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

EXECUTIVE SUMMARY



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



Executive Summary of Landscape Analysis Reports

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Executive Summary: Landscape Analysis Reports

Background

Breast cancer is the most common cancer diagnosed among women in the United States (U.S.) and is the second leading cause of cancer death among women after lung cancer. One in eight women in the U.S. will develop breast cancer over the course of her lifetime. With the increasing availability of 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.

While overall breast cancer incidence among Black women is lower than among 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 compared to 92 percent for white women (Howlader et al., 2020). However, 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).

In 2015, in partnership with Fund II Foundation, Komen launched an initiative (now known as Stand for H.E.R.) to improve breast health equity for Black women by identifying and addressing the systemic barriers that drive differences in breast cancer outcomes. Stand for H.E.R., a Health Equity Revolution, aims to reduce breast cancer disparities experienced by Black women starting in the 10 U.S. metropolitan areas (referred to throughout this report as MTAs or metro) where the inequities are 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 this initiative, 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 the landscape analyses 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.

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 to 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.

Overview of Methods

The landscape analyses were prepared by Komen and John Snow, Inc. (JSI), a mission-driven national and international public health research and consulting organization dedicated to advancing the health of individuals and communities. The development of this report was made possible by Komen with funding from the Fund II Foundation and Merck.

A subset of quantitative data was used to inform sampling and select priority counties (or their equivalent) in each MTA as the focus of the qualitative data collection. Priority counties (or their equivalent) were identified based upon the following factors: sample availability, breast cancer burden, Social Determinants of Health (SDOH) burden, other health metrics (e.g., life expectancy) and health systems availability. All data collection tools and protocols were approved by JSI's Institutional Review Board.

Semi-structured interview and focus group discussion tools were developed based on literature review and included some questions from validated tools that have been used to measure experiences of everyday racism and discrimination (David R. Williams et al., 2008). Focus group eligibility criteria included: being 18 years of age or older, being a resident of the priority county areas, being Black, and, in the case of breast cancer specific focus groups, having had breast cancer.

In addition, eligibility criteria for key informant interviews included: being at least 21 years of age or older and being a breast cancer specialist or primary care provider serving Black patients in the priority areas, or a community health/patient navigator. JSI worked with local Komen Affiliates, community advisors and community partners (e.g., breast cancer coalitions, hospitals, community-based organizations (CBOs), churches, universities and the local health departments) to conduct outreach, engagement and recruitment for the focus groups and to identify key informant interviews.

Focus groups and interviews were recorded and transcribed. Transcripts were analyzed using a previously defined approach (Strauss & Corbin, 1998) to create a codebook describing codes and their meanings, and two staff per MTA coded all data units using this codebook to ensure consistency and accuracy in data analysis. Data was queried to develop themes and memos captured additional meaningful information relevant to the research questions.

Full reference list is available upon request.

Overview of Findings and Recommendations

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 racism, discrimination and a lack of quality care.

Black women exercising decision-making and/or practicing self-advocacy within the health care setting are often ignored or met with disapproval. For some women, experiences of not being listened to by their providers led to delays in treatment and deepening mistrust. Many examples in the literature have shown that Black Americans are systematically undertreated for pain relative to white Americans, and a recent study suggests that doctors' false beliefs about biological differences between Black and white patients contribute to racial disparities in pain assessment and treatment. Historical injustices inflicted by the health care system and continued personally-mediated provider biases exacerbate barriers to care.

Given the importance of patient-provider communication and the ability of providers to exercise cultural sensitivity, the role of patient navigators as "translators" during health care visits, and as a "support system" after the visit, is essential. Evidence indicates that patient navigation can be effective in improving mammography screening (Baik, Gallo, & Wells, 2016; Scheitler, Shimkhada, Ko, Glenn, & Ponce, 2018); improving time to diagnostic resolution; and supporting completion of breast cancer treatment (Castaldi, Safadjou, Elrafei, & McNelis, 2017; Markossian, Darnell, & Calhoun, 2012).

Furthermore, the field needs diverse and culturally responsive navigators who have expertise and knowledge of the Black community, and are responsive to cultural and social norms, including at the intersection of religion and breast cancer care. According to focus group participants, Black patient navigators were highlighted as particularly valued resources. Black patient navigators are more likely to reflect the lived experience of Black breast cancer patients, and therefore can serve as a key conduit between patients and their providers.

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, including financial barriers, fear and mistrust of the healthcare system.

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

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 of care. To establish and solidify that relationship, providers need 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 soon 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.

However, the healthcare setting itself needs further scrutiny. Research and subsequent mobilization by the Metropolitan Chicago Breast Cancer Taskforce (renamed Equal Hope), 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 mammography screening, and less likely to have dedicated breast imaging specialists reading the films. This experience is replicated in many of the communities serving predominantly Black women.

Tied to inequitable care is inequitable research. Cancer among Black women has been understudied in clinical trials, which has hampered the state of knowledge regarding incidence and the best treatment options for Triple Negative Breast Cancers and their predilection for recurrence within two years. The identification of subtypes and recent strides in adjuvant chemotherapy, PARP inhibitors, immunotherapy and adjuvant chemotherapy with people who are partial responders, is just now starting to show promise. Comorbidities, that also arise from racial inequities and are therefore 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.

From a community level, 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 living initiatives. Each of these areas arose as deserving improvement based on county-level data, indicating that Black women in these MTAs are heavily burdened by SDOH. A high percentage of the Black community are medically underserved, below 200 percent of the Federal Poverty Level (FPL), and/or 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.

A much larger share of Black women with breast cancer experience a negative financial impact and these gaps remain large after controlling for social and economic variables (Wheeler, et al, 2018). Black women are nearly three times more likely to forego prescription medicine and much more likely not to see a doctor than white men because they cannot afford it. The fact that Black women are one-third more likely to cite health issues as a barrier to work than white individuals suggests that closing the health gap would also narrow the earnings and wealth gaps. On the other hand, health disparities likely also contribute to economic disparities. According to the Survey of Household Economics and Decision-making from Goldman Sachs Global Investment Research, one-third of Black women are not working or working less than they want due to health reasons or disability.

Reducing breast cancer disparities relies as much on public policy as it does on research breakthroughs. 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 without burdensome restrictions 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 Prevention and Treatment Act created three eligibility options for states to enroll women for treatment of breast cancer, however many still use the most restrictive option, limiting access to critical services. Additionally, the National Breast and Cervical Cancer Early Detection Program (NBCCEDP), a federal-state collaborative program that serves as a safety-net service for many in the underserved Black community, requires states to contribute funding to their state programs. Many states can allocate additional dollars from their budget and/or expand eligibility to ensure increased access to their state screening programs to serve all those who need it. These policy changes, and others like it, have the potential for significant improvements on public health and can help address the persistent disparities we see today. Policy work may also extend to re-examining breast cancer screening and clinical care guidelines with a racial equity lens, to develop strategies (e.g., new guidelines, policies, practices) that aim to address the multi-level influences that lead to breast health disparities. While this report focuses on the impact of breast cancer on the Black community, it is important to note that the issues manifest to drive poor health overall. According to the CDC's Behavioral Risk Factor Surveillance System, Black women are 35 percent more likely to report fair or poor health—rather than good, very good, or excellent—than white women.

Interventions

Findings from the analyses suggest that the work ahead requires interventions at multiple levels of the system: **the micro level** (the level at which patients and providers interact), **the mezzo level** (the level at which systems interact), and **the macro level** (the policy level).

This framework reveals that the health system is multidimensional, ever-changing, and has the potential to facilitate or impede population health. For most, the lasting impression of the health system begins at the **micro level** – where providers and patients interact. As Black women progress along the breast cancer continuum of care, they encounter other microsystems and the complexity of their experience increases. Access to these systems and the quality of the care and experience received in 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 recommendations in this report 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 are offered as evidence-informed strategies to start reducing breast cancer disparities among 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 members of the larger breast cancer community.

Komen will adopt select recommendations as aligned with the Stand for H.E.R. budget and budget narratives herein.

Key Findings & Recommendations by Metropolitan Area

Atlanta, GA: Key Findings

- Throughout the Atlanta MTA, Black women are more likely to die from breast cancer than their white counterparts.
- Yet there are differences among the counties. For example, the mortality rates in Cobb, DeKalb, Fulton and Fayette counties are higher for Black women than white women living in these counties. Notably, these counties account for 58 percent of the MTA's Black population. Spalding, Rockdale and Douglas counties have smaller Black populations than most other counties in the MTA and are the only places where white women are more likely to die from the disease than Black women.
- At the same time, Black women in the MTA are also more likely to receive screening mammograms and get diagnosed with the disease at lower rates.
- Although there is no uniform trend in breast cancer incidence rates within the Atlanta MTA, with notably higher rates among white women in some counties and higher rates among Black women in others, it is notable that Clayton, DeKalb and Fulton counties report rising rates of breast cancer incidence and *in situ* incidence among Black women (see glossary for *in situ* and invasive breast cancer definitions). In all but two counties (Clayton and Coweta) where data are available, the late-stage incidence rate is higher among Black than white women.
- Decades of discriminatory practices have led to striking residential segregation in the Atlanta MTA, which also results in differences in financial and health security depending on where you live.
- Clayton County reports the highest percentage (48%) of the population below 200 percent of the FPL in the MTA, and the highest percentage (20%) of the population that is uninsured. Fulton County reports the highest percentage (21%) of Black women over the age of 45 who live under the poverty line.
- Only one county in the MTA, Fayette County, has an insured rate (94%) that is higher than the national average, while the remaining 15 counties have insurance rates that are lower than the national average.
- In October 2020, Georgia was approved for a Section 1115 waiver for partial Medicaid expansion for people earning up to 100 percent FPL, an estimated \$12,000 annually. This partial expansion does not fully insure the estimated 255,000 people in the coverage gap.
- Clayton, Cobb, DeKalb and Douglas counties all reported the highest percent of Black women feeling like their experiences seeking health care have been worse than other races at 13 percent.

Atlanta, GA: Recommendations

Micro-Level Strategies

- Increase access to culturally responsive patient navigators.
- Implement a culturally-relevant health promotion campaign intended to increase knowledge of screening guidelines.
- Increase education about family health history to identify high-risk families and offer genetic counseling and testing to meet the need.
- Support implicit bias trainings for providers, administrators and health care staff.
- > Expand financial assistance programs for Black women diagnosed with breast cancer.

Mezzo-level Strategies

- Support Quality Improvement (QI) initiatives along the breast cancer continuum of care.
- > Increase access to integrated care to improve the breast cancer care experience.
- Fund collaborative initiatives at the community level to address economic insecurity of Black women in the Atlanta MTA.

- > Support a root-cause analysis to uncover the drivers of late-stage diagnosis rates.
- Support efforts to develop guidelines and policies that address disproportionate breast cancer mortality among Black women, including increased genetic counseling and testing services.
- Advocate to expand Medicaid eligibility and eliminate burdensome restrictions that would limit Medicaid access to Medicaid in Georgia.
- Conduct an analysis of state policies to identify those that present barriers to high-quality care in the Black community.

Chicago, IL: 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 all 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 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 illuminates 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 FPL and the highest premature age-adjusted mortality for Black men and women.
- > There is food insecurity across all of the counties.

Chicago, IL: Recommendations

Micro-level Strategies

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

- 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.

Dallas-Fort Worth, TX: Key Findings

- In three of the four counties for which data are available by race, late-stage incidence rates among Black women are higher than they are among white women. The greatest disparity is in Ellis County, where the late-stage breast cancer incidence rate is 44.9 among white women and 63.6 among Black women. Dallas and Tarrant counties have the highest concentrations of late-stage incidence, with the majority among Black women in Dallas County and white women in Tarrant.
- In the Dallas—Fort Worth MTA, the likelihood of receiving a breast cancer diagnosis, the stage of diagnosis, and the likelihood of death vary along geographic, socioeconomic and racial lines.
- In situ breast cancer incidence rates for most counties in the Dallas—Fort Worth MTA are higher than the state rate of 22.9 per 100,000, but are comparable to the national rate of 28.3. Rockwall County reports the highest age-adjusted in situ incidence rates, at 35.3 overall. Of the three counties in the Dallas—Fort Worth MTA that have data available by race, Dallas County's in situ incidence rate was found to be higher among Black women, with a rate of 32.4, than among white women, with a rate of 27.2.
- In every county in the Dallas–Fort Worth MTA where disaggregated data are available (three counties), the breast cancer mortality rate among Black women is higher than the rate among white women. The racial disparity in breast cancer mortality rates is greatest in Dallas County, where the age-adjusted mortality rate for white women is 18.8 compared to 33.2 per 100,000 for Black women.
- The percentage of women receiving a screening mammogram varies throughout the Dallas–Fort Worth MTA from 62 percent in Dallas County to 81 percent in Rockwall County. Racial differences in mammography screening reported in Texas show that Black women are screened for the disease at a higher rate than white women.
- > Patient navigators noted the importance of navigation during diagnosis.
- > Medical providers specifically mentioned a need for more resources to support diagnostic mammograms.
- Patient navigators described the cost of diagnostic procedures as a significant barrier to timely diagnosis, even when the safety-net hospital offers financial assistance programs for women who are uninsured.
- > Texas also has not elected to expand eligibility for its Medicaid program.
- Focus group participants also elevated transportation as a significant barrier to accessing screening mammography in the Dallas–Fort Worth MTA.
- Additionally, the need for imaging centers that are in predominately Black communities and that will accept people without insurance was identified as a need.
- Survivors described positive treatment experiences that involved having a choice of providers, care coordination, and increased engagement with doctors outside of in-person visits. Some community members correlated the level of care they received with the quality of their insurance.
- > Providers, navigators, undiagnosed women and survivors all noted the importance of social support.
- Data suggest that there are significant disparities in the health system in the Dallas MTA, including in health care facilities and the proportion of the population that is medically underserved.
- Decades of discriminatory practices have led to striking segregation in the Dallas–Fort Worth MTA. The Dallas–Fort Worth MTA is segregated across a number of dimensions, including race and socioeconomic factors, creating stark contrasts by geography.
- Overall, breast cancer disease burden measures suggest that in most counties in the Dallas–Fort Worth MTA where data are available, Black women are more likely to receive a breast cancer diagnosis, are more likely to receive a late-stage breast cancer diagnosis and are more likely to die from breast cancer than their white counterparts, even though they are more likely to receive a screening mammogram.
- The data suggest breast health inequities among Black women in the Dallas—Fort Worth MTA could be explained by economic vulnerability driven by late-stage diagnoses and disparities in access to care.

Dallas-Fort Worth, TX: Recommendations

Micro-Level Strategies

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

Mezzo-Level Strategies

- > Increase access to integrated care to improve the breast cancer care experience.
- > Increase awareness of free screening to promote early-stage diagnosis.
- Partner with community organizations, place-based efforts, and philanthropy organizations to address systemic barriers to equity.

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

Houston, TX: Key Findings

- Incidence rates are comparable across counties and to the state average and lower than the national average. However, there are noteworthy differences in incidence rates comparing Black to white women. For example, in Harris County, the incidence rate is higher among Black women at 121.2 new cases per 100,000 individuals per year as compared to white women at 112.2 new cases per 100,000 individuals per year as compared to white women at 112.2 new cases per year. The trends are similar in Galveston County, the incidence rate is higher for Black women compared to white women (117.3 versus 113.5), and the five-year incidence rate trend is rising for Black women while it is stable for white women.
- The late-stage breast cancer incidence rates are comparable to the state rate of 37.7 cases per 100,000 individuals and lower than the national rate of 42.3 cases per 100,000 individuals. Harris County is the exception, it is the only county in the metro area that reports a late-stage incidence rate above the national rate of 45.4. Importantly, in three out of five counties (Fort Bend, Galveston and Harris counties) that comprise the Houston MTA, the late-stage breast cancer incidence rates are higher among Black women compared to white women. Black women in Harris County had the highest average count of cases that are late-stage (n=214) as compared to Black women and white women residing in other Houston counties.
- On average, the overall screening mammography rates, not disaggregated by race, in most counties in the Houston MTA are higher than the overall state average at 65 percent, but well below the national average at 73 percent. Fort Bend is the only exception; it has the highest screening mammography rate among all women in the Houston MTA at 77 percent.
- In terms of access to screening, several focus group participants noted free and convenient breast cancer screening availability in their communities. According to participants, opportunities for free mammograms at work and churches are convenient and facilitate women getting their first and annual mammograms.
- Despite access to screening through non-healthcare setting as noted above, several focus group participants noted barriers in the form of restrictive work policies, and the fear of losing their jobs if they tried to take time off work to have mammograms.
- Others expressed some confusion around screening guidelines, particularly what is the right age to receive a screening mammogram. The focus groups data revealed that self-examination is a common practice.
- Insights from qualitative data collected among community members suggests that access to and utilization of diagnostic procedures may be more limited in the Houston MTA and may be associated with delayed diagnosis. The high costs of diagnostic procedures for women, who are insured and uninsured alike was reported as a challenge.
- Age-adjusted breast cancer mortality rates are comparable with state and national rates. Across the Houston MTA, however, there are notable differences by race. In four out of five counties, the breast cancer mortality rate is higher among Black women as compared to white women. Harris County reports both the highest mortality rate (32.2 deaths per 100,000 deaths) in the metro for Black women as well as the greatest disparity between Black and white women (20.7 for white women versus 32.2 for Black women). Galveston follows closely in both respects: it has the second highest mortality rate (31.8) and the second greatest disparity between white women and Black women (22.2 for white women versus 31.8 for Black women).

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

Houston, TX: Recommendations

Micro-Level Strategies

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

Mezzo-Level Strategies

- > Increase access to integrated care to improve the breast cancer care experience.
- Create avenues for social support and community connection and strengthen networks of culturally responsive patient navigators.
- > Invest in Black-led CBOs providing non-medical services.

Macro-Level Strategies

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

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

Los Angeles, CA: Key Findings

- Throughout the Los Angeles MTA, Black women are more likely to die from breast cancer than their white counterparts, even though the incidence rates are comparable and often lower among Black women compared to white women. In both counties for which data are available, Black women die from breast cancer at a higher rate than do white women who live in the same place.
- In the Los Angeles MTA, Black women receive mammograms less frequently than their white counterparts, and therefore are diagnosed with breast cancer at a later stage when treatment options are more limited.
- A closer look at the data suggests that there is a trend in terms of late-stage incidence rates comparing Black women to white women. In Los Angeles and Orange County, the late-stage incidence rates are higher among Black women.
- Overall, a study of breast cancer disease burden measures suggests that throughout the Los Angeles MTA, Black women are more likely to die from breast cancer than their white counterparts, even though they are diagnosed with the disease at lower rates. This pattern is evident in Orange County, where the breast cancer incidence rate among Black women is lower than that of white women, at 110.8 for Black women and 131.8 for white women.
- Decades of discriminatory practices have led to striking segregation in the Los Angeles MTA. The Los Angeles MTA is segregated across a number of dimensions, including race and socioeconomic factors, creating stark contrasts by geography. Approximately 6.1 million people of color live in the Los Angeles MTA, comprising 46 percent of the region's total population. More than 85 percent of the 928,000 members of the Black community who live in the Los Angeles MTA reside in Los Angeles County.
- That being said, both counties in the MTA have low percentages of Black residents. In addition to the MTA not having many Black residents, both of the counties in the MTA are 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.
- The stories of Black women, breast cancer survivors and undiagnosed, convey their experience of fear and shame, racism, quality of mammograms, and access to screening.
- Finally, patients who are interested in alternative treatment but are not granted their preferred treatment from their provider are lost in the continuum of care, a finding which emerged from our qualitative data.
- Overall, the data suggest breast health inequities among Black women in the Los Angeles MTA could be explained by economic vulnerability driven by institutionalized racism and disparities in access and quality of care.

Los Angeles, CA: Recommendations

Micro-Level Strategies

- > Support Quality Improvement (QI) initiatives along the breast cancer continuum of care.
- > Increase access to culturally responsive patient navigators.
- > Develop education and programming to better serve Black women in treatment.
- > Implement implicit bias trainings for providers, administrators and health care staff.
- Increase education about family health history in the community to identify high-risk families and offer genetic counseling and testing and breast cancer screening to meet this need.
- > Expand financial assistance programs for African American women diagnosed with breast cancer.

Mezzo-Level Strategies

- > Increase access to integrated care to improve the breast cancer care experience.
- Implement a culturally relevant health promotion campaign intended to increase knowledge of screening guidelines.
- Support a community-based participatory applied research project to explore how to support breast cancer patients experiencing mental strain.
- Support a community-based participatory research project to identify and implement strategies for culturally relevant survivorship support.

- > Conduct a root cause analysis relating to delays in breast cancer diagnosis.
- Support efforts to develop guidelines and policies that address disproportionate breast cancer mortality among Black women, including increased genetic counseling and testing services.

Memphis, TN: Key Findings

- In both DeSoto County, MS, and Shelby County, TN, incidence rates for Black women are lower than or equivalent to those for white women.
- In the Memphis MTA, the likelihood of receiving a breast cancer diagnosis, the stage of diagnosis, and the likelihood of death from the disease vary along geographical and racial lines.
- There are no significant trends among incidence rates for white women versus Black women, as the incidence rates are higher among white women in some places and higher among Black women in others. The greatest disparity is reported in Crittenden County, AR, where the incidence rate is 78.9 for white women compared to 104.8 for Black women.
- In two of the three Memphis MTA Counties (Crittenden County, AR, and DeSoto County, MS), in situ incidence rates among Black women are higher compared to white women. The disparity is greatest in DeSoto County, with the rate reported at 25.0 for white women and 33.1 for Black women.
- Almost all age adjusted late-stage rates (overall and racially disaggregated) are lower in the MTA than the corresponding state's average. The exception is Shelby County, TN, where the overall rate is on par with the state average of 49.6 and the rate reported for Black women (the highest in the MTA) is 51.1, compared with 48.9 for Black women overall in Tennessee.
- In both DeSoto County, MS, and Shelby County, TN, mortality rates are higher for Black women compared to white women (21.1 white and 32.7 Black in DeSoto, 23.3 white and 34.5 Black in Shelby).
- In the Memphis MTA, particularly in DeSoto County, MS, Black women are more likely to die from breast cancer than their white counterparts, even though they are more likely to receive a screening mammogram and are diagnosed with the disease at lower rates.
- Overall screening mammography rates, not disaggregated by race, in the Memphis MTA are lower than the state and national levels. Crittenden County, AR, however, has the lowest rate of women receiving mammograms, yet their mortality rate is 22.4, which is lower than that of Shelby County, TN (28.5). This suggests that residents who are diagnosed in Crittenden County, AR, are more likely to survive breast cancer after receiving a screening mammogram than their counterparts in Shelby County, TN.
- Several focus group participants noted free and convenient breast cancer screening availability in their communities, but lack of awareness surrounding these programs. Free screening resources are not available where younger women congregate, and providers are not aware of where to refer uninsured patients for screening mammogram.
- > Providers also expressed concerns about the quality of screening at facilities in areas that are low income.
- Insights from qualitative data collected among community members suggest barriers to care due to challenges for patients navigating the diagnosis systems, complicated diagnosis process, and insurance barriers.
- There were numerous accounts of deductibles being too high and women foregoing care for financial reasons.
- Survivors and undiagnosed women all noted that historic distrust of the health care system, family and personal experiences of implicit bias, racism and discrimination rather than empathy in everyday life generally and in the health care system impact quality of care and retention in treatment for Black women.
- All focus group participants also noted how Black women are vulnerable due to poverty and demanding gender roles.

Memphis, TN: Recommendations

Micro-Level Strategies

- > Support Quality Improvement (QI) initiatives along the breast cancer continuum of care.
- > Develop a diverse and culturally responsive patient navigation workforce.
- > Expand financial assistance programs for Black women diagnosed with breast cancer.
- > Implement implicit bias trainings for providers, administrators and health care staff.
- Increase education about family health history in the community to identify high-risk families and offer genetic counseling and testing and breast cancer screening to meet this need.
- To implement a culturally relevant health promotion campaign intended to increase knowledge of current screening guidelines.

Mezzo-Level Strategies

- > Increase access to integrated care to improve the breast cancer care experience.
- Create avenues for social support and community connection and strengthen networks of culturally responsive patient navigators.

- > Conduct a root cause analysis relating to healthcare quality.
- Support efforts to develop guidelines and policies that address disproportionate breast cancer mortality among Black women, including increased genetic counseling and testing services.

Philadelphia, PA: Key Findings

- Throughout the Philadelphia MTA, Black women are more likely to die from breast cancer than their white counterparts.
- A pattern of lower breast cancer incidence rates but higher mortality rates among Black women is evident in seven out of the MTA's eleven counties.
- Research and data on screening mammography rates indicate that Black women receive screening mammograms at a higher rate than white women. However, the lack of awareness around free screening programs in the Philadelphia MTA was also noteworthy.
- The data suggest that there is no uniform trend in terms of late-stage incidence rates comparing Black women to white women. In some counties, the late-stage incidence rates are higher among white women, while in other counties, the reverse is true.
- The highest overall late-stage incidence rate is in Bucks County, PA, at 57.4 per 100,000 women. Salem and Cecil counties are noteworthy because their incidence rates for Black women are the highest in the MTA, but absent disaggregated mortality data for these counties warrants further investigation.
- Decades of discriminatory practices have led to striking segregation in the Philadelphia MTA. The Philadelphia MTA is segregated across a number of dimensions, including race and socioeconomic factors, creating stark contrasts by geography. In addition to the MTA 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, including mortality rates, with Philadelphia and Camden counties being areas of concentrated disadvantage.
- The stories of Black women, breast cancer survivors and undiagnosed, convey their experience of poorquality care, racism, microaggressions and health care discrimination. While this is not a new finding, it was particularly salient in this study.
- Finally, the challenge of retaining patients in the continuum of care with a history of or active psychiatric and behavioral health issues emerged as a more novel finding in the study from our qualitative data.
- Overall, the data suggest breast health inequities among Black women in the Philadelphia MTA could be explained by economic vulnerability driven by institutionalized racism and disparities in access and quality of care.

Philadelphia, PA: Recommendations

Micro-Level Strategies

- > Support Quality Improvement (QI) initiatives along the breast cancer continuum of care.
- > Increase access to culturally responsive patient navigators.
- > Implement implicit bias trainings for providers, administrators, and health care staff.
- Increase education about family health history in the community to identify high-risk families and offer genetic counseling and testing and breast cancer screening to meet this need.
- > Expand financial assistance programs for Black women diagnosed with breast cancer.
- Implement a culturally relevant health promotion campaign intended to increase knowledge of current screening guidelines.
- Implement a culturally relevant health promotion campaign intended to increase awareness of free screening.

Mezzo-Level Strategies

- > Increase access to integrated care to improve the breast cancer care experience.
- Support a community-based participatory applied research project to explore how to retain breast cancer patients with substance use/mental health issues.
- Identify and implement strategies for survivorship planning.
- Conduct broader outreach to Black women.

- Conduct a root cause analysis relating to healthcare quality.
- Support efforts to develop guidelines and policies that address disproportionate breast cancer mortality among Black women, including increased genetic counseling and testing services.
- > Advocate for expansion of eligibility requirements for free screening programs to improve access.

St. Louis, MO: Key Findings

- Although there is no consistent trend in local incidence rates, comparing Black women to white women across the different counties in the St. Louis MTA, Black women are consistently more likely to die from the disease compared to white women.
- St. Louis County stands out with breast cancer mortality rates among Black women that are almost twice that compared to white women.
- Late-stage diagnoses are higher for Black women versus white women in St. Louis City, MO, yet are not as apparent in other counties in the MTA.
- The rates of mammography screening are lower than state rates in Madison County and St. Clair County, IL, and in Jefferson County, MO. At the same time, disparities in mortality rates exist in St. Louis City and St. Louis County, MO, that have similar or higher rates than the state of the percentage of women who get a screening mammogram.
- Decades of discriminatory practices have led to striking segregation in the St. Louis MTA. The St. Louis MTA is segregated across several dimensions, including race and socioeconomic factors, creating stark contrasts by geography. In addition to the entire MTA 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 four counties with the largest Black populations, St. Louis City and County in Missouri as well as St. Clair and Madison County in Illinois, tend to have the greatest percent of those who are medically underserved, below 200 percent of the FPL, and food insecure.
- The data suggest breast health inequities among Black women in the St. Louis MTA could be explained by economic vulnerability driven by institutionalized racism and disparities in access and quality of care.

St. Louis, MO: Recommendations

Micro-Level Strategies

- > Support Quality Improvement (QI) initiatives along the breast cancer continuum of care.
- > Increase access to culturally competent patient navigators and community health workers (CHWs).
- Support financial assistance programs.
- 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 this need.
- To implement a culturally relevant health promotion campaign intended to increase knowledge of current screening guidelines.

Mezzo-Level Strategies

- > Increase access to integrated care to improve the breast cancer care experience.
- Fund Black-specific support groups across the MTA, particularly those that are taking leadership roles in building collaborations and strengthening advocacy.
- > Encourage health institutions (health care systems and payers) to invest in high-need areas.

- Implement a health promotion campaign intended to increase awareness of breast cancer inequities among Black women.
- > Support expeditious implementation of Medicaid Expansion in Missouri.
- > Conduct a root cause analysis relating to delays in breast cancer diagnosis.
- > Fund collaborative initiatives at the community level to address root causes of breast cancer disparities.

Virginia Beach/Tidewater, VA: Key Findings

- The breast cancer disease burden in the Tidewater MTA is largely influenced by two factors, where a person lives and their race. The data illuminate inequities across a number of metrics, including late-stage incidence and mortality rates, with Chesapeake and Suffolk Cities being areas of concentrated disadvantage.
- Suffolk City and Chesapeake City, in particular, stand out because their incidence rates (166.9 and 153.9), late-stage incidence rates (72.2 and 63.4) are all the highest or among the highest in the MTA for Black women. They also show the highest discrepancies between Black women and white women across all breast cancer burden measures.
- A pattern of lower breast cancer incidence rates but higher mortality rates among Black women is evident in four out of the MTA's eight cities/counties for which there was data. In about half of the cities of the MTA, white women have higher late-stage incidence rates than Black women (Hampton City, Newport News City, Portsmouth City). The two counties that are part of the MTA and Poquoson City did not have enough Black women to calculate late-stage incidence.
- However, in the remaining four cities (Chesapeake City, Norfolk City, Suffolk City, and Virginia Beach City), Black women have higher late-stage incidence rates than their white counterparts.
- Throughout the metropolitan area, Black women are more likely to die from breast cancer than their white counterparts who live in the same place.
- Further investigation may be warranted to better understand this narrative of why the screening rates are relatively high with relatively no discrepancies between Black women and their white counterparts, yet across the board, breast cancer mortality is higher for Black women in all cities/counties for which there was data.
- Suffolk City and Chesapeake City mortality rates (42.8 and 33.7) are all the highest or among the highest in the MTA for Black women.
- Black women have either the same or higher rates of mammography screening and lower incidence of breast cancer in half of the cities/counties examined for this analysis.
- Decades of discriminatory practices have led to striking segregation in the Tidewater MTA. The Tidewater MTA is segregated across a number of dimensions, including race and socioeconomic factors, creating stark contrasts by geography. Many of the cities/counties in the MTA are also internally racially segregated.
- The stories of Black women, breast cancer survivors and undiagnosed women, convey their experience of poor-quality care, racism, microaggressions and health care discrimination. While this is not a new finding, it was particularly salient in this study.
- Overall, the data suggest breast health inequities among Black women in the Tidewater MTA could be explained by economic vulnerability driven by institutionalized racism and disparities in access and quality of care.

Virginia Beach/Tidewater, VA: Recommendations

Micro-Level Strategies

- Increase access to culturally responsive patient navigators.
- > Support Quality Improvement (QI) initiatives along the breast cancer continuum of care.
- Support Financial Assistance Programs.
- > Implement implicit bias trainings for providers, administrators, and health care staff.
- Increase education about family health history in the community to identify high-risk families and offer genetic counseling and testing and breast cancer screening to meet this need.
- To implement a culturally relevant health promotion campaign intended to increase knowledge of current screening guidelines.

Mezzo-Level Strategies

- > Increase access to integrated care to improve the breast cancer care experience.
- Invest in high-need areas by health institutions, systems, and payers.
- Identify and implement strategies for survivorship planning.
- Support a community-based participatory research project to uncover the drivers of late-stage diagnosis rates.
- > Conduct broader outreach to Black women.

- > Influence the State Cancer Plan to Address Structural Barriers.
- > Conduct a root cause analysis (RCA) relating to delays in breast cancer diagnosis and healthcare quality.

National Capital Area/Washington, D.C.: Key Findings

- > Black women in the MTA are consistently more likely to die from the disease compared to white women.
- As with breast cancer mortality, there is a clear racial disparity for late-stage diagnosis. The late-stage breast cancer incidence rate among Black women in the MTA is higher than the rates for white women in five of the nine counties in the MTA, and highest in Prince George's County, MD, and Washington, D.C., where over 50 percent of Black women reside.
- Arlington County stands out as unique with the highest breast cancer mortality rates among Black women compared to white women. Overall, the data on breast cancer disease burden, comparing and contrasting across counties and by race suggests that the disease is most fatal for Black women who live in Arlington County, VA, Washington, DC., and Prince George's County, MD, and least fatal for white women living in Arlington County, VA.
- This is despite the fact that Black women are more likely to have had a screening mammogram or clinical breast exam compared to white women in both locations. In Washington, D.C., and Prince George's County, MD, where the majority of Black women over 45 reside in the MTA, Black women are more likely to be diagnosed with breast cancer, at later stages, and are more likely to die than their white counterparts.
- Decades of discriminatory practices have led to striking segregation in the National Capital MTA. The National Capital MTA is segregated across a number of dimensions, including race and socioeconomic factors, creating stark contrasts by geography.
- In addition to the MTA as a whole being racially segregated (with most people of color living predominantly in a few of the counties), many of the counties in the MTA are also internally racially segregated.
- The data illuminate the resulting inequities across a number of metrics, with Washington, D.C., being an area of concentrated disadvantage. The data suggest breast health inequities among Black women in the National Capital MTA could be explained by economic vulnerability driven by institutionalized racism and disparities in access and quality of care.

National Capital Area/Washington, D.C.: Recommendations

Micro-Level Strategies

- > Increase access to culturally responsive patient navigators.
- > Fund Black-specific support groups, particularly in Prince George's County, MD.
- Increase education about family health history in the community to identify high-risk families and offer genetic counseling and testing and breast cancer screening to meet this need.
- To implement a culturally relevant health promotion campaign intended to increase knowledge of current screening guidelines.

Mezzo-Level Strategies

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

Macro-Level Strategies

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