

Prostate Cancer Coalition of North Carolina, Inc.

Needs Analysis

Together, we will reduce the death rate from prostate cancer!

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2008



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Executive Summary

Prostate cancer is common. It is broadly stated that, “if you are a man, and live long enough, you will develop some form of prostate cancer.” 100% of prostate cancers can be effectively treated with early detection.¹ Currently, North Carolina ranks 38th in the nation for prostate cancer incidence and 8th in the nation for deaths.² Our relatively low incidence, coupled with a high death rate, indicate serious gaps in public awareness, early diagnosis, and access to information, treatment, and care for men.

Much has been learned over the past decade about both the importance of early detection and methods of refining the use of prostate screening to promote the early detection of prostate cancer as well as other benign conditions.^{3,4,5,6} The efficient communication of these advances, their benefit to the general population, and application in primary care settings, is a much needed, but missing, critical first step necessary for reducing the death rate from prostate cancer.^{7,8,9,10}

While prostate cancer is the second leading cancer killer of men in the United States,² the disease has broadly varying diagnostic implications. Some studies indicate that many men diagnosed with prostate cancer may be best served with less aggressive treatment. The importance of patient education must be emphasized. A thorough and expedient understanding of diagnosis and multidisciplinary communication must occur prior to decision making.^{9,10,11} Additionally, many men and their families are including complimentary integrative approaches to their treatment and need access to information about the risks and benefits of these treatments in order to make informed choices.¹²

The recommendations proposed by the Prostate Cancer Coalition of North Carolina in this report encompass widespread awareness of advances and refinements in the application of current gold standard guidelines for screening and diagnosis; strategies for risk reduction; and “best practices” patient care and support that encourages enhanced pre-treatment education and patient involvement.



The following Needs Analysis provides further support and direction gleaned from the input of patients, clinicians, researchers, screening organizers, caregivers, and public health activists.

Introduction

The Prostate Cancer Coalition of North Carolina, Inc. (hereafter PCCNC) is a 501(c)3 non-profit organization. The PCCNC consists of a diverse multidisciplinary network of groups and individuals spanning the state of North Carolina, each working to reduce the death rate from prostate cancer while improving the quality and quantity of life for patients and survivors.

During its seven-year history, the PCCNC has developed a broad network of stakeholder groups and individual leaders, each with a unique understanding of the impact of prostate cancer on North Carolinians. By conducting a series of interviews the PCCNC has further refined an understanding of the issues around prostate cancer and the recommendations for change brought forward by community leaders. The purpose of this process was to build a framework for a comprehensive approach to effectively and efficiently address disease related issues in a way that fosters greater collaboration and propels us collectively towards realistic solutions that serve the public interest of the citizens of our state.

Participants

Interview participants include researchers, clinicians and medical professionals from some of North Carolina's leading facilities specializing in prostate cancer treatment, care, support and research: Cancer Centers of NC; Carolinas Medical Center; Duke Prostate Center; the Leo Jenkins Cancer Center; Novant Health; Rex Healthcare; UNC-Chapel Hill Urology; Wake Forest University Baptist Medical Center; and others. Facilitators from thirty prostate cancer patient support groups, and long-time organizers of successful prostate screening events, also participated.

In addition, representatives from PCA Racing; the Ronnie Sox Memorial Driver Safety Campaign; the North Carolina Minority Prostate Cancer Awareness Action Team; the EMPOWER Ministry; Men for Living; the NC Grand Chapter Order of the Eastern Stars; 100 Black Men Triangle East Chapter; 100 Black Men Greenville Chapter; the NC Coalition of the



National Black Leadership Initiative on Cancer; the Lumbee Tribe; Alliance Health Ministry; implementers of the UsToo Minority and Underserved Populations Outreach and Awareness program; and the American Cancer Society (ACS) also provided valuable insights.

Every participant provided valuable perspective on challenges related to promoting awareness, access to screening, continuum of care past the point of abnormal screening, and issues around decision making information and care.

We asked survey participants to tell us what is working well in prostate cancer messages, services and programs in North Carolina, what doesn't work, what the PCCNC is doing well and what we could do better, what should we keep doing. We asked participants to tell us what we, the PCCNC, should be collectively doing, as a coalition, to create a framework to function more effectively as a coalition, united in our dedication to significantly reduce suffering and death from prostate cancer in North Carolina within the next five years.

The following outlines the key themes that emerged from the PCCNC Needs Analysis interviews.

Gap Analysis

"Single aspect shotgun approaches just don't work." In order to effectively address the issue of prostate cancer, we must project a unified, integrated, multidisciplinary message that projects collectively the very best of what is known.

Public Health Message

There is no broadly communicated public health message that projects current evidence-based information about prostate cancer awareness, early detection, and the importance of informed decision making in regard to treatment selection. Inconsistent, unclear messaging causes confusion and encourages inaction.

For many, lack of awareness is as simple as understanding personal anatomy. New evidence is constantly emerging around strategies for risk reduction and the importance of annual physicals and health screenings that can promote early detection. However, this information is not systematically, broadly, and cohesively communicated. Older and less effective screening



guidelines and information about treatment options are often circulated as ‘best practices.’ These may lead to an unnecessarily high death rate and a long-term reduction in quality of life for men with prostate cancer.

Common Misperceptions

Prostate screening is often mistakenly referred to as a diagnostic tool for prostate cancer. *It is not.* Screening is an indicator of prostate health and can be used to identify several benign, potentially uncomfortable, but treatable, conditions - in addition to facilitating the early detection of prostate cancer. Some of these non-cancerous conditions are thought to be possible precursors to prostate cancer, indicating that having these conditions treated in a timely and effective manner may actually prevent some forms of prostate cancer. The scenario of follow-up avoidance fuelled by a lack of understanding about abnormal screening results is not uncommon.

Many are under the mistaken impression that the Prostate Specific Antigen (PSA) blood test replaces the Digital Rectal Exam (DRE). This is untrue. *Both* tests facilitate the early detection of some prostate cancers (along with other benign treatable conditions). Both tests, undertaken in conjunction with one another, constitute a full prostate screening.

The Role of the Primary Care Physician (Family Care, General Practitioners, and Internists)

With the introduction of products such as Viagra™ and FloMax™, there is concern that some prostate health issues in general may not be addressed. These medications can both alleviate and mask symptoms that are telling symptoms of prostate health issues, including cancer, such as difficulty with achieving or maintaining an erection or trouble passing urine.

The importance of working with medical professionals to explore the possible root cause of symptoms that may indicate prostate cancer or another prostate health condition such as infection or inflammation cannot be understated. To the credit of the producers of these products, they both encourage men to explore the possibility of prostate cancer. However, there remains concern in the medical community that such exploration may not be broadly requested by patients, or applied by physicians, in a clinical setting.



The “screening controversy” has fueled frontline complacency for years. It is broadly recognized by medical professionals specializing in the care and treatment of prostate cancer patients that prior to the clinical application of prostate screening as a method to promote the early detection of prostate cancer, “*nearly three out of four men diagnosed with prostate cancer had advanced, aggressive, late stage disease that is difficult to treat and potentially fatal.*” The application of prostate screening, in particular the use of the PSA blood test in conjunction with the DRE, has inverted that statistic.

This controversy, coupled with concerns about overly aggressive diagnostic testing or treatment after referral, have left some of our state’s busiest medical professionals (primary care physicians and medical professionals) overwhelmed in their pivotal role as gatekeepers for early detection and diagnosis. Ongoing access to consistent, up-to-date, reliable information that promotes long-term prostate health is greatly needed.

The introduction of new ED therapies that require physician prescription presents an important and unmet opportunity for dialogue between men and their primary care physicians about prostate cancer early detection. It is recommended that the PCCNC explore existing social marketing campaigns linked to marketing of ED medications and prostate cancer discussions between men and healthcare providers for potential application in North Carolina.

Laboratory Reporting

Some additional challenges can come into play even for those primary care medical professionals striving to adopt up-to-date prostate screening guidelines in regard to lab reports. Some labs do not display the actual PSA number on their reports, and some still qualify the outdated guideline of a PSA value less than 4.0 mg/mL as normal.

Follow-up Care

North Carolina insurance statutes require that “all insurers provide coverage for prostate-specific antigen (PSA) tests or equivalent tests) for the presence of prostate cancer when recommended by a physician.” There are at least 50 low and no cost community screening events held throughout the state of North Carolina, usually during the month of September (prostate cancer



awareness month). However, biopsy services available to uninsured men who receive a worrying result from such screening remain limited.

Inconclusive biopsy results can create unnecessary financial burden, discomfort and minimally useful diagnostic results. Most urologists specializing in the treatment and care of prostate cancer patients defer to the American Urological Association (AUA) for guidance on current standards of care in regard to performing a prostate biopsy. The AUA protocol facilitates more detailed information from the biopsy that can be used to better guide treatment choices.

However, some insurance providers refuse to cover the additional cost associated with this enhanced protocol.

Patient Education and Decision Making Support

Accounts of men having unnecessary aggressive procedures permeate the patient community and survivor circles. Even more so, stories of men waiting too long for one reason or another before making the decision to take aggressive action to treat their now fatal, but at one time potentially curable, disease are all too common. The importance of pre-treatment education cannot be understated.

Access to information that facilitates understanding of diagnosis and which in turn helps care teams match treatment choice to individual prognosis and priorities *before treatment takes place* is severely lacking in many parts of the state. Widely available information on strategies for management of prostate cancer as a chronic condition, along with information and understanding about the possibility of disease recurrence also is not broadly in place, and it has to be if early detection is to translate into long-term quality and quantity of life for patients and survivors.

North Carolina has at least 30 active prostate cancer support groups throughout the state. But only about 4% of men diagnosed with prostate cancer are leveraging this powerful resource. Awareness of these groups as invaluable education and information resources should be broadly communicated and group participation should be encouraged and supported by the medical community. This is happening in some areas, but not all. Additionally, introverted and reserved men who are more prone to isolation during times of crisis typically do not have access to, or knowledge of, supportive mechanisms that allow for optimal decision making.



Special Needs of African American population in North Carolina

Rates of prostate cancer in the U.S. are **60% higher among African American men**, and the mortality rate is **2.45 times** that of white men. Studies are being done on potential differences in physiology, diet, and access to health care.

Input Summary

Almost **100%** of men diagnosed with prostate cancer are **still alive in 5 years.**²

Over 90% of prostate cancer cases are found while the cancer is still either **local or regional**, and nearly **100%** of these men are still alive 5 years after being diagnosed.

In cases where the cancer has spread to distant parts of the body, **34% survive** 5 years.

After 10 years, about **97.9%** of men diagnosed with early stage prostate cancer are still alive,² but only **17.6%** of those diagnosed with advanced stage prostate cancer survive 10 years.²

The issues put forward as the potential positive and negative health impacts embodied in the screening versus risks debate (the “screening controversy”) are hinged closely to the broad variation in which prostate cancer develops. According to the American Urological Association (AUA), autopsy studies have shown that *“approximately one in three men over the age of 50 years has histologic evidence of prostate cancer, with up to 80% of these tumors being microscopic in size or clinically insignificant.”*

It is the goal of the PCCNC to insure that all men who are screened have access to the best clinical knowledge and practice to promote earliest possible detection of prostate cancer, and upon diagnosis, project the importance of -and facilitate timely access to- information that will allow him to understand his cancer, know his options for managing it, and the benefits and risks of each choice appropriate to his situation.



What PCCNC can do:

PCCNC Annual Prostate Screening Guidelines

Specializing physicians broadly agree that the optimal clinical application of prostate screening to promote the early detection of prostate cancer is captured in the *National Comprehensive Cancer Network (NCCN) guidelines for early detection*, with some allowance made for applying the *American Urological Association (AUA) Best Practice Policy* which provides additional guidance on age and race adjustments.

In response to this, the PCCNC developed an initiative to produce a concise, one page laminated document that outlines referral prompts and important patient-specific risk considerations including family history; age; race; weight; and presence of other conditions as specified in the most recent versions of the *National Comprehensive Cancer Network (NCCN) Guidelines for Early Detection* and the *American Urological Association (AUA) Best Practice Policy*. Prior to publication and distribution, these PCCNC guidelines are reviewed by, and receive support from, key North Carolina Urologists specializing in the treatment of prostate cancer.

The first set of these guidelines were distributed in 2005 at the North Carolina Academy of Family Physicians annual conference and during the North Carolina Community Health Centers Associations quarterly board meeting. The second updated publication was distributed as a laminated insert via NCF, the official journal of the North Carolina Academy of Family Physicians. The NCF's distribution includes every family care physician in North Carolina, thus ensuring that every practicing family care M.D. in the state has access to these guidelines.

Feedback consistently and strongly supports the importance of the publication, distribution, and broad-based adoption of these guidelines as critical to the success of everyone involved and committed to reducing prostate cancer death in NC. Despite annual doctor visits, men are all too often referred by their primary care physician to a urologist only after his cancer has advanced to the point where it can no longer be effectively treated or well managed.



There may be opportunities to broaden the distribution of guidelines and increase awareness of the ongoing availability of men to download these guidelines from the PCCNC website with recommendations about the questions they can ask their doctors to start the dialogue about PSA.

Support & Promotion of Community Prostate Screening Events

Another valuable resource identified through the interviews is the Prostate Cancer Education Council (PCEC). PCEC is one of the oldest and most successfully coordinated national screening initiatives. Affiliated sites are associated with a network of doctors, screening coordinators and health centers across the nation, all of whom support the importance of prostate screening. The PCEC has recently reached an informal agreement to assume the ongoing tracking of NC community prostate screening events; once an official Memorandum of Understanding (MOU) between PCEC and PCCNC is in place, we can divert our attention to promoting awareness of these events in collaboration with local activists and media sources.

Input Recommendations

Core Public Awareness Message & Broadcast Support

A broad-based social marketing message throughout the state that fosters increased awareness; delivers a consistent evidence-based message about early detection and care; supports the development of local and regional collaboration to battle prostate cancer; and encourages enhanced patient involvement, multidisciplinary approaches to treatment, and an integrative approach to management and care is greatly needed.

Today, even the softest guidance from conservative health organizations suggest informed or shared decision making when it comes to prostate screening. Both patients and medical professionals sharing in these decisions must have easy access to the current best thinking and guidelines for standard of care, especially as it pertains to screening, so that they can make good decisions and apply those decisions in the most beneficial way.

Individuals and organizations who passionately promote public awareness of prostate cancer can be found in every corner of the state. Among these groups, it is broadly recognized that men's health is a hard sell. Several reasons for this are typically cited, most of which pertain to issues around male socialization.



The traditional male role in the family makes it difficult for many to become personally involved with advocating for themselves. This likely explains the contradiction inherent in there being more male breast cancer advocates than male prostate cancer advocates. Men are less likely to be open in regard to concerns about physical function, finances, or to openly share painful and potentially embarrassing experiences. These psychological factors all present particular challenges for both recruiting volunteers and being able to talk effectively to others- particularly those at the greatest risk of developing the disease- about the importance of prostate cancer awareness.

There is a strong need for innovative approaches to outreach that incorporate psychological strategies *that appeal to the male psyche in general*. Men should be made broadly aware of the need to be informed consumers in regard to medical services, and to evaluate healthcare in the same way they would research and evaluate any major choice. Personal health is certainly as important as buying a car or a computer. There must be ingrained a sense of personal empowerment to insure they are receiving quality, thorough examinations that allow for the earliest possible detection of potentially damaging health issues.

This awareness methodology should project forward helping men understand the importance of being equally informed in their thinking about treatment should they find themselves in a position of diagnosis.

It is clear that the power behind the message comes from the passion of the person delivering it. Our message should provide a core that allows enough flexibility to allow for the incorporation of personal style and detail, and be additionally supported and punctuated via broad-based, state-wide media support.

Improving Access to Screening and Continuum of Care

Some clinics offer low or no cost screening to high risk men, such as the Cabarrus Health Alliance's "Prostate Outreach Program for Screening (POPS)". "POPS offers free prostate screening throughout the year to all men 40+ during Saturday morning clinics and various weekday afternoons. POPS also provides biopsy services and works with uninsured men to find avenues for treatment. Similar models exist in Craven County (via the Craven County Health



Department), Wake County (via the Rex Senior Health Center), and through partnerships formed between some of our state's leading cancer treatment centers and urology practices. This kind of model must be encouraged throughout the state's diverse and often underserved regions.

Pushing for Better Communication of Prostate Screening Results

A valuable piece of information obtained through a component of annual screening is the rate of change in the PSA level from year to year. Laboratory facilities that clearly communicate these changes should be broadly commended. Based on NCCN prostate screening guidelines, men with an average annual PSA value of ≤ 2.5 ng/mL, should be referred to a urologist if they have a PSA velocity (absolute numeric change over a period of 12 months) of >0.35 ng/mL/y. All other men should be referred to a urologist if their PSA velocity is >0.75 ng/mL/y.

In addition to encouraging access to these additional details from the labs, patients who opt for annual prostate screening should also be encouraged to keep personal health records and track their own PSA velocity. Several activists have developed Prostate Screening Trackers to record PSA values and DRE results: these tracking tools should be widely disseminated.

Improving Additional Cross-Disciplinary Communication

The biopsy- the only current means of diagnosing prostate cancer- can be relatively invasive and costly to many. It a procedure that should be explored when there is a sense of urgency in regard to diagnosis, or after the possibility of other benign treatable conditions has been ruled out. Concern exists in the primary care setting about unnecessary invasive procedures. There is a need to foster greater cross-disciplinary communication between general practitioners and specialists, creating avenues for confident referral throughout the state.

Mechanisms must be in place to assure referring physicians that their patients will receive thoughtful evaluation of *all* possible prostate conditions prior to the undertaking of invasive procedures.

Patient education cards, or "referral kits" detailing what screening results actually mean, not limited to prostate cancer, to be distributed during community screening events and provided to patients upon urologic referral would provide confidence to referring physicians (and community



prostate screening organizers). These cards would include information for patients who may need to undergo a biopsy and a primer for newly diagnosed men stressing that there is a lot to consider.

Tissue samples obtained during a biopsy can be used to gauge the aggressiveness of cancer and guide treatment decision. Urologists who both obtain and package these results in a way that facilitates the most informative diagnostic reports should also be commended.

Broad-based Emphasis on the Importance of Understanding Diagnosis

Prostate cancer is a complicated disease. It can manifest itself in many ways, some aggressive. Thorough understandings of diagnosis, and second (and sometimes third and fourth) opinions, are highly warranted. Cross-disciplinary consultation is necessary, and multidisciplinary care is often beneficial. The value of an integrative approach to treatment is particularly powerful for prostate cancer patients and survivors.

Diagnosing cancer in time to treat it effectively is crucial. Just as important as finding cancer early is an understanding what kind of cancer you have. This is essential for selecting effective treatment options that allow for optimal quality and quantity of life. Some prostate cancers are very slow-growing and never need treatment; others are much faster growing and may progress rapidly. Some men can afford to "watch and wait" while others may require urgent attention and treatment in order for survival.

Regardless of stage at diagnosis, studies repeatedly demonstrate the advantages of active participation in treatment decision. Active participation increases satisfaction with the process and in relationships with others involved in that process; improves ability to cope with the stress of diagnosis and the disease itself; enhances ability to cope during the treatment and recovery process; and eases communication of disease-related information with family members.

Patient Communication, Training, Education, & Support

Some men may be more likely to understand and respond to strongly worded messages such as those which emphasize that, when it comes to prostate cancer, they have been invaded by a "potentially hostile enemy." Depending upon the strength of this enemy, there may be a



possibility of long-term diplomatic management (Watchful Waiting/ Vigilant Surveillance) or a more aggressive approach may be warranted (surgery or radiation). A variety of key messages, styles and approaches will help address diverse learning styles, language barriers and cultural differences, especially targeting higher-risk African American men and their families.

Support Groups

North Carolina has at least 30 active support groups throughout the state. Most groups are hospital hosted and affiliated, with a few hosted out of churches and community health centers. About 1/3rd of these groups are affiliated with American Cancer Society (ACS)'s Man to Man, and at least half are affiliated with UsToo International. UsToo resources are very well respected and are a valuable resource for affiliated groups.

These groups have the potential to provide considerable information to the many men throughout the state of NC who will be diagnosed with prostate cancer. The men who facilitate and frequently attend these meetings become extremely informed about virtually every aspect of treatment and care.

Peer to Peer Navigation

Because of the often overwhelming complexity associated with decision-making, management, and care, many patients accumulate a deep and thorough understanding of many highly technical issues, while others have limited or no access to such knowledge which is essential to their survival and/ or quality of life.

Given scarce resources, one important and innovative opportunity for insuring that information regarding care and disease management are accessible and applied by men and families who will benefit from them is to develop a peer to peer patient navigator program. Such a program will allow patients, caregivers, and healthcare professionals with a desire to contribute to the cause the opportunity to apply personal knowledge and expertise developed through experiences with prostate cancer, to helping others.

Existing program models have been developed and implemented in other areas, and PCCNC can accelerate the introduction of a state-wide pilot program.¹²



This curriculum could be modified developed in partnership with UsToo International and or other credible national partners. The PCCNC patient navigator curriculum should provide a clear curriculum for understanding diagnosis; annual updates on the broad spectrum of options; detailed advice to men on preparing for and managing side-effects; tools for evaluating healthcare services and developing your care team; methods for simplifying the message (by remembering what life was like before you became an expert on prostate cancer!!) and how to empathize with men still coping with the shock of diagnosis.

PCCNC would need the support and involvement of regional cancer centers. These critical locations would ideally provide "hotlines" and regionally hosted "navigator hubs." Such a program would necessarily require annual certification along with some levels of committed sponsorship to insure ongoing quality control.

Based on survey input, PCCNC should consider a database of trained volunteer navigators that would indicate their relative expertise in regard to issues specific to the disease. This "*should be outside of HIPAA,*" - as our program will not be limited to survivors: caregivers (male or female), patient counselors and other medical professionals would all have the opportunity to act as volunteer navigators.

Goals and Objectives

- Achieve broad-based organizational consensus in regard to key messages from the PCCNC regarding age, protocol, purpose, frequency, and interpretation of prostate screening.
- Project a clear broadcast message throughout the state that enforces and punctuates this message.
- Improve generalist compliance with current gold standard clinical application of screening and diagnosis.
- Create regional collaborations that enhance and assure patient education resources for newly diagnosed men, patients working to prevent recurrence, and survivors working to manage advanced disease.
- Facilitate the creation of strong community networks that effectively address prostate cancer on a local level.



Short-term Goals

- Set specific targets for increasing participation in prostate cancer screening programs, measuring compliance with standards and guidelines for treatment, increasing rates of early diagnosis.
- Leverage our network to communicate a broad based message that consistently reflects awareness of current gold standard care for prostate cancer risk reduction and early detection by developing a core message audio/ visual campaign, customized with personal stories of North Carolina activists willing to be spokespersons.
- Insure that NC Primary Care Physicians have convenient access to accurate and reliable resources that capture the current clinical gold standard as defined by leading specialists in prostate cancer treatment and care.
- Enhance participation and tracking of NC prostate screening events and further coordinate the promotion of these events during the month of September (prostate cancer awareness month).
- Work with local cancer centers to create a peer-to-peer navigator program that will allow broader informed consultation with lay health experts throughout the state.
- Ongoing website maintenance and support, and production of a statewide newsletter that would capture prostate cancer clinical trials recruiting in NC, “gold nuggets” from support group leaders, known screening and outreach events, reiteration of our core message, and recognition of local heroes.

Intermediary Goals

- Form active collaborations with state employers to implement stronger employee health programs and policies, ‘lunch and learns’, on-site screening opportunities, health fairs, etc.
- Form strong partnerships and alliances with colon cancer, breast cancer and heart disease activists that share our commitment to risk reduction and early detection.
- Collaborate with laboratory companies to reflect advances in the use of velocity as an indicator of prostate health issues.
- Support the NC Comprehensive Cancer Programs effort towards a comprehensive survivorship plan for all NC Cancer Patients.



Long-term Goals

Based on outcomes from the Tyrolean study¹¹ and the research of Charles “Snuffy” Myers¹³, with awareness and access to “best practices” early detection and care, we can significantly reduce the death rate from prostate cancer by as much as 50% within 5 years.

- The state of North Carolina must be a leader in the prevention, diagnosis, treatment and care of prostate cancer.
- The physicians in North Carolina must be well informed regarding all the issues associated with the diagnosis, treatment and care of prostate cancer.
- The major medical institutions in North Carolina collaborate to provide leading edge research and the best possible care for those affected by this disease. World-class diagnostic and treatment facilities, equipment and services must be available to the men of North Carolina.
- The prostate cancer patient in North Carolina should be a well-informed patient.
- The citizens of North Carolina must be aware of the threat of prostate cancer and their best course of action to protect themselves or their loved ones.
- The citizens of North Carolina should be aware of the health and dietary choices that will reduce their risk of prostate cancer.
- Screening and care resources must be readily available to all of our citizens.
- There should be support groups easily accessible to all of our citizens.
- There should be knowledgeable survivors and spouses available for prostate cancer consultation with men or their families.
- The death rates from prostate cancer in North Carolina should be among the lowest in the Nation for every ethnic and social group.



Board Representation

CURRENT

Breast Cancer Advocate: to help us apply the decades of expertise around breast cancer as an issue.

Media Expert: to help us understand and leverage the power of mass media in building and supporting our message.

Primary Care MD: to help us understand the challenges and hurdles associated with communicating disease specific information to General Practitioners.

Survivor/ Rural Community Leader: to help us effectively communicate and understand the issues surrounding the men in our state who are at the greatest risk of developing prostate cancer, and who have the greatest set of challenges around managing their disease.

NEW

Lawyer: to insure that we are in compliance with the laws set forth by the Secretary of State for the management of 501(c)3 non-profits.

Accountant: to assist in the management of recordkeeping, bookkeeping, annual filings, bank deposits, and other financial compliance issues relating to the management of 501(c)3 non-profits.

Financial Advisor: to assist in financial planning for possible patient assistance funds, research, and other potential programs (planned giving, etc.).

Fundraising Expert: for assistance in event organization, planning and management which serves a dual purpose of promoting awareness and raising funds/ insuring the continuance of specific programs

Medical Oncologist: to lend inside expertise to the business of cancer and to insure that the PCCNC continues its role as a uniting force for all of those concerned about the human (versus the financial and political aspects of cancer).

Academic Urologist: to bring balance to our thinking in regard to prostate cancer as a Urologic disease.



Budget

Statewide radio and television broadcast awareness campaign: \$25,000

- Production
- Air Space

PR for Community Screening Events: \$5,000

- Ad Space

Screening Guidelines: \$7,500

- Production
- Distribution

Seed money for peer to peer navigator program: \$25,000

- DVD production
- Other support group facilitator requested patient education tools and resources

Annual statewide meeting: \$5,000

Quarterly (email and snail mail) state awareness highlighting local initiatives and statewide calls to action: \$5,000

Stipend for periodic regional meetings: \$1,000 (5@\$200)

TOTAL: \$73,500

Committees

- Community Awareness Application Committee
- Community Screening Promotion Committee
- Laboratory & Best Practices Biopsy Award Committee
- Patient Navigator Committee
- Communications (newsletter & web)
- Fundraising (grant writing and special events)
- More?

Possible Funding Sources

NIH Grant (Community Outreach Application)

Lance Armstrong Foundation Grant (Peer to Peer Patient Navigator Program)



Special Events (golf tournaments, car and bike shows, black tie events, etc.)

Conclusion

Communities must bond together to protect those of us who are most vulnerable- the disenfranchised, underserved and uninsured. By doing all we can to support facilities providing screening and care resources, we insure these services remain and continue to become more available and accessible. Working together to leverage scarce resources, we can create a truly informed patient community, and insure that the men identified during these screenings have access to consultation, support, and follow-up care necessary to effectively manage their abnormal screening results.

If we work together, each doing what we can, the death rate from prostate cancer in North Carolina will be among the lowest in the Nation for every ethnic and social group.



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Appendices

Appendix A: Interview Quotes

Appendix B: PCCNC Mission

Appendix C: PCCNC Vision

Available online at www.pccnc.org

- Public Awareness Programs & Events
- PCCNC 2007 Screening Guidelines
- National Comprehensive Cancer Network (NCCN) guidelines for early detection (reference pages 6-8)
- Prostate Cancer Education Council (PCEC) prostate screening event resources
- NC Community Prostate Screening Hosts
- NC Prostate Cancer Patient Support Groups
- Patient Resources
- NC Prostate Cancer Clinical Trials

Click on Report Appendices under “What’s New”



Appendix A: Interview Quotes

What Works?

“For real sustainable change, we need to apply a multifaceted approach.”

“Direct and edgy approaches are most effective.”

What Doesn’t Work?

“Single aspect shotgun approaches just don’t work.”

“Approaches that stifle creativity don’t work.”

“Feminine approaches do not work when reaching men. However, reaching women IS very important.”

What Should We Keep Doing?

“We need to keep growing our commitment to education and awareness.”

“From beginning to end, our (the PCCNC) job is education and awareness.”

“Emphasis, of course, needs to continue to be put on the fact that getting diagnosed early is to your long-term benefit.”

“There are still GPs that don’t think that prostate cancer kills people.”

“If I hadn’t attended a health fair at my church, I would not have become aware that my Doctor was using out of date guidelines and had failed to recognize that given my age and race, my PSA was high. My biopsy showed that I had prostate cancer that almost surely would have been fatal if I waited.”

“Reaching general practitioners can be a hurdle – late referral to the Urologist is the problem... our focus should be here...”

“Before the introduction of the PSA blood test in conjunction with the DRE, nearly three out of four men diagnosed with prostate cancer had advanced, aggressive, late stage disease that is



difficult to treat and potentially fatal. This advance in screening to promote the early detection of prostate cancer has inverted that statistic.”

“the PCCNC screening guidelines are a great tool – just right for promoting best practices prostate screening... maybe we can develop a complimentary piece for patients with a PSA velocity tracker... we should also target companies and organizations who are doing screenings to push the application of the PCCNC screening guidelines.”

“We need to promote awareness with the Doctors more... encourage them to push good information into practice as it emerges. Push for use of the better guidelines.”

“We need those parameters in regard to screening... consistent access to reliable, up to date guidelines.”

*“The PCCNC screening guidelines had a huge impact on getting the primary care physicians locally to acknowledge that screening needs to be promoted. This broke down some major barriers – we would not have been able to move as far as we have in partnership with primary care Drs. without them **DO THIS MORE!!! THIS DROVE SERIOUS CHANGE... THE MORE OF THIS WE CAN DO THE BETTER...** the Urology endorsement is so powerful... getting those broadly adopted... Don’t underestimate the power of that piece and please create more pieces like that.”*

“We are starting to see more and more men referred based on velocity or who were screened early due to race or family history.” Since first publication, the PCCNC Screening Guidelines stress the importance of velocity, risk factors, and age and race adjusting.

“We are seeing more and more early diagnosed men (at our support group).”

“Continue to track and promote community screenings.”

“We should be helping the medical community build data to support better treatment.”



What Should We Be Doing As a Coalition?

“Men’s health resources are scarce. This might not change any time soon, and it certainly won’t if we don’t all make a concerted effort to advocate for it.”

“As a community we must bond together to do what we can to support these initiatives that are proactive approaches to health.”

“If we all do what we can, we can make it happen.”

Communicating a core evidence based message

“As a coalition, we need a consistent evidence based message that we can customize... the PCCNC should be a clearing house for that kind of information.”

“There are a lot of mixed, and usually outdated, messages out there in regard to what age to get screened and understanding screening results ... this is very confusing to people... often when people are confused about what to do, they end up doing nothing...”

“Our message should clearly communicate the current best thinking around the most beneficial application of prostate screening.”

“We all need to use a consistent message to break down barriers as we continue to reach out to areas where we've had little contact.”

“Men need to know the facts they need to know to take good care of themselves”

“Help people feel empowered, to assert themselves with their Doctors, while showing respect to local professionals and showing humility.”

“Insist on solutions that identify reasons for pain and discomfort – find the disease – don’t just treat the symptom.”

Addressing Concerns about Common Misconceptions

“The problem we run into with screening opponents is that the tests are not specific to cancer. We need to facilitate a broader understanding that prostate, not prostate cancer, screening is about overall prostate health, not just finding cancer.”



“I thought the PSA replaced the DRE.”

“So many men are more concerned about their ability to function than health. They’ll push their doctors to mask the obvious signs of prostate trouble like ED and incontinence now that those products are widely available. I hope GPs can convey the importance of ruling out cancer and other conditions that could benefit from treatment before prescribing medications that can mask tell tale side-effects.”

Showing respect for our differences and letting “men be men”

“Some past approaches have applied strategies that work well for reaching women. We need to better understand and respect and even leverage the differences between men and women.”

“Women should be encouraged to remind their husbands to screen for themselves and their families.”

“Men think they are there to provide and protect and they don’t want to lose their role as provider and protector – let men continue to be providers and protectors by increasing their understanding that by taking care of themselves / managing their disease – they are providing and protecting.”

“Men are prideful and independent and socialized differently”

“When men understand what they need to do, they do step up to the plate.”

“Men are going to be men... a core message from MDs would be powerful.”

“Many African-American men think that having the disease makes them less of a man... We need prominent African-American men to come forward and be spokespersons.”

Providing information about proactive, empowering, and actionable strategies for risk reduction

“Be positive and life affirming in our approach to awareness.”

“We need to dispel myths with good information”



“Our message should use the facts to mainline the disease... If you live long enough you will get it... so how do you prolong the time before you get it, and improve odds of recovery?”

“If we are going to provide information that causes anxiety, we need to also provide proactive solutions to potentially managing it.”

“Some men are proactive, some are reactive. One useful internal motivation, nobody wants to get cancer and nobody wants to die...”

“We should draw clearer lines between diet and nutrition and its importance in conjunction with early detection to survival and quality of life.”

“With evidence building around the links to heart disease related risk factors, such as cholesterol, obesity, belly fat, and diet, some alliance with activists promoting awareness of heart disease may be worth considering”

“Emphasis should be put on a collective, consistent message that is flexible enough to allow presenter creativity and audience engagement.”

Respecting and supporting personalization, creativity, and innovation in regard to promoting awareness

“We need to reach everyone, and everyone has their own set of people they can be influential with, based on their own experience, approach and delivery.”

“it's all about being innovative, doing things differently, doing what works for you... you can't stifle creativity, and brochures are meaningless without personal contact.”

“Personal involvement is very important– people with some knowledge taking the time to do it - and delivering the message their way.”

Broadcast reinforcement

“We need local radio and television (public service announcements) to reinforce our message.”

“Could develop personalized public service announcements with messages such as "I'm a widow because my husband was too busy (to get screened)...", "I wish my grandfather was still



around", etc. It's a domino effect... capture the broader impact of the disease and emphasis that these situations are preventable."

"Rural and radio networks are a great method of spreading awareness. Provide grassroots activists with tools to leverage those local connections"

"More broad based promotion and advertising... We really need things like press coverage and advertising."

"Television, radio and media would open doorways for discussion and encourage awareness."

"Everything works a little bit... traditional advertising to engage black men – newspaper, TV, radio don't work on their own, they enforce the message, but personal contact and trust is so key."

Addressing Access to Screening

"Unless these men have a job that requires them to have annual physicals... they typically don't. We work with area businesses to hold lunch and learns for employees... employers and employees who benefit from these events can make donations to sponsor community screenings. There are lots of opportunities for community engagement."

"We should press for more community screening support that addresses continuum of care for the often underserved and/ or uninsured men receiving medical services during these events"

"As screening organizers, we should collectively share our lessons. Using successful models as a framework, we could facilitate the sharing of organizational methodologies and processes from our state's most successful ongoing community screening initiatives."

"Collaborate or partner with the Prostate Cancer Education Council (PCEC) to track and support these efforts."

"To display our solidarity and commitment to providing adequate healthcare to the men of North Carolina, the PCCNC should sponsor statewide public service advertisements and press releases"



for September (prostate cancer awareness month), promoting collectively all known prostate screening events, most of which are held in September, prostate cancer awareness month.”

Pushing for Clearer Understanding of Screening Results

“We could approach the big labs and ask them to lower the threshold from 4 to 2.5. The trick with that is 4 is FDA approved, 2.5 isn’t.”

“One valuable resource that may help to address some of our issues is the Prostate Cancer Education Council (PCEC).”

“Maybe we can talk to the labs about communicating velocity... but then they’d have to have access to the patients past PSAs.”

“A consolidated version of the PCCNC screening guidelines in a wallet sized booklet with room for tracking personal PSA might be a good idea.”

“Some men never follow up with their abnormal screenings... they think an abnormal result means cancer.”

“We could develop patient education cards detailing what screening results actually means, not limited to prostate cancer, to be distributed during community screening events and provided to patients upon Urologic referral .”

“We should address the discomfort some GPs have with referral... we could put together referral kits for primary care to give to patients that would help men understand their diagnosis and how to find help. We could include information for patients who may need to undergo biopsy and a primer for newly diagnosed men stressing that there is a lot to consider.”

Addressing lack of awareness in regard to biopsy protocol

“With the standards for biopsy commonly applied today, the quality of its diagnostic value is overrated... without the 12 cores and tertiary analysis the information for evaluating your best option isn’t as useful, and even one higher gleason actually trumps the lower scores. We need better tests and to teach patients strategies for measuring the severity of the cancer.”



Preparing for the storm

“Given our pronounced racial health disparity in the east, and high concentration of retirees in the west, coupled with the aging baby boomer population, on the care side, North Carolina is in a position for creating the prostate cancer “perfect storm.”

“There is a strong potential for a lack of Urologists specializing in the care and treatment of prostate cancer available to men.”

“The patient needs to take on responsibility and be a part of his care team – with an active voice.”

“Patients tend to have improved continence and potency - and cure rates are improved as a Dr. gains experience treating a specific disease. Second opinions are also important, and the willingness to understand and consider a multidisciplinary approach to decision making regarding treatment.”

“Analyzing options is hard and in some parts of the state Urologists/ specialists do not have the resources, time, and specialized knowledge to offer information and options.”

“Availability of MDs in eastern NC is an issue. Pitt County has had a major out flux of Urologist - from 5 down to 1 in one year. Of course we need to push the importance of getting a second opinion! In Greenville, it's kind of hard to get a second opinion with only one Urologist!”

“In regard to care, the best thing we can do is discuss patient issues in a supportive setting. There are no real resources for anything beyond that.”

“We need to find ways to improve cross disciplinary communication for those involved with treatment. The system is not set up for the type of consultation men need to facilitate good decision making.”

“For prostate cancer patients, there is a need for a lengthy consultation... maybe identify navigators with healthcare providers working under a nurse navigator... and an annual training for navigators – and stipend for certified navigators...”



“ we should be inspiring men to be advocates... training camps for support groups to spread awareness and help each other – this gives men a great deal of personal support in addition to helping the community... instill the facts... awareness, emotional support, share information with other groups... get men thinking about venues for getting the word out.”

“The problem patients have in seeing multiple discipline experts... having the team approach that UNC and Duke take is good – typically this is not happening collectively... plus 1/3rd of population is uninsured. Once a man is diagnosed, he tends to either rely on or develop a personal support network or he becomes an island unto himself, with little access to decision making information or the fact that he needs to evaluate his decision.”

“On the care side – it really depends on the Doctor. Men should be encouraged to talk to a medical or radiation oncologist for consultation prior to treatment.”

Working towards Better Education for Newly Diagnosed Men/ Resources and Support for Pre-Treatment Decision Evaluation

“Decisions pertaining to treatment are often rushed. Conversely, some men are under the mistaken impression that prostate cancer is always slow growing. This is not the case. Prostate cancer can be a vicious killer.”

“Patients must not necessarily rush to treatment. But they must have the ability to quickly, and as accurately as possible, assess the severity of their situation.”

“There's a big need for pre-treatment education... if the patient has a high margins... if the chance of recurrence is high... surgery may not be the best option... with salvage radiation, the patient has to cope with side-effects from both treatments.”

“Treatment needs to be driven by what is best for the patient versus what is most financially beneficial for the practice...”

“Multidisciplinary committees and tumor review protocol are a good idea for everyone treating prostate cancer. We must treat the patient not just the psa/ not the disease...”



“As support group facilitators, I've heard horror stories... men getting prostatectomies who do not have cancer. They were misdiagnosed.”

“We could help other coalition members build a better awareness of strategies to improve outcomes by providing some educational events on nutrition and other management strategies for patients.”

“There is a lot to choose from now. Men need to know about their choices and encouraged seek follow-up care.”

“Community screenings are improving access to the test overall, but follow-up for African-American men after screening is a challenge due to shame. A lot of men underestimate the severity so they end up procrastinating until the situation is out of control – once they get treatment they are at a point of no return. Better patient information is critical upon the receipt of abnormal results and through the diagnosis... follow up really needs to be extenuated.”

“There is a real need for access to a practical survivorship plan... maybe a boiler plate with information on lifestyle/ nutrition and supplementation to slow or prevent recurrence – that could then be customized by the patients care team. Doctors need to treat the patient – not just the disease... the plan should include information on recurrence... what to if... managing side-effects and other quality of life issues.”

“We need to build mechanisms for continuum of care, on a regional level, letters of understanding where Drs. can commit to provide care for some number of uninsured men. Follow-up for men with abnormal screenings is important - and awareness and education seminars for newly diagnosed men could be conducted by support group leaders... patients often need a hiatus to digest their diagnosis and understand their prognosis... a multi-team approach should be emphasized... education has to happen on all levels. A lot of men are living with (versus dying of) prostate cancer... we need navigators to help men better manage their disease.”

“Ultimately – we all need to be our own advocates...”



“When we talk about care that gives the patient his best quantity and quality of life, I think patient education is the big challenge... across the gamete.”

“A lot of people are at the mercy of how they feel about cancer and what the Dr. tells them. It’s important to educate pre-treatment. There are lots of unnecessary “cut it out” reactions.”

“...build awareness that PC can be a kitten or a tiger.”

Stressing the Importance of Peer Support

“We have a great process where men are invited to the support group upon diagnosis. They are strongly encouraged by the hospital to attend, and (when they are building their care team), they are encouraged by hospital to ask their primary Drs. who they would go to (for care).”

“Our UsToo Support group has good turnout (min. 20). We have the support of about 13 area Urologists... at least 10 are strong supporters. In regard to side-effects, most of the Drs. are good about informing men pre-treatment. ED and incontinence are big fears for men.”

“Don’t know if cost enters into the choice – time is a bigger issue/ consideration for most men... and other QOL issues.”

“Support groups are greatly underutilized; most men come to deal with side-effects, not to learn about primary treatment.”

“The male instinct to “go into his cave” or “cut it out” is strong for many men.”

“We need to find a way to promote support groups for newly diagnosed men – let them know that it is more about information than the “touchy feely” women’s support group. Men should be encouraged to explore their options... there's too much rushing to treatment and uninformed decision making...”

“What is important to the patient needs to be considered. Detail of side-effects vs. benefit from the physician is a big point. For anyone who can’t pay out of pocket, treatment is dictated by insurance. There are physiological, social and financial side-effects... Attending a support group and talking to survivors... mechanisms that help men grasp expectations around side-



effects – greatly decreases anxiety. Attending a support group and/ or researching online should be viewed by patients like checking references for a contractor. This helps them feel better about options and cope side-effects, regardless.”

Considering the Ongoing Needs of Some Patients (Long-Term Management, Side-effects and Recurrence)

“Lots of men do drop out after initial treatment and resurface if there is a recurrence.”

“Lots of men disappear from support groups after treatment and resurface after recurrence. (This is a challenge because) ongoing health maintenance and encouraging members to keep an eye on bone density and monitoring other possible less noticeable side effects is important, pre-treatment bone density measurement can be important. ED is another big challenge is a big hurdle for lots of men. That requires emotional support and advice that a lot of men don’t like to ask for.”

“Treatment of PCa as a chronic condition is taking on more and more importance pertaining to both “watchful waiting” and particularly recurrence. There are good resources for management and care... UsToo Hot Sheets & the What Now publication are particularly value to the support group leaders.”

“Long-term follow-up is key.”

“Push for access to better information and tools for understanding and managing side-effects.”

“Patients and caregivers need to find better communication mechanisms... to network more... to communicate about cutting edge treatment... and other tools that are new and helpful like the male surgical sling...”

Peer to Peer Support

“We need mechanisms and programs for matching patients to patient – peer to peer... Books are good – but not everything gets written down.”

“Maybe we could have a lay health advisors area on the website... prostate cancer patients and caregivers who are “experts” on prostate cancer survivorship.”



“Many men make a decision before they have the knowledge necessary to make a good decision.”

“What would really help is a method for matching retired patients with non-retired... many men want to give back once they've coped with their own treatment. PCCNC should develop a "mentor sign up" – where men can submit requests for patient support- online and via phone - so experienced patients can benefit (psychologically) from helping newly diagnosed men, and vice versa. Such a program run by the PCCNC “should be outside of HIPAA”

“(Providing men with the opportunity to volunteer) gives them another method of reaching out... the world becomes their support group.”

“The new trend in treatment of more patient involvement can lend itself to this cause.”

“A navigator program, not limited to survivors... but open to lay health professionals with some level of treatment specific expertise... caregivers (male or female), patient counselors and other medical professionals could all have the opportunity to act as volunteer navigators.”

“We could develop a peer navigator training program in partnership with UsToo International and with the guidance of our state’s leaders in prostate cancer treatment and care. Training could cover such initially complex topics essential to understanding diagnosis such as an in depth understanding of Gleason Score, Staging, use of the Partin Tables, along with updates pertaining to the broad and constantly evolving set of diagnostic imaging constantly on the horizon. Strategies could be taught by psychological experts for how to validate and personalize the understanding of treatment options, decision analysis, and decision making, along with the preparation for and management of side-effects in a “non-emotional” masculine way.”

“Interfacing with UsToo International is very important for support group leaders.”

Other

“Imaging is really our biggest issue and challenge with treating prostate cancer...”



Appendix B

Mission

Prostate cancer is a major health issue in North Carolina. The death rate from prostate cancer in North Carolina is the one of the highest in the nation; African-American men in North Carolina have one of the highest death rates from prostate cancer in the world. Not nearly enough is being done in North Carolina to battle this health crisis.

The coalition focuses on three goals:

1. Raising awareness of prostate cancer as a major health threat to North Carolina families.
2. Promoting community, state and national actions to battle this disease.
3. Uniting and coordinating our efforts to increase the -effectiveness of those affected or concerned about prostate cancer.



Appendix C

Vision

By working together the citizens of North Carolina will see a day when prostate cancer is no longer a threat to the families of our state.

Critical Success Factors

- The state of North Carolina must be a leader in the prevention, diagnosis, treatment and care of prostate cancer.
- The physicians in North Carolina must be well informed regarding all the issues associated with the diagnosis, treatment and care of prostate cancer.
- The major medical institutions in North Carolina collaborate to provide leading edge research and the best possible care for those affected by this disease. World-class diagnostic and treatment facilities, equipment and services must be available to the men of North Carolina.
- The prostate cancer patient in North Carolina should be a well-informed patient.
- The citizens of North Carolina must be aware of the threat of prostate cancer and their best course of action to protect themselves or their loved ones.
- The citizens of North Carolina should be aware of the health and dietary choices that will reduce their risk of prostate cancer.
- Screening and care resources must be readily available to all of our citizens.
- There should be support groups easily accessible to all of our citizens.
- There should be knowledgeable survivors and spouses available for prostate cancer consultation with men or their families.
- The death rates from prostate cancer in North Carolina should be among the lowest in the Nation for every ethnic and social group.