



BLACK MEN'S PROSTATE CANCER PREVENTION PROJECT



Prostate Cancer Prevention (PCaP), Early Detection and Treatment Decision-Making

A Community Decision-Making Toolkit User Manual

Research Development and Design
V. Diane Woods, Dr.P.H., M.S.N.
African American Health Institute of San Bernardino County



PCaP Toolkit®

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Disclaimer: Blacks and African Americans are terms used interchangeably because people continue to refer to themselves in that manner. They are terms used to represent people of African ancestry.

A Welcome Letter To Men of African Ancestry



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Thank you for taking the time to open this toolkit User Manual. When it comes to prostate cancer prevention, early detection and proper treatment decision-making, we believe you will find in this *PCaP Toolkit*® has the tools you need to help save your life.

How was this *PCaP Toolkit*® created? Men of African ancestry, which included African Americans, Centennial Africans, Afro-Caribbean, Afro-Latinos, and African any other nationality, living in San Bernardino, Riverside and Los Angeles Counties of Southern California participated in a prostate cancer prevention research study with Dr. Susanne B. Montgomery, Dr. V. Diane Woods and their colleagues from Loma Linda University School of Public Health. The aim of the research was to better understand from our perspective why we think Blacks continue to die prematurely from prostate cancer. Also, we were asked what do we think needs to be done to stop this crisis. We started participating in the research study in 2001.

Outcomes of the study indicated that complex reasons consistently emerged related to social issues, physician/patient interaction, prevention education, the health system, and personal health choices that affect our poor prostate health outcomes. After discussions in focus groups and completing a comprehensive questionnaire, we identified one major problem. Almost all men reported they did not have information about prostate cancer prevention and treatment shared with them in a way that made sense. So, we reviewed the information that was available at that time, and decided to create the *PCaP Toolkit*® with information that was meaningful and simple to understand. We believe we have assembled the right tools for any man to understand the issues related to prostate cancer prevention, early detection and treatment options.

What can you expect from the *PCaP Toolkit*®?

First, the User Manual has four sections. Each one is written in simple easy to understand language. Second, it has pictures so you can see the prostate gland and see what happens when it has problems. The toolkit is packed with life size models so you can see the prostate gland, and see what happens when there are problems. Third, the toolkit contains information about how to keep the prostate gland healthy. Fourth, it explains the prostate exams, what the results mean, and what you need to know about treatments. When you finish with this decision-making User Manual you will be able to have an intelligent discussion with your doctor about prostate cancer issues. What is different about this toolkit? It's simple. It makes sense. We promise. Take your time. Use these tools and experience the difference.

Listen, learn, and live. The life you save may be your own.

Your Brothers in Southern California

PCaP Toolkit® *Affiliates*

The *PCaP Toolkit*® was made possible because of input from many individuals over nearly a 10 year long research project. The community-based project started in 2001 with a cohort of 276 men of African ancestry in San Bernardino County, California. Cohort participant affiliates are listed below.



Participant Organizational Affiliations

Mt. Olive Lodge #71

Saint Andrews Masonic Lodge #16

Prince Hall Masonic Lodge #17

American Legion #710

Arrowhead Elks Lodge #896

High Desert Masonic Lodge #107

J W Vines Medical Society and Foundation (affiliate of NMA)

Inland Empire Concerned African American Churches (IECAAC)

Victor Valley African American Chamber of Commerce (VVAACC)

Phi Beta Sigma Fraternity

Kappa Alpha Psi Fraternity

Men of African Descent (MOAD)

Westside Action Group (WAG)

African American Health Institute of San Bernardino County (AAHI-SBC)

Academic Affiliations



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Loma Linda University (LLU) School of Public Health (SPH)

Susanne B. Montgomery, Ph.D., M.P.H., Director (2001-2007)
Center for Health Research & Evaluation Research Unit (ERU)

Stuart M. Belle, MPH, Project Manager, ERU (2001-2004)

J. Jacob Nortey, Ph.D. Candidate, Graduate Research Assistant, ERU (2001-2003)

V. Diane Woods, Dr.P.H. Candidate, Graduate Research Assistant, ERU (2001-2005)

LLU School of Medicine

Center for Health Disparities Research and Molecular Medicine

Susanne B. Montgomery, Ph.D., M.P.H., Co-Principle Investigator (2005-2007)

V. Diane Woods, Dr.P.H., Co-Investigator (2005-2007)

SPH Graduate Research Assistants (2005-2007)

Clara Omogbai, Dr.P.H. Student

Maria De Borba-Silva, Dr.P.H. Student

Scholastique Nikuze, M.P.H. Student

Patricia Green-Lee, Community Research Assistant

Summer Student Interns (2006)

Lerone Allen

Courtney Young

Community Affiliations



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African American Health Institute of San Bernardino County (AAHI-SBC)

Olivia Swift-Ford, M.H.A., RN, Chair, Cancer Committee
Alton Garret, M.P.A., Co-Chair, Cancer Committee

Toolkit Research Development and Design

V. Diane Woods, Dr.P.H., M.S.N., RN, Principle Investigator
AAHI-SBC Founding President and CEO

AAHI-SBC Graduate Interns

Scholastique Nikuze, M.P.H. Student (2007)
Eryn Young, M.P.H. Student (2008)
Nacole Smith, M.P.H. Student (2008-2010)

San Bernardino County, Department of Public Health

Disep Obuge Ojukwu, MPH, Statistician

Institutional Partnerships (2005-2007)

California Division of the American Cancer Society, Atlanta, GA
Jerry E. Pettis Memorial Veterans Administration Medical Center, Loma Linda, CA
Loma Linda University Medical Center, Loma Linda, CA
Arrowhead Regional Medical Center, Colton, CA

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#U36/CCU300430-22 & S1391-20/21 (2001-2004)

NIH P-20 EXPORT Grant #5 P20 MD001632-02, LLU Center for Health Disparities Research
& Molecular Medicine (2005-2008)

LLU Center for Health Research Grant #0883-SUB (2006-2007)

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The California Wellness Foundation Grant #2007-226 (2009)

Kaiser Foundation, Fontana Medical Center Grant #20609208 (2009-2010)

Introduction



According to the Centers for Disease Control and Prevention (CDC, 2010), prostate cancer is made up of normal cells that do not grow normally. The cells divide and create new cells that the body does not need, forming a mass of tissue called a tumor. These abnormal cells sometimes spread to other parts of the body, multiply, and cause death. Prostate cancer is the second **most common cancer** in American men (skin is #1). In 2009, an estimated 27,130 cases of prostate cancer occurred in African American men, accounting for 34% of all cancer diagnosed in African American men (American Cancer Society (ACS), *Cancer Facts & Figures for African Americans 2009-2010*, 2009).

Research indicates that African Americans bear a heavy burden of cancer. African Americans have the highest death rate of any racial/ethnic group for all cancers combined and for most major cancers. The ACS reports that **prostate cancer is the second leading cause of cancer deaths in American men** (lung is #1).

Experts at the American Institute for Cancer Research (AICR, 2008), National Cancer Institute (NCI, 2008), American Urology Association (AUA, 2008), ACS, CDC, and the National Institutes of Health (NIH) also document that across all racial/ethnic groups, *African American men* have the **highest risk** of dying from prostate cancer, they have the **highest death rate in the WORLD from prostate cancer**, their increased risk begins at earlier ages, and African American men die 2.4 times greater than White men.

Research demonstrates that nationally African American men are less likely to participate in prostate cancer screening. Currently, there are several studies underway to determine the most effective strategies to reach and educate American men of African ancestry about prostate cancer screening. Peer-navigation is one of the strategies. A peer-navigator is a person that is similar to another person in age, background, culture, and other factors, and works with that person to assist in negotiating a specific course of action. Other strategies include outreach at barbershops, male social clubs, churches, sports events, and different media outlets.

How is the *PCaP Toolkit*® different? The difference is content, time and delivery. The toolkit can be used in group meetings, at home with your family and loved ones, or take it to the office to help education others about this critical issue. It's simple. The information is easy to understand. Over 500 Black men had input in creating this toolkit, and the tools work. Use your tools.

Now let's get going. We can tackle this problem and WIN!

PCaP Toolkit® Learning Objectives



After using this PCaP Toolkit® men of African ancestry will be able:

1. To bring about and sustain long-term behaviors towards promoting prostate health
2. To decrease the amount of personal time it takes to make a decision to go in for a prostate exam
3. To decrease the occurrence of late stage prostate cancer diagnosis by taking action to regularly check the prostate to increase early detection
4. To change behavior patterns, increase participation in prevention activities, and increase personal decision-making toward prostate cancer prevention, screening and early detection