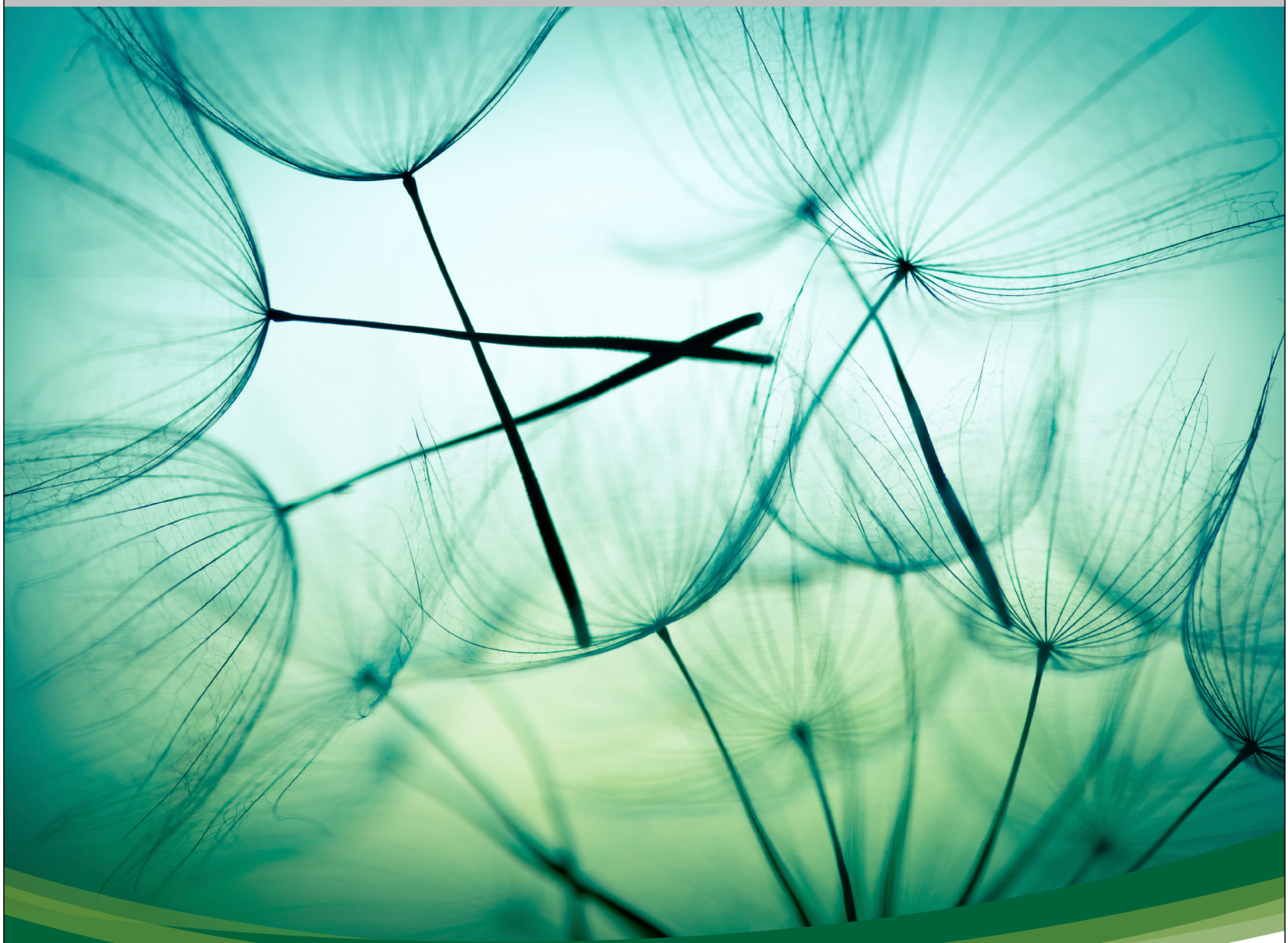
Cancer Community Needs Assessment Report



The heart and science of medicine.

THE University of Vermont MEDICAL CENTER

Prepared for:

The University of Vermont Medical Center

June 2016 by

Center for Rural Studies at the University of Vermont

TABLE OF CONTENTS

Introduction

The University of Vermont Medical Center, along with The University of Vermont College of Medicine and College of Nursing and Health Sciences, is one of 138 academic medical centers in the country. Through The University of Vermont Health Network and collaborative relationships throughout Vermont and northern New York, we are able to provide the highest quality care, informed by academic research, to patients throughout our region.

The UVM Medical Center is committed to the development of an Integrated Delivery System which provides high value health care to the communities we serve and enhances our academic mission.

As part of its accreditation through the American College of Surgeons, Commission on Cancer, UVM Medical Center Cancer Committee has prepared this Cancer Community Needs Assessment. The Needs Assessment is divided into four parts:

(1) A description of the methods used to determine the community needs

(2) An identification and description of the community served by the UVM Medical Center

(3) Identification of the primary needs of the cancer community

(4) A high level overview of key strategies and practices undertaken by the UVM Medical Center to address these needs

Methods

The UVM Medical Center worked with the Center for Rural Studies (CRS) at the University of Vermont to compile and analyze secondary data sources including academic journal publications, Vermont Department of Health data, and stakeholder interviews to better understand the community and its cancer care related needs.

CRS interviewed UVM Medical Center staff, stakeholders, patients, and patient advocates in multiple group settings to understand and document the strategies that have already been employed to address these needs in the community. This Cancer Community Needs Assessment is intended to be a companion piece to the 3-year Community Health Needs Assessment undertaken by the University of Vermont Medical Center, also with the consultative services of the Center for Rural Studies.

A list of all sources used in this report can be found in the references section at the end of this report.

Part 1.
Describing the UVM Medical Center Community

COMMUNITY IDENTIFICATION

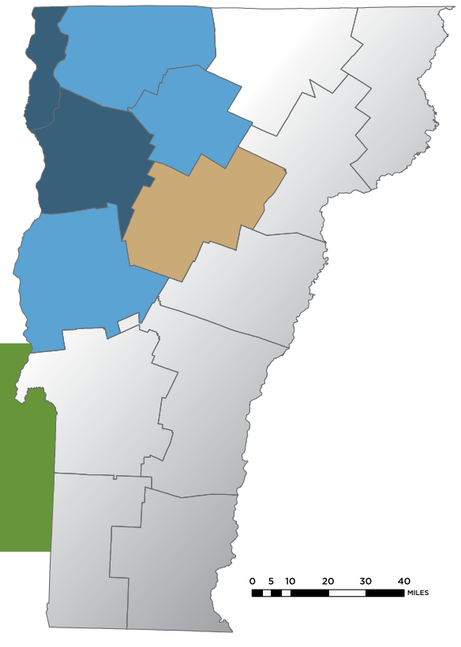
Vermont is a small, sparsely populated, primarily rural state with a relatively older but overall healthy population. With a total population of 625,000, Vermont is one of the least populated states in the U.S and ranks second in percentage of aging population. The median age of the U.S. in comparison is 37.2 (US Census, 2011).

One of the particular challenges posed to health service provision in Vermont is the largely rural and dispersed nature of the population. 61.1% of the population of Vermont is classified as rural, a much higher percentage than the U.S. overall where 19.3% of the total population is classified as rural (US Census, 2010).

Nearly all cancer patients in Chittenden and Grand Isle counties are treated at the UVM Medical Center. In addition 70% or more of the cancer patients in Addison, Lamoille and Franklin counties are treated at the UVM Medical Center and just under half (48%) of cancer patients in Washington County are treated at the UVM Medical Center. Chittenden County, where 25% of the Vermont population resides and where the UVM Medical Center is located, is the most densely populated county in the state. When the surrounding counties are included, approximately 44% of the state's 625,000 residents are included in the UVM Medical Center service region.

UVM MEDICAL CENTER SERVICE REGION

CHITTENDEN AND GRAND ISLE COUNTIES, VERMONT



44% of the Vermont population resides in the UVM Medical Center Service Region

COMMUNITY DESCRIPTION

Vermont is predominantly a racially homogenous state, with only a small proportion of non-English speaking residents. Overall 95% of Vermont residents are white, and Chittenden is the most diverse county in the state with 9.5% of its residents being from racial or ethnic minority groups. As a result of being a federally designated refugee resettlement community since 1989, at least 6,300 men, women and children of other nationalities have come to Vermont, primarily settling in Chittenden County. Only 5.2% of the state's population speak a primary language other than English at home.

Vermont Population Statistics

White	**95%***
Female	**50.7%**
Well Educated (BA or Higher)	**34.8%***
Primary non-English at home	**5.2%***
65 and over	**16.9%***
Median income	**$54,267**
% in poverty	**11.8%***

**Source: US Census American Country Survey 5-year Estimate*

Low income and household poverty pose challenges, particularly in certain regions of the state. Overall the median household income in Vermont is $54,267 and the poverty rate is 11.8%. Within the UVM Medical Center service area these metrics range from a median household income of $63, 086 in Chittenden County to $50,447 in Lamoille County and poverty rates of 7.9% in Grand Isle, to 13% in Lamoille.

Compounding challenges faced by households with low income are raising the cost of health care in Vermont and the U.S. Health care costs have been rising steadily since the mid-90s and before. Hospitalization charges are rising faster than overall healthcare costs even in the presence of declining rates of hospitalization. As indicated in the graph below, per capita hospitalization charges have been rising at an even greater rate than overall health care costs, while during the same period total hospitalizations have declined slightly.

Population Statistics of Counties in UVM Medical Center Service Region

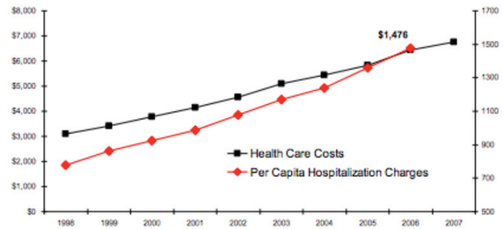
	Addison	Chittenden	Franklin	Grand Isle	Lamoille
Population	**36,821**	**156,545**	**47,746**	**6,970**	**24,475**
Median age (years)	**41.3**	**36.2**	**39.6**	**45.5**	**39.7**
Percent 65+	**13.9%**	**11.3%**	**12.2%**	**14.05%**	**13.3%**
Percent Female	**50.1%**	**51.3%**	**50.4%**	**50.1%**	**50.0%**
Percent White	**95.3%**	**92.3%**	**95.6%**	**95.3%**	**96.7%**
Percent Well-educated	**35.4%**	**48.0%**	**23.2%**	**32.4%**	**35.3%**
Percent Non-English speaking	**5.0%**	**5.2%**	**3.8%**	**4.2%**	**4.2%**
Percent in poverty	**10.2%**	**11.3%**	**10.0%**	**7.9%**	**13%**
Median income (dollars)	**$59,274**	**$63,086**	**$57,159**	**$61,338**	**$50,447**

Source: US Census American County Survey 5-year Estimate

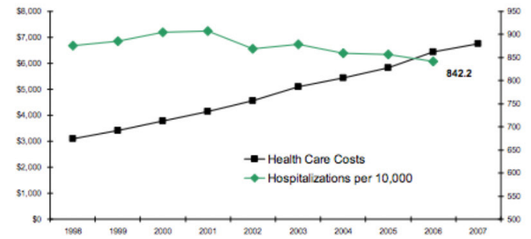
Vermont is the second healthiest state in the U.S. as ranked by the United Health Foundation (2016). Major contributing factors to this high ranking include a high percentage of the population with health insurance in the state, a low violent crime rate, and low infant mortality rate (United Health Foundation, 2016). Vermont ranks among the lowest in the nation for rates of obesity and sedentary lifestyle. The adult obesity rate in Vermont in 2015 was 24.8%, the fifth lowest in the nation, and the physical inactivity rate was 19.31%, the 8th lowest in the nation.

Vermonters also eat relatively healthy diets and smoke tobacco at lower rates than many other states. As of 2011 22.7% of Vermonters consumed fruits and vegetables 5 or more times daily and in 2015 only 16.4% of Vermonters were current tobacco smokers, 15th lowest in the nation (United Health Foundation, 2016).

Vermont Per Capita Health Care Costs and Hospitalization Charges



$R^2 = 0.99$
Significance < 0.001



$R^2 = 0.54$
Significance = 0.02

Source: VT Department of Health, 2010

Each year 3,600 Vermonters (0.57% of population) are diagnosed with cancer and approximately 1,300 Vermonters die from cancer (VT Department of Health, 2016). Nationally it's estimated that 1,685,210 (0.52% of the population) people are diagnosed with cancer each year and 595,690 people die from the disease (National Cancer Institute, 2016). The Vermont Cancer Registry estimates that 35,000 Vermonters (5.58% of population) have been diagnosed with at least one form of cancer (not including non-melanoma skin cancer). Prostate, breast, lung, colorectal, bladder, uterine, and melanoma are the most commonly diagnosed cancers in Vermont (VT Department of Health, 2016b). Data from the Vermont Department of Health Environmental Public Health Tracking (2016) tool indicates that rates of diagnoses for major cancer types do not vary significantly by region or town within the state.

Cancer Deaths/100k

Ranks 26th
lowest in the rate of cancer deaths.
(United Health Foundation, 2016)

National Average
for cancer mortality in men and women.
(National Cancer Institute, 2016)

The Healthy Vermonters 2020 Initiative

Goal:

to reduce cancer death rate to 151.6/100k by 2020

Action Steps:

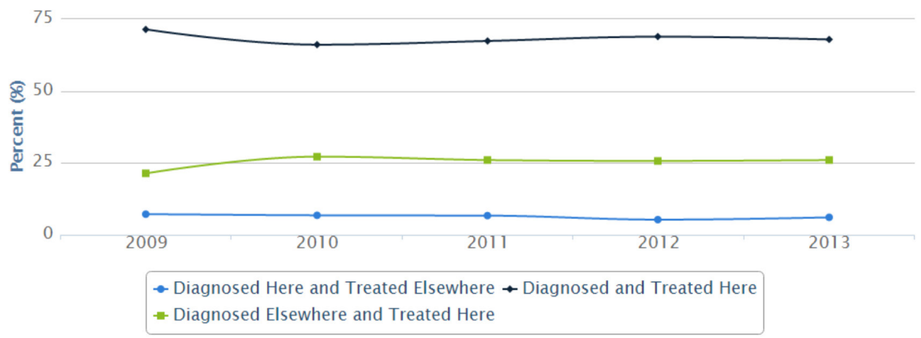
high goals for screening rates

- cervical
- colorectal
- breast
- prostate cancers

(VT Department of Health, 2016)

According to data from the National Cancer Data Base, since 2010 the proportion of patients diagnosed and treated at UVM Medical Center has remained unchanged. Before 2010, a somewhat lower proportion of patients were diagnosed elsewhere but treated at UVM Medical Center. With the high survival rates and other positive outcomes achieved at UVM Medical Center and an increasing focus on collaboration with PCPs, UVM Medical Center might expect this proportion to increase further in the future.

UVM Medical Center Cancer Diagnosis and Treatment, 2009-2013



	2009	2010	2011	2012	2013
Diagnosed Here and Treated Elsewhere	7.2 % (n=137)	6.8 % (n=126)	6.7 % (n=128)	5.3 % (n=104)	6.1 % (n=120)
Diagnosed and Treated Here	71.4 % (n=1350)	66.1 % (n=1232)	67.4 % (n=1295)	68.9 % (n=1350)	67.9 % (n=1344)
Diagnosed Elsewhere and Treated Here	21.4 % (n=404)	27.2 % (n=507)	26 % (n=499)	25.7 % (n=504)	26 % (n=514)

The patient population at the UVM Medical Center has undergone little transition to other facilities once diagnosis and treatment are underway. In 2013, the majority (67.9%) of UVM Medical Center patients were diagnosed and treated at UVM Medical Center, while 26% were diagnosed elsewhere and treated at UVM Medical Center, and only 6.1% were diagnosed at UVM Medical Center and treated elsewhere. These levels have been essentially flat since 2010.

In Vermont, the percentage of cancer survivors (30%) that reported being obese is similar to those never diagnosed with cancer (24%) (2012-2014). There were also no differences between adult Vermont cancer survivors and those never diagnosed with cancer in the percentage eating fewer than five servings of fruits and vegetables daily (2011 and 2013) and in the percentage failing to meet aerobic physical activity recommendations (2011 and 2013).

Among people with cancer, the rate of cardiovascular disease is higher than the rate of cardiovascular disease among people without cancer. Additionally adult cancer survivors in Vermont reported being current smokers at a higher rate (31%) than those Vermont adults who never had a cancer diagnosis (17%, 2012-2014). A similar percentage of cancer survivors who smoke reported recently trying to quit (53%) as those smokers never diagnosed with cancer (59%, 2012-2014) (United Health Foundation, 2016).

Part 2. UVM Medical Center Core Community Needs

In the recently released 2020 State Cancer Plan, the Vermont Department of Health identified five priority areas for the state to address. While these are not specific to the UVM Medical Center, the priorities provide a lens from which to consider the needs of the UVM Medical Center community. The five main categories of needs identified in the 2020 Vermont State Cancer Plan are listed in the sidebar to the right.

These needs relate to:

- addressing disparities in health care access experienced by different groups of patients
- increasing cancer preventive measures, improving early detection
- addressing cancer therapies, survivorship, and end of life care

As a treatment center for the most populated region in the state, UVM Medical Center community needs overlap with those outlined for the 2020 Vermont State Cancer Plan. This needs assessment focuses and condenses these into three core needs categories.

2020 Vermont Cancer Plan Community Needs

1. **Address disparities related to:**
   - Low income
   - Cancer survivorship
2. **Prevention measures including:**
   - Tobacco cessation
   - Oral health
   - Physical activity/nutrition
   - HPV
   - Environmental hazards
3. **Early detection of prevalent cancers including:**
   - Colorectal
   - Cervical
   - Breast
   - Lung
   - Prostate
4. **Cancer directed therapy & supportive care**
5. **Survivorship & end of life care**

UVM MEDICAL CENTER CORE COMMUNITY NEEDS

REDUCE DISPARITIES IN CANCER CARE QUALITY AND ACCESS BETWEEN:

a. Urban and rural patients

b. Patients with varying health literacy levels

c. Patients with varying income & insurance levels

INCREASE RATES OF PREVENTIVE SCREENING AND EARLY DETECTION, INCLUDING:

a. Awareness of available screening services

b. Building connections between UVM Medical Center and Primary Care Providers

c. Developing linkages between all aspects of treatment

CONTINUE TO IMPROVE CANCER DIRECTED THERAPY & SUPPORTIVE CARE AFTER TREATMENT BY:

a. Refining processes to create a more easily navigable patient care system

b. Strengthening connections at all points of treatment and patient care

c. Providing care services for physical as well as mental and emotional distress

d. Communicating clear and detailed patient information regarding effective treatment options

e. Providing survivorship resources that serve the wide spectrum of patient needs

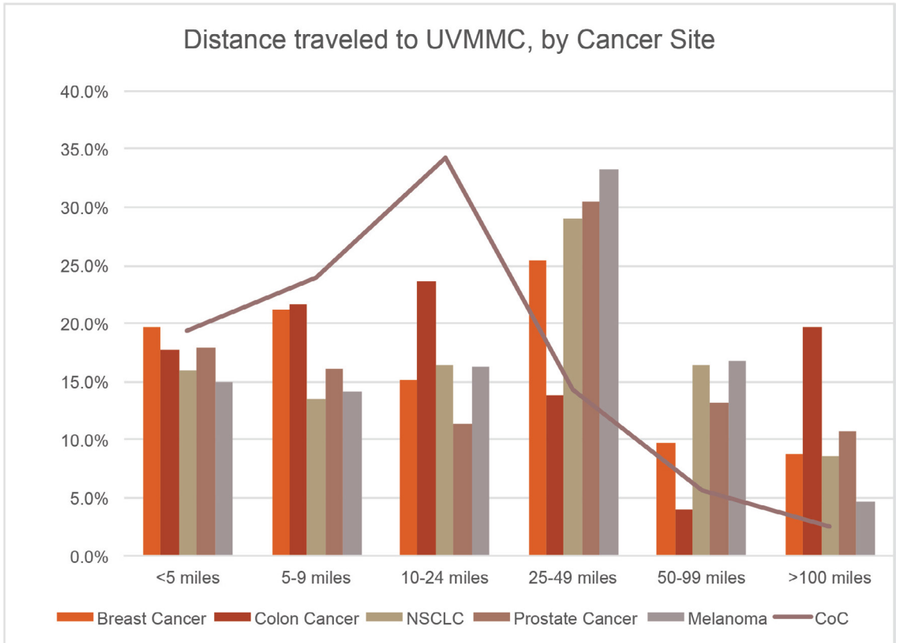
THESE CORE NEEDS ARE DESCRIBED IN FURTHER DETAIL IN THE FOLLOWING SECTIONS.

REDUCE DISPARITIES IN CANCER CARE QUALITY AND ACCESS

URBAN AND RURAL PATIENTS

The 2020 Vermont State Cancer Plan notes that *"certain vulnerable populations often face barriers to good health care. As a result these individuals are more likely to suffer from disease and may die earlier than other population groups."*

One of the significant causes of disparity in healthcare access in Vermont is the distance which residents must travel to UVM Medical Center and other health care centers to access care services. The line in the graph below represents the average distance traveled by all patients treated by Commission on Cancer (CoC) accredited programs nationwide.



Overall UVM Medical Center patients traveled 25 miles or more to treatment facilities at nearly twice the rate of average patient rates to CoC facilities nationally. This information highlights the significant challenge of serving a sparsely populated, rural community, one that is being addressed by a wide variety of state, regional, and municipal resources as will be expanded on in a later section.

Overall, a significant number of patients in the state bear substantial economic and time costs to receive the care they need. The graph above, based on data from the National Cancer Database, illustrates the disparity in miles. Put in terms of time, a distance of 25-49 miles is likely to take 45-90 minutes (or 90-180 minutes round trip), while a distance of 10-24 miles might be covered in 20-45 minutes (or 40-90 minutes round trip). In addition to fuel or public transit costs, this time cost represents missed work hours, family time, and time that children may require child care (Kim, 2007), all of which equate to larger costs accruing to populations that are more distant from health care centers.

There are also other disparities between urban and rural populations that extend beyond travel cost and relate to environmental hazards associated with the place one lives and works, as well as the physical demands of jobs that vary between the urban and rural population.

HEALTH LITERACY LEVELS

Patients within the UVM Medical Center service region possess a wide range of health literacy skills. Health literacy is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions (U.S. Department of Health and Human Services, 2000). Patients with inadequate health literacy are challenged in performing basic healthcare tasks like reading and understanding prescription labels or appointment slips. Approximately 80 million U.S. adults are thought to have limited health literacy, which puts them at risk for poorer health outcomes. Rates of limited health literacy are higher among elderly, minority, and poor persons and those with less than a high school education (Kutner et al., 2006).

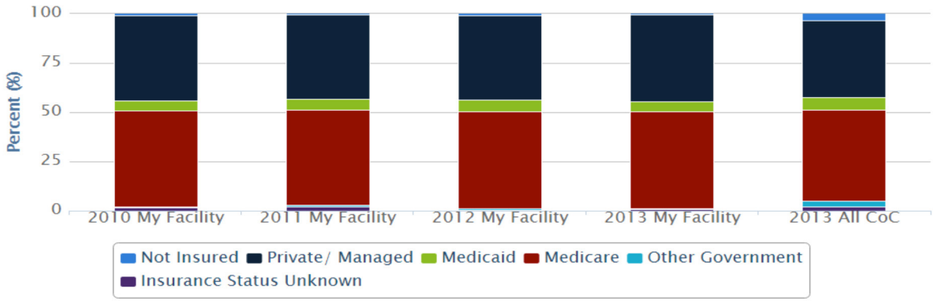
INCOME AND INSURANCE

Disparities related to income level often relate to type and quality of insurance, necessity to take time off from work without pay for treatment, expense of travel to treatment facilities, and out-of-pocket treatment expenses.

The Vermonters Taking Action Against Cancer (VTAAC) focus group sessions in 2006 found that individuals experienced denied claims, extraordinarily high deductibles, lack of prescription drug coverage, lack of coverage for Complementary and Alternative Medicine, and limitations on coverage for certain therapies. This challenge has been corroborated by UVM Medical Center physicians and staff as existing to this date.

The chart below indicates health insurance coverage types for the UVM Medical Center (indicated as My Facility)

Health Insurance Coverage for Patients at UVM Medical Center



	2010 My Facility	2011 My Facility	2012 My Facility	2013 My Facility	2013 All CoC
Not Insured	0.8 % (n=14)	0.6 % (n=11)	0.7 % (n=13)	0.5 % (n=10)	3.5 % (n=44003)
Private/ Managed	43.1 % (n=804)	42.5 % (n=816)	42.8 % (n=838)	43.9 % (n=869)	38.8 % (n=482482)
Medicaid	5.4 % (n=101)	5.6 % (n=108)	5.9 % (n=116)	5.2 % (n=102)	6.3 % (n=78021)
Medicare	48.6 % (n=907)	48.2 % (n=927)	49.4 % (n=968)	49.1 % (n=972)	46.4 % (n=575986)
Other Government	0.3 % (n=6)	0.8 % (n=16)	0.6 % (n=11)	0.6 % (n=11)	2.8 % (n=35362)
Insurance Status Unknown	1.8 % (n=33)	2.3 % (n=44)	0.6 % (n=12)	0.7 % (n=14)	2.1 % (n=26350)

In 2013 over 98% of UVM Medical Center patients were covered by Private / Managed insurance, Medicaid, or Medicare, with the remainder covered by other government (0.6%), not insured (0.5%), or insurance status unknown (0.7%). There is very little variation in coverage rates in these categories between 2010 & 2013. Once data become available, determinations can be made on how transitioning to coverage under the Affordable Care Act and subsequent enrollment in VT Health Connect will affect these ratios.

While rates of uninsured appear low, this data does not capture the percentage to patients who are underinsured or whose coverage plans have high out-of-pocket costs due to high deductibles and copays. It is recognized by UVM Medical Center staff that incidences of under-insurance are prevalent among those in the “middle” class, as many in this population demographic are not eligible for public coverage plans and do not possess the resources to afford higher end insurance plans that have lower out-of-pocket expenses.

INCREASE RATES OF PREVENTIVE SCREENING AND EARLY DETECTION

Early detection of cancers is associated with significantly higher survival rates. While UVM Medical Center early-detection rates compare favorably with regional and national counterparts, a primary focus must remain on early detection in an effort to boost survivorship. As highlighted in this needs report, these efforts include preventive screening measures, enhanced connections between UVM Medical Center and Primary Care Providers (PCPs), and effective links between all aspects of treatment. The Vermont State Cancer Plan identified prevention and early detection efforts as particularly beneficial when focused on colon, cervical, breast, lung, and prostate cancer sites.

AWARENESS OF AVAILABLE SCREENING RESOURCES

Patient population awareness of available screening resources is critical to connecting target population groups to screening centers. At this time approximately 10,000 Vermonters qualify for lung cancer screening. Identifying, contacting, and directing this patient population requires coordinated efforts between UVM Medical Center, PCPs, tobacco cessation counselors, and other care providers.

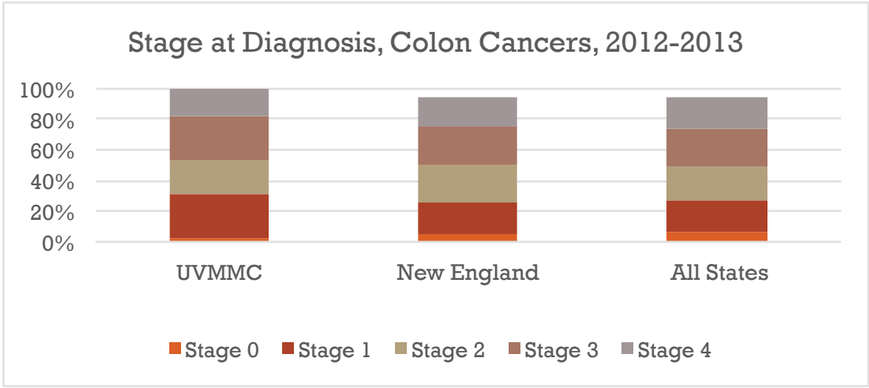
The figures below show the stage at diagnosis for the most prevalent cancer sites for UVM Medical Center patients compared to New England and nationwide, based on Vermont Cancer Registry data. In general, UVM Medical Center has comparable or better rates of early (Stage 0 and 1) diagnosis than most cancer sites. Rates of detection and diagnosis at advanced Stages (3 &4) at UVM Medical Center are lower for cervical and skin cancers than at New England and national counterpart hospitals, and very slightly lower for breast cancer.

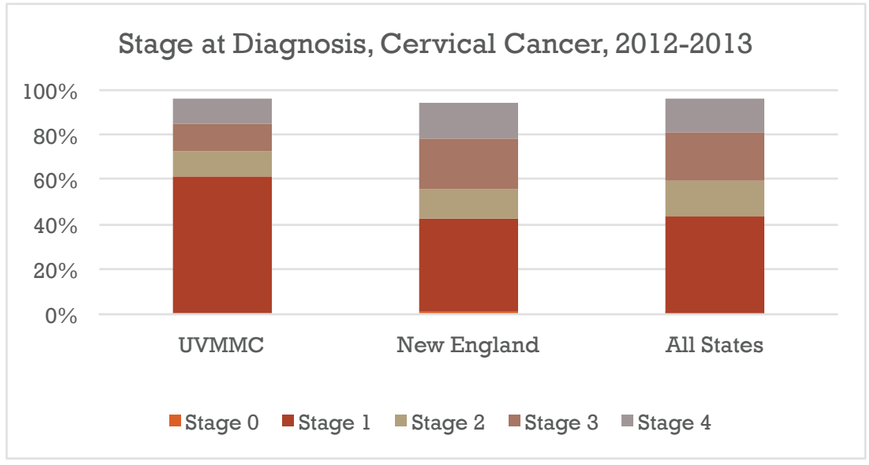
"Preventing cancer and cancer recurrence is fundamental to the overall reduction of cancer…although not all cancers are preventable."

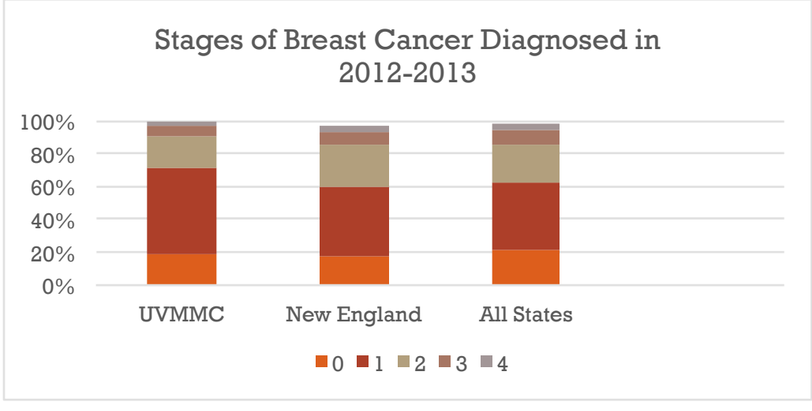
VTAAC, 2016

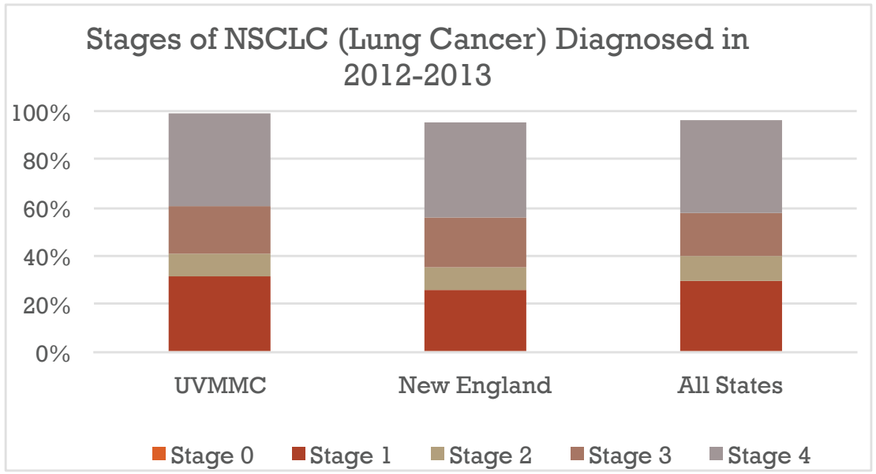
"Early detection of cancer in people without symptoms can help doctors find and treat cancer early, leading to better outcomes."

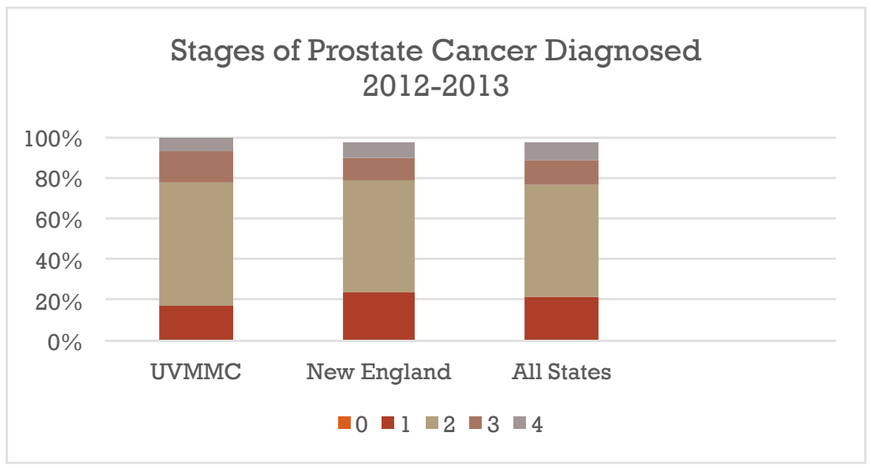
VTAAC, 2016











BUILD CONNECTIONS BETWEEN UVM MEDICAL CENTER AND PRIMARY CARE PROVIDERS

Efficiently connecting PCPs with UVM Medical Center staff and physicians is a critical link to provide appropriate screening services. PCPs are the main link between patients, screening, and early detection resources, as they can most effectively direct patients to the necessary screening centers. However, in order to do so, they must be informed and able to coordinate easily with screening centers.

Maintaining the PCP connection to the treatment plan throughout cancer-care services can provide patients with consistency throughout their care routine and lead to positive outcomes regarding follow-up and monitoring for recurrence.

DEVELOP LINKAGES BETWEEN ALL ASPECTS OF TREATMENT

Patients undergoing cancer care often require a variety of treatments and consultation with numerous specialists, which, in turn, may lead to an overwhelming amount of information for the patient to process. This problem is compounded if the information is not synthesized between specialists into a manageable care plan which patients can understand, assess, and respond to.

Further, patients require numerous appointments during treatment plans. Linking these appointments to minimize travel time and missed work hours reduces patient stress and can lead to better overall outcomes.

CONTINUE TO IMPROVE CANCER DIRECTED THERAPY & SUPPORTIVE CARE

While Vermont ranks as the second healthiest state in the U.S (United Health Foundation, 2016) and over 80% of cancer patients report satisfaction with their personalized care plans (VTAAC, 2016), there remain opportunities to improve cancer-directed services for therapy treatments, supportive care, survivorship, and end of life care.

REFINING PROCESSES TO CREATE A MORE EASILY NAVIGABLE PATIENT CARE SYSTEM

Cancer diagnoses and treatments often require that patients visit multiple physicians on the same day and involve numerous tests, scans, x-rays, and biopsies. These multiple visits in a short time frame can lead to complex and potentially overwhelming patient experiences. Health navigation systems that coordinate these visits and guide patients are essential for efficient cancer therapy and supportive care. Health navigation ensures that connections between all points of treatment and patient care are seamless and connections between complex health care systems, collaboration with PCPs, and screening for psychosocial distress and ongoing well-being are available and effective.

"Prompt, thorough medical treatment and complementary care are essential to prolonging a patient's life, decreasing side effects and improving quality of life."

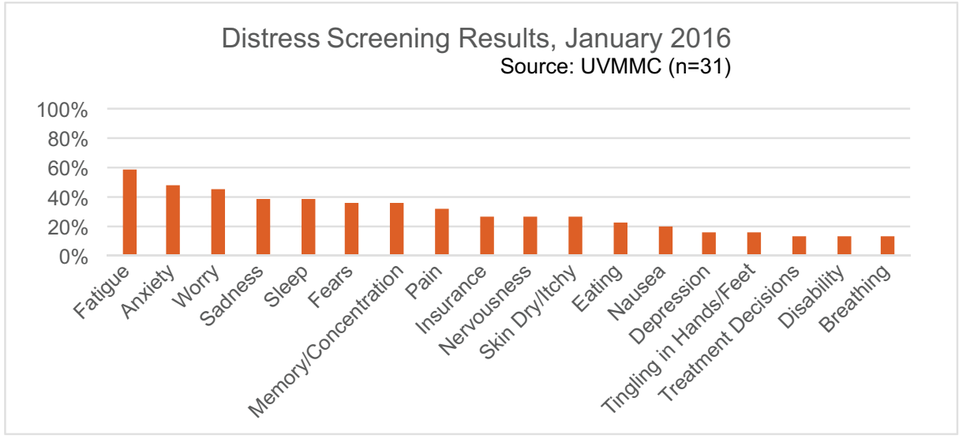
VTAAC, 2016

STRENGTHENING CONNECTIONS AT ALL POINTS OF TREATMENT AND PATIENT CARE

Patient care increasingly requires collaboration with multiple providers, therefore connections between the UVM Cancer Center and the broader UVM Medical Center are essential to facilitating optimal care. There is a general lack of awareness about exiting survivorship and supportive care options available to patients.

PROVIDING CARE SERVICES FOR PHYSICAL AS WELL AS MENTAL AND EMOTIONAL DISTRESS

Cancer patients suffer from mental and emotional distress in additional to the physical conditions brought about by their cancer. UVM Medical Center is implementing a psychosocial distress screening process and assuring that connections to needed services are created based on the screening and assessment. This patient-centered approach helps to identify the areas of patient concerns that play a role in the quality of care received.



COMMUNICATING CLEAR AND DETAILED PATIENT INFORMATION REGARDING EFFECTIVE TREATMENT OPTIONS

Patients and patient caregivers report overwhelming amounts of information to process at a time when they are already overwhelmed by the implications of a cancer diagnosis. Patients and patient advocates report not wanting to have information "over simplified." They want all the information they can get in order to make informed decisions regarding the course of action they take. However, they need to have this information provided effectively and to be given the time to process before being requested to respond to proposed treatment regimens.

PROVIDING SURVIVORSHIP RESOURCES THAT SERVE THE WIDE SPECTRUM OF PATIENT NEEDS

Cancer survivors are a diverse population which represent many demographics, particularly in terms of age and income. Survivors report that, while a host of beneficial resources are available, their accessibility is limited for those who must work during traditional business hours and cannot regularly take time off once essential treatment has completed.

Part 3.
Goals, Barriers, Resources, and Gaps

This section identifies the goals, barriers, resources, and gaps that relate to each of the three core needs identified in Part 2. Goals are identified using the 2016-2020 Vermont Cancer Plan (VTAAC, 2016). Barriers, resources and gaps are identified using research reported by Geller et al. (2014) and interviews with key UVM Medical Center staff and stakeholders.

DISPARITIES IN CANCER CARE QUALITY AND ACCESS

Due to the dispersed nature of the population in Vermont, access to cancer care is not uniform. Those in rural areas must travel greater distances to receive care at the UVM Medical Center than those in the Greater Burlington and Chittenden County area. Compounding the issue is the fact that poverty, low income, and lower health literacy are correlated with rurality (Zahnd, Scaife & Francis, 2009). Among this population there are also highly variable levels of public and private health insurance coverage.

GOALS

- Reduce disparities of cancer care caused by rurality, health literacy, income, and insurance coverage.

BARRIERS

- Transportation requires time and dollar investment by patients and is higher for those in more distant, rural communities.
- Low health literacy leads to a lack of effective communication with patients.
- Denied claims create financial and logistical hardships.
- High deductibles create financial disincentives for receiving the appropriate care.
- Lack of prescription drug coverage reduces the effectiveness of treatment prescriptions.
- Disproportionate financial burdens accrue predominantly to middle class patients due to private coverage plans that provide insufficient coverage.

Transportation to and from cancer care facilities is a significant indirect cost of cancer care, which also include lost wages from missed time at work, and the expense of childcare (Kim, 2007). For populations with lower health literacy rates, effective communication with physicians and caregivers is a challenge. The variable nature of private insurance coverage, coupled with the limited extent of patient knowledge of their plans, lead to financial barriers and hesitancy to undergo essential treatment options. This issue disproportionately affects middle class patients, as lower income patients are often covered by Medicare and Medicaid while higher income patients are more likely to have “Cadillac” plans with low co-pays and deductibles.

RESOURCES

- County Transportation Agencies
- Town level Elderly and Disabled (E&D) waivers for transportation resources
- ADA ParaTransit
- Agency on Aging emergency funds to meet critical needs
- Road to Recovery volunteer based transportation
- Sally Fox Recovery Fund
- Hospital taxi vouchers
- Accelerated treatment schedules for certain cancer sites to reduce length of treatment period and number of visits
- Rural health literacy coaching
- Appeals to insurance companies regarding coverages
- Compassionate care prescription drug provision
- Oncology Specialty Pharmacy program

Patients have access to emergency transportation funds and transport options through Chittenden County Transportation Agency (CCTA), Special Services Transportation Agency (SSTA), and other county transportation agencies. A wide variety of other subsidized and volunteer-based transportation options can help patients access the care they need.

Disparities in health literacy are being addressed by ongoing promotion of health literacy via Rural Health coaching services, community talks, social media, and the use of in person and electronic interpreter services.

Several options are in place to address income disparities of treatment and care; they include implementing co-pay assistance and specialty pharmacy options aimed at reducing the out-of-pocket cost for individuals unable to bear the costs of treatment. Pharmacy options are aimed at improving access and affordability of treatment prescriptions. UVM Medical Center has developed the Oncology Specialty Pharmacy with resources to work on co-pay assistance for patients and to ensure cancer medications are covered and available.

GAPS

- Approximately 5-10% of population fall through the gaps and do not qualify for the above-mentioned transportation resources.
- Current transportation options require a minimum of 48 hours' notice and at times patient needs require immediate access.
- Lack of communication with PCPs regarding full spectrum of assistance options.
- Assistance with day-to-day bills for patients lacking short term disability.

Transportation assistance has helped a large portion of the patient population ease their burden in accessing care. UVM Medical Center staff estimate that 5-10% of the population in need currently do not qualify for the various assistance options due to income or geographic circumstances. Precisely identifying this population and determining the barriers to assistance will be helpful in closing this gap.

PCPs are a key link in the cancer care system. In certain instances there is an identified gap between available resources at the UVM Medical Center and PCP awareness of these resources. Additionally, cancer patients without long-term disability insurance face increased financial strain during periods of cancer care when they are unable to work as normal.

PREVENTIVE SCREENING AND EARLY DETECTION

Prevention and early detection are the most effective strategies for addressing rates of cancer diagnosis at early stages and ultimately achieving higher survival rates. For many cancer site diagnoses, UVM Medical Center has equal or higher rates of cancer diagnosis at earlier stages (more Stage 0 & 1 and fewer stage 2-4 diagnoses) compared to regional and national counterparts.

GOALS

The 2020 Vermont State Cancer Plan identifies the following goals for cancer prevention and early detection.

- Increase colorectal screening for ages 50-75 from 71% to 80% by 2020
- Increase percentage of women 21-65 receiving Pap tests from 86% to 100% by 2020
- Increase percentage of women 50-74 receiving mammograms from 79% to 95% by 2020
- Decrease advanced stage lung cancer detection from 210 per 100,000 to 199.5 per 100,000 by 2020

Early detection is achieved via preventative screening, promotion of health literacy, collaboration with pcps, and early detection clinics.

Existing early detection and screening efforts include low dose lung screening through UVM PCPs, integration of additional providers, particularly in NY, with the UVM network, women's screening day pilot programs, targeted lung cancer screening programs, and funding for colon cancer screening.

BARRIERS

- Challenge of targeting those with greatest cost benefit return of screening
- Awareness among PCPs about screening resources
- Reducing the portion of population seeking screening that are not the target group (inefficient use of resources)
- Lack of protocolized approach to referrals and follow up for tobacco cessation

The barriers to improving prevention and early-detection efforts relate to the efficient use of screening resources to target the correct populations. Resources exist to provide lung cancer screening to as many as 10,000 qualifying patients in the UVM Medical Center service area. As reported by UVM Medical Center staff, many patients are unaware these screening resources are available. In some instances, PCPs are also unaware and, thus, do not direct patients to these resources.

In other instances, nurse and patient navigator staff indicate that screening resources are used inefficiently because of patient populations who request screening services when they are not in the target demographic in need of the particular screening.

RESOURCES

- Choosing Wisely Campaign
- Patient Navigators
- Lung Cancer Screening Clinic
- Referral programs to counselors for patients still smoking

Choosing Wisely is an initiative of the ABIM Foundation that aims to help patients choose care that is supported by evidence, not duplicative of other tests, free from harm, and truly necessary.

Patient Navigators help patients with same-day coordination of multiple physician and specialist visits. Their input is able to help reduce unnecessary treatments and testing, which in turn helps to improve the efficiency of screening resources, and to reduce the travel time requirements of patients.

GAPS

- Large portion of Vermonters qualify for lung cancer screening but are not yet aware of the resources available.

CANCER DIRECTED THERAPY AND SUPPORTIVE CARE

Supportive care beyond treatment is important to ongoing health and quality of life for cancer patients. The top unmet needs of the cancer survivor population as identified by Geller (2014) are:

- help in reducing stress in life,
- a need for more information about aftereffects of cancer,
- help finding ways to reduce worrying,
- help managing concerns about cancer coming back, and
- help dealing with the impact of cancer on relationships with one's partner.

In addition, relevant community goals have been identified by the VTAAC 2016-2020 Cancer Plan as well as community feedback gathered during the 2016 Stowe Weekend of Hope by the VTAAC Quality of Life Workgroup.

GOALS

- A more easily navigable cancer care system
- Connections at all points of the patient care network
- Effective care for the mental and emotional as well as physical state
- Increase number of Palliative Care Physicians, APNs, and RNs in Vermont
- Increase percentage of cancer patients treated by CoC cancer programs receiving survivorship care plans from 2% to 100%
- Improve access to complementary / integrative medicine
- Implement survivorship care plans
- Improve optimal physical health for cancer survivors
- Improve optimal psychosocial health for cancer survivors
- Improve access to appropriate end-of-life care

Several means of reaching the goals of cancer directed therapy and supportive care have been identified. These include help navigating the system with help from nurses and social workers and welcome packets. Also included is continuity of care by providing a seamless patient experience, collaboration with all providers, shared screening information, continuity from hospital to community, and ongoing screening.

BARRIERS

- Lack of protocolized approach to referrals and follow up for tobacco cessation
- Logistical and operational challenges in providing survivorship care plans and psychosocial distress screening
- Lack of oncology specific “health maintenance” functionality in EPIC EMR for proactive identification and addressing of survivorship issues
- Lack of patient awareness about existing survivorship and supportive care options
- UVM Medical Center website presence is not conducive to patient learning about services
- Logistical challenges in connecting patients to other patients
- Optimizing capacity and availability of direct care staff to meet patient needs

The primary barriers identified during patient and stakeholder interviews were lack of effective communication, connection between patients, and well-trained staff. Patient and patient advocates were quick to note the many excellent staff they encountered, but frequently noted that everyone was rushed for time. This led to rushed communication concerning highly complex and high stakes decisions concerning course of treatment. Patients noted being placed in the decision-maker position for a condition they had no knowledge of.

RESOURCES

- Patient Navigators
- UVM Medical Center Transforming Oncology Care Initiative
- UVM Medical Center Palliative Care Physician Leader
- Community Events such as Stowe Weekend of Hope
- Oncology Rehabilitation Program
- Support groups
- Survivorship Now community offerings
- UVM Medical Center HealthSource free wellness classes

“It should be the health professional’s role to know the best course of treatment, not the patient”.

UVM MEDICAL CENTER PATIENT FOCUS GROUP

Patient Navigators play an important role in helping patients access and manage their cancer-directed care services. Their two major functions include helping patients navigate the system and achieving continuity of care. As system navigators, they address patient emotional concerns, provide information packets, promote baseline services, and increase clinic awareness. To help patients achieve continuity of care, navigators take care of registering patients for their visits, link medical staff to surgery and radiation departments, and streamline processes for lab work.

An array of community programs and support groups exist for cancer patients and survivors. Patients and patient advocates report that there could be more opportunity to connect patients with each other to leverage support at low, or no cost. Patients have a desire for relatable information from others who have gone through similar experiences and survivors have a desire to share their experience for the benefit of others. Connecting these two groups via a database and opt-in program could significantly increase the decision-making capacity of patients and reduce the information-sharing burden on paid healthcare providers.

GAPS

- Lack of comprehensive information upon which to base treatment decisions
- Lack of male-specific support groups
- Low numbers of survivor referrals to oncology rehabilitation
- Lack of gynecologic cancer specific support groups
- Lack of supportive home care options for non-critical cancer survivors
- Lack of connections to other patients and survivors with similar cancers and demographics, i.e. people the patient can relate to directly

Patients indicate a fine line between being overwhelmed by information and not getting the necessary input to base decisions on. Timing is critical, as during the initial stages patients may be in shock from a cancer diagnosis and not processing information.

Support groups that are relatable to the patient are beneficial to emotional and mental well-being. Both male and female patients indicated that there could be more tailored support groups to meet a variety of patients needs with varying demographics and cancer types.

Conclusion

The first of three core needs of the UVM Medical Center patient community relates to addressing disparities in cancer care services due to urban and rural geographies, health literacy levels, and income and insurance levels. Each of these disparities in the patient population has an impact on the ability of patients to access cancer care, and ultimately the outcome of treatment regimens. Given the potential disparities in initial patient conditions, the challenge facing the UVM Medical Center is to reduce the disparities in cancer treatment outcomes. To this end, a large amount of resources has been leveraged and has successfully closed many of the transportation, health literacy, and insurance/income gaps. While it is true that a relatively small percentages of the population fall through the gaps in assistance, these gaps are narrowing, and continued assessment and evaluation of assistance programs will ensure that they continue to do so.

The second core need is for preventive screening and early-detection services that are targeted to the appropriate populations and easy to access. The UVM Medical Center performs at or better than regional and national CoC counterparts in stage 0 and 1 diagnoses for colorectal, cervical, breast, and lung cancers. Early detection is critical to surviving a cancer diagnosis and ongoing efforts are aimed at continued improvement on this front. Efficient use of screening resources is essential and will be best served by partnerships with PCPs that help to direct the highest need patient populations to the appropriate screening clinics.

As shown in this report, UVM Medical Center Cancer Center demonstrates diagnosis and treatment outcomes that meet or exceed metrics for peer facilities for the majority of the most prevalent cancers. While ongoing efforts have greatly advanced the level of cancer treatment and supportive care UVM Medical Center patients receive, there will always be a need to continue to advance these benchmarks. The third core need reflects the need for continued development of cancer-directed therapies and post-treatment supportive care programs.

Coordination and communication are key needs during the treatment phase and patient navigators are a key resource available at the UVM Medical Center to meet this need, although the high demand on this resource leaves an inevitable gap for patients needing extended mental and emotional support. There is a need among both male and female cancer patients and survivors to connect with others they can relate to and learn from while undergoing treatment. This population indicates a desire to build connections that strengthen the foundation laid by UVM Medical Center doctors and staff. Patients and survivors, when given the necessary space and coordination assistance, may be willing and able to provide relatively low-cost support for mental and emotional distress, thus reducing the demand on UVM Medical Center staff and providing the relatable, human connection that patients undergoing cancer treatment desire.

Appendix A. Logic Model

NEED CATEGORY	EXISTING COMMUNITY CONDITIONS	GOALS
Disparities • **Urban & Rural** • **Health literacy level** • **Income & insurance level**	Dispersed VT population Poverty, low income, and lower literacy correlated with rurality ~50% UVM Medical Center patients have inadequate health literacy Highly variable private and public insurance coverages	Reduce disparities of cancer care caused by rurality, health literacy, income, and insurance coverage.

BARRIERS	RESOURCES	GAPS
Transportation requires time and dollar investment by patients and is higher for those in more distant, rural communities. Low health literacy leads to a lack of effective communication with patients. Denied claims create financial and logistical hardships. High deductibles create financial disincentives for receiving the appropriate care. Lack of prescription drug coverage reduces the effectiveness of treatment prescriptions. Disproportionate financial burdens accrue predominantly to middle class patients due to private coverage plans that provide insufficient coverage.	County Transportation Agencies Town level Elderly and Disabled (E&D) waivers for transportation resources ADA ParaTransit Agency on Aging emergency funds Road to Recovery Sally Fox Recovery Fund Hospital taxi vouchers Accelerated treatment schedules Rural health coaching Appeals to insurance companies Compassionate care drug provision Oncology Specialty Pharmacy program	Approximately 5-10% of population fall through the gaps and do not qualify for the above mentioned transportation resources Current transportation options require minimum of 48 hours notice Lack of communication with PCPs regarding full spectrum of options Assistance with day-to-day bills for patients lacking short term disability

Appendix A. Logic Model

NEED CATEGORY	EXISTING COMMUNITY CONDITIONS	GOALS	BARRIERS	RESOURCES	GAPS
Prevention & Early Detection	At or exceeding regional & national Stage 0 & 1 diagnoses for colon, cervical, breast, and lung cancers Slightly lagging regional & national Stage 0 & 1 diagnoses for prostate cancer	Increase colorectal screening for ages 50-75 from 71% to 80%** Increase % women 21-65 who received Pap test from 86% to 100%** Increase % women 50-74 receiving mammograms from 79% to 95%** Decrease advanced stage lung cancer detection from 210 per 100,000 to 199.5**	Challenge of targeting those with greatest cost benefit return of screening Awareness among PCPs about screening resources Reducing the portion of population seeking screening that are not the target group (inefficient use of resources) Lack of protocolized approach to referrals and follow up for tobacco cessation	"Choosing Wisely" campaign Patient navigators Leading the region in lung cancer screening for early detection and treatment	Approximately 10,000 Vermonters qualify for lung cancer screening but most are not yet aware of the resources available.

*Geller et. al. (2014)
**VTAAC (2016)
***Cranmer, D. & McBeth, K. (2016)

Appendix A. Logic Model

NEED CATEGORY	EXISTING COMMUNITY CONDITIONS	GOALS
Treatment & Survivorship	80% of patients satisfied with their personalized care plans**	A more easily navigable system
	VT is 2nd healthiest state in the U.S.	Connections at all points of patient care
	VT cancer survivors have higher incidence of cardiovascular disease and smoke at higher rates than adults who never had a cancer diagnosis	Care for mental as well as physical state
		Increase # of palliative care physicians, APNs and RNs in VT**
		Increase % of cancer patients treated by CoC cancer programs receiving survivorship care plans from 2% to 100%**
		Improve access to complementary / integrative medicine***
		Implement survivorship care plans***
		Improve optimal physical health for cancer survivors***
		Improve optimal psychosocial health for cancer survivors***
		Improve access to appropriate end-of-life care***

BARRIERS	RESOURCES	GAPS
Lack of protocolized approach to referrals and follow up for tobacco cessation	Patient navigators	Reducing stress*
Logistical and operational challenges in providing survivorship care plans and psychosocial distress screening	UVM Medical Center Transforming Oncology Care Initiative underway, defining ideal patient encounter and strategies to achieve better patient experience with services	Information about after effects of treatment*
Lack of oncology specific “health maintenance” functionality in EPIC EMR for proactive identification and addressing of survivorship issues	UVM Medical Center Palliative Care physician leader joins team in May 2016 to help lead our efforts in this area	Help reducing worry*
Lack of patient awareness about existing survivorship and supportive care options	Annual community events for survivors - Stowe Weekend of Hope, Women’s Health Conference and Men’s Health Conference can be leveraged to address survivorship educational needs	Managing concerns about recurrence*
UVM Medical Center website presence is not conducive to patient learning about services	Robust Oncology Rehabilitation Program (underutilized at present)	Dealing with impacts on partner*
Logistical challenges in connecting patients to other patients	Support groups	Addressing problems with sex life*
Optimizing capacity and availability of direct care staff to meet patient needs	Survivorship Now community offerings	Info about side effects*
	UVM Medical Center HealthSource free wellness classes • Healthier Living with Diabetes • Healthier Living with Pain • Cancer: Thriving and Surviving • Diabetes Prevention Program • Tobacco Cessation	Low number of survivors referred for oncology rehabilitation
		Lack of gynecologic cancer specific support group (Identified by attendees at women’s Health Conference in 2015)

*Geller et. al. (2014)
**VTAAC (2016)
***Cranmer, D. & McBeth, K. (2016)

References

Beatty, J. D., Adachi, M., Bonham, C., Atwood, M., Potts, M. S., Hafterson, J. L., & Aye, R. W. (2011). Utilization of cancer registry data for monitoring quality of care. The American journal of surgery,201(5), 645-649.

Butow, P. N., Phillips, F., Schweder, J., White, K., Underhill, C., & Goldstein, D. (2012). Psychosocial well-being and supportive care needs of cancer patients living in urban and rural/regional areas: a systematic review. Supportive Care in Cancer, 20(1), 1-22.

Cranmer, D., McBeth, K. (2016). VTAAC Quality of Life Workgroup Community Feedback. Unpublished findings from 2016 Stowe Weekend of Hope.

Del Giudice, M. E., Grunfeld, E., Harvey, B. J., Piliotis, E., & Verma, S. (2009). Primary care physicians' views of routine follow-up care of cancer survivors. Journal of clinical oncology, 27(20), 3338-3345.

Edge, S.B. (2010). Commentary: "Help the Doctor"- The Culture Shift to 21st Century Care Management. Journal of Oncology Practice. 6(2). 89-90.

Fowler, F. J., Bin, L., Collins, M. M., Roberts, R. G., Oesterling, J. E., Wasson, J. H., & Barry, M. J. (1998). Prostate cancer screening and beliefs about treatment efficacy: a national survey of primary care physicians and urologists. The American journal of medicine, 104(6), 526-532.

Garfin, E. (2006). Cancer Survivor Focus Group Study. Retreived 4/6/16 from http://healthvermont.gov/prevent/ccc/documents/CancerSurvivorFocusGroups.pdf

Geller, B.M., Mace, J., Vacek, P., Johnson, A., Lamer, C., Cranmer, D. (2011). Are Cancer Survivors Willing to Participate in Research? Journal of Community Health. Vol. 36. Iss. 5. Pp 772-778.

Geller, B.M., Vacek, P.M., Flynn, B.S., Lord, K., & Cranmer, D. (2014). What are cancer survivors' needs and how well are they being met? The Journal of Family Practice. Vol. 63. No. 10. Pp E7-E16.

Grassi, L., Giraldi, T., Messina, E. G., Magnani, K., Valle, E., & Cartei, G. (2000). Physicians' attitudes to and problems with truth-telling to cancer patients. Supportive Care in Cancer, 8(1), 40-45.

Johnson, A., Rees, J. R., Schwenn, M., Riddle, B., Verrill, C., Celaya, M. O., ... & Rutstein, L. (2010). Oncology care in rural northern new England. Journal of Oncology Practice, 6(2), 81-89.

Kantsiper, M., McDonald, E. L., Geller, G., Shockney, L., Snyder, C., & Wolff, A. C. (2009). Transitioning to breast cancer survivorship: perspectives of patients, cancer specialists, and primary care providers. Journal of general internal medicine, 24(2), 459-466.

Kim, P. (2007). Cost of Cancer Care: The Patient Perspective. American Society of Clinical Oncology. Vol. 25 no. 2. Doi: 10.1200/jco.2006.07.9111.

Klabunde, C. N., Frame, P. S., Meadow, A., Jones, E., Nadel, M., & Vernon, S. W. (2003). A national survey of primary care physicians' colorectal cancer screening recommendations and practices. Preventive medicine, 36(3), 352-362.

Kripalani, S., LeFevre, F., Phillips, C. O., Williams, M. V., Basaviah, P., & Baker, D. W. (2007). Deficits in communication and information transfer between hospital-based and primary care physicians: implications for patient safety and continuity of care. Jama, 297(8), 831-841.

Kutner M, Greenberg E, Jin Y, Paulsen C. (2006). The Health Literacy of America's Adults: Results From the 2003 National Assessment of Adult Literacy (NCES 2006-483). Washington, DC: U.S. Department of Education, National Center For Education Statistics.

Mackenzie, L. J., Sanson-Fisher, R. W., Carey, M. L., & D'Este, C. A. (2013). Radiation oncology outpatient perceptions of patient-centred care: a cross-sectional survey. BMJ open, 3(2), e001265.

Memorial Sloan-Kettering Cancer Center. (2015). 2013-2015 Community Health Needs Assessment and Community Service Plan. Retrieved 4/6/16 from https://www.mskcc.org/sites/default/files/node/39068/documents/2013-2015-community-health-needs-assessment-and-community-service-plan.pdf

National Cancer Institute. (2016). Cancer Statistics. Retrieved 4/25/16 from http://www.cancer.gov/about-cancer/what-is-cancer/statistics

Nissen, M. J., Beran, M. S., Lee, M. W., Mehta, S. R., Pine, D. A., & Swenson, K. K. (2007). Views of primary care providers on follow-up care of cancer patients. FAMILY MEDICINE-KANSAS CITY-, 39(7), 477.

Seattle Cancer Care Alliance. (2015). Community Health Needs Assessment 2012-2015. Fred Hutchins Cancer Research Center. Retrieved 4/6/16 from http://www.seattlecca.org/client/documents/SCCA_Community-Health-Needs-Assessment_2012-2015.pdf

Shaw, J.G. (2015). Health Literacy and Plain Language. Vermont Legal Aid. Retrieved 4/6/16 from http://www.vtlegalaid.org/sites/default/files/Health%20Literacy%20and%20Plain%20Language.pdf

Soothill, K., Morris, S. M., Thomas, C., Harman, J. C., Francis, B., & McIllmurray, M. B. (2003). The universal, situational, and personal needs of cancer patients and their main carers. European Journal of Oncology Nursing, 7(1), 5-13.

Sowden, M., Vacek, P., Geller, B.M. (2014). The impact of cancer diagnosis on employment: is there a difference between rural and urban populations? Journal of Cancer Survivorship. Vol. 8 Iss. 2 pp 213-217.

United Health Foundation. (2016). America's Health Rankings. Retrieved 4/1/16 from http://www.americashealthrankings.org/VT

US Census. (2016). American Community Survey (ACS). Retrieved 4/6/16 from https://www.census.gov/programs-surveys/acs/

US Census. (2010). 2010 Census Urban and Rural Classification and Urban Area Criteria. Retrieved 3/28/16 from https://www.census.gov/geo/reference/ua/urban-rural-2010.html.

US Census. (2011). Age and Sex Composition: 2010. Retrieved 3/28/16 from http://www.census.gov/prod/cen2010/briefs/c2010br-03.pdf

U.S. Department of Health and Human Services. 2000. Healthy People 2010. Washington, DC: U.S. Government Printing Office.

VTAAC. (2016). 2016-2020 Vermont Cancer Plan: A Framework for Action. Retrieved 3/28/16 from http://vtaac.org/wp-content/uploads/vt-cancer-plan_2016-2020.pdf.

Vermonters Taking Action Against Cancer. (N.D.)Vermont Cancer Survivor Community Study. Retrieved 4/6/16 from http://vtaac.org/wp-content/uploads/CSCS-article.3.pdf

VT Department of Health. (2010). Vermont Blueprint for Health. Retrieved 4/1/16 from http://healthvermont.gov/research/documents/health_trends_vt_2010.pdf

VT Department of Health. (2016). Vermont Cancer Registry. Retrieved 4/1/16 from http://healthvermont.gov/research/cancer_registry/registry.aspx.

VT Department of Health. (2016b). Vermont Cancer Incidence Maps and Data. Retrieved 4/1/16 from http://healthvermont.gov/prevent/cancer/maps_data.aspx#access

VT Department of Health. (2016c). Cancer Performance Dashboard. Retrieved 4/1/16 from http://healthvermont.gov/hv2020/dashboard/cancer.aspx

VT Department of Health. (2016d). 2016-2020 Vermont Cancer Plan: A Framework for Action. Retrieved 4/6/16 from http://healthvermont.gov/pubs/cancerpubs/documents/VTCancerPlan.pdf

Vermont Department of Health. (2016e). Cancer Screening Recommendations. Retrieved 4/6/16 from http://healthvermont.gov/prevent/cancer/documents/CancerScreening_Providers.pdf

Vermont Department of Health Environmental Public Health Tracking. (2016). Retrieved 4/25/16 from https://apps.health.vermont.gov/ias/querytool

Wagner, E. H., Austin, B. T., Davis, C., Hindmarsh, M., Schaefer, J., & Bonomi, A. (2001). Improving chronic illness care: translating evidence into action. Health affairs, 20(6), 64-78.

Zahnd, W.E., Scaife, S.L., Francis, M.L. (2009). Health Literacy Skills in Rural and Urban Populations. American Journal of Health Behavior. Vol. 33. No. 5. Pp. 550-557. DOI: http://dx.doi.org/10.5993/AJHB.33.5.8

FOR QUESTIONS OR COMMENTS, PLEASE EMAIL:
PublicCommentCHNA@uvmhealth.org

THE
University of Vermont
MEDICAL CENTER

blog

UVMHealth.org/MedCenter