MATERIALS TESTING FOR
THE MEN’S HEALTH PARTNERSHIP
AND THE MASSACHUSETTS
DEPARTMENT OF PUBLIC HEALTH

Prepared for:

causemedia, inc.
Boston, Massachusetts

Prepared by:

Market Street Research, Inc.
Northampton, Massachusetts

June, 2004
SUMMARY OF FINDINGS

The Massachusetts Department of Public Health (DPH) and the Men’s Health Partnership project have developed a variety of brochures, posters and fact sheets in many languages aimed at motivating men from various ethnic and cultural backgrounds to take positive steps toward good health. This report presents findings from a total of eight focus groups with African-American, Caucasian, Brazilian, Cape Verdean, Haitian, Chinese, Russian, and Puerto Rican and Dominican men age 40 and over. The goal of this research is to test the efficacy of the messages contained in the printed materials, obtain feedback about how they can be improved, and determined what other types of health-oriented printed materials would be helpful to participants. causemedia is assisting the DPH and the Partnership project, and will use these results to inform the development of future printed materials.

Overall, despite the fact that most men in this research have encountered information about prostate cancer at some point, most have a superficial understanding of prostate cancer at best. Many are aware that prostate cancer is related to sexual health and functioning; that the disease primarily affects older men; and that early detection may prevent death. Some men, however, lack even a basic understanding of prostate cancer: for example, a few men had never heard of prostate cancer or the prostate gland prior to attending the focus group; a few did not distinguish the difference between “prostate gland” and “prostate cancer” and believed “prostate” was the name of a disease; and a few believed women could develop prostate cancer. Some of the men in this research had been treated for prostate cancer themselves, or had a relative with prostate cancer, and even these individuals were not highly informed about the disease.

In the absence of specific information about prostate cancer, most men catastrophize the disease. Men react strongly to the word “cancer,” and do not differentiate among types of cancer. They believe that any type of cancer is likely to be fatal, and since prostate cancer is a type of cancer, prostate cancer must also be fatal. Very few men are aware that some forms of prostate cancer can be slow-growing, and a few who are aware of this interpret this to mean that prostate cancer will involve a slow and agonizing death. Men are not well-informed about the treatment methods used for prostate cancer, the effectiveness of these methods, or the possible side effects associated with them. They did, however, express grave concerns about their sexual health and functioning and their quality of life following a diagnosis of prostate cancer.

Most men are generally aware that preventive care and prostate cancer screenings will enable providers to detect prostate cancer in its early stages and may result in a better prognosis. Most men are aware of the need for regular physical exams, and most claimed to have a check-up within the past year. Many men in this research have had a prostate exam at some point. While men uniformly described the experience as embarrassing and uncomfortable, most men agreed that the experience was not painful or unbearable. Those who have had prostate exams described a number of motivating factors. Some visited a physician for an exam because they were experiencing physical discomfort or symptoms, such as difficulty urinating or impotence. Some did not consciously decide to have a prostate exam, but received one automatically in the course of their annual check-up. Others were more proactive about seeking prostate cancer screenings, because they had a friend or relative who was diagnosed with prostate cancer, because they encountered information about the disease that made them realize they might be at risk, or because they had a health care professional, relative, friend, or loved one recommend that they get tested. Some men said that they felt more invested in their health and well-being now that they were beginning to get older.
Men who have not had prostate exams described several practical and attitudinal barriers that had prevented them from obtaining the test. Among the **practical barriers** identified, some men have not been screened due to financial reasons: they lack adequate health insurance, and cannot afford to pay for health care services out of pocket. Some men lack information about prostate cancer that might otherwise have motivated them to acquire testing. In terms of **attitudinal barriers**, men often said that they perceived no need to get a prostate exam because they were not experiencing any symptoms or physical discomfort. Others had a negative perception about physicians and health care in general that made them reluctant to seek health care services. Some men avoid testing because they are fearful of being diagnosed with prostate cancer; these men believe that their health will be adversely affected by a diagnosis. In some cases, this is due to feelings of superstition (being tested for a disease will cause a disease to manifest), and in some cases, men believe that a diagnosis will cause a perceptual shift: they will cease to view themselves as strong, healthy men and will begin to view themselves as weak, sick men, which will in itself adversely affect their health. Finally, some men have avoided prostate exams out of fear or embarrassment about the exam itself. They may be reluctant to discuss sexual or urinary problems with their physician, or wish to avoid receiving a Digital Rectal Exam (DRE).

With regard to the materials tested in this research, **men responded positively to the brochure overall**, and preferred it to all other printed formats they viewed. They recognized that the purpose of the brochure was to inform men about prostate cancer and encourage them to obtain a screening. They liked the “question and answer format” and the amount of information contained in the brochure, and considered it generally credible. The information about symptoms and treatment methods was considered particularly useful. Most men felt that they learned a great deal from reading the brochure—for many, this information challenged their perception that prostate cancer was a fatal illness simply by virtue of being a type of cancer, and they felt encouraged and optimistic by what they had learned. Many men said they would be more likely to speak to their physician about obtaining a prostate exam as a result of what they had learned.

Men also voiced several consistent **concerns about the brochure**. To begin, the brochure was not considered visually appealing. Men felt the colors were depressing and dull, and felt that brighter colors would both be more likely to catch their eye if they saw the brochure, and convey a more optimistic message about men’s chances for surviving prostate cancer. Most men had not heard of the prostate cancer survivors pictured in the photograph and did not identify with them, as these survivors looked like affluent professionals.

Another concern about the brochure was the **text discussing what is not yet known about prostate cancer**, particularly the information about a possible association between vasectomies and prostate cancer. In general, men preferred to read concrete information about what is known about prostate cancer; indefinite information provoked feelings of anxiety or distrust. In addition, it is important to note that men **misinterpreted some of the information in the brochure**, particularly information about treatment methods. Some men had difficulty understanding the concept of “watchful waiting,” for example, and believed this meant they would be denied treatment for a fatal disease. Others misinterpreted the information about the types of men who would be likely to choose surgery, and felt that men who did not possess these characteristics could not have the cancer removed.

There are numerous differences among men **belonging to different ethnic or cultural groups**, with regard to the extent to which they are informed about prostate cancer, their orientation toward preventive care, and their reactions to the brochure. These differences are discussed in detail throughout the report. The most striking difference is that **Russian and Chinese** men are much less oriented toward preventive care, and much less informed about prostate cancer than other men in this research.
STATEMENT OF THE PROBLEM AND KEY QUESTIONS

causemedia has been asked by the Massachusetts Department of Public Health (DPH) to assist in its efforts to support the Men’s Health Partnership project. The Partnership and DPH have developed a variety of brochures, posters and fact sheets in many languages aimed at educating men from various ethnic and cultural backgrounds in the state about prostate cancer, and motivating them to have regular prostate cancer screenings. The DPH and the Partnership currently have brochures printed in six different languages including: English; Spanish; Portuguese; Haitian Creole; Chinese; and Russian. The Partnership and DPH need to test the efficacy of the messages contained in the printed materials, obtain feedback about how they can be improved, and determine what other types of health-oriented printed materials would be helpful to participants.

In order to meet these objectives, causemedia and DPH contracted with Market Street Research, Inc. of Northampton, Massachusetts, to conduct focus groups with men of different ethnic and cultural backgrounds targeted by these materials.

**Key Questions:** The specific objectives of the study were to determine:

- men’s **awareness of and knowledgeability** about prostate cancer;
- **potential barriers** that exist to testing for prostate cancer, and the factors that have motivated men who have been tested to obtain screenings;
- men’s **responsiveness to the brochure** and other materials prepared by DPH and the Partnership, including how appealing the brochure is visually; the clarity and believability of information provided; the helpfulness of information provided; ways materials could be improved; and men’s likelihood of taking action based on seeing and reading the materials; and
- the best **places for educational materials to be distributed**.

Market Street Research conducted a total of eight focus groups of ethnically homogeneous men aged 40 and over living in Massachusetts who are from the identified ethnic communities in the state to help the Partnership and the DPH in their effort to assess and improve their men’s health-oriented printed materials. Differences between groups will be discussed wherever present.
METHODS

To achieve the research objectives, Market Street Research conducted eight focus groups, including one group each with men age 40 and over from the following ethnic/cultural backgrounds: African-American; Russian; Caucasian; Cape Verdean; Chinese; Brazilian; Haitian; and Puerto Rican and Dominican. We began by meeting with representatives of causemedia and DPH to discuss the objectives of the study. Market Street Research then prepared a draft of the moderator’s guide, which causemedia and DPH representatives reviewed and approved prior to the focus groups. Copies of the final moderator’s guides are presented in the appendices of this report.

Market Street Research conducted six focus groups in eastern Massachusetts, and two in western Massachusetts, based on the concentration of the populations of men in the ethnic/cultural backgrounds targeted for this study in those areas. All participants were 40 years of age or over and were screened for literacy. In addition, we screened participants to ensure that they were of the ethnic/cultural background targeted for each particular group; that we had a mix of participants of low to moderate income levels; that there was a mix of insured and uninsured participants; and that participants were articulate, and fluent in the language in which the group was being conducted.

The Caucasian group was recruited by Bernett Research, a focus group facility located in Boston, Massachusetts. Caucasian participants were recruited from Bernett Research’s database. All other groups were recruited using a community-based approach, using a combination of personal contacts, flyers, and newspaper notices. All participants were offered a $60 incentive to participate. The focus groups were moderated by professional moderators of the same ethnic/cultural background as the participants. The Russian, Cape Verdean and Chinese groups were moderated by community leaders trained specifically by Market Street Research to moderate their respective focus groups.

All groups were audiotaped and transcribed to facilitate analysis, and the African-American and Caucasian groups were also videotaped. Groups conducted in languages other than English were translated into English and transcribed. For the analysis of these focus groups, a Market Street Research analyst collected summaries from focus groups moderators; read the transcriptions of the focus groups; and took detailed notes to record reactions and identify emerging themes. Transcripts were read in conjunction with viewing a videotape for groups that were videotaped. When needed, moderators were asked follow-up questions to clarify points.

It should be noted that most of the non-English speaking men in this research have lived in the U.S. for widely varying time periods; some have lived in this country for a fairly short period of time (three years or less), while others have lived in the U.S. for ten years or longer. Most non-English speaking men in this research are only minimally acculturated.

The table on the next page presents detailed information on the focus groups, including the date and time they were held, the language in which they were conducted, location, and number of participants.
### Characteristics of Focus Group Participants

<table>
<thead>
<tr>
<th>Group Description</th>
<th>Language</th>
<th>Date and Time</th>
<th>Location</th>
<th>Town</th>
<th>Number of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Men from former Soviet Union</td>
<td>Russian</td>
<td>April 29, 2004 at 6:00 p.m.</td>
<td>Professional Development Center</td>
<td>West Springfield</td>
<td>10</td>
</tr>
<tr>
<td>Age 40 and over</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>African-American men</td>
<td>English</td>
<td>April 29, 2004 at 7:00 p.m.</td>
<td>Dimock Community Health Center</td>
<td>Roxbury</td>
<td>11</td>
</tr>
<tr>
<td>Age 40 and over</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian men</td>
<td>English</td>
<td>May 3, 2004 at 6:00 p.m.</td>
<td>Bill’s Restaurant</td>
<td>Greenfield</td>
<td>10</td>
</tr>
<tr>
<td>Age 40 and over</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cape Verdean men</td>
<td>English</td>
<td>May 6, 2004 at 5:30 p.m.</td>
<td>Cape Verdean Association</td>
<td>Brockton</td>
<td>10</td>
</tr>
<tr>
<td>Age 40 and over</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Brazilian men</td>
<td>Portuguese</td>
<td>May 6, 2004 at 6:00 p.m.</td>
<td>East Cambridge Community Health Center</td>
<td>East Cambridge</td>
<td>10</td>
</tr>
<tr>
<td>Age 40 and over</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Haitian men</td>
<td>Haitian Creole</td>
<td>May 8, 2004 at 10:00 a.m.</td>
<td>Codman Square Health Center</td>
<td>Dorchester</td>
<td>11</td>
</tr>
<tr>
<td>Age 40 and over</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Puerto Rican and Dominican men</td>
<td>Spanish</td>
<td>May 10, 2004 at 6:00 p.m.</td>
<td>Latino Health 2010</td>
<td>Lawrence</td>
<td>10</td>
</tr>
<tr>
<td>Age 40 and over</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chinese men</td>
<td>Cantonese</td>
<td>May 11, 2004 at 11:00 a.m.</td>
<td>Asian-American Civic Association</td>
<td>Boston</td>
<td>10</td>
</tr>
<tr>
<td>Age 40 and over</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
DETAILED FINDINGS
AWARENESS OF AND ATTITUDES TOWARD MEN’S HEALTH ISSUES

Health maintenance and regular preventive care appointments play a vital role in ensuring prostate health and early detection of prostate cancer. In general, however, most research on men’s health indicates that men are less likely than women to seek medical care, and are less proactive about health monitoring and maintenance. Men from ethnic and cultural minorities living in the U.S. may experience additional problems accessing needed medical care, such as language barriers and culture-based attitudinal barriers to receiving health care.

One of the goals of this research is to understand more about attitudes toward health issues and preventive care among men belonging to the ethnic and cultural groups included in this research (i.e., Caucasian, African-American, Russian, Cape Verdean, Chinese, Brazilian, Haitian, and Puerto Rican and Dominican men), as well as the extent to which these men are familiar with prostate cancer and aware of the need for annual screenings. The following sections will present findings regarding men’s attitudes toward health and preventive care and the extent to which they are informed about prostate cancer. We will also discuss the factors that have motivated men to obtain screenings, as well as those that prevented men from obtaining prostate cancer screenings.

Awareness of Health Problems and Preventive Care

We asked men several questions about their awareness of health problems that may affect them, and the types of care and testing they should be obtaining. Overall, men in this research are generally aware of the need for healthy behaviors, and of the possible health problems they may face.

First, most men in this research are aware of the need to maintain healthy behaviors, including having a healthy diet, getting regular exercise, and eliminating unhealthy behaviors, such as quitting smoking. For example, a Chinese man discussed his efforts to maintain a healthy lifestyle: “I do what I think to maintain good health. . . . I do sufficient exercises every day, one hour per day of exercise. In terms of diet, I maintain a balanced diet. Not too salty, not too greasy. Eat more vegetables. Watch your diet and bowels, not to be constipated. That is important.” Puerto Rican and Dominican men are particularly oriented toward sexual health issues and the need to protect themselves from STDs. “A big problem are the serious diseases that exist today,” as one Latino said. “When you are a womanizer, you are exposed to getting a disease that you don’t want to have.”

Most men in this research have encountered information about potential health problems, with men saying they had seen or heard information about high blood pressure; diabetes; heart problems; cancer in general and specific types of cancers, including colon cancer; stress; high cholesterol; and STDs. Almost all men have encountered information about prostate cancer and prostate cancer screenings, although this differed depending on the ethnic or cultural group to which men belonged. Specifically, Russian and Chinese men are less likely than other men in this research to have encountered information about prostate cancer or prostate cancer screenings. Several men belonging to these ethnic groups had not encountered any information about prostate cancer and were generally uninformed about the issue, while almost all other men in this research had seen or heard something about prostate cancer.

Men have encountered information about health problems through the following sources: physicians and health care professionals; friends and family members; print information (including posters, pamphlets, or brochures in physicians’ offices and hospitals; bulletin boards at
their place of employment); online (including Internet searches and email newsletters); television (including public service announcements, news programs, educational programming, and advertisements from pharmaceutical companies); newspaper articles (including articles in The Boston Globe, The Boston Herald, and The Boston Metro); magazines (including magazines about men’s health and fitness); the library; billboards; radio stations (including 1090 WILD); and health insurance companies (including Blue Care® 65, Blue Cross Blue Shield’s Medicare+Choice plan).

Some African-American men recalled public service announcements about prostate cancer that featured celebrities who have survived prostate cancer; for example, one man said, “A lot of celebrities over the last few years have come forward saying, ‘Well, I have prostate cancer.’ Robert DeNiro, Bob Watson from the Yankees, and a few others.” In addition, it should be noted that a few non-English speaking men in this research commented on the poor quality of translations in the print information they have encountered. For example, a Brazilian man who has read pamphlets at a hospital in both English and the Portuguese translation said, “The translations done are of a terrible quality. Portuguese that’s absolutely wrong. Closer to Spanish, but also grave translation mistakes. Because I read it in English [also], I read English, and I see the difference. Grave translation problems.”

We asked men several questions about their perceptions of appropriate medical care and testing, including how frequently they believe men should obtain a check-up or physical exam by a doctor, separate from a specific health problem; and how often they believe men should have tests for specific problems, including their blood pressure and their prostate. In general, men clearly perceive a need for greater attention to health care as they age. They might not have paid much attention to their physical health when they were younger, and always felt strong and healthy. As they age, however, men are more likely to experience symptoms that motivate them to pay more attention to their health and to visit doctors. Some men care more about health maintenance now, and want to ensure that they will have a long and healthy life, either for their own sake or for the sake of their partner or children.

Men tended to believe that they should seek care and tests regularly, with most men believing that they should have their blood pressure checked several times a year; obtain a physical exam at least once a year; and have their prostate checked at least once a year. Specifically, men believed they should have their blood pressure checked quite frequently. Almost all men believed they should have their blood pressure checked at least once a year, with some men saying that this should be checked on a monthly or weekly basis. This perception may stem from the fact that it is fairly easy for men to check their blood pressure without visiting a doctor. For example, Caucasian men talked about the availability of blood pressure machines at local pharmacies and Wal-Marts; as one man said, “When I get my prescriptions, I always sit down [to test my blood pressure] while I’m waiting.”

With regard to physical exams, most men in this research are aware that men should have check-ups on at least an annual basis, with some men believing that men should have check-ups twice a year or more often. Those who believe in annual check-ups said they believe this is what is generally recommended by health care professionals; as one African-American man said, “That seems to be the consensus, what I’ve heard through the years.” Some men spoke to the fact that men should obtain regular exams even when they feel healthy, as they may be unaware or not experiencing symptoms of existing problems; for example, one Russian man said, “He has to go, by all means, even if nothing is bothering him, at least starting at forty years old, at least once a year. Because when something starts to bother [him], it’s too late.”

Men who believe that they should obtain check-ups more frequently than once a year gave several reasons for this orientation. First, some men believe that while annual check-ups are
recommended for healthy men, men with existing problems should see physicians more frequently in order to maintain their health. Similarly, some men believe that while annual check-ups are a good idea for younger men, the number of health concerns they may experience increases with age, and older men should visit physicians more often. Some men also feel that health problems can manifest quickly, and biannual checkups will ensure that problems are caught and controlled before they can do serious damage. Related to this, some men feel that health problems may be overlooked during a routine exam, and that more frequent exams will increase the chance that a physician will detect problems.

While most men in this research believed that men should have their prostate checked annually as well, men tended not to have as proactive an orientation toward prostate exams, compared with blood pressure and regular check-ups. They seemed very proactive about blood pressure testing, and aware that they needed to schedule regular check-ups; by contrast, they seemed less inclined to make inquiries about prostate exams. Several said that their prostate is checked as part of their annual physical exam, and felt that their physician would incorporate this into their check-up whenever it was appropriate.

Many men said that they heard recommendations to have their prostate checked from their doctor. Some men said that others, including spouses, friends and family members, have recommended that they speak to their doctor about prostate cancer screenings. Individuals said that regular check-ups and prostate cancer screenings are required by their employers. With regard to their perceptions about the recommended age to begin prostate cancer testing, most men said they believed they should have their prostate checked regularly around age 40, and some felt this was recommended for men age 50 and over.

In terms of differences among men, Russian men were less likely than other men to express an orientation toward annual check-ups or perceive a need for regular prostate exams. Most Russian men in this research believed that they should only visit a doctor when they were experiencing a specific health concern. As one Russian man said with regard to prostate cancer screenings, “I think when there is something that bothers [you], naturally, one must [visit a doctor]. But if there is not, why worry?” Some attributed this to the fact that preventive care is not a part of Russian culture, and said that it is difficult for them to adjust to health care practices in the U.S. In addition, many Chinese men said that they have never had a recommendation to speak to their doctor about prostate cancer screenings, and tended to think that a screening would be appropriate only for men who had begun to experience problems. For example, one Chinese man said, “I think if one completely loses his sexual abilities after age 60, then it is time to go for routine examination. That’s a smart thing to do.”

In summary, most men in this research have encountered information about health problems. They have encountered such information through a variety of sources, including talking with other people, information they have encountered in health education materials or in the media, and information they have looked for themselves. Men are generally aware of the need to maintain healthy behaviors, and to seek preventive care and testing for health problems. Russian and Chinese men are less likely than other men to have encountered information about prostate cancer and screenings, and are not as oriented toward preventive care measures. Next, we will present findings about men’s awareness of and familiarity with prostate cancer, specifically. Later in this report, we will present findings about the extent to which men in this research have actually received regular preventive care and prostate exams.
Awareness of and Familiarity with Prostate Cancer

Prostate cancer is, after skin cancer, the most common type of cancer among men in the United States. About one in six men will be diagnosed with prostate cancer at some point in their lives, and about one in 33 will die of prostate cancer. Some prostate cancers grow quickly and spread beyond the prostate gland to other parts of the body, becoming a serious threat to health and possibly causing death. Other prostate cancers, however, grow slowly and never become a serious health threat.1

We asked men in this research several questions about prostate cancer in order to assess how much they know about the problem. Overall, men are not well-educated about prostate cancer. Some feel that they are informed about prostate cancer, but this information tends to be superficial, and limited to the understanding that prostate cancer affects older men, and that men should get tested in order to detect the cancer in its early stages. A few men lack even a superficial understanding of prostate cancer. For example, some men had never heard of the prostate gland prior to attending the focus groups, or believed that women could develop prostate cancer. In general, Russian, Chinese, Brazilian, and Puerto Rican and Dominican men tended to be less well-informed about prostate cancer than other men. Some men who participated in the focus groups had either undergone treatment for prostate cancer themselves or had a relative with prostate cancer, and even some of these men were not very well-informed about the disease.

Without specific, accurate knowledge about prostate cancer, men tend to catastrophize the severity of prostate cancer. This appears to be related to fears and misconceptions about cancer in general, and the fact that men do not differentiate among types of cancer. They believe prostate cancer will result in death unless it is detected and treated in its early stages, which is their perception of the prognosis for all cancers. They are generally unaware of the treatments that would be used for prostate cancer, although they assume that surgery, radiation, and chemotherapy would be the primary treatment methods. They assume the side effects of treatment would involve hair loss and sexual dysfunction, and expressed concern that the sexual dysfunction would be permanent or long-term.

On the following pages, we will present more detailed findings regarding men’s awareness of prostate cancer, including their perceptions about incidence rate, severity, high-risk groups, and the available treatment options and their side effects.

Awareness of Incidence Rate and Severity: We asked men how big a problem they believe prostate cancer is, and what they have heard about the severity of the disease. In general, men believe prostate cancer is common and extremely serious. Most men do not seem to be basing these perceptions on actual information they have encountered about prostate cancer, but rather are basing their perceptions on their fears about cancer in general. They do not have any real understanding of how common prostate cancer is; men tended to assume the disease is common, but rarely gave any concrete reasons for this perception. A few felt that they might have encountered some information at some point about the incidence rate for prostate cancer, but they had difficulty remembering what they might have heard or read. For example, a Caucasian man said, “I think I may have read that it’s as common as breast cancer, but doesn’t get as much publicity. I do get a prostate newsletter . . . I can’t remember the name of the organization; it’s some sort of national prostate organization. I started getting it, I think, after I had my first

prostate check.” A Russian man said, “Ninety-five percent of men in the whole world die—well, I don’t know.”

Men had much less ambiguous perceptions of the severity of prostate cancer. The general consensus was that prostate cancer is fatal because it is a form of cancer, and all cancers are fatal. As one Russian said, “The word ‘cancer’ speaks for itself.” An African-American man said, “Anything associated with the word ‘cancer’ is serious, ‘cause I guess it eats away at your body.” A Haitian man said, “It is a cancer. Cancer is serious.” These comments are very typical of how most men in this research perceive prostate cancer.

Many men believe that prostate cancer, like any cancer, can be treated if detected early. As a Cape Verdean man said, “Since the doctor always recommends that you must check at least once a year, it seems to me that, this kind of disease, there might be a possibility to cure it. If you catch it in the early stages, maybe there’s a chance you can get rid of it. Like, if you never check and by the time you check it, it’s really deep and you don’t have a chance. I don’t really know. The doctor seems very serious about it. He’s always pressuring you to check it at least once a year, so it seems that if you catch it in the early stages, you might be able to get rid of it.”

Most believed that, if undetected, the prostate cancer would eventually spread to other parts of the body and cause death. Very few men are aware that some forms of prostate cancer can grow slowly. A few Caucasian and Brazilian men said they had heard that prostate cancer could grow slowly; most other men did not mention this perception. One Caucasian man said, “I’ve been told that it can be very slow growing, and that, in fact, all men when they die are—not all men, but almost all men, when they die have some cancer in their prostate, although it can be very tiny.” In the group of Brazilian men, while some men acknowledged that prostate cancer can grow slowly, they tended to interpret this as meaning that men with prostate cancer would face a slow and agonizing death. For example, one Brazilian man shared the following experience: “The big problem is that it acts quickly, but it doesn’t kill right away, you know. The guy goes on suffering, suffering. This neighbor, this neighbor of mine, this man whose death I watched, when his prostate cancer was diagnosed he suffered another three years, screaming. And then later he died. It was of no use, there was no medication, there was no morphine, there was nothing that would stop it.”

Awareness of High-Risk Groups: We asked men if they are aware of any types of men who are more likely to get prostate cancer. Most men do believe certain types of men are at a higher risk for prostate cancer, and most know that the disease primarily affects older men. Some are aware that men with a family history of prostate cancer would be at greater risk, and that prostate cancer is more common among African-American men. Puerto Rican and Dominican men tend to think that all non-whites are more susceptible to prostate cancer than white men, and some Chinese men guessed that Asians would be at greater risk for developing prostate cancer.

Many men also believe that prostate cancer is related in some way to sexual activity. Some African-American and Caucasian men believe that men who are less sexually active are at greater risk for developing prostate cancer. “I just read something [online] recently, a study, where men who have sex more often or who masturbate have less chance of contracting prostate cancer,” one African-American man said. By contrast, many Chinese men believe that men who are more sexually active are at greater risk for developing prostate cancer. Some Cape Verdean and Haitian men believe there is a relationship between prostate cancer and sexual activity, but they are unsure whether men with a higher or lower level of sexual activity would be at greater
risk. Russian, Brazilian, and Puerto Rican and Dominican men did not mention a perceived relationship between sexual activity and prostate cancer.

Men also mentioned other factors they believe can increase a man’s risk for developing prostate cancer. Some men believe they are more likely to develop prostate cancer if: they have an occupation that requires them to be inactive for long periods of time; they have a high-fat diet, or eat foods containing hormones; they have bad luck; they take certain anti-inflammatory medications that cause prostate cancer; and if they suffer from environmental or other types of stress.

We asked men if there are types of men who are more likely to have advanced cancer when it is diagnosed. In general, they believe that men who do not receive regular preventive care are likely to have more advanced cancer when it is diagnosed. A few men also feel that men who have additional health problems, have a lot of anger, or sunbathe regularly are likely to be at greater risk for having more advanced cancer at the time of the diagnosis.

In terms of differences among men, African-American, Caucasian, and Haitian men tended to have the best understanding of at-risk groups; they were likely to be aware that older men, African-Americans, and men with a family history of prostate cancer are at greater risk for developing prostate cancer, and they were less likely to mention other factors as contributing to prostate cancer development. Cape Verdean and Brazilian men are also moderately aware of at-risk groups.

Russian, Chinese, and Puerto Rican and Dominican men tended to be less well-informed than other men. Specifically, Russian men focused on the relationship between occupation and prostate cancer; as one Russian man said, “Say you are a driver; you spend eighteen hours sitting behind the steering wheel and everything suffers from that.” A few Russian men mentioned “bad luck” as a risk factor and felt it was not credible that prostate cancer would differ among racial or ethnic groups. Some Chinese men did not have any perceptions about at-risk groups; as one Chinese man said, “I am uncertain about matters like this. I don’t have enough understanding of it. When I hear ‘cancer,’ I don’t feel good. How cancer comes about—I’m sure there are many reasons for it.” Puerto Rican and Dominican men tended to attribute prostate cancer development to a variety of other factors, including occupation, sunbathing, and anger, and a few believed that there are no high-risk groups, because prostate cancer is “very democratic.”

---

For the purposes of this research, we focused on men’s awareness of risk groups as outlined by the Massachusetts Department of Public Health in the brochure tested here. It is important to note that further research is needed to understand the exact causes of prostate cancer, and that men who mentioned “other factors” may, in fact, be accurately describing factors that contribute to prostate cancer development. For example, with regard to several respondents’ perception that men in sedentary occupations may be at greater risk for developing prostate cancer, a 2002 study conducted at the Department of Medical Epidemiology, Karolinska Institutet, in Stockholm, Sweden found that the relative risk for prostate cancer increased with decreasing levels of occupational physical activity. Researchers found no association between occupational activity and prostate cancer mortality, and determined that further studies are needed to better understand the potential role of physical activity for prostate cancer (Norman, A. et al. “Occupational physical activity and risk for prostate cancer in a nationwide cohort study in Sweden.” British Journal of Cancer. 2002 Jan 7;86(1):70-5).
Awareness of Prostate Cancer Treatments: We asked men several questions about the treatments available for prostate cancer, including how effective the treatments are, what side effects they may have, and whether awareness of these side effects would have an impact on their likelihood of being tested for prostate cancer.

There are several treatment options available for prostate cancer, including watchful waiting; cancer drugs or hormone therapy; surgery; radiation; and cryosurgery. **Men are generally not well-informed about these options.** None of the men in this research mentioned either cryosurgery or watchful waiting, and only two Caucasian men are aware of hormone treatments. Men are **most likely to be aware of surgery and radiation as treatment options for prostate cancer**, with some African-American, Caucasian, Brazilian, and Haitian men mentioning these options. One Latino who had prostate cancer described being treated with brachytherapy, although he did not have a clear understanding of the treatment he had undergone, and seemed to believe it was a preventive measure. ³ This man explained, “I went to the doctor—he never put the small seed in there in my whole life. It’s something they insert inside [the penis]. They pull the penis back and they insert it and it goes down . . . and it works well. They take a photograph after three months. At three months they tell you, ‘Now you don’t have any danger.’”

Men also mentioned other options they believe would be used to treat prostate cancer. While chemotherapy may be used when prostate cancer has spread beyond the prostate gland, it is generally not the primary therapy for prostate cancer patients. Many men assumed that chemotherapy would be the most likely form of therapy, however; chemotherapy is the treatment option they think of when they think of cancer. In addition, Cape Verdean and Chinese men mentioned herbal or natural remedies. A Haitian man believed laser treatments would be an option. In terms of differences among men, **Russian, Chinese, and Puerto Rican and Dominican men tended to be the least well-informed about treatment options.** While other groups were able to name at least two of the five options, these groups were unaware of any of these options. As described above, one Latino who had undergone treatment for prostate cancer himself was not highly informed about the treatment he received.

**Overall, men had no sense of the effectiveness of the treatment methods available for prostate cancer.** Their knowledge of the effectiveness of treatment methods extended no further than their general perception that the effectiveness of treatments depends on the stage at which the cancer is detected, and that early treatment is likely to result in a better prognosis.

**Men are not well-informed about the side effects of the treatment options available for prostate cancer.** Russian and Chinese men are the least knowledgeable about side effects. They were unable to identify any specific side effects, although some said they would assume that any treatment would be likely to have side effects.

Many men are aware that **impotence** is a possible side effect of prostate cancer treatment, although they tend to have a vague or inaccurate perception of the problem. Men are clearly uncertain about how their sexuality would be affected by prostate cancer treatment, and expressed feelings of anxiety over the possible loss of sexual functioning. They believed impotence would be permanent; that they would no longer be capable of intercourse or orgasm; or that it would be a year or more before they could resume normal sexual relations. As one Caucasian man put it, “After removal, there’s no more mud for your duck.” A few men believed that prostate cancer

---
³ Brachytherapy is a form of radiation therapy that involves implanting radioactive seeds into the prostate to destroy cancer cells.
surgery was synonymous with castration, with one Haitian man reporting that this is a common perception among Haitians.

Men were much less likely to mention incontinence as a side effect of prostate cancer treatment. A few Cape Verdeans mentioned urinary and bowel incontinence, and a few Puerto Rican and Dominican men believed painful, burning urination would be a side effect of treatment. As one Latino described, “When you urinate it burns badly, and on the sides of your penis . . . it’s like fire. It feels very hot, and slowly, over an hour or so, your body goes back to normal.” None of the other groups of men in this research mentioned a connection between prostate cancer treatment and urination.

Men also mentioned other side effects that are not typically associated with prostate cancer treatment. The most commonly perceived side effects relate to men’s perception that chemotherapy would be used to treat prostate cancer; men tended to name the side effects they were aware of for chemotherapy, particularly hair loss. Some believed men would suffer from exhaustion, low blood iron levels, psychological problems, and increased susceptibility to additional illnesses.

In addition, Haitian men had a fairly unique perception of the side effects of prostate cancer treatment. Rather than focusing exclusively on the adverse effects on the man’s physical or emotional health after treatment, Haitian men focused on how their families would suffer as a result of prostate cancer treatment. “It affects your family, and when it affects your family, it is the whole chain of relationships that is being destroyed,” one Haitian man explained. These men worried that they would no longer be capable of providing financial support for their partner and children. They believed the amount of time the man used to devote to his family would now be spent on recovery, and that men might require more help after treatment, both of which could strain family relations. They also expressed concern that they would no longer be able to engage in sexual relations with their partner, and as a result, their partner would seek gratification elsewhere.

We asked men whether knowing about the side effects of treatment would have an impact on them in terms of being tested for prostate cancer. Many men believe that prostate cancer will be fatal unless detected and treated early, and that the side effects, as unpleasant as they perceive them to be, will be better than dying. As one African-American man explained, “If you’re going to die, I would prefer to live. I could care less about the side effects. If [the treatment is] going to make me live longer, I’m going to do what I have to do to live. I don’t care. If I can’t have sex for a year, it’s fine. I just don’t have sex for a year, and I’ll live longer. Would I rather have the sex and die two years later? What fun is that?”

Men have grave concerns about the quality of life they can expect after treatment, however, and some men believe that it is fairly common in their communities for men to avoid health testing: men may fear bad news, and believe that they are “safe” from poor health as long as they can avoid being diagnosed with a disease. For example, a Cape Verdean man explained this phenomenon, “I think there’s a prevailing attitude that if you don’t know, it can’t hurt you. People avoid going for check-ups. They hear the horrors, but they avoid going, which is obviously wrong. You know, what you don’t know is the thing that can hurt you. I think, in general, from the people I know, [it] is the prevailing attitude: keep it out of mind, and it won’t happen to you.”
Perceptions About Cancer Monitoring Among African-Americans: African-American men with prostate cancer are more likely than other men to have their cancer monitored than to have aggressive treatment. We asked African-American men if they had any thoughts about why this occurs. To begin, African-American men tended to interpret this phenomenon as African-American men being denied appropriate health care. They had very negative feelings about the idea of cancer being monitored, and could see no reason for letting cancer go untreated.

African-American men believe that several factors may be responsible for higher rates of cancer monitoring among African-American men. First, they believe African-American men may not be well-educated about their health care and treatment options. They feel that there are not a lot of open discussions about men’s health problems within their communities. African-American men may therefore not be informed about their options or their prognosis following aggressive treatment, which may inspire feelings of fear that prevent them from pursuing treatment, and, if they are tested and diagnosed with a health problem, may prevent them from actively advocating for themselves and the treatments that are in their best interests.

Secondly, some African-American men feel that this phenomenon may be at least partially attributable to racism. They believe white doctors may be less likely to encourage African-American men to pursue aggressive treatment, because white doctors feel less invested in African-Americans’ health and safety than they do that of whites; as one African-American man said, “Regardless of what anyone says, if you don’t look like me, I don’t care as much for you.” A few believed that physicians may choose not to recommend aggressive treatment to African-American men in order to use them as research subjects; as one African-American man said, “’Cause they research on us, they experiment on us. We’re the ones who tend to get it more, so why not go to the source who has the problem the most?” Finally, some believe that the high cost of health care may prevent African-American men from obtaining aggressive treatment for prostate cancer.

In summary, men are not well-educated about prostate cancer. At best, they have a superficial understanding of the disease: most know that the prostate gland is connected with their sexual health and functioning; that prostate cancer affects older men; and that early detection may prevent death. Most men do not differentiate among types of cancer, assuming that all cancers will be fatal if left untreated, and that treatment is likely to entail surgery, radiation, and chemotherapy. Men generally do not have a clear understanding of the side effects involved in prostate cancer treatments, although they tend to believe the side effects will be severe and painful, and will likely result in a permanent or long-term loss of sexual functioning. While many men said that these perceived side effects would not prevent them from getting tested for prostate cancer, given that they believe the alternative to treatment is death, they expressed evident fear about the quality of life they could expect as prostate cancer survivors. In the next sections, we will present findings about men’s experiences with physical exams and with prostate cancer screenings.
Utilization of Physical Exams and Prostate Cancer Screenings

As described earlier in this report, most men in this research are generally aware that they should have annual check-ups or physical exams and prostate cancer screenings. In this section, we will present findings regarding men’s utilization of check-ups and prostate cancer screenings. It is particularly important to understand men’s utilization of routine physical exams given that men tend to be less proactive about obtaining prostate exams: most men assume that this test will be part of their annual physical, and so they are more likely to ensure that they obtain routine check-ups than they are to specifically request prostate exams.

In general, previous research we have conducted on men’s health has indicated that men are generally likely to obtain regular preventive care when they are young, when annual physicals tend to be ensured by their mother or scholastic institution. Men between the ages of 25 and 45 are generally less likely to obtain preventive care and more likely to seek health care for traumatic injuries or acute illness. Older men are likely to begin accessing health care on a more regular basis again, however, as they begin to experience more health problems. The extent to which even older men access health care may be limited by their socioeconomic status and education levels, as well as insurance coverage.

The findings from these focus groups support those described above. Many of the men in these groups, all of whom are age 40 and over, report having had a physical exam within the past year. Some men spoke to the fact that they felt a stronger need for preventive care appointments now that they are getting older. Nonetheless, some men are not seeking routine exams for themselves as frequently as they believe is recommended. Some have not had check-ups within the past year, or confessed that the most recent check-up they had was the first in several years. A few men have never had a check-up, could not remember when they last had a check-up, or said that they only visit the doctor when they have a specific health problem.

In terms of differences among ethnic groups, all or almost all of the African-American, Haitian, Puerto Rican and Dominican, and Cape Verdean men in this research claimed to have had a check-up within the past year. Many of the Caucasian and Chinese men in this research claimed to have had check-ups within the past year, while others expressed reluctance in scheduling check-ups, saying that they prefer to see doctors only when they have a specific health problem. As one Chinese man said, “I feel if I do not have any problems, I do not need a physical exam. I have never had one.”

Brazilian and Russian men are least likely to have had check-ups within the past year. Some Brazilian men could not remember when they last had a check-up, and others said that they last visited the doctor for a specific health problem. Most Russian men had not had a physical exam within the past year, and a few had never had a physical exam. A few Russian men said that regular preventive care is not a part of Russian culture, and that it is difficult for them to adjust to health care practices in the U.S. For example, one Russian man said, “We came from another culture, and usually, how it used to take place there, we run to a doctor when something is bothering us . . . I went once, when I came here six years ago. But I think it’s wrong; one has

---

4 It should be noted that these findings reflect men’s reporting of their utilization of check-ups and prostate cancer screenings, and that these findings may not accurately reflect men’s actual utilization of check-ups and prostate cancer screenings. For example, while all of the Haitian men in this research reported that they had a check-up in the past year, a few men made remarks later in the discussion indicating that they would be unlikely to make appointments to visit a doctor unless they were seriously ill.

Another Russian man said, with regard to check-ups, “If nothing is bothering, why go? Ask for trouble.”

We asked men if they had ever had an exam that checked their prostate, and if so, what that experience was like for them. Men’s likelihood of having had prostate cancer screenings varied among racial and ethnic groups. Most African-American, Haitian, Puerto Rican or Dominican, and Cape Verdean men in this research claimed to have had a prostate exam at some point, and many Caucasian and Brazilian men claimed to have had them. Russian and Chinese men are less likely to have had a prostate exam.

Among those who had prostate exams, the majority described Digital Rectal Exams (DREs). A few men had the Prostate-Specific Antigen (PSA) test, for which a blood sample is drawn. One individual described having a cystoscopy, a procedure that enables physicians to view the bladder and urethra with an endoscope, and which can be used to diagnose an enlarged prostate.

Men uniformly described their experiences with prostate exams as being uncomfortable and embarrassing. One Haitian man said, “The sensation was not good at all, at all, at all.” A Chinese man described his DRE experience, saying, “I felt very embarrassed . . . because I had to take off my pants, and have someone tugging with his hands. It hurts. I have to have it examined . . . but it is very embarrassing.” One Latino expressed strongly negative feelings about the DRE exam, likening the experience to rape: “That thing with the finger, it’s very antiquated for the way medicine is so advanced these days. . . . That is illegal, anyway. Rape is against the law, anyway.” This was not the norm, however; most men who had prostate exams considered the experience unpleasant but necessary. Most said that the exam stopped short of being painful, and a few said that they felt relief from worrying after the exam, which made them feel the experience had been worthwhile. Men frequently used humor to deal with their feelings of embarrassment when discussing their DRE experiences.

The few men who had PSA tests did not find this experience particularly unpleasant; a few liked the fact that the test was quick, and they considered it a less embarrassing and uncomfortable alternative to the DRE. The individual who described having a cystoscopy had the procedure under general anesthesia and therefore experienced no discomfort, although he did mention that a relative had the procedure without general anesthesia and “said it was like torture; it was the worst experience he ever had in his entire life.” In the next sections, we will describe the factors that motivated men to obtain prostate cancer screenings, and the barriers that prevented them from doing so.

Motivation to Obtain Prostate Cancer Screenings

As described above, many of the men in this research have had prostate exams. We asked these men what motivated them to get tested. Men described six major motivators that led them to obtain a prostate exam:

- physical discomfort and problems;
- passive motivation; in other words, having a prostate exam not as a result of a conscious choice but because it is a routine part of their annual physical exam;
- having a friend or relative diagnosed with prostate cancer;
- information and education about prostate cancer;
- recommendations or encouragement from others to get tested; and
• increased investment in their own health and future.

To begin, some men visited the doctor when they experienced physical discomfort and problems, including difficult or painful urination, erectile dysfunction, or intestinal discomfort. For example, a Chinese man said, “I felt my urination was not smooth. I felt the urge to pee, but it wasn’t flowing, so I went for an exam. I felt I didn’t have the strength to pee.” Men who are experiencing these symptoms want them to end, and therefore visit the doctor so that the cause of the symptoms will be discovered and treated. A Caucasian man said, “I was having trouble getting it up, and that was one of the issues that we explored in that. I was concerned about that.” It should be noted that some men indicated that they were in severe pain before they visited a physician, as in the case of a Russian man who described his motivation to get a prostate exam thusly: “When you suffer from pain to such a degree that you lose consciousness, and it pushes you to go and ask a doctor, the primary doctor, so that he sends you to the urologist, because there is no choice.”

It is fairly common for men to obtain prostate cancer screenings passively, in the course of a routine check-up or other health care visit. These men did not consciously choose to have a prostate exam or ask their physician about screenings. Rather, the exam was performed as part of a routine check-up and they did not have to think about it. A Chinese man said, “I go for a big exam every year. That is, my heart, prostate, stomach, liver, all gets examined. Every year.” An African-American man explained that he has always received prostate exams as part of his routine physical, beginning when he enlisted as a teenager: “Ever since I went in the service when I was 18, every time I had a physical. I had a prostate exam anywhere that I went.”

Some men said that they had a friend or relative who developed or died of prostate cancer. In these cases, the reality of prostate cancer “hits home” and can cause men to become aware of the possibility that they may be at risk for developing prostate cancer. Men who are aware that having a family history of prostate cancer puts them in the high-risk group can be highly motivated to get tested following a relative’s diagnosis. For example, a Caucasian man explained, “When I did it, it was because of a family history. My father died of prostate cancer and my uncle had his prostate removed.”

Related to this, some men were motivated to get a prostate exam as a result of information and education about prostate cancer. These men encountered information about prostate cancer that made them realize that they might be at risk. An African-American man who had encountered statistics about African-American men and prostate cancer explained, “The high rate among African-American men after the age of 45: that’s what motivated me.” Similarly, a Cape Verdean man talked about how motivating such information can be: “Being associated with a particular culture or something, and finding out that a study indicates that a particular group of people have a higher rate of any kind of disease would sort of scare most people in that particular culture. Or a particular community, like I hear that people who live in other towns like Hyannis with high incidence and some areas in Cape Cod. I think if I was in those areas and I heard that report, I would definitely make an effort to go check. If there was a report in the general area which I live in that said something to the fact that in this particular area the rate of prostate cancer was high, that’s a great motivator to go have it checked.” Public service announcements featuring celebrities with specific health problems can also be highly motivating for those who encounter them; this, again, underscores the reality of the problem, and can give men the sense that “if this celebrity can get the disease, anyone can.” For example, an African-American man talked about the effect that Magic Johnson’s well-publicized 1991 announcement about his HIV status had on his perception of this health problem: “I think when
Magic got the virus, it took it to a whole other level. . . . When celebrities come out and talk about it, or famous people . . . it hits home, you know?

Some men said that someone in their lives recommended that they get a prostate exam or encouraged them to do it. For some, this individual was a physician or another health care professional. Spouses or partners, relatives, friends, and neighbors also encouraged men to get prostate exams. Encouragement from their own partners is particularly compelling, as it underscores the connection between prostate exams and maintaining sexual health. As one Haitian man put it, “My wife knows what she is protecting.”

We asked men who are married or in a relationship specific questions about the role that their partner plays in their health care. Overall, men’s partners play a very important role in motivating men to see physicians and have tests, including prostate exams, performed. Most men said that their partners regularly urge them to pay more attention to their health and to visit physicians; as a Cape Verdean man said, “My wife is—chronically, man—she’s always recommending, ‘You got do this, you got to exercise, watch what you’re eating, watch your weight, blah, blah, blah.’ She always pushes me, which is good.” Many said that this type of encouragement typically results in men changing their behaviors or scheduling visits to physicians; for example, a Caucasian man said, “I won’t go on my own until I’m on death’s door, so it took the pressure from the significant other [saying], ‘Do it or get out.’” A Brazilian man even reported that he continues to receive encouragement from a woman he had been involved with years ago: “My ex, who’s been eight years far from me, called me the other day to [tell me to] have a prostate exam.” Most men said that they would be more likely to talk to their doctor about a prostate cancer screening if their partner talked to them about it.

As described earlier, some men experience an attitudinal shift as they get older, and report that they feel an increased investment in their own health and future. They are more conscious of their mortality, more aware of the changes in their bodies as they age, and are motivated to develop healthy behaviors in order to ensure that they will have a longer, healthier life. For example, an African-American man attributed his desire to seek medical care to “just beginning to care about myself more, you know, and wanting to live longer, and say, ‘Well, listen, if I want to live a healthy life, let me do some of the things that make that possible.’ I mean, if you have an automobile, it’s easy to take the automobile to a mechanic [and] look under the hood, because you care about it. But when it comes to ourselves, we sometimes—you know. And so as I got older, that turned around a little bit, you know? [At age] 40 and 42 now, so everything is changing. Life is more precious.”

Men who believe that prostate cancer screenings can help ensure normal sexual functioning found this motivating; they want to continue to enjoy this part of their lives, both for their own pleasure and to maintain their intimate bond with their partner. For example, an African-American man who said that his sexual health was a motivating factor in his decision to get a prostate exam said, “I know [the] prostate is a sex gland, and as we get a little older, man, . . . you just can’t do like we did back when we were 20 and 30.” It is important to note, however, that men do not tend to view prostate exams as a means of maintaining their sexual health; rather, many men associate prostate exams with sexual dysfunction. That is, they worry that a prostate exam might result in a diagnosis of and treatment for prostate cancer, which would then result in permanent or long-term impotence.

In summary, fear, in a variety of forms, is a major underlying factor that motivates men to get prostate exams. Some men have prostate exams performed as a reactive measure against the manifestation of distressing physical symptoms, or obtain the exam simply because it is
performed as part of their annual physical. Others are more proactive, and consciously seek out prostate exams in order to keep themselves healthy. Education about the disease, spousal or partner encouragement, and their own investment in their future can be powerfully compelling. In the next section, we will present findings about the barriers that have prevented men from obtaining prostate cancer screenings.

**Barriers to Obtaining Prostate Cancer Screenings**

As described earlier, while many men in this research have obtained prostate exams, some have not, with Russian and Chinese men particularly likely to have avoided testing. We asked men who have never had a prostate exam why they had not been tested, and what might motivate them to obtain an exam. Men expressed both practical and attitudinal barriers to obtaining prostate cancer screenings.

To begin, there are two major **practical barriers** that have prevented men from obtaining prostate cancer screenings: (1) not being able to afford care; (2) lacking information about prostate cancer that might motivate them to get tested. **The most common practical barrier to obtaining prostate exams is financial.** Some men are currently unemployed and do not have health insurance coverage. For these men, it may be too costly to pay out of pocket for exams. A Haitian man explained that he cannot afford to take time off of work to visit a physician, as his employer would not pay him for the time he was at the physician’s office, and long waits in the waiting room would therefore result in several hours of lost wages. “I don’t go, one, because I cannot pay for it. That’s the first thing,” this man said. “The second reason why you neglect to go for the test, suppose that you are working. . . . You are always reticent to lose a day to go and have a test. And sometimes when you arrive at the doctor, it’s not just come and go. You are on a line and you stay for hours there.”

Some men may also **lack information about prostate cancer and prostate exams** that might motivate them to get tested. Some may not be aware that they are part of a high-risk group. Some men lack basic health education (for example, a few men had never heard of, or had only a vague awareness of, the prostate gland) or may not be sufficiently informed about the benefits of preventive care. This was particularly the case among Russian men in this research, several of whom said that preventive medicine was not a component of Russian culture, and they had not yet adopted an American approach to health care, despite the fact that most had lived in the U.S. for at least a few years.

In addition to these major practical barriers, a few men identified **language barriers** as a problem that might prevent men from obtaining prostate cancer screenings. It should be noted that men who participated in this research who do not speak English as their primary language generally did not indicate that language barriers are a problem for them. A few suggested that this might be a problem preventing others from obtaining care, however.

There are four major **attitudinal barriers** that have prevented men from getting tested for prostate cancer: (1) health care is not a priority; (2) negative prior health experiences; (3) fear of bad news; and (4) feelings of embarrassment or fear about the exam.

To begin, the most common attitudinal barrier preventing men in this research from obtaining prostate exams is that **health care is not a priority** for them. Many men who had never had a prostate exam, for example, said they had never perceived the need for an exam because they feel fine. As one Chinese man said, “I feel very normal. There’s no need to go for examination.” These men may not be oriented toward preventive care in general, either because they are not acculturated to American ideas about health care, or because they share a cultural
attitude in which men do not seek out health care. As one Caucasian man said, “We’re men. Women go to the doctor regularly, men don’t.”

The most extreme example of this way of thinking can be illustrated by the attitude of one Haitian man, who expressed the belief that health care would interfere with nature and that if he is meant to die, he should not take any action to prevent this from occurring. “I don’t want to disturb any natural process,” this man explained. “If it is that illness that would kill me, I have no problem.”

Some men have not had prostate exams because of negative prior health experiences. These men are typically Caucasian or African-American, and expressed feelings of resentment or distrust about the current health care climate, often related to their perceptions of HMOs. For example, Caucasian men had the following exchange during a focus group:

“Part of [the reason I have not had a prostate exam] is lack of health insurance and spotty employment with health insurance; and another part of it is I haven’t had very good experiences with doctors in the past.”

“The experiences with the doctors and the way the insurance has changed, and when [you] have it, you got to get to this health plan, to this health plan, and it gets confusing. . . . Like, because if you have health insurance, it changes . . . You can only go to certain doctors, and you can’t keep this doctor, and then you get familiar with that doctor, and then something else comes in, and you got to go to that doctor.”

“The problem I had, I moved up here roughly 15 years ago from New York and was working for Food Mart there, and when I didn’t have a doctor and the first time I got sick and I tried to get a doctor and got on the telephone, I went through the whole telephone book and nobody would see me, because they didn’t either have the time or not the right coverage.”

“Well there’s too few of them, and they have too little time to spend talking. They want to get in, it’s that production line thing: slam, bam, thank you ma’am, move on. Do sixty an hour and get sixty bucks a pop.”

“They seem to have their hand on the door knob while you’re still trying to explain things to them.”

“I have a friend who was a physician with an HMO, and they required him to see a minimum of five patients an hour.”

African-American men expressed considerable distrust of the medical industry, and feel that some of the information available about health care issues is not credible, or is too vague to be useful. These men felt negatively about what they perceive to be “guesses” made by physicians, and expressed a need for clear, concrete information that would be applicable in all cases. One African-American man shared his frustration with how he has been treated by physicians and with the nature of health care information, saying, “I don’t like how I’ve been treated, for one. Secondly, I don’t like how they portray themselves. They don’t have answers. They have calculated guesses, you know, based on statistics. But medicine isn’t science; it’s still calculated. It’s not absolute, like math. Okay, if the equations just don’t work, you know, people survive, people don’t get it. People smoke all their lives and don’t get lung cancer. It’s like, how does that one [get lung cancer], and then somebody else, they smoked a little while, and they have cancer? It’s like, how does that work? . . . They keep proving it to me. . . . I have a simple thing, eczema, just like psoriasis. ‘Well, we can treat it.’ It’s like, but you can’t cure it, and in
most cases, you can’t even treat it, because I’ve gone through 15 to 20 drugs [and] my body keeps adapting, adapting, adapting. So, obviously you can’t treat it.”

Some men also expressed considerable fear about receiving bad news after a prostate exam. These men tend to be less acculturated, with Haitian men particularly likely to verbalize these concerns. Some have superstitious beliefs about disease, wherein hearing a diagnosis will make the disease real; if they can avoid a diagnosis, they are therefore less likely to become ill. Some also believe that if they are diagnosed with a serious disease, they will experience a perceptual shift from thinking of themselves as strong, healthy men, to thinking of themselves as weak, sick men. They believe that the this perceptual shift and their own anxiety about their illness will, in itself, adversely affect their health, as in the case of a Haitian man who said, “If I don’t know that I have something like that, I live normally. As soon as I find out: panic! Worries!”

Some men also expressed feelings of embarrassment or fear about prostate exams. Men may find it difficult to talk frankly with a physician about their bodies, particularly when it comes to concerns they may have about urinary, intestinal, or sexual health. A Russian man spoke to this reluctance, saying, “There are people that are too shy to go, especially when it has to do with prostate, when it has to do with intestines. People are different, right? So whatever has to do with urinary and reproductive system, and the intestines.” A few men said that their knowledge of what a prostate exam entails—specifically, the DRE—has prevented them from obtaining the exam, as they do not want to undergo what they believe is likely to be a humiliating and uncomfortable experience.

We asked men who had not had prostate exams what might motivate them to obtain an exam in the future. They often said that they might be more motivated to get tested if they had more information about prostate cancer. Specifically, they wanted to have more information about the exam itself (such as illustrations of the procedure, so that they know what to expect); how the benefits of testing and treatment for prostate cancer outweigh the potential risks; the quality of life they might expect following treatment, particularly with regard to their sexual health; and the incidence of prostate cancer among minorities.

Others said that they would be motivated to have an exam if they were to experience symptoms, such as difficulty urinating or impotence. Some said that the best way of ensuring that they receive regular prostate exams would be for physicians to assume this responsibility. They believe that men should not have to be proactive about seeking prostate exams, and that this should be performed during routine physical exams for all men who meet the criteria for screenings. For example, a Russian man said, “This should be primary care physician’s concern. . . . No asking, there are principles.”
RESPONSES TO DPH BROCHURE

During the focus groups, we showed men the brochure illustrated at left, “What Every Man Should Know About Prostate Cancer.” During the focus groups, men went through the brochure and discussed each page in detail.

Overall, men had a highly positive response to the brochure. They believed the purpose of such a brochure would be to educate men about prostate cancer and encourage them to get tested. “The purpose is to save lives,” as one Latino said. Men acknowledged the need for information about men’s health, saying that men suffered from a lack of open communication about these issues. A Brazilian man said, “It seems like a taboo between men. I think there should be more openness.” Men felt this brochure was very informative, credible, and useful. For many, the brochure challenged their perception that prostate cancer was a fatal disease; it conveyed a message of hope, and made men realize they could treat and survive this disease.

In terms of the most common reactions to the brochure, most men felt that the brochure could be made more appealing if it used brighter, more eye-catching colors. Most men did not know who the men in the photograph were, although they understood that these were “real people,” rather than models. They had difficulty identifying with these prostate cancer survivors, as these men appeared to be affluent professionals; they would prefer a photograph of more casual or “blue collar” men. In general, men (particularly less acculturated men) expressed a desire for more illustrations and photographs than are currently used in the brochure.

Men liked the “question and answer” format used in the brochure. Symptoms and treatment methods are generally perceived to be the most important information in the brochure, and some men believed symptoms would not be provided in the brochure because it did not appear under the list of Frequently Asked Questions. With regard to treatment options, African-American men reacted very negatively to the concept of “watchful waiting,” and interpreted this as being denied treatment for a fatal illness. In general, men found some of the information about the available treatment methods confusing.

Men disliked the way that the question about the association between vasectomies and prostate cancer was handled in the brochure. This was felt to be needlessly alarming, as it was not a question that would have occurred to them on their own—many, in fact, did not know what a vasectomy was. They felt that it was inappropriate to raise a question that the brochure is unable to answer.

Men found the statistics and concrete information in the brochure highly compelling. This was particularly true among African-American men, who reacted very negatively to any text in the brochure that seemed indefinite or that suggested the health care industry does not yet have all the information about prostate cancer.

Men would like the brochure to include more information about how they could obtain prostate cancer screenings, particularly for men who are underinsured or who do not have health insurance. For example, men would like for the list of informational resources to include a telephone number they could call to find out if they are eligible for a free screening.
It should be noted that some non-English speakers commented on the translations of the brochures they reviewed. Brazilian men tended to be very critical of the Portuguese translation they read, and felt that the brochure had numerous grammatical and typographical mistakes, although one commented that the “street Portuguese” used in the translation was very easy to understand. Haitian men, on the other hand, felt that the brochure they read was very well-translated; “I congratulate the person who did the translation,” one man commented.

In addition, some men believed these brochures would be difficult for men with literacy problems. Cape Verdean men (who read an English version of the brochure) believed that some technical words should be simplified, to make it more comprehensible for men for whom English is a second language. In addition, Puerto Rican and Dominican men also said they could not understand some of the words used in the brochure.

Many men said that they would be likely to speak to their physician about prostate cancer screenings after reading this brochure. A few men felt that having this brochure might make it easier to speak to their physician about their health concerns; as one Cape Verdean man said, “It can help you in talking to the doctor. Sometimes you are sick and can’t explain to the doctor the symptoms.” Some also said they would share this information with others, and felt motivated to make a concerted effort to develop healthy behaviors.

Some men, however, continued to express reluctance about prostate cancer screenings after viewing the brochure. They said they would speak to a physician if they experienced any physical discomfort, but did not indicate that they would seek out a preventive screening. A few Puerto Rican and Dominican men said they would be more likely to visit their physician if they could receive the PSA test, rather than the DRE.

It should also be noted that Chinese men may be particularly resistant to the types of information contained in the brochure. During the focus group, Chinese men made few specific comments about the information they were encountering. Most men, when asked for their reactions to aspects of the brochure, said that they would need to study the brochure in greater detail later at home. While this type of remark sounds as if Chinese men intend to give the brochure serious consideration, it is important to note that Chinese men may communicate in less direct ways than Americans. Research that has been conducted regarding Japanese, Chinese, and Southeast Asian communication finds that value is placed on ambiguity and tact in conversation, and that rather than saying “no,” people from these cultures are more likely to suggest that the matter be given further study. These observations suggest that this type of statement—for example, “I need to take the booklet home to read”—may in fact mean that Chinese men are politely rejecting the information contained in the brochure.

We asked men several questions about the types of information they would like to have about prostate cancer. First, we asked them if they would prefer to have a lot of information, or a summary of the information. Most men preferred to have a lot of information, although several men added the caveat that if they felt overwhelmed by the amount of information provided, it would be difficult to absorb. Most felt that the brochure contained the right amount of information. Most Russian and Chinese men, however, expressed a desire for less information, and summaries.

We also asked them whether they would prefer to read facts and statistics, or personal stories about men who have had prostate cancer. There was no strong preference for one of these types of information over the other. Many men said that it would be ideal to have both types of information available, as each would suit different personalities. Men who did indicate a preference tended to prefer facts and statistics; African-American men, specifically, voiced a strong preference for facts and statistics.
Men who liked the idea of hearing personal stories said they would like to hear optimistic stories about men who have survived prostate cancer. A few said they would have to be able to identify with the men (for example, the survivors would need to belong to their same ethnic or racial group) in order for these stories to be most effective. Brazilian men indicated a slight preference for personal stories.

Next, we will present detailed findings about men’s reactions to each page of the brochure.
Comments About Front and Back Covers

1. Image. First, in terms of what men found appealing about this image, they felt the image portrays diverse ethnic and age groups. Some felt the image conveyed the message that prostate cancer did not discriminate; as one Latino said, “Cancer of the prostate doesn't have any limits; it doesn't distinguish from one person to another.” A few men felt this image also spoke to the increased incidence of prostate cancer among African-Americans, as two of the four men in the image are perceived to be of African-American ethnicity.

In general, most men perceived these men as either belonging to their own age group or as being younger than themselves, which appeared to challenge their perceptions about prostate cancer. They appeared to think of prostate cancer as only affecting men older than themselves, and that this image made them feel that prostate cancer could affect younger men as well, and therefore, could affect them. Some believed that the man on the far right was significantly younger than the other men in the photograph.
Men voiced one major, consistent concern about this image: the men in the photograph appeared **affluent and well-dressed**. Most men said they could not identify with the men in the photograph for this reason, and would have preferred that the image portray a more diverse range of socioeconomic groups. As one Caucasian man said, “*To me, they are suits.*” They wanted to see men in more casual attire, “blue collar” workers, and laborers.

In terms of other perceptions about the image, a few men commented that these men were serious and unsmiling, which to them conveyed the message that this was a serious issue. One man’s interpretation of this image was that the man sitting down had prostate cancer, while the men standing had overcome prostate cancer. It should be noted that the brochure Chinese men reviewed showed an image of Asian-American men; they did not, however, have any unique reactions to the image.

2. **Prostate cancer survivors.** Men generally find public service announcements featuring celebrities with health problems highly compelling. In general, however, men in this research are **not very familiar with the prostate cancer survivors** depicted in this brochure. Some have heard of Charles Austin, and a few have heard of Louis Brothers, but in general, most men had not heard of these prostate cancer survivors. Some men felt that having more nationally-known survivors would enhance the appeal of the brochure.

Some men remarked, however, that they liked the fact that the brochure depicted “*real people,*” which was conveyed by the inclusion of the survivors’ names, regardless of whether the men had ever heard of these men before. A few Haitian men felt that “Charles Austin” is a Haitian name, which they found appealing; similarly, a Cape Verdean man felt that one of the names was Portuguese.6

3. **Colors.** Men had **fairly consistent, negative reactions to the colors** used for the brochure. The blue and brown shades used here were felt to be too somber, and few men found them appealing or eye-catching. Some felt the dark colors portrayed a sense of hopelessness; they are, as one Brazilian man described them, “*mournful colors.*” Men felt that brighter colors would both be more likely to catch their attention if they saw the brochure, and would make men feel more optimistic about prostate cancer. For example, a Chinese man said, “*Cancer is already very scary. But you designed the cover to [look] as if it’s leaning towards death... They should design it to be brighter—a feeling that if you understand the knowledge inside, and you are attracted enough to read it, you can prevent it earlier or seek treatment, so you have a chance to survive.*”

Related to this, men generally did not find the **design or layout of the brochure** particularly appealing; they would look at this because of the information they believed it would contain, but there was nothing about the visual appeal of the brochure itself that would attract them. One Russian man compared the layout of the brochure to Russian artist Kasimir Malevich’s “Square” paintings. One Chinese man who disliked the brochure’s layout said, “*I would emphasize the fact that the cover is not appealing enough. There is a lot of space here that is somewhat wasted. You can include more detailed information or diagrams or pictures to help people understand better.*”

4. **Title.** Many men said that this title would definitely attract their attention. “*If I saw this brochure, I would have taken it because it says ‘what everybody needs to know’ on it,*” one Russian man said. A few men said they would like to see the words “prostate cancer” or “cancer” in a larger font; as one Caucasian man said, “*The word ‘prostate cancer’ is in the same font size, and so from across the room, you wouldn’t know what it is.*”

---

6 Portuguese is the official language of Cape Verde.
1. Frequently Asked Questions. Men responded very positively to the “Frequently Asked Questions” format of the brochure. They feel familiar and comfortable with this method of providing information. Some men felt that they learned the most important thing they could learn simply by reading this list of questions: they learned how much they do not know about prostate cancer. For example, one African-American man said that he learned “there’s a lot that I don’t know. ‘Cause I was trying to answer these questions and I really don’t have answers for any of them. I’ve got some guesses and assumptions, but I don’t have answers.”

Many of the questions included on this list provoked comment at this point in the discussion. We will discuss men’s reactions and concerns to these questions later, during the presentation of comments about the pages on which these questions appear. It should be noted, however, that some men felt that there was information missing from this list. Specifically, men believed this list of FAQs should include a question about the symptoms of prostate cancer. While information about symptoms does appear in the brochure, it does not appear on this list of FAQs, as it is not presented in the question and answer format, but in a separate column of text. As this list of FAQs also functions as a table of contents, some men interpreted the absence of symptoms on the FAQ list to mean that this information would not appear in the brochure. As a Chinese man said, “I feel there is no mention of early symptoms or what to watch out for, and
when to know to go for your examination. We all know there are early symptoms. This booklet does not mention any of them.”

2. Men’s Health. A few men felt that the title “Men’s Health” was too general and less compelling than something more specific, such as “prostate health” might be. These men felt it would be more effective to have their attention drawn immediately to the fact that this information relates to their sexual health and functioning. For example, an African-American man said, “It just says ‘Men’s Health,’ and if we’re talking about prostate or we are talking about a sexual organ, I think if we want to really get our attention, you put something about ‘penis’ there or something about ‘genital area,’ you’re going to get my attention a lot quicker. . . . If you’re saying [something] about my sexual organ, you’re going to get my attention. I’m going to read.”

3. “Men are often reluctant…” The text about men’s reluctance to discuss problems with their bodies resonated with many men. A Cape Verdean man said, “I think it’s true. Many men may be afraid to see their doctor, to actually know the truth. It’s a mistake, but I think it’s true.”

4. Healthy lifestyle. With regard to the description of a “healthy lifestyle,” some men appreciated the reminder to maintain healthy habits. “I take this as a reminder for myself,” a Chinese man said. “First is to watch my diet. Eat more vegetables and fruits, and it is important to quit smoking.” Some men interpreted this paragraph as claiming that these healthy habits would prevent prostate cancer, which they did not believe was credible.

Several men felt that exercise should be mentioned in this paragraph as well. As a Cape Verdean man said, “They’re saying that you should pay attention to developing a healthy lifestyle, but they just talk about eating fruits and vegetables, stop smoking and reducing stress. They don’t talk about exercising, and exercising is a major component of improved lifestyle.”

5. Smoking cessation, stress reduction. The benefits of stress reduction resonated with some men, as in the case of a Haitian man who said, “Another important thing that I see here is to reduce stress. . . . People often do not see the relationship between stress and health, because if you are ill and under stress, your illness can aggravate.” Some men who are current smokers reacted somewhat negatively to the mention of smoking in the information about healthy lifestyles, responding with defensiveness or, in the case of one Caucasian man, the humorous assertion that the idea of stopping smoking was not believable to him.

A few Russian men who are current smokers had different perceptions about smoking cessation, however. These men may lack an awareness of the health risks associated with smoking. For example, one Russian man believes that there can be little relationship between smoking and prostate cancer, explaining that it seems to him that the “distance from the smoking spot to the prostate spot is so large, and the risk is so low.” This man also considered the guidance to “stop smoking” and “reduce stress” to be contradictory, because he uses nicotine as a stress reliever.
1. **Cancer Facts.** Many men would like the brochure to include a brief definition of the word “cancer.”

2. **“Men in the United States.”** Brazilian men remarked that in the brochure they read, “men in the United States” had been translated to “American men.” “American men” could mean men in North, Central, or South America, and they therefore found this information confusing.

3. **Statistics.** The statistics provided on this page are highly compelling.\(^7\) Attaching numbers to this issue seemed to make the issue much less abstract, and men tended to find the projections for new cases and deaths resulting from prostate cancer alarming. As a Cape Verdean man said, “One in ten will die of it: that’s a pretty staggering number.” A Brazilian man said, “It shocks men, you know?” Men also found the comparison to skin cancer in the preceding paragraph useful for conveying how common prostate cancer is, although this information did not elicit an emotional response the way that the 2004 projections did.

---

\(^7\) It should be noted that the brochures provided for the focus groups included recent as well as older copies. The projections provided on this page varied depending on the year in which the brochure had been printed. Men’s comments may therefore reflect reactions to projections from different years.
4. “Early detection…” This sentence challenged some men’s perceptions about the disease; as a Haitian man said, “You say at the beginning that the prostate is a cancer, but in the conclusion, you say that early detection can lead to treatment. . . . If it is cancer, it won’t be cured.” Some men found this sentence encouraging, as it conveys the message that being diagnosed with prostate cancer is not, as many men had assumed, a death sentence.

5. “Are all men equally at risk…” A few men misread the text of this question on the FAQ page, transposing the first and third words to read, “All Men Are Equally At Risk For Developing Prostate Cancer,” which they did not consider credible.

6. “Should only older men be concerned…” Cape Verdeans brought up several concerns about this paragraph. A few felt that the first sentence of the answer to this question was awkward, and should be rephrased. One man felt that having a family history of prostate cancer might be even more important than age as a risk factor, and this should be mentioned first. Another man brought up an interesting point about this question. This question may be self-limiting; men tend to think of themselves as “young” regardless of the age category into which they fall. This participant felt that men might be more likely to read the answer to a more “open-ended” question; he explained, “I think the third question can be rephrased better. It reads, ‘Should only older men be concerned?’ I would rewrite it to [read], ‘At what age should you be concerned?’ In that sense—this is actually targeted for older men. And everyone thinks they’re young, so they’ll pick this up and say, ‘Oh, it’s not for me, I’m young.’ But if it reads ‘At what age should you be concerned,’ everyone will pick it up to see if it’s for them.”

7. “Does vasectomy cause prostate cancer?” Men had a consistent, strongly negative reaction to the information provided about the possible association between vasectomies and prostate cancer. This information was considered alarming and unnecessary. Many men commented on this question when they saw it on the list of FAQs, and it provoked anxiety at that point: many men did not know what a vasectomy is, and so they had no way of knowing whether or not this information applied to them. These men felt that a definition should be provided for this term.

The inclusion of this possible association on the FAQ page led many men to assume that there must be an association between vasectomies and prostate cancer, which was alarming for men who had had vasectomies. “My doctor lied to me if this here is true,” a Brazilian man said. “Because I did a vasectomy fifteen years ago and he didn’t tell me. I asked him about cancer, and he told me that there was no risk.”

Once men reached this page, they were very disappointed with the way the question was answered. The way the issue was addressed in the brochure seemed to provoke needless concern: most men had never considered that there might be an association between vasectomies and prostate cancer, and they felt it was inappropriate for the brochure to raise the question when it was not able to provide an answer. “I think the question about vasectomy kind of bothers me,” a Cape Veredian man said. “I don’t think it should be included here, because there isn’t a real answer. ‘More research is needed.’ It doesn’t really give you an answer, and if they can’t provide an answer or at least advice for your specific need, I don’t think there’s a need to put it in this brochure.”

Related to this, African-American men tended to react negatively to any information that seemed indefinite or that spoke to what is not yet known about prostate cancer. For these men,
this type of information only underscored existing concerns they have about health care and physicians; namely, that medicine is not absolute. As one African-American man said, “Page two is guessing. ‘We’re just guessing.’ It doesn’t tell me, the front page doesn’t tell me anything. I have to turn the page ‘cause it doesn’t say anything. It doesn’t tell me anything. So, like, basically we’re guessing this and we’re guessing that, we’re guessing that.”

8. **Illustration.** Men, particularly Haitians, Cape Verdeans, and Puerto Rican and Dominican men, responded positively to the illustration on this page. This illustration helped some men to visualize the relationship between prostate cancer and the symptoms they might experience. This illustration may be particularly helpful for men who are not well-informed about male anatomy. In general, these men would like to see more illustrations and photographs in the brochure.
1. “We don’t know how to prevent it.” As described earlier, African-American men had a strongly negative reaction to any text in the brochure that referred to what is not yet known about prostate cancer. For example, one African-American man reacted to this text by saying, “This is so damn iffy. I mean, they say, ‘We’re working on it. We don’t know, but check this out: eat some low-fiber, man.’” Another man agreed, “How can they dare write this, anyway? ‘We don’t know how to prevent it but [this] can help prevent this cancer.’ It’s like—wait a minute. You say you don’t know how . . . and then you say, yes, you do.” These men wanted to have specific, factual, concrete information about what is known about prostate cancer, and did not want to read information referring to what is unknown or aspects of prostate cancer requiring further research. As one African-American man said, “When I see the word ‘research,’ that’s a turnoff for me. It means that—that’s basically saying . . . ‘We don’t know.’”

2. “Eat a low-fat diet.” It should be noted that one Caucasian man expressed a need for more information about diet recommendations than was provided in the brochure. This man is following an Atkins diet plan, which emphasizes a high protein and low carbohydrate intake, and he wanted to have information about whether or not this diet would help prevent prostate cancer.
3. “Quit smoking!” A few men who are current smokers reacted with some defensiveness to the mention of smoking cessation. One Caucasian smoker acknowledged that there may be a gap for many men between knowing what is good for them and doing what is good for them. This man perceived healthy habits to involve a balance of risk and pleasure, and felt that some decisions about unhealthy behaviors amounted to decisions about quality of life; as he said, “The quality of my life is definitely as important as the quantity, and I love coffee and I love cigarettes, and I’d still be drinking, but it would have killed me 20 years ago, so I stopped.” This man also felt that if smoking truly had an effect on prostate cancer development, “smokers” should be added to the list of men who should consider annual prostate cancer screenings. Previous research we have conducted among smokers regarding cessation has indicated that these types of attitudinal barriers are extremely common among smokers.

It should also be noted that, with regard to the description of healthy habits in general, some Brazilians feel it is unrealistic that Brazilians would follow this advice. “In truth . . . the information here, ‘follow a diet with a low-fat content,’ all the things that are here, ‘cholesterol,’ ‘cigarettes,’ et cetera, et cetera—the Brazilian who lives here in the United States doesn’t do that.”

4. “African-American men over the age of 40.” A few African-American men focused on the ten-year difference in the risk group descriptions for African-American men and other men. Some attributed this to their sense that African-American men experience more stress than other men, and a few thought this might be related to their diet. During the focus groups, a few men (not all of them African-American) wished to have information about the reasons that African-American men are more susceptible to prostate cancer.

5. Screening tests. A few men wanted to have information about how they should arrange for a screening test. They were unsure whether they would need to make a specific request for the test, or if they could rely on their primary care provider to recommend the test for all men age 50 and over. Others wanted information about how much such an exam would cost, or how men without health insurance who are unable to pay for screenings would obtain them.

In addition, Brazilian men felt that “Digital Rectal Exam” had been poorly translated, and recommended “examen do toque retal” as an alternative. It should be noted that Brazilian men had other concerns about the Portuguese translation as well (e.g., “In the second paragraph, it’s not ‘mais’ [more] it’s ‘mas’ [but], right?”). Finally, one man suggested that the PSA be moved before the DRE on the numbered list, as men may feel more comfortable with the idea of blood tests.

6. Elevated PSAs, abnormal DREs. African-American men responded very positively to the information about screening tests: this is the type of specific, factual information they prefer. In addition, a few men said that they would like to have information about what constitutes an acceptable PSA level.

7. Acronyms: PSA, DRE, BPH. Several non-English speaking men remarked on the fact that the acronyms PSA, DRE, and BPH do not make sense in other languages (for example, in the suggested Brazilian translation above, “digital rectal exam” would become “examen do toque retal,” and the acronym would be ETR).
8. “Don’t be fooled…” Several men remarked on this paragraph, and believed this was a good reminder about the importance of preventive care. This information encouraged them to speak with their physician. As a Haitian man said, “They also say that sometimes there are no symptoms, that someone can function normally without feeling anything, and then suddenly find that he has a serious illness. That is why it is important when you get to be that age to get information from your doctor, to talk about it, to be tested.”

9. Benign Prostatic Hyperplasia. A few men interpreted the information about Benign Prostatic Hyperplasia (BPH) to mean that men who experience symptoms such as urinary problems and impotence may not have prostate cancer, and that therefore there would be no need to visit a physician. As a Haitian man said, “There is a type of subtle prostate cancer. . . . Meaning, for me, anytime someone is impotent . . . you don’t have the serious prostate. The one that you don’t have to go and get a check-up for.” This suggests that information about BPH might be demotivational for some men.
Comments About Pages Five and Six

1. **Symptoms.** Many men felt that these pages were particularly helpful. They liked the specific information about symptoms included here, and some felt this information should appear earlier in the brochure. Several men had experienced at least one of these symptoms, and this might motivate them to see their physician. A few felt that the brochure might be a useful tool in discussing their concerns with their physician. One man wondered whether the symptoms listed here would remain lifelong problems for men diagnosed with prostate cancer or if treatment would relieve these symptoms.

2. **Back pain, pain during sex.** A few Haitian men found these two symptoms confusing. They felt that pain or stiffness in the lower back would be related to muscular strain, and they did not see how this related to prostate cancer. One man was confused by the idea of experiencing pain during intercourse, as this seemed contradictory to him. “That is when you are supposed to feel relaxed,” he said. “It is something that is a little weird.”

3. **Treatment options.** For the most part, men liked the specific information about treatment options included here. For some men, this was encouraging information, as it suggested prostate cancer could be detected and cured. “It’s not necessarily a mortal disease,” as one Latino said. A few men felt that the information contained on these pages was too technical; most, however, found the information fairly clear and easy to understand.
4. **Watchful waiting.** African-American men had a strongly negative reaction to the concept of “watchful waiting.” They interpreted this to mean that they would be denied treatment for a fatal illness. As one man said, “That is crazy. That’s ridiculous. Why would I want to watch my cancer? Get rid of my cancer, please. Today! Watch my cancer?—do what?” In addition, one Cape Verdiean did not consider the information about watchful waiting credible; as he said, “I don’t believe that watchful waiting is a treatment option for prostate cancer.”

Caucasian men also discussed watchful waiting, and had more divided opinions about it. The concept seemed “way too passive” and was anxiety-provoking for some, as it has been for African-American men. “The watchful waiting—that would be very nerve wracking in my mind,” one Caucasian man said. Others, however, saw this as a valid option. They felt that surgeons can be too eager to operate, and that it might be better in some cases to pursue less invasive therapies. For some of these men, watchful waiting seemed to assuage concerns they had about the quality of life they might expect after surgery. One Caucasian man explained, “I’m far more leaning towards the watchful waiting, at least for a short period of time to find out what kind of growth or what kind of effect this is going to have, versus jumping right in for some other invasive therapy.”

5. **“Whose life expectancy is anticipated to be no greater than ten years following diagnosis…”** African-American men misinterpreted these statements to mean that men would have a life expectancy of ten years as a result of prostate cancer. As one man said, “What this generally says is if you’re diagnosed with prostate cancer, on average you’re only going to live 10 years.”

6. **Surgery.** Some men were confused by the reference to the “prostate gland” in this paragraph. These men tended not to understand the difference between the “prostate gland” and “prostate cancer,” and assumed that the word “prostate” was the name of the disease. In addition, a few Cape Verdiean men were confused by the sentence about surgery being chosen by men in their 50s and 60s; they misinterpreted this to mean that younger men would not be able to have their cancer removed.

7. **Radiation.** Brazilian men were very critical of the translation of these pages. They felt the translation was confusing, and that there were numerous grammatical and typographical errors on the page. Men objected to indiscriminate use of crasis (wherein two vowels are contracted into one long vowel, or into a diphthong), for example. One man said, “Horrible [grammatical mistakes]. Now, here on the radiation part, for that you just have to put it through a Portuguese spell checker to correct. You don’t even have to study Portuguese. And in the radiation part here, this text is absolutely confusing. ‘With the external beam radiation therapy, and radiation is used for—.’ I think that what he wanted to say there was, ‘Radiation. Radiation is used for—’ and such. I think that’s what he wanted to say and then an additional sentence there he forgot to erase it.” It was not clear to this individual that two types of radiation therapy (external-beam, and seed implant) were being discussed in this paragraph.

One Cape Verdiean man was confused by the concept of seed implant therapy. “Some words may confuse me, like seed implant therapy,” he said. “I don’t know what they mean by ‘seed.’”

8. **Freezing.** One Russian man was concerned about the concept of freezing the prostate; he said, “You can freeze it, but will it thaw out?” Another agreed, “They will freeze something else along with the prostate.”
Comments About Pages Seven and Eight

1. Prostate cancer is treatable. Men found the information about survivors encouraging. “At least I learned that it doesn’t always mean death, and I can tell other people that,” a Chinese man said. Some believed that hearing about survivors’ experiences can be comforting; as a Latino said, “I lost an arm, and what happened with me was they would send people who had the same thing happen to them come and talk with me. So, when you talk to a cancer survivor, I think that [is] the best consolation you can get.”

Some men also liked the message that “each man is different.” For example, a Haitian man said, “There is a lot of hope; it has a treatment. . . . If a friend of mine had surgery, for instance, that does not mean that if I have the illness, I have to have surgery also.”

2. Second opinion. It should be noted that a few Caucasian men misinterpreted the mention of a “second opinion” as advocating the watchful waiting treatment method. “They are recommending the wait and see,” one man said. Others expressed frustration over the need for a second opinion, and interpreted this sentence as obtaining a second opinion with regard to the diagnosis, rather than the best treatment methods to pursue. For example, one Caucasian man said, “They don’t have their act together. There should be a solid—why second opinion? I mean,
you either have it or you don’t, and it should be very, very apparent from the tests that are taken. I don’t understand why . . . if you have a blood test and a physical exam that indicates prostate cancer, what a second opinion would do. Would the second opinion be, ‘Oh, you don’t have it? ’ So, which one do you believe?”

3. **Information resources.** In response to the title, “What if I find out that I have prostate cancer,” African-American men said that if they found out that they had prostate cancer, they would visit a physician. These men suggested rewording this question to read, “Where can I go to find out more about prostate cancer,” to emphasize the role of these organizations as **information resources.**

   Men would like to see additional information included on this page. First, many would like web sites for these organizations included. “Everyone has computers now,” a Caucasian man said. Others would like street addresses as well.

   Non-English speaking men wanted to know whether they would be able to speak with someone in **their own language** if they contacted these organizations, and felt this would be very useful information to include. A Brazilian man said, “How am I going to call if I don’t speak English? . . . Then you lose interest in looking. If you know that there is someone there who speaks Portuguese, who’s going to wait on you, who’s going to clarify your questions, you are going to call right away, certainly.”

   In addition, some men felt this page should include information about **free prostate cancer screenings.** For example, underinsured and uninsured men at high risk for prostate cancer may be able to receive periodic free screenings through the Massachusetts Department of Public Health’s Prostate Health Awareness Program, or through community hospitals. “It would be nice if this last page said, ‘To determine if you can qualify for a free exam, call this place,’” one Cape Verdean man said. “If there was such a free exam, that would help a lot of people that are uninsured to go.”

4. **Image.** Some men commented on the fact that the men are shown with serious expressions on the front of the brochure, and **smiling in the image on this page.** A few men liked the fact that the men were shown smiling in this image, and felt it conveyed a sense that they were in good health following treatment for prostate cancer. A Latino said, “I think in the first part they are sort of serious, and in the last part they are laughing, and that means that they had the exam.” One Brazilian man, however, felt that the smiling men in this image were not doing anything to prevent the disease.
RESPONSES TO OTHER MATERIALS

During the focus groups, we presented men with a variety of other formats that could be used to convey information about prostate cancer. These formats included: (1) a wallet card; (2) a tri-fold brochure; (3) a poster; (4) a fact sheet with information about prostate cancer among African-Americans; and (5) a tear-out sheet. All men were shown the wallet card and tri-fold brochure format. Other formats were only shown among certain groups of men (the group of African-American men was the only group to view all of these formats). We also asked all men if there were any other ways that they would prefer to have information about prostate cancer presented to them.

Overall, while many men said that it would be useful to have information provided in a variety of formats to suit different personalities, most preferred the brochure to all other formats. They felt the brochure was more likely to attract their attention, easier to read, and contained more information than these formats. Men who were shown a fact sheet responded positively to this format: they considered this easy to read, and they liked the straightforward, factual information about prostate cancer. More detailed findings regarding each of these formats are presented below.

Reactions to Wallet Card: We showed all men a 3 ¼” by 10 ½” folded wallet card, “Prostate Cancer 101,” that presents information about the myths, reality, and facts surrounding prostate cancer. Both sides of the wallet card are illustrated at left. A few men liked the fact that the wallet card offered a more compact size, and could be conveniently slipped into their pockets or wallets.

In general, however, most men did not respond positively to the wallet card. Many felt the wallet card was too small, and would not attract their attention. They felt that if they did pick it up, it would be easy for the wallet card to get lost or thrown away. Several men said that the print was too small and difficult to read, particularly for information that was targeting older men who might have poor eyesight. A few men said they would be unlikely to carry this card in their wallet or on their person, given that they found the topic embarrassing. A few men also reacted negatively to the colors used for the wallet card, feeling that the light blue and yellow color scheme was inappropriately feminine.

Most men preferred the brochure to the wallet card. They felt that the brochure was a more appealing size: aesthetically pleasing and eye-catching, and they felt that the brochure contained more comprehensive information and was therefore more useful than the wallet card.
Reactions to Tri-Fold Brochure: We showed men a tri-fold brochure (illustrated at left). In general, most men preferred the brochure to the tri-fold brochure. Several Caucasian men, however, responded very positively to the tri-fold brochure format, saying that this would be easier to fold and transport, and that it would take less time to read and absorb the information, compared with the full brochure.

Reactions to Poster: We showed some groups of men a large poster (illustrated at right) that uses the image from the front cover of the brochure, and includes a tag line reading “What you learn about prostate cancer may save your life.” In general, men strongly preferred the brochure to the poster. Most said they might glance at it, but that it would not really catch their attention. They preferred the brochure, which they considered much more comprehensive and informative.

Reactions to Fact Sheet: We showed African-American men an 8 ½” by 11” fact sheet (illustrated at left) that includes statistics and information about prostate cancer among African-Americans. African-Americans responded very positively to the fact sheet. They liked the fact that the information was about African-Americans, and they found the statistics very compelling. The fact sheet effectively conveyed the idea that they are at risk. Most wanted to see this information included in the brochure as well.
Reactions to Tear-Off Sheet: We showed some groups of men a 3 ½” by 4” tear-off sheet, printed on the front and back. The tear-off sheet is illustrated above. In general, men disliked this format, and preferred the brochure. The general consensus was that the tear-off sheet was too small, and not eye-catching.

Other Methods for Presenting Information: We asked men what other methods would be effective for presenting information about prostate cancer. Many men expressed strong interest in information on television. They tended to feel that a television ad was more likely to catch their attention than print information. Men also felt this would be an effective means of educating illiterate men about prostate cancer. Cape Verdean and Haitian men, in particular, said that television would be the best way of informing these communities about prostate cancer, due to the number of Cape Verdians and Haitians who cannot read. For example, a Cape Verdean man said, “I can see that 30% of our people cannot read. They’re not interested. . . . If they see something like that on television—have it in different languages, Haitian, Cape Verdean, Portuguese—thousands of Cape Verdians watch TV. Providence has the Cabo Verde TV. There’s CaboVideo, Selo Ernestina and Arco Iris.”

It should be noted that, in addition to American networks specifically programmed for particular ethnic groups (such as Univision, Telemundo, or GEMS), satellite television providers enable viewers to subscribe to foreign programming subscription packages. For example, one satellite television provider serving Massachusetts, DISH Network, offers subscription programming in Cantonese, Mandarin, Korean, Urdu, Punjabi, Pushto, Greek, Portuguese, French, Hindi, Arabic, Russian, Polish, Spanish, Japanese, Italian, and Dutch.

A few other men identified particular channels or programs they are likely to watch. Brazilian men said that advertisements during prime-time soap operas would be seen by many Brazilians. African-American men said that many African-Americans watch religious programming, such as Sunday morning gospel shows, and many African-American men in this research said that they watched Spanish-language programming on a regular basis, even though they did not speak Spanish. Russian men said that Russian-language television programming would be a good place for this information; for example, one Russian man said, “The Russian TV
often airs—probably everybody here has it—a lot of ads. . . . There was a time when Russian doctors would present in Russian and tell viewers about different kinds of diseases. If this disease, prostate cancer, is discussed in a plain language, not through ads, it would be more help and people will certainly go understanding that this is very serious.”

Many men expressed a strong desire for community outreach and more interactive methods of communicating information about prostate cancer. This was especially true among Cape Verdean, Brazilian, and Haitian men. While Puerto Rican and Dominican men in this research did not discuss community outreach methods, it is worth noting that previous research we have conducted among Latinos indicates that this population is highly oriented toward interactive discussion and community outreach as well.

A few men would like to hear information about prostate cancer on the radio, which they believed would also be an effective method for informing illiterate men about prostate cancer. A few men would like to have information available online. One man would like to view a short educational video about prostate cancer in the waiting room of his physician’s office.
**DISTRIBUTION OF MATERIALS**

We asked all men where they felt would be the best places for brochures about prostate cancer to be distributed. In general, most men expected to find these brochures at local health care facilities. They also felt that the brochures should be available in a wide variety of other locations. Russian men made the point that this would be particularly important in order to reach men who are not regularly visiting physicians or hospitals. Specifically, the types of places that men would expect to find brochures about prostate cancer include:

- **Health care facilities**, including hospitals, physicians’ offices, and clinics. A few men would also like to see these brochures on the counter at local pharmacies;

- **Health and human service organizations and government agencies**, including the Registry of Motor Vehicles, Social Security field offices, Supplemental Security Income (SSI) offices, the Department of Transitional Assistance (DTA) and food stamp outreach locations, the YMCA, men’s shelters, and welfare organizations;

- **Recreational and entertainment venues**, particularly those likely to be patronized by men, including movie theaters, sporting events, bars and nightclubs, restaurants, and concerts;

- **Local stores and service establishments**, including supermarkets, farmer’s markets, convenience stores, package stores, barbershops, banks, gas stations, car dealerships, men’s clothing stores, gyms and fitness centers;

- **Human Resource departments at local employers**; and

- **Public transportation**, including print advertisements at MBTA and other public transportation stations, and on the sides of buses.

In addition, a few individuals would like to see information available at **community organizations** (such as Cape Verdean associations) and at their local **library**. Some men would like to see information available at local **churches** as well, while others felt this would be an inappropriate place for information about prostate cancer. They believed that prostate cancer was too strongly associated with sexual health and functioning, and one man likened the idea of encountering prostate cancer information at church with that of having condoms available at church.
LIMITATIONS OF THIS STUDY

Focus groups are an appropriate method for assessing men’s awareness of prostate cancer and their responsiveness to educational materials regarding prostate cancer that DPH and the Partnership would like to provide. By definition, however, focus groups are qualitative; that is, they involve relatively small numbers of respondents, so the results may not be representative of all men of these ethnic and cultural backgrounds. The results should provide DPH and the Partnership with an indication of how men will respond to the materials and ways to make them more effective. The information, however, should be interpreted in general terms only and not in terms of percentages.
RECOMMENDATIONS

Overall, men responded very positively to the DPH informational brochure. Based on the findings of these focus groups, we have the following recommendations for revising the brochure in the future:

- Redesign the brochure with **brighter, more eye-catching colors**.

- Ideally, a wider range of men should **identify with the prostate cancer survivors** in the photograph. Men in this research are more likely to respond to images of nationally-known celebrities, or to images of “regular guys” like themselves.

- Consider ways of strengthening the association between prostate cancer exams and the **maintenance of sexual health and functioning**, and address concerns about the **quality of life** men can expect following treatment.

- Shift attention from what is **not** yet known to **what is known about prostate cancer**. The facts and statistics included in the brochure are very compelling; men would like to hear more information like this. Provide information about healthy behaviors, probable causes, and treatment options without qualifying the need for more research. Remove the information about vasectomies and prostate cancer, specifically. Condense information about the need for more research into one summary at the end of the brochure.

- Provide a glossary, or **brief definitions** for terms with which some men may be unfamiliar.

- The **information about treatment options** should be carefully considered and revised. It will be important to convey this information in a manner that is both clear and not alarming to men. For example, it may be useful to emphasize the fact that prostate cancer can grow extremely slowly, and so many patients may die of another cause before the cancer can become problematic.

- Ideally, the information resources listed in the brochure should include **website addresses** and information about **free prostate cancer screenings**.

- Given Brazilian men’s concerns about the **Portuguese translation** for the brochure they reviewed, it may be advisable to conduct an additional quality check on this brochure, or consider a different vendor for the translation.

In addition to these revisions to the brochure, we recommend that, if it is not doing so already, the DPH consider a **television campaign** in the future. Men in this research believed that television was a highly effective medium for conveying information about health issues, and that this would be a good way to reach less literate men.

The DPH may also want to consider conducting a **widespread community outreach campaign** in the future. Many men expressed a desire for more interactive ways of learning about prostate cancer, such as workshops and discussions about the disease. This type of strategy will also be an effective way of reaching men with literary barriers. A well-orchestrated community outreach campaign may further have the benefit of enhancing the credibility of information about prostate cancer and helping to break down barriers to obtaining tests. If members of ethnic or cultural minorities have the opportunity to hear about prostate cancer from
a man with a high standing in their own community and talk about the issue openly with other men, this is likely to prove highly effective for encouraging men to obtain screenings.

In addition to targeting men with information about prostate cancer, the DPH may want to consider a campaign targeting **primary care physicians**. The purpose of such a campaign would be to encourage primary care physicians to ensure that men belonging to high-risk groups automatically receive prostate cancer screenings as part of their annual physical. Men tend to be more proactive about scheduling check-ups than requesting prostate cancer screenings, and felt it was their providers’ responsibility to ensure that they received appropriate testing.

In summary, men in this research are not well-informed about prostate cancer currently, and they tend to catastrophize the disease. Information about prostate cancer—such as realizing that they belong to a high-risk group, and that they have a good chance of survival if they are diagnosed when the cancer is in its early stages—is a good motivator for getting men to obtain a screening. Men in this research considered the brochure very informative, and felt more optimistic about prostate cancer after learning more about the disease.
APPENDIX A: MODERATOR’S GUIDE
FOR AFRICAN-AMERICAN GROUP

I. INTRODUCTION (10 minutes)

• Welcome respondents and explain the purpose of today’s discussion groups—i.e. to talk about health. Specifically, how they think about their health and what might they be doing or not doing to try to remain healthy and prevent illnesses in the future, and what they think about some educational materials about health.

• I need your written permission to talk to you today, so I’d really appreciate your signing the consent form. These forms will be filed away. Again, no names related to this project will be released or shown to anyone outside the Market Street Research. Our research is pooled and presented as combined information.

• Explain the ground rules

We are (video and) audio taping this meeting. We are taping it for two reasons. First, so I can review the tape after the meeting to prepare a report—by having the tape I don’t have to take a lot of notes and can concentrate on listening to what you have to say. Second, the tape will be used to reinforce some of the points you are making. If you have a suggestion, it can be more powerful to have you say it than to have me summarize it.

I want to assure you, that all of your comments are confidential and will be used only for research purposes. Nothing you say will be connected with your name. Also, if there are any questions you would prefer not to answer, please feel free not to respond to them.

Also, there are a few ground rules that we use for meetings like this that help them to run more smoothly. The first is we really want to hear from everyone. We are only holding a small number of these groups, so each of you is representing a lot of people. So even if you are the only person who holds a specific opinion, I really want to hear it because there are a lot of other people in the area that have that same opinion.

I also want to emphasize that there are no right or wrong answers to the topics we’ll be discussing—we’re interested in everyone’s opinions.

Second, it is really important that only one person speak at a time. There may be times when you are tempted to start a side conversation with the person next to you, but I’d appreciate it if you’d hold back. I want to hear whatever you have to say and the audio on the tape will be impossible to understand if more than one person is speaking.

Also, if you have a cell phone or a beeper, I would appreciate it if you could turn it off (or set it to vibrate if you have to keep it on).
• Have respondents interview the person sitting next to them as a way to get them comfortable in the room, and have them introduce each other to the group. Ask them to find out their first name, where they live, what they do, and something about their family life.

1. AWARENESS OF PROSTATE CANCER, BARRIERS TO TESTING (10 minutes)

My first questions are about what types of things you think men should do to take care of their health.

- How often do you think a man should have a check-up or physical exam by a doctor, separate from a specific problem? Why? Why not?

- When was the last time you went to a doctor for a check-up or physical exam by a doctor, separate from a specific problem?

- How often do you think a man should have tests for specific problems, for example, how often should men have their blood pressure tested? Their prostate?

- Have you heard about prostate cancer screenings? What have you heard? At what age do you think men should have their prostate checked regularly?

- Has it ever been recommended to you that you talk to a doctor about having your prostate checked? By whom?

- Have you ever had an exam that checked your prostate? [IF SO] What motivated you to get tested? What was the experience like?

- [IF NOT] Why haven’t you been tested? [PROBE FOR SPECIFIC BARRIERS INCLUDING COST]

- What information would motivate you to get screened? [PROBE FOR STATISTICS, ENCOURAGEMENT FROM FRIENDS ETC]

2. INFORMATION ABOUT PROSTATE CANCER (10 minutes)

- Have you ever seen or heard any information for men about what types of health problems they should be aware of and when they should be checked for them? What did you see and where did you see it?

- Have you ever seen any information about prostate cancer specifically? What did you see and where did you see it?

- From what you know or have heard, how big a problem is prostate cancer?

- Are there any types of men who are more likely to get prostate cancer? [PROBE FOR HEREDITY, RACE] Do you know whether there are types of men who are more likely to have advanced cancer when it is diagnosed? [IF SO] Why do you think this happens?
- What have you heard about prostate cancer in terms of how serious of a disease it is?

- What have you heard about prostate cancer in terms of the treatments that are available for it? From what you know or have heard, how effective are the treatments?

- What kinds of side effects are there from the treatments for prostate cancer?

- Does knowing about the side effects of treatment have an impact on you in terms of being tested for prostate cancer?

- African American men with prostate cancer are more likely than other men to have their cancer monitored than to have aggressive treatment. Do you have any thoughts on why that happens?

3. RESPONSES TO DPH BROCHURE (30 minutes)

I’d like you to look at this brochure. [HAND OUT BROCHURES]

- What’s your impression of the brochure? What do you think the purpose of this brochure is?

- Next, I’d like you to look at the front and back covers. What do you think of the covers? If you saw this brochure somewhere, do you think you’d be likely to look at it? Why or why not?

- What do you think of the picture? Do you identify with the men in the picture? Why or why not?

- Next, I’d like you to open the brochure and read the information as I read it to you. [READ THE TEXT OUT LOUD] What do you think about the information on these two pages? Does it interest you in reading the rest of the brochure? Why or why not?

- What are the main points and messages on these pages?

- Is there anything confusing on these two pages?

- Did you learn anything from these pages?

- Is there anything on these pages that is not believable to you?

- Next, I’d like to turn the page and read the information on pages 1 and 2. [READ THE TEXT OUT LOUD] What do you think about the information on these pages?

- Is this information interesting to you? Why or why not?

- What are the main points and messages on these pages?

- Is there anything confusing on these two pages?

- Did you learn anything from these pages?
- Is there anything on these pages that is not believable to you?

- Next, I’d like to turn the page and read the information on pages 3 and 4. [READ THE TEXT OUT LOUD] What do you think about the information on these pages?

- Is this information interesting to you? Why or why not?

- What are the main points and messages on these pages?

- Is there anything confusing on these two pages?

- Did you learn anything from these pages?

- Next, I’d like to turn the page and read the information on pages 5 and 6. [READ THE TEXT OUT LOUD] What do you think about the information on these pages?

- Is this information interesting to you? Why or why not?

- What are the main points and messages on these pages?

- Is there anything confusing on these two pages?

- Did you learn anything from these pages?

- Next, I’d like to turn the page and read the information on pages 7 and 8. [READ THE TEXT OUT LOUD] What do you think about the information on these pages?

- Is this information interesting to you? Why or why not?

- What are the main points and messages on these pages?

- Is there anything confusing on these two pages?

- Did you learn anything from these pages?

- Next, I’d like you to think about the whole brochure. What do you think the purpose of this brochure is?

- Do you think this is a helpful brochure? Why or why not?

- Do you think this brochure is easy or difficult to read? What makes it easy or difficult?

- How could this brochure be improved to make it more helpful? [PROBE FOR: use of color, photos vs. illustrations, use of white space, amount of copy]
- Do you think you would take any actions after reading this brochure? What would you be likely to do?

- Do you think you’d be likely to ask your doctor about a prostate cancer screening after reading this brochure? Why or why not?

- What do you think could make you likely to talk to your doctor about a prostate cancer screening?

4. RESPONSES TO OTHER MATERIALS (15 minutes)

Next, I’d like to show you some other materials that about prostate cancer.

First, I’d like to show you this poster. Does this catch your eye? If you saw this poster in a doctor’s office or health clinic, do you think you’d read it? Why or why not? Which would you prefer for getting information about prostate cancer—a poster or brochure?

Another way of providing information about prostate cancer is through a card like this. [SHOW WALLET CARD] If a card like this was available at your doctor’s office or a clinic, do you think you’d pick it up? Do you think you’d read it? Why or why not? How likely would you be to take it home? Which would you prefer for getting information about prostate cancer—a wallet card or brochure?

I also have this handout specifically for African Americans. [HAND OUT COPIES AND READ OUT LOUD]

- How does this information compare to the brochure you just read?

- Is it more or less interesting?

- Is it more or less understandable?

- Is there anything in this material that you think should have been included in the brochure?

- Would you be more likely to ask your doctor about a prostate cancer screening if you read the brochure or the fact sheet? Why?

- In general, how much detail should materials like this provide you about prostate cancer—do you want a lot of information, facts, and statistics, or do you prefer a summary of the information? Would you prefer to read facts and statistics or personal stories about men who have had prostate cancer? Which would be most effective in getting you to act?

- In general, do you think the brochure is the best way to get information to men like yourselves about prostate cancer? Are there other ways to get information to you that would be better? What about a smaller brochure like this? [SHOW TRI-FOLD BROCHURE]
- For those of you that are married or in a relationship, how much of a role does your partner play in you going to the doctor or taking care of your health? Does your partner ever say that you should see a doctor or that you should have tests done? Does that make you do it? Would you be more likely to talk to your doctor about a prostate cancer screening if your partner talked to you about it?

5. DISTRIBUTION OF MATERIALS (5 minutes)

Next, I’d like to talk about where you think brochures on prostate cancer should be made available? Where would be the best places for these brochures to be distributed? (doctor’s offices, churches, barbershops, sporting events, men’s clubs)

6. WRAP-UP (5 minutes)

- Questions from the back room.
- Is there anything we haven’t discussed, or anything else you’d like to add to the discussion before we wrap up?
- Thank respondents for their time and thoughts.
APPENDIX B: MODERATOR’S GUIDE
FOR ENGLISH-SPEAKING GROUPS

I. INTRODUCTION (10 minutes)

- Welcome respondents and explain the purpose of today’s discussion groups-i.e. to talk about health. Specifically, how they think about their health and what might they be doing or not doing to try to remain healthy and prevent illnesses in the future, and what they think about some educational materials about health.

- I need your written permission to talk to you today, so I’d really appreciate your signing the consent form. These forms will be filed away. Again, no names related to this project will be released or shown to anyone outside the Market Street Research. Our research is pooled and presented as combined information.

- Explain the ground rules

  We are (video and) audio taping this meeting. We are taping it for two reasons. First, so I can review the tape after the meeting to prepare a report – by having the tape I don’t have to take a lot of notes and can concentrate on listening to what you have to say. Second, the tape will be used to reinforce some of the points you are making. If you have a suggestion, it can be more powerful to have you say it than to have me summarize it.

  I want to assure you, that all of your comments are confidential and will be used only for research purposes. Nothing you say will be connected with your name. Also, if there are any questions you would prefer not to answer, please feel free not to respond to them.

  Also, there are a few ground rules that we use for meetings like this that help them to run more smoothly. The first is we really want to hear from everyone. We are only holding a small number of these groups, so each of you is representing a lot of people. So even if you are the only person who holds a specific opinion, I really want to hear it because there are a lot of other people in the area that have that same opinion.

  I also want to emphasize that there are no right or wrong answers to the topics we’ll be discussing—we’re interested in everyone’s opinions.

  Second, it is really important that only one person speak at a time. There may be times when you are tempted to start a side conversation with the person next to you, but I’d appreciate it if you’d hold back. I want to hear whatever you have to say and the audio on the tape will be impossible to understand if more than one person is speaking.

  Also, if you have a cell phone or a beeper, I would appreciate it if you could turn it off (or set it to vibrate if you have to keep it on).

- Have respondents interview the person sitting next to them as a way to get them comfortable in the room, and have them introduce each other to the group. Ask them to find out their first name, where they live, what they do, and something about their family life.
1. AWARENESS OF PROSTATE CANCER, BARRIERS TO TESTING (10 minutes)

My first questions are about what types of things you think men should do to take care of their health.

- How often do you think a man should have a check-up or physical exam by a doctor, separate from a specific problem? Why? Why not?
- When was the last time you went to a doctor for a check-up or physical exam by a doctor, separate from a specific problem?
- Have you ever seen or heard any information for men about what types of health problems they should be aware of and when they should be checked for them? What did you see and where did you see it?
- How often do you think a man should have tests for specific problems, for example, how often should men have their blood pressure tested? Their prostate?
- Have you ever seen any information about prostate cancer specifically? What did you see and where did you see it?
- Have you heard about prostate cancer screenings? What have you heard? At what age do you think men should have their prostate checked regularly?
- Has it ever been recommended to you that you talk to a doctor about having your prostate checked? By whom?
- Have you ever had an exam that checked your prostate? [IF SO] What motivated you to get tested? What was the experience like?
- [IF NOT] Why haven’t you been tested? [PROBE FOR SPECIFIC BARRIERS INCLUDING COST]
- What information would motivate you to get screened? [PROBE FOR STATISTICS, ENCOURAGEMENT FROM FRIENDS ETC]

2. INFORMATION ABOUT PROSTATE CANCER (10 minutes)

Next, I want to talk more about what you know about prostate cancer.

- From what you know or have heard, how big a problem is prostate cancer?
- Are there any types of men who are more likely to get prostate cancer? [PROBE FOR HEREDITY, RACE] Do you know whether there are types of men who are more likely to have advanced cancer when it is diagnosed? [IF SO] Why do you think this happens?
- What have you heard about prostate cancer in terms of how serious of a disease it is?
- What have you heard about prostate cancer in terms of the treatments that are available for it? From what you know or have heard, how effective are the treatments?

- What kinds of side effects are there from the treatments for prostate cancer?

- Does knowing about the side effects of treatment have an impact on you in terms of being tested for prostate cancer?

3. RESPONSES TO DPH BROCHURE (30 minutes)

I’d like you to look at this brochure. [HAND OUT BROCHURES]

- What’s your impression of the brochure? What do you think the purpose of this brochure is?

- Next, I’d like you to look at the front and back covers. What do you think of the covers? If you saw this brochure somewhere, do you think you’d be likely to look at it? Why or why not?

- What do you think of the picture? Do you identify with the men in the picture? Why or why not?

- Next, I’d like you to open the brochure and read the information as I read it to you. [READ THE TEXT OUT LOUD] What do you think about the information on these two pages? Does it interest you in reading the rest of the brochure? Why or why not?

- What are the main points and messages on these pages?

- Is there anything confusing on these two pages?

- Did you learn anything from these pages?

- Is there anything on these pages that is not believable to you?

- Next, I’d like to turn the page and read the information on pages 1 and 2. [READ THE TEXT OUT LOUD] What do you think about the information on these pages?

- Is this information interesting to you? Why or why not?

- What are the main points and messages on these pages?

- Is there anything confusing on these two pages?

- Did you learn anything from these pages?

- Is there anything on these pages that is not believable to you?
Next, I’d like to turn the page and read the information on pages 3 and 4. [READ THE TEXT OUT LOUD] What do you think about the information on these pages?

- Is this information interesting to you? Why or why not?
- What are the main points and messages on these pages?
- Is there anything confusing on these two pages?
- Did you learn anything from these pages?
- Is there anything on these pages that is not believable to you?

Next, I’d like to turn the page and read the information on pages 5 and 6. [READ THE TEXT OUT LOUD] What do you think about the information on these pages?

- Is this information interesting to you? Why or why not?
- What are the main points and messages on these pages?
- Is there anything confusing on these two pages?
- Did you learn anything from these pages?
- Is there anything on these pages that is not believable to you?

Next, I’d like to turn the page and read the information on pages 7 and 8. [READ THE TEXT OUT LOUD] What do you think about the information on these pages?

- Is this information interesting to you? Why or why not?
- What are the main points and messages on these pages?
- Is there anything confusing on these two pages?
- Did you learn anything from these pages?
- Is there anything on these pages that is not believable to you?

Next, I’d like you to think about the whole brochure. What do you think the purpose of this brochure is?

- Do you think this is a helpful brochure? Why or why not?
- Do you think this brochure is easy or difficult to read? What makes it easy or difficult?
- How could this brochure be improved to make it more helpful?  [PROBE FOR: use of color, photos vs. illustrations, use of white space, amount of copy]

- Do you think you would take any actions after reading this brochure? What would you be likely to do?

- Do you think you’d be likely to ask your doctor about a prostate cancer screening after reading this brochure? Why or why not?

- What do you think could make you likely to talk to your doctor about a prostate cancer screening?

4. RESPONSES TO OTHER MATERIALS (15 minutes)

Next, I’d like to show you some other materials that about prostate cancer.

First, I’d like to show you this poster. Does this catch your eye? If you saw this poster in a doctor’s office or health clinic, do you think you’d read it? Why or why not? Which would you prefer for getting information about prostate cancer—a poster or brochure?

Another way of providing information about prostate cancer is through a card like this. [SHOW WALLET CARD] If a card like this was available at your doctor’s office or a clinic, do you think you’d pick it up? Do you think you’d read it? Why or why not? How likely would you be to take it home? Which would you prefer for getting information about prostate cancer—a wallet card or brochure?

- In general, how much detail should materials like this provide you about prostate cancer—do you want a lot of information, facts, and statistics, or do you prefer a summary of the information? Would you prefer to read facts and statistics or personal stories about men who have had prostate cancer? Which would be most effective in getting you to act?

- In general, do you think the brochure is the best way to get information to men like yourselves about prostate cancer? Are there other ways to get information to you that would be better? What about a smaller brochure like this? [SHOW TRI-FOLD BROCHURE]

- For those of you that are married or in a relationship, how much of a role does your partner play in you going to the doctor or taking care of your health? Does your partner ever say that you should see a doctor or that you should have tests done? Does that make you do it? Would you be more likely to talk to your doctor about a prostate cancer screening if your partner talked to you about it?

5. DISTRIBUTION OF MATERIALS (5 minutes)

Next, I’d like to talk about where you think brochures on prostate cancer should be made available? Where would be the best places for these brochures to be distributed? (doctor’s offices, churches, barbershops, sporting events, men’s clubs)
6. WRAP-UP (5 minutes)

- Questions from the back room.
- Is there anything we haven’t discussed, or anything else you’d like to add to the discussion before we wrap up?
- Thank respondents for their time and thoughts.
APPENDIX C: MODERATOR’S GUIDE
FOR PORTUGUESE-SPEAKING FOCUS GROUP

I. INTRODUCTION (10 minutes)

• Welcome respondents and explain the purpose of today's discussion groups-i.e. to talk about health. Specifically, how they think about their health and what might they be doing or not doing to try to remain healthy and prevent illnesses in the future, and what they think about some educational materials about health.

• I need your written permission to talk to you today, so I’d really appreciate your signing the consent form. These forms will be filed away. Again, no names related to this project will be released or shown to anyone outside the Market Street Research. Our research is pooled and presented as combined information.

• Explain the ground rules
  - We are (video and) audio taping this meeting. We are taping it for two reasons. First, so I can review the tape after the meeting to prepare a report – by having the tape I don’t have to take a lot of notes and can concentrate on listening to what you have to say. Second, the tape will be used to reinforce some of the points you are making. If you have a suggestion, it can be more powerful to have you say it than to have me summarize it.
  
  - I want to assure you, that all of your comments are confidential and will be used only for research purposes. Nothing you say will be connected with your name. Also, if there are any questions you would prefer not to answer, please feel free not to respond to them.
  
  - Also, there are a few ground rules that we use for meetings like this that help them to run more smoothly. The first is we really want to hear from everyone. We are only holding a small number of these groups, so each of you is representing a lot of people. So even if you are the only person who holds a specific opinion, I really want to hear it because there are a lot of other people in the area that have that same opinion.
  
  - I also want to emphasize that there are no right or wrong answers to the topics we’ll be discussing—we’re interested in everyone’s opinions.
  
  - Second, it is really important that only one person speak at a time. There may be times when you are tempted to start a side conversation with the person next to you, but I’d appreciate it if you’d hold back. I want to hear whatever you have to say and the audio on the tape will be impossible to understand if more than one person is speaking.
  
  - Also, if you have a cell phone or a beeper, I would appreciate it if you could turn it off (or set it to vibrate if you have to keep it on).

• Have respondents interview the person sitting next to them as a way to get them comfortable in the room, and have them introduce each other to the group. Ask them to find out their first name, where they live, what they do, and something about their family life.
1. AWARENESS OF PROSTATE CANCER, BARRIERS TO TESTING (10 minutes)

My first questions are about what types of things you think men should do to take care of their health.

- How often do you think a man should have a check-up or physical exam by a doctor, separate from a specific problem? Why? Why not?

- When was the last time you went to a doctor for a check-up or physical exam by a doctor, separate from a specific problem?

- Have you ever seen or heard any information for men about what types of health problems they should be aware of and when they should be checked for them? What did you see and where did you see it?

- How often do you think a man should have tests for specific problems, for example, how often should men have their blood pressure tested? Their prostate?

- Have you ever seen any information about prostate cancer specifically? What did you see and where did you see it?

- Have you heard about prostate cancer screenings? What have you heard? At what age do you think men should have their prostate checked regularly?

- Has it ever been recommended to you that you talk to a doctor about having your prostate checked? By whom?

- Have you ever had an exam that checked your prostate? [IF SO] What motivated you to get tested? What was the experience like?

- [IF NOT] Why haven’t you been tested? [PROBE FOR SPECIFIC BARRIERS INCLUDING COST]

- What information would motivate you to get screened? [PROBE FOR STATISTICS, ENCOURAGEMENT FROM FRIENDS ETC]

2. INFORMATION ABOUT PROSTATE CANCER (10 minutes)

Next, I want to talk more about what you know about prostate cancer.

- From what you know or have heard, how big a problem is prostate cancer?

- Are there any types of men who are more likely to get prostate cancer? [PROBE FOR HEREDITY, RACE] Do you know whether there are types of men who are more likely to have advanced cancer when it is diagnosed? [IF SO] Why do you think this happens?

- What have you heard about prostate cancer in terms of how serious of a disease it is?
What have you heard about prostate cancer in terms of the treatments that are available for it? From what you know or have heard, how effective are the treatments?

What kinds of side effects are there from the treatments for prostate cancer?

Does knowing about the side effects of treatment have an impact on you in terms of being tested for prostate cancer?

3. RESPONSES TO DPH BROCHURE (30 minutes)

I’d like you to look at this brochure. [HAND OUT BROCHURES]

What’s your impression of the brochure? What do you think the purpose of this brochure is?

Next, I’d like you to look at the front and back covers. What do you think of the covers? If you saw this brochure somewhere, do you think you’d be likely to look at it? Why or why not?

What do you think of the picture? Do you identify with the men in the picture? Why or why not?

Next, I’d like you to open the brochure and read the information as I read it to you. [READ THE TEXT OUT LOUD] What do you think about the information on these two pages? Does it interest you in reading the rest of the brochure? Why or why not?

What are the main points and messages on these pages?

Is there anything confusing on these two pages?

Did you learn anything from these pages?

Is there anything on these pages that is not believable to you?

Next, I’d like to turn the page and read the information on pages 1 and 2. [READ THE TEXT OUT LOUD] What do you think about the information on these pages?

Is this information interesting to you? Why or why not?

What are the main points and messages on these pages?

Is there anything confusing on these two pages?

Did you learn anything from these pages?

Is there anything on these pages that is not believable to you?
Next, I’d like to turn the page and read the information on pages 3 and 4. [READ THE TEXT OUT LOUD] What do you think about the information on these pages?

- Is this information interesting to you? Why or why not?
- What are the main points and messages on these pages?
- Is there anything confusing on these two pages?
- Did you learn anything from these pages?
- Is there anything on these pages that is not believable to you?

Next, I’d like to turn the page and read the information on pages 5 and 6. [READ THE TEXT OUT LOUD] What do you think about the information on these pages?

- Is this information interesting to you? Why or why not?
- What are the main points and messages on these pages?
- Is there anything confusing on these two pages?
- Did you learn anything from these pages?
- Is there anything on these pages that is not believable to you?

Next, I’d like to turn the page and read the information on pages 7 and 8. [READ THE TEXT OUT LOUD] What do you think about the information on these pages?

- Is this information interesting to you? Why or why not?
- What are the main points and messages on these pages?
- Is there anything confusing on these two pages?
- Did you learn anything from these pages?
- Is there anything on these pages that is not believable to you?

Next, I’d like you to think about the whole brochure. What do you think the purpose of this brochure is?

- Do you think this is a helpful brochure? Why or why not?
- Do you think this brochure is easy or difficult to read? What makes it easy or difficult?
- How could this brochure be improved to make it more helpful? [PROBE FOR: use of color, photos vs. illustrations, use of white space, amount of copy]
- Do you think you would take any actions after reading this brochure? What would you be likely to do?
- Do you think you’d be likely to ask your doctor about a prostate cancer screening after reading this brochure? Why or why not?
- What do you think could make you likely to talk to your doctor about a prostate cancer screening?

4. RESPONSES TO OTHER MATERIALS (15 minutes)

Next, I’d like to show you some other materials that about prostate cancer.

Another way of providing information about prostate cancer is through a card like this. [SHOW WALLET CARD] If a card like this was available at your doctor’s office or a clinic, do you think you’d pick it up? Do you think you’d read it? Why or why not? How likely would you be to take it home? Which would you prefer for getting information about prostate cancer—a wallet card or brochure?

- In general, how much detail should materials like this provide you about prostate cancer—do you want a lot of information, facts, and statistics, or do you prefer a summary of the information? Would you prefer to read facts and statistics or personal stories about men who have had prostate cancer? Which would be most effective in getting you to act?

- In general, do you think the brochure is the best way to get information to men like yourselves about prostate cancer? Are there other ways to get information to you that would be better? What about a smaller brochure like this? [SHOW TRI-FOLD BROCHURE]

- How about posters—would that be better than a brochure?

- For those of you that are married or in a relationship, how much of a role does your partner play in you going to the doctor or taking care of your health? Does your partner ever say that you should see a doctor or that you should have tests done? Does that make you do it? Would you be more likely to talk to your doctor about a prostate cancer screening if your partner talked to you about it?

5. DISTRIBUTION OF MATERIALS (5 minutes)

Next, I’d like to talk about where you think brochures on prostate cancer should be made available? Where would be the best places for these brochures to be distributed? (doctor’s offices, churches, barbershops, sporting events, men’s clubs)
6. WRAP-UP (5 minutes)

- Is there anything we haven’t discussed, or anything else you’d like to add to the discussion before we wrap up?
- Thank respondents for their time and thoughts.
APPENDIX D: MODERATOR’S GUIDE
FOR SPANISH-SPEAKING FOCUS GROUP

I. INTRODUCTION (10 minutes)

- Welcome respondents and explain the purpose of today’s discussion groups - i.e. to talk about health. Specifically, how they think about their health and what might they be doing or not doing to try to remain healthy and prevent illnesses in the future, and what they think about some educational materials about health.

- I need your written permission to talk to you today, so I’d really appreciate your signing the consent form. These forms will be filed away. Again, no names related to this project will be released or shown to anyone outside the Market Street Research. Our research is pooled and presented as combined information.

- Explain the ground rules
  - We are (video and) audio taping this meeting. We are taping it for two reasons. First, so I can review the tape after the meeting to prepare a report - by having the tape I don’t have to take a lot of notes and can concentrate on listening to what you have to say. Second, the tape will be used to reinforce some of the points you are making. If you have a suggestion, it can be more powerful to have you say it than to have me summarize it.
  
  - I want to assure you, that all of your comments are confidential and will be used only for research purposes. Nothing you say will be connected with your name. Also, if there are any questions you would prefer not to answer, please feel free not to respond to them.
  
  - Also, there are a few ground rules that we use for meetings like this that help them to run more smoothly. The first is we really want to hear from everyone. We are only holding a small number of these groups, so each of you is representing a lot of people. So even if you are the only person who holds a specific opinion, I really want to hear it because there are a lot of other people in the area that have that same opinion.
  
  - I also want to emphasize that there are no right or wrong answers to the topics we’ll be discussing - we’re interested in everyone’s opinions.
  
  - Second, it is really important that only one person speak at a time. There may be times when you are tempted to start a side conversation with the person next to you, but I’d appreciate it if you’d hold back. I want to hear whatever you have to say and the audio on the tape will be impossible to understand if more than one person is speaking.
  
  - Also, if you have a cell phone or a beeper, I would appreciate it if you could turn it off (or set it to vibrate if you have to keep it on).

- Have respondents interview the person sitting next to them as a way to get them comfortable in the room, and have them introduce each other to the group. Ask them to find out their first name, where they live, what they do, and something about their family life.
1. AWARENESS OF PROSTATE CANCER, BARRIERS TO TESTING (10 minutes)

My first questions are about what types of things you think men should do to take care of their health.

- How often do you think a man should have a check-up or physical exam by a doctor, separate from a specific problem? Why? Why not?

- When was the last time you went to a doctor for a check-up or physical exam by a doctor, separate from a specific problem?

- Have you ever seen or heard any information for men about what types of health problems they should be aware of and when they should be checked for them? What did you see and where did you see it?

- How often do you think a man should have tests for specific problems, for example, how often should men have their blood pressure tested? Their prostate?

- Have you ever seen any information about prostate cancer specifically? What did you see and where did you see it?

- Have you heard about prostate cancer screenings? What have you heard? At what age do you think men should have their prostate checked regularly?

- Has it ever been recommended to you that you talk to a doctor about having your prostate checked? By whom?

- Have you ever had an exam that checked your prostate? [IF SO] What motivated you to get tested? What was the experience like?

- [IF NOT] Why haven’t you been tested? [PROBE FOR SPECIFIC BARRIERS INCLUDING COST]

- What information would motivate you to get screened? [PROBE FOR STATISTICS, ENCOURAGEMENT FROM FRIENDS ETC]

2. INFORMATION ABOUT PROSTATE CANCER (10 minutes)

Next, I want to talk more about what you know about prostate cancer.

- From what you know or have heard, how big a problem is prostate cancer?

- Are there any types of men who are more likely to get prostate cancer? [PROBE FOR HEREDITY, RACE] Do you know whether there are types of men who are more likely to have advanced cancer when it is diagnosed? [IF SO] Why do you think this happens?

- What have you heard about prostate cancer in terms of how serious of a disease it is?
What have you heard about prostate cancer in terms of the treatments that are available for it? From what you know or have heard, how effective are the treatments?

What kinds of side effects are there from the treatments for prostate cancer?

Does knowing about the side effects of treatment have an impact on you in terms of being tested for prostate cancer?

3. RESPONSES TO DPH BROCHURE (30 minutes)

I’d like you to look at this brochure. [HAND OUT BROCHURES]

What’s your impression of the brochure? What do you think the purpose of this brochure is?

Next, I’d like you to look at the front and back covers. What do you think of the covers? If you saw this brochure somewhere, do you think you’d be likely to look at it? Why or why not?

What do you think of the picture? Do you identify with the men in the picture? Why or why not?

Next, I’d like you to open the brochure and read the information as I read it to you. [READ THE TEXT OUT LOUD] What do you think about the information on these two pages? Does it interest you in reading the rest of the brochure? Why or why not?

What are the main points and messages on these pages?

Is there anything confusing on these two pages?

Did you learn anything from these pages?

Is there anything on these pages that is not believable to you?

Next, I’d like to turn the page and read the information on pages 1 and 2. [READ THE TEXT OUT LOUD] What do you think about the information on these pages?

Is this information interesting to you? Why or why not?

What are the main points and messages on these pages?

Is there anything confusing on these two pages?

Did you learn anything from these pages?

Is there anything on these pages that is not believable to you?
- Next, I’d like to turn the page and read the information on pages 3 and 4. [READ THE TEXT OUT LOUD] What do you think about the information on these pages?

- Is this information interesting to you? Why or why not?

- What are the main points and messages on these pages?

- Is there anything confusing on these two pages?

- Did you learn anything from these pages?

- Is there anything on these pages that is not believable to you?

- Next, I’d like to turn the page and read the information on pages 5 and 6. [READ THE TEXT OUT LOUD] What do you think about the information on these pages?

- Is this information interesting to you? Why or why not?

- What are the main points and messages on these pages?

- Is there anything confusing on these two pages?

- Did you learn anything from these pages?

- Is there anything on these pages that is not believable to you?

- Next, I’d like to turn the page and read the information on pages 7 and 8. [READ THE TEXT OUT LOUD] What do you think about the information on these pages?

- Is this information interesting to you? Why or why not?

- What are the main points and messages on these pages?

- Is there anything confusing on these two pages?

- Did you learn anything from these pages?

- Is there anything on these pages that is not believable to you?

- Next, I’d like you to think about the whole brochure. What do you think the purpose of this brochure is?

- Do you think this is a helpful brochure? Why or why not?

- Do you think this brochure is easy or difficult to read? What makes it easy or difficult?
- How could this brochure be improved to make it more helpful? [PROBE FOR: use of color, photos vs. illustrations, use of white space, amount of copy]
- Do you think you would take any actions after reading this brochure? What would you be likely to do?
- Do you think you’d be likely to ask your doctor about a prostate cancer screening after reading this brochure? Why or why not?
- What do you think could make you likely to talk to your doctor about a prostate cancer screening?

4. RESPONSES TO OTHER MATERIALS (15 minutes)

Next, I’d like to show you some other materials that about prostate cancer.

Another way of providing information about prostate cancer is through a card like this. [SHOW WALLET CARD] If a card like this was available at your doctor’s office or a clinic, do you think you’d pick it up? Do you think you’d read it? Why or why not? How likely would you be to take it home? Which would you prefer for getting information about prostate cancer—a wallet card or brochure?

- In general, how much detail should materials like this provide you about prostate cancer—do you want a lot of information, facts, and statistics, or do you prefer a summary of the information? Would you prefer to read facts and statistics or personal stories about men who have had prostate cancer? Which would be most effective in getting you to act?
- In general, do you think the brochure is the best way to get information to men like yourselves about prostate cancer? Are there other ways to get information to you that would be better? What about a smaller brochure like this? [SHOW TRI-FOLD BROCHURE]
- How about posters—would that be better than a brochure?
- For those of you that are married or in a relationship, how much of a role does your partner play in you going to the doctor or taking care of your health? Does your partner ever say that you should see a doctor or that you should have tests done? Does that make you do it? Would you be more likely to talk to your doctor about a prostate cancer screening if your partner talked to you about it?

5. DISTRIBUTION OF MATERIALS (5 minutes)

Next, I’d like to talk about where you think brochures on prostate cancer should be made available? Where would be the best places for these brochures to be distributed? (doctor’s offices, churches, barbershops, sporting events, men’s clubs)
6. WRAP-UP (5 minutes)

- Is there anything we haven’t discussed, or anything else you’d like to add to the discussion before we wrap up?

- Thank respondents for their time and thoughts.
APPENDIX E: MODERATOR’S GUIDE
FOR ALL OTHER ETHNICITIES

I. INTRODUCTION (10 minutes)

- Welcome respondents and explain the purpose of today’s discussion groups—i.e. to talk about health. Specifically, how they think about their health and what might they be doing or not doing to try to remain healthy and prevent illnesses in the future, and what they think about some educational materials about health.

- I need your written permission to talk to you today, so I’d really appreciate your signing the consent form. These forms will be filed away. Again, no names related to this project will be released or shown to anyone outside the Market Street Research. Our research is pooled and presented as combined information.

- Explain the ground rules
  - We are audio taping this meeting. We are taping it for two reasons. First, so I can review the tape after the meeting to prepare a report—by having the tape I don’t have to take a lot of notes and can concentrate on listening to what you have to say. Second, the tape will be used to reinforce some of the points you are making. If you have a suggestion, it can be more powerful to have you say it than to have me summarize it.

  - I want to assure you, that all of your comments are confidential and will be used only for research purposes. Nothing you say will be connected with your name. Also, if there are any questions you would prefer not to answer, please feel free not to respond to them.

  - Also, there are a few ground rules that we use for meetings like this that help them to run more smoothly. The first is we really want to hear from everyone. We are only holding a small number of these groups, so each of you is representing a lot of people. So even if you are the only person who holds a specific opinion, I really want to hear it because there are a lot of other people in the area that have that same opinion.

  - I also want to emphasize that there are no right or wrong answers to the topics we’ll be discussing—we’re interested in everyone’s opinions.

  - Second, it is really important that only one person speak at a time. There may be times when you are tempted to start a side conversation with the person next to you, but I’d appreciate it if you’d hold back. I want to hear whatever you have to say and the audio on the tape will be impossible to understand if more than one person is speaking.

  - Also, if you have a cell phone or a beeper, I would appreciate it if you could turn it off (or set it to vibrate if you have to keep it on).

- Have respondents interview the person sitting next to them as a way to get them comfortable in the room, and have them introduce each other to the group. Ask them to find out their first name, where they live, what they do, and something about their family life.
1. AWARENESS OF PROSTATE CANCER, BARRIERS TO TESTING (10 minutes)

My first questions are about what types of things you think men should do to take care of their health.

- How often do you think a man should have a check-up or physical exam by a doctor, separate from a specific problem? Why? Why not?

- When was the last time you went to a doctor for a check-up or physical exam, separate from a specific problem?

- Have you ever seen or heard any information for men about what types of health problems they should be aware of and when they should be checked for them? What did you see and where did you see it?

- How often do you think a man should have tests for specific problems, for example, how often should men have their blood pressure tested? Their prostate?

- Have you ever seen any information about prostate cancer specifically? What did you see and where did you see it?

- Have you heard about prostate cancer screenings? What have you heard? At what age do you think men should have their prostate checked regularly?

- Has it ever been recommended to you that you talk to a doctor about having your prostate checked? By whom?

- Have you ever had an exam that checked your prostate? [IF SO] What motivated you to get tested? What was the experience like?

- [IF NOT] Why haven’t you been tested? [PROBE FOR SPECIFIC BARRIERS INCLUDING COST]

- What information would motivate you to get screened? [PROBE FOR STATISTICS, ENCOURAGEMENT FROM FRIENDS ETC]

2. INFORMATION ABOUT PROSTATE CANCER (10 minutes)

Next, I want to talk more about what you know about prostate cancer.

- From what you know or have heard, how big a problem is prostate cancer?

- Are there any types of men who are more likely to get prostate cancer? [PROBE FOR HEREDITY, RACE] Do you know whether there are types of men who are more likely to have advanced cancer when it is diagnosed? [IF SO] Why do you think this happens?

- What have you heard about prostate cancer in terms of how serious of a disease it is?
- What have you heard about prostate cancer in terms of the treatments that are available for it? From what you know or have heard, how effective are the treatments?

- What kinds of side effects are there from the treatments for prostate cancer?

- Does knowing about the side effects of treatment have an impact on you in terms of being tested for prostate cancer?

3. RESPONSES TO DPH BROCHURE (30 minutes)

I’d like you to look at this brochure. [HAND OUT BROCHURES]

- What’s your impression of the brochure? What do you think the purpose of this brochure is?

- Next, I’d like you to look at the front and back covers. What do you think of the covers? If you saw this brochure somewhere, do you think you’d be likely to look at it? Why or why not?

- What do you think of the picture? Do you identify with the men in the picture? Why or why not?

- Next, I’d like you to open the brochure and read the information as I read it to you. [READ THE TEXT OUT LOUD] What do you think about the information on these two pages? Does it interest you in reading the rest of the brochure? Why or why not?

- What are the main points and messages on these pages?

- Is there anything confusing on these two pages?

- Did you learn anything from these pages?

- Is there anything on these pages that is not believable to you?

- Next, I’d like to turn the page and read the information on pages 1 and 2. [READ THE TEXT OUT LOUD] What do you think about the information on these pages?

- Is this information interesting to you? Why or why not?

- What are the main points and messages on these pages?

- Is there anything confusing on these two pages?

- Did you learn anything from these pages?

- Is there anything on these pages that is not believable to you?
- Next, I’d like to turn the page and read the information on pages 3 and 4. [READ THE TEXT OUT LOUD] What do you think about the information on these pages?

- Is this information interesting to you? Why or why not?

- What are the main points and messages on these pages?

- Is there anything confusing on these two pages?

- Did you learn anything from these pages?

- Is there anything on these pages that is not believable to you?

- Next, I’d like to turn the page and read the information on pages 5 and 6. [READ THE TEXT OUT LOUD] What do you think about the information on these pages?

- Is this information interesting to you? Why or why not?

- What are the main points and messages on these pages?

- Is there anything confusing on these two pages?

- Did you learn anything from these pages?

- Is there anything on these pages that is not believable to you?

- Next, I’d like to turn the page and read the information on pages 7 and 8. [READ THE TEXT OUT LOUD] What do you think about the information on these pages?

- Is this information interesting to you? Why or why not?

- What are the main points and messages on these pages?

- Is there anything confusing on these two pages?

- Did you learn anything from these pages?

- Is there anything on these pages that is not believable to you?

- Next, I’d like you to think about the whole brochure. What do you think the purpose of this brochure is?

- Do you think this is a helpful brochure? Why or why not?

- Do you think this brochure is easy or difficult to read? What makes it easy or difficult?
- How could this brochure be improved to make it more helpful? [PROBE FOR: use of color, photos vs. illustrations, use of white space, amount of copy]

- Do you think you would take any actions after reading this brochure? What would you be likely to do?

- Do you think you’d be likely to ask your doctor about a prostate cancer screening after reading this brochure? Why or why not?

- What do you think could make you likely to talk to your doctor about a prostate cancer screening?

4. RESPONSES TO OTHER MATERIALS (15 minutes)

Next, I’d like to show you some other materials about prostate cancer.

Another way of providing information about prostate cancer is through a card like this. [SHOW WALLET CARD] If a card like this was available at your doctor’s office or a clinic, do you think you’d pick it up? Do you think you’d read it? Why or why not? How likely would you be to take it home? Which would you prefer for getting information about prostate cancer—a wallet card or brochure?

- In general, how much detail should materials like this provide you about prostate cancer—do you want a lot of information, facts, and statistics, or do you prefer a summary of the information? Would you prefer to read facts and statistics or personal stories about men who have had prostate cancer? Which would be most effective in getting you to act?

- In general, do you think the brochure is the best way to get information to men like yourselves about prostate cancer? Are there other ways to get information to you that would be better? What about a smaller brochure like this? [SHOW TRI-FOLD BROCHURE]

- How about posters—would that be better than a brochure?

- For those of you that are married or in a relationship, how much of a role does your partner play in you going to the doctor or taking care of your health? Does your partner ever say that you should see a doctor or that you should have tests done? Does that make you do it? Would you be more likely to talk to your doctor about a prostate cancer screening if your partner talked to you about it?

5. DISTRIBUTION OF MATERIALS (5 minutes)

Next, I’d like to talk about where you think brochures on prostate cancer should be made available? Where would be the best places for these brochures to be distributed? (doctor’s offices, churches, barbershops, sporting events, men’s clubs)
6. WRAP-UP (5 minutes)

- Is there anything we haven’t discussed, or anything else you’d like to add to the discussion before we wrap up?

- Thank respondents for their time and thoughts.