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**BECAUSE
EVERY WOMAN IN
LAKE COUNTY
DESERVES AN
EQUAL CHANCE
AT SURVIVAL.**

**This work has been generously supported by a grant
from the Healthcare Foundation of Northern Lake County and
by the Florence and Laurence Spungen Family Foundation.**

Breast cancer is a disease today that when found early is highly treatable and most people survive. In fact, 99% of women with localized breast cancer are alive 5 years later. However, some women do not have as good a chance at survival. Over the last few years, a lot of research has been done in Chicago, Illinois. The spotlight was shone on Chicago in 2006 when disturbing research showed that the gap in survival between Black and White women was large and growing. This prompted the creation of the Metropolitan Chicago Breast Cancer Task Force (the Task Force).

However, far less attention has been placed on what is going on in Lake County – a county with great affluence but also changing demographics and a growing poorer population. We have learnt much from our work focused on Cook County. We believe the time is right to use what we have learnt and apply it in Lake County. We also want to conduct research to better understand what is unique about Lake County’s breast health system, to make progress in Lake County so that we can save more women’s lives.



WHY HAVE BLACK WOMEN IN CHICAGO BEEN DYING AT A HIGHER RATE COMPARED TO WHITE WOMEN?

Research shows that African American women go less often for mammograms compared to White women. And when they do go, they are more likely to have poorer quality mammography. The Task Force has a project known as the Chicago Breast Cancer Quality Consortium, which collects mammography quality data all across Illinois. It has found significant variation in mammography quality, with venues serving primarily poor, uninsured and publicly insured patients (safety net venues) more challenged to meet quality standards. Research from the University of Illinois looked at women who were diagnosed with breast cancer who had a mammogram 1 to 2 years before their diagnosis and often saw evidence of the breast cancer on the prior mammogram. The “potential miss rate” was much higher for poor women, publicly insured women and women with less education. This is not because their

breasts were different but because they got poorer quality mammography.

We also know that both nationally and in Chicago, African American and Latina women are diagnosed with breast cancer later and have more negative prognostic factors upon diagnosis. Task Force related research has also found significant fragmentation of care in particular for women accessing care on Chicago’s south side. This fragmentation involves women having to go to multiple sites to get all the breast cancer treatments they need (e.g. surgery, chemo, hormone treatment, radiation). Often they don’t get all the necessary treatments and this affects survival.

While there is still much to be understood about the disparities in breast cancer across Metropolitan Chicago, most of the studies have focused on Cook and DuPage counties. Lake County has unique challenges related to significant unmet health needs and

changing demographics along with greater affluence and thus a much reduced presence of safety net providers.

WHAT IS GOING ON IN LAKE COUNTY WITH RESPECT TO BREAST CANCER DISPARITIES?

The Lake County Breast Health Collaborative was made possible by the generous funding of the Healthcare Foundation of Northern Lake County (HFNLC) to the Metropolitan Chicago Breast Cancer Task Force (Task Force). Four Lake County organizations working in health and/or community services in partnership with the Task Force are taking the lead in improving access to quality breast health services for all women in Lake County, Illinois. The partner organizations are Family First Center, Lake County Health Department/Community Health Center, Waukegan Public Library and the YWCA.

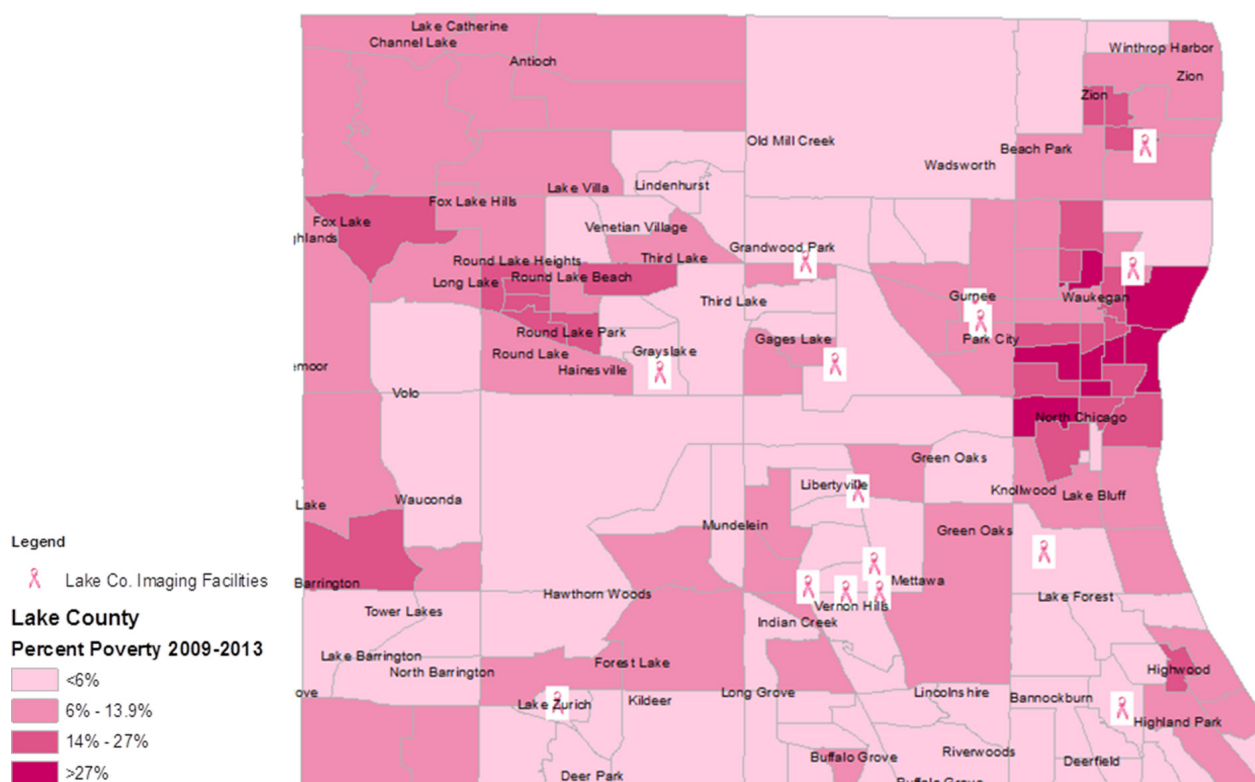
To better understand the breast healthcare system and breast healthcare resources in Lake County, the Task Force designed a multi-year community needs assessment. This report represents a summary of the findings from Phase I of this community needs assessment aimed at beginning to document and understand the distinctive barriers to care along the breast health continuum (from screening mammography, through diagnostic follow up, biopsy, treatment and survivorship) for the most vulnerable women in Lake County. Based on the findings, recommendations are provided, which highlight areas amenable to targeted tailored interventions that can address the factors contributing to disparate outcomes.

HIDDEN MORBIDITY AND MORTALITY IN LAKE COUNTY

Most of the underlying causes of Chicago's disparity also exist in Lake County, so there is good reason to believe that similar disparities exist in Lake County for African American women and Latinas. The following data suggests that indeed this is true. Racial disparities in utilization of breast cancer screenings are present, which would predict racial/ethnic disparities in breast cancer outcomes.

- **Poverty.** According to American Community Survey (ACS) five-year estimates, of the 683,517 individuals living in Lake County, 22% (150,373 individuals) are living under 200% of the Federal Poverty Level.
- **Lack of Health Insurance.** There were 10,273 uninsured women aged at least 45 years in Lake County prior to the implementation of the Affordable Care Act (ACA). Based on data available from Illinois Health Matters, Lake County's uninsured population is 34% Hispanic and 10% Black. If the racial distribution holds for women aged 45+, there are 4,520 uninsured Latina or Black women in Lake County.
- **Financial Barriers to Healthcare.** According to the Behavioral Risk Factor Surveillance Survey (BRFSS), 8.2% of all Lake County residents did not seek healthcare due to cost, and an alarming 33% of residents have not had an annual checkup within the past 12 months. BRFSS tends to underestimate these rates because it relies on self-reported data and people are often reluctant to say they have not gotten necessary healthcare. True levels of annual screening are likely to be significantly lower and researchers at the University of Illinois have demonstrated this fact with respect to breast cancer screenings. To get a mammogram, a woman often needs to get a doctor's order. But poorer women go to the doctor less often for well visits and doctors often only address preventive screens during well visits rather than during sick visits. So if poor women go less often to the doctor for a well visit, then they are less likely to get advised on preventive screens and less likely to get an order for such a screen (e.g., a mammogram). This leads to lower utilization of services that require orders (mammograms, colonoscopies).
- **Availability of screening mammograms for uninsured women in Lake County.** Based on our findings to date, uninsured women may be able to access screening mammography through three channels: the Lake County Health Department, the YWCA, and previously through HealthReach when it was a free clinic. The total number of free screenings provided in FY2014 was approximately 2,040, of which 420

ACHIEVING HEALTH EQUITY IN LAKE COUNTY HOW DO WE GET THERE?

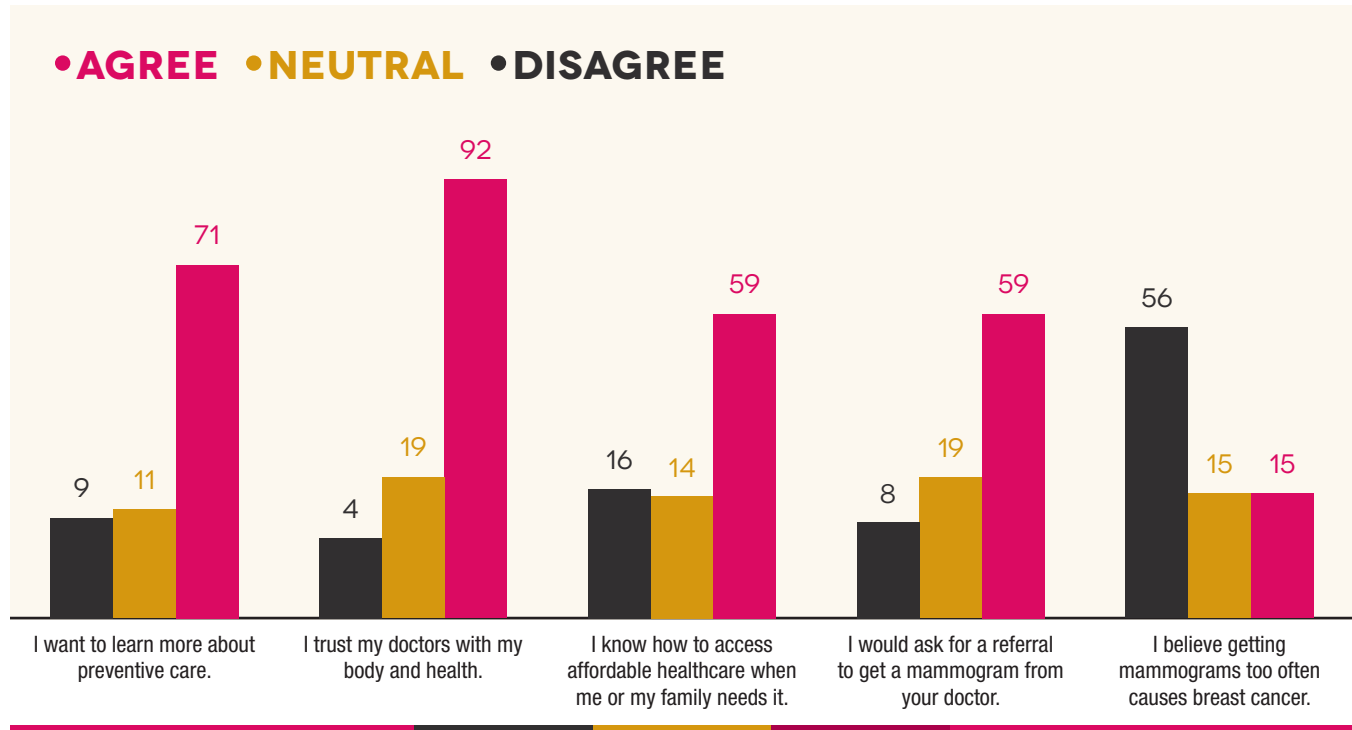


were provided through HealthReach. While there are 10,273 uninsured women over age 45 in Lake County, only 2,014 free mammograms were available, suggesting that over 8,000 more screening mammograms were needed in 2014 compared to those that were available. This may worsen with HealthReach's acquisition by Erie Family Health Center and their policy to require a physician's order for mammography and a sliding fee copay due for the visit.

Similar to Cook County, mammography resources in Lake County are not evenly distributed across the county. The imaging facilities tend to be close to the more affluent areas. This can be seen in the accompanying map that shows Lake County's distribution of poverty and where the mammography facilities are.

ardless of immigration status. Women whose mammograms indicate a need for diagnostic follow up receive case management from program staff to ensure that they access appropriate care. In Fiscal Year 2014, the program was so short of funding that it was unable to provide screening mammograms. Instead, it was only able to provide mammograms for women who needed diagnostic mammograms. In the prior year, the Lake County Health Department provided 1,319 mammography screenings, and 719 diagnostic mammograms for a total caseload of 1,341 individuals.

- Funding Crisis in the Illinois Breast and Cervical Cancer Program.** Lake County Health Department is the lead agency in Lake County for the Illinois Breast and Cervical Cancer Program (IBCCP). This program provides free screening and diagnostic mammograms to low-income, uninsured women in Lake County re-
- Increasing Late-stage diagnosis rates.** Alarminglly, the incidence of late stage diagnosis of breast cancer in Lake County is increasing at a rate of 1.9% per year, in contrast to the national trend in which late stage diagnosis rates are declining at a rate of 1.2% per year. Notably, Hispanic women have been found



to present at later stages in the Komen Chicagoland Affiliate Service Area (which includes Lake County) report, likely due to limited access to low to no-cost mammography screening services.

- **Estimated utilization of screening mammography.** According to BRFFS statewide self-reported data, 25.8% of White women, 24.5% of Black women, and 34.6% of Hispanic women over the age of 40 had not had a mammogram for the past two years. As mentioned earlier, when individuals self-report health behavior, they tend to over report in favor of what they perceive as the desired behavior. University of Illinois researchers reviewed actual medical records to verify screening utilization rates, and found significant over-reporting – in particular by minority women.

This data served as the foundation from which we developed a more focused disparities assessment that would provide insight into county specific barriers contributing to the suggested racial/ethnic disparities in mammography utilization and/or breast cancer outcomes.

METHODOLOGY

Between April and June 2015, the Task Force and its

partners implemented a community needs assessment aimed at obtaining valuable insight regarding the obstacles that hinder underserved women from accessing mammography and other preventative health screenings. Data collections tools, a survey, and focus group discussion scripts, were created specifically to capture the beliefs, attitudes and knowledge of both women and men residing in Lake County, Illinois.

Quantitative Data Collection

A survey tool was created to collect demographic information of individuals who self-identified as being residents of Lake County as well as users of medical services within the county. In addition, the survey was utilized to identify knowledge, behavior, and attitudes toward general and breast health from Lake County residents. The survey and informed consent was professionally translated into Spanish for Spanish-speaking participants. A total of 133 surveys and signed informed consents were collected in which 31 were from participants at focus groups and 102 were clients served by the organizations collaborating. The responses were entered and analyzed to identify significant and quantifiable beliefs and behaviors.

Qualitative Data Collection

Five focus group discussions were conducted by project staff in various locations in Lake County. A total of 59 community residents including, African American and Latina women, Latino men and health department staff participated in focus group discussions. Focus group participants provided informed consent following Rush University Medical Center Institutional Review Board protocol. Audio recordings were transcribed and translated into English. Transcripts were analyzed for themes to identify existing health system or interpersonal barriers that contribute to poor health outcomes for underserved populations in Lake County.

LESSONS LEARNED

Women of Color and Poor Women Struggle to Access Service. This needs assessment revealed that historically disadvantaged groups (racial minorities, low-income individuals) in Lake County encounter challenges similar to groups across the country when attempting to engage the healthcare system for preventative healthcare. The literature shows that these populations often experience difficulties accessing health care due to a variety of barriers, such as: lack of transportation, health insurance and childcare, housing insecurity and competing attention to co-morbidities.¹ While similar in nature, this assessment was conducted to understand specific challenges for women in Lake County. A mixed method approach was employed. A survey was distributed to collect basic sociodemographic information along with the participant's recent preventative health behaviors and

views on adherence to mammography. Focus group discussions were conducted with small groups of women or men of various racial and ethnic identities to create a more intimate setting to document cultural views, beliefs, and participant experiences of accessing services in the Lake County healthcare system. The focus group participants who were majority Latina or African American echoed the barriers presented in the literature as persistent barriers faced in Lake County. Four major barriers to accessing and utilizing preventive health care particularly breast health services were identified including lack of affordability/health insurance; fear; lack of resources/information/facilities; and cultural/language/misinformation.

Lake County is Changing. Lake County is comprised of a growing Latino/Hispanic population and a historically underserved African American population. While the participants of the former group cited particular health systems issues related to provider-patient cultural and language barriers and lack of insurance due to immigration status, both groups highlighted similar obstacles when seeking to access high quality healthcare in Lake County: transportation challenges, appointment availability, mistrust of western medicine, and low literacy in health and insurance. The quality of healthcare delivery to low-income, uninsured groups was a popular topic of discussion among all focus group participants. Concerns regarding the current health system include long appointment wait times, disorganization and hesitancy to provide care to undocumented or uninsured patients.

“I THINK A LOT IS FEAR, PAST HISTORY. PEOPLE PASSED AWAY AND WHEN THEY GET CANCER THEY THINK IT’S A DEATH SENTENCE. I THINK WHEN WE EDUCATE THEM AND PEOPLE ARE ACTUALLY HEALING AND THEY SEE PEOPLE STRIVING AND BEING HEALTHY, IT CHANGES THE STIGMA. THAT’S WHY SHARING OUR STORY IS A MUST. THAT’S WHY WE MUST CONTINUE AND I’M VERY VOCAL ABOUT BEATING BREAST CANCER 20 YEARS AGO BECAUSE IT’S A GIFT.”

—African American woman, breast cancer survivor

The Lake County Breast Health Collaborative has partnered to create a multi-faceted platform to address the above mentioned barriers. This needs assessment is the first of many steps, which have helped to inform interventions necessary to meet the needs of women in Lake County. Cultural competency classes, provider education on mammography referral processes and education on reimbursement incentives for Medicaid patients are just some health systems interventions the collaborative plans to develop guided by the Task Force's previous work in this area. Barriers related to access, such as transportation and housing insecurity, can start to be addressed through cultivating working relationships with other community service organizations in Lake County. The Next Steps section of this report will further outline how the collaborative will address the health access challenges of this population through tailored interventions.

WHERE DO WE GO FROM HERE?

Issues this initiative seeks to address using tailored interventions:

Direct provision of services to those that have barriers to access. This collaborative has focused on undocumented, Spanish-speaking and African American communities in Lake County. Specific educational tools, outreach at community events, and increased partnerships to build availability of free to low-cost breast health services for uninsured and underinsured women will be pursued during the second year of the Lake County Breast Health Collaborative.

Linking individuals without a regular source of care to a medical home. By informing local medical providers of the collaborative's efforts to improve access to breast cancer screening and regular medical care, this initiative seeks to expand its ranks with providers dedicated to serving medically disenfranchised Lake County residents. Along with providing free screening services for uninsured women, this partnership seeks to simultaneously connect women and their families to a local medical home to ensure continuity of care.

Increasing the number of providers available to provide care. The Task Force will provide direct service support by navigating 300 newly insured Medicaid clients. Additionally, the Task Force will continue the solicitation of donations to secure mammography services for uninsured and underinsured Lake County residents.

Addressing system issues or deficiencies that impede access to healthcare. The Task Force seeks to raise the awareness of primary care providers and other partners who potentially have influence on the behavior of populations with strong cultural beliefs. The Task Force will expand the analysis of systems barriers by also conducting an environmental scan of the primary care and mammography healthcare network in the county. Supplied with specific information, referral process delays and health systems barriers can be ameliorated and access to vital health services can be improved.

¹ Roman et al. Individual, Provider, and System Risk Factors for Breast and Cervical Cancer Screening Among Underserved Black, Latina, and Arab Women Journal of Women's Health Volume 23, Number 1, 2014.

IN CONCLUSION

While Lake County is Illinois' most affluent county, its demographics are changing. The poor in Lake County have far fewer options for accessing healthcare and have greater barriers, including transportation barriers, compared to those living in Cook County. Given the resources in Lake County, we believe that there is great opportunity to improve the breast health system in Lake County. By working with those who care about Lake County and its residents, we can significantly improve access to breast healthcare services and in so doing, we can save lives. We hope that you will join us.

ACHIEVING HEALTH EQUITY IN LAKE COUNTY HOW DO WE GET THERE?

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METROPOLITAN CHICAGO

Breast Cancer Task Force

Uniting to End Disparity

CHICAGOBREASTCANCER.ORG

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