

**BARRIERS TO PROSTATE CANCER SCREENING FOR AFRICAN-
AMERICAN AND LATINO MEN**

Prepared for:

The Comprehensive Cancer Prevention and Control Program at
The Colorado Department of Public Health and Environment

Prepared by:

Center for Research Strategies, LLC
225 E 16th Avenue, Suite 1150
Denver, Colorado 80203
303/860-1705
303/860-1706 fax

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BACKGROUND

Prostate cancer is the second leading cause of cancer-related deaths in men in the United States. Age, race and ethnicity are all factors that contribute to a man's risk for prostate cancer:

- About 80% of all men with clinically diagnosed prostate cancer are aged 65 years or older.
- African Americans have the highest incidence of prostate cancer in the Colorado and they are more likely to die from this disease.
- In Colorado, Latinos experience a lower incidence of prostate cancer than other racial groups (see Table 1).¹ However, studies have found that Latinos tend to seek treatment from their doctors with more clinically advanced-stage prostate cancers than do non-Latino whites.²

TABLE 1: AVERAGE ANNUAL INCIDENCE AND MORTALITY RATES FOR PROSTATE CANCER PER 100,000 FOR COLORADO BY ETHNICITY³

	Rate of Incidence	Rate of Mortality
Overall*	145.6	23.1
African Americans**	186.1	67.9
Whites**	164.4	32.3
Latinos**	130.8	25.9

*Rates for 1993-1997

**Rates for 1995-1999

Currently, there are two primary methods used to screen for prostate cancer: the digital rectal exam (DRE) and prostate-specific antigen (PSA) testing. Recommendations for the type screening used and the frequency of the screening vary. The U.S. Preventive Services Task Force does not recommend any type of screening while the American Cancer Society recommends that men be offered the option of PSA testing yearly, beginning at age 50, and that African-American men be offered the option starting at age 45. Currently, many men do not receive prostate cancer screening on a regular basis. For example, one analysis of Medicare claims data for men aged 65 and over found that less than 35% had a PSA test biannually or more frequently.⁴ In another survey, only 46% of respondents reported receiving a DRE in the previous year.⁵

¹ <http://www.cdc.gov/cancer/prostate/prostate.htm>

² Hoffman RM, et al. Racial and ethnic differences in advanced-stage prostate cancer: the Prostate Cancer Outcomes Study. *J Natl Cancer Inst* 2001;93:388-95.

³ <http://www.cdphe.state.co.us/pp/cccr/93-98/cc9398prostate.pdf>

⁴ Etzioni R. Berry KM. Legler JM. Shaw P. Prostate-specific antigen testing in black and white men: an analysis of Medicare claims from 1991-1998. *Urology* 2002;59(2):251-5.

⁵ Carter F. Graham E. Pal N. Gonzalez E. Roetzheim R. Prostate cancer screening in primary care. *Southern Medical Journal* 1999;92(3):300-4.

In order to gain a better understanding of the barriers men face in seeking prostate cancer screening, focus groups were held with African-American and Latino men. This report describes the results of these focus groups and includes three major sections: methods, focus group results and recommendations.

METHODS

This study is part of a larger initiative sponsored by the Comprehensive Cancer Prevention and Control Program through a grant from the Centers for Disease Control to investigate diagnosis and treatment issues related to prostate cancer in Colorado. For the purposes of this study, twelve focus groups were conducted over a three-month period, six with Latino men and six with African-American men. The focus group participants were recruited from five Colorado communities: Denver, Pueblo, Colorado Springs, Carbondale and Alamosa. Table 2 shows the number of groups held in each community. Compared to other areas in the state, the chosen communities had high percentages of African-American and/or Latino men.

Table 2: FOCUS GROUP LOCATION AND NUMBER OF SESSIONS PER LOCATION

<i>Group</i>	<i>Alamosa</i>	<i>Colorado Springs</i>	<i>Denver</i>	<i>Pueblo</i>	<i>Carbondale</i>
<i>Latino</i>	1		3	1	1
<i>African American</i>		1	5		

RECRUITMENT

The recruitment of the focus group participants was carried out with the help of key community contacts. Each community contact was provided with a recruitment guide that defined who would be eligible for the focus groups, suggestions as to how to recruit participants and recommendations regarding arrangements for a meeting room and refreshments for the group (see Appendix A).

Eleven of the groups were recruited from a local agency, church, fraternity organization or business (see Table 3). To encourage participant attendance, each group was held at a location near the area from which the participants were recruited. The twelfth group entailed the recruitment of local community leaders and was conducted at a local TV station. Recruitment methods varied depending on the host organization. The most common methods included posting flyers at the focus group location, making an announcement during a community/organizational meeting and/or making phone calls to prospective participants. In most communities, the participants in the focus groups were contacted on a one-on-one basis by intermediaries who were themselves representative of, and familiar with, these target communities.

Table 3: FOCUS GROUP DATE, ORGANIZATION, LOCATION AND NUMBER OF PARTICIPANTS BY ETHNIC GROUP

Date	Organization/Location	# of Participants	Ethnicity of Group
2/24/02	Our Lady of Guadalupe/Denver	14	Latino
3/17/02	Our Lady of Guadalupe/Denver	11	Latino
4/4/02	Kappa Psi Fraternity/Denver	10	African American
4/9/02	DCTV/Denver	8	African American
4/20/02	Hersfield Towers/Aurora	15	African American
4/21/02	GI Forum/Denver	8	Latino
4/27/02	Project Heritage	8	African American
5/4/02	Carson Air Force Base/Colorado Springs	10	African American
5/5/02	Sangre de Cristo Parish/San Luis Valley	11	Latino
5/11/02	Park Hill Golf Course/Denver	4	African American
6/2/02	El Centro del Quinto Sol/Pueblo	8	Latino
6/19/02	Mary of the Crown/Carbondale	15	Latino

FOCUS GROUP FORMAT

Two male facilitators, both over 50 years of age, conducted the 12 focus groups. An African-American facilitator conducted the six African-American groups and a Latino facilitator conducted the six Latino groups, including two groups composed of Spanish-speaking men. The facilitators were provided with a guide (Appendix B) to ensure that each group was conducted following a similar format.

Before the group discussion began, participants were asked to complete a consent form and a demographic profile. Next, the facilitator gave the participants background information about prostate cancer, prostate cancer screening and the purpose of the focus group. Participants were then asked to respond to questions related to four topic areas (Appendix C):

- (1) Understanding of prostate cancer prior to the group
- (2) Communication with their doctor about prostate cancer
- (3) Barriers to receiving a screening and
- (4) Strategies to help get men into screening.

FOCUS GROUP ANALYSIS

Each focus group lasted about 2 hours during which the proceedings were taped and then later transcribed. The analysis of the text data focused on the four broad question areas mentioned above. As a first step, a team of analysts read through the transcripts highlighting issues, examples and quotes that were frequently repeated. After the initial analysis, the transcripts were then reviewed a second time to confirm the themes and to develop an overarching framework into which these themes could be organized. Quotes illustrating each theme were compiled and organized to support and refine the analysis framework. As a final step, each facilitator was asked to read a draft of the final report to confirm that all the themes from the focus groups had been highlighted and presented in the final report.

RESULTS

PARTICIPANTS

In total, 122 men participated in the focus groups. Of this number, 55 percent were Latino and 45 percent were African Americans. The focus group participants ranged in age from 45 to 65 (Table 4). Over half of the participants (68%) were working either part-time or full-time and 55% were married.

Table 4: DESCRIPTION OF FOCUS GROUP PARTICIPANTS

Demographics	Percent
Race	
Latino	55%
African American	45%
Age	
49 or under	36%
50-54	21%
55-60	21%
60-64	10%
65 or older	11%
Marital Status	
Married	55%
Divorced	26%
Never been married	11%
Other	8%
Employment	
Working full-time	56%
Working part-time	12%
Retired	17%
Other	15%
Education, Highest Grade Completed	
Never attended school	2%
Grades 1-8	11%
Grades 9-11	10%
Grade 12 or GED	19%
College 1 year – 3 years	24%
College 4 or more	34%

Over half (64%) of the participants reported that they had a health care provider whom they visited regularly and 61% had some form of health insurance. When asked about how knowledgeable they were about prostate cancer, 62% of the participants felt they were “somewhat informed” or “knew quite a bit” about the issue of prostate cancer. Sixty-one percent had had a prostate cancer screening at some point in their lifetime. Of those 39% who had not received a screening, 22% said it was because they did not know about prostate cancer screening (see Appendix D).

FOCUS GROUP THEMES

The focus group discussions demonstrated that the participants shared similar experiences and perceptions regarding prostate cancer screening. Three recurring themes were repeated by the men regarding factors that limited their use of screening options:

- (1) Health seeking behaviors/attitudes
- (2) Knowledge and
- (3) Access to the health care system.

After detailing the ways in which the focus group participants described these barriers, we summarize the strategies recommended by the participants to encourage more men to receive prostate cancer screening. Table 5, at the end of this section, provides an overall summary of the broad themes that emerged from these groups and the ways in which these themes were characterized by the group participants.

Barriers to Prostate Cancer Screening

KNOWLEDGE

The focus group participants varied in their knowledge about their own prostate cancer risk and about the importance of regular screenings.

In three of the groups, men were candid about their lack of knowledge around prostate cancer and prostate cancer screening. Our findings support the results of many research studies that document that not all men have the information they need about this important health practice. One recent survey of Latino men found that nearly a third of them had never heard of the DRE procedure.⁶ Similarly, approximately half of a sample of African-American men in New York City reported that they were unfamiliar with tests to screen for prostate cancer.⁷

Beyond a lack of familiarity with prostate cancer and its associated screening procedures, our focus group participants also indicated that they did not know where to get a screening, the cost of screening or at what age it was appropriate to get a screening.

Lack of Knowledge about Prostate Cancer

- *Well, in my case, honestly, I haven't talked about it with anybody. I don't know very much about it.*
- *I haven't really talked about any doctor in particular about this....So, when I continued going to the doctor, they would.....we were talking more about diabetes then.....and not about the prostate. So, that's it.*

⁶ Talavera GA, et al. Predictors of Digital Rectal Examination in U.S. Latinos. *Am J Prev Med* 2002; 22(1):36-41.

⁷ Ashford AR, et al. Prostate Carcinoma Knowledge, Attitudes, and Screening Behavior among African-American Men in Central Harlem, New York City. *Cancer* 2001; 91:164-72.

Lack of Knowledge about Prostate Cancer Screening

- *I think what it is with a lot of people is they're not scared of the screenings and stuff like that. But, nobody knows where to go to get a screening, and the cost.*
- *And, I think if you don't know.....and the doctor says here, "Let's talk about it." If we don't get more people to talk about it.....because I was at the first stage of knowledge, which is not good enough. We need to be at the complete stage of knowledge so that you know what that exam is about, and how important it is. Now, I am constantly getting the PSAs. And, I'm getting them both [types of screening] every year.*
- *I had heard something that you were supposed to be around 40 [when you have a prostate cancer screening]. But, I guess I figured I'm way past that.*

HEALTH SEEKING BEHAVIORS/ATTITUDES

One topic common in all of the group discussions related to the participants' behaviors and attitudes towards health care. The participants spent a lot of time talking about how their opinions about their health in general and their overall experiences with the overall health care system kept them from going to the doctor and also from taking preventive measures. Participants mentioned that even though they might be knowledgeable about prostate cancer screening, knowing about their risk is not always enough to prompt them to seek screening.

Three barriers discussed by the participants were: their tendency to take a passive approach to health care, being in denial about their health and having distrust in the health care system. Many participants believed that one of the biggest barriers to prostate cancer screening was the fact that men tend to only go to the doctor if they are very sick. Several national studies confirm that African-American men in particular, tend to ignore symptoms of health problems and will only seek care as a last resort.⁸⁹

It was also noteworthy that the DRE process evoked certain negative concerns in men who considered the process to be personally offensive.

Participants also talked about the fear men have of prostate cancer and that as a result many men ignore the issue all together. Finally, both in the African-American and Latino groups there was a discussion about how some men of color do not trust that health providers give them the same quality of care as they give other patients.

Passive Approach to Health Care

- *Because, the problem...the lack or response goes greater than lack of knowledge. I really do think there is more awareness now than ever before about the problems and the reasons why black males need to have the exam... I'm guessing that there's not been an increase in blacks who have had the exam to the degree that there have been blacks who have been made more aware of the need to have it. You have the awareness and then you have this lag. And, I think some of that is cultural.*

⁸ Plowden KO, Miller JL. Motivators of health seeking behavior in urban African-American men: an exploration of triggers and barriers. J of Ntl Black Nurses Association 2000; 11(1):15-20.

⁹ Conigliaro J, et al. Delay in presentation for cardiac care by race, age, and site of care. Medical Care 2002; 40(S):97-105.

- *Well, the reason why I haven't really talked to a doctor about it is that I've never gone to a doctor.*
- *In my other group [of friends] I asked them "Would you go for a screening?" And, they said, "No, because it's not my problem. I don't have that problem."*

Denial/Fear

- *And, plus I think there's a fear factor that what if there's something inside. And, it's like, "Then I'll know." And, they would have fear and anxiety. I think some people may operate from the vantage point that not to know is better than to know. And, we know that's fool hardy. But, I think that's part of it for some people.*
- *I wonder if it could be also I've heard...and I guess it's true. If you have prostate cancer and you have surgery that it can affect your ability to have sex. And, basically, some men would say, "Hey, if I can't have sex, then take me *** The radiation or nothing is going to affect my ability to do that."*
- *My father, for an example. He's 66 years old right now. And, he went to get checked about five years ago...only because he got to feeling bad. But, the reason why he never got checked before was because no news is good news. He was feeling fine. And, basically, I think we're scared. We don't want to hear bad news.*

Distrust in the Health Systems

- *I don't know. It's just a mistrust. I don't know where it comes from. I think that some things that I was treated for in the past that I don't feel like I've gotten the best treatment. I've seen others that have had similar symptoms like mine, and they seem to have gotten further along in the process for treatment than I did receive...for me the confidence is not there.*
- *But, it you know there is a little historical thing and I think we can probably go back further to in our own communities we can go back even further in terms of it was eluded to...in terms of our distrust...or misalignment with the system. We look at history...every interaction that we had with the system wasn't that great... so we got a learned distrust.*
- *In the African American community especially...and in low income areas doctors will not always perform certain tests on the lower scale...so called, lower scale people of this country. So, they're leaving us in darkness about certain problems that we may be having -- that I think still is a big problem in this country.*

ACCESS TO HEALTH CARE

Participants in over half of the groups talked about the cost of the screening and lack of health care insurance and how that is often a barrier for men who lack financial resources. In other studies, having the ability to pay for services is often cited as a strong predictor of whether a prostate cancer screening will be received.¹⁰ In the two Latino groups held in rural Colorado, participants also talked about the lack of services available not only for people with lack of insurance but for the community as a whole.

¹⁰ Talavera GA, et al. Predictors of Digital Rectal Examination in U.S. Latinos. Am J Prev Med 2002; 22(1):36-41.

Financial

- *There was an article in the Denver Post last week I should have brought it, it told about the poor Latino community. It's like when they go to Denver General Hospital...I guess they charge them \$20. Some people can't afford that \$20. Part of the problem is they just can't afford it.*
- *The screenings. What we need to improve is getting the people there to get the screenings. But, there are two problems. And, they're both economic. One, most of them can't get away from work. Two, they have no insurance. Doctors don't discriminate against races. They discriminate if people don't have money.*

Strategies to Deal with Barriers

KNOWLEDGE

Most of the participants emphasized the need for men of color to receive additional education about prostate cancer, the prevalence of this cancer among men of color and the recommended schedule for seeking screenings. There were a number of avenues mentioned in the groups for disseminating this information including using community leaders and churches to offer educational programs to African-American and Latino men. Such methods have been used previously with a good deal of success. For example, the Detroit Education and Early Detection (DEED) program uses churches to recruit African-American men who might be reluctant to receive screening otherwise.¹¹

Several other outreach strategies were suggested by the groups, many of which are recommended through published research. These include educating family members and ensuring that information is provided in Spanish.^{12 13}

Use Community Leaders to Help Educate

- *A couple of years ago Mayor Webb was diagnosed with prostate cancer. And, the media followed him left and right. And, afterwards he came out and was promoting more exams for prostate cancer. That got me thinking about it...a couple of years ago...You might profile people [like that who can] really educate a lot of people to get an annual check.*
- *Well, I think what we're really going to have to try to focus on is to find spokespeople...other than ourselves...in that celebrity realm. Whether it be a Michael Jordan. Or, whether it be a Magic. Magic did an incredible job for AIDS. Once he spoke, it all opened up and the money started flowing. So some kind of way we have to figure out.*

Use Churches as a Venue for Education

- *I was talking to my pastor recently about that. And, that's what I'm about to do at our church, and some other churches that we fellowship with...is to raise the awareness. I mean we talk about the Lord. And, we say He's a healer. Yes he is. But, he didn't make you dumb either.*

¹¹ Powell IJ, et al. A successful recruitment process of African American men for early detection of prostate cancer. *Cancer* 1995; 75:1880-1884.

¹² Plowden KO, Miller JL. Motivators of health seeking behavior in urban African-American men: an exploration of triggers and barriers. *J of Ntl Black Nurses Association* 2000; 11(1):15-20.

¹³ Jacobs EA, et al. Impact of interpreter services on delivery of health care to limited-English-proficient patients. *J Gen Intern Med* 2001; 16(7):493-495.

- *Perhaps utilize the churches. We need to disseminate more information. Perhaps the churches can do it.*

Educate our Family

- *I think that's one of the positive things about the current advertising approach that's taken. And, that is the female. The female is the one that sees the end result of a non-evolving male. So, as we continue to add...direct advertisements...[we need to] get involvement of the wives, the mothers, the aunts, the sisters of individuals, they will go because their wives insist that they go to do this. So, the better we educate the female community.... Because, they are the ones that do get us to the doctor's office. They're the ones who end up taking us to the hospital when we're really sick.*
- *Well, in my case, yeah, I know about it. My son is really urging me to go. But, I haven't had a chance to make an appointment and go.*

Hold Community Forums/Discussion Groups

- *Someone has to step up in our communities. Like this is going on right now. I mean, in my neighborhood where I grew up in the east side of Five Points, I know quite a few kids over there. If I took the initiative...literally took the initiative and say, "Hey, fellas let me talk to you a for a minute. You ever heard of such and such a thing?"*
- *I think the thing is, if we can keep groups like this and get these guys talking about it, and talking about it openly. That's what we want to do more. Really get the word out where we have discussions.*

Sponsor Public Service Announcements

- *Well, I think there should be more information available. And, more promotion. I think they could do more promotion...some of those health fairs...or on the exams themselves...we would get more men to go. If we could do it on radio, on television.... that way. So, we could hear about it. That would motivate us to go.*
- *I think there are a variety of things that you could do. Number one is increasing the number of public service announcements. Perhaps on television and radio. I don't think I've ever seen one on prostate cancer.*

Start Education Young

- *Then I think you have to really focus on the younger kids. Talk to the young boys in middle school and grade school. And say, "Hey, these are the problems we've had. These are all of the tools necessary now to overcome this."*
- *We have to start educating people younger. I think that [name] mentioned that you have to start a lot younger than you would ever suspect. Not just prostate cancer. But, the whole health issue: eating right, exercising and perhaps in 10-20 years you would see a result.*

Provide Educational Materials that the Reader Can Understand

- *And for us that are Spanish speakers, or a Spanish-speaking community information in Spanish. Absolutely.*
- *Yeah, if we could have some materials that we can understand that would be great.*

HEALTH SEEKING BEHAVIORS

The focus group participants also talked about the importance of empowering men to start taking more responsibility for their health. They believe that men should take a more proactive approach to taking care of themselves.

Take Responsibility for One's Health

- *We have to learn to take responsibility for ourselves. And, this is what we need.*
- *You want to have that done, especially people our age, after 45, or something like that. And, especially if you have health insurance. Just tell your doctor that you're of this age and you want it [prostate screening].*

DOCTOR/PATIENT RELATIONSHIP

The other area that men mentioned as being important was using the doctor/patient relationship as a means of getting men to seek screenings. They talked about the need to improve communication with the doctor and to educate doctors about understanding a patient's culture and background. The men in the Latino groups also mentioned the desire to be able to see a provider that was able to speak Spanish. Studies confirm that minority men report less satisfaction with and greater mistrust of their physician visits than do Caucasian men.¹⁴ The reasons for this imbalance are still under investigation. Some researchers find a perceived lack of communication between minority men and their doctor, especially when the physician and patient are racially discordant.¹⁵ This results in patients feeling unable to participate fully in decision-making regarding their health, and frustration with the entire health care experience.

Improve Communication regarding Prostate Cancer Screening

- *This is all preventative. Like giving people the information that they need to stop it before it happens. Really, that's what the doctor's job should be. A doctor's job should be to stop people from getting the disease. Not to help them after they're sick. It's to stop them from getting sick in the first place.*
- *Well, I think if we could...if they could be more communicative...if the doctors could be more communicative. If they would really explain things more clearly. That would really help a lot.*

Educate Doctors about Patients' Culture and Background

- *Because, we have a shortage of African American physicians in the community. So, you have no options but to go to a majority physician. How do we educate them in terms of how they deal with the African American males?*

¹⁴ LaVeist TA, Nickerson KJ, Bowie JV. Attitudes about racism, medical mistrust, and satisfaction with care among African American and white cardiac patients. *Medical Care Research & Review* 2000; 57 Suppl 1:146-61.

¹⁵ Cooper-Patrick L, et al. Race, gender, and partnership in the patient-physician relationship. *JAMA*. 1999 Aug 11;282(6):583-9.

TABLE 5: SUMMARY OF FOCUS GROUP THEMES

Theme Area	Themes	Description of Theme
Barriers		
Knowledge	Lack of Knowledge about Prostate Cancer	Lack of knowledge about prostate cancer was a barrier discussed by the focus group participants.
	Lack of Knowledge about Screening	Some participants had a limited understanding about where to go to get screened and when to have it done.
Health Seeking Behaviors/ Attitudes	Passive Approach to Health Care	Participants believed that men in general take a passive approach to their health care tending to seek services only when they're sick.
	Denial/Fear	Men talked about their fear of the consequences of prostate cancer which then leads them to deny their need for screening.
	Distrust in System	Some men have developed a distrust of health providers, which limits their use of health care services.
Access to Care	Financial	Lack of money to pay for screening limited the use of this service for some men.
Strategies		
Knowledge	Use Community Leaders	Participants suggested using community leaders to help educate men about the importance of prostate cancer screening.
	Use Churches	Churches were a place where men thought education should take place.
	Educate our Families	Family members were suggested as people who can motivate men to seek screening.
	Hold Community Forums/Discussion	Many participants suggested that community forums or discussion groups are a strategy for increasing the awareness of men about prostate cancer.
	Sponsor Public Service Announcements	Using public service announcements was mentioned by a number of participants as an educational strategy.
	Start Education Young	Participants suggested starting the education of young men about prostate cancer as early as high school.
	Provide Reader-Focused Materials	Participants want to read educational materials that are easy to understand and available in Spanish.
Health Seeking Behaviors/ Attitudes	Take Responsibility for One's Own Health	Most participants thought that men need to take better care of themselves and to assume more responsibility for their health care.
Doctor/ Patient Relationship	Improve Communication	Improving communication between doctors and their patients was also mentioned as a strategy.
	Educate Doctors about Patients' Culture	Men talked about the need to educate doctors about patients' culture.

RECOMMENDATIONS FOR NEXT STEPS

During the twelve focus groups, participants were eager to give suggestions about how to increase screenings for prostate cancer. In this final section, we have grouped these suggestions into three categories: statewide strategies, provider-based strategies and community based strategies. In addition to the suggestions mentioned by the focus group participants, we have included strategies mentioned in the Colorado Cancer Plan 2005 (indicated with *) and from the current literature.

STATEWIDE STRATEGIES

- Create targeted awareness campaign aimed at dispelling myths and correcting misinformation regarding prostate cancer treatment*
- Sponsor a comprehensive media campaign using billboards, posters, and pamphlets in several languages to target specific population groups
- Support collaborative efforts that provide free screening, such as the American Cancer Society's Prostate Cancer Screening Campaign*
- Support programs offering free screening for underinsured and uninsured men at high risk for prostate cancer*
- Create materials, in both English and Spanish, to educate men about prostate cancer
- Sponsor radio campaigns on English and non-English stations

COMMUNITY-BASED STRATEGIES

- Use community leaders to educate their community members about the importance of prostate cancer screening
- Use culturally specific education through local community institutions to remove barriers to the health care system and to inform men about screening methods for prostate cancer¹⁶
- Create targeted outreach programs for high risk men especially African Americans*
- Create church-based educational programs and health fairs
- Use community health workers, who are members of the community, to educate men about the importance of screening.

PROVIDER-BASED STRATEGIES

- Hold an annual symposium to provide an opportunity for healthcare professionals to present and discuss approaches to the diagnosis and treatment of prostate cancer
- Conduct training, technical assistance, and consultation for providers on prostate cancer through monthly teleconferences, site visits, and quarterly regional meetings
- Develop professional reference tools for health care providers
- Educate and encourage health providers to perform Digital Rectal Exams and offer Prostate-Specific Antigens screenings during physical exams of men age 50 and older*
- Educate health care providers about the barriers to prostate cancer screening and strategies they can use to promote screening¹⁷

¹⁶ Powell IJ, et al. A successful recruitment process of African American men for early detection of prostate cancer. *Cancer* 1995; 75(7): 1880-1885.

APPENDIX A

Recruitment Guidelines

¹⁷ Sheinfeld, et al. Cancer education among primary care physicians in an underserved community. *Am J Prev Med* 2000; 19(1): 53-58.

Focus Group Instructions Recruiting the Group

Background

The Center for Research Strategies and the Colorado Department of Public Health and Environment are currently conducting discussion groups with Hispanic and African-American men to understand the barriers to prostate cancer screening. A copy of the questions is attached.

Recruiter's Role

You will be responsible for completing two tasks: 1) recruit the participants for group and 2) arrange for a focus group location, a meeting room and refreshments for the participants.

Arrange Location, Room and Refreshments

1. Location

Determine a location for the focus group. The location should be accessible to all the participants and should have a meeting room that can be reserved for group events. Ideas for a location include a church, a community center, a school, a library or a medical clinic.

2. Reserve a Meeting Room

Reserve a room that is big enough for the facilitator and all participants to sit comfortably at one table. You will also need an additional table for refreshments. Be careful, however, not to get a room that is too big. A larger room makes it more difficult to tape record the groups.

3. Order Refreshment for the Participants

You will also need to order food and drinks for those attending the group discussion. One of the easiest choices is to order pizza/soda and have it delivered to the focus group location. Other options include providing a boxed meal from a local deli or having a hot meal provided from a local caterer.

4. Confirm Focus Group Arrangements

At least two days before the group call the focus group location and confirm your room reservation.

Recruitment

Criteria for Participation

Participation will be limited to men who meet the following criteria:

- Age: 50-64
- Ethnicity: African American
- Health Care: Seen a health care provider in the last year.

Number of Participants

The ideal number of participants for the focus group is 8-10. The best way to guarantee attendance of 8-10 men is to recruit 13-14 ***Incentives***

Each participant will be given \$25 after they have participated in the group. Be sure to mention this point when you are talking with each of the qualified candidates.

Develop a List of Possible Participants

Before you begin recruiting, develop an initial list of people who you think will qualify for and be interested in the focus group. This list can include people you work with, you socialize with, you provide services for, etc. As you make each contact, work on developing your list by asking your contact for additional names and telephone numbers.

Steps of the Recruitment Process

1. Initial Contact – Screening Participation

You will be responsible for determining if each person you contact is actually qualified to participate in the group. In order to help you with this process, we have developed a screening form to use during your initial contact. The screening form includes a description of the discussion group, a place to collect background information on the contact person, and a set of screening questions.

2. Invite Qualified Men to Participate

If the person qualifies for the focus group, extend a verbal invitation to participate. During this conversation, describe the purpose of the group, provide information about the date, time and location of the group and let them know about the incentive.

3. Send Confirmation Letter

Send a letter to each person who agrees to attend the discussion group. The letter should contain details about the group including purpose, time, date, and location. A sample letter has also been provided.

4. Place a Reminder Call

One or two days prior to the group, call each participant to remind them about the time, date and location of the group.

5. Arrange for alternates to attend (if needed)

If some of the initial participants cancel, contact people on your alternate list and invite them to participate.

Participant Screening

Background Information About Participant

Name of participant: _____

Address: _____

Phone or other contact information:

Explanation of Study

Hello, my name is [name}. I'm calling from [organization/group] We're helping the Colorado Department of Public Health and Environment put together a discussion group about prostate cancer screening. If you qualify for this study, we ask that you come to [location of the group] to give your opinions in a group discussion that would last about two hours. You will be paid for your time. May I ask you a few questions?

Screening Questions

Which of the following age ranges do you fall into?

_____ 49 or younger [*Thank respondent and end call.*]

_____ 50 or older

Which category best describes your ethnicity?

_____ African American

_____ Other [*Thank respondent and end call.*]

Invitation

As I mentioned earlier, we are scheduling a small group discussion. If you are able to attend, you will be paid \$25 for your time, and refreshments will be served before the discussion. Will you be able to attend on [day/ date] from [__ o'clock to __ o'clock]?

Sample Confirmation Letter

[Date]

Dear Mr. [Name]:

Thank you for agreeing to participate in the prostate screening discussion group. The following letter provides the details of the group.

DATE

[provide date]

TIME

[provide time]

PLACE

[provide address and description of meeting room]

DIRECTIONS

[provide detailed directions to the location of the focus group – you may even want to provide a map]

Prior to [date], I will call to remind you about the discussion group. In the mean time, if you have any questions or find that you are unable to attend please do not hesitate to contact me at [phone number].

Sincerely,

[your name]

APPENDIX B

Facilitation Guidelines

Steps for the Focus Groups

1. Participants Arrive (2:30 pm – 2:40 pm)

- Invite them to help themselves to the lunch
- After they are seated ask them to complete a nametag and a demographic questionnaire.

2. Purpose of Group/Provide Background Information on Prostate Cancer (2:40 pm –2:45 pm)

- Introduce yourself
My name is LALO. I will be the facilitator for the group today. First, I want to thank all of you for attending this discussion group. The purpose of this group is to get a better understanding of your experiences and perceptions of prostate cancer and prostate cancer screening.
- Give information about prostate cancer
Before we proceed I want to make sure we are all on the same page so I am going to tell you some basic information about prostate cancer. I will be handing out a more complete packet of information at the end of the group.
 - *The prostate, found only in men, is a walnut-sized gland located in front of the rectum, at the outlet of the bladder. It contains gland cells that produce some of the seminal fluid, which protects and nourishes sperm cells in semen.*
 - *We still do not know exactly what causes prostate cancer.*
 - *Risk factors include being over 50, being African American, and being from North America.*
 - *There are currently two types of screening men can get to help detect prostate cancer. Prostate cancer can often be found early by testing the amount of prostate-specific antigen (PSA) in your blood. Another way prostate cancer is found early is when the doctor performs a rectal examination.*

3. Consent Form (2:45 pm – 2:50 pm)

- Hand out the consent form
- Read the consent form out loud
- Ask each participant sign the consent form
- Collect the consent forms

4. Confidentiality and Tape Recording (2:50 pm – 2:55 pm)

- Tell the group about the tape recording process and the procedures we will take to protect their confidentiality

The discussion tonight will be taped and transcribed. We tape the discussion because we don't want to miss any of your comments. However, everything we discuss tonight will be confidential. Although the tapes will be transcribed, there will be not names on the transcript. We also ask each of you to keep this group confidential – in other words, please do not discuss what is said in the group with people out the group. Does everyone agree?

5. Ground Rules (2:55 pm – 3:00 pm)

- Cover the basic ground rules for the group
- In addition the confidentiality rules, there are some other ground rules I would like to cover before we get started.*
- a. Since were are taping this discussion we want to be sure that only one person talks at a time*
 - b. There are no right or wrong answers – we want to hear everyone's opinion – both positive and negative*
 - c. You can choose not to answer any of the questions we ask you during the group*
 - d. Be respectful of others in the group*

6. Group Discussion (3:00 pm – 4:25 pm)

- Start the discussion using the questions provided for you

7. Wrap-up (4:25 pm – 4:30 pm)

- Present certificate of completion to each participant
- Hand out incentives and have each person sign sheet to verify that they received the incentive
- Give each participant a packet of information about prostate cancer

APPENDIX C

Focus Group Questions

Barriers to Prostate Screening Focus Group Questions

Introductions

Facilitator:

1. Welcome the group.
2. Introduce yourself.
3. Relate the nature and purpose of the focus group, describe the process, and thank the members for their participation.
4. Stress the ground rules for an effective focus group exchange.
5. Stress the expected benefits of their participation.

Discussion:

Let's start the discussion by introducing ourselves. Please state your name and how long you have lived in this community.

Understanding and Perceptions of Prostate Cancer

Facilitator:

1. Stress that no one will be personally identified in any subsequent reporting of the focus group outcomes.
2. Keep a headcount of attendance.
3. Attribute comments only by gender and an identifying number. For example: M1 refers to Man #1.

Discussion:

1. How often do you visit a health care provider about any aspect of your personal health?
2. Let's talk about your experiences with anyone who has had prostate cancer. How many of you have known someone with prostate cancer? Please tell us about their experiences with this disease.

Probes:

What is your understanding of the condition known as prostate cancer?

- What is it?
- What causes it?
- What are the consequences of it?
- Is it curable?
- Are you aware that this problem is especially common among black males?

- Why do you suppose that is true?

If you know, or know about others who have this condition:

- How did the prostate cancer affect the quality of their lives?
- What were their experiences with diagnosis?
- With treatment?
- What negative experience did they have?

3. What have you heard about prostate cancer screening?

Probes:

What are your opinions about prostate cancer screening?

Is screening valuable?

Should everyone be screened?

Do you know where to go to be screened?

Communications About the Disorder

Discussion:

4. Have you ever talked with any health care provider about being screened for prostate cancer?

- If *yes*, please describe the conversation.

Probes:

Who initiated the conversation?

What topics were discussed during the conversation?

What did you find to be most helpful about the conversation?

What did you find least helpful about the conversation?

Did your provider recommend you have a prostate screening?

- If *no*, why have you never discussed this issue with your health care provider?

Probes:

Are you concerned about prostate cancer?

Do you ever talk to your provider, or anyone else, about disease prevention?

5. What can be done to improve communications between you and the health care providers who are knowledgeable on this subject?

Decision Making

Discussion:

6. Have you ever been screened for prostate cancer?

Probes

Why or why not?

How did you make the decision to have a screening?

Who, if anyone, helped you decide to go for a screening?

What role did your health care provider play in helping you decide to have a prostate cancer screening?

Knowing what you now know, would you go for another screening?

7. What can be done to improve the prostate cancer screening services?

APPENDIX D

Results from Demographic Survey

DO YOU HAVE A HEALTH CARE PROVIDER WHOM YOU SEE REGULARLY?

Response	Latino Groups (n=43)	African American Groups (n=66)	All Participants (n=109)
Yes	47%	76%	64%
No	54%	24%	36%

WHEN DO YOU GO SEE A HEALTH CARE PROVIDER?

Response	Latino Groups (n=43)	African American Groups (n=66)	All Participants (n=109)
When I have a health problem	48%	36%	41%
For annual check ups	50%	48%	49%
For a chronic health condition	16%	18%	17%

HOW MUCH WOULD YOU SAY THAT YOU KNOW ABOUT PROSTATE CANCER SCREENING?

Response	Latino Groups (n=43)	African American Groups (n=66)	All Participants (n=109)
Nothing at all	14%	12%	13%
Only a small amount	33%	16%	23%
Somewhat informed	42%	53%	48%
Know quite a bit	12%	16%	14%

FROM WHICH OF THE FOLLOWING SOURCES HAVE YOU RECEIVED INFORMATION ABOUT PROSTATE CANCER SCREENING? (Check all that apply)

Response	Latino Groups (n=43)	African American Groups (n=66)	All Participants (n=109)
I have never received any information on prostate cancer screening	32%	20%	25%
Health provider	39%	54%	48%
Friends/family	32%	34%	33%
Video/TV	11%	22%	18%
Written Information	43%	46%	45%
Other	14%	14%	14%

WHICH SOURCE OF INFORMATION DID YOU FIND TO BE MOST HELPFUL? (Check all that apply)

Response	Latino Groups (n=43)	African American Groups (n=66)	All Participants (n=109)
I have never received any information on prostate cancer screening	40%	15%	25%
Health provider	29%	41%	36%
Friends/family	12%	15%	14%
Video/TV	12%	13%	13%
Written Information	27%	32%	30%

HAVE YOU EVER BEEN SCREENED FOR PROSTATE CANCER?

Response	Latino Groups (n=43)	African American Groups (n=66)	All Participants (n=109)
Yes	50%	70%	61%
No	50%	29%	38%
Don't know		2%	1%

WHAT ARE THE REASONS THAT YOU HAVE NOT HAD A PROSTATE CANCER SCREENING?

(Check all that apply)

Response	Latino Groups (n=43)	African American Groups (n=66)	All Participants (n=109)
I have had a prostate cancer screening	12%	16%	14%
Too expensive	0%	2%	1%
I am not a risk for prostate cancer	4%		1%
My insurance does not cover prostate cancer screenings	11%	6%	8%
I don't know about prostate cancer screening	28%	20%	22%
I don't know where to get prostate cancer screening	31%	8%	16%

WHAT IS YOUR AGE?

Response	Latino Groups (n=43)	African American Groups (n=66)	All Participants (n=109)
49 or under	36%	37%	36%
50-54	18%	23%	21%
55-60	21%	22%	21%
60-64	10%	10%	10%
65 or older	15%	8%	11%

WHAT IS YOUR RACE?

Response	Latino Groups (n=43)	African American Groups (n=66)	All Participants (n=109)
African American		100%	61%
Hispanic	100%		39%

ARE YOU:

Response	Latino Groups (n=43)	African American Groups (n=66)	All Participants (n=109)
Married	76%	42%	55%
Divorced	16%	32%	26%
Widowed	3%	3%	3%
Separated		3%	2%
Never been married		18%	11%
A member of an unmarried couple	5%	2%	3%

WHAT IS THE HIGHEST GRADE LEVEL OR YEAR OF SCHOOL YOU HAVE COMPLETED?

Response	Latino Groups (n=43)	African American Groups (n=66)	All Participants (n=109)
Never attended school	5%		2%
Grades 1 through 8	30%		11%
Grades 9 through 11	14%	8%	10%
Grade 12 or GED	11%	25%	19%
College 1 through 3 years	22%	25%	24%
College 4 or more years	19%	43%	34%

WHAT IS YOUR EMPLOYMENT STATUS?

Response	Latino Groups (n=43)	African American Groups (n=66)	All Participants (n=109)
Working full-time	53%	57%	56%
Working part-time	16%	10%	12%
Retired	18%	16%	17%
Other	13%	16%	15%

DO YOU HAVE HEALTH INSURANCE?

Response	Latino Groups (n=43)	African American Groups (n=66)	All Participants (n=109)
Yes	45%	72%	61%
No	55%	27%	38%