

ANNUAL REPORT & RECOMMENDATIONS

2013



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FLORIDA PROSTATE CANCER ADVISORY COUNCIL ANNUAL REPORT & RECOMMENDATIONS

SUBMITTED TO

THE GOVERNOR
THE PRESIDENT OF THE SENATE
THE SPEAKER OF THE HOUSE OF REPRESENTATIVES
THE STATE SURGEON GENERAL

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The Honorable Rick Scott, Governor
The Honorable Don Gaetz, Senate President
The Honorable Will Weatherford, House Speaker
Dr. John Armstrong, State Surgeon General

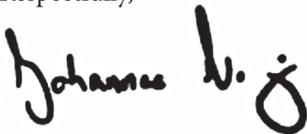
Dear Governor Scott, President Gaetz, Speaker Weatherford, and Surgeon General Armstrong,

Despite the confusion and recent controversy over prostate cancer screening, the number of new diagnoses in Florida continued to increase and has grown from an estimated 13,700 in 2000 (American Cancer Society Facts and Figures 2000) to an estimated 17,330 diagnoses in 2013 (American Cancer Society Facts and Figures 2013)¹. This equated to 47 men per day being diagnosed with prostate cancer in Florida and unfortunately, when compared to 2000, is an increase of an additional 10 men per day who are being provided with the unwanted and life-changing news that they have cancer. With this stated, prostate cancer is the number one cancer risk facing the Floridian men that we serve, and the statewide rate of incidence is second only to lung/bronchus cancer (17,960); however, Florida has made a significant investment, an estimated \$64.3 million last year alone (tobaccofreekids.org), on tobacco prevention in Florida that will provide a long-term healthy return while the investment in prostate cancer was, and is, disappointingly diminutive in comparison.

To date, the Prostate Cancer Advisory Council has worked diligently to limit the impact that prostate cancer will have on Floridians by utilizing the prostatecanceradvisorycouncil.org communications platform to clarify the confusion and enhance the statewide discourse between stakeholders, prostate cancer patients and their loved ones. Additionally, the Council commenced the foundational work that the Florida prostate cancer system of care will be built upon. Once implemented, the guidelines, coupled with seamless navigation, will ensure that all those impacted by prostate cancer, from the patients with questions to the physicians of all specialties who are providing and coordinating the care, have access to the evidence-based information required to facilitate sound decision making.

Through the Prostate Cancer Advisory Council, we've created a highly functioning collaborative framework that captures input from the academic, tertiary, and community prostate cancer stakeholders throughout the state, and we've generated the significant momentum required to facilitate positive changes for those who are afflicted with the disease, those who are treating it and the researchers who are diligently searching for a cure. Nevertheless, without a funding mechanism we cannot ensure that this momentum will continue, despite the ever-increasing number of Floridian men, and their family members, who will be impacted by this disease today and in the future.

Respectfully,

A handwritten signature in black ink that reads "Johannes V. J." with a stylized flourish at the end.

Johannes Vieweg, MD, FACS
Chairman, Florida Prostate Cancer Advisory Council
Executive Director, University of Florida Prostate Disease Center
Chairman, UF Health Department of Urology

EXECUTIVE SUMMARY & RECOMMENDATIONS

INTRODUCTION:

The objective of the 2013 Florida Prostate Cancer Advisory Council Annual Report is to summarize the Council's accomplishments over the last reporting period and to highlight the future scope of work that will enhance the awareness and education of the Floridians that we serve and to increase the research synergies required for new discoveries. Additionally, the recommendations will underscore the tactical accomplishments and objectives required to ensure that work will continue well into the future.

2013 marked a year of significant accomplishments for the Prostate Cancer Advisory Council that was highlighted by the publication of the Florida Prostate Cancer Atlas, which documented progress on the prostate cancer system of care; participation in a pan-Florida education and awareness event; and through the alignment of collaborative research opportunities that will support and supplement the evidence-based prostate cancer guidelines that are currently being developed. Nevertheless, with thousands of Floridian men living with the disease, we recognize that our current progress is not enough to match the ever-increasing burden to patients, family members, and healthcare providers and that new strategies are required to positively effect a disease that is negatively impacting so many.

RECOMMENDATIONS:

In order to meet the mission of being the reliable source of prostate cancer information, coupled with our unwavering objective of improving the outcomes and reducing the ethnic and racial disparities related to prostate cancer, the following recommendations were thoughtfully drafted with a sincere sense of urgency for those who have, or will be diagnosed with prostate cancer:

CLINICAL:

In an effort to reduce the potential practice variability and confusion associated with prostate cancer treatment:

- Present the inventory of the current clinical practice guidelines and the methodological quality assessment of the inventoried guidelines at the American Urological Association(AUA) meeting.
- Use the feedback from the AUA meeting and the feedback from the stakeholder organizations to finalize the evidence-based guidelines for Florida.
- Work with stakeholders throughout the state on implementing the guidelines.

EDUCATION:

Once the new evidence-based guidelines are finalized:

- Utilize the Florida Prostate Cancer Atlas — an epidemiologic environmental assessment of prostate cancer incidence and treatments in Florida — to help pinpoint the geographic areas of potential practice variability and create a strategy to enhance the education of patients and physicians within this area.
- Work with the Florida Cancer Collaboratives to promote the systemic patient education and the statewide adoption of the guidelines by care providers.
- Partner with the coordinators of the 2nd Annual People's Scientific Conference to Promote Health and Eliminate Health Disparities to create a venue for an interactive new guidelines discourse between patients, family members, and physicians.
- Redesign and transform the prostatecanceradvisorycouncil.org website into an interactive tool for patients, family members, and physicians that highlights the evidence required to support sound prostate cancer decision-making.

RESEARCH:

Capitalize on the high level of multi-institutional collaboration to enhance the statewide prostate cancer research infrastructure:

- Create a formal proposal for the Prostate Cancer Advisory Council to assume the coordination of prostate cancer research in Florida (grant reviews, fiscal oversight, creating collaborations between researchers, measuring the return on the research investment, etc.).
- Create a coordinated clinical trials consortium that inventories and catalog the clinical trials and their corresponding locations within the state — additionally, act as the catalyst to inform participating institutions of new clinical trials that are becoming available.
- Lastly, create a mechanism for access to current datasets; thus, allowing timely monitoring of the prostate cancer system of care.

CRITICAL ISSUE:

To date, the work of the Florida Prostate Cancer Advisory Council has been financially sponsored through the host institution, the University of Florida Prostate Disease Center, and has obtained additional support from the H. Lee Moffitt Cancer Center & Research Institute — nevertheless, to continue with the deliverables, a source of funding will need to be procured to offset the variable costs that extend beyond what can be absorbed at the hosting institution.

CONCLUSION:

The Prostate Cancer Advisory Council has worked diligently over the last 24 months to create the bedrock that future clinical, educational, and research successes will be built upon. However, to transform the foundational work into an evidence-based system of care and research collaboratives that will promote the appropriate care today and the new clinical pathways of tomorrow, it will require an investment to keep the aggressive scopes of work moving forward. The 14 members of the Prostate Cancer Advisory Council have selflessly donated their time and many talents while carrying the burden of knowing that every day an additional 47 Floridian men, and their families, are counting on us.

2013 ACCOMPLISHMENTS

INTRODUCTION:

In an effort to enhance the prostate cancer awareness and education of the Floridians that we serve and with an unwavering focus on reducing the ethnic and racial disparities that are plaguing our African American citizens and rural communities, the Prostate Cancer Advisory Council collectively, as well as its members individually, undertook an aggressive scope of work in 2013. With this stated, the common thread that held the tapestry of projects together was increasing the Floridian stakeholders' comprehension of prostate cancer and the corresponding issues that are unique to this disease. Specifically, the projects were designed to increase the fund of knowledge as it pertains to evidence-based guidelines for prostate cancer care, enhancing patient and family member awareness, and developing a deeper understanding of the patterns of care, variations and disparities that are occurring throughout the state.

CLINICAL:

Prostate Cancer System of Care

Background

Clinical practice guidelines (CPGs) are defined as systematically developed statements to help practitioner and patient decisions about appropriate health care for specific clinical circumstances.² They are important tools for promoting high quality, evidence-based clinical care and reducing undesirable variation in care as well as health care disparities. Ideally, CPGs from different professional organizations would use consistent transparent and rigorous methodology to develop actionable clinical practice recommendations to be used both at the point of care as well as for health policy decision-making. Select recommendations can then become quality of care measures to promote certain medical practices and discourage others and then can be systematically disseminated and monitored in efforts to promote high quality of care and eliminate disparities.

However, past studies of existing CPGs for the management of prostate cancer suggest that this is not the case.³ In fact, existing CPGs often use outdated quality of evidence rating systems that do not distinguish between the quality of evidence and strength of recommendations, are outdated and/or fail to consider stakeholder involvement.⁴ There is also considerable concern over the way guideline developers have historically managed conflicts of interest.^{5,6} The importance of standards for CPGs is further underscored by the recent report by the Institute of Medicine with the title "Clinical Practice Guidelines We Can Trust."⁷

Specific Aims

As part of the Prostate Cancer Advisory Committee's (PCAC's) mission to promote high quality, evidence-based care for all Floridians and develop a Florida System of Care that defines the benchmarks for what such care should look like, the group performed a study with the following specific aims:

Aim #1: To systematically assess the quality of existing CPGs related to the management of men with prostate cancer.

Aim #2: To create an inventory of clinical practice guideline recommendations as a basis for quality of care measures for the Florida System of Care.

Methods

PCAC performed a systematic review of published (online or print) CPGs for the management of prostate cancer for the last five years (2008-2012) in the English language. We included all guidelines that addressed questions of therapy and prevention but excluded CPGs limited to questions of diagnosis. Due to the availability of a recent, high quality study related to CPGs focused on the question of prostate cancer screening,⁸ we excluded guidelines with a focus on screening. We searched the National Library of Medicine (<http://www.ncbi.nlm.nih.gov/pubmed>), the National Guidelines Clearing House (<http://www.guideline.gov/>) and Guidelines International Network (GIN; <http://www.g-i-n.net/>) for eligible guidelines. The methodological quality of CPGs were assessed using the updated instrument of the **A**ppraisal of **G**uidelines for **R**esearch and **E**valuation which is a validated instrument to assess the quality of CPGs.^{9,10} We used four independent reviewers to assess the CPG quality; all of them completed the training module offered on the AGREE website (<http://www.agreetrust.org/>) and a pilot phase based on other, non-prostate cancer related guidelines.

Preliminary Results

We identified 13 distinct guidelines from different professional organizations that we assessed in the six dimensions included by the AGREE II instrument, which are: Scope and purpose, stakeholder involvement, rigor of development, clarity, applicability, and editorial independence. CPG quality was scored according to AGREE II procedures on a scale of 0% to 100% with higher scores representing higher quality. Among these, CPGs from five major United States-based professional organizations were selected as most relevant to the Florida System of Care initiative. These were the American Brachytherapy Society (ABS), the American Urological Association (AUA), the American Society of Clinical Oncology (ASCO), The American Society for Radiation Oncology (ASTRO) and the National Comprehensive Cancer Network (NCCN). The preliminary results were tabulated and will serve as the framework for discourse and consensus building between the five United States professional organizations selected for this research.

Conclusions and Future Direction

The aforementioned research provided the preliminary foundation for the future efforts of the PCAC to develop a Florida System of Care. Future efforts will be directed towards facilitating an accord between the professional organizations through the development of a final list of evidence-based prostate cancer guidelines and by prioritizing high impact clinical questions that should be selected as quality of care measures.

EDUCATION:

Pan-Florida Educational Event

Florida health disparities data show that racial/ethnic minority and underserved communities experience significant health disparities with prostate cancer being one of the documented areas of continued concern. Based on this issue, the Prostate Cancer Advisory Council, through its host institution – the University of Florida Prostate Disease Center – partnered with the University of Florida Health Disparities Research and Intervention Program and worked under the direction of Dr. Carolyn Tucker, Florida Blue Endowed Chair in Health Disparities Research and the Richard and Thelma O. C. Barney Endowed Term Professor of Health Disparities at the University of Florida, to offer a pan-Florida educational conference that was designed to promote healthy behaviors and help eliminate health disparities.

Specifically, the People’s Scientific Conference to Promote Health and Eliminate Health Disparities (The People’s Scientific Conference) was a first-of-its-kind conference, held June 14 -15, 2013, in which members of these communities and diverse researchers and health care providers came together to learn from and teach each other information that will foster research and evidence-based interventions to promote health and eliminate health disparities. The conference also launched a mentoring program to inspire and train the next generation of researchers to conduct research that has implications for promoting health and eliminating health disparities in racial/ethnic minority and underserved communities. Additionally, it provided training for lay community members most negatively impacted by health disparities in Florida to be teachers and presenters of information that can inform research and interventions to promote health.

Additionally, from an educational perspective, a major emphasis was placed on providing participating community members, researchers, and health care providers with answers to their questions and the educational roles were reversed by creating a forum for culturally diverse patients to identify health care provider behaviors, attitudes, and types of knowledge that enable patients to feel trusting of, respected by, and comfortable with their health care providers. Lastly, lay community members were empowered to learn about and help shape research and evidence-based interventions that can promote health and eliminate health disparities. An innumerable number of diverse community members were in attendance; thus, fulfilling the aim of this educational event being a transformational people’s conference.

17th Annual Black Men’s Health & Wellness Expo

The Annual Black Men’s Health Summit and Semi-Annual Crossing Bridges: Hip-Hop Teen Health Summit are sponsored by the Central Florida Pharmacy Council (CFPC). The CFPC is a not-for-profit organization founded in 1996 by council member Angela Adams, PharmD, a pharmacist with a mission to improve the health and wellness of African Americans and minorities through the development and presentation of culturally specific health education programs. The summits address health concerns of all men of color who suffer disproportionately from illnesses such as prostate cancer, heart disease, stroke, diabetes, hypertension, etc.

The summits are “male only,” open to the public at no cost and offer breakfast, health screenings, information workshops and wellness exhibits. The Black Men’s Health Summit targets men 19 years and older and the Crossing Bridges: Hip-Hop Health Teen Summit targets males between the ages of 12 and 18. Dr. Adams’ unwavering dedication to promoting health, wellness, education and awareness resulted in 3,000 men attending the expo.

RESEARCH:

Florida Prostate Cancer Atlas

Principal investigator Dr. Scott Gilbert, an assistant professor at the University of Florida Department of Urology, noted that, “Substantial differences in (prostate cancer) treatment have been noted across the country with little explanation of why surgery is more common in Central and Southwest Florida, for example, compared to other parts of the state.”¹¹ (Gilbert, et al., 2013, p.5). Based on the documented variability in incidence rates, disparities and prostate cancer treatments, and coupled with the Council’s unwavering focus on enhancing education and awareness of the disease, the atlas highlights communities that are at risk, provides crucial information on where outreach efforts need to be focused, and raises additional important questions as highlighted within the following tables:

TABLE 1

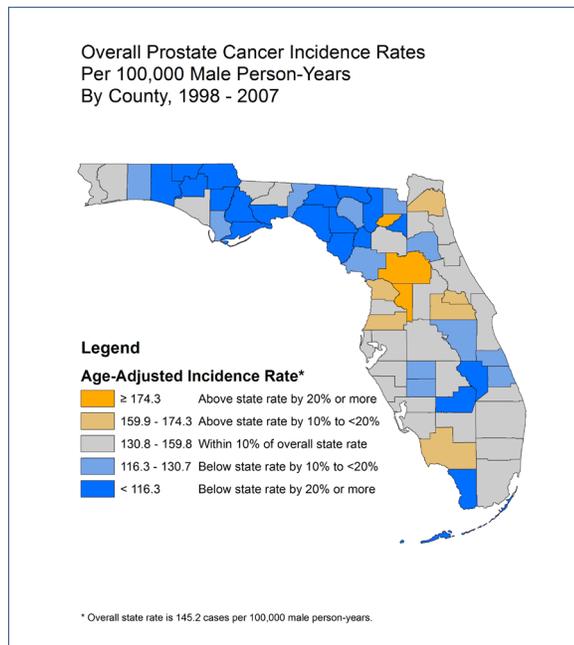


TABLE 2

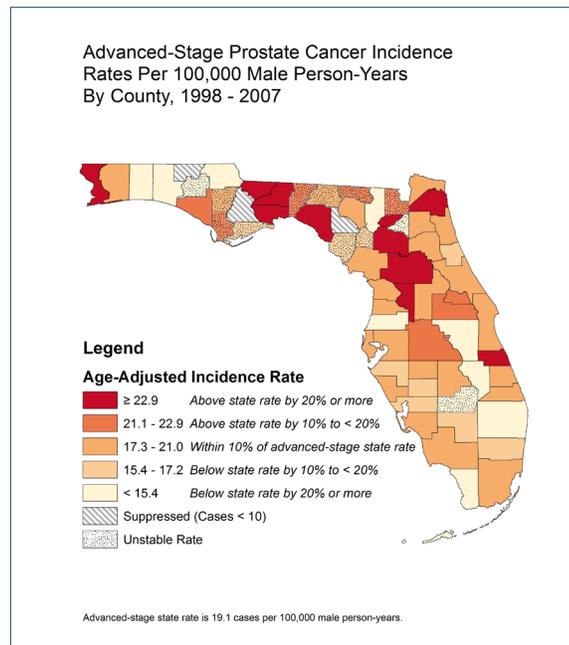


Table 1 demonstrates that there are nine counties in Florida where the prostate cancer incidence rate is above the state average; however, when examining advanced stage diagnoses in Table 2, Florida’s Panhandle becomes an area of increasing concern due to the disproportionate number of men presenting with advanced disease. This highlights the state’s need for the granular and timely information required to understand and confront the prostate cancer related issues facing Floridian men.

This assertion is further captured by Table 3 that highlighted the disparity facing African American men as the number of diagnoses per capita were above the state average in a vast majority of Florida’s counties. Additionally and troublingly, Table 4 captured that not only were African American men diagnosed with prostate cancer more frequently, they were diagnosed with late stage disease more frequently which impacts their prognoses and long-term outcomes. Why are Florida’s African American men more prone to being diagnosed with prostate cancer? Why are African American men throughout Florida and the residents of the Panhandle diagnosed at later stages? These are the questions that are propelling the clinical, educational, and research work focuses of the council.

TABLE 3

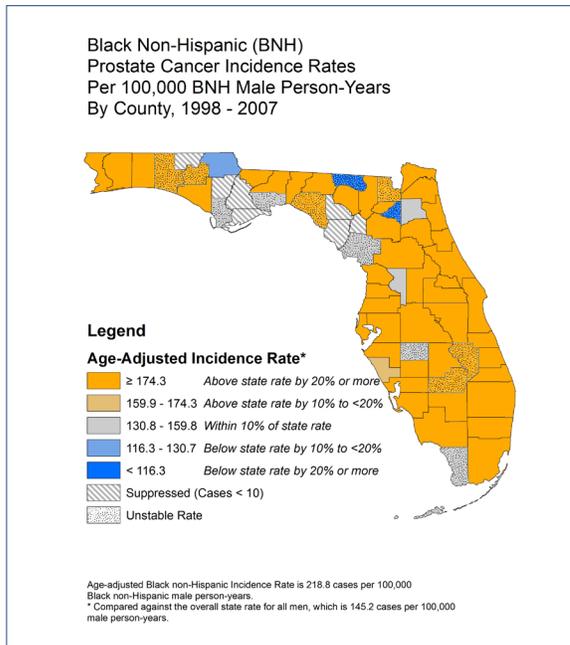
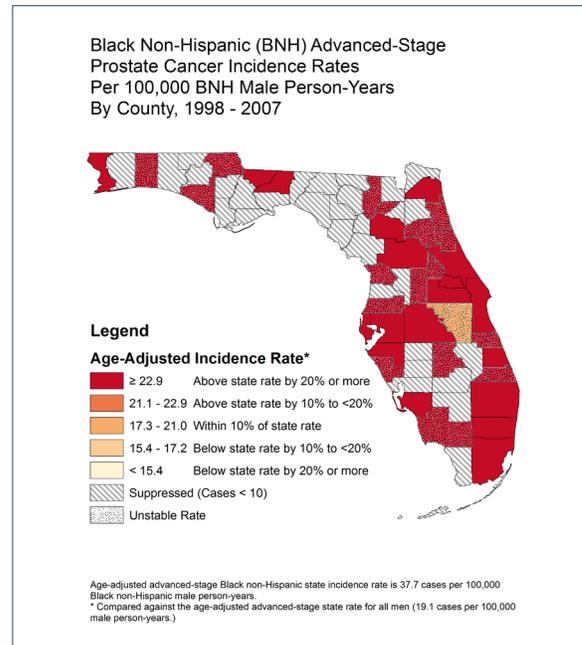


TABLE 4



Additional data analyses are required to understand the patterns of care, variations and the disparities that are plaguing counties throughout Florida. The information would support the council’s outreach and educational efforts and would allow for targeted interventions that follows the “no Floridian man left behind” mantra that guides our work.

Building an Infrastructure for Research and Systemic Collaborations

Under the leadership of council member Julio Pow-Sang MD, chairman of genitourinary oncology at the Moffitt Cancer Center, and with the financial and administrative support of the Moffitt Cancer Center and the Advanced Prostate Cancer Collaboration (APCC), the Florida Prostate Cancer Research Collaboration was created in 2010 with the mission of serving as a sustainable platform to foster interactions between researchers in basic, translational, clinical and population sciences throughout the state that would lead to cutting-edge team-science multi-institutional research and make Florida one of the top national leaders in prostate cancer research. The initial three-year goals of the collaboration were to:

- Develop a network of prostate cancer investigators throughout the state of Florida.
- Inform investigators regarding ongoing prostate cancer research in the state of Florida.
- Establish a real-time repository of research trials for the state of Florida.
- Establish a mechanism for developing multi-institutional, team-science research projects in prostate cancer.
- Seek competitive funding at the state, federal and private levels through team-science efforts.

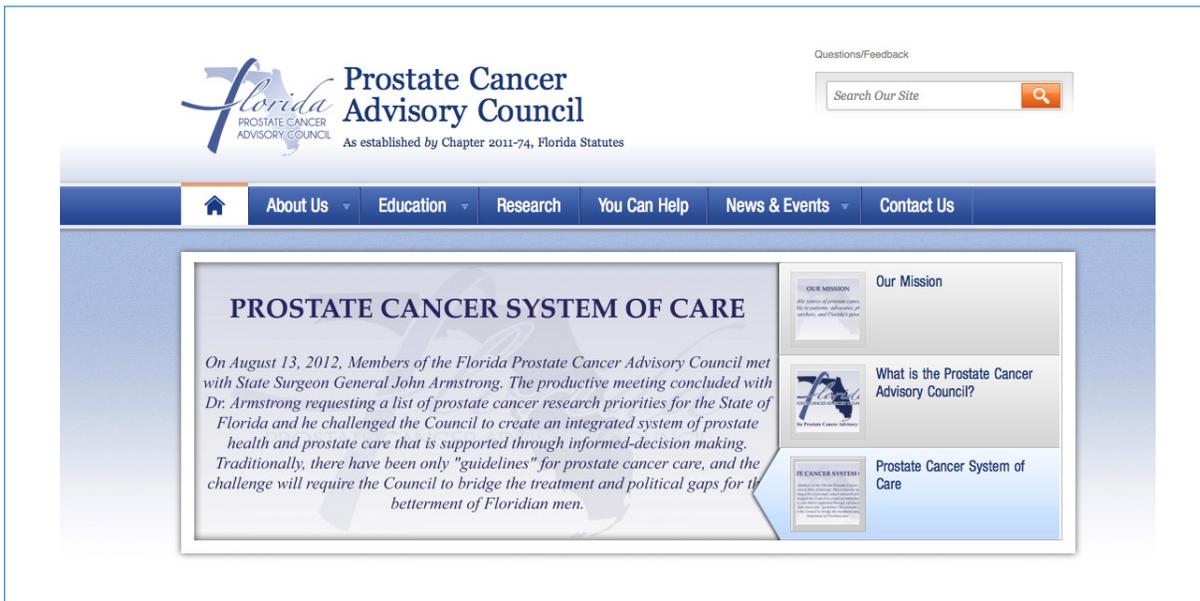
The collaboration achieved its first three goals through year one and two culminating with the first Florida Prostate Cancer Research Symposium in May 2012. Forty-five researchers from across the state shared their research initiatives in podium and poster formats and committed to work together to collaborate on research initiatives. A repository of research trials was created and made available through a web-based resource. The second Florida Prostate Cancer Research Symposium in March 2013 enlarged the network to 55 members and initiated work on the fourth goal by providing seed funding to support three multi-institutional team-science projects involving scientists from all of Florida’s research institutions. The third Florida Prostate Cancer Research Symposium in March 2014 will strive to enhance and solidify the previous achievements and to develop formal mechanisms to seek competitive research funding at the state, federal, and private level through high impact multi-institutional team-science projects.

PCAC INFRASTRUCTURE DEVELOPMENT:

Revised Website

In an effort to enhance the Prostate Cancer Advisory Council's web presence and with a goal of utilizing the Internet as a tool to enhance communication between prostate cancer stakeholders, the prostatecanceradvisorycouncil.org website was redesigned and subsequently has increased the number of patients/family members who have made contact due to our easily navigable web presence.

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Over the next reporting period, the prostatecanceradvisorycouncil.org website will be continually developed in an effort to create an interactive tool that educates patients and provides physicians and clinicians with evidence-based information that supports the system of prostate cancer care and reduces variability.

Governance Infrastructure

To ensure that the synergy between the Prostate Cancer Advisory Council's member institutions continues well into the future and in an effort to ensure that there is clarity, transparency, and the continued collaboration required for decision-making, the PCAC members began working through a draft governance infrastructure that will consist of bylaws, officer job descriptions, and a formal council self-evaluation process.

The governance infrastructure will provide the framework for the way the council will function and outline the individual roles and responsibilities of its members to ensure that PCAC continually strives toward the fulfillment of Florida Statute Chapter 2011-74, its approved mission and adopted vision. With this stated, the council understands its responsibility over the work that needs to be completed today and is working to provide a clear collaborative pathway for future council members.

SUSTAINING THE MOMENTUM:

The work of the Prostate Cancer Advisory Council has been tied together with shoestring funding from the host institution, the University of Florida Prostate Disease Center, and the H. Lee Moffitt Cancer Center. Specifically, both institutions have sponsored face-to-face meetings and some of the work highlighted within this report. However, without a reliable source of funding, sustaining the momentum, continuing our current scope of work, reaching the geographic areas of concern, and finalizing the prostate cancer system of care will be difficult due to a lack of resources. With this stated, the critical issue standing in the path of the Prostate Cancer Advisory Council's ability to achieve its mission and continue progressing toward its vision is procuring the funding required to perpetuate the work.

RECOMMENDATIONS:

The work completed to date has been in pursuit of achieving the council's mission of being the reliable source of prostate cancer information and has propelled us toward our shared vision of improving the outcomes and reducing the ethnic and racial disparities related to prostate cancer. With this stated, the following recommendations were thoughtfully drafted with a sincere sense of urgency for those who have, or will be diagnosed with prostate cancer in Florida:

CLINICAL:

In an effort to reduce the potential practice variability and confusion associated with prostate cancer treatment:

- Present the inventory of the current clinical practice guidelines and the methodological quality assessment of the inventoried guidelines at the American Urological Association meeting.
- Use the feedback from the AUA meeting and the feedback from the stakeholder organizations to finalize the evidence-based guidelines for Florida.
- Work with stakeholders throughout the state on implementing the guidelines.

EDUCATION:

Once the new evidence-based guidelines are finalized:

- Utilize the Florida Prostate Cancer Atlas — an epidemiologic environmental assessment of prostate cancer incidence and treatments in Florida — to help pinpoint the geographic areas of potential practice variability and create a strategy to enhance the education of patients and physicians within this area.
- Work with the Florida Cancer Collaboratives to promote the systemic patient education and the statewide adoption of the guidelines by care providers
- Partner with the coordinators of the Second Annual People's Scientific Conference to Promote Health and Eliminate Health Disparities to create a venue for an interactive new guidelines discourse between patients, family members, and physicians.
- Redesign and transform the **prostatecanceradvisorycouncil.org** website into an interactive tool for patients, family members, and physicians that highlights the evidence required to support sound prostate cancer decision-making.

RESEARCH:

Capitalize on the high level of multi-institutional collaboration to enhance the statewide prostate cancer research infrastructure:

- Create a formal proposal for the Prostate Cancer Advisory Council to assume the coordination of prostate cancer research in Florida (grant reviews, fiscal oversight, creating collaborations between researchers, measuring the return on the research investment, etc.).
- Create a coordinated clinical trials consortium that inventories and catalog the clinical trials and their corresponding locations within the state — additionally, act as the catalyst to inform participating institutions of new clinical trials that are becoming available.
- Lastly, create a mechanism for access to current datasets; thus, allowing timely monitoring of the prostate cancer system of care.

CRITICAL ISSUE:

To date, the work of the Florida Prostate Cancer Advisory Council has been financially sponsored through the host institution, the University of Florida Prostate Disease Center, and has obtained additional support from the H. Lee Moffitt Cancer Center & Research Institute. Nevertheless, to continue with the deliverables, a source of funding will need to be procured to offset the variable costs that extend beyond what can be absorbed at the hosting institution.

PLAN OF WORK 2014

The following list comprises the Prostate Cancer Advisory Council's plan of work for 2014. Note — the plan of work will address the following objectives:

- Prostate cancer system of care
- Enhance Stakeholder education awareness for the following constituency groups:
 - » Patients
 - » Family members
 - » Advocates
 - » Physicians (all specialties)
 - » Legislators and policy makers
- Statewide research collaborations and prostate cancer team science
- Funding

CLINICAL:

- Finalize the evidence-based guidelines recommendations
- Conduct a prostate cancer stakeholder “think-tank” meeting on how to communicate and systemically implement the guidelines

EDUCATION:

- Participate in a second pan-Florida prostate cancer awareness meeting and other educational venues throughout the state with an objective of promoting the evidence-based guidelines
- Further develop the prostatecanceradvisorycouncil.org website into an interactive tool for patients, family members, advocates, and physicians that promotes evidence-based decision making

RESEARCH:

- Determine how to procure the current data sets required to measure if the implementation of the evidence-based guidelines were successful and to highlight the geographic areas that require additional attention
- Continue to endorse, promote, and conduct prostate cancer research collaborations and inter-institutional team science
- Inventory the clinical trials offered in the state and utilize the website as tool to educate, and direct patients to the appropriate locations as applicable

CRITICAL ISSUE:

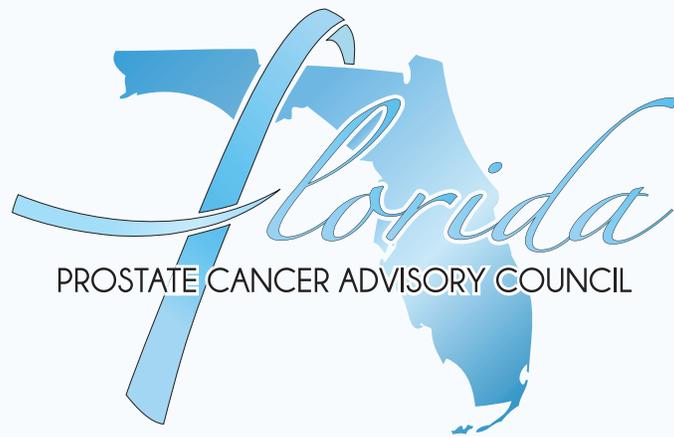
- Raise the funds required to sustain the momentum, complete the prostate cancer system of care/the 2014 scope of work and ensure that largest cancer risk facing the Floridian men that we serve continues as a priority

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In Collaboration With





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