THE 2020 SCOPE OF WORK:
2019 YEAR IN REVIEW

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http://prostatecanceradvisorycouncil.org/

Situation Analysis

The Florida Prostate Cancer Advisory Council (PCAC) was established in 2004 by state statute 381.911 and remains under the direction of the University of Florida Prostate Disease Center (UFPDC). The task of PCAC is to advise the governor, state surgeon general and state legislature on statewide issues regarding prostate cancer incidence and mortality as well as related health disparities for access to care and prostate cancer treatment. PCAC is a collaborative, multi-institutional and inter-disciplinary advisory body focused on a communication platform that promotes education and awareness as well as improved detection and management of prostate cancer statewide.

Membership in the UFPDC PCAC is by appointment of the executive director of the UFPDC in consultation with the Department of Health's Comprehensive Cancer Control Program and state surgeon general to cover a geographically and institutionally diverse advisory council that shall consist of 9 members:

- Two persons from prostate cancer survivor groups or cancer-related advocacy groups
- Four persons, one of whom is a physician licensed under chapter 458, one of whom is a physician licensed under chapter 459, one of whom is a scientist, one of whom is the executive director of the UFPDC or designee
- Three persons who are engaged in the practice of cancer related medical specialty from health organizations committed to cancer research and control

One member of the council completed a two year term on December 31, 2019:

- Matthew Abramowitz, M.D.
- Statute: Cancer Related Specialty

Dr. Abramowitz is proposed for renewal of a two-year term, pending approval of the Florida Surgeon General

Executive Summary

The 2019 annual meeting of PCAC was held December 7th within the Department of Urology at UF in Gainesville, Florida. Participants included PCAC board members, invited guests and prostate cancer-focused expert speakers. Institutional thought leaders represented UF Gainesville, UF Jacksonville, Mayo Clinic Jacksonville, University of Miami, Orlando Health and H. Lee Moffitt Cancer Center. Board members and guest participants provided valuable opinions and insight to help facilitate the impact of PCAC policies on statewide prostate cancer incidence and treatment. Additionally, the Department of Health (DOH) was represented by the State Surgeon General, Dr. Scott Rivkees, the Florida Cancer Control and Research Advisory Council (CCRAB) was represented by Chairperson Dr. Christopher Cogle, and the Florida Biomedical Research Advisory Council (BRAC) was represented by Chairperson Dr. Daniel Armstrong.

PCAC work goals for 2019 included a focused collaboration with Florida Cancer Control & Research Advisory Council (CCRAB) for the development of prostate cancer detection guidelines within the 2020-2025 Florida Cancer Plan. As a result of that effort, proposed plan language now includes parameters for shared decision-making discussions as well as mechanisms to address disparities and increase screening for the high-risk male populations within Florida. These objectives include achieving measurable improvements in the percentage of men both discussing and undergoing prostate cancer screening.

Meanwhile, PCAC remains dedicated to be the educational source of prostate cancer information across the state that is accessible to patients, advocates, physicians (primary care and specialists), care providers, researchers and to Florida's governing officials. Through the PCAC website at http://prostatecanceradvisorycouncil.org/, links have been established to the Centers for Disease Control and Prevention (CDC), state statute-driven like organizations, and private practices. Council members are routinely updated on changes, including additions to the clinical trials tab. The website is currently awaiting UF approval for an improved, user-friendly format. Regardless of PCAC's continuous efforts to provide pertinent and usable content, the website's success will rely on broadened readership which PCAC will include as one of its ongoing priorities. PCAC aspires to be the state-sanctioned clearing house for prostate

cancer information with links to timely and credible prostate cancer-related materials.

2019 work goals for PCAC additionally centered on expanded working partnerships with patient advocacy and prostate cancer survivor groups. This included working with the Regional Cancer Control Collaborative to improve prostate cancer awareness and education statewide through existing voluntary organizations. PCAC partnered with the Regional Cancer Control Collaborative on the introduction of prostate cancer detection initiatives for the 2020-2025 Florida Cancer Plan.

Additionally, work continues to develop collaborative quality initiatives (CQI's) with our private practice partners to integrate care with academic institutions to improve and standardize patient care related to prostate cancer. We previously achieved institutional approval to participate in a national data registry to facilitate these initiatives.

Each year, over 12,000 Florida men are diagnosed with prostate cancer and over 2,000 will die of the disease. PCAC-published prostate cancer detection guidelines in 2016 recommended provider-patient discussions on prostate cancer beginning at age 40 that addressed both advantages and disadvantages of early screening. PCAC recommends initial annual prostate specific antigen (PSA)-based screening including blood testing and digital rectal exam (DRE) beginning at age 50 for average-risk males, with consideration for longer interval screening if the initial screening PSA is <1 ng/ml and DRE is non-suspicious for cancer. However, prostate cancer awareness is especially important to sub-populations of men at increased risk of aggressive disease. Risk factors for earlier onset and more aggressive disease include African American (AA) race especially of West-African descent, men with a strong family history of disease, known germ-line mutations (e.g. BRCA 1/2), and environmental exposure (Agent Orange) risks. PCAC recommends shared decision-making discussions and initiation of PSA-based screening beginning at age 40 for higher-risk populations.

Delayed diagnosis can result in a loss of curative options for treatment. AA men have the highest incidence of prostate cancer and the greatest mortality rates compared to other population groups in the United States. However, AA men have the lowest rate of participation in prostate cancer screening. Although there was

an immediate and persistent decline in PSA testing in men of all age groups following the U.S. Preventive Services Task Force (USPSTF) 2012 recommendations against routine screening, it was most pronounced in the AA population and in men with lower levels of income and education. It is a goal of PCAC not only to develop a strategy to improve education, especially for populations at increased risk for prostate cancer, but also to facilitate accessibility and remove potential financial and cultural hurdles for testing. This includes the specific utilization of black male community health workers to help bridge cultural sensitivities related to prostate cancer diagnosis.

The 2019 Annual PCAC meeting was highlighted by presentations given by expert speakers and stakeholders on state-of-the-art topics related to prostate cancer incidence and detection.

PCAC was especially privileged to have the State Surgeon General and Department of Health standard bearer, Dr. Scott Rivkees, in attendance. As our partner in the effort to address statewide prostate cancer incidence, mortality and related health disparities, Dr. Rivkees emphasized practical PCAC policies to address messaging, equity and workforce issues.

Samsun Lampotang, PhD, Joachim S. Gravenstein Professor of Anesthesiology and Director of the Center for Simulation, Safety and Advanced Learning Technology (CSSALT) at UF followed last year's presentation on the development of a simulation model for the improvement of spatial distribution of biopsy cores during systematic biopsy with a presentation on the impact of falsely negative prostate biopsies. He demonstrated that variation of technique as well as template deviation resulted in a higher percentage of false negative biopsies with the potential for delay in treatment and subsequent worsening of outcomes. CSSALT is applying for funding for the patient-testing phase that it plans to continue conducting at several North American centers.

Lisa Brown, MS, CGC Genetic Counselor for the UF Health Hereditary Cancer Program, provided a provocative lecture on germline mutations that increase the risk of prostate cancer. The lifetime risk for prostate cancer without a family history is 8%. This increases to 35-45% lifetime risk for hereditary prostate cancer defined by specific germline mutations. Current and future research will help to better identify individuals who will benefit from germline testing. Specifically,

National Comprehensive Cancer Network (NCCN) guidelines currently recommend that men with germline BRCA 1/2 mutations consider annual screening beginning at age 40.

In addition, intraductal carcinoma of the prostate (IDC-P), was discussed as a widely recognized and lethal variant of prostate cancer. IDC-P is reported in almost half the men harboring germline deleterious mutations of deoxyribonucleic acid (DNA) damage repair genes (DDR) compared to only 12% of the men without the mutations. Moreover, in men with metastatic prostate cancer, the DDR mutation rate of 11.8% significantly exceeds the mutation rate of 4.8% in men with localized prostate cancer and 2.7% of persons diagnosed with any cancer. DDR mutations are the only clinically targetable mutations in men with prostate cancer and the Food and Drug Administration (FDA) granted a breakthrough therapy designation for poly (ADP-ribose) polymerase (PARP) inhibitors for men with castration resistant prostate cancer (CRPC). PCAC endorses NCCN guideline recommendations for genetic testing for men diagnosed with IDC-P as well as for men with metastatic prostate cancer.

Lisa Richardson, MD, MPH, Director of the Division of Cancer Prevention and Control at the CDC, defined the agency's long-standing role in providing prostate cancer education that includes online decision aids for prostate cancer screening. Additionally, the CDC has focused specifically on developing tools to support and enhance discussions between physicians, patients and family members that include use of active surveillance and the trade-offs of various treatment options. The CDC also addresses the burden of prostate cancer, including monitoring trends of incidence and enhancing prostate cancer data quality. Supported research addresses the stage at diagnosis, patient ethnicity and patterns of care through the National Comprehensive Cancer Control Program. The CDC has continued to enhance an expanded educational tool for cancer patients, including a new interactive Avatar that applies to prostate cancer screening and treatment.

Folakemi Odedina, PhD, Professor and Chair of the College of Pharmacy Diversity and Inclusion Task Force addressed the board on global prostate cancer disparities. Significant differences in incidence and mortality of prostate cancer based on race and ethnicity were outlined. She offered a predictive model of

prostate cancer based on risk, protective and personal factors which additionally emphasized ethnic variability of risk within the black population.

Christopher Cogle, MD, Chairperson of Florida CCRAB provided an update on the proposed 2020-2025 Florida Cancer Plan. The Plan addresses objectives and strategies within goals that include collaboration, data, prevention and risk reduction, screening and early detection, diagnosis and treatment, quality of life, survivorship and end of life care, childhood cancers and research and technology development. PCAC endorses the Plan and the importance of cancer control in Florida, collaboration among stakeholders, health equity and policy change to benefit the population. The Plan itself is a blueprint to reduce the burden of and suffering from cancer for all people living in Florida.

Daniel Armstrong, MD, Chairperson of Florida BRAC addressed 2018-19 funding recommendations available for the Bankhead Coley and the James and Ester King programs. Bankhead Coley had 140 submissions of which 15 were funded, including 2 in prostate cancer representing 13% of projects funded. James and Ester King had 85 applications of which 10 were funded and no prostate cancer grants. Challenges continue for well written applications to achieve funding status.

Finally, Ali Kasraeian, MD, as a new PCAC board member, addressed the council on mechanisms to enhance community outreach including engaging local and regional partners with a similar focus. This pertains especially to existing focused awareness efforts such as Project Zero, Relay for Life and Prostate Cancer Awareness month. New partners such as the Jacksonville Jaguars are potential collaborators in his broadening community effort.

The goals of prostate cancer screening are essentially two-fold. One is to identify high-risk disease that can be successfully treated. The other is to prevent the mortality and morbidity of advanced disease at diagnosis including painful bone metastases and urinary tract obstruction.

PCAC is uniquely comprised of scientists, physicians, and patient advocates representing diverse communities and institutions. The Council is dedicated to the improvement of prostate cancer related outcomes across the state.

Scope of Work 2020

1. Continue collaborative efforts with CCRAB, the Regional Cancer Collaborative, and other state cancer control stakeholders to increase the percentage of Florida men aged 40-85 years old who have discussed the advantages and disadvantages of prostate cancer screening with a healthcare provider (2020-2025 Florida Cancer Plan Objective 13.1).

2. Continue collaborative efforts with BRAC to support state investment into research that improves cancer prevention, detection, biopsy technique, access to care, treatment and survivorship (2020-2025 Florida Cancer Plan Goal 13).

3. Work with CCRAB, the Florida DOH, and other state cancer control stakeholders to identify or develop a surveillance method that measures the percentage of men who are above-average risk for prostate cancer and who have undergone prostate cancer screenings (2020-2025 Florida Cancer Plan Objective 13.2).

4. Continue to expand community outreach, including the incorporation of community health workers and patient navigators, to help address cultural sensitivities related to prostate cancer diagnosis. Explore "closing the gap" initiatives that address cultural, economic and local access barriers to prostate cancer screening, biopsy and treatment. Explore remedies that address workforce issues that impact access to physicians and care providers, especially in rural areas of Florida.

5. Develop a guide on genetic counseling resources within the state including best practices for genetic testing for prostate cancer. Consider the development of a tool to help physicians identify patients needing genetic testing similar to the USPSTF statement for BRCA-related breast cancer.

6. Expand efforts to partner with the statewide Regional Cancer Control Collaborative to improve prostate cancer awareness and education through existing voluntary organizations.

7. Promote PCAC as the statewide educational resource for the most updated, reliable and credible information relating to prostate cancer detection and management for patients, providers, advocates and families.

Provide educational tools including electronic, pamphlets, speakers and webinars to disseminate information. Facilitate the standardization of the message content provided by physicians to patients.

a. Provide a clear, dependable and understandable source document for prostate cancer that addresses the benefits and risks of screening including prostate biopsy which is risk-adjusted and promotes shared decision-making. The document is to be Florida-focused, nationally aligned and adjusted real-time to reflect updates in guideline recommendations.

b. Continue to expand web presence, including links to recognized expert websites.

8. Develop CQI's with academic and private practice physicians to integrate and improve patient care related to cancer. This includes the potential for simulation-based training and data-sharing in regards to ultra-sound guided template (systematic) prostate biopsy techniques to reduce the false negative prostate biopsy rates.

9. Update PCAC Board membership per statute to maintain geographic and institutional diversity as well as broad stakeholder input and direction. Institute a viable and supportive succession plan.

Respectfully Submitted by

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