Community Cancer Needs Assessment

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UNC Cancer Network, Administrative Clinical Director
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This document has been prepared to fulfill the requirements of the CoC Standard 3.1. It will be used to guide the UNC Cancer Committee to comply with the community outreach standards and/or the psychosocial services eligibility criteria.
Purpose
To identify the cancer-related needs of our identified community/population in order to improve
cancer-health disparities and current gaps in existing resources within and outside of UNC Lineberger
Comprehensive Cancer Center. Our identified community/population are the patients and communities
served by UNC Health Care.

Goal
To evaluate existing programs and identify future program development that will ensure the needs of
our population are met. The American College of Surgeons, Commission on Cancer (CoC) has mandated
that all accredited cancer programs have the new patient centered care standards incorporated by
2015. The current standards address the full spectrum of cancer care, from cancer prevention to
survivorship and end-of-life care. The most recent revisions of these standards included the
development of new “patient-centered” processes. This includes the provision of palliative care
services, treatment and survivorship plans, psychological distress screening and patient navigation
processes.

We anticipate accomplishment of this by:
   a. Continued monitoring and support of current and future patient navigation, distress
      screening and survivorship processes to ensure all of the needs of the cancer patients
      are met throughout the continuum. This includes the identification of measureable
      outcomes to ensure these standards are being implemented appropriately.
   b. Development of cancer-related processes inside and outside of UNC Lineberger
      Comprehensive Cancer Center to ensure underserved populations have easier access to
care as well as a basic understanding of the importance of having a healthy lifestyle
      and of reducing their high risk.

Methods
The cancer program has chosen secondary data analysis as the tool for the majority of this assessment.
Data gathered for this report includes data from NCI’s State Cancer Profiles:
Health Disparities in North Carolina Report Card 2010;
http://www.schs.state.nc.us/SCHS/pdf/MinRptCard_WEB_062210.pdf; NC Minority Health Facts:
Hispanics/Latinos: www.schs.state.nc.us/SCHS/pdf/Hispanic_FS_WEB_080210.pdf; CDC Center for

Introduction
North Carolina has a total population of 9,752,073 people (U.S. Census Bureau, estimate, 2012, North
Carolina). The adult population (18 years old or over) makes up 76.5% the total population, and nearly
38% of the population are of a minority ethnicity. The minority population includes African Americans,
American Indians, Asians; Native Hawaiians and other Pacific Islanders, Hispanics or Latinos. The
poverty rate is the number of people living below the federal poverty line as a percentage of the total
population. It is estimated that about 16.1% of the total adult population are below the poverty level in
North Carolina. The poverty rate for the United States is 14.3%.

There are 100 counties in NC. There are 123 licensed hospitals in 83 counties. Seventeen counties
currently do not have a hospital. Duke University Hospital is currently the largest hospital, with 1,002
total hospital beds and operating rooms. Bertie Memorial Hospital is currently the smallest with eight total hospital beds and operating rooms. Charlotte has the highest concentration of hospitals, with seven. Four hospitals serve as Academic Medical Centers including: Duke University Hospital, Pitt County Memorial Hospital, UNC Hospitals and Wake Forest Baptist Medical Center. There are 39 CoC accredited cancer programs. Out of those, there are 3 NCI-designated cancer centers including UNC Lineberger Comprehensive Cancer Center in Chapel Hill; Duke Cancer Institute in Durham and Comprehensive Cancer Center of Wake Forest University in Winston-Salem.

Cancer Incidence in NC:

Cancer is a significant health problem in North Carolina, impacting the physical, emotional, economic and social well-being of individuals, their families and communities. Cancer was the leading cause of death in North Carolina in 2010, surpassing heart disease (NC Vital Statistics, 2011). Cancer Profiles, NC, 2013 report that the top cancer sites for mortality were colo/rectal; pancreas; lung; breast and prostate. Mortality rates for the top cancers show that, overall, most cancer deaths are due to lung cancer (56.0%) and prostate cancer (25.6%). These cancers account for a substantial percentage of North Carolina’s cancer deaths and new cases. They are also associated with screening and/or preventive behaviors that can reduce deaths and new cases (CANCER in North Carolina, 2008 report).

- Colorectal cancer incidence rates in NC fell from 45.7 per 100,000 population in 1999 to 37.8 cases per 100,000 in 2012. It should be noted that more new cases of colorectal cancer were diagnosed during the late stage of the condition than the early stage, demonstrating the need for earlier diagnosis.

- Although rates of breast cancer fluctuated from 1999-2012, overall, the age-adjusted incidence rate of breast cancer for NC women increased from 145.5 per 100,000 population in 1999 to 158.9 cases per 1000,000 population in 2012.

- It should also be noted that during 1999-2012, white women consistently reported the highest age-adjusted incidence rate of breast cancer, while Asian and Latina women reported the lowest age-adjusted incidence rates of breast cancer.

- Between 1999 and 2012, black men consistently reported the highest incidence rate of prostate cancer compared to all other racial/ethnic groups.
TOP 10 CANCER SITES NC

Incidence 2007-2011 per 100,000 population 242,433 cases (rate=496.7)

<table>
<thead>
<tr>
<th>Case</th>
<th>Cases</th>
<th>Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Breast</td>
<td>42,701</td>
<td>157.4</td>
</tr>
<tr>
<td>2. Prostate</td>
<td>35,369</td>
<td>150.6</td>
</tr>
<tr>
<td>3. Lung</td>
<td>36,758</td>
<td>73.4</td>
</tr>
<tr>
<td>4. Colo-rectal</td>
<td>20,650</td>
<td>41.5</td>
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<tr>
<td>5. Uterine</td>
<td>6,622</td>
<td>23.7</td>
</tr>
<tr>
<td>6. Melanoma</td>
<td>10,968</td>
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<tr>
<td>7. Bladder</td>
<td>10,201</td>
<td>20.7</td>
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<tr>
<td>8. NHL</td>
<td>9,274</td>
<td>18.8</td>
</tr>
<tr>
<td>9. Leukemia</td>
<td>8,688</td>
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<td>10. Kidney</td>
<td>8,469</td>
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</table>

Mortality 2008-2012 per 100,000 population 89,505 cases (rate=176.5)

<table>
<thead>
<tr>
<th>Case</th>
<th>Cases</th>
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<tbody>
<tr>
<td>1. Lung</td>
<td>27,199</td>
<td>53.2</td>
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<tr>
<td>2. Prostate</td>
<td>4,356</td>
<td>23.4</td>
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<tr>
<td>3. Breast</td>
<td>6,357</td>
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<tr>
<td>4. Colo-rectal</td>
<td>7,466</td>
<td>14.8</td>
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<td>5. Pancreas</td>
<td>5,330</td>
<td>10.5</td>
</tr>
<tr>
<td>6. Ovarian</td>
<td>2,161</td>
<td>7.5</td>
</tr>
<tr>
<td>7. Leukemia</td>
<td>3,336</td>
<td>6.8</td>
</tr>
<tr>
<td>8. NHL</td>
<td>2,899</td>
<td>5.9</td>
</tr>
<tr>
<td>9. Brain</td>
<td>2,194</td>
<td>4.3</td>
</tr>
<tr>
<td>10. Bladder</td>
<td>2,058</td>
<td>4.2</td>
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</table>

*CSource: NC Central Cancer Registry 1/2013

Cancer Mortality and Survivorship in NC:

According to data from the CDC and Prevention, the leading cause of death in NC is cancer, followed by heart disease (CDC, 2007). Overall, males living in NC had a greater cancer mortality rate than females (210.9 deaths per 100,000 population vs 142.8 deaths per 100,000 population). The NC Central Cancer Registry reports that according to population data from 2006-2010, there are 148,322 cancer survivors living in North Carolina.

Furthermore, cancer mortality rates were not equal across racial/ethnic groups. African Americans have a higher mortality rate. Among African Americans, there were 206.2 deaths due to cancer per 100,000 population compared to 173.2 for White, as shown in the table below.

Age-Adjusted Cancer Mortality in NC by Leading Types of Cancer, by Race/Ethnicity, 2007-2010

<table>
<thead>
<tr>
<th>White</th>
<th>Black</th>
<th>Latino</th>
<th>Asian</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer Rate</td>
<td>Cancer Rate</td>
<td>Cancer Rate</td>
<td>Cancer Rate</td>
</tr>
<tr>
<td>Lung 55.9</td>
<td>Prostate 55.6</td>
<td>Lung 19.0</td>
<td>Lung 21.3</td>
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<td>Prostate 22.8</td>
<td>Lung 54.1</td>
<td>Breast 13.1</td>
<td>Liver 8.9</td>
</tr>
<tr>
<td>Colo-rectal 14.5</td>
<td>Breast 30.1</td>
<td>Prostate 15.4</td>
<td>Colo-rectal 6.9</td>
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<tr>
<td>All Cancer 176.8</td>
<td>All Cancer 211.3</td>
<td>All Cancer 92.4</td>
<td>All Cancer 94.8</td>
</tr>
</tbody>
</table>

*Source: NC Central Cancer Registry 1/2013
Cancer death rates by race in NC show the following trends:

- African Americans (56.5%) are dying from prostate cancer at a far higher rate than Caucasians (19.5%) or any other race, including Hispanics and Asians.
- Caucasians have the most deaths resulting from lung cancer (55.9%). African Americans also have a high death rate due to lung cancer (54.1%).
- African Americans are dying from cervical cancer (3.5%) and female breast cancer (30.0%) at a higher rate than any other race.
- Asian Americans are twice as likely to die from stomach cancer than non-Hispanic white men, and Asian American women are 2.7 times as likely to die from stomach cancer than non-Hispanic white women.

UNC Health Care
UNC Hospitals opened its doors six decades ago with a purpose to serve the health care needs of North Carolinians. Today, it is a 830 bed academic medical center that has been providing healthcare to the residents of NC since 1951. It is the state’s first and only state-owned hospital. The hospital has transformed into a fully integrated health care system that is connected to communities all across North Carolina. Four other hospitals and several clinics have been built on and around the Chapel Hill campus. Together, these facilities now are called UNC Hospitals and patients are served from all 100 counties.
N.C. Cancer Hospital
The N.C. Cancer Hospital, opened in September 2009, and is the clinical home of the UNC Lineberger Comprehensive Cancer Center. It serves as the home to 110 faculty physicians, all members of UNC Cancer Care. Designed with input from patients and health care providers, the hospital is a tangible symbol of UNC’s dedication to fighting cancer with every resource available. The physicians and scientists are faculty in the University of North Carolina School of Medicine and national leaders in the areas of cancer treatment, research and prevention. Research is ongoing to determine what causes cancer, how to prevent it and how best to treat it. The NC Cancer Hospital provides the latest technology to diagnose and treat cancer. Patients, families and communities are provided with the most-up-to-date prevention strategies and newest therapies. Future physicians, nurses, scientists and public health professionals are also trained.

UNC Lineberger Comprehensive Cancer Center
The UNC Lineberger Comprehensive Cancer Center was established at the University of North Carolina (UNC) at Chapel Hill in 1975, when it received NCI designation as a cancer center. The comprehensiveness designation was granted by NCI in 1990. Today, it is ranked among the top 10 institutions nationally in cancer research funding and given an exceptional rating by the NCI in its last comprehensive review – the Institute’s highest ranking. UNC Lineberger is home to internationally-recognized research programs, including a SPORE (Special Projects of Research Excellence) program for breast cancer.

The mission of the UNC Lineberger is to reduce cancer occurrence and death through research, treatment, training, and outreach. UNC Lineberger physicians have been offering multidisciplinary, patient-centered care for more than a quarter of a century. Building upon Lineberger Comprehensive Cancer Center’s national and international recognition of leading cancer research discoveries, patients are also given the opportunity of participating in clinical trials that may offer access to new and innovative treatments.

- Physicians at the NC Cancer Hospital treat patients from every county in North Carolina with more than 135,000 patient visits each year
- All types of cancer, are treated providing multidisciplinary programs for most, giving adult and pediatric patients the benefit of many medical specialists in one place, often in one visit
- Offers more than 250 clinical trials of the latest treatments developed at UNC or available through affiliation with national clinical trial groups
- Is the largest research entity at UNC, with faculty holding more than $212 million in external grant funding
- Has more than 300 researchers from more than 25 departments across campus

North Carolina’s population is expected to grow by 4 million people by 2030, and that population is also growing older. In 20 years, more than 2 million people age 65 and older will live in NC, which is one-fifth of the state’s entire population.

At the same time, the physician population is aging, and by 2020, one-third of today’s practicing physicians will have retired. NC will have 25% fewer primary care doctors than needed. UNC’s growing
medical school and UNC Health Care’s training partnerships with hospitals across the state, will be critical in addressing the anticipated shortage of physicians, particularly in rural and underserved areas.

**UNC Health Care Statewide Partnerships and Affiliations**

**Include Clinical Research, Telemedicine and Patient Navigation**

- UNC Pardee Health Care, Hendersonville
- UNC High Point Regional Health System, High Point
- UNC Rex Health Care, Raleigh
- UNC Chatham Hospital, Siler City
- UNC Caldwell Memorial, Lenoir
- UNC Johnston Health, Smithfield
- UNC Nash Health Care System, Rocky Mount

**UNC Cancer Network Statewide Partnerships**

<table>
<thead>
<tr>
<th>Alamance Cancer Center, Burlington</th>
<th>Kinston Medical Specialists, Kinston</th>
</tr>
</thead>
<tbody>
<tr>
<td>Angel Medical Center, Franklin</td>
<td>Leo Jenkins Cancer Center, Greenville</td>
</tr>
<tr>
<td>Ashville Hematology &amp; Oncology, Ashville</td>
<td>Levine Cancer Center, Charlotte</td>
</tr>
<tr>
<td>Boice Willis Clinic, Rocky Mount</td>
<td>Marion L. Shepard, Washington</td>
</tr>
<tr>
<td>Cancer Center of Western NC, Ashville</td>
<td>Mission Cancer Center, Asheboro</td>
</tr>
<tr>
<td>Cape Fear Valley Cancer Center, Fayetteville</td>
<td>New Bern Cancer Center, New Bern</td>
</tr>
<tr>
<td>Carteret General Hospital, Morehead City</td>
<td>Randolph Cancer Center, Asheboro</td>
</tr>
<tr>
<td>Comprehensive Cancer Center of Wake Forest, Winston-Salem</td>
<td>Seby Jones Cancer Center, Boone</td>
</tr>
<tr>
<td>Cone Health Cancer Center, Greensboro</td>
<td>Southeastern Medical Oncology Center, Goldsboro, Clinic, Wilson, Jacksonville</td>
</tr>
<tr>
<td>Duke Cancer Institute, Durham</td>
<td>Wilson Medical Center, Wilson</td>
</tr>
<tr>
<td>First Health Cancer Center, Pinehurst</td>
<td>The Outer Banks Hospital, Nags Head</td>
</tr>
<tr>
<td>Hillsborough Oncology, Hillsborough</td>
<td>Zimmer Cancer Center, Wilmington</td>
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<tr>
<td>Hope Cancer Center, Erwin</td>
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</table>

**UNC Lineberger Clinical Trials:**

With research that spans the spectrum from the laboratory to the bedside to the community, UNC Lineberger faculty work to understand the causes of cancer at the genetic and environmental levels, to conduct groundbreaking laboratory research, and to translate findings into pioneering and innovative clinical trials. Participants in clinical trials can play a more active role in their own health care, gain access to new research treatments before they are widely available, and help others by contributing to medical research. All clinical trials have guidelines about who can participate. Researchers use protocols with defined criteria to identify appropriate participants and maintain safety standards.
Population Characteristics of Patients Served

STATEWIDE UNC HEALTH CARE REGIONS

CCSG Catchment Area

Two choices:
1) 14-county UNC Health Care geographically-contiguous, primary + secondary catchment area
2) The state as a whole
UNC Health Care’s 14 county catchment area:

- Accounts for ~29% of the state’s population and the state’s populations > 50 yrs old
- Has a population that is younger and a little more diverse than the state as a whole
- Contributes ~ 64% of UNC tumor registry cases

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**Top 10 Sites: CY 2011 UNC Tumor Registry (n = 4,140)**

1. Breast (484)
2. Melanoma (466)
3. Prostate (320)
4. Lung (318)
5. Corpus Uteri (263)
6. Kidney/Renal (168)
7. Leukemia (161)
8. Colon (153)
9. Bladder (137)
10. Non Hodgkin (134)

Next 5: Liver (119), Rectum (101), Ovary (95), Pancreas (94), Multiple Myeloma (94)

Other Groupings: All Blood, Bone Marrow; Lymphatic = 436, All GYN = 471
Minority Disparity Programs

The Carolina Community Network Center to Reduce Cancer Health Disparities (CCN II)
This is a regional cancer network aimed at reducing prostate, breast and colorectal cancer disparities among adult African Americans in North Carolina. CCN II combines the strengths of the community with resources and research expertise at UNC to reduce cancer disparities through education, research and training.
Based at the University of North Carolina at Chapel Hill, CCN II is comprised of a Research Program, Community Outreach Program, Training Program and Administrative Core.

Community Bridges to Cancer Clinical Trials
A community based participatory research project to enhance community awareness, access, and decision-making regarding cancer clinical trials. The project combined the expertise of academics, a cancer clinical trials education organization and community organizations delivering cancer education to people at risk for cancer.

Project CONNECT
A Research Registry Based at UNC
Registry staff distribute enrollment opportunities to registry members and provide consultation to researchers to accrue minority participation. The confidential registry collects basic participant data. Currently the registry includes 843 individuals aged 18 to 70+. The majority are African American (77%) and female (69%). Nearly half (48%) reported a diagnosis of at least one medical condition such as asthma, cancer, diabetes, hypertension, or mental health condition.

ICISS: The Integrated Cancer Information and Surveillance System

Vision
Improve cancer outcomes in North Carolina by enabling innovative research for understanding how to:

- discover risk factors for cancer
- best prevent and treat cancer
- disseminate and implement proven prevention, early detection, and health systems changes
- improve life after a cancer diagnosis

What is ICISS?
The Integrated Cancer Information and Surveillance System provides a prospective data linkage between metrics of cancer incidence, mortality, and burden in North Carolina and data sources at an individual and aggregate level that describe health care, economic, social, behavioral, and environmental patterns.
Catchment Area Minority Disparity Research

- **Prostate** – Louisiana, NC PCaP (CPC & CR)
- **Endometrial** – minority obesity interventions/metformin trial (CPC & CR)
- **Cervical** – HPV vaccine and screening interventions (CPC)
- **Colorectal** – Colonoscopy interventions African-American and Hispanic populations (CPC)
- **Breast** – Carolina Breast Cancer Study (Breast, Epi, Genetics)
- **Lung** – Intervention to increase early detection and lung cancer surgery in African American populations (CPC)
- **Bladder** – Investigating increased African American incidence
- **Pancreas** – Link to obesity & subtypes
- **Multiple Myeloma** – Planning & MM North Carolina Network

Minority Disparities Publications


**Patient Centered Support Programs at NC Cancer Hospital**

**Partnering with Patients and Families: “Promoting the Voice of the Patient and Caregiver”**

The NC Cancer Hospital Patient and Family Advisory Board (PFAB) was created in 2009 to impact excellent patient care. Hospital leadership identified the importance of partnering with patients and families to improve communication and patient satisfaction using several evidence based reports including *Patient Advocacy for Health Care Quality: Strategies for Achieving Patient-Centered Care* by Earp, J., French, E.A, and Gilkey, M.B. This book served to guide the development of this successful model of support.

The board is comprised of 20 patient/caregivers and 12 NC Cancer Hospital staff. Members are recruited from staff and board recommendations and are invited to serve on hospital committees while attending the monthly PFAB meetings.

The goal of the PFAB is to:

- transform the culture of our cancer center to become more patient and caregiver centric
- help shape policies and programs to improve healthcare outcomes and patient satisfaction

Accomplishments include:

- consultants for developing patient education materials
• serving on 11 standing North Carolina Cancer Hospital committees and 5 standing committees within UNC Health Care
• development of patient liaison roles in order to obtain patient feedback regarding internal operation

Most recently, they have partnered with the UNC Cancer Network and UNC Volunteer Services to develop a model of support utilizing trained lay navigators for patients and families facing a cancer diagnosis at the North Carolina Cancer Hospital. The first training is scheduled for February, 2014.

Patient Navigation Process at UNC Cancer Care
STANDARD 3.1

The role of the Oncology Nurse Navigator is to help coordinate the plan of care, including inpatient and outpatient services, that has been outlined. The objective is to provide high-quality, patient-centered care that focuses completely on the patient and their family.

The Oncology Nurse Navigator works with the entire team of cancer professionals, including physicians, nurses, social workers, dietitians, chaplains, cancer researchers, librarians, health psychologists, complementary-medicine providers and community-resource providers.

Background of the UNC Patient Navigation Model

In 2007, key cancer center leaders and administrators understood the importance of delivering patient centered care that was seamless and well-coordinated. Conducting a comprehensive assessment of existing care management resources enabled the model to be developed to avoid duplication while identifying gaps in care. Experienced oncology nurses were integrated into the role of the Oncology Nurse Navigator (ONN). The program is disease specific and patients are identified at their portal of entry into the healthcare system. Today, there are 20 oncology nurse navigators working within 12 disease clinics.

Working closely with physicians, and other members of the healthcare team, the ONN is the main point of contact for patients. They assist physicians in designing the care plan, while coordinating with multiple providers and engaging the patients and caregivers regarding the importance of ongoing self-management. The navigation model has been used successfully by other cancer centers and oncology programs across the state and nation as evidenced by physician and patient satisfaction and the ability to achieve optimal patient outcomes.

The Oncology Nurse Navigator:

• Provides individual and support services to patients and their families
• Coordinates elements of care
• Assists with communication to ensure physicians have all the necessary information to diagnose and develop effective treatment in a timely manner
• Identifies additional cancer resources within and outside of the NC Cancer Hospital
• Provides emotional support
• Identifies barriers to care
• Serves as the point of contact for patients and families
• Facilitates referrals to the UNC Comprehensive Cancer Support Program
• When possible, accompanies patients to initial appointments
• Assesses patients’ physical, emotional, psychosocial, spiritual and financial needs
• Initiates referrals to ensure patients are connected with community resources
• Coordinates diagnostics, procedures and specialist appointments
• Provides patient education

There are currently 20 nurse navigators on site at the NC Cancer Hospital representing 11 cancer sites and the UNC Cancer Resource Center.

<table>
<thead>
<tr>
<th>Breast</th>
<th>Sarcoma</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lung</td>
<td>Leukemia/Lymphoma</td>
</tr>
<tr>
<td>GI</td>
<td>Head &amp; Neck</td>
</tr>
<tr>
<td>Urology surgical</td>
<td>Multiple Myeloma</td>
</tr>
<tr>
<td>Urology med onc</td>
<td>Neuro Oncology</td>
</tr>
<tr>
<td>Melanoma</td>
<td>Patient/Family Resource Center</td>
</tr>
</tbody>
</table>
In an effort to better serve the needs of the North Carolinian cancer patients and their caregivers, the UNC Cancer Network identified a number of clinical, education, research and survivorship goals in 2008. Careful consideration was given to ensure that the outreach efforts extended to the entire state. One goal was to standardize patient navigation as a model that would save lives, eliminate barriers to quality care and ensure speedy delivery of appropriate services. The sites selected would expand UNC’s ability to reach all communities served. UNC Lineberger Comprehensive Cancer Center would additionally provide additional expertise in cancer care to health care providers, health departments and community-based agencies.

To create the model, a project team was developed that included representatives from hospital administrators at UNC NC Cancer Hospital, leadership from UNC Lineberger Comprehensive Cancer Center, Mission Health, Leo Jenkins Cancer Center, physicians, staff with patient navigation
experience, oncology nurses, researchers, social workers, members from the Dare County Department of Public Health, County Commissioners, cancer survivors and members from the various communities.

The development took place in 3 phases.

**Phase I:**
Literature review evaluating existing patient navigation training programs and program development. The review included more than 15 clinical and non-clinical patient navigators articles. Identification of barriers to care and health care disparities resulted from participating in: town hall meetings, focus groups and staff interviews.

**Phase II:**
Monthly teleconference with committee members to develop the role and responsibilities of the nurse navigators based upon the needs of the individual communities.

**Phase III:**
Role Definition and Program Development

**Key Findings/ Barriers to Care**

The following provides a brief overview of the key findings that emerged from the town hall meetings, focus groups and staff interviews that were identified as key barriers to care.

**Community Perception of Cancer**

- Participants stated that in their opinion, a cancer diagnosis was a death sentence
- Many felt that cancer was a personal and private matter
- Skepticism and distrust was common around academic institutions. Many expressed concern that UNC was just having another “dog and pony show”
- Fear and distrust in healthcare systems
- Need to enhance public perception of local providers to ensure that health care remains local
- Need to promote visibility of existing cancer resources

**Cancer Prevention/Survivorship**

- There was a general lack of awareness regarding the causes of cancer and prevention
- Participants stated that it was difficult to get information and that they were unaware of available cancer resources
- Many did not view cancer screening in a positive manner and were fearful to disclose
- Lack of understanding from community and local health care providers about the survivorship needs of cancer patients
- Need for education to promote healthy lifestyles and cancer prevention with community and local providers
Access to Care

- Lack of primary care providers
- High cost of health care and lack of insurance was a primary concern
- Many expressed difficulty with navigating a fragmented healthcare system. This included scheduling appointments and failure to complete follow up appts.
- Limited access to screening for underserved groups
- Transportation problems due to geographic isolation of many communities
- Language literacy limitations
- Lack of understanding of available resources
- Lack of psychosocial support

RESULTS

Role Development for the UNC Nurse Navigator and UNC Lay Navigator

<table>
<thead>
<tr>
<th>Knowledge</th>
<th>Nurse Navigator</th>
<th>Volunteer Lay Navigator</th>
</tr>
</thead>
</table>
| Role & Responsibility              | Clinical Knowledge of disease process  
Clinical Trial Information  
Symptom Management  
Psychosocial Assessment          | General knowledge of cancer and available resources                              |
| Healthy Lifestyle and Health Promotion | Assess education needs of patient  
Provide patients disease specific information including symptom management and psychosocial support | Provide general health promotion at the individual and community level including: physical activity, healthy eating habits, stress reduction, sunscreen, tobacco cessation and reduction of other risky behaviors to reduce risk of cancer. |
| Barriers to Care/Health Disparities | Address clinical and health system barriers to care.  
Provisions of services to at-risk populations as identified on Nurse Navigation Tracking Tool. | Address non-clinical barriers to care including accommodations, transportation, lack of social support, financial issues |
| Communication                      | Facilitates communication with all members of the health care team.  
Provides one-on-one counseling to address emotional and psychosocial needs of patients and caregivers. | Facilitates communication between patient and nurse navigator or UNC volunteer coordinator |
| Community Resources                | Focus will be on clinically oriented referrals: second opinion, outside testing, treatment in home town, psychosocial support. | Provides assistance accessing internal and external community resources to assist with financial barriers, transportation, accommodations and access to care barriers. |
| Cultural Competency                | Provides clinical care and educational materials in culturally competent manner. | May act as a liaison between community and healthcare system using culturally appropriate educational materials. |
| Psychosocial Support               | Screen and assess for psychosocial distress. Provides psychosocial support services such as emotional support and appropriate referrals. | Identifies resources inside and outside the health system for emotional and social support. |

Oncology Nurse Navigation Pilot Projects

- Mission Health System in Asheville, NC (Thoracic patients)
- Leo Jenkins Cancer Center at East Carolina University (GI, Head & Neck, Melanoma)
- Dare County, located on North Carolina’s Outer Banks, in collaboration with the Outer Banks Hospital (working in the community under the supervision of the on-site Medical Director)

Since 2008 through 2011, six (6) oncology nurse navigators have addressed the needs and facilitated access to the health care system. Outcome measures and metrics were identified based upon the barriers of care and high risk indicators. High risk patients are identified as being from diverse backgrounds with low socioeconomic status, living alone, over the age of 70, multiple medications, multiple hospital admissions and low literacy. More than 3,200 new patients residing in over 40 counties in North Carolina have been served. (See data collection tool)
Community Events and Health Fairs: An important component of the role of the UNC Nurse Navigator is to participate in community events. This serves as a vehicle for educating communities about cancer prevention, early detection, clinical trial participation and treatment information based upon the results of the NC state cancer statistics. It also allows for the nurse navigators to develop trust with the communities they serve. From 2008 through 2011, over 32,000 individuals across the state have been reached through community outreach and educational events.

Community Outreach Presentations and Health Fair Topics  
2012-2014  
STANDARD 1.8

| Oral Screening & Education for Head & Neck Cancer | Colon Cancer Awareness |
| Melanoma Screening & Education | Prostate Cancer Awareness |
| Tobacco Cessation | Facts and Myths of Cancer |
| Are you at a high risk for cancer | Understanding the role of your pharmacist |
| Healthy Lifestyles and Cancer Prevention | Locating Cancer Resources on the Internet |
| Breast Cancer Awareness | Survivorship and Sexuality after Cancer |
| Living with Advanced Disease | Financial & Legal Needs |
| What is Integrative Medicine? | Advanced Directives: It’s Never too Early to Talk |
| Understanding Blood Clots | Understanding the role of vitamins and supplements |

Partnering with the local academic institutions and community hospitals has been identified as an essential component of the success of this program. These programs have demonstrated the importance of having a consistent nurse navigator to enhance the communication and care experience, identify problems and delays in care, and to help patients develop the confidence and skills to manage their illness and treatments.

Lay Navigation Program Development  
STANDARD 3.1

In 2009, the UNC Cancer Network developed a model of lay navigation that integrates trained lay navigators with patients and caregivers to increase support and access to information. The Oncology Nursing Society defines a lay navigator as a trained nonprofessional or volunteer who provides individualized assistance to patients, families, and caregivers to help overcome healthcare system barriers and facilitate timely access to quality health and psychosocial care from pre-diagnosis through all phases of the cancer experience (Oncology Nursing Society [ONS], 2010b).

The lay navigation model of support was developed to work in tandem with the existing hospital volunteer program and members from the Patient & Family Advisory Committee. Lay navigators receive additional training to ensure they have the necessary skills for the development of their confidence and success when interacting with patients, caregivers and members of the health care team.
UNC Health Care is currently in the process of developing the Heels of Hope Lay Navigation Program to implement within their cancer clinics within the NC Cancer Hospital. A training manual has been developed to provide additional information on communication skills, providing emotional support, an awareness of cancer, prevention and risk factors as well as an overview of cancer support resources.

**UNC Comprehensive Cancer Support Program (CCSP)**

The vision of the UNC Comprehensive Cancer Support Program is to provide compassionate and effective care for all North Carolina cancer patients and their families.

The mission is to operate outstanding clinical and educational programs for cancer patients and their caregivers and a world-class training and research site for health care professionals who work with cancer patients.

CCSP is a multidisciplinary program dedicated to helping patients and their caregivers with cancer treatment, recovery and survivorship. The following programs are included:

- **Mental Health Services (in person and via telemedicine) *pilot program**
  Providing support and symptom management for the psychological challenges that may accompany a cancer diagnosis

- **Pastoral Care**
  The N.C. Cancer Hospital chaplain works with people of all faiths and religious backgrounds

- **Patient and Family Resource Center**

- **Pharmacy and Medication Consultation**
Located in the heart of the N.C. Cancer Hospital lobby, the center offers services to help address the challenges families face related to their medical treatment and life issues that surround the diagnosis of cancer.

**Cancer Genetics Counseling**
The Cancer Genetics Counseling Services provide consultations during which the family history of cancer is assessed, information about genetic testing is given and genetic testing facilitated when appropriate.

**Smoking Cessation**
Helping cancer patients and family members quit smoking and other tobacco use.

**Carolina Well**
Carolina Well started the UNC Lineberger Survivorship Program. It is the public name for the LIVESTRONG Center of Excellence in Cancer Survivorship Grant that UNC received 5 years ago.

**Single Fathers Due to Cancer Support Program**
The Single Fathers Due to Cancer program is dedicated to helping the thousands of fathers who each year lose their spouses to cancer and must adjust to being sole parents.

**Integrative Medicine**
A personalized solution to healing that focuses on the whole person.

**Supportive Care (Palliative Care Support Team)**
A team dedicated to care that improves the quality of life for cancer patients.

**Nutrition**
Individual nutrition counseling and other services from an oncology-certified registered dietitian.

**Survivorship Programs and Services**
Tools to help patients survive cancer with confidence, provided by Carolina Well, UNC Lineberger Cancer Survivorship Program.

**Risk Assessment & Genetic Counseling**

**STANDARD 2.3**
The UNC Cancer Genetics Program provides consultations for individuals who may be at an increased risk of developing cancer. The cancer genetics team is comprised of two board certified medical geneticists, several board certified genetic counselors, and faculty from the molecular diagnostic laboratory. This core team works with members of other multidisciplinary programs to provide fully integrated care for patients at UNC. All patients seen by this multidisciplinary team receive comprehensive risk assessment, counseling and testing services so that appropriate cancer preventative measures can be implemented when needed. This service is provided on-site or by referral.

**Palliative Care Services**

**STANDARD 2.4**
The UNC Palliative Care Program envisions a health care system that provides excellent palliative care for all patients and families in need. The Program, an interdisciplinary group of professionals, works collaboratively to promote the research, scholarship, and education necessary to achieve this goal. The
core activities include an inpatient palliative care consult service, an outpatient supportive care consult service, education and clinical training in palliative care, and research relevant to the practice of palliative care.

**Distress Screening at the NC Cancer Hospital**

**STANDARD 3.2**

The CoC requires the Cancer Committee to develop and implement a process to integrate and monitor on-site psychosocial distress screening and referral for the provision of psychosocial care. Screening for distress will become a required component of quality cancer care in 2015. Within the NC Cancer Hospital, routine psychosocial distress screening is not being used at this time. The convergence of the new electronic health record (EPIC) with Beacon Oncology lends itself to a new delivery system using patient reported outcomes to capture a variety of symptoms including distress/anxiety. We will meet the CoC standard by implementing a process to screen and make appropriate referrals for the provision of psychosocial care.

**Cancer Survivorship at the NC Cancer Hospital**

**STANDARD 3.3**

Survivorship care plans (SCP) are also becoming a required component of quality cancer care. Within the NC Cancer Hospital, however, SCP have not been routinely used in most cancer disease groups. The convergence of the new electronic health record (EPIC) with Beacon Oncology and the expectations of the CoC to implement this standard by 2015 lends itself to a systematic Lean-Six Sigma approach. Each disease and treatment modality group will have variations in applying processes for SCP, including identifying who will develop and deliver them and identifying when they will be delivered to the patient and primary care provider. We propose a healthcare quality improvement using Lean Six Sigma to establish and initiate the processes for developing and delivering the SCP to new adult oncology patients completing active treatment at NCCH during the coming 12 months. We will meet the CoC standard by implementing SCP which is a measure of quality cancer care.

**Survivorship Research**

Cancer survivorship is a high clinical and research priority both nationally and at the University of North Carolina. We are conducting a randomized pilot study testing the development, implementation and evaluation of a parallel patient and streamlined provider version of a personalized Survivorship Care Plan (SCP) with and without an additional structured coordinated care visit with the primary care provider for 60 cancer patients at Rex Cancer Center (D. Mayer, PI) funded by Health-e-NC. The aims of the study are to compare the change in confidence about future survivorship care needs between patients who receive a coordinated care visit with their PCP (intervention group) compared to those who do not have this visit (control group).

**Publications on Navigation, Distress Screening and Survivorship**


Hanson, LC, Green, MA, & Earp, JA Circles of care: Implementation and evaluation of support teams for african americans with cancer. Health Educ Behav retrieved from http://heb.sagepub.com/content/early/2013/12/10/1090198113512127


Kenyon, M., Mayer, DK. The Late and Long-Term Effects of Breast Cancer Treatment. *Journal of Obstetric, Gynecologic, & Neonatal Nursing (special supplement on breast cancer)*, in press.


Care Plans (SCP) for Colon Cancer Survivors In A Comprehensive Cancer Center. Oncology Nursing Forum, in press.


Nevidjon, B, Mayer, D. K. (2012). Death is not an option but how you die is. Nursing Economics$, 30, 148-152.

Oncology Nursing Society, the Association of Oncology Social Work, and the National Association of Social Workers Joint Position on the Role of Oncology Nursing and Oncology Social Work in Patient Navigation, 2010


**UNC Cancer Network’s Role in Advancing Statewide Patient Navigation, Distress Screening and Survivorship**

The UNC Cancer Network collaborates with other statewide partners to share expertise and proactively promote patient navigation, distress screening and survivorship processes. Quarterly video conference calls are held to identify solutions to system barriers.

Current patient navigation sites include:

<table>
<thead>
<tr>
<th>Appalachian Regional Health System Seby Jones Cancer Center</th>
<th>Boone, NC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carteret General Hospital Raab Cancer Clinic</td>
<td>Morehead City, NC</td>
</tr>
<tr>
<td>Mission Health System</td>
<td>Ashville, NC</td>
</tr>
<tr>
<td>UNC Rex Hospital</td>
<td>Raleigh, NC</td>
</tr>
<tr>
<td>UNC Pardee Health System</td>
<td>Hendersonville, NC</td>
</tr>
<tr>
<td>The Outer Banks Hospital</td>
<td>Nags Head, NC</td>
</tr>
<tr>
<td>Wilson Medical Center</td>
<td>Wilson, NC</td>
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</table>
North Carolina Oncology Navigators Association (NCONA)

UNC has been proactive in supporting the North Carolina Oncology Navigator Association. This is a membership group of approximately 300 patient navigators. Educational and networking opportunities for patient navigators throughout North Carolina have been ongoing since 2008. An up-to-date directory and resource directory is maintained to enable patient navigators, at all healthcare institutions, to have the ability to coordinate care for a patient, regardless of their place of residence.

Education & Training Conferences

- 2-1-2012  Patient Navigation Update: The State & Science of our Art
- 6-15-2012  Patient Navigation Training: Paving the way in Colon Care Screening
- 6-28-2013  Patient Navigation Training: The Art of Active Listening

NCONA partnerships include UNC Lineberger Comprehensive Cancer Center, The North Carolina Cancer Control Program, Duke Cancer Care and the American Cancer Society.

Annual UNC Lineberger Coping with Cancer Symposium
Kitty Hawk, NC

The UNC Lineberger Comprehensive Cancer Center, the UNC Comprehensive Cancer Support Program and the UNC Cancer Network recognize that addressing the needs of cancer patients has garnered significant national attention since the recent publication from the 2013 Institutes of Medicine’s Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis publication and the American College of Surgeon’s (ACoS) Commission on Cancer’s (CoC) Cancer Program Standards 2012: Ensuring Patient-Centered Care. These organizations are designed to help cancer programs improve their quality of care by focusing on patient-centered care initiatives.

This 1 and 1/2 day symposium provides the perspectives of professionals across the region, who are working to help programs meet the CoC, patient centered standards. Presenters share practical tips and strategies as well as pitfalls they have experienced during the development and implementation of their patient navigation, distress screening and survivorship programs. They also broadly discuss emerging treatment strategies for working with cancer survivors and caregivers to facilitate optimal psychosocial care. This symposium is relevant for a broad audience of cancer center administrators, physician-leaders, nurses, social workers and psychosocial-oncology professionals.

This program has been offered since the spring of 2009 in eastern North Carolina.

Annual UNC Conference on Melanoma
Chapel Hill, NC

“A Multidisciplinary Perspective” is a day-long educational conference designed for a multidisciplinary view of the care of the melanoma patient. The course faculty examine common clinical issues which confront the clinician and provide information that will help in their clinical decision making.
The conference is geared to Dermatologists, Medical Oncologists, Dermatologic Surgeons, Surgical Oncologists, General Surgeons, Plastic Surgeons, Physician Assistants, Nurse Practitioners and other health professionals interested in the treatment of melanoma.

UNC Cancer Network Telemedicine Program

Virtual Multidisciplinary Tumor Boards
The UNC Telemedicine Program extends the reach of UNC experts to 42 sites in more than twenty communities across the state. Affiliated physicians videoconference with a team of UNC experts from a wide variety of specialties who meet and discuss treatment plans for patients during weekly Multidisciplinary Oncology Tumor Boards.

The UNC Telemedicine Program received the Interactive Cancer Access Network Grant that allows rural communities to access educational content from the UNC Cancer Network. Angel Medical Center and Chatham Hospital were designated as rural by the USDA and were added to the network from this grant.

Telehealth Medical Lectures
The UNC Telemedicine Program provides bi-monthly telehealth continuing education lectures to physicians, nurses and allied health professionals across North Carolina through live, interactive medical and nursing lectures delivered by UNC faculty. This lecture series allows practitioners to access timely and evidence-based oncology therapeutic updates from the convenience of their own practice. These lectures inform learners about new developments in cancer diagnosis and treatment, which gives them tools to improve patient care and outcomes. The average number of medical professionals attending each virtual lecture in 2013 was 63 and participation ranged from 25-99 participants per lecture. These lectures, which also award continuing education credits, help oncology professional keep abreast of the latest treatments, clinical trials and wrap-around services available to North Carolina cancer patients.

Lunch and Learn Lectures for the Community
STANDARD 1.8
The Telemedicine Program also offers lectures to the public that are delivered through Telehealth technology to cancer centers across the State. Topics are selected based upon the cancer health disparities and needs identified. A variety of topics are presented such as the importance of understanding cancer prevention, healthy lifestyles, smoking cessation, signs and symptoms of melanoma, psychosocial support, medication management, survivorship and sexuality.

There is also an opportunity for local cancer centers to highlight their local support services and providers on the month that UNC does not broadcast.

The overall goal of our community outreach program is to reduce the burden of cancer in North Carolina through collaborative patient navigation partnerships and educational programs.
Health-E-NC Study Trains Leaders of Cancer Transitions Groups Across NC

In this two-phase, multi-site dissemination study, community group leaders across the state were trained and supervised via telemedicine (iPads) to offer Cancer Transitions: Moving Beyond Treatment at eight locations across NC.

Of the 72 participants who completed both pre and post measures, 63% reported a decrease in distress, 54% reported a decrease in depressive symptoms, and 70% agreed they had more control over their attitude if their cancer returns following the Cancer Transitions program. Almost all of the Cancer Transitions group participants interviewed characterized their Cancer Transitions group experience as extremely successful.

These findings suggest that training group leaders via telemedicine to facilitate the Cancer Transitions program is a feasible alternative to in-person training for geographically diverse participants.

FUTURE DIRECTIONS

UNC Lineberger Comprehensive Cancer Center is on the front lines of supporting and collaborating on programs designed to eliminate disparities in all cancers including breast, colon, and prostate cancer. The following facts have led us to look closer at the populations affected by lung and prostate cancer.

- CDC reports more people in the United States die from lung cancer than any other type of cancer. This is true for both men and women.
- African-American men have the highest incidence of prostate cancer in the US and are more than twice as likely as Caucasian men to die of the disease, according to the NCI.
- Access Barriers: Patients deal with significant challenges beyond coverage when encountering our health care system. Access barriers are associated with a high risk in cancer incidence and mortality among communities of color.
- There is a targeted need to reach the minority population in order to ensure their understanding of their risk and available resources to improve outcomes.
- There is a need to define the best measurable outcome at the onset of the implementation of distress screening and survivorship care plans. This will ensure the new standards are being appropriately implemented to help deliver appropriate quality care to cancer patients and survivors.

Disparities in Tobacco Use in NC

Smoking among adults

Epidemiological data show that smoking still affects many North Carolinian residents, particularly Blacks and Hispanics. The most recent estimate (2010) by the National Cancer Institute of the smoking rate among North Carolinians aged 18 and older is 20.9%, placing North Carolina thirty-eighth among all U.S. states but falling short of the 12% goal set by the U.S. Department of Health and Human Services “Healthy People 2010” prevention plan [4]. The 12% benchmark remains a current objective under the “Healthy People 2020” plan. Among adults aged 35+ years, over 12,300 died as a result of tobacco use
per year, on average, during 2000-2004. The represents a smoking-attributable mortality rate of 298.4/100,000. The range across states is 138.3/100,000 to 370.6/100,000. North Carolina’s smoking-attributable mortality rate ranks 38th among the states (SAMMEC). Caucasians have the most deaths resulting from lung cancer (55.9%). African American also have a high death rate due to lung cancer (54.1%).

**Smoking versus education**
Reports indicate that tobacco use increases as age and grade increases. Students in the 12th grade are nearly twice as likely to report use than students in the 9th grade (35.9% versus 18.2% in 2009). It is also reported that white students had the highest use among racial and ethic groups. (Healthy North Carolina 2020: A Better State of Health)

**Smoking versus income**
Smoking rates are highest among poorest Americans, as indicated by data from various studies that show a notable and consistent increase in smoking rates at each lowered level of income [6,7]. Data also indicate that while the percentage of smokers who make an attempt to quit only slightly increases with income, the percentage of quit attempts that are successful is notably higher among wealthier Americans.

**Percentage of Smokers Calling Quitline**

*Best Practices* estimates 8% of smokers could access quitlines each year. In North Carolina, 1.2% of current smokers who made a quit attempt in the past year called a quitline.

The Medicaid fee-for-service program in North Carolina provides full coverage for tobacco dependence treatment. North Carolina’s Medicaid policy provides coverage for both bupropion and varenicline. North Carolina’s Medicaid policy does not provide coverage for individual, group, or telephone counseling.

<table>
<thead>
<tr>
<th>Nicotine Replacement</th>
<th>Varencline</th>
<th>Bupropion</th>
<th>Counseling</th>
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<tbody>
<tr>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
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</table>

Source: MMWR 2009;58(43):1199-

**Statewide Collaboration**
As the state’s leading non-profit organization supporting lung cancer research and education, Lung Cancer Initiative of North Carolina specializes in connecting patients, survivors and loved ones with the medical and research community. Formerly the North Carolina Lung Cancer Partnership, our organization’s mission is to decrease deaths and provide support to those affected by lung cancer through research, awareness, education and access programs across North Carolina.
Disparities in Prostate Cancer Care in NC

Disparities

The burden of death due to prostate cancer is higher among African Americans than any other ethnic or racial group in the US. African Americans are less likely to receive recommended treatments.

In North Carolina, African Americans (56.5%) are dying from prostate cancer at a far higher rate than Caucasians (19.6%) or any other race, including Hispanics and Asians.

As reported by Chen, Carpenter, (2013), in NC there is under-treatment of elderly but healthy patients with high-risk prostate cancer which is the most aggressive form of this disease.

There is a need for education to reach this minority population in order to ensure their understanding of their risk factors and available resources to improve their outcome.

Statewide Collaboration

It will be critical to partner with national and statewide organizations including The Prostate Health Education Network, Inc., (PHEN) is a non-profit 501(c)3 organization. PHEN was founded in 2003 by Thomas A. Farrington, a prostate cancer survivor and author of the books, "Battling the Killer Within", and "Battling The Killer Within And Winning". PHEN is governed by a board of directors, and works with advisory boards, sponsors, partners and volunteers to implement its programs and initiatives.

In North Carolina PHEN is interested in highlighting the works of local prostate cancer survivors and organizations that are focusing on education, awareness, outreach and support targeting Black men

http://www.prostatehealthed.org/OpenCity.php?CityID=33

CONCLUSIONS

As an NCI-designated comprehensive cancer center, UNC Lineberger Comprehensive Cancer Center is already leading the state in research, technology and patient care. We will continue to ensure that our programs are developed to improve cancer prevention, treatment and improved outcomes for our community and the entire state by looking at the following:

1. Cancer Burden: There is a disproportionately greater cancer incidence and mortality in our lung cancer and prostate cancer population, specifically among diverse racial and ethnic populations.
2. Access Barriers: Patients deal with significant challenges beyond coverage when encountering our health care systems. Examples include cost barriers (i.e. co-pays) and lack of trust, transportation and health care literacy. Access barriers are associated with a higher risk in cancer incidence and mortality among communities of color. Program development needs to ensure that these barriers are addressed. Ongoing evaluation is critical in order to redefine
patient navigation to improve care in populations traditionally facing barriers to access or quality care.

3. Defining the best measureable outcomes at the onset of the implementation of the patient navigation, distress screening and survivorship care plans. This will ensure that the new standards are being appropriately implemented to help deliver appropriate quality care to cancer patients and survivors.

4. Ensuring that patients are involved in their treatment plans and that issues arising during and after treatment are addressed quickly.

North Carolina is a state rich in health care resources but many populations struggle with health-related disparities. UNC Lineberger Comprehensive Cancer Center continues to develop a strong and coordinated focus on cancer research, quality cancer care and how it can impact local communities. This allows the expansion of clinical and educational support in regions hundreds of miles away from the Chapel Hill campus. Partnerships will also allow an improvement to access to care and help communities connect with the health care resources they need, provided by the hospitals and doctors they trust.