2017 COMMUNITY CONVERSATIONS REPORT

An assessment of community needs and solutions gathered from local stakeholders to reduce and eliminate the African-American breast cancer mortality disparity in Columbus, Ohio. We believe in harnessing the collective power of our community to save lives.
Introduction

What is health equity?

A basic principle of public health is that all people have a right to health. Differences in the incidence and prevalence of health conditions and health status between groups are commonly referred to as health disparities. Most health disparities affect groups marginalized because of socioeconomic status, race/ethnicity, sexual orientation, gender, disability status, geographic location, or some combination of these... Health equity, then, as understood in public health literature and practice, is when everyone has the opportunity to “attain their full health potential” and no one is “disadvantaged from achieving this potential because of their social position or other socially determined circumstance”.

- From “Promoting Health Equity: A Resource to Help Communities Address Social Determinants of Health, Centers for Disease Control

What are Social Determinants of Health (SDOH)?

Health starts in our homes, schools, workplaces, neighborhoods, and communities. We know that taking care of ourselves by eating well and staying active, not smoking, getting the recommended immunizations and screening tests, and seeing a doctor when we are sick all influence our health. Our health is also determined in part by access to social and economic opportunities; the resources and supports available in our homes, neighborhoods, and communities; the quality of our schooling; the safety of our workplaces; the cleanliness of our water, food, and air; and the nature of our social interactions and relationships. The conditions in which we live explain in part why some Americans are healthier than others and why Americans more generally are not as healthy as they could be.

- From “Social Determinants of Health”, HealthyPeople 2020, Office of Disease Prevention and Health Promotion

What is implicit bias?

Also known as implicit social cognition, implicit bias refers to the attitudes or stereotypes that affect our understanding, actions, and decisions in an unconscious manner. These biases, which encompass both favorable and unfavorable assessments, are activated involuntarily and without an individual’s awareness or intentional control. Residing deep in the subconscious, these biases are different from known biases that individuals may choose to conceal for the purposes of social and/or political correctness. Rather, implicit biases are not accessible through introspection.

- From the Kirwan Institute's State of the Science: Implicit Bias Review 2015

Who are we including when we discuss “African-American”?

For the purposes of this report, we will use the United States Office of Management and Budget definition of “Black or African-American” as a person having origins in any of the Black racial groups of Africa. This definition is also used by the Center for Disease Control and Prevention and the United States Census Bureau, and is inclusive of immigrant black populations. It is not inclusive of Hispanic or Latino individuals, unless specifically noted due to a specific data source. We currently lack data on breast cancer specifically among immigrant populations as a subgroup. Future work will attempt to look more fully at barriers that may be unique to immigrant populations in Franklin County.

Populations have different risk of diseases, including breast cancer. In addition, some populations experience social circumstances (factors like poverty, education and basic need), often referred to as social determinants of health, that also affect their health. The interaction of a population’s risk of disease and the way determinants of health affect them may result in a disparity, or differences in health outcomes, like higher death or incidence rates. Because of this, populations with disparities may require different approaches and interventions to achieve equity in health outcomes (Warnecke, 2008). The issue of breast cancer disparities is immensely complex, a blend
of personal risk, inherited or genetic risk, social determinants of health and healthcare delivery barriers, resulting in a 41% higher rate of mortality in the Franklin County African-American population, as compared to white women (National Cancer Institute, Centers for Disease Control, 2017). Even among African-American women in across the state, women in Franklin County have a higher mortality rate than African-American women in other counties in Ohio. (National Cancer Institute, Centers for Disease Control, 2017)

**Purpose**

Some of the what’s necessary to address disparities includes developing new therapies and research into genetics and tumor biology. This is occurring at other levels within Susan G. Komen and partner organizations across the world.

The focus of this report is opportunities to address disparities through community solutions. By fostering more productive and efficient collaboration, strengthening and building community-based solutions, organizations can work as a coalition towards strategic policy change that can reduce the disparity in our community. This report will summarize what we currently know, gaps where we need more information, and how these trends are observed locally and documented in our initial civic engagement work. Our goal is to avoid making any assumptions about causes. We still need critical data and information to better understand more about the root causes and the connected solutions. A follow-up report will make recommendations about future work may be successful in reducing this disparity.

**Methods**

From September 2016 through March 2017, Komen Columbus met with community leaders, policy makers, healthcare providers, social service agencies, faith-based community members, corporate partners and health care plans to hold discussions inventorying gaps and assets in the local community that may be contributing to disparities or may be opportunities to improve breast health among African-American women. Engaging stakeholders at all levels of this work will be critical to any success, and will continue in the years to come. The work to address breast health disparities, as with any health disparity, becomes a continuous conversation about addressing underlying social determinants of health, with access to care, implicit bias, and trust and accessibility of healthcare layered on top. None of these issues can be addressed solely by one organization, approach, program, or policy. Thus, the work of Susan G. Komen Columbus’ Health Equity Initiative will first focus on assessing the landscape for existing resources and partners for opportunity, maximizing our assets together with best practice, collaboration and learning, and aligning our work to focus on key action steps that can arm us with more tools and information in the coming years.
Identifying the Disparity

Overall, African-American women are more likely to die from breast cancer than white women, though white women are slightly more likely to get breast cancer. Breast cancer mortality is about 40% higher in African-American women nationally (Daly B, 2015).

The mortality rate among white women in Franklin County from 2009-2013 ranks 26th in Ohio (23.9 per 100,000 women), while the mortality rate among black women (including Hispanic women) is the third highest in the state (33.7 per 100,000 women). This data shows mortality is 41% higher among Franklin County black women. Over the past five years, trend data shows mortality rates are falling among white women, but remaining stable among African-American women. (National Cancer Institute, Centers for Disease Control, 2017)

Among never married females in Franklin County, the death rate for African-American women is more than double the rate for white women, but was slightly less than statistically significant. This could indicate stress and social isolation may play a role in mortality, as described in other health disparity research. The percentage of African-American women diagnosed with breast cancer at a regional stage is statistically significantly more than that of white women (25.1% white; 30.6% African-American). (Ohio Cancer Incidence Surveillance System, 2016)

While there are many, complex contributing factors to this disparity, the overall cause is that African-American women have not shared equally in the improvements in survival rates over the past 30 years. During 2009-2013, incidence was higher among black women under 60, while lower among black women over 60, when compared to white women. Nationally, death rates have declined among women over 50 significantly faster among white women compared with black women, however rates of decline were the same among women under 50. (Richardson, Henley, Miller, Massetti, & Thomas, 2016). The late stage diagnosis rate among African-American women is 22% higher than white women (Ohio Cancer Incidence Surveillance System, 2016).

There are not many sources for data to describe other possible contributors to the disparity available by race/ethnicity at the county-level. Ohio Cancer Incidence Surveillance System data was analyzed for socioeconomic indicators that may correlate with the disparity. Overall, patterns of social isolation, social determinants of health/ low-income, and quality of care appear to correlate with poorer mortality rates more than screening rates.

One major weakness is that sufficient race and ethnicity data is lacking at the county level, limiting the ability to isolate risk factors, barriers, and other contributors at the local level. More data on follow-up compliance, and quality measures for treatment would help isolate possible causes. A major suggestion from stakeholders has been to work with health providers and health plans, especially Ohio’s Medicaid program, to make sure that key indicator data is collected and available by race and ethnicity.
Tumor biology and genomics

“Breast cancer is not a single disease, but a family of diseases. There are different tumor characteristics used to determine prognosis and help guide treatment. These tumor characteristics are based on tumor markers, or indicators, as to whether or not the tumor will respond to currently available treatments defined by one of three proteins: estrogen receptors (ER); progesterone receptors (PR); and HER2/neu. African-American women often have aggressive forms of breast cancer.” (Daly and Olufunmilayo as summarized by Susan G. Komen, 2016)

Triple Negative Breast Cancer

TNBC is named for the things it is missing. TNBC are:
- Estrogen receptor-negative,
- Progesterone receptor-negative, and
- HER2-negative

TNBC tumors are often aggressive and need to be treated aggressively with chemotherapy. Although they can be treated, these tumors often become resistant to chemotherapy and cannot be treated with hormone therapy or HER2 targeted therapies, because they are ER-negative, PR-negative, and HER2-negative.

African-American women are more likely than white women to get TNBC, which partly explains the disparity seen in mortality for African-American and white women. It is important that women do not delay treatment of TNBC or forgo chemotherapy. (Daly B, 2015)

More than $111 million in over 150 research grants and 30 clinical trials supported by Susan G. Komen are focused on TNBC. So far, we’ve learned there are at least six different subtypes of TNBC, each with different abnormalities, which may be treated using drugs that target these abnormalities. We learned new combinations of therapies may be more effective at treating TNBC than chemotherapy alone. And we’ve worked to develop a blood test that detects specific genetic biomarkers which may be used to identify TNBC patients with BRCA mutations, resulting in earlier intervention and improved treatment strategies. Current grants are investigating:
- Identifying and developing new therapies for TNBC and testing them in clinical trials
- Developing strategies for preventing TNBC, including chemoprevention and lifestyle factors such as diet and exercise
- Understanding why African-Americans, young women and women with a BRCA mutation appear to be at higher risk for TNBC

For more information, read about Komen grantee, Dr. Lisa Newman’s work at the University of Michigan and in sub-Saharan Africa to uncover the factors that contribute to breast cancer disparities related to TNBC and African ancestry.

As part of Susan G. Komen’s bold goal to reduce breast cancer deaths by 50% by 2026, research investments will have an enhanced emphasis on better therapies for aggressive forms of breast cancer resistant to standard treatments, including TNBC and other types of breast cancer, as well as more effective treatments for metastatic breast cancer. (Susan G. Komen, 2016)
Hormone Receptor Status

“People with hormone receptor-positive tumors tend to have slower-growing tumors and better overall survival with treatment. They also have a slightly lower chance of breast cancer recurrence within the first five years of diagnosis than those with hormone receptor-negative tumors.

Overall, the majority of African-American women have hormone receptor positive tumors, but they are more likely to have hormone receptor-negative tumors than white women. Because hormone receptor-negative tumors do not have hormone receptors, they do not respond to hormone therapy. Some cancer cells have a protein, HER2 (human epidermal growth factor receptor 2), that appears on the surface (it may also be called HER2/neu or ErbB2). This protein is an important part of cell growth and survival. HER2 status helps guide treatment.

Did you know that HER2-positive breast cancer used to be the most aggressive type of breast cancer until drugs that target HER2 positive breast cancers were developed?

Those with HER2-positive breast cancers now benefit from targeted therapies, such as trastuzumab, tykerb and perjeta, but those with HER2-nagtaive breast cancers do not. Even though there might not be large differences between white and African-American women when it comes to the incidence of HER2-positive breast cancer, access to timely diagnosis and effective treatment may be limited in resource-poor settings, leading to worse outcomes for African-American women.” (Daly and Olufunmilayo as summarized by Susan G. Komen, 2016)

Genomics

“Genomics is the study of genes and their functions. It can provide clues about inherited susceptibility and about how to treat tumors that can help guide breast cancer management.

About 5–10 percent of breast cancer cases in the U.S. are due to inherited gene mutations. BRCA1/2 are the most common genes linked to breast cancer risk. BRCA1/2 mutations are rare in the general population. Most people with breast cancer who have a BRCA1/2 mutation are diagnosed at a younger age and have more aggressive tumors.

African-Americans are more likely to be diagnosed with breast cancer at an earlier age. African-American breast cancer patients who have had genetic testing are more likely to have BRCA1/2 mutations compared to other populations.” (Daly and Olufunmilayo as summarized by Susan G. Komen, 2016)

More than $53 million in over 130 research grants and 30 clinical trials focused on BRCA mutations in breast cancer. These studies have discovered, for example, that women from the Bahamas appear to be twice as likely to have a BRCA1 mutation than the general population. Newly identified risk factors may help predict which women with the BRCA mutation will get breast cancer, and that different populations have different types of BRCA mutations, which may affect their relative risk of developing breast cancer. New research focuses on new ways to prevent breast cancer in BRCA mutation carriers, including new drugs, hormone therapies and dietary approaches, as well as identifying environmental or hormonal factors that may contribute to breast cancer risk in women with the BRCA mutation, and understanding how BRCA mutations lead to both inherited and sporadic (not inherited) breast cancer so that targets for new drugs can be identified. (Susan G. Komen, 2016)
BRCA mutations account for only 20 to 25 percent of all hereditary breast cancers. There are many other inherited gene mutations, including PALB2, CHEK2, ATM and TP53, but many yet to be discovered. More than $28 million has been invested in investigating other hereditary breast cancers, including using cutting edge genomic technology to identify new genes linked to inherited breast cancer, and testing whether Everolimus, a drug used to treat metastatic ER+ breast cancer and other cancers, can be used to prevent breast cancer in women with a BRCA mutation. We’ve learned mutations in a gene called RECQL are associated with inherited breast cancer and may increase risk by as much as 50 percent, depending on the mutation. An inherited mutation in the PALB2 gene may increase the risk of breast cancer by 30 to 60 percent. We’ve also learned a family history of other cancers, such as prostate and pancreas, may help improve breast cancer risk prediction tools like BRCAPRO. (Susan G. Komen, 2016)

As part of Susan G. Komen’s Bold Goal to reduce breast cancer deaths in the U.S. by 50% by 2026, research investments will have an enhanced emphasis on leveraging the use of transformative, next-generation technology to detect and treat breast cancer at the very earliest stage, before it has spread or returned, and when treatment is most effective. Identifying other inherited gene mutations is an important step in helping women and men understand their individual risk, and empowering them to take action.

**Patterns of Care**

“Although differences in tumor biology and genomics appear to contribute to disparities in breast cancer mortality, there are other factors that may contribute to health disparities. For example, differences in the quality of mammograms African-American women receive, issues with appropriate follow-up or delays in diagnosis, treatment delays and misuse (or underuse) of treatment are some of the obstacles African-American face.”

– from “A Perfect Storm” (Daly B, 2015)

**Local landscape: Risk perception, patient education, provider communication**

With this information about family history and personal health history, women can engage in empowered discussions with their providers to make informed decisions about genetic counseling and screening. One barrier uncovered through local conversation is risk perception among African-American women. Patients can’t make informed decisions about reducing risk and genetic counseling when they don’t have sound education about risk. A clear understanding of both personal risk and what family history means for genetic or inherited risk is critical. Misinformation and myths about genetics and risk abound. This interferes with referral for genetic counseling, and motivation for screening.

Common myths about personal breast cancer risk included cell phones, breast size, deodorant and other disproven factors as causes. Many believed family history translated directly to breast cancer being “hereditary”, often associated with feelings of fate and predetermination. Others believed their family history did not affect them.
Misinformation and confusion about breast density, cysts and genetic testing was only further muddied by recent changes in screening recommendations by age. Changes in age recommendations for screening by major organizations was mentioned frequently as a point of frustration and as damaging to trust. Participants said they didn’t think screening could be that important if no one could agree when it was needed. Confusion also centered around screening technology like 3-D mammography or tomosynthesis. Many women also believe they need a prescription for a mammogram. Though discussion with a healthcare provider is recommended, the perception that a prescription is required created another barrier.

Focus group discussions highlighted issues about not understanding dense tissue, risk associated with dense tissue, and both fear and ambivalence associated with being called back for frequent abnormal results. Local providers indicated that genetic referrals for low-income, uninsured women are difficult.

Risk perception and education becomes critical when making decisions about healthcare or other priorities. An individual can’t make an informed decision to make their breast health a priority when they don’t understand their risk. A common theme of focus group conversation was that breast health and other preventive care simply can’t be priorities when there are so many other needs competing for priority, even when cost is not a barrier and insurance or other programs provide financial access.

Challenges with communicating with providers were a consistent theme. Many expressed a hesitancy to ask questions, and a culture of respecting the authority of medical providers without questioning. Stakeholders at the summit also emphasized that women need to know what to ask and what standards to expect from their care, in order to guarantee that they receive high quality care. They expressed a need for tools and help knowing what to ask, and how to best advocate for themselves. (Susan G. Komen’s Questions to Ask the Doctor communication tools will be a helpful asset.)

Empowering women with clear understanding of their own risk will enable them to make informed decisions for their own healthcare. This includes addressing the specific myths and points of education that have emerged through community conversation. Since many myths and misunderstandings persist from word of mouth, locally tailored education can be a powerful tool. Focus on individualized risk and informed decision making with a healthcare provider can avoid the confusion of general age-based screening recommendations. Susan G. Komen’s breast self-awareness messaging emphasizes the importance of talking with a healthcare provider about risk and screening over universal age recommendations. Currently, Komen Columbus navigation programs include several community health workers focusing on education and navigating women through screening, ready to meet some of the identified educational needs, as well as trained...
faith-based breast health coordinators through the Worship in Pink program. For more information about these educators, please contact outreach@komencolumbus.org.

Local landscape: Fear, peer to peer networks and support

Focus group conversations included much discussion of fear, what contributes to it, what mitigates it, and who women turn to for support. As one participant highlighted, stories and information shared by friends and family are valued much more than education from professionals in healthcare. This offers a valuable resource for peer to peer education, but also shows the importance of making sure trusted individuals in the community are armed with accurate information. Misinformation, poor experiences with healthcare, and stories spread by trusted family members are difficult to combat.

The first barrier often mentioned, from focus groups to care managers at insurance plans working to get members into screening, was fear. The phrase “I don’t want to know” was common, and often followed by feelings of fatalism—“what can I do about it anyway”. In this vein, screening is often viewed as discretionary, so when it’s not necessary, or not viewed as a tool to empower women with choice or lifesaving information, many forego using it. Emphasizing screening as a tool to empower, rather than diagnose, may be powerful.

Other reasons for fear included a lack of knowledge about what to expect from the whole process. Many mentioned fear of pain associated with a mammogram. Making it very clear what happens at a mammogram (what to wear, how long it takes, who will be there, etc.), or what it means to be called back for follow-up after an abnormal screening result and what to expect at that visit, could reduce fear. Susan G. Komen’s mammography resources can be a tool here.

Women mentioned positive experiences from celebrating survivors, an underutilized tool for education. Creating ambassadors in the community from breast cancer survivors with positive experiences can help reduce fear about the process, stigma and fatalism. Another point for education is what an abnormal result means, and reducing the fear and fatalism associated with abnormal results, to increase follow-up testing adherence. Education about the likelihood of a cancer diagnosis, diagnostic process and options for treatment are important tools to reduce fear. Many of these materials and resources are already available, but more partnerships and training to share them with the community are needed.

“People don’t want to talk about it because they think it’s something they did. ... It’s like there’s guilt there.”

“They invite me to support groups, it’s like, ‘I already got one, so I’m not going to the support group. I’m fine with my mom and my sis. We’re good.’”

“When [my sister] told my family, my grandmother was hysterical, and so I think with my family, because my grandmother went through it and she’s the head of our family, we’re all very conscious about making sure that we get checked.”

“I went two years without getting an exam because I was so petrified. She kept hounding me, ‘You need to get this done.’ ...with all the women in the family, she’s the one who always, for some reason she keeps track... ‘Did you go get it done?’ She does it with me, my nieces, my sister-in-laws, and she’s just amazing to me. She is truly ... she’s so strong and each day, because she lives with me and I see her every day and it makes me happy to know that my mother is still here. It could have been something else.”

Focus Group Participants
Conversations about sources of support and commonly sought resources for information highlighted well-known approaches, including salons, barber shops, sororities and faith-based outreach. As so much conversation focused on other women and word of mouth as sources of education and influence, increased focus on groups of women supporting each other and leaning on one another to screen and follow-up are important. Ensuring staff at other agencies and organizations addressing other needs of low-income women facing barriers to screening or follow-up have easy to share breast health information and resources will be an important tool.

Focus group participants suggested social media campaigns, creating social events around getting screenings scheduled and done together, and leveraging spouses to have important screenings together as positive ideas. It is critical to make sure that notable and respected members of the community are visible and vocal. All groups agreed education needs to come from peers and community leaders.

Participants also highlighted the need to educate younger women to create a generational change in the mindset of women to use preventive care beyond breast health screening, and empower positive healthcare experiences. Suggestions included role playing and skits to teach younger women how to self-advocate in interactions with healthcare providers, as well as place them in the role of provider and reduce any fear of questioning providers, as well as creating a children’s “book” that could be taken home to share with parents, leading to generational change in trust in the healthcare system and engagement.

Participants mentioned a lack of visibility of breast health and screening throughout targeted neighborhoods. They recommended increasing the presence and visibility of breast health and screening information, and making sure it was year-round and not centered around October (Breast Cancer Awareness Month).

While many of these conversations discussed screening, screening does not appear to be a main contributor to this disparity. Instead, many of these same lessons and barriers may be affecting follow-up care after abnormal screening results, which is suspected to play a larger role.

**Local Landscape: Screening access and quality**

Screening tests are used to find breast cancer early before it causes signs or symptoms. Mammography can find breast cancers early, when they are small and the chances of survival are highest. Overall, mammograms are the most effective screening tool used today to find breast cancer. In the past, African-American women had lower screening rates than white women nationally, but now screening rates are about the same (Daly B, 2015). This holds locally in Ohio, where among ages 50-74, in the last 2 years, 84.0% of black/ African-American women had been...
screened in the past two years, while 77.7% white women had been. The general screening rate was 77.7% (Ohio Department of Health, 2015).

While screening rates are similar in general among African-American and white women, we also know that screening rates are higher among women with a higher income and education level, so these social determinants of health may be interacting with risk to lead to later stage diagnosis among particularly vulnerable African-American women. This is true among Ohio’s Medicaid population which has a 47% lower screening prevalence than the general Ohio population. While screening may not be a sole contributor, a focus on improving screening among low-income women is important.

In addition, there may be differences in the quality of the screening African-American women receive, and/or delays in follow-up after an abnormal screening before a diagnosis is made or treatment begins. Again, this may be exacerbated in low-income populations. Furthermore, though screening rates are not statically significantly different between African-American and white women, it’s possible that, since breast cancer can be more aggressive and occur earlier in African-American women, our measurement of screening for women over 50, women under 50 may not be getting screenings.

Currently, the Affordable Care Act requires private and public insurance plans to cover screening mammography at no cost to a patient. Many women do not know this about their insurance benefits, another point for education, and many do not make use of this benefit at all, as demonstrated by the low screening rates among Ohio’s Medicaid population. In addition to no-cost breast cancer screenings and genetic screenings (for appropriate patients), the Affordable Care Act guaranteed no coverage limits for treatment for patients, no denial for pre-existing conditions, coverage for preventive medicine for those at high-risk (Tamoxifen) and led to the expansion of insurance coverage to the lowest uninsured rates in a decade.

“A lot of women are still under the impression that they can’t get it done because they don’t have insurance, so they don’t ... ‘Oh, I can’t pay for it.’ I think if there was more out there to let them know that you can get this done and you don’t have to pay for it, it’s lifesaving.”

Focus Group Participant

“Typically, with the hospitals, they have to have multiple visits before they’re seen for the problem. Just in particular, we had a woman that came in that was in her late 40s that had bloody nipple discharge, but it was very dramatic. It was very clear that there was something very wrong. We sent her to X, and they made her an appointment, and when they found out she had no insurance they canceled it, and then made her a financial appointment, and she had at least one of those, maybe more. Ultimately, she was diagnosed with invasive ductal carcinoma. There has to be a better way, when I think about patients like that.”

Local Clinic Provider
For the uninsured, the Ohio Breast and Cervical Cancer Project (BCCP) provides screening and diagnostics (education and patient navigation) for women with incomes under 200% of the federal poverty level. Efforts for expansion of the eligibility of this program are underway. Women in Ohio with incomes under 138% of the federal poverty level have access to Medicaid coverage. Through these programs, the cost barrier is removed for women who enroll. However, again, ensuring women are referred to and enrolled in these programs is a critical step.

For the uninsured who are not eligible for Medicaid or BCCP, cost for screenings may remain a barrier. From June 30, 2015 to June 29, 2016, 17% of those served by the program in the Central region (which includes Franklin and several contiguous counties with non-metropolitan areas) self-reported as African American. This may show slight underrepresentation of the Franklin County African-American community, estimated to be 22.5% of the Franklin county population, though the numbers of women served are inclusive of other counties with smaller African American populations. Komen Columbus creates a portfolio of programs to meet unmet financial need annually. Promotion of and referral to these programs by all relevant partners is critical to their ability to ensure any remaining cost barriers are overcome. Integrating breast health resource information into other social service program points of contact would be beneficial. For example, the community connectors activated on infant mortality programs may be effective referral sources for screening among mothers or grandmothers and their networks.

According to the Ohio Medicaid Assessment Survey, 33.6 percent of African-American women in Ohio have insurance coverage through Medicaid (see Table), compared to 22.1 percent of females overall or 19.0 percent of white females with Medicaid coverage. More African-American women get coverage through Medicaid, proportionally, than white women in Franklin County, or African-American or white women in Ohio.

Since screening appears as a factor among a specific subset, low-income women with Medicaid coverage or uninsured, many of the barriers discussed may be contributing to the significant delays we see from diagnosis to treatment, as opposed to screening barriers alone, in the general population.

More than 86 percent of the state’s Medicaid population are served by five managed care plans (MCP), Buckeye, CareSource, Molina Healthcare of Ohio, Paramount Advantage, UnitedHealthcare) (Medicaid, Managed Care Enrollment for New Populations, 2016). The Ohio Dept. of Medicaid (ODM) requires Healthcare Effectiveness Data and Information Set (HEDIS)
performance measures related to care management and utilization on breast cancer screening. Breast cancer screening, measured as percentage of women 50-74 who had a mammogram (which excludes high risk women with a personalized risk of breast cancer that may warrant screening outside these guidelines), shows that all five plans reported rates from 48%-57.2% for a statewide average of 53.5%. (Medicaid, State Fiscal Year 2016 HEDIS Aggregate Report for The Ohio Medicaid Managed Care Program, October 2016) It should also be considered that any policy changes in availability of Medicaid or other insurance coverage through legislation may have a pronounced effect on vulnerable populations. A weakness of our understanding of this data is that HEDIS measures are not available by race or ethnicity. Access to such data would be instructive.

Care management is available to all MCP members, and individuals with special or complex health care needs are automatically enrolled in care management. A care manager from each MCP works with members and providers to advocate, assist, refer and link the member to community resources. Care managers may be a target for training in breast health, disparities, barriers, and available resources. Promoting the use of care managers, while offering additional patient navigation through local programming, to those who have Medicaid, would help address many barriers to screening, follow-up and additional underlying social determinants of health. Individuals with abnormal screening results are not necessarily linked into a care management to ensure adherence to follow-up care. This is an opportunity to leverage an existing resource to improve follow-up among a low-income population.

Among higher income women, discussions about access focused more on convenience than cost as a barrier. Appointment times before or after hours, or the utilization of mobile mammography or workplaces allowing work time for appointments increase accessibility for those who have employer-based insurance.

Beyond cost barriers, transportation, knowledge of how to access available resources, ability to navigate the healthcare system can be barriers to follow-up resulting in delays among both Medicaid clients and African-American women. Training for care managers at health plans and other navigators and clinicians on the specific barriers experienced in the local community in accessing screening could be impactful. Many partners expressed interest in scripts detailing recommended responses for various types of barriers. In many cases, resources are available already to address most barriers, but women are not being linked to them at the moment of need. For example, many current Komen Columbus programs offer cab vouchers to assist in transportation barriers, but local clinicians who felt that the bus passes available via Title 9 funding were too difficult for some patients to use were unaware that that resource was available.

“They’ll walk out and they’ll go, "Wow, I really felt like somebody cared about me." They know you took that extra step, they know you fit them in. Then they’ll call you when they’ve got a problem or they need something. They know where to go. Then they’ll tell their friend, and their friend shows up.”

Local Clinic Provider

“I said that you’re not going to find anything now, but you send me this letter that I’ve got dense breasts and you have me keep coming back for the same test, because basically they never did a different test on me, they just said that it was dense and they needed to redo it.

“The cure is just as bad as the cancer. You know, the cure is just as bad as the cancer, so they’ll go that route and I ain’t getting anything done, I’m not going to that radiation, I’m going to be sicker. All of a sudden cancer do it’s own thing and some have a fear that radiation, the cure, is making it worse. They don’t trust the medical providers

“You know that thing when you walk into a department store and the bells start going off, ‘Black person in store. Medicaid person in room.”

Focus Group Participants
Current assets in addressing not only cost, but other barriers, including health literacy and use of insurance, include:

- Komen Columbus is funding a partnership between Mount Carmel’s Imaging, Urban Health office, mobile units and the Heart of Ohio Family Health Centers.
- The Research Tested Intervention Program “Friend to Friend” is a peer to peer education model for housing developments. Potential deployment of this model could partner with development companies established on the east side of Columbus.
- Komen Columbus is funding a patient navigation program at the Stefanie Spielman Comprehensive Breast Center which will support community health workers and patient navigators to help women overcome barriers to screening and help high-risk women navigate the health care system for follow-up.
- Komen Columbus is funding a program at the Columbus Cancer Clinic for navigation to screening through a community health worker.
- Komen Columbus is funding a program in partnership with OhioHealth which deploys community health workers to navigate women to screening and through any follow-up. The program has served Latina and Hispanic women, but recently added a pathway for African-American women.
- Care management teams at the Managed Care Plans could receive education about this disparity, barriers and resources to overcome them.

Ohio’s BCCP also offers navigational resources to any woman with an income less than 200% Federal Poverty Level, including interpretation of test results, referral to specialty providers under the client’s insurance, transportation assistance and more.

It may not be that screening rates and barriers to screening are the issue— but instead the quality of the screening. The Breast Cancer Care in Chicago study found women with symptomatic discovery of their breast cancer despite having a recent screening was higher among black women than white patients, as was associated with higher grade disease. Their conclusion was that the facility quality itself and tumor aggressiveness combined for poorer outcomes to create this disparity. Centers screening patients that relied on dedicated radiologists and imaging centers of excellence had less of these outcomes. (Mortel, Rauscher, Murphy, Hoskins, & Warnecke, 2015). Beyond accreditation status, no quality data is publicly available currently. A quality assessment study of Franklin County screening, diagnostic and treatment facilities would help in evaluation of this possible contributor to disparities.

**Local landscape: Follow-up diagnostics, treatment access and quality, social determinants of health and implicit bias**

Despite advancements in insurance coverage and preventive care requirements, cost remains a barrier for follow-up diagnostics, which can range $200-$2000, and are most often subject to cost sharing. Patients with high deductibles often face difficult choices when faced with an abnormal screening results requiring further testing to determine a diagnosis. These cost barriers persist for many patients, whether they are insured or not.

African-American women experience delays in follow-up after abnormal screening results. Specific data on delays in follow-up are not publicly available and would be a critical part of uncovering and addressing these issues.

The percentage of African-American females diagnosed with breast cancer who are uninsured or self-pay is statistically significantly higher than that of white females (6.0% African-American; 2.7%
The percentage of African-American women diagnosed with breast cancer who have private insurance (45.2%) is lower than that of white females (50.9%). The percentage of African-American women diagnosed with breast cancer who have Medicaid (15.0%) is higher than that of white females (3.9%). Additionally, the percentage uninsured or self-pay women diagnosed at distant stages or regional stages is more than that of females with private insurance, statistically significantly. The percentage of African-American women diagnosed with breast cancer who live in a neighborhood with more than 20% poverty (57.1%) is higher than that of white females (19.0%). (Ohio Cancer Incidence Surveillance System, 2016)

<table>
<thead>
<tr>
<th>Zip codes where 50% of African-American mortality in Franklin County occurs</th>
<th>Neighborhood</th>
<th>Avg. days between diagnosis and treatment rank (out of 40)</th>
</tr>
</thead>
<tbody>
<tr>
<td>43211</td>
<td>North Linden</td>
<td>11th</td>
</tr>
<tr>
<td>43213</td>
<td>Whitehall</td>
<td>7th</td>
</tr>
<tr>
<td>43219</td>
<td>Northeast Columbus</td>
<td>9th</td>
</tr>
<tr>
<td>43229</td>
<td>Forest Park East</td>
<td>15th</td>
</tr>
<tr>
<td>43232</td>
<td>Southeast Columbus</td>
<td>4th</td>
</tr>
</tbody>
</table>

African-American females, on average, have 10 more days between their initial breast cancer diagnosis and when they began treatment than white women, which is statistically significant, however the median days between diagnosis and treatment are similar. Women who have Medicaid, on average, have 14.7 more days between their initial breast cancer diagnosis and when they began treatment than those with private insurance, a statistically significant difference. However, the median day difference was lower, which may indicate that one or more women who waited longer for treatment skewed the average. Delays in treatment may indicate quality issues.

Nearly half of all breast cancer deaths in African-American women in Columbus are found in five zip codes, to be the focus area of the program (43211, North Linden; 43213, Whitehall; 43219, Northeast Columbus; 43229, Forest Park East, Minerva Park; 43232, Southeast Columbus) (Chronic Disease Epidemiology and Evaluation Section and the Bureau of Vital Statistics, Ohio Department of Health, 2016.). In addition, those five zip codes rank among the zip codes with the highest mean number of days between diagnosis and treatment (43211, 11th; 43213, 7th; 43219, 9th; 43229, 15th; 43232, 4th; of 40 zip codes)

In addition to delays in follow-up, many studies also show the time from diagnosis to treatment is longer among African-American women, as evidenced in the OCISS data. Once treatment is initiated, studies have shown African-American women often do not receive the recommended standard of care. In comparison to white women, studies have found lower rates of radiation therapy after lumpectomy, lower doses of chemotherapy; and lowered adherence to tamoxifen. Cost, physician beliefs, or unidentified factors may be issues contributing to these differences. In another study, African-American women were more likely to stop treatment early or have treatment delays than white women, possibly due to difficulty in arranging child care, missing work, and transportation barriers (Daly B, 2015). A 2015 study of New York and California Medicaid enrollees found Medicaid enrollment was associated with decreased likelihood of receiving all recommended treatments, except chemotherapy, in both states (Daly B, 2015). Only 35% patients received care concordant with all recommendations. African-Americans were less likely to receive recommended surgery, radiation and hormone therapy than whites. (Hassett, Schymura, Chen, Gesten, & Schrag, 2015) As a large proportion of African-American women diagnosed at a late stage have Medicaid coverage, considering the quality of treatment is important. Ensuring the standard of care for breast cancer treatment for all women improves survival. There was a clear perception during community conversations that those with Medicaid or other public insurance
received different quality care than those with private insurance. Many indicated they thought this was a factor more than race.

If quality data or HEDIS data was available stratified by race/ethnicity, known quality improvement strategies could be applied to address the issues uncovered by analysis. This topic was emphasized at the summit meeting.

A significant barrier may be the perception that free medical care is associated with poor care. A significant, newly insured population has the perception that their care is not of the same quality as that provided to those with private insurance. Discussions with providers and health plans highlighted successes and best practices in clinic and resource flexibility that was helpful in building trust and facilitating use of resources in the community. A particularly useful trust-building and impactful approach was for care managers at MCPs to help address other SDOH needs, not only for the plan member but for other members of the family or household. This helped not only meet other SDOH needs, but improve health equity for that member and improve their ability to utilize the health benefits available to them. High quality customer service and positive interactions spread through word of mouth around the community, building referrals and health relationships with healthcare providers.

The newly insured need education on how to use these tools newly available to them. They don’t have a pattern of using preventive care, and many don’t understand the benefits of their new coverage. Many clinics that used to see uninsured patients have seen increases in the proportion of Medicaid patients they are working with, and facilitating utilization of those benefits, particularly the care management and transportation benefits offered, are an opportunity to improve the experiences and healthcare quality of patients.

Discussion with stakeholders at the summit emphasized the need for lists of trusted resources that the community knows, trusts and can rely on for high quality care. This may be particularly helpful with immigrant populations. The National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care provide a useful metric and guide for building the capacity of providers and trust from the community.

All-in-one days were suggested and viewed favorably- days to get all necessary screenings and primary care in one visit for the whole family. Other suggestions included emphasizing flexibility on appointment times, particularly for missed appointments and walk-ins, especially on mobile units doing community screening, and making it a goal to use whatever reason a patient sought care as an opportunity to assess and address all other needs, including social determinants of health. This involves a culture shift, and making it part of the mission to be more flexible, which helps to build trust and sustainable primary care utilization among this at-risk population. Bad experiences and negative perceptions hurt trust and utilization.

Patient navigation is an evidence based way to ensure women with abnormal results are not lost to follow-up in the system and can address the spectrum of social determinants of health along the way.

Conclusions and recommendations
On March 23, 2017, Susan G. Komen Columbus held a Breast Health Equity summit with community leaders, experts and community members to educate and discuss the existing disparity. Preliminary findings from this report were shared, and community members validated the observations made and summarized in this report with their own observations and experiences.
Susan G. Komen's **Bold Goal** is to reduce the current number of breast cancer deaths by fifty percent. Research focused on new therapies for hard to treat types of breast cancer, disparities, new technology and metastatic breast cancer will be a critical part of meeting this goal and reducing disparities caused by tumor biology and genetics. Community work focused on making sure all women get high quality and timely care will also reduce mortality. Particularly, we will focus on identifying populations that may experience disparity in quality or timeliness of care and work with the community to identify and implement solutions.

These themes are further supported by Health Policy Institute of Ohio’s Health Value Dashboard, which found that though Ohio performs well on health access issues, like breast health screening, performance is poor on population health, demonstrating access alone is not enough to improve health. (Health Policy Institute of Ohio, 2017) Public health consensus is that eliminating health disparities can only be achieved through universal health equity approaches like improving the social and economic environment and strengthening public health and prevention approaches, including preventive health education. While access plays an important role, as evidenced in the breast cancer disparity evaluated here, access and safety-net funding are not the only determinants at play. A combination of the following factors interact to create the disparity faced in Franklin County: healthcare delivery, social and economic factors, the physical environment, population-based education and prevention strategies, screening behavior, genetics and tumor biology.

It is only through highly collaborative, intersectional and innovative system level and policy change, combined with community-based solutions that this disparity can be reduced and eliminated, to achieve health equity. The March 23rd Summit was the first of many collaborative efforts which will pull together important community partners around this area. In addition, stakeholders agreed that additional projects replicating other health equity approaches to improve health disparities would be an ill-advised use of resources. More can be gained from the alignment of a working group to use its collective energy and resources towards cancer equity overall, including legislative approaches.

Based on community input from the summit and the findings of this report, we believe the areas of focus areas should be multi-level and include:
Identify all necessary community partners, determine their roles, and determine organization and process for moving forward

- Consider existing coalition structures
- Consider a statewide approach where more and higher quality data is available at the state-level and many of the solutions will involve policy-level, statewide approaches
- Supplement missing information in this report on barriers and experiences among immigrant populations, who are also affected by this disparity

Create and deliver custom education in response to specific education gaps of local community, including information for high risk women under 50 and genetic testing education

- Encourage a preventive mindset towards healthcare that may not exist in traditionally underserved and marginalized populations through consumer empowerment and patient communication skills
- Leverage peer to peer education and visible members of the community
- Existing assets: Worship in Pink, Sister Screen Saver, Susan G. Komen African-American Breast Health Education Toolkit, Ohio Partners for Cancer Control, Susan G. Komen “Questions to Ask the Doctor” tools

Improve screening among specific subset of population with lower screening rates (low-income women with Medicaid coverage or uninsured)

- Investigate impact for African-American women under 50 not included in screening guidelines
- Work to increase screening rate among Medicaid populations in partnership with Medicaid managed care plans
- Improve visibility and referral to existing local resources through media campaigns and outreach to local community assets
- Existing assets: Current safety-net screening programs including Ohio’s Breast and Cervical Cancer Project and Komen Columbus Patient Navigation programs, Managed Medicaid Care Plans care management teams, mobile mammography resources, best practices for improving screening rates (ACS and The Community Guide, HRSA.gov, Ohio Partners for Cancer Control

Identify and address issues contributing to lower quality of screening or care, delays from diagnosis to treatment, and nonadherence to follow-up or treatment

- Inventory and map community assets, healthcare facilities and mortality, including quality assessments
- Consider quality improvement projects, implicit bias and cultural humility training for healthcare providers
- Consider data sharing to improve understanding of follow-up and compliance barriers
- Share best practices in improving quality and timeliness, offering services with cultural humility, and meeting social needs of patients
- Existing assets: Ohio Partners for Cancer Control, The Community Guide, HRSA.gov, Commission on Cancer Hospital Comparison Benchmark Reports, need more data

Advocate for policies that improve overall social determinants of health through a Health in All Policies approach

- Link patient navigation into wrap-around projects that meet social needs through partnership with social service agencies, rather than addressing disparities with separate, siloed approaches
- Develop health equity policy summit to educate policymakers in partnership with other health equity organizations and agencies
- Existing assets: Partners addressing other health equity topics and social determinants of health, current Komen Columbus patient navigation programs
Partners and Assets

Partnerships are essential to reducing the African-American mortality disparity. No one group can make a significant impact on something so deeply entrenched in social determinants of health, policy and environment, when working alone or in isolation. Through partnership moving forward, a coalition has the potential to pool information, improve policy and make system level change, increase understanding of community needs and resources, engage together on complex issues and develop solutions, minimize duplication, cross train and integrate programming. Together, our chances of making meaningful change on not only breast health, but other health disparities, improve.

It is helpful to have inventory of resources already available, which will influence the capacity and priorities of this work. We also know many other groups are already created and working to address different health disparities and SDOH among the same group or different disparities and SDOH among other groups. Leaning into existing work, partnering wherever possible to deepen impact, and learning from the lessons of others must be priorities. Potential partners, resources, and parallel work suggested by participants throughout the process to date are listed below. Those noted have some relationship or involvement with the project so far. Others are resources and partners that need connection.

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**Partnership Principles**

_We are committed to equity, collective decisions, and collective action. Knowledge originates and resides in all partners. All partners are encouraged to participate in all phases of the process._

_We are committed to addressing social inequities that affect health, including those that constrain the meaningful participation of individuals and communities in the decision-making process._

_We will maximize opportunities for learning within the local community and associated organizations. We encourage shared leadership, input, development and implementation._

(adapted from “Promoting Health Equity: A Resource to Help Communities Address Social Determinants of Health, Centers for Disease Control

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Thank you to Columbus Public Health, Central Community House, Cardinal Health’s African American Women’s Resource Group and community Worship in Pink coordinators for their contributions to the data in this report.
References


Daly and Olufunmilayo as summarized by Susan G. Komen. (2016). “A Perfect Storm” by Bobby Daly and Olopade Olufunmilayo as summarized by Susan G. Komen.


