An historic conference titled “A Leadership Conference—Prostate Cancer in the African-American Community: An Agenda for Action” was held November 20 to 22, 1997, in Houston, Texas. The meeting—which was a collaborative effort of the American Cancer Society, the Centers for Disease Control and Prevention, and the National Cancer Institute—examined the unique challenge that prostate cancer poses to the African-American community.

Among the relevant research findings (and the investigators responsible for the findings) were the following:

1. Tracking disease patterns by “race” is inherently difficult because of multiple confounders, such as socioeconomic status and lifestyle choices. Susceptibility to disease can be studied more rigorously using specific allelic domains as opposed to broad racial and genetic hypotheses. (Richard S. Cooper, MD, and Vincent L. Freeman, MD, Loyola University, Stritch School of Medicine, Marywood, IL.)

2. Young African-American men may have increased exposure to elevated levels of androgens. Evidence exists for genetic differences among men of differing races that could correlate with variations in prostate cancer incidence and aggressiveness. (Curtis A. Pettaway, MD, University of Texas M.D. Anderson Cancer Center, Houston, TX.)

3. Early detection tests generally identify clinically significant prostate cancers and have greatly reduced the number of men initially diagnosed with advanced disease. Some evidence suggests that the recent small decline in prostate cancer mortality may be, in part, the result of early detection; however, corroborative studies have not yet been completed. (Robert A. Smith, PhD, and Harmon J. Eyre, MD, American Cancer Society, Atlanta, GA.)

4. African-American women significantly influence health-related behaviors of African-American men. Preliminary data also suggest that African Americans are more likely to carry the genes associated with prostate cancer diagnosis at an earlier age. African-American males also may be at higher risk because of high dietary fat and low levels of lycopene compared with other groups. (Isaac J. Powell, MD, Wayne State University, Detroit, MI.)

During the conference, the American Cancer Society confirmed its commitment to earmark 10% of its annual $80 million research budget for prostate cancer. A National Blueprint for Action was developed and is included in this article. A follow-up news conference announcing the Leadership Conference’s findings and recommendations was held in January 1998.
Prostate Cancer National Blueprint for Action

PREAMBLE

The possibility—and the fear—of developing prostate cancer are common to all men. The statistics alarm all of us: prostate cancer is the second leading cause of cancer death in men. In 1998 it is estimated that 184,500 men will be diagnosed with prostate cancer and that approximately 39,200 men will die of the disease.1 As frightening as these figures are, we must note the special circumstances of African-American men regarding prostate cancer. Prostate cancer incidence rates are nearly two times higher for African-American men than for white men.

For reasons that we do not yet fully understand, African-American men live out their lives with a disproportionately high risk for developing and for dying of prostate cancer. African-American men in the United States have the highest rate of incidence for prostate cancer in the world, and their mortality rate is more than twice that of white American men.

We do not know why this is true, and we do not yet have answers to the many questions about prostate cancer. Can prostate cancer be prevented? Does screening save lives? Does aggressive treatment save lives? How can we create a demand for information about prostate cancer among the African-American population? What can we do to build trust in the health care system among African Americans? How do we go about involving more African-American scientists and patients in prostate cancer research? How can we enhance the capacity of health care providers and systems to deliver the best care possible both to African Americans who are in a system of care and to those who are currently outside a system of care?

The number of questions we have about this disease complicates the task at hand. Often it is not clear which prostate cancer patients will benefit from treatment. Choosing treatment can be difficult because each treatment option has its own set of benefits and complications. In addition, a disproportionate number of African-American men are poor, are not well educated about medical issues, and may have less access to medical counseling than do white American men. If we are to target this population, how do we go about creating a population of African-American men who can make informed decisions about prostate cancer and its treatment?

Those who are devoted to relieving the burden of prostate cancer in the African-American community—scientists, health care providers, national organizations, African-American community leaders, and prostate cancer survivors—are united in their desire to answer these questions.

To this end, in November 1997 the American Cancer Society, the National Cancer Institute, and the Centers for Disease Control and Prevention sponsored “A Leadership Conference on Prostate Cancer in the African-American Community.” Developed in cooperation with the Intercultural Cancer Council, the National Black Leadership Initiative on Cancer, and the National Prostate Cancer Coalition, the Leadership Conference has developed a Blueprint for Action that aims to address the questions noted earlier and many others also. The 100 Black Men of America, Inc. was particularly helpful in leading the conference.

The Leadership Conference has outlined action steps to be undertaken in the following areas:

- Research in basic and behavioral science
- Health promotion and education based on science
- Education and support for patients
- Public policy

This conference represents the first step in developing a blueprint that will guide a nationwide initiative regarding
prostate cancer in the African-American community. Each group represented at the Leadership Conference makes a unique contribution to this collaboration and benefits from the work of all the partners involved in this effort. Our goal for the Leadership Conference is to help, in whatever way we can, those in the African-American community who have been touched by prostate cancer.

**ACTION STEPS**

**Research in Basic and Behavioral Science**

- Increase research into the disproportionate incidence of and mortality from prostate cancer in African-American men and further clarify effective treatment and prevention modalities for the disease.
- Increase research to identify risk factors associated with prostate cancer in African-American men. This research should include, but not be limited to, gene-environment interaction, genetic mutations and variations more prevalent in or unique to African Americans, research to distinguish between aggressive and nonaggressive tumors, and basic and behavioral research on dietary factors.
- Test new technologies for the early detection, diagnosis, and treatment of prostate cancer and apply them when the technologies are proved effective.
- Work with agencies and organizations involved in funding research efforts (i.e., American Cancer Society, American Urological Association, CaP CURE, Centers for Disease Control and Prevention, Department of Defense, National Cancer Institute, and others) to identify and address barriers, such as education, trust, understanding, and communication, that are responsible for low minority participation in clinical research trials of early detection and prevention initiatives. Additional research should address the development of effective messages, intervention approaches, mechanisms to deliver information to patients and survivors, and model follow-up programs.
- Perform research on how African-American men seek medical information and medical attention and follow up on treatment recommendations. This information should be used in the development and dissemination of messages about early detection and treatment of prostate cancer for African-American men and their families by state health departments and community-based organizations.
- Involve African-American scientists, institutions, and laypersons to a greater extent in prostate cancer research. Their involvement should include management and participation in research and advocacy for research. Related activities should include creating opportunities and funding that target African-American students for science careers.
- Increase minority professional and patient participation in the development and implementation of clinical trials.
- Develop creative new approaches to increase participation in clinical trials and enhance trust on the part of African Americans. Research opportunities should not be limited to populations available to universities or cancer centers but should be open to men going to community cancer centers and to rural and inner city populations.

**Health Promotion and Education Based on Science**

- Formulate and evaluate simple and concise educational messages about increased mortality from prostate cancer in the African-American community and the limitations and benefits of early detection methods. The message should be multifaceted and should be delivered primarily via radio but also via television and print media. Marketing experts should be involved in the framing and delivery.
- Collaborate with the medical and
lay leadership of the African-American community to develop creative and innovative public education programs and local and regional symposia on prostate cancer. These programs should focus on conveying knowledge about prostate cancer and on allaying common fears of early detection examinations. The programs must work to dispel the distrust that many African-American men may feel toward the medical system. Community leaders should be asked to serve as resources when primary care practitioners work with communities.

• Promote effective communication among the medical and scientific community, the lay public and grass roots organizations, and survivor and spouse groups using high-quality, relevant materials.

• Improve professional and public awareness and understanding of the benefits of clinical trials. This should include improved communication between the cancer research community and primary care physicians.

• Develop and carry out strategies to reduce the full range of barriers to the delivery of early detection counseling by community physicians and other providers. Primary care practitioners need to be educated well enough to interact with patients and participate in discussions that will lead to informed decisions by the patient.

• Increase consideration of interdisciplinary management of prostate cancer. Educate patients to seek a full range of treatment consultations and options.

• Educate health care providers and consumers on prostate cancer risk factors, including recommendations to reduce the percentage of fat in the diet of the American population to less than 30% of total calories. Emphasis should be on changing the diet of people of all ages, including children and adolescents.

• The medical and scientific community must resolve the different messages on early detection and screening for the public. Health care providers should discuss these issues with men in appropriate age groups.

Education and Support for Patients

• Provide comprehensive education about prostate cancer for African Americans in their communities, with emphasis on peer education. Community members, families, and survivors must help in framing and delivering messages. Education should focus on early intervention and promote informed decision making. It should be honest and should create reasonable expectations about the disease. Information should be spread about local education and support activities and services. Individual messages should be tailored to the state of readiness for information, age, family history, and other factors.

• Provide opportunities for men who have been diagnosed with prostate cancer to have ongoing personal follow-up and contact through education and support groups such as Man to Man and US TOO. Develop programs to address and meet local community needs for education and support. Programs should be evaluated and updated regularly. Groups should be survivor-driven. Recognize that the needs of newly diagnosed men may differ from those of long-term survivors.

• Explore and develop appropriate collaborations (i.e., community and religious leaders, pharmaceutical companies, local hospitals, health care providers, health care organizations) to reach the target audience. Gain support of health care providers and ask them to invite men and their families to education and support programs. Endorsement by church leaders and local community leaders gains credibility and acceptance for messages about prostate cancer.

• Reach out, educate, and invite appropriate national and local leaders and organizations to help spread messages and encourage facilitation of educational and support programs.
Empower patients in their relationships with their medical providers so that they are comfortable asking questions and making decisions about their own health care. Spouses or partners and family of patients should accompany them to appointments and treatment so that family and partners can help in decision making and support.

**Public Policy***

- Develop innovative strategies and approaches that eliminate barriers to participation of African-American men in clinical trials.
- Advocate for significantly increased funding for basic clinical, psychosocial, and applications research programs to be supported by, for example, the Agency for Health Care Policy and Research, the American Cancer Society, the American Foundation for Urologic Disease, CaP CURE, the Centers for Disease Control and Prevention, the Department of Defense, the Department of Veterans Affairs, the Mathews Foundation for Prostate Cancer Research, the National Cancer Institute, the National Prostate Cancer Coalition, and others. Research and the application of research offer the greatest promise for action against prostate cancer in the African-American community.
- Advocate for coverage by private and public insurers of the costs of early detection of prostate cancer for men at highest risk for the disease, including men 50 years of age and older and younger African-American men who are at high risk. Advocacy should aim for specific state-by-state mandates for coverage. Still, the decision to be screened for prostate cancer will be made by a man in consultation with his doctor. Men who decide with their doctors to be tested for prostate cancer should not have their decision altered by financial considerations.
- When possible, work with other groups that have special health concerns (such as those with an interest in breast cancer) to bring about more sweeping change in the health care system and avoid competition for funds.
- Ensure the availability of follow-up care and treatment for men found to have cancer during early detection screening. Programs should make provisions for those who have no public insurance and those in rural areas who have transportation and lodging needs.
- Speak with one voice for African-American men and women when public policies are being formed and funding decisions are being made. Action to address prostate cancer in the African-American community can be achieved only by overcoming the exclusion, indifference, and lack of organization that prevent African-American men and their families from influencing public policy related to prostate cancer.
- Strengthen the capacity of national grass roots organizations, particularly those representing African Americans, to engage in advocacy at every level of government and to mobilize their constituencies in a coordinated manner on prostate cancer issues. Ongoing grass roots activism should be guided by cost:benefits analysis and must be supported with dedicated staff resources, advocacy training, and timely information about how and when to mobilize to influence public policy.

* The American Cancer Society was the sole sponsor of the public policy portion of the Leadership Conference. The public policy action steps in this document represent advocacy directives for the American Cancer Society and other nongovernmental agencies and do not represent the position of the National Cancer Institute and the Centers for Disease Control and Prevention.

**Reference**

1. Landis SH, Murray T, Bolden S, et al: Cancer statistics, 1998. CA Cancer J Clin 1998;48:6-29.