test was lack of awareness of the availability of this service (Glenn *et al.*, 2012). In addition, health care providers may not obtain family history information from non-White women at the same rates as White women (Murff *et al.* 2005). Lower rates of discussing family history of breast cancer with Black women may further translate into reduced rates of referring these women to genetic counseling.). 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 Black women over the age of 40 is 79.4 percent, compared to 72 percent of white women in the same age range. While Black women are getting

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

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

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

Mezzo-Level Strategies

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

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

Support Quality Improvement (QI) initiatives along the breast cancer continuum of care.

Quality improvement (QI) initiatives employ qualitative and quantitative methods to enhance the effectiveness of interventions, programs, and policies. Institutionalizing a commitment to quality improvement supports continuous learning and refinement in ways that ensure limited resources are used optimally and service delivery objectives (e.g., quality care) are achieved. The breast cancer community can support QI initiatives in the major health systems in the MTA, especially in cities that have large Black populations.

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

Increase awareness of free screening to promote early-stage diagnosis.

The breast cancer community can leverage local partnerships to implement a health promotions campaign intended to increase awareness of free screening. Health care facilities and breast cancer resources are concentrated in Dallas County. However, given the challenge of Black women more often receiving late-stage diagnoses, Komen Stand for H.E.R. may want to support a health promotion campaign that is intended to ensure Black women know that free screening mammograms are available, and to encourage further assessment of suspicious findings through diagnostic exams. This campaign should be rigorously evaluated, and if done effectively should demonstrate addressing the root causes of late-stage diagnosis among undiagnosed Black women. Furthermore, we recommend that Stand for H.E.R. encourage major treatment centers in the aforementioned counties provide a clinical visit for free so that women can access mammograms, as our findings indicate that sometimes having even a small copay can create a barrier to getting screened.

Partner with community organizations, place-based efforts, and philanthropy organizations to address systemic barriers to equity.

The breast cancer community can partner with other community organizations, place-based efforts, and philanthropic organizations focused on racial equity. Research shows that the impacts of institutionalized racism and discrimination compound over time, reinforcing inequities that manifest in the form of disparities in SDOH. This pattern is readily evident in the Dallas—Fort Worth MTA. Personally mediated racism warrants urgent attention in order to mitigate and ideally end racism at the institutional levels. As Komen’s Stand for H.E.R. pursues its goal of advancing racial breast health equity, it may consider aligning efforts with community organizations and philanthropy in Dallas—Fort Worth that are committed to promoting racial equity. For example, by supporting multi-sector, place-based partnerships focused on equity that seek to ensure accountability of the many mutually reinforcing systems (e.g., housing, education, employment, earnings, credit, and criminal justice) that perpetuate the legacy of racism. Or, by supporting efforts to build power and efficacy in historically disempowered communities through community organizing, and by supporting the creation of diverse leadership pipelines in key sectors. Or, by helping to integrate research on institutionalized racism into the medical and scientific community discourse in order to draw attention to the context and systems in which health care is practiced and systemic change is needed.

Create support groups led by community health workers for social support and connection. 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. 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. Stand for H.E.R. may want to support avenues for community connection in order to foster social connectedness as well as increase awareness and understanding of breast cancer screening and treatment options.

Macro-Level Strategies

Conduct a root cause analysis of risk factors for late-stage diagnoses in Dallas—Fort Worth.

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

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

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

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

As an example, breast cancer risk is one area that warrants further investigation, particularly with regard to differences in risk factors by race/ethnicity, that could inform more personalized strategies for breast cancer screening and treatment. In March 2018, the American College of Radiology (ACR) and the Society of Breast Imaging (SBI) recommended that all women, especially Black women (and those of Ashkenazi Jewish descent), have a breast cancer risk assessment no later than age 30 so those at higher risk can be identified and their screenings and breast health care be appropriately modified. The societies also made recommendations for modifications to the screening approach for women with specific risk factors and/or at higher risk of developing breast cancer; modifications included changes to the age at which screening should start, as well as the frequency and modality (mammography, ultrasound, MRI, etc.) of screening.

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

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

The breast cancer community can have a high impact on the current debate on Medicaid expansion. One of Komen’s broader 2019-2020 policy strategies is to ensure continued access to Medicaid coverage without burdensome restrictions.

An eligibility expansion would ensure that more women receive timely screening and breast cancer care services. Stand for H.E.R. should continue to build on advocacy relationships in the state and examine partnerships to advocate for 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 Dallas—Fort Worth MTA. 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 Dallas and Tarrant counties. 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).

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

Appendix A. Map Measures

TABLE 25. DALLAS–FORT WORTH METRO AREA TABLE MAPS

	Map 3: Percent of Population that is Black	Map 7: Social Vulnerability Index Score	Map 8: Percent of Households that are Housing-Cost Burdened	Map 4: Residential Segregation Score
Collin	9%	0.14	26%	27
Dallas	22%	0.77	34%	49
Ellis	9%	0.46	25%	40
Johnson	3%	0.56	23%	42
Rockwall	6%	0.12	25%	30
Tarrant	16%	0.54	30%	48

Sources: American Community Survey 2013-2017 5-Year Estimates (US Census Bureau); 2016 Social Vulnerability Index (US Centers for Disease Control and Prevention); 2016 Comprehensive Housing Affordability Strategy dataset (US Department of Housing and Urban Development); 2019 County Health Rankings (County Health Rankings)

Appendix B. Abbreviations & Glossary

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

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

Black/White dissimilarity index: A measure of residential segregation that illustrates the evenness with which two mutually exclusive groups (in this case, Blacks and Whites) are distributed across the geographic units (in this case, census tracts) that make up a larger geographic entity (in this case, counties). Calculated by County Health Rankings (CHR) using the Index of Dissimilarity formula and data from American Community Survey (ACS) 5-year. Scores range from 0-100 and scores closer to 100 indicate greater segregation. CHR only calculates this measure for counties with at least 100 Black residents (County Health Rankings, 2020e).

Breast cancer stage: An approach to classify and describe cancer’s spread or growth in the body. There are various approaches to staging. Health care providers commonly use “TNM” to assess the stage, which stands for:

- Tumor: size and location of tumor,
- Node: whether the tumor has spread to the lymph nodes, and
- Metastasis: whether the cancer has spread to other parts of the body and to what extent.

Clinical breast examination: A physical exam that a provider performs to check the breasts and underarms for any concerns (e.g., lumps).

Collective impact: A cross-sector approach to solving complex issues on a large scale that offers a different way of working wherein whole systems – health departments, government, businesses, CBOs and participants with lived experiences make a unified effort to collectively address the issue from multiple angles (Kania & Kramer, 2011).

Confidence Interval (CI): Statisticians use a confidence interval to express the degree of uncertainty associated with a sample statistic (e.g., mean, median or other measure). It is usually presented with a probability statement.

Continuum of Care: The clinical continuum of care for breast cancer includes all aspects of screening, detection, diagnosis, treatment, and follow-up.

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

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

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

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

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

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

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

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

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

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

(numerator) divided by the total number of households (denominator) (Office of Policy Development and Research (PD&R), 2019).

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Appendix C. Focus Group Guides

Stand for H.E.R.: 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?

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

3. How has discrimination or racism affected your health?

PROBES TO USE AS NECESSARY:

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

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

4. Before being diagnosed with breast cancer, had you received clinical breast exams? Screening 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?*
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 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*
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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 healthcare system?*
- d. *Have you received access to a full team of providers (i.e. including a PCP, radiation oncologist, medical oncologist, surgeon/surgical oncologist, plastic surgeon (reconstruction), dietitian, social worker, receptionist/scheduler/front desk staff, chaplain/other religious contact, new patient coordinator, Program RN, patient navigator)?*
 1. *Which members of your cancer team did you feel most comfortable seeing?*
 2. *What is it about that provider that makes you feel comfortable?*
 3. *Did you have any uncomfortable experiences? What made you uncomfortable?*
 4. *Which members do you wish you could have had greater interaction with and why?*

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

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

Survivorship

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

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

PROBES TO USE AS NECESSARY

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

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

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

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

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

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

PROBES TO USE AS NECESSARY

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

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

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

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

1. *If used, how were the services beneficial?*

2. *If they were not beneficial, why not?*

c. *Were there times when you felt challenged or unable to access the support, information, or resources you felt you needed? Why?*

1. *Would it be useful to have learned about these resources sooner than you did?*
2. *At what point would the services have been more useful?*
3. *Was there a cost/fee to access any of the resources/information?*

14. **What else might be helpful to you or other Black women cancer survivors and their families?**

Step 8: Thank you for your participation.

Black 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?**[Text Wrapping Break]

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

3. How has discrimination or racism affected your health?**PROBES TO USE AS NECESSARY:**

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

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

4. Before being diagnosed with breast cancer, had you received clinical breast exams? Screening 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?*
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 - 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*
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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 healthcare system?*
- d. *Have you received access to a full team of providers (i.e. including a PCP, radiation oncologist, medical oncologist, surgeon/surgical oncologist, plastic surgeon (reconstruction), dietitian, social worker, receptionist/scheduler/front desk staff, chaplain/other religious contact, new patient coordinator, Program RN, patient navigator)?*
 1. *Which members of your cancer team did you feel most comfortable seeing?*
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 4. *Which members do you wish you could have had greater interaction with and why?*
 5. *Did you feel you had enough time to ask questions and/or absorb information?*
- e. *Were there times when you felt challenged or unable to access the medical care you felt you needed? Why?*

Survivorship

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

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

PROBES TO USE AS NECESSARY

- a. *How has your care been coordinated between your oncology team and your primary care provider? Did you receive a survivorship care plan? Was this helpful?*
- b. *Have you had adequate support to address your emotional/social, health, and economic needs as a cancer survivor?*
- c. *What support has your family needed? When? At diagnosis? After treatment?*
- d. *Have you made any lifestyle changes as a result of your experience as a cancer survivor?*
- e. *Have you sought additional support from fellow survivors (i.e., support groups)?*

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

PROBES TO USE AS NECESSARY

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

Step 8: Thank you for your participation.

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