Cancer Disparities Capacity Building Project

Phase I Needs Assessment Final Report

Conducted by the
Public Policy Center at UMass Dartmouth
for Greater New Bedford Allies for Health and Wellness

June 2015
ABOUT GREATER NEW BEDFORD ALLIES FOR HEALTH AND WELLNESS

Greater New Bedford Allies for Health and Wellness, Inc. is a partnership of over 100 organizations and services that have joined together to promote healthy living and serve the needs of vulnerable children and adults in our communities. GNB Allies is one of 27 Community Health Networks (CHNAs) designated by the Massachusetts Department of Public Health to promote healthy communities and serves the communities of Acushnet, Dartmouth, Fairhaven, Freetown, Marion, Mattapoisett, New Bedford, Rochester and Wareham.

GNB Allies’ mission is to channel the communities of Greater New Bedford into action to achieve a better quality of life for everyone. It provides information about our resources and services in order to promote coordination and to encourage their use by the public; address needs and build on community assets; and celebrate and reward community successes. More about Greater New Bedford Allies for Health and Wellness can be found at: http://www.gnballies.org/.

ABOUT THE PUBLIC POLICY CENTER AT UMASS DARTMOUTH

The Public Policy Center (PPC) at UMass Dartmouth is the University’s applied social science research, technical assistance, and public service unit based in the College of Arts and Sciences. An interdisciplinary applied public policy research and technical assistance provider, the Center seeks to inform evidence-based policymaking at the state, regional, and local level through collaborative engagements with public, private, and non-profit partners.

The Center is supported by a highly experienced team of professionals who leverage the skills and expertise of UMass faculty, staff, and students to meet the needs of our clients and partners. Services provided by the PPC include survey research, program evaluation (summative and formative), economic and workforce analysis, demographic and socioeconomic analysis, technical assistance, and needs assessment. These services are offered in the areas of economic development, community development, education, public health, transportation, housing, and environment. More about the Public Policy Center can be found at: http://publicpolicycenter.org/.

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ACKNOWLEDGEMENTS

Greater New Bedford Allies for Health and Wellness, Inc. and the Public Policy Center would like to thank the following individuals and organizations for their contributions to this process.

Ana Silva, CHW, YWCA Southeastern Massachusetts
Anabela Loaiza, CHW, Greater New Bedford Community Health Center
Anabela Oliveira, CHW, Immigrants’ Assistance Center
Cecil Hickman, Dog Tags Navigators, GNB Allies
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Community Health Workers of Catholic Social Services
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Helena DaSilva-Hughes, Immigrants’ Assistance Center
Joyce Dupont, Greater New Bedford Community Health Center
Junta Directiva of Centro Comunitario de Trabajadores (CCT Workers’ Center) of New Bedford
Kathleen Murphy, United Interfaith Action, GNB Allies
Kathy Tsonis, Southcoast Cancer Center, GNB Allies
Kerry Mello, Southcoast Health System, GNB Allies
Laura Diogo-Carreau, Dog Tags Navigators
Leonard Pittsley, CHW
LindaMae Pittsley, CHW
Philomene Tavares, CHW, Immigrants’ Assistance Center
Reverend David Lima, InterChurch Council of Greater New Bedford, GNB Allies
Reverend Marc Fallon, Catholic Social Services
Reverend Russ Chamberlain, Dog Tags Navigators Chaplain/CHW
Valentina Martinez, CHW, YWCA Southeastern Massachusetts

This publication was supported by the Centers for Disease Control and Prevention (CDC) Cooperative Agreement Number U58/DP003920-03. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the CDC.
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Executive Summary

Greater New Bedford Allies for Health and Wellness, Inc. (GNB Allies) is a partnership of over 100 organizations and services that have joined together to promote healthy living and serve the needs of vulnerable children and adults in the Greater New Bedford area. GNB Allies was awarded a grant in the spring of 2015 from the Massachusetts Comprehensive Cancer Prevention and Control Network to conduct a Needs Assessment that identifies barriers faced by the region’s vulnerable residents who have difficulty accessing both preventive and comprehensive cancer care. The results of the Needs Assessment presented in this report will inform Phase II of the project, which includes generating strategies and taking action based off this work.

The Public Policy Center (PPC) at UMass Dartmouth provided research and technical assistance for the Phase I Needs Assessment, which included three types of community outreach conducted by community health workers and community leaders:

1. **Focus Groups** with various constituent groups.
2. **Key informant interviews with Community Leaders.** Community leaders are individuals who work with a specific community and provide an overview for that community.
3. **Key informant interviews with Community Members.** Community members are specific people within groups, for example, a fisherman, Veteran, cancer survivor, senior, or family member of someone who has cancer.

Community health workers and community leaders facilitated 8 focus groups and conducted interviews with 51 community members and 16 community leaders with diverse demographic and cultural backgrounds. Focus groups included Hispanic women and men, food pantry recipients, young adults, homeless individuals, Veterans, elderly Portuguese women, Central Americans (many undocumented), and health providers.

**Key Findings**

The overarching conclusion of the Needs Assessment is that most individuals report similar barriers and challenges in terms of maintaining overall health and accessing both preventive and comprehensive cancer care. This result is primarily a factor of shared social determinants of health in which health and wellness fit within a larger framework of day to day needs and crises; from issues of housing, childcare, finances, and transportation, to employment, immigration, and safety.

As a result, one’s health is often addressed after more immediate needs are met, if at all. As one community leader working with veterans noted, “Their daily life is more important and cancer is the last thing they think about.” This thought was echoed by a community leader who works with Portuguese immigrants, noting that “clients are overwhelmingly concerned with providing for their families and therefore there is often not time to address their own health needs.”
This is not to say that different groups do not face unique problems and circumstances or familiar challenges of a greater magnitude. However, needs that cut across groups are evident and important to address. Specific barriers and challenges related to health, cancer screening, and cancer treatment follow.

**Health Literacy**

Health literacy can be defined as the degree to which individuals have the capacity to obtain, process, and understand basic health information needed to make appropriate health decisions and services needed to prevent or treat illness. Overall, most participants possess a foundational understanding of what is important for good health and acknowledge the importance of diet, positive lifestyles (e.g., exercise, no drugs, not smoking), and regular visits to the doctor as important steps in being healthy.

However, participants as a whole possess lower levels of functional health literacy in that they have limited capacity to utilize health-related knowledge to make informed choices about their health. For instance, community members face barriers that limit their ability to translate health literacy into action.

A focus group of healthcare providers notes that one contributing factor to low levels of functional health literacy is that discussions and materials provided by health providers are not always tailored to the individual. These providers identify a need to assess the health literacy and research ability of patients when they come for visits; that is, there is no one size fits all option available to providers for addressing patients’ needs. Relatedly, participants report that their main sources of health information are television and the Internet, with one community leader noting about his clients that “…if they hear it on TV it must be true.”

This issue was further expressed by providers and community health workers, who noted that their clients often do not participate in cancer screenings because they are confused either by language barriers or by instructions. For example, it was noted that while many clients are provided colon cancer screening kits, they often do not return the kits because they are confused by the instructions.

**Language Barriers**

Language barriers contribute greatly to functional literacy, including the effectiveness of a patient’s interactions with health practitioners. Use of family members as interpreters was common among participants whose first language is not English, but patients also use professional services offered through medical offices. Some focus groups members highlighted difficulty with translation in a medical setting, noting that many professional interpreters they encounter speak more than one language (as a cost savings for the medical practice), while failing to speak any one language adequately.

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Also, while family members are often called on to translate, many do not have the medical knowledge or vocabulary to adequately interpret for the doctor or health practitioner. Thus, the patient often does not fully understand doctor’s orders or advice when they leave the appointment.

In addition, many available health materials and screening tools (e.g. colon cancer screening kits), are not printed in appropriate languages. These language barriers, compounded with low health literacy levels to begin with, result in low participation rates in cancer screenings.

**Provider Appointments**

It was noted by several community leaders that many of their constituency do not have a primary care physician, even though most have insurance. And the experience for those who visit the doctor is not always effectual; many community members note that health providers fail to answer their questions adequately and listen to their concerns. This is partly a function of language and cultural barriers, but community members also are generally uncomfortable asking their health provider questions because of a lack of trust, fear of misunderstanding or judgment, being ashamed, and other culturally related issues.

Community members report they are most comfortable discussing health issues with family members and friends, and peer-to-peer advocacy seems to be especially helpful for Veterans. Participants note that doctors could improve communication by taking their time, listening more intently, and explaining more adequately. Others suggested that a health advocate, possibly a Community Health Worker (CHW), would increase trust levels and make communication between doctor and patient more effective.

**Fear and Trust**

Many participants noted that they first think of “death” when they hear the word cancer. For instance, a community leader noted that their clients equate a cancer diagnosis with a “death sentence.” Fear is a common theme throughout the interviews: fear of doctor visits, fear of finding out one has cancer, fear of what the treatment will entail, fear that they won’t be able to afford treatment, fear that tests will be ordered that they don’t need, and fear in general of navigating a health care system about which they know very little.

As a result, many participants only visit the doctor when they feel sick, and even then many will wait until the symptoms become unbearable, hoping that eventually the symptoms will disappear. This was confirmed by a community leader who noted that “cancer is a topic that members of [their] community do not think too much about until it becomes an issue for them or someone they know.”

While overcoming fear is a significant obstacle, it was noted by several community leaders that CHWs provide the key to getting people to the doctor for regular visits, health
screenings, and also treatment, since they are part of the community and have high trust value among these diverse groups.

Healthcare Costs

Most community members have health insurance. However, interviewees face a number of issues related to insurance coverage and cost. For instance, some have difficulty finding a provider that accepts the patient’s insurance. Of note, the cost of deductibles and other out-of-pocket expenses as well as the cost of medication are significant issues for community members.

As a salient example, Dr. Therese Mulvey, Physician in Chief, Oncology Services at Southcoast Hospital makes home visits each month. She notes “I am appalled at the depth of poverty of my patients. This winter I encountered a family who lived in a cottage in Wareham who could not afford heat and hung blankets on their walls to stay warm. As health care providers, we don’t often see this. We don’t understand the magnitude of their poverty. They’ve lost cars, homes, don’t have food. Cancer is just another thing on the list.”

Navigating the Health System

Even if they have health insurance, the healthcare system can be a confusing maze for most people, but especially for newer immigrant groups with no background in dealing with health systems. Leaders agree that their communities often experience difficulty navigating the health care system, particularly in terms of insurance requirements.

It was noted that CHWs may hold the key to demystifying the health system for their clients, many of whom require guidance throughout the entire process, from improving basic health literacy, to getting the client to a doctor, to navigating the health system, and then following through on screening and treatment. This is particularly true of newer immigrants, often hail from countries where health systems are less developed or non-existent.

Inconvenient Appointment Times

Many of the region’s poorest residents work long hours, sometimes at more than one job, and often the hours that healthcare providers are open are not convenient for the working population. Most don’t have the type of jobs that allow flexibility during the day to make office visits. For example, the Mayan community work 12 hour shifts and generally do not leave work until after 6pm when most healthcare offices are closed. Even when Saturday hours are offered, many greater New Bedford residents use that time to address more immediate needs such as grocery shopping, laundry, banking, and other errands.

“Patients in treatment are having to make tough decisions about utility bill payments or picking up their medication.”
Transportation

A significant number of participants noted that transportation is a major barrier, including transportation to appointments, screenings, and treatment. As a result, individuals often cannot get to appointments even when they have the desire to seek out preventative care or when they require cancer treatment. Exacerbating the issue is that some cancer patients are sent to Boston for treatment, including those who do not own a car. The focus group of providers (e.g., doctors, nurses, and counselors) acknowledged that care coordinators spend hours arranging transportation for patients.

Lack of Regular Physicals

Community leaders expressed that one of the primary reasons their constituents are not knowledgeable about cancer screenings is due to a lack of regular physicals, even though most have health insurance and the cost for most annual physicals is covered. In fact, it was noted that many of the people they work with do not even have primary care physicians.

Environment

Many of the community members interviewed live and work in environments that are unsafe and can actually contribute to developing cancer. For instance, conversations with the K’iche’ Mayan community leaders reveal that some members of that community work in the unregulated “shadow economy” and are therefore more likely than the general population to be exposed to carcinogens at work. Social marginalization is also a concern expressed by Mayan leaders. They note that their community exists at the edges of the political landscape and their needs often go ignored, although they are a vital component of New Bedford’s nation-leading fishing industry.

Along with unsafe occupations, many of the region’s residents live in unsafe neighborhoods and crime can be a daily trial. For example, a member of the Mayan community who was conducting surveys for this project spent a week in the hospital after he was brutally mugged. Many of New Bedford’s undocumented residents have been victims of crime because they are easily identifiable (e.g., predictable work hours and paths of travel) and because they are unlikely to report these crimes to the police because of their undocumented status.

Recommendations

Community leaders noted the difficulty that many community members have with navigating the health system, and they highlight caseworkers and community health workers (CHWs) as valuable resources for dealing with this barrier. Specifically, expanding the ranks of caseworkers and CHWs was suggested by nearly all leaders.

Leaders suggested several strategies to improve levels of health literacy, including focusing on sites with high concentrations of need and poverty, modeling best practices, assessing the health literacy and research ability of patients, and developing a health literacy toolkit for use by providers.

“I didn’t hesitate getting treatment. I’m surprised this would be a problem for people. The treatment will keep you alive longer, so why wouldn’t you make that a priority?”
Leaders gave the following recommendations for increasing cancer screening and treatment;

- offer free screenings and education,
- make available a mobile source of information and resources, for example the Southcoast Health Van,
- schedule quarterly on site screenings, for example at housing authority sites,
- offer screenings during “off hours,”
- develop outreach programs that are engaging,
- facilitate meaningful and culturally sensitive conversations,
- encourage participation from nursing students from local colleges, and
- utilize social media.

Community members noted that doctors could serve them better by taking their time during appointments, listening more intently, explaining more adequately, increasing evening availability, and being aware of patient anxiety about financial issues.
1.0 PROGRAM BACKGROUND

Greater New Bedford Allies for Health and Wellness, Inc. (GNB Allies) is a partnership of over 100 organizations and services that have joined together to promote healthy living and serve the needs of vulnerable children and adults in the greater New Bedford area. Over the past two years, GNB Allies has sponsored a Health Equity and Cancer Disparities project that provided training for over 20 community health workers and distributed small capacity building grants to three local agencies that address health equity issues in the region.

In the spring of 2015, GNB Allies received a $100,000 grant from the Massachusetts Comprehensive Cancer Prevention and Control Network, a program within the Massachusetts Department of Public Health’s Division of Prevention and Wellness, to build on its efforts to reduce health inequities for cancer and other diseases. Phase I of the grant provided funding that enabled GNB Allies and its partners to train community health workers to conduct a cancer-focused disparities needs assessment, and to develop an action plan to address priorities from the needs assessment. A primary goal of Phase I, the results of which are presented in this report, identifies barriers faced by vulnerable residents who have difficulty accessing both preventive and comprehensive cancer care and establishes a blueprint for future cancer-related initiatives.

2.0 REGIONAL HEALTH DISPARITIES

The Centers for Disease Control and Prevention defines social determinants as the “complex, integrated, and overlapping social structures and economic systems that are responsible for most health inequities.” These social structures and economic systems include the social environment, physical environment, health services, and structural and societal factors. The Robert Wood Johnson Foundation Commission to Build a Healthier America notes that health status improves as income rises (see Figure 1), and this is true for African Americans, Hispanics, and Whites.

\[\text{Figure 1}\]

**Income & Health Status**

<table>
<thead>
<tr>
<th>% Adults Age 25+ With Poor/Fair Health</th>
<th>&lt;100% FPL</th>
<th>100%-199% FPL</th>
<th>200%-299% FPL</th>
<th>300%-399% FPL</th>
<th>400%+ FPL</th>
</tr>
</thead>
<tbody>
<tr>
<td>30.9%</td>
<td>21.2%</td>
<td>14.9%</td>
<td>10.1%</td>
<td>6.6%</td>
<td></td>
</tr>
</tbody>
</table>

The National Healthcare Disparities Report from the Agency for Healthcare Research and Quality (mandated annually by Congress) concludes that while quality of care is improving, issues regarding access to care are actually increasing. The report points out that “these disparities may be due to differences in access to care, provider biases, poor provider-patient communication, or poor health literacy.” In addition, a growing body of research indicates that living and working conditions, including housing quality, exposure to pollution, worksite safety, access to healthy and affordable foods, and proximity to safe places to exercise have a more significant effect on health than risky behaviors.

Regional Backdrop

Per capita income levels for Fall River and New Bedford are below the state average. While the per capita income for Massachusetts is $35,763, the per capita income is $21,056 in New Bedford and $21,257 in Fall River. Relatedly, Fall River and New Bedford have much higher poverty rates than the state as a whole. In 2013, the US Census Bureau reported an individual poverty threshold of $11,888. Just over 23 percent (23.3%) of Fall River residents and 23.5 percent of New Bedford residents lived in poverty, which compared to 11.4 percent statewide. Poverty rates for children under 18 for Fall River and New Bedford are 36 percent and 34 percent, respectively (see Figure 2).

Furthermore, Fall River and New Bedford have low rates of educational attainment compared to the state as a whole. While the 2014 graduation rate was 86.1 percent statewide, it was 60.8 percent for Fall River and 68.6 percent for New Bedford. Figure 3 shows graduation rate trends over time.

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7 U.S. Census Bureau, American Community Survey 5-year estimate, 2009-2013
Regional Health Disparities

In the Southcoast, approximately four times as many people who earn less than $50,000 per year report having fair or poor health as compared to those who earn above that threshold (25.0 percent versus 6.2 percent in Greater Fall River and 22.5 percent versus 6.4 percent in Greater New Bedford).9 Furthermore, while fewer than nine percent of those with a college degree report having fair or poor health, more than one-quarter of those with a high school degree or less report the same (27.1 percent in Greater Fall River and 25.0 percent in Greater New Bedford).10

From 2002 to 2007, smoking rates for those earning less than $50,000 per year were 32.9 percent in Greater Fall River and 26.1 percent in Greater New Bedford, which compared to less than 20 percent in both regions among those who earned more than $50,000. Overall, the Southcoast has a significantly higher smoking prevalence than the state; in 2013,11 the smoking rate was 33.0 percent in Fall River, 19.5 percent in New Bedford, and 16.6 percent statewide.12

Overall, screening for cancer among Southcoast residents is lower than the state average (see Table 1).13

Table 1

<table>
<thead>
<tr>
<th></th>
<th>Colonoscopy</th>
<th>Mammogram*</th>
<th>Breast exam*</th>
<th>Pap smear</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fall River</td>
<td>46.9%</td>
<td>61.4%</td>
<td>77.7%</td>
<td>77.5%</td>
</tr>
<tr>
<td>New Bedford</td>
<td>43.7%</td>
<td>68.7%</td>
<td>80.6%</td>
<td>82.7%</td>
</tr>
<tr>
<td>Greater Fall River</td>
<td>51.4%</td>
<td>66.8%</td>
<td>80.7%</td>
<td>79.6%</td>
</tr>
<tr>
<td>Greater New Bedford</td>
<td>47.3%</td>
<td>72.3%</td>
<td>83.5%</td>
<td>82.2%</td>
</tr>
<tr>
<td>Massachusetts</td>
<td>54.6%</td>
<td>69.5%</td>
<td>86.1%</td>
<td>85.0%</td>
</tr>
</tbody>
</table>

*adult women only

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9 Behavioral Risk Factor Surveillance System (BRFSS), Massachusetts Department of Health, 2002-2007
10 U.S. Census Bureau, American Community Survey 5-year estimate, 2007-2011
11 Behavioral Risk Factor Surveillance System (BRFSS), Massachusetts Department of Health, 2013. Interpret this data with caution as the sample size for this year was small.
12 Massachusetts Cancer Disparities Assessment: Priority Region Recommendation, March 20, 2013. JSI.
13 Southcoast Health System Community Needs Assessment 2013, University of Massachusetts Dartmouth Center for Policy Analysis. BRFSS, MassCHIP (colonoscopy & mammography: 2002-07; breast exam & pap smear: 2002-06)
The Hispanic population in the Southcoast is particularly underserved regarding cancer screenings and access to doctors (see Table 2).  

### Table 2

<table>
<thead>
<tr>
<th>Clinical Care</th>
<th>Cannot See a Doctor Due to Cost</th>
<th>Colorectal Cancer Screening</th>
<th>Mammogram Within Last Two Years</th>
<th>Pap Smear Within Last Three Years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Greater Fall River</td>
<td>White 7.4% Black NA Hispanic 21.3%</td>
<td>White 65.5% Black 66.4% Hispanic 68.5%</td>
<td>White 87.1% Black NA Hispanic 87.8%</td>
<td>White NA Black 81.8% Hispanic 84.4%</td>
</tr>
<tr>
<td>Greater New Bedford</td>
<td>8.0% NA 19.4%</td>
<td>66.4% 88.5% 57.8%</td>
<td>84.3% 87.1% 84.4%</td>
<td>84.1% NA 70.2%</td>
</tr>
<tr>
<td>Massachusetts</td>
<td>5.4% 10.9% 16.7%</td>
<td>74.6% 71.2% 63.5%</td>
<td>87.8% 84.7% 69.9%</td>
<td>80.9% 84.9% 79.0%</td>
</tr>
</tbody>
</table>

Source: BRFSS, via MassCHIP Instant Topics (2010-2013)

Southeastern Massachusetts, which includes the Southcoast, has been identified as one of two regions in the state with the greatest disparities in cancer incidence, hospitalization, and mortality. Illustrating this point, cancer incidence in 2008 was higher than the state average in New Bedford, Wareham, and the Greater New Bedford area. Moreover, the age-adjusted incidence rate of all types of invasive cancer increased in each area from 1990 to 2008, which may partly be a result of better detection (see Figure 4).

### Figure 4

**Invasive Cancer Incidence Rate (All Types)**

Despite this rise in cancer incidence, age-adjusted mortality rates for all types of cancer decreased in all areas between 1999 and 2010. Unfortunately, mortality rates were higher than the state average in 2010 in Fall River, New Bedford, Wareham, and the Greater Fall River area (see Figure 5). The age-adjusted mortality rate for colorectal cancer in Greater Fall River was 17.5 for men and 12.4 for women between 2008 and 2010. The

14 Behavioral Risk Factor Surveillance System (BRFSS), MassCHIP Instant Topics, 2010-2013
16 Massachusetts Department of Health, MassCHIP, 2008
17 Massachusetts Department of Health, MassCHIP, 2008
18 Mortality rates for specific cancers were from MassCHIP Instant Topics at: http://www.mass.gov/eohhs/researcher/community-health/masschip/instant-topics.html
rates were 23.0 for men and 11.1 for women in Greater New Bedford. Regarding breast
cancer, the age-adjusted rate was 14.6 for the Greater Fall River area between 2008 and
2010 and 18.6 for Greater New Bedford. For lung cancer, the age-adjusted rate for
Greater Fall River from 2008 to 2010 was 76.2 for males and 38.7 for females. The rate
for Greater New Bedford was 65.6 for males and 34.9 for females.

Overall, the region has lower incomes and educational attainment as well as higher
poverty rates than the state as a whole. This is associated with poorer health outcomes,
a lower cancer screening rate, and disparities in cancer incidence, hospitalization, and
mortality. It is readily apparent that these disparities have a negative effect on the health
and well-being of the Southcoast population. Efforts to further understand the nature and
causes of these disparities and to develop solutions to address them will have a profound,
positive effect on the population of this region.
3.0 METHODOLOGY

GNB Allies commissioned the Public Policy Center (PPC) at UMass Dartmouth to provide research and technical services for Phase I of the grant that included:

- Designing an interview script and survey instruments used by community health workers to interview key informants and to conduct focus groups.
- Training community health workers in key informant interview and focus group techniques.
- Analyzing data obtained from the key informant interviews and focus groups.

Three types of community outreach were conducted by the community health workers:

1. **Focus Groups** with various constituent groups.

2. **Key Informant Interviews with Community Leaders**. Community leaders are individuals who work with a specific community and provide an overview for that community.

3. **Key Informant Interviews with Community Members**. Community members are specific people within groups, for example, a fisherman, veteran, cancer survivor, senior, or family member of someone who has cancer.

Survey and focus group documents were translated into the appropriate language, including Spanish, Portuguese, and Mayan K’iche’. Interviews were conducted at various locations such as cultural organizations, churches, healthcare facilities, prisons, homeless shelters, and food banks. Note that this study represents Phase I of the Massachusetts Comprehensive Cancer Prevention and Control Network grant. Phase II involves generating strategies and taking action based on this work.

3.1 Data Analysis

A mixed-methods design was utilized, meaning the study included both a qualitative and quantitative component. Focus groups of community members as well as key-informant interviews with community leaders form the qualitative component, and community member surveys form the quantitative component. A concurrent embedded form was used in which both components proceeded simultaneously,\(^1\) with the quantitative component embedded within the qualitative one. Thus, quantitative analysis complements qualitative analysis in this study.\(^2\) A comprehensive account of health literacy was desired in which context could be understood and this is among the main rationales behind a mixed-methods approach.\(^3\)

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\(^2\) One reason for employing this design is that an insufficient number of participants completed the community member survey \((n = 51)\) to warrant statistical analysis.
Qualitative questions from focus groups and community leader interviews were fairly directed yet open-ended. For instance, one question directs the participant’s attention toward causes of cancer while allowing them to respond freely. Probe questions are offered as a tool for use by interviewers to help facilitate discussion by the participant. Designing questions in this way allowed the interviewer to address specific topics of concern while allowing for flexibility in participants’ responses.

Responses were analyzed in a bottom-up, inductive manner. First, responses were summarized for each question on the focus group and community leader instruments at the level of the individual participant. These participant-specific summaries were then compared across participants in order to identify main themes for each question. Questions regarding theme generation were ultimately decided by the lead author. Data from community member surveys were analyzed via descriptive statistics (e.g., frequencies) rather than inferential statistics, again due to low sample size. Results from the community member surveys were integrated into the focus group findings. A main point of comparison was made between the responses of community leaders and members of the community at large.

Focus group and community leader interview questions were divided into five main sections: Health Literacy, Knowledge and Attitudes about Cancer, Cancer Screening, Treatment, and Barriers, Health Information, and Closing Thoughts.

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21 Please see Appendix B for copies of the survey instruments.
4.0 SUMMARY OF FOCUS GROUP, KEY INFORMANT INTERVIEWS, AND COMMUNITY MEMBER SURVEY

Community Health Workers and Community Leaders facilitated 8 focus groups and conducted interviews with 51 community members and 16 community leaders. Community members also participated in focus groups. It is important to note that focus group members and community member survey respondents are two different groups of people. Results in this report focus primarily on focus groups, with frequency analyses from the community member survey as supplementary material. Community leader input is added to provide additional context. The response rate obtained in this study is due to the efforts of the Community Health Workers.

Table 3
Summary of Interviews Type

<table>
<thead>
<tr>
<th>Type</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Focus Groups</td>
<td>8</td>
</tr>
<tr>
<td>Community Leader Surveys</td>
<td>16</td>
</tr>
<tr>
<td>Community Member Surveys</td>
<td>51</td>
</tr>
</tbody>
</table>

4.1 Focus Groups

Focus groups included Hispanic women, Hispanic men, food pantry recipients, young adult immigrants, elder Portuguese women, undocumented Central American immigrants, health care providers, and homeless women. These groups were held from late March to mid May 2015. Table 4 displays the number and type of participants in each focus group.

Table 4

<table>
<thead>
<tr>
<th>Focus Group</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hispanic women</td>
<td>125</td>
</tr>
<tr>
<td>Hispanic men</td>
<td>14</td>
</tr>
<tr>
<td>Food Pantry Recipients (Saint Anthony’s Food Pantry)</td>
<td>10</td>
</tr>
<tr>
<td>“Young adults,” Immigrants’ Assistance Center</td>
<td>4</td>
</tr>
<tr>
<td>Elderly Portuguese Women (over 60)</td>
<td>15</td>
</tr>
<tr>
<td>Men and women, Central American, many undocumented</td>
<td>15</td>
</tr>
<tr>
<td>Women, 18-38, Harbor House Homeless Shelter (New Bedford)</td>
<td>6</td>
</tr>
<tr>
<td>Southcoast providers; 4 Doctors, 1 Nurse, 1 Outreach Coordinator, 1 Patient Financial Counselor, 1 Nurse Navigator, 1 Social Worker, and 1 Oncology Nurse Practitioner</td>
<td>10</td>
</tr>
</tbody>
</table>

4.2 Community Leaders

Sixteen community leaders were interviewed. Three of the community leaders work at social services agencies, two work at food pantries, two are shelter directors, one is the director of the Hispanic Women’s Conference, one is a veterans organization director, three are clergy, one works at an addiction treatment center, one is a Mayan community
leader, and one is an immigrant assistance worker. Occupational data were unavailable for one community leader.

4.3 Community Members

A total of 51 community surveys were conducted, 37 percent of which were with Veterans. These surveys were completed on a one-on-one basis with community health workers.22 The tables below provide information on the sample of community member survey respondents. Note that race categories in the table below include both Hispanic and non-Hispanic individuals. Furthermore, of the seven individuals without health insurance, two were born in the United States, four were Hispanic, and six made between $10,000 and $50,000 per year.

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Live in New Bedford</td>
<td>65.0%</td>
</tr>
<tr>
<td>Male</td>
<td>55.0%</td>
</tr>
<tr>
<td>Hispanic</td>
<td>12.0%</td>
</tr>
<tr>
<td>Speak English &quot;Most Often&quot;</td>
<td>78.0%</td>
</tr>
<tr>
<td>Born in United States</td>
<td>63.0%</td>
</tr>
<tr>
<td>Married</td>
<td>33.0%</td>
</tr>
<tr>
<td>Children Under 18</td>
<td>6.0%</td>
</tr>
<tr>
<td>Routine Physical Within Last Year</td>
<td>63.0%</td>
</tr>
<tr>
<td>Visit Greater New Bedford</td>
<td>31.0%</td>
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</table>

<table>
<thead>
<tr>
<th>Age Bracket</th>
<th>Percent</th>
</tr>
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<tbody>
<tr>
<td>18-34</td>
<td>15.7%</td>
</tr>
<tr>
<td>35-44</td>
<td>13.7%</td>
</tr>
<tr>
<td>45-64</td>
<td>39.2%</td>
</tr>
<tr>
<td>65 and Over</td>
<td>27.5%</td>
</tr>
<tr>
<td>No answer</td>
<td>3.9%</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Race</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Black</td>
<td>7.8%</td>
</tr>
<tr>
<td>White</td>
<td>68.6%</td>
</tr>
<tr>
<td>No Answer</td>
<td>5.9%</td>
</tr>
<tr>
<td>Other</td>
<td>17.7%</td>
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</table>

<table>
<thead>
<tr>
<th>Income Bracket</th>
<th>Percent</th>
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<tbody>
<tr>
<td>Less than $10,000</td>
<td>11.8%</td>
</tr>
<tr>
<td>$10,000 to $24,999</td>
<td>33.3%</td>
</tr>
<tr>
<td>$25,000 to $49,999</td>
<td>27.5%</td>
</tr>
<tr>
<td>$50,000 to $74,999</td>
<td>7.8%</td>
</tr>
<tr>
<td>$75,000 or more</td>
<td>5.9%</td>
</tr>
<tr>
<td>No answer</td>
<td>13.7%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Insurance Coverage Type</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>No coverage</td>
<td>14.3%</td>
</tr>
<tr>
<td>Public Safety Net</td>
<td>46.9%</td>
</tr>
<tr>
<td>Employer</td>
<td>16.3%</td>
</tr>
<tr>
<td>Multiple sources</td>
<td>8.2%</td>
</tr>
<tr>
<td>Tricare</td>
<td>2.0%</td>
</tr>
<tr>
<td>Purchased on own</td>
<td>8.2%</td>
</tr>
<tr>
<td>Other</td>
<td>4.1%</td>
</tr>
</tbody>
</table>

22 The small sample size of community member surveys represents only a fraction of the initial goal because the data collection period for Phase I was cut from eleven months to three months. Also, to improve data collection quality, it was decided that CHWs would conduct the community member surveys individually with respondents rather than simply handing out the survey at various events. Conclusions from the community member survey should be made with caution due to the sample size.
5.0 FINDINGS

Results of the interviews and surveys are presented in five sections: Health Literacy, Knowledge and Attitudes about Cancer, Cancer Screening, Treatment, and Barriers, Health Information, and Closing Thoughts. Sub-sections are also delineated to assist with interpretation of the data.

5.1 Health Literacy

Important Factors for Good Health

Community members overall seem to have a foundational understanding of how to maintain health and wellness; community members noted the importance of a healthy diet, positive lifestyle choices (e.g., limited alcohol consumption, not smoking), regular visits to a doctor, and religion for good health. However, some community leaders (e.g., leader of Veteran group, food pantry director) believe that the groups they work with are not particularly knowledgeable about healthy habits and wellness.

Importantly, some leaders acknowledged that individuals may be aware of the requirements of a healthy lifestyle but may face significant barriers, chief among them being a lack of transportation, child care options, and cost of healthcare. Leaders also noted that their communities often experience difficulty navigating the health care system (e.g., insurance requirements). Perhaps caseworkers would be helpful. Some leaders noted that immigrant communities may have no background of dealing with health care systems, only adding to the confusion that some individuals face. Unfortunately, a focus group consisting of providers (e.g., doctors, nurses, and counselors) did note that patients sometimes smoke even after receiving a cancer diagnosis, which is a source of considerable frustration for providers.

Leaders offered a number of suggestions for educating community members. These suggestions included visiting sites with concentrations of illness or poverty, providing recipes for healthy meals, and modeling best practices (e.g., providing healthy snacks at meetings). The focus group of providers also noted that it is important to assess the health literacy and research ability of patients and the potential utility of developing a literacy toolkit for providers. Interestingly, a leader who works with Portuguese immigrants noted an improvement in health education among later generations of immigrant families, and a leader who works with veterans noted that lack of health-related knowledge is particularly problematic in this population.

Health Decisions

Focus group members noted that either they or their spouse typically make health decisions for the family. Eighty percent of community member respondents make their own health decisions. The remaining 20 percent noted that their spouse or another family member made decisions either for them or with them. Perhaps this highlights the utility of patient-centered education efforts.
Interactions with Doctors

**Comfort:** Three focus groups as a whole expressed feeling comfortable with asking their doctor a question, two of which mentioned the gender of their provider as a significant factor. For instance, 12 out of 14 members of a group of Hispanic men mentioned that they would be comfortable with a male doctor but not a female doctor. Members of two groups did not feel comfortable asking questions because they felt that the doctor was often in a rush.

Sixty four percent of community member survey respondents, mostly men, reported they feel comfortable asking their doctor a question. Community leaders also gave mixed results regarding patient comfort with visiting the doctor. Those who said that their community is uncomfortable mentioned language barriers, navigation of insurance requirements, lack of trust, and fear of forms and bureaucracy, especially among Veterans. One leader mentioned that it is difficult to find resources for those with mental health issues.

Results were mixed among community member focus groups regarding disclosing information of a personal nature. Some indicated that they would feel uncomfortable discussing such topics because they feared misunderstanding, judgment, or language barriers and sex differences. One group felt that doctors sometimes force patients to disclose personal information. Supporting the focus group finding, forty nine percent of community member survey respondents indicated that they feel comfortable speaking with a medical professional regarding topics of a personal nature. Most of the respondents reporting feeling uncomfortable were men.

**Communication:** Overall, community focus group participants feel that doctors fail to answer their questions adequately. Importantly, one group noted a disconnect between what doctors and nurses say. Corroborating this finding, only 61 percent of survey respondents felt that their doctor listens to their concerns, and mostly men felt that their doctor does not listen to their concerns. Furthermore, 73 percent noted that their providers encouraged them to ask questions at least “sometimes” in the past year (see table below).

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Providers &quot;sometimes&quot; encourage questions</td>
<td>73%</td>
</tr>
<tr>
<td>Doctors listen to patient concerns</td>
<td>61%</td>
</tr>
<tr>
<td>Doctors &quot;usually&quot; listen to reason for visit</td>
<td>51%</td>
</tr>
<tr>
<td>Doctors &quot;sometimes&quot; use inaccessible medical jargon</td>
<td>35%</td>
</tr>
<tr>
<td>Doctors &quot;sometimes&quot; hard to understand</td>
<td>26%</td>
</tr>
</tbody>
</table>

**Provider Response:** When asked what doctors could do better to help them with their concerns, community members and focus group members noted that doctors should take

**Community leaders feel that the groups they work with are not particularly knowledgeable about healthy habits and wellness.**
their time, listen more intently, explain more adequately (e.g., medical jargon), increase evening availability, and have an awareness of discomfort surrounding finances. Twenty four percent of community member respondents specifically noted that their doctor serves them well. However, other respondents corroborated focus groups' concern about listening and not rushing. Explaining medical jargon and options as well as increased evening availability were also discussed.

Language and Interpretation

No consensus emerged among focus group participants on who interprets for the patient. Use of family members seems common, but patients also use services offered through the medical office. One group felt that “it is not an interpreter who speaks your language, it is a family member.” Overall, those who used a translator seemed satisfied. However, one group highlighted difficulty with translation in a medical setting. They felt that most professional interpreters often speak many languages (to save money) while failing to speak any one adequately. Furthermore, translation of medical jargon is unhelpful to patients, and translations by family members may be inaccurate. Little could be gleaned from the community member survey regarding this topic because only 6 percent of respondents utilize a translator.

5.2 Knowledge of and Attitudes about Cancer

Experience with Cancer

Eighteen (35 percent of) community member respondents have been told by a medical professional that they have cancer, and 48 respondents (94 percent) know someone who has had cancer. These data were not available for focus group members. However, this level of familiarity among community member respondents necessitates caution in interpreting findings related to cancer and cancer screening. This is because knowledge of and attitudes toward cancer and cancer screenings may be different merely because of level of exposure in this sample.

Perceptions of Cancer

Focus group participants first think of death when they hear the word cancer. Some also think about faith, uncertainty, and family. Overall, community member survey respondents seemed to first think of death and prolonged sickness.

Overall, community leaders felt that cancer is a topic that members of their community do not think too much about until it becomes an issue for them or someone they know. For instance, a leader who works with veterans felt that dealing with daily life is more important and that “screening is not at the high end of anything.” A leader who works with Portuguese immigrants mentioned that cancer is not at the forefront of the community they serve and that clients are overwhelmingly concerned with providing for their families.
Environment, lifestyle, and heredity were identified as main causes of cancer by community members. Leaders acknowledged that unsafe environments are a problem for some of the populations with which they work. For instance, a survey of K’iche’ Mayan community leaders revealed that some members of that community work in the unregulated “shadow economy” and are therefore more likely than the general population to be exposed to carcinogens at work. Social marginalization was also a concern expressed by Mayan leaders.

**Avoiding Cancer**

Diet, lifestyle, and screenings were identified by all community members as factors in avoiding cancer. Focus group participants added less stress and education about cancer to the list.

Focus group participants noted that cancer screenings are very important for protecting their health, and they expressed that early detection often saves lives. Corroborating this finding, 53 percent (27) of community member survey respondents noted that cancer screenings are “very important” to protecting one’s health. Furthermore, an overwhelming majority of respondents (43, or 84 percent) noted that finding cancer early saves lives. Despite these findings, the majority of leaders interviewed felt that the communities they serve are not knowledgeable about cancer screenings. Two leaders mentioned that this trend is due in part to a lack of regular physicals. One leader noted that some clients feel as though “the cure is worse than the kill.”

**5.3 Cancer Screening, Treatment, and Barriers**

**Screening Prevalence**

Little data were available from community member focus groups regarding cancer screening rates, but most reported they had cancer screenings in the past. Among female community member survey respondents, 41 percent have had a mammogram and 26 percent have had a pap smear within the last year. Eighty four percent of community member survey respondents have heard about colon cancer, and 49 percent have had a test done for colon cancer.

**Cancer Screening Barriers**

Lack of insurance, lack of knowledge, and cost were the primary reasons given by focus group members for why people fail to get recommended cancer screenings. Community members were able to select multiple answers for survey questions about screening barriers. The following table highlights barriers mentioned by at least 20 percent of community member survey respondents.
<table>
<thead>
<tr>
<th>Indicator</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fear of results</td>
<td>59%</td>
</tr>
<tr>
<td>Inadequate access to insurance</td>
<td>41%</td>
</tr>
<tr>
<td>Dislike taking medication</td>
<td>37%</td>
</tr>
<tr>
<td>Cost of out-of-pocket expenses (e.g., deductibles)</td>
<td>35%</td>
</tr>
<tr>
<td>Concern that test causes pain</td>
<td>33%</td>
</tr>
<tr>
<td>Doubts about screening efficacy</td>
<td>33%</td>
</tr>
<tr>
<td>Not taking care of oneself</td>
<td>33%</td>
</tr>
<tr>
<td>Inconvenient appointment times</td>
<td>31%</td>
</tr>
<tr>
<td>Difficulty taking time off from work</td>
<td>31%</td>
</tr>
<tr>
<td>Transportation issues</td>
<td>31%</td>
</tr>
<tr>
<td>Scarcity of time</td>
<td>29%</td>
</tr>
<tr>
<td>Not at age to worry</td>
<td>28%</td>
</tr>
<tr>
<td>Lack of information about screenings</td>
<td>26%</td>
</tr>
<tr>
<td>Lack of information about screening locations</td>
<td>26%</td>
</tr>
<tr>
<td>Uncomfortable discussing with doctor of opposite sex</td>
<td>23%</td>
</tr>
<tr>
<td>Difficulty finding doctor that takes their insurance</td>
<td>20%</td>
</tr>
</tbody>
</table>

A leader who works with homeless individuals noted the lack of stability as a reason that particular population does not get recommended screenings. One leader mentioned a cultural paradigm under which people wait to seek medical attention until absolutely necessary. As they put it, “if you don’t know about it, then you don’t have it.” Fear, lack of knowledge, lack of primary/family doctor, cost, doubts about the efficacy of screenings, and priorities such as work and family concerns were all mentioned as reasons that people fail to get recommended screenings. Leaders also recognized that fear of the negative effects of a cancer diagnosis on their family could keep some individuals from getting the screenings that they need.
Cancer Treatment Barriers

Focus group participants noted that not having insurance, cost, and lack of transportation were the primary reasons given for not receiving necessary treatment once diagnosed with cancer. Few community member respondents offered an answer to the interview question regarding barriers to treatment. The answers that respondents did offer included cost, having to take unpaid leave, no insurance, pain, ineffective treatment, and not taking care of oneself. One respondent noted: “Once I heard that I had cancer I didn’t hesitate getting treatment. I’m surprised this would be a problem for people. The treatment will keep you alive longer, so why wouldn’t you make that a priority?”

Following are the reasons identified by a majority of interviewed leaders for clients not receiving the cancer treatment they need. These include:

- Appointment times are not convenient
- Can’t take time off from work
- Child care issues and family obligations
- Concern that the test causes pain
- Cost of deductibles and other out-of-pocket expenses
- Cost of medication
- Difficulty finding a provider that accepts their insurance
- Lack of information about screening
- Language barrier
- No health insurance
- Not at the age to worry
- Not taking care of oneself
- Transportation issues
- Work and family serve as higher priorities

A focus group of providers (e.g., doctors, nurses, and counselors) acknowledged that care coordinators spend hours arranging transportation for patients. They also noted that cost serves as a significant barrier to both eating healthy and receiving medical care. Some are unaware of financial programs, and some live in abject poverty. For instance, Dr. Therese Mulvey, Physician in Chief, Oncology Services at Southcoast makes home visits each month. In her own words, “I am appalled at the depth of poverty of my patients. This winter I encountered a family who lived in a cottage in Wareham who could not afford heat and hung blankets on their walls to stay warm. As health care providers, we don’t often see this. We don’t understand the magnitude of their poverty. They’ve lost cars, homes, don’t have food. Cancer is just another thing on the list.”

Furthermore, leaders gave the following recommendations for increasing cancer screening and treatment: Offer free screenings and education, make available a mobile source of information and resources (e.g., a screening van), schedule quarterly on site screenings, offer screenings at “off hours,” outreach programs that are engaging,
Both focus group participants and survey respondents acknowledged the important role cancer screenings play in protecting their health.

“The treatment will keep you alive longer, so why wouldn’t you make that a priority?”

facilitate meaningful and culturally sensitive conversations, encourage participation from nursing students from local colleges, and use social media.

5.4 Health Information

Communication

Focus group participants indicated feeling comfortable discussing health issues with family members, friends, and church members or spiritual leaders. Thirty nine percent of community member respondents noted feeling comfortable talking about health issues with family members, 29 percent noted best friends, 29 percent noted a family doctor, and 18 percent noted religious leaders.  

Leaders reported that members of their community were comfortable talking about health issues to family members, friends, social workers, medical professionals, and community health workers. Half of them noted family members and friends. They also noted that social workers, religious leaders, case managers, food pantry staff, Veterans service organizations, family members, and elected officials all serve as advocates for the communities with which they are involved. A leader who works with veterans noted that they also utilize peer-to-peer advocacy. Half of the leaders thought these advocates could change the way people think about cancer screenings or could help people navigate around barriers. Two felt that these advocates could not help, and the remainder mentioned increases in capacity (e.g., too few advocates available).

Information Sources

Most focus group participants get their health information from the Internet or other media such as television and radio. Forty three percent of community member respondents get their health information from the internet, 33 percent from brochures, and 37 percent from television. Other responses (e.g. priest/pastor, word of mouth) received less than 20 percent support from respondents.

Leaders felt that their clients received health information from media, the Internet, professionals (e.g., case managers), and by word of mouth. Television was emphasized as influential by one leader, and another noted that their clients feel as though “if they hear it on TV it must be true.”

23 Other responses had less than 18 percent of support among respondents.
5.5 Reflections

Leaders provided some closing thoughts after conducting their interviews or focus groups. One lamented that healthcare is changing to “more of a business feel,” and they emphasized inadequate appointment length and a corresponding lack of consideration of emotions and the many questions that patients may have. Financial hardship and lack of transportation were also emphasized by some leaders at the end of their interviews, and another emphasized the need for more free screening events. Still another leader emphasized the need for more social workers and the importance of improving communication between medical staff.

A leader who works with the Immigrants’ Assistance Center (IAC) noted the importance of Community Health Workers and their trusted status in the community. Furthermore, they noted that sustaining funding is necessary in order to continue to provide this valuable resource to the immigrant community.

The leader of Dog Tags Navigators, which aids Veterans, noted the continued difficulty of working as an advocate, in his own words: “Unfortunately in our business there is no happy ending: just endless battles.” Furthermore, he highlighted the difficulty his clients face by noting that one individual went to 39 agencies and all of them failed to provide emergency shelter. Dog Tags is planning to focus on veterans struggling with cancer for their part of the phase two intervention plan. Furthermore, they are seeking registered nurses to supervise a team of UMass Dartmouth nursing students who will help veterans in need.

A Dog Tags Community Health Worker gave an overall summary of their experience interviewing community members. They noted that most of the people they talked to thought they would someday have cancer, and they all knew someone who had cancer. The CHW believes that fear of having cancer, lack of transportation, inconvenient times, screening cost, and the cost of potential treatment all deter interviewees from getting screened for cancer. The CHW also emphasized the importance of trust in facilitating interviews and that the difficult, busy lifestyle that many people currently face gets in the way of them staying healthy. A worker with Veterans Guardian Angels also emphasized the key role of trust and honesty in completing these interviews, especially in a population that has “had too many broken promises.”

A CHW at Greater New Bedford Community Health Center also noted concerns of health insurance cost and requirements. She noted that fear of being responsible for paying medical bills they cannot afford keeps some community members from going to the doctor. She reiterated that some community members feel that doctors are in a rush and fail to value their status as individuals. One leader she interviewed noted that his church needed to increase its level of knowledge of local resources. Overall, she noted that “fear, frustration, confusion, and lack of knowledge” contribute to the lack of screening among community members.
A worker with Veterans Guardian Angels also emphasized the key role of trust and honesty in completing these interviews, especially in a population that “has had too many broken promises.”

A CHW at First Baptist Church in Fall River noted that homeless individuals lose their benefits when they lose their address. This is especially problematic when these individuals are struggling with substance abuse and is perhaps a contributing factor to relapses. She also reiterated that some individuals are afraid of being diagnosed with cancer because it would have a negative effect on their families. Reflecting upon her experience as a CHW, she noted that “the more educated we are (CHWs) the more we can contribute to helping our communities live healthier and make more educated decisions for themselves with us as their guides.”

The Co-chair of the South Coast Community Health Worker Collaborative noted the unique and important role that CHWs play. In her own words, “as trusted and valued members of their communities, our area CHWs, and in particular, those CHWs and agencies involved in this Cancer Disparities Project, possess the lived experience and are part of the history of the communities that they now serve. Equally important, is that these CHWs, as well as the leaders from within these communities, are extremely knowledgeable about what resources are available, how best to access them and what resources are lacking and why.” She also noted that “…we need to build capacity of CHWs in our region if any meaningful work in terms of health equity and health access is to happen.”
APPENDIX A – FOCUS GROUP/SURVEY QUESTIONNAIRES

Cancer Disparities
Focus Group Facilitator’s Guide

Step 1: Ice Breaker Questions

Convene the group, welcome everyone, and let’s introduce ourselves. Can we go around and everyone say their first name, what neighborhood/town you live in and one talent that you have that many people don’t know you have?

Step 2: Read Introductory Script (below)

“Thank you for spending time with us today to share your story and experiences. I would like to share with you why we have invited you to talk with us today about your experiences and stories. The Massachusetts Department of Public Health has asked us to better understand the reasons for the high rates of cancer among different groups in Greater New Bedford. This project involves talking with people from the general community, people who have been diagnosed with cancer, providers, and community leaders who work closely in the communities affected. This helps us to gather information from different groups to better understand what is preventing people in our community from getting early detection and treatment.”

“Our time today will be spent hearing from you about your experiences and knowledge of getting cancer screenings and what you are hearing from other people within your families or friendship circles about this health concern. In addition, we are hoping to learn from you about any barriers that may prevent people from being screened for cancer or from receiving treatment.”

“Your participation in this focus group is completely voluntary and will not affect your benefits or the medical care you receive. All information you share will be kept confidential and will not be associated to you by name.”

We encourage you to share your thoughts and opinions openly and freely. But, please also be respectful of other participants’ opinions. At no time should you feel you have to answer a question.”

“We will be taking notes to make sure we have all the information you share. We are not recording your names. The information from our conversation will be summarized and provided to MDPH to use to improve cancer detection and treatment.

“Are there any questions about what I’ve just said, why we’re here, or what we are going to do today?”
Step 3: Answer Questions from Participants

Step 4: Confirm Consent to Participate

“Based on what we just shared, we want to confirm that each of you consents or agrees to participate in today’s discussion. Please read and sign the consent form that is being distributed to say “Yes” if you understand and wish to participate or “No” if you do not wish to participate, and you are free to leave before we begin.

“Are there any other questions?”

Step 5: Begin Discussion with Questions Below

1. **Health Literacy**

   1. What do you feel is most important for good health?
      
      **Probe:** How about things like exercise, diet, sleep, not smoking, regular visits to a doctor, religion, stress, being a good person?

   2. Who usually makes the health decisions in your family?

   3. Do you feel comfortable asking a doctor or other health provider a question or are you hesitant to express your concerns?
      
      **Probe:** Why are you hesitant or why do you have concerns?

   4. Do you feel that your doctor or other health provider listens to your concerns?
      
      **Probe:** Why do you think your doctor does not listen to your concerns?

   5. What can your doctor or other health provider do to better help you with your concerns?

   6. Do you feel that you could tell a doctor or nurse anything, even things that are very personal?
      
      **Probe:** Why not?

   7. Who usually interprets for you when you visit the doctor or health provider?
      
      **Probe:** For example, a family member, a nurse or medical assistant, clerk or receptionist from the office.

   8. For those who have used an interpreter, are you satisfied with the interpreter?
      
      **Probe:** Do you feel that the interpreter does a good job in communicating your concerns, or do you sometimes find it frustrating?

   9. Does your doctor or health provider answer all your questions to your satisfaction?
II. Knowledge and Attitude About Cancer

10. What’s the first thing that comes to mind when you hear the word cancer?

11. What do you think is most responsible for causing cancer?
   Probe: For example, smoking, your surroundings, heredity, diet, lifestyle, bad habits, poor nutrition where you work, where you live, being in the military.

12. What are some of the things you feel you can do to avoid getting cancer?

13. How important do you feel that cancer screenings are in terms of protecting your health?
   Probe: For example, would you say cancer screenings are very important, somewhat important, somewhat not important, not important at all?

14. How often do you feel that finding cancer early means that treatment saves lives?
   Probe: For example, none of the time, some of the time, most all of the time

III. Cancer Screening, Treatment, and Barriers

15. How many people here have ever had a cancer screening, such as screening for skin, breast, colon, or other types of cancer?
16. What are some of the reasons that you feel people don’t get recommended cancer screenings?

**Probes:** Possible responses are below, although there likely will be some mentioned that are not on this list. Use these lists as prompts. It is important that focus group members/key informants understand that this question is about cancer screenings. The cancer treatment question is below.

<table>
<thead>
<tr>
<th>Insurance/Cost</th>
<th>Structural Barriers</th>
</tr>
</thead>
<tbody>
<tr>
<td>• No health insurance</td>
<td>• Have more important priorities like work</td>
</tr>
<tr>
<td>• Difficulty finding a provider that accepts their insurance</td>
<td>• and taking care of family</td>
</tr>
<tr>
<td>• Deductibles/Out-of-pocket expenses too high</td>
<td>• Transportation issues</td>
</tr>
<tr>
<td>• Can’t afford medication</td>
<td>• Childcare issues/Family obligations</td>
</tr>
<tr>
<td></td>
<td>• Doctors and health professionals don’t speak their language</td>
</tr>
<tr>
<td></td>
<td>• Not enough time</td>
</tr>
<tr>
<td></td>
<td>• Appointments times are not convenient</td>
</tr>
<tr>
<td></td>
<td>• Can’t take off time from work</td>
</tr>
<tr>
<td>Information/Health Literacy</td>
<td>Cultural</td>
</tr>
<tr>
<td>• Don’t have enough information about cancer screening</td>
<td>• Shame or embarrassment about one’s body</td>
</tr>
<tr>
<td>• Don’t know where to go for cancer screenings</td>
<td>• Concern that the test causes pain</td>
</tr>
<tr>
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<td>• Cancer is a private matter and should not be</td>
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<td>issues with a doctor or nurse of the opposite sex</td>
</tr>
<tr>
<td>Behavior</td>
<td></td>
</tr>
<tr>
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<td></td>
</tr>
<tr>
<td>• Don’t like taking medication</td>
<td></td>
</tr>
</tbody>
</table>
17. OK, we just talked about cancer screenings. What are some of the reasons you feel prevent people from getting the cancer treatment they need, that is, once they've been told by a doctor that they have cancer and need to seek treatment?

   Probe: Use list above to probe if necessary.

IV. Health Information

18. Which person do you feel most comfortable with in talking about health issues?

   Probe: Is it a family member, friend, doctor, Community Health Center, Community Health Worker, nurse, social worker, church members, spiritual leader, pharmacist, priest/pastor/reverend/rabbi.

19. What other sources do you get your health information from?

   Probe: For example, health reports on TV, health magazines, Internet, hospital, ethnic media, i.e. radio, television, and print media in a non-English language

20. Does anyone have anything else to add?

Focus Group Description:

Date __________________________________________

Location _______________________________________

Number of focus group members _______________

General description of group (e.g. fishermen, Hispanic women, people who have had cancer)

___________________________________________
Cancer Disparities Facilitator’s Guide
Key Informant Interviews

Community Leaders

STEP 1. Intro: “Thank you for spending time with me today to share your story and experiences. I would like to discuss why we have invited you to talk with us today. The Massachusetts Department of Public Health has asked us to better understand the reasons for the high rates of cancer among different groups in Greater New Bedford. This project involves talking with people from the general community, people who have been diagnosed with cancer, providers, and community leaders who work closely in the communities affected. This helps us to gather information from different groups to better understand what is preventing people in our community from getting early detection and treatment.”

“Your participation in this project is completely voluntary. All information you share will be kept confidential and will not be associated to you by name.”

“We will be taking notes to make sure we have all the information you share. We are not recording your name. The information from our conversation will be summarized and provided to MDPH to use to improve cancer detection and treatment.

“Are there any questions about what I’ve just said, why we’re here, or what we are going to do today?”

Step 2: Confirm Consent to Participate

“Based on what we just shared, we want to confirm that you consent or agree to participate in today’s discussion. Please read and sign the consent form to say “Yes” if you understand and wish to participate or “No” if you do not wish to participate, and you are free to leave before we begin.

“Are there any other questions?”

Step 3: Key Informant Description:

Date of Interview __________________________

General description of the group that key informant works with, (e.g. fishermen, Hispanic women, cancer survivors, seniors)

______________________________

Step 4: Begin Discussion with Questions on Next Page

I. Health Literacy
(note: the questions in this section are about health in general, not cancer-specific)

1. Do you feel this group is knowledgeable about healthy habits and wellness, for example, the importance of exercise, nutrition, not smoking, regular visits to a doctor etc.?

   Probe: How do you think this group can become more educated about health and wellness?
2. Do you feel this group is comfortable visiting the doctor or other health providers?

_Probe:_ If no, why not?

What are some of the strategies that health providers can implement to help the people you work with to feel more comfortable? For example, do they need help navigating insurance or finding a doctor, is language an issue or are appointment times not convenient?

II. **Knowledge and Attitude About Cancer**

3. Overall, how does this group feel about cancer? For example, is it a topic they don’t think much about or is it an issue that is at the forefront of that community?

_Probe:_ Why do you think that is?

4. Overall, do you feel this group is knowledgeable about the importance of cancer screenings?

_Probe:_ For example, the age at which they should be screened, types of tests, what the tests involve?
III. Cancer Screening, Treatment, and Barriers

5. What are some of the reasons that you feel people in this group do not get recommended cancer screenings?

   Probe: Possible responses are below, although there likely will be some mentioned that are not on this list. Use these lists as prompts. It is important that focus group members/key informants understand that this question is about cancer screenings.

6. What are some of the reasons you feel prevent people in this group from getting the cancer treatment they need, that is, once they’ve been told by a doctor that they have cancer and need to seek treatment?

<table>
<thead>
<tr>
<th>Insurance/Cost</th>
<th>Structural Barriers</th>
</tr>
</thead>
<tbody>
<tr>
<td>▪ No health insurance</td>
<td>▪ Have more important priorities like work</td>
</tr>
<tr>
<td>▪ Difficulty finding a provider that accepts</td>
<td>and taking care of family</td>
</tr>
<tr>
<td>their insurance</td>
<td>▪ Transportation issues</td>
</tr>
<tr>
<td>▪ Deductibles/Out-of-pocket expenses too high</td>
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</tr>
<tr>
<td>▪ Can’t afford medication</td>
<td>▪ Doctors and health professionals don’t</td>
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<tr>
<td></td>
<td>speak their language</td>
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<tr>
<td></td>
<td>▪ Not enough time</td>
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<tr>
<td></td>
<td>▪ Appointments times are not convenient</td>
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<tr>
<td></td>
<td>▪ Can’t take off time from work</td>
</tr>
<tr>
<td>Information/Health Literacy</td>
<td>Cultural</td>
</tr>
<tr>
<td>▪ Don’t have enough information about cancer</td>
<td>▪ Shame or embarrassment about one’s body</td>
</tr>
<tr>
<td>screening</td>
<td>▪ Concern that the test causes pain</td>
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<td>▪ Don’t know where to go for cancer screenings</td>
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</tr>
<tr>
<td>▪ Not at the age to worry</td>
<td>sex</td>
</tr>
<tr>
<td></td>
<td>▪ Prefer natural/homeopathic treatment</td>
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</tbody>
</table>
7. What strategies would you recommend to increase cancer screening and treatment among members of this group?

IV. Health Information

8. Which person do you feel people in this group are comfortable with in talking about health issues?

   Probe: Is it a family member, friend, doctor, Community Health Center, Community Health Worker, nurse, social worker, church members, spiritual leader, pharmacist, priest/pastor/reverend/rabbi?

9. Who is generally the advocate for this community, that is, a person or group they turn to when they have an issue, even if it is not health related?

10. Do you think this advocate, whether a person or group, can play a role in getting people to think about the importance of cancer screenings or to help people navigate through obstacles and barriers that prevent screenings and treatment?

    Probe: How might this be accomplished?

11. From what other sources do people in your group receive health information?

    Probe: For example, health reports on TV, health magazines, Internet, hospital, ethnic media, i.e. radio, television, and print media in a non-English language

12. Do you have anything else to add?
Cancer Disparities Facilitator’s Guide
Key Informant Interviews
Community Members

STEP 1. Intro: “Thank you for spending time with me today to share your story and experiences. I would like to discuss why we have invited you to talk with us today. The Massachusetts Department of Public Health has asked us to better understand the reasons for the high rates of cancer among different groups in Greater New Bedford. This project involves talking with people from the general community, people who have been diagnosed with cancer, providers, and community leaders who work closely in the communities affected. This helps us to gather information from different groups to better understand what is preventing people in our community from getting early detection and treatment.”

“Your participation in this survey is completely voluntary. All information you share will be kept confidential and will not be associated to you by name.”

“We will be taking notes to make sure we have all the information you share. We are not recording your name. The information from our conversation will be summarized and provided to MDPH to use to improve cancer detection and treatment.

“Are there any questions about what I’ve just said, why we’re here, or what we are going to do today?”

Step 2: Confirm Consent to Participate

“Based on what we just shared, we want to confirm that you consent or agree to participate in today’s discussion. Please read and sign the consent form that is being distributed to say “Yes” if you understand and wish to participate or “No” if you do not wish to participate, and you are free to leave before we begin.

“Are there any other questions?”

Step 3: Begin Discussion with Questions Below

I. Respondent Background

1. In which city or town do you live? Note: We are only interviewing residents of the communities below:
   - Acushnet
   - Dartmouth
   - Fairhaven
   - Freetown
   - Marion
   - Mattapoisett
   - New Bedford
   - Rochester
   - Wareham

2. Which language do you speak most often?
   - English
   - Cape Verdean Creole
   - Spanish
   - Portuguese – Brazilian
   - Portuguese – Portugal
   - K’iche’ (Quiché)
   - Other ______________________________
II. Health Insurance and Doctor Visits

3. What is the primary source of your current health care coverage? Is it... [Please check all that apply]
   - None (no coverage)
   - A plan purchased through an employer or union (includes plans purchased through another person’s employer such as a spouse, partner, or parent)
   - A plan that you or another family member buys on your own (including insurance purchased through the Massachusetts Health Connector)
   - Medicare
   - Medicaid or other state program (including insurance purchased through the Massachusetts Health Connector)
   - MassHealth or ConnectorCare
   - TRICARE (formerly CHAMPUS), VA, or Military
   - Alaska Native, Indian Health Service, Tribal Health Services
   - Some other source (please specify) _____________________________
   - Don’t know/Not sure

4. If you purchased insurance from the Massachusetts Health Connector in 2014, did you remember to re-enroll for 2015?
   - Yes
   - No
   - Don’t know/Not sure

5. Do you have one person you think of as your personal doctor or health care provider?
   - Yes
   - No
   - Don’t know/Not sure

6. About how long has it been since you last visited a doctor for a routine checkup? A routine checkup is a general physical exam, not an exam for a specific injury, illness, or condition.
   - Within the past year (anytime less than 12 months ago)
   - Within the past 2 years (1 year but less than 2 years ago)
   - Within the past 5 years (2 years but less than 5 years ago)
   - 5 or more years ago
   - Don’t know / Not sure
   - Never

7. Do you go to the doctor just when you feel sick or do you also go for regular checkups?
   - Yes
   - No
   - Don’t know/Not sure

8. Where do you normally visit the doctor?
   - Private office
   - Hospital
   - Urgent Care Center
   - Minute clinic
   - Greater New Bedford Community Health Center
   - VA hospital
   - Other _________________________________
9. [For Veterans] When you visit the doctor or other health care provider, do they ever ask if you are a veteran?
   ○ Yes  ○ No  ○ Sometimes  ○ Don’t know/Not sure

10. [For Veterans] Have they ever discussed the adverse health effects of Agent Orange with you?
    ○ Yes  ○ No  ○ Sometimes  ○ Don’t know/Not sure

11. [For Veterans] Have they ever discussed the adverse health effects of Agent Purple with you?
    ○ Yes  ○ No  ○ Sometimes  ○ Don’t know/Not sure

III. Health Literacy
12. What do you feel is most important for good health (e.g. exercise, diet, sleep, not smoking, regular visits to a doctor, religion, stress, being a good person)? [Note: this question is about health in general, not cancer specifically].

13. Who makes the health decisions in your family?
    ○ I do  ○ Both equally  ○ Leave it to the doctor
    ○ My spouse  ○ Another family member  ○ Other _____________________

14. Do you feel comfortable asking a doctor a question?
    ○ Yes  ○ No  ○ Don’t know/Not sure

15. Do you feel that your doctor listens to your concerns?
    ○ Yes  ○ No  ○ Don’t know/Not sure

16. What can your doctor do to better help you with your concerns?

17. Do you feel that you could tell a doctor or nurse anything, even things that are very personal?
    ○ Yes  ○ No  ○ Don’t know/Not sure
18. An interpreter is someone who helps you talk with others who do not speak your language. Interpreters can include staff from the provider’s office or telephone interpreters. In the last 12 months, was there any time when you needed an interpreter at a doctor visit?

   ○ Yes   ○ No   ○ Don’t know/Not sure

[If yes] who was the interpreter you used most often?

   ○ A nurse or medical assistant
   ○ Clerk or receptionist from the office
   ○ An interpreter provided in person in this office
   ○ A telephone interpreter provided by this office
   ○ Someone else provided by this office
   ○ Other _________________________

[If no] who interpreted for you? Or do you not need an interpreter?

19. Are you satisfied with interpretation services at your doctor’s or health provider’s office?

   ○ Yes   ○ No   ○ Somewhat   ○ Don’t know/Not sure

20. In the last 12 months, how often did the doctors and providers you met with encourage you to ask questions?

   ○ Never
   ○ Sometimes
   ○ Usually

21. In the last 12 months, how often did the doctors and providers you met with listen to your reasons for the visit?

   ○ Never
   ○ Sometimes
   ○ Usually

22. In the last 12 months, how often did the doctors or providers you met with give you an easy to understand explanation about the next steps for any health questions or concerns you had?

   ○ Never
   ○ Sometimes
   ○ Usually

23. In the last 12 months, how often were the explanations this doctor or provider gave you hard to understand because of an accent or the way the provider spoke English?

   ○ Never
   ○ Sometimes
   ○ Usually
24. In the last 12 months, how often did this doctor or provider use medical words you did not understand?
   - Never
   - Sometimes
   - Usually

25. In the last 12 months, how often did this doctor or provider answer all your questions to your satisfaction?
   - Never
   - Sometimes
   - Usually

IV. Knowledge and Attitude About Cancer

26. What’s the first thing that comes to mind when you hear the word cancer?

27. What do you think is most responsible for causing cancer? (Prompts: smoking, your surroundings, heredity, diet, lifestyle, bad habits, poor nutrition where you work, where you live, being in the military)

28. What are some of the things you can do to avoid getting cancer?

29. How important do you feel that cancer screenings are in terms of protecting your health? Would you say cancer screenings are:
   - Very important
   - Somewhat not important
   - Somewhat important
   - Don’t know/Not sure
   - Not important at all

30. How often do you feel that finding cancer early means that treatment saves lives?
   - None of the time
   - Some of the time
   - Most all of the time
   - Don’t know/Not sure

31. Have you EVER been told by a doctor or other health professional that you had cancer or a tumor of any kind?
   - Yes
   - No
   - Don’t know/Not sure

32. Do you know someone who has had cancer?
   - Yes
   - No
33. How likely do you think it is that you will someday have cancer?
   - Very likely
   - Somewhat likely
   - Not very likely
   - Not likely at all
   - Don’t know/Not sure

V. Cancer Screening

34. Have you ever been screened for skin cancer?
   - Yes
   - No
   - Don’t know/Not sure

35. [For women only] Do you know what a mammogram is?
   - Yes
   - No
   - Don’t know/Not sure

35a. [If yes] Have you ever had a mammogram?
   - Yes
   - No
   - Don’t know/Not sure
   If Yes, how often do you have a mammogram? (Prompt: one a year, every two years, had only one in my lifetime).

36. [For women only] Do you know what a Pap smear or Pap test is?
   - Yes
   - No
   - Don’t know/Not sure

36a. Have you had a Pap smear or Pap test DURING THE PAST 12 MONTHS? Prompt: A Pap smear or Pap test is a routine test for women in which the doctor examines the cervix, takes a cell sample from the cervix with a small stick or brush, and sends it to the lab.
   - Yes
   - No
   - Don’t know/Not sure

37. Have you ever heard of colon cancer?
   - Yes
   - No
   - Don’t know/Not sure

37a. Have you ever had any test done for colon cancer?
   - Yes
   - No
   - Don’t know/Not sure
VI. **Barriers (Prevention, Detection, Treatment)**

38. **What are some of the reasons that you feel people don’t get recommended cancer screenings?**

   **Prompt:** Possible responses are below, although there likely will be some mentioned that are not on this list. Use these lists as prompts. It is important that focus group members/key informants understand that this question is about cancer screenings. The treatment question is below.

   **Insurance/Cost**
   - No health insurance
   - Difficulty finding a provider that accepts their insurance
   - Deductibles/Out-of-pocket expenses too high
   - Can’t afford medication

   **Information/Health Literacy**
   - Don’t have enough information about cancer screening
   - Don’t know where to go for cancer screenings
   - Doubts about whether screen is effective
   - Information is too hard to understand
   - Never was advised by a doctor to have one
   - Just don’t need to
   - Not at the age to worry

   **Behavior**
   - Not taking care of oneself (Descuido)
   - Don’t like taking medication

   **Structural Barriers**
   - Have more important priorities like work and taking care of family
   - Transportation issues
   - Childcare issues/Family obligations
   - Doctors and health professionals don’t speak their language
   - Not enough time
   - Appointments times are not convenient
   - Can’t take off time from work

   **Cultural**
   - Shame or embarrassment about one’s body
   - Concern that the test causes pain
   - Religious and/or cultural reasons
   - Cancer is a private matter and should not be discussed
   - Feel uncomfortable talking about health issues with a doctor or nurse of the opposite sex
   - Afraid of the results

39. **OK, we just talked about cancer screenings. What are some of the reasons you feel prevent people from getting the cancer treatment they need, that is, once they’ve been told by a doctor that they have cancer and need to seek treatment?** **Probe:** Use list above to probe if necessary.

40. **Which person do you feel most comfortable with in talking about health issues?**

   - Family member
   - Best friend
   - Gynecologist
   - Community Health worker
   - Nurse
   - Social workers
   - Family physician
   - Church members
   - Spiritual leader
   - Priest/Pastor/Reverend/Rabbi
   - Pharmacist
   - Other ______________________

41. **What other sources do you get your health information from? (Check all that apply)**

   - Health reports on TV
   - Health magazines
   - Internet
   - Hospital
   - Brochures
   - Priest/Pastor/Reverend/Rabbi
   - Ethnic media
   - Other ______________________
VII. Respondent Background

42. How old are you?
   O Under 18  O 45 – 64
   O 18 – 34  O 65 and over
   O 35 - 44

43. What is your gender?
   O Female
   O Male
   O Other (specify ____________________)
   O Unknown/not specified

44. What is your ethnicity? (You can specify one or more)
   O African (specify ____________________)
   O African American
   O American
   O Asian Indian
   O Brazilian
   O Cambodian
   O Cape Verdean
   O Caribbean Islander (specify______________________)
   O Colombian
   O Cuban
   O Dominican
   O European
   O Filipino
   O Guatemalan
   O Haitian
   O Honduran
   O Mayan
   O Mexican, Mexican American, Chicano
   O Middle Eastern (specify__________________________)
   O Portuguese
   O Puerto Rican
   O Salvadoran
   O Vietnamese
   O Other (specify______________________________)
   O Unknown/not specified

45. What is your race? (You can specify one or more)
   O American Indian/Alaska Native
   O Asian
   O Black
   O Native Hawaiian or other Pacific Islander
   O White
   O Other (specify______________________________)
   O Unknown/not specified

46. Are you Hispanic/Latino/Spanish?
   O Yes
   O No

47. What is your country of birth? _________________

48. How many years have you lived in the U.S.? _____

49. What is the highest degree or level of school you have completed?
   O Less than a high school diploma
   O High school graduate, no college
   O Some college or associates degree
   O Bachelor’s degree
   O Advanced degree (Masters, RN, PhD, JD, MD)

50. What was your total household annual income before taxes in 2014 (include all earners in your household)?
   O Less than $10,000
   O $10,000 - $24,999
   O $25,000 - $49,999
   O $50,000 - $74,999
   O $75,000 or more

51. What is your marital status?
   O Single
   O Married
   O Divorced
   O Widowed
   O Domestic partnership
   O Civil Union
   O Other

52. If married, is your spouse here with you in the U.S.?
   O Yes
   O No

53. Do you have children under the age of 18 at home?
   O Yes
   O No