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¹ Using CBPR to Extend Prostate Cancer Education, Counseling and Screening Opportunities to Urban-Dwelling African Americans

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Background

Prostate cancer has a profound effect on the African-American community. African-American men have a higher lifetime risk for developing prostate cancer, develop the disease at earlier ages in life, and die from prostate cancer at more than twice the rate of white men [1, 2]. Although much remains unknown about the natural history of prostate cancer and professional organizations disagree on screening recommendations for the general population, there is consensus among medical and public health professionals that screening can be particularly useful for men in high risk groups such as African Americans [1, 3].

Cancer prevention and control experts agree that prostate cancer screening should not be offered to men who are not equipped to make informed decisions. Typically, men develop the capacity to make informed screening decisions after they have been exposed to and process information about a host of issues including what is currently known and unknown about the disease, the limitations and advantages of the two gold standard screening procedures (prostate specific antigen [PSA] blood test and digital rectal examination [DRE]), and the sequelae of diagnostic and treatment procedures that will have to be considered in the event that screening results are abnormal [1, 2]. Men who are contemplating screening are also encouraged to have screening discussions with a physician to ensure they understand the role of individualized risks and benefits.

The literature is quite clear that prostate cancer screening does not occur in a vacuum. A variety of patient (e.g., knowledge, risk perception), provider (e.g., communication about screening), and practice level (e.g., hours of operation) factors interact to facilitate or restrict

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access to screening opportunities [4,5]. Given that several aspects of the prostate cancer screening process involves interaction with a health care provider, men who are underinsured, uninsured, or have lower socioeconomic status (SES) are more likely to encounter obstacles when trying to undergo screening. In an effort to minimize the accumulation of disadvantages experienced by these men, the authors of this publication sought to build an infrastructure within a community to link urban-dwelling, African-American men with integrated prostate cancer education, physician counseling, and screening opportunities. The activities reported here were based on the principles of community-based participatory research (CBPR).

Community-Based Participatory Research (CBPR)

It is well recognized that health promotion activities developed with target population input are more culturally appropriate and better received than those that are developed without target population involvement [6, 7]. Over the past 20 years, public health practitioners working on health disparities issues have increasingly used a community-based participatory research (CBPR) approach to develop culturally appropriate solutions for local health problems that impact medically underserved populations [8,9]. CBPR differs from other program development approaches in that members of the community being served are involved in all aspects of a project from inception to the dissemination of program results. Principles such as partnership, co-learning, capacity building and sustainability of projects are central when using a CBPR approach. The way that CBPR principles are operationalized depends on many factors including the target community, the target health issue and the community context [8–11]. There are many examples of how CBPR has been useful for generating culturally specific solutions for a variety of different health issues affecting African Americans [12, 13]. However, few examples exist in the literature on how the CBPR approach can be applied to address prostate cancer control issues among African-American men [14–17].

Context

The site of this community-based participatory project was the city of Buffalo, located in Erie County, New York. Erie County is the 8th most populous county in the state of New York, and Buffalo is the largest city in the county. African Americans comprise more than a third (38.6%) of the city's population. The proportion of Buffalonians who live below the federal poverty line is more than twice that of the state (38.6 vs. 15.3%, respectively) [18]. The prostate cancer mortality rate for African Americans (45.3/100,000) in Erie County is 2.3 times higher than the rate for Whites (19.4/100,000) [19]. Currently, Erie County residents who are uninsured or underinsured can receive subsidized breast, colorectal and cervical cancer screening through the county department of health. However, no such programs currently exist for medically underserved men who want to be screened for prostate cancer.

Town and Gown Partnership

Community participation throughout a project's lifespan is critical when using a CBPR approach. From the outset of this initiative, several community and academic partners worked collaboratively to plan an integrated prostate cancer education and screening opportunity. Academic partners included: a physician researcher, a urology nurse, a cancer health educator and two outreach specialists from a cancer hospital. Community partners included two health educators from a local safety net hospital, an outreach specialist from the local American Cancer Society, representatives from several African American churches and eight founding members from a local community-based prostate cancer advocacy group—**Minorities Allied for the Need to Understand Prostate cancer (MAN UP)** (Figure 1).

The **MAN UP** prostate cancer advocacy group is a volunteer, grass-roots organization that is focused on reducing the burden of cancer among men in Western New York (WNY). The men of **MAN UP** initially came together while working on a community advisory board (CAB) in 2006 to help provide community informed outreach strategies for a newly formed unit at a local hospital. After two years of working as community advisors, the men became more sophisticated in their knowledge of cancer disparities and began organizing their own outreach activities to educate men in the community. **MAN UP** was officially formed in 2008. The men of **MAN UP** are influential members of the community with strong community ties. At the time this publication was started, **MAN UP** members included a former NFL player, a local businessman, three retired educators, a professional actor, a community activist, and a retired law enforcement official. These men have a variety of personal experiences with prostate cancer that mirror those found in the general population (Table 1). While all of the founding members of **MAN UP** were African American or Latino, current **MAN UP** membership is more racially diverse and includes white men. To reflect the broader membership of the group, the word “**Minorities**” in the **MAN UP** acronym has been replaced with the word “**Men**.” **MAN UP** is still operational and has received a 501 (c) (3) tax-exempt, non-profit designation in 2014.

Needs Assessment (Pre-Event Planning)

Early in the partnership, community and academic partners devoted a great deal of time to information sharing sessions to better understand the prostate cancer problems experienced by men of color in the city. Academic partners helped community partners better understand secondary data, interpret findings from news reports and published research studies, and reconcile seemingly contradictory positions on screening that were publicly supported by different professional organizations. Community partners informed academic partners by providing an end-user's perspective on screening issues and insights into reasons why prior community-based screening initiatives succeeded or failed. After triangulating the information produced through this initial co-learning process, the partners agreed that there were a multitude of prostate cancer-related issues that could be dealt with and that their programmatic priorities would be best established after assessing the needs of local community members.

During the winter of 2010, the partners used a participatory approach to develop a survey to rapidly assess local cancer needs. The partners' efforts produced a 20-item survey that allowed for the collection of demographic information, information on cancer history, cancer screening behavior, prostate cancer knowledge and perceptions of gaps in cancer services within the community. During the planning process for administering the survey, **MAN UP** members recommended that a strategy be used in which survey information could be obtained while still servicing the community. The **MAN UP** advocates felt it was important for survey participants to be left with educational information that could be reviewed repeatedly and/or shared with others. After brainstorming options that could support this recommendation, it was agreed that a tri-fold brochure with a third-panel perforated tear-off would be appropriate.

The brochure was designed so that prostate cancer education information was included on both sides of the first two panels and survey questions were included on the front and back sides of the third panel (the perforated tear off). Key points highlighted in the educational information included: (1) "What is the prostate?"; (2) "Where is the prostate located in the body?"; (3) "What is prostate cancer?"; (4) "How common is prostate cancer?"; (5) "What are prostate cancer risk factors?"; (6) "What are high-risk groups?"; (7) "What are prostate cancer symptoms?"; (8) "What is baseline testing?"; (9) "What should men consider before getting a baseline test?"; (10) "What should men do if their test screening test results suggest they need further testing?"; and (11) "What should men do if their screening test results suggest they do not need further testing at the moment?". The contents of the brochure were tailored from existing educational materials and the information was written at an 8th grade reading level.

After several rounds of revising the images, language and layout of information, the partners approved the brochure for production and several hundred copies were made. Next, the partners discussed where and when the brochures would be distributed. After considering the pros and cons of many potential venues and forecasting the partner's availability over the coming months, it was agreed that the brochures should be disseminated at an upcoming annual community event—a city-wide basketball tournament. Several of the academic and community partners had attended the tournament in the past and recounted that a large number of African-American men were always in attendance. The partners who were available volunteered to "work the event" in teams of two to three for shifts ranging from two to four hours. All teams included at least one academic partner and a community partner, and all team members were men. A comprehensive list of team members and their selected shifts was generated and disseminated to all partners a week before the event. Twenty-four to forty-eight hours before the tournament, an outreach specialist from the cancer hospital made phone calls to all event team members to confirm their availability or to make changes to the schedule as needed.

A tent-covered table and folding chairs served as the partner's point of contact with the community at the tournament. All team members were dressed casually wearing jeans and a black and white polo shirt that displayed the **MAN UP** logo. All partners used a convenient sampling, street intercept approach to engage participants who walked by, rested or gathered near the tent area. All men who completed a survey on the spot received a blue-plated

prostate cancer awareness pin and the opportunity to win a **MAN UP** t-shirt. While anyone who showed interest in completing a survey was allowed to do so, only survey results from men were considered for program planning purposes.

More than 400 brochures were disseminated and 82 completed surveys were returned by male participants. Information obtained from these surveys indicated that fewer African Americans had ever been screened for prostate cancer via the PSA blood test (46% African Americans vs. 55% Whites) or DRE (46% African Americans vs. 55% Whites). Survey results also indicated that African-American men had lower levels of knowledge about prostate cancer prevention and control than white men (6.21_{African Americans} vs. 7.50_{Whites}) [2]. Men who were surveyed also expressed a desire to have more prostate cancer prevention and control services made available in the community (47%) over other types of cancers such as breast (27%), colorectal (21%), and lung (31%).

The partners' views of the needs assessment process were captured at a follow-up debriefing meeting. The points of view expressed at this meeting revealed that everyone thought the needs assessment process was well-organized, efficient and collaborative. Partners also indicated they were comfortable with the roles they volunteered for during the needs assessment process.

Town and Gown Event Planning

Equipped with local data identifying the community's need and readiness for a prostate cancer education and screening event, the next phase in the process was to develop an event action plan. Throughout the entire action planning process, one of the male outreach specialists from the cancer hospital provided administrative support for the partners as part of his normal workload. In this administrative role, he was responsible for organizing all meetings, taking meeting minutes, disseminating meeting information, and coordinating all project-related communications. Depending on the tasks involved, administrative activities took between 4 – 10 hours per/week to complete.

Based on current best practices, the partners agreed that their event should focus on three outcomes for men 40 years of age and older who had not been diagnosed with prostate cancer. The outcomes were (1) receiving prostate cancer education, (2) participating in screening-related counseling with a physician, and (3) undergoing prostate cancer screening via PSA and DRE (if desired). Given that screening was to be a major event component and the partners did not have a collaborative history of doing clinical outreach, a fair amount of early action planning efforts were devoted to organizing clinical activities. Because the physician partner had the most clinical expertise and clinical connections, the partners unanimously agreed that he would be the event's clinical coordinator. In the clinical coordinator role, the physician obtained financial support to pay for up to 250 PSA tests and digital rectal examinations. He also obtained verbal commitments from clinical staff at his place of employment to volunteer to work the event. The partners agreed that the event

²Prostate cancer knowledge was assessed with 10 items using a true/false response option. One point was provided for each correct response. The range of knowledge scores was 0 – 10.

should be held on a Saturday morning in September to coincide with Prostate Cancer Awareness Month. Saturday morning was selected to maximize opportunities for working-class men to participate.

With an event date established and clinical resources secured, the partners then met to select a venue and develop event promotion strategies. This work was done by several small working groups comprised of members from the larger planning committee (Figure 1). Although both hospitals had the clinical capacity to host the event, many committee members viewed them as less than ideal locations because they were not easily accessible by public transportation and they were viewed as places where sick people went for treatment. Since this was supposed to be a health promotion event, many of the community partners thought that a neutral location should be selected. To accommodate this request, one of the working groups took the lead on securing a community venue that could be repurposed into a “make-shift clinic.” The working group identified a high school that was large enough to ensure privacy, easily accessible by public transportation, had adequate parking for privately owned vehicles, and was well-known in the African-American community. The partners agreed that the event should be promoted using flyers, church bulletins, African American focused media outlets, and word-of-mouth.

Venue Set-Up and Event Progression

One month before the event, the partners did a walk-through of the school to design the “make-shift clinic” and to determine how men would advance through event components (event flow). After viewing the space that was available to them, the partners decided there would be four checkpoints. Checkpoint one was prescreening education, check-in and registration. Checkpoint two was the PSA blood test. Checkpoint three was the DRE exam. Checkpoint four was check-out and event completion (Figure 2).

The event was arranged so that participants would advance through all four checkpoints in the prescribed manner. Checkpoint one (prescreening education, check-in, registration) was setup inside of the building near the entrance and was staffed by three volunteers. Event crew members staffing this checkpoint were responsible for verifying participant interest and determining their eligibility (i.e., 40+ years, no previous prostate cancer diagnosis). At this first checkpoint, eligible men who expressed an interest in being screened were given a prepackaged envelope containing: pre-screening educational information, a placard with a listing of the event’s checkpoint sequence and a brief description of checkpoint activities, clinical forms for recording DRE and PSA test information, and adhesive name labels. After being checked-in, men were directed to checkpoint two for the PSA blood test.

Checkpoint two was located in a large science lab on the second floor of the building. This room had more than 20 desks and was staffed by four phlebotomists. Men who wanted to have the PSA test gave their prepackaged envelopes to a phlebotomist who verified their identities and drew their blood. After the blood draw was complete, participants were ushered into a holding area where they waited to be called into checkpoint three (the digital rectal examination room). The waiting area was connected to the PSA testing room and was staffed by several outreach specialists and men from **MAN UP**. The waiting area had

additional print and audio-visual resources for men to read and view. This area also had healthy snacks and juice for men to consume while they waited. Waiting times in this area averaged between 10 – 15 minutes. While waiting, men talked with each other, talked with event staff or reviewed educational material.

Checkpoint three (DRE) was located in two small offices equipped with portable exam tables. A small private bathroom was located in one of the “exam rooms” and a larger community bathroom was located next to the second “exam room” to allow men easy access to resources to clean-up after the DRE, if required. Each exam room was staffed by a urologist. A urology nurse floated between the two rooms and provided assistance as needed.

Checkpoint four (check-out and event completion) was located in a hall near the stairwell between the two exam rooms. This checkpoint was staffed by **MAN UP** members and other event staff. After going through all four checkpoints, men had the opportunity to receive two complimentary tickets to the local zoo and a free parking pass. While it was necessary for men to go through all four checkpoints, men did not have to complete all checkpoint activities to be eligible for zoo passes.

Outcomes

The entire screening event lasted three hours from 8:00AM – 11:00AM. A total of 55 men from 16 zip codes attended the event. All 55 attendees received free prostate cancer education, and 35 (63%) chose to undergo screening. The reasons men provided for not being screened included: (1) they had been screened in the past 12 months, (2) they didn’t have time to do it right now, (3) they didn’t feel that screening was right for them at the moment, or (4) they were just stopping by the event to see what was happening.

Of the 35 men who were screened, the majority ($29/35 = 83\%$) were African American. Many of those screened ($16/35=46\%$) attended the event with a “buddy” (male family member, co-worker or friend). Nearly all of those screened ($34/35 = 97\%$) received both a PSA test and a DRE. One man received the PSA but decided to forgo the DRE because he felt uncomfortable having the physical exam in that particular setting. Event planners were pleased that nearly three-fourths of those screened ($26/35 = 74\%$) were first time screeners. All event attendees ($55/55 = 100\%$), even those who elected not to screen, had an informed screening discussion with one of the attending urologists. All participants were mailed their screening results within two weeks, along with personalized instructions for following up with their primary care physician.

Lessons Learned

This paper described a collaborative process for developing an infrastructure with a community to link inner-city, African-American men to free prostate cancer education, physician counseling and PSA/DRE screening opportunities. The academic and community partners on this community outreach initiative worked collaboratively to contextualize a local public health issue and coordinate shared resources to develop and implement a culturally-acceptable outreach program. The education and screening event attracted a

diverse population, both first-time and repeat screeners attended. While the program was viewed as a success, the partners learned some lessons that might be helpful for others who seek to develop similar initiatives.

Clarity of eligibility requirements is essential when designing recruitment materials. This outreach program was intended to help community residents learn their prostate cancer status by giving them access to free prostate cancer screening services. The intended population was men who had not already been diagnosed with prostate cancer. However, several prostate cancer survivors who had already completed treatment or were actively monitoring their disease attended the event to get their PSA test done for free. While only a handful of survivors showed up for a free PSA test, these men created a slight backlog at the registration checkpoint because registration staff wanted to accommodate them but did not have a process in place for men fitting this category. All survivors who wanted a PSA test were accommodated at this event because we did not exceed our event quota of 250 tests. However, resources may not always allow this to happen. To prevent any potential uncomfortable situations from occurring, we recommend that recruitment materials clearly specify who is eligible and who is not. As always, when developing inclusion and exclusion messages, we recommend that they be pretested with the target audience members for clarity and appropriateness.

Event activities should be streamlined to allow participants to enter, participate, and depart quickly. It is important to remember that any given community event is just one of the many activities that men will probably be doing that day. While some men might want to use this opportunity to fellowship, most will want to get in and get out quickly. Having event steps displayed is one way to reassure participants that event activities are organized and will not take up too much of their time. Having single-page, data collection forms also inspires confidence that the event will not be too time consuming. Because the desired outcome is to ultimately serve the community, coordinators should avoid overwhelming participants with requests for large amounts of data. Community events are attractive to participants especially when they are viewed as being inexpensive, efficient, and convenient.

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Figure 1.
Community-Academic Partnership

Figure 2.
Event Flow Chart.

Table 1

MAN UP Member Information

MAN UP Member Title	Gender	Race/Ethnicity	Profession	Prostate Cancer Status
Prostate Cancer Educator & Advocate	Male	African American	Retired NFL Player	<ul style="list-style-type: none"> Elevated PSA Three negative prostate biopsies
Prostate Cancer Educator & Advocate	Male	African American	Local Businessman	<ul style="list-style-type: none"> Prostate cancer survivor Treated via radiotherapy
Prostate Cancer Educator & Advocate	Male	African American	Retired Middle School Principal	<ul style="list-style-type: none"> Not directly affected by prostate cancer
Prostate Cancer Educator & Advocate	Male	Latino	Retired Law Enforcement Official	<ul style="list-style-type: none"> Prostate cancer survivor
Prostate Cancer Educator & Advocate	Male	African American	Professional Actor	<ul style="list-style-type: none"> Prostate cancer survivor Treated via robotic surgery
Prostate Cancer Educator & Advocate	Male	African American	Community Activist	<ul style="list-style-type: none"> Family history of multiple types of cancers
Prostate Cancer Educator & Advocate	Male	African American	Retired Educator	<ul style="list-style-type: none"> Multiple cancer survivor