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Applying a Socio-Ecological Framework to the Uptake of an Online Breast Cancer Genetic Referral Screening Tool in Georgia

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2014

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Rollins School of Public Health of Emory University
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Abstract

Applying a Socio-Ecological Framework to the Uptake of an Online Breast Cancer Genetic Referral Screening Tool in Georgia

By Emily Wiggins

BACKGROUND. In 2013, the United States Preventive Services Task Force (USPSTF) published recommendations regarding genetic risk assessment and testing for breast/ovarian cancer susceptibility. Since these guidelines were published, a recognized need has been acknowledged for the development of screening tools to improve identification of those at increased risk for hereditary breast and ovarian cancer. This study aims to answer the following research questions: 1) What is the distribution of the use of an online referral screening tool among Georgia public health districts?? and 2) Are macro-level factors, such as demographic characteristics, income, race and access to healthcare resources associated with screening uptake among eligible women seen in Georgia public health districts?

METHODS. Participants in this study were individuals who used the online referral screening tool embedded in the website (https://www.breastcancergenescreen.org/) between October 2014 and October 2017. This study incorporated several data sets. The online referral screening tool website was used to identify the number of women who passed through screened Georgia public health districts. Census Data and BRFSS Data were also the sources for macro-level variables.

RESULTS. The proportion of women screened in districts was ascertained by collecting available population data from the OASIS tool, a tool by the Georgia Department of Public Health that derives data from the Census. Screening districts were categorized into High, Moderate to Low. Race percentages and mean age were calculated from available data. Two case studies were developed from these data to characterized as high and low screening district and breast cancer incidence, community characteristics, and organizational priorities for screening.

CONCLUSION. The online genetic referral screening tool is helpful for detecting the risk of hereditary breast cancer in the state of Georgia. This tool is widely used throughout districts of public health in the state, and when used correctly, can improve women's knowledge about their possible risk for hereditary breast cancer. Although there is consistent training and education with staff, there remains a wide disparity in consistent use. These disparities can be interpreted by considering socio-ecological factors, such as income, race/ethnicity in each district, proportion of providers to patients, and overall incidence/prevalence of breast cancer in that region.

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CHAPTER I: INTRODUCTION

In 2013, the United States Preventive Services Task Force (USPSTF) published guidelines regarding genetic risk assessment and testing for breast/ovarian cancer susceptibility. Since these guidelines were published, a recognized need has been acknowledged for the development of screening tools to improve identification of those at increased risk for hereditary breast and ovarian cancer. The recommendations specifically stated that "women whose family history is associated with an increased risk for deleterious mutations in BRCA1 or BRCA2 genes be referred for genetic counseling and evaluation for BRCA testing (USPSTF, 2013)."

In 2011, the Center for Disease Control and Prevention (CDC) and the Division of Cancer Prevention and Control released a three-year funding opportunity announcement for a cooperative agreement to enhance the capacities of state health departments to promote the application of breast cancer genomics (Trivers et al, 2015). Georgia was one state that received this funding opportunity. In response to the funding agreement, it established the Georgia Breast Cancer Genomic Health Consortium, a public-private partnership aimed at reducing disparities among minority women. In addition, educational tools were developed for both patients and providers (Trivers et al, 2015). To increase screening for BRCA1 and BRCA2 mutations, a Breast Cancer Genetics Referral Screening Tool was deployed in some women's health clinics to identify women who would be appropriate for genetic counseling (Bellcross, 2009). The online tool uses family history and six questions to identify individuals at risk, and then refers them to an advanced practice nurse who can provide genetic counseling.

Georgia’s funding from the CDC ended in 2014, at which time no additional funding was received. Since that time, the Georgia Department of Public Health (GDPH) has funded the project.

Purpose of Study

As of 2018, the gene screen tool is used in 14 of 18 Districts of Public Health within the Georgia Department of Public Health. These districts are composed of multiple public health departments within Georgian counties. Each county is typically served by one public health department. Within these departments , staff have been trained in the use of the online referral tool and have been given a username and password to access the site. However, not all centers consistently utilize this tool. This project aims to use the Socio-Ecological Model (SEM) to understand the individual, organizational, community and policy-level facilitators and barriers to screening uptake within the state of Georgia.

This study aims to answer the following research questions: 1) What is the distribution of the use of an online referral screening tool among Georgia public health districts? and 2) Are macro-level factors, such as demographic characteristics, income, race and access to healthcare resources associated with screening uptake among eligible women seen in Georgia public health districts? These questions are important to consider to understand where genetic screening can be improved in Georgia. It is also important to consider which areas of the state are screening more women and if these factors are indicative of overall socio-contextual determinants.

To answer these questions, a mixed-methods approach was undertaken. Data from the online referral screening tool dating back to 2014 was used. This year was selected as grant funding from the CDC ended this year, and the Georgia Department of Public Health began independently funding the genetic screening program. In addition to data from the online referral screening tool, the most recently available Census data and BRFSS data was used to collect macro-level variables.

CHAPTER II: LITERATURE REVIEW

National Breast Cancer Causes and Statistics

Breast cancer is the most common cancer diagnosed in women worldwide, and the second leading cause of cancer death in women (American Cancer Society, 2017). According to the American Cancer Society (ACS), in 2017, about 252,710 new cases of invasive breast cancer will be diagnosed in women nationally. Out of these diagnosed cases, about 40,610 women will die from breast cancer (American Cancer Society, 2017). Mortality from breast cancer has declined steadily since 1990 largely due to improvements in treatment and early detection.

Cancer is typically caused by the mutation of genes; tumors may be either malignant or benign. Malignant tumors are caused by cells that are abnormal and divide without control while invading nearby tissues, while benign tumors are not cancerous and do not spread to other parts of the body (NCI, 2018). Breast cancer begins in breast cells and originates from the milk ducts or the lobules responsible for milk supply (Majeed et al., 2014). Risk factors involved in breast cancer include obesity, use of hormone therapies, breast tissue density, physical inactivity and alcohol use (Majeed et al, 2014). The overall rate of breast cancer is higher in American and European women than in Asian women (Karami et al, 2013), while Black women have a higher incidence of early-age onset breast cancer and triple-negative breast cancer (Jones et al, 2017). Most breast cancer occurs sporadically, i.e. with no known familial link to that cancer, with a frequency ranging from 90% to 95%, with the other 5-10% linked to familial breast cancer (Karami et al, 2013).

Breast Cancer Statistics in State of Georgia

Cancer is the second-leading cause of death in Georgia, with 45,000 cases of cancer diagnosed yearly and 15,500 dying from the disease each year (Georgia Cancer Data Report, 2016). In 2013, cancer accounted for 22% of all deaths in Georgia, placing it as the second-leading cause of death (Georgia Cancer Data Report, 2016). In 2015, there were 7,230 new breast cancer cases in the state and 1,300 women died from breast cancer. Breast cancer is the leading cause of cancer incidence in Georgia and accounts for 30% of all cancer incidence yearly.

Breast Cancer and Genetic Risk

BRCA1 and *BRCA2* gene mutations are the most common genes implicated in breast cancer. *BRCA1* and *BRCA2* mutations exist in diverse populations and enhance the risk of breast cancer to 59%-87% and 38%-80% respectively (Karami et al, 2013). Inherited *BRCA1* and *BRCA2* mutations are referred to as germline mutations, which are present at birth and not influenced by environmental factors. *BRCA1* and BRCA2 are associated with higher grades of breast tumors, and loss of function in *BRCA1* and *BRCA2* genes also is responsible for male breast cancer, as well as ovarian and prostate cancers (Karami et al, 2013). Over 2,000 various mutations have been recorded in *BRCA1* and *BRCA2* genes (Karami et al, 2013).

Genetic testing plays a key role in identifying *BRCA1* and *BRCA2* mutations. In the United States (U.S.), oncology nurses and advanced practice nurses are asked to educate patients about genetic tests or may assess a patient’s family history in order to determine if genetic testing is needed (Lynch et al, 2015). Individuals will be referred to genetic testing if one or more of the following conditions are met: 1) rare cancers present at any age in the family, 2) breast, colorectal, or endometrial cancer diagnosed before age 50, 3) two primary breast cancers or clustering of breast and ovarian cancer, 4) bilateral breast cancer, 5) multiple cancers at a young age, 6) family history of male breast cancer, or 7) two or more kinds of *BRCA1* or *BRCA2* related cancers in one family member (Lynch et al, 2015).

When an individual is referred to genetic counseling, a comprehensive family history is obtained. Clients are questioned about their personal and family histories, which involves targeted questions about the health of each family member for three generations (Lynch et al, 2015). Clients' knowledge and perceptions of genetic and genomic information is also assessed (Jenkins, 2011). Next, appropriate genetic test will be selected. Informed consent will also be obtained and genetic counselors will help the patient cope with the emotional and medical implications of learning the results of their genetic tests (Lynch et al, 2015).

Genetic testing is a form of risk assessment. A genetic test may yield negative results, positive results, or a variant of uncertain significance, which means that a genetic change was identified, but its link to cancer risk is unknown (Lynch et al, 2015). In order to make an informed decision about risk management for breast cancer, women who identify positive for *BRCA1* or *BRCA2* mutations must understand their cancer risks as well as risk-reduction impact. Further, when genetic risk is properly communicated, this may prevent the feeling of fatalism caused by unchangeable genetic predispositions and increase motivation to change unhealthy lifestyles (Lynch et al, 2015). Other preventive strategies may be considered as well. The most common strategy for an individual with a *BRCA1* or *BRCA2* mutation is increased surveillance.

Increased surveillance includes MRI, semiannual clinical breast exams, and annual mammograms (Lynch et al, 2015). Surgical interventions, including prophylactic breast or ovarian surgery, can reduce breast cancer incidence more effectively than surveillance or chemoprevention (Lynch et al, 2015).

Health Disparities in Breast Cancer

There are several social determinants involved in the health disparities of breast cancer, including race, ethnicity, region of the United States, insurance coverage, socioeconomic status, and patient-health system interaction (Wheeler et al, 2013). This next section will describe these factors.

Race

Pertaining to race, breast cancer is diagnosed more often in white women and mortality is higher among black women (Wheeler et al, 2013). Younger Black women exhibit higher incidence of breast cancer than younger white women (Wheeler et al, 2013). This trend exists until menopause, when older white women have higher breast cancer incidence (Wheeler et al, 2013). SEER data from 1975 to 2011 has shown that white women had a 23% increase in breast cancer incidence and a 34% decrease in mortality (Daly et al, 2015). However, African American women experienced a 35% increase in incidence and a 2% increase in mortality in this time period (Daly et al, 2015). According to a study conducted by Jones et al. (2017), African American women affected with breast cancer are less likely to undergo *BRCA1/2* genetic testing compared to white women with the disease. As African American women display a higher incidence of early-age onset breast cancer before age 50 (33% vs. 21.9%) and are twice as likely to be diagnosed with triple-negative breast cancer (Jones et al, 2017), it is crucial that disparities in screening are acknowledged and reduced.

In Georgia, age-adjusted incidence rates of breast cancer are nearly the same for Black women as White women. There are 127.2 cases of breast cancer per 100,000 women in Black women, 126.0 cases per 100,000 women in White women, and 88.4 cases per 100,000 women in Hispanic women (Georgia Cancer Data Report, 2016). However, age-adjusted breast cancer mortality rates in Georgia differ by race, with 28.9 per 100,000 Black women dying of breast cancer and 19.6 per 100,000 White women dying of breast cancer (Georgia Cancer Data Report, 2016). This difference was found to be statistically significant (Georgia Cancer Data Report, 2016).

Geographic Region

In addition to disparities among race, disparities also exist within regions in the U.S. From 2007-2011. Breast cancer death rates decreased in white women in all 50 states. Among African American women, breast cancer death rates increased in two states, remained the same in 24 states, and decreased in 11 states. The states in which African American breast cancer death rates were level or rising were in the Midwest and the South (Daly et al, 2015).

In Georgia, geographic location also matters. According to the Georgia Cancer Data Report, age-adjusted breast cancer incidence rates were significantly higher than the state rate of 123.8 cases per 100,000 women in the Atlanta metro area, lower than the state rate in the Northwest and Southeast corners of the state, and not significantly different throughout all other regions (Georgia Cancer Data Report, 2016). The age-adjusted breast cancer mortality rate for the state of Georgia was 22.3 per 100,000 females, with mortality rates being higher in the Fulton County area of Georgia, mortality rates being lower in the Northeast and Southwest corner of the state, and no significant difference in mortality rate throughout the rest of the state (Georgia Cancer Data Report, 2016). Moss et al (2017) found that breast cancer incidence rates were 9% higher in urban areas when compared with rural areas. The higher incidence rates of breast cancer in the Atlanta metro area than elsewhere in the state is consistent with this finding.

Socioeconomic Status (SES)

According to Akinyemiju et al (2015), higher socioeconomic status measured at the individual or residential level is associated with higher breast cancer incidence (2015). Women of higher SES are more likely to obtain mammography screening and have better access to preventive healthcare, which increases the detection of breast cancer (Akinyemiju et al, 2015).

From the aspect of lower socioeconomic status, lack of transportation, poor access to care, low educational attainment and poor health literacy impact the disparities in breast cancer screening (Wheeler et al, 2013). Women of lower SES may also be at higher risk for triple-negative breast cancer because they have higher parity but lower breast-feeding rates (Akinyemiju et al, 2015).

Health System Access

Various barriers to access may exist for individuals seeking cancer screening and care. For example, women without health insurance are far less likely to report having had a mammogram within the past two years (Georgia Comprehensive Cancer Control Plan, 2014). In addition, some ethnic groups may prefer access to health care facilities that address language barriers, and several healthcare systems do not offer such services (Wheeler et al, 2013). Further, innovative approaches to cancer screening may be distributed unequally, benefiting certain women over others, especially those of higher socioeconomic status (Wheeler et al, 2013). Patient sociodemographics may also be associated with the quality of providers available to the population. According to Wheeler et al, African American cancer patients may have worse access to well-trained providers and are more likely to be treated by physicians who lack measurable skills and board certification.

Other barriers to genetic testing include lack of understanding and skills by physicians (Suther et al, 2009). Primary care physicians may lack information about genetic services available to patients, which lessens the chance that a high-risk patient will be referred to a genetic counselor in a timely manner (Suther et al, 2009). Belcross et al (2011) administered surveys to primary care physicians to assess their awareness on *BRCA* testing. This study found that 87% of physicians sampled were aware of *BRCA* testing, and 25% reported having ordered testing for a patient in the past year (Belcross et al, 2011). It also found that ordering tests was most prevalent among obstetricians/gynecologists in practice for more than 10 years who had more affluent patients (Belcross et al, 2011). Overall, the study showed that providers needed to improve knowledge about existing recommendations for *BRCA* screening.

Overall, the uptake of *BRCA*1/2 testing is higher in persons of higher socioeconomic status who have health insurance, who show knowledge of genetic testing, and who have more relatives affected by breast cancer (Schlich-Bakker, 2007). Cancer-specific distress plays a significant role in the choice to seek testing for

*BRCA*1/2 mutations, as well as perceiving the risk of being a mutation carrier to be high or perceiving that the advantages of testing outweigh the disadvantages (Schlich-Bakker, 2007).

Initial Implementation of Breast Cancer Genetic Screening in Georgia

In 2011, the CDC provided funding to three state health departments for a 3-year cooperative agreement to develop activities related to the promotion of breast cancer genomics (Traxler et al, 2014). Georgia, Michigan, and Oregon received the award for 2011 to 2014 (Traxler et al, 2014). In response to this award, the Georgia Breast Cancer Genomic Health Consortium was formed in order to reduce disparities in breast cancer screening in high-risk, minority women (Traxler et al, 2014). The online referral screening tool, which was developed prior to the project and primarily used in mammography centers and in an academic setting, was utilized and evaluated as a screening tool to use in selected Georgia public health centers that primarily served disadvantaged and minority women (Traxler et al, 2014). At the initiation of use of online referral screening tool, nurse personnel were selected at various health centers and underwent a training session that included basic information on hereditary breast and ovarian cancer as well as guided practice with the online genetic screening tool (Traxler et al, 2014). Educational sessions were provided to six Georgia public health centers, which included DeKalb, Bibb, Chatham, Gwinnett, and Cobb/Douglas counties (Traxler et al, 2014). These health centers were selected due a disproportionate cancer burden among minority women (Traxler et al, 2014). These educational sessions were used to increase the staff’s knowledge of hereditary breast and ovarian cancer and to facilitate the implementation of screening with the Breast Cancer Gene Screen tool to identify women at high risk for hereditary breast and ovarian cancer (Traxler et al, 2014). Program staff administered pretest and posttest evaluations to each staff participant to assess knowledge on HBOC screening (Traxler et al, 2014).

Implementation of Screening Project

During the 3-year implementation of this project, 2,159 women were screened, with 73.2% being African American and 8% being Hispanic/Latino (Traxler et al, 2014). 88.3% were between the ages of 18 and 49 years of age (Traxler et al, 2014). 130 (6%) of the women screened positive for a possible *BRCA1* or *BRCA2* mutation, and 110 of these women agreed to a follow-up call to discuss family history and possible genetic testing with the advanced practice nurse in genetics (Traxler et al, 2014). Overall, this assessment of the online referral screening tool successfully identified underserved and minority women who were at an increased risk for hereditary breast and ovarian cancer who would not otherwise have access to screening (Traxler et al, 2014), as 60.9% of women who were screened were contacted for follow-up testing (Traxler et al, 2014).

Theoretical Framework

The Socio-Ecological Model (SEM)

The Socio-Ecological Model was applied to address the research questions for this study. The Socio-Ecological Model is used to assess individual, organizational, community, and policy level factors that impact health (CDC, 2015). This framework is ideal for this study because breast cancer is not simply rooted in individual factors, but a host of higher-levels of influence depending on the environment in which an individual finds himself or herself. The individual level factors attributed to the Socio-Ecological Model include internal cues to action for engaging in a particular behavior. For the purpose of this study, individual-level factors to engage in breast cancer genetic screening were operationalized by analyzing demographic data including age and race from the screening tool. Interpersonal level factors were not accounted for in this study, as no qualitative data was collected.

Organizational level factors to promote organizational messages and support in the Socio-Ecological Model include healthcare systems, employers or worksites, health care plans, local health departments, and professional organizations. This can include promoting the use of client and provider reminder systems, encouraging coverage and expansion of benefits for screening, and adopting worksite policies that support preventive care (CDC, 2015). For the purpose of this study, organizational-level factors were operationalized by assessing how many health care centers utilize the online referral screening tool.

Community-level factors for behavior change in the Socio-Ecological Model include comprehensive cancer control coalitions, media, and community advocacy groups. For the purpose of this study, community-level factors were assessed through demographic characteristics of the community, geographic region of Georgia, overall breast cancer screening resources and prevalence/incidence in the community, and income-level.

Policy-level factors for behavior change in the Socio-Ecological Model include federal, state, and local agencies that support policies that promote breast cancer screening. For the purpose of this study, policy-level factors were operationalized by accounting for breast cancer policies and programs in the state of Georgia.

CHAPTER III: METHODS

Participants

Participants in this study were women whose clinicians used the online referral screening tool (https://www.breastcancergenescreen.org/) in public health centers between the years of October 2014 and October 2017. These three years were selected because the grant given to the Georgia Department of Public Health ended in 2014. Thus, examination of these years will allow trends to emerge about how selected public health districts used the tool after the end of the grant. Women were included in the study if they were screened using the online referral screening tool from October 2014 to October 2017. Thirteen public health districts screened 7,304 women of African American, Caucasian, Hispanic/Latino or “other” descent during this time period. Participants were approached during Women’s Wellness or Family Planning appointments in public health centers, asked questions from the tool, categorized by risk, and contacted by the program Advanced Practice Nurse (APN) if results from the online referral screening tool reflected high risk. Figure 1 below further explains this process.

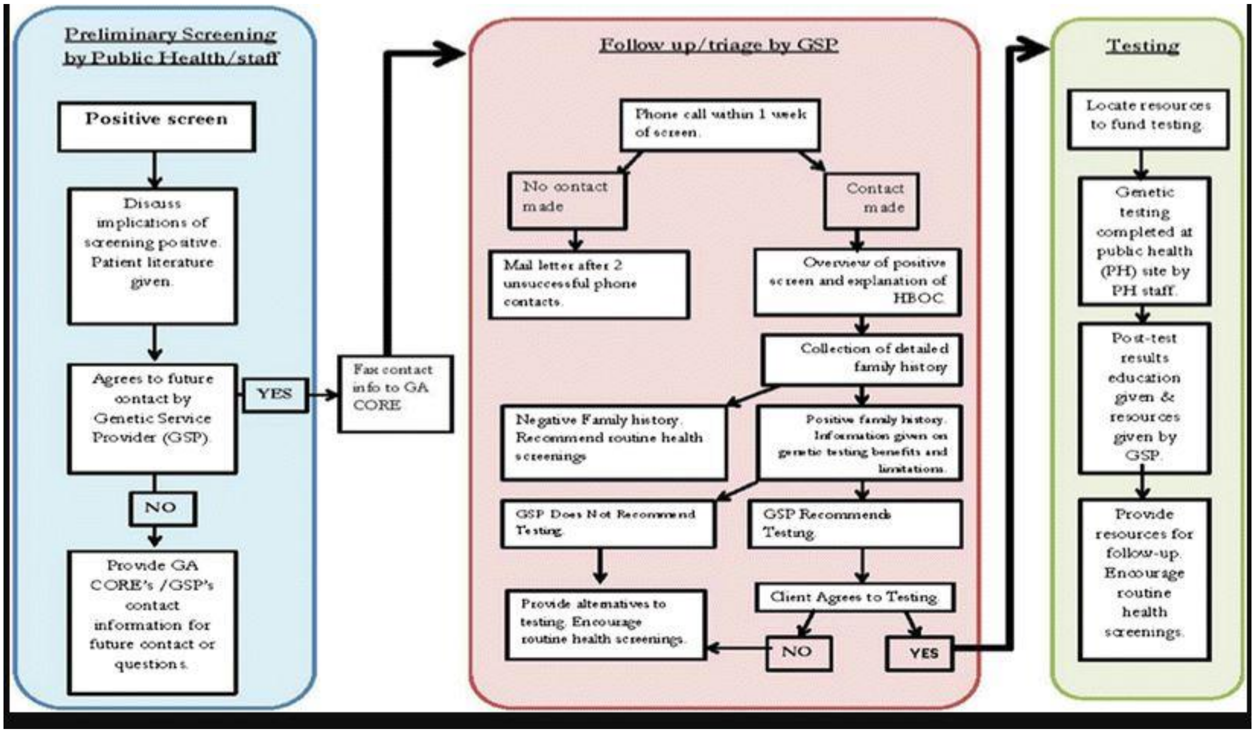

Figure 1. Patient flow through screening, follow-up, and testing. Georgia Department of Public Health. Used with permission.

The study was reviewed and received approval by the Emory University Institutional Review Board.

Measures

This study incorporated several data sets. The Breast Cancer Screen website was used to identify the number of women who were screened using the online referral screening tool in the Georgia public health districts. The breast cancer gene screen tool asks 6 questions: history of breast cancer in family (yes/no) women in family who have been diagnosed with breast cancer (yes/no), women in family who have been diagnosed with ovarian cancer (yes/no), women in family who have been diagnosed with both breast and ovarian cancer (yes/no), men in family who have been diagnosed with breast cancer (yes/no), and Jewish ancestry in family (yes/no). Age and race also are recorded in the tool. Once the user has completed all six questions, her risk screening for a *BRCA* mutation is arranged into three categories: 1) negative low-risk, 2) negative moderate risk, or 3) positive.

In addition to the online referral screening tool, open-source Census data and BRFSS data were used to understand the greater landscape of breast cancer screening uptake in Georgia. These data sets were also utilized to understand the macro-level factors that may impact access to care for breast cancer screening. Variables included in these datasets that were analyzed include number of breast cancer diagnoses in the public health district, demographic characteristics of the state, geographic location (urban vs. rural), and percentage of poverty.

Due to the de-identification in these datasets, no participants were recruited or consented for this study. Once data from these data sets were analyzed, a case study was compiled for two public health districts to give an overview of the uptake of the online referral screening tool in this area.

Procedure

This study was a mixed-methods design. Data were abstracted from the Breast Cancer Gene Screen tool website from 2014-2017 and divided by public health district and uptake proportions. Data from the online referral screening tool were included if age and race variables were complete. Data were excluded if age and race variables were missing. Public health districts were anonymized and arranged into tertiles by percentage: 1) high uptake, 2) moderate uptake, and 3) low uptake. User demographics were assessed from the online referral screening tool. The Georgia public health districts used for this study can be found in Table 1.

Table 1: District Characteristics

District Pseudonym	**District Location**	**Number of Counties in District**
District A	South GA	10
District B	Southwest GA	14
District C	North GA	13
District D	Northeast GA	10
District E	ATL Metro	1
District F	Central GA	16
District G	West GA	12
District H	East GA	13
District I	Northwest GA	10
District J	ATL Metro	2
District K	ATL Metro	3
District L	Central GA	13
District M	South GA	8

Five of the 18 Public Health Districts were excluded from this study because they did not have data for this time period.

Data from the Census were taken from the most recent year available, as were data from the BRFSS. All demographic variables, including population, age, race and cancer rates were compared to those demographics analyzed in the screening tool. The BRFSS and Census data sets were used specifically to better understand the macro-level factors that may influence breast cancer screening in the state to capture the overall picture of individual, organizational, community and policy-level factors that exist. Once the data were compiled and analyzed, case studies were developed from high and low screening districts in order to understand where specific public health districts succeed and where changes should be made. These case studies will utilize the Socio-Ecological Model constructs of to explain these screening successes and possible improvement areas.

Analysis

The data analysis involved in this study was considered secondary data analysis. All datasets were de-identified and were analyzed using IBM SPSS. Descriptive statistics were analyzed for each data set. The online referral screening tool data were split into three screening rates: 1) high, 2) low, and 3) moderate screening. High screening was defined as any screening rate between 0.17% and 1.25% of the female population for that public health district, as ascertained from 2016 Census data collected from the Online Analytical Statistical Information System (OASIS). Numbers were calculated by locating the number of women between the ages of 18-74 in each public health district. Then, the number of women screened in that public health district was divided by that number of women in each age category in order to obtain a percentage. Moderate screening was defined as any screening rate between 0.11% and 0.15% of the female population for that public health district. Low screening was defined as between 0.0009% and 0.05% of the female population for that public health district.

Women screened through the online referral screening tool were characterized as negative-low risk, negative-moderate risk or positive. Women who are characterized as positive risk have a 5-10% or greater chance of carrying a mutation in *BRCA1* or *BRCA2* (BRST Genetic Referral Screening Tool, 2018). These women are referred for cancer genetic counseling. Women are considered moderate risk if they do not have a family history suggestive of hereditary cancer but may have a risk for breast and/or ovarian cancer that is somewhat increased above that of the general population (BRST Genetic Referral Screening Tool, 2018). Further risk assessment and/or enhanced screening or prevention strategies may be appropriate for some of these individuals (BRST Genetic Referral Screening Tool, 2018). Women characterized as low risk, i.e., those who 1) have indicated there is not a history of breast cancer in their family or 2) breast cancer in their family was diagnosed after a family member was over age 50 are unlikely to have a genetic mutation in a BRCA gene, are unlikely to be at increased risk for Hereditary Breast/Ovarian Cancer, and are not expected to be at greater risk than the average population (BRST Genetic Referral Screening Tool, 2018).

CHAPTER IV: RESULTS

Results

Proportion of Women Screened in Districts

The proportion of women screened in districts was ascertained by collecting available population data from the OASIS tool, a tool by the Georgia Department of Public Health that derives data from the Census. The OASIS tool displayed data for public health district population broken down by county and age range (18-19, 20-29, 30-44, 45-59, 60-74). Numbers were totaled across age ranges. Then, the number screened was divided by this number to produce a proportion to determine high, moderate, and low screening districts. High-screening districts include District A, District B, District C, District D, and District E. Moderate screening districts included District F, District G, District H, and District I. Low screening districts included District J, District K, District L, and District M. These tertiles are represented in Table 2.

Table 2: Proportion of Women Screened in Districts

District	**Valid Number Screened**	**Female Population between ages 18-74**	**Percentage of Female Population Screened**
High Screening Districts:			
District A	1,155	91,788	1.25%
District B	1, 412	124,258	1.14%
District C	2,355	242,242	0.97%
District D	470	181,987	0.25%
District E	480	284,598	0.17%
Moderate Screening Districts:			
District F	199	130,614	0.1524%
District G	466	306,964	0.1520%
District H	216	174,678	0.12%
District I	272	235,831	0.11%
Low Screening Districts:			
District J	170	330,999	0.05%
District K	95	395,910	0.02%
District L	12	191,073	0.006%
District M	2	223,872	0.0009%
Total:	7,304	2,914,814	0.25%

Race in Public Health Districts

Race was measured and compared across public health districts. Proportions of African American, White, and Other race categories were analyzed across public health districts from data in the online screening referral tool. Table 2

Table 2: Race in Screened Public Health Districts

District	African American	White	Other
High Screening Districts:			
District A	495 (42.9%)	423 (36.6%)	237 (20.5%)
District B	917 (64.9%)	355 (25.1%)	140 (10%)
District C	257 (10.5%)	1471 (62.5%)	637 (27%)
District D	126 (26.8%)	253 (53.8)	91 (19.3%)
District E	451 (94%)	15 (3.1%)	14 (2.9%)
Moderate Screening Districts:			
District F	133 (66.8%)	42 (21.1%)	24 (12.1%)
District G	180 (38.6%)	145 (31.1%)	141 (30.3%)
District H	133 (66.8%)	122 (56.5%)	33 (15.3%)
District I	49 (18%)	149 (54.8%)	74 (27.2%)
Low Screening Districts:			
District J	50 (29.4%)	32 (18.8%)	88 (51.8%)
District K	36 (37.9%)	7 (7.4%)	52 (54.7%)
District L	8 (66.7%)	4 (33.3%)	N/A
District M	2 (100%)	N/A	N/A
Total	2,837	3,018	1,531

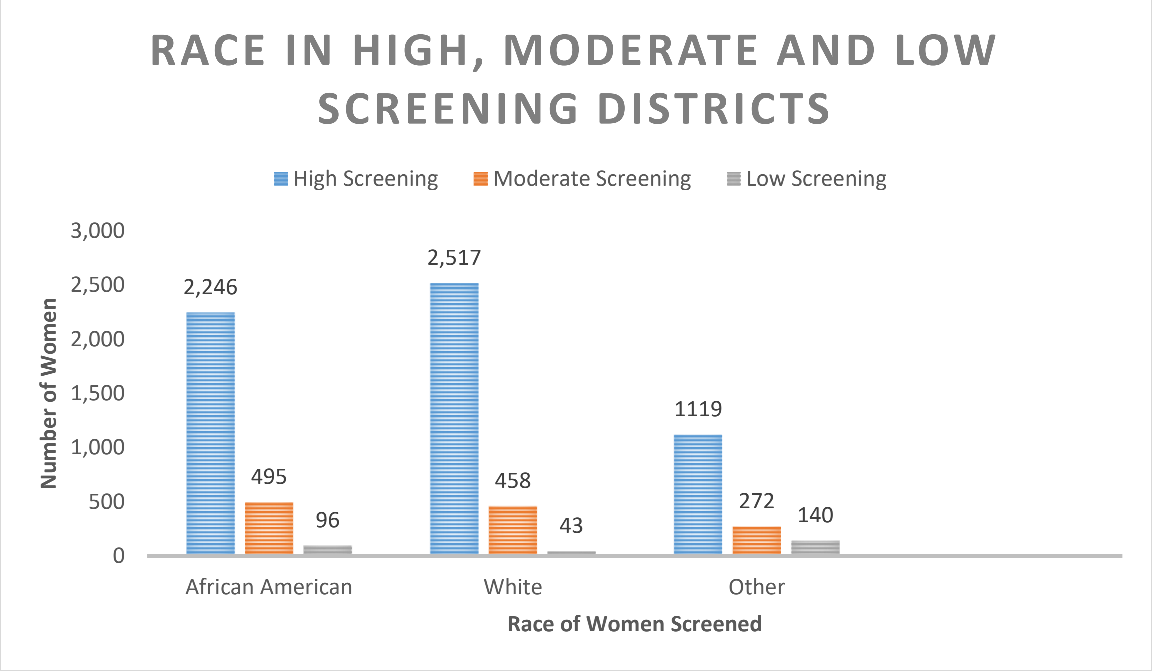

Figure 2: Visualization of Race in High, Moderate and Low Screening Districts

Mean Age in Public Health Districts

Age was calculated from women aged 18 and over from the online genetic referral screening tool. Mean ages ranged from 27.58 years to 47.50 years.

District	Age
High Screening Districts:	
District A	36.41 (SD=13.37)
District B	32.63 (SD=12.08)
District C	34.20 (SD=12.34)
District D	31.13 (SD=11.41)
District E	31.96 (SD=12.09)
Moderate Screening Districts:	
District F	27.58 (SD=6.9)

District G	35.99 (SD=11.87)
District H	32.92 (SD=11.05)
District I	38.59 (SD=12.66)
Low Screening Districts:	
District J	36.98 (SD=10.47)
District K	34.13 (SD=9.69)
District L	33.08 (SD=12.92)
District M	47.50 (SD=6.36)

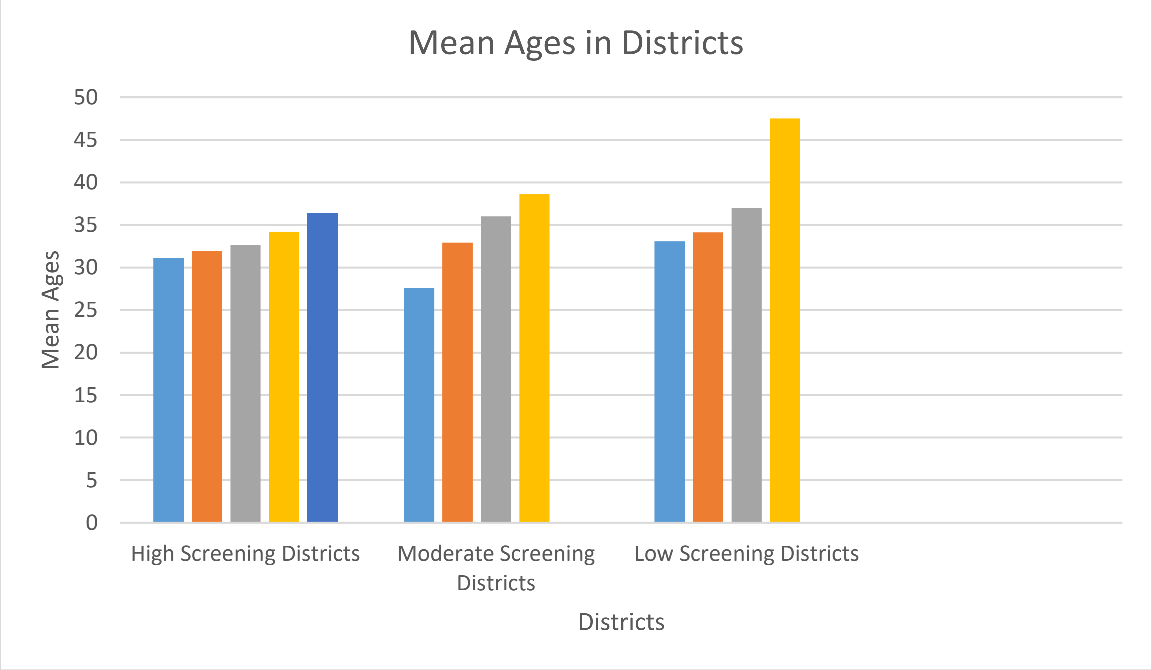

Figure 3: Mean Ages in Screened Public Health Districts

Hereditary Breast Cancer Risk in Public Health Districts

Hereditary breast cancer risk was calculated from available district data from the online screening referral tool (Table 4). Need to add sentence about Fig 4

Table 4: Hereditary Breast Cancer Risk

District	Positive Risk	Moderate Risk	Negative Risk
High Screening Districts:			
District A	92 (8.0%)	170 (14.7%)	893 (77.3%)
District B	60 (4.2%)	169 (12.0%)	1,183 (83.8%)
District C	150 (6.4%)	1,896 (80.5%)	309 (13.1%)
District D	44 (9.4%)	80 (17%)	346 (73.6%)
District E	22 (4.6%)	69 (14.4%)	389 (81.0%)
Moderate Screening Districts:			
District F	8 (4%)	27 (13.6%)	164 (82.4%)
District G	37 (7.9%)	63 (13.5%)	366 (78.5%)
District H	23 (10.6%)	48 (22.2%)	145 (67.1%)
District I	25 (9.2%)	45 (16.5%)	80 (47.1%)
Low Screening Districts:			
District J	44 (25.9%)	46 (27.1%)	80 (47.1%)
District K	7 (7.4%)	6 (6.3%)	82 (86.3%)
District L	0 (0%)	2 (16.7%)	10 (83.3%)
District M	1 (50%)	0 (0%)	1 (50.0%)
Total	513 (7.14%)	2,621 (36.49%)	4,048 (56.36%)

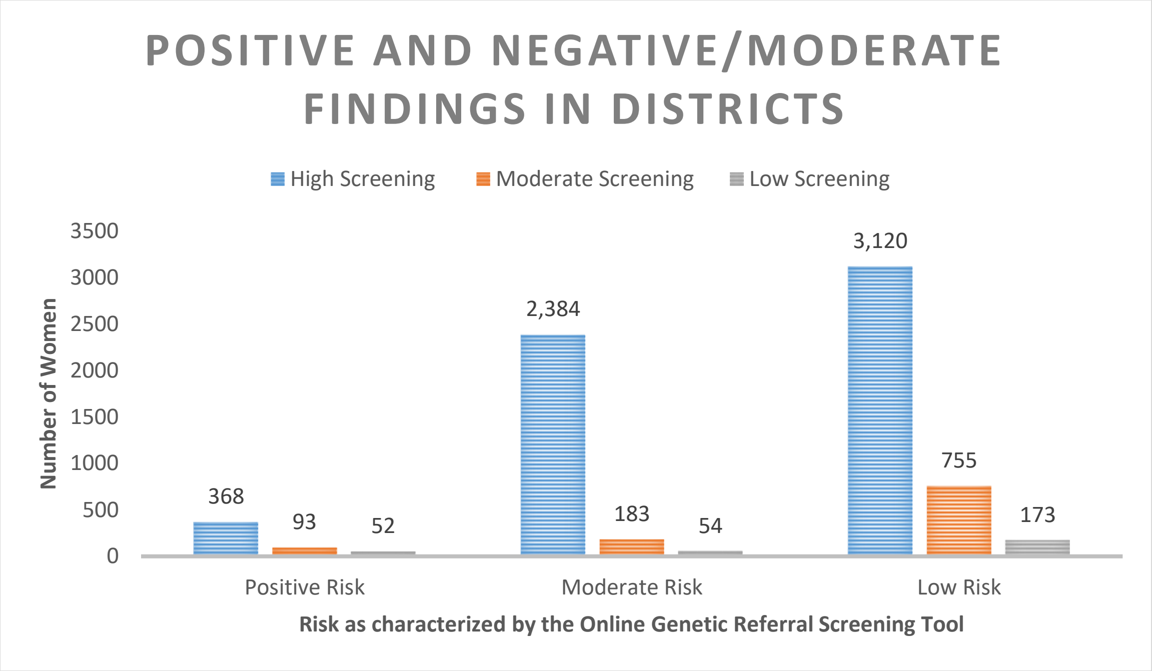

Figure 4: High, Moderate and Negative Risk for BRCA1/2 in Public Health Districts

Case Study #1: High Screening Rate District

District C

Policy

Regarding local policy, cancer was identified as one of the top community prioritization areas of need in a 2013 Community Needs Assessment (Northeast Georgia Medical Center, 2013). State policy has indicated that cancer is a major health problem, as breast cancer accounts for 30% of all cancer incidence in women and is the leading cause of cancer incidence (Georgia Cancer Report, 2016). There are several cancer resources in the state of Georgia, for example, the Breast Cancer License Plate tag fund, which supports Breast Cancer programs; Cancer State Aid, which provides funding for underinsured and uninsured Georgia adults (Georgia Breast Cancer Coalition Fund, n.d.), among others.

Community

Community characteristics for District C are characterized by population, income, racial demographics, and availability of healthcare resources in the community. As District C is composed of 13 separate public health centers (one per county), the race, income, poverty, and urban vs. rural characteristics were assessed for the city where the public health district office is located.

Table 5 displays population characteristics for this district.

Table 5. District C Population Characteristics

Population	Race	Income	Poverty	Urban vs. Rural
242,242	-87.3% White -8.1% African American	$51,902	13.7%	-79.4% Urban -20.6% Rural

Income is approximately $900 more than median household income in the state, and percentage of poverty is lower than the state average, which is 16% (Census Data, 2016). This city had a 1:61 clinician per patient ratio. Individuals aged 6-17 were most likely to be insured.

According to the Georgia Cancer Report of 2016, District C had no significant difference of age-adjusted breast cancer incidence rates as compared to the rest of the public health districts in the state (Georgia Cancer Report, 2016). Regarding age-adjusted breast cancer mortality rates, District C had significantly lower deaths as compared to other public health districts in the state (Georgia Cancer Report, 2016). Referring to the study conducted by Moss et al. that shows breast cancer incidence rates are higher in urban areas. As this District is more urban than rural, this conflicts with the findings from the literature. In addition, higher income is associated with higher rates of breast cancer (Akinyemiju et al, 2015). The findings from District

C are not consistent with the literature, as this District has a higher household income and lower rate of poverty, but still displays no significant difference in age-adjusted breast cancer incidence rates (Georgia Cancer Report, 2016).

Organizational

The process of using the online referral screening tool relies upon the consistent use of login/password information on the website. Each public health district is given a login/password for the tool. Screenings are logged for each district accordingly. The high number of screenings for District C suggests that clinicians within departments of public health in this district have found ways to integrate the tool into routine practice.

Individual

As individual knowledge and attitudes could not be assessed for this study, individual characteristics are operationalized by the number of individuals screened during this time period (n=2,355). This public health district screened the highest number of women of any other district, but the third-highest by percentage of population.

In addition, BRFSS data on preventive practices was available for the year 2014, indicating that 77.9% of the 151 women sampled in this district had received a mammogram in the last 2 years (BRFSS, 2014).

Case Study #2: Low Screening Rate District

District J

Policy

Regarding state and local policies and resources, individuals in the Atlanta metro have access to a breadth of resources, including many genetic professionals (National Society of Genetic Counselors). However, the low screening rate of *BRCA1* and *BRCA2* coupled with significantly higher incidence rates indicate that breast cancer screening should be a higher priority for this county.

Community

Community characteristics are defined by population, percent in poverty, race, rurality, breast cancer rates, and doctor to patient ratio present in the district.

Table 6. District J Population Characteristics

Population	Race	Median Income	Poverty	Urban vs. Rural
330,999	-63.6% White -28.1% African American	$68,818	10%	-99.8% Urban -0.2% Rural

The doctor to patient ratio in this county is 1:69 (Census, 2014). Individuals aged 6-17 are the most likely to be insured in this district (Census, 2014). District J has a significantly higher incidence rate of breast cancer than the state rate (Georgia Cancer Report, 2016), which supports the findings in the literature that urban areas have a higher incidence of breast cancer. However, age, adjusted mortality rates are significantly lower than the state average (Georgia Cancer Report, 2016).

Organizational

Screenings in this district were among the lowest of all public health districts. This could indicate a truly lower uptake of the tool in the district, or that the tool is not being used correctly by staff with a login/password and referrals are instead being made directly to the Advanced Practice Nurse who performs genetic testing in the district. This low screening rate could also indicate general lower uptake of Department of Public Health services due to a wide range of other medical resources in this district. There are four hospitals in this District (OASIS, 2018), as well as several Federally Qualified Health Centers (OASIS, 2018), that individuals may choose over the Department of Public Health.

Individual

170 out of 330,999 women were screened in this time period, making District J one of the lowest screening districts of all 13 districts of public health. Additionally, according to BRFSS data, mammograms over the last 2 years were reported by 77% of women surveyed (BRFSS, 2014). This is the second-lowest reporting rate in the state (BRFSS, 2014).

Chapter V: Discussion

From these data, it is clear that some public health districts in Georgia are screening significantly higher numbers of women than others, while there is underutilization by the Atlanta metro districts, Central, and Southern districts. This represents a structural barrier in the public health departments across Georgia. To have a robust tool for hereditary breast cancer screening in Departments of Public Health, the online referral screening tool must be further utilized.

Another surprising finding from the results was the low uptake of the tool in the Atlanta metro area. As the Atlanta metro area is saturated with breast cancer resources, an expected outcome would be that these metro districts of public health would have some of the highest screenings of all districts. However, it could be that because of these resources, the Department of Public Health is underutilized. In addition to the low proportion of screening rates, two districts in the Atlanta metro do not use the screening tool at all.

An additional interesting finding from the data is that those using the screening tool are largely between the ages of 27 and 34. As the risk for breast cancer in women increases after age 50, this high volume of younger women using the online referral screening tool shows that practitioners who are using the tool are using it to screen women as early as possible. As these women may be found to have the *BRCA1/BRCA2* mutation, it is incredibly valuable that they are being screened likely before they have a breast finding.

Regarding the findings from High Screening District C, a higher percentage of African American women were screened through the online genetic referral screening tool in clinics as compared to the percentage of African Americans in the county (10.5% versus 8.1%). This shows that many African American women are utilizing the services offered within this district. Mortality from breast cancer is lower in this district as compared to other districts in the state, but it is not possible to draw the conclusion that this is due to screening in the public health districts, although it probably has some influence. The income and poverty levels for this district are also lower than the rest of the state, which may have an impact on the access to breast cancer screening resources.

The low screening rate of District J was again surprising due to its location in the Atlanta metro area. A higher proportion of African American women were screened in this district as compared to white women, which indicates that white women may not utilize the services of this Department of Public Health as much as African American women do. Additionally, the income level of this county/district is higher than the rest of the state, which may indicate that women are going to primary care providers at private practices, other clinics, or utilizing other resources in the Atlanta metro area for their breast cancer screening needs. Alternatively, the low number of screens could be due to the lack of utilization of the tool by the district, and they could be using an alternative method to keep track of women who present as possible high risk for *BRCA1/2* mutations. Regardless, this district has a higher incidence rate of breast cancer as compared to other districts in the state, so utilization of this screening tool should be emphasized in order to get a full understanding of possible *BRCA1/2* mutations in this area. There is also a very high proportion of positive screens in this district, further creating a need for higher utilization of the tool.

Recommendations

The implementation of this *BRCA1/2* tool by practitioners in districts of public health would create a robust surveillance system for detecting how many women should be referred to genetic counselors for genetic counseling across the state. Therefore, practitioners in districts of public health should be trained and encouraged to use it often. Practitioners are often burdened by other health priorities in these departments of public health, so the ultimate goal should be to incorporate this screening tool in the preferred Electronic Medical Record (EMR) system. According to a report by the Institute of Medicine, EMRs and self-report databases could be valuable for storing and accessing clinical genomic information, but the healthcare system is currently unprepared to handle information on this scale (Institute of Medicine, 2015). By incorporating the tool into the EMR, practitioners could easily prioritize asking the screening questions and it would be a seamless part of health center practice.

Future studies could explore how many true positive *BRCA1/2* mutations resulted from the online referral screening tool, as well as an assessment of healthcare practitioner knowledge and use of the tool.

Overall, early screening and detection of *BRCA1/2* should be continued to be prioritized in the state, as well as greater attempts to minimize screening disparities and greater attempts to utilize this tool throughout the state.

Limitations

This study has several limitations. One limitation of this study was the exclusion of participants who may have accessed the online referral screening tool outside of a clinician's office, as the tool is also available for public use. Although zip code and state information are available for these individuals on the screening tool, these responses were not considered due to the possibility of zip code/state entry error. It is also possible that practitioners in other clinics or private practices are ordering genetic tests (particularly in the metro Atlanta area), but this information is not available through the screening tool.

Data also were only considered to the point of screening; data from the results of genetic testing were not considered for ethical reasons and IRB approvals. Subsequent studies may consider comparing the rate of screening to the rate of true positives or true negatives in *BRCA1/2* genetic testing.

Another limitation is that this

A final limitation is that screening in districts is completely reliant upon staff members in centers utilizing the tool in a manner that requires a login and password given to the staff. Some districts are completing questions but are not recording it through the tool, and the APN nurse catering to this population is only informed when there are positive results.

Conclusion

The online referral screening tool is helpful for detecting the risk of hereditary breast cancer in Georgia. This tool is widely used through districts of public health in the state, and when used correctly, can improve women's knowledge about their possible risk for hereditary breast cancer. Although there is consistent training and education with staff, there remains a wide disparity in consistent use. These disparities can be interpreted by considering socio-ecological factors, such as income, race/ethnicity in each district, proportion of providers to patients, and overall incidence/prevalence of breast cancer in that region.

In order to promote understanding of hereditary breast cancer and reduce disparities in breast cancer screening, all districts across the state should prioritize and consistently use the online referral screening tool. Ultimately, this tool should be incorporated into the Electronic Medical Records system in each district to create ease of access of information.

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Appendix A

Map of Public Health Districts in Georgia