Overview of H.R.7750, the PC-CARE Act

Congressional Ask:

The Prostate Cancer Community Assistance, Research and Education (PC-CARE) Act – Rep. Greg Murphy (R-NC) and Rep. Bobby Rush (D-IL) are leading the PC-CARE Act to establish a Prostate Cancer Coordinating Committee to monitor, coordinate, and evaluate the activities of Federal prostate cancer research programs. This bill (H.R.7750) would ensure that federal agencies – including the NIH, DoD, CDC, VA, and others – are meeting regularly to discuss priorities in prostate cancer research and align their work with private funders in order to maximize value and move more quickly toward a cure. We ask for your support and cosponsorship of the PC-CARE Act, H.R.7750.

Background:

There are dozens of offices and agencies across the federal government involved in prostate cancer care, treatment and research. Many important formal partnerships and informal networks exist to link the disparate federal agencies with each other and with the prostate cancer community. However, our community could benefit significantly from a formalized structure to ensure that the major funders of research and policy writers are informed by each other’s activities and by the patient community. Many other disease groups, including Alzheimer’s,1 muscular dystrophy,2 breast cancer,3 HIV/AIDS,4 autoimmune diseases,5 arthritis,6 tick-borne diseases,7 asthma,8 sickle cell disease,9 and autism10, have had their coordination aided by federal leadership in convening and organizing the various entities involved in their research and treatment policies. We believe this approach could be beneficial for the prostate cancer community as well.

Prostate Cancer Relevant Organizations:

The federal agencies most commonly engaged in prostate cancer research and research-informed policy include:

**National Institutes of Health (NIH).** The NIH provides almost $40 billion in biomedical research support annually to academic and industry partners across the country. Within the NIH, the National Cancer Institute (NCI) is responsible for the lion's share of the $280 million in extramural prostate cancer research granted out each year by the NIH. The National Institute for Biomedical Imaging and Bioengineering (NIBIB) and the National institute on Minority Health and Health Disparities (NIMHD) also have important contributions to prostate cancer research. Additionally, the NIH Clinical Center conducts intramural prostate cancer research.

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1 https://aspe.hhs.gov/collaborations-committees-advisory-groups/napa/napa-advisory-council
2 https://www.mdcc.nih.gov/
3 https://www.cdc.gov/cancer/prostate/what_cdc_is_doing/prostate_cancer_and_young_women.htm
4 https://www.niaid.nih.gov/about/committees-aids-research
5 https://www.niaid.nih.gov/about/autoimmune-diseases-committee
6 https://www.fda.gov/advisory-committees/human-drug-advisory-committees/arthritis-advisory-committee
7 https://www.fda.gov/advisory-committees/tickborne-disease/index.html
10 https://iacc.hhs.gov/about-iacc/overview/
Department of Defense (DoD). The DoD’s Congressionally Directed Medical Research Program (CDMRP) provides $110 million in extramural research grants to academic and industry investigators. The DoD’s military treatment facilities, including the Walter Reed Prostate Cancer Center of Excellence, provide screening and care to active-duty service members diagnosed with prostate cancer. The Defense Health Agency (DHA) decisions about Tricare’s coverage of prostate cancer treatment for active-duty service members, their dependents and retirees.

Veterans Administration (VA). The VA’s Veterans Health Administration provides screening and treatment to veterans diagnosed with prostate cancer at clinics and hospitals across the VA’s national system. The VA also conducts intramural research with its academic partners on prostate cancer.

Food and Drug Administration (FDA). The FDA is responsible for reviewing and approving drugs, biologics, and medical devices for medical use in the United States. The agency plays a significant role in moving research breakthroughs to bedside treatments for prostate cancer.

Centers for Medicare and Medicaid Services (CMS). CMS sets prostate cancer screening and treatment reimbursement rates for Medicare and Medicaid, the government health insurance programs for older, low-income, and disabled Americans. The agency also makes determinations about what prostate cancer services will or will not be covered and under what circumstances those services can be offered. CMS sets the tone for how private payers engage with providers, and private insurers are greatly influenced by CMS rates and coverage decisions.

Health Resources and Services Administration (HRSA). HRSA’s oversees the Health Center Program, a national network of health centers that provide comprehensive primary health care services to more than 27 million people nationwide, regardless of a patients’ ability to pay. HRSA’s screening decisions for prostate cancer are important because health centers are often the key primary care provider for low-income individuals.

Centers for Disease Control and Prevention (CDC). The CDC provides grants to states to conduct cancer education and prevention work, and many states have prostate cancer activities incorporated into those programs. The CDC also conducts outreach and education on prostate cancer at a national scale, engaging private sector partners to help disseminate their materials and information about screening and treatment options. Importantly, the CDC also conducts vital surveillance around prostate cancer and runs the nation’s cancer registries.

Coordination between these agencies, and several other smaller federal offices involved in prostate cancer treatment and research, is imperative for our community to work collaboratively to eliminate prostate cancer deaths and reduce its incidence rate across the country. While some agencies do engage each other in formal and informal ways (for example the DoD includes NIH program managers on its integration panels and conducts outreach to the VA on prostate cancer incidence among veterans), these agencies do not routinely meet to discuss their priorities in prostate cancer research and treatment.

In addition to federal government organizations, private sector groups can also play a vital role in informing prostate cancer policies. Organizations representing providers and patients and funding research all have unique perspectives and relationships with federal agencies that when coordinated can provide strong, complementary and comprehensive inputs into a broader prostate cancer strategy. For example, the Prostate Cancer Foundation (PCF) is one of the largest private funder of prostate
cancer research, awarding over $20 million a year in research grants. PCF hosts scientific conferences and partners individually with some federal agencies, like the VA. Additionally, the **American Urological Association** (AUA) is the premiere medical society for urologists with over 23,000 members. They conduct extensive continuing education for members and establish standards of care and clinical guidelines for the treatment of prostate cancer. The AUA often works with agencies like CMS on reimbursement issues. **ZERO** also provides a unique and complementary perspective focused on patients and with strong relationships with the DoD and CDC.

**Coordinating Committee Model:**

Congress, the President, and agency heads can establish federal advisory committees (which can also be called commissions, councils, task forces, or working groups) to assist congressional and executive branch policymaking and grantmaking. In some cases, federal advisory committees assist in solving complex or divisive issues while others provide ongoing advice on long-standing topics of concern. There are over 1,000 federal advisory committees. The Federal Advisory Committee Act (FACA) regulates how these committees are run, dictating requirements for meetings be open to the public, accept comments, and for committee to be accessible to the public.

Among the various federal advisory committees, there are several models for organizing. For some groups, all the members are from the private sector, while other committees have a mix of government and private sector members. In general, one agency acts as the sponsoring organization for the committee and provides administrative support for the committee’s activities.

**PC-CARE Act:**

Representative Greg Murphy (R-NC) is a urologist with a strong interest in prostate cancer issues. He introduced the Prostate Cancer Community Assistance, Research and Education (PC-CARE) Act (H.R.7750) with Congressman Bobby Rush (D-IL), a longstanding supporter of the prostate cancer community. This legislation would create a prostate cancer coordinating committee administered by NIH to monitor, coordinate, and evaluate prostate cancer research programs carried out by Federal agencies. The coordinating committee would meet times a year, and in its first year would produce a report outlining federal work of the Departments of Defense, Veterans Affairs, and Health and Human Services with regard prostate cancer programs and activities. This report would also evaluate the effectiveness of the following activities and make recommendations for improvements related to:

- Research activities on the underlying causes, prevalence, treatment, and mortality of prostate cancer, including disparities for high-risk men;
- Current screening and diagnostic techniques;
- Current treatments;
- Clinical practice guidelines;
- Clinical pathways;
- Research on quality of life improvements for survivors; and,
- Outreach and education programs for providers and the public, including high-risk men.

The committee would be required to update the report every three years. The committee would be limited to 24 members on three-year rotating terms. Half of the membership would be required to be physicians, and half would be representatives from federal agencies. Federal government members would be from the NIH, CDC, HRSA, CMS, FDA, DoD, and the VA. Non-government members would include at least three of each of the following categories: patients (or their caregivers), clinicians, researchers, patient group representatives, and professional medical society representatives. These groups can overlap. For example: a physician employed by the NIH to do intramural research could fulfill the physician, NIH representative, and researcher membership requirements.