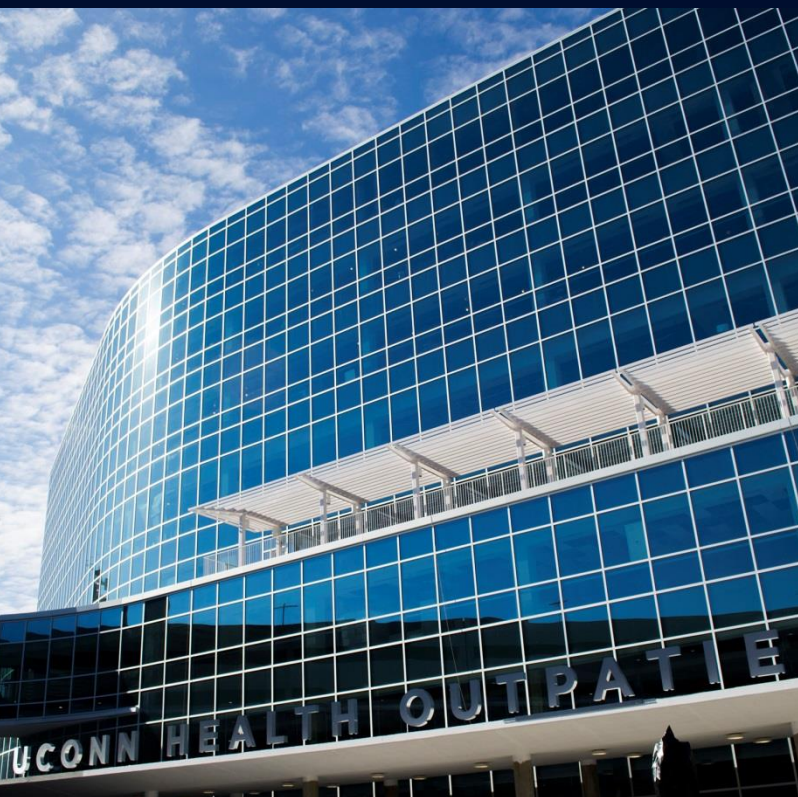


# Comprehensive Cancer Care

## Community Needs Assessment

March 2016



**UConn**  
HEALTH

## Acknowledgements

This assessment would not have been possible without the input of our cancer center patients that gave generously of their time to complete a needs assessment survey in the midst of their cancer treatment. It is with them in mind that we undertake this work to understand barriers to care and translate findings to improve our patient navigation program.

This community needs assessment was made possible through collaboration with the Health Disparities Institute at UConn Health.

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# 1. Executive Summary

The Community Needs Assessment was conducted to identify disparities in cancer care and resources to manage this diverse patient population. For UConn the primary service area covers 12 towns in the greater Farmington area with a secondary service area that come from many small rural towns in Connecticut. This document is also used to define the use of patient navigation to eliminate barriers from timely diagnosis to treatment for cancer care. The needs assessment will be used to explore the current medical system barriers and address our current patient navigation services. Data for this report was collected through Connecticut Department of Public Health, UConn Tumor Registry, and patient and key employee interviews.

## Summary of Key Findings

To address the needs of the community, it is important to understand the patient population that seeks their medical care at UConn. The UConn Health Cancer Center community is predominantly Caucasian at 87.2% with minorities as follows: Black 6.5%, Hispanic 4.4%, Asian 1.4% and Other 0.5%. According to the Connecticut Tumor Registry the most commonly seen cancer diagnosis at UConn are breast, head/neck, prostate, lung and bladder cancers. This registry data also supports that skin cancers are the most common type of cancer at 24%. This population, managed in the Dermatology Department refers patients with melanoma, squamous cell and merkle cell of which we navigate 100% of them.

The inception of the Breast Navigator Program was in 2012 under a Susan G. Komen grant. The program quickly became successful with a team of medical, surgical and research physicians and several years into it, it was recognized that there was a greater need to reach out to the Black and Hispanic community. An outreach program was established in 2015 with a bilingual lay navigator who focused her efforts on patients in the Hartford area in poor, underserved neighborhoods, providing access and screening education. This allowed for the UConn Breast Patient Navigator to focus her efforts on cancer education for medical/surgical interventions and to provide resources for basic needs i.e., transportation and financial assistance. This program also uses philanthropic funding to support patients with gift cards for gas and groceries. To date there has been 77 patients referred and 37 patients screened. In 2014, a General Nurse Navigator Program was initiated. The focus on the development of this program was to assist patients with access and appointments. The need at this time is to create a standardized patient navigation program that will include all aspects of navigation such as prevention, detection, diagnosis, treatment and survivorship. To establish the continuum is critical to the development of the program. Other areas that have been identified as areas for growth are:

- Financial assistance programs to address expenses related to cancer therapies
- Improve access for transportation and parking challenges
- Hire an Outreach Worker to advertise, increase awareness and to educate on importance of screening

- Launch database for standardized documentation and access across the continuum
- Improved access for referrals not currently captured
- Addition of another social worker to provide more varied services
- Develop a system for educational handouts in other languages to be available on the day of visit
- Create a “Resource Guide” for referral to complementary and alternative therapies in the area
- Develop an on-line support group or referral guide for other psychosocial support systems

# Overview of UConn Health Cancer Center



## 2. Overview of UConn Health Cancer Center

### 2.1 Academic Cancer Center

UConn Health's Cancer Center history begins with Carole and Ray Neag. Their motivation is simple: to improve the lives of Connecticut families today and in years to come. In 2004, the Neag's made an extraordinary \$10 million gift – the largest philanthropic donation in UConn Health's history – to the cancer program, now called the Carole and Ray Neag Comprehensive Cancer Center. This generous gift continues to support cancer research and clinical services. Their lasting goal is that Connecticut residents will never have to travel far for world class cancer care.

We are committed to providing compassionate care through a wide range of state-of-the-art services in a multidisciplinary setting. Our team includes experienced providers in the fields of medical and surgical oncology, gynecologic oncology, hematology, radiation oncology and more. Experts work together to provide all patients a complete approach to care.

### 2.2 Cancer Programs, Areas of Specialization, Community Outreach

The Neag Comprehensive Cancer Center is committed to providing expert care while continuously pursuing the newest discoveries in cancer prevention, diagnosis, treatment and cures of tomorrow. Here are a few of the treatment areas the Neag Comprehensive Cancer Center specializes in: breast health, gynecologic cancers, blood disorders, radiation oncology, cancer prevention programs, reconstructive surgery, head and neck cancer/oral oncology program, skin cancer, and endocrine neoplasia.

We are deeply committed to our community. Every year, experts from the Neag Comprehensive Cancer Center participate in dozens of lectures and screenings to help educate and empower men and women about new advances in cancer prevention, early detection and state-of-the-art treatments. We proudly join thousands of others every year to participate in events such as the Jim Calhoun Cancer Challenge Ride and Walk to raise both awareness and vital funds for research and patient care. Here are some more events the Neag Comprehensive Cancer Center participates in every year: Annual Cancer Survivor's Day, Coast to Coast for a Cure, to benefit the Lea's Foundation for Leukemia Research, Connecticut Race in the Park, to benefit the Connecticut Breast Health Initiative, Inc., Making Strides Against Breast Cancer, Relay for Life and the Susan G. Komen Race for Cure, Connecticut.

### 2.3 Workforce Diversity

Below are tables summarizing some demographics of UConn Health employees. The five categories listed were selected because they work within the Cancer Center. A subset of the workforce breakdown by race/ethnicity for UConn Health is as follows:



Category (Full Time + Part Time)	White	Black	Hispanic	Other	Total
Executive/Administrative	176 (88%)	15 (7.5%)	3 (1.5%)	6 (3%)	<b>200</b>
Professional/Non-Faculty	1681 (81.5%)	155 (7.5%)	93 (4.5%)	134 (6.5%)	<b>2063</b>
Secretarial/Clerical	557 (72%)	105 (14%)	89 (12%)	17 (2%)	<b>768</b>
Technical/Paraprofessional	587 (66%)	156 (17%)	122 (14%)	25 (3%)	<b>890</b>
Faculty	436 (71%)	18 (3%)	28 (5%)	130 (21%)	<b>612</b>

\*Source: UConn Health Office of Diversity and Equity

Category (Full Time + Part Time)	Male	Female	Total
Executive/Administrative	73 (36.5%)	127 (63.5)	<b>200</b>
Professional/Non-Faculty	436 (21%)	1627 (79%)	<b>2063</b>
Secretarial/Clerical	44 (6%)	724 (94%)	<b>768</b>
Technical/Paraprofessional	168 (19%)	722 (81%)	<b>890</b>
Faculty	365 (60%)	247 (40%)	<b>612</b>

- Overall, employees are mainly white and female.
- Males make up a majority of the faculty; the only category where males outnumber females.

## Background



## 3. Background

### 3.1 National Cancer Disparities

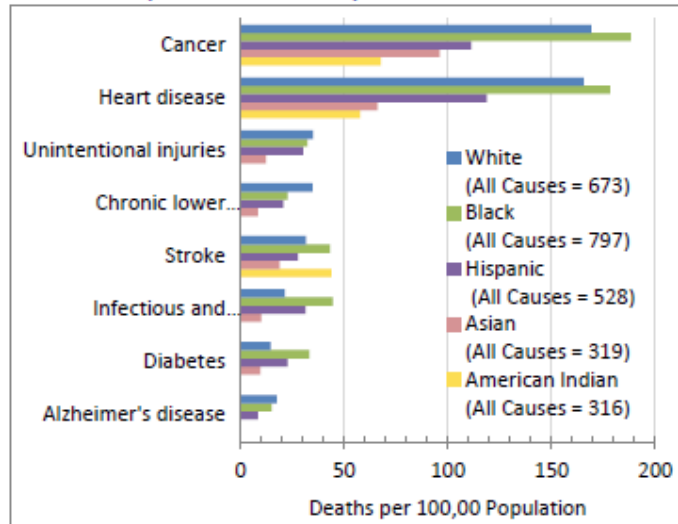
At a national level, inequities have been documented across the cancer care continuum (e.g., prevention, screening and treatment), leading to persistent disparities in mortality rates based on race, age and socioeconomic status (SES).

- Black patients are less likely than white patients to receive cancer screening; are more likely to present with advanced stage disease; are less likely to undergo surgery and receive adjuvant therapy; and are less likely to have reconstructive surgery for breast cancer.<sup>2,4</sup> Racial differences in outcomes have been reported for almost all cancer types and black-white differences in survival persist even when controlling for stage at presentation.<sup>4</sup>
- Lack of insurance (or having inadequate insurance) has been strongly associated with lack of cancer screening and treatment for poor, low-income, and middle-income patients.<sup>1,3,7</sup> Medicaid insured and low-income patients are less likely than privately insured and high-income patients to receive recommended care.<sup>3</sup>
- Non-financial barriers to cancer screening and treatment include low health literacy; mistrust; limited English proficiency; lack of usual source of primary care<sup>1</sup>; lack of transportation, childcare and time; fear of cancer diagnosis and treatment<sup>3</sup>; misconceptions about cancer treatment<sup>7</sup>; lack of social support; and strongly held beliefs that faith and prayer will cure cancer.<sup>4,7</sup>
- Inequality in cancer care is associated with delays in follow-up for abnormal screening, uncoordinated care, and mismanagement of cancer among racial/ethnic minorities and the poor.<sup>6</sup>
- Physician-patient communications influence uptake of cancer treatment recommendations and a correlation exists between a patient's negative perceptions of this interaction and underuse of surgery across races.<sup>4</sup>
- Race, SES, and age[ism] have been shown to influence physician's perceptions and treatment recommendations.<sup>4</sup>

### 3.2 State-wide Cancer Statistics

Cancer is the leading cause of premature mortality in Connecticut, followed by heart disease and unintentional injuries.<sup>8</sup> Cancer statistics regarding Mortality, Incidence, Survival, Type, and Stage from the Connecticut Department of Public Health are included below.

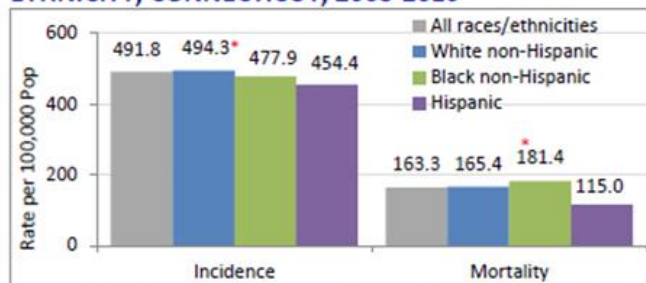
**Fig. 21. AGE-ADJUSTED MORTALITY RATES FOR LEADING CAUSES OF DEATH, BY RACE AND ETHNICITY, CONNECTICUT, 2006-2010**



Note: N/A indicates data not available; all racial groups are non-Hispanic. "Infectious and parasitic diseases" is not a standard category using in ranking "Leading causes of death," but it is included for descriptive purposes.

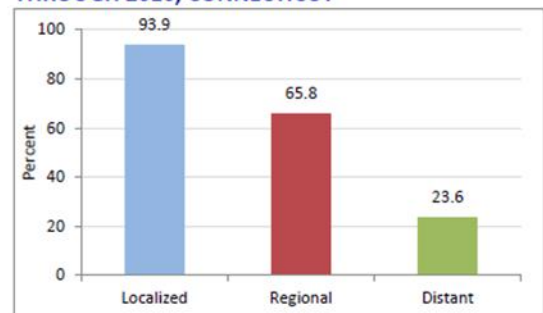
Source: Connecticut Department of Public Health, Age-Adjusted Mortality Rate Tables, 2006-2010.

**Fig. 120. CANCER INCIDENCE AND MORTALITY RATE FOR ALL INVASIVE CANCERS, BY RACE AND ETHNICITY, CONNECTICUT, 2008-2010**

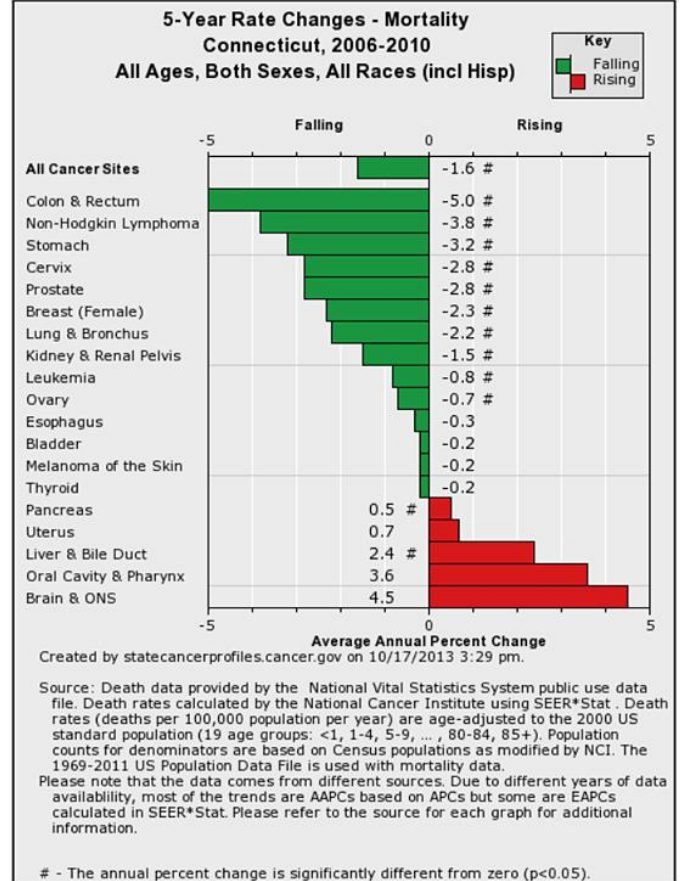
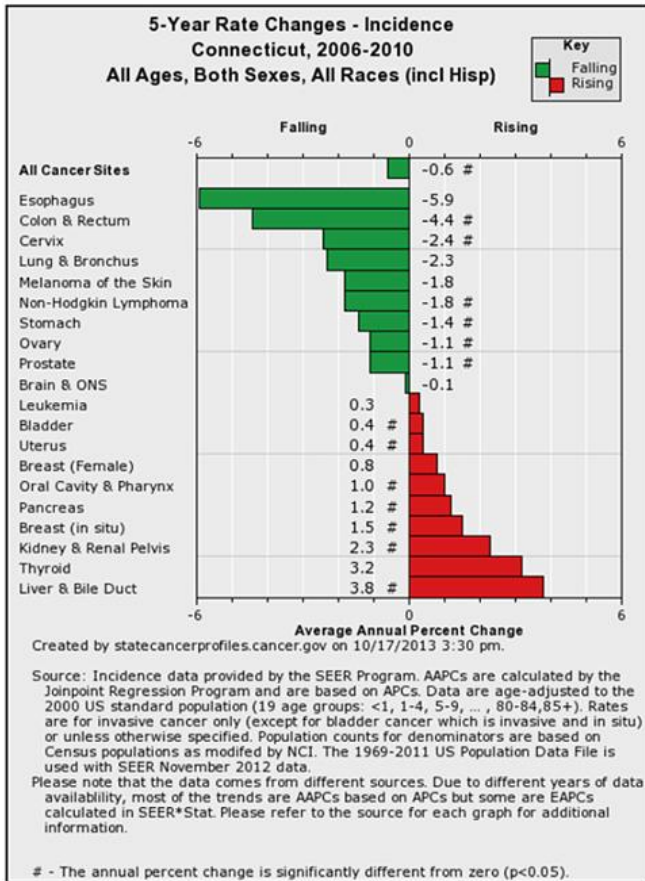


Note: \* Indicates significantly higher incidence for white non-Hispanics relative to Hispanics and difference in mortality rate across racial and ethnic groups ( $p < 0.05$ ). Source: Connecticut Tumor Registry, Connecticut Department of Public Health.

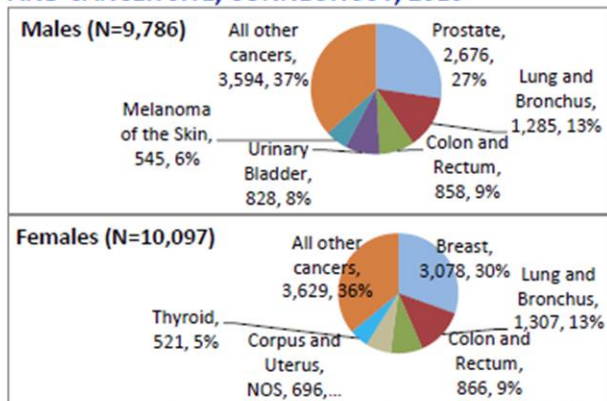
**Fig. 122. FIVE-YEAR CANCER RELATIVE SURVIVAL FOR ALL INVASIVE CANCERS, BY CANCER STAGE, FOR PERSONS DIAGNOSED 2004-2009, FOLLOWED THROUGH 2010, CONNECTICUT**



Source: Connecticut Department of Public Health.

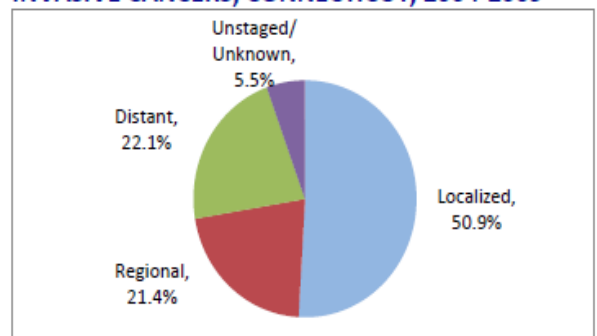


**Fig. 118. NUMBER OF NEW CANCER CASES, BY SEX AND CANCER SITE, CONNECTICUT, 2010**



Source: Connecticut Tumor Registry, Connecticut Department of Public Health.

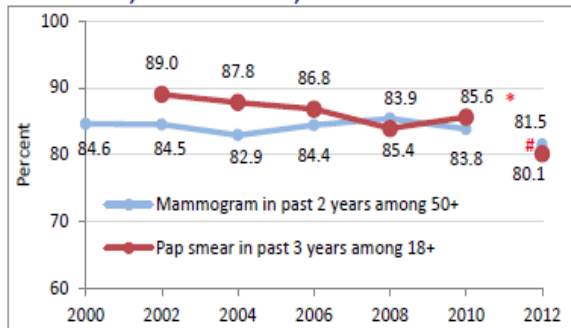
**Fig. 121. STAGE OF CANCER DIAGNOSIS FOR ALL INVASIVE CANCERS, CONNECTICUT, 2004-2009**



Source: Connecticut Department of Public Health.

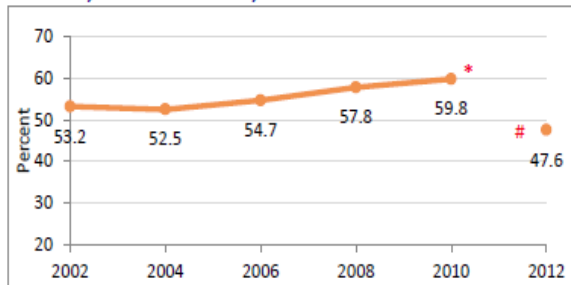
Cancer statistics regarding Screening from the Connecticut Department of Public Health are included below.

**Fig. 141. BREAST AND CERVICAL CANCER SCREENING, CONNECTICUT, 2000-2012**



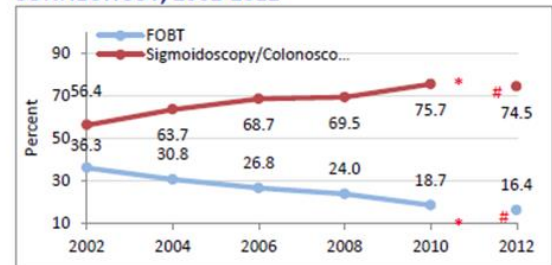
Note: \* Indicates significant decrease in Pap smear testing from 2002 to 2010 ( $p < 0.05$ ). # Break in trend due to new weighting in 2011.  
Source: Connecticut Department of Public Health, Connecticut Behavioral Risk Factor Surveillance System, 2000-2012.

**Fig. 142. PROSTATE CANCER SCREENING BEHAVIORS, AMONG MALES AT LEAST 40 YEARS OF AGE, CONNECTICUT, 2002-2012**



Note: \* Indicates significant increase in percent who received PSA test within past 2 years from 2002 to 2010 ( $p < 0.05$ ). # Break in trend due to new weighting in 2011.  
Source: Connecticut Department of Public Health, Connecticut Behavioral Risk Factor Surveillance System, 2002-2012.

**Fig. 143. COLORECTAL CANCER SCREENING AMONG PERSONS 50 YEARS OF AGE OR OLDER, CONNECTICUT, 2002-2012**

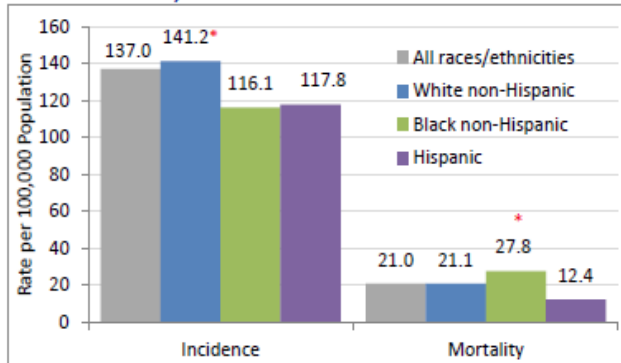


Note: \* Indicates significant increase in sigmoidoscopy/colonoscopy screening and decrease in FOBT from 2002 to 2010 ( $p < 0.05$ ). # Break in trend due to new weighting in 2011.  
Source: Connecticut Department of Public Health, Connecticut Behavioral Risk Factor Surveillance System, 2002-2012.

## Breast Cancer in Connecticut

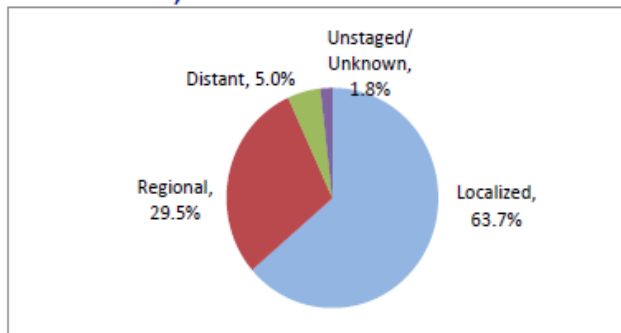
Connecticut has one of the highest incidence rates of breast cancer in the nation, with mortality rates for black women higher than white women, despite blacks continuing to have lower incidence rates; notably the gap between white and black mortality rates has been increasing. Five-year relative survival rates were significantly lower for black women than for white and Hispanic women, and there is a higher proportion of late stage diagnoses in black women.

**Fig. 123. FEMALE BREAST CANCER INCIDENCE AND MORTALITY RATE, BY RACE AND ETHNICITY, CONNECTICUT, 2008-2010**



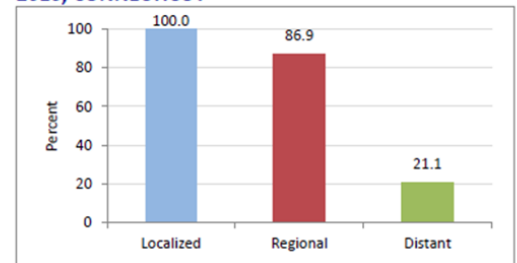
Note: \* Indicates significantly higher incidence for white non-Hispanics than black non-Hispanics and Hispanics and difference in mortality rate across racial/ethnic groups ( $p < 0.05$ ).  
 Source: Connecticut Tumor Registry, Connecticut Department of Public Health.

**Fig. 124. STAGE OF BREAST CANCER DIAGNOSIS, CONNECTICUT, 2004-2009**



Source: Connecticut Department of Public Health.

**Fig. 125. FIVE-YEAR BREAST CANCER RELATIVE SURVIVAL, BY CANCER STAGE, FOR FEMALES DIAGNOSED 2004-2009, FOLLOWED THROUGH 2010, CONNECTICUT**



Source: Connecticut Department of Public Health.

## Community Needs





## 4. Community Needs

### 4.1 Community Description

Connecticut is comprised of 169 towns; the designated UConn Health primary service area spans 12 and cancer patients hail from 123 towns. This far reach is challenging from a community outreach and engagement perspective as 50% of patients are geographically diffused in small numbers across many communities. UConn Health also provides cancer care to the Department of Corrections, which accounts for 2.5% of the cancer patient base. For purposes of this community needs assessment, the service area is defined as: the primary and secondary service areas for the organization. As a proxy for this report, community data will reflect Hartford County, as well as seven towns from Litchfield County and one town from Tolland County. A complete list of the towns can be found in Appendix A.

### 4.2 Community Demographic Profile

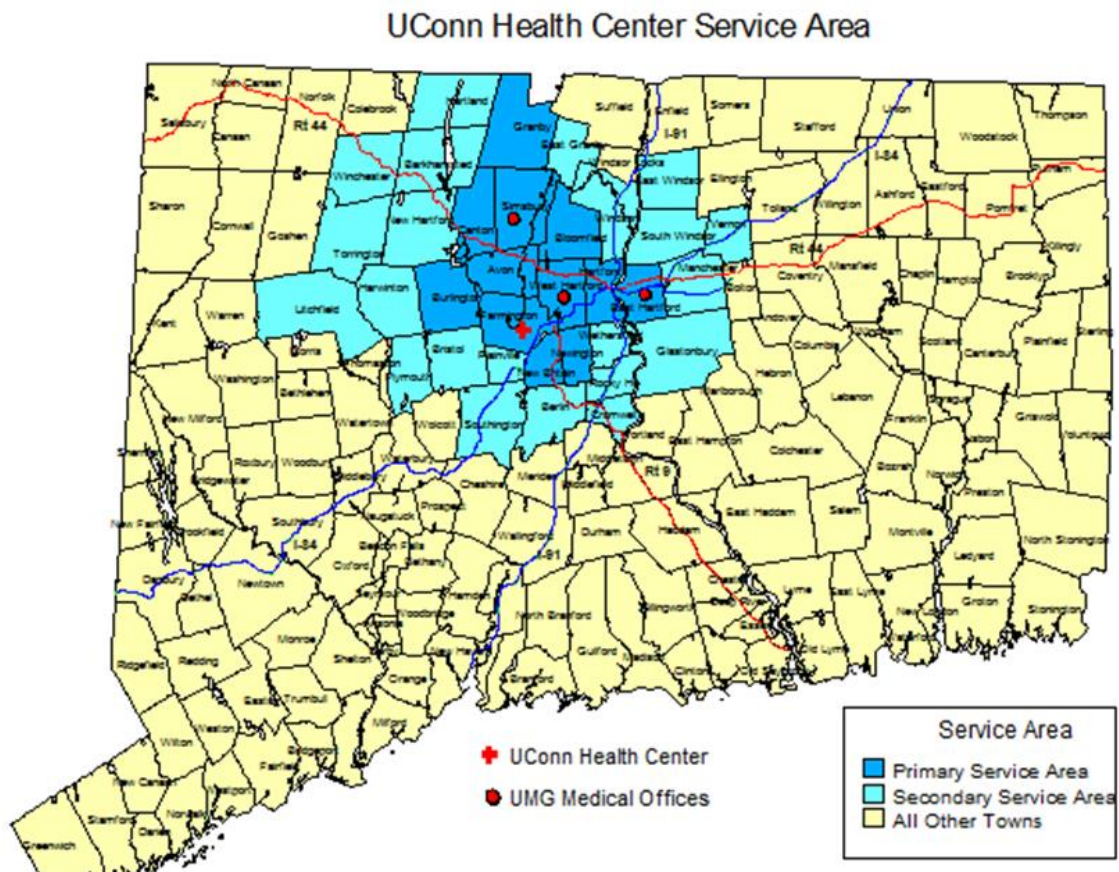


Figure 1.0 Community Demographics

	Hartford County*	Litchfield County	Tolland County (Town of Vernon)
Population	897,985	184,993	29,098
Race – White	77.3%	94.6%	85.1%
Race - Black	15%	1.8%	5.8%
Race – American Indian & Alaska Native	0.5%	0.3%	0.2%
Race - Asian	4.8%	1.8%	1.3%
Race – Native Hawaiian and other Pacific Islander	0.1%	0.1%	--
Ethnicity - Hispanic	16.6%	5.2%	6.5%
Age – under 5	5.5%	4.3%	5.7%
Age – under 18	21.9%	20%	19.4%
Age – 65 and older	15.4%	17.8%	15.6%
Median Income	\$64,967	\$71,338	\$61,038
Bachelor’s Degree +	34.9%	33.4%	32.8%
Home Ownership rate	65.5%	78.1%	Not listed
Poverty Rate	11.6%	6.4%	9.3%

<http://quickfacts.census.gov/qfd/states/09/09003.html>

### 4.3 Community Cancer Statistics – UConn Health Designated Community

The Connecticut Department of Public Health culled its statewide cancer data to identify incidence of cancer for UConn Health Cancer Center’s designated community.

Figure 2.0 Incidence for Top 10 Cancers in UConn Health’s Designated Service Area

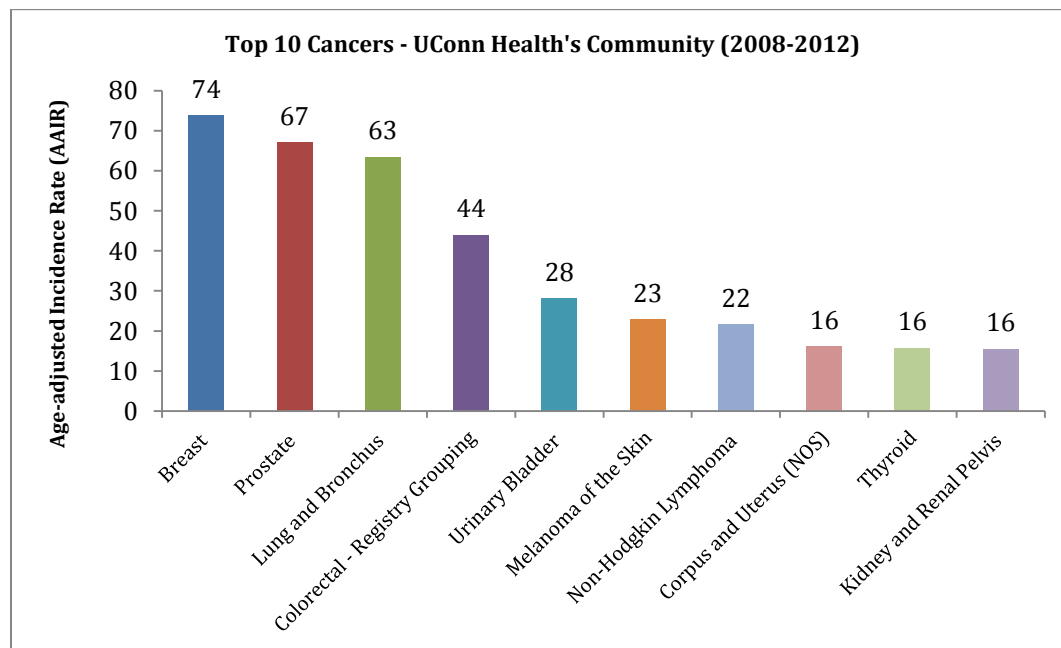


Figure 2.1 Incidence by Stage for Top 10 Cancers in UConn Health's Designated Service Area

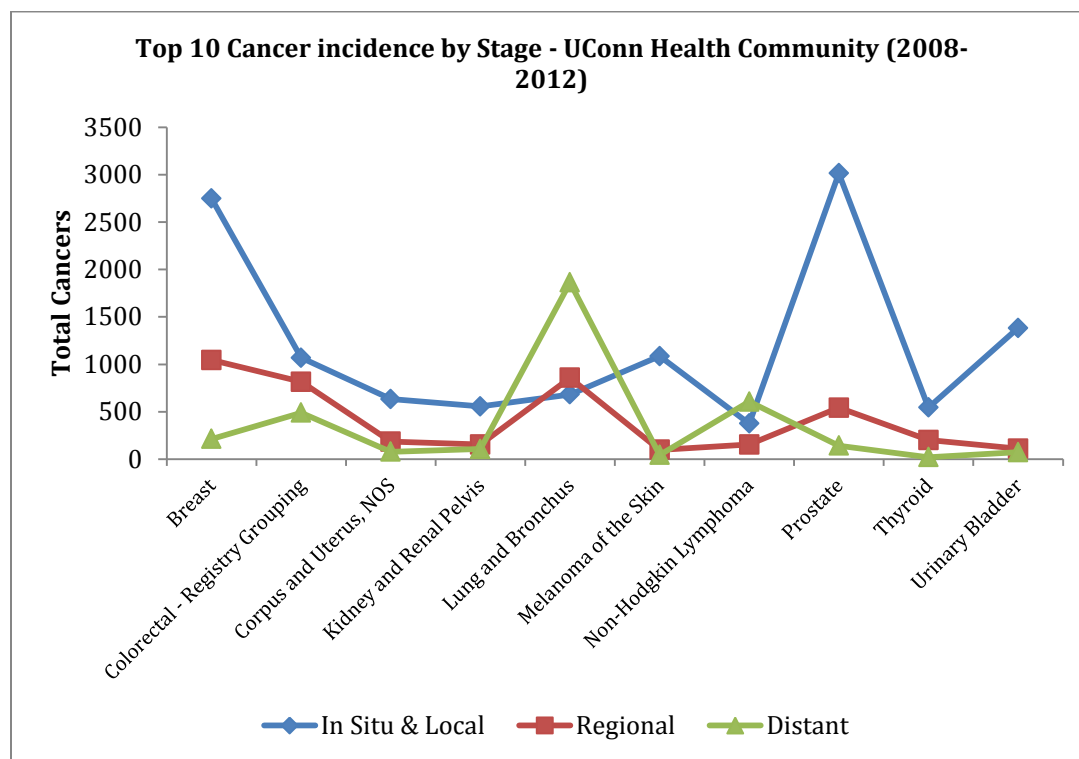


Figure 2.2 Incidence by Race/Ethnicity for Top 10 Cancers in UConn Health's Designated Service Area

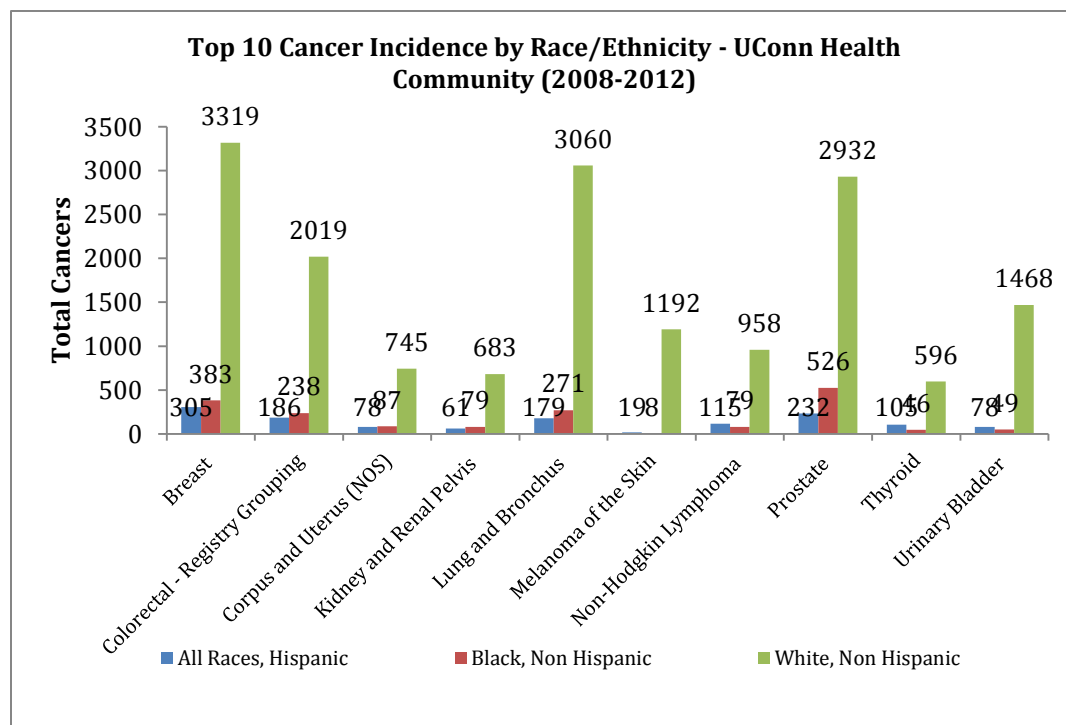


Figure 2.3 Top 10 Cancer Deaths by Race/Ethnicity in UConn Health's Designated Service Area

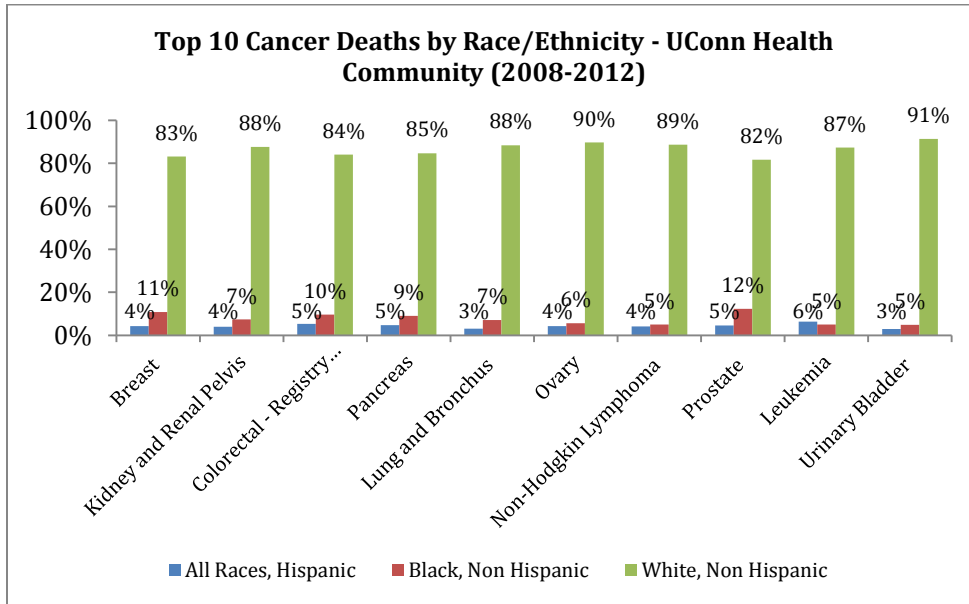


Figure 2.4 Top 10 Cancer Deaths among Hispanics in UConn Health's Designated Service Area

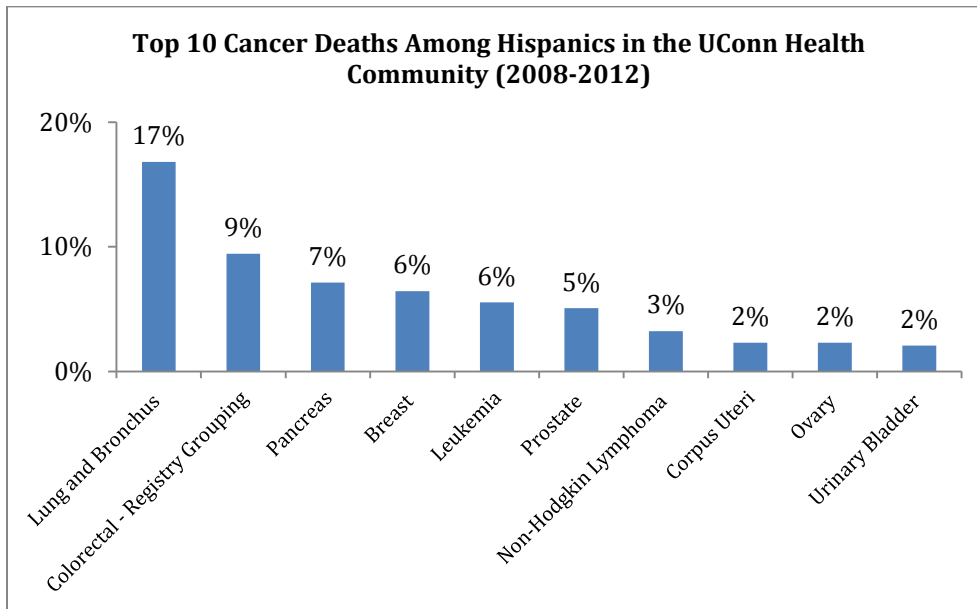


Figure 2.5 Top 10 Cancer Deaths Among Blacks in UConn Health's Designated Service Area

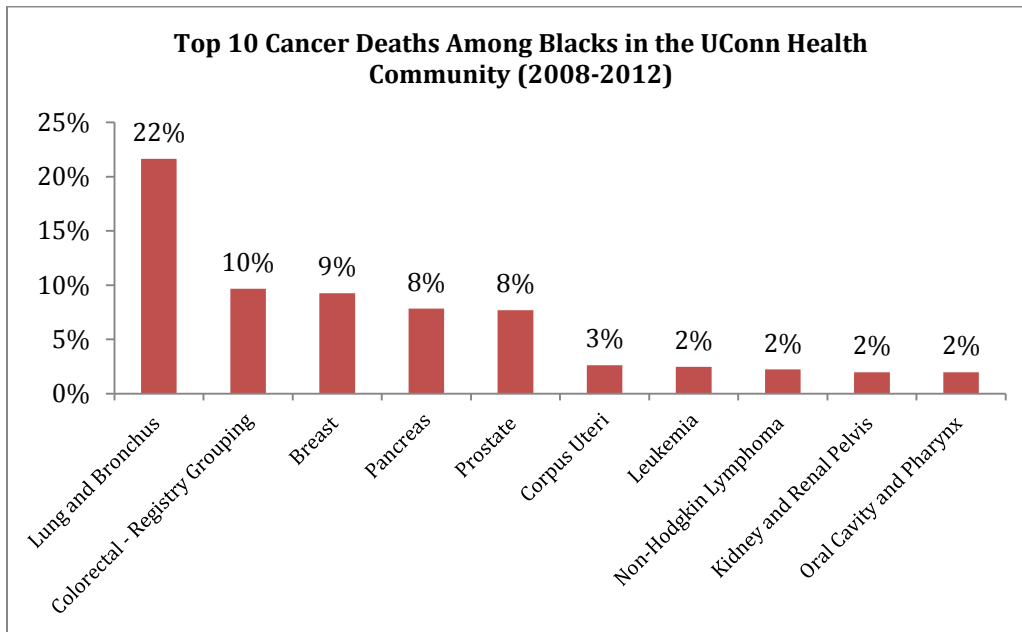
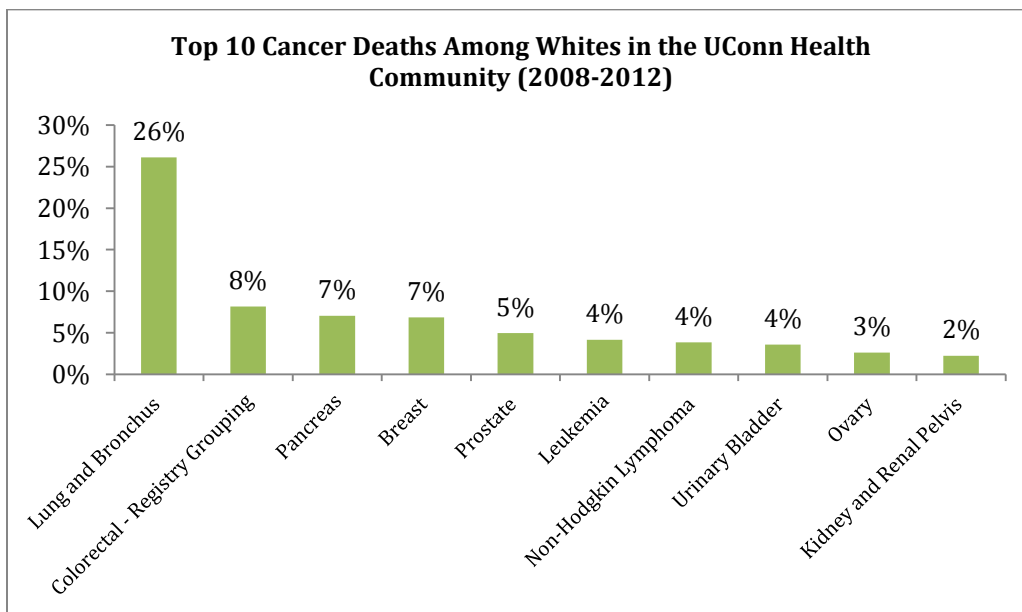


Figure 2.5 Top 10 Cancer Deaths Among Whites in UConn Health's Designated Service Area



When we compare cancer numbers in UConn Health Cancer Center’s designated community to its patient base, we find some alignment for skin, breast, prostate, lung, bladder, and thyroid cancer. That is, those cancers overlap as the top ten cancers for UConn Health and for its community. 80% of UConn Health cancer patients received first course of treatment for ten types of cancer, with a concentration in skin (25%), urinary tract (12.2%) and breast (10%) during the three-year review. The remaining 20% of patients were treated for thirty-seven different types of cancer.

Figure 2.6 A Top 10 Cancers for 80% of UConn Health Patient Base

2011-2013				80% of Patients Diagnosed with 10 Types of Cancer
Category	Type	Total	%	
Skin	<i>Skin</i>	694	24.7%	
Breast	<i>Breast</i>	282	10.0%	
Head and Neck	<i>Head and Neck</i>	245	8.7%	
Urinary Tract	<i>Prostate</i>	186	6.6%	
Respiratory	<i>Lung</i>	182	6.5%	
Urinary Tract	<i>Bladder</i>	158	5.6%	
Endocrine	<i>Thyroid</i>	134	4.8%	
Brain & Spinal Cord	<i>Brain &amp; Spinal Cord</i>	127	4.5%	
Hematological	<i>Bone Marrow</i>	124	4.4%	
Gynecological	<i>Endometrial</i>	121	4.3%	
<b>Total</b>		<b>2253</b>	<b>80.1%</b>	

Figure 2.6 B Summary of Cancers for Remaining 20% of UConn Health Patient Base

2011-2013				20% of Patients Diagnosed with 37 Different Types of Cancer within Categories
Category	Type	Total	%	
Gynecological	7	118	4.2%	
GI	11	117	4.2%	
Colorectal	4	105	3.7%	
Hematological	3	59	2.1%	
Urinary Tract	3	55	2.0%	
Endocrine	2	45	1.6%	
Musculoskeletal	3	27	1.0%	
UNK	N/A	18	0.6%	
Male Reproductive	2	15	0.5%	
Respiratory	1	1	0.0%	
Head and Neck	1	1	0.0%	
<b>Total</b>	<b>37</b>	<b>561</b>	<b>19.9%</b>	

Source: UConn Health Tumor Registry. Patients were counted if (1) they were diagnosed and received their first course of treatment at UConn Health; or (2) they were diagnosed elsewhere but received their first course of treatment at UConn Health. These patients are “analytic cases” in the Tumor Registry.

## 4.4 UConn Health Patient Base Profile

Using the cancer tumor registry for analytic cases from 2011-2013, we find that UConn Health's cancer patients are representative of the demographics of its designated community. More than 90% of the patients are white, and are insured privately or through Medicare. Patients that could be described as traditionally underserved disparity populations included: 11% minority (6.5% Black, 4.4% Hispanic), 2.6% uninsured, 10.2% insured through Medicaid, and 2.5% incarcerated inmates. We are unable to quantify the number of cancer patients that do not speak English as their primary language. While this data is captured at the point of initial encounter in the patient registration system, the tumor registry is not currently, as this data is not captured in the tumor registry.

Figure 2.7 UConn Health Patient Base by Age 2011-2013

Age	Total	Percent
18-50	542	20.3%
51-64	881	33.0%
65-79	803	30.1%
>=80	440	16.5%
<b>Total</b>	<b>2666</b>	<b>100.0%</b>

*Note - The total here includes duplicate patients that were diagnosed at different ages.*

Figure 2.8 UConn Health Patient Base by Sex 2011-2013

Sex	Total	Percent
Male	1220	46.6%
Female	1401	53.5%
<b>Total</b>	<b>2621</b>	<b>100.0%</b>

Figure 2.9 UConn Health Patient Base by Race 2011-2013

Race	Total	Percent
White	2402	91.7%
Black	169	6.5%
American Indian, Aleutian, Eskimo	1	0.0%
Vietnamese	4	0.2%
Asian Indian or Pakistani, NOS	24	0.9%
Asian Indian	5	0.2%
Other Asian, Including Asian/Oriental, NOS	3	0.1%
Other	1	0.0%
Unknown	12	0.5%
<b>Total</b>	<b>2621</b>	<b>100.0%</b>

Figure 2.10 UConn Health Patient Base by Hispanic Origin 2011-2013

Spanish/Hispanic Origin	Total	Percent
Non-Spanish; Non-Hispanic	2473	94.4%
Hispanic (Mexican, Puerto Rican, Cuban, South or Central American (except Brazil))	114	4.4%
Unknown whether Spanish or not, not stated in patient record, Spanish surname only	34	1.3%
<b>Total</b>	<b>2621</b>	<b>100.0%</b>

Figure 2.11 UConn Health Cancer Patients and Stage by Age 2011-2013

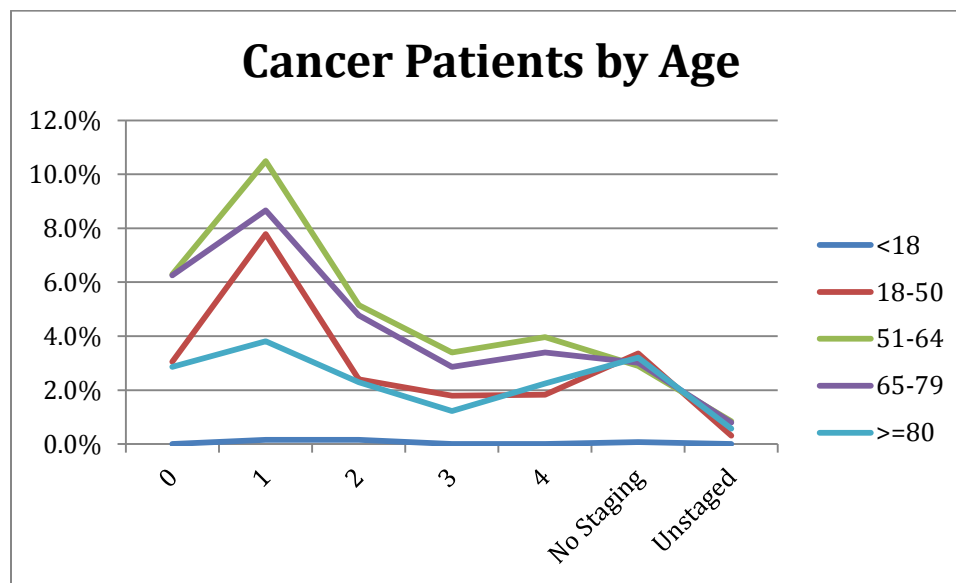




Figure 2.12 UConn Health Cancer Patients and Stage by Gender 2011-2013

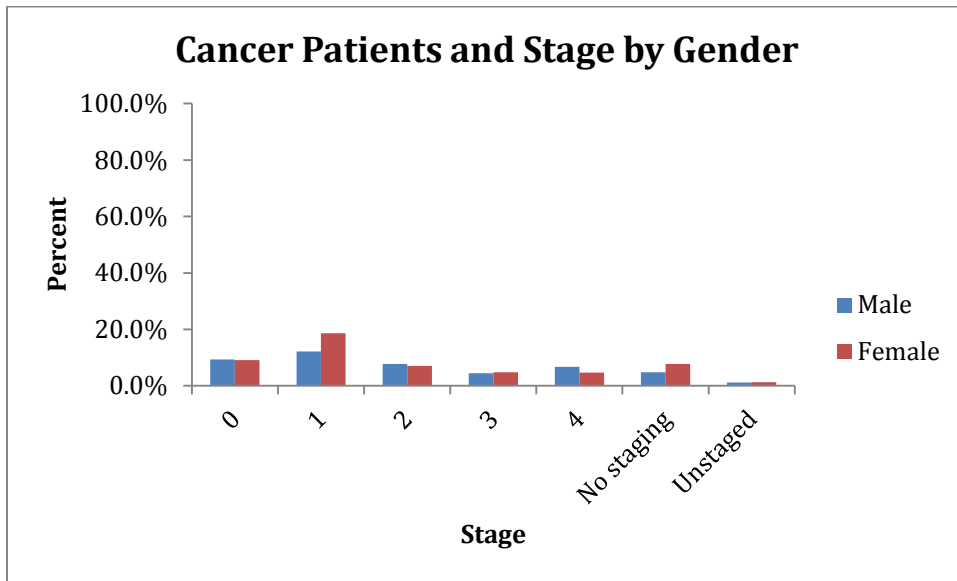


Figure 2.13 UConn Health Cancer Patients and Stage for Whites 2011-2013

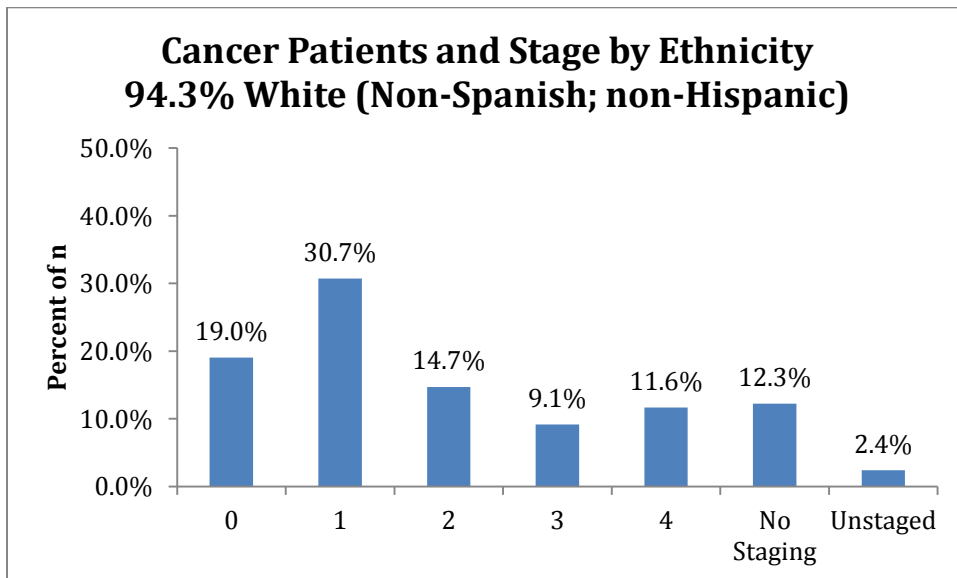


Figure 2.14 UConn Health Cancer Patients and Stage for Hispanics 2011-2013

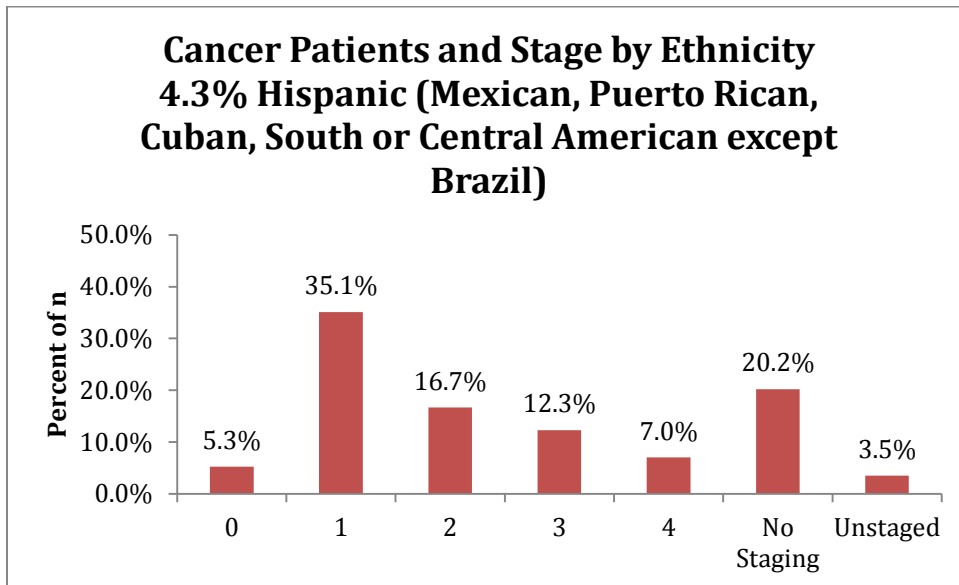
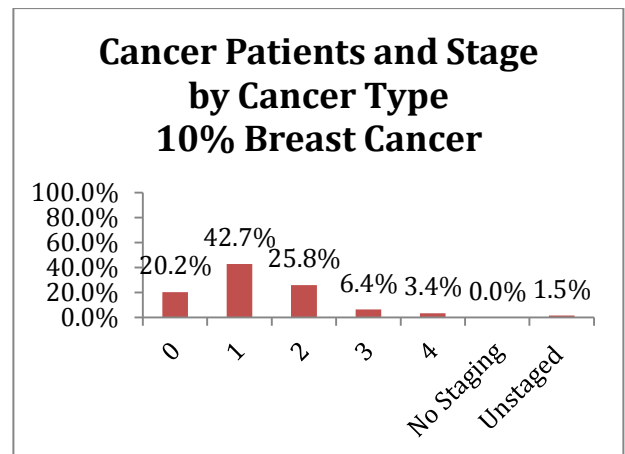
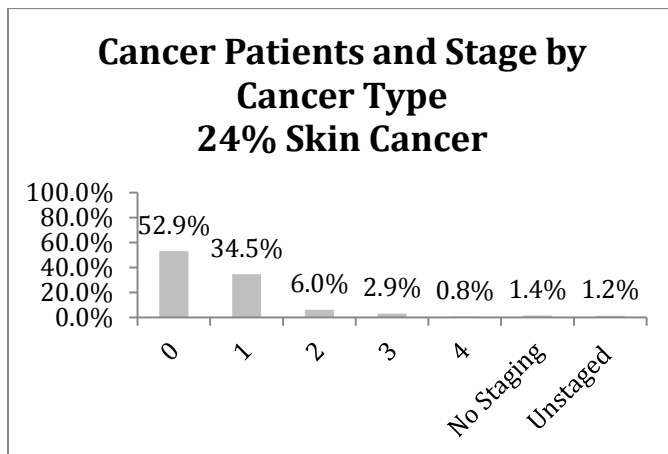
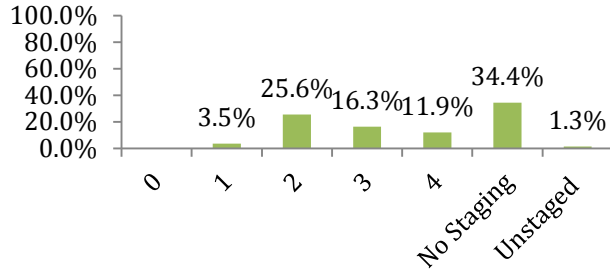


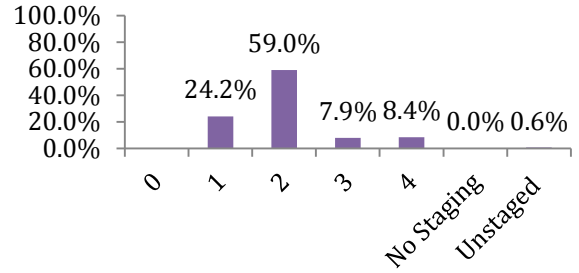
Figure 2.15 Cancer Patients and Stage by Cancer Type and Stage, for Top 10 Cancers Treated at UConn Health Cancer Center 2011-2013



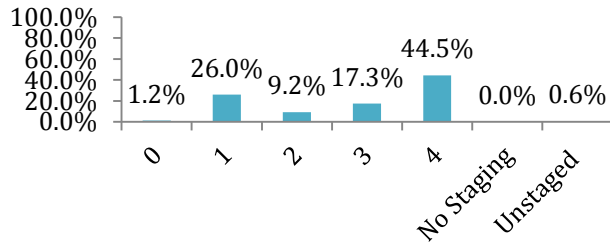
**Cancer Patients and Stage by Cancer Type**  
**8% Head and Neck**



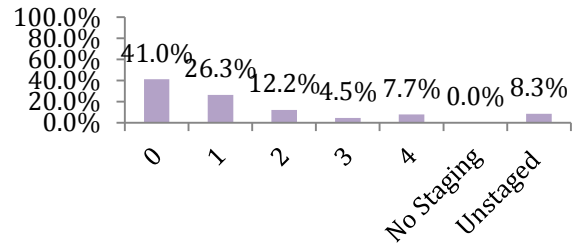
**Cancer Patients and Stage by Cancer Type**  
**7% Prostate**



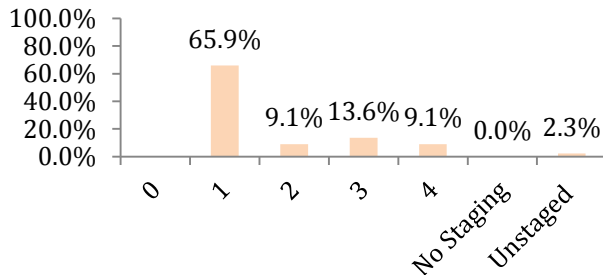
**Cancer Patients and Stage by Cancer Type**  
**6% Lung**



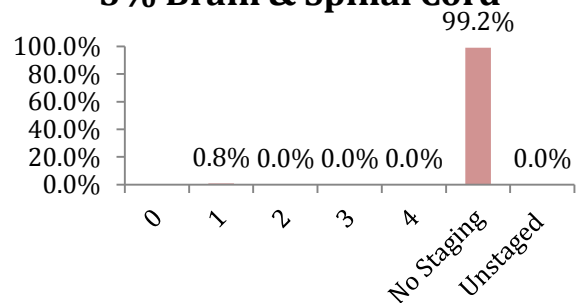
**Cancer Patients and Stage by Cancer Type**  
**6% Bladder**



**Cancer Patients and Stage by Cancer Type**  
**5% Thyroid**



**Cancer Patients and Stage by Cancer Type**  
**5% Brain & Spinal Cord**



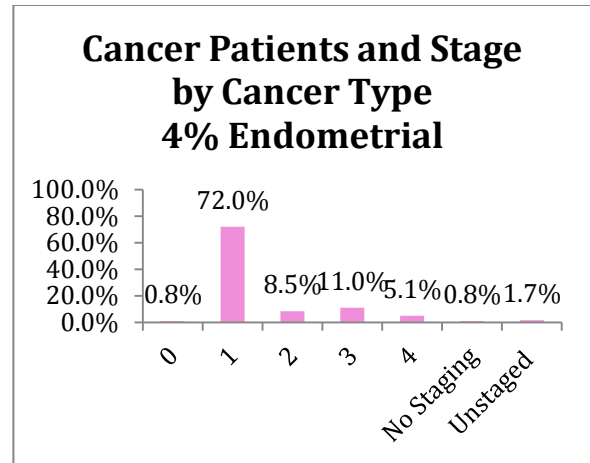
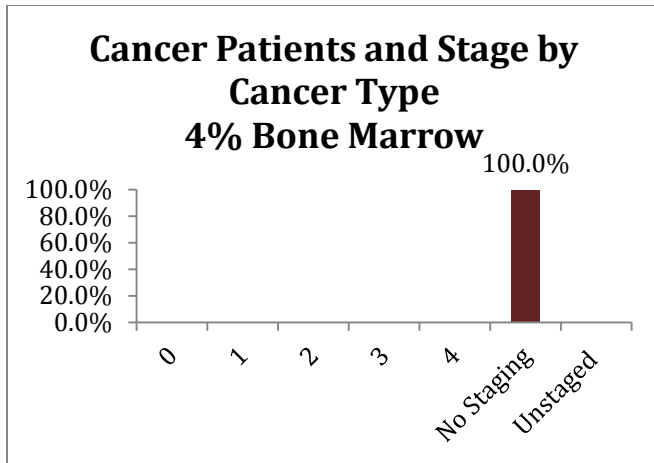
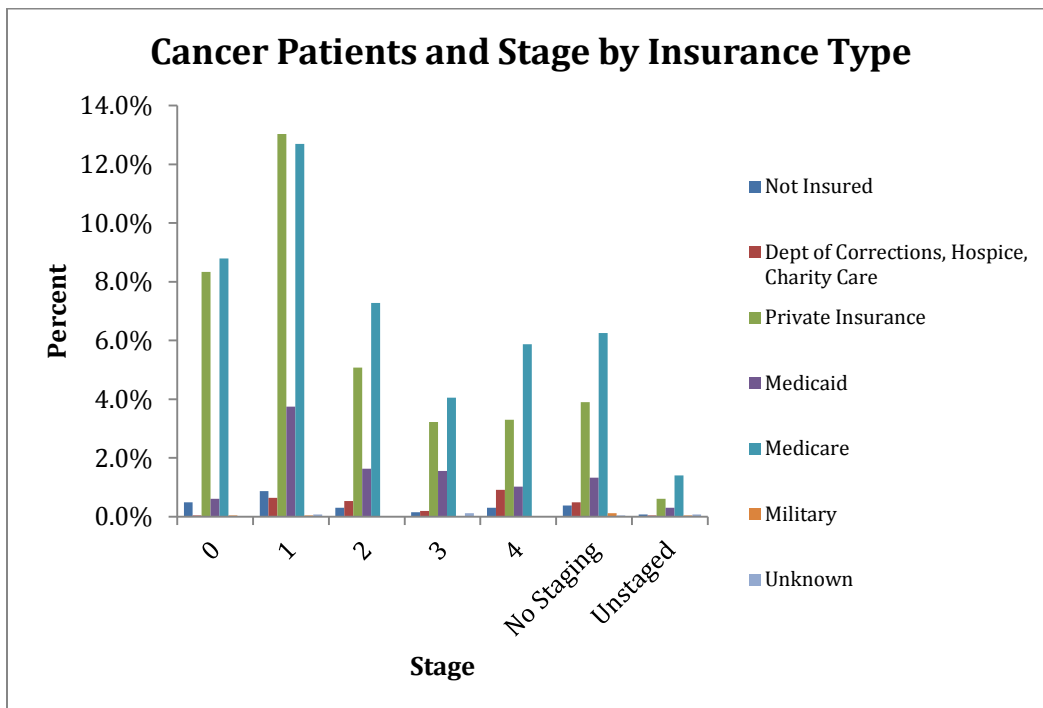


Figure 2.16 Cancer Patients and Stage by Insurance Type 2011-2013



# Patient Navigation Program



# 5. Patient Navigation Program

## 5.1 Program Description

UConn Health initially developed a Breast Nurse Navigator role in 2012, started as a grant program, to provide an individualized supportive care approach including easy access for patients who have an undiagnosed breast tumor. The Navigator provides care coordination by collaborating with multiple physicians and supportive resources from the point of diagnosis and beyond. The goal is to improve patient outcomes through education, support and monitoring using available resources within the organization.

Quickly, the value of the program was recognized and within a year, a General Nurse Navigator was hired to facilitate a similar approach to all other solid tumor diagnoses. Since most patients with solid tumors are sent to the oncologist after the diagnosis the approach is slightly different. At this time GYN oncology patients have not been incorporated in the program due to their internal clinical team which has both a medical and surgical component with an alternative approach to care. Additionally, the Head and Neck Cancer patients are part of an interdisciplinary team model which includes Radiation Therapy, ENT services and Medical Oncology all part of deciding the plan of care for the patient.

The effectiveness of both Navigator programs has been based on the education of the nursing staff who are bachelors prepared, with oncology experience and can offer cancer education, supportive care and appropriate referrals after diagnosis and throughout the treatment phase. Different models such as GYN, Endocrine Neoplasia and Head and Neck Cancer team approach have also been effective in addressing all issues related to a newly diagnosed patient.

### Background

*Staffing.* UConn Health deploys a multi-tiered approach to cancer center patient navigation, staffing two nurse navigators (general and breast), and one lay navigator (funded by the American Cancer Society). Additionally, clinical nurses in medical, radiation, and surgical oncology provide coordination assistance and referrals to patients throughout their course of treatment. According to 2012 data analyzed by Cordata Healthcare Innovations, LLC, a nurse navigator can track 225-250 breast cancer patients per year on average when using Oncology OnTrack [www.cordatahealth.com](http://www.cordatahealth.com).

*Access to Navigation.* The Patient Navigation process begins at the point of diagnosis and continues through the continuum of care and survivorship. Patients do not need to opt-in or out of navigation services; 100% of cancer center patients receive navigation services.

A prevalent theme across staff interviews centered on the logistical difficulty of efficiently and effectively navigating patients without the use of patient navigation or electronic health records software. While some information is tracked manually in Excel spreadsheets, the lack of automated alerts found in typical industry software solutions creates barriers to optimal patient navigation.

*Services Offered.* Nurse Navigators have identified key components relevant to an effective program. They are as follows:

- Coordination of care providers with both internal and external providers
- Appointment scheduling
- Offer psychosocial support and access to resources
- Transportation
- Education for informed decision making process
- Medical/imaging records Access
- Body image support

## Program Goals

1. Improved rates of screening and follow-up
2. Lower level of clinical stage at diagnosis
3. Improvement in completion rates of treatment recommendations
4. Improved psychosocial support
5. Increased patient satisfaction and outcomes
6. Increased enrollment in clinical trials

## 5.2 Patient Barriers Identified

During the period of June 1, 2015 to September 30, 2015 a patient survey and cancer center staff interviews were conducted to identify barriers to accessing, receiving and adhering to recommended cancer care. These findings inform recommendations for the Patient Navigation program.

Cancer Center staff handed the survey out to patients already in treatment at UConn Health. It was available in English and in Spanish but no completed Spanish surveys were returned. There were 51 patient surveys completed and 7 staff interviews conducted.

The patient sample responding to the patient survey consisted of 76.5% White respondents, 9.8% Hispanic, 5.9% Black/African-American, and 2.0% Asian. There were 74.5% women and 23.5% men who completed a survey. In terms of sexual orientation, 88.2% of respondents were heterosexual/straight, 5.9% were gay/lesbian, and 2.0% were bisexual. Marital status breakdown consisted of 54.9% people being married, 25.5% were divorced, 7.8% were widowed, 5.9% were never married, and 3.9% were separated.

Participants ranged from 22 to 85 years old. Only 6.1% were under 40 years old, 22.3% were between 40 and 49 years old, 10.0% were between 50 and 59 years old, 32.5% were between 60-69 years old, and 28.4% were 70 years old or older. Patients answered that they were in the following cancer stage: 17.6% were in stage 3, 17.6% were in stage 4, 15.7% were in stage 2, 13.7% were in stage 1, 13.7% did not know what stage they were in, 9.8% had no stage cancer, and only 2.0% had stage 0.

For insurance, respondents answered that 47.1% had Medicare, 19.6% had Medicaid/husky, 15.7% had health insurance through their job, 11.8% had something else, and 2.0% had a policy that they obtained directly from a health insurance company. Educationally, 45.1% of patients had a college or advanced degree, 25.5% had some college education, 23.5% had completed high school, and 2.0% completed elementary school.

## Barriers – Access – Insurance/Financial/Out-of-Pocket Expenses

Responses from interviews indicate that expenses related to cancer treatment can be a deterrent to needed care. Even patients with insurance sometimes end up with bills they cannot afford. Patients that do not work cannot afford the copay or treatment costs, and patients in chemotherapy cannot work during the treatment. Staff also mentioned that many patients while in treatment are too overwhelmed to pay attention to financial paperwork they may be receiving. There are some resources that exist for certain patient groups like pharmaceutical company subsidies. The hospital's billing department helps with questions and bills from external institutions for testing as well as assisting patients in enrolling in Obamacare. The cancer center's social worker was also identified as a resource for patients needing financial assistance, such as for food stamps.

Staff suggested identifying additional resources to help with financial costs to treatments and copays. Possibly hiring one dedicated person to finding additional funding for patients may resolve some of the issue as it can be very time consuming. Also, conducting trainings for staff to understand how the finance department can assist patients would be helpful along with developing a resource guide for staff to use with patients that includes a contact person that patients can call with questions. Avoiding unnecessary appointments may help limit patient expenses as well.

Patients indicated that finding doctors that accept their insurance (over 85%), understanding their medical bills and what they have to pay (63%) and getting help when insurance won't pay claims (75%) was easy or very easy. Affording medication (over 72%) and cancer treatment (over 71%) was also found to be easy or very easy. Help with housing and paying bills while coping with treatment was found to be easy or very easy (67%) but 21% of respondents found it very difficult.

Treatment for cancer affected patients' ability to go to work in the following ways: 33.3% did not have jobs when they learned they had cancer, 21.6% were affected in other ways described later, 13.7% had a job but quit because they were too sick from cancer treatment to work, 7.8% are now on disability, 5.9% used all of their sick days, 5.9% get paid for disability from their job, and 3.9% are paid by their job for sick days.

The 21.6% of patients that were affected in other ways gave reasons like self-employment, retirement, currently employed, and some were advised not to work due to exposure. About 11.8% of respondents said they missed the entire past month of work because of cancer treatment or side effects. There were 2% that said they missed at least 20 days, and 13.8% missed less than 10 days in the previous month.

## Barriers – Screening

Interviews indicate that low literacy is a barrier to screening as people don't understand many of the guidelines for the different types of screening. Feedback from staff suggested that patients from underserved communities tended to come in with later stage diagnoses. Patients are unaware of the requirements in terms of age, and where they can get particular screenings although many are free. Free screening resources are offered through grants; free mammograms for example. Patients in survivorship are in particularly higher risk and are encouraged to follow-up with necessary screening.



Some patients are afraid to be screened or to learn that they have cancer or are in denial. One recommendation made was to make screening part of the template of care to better understand the reasons patients don't get screened. The cancer center participates in community events to create awareness and educate people through walks, the Connecticut Women's Health Expo, and Celebrate West Hartford, a town fair, however, more community outreach was recommended. For example, an open house, additional advertising for the 'cancer of the month' services and warning signs may attract more patients to UConn Health. There is also a community navigator placed within a Hartford community organization to encourage screening among residents. They make appointments at UConn for Hartford residents and provide bus passes to those who need them. Perhaps hiring an outreach worker, advertising screening events, and attending more community events would help at increasing awareness on the importance of screening. Another idea was to provide doctors with an app for their smartphones to quickly assess the need for screenings based on the patient's age/gender, etc.

The UConn Health cancer center patient base analyses by stage show that for breast cancer, 3.4% were in stage 4. Prostate cancer showed 8.4% of patients in the tumor registry were in stage 4, and less than 1% for those with skin cancer were in stage 4.

### Barriers – Access – Transportation/Parking

In a previous survey conducted in 2013 by patient navigators, patients reported barriers with both transportation and parking. One staff member found that 75% of the time, patients had an issue with transportation. Currently, many patients have no way of getting to the cancer center and in other cases have disabilities. They may go to a hospital closer to where they live because they don't have a ride. There are transportation services available for those without insurance but they require advance notice which is sometimes not possible or can be complicated if appointments change. Another service relies on the availability of volunteers, which is not always a dependable solution. UConn Health offers gas cards, and bus rides but resources are limited. The new CT Fast track bus now includes UConn Health, making it easier and faster for patients to get to and leave the hospital, but for cancer patients undergoing chemotherapy, it is not a feasible option. Patients that fall in between Medicaid status and no transportation needs, seem to be the group with the most trouble since they need funds to pay for buses or cabs. Patients arriving in stretchers may also face some confusion since the ambulance would need to know the appropriate entrance for the patient.

Feedback from patients was that valet parking works out well and that the new garage has made parking better since tickets are validated. Overall, parking at the new Outpatient Pavilion is better. However, mammograms and ultrasounds are still conducted in the main hospital building which requires patients to travel up the hill to the main building for those procedures and then return to the Outpatient Pavilion to see their doctor. This can be time consuming and inconvenient for patients.

Elderly and acutely sick patients especially, should not be driving themselves to and from certain treatments and often complain if they are in the garage and cannot physically make it over to the cancer center on their own. Having volunteers available near the garage in these cases (or advance planning), to assist patients in wheelchairs, etc. would be helpful. However, currently volunteers are only allowed to transport patients as far as the lobby. Patients then have to make it to their vehicles on their own since many of them are alone. One suggestion was to develop a checklist to be used at the time of diagnosis so that doctors and nurses could quickly identify the patient's immediate issues (i.e., transportation, finances, social support, etc.). Additional funds to provide taxi rides for last minute appointments would be helpful as well.

Also considering a ‘resource navigator’ position to assist the social worker in identifying support services instead of working in the clinical area was suggested.

The patient survey showed that overall 70.6% of patients that responded found transportation to their cancer treatments easily. About 15.7% of respondents said it was slightly difficult for them.

### Barriers – Access – Language/Cultural Alignment

We cannot quantitatively determine the size of the UConn Health cancer patient population that does not speak English as a primary/preferred language. Patient language is not a data field in the Tumor Registry. While primary language information is collected at the point of encounter by UConn Health’s John Dempsey Hospital and recorded in the patient registration system, the Tumor Registry is not integrated with the registration system. The cancer center does not currently use patient navigation software or electronic medical record software that could potentially house primary or preferred language designation.

From a qualitative perspective, through interviews with cancer center staff, Patient Navigators estimate 25% of cancer patients prefer to speak Spanish. Additionally, cancer center staff uses language line when needed since there are not always providers who speak a particular language. However, it can take some time on hold waiting for the interpreter to get on the line. Staff indicated that patients that do not speak English do not answer their calls but language line is helpful in those cases. Inpatients were found to experience greater cultural issues during their time in the hospital. A particular cultural issue discussed by staff was the unavailability of a chaplain in the Outpatient Pavilion, where the cancer center is located. Language and cultural issues were also seen as barriers in terms of consenting patients, and determining why they don’t show for appointments.

Interpreter services are available and staff indicated a need for more since it takes a while to obtain one. Prior to moving to the new Outpatient Pavilion building, in-person interpreters were quickly accessed but now it must be scheduled ahead of time. For patients who waive their right to an interpreter, they ultimately waive their right for all subsequent visits as well. One staff member shared that a particular patient stated they transferred to another hospital because it was closer to their home and had a greater number of Spanish speaking staff. The cancer center does offer informational kits in other languages like Indian, Russian, Chinese, and Spanish which is the most in demand. Offering education in other languages, like chemotherapy, was suggested as well. Patients in the waiting room could be given a handout that briefly assessed any cultural needs they may have prior to their visit. This would save the allotted appointment time to focus on their health and treatment needs.

The UConn Health website does not contain a Spanish language translation option; neither do the websites of the Commission on Cancer or CT Cancer Partnership. This indicates a system-wide problematic barrier for Spanish speaking patients to access information about their cancer, staging, treatment options, side effects and benefits, provider options, psychosocial supports and more. Spanish speaking patients are more likely to present for their first course of treatment with far less information than their English speaking peers.

The patient survey shows that 95.0% of respondents found it easy or very easy to find doctors that speak their language. However, all surveys were completed by English speakers. About 5.0% found it slightly difficult to do so. There were 14.8% of patients that said it was slightly or somewhat difficult to find doctors that are their race, ethnicity, culture or faith. Most of the respondents, 85.2%, found it to be easy or very easy.

## Barriers – Low Health Literacy

A recommendation was made to conduct a focus group with patients of all cancer types to assess what information from current material they understood and determine what was appropriate. Often times, patients have to conduct their own research on their condition to understand the information. Staff members varied in their perceptions of patient health literacy levels from no clear indication of the degree of literacy to seeing many patients with low health literacy. Feedback indicated that one-on-one time needs to be reserved for navigators and social workers to thoroughly explain procedures to patients and that education on terminology would be helpful. The American Cancer Society serves as a resource for questions as it offers a 24-hour hotline. Patients are discouraged from googling their conditions and treatments as much of the information on the internet can be frightening. There is also a breast cancer guide provided to those patients that includes descriptions of treatments and pictures of the physicians. One suggestion was to provide patients with written care plans with directions on their treatment. It may also help patients to have a meeting to discuss only their care plans and another visit to schedule all of the necessary appointments.

The patient survey showed that 74.5% of respondents found that understanding their treatment plans and what would happen next to be easy or very easy. There were 17.6% of patients that found it to be slightly difficult, and 7.9% found it to be somewhat or very difficult. Finding information to help patients make treatment decisions was not found to be a challenge for respondents. About 80% said it was easy or very easy, 12% said it was slightly difficult, and 8% said it was somewhat or very difficult. Knowing which doctors would be needed during the course of treatment was also found to be easy or very easy for about 89.8% of respondents. About 10.2% of patients said it was slightly difficult.

Understanding if genetic testing could be helpful was mainly found to be easy or very easy (77.8%), while 22.2% of patients said it was slightly or somewhat difficult. About 67% of respondents said that finding out if clinical trials might be right for them was easy or very easy.

## Barriers – Lack of Communication/Coordination with Health Care Providers

In a previous survey conducted in 2013 by patient navigators, patients reported a desire to be better informed of and referred for complementary and alternative therapies. Currently, the cancer center offers assistance in finding suppliers for wigs, and doctors that support medical marijuana, but does not offer alternative therapies. They can refer patients out but the services may not be covered under insurance. Some staff reported that they didn't know who to refer patients to as there are not many resources for alternative therapies. One suggestion was to have resource guides on site as some staff was not aware if UConn Health offered any complimentary services.

Most patients responded that they found scheduling appointments with different doctors easy or very easy (90%), as well as getting their test/image results to different doctors (93%). Accessing medical records was found to be easy or very easy by 83% of respondents to the patient survey. Finding doctors that support medical marijuana was found to be very easy or easy by 69% of respondents, while 25% said it was somewhat or very difficult. Only 6% said it was slightly difficult.

Finding alternative ways to manage pain, nausea, and side effects was seen as very easy or easy by 74% of respondents while 23% said it was slightly or somewhat difficult. Only 3% found it to be very difficult. Locating help for sexual health was seen as easy or very easy by 62% of

patients while 38% said it was slightly or somewhat difficult. Getting referrals for physical therapy or lymphatic massage was said to be easy or very easy by 69% of respondents, 23% said it was slightly or somewhat difficult and 8% said it was very difficult.

Finding home health care aides/visiting nurses and suppliers for needed things like wigs or medical equipment were both found to be easy or very easy by at least 85% of respondents. Locating help for nutrition/weight gain/weight loss was seen as very easy or easy by 79% of patients but 21% said it was slightly or somewhat difficult. Getting referrals for family/marital counseling was found to be easy or very easy by 86% of respondents.

### **Barriers – Childcare, Time**

Staff reported that few patients experience problems with child or elder care. There are no childcare or eldercare services offered by the cancer center. Occasionally, patients receiving iron fusion have brought their kids with them but children are not allowed to be present during this treatment. Children are allowed to attend clinic visits if needed, but not treatment visits. Patients usually miss work due to treatments, which means they cannot pay for childcare. This may be an indication that patients needing these services are seeking treatment elsewhere.

Staff suggested creating a grid for a ‘caregiver team’ for each patient. This would indicate any needed help for the individual and people that had offered to help (relatives, friends, etc.). Thus, any child care or elder care needs would be met from the beginning of treatment. Another suggestion was to collaborate with the onsite childcare teachers to offer childcare for kids of patients in treatment.

About 85% of patients responded that finding child/elder care during treatments was easy or very easy.

### **Barriers – Lack of Social/Psychosocial Support**

In a previous survey conducted in 2013 by patient navigators, patients reported a desire to be connected with support groups. Currently there is a cancer support group offered to patients but it covers all types of cancer. Only bladder cancer has its own patient led support group. There have been groups of ovarian and neck cancer in the past but they fizzle out due to low attendance. Patients are referred to groups conducted at other hospitals but have expressed their desire for groups at UConn. Staff shared that more time would be needed to develop a group and identify facilitators. Also, determining how to publicize the group would require additional resources. However, support groups would be helpful since patients are more open to share their experiences in a group setting. There is a phone buddy service where patients are matched up and given phone numbers to support groups. One suggestion was to create an online support group. There is a psychiatrist in the cancer center who sees patients with mental health issues who need additional support. A meditation option is also being offered to patients and their caregivers during their treatment time. Staff reported that a distress tool is used to assess patient needs in terms of support. It was suggested that a monthly huddle be coordinated to discuss feelings around patients that were lost and other difficult cases for staff.

One major barrier discussed was that there is only one social worker in oncology and their time is split between the cancer center and John Dempsey Hospital. They don’t have enough available time to work with the care teams or patients who need additional support like those in survivorship. Seven out of ten of those in survivorship experience fear and need additional support. In September of 2015, the star program was scheduled to begin for cancer survivors.

This program involves all care team members meeting with patients at the time of diagnosis to implement their rehabilitation through referrals and monitoring.

The patient survey showed that finding support groups or people to talk to and finding help for emotional feelings, depression, and anxiety was easy or very easy for about 71% of respondents. The remaining 29% said it was slightly or somewhat difficult.

## Barriers – Access – Awareness of UConn Health Cancer Center

When it comes to choosing a cancer center, patients in the community have a lot to choose from. There are ten other Commission on Cancer (CoC) accredited cancer centers within a twenty-five-mile radius of UConn Health; two Academic, six Comprehensive, and two Community. Some cancer centers in Connecticut have partnered with high-profile “household names” in regional cancer care to attract patients, such as Dana-Farber (Lawrence Memorial Hospital), Sloan Kettering (Hartford Hospital), and Smilow (Griffin Hospital).

A newly diagnosed patient searching for a cancer treatment center may go to the American Cancer Society website to “find a cancer hospital”, which links them to the CoC search tool for accredited cancer centers. If the patient selects “Connecticut” and types in “Hartford” or “West Hartford” or other city names and selects “within 5, 10, 25 miles”, UConn Health doesn't come up in the search results even though it is sited within the search parameter. Only the cancer centers located in the selected city are listed. If a prospective patient doesn't know that UConn Health has a cancer center or that it is located in the town of Farmington, the patient could leave the ACS website thinking they were limited to receiving accredited cancer care at other cancer centers.

Once UConn Health comes up in the ACS search results (by either specifically entering the town of “Farmington” or by leaving the city blank and entering only the zip code) and the prospective patient clicks to get more information, there is no Facility Case Volume data available for UConn. Eight of the ten other cancer centers in the community have access to data as well as narrative about how long the cancer center has been accredited, etc. Prospective patients may wonder why no data is reported or think other cancer centers are better or more experienced than UConn Health as a result.

The ACS search results include a link to the UConn Health website. Unfortunately, it brings the prospective cancer patient to the health center home page, not to the Cancer Center home page. Brand confusion is created when the cancer center is alternatively referred to as “Carole and Ray Neag”, “UConn Health”, and “the University of Connecticut Health Center”. Finding the Cancer Center from the UConn Health website is not easy (even when doing so without the worry of a potential diagnosis or shock of a new diagnosis getting in the way of clear-headed navigation). There is no drop down menu on the Medical/Dental Service tab for speedy navigation. Once the tab is clicked, the A-Z search listing falls “below the fold”, so a prospective patient may not even realize if they scroll down there will be more options from which to search. Unfortunately, the Cancer Center does not appear “above the fold”.

Once the potential patient is on the Cancer Center home page, there is no CoC “gold seal of approval” to greet them. Instead, they would have to click on About Us to see that the cancer center is, indeed, accredited and what that means. Other cancer centers leverage the CoC logo in more obvious ways. Of particular note, on the UConn Health home page, if the patient clicks on About Us and then Awards & Accreditations, CoC isn't listed.

In summary, patients in the community have a lot of options for cancer care, may not be aware of the UConn Health Cancer Center, may not be able to find information helpful to make an informed decision to seek care at UConn Health, and may be confused by brand weakness.

# Patient Navigation Program Recommendations



## 6. Recommendations for Patient Navigation

### Goals and Key Objectives

The need at this time is to create a standardized patient navigation program that will include all aspects of navigation such as prevention, detection, diagnosis, treatment and survivorship. To establish the continuum is critical to the development of the program. The concept of patient navigation is based on the care management or case management model, which has four components.

- I. The first is case identification, which is a systematic approach to the identification of those individuals with abnormal cancer screening in need of follow-up care or incident cancers.
- II. The second is identifying individual barriers to receiving care. Navigators contact patients and elicit information regarding the barriers to completion of recommended care.
- III. The third is developing an individualized plan to address the barriers that are identified.
- IV. The fourth is tracking, which is a systematic method of following each case through resolution of the problem. In the case of cancer navigation, this means a resolution of a diagnostic evaluation when a benign condition is diagnosed or follow-up to the completion of primary therapy when a cancer or premalignant condition is diagnosed.

### Implementation Strategy/Plan

These are the areas of growth that have been identified in order for our program to work toward the care management model for the General Nurse Navigator:

- The Nurse Navigator should have one to two cancer types at most to be able to specifically address each component of the model with each patient.
- Dedicated Nurse Navigation Software should be obtained to allow the Navigators the ability to keep track of each patient throughout their specific continuum of care and to eliminate data entry redundancy.
- A designated Physician Champion for the General Nurse Navigator to have support and assistance in pioneering this new program and visiting PCP offices for education on Navigator assistance.
- A fully developed Survivorship program with a survey that can be administered from our Software program to initiate the process.
- Create a nurse navigator website with a link from the UConn site that could incorporate prevention and detection strategies, resources and contact information.
- Develop a survey to administer for success of the navigation program.
- A Cancer Outreach Coordinator should be hired to assist with increased awareness, promotion of cancer screening and detection in low income and minority neighborhoods.
- Hire a second Social Worker to access and develop programs for financial and insurance assistance, transportation, childcare related issues, etc.



## 7. Methods

- Used the Elektra cancer registry.
- Downloaded queried data for 2011, 2012, and 2013.
- Queried analytic cases – patients that were diagnosed and received first course of treatment at UConn Health and patients that were diagnosed elsewhere but had their first course of treatment at UConn Health.
- Since the goal of the patient survey was to assess and enhance the Patient Navigation program, UConn Health IRB approved the survey as a performance improvement project; therefore, no human subjects research review was required.
- Source of cancer stages: American Joint Commission on Cancer.
- It was determined that the patient survey would (1) be paper and pencil based; (2) not be more than 1-page (double-sided); (3) be disseminated to patients that had already been diagnosed with cancer (rather than diagnostic patients); (4) be disseminated to patients that were in the midst of treatment (rather than newly diagnosed or post-treatment); (5) not contain PHI.
- Department of Corrections patients were included in patient data, and distinguished in analyses where possible.
- Patient Survey was adopted and modified from the validated survey instrument “Supportive Care Needs Survey Short Form 34 (SCNS-SF34).
- Staff interviews were conducted by independent HDI staff and were kept confidential.
- CT DPH provided state level data as well as data for UConn Health’s service area.

## 8. Appendices

### A. UConn Health Service Areas

#### **Hartford County**

Avon  
Berlin  
Bloomfield  
Bristol  
Burlington  
Canton  
East Granby  
East Hartford  
East Windsor  
Farmington  
Glastonbury  
Granby  
Hartford  
Hartland  
Manchester  
New Britain  
Newington  
Plainville  
Rocky Hill  
Simsbury  
Southington  
South Windsor  
Suffield  
West Hartford  
Wethersfield  
Windsor  
Windsor Locks

#### **Litchfield County**

Barkhamsted  
Harwinton  
Litchfield  
New Hartford  
Plymouth  
Torrington  
Winchester

#### **Tolland County**

Vernon

## B. Patient Survey

### UConn Health Cancer Center Patient Survey

To help us provide better services for people undergoing treatment for cancer, we are interested in what problems you may have experienced. **Circle the number** that best describes how easy or difficult the following experiences were for you **in the last month**.

	Very Easy	Easy	Slightly Difficult	Somewhat Difficult	Very Difficult
1. Understanding my treatment plan, what happens next	1	2	3	4	5
2. Finding information to help me make treatment decisions	1	2	3	4	5
3. Knowing which doctors I will need during the course of my treatment	1	2	3	4	5
4. Scheduling appointments with different doctors	1	2	3	4	5
5. Getting my test/images results to different doctors	1	2	3	4	5
6. Accessing my medical records	1	2	3	4	5
7. Finding doctors that will accept my insurance	1	2	3	4	5
8. Understanding my medical bills and what I have to pay	1	2	3	4	5
9. Getting help when my insurance won't pay my claims	1	2	3	4	5
10. Affording my medication	1	2	3	4	5
11. Affording my cancer treatment	1	2	3	4	5
12. Finding transportation to cancer treatment	1	2	3	4	5
13. Finding child/elder care when I have treatment	1	2	3	4	5
14. Finding support groups / people to talk to	1	2	3	4	5
15. Finding help for emotional feelings, depression, anxiety	1	2	3	4	5
16. Finding alternative ways to manage my pain, nausea, side effects	1	2	3	4	5
17. Finding home health care aides/visiting nurses	1	2	3	4	5
18. Finding suppliers for things I need (e.g. wigs, medical equipment)	1	2	3	4	5
19. Finding doctors that are my race, ethnicity, culture or faith	1	2	3	4	5
20. Finding doctors that speak my language	1	2	3	4	5
21. Finding doctors that support medical marijuana	1	2	3	4	5
22. Finding help for nutrition/weight gain/weight loss	1	2	3	4	5
23. Getting referrals for family/marital counseling	1	2	3	4	5
24. Finding help for sexual health	1	2	3	4	5
25. Getting help with housing or paying bills while I cope with treatment	1	2	3	4	5
26. Getting referrals for physical therapy, lymphatic massage	1	2	3	4	5
27. Understanding if genetic testing could be helpful to me	1	2	3	4	5
28. Finding out if any clinical trials might be right for me	1	2	3	4	5

Just a few more questions continued on back 

1. How has cancer treatment affected your ability to go to work? (select all that apply)

- I did not have a job when I found out I had cancer.
- I had a job but had to quit because I was too sick from cancer treatment to work.
- I get paid by my job for sick days.
- I used all of my sick days.
- I get paid for disability from my job.
- I am now on disability.
- Other (please describe): \_\_\_\_\_

2. How many days of work have you missed in the past month because of cancer treatment or side effects? \_\_\_\_\_

3. What is the stage of your cancer?

- I don't know
- 0
- 1
- 2
- 3
- 4
- No Stage

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4. What is your race/ethnicity? (select all that apply)

- American Indian/Alaskan Native
- Asian
- Black/African-American
- Hispanic
- White
- Other

5. What is your gender?

- Woman
- Man

6. What is your sexual orientation?

- Heterosexual/Straight
- Gay/Lesbian
- Bisexual
- Other

7. What is your marital status?

- Never Married
- Married
- Separated
- Divorced
- Widowed
- Partnered

8. What is your age? \_\_\_\_\_

9. What is your health insurance?

- I do not have health insurance.
- I have health insurance through my job.
- I have Medicare.
- I have Medicaid/Husky.
- I have a policy that I obtained directly from a health insurance company.
- I have health insurance from the new Access Health insurance marketplace.
- I have insurance through the Veteran's Administration
- Something else

10. What is the highest level of education you completed?

- None
- Elementary school
- Some high school
- High school
- Some college
- College or advanced degree

Thank you for your help today!



## C. Cancer Center Staff Interview List

Sue Chellis (not interviewed)

### Nurse Navigators

Wendy Thibodeau  
Margaret Tsipouras

### Patient Navigators

Nancy Baccaro  
Michelle Safo-Agyeman (ACS Patient Navigator)

### Patient Administration

Kim Hackett

### Oncology Social Worker

Marie Ziello (not interviewed)

### Clinical Nurses

Kristi Dubey (not interviewed)  
Jen Stapell  
Laura Sabourin

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