# Future Directions for Public Health Practice and Research in Prostate Cancer

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# Acronyms

| | |
|---|---|
| ACS | American Cancer Society |
| AUA | American Urological Association |
| BPH | benign prostatic hyperplasia |
| BRFSS | Behavioral Risk Factor Surveillance System |
| CDC | Centers for Disease Control and Prevention |
| CME | continuing medical education |
| DRE | digital rectal examination |
| HCFA | Health Care Financing Administration |
| HEDIS | Health plan Employer Data and Information Set |
| IGF | insulin-like growth factor |
| NCI | National Cancer Institute |
| NDI | National Death Index |
| NHANES | National Health and Nutrition Examination Survey |
| NHIS | National Health Interview Survey |
| NIH | National Institutes of Health |
| NPCR | National Program of Cancer Registries |
| NVSS | National Vital Statistics Systems |
| PIN | prostatic intraepithelial (or intraductal) neoplasia; a pathologically identifiable condition believed to be a possible precursor of prostate cancer; also known more simply as dysplasia |
| PLCO | Prostate, Lung, Colorectal, and Ovarian Cancer Screening Trial |
| PSA | prostate-specific antigen |
| RFP | request for proposals |
| SEER | Surveillance, Epidemiology and End Results |
| SES | socioeconomic status |
| TNM | a system for classification of tumor spread |

# Executive Summary

Prostate cancer is a common cause of cancer-related morbidity and death in the United States (U.S.), and public health agencies and other organizations involved in cancer prevention and control are increasingly asked to play an active role in the effort to reduce the burden of prostate cancer. Yet, there is very little consensus among scientists and public health practitioners on effective prevention and control measures. There are no commonly recognized modifiable risk factors for prostate cancer. In addition, although prostate specific antigen (PSA) testing and digital rectal exams (DREs) are commonly used to screen for prostate cancer, there is no consensus that screening reduces risk of death or increases quality of life. Since prostate treatments commonly cause serious side effects, there is no consensus that the potential benefits outweigh the harms of screening and treatment.

To help address this situation, the Centers for Disease Control and Prevention (CDC) organized a workshop—*Future Directions for Public Health Practice and Research in Prostate Cancer*. The purpose of the meeting was to provide a forum for discussion of issues in prostate cancer prevention and control and to develop suggestions on how public health organizations can engage in research and program activities to address prostate cancer. Eighty-nine researchers, public health and medical practitioners, and representatives of community organizations and volunteer associations from Canada, Europe, and the U.S. attended. The meeting was held in San Diego, California on December 6 - 8, 2000.

Meeting participants were asked to discuss four major issues in prostate cancer prevention and control: understanding the risk and burden of the disease and its associated interventions, primary prevention, secondary prevention and treatment, and quality of life for survivors. Participants were also asked to suggest future public health activities in four areas: surveillance and monitoring, research, health communications, and other programs and services.

Because a number of controversies surround the issue of prostate cancer prevention and control, the meeting organizers did not anticipate consensus among the meeting participants. The meeting was organized to provide a range of suggestions reflecting the diversity of thought and, where possible, to reflect general or partial agreements among meeting participants on some specific recommendations. Recommendations regarding screening for prostate cancer were not the focus of the meeting. CDC, the meeting organizer, supports the recommendations developed by the U.S. Preventive Services Task Force. The Task Force does not recommend screening because there is insufficient evidence available that screening is effective or that benefits outweigh harms.

Small groups in breakout sessions discussed each of the four prostate cancer control issues and each of the four categories of public health activity. Groups discussed recommendations about what public health organizations should be doing in each area. They also selected a set of suggestions to be highlighted and reported these suggestions back to the meeting as a whole.

Participant recommendations are summarized in the chapter for each session. Highlighted suggestions are listed at the end of the chapter summary. The diversity of the discussions and recommendations cannot be captured in this executive summary. However, several recommendations that emerged repeatedly in discussion and in highlighted suggestions are summarized here. Although prostate cancer screening recommendations were not the focus of discussions, much discussion centered on public health activities related to screening.

A common topic in discussion during many of the sessions was the need for better communication about secondary prevention of prostate cancer. One suggestion from several sessions was that public health agencies, and CDC in particular, should be active in developing both messages and strategies to communicate to the public and to practitioners the uncertainties about the effectiveness of screening and the balance of potential benefits and harms from screening and treatment of screen-detected cancer. This activity should include reviewing scientific evidence on the effectiveness of screening, conducting research on how to summarize and communicate this complex information (e.g. through decision aids) and developing programs to deliver the information to the public and providers. Meeting participants recommended collaboration by public health agencies with other organizations to review evidence, provide better access to information, and address barriers to communication.

For other public health programs and services, participants recommended that public health organizations build infrastructure to facilitate collaborative research in secondary prevention and develop programs to encourage participation in clinical trials of primary and secondary prevention and treatment.

In the area of public health monitoring and surveillance of prostate cancer, participants commonly recommended improved surveillance of prostate cancer screening and of provider and public knowledge about prostate cancer. To complement clinical trials of the effectiveness of screening and treatment and research on risk factors, it was recommended that cancer registries expand the kinds of data collected and link registry information to other data sources to facilitate related analyses. Another recommendation was that public health conduct additional and longer term follow-up studies of men with prostate cancer compared with men without cancer, to provide better information on screening and treatment outcomes and quality of life.

In public health research, in addition to recommendations noted above, a major focus was on research to better understand disparities among U.S. population subgroups in prostate cancer incidence, mortality, and other measures of disease burden. Because of the great variation in risk and burden by race/ethnicity and other demographic characteristics, emphasis was placed on the need for improved understanding of the reasons for these disparities, from risk factors through health services. Another focus of research interest was in development of better information on quality of life of prostate cancer survivors and the development of better measures of quality of life for use in follow-up studies of survivors.

The issue of disparities was also addressed in terms of the need to develop and provide communications that are specific for population subgroups, the need for programs to facilitate access to services and information, and the need for improved surveillance of different demographic subgroups.

# Overview

Prostate cancer is a common cause of cancer-related illness and death among men in the United States. Although public health agencies and other organizations involved in cancer prevention and control are increasingly asked to play an active role in reducing the burden of prostate cancer, scientists and public health practitioners have not yet established a consensus on effective prevention and control measures. A number of questions and controversies surround the issue of prostate cancer prevention and control. There are no commonly recognized modifiable risk factors for prostate cancer. In addition, although prostate specific antigen (PSA) testing and digital rectal exams (DREs) are commonly used to screen for prostate cancer, there is no consensus that screening reduces risk of death or increases quality of life. Since prostate treatments commonly cause serious side effects, there is no consensus that the potential benefits outweigh the harms of screening and treatment.

To provide a forum for discussion of these issues and to develop suggestions for public health research and program activities, the Centers for Disease Control and Prevention organized a workshop entitled *Future Directions for Public Health Practice and Research in Prostate Cancer.* On December 6–8, 2000, 89 researchers, public health and medical practitioners, and representatives from community organizations and volunteer associations attended the workshop in San Diego, California (Appendix A: Plenary Session).

At the workshop, participants discussed four major topics in prostate cancer prevention and control:

I. Disease Burden and Risk
II. Primary Prevention
III. Secondary Prevention and Treatment
IV. Quality of Life for Survivors

Participants were also asked to recommend future public health activities in four areas:

V. Surveillance and Monitoring
VI. Research
VII. Public Health Programs and Services
VIII. Health Communication

In breakout groups, participants discussed the four main topics in prostate cancer prevention and control and the four future public health activities. The groups then selected a few suggestions to highlight in a report of the results of their discussions to the larger meeting of all participants. Because CDC follows the screening recommendations established by the U.S. Preventive Services Task Force, participants did not focus on prostate cancer screening guidelines at this workshop. The Task Force does not recommend screening because there is insufficient evidence available that screening is effective or that benefits outweigh harms.

# I. Disease Burden and Risk

In this session, participants focused their discussion on the disease burden of prostate cancer in the United States. Disease burden was defined as the number of new cases a year (incidence) and included the number of cases per age category and variations in incidence due to geography and race, and the associated morbidity. Some participants suggested that economic burden and health care costs also should be considered burdens of the disease. Others added that disease burden goes beyond the physical problems and pain of prostate cancer to include the emotional burden and anxiety of both the patient and his loved ones.

Participants addressed four areas of public health activity in prostate cancer: surveillance and monitoring, research, services and programs, and health communications.

**Surveillance and Monitoring**

The participants recommended three public health activities in the area of surveillance. First, public health organizations should use a number of resources and complementary data sources, such as population-based data sources, to complement research findings from randomized clinical trials. Population-based data sources include the National Health and Nutrition Examination Survey (NHANES), the National Program of Cancer Registries (NPCR), National Vital Statistics Systems (NVSS), and the Surveillance, Epidemiology, and End-Results (SEER) Program. Public health surveillance systems should include information that would allow epidemiologists to track the natural history of prostate cancer and study trends over time. This information should include race and ethnicity (subgroup data), geographic distribution, demographics, family history, socioeconomic status, median survival, disease-free survival, and long-term outcomes. Currently, clinical trials are designed to measure the effectiveness of screening and treatment, but the data cannot provide information for all U.S. sub populations.

Second, cancer registries that include men diagnosed with prostate cancer should be linked to large national health surveys that have information on risk factors and health behaviors for prostate cancer. Linking such data might be useful for both SEER and NPR. The participants suggested the following resources: the National Health Interview Survey (NHIS), the National Death Index (NDI), the Health Care Financing Administration (HCFA) and the Social Security Administration databases, and administrative records.

Participants stressed the importance of longitudinal studies in the surveillance of prostate cancer because most studies are cross-sectional. The study data should also be linked to registries with other data sources to allow for research on risk factors for prostate cancer. Members of the workshop also suggested that questions regarding PSA testing, such as "Have you had a PSA test in the past 12 months?" should be added to national surveys, and might provide useful information.

For the third recommendation, participants stressed the importance of including race/ethnic subpopulations in surveillance systems for prostate cancer. To clearly define the burden of prostate cancer disease and risk, public health organizations should collect demographic and

geographic details and risk factor status (socioeconomic status). Small race/ethnic groups should also be studied to avoid the need to use estimates. Because prostate cancer is so prevalent, the workshop members suggested that these data would be readily obtainable.

**Research**

In the area of disease burden and risk research, participants suggested that public health organizations use surveillance data to measure the efficacy of prostate cancer treatments for at least 2 years after surgery or treatment. Participants agreed that in the interim, public health organizations should be using existing surveillance systems to examine efficacy.

Participants discussed the need for better health profiles to adequately assess risk. To accomplish this goal, they suggested that public health organizations conduct individual-level and ecological-level studies of relationships between socioeconomic status and incidence, mortality, and morbidity of prostate cancer. These studies should include information on the duration and severity of concurrent morbid (comorbid) conditions. Because research suggests that 50 percent or more of an untreated population with prostate cancer die of other diseases, the participants stressed the importance of studying comorbid factors. They also recommended that public health organizations use cost data to study the economic burden of prostate cancer.

The participants outlined additional, relevant research topics:

- Determine how characteristics, such as stage of cancer, change over time.
- Identify the effects of repeated PSA testing.
- Determine and outline the problems associated with using PSA as a screening device.
- Study the use and effectiveness of intervention strategies other than surgery and radiation for early disease.
- Establish the usefulness of the ratio of free to total PSA as a guide to treatment modality.
- Study the long-term outcomes after surgery (at least two years after treatment).
- Collect data to evaluate severity of prostate cancer.
- Identify the severity of the side effects, such as incontinence and impotence, that are associated with prostate cancer treatments.
- Determine the length of time of recovery following prostate cancer treatments with respect to functions such as mobility, continence, and sexual potency.
- Develop the most appropriate messages to communicate about prostate cancer and screening.
- Identify the best way to communicate appropriate messages about prostate cancer and screening.
- Subject new tumor markers to prospective studies before using the markers in clinical practice.

**Services and Programs**

The participants emphasized the importance of developing programs that would help men and boys become more aware of men's health issues. They suggested that these programs could be modeled after those that target women's health issues. It was noted that programs and

services for men and boys lag far behind those for women, and that public health organizations should identify ways to address the health issues of men and boys. Participants recommended that these programs should also target physicians because some studies show that men do not want their doctors to discuss men's health issues with them.

The participants discussed the potential use and problems of potential Health plan Employer Data and Information Set (HEDIS) measures for prostate cancer.

The participants also discussed whether PSA and DRE should be used as screening tools in employer wellness programs. Some participants argued that without appropriate counseling services, employers should not offer screening because the consequences of an elevated PSA level may be unclear. It was suggested that before advocating any screening programs, public health organizations must decide on a message for prostate cancer screening.

The participants suggested that the Surgeon General's office could prepare a report on prostate cancer that could, in turn, help frame messages to make the public aware of prostate cancer and prostate cancer programs and services. They also prepared the following list of barriers to delivering appropriate programs and services:

- Messages that lack clarity hinder program development.
- Lack of time among primary care physicians limits discussion about prostate cancer issues.
- Lack of knowledge of existing prostate cancer programs hampers the use of these programs.
- Lack of knowledge about prostate cancer and men's health issues hinders awareness among different U.S. populations.

**Health Communications**

The first step in communicating information about prostate cancer is to identify the audiences that public health organizations want to target. The participants suggested the following audiences—the general public, caregivers, primary care providers (including interns), the public health community, and policy makers.

Because the disease burden of prostate cancer is not well understood, the group suggested that the general public needs to be educated about the incidence and disease burden among various racial and cultural groups and the early warning signs and symptoms of the disease.

The group discussed the difficulty of communicating the significance of PSA levels to the public and that early detection saves lives. Men should talk about PSA screening with their physicians because screening is not appropriate for all ages and subgroups of men. A major problem among men is that many do not see a doctor regularly. Some participants suggested that the best way to reach men might be through women because women traditionally oversee the health care needs in families. These participants noted that public health organizations might "get to Mars by going through Venus" and educate women about the need for men to obtain prostate cancer screening.

The group also emphasized the importance of reaching both primary care providers and interns with the language and terminology in the field of prostate cancer and providing them with a better understanding of the symptoms of the disease. Two approaches were suggested. Re-accreditation could be offered in this area through Continuing Medical Education (CME), although CME accreditation varies by state. Another way to reach primary care providers might be through Web sites or pharmaceutical advertising.

The participants also recommended that public health organizations clearly indicate what they want policy makers to do—approve more research, increase funding, or increase reimbursement. Some of the members discussed personal experiences, how prostate cancer affects constituencies of policy makers, funding levels for prostate cancer research versus funding for other research, and the efficacy of PSA testing.

The second step in communicating information about prostate cancer is to identify the content of the messages. A key issue discussed was the problem of determining what messages should be communicated to the public and to public health practitioners. Participants agreed that the message should clearly outline the current knowledge about prostate cancer research, screening, testing, and treatment. Because the information about the disease is uncertain, the participants suggested that different messages should be developed for different subpopulations. For example,

- Develop and communicate risk assessments for specific subgroups.
- Discuss family history and risk profile with primary care provider.
- Encourage counseling before PSA tests are ordered.
- Develop specific messages appropriate for different subpopulations.
- Consider conducting a consensus conference to help public health organizations frame appropriate messages for different subgroups.
- Develop key messages, including the advisability of examinations and screening tests, facts about prostate cancer, and what patients can do when prostate cancer is diagnosed.

Participants made several other recommendations. Encourage public health practitioners and opinion leaders to craft clear messages for various groups. If the message is too simple, it may not convey any meaning. Messages and print materials must convey information that is easy to understand and is clearly designed for both the general public and for health care professionals. The participants suggested the following guidelines for crafting clear messages:

- Clearly address the controversies surrounding PSA testing.
- Produce materials and messages that develop an understanding of the treatment options and their trade-offs.
- Highlight the differences in risk for different demographic groups.
- Encourage public health organizations to disseminate the information to the appropriate groups.
- Develop clear messages for target high-risk groups.
- Conduct social marketing campaigns.
- Actively participate in disseminating the messages.
- Identify barriers to understanding the topics related to prostate health and prostate cancer.

- Communicate issues of risk carefully to avoid public confusion.
- Consider using celebrities to deliver simple messages.

**Highlighted Suggestions**

The group selected the following suggestions to be highlighted for all meeting participants:

***Surveillance and Monitoring***

1. Use population-based prostate cancer-related data sources, such as NPCR, NVSS, and NHANES to complement randomized evidence from clinical trials to address questions about the effectiveness of screening.

2. Link NPCR and SEER registry data with data from large national surveys; longitudinal studies, including NHIS and NDI; health care databases, such as HCFA, Social Security Administration, and hospital discharges; and administrative records.

3. Collect more data on population subgroups and include these data in registries and surveys. The data should include demographic and geographic detail, risk-factor status, and socioeconomic status.

***Research***

1. Use surveillance data to conduct research to supplement information from clinical trials to determine the efficacy of different screening procedures.

2. Conduct research to better describe the disparities in risk and disease burden (incidence, mortality, economic costs, and other measures) among underserved populations. Use race/ethnicity, socioeconomic status, geographic location, and other measures to develop and define underserved populations, particularly African American men. Consider the burden of illness in terms of costs and the use of resources for patients, the workforce, families, and communities.

3. Study the effects of comorbid conditions on the treatment and survival of men with prostate cancer.

4. Conduct research to better understand the economic burden of prostate cancer.

5. Study the duration and severity of morbidity associated with prostate cancer.

***Services and Programs***

1. Use a men's and boy's health paradigm similar to the paradigm developed for women's public health programs.

2. Prepare a Surgeon General's report on prostate cancer.

3. Address barriers to gaining a better understanding of prostate cancer: health messages that lack clarity, lack of time and knowledge on the part of primary care providers, and health literacy among the general population.

4. Encourage employer wellness programs to include information about the uncertainty concerning the risks and burden of prostate cancer and prostate cancer screening.

5. Include measures of informed decision making for prostate cancer screening in HEDIS.

***Health Communications***

1. Address a broad audience—the public, caregivers, primary care providers, the public health community, and policy makers—with appropriate messages for each audience.

2. Focus content of communication on sharing uncertainty about PSA screening, including risk assessment. Stress the importance of having providers discuss screening options with patients in conjunction with risk profile.

3. Request that CDC take an active role in framing messages about prostate cancer.

4. Vary messages depending on risk profile and comorbid conditions of patients.

**Session Participants**

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## II. Primary Prevention

In this session, participants discussed primary prevention of prostate cancer in the United States. To avoid confusion, they agreed on the following definitions of terms:

**Public health—**Includes activities of state public health agencies, CDC and other government institutions, voluntary organizations, and the partnerships of these organizations.
**Surveillance—**The collection and presentation of data to describe trends and patterns of disease, behaviors, the environment, programs, policies, and the use of services.
**Research—**An analytic process that focuses on relationships between disease occurrence, disease characteristics, and risk factors for the disease.
**Communication—** Strategies to raise awareness, key messages, the intent of the message, and how the message should be delivered.
**Programs and services—** Specific services, policies, or environmental characteristics.
**Primary prevention—** Measures intended to reduce the incidence of cases of prostate cancer among individuals before the disease is initiated.
**Secondary prevention—** Detection and treatment of existing disease.

Several participants pointed out that primary prevention of prostate cancer is not possible because the modifiable risk factors for the disease are not known. Thus, determining the cause or causes of prostate cancer and understanding the etiology of the disease is absolutely necessary. This need was reiterated throughout the session.

The participants raised a number of issues regarding primary prevention of prostate cancer:

- How and when to convey information to the public.
- Disseminating information about studies that are underway to dispel beliefs that hypotheses are fact and that results of single studies are fact.
- Communicating the lack of knowledge about the primary prevention of prostate cancer.
- Measuring the success of primary prevention.
- Identifying populations at high risk for prostate cancer.
- Considering possible preventive measures such as diet change not just for prostate cancer, but for other chronic conditions.
- Integrating potential prostate cancer preventive measures into prevention activities for men's health in general.
- Assessing the fragmentation of the public health effort.
- Identifying environmental agents, chemopreventive agents, and dietary factors that affect risk.
- Evaluating self-medication with dietary supplements, such as saw palmetto.
- Identifying risk factors.

The group unanimously agreed that administering the PSA test is not primary prevention.

**Surveillance and Monitoring**

In their discussion of surveillance and monitoring, the participants developed a number of suggestions. First, the public health community should monitor potential modifiable risk factors for prostate cancer. Because the purpose of primary prevention is to lower the risk of new disease, it is essential that risk factors for prostate cancer be identified. To accomplish this goal, epidemiologists should collect data to correlate diet, environment, behavior, and other potentially modifiable risk factors with the onset of prostate cancer. Monitoring all potential modifiable risk factors is unreasonable, so the participants suggested that public health organizations begin to monitor four specific factors—sexually transmitted diseases, eating red meat, consuming dairy products, and low consumption of fruits and vegetables. Some research indicates that these may be risk factors.

Second, to identify risk factors for prostate cancer, the public health community should develop clear consensus on the data to be collected and the monitoring systems to be used. Consensus is needed in coding the stage and grade of prostate cancer. To conduct meaningful trend studies, uniform definitions and coding for stage and grade need to be applied to data from previous years. A committee of experts should be assembled to accomplish this goal. Because several cancer data collection systems are already in place—SEER, NPCR, the Behavioral Risk Factor Surveillance System (BRFSS), and state registries—public health organizations do not have to generate a new system. Rather, the existing systems should be refined, coordinated, and integrated.

The participants pointed out the importance of determining and monitoring the public's awareness of modifiable risk factors for prostate cancer, potential modifiable risk factors, and risk factors that cannot be modified. To gain an understanding of the public's awareness, public health professionals should collect data on what the general public knows about risk factors for prostate cancer and determine the degree to which they are misinformed. The public health community also needs to characterize various populations with respect to their awareness of prostate cancer and related issues. Knowledge of the public's awareness is necessary to learn what needs to be done to clarify some of these issues, particularly for populations at highest risk. More information is needed to know what channels are being used to obtain information about prostate cancer and what sources of information are the most influential.

The group identified several additional areas that require surveillance and monitoring. For example, data are needed to determine the relationship between premalignant stages and high-risk conditions that lead to prostate cancer. To this end, data are needed to identify ways of classifying people in terms of risk. One pathologically identifiable condition the may be a precursor to prostate cancer is prostatic intraepithelial (or intraductal) neoplasia (PIN). Identifying a marker for PIN and developing an understanding of its natural progression is important for a clearer understanding of prostate cancer.

A system is needed to monitor cancer-related behaviors and the incidence and mortality of prostate cancer. This monitoring system should be in place to track behavior changes that men make to avoid prostate cancer. For example, surveys indicate that men are drinking tomato juice and green tea and taking saw palmetto. The participants pointed out the importance of

identifying markers of sexually transmitted diseases and including this information in the monitoring systems because these diseases may be risk factors for prostate cancer.

**Research**

The participants defined applied research in prostate cancer as any research, including epidemiology but not etiology. Applied research in prostate cancer might include improved surveillance methods and use of health services.

The group discussed research to find the causes of prostate cancer. The agreed that, if primary prevention is the goal, the only useful research is to identify the causes of the disease. Although basic research was not the purview of this session, the group stressed the importance of preparing for the day when solid information is available about the causes of prostate cancer. To develop criteria for primary prevention research, the participants suggested several research projects. Three are summarized here:

- The public health community should set up mechanisms to generate hypotheses on the cause(s) of prostate cancer. Epidemiologists should conduct systematic reviews of the prostate cancer literature and perform metaanalyses. These reviews should have a global perspective and should highlight hypotheses concerning risk factors. The goal of the reviews and analyses should be to identify known and potential risk factors and to determine whether the research in other countries is applicable to prostate cancer in the United States. Combining information on human activities with survival or outcome data would be an ongoing mechanism to generate hypotheses. (Although some participants regarded this as a very important research topic, others argued that excellent reviews have already been published in such journals as *Epidemiologic Reviews.*)

- Public health professionals should conduct a historic review of incidence and trends of prostate cancer and correlate these data with events such as PSA testing or changes in diet. This type of analysis might reveal some cause-and-effect relationships.

- Public health professionals should sponsor research on the psychosocial aspects of effective communication. The chief aims of this research should be to learn the public's opinion on risk, what the public knows, how best to communicate the current state of knowledge on prostate cancer risk factors to the public, and how and why individuals change behaviors and lifestyles. The group agreed that determining the factors that motivate behavioral changes would help in efforts to affect change rapidly and effectively, once concrete information is available about actual risk factors for primary prevention.

The participants recommended the following additional research options for primary prevention:

- The public health community might consider enlisting the participation of members of the saw palmetto sales industry to query men who have used this product to determine their prostate health outcomes.

- Public health professionals might encourage investigators to undertake basic research in the following areas: collecting biological samples; conducting research to improve surveillance; investigating the effectiveness of educational methods for different populations; identifying how different populations, particularly ethnic groups, respond to different types of education; and identifying biomarkers.

- Conduct research that includes African American men, Hispanic men, and men from other ethnic minority populations.

- Include men from ethnic minority groups in clinical trials.

**Programs and Services**

The participants addressed the role of the public health community in providing programs and services for primary prevention. They discussed the overlap between programs and services and communication because communication programs are both a program and a service.

The group suggested that the public health community explore the feasibility of programs to reduce the cost of healthy behaviors. Diets high in fresh fruits and vegetables may be more expensive than diets high in fat. One participant had told an audience of native Hawaiians that their traditional diet, which was heavily based on fresh seafood and vegetables, may have protected against cancer. Members of that audience quickly replied that traditional Hawaiian foods, such as taro and fresh fish, are very expensive in grocery markets. Still other participants noted that it might not be prudent to spend money on promoting traditional foods when it is not known whether dietary factors are risk factors for prostate cancer.

The participants highlighted the need to determine the best ways to deliver programs and services to priority populations, including determining the most effective formats for target populations and the best methods to disseminate information widely. They suggested that public health organizations sponsor a white paper to review international programs and services, with an emphasis on examining the programs and services already in place in other countries. It was noted that some countries, such as Canada and Germany, have very effective and worthwhile programs.

The group members suggested that the public health community also explore the feasibility of partnering with food producers to provide consumers with low-fat whole foods as an alternative to altered foods with reduced fat that have recently entered the marketplace in response to recommendations from the public health community. They pointed out that food producers are focused on making money and have an agenda different from that of the public health community.

To provide consumers with information about healthful foods and diet, the participants offered several suggestions:

- Work with restaurants to encourage them to decrease portion sizes. Many restaurants serve meals that are 1,900 calories or more.

- Partner with grocery stores to post signs about beneficial foods and advertise their benefits. Current research, however, indicates that supermarket interventions have been unsuccessful, probably because supermarkets are saturated environments where added visual stimulation is not noticed by shoppers.

- Organize meetings that bring together scientists, policy makers, patient advocates, government representatives, and food industry representatives, including chief executive officers.

- Craft messages, using the research from a white paper, to let the public know that no solid information exists about what can be done to reduce the risk of developing prostate cancer. A statement clarifying the lack of information would be a service to those who might otherwise spend time and money on products of uncertain value, such as alternative medicine products. However, men are already aware that scientists do not know the causes of prostate cancer. Thus they take herbal products, such as saw palmetto.

- Develop programs that include men from racial and ethnic minority groups in research studies and in clinical trials.

**Health Communications**

The group made three suggestions about actions the public health community should take to communicate information about primary prevention of prostate cancer. First, educate health care providers, particularly primary care physicians, about the current state of knowledge regarding primary prevention for prostate cancer. Educational efforts should encourage physicians to spend about five minutes with each male patient talking about the disease and primary prevention issues.

The public health community should form partnerships and coalitions for communication with support groups and other organizations. For example, public health organizations should partner with consumer support groups, such as the American Association of Retired Persons, which regularly communicates with a population at risk for prostate cancer, and US TOO! International, which has a direct path to target audiences. US TOO! International has published booklets about prostate cancer. Developing partnerships with the National Cancer Institute (NCI) will also be important, because NCI funds a system of well-funded centers for cancer communication around the country.

The public health community should develop communication strategies that are effective in conveying information to all target populations. Communicating information about primary prevention requires reactive models in addition to proactive models. Communication should be a two-way street. A mechanism is needed for the public health community to learn what patients want to know. Interactive Web sites in which viewers ask questions are a good example, but other ways exist to provide the public with an opportunity to frame questions in ways that are meaningful to them. Studies indicate that an effective way to communicate with many men is through their spouses. The public health community should establish mechanisms to communicate with spouses. In many traditional U.S. homes, especially those with older men, the

women buy the groceries, prepare the meals, and have a significant impact on men's diets and lifestyles.

To communicate information about prostate cancer, the participants highlighted the importance of tailoring educational materials to different learning styles and belief systems. They agreed that public health organizations should select the best spokespersons for each target audience. For some communities, the spokesperson might be a celebrity, but for others, the person might be a religious figure, a local politician, or a scientist who is a reliable, authoritative source.

The participants also suggested that a mechanism is needed for public health practitioners to quickly obtain information about the biology of prostate cancer from scientists at the National Institutes of Health (NIH) and from other organizations. Public health organizations should communicate information about primary prevention to the public in a standard way to lessen the impact of information communicated through nonstandard sources.

The group suggested that to communicate information and messages to hard-to-reach populations, public health organizations should collaborate with the Advertising Council. Participants noted that flexibility is key to effective communication among target audiences. Because effective communications strategies are predicated on having something to say, the participants stressed the importance of basic research into the causes of prostate cancer.

**Highlighted Suggestions**

The participants highlighted the following recommendations to develop and clarify primary prevention of prostate cancer:

***Surveillance and Monitoring***

1. Formulate a clear consensus on the data to be collected.

2. Monitor modifiable risk factors, such as diet and environment.

3. Use NPCR and the SEER cancer registry to collect risk factor data and link these data to incidence and mortality data.

4. Conduct surveillance to provide a better understanding of the associations between premalignant changes, including biological markers, in the prostate and the risk of prostate cancer.

***Research***

1. Perform a systematic review of the literature on potential risk factors, including metaanalyses.

2. Perform a historic review of prostate cancer incidence, mortality, and survival; identify trends and correlate these trends with changes in potential risk factors, screening, diagnostic procedures, and treatments.

3. Conduct research on the psychosocial aspects of effective communication for target audiences.

***Programs and Services***

1. Develop a white paper to document what is known about primary prevention issues.

2. Determine ways to best deliver programs and services to priority populations.

3. Explore the feasibility of a program to reduce the cost of healthy behaviors, e.g. healthful diet, and of living a healthy lifestyle.

***Health Communications***

1. Educate appropriate health care professionals about the current state of knowledge on primary prevention; encourage primary care physicians to discuss health issues related to the prostate and prostate cancer.

2. Develop coalitions and partnerships with organizations, such as the American Association of Retired Persons and US TOO! International, and links with NCI communication centers.

3. Develop communication strategies (two-way communications between patients and the public health community), involve spouses, and identify the best spokespersons to reach target populations.

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# III. Secondary Prevention and Treatment

Secondary prevention was defined as an attempt to reduce the consequences of disease among persons with symptoms of disease.

**Surveillance and Monitoring**

Surveillance is useful for research but also for the allocation of resources and policy development. In this session, the participants suggested that screening practices be monitored. The group members stressed the importance of identifying current screening practices and determining where the system is broken. They noted that despite the lack of certainty about the value of prostate cancer screening, physicians are screening. To learn more about the results of the screening, epidemiologists need to know how much and what type of screening is taking place among men in the population.

Some participants noted that the current studies on screening have not been inconclusive; they simply have not been sufficiently conclusive to be convincing. In one study, for example, the number of PSA tests performed on asymptomatic men could be determined, but because the study lacked clarity and surveillance, it lost the precision necessary to make a stronger statement about screening efficacy.

The participants also questioned how and whether the DRE should be used in routine preventive screening. Some participants stated that it is not clear whether DRE is a valuable screening method, either alone or as an adjunct to the PSA test. Some participants stated that the DRE is used by some clinicians to make PSA screening more selective, to reduce overdiagnosis. Some participants noted that DRE may increase the number of diagnoses by adding positive DRE tests to positive PSA tests. Some participants indicated that they never do DREs routinely. In Indian Health Services facilities, however, DRE may be the only screening method available.

The participants addressed the importance of monitoring current screening methods because when the methods change, the old results no longer apply. They discussed the change of biopsy techniques. PSA results do not provide information on the location of the tumor. Some cancers are serendipitously detected by biopsy. The amount and location of tissue removed during a biopsy affects the likelihood of finding a tumor. The participants thought that it would be useful to determine how often serendipitous tumor finding occurs with current biopsy techniques. The group also thought it would be helpful to learn what clinicians are doing the screening and what clinicians are treating men with prostate cancer.

The participants discussed the importance of building public health infrastructure and fostering collaborations. Public health organizations were urged to foster better collaborations between government and research groups and to ensure that good research ideas are funded. Participants noted several points. Committees, departments, or governments should not dictate research questions. Government offices are better at addressing global questions and policy than developing research questions. Government agencies can contribute to research by providing

funding to support networking of researchers, such as establishing research consortia. An example of a successful consortium is Heal-Net, a multicenter, multiresource network in Canada.

Group participants discussed several suggestions for the role of public health. The public health community could also foster networking, by organizing and by funding data workshops in which researchers can share information. At the present time, it can be difficult to obtain data for secondary analyses. A recent attempt at conducting a metaanalysis of five studies was only successful in obtaining data from three of the studies. Investigators often fear losing credit in sharing data and do not want to invest time and expenses. Data-sharing workshops would help researchers locate resources, as well as provide opportunities for combining data, resources, and methodological capabilities.

The members discussed the importance of expanding and improving cancer registries. Registries with underserved populations are needed, and the registries must improve the accuracy of reporting race/ethnicity. Currently, North and South Dakota are not included in the registries. Thus, data from the present registries do not allow epidemiologists to generalize from one group to another, especially between Native American groups. In addition, prostate cancer data from the SEER study cannot be applied to populations in the northern plains or the northwest.

The participants also suggested that registries must be validated and that their inaccuracies and biases, such as those occurring in the coding of deaths, must be corrected. They noted that underreporting of the number of deaths due to prostate cancer may be occurring in many regions in the United States. The Prostate, Lung, Colorectal, and Ovarian Cancer Screening Trial (PLCO) demonstrated the difficulty of reviewing a registry record to determine which treatments were provided for prostate cancer patients. The participants suggested that fields could be added to the registries to indicate the method of diagnosis of cancer, for example, by adding a field that indicates whether the patient's cancer was diagnosed by PSA screening or independent of screening. Presently, the stage of cancer is required in the registry, but PSA status is not. No distinction is made between diagnostic and postoperative staging. Data from both staging methods are needed.

The group suggested that the current practices for obtaining informed consent for screening should be monitored. The public health community should determine what physicians are telling their patients about the comorbidity and mortality issues related to current screening and treatment recommendations. Some participant stated that much of the information available to patients does not meet the criteria for informed decision making. It was noted that many health care providers believe that obtaining a blood sample for a PSA test is easier than taking 5 to 10 minutes to discuss the pros and cons of the test first. Thus, the group recommended that an appropriate process to obtain informed consent for prostate cancer screening should be developed.

Participants discussed a 4-year study conducted by the U.S. Army War College, which included commissioned military officer personnel, used an informed consent document that presented the pros and cons of screening. Of those in the study, approximately 98 percent of the men in their 40s elected to have screening despite the potential negative effect that having

prostate cancer diagnosis could have on their military careers. However, it was not clear to some participants whether the informed consent process accurately presented the risks of overdiagnosis and overtreatment or the magnitude of the potential harm.

The group ended this part of the session with a discussion of the importance of conducting retrospective surveillance studies to provide better information about the natural history of prostate cancer. It is not clear what it means for a 50-year-old man to have a PSA level of 3 that rises to 4 ten years later. One of the difficulties with conducting surveillance studies is that the disease develops very slowly and long-term follow-up is needed. The public health community might use existing resources to retrospectively evaluate current treatment practices and study outcome patterns. Serum repositories have been used in the past to combine PSA data from analysis of stored samples with clinical data collected in longitudinal studies. Serum and data collected for unrelated diseases could be used for prostate cancer research. One example is a cardiology study with available serum samples of approximately 13,000 men. The husbands of the nurses who participated in a nurses' health study are another potential resource. However, regulatory policies in the United States may require that investigators obtain new informed consent from the participants.

**Research**

The participants began this part of their discussion by focusing on the importance of conducting research that targets specific subgroups. Priority in research should be given to men who might benefit most from screening such as men of certain ages or ethnicities or with certain risk factors. Clinical trials are needed to answer questions about specific subgroups, such as African Americans or Native Americans.

The group noted that controversy exists about population-based screening, but screening among high-risk populations is being conducted. Currently, the evidence is not clear as to whether it is appropriate to conduct testing, or case finding, for particular high risk groups. If screening turns out to be harmful rather than beneficial, men in the high-risk group will be inadvertently harmed. African American men are clearly at higher risk for prostate cancer because they are more likely to have disease 5 to 7 years earlier than white men are.

The group also discussed difficulties in recruiting underserved populations into studies. Although research on underserved populations is needed, it is difficult to persuade these individuals to participate in clinical trials. The PLCO investigators created a screening center that focused on recruiting men from underserved groups. They had hoped to randomize a high percentage of the participants from underserved populations. Despite the investment of millions of additional dollars, these enrollment goals were not met. Screening centers in Detroit, Michigan, and Cleveland, Ohio, were successful, and special projects were created to try to understand how underserved men reacted to study recruitment messages. In Denver, Colorado, an effort was made to enroll Hispanics and other target groups, including African Americans, Native Americans, and Pacific Islanders. The costs of enrolling underserved groups were high. Education level, not the skin color, appeared to some meeting participants to be the factor that most influenced participation. However, some program participants noted that African Americans might refuse to participate because they might believe that the study was designed to

help white men. Many resources are required to learn why men from different ethnic groups do not participate in screening studies.

The group stated that treatment trials are different. Once prostate cancer has been detected, the issue becomes whether equitable resources are available for everyone to obtain all the available treatment options. The overall enrollment in the PIVOT trial was said to have been about 25 percent African American and 5 percent Hispanic. It was unclear how representative that trial is of other treatment trials.

The group noted that both low-literacy populations and populations with limited economic resources should be targeted. Eighty percent of the subjects in many clinical trials have a college education. The PLCO trial has made an effort to include the underserved, but with limited success. More information is needed about what is required to enroll people from low socioeconomic levels into clinical trials.

The participants briefly discussed the value of the Department of Defense Center for Prostate Disease Research (CPDR) prostate cancer study. The CPDR is a large multimillion-dollar effort that involves approximately 50 study personnel and nine military hospitals. The military is a captive population that provides the opportunity to collect more comprehensive data than is possible with other populations. The disadvantage of the study appears to be that, because this is a military population, the data may not be applicable to other groups. Moreover, the trial is not randomized, so the observed relationship between screening and outcome can be biased. Nevertheless, the group concluded that data from multiple, longitudinal, observational cohort studies are vital.

Another topic of discussion focused on the social and behavioral issues of research. Participants stated social science can be used to determine attitudes toward shared decision making and to understand the differences in knowledge levels, attitudes, and beliefs among population subgroups. Another social and behavioral issue that was said to deserve attention was the role of family members and loved ones after diagnosis.

A behavioral issue that was mentioned repeatedly during the session was the need to better understand attitudes and decisions regarding participation in clinical trials. The difficulty is determining how to encourage patients to enroll and how to convince physicians to participate. The public health community could conduct research to identify the barriers to participation and ways to break down these barriers by making participation a desirable option. A message is needed that supports entry into trials as a treatment choice. Participation in trials should be the preferred treatment choice and a good standard of practice.

Participants noted that enrolling subjects from underrepresented groups, such as African Americans, Native Americans, migrant populations, low-literacy populations, non-English-speaking peoples, and those from different geographic regions of the country is particularly difficult. Trials that have deliberately attempted to enroll African Americans have had minimal success, and some centers are working to evaluate racial representation. CDC provides funding for trials in Detroit, Michigan, and Pittsburgh, Pennsylvania, to examine the reasons why African Americans participate in trials. Men also need to be encouraged to continue to participate in

trials after they have agreed to enter a study. For example, a study in Detroit, Michigan, experienced a huge enrollment of African American patients, but many patients were lost to follow-up after the initial PSA screening. No inquiry was made into why so many of the study participants discontinued, and the study ended prematurely.

It was noted that a research group developed a questionnaire that asked men why they chose to participate or not participate in clinical trials and created a video presentation summarizing the results. The video was used in the informed consent process to help men decide whether to be enrolled in a study; the research group achieved a 50 percent rate of participation.

The third area of discussion focused on research to obtain baseline information. Baseline information is needed to learn the level of public knowledge about the prostate gland and prostate cancer. Although the public may not want to know this information, the public health community has been pressed to conduct awareness campaigns. A question that merits research is whether more awareness is desirable if it is uncertain how to address prostate cancer prevention. Another area that should be researched is the public's perception of the message of uncertainty about prostate cancer prevention and prostate cancer screening.

Participants discussed the importance of developing risk assessment technologies for men with prostate cancer and conducting prospective clinical studies to determine the risk associated with different treatment choices. Participants noted that studies are needed that focus on factors and comorbidities that affect treatment outcomes, such as survival and quality of life, especially in the underserved populations. They suggested that existing resources could be used to conduct population-based studies of treatment patterns and outcomes because a considerable amount of treatment is occurring right now. They commented that the cancer registries are unable now to collect all of the treatment information.

The participants suggested that research end points should be evaluated and appropriate inclusion criteria identified for clinical trials. The definitions of endpoints, such as incontinence, presently vary from study to study and should be standardized. The public health community can help define valid, reproducible outcome measurements that would help make the results of different studies comparable.

The group recommended research on the outcome of untreated disease. Studies have indicated that among the men with palpable tumors who are managed by watchful waiting, 80 percent are still living 15 years later. It would be valuable to determine the comparable survival of men who are detected by PSA testing, have clinically unapparent tumors, and are managed similarly.

The participants suggested that the public health community might play a role in determining the cost-effectiveness of screening strategies, as more data are gained on the effectiveness of screening. They discussed several other suggestions related to screening and treatment. Economic factors should also be included in the decision making process related to prostate cancer because of the futility of screening men who do not have the financial means for treatment, such as those without health insurance. Evaluating the extent of and reasons for variations in treatment outcomes and complications by area and provider would also provide

valuable information. One difficulty in conducting treatment research is the considerable variation in treatment complications at different centers, from different providers, and in different geographic areas. Thus, research outcome measurements should be standardized. Access to health care also needs to be considered in screening and treatment decisions because in some areas, limited resources for various treatments are available.

The group provided the following additional suggestions for research-related topics:

- Identify adjunct screening tests that would make screening more selective by helping to determine the aggressiveness of the tumor before invasive diagnostic tests or treatments are used.
- Develop tools that help patients make informed decisions about all treatment options.
- Create a video (similar to the one designed to aid in the informed consent process for a randomized clinical study) to help men evaluate treatment options.

**Services and Programs**

In this session, the participants suggested that the public health community identify ways to help health care providers understand and convey to their patients the uncertainties related to prostate cancer screening and treatment.

The first topic discussed was how the public health community could help practitioners become comfortable about telling patients that the medical community is uncertain about the best ways to screen for and treat prostate cancer. Some participants noted that some choices offered to men may be based on the provider's specialty, not on the scientific evidence, which is uncertain. For example, urologists usually recommend surgery, and radiation oncologists recommend radiation therapy. Participants commented that providers in the United States also tend to promote the more aggressive therapies; whereas, providers in other countries do not. Patients need information that helps them understand their options and the implications of different choices.

The participants also suggested that the public health community foster a better understanding of the issue of overdiagnosis due to screening. For example, preliminary results from a European randomized clinical trial of prostate cancer screening among 17,000 men aged 55 to 75 years demonstrated a high rate of overdiagnosis in the screened group. The rate of diagnosis per thousand men was 34 in the screened group but only 4 in the control group. Because the mortality rate from prostate cancer was 1.25, the ratio of diagnosis to death was 20 in the screened group and 3 in the unscreened group. These results indicate a much higher level of overdiagnosis in the screened group. The rate of diagnosis in the screened group is expected to decrease in the future with repeated screens, but the diagnosis rate may not approach the rate of disease mortality, which is the best measure available for a true diagnosis at the present time.

Participants stressed the importance of evaluating how men's health awareness affects the use of health care services. They suggested that the public health community conduct research to determine how increased awareness about men's health issues affects the use of health care services. They noted that the public does not believe that the health care system in the U.S. is

adequate. Thus the potential role of the patient in actively participating in prostate cancer decision-making is uncertain.

Participants discussed how high risk men might be recruited to screening if it becomes clear that screening is effective. Some of the participants suggested that public health organizations should then provide screening services.

**Health Communications**

Participants discussed the importance of devising methods to convey the present uncertainty about the effectiveness of prostate cancer screening and treatment. The most important issue is to develop and convey a public health message about prostate cancer. The message will depend on the answers to questions that are yet to be solved and require additional research. The message must be sufficiently flexible to allow for changes as new information becomes available. One challenge in communications is how to convey uncertainty about prostate cancer screening and treatment without undermining public trust in public health institutions and patient trust in providers.

CDC follows the prostate cancer screening policy outlined by the U.S. Preventive Services Task Force (USPSTF). The USPSTF does not recommend screening because there is insufficient evidence that screening is effective in reducing mortality and the balance of harms and benefits is uncertain. However, not all practitioners agree with this policy. In this context, informed decision-making should be publicly supported. Participants noted that many men are already aware of prostate cancer and many believe that screening is the right thing to do. Men need to be educated to make informed decisions. Some participants stated that men may not understand that screening creates an entire course that can result in overdiagnosis, treatment, side effects, and the other problems. Men should receive information about screening that makes them aware of the possible treatment and health consequences of their decisions about screening.

Many group participants agreed that because free PSA screening and proscreening pamphlets are commonly available nationwide, men should receive education about potential harms as well as benefits before they receive any type of screening. Some participants stated that the public health message should be against community screening outside of a full-care context. If screening is harmful, all patients should have access to adequate follow-up and treatment. In areas where PSA testing is available but no access to follow-up care is available, the message should be that screening should always be offered in the context of complete care. One survey found that at least one third of men who underwent PSA testing did not even know they had received the screening test.

Participants added that information about the risks for different subgroups of the population should be communicated to those groups. Data about some groups is inconclusive, and public health professionals should provide additional information about the risks in those populations.

A discussion about screening high-risk men revealed a controversy. One participant argued that for high-risk men, such as those with a family history of prostate cancer, physicians are now engaged in case finding rather than screening. Another questioned whether all members of high-risk groups should be screened, arguing that case finding is really just "sloppy screening." Case finding as an aggressive search among asymptomatic men for those who test positive might be harmful because no determination has yet been made as to whether screening and treatment of screen-detected prostate cancer is effective. Thus, it is not clear what message should be conveyed, although messages about screening may vary for different populations.

Several participants concluded that "Talk to your doctor" is probably not the appropriate message. Doctors may not know how uncertain information is about the effectiveness of screening and treatment for prostate cancer. They stated that because conclusive evidence is not available, the message to the public should be that investigators are trying to determine if screening is effective, and that more people are needed to enroll in clinical trials to help answer questions about prostate cancer.

In discussing the importance of making informed decisions, participants considered several different points. The group noted that many people spend months trying to make a treatment decision by conducting their own research on the World Wide Web, by reading books, and by talking to people. To help people make informed decisions, a broad-based message is needed. Screening is regarded as a course ending in diagnosis and treatment decisions, but men tend to face one decision at a time. They may not consider the risks of treatment when they are trying to decide whether to have the screening test. For example, some participants suggested that, a certain percentage of military men in the U.S. Army study decided to be tested when offered the choice may not have understood the uncertainty and risks involved in treatment. Thus, those participants recommended that the public health community must convey the uncertainty about potential benefits and harms of prostate screening and treatment together.

Some participants suggested that a consensus statement on prostate cancer screening be developed among professional and voluntary organizations. This document would be similar to the 1989 consensus statement on mammography that 11 organizations signed.

A major discussion involved whether the evidence for the effectiveness of prostate cancer screening was analogous to the evidence for cervical cancer screening. Cervical cancer screening was approved for routine practice based not on the basis of evidence from clinical trails but on convincing population-based data. Some participants thought that the combined results of the Austrian study, SEER data analyses, military studies, and a Mayo Clinic study showing reductions in mortality with screening were strong enough to support a similar conclusion for prostate cancer screening. Others found the arguments unconvincing for several reasons. Some population data do not show a relationship between mortality reductions and screening. Other factors besides screening may be responsible for the changes in prostate cancer mortality in those populations. Changes in mortality for cervical cancer were greater than for prostate cancer. Cervical cancer screening involves detection and treatment of precancerous lesions—a situation not comparable to prostate cancer screening.

Many group members recommended that the public health community, and perhaps CDC in particular, should have a greater presence in communications about prostate cancer. They thought that the public health community should review, explain and interpret the studies that have been conducted. For members of the public and even physicians, assessing each individual study and or trying to evaluate all studies in combination is difficult or impossible.

Canada provides a well-researched guideline on breast cancer screening to all doctors in Canada and has developed a lay version of the scientific basis of the guideline that a woman can bring to her doctor's office. It shortens the interview time and improves the understanding of issues. This example could be adapted to prostate cancer.

The group stressed the importance of conveying to the public a health message about prostate cancer screening and treatment. They drafted a four-part proposal:

- Ensure consistent press coverage every day.
- Have a comprehensive balanced message.
- Use all communication channels, including radio, talk shows, World Wide Web, 24-hour health channels, and television.
- Use a spokesperson who conveys trustworthiness.

Participants emphasized that the unintended negative consequences of communications related to prostate cancer should be anticipated and avoided whenever possible. For example, some people, on hearing about the importance of genetics, might conclude they do not have to think about prostate cancer if they have no family history of the disease. Others may think prostate cancer is like breast cancer and that screening for either is effective. Stories about a single patient's experience and thoughts on prostate cancer should not be allowed to negate the message that the effectiveness of prostate cancer screening is uncertain.

The participants also discussed the importance of creating strategies to inform the media about the controversies, uncertainties, and need for individualized informed decisions about prostate cancer screening and treatment. They noted that much misinformation is presented by the broadcast and print media and on the World Wide Web. The public health community should reach out to journalists and Web providers to craft correct information and to help correct misinformation.

Some members of the group suggested that spokesmen be selected to present the "other side" of the prostate cancer screening and treatment issue. These men would present their reasons for choosing to not have screening tests or treatments for prostate cancer. The messenger is important. The personal views of people considered trustworthy are powerful. The Mayor of Denver, Colorado, is a prostate cancer survivor who was successfully treated and his message is "Get screened." Unfortunately, the positive experiences usually covered by the press are rarely balanced with negative stories. In the Netherlands, the Queen's husband had a radical prostatectomy and radiotherapy. He experienced severe side effects that required additional surgical procedures, including a colonostomy. Crafting a message using this experience could send a powerful message about the risks of prostate cancer treatment.

Members of the group noted that the most effective person or group to deliver the message may be different for different groups of people. The type of authority figure accepted by different people varies; some listen to physicians, but others do not. In the United States, the physician's ability to get people's attention is not as strong as that of certain celebrities.

Some group members suggested that messages be targeted to spouses. In a family, the best individuals to target may be women because they are often the decision-makers regarding family health issues. If so, women's perceptions of prostate cancer information must be understood. Messages about uncertainty should be crafted for women.

The group had the following discussion on educating men about prostate health. Educating men about how the prostate organ functions rather than about diseases of the prostate might capture the interest of the public. Prostate cancer could then be addressed as a subset of information regarding the prostate gland. With this model, the public health community might integrate prostate cancer education into a general health care screening and management program with primary care providers and their patients.

To help men make informed decisions, the participants suggested that the public health community create patient decision making tools. These tools might include a rationale for the watchful waiting approach to treatment. In some circumstances, such as in rural areas of the United States or at Indian Health Services facilities, the factors to be considered in helping a patient make a choice may be limited to issues of access to health care and economic factors, such as health insurance coverage.

The participants ended this session by discussing the importance of engaging policy makers and insurers to develop consistent policies on prostate cancer screening and treatment. Currently, policies are not consistent from state to state. Health care purchasers and insurers must also be engaged in these discussions rather than just receiving a set of recommendations.

**Suggested Highlights**

***Surveillance and Monitoring***

1. Use registries to monitor screening practices for patients diagnosed with prostate cancer and include information on types of health care providers involved.

2. Monitor screening practices (DRE and PSA) and how patients are informed.

***Research***

1. Conduct research on and devise methods to convey the uncertainty regarding the effectiveness of prostate cancer screening and treatment and facilitate informed decision-making.

2. Focus research on specific high risk groups, including research on how to convey uncertainty about screening and treatment and on the factors that may lead to longer survival and better quality of life following treatment for prostate cancer.

3. Perform research to develop aids for practitioners to help them better understand and communicate uncertainty about potential harms and benefits of screening and treatment and become more comfortable with both scientific uncertainty and the threat of lawsuits.

4. Focus research on social and behavioral issues related to screening and treatment. In particular, conduct research on what the public knows about screening, follow-up after screening, treatment, and shared decision making and what the public is doing in each of these areas.

***Services and Programs***

1. Build an infrastructure to foster and reward research collaboration, e.g., like Canada's HEALNet program, and, promote health insurance coverage of clinical trials and promote physician participation in clinical studies.

2. Develop the technology to assess the risk of prostate cancer and conduct prospective clinical studies that take risk into account when assessing a choice of treatment and its associated outcomes.

***Health Communications***

1. Craft communication strategies to communicate the uncertainty about prostate cancer screening and treatment and to reach multiple and diverse audiences. Use multiple channels, and tailor the messages for each audience.

2. Provide aids for practitioners to help them better understand and communicate uncertainty. Help practitioners become comfortable with both scientific uncertainty and the threat of lawsuits.

3. Foster a better understanding of the issue of overdiagnosis.

4. Increase the presence of the public health community and CDC in everyday communications to the public about public health issues.

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# IV. Quality of Life and Survivorship

To begin this session, the participants defined quality of life as functional status, health, and comorbid conditions of persons with prostate cancer; the definition was further refined to include the ease with which an individual completes his daily tasks.

**Research**

The participants suggested that the most important research priority should be to establish valid and reliable measures of quality of life that are specific to prostate cancer. To support this suggestion, the group cited examples of European models. They suggested that the public health community undertake the following activities:

- Assess existing quality-of-life instruments to establish their validity and reliability for different population groups, including different age groups, race and ethnic groups, income levels, education levels, and occupations.
- Develop instruments that are valid and reliable for different groups and for diverse populations.
- Define the dimensions to be measured and use these dimensions and measures consistently from study to study.
- Specify when quality of life data are to be collected—at diagnosis, during treatment, or after treatment.
- Measure change in quality of life—at diagnosis, during treatment, and after treatment.
- Examine treatment preferences of men diagnosed with prostate cancer.
- Identify functional changes resulting from general aging rather than from prostate cancer.
- Assess the quality of life for the families of men with prostate cancer, as well as that for prostate cancer patients and determine the impact of the disease on the family, which plays an important role in treatment and follow-up decisions.
- Examine patterns of survival and the basis of intervention. Compare survival among men with and without functional limitations.
- Assess how many men try alternative therapies, such as saw palmetto, and the psychological or placebo effect of such therapies.
- Determine whether all men require active participation in deciding on treatment options. (The group discussed the possibility that in the U.S. men are more likely to believe that actively participating in decisions regarding health issues is an important component to successful treatment and outcome; whereas in Europe, men may prefer to leave treatment decisions to the physician.)

The participants also agreed to the need for studies to compare quality of life among men with prostate cancer and a control group of men of the same age who do not have prostate cancer and to measure quality of life among men in both groups over time. Only in this way can the effects of prostate cancer be separated from the effects of aging on men's functioning.

To better identify and understand differences in quality of life among persons in different subpopulations, the group agreed that quality of life studies should include men of different demographic backgrounds. Comparing different treatment cohorts is very important for policymakers to make informed decisions regarding treatment options. Because people interpret survey questions differently, epidemiologists face many methodological challenges. An instrument's effectiveness is based on how well the instrument works in existing surveys for different population groups and on how well it captures the information it is intended to capture. Surveys in Europe are validated cross-culturally and address more confidence issues and are generically meaningful across many cultures.

The group discussed the importance of evaluating the effects of patient compliance with treatment protocols on disease outcomes. Once treatment is established, the impact of the intervention needs to be understood. In conducting quality of life research among prostate cancer patients, investigators should consider including measures of compliance, preference-based measures (in addition to other quality of life measures), and access to and use of different treatment procedures.

One participant suggested that a broad population-based survey could determine issues of real concern to men, rather than issues that physicians believe to be important. For example, recent studies indicate that men are more concerned about incontinence than about impotence. To identify these issues, the public health community must conduct research among men with prostate cancer. For example, a patient may think, "I get up six times a night, but I'm alive."

**Programs and Services**

The participants suggested that the public health community consider the following programs and services for all men:

- Screening and treatment information should be synthesized for clinicians and patients and should be made available using interactive technologies, such as on Web sites. These sites could allow men and clinicians to easily seek and access information that is most useful to them and to move through a decision making process by entering their own preferences.

- Men and physicians should be able to access information and community services for cancer- and treatment-related morbidity, such as incontinence and impotence. These programs should be strengthened and improved.

- Programs and services are offered through the American Cancer Society (ACS), US TOO!, support groups, and referral sources. Some groups are proactive and seek opportunities to speak and educate; others are more reactive.

- Focus groups could discuss the needs that the system does not provide. Benefiting from patients' experience is one answer; another is for physicians to do a better job of synthesizing available information. Although patients want to be involved, sometimes too much information is available. Public health organizations and government agencies

could play a role in helping synthesize available information and providing interactive tools, for example one into which a patient could enter a value, such as longevity versus quality of life.

Programs and services are available for members of the public who, if informed, may choose screening. Services are not available for those who want screening for prostate cancer, especially in underserved areas, and health services could initiate these services. If screening is to be provided, diagnostic services and treatment must also be provided.

**Surveillance and Monitoring**

The participants stated that surveillance includes tracking and monitoring, as well as communicating the information collected. Issues in surveillance include appropriate reference points for data collection; timing; sensitivity, reliability and validity of measures; incorporating measures of function; and infrastructure. Current surveillance systems may have some limitations. Information is needed on how quality of life might change through the process of diagnosis, treatment, and post-treatment, and the costs associated with each phase.

The group noted that quality of life should be monitored over time, both in the United States and overseas. Studying the health programs in other countries could be informative because other countries may have developed interventions that could work in this country.

Participants commented that patients do not always know whether they have been screened. However, if surveillance systems were linked to claims data, screening could be monitored by determining from claims data who has had a PSA test. For some cancers, such as colon cancer, prior screening predicts current screening. It is not known if this is true for prostate cancer. Surveillance systems could help address these questions.

Group members suggested that prostate cancer patients should be included in longitudinal studies. A system could be developed to monitor quality of life after treatment. Healthy People 2010 include new measures of healthy life expectancy, and similar measures could be included in studies of men with prostate cancer. The group participants pointed out that quality of life surveillance may occur at every point of treatment and beyond. They suggested that a system be developed to monitor quality of life indicators after treatment, to include such measures as occupational history and function. In such a study, a system should be set up in which patients are contacted on a regular basis.

To measure quality of life before and after diagnosis and treatment for prostate cancer, the participants suggested that the public health researchers collect data on initial treatment, such as radiation treatment, surgery, or watchful waiting. The group pointed out the importance of a dynamic surveillance system because a treatment pattern of watchful waiting can change to treatment in a few months.

Participants suggested that a Medicare beneficiary survey with coordinating modules or a health outcome survey focusing on treatment rather than screening could examine physical and emotional data and study the ability of health plans to improve outcomes.

In summary, the participants suggested that the public health community should conduct the following:

- Assess the psychometric properties of quality of life instruments for different population groups.
- Assess quality of life of prostate cancer patients by using a control group with similar demographic groups for comparison.
- In quality of life studies, identify who is being screened and when.
- In quality of life studies, assess quality of life at different points in time—at screening, at diagnosis, during treatment, and during follow-up.
- Incorporate quality-of-life measures into existing surveillance systems, such as BRFSS, NHIS, NHANES, and in special studies or surveys.

**Health Communications**

Participants recommended that patients and physicians need to know what treatments are available for prostate cancer and that Medicare covers PSA testing. Some participants thought that special awareness programs similar to Breast Cancer Month are needed. It was noted that if the prostate cancer messages are weak or unclear, they will not be newsworthy. Participants said that positive messages for breast cancer screening are available, but PSA testing does not have the same positive message. Prostate cancer awareness is far behind breast cancer awareness. Part of the public's confusion is because the debate about the value of early detection has not yet been resolved.

Participants suggested that the public health community craft messages to help physicians and the public understand the controversial issues surrounding prostate cancer screening. More research is needed to provide information for those messages. From a public health perspective, investigators must compare quality of life among men with prostate cancer to that of men without the disease, compare patients who receive treatment and those who elect to have no treatment, and compare those who are screened with those who are not. Testing instruments for measuring quality of life should apply reliably across population groups. Currently, major gaps exist in instruments for African American men.

The participants suggested that quality of life and communications are related. How information is communicated at every level affects quality of life and the family.

Participants offered differing views on what should be communicated about the use of DRE. At issue were the following:

- Some men reject DRE.
- Use of DRE may do more harm than good.
- Using DRE may provide screening to men who would otherwise not be screened.

The group proposed that evidence-based computer assessments or guidelines on the issues physicians should discuss with patients could be developed. These guidelines should be standardized so that the information men receive is consistent and does not vary by practice or

physician. Because not all men have access to computers and Web-based technology, the participants suggested that culturally appropriate materials be developed.

The group also noted the importance of developing a better method of communicating the value of clinical trials with patients. Currently, the possibility of participating in clinical trials is not discussed with 85 percent of patients.

The participants made the following suggestions in the area of communications:

- Convey information to the public that includes the risks and benefits of screening and information about functional limitations following different treatment options.
- Communicate information that is appropriate for the audience, considering such factors as age and literacy level.
- Raise awareness of the importance of clinical trials among patients.
- Develop a consensus agreement with public health agencies and other organizations to help educate the public about screening and treatment options for prostate cancer.

**Discussion**

The participants discussed the importance of comorbid conditions and the effect these conditions can have on quality of life. In the late 1980s, prostate cancer became the second most common cause of cancer death among men. Most cases were advanced and incurable and the focus shifted to early detection. Controversy arises about screening and treatment because a patient may be more likely to die of comorbid condition than of the prostate cancer. The unnecessary detection of prostate cancer and the slow-growing nature of some tumors make decision making difficult.

Participants stated that many questions exist about the reliability of treatment methods and how to convey information about treatment, comorbidity, and side effects of treatment. From the patient's perspective, flexibility of treatment decisions is a very complex issue. Information should be conveyed to allow the patient to make an informed decision. Any man who undergoes a screening test and who receives a diagnosis of prostate cancer must carefully consider all the different treatment options and complications so he can make an informed decision.

Participants noted that the vast majority of prostate cancer patients are elderly and have comorbid conditions that effect urinary and sexual functions. It is no longer unusual, however, to find that young men have prostate cancer. The participants pointed out that younger men have very different quality of life issues than older men.

The group had the following discussion of the importance of the timing of measurements of quality of life in research. Research is needed on how often quality of life should be assessed and a sensitivity of measurements of quality of life changes. Issues that are important to the patient must also be determined. The patient might be concerned, for example, about the risk of death, loss of erectile function, incontinence, or the psychological anxiety of living with cancer.

The participants pointed out that prostate cancer also affects employment status when it occurs early in life. Professionals are more concerned about how a diagnosis will be seen by the public and may prefer to keep diagnosis a secret; older men who are no longer employed may be less concerned with secrecy.

The group noted that screening affects different men in different ways. Some men may actually feel relief that a cancer is found. A negative screening test may provide reassurance for others. Cost of treatment affects quality of life. Some patients may reorder their priorities after diagnosis to live a more meaningful life.

Participants discussed a number of study design issues related to quality of life. Studies of quality of life among prostate cancer patients are not possible without a comparison group. Comparing quality of life to a baseline is virtually impossible unless the quality of life of the entire population is measured. The baseline has already changed when an individual is diagnosed. The question is when to start the baseline because age-related changes will have occurred apart from the cancer. An individual's perspective of what constitutes quality of life may change over time. Some men may consider a trade-off between quantity and quality when making treatment decisions and choose longer life over quality. Use of a control group without prostate cancer would not provide a complete picture but would allow epidemiologists to compare quality of life issues with individuals with similar demographic characteristics.

The group discussed several issued related to access to information. Health care professionals could provide information to the media without overstating the negative effects of screening and treatment. The public health community could work with the media to clarify quality of life issues and play a role in supporting informed decision-making and helping ensure access to information.

Participants discussed a Florida statute requiring physicians to explain treatment options for breast cancer could be expanded to include prostate cancer. Florida recommendations include educating the medical community, as well as the patient. The basic role of public health professionals is to educate the public and to dispel myths, such as belief that prostate cancer is only a disease of older men and that prostate cancer is always a slow growing cancer.

The public health community also has an important role in helping men understand quality of life issues in early screening. It is impossible to disclose the full impact of treatment on quality of life. Prostate cancer is a very common disease, but the public health field is doing a poor job of educating people on the pros and cons of treatment. Patients need to have informed counselors.

Controversy exists about whether to educate men about the pros and cons of treatment for prostate cancer before they receive a positive result from the screening test. Some participants commented that it is extremely difficult to fully inform a person about treatment options and side effects before screening. Because 85% of the men who have screening have negative results, these participants noted that it might be better to wait for the screening results before attempting to inform the men about treatment options. However, other participants noted that this approach can produce a trap: some of the 15% with positive results might not want treatment even if a diagnosis of prostate cancer is confirmed. If men decided before screening that they would not

want treatment because of side effects, it would be better if the cancer was not discovered by screening. Once the cancer is diagnosed, psychological pressure and a great deal of anguish result for men who are concerned about effects of treatment.

**Highlighted Suggestions**

***Research***

1. Assess and establish the validity and reliability of existing quality of life instruments for different population groups.

2. Identify quality of life outcomes that are important to the men who are diagnosed with prostate cancer, as well as their families.

3. Use quality of life measures that are consistent across studies.

4. Conduct follow-up studies of patients and a comparison group, from screening through diagnosis, treatment, and follow-up.

***Programs and Services***

1. Synthesize screening and treatment information and make it available to clinicians and patients.

2. Improve patient and physician access to information and community services for cancer- and treatment-related morbidity.

3. Take a lead role in developing consensus among agencies and organizations to help educate the public about prostate cancer, screening, and treatment.

***Surveillance and Monitoring***

1. Assess the psychometric properties of quality of life instruments for different populations.

2. Assess quality of life at baseline and at different points in the course of the disease from screening and diagnosis through treatment and follow-up.

3. Identify who has been screened and when.

4. Incorporate measures of quality of life that are relevant to prostate cancer into existing surveillance systems, such as the BRFSS, NHIS, and NHANES.

***Health Communications***

1. Communicate to the public the risks and benefits of screening.

2. Provide information on functional limitations following different types of treatment.

3. Communicate information in a manner appropriate to the audience; taking into consideration age, literacy level, cultural background, and socioeconomic status.

4. Increase awareness of clinical trials among patients.

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# V. Surveillance and Monitoring

In this session, the participants defined surveillance as the routine and ongoing collection of health information about populations and the timely analysis, interpretation, and communication or dissemination of this information for the purpose of public health action. This action was further defined as being related to the prevention and control of prostate cancer without necessarily referring to governmental public health, but rather to activities at an organized community level to improve the health of a defined population rather than an individual.

Overall, the participants agreed that a major issue in surveillance is confidentiality of the data. They also discussed the need to inform the public about the collection of those data. Once biomarkers and genetic testing are available, confidentiality will become even more important. The availability of PSA testing means that the public needs to be told the extent of testing, as well as why it is done. The public will need to be educated about the need to collect these confidential data and the uses to which they will be put, as well as reassured that the data will remain confidential. The public needs to appreciate that data are collected to increase understanding of variations in the disease and the population, to describe the disease burden, and to obtain guidance on the directions for future research. Once data are collected, the public health community will have information on which to base its efforts for research in specific areas.

Participants noted that drawing public attention to the SEER and NPCR registries would be useful because these data show how cancer surveillance benefits people, which will help to ensure the continuation of the registries.

The more public health agencies can show the use of surveillance systems through different products and studies, the more likely the public will see the benefits of these systems and of continuing to fund these studies. Two types of studies are being conducted: those that are part of ongoing, routine surveillance systems and a special set of studies nested within surveillance systems. Additional surveillance is needed regarding prostate cancer treatment and its complications.

**Disease Burden and Risk**

A goal of understanding disease burden is to be able to prioritize resources for intervention. To understand disease burden, the population needs to be monitored through either a registry or another type of survey system. The availability of PSA testing causes an increase in disease burden.

The group noted the following key points:

- Surveillance needs to be more specific to ethnic and geographic subpopulations.
- Data on SES and social class would be useful.
- Surveillance of PSA testing is needed to determine what men are being tested and why.
- Improving data quality, completeness, and timeliness should be an ongoing goal.
- Local and public health practitioners should be able to access data more readily.

Some participants suggested that BRFSS might collect additional information that is specific to topics related to prostate cancer. Risk factors other than age, family history, and ethnicity might be identifiable by BRFSS, which surveys 160,000 people each year. For example, more information on dietary practices or physical activity might prove useful in identifying risk factors. One drawback to current BRFSS studies is the low number of Native Americans with telephones and the undersampling of this population. The public health community might consider funding a separate BRFSS-type survey that is focused on prostate cancer, because the current BRFSS survey may not provide adequate data.

One participant suggested that since NCI is studying ethnic differences in incidence, CDC does not need to duplicate this effort. Another participant disagreed, arguing that this is an appropriate issue for the public health community to address. The role of CDC is to facilitate research in specific areas and identify why it wants specific types of data collected. The goal is to determine how best to allocate resources.

**Primary Prevention**

The group noted additional possible activities related to risk factors. One intention of surveillance is to identify people at high risk. To date, surveillance has shown that race, age, family history, and geographic location appear to be the primary risk factors for prostate cancer. An area in which further surveillance is needed is lifestyle factors. To whatever extent possible, surveillance on key lifestyle factors should be conducted for prostate cancer and for other cancers as well. These factors should include diet, physical activity, and micronutrients.

Fat intake is a possible dietary risk factor, because incidence of prostate cancer changes when racial groups migrate. The genes have not changed, so presumably lifestyle factors affect incidence. For example, prostate cancer rates increase among Asians who have immigrated from China and Japan to Hawaii. This increase may correlate with changes in diet. Additionally, the incidence of prostate cancer among first generation Vietnamese in the United States is low. As part of a study of risk factors, the public health community might conduct surveys to determine whether the incidence rises with succeeding generations.

Participants said that making recommendations in the area of primary prevention is difficult because it is not yet known how to prevent prostate cancer. Although PSA screening is now available, it merely detects prostate cancer without predicting or preventing it. Better biological markers are needed to predict which men are more likely to develop prostate cancer, so that these individuals can be monitored.

The group discussed the difficulty of truly assessing changes in risk of death from prostate cancer. As deaths decrease from other causes, such as cardiovascular disease, deaths from prostate cancer rise because men are living longer. In the same vein, the availability of PSA testing has now given more men a diagnosis of prostate cancer. When they die, they may be more likely to have prostate cancer indicated as the cause of death, even though death may have resulted from another condition. This may make it appear that more men are dying from prostate cancer than has been the case historically.

**Secondary Prevention and Treatment**

Secondary prevention was defined as early detection. Some participants stated that for early detection of cancer, public health officials need to identify those at higher risk and ensure that these men are screened. SES can be a barrier to screening.

The group discussed several adaptations to surveillance systems to make them more useful for research. Because biomarkers may be the next step in understanding prostate cancer progression, these markers should be included in surveillance systems. Also, surveillance should include a search for geographic variation in incidence and mortality to identify possible risk factors.

Participants noted that linking existing surveillance systems, particularly cancer registries, with other data sources holds great promise because it aids in interpreting outcomes. Special studies on patterns of care, following the SEER model, should be instituted.

The group discussed the possibility that the public health community examine why biopsies are being done and evaluate their positive predictive value. Although this may be more a research than a surveillance question, members of the group agreed that this is an important issue. They noted that surveillance data might also address whether or not a PSA test led to the prostate cancer diagnosis and if so, why the test was performed. With current surveillance of PSA testing, it is not possible to know which cancer patients were detected with PSA screening. Unfortunately, no consensus exists about how to include PSA information in a cancer surveillance system. The group also discussed the usefulness of including information about whether or not a DRE was performed and what the results showed.

The group recommended that CDC and other public health organizations should implement the recommendations from the Institute of Medicine's recently released report, Enhancing Data Systems to Improve the Quality of Cancer Care.

The participants discussed the need to pay more attention to the complications of treatment and recurrence of the disease. At a minimum, the public health community should undertake pilot studies to examine how additional data elements could be added to surveillance in the area of treatment. An improved treatment surveillance system might include information on which segments of the population receive what kinds of treatment. Neither the SEER nor the NPCR registries catalog all the chemotherapeutic modalities used, and even less surveillance is available on hormone and other types of therapies. Watchful waiting and complications of other therapies should be added to surveillance systems. Electronic data sharing between hospitals may facilitate gathering of this information. However, this type of system would miss treatments conducted at physicians' offices unless they were linked with the communication system. A goal of treatment surveillance might be to determine which therapies are most effective at different stages of cancer; both complications and mortality should be examined.

A hindrance to the collection of data on the side effects of therapy might be that patients are reluctant to admit in a telephone survey that they are experiencing some of the common side effects of therapy, such as incontinence and impotence. The public health community might

conduct research on which complications are important to patients and determine how they perceive the severity and impact of these side effects.

**Survivorship and Quality of Life**

Participants noted that because survival and quality of life are separate issues, the public health community should incorporate and improve surveillance of subgroups. Survival should be monitored to determine whether longer survival is due to earlier diagnosis, better treatment, or improved control of comorbid conditions.

Improving existing measures and understanding the patient's perceptions of what is important are paramount in quality of life issues. For example, a treatment side effect or complication that one patient finds intolerable might not bother another patient. It will be important to include a method of measuring patients' perceptions of severity.

Participants suggested that the CDC's NPCR program should use the SEER outcome studies as a baseline and model for conducting special studies to establish quality of life surveillance systems. Existing systems could be used to obtain greater detail on survival and quality of life. The group spent some time discussing the problem of patients moving out of the study area and how this affects data collection.

The participants discussed the possibility of developing a survey to assess quality of life after treatment, given that treatment carries the risk of severe side effects. Telephone surveys should be conducted on a regular basis to track functional disabilities, such as impotence and urinary incontinence, and relate changes to treatments. Functional status may also change over time. Patterns of functional status could be associated with different stages of disease, treatment modalities, and comorbid conditions. These studies could be conducted on a cohort rather than the general population.

The group discussed SES and how this variable might account for some of the variability in cancer incidence in certain racial groups. Studies show that among men with prostate cancer, white men survive longer than black men do, but this finding may be a result of socioeconomic rather than racial characteristics. For example, the wealthier the man, the more likely he is to receive a radical prostatectomy, regardless of age or symptoms. Thus, better information is needed to determine how race and SES affect survival.

The group also suggested that the public health community should consider measuring the recurrence of prostate cancer. One difficulty with this lies in obtaining records from physicians' offices. Public health investigators do not have access to these records and because submission of these records would be voluntary, and collection of such data could be erratic. Some participants thought recurrence data were very important.

## Health Communication

Participants suggested that the public health community should be very specific and clear in its rationale for surveillance and should communicate this rationale widely, because these programs depend upon political systems, which in turn depend upon acceptance by the public. They noted that if the value of surveillance systems is not provided to this broader audience, funding for surveillance will not continue.

The group recommended that the needs and benefits of surveillance should be explained to the public to maintain public trust in public health organizations' stewardship of confidential data. Members of the public need to be assured that the collection of personal information is not a threat to them, their security, or their future health. It is essential that the public health organizations cultivate public trust in surveillance and that the public understands the value of collecting, maintaining, and using surveillance information.

## Other Comments About Surveillance

Current surveillance activities include the SEER and NPCR registries. A common feature of cancer registries is identification of incident cases and information about demographic characteristics, place of residence, characteristics of the cancer, and first course of treatment. Registries differ in extent and type of follow-up, which can be either active or passive. Participants suggested that an initial survey could be used to define additional needs for data. Surveillance systems could then be modified to collect more focused or in-depth information.

In addition to cancer registries, other relevant public health surveillance systems exist including, such as NHIS and NHANES.

The group noted that because PSA screening was introduced before its efficacy in reducing mortality being thoroughly established, surveillance data have been used to examine the efficacy of this screening. A similar scenario may occur for other biologic markers. Public health should anticipate future introduction of new biologic markers for cancer risk and prognosis and consider how they might be incorporated into surveillance systems.

## Highlighted Suggestions

### *Disease Burden and Risk*

1. Conduct surveillance of incidence among ethnic and geographic subpopulations and search for variations in incidence to identify possible risk factors.

2. Improve quality, completeness, and timeliness of data.

***Primary Prevention***

1. Conduct surveillance of key potentially prostate cancer-related, lifestyle factors identified as risk factors for other cancers, such as diet and physical activity.

2. Prepare to collect information on biological markers.

***Secondary Prevention and Treatment***

1. Conduct surveillance on PSA testing, treatment, complications of the disease and treatment, and recurrence. For treatments and comorbidities, consider links to other data sources.

2. Develop mechanisms for studies of patterns of care for prostate cancer.

3. Develop BRFSS and other surveys to collect data on use of the PSA test and on other tests developed in the future.

4. Develop surveillance on biopsies—determine the reasons biopsies are performed and their positive predictive value.

***Survivorship and Quality of Life***

1. Conduct research to improve existing measures of quality of life by testing reliability and validity and by ensuring that the measures include information about patients' perceptions of what is important to them.

2. Conduct population-based survival studies for subgroups.

3. Use SEER outcome data as a baseline, and conduct studies to establish quality of life surveillance systems.

4. Disentangle reasons differences in survival using existing surveillance systems.

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# VI. Public Health Research

In this session, the participants considered the role of the public health community in applied public health research in the areas of disease burden and risk, primary prevention, secondary prevention, and survivorship and quality of life. They summarized the following priorities:

***Disease Burden and Risk***

- Explore factors responsible for the increased risk and the disparity in disease burden among African American men and other racial and ethnic minority groups.
- Elucidate those risk factors.
- Assess variations in quality of care and access to care, particularly for underserved groups.

***Primary Prevention***

- Develop large cohorts of African American men.
- Develop new methodologies to identify risk factors.
- Increase participation of minority and medically underserved men in research studies.

***Secondary Prevention***

- Develop tools to aid in decision making and conduct research on how these tools affect the decision making process.

***Survivorship and Quality of Life***

- Consider how the uncertainties of screening and treatment of prostate cancer can be communicated to health care providers and patients.
- Study modifiable risk factors for prostate cancer.

**Disease Burden and Risk**

Participants agreed that further research on risk factors is critically important. Most risk factors have not been explored prospectively in cohort studies. Trials should be designed with endpoints and inclusion criteria to allow extensive risk factor study. Research using human prostate cancer cells in mice should be conducted to evaluate protective and promotive substances.

Available information about risk factors is still inconclusive, and the public health community should give priority to determining the impact of these factors. Reliable information at the population level about disease trends and occurrence needed for the U.S., but it is currently unavailable outside of the SEER program areas. Known risk factors of race and family history should be examined in relation to disease trends. The CDC should develop a white paper—a detailed literature review—of what is and is not known about risk factors.

The group noted that research should include developing tools to study quality of life among cancer patient survivors and should examine how perceived quality of life changes over time and how it varies among population subgroups.

Participants suggested that the public health community could improve surveillance data quality, particularly with regard to disease stage and tumor grade. Public health should also be responsible for a consistent, high-quality expansion of cancer registries apart from SEER.

The group suggested that NCI and the CDC might cooperate on research, with CDC expanding public health research beyond program or service delivery. Although it might be inappropriate for CDC to concern itself with etiological research or basic science, a collaborative effort between CDC and NCI could take place with CDC translating basic science into community intervention.

Public health research is needed to determine reasons for the greater disease burden and risk among African Americans, whether this disparity is the result of biology, behavior, or a combination of several factors. Details about disease burden among other minority ethnic groups are not well known. Because migration studies provide opportunities to study changes in cancer incidence by generation, the group suggested adding birthplace to cancer registries to allow for such studies.

The participants also discussed the importance of developing more comprehensive assessments of disease burden in the U.S. population. Available data could be used to better quantify complications, quality of life, and the cost and use of resources.

The group discussed the need for greater understanding of the mechanisms associated with survivor disparities, such as access to health care or poverty. Participants noted that differences are clearly not limited to poverty; race does play a role, particularly for African American men.

To further the understanding of the relationship between ethnicity and disease burden, the group suggested that public health researchers conduct additional research on factors that affect men's decisions about screening and develop instruments to measure screening behaviors and factors that influence decisions about screening. These factors could include men's attitudes, access to screening and treatment, knowledge, and other health related behaviors. Currently, no standardized tools exist to determine whether prostate cancer testing was done for screening or for diagnosis. Such tools should be developed and tested for appropriateness in ethnically diverse populations and for literacy levels in specific populations.

Participants noted that screening tests can be evaluated through a case-control design only when use of the test has saturated the population and reached a steady-state level. A test that is relatively new cannot be evaluated because use in the control population will not be properly measured in relation to use in the case population. The rate of PSA testing is increasing so rapidly that more prostate cancer cases are being discovered, but use of the test has not saturated the overall population.

Evaluating whether screening with PSA affects the probability that men die of prostate cancer, is difficult, too, using medical records. Many more urologists use PSA screening to monitor benign prostatic hyperplasia (BPH), because a study showed an association between PSA levels and the progression of BPH.

The participants discussed the need to assess quality of care and whether variations in quality of care contribute to differences in disease burden. The group decided that burden should be examined in relation to financial and geographic access to care and to perceived access to care, including such factors as trust, communication, and language. Furthermore, they suggested that studies examine effects of differences in cancer culture, the extent to which men's knowledge and beliefs influence them to seek professional health advice when symptoms are present.

The group also suggested that because the diagnosis of prostate cancer has changed over time and throughout the world, international comparisons should be updated and revisited. For example, researchers in different countries should use the same specimens and records to compare pathology assessments made in the past with assessments made today. Studies should also compare assessments of the same sets of specimens and records by pathologists from the United States and from other countries.

The group discussed the perception that African men have lower incidence of prostate cancer than do African American men in the United States. Recent data from Nigeria, South Africa, and Canada indicate that this perception may be inaccurate because earlier studies may not have been well designed. Some participants thought that public health researchers should collect specimens and records from pathology data banks in these countries. These data could include microscopic and premalignant lesions and clinically detected prostate cancer. Others disagreed and stated that such research would not be an appropriate use of time and money for prostate cancer research in the United States.

Participants suggested that tools to study quality of life should be developed to address the question of how perceived quality of life differs over time or among subpopulations. The quality of surveillance data should also be improved and the expansion of cancer registries should be consistent and of high quality.

The group discussed how to effectively change behavior through behavioral modification and by targeting high-risk groups.

They suggested that public health researchers develop standardized tools that are easily understood and culturally appropriate for low-literacy populations in order to measure knowledge, attitudes, and behaviors.

**Primary Prevention**

The group discussed a recommendation that public health investigators identify questions in primary prevention that have not been previously addressed by research. More multiethnic cohorts and more diverse populations are needed in clinical trails such as the Prostate Cancer Prevention Trial. Because results of clinical trials strongly influence policies, investigators need to increase participation among African American and Hispanic men and men with low SES in

clinical studies. The Veterans Administration has begun studies on differences in participation in prostate cancer research between African American men and white men.

Participants discussed the need for clinical trials on the recruitment process to improve methods of recruitment. The majority of the trials focus on the disease rather than the recruitment issues. Millions of dollars have been spent on recruiting racial/ethnic minority groups. The University of Alabama study focused on African Americans in one study, but even with enormous effort, recruitment was very difficult, and the recruitment period was extended. Two related issues are retention and compliance with the study protocol.

Socioeconomic status, rather than skin color, could be the most important issue in study participation. If the studies address issues that are not perceived to be pertinent to the lives of the men, then their behavior will be different from that of men who regard issues as pertinent to them.

The group suggested that new strategies are needed to examine environmental risk factors for prostate cancer. Participants noted that newer, quicker methods are needed for laboratory studies using animals to test the effects of environmental exposures on the prostate. The criteria needed to start a large clinical trial with humans should be better evaluated and more clearly established, particularly criteria involving results from animal research.

**Secondary Prevention and Treatment**

The effectiveness of secondary prevention in reducing mortality is not clear. Participants noted that the PLCO trials will eventually determine the effectiveness of screening and secondary prevention in reducing mortality. The public health community should survey and monitor current community screening practices. Research on patients' perceptions of their treatment options and how they interpret the information given by health care providers about treatment options is also needed. The role of public health agencies in disseminating correct information to the public needs to be clarified.

Participants suggested that because physicians are unlikely to know how to communicate uncertainty about the effectiveness of prostate cancer screening, ways to communicate key issues of uncertainty should be developed. Tools are needed to help physicians convey this uncertainty to patients.

The group noted that ways of increasing recruitment of medically underserved men to randomized treatment trials are needed. Methods for explaining risk need to be improved by considering literacy, racial, or SES impediments, with a variety of messages tailored to selected subgroups.

Participants recommended creation of a core of credible information on prostate cancer screening from independent clinical sources. Public health agencies have a role in disseminating that core information. However, more research is needed on the most effective way to provide education on the uncertainty of the risks and benefits of screening.

Participants questioned how selected tools influence decision-making processes. Clinical materials that help in decision making should be developed to help patients make informed decisions about screening and treatment. Patients do make complex medical decisions, but what prompts the final decision is not known. The decision making tool may not be the only factor in making a particular decision. Other sources of information, such as television or spokespersons and organizations that recommend screening, should be factored in. Research is needed on how specific tools affect the decision making process in the context of these other factors.

The group discussed issues related to survivorship including living with the disease as opposed to survival rate. It was suggested that survivorship means living with the diagnosis. It takes many years to determine the efficacy of prostate cancer treatment, making survivorship an important component. However, survival rates are also important as the classical measure of overall treatment outcome, although they do not help in assessing effectiveness of early detection because of lead-time bias. Mortality may be the only reasonable outcome measure for early detection or screening trials. Treatment research must include research or overall survival. Lead-time bias and length bias affect survival estimates when a disease is as susceptible to early diagnosis as prostate cancer. But while this complicates the interpretation of survival, it does not invalidate it. Lead-time and length bias also affect survival with breast cancer and a number of other malignancies, and survival rates are measures for these diseases.

Participants suggested that surveillance of survival rates should be maintained for research purposes. Overdiagnosis affects survival but it is not the same thing as lead time. The group also had other suggestions. The short- and long-term effects of treatment on prostate cancer patients and their families should be assessed. Biologic behaviors of tumor subgroups by histologic grade should be evaluated and therapies or strategies should be linked to subgroups at risk.

**Survivorship and Quality of Life**

The participants suggested that quality of life should be measured throughout the disease continuum of screening, diagnosis, treatment, and follow-up, and quality of life should be incorporated into existing surveillance systems, such as BRFSS, NHIS and NHANES. Decisions on what to measure, however, should be made in advance. The existing measures and their applicability, reliability, validity, and responsiveness should be assessed. The time periods that should be used for frequency and assessment also need to be determined.

Participants noted that research is needed to determine which changes in functional status and quality of life result from disease and which from the aging process. Baseline quality of life should be established for cancer patients and a comparable disease-free group. Quality of life should be measured in these two groups over time. Family members' quality of life should also be assessed, as well as patient preferences. Information is needed on what outcomes are important to individual patients. Changes in quality of life should be captured over time.

The group recommended that physicians be helped to discuss screening and treatment options with their patients, perhaps with an information summary by means of interactive technology that guides providers through the discussion. Public health agencies, such as CDC,

should coordinate and disseminate the information. Uncertainty needs to be communicated in a useful manner, so patients can make more informed choices. An increase in knowledge can be measured, but the increase needs to be in concordance with the values involved in decision-making. Side effects and negative treatment outcomes should be communicated more clearly, and the potential for harm should be reduced. After participating in an informed decision making process, older men with a lower likelihood of benefit, or even net harm, are less likely to choose PSA testing. The content of messages to be communicated to patients must be determined. The risk-benefit analysis related to family history and personal risks should be stated in an understandable manner.

In was suggested that messages need to translate science into common language. Visual analog scales can be used. Ongoing efforts to help men evaluate risk versus benefit should be continued to help men make decisions. The efforts may increase patient comprehension. Attitudes and behavior still need to be addressed.

Participants discussed the need to study lifestyle changes following diagnosis that may be related to quality of life. The impact of a prostate cancer diagnosis on other chronic diseases also needs evaluation. From a research standpoint, it is important not only to study prostate cancer incidence, but to examine factors that may affect recurrence of prostate cancer and survival. Patients should be helped to determine what their preference is so that they can have more autonomy in decision-making.

The group listed these additional questions that should be addressed by public health research:

- When should intervention take place and what is its impact on quality of life?
- Is intervention at the first occurrence of elevated PSA levels preferable to later intervention?
- What are the treatment thresholds?
- What additional treatments should be evaluated?
- What information is shared with the patient?

**Highlighted Suggestions**

***Disease Burden and Risk***

1. Conduct research to describe disparities in disease risk and disease burden by race and ethnicity, particularly for African Americans. Consider the burden of illness in terms of costs and the use of resources for patients, the workforce, families, and communities.

2. Conduct research to increase knowledge of the factors that are responsible for increased risk and the disparity in burden, such as access to health care and poverty.

3. Develop a white paper—a detailed literature review of what is known about these two issues at this time.

***Primary Prevention***

1. Conduct research on a cohort that includes African Americans, Hispanics, and other underserved populations.

2. Develop new methods to measure risk factors (environmental exposures) and use new models (e.g., animal models).

3. Increase participation of members of race/ethnic minority groups, the poor, and other underserved men in research studies, including clinical trials (e.g., trials on the preventative effects of vitamin E or selenium).

***Secondary Prevention and Treatment***

1. Conduct research to develop tools to aid men, their families, and clinicians in decision-making.

2. Perform research on how those tools affect the decision making process—how patients perceive their treatment options or interpret information that providers give and how patients understand and appreciate the uncertainties of screening tests.

3. Conduct research to determine how complex medical decisions are made and study how the incontinence, impotence, and treatment experiences play in decisions about prostate cancer screening and treatment.

4. Increase participation in screening trials of men from racial and ethnic minority groups, poor, and medically underserved men in screening trials.

***Survivorship and Quality of Life***

1. Conduct research on how to communicate uncertainty about screening and treatment to health care providers and patients.

2. Perform research on factors that may modify recurrence and survival.

3. Conduct research on thresholds for different treatments and on optimal treatments.

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# VII. Communication

A fundamental purpose of health care communications is to provide adequate information to physicians and patients to enable them to make informed decisions. In this session, the participants addressed how best to communicate information about prostate cancer.

The group was asked to address issues about communication regarding prostate cancer in four areas—disease burden and risk, primary prevention, secondary prevention and treatment, and survivorship and quality of life and to make suggestions on what to communicate and how to communicate it.

This group gave priority to the following messages that should be communicated about prostate cancer:

- Prostate cancer is a serious and important health issue.
- Considerable scientific uncertainty exists regarding screening and treatment issues.
- Many decision points and options exist for screening and treatment.
- Clinical trials under way now may answer many questions.
- Additional resources for health care providers and patients are needed to assist in decision-making.
- Men have a right to be educated and informed about prostate cancer issues, including screening.
- Men have a right to make choices on these issues.
- Men should talk with their providers about prostate cancer issues, including personal risk.
- Providers need information, skills, and resources to provide counsel for patients.

The group identified several needs for health care providers and the public. To meet those needs, the public health community should do the following:

***Health Care Providers***

- Provide validated tools to convey the risks and benefits of prostate cancer screening and treatment.
- Train clinicians to be able to educate patients that decision-making must be individualized and that there is no right or wrong approach to prostate cancer screening and treatment.

***The Public***

- Provide ways to help men and their families better understand shared decision-making.
- Provide ways for men to participate in shared decision-making, such as providing a list of questions to discuss with their health care providers.
- Develop tools to help men interpret prostate cancer risk.
- Help men to understand the potential trade-off between quality of life and lifespan of prostate cancer treatment.

- Provide Web-based aids for decision making related to screening and treatment.

In addition, the public health community also needs to:

- Determine, through the use of public opinion polls, what the public knows about prostate cancer, including attitudes and behaviors.
- Convey to the public what is known regarding the risks and benefits of prostate cancer screening and treatment.

Although participants did not reach consensus on the specific messages that should be delivered, they identified health care providers and the public as the main audiences to whom public health agencies should communicate. The group noted that different messages must be crafted for target audiences. The participants agreed that policy makers and the media should be as well educated about prostate cancer as they are about breast cancer. To accomplish this goal, the public health community needs to develop educational materials for the media. One of the best ways to communicate with the public and policy makers is through the media.

The field of prostate cancer screening and treatment is evolving and the messages may change as new information becomes available. The group suggested that the public health community should test the effect of different messages to determine their impact and how people make decisions based upon the information provided.

Participants suggested the public health community develop a comprehensive communication plan that identifies target populations, specific messages, strategies, and methods of delivery. The messages need to be clear, straightforward, and basic, especially for lower income, urban populations. Because the field of prostate cancer screening and treatment is fraught with uncertainty, the participants discussed the importance of communicating this uncertainty to the public. They agreed that different messages should be crafted for different groups. Patients need to know that there is no single right answer.

In addition to identifying target groups and developing messages appropriate for those groups, public health researchers need to identify what specific actions those groups should take, e.g., whether they should be screened or not and whether they should seek aggressive or more conservative treatment.

**Disease Burden and Risk**

The group noted that the public health community should communicate to the public that the risk of prostate cancer—approximately 1 in 10—is nearly the same as that for breast cancer. Although the highest risk group is older men, the participants suggested that one goal of communication should be to dispel the myth that prostate cancer is a benign disease that only older men develop. They discussed the importance of targeting messages to the highest risk groups, including African American men and men with a family history of the disease, and those who may be the most likely to benefit from treatment, middle-aged men or men without a high degree of comorbidity.

Because a significant proportion of prostate cancer is undiagnosed, the participants agreed that defining disease burden is difficult and communicating about it is complicated. The public health community needs to communicate the risk of various treatment options, as well as the risk of nontreatment.

Lack of knowledge of the risk factors for prostate cancer makes it difficult to craft messages clearly. The group discussed determining the best way to frame messages and whether these messages should present specific information for men in different age groups or should communicate overall risk. Public health officials could provide a list of questions for patients to ask physicians about prostate cancer screening and the risks and benefits of treatment. The group suggested that to develop and deliver these messages, public health agencies should work in concert with state health departments, ACS, the American Urological Association (AUA), and other organizations.

**Primary Prevention**

Information on prevention of prostate cancer appears to be lacking. Whether diet, exercise, and nutritional supplements can lower the risk of developing prostate cancer is unknown. Until study results are available, communication in this area will be difficult. In general, following a healthy lifestyle that includes eating fruits and vegetables, avoiding fats, getting adequate exercise, and remaining slim appears to be advisable, even if these factors do not specifically prevent prostate cancer. The message in this area seems to be that the risk factors for prostate cancer are unknown at this time.

Participants made several other suggestions. The public health community needs to be a leader in approaching policy makers about legislation on men's health issues. Public health organizations should request funding for increased surveillance and for increasing the collection of behavioral and psychosocial data to determine the factors that might be involved in primary prevention. Identifying and developing relationships with people of influence who can communicate with and influence policy makers is important.

**Secondary Prevention and Treatment**

The group suggested that the CDC needs to educate health care providers that no right or wrong answer exists regarding prostate cancer screening and treatment. The public health community can help physicians develop methods to communicate this uncertainty to patients.

Participants suggested several points should be included in decision aids to help clinicians help their patients decide about prostate cancer screening. PSA screening is approved by the U.S. Food and Drug Administration and paid for by Medicare. This should be communicated to providers and patients. Risk profiles could be developed to help men assess their risk of developing prostate cancer. Patients need to be informed that if they choose to have a PSA test and the test is positive, they will have to make certain decisions, including whether to have a biopsy, whether to be treated if the biopsy is positive, and the type of treatment they want. Patients need to be made aware of the risks and benefits of the various treatment options. Some patients will choose not to be treated, or screened.

The participants discussed the importance of clinical trials and agreed that the public health community could communicate the need for physicians to participate in clinical trials. However, barriers to participation exist. Physicians are busy and gain no immediate benefit. The group noted that more could be done to help physicians realize that scientific advances can be made more readily if more physicians participate in clinical trials. Barriers also exist in the minds of the patients who may be uncomfortable being part of an experiment for the benefit of others.

**Survivorship and Quality of Life**

The group discussed the need for messages that convey the information that prostate cancer is not always a death sentence and that survivorship is generally good. However, nearly 40,000 men die each year of prostate cancer, so the message should not be that prostate cancer can be ignored. Men also need to be aware of the risks of treatment and of non-treatment. Another message is that the risk of mortality from prostate cancer is higher among African American men.

Participants suggested that to better understand the impact of the lack of health care, public health officials might consider documenting differences in quality of life and survivorship between men who have access to health care services and those who do not.

The participants also discussed the importance of considering the issue of quality of life rather than just survival. For example, quality of life tradeoffs may be required for longer survival. A recent study showed that 80 percent of men were impotent 2 years after prostectomy and that about 50 percent of men were impotent after radiation. Incontinence after treatment is another consideration. Rates of these side effects vary among populations and clinical practices. These rates might be improved if treatments were performed at centers with a high volume of treatment of prostate cancer patients. The group also pointed out that information about alternative treatments, long-term complications, and availability of resources and follow-up, need to be communicated.

To address survivorship, the participants suggested that public health officials partner with organizations such as the National Coalition for Survivorship. Spouses of survivors need support as well. The public health field should consider communicating with spouses of prostate cancer patients about quality of life and coping strategies and offer information on resources and support groups.

**Highlighted Suggestions**

***Disease Burden and Risk***

1. Communicate to the public that prostate cancer is a serious and important health issue that men have a right to know about.

2. Provide men with information, including Web-based materials, to allow them to better understand their risk. Encourage men to talk to their health care providers about their prostate cancer risk.

3. Provide practitioners with information, skills, and resources, such as validated tools to convey risks and disease burden that can be used to counsel patients.

4. Base communication methods on current research on what the public and providers know about disease burden and risk.

***Primary Prevention***

1. Provide information on a prudent lifestyle that includes a healthy diet and physical activity.

2. Provide information on the effectiveness or ineffectiveness of alternative prevention measures, such as the use of herbals.

***Secondary Prevention and Treatment***

1. Communicate to the public about the considerable scientific uncertainty about the potential harms and benefits of screening and treatment for prostate cancer, the potential tradeoffs between quality of life and life span related to screening and treatment, and the ongoing clinical trials that will answer many questions in the future.

2. Provide practitioners with information, skills, and resources (validated tools) to counsel patients and assist in decision-making.

3. Educate men about the issues of prostate cancer screening, provide information on the risks and benefits, and provide decision aids, including tools on the Internet.

4. Help members of the public to better understand shared decision making and equip them with tools, such as questions to ask health care providers, to participate in shared decision making. Men should know and understand that there is no right or wrong answer to questions on prostate cancer screening and treatment. Encourage men to talk to their providers about screening and treatments.

5. Base communications methods and messages on current research on what the public and providers know about screening and treatment of prostate cancer.

***Survivorship and Quality of Life***

1. Communicate to the public about the considerable scientific uncertainty about the potential hazards and benefits of treatments for prostate cancer and the potential trade-offs between quality of life and life span.

2. Provide information on alternative and complementary medicines.

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# VIII. Programs and Services

In this session, the participants considered public health programs and services that could be implemented to address issues of disease burden and risk, primary prevention, secondary prevention, and survivorship and quality of life, in particular programs and services, as well as communication and health education. Other topics included in this discussion were problems of underserved populations and the infrastructure and resources that the public health community needs to implement prostate cancer programs and services. Participants discussed the need to focus on public health programs and services separate from research, surveillance, and communications.

The participants discussed environmental factors, public health policies, access to health services, and insurance coverage. Public health was considered in a broad sense to include state public health agencies, CDC and other government institutions, voluntary organizations, and partnerships with public health organizations.

For each topic, e.g., disease burden, topics presented here are listed in the order of their importance as judged by group participants.

**Disease Burden and Risk**

Participants discussed a wide range of suggestions:

***1. Analyze screening outcomes.***

The core of the public health approach to disease burden and risk is to understand and communicate information about burden and risk. Accomplishing this communication goal requires surveillance, research, and an accurate understanding of disease burden. Participants noted that public health officials can do very little until a message to the public can be crafted to address the effectiveness of screening and treatment.

One of the factors that must be understood and communicated is the expected mortality risk of men who are diagnosed with prostate cancer. Risks are usually communicated in terms of 5-year survival, but a recent study described the fallacy of using 5-year survival rates when diseases are being detected earlier. For example, recent 5-year survival rates of men with prostate cancer have risen from 50 to 90 percent. Although this increase implies that practitioners are "doing something right," this may be misleading if 5-year rates do not correlate with actual mortality rates.

Participants discussed PSA testing on both incidence and survival rates. The incidence is increased because PSA testing may identify more latent cases that might not have otherwise been identified and treated. Survival rates increase because PSA testing can result in earlier detection, which lengthens the time from diagnosis to death. Follow- up of patients for a longer period of time will be necessary to determine the true rate of survival.

The group discussed the Cochrane Collaboration, a group that conducts systematic reviews, primarily of randomized trials, to assess the risks and benefits of health care interventions and provide a body of evidence. This Collaboration also provides a registry of all randomized trials conducted for prostate cancer. A key issue for prostate cancer is to define evidence and uncertainties, as the Cochrane Collaboration does.

***2. Establish better communication between public health and grassroots organizations.***

The group discussed communications between public health agencies, including CDC, and grassroots organizations. Grassroots organizations, such as small volunteer groups, usually have few resources but are well positioned for disseminating messages. At present, CDC has not worked closely with these groups.

The Florida Prostate Cancer Task Force is an example of how volunteer groups can influence prostate cancer issues. This task force was created by patient advocacy groups to demand that the state examine current practices and develop a comprehensive plan for addressing prostate cancer in the state. The Florida Health Department has not identified prostate cancer as an issue of concern, so the task force is pressuring the legislature. The creation of this task force was driven by the patient community, which could have benefited from assistance by public health agencies. The CDC could encourage state health departments to work with similar volunteer groups. One group which reviewed NCI activities concluded that the organization does not have a clear picture of what is being done for prostate cancer across the country.

Participants noted that about 10 to 15 years ago, the Surgeon General conducted a study to determine the value of self-help or support groups for the health and survival of cancer patients. The investigators found that regardless of the type of cancer, belonging to a group and talking to others with common problems alleviated the mental stress of the patient's condition, and made treatments more effective, and resulted in longer survival. Groups such as US TOO! International receive a great deal of support from a variety of sources, including commercial organizations. Group participants noted that public health agencies should consider becoming more proactive in supporting these groups or in working with them to train others to reach more prostate cancer patients. This approach is highly cost effective because the groups are led by unpaid volunteers.

The group discussed issues public health and voluntary groups should include in communications. Men who select watchful waiting as their treatment choice may not be comfortable in self-help groups because of the fear that others may try to convince them that they have made the wrong decision or that they are being too passive. Men who choose to not be screened are also unlikely to join a prostate cancer support group because of their advocacy of screening. Both of these groups of men need to be included in the public health communication process, because current self-help groups are not likely to reach them or include them.

The Massachusetts Public Health Department funds support groups for all men who have prostate cancer and their families regardless of treatment choice. For men without cancer, men's health events or open forums are organized according to the particular needs of the community. Topics for discussion may include substance abuse, cardiovascular disease, or issues related to

prostate health. Funding is in the form of yearly mini grants to a network of support groups. The groups respond to a request for proposals (RFP) every year and explain what they will do with the grant. Selections are based on the RFP and the location; the aim is to spread the grants among communities.

The group discussed another suggestion that support groups collaborate and increase communication among themselves to discuss effective strategies.

***3. Promote the sharing of information across states.***

A participant asked what CDC was doing in the area of prostate cancer and how much resources were being providing to communities to help accomplish their goals. Congress has provided the CDC with approximately $9 million for prostate cancer work to help develop the prostate cancer case registry and to build a strong science base by supporting specific research programs and surveillance activities. Few resources are available yet for a state program but information on infrastructure at the state level is being collected. Six comprehensive cancer control programs are being funded on a competitive basis.

Resources are not sufficient to fund all of the states. Funding of approximately $350,000 per year is provided to each program to help build infrastructure.

Participants noted that Massachusetts may be a model state for addressing the prostate cancer issue. Sharing the Massachusetts model with other states would be valuable. Unfortunately, many other states do not have the resources and plans to put together symposia or other kinds of programs. Most know little about what occurs in other states and what does and does not work. Participants suggested that the CDC could serve as a catalyst for sharing this kind of information.

***4. Fix problems with coding of death certificates issue.***

Participants discussed evidence indicating that miscoding is a problem with death certificates. Men who receive early intervention for prostate cancer are less likely to have physicians list prostate cancer as cause of death than are men who were not tested and men who were treated with watchful waiting. This coding bias can be as much as 20 percent. Many physicians have not been trained in how to complete death certificates. This biases mortality statistics and survival rates.

***5. Conduct surveillance of sub-populations.***

New tools are needed to track trends in subpopulations, and the cancer registries need to be improved so that they provide information on specific subpopulations.

**Primary Prevention**

Participants discussed a number of suggestions.

*1.* ***Determine the impact of communication at the provider level****.*

Participants suggested that the public health agencies should consider supporting public symposia for prostate cancer survivors and physicians to present information on risk-benefit assessment and to help extend volunteer group efforts beyond the groups' own neighborhoods. Some of these symposia may be specialized, but most would provide general information. Massachusetts is a model state that mandates the support of prostate cancer research and yearly information symposia. The CDC might help states seek legislation to encourage programs like those of Massachusetts.

Public health officials might also play a role in fostering cooperation between the grassroots organizations and health care providers. There has been some concern that the two groups may sometimes have an adversarial relationship. Providers may claim that support groups are saying the wrong things and are not helpful. Health care providers often do not see men with prostate cancer until they are seriously ill, when wrong decisions may be made because they are based on assumptions. Sometimes, health care providers seem to convey the idea that survival is not an option, whereas support groups provide evidence that men with prostate cancer can survive. Support groups can be of service to physicians who lack the time to discuss prostate cancer issues with patients.

***2. Encourage men at high risk to participate in clinical trials****.*

The group discussed the possibility that local health departments could encourage men at high risk to participate in clinical trials that are testing chemoprevention for prostate cancer or that are investigating whether dietary interventions are useful. Public health organizations could fund research on why people and physicians do not participate in these trials.

***3. Integrate prostate cancer into other public health prevention programs.***

Dietary changes to prevent prostate cancer should be investigated as part of public health research on diet and nutrition.

***4. Develop messages about evidence and uncertainty concerning prostate cancer risk.***

Prostate cancer should be placed in the context of other risks. Putting prostate cancer risk in perspective by comparing it with environmental risks may be useful. Multiple risks exist and may include genetic, environmental, and behavioral risks. It is often difficult for an individual to understand all these risks.

A tremendous amount of uncertainty exists around the prostate screening and treatment. Some participants noted that a principle that has been applied to carcinogens and other health risks is that if an intervention is believed to be beneficial, it will be used regardless of the

scientific evidence. CDC can help by taking a leadership role in evaluating the evidence about the effectiveness of prostate cancer screening and treatment and formulating messages regarding the evidence and uncertainties.

A Madison Avenue-type marketing organization might help craft and promote messages with the understanding that the messages must be based on the available evidence.

Public health agencies use experts in health communications development and should consider their involvement in promoting, and possibly aiding in crafting, prostate cancer messages.

A Web-based information clearinghouse might be created so that state health departments, for example, could communicate with one another to learn what works and what does not, to communicate uncertainty, or to find available tools. A prostate cancer-specific tool, similar to the colorectal cancer slide program that provides disease-specific information to physicians and patients, would be useful.

Participants discussed the possibility that part of the prostate cancer risk messages could be comparative risk assessments or opportunity-cost analyses. Every dollar spent on prostate cancer control is one not spent on lung cancer control, colorectal cancer screening, etc. The message should include the fact that screening should only be done in the context of primary care and that it is not for everyone.

***5. Encourage disease-risk counseling***.

Participants noted that disease risk counselors could help physicians discuss prostate cancer risk with their patients. This role would be similar to the role of genetic counselors in discussing breast cancer genetic susceptibility testing or counselors for HIV risk. Physicians often have no time to discuss risk with their patients. The additional burden to the physician in the case of prostate cancer is to determine the kind of information needed. Programs that empower the physician by providing accurate knowledge about prostate cancer risk would also be useful.

Participants discussed the possibility that public health professionals may need to focus prostate cancer education on low-risk groups, as well as high-risk groups. Low risk groups should be included because these population groups are unlikely to benefit from screening and treatment. These may include older men in poor health or race/ethnic groups at low risk of prostate cancer. Insurance companies often make the mistake of screening 80-year-old men for prostate cancer when they are more likely to die of other causes. One Veterans Administration study found that men who were older than 70 years and in fair-to-poor health were just as likely to be screened for prostate cancer as younger healthy men. Both the public and providers need to be educated about age- and health status-related differences in disease risk.

The Veterans Administration practice guideline recommends that all men between the ages of 50 and 70 years be counseled about risks and benefits. On average about 40 to 50 percent of men are counseled. Yet, many men who have been tested are not aware that they have been tested.

***6. Provide prostate cancer education as a subcategory of prostate health or of men's health.***

The group discussed prostate health in general. The men's health program has been driven by prostate cancer, but information is often lost by focusing too much attention on prostate cancer. The issue is really total health. Community health programs focusing on prostate cancer do not engage people's attention. A focus on prostate health and overall health encourages engagement. Most men know little about the prostate gland. Education programs could be organized around symptoms, such as urgency and frequency of urination. Patients would come in to deal with symptoms and learn about prostate cancer at the same time.

Although prostate cancer is important, men die more often of heart disease. One successful, well-attended program, Men's Sexual Health Issues, covered heart disease, colon cancer, and other topics besides prostate cancer. The military once provided statistics on men's health but has not done so recently. CDC and other public health agencies could participate in collecting and presenting prostate cancer data under the broad issue of men's health.

***7. If a state was given $50 million to run a prostate program, what would it look like?***

Participants discussed the possibility that a population-based study be conducted to determine how to reach the greatest number of people. Different subgroups need different approaches, and programs could be organized to make education available, perhaps in the form of pamphlets directed to specific issues. An appeal to spouses, as well as to men, would probably be effective. The topic of prostate cancer could be presented as part of other men's health issues because it is easier to talk about prostate health than prostate cancer.

The group discussed a suggestion to set up screening and prostate health programs similar to the language of legislation proposed in the U.S. Senate. But, a program that provides only screening is of little use. A few years ago, the Michigan Department of Health's budget provided money to be used specifically for a prostate cancer screening program. The program ended up as a demonstration program that was not widespread or research-focused.

Participants noted that prostate cancer may be overemphasized to the disadvantage of more important public health issues for which proven effective interventions exist. Smoking cessation efforts might need funding more than prostate cancer, because such funding would save more lives. Pancreatic and esophageal cancer can kill, and yet screening is not conducted for these cancers, perhaps because no good disease markers exist. Prostate cancer is the second leading cause of cancer deaths represents a small proportion of the major causes of death.

Participants noted that one of the most important questions to be answered is how to distinguish benign or latent forms of prostate cancer from malignant prostate cancer. Autopsies indicate that two thirds of Americans have latent or occult prostate cancer at the time of death. The problem of distinguishing benign from malignant disease is a scientific issue and which may not come under the purview of public health agencies like CDC. NCI should expand its program on prostate cancer biology to address this issue. CDC does have a role in communicating the risks and potential downside of screening.

Public health officials should focus on determining how to convey the message of uncertainty once it is clear what that message should be. At the present time, not enough evidence exists to recommend avoiding screening, but the scientific community has not yet identified clear markers for prostate cancer.

**Secondary Prevention and Risk**

The group identified several suggestions for secondary prevention:

***1. Fully assess the frequency of adverse outcomes.***

Participants noted that public health researchers should take greater interest in identifying the real frequency of adverse events, such as incontinence and impotence. The existing data are believed to be extremely unreliable. The questions need to be addressed to the patient to obtain a reasonably accurate answer, but patients often lie to their physicians about these problems because of the associated shame.

***2. Assess the morbidity and quality of life measurements.***

The long-term consequences of hormonal therapy should be investigated. Psychosocial issues are being addressed by a few studies. One question that occurs frequently is how men rate the value of survival versus quality of life.

***3. Revise the current screening and treatment recommendations.***

One role of the public health field in secondary prevention is in the development and promulgation of guidelines and encouraging implementation and evaluation. In the absence of evidence-based guidelines, consensus-based guidelines might be developed. However, it is not clear how meaningful consensus guidelines would be developed for prostate cancer. The conundrum is that randomized trial results were not conducted before screening for PSA began. The issue has become highly emotional and politicized, but the science is not being allowed to break through and provide guidance. Although CDC might fund research on secondary prevention and promote interim consensus guidelines, it might not want to be in the guideline business, because other federal agencies have that responsibility.

The group noted that many men with prostate cancer are being treated with surgery and radiation therapy whether or not there is agreement on effectiveness. Public health organizations could conduct surveillance studies of prostate cancer treatment practices. Ways may exist to selectively target patients with localized early disease to prevent disease progression, but how these patients should be monitored is not clear.

Systematic reviews have been useful for analyzing the effectiveness of hormonal and immunosuppression therapy. A large body of evidence exists on advanced prostate cancer. The group suggested that this information needs to be communicated to patients and providers, and public health could help assemble this information. Others suggested that the public health emphasis could be on understanding the complexities involved in screening and treatment and creating a decision making process to determine the best route.

***4. Develop better methods to more accurately assess the causes of death.***

In most cases, the death certificate is written on the day of death, without performance of an autopsy. In one case, prostate cancer had metastasized to the liver, and the cause of death was listed as liver cancer. Better methods are needed to determine and to code the cause of death.

**Survivorship and Quality of Life**

Prostate cancer screening may save lives, lead to unnecessary treatment and treatment-related morbidities, or both. Research and surveillance involving prostate cancer screening and its outcomes are needed to address these issues. However, screening practices in communities may not follow public health recommendations or wait for scientific evidence.

**Highlighted Suggestions**

***Disease Burden and Risk***

1. Public health organizations, including CDC, should collaborate with and support prostate cancer-related self-help groups, following the lead of the Massachusetts Department of Health, by developing community training materials; training individuals, including prostate cancer survivors, supporting self-help groups; facilitating community forums; and holding symposia.

2. Provide better tools for communicating the uncertainties about prostate cancer screening.

***Primary Prevention***

1. Implement programs to encourage men at high risk of prostate cancer to participate in primary prevention studies, such as those on selenium and vitamin E.

2. Integrate prostate cancer into other chronic disease prevention programs, such as prostate health programs or men's health programs.

***Secondary Prevention and Treatment***

1. Conduct follow-up studies of men who have been screened for prostate cancer.

2. Perform studies to evaluate treatment practices to include what is being done and how to measure outcomes.

***Survivorship and Quality of Life***

1. Conduct research to more fully and carefully assess frequencies of adverse outcomes in men treated for prostate cancer.

2. Perform research on the validity of death certificates in reflecting the true cause of death.

3. Assess morbidity measures, improve quality of life measures, and ensure consistent use of measures across studies.

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# Appendix A

## Plenary Session and Meeting Organization

Dr. Nancy Lee, Director of the Division of Cancer Prevention and Control at the CDC, presented an overview of prostate cancer and an introduction to the CDC and the Division of Cancer Prevention and Disease Control.

She explained that prostate cancer is the most commonly diagnosed, nondermatologic cancer among U.S. men and is second only to lung cancer as a cause of cancer deaths in men. Unfortunately, effective measures to prevent prostate cancer have not been identified. Furthermore, there is substantial controversy surrounding prostate cancer screening because there is no good evidence that treatment of asymptomatic or early stage prostate cancer can reduce mortality from the disease. The CDC follows the U.S. Preventive Services Task Force recommendations, which do not promote widespread screening.

Public health agencies and other organizations are increasingly asked to play an active role in efforts to reduce the burden of prostate cancer. The CDC planned this conference to obtain advice on programmatic activities in prostate cancer. The CDC is seeking suggestions about what steps the broader public health community should take in prostate cancer surveillance, research programs, services, and communications.

The CDC is an agency within the U.S. Department of Health and Human Services, whose role is to monitor health and prevent disease. It accomplishes this role by:

- Conducting research to enhance disease prevention,
- Developing and advocating sound public health policies,
- Implementing prevention strategies,
- Promoting healthy behaviors,
- Promoting safe and healthful environments, and
- Providing leadership and training in public health.

The CDC fulfills its role by partnering with:

- State and local health departments,
- Academic institutions,
- Community organizations,
- Other U.S. governmental agencies,
- Philanthropic foundations,
- Schools,
- Churches,
- Industry, and
- Labor.

The Division of Cancer Prevention and Disease Control is part of CDC's National Center for Chronic Disease Prevention and Health Promotion. The role of this division is to conduct surveillance of cancer incidence, mortality, risk factors, and preventive behaviors. The division also conducts research and evaluation and develops educational campaigns. The division

focuses primarily on breast, cervical, ovarian, skin, prostate, and colorectal cancers. Lung cancer is addressed by another division.

The division has a number of programs, including the NPCR, which has funded cancer registries in 45 states since 1994. The other five states are funded by the NCI's SEER system. For the NPCR, the CDC provides funds to state health departments or their designees to support population-based statewide cancer registries. The quality of data from these registries has improved since 1994. More than 50 percent of the U.S. population is now covered by high-quality registries, from which the CDC will begin receiving annual data in 2001.

The division has active programs in:

- Early detection of breast and cervical cancer,
- Colorectal cancer prevention and control,
- Ovarian cancer control, and
- Skin cancer prevention education.

Dr. Durado Brooks, Director of Prostate and Colorectal Cancer Programs at the American Cancer Society, discussed the role of the ACS in prostate cancer. The society develops guidelines and support programs for prostate cancer patients and survivors. He pointed out that prostate cancer screening and treatment remain challenging areas.

Dr. Richard Williams of the American Urological Association pointed out that the AUA's mission is to foster the highest standards of care by providing education to physicians and their patients and by serving as a health policy advocate. Combating prostate cancer will involve public health initiatives in prevention, early detection, treatment, and palliation. It also involves recognition that not all prostate cancer patients require active treatment.

The death rate from prostate cancer is declining. Some of the reasons may be:

- Earlier detection,
- Improved management,
- Changes in competing causes of death,
- Changes in reporting deaths, and
- Lead time bias.

Research into quality of life issues is needed to determine whether to screen and how to manage patients as individuals. For this, health care professionals, the public, and patients need to be better informed.

The AUA has partnered with the federal government to further the cause of basic research into prostate cancer and hopes to partner with the CDC on applied prostate cancer research. The role of public health professionals in surveillance, information management, and dissemination of information is essential to the success of those endeavoring to improve the management of prostate cancer. Patient advocacy groups can provide a reality check to determine whether doctors are providing patients with the information and services they need, expect, and deserve. As frontline providers of health care, physicians are pleased to be able to work with public health professionals.

Dick Johnson has been the Director of Health Programs for the U.S. Conference of Mayors since 1982. He explained that the Conference of Mayors is a membership and service organization of mayors of cities with populations over 30,000. With a membership of 1,100 mayors, this group is one of Washington's seven major public-interest lobbying groups.

The principal role of the Conference of Mayors is to:

- Aid in the development of effective urban policy,
- Strengthen relationships between the federal government and cities,
- Ensure that federal policy meets urban needs, and
- Provide mayors with leadership and management tools for their cities.

Concern about cancer prompted the Conference to establish the Mayors' Coalition for Prostate Cancer Awareness and Education. The Conference of Mayors is conducting an awareness and education campaign that it hopes will lead to informed decision making.

Dr. Ross Brownson, a professor of epidemiology at Saint Louis University, delivered the keynote address. He spoke about public health approaches to disease prevention and control and presented an overview of public health issues.

According to Dr. Brownson, public health can be defined as a societal interest in the variety of conditions that make people healthy. Roles exist for both government and the private sector in public health, with a focus on partnerships. Public health is multidisciplinary, with contributions from prevention science, research, epidemiology, and other fields.

The causes of death in the United States have changed dramatically over the past century. Although infectious diseases were at the top of the list at the turn of the 20th century, chronic diseases are now the number one cause of death. Over the past century, the average life span in the United States has increased by 30 years. Basic public health measures such as immunizations, refrigeration, and cleaning the air and water, have contributed to this increase. The goal now is not necessarily to increase life span, but to increase health span—the amount of time that an individual remains healthy.

In 1994, state public health agencies spent five percent of their budgets on chronic disease prevention and control and this number is rising. About 70 percent of health care dollars are spent on chronic diseases that occur at the end of life.

The contributing factors to chronic disease and death include tobacco use, diet, physical activity, and alcohol use. Each of these factors is amenable to some type of prevention effort.

Research design in public health differs from clinical trials research. In public health research, randomizing is usually not possible, so public health investigators rely on surveillance data and study designs that are only quasi-experimental and not random, to analyze what is occurring in the real world to a real population. Public health surveillance is the collection and analysis of numbers and information. Public health researchers determine whether a trend has occurred as a result of an intervention. Part of public health is putting a program or policy in place and assessing whether it is effective. Public health researchers study surveillance,

numbers, and other forms of data. Public health investigators use epidemiologic information to form causative associations.

Education is another important component of public health. Coalitions and partnerships are key to the success of public health.

Some future challenges for public health are:

- The rapid changes in the field of public health, as well as in the field of health care. For example, molecular biology and the human genome project will continue to effect change in the predictability of contracting certain types of cancer.
- The risk factors for prostate cancer are not well established and remain a challenge for the future.
- Improving surveillance, because good information forms the foundation for intelligent decision-making.
- Primary prevention of prostate cancer.

Dr. Ralph Coates provided some examples of the variety of prostate cancer activities at CDC. Examples were included for each areas of discussion at the meeting: 4 different types of public health activities, including surveillance, research, health communication, and other programs & services, and 4 different types of issues in prostate cancer, including risk and disease burden, primary prevention, secondary prevention and treatment and quality of life. Examples from states participating in a CDC Cancer Control Program were also included.

CDC has a number of activities in public health surveillance. A major CDC activity is the National Program of Cancer Registries (NPCR), previously discussed by Dr. Lee. The NPCR has helped the states that are not participants in the National Cancer Institute SEER cancer registry program develop their registries to provide information on prostate cancer for populations not included in the SEER program. The National Center for Health Statistics at CDC, collects and publishes prostate cancer mortality information for the nation. In cooperation with state health departments, CDC supports a number of other surveillance systems, including the Behavioral Risk Factor Surveillance System, that can monitor risk factors and intervention programs for prostate cancer, as risk factors for prostate cancer are identified. CDC has worked with NCI to collect the first national data on PSA test use through the National Health Interview Survey. Additional data will be collected by state health departments and CDC through the BRFSS, providing state level information. Several states and an Indian Health Board are conducting additional surveys of public and provider knowledge about prostate cancer and their prostate cancer screening practices. Surveillance is also being conducted on quality of life for men with prostate cancer using the BRFSS and NHIS.

In the area of public health research, CDC funds studies to evaluate how completely registries identify the prostate cancers diagnosed in their regions. Research on primary prevention of prostate cancer has not been a major activity at CDC, but studies based on the CDC's National Health Interview Surveys and National Health and Nutrition Examination Surveys have contributed important research findings. CDC evaluations of the 5-A-Day program to increase fruit & vegetable intakes and evaluations of STD prevention programs might be considered primary prevention research. CDC is doing a case-control study of the

effectiveness of prostate cancer screening and is collaborating with the NCI on the Prostate, Lung, Colorectal and Ovarian Cancer Trial. CDC is doing research on the validity of self-reports of prostate cancer screening and in a study using NHANES will provide information on PSA levels in U.S. men. CDC has a number of studies of methods to improve the prostate cancer screening decision-making process for men and their physicians. CDC also has studies examining reasons for racial differences in survival and on end-of-life care.

In communication, CDC Division has in development a video on decision making for screening and training materials for physicians to help them in the process of informed decision making. Many state health departments have prostate cancer education campaigns for the public and for providers. One has unique effort to increase awareness of clinical trials for prostate cancer.

Two types of CDC activities that might qualify as primary prevention efforts for prostate cancer are the 5-A-Day program to increase fruit and vegetable intakes and efforts to reduce risk of sexually transmitted diseases, but there is no scientific consensus on the effects these activities are on prostate cancer risks. CDC does not fund or conduct screening programs for prostate cancer. However, at least two state health departments have implemented screening programs, although one stopped.

Kevin Brady of the CDC's Office Of Program and Policy Information discussed the format of the breakout sessions. The CDC had recently used this type of invitation-only working conference to gain useful information about public health needs in the area of ovarian cancer. He explained that the CDC hopes to gain suggestions for future direction and action, rather than formal recommendations.

Meeting Process

The remainder of the meeting was in the form of eight breakout sessions:

I. Disease Burden
II. Primary Prevention
III. Secondary Prevention
IV. Quality of Life
V. Public Health Surveillance
VI. Public Health Research
VII. Public Health Communications
VIII. Public Health Programs and Services

Each participant was assigned to two sessions. Each session had a facilitator, an expert reporter to summarize the group's findings and present them to the group on the final morning, and a writer and editor to produce a written summary of the session. Transcribers were present in each session to produce word-for-word transcripts. Participants were asked to provide suggestions in a number of areas in a brainstorming session, and then to prioritize the ideas in order to develop a list of suggestions for future action by the CDC. Because the sessions overlapped somewhat in the nature of the questions asked, there was some overlap and duplication in suggestions.

# Appendix B

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