



GREATER LOWELL CANCER DISPARITIES NEEDS ASSESSMENT

JUNE 2015



GLHA
GREATER LOWELL HEALTH ALLIANCE





Executive Summary	3
Introduction	4
Methodology	5
Service Area and Population	6
Acknowledgement of Limitations	7
Section 1: Findings: Cancer, Cancer Prevention and Educational Outreach	8
Section 1: Recommendations: Cancer Prevention and Educational Outreach	12
Section 2: Understanding Barriers To Screening, Treatment And Care	14
Section 2: Recommendations For Reducing Barriers To Screening, Care And Treatment For Those At Greatest Risk For Cancer Disparities In The Greater Lowell Area	18
Next Steps: Identifying Top Priorities And Action Plans	20
Appendix A - Individuals Interviewed	22
Appendix B - Key Informant Interview Facilitator Guide	23
Appendix C - Community Focus Group Facilitator Guide	23
Appendix D - Health Director Round Tables Facilitator Guide	24
Appendix E - Professional Focus Group Facilitator Guide	24
Appendix F - Provider Focus Group Facilitator Guide	25
Appendix G - Data Summary	25
Appendix H - Incidence, Hospitalizations and Mortality of Top Area Cancers	27

Greater Lowell Cancer Disparities Needs Assessment
Conducted on behalf of Greater Lowell Health Alliance
Authors: David Turcotte, ScD; Michele Ross, MA; and Emily Chaves, MA
University of Massachusetts Lowell
June 2015

EXECUTIVE SUMMARY

The Greater Lowell Health Alliance, in partnership with the University of Massachusetts Lowell, conducted an assessment of cancer disparities for the Greater Lowell area, which includes the towns of Billerica, Chelmsford, Dracut, Dunstable, Lowell, Tewksbury, Tyngsborough, and Westford. The purpose of this assessment is to evaluate what providers, professionals and community members know, think, and understand about cancer and cancer disparities facing area residents. By identifying the key factors and concerns involved in the higher prevalence of cancer in the Greater Lowell area, recommending actions to address priority concerns, and providing information that informs a community process, this assessment intends to build consensus around strategies to improve the cancer outcomes of Greater Lowell residents.

This report summarizes the major findings from our cancer disparities assessment. The primary data sources included interviews with nine key informants, twelve focus groups, and provider roundtables – for a total of 116 participants – and secondary data sources included demographic, socioeconomic, and public health data.

The top concerns and issues identified in the focus groups and interviews, and supported by public health data, include lack of insurance or access to insurance, lack of access to providers, lack of cultural awareness/sensitivity/competency on the part of providers, lack of cancer prevention education geared toward non-English-speaking communities, lack of culturally appropriate outreach at the community level, and poverty/low socioeconomic status (SES). The residents identified at greatest risk of cancer care disparity include documented and undocumented immigrants of a variety of ethnicities, those in minority communities, low income individuals, the uninsured, the elderly in the previously identified communities, and those in the homeless populations.

The major issues identified include insufficient access to insurance, insufficient low income/free care in local hospitals, insufficient cultural awareness/sensitivity/competency on the part of some providers, and inadequate culturally sensitive prevention outreach efforts. In addition, community-level focus groups indicated a lack of availability of the following services: care navigator support for non-English-speaking patients, interpreting/translation services, and Portuguese- and Khmer- language support groups for cancer patients and their families.

Social determinants that affect community health in general and cancer specifically are highlighted below:

- For members of minority communities, discrimination on the basis of race and ethnicity is an issue when accessing care.
- For members of newly immigrated communities, cultural factors contribute to cancer disparities.
- The high incidence of tobacco use in immigrant communities, specifically the Asian community, contributes to lower health outcomes in general, and higher incidence of all cancers.
- For those with no insurance, insufficient insurance coverage, or those who are undocumented, lack of local free care for cancer in the Greater Lowell area is a barrier.
- For those of lower SES, access to nutritious foods is inadequate, and more affordable nutritious foods are less accessible to those without transportation.
- For those in low wage jobs, access to afterhours appointments with providers and for screening services is a barrier.
- For those with lower SES, health care is often a luxury.
- For those with no insurance, insufficient insurance coverage, or those who are undocumented, lack of local free care for cancer in the Greater Lowell area is a barrier.

Key recommendations suggest a two pronged approach: first, improving access to health care services for under insured, minority, undocumented and low SES populations; and second, increasing the cultural awareness and competency of area providers, increasing the availability of culturally and linguistically appropriate outreach directly into communities. The efforts could include improving access to health care services for the un and under insured; increasing health care advocacy for the uninsured, those of lower SES and minority populations; increasing community outreach and focus on community-level culturally appropriate strategies for cancer prevention and lifestyle awareness including smoking cessation and nutrition programs; providing cultural competency and sensitivity training for providers at all levels; expanding interpreter/language services; implementing strategies to make the health delivery system more sensitive to the needs of minority patients, for instance increasing the number of care navigators for non-English speakers, expanding care related transportation services; and increasing the availability of afterhours care.

The Greater Lowell Health Alliance, in partnership with the University of Massachusetts Lowell, conducted an assessment of cancer disparities for the Greater Lowell area, which includes the towns of Billerica, Chelmsford, Dracut, Dunstable, Lowell, Tewksbury, Tyngsborough, and Westford. University of Massachusetts Lowell Faculty, staff and students collaborated with community partners to complete this assessment to better understand how to prevent and control cancer and health disparities in the Greater Lowell region of Massachusetts.

The objectives of this assessment were to:

- Evaluate what community members know, think and understand about cancer and cancer disparities facing area residents and the populations at greatest risk.
- Identify the strengths and weaknesses of the local healthcare system and the delivery of cancer related services.
- Involve a broad spectrum of providers, professionals and residents, including newer immigrant communities.
- Provide recommendations to improve the delivery of cancer related education, outreach and care.
- Identify key issues and factors contributing to disparities in rates of screening, diagnosis and mortality, recommend actions to address priority concerns, and provide information that informs a community process to build consensus around strategies to improve the cancer outcomes of Greater Lowell residents.
- Implement strategies to address these priority concerns with the goal of both improving cancer outcomes and reducing cancer disparities for Greater Lowell residents.

This report summarizes the major findings from our cancer disparities needs assessment.

This assessment involved primary data collection using focus groups and key informant interviews, as well as analysis of secondary data sources, including the Massachusetts Department of Public Health MassCHIP database and the United States Census. A more detailed description is below:

Focus Groups and Provider Roundtables

Twelve focus groups and provider roundtables with 116 total participants were conducted from April 21 through June 15, 2015. Several participants were either cancer survivors or had family members that have the disease or died from the disease. The composition and number of the focus groups organized and the list of individuals invited were determined by the University of Massachusetts Lowell research team, the Greater Lowell Health Alliance and our Advisory Committee Alliance, as well as other community partners. Each focus group averaged about 90 minutes and included 15-20 questions, depending on the group. University of Massachusetts Lowell researchers and community partners developed several community and professional focus group and provider roundtable facilitation guides (see appendices B-F) that were tailored based on the type of participants. Professional focus group and provider roundtable participants were provided with a data summary compiled by University of Massachusetts Lowell about cancer disparities in Lowell and the Greater Lowell Area to offer context for this needs assessment and to inform participants about the presence of specific cancer disparities in the region.

Six of the focus groups/provider roundtables were organized by professional or organizational grouping. These included groups such as The Hunger Homeless Commission, public health directors and public health nurses from surrounding towns and cities, Lowell General Hospital and Cancer Center oncologists, nurses and social workers, Lowell Community Health Center physicians and nurses, and Lowell General Hospital/Circle Home providers. A data summary including area demographics and cancer incidence statistics was provided to provider roundtable and professional focus group attendees.

Providers were asked to discuss the following topics:

- General responses to the data showing cancer disparities in the Greater Lowell area and whether or not they have noticed elevated cancer incidence among their patients.
- Reasons for higher cancer diagnosis among Greater Lowell residents: risk factors for cancer in Greater Lowell residents 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 Greater Lowell 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 education and outreach, screening, treatment, and follow-up with residents.

The remaining six focus groups took place at the community level. Community focus groups were not provided a data summary as they were interviewed as individuals and members of their specific communities. All focus groups were audio recorded and notes were also taken. The team of focus group facilitators included UMass Lowell faculty, staff and graduate students, as well as individuals from the Cambodian Mutual Assistance Association, the Massachusetts Alliance of Portuguese Speakers and the Lowell Community Health Center. Focus groups were conducted in English, Khmer, Portuguese and Spanish.

Community members were asked to discuss the following topics in relation to their own knowledge and perspectives, and what they have heard or learned from other people in their community:

- General awareness and knowledge of cancer: community members' awareness and familiarity with cancer in general, different types of cancer, signs and symptoms of cancer.
- Cancer prevention and modifiable risk factors: the factors that cause cancer and what can be done to reduce cancer risk.
- Cancer screening: history of cancer screening among the community members, family and friends, 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 community members would like to receive education and outreach related to cancer prevention and care, and recommendations for how to address barriers to receiving care.
- Overall recommendations for the Massachusetts Department of Public Health to improve cancer outreach and education, screening, and treatment in the Greater Lowell area.

Key Informant Interviews

The University of Massachusetts Lowell conducted nine interviews with individuals identified by the University of Massachusetts Lowell research team, the Greater Lowell Health Alliance, and our Advisory Committee, as well as other community partners, as key community informants because of their positions and knowledge of community health needs (see appendix). Those interviewed were asked to participate as private individuals and not as official spokespersons

for their organizations. David Turcotte and Michele Ross conducted both in-person interviews and telephone interviews from April 16, 2015 to May 28, 2015. All interviews were audio recorded with notes also taken, and they lasted approximately 45 minutes. Interview questions were similar to those used in the focus groups and provider roundtables. Key informants were provided with the data summary sheet compiled by University of Massachusetts Lowell about cancer disparities in Lowell and the Greater Lowell Area to offer context for this needs assessment and to inform participants about the presence of specific cancer disparities in the region.

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

- General awareness and knowledge of factors behind data showing cancer disparities in the Greater Lowell area.
- Cancer prevention and modifiable risk factors: perspectives on factors behind higher cancer incidence among Greater Lowell 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 Greater Lowell residents, issues and barriers related to screening, and recommendations to address these concerns.
- Cancer treatment and survival: reasons for higher cancer mortality among all Greater Lowell 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 for the Massachusetts Department of Public Health to improve cancer education and outreach, screening, treatment, and follow-up with residents of the Greater Lowell area as well as recommendations for others with whom researchers should speak to learn about cancer disparities and strategies to address them in the Greater Lowell area.

Analysis of Secondary Data Sources

Most population cancer data was accessed through the MassCHIP database. This data was used to provide an overview of cancer disparities among the residents of Lowell General Hospital's service area, the Greater Lowell Community Health Network Area (also known as CHNA-10). Data were generally comparatively analyzed and presented at the Lowell, Greater Lowell CHNA, and statewide levels. Data on the City of Lowell was analyzed and presented because of the size and diversity of the City of Lowell community, and the city's greater number of health related issues and needs. Data are mostly presented using bar charts and graphs (see Appendix H).

Other secondary data sources included the US Census and local governmental reports.

SERVICE AREA AND POPULATION

Lowell, Massachusetts has a population of 107,466 (2013). 22.9 % of the population is less than 18 years old, and 10.7% is 65 years old or older. 19.8 % identify as Asian, 17.6% identify as Hispanic or Latino. 19% are living in poverty. In 2011, 26.2% of Lowell's population smoked compared to 22.3% of the Greater Lowell Region population and 18.2% of the Massachusetts population.

The Greater Lowell Region of Massachusetts has a population of 279,382. 23.4% of the population is less than 18 years old, and 12.3% are 65 years old or older. 11.3% identify as Asian and 8.7% identify as Hispanic or Latino. 10% are below poverty level. The median income is \$76,493 in the Greater Lowell Region.

The City of Lowell, the largest community, differs significantly from its surrounding suburbs. Since its founding in 1820 as a planned industrial city for textile manufacturing, the City of Lowell has been a gateway for newer immigrants arriving to Massachusetts. Immigration has been an important factor for Lowell's population growth in its early history and population stability over the last 30 years. In the 1800s, immigrants predominately arrived from Europe and Quebec, Canada. Today, Lowell continues to attract newer immigrant populations. Currently, most recent arrivals have come from Latin America, Asia and Africa. As a result, Lowell has the largest percent of foreign born (24.8%) in the service area.

Conversely, most suburban communities have less than 10% foreign born, with Westford the exception at 13.2%. Lowell is more diverse, with a 41.9% non-white population, an Asian population of 19.8% and a Latino population of 17.6%. Westford and Chelmsford have sizable Asian populations (13.4% and 8.1%, respectively) compared to other area towns.

The economy of Lowell has also changed significantly since the 1800s; it is no longer the economic center for the region. As the overall regional economy has moved from traditional manufacturing to high tech and services, the number of jobs in Lowell has declined considerably. Few manufacturing jobs remain. As is common in today's economy, those who lack higher education and training face a job market comprised of mainly low-paying service jobs. These jobs often lack benefit packages and do not offer the upwardly mobile manufacturing opportunities previously available. Accordingly, Lowell also has the highest unemployment rate in the region (7.7%), 13% more than the next highest rate in the area. 9.2% (2010) of the population reports not having insurance. Lowell also has the highest poverty rate (19%), notably higher than other communities and 10 times higher than Westford (1.8). Overall, Lowell is the least affluent community with a median household income of \$49,452 which is less than half the income of the towns, such as Westford (\$124,464) and Dunstable (\$119,022).

ACKNOWLEDGEMENT OF LIMITATIONS

While the University of Massachusetts Lowell research team, the Greater Lowell Health Alliance, and their community partners have identified several factors that may be affecting cancer disparities in the Greater Lowell area, these results and findings have the following limitations:

- The research team was able to gain valuable information through round table discussions, interviews and focus groups, the findings are qualitative not quantitative and are based on a small, non-random sample, due to the time constraints of 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 this research team was unable to explore. Because this research team looked at a range of factors including prevention (lifestyle, physical activity, and nutrition), screening and treatment, the findings described in this report reflect a broad overview of many different issues and factors related to cancer disparities rather than greater details on one issue or factor.
- The assessment was geographically limited due to limited resources. Community focus groups were conducted in Lowell and participants were predominately Lowell residents.
- The views expressed in this report are of the roundtable, focus group and interview participants and are based on a small, non-random sample. Therefore, the findings do not represent the population as a whole.

Table – Basic Demographic Data, Cities and Towns in the Greater Lowell CHNA

CITY/TOWN	POPULATION	% WHITE	% FOREIGN BORN	% AGED 0-17	% AGED 65+	% BELOW POVERTY	% UN-EMPLOYED	MEDIAN HOUSEHOLD INCOME	% BLACK	% ASIAN	% HISPANIC
Billerica	40,932	91.0	9.8	22.8	12.7	6.3	5.7	88,296	1.7	4.8	3.1
Chelmsford	34,199	88.2	11.4	23.0	16.0	4.3	4.5	96,336	0.6	8.1	4.1
Dracut	29,968	90.5	6.1	23.5	12.5	4.3	5.0	78,169	2.9	3.7	4.6
Dunstable	3,255	94.3	4.5	25.7	11.7	1.2	3.6	119,022	0.0	2.4	0.3
Lowell	107,466	58.1	24.8	22.9	10.7	19.0	7.7	49,452	6.8	19.8	17.6
Tewksbury	29,466	93.3	6.9	21.2	15.3	3.1	5.2	89,241	1.8	3.0	1.8
Tyngsborough	11,675	92.8	6.6	22.9	10.3	5.9	6.8	90,987	0.6	5.0	2.6
Westford	22,458	82.8	13.2	29.7	10.4	1.8	5.5	124,464	0.7	13.4	2.2
Total/Weighted Ave.	279,382	77.6	15.1	23.4	12.3	10.0	6.2	76,493	3.5	11.3	8.7
Massachusetts	6,605,058	80.5	14.6	21.3	14.1	11.4	6.0	66,866	6.9	5.6	9.9

Data retrieved from the American Community Survey 2009-2013 five-year estimates.

SECTION 1:

CANCER, CANCER PREVENTION AND EDUCATIONAL OUTREACH

The findings and recommendations developed from information shared by professionals, providers, key informants, and community members who participated in the needs assessment have been organized into two sections. The first presents findings that affect cancer prevention and outreach. The second section of this report includes findings and recommendations regarding cancer screening and treatment.



Finding 1: Risk Factors for Cancer in the Greater Lowell Area are Primarily Related to Low Socioeconomic Status (SES).

Providers, professionals and community members cited concerns and issues that they believe may contribute to the high rates of cancer overall as well as specific types of cancer in the region. Participants cited social determinants of health including low SES, and lack of living wage employment opportunities. These were considered to be drivers of many of the factors contributing to cancer disparities and health inequities. Among the most often mentioned contributors were risk factors including lifestyle choices such as smoking and diet, cultural issues related to accessing care, access issues related to lack of insurance, and lack of physical access to care. Also noted were the impacts of low SES on lifestyle choices.

Providers, professional group respondents and key informants cited low SES, and lifestyle choices including smoking as contributing to cancer disparities in Greater Lowell. Specific risks identified as being associated with low SES include lack of cancer and health awareness, smoking, diet, physical activity and obesity. It is generally agreed that lifestyle issues including diet and smoking among immigrant population groups contribute to differences in disparities in incidence. Specifically mentioned was the high incidence of culturally influenced smoking among Asian populations influencing lung cancer rates in that community¹. Providers and professionals cited post immigration diet and access to healthy food choice in immigrant communities as issues contributing to disparities among immigrant populations.

Also associated with SES are frequently cited employment issues, including working long hours, multiple jobs, lack of time off and loss of income when taking time off. Those working low wage jobs, sometimes more than one, generally do not have sick leave and cannot afford to take time away from work to see a doctor. Additionally, those interviewed cited access to screening and physical/logistical issues (transportation, hours of operation, location of facility) as contributing to the data on cancer disparities. Those in low wage jobs, if they can take time away from work to go to an appointment, find that it is logistically impossible to make an appointment when they are available because care is generally not offered outside of traditional business hours. One key informant acknowledged that the *'local health delivery system has not adapted to change of demographics fast enough.'*

Community level respondents also cited low SES, and lifestyle choices as reasons for the higher rates of cancer in the Greater Lowell area, but as important to community members were language and cultural issues. Many don't have insurance, and many have insurance that does not cover everything. Many do not have extra money for co pays. Some cited cultural/generational/religious factors as barriers, such as language and the lack of Portuguese interpreters,

others cited attitude/perception/fear as barriers – they did not want go to the doctors for fear of bad news, and fear of the tests themselves. Several respondents felt that the higher rate of cancer diagnosis reflected that, for some populations, health care is not a priority. In community focus groups for Khmer and Portuguese speakers, the general consensus is that cancer leads to death. Many feel that a diagnosis of cancer is considered a death sentence. A Cambodian community member, in translation, said that *"cancer is a chronic disease, terminal, a lost battle, how we get the news doesn't matter..."* Few respondents in community groups felt that cancer is curable. While some community members know that cancer is influenced by lifestyle, most feel it is a hereditary condition. Within the immigrant communities, many acknowledge insurance related issues and fear that they will have to bring immigration documents with them when seeking health care of any kind. The majority of community members acknowledged that screening and annual visits with primary care providers are the best way to find out if they have cancer, but felt that cultural issues were barriers to seeking care, and some cited logistical issues such as long waits for appointments and distance from doctors as problematic.

Other risk factors mentioned include: environmental exposures including old and substandard housing, chemical pollutants and exposure to chemical agents, and occupational hazards, and pre immigration exposure to chemicals in native countries or refugee camps.

Finding 2: There is a Lack of Awareness of Cancer Risk Behaviors and Prevention Within the Populations with Highest Risk of Cancer and Cancer Related Health Disparities.

Populations at greatest risk of cancer and cancer related health disparities are those with low SES, the uninsured and underinsured and immigrant and minority populations of the Greater Lowell area.

Providers, professionals and key informants felt that patient education and awareness of risk and prevention along with culture, lifestyle choices and attitudes about health care in general and cancer specifically play a large role in higher cancer rates and negative outcomes. They acknowledged that some lifestyle choices are cultural and may result from a lack of understanding and a lack of education about risk and prevention, screening and treatment. All agreed that an increase in outreach and education is needed in order to address cancer disparities.

At the community level, while there were members of focus groups with an awareness of risk and prevention, many in immigrant communities had attitudes about prevention that reflect deep seated cultural beliefs. One community member stated *"some religious beliefs force us not to allow a doctor to cut away any part of our body"*

¹According to a CDC Racial and Ethnic Approaches to Community Health (REACH) Project, "Some of the highest smoking rates in the United States have been reported among Southeast Asian men, and socioeconomic status has been strongly associated with smoking" www.cdc.gov/mmwr/preview/mmwrhtml/su6301a7.htm

(translated from Khmer, Cambodian Focus Group). Another said “*my father said that we mustn't see a doctor*” (translated from Khmer, Cambodian Focus Group). A Latino community member referred to cancer as “*a silent enemy*” (translated from Spanish, Latino Focus Group). In all community level focus groups, while knowledge and awareness of risk was spotty, members acknowledged the need for educational outreach to increase awareness of risk, prevention, screening, and treatment for their communities. The majority of community members in focus groups would like to receive prevention information at the community level – churches, fairs targeting specific populations, senior centers and community forums with providers who speak Portuguese and Khmer. Many felt that providers who speak their language would be more culturally sensitive, in addition, more able to convey important information about cancer in a way they can easily understand. Many felt that more outreach targeted at specific populations could improve awareness and increase understanding of how lifestyle choices can lead to cancer. In the Brazilian community, members of community focus groups felt that outreach should target men. “*The young men do not see the doctor... they usually wait until they feel some kind of pain...*” (translated from Portuguese, Portuguese Brazilian Senior Center community forum).

Finding 3: There is a Lack of Culturally Appropriate Information About Prevention and Wellness Available to Those in Communities at Highest Risk.


Providers, professionals and key informants felt that there is a lack of culturally and linguistically appropriate materials available for communities at greatest risk of disparity. Within immigrant communities, there seems to be a lack of access to culturally sensitive, translated materials about cancer prevention and treatment where people meet and congregate regularly. Providers felt that information must be brought into communities to be truly available, and that agencies and providers should not be waiting for community members to come to them for information. All agreed that informational outreach about risk, prevention, screening and treatment is needed at the grassroots community level, administered by community members in order to be culturally relevant. It is essential to begin working more closely with faith based and business communities and engaging with the leaders of the faith based networks and culturally relevant businesses to build relationships that can help get information into the community through trusted channels. One key informant from the Portuguese community suggested making materials available in front of the Portuguese bakeries before the bakery opens in the morning, perhaps in the form of an outreach table. These sentiments were echoed at the community level, where respondents felt that they need more access within their communities to translated, culturally sensitive materials about risk and prevention as well as about insurance and how to access health care in

Massachusetts. As one Portuguese member stated: ‘there is a big lack of information about the health insurance coverage ... which causes people to be afraid to be tested or even to see doctors’ (translated from Portuguese community focus group).

Finding 4: Low SES Inhibits Wellness and Overall Health on Many Levels.

Providers, professionals and community group members, as well as key informants felt that low SES inhibits wellness on many levels. Poverty, inconsistent financial stability and related logistical issues including working multiple jobs, lacking insurance through employment, lacking the financial resources to pay for insurance privately, lacking the resources to pay for copays and even basic over the counter health care supplies were cited by all groups as being major issues for Greater Lowell's communities at highest risk for cancer disparities. Community members frequently cited employment issues, including working long hours, multiple jobs, lack of time off and loss of income when taking time off. For those confronting these issues, health care is a luxury. Professionals and key informants acknowledged that people working low wage jobs, even if they have some sort of insurance coverage, generally do not have sick leave and cannot not afford to take time away from work to go to the doctor. For this population, if they can take time away from work to go to an appointment, many find that it is logistically impossible to make an appointment at that time they are available because care is not offered outside of traditional business hours. Because there is little afterhours care available, for some in these communities, the ER at Lowell General Hospital may be the only option for care.

With regard to risk factors, again, low SES is a major driving force. Life style choices such as diet and exercise are cited as contributing factors to overall disparities of health and wellness but those with inconstant financial stability find it difficult to stretch a SNAP budget over a month's time and include healthy food in their buying choices. Farmer's markets are prohibitively expensive, and families often resort to quantity vs. quality when making food choices. For many living in poverty, simple transportation to appointments is difficult. These difficulties lead to embarrassment and shame within the community, and a sense of ‘*not wanting to be a burden*’ as one community respondent put it. Living within the stress of financial instability contributes to many chronic conditions including obesity, diabetes, heart disease and high blood pressure. Stress reduction and coping choices that include smoking and alcohol use are also quick, cheap attempts to alleviate the stress and fear related to living with low SES and are known to increase risk to all disease, including cancers. One respondent in a group of seniors said ‘*people end up choosing to pay their mortgage, food ... over going to the doctor.*’ The cycle of poverty perpetuates poor health outcomes and increases health disparities for the most at risk populations of the Greater Lowell area.



Finding 5: Institutional and Structural Issues Pose Significant Barriers to Accessing Information About Prevention and Wellness Care.

Professionals, providers and key informants agreed that lack of insurance and lack of access to health care in general are issues that need to be addressed in the Greater Lowell area. Changes are necessary in the way we access insurance, especially for those in the low SES populations. Several cited the high cost of health care and its impact on lower income and undocumented populations. Providers, professionals and key informants alike acknowledged that often the biggest barrier is getting a patient into the system, and that often this difficulty is primarily due to insurance and access to insurance. If a patient is in the system, (meaning they have gained some sort of access to care, either through insurance or qualifying for subsidized care), education and follow up guidance about prevention becomes routine. But because of insurance issues, many have no choice but to access care by hospitalization through the ER, or have trouble finding providers who accept Medicare and Mass Health, and struggle with insurance related paperwork. Providers stressed that while the hospitals do take the uninsured, it is a struggle to keep the uninsured in care. Logistically, it is difficult for those working nontraditional hours to access care, transportation is an issue, waitlists are long, and the cost of some treatment medications can be prohibitive. Those in undocumented communities are at greatest risk because their status often prevents them from seeking care options in the first place. Faced with these barriers, many in the highest risk communities do not to access care or preventive services.

SECTION 1:

RECOMMENDATIONS FOR CANCER PREVENTION AND EDUCATIONAL OUTREACH

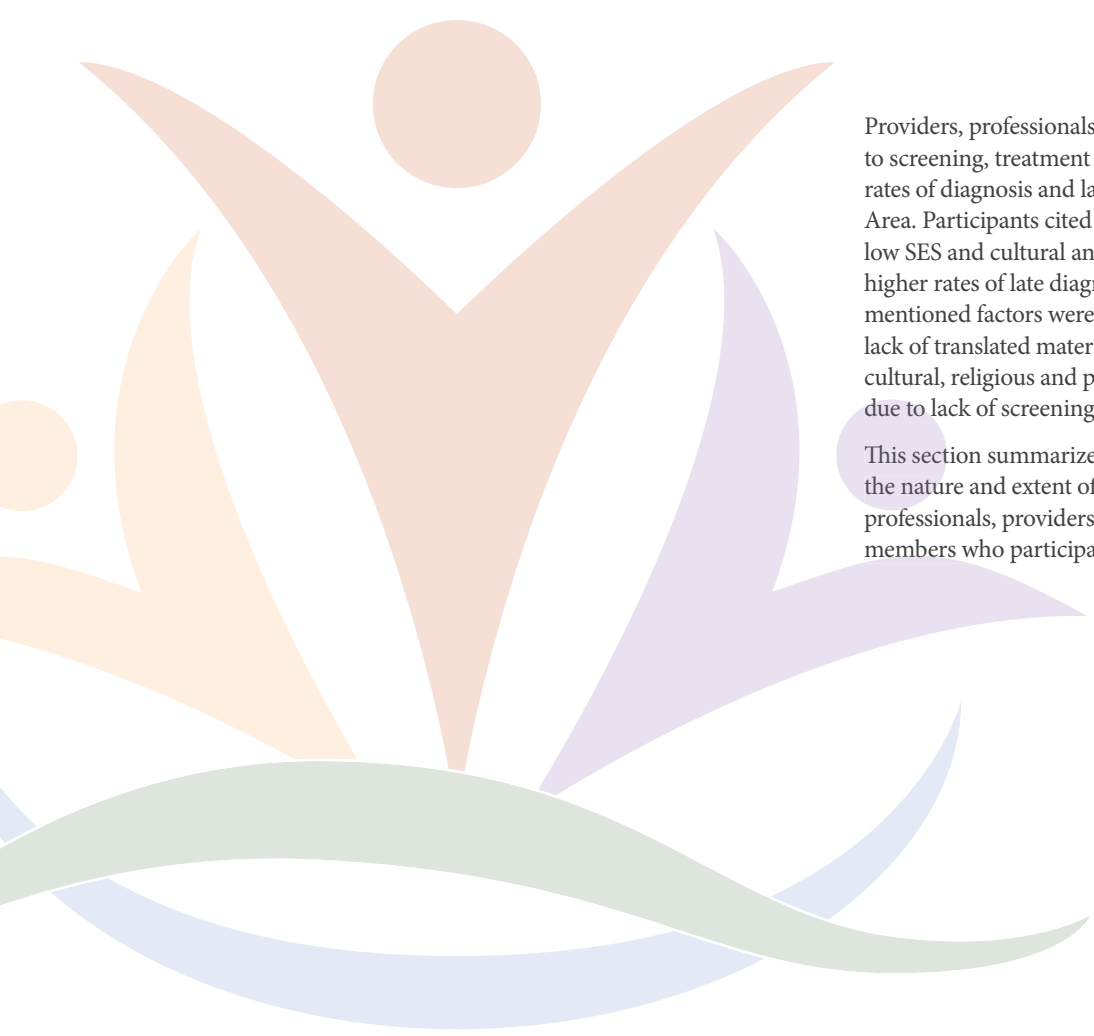
Recommendations for improving cancer prevention and educational outreach are summarized below:



-
- Cultural competency and sensitivity training for health care providers is essential. Providers acknowledged that they bear responsibility to increase their cultural sensitivity and awareness, and that this could help change the perception of health care in the area. Professionals suggested developing a standard of care/ screening protocol based on country of origin/cultural background as a way to ensure both cultural sensitivity and screening for issues related to past exposures. Providers must be aware and sensitive to the cultural needs, beliefs and practices of the populations they are serving and be aware of the health disparities faced by the underserved populations in the area. A deeper understanding, on the part of providers, of the issues faced by those whose lives are affected by low SES, lack of employment opportunities, and discrimination based on race and ethnicity is needed to change patient perceptions about health care in general and accessing care locally. Providers also suggested that health and cancer related education should begin early in grammar school, and high school students should be encouraged to seek futures in health care occupations to ensure a larger pool of diverse providers.
 - Community level, linguistically and culturally relevant outreach is crucial to communities with greatest disparities. Education and outreach efforts need to be increased, with better identification of those who are in need. Grassroots level educational and informational outreach on risk, prevention, and screening that is culturally sensitive and appropriate must involve community leaders in order to reach those at highest risk. Special recommendations to facilitate these changes include working more closely with faith based community leaders to engage the faith based networks and build relationships that will create safe spaces for those from different cultures to learn about risk, prevention and accessing care. Social workers and other professionals suggested that an increase in culturally and linguistically sensitive and appropriate support groups for survivors and families may improve experiences for Lowell area residents, along with culturally specific care locations embedded in communities.
 - Risk factors that are influenced by lifestyle choices such as smoking, diet, obesity, and alcohol must be addressed in culturally appropriate outreach efforts that involve community leaders. Several key informants acknowledged that the pre-immigration diets of new immigrants to our area are often better than the post-immigration American diet that families adopt. Education around how to make healthy eating choices locally is essential to reversing this trend. Broad dissemination should be made to community centers, senior centers, churches, mosques, temples, and businesses and gathering places popular in immigrant communities.
 - A renewed effort at promoting smoking cessation is needed in communities with the greatest disparities. Smoking was cited by all providers, professionals and key informants as a major risk behavior leading to cancer. In many communities, smoking is both a cultural behavior and a stress management choice. Smoking cessation programs must be made more accessible, and the costs of accessing these programs should be covered, perhaps through Department of Public Health funding.
 - An increase of patient advocates and patient care navigators with Portuguese, Khmer and Spanish language skills as well as knowledge of cultural mores and practices is essential at all levels: hospital, provider's office, and within the community. There are not enough social workers and patient navigators to serve the community in a culturally and linguistically responsible way. Patient navigators are needed to help those with language and cultural barriers understand their care options, insurance choices, and how to navigate the health care system with regard to referrals and booking appointments. Key Informants acknowledge that there is a special need to reach out to the undocumented populations and increase the services offered to that community. These populations are at particular risk – they lack documentation and very often fear accessing screening and other services because of their status.
 - Community members in the Portuguese, Latino and Cambodian communities suggested language appropriate hotlines for questions related to access and care. Many said that local care facilities should have Facebook campaigns targeting their populations, in their native languages; to keep them informed of cancer related facts and preventive lifestyle choices.
 - People in the Greater Lowell area need outreach, prevention materials and care during nontraditional business hours. Both the Cambodian and the Portuguese communities called attention to the fact that people in their communities work several jobs, many of which offer no sick days or flexible time off for doctor appointments. A key informant suggested bringing screening directly into the community using the flu shot model, making some screenings available at the pharmacy level to increase access for those with nontraditional schedules.
 - Additional advocacy for those experiencing low SES and financial instability is necessary to begin to break the cycle of poverty that permeates some of the communities at greatest risk for cancer disparities in the Greater Lowell area. A renewed effort at outreach about nutrition support (SNAP, food banks, etc.), as well as other support services, specifically in new immigrant communities, that are culturally sensitive will help reduce stigma and encourage those experiencing issues of insecurity feel safe coming forward. There are many culturally based feelings of shame associated with asking for help. By working with spiritual leaders to strengthen social service navigation services in these communities, more people can be made aware of available programs for help with health issues.

SECTION 2:

UNDERSTANDING BARRIERS TO SCREENING, TREATMENT AND CARE



Providers, professionals and community members cited barriers to screening, treatment and care that may affect the overall higher rates of diagnosis and late stage diagnosis in the Greater Lowell Area. Participants cited social determinants of health including low SES and cultural and language issues as factors contributing to higher rates of late diagnosis and mortality. Among the most often mentioned factors were lack of insurance or being underinsured, lack of translated materials, fear of the tests themselves based in cultural, religious and personal beliefs, and logistical access issues due to lack of screening appointments on weekends.

This section summarizes the information that was shared about the nature and extent of each of these barriers as described by professionals, providers, key informants, and community members who participated in the needs assessment.

Finding 1: There are Multiple Barriers to Accessing Screening for Cancer in Populations at Highest Risk for Cancer Disparities.

Providers, professionals and key informants felt that barriers to screening are related to low SES, including lack of access to insurance, logistical issues, as well as language and cultural issues, and lack of education about risk and prevention. For those with no insurance through their jobs, no documentation, or without the financial resources to purchase insurance on the private market or on the state exchange, accessing screening is impossible. Providers acknowledge that in order to make an appointment for screening, patients must have a referral from a primary care provider (PCP), and there is a chronic lack of PCPs or PCPs accepting the uninsured and patients with certain types of insurance plans in the area. A key informant acknowledged that some providers do not know how the insurance system works for the un- or underinsured and do not realize that their patients may not be able to access the testing they recommend, or insurance may not cover the recommended treatment. In addition to these barriers, some insurance plans do not offer full coverage for some screenings, and oftentimes, the un- or underinsured need the assistance of a patient navigator to help them navigate through the referral process and insurance issues they may encounter when pursuing screening and treatment. Key informants acknowledge that there is a need to reach out to and advocate for the undocumented populations and increase the services offered to that community. These populations are at particular risk – they lack documentation and very often fear accessing screening and other services because of their status. The undocumented populations are at very high risk for all health disparities. Again, providers, professionals and key informants acknowledge that, for patients working nontraditional hours or several jobs, the availability of afterhours screening is an issue. A key informant suggested using the flu shot model for screening so that patients could access simple screenings at the drugstore or pharmacy.

Providers, professionals and key informants also felt that screening for cancer may not be a priority in some communities, due to cultural norms, and culturally and religiously based fears, as well as issues to do with cost and insurance. Cultural issues include the reluctance by some patients to see doctors other than their PCP. Additionally, many women in Asian populations do not disrobe in front of others, do not allow contact, and avoid health interventions and intrusive tests unless seeing symptoms. A provider at a round table mentioned myths about needles and the taking of blood that are pervasive in some cultures. Several providers acknowledged that their patients often mention a fear of the tests themselves. Many people of different cultural backgrounds have little or no interaction with the health care system. Both providers and professionals acknowledged that there is a lack of translated material about screening, and many patients are not aware of translation services available to them.

Like professionals, providers and key informants, the participants in community groups most often cited access to insurance, logistical issues, language and cultural issues, and low SES as factors that make it difficult to be screened for cancer. Many respondents in the community level groups do not have insurance, and many have insurance that does not cover everything. Many do not have extra money for copays. Some community members said language barriers and lack of Portuguese, Spanish and Khmer interpreters keep people from screening. Others said that fears of finding disease keeps people from screening and some in the Cambodian community fear the test itself. A respondent in the Latino group said “*Why so many tests if I am going to die anyway?*” (translated from Spanish, Latino Focus Group). For some in the community, logistical issues such as long waits for appointments and transportation issues make screening difficult. Many in the Portuguese community fear immigration and documentation issues.

Finding 2: Community Level Perceptions and Cultural Attitudes Within Some Communities are Barriers to Seeking Screening and Treatment for Those in Populations at Highest Risk for Cancer Disparities.

Providers, professionals and key informants felt overall that patient perception of cancer care in the Lowell area is poor, that patient perception of care in Boston is better, and acknowledged that perception of quality of services is an issue. The screening and treatment protocol followed in Lowell is the identical screening and treatment protocol followed in Boston hospitals, but patients perceive that the care in Boston is of higher quality. One key informant attributed this to a higher degree of cultural competency at Massachusetts General Hospital, suggesting that care is about perception; – if someone perceives that they are receiving poor treatment (lack of cultural competency, etc.), they will feel that their care is inferior. Another key informant suggested that quality of care is, in fact, lower for minorities in general. Cultural and socioeconomic sensitivity on the part of health care providers was stressed as important to changing perceptions of care in the Lowell area – a respondent reported that some patients feel “snobbed” when accessing care due to their SES.

At the community level, it is clear that perception of local screening and care is tied, in part, to cultural and linguistic issues that make those from immigrant communities hesitant or reluctant to pursue care, as well as a lack of understanding about insurance coverage. Some felt that doctors do not listen to patients. Many in both the Cambodian and Portuguese communities fear the screening process itself; they fear the pain and discomfort associated with certain screenings and choose to avoid the tests altogether. Several in the Portuguese community cited a need for more Portuguese speaking care providers and translation services, still others expressed a need for additional patient navigators who speak their language to help them navigate and understand the process of accessing care locally.

Many times, those with Medicaid or certain Affordable Care Act plans are referred to Boston hospitals because local facilities are not able to provide care for reasons related to insurance or lack of insurance. This leads to perceptions within communities that they are being discriminated against. Some stated that the perception of care in the Lowell area is poor; doctors in Lowell are not trusted, doctors in Boston are trusted. It is clear from community focus groups that many in immigrant and low SES populations do not understand how insurance and free care work. In community groups, people felt that they needed education about insurance and what type of coverage to choose. Portuguese respondents reported needing more information about Medicare and Medicaid and how coverage works in general. In all focus groups conducted in immigrant communities, the lack of support groups in native languages also contributed to the negative perception of local care.

Finding 3: Many Factors Contribute to Higher Rates of Late Diagnosis and Higher Mortality Rates Overall in those at Highest Risk for Cancer Disparities in the Greater Lowell Area.

All groups agreed that access to screening plays a large role in disproportionately high rates of late stage cancer diagnosis and high mortality. Factors that affect access to screening, as explained above, include low SES and the resulting lack of insurance and logistical issues related to afterhours care, as well as lack of culturally appropriate materials pertaining to screening, and overall perceptions and attitudes about seeking care in general. In addition to these factors, for men in at risk populations, male cultural machismo may play a role in late stage diagnosis. A special recommendation cites logistics and physical access – for many men, especially those working nontraditional hours, there is a lack of availability of treatment when they are available – after hours, evenings, and weekends. Another key informant cited the fact that men don't talk about broader health issues with providers. An increase in awareness for providers and a different, more culturally sensitive approach to men in the examining room may help address this issue. It was stated more than once that men lack the motivation to seek care and that many men lack the support networks needed to endure care and treatment for cancer.

For those struggling with low SES and financial instability, related factors such as lack of insurance, no access to insurance, high deductibles on insurance, and the inability to pay copayments come into play when considering screening and treatment options. These factors often lead to late stage diagnosis. Especially frustrating to those in the community is the knowledge that while there may be care available in Lowell, they may be referred to a Boston facility due to their insurance status, and the transportation furthers the financial burden. Those in undocumented populations are especially affected by these factors.

Professionals acknowledged that some insurance plans do not cover some screening or cover oral chemotherapy treatments and other expensive pain related medications, yet approve therapy for very late diagnosis cases.

Local perceptions toward care also contribute to late diagnosis and high mortality in some communities. Culturally influenced personal and cultural concerns are previously mentioned, but bear mention again here. Personal and culturally influenced concerns such as family mythology, denial, lack of family support, and not wanting to burden the family are significant in the lives of those in the communities most at risk for disparities. In a Portuguese focus group, another acknowledged that people may have had poor health outcomes in local hospitals and may have lost faith in the care available in the area.

Finding 4: Low Socioeconomic Status Inhibits Access to Screening, Care and Treatment for those at Greatest Risk for Cancer Disparities in the Greater Lowell Area.

For most interviewed, low SES and its impact on access to screening and care are the most consistently cited reasons for late diagnosis and higher cancer mortality among all Greater Lowell residents. Providers acknowledged that access to care is paramount. They recalled seeing patients for the first time who were presenting with symptoms of cancer, yet had had no annual visits during which screening could have been recommended or taken place. These patients are un- or underinsured due to immigration/documentation status, employment status, lack of financial stability and the resulting inability to purchase insurance in the private market or through the state exchange. Additionally, because of insurance issues, many access care by hospitalization through the ER, and still more have trouble finding providers who accept Medicaid and other subsidized Mass Health plans. Providers stressed that while the hospitals do take the uninsured and underinsured, it is a struggle to keep these populations in care. At the community level, respondents acknowledge being forced to choose between paying for food and shelter, and paying for health care needs. Said one respondent in the Cambodian community: “we must ask the government to help us with more good plans” (translated from Khmer, Cambodian Focus Group). Many community members acknowledged a lack of advocacy and financial assistance for those with low SES facing a diagnosis of cancer.

Finding 5: Institutional and Structural Issues Pose Significant Barriers to Accessing Screening and Treatment and Contribute to High Rates of Late State Diagnosis and High Mortality Among those at Greatest Risk for Cancer Disparities in the Greater Lowell Area.

Professionals, providers and key informants agreed that lack of insurance and lack of access to health care in general are issues that lead to late diagnosis and may affect higher mortality rates for those at greatest risk for cancer disparities in the Greater Lowell area. This is a significant barrier for those in low SES populations, and those within the undocumented communities. Providers stressed that while local hospitals do take the uninsured, it is a struggle to keep the uninsured in care through the full course of treatment. Providers, professionals and key informants alike acknowledged that the biggest barrier often is getting a patient into the system, and often this difficulty is primarily due to under-insurance and lack of access to insurance. As stated earlier, because of insurance issues, many have no choice but to access care by hospitalization through the ER, or have trouble finding providers who accept Medicare and Mass Health. While our local facilities refer these patients to Boston hospitals which are able to offer more subsidized care for the uninsured or underinsured, transportation to Boston is often difficult for those in low SES populations. Previously mentioned logistical issues that make it hard for marginalized communities to access health care, such as working long hours and not having sick time are also factors that contribute to late stage diagnosis and higher mortality rates. Faced with these barriers, many in the marginalized communities either choose not to try to access care, or find that they are unable to complete treatment, leading to poor health outcomes.

SECTION 2:

RECOMMENDATIONS FOR REDUCING BARRIERS TO SCREENING, CARE AND TREATMENT FOR THOSE AT GREATEST RISK FOR CANCER DISPARITIES IN THE GREATER LOWELL AREA

Recommendations for improving access to screening, care and treatment are summarized below:



- Providers, professionals and key informants acknowledge the need for more advocacy around health disparities and health equity in general for those in low SES populations. Key informants recommended that the Massachusetts Department of Public Health work for changes in the way insurance is accessed, as in many cases, it is lack of insurance, or underinsurance that prevents access to care. All respondents in professional and provider groups agreed that structural issues regarding how care is accessed through insurance and issues around provider cultural competency that influence community level perceptions of local care are the most important targets for change. Logistical issues that make it hard for marginalized communities to access health care, such as working long hours and lack of sick time need to be addressed through legislative initiatives that create changes in employer requirements to provide paid sick time to workers in low wage jobs.
- Attitudes, opinions and perceptions of local care that are preventing people from seeking care must be addressed at both the community level and at the provider level. Providers must have knowledge of the stigmas, rumors and myths that exist in the community in order to understand why certain segments of the population are not accessing screening, care and treatment for cancer. Once this knowledge and sensitivity is attained at a granular level, providers and facilities must work in collaboration with leaders within communities to dispel stigmas, myths and rumors around local care that impact overall perception of care in the Greater Lowell area. Faith based and community leaders are trusted members of these communities and can help members of their communities understand the reasons for certain referrals to Boston hospitals, for example, or the way to access services available for those with limited means in culturally responsible and appropriate ways. For many in the immigrant communities, reducing stigmas and dispelling "word on the street" type rumors of poor quality care in the area will help rebuild trust in local facilities.
- Local care facilities must increase the cultural competency of their provider pool. A key informant suggested exploring the programs offered through the Massachusetts General Hospital's Disparities Solution Center. This group offers training opportunities for facilities and providers that could be implemented locally in order to develop culturally competent disease management programs that ensure high quality and culturally appropriate care for all patients. Those trained in these programs will become leaders in ensuring that cultural competency remains at the forefront for all administering care to Greater Lowell's communities at high risk for cancer disparities.
- Education about care and treatment protocol is needed in communities as highest risk for cancer disparities. At the community level, there is confusion about cancer care protocols. This confusion may be contributing to poor perceptions of local care. Providers feel that local residents may not know that for the most part, cancer treatment protocols are consistent throughout the area and expressed a desire to let the general public know that

this is the case. This could be done through marketing directly to communities with disparities using culturally sensitive campaigns designed to educate about treatment options in general.

- An increase of patient advocates and patient care navigators with Portuguese, Khmer and Spanish language skills and knowledge of cultural mores and practices is essential at all levels: hospital, provider's office, and within the community. As previously stated, there are too few social workers and patient navigators to serve the community in a culturally and linguistically responsible way. Patient navigators are needed to help those with language and cultural barriers understand their care options, insurance choices, and how to navigate the health care system with regard to referrals and booking appointments. Community and spiritual leaders are valuable resources to help strengthen social service navigation services in these communities. By enlisting the help of these important, trusted leaders, more people in need can be made aware of available programs that offer help with these issues.
- Advocacy and outreach campaigns directed specifically to the undocumented populations are needed in the Greater Lowell area. Key informants acknowledge that there is a special need to reach out to the undocumented populations and increase the services offered to that community. Community outreach that includes information and help navigating the process of becoming insured, accessing Medicaid and other free care programs, and help filling out forms must be provided to these populations in a sensitive manner that helps dispel fear and worry. As earlier stated, these populations are at particular risk; they lack documentation and often fear accessing screening and other services because of their undocumented status.
- As earlier stated, an increase in language and interpretation services is needed in the Greater Lowell area. In order for those in immigrant communities to access health care, culturally and linguistically appropriate materials and translation services are essential.
- The Massachusetts Department of Public Health (MDPH) must put processes in place to ensure that funding for advocacy and disparity assessment dialog remains intact. MDPH must be more diligent about ensuring that MDPH funded programs and grantees are truly culturally sensitive and that providers are culturally competent.
- Populations who need health care and are working nontraditional hours are underserved in the Greater Lowell area. Monthly screening nights at local facilities were suggested as a solution, as were screening locations at local pharmacies such as CVS and Walgreens.
- Many in the Greater Lowell area need access to free or subsidized transportation in order to receive care in Lowell and Boston. This barrier is significant in populations who are routinely referred to Boston facilities for care. Local transportation services could be encouraged to increase the number of facilities they visit in the Greater Lowell and Boston area. Coordination of local transportation provider schedules with train and bus schedules is also needed.

NEXT STEPS:

IDENTIFYING
TOP PRIORITIES
AND ACTION
PLANS



The objectives of this Cancer Disparities Needs Assessment Report are to evaluate what community members know, think and understand about cancer and cancer disparities facing area residents and the populations at greatest risk, identify the strengths and weaknesses of the local healthcare system and the delivery of cancer related services and identify key issues and factors contributing to disparities in rates of screening, diagnosis and mortality, recommend actions to address priority concerns, and provide information that informs a community process to build consensus around strategies to improve the cancer outcomes of Greater Lowell residents. This information will be used to inform a community process that will identify priority health needs and develop action plans to address these priorities and build organizational capacity and sustainability to rectify cancer disparities. The Greater Lowell Health Alliance is committed to a collaborative approach involving other community stakeholders with the goal to identify top priorities and formulate action steps that will improve the key issues and factors contributing to disparities in rates of screening, diagnosis and mortality.

Our next step after the completion of the Cancer Disparities Needs Assessment Report is to share this information with the community

and with the many civic and healthcare organizations that are directly involved with the overall health of the community. To maximize community involvement, the Greater Lowell Health Alliance will schedule community input sessions and are planning additional forums. The goal of these meetings is to prioritize and put together an action plan for initiatives in specific areas. The Greater Lowell Health Alliance, a 501(c) (3) organization with a goal to improve the overall health of the community, is best positioned to take the lead on addressing many of the needs recognized by this study, helping to drive initiatives to address cancer disparities that can be implemented in the community.

The Greater Lowell Health Alliance will play a critical role in meeting the needs for outreach and education about cancer in our region by bringing together healthcare providers, business leaders, educators, civic and community leaders with a common goal to help the Greater Lowell community improve the cancer outcomes and overall health of our communities.

Below is a tentative schedule for community forums:

Community Forum Timeline

Lowell Community Professional Groups daytime	September - November
Neighborhood Associations and Groups evening	September - November
Cambodian community	September - November
Latino community	September - November
Portuguese community	September - November
Lowell Community Health Center (LCHC) (English and Spanish)	September - November
Lowell Senior Center	September - November
Hunger Homeless Commission – English	September - November

Lowell General Hospital – English	September - November
Middlesex Community College – English	September - November
GLHA Annual Meeting	September
Dracut	September - November
Chelmsford	September - November
Westford	September - November
Billerica	September - November
Tewksbury	September - November
Tyngsborough	September - November

APPENDICES

APPENDIX A Individuals Interviewed

Mercy Anampiu
Lowell Community Health Center

Elisa Choi, MD, FACP
Vice-Chair & Commissioner
Chair, Healthcare Subcommittee
Asian American Commission of the Commonwealth of MA

Michelle Davis
Vice President External Affairs Lowell General Hospital

Tami Gouvela
Executive Director
Tobacco Free Massachusetts

Diane Knight
Director
Northeast Tobacco Free Community Partnership

Allesandra Lopes
Massachusetts Alliance of Portuguese Speakers

Paul Muzhuthett
Regional Director
Northeast Regional Health Office, Department of Public Health

Lozitha Nzula
Greater Lowell Health Alliance

Sue Rosa
Chelmsford Board of Health

APPENDIX B

Key Informant Interview Facilitator Guide

1. What do you think drives these data on cancer disparities in Greater Lowell, MA?
2. Why do you think we are seeing higher cancer incidence (newly diagnosed cases) among Greater Lowell, MA residents?
3. What are the risk factors for cancer in Greater Lowell, MA?
4. What other chronic diseases are associated with these risk factors?
5. How do these risk factors differ among population groups with disparities in incidence?
6. What other reasons may account for higher cancer diagnosis for total cancer and specific cancers for all Greater Lowell residents. What other reasons may account for disparities among certain population groups with disparities in incidence?
7. What changes will have to occur to address these concerns?
8. Why are we seeing disproportionately high rates of late stage cancer diagnosis among Greater Lowell residents?
9. Is screening a problem? If yes, what are the facilitators and barriers on the health care system as well as on the patient level?
10. What role does access to screening play?
11. What changes will have to occur to address these concerns?
12. Why are we seeing higher cancer mortality among all Greater Lowell residents; and particularly among men?
13. In addition to late stage diagnosis, are there other factors in treatment and care?
14. What role does access to care play?
15. Does quality of treatment need to be addressed?
16. 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?
17. What changes will have to occur to address these concerns?
18. Based on your experiences, what recommendations do you have for the Massachusetts Department of Public Health to improve cancer screening and treatment experiences and follow up with residents?
19. Are there others you recommend we speak with to learn more about cancer disparities and strategies to address them in the Greater Lowell region?

APPENDIX C

Community Focus Group Facilitator Guide

1. What do you know about cancer? What do you think is the best way for people to find out if they have cancer?
2. Have you, or anyone you know (family, friends, etc.) ever been screened or checked for any type of cancer? If yes, what type(s)?
3. How important is it to you, and those you know, to be checked for cancer or have cancer screening? Why?
4. What factors or things make it difficult to get checked or screened for cancer?
5. What suggestions do you have to help improve the number of people screened for cancer?
6. How do you, or other [target population] residents of Greater Lowell view cancer treatment and care services?
7. What tends to make it difficult for area residents to start treatment for cancer?
8. Continue the full course of treatment?
9. Have high quality treatment?
10. What changes will have to happen to address these barriers or difficulties to receiving high quality cancer treatment?
11. Where do you go to get health care? Where would you go if you needed cancer treatment?
12. How would you, and those you know [in the target population], like to get information on cancer prevention and care?
13. Based on your experiences, what would you like to see changed to improve access to and coverage for cancer care?

APPENDIX D

Health Director Round Tables – Facilitator Guide

1. What do you think about these data on disparities in Greater Lowell?
2. Why are we seeing higher cancer diagnosis among Greater Lowell MA residents?
3. What are the risk factors for cancer in Greater Lowell MA?
4. How do these risk factors differ among populations with disparities in incidence?
5. What other reasons may account for higher cancer diagnosis for total cancer and specific cancers for all Greater Lowell residents and disparities among population groups with disparities in incidence?
6. What changes will have to occur to address these concerns?
7. Are health care providers seeing disproportionately high rates of late stage cancer diagnosis among Greater Lowell residents?
8. Is screening a problem? If yes, what are the facilitators and barriers on the health care system as well as on the patient level?
9. What role does access to screening play?
10. What changes will have to occur to address these concerns?
11. Why are we seeing higher cancer mortality among all Greater Lowell residents; and particularly among men?
12. In addition to late stage diagnosis, are there other factors in treatment and care?
13. What role does access to care play?
14. Does quality of treatment need to be addressed?
15. 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?
16. What changes will have to occur to address these concerns?
17. 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?

APPENDIX E

Professional Focus Group Facilitator Guide

1. What do you think about these data on disparities in Greater Lowell?
2. What are the risk factors that are leading to higher incidence of cancer in Greater Lowell MA?
3. How do these risk factors differ among populations groups?
4. What other reasons may account for higher cancer diagnosis for Greater Lowell residents and disparities among population groups highlighted in the Data Summary Sheet?
5. What changes will have to occur to address these concerns?
6. What factors or things make it difficult to get checked or screened for cancer?
7. What role does access to screening play?
8. What changes will have to occur to address these concerns?
9. Why are we seeing higher cancer mortality among all Greater Lowell residents?
10. In addition to late stage diagnosis, are there other factors in treatment and care?
11. What role does access to care play?
12. Does quality of treatment need to be addressed?
13. 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?
14. What changes will have to occur to address these concerns?
15. 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?

APPENDIX F

Provider Focus Group Facilitator Guide

1. What do you think about these data on disparities in Greater Lowell?
2. Why are we seeing higher cancer diagnosis among Greater Lowell MA residents?
3. What are the risk factors for cancer in Greater Lowell MA?
4. How do these risk factors differ among populations with disparities in incidence?
5. What other reasons may account for higher cancer diagnosis for total cancer and specific cancers for all Greater Lowell residents and disparities among population groups with disparities in incidence?
6. What changes will have to occur to address these concerns?
7. Are you seeing disproportionately high rates of late stage cancer diagnosis among Greater Lowell residents?
8. Is screening a problem? If yes, what are the facilitators and barriers on the health care system as well as on the patient level?
9. What role does access to screening play?
10. What changes will have to occur to address these concerns?
11. Why are we seeing higher cancer mortality among all Greater Lowell residents; and particularly among men? Mortality?
12. In addition to late stage diagnosis, are there other factors in treatment and care?
13. What role does access to care play?
14. Does quality of treatment need to be addressed?
15. 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?
16. What changes will have to occur to address these concerns?
17. 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?

APPENDIX G

Data Summary

Greater Lowell Region of Massachusetts Cancer Disparities

Greater Lowell Region

The Greater Lowell Region of Massachusetts has a population of 274,404. 24.9% of the population are younger than 18 years old, and 11.8% are 65 years old or older. 7.7% identify as Asian, 4.1% identify as Hispanic or Latino. 17.6% are below poverty level. The median income is \$86,865 in the Greater Lowell Region. In 2010, 95.9% had health insurance, compared to 97% in Massachusetts.

Lowell, Massachusetts

Lowell Massachusetts has a population of 106,519 (2010). 49.64% are male, 50.36% are female. 23.72 % of the population are younger than 18 years old, and 10.06 % is 65 years old or older. 20.2 % identify as Asian, 17.3% identify as Hispanic or Latino. 5.2% are below poverty level. 41.9% speak a language other than English, 21.2 % have less than a high school education. 19 % are living in poverty. 9.2% (2010) of the population reports not having insurance. The median income is \$51,471 in Lowell.

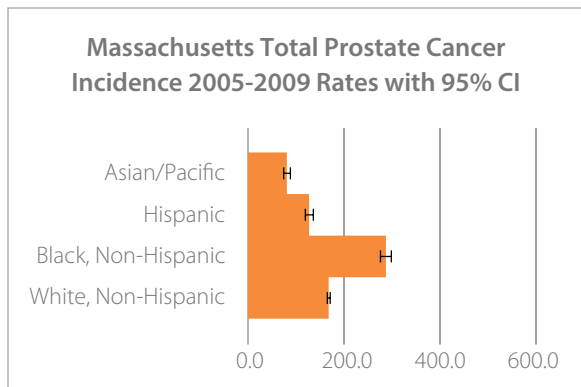
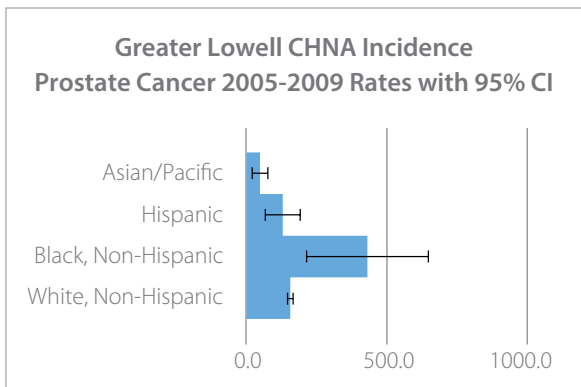
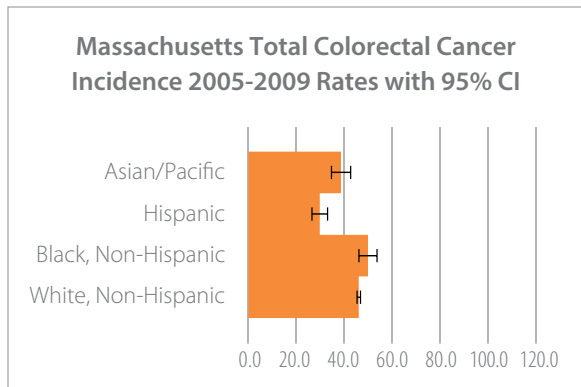
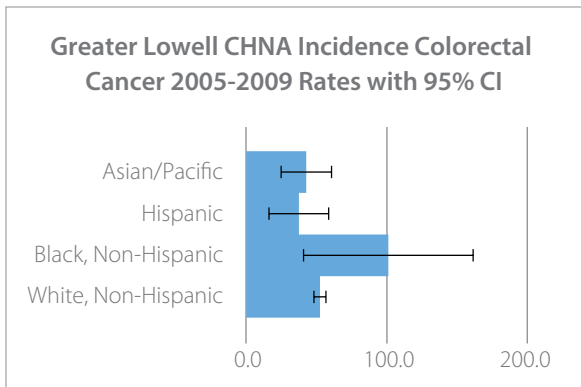
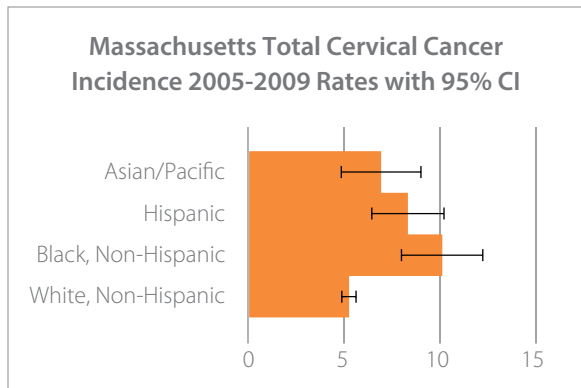
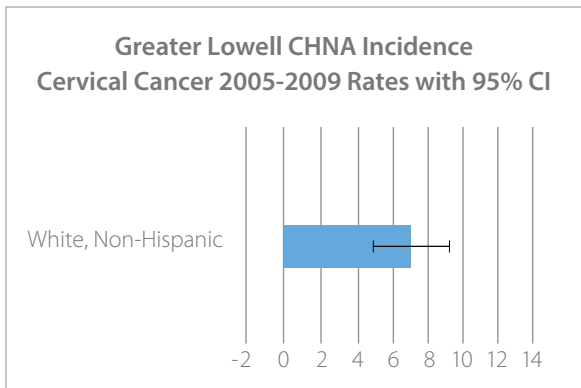
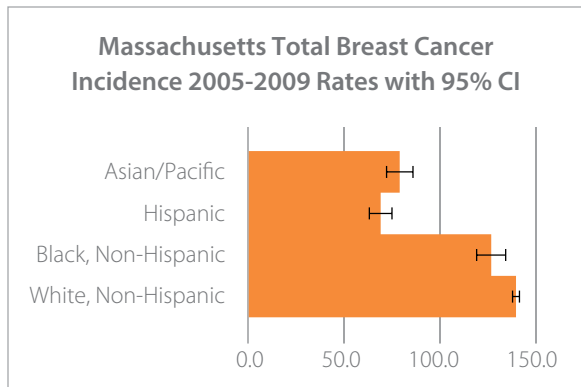
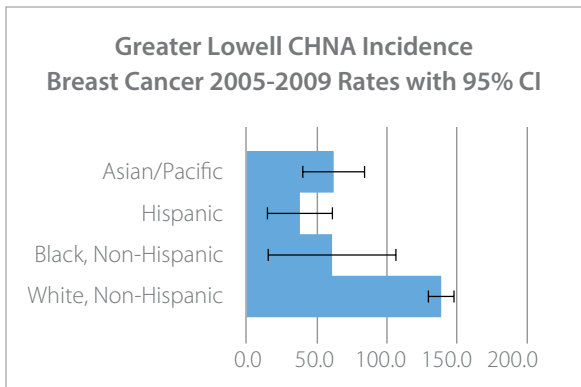
In 2011, 26.2% of Lowell's population smoked while the 22.3% of the Greater Lowell Region population and 18.2% of the Massachusetts population smoked.

Cancer Disparities Data Summary

The Greater Lowell Region of Massachusetts was selected for this needs assessment based on the following data:

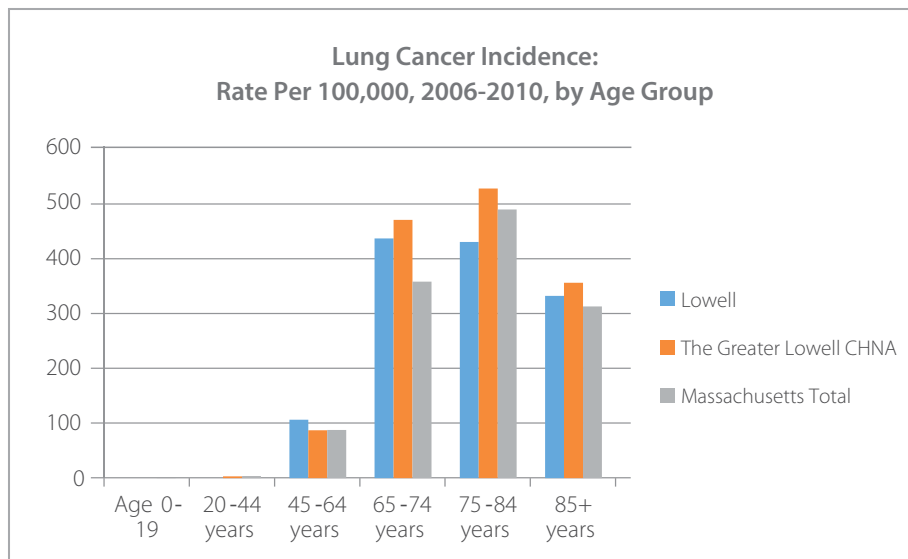
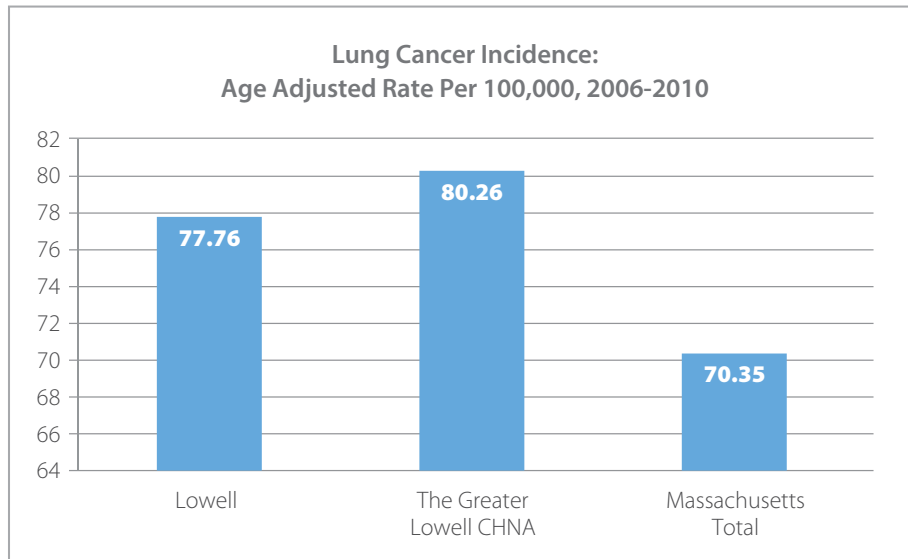
Cancers

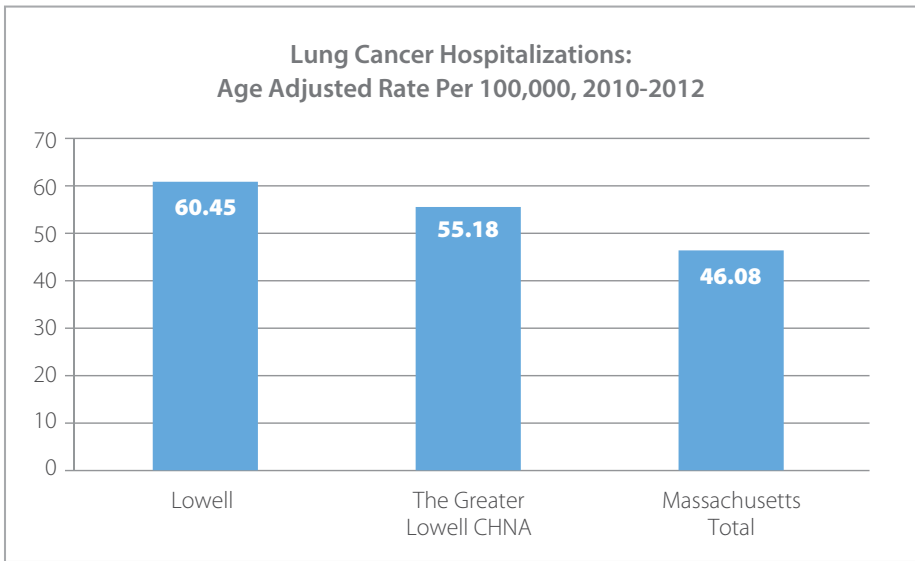
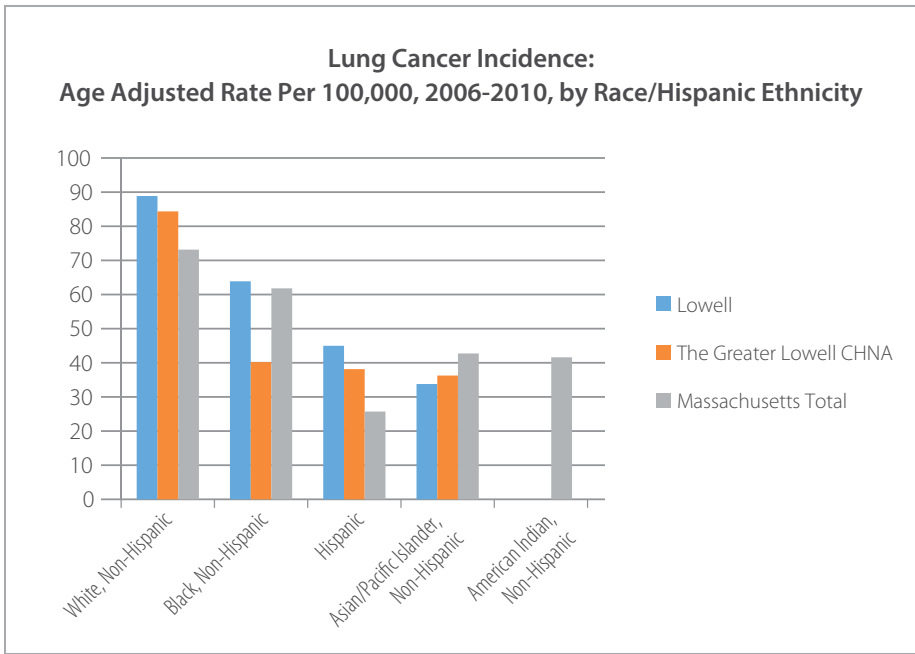
- Cancer rates in all three regions have been slowly rising since 1985. In 1985 the rates were 430 – 450 per 100,000, and in 2008 the CHNA had the highest rate, 559, Massachusetts had a rate, 514, and Lowell had the lowest rate, 487.
- Residents of the Greater Lowell region have a higher incidences of colorectal, lung and breast cancer than Massachusetts overall. Black/non-Hispanic and Hispanic men in the Greater Lowell region have a higher incidence of prostate cancer and colorectal cancer, and Caucasian women have higher incidence of cervical cancer than Massachusetts overall. Residents of the Greater Lowell region have a higher incidence of hospitalization and death due to lung cancer than the rest of Massachusetts.



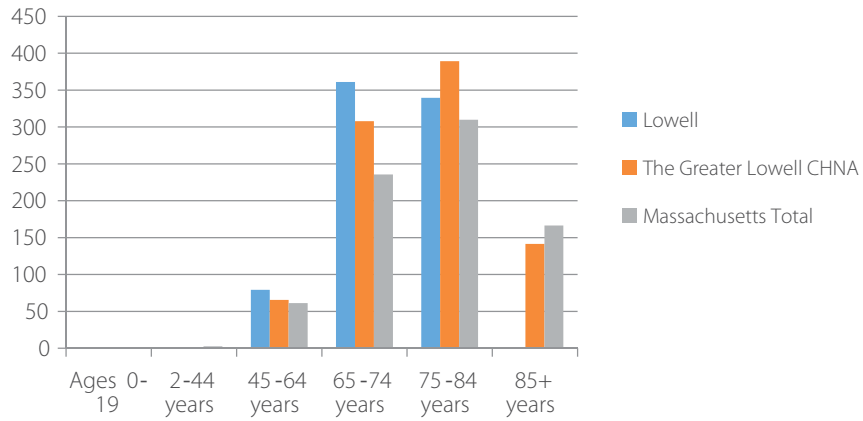
APPENDIX H
Incidence, Hospitalizations and Mortality of Top Area Cancers

Lung Cancer

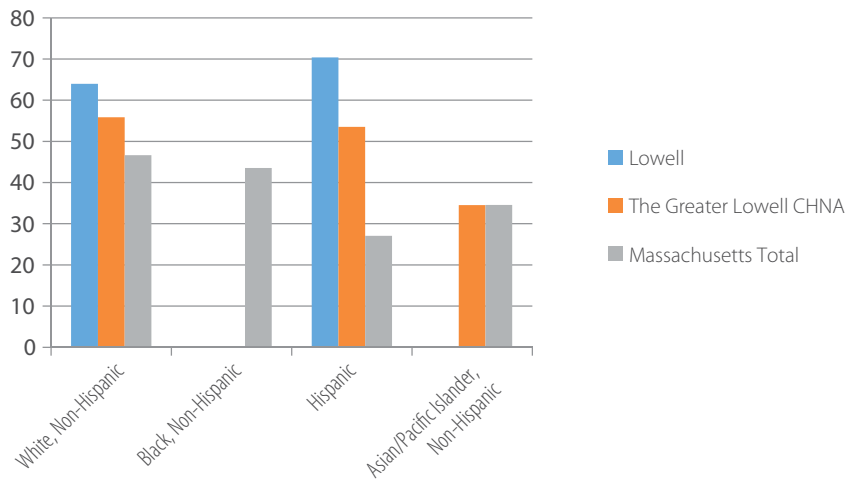


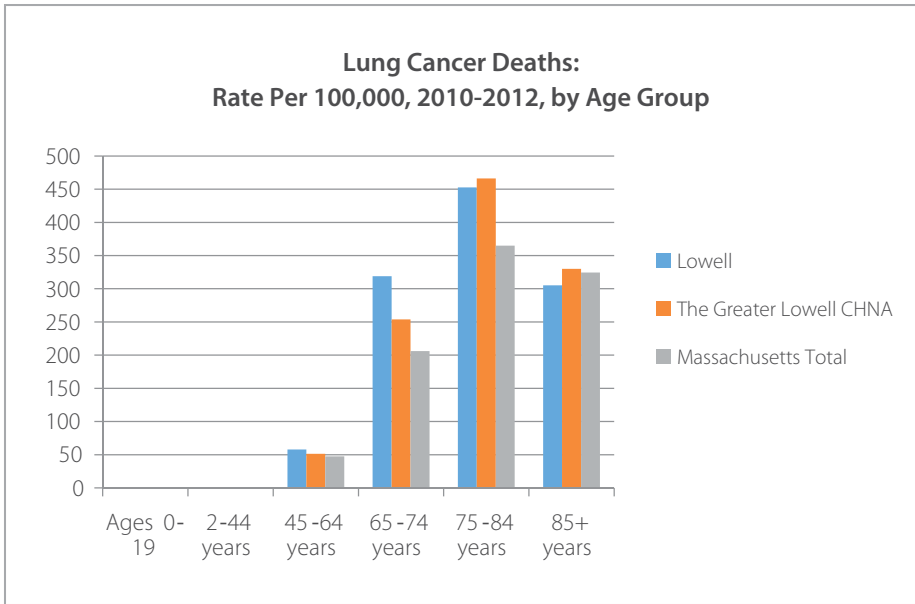
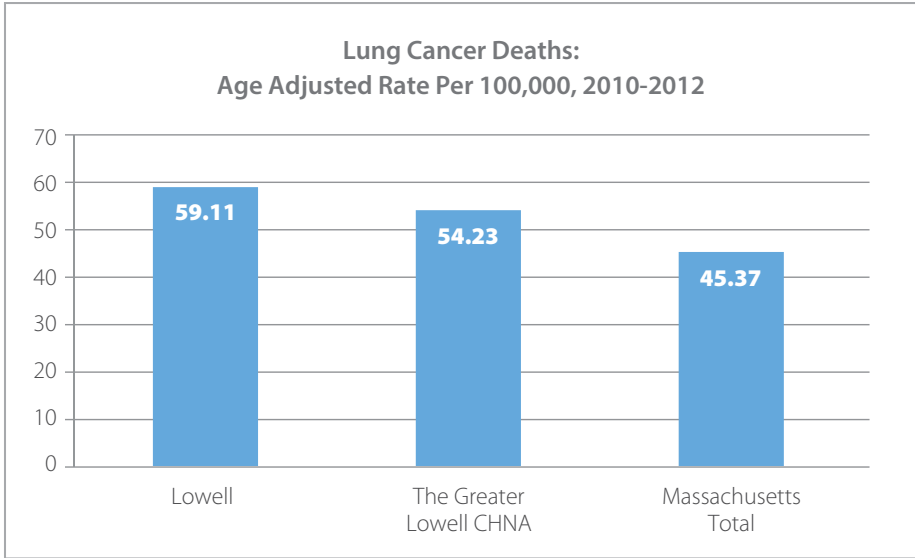


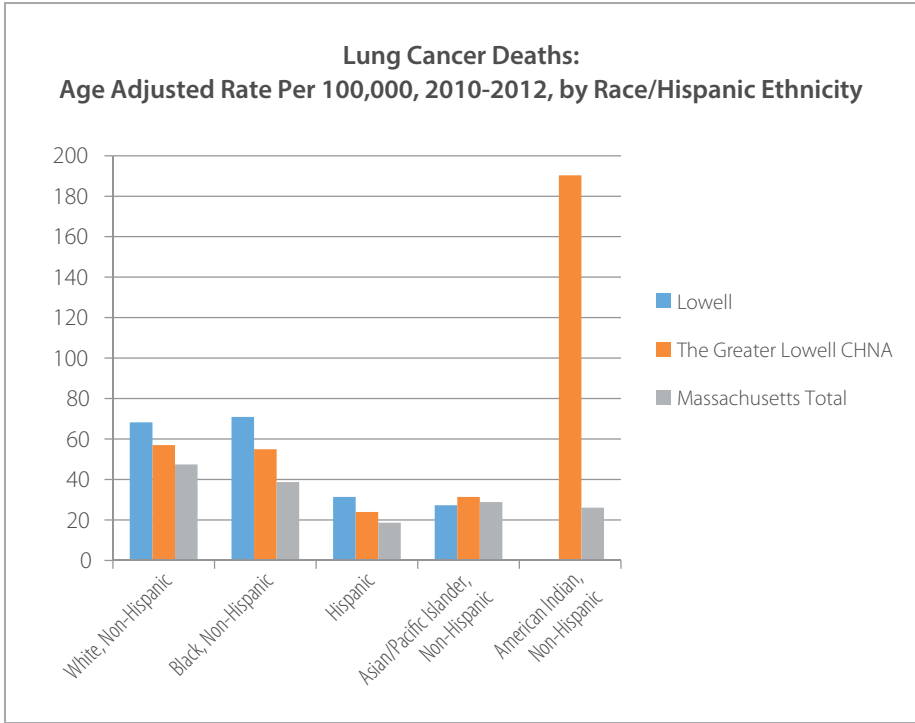
**Lung Cancer Hospitalizations:
Rate Per 100,000, 2010-2012, by Age Group**



**Lung Cancer Hospitalizations:
Age Adjusted Rate Per 100,000, 2010-2012, by Race/Hispanic Ethnicity**

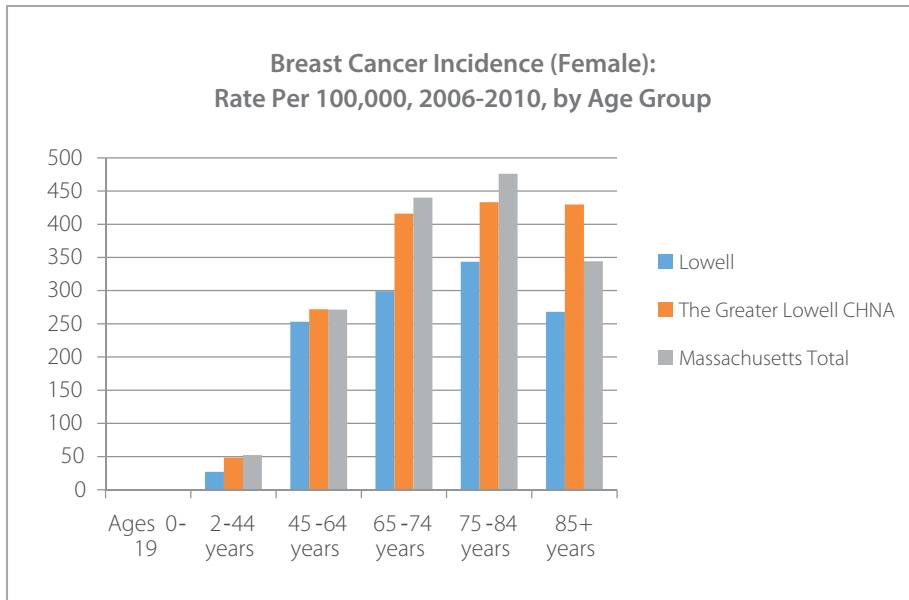
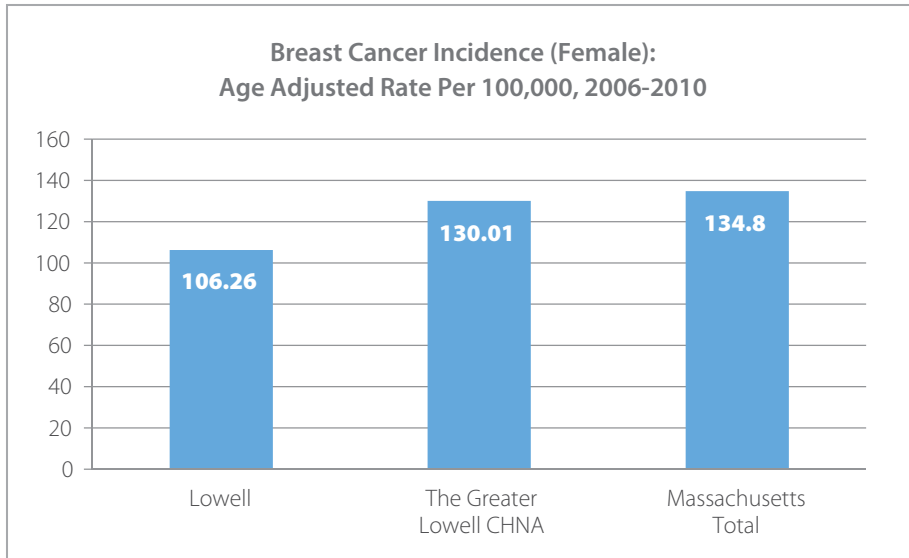


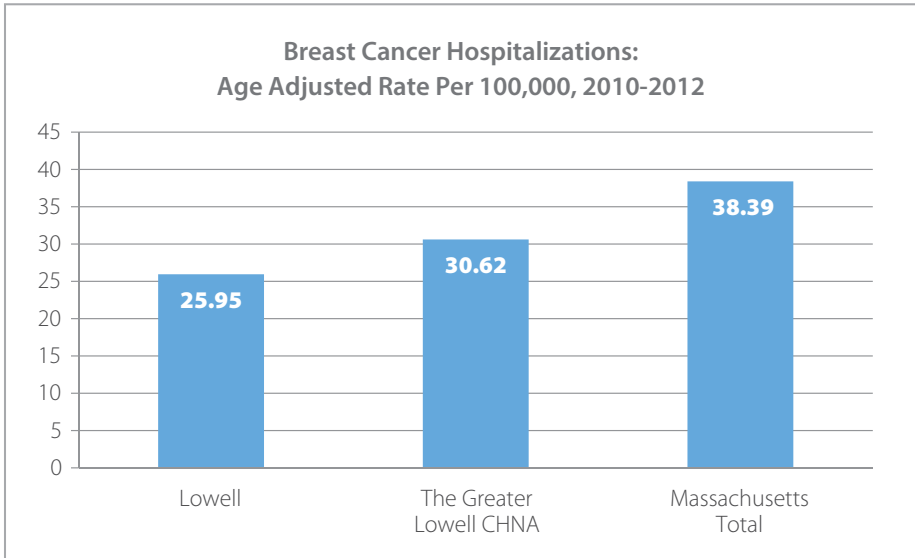
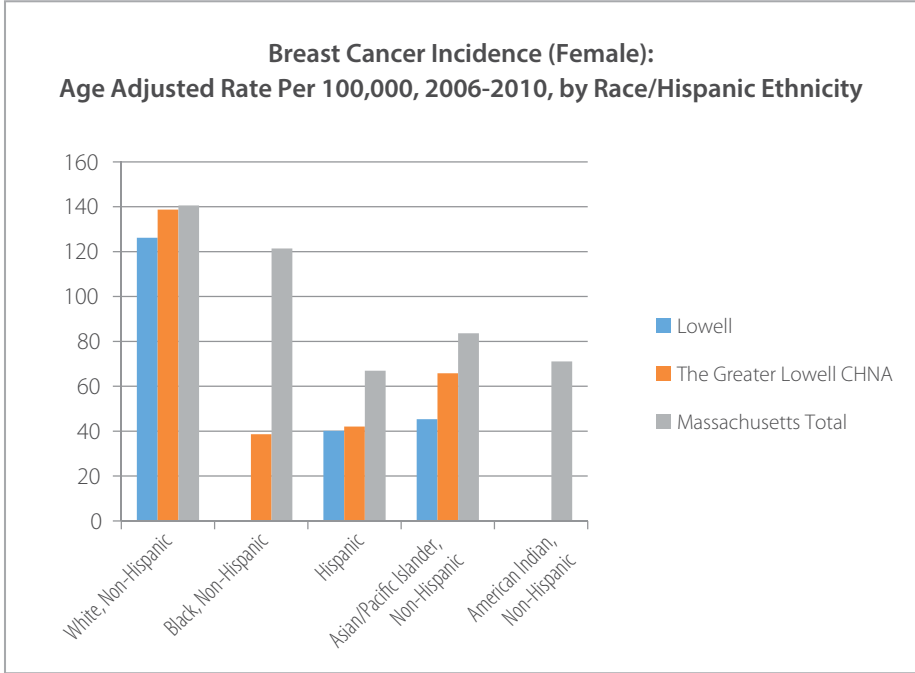


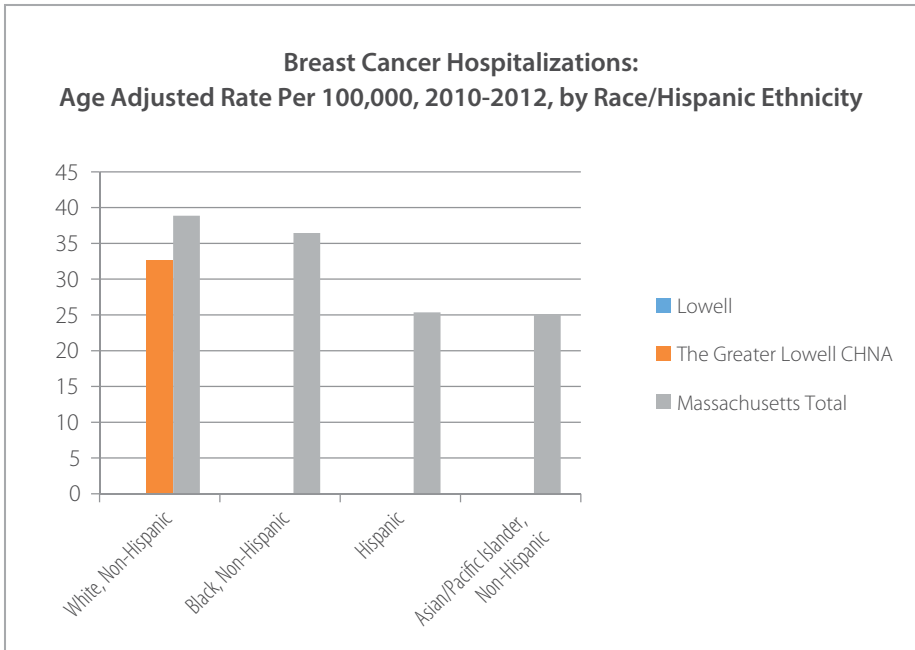
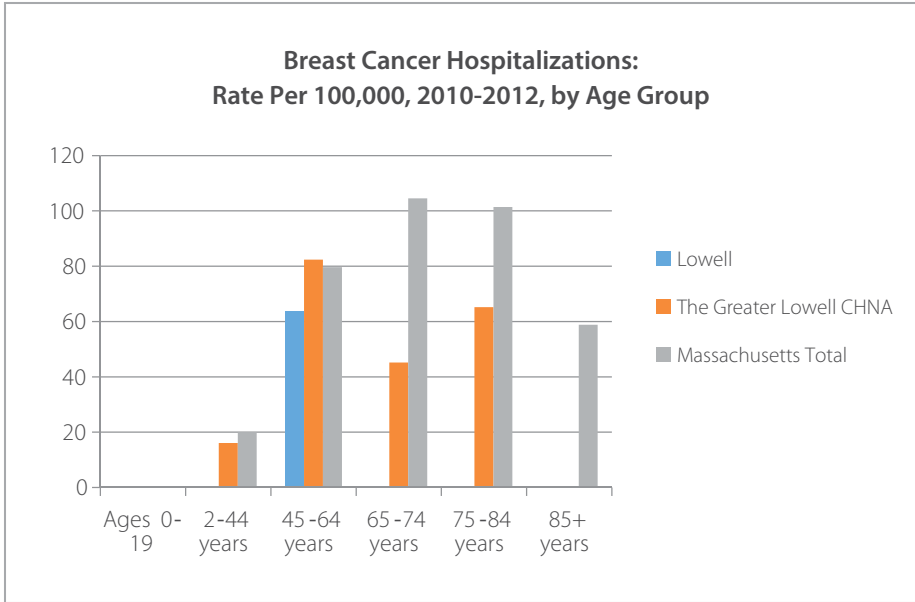


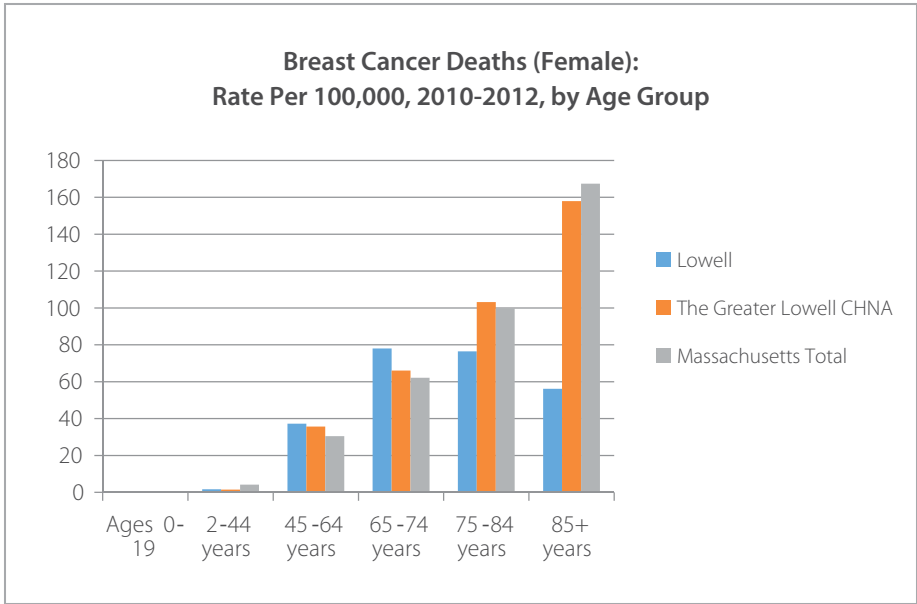
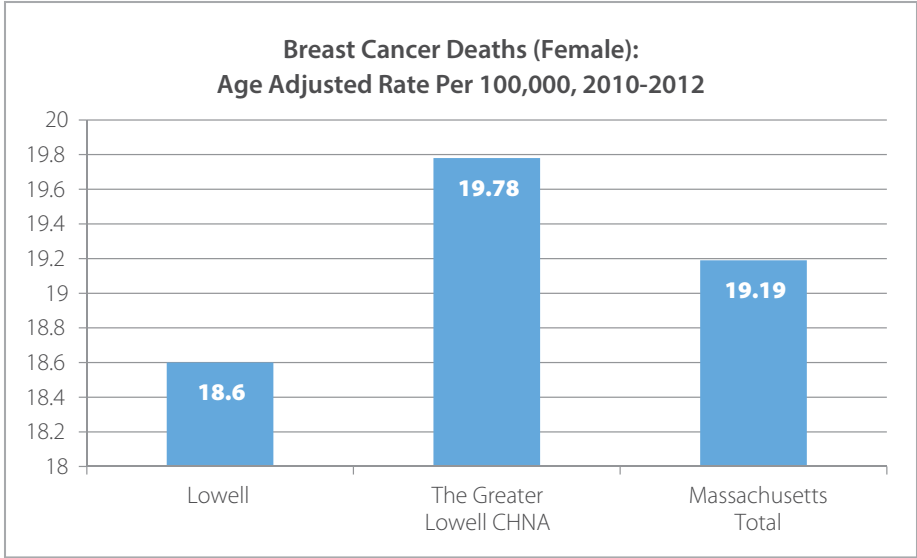
APPENDIX H
Incidence, Hospitalizations and Mortality of Top Area Cancers

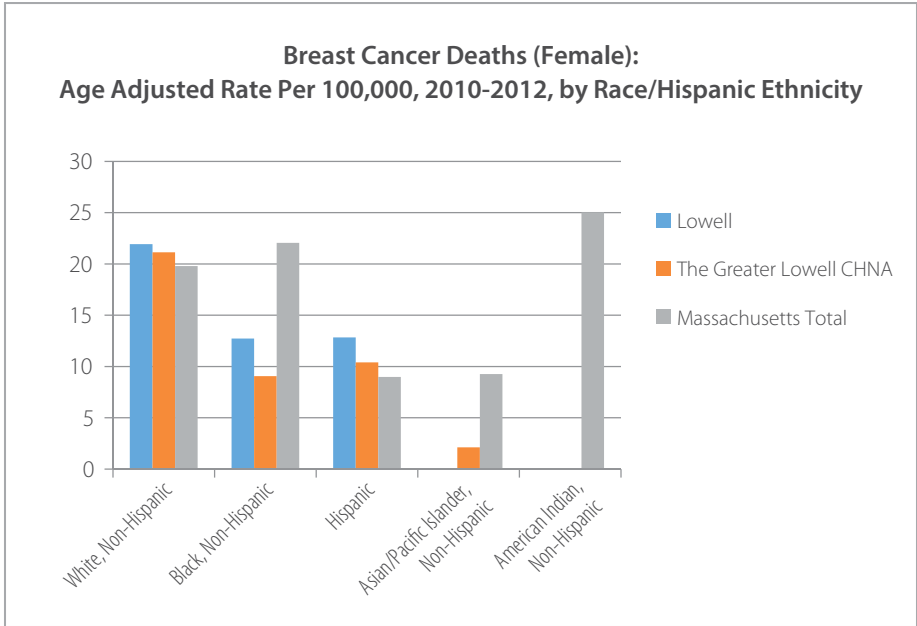
Breast Cancer





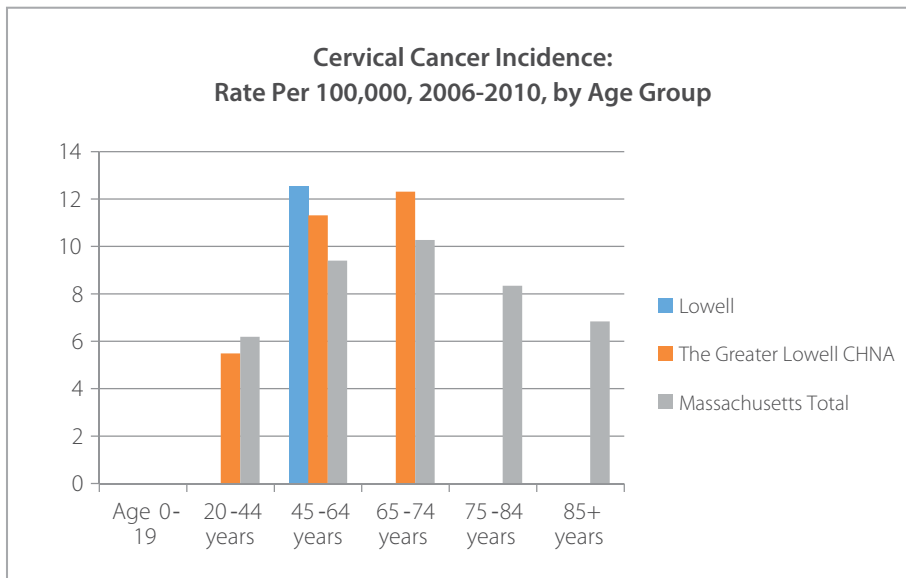
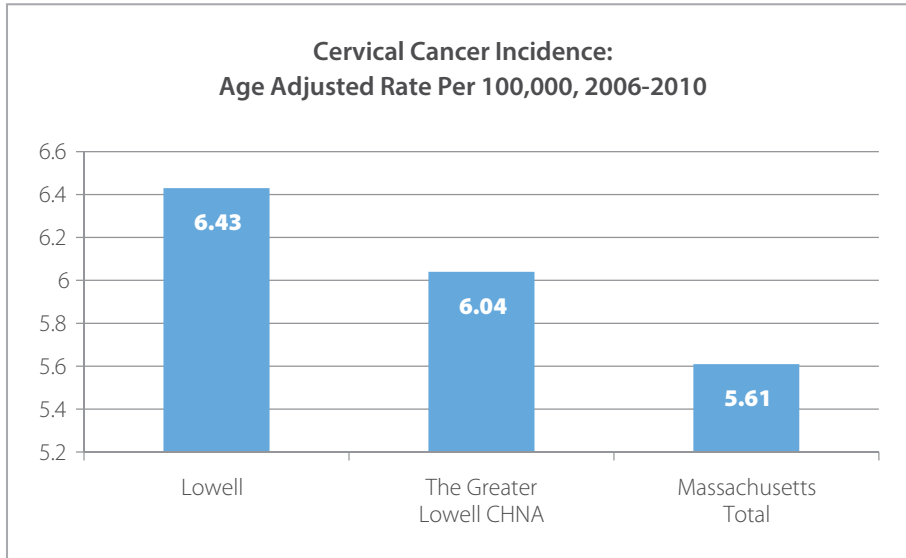


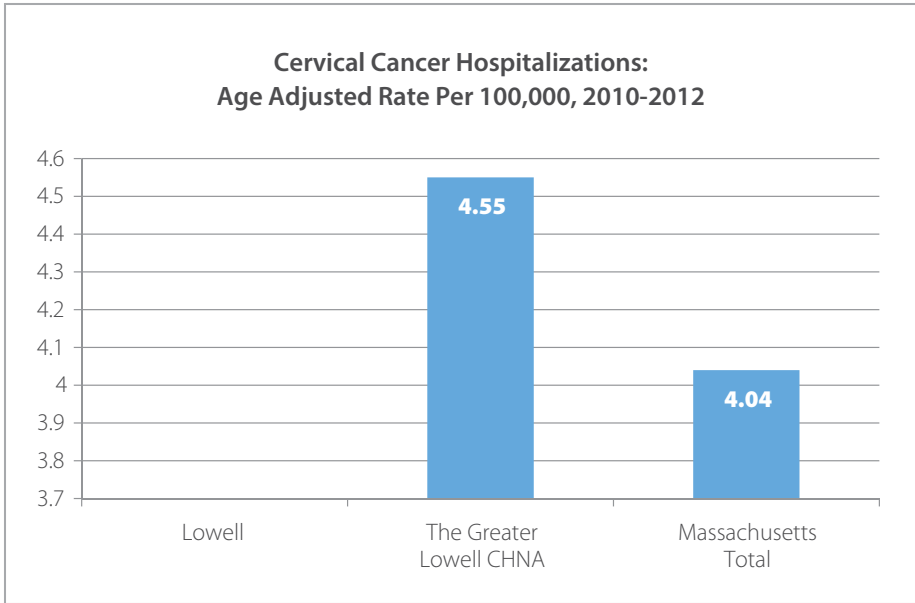
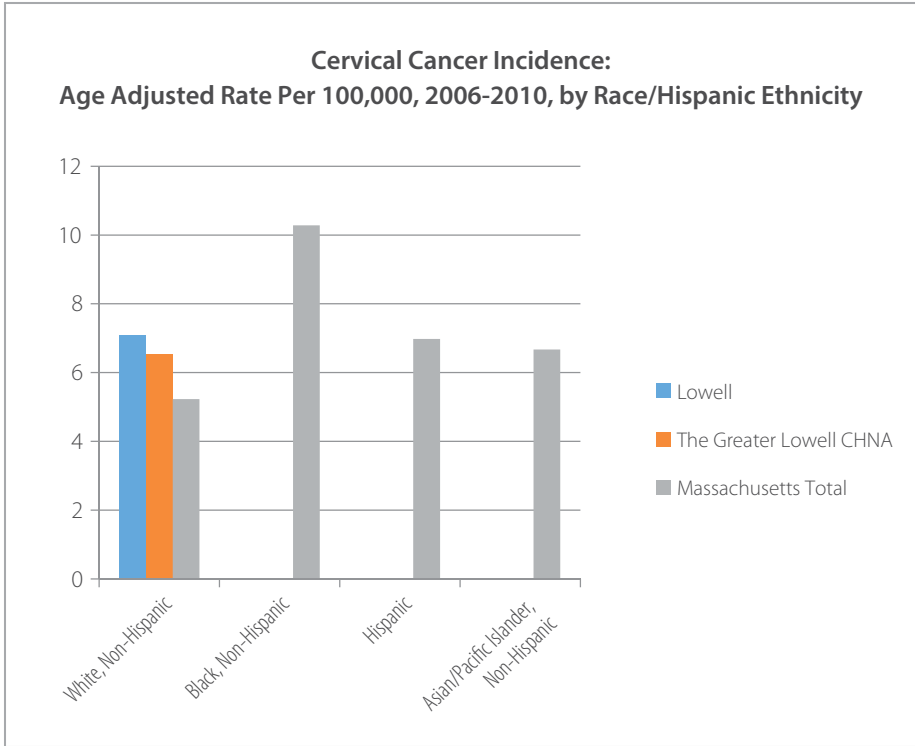


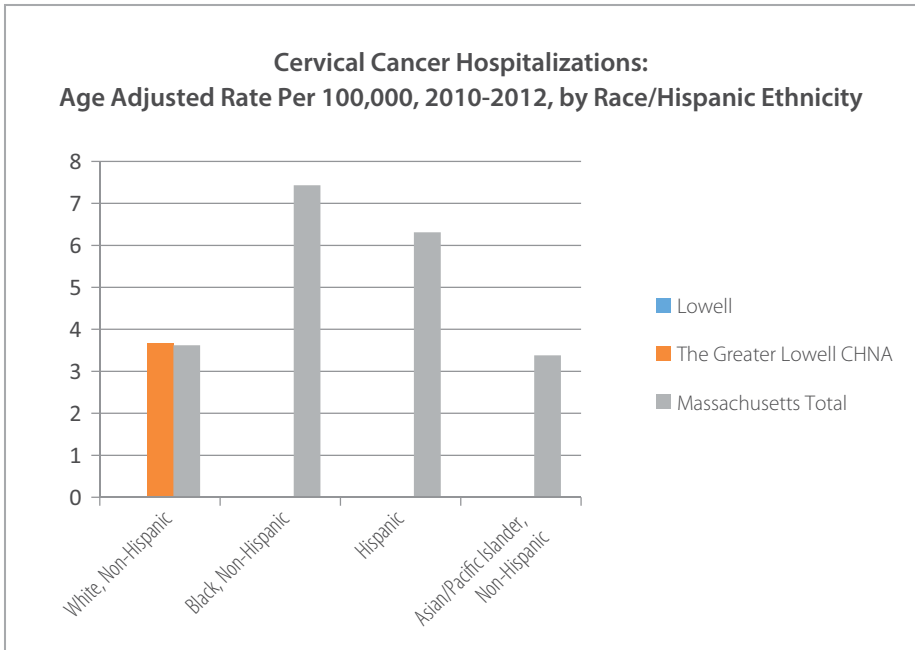
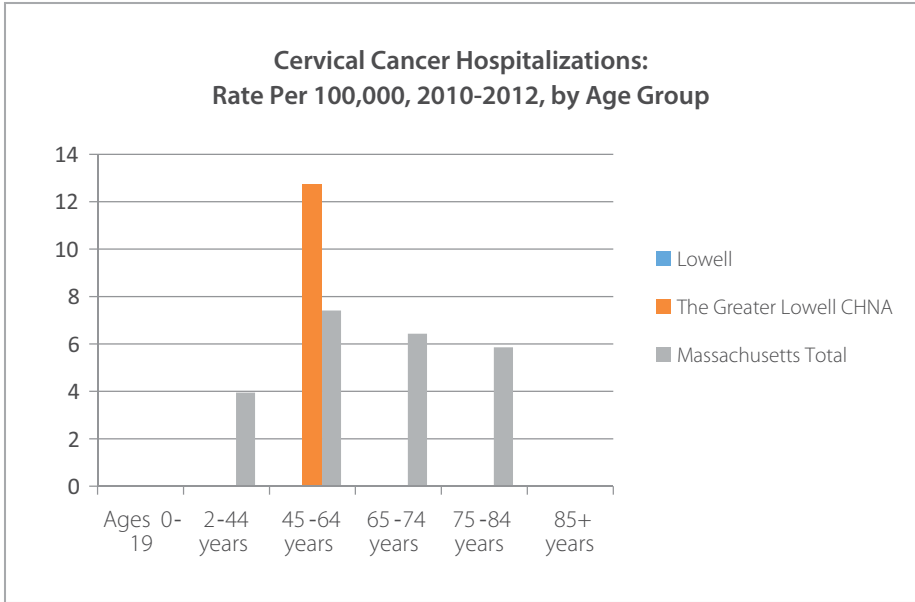


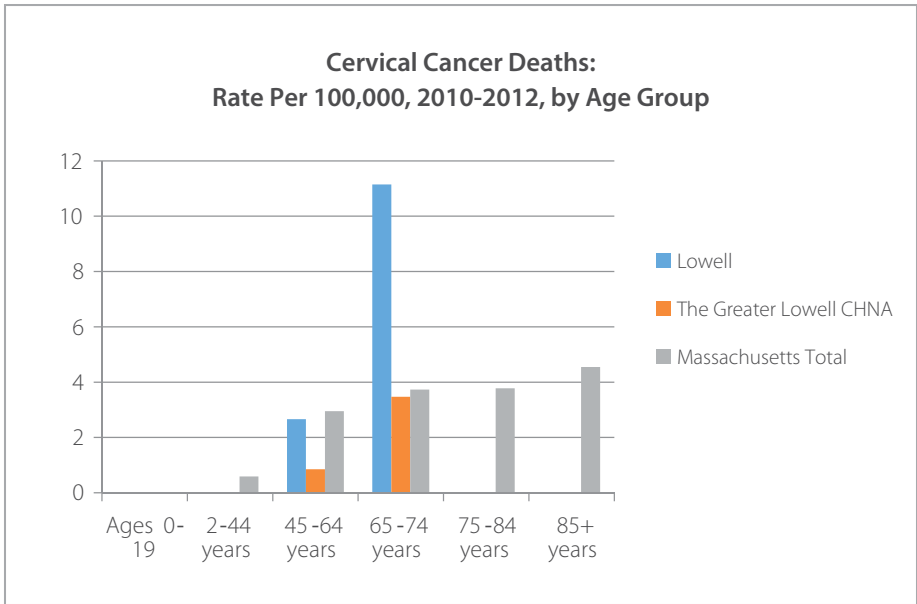
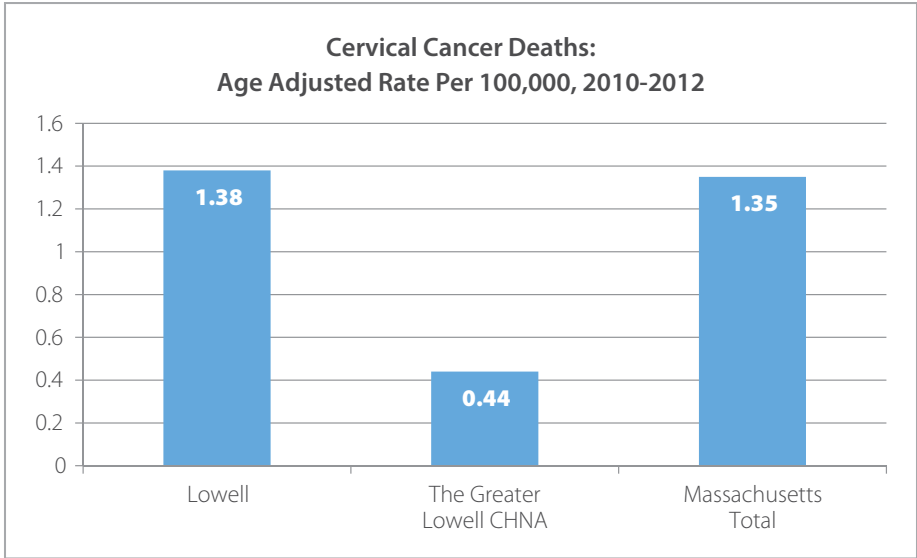
APPENDIX H
Incidence, Hospitalizations and Mortality of Top Area Cancers

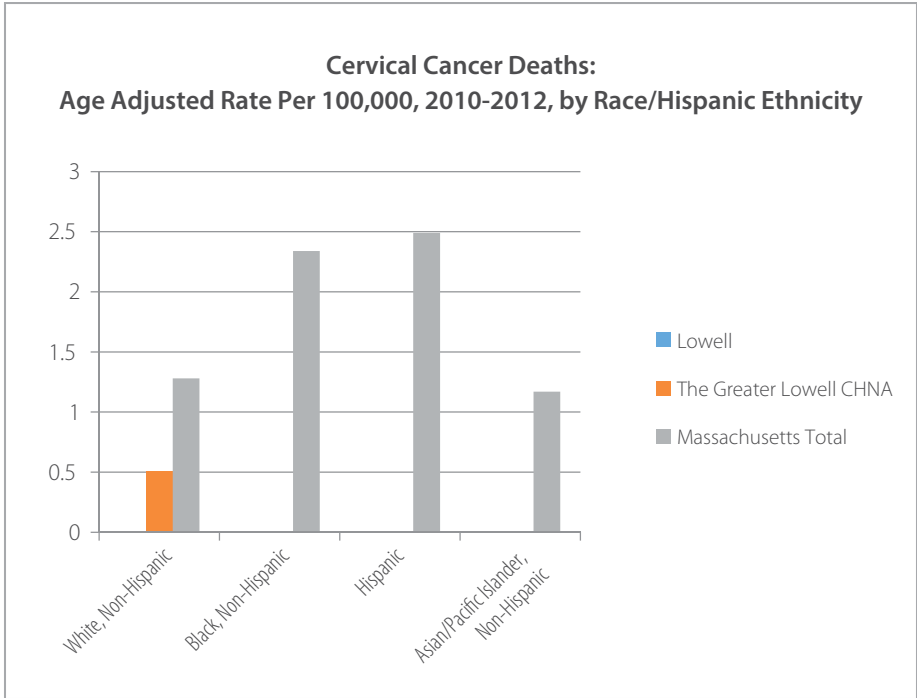
Cervical Cancer





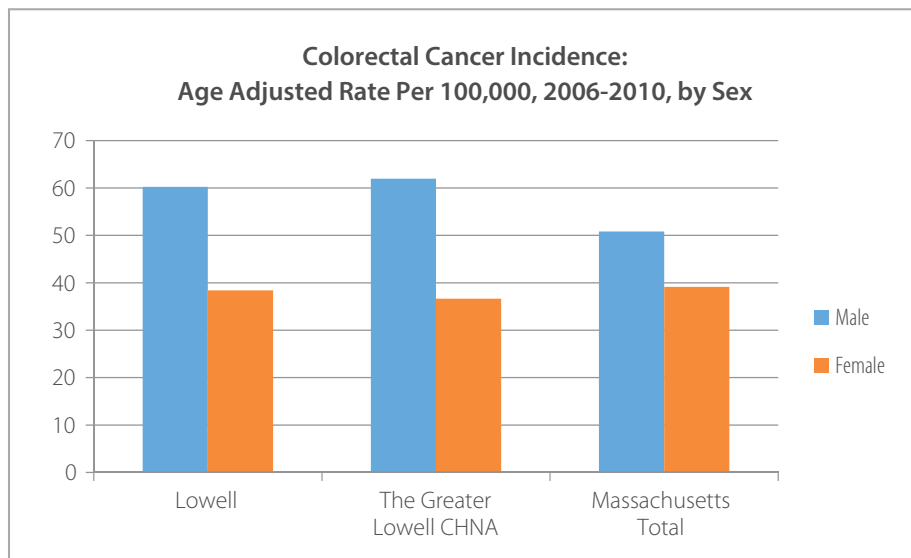
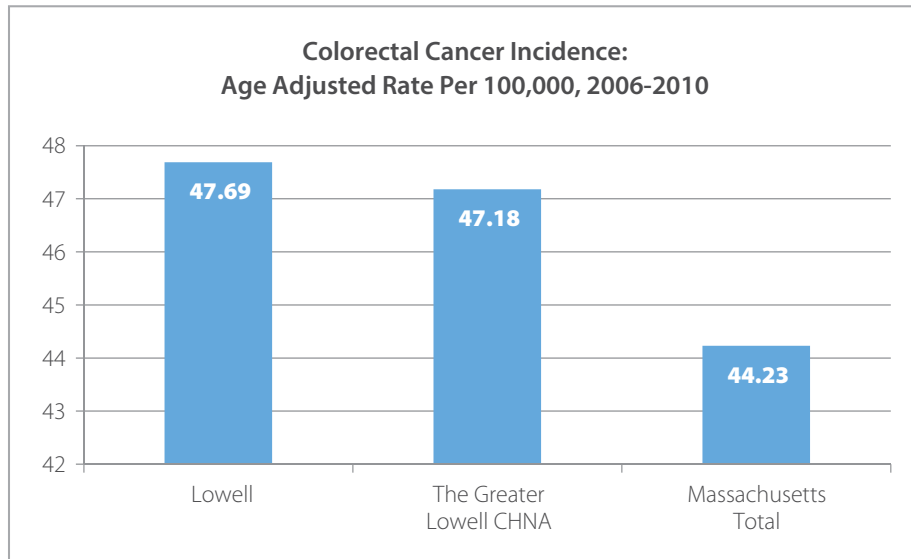


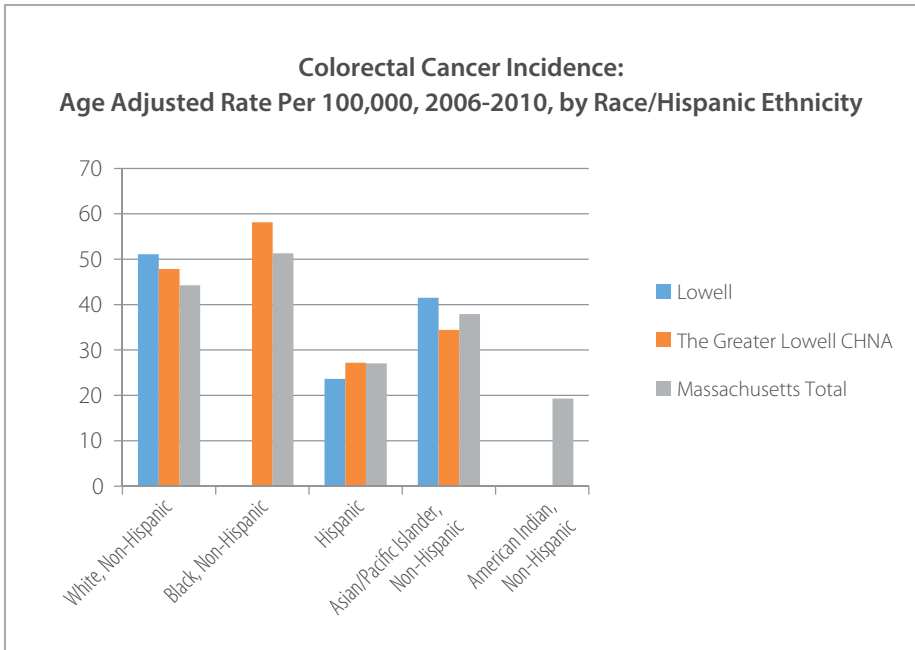
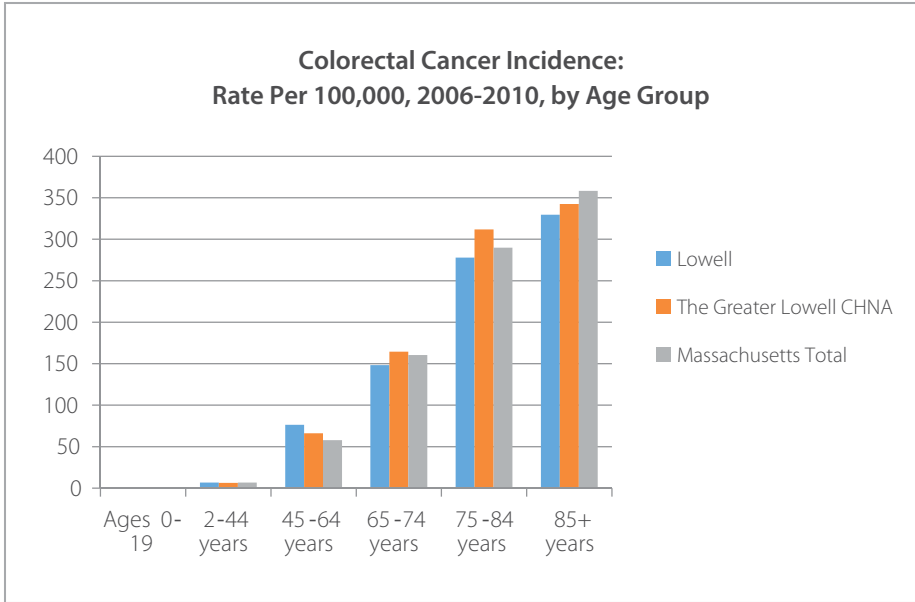


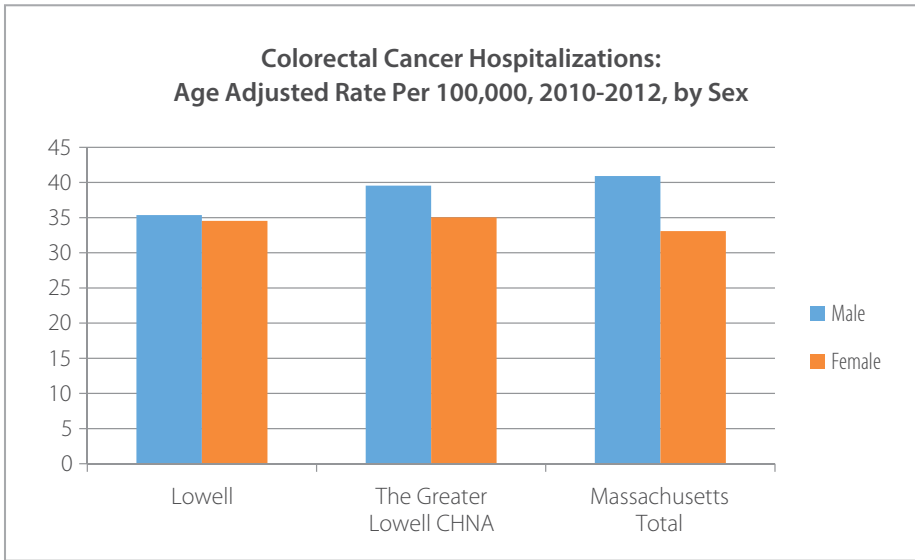
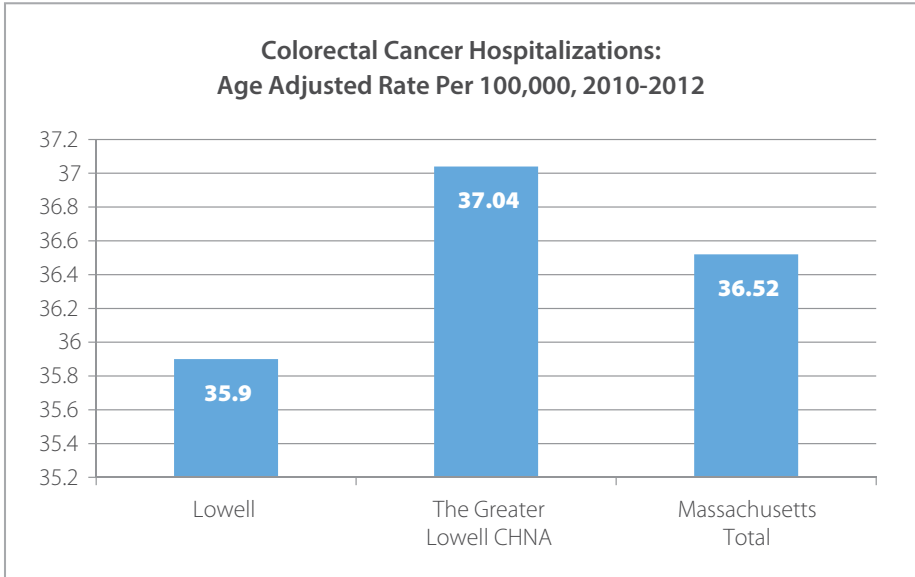


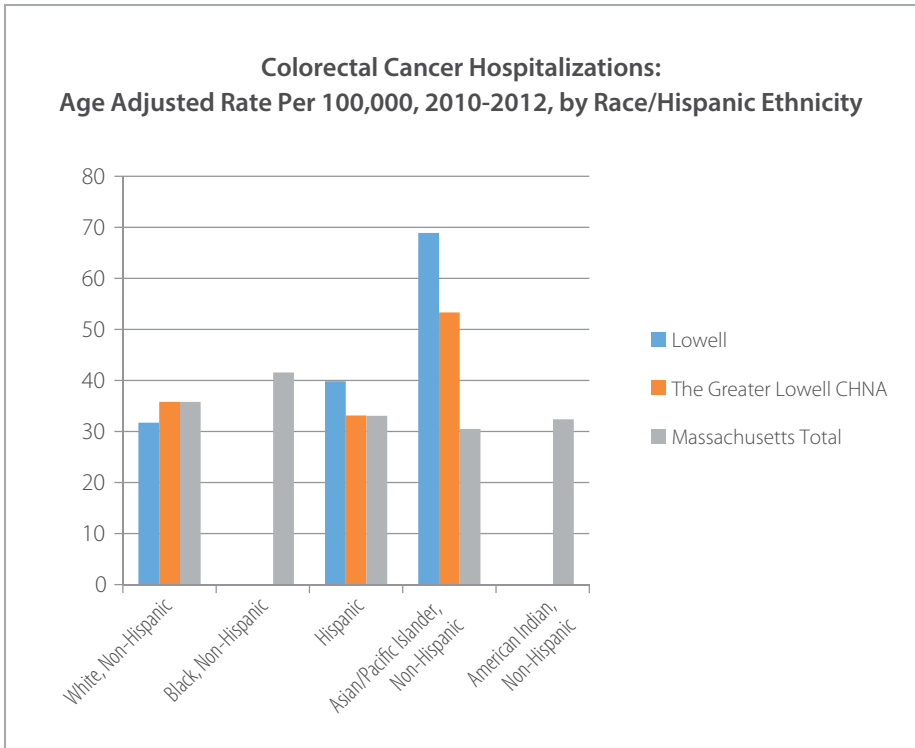
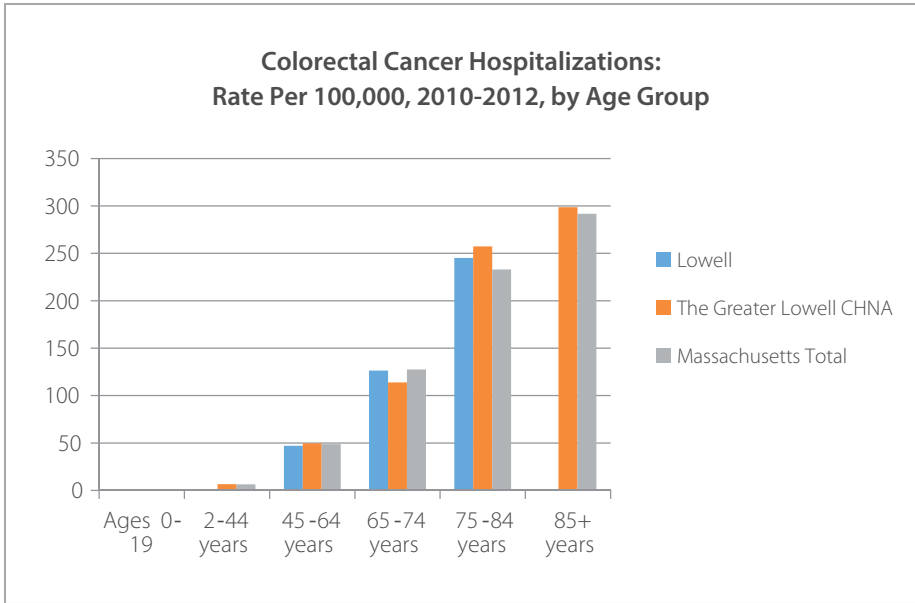
APPENDIX H
Incidence, Hospitalizations and Mortality of Top Area Cancers

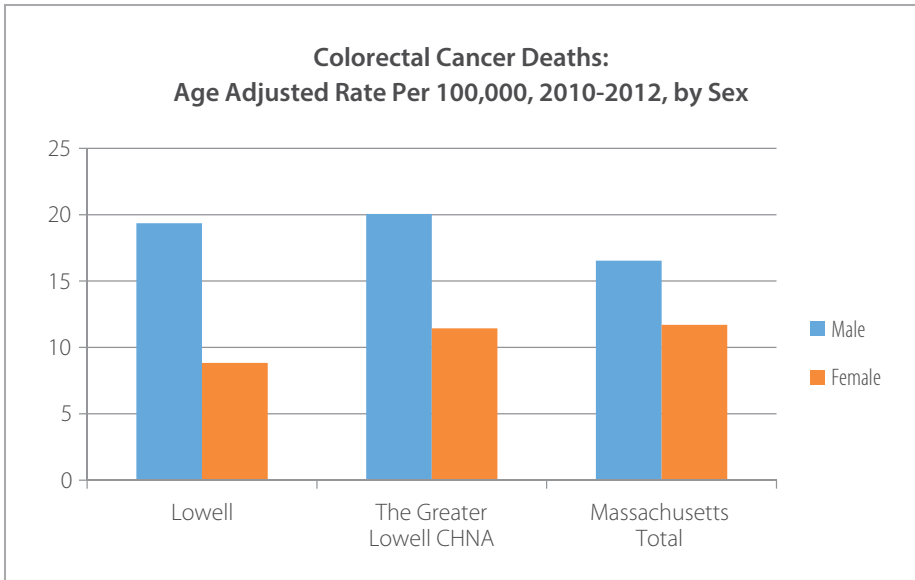
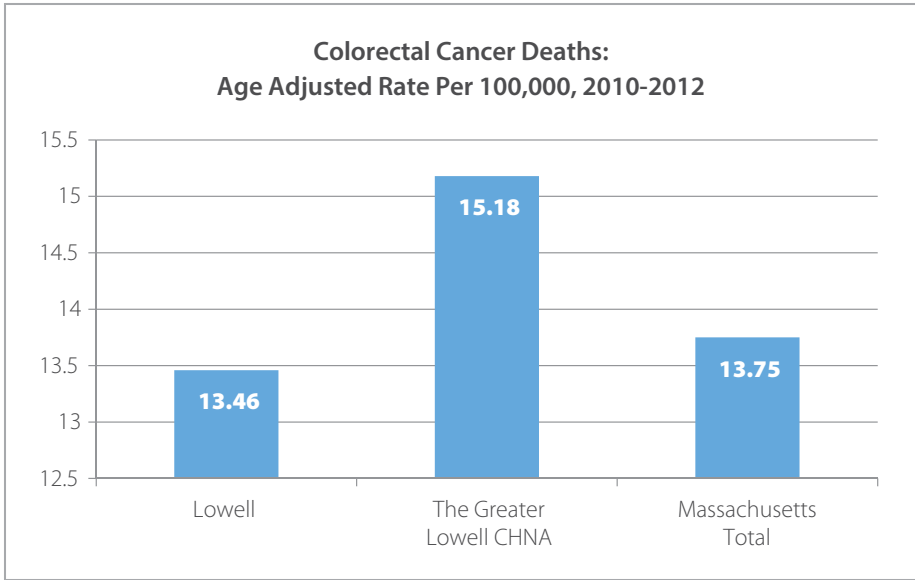
Colorectal Cancer

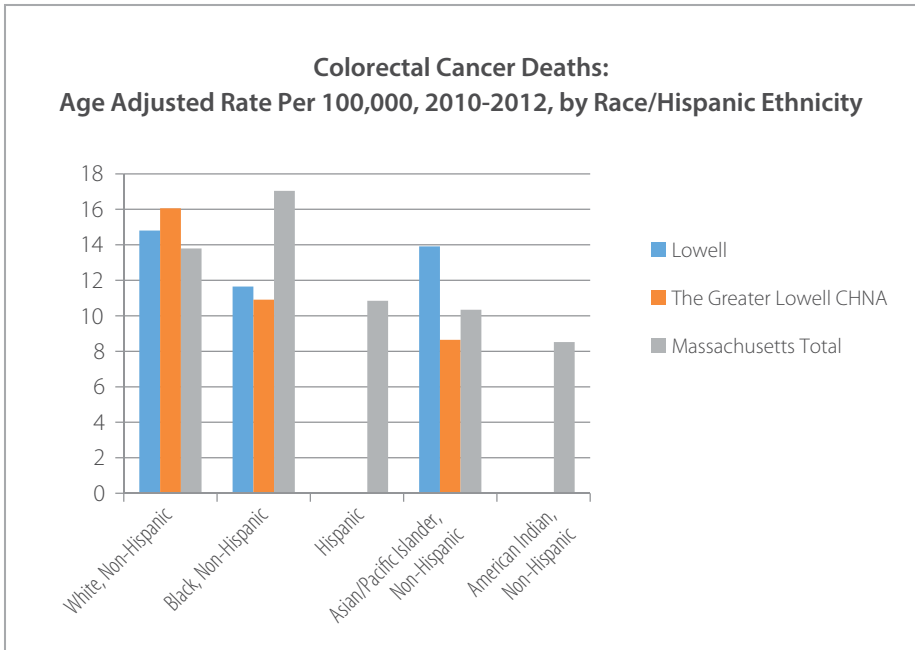
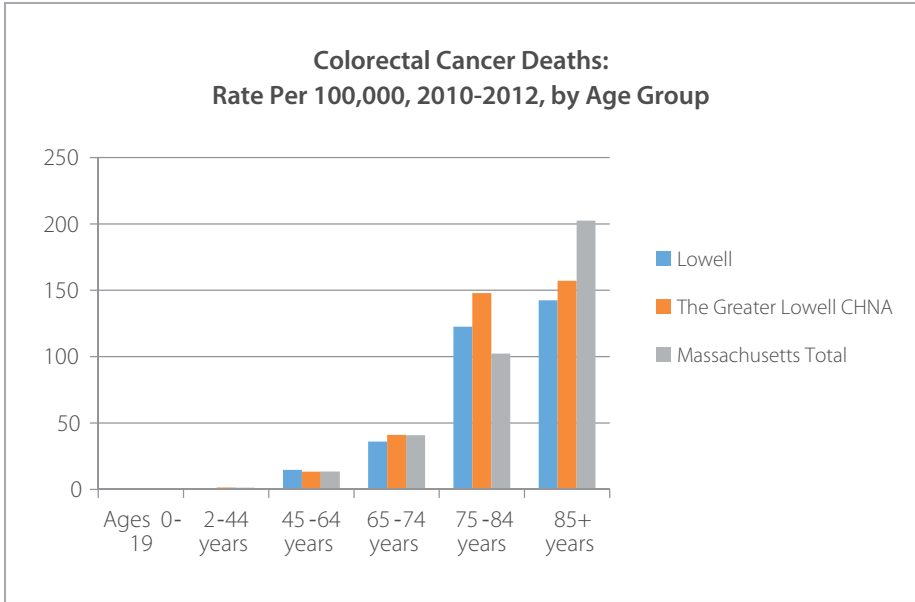






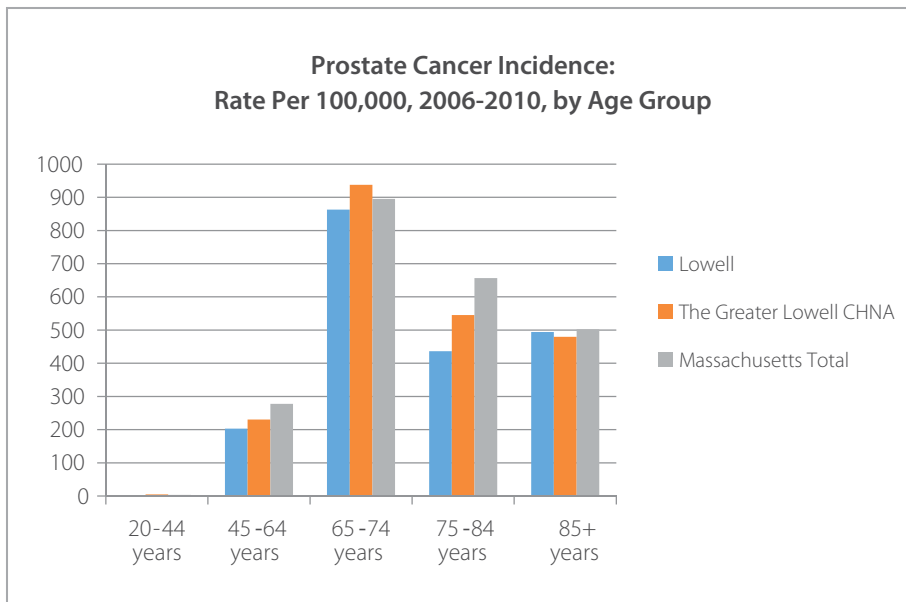
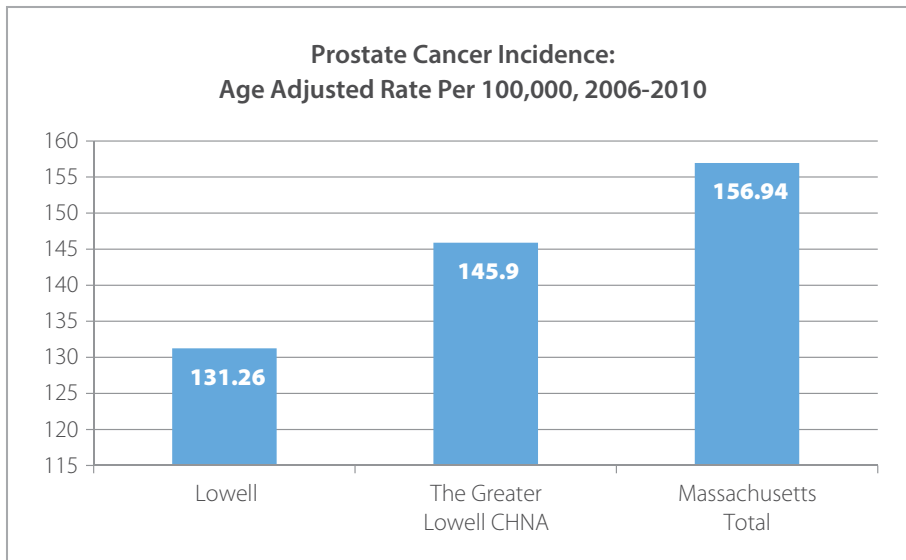




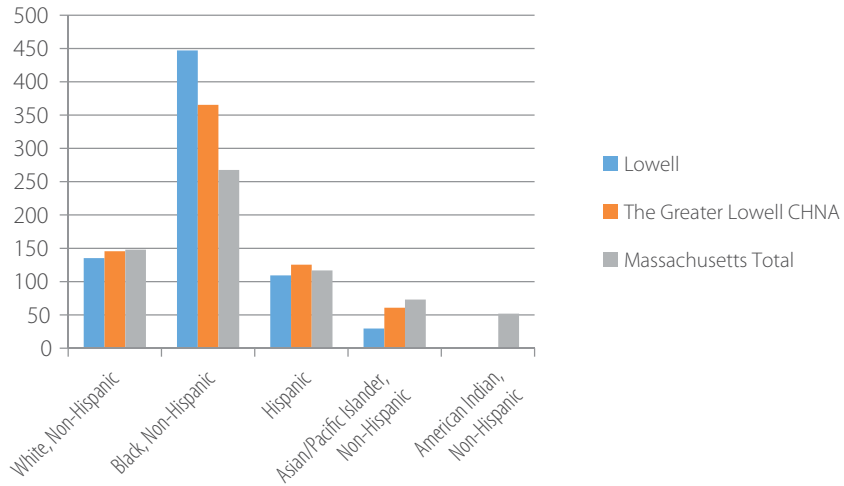


APPENDIX H
Incidence, Hospitalizations and Mortality of Top Area Cancers

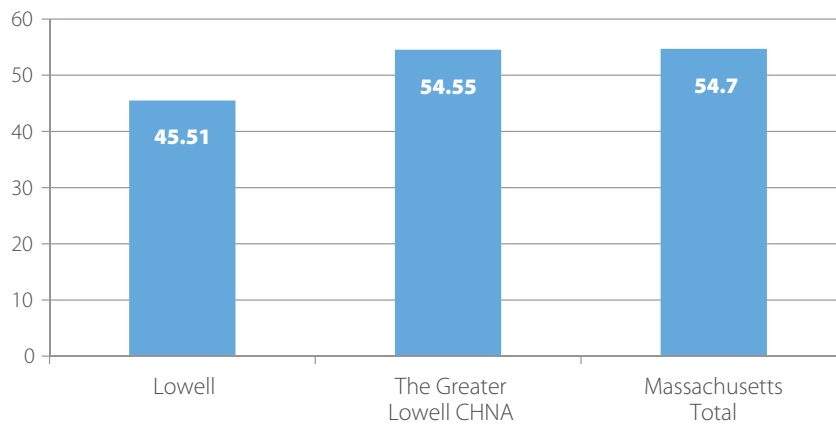
Prostate Cancer



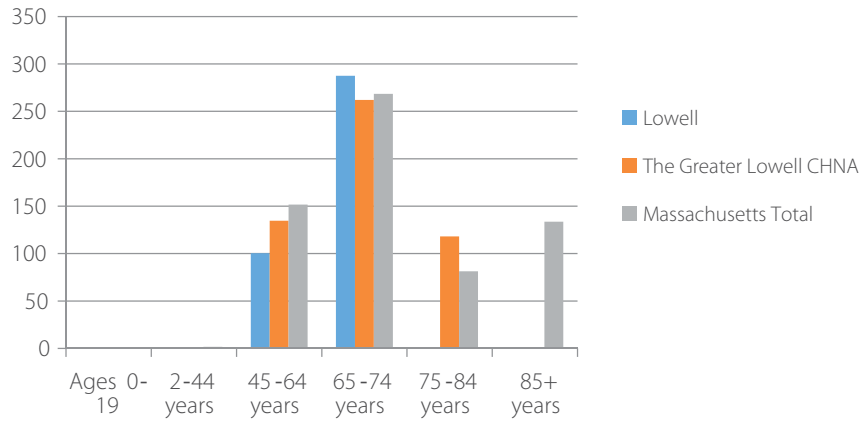
**Prostate Cancer Incidence:
Age Adjusted Rate Per 100,000, 2006-2010, by Race/Hispanic Ethnicity**



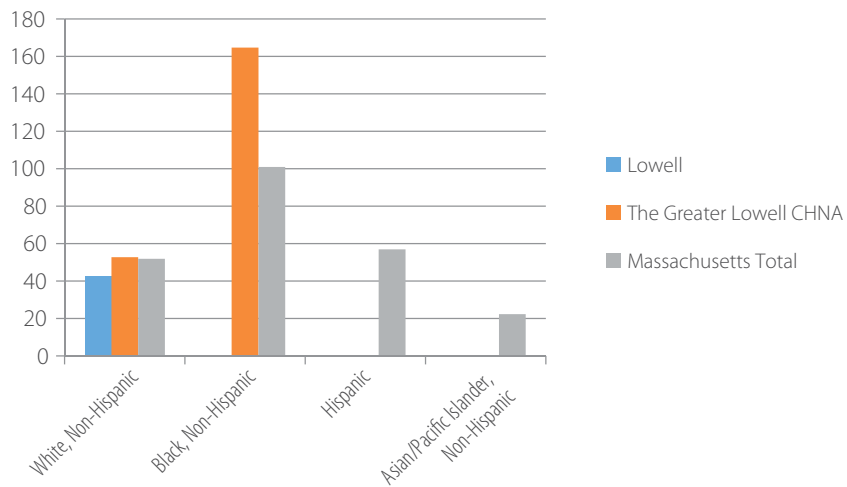
**Prostate Cancer Hospitalizations:
Age Adjusted Rate Per 100,000, 2010-2012**

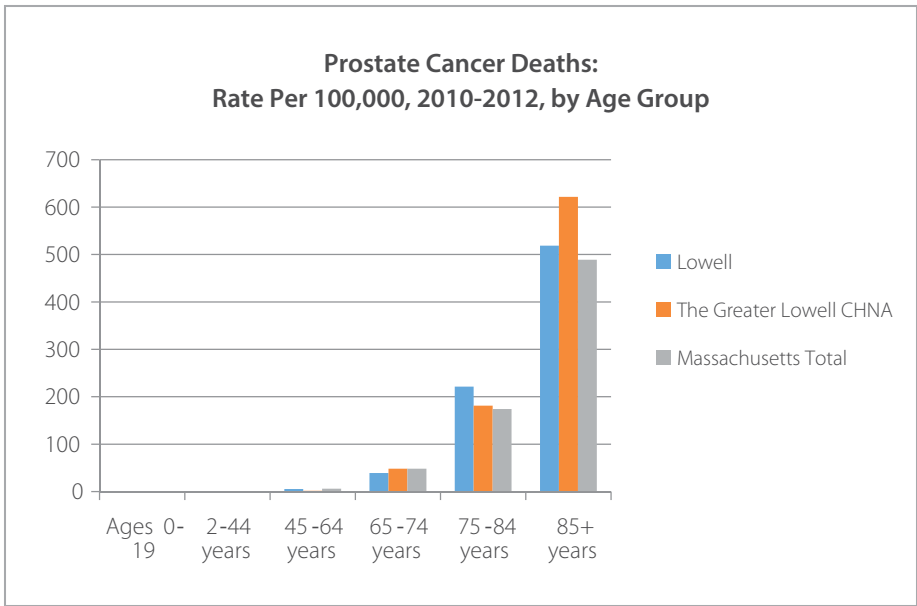
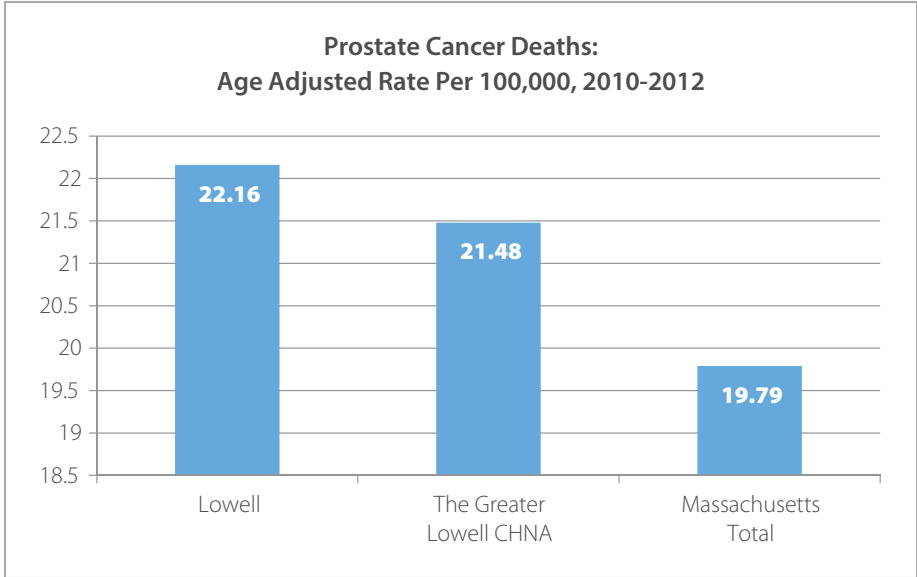


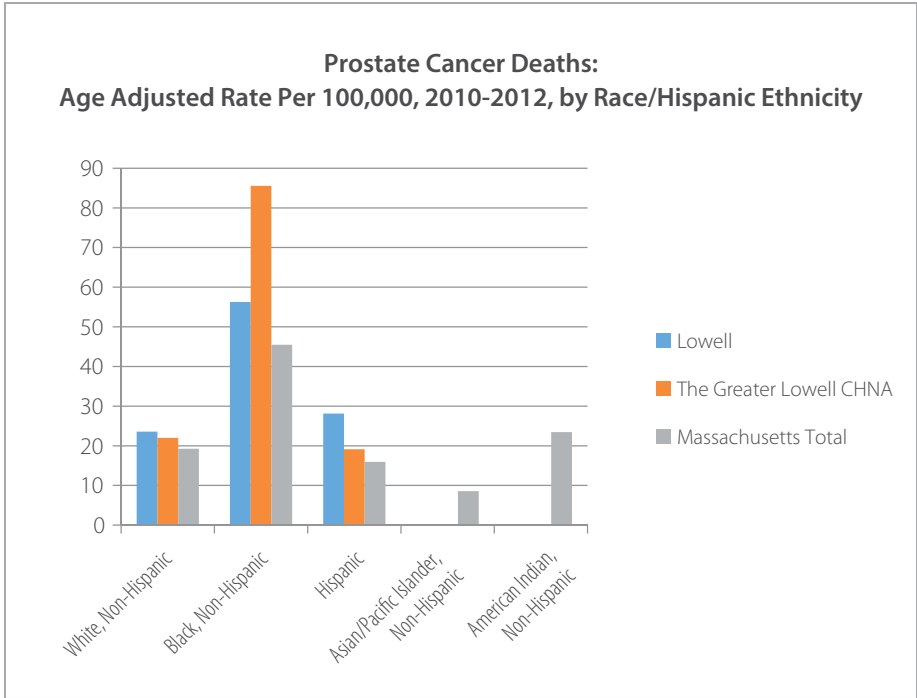
**Prostate Cancer Hospitalizations:
Rate Per 100,000, 2010-2012, by Age Group**



**Prostate Cancer Hospitalizations:
Age Adjusted Rate Per 100,000, 2010-2012, by Race/Hispanic Ethnicity**

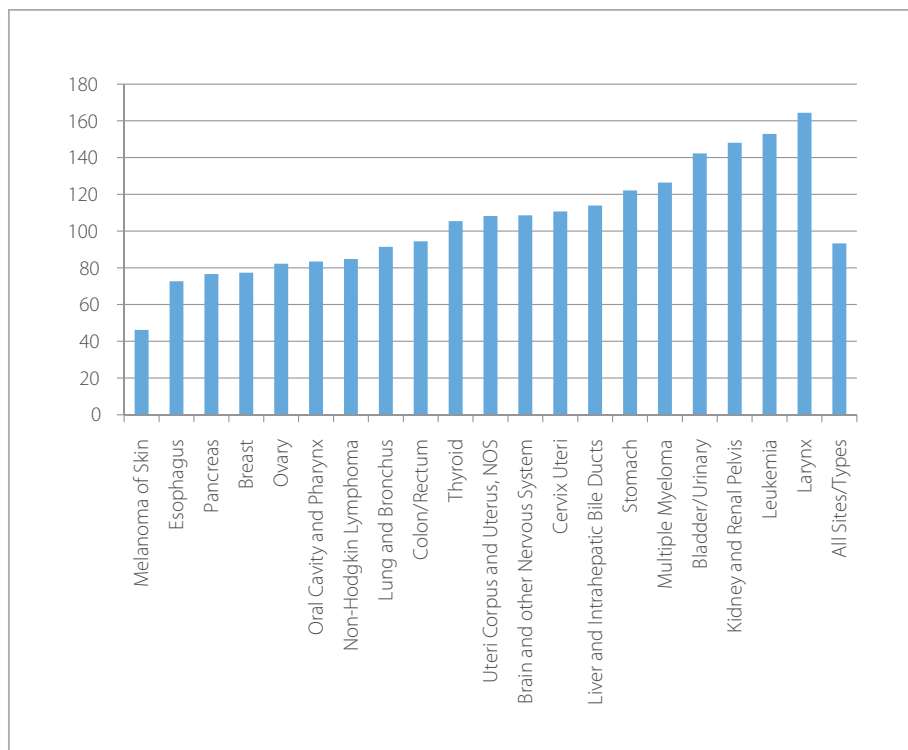






APPENDIX H
Incidence, Hospitalizations and Mortality of Top Area Cancers

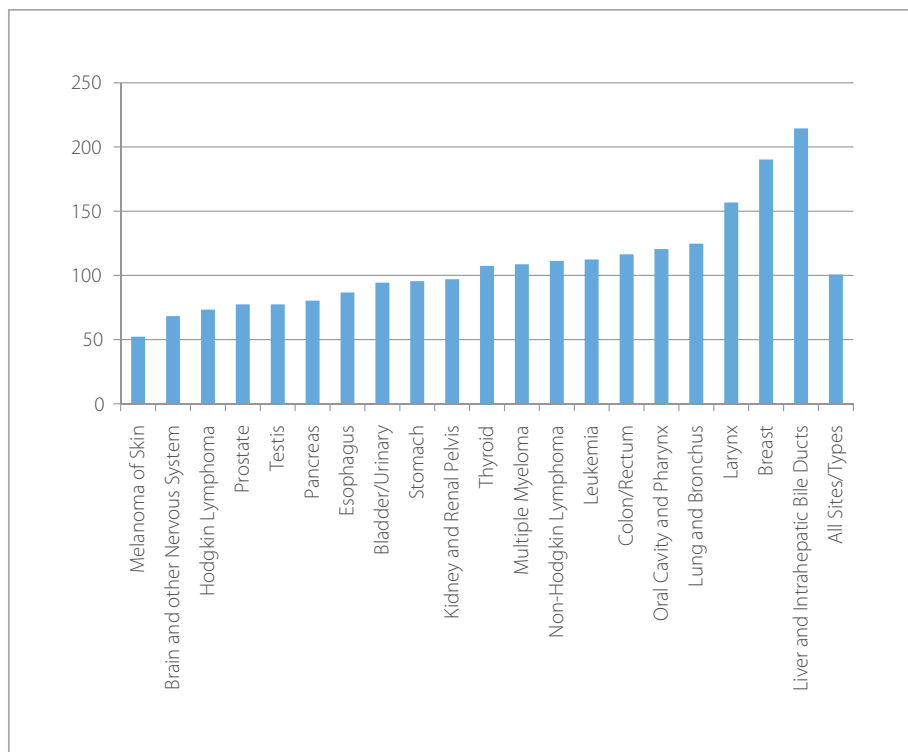
Standardized Incidence Ratios for Cancers, 2006-2010, Lowell Females



Source: CANCER INCIDENCE IN MASSACHUSETTS 2006 – 2010: CITY AND TOWN SUPPLEMENT, Office of Data Management and Outcomes Assessment, Massachusetts Department of Public Health, November 2014

APPENDIX H
Incidence, Hospitalizations and Mortality of Top Area Cancers

Standardized Incidence Ratios for Cancers, 2006-2010, Lowell Males



Source: CANCER INCIDENCE IN MASSACHUSETTS 2006 – 2010: CITY AND TOWN SUPPLEMENT, Office of Data Management and Outcomes Assessment, Massachusetts Department of Public Health, November 2014

Note:

An SIR of more than 100 indicates that a city/town's incidence of a certain type of cancer is higher than expected for that type of cancer based on statewide average annual age-specific incidence rates. For example, an SIR of 105 indicates that a city/town's cancer incidence is 5% higher than expected based on statewide average annual age-specific incidence rates. An SIR of less than 100 indicates that a city/town's incidence of a certain type of cancer is lower than expected based on statewide average age-specific incidence rates. For example, an SIR of 85 indicates that a city/town's cancer incidence is 15% lower than expected based on statewide average annual age-specific incidence rates.

Acknowledgements

We would like to acknowledge and thank the following for their assistance with this cancer disparities needs assessment and this report:

Kerrie D'Entremont Executive Director, Greater Lowell Health Alliance, for her direction and guidance with this endeavor, and Lozitha Nzula, Administrative Assistant, Greater Lowell Health Alliance, for her help with scheduling focus groups, key informants interviews, participant, facilitator and Notetaker recruitment, facilitating the translation of materials from English to Khmer, Brazilian Portuguese and Spanish.

Thank you to those who helped organize and host provider round table and professional focus groups: Lowell Community Health Center, The City of Lowell Hunger and Homelessness Coalition, Lowell Community Health Center, Merrimack Valley Health Directors, Cambodian Mutual Assistance Association, Massachusetts Alliance of Portuguese Speakers, Circle Health Center, Circle Health.

Thank you to those who agreed to be interviewed as key informants: Mercy Anampiu, Lowell Community Health Center; Elisa Choi, M.D., FACP, Vice-Chair & Commissioner, Chair, Healthcare Subcommittee, Asian American Commission of the Commonwealth of MA; Michelle Davis, Vice President External Affairs, Lowell General Hospital; Tami Gouveia Executive Director, Tobacco Free Mass; Diane Knight, Director, Northeast Tobacco Free Community Partnership; Allesandra Lopes, Lowell Office Manager/Domestic Violence and Sexual Assault Advocate, Massachusetts Alliance of Portuguese Speakers; Paul Muzhuthett, Regional Director, Northeast Regional Health Office, Department of Public Health; Lozitha Nzula, Greater Lowell Health Alliance; Sue Rosa, Chelmsford Board of Health;

Thank you to University of Massachusetts Lowell researcher Emily Chaves, for data collection using MassCHIP and creation of bar charts and graphs for the report;

Thank you to our Advisory Committee members for their advice and guidance to ensure we were broadly inclusive in outreach to our diverse and often underserved communities;

Thank you to those who agreed to be facilitators and note takers, as well as the over 100 providers, professionals and community members, without whom the cancer disparities needs assessment would not have been possible.

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



Lowell General Hospital Saints Campus
1 Hospital Drive, Lowell MA 01852
P 978-934-8368
F 978-934-8521

www.greaterlowellhealthalliance.org