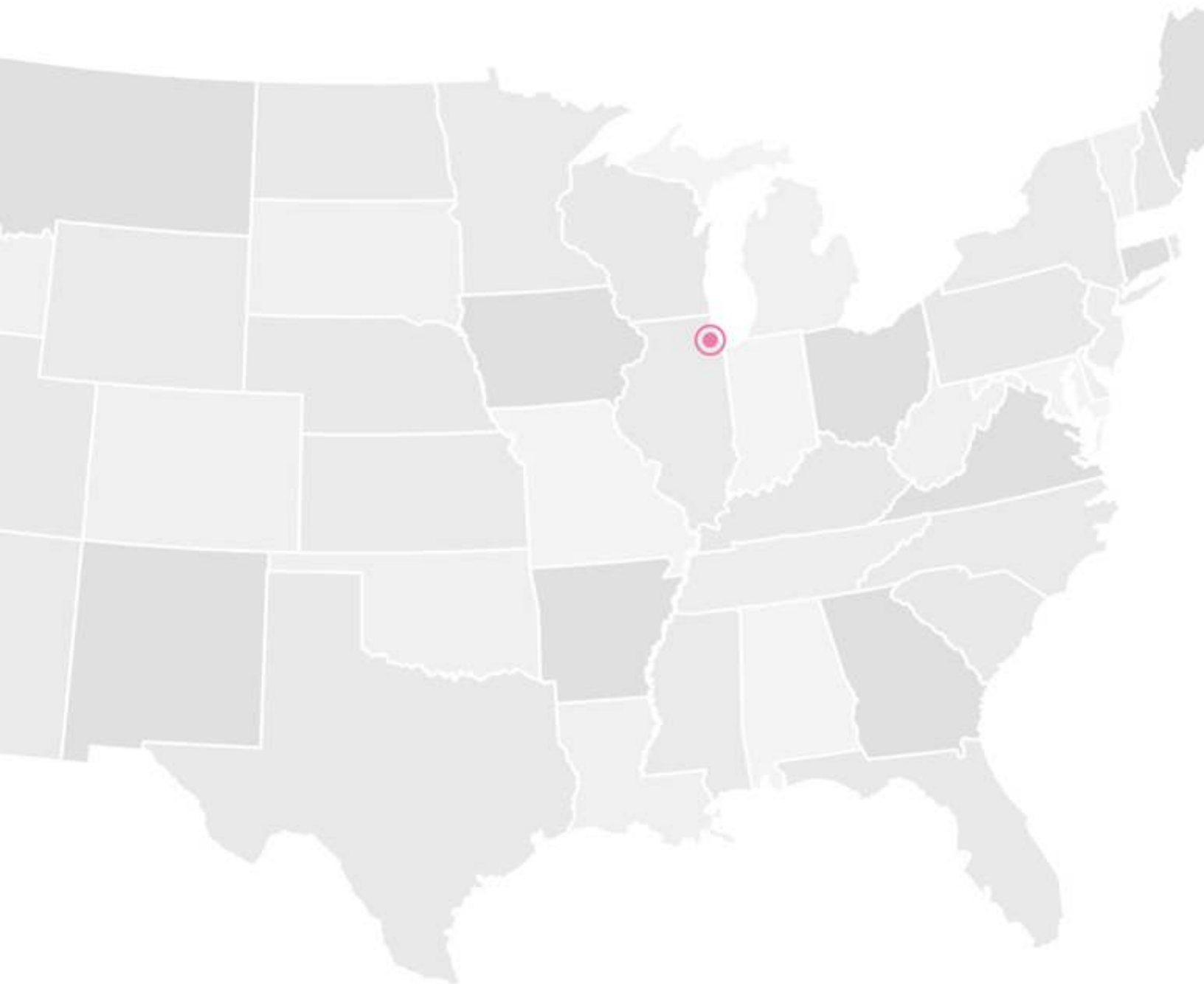


Closing the Breast Cancer Gap:
A Roadmap to Save the Lives
of Black Women in America

2021

CHICAGO



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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 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. has declined by 41% from 1989 through 2018 (American Cancer Society, 2019a). However, these trends vary by race and ethnicity.

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

About This Report

In 2015, in partnership with Fund II Foundation, Komen launched the African American Health Equity Initiative (AAHEI), now known as Stand for H.E.R., 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, DC.

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

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

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

Rather, the analysis aims to:

- 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

- Across the different counties in the Chicago MTA, Black women are consistently more likely to die from the disease compared to white women in every county.
- All nine of the counties in the Chicago MTA have late-stage incidence rates that are above the national average.
- The highest late-stage incidence rate is among Black women in Cook County.
- Both Indiana and Illinois are states in which the incidence of breast cancer among Black women has exceeded the incidence among white women.
- Incidence rates in the MTA are higher for Black women as compared to white women in four of the eight counties where racially disaggregated data are available, namely, Porter, Cook and Kane counties in Illinois, and Lake County in Indiana.
- The rates of screening mammography are lower in Indiana than Illinois, which has rates similar to national rates.
- Counties in the Chicago MTA tend to have similar rates to that of their respective state rates.
- Cook County has the lowest overall rate of screening mammography of the Illinois counties, while Lake County, IN, followed by Porter County, IN, have the lowest screening mammography rates across the Chicago MTA.
- Cook County, IL Lake County, IN and Porter County, IN also have the highest breast cancer mortality rates; although Dupage County, IL, has the highest breast cancer mortality rate for Black women.
- Cook County, IL, Dupage County, IL, and Lake County, IN, stand out with breast cancer mortality rates among Black women that are notably greater than that of white women.
- Decades of discriminatory practices have led to striking segregation in the Chicago MTA.
- The Chicago MTA is segregated across a number of dimensions, including race and socioeconomic factors, creating stark contrasts by geography.
- In addition to the MTA as a whole being racially segregated (with most people of color living predominantly in a few of the counties), many of the counties in the MTA are also internally racially segregated. The data illuminate the resulting inequities across a number of metrics.
- The counties with the largest Black populations, Cook County, IL, and Lake County, IN, have the greatest percent of population below 200 percent of the federal poverty line (FPL) and the highest premature age-adjusted mortality for Black men and women.
- There is food insecurity across all of the counties.

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

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

Micro-level Strategies

- Increase access to culturally responsive patient navigators and Community Health Workers (CHWs).
- To implement a culturally relevant health promotion campaign intended to increase knowledge of current screening guidelines.
- Continue to grow culturally relevant health promotion campaigns intended to increase awareness of breast cancer inequities among Black women.
- Increase education about family health history in the community to identify high-risk families and offer genetic counseling and testing and breast cancer screening to meet the need.
- Expand financial assistance programs to support breast cancer care.
- Strengthen and expand survivorship programs.

Mezzo-level Strategies

- Support implicit bias trainings for providers, administrators and health care staff.
- Increase access to integrated care to improve the breast cancer care experience.
- Support Quality Improvement (QI) initiatives along the breast cancer continuum of care.
- Encourage health institutions (health care systems and payers) to offer services in high-need areas.
- Fund collaborative initiatives at the community level to address social determinants of health.

Macro-level Strategies

- Support efforts to develop guidelines and policies that address disproportionate breast cancer mortality among Black women, including increased genetic counseling and testing services.
- Advance clinical trials and tailored treatment focused on Black women.
- Support a root-cause analysis to uncover the drivers of late-stage diagnosis rates.
- Conduct an analysis of state policies to identify those that present barriers to high-quality care in the Black community.

This landscape analysis report conveys comprehensive issues facing the Black community 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 U.S. and is the second leading cause of death among women after lung cancer. Women in the U.S. have a one in eight chance of developing breast cancer over the course of their lifetimes. With the increasing availability of screening mammography screening, earlier detection, and improvements in breast cancer treatment, the overall breast cancer mortality rate among women in the U.S. declined by 41 percent over the last 30 years (American Cancer Society, 2021).

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

Black women are, on average, 40 percent more likely to die of the disease as compared to white women (Howlader et al., 2018). The five-year breast cancer survival rate for Black women is 83 percent as compared to 92 percent for white women (Howlader et al., 2020).

However, while overall breast cancer incidence among Black women is lower than among white women, the incidence rates are higher among Black women under age 40 (where incidence is the number of new cases that develop in a specific time period) (American Cancer Society, 2020). Black women are also more likely than white women to be diagnosed with aggressive breast cancers, such as Triple-Negative Breast Cancer (TNBC) and inflammatory breast cancer and are more likely to be diagnosed at a later stage, when treatments are limited, costly, and the prognosis is poor (American Cancer Society, 2019; Williams et al., 2016).

Through the Stand for H.E.R. Initiative, 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, DC.

As part of the Stand for H.E.R., Komen engaged JSI, a public health research and consulting organization, to conduct a landscape analysis in each MTA to better understand the underlying causes of breast cancer inequities across the care continuum among Black women. Findings from each landscape analysis report serve to inform the design and implementation of Komen’s long-term and cross-sector collaborative efforts as well as serve as a call to action for all community-based organizations, policymakers, hospitals, healthcare providers, faith-based organizations, civic leaders and citizens to engage in evidence-informed strategies to reduce breast cancer disparities among Black women.

Project Objectives

The specific objectives of the landscape analysis are:

- To understand breast cancer disease burden in each MTA by describing breast cancer measures (incidence, *in situ* incidence, late-stage diagnosis and mortality) and other key health metrics (such as life expectancy and age-adjusted mortality), comparing Black to white women, per data availability.¹
- To describe systemic barriers, including adverse SDOH, and other socioeconomic and contextual factors that may contribute to breast cancer inequities, comparing counties within each MTA.
- To explore community members’ perspectives regarding their experiences with breast cancer screening and treatment, and their perceptions regarding barriers/facilitators to obtaining care, factors contributing to breast cancer inequities, and suggestions for advancing breast health equity.
- To explore health care provider perspectives regarding individual, community, and health systems factors contributing to breast cancer inequity, along with their recommendations for system-level change.
- To identify 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 Chicago 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 “in place,” and in the context of breast cancer refers to a condition where abnormal cells are found in the milk ducts or lobules of the breast, but not in the surrounding breast tissue. late-stage diagnosis indicates that breast cancer has spread beyond the breast to lymph nodes, surrounding tissue or other organs in the body (most often the bones, lungs, liver or brain).

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

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

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

Methods

The methods include a literature scan, compiling quantitative data, reviewing federal and state policies, and collecting qualitative data from community members and healthcare providers to prepare this landscape analysis report. This study defines the Chicago MTA in accordance with the U.S. Office of Management and Budget's 2015 definition of central counties in the Chicago-Naperville-Elgin metropolitan statistical area (MSA). This area encompasses the city of Chicago and comprises Cook, Dupage, Kane, Kendall, Lake, McHenry and Will counties in Illinois, and Lake and Porter counties in Indiana (Office of Management and Budget, 2010; U.S. Census Bureau). Data are generally unavailable at the MSA-level of geographic specificity, so researchers collected and analyzed data at the county level (a sub-MSA unit) for most indicators. State- and national-level data (both super-MSA units of measure) were collected for measures related to breast cancer disease burden to provide additional points of comparison.

TABLE 1. CHICAGO METRO AREA DATA METHODS AND SOURCES

Demographics		
Subcategory	Indicator	Source
Population	Total Population	American Community Survey 2013-2017 5-Year Estimates (U.S. Census Bureau)
Sex	Percent of Population that is Male	American Community Survey 2013-2017 5-Year Estimates (U.S. Census Bureau)
Sex	Percent of Population that is Female	American Community Survey 2013-2017 5-Year Estimates (U.S. Census Bureau)
Age	Percent of Population that is Under Age 18	American Community Survey 2013-2017 5-Year Estimates (U.S. Census Bureau)
Age	Percent of Population that is Age 18-64	American Community Survey 2013-2017 5-Year Estimates (U.S. Census Bureau)
Age	Percent of Population that is Over Age 65	American Community Survey 2013-2017 5-Year Estimates (U.S. Census Bureau)
Race	Percent of Population that is White	American Community Survey 2013-2017 5-Year Estimates (U.S. Census Bureau)
Race	Percent of Population that is Black	American Community Survey 2013-2017 5-Year Estimates (U.S. Census Bureau)
Race	Percent of Population that is Asian	American Community Survey 2013-2017 5-Year Estimates (U.S. Census Bureau)
Race	Percent of Population that is American Indian or Alaska Native	American Community Survey 2013-2017 5-Year Estimates (U.S. Census Bureau)
Race	Percent of Population that is Native Hawaiian or Other Pacific Islander	American Community Survey 2013-2017 5-Year Estimates (U.S. Census Bureau)
Race	Percent of Population that is Some Other Race	American Community Survey 2013-2017 5-Year Estimates (U.S. Census Bureau)
Race	Percent of Population that is Two or more Races	American Community Survey 2013-2017 5-Year Estimates (U.S. Census Bureau)

Race	Percent of Population that is Hispanic/Latino	American Community Survey 2013-2017 5-Year Estimates (U.S. Census Bureau)
Race	Percent of Population that is White not Hispanic	American Community Survey 2013-2017 5-Year Estimates (U.S. Census Bureau)
Race	Percent of Population that is Minority Race	American Community Survey 2013-2017 5-Year Estimates (U.S. Census Bureau)
Target Population	Number of Black Women over age 45	American Community Survey 2013-2017 5-Year Estimates (U.S. Census Bureau)

Social Determinants of Health

Subcategory	Indicator	Source
Social Vulnerability	Social Vulnerability Index Score	2016 Social Vulnerability Index (U.S. Centers for Disease Control and Prevention)
Economic Security	Percent of Population that is Uninsured	American Community Survey 2013-2017 5-Year Estimates (U.S. Census Bureau)
Economic Security	Percent of Population Below 200% FPL	American Community Survey 2013-2017 5-Year Estimates (U.S. Census Bureau)
Economic Security	Percent of Black Women over age 45 who live Below Poverty Level	American Community Survey 2013-2017 5-Year Estimates (U.S. Census Bureau)
Food Security	Location of Food Deserts	2019 Food Access Research Atlas (U.S. 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 (U.S. Census Bureau)
Education	Percent of Population over age 25 that has High School Degree or Higher	American Community Survey 2013-2017 5-Year Estimates (U.S. Census Bureau)
Education	Percent of Population over age 25 that has Bachelor's Degree or Higher	American Community Survey 2013-2017 5-Year Estimates (U.S. Census Bureau)
Education	Percent of Black Women over age 25 without a High School Degree	American Community Survey 2013-2017 5-Year Estimates (U.S. Census Bureau)
Transportation	Percent of Households without a Vehicle	American Community Survey 2013-2017 5-Year Estimates (U.S. Census Bureau)
Transportation	Percent of Total Population Commuting more than 45 Minutes to Work	American Community Survey 2013-2017 5-Year Estimates (U.S. Census Bureau)
Transportation	Percent of Total Population that Commutes to Work using Public Transportation	American Community Survey 2013-2017 5-Year Estimates (U.S. Census Bureau)
Transportation	Percent of Population Commuting to Work by Foot/Bike/Other	American Community Survey 2013-2017 5-Year Estimates (U.S. Census Bureau)

Housing Stability	Percent of Households that are Housing-Cost Burdened	2016 Comprehensive Housing Affordability Strategy dataset (U.S. 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 (U.S. Census Bureau); American Community Survey 2008-2012 5-Year Estimates (U.S. Census Bureau)
Housing Stability	Percent Change in Median Household Income	American Community Survey 2013-2017 5-Year Estimates (U.S. Census Bureau); American Community Survey 2008-2012 5-Year Estimates (U.S. 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 (U.S. Department of Housing and Urban Development, Office of Fair Housing and Equal Opportunity)
Racism	Number of Black residents 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 (U.S. 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 (U.S. Department of Health and Human Services, Health Resources & Services Administration)
Primary Care	Location of FQHCs	HRSA Data Warehouse (U.S. Department of Health and Human Services, Health Resources & Services Administration)
Primary Care	Location of Hospitals	HRSA Data Warehouse (U.S. 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 (U.S. Centers for Disease Control and Prevention; National Institutes of Health)
Incidence	Age-Adjusted Incidence Rate	2012-2016 State Cancer Profiles (U.S. Centers for Disease Control and Prevention; National Institutes of Health)
Incidence	5-year Incidence Rate Trend Direction	2012-2016 State Cancer Profiles (U.S. Centers for Disease Control and Prevention; National Institutes of Health)
Incidence	Age-Adjusted Incidence Rate for White Women	2012-2016 State Cancer Profiles (U.S. 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 (U.S. Centers for Disease Control and Prevention; National Institutes of Health)
Incidence	Age-Adjusted Incidence Rate for Black Women	2012-2016 State Cancer Profiles (U.S. 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 (U.S. Centers for Disease Control and Prevention; National Institutes of Health)
In Situ Incidence	Age-Adjusted In Situ Incidence Rate	2012-2016 State Cancer Profiles (U.S. 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 (U.S. 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 (U.S. 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 (U.S. 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 (U.S. 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 (U.S. Centers for Disease Control and Prevention; National Institutes of Health)
Late-Stage Incidence	Age-Adjusted Late-Stage Incidence Rate	2012-2016 State Cancer Profiles (U.S. 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 (U.S. 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 (U.S. 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 (U.S. 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 (U.S. 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 (U.S. Centers for Disease Control and Prevention; National Institutes of Health)
Mortality	Age-Adjusted Mortality Rate	2012-2016 State Cancer Profiles (U.S. Centers for Disease Control and Prevention; National Institutes of Health)
Mortality	5-year Mortality Rate Trend Direction	2012-2016 State Cancer Profiles (U.S. Centers for Disease Control and Prevention; National Institutes of Health)
Mortality	Age-Adjusted Mortality Rate for White Women	2012-2016 State Cancer Profiles (U.S. 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 (U.S. Centers for Disease Control and Prevention; National Institutes of Health)
Mortality	Age-Adjusted Mortality Rate for Black Women	2012-2016 State Cancer Profiles (U.S. 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 (U.S. 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 (U.S. Centers for Disease Control and Prevention; State Cancer Profiles; National Institutes of Health)

Qualitative Data

In the Chicago MTA, a total of eight focus groups were conducted with 73 participating community members. An additional focus group was conducted with six community health workers (CHWs) and/or patient navigators who serve Cook County and Will County, IL. In addition, two provider interviews were conducted along with an individual patient navigator interview.

Table 2 summarizes the demographic characteristics of 73 community member focus group participants, representing both breast cancer survivors and undiagnosed. Among breast cancer survivors, the plurality were above 55 years of age with Medicare, followed by private insurance or Medicaid, and many had been diagnosed with stage 1 or stage 2 breast cancer (both 38.9%). Undiagnosed women included younger women, with 9.8 percent younger than age 45. The largest proportion was covered by Medicaid, with many insured under Medicaid and also reporting access to private insurance. Non-provider participants were Black. Demographics were not collected for CHWs, patient navigators or clinical providers.

TABLE 2. CHICAGO METRO AREA QUALITATIVE DATA COLLECTION

Variable Name	Breast Cancer Survivors (n=20)	Undiagnosed Women (n=53)
Age		
18-24 years	0.0%	1.9%
25- 34 years	0.0%	4.0%
35-44 years	0.0%	7.5%
45-54 years	25.0%	15.1%
55-64 years	30.0%	26.4%
65-74 years	40.0%	32.1%
75 and above	5.0%	13.2%
Zip Codes		
	Breast Cancer Survivors (n=20)	Undiagnosed Women (n=53)
46307	N/A	1.9%
46404	N/A	9.4%
46406	N/A	1.9%
46409	N/A	1.9%
60403	N/A	3.8%
60421	N/A	1.9%
60432	N/A	5.7%
60433	N/A	7.5%
60435	N/A	5.7%
60436	N/A	3.8%
60556	N/A	1.9%
60617	N/A	1.9%
60620	N/A	1.9%
60628	N/A	1.9%
60629	N/A	1.9%
60653	N/A	3.8%
60657	N/A	1.9%
46402	5.0%	28.3%
46407	5.0%	9.4%
60649	5.0%	1.9%
60623	5.0%	1.9%
60707	5.0%	N/A
60616	5.0%	N/A
46320	5.0%	N/A
60645	5.0%	N/A
60429	10.0%	N/A

60637	5.0%	N/A
60616	5.0%	N/A
60487	5.0%	N/A
60473	5.0%	N/A
60472	5.0%	N/A
60432	5.0%	N/A
60433	10.0%	N/A
60673	5.0%	N/A
60645	5.0%	N/A

Insurance Status	Breast Cancer Survivors (n=20)	Undiagnosed Women (n=53)
I don't have health insurance	0.0%	2.0%
Medicaid	21.1%	47.1%
Medicare	47.4%	41.2%
Military Healthcare	0.0%	0.0%
Private Insurance	42.1%	39.2%
Through my parents	0.0%	0.0%
Not sure	5.3%	0.0%

Ever Been Screened for Breast Cancer	Breast Cancer Survivors (n=20)	Undiagnosed Women (n=53)
Yes	N/A	75.5%
No	N/A	20.8%
Unsure	N/A	3.8%

Type of Breast Cancer Screening or Assessment	Breast Cancer Survivors (n=20)	Undiagnosed Women (n=53)
Clinical breast exam	52.9%	35.0%
Mammogram	76.5%	89.6%
3D Mammogram	52.9%	29.2%
Breast self-exam	35.3%	22.9%
Other	11.8%	4.2%

Stage of Breast Cancer at Diagnosis	Breast Cancer Survivors (n=20)	Undiagnosed Women (n=53)
Stage 0	5.6%	N/A
Stage 1	38.9%	N/A
Stage 2	38.9%	N/A
Stage 3	11.1%	N/A
Stage 4	16.7%	N/A

Policy Data

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

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

Limitations

Findings presented in this report should be examined considering several limitations. The first is the issue of data availability and quality. Data were not easily available for all measures at the county level. For example, breast cancer prevalence data are not available at the county level, and racially disaggregated breast cancer incidence rates are not available for all counties. Due to the complexity in calculating breast cancer prevalence, obtaining raw data from state cancer registries to conduct analysis would have required entering into subcontracts with a fee, which was beyond the scope of this landscape analysis project. In some instances, populations might not have had enough annual breast cancer cases or breast cancer deaths to support the generation of reliable statistics, or data were suppressed to protect confidentiality. In other instances, a small number of cancer cases are reported to cancer registries with as much as a five-year delay. These data problems can create inconsistencies at smaller geographic levels, but they do not significantly alter data reported at the state level.

Second, there are limited publicly available data sources measuring the experience of racism and discrimination. Academics and practitioners were engaged who are (please see acknowledgements section) working at the intersection of racism and health and conducted searches to obtain publicly available data at the county level on factors that lie along the pathway from racism and oppression to adverse health outcomes, and, as such, could serve as proxies for the prevalence of institutional and structural racism. For example, incarceration and conviction rates, or experience of racism in the workplace. Data on these factors, however, are not available at a county level. Or, even if surveys to collect these data were developed by scholars, they were not mandatory, and data collection over the past few years in these areas has been scarce. Although several academics have conducted research on many of these factors, the study sites do not align with the Stand for H.E.R. MTAs. Moreover, data are the intellectual property of the scholars and, as such, are not available for public use. However, findings from these research efforts, whenever relevant, have been cited in the report. The three racism indicators that were available for the Chicago MTA are included in this report, and their sources are enumerated in Table 1 above. There are relevant research efforts underway (e.g., measurement of area-level racial hostility and racial bias on Twitter using machine learning) where open-source, cleaned datasets are likely to be available in the next few years. Komen may want to track these efforts once they become usable.

Third, qualitative data collection findings are not from a representative sample, but rather from priority areas selected with Komen input. This approach aligns with the goals of qualitative research, which is not to obtain a representative sample and make generalizable findings, but rather to gain an in-depth understanding of complex problems and people's lived experiences to ensure that program design accurately reflects the real needs of people.

Fourth, per the primary goals of this study, the research methods focused on understanding community member perspectives regarding the underlying systemic and SDOH that may be driving breast cancer inequities throughout the breast cancer continuum of cancer. The study sample, research areas of inquiry, and methodology do not lend themselves to arriving at concrete insights. The 5-step Collective Impact approach, Root Cause Analysis, and other community planning approaches are better suited to gaining actionable insights and strategies. Further, per study methods, this is not an epidemiological study, but rather a review of secondary data. As such, this study does not attempt to establish causality between underlying risk factors and breast cancer outcomes. The review of data raises some potential hypotheses that may be worthy of further research.

Section 1 Findings: Burden of Breast Cancer

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

Demographics

The Chicago metropolitan area is a nine-county region in the Midwest that is centered around Chicago, Illinois. The MTA spans two states (Illinois and Indiana) and is home to 9.2 million people. Its population is 65 percent white and 17 percent Black (see Table 3). The number of Black women over age 45 is noted for each county in the MTA because this Census-designated delineation best aligns with breast cancer metrics (e.g., percentage of women over age 40 who have received a screening mammogram in the last two years).

TABLE 3. CHICAGO METRO AREA DEMOGRAPHICS

Gender	
Male	49%
Female	51%
Age	
Under Age 18	24%
Age 18-64	63%
Over Age 65	13%
Race/Ethnicity	
White	65%
Black	17%
Asian	7%
American Indian or Alaska Native	0%
Native Hawaiian or Other Pacific Islander	0%
Some Other Race	8%
Two or More Races	3%
Hispanic/Latino	22%
White not Hispanic	52%
Minority Race	35%
Number of African-American Women Over Age 45	347,092
Total Population	9,179,033

Source: American Community Survey 2013-2017 5-Year Estimates (U.S. Census Bureau)

screening mammogram

TABLE 4. CHICAGO 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
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Cook County, IL	5,238,541	51%	24%	283,548
DuPage County, IL	931,826	51%	5%	7,679
Kane County, IL	529,402	50%	6%	4,857
Kendall County, IL	122,933	51%	7%	1,146
Lake County, IL	704,476	50%	7%	8,460
McHenry County, IL	308,043	50%	1%	599
Will County, IL	687,727	50%	11%	14,374
Lake County, IN	488,694	52%	24%	25,672
Porter County, IN	167,391	51%	4%	757

Source: American Community Survey 2013-2017 5-Year Estimates (U.S. Census Bureau)

More than 56 percent of all residents of the Chicago MTA (5.2 million people) live in Cook County, IL (see Table 4). The other 44 percent of the region's population is spread across eight other counties in the MTA: DuPage County, IL, Kane County, IL, Kendall County, IL, Lake County, IL, McHenry County, IL, Will County, IL, Lake County, IN, and Porter County, IN. Refer to Table 4 for demographic information specific to each county within the MTA. The number of Black women over age 45 is noted for each county in the MTA because this Census-designated delineation best aligns with breast cancer metrics (e.g., percentage of women over age 40 who have received a screening mammogram in the last two years).

Breast Cancer Disease Burden in the Chicago MTA

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

A helpful measure for breast cancer disease burden is prevalence, or the proportion of the population that has the disease at a given time. It is important to note that prevalence is measured in multiple ways depending on the time period of interest, and this report uses age-adjusted complete prevalence, which represents the proportion of people alive on a certain day who have been diagnosed with breast cancer, regardless of when the diagnosis was made (National Cancer Institute, 2020). Prevalence statistics are only available at the state level. In Illinois, where seven of the nine counties in the MTA are located, the age-adjusted complete prevalence percentage is 1.70. In Indiana, where two counties are located, the age-adjusted complete prevalence percentage is 1.62. The prevalence in both Illinois and Indiana is similar to 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 Kendall County, IL, McHenry County, IL, and Porter County, IN, as too few Black women live in these places to calculate the rates.

TABLE 5. CHICAGO METRO AREA BREAST CANCER INCIDENCE RATE (PER 100,000)

County	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
Cook County, IL	130.1	stable	129.5	stable	136.5	stable
DuPage County, IL	144.8	stable	150.1	stable	131.0	stable
Kane County, IL	123.8	stable	124.9	stable	130.1	stable
Kendall County, IL	137.8	stable	141.0	stable	92.0	*
Lake County, IL	141.3	stable	144.6	stable	125.1	stable
McHenry County, IL	137.2	stable	139.8	stable	*	stable
Will County, IL	135.8	stable	138.5	rising	124.3	stable
Lake County, IN	125.7	stable	122.4	stable	139.7	stable
Porter County, IN	124.3	stable	124.9	stable	166.6	stable
Illinois	131.9	stable	133.1	stable	133.5	stable
Indiana	121.9	stable	122.1	stable	127.5	stable
National	124.2	stable	126.1	stable	124.0	stable

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

Breast cancer age-adjusted incidence rates in the Chicago MTA range from 123.8 new cases per 100,000 individuals per year in Kane County, IL, to 144.8 in DuPage County, IL (See Table 5). Incidence rates in the MTA are higher for Black women as compared to white women in four of the eight counties that have data available by race. These counties are: Porter County, IL, which has the greatest disparity of

166.6 among Black women compared to 124.9 for white women; Cook County, IL; Lake County, IN; and Kane County, IL. Incidence rates are higher among white women as compared to Black women in Dupage County, IL, Kendall County, IL, Lake County, IL, and Will County, IL. Counties within the MTA tend to have incidence rates that are similar to or higher than the national incidence rate of 124.2. The age-adjusted Incidence rate throughout the state of Indiana of 121.9 is lower than the national rate, while the rate in Illinois of 131.9 is higher than the national rate. Both states have higher incidence rates among Black women (133.5 in IL, 127.5 in IN) than among white women (133.1 in IL, 122.1 in IN). Nationally, white women have a higher incidence rate of 126.1 than do Black women at 124.

TABLE 6. CHICAGO METRO AREA BREAST CANCER IN SITU INCIDENCE RATE (PER 100,000)

County	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
Cook County, IL	34.5	stable	34.3	stable	36.0	stable
DuPage County, IL	44.1	stable	44.1	stable	51.0	stable
Kane County, IL	30.2	stable	30.5	stable	33.6	stable
Kendall County, IL	42.8	stable	43.1	stable	*	*
Lake County, IL	41.2	falling	41.4	stable	33.8	stable
McHenry County, IL	29.9	stable	29.7	stable	*	*
Will County, IL	39.2	stable	37.8	stable	45.9	stable
Lake County, IN	31.3	stable	29.7	stable	37.8	stable
Porter County, IN	30.2	stable	29.7	stable	*	*
Illinois	33.8	stable	33.4	stable	36.6	stable
Indiana	27.2	stable	26.6	stable	35.5	stable
National	28.3	stable	29.7	stable	31.8	stable

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

High rates of *in situ* breast cancer may indicate greater trend in incidence, yet are more likely to be indicators that women are being screened in a timely fashion to catch this early pre-invasive stage of

disease when it can be treated most successfully. *In situ* breast cancer incidence rates (overall total among women of each race) are higher in Chicago MTA counties than the national rate of 28.3. These county rates tend to be similar or higher than their respective state rates of 33.8 for Illinois and 27.2 for Indiana (see Table 6). The lowest overall rates of *in situ* breast cancer among women are found in McHenry County, IL, Kane County, IL, and Porter County, IN, at 29.9, and 30.2, 30.2, respectively. *In situ* incidence rates are higher among Black women than among white women in five out of the six counties where data are available for both Black and white women. Lake County, IL, reports the greatest disparity in *in situ* incidence rate, with a rate of 33.8 for Black women compared to a rate of 41.4 for white women. While sometimes comparable or higher than white women and both state and national averages, rates are also on the lower end among Black women in Kane County, IL, at 33.6 and Cook County, IL, at 36.0 (Table 6).

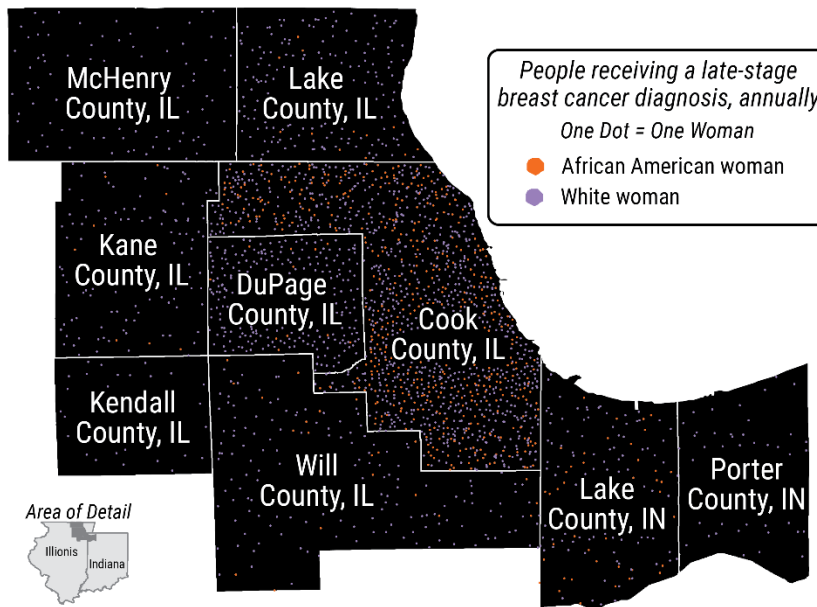
TABLE 7. CHICAGO METRO AREA LATE-STAGE BREAST CANCER INCIDENCE RATE (PER 100,000)

	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
Cook County, IL	52.2	1411.0	49.3	868.0	63.1	450.0
DuPage County, IL	52.9	251.0	56.4	219.0	41.7	11.0
Kane County, IL	44.7	118.0	45.1	105.0	46.2	8.0
Kendall County, IL	45.0	28.0	47.1	26.0	*	*
Lake County, IL	52.0	183.0	54.7	160.0	44.1	12.0
McHenry County, IL	55.3	85.0	57.1	84.0	*	*
Will County, IL	52.6	182.0	54.1	152.0	46.2	20.0
Lake County, IN	53.8	136.0	52.9	94.0	58.9	41.0
Porter County, IN	51.5	44.0	51.6	41.0	*	*
Illinois	52.7	3451.0	53.1	2708.0	56.5	588.0
Indiana	47.0	1569.0	48.0	1394.0	44.3	155.0
National	41.0	78641.0	41.4	62240.0	51.0	11590.0

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

As shown in Table 7, in some counties the late-stage incidence rates are higher among white women, while in other counties the reverse is true. However, there is a significant racial disparity in Cook County, IL, where the age-adjusted late-stage incidence rate is 63.1 for Black women as compared to 49.3 for white women. A disparity is also evident in Lake County, IN, where the Black rate is 58.9 compared to 52.9 for white women. The age-adjusted late-stage incidence rate of breast cancer among all women is highest in McHenry County, IL, at 55.3. Rates in Lake County, IN, follow as second highest at 53.8. All nine of the counties in the Chicago MTA have late-stage incidence rates that are above the national average of 41.0. Almost all of these county rates are similar to or higher than their respective state rates of 52.7 for Illinois and 47.0 for Indiana.

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



Map 1 shows the concentration of women who receive late-stage breast cancer diagnoses annually in the Chicago MTA. Observed patterns align with population trends. The density of diagnoses increases closer to the center of the MTA, with the highest concentration in Cook County, IL, where Black women comprise the majority of late-stage diagnoses. DuPage County, IL, the second most populated county, yet with a much smaller percentage of Black residents, also has a high concentration of late-stage diagnoses, the majority of which are among

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

white women. The surrounding counties have moderate concentrations of late-stage diagnoses, while places farther away from Chicago have much lower concentrations of late-stage diagnoses, which reflects the region’s population density.

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

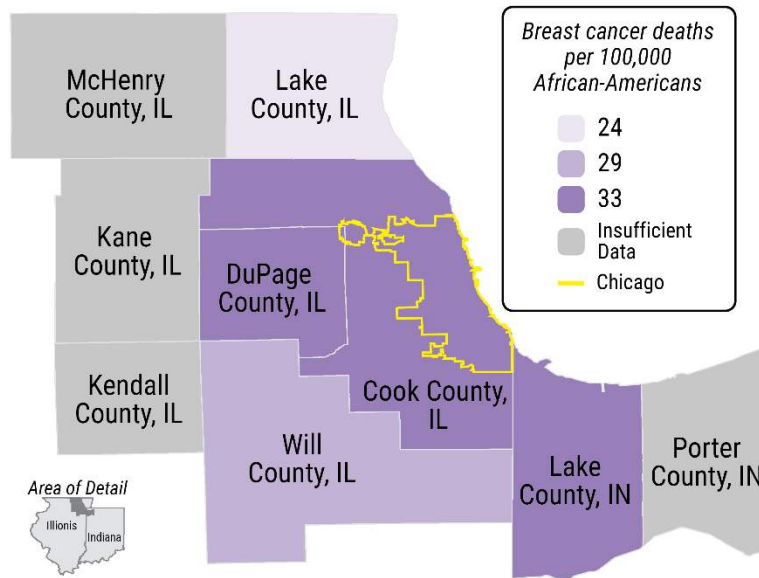
	Age-Adjusted Mortality Rate	5-Year Mortality Rate Trend Direction	Age-Adjusted Mortality Rate for White Women	5-Year Mortality Rate Trend Direction for White Women	Age-Adjusted Mortality Rate for Black Women	5-Year Mortality Rate Trend Direction for Black Women
Cook County, IL	23.1	falling	20.5	falling	32.7	falling
DuPage County, IL	20.5	falling	21.5	falling	33.0	stable
Kane County, IL	18.3	falling	18.6	falling	*	*
Kendall County, IL	18.0	falling	18.6	falling	*	*
Lake County, IL	20.0	falling	20.7	falling	23.6	stable
McHenry County, IL	22.7	falling	22.8	falling	*	*
Will County, IL	21.1	falling	20.5	falling	28.5	stable
Lake County, IN	24.6	falling	22.4	falling	32.6	falling
Porter County, IN	23.8	falling	24.4	falling	*	*
Illinois	21.8	stable	20.9	falling	30.7	falling
Indiana	21.4	falling	20.9	falling	29.3	falling
National	20.6	falling	20.1	falling	28.1	falling

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

In every county in the Chicago MTA where disaggregated data are available (five counties), the breast cancer mortality rate is higher among Black women as compared to white women (see Table 8). The racial disparity in breast cancer mortality rates is greatest in Cook County, IL, where the age-adjusted mortality rate for white women is 20.5 compared to 32.7 for Black women. A similar disparity is found in Dupage, IL, where the age-adjusted mortality rate for white women is 21.5 compared to 33.0 for Black women. As noted earlier these higher rates among Black women exist despite Dupage having a smaller proportion of Black residents than many other counties in the MTA. The next greatest disparity is found in Lake County, IN, where the age-adjusted mortality rate for white women is 22.4 compared to 32.6 for Black women. Lake County, IN, reports the highest overall mortality rate in the MTA at 24.6, even

though its incidence rate is one of the lowest at 125.7 (see Table 8). The lowest overall mortality rates are 18.3 and 18.0 in Kane County, IL, and Kendall County, IL, respectively. Extending beyond the county data, the racial disparities in mortality rates exist in Illinois, Indiana, and nationally.

MAP 2. CHICAGO METRO AREA BLACK BREAST CANCER MORTALITY RATES



As seen in Map 2, Dupage County, IL, has the highest breast cancer mortality rates for Black women at 33 deaths per 100,000 (see Table 8). Cook County, IL, and Lake County, IN, have the next highest reported rates at 32.7 and 32.6 per 100,000. Next are Will County, IL, at 28.5 and Lake County, IL, at 23.6 per 100,000. In Porter County, IN, McHenry County, IL, Kendall County, IL, and Kane County, IL, these rates are not reported due to insufficient data.

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

The research of Sighoko, et al., 2018 offers a look at the mortality data disaggregated by race and age in the City of Chicago from 1999-2013, with findings that the

disparities are greatest among younger age groups. Women younger than 40-years-old who are Black had almost three times the mortality rate of white women in that age group (RR 2.57, 95% CI [1.87; 3.52]). Women 40-49 had a rate approximately twice as high (RR 1.93, 95% CI [1.62; 2.31]), while women 50-64 had a rate that was 72 percent higher (RR 1.72, 95% CI [1.54; 1.91]), and women 65 or older had a rate that was 19 percent higher (RR 1.19, 95% CI [1.11; 1.28]). It should be kept in mind that since the number of women with breast cancer increases with age, the combined effect is that even at lower rates of mortality, the excess risk of early mortality was largest among Black women in the 50-64 age category, calculated as 418 individuals. Excess mortality among Black women within other age groupings were 93 individuals under 40, 197 individuals between 40 and 49, and 234 individuals over age 65 (Sighoko et al., 2018).

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

	Percent of Women Getting Mammograms
Cook County, IL	70%
DuPage County, IL	72%
Kane County, IL	74%
Kendall County, IL	77%
Lake County, IL	72%
McHenry County, IL	71%
Will County, IL	73%
Lake County, IN	59%
Porter County, IN	64%
Illinois	73%
Indiana	67%
National	73%

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

The percentage of women receiving a screening mammogram varies throughout the Chicago MTA, from 59 percent in Lake County, IN, to 77 percent in Kendall County, IL (see Table 9). Most of the screening mammography rates in the MTA hover near their respective state rates. The two Indiana counties, Lake and Porter, have the lowest screening mammography rates. Indiana state rates are lower in general at 67 percent than rates in Illinois at 73 percent, which parallels the national rate of 73 percent. Racially disaggregated screening mammography rates are not available at the county level, but these data are available at the state level. In Indiana, where two of the MTA's counties are located, 72 percent of Black women over age 40 received a screening mammogram in the last two years compared to 67 percent of white women in the state. In Illinois, where seven of the MTA's counties are located, 80 percent of Black women over age 40 received a screening mammogram in the last two years compared to 73 percent of white women in the state. It appears that rates of recent screening mammography screening alone are not a good predictor of disparities in breast cancer mortality observed for Black residents over age 40 in Illinois or Indiana. That said, county rates may vary, and total screening mammography rates are less

than state rates in the two counties within the Chicago MTA with the largest number of Black women over age 45.

Overall, an examination of breast cancer disease burden measures suggests that throughout the Chicago MTA where disaggregated data are available, Black women are more likely to die from breast cancer than their white counterparts. They are diagnosed with the disease at rates that fluctuate from higher to lower than white women in their respective counties or than their respective statewide rates. Late-stage incidence is a clear concern, with significant disparities among Black women as compared to white women in counties with the largest numbers of Black residents. Screening mammography rates appear to be low in these counties, although data is not disaggregated by race. At the same time, however, rates of *in situ* breast cancer tend to be high, which can be an indicator of access to timely screening that catches cancer at this early stage. Patterns vary in other parts of the country that have been explored in the literature. A study in South Carolina, for example, found that while the breast cancer incidence rate was higher for white women compared to Black women (124 versus 118.5 per 100,000 women), the breast cancer mortality rate was higher for Black women (29.8 versus 21.3 per 100,000 women) (Samson, Porter, Hurley, Adams, & Eberth, 2016). The study further reported that Black women were even more likely to have had a screening mammogram or clinical breast exam compared to white women (81.9% of Blacks versus 74% of whites), and more likely to have late-stage breast cancer at the time of diagnosis (47% of Blacks versus 35% of whites).

Research from other parts of the country 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.

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 Chicago MTA. Interwoven throughout the findings are the many barriers and facilitators participants discussed that affect health promotion and ability to access health care across the care continuum, and therefore possibly contribute to the onset of the disease and its progression. Based on a review of the quantitative findings, priority counties for qualitative data collection in the Chicago MTA were identified as Cook County and Will County, Illinois (IL), and Lake County, Indiana (IN) (not to be confused with Lake County, Illinois, that also falls within the Chicago MTA). These locations have the highest breast cancer disease burden, high SDOH burden, and score poorly on other health measures. Further, these locations have the highest proportion of Black women in the MTA, and, as such, have sample availability for qualitative data collection. The themes shared below represent the perspectives of community members from these three locations, not the entire Chicago MTA.

Screening

There are different screening guidelines for those at average risk and for those at higher risk. Recommendations for those at higher risk also vary from one organization or professional society to another. There is some inconsistency for screening recommendations among organizations for those at higher risk (Komen 2021a). Black women age 40 and older receive mammograms at a higher rate than white women in Indiana and Illinois; yet, overall screening rates are lower in Indiana (where the state rate is 67%) than in Illinois (73%). Screening rates within the Chicago MTA are lowest for the two Indiana counties at 59 percent for Lake County, IN, and 64% in Porter, IN. Screening mammography rates are also lower than state rates in several of the Illinois counties. Data are not available for county rates disaggregated by race within the MTA. Focus group participants' perspectives give some indication of the experiences of Black women seeking and obtaining breast cancer screening.

Screening guidelines. Survivors and undiagnosed women shared the influence that provider recommendations tied to guidelines had on when they started screening and how regularly they screened. A survivor in Joliet, IL for example, started screening at age 40 as part of her regular physical because her doctor, a caring Black woman, insisted upon them. The provider's advice led to her getting screened after missing two years, which is how she was diagnosed.

"After 40 it's like you have to get them. And I skipped two years and then the next year I went and got it. [My physician, who was a Black woman] was like, 'No. You got to go get it.' And that's when they found it." – Survivor

Survivors recounted incidents where inconsistent application of screening guidelines created barriers that delayed their treatment. A young survivor described her struggles to obtain cancer screening at her age, despite having both a personal and family history of breast cancer:

"I knew that I should start checking, or being more aware, because my mom had it twice. She had it once at 47, and then once at 51, so she had two mastectomies, and I found the lump...the doctor clearly had on the order that it was family history, but they charged me [for the screening]. [I was] maybe 34 or 35 [when I got it again] at 37 I was like, 'They gon' still do the same thing that they did the first time,' which was try to charge me; it wasn't covered. But I fought it...and I ended up not having to pay, but that was discouraging...it did take me a while to go in because I'm like, 'I don't want to go through this anymore.'...I'm definitely going to have my daughter to start [screening] at 27, next year." – Survivor

Patient navigators also find that patients tend to follow their doctor's advice and that it can vary widely. Navigators emphasized the need for more consistent guidelines and their application across institutions. They expressed frustration that insurance or health care institutions they work with may restrict screening to women starting at age 45 and only recommend biennial screening, when American Cancer Society (ACS) guidelines recommend offering women the option of yearly screening through shared decision-making discussions with providers starting at age 40, and younger women with a family history may benefit from starting even earlier. They also had clients who had been told to stop screening at age 70 (earlier than recommended by guidelines), who they felt could have benefitted from continued screening.

“I have patients that haven't had their screening mammogram in four years and [say], ‘Oh, because my doctor told me that I was 70 and I don't need it anymore.’...It's tricky, but I feel often doctors have a lot of control over who gets what screening.” – Patient Navigator

A provider confirmed that screening is not yet tailored to early onset that is more prevalent in Black women. They explain that they may not have leeway to recommend screening at ages younger than national guidelines.

“A lot of primary care providers, that are the clinical workforce that tries to pick up cancer before it becomes too advanced, their hands are tied based on guidelines that are set by institutions such as USPSTF, that base their guidelines on average risk individuals that are predominantly Caucasian and middle to higher income. We don't recommend screening [as we should] starting at [a younger] age because you are at a higher risk as you are a certain race/ethnicity. We need to develop more personalized guidelines that are based on individual risk factors.” – Provider

Community Outreach and Engagement. Participants described a general lack of information for and discussion among Black women about breast cancer. This was true across the continuum of prevention and care, from risk factors to screening and diagnostic procedures, treatment options, and support resources. Some survivors stated they did not receive any information about breast cancer until they were diagnosed, and many of those who were undiagnosed came to the focus groups hoping to learn more to protect themselves and their families.

Other respondents, however, did describe events in the Chicago area that have large reach. “Beyond October” outreach in partnership with faith-based organizations are held year-round by the coalition Equal Hope, with Komen support. Patient navigators discussed numerous venues at which they participate in outreach events in Cook County and Will County, IL. These include presentations and education at churches, food pantries, schools, cultural institutions and factories. Black women in Lake County, IN, an area outside of the former Komen Chicagoland service area, described breast cancer outreach as more limited. There, the outreach events are mostly held at hospitals during October breast cancer awareness month, when there are health fairs for seniors and free breast cancer screenings. Indiana participants did not feel these opportunities were adequate and recommended more be made available beyond hospital settings and tailored to Black women.

“There are free mammograms in October. If they don't see it on social media or [on a flyer], a lot of people don't know and don't get it.” – Undiagnosed

Providers similarly see the importance of outreach being conducted where Black women already congregate and through peer networks. Providers further asserted that community outreach should not just focus on when and where to get screened, but also on what has improved in breast cancer screening and treatment.

“One of the biggest things that I see make the biggest impacts are when there is a gathering of people for a similar interest, that it's then presented there. So, if you're specifically targeting African American women, what other social gathering are they already going to, that if it's presented in that realm so that the education is not

presented individually to each person but that it becomes a group effort, to make sure that your fellow sister in arms go to get their screening mammogram, that this is not an unusual kind of thing. I think that that tends to be quite helpful in motivating women to go take care of themselves.” – Provider

“For people to be able to [learn more about improvements in treatment], before they're even told they have an abnormal screening mammogram, I think is something that would be helpful with the stress of the idea...It would also be helpful to patients who are in denial and they want to ignore the idea of getting a screening mammogram because they'd rather just not know.” – Provider

Newly emerging priority populations. Patient navigators relayed that they are more recently having clients who are African immigrants from a Muslim culture. Such immigrants may not speak English fluently, nor have familiarity with U.S. health care systems or preventive care, and live within different cultural and religious norms. The barriers they face are therefore compounded, and the faith and community-based organizations they rely upon are likely to differ from other Black women. Patient navigators requested more information to best serve this growing population.

Screening experiences. Having had a negative screening experience can compound barriers for women who may already be uncomfortable with health care due to historic racism. The following experience, in which the woman was not listened to as she experienced great pain, is an example of delays in regular screening being due to disrespectful care. Hearing others share bad experiences created barriers among Black women already mistrustful of health care systems.

“My second time, they twist it and turn it. It really hurt. I'd rather have a pelvic exam than a screening mammogram. They were rough. It hurt so much...I was explaining to them that it's sore; it's hurting. You all are hurting – you're literally hurting me. When I came out, I was in tears. It took me 2-3 more years until I could go back for another screening mammogram.” – Undiagnosed

Diagnosis

Delays in Diagnostic Procedures. Some of the factors Black women participants described as contributing to delays in getting diagnosed included health care systems that are not responsive in offering timely services and that often present many institutional and insurance barriers. Survivors also mentioned provider complacency as leading to their delays in diagnosis.

“I didn't think to get a screening mammogram, and the reason why I ended up getting [one is]...because, I was putting lotion on my body and I felt like a baby elbow on my breast and I was like, ‘Oh that ain't nothing, that's just a cyst.’ I had a medical card and I called to get my appointment. They gave it to me a month later. It wasn't urgent to them.” – Survivor

“When I got diagnosed at that particular time I...did my screening mammogram and was fine a year before. So, I felt my own lump. I noticed the first week, and...I felt it getting a

little larger...So I went to the primary doctor, and I told him that I need to get tested...I found out and they did everything, but they could not take me because I had County Care [a Medicaid Managed Care Health Plan].” – Survivor

Community members also described how financial barriers and competing priorities led them to delay screening and care and adopt a fatalistic attitude.

“I was doing mammograms [sometimes]...But see, I get so caught up in being busy because I was a housekeeper...I just work, work, work. Then I start getting bad headaches...So I went to the hospital when I was 57 years old. The doctor gave me a checkup. That's when he told me I had breast cancer...But how I looked at cancer was like I already had put myself in a casket.” – Survivor

Navigation and Self-Advocacy. Black women reported contending with being dismissed offhand and confronting racial discrimination in the health care setting when presenting with symptoms. They had to rely on their own research to get more information about their symptoms and stand up for themselves to have their medical concerns heard and addressed, as this survivor describes:

“We don't always educate ourselves before we get to the medical professional. A lot of times they're playing the guessing game with us versus someone else. And if you don't come in there armed with some knowledge, being familiar with your body and being able to voice ‘This is what I'm experiencing right now, and this is what I'm feeling. Something's not right with my body, I know how I normally function, and this isn't what's happening right now.’ If you don't come in there informed, and a little bit forceful with the doctors, they will run over you. Whether it's the Caucasian doctor, whether it's the Indian doctor, whether it's the African doctor...If you don't force the issue and make them really talk with you and make them listen to you, they won't.” – Survivor

Patient navigators explained how they assist women in developing such self-advocacy skills. They described that a key part of their role was to make it easier for women by doing groundwork that can include setting up the doctor’s appointment and arranging for free transportation—“Whatever it takes for the patient to get her screening mammogram, we'll be in assistance.” At the same time, they promote women to take control of their own care. A navigator describes:

“A lot of times, setting up appointments have proved challenging for a lot of our clients. And so, they get frustrated and they do just say, ‘Forget it.’ But having somebody help them navigate through the process, at the same time keep encouraging like, ‘This is what we're going to do this time.’ So next time to empower them to be able to take on those roles...it's great for somebody to do something for you and make it easy. I would want you to do it again too, but we still want to empower them to come through it and do it the next time for themselves...‘So now I feel confident to do it by myself this time. And note that my body changes, my breast tissues can change, or knowing that I had previous family history. And this needs to be done.’ So, I think having all those pieces in place is crucial.” – Patient Navigator

Providers found it valuable to have patient navigators on their teams who live or grew up in the community to establish trusting relationships. Providers confirmed the importance, maintaining that navigation and outreach and support services were needed in both the clinic and out in the community, and that such services need to span the entire continuum of care. A provider also reflected on a nurse navigator's importance to ensuring that there is no delay in diagnosis or treatment:

“The Breast Cancer Nurse Navigator is phenomenal and they do everything they can when the patient has an intake or new diagnosis of breast cancer to help in the beginning to diagnose or notice whether or not there to be hindrances to treatment or delay.” – Provider

Quality of Diagnostics. Early, regular screening by screening mammography did not ensure high-quality diagnostics. As identified in the pivotal 2009 study (Ansell 2009, see Findings Section 2 below), the equipment that is available in the Black neighborhoods of Chicago may be lower quality, and access to skilled providers to administer tests and to interpret results are limited. A provider noted that initiatives of the Metropolitan Chicago Breast Cancer Task Force/Equal Hope, that Komen has supported, to standardize screening mammography, make mammograms accessible, and to get people access to care have made a real impact. Below they explain why more is needed to improve access to NCI-certified cancer treatment centers uniformly across the Chicago MTA:

“Quality does matter. If you get your care at an NCI-designated cancer center, then quality standards have been met. Not every place has the same level of provider training the same degree of technology upgrades. If you get your screening mammogram at a place that has equipment that is very, very old and not that functional and the technician is not that qualified and doesn't make adjustments for body habitus [related to obesity] and the mammographer does not just do mammograms, but does other things, the chances of having a small tumor picked up is a lot lower than somebody who gets high quality diagnostic services at a center that all they do is breast imaging.” – Provider

Treatment

As in screening and diagnosis, participants (providers, patient navigators and community women) pointed to access barriers related to insurance, lack of nearby high-quality treatment centers that accepted all women, and challenges relating to SDOH as being the most important drivers of inequities tied to treatment. Community members shared their negative experiences stemming from experiences of discrimination and lack of patient-centered care. While some patient navigators and community members linked lack of information, fear and stigma to delays and avoidance of treatment, providers observed these factors were less likely to present a significant barrier among their patients once a woman had been diagnosed. Providers called for improvements in treatment regimens tailored to Black women, while survivors described a need for expanded social and auxiliary support services.

Limited Insurance and Resources. Community members reported that the biggest barrier to timely and high-quality breast cancer treatment were financial reasons, including lack of adequate insurance, as well as competing needs for time and resources. Needing to care for young children and/or having jobs they couldn't take time away from were among factors in delays to treatment. The need to

accommodate work and family schedules through treatment required women to have perseverance and to draw on social capital, such as friends, as described by this survivor:

“I had to have radiation every day from work. Leave work, and I didn't have a car. So it was my friends that came and picked me up from work every day. I would come and work an hour early so I can get off at three to go have my radiation. I did that for seven weeks.” – Survivor

Patient navigators confirm such barriers, finding a lack of insurance to be increasing in recent years among Black women:

“[There are] financial reasons behind it. A lot of them, some don't have insurance. And instead of going to take care of themselves, they'd rather provide for their family with what they have.” – Patient Navigator

“We've noticed a high increase of African American women having less access to insurance...I've noticed that before two years ago, or three years ago, most African American women were insured, and now...that makes it harder because if there's no insurance, then we have to go to a different sort of navigation process for them. And again, that might be political, I'm not sure if that's going to change depending on the climate moving forward. But definitely I've noticed the increase, the hike in uninsured African American women, which before used to be mostly Latinas, but now it's getting up there.” – Patient Navigator

State-funded insurance programs, such as those available through the Illinois Breast and Cervical Cancer Program (IBCCP) to women without insurance who receive a breast cancer diagnosis can be of great assistance; yet, as described by this patient navigator and provider, are not available at every facility. Such programs may also require a breast cancer diagnosis for eligibility, at which point care has been delayed.

“I wish every hospital had IBCCP or those federal funding grants that other hospitals have, because I think a disparity for African American women would definitely decrease if we were to expand IBCCP across Illinois, not just certain hospitals.” – Patient Navigator

“Getting diagnosed stage 3 breast cancer in this country gives you the ability to access health insurance, but you got stage 3 breast cancer because you didn't have health insurance.” – Provider

Health care discrimination. Community members described personal experiences of inappropriate treatment that they felt was due to their race, presumptions of what they could afford, and/or insurance status. The following survivor worked in health care as a technician and observed how race, income and insurance status intertwine to foster discrimination in health care systems that favored those with greater economic and social status.

“I've worked in health care for almost 30 years doing x-rays and then MRIs, and they tend to discriminate. When you see a patient come in, and they may have Medicaid or Medicare, and they would make those patients wait longer, or they just have this assumption because, ‘Oh, you just have Medicaid.’ They belittle the people like they're lower. It's always that mistreatment. Or, it's like they [assume you] can't pay. ‘You don't have enough money to pay for this MRI.’ And it's not coming out of your pocket in the first place, it's Medicaid, but there's a difference in the way that people are treated because of the type of insurance that they carry and you can see it.” – Survivor

Inequitable access to treatment facilities. Treatment facilities, especially those that are high quality NCI-certified, were less available in Black neighborhoods in Chicago (Ansell et al., 2009; Sighoko et al., 2017). Community members in Lake County, IN, near Gary, IN, described breast cancer services at many hospitals, but were not aware of any stand-alone clinics that offered breast health services.

“[The hospital is the only cancer facility, it is only in the hospital there are no local breast cancer clinics.” – Undiagnosed

Survivors in Cook County relayed that health facilities that had merged and been renovated would no longer accept Medicaid managed care plans and otherwise withheld care favoring those with coverage that was more profitable to the institution. Participants frequently commented on this type of gentrification of health care, including these survivors, one of whom had been turned away from a breast cancer treatment facility that they used to frequent once renovations were completed. The other survivor was turned away once she lost her husband's insurance and had to switch to a Medicaid plan:

“When they were over in the little raggedy building they [were] blind to see [the color of your skin]. They know you. But now, [that] they got the big, new cancer center everything's changed.” – Survivor

“I had good insurance with my husband's insurance. And then things happened, we no longer can afford it...and when I got diagnosed, I didn't have insurance, so I had to go to the aid office again...I was at St. Franciscan hospital in Chicago Heights, at the time it was in between switching over [to their relocated facilities]...[After diagnosing me] they could not take me [for treatment] because I had County Care [a Medicaid Managed Care Health Plan]...So I didn't really know who to pick anymore.” – Survivor

Institutional and structural lack of investment in Black women's health. Such restrictive and discriminatory institutional policies were coupled with reports of hospital closures in Black neighborhoods.

“We had two hospitals here. We've got one hospital now....I could go to the emergency room, for instance, and be there all night. I know for a fact I've been mistreated. I don't know, because of racism or what...They'll bypass my room, and go up to another

person's room and have me laying there forever and a day...That's not right. I'd be waiting on them and then I hear giggling. I said, 'Ain't nothing funny.' That's all...I disconnected that IV and got the heck out of there. I ain't been back since." – Survivor

In contrast, a surgeon in a different county noted improvements in services available for Medicaid patients that had been adopted across their entire health care system. They now require that specialty services, such as breast cancer surgery and oncology, cannot be declined if the patient had been referred by an in-network provider. Despite this, they note delays in making their own out-of-network referrals to specialists. For example, their system does not have a plastic surgeon, and she's found that her referrals to those services can get delayed for long periods due to insurance barriers.

"There are Medicaid specific changes that have opened the patients up to a little bit better health care...If for some reason I don't take...Medicaid, but one of my primary care physicians takes it, that patient sends them to me, no questions asked, that patient gets to see me whether we take the insurance or not...From time to time where patients have had difficulties...is when they're trying to go from me to seeing somebody else [not in our medical group, such a plastic surgeon for reconstruction], and that's where it actually becomes a hindrance." – Provider

Options to improve access to quality treatment services face barriers of hospital closures (see Access to Health Services in Findings Section 2, below). One interviewed provider advocated for improvements at, or in partnership with, an FQHC as these are the accessible, trustworthy locations where low-income Black residents go for their health care.

Social determinants of health. SDOH affect access to and delays in seeking treatment. Chicago was described as a very difficult city to travel by public transportation. A provider attributes the difficulty getting to care as a major difference between Chicago and New York City, where they used to practice that does not have the same levels of breast cancer disparities among Black women. Lack of housing and food insecurity were among the intertwining SDOH barriers raised.

"In places like Chicago, transportation is so important to your ability to access care in a timely manner and getting standard of care treatment. You need to be able to get to the treating facility without having to take 10 buses and a train, and you need to be able to pay for your ability to get to that facility...it is a huge problem...It's not the only thing. People think that if you throw money at one thing it will solve everything and it doesn't. You can give people access to transportation, but if they are about to get evicted from their home or don't have housing where are you going to transport them from?" – Provider

The University of Illinois Chicago was noted as having launched a pilot that provided housing during the winter months to frequent users of the Emergency Room (ER) who were housing insecure. This program was described as having been effective at reducing ER utilization. Such an initiative for housing insecure women who are undergoing breast cancer treatment was suggested by this provider as potentially beneficial to advancing completion of treatment.

Fear and stigma. Several participants described how fear, denial and stigma present barriers across the cancer continuum, including delaying or averting treatment once cancer was found. Participants reported that women are generally afraid of how terrible chemotherapy will be based on poor responses to treatment that they have seen among friends and family. Stigma was discussed by many as surrounding breast cancer, and was said to arise from many sources, including the potential to be perceived as being weak when Black women are expected to be strong, especially as they face a society that constantly challenges them.

“I know some people, because of their shame, wouldn't even get treated. Like, ‘I'm just gon' die with it.’...It's the fear of not being yourself. They like, ‘I don't want to look not like me.’ And a stigma being a cancer person, having cancer because in our culture, they didn't talk about that. You know the saying they used to say, ‘What goes on in this house stays in this house.’” – Survivor

“I know my godmother passed from cancer. I found out she had cancer, because she didn't have any children and I was the one helping take care of her and she said, ‘I don't want any visitors, don't let them put me on the cancer floor.’ Even today, 2020, if you have a friend and they find out that you have cancer, sometimes you lose your friendship because they don't know how to deal with it themselves.” – Survivor

Both providers interviewed, however, did not find that denial was a significant factor among their patients. Rather, they traced the lack of treatment and delays to other barriers, from lack of access to screening and consequently diagnosis, to the time commitment involved and transportation barriers as well as institutional delays.

“I think it boils down to that same population is also vulnerable to not having adequate health care access in general...It's not a denial thing. Once they've been told, ‘Yes, we think this [may be breast cancer]’ They show up; they're there; they want treatment; they get care. Where I do sometimes see delays in treatment comes from post-operative care, so delays in being able to receive the radiation, and a lot of that comes down to the time commitment that's involved in the radiation and the access to frequent car rides and trips to be able to get to their radiation. That is an issue that does tend to be more common in the African American population than my other patients.” – Provider

Community Outreach and Engagement. Providers observed that the information that Black women have via family or informal networks tends to be dated and not account for improvements in treatment and survival, and older women who have not had good access to the medical system do not have information on what is available and where.

“Generally speaking, the breast cancer patients, especially the ones with more advanced disease tend to be the older patients. The 50 plus have had a longstanding issue with getting access to health care [such] that, although it is much easier now, they may not understand, or they may not know, where the resources are in order to get easier access. So, they're not getting it. It's not because the door is not open. They don't even know that there's a door, you know? What I try to impress upon my patients, particularly those

with the earlier stage breast cancers, is that yes, you have breast cancer, but we are really good at treating this...People don't die from breast cancer like your grandparents did.” – Provider

Supports during treatment. Patient Navigation and informational resources of Cancer Support Centers were also described as highly valuable by women from all three counties. Support from family, friends, church and breast cancer support groups was also vital yet not always available.

“During that time, I was able to have a good rapport and I still had that same relationship with my nurse navigator, and she was like my right hand. She was there all doing different treatments. And then [that ended]...I like the cancer support center at Homewood [Illinois]. They have a library that's free, that's open and you can borrow books and I started attending workshops because I was in this all by myself.” – Survivor

“Some of the reasons why I could have delayed [treatment] was just caring for my kids. I have a six and a nine-year-old and if my mom wasn't there, if I didn't have the friends who were willing to say, ‘Okay, well I'll pick up the kids, or I'll do this with the kids...If I didn't have the support that I have as far as family, given that I have two small kids, it possibly could have delayed me starting my treatment.” – Survivor

Need for patient-centered care. Health providers described how the provision of care in the Chicago MTA has been in transition, from days when mistreatment and experimentation on Black people was uncontrolled to current efforts to deliver respectful, patient-centered care. They explained that patient-centered care recognizes the importance of positive patient experiences, emphasizing strong doctor-patient relationships and team-based care. Important features are providers who show cultural humility that is respectful of the diversity of patients, including their religious beliefs; employ shared decision making processes with patients as they partner to select health care options; and attend to SDOH needs.

Community participants shared incidents of discriminatory treatment and personally mediated racism. These experiences demonstrate the need to confront remaining prejudices and bolster provider competency and incentives to offer patient-centered care. While problems with timely care seeking and retention in care have traditionally been framed as tied to patient individual behaviors, we heard from women, patient navigators, and providers that the barriers of personally mediated as well as institutional and systemic racism are more often pivotal.

“I feel like the doctor might not be able to connect with the patient, because most of the times, the doctors are coming from the suburbs, or coming from other areas that are North Side [of Chicago]. I feel that's one of the reasons why they don't treat the patient the way the patient should be treated. They don't have a knowledge of what's going on in the community [there are food deserts], or they don't have knowledge of our culture here in the communities. I feel that's another reason for barriers and disconnect with the patient and the hospital.” – Patient Navigator

Not being presented with options through a respectful, shared decision-making process led to significant delays in treatment, as experienced by this survivor from Lake County, IN.

“In my left breast, [I found a lump the size of a] medium sized egg and it continued to grow. But they wanted to take all the live tissues out, both breasts. ‘Oh your husband got good insurance.’ That’s what they were telling me. And I told them I did not want them to take all my live tissues out of there. So I just let it go on for years and years, and it caught up with me 20 years ago.” – Survivor

Conversely, another survivor described their high satisfaction with respectful, team-based support that helped her make informed decisions and proceed with timely care through all aspects of her treatment.

“After my primary doctor gave me the diagnosis, she [said] we need you to come in right away so that we can meet with the team and we can discuss what your treatment options are...I went to the University of Chicago, that was my primary doctor at the time and the nurse navigator, the medical oncologist, the surgical oncologist, the plastic surgeon, the radiologist, and someone else came in. I was there for a few hours and each person came in and they sat with me and they took their time and they answered my questions and they told me what piece they play.” – Survivor

This experience is echoed by others, including a provider who formerly worked at a FQHC and found that trusted relationships were more important than the many other barriers to timely and full completion of treatment. They recommended that training in patient-centered communication and shared decision making be mandatory for medical residents and align with standards that are evaluated.

“A lot of the patients that I see in the Federally-Qualified Health Center; especially late-stage patients, are there because somebody from the community says ‘Oh, this is a good place, so even if you had a bad experience, go to this place because you will be listened to.’ The initial part of the encounter is discussing the trauma that they experienced and their negative interactions with [other] providers, earning their trust so that they understand why you are making your recommendations. Because if you don’t trust the person delivering information, why would you go to a place to have toxic treatment?” – Provider

Patient navigators called out health literacy as another component of patient-centered care that providers need to anticipate and address. Patient navigators described a case where a client was missing appointments because they were not literate and did not want to share that; having built trust with a patient navigator who could accompany them facilitated being able to keep their screening appointments.

“I spoke to the patient over the phone and she missed quite a few screening mammogram appointments. I found out that she wasn’t able to write or read and that was one of the reasons why she was missing her appointments. By a community health worker being there, she was able to rely on us to assist her and she had her screening mammogram done. So I think that’s the next step that we take for our patients here at health [appointments to] assist the patient.” – Patient Navigator

Patient navigators also described how the lack of coordinated care across health care can also hamper patient services. They point to issues referring out of a particular health care system.

“I think there needs to be more unity among the hospitals. There's a lot of territorial behavior. Sometimes we're trying to connect somebody to another hospital, and they get upset, like we're stealing their patients. We're not stealing them, we just want to make sure that that woman gets the care that she needs.” – Patient Navigator

Comorbidities and tailored care. Several survivors described the treatment they received for triple-negative breast cancer as being particularly harsh. The pain and fatigue were said to cause some women to abandon or avoid treatment. Survivors discussed their own will and motivations, such as staying alive for their families, but rarely mentioned having full medical support throughout their treatment to manage side effects. Not having optimal options for pain management due to insurance barriers was discussed by one survivor, who had to launch her own advocacy for proper management.

“I had some hard times doing [the treatment]. The insurance company denied me; I had PPO and they denied me my pain medicine so I ended up taking morphine pills...Then there's other medicine that you had to take because the chemo we had was double because...you had triple negative and [the chemo's] very strong and as you take the chemo the following day you had to get a shot in your stomach. That's what really puts you on your back...I would be in so much pain every time I had the chemo, got the shot the following day. That afternoon I was in the emergency room. They would wrap me up in a white towel. Put towels and blankets on me and put me in a room and gave me morphine...I had to go through it and sit down and write a letter [in order to advocate for myself to get pain medicine].” – Survivor

Faced with such experiences, survivors discussed wanting to avoid medications and to try alternative options from diet changes to natural medicines. Decisions on whether to rely on alternative medicines, traditional treatment, or a combination were influenced by many factors. Being vulnerable to feeling shame (that it may have been their fault they got breast cancer) made some emphasize changing their lifestyle. Wanting a process that they could control, valuing privacy above all else, experiencing mistrust of health systems, and feeling that treatment was too invasive were among the many factors in their decisions and those of others they knew. It was clear that more information helps women sort through what is healthy and what is not as they balance various approaches.

“She wanted hers to be more of a holistic healing...She passed away quick, but, it was her choice. You get to choose whatever type of treatment you want. Path you want to take.” – Survivor

“Since mainstream research isn't looking into this, looking into natural treatments that don't take you into getting poisoned or mutilated [would be extremely helpful]. Looking into things that would be less invasive. Alternative medicine research. That is all that is missing is the money to look into something that is less invasive.” – Undiagnosed

A provider explained that the lack of research and clinical trials that engage Black women leads to suboptimal care that is not tailored and can be dangerous. They pointed out that competing causes of mortality are a large contributing factor to worse survival among Black women and other minorities. Treatment regimens may not be as effective and the side effects of standard medications may be very dangerous given common comorbidities, such as hypertension, diabetes and high cholesterol. The common chemotherapy agent, Adriamycin, for example, they claimed is much more likely to induce heart toxicity in those with such conditions.

“There are issues around clinical trials; in the cancer world clinical trials can save lives. Minorities have difficulty with access to clinical trials. We don’t understand whether regimens will work as well for you. There is the issue of whether proven therapies are available for you because of costs and insurance coverage. Or whether these will be more toxic for you because of a certain genetic makeup. We don’t know what effect it will have for you.” – Provider

Survivorship

Providers characterized survivorship as a vital stage of ongoing care that prevents recurrences and poor outcomes, including permanent disabilities and early mortality. Survivors described the many challenges they faced following treatment that are often exacerbated by racism. Some were referred to breast cancer support groups and ongoing services; yet many others felt adrift and without connection to their treatment facility nor to other sources of emotional/mental health, social service or medical support.

Comprehensive survivorship programs. Optimal survivorship programs were described as much more robust, long-lasting, and vital as integrated into ongoing care, rather than just optional services that ease transition out of care. Providers in Will and Cook counties noted that they offer many free supports to patients as they leave treatment to enhance survivorship, from genetic testing for those with high-risk profiles, to mental health counseling, stress reduction options such as yoga and fitness programs, and resource listings that assessments have shown to be of continued value. Access to physical and occupational therapy early on was found to decrease risk of long-term impacts. Some survivorship programs embed a social worker for social issues such as food security, transportation, caregiver support and depression.

Partnerships to offer wellness programs through accessible and trusted, local venues, such as the Mile Square Englewood Clinic in South Side Chicago, an FQHC, noted by several survivors and providers alike as being important. Here again during survivorship, patient-centered care was described as being vital.

“The most important thing I do is build trust and help them understand it’s a partnership and explaining things in a way that makes sense to people. Helping people feel empowered and feel that nothing is being done to them and they are choosing options that they feel comfortable. People stay within the care system if they feel it is benefiting them. Ultimately all of survivorship is shared decision making. A lot is not evidence-based and so you have to discuss risks vs benefits of each option. The risks are being taken by the patient and not the provider and so you have to discuss the implications of each treatment option.” – Provider

Lack of follow-up post treatment. Many survivors shared that they lacked access to such comprehensive services. Some were not given basic information on what to expect post treatment and how to monitor the course of their illnesses. They also discovered that providers may not be fully overseeing their progress. One woman, for example, was told that she would be fine after treatment, and thought she was being fully checked during her recovery, but learned after the fact that post-treatment screenings did not check for bone metastasis (which she discovered when she fell and broke her leg).

“I'm back to work and I'm moving around. I'm coming home and I'm coming up the stairs and my foot slipped and I busted up this leg. And when I got in there and doctors went in to check it out, they said it was cancer in the bone, and I'm like, ‘Okay. So, I was doing my exams.’...They ain't checking the whole body.” – Survivor

Survivors from Lake County, IN, tended to more frequently describe a lack of support services for breast cancer after treatment. They spoke of the need for ancillary services for women’s health and wellbeing in general. Recommendations to Komen, echoed by several participants, were to open up information and support centers in Lake County, IN, focused on breast cancer, but also other areas of women’s health.

“We have medical services, doctors, but I don't think we have services to do with other supports, ancillary...There are social services, but it's [hard to find.] As far as for breast cancer, you can go to the hospital. You don't know when they are having seminars. There is nothing like a woman's outreach resource center.” – Undiagnosed

Even in the City of Chicago, limited support services were said to exist, and social services were noted to have month-long wait periods. Patient navigators described the need for community drop-in centers that are culturally competent and that link cancer patients and survivors to the resources they need in real time throughout the continuum of care, including those that address SDOH and needs for childcare. Such wraparound care could be facilitated through facilities with strong linkages.

“They need a place that they can be and feel like this is my community...But again, it needs to be a culturally competent facility in the community that is familiar with the cultural norms of the population that they are serving. So, they need to have more centers suited around that social support for those who are going through the process that would make a lot of sense. A competent place that's pretty, and that was aesthetically nice, and because our places are cold and static. Because again, when somebody is going through a process, it's more than just the illness. There's a lot of things that are attached to that. And you can't just really address one without addressing the other. Then you would do yourself a disservice for what you're even providing.” – Patient Navigator

Insurance barriers. Significant insurance barriers arose during survivorship. Survivors described not being able to maintain continuity of care.

“I even went last year to see my cancer doctor; I hadn't seen him in a while because my insurance has changed. And so, when I went now I have Medicare, and they were like, ‘We don't take this insurance.’ I'm like, ‘Why did you give me an appointment?...This is the doctor I've been seeing for five years now, since I've had cancer.’ They was like, ‘No, doesn't matter.’” – Survivor

Participants further reported that insurance discriminated when approving or denying essential services they needed to maintain quality of life. Self-advocacy and support from the doctor (for example, a survivor received a listing of laws from their doctor's office that specify what they should be entitled to) helped them overcome such barriers.

“I feel that I was just discriminated against. I felt when after surgery and I was just told that I should be able to get equipment that I needed after surgery. That the insurance should cover it no questions asked, but that didn't happen. That did not happen initially, but it has since changed because...I did speak to the insurance and I had...a sheet with some kind of laws that they gave me at the doctor's office saying that I should be entitled to this...I felt that [it was because of the color of my skin] because I didn't hear anybody else complaining about it.” – Survivor

Genetic testing as preventive health. Disparities in access to genetic counseling, testing and follow-up preventive options and surveillance were raised as missed opportunities to reduce the burden of breast cancer among Black women. A provider analyzed patient records at their Chicago FQHC and found that 30 percent met characteristics such that they would benefit from genetic counseling.

“Access to genetic counseling is part of their survivorship. If you are African American you are less likely to get the necessary genetic counseling and even if you are a genetic carrier you are less likely to get access to surveillance and preventive services. There should be mandates and standards to survivorship care and it should be mandated in minority communities.” – Provider

This provider observed that this also serves as an example of how analysis of FQHC data could be used for much needed research on breast cancer survivorship and other areas of racial and ethnic health disparities among underserved populations. Such research was said to be limited as FQHC data is not compiled in a national database.

“We need research on underserved populations. A lot of things we can't do is because we don't have that information. 28 million Americans use FQHC every year, 95% are at or below poverty level, minority, uninsured. Yet there is no national database at all; although everybody is acutely aware that this is the population with the greatest disparities.” – Provider

Social determinants of health. Staying healthy post-treatment relies upon access to not only health care and direct breast cancer services, but to an array of SDOH that Black women described as not being readily available in all neighborhoods and households. Among these is a lack of access to healthy foods,

with food deserts described in Black neighborhoods of East Chicago and South Chicago, IL, and Lake County, IN. Prejudiced assumptions about Black communities were thought to contribute to lack of healthy food options, while transportation barriers and economic declines were also mentioned as root factors.

“Because I ended up having breast cancer, I lost my house. I couldn't live in it, so I tried to find something that was comfortable to what I had, for me and my son.” – Survivor

“The grocery stores in our neighborhoods, for the most part, a lot of what they are selling is not healthy. They keep what they think ‘we’ eat, and not all of us eat that way [chips, sodas]. That’s what they put on their shelves, and if they don’t have transportation then they’re stuck at that store.” – Undiagnosed

“TriCity is a food desert, there is no place you can shop. They have to come here [to Gary].” – Undiagnosed

Women over 65 in Lake County, IN, found the availability of Medicare-sponsored exercise programs such as Silver Sneakers very helpful. Younger women, or those either far from or unaware of such programs, found it hard to identify affordable, convenient exercise programs.

“[Komen could offer] a wider range of services afterwards. Maybe some healthy cooking classes, discounts for exercise or fitness classes, because every doctor will tell you, ‘Well, you know you need to exercise.’” – Survivor

Daily discriminations. The daily emotional, physical and economic stresses survivors faced directly affected their survivorship experiences. Compounding the difficulties, survivors discussed incidents of microaggressions. For example, they discussed encounters in stores, where security followed them around and accused them of being lazy when they needed to use a cart to ride in due to weakness from treatment or injuries.

“If I go... I'm going to have to ride in the cart; me in the walker can't go far. Especially with this bad leg; it swells up real bad. They were like, ‘Why are you on that cart? Why all the Black folks want to ride the cart instead of walking around?’...And that's exactly how the [white] folks see you. They don't care whether you're handicapped or not. They see the color of the skin and think that you're a little chunky and you're lazy.” – Survivor

Black women countered such experiences of daily discrimination and racism that surround them with great pride and resilience.

“I love being Black. The strong sense of community just walking down the street, the instant connection I feel with people who nod and smile or say hello. And my white friends will be like, ‘You know them?’ I'm like, ‘I don't have to.’ It's like a top secret club. I love it. So, it's just a beautiful thing and I'm so proud of being a Black woman and surrounded by other Black women.” – Undiagnosed

“What I love about being Black is our creativity knows no bounds. When I look at Black people here, and the diaspora on the continent, we're just so creative in every aspect of our lives. It's just beautiful and amazing and I'm so proud.” – Undiagnosed

“Being a Black woman, unashamed, unapologetically Black. I love our skin texture, tone, our attitude our swag. Our pizzazz, our strength. I love being Black...The one powerful thing, looking at our ancestral backgrounds, the strength - all that our people have been through.” – Undiagnosed

Importance of Komen racial equity work. Community participants valued Komen’s commitment to breast cancer over the years and appreciated that they had been asked their views on addressing the needs and building upon existing assets in their communities. They felt that the name Susan G. Komen would inspire trust in resources were Komen to extend into the Lake County, IN, area.

“Could [they] [sic] open a brick and mortar place [support center] with her name on it? Because everybody knows Susan G. Komen. People would just flock to that because of the name and the support [they’ve] given over the years. That would help a lot. They have that cancer walk in Chicago every year. If [they] could branch out with her name that would be good. There are plenty of vacant buildings around here.” – Undiagnosed

“I just wanted to thank you all for taking the time out of your day to come here and it's very important that you're here and we appreciate you.” – Survivor

Section 2 Findings: Systemic and Social Determinants of Health

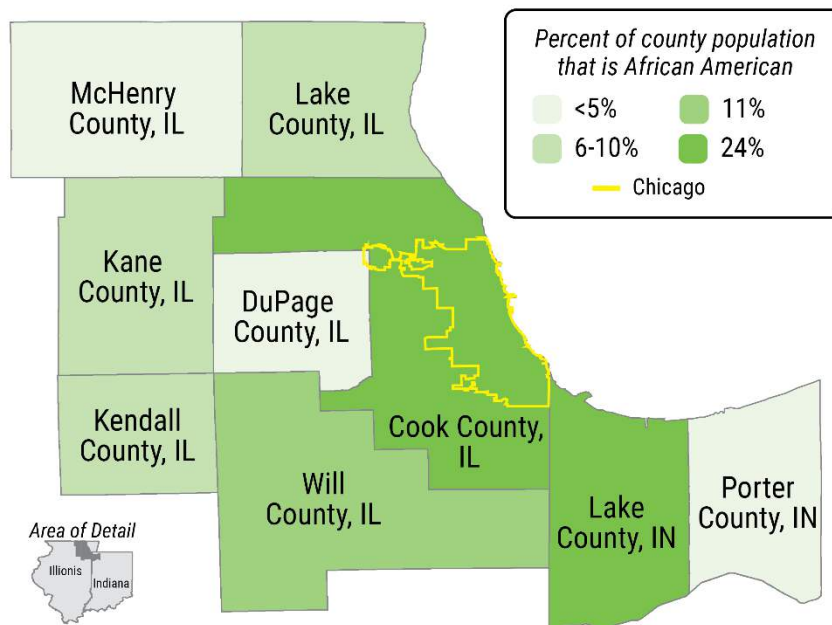
Section 2 explores the systemic and SDOH that may drive breast cancer inequities. The set of factors explored in this section—residential segregation, economic vulnerability, experiences of racism, SDOH—were informed by consultations with Komen’s team, academic experts (see Acknowledgements for details),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

Residential Segregation

The Chicago MTA is segregated along racial and socioeconomic lines, creating stark contrasts by geography. Approximately 3.2 million people of color live in the Chicago MTA, comprising 35 percent of the region’s total population (see “Minority Race” in Table 3). More than half of the approximately 1.6 million Black residents who live in the Chicago MTA reside in Cook County, IL (see Tables 3 and 4).

Both Cook County, IL, and the less populous Lake County, IN, have populations that are 24 percent Black. Conversely, McHenry County, IL, DuPage County, IL, and Porter County, IN, have populations that are less than 5 percent Black (see Map 3 and Table XX in the Appendix).

MAP 3. CHICAGO METRO AREA AFRICAN AMERICAN POPULATION



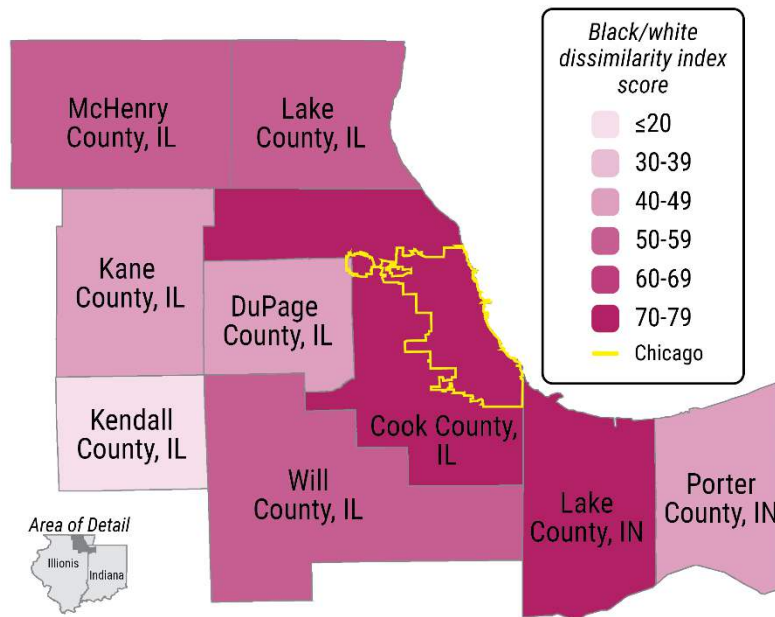
Source: American Community Survey 2013-2017 5-Year Estimates (U.S. Census Bureau)

In addition to the MTA as a whole being racially segregated (with most people of color living in just a few of the counties: predominantly Cook County, IL, followed by Lake County, IN, and Will County, IL - see Map 3), many of the counties in the MTA are also internally racially segregated. Counties’ internal segregation can be measured using the Black/white dissimilarity index to assess the extent to which there may be residential segregation (see Map 4). Index scores range from 0 to 100 and correspond to the percentage of people within a racial group who would need to relocate in order for a

county to achieve integration. Zero indicates complete integration of the two races and 100 indicates complete segregation of the two races. For example, a score of 35 means that 35% of whites within a

particular county would need to move to a different neighborhood within the county in order to achieve racial integration.

MAP 4. CHICAGO METRO AREA RESIDENTIAL SEGREGATION



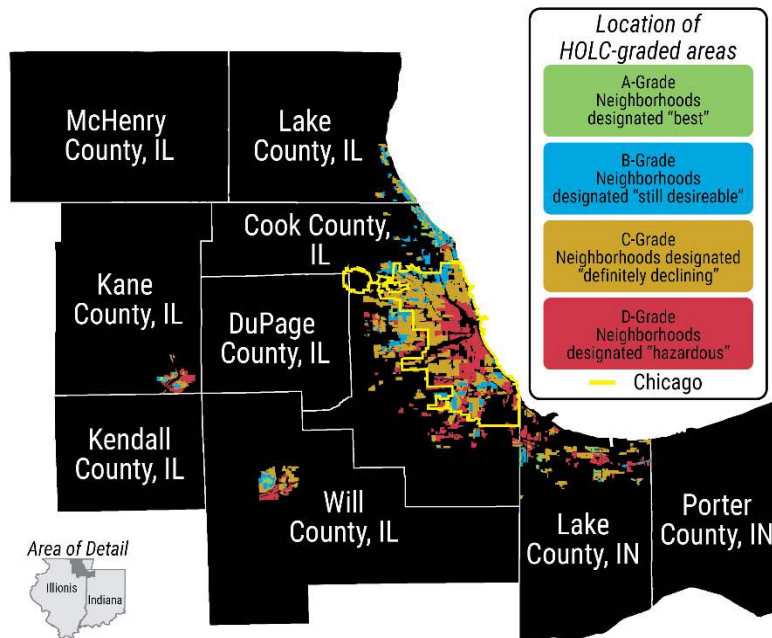
Source: 2019 County Health Rankings (County Health Rankings)

As seen in Map 4, Cook County, IL, has the highest score (78), indicating that it is the most segregated place in the MTA. Lake County, IN, has the next highest score at 74. Counties' scores decrease the further one moves away from the Chicago epicenter, with Kendall County, IL, Kane County, IL, and Porter County, IN, having the lowest 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 Chicago 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).

MAP 5. CHICAGO METRO AREA REDLINING



Source: 2019 Mapping Inequality Project (University of Richmond)

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

lending practices and policies throughout the Chicago MTA. Map 5 shows areas within the Chicago MTA that were included in the “residential security” maps created by HOLC agents in the first half of the twentieth century. Portions of Cook County, IL, and Lake County, IL, are redlined on the 1939 map of Chicago, IL. Additionally, portions of Lake County, IN, appear on the 1937 map of Gary, IN; Will County, IL, appears on the 1938 map of Joliet, IL; and Kane County, IL, appears on the 1938 map of Aurora, IL. All four of these municipalities are located in the Chicago MTA.

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

“I was trying to secure an apartment up north [Lake Shore Drive, IN], and it was because of my color [that I was denied it]. I should have gotten it. I had the income. I had a great reference. I could afford it.” – Survivor

“Hammond [Lake County Indiana] is a very prejudice city. I've lived there all my life, and I love it, but by the same token I know that they're prejudiced. They try to cover it up. Hidden racism, and a lot of people don't know hidden racism, they think, no...Growing up in Hammond...I might've been one of the only black children in my classroom...We

couldn't go past this one park. The park is now named Martin Luther King (we got it named a few years ago)...You could go from school to maybe the Brownie leader house, but you were going to be back on your side of town before it got dark. Okay. It was just like being down South.” – Survivor

“Chicago is very segregated in neighborhoods, unlike New York City. A lot of things we recommend are challenging for patients who are afraid to go outside at night when it's dark out, concerned about the sidewalks, and so I have to modify my recommendations to an indoor mall and walk around the mall...People are starting to look at air quality in different neighborhoods. We see cancer clusters that are not well investigated. The abundance of factories in that neighborhood has an impact. We would see a lot of genetic mutations and malformations that are not that far away from the University of Chicago.” – Provider

Personally Mediated Racism

Data suggest that in addition to institutionalized racism, the Black community in the Chicago 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).

TABLE 10. CHICAGO METRO AREA RACISM

County	Number of Black Residents Killed by Police	Number of Hate Crimes Committed with a Race/Ethnicity/Ancestry Bias Motivation	Number of Fair Housing Act Cases Filed with a Race Basis
Cook County, IL	22	19	1,013
DuPage County, IL	0	2	146
Kane County, IL	0	0	46
Kendall County, IL	0	0	11
Lake County, IL	1	2	90
McHenry County, IL	0	1	57
Will County, IL	1	0	19
Lake County, IN	0	2	13
Porter County, IN	0	2	184

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

As seen in Table 10, Cook County, IL, reports the highest level of racism when compared to the other counties in the Chicago MTA. In 2016 and 2017, 22 Black people were killed by the police in Cook County (See Table 10). Further, in Cook County, IL, there were 19 hate crimes committed with a racial bias motivation in 2015, and 1,013 Fair Housing Act cases filed with a racial basis since 2006. No other county in the region reports the same level of racism as measured by these data points; aside from Cook County, no other county reports more than two Black residents killed by the police or more than 200 Fair Housing Act cases filed with a racial basis.

“Well, I like to say: ‘Where have I not seen it [racism]?’...I mean I’ve seen it everywhere. I see it every day. I almost see it every minute.” – Undiagnosed

The experiences of community members from the Chicago MTA provide additional insights about experiences of racial segregation and of personally mediated racism that the Black community experiences. As noted above (see Findings I), focus group participants reported receiving poorer quality care and differential treatment at the diagnosis and treatment stages in the breast cancer continuum. Focus group participants reported encountering racial segregation and discrimination in their neighborhoods that shifted over time. Racism contributed to general stress and poor SDOH. It also affected ability to access resources, including health care. Participants discussed mixed race neighborhoods where they didn’t experience divisions, such as the harbor area of East Chicago. At the same time periods, areas closer to the inner city of Chicago were said to be very segregated, such that Black people could not even visit or travel through safely.

“I grew up in East Chicago. I grew up going to school with the white people, Mexicans, Puerto Ricans – back then we all go along. My dad all his friends were White guys. Over by the Harbor...” – Undiagnosed

“You didn’t live in East Chicago proper then. Because over in Bishop knoll it was prejudiced. The harbor was different...There was a time, back in the 50s, when Black people couldn’t go to downtown Chicago, only if you were a maid.” – Undiagnosed

“I’m from Chicago and I used to really hate this city. It’s so segregated...But I love it now because of the diverse things that you can do in the summer; it’s really awesome. And because I’m older and more mature. And Chicago is a pretty city and I love...the transportation.” – Undiagnosed

Participants shared that Gary, IN, used to be predominantly white and had been segregated to the extent that Black people were not previously allowed to freely enter the building on Main Street where the focus groups for this project had been held. Over time, as Black residents moved into Gary, white people moved out to their own neighborhoods that they renamed to distinguish from Gary. Many described the economic depression, caused in part by white flight that has faced Black communities in

Lake County, IN. Nevertheless, they also described how a deep sense of community and social cohesion abounded.

“Blacks used to not live in this area of Gary. This building, it was the Gary hotel. Blacks had to go in the back of the building...Once Blacks came in the whites moved to Merrillville. Merrillville used to be part of Gary. All these big houses used to be white owned. Lake Station was East Gary, IN, then they changed the name once Gary became majority Black.” – Undiagnosed

“I was born and raised here. And I like Gary [Indiana] because we have a lot of beautiful spirited people just like the people in this room.” – Undiagnosed

“I try to keep a positive attitude about Gary, hoping that it will get back to the way it used to be and get better.” – Undiagnosed

Participants living in Will County, IL, similarly described a range of experiences, from being among the only Black children growing up with white children without noticing discrimination leveraged against them, to pervasive experiences of day-to-day racism. As one participant described it, the day-to-day prejudices in the area can make them feel trapped; yet many said they stayed because of work or family.

“I really don't like it [in Joliet] but I got stuck...because the racial thing was still blunt...Where I came from it was bad and came here, it was worse. I thought I was going to a bad place, but it was much worse. The first [bad experience] I had was the pass on Collin Street. Trying to rent an apartment above a drugstore. The XX of disasters. But I got life and I got stuck. Then I had kids, kids, kids, four of them and I just got stuck in a rut and decided to stick it out.” – Undiagnosed

“I was born and raised here, so that means I've been here for 69 years and I really like Joliet and actually my father was one of the first African American Police officers with the city of Joliet. My father had a lot of Caucasian and all color friends, and they all stood together. I had a great experience with a lot of them coming to my parents' house every year we had what they called was a Policeman's picnic and we were basically the only African American kids that were there, but you couldn't tell. So, it was really hard for me to say that I was in town with racists to a young girl who lived in Joliet because of the environment I was in and surrounded with because of my parents.” – Undiagnosed

Health Disparities

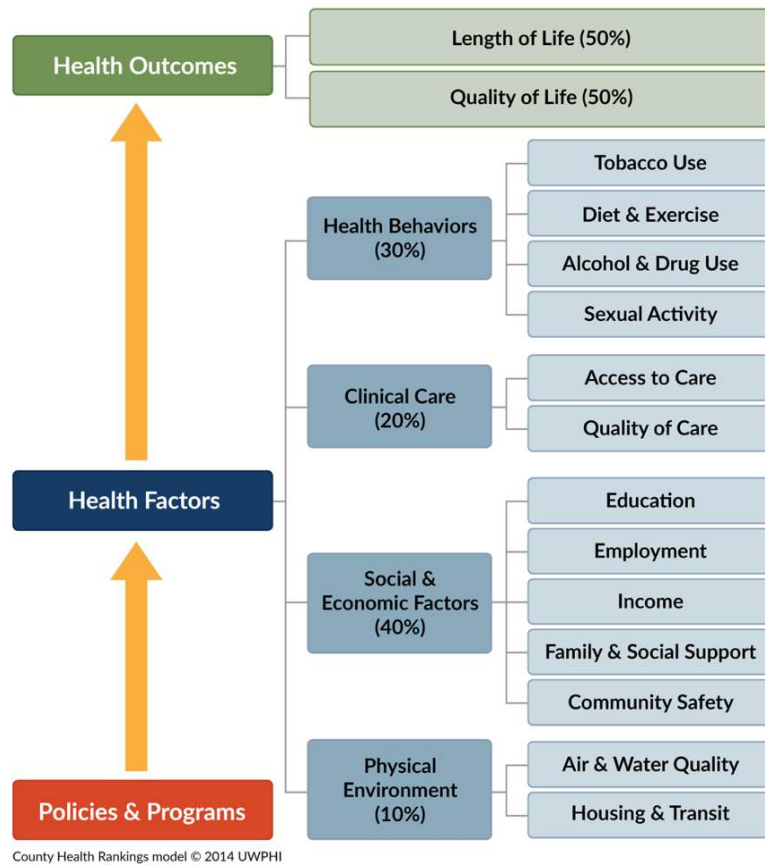
TABLE 11. CHICAGO METRO AREA HEALTH AND WELLBEING

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
Cook County, IL	51%	18%	3.6	3.6
DuPage County, IL	2%	14%	3.4	3.1
Kane County, IL	6%	16%	3.6	3.1
Kendall County, IL	3%	13%	3.3	3.2
Lake County, IL	9%	15%	3.5	3.2
McHenry County, IL	5%	13%	3.4	3.3
Will County, IL	12%	14%	3.4	3.1
Lake County, IN	78%	19%	4.1	3.9
Porter County, IN	29%	17%	3.8	3.9

Source: 2019 County Health Rankings (County Health Rankings)

Data suggest that there are significant disparities in the Chicago MTA in terms of overall health and wellbeing. In Lake County, IN, 19 percent of adults report that their health is “fair” or “poor” (Table 11). In Kendall County, IL, and McHenry County, IL, on the other hand, only 13 percent of adults report that they have “fair” or “poor” health. All counties in the MTA report that their residents have between 3.3 and 4.1 poor physical health days per month, with Kendall County, IL, reporting the fewest days and Lake County, IN, reporting the most days. In terms of mental health, residents of DuPage County, IL, Kane County, IL, and Will County, IL, report the fewest number of poor mental health days per month (3.1 days in all three counties). Residents of Lake County, IN, and Porter County, IN, report an average of 3.9 poor mental health days every month, the most of any place in the MTA.

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). Five of the six Illinois counties in the MTA rank in the top 12 percent of all counties in Illinois (which is composed of 102 counties). Cook County, IL, is the outlier, falling in the 51st percentile in the CHR. In Indiana, which has 92 counties, Porter County, IN, ranks in the 29th percentile while Lake County, IN, ranks quite low, in the 78th percentile of the CHR (see Table 11).

TABLE 12. CHICAGO METRO AREA HEALTH BEHAVIORS

County	Percent of Adults Who Are Obese	Percent of Adults Who Drink Excessively	Percent of Adults Who Are Physically Inactive
Cook County, IL	27%	22%	21%
DuPage County, IL	25%	22%	17%
Kane County, IL	29%	21%	17%
Kendall County, IL	30%	24%	20%
Lake County, IL	25%	18%	19%
McHenry County, IL	31%	23%	20%
Will County, IL	31%	21%	22%

Lake County, IN	35%	17%	27%
Porter County, IN	34%	20%	24%

Source: 2019 County Health Rankings (County Health Rankings)

Lake County, IN, reports the highest rate of obesity in the MTA, with 35% of adults who are obese and 27% of adults who are physically inactive (Table 12). Kendall County, IL, has the highest rate of excessive drinking, with an estimated 24% of its population engaging in excessive drinking. DuPage County, IL, has comparatively low rates of obesity and physical inactivity (25% and 17%, respectively), but they have a considerable rate of excessive drinking (22% of adults).

TABLE 13. CHICAGO METRO AREA LIFE EXPECTANCY

County	Life Expectancy	Life Expectancy for Whites	Life Expectancy for Blacks
Cook County, IL	79	81	73
DuPage County, IL	83	82	80
Kane County, IL	82	81	77
Kendall County, IL	82	81	79
Lake County, IL	82	81	77
McHenry County, IL	80	80	81
Will County, IL	80	79	78
Lake County, IN	76	77	73
Porter County, IN	79	78	75

Source: 2019 County Health Rankings (County Health Rankings)

Life expectancy in the MTA is lowest in Lake County, IN, at 76 years (Table 13). It is only slightly higher in Cook County, IL, at 79 years. Notably, the life expectancy for white people in Cook County, IL, is considerably higher for white people (81 years) than it is for Black residents (73 years). Cook County's life expectancy for Black people is tied for the lowest in the MTA with Lake County, IN. The disparity between whites and Blacks in Cook County, IL, is the greatest at eight years. The county with the highest life expectancy for Blacks is McHenry County, IL, where Black residents live an average of 81 years. The highest overall life expectancy (not disaggregated by race) is in DuPage County, IL, at 83 years.

TABLE 14. CHICAGO 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
Cook County, IL	338	281	583
DuPage County, IL	212	230	300
Kane County, IL	242	255	427
Kendall County, IL	241	248	319
Lake County, IL	242	249	445
McHenry County, IL	270	284	233
Will County, IL	281	293	367
Lake County, IN	428	407	588
Porter County, IN	347	354	436

Source: 2019 County Health Rankings (County Health Rankings)

Premature age-adjusted mortality measures the number of deaths per 100,000 among people under age 75. Lake County, IN, has the highest premature age-adjusted mortality rate, at 428 (Table 14). In Cook County, IL, the disparity between age-adjusted mortality rate among white people (281) and Black people (583) is by far the greatest of any county, with a disparity of 302 deaths. The premature age-adjusted mortality rate is lowest in DuPage County, IL, at 212. The county with the lowest racial disparity between white and Black people is McHenry County, IL, where the premature age-adjusted mortality is 284 for whites and 233 for Blacks. McHenry County, IL, is also the only county where the number is higher for whites than Blacks; in every other county, the age-adjusted mortality rate is higher for Black residents.

Access to Health Services

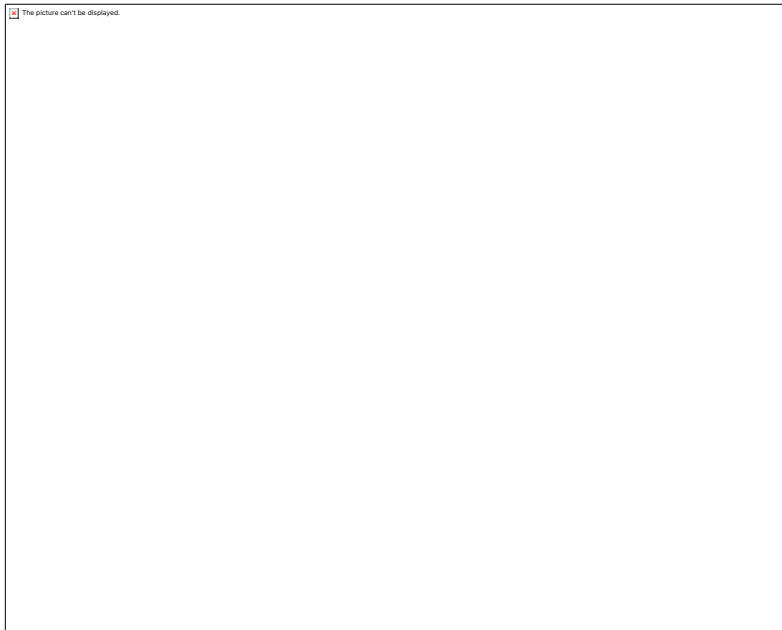
TABLE 15. CHICAGO METRO AREA HEALTH SYSTEMS

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
Cook County, IL	64%	4,977	1,046	71	1,410	3,477	8
DuPage County, IL	5%	1,231	755	72	1,392	1,221	5
Kane County, IL	12%	225	2,363	64	1,563	223	2
Kendall County, IL	0%	46	2,711	29	3,411	48	3
Lake County, IL	17%	772	911	63	1,595	764	2
McHenry County, IL	9%	158	1,943	41	2,415	129	1
Will County, IL	6%	391	1,764	53	1,882	282	4
Lake County, IN	26%	269	1,806	69	1,450	264	5
Porter County, IN	100%	99	1,695	54	1,851	91	1

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

Data suggest that there are significant disparities in the health system in the Chicago 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 Porter County, IN, 100 percent of the population is medically underserved. In Cook County, IL, 64 percent of the population is medically underserved (Table 15). In Kendall County, IL, none of the population is medically underserved, and in Will County, IL, only 6 percent of the population is medically underserved.

MAP 6. HEALTH SYSTEMS IN THE CHICAGO METRO AREA



The health systems map (Map 6) shows the concentration of health care facilities across the Chicago MTA. Most resources are centered around the city of Chicago in Cook County, IL. Specifically, most of the Federally Qualified Health Centers (FQHCs) and hospitals are in Cook County, IL, as well as the MTA’s two comprehensive cancer centers. The majority of the screening mammogram facilities are located in Cook County, IL, as well as the counties immediately surrounding it. For example, there is a high concentration of screening mammogram facilities in DuPage County, IL.

Source: HRSA Data Warehouse, 2019 dataset (U.S. 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)

Over the past 20 years, 22 percent of Cook County's hospitals have closed. Recent plans are to close additional

safety-net hospitals, the latest, Mercy hospital, slated to close December 1, 2020 (Goudie, Markoff, Tressel, & Weidner, 2020). This would be the fourth hospital on the South or West sides to close since 2018. Two health centers have also been recently slated to close on December 1, 2020 -- Cook County Health's (CCH) Woodlawn and Near South health centers (Gettinger, 2020).

TABLE 16. CHICAGO METRO AREA BREAST CANCER RESOURCES

County	Number of Mobile Screening mammography Centers	Number of Cancer Coalitions	Number of Survivor/ Support Groups
Cook County, IL	70	2	46
DuPage County, IL	0	0	0
Kane County, IL	0	0	0
Kendall County, IL	0	0	0

Lake County, IL	0	1	0
McHenry County, IL	11	0	0
Will County, IL	0	1	3
Lake County, IN	0	0	0
Porter County, IN	0	0	0

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

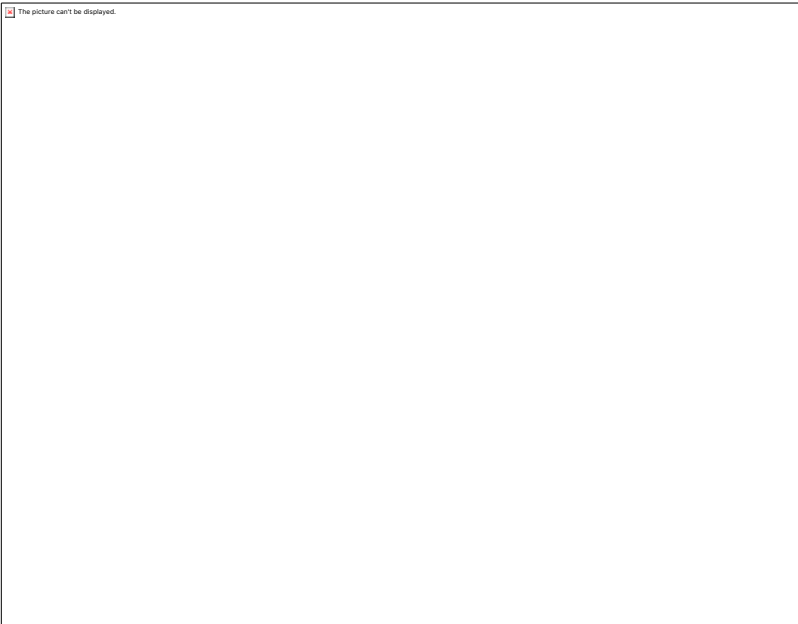
As with health care facilities, most of the specific breast cancer resources in the Chicago MTA are located in Cook County, IL. The county has 70 mobile screening mammography centers, two cancer coalitions, and 46 survivor support groups (Table 16). All three of these measures are significantly higher in Cook County, IL, than any other county in the MTA, where these resources are virtually nonexistent. The only exceptions are in McHenry County, IL, which has 11 mobile screening mammography centers, and Will County, IL, which has one cancer coalition and three 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, Wise, Palmer, & Rosenberg, 2009; Institute of Medicine of the National Academies, 2011).

MAP 7. CHICAGO METRO AREA SOCIAL VULNERABILITY



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. Lake County, IN, has the highest SVI score at 0.73, with Cook County, IL, coming in close behind at 0.69. Kendall County, IL, and McHenry County, IL, have the lowest SVI scores, at 0.11 and 0.08, respectively. Individual factors influencing a county’s SVI score can be parsed by looking at specific indicators.

Source: 2016 Social Vulnerability Index (U.S. Centers for Disease Control and Prevention)

TABLE 17. CHICAGO METRO AREA ECONOMIC SECURITY

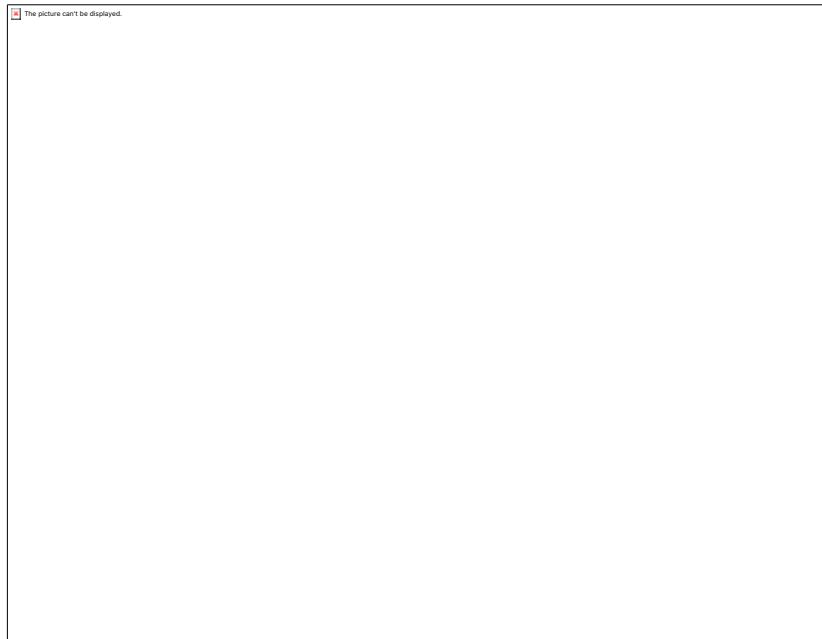
County	Percent of Population That Is Uninsured	Percent of Population Below 200% FPL	Percent of Black Women Over Age 45 Who Live Below Poverty Level
Cook County, IL	10%	34%	22%
DuPage County, IL	5%	18%	16%
Kane County, IL	9%	26%	16%
Kendall County, IL	4%	18%	4%
Lake County, IL	7%	22%	15%

McHenry County, IL	6%	18%	12%
Will County, IL	7%	20%	9%
Lake County, IN	5%	35%	13%
Porter County, IN	10%	24%	21%

Source: American Community Survey 2013-2017 5-Year Estimates (U.S. Census Bureau)

As suggested by their high SVI scores, Lake County, IN, and Cook County, IL, report the highest percentages of the population below 200 percent of the FPL in the MTA, at 35 percent and 34 percent, respectively (Table 17). Cook County, IL, also has the highest percentage of Black women over age 45 who live below the FPL, at 22 percent. In addition, Cook County, IL, and Porter County, IN, have the highest percent of the population that is uninsured, at 10 percent in each county. Will County, IL, reports lower percentages across these metrics, with 7 percent of their population uninsured, 20 percent of their population below 200 percent of the FPL, and 9 percent of Black women over age 45 below the FPL.

MAP 8. CHICAGO METRO AREA HOUSING-COST BURDEN



The measure illustrated in Map 8 indicates the percentage of renters and homeowners that spend 30 percent or more of their total income on housing. Cook County, IL, reports the highest percentage in the MTA, with 38 percent of households defined as housing-cost burdened. Other counties in the MTA range between 24 percent (in Porter County, IN) and 33 percent (in Kane County, IL) (Map 8).

Source: 2016 Comprehensive Housing Affordability Strategy dataset (U.S. Department of Housing and Urban Development)

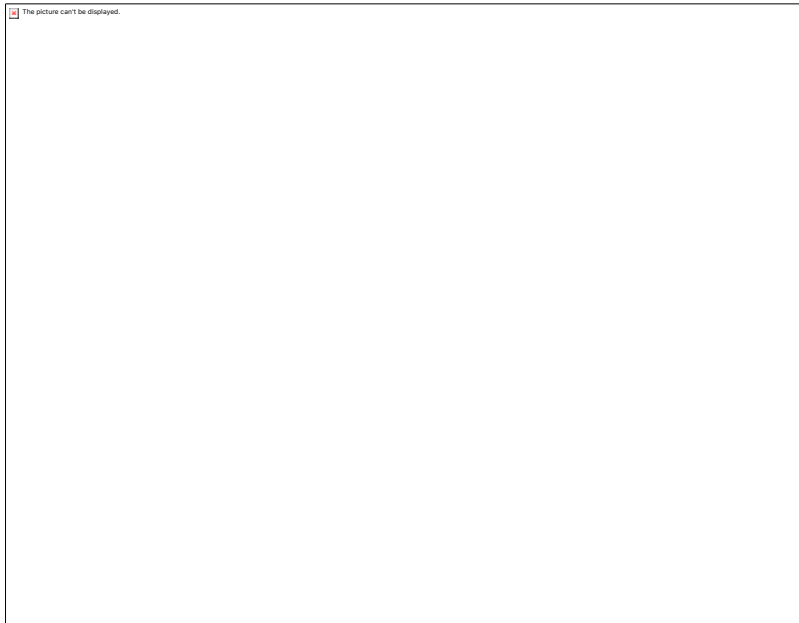
TABLE 18. CHICAGO METRO AREA FOOD SECURITY

County	Percent of Population That Is Food Insecure	Percent of Total Population with Limited Access to Healthy Foods	Percent of Black Households Receiving SNAP/EBT
Cook County, IL	13%	2%	33%
DuPage County, IL	7%	4%	20%
Kane County, IL	6%	4%	35%
Kendall County, IL	6%	3%	25%
Lake County, IL	7%	6%	31%
McHenry County, IL	8%	6%	28%
Will County, IL	11%	8%	16%
Lake County, IN	7%	7%	24%
Porter County, IN	15%	10%	30%

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

With regard to food security in the Chicago MTA, Kane County, IL, has the highest percent of Black American households receiving SNAP/EBT at 35 percent (Table 18). Cook County, IL, comes in close behind at 33 percent of Black households receiving SNAP/EBT. Only 2 percent of the total population in Cook County, IL, has limited access to healthy foods, although 13 percent of the population is food insecure and participants describe barriers in accessing healthy foods that, while in proximity, are difficult to reach by public transportation and/or to afford. Will County, IL, has 16 percent of Black households receiving SNAP/EBT, which is the lowest in the county. At the same time, it reports that 11 percent of its total population is food insecure, and 8 percent of the population is defined as having limited access to healthy foods.

MAP 9. FOOD DESERTS IN THE CHICAGO METRO AREA



As seen in Map 9 most of the food deserts in the MTA are located in southern Cook County, IL, as well as in Lake County, IN, and Will County, IL. Food deserts are census tracts designated by the USDA as low-income areas with low access to food within one mile. There are no food deserts in Kendall County, IL, and the remaining counties have few or small food deserts.

Source: 2019 Food Research Atlas (U.S. Department of Agriculture, Economic Research Service)

TABLE 19. CHICAGO METRO AREA TRANSPORTATION

County	Percent of Households Without a Vehicle	Percent of Total Population That Commutes More Than 45 Minutes to Work	Percent of Total Population That Commutes to Work Using Public Transit	Percent of Total Population That Commutes to Work by Foot/Bike/Other
Cook County, IL	18%	28%	19%	7%
DuPage County, IL	4%	22%	7%	3%
Kane County, IL	5%	23%	3%	3%
Kendall County, IL	2%	29%	3%	2%
Lake County, IL	5%	23%	4%	4%
McHenry County, IL	4%	29%	4%	2%
Will County, IL	4%	17%	1%	3%
Lake County, IN	4%	32%	3%	2%

Porter County, IN	9%	20%	3%	3%
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Source: 2019 County Health Rankings (County Health Rankings); American Community Survey 2013-2017 5-Year Estimates (U.S. Census Bureau)

Cook County, IL, is the most urban county in the Chicago MTA and has by far the highest percentage of households without a vehicle (18%), as well as the highest percent of the population that commutes to work using public transportation (19%) or by foot/bike/other (7%) (Table 19). Many of the counties on the western side of the MTA, such as Kane County, IL, Kendall County, IL, and McHenry County, IL, have much lower percentages of households without a vehicle (2%-5%). Lake County, IN, has the highest percent of the total population that commutes more than 45 minutes to work at 32 percent.

TABLE 20. CHICAGO 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
Cook County, IL	86%	37%	13%
DuPage County, IL	92%	48%	7%
Kane County, IL	83%	32%	14%
Kendall County, IL	92%	35%	7%
Lake County, IL	90%	44%	12%
McHenry County, IL	91%	34%	3%
Will County, IL	92%	28%	6%
Lake County, IN	93%	33%	8%
Porter County, IN	88%	21%	10%

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

Lake County, IN, and Will County, IL, are two of the counties with the highest percent of the population over age 25 that has a high school degree or higher, at 93 percent and 92 percent of the population, respectively (Table 20). DuPage County, IL, has the highest percent of the population over age 25 that has a bachelor's degree or higher, at 48 percent. Lake County, IL, and Cook County, IL, have the highest

percent of Black women over age 25 without a high school degree, at 12 percent and 13 percent, respectively.

TABLE 21. CHICAGO METRO AREA GENTRIFICATION

County	Proportional Change in Population With a Bachelor's Degree or Higher	Percent Change in Median Household Income
Cook County, IL	3%	9%
DuPage County, IL	2%	8%
Kane County, IL	1%	9%
Kendall County, IL	1%	7%
Lake County, IL	2%	5%
McHenry County, IL	1%	6%
Will County, IL	2%	6%
Lake County, IN	2%	7%
Porter County, IN	2%	6%

Source: American Community Survey 2013-2017 5-Year Estimates (U.S. Census Bureau); American Community Survey 2008-2012 5-Year Estimates (U.S. 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. Cook County, IL, and Kane County, IL, both report a 9 percent change in the proportional change in median household income (Table 21). All counties in the MTA have a positive proportional change in the population with a bachelor's degree or higher, yet all counties report relatively low proportions, with Cook County, IL, having the highest proportional change at 3 percent.

Policy Context

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

The Patient Protection and Affordable Care Act (ACA)

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

- **Preventive Services Mandate.** The preventive services mandate requires that almost all private health insurance plans cover certain preventive services without patient cost sharing. This mandate does not apply to grandfathered plans or policies, a very minor share of plans in existence prior to the passage of the Affordable Care Act on March 23, 2010, that have not undergone major changes to benefits. These preventive services are determined by guidelines from expert clinical entities, including the U.S. Preventive Services Task Force (USPSTF) and the Health Resources and Services Administration (HRSA). In accordance with these guidelines, plans must provide coverage for mammograms beginning at age 40 without cost sharing. For women at high risk of breast cancer, plans must also cover genetic screening and preventive medication for breast cancer (The Henry J. Kaiser Family Foundation, 2015).
- **Pre-Existing Conditions Protections.** Per the ACA and effective as of 2014, health insurers cannot deny coverage to an individual or charge more for coverage due to a pre-existing condition. For example, insurers cannot discriminate based on a previous or current breast cancer diagnosis or other health condition. Additionally, health insurers cannot refuse to provide coverage for treatment and other services related to a pre-existing condition (U.S. Department of Health & Human Services, 2017).
- **Medicaid Expansion.** Under the ACA, states have the option to expand their Medicaid program to individuals with incomes of up to 138% of the FPL. Both Illinois and Indiana (the two states relevant to the Chicago MTA for Komen's Stand for H.E.R.) have elected to expand their Medicaid programs.

Recent research indicates that the uninsured rate among nonelderly adults has decreased for all racial/ethnic groups with larger decreases among non-Hispanic Black and Hispanic groups compared to non-Hispanic whites. See Figure 3 below for trends of uninsured rates for the nonelderly in Illinois and Indiana (2013-2017), comparing rates among Black and white residents in each state. There is an overall downward trend of uninsured rates for both Blacks and whites in Illinois and Indiana, but an inequity in uninsured rates remains between the groups.

The coverage disparities have narrowed compared to before the ACA, but disparities in coverage by race and ethnicity remain (Artiga, Orgera, & Damico, 2020). Regarding screening, research

suggests that states that expanded their Medicaid program eligibility standards have improved cancer screening rates compared to states that did not, and that early adoption of the Medicaid expansion is associated with greater improvements in screening (Fedewa et al., 2019; Swift, 2019). Some studies suggest it is possible that the racial disparity in mammograms has been closed or reversed (Fazeli Dehkordy et al., 2019).

FIGURE 3. TRENDS OF UNINSURED RATES FOR THE NONELDERLY IN ILLINOIS AND INDIANA



Source: JSI analysis of Kaiser Family Foundation data (The Henry J. Kaiser Family Foundation, 2018).

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

In Illinois, the screening program is known as the Illinois Breast and Cervical Cancer Program (IBCCP). Women living in Illinois, who are without insurance and are 35 to 64 years old, are eligible for this program (Illinois Department of Public Health, 2020). In Indiana, the program is called the Indiana Breast and Cervical Cancer Program (BCCP); women living in Indiana, 30 to 64 years old, at or below 200 percent of the FPL, and uninsured are eligible for this program (Indiana Department of Health, 2020). From July 2014 to June 2019, 51,192 mammograms were provided in Illinois through the NBCCEDP (Centers for Disease Control and Prevention, 2020). From July 2014 to June 2019, 9,340 mammograms were provided in Indiana through the NBCCEDP (Centers for Disease Control and Prevention, 2020).

In Illinois, women who are diagnosed (either through the ICCBP or through another means) may be eligible for treatment through the ICCBP Medicaid if they meet certain requirements. In Indiana, women who are diagnosed (either through the BCCP or through other means) may be eligible for treatment through the Indiana Medicaid program.

TABLE 22. OVERVIEW OF SCREENING IN THE CHICAGO METRO AREA

State	Age Eligibility and Screening Guidance	Insurance Status	Program Services
Illinois Illinois Breast and Cervical Cancer Program (IBCCP)	35 to 64 years old	Without insurance	Screening: Mammograms, breast exams, pelvic exams and Pap tests
Indiana Indiana Breast and Cervical Cancer Program (BCCP)	30 to 64 years old	Without insurance	Screening: Clinical breast exam, mammograms, pap test, office visit, diagnostic testing for participants whose screening outcome is abnormal

Sources: IL Breast & Cervical Cancer Program (IBCCP) (Illinois Department of Public Health, 2020), Indiana Health Coverage Program Policy Manual (Indiana Department of Health, 2015)

TABLE 23. MEDICAID FOR BREAST AND CERVICAL CANCER IN THE CHICAGO METRO AREA

State	Age	Insurance Status	Program Services
Illinois	35 to 64 years old	Without insurance	Breast cancer treatment services
Indiana	18 - 64 years old	Uninsured or underinsured (cancer treatment not covered), otherwise ineligible for Medicaid, not enrolled in Medicare	Treatment: Lumpectomy, mastectomy (partial or modified radical), sentinel node biopsy, chemotherapy, radiation, PET scans, bone scans, estrogen-blocking therapy, prescription medicine, breast reconstruction

Sources: IL Breast & Cervical Cancer Program (IBCCP) (Illinois Department of Public Health, 2020), Indiana Health Coverage Program Policy Manual (Indiana Department of Health, 2015)

Flexibility in the Medicaid Program via Medicaid Waivers

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

The Trump administration has promoted work requirements through Medicaid waivers which have previously not been approved (Brooks, Roygardner, & Artiga, 2019). Several states have applied to enact work requirements, meaning that Medicaid eligible enrollees would have to report working a certain number of hours or involvement in a volunteer role, in school, or in time spent looking for a job. Their Medicaid coverage would be contingent on meeting these requirements. Illinois has not implemented work requirements for its Medicaid program, but Indiana has implemented such requirements through its Medicaid expansion (The Henry J. Kaiser Family Foundation, 2020).

Unlike most other states that elected to expand their Medicaid programs, Indiana expanded its program by employing a Section 1115 Medicaid waiver (Section 1115 of the Social Security Act); this program is called the Healthy Indiana Program. In its current state, the Healthy Indiana Program includes the following restrictions (Musumeci, Rudowitz, & Hinton, 2018):

- Imposes work requirements and restricts Medicaid eligibility based on meeting those work requirements.
- Charges monthly premiums for adults in the expansion population and low-income parents
- Imposes a “coverage lock-out” of six months if individuals do not pay premiums within a 60-day grace period.
- Disenrolls adults who do not complete their Medicaid eligibility renewal process within a specified time.

Work requirements in Medicaid are a widely criticized strategy that constrict access to Medicaid coverage, do not reach their purported goal of increasing work among Medicaid enrollees, and likely harm health by limiting access to insurance coverage (Cauley Narain & Zimmerman, 2019). CMS bases the work requirements on the assumption that work improves health, but such an assumption is flawed, particularly for Medicaid enrollees (Centers for Medicare & Medicaid Services). Research indicates that healthier Medicaid enrollees are more likely to be able to work, and that Medicaid enrollees with more serious illnesses are unable to work due to their debilitating illnesses and the burden of treatment. Other enrollees who are not working are often students or caregivers for family members (Garfield, Rudowitz, Orgera, & Damico, 2019). Further, most adults enrolled in Medicaid are already working. Among adult Medicaid enrollees who work full-time, most work in low-paying jobs and in sectors that do not tend to offer employer-sponsored insurance (Garfield et al., 2019).

Illinois Comprehensive Cancer Control Plan

The Illinois Comprehensive Cancer Control Plan is developed by the Illinois Cancer Partnership (ICP), a partnership involving public sector, private, and nonprofit partners. The most recent plan covers the time period of 2016-2021 (Illinois Department of Public Health, 2016).

In the plan, the specific goal related to breast cancer is to increase the proportion of women 40 and older who receive a screening mammogram through promotion of the Illinois BCP and faith-based, community-based partners. Not specific to breast cancer, but relevant to breast cancer survivors, the Illinois Comprehensive Cancer Control Plan also includes a strategy to educate health care providers and patients to increase the awareness of issues relevant to cancer survivors (such as a communications campaign on improving survivorship, faith-based survivorship programs, etc.). While the plan describes breast cancer inequities by race, the state plan does not provide specific recommendations to address breast cancer inequities.

Indiana Cancer Control Plan

The Indiana Cancer Consortium (ICC) develops the Indiana Cancer Control Plan. The most recent plan, 2018-2020, is intended to guide Indiana efforts in cancer control and to promote collaboration (Indiana Cancer Consortium).

The goals related to breast cancer include:

- Increase rates of evidence-based cancer screening (with a goal to increase the proportion of women 50-75 years old who have had a screening mammogram in the past two years from 72.5% to 81.1%).

The other goals in the Indiana Cancer Control Plan are not breast cancer-specific but are broadly relevant to all types of cancer. These goals include:

- Promote shared decision-making and ensure accessible and evidence-based care.
- Improve quality of life for all those affected by cancer.

The most recent Indiana plan does not closely examine racial inequities in breast cancer and does not provide any specific recommendations to address breast cancer inequities.

State Laws Impacting the Breast Cancer Community

- **Diagnostic Imaging.** Illinois has passed legislation that eliminates the out-of-pocket costs for medically necessary diagnostic mammograms, breast ultrasound and breast MRI. **Metastatic Step Therapy.** Illinois has passed legislation that prohibits the use of step therapy or “fail-first” protocols for advanced, metastatic cancer patients.
- **Oral Parity.** Illinois and Indiana have passed legislation that ensures patient cost-sharing for oral chemotherapy treatments are no less favorable than the patient cost-sharing for intravenous chemotherapy treatments.

Discussion and Conclusion

This landscape analysis sought to understand the underlying causes of breast cancer inequities across the care continuum among Black women in the Chicago MTA, with a focus on systemic racism and SDOH. Examining multiple measures of disease burden together underscores how race is strongly influencing breast cancer disease burden. As compared to white women in the Chicago MTA, Black women die from the disease at higher rates in every county with disaggregated data, a pattern that may indicate deep and persistent inequities in access to and/or quality of treatment (see Table 8).

Breast Cancer Disease Burden

This strong trend of disparities along racial lines are greatest in Cook County, IL, where the age-adjusted five-year mortality rate is 32.7 among Black women compared to 20.5 among white women. Cook County, which encompasses the South Side of the City of Chicago, is where over 80 percent of Black women over 45 in the Chicago MTA reside, therefore such disparate rates are of great significance.

A factor at play is that cancers are more advanced at the point of diagnosis. Although rates may be higher among white than Black women in some of the MTA counties, it is Black women in Cook County, IL, and Lake County, IN, who have the highest rates of late-stage diagnosis. Late-stage diagnosis rates among Black women are a striking 63.1 rate of late-stage diagnosis compared to 43.1 among white women in Cook County, IL, and 58.8 vs 52.9 in Lake County, IN. Late-stage diagnosis may indicate lower access to breast cancer screening that would catch cancers early. These counties, along with Porter County, IN, each have total incidence rates that are higher among Black women than white women. Furthermore, in situ rates are actually higher among Black women than among white women in five out of the six counties where disaggregated data are available (all except Lake County, IL, which does have a disparity of 33.8 for Black women compared to 41.4 for white women).

It does appear that low rates of screening mammograms may be a partial factor in late-stage incidence. In six of the nine counties in the MTA, screening mammography rates fall below the national rate of 73 percent, with Lake County, IN, at 59 percent, Porter County, IN, 64 percent, and Cook County, IL, 72 (see Table 9). These rates are not available by race and are just one potential contributor. Community participants across the MTA describe many barriers to screening and to diagnostic services, some of which are the focus of current breast cancer initiatives in the area. They range from lack of time due to the heavy demands of work and family, fear of a diagnosis when they believe that breast cancer would not be survivable and/or that treatment would be a great burden, mistrust of a medical system which continues to discriminate against them, and barriers such as lack of childcare or an inability to easily travel to screening and diagnostic sites.

The guidelines for screening and inconsistent provider adherence to guidelines were also identified by participants as leading to late-stage diagnoses. Guidelines have been based on disease progression observed in white women. They do not account for the earlier and more rapid progression among Black women. The needed attention to screening among younger Black women is bolstered by research that found the City of Chicago (from 1999-2013) had the greatest disparity among younger age groups. The mortality rate ratios for Non-Hispanic Black women contrasted to Non-Hispanic White women were at 2.57 for women under 40 and reduced in each age grouping to be nearly comparable for women over age 65 at 1.19 (Sighoko et al., 2018). The greater level of disparities among younger women highlights

the need to advance measures tailored to these age groups. Young survivors and patient navigators point out the many obstacles to early screening and diagnostics that are accurate for younger women. Physicians interviewed also emphasized the need to take family histories and to follow up by offering and reimbursing genetic testing, closer monitoring and preventive care options.

Additional research conducted of breast cancer mortality rates by race in the City of Chicago has shed more light on trends and underlying factors that include quality of care. Disparities in breast cancer mortality were 116 percent greater among Black than white women in the City in 2005. This was a dramatic rise since the 1980s when rates across these groups were comparable. The gap expanded as rates fell among white women during this period yet remained steady or rose slightly among Black women. This raised the likely specter of inequitable access to advancements in breast cancer services. Researchers subsequently confirmed that screening facilities serving racial and ethnic minority populations were found to have poorer quality of care as compared to facilities predominantly serving white women. Facilities serving racial and ethnic minority populations had fewer dedicated breast imaging specialists and facilities as well as staffing limitations found to impair adequate screening mammography screening and delay initiation of chemotherapy, radiation and surgery (Ansell et al., 2009; Sighoko et al., 2017). Studies have also found racial differences in time to breast cancer diagnosis (Hoffman et al., 2011).

Quality of Care

Beyond screening and diagnosis, multiple factors impair timely access to treatment, completion of treatment, and efficacy of treatment. Research on breast cancer disparities show racial differences in time to breast cancer treatment (Halpern & Holden, 2012; Ko, Andreopoulou, & Moo, 2016; Nurgalieva et al., 2013), type of breast cancer treatment (Curtis, Quale, Haggstrom, & Smith-Bindman, 2008), and completion of breast cancer treatment (Green et al., 2018; Ko et al., 2016). The literature and providers interviewed emphasize the need for greater clinical trials and research on treatment that is effective and safe for Black women. Of great concern to survival are the impacts of comorbid conditions, including hypertension, diabetes and obesity (Houterman et al., 2004; Nagel, Wedding, Rohrig, & Katenkamp, 2004). A provider interview explained that these comorbidities can lead to life-threatening side effects of standard chemotherapy agents given to treat triple negative breast cancer.

The same barriers to accessing screening and diagnosis impact treatment yet are magnified. Survivors faced difficulty accessing high-quality treatment facilities even when quality services are in proximity (which they often were not). They confronted discrimination and obstacles due to insurance status, finding themselves discouraged or even in some cases turned away from health care institutions that are increasingly seeking more affluent clients with profitable insurance policies. Cook County, IL, has the highest percentage of medically underserved populations at 64 percent followed by Lake County, IN, at 25 percent. While the data are not available by race, community participants described racial barriers that include more difficult access for Black women; especially those on Medicaid and in institutions that do not participate in the IBCCP that covers expenses of the uninsured.

The data examined for this study are consistent with the literature showing that among Black breast cancer patients, a woman's insurance type was a significant predictor of mistrust of the medical establishment. Women with Medicaid expressed greater mistrust and suspicion compared to women with private insurance or private insurance and Medicare (Sutton, He, Edmonds, & Sheppard, 2019). A qualitative study in Chicago found 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). Insurance barriers may be among the factors that explain why the disparities in mortality rates are greatest among women below the age of 65 and fade afterwards when they become eligible to receive Medicare that is more likely to be accepted by providers.

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

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. Black women do not participate in genetic testing at the same rate as white women (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).

Once in care, survivors shared the toll of completing treatment regimens that left them depleted while necessitating time, travel and burdensome costs. Even more central to completion of treatment was trust and respect by provider teams. Stressful interactions with providers and hospital staff caused some to question whether to continue. Women told of facing such discrimination with grace and resilience. They confronted situations, but focused on their strength, character and self-worth rather than victimhood. They found means of self-advocating and gaining greater strength by joining together. Such experiences were contrasted to respectful, shared decision-making processes that are increasingly, if not uniformly, being employed. A provider discussed the commitment to positive doctor-patient communication and cultural humility that were emphasized in New York City, where she initially trained and practiced and where racial disparities in breast cancer mortality are among the lowest in the nation. She observed such training was not yet required in all medical schools nor evaluated with mandatory standards across providers and institutions. Patient navigators recommended that even greater coordination of care across health care and referral institutions as well as within and across neighborhoods and systems could also improve patient-centered care.

Survivors found that connections to patient navigators assisted them greatly across the continuum of care, as did access to peer support groups that bolstered access to resources, self-advocacy and opportunities to engage as leaders in initiatives on behalf of Black women in their communities. Arising needs for culturally appropriate care were necessary to serve changing demographics. For example, patient navigators described a shift in populations needing support in Chicago to include more African immigrants with Muslim culture, and a consequent need for more background to best serve this growing population.

Patient navigation was more readily available in Cook County and Will County, IL, and to a lesser extent in Lake County, IN. Peer support groups led by, and specific to the needs of, Black women breast cancer survivors were only described in Cook County, IL. Survivorship programs, however, were growing in all three counties. The more robust programs were offering an array of supportive services through community/clinical partnerships, while also closely monitoring survivors in recognition of the high rates of complications and recurrence among Black women.

Prevention and survivorship may lie at opposite ends chronologically in the breast cancer continuum; yet they are both influenced by the ability to lead healthy lifestyles. Historic and systemic racism can be found in redlining practices that have led to disinvestment, such that many Black neighborhoods in the Chicago MTA continue to lack not only health care, with high percentages of those who are medically underserved, but healthy foods, housing, and walkable conditions. Lack of transportation availability and affordability also arises as a “major barrier” to accessing care across the breast cancer continuum.

Social Determinants of Health

A growing body of research further 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, Valdimarsdottir, Guevarra, & Bovbjerg, 2003). The research also points to the links between personally mediated racism and biomarkers of disease, including allostatic load (Williams & Mohammed, 2013). Such burdens may be reflected in the unacceptable racial disparities found in reduced life expectancy and premature age-adjusted mortality due to all causes that are observed in the Chicago MTA.

These forms of racism are evident to the extent that participants recalled growing up not having been allowed to enter the front door of the building in Gary, IN, where focus groups were held, nor being safe entering several white neighborhoods, including those where prominent white politicians in Chicago were raised. Evidence of continued racism is seen in data on high levels of racially motivated hate crimes, police violence, and over a thousand fair housing complaints with a racial bias filed since 2006 in Cook County, IL.

Formation of a Metropolitan Breast Cancer Task Force (MBCTF) in 2007 (currently renamed Equal Hope) has led to an impressive array of collaborative initiatives that address racial breast cancer inequities. These have been supported by Komen and other funders while benefiting from in-kind services of health care institutions. Included has been targeted quality improvement, low or no-cost screening and diagnostic services, patient navigation, genetic counseling, and outreach and education initiatives. Policy campaigns have also focused on improving equity. The Illinois Breast Cancer Excellence in Survival and Treatment (BEST) ACT, passed in 2015, is an example that helps improve access to high-quality breast cancer services for Medicaid recipients.

There are indications that such comprehensive efforts are achieving great success. A review of data from 2006 through 2013 found that rates among Black women in Chicago started to fall, in fact falling more than nine other major cities. In concert, racial disparities in mortality rates declined by a substantial 20 percent (Sighoko et al., 2017), and more recent data indicate this trend has continued. As a consequence, many lives have been saved as the number of excess deaths due to breast cancer for NHB women in Chicago declined by 29 percent: from 537 cases in 1999–2005 to 394 in 2006–2013 (Sighoko et al., 2017).

This progress is highly encouraging even as disparities remain a significant concern. This Landscape Analysis points to several key areas that are important to address. Among the most challenging may be the trend for health care institutions to pull resources away from underserved communities. In Cook County, IL, there have been two hospital closures in 2019, and one more that was recently announced, planned for 2021. Komen and its partners will need to battle these trends while they pursue innovative solutions that may include bolstering the trusted health care and community resources that remain.

Breast cancer inequities across the care continuum in the Chicago MTA persist due to systemic policies and practices and lack of access to quality health care services. Economic vulnerability, incongruence between guidelines and implementation, variation in messaging about screening guidelines, and experiences of personally mediated racism in health care settings are also evident. Community members across the three priority counties report having been turned away from services due to insurance status and avoiding care due to instances of personally mediated and institutional racism. Taken together, these factors severely reduce the timeliness and quality of care that Black women receive across the cancer care continuum.

Particular aspects of the breast cancer continuum that warrant further investigation and intervention include the availability of accessible, high-quality screening and diagnostic mechanisms and treatment options for Black women living across underserved counties and/or with poor insurance. Changing demographics, health care infrastructure, and socioeconomic factors warrant continued research.

Chicago is an area with great access to medical research and collaborative partners that have pioneered a focus on health disparities and underlying racial inequities. Strong networks to uncover and address breast cancer disparities exist that Komen participates in, and draws upon, to support people in Illinois. These collaborations need continued support and strengthening to be preserved and to potentially extend beyond the city of Chicago to areas such as Lake County, IN.

Opportunities to expand upon growing clinical/community partnerships present themselves across the continuum of care. Such collaborations can enhance not only education and outreach for residents and providers, but hold promise in strengthening policies, systems and environments. Resulting improvements in economic, physical and social conditions are among determinants that can lead to healthier Black neighborhoods.

Recommendations

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

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

This framework reflects that the health system is multidimensional, ever-changing, and has the potential to facilitate or impede population health. For most, the lasting impression of the health system begins at the **micro** level – where providers and patients interact. As Black women progress along the breast cancer continuum of care, they encounter other microsystems, and the complexity of their experience increases. Access to and quality of these microsystems vary, and there is a need for these systems to interact and relate in a manner that centers on the experiences of 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 a collaborative approach to advance breast health equity for Black women. This provides a mechanism for community/stakeholder engagement and recognizes the informal and formal systems and networks of social support that are accessed by Black women.

These recommendations represent actionable strategies as the bridge between social determinants of health and the breast cancer care experience of Black women, and 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.

Micro-Level Strategies

Increase access to culturally responsive patient navigators and Community Health Workers (CHWs).

The breast cancer community can ensure there is support and clinical teams in community settings who is consistently available to help Black women reduce barriers to care and address quality-of-life issues along their breast cancer journey. These individuals should be responsive to cultural and social norms, including the intersection of religion and breast cancer care. Culturally responsive, trained patient navigators offer expertise in navigating the health care system; and can offer resources to help integrate clinical care with mental health and related support. This includes increasing the number of

navigators and CHWs, and assuring they are geographically accessible. A study conducted in Chicago reported that patient navigation programs improved timely care to diagnostic resolution, while another found patient navigation also supported completion of breast cancer treatment (Castaldi, Safadjou, Elrafei, & McNelis, 2017; Markossian, Darnell, & Calhoun, 2012).

The breast cancer community should continue to fund patient navigator services to increase breast cancer patients' access to these invaluable services as well as expansion into neighboring Indiana and Illinois counties within the Chicago MTA. While robust networks of patient navigators were available in Cook County, IL, and were often affiliated with hospitals throughout the Chicago MTA, it became apparent that the need in some areas was much greater than the current patient navigator workforce could manage. Patient navigation was described as least available in Lake County, IN. Patient navigators in Cook County further identified needs to improve services tailored to Muslim African immigrants, a growing population they serve who face unique cultural and linguistic barriers to care and community resources that they rely upon for support. Furthermore, they recommended greater coordination across facilities so that they could more readily make cross-institution, out-of-network referrals.

The breast cancer community can even further continue to grow and strengthen the CHW workforce, including leveraging efforts to expand coverage for services under health care financing systems and supporting CHW training leading to certification. The Illinois Community Health Worker Advisory Board recommends that the Illinois Department of Healthcare and Family Services (HFS) amend contracts with managed care entities (MCE) to allow MCEs to hire CHWs or subcontract with community-based organizations that employ CHWs. They further recommend that HFS file a state plan amendment (SPA) in order for CHW services to be reimbursed by Medicaid. Often hired due to their lived experience and close cultural ties to the Black community and other priority communities, CHWs can be particularly valuable; yet at the same time face their own challenges of microaggressions and lack of stature working in the highly professionalized medical field. The breast cancer community could advance CHWs by serving on CHW advisory boards and supporting trainings for provider teams on how to work effectively with CHWs while avoiding microaggressions.

Implement a culturally relevant health promotion campaign intended to increase knowledge of current screening guidelines.

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

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

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

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

Continue to grow culturally relevant health promotion campaigns intended to increase awareness of breast cancer inequities among Black women.

Community member participants in this landscape analysis discussed that a need remains for outreach in other counties further outside the City of Chicago and extending into Indiana counties within the Chicago MTA, particularly Lake County, IN, which includes neighborhoods that are largely Black. All such outreach campaigns should be tailored to the Black community to ensure that they have adequate information about the elevated risks for late-stage diagnoses, triple negative diagnoses, rapid disease progression, and increased mortality due to breast cancer. Participants recommended that the breast cancer community support health promotion campaigns that ensure Black women and their social and health care supports know about such disparities and inequities and how they can be addressed. The goal would not be to frighten women, but to emphasize what they can do to protect themselves and support one another. Advice would include the importance of screening at relatively early ages; the importance of genetic counseling and testing for women with hereditary risk for breast cancer; where and how to obtain high quality, tailored treatment that can improve survival; and important supports and monitoring following treatment. Furthermore, the leadership of Black women in such campaigns and related policy advocacy efforts was an important asset highlighted by community participants.

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

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

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

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

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

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

Expand financial assistance programs to support breast cancer care.

To lessen the burdens of care and mitigate barriers to screening, diagnosis and treatment, different types of programs specifically for Black women in the MTA should be established or where existing, expanded. Financial assistance programs contribute toward costs associated with breast cancer care, including copays, costs of medications and supplies, as well as costs of childcare, transportation and living expenses. Other programs may provide direct services, including childcare, transportation to/from appointments, housecleaning, and nutritional services to lessen the burdens Black women may face when seeking and receiving breast cancer care. Programs should be tailored by county to address the barriers and burdens of care in specific areas of the MTA.

The breast cancer community can also drive collaboration health systems, counties and/or county partners to advocate for financial assistance programs to meet deductibles for high-deductible health plans or cost sharing for underinsured women. Non-profit health systems could examine whether offering financial assistance programs would qualify under Community Benefit, the Internal Revenue Service Requirement that nonprofit 501(c)(3) hospitals provide services or support activities that promote health in their communities to maintain tax-exempt status (Community Benefit Connect).

Strengthen and expand survivorship programs.

Findings from this study indicate that there are opportunities to offer much more robust survivorship support that includes, but goes beyond, access to breast cancer support groups. Providers described optimal survivorship programs as being integrated into ongoing clinical care and offering adjunct support services that together work to improve outcomes from permanent disabilities to early mortality.

Survivors described the many challenges they faced following treatment and ongoing needs for emotional/mental health, social service or medical support. Among recommended program components were: routine follow-up care to closely monitor survivors, genetic testing for those with high-risk profiles, mental health counseling, and access to resources for stress reduction and fitness. Access to physical and occupational therapy early on was said to decrease the risk of long-term impacts, while embedding a social worker for social issues can help address food security, transportation, caregiver support and depression. Survivors further mentioned the needs for close referral linkages to ensure timely access to substance use and battered women’s services.

It was recommended to offer such programs through clinical/community partnerships based out of accessible and trusted local settings in Black neighborhoods, such as FQHCs, or to establish stand-alone Komen-supported women’s centers in underserved areas such as Gary, IN. A model was described as operating out of the Mile Square Englewood Clinic in South Side Chicago. Komen recommends the breast cancer community partners with FQHC and other community sites that are readily accessible to survivors in Cook County, IL, Will County, IL, and Lake County, IN, to bring to scale what has been demonstrated to be effective, evidence-based survivorship programs.

Mezzo-Level Strategies

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

Providers, patient navigators and Black women in focus groups all noted how important the doctor-patient relationship can be to supporting women’s successful management of breast cancer across the continuum. To establish and solidify that relationship, providers need this type of training that was said to rarely be offered in medical school. Health care institutions traditionally frame barriers to completing screenings and treatment as individual behaviors and choices, while women described barriers due to personally mediated and institutional racism that arose as they walked into the door of a health care facility. Increased awareness of unconscious bias, the role of cultural humility, and how health care settings have played a part in historic and systemic racism can reframe barriers with a racial equity lens and thereby underpin a much-needed shift in services. It is important that providers and administrators connect health disparities to racial inequities as they closely examine their practices as well as larger policies and systems. They first need greater understanding of the context faced by patients.

“I feel like the doctor might not be able to connect with the patient, because most of the times, the doctors are coming from the suburbs, or coming from other areas that are North Side [of Chicago]. I feel that’s one of the reasons why they don’t treat the patient the way the patient should be treated. They don’t have a knowledge of what’s going on in the community [there’s food deserts], or they don’t have knowledge of our culture here in the communities. I feel that’s another reason for barriers and disconnect with the patient and the hospital.” – Patient Navigator

Therefore, the breast cancer community should support racial equity trainings for providers and across health care staff. The focus of the trainings could include: 1) basics of implicit bias and the need for cultural responsiveness; 2) challenging racial/ethnic stereotypes using results from this study as stimulus for case examples and content; 3) examining historic and systemic racism in Chicago and their impact on SDOH; and 4) reframing exercises that apply a racial equity lens to health care services and settings. As a

provider recommended, provider trainings in doctor-patient relationships could also be tied to ongoing monitoring and evaluation applying appropriate standards of care.

Provider trainings in doctor-patient relationships could also be tied to ongoing monitoring and evaluation and quality improvement programs.

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.

Research and subsequent mobilization by the Metropolitan Chicago Breast Cancer Taskforce (renamed Equal Hope) in the City of Chicago identified needs for quality improvement as being pivotal to addressing racial inequities in breast cancer. The Taskforce found that facilities that served predominantly minority women were less likely to be academic or private institutions, less likely to have digital screening mammography, and less likely to have dedicated breast imaging specialists reading the films. Collaborative QI efforts, such as those launched through the Taskforce, successfully reduced mortality rate disparities in Chicago observed in 2005, such that the ratio between Black and white women has fallen to half the differences in rates and remains in a downward trend (Sighoko et al., 2017) (see Table 8).

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. QI initiatives in the major health systems in the Chicago MTA are recommended, 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. Consideration should also be given to ways to support QI initiatives in non-hospital and non-health system care settings (in addition to hospital and health system settings), such as federally qualified health centers that are more accessible to priority populations.

Encourage health institutions (health care systems and payers) to offer services in high-need areas.

The review of secondary data shows, and the observations of participants reflect, that the Chicago MTA

– like other parts of the country – has experienced closures, mergers and relocations of hospitals that primarily served low-income and/or uninsured populations. Health systems and hospitals, especially those offering higher quality care and state-of-the-art breast cancer services, appear to be increasingly concentrated in places that are more accessible to non-Medicaid patients, while those that remain in the area increasingly turn away Medicaid clients. Mercy hospital in the South Side Chicago is the latest among safety net hospitals that has planned to close. Provident Hospital, the first hospital in the country to be owned and operated by Black health care providers (although it is no longer an African American-run institution), remains in the area (Bouscaren, 2017).

The breast cancer community may favorably influence health systems and payers to ‘give back’ to historically disenfranchised communities by: 1) incentivizing health systems and payers to invest in Black communities; 2) requiring grantees from major health institutions to invest in community benefits to provide breast health services in community health centers; and 3) partnering with non-profits to fund standalone breast clinics that could replace the breast health services that were previously available at now-closed or closing hospitals. In Cook County and Will County, IL, health care systems have participated in model breast cancer initiatives, volunteering services from screenings and diagnostics, and participating in improvements to ensure access for Medicaid.

An initiative mentioned by one health care system that could be more broadly replicated was mandating that their providers, including breast cancer specialists, accept any referral made by other providers in their system regardless of insurance status. While limited to internal referrals this is a step in the right direction.

Fund collaborative initiatives at the community level to address social determinants of health.

Collaborative approaches promise to leverage more of the significant resources needed to attain ambitious goals that lie beyond the capacity of individual institutions or foundations. Such collaborations must extend beyond traditional silos. The intersectional issues that weave together to create the SDOH in any community require full engagement of not only medical and public health sectors, but social services, housing and urban planning, economic development, environmental and occupational protections, educational systems, transportation infrastructure, and healthy eating and active living initiatives. Each of these arenas arose as deserving improvement based on county-level data, indicating that Black women in the Chicago MTA are heavily burdened by SDOH. A high percentage of Black populations in these four locations are medically underserved, below 200 percent of the FPL, and food insecure. These data suggest that even if a Black woman in any of these places is physically proximate to a treatment facility, she may be unable to access care due to economic barriers or other burdens related to SDOH. Participant observations called out conditions that were particularly distressed in Cook County, IL, and the Black neighborhoods of and proximal to Gary, IN, within Lake County, IN. Fostering the requisite conditions that promote health demands collective action. The robust collaborations that exist in the Chicago MTA are available to build upon.

Macro-Level Strategies

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.

Advance clinical trials and tailored treatment focused on Black women.

Tied to inequitable care is inequitable research. Only recently has cancer among Black women been researched in clinical trials, which was said to have hampered the state of knowledge regarding incidence and the best treatment options for triple negative breast cancers, their increase and their

predilection for recurrence within two years. The identification of subtypes and recent strides in adjuvant chemotherapy, PARP inhibitors, and immunotherapy, and adjuvant chemotherapy with people who are partial responders, is just now starting to show promise. As pointed out by a Chicago provider, comorbidities (that also arise from racial inequities and so are more prevalent among Black women undergoing treatment), such as hypertension, diabetes, and high cholesterol, place them at risk of severe, life-threatening side effects when given standard forms of chemotherapy as determined by clinical trials that were conducted on white, more affluent populations. The vibrant research community in the Chicago MTA dedicated to addressing breast cancer inequities offer valuable assets.

Clinical trials that prioritize Black women and their unique breast health issues are recommended, however past harms perpetuated against Black women in the name of research must be given voice in order to build trust.

Support a root-cause analysis to uncover the drivers of late-stage diagnosis rates.

In Cook County, IL, where the majority of the women in the MTA reside, the Black-white disparity in late-stage incidence is noteworthy. Black-white disparity in breast cancer mortality is striking in Cook County, IL, and elevated in each of the counties in the Chicago MTA. These data are reinforced by both quantitative and qualitative data findings indicating that Black women experience significant barriers and failures along the breast cancer continuum of care and face many barriers tied to SDOH from lack of access to transportation, food insecurity, and unstable housing. Data further suggest that Black women in the Chicago MTA experience several forms of personally mediated, institutional and systemic 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, Cook County, IL, reports the highest number of race-based incidents, including over a thousand Fair Housing Act cases and 22 Black people killed by police.

A further root cause analysis (RCA) process may identify the contributing factors and underlying causes of late-stage incidence, as well as the key leverage points where intervention would have a significant impact on breast cancer inequities, strengths and areas of opportunity. By conducting a RCA, stakeholders, including non-health stakeholders, can begin to understand the complexity of late-stage incidence and poorer survival in their community. Participants of a RCA process should include breast cancer survivors, community-led efforts (e.g., workers' unions, non-profits, food banks, community health centers, women's organizations, housing alliances, etc.), and research centers with long-standing academic-community partnerships. The RCA includes an action planning process to determine how to maximize key leverage points to address root causes. Additionally, the RCA process can spur innovative ideas and strategies guided by best practices for addressing the factors and underlying causes that impact late-stage incidence and survival in the MTA. The RCA can build upon analyses of the reach and quality of breast cancer services that have already been conducted by area researchers and their collaborators (Ansell et al., 2009); yet place a greater emphasis on racial equity and prevailing SDOH.

Once complete, the recommended next step is to engage in partnerships with the RCA stakeholders and provide grants to implement the RCA action plan among these organizations' respective members and networks.

Conduct an analysis of state policies to identify those that present barriers to high-quality care in the Black community.

Reducing breast cancer disparities relies as much on public policy as it does on research breakthroughs. Lawmakers and policymakers at all levels of government play a critical role in making decisions that can help save more lives from breast cancer. While Medicaid expansion is an important part of these efforts, there are many policy issues that can impact access to high quality care, and these vary across states. For example, the Breast and Cervical Cancer Treatment Act created an option for states to provide treatment for women whose cancer was detected through the National Breast and Cervical Cancer Early Detection Program – a program that is a safety-net service for many in the underserved Black community. However, many states are not making the minimum contribution to this program to serve all those who need it. These decisions, and others like it, have a detrimental effect on public health and cause persistent disparities.

The public policy landscape should be reviewed to determine if, and which, barriers to high-quality care for Black communities must be addressed through legislative intervention.

This landscape analysis report conveys comprehensive issues facing Black women in the target 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 Black women.

Appendix A. Map Measures

TABLE 24. CHICAGO METRO AREA TABLE MAPS

	Map 3: Percent of Population that is Black	Map 4: Residential Segregation Score	Map 7: Social Vulnerability Index Score	Map 8: Percent of Households that are Housing-Cost Burdened
Cook County, IL	24%	78	0.69	38%
DuPage County, IL	5%	42	0.16	31%
Kane County, IL	6%	47	0.44	33%
Kendall County, IL	7%	17	0.11	29%
Lake County, IL	7%	57	0.35	32%
McHenry County, IL	1%	51	0.08	31%
Will County, IL	11%	54	0.22	31%
Lake County, IN	24%	74	0.73	28%
Porter County, IN	4%	45	0.18	24%

Sources: American Community Survey 2013-2017 5-Year Estimates (U.S. Census Bureau); 2016 Social Vulnerability Index (U.S. Centers for Disease Control and Prevention); 2016 Comprehensive Housing Affordability Strategy dataset (U.S. 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 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 U.S. 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 U.S. 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 U.S. Census Bureau and indicate the percentage of the population whose annual income is less than twice the 2017 FPL (i.e., 200% FPL). In 2017, the FPL was \$24,600 for a family of four and \$12,060 for an individual. (Office of the Assistant Secretary for Planning and Evaluation).

Food deserts: Areas defined by the U.S. 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 U.S. Department of Housing and Urban Development using the Consolidated Housing Affordability Strategy dataset and the following formula:

number of renters and homeowners who spend 30 percent or more of their total income on housing (numerator) divided by the total number of households (denominator) (Office of Policy Development and Research (PD&R), 2019).

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Appendix C. Focus Group Guides

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

Step 1: Introduction of project and confidentiality

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

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

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

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

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

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

How data will be used, privacy and confidentiality

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

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

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

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 African-American 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 African-American 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 African-American 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 African-American 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 African-American 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, African-American patients? If so, does this information influence your recommendations for screening?*
5. What factors promote (or encourage) regular screening among African-American 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 African-American 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 African-American 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 African-American 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 African-American 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 African-American 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 African-American 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 African-American 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 African-American women in [insert name of metro]?
13. Anything else you would like to share with us?

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

Step 1: Introduction of project and confidentiality

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

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

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

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

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

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

How data will be used, privacy and confidentiality

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

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

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

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

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

Does anyone object to being recorded?

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

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

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

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

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

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 screening mammography? If yes, what motivated you to get screened?

PROBES TO USE AS NECESSARY

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

PROBES TO USE AS NECESSARY

- a. *What options were offered to you?*
- b. *How did you feel throughout the process?*
 - 1. *Were there times you felt uncomfortable or unable to access screening?*
 - 2. *Did you feel you had enough time to ask questions and/or absorb information?*
 - 3. *Did you feel you were treated with less courtesy or respect than other people?*
 - 4. *Did you feel you received poorer service than other patients?*
 - 5. *Did you feel the provider or the staff acted as if they think you are not smart?*
 - 6. *Did you feel the provider or staff acted as if they are afraid of you?*
 - 7. *Did you feel threatened or harassed?*
- c. *How old were you the first time you were screened? How often did you go after your first time?*
- d. *Explore the influence of*
 - 1. *Providers, staff: temperament, cultural competency, kind, respectful*

2. *Process and systems: forms, wait time, referrals, timely, follow-up*
 3. *Overall environment: location, privacy, welcoming, feels safe*
 4. *Accessibility: easy to reach, timely*
- e. *Assess comprehensives and quality of care.*

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

PROBES TO USE AS NECESSARY

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

7. Was hormonal therapy (e.g. Tamoxifen, Arimidex, Femara, Aromasin) part of your treatment? If so, was five years or ten years prescribed?
- a. *PROBE: Were you able to stay on hormonal therapy for the recommended length of time? Why or why not? (they may still be on it)*
 - b. *PROBE: Did you ever skip a dose or cut the pills in half? If so, why or why not?*
 - c. *PROBE: What were the challenges?*
8. Please share some of the factors in the decision to start treatment based on your personal experience or the experience of other African-American women, you know.

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

PROBES TO USE AS NECESSARY

- a. *Who was involved in the decision to start treatment?*
 1. *Partner*
 2. *Family*
 3. *Friends*
 4. *Pastor /Clergy*
- b. *Was the decision-making process different for different types of treatment (chemotherapy, surgery, radiation)?*
- c. *What may make it difficult for an African-American woman in your area to start and continue the full course of breast cancer treatment if they need it?*
- d. *What would facilitate the completion of the full course of treatment (for example, a full course of chemotherapy)?*
 1. *Family considerations: Caretaking responsibilities, spousal support*
 2. *Personal/life: Scheduling, time off from work, meeting family responsibilities*
 3. *Fears: Concerns about the procedure, concerns about side effects of treatment*
 4. *Faith Practices: Spiritual/religious beliefs*
 5. *Accessibility: Insurance, easy to reach, distance, affordable costs/co-pays, time off from work*
 6. *Process and systems: Forms, wait time, referrals, timely, follow-up*
 7. *Providers and staff: Temperament, cultural competency, kind, respectful, perceived racism, perceived trust and respect, bias, provider hostility, mistrust about the health system, no relationships with providers*
 8. *Overall environment: Location, privacy, welcoming, feels safe*

9. What factors may lead to delays in starting treatment or not completing treatment even if someone has access?

PROBES TO USE AS NECESSARY

- a. *What factors may contribute to a delay in starting treatment? Ending treatment early/discontinuing treatment?*
1. *Family considerations: Caretaking responsibilities, spousal support*
 2. *Personal/life: Scheduling, time off from work, meeting family responsibilities*
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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 African-American 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 African-American women cancer survivors and their families?

Step 8: Thank you for your participation.

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

Step 1: Introduction of project and confidentiality

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

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

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

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

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

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

How data will be used, privacy and confidentiality

Your participation in this focus group is completely voluntary, and all information you share will be kept confidential. At no time should you feel you have to answer a question. We will begin with some general

questions about your general knowledge of breast cancer. Then we will move to more specific questions. This discussion should last no longer than 90 minutes, about an hour and a half.

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

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

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

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

Does anyone object to being recorded?

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

Step 3: Answer Questions from Participants

Step 4: Confirm Consent to Participate

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

Step 5: Answer Questions (if needed)

Step 6: Turn on the Recorder

Step 7: Begin Discussion with Questions Below

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 African-American women. An important aspect for us to discuss is your

experiences with racism in your community and workplace and how racial discrimination affects the health of African-American women.

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 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?*
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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 African-American women, you know.

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

PROBES TO USE AS NECESSARY

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

Step 8: Thank you for your participation.

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