

Access, Awareness, Outreach, and Advocacy: Mobile Prostate Cancer Screening as a Model for Reaching and Organizing Men

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In the United States, prostate cancer is the most commonly diagnosed non-skin cancer.¹ According to the American Cancer Society, approximately 180,000 men will be diagnosed with the disease and 32,000 men will lose their lives this year.² These numbers are comparable with those of breast cancer incidence and mortality in the United States.³ Only about 7 percent of U.S. government cancer research dollars are spent on finding a cure for a disease that accounts for nearly 16 percent of all cancer cases.⁴ Given these facts, the National Prostate Cancer Coalition (NPCC) developed a mobile prostate cancer screening program as a means to not only increase awareness of the disease but also to motivate men, women and families to urge the government to take a more aggressive posture towards finding a cure for prostate cancer.

While breast cancer and HIV/AIDS advocates are very effective at motivating women and families to participate in awareness and education activities such as bicycle rides, races, mountain climbs and multitudes of other “stunts” and events, prostate cancer advocates meet with resistance and apathy in attempts to engage men on a large scale. *Thor Industries* success with mobile prostate cancer screening and Dr. David Crawford’s work with Prostate Cancer Awareness Week helped NPCC to conclude that screening was the only activity that appeared to excite men about their own health. Therefore, NPCC has developed a partnership with *Thor Industries* to manage the mobile prostate cancer screening vehicle and to test methods for optimizing men’s participation in healthy activity.

Based on data gleaned from focus groups and user surveys as well as large scale phone surveys and anecdotal evidence, NPCC believes that it can motivate men and families to participate in healthy activity, such as prostate cancer screening, if it is presented at the right location and time with the blessing of local government and social leaders and with support from local prostate cancer survivors. NPCC asserts that education of the masses through novel screening events will provide men access to cutting-edge medicine, raise awareness, expand NPCC’s ability to reach out to disparate groups and create new health advocates. Most importantly, these events have the potential to save lives.

¹ American Cancer Society, Cancer Facts and Figures 2002. American Cancer Society; 5, 2002.

² American Cancer Society, 10.

³ American Cancer Society, 10.

⁴ Data compiled from the American Cancer Society, Cancer Facts and Figures 2002. American Cancer Society: 10, 2002 and the National Institute of Health’s Budget Office.

Since February 2002, NPCC has performed 6,507 screenings over 72 days in more than 15 cities in the United States. On average 90 men per day are screened by the vehicle. Of the total number of men screened, 455 were found to have PSA results greater than or equal to 4 ng/ml which is considered above normal. One man registered a PSA of 172 ng/ml. The average age of participation is about 56. The average age suggests that the message of early detection and awareness of prostate cancer is reaching the target audience.

From February until November 2002, media monitors reported more than 65 million media impressions on radio, television, newspapers, magazines and the Internet. Television newscasts from all of the Top 25 United States media markets aired stories on the prostate cancer screening vehicle. Total television coverage amounted to a Nielsen Rating audience of 18.08 million viewers. Prior to undertaking screening efforts, NPCC registered only 24 million media impressions for an entire year. The prostate cancer screening vehicle accounts for about half of the total media impressions received by NPCC.

Results from the last nine months of screening are strongly indicative that NPCC's "natural" experiment is paying off. Men are becoming involved in an activity that motivates them to change behavior, at least on screening for prostate cancer, and to educate themselves about the disease. The larger goal of turning patients into advocates remains to be seen.

Quantum advances in the realms of science and medicine, from the microprocessor to the mapping of the human genome, have the potential to dramatically benefit humanity. Medical researchers are inching towards finding the causes of cancer and the cure for HIV/AIDS. However, much of the world lacks access to current lifesaving and cutting edge treatments and diagnostics. Many populations are unaware that they are at "high risk" for certain ailments. Awareness of tests and procedures that may provide early detection of disease is limited and sometimes the nature of the examination, the digital rectal exam used for prostate cancer as an example, is culturally unpalatable. As an advocacy organization seeking an end to a devastating disease, how does NPCC meet the challenges of access, awareness, outreach and advocacy so that more people are able to participate in medical advances and are empowered to help maintain their own health?

NPCC's mobile prostate cancer screening program offers an interesting model for study and possible export to other medical service providers. Patient access to the program is provided via a specially outfitted 39 foot Airstream Land Yacht XL mobile medical vehicle. Awareness of the program and its message is delivered through a multitude of outlets including the media, religious centers, government entities, social organizations and "leafleting" in the service area prior to the vehicle's arrival. Outreach is done to the designated community by engaging local social and government leaders and by providing culturally appropriate educational materials and locations. Participants engage in

advocacy through satellite-based Internet access that provides participants with an opportunity to communicate with the government about health-care issues and to retrieve educational information from the Internet. The “Drive Against Prostate Cancer,” (DAPC) as the program is formally titled, attempts to use each of the elements to create an enduring message. While the vehicle may only be able to screen men for prostate cancer for one day in a given area, the hope is that media exposure and education of social and government organizations and the general public will raise awareness of prostate cancer and its danger to the community and will alter the tendency of American men to be disengaged about their health.

For many years, the major prostate cancer organizations have attempted to make their case for public awareness and government action on the numbers. The case is fairly simple: the incidence and mortality of the disease justifies a significant response from the government. However, time and experience have shown that this argument has a very limited capacity for producing results. Until 1996, prostate cancer research garnered only \$93 million from the U.S. government.⁵ The breast cancer and HIV/AIDS movements have clearly demonstrated that significant numbers of people demanding change is the most effective method for altering government policies towards disease research. In both cases, broad public awareness and education coupled with advocacy, changed government positions on their respective diseases. Also, both movements have been very effective at translating their causes into “rights” rather than special-interest issues. The prostate cancer community has yet to make its case on the national and international scene as effectively as its counterparts in breast cancer and HIV/AIDS.

One particular aspect that makes the marketing of prostate cancer difficult is the patient. Men are different than women and those differences present challenges. A recent column in the *Chicago Tribune* by health editor Ross Werland suggests that many men treat their bodies like cars – only seeking treatment when something in the body has broken down rather than giving it that preventative 3,000 mile mandatory oil change.⁶ Compounding the problem is the tendency of men not to communicate with their doctor or even their family about health problems. While women, especially in the United States, are often the portal to health care, men are often the road block. Painting in broad strokes, it is inappropriate for men to show pain or weakness in many cultures. Machismo, face, pride, manliness, whatever term one chooses to describe the art of being a man, affects all aspects of male outreach. The challenges of marketing to men defy the shop worn techniques of political organizing and social awareness.

Further complicating the issue is the fact that millions of men in the United States are either without health insurance or have policies that do not include annual

⁵ Data compiled from the National Institutes of Health Budget Office and the budget office of the Congressional Directed Medical Research Program.

⁶ Werland, Ross. “Check the oil and the prostate”. *Chicago Tribune*, September 29, 2002.

prostate cancer screenings. Many men find the lack of a required screening for prostate cancer to be as good as any excuse for not participating in healthy behavior. In the inner cities of the United States, numerous studies detail higher rates of death from cancer and heart disease and significantly higher incidences of HIV/AIDS, and diabetes.⁷ The populations of these inner city neighborhoods are predominantly black, Asian and Latino. Current data indicates that blacks have the highest incidence and mortality of prostate cancer and so their position is doubly impacted by the lack of access to care and lack of awareness of the disease.⁸ The Latino and Asian communities are hampered by language barriers as well as access issues.

Heaping together the natural non-communicative tendencies of men in general with cultural challenges and logistical hurdles such as access, the task of changing behavior and building an enduring message requires novel and innovative techniques.

The heart of the program is the screening vehicle. Thor built the vehicle because its President and Chief Operating Officer Wade Thompson is a prostate cancer patient and credits his survival and recovery to early detection of the disease. Mr. Thompson had the vehicle built as a way to draw attention to a disease that is seldom talked about among American men. In February of 2002 the National Prostate Cancer Coalition began to manage the vehicle in order to expand the program.

DAPC boasts two fully stocked private examination rooms, two phlebotomy stations, a state-of-the-art stereo sound system and a 42" flat screen television. An on board generator provides electricity to power the vehicle as well as to control the interior climate. The generator also supplies refrigeration for blood samples. Freshwater tanks provide running water and a chemical toilet is provided for convenience. DAPC is wired to have telephone service throughout the vehicle. Computer networking is also provided. Overall, DAPC has all the capacities of a standard doctor's office. The advantage of course is that this office can come to the patient.

The dynamics associated with traditional doctor offices often act as impediments to screening. There is a laundry list of aggravating circumstances and it only starts with the association of long waits. There is also the problem of finding a local doctor who takes new patients and belongs to the same health care provider ring prescribed the insurance company. Often appointments are made two to four months in advance and are sometimes scheduled for the middle of the afternoon forcing many workers to take a half-day of personal time. The process appears to be a huge time investment for someone who seemingly has nothing wrong with him.

⁷ Williams, Rose Marie, Breast and prostate cancer: a look at the environment; Health Risks and Environmental Issues. Associated Press, June 1, 2002.

⁸ American Cancer Society. Cancer Facts and Figures 2002. American Cancer Society: 28, 2002.

These obstacles do not exist aboard DAPC as talented local physicians are brought to the patient. This technique drastically cuts the wait to a fraction one would expect in a traditional doctor's office, eliminates the need for appointments and most importantly the need for an insurance provider as DAPC does not charge for the screenings.

Several very important elements come into play with the mobile vehicle. The size of the vehicle and its unique design appear to be natural attractants to men. When the vehicle is parked in a highly trafficked area, it automatically builds a small crowd. When men get on the vehicle they are impressed by the professionalism of the interior and the reassuring presence of medical personnel. While this is a fully functioning medical office, it lacks the stigma of a hospital, medical center or clinic. More than 300 men attended a DAPC screening in Des Moines, Iowa. Men are further mesmerized by the gadgets such as the flat screen television. An additional level of comfort is provided by broadcasting sporting events such as the World Cup. As a stand alone entity, DAPC is able to draw a crowd and provide an immediate impact on the area in which it is screening. NPCC works to enhance the natural assets of the vehicle to create a program with lasting benefit.

If the heart of the program is the vehicle, the medical philosophy is the program's backbone. NPCC strives to provide the highest level of healthcare possible to the patients that use the vehicle. To insure the most accurate results, NPCC always offers both prostate cancer diagnostic examinations, the Prostate Specific Antigen (PSA) blood test and the Digital Rectal Exam (DRE).

The Prostate Specific Antigen (PSA) blood test checks for elevations of a specific protein in the blood that could indicate the presence of cancer. The PSA test is currently used as a specific diagnostic marker for the early detection of the disease. Studies have shown that before the advent of the PSA test, about three-fourths of all prostate cancer cases were diagnosed in late stage where the disease is not readily treatable or curable.⁹ Since widespread use of the test starting in the mid-1990s, the statistic has reversed itself. Now, three-fourths of the cases are found early – giving men a fighting chance against prostate cancer.¹⁰ Bayer Diagnostics has recently switched NPCC's testing kits to the most accurate PSA test available, the Complexed Prostate Specific Antigen test (cPSA).¹¹

The DRE or physical exam, where a physician actually feels the surface of the prostate for tumors or other abnormalities, sometimes provides data that is not revealed by the PSA blood test. By offering both tests, NPCC is able to give

⁹ Gilliland, FD et al., Male Genital Cancer. Cancer 75:295-315, 1995.

¹⁰ Gilliland, FD et al., Male Genital Cancer. Cancer 75:295-315, 1995.

¹¹ Brawer et al., Retrospective Multicenter cPSA Trial. Journal of Urology 163:1476-80, May 2000.

patients the highest level of care and the most effective screening system in the cancer world.

Healthcare is much more than “rope them and poke them.” It is inhumane to test a man for a disease, have him diagnosed and then leave him without the capacity to have this disease treated if he so desires. NPCC works with local and state governments as well as the local medical establishment to guarantee that there will be follow-up treatment, as necessary, for those men that are under-insured or uninsured. All men screened on DAPC receive a letter by post detailing the results of their screening. For those men with a PSA outside of the “normal” range, typically greater than or equal to 4ngl/ml, they receive a second letter by post urging them to seek further medical follow-up.¹² All men may call, via a toll-free number, either the NPCC or its notification partner, the Dattoli Cancer Foundation, for a better explanation of their screening results or to answer questions about prostate cancer. NPCC also maintains a web site with links to educational and informational material for those men with access to the Internet.

DAPC’s soul is the awareness and outreach work that extends before, during and after the event. NPCC’s growing expertise in male screening event management is crucial to the maintenance of an enduring awareness message and changes in male health behavior.

Several weeks before the vehicle is to make a stop in any given city, an outreach campaign begins. The NPCC utilizes its partnerships with many ethnic, religious, and fraternity based organizations across the country as a means for engaging at-risk and underserved communities. Organizations such as the Veterans of Foreign Wars, Church of God and Christ, the 100 Black Men of America and the National Medical Association are a few of the national organizations that have numerous local chapters that NPCC accesses for volunteers and for support of the screening event. Community volunteers post bulletins in local churches, veterans’ halls and medical centers as well as notifying neighbors and engaging local leadership.

The NPCC calls into action other partnerships it has with cancer based organizations like the American Cancer Society and US Too! International (a prostate cancer survivor support group) to recruit volunteers to staff the vehicle, to assist patients with paperwork and to answer basic questions about prostate cancer or men’s health. Prostate cancer survivors are particularly effective at communicating the NPCC’s message because prospective patients realize that the prostate cancer survivor who is staffing the vehicle really isn’t much different from themselves. Survivors at the vehicle help to disabuse untested men of the notion that prostate cancer can’t happen to them.

¹² Vashi AR, Oesterling JE, Percent free prostate-specific antigen: entering a new era in the detection of prostate cancer. *Mayo Clin Proc* 72: 337-44. 1997.

The media is constantly looking for something out of the ordinary to report to the public – a large purple and white recreational vehicle that screens for prostate cancer falls into that niche. Media outreach is not only a major key in letting many know that free screenings are available, it serves as a reminder to those who can not make it to the screenings to make a doctor's appointment on their own. And for those who know very little about the risks of prostate cancer, the stories appear to relay at least one or two facts about how serious the threat of the disease is to themselves or someone who is close to them.

While there are many mobile medical units screening for breast cancer in the United States, television stations key in on the story of the first mobile medical unit built just for men and a disease that is very common and far too often overlooked. DAPC is a positive story for the evening news. Often news crews will pick one man and follow him through most of the screening process to illustrate the ease with which a man may be screened. Ideally, *The Drive Against Prostate Cancer* screens for multiple days in a city which allows the public to witness the vehicle in action with the message that "it's not too late for your free screenings, testing is available tomorrow as well."

Wives, children and other family members tend to see the segment on the evening news and alert the over 40 man in their life about the free screenings. They start asking questions like: When's the last time you were at the doctor? And did you know it's free? Did you know it takes 10 minutes and they're giving away free golf caps? Prepared with information that deposes common excuses, family members are able to begin to breakdown the anxiety barrier and persuade men to get a quick and confidential screening with little to no wait.

When possible, NPCC likes to employ celebrities at screening events. Celebrities not only draw people to the event, they help to legitimize the issue. The breast cancer movement benefited in the 1970s from First Lady Betty Ford's public announcement that she was being treated for breast cancer. Mrs. Ford's leadership on the issue made it "OK" to be tested for breast cancer and her courage started to strip away the shame of having breast cancer. In 1999, then New York City Mayor Rudy Giuliani and Joe Torre, manager of the New York Yankees were diagnosed with prostate cancer within three months of each other. The news catapulted the issue forward and made many people take notice of the disease. In New York City every June there are now citywide prostate cancer screening initiatives and prostate cancer specific events.

Even those celebrities who do not have prostate cancer play a role in spreading the message – especially when it comes to minority communities in cities where racial barriers exist. In May of 2002, the NPCC worked with singer and songwriter Lou Rawls in bringing *The Drive Against Prostate Cancer* vehicle to the Las Vegas Black Expo. Before performing that night, Mr. Rawls was screened on the vehicle, signed autographs and genuinely talked about the importance of prostate cancer screening in the African American community. Mr.

Rawls not only legitimized the activity and drew more participants; he helped the men deal with their own anxiety by talking openly about his.

Outreach to minority communities is essential because awareness and education about the disease is lacking in many areas. Cities with diverse populations need specially tailored, culturally sensitive press materials. NPCC is equipped with information in several different languages. Volunteer interpreters are recruited from the community to help overcome language barriers and to speak to ethnic media outlets.

Listings and preview stories in the local Korean or Chinese newspaper, for example, makes a large impact on attendance. Many times, members of a minority community in a city use the ethnic paper as the main source for local newsgathering. A posting in one of the local non-English newspapers is virtually guaranteed reading by nearly every member of that community. Proof of this is seen in cities like Houston, Texas where NPCC screened several hundred Hispanic males over four days – the majority citing Hispanic radio stations and weekly newspapers as the source of the screening information.

Political outreach is another key component of event preparation. All local executive officials are notified of the screening and the mayor is always invited to participate. An area's federal legislators, the Congressperson and both Senators, are also notified about the screening event and are invited to attend. These invitations not only help to secure support for the event, but the participation by local and federal leaders helps to increase media coverage and patient participation as well as giving NPCC an opportunity to educate influential leaders about the importance of prostate cancer early detection and the need to find a cure for the disease.

During the event, NPCC is able to educate those patients that are participating as well as updating the doctors and phlebotomists performing the screening. Without a wait, the average screening takes approximately twenty minutes. A portion of that time is spent reading and completing the consent forms. The consent forms cover the legal issues involved with screening and they educate participants about the two diagnostic tests that are available. After completing the intake forms, it takes approximately five minutes to draw a blood sample for the PSA test and another few minutes for the physical exam or DRE. Every patient has the opportunity to spend at least 12 minutes with the doctor though few men take advantage of this extended one-on-one time. On the way out, sponsors often provide free merchandise to the men such as health bars and golf caps. NPCC also generally provides fruit juices, water and fruit or other healthy snacks.

While a man is waiting to have his blood drawn, he has the opportunity to use the two on-board notebook computers to do two things on the Internet. The first opportunity is to send an electronic letter to his Congressional representatives.

Using a web-based communications system, men are able to send either a letter template or compose their own letter to Congress about the need for more prostate cancer research funding. Surfing the Internet for more prostate cancer materials is the second opportunity. Internet access is made possible through a newly installed self-acquiring satellite dish. This dish gives broadband access to the Internet so long as there is access to the southern sky.

Several forces work together to extend the amount of time that participants spend with the vehicle. First, a table laden with educational and awareness materials is set up outside of the vehicle. Many men use browsing the table as a precursor to participating in the screening. Knowledgeable prostate cancer survivors are also available to talk to the men about all aspects of life with the disease. As a crowd builds, wait times increase giving men more time to talk with each other and with vehicle personnel. Another effect of crowd building is that a locker room or club mentality begins to assert itself. Screening inhibitions and anxieties are lessened by a sense of "we are all in this together." Taken with a group, screening is not such terrible medicine.

As men board the vehicle, they are able to watch and listen to the familiar rhythms of televised sporting events. At this point the men are relaxed and ready to learn from both the doctors and the phlebotomists about the tests, the disease and how better to take care of themselves. While few men would say that prostate cancer screening is a pleasurable experience, the atmosphere of the event substantially reduces the amount of anxiety. Data from two screenings in Chicago, Illinois partially describes the tremendous importance of atmosphere.

In a two day period, NPCC screened more than 600 men for prostate cancer. The events occurred in two separate locations, one in an affluent area and another in an under-served area. During the period of the screenings only two men refused the DRE. Traditional thinking about prostate cancer screening says men don't get screened because of the cultural implications of the DRE. This school of thought also argues that only PSA testing should be carried out because a partial screen is still better than no screen at all. NPCC's data clearly indicates that men will participate in a complete prostate cancer screening if the situation is appropriate.

Screening location is another factor that affects program success. NPCC attempts to pick locations that have large numbers of pedestrians or that have built in event populations such as sporting events. In San Jose, California screenings were mistimed such that screening hours inadvertently failed to mesh with the schedules of the target audience. The largely Hispanic population of farm workers could not attend a screening that started three hours after their own work day began and ended less than an hour after they finished work. The lesson was learned too late to alter the schedule. Timing is now as critical an element as location.

After a screening is completed NPCC maintains contact with its new network through a variety of means. All participants in the program receive a letter by post notifying them of the results of their PSA test. Aboard the vehicle, doctors discuss the results of the digital rectal exam immediately with the patient, advising him on related medical issues, and making referrals to other doctors for specialized questions. It is not uncommon for the doctor to direct the patient to seek immediate care for another apparent existing medical problem. The news media is often contacted with aggregate outcomes of the screening – the number of men screened and the number of high PSA's. This information often results in a follow-up story on television or in the newspaper about prostate cancer. Event sponsors receive a detailed post-event synopsis and those patients that request more information are sent materials. Many participants elect to take NPCC's twice-weekly email newsletter in order to keep abreast of the latest developments in the field of prostate cancer. Also, those participants that want to become advocates are put in contact with local organizations that share their passion for finding a cure for the disease. In some instances, DAPC participants are referred to local and state prostate cancer coalitions. Overall, NPCC attempts to provide an enduring message that begins before DAPC arrives and survives long after DAPC has left.

Mobile prostate cancer screening has far exceeded NPCC's expectations for delivering awareness of prostate cancer. The program has been instrumental in helping us engage national organizations such as the Vietnam Veterans of America, The American Legion and the Church of God in Christ. As an outreach tool, the program is unrivaled. Men now actively seek out the NPCC to learn how they can either bring the vehicle to their area or establish a local screening program. The 65 million media impressions are staggering considering that it was a commonly held belief in the prostate cancer community, just two years ago, that the majority of American men did not even know they had a prostate, let alone that it could be cancerous. NPCC's message is hitting home.

DAPC must continue to improve. A conservative estimate gives the program approximately three years before the general population becomes inured to the concept of screening in its current format and the media is unwilling to cover the program's activities. Hopefully, adding new medical technologies such as portable body scans and telemedicine to the vehicle will make it possible to offer a complete physical to men with a consultation via the Internet with top healthcare professionals. The goal is to provide more and better healthcare and in order to do so, the program must be committed to pursuing the most-effective and cutting-edge diagnostic tools. A sustained effort with an evolving program should provide NPCC with the ultimate goal, a substantial advocacy network that can change government policies and insure that everything possible is done to find a cure for prostate cancer. It would be nice at the end of three years to convert the vehicle for another use because a cure for prostate cancer has been found.