



"My mother had cancer; my son is now in therapy for cancer...
the disease has affected my life in many ways."

- Translation of comment from Portuguese focus group



Cancer Disparities/Health Equity Strategic Planning Needs Assessment in Southeastern Massachusetts

FINAL REPORT



JSI Research & Training Institute, Inc.

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Comprehensive Cancer Prevention and Control Program
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EXECUTIVE SUMMARY

This needs assessment was conducted in Southeastern Massachusetts to assist in the Massachusetts Department of Public Health (MDPH)'s strategic planning to reduce cancer disparities and promote health equity for the region. The assessment was supported and guided by the MDPH Comprehensive Cancer Prevention and Control Program (MCCPCP) as a strategy in the 2012-2016 Massachusetts Comprehensive Cancer Prevention and Control Plan. In March 2013, JSI Research & Training Institute, Inc. (JSI), a nonprofit public health consulting company headquartered in Boston, was selected to carry out the assessment. Throughout the process, JSI and MDPH worked in collaboration with the Massachusetts Disparities/Health Equity Workgroup, comprised of leaders in cancer prevention and control for underserved populations in the Commonwealth.

There were two phases to the assessment: 1) selection of the region, and 2) identifying needs and opportunities to address cancer disparities.

In the first phase, data were analyzed to select a region/sub-region to be the focus of the Cancer Disparities/Health Equity Strategic Planning Needs Assessment. Southeastern MA was selected due to several factors. Among these were a number of disparities in cancer apparent from the recent data. The Southeastern region had higher incidence rates (new diagnoses) than Massachusetts as a whole for all cancers combined, as well as for lung and prostate cancer. Cancer was more frequently diagnosed at a late stage when it can be more difficult to treat and leads to higher mortality. More residents in the region were hospitalized for cancer, with breast, lung, and prostate cancer hospitalization rates higher than the state overall. Mortality was also higher in the region than in Massachusetts for all cancers overall and for lung cancer specifically. There were also cancer disparities by race and gender and a previous study identified disparities in income and education in the Southcoast region (comprised of towns in Bristol and Plymouth counties). Smoking was particularly common in Southeastern MA and it is a major risk factor for chronic diseases including cancer, diabetes, heart disease, and stroke.

In the second phase, JSI, with assistance from the Southeastern MA Regional DPH office, worked with individuals and organizations in the region to develop a broad understanding of the barriers and factors that lead to health inequity. The goal was to identify existing initiatives and how they could be advanced to better promote cancer prevention and control and general wellness in the region. JSI contacted local and regional stakeholder groups to gather information about regional cancer issues and resources. JSI conducted four focus groups with target populations that are at high risk of cancer and held key informant interviews and group discussions with members of area health coalitions, community health workers from cancer education and outreach programs, providers and administrators from health care organizations, and others providing community services in the region.

The process identified needs, priorities, and barriers to care, as well as recommendations for strategies or programmatic options to advance and help inform regional prevention

activities, ensure appropriate screening, and improve access to culturally competent, high-quality healthcare services.

JSI developed focus group facilitation guides, recruited participants with assistance from area organizations, facilitated groups, analyzed findings, and produced a final report. A total of 32 community leaders (including 9 community health workers and 11 key informants), 40 residents (11 Portuguese-speakers, 9 non-Hispanic Black men, 6 students in GED adult education classes, and 14 older adults), and 18 hospital and health center providers' perspectives and opinions led to the following key findings:

FINDINGS ON CANCER PREVENTION AND WELLNESS

- 1.** Multiple risk factors exist for cancer and other chronic diseases in Southeastern Massachusetts.
- 2.** Certain populations face higher cancer risks.
- 3.** General awareness of cancer prevention is limited among vulnerable, high-risk populations.
- 4.** Residents need more knowledge about the link between a healthy diet, physical activity, and reduced cancer risk.
- 5.** While progress is being made in cancer prevention and wellness activities, not all residents are being included and engaged.
- 6.** Social determinants of health including poverty, discrimination, and disparate access to safe and healthy environments pose significant barriers to prevention and wellness.

FINDINGS ON CANCER SCREENING AND TREATMENT

- 7.** Cultural and religious beliefs, access to information, ability to advocate for one's health—as well as discomfort and fear—affect the decision to get screening and treatment.
- 8.** Initiatives targeted to specific populations can increase screenings.
- 9.** Barriers to accessing treatment remain even with healthcare reform improvements.
- 10.** Challenges in the patient-provider relationship impact screening, treatment, follow-up, and quality of care.
- 11.** Health providers need updated guidance and continual support on cancer screening guidelines, insurance coverage, tertiary care systems, and availability of local services.

RECOMMENDATIONS BASED ON THE FINDINGS:

Near-term recommendations:

1. Expand on cancer prevention awareness campaigns in community, faith-based, and workplace settings.
2. Integrate cancer prevention more fully into wellness campaigns.
3. Engage those from under-served neighborhoods in wellness coalitions.
4. Use culturally-appropriate key messages and channels of communication to reach high-risk populations.
5. Employ evidence-based models—such as those that use social approaches to increase engagement of men in prevention and wellness programs and activities.
6. Hold peer-led cancer awareness discussion groups and fund stipends for community organizations to assist in outreach.
7. Educate youth and promote youth leadership in fostering cancer and wellness awareness among their families and communities.
8. Expand opportunities for physical activity in schools and senior centers.
9. Increase provider referrals for screening made during regular check-ups and at community settings.
10. Ensure patients are treated with care and respect.
11. Provide targeted outreach to engage indigent and incarcerated populations in cancer screenings.
12. Build capacity of community-based organizations to sustain prevention efforts.
13. Extend availability of cancer support groups and survivor resources.

Long-term recommendations:

1. Ensure access to affordable, healthy food.
2. Increase support for smoking and substance abuse prevention and treatment.
3. Facilitate health insurance reimbursement for community health worker cancer outreach services.
4. Collaborate to further develop resources/opportunities for cancer screening and treatment in areas where services are not accessible.
5. Support improving community infrastructure to enhance wellness in all neighborhoods.
6. Assist community leaders in addressing environmental and occupational health concerns.
7. Further the promotion of economic development.
8. Extend hours of social services to evenings and weekends.
9. Develop a more diverse and culturally competent healthcare workforce (doctors, community health workers, translators, psychologists, and grief counselors).
10. Address gaps in healthcare coverage to ensure access to screening and treatment for all populations.

INTRODUCTION AND BACKGROUND

Cancer is one of the leading health concerns that continue to pose a tremendous burden for vulnerable and underserved populations. It is a health concern that requires immediate and urgent action to improve the outcomes of this disease. According to the Massachusetts Cancer Registry (MCR), every day nearly 100 Massachusetts residents are diagnosed with cancer and 36 Massachusetts residents die of cancer, representing a quarter of all deaths. From 2005 to 2009, cancer was the leading cause of death in Massachusetts, and lung cancer was the leading cause of cancer deaths among all cancers.¹

Since Massachusetts is a diverse state with a wide range of local and regional population characteristics, factors such as ethnic and racial background, percentage of foreign and domestic born residents, language and literacy, and income and education levels all contribute to barriers in accessing health care and treatment.

Significant disparities persist in cancer prevention, incidence, hospitalization and mortality for certain populations, with particular racial and ethnic groups often disproportionately affected. Cancer is the leading cause of death for Blacks (both non-Hispanic and Hispanic), and Asians in Massachusetts. The same pattern holds for prostate cancer, for which Black, non-Hispanic men had significantly higher incidence and mortality rates than other ethnic groups. Among women, overall cancer incidence is higher among White, non-Hispanic women, but overall mortality is higher among Black, non-Hispanic women. The MCR reports this disparate mortality rate between Black and White, non-Hispanic women specifically for breast cancer as well. From 2005 to 2009, Black, non-Hispanic males had the highest incidence rate of all cancer types combined.

The 2012-2016 Massachusetts Comprehensive Cancer Prevention and Control State Plan prioritized strategies for the Commonwealth. Among these was to conduct a comprehensive community needs assessment in the most impacted region of Massachusetts. In March 2013, JSI Research & Training Institute, Inc. (JSI), a nonprofit public health consulting firm headquartered in Boston, was selected to carry out the assessment. Throughout the process, JSI and MDPH worked in collaboration with the Massachusetts Disparities/Health Equity Workgroup, comprised of leaders in cancer prevention and control for underserved populations in the Commonwealth.

There were two phases to the assessment: 1) region selection, and 2) identification of needs and opportunities to address cancer disparities.

¹ Cancer Incidence and Mortality in Massachusetts, 2005-2009: Statewide Report Massachusetts Cancer Registry; Massachusetts. Bureau of Health Statistics, Research and Evaluation. (Commonwealth of Massachusetts, Dept. of Public Health, Bureau of Health Statistics, Research and Evaluation, Massachusetts Cancer Registry, Dec, 2012.)

In phase 1, JSI, in collaboration with MDPH and the Disparities/Health Equity Workgroup, identified the Southeastern MA Regional Health District² as the focus of the Cancer Disparities/Health Equity Strategic Planning Needs Assessment. (Further details about the selection process are available in the Massachusetts Cancer Disparities Assessment: Priority Region Recommendations report).

The total population of Southeastern Massachusetts is 1,264,497 persons. Table 1 provides key population demographics for the Southeastern MA region.

TABLE 1: SOUTHEASTERN MASSACHUSETTS POPULATION CHARACTERISTICS³

POPULATION CHARACTERISTIC	SOUTHEAST MA	MASSACHUSETTS
Males	48%	48%
Under 18 years of age	22%	22%
65 years of age or older	16%	14%
Non-Hispanic Black	5%	6%
Hispanic	4%	9%
Portuguese ancestry	16%	5%
Speaks a language other than English	15%	21%
Less than a high school education	13%	11%
Living in poverty	9%	11%
Children living in poverty	13%	14%
Older adults living in poverty	8%	9%
Unemployment rate in Southeastern MA (which is higher than any other EOHHS region in the state)	8%	7%
Reports having insurance	97%	97%

Data sources: Demographics and socioeconomic data from 2007-2011 American Community Survey (ACS); Unemployment from December 2012 MA Executive Office of Labor and Workforce Development data; Health insurance from 2010 MA Behavioral Risk Factor Surveillance System (BRFSS).

² The Southeastern MA regional health district is among six regional health districts defined by the Executive Office of Health and Human Services (EOHHS). The six regions are (1) the Western region; (2) the Central region; (3) the Northeast region; (4) the MetroWest region; (5) the Boston region; and (6) the Southeast region.

³ JSI Research & Training Institute, Inc., *Massachusetts Cancer Disparities Assessment: Priority Region Recommendation*, March 20, 2013.

The phase 1 analysis using the MDPH Cancer Registry data found that the Southeastern region had higher incidence rates (new diagnoses) for all cancer combined, as well as for lung and prostate cancer than Massachusetts as a whole. Cancer was more frequently diagnosed at a late stage when it can be more difficult to treat, leading to higher mortality. According to MA Hospital Discharge Data, more residents in the region were hospitalized for cancer—with breast, lung and prostate cancer hospitalization rates higher than the state rate. Massachusetts mortality data show that mortality was also higher in the region than in Massachusetts for all cancers overall and for lung cancer specifically. There were cancer disparities by race and gender, while a previous study also identified disparities in income and education in the Southeastern MA region. Smoking is particularly common in Southeastern MA and is a major risk factor for chronic diseases including cancer, diabetes, heart disease, and stroke.

In phase 2, JSI worked with individuals and organizations in Southeastern MA to develop a broad understanding of the health needs, barriers, and other factors that lead to health inequity in the region.

To initiate the assessment, JSI met with Ron O'Connor, Director of the Southeastern MA Regional DPH, and Maria Evora-Rosa, the Regional Office's Community Liaison and Policy Coordinator. Both shared important context and contacts to begin a process of identifying regional stakeholders.

JSI engaged local and regional stakeholders through key informant interviews and group discussions to gather information about regional cancer issues and learn about ongoing initiatives and new opportunities to advance cancer prevention and control. JSI also conducted focus groups with target populations at high risk of cancer as well as discussion groups with hospital and community health center providers and members of other community organizations and coalitions working to address cancer and promote general wellness.

This report details the process and findings of phase 2 of the assessment and identifies needs, priorities, and barriers to care. It also offers recommendations for strategies or programmatic options to advance and help inform regional prevention activities, ensure appropriate screening, and improve access to culturally competent, high quality healthcare services.

METHODOLOGY

In conjunction with the MDPH Comprehensive Cancer Prevention and Control Program (MCCPCP), JSI identified key research questions and developed focus group, key informant interview, and provider round table facilitation guides around these questions (See *Appendices 1-3*). After recruiting participants for the groups, JSI conducted a series of focus groups, key informant interviews, and provider round table discussions between May and October 2013. A total of 32 community leaders (including 9 community health workers and 11 key informants), 40 residents (11 Portuguese-speakers, 9 non-Hispanic Black men,

6 students in GED adult education classes, and 14 older adults), and 18 hospital and health center providers participated.

RECRUITMENT

Maria Evora-Rosa and Ron O'Connor from the Massachusetts DPH Southeast Regional Health Office recommended many of the initial key informants to include in the assessment and provided JSI with their contact information. Each of the key informants was asked to provide additional referrals for other groups and individuals who should be included in the assessment. Helena DaSilva Hughes, Executive Director of the Immigrants' Assistance Center, Inc. in New Bedford, MA, should be especially recognized for her recruitment of participants for both of the groups that were held at the Immigrants' Assistance Center, Inc., including one with a group of mixed-gender Portuguese-speaking individuals and another with a group of community health workers.

FACILITATION GUIDES

JSI developed several focus group, key informant interview, and provider roundtable facilitation guides (See *Appendices 1-3*) that were tailored based on the location of the group (e.g., Southeastern coastal cities vs. Brockton) and the type of participants (e.g., providers, populations at high risk of cancer, or key informants such as religious leaders, environmental health activists, or leaders from community organizations). Focus group and key informant interview participants were provided with a data summary sheet compiled by JSI about cancer disparities in Southeastern MA (See *Appendix 5*) to provide context for JSI's selection of Southeastern MA for this needs assessment and to inform participants about the presence of specific cancer disparities in the region.

Consumers were asked to discuss the following topics in relation to: a) their own knowledge and perspectives, and b) What they have heard or learned from other people in their community:

- **General awareness and knowledge of cancer:** consumers' familiarity with cancer in general and different types of cancer.
- **Cancer prevention and modifiable risk factors:** how specific types of cancers develop and/or can be prevented, ways to reduce cancer risk, use of tobacco products, and the role of a healthy diet and physical activity in cancer prevention.
- **Cancer screening:** history of cancer screening among the consumer, family members and/or friends, signs and symptoms of different types of cancer, factors that make it difficult to get cancer screening, and recommendations for how to address barriers to cancer screening.
- **Cancer treatment:** barriers to cancer treatment and care services including factors that make it difficult for area residents to start cancer treatment, continue the full course of treatment, and access high quality treatment, how consumers would like

to receive information related to cancer prevention and care, and recommendations for how to address barriers to receiving high quality cancer treatment.

- Overall recommendations for the Massachusetts Department of Public Health to improve cancer screening, treatment, and follow up in Southeastern MA.

Key informants were asked to provide perspectives on the following topics:

- **General awareness** and knowledge of factors behind data showing cancer disparities in Southeastern MA.
- **Cancer prevention and modifiable risk factors:** perspectives on factors behind higher cancer incidence among Southeastern MA residents, risk factors for cancer and chronic diseases, how these risk factors differ in incidence among population groups with disparities, and recommendations for changes to address these disparities.
- **Cancer screening:** reasons for disproportionately high rates of late stage cancer diagnosis among Southeastern MA residents, issues and barriers related to screening, and recommendations to address these concerns.
- **Cancer treatment and survival:** reasons for higher cancer mortality among all Southeastern MA residents and men in particular, factors related to quality and access to care, cultural and religious factors related to health practices, and recommendations to address these concerns.
- **Other recommendations:** recommendations for the Massachusetts Department of Public Health to improve cancer screening, treatment, and follow-up with residents of Southeastern MA, recommendations for others whom JSI should speak with to learn about cancer disparities and strategies to address them in Southeastern MA.

Providers were asked to discuss the following topics:

- **General responses** to the data showing cancer disparities in Southeastern MA and whether or not they have noticed elevated cancer incidence among their patients.
- **Reasons for higher cancer diagnosis among Southeastern MA residents:** risk factors for cancer in Southeastern MA and the chronic diseases that are associated with these risk factors, how risk factors differ among population groups with disparities in incidence, other reasons that may account for higher cancer diagnosis and disparities among certain population groups, and recommendations for how to address these concerns and disparities.
- **Reasons for disproportionately high rates of late stage cancer diagnosis among Southeastern MA residents:** issues, facilitators, and barriers related to cancer screening and recommendations for how to address these factors.

- **Reasons for higher cancer mortality overall and particularly among men:** other factors in treatment and care other than late stage diagnosis, the role of access to quality treatment and care, trends and factors related to culture and religion, and recommendations to address these concerns.
- **Additional recommendations** for the Massachusetts Department of Public Health to improve cancer screening, treatment, and follow-up with residents.

Table 2 provides information on the date, location, and number of participants in each focus group or discussion group.

TABLE 2: SUMMARY TABLE OF FOCUS GROUPS AND PROVIDER ROUNDTABLES

DATE	LOCATION	NUMBER OF PARTICIPANTS
COMMUNITY LEADERS DISCUSSION GROUP (1):		
5/28/13	Voices for a Healthy Southcoast Committee (MDPH Southeast Regional Health Office)	13
COMMUNITY HEALTH WORKERS DISCUSSION GROUP (1):		
5/29/13	Community Health Workers (Immigrants' Assistance Center, Inc.)	9
CONSUMER FOCUS GROUPS (4):		
6/3/13	GED class (Bristol Community College)	6
6/25/13	Portuguese-speaking mixed-gender group (Immigrants' Assistance Center, Inc.)	11
7/18/13	Non-Hispanic Black men group (Brockton Neighborhood Health Center)	9
10/8/13	Senior citizens (Wareham Multi-Service Center)	14
PROVIDER ROUNDTABLES (2):		
9/18/13	Brockton Neighborhood Health Center	3
9/25/13	Greater New Bedford Community Health Center	15

On May 28, 2013, the first discussion group was held at the MDPH Southeast Regional Health Office in New Bedford with members of the Voices for a Healthy Southcoast Committee. The second discussion group was held on May 29th at the Immigrants' Assistance Center, Inc. with a group of community health workers (CHWs) from Coastline Elderly Services, Inc., the Immigrants' Assistance Center, Inc., and YWCA Southeastern Massachusetts. Four consumer focus groups were held with the following groups: 1) a GED class at Bristol Community College on June 3rd, 2) a Portuguese-speaking mixed-gender group on June 25th, and 3) a group of non-Hispanic Black men on July 18th, and 4) a group of senior citizens in Wareham on October 8th. The remaining two groups were held with providers at the Brockton Neighborhood Health Center and the Greater New Bedford

Community Health Center. The following table summarizes the types of participating providers:

TABLE 3: TYPES OF PROVIDERS

TYPE OF PROVIDER	N
Doctors (including one medical director and one assistant medical director)	7
Nurses (registered nurse, nurse practitioner, clerical nurse, nurse midwife, certified nurse midwife)	11
Total Providers	18

PARTICIPANT DEMOGRAPHICS

Participants in the focus groups were asked to complete a one-page demographic survey (see *Appendix 8*).

Among the 40 consumer focus group participants, 49% were over the age of 65, 23% were between the ages of 45-64, 18% of the participants were between the ages of 18-34, and 10% were between the ages of 35-44. 59% of the participants were female and 38% were male while 3% of participants did not specify their gender. Regarding their ethnicity, 26% of participants responded that their ethnicity was Portuguese, 21% were Haitian, 18% were American, 10% were Cape Verdean, 10% were European, 8% were Puerto Rican, 3% were African American, 3% were Honduran, and another 3% did not specify their ethnicity. 56% of the consumer focus group participants responded that they were white, 26% were black, 12% were “Other,” 3% were American Indian, and 3% did not specify their race. In response to the question “What is your country of birth?” 41% of consumer focus group participants said that they were born in the United States, 23% were born in Portugal, 18% were born in Haiti, 5% were born in Cape Verde, 5% did not specify where they were born, 3% were born in Ireland, 3% were born in Italy, and 3% were born in Puerto Rico. When asked “Are you Hispanic, Latino, Spanish?” 36% of the participants said “no,” 8% said “yes,” and 8% did not specify.

45% of the nine CHWs were between the ages of 45-64, 33% were between the ages of 35-44, and 22% were between the ages of 18-34. All of the CHWs were female. 44% of the CHWs responded that their ethnicity is Portuguese, 22% were Cape Verdean, 22% are Puerto Rican, and 12% were Dominican. 44% of CHWs responded that their race was “Other,” 34% were white, and 22% did not specify their race. 45% of the CHWs responded that they were born in Portugal, 22% were born in Puerto Rico, 11% were born in the Dominican Republic, 11% were born in Senegal, and 11% were born in the United States. When asked “Are you Hispanic, Latino, Spanish?” 67% of the CHWs said “no” and 33% said “yes.”

The following charts summarize the income, education, and health insurance status of consumer focus group participants. Fifty-one percent of participants had a total household annual income of less than \$25,000. Forty-seven percent of participants had less than a

high school diploma. It is noteworthy that ninety-five percent of participants reported having health insurance, yet as we discuss, several described barriers to maintaining consistent and adequate coverage.

(See *Appendix 9* for individual focus group participant demographics.)

FIGURE 1

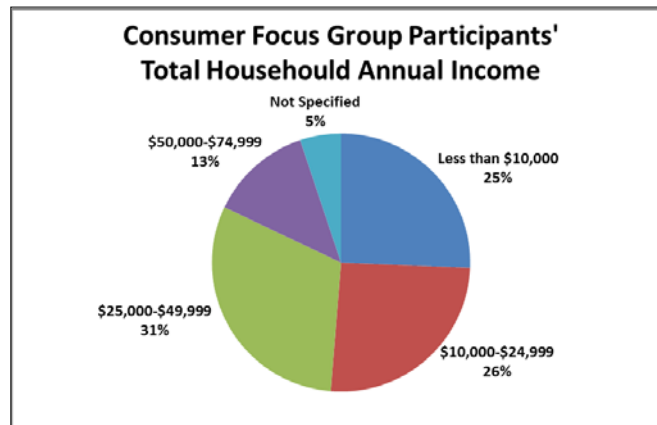


FIGURE 2

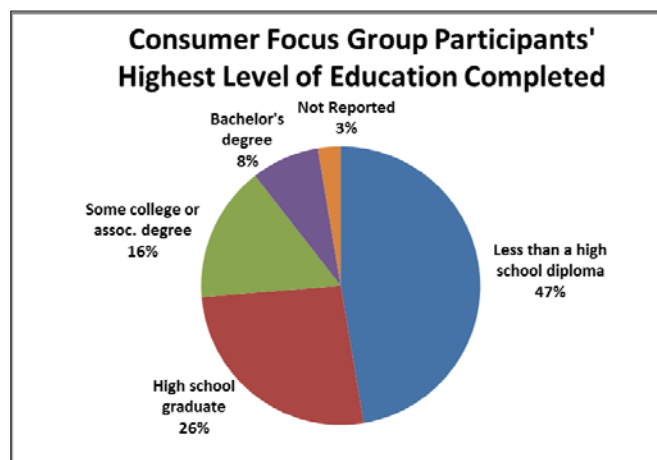
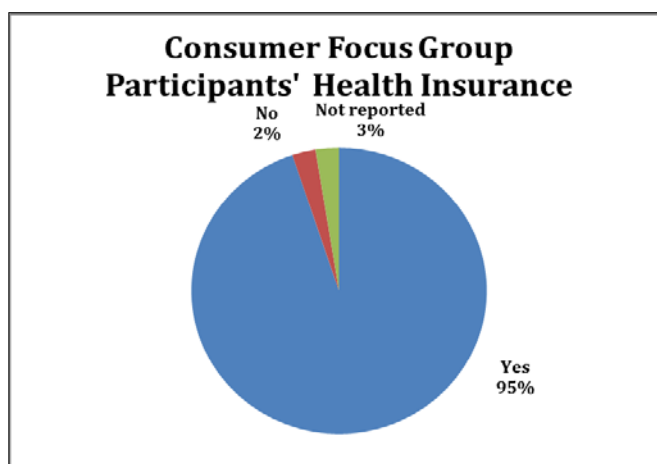


FIGURE 3



MAP OF FOCUS GROUP AND PROVIDER ROUNDTABLE LOCATIONS

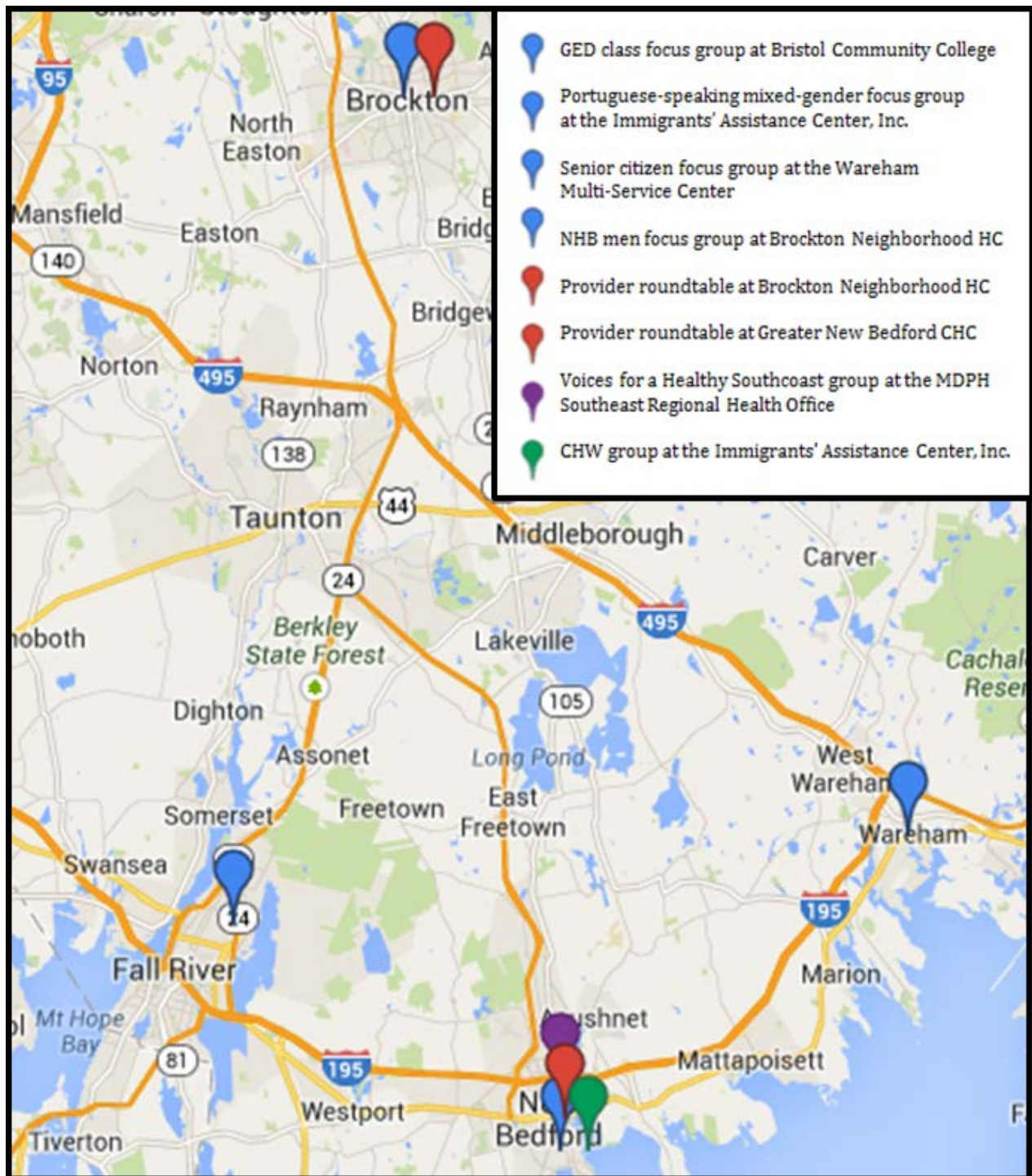


Table 4 provides information on the date and participants in each key informant interview.

TABLE 4

Date	Affiliation
KEY INFORMANT INTERVIEWS (11)	
5/10/13	Old Bedford Village Development Corporation
5/10/13	YMCA Cancer Outreach
5/13/13	Coastline Elderly Services
5/14/13	Brockton National Association for the Advancement of Colored People (NAACP)
5/15/13	Healthy City Fall River/Voices for a Healthy Southcoast
5/20/13	Brockton Neighborhood Health Center
5/28/13	Latin American Health Institute (LHI)
5/29/13	New Bedford Immigrants' Assistance Center
5/30/13	Southcoast Health System
7/23/13	YMCA Southcoast
7/23/13	Lead Hazard Control & Healthy Homes/Greater Brockton Asthma Coalition

LIMITATIONS

Although JSI has been able to identify several factors that may be affecting cancer disparities in Southeastern MA, results and findings have the following limitations:

- While JSI was able to gain valuable information from phase 2 interviews and discussions, the findings are qualitative not quantitative and there were a limited number of participants given time constraints for the assessment.
- The assessment focused on a range of different types of cancers across very different populations. There will be differences in other sub-populations and/or for specific cancers that JSI was unable to explore. JSI also looked at a range of factors from prevention (wellness, physical activity, and nutrition) through screening and treatment, so the findings provide a broad look at many different issues related to cancer disparities rather than greater details on any one aspect.
- The assessment was geographically limited due to limited resources,. JSI focused mostly on the cities within Plymouth and Bristol counties, while including Brockton as another major city in the region. There are other areas within the Southeastern MA EOHHS region that were not covered in the assessment, including Cape Cod. As there are town-by-town differences in cancer rates, it may be helpful to further explore other areas of Southeastern MA.
- The views expressed in this report are of the interview and focus group participants and are based on a small, non-random sample. Therefore, the findings do not necessarily represent the population as a whole.

SECTION I: CANCER PREVENTION AND WELLNESS

The findings have been categorized into two sections. The first section presents six findings that affect cancer prevention and wellness. Each of these is discussed, including a number of quotes that illustrate common themes. Following the six findings are recommendations offered by participants and those suggested by JSI to improve prevention and wellness. The second section of the report beginning on page 29 contains findings and recommendations regarding cancer screening and treatment.

FINDING 1: MULTIPLE RISK FACTORS EXIST FOR CANCER AND OTHER CHRONIC DISEASES IN SOUTHEASTERN MASSACHUSETTS.

The health and social service providers as well as residents interviewed detailed a number of concerns they believe may contribute to the high rates of cancer overall as well as specific types of cancer in the region. Some of these factors are reported to be more common in the Southeastern region than in other parts of the Commonwealth.

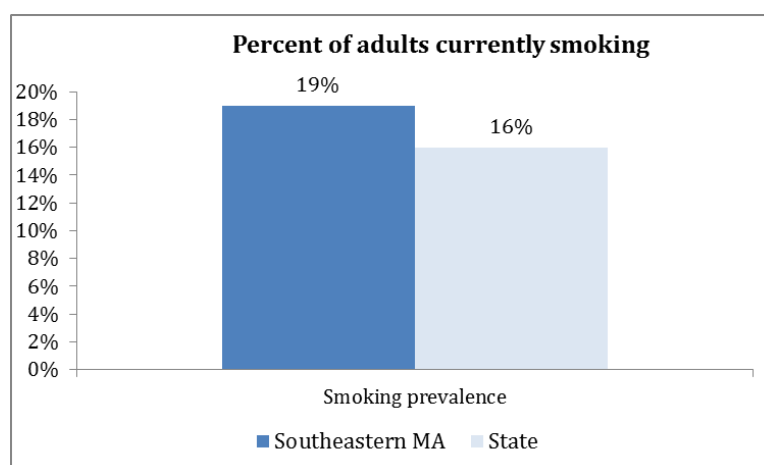
Among preventable risk factors mentioned of particular concern were smoking, alcohol and drugs, sun exposure, and cancer-causing agents due to environmental and occupational exposures. Participants cited social determinants of health including poverty, lack of employment opportunities, and a history of discrimination. These were considered to be drivers of many of the factors contributing to cancer disparities and health inequities.

This section summarizes the information that was shared about the nature and extent of each of these risk factors as described by residents, service providers, and experts who participated in the needs assessment.

FIGURE 4

Smoking: Smoking was recognized as a serious problem across the region. Phase I analysis found that Southeastern MA had significantly higher smoking prevalence than the state, Figure 4 (from 2008-2010 MA BRFSS). The non-Hispanic other race population, men and young adults had high smoking prevalence in Southeastern MA. Participants pointed to New

Bedford, Fall River, and Wareham as having among the highest prevalence of persons who smoke in the state. Smoking was described by service providers as being particularly prevalent among residents with low socioeconomic status (SES), men, Puerto Ricans,



Khmer, and African Americans—particularly those who had served in the military. Participants shared many reasons why residents initiate smoking and have difficulty quitting. These include starting smoking at a young age, growing up with parents who smoke, cultural acceptance of smoking, actors smoking in movies, and ongoing exposure to second-hand smoke from family members and/or smoke from other apartments in multi-unit housing.

Many of the residents who participated in the assessment were smokers, or had been former smokers. Most had tried to quit, and while some had succeeded in doing so, many had relapsed. They had often started young, at ages 12-13 and several mentioned that having parents who smoked influenced their decision to start. Health providers recounted seeing children who are even younger who already smoke cigarettes. They noted that while price increases may help cut down smoking rates, many roll their own tobacco to cut costs.

Residents were worried about the risks of cancer and mentioned being aware of, and/or having other conditions that were worsened by smoking, including difficulty breathing, asthma, heart disease, stroke, and worse colds. They claimed that pressure from others to quit doesn't help. Several who tried to quit did it on their own without support; especially Haitian men interviewed. Cessation classes were mentioned as being helpful by at least one senior in Wareham:

I took the class that was offered years ago in Wareham at the Town Hall. It was the best thing I ever did. I didn't think I was going to make it because I smoked like a crutch kind of thing. – Senior in Wareham

Women interviewed tended to attempt to quit with the support of nicotine-replacement patches and/or Chantix, although several found that both of these treatments made them sick and they expressed concern over side effects, such as increased risk of suicide.

Individuals who had tried but were unable to quit said that they were very upset with themselves, even though they knew it was hard to quit. Health providers suggested that they need to educate patients better on smoking as an addiction. They found it helps if they explain how receptor sites grow in the brain and how Chantix works on those receptors as well as to advise patients that if they get nauseous it is just that the dose is too high and needs to be adjusted.

We do a terrible job of really teaching people about smoking and about cessation. We still blame the smoker that it is a bad habit. It is a cellular addiction...When we explain that to patients it is so helpful. They break down crying...It's a chronic treatment that they need, it's not a quick intervention... and we don't get enough support on that. – New Bedford Health Provider

Living with, or visiting family members and others who smoke cigarettes or marijuana was mentioned as an obstacle. This was particularly difficult in multi-unit housing where many smoke, which also made them concerned for their children. Other reasons for

smoking included stress in their lives—including work and parenting, not having family support, and smoking provides a form of distraction.

The region was noted to have a history of strong initiatives that promote smoking cessation. Many health providers refer patients to free smoking cessation services offered through the MA Smoker's Helpline. Community-based tobacco initiatives intended to increase the effectiveness of existing programs were also discussed. For example, the new Community Transformation Grants (CTG) have been focused on community-based tobacco cessation including new smoke-free housing (targeting public and low-income multi-unit housing) and workplace initiatives. Further study could help identify which elements of the various initiatives to address smoking in the region have had the most impact.

Alcohol and drugs: Alcohol and drugs are also substances that can increase risk of cancer. While described as prevalent, there was not as much focus on the role of these substances in cancer prevention initiatives. Community health workers (CHWs) who provide outreach services on cancer noted that alcohol is seen as a way of reducing stress and can be tied to important cultural factors that vary among residents, such as traditions involving making wine among the Portuguese. Health providers observed that smoking cessation does not seem to be linked to substance abuse programs, and that they have patients who started smoking during treatment for other addictions.

Drugs were a strong concern raised by resident advocates. The use of drugs with severe health consequences and addictive properties, including Oxycodone, heroin, and the relatively new and dangerous “K2,” otherwise known as synthetic marijuana or “spice,” were said to be very prevalent in the poorer neighborhoods of New Bedford, with K2 being especially popular among youth. Health providers recounted that smoking marijuana is very common among their patients. A neighborhood advocate from Old Bedford Village expressed that the Department of Public Health (DPH) and regional programs that address only smoking and diet are ignoring the devastation drugs cause to residents and neighborhoods, which they observed as having lasting, intergenerational impacts.

Sun: Southeastern MA is an area with many outdoor occupations and activities that can increase risk of sun exposure, a major risk factor in skin cancers. Several residents were aware that sun exposure is a risk factor for cancer; one mentioned losing a family member to the disease. CHWs working with fishermen (noted to be a common occupation of immigrant workers largely from Latin America) who are continually exposed to the sun, have found that the men do not tend to use sunscreen and do not focus on self-protection as they feel that lotions are for women. Many men and women were reported to not put on sunscreen because they want to tan and think that if they do tan, they don't need sunscreen.

Just like going to the beach and they think if they tan, they don't need it [sunscreen]...or they want to get tan—cosmetics is more important than your actual health. - Fall River GED focus group participant

Worker exposure: Occupational health was also described as often entailing cancer risk, particularly for immigrants, those who are low-income, and those with less education. Participants noted the concentration of factories, which were large employers in Fall River, New Bedford, and Brockton and felt these factories exposed workers to cancer-causing substances (carcinogens). Occupations involving pesticides were noted as common. Many people currently work as landscapers and employment in cranberry bogs was reported as a common form of employment in families for many generations. Health providers believed that exposures in these occupations could affect the high cancer rates among older populations. Additional occupations mentioned as common include cleaning, housekeeping, welding, and construction, which can entail exposure to toxic chemicals.

Many people from the area work in factories, or if you live close it might be dangerous. - Fall River GED focus group participant

Environmental contamination: Environmental advocates, along with residents, health providers, and a number of other key informants, expressed concern that Southeastern MA contains areas with an extensive history of contamination. Point (factories, power plants), mobile (diesel boats, trucks, cars), and nonpoint sources of pollution (farming, hazardous waste sites) were described. Some of these sources of pollution have ended and the contamination has been mitigated (cleaned up or otherwise addressed), while a number remain active concerns. Study participants believe these contribute to cancer disparities and pointed out exposures that are either more common or less likely to be addressed in low-income, minority neighborhoods.

Participants talked about factories in the area that they believed had resulted in hazardous waste sites. Some have been cleaned up, but others remain unaddressed, especially in poorer neighborhoods and also within densely populated residential areas. The Old Bedford Neighborhood Association expressed strong concern regarding conversion of factories into low-income housing without proper remediation (clean-up) of the contaminated land and buildings. Advocates from Healthy City Fall River noted that pollution from ongoing industrial releases should be explored for potential contributions to cancer disparities.

I associate cancer with environmental health. It is my view that it is caused by environmental health, not just smoking. I am adamant that a majority of cancers for young and old are due to the environmental issues in our city. Until we get a public health department in our city and our state willing to address these issues, it will never be solved. - Community advocate key informant

Historical contamination that left extensive PCB contamination in New Bedford, including on land where schools were sited, was mentioned by several participants to be a risk for the students and teachers who had been at those schools. While identifying the environmental risks across the region was beyond the scope of this assessment, a conversation with the Toxics Action Network noted that area residents have been organizing to address issues that include the Pilgrim nuclear power plant, the Brayton Point coal-fired plant, and area landfills. (Note: more information on environmental health assessments in the region is available from several sources including: the MDPH Bureau of

Environmental Health; the Massachusetts Department of Environmental Protection; the U.S. Environmental Protection Agency, Region I; and the Agency for Toxic Substances and Disease Registry).

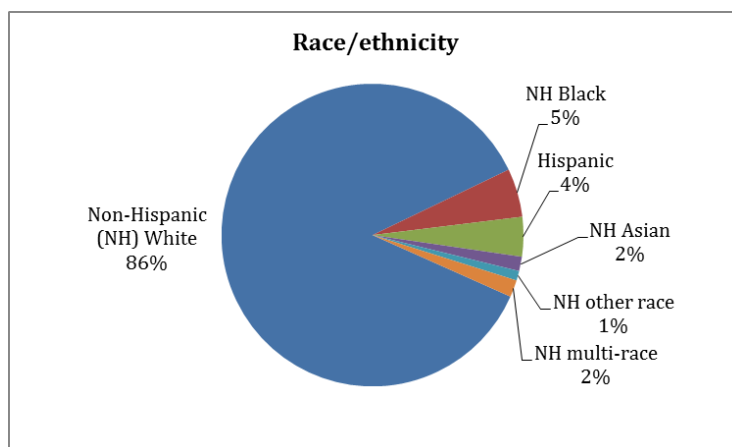
Other risk factors: There are several other cancer risk factors, such as inherited family risk and aging, which were not part of this assessment. Physical activity, nutrition, and general wellness can also help to prevent cancer development, and these are discussed later in this report.

FINDING 2: CERTAIN POPULATIONS FACE HIGHER CANCER RISKS.

Southeastern Massachusetts is home to very diverse populations, necessitating well-targeted, linguistically and culturally appropriate efforts to improve cancer and chronic disease prevention and control. This section discusses the high-risk populations that were identified in the needs assessment. During discussions, participants were asked to identify populations they believe are at particularly high risk of cancer. The following diverse populations were mentioned.

Racial and ethnic groups: Figure 5 depicts the racial and ethnic composition of Southeastern Massachusetts (from 2007-2011 ACS):

FIGURE 5



Below, by location, are racial and ethnic groups mentioned by participants to be at high risk of cancer or cancer risk factors. See the Phase I Report for demographic data. Note that this list is not comprehensive and that there are a number of subgroups from different backgrounds and nationalities within these racial and ethnic groups.

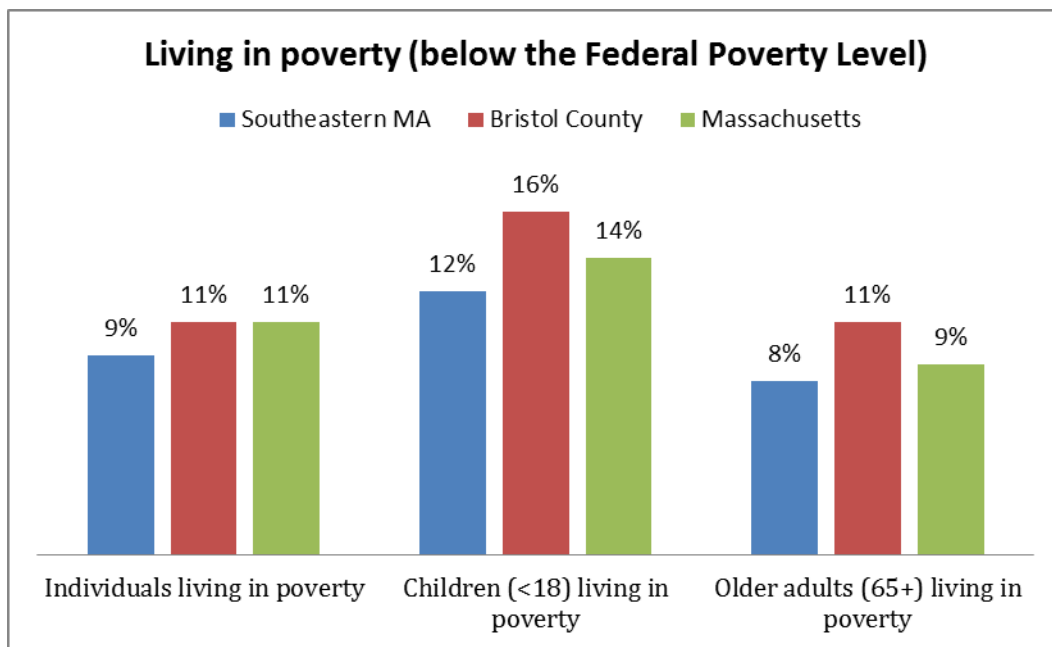
- o **New Bedford:** Latino (Puerto Rican, Central American), Portuguese-speaking (Cape Verdean, Portuguese), Asian, African American.
- o **Fall River:** Puerto Rican, Central American, Portuguese-speaking (Brazilian), Khmer.

- o **Brockton:** Cape Verdean, Haitian, African Americans.

Gender: Men were more likely to engage in high-risk activities like smoking, and were less likely to seek health services.

Low-income: Widespread poverty and unemployment were described as important drivers of disparities and inequity. Figure 6 indicates poverty in the Southeastern MA region alongside data from Bristol County which shows much worse economic conditions and Massachusetts as a whole (from 2007-2011 ACS). While poverty in the region falls below state rates, Bristol County rates are higher. *Finding 6* (page 27) provides further information about concentrated areas of poverty and unemployment that are even greater within Southeastern MA cities.

FIGURE 6



Limited education: The level of education is low in the region and there are very high drop-out rates in area cities. This affects access to resources and health information. *Finding 6* (page 27) provides more details on how the lack of education creates barriers to prevention and wellness.

Prisoners: Women in prisons were noted as not getting cancer screenings and needed treatment.

Those with multiple health concerns: Having several chronic diseases as well as having physical and/or cognitive challenges was described as common and particularly challenging for navigating needs around cancer prevention. Clinicians observed greater smoking in this sub-population. Those with mental health conditions were noted to

comprise 15-20% of the Fall River population and a large proportion of New Bedford and Brockton residents as well. Many residents are receiving disability assistance.

Language and literacy: The ability to obtain and use health information was noted by participants to be strongly affected by language and reading abilities. The primary language of residents varies widely. We spoke with Portuguese-speaking residents from Cape Verde and Brazil; French-speaking Haitian men, Puerto Ricans as well as Spanish-speaking CHWs who work with immigrants from Mexico and other Central and South American countries. Many other languages are spoken, highlighting the need for outreach and services in many languages. Spanish-speaking residents pointed out that they receive improperly translated health information materials, which makes it confusing to read. Literacy can also present a challenge for those speaking English and other languages, particularly when residents are presented with complex health information or instructions for medications and care.

Culture: Culture appears to impact cancer risk factors. Asian men in the region have particularly high rates of lung cancer and Khmer men, for example, were noted to have high rates of smoking, which was described as being integral to their lives and particularly difficult to shift. Puerto Rican men were similarly described as heavy smokers. The presumed right to smoke by “patriarchs” was found to make it difficult for initiatives to curb second-hand smoke exposure for family members. While children were said not to smoke in Puerto Rico, once in the U.S., participants claim that many youth smoke; more so than those from other Spanish- or Portuguese-speaking backgrounds.

The value of culturally appropriate outreach and services was apparent and not simply limited to translation services. Residents described several cultural factors that impact their choices affecting health and the services that they seek- or not. CHWs and their supervisors described many benefits of outreach that is tailored to specific cultures and delivered by those within the community.

FINDING 3: GENERAL AWARENESS OF CANCER PREVENTION IS LIMITED AMONG VULNERABLE, HIGH-RISK POPULATIONS.

While several residents told us that cancer had affected their family members and were aware of the most common types of cancer, many residents told us that they did not have much information on causes or how different types of cancer develop.

My mother had cancer; my son is now in therapy for cancer... the disease has affected my life in many ways. – Translation of comment from Portuguese focus group participant

I'm not sure how to prevent cancer; I don't know a lot more than that it kills people. – Translation of comment from Portuguese focus group participant

During focus group discussions with residents, it became clear that cancer was not a topic that was often discussed. Stigma and fear were apparent; yet residents welcomed the

opportunity to participate in discussions to learn more about cancer. Health providers noted that many patients do not know about their family history for cancer.

When I hear the word “cancer” I think of “fear”. My mother passed away from cancer.
– Senior in Wareham

There is a lot of ignoring it. People don’t want to know and it’s based on fear. If I hadn’t worked in healthcare and seen people I might have been just the same.
– Senior in Wareham

There was confusion between the concept that some cancers could be successfully treated if caught early through screening and the idea that some types of cancer can actually be prevented entirely. While there is awareness that smoking can cause cancer, some did not believe that fact because they know smokers who have lived cancer-free. Other residents relayed that if you do not smoke, you will not get cancer. They did not realize that while not smoking will reduce your risk, one can still get cancer.

It’s hard to say if smoking causes cancer... some people smoke and get cancer and others smoke and don’t get it... you can’t really say if smoking increases your risk for cancer. It is very difficult to generalize about the causes of cancer. – Translation of comment from Portuguese focus group participant

While many residents were aware that there are multiple risk factors for cancer, others thought that only smoking-related cancers and skin cancer could be prevented. The CHWs, who are conducting cancer outreach, were quite knowledgeable. Yet even they were unaware that alcohol is a risk factor for certain types of cancer including breast, stomach, and oral cancers. While some infectious diseases, such as HIV and human papilloma virus (HPV), can increase risk of cancer, these factors were not mentioned. Adult education students shared concerns that germs from sharing cups could cause cancer, which is not a known risk. Seniors in Wareham also thought that you could catch cancer directly from being near those with cancer.

Both residents and CHWs find that the recommendations to reduce cancer risk can be overwhelming. Some were tempted to say that there is too much to worry about and one should just enjoy life and not curtail what is enjoyable.

Information about cancer so often contradicts itself and isn’t consistent.
– Translation of comment from Portuguese focus group participant

These days it seems like just about everything causes cancer. – Translation of comment from Portuguese focus group participant

Several participants whose backgrounds varied across racial and ethnic groups noted the belief that cancer is really a matter of fate, which cannot be changed, while some expressed that religious faith is most important.

Prayer helps, faith, de-stressing yourself. – Senior in Wareham

It's something that you just have to leave in God's hands. That's what I say.
– Fall River GED focus group participant

Many residents view destiny from a religious perspective: If God's going to take me I already have my destiny. – CHW

Participants noted that they had learned about health information from media campaigns.

Men can get breast cancer too and I would have never known that when I was younger. I found that out on the TV/news. – Senior in Wareham

"I think the anti-tobacco campaign when it first started out was a big tipping point... it's bringing awareness to the public." The lady with the tracheotomy on TV (and magazines back in the 80s). "Before you used to be the odd guy out if you didn't smoke, then it tipped."

FINDING 4: RESIDENTS NEED MORE KNOWLEDGE ABOUT THE LINK BETWEEN A HEALTHY DIET, INCREASED PHYSICAL ACTIVITY, AND REDUCED CANCER RISK.

A healthy diet, maintaining a proper weight, and regular physical activity can reduce the risk of cancer and other chronic diseases. Residents tended to value fitness and nutrition yet do not know that they can affect cancer risk. They shared information about their approaches to food and physical activity.

Education and awareness: Residents are not fully aware of the impact of physical activity and diet upon cancer. Participants felt that people understand that exercising and eating fruits and vegetables can generally improve health. However, many were not aware that poor diets, obesity, and lack of physical activity increases the risk of many types of cancer. When asked whether exercising and a healthy diet or lifestyle can help prevent certain types of cancer, some residents were adamant that they would not. It seems that having known people who led healthy lifestyles yet still got cancer (and conversely those who were not so careful but never got cancer) made it seem impossible, even insulting, to suggest that lifestyle could affect cancer risk.

Those things prevent cancer? No absolutely not. My family did everything and cancer has still affected us in so many ways. – Translation of comment from Portuguese focus group participant

They say that diet and exercise can help prevent cancer but my 85 year old grandmother has done neither of those things and she's never had cancer. I also knew a 14-year old who did everything right and died from cancer. It seems to me that the more you do to prevent getting cancer the more likely you are to get cancer.
– Translation of comment from Portuguese focus group participant

How many people never smoke and never drink alcohol who still get cancer? I've seen people take all sorts of vitamins and eat good things and it doesn't help.

– Translation of comment from Portuguese focus group participant

Others were open to the possibility that a healthy diet and physical activity can prevent cancer:

Maybe they could help with preventing cancer. – Translation of comment from Portuguese focus group participant

I don't know if exercise helps with preventing cancer, but it definitely helps with the health of other parts of your body generally. – Translation of comment from Portuguese focus group participant

What I've learned is that you can get cancer from many things. You can get it from the environment. There are many chemicals that give you cancer. If we don't eat right, you can get cancer. – Haitian men's focus group participant

Approach to food: Residents' approaches to diet and physical activity are affected by many factors. Participants shared a number of cultural factors that can affect diet. While some noted that traditional food in countries of origin often included more vegetables and few desserts, Portuguese and Spanish-speaking populations were recounted by CHWs as tending to cook in oil/lard and salt, and for some groups, vegetables are rarely included. CHWs said that it can be seen as offensive to suggest changes in people's diets or for guests or family members not to eat what is offered.

Haitian men described how healthy their traditional diet is and while they preferred to maintain that in the U.S., sometimes it was hard to do so as lifestyles change and there is reduced access to farm-fresh food:

Haitian food always has a lot of vegetables on the plate.

Haitians who move to America eat the same food and the same way. They try to be healthy.

Some men have problems with women in this country when they move here. You know, we are used to eating fresh food all the time. We don't like to eat leftovers. No way. And, women here sometimes they cook food one day, and don't cook for three days.

Seniors who grew up in America also described a cultural shift over time away from fresh, healthy foods. Several discussed having grown their own vegetables and having local goats milk and farms nearby when they were growing up that no longer exist.

Community-based organizations including health and service providers noted that young people do not tend to cook because they do not know how, have no time, and/or prefer fast foods. They noted the increase in fast food portion sizes as a factor. They also found it frustrating that institutions, such as after-school programs, assume that children will not eat healthy food and so serve unhealthy foods even when asked by those promoting wellness to serve healthy options.

Residents noted very different perspectives on barriers to healthy eating:

Living with my mother, I realized that she was aware of cancer. She was conscious about it. She ate healthy as much as she could. With my cousins it's different. They eat terrible. They know about cancer, but they don't really care about it. They eat fast food all the time. No vegetables. – Brockton Haitian men's focus group participant

For some people it's difficult to get around without vehicles and so they just walk to the closest thing, which is McDonalds. – Fall River GED focus group participant

Some turn to potentially dangerous options. Several women who wanted to lose weight to improve their health were planning to have bypass surgery. One noted that she had found information about bypass surgery through searching videos on YouTube.

Approach to physical activity: Several factors also shape residents' approaches to physical activity. Seniors who grew up in Wareham observed that they didn't have cars and so used to walk everywhere as children. Community-based organizations noted that people who were active in their countries of origin no longer walk very often. They are not used to organized sports and using a gym, although others noted that immigrant men tend to use bicycles for transportation and may perform work that entails physical activity. They further observed that "children don't know how to play." Among other barriers mentioned were the cold New England weather and not having enough time outside work or other obligations. CHWs have found that a doctor's advice to engage in physical activities may be heeded. Community physical activity initiatives, such as those offered by Healthy City Fall River, have had growing participation over the years. Despite this, some said they do not participate because there are costs involved in joining and so they just walk on their own.

Haitian men explained that they tend to engage in a lot of physical activities. A limiting factor was time due to work obligations.

People exercise but they work many hours.

Sometimes we are too busy to exercise. We have to work to make money to pay the bills.

FINDING 5: WHILE PROGRESS IS BEING MADE IN CANCER PREVENTION AND WELLNESS ACTIVITIES, NOT ALL RESIDENTS ARE BEING INCLUDED AND ENGAGED.

Integrating cancer prevention and control into general health wellness activities can foster awareness about the links between healthy diet, increased physical activity, and reduced cancer risk. Southeastern MA has a number of well-planned outreach efforts that engage multiple partners in cancer awareness and general wellness. Some of these have demonstrated success in engaging high-risk populations in prevention and wellness activities. Even with such success, however, they can be difficult to maintain because funding streams fluctuate. Community advocates working in some of the most distressed neighborhoods are not included as partners in some of the larger initiatives that have more stable funding. Feedback on several different types of initiatives is discussed below.

Wellness initiatives: Collaborative initiatives to advance wellness exist in the southeastern cities included in this assessment. Strong partnerships have developed with very active and committed members from diverse healthcare, public health, and community organizations. Voices for a Healthy Southcoast is one collaboration with whom we held a group discussion. Several of the collaborating organizations are engaged in broad community initiatives, including Healthy City Fall River, which has been active since 1993, and new initiatives under Mass in Motion—supported by a major Community Transformation Grant (CTG) obtained in 2013. The CTG partners are implementing new smoke-free public housing and workplace initiatives.

Peer outreach: Important resources include a number of trained community health workers who are conducting cancer and wellness outreach through initiatives of the YMCA in public housing and workplaces in Fall River, New Bedford, and Wareham; Coastline Elderly Services for seniors; and the Immigrants' Assistance Center, Inc. for New Bedford area residents from diverse racial and ethnic backgrounds.

Trained CHWs are encouraging healthier traditional foods and physical activity, providing health information, and helping individuals navigate their healthcare. In Brockton, CHWs are performing case management, education in the HIV clinic, and run patient groups for Haitian, Cape Verdean, and Spanish clients that focus on healthy lifestyle and chronic disease. Brockton Neighborhood Health Center reported success in promoting prostate and cervical cancer awareness using peer outreach; yet these initiatives ran out of funding (*see Finding 8, page 40*). Providers at the Brockton NHC pointed out that more could be done if CHW services were billable, rather than grant supported.

Marginalized communities: Despite such efforts, organizations working directly in high-risk New Bedford communities voiced their opinion that they are marginalized from grant funding and commented that meetings are held far away and therefore are difficult to attend. They claim that services and improvements are not targeted at the most pressing needs of the highest-risk neighborhoods.

Referral to smoking cessation: According to health providers, Fall River and New Bedford hospital-based providers often refer patients to the MA Smokers Helpline for smoking cessation services through strong partnerships with Southcoast Hospital. Providers at the Greater New Bedford CHC use a new in-house cessation center as well as the MA Smoker's Helpline for those who have difficulty coming into the center. These clinicians also requested more information about chronic nicotine replacement therapy. They noted that some clients (particularly mental health patients) may need lifelong treatment and they would like more support on that process while they recognized a need to move away from blaming smokers for bad habits and recognizing that smoking is a very difficult addiction to overcome.

Several New Bedford health providers lamented that their patients rarely show up for referred local smoking cessation classes. One key informant mentioned a missed opportunity when patients who quit during a hospital stay are not provided with nicotine replacement therapy to help them continue the process after they are released and sent

home. Providers also recommend that insurance should not limit the number of prescriptions for Chantix that can be covered in a year as their patients often need to make more than one quit attempt to succeed. With more health insurance coverage in the state, several hospitals are now filtering those who do not really need emergency department services to a clinic. This makes it even more important to engage providers in diverse clinical settings to make referrals for smoking cessation services. The emergence of e-cigarettes was discussed as a largely unknown factor that may change the risks and strategies for promoting cessation.

Mass media promoting cessation services: With American Recovery and Reinvestment Act (ARRA) funding, billboards were first posted in 2012 in the Fall River/New Bedford area to encourage residents to get Quitworks referrals from their doctors. A second round in 2013 has resulted in more people calling in response to the commercials, possibly because there is a paradigm shift as awareness of health concerns grows. Health providers in Brockton felt that their area had not been targeted in recent years for mass media tobacco campaigns. The new Community Transformation Grants (CTG) that started in 2013 have focused on community-based tobacco cessation, which we note may have helped raise awareness and provided an incentive for residents to seek cessation services. Seniors in the Wareham focus group discussed that warnings about smoking seemed more targeted to women than to men and would like to see more promotion targeted to men.

As far as smoking, I don't think that's pushed a lot about the danger of cigarettes for men. There was more effort/focus on women. – Senior in Wareham

FINDING 6: SOCIAL DETERMINANTS OF HEALTH POSE SIGNIFICANT BARRIERS TO PREVENTION AND WELLNESS.

Conditions in Southeastern MA communities were said to foster cancer inequities and limit efforts of residents and their allies to improve health. Community and government partners recognize and are working to address broader social determinants of health that extend well beyond the need for individual lifestyle changes. Broader investment in the region's economy and community infrastructures will be needed to have the necessary impact. Issues that arose include:

Food access: Health providers at Greater New Bedford CHC note that nutrition is very poor among their clients, which they largely attribute to poverty, lack of fresh vegetables in subsidized food programs (although they acknowledged the ability to use SNAP benefits at farmers markets), and American diets that include sweets and fast foods. They relate the City's high rates of obesity (10% in New Bedford versus 7.2% statewide) and heart disease to poor nutrition and have consequently adopted the Healthy Weight Initiative in their pediatric department.

Some participants claim there are many food deserts (in Brockton, Fall River, and New Bedford). Yet a Fall River study showed that there is physical access to healthy food in that city. Affordability of food, and particularly vegetables and other healthy food, was stressed as the key issue.

If the kids eat Oodles of Noodles every week it is because that is all they can afford... I don't want to hear that nobody can access fresh foods – there are supermarkets, small stores, and food at Walmart, but they cannot afford the food. – Community advocate key informant

The [food] pantries give you a bunch of cans, but not vegetables. The food can be canned but there is not a lot of low salt, low sugar, organic [offerings]. – Senior in Wareham

Limited physical activity at school: Participants in Voices for a Healthy Southcoast as well as New Bedford area health providers cite that time for physical activity at schools has been cut dramatically. Wellness partners are trying to work with schools, but they have different priorities for the time and resources. Connections between learning and physical activity are being emphasized to increase school buy-in.

Safety: Safety is a great concern that prevents residents from exercising as much as they would like. Parents said they do not let children out to play because of fear of gangs, violence, and drugs. Bicycles were mentioned as being stolen. Portuguese CHWs in New Bedford discussed obstacles of paying for transportation and gym fees as well as safety:

To walk you have to be a safe community. It's not safe to walk your kids to school... Do you know how many shootings have taken place right in our neighborhood? Culturally we walked everywhere; Portuguese we walked everywhere...here you are not going to let your kids walk to school, it's not safe for you to walk either. It's a safety issue. – CHW

Where I live it [physical activity] is not easy to do. I knew a neighbor who was attacked by somebody passing by in the road. – Translation of comment from Portuguese focus group

Built environment: Sidewalks were described as not walkable and parks as unavailable (Brockton and Old Bedford Village, a New Bedford neighborhood). There are initiatives to build new bicycle paths and parks in the region; yet a key informant was upset that these are not planned for many of the poorest neighborhoods.

Seniors in Wareham relayed that it was too expensive to join gyms such as the YMCA. Several had participated in line dancing at the Senior Center, but the funding from the Council on Aging ran out. They felt that lack of safe roadways present an obstacle to outdoor physical activity.

Safety [is a concern] – roadways are not conducive to walking or riding a bike. It takes a long time to get anything like that in this area. – Senior in Wareham

Poverty, unemployment, and lack of education: Poverty was mentioned across resident and professional groups as the key factor that drives cancer disparities and health inequity in the region. 10.7 percent of Massachusetts residents live below the poverty line. While 9

percent of individuals are living in poverty in the entire Southeastern MA EOHHS region, 21.7 percent are below poverty in New Bedford, 21.4% in Fall River, 15.6% in Brockton, and 24.4% in the town of Wareham which also has notable cancer and smoking disparities.⁴ Southeastern cities of New Bedford (at 11%), Fall River (at 14%), and Brockton (at 13.2%) were noted as having among the highest unemployment rates in Massachusetts, which has a statewide unemployment rate of 8.1%.⁵ Economic declines have been severe in the region, with many employers described as having left the area. Lack of education was noted as limiting employment opportunities. The percentage of adults over 25-years old in New Bedford who have less than a high school education is 37.3%, in Fall River 32%, in Brockton 18.4% and in the Southeastern MA region overall, 12.6%. This compares to 4.9% across Massachusetts.⁶

In making recommendations to reduce risk factors for cancer, participants frequently raised suggestions that involved addressing these social determinants of health particularly around improving employment. Marginalized residents without job security were noted to have little ability to improve their conditions at work (such as reducing occupational exposures, having time to seek healthcare, and engaging in wellness activities). Poverty and lack of quality employment were also claimed to fuel the use of drugs and alcohol.

Disabilities and co-morbidities: Participants also noted that many residents in the region have disabilities and multiple chronic diseases (co-morbidities), further complicating their decisions on seeking care and following through with treatments. Those interviewed by JSI were unsure whether the high rate of people with disabilities in the area is due to a greater risk of becoming disabled because they live there, or whether people who are disabled move to the area because it is much cheaper to live there on a fixed income. Living with disabilities was noted to isolate individuals, make it harder for them to obtain transportation, and increase their overall living and healthcare expenses.

Discrimination: Participants mentioned the role of discrimination as affecting exposure to risk factors, such as occupational exposures or neighborhood contamination. Several participants emphasized that current and former experiences of discrimination can also exert a large impact on health-seeking and health decision-making. Fear of deportation was a frequently mentioned barrier to seeking preventive health services. Those providing workforce wellness initiatives have found workers to be hesitant to participate as they could be penalized for taking time off and seeking care. This remained a barrier even when mobile services were provided at the worksite, necessitating initiatives to educate employers about healthy workforce practices and benefits and engage business representatives in public health activities. Additionally, when patients feel that providers are discriminatory or simply unable to understand and respect their needs, it can also play a major role in their decisions to seek or follow up with care (*see Finding #8, page 40*).

⁴ U.S. Census Bureau, 2007-2011 American Community Survey, <http://factfinder2.census.gov>, accessed 11/7/2013.

⁵ Ibid

⁶ Ibid

SECTION I: RECOMMENDATIONS FOR CANCER PREVENTION AND WELLNESS

Recommendations for improving cancer prevention and general wellness in Southeastern MA are summarized below.

CANCER PREVENTION AWARENESS

Linguistically and culturally relevant information: Basic fact sheets in multiple languages (including Portuguese) and tailored to local cultures and literacy levels are needed by residents, health providers, and community-based organizations. Broad dissemination should be made to community health centers and hospitals, area programs, community centers, and other locals (e.g., senior centers, faith-based organizations, barber shops, laundromats, etc.).

We need more information outside hospitals... there is nowhere to find information about prevention outside of health facilities and we need it. Even in clinics you don't see a lot of information... it's not like in Boston. Even in hospitals there isn't a ton of information. --Translation of comment from Portuguese focus group participant

Multimedia campaigns: Community-based organizations in Southeastern MA recommended constant media messaging which they say has had success. A common theme voiced through the assessment is the impact of storytelling and how this can help people change their views of health. A social marketing approach would aid in developing and conducting media and social networking campaigns. Several Fall River participants noted that they like to get information from the radio and the Internet (Google and YouTube rather than peer-reviewed medical sites). They listen to K-Love radio (Christian station 91.1 FM) to learn about other people's experiences, and how and when people go to healthcare facilities.

They give you courage to keep going on. People talk about what they pass through, they just help us to keep going on. – Fall River GED focus group participant

They encourage people 'to pray, to have faith.' It's more spiritual. – Fall River GED focus group participant

Peer outreach: To address risk factors that are most modifiable in the near term, increasing outreach and peer support that facilitates prevention and wellness is critical. Outreach conducted by fellow residents is seen as a promising approach that has been growing recently, with several organizations using CHWs to provide education and link residents to available resources. CHW services could be expanded and sustained if they were reimbursable by health insurers. Peer-led cancer discussion groups were also recommended by both Portuguese-speaking (mixed gender) and Haitian (male) focus groups. We note that many of the current outreach initiatives were not as successful at engaging men as women. While women were often health advocates for men in their

families, there are models available to expand direct engagement of men as peer leaders in the region. Old Bedford Neighborhood Association, for example, has engaged approximately 60 young men who are former gang leaders in community betterment. The Men of Color Health Awareness (M.O.C.H.A) peer network being operated with MDPH support by the YMCA in Springfield, MA might serve as a useful model for replication.

There are no groups that talk about this stuff... we need meetings and information sessions. – Translation of comment from Portuguese focus group participant

Youth outreach: Community-based organizations and health providers recommended focusing on educating children about wellness and cancer prevention. Engaging schools as partners in physical activity and nutrition programs is also needed. Adopting wellness targets may become more widespread as school administrators learn their value in attaining educational benchmarks. After-school programs offering affordable access to physical activity in community-settings can also be highly valuable.

Mobile health vans: Given that lack of transportation and time were identified as significant barriers, using mobile health vans to increase access is a valuable resource to continue and expand on. Clinicians suggested that mobile vans could not only offer prevention education but resources such as free Nicotine Replacement Therapy and Chantix.

Workplace wellness initiatives: Near-term gains can be made by reducing exposures to risk factors and promoting wellness by expanding existing worksite programs. Current workplace wellness initiatives target men and their employers need to be continued with lessons learned applied broadly across the region for replication. Adding health to job training programs was also recommended, especially for youth. These initiatives require building long-term relationships to gain trust and convey the benefits to employers while engaging them as partners in public health planning. Expanding employer representation in wellness coalitions will aid this effort.

Healthy eating & active living: Participants recommended continuing successful promotional campaigns. The Healthy City Fall River (Healthy FR) initiative, for example, noted that they are seeing reduced soda sales. Healthy FR also has walking programs that are increasingly engaging residents and New Bedford Family Fun (physical activity and nutrition) nights have been successful. More outreach and expanded venues are needed to include families in all neighborhoods and to engage men, who are not drawn as much by the current social approaches to group physical activity and nutrition programs.

INFRASTRUCTURE IMPROVEMENTS

Community centers: All neighborhoods need accessible community centers to help engage residents and provide space for education and programming. Some neighborhoods in New Bedford and Brockton have no meeting spaces, teen centers, etc.

Transportation and zoning reforms: Recommended improvements include connecting communities through improved sidewalks and biking routes. Partners are working on new bike paths, sidewalks, and parks and reaching out to school administrators to plan safe routes to schools and encourage their use. Greater engagement of residents and partner organizations across neighborhoods is called for to ensure that the needs of less affluent neighborhoods are given weight when deciding priorities for infrastructure improvements.

Environmental health and justice: Participants pointed to a number of serious environmental health and justice concerns that need to be addressed. Housing renovations are needed to rectify poor conditions and in some cases contamination. Redevelopment has occurred, but has not always been sustained, especially in some of the most distressed neighborhoods.

Substance abuse prevention: Community leaders facing pressing substance abuse problems in their neighborhoods wanted to see such issues integrated into wellness and chronic disease initiatives. At the community and family level, it is apparent that public health is more meaningful when it addresses a full spectrum of concerns.

Smoke-free housing: Smoke-free housing was seen as important to helping protect residents and prevent children from starting to smoke and assisting smokers to be more successful in their quit attempts. Public and senior housing residents are among the most vulnerable.

Economic development: Many participants recommended focusing on economic development because poverty is recognized as a key driver behind most of the inequities that impact social determinants of health. Among specific recommendations mentioned several times was to extend the train to the Southeastern MA cities to assist in creating and commuting to jobs and encouraging tourism.

Broad engagement: The full participation, especially from residents and community leaders from under-served neighborhoods, will help ensure that prevention and wellness initiatives are targeted to the most pressing needs of the region. Whatever the approach, it is important to engage neighborhood associations, which are strong in the New Bedford/Fall River area and in Brockton.

There needs to be transparency, community engagement, and involvement of the real stakeholders, who are the residents. –Community advocate key informant

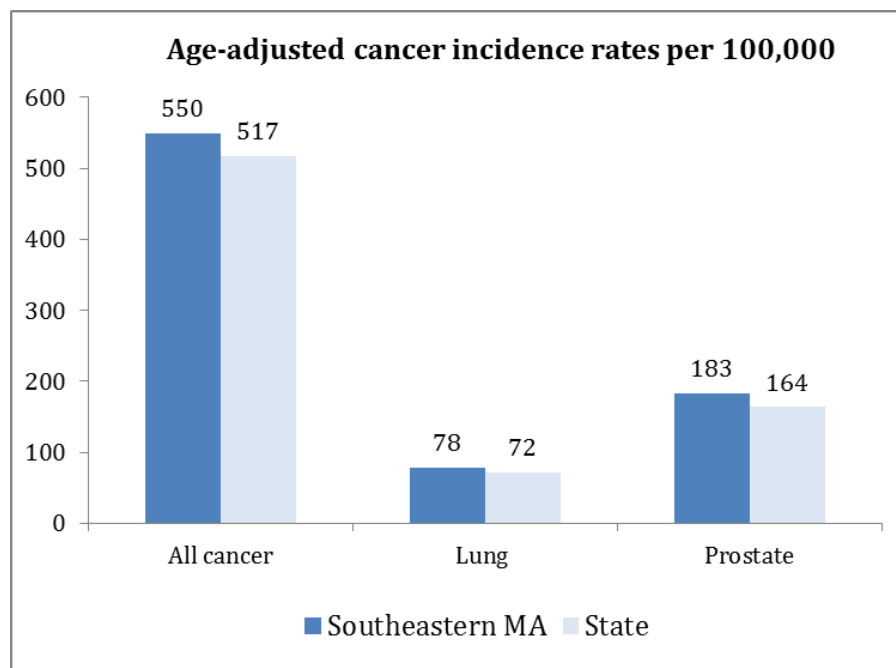
SECTION II: CANCER SCREENING AND TREATMENT

This section provides an overview of disparities in cancer outcomes in Southeastern MA and then presents additional findings regarding cancer screening and treatment. Following the four findings are recommendations offered to improve screening and treatment. Note that some of the factors that influence prevention and wellness also play a part in screening and treatment.

DISPARITIES IN CANCER OUTCOMES

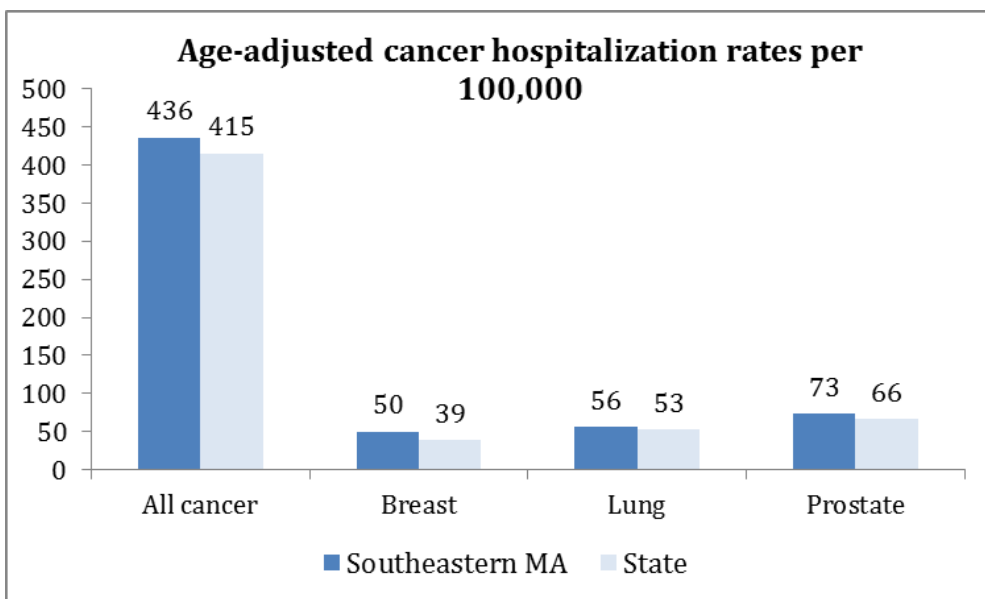
The Phase I report published in March 2013 identified concerns related to screening and treatment in Southeastern MA. Using data from the 2004-2008 MA Cancer Registry, the report found that the percent of new cases of cancer (total cancer incident cases) diagnosed at a distant (spread from the original site of cancer) or late stage was greater in the region than other parts of the state. Southeastern MA had higher rates of hospitalization for all types of cancer, including breast, lung, and prostate cancer. The non-Hispanic Black population and men were more likely to be hospitalized for any type of cancer in Southeastern MA. Furthermore, men were more likely to be hospitalized for lung cancer and non-Hispanic Black men were more likely to be hospitalized for prostate cancer. Southeastern MA had higher mortality rates for any type of cancer and lung cancer. The non-Hispanic Black population and men were more likely to die from any type of cancer; men were more likely to die from lung cancer as well in Southeastern MA.

FIGURE 7



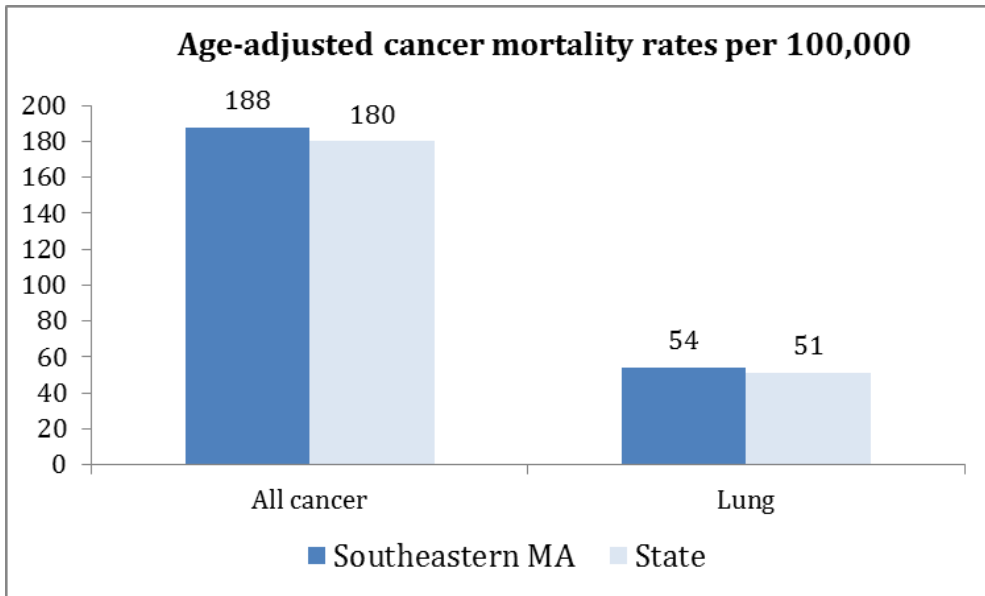
Data source: 2004-2008 MA Cancer Registry data

FIGURE 8



Data source: 2005-2009 MA Hospital Discharge Data

FIGURE 9



Data source: 2005-2009 MA Mortality Data

TABLE 5

TOTAL CANCER (ALL TYPES COMBINED)	GROUPS THAT HAVE HIGH RATES
Incidence (those newly diagnosed with cancer)	• All residents (higher than state) • Higher in men (than females in SE and men in the state)
Percent of new cases diagnosed at a distant or late stage	• All residents (higher than state)
Cancer hospitalization	• All residents (higher than state) • Higher in men (than females in SE and men in the state) • Non-Hispanic Black individuals (higher than NH White in SE)
Mortality (cancer as a cause of death)	• Same groups as hospitalization above

TABLE 6

SPECIFIC CANCER TYPES	BREAST (FEMALES)	LUNG	PROSTATE (MALES)
Incidence (those newly diagnosed with cancer)		• Non-Hispanic Asian/Pacific Islanders • Men	• Non-Hispanic Black Men
Percent of new cases diagnosed at a distant or late stage			
Cancer hospitalization	• Women	• Men	• Non-Hispanic Black Men
Mortality (cancer as a cause of death)		• Men	

Overall cancer screening rates were generally similar in the Southeastern MA region to other regions of the state. However, the Phase I report did find low screening among subpopulations in the region when compared to others in the region.

Women with less education and lower incomes were less likely to have had a clinical breast exam in the past two years, or over their lifetimes, than other women from similar demographic groups in Southeastern MA. Hispanic women were also less likely to have ever had a clinical breast exam or had a Pap smear to test for cervical cancer in the past three years or over their lifetimes. Cervical cancer is highly treatable if caught early. Women aged 55-64 were least likely to have had Pap smears in the past three years, while young women were more likely to have had the test.

TABLE 7: DISPARITIES IN RECOMMENDED CANCER SCREENINGS

Cancer Screening Test	Subpopulations with Screening Disparities					
	Ages	Gender	Races	Ethnicities	Education Levels	Annual Income Levels
Colorectal Cancer						
Sigmoidoscopy/Colonoscopy test						
<i>within 5 years (Ages 50+)</i>		Female			Less than high school graduation	Less than \$25,000
Breast Cancer						
Mammogram						
<i>in lifetime (Women 40+)</i>	<i>No significant disparities observed (however trends follow income and education levels)</i>					
<i>within last 2 years (Women 40+)</i>						Less than \$25,000
Clinical Breast Exam						
<i>in lifetime (Women 40+)</i>				Hispanic	High school graduation or less	\$25,000 - \$34,999 or less
<i>within last 2 years (Women 40+)</i>					College graduation or less	\$25,000 - \$34,999 or less
Cervical Cancer						
Pap Smear						
<i>in lifetime (Women 18+)</i>	Age 18-34 yrs			Hispanic	High school graduation or less	\$25,000 - \$34,999 or less
<i>in past 3 years (Women, 18+)</i>	Age 55-64 yrs				College graduation or less	\$25,000 - \$34,999 or less
Prostate Cancer						
Prostate specific antigen (PSA) blood test						
<i>in lifetime (Men 50+)</i>					Less than high school graduation	
<i>within year (Men 50+)</i>					Less than high school graduation	Less than \$25,000
Digital rectal exam (DRE)						
<i>in lifetime (Men 50+)</i>					Less than high school graduation	Less than \$25,000
<i>within year (Men 50+)</i>					Less than high school graduation	Less than \$25,000

Note that those with higher incomes and/or more education were more likely to have received each of these tests. This is true even when the differences between those grouped by education or income level did not reach statistical significance.

FINDING 7: CULTURAL AND RELIGIOUS BELIEFS, ACCESS TO INFORMATION, ABILITY TO ADVOCATE FOR ONE'S HEALTH, AS WELL AS DISCOMFORT AND FEAR AFFECTS THE DECISION TO GET SCREENING AND TREATMENT.

Several potential factors were identified through the assessment that may contribute to low screening and late treatment rates among high-risk populations. Health providers emphasized that health literacy is low regarding screening, mentioning colonoscopy and recognizing symptoms of lung cancer in particular. They stress the importance of providing patients with health information, addressing language barriers, and also following up with clients multiple times to ensure they get recommended screenings.

It's all about follow-up for my patients. If there is no issue currently and you want them to do something preventative... you refer them 3 times and they don't show up. They say they didn't want to do that; it was not necessary.

I think that most lung cancers are found incidentally. You might not have any symptoms at all.

Smokers are so used to be short of breath and tired. As they get older and those symptoms just build subtly... they don't associate their symptoms with being sick because they are so used to that just being a part of smoking. – various Community Health Center Providers

Among attitudes and behaviors, both CHWs and residents pointed out that many residents do not see a doctor unless they feel very ill and that there is a lack of familiarity with preventive care, especially among those who grew up in areas where such care was not available.

The Haitian men in the Brockton focus group described:

The problem is that sometimes women in Haiti can't find treatment for cancer. Hospitals are difficult to find.

If people live in the countryside it's not easy to get to a hospital, so people try to treat diseases by themselves.

While these men knew some of the symptoms for prostate cancer and thought early detection and treatment could help survival, they said they had never been screened and did not know many others who had. They were not aware of screening guidelines. Language was mentioned as a barrier. Some thought that doctors did not care much about them while others felt that traditional remedies would work better than Western medicine.

I don't know too many people that have been screened for cancer.

Even though the focus group was held at the Brockton Neighborhood Health Center, the focus group participants were not aware of where to get screening. Several thought that screening was only performed at a hospital. Health providers at the Brockton NHC said that their provider panels are almost full which presents an obstacle to conducting outreach to high-risk populations to inform them about screening.

New Bedford and Fall River residents said that they do not talk about cancer. CHWs noted that residents are unaware of the signs and symptoms of cancer and they are not comfortable asking for screening.

We do a lot of education – in churches, in job sites. A lot of people that is the first time that they hear about how to do their breast self-examination or what 's going on with the doctor when they are doing a Pap smear... [few know about] colonoscopies.
– CHW

When I asked her [the woman's sister] why she hadn't had a mammogram, she said 'Oh, my doctor hasn't sent me.' – CHW

They think the doctors are like the Gods and they should tell you. That's another cultural thing. – CHW

Even if someone has a positive test, they do not want to “worry” family members. Some believed there is no cure for cancer. Those who felt cancer could be cured tended to be those who knew a survivor. Direct experience was very important to perceptions across cultural groups.

Within our community, Portuguese, Cape Verdean, and... Spanish too, the word cancer is being envisioned like a death. That is embedded in our community. Nobody wants to talk about it...Nobody wants to know if they have it. – CHW

I deal with people that don't even want to say the word cancer. – CHW

A CHW recalled her mother's views: 'You're going to die of something some way, someday...So you have to live life to the fullest and don't worry about anything'... When they did a Pap smear they found something and were supposed to remove it. She said 'They're not removing anything out of my body and I'm not going back for no Pap smear.' – CHW

Many who had cancer suffered and died even though they had treatment, so people think why bother, unless you meet others who have survived. – CHW

I know someone 21 years old who just got diagnosed with cervical cancer. She doesn't want to talk about it or tell her mother, its fear. – Senior in Wareham

Men were said to be less likely to acknowledge health problems, and men who were interviewed said that their focus is on providing for the family rather than themselves.

CHWs noted that men are uncomfortable advocating for their health and that women are more willing to serve as health advocates for men.

Others mentioned not wanting to get tested because of the stress of waiting for results. Fear of tests being painful was raised (specifically with colposcopy and mammography). This was extreme enough that more than one woman who had been referred to a colposcopy after a positive Pap test would not make the appointment because they were told by others that it was very painful.

"Of course I'm concerned [about it developing into cancer], but I'm petrified of having to do this procedure... They were very nasty [when I asked for pain medication]. A family planning place in Fall River, the woman actually told me 'Get one of your friends to get you a pain pill.' That's pretty unprofessional. She's pretty much telling me to take drugs before I go for the test so it won't be that painful." –Consumer

Experiences of being disrespected or simply uncomfortable with doctors were frequently mentioned as a barrier. Discomfort was said to be especially common among older persons and men in general who do not like to be naked or examined by male doctors.

Some people are ashamed to be naked in front of a doctor... my grandmother was embarrassed to be that way in front of a male doctor. My grandmother could not demonstrate her body that way in front of a man who wasn't her husband.
--Translation of comment from Portuguese focus group

Many husbands won't let their wives get checked because they don't want doctors to see their wives naked. – Translation of comment from Portuguese focus group

Portuguese-speaking focus group participants all felt that screening was very important and the mixed-age and gender group reported having regular screening. These residents were recruited by the Immigrants' Assistance Center, Inc. in New Bedford whose outreach and patient advocacy may be a factor.

Puerto Rican residents expressed that younger family members, including children (under eighteen and adult children), often play an important role in advising their older family members about health care. Instances were mentioned where this led to older adults being encouraged to pursue cancer screening and treatment and conversely, when those who do not view Western medicine as beneficial convinced family members to forgo taking medicines to treat cancer. Residents of different cultural backgrounds relayed the choice of relatives who had been diagnosed with cancer to forgo treatment and choose to let the cancer run its course at home; particularly after being told by health providers that the cancer was too advanced to be cured.

CHWs and service providers have found that the frequent changes in both treatment and screening guidelines cause confusion among residents, outreach workers, and even providers. Residents also were not aware that one could still be at risk of cancer even if it is not in the family. Additional confusion was raised, such as that some thought they did not need Pap smears because they were given the Gardasil vaccine to prevent human papilloma virus.

FINDING 8: INITIATIVES TARGETED TO SPECIFIC POPULATIONS CAN INCREASE SCREENINGS.

Targeted initiatives appear to have helped increase screening among target populations in specific geographic areas by providing culturally-tailored outreach and improving access to screening services. The Greater New Bedford and Brockton areas, for example, were reported by Southcoast Hospital and Brockton NHC as having good rates of mammography screening, in part due to availability of grant programs. The YWCA breast cancer outreach program uses both CHWs and the Southcoast Hospital's mobile van, which the program found to increase screening. Screening for prostate and colon cancer remains a challenge for the region. Health providers find that many patients are not familiar with colonoscopies and may not know whether they have had the procedure or not. Brockton NHC noted that they were able to increase prostate as well as cervical cancer screening during pilot initiatives. However, time-limited funding streams can undermine progress.

The Brockton NHC staff explained that due to HRSA's mandate for patient-centered care, health centers received some funding that is used for staff to focus on increasing cervical cancer screening. They also described previous extensive prostate cancer awareness initiatives targeting Black men that were supported in the Brockton area by DPH, Good Samaritan Medical Center, Signature Healthcare, American Cancer Society, the City of Brockton, and the Veteran's Administration. As a group they developed a prostate cancer screening/educational DVD for the public in four languages that was narrated and recorded by cancer treatment physicians representative of the respective cultures. Trainings were provided for community leaders from area health, community, and faith-based organizations who are working with a group of survivors of prostate cancer to hold discussions in the target population's primary language.

While the training and outreach materials still exist, the program's grant funding has ended. Consequently, the evaluation found that the outreach has stopped without the ability to fund community partners to conduct the targeted outreach.

Brockton NHC and its collaborators also have a train-the-trainer curriculum on women's health and mentor relationships, which they used when funding was previously available to establish liaisons between faith-based organizations and health organizations. Funds for community stipends and multi-lingual staff (1FTE total divided among four staff) were required to hold groups in English, Spanish, Portuguese, and Haitian Creole with churches, adult learning centers, Department of Transitional Assistance, the local housing authority, health center patients, and groups at the barber shop. This outreach was unable to be continued after the grant period ended.

A CHW working with women in prisons stressed that cancer screening and treatment was inadequate and unavailable. In Fall River, a key informant noted that there is a need for more targeted promotion for cancer screenings:

I can't recall a screening promotion by DPH in 10 years in this area. You must do such promotion over a long period of time.

FINDING 9: BARRIERS TO ACCESSING TREATMENT REMAIN EVEN WITH HEALTHCARE REFORM IMPROVEMENTS.

Costs: Insurance

Healthcare reform has increased the proportion of Massachusetts residents with health insurance. In 2012, 95.4% of MA residents had health insurance and only 4.6% were uninsured.^{7,8} Despite the growing coverage of MA residents, key informants relayed that coverage can be sporadic over time. Indeed the 2012 Massachusetts Health Reform survey indicates that as many as 10.6% of all adults (ages 19-64) did not have insurance coverage at some point during the past 12 months. The Survey also identifies Southeastern MA as a region with disproportionately high rates of those without insurance (*See Appendix 10*). Across Massachusetts, the uninsured are disproportionately low-income, younger, male, Hispanic, and non-citizens with low levels of educational attainment and limited English proficiency.⁹ Furthermore, despite improvements in coverage, 25% of non-elderly adults reported unmet need for care that was mostly attributed to the cost of health care.¹⁰

A number of barriers to accessing treatment were described during the needs assessment. These included lack of transportation, limited time to seek services, lack of adequate insurance for many residents, and difficulty navigating the healthcare system. Strong concern was voiced in the area that access to follow-up additional cancer screening and treatment services was not assured after free screening tests were performed.

If we have somebody without insurance [with positive blood stool tests] we have to refer them to Boston for a colonoscopy. They don't speak English; their family doesn't speak English. They don't know how to use the bus; they don't know how to get around Boston and forget it. I have no options; I have no way to help them get there.

Despite healthcare reform, not having health insurance remains a significant barrier for many in the area. This includes undocumented residents who do not qualify for MassHealth. But some residents also shared that they make too much money to qualify for MassHealth and decided to pay the penalty fee to not carry health insurance because they do not earn enough to afford the mandatory insurance.

...We were able to get MassHealth while he [her husband] was unemployed. But now that he went back to work, his company wanted \$240 a week for health insurance. We

⁷ CDC Office of Surveillance, Epidemiology, and Laboratory Services Behavioral Risk Factor Surveillance System, accessed 9/12/2013.

<http://apps.nccd.cdc.gov/brfss/display.asp?cat=HC&yr=2012&qkey=8021&state=MA>

⁸ Massachusetts Department of Public Health. 2013. *A Profile of Health Among Massachusetts Adults, 2012: Results from the Behavioral Risk Factor Surveillance System* (DRAFT Report).

⁹ Sharon K. Long, Dana Goin, and Victoria Lynch. *Reaching the Remaining Uninsured in Massachusetts: Challenges and Opportunities*. Urban Institute (March 2013).

¹⁰ Sharon K Long, Karen Stockley, and Heather Dahlen. *Massachusetts health reforms: uninsurance remains low, self-reported health status improves as state prepares to tackle costs*. Health Aff (Millwood). 2012;31(2):444–51.

couldn't afford that despite the fact he makes decent money, so we've been without insurance for almost a year now...We're screwed if we have an emergency, quite frankly. And we can't get MassHealth either. It's cheaper to just pay the penalty.
– Fall River GED focus group participant

If your employer offers you insurance, you have to take it through them; you can't get MassHealth—it's not right. If it is going to be a law, affordable insurance has to be available to us. – Fall River GED focus group participant

Health providers find that many of their patients may have insurance one visit and then not the next. They have to renew often, including when they move, which is often for high-risk populations. Residents and service providers said it is hard for uninsured residents to find providers who will take uninsured patients for free or low-cost services.

Insurance is a big problem as it is only accepted at certain places and really limits your options. – Translation of comment from Portuguese focus group participant

Many doctors will say they don't take certain companies or plans. – Translation of comment from Portuguese focus group participant

For those with insurance, including seniors with Medicare and those on MassHealth, the cost of co-payments, uncovered services, and medicines can also be a barrier. Health providers at Greater New Bedford CHC have found that patients will not get follow-up to positive screenings because of uncovered costs, such as radiology readings. CHWs reported having patients who take medicines less frequently than prescribed in order to be able to afford them.

Price of co-payments also makes a big difference to people here. – Translation of comment from Portuguese focus group participant

There are clinics that do screening, but you have to pay even if you don't have insurance. You pay 50 or 100 bucks just to be seen. That's not including the tests. That's a lot for some people out here. People are just scraping by. – Fall River GED focus group participant

CWHs said that residents consider it to be less expensive and less burdensome to rely on home or traditional remedies. Residents do not have time as they work multiple jobs. They cannot afford to lose a day's work. A participant in the Haitian men's group in Brockton described making his own remedies (although not while in the United States):

I have a remedy that makes sure you will not have a problem with prostate cancer. It's a special remedy that I make... I make the remedy using herbs and other ingredients. It's guaranteed to cure you... I once gave it to a man and he no longer had problems with cancer... It's for everyone. Women can drink it and it will help them.

Access: Transportation

Programs working with public housing residents in Wareham, Fall River, and New Bedford expressed that transportation is the largest barrier to residents' access to care. This concern was echoed by New Bedford CHWs:

They have an oncology center in Fairhaven and Dartmouth... We have no oncology treatment in New Bedford. If you don't have a way to get there, somebody to bring you, how are you going to get there? – CHW

I see some of my patients losing their appointments because they don't have a way to get there. The Oncology Center has emergency vouchers for cabs, but a lot of people don't know that. – CHW

Referrals

Community health centers were described by participants as an entry point to health services that meet diverse needs and tend to be accessible. However, they were also said to be overburdened and unable to provide more specialized cancer treatment services.

I usually go to the only option... the walk in clinic. That is the only option around me. For me and my daughter. There are not a lot of other options around because you have to travel far. – Translation of comment from Portuguese focus group participant

CHC providers mentioned a number of barriers related to the referral system and to patients' ability to access screening and treatment services. Primary care providers report a breakdown in communication when they refer patients to specialists. For example, certain specialists simply mail patients appointment packets with complex forms only in English. Patients are unlikely to understand these packets and to follow-up for necessary care without support to overcome language and health literacy barriers. Additionally, primary care providers said continuity of care suffers as the system does not allow for clear and effective collaboration between primary care providers and specialists.

Partnering with the Southcoast Hospital's mobile van has helped with screening, but CHWs noted that not all of the necessary follow-up care was available. They noted that while screening was provided for free at the van or at the Greater New Bedford Community Health Center, surgery was not always covered if a person was diagnosed with cancer if they were uninsured or undocumented. Representatives of Southcoast Hospital explained that those needing treatment are eligible for care. They elaborated that there may be some private specialists who will not see those without certain forms of insurance. If a client is screened and needs treatment, but does not have adequate insurance, CHWs help them navigate and may send them to Boston for care under the Health Safety Net.

We do a lot of navigating. A lot of begging, and a lot of writing letters saying that 'This patient has no insurance.' We do a lot of that. – CHW

Brockton NHC and Greater New Bedford CHC providers said they refer patients to Boston for many procedures, including colposcopies and colonoscopies, in part because they claim coverage under the Health Safety Net is not available locally. These providers are concerned that patients referred to Boston often do not follow-up because of the distance and their lack of transportation or concern that they will be billed beyond what they can afford. Furthermore, they noted that they do not have a system to track whether patients have received follow-up care. They claim that the overall cost of care to the state would be lowered if they could refer to local radiology and other necessary specialty services.

Other Barriers

An administrator at the Brockton NHC described additional problems. The Dana Farber mammogram van comes about twice a year to Brockton; yet an access issue has recently arisen due to the new insurance regulations. They have been doing this for about five years; prior to last spring, they focused mostly on women without or with limited health insurance. According to the Brockton NHC Administrator, however, since last spring, women without insurance or with deductibles are no longer covered for the Dana Farber mammography van services. Close to 30% of the Brockton NHC patients are covered through Health Safety Net which will cover the mammography van; although not all of the other sites where Brockton NHC refers women for mammograms accept Health Safety Net. The Administrator states that even with the Dana Farber van, there are frequent issues relating to women's lapses in insurance (possibly because the patient may have moved and missed notification letters for renewal, could not afford the insurance they had, or were undocumented). Now the Dana Farber van requires a waiver that women must sign saying that they are responsible for any cost from the van not covered by their insurance, while prior to last spring, this was "free." This changes how the health center is able to do outreach as they can no longer promote the services as being free and are concerned about what women will be charged. Brockton health providers also said that obtaining health records from the mammography van was also more difficult than from a local hospital, which impeded follow-up. At the same time, health providers from both health centers did see advantages of mobile health vans, which they would also like to see offer colon cancer screenings and tobacco cessation outreach and cessation therapies.

Cancer survivors mentioned that financial and time constraints limited their ability to take part in recovery services. One Cape Verdean woman, for example, felt she had no support. She mentioned that the charge for a hat and wig was unaffordable and she was surprised that the treatment center didn't have reduced costs. She also found it was not possible to see a social worker because the available hours were only when she worked.

For family members who serve as caretakers for their relatives with cancer, costs can mount whether or not they have insurance. This was mentioned as an additional stress on the family.

FINDING 10: CHALLENGES IN THE PATIENT-PROVIDER RELATIONSHIP IMPACT SCREENING, TREATMENT, FOLLOW-UP, AND QUALITY OF CARE.

Costs and access are not the only barriers that were identified. Perceptions regarding quality of care, service delivery, and whether patients feel they are being listened to and respected all were said to impact whether residents sought healthcare services in the region.

Several residents reported dissatisfaction with what they viewed as discriminatory practices, such as not taking uninsured patients, very long wait times, and being treated poorly. Some residents had such great distrust of the medical profession that they believed that doctors were purposely withholding treatments to control the size of the population or to make money for the healthcare industry. They also spoke of understaffing for emergency care as well as limited availability and choice of primary care and other physicians, mentioning that few doctors were of their racial/ethnic background. At the same time, even those patients who were White and not recent immigrants felt that they were looked down upon for being from such poor cities. They said they felt mistreated and spoken to harshly.

Residents in different Fall River and New Bedford focus groups seemed to feel that quality of care was better in the Boston area and explained that they and their family members went to Boston for serious health concerns. Counter to these concerns about lack of local services, an administrator from Southcoast Hospital reported that 80% of residents stay in the area when they need care. They claim that both service availability and care is very good in the area, especially for common cancers such as lung cancer. Key informants from New Bedford and Fall River neighborhood organizations noted significant improvements in area cancer treatment facilities including newer facilities with more services and locations. As with views on the value of cancer prevention, direct experiences of people they know shape residents' opinions. Those residents who had a negative experience themselves, or whose relatives or friends had poor encounters, stated that they did not trust the facility and sought care elsewhere.

Boston has more resources generally so I would go there. – Translation of comment from Portuguese focus group participant

It was mentioned by participants from community-based organizations that there are many health nonprofits in the area that are shifting to becoming for-profit institutions and that the quality of care has changed following the acquisition of smaller area hospitals by larger health systems. Residents find that they are not receiving the same level of services under the new management, claiming that the focus has shifted to serving those with higher incomes and that these facilities are less welcoming of low-income residents.

At the same time, CHWs noted that the new Oncology Center in Fairhaven was very valuable:

Right now they go to the Oncology Center in Fairhaven. I have nothing negative to say about them. They've been great.

Several strategies are being employed in the area to support screening and treatment for residents. Community health workers for cancer and other chronic diseases are not only providing outreach information on cancer; they also provide important assistance to residents in navigating healthcare systems. As mentioned, mobile vans help expand access for screening—though are limited if treatment is needed. It was also pointed out that women are more likely to take advantage of mobile vans and other strategies to improve access than are men. Community-based organizations are trying to increase worker participation in screenings. For example, The Fisherman’s Partnership, which works with employers of fisherman, is training fisherman’s wives as CHWs, and health fairs are being organized in community locations (e.g., Walgreens has partnered with Brockton Hospital).

FINDING 11: HEALTH PROVIDERS NEED UPDATED GUIDANCE AND CONTINUAL SUPPORT ON CANCER SCREENING GUIDELINES, INSURANCE COVERAGE, TERTIARY CARE SYSTEMS, AND AVAILABILITY OF LOCAL SERVICES.

Health providers in roundtables were themselves confused by changes in screening guidelines and complexities in insurance coverage. They are eagerly awaiting new guidance on lung cancer screenings for high-risk patients anticipated from the U.S. Preventive Health Services Task Force, as they are seeing many lung cancers diagnosed at a late stage. The efficacy of prostate cancer screenings and the best protocols to follow were called into question.

Providers were not all clear on what coverage was offered under MassHealth and other insurance plans. For example, whether Chantix was covered to aid patients in smoking cessation, what tertiary care is covered, and when prior authorizations from primary care providers are needed across different insurance providers.

I have a couple of patients who had positive stool cards years ago and still won't go for follow-up care because of the chance they might get a bill. I don't know how the tertiary care centers really work in order to guarantee [whether] they will get a bill or they won't. That knowledge would be really helpful to get those patients into the system. – Community Health Center Provider

New Bedford Community Health Center providers pointed out that more of the burden for providing health services for low-income residents has been falling upon them in recent years. As an example, they mentioned that the regional DPH no longer provides residents with flu vaccines (we note that the health center may still be reimbursed by the state for the costs of providing such vaccines).

Additionally, providers would like to share information more fully across health institutions; yet they found that privacy protections ensured by the Health Insurance Portability and Accountability Act (HIPAA) was often presented as an obstacle. This could be surmounted with better guidance.

SECTION II: RECOMMENDATIONS FOR CANCER SCREENING AND TREATMENT

Summarized below are recommendations for improving cancer screening and treatment in Southeastern MA. As with Section I recommendations, they include recommendations directly from participants as well as additional recommendations offered by JSI based on assessment findings.

OUTREACH

Linguistically and culturally relevant information: As with prevention and wellness, screening and treatment initiatives are aided by multi-cultural, linguistically appropriate materials such as videos that feature individuals and providers from their community and culture speaking about the process of screening and treatment and surviving cancer. Providers recommended that health educational materials tailored for different target populations should be attached to electronic medical records (EMR). While this is available in some EMR systems, for example some systems have health education materials associated with specific health conditions that providers can print out and give to their patients, it is not widespread and rarely in Portuguese or at low-literacy.

Community-based outreach: Outreach initiatives that have an evidence base in the region, and which can be implemented at modest cost, deserve to be replicated and provided with sustained funding. Recommendations in Brockton were to hire CHWs, provide continued funding for prostate and breast cancer outreach, and offer stipends for those providing targeted outreach. Holding discussions in community settings, from houses of worship to barbershops and community service organizations, was found to be effective at increasing screening and treatment during Brockton outreach initiatives.

Peer support: Among the excellent recommendations from participants, JSI would like to highlight the importance of peer networks in supporting health-seeking behaviors, such as cancer screening. Community health workers are providing essential support in home, workplace, and community settings, and their network needs to be expanded and sustained to have an even greater reach. CHWs discussed the importance of, and need for, further increasing community outreach by going out more often into the community, including via faith-based institutions, worksites, and housing, as well as the need for prison outreach services. CHWs and other participants emphasized that women were helpful health navigators for their families. Residents also described faith-based outreach as particularly effective (including through parish nurses) while seniors suggested outreach through senior centers and Councils on Aging.

Expanded screening locales: Innovative ideas were raised that participants suggested be explored further to determine their feasibility. For example, residents asked that doctors offer cancer screening during regular office visits (while acknowledging at the same time that many do not get routine healthcare), while health providers suggested family screenings at schools. Physicians would like to see mobile vans offer screenings for multiple cancers that are elevated in the region to the fullest extent feasible.

HEALTHCARE SYSTEMS IMPROVEMENTS

Provide clear information on insurance eligibility: More information is needed on what will and will not be covered, and how low-income, uninsured, or underinsured residents can obtain needed care through the free pool. Residents sought better information on insurance eligibility and the re-enrollment process (including as they move addresses). Health providers would like to have a central conduit for referrals: “One phone call for where to get our patients help depending on their insurance as opposed to having to call every hospital in Boston.”

Fill gaps in healthcare coverage: It is important to fill the gaps in access to screening and treatment. Initiatives which target those with the least access, including undocumented immigrants, uninsured and underinsured, those with disabilities, the incarcerated, non-English speakers, and/or those with limited health literacy are a priority. Simplification of the reenrollment process, through the Mass Health Connector or other means, is needed to ensure continuity of coverage. Residents across areas also requested more affordable insurance coverage. The Administrator from the Brockton NHC stressed that it is important to address gaps in low-income, indigent women’s healthcare coverage for mammograms and Pap smears. Health providers both in Brockton and in New Bedford suggested a pilot grant to fund a local provider that could provide colon and prostate cancer screenings for Mass Health Limited/Health Safety Net Patients. Those working with incarcerated women recommended improved screening programs. Research has identified that incarcerated individuals are at greater risk for certain cancers; several studies recommend screenings, including for HPV and Hepatitis that can be precursors to cancer development.^{11,12,13} The Hamden County Sheriff’s department and Massachusetts Public Health Association developed a **Public Health Model For Correctional Health Care** that could provide guidance for implementation in Southeastern MA facilities.¹⁴

Address shortages in primary care providers: Health providers at the Greater Brockton NHC discussed that their panels were full for most of their physicians. This shortage needs to be addressed prior to expanding outreach that would bring a broader base of residents in for screening and health services.

Expand local facilities: Health providers discussed that having more local specialized (tertiary) cancer treatment options would assist their most vulnerable populations for

¹¹ 70.Nijhawan AE, Salloway R, Nunn AS, Poshkus M: *Preventive healthcare for underserved women: results of a prison survey*. J of Women’s Health 2010, 19(1):17-22.

¹² HCV screening of prison inmate drug users: an interview with Dr. Arthur Kim, Massachusetts General Hospital and Harvard Medical School. <http://www.news-medical.net/news/20130501/HCV-screening-of-prison-inmate-drug-users-an-interview-with-Dr-Arthur-Kim-Massachusetts-General-Hospital-and-Harvard-Medical-School.aspx>, Posted May 1, 2013, accessed 1/29/14.

¹³ Ank E. Nijhawan, Rachel Salloway, Amy S. Nunn, Michael Poshkus, and Jennifer G. Clarke. Journal of Women's Health. January 2010, 19(1): 17-22. doi:10.1089/jwh.2009.1469.

¹⁴ Conklin T, Lincoln T, Wilson R, Gramarossa G. *A Public Health Model for Correctional Health Care*. Hampden County Correctional Center. October 2002.

which free care is only available in the Boston area. A Community Health Advocate noted that while Fall River used to be considered a medically-underserved area, they now have many facilities and the mayor has instituted zoning reforms to encourage their development. A new \$12 million health clinic was built with ARRA funding. Despite this increase, focus group participants in Fall River said they would like to increase the number of healthcare facilities in Fall River, potentially redeveloping abandoned warehouses as clinics. A New Bedford resident also requested a local trauma center having lost a family member when adequate trauma care was not available locally.

Ensure services after privatization: As more healthcare facilities are becoming for-profit, discussants in health coalitions called for greater oversight and advocacy during the process to improve adherence to regulations that require such institutions to provide care to the uninsured and to offer preventive services. These participants cautioned that regulations requiring preventive and cessation services from new for-profit institutions only apply for a limited period.

Extend service hours: Many individuals do not have free time during the work week. The need therefore exists for evening and weekend hours for social services (which the Brockton NHC Administrator noted was not available in Brockton).

Expanded supports: Additional support for individuals to participate in screening and treatment and to aid in the recovery from cancer is needed. Cancer survivors would like to have resource listings provided on where to get subsidized social support, living assistance, and items such as wigs. More extensive systems to help patients follow-up on screenings and treatment and not miss appointments—such as support from CHWs and improved follow-up through tracking systems—were seen as a priority. Transportation arose as one of the most significant issues, whether to local services or to specialists located outside the region. Support groups and other resources for those with cancer and their family members need to be made more broadly available and widely publicized.

Treat patients with care and respect: Participants at all sites highlighted the need to build trust (including allaying fears of undocumented immigrants) and ensure positive interactions between providers/healthcare systems and clients so that clients return. Healthcare institutions in the region are working in difficult contexts to provide high-quality, innovative services. Nevertheless, quality improvement initiatives can enhance services and be sensitive to the fact that a negative encounter can influence a wide network of residents who are already hesitant to seek services.

Develop diverse, culturally-competent workforce: Residents sought a more expansive, representative, and culturally competent healthcare workforce that includes diverse healthcare providers, CHWs, translators, psychologists, and grief counselors. Improvements are needed in the level of care and cultural competency of all providers to learn how best to interact with those of different cultures and backgrounds. Healthcare institutions acknowledged the need for health providers to develop competencies in culturally and linguistically (language and literacy) appropriate services (Southcoast Hospital, for example, recognized the need to further develop cultural competency among their providers based on the hospital's previous community needs assessments).

Integrate CHWs in cancer care teams: Health providers had varied familiarity with how to best work with CHWs. Those who did work closely as a team found them highly valuable and would like to see their service reimbursable by health insurance. Health providers requested better communication systems with CHWs to track outcomes of CHW services.

Southcoast Focus Group

FACILITATOR'S GUIDE

Step 1: Ice Breaker Questions

Convene the group, welcome everyone. "My name is _____ and this is my colleague _____. We are from the JSI Research & Training Institute, Inc. (JSI). Thank you for joining us today. It is very much appreciated. Since it is spring and the weather is getting nicer, let's get to know a little about each other by just going around the room, saying your first name, how long you've lived in the Southcoast, and sharing one of your favorite foods to eat at a barbeque or picnic. My favorite is _____. "*Go around the room.* "That's great. Now I'm hungry! If you are, we have some snacks you can help yourself to. Also I should point out that there is a restroom..."

Step 2: Use Script as a Guide

"Before we begin, I am going to explain the purpose of the session. I will then answer any questions you have, and then we will start the discussion.

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 (MDPH) has asked JSI to help them gather information that will help them better understand how to prevent and control cancer in the Southeast region of MA, with a particular focus on the Southcoast. This project involves talking with residents from the region and community leaders. These discussions allow us to gather information from different groups to better understand what steps can be taken to prevent and better control cancer, as well as to support those affected by the disease.

Today we hope to learn from you about your knowledge and experiences with cancer. We are also interested in learning what you have learned or heard from other residents, especially [target population] about their experiences with cancer and factors that may increase the risk of cancer. We would also like to hear from you how these factors can affect other diseases including diabetes, heart disease and stroke.

Your participation in this focus group is completely voluntary and all information you share will be kept confidential and will not be associated to you by name.

We will begin with some general questions about your general knowledge of cancer and specific cancers such as _____. Then we will move to more specific questions. We encourage you to share your thoughts and opinions openly and freely. But, please also be

respectful of other participants' opinions. We may have to politely interrupt you in order to get everyone's opinion. At no time should you feel you have to answer a question.

We will be taking notes and recording our conversation to make sure we have all the information you shared. We are not recording your names. Does anyone object to being recorded? This discussion should last no longer than _____ hours.

The information from our conversation will be summarized and provided to MDPH and their partners in the region to use to improve cancer prevention and control. At the end of the session, we will provide you with vouchers worth \$__ in appreciation of the time you have taken out of your busy day to be part of this discussion.

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 conversation. 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 4: Answer Questions (if needed)

Step 5: Turn on the Recorder

Step 6: Begin Discussion with Questions Below

A. General Awareness and Knowledge

- 1. First I want to discuss your general awareness and knowledge of cancer. As you answer these questions, please also think about the people in your community and what you have heard or learned about their views and experiences.**

Remember this is not a test and we don't mean to put you all on the spot. But we do need to try to get a sense of what people in the region in the region think about cancer.

- a. How familiar are you with cancer?**

[Probe:

- What is cancer?

- Are they aware that there are many types of cancer?
- Do they know which types of cancer are most common?
- Are they aware that many types of cancer can be prevented]

B. Cancer Prevention and Modifiable Risk Factors

2. How does [specific cancer or/the most common cancers: lung, breast, colorectal, and prostate cancer] develop?

[Probe for their knowledge and that of others in the target population, about modifiable risk factors, such as:

- Smoking as a risk factor for many chronic diseases including lung and other cancers. *Smoking is more common in the Southcoast. Residents also don't have as much success quitting than in other parts of the state. Why do you think that might be the case?*
- Alcohol as a risk factor for breast cancer.
- That regular physical activity and a healthy diet may be protective for some types of cancer.
- Note any concerns about occupational or environmental exposures.
- Avoiding risk factors and increasing protective factors may lower your risk but it does not mean that you will not get cancer.]

3. A) "What do you think might be some of the ways to reduce your risk of getting these types of cancer?"

B) "What do others among your network of families and friends think about whether cancer can be prevented, and if so how?"

4. Have you, or others you know (family, friends, etc.), ever used tobacco products, including cigarettes, cigars, pipes, or chew tobacco?

[Probe:

- For those of you who have used tobacco products, why did you start and at what age? Do you know many others [in target population] who use tobacco products? What are reasons they started?
- Have you ever tried to quit? If yes, why? If not, why?
- Was it difficult to quit? If yes, why? If not, why not? What may make it difficult for [target population] to quit smoking?
- For those of you who have not used tobacco products, why didn't you start?

Probe for target population: lifestyle factors, cultural factors, other social determinants of health (poverty, second-hand smoke...). Try to get specific examples of circumstances or experiences.]

5. **A) What can motivate people [in the target population] to try to quit using tobacco products? B) What can help them succeed?**
6. **What do you think about the role that a healthy diet and physical activity can play in preventing some types of cancer?**

[Probe: Point out that a healthy diet and physical activity can help prevent some types of cancer, while being overweight or obese can increase the risks of some cancer.

- What other health conditions can be affected by diet and physical activity?
- What may make it difficult to have a healthy diet?
- What may make it difficult to be more involved in physical activity?

Probe for target population: lifestyle factors, cultural factors, other social determinants of health (poverty, limited time...). Try to get specific examples of circumstances or experiences.]

7. **What are opportunities to support [target population] to A) eat more healthy food and B) participate in more physical activity?**

C. Cancer Screening

Let's move on to discussing cancer screening and treatment.

8. **Have you, or anyone you know (family, friends, etc.) ever been screened for any type of cancer? If yes, what type(s)?**

[Probe for specific cancers, experience of others from the target populations, capturing specific examples of circumstances or experiences:

- a. How aware do you feel you are of the signs and symptoms that one might have cancer; in particular [specific cancer or/colorectal, lung, breast, or prostate cancer]?
- b. If one gets [specific] cancer, could you survive the disease? [probe what others from the target population think]

- c. Why would one get screened for cancer? [Probe: Do they understand that early screening can catch many types of cancer when they might be easier to treat?]

9. How important is it to you, and those you know, to have cancer screening? Why?

[Probe what others from the target population think]

10. What factors make it difficult to get screening for cancer?

[Probe for target populations, capturing specific examples of circumstances or experiences:

- Lifestyle factors
- Cultural factors
- Other social determinants of health (poverty, insurance, transportation, distance...)
- Systems barriers (procedures, policies, difficulty navigating the healthcare system)
- Provider cultural and general competence/relationships with screening providers]

11. What changes will have to happen to address these barriers to cancer screening?

D. Cancer Treatment

12. How do you, or other [target population] residents of the Southcoast view cancer treatment and care services?

[Probe for issues, capturing specific examples of circumstances or experiences:

- Ease of access to treatment services and care
- Quality of the treatment services and care
- Not worth getting treatment because cancer=death
- Fear of treatment because of lack of knowledge]

13. What tends to make it difficult for area residents to

- a. Start treatment for cancer?**
- b. Continue the full course of treatment?**
- c. Have high quality treatment?**

[Probe for target populations, capturing specific examples of circumstances or experiences:

- Lifestyle factors
- Cultural factors
- Other social determinants of health (poverty, insurance, time, responsibilities, transportation, distance...)
- Provider cultural and general competence/relationships with providers]

14. What changes will have to happen to address these barriers to receiving high quality cancer treatment?

15. Where do you go to get health care? Where would you go if you needed cancer treatment?

[Probe: What type of health facility? (Hospital, Community Health Center, HMO, etc.)

16. How would you, and those you know [in the target population], like to get information on cancer prevention and care?

[Probe:

- Primary care provider?
- Other doctor?
- Friend
- Internet?— any particular sites?
- Book, newspaper, article?
- Radio? — any particular station?
- Public health department (local vs. state)?
- Other organizations?
- Fact sheets at public places (where)?
- Other source?]

17. Based on your experiences, what recommendations do you have for the Massachusetts Department of Public Health to improve cancer screening and treatment experiences for and follow up with residents?

Step 7: Thank you for your help.

Handout project fact sheet, forms for reimbursement, and vouchers.

Step 2: Use Script as a Guide

“Thank you for speaking with me today. It is very much appreciated. Before we begin, let’s review why we have invited you to talk with us today and answer any questions you may have. The Massachusetts Department of Public Health has asked JSI Research & Training Institute, Inc. (JSI) to conduct a needs assessment to better understand how to prevent and control cancer in the Southcoast region of MA. This area needs assessment involves discussions and key informant interviews with health and service providers, focus groups with residents from the region and talking with community leaders who work closely in the communities affected. The process will allow us to gather information from different groups to better understand what steps can be taken to prevent and better control cancer, as well as to support those affected by the disease.

We encourage you to share your thoughts and opinions openly and freely. We will be recording and taking notes to make sure we have all the information you shared. Is that alright? This discussion should last no longer than _____ minutes.

[Refer to summary data on disparities sent in a separate chart]. We sent you a chart on cancer in Southeastern MA. The rates of cancer tend to be greater in Southeastern MA; especially among certain groups of people. Men, for example, have higher rates of lung cancer than the state and higher rates than women in the region. This is also true for Asian-Pacific Islanders. Black men tend to have higher prostate cancer than other men in the region or men in the state. Those residents who have cancer seem less likely to get early treatment. Smoking is high among men and young persons. We want to begin talking with you about cancer in Southeastern MA [in particular on the Southcoast] so that we can learn more about what may contribute to these facts. We will first talk about what might increase the chances for people in the region to get cancer. Then we will talk about what affects whether people in the area get screened for cancer. Lastly we want to talk about what can affect treatment for cancer in the region. *[Note any additional particular topics for this informant. For example: As a physician, we are also interested in learning from you about the experiences of your patients, their views and beliefs regarding cancer, and opportunities to address cancer risk factors]*. Let’s begin talking about possible explanations for cancer health disparities in Southeastern MA with a focus on the Southcoast.

Discussion Questions

E. General Awareness and Knowledge

1. What do you think drives these data on cancer disparities in Southeastern MA?

F. Cancer Prevention and Modifiable Risk Factors

2. Why do you think we are seeing higher cancer incidence (newly diagnosed cases) among Southcoast MA residents?

- a. What are the risk factors for cancer in Southcoast MA?

[Probe Lifestyle: Tobacco use, physical activity, nutrition, stress; co-morbidities - obesity]

Social Determinants: Environment, occupation, those cultural, economic, educational and other factors that contribute to lifestyle risk factors]

- b. What other chronic diseases are associated with these risk factors?

- c. How do these risk factors differ among populations groups with disparities in incidence?

[Probe regarding disparities among:

- i. Men (All, Lung cancer, Prostate)
- ii. Non-Hispanic Black (Prostate – men)]

- d. What other reasons may account for higher cancer diagnosis for total cancer and specific cancers for all SE MA residents and disparities among certain population groups with disparities in incidence?

- e. What changes will have to occur to address these concerns?

[Probe for: Opportunities to integrate with wellness initiatives]

G. Cancer Screening

Now that we have discussed cancer prevention, let us talk about cancer screening.

3. Why are we seeing disproportionately high rates of late stage cancer diagnosis among Southcoast MA residents?

- a. Is screening a problem? If yes, what are the facilitators and barriers on the health care system as well as on the patient level?
- b. What role does access to screening play?
- c. What changes will have to occur to address these concerns?

[Probe regarding disparities among:

- i. Women (Breast cancer)
- ii. Men (Lung cancer)
- iii. Men, non-Hispanic Black men (Prostate)]

H. Cancer Treatment

Let's move on to discuss cancer treatment and survival.

- 4. Why are we seeing higher cancer mortality among all Southcoast MA residents; and particularly among men?
 - a. In addition to late stage diagnosis, are there other factors in treatment and care?
 - b. What role does access to care play?
 - c. Does quality of treatment need to be addressed?
 - d. Are there other trends and factors we should be aware of, such as cultural factors among populations and provision of culturally-appropriate outreach and services? Are there religious beliefs that may hinder any health practices?
 - e. What changes will have to occur to address these concerns?

I. Other Recommendations

As we start to wrap-up our discussion, let me ask a few more general recommendations you might have....

5. Based on your experiences, what recommendations do you have for the Massachusetts Department of Public Health to improve cancer screening and treatment experiences for and follow up with residents?

[Probe:

- Are you familiar with the Affordable Care Act?
- Do you foresee ways the Act could provide new opportunities to address cancer disparities by improving prevention, screening, treatment and care?]

6. Are there others you recommend we speak with to learn more about cancer disparities and strategies to address them in the Southcoast?

[Post and handout data charts; project fact sheet.].

Step 1: Ice Breaker Questions

Convene the group, welcome everyone, and let's introduce ourselves. Can we go around and everyone say their name, affiliation, and a brief description of work they are engaged in to address cancer disparities in Southeastern MA?

Step 2: Use Script as a Guide

"Thank you for joining us today. It is very much appreciated. Before we begin, let's review why we have invited you to talk with us today and answer any questions you may have. The Massachusetts Department of Public Health has asked JSI Research & Training Institute, Inc. (JSI) to conduct a needs assessment to help them better understand how to prevent and control cancer in the Southcoast region of MA. This needs assessment involves discussions and key informant interviews with health and service providers, focus groups with residents from the region and talking with community leaders who work closely in the communities affected. The process will allow us to gather information from different groups to better understand what steps can be taken to prevent and better control cancer, as well as to support those affected by the disease.

We encourage you to share your thoughts and opinions openly and freely, but please understand that we may have to politely interrupt in order to get information from everyone. We will be taking notes and recording our conversation to make sure we have all the information you shared. Does anyone object? This discussion should last no longer than _____ hours.

[Review chart data on disparities]. Based on these data that were just presented, let's have a conversation about possible explanations for cancer health disparities in Southeastern MA with a focus on the Southcoast.

Discussion Questions

6. What do you think about these data on disparities in the Southcoast?

[Probe: Have you noticed elevated incidence of cancer among your clients?
If yes, among which groups?]

7. Why are we seeing higher cancer diagnosis among Southcoast MA residents?

a. What are the risk factors for cancer in Southcoast MA?

[Probe Lifestyle: Tobacco use, physical activity, nutrition; co-morbidities - obesity]

[Social Determinants: Environment, occupation, those cultural, economic, educational and other factors that contribute to lifestyle risk factors]

- What other chronic diseases are associated with these risk factors?

b. How do these risk factors differ among populations groups with disparities in incidence?

[Probe regarding disparities among:

- i. Men (All, Lung cancer, Prostate)
- ii. Non-Hispanic Black (Prostate – men)]

c. What other reasons may account for higher cancer diagnosis for total cancer and specific cancers for all SE MA residents and disparities among population groups with disparities in incidence?

d. What changes will have to occur to address these concerns?

8. Why are we seeing disproportionately high rates of late stage cancer diagnosis among Southcoast MA residents?

a. Is screening a problem? If yes, what are the facilitators and barriers on the health care system as well as on the patient level?

b. What role does access to screening play?

c. What changes will have to occur to address these concerns?

[Probe regarding disparities among:

- i. Women (Breast cancer)
- ii. Men (Lung cancer)
- iii. Men, Non-Hispanic Black men (Prostate)]

- 9. Why are we seeing higher cancer mortality among all Southcoast MA residents; and particularly among men?**
- a. In addition to late stage diagnosis, are there other factors in treatment and care?**
 - b. What role does access to care play?**
 - c. Does quality of treatment need to be addressed?**
 - d. Are there other trends and factors we should be aware of, such as cultural factors among populations and provision of culturally-appropriate outreach and services?**
 - e. What changes will have to occur to address these concerns?**
- 10. Based on your experiences, what additional recommendations do you have for the Massachusetts Department of Public Health to improve cancer screening and treatment experiences for and follow up with residents?**
- [Probe:
- Are you familiar with the Affordable Care Act?
 - Do you foresee ways the Act could provide new opportunities to address cancer disparities?]

APPENDIX 4: FOCUS/PROVIDER GROUP INVITATION SAMPLE

The Massachusetts Department of Public Health (MDPH) Comprehensive Cancer Prevention and Control Program (MCCPCP) in collaboration with JSI Research & Training Institute, Inc. (JSI) and the Massachusetts Cancer Disparities/Health Equity Workgroup invite you to attend a community leader roundtable to discuss the following topic:

How can we prevent cancer in Southeastern Massachusetts and best serve residents with cancer?

Join the discussion!

Receive a \$50 Gift Certificate

Monday June 3rd, 2013

12p.m.-1:30p.m. (lunch provided)

Bristol Community College

1082 Davol Street, 2nd Floor

Fall River, MA 02720



Our goal is to learn more about needs and opportunities to address cancer in Southeastern Massachusetts. The region has higher rates of cancer, and these are often diagnosed later when it is harder to treat. Men and young adults, as well as individuals who are Black, Asian/Pacific Islanders, and other groups tend to be at higher risk and/or to have worse outcomes than others in the region and the state. Smoking is particularly common in Southeastern MA and there are other risk factors for cancer and other serious health conditions that can be prevented which we will explore.

At the same time, many community and regional organizations are actively working to address cancer in Southeastern MA.

**To RSVP for the meeting or for more information,
please contact:**

Janie Hynson
Phone: 617.385.3757
E-mail: jhynson@jsi.com



Data Summary: Southeastern Massachusetts Cancer Disparities

Southeastern Massachusetts

The Southeastern MA region has a population of 1,264,497 with nearly half of the population male (48%). Eighteen percent of the population is less than 18 years of age and 11% is 65 years or older. Five percent of the population is non-Hispanic Black and 4% is Hispanic. Sixteen percent of the population identifies as Portuguese ancestry. Fifteen percent speak a language other than English. 13% have less than a high school education. Nine percent of individuals are living in poverty – more specifically, 13% of children live in poverty and 8% of older adults live in poverty. The unemployment rate is higher in Southeast MA than any other Executive Office of Health and Human Services region in the State at 8%. Ninety-seven percent of the population reports having insurance.

Cancer Disparities Data Summary

Southeastern MA was selected for this needs assessment based on the following data:

- *Cancer incidence:* Southeast MA had higher rates of overall cancer incidence (new cases), lung and prostate cancer than the State. Groups disproportionately affected in Southeast MA included men (all types of cancer and lung cancer), non-Hispanic Asian/Pacific Islanders (lung cancer) and non-Hispanic Black men (prostate cancer).
- *Late diagnosis of cancer:* Southeast MA had a higher proportion of late/distant stage cancer for all types (no subgroup disparities found).
- *Cancer hospitalization:* Southeast MA had higher rates of hospitalization for all types of cancer, breast, lung and prostate. The non-Hispanic Black population and men were more likely to be hospitalized for any type of cancer in Southeast MA. Further, men were more likely to be hospitalized for lung cancer and non-Hispanic Black men were more likely to be hospitalized for prostate cancer in Southeast MA.
- *Cancer mortality:* Southeast MA had higher mortality (death) rates for any type of cancer and lung cancer. In Southeast MA, the non-Hispanic Black population and men were more likely to die from any type of cancer and men were more likely to die from lung cancer.
- *Smoking as a risk factor:* Central MA and Southeast MA had significantly higher smoking than the State. The non-Hispanic other race population, men and young adults had high smoking prevalence in Southeast MA.





Cancer Disparities Needs Assessment

The Massachusetts Department of Public Health (MDPH) is carrying out a community assessment in Southcoast Massachusetts. MDPH selected JSI Research & Training Institute, Inc. (JSI) to conduct the study. It has two phases, described below:

Selecting the Region

The Southcoast communities were selected because, when compared to MA as a whole:

- There are more new cases of cancer in the region.
- Cases of lung and prostate cancer are high.
- Cancer is more often diagnosed at a late stage when it can be more difficult to treat.
- Breast, lung, and prostate cancer hospitalization rates are higher.
- Death rates are higher for all cancers and for lung cancer specifically.

Race, gender, age, income, and education each affect cancer rates in the area. Smoking tends to be common in the region. Smoking increases the risk for chronic diseases including cancer, diabetes, heart disease and stroke. The effect of diet, physical activity, obesity, and environmental health will also be explored during the assessment.

Identifying Needs and Opportunities

Many local organizations are actively working to address cancer in the Southcoast MA. JSI will be working with individuals and organizations to gather information about cancer issues in the area. This includes holding individual interviews, focus groups, and group discussions. This process will identify needs, priorities, and barriers to care. It will help gather recommendations to inform prevention activities. Also to improve access to high quality health care services that meet the needs of residents of all backgrounds and cultures.



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MDPH Comprehensive Cancer Prevention and Control Program



Cancer Disparities/Health Equity Strategic Planning Needs Assessment

The Massachusetts Department of Public Health (MDPH) Comprehensive Cancer Prevention and Control Program (MCCPCP) is supporting a comprehensive community assessment in Southeastern Massachusetts, with a focus on the Southcoast. This activity is one of the strategies of the disparities and health equity goal of the 2012-2016 MCCPCP State Plan. JSI Research & Training Institute, Inc. (JSI) a public health consulting company headquartered in Boston, was selected to carry out the assessment. The assessment is comprised of 2 phases: 1) selection of the region, and 2) identifying needs and opportunities to address cancer disparities.

Selecting the Region

In the first phase of the project, JSI worked in collaboration with MDPH and the Disparities/Health Equity Workgroup to identify a region/sub-region that is the focus of the Cancer Disparities/Health Equity Strategic Planning Needs Assessment. Southeastern MA was selected due to several factors. Among these were a number of disparities in cancer apparent in the recent data that were analyzed. The Southeastern region has higher incidence rates (new diagnoses) for all cancer combined, as well as for lung and prostate cancer than Massachusetts as a whole. Cancer was more frequently diagnosed at a late stage when it can be more difficult to treat and leads to higher mortality. More residents in the region were hospitalized for cancer, with breast, lung and prostate cancer hospitalization rates higher than the state. Mortality was also higher in the region than in Massachusetts for all cancers overall and for lung cancer specifically. There were also cancer disparities by race, gender, and age while a previous study identified disparities also in income, and education in the Southcoast region. Smoking is particularly common in Southcoast MA and it is a major risk factor for chronic diseases including cancer, diabetes, heart disease and stroke. Other preventable risk factors that we will explore include poor nutrition, lack of physical activity, obesity, and environmental health. The assessment also identified many community and regional organizations actively working to address disparities in Southcoast Massachusetts.



Identifying Needs and Opportunities

JSI will be working with individuals and organizations in the region to develop a broad understanding of the barriers and factors that lead to health inequity. The JSI team will contact local and regional stakeholder groups to gather information about regional cancer issues. JSI will conduct focus groups with target populations that are at high risk of cancer and key informant interviews and group discussions with local stakeholders.

This process will identify needs, priorities, and barriers to care and offer recommendations for strategies or programmatic options (e.g. targeted educational outreach for underserved groups and quality improvement projects for providers) to advance and help inform regional prevention activities, ensure appropriate screening and improve access to culturally competent, high quality health care services.

For more information contact:

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TELL US ABOUT YOU 1

1. How old are you?

- ☐ 18 - 34
☐ 35 - 44
☐ 45 - 64
☐ 65 and over

2. What is your gender?

- ☐ Female
☐ Male
☐ Other (specify _____)
☐ Unknown/not specified

3. What is your ethnicity? (You can specify one or more)

- ☐ African (specify _____)
☐ African American
☐ American
☐ Asian Indian
☐ Brazilian
☐ Cambodian
☐ Cape Verdean
☐ Caribbean Islander (specify _____)
☐ Chinese
☐ Colombian
☐ Cuban
☐ Dominican
☐ European
☐ Filipino
☐ Guatemalan
☐ Haitian
☐ Honduran
☐ Japanese
☐ Korean
☐ Laotian
☐ Mexican, Mexican American, Chicano
☐ Middle Eastern (specify _____)
☐ Portuguese
☐ Puerto Rican
☐ Russian
☐ Salvadoran
☐ Vietnamese
☐ Other (specify _____)
☐ Unknown/not specified

4. What is your race? (You can specify one or more)

- ☐ American Indian/Alaska Native
 (specify tribal nation _____)
☐ Asian
☐ Black
☐ Native Hawaiian or other Pacific
 Islander (specify _____)
☐ White
☐ Other (specify _____)
☐ Unknown/not specified

5. What is your country of birth?

6. Are you Hispanic/Latino/Spanish?

- ☐ Yes
☐ No

7. What is the highest degree or level of school you have completed?

- ☐ Less than a high school diploma
☐ High school graduate, no college
☐ Some college or associates degree
☐ Bachelor's degree
☐ Advanced degree (Masters, RN, PhD, JD, MD)

8. Do you have health insurance?

- ☐ Yes
☐ No

9. What was your total household annual income before taxes in 2011 (include all earners in your household)?

- ☐ Less than \$10,000
☐ \$10,000 - \$24,999
☐ \$25,000 - \$49,999
☐ \$50,000 - \$74,999
☐ \$75,000 or more

APPENDIX 9: INDIVIDUAL FOCUS GROUP PARTICIPANT DEMOGRAPHICS

COMMUNITY HEALTH WORKERS GROUP – IMMIGRANTS’ ASSISTANCE CENTER, INC. (9 PARTICIPANTS):

PARTICIPANT	AGE	GENDER	ETHNICITY	RACE	COUNTRY OF BIRTH	HISPANIC/LATINO/ SPANISH	EDUCATION	HEALTH INSURANCE
1	18-34	F	Cape Verdean	Not reported	U.S.	No	Some college or assoc. degree	Yes
2	45-64	F	Portuguese	Not reported	Portugal	No	High school	Yes
3	45-64	F	Cape Verdean	Black & white	Senegal-West Africa	No	Bachelor's degree	Yes
4	35-44	F	Puerto Rican	Hispanic	Puerto Rico	Yes	Some college or assoc. degree	Yes
5	45-64	F	Portuguese	White	Portugal	No	Some college or assoc. degree	Yes
6	18-34	F	Puerto Rican	Multiracial	Puerto Rico	Yes	Some college or assoc. degree	Yes
7	45-64	F	Portuguese	White	Portugal	No	Advanced degree	Yes
8	35-44	F	Portuguese	Portuguese	Portugal	No	Bachelor's degree	Not reported
9	35-44	F	Dominican	Hispanic	Dominican Republic	Yes	Bachelor's degree	Yes

GED CLASS – BRISTOL COMMUNITY COLLEGE (9 PARTICIPANTS):

PARTICIPANT	AGE	GENDER	ETHNICITY	RACE	COUNTRY OF BIRTH	HISPANIC/LATINO/ SPANISH	EDUCATION	HEALTH INSURANCE	INCOME
1	18-34	F	Puerto Rican	Spanish	Puerto Rico	Yes	Less than a high school diploma	Yes	\$25,000-\$49,999
2	18-35	F	American	White	U.S.	No	Less than a high school diploma	Yes	\$25,000-\$49,1000
3	35-44	F	Honduran & Other	Other	U.S.	No	Less than a high school diploma	Yes	Less than \$10,000
4	18-34	F	Puerto Rican	Spanish	U.S. (PA)	Yes	Less than a high school diploma	Yes	\$25,000-\$49,999
5	35-44	F	American	White	U.S. (MA)	No	Less than a high school diploma	Yes	Less than \$10,000

6	18-34	F	Puerto Rican	Hispanic	U.S. (Boston, MA)	Yes	Less than a high school diploma	Yes	Less than \$10,000
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PORTUGUESE-SPEAKING MIXED-GENDER GROUP – IMMIGRANTS’ ASSISTANCE CENTER, INC. (11 PARTICIPANTS):

PARTICIPANT	AGE	GENDER	ETHNICITY	RACE	COUNTRY OF BIRTH	HISPANIC/LATINO/ SPANISH	EDUCATION	HEALTH INSURANCE	INCOME
1	65 and over	F	Portuguese	White	Portugal	Not reported	Less than a high school diploma	Yes	\$25,000-\$49,999
2	65 and over	F	Portuguese	White	Portugal	No	High school graduate	Yes	\$25,000-\$49,999
3	65 and over	M	Portuguese	White	Portugal	No	Some college or assoc. degree	Yes	\$25,000-\$49,999
4	45-64	F	Portuguese	White	Portugal	No	High school graduate	No	\$10,000-\$24,999
5	65 and over	F	Portuguese	White	Portugal	No	Less than a high school diploma	Yes	\$25,000-\$49,999
6	18-34	M	Cape Verdean	Black	Cape Verde	No	High school graduate	Yes	\$25,000-\$49,999
7	18-34	F	Cape Verdean	Mixed race	Cape Verde	No	Some college or assoc. degree	Yes	\$25,000-\$49,999
8	65 and over	M	Portuguese	White	Portugal	No	Less than a high school diploma	Yes	\$10,000-\$24,999
9	65 and over	Not reported	Portuguese	White	Portugal	Not reported	Less than a high school diploma	Yes	\$10,000-\$24,999
10	65 and over	F	Portuguese	White	Portugal	No	Less than a high school diploma	Yes	\$10,000-\$24,999
11	65 and over	F	Portuguese	White	Portugal	No	Less than a high school diploma	Yes	Less than \$10,000

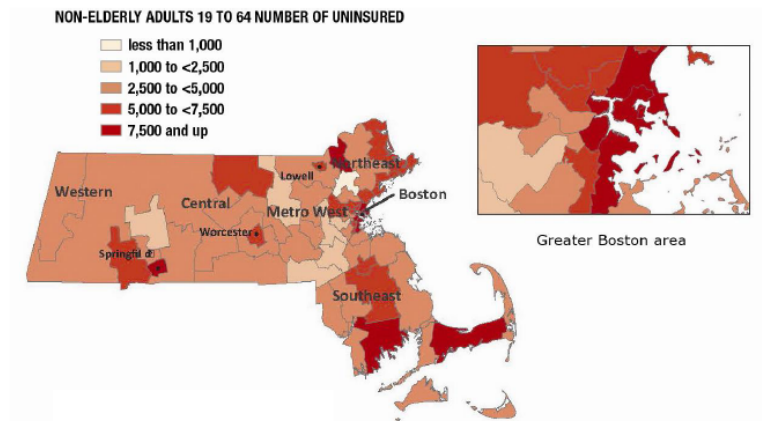
NON-HISPANIC BLACK MEN GROUP – BROCKTON NEIGHBORHOOD HEALTH CENTER (9 PARTICIPANTS):

PARTICIPANT	AGE	GENDER	ETHNICITY	RACE	COUNTRY OF BIRTH	HISPANIC/LATINO/ SPANISH	EDUCATION	HEALTH INSURANCE	INCOME
1	45-64	M	Haitian	American Indian/Alaska Native	Haiti	No	High school graduate (Secondary education)	Yes	Not reported

2	45-64	M	Haitian	Black	Not reported	No	Less than high school diploma	Yes	\$50,000-\$74,999
3	65 and over	M	Haitian	Black	Haiti	No	Less than high school diploma	Yes	Less than \$10,000
4	18-34	M	Haitian	Black	Haiti	No	High school graduate	Yes	Less than \$10,000
5	35-44	M	Haitian	black	Haiti	No	Not reported	Not reported	Not reported
6	35-44	M	Haitian	Black	Haiti	No	Some college or associates degree	Yes	\$25,000-\$49,999
7	45-64	M	Haitian	Black	Haiti	No	Some college or associates degree	Yes	\$50,000-\$74,999
8	45-64	M	African American	Not reported	USA	No	Advanced degree	Yes	\$50,000-\$74,999
9	45-64	M	Haitian	Black	Haiti	Not reported	Less than high school diploma	Yes	Less than \$10,000

APPENDIX 10: INSURANCE RATES AMONG SOUTHEASTERN MA WORKING ADULTS

NUMBER OF UNINSURED NON-ELDERLY ADULTS 19 TO 64 IN MASSACHUSETTS, 2010



SOURCE: 2010 American Community Survey (ACS).

- In 2010, the highest number of uninsured non-elderly adults in Massachusetts was in the Greater Boston Area, with pockets of uninsurance in Springfield and the Southeastern part of the state.
- The places in the state with the highest number of uninsured non-elderly adults over the 2008-2010 period were New Bedford (6,415), Lowell (6,422), Worcester (7,630), Springfield (8,792) and Boston (31,473) (data not shown).

Source: Sharon K. Long, Dana Goin and Victoria Lynch. *Reaching the Remaining Uninsured in Massachusetts: Challenges and Opportunities*. Urban Institute (March 2013).