HANDBOOK FOR PROSTATE CANCER ADVOCACY

Principles & Best Practices

Edited By

Folakemi Odedina, PhD

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Handbook for Prostate Cancer Advocacy: Principles & Best Practices

Editor:

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The Prostate Cancer
Closing the Gap
Transatlantic Consortium

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Foreword

According to the World Health Organization, advocacy is the "*effort to influence people, primarily decision-makers, to create change, which in the context of cancer control results in comprehensive policies and effective program implementation, through various forms of persuasive communication*." Making available sensitive and specific cancer screening programs and effective cancer treatments will not work alone. Active cancer advocacy is necessary to turn the tide on the prostate cancer crisis and make prostate cancer issues a high priority in Black communities globally. In line with our research interests in addressing the epidemic of prostate cancer in Black men, the Prostate Cancer Transatlantic Consortium (CaPTC) has collaborated with several cancer advocacy organizations to develop this Handbook. Since 2010, the prostate cancer advocacy movement spearheaded by our team has grown significantly with multiple achievements, including training workshops in several countries, public and scientific disseminations, and the development of a global network to facilitate sharing of resources globally.

Our goal to make prostate cancer a top priority for people of African ancestry can be achieved by increasing the manpower for prostate cancer advocacy and strengthening the network of prostate cancer advocates globally. Thus, the need to publish the **Handbook for Prostate Cancer Advocacy.** With this Handbook as a foundation for our training programs, we plan to train prostate cancer advocates who will be empowered to engage their communities, develop, and implement cancer health and survivorship programs. Utilizing an innovative framework for our training activities, we will provide the skills to: (1) mobilize resources globally for health promotion, prevention, and survivorship strategies; (2) partner with key stakeholders to accomplish targeted objectives; (3) raise funds to support advocacy activities; (4) develop and successfully organize community-centered programs; and (5) foster a global network of prostate cancer advocates.

We have assembled a team of internationally renowned advocates to develop this Handbook. Although, primarily driven by the needs of prostate cancer advocates in the US, this Handbook aims to educate prostate cancer advocates within and outside the United States.

Thanks for joining our global fight against prostate cancer!

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Preface

Advocacy is an indispensable tool for those engaged or interested in cancer prevention, care, research and treatment. It provides opportunity to educate stakeholders and increase awareness of the disease, but also to mobilize resources to address issues related to prevention, care, research and treatment of cancer. To address the disparities in prostate cancer burden in the Black community requires a concerted effort to make the fight against cancer a high priority nationally and globally. This Handbook is a step in that direction.

The primary objectives of this Handbook are two-fold: to immerse the reader in advocacy in all its forms and to provide best practices of how advocacy has been used to advance the health and well-being of populations across the world. The emphasis of this Handbook is to equip you the reader with the knowledge to lead change in cancer care, prevention, research and treatment. The case studies provide real life application of the concepts covered in each chapter and allow for a deeper understanding and analysis of the issues covered.

Chapter 1 introduces prostate cancer while chapter 2 takes it further to paint a picture of the disparities in the burden of this disease among different populations. The third chapter offers a foundation in the understanding of advocacy. For those with no prior experience in advocacy, the first three chapters provide the building blocks on which the rest of the other chapters stand. The remaining chapters delve into different facets of advocacy such as education, support, community outreach, policy, research and fundraising. This Handbook also address communication and literacy issues in advocacy, public health considerations in advocacy and the importance of evaluating intervention programs to measure progress or the lack thereof.

We assembled leading experts with diverse backgrounds in prostate cancer care, control and/or advocacy to author chapters. You will find this Handbook a treasured tool for planning and engaging in cancer advocacy to create awareness, propose solutions and to change policies for the greater good of healthy communities. We must have a mind set to **Positively Stay Alive (PSA)** for the next generation.

Anthony C. “Tony” Hills, Sr.
Former State Senator, Florida.

Acknowledgements

We thank the men who participated in the Prostate Cancer Care and Survivorship (CaPCaS) study, which led to the development of this Handbook. We also thank the CaPCaS project Community Advisory Board chairs (Mr. Jim West, Dr. Angela Adams and Prince Oladapo Odedina) and all the CaPCaS project Community Advisory Board members for their effort throughout the CaPCaS project. Finally, we will like to recognize the effort of additional CaPCaS scientific team, especially the Co-Principal Investigator, Dr. Mary Ellen Young; the project Medical Director, Dr. Christopher Williams; and the primary interviewer, Mr. Kenneth Stokes.

The CaPCaS study was funded by the US Department of Defense PCRP Health Disparity Award # W81XWH1310473. In addition, weekly meeting support for this study was provided by the University of Florida (UF) MiCaRT Center. The MiCaRT Center is funded by the NIH/National Cancer Institute Award **#** 1P20CA192990-02.

About the Authors

Folakemi Odedina, PhD (Editor and Chapter 2) is Professor in the Colleges of Pharmacy and Medicine; and Director of Diversity and Inclusion for the UF CTSI Translational Workforce Development Program. She is also the Program Director of the NIH/NCI Florida MiCaRT Center; Director of the Research Core for the Florida Health Equity Research Institute (HERI); PI of the NCI EGRP Prostate Cancer Transatlantic Consortium (CaPTC); and founding chair of the Florida Prostate Cancer Health Disparity group. In 2009, her leadership in health disparities was recognized by the American Society of Health-Systems Pharmacy (ASHP) and the Association of Black Health-System Pharmacists (ABHP) when she was awarded the Inaugural (1st) Leadership Award for Health Disparities. Due to her extensive experience in prostate cancer disparity research, she was selected by the US Congressionally Directed Medical Research Programs to give the inaugural (1st) Dr. Barbara Terry-Koroma Health Disparity Legacy Lecture in 2013.

Dr. Odedina has a global consortium focused on understanding the burden of prostate cancer (CaP) disparities in Black men of West African ancestry, and developing tailored and targeted community-centered interventions to eliminate health disparities in minority populations. Her research traverses across the world with an international consortium group in the United States, Africa, Caribbean Islands, and Europe. Supported by funds from the NIH/National Cancer Institute (NCI) and Department of Defense, she is working with multiple investigators to develop a global bio-behavioral model of CaP risk factors in Black men. She has directed over 30 research projects. She is well published, has received numerous national and international awards for her work, and serves on several national and international cancer initiatives. Her landmark research on CaP disparities has been recognized by many organizations, including the American Association for Cancer Research (AACR) during the 2010 Cancer Disparities Conference and the DOD PCRP during the 2011 Innovative Minds in Prostate Cancer Today (IMPaCT) conference. Her work has also been featured in multiple medical news including the Medscape Medical News and Oncology News. Her international accomplishments includes leading the African Cancer Control Plan published by AORTIC, contributing to the preparation of the World Cancer Report 2013 by the World Health Organization (WHO) and authoring two chapters of a Handbook for Cancer Research in Africa being published by the WHO.

Brandon Otto, MD (Chapter 1) serves as an assistant professor in the department of urology at the University of Florida. He has a focus in the medical and surgical management of kidney stones, as well as laparoscopic and robotic surgery for the management of benign and malignant conditions of the prostate and kidney. He earned his medical degree at Weill Cornell Medical College in New York and completed his residency in urology at New York Presbyterian Hospital-Weill Cornell Medical College. He then pursued additional training in the endourology and minimally invasive surgery fellowship program at the University of Florida.

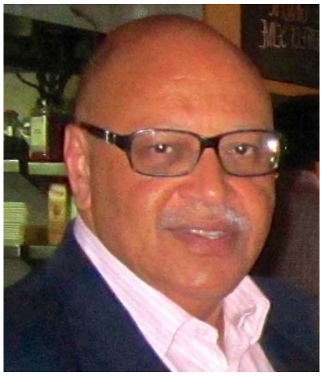
Lauren Rose Gilbert, PhD (Chapter 3 & Supplement) earned her doctoral degree in the Department of Sociology and Criminology & Law at the University of Florida, in addition to a Master's in Public Health Degree, concentrating on Public Health Management and Policy. Lauren is mentored by Dr. Folakemi Odedina, and has collaborated on a variety of projects, including: the predoctoral trainee on the Department of Defense (DoD) Grant PC121924 - "Development of a Model of Prostate Cancer Care and Survivorship for Black Men: A Grounded Theory Study of Ethnically Diverse Black Men"; an intern with the Florida Minority Cancer Research & Training (MiCaRT) Center; and working with the University of Florida Prostate Disease Center and the Alachua County Prostate Cancer Alliance to support local community efforts. Her dissertation work with black prostate cancer survivors seeks to better understand and support their experiences as advocates that empower their communities. As a sociologist, Lauren explores the social forces that shape the disease of prostate cancer; how black men and their support systems deal with prostate cancer; and how the diagnosis, treatment and recovery from prostate cancer can impact a man's identity.

Dr. Gilbert is currently an Assistant Research Scientist at the Wyoming Survey & Analysis Center (WYSAC) at the University of Wyoming. Her current health policy research focuses on program evaluation of community capacity within local substance abuse and suicide prevention systems in Wyoming.

Mary (Dicey) Jackson Scroggins, MA (Chapters 4 & 8), a 20-year ovarian cancer survivor and health activist, is a writer, producer, and founding partner in Pinkie Hugs, LLC—a mother-daughter writing and film production firm specializing in social justice-focused documentaries. She is also a co-founder of In My Sister's Care, an organization focused on improving gynecologic cancer awareness and care for medically underserved women and on eliminating health disparities. Her activism is driven by a commitment to improved awareness, access, care, survival, and survivorship and by a commitment to medical/health equity.

The recipient of the 2016 AACR Distinguished Public Service Award, Dicey is a Prostate Cancer Community Awareness Educator and a member of the Executive Committee for the "Globe-athon to End Women's Cancers," the Leadership Committee for MD Anderson Cancer Center's "Women's Cancer Moon Shots Program," the President's National Cancer Moonshot Blue Ribbon Panel Working Group on Precision Prevention and Early Detection, and NCI's Cancer Prevention and Control Central IRB and its Investigational Drug Steering Committee.

In keeping with her interest in global health, Dicey was a member of the Working Group to Facilitate International Cooperation on Non-Commercial Clinical Trials of the OECD, has visited hospitals and spent time in an HIV/AIDS collective in Kenya, planted trees on the Maasai Mara "for all cancer survivors," and visited a cervical cancer screening project housed in renovated freight containers in Khayelitsha—a South African township of perhaps half a million residents, most living in corrugated iron lean-tos. She has also participated in and provided training at African Organisation for Research and Training in Cancer biennial conferences since 2007 and has spoken internationally at meetings such as the 6th Clinical Trial Nurse Symposium in Tokyo in 2013. Through Pinkie Hugs, she and her daughter/partner Nneka are the official documentarians of the "Globe-athon," an international movement to spread gynecologic cancer awareness and save women's lives.



Virgil H. Simons, MPA (Chapters 5 & 9) is the Founder & President of The Prostate Net, a non-profit patient education and advocacy organization committed to providing credible and actionable information that will minimize the negative impact of prostate cancer. Using the experiences gained as a 20-year survivor of prostate cancer and advocate, he has built, over the past 18 years, an international organization that uses a matrix of informational and interventional techniques to address disease risk awareness, early disease interdiction and advanced stage disease management.

The Prostate Net has shown that it can provide an on-going conduit for information from the medical establishment into at risk communities not only relating to prostate cancer, but to the entire panoply of medical conditions disproportionately manifest within these communities, e.g. diabetes, cardiovascular disease, hypertension, etc. Because it has been proven that a shift is increasing toward electronic, broadcast and Internet-based media away from traditional printed vehicles, The Prostate Net, utilizing its vision for the future, is moving the thrust of consumer informational and patient educational vehicles into those formats most receptive for the target audience of men 50 and over with lower techno-literacy levels as well as preparing to embrace those younger men who grown up with more technological awareness, e.g. Website innovations, YouTube, PodCasts, Facebook and other social media, etc.

Mr. Simons has received several awards in recognition of his work on behalf of those affected by a diagnosis of prostate cancer including the **Cancer Leadership Award** from the American Association for Cancer Research, the **Catherine Logan Award for Service to Cancer Survivorship** from the National Coalition for Cancer Survivorship, and the **HOPE AWARD** of the Intercultural Cancer Council. Prior to his involvement in healthcare, he had an extensive career in the textile, financial services, international trade and retail markets as a senior executive and/or entrepreneur. He has completed course work for an MBA, and recently received a MPA degree concurrent with the public health mission of The Prostate Net.

Angela D. Adams, PharmD. MPH (Chapter 6) is the executive director for the Central Florida Pharmacy Council and currently, serves as the Community Engagement Core Director, Florida Health Equity Research Institute. Dr. Adams is a true community advocate. Her career as an advocate began while she was a pharmacy student at the University of Kentucky when she developed and implemented health education programs in a local church more than 30 years ago. She is a “Master Trainer/Mentor” for the AORTIC Cancer Advocacy Trainer Program during the Biennial Science of Global Prostate Cancer Disparities in Black Men Conference and an instructor and mentor for ReTOOL Prostate Cancer Advocacy Training Workshops.

As a Pharmacist, she has seen firsthand the health disparities that impact the community. Dr. Adams has a passion for decreasing health disparities experienced by Black men with an emphasis on prostate cancer. Since 1997, she has organized and hosted the Black Men’s Health Summit reaching more than 3,000 men annually. Dr. Adams founded the Health Outreach & Prevention (HOPE) Training Academy as a mechanism to provide a formal training program for community advocates. She also publishes an African American Health Directory for the Central Florida Area. Recognizing that health behaviors are develop prior to becoming an adult man she organized *Crossing Bridges: Hip Hop Teen Health*. This program addresses relevant health issues empowering teen boys to take control of their health.

A native of Kentucky she received her BS Degree in Pharmacy from the University of Kentucky, Masters of Public Health from the University of Alabama and PharmD from Xavier University-New Orleans. She currently is a Commander, Medical Service Corps in the United States Navy Reserves. She is the recipient of several honors and awards including Navy Reserve Pharmacist of the year, Martin Luther King Drum Major Community Service Award, Rosa Parks Community Service Award and Orange County Florida Citizen of the year.

Ernest Kaninjing, DrPH (Chapters 7 &11) is a postdoctoral associate with the University of Florida's Minority in Cancer Research Training (MiCaRT) center. He manages projects in the MiCaRT center and projects relating to the Prostate Cancer Transatlantic Consortium (CaPTC). In addition, Dr. Kaninjing is responsible for recruitment and management of the Florida Prostate Cancer Research Training Opportunity for Outstanding Leaders (ReTOOL) program. Prior to joining the University of Florida, he worked as a research associate for the Florida A&M University's Community Outreach and Preventive Services (COPS) program. Dr. Kaninjing earned his doctoral degree in Public Health from Florida A&M University. His dissertation work focused on factors that influence screening for prostate cancer among men in Bamenda, Cameroon. Dr. Kaninjing's research interest are in cancer disparities and community health outreach.

Anthony C. "Tony" Hills, Sr. (Preface & Chapter 7) formerly served as Federal Policy Director for Mayor Alvin Brown, the first African American Mayor elected to the office of Mayor in Jacksonville, FL. He is a Life Member of Omega Psi Phi Fraternity, Inc., (Theta Phi Chapter) and Chair of the NAACP Florida State Conference Labor Roundtable. Senator Hill currently holds two Honorary Doctorate of Law degrees, the first from Edward Waters College in 1995 and most recently from Bethune-Cookman University. In August 2012, he received a rare and prestigious honor and joined the ranks of a select group of men inducted into the historic Montford Point Marine Association Hall of Fame.

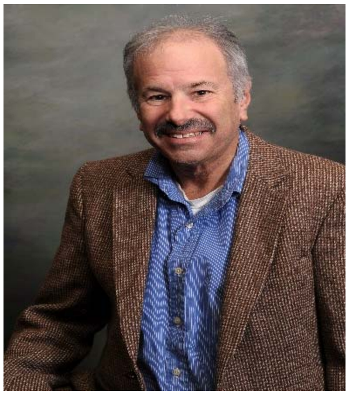
Long known for his advocacy of family and commitment to youth, in 2010 Senator Hill was elected to a three-year term on the Board of Directors of Neighbor to Family (NTF), a 501(c) (3) non-profit organization dedicated to foster placement for sibling groups. NTF's revolutionary national program offers an array of services designed to keep siblings together while building healthier families and stronger communities through a comprehensive set of programs supporting children's safety, permanency, stability and well-being.

A dedicated humanitarian and community advocate, Senator Hill sponsored a bill to create the first-ever State Capitol Civil Rights Hall of Fame, making Florida the first state in the nation's history to have such a Civil Rights Hall of Fame. In 2007, Senator Hill also sponsored legislation that would have mandated health insurance companies in Florida to cover preventive screening for prostate cancer among all men aged 40 or older in the state of Florida.

Recipient of the Lester Granger Award from the Montford Point Marine Association, Inc., in February 2010; the Public Official Award of The Year from the Children's Home Society in Jacksonville (March 2010); the U.S. Department of Transportation's National Highway Traffic Safety Public Service Award (April 2010). Honored by the Haitian Historical Society for his outstanding contributions (August 2009), the Humanitarian of the Millennium Award, by One Church One Child (April 2008) and the Norman Hill Award – A. Phillip Randolph Institute's highest honor, usually reserved for international candidates (July 2009).

In the August 2009 Special Issue of Florida Trend Magazine, Senator Hill was featured as one of the "Must-Know Jacksonville Leaders" noting "State Sen. Tony Hill was an early supporter of President Barack Obama. He still has Obama's ear." In the following month, National Political, a campaign and elections magazine included Senator Hill as one of the fifty Democrats in "People of Influence in Florida."

Jenn Nguyen, PhD (Chapter 10) is a postdoctoral associate in the Department of Pharmacotherapy and Translational Research in the College of Pharmacy. She graduated with a PhD in Public Health in 2015, focusing on health literacy and cancer control/prevention. Dr. Nguyen is interested in learning about how health literacy affects one's ability to make informed health decisions, especially among patients facing prostate and colorectal cancer. She understands the importance of evidence-based health communication and aims to help advocates ensure that their message is appropriate and reaching the right audience.



Richard Segal, PhD (Chapter 12) is Professor and Associate Dean at the University of Florida College of Pharmacy and is a Member of the University of Florida Cancer Center. He has authored or co-authored more than 125 papers in the areas of the socio-behavioral aspects of drug therapy and the psychology of the medications use process and has received regional and national awards for his research in the areas of pharmaceutical care and outcomes research. Dr. Segal also chairs the research division for the University of Florida's Medication Therapy Management (MTM) Center, which oversees the research arm of an initiative providing MTM services to more than 1 million patients in the United States. His research in the area of changing prescribing behavior has been the basis of prescribing interventions throughout the world. Dr. Segal was Co-Principal Investigator on the first major research project in the United States, called Therapeutic Outcomes Monitoring, focused on training community pharmacists to identify and prevent drug related problems which contribute to preventable drug related morbidity. Their research has helped to shape many medication therapy management interventions used in the United States and in many other countries.

Chapter 1

Prostate Cancer 101

Brandon Otto, MD

What is the Prostate?

The prostate is part of the male reproductive system. Its main function is to make fluid that helps nourish and protect sperm in the female reproductive tract. Additionally, the urethra, which transports urine from your bladder passes through the prostate. This is why changes in your prostate health often translate into urinary tract symptoms.

What is Prostate Cancer?

Prostate cancer occurs when the normal cells of the prostate divide too quickly or die too slowly. This usually results from mutations or changes of the genes or blueprints of prostate cells.

How Common is Prostate Cancer?

Prostate cancer is the **most common** non-skin cancer in U.S. males. In 2016, there will be 180,890 new cases, representing 21% of new cancer diagnoses in men (Siegel, Miller, & Jemal, 2016). 1 in 7 men will be diagnosed with prostate cancer in their lifetime.

How Deadly is Prostate Cancer?

Prostate cancer is tied with colorectal cancer as the **second deadliest** cancer in U.S. males. In 2016, there will be 26,120 deaths from prostate cancer, representing 8% of cancer deaths in men. (Siegel et al., 2016)

What are the Risk Factors for Developing Prostate Cancer?

The three major risk factors for prostate cancer are age, family history and African American race. Almost **two thirds of men are over the age of 65 at the time of diagnosis**. It is rare to develop prostate cancer before the age of 50.

Up to 1 in 3 men with a family history of prostate cancer will be diagnosed with prostate cancer. The risk is higher the more closely the relative is related to you, (for example having a first degree relative (father/brother) with prostate cancer increases your risk more than having a second degree relative (uncle/grandfather) with prostate cancer), the younger the relative was at the age of diagnosis (especially if <65 years old), and having multiple relatives with prostate cancer.

Up to 1 in 5 African American men will be diagnosed with prostate cancer. In addition to being diagnosed with prostate cancer more frequently, **African Americans are twice as likely to die from prostate cancer than Caucasians**. (Siegel et al., 2016) Many biologic, environmental, and social hypotheses have been used to explain these differences and the answer is most likely multifactorial.

Can we Prevent Prostate Cancer?

Unfortunately, no single strategy has been proven to prevent prostate cancer. **Smoking within 10 years of prostate cancer diagnosis appears to increase the risk of worse outcomes**, however it is unclear if smoking cessation reduces the risk of developing prostate cancer. (Kenfield, Stampfer, Chan, & Giovannucci, 2011) A variety of supplements including vitamin E, vitamin C, selenium, lycopene, soy and multivitamins have been studied and do not appear to prevent prostate cancer. 5-alpha-reductase inhibitors (a class of medications used to help shrink the prostate and alleviate the urinary symptoms of an enlarged prostate) were initially shown to decrease the risk of developing prostate cancer by 25%, however further analysis showed that they only decreased the risk of developing low risk prostate cancers and slightly increased the risk of developing higher risk prostate cancers (Thompson et al., 2003). Multiple diets have been studied and none has been consistently shown to prevent prostate cancer, however a diet that is low in animal fat and high in fruits and vegetables is often recommended.

What are the Signs and Symptoms of Prostate Cancer?

Most men with prostate cancer are asymptomatic. Advanced cancer may present with blood in the urine, difficulty with urination, blockage of your kidneys or bone pain.

How do we Check for Prostate Cancer?

Prostate cancer is common and can be deadly, however it often does not present with signs or symptoms until it has reached an advanced stage at which point cure is unlikely. Therefore, it is important to check for prostate cancer using screening programs to catch it before it spreads outside of the prostate. Over 90% of prostate cancers detected by screening are confined to the prostate.

The American Urologic Association recommends discussing the risks and benefits of prostate cancer screening for all men aged 55-69. African Americans and those with a family history should discuss screening earlier (ages 40-54) (Carter et al., 2013). Screening should occur every 1-2 years until a man reaches the age of 70 or until life expectancy becomes less than 10-15 years.

What does Prostate Cancer Screening Consist of?

Prostate cancer screening involves a blood test and a physical exam. The blood test measures the amount of prostate specific antigen (PSA) in your blood. PSA is a protein made by the prostate that liquefies semen. No single value of PSA can definitively tell us if you have prostate cancer or not, it just gives us an estimation of your risk of having prostate cancer. In general, the higher the PSA, the higher the risk of having prostate cancer. PSA can be elevated for reasons besides prostate cancer such as increasing age, an enlarged prostate, infection, and recent ejaculation. As a result of this, an abnormal test is usually repeated.

The second part of screening is the physical exam which consists of a digital rectal exam (DRE). For the DRE, a physician places a gloved and lubricated index finger into your rectum and examines the area of the prostate where tumors often grow. It provides important information about the clinical stage of the prostate cancer.

The benefits of screening include (1) potentially putting your mind at ease if everything is normal, (2) detecting cancer before it spreads, and (3) allowing for earlier treatment, which may help slow the spread of disease and improve survival in some men. The risks of screening include (1) a “normal” PSA may miss some cancers, (2) an elevated PSA does not always mean something is wrong and may subject you to unnecessary tests, and (3) overtreatment as some prostate cancers are likely to never affect you.

How is Prostate Cancer Diagnosed?

If either the PSA test or DRE is abnormal you may be recommended to undergo a prostate biopsy. This is a small procedure often performed in the urologist’s office where systematic samples of the prostate are taken and sent to a pathologist to look for prostate cancer cells using a microscope.

What is the Gleason score?

The Gleason grading system is how pathologists rate the aggressiveness of prostate cancer. It is based on the microscopic appearance of the biopsy tissue and each area of cancer is given a score of 3 to 5 (the higher the number, the more aggressive the cancer). The Gleason score is the sum of the two most common grade patterns in your biopsy and can range from 6-10. Most common combined scores are Gleason 6 or 7.

How do you Risk Stratify Patients with Prostate Cancer?

All prostate cancers are not the same in terms of their ability to affect your life. As a result, we risk stratify patients with prostate cancer to help determine which treatment strategy is best. Risk stratification involves looking at your PSA value, clinical stage from the DRE, and your Gleason score from your biopsy. The table below outlines the different risk groups.

Risk Group	PSA Value	Clinical Stage	Gleason Score
Very Low Risk	<10 ng/ml	T1c	6, <3 cores, <50% of each core, PSA density < 0.15 ng/ml/cc
Low Risk	<10 ng/ml	T1-T2a	6
Intermediate Risk	10-20 ng/ml	T2b-T2c	7
High Risk	>20 ng/ml	T3-T4	8-10

T1c: normal exam, T2a: involves one-half of one lobe or less, T2b: involves more than one-half of one lobe, T2c: involves both lobes, T3: extends through prostatic capsule, T4: invades other structures

How is Prostate Cancer Treated?

Treatment is based on your life expectancy, prostate cancer risk group and your preferences. For localized prostate cancer, treatment options include active surveillance, radiation therapy or surgery to remove the prostate. For a given risk group, no treatment strategy has been proven to be superior to the others. Each treatment has its own risks and benefits and you are encouraged to explore all available options before deciding which is best for you.

Active surveillance is emerging as the treatment of choice for most patients with very low risk prostate cancer and many men with low risk prostate cancer. It involves regularly scheduled PSA checks, DRE's, and periodic prostate biopsies to make sure that your prostate does not develop or contain a higher risk prostate cancer. It preserves urinary and sexual function while looking for any changes in the amount or aggressiveness of your prostate cancer at which point definitive treatment with surgery or radiation can be offered.

Radiation therapy is a definitive treatment option for low, intermediate and high-risk prostate cancer. For men with intermediate and high-risk prostate cancer, radiation is often combined with a period of androgen deprivation therapy to improve its effectiveness. It involves energy being transferred from an external source through the body and to the prostate without removing it. It is less invasive than surgery. It can cause bladder and bowel irritation as well as erectile dysfunction.

Radical prostatectomy is a definitive surgical treatment option for low, intermediate and high-risk prostate cancer. It is most commonly done in a minimally invasive fashion using a robotic surgery platform. The prostate is completely removed from the body. Most patients go home the day after surgery. For men with intermediate and high-risk prostate cancer, radiation may be required afterwards to improve its effectiveness. It can cause stress urinary incontinence as well as erectile dysfunction.

What is life like after treatment for prostate cancer?

Prostate cancer survivors represent 1 in 5 of all cancer survivors and over 4 in 10 male cancer survivors in the United States. (Skolarus et al., 2014) The needs of this group in terms of monitoring for cancer recurrence and managing the effects of treatment is being increasingly recognized.

No matter what treatment strategy you choose, you will need to continue to have your PSA checked periodically to monitor for recurrence of your prostate cancer. If the PSA is found to be rising, you may require additional testing and/or treatment.

Both surgery and radiation can cause erectile dysfunction and urinary dysfunction. There are multiple treatment strategies available to assist with restoring both erectile function and urinary function. For erectile dysfunction, there are oral medications, injection therapies and penile prosthesis surgeries. For urinary dysfunction, there are medications that can help with urinary symptoms such as urgency and frequency as well as surgical therapies that can help with urinary leakage.

What are some of the Emerging Tools in Prostate Cancer?

There is a lot of effort being placed in trying to improve our ability to risk stratify patients with prostate cancer. In the screening setting, new blood tests (Prostate Health Index) and urine tests (PCA3) are being increasingly used to help us decide who needs a biopsy. In the diagnosis and treatment settings, MRI and genomic testing are being increasingly used to help us detect the location and aggressiveness of prostate cancer.

Take Away Points:

- Prostate cancer is common, however most men die with and not from their prostate cancer.
- African Americans are more likely to get and die from prostate cancer.
- Prostate cancer is usually asymptomatic; therefore, regular screening is important to ensure early detection.
- Treatment options are based on your life expectancy, risk categorization, and preferences.

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**** End of Chapter 1****

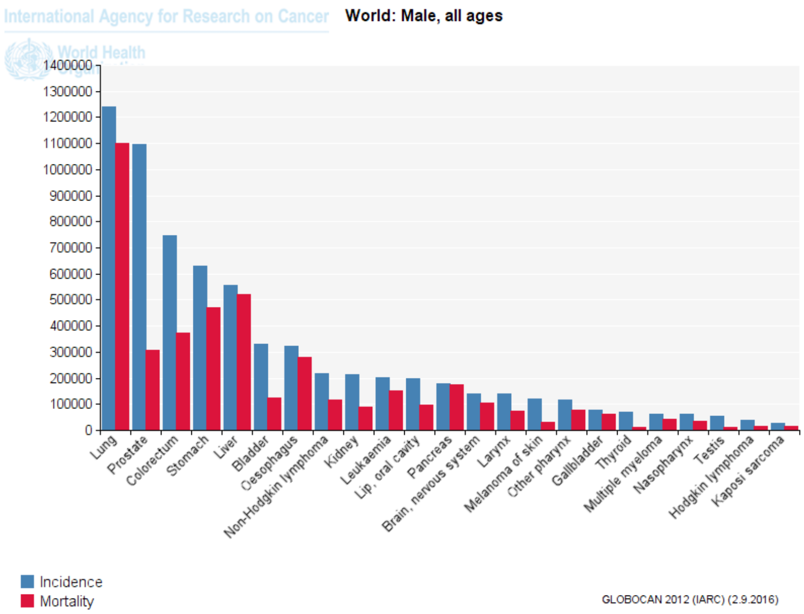
Chapter 2

The Burden of Prostate Cancer in Black Men

Folakemi Odedina, PhD

Global Impact of Prostate Cancer in Black Men

Prostate cancer impacts men all over the world as the 2nd most common cancer among men and the 4th leading cause of cancer death in men globally (Ferlay et al., 2013). The devastating impact of prostate cancer on the Black population as a race is seen in the countries that are most affected by prostate cancer. According to the World Health Organization, the countries/Islands with the highest prostate cancer mortality are: (1) Trinidad and Tobago; (2) Barbados; (3) Guadeloupe; and (4) Martinique (Ferlay et al., 2013). The racial composition of these four Islands are mostly Blacks of African ancestry or people of mixed Black ancestry.



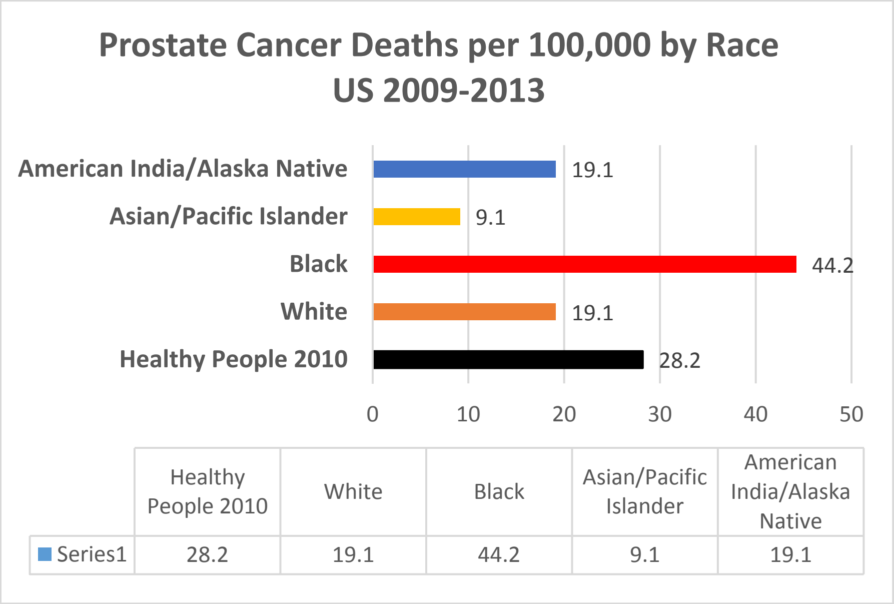
In a published paper by Odedina and colleagues (Odedina et al., 2009a) examining prostate cancer in Black men of African ancestry, the authors found several published studies documenting high prostate cancer burden in sub-Saharan African countries, including Nigeria and Ghana. The authors also found prostate cancer morbidity and/or mortality data from the Caribbean Islands and among Blacks in the United Kingdom to be comparable or worse than the prostate cancer burden seen in United State (US) Blacks. The pattern of prostate cancer seen in Blacks globally appears to link populations of Black men connected by the Transatlantic Slave Trade, including Blacks of West African ancestry from Africa, Americas, the Caribbean and Europe.

Although it is widely recognized that Black men, as a group, are most affected by prostate cancer compared to any other racial/ethnic group, researchers have found within-group differences among Black men based on their country or continent of origin. One of the research groups that studies prostate cancer in Black men is the Prostate Cancer Transatlantic Consortium (CaPTC). Landmark studies by the CaPTC documented for the first time the within group differences among African, Caribbean, and US Black men relative to prostate cancer-related lifestyles, cultural beliefs, and values (Odedina et al., 2009b; Odedina et al., 2011). CaPTC researchers have found that: (1) prostate cancer incidence is highest among US-born Black men; (2) prostate cancer mortality is highest among Caribbean-born Black men; and (3) prostate cancer tumor stage and grade at diagnosis is highest among sub-Saharan Black men.

Prostate Cancer in US Black Men

In the United States, prostate cancer is the most common cancer among men and the 2nd leading cause of cancer death in US men (American Cancer Society, 2016). Although prostate cancer mortality and morbidity have declined since the 1990s, Black men in the US are still disproportionately affected by prostate cancer. According to the American Cancer Society, US Blacks face a huge risk for prostate cancer. The risk for prostate cancer is 70% higher in Blacks compared to non-Hispanic Whites. In 2016, about 30,000 Black men will hear the words, “you have prostate cancer” and start a journey that would forever change their lives.

To fully understand how prostate cancer affects Black men in the US, let us examine the Healthy People program. Health People is a national program that provides 10-year objectives for improving the health of all Americans. For 30 years, Healthy People has provided specific health target that the nation needs to meet, including target for prostate cancer death rate. For the year 2010, the Healthy People objective was to reduce the prostate cancer death rate to 28.2 per 100,000 men. The figure on the right provides the prostate cancer death rates for different races in the US for the years 2009-2013 (SEER, 2016). **As seen in the figure, Black men were the only racial/ethnic group that did not meet the Healthy People 2010 objective for prostate cancer.** For Black men, the Healthy People objective is like a moving target. Although US Black men did not meet the Healthy People 2010 objective, the Healthy People 2020 objective for prostate cancer death rate has been reduced to 21.2 per 100,000 men. From the Figure, all other racial groups except Black men have exceeded the Healthy People 2020 objective.



	Healthy People 2010	White	Black	Asian/Pacific Islander	American India/Alaska Native
■ Series1	28.2	19.1	44.2	9.1	19.1

Prostate Cancer in Florida Black Men

As of 2016, Florida ranks 2nd in estimated new prostate cancer cases and 2nd in estimated prostate cancer deaths among all states in the US (American Cancer Society, 2016) Similar to the US, disparities in prostate cancer also continue to be a major problem in Florida, especially for Black men. For example, Black men in Florida was the only racial/ethnic group that did not meet the Healthy People 2010 objective to reduce the prostate cancer death rate to 28.2 per 100,000 men. In addition, Black men was the only racial/ethnic group that has not met the Healthy People 2020 objective for prostate cancer to reduce the prostate cancer death rate to 21.2 per 100,000 men. Based on the 2013 prostate cancer mortality rates for Florida (Florida Cancer Data System, 2016), the death rate for Black men (37.49/100,000) is almost twice the Healthy People 2020 objective (see the figures on the next page).

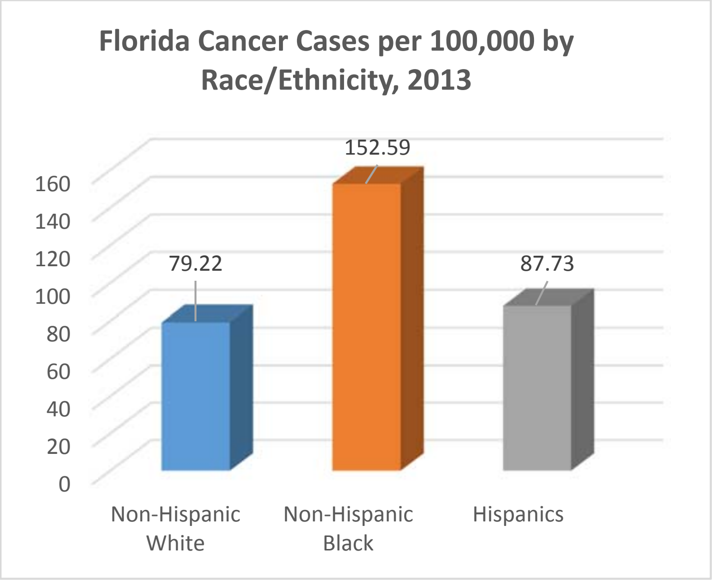
Prostate Cancer in Black Men: The Last Decade

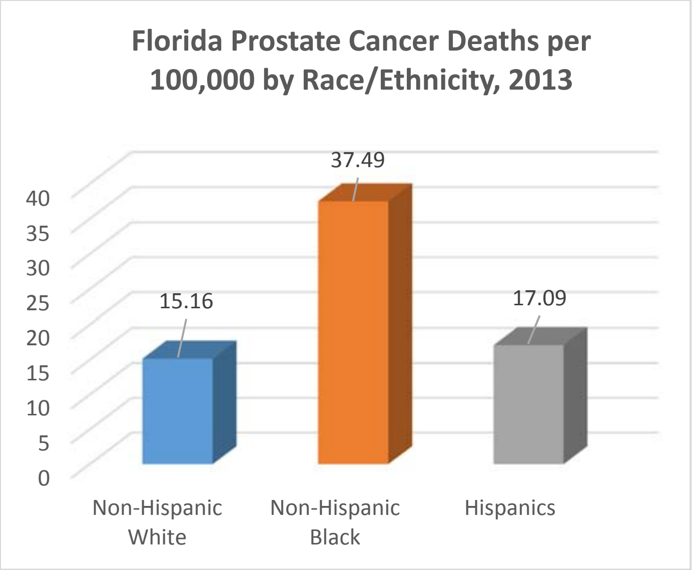
To understand the progress that has been made and the challenges that we still face relative to prostate cancer in Black men, we conducted a review on a US National Library of Medicine® database called PubMed. PubMed provides free access to over 26 million citations and abstracts of biomedical journal articles. Using the keywords prostate cancer, Black men and disparity, we reviewed articles published between 2005 and 2016. Some of the findings were:

- There is unequitable access for Black men across the prostate cancer care continuum, including prevention, early detection and high-quality treatment. For example, Black men report more treatment-related side effects that translates to reduced Quality of Life.
- Compared to White men, prostate cancer grows more in Black men. In addition to higher incidence and higher mortality, the 5-year relative survival for prostate cancer is lower for Black men. Black men also

present with more advanced disease, with earlier transformation from latent to aggressive prostate cancer occurring more in Black men.

- Black prostate cancer patients tend to have more co-morbidities compared to White prostate cancer patients.
- Black men are more likely to experience a longer wait time between prostate cancer diagnosis and treatment. There is a low use of follow-through diagnostic care by Black men after Prostate-specific antigen (PSA) elevation. The obstacles to timely diagnosis and appropriate care include distrust of physicians by Black men.
- Black men are less likely to receive life-saving definitive therapy. Having health insurance was noted to be one of the factors responsible for this treatment disparity.
- Black prostate cancer patients tend to have high prevalence of clinically significant traumatic stress symptoms.
- Socioeconomic factors such as education and income increase the disparity in prostate cancer survival among Black men.
- There is underrepresentation of Blacks in clinical trials/biomedical research. This includes limited biological samples from Black men to conduct genetic studies.





Addressing Prostate Cancer in Black Men: A Global Fight!

The complexity of the prostate cancer disparity seen in Black men, and the need for a unique approach to better understand and address this complex disease led to the formation of the **Prostate Cancer Transatlantic Consortium (CaPTC).** The CaPTC, a US National Cancer Institute (NCI) Epidemiology and Genomics Research Program (EGRP) supported consortium, was formed in 2005 to address the global disproportionate burden of prostate cancer among Black men. It is an open consortium comprising a team of prostate cancer scientists, clinicians, survivors, and advocates from North America, Europe, the Caribbean Islands, and West Africa. Consortium members work together to fight prostate cancer in Black men through research, education, training, and advocacy. The CaPTC has over 75 members from 23 countries.

The official scientific conference for the CaPTC is the "***Biennial Science of Global Prostate Cancer Disparities (SGCaPD) in Black men conference***", which is held every two years in different countries. The SGCaPD conference was established to:

1. Provide opportunities for mutual learning, knowledge transfer, and collaborations among prostate cancer scientists, clinicians, survivors and advocates;

2. Promote trans-disciplinary and multi-disciplinary prostate cancer research globally;
3. Facilitate networking among individuals involved in all aspects of prostate cancer control, education and research in Black men;
4. Facilitate the development of a global community of practice to address common challenges in prostate cancer, including prevention, detection, diagnosis, treatment and survivorship; and
5. Contribute to a global impact against prostate cancer through research, training, education, and advocacy programs.

The SGCaPD conferences started in 2010, with previous conferences held in Jacksonville-Florida, USA (2010), The Bahamas (2012), and Jamaica (2014). The 2016 conference will be held November 9-12 in Orlando-Florida, USA and the 2018 conference in Nigeria (Africa). Participants of the SGCaPD:

- ✓ **Learn** from internationally renowned speakers recognized in prostate cancer disparities and survivorship research;
- ✓ **Discover** the latest research findings on prostate cancer Prevention, Early Detection, Diagnosis, Treatment, Survivorship and End-of-Life;
- ✓ **Connect** with other Researchers, Clinicians, Patients, Advocates and Policy makers from North America, South America, Europe, Africa, and the Caribbean;
- ✓ **Share** ideas with other conference delegates involved in all aspects of prostate cancer control and research in Black Men;
- ✓ **Explore** the world of trans-disciplinary prostate cancer research; and
- ✓ **Develop** a global community of practice to address common challenges in prostate cancer disparities.

To join the global fight against prostate cancer, go to www.globalprostatecancerconference.com or http://epi.grants.cancer.gov/captc/ . You can also send an email to captc@cop.ufl.edu .

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**** End of Chapter 2 ****

Chapter 3

ABCs of Advocacy

Lauren Gilbert, PhD

Advocate (n.)

- a person who speaks or writes in support or defense of a person, cause, etc.; a person who pleads for or in behalf of another; intercessor

Advocacy (n.)

- the ongoing process of changing attitudes, actions, policies and laws by influencing individuals, groups and organizations

How do Advocates Define Themselves?

Advocates define themselves as individuals who are actively working and speaking out for the benefit of others in their communities. Advocates want to spread their message of awareness and educate others about prostate cancer. Some of the most common words that advocates use when they define advocacy are:

- "One who strives to enlighten, educate, and promote any situation that…can help mankind."
- "An advocate is someone who can speak with great knowledge, sound knowledge, evidence based knowledge about prostate cancer and prostate treatment. And I don't speak about it in terms of educating and informing them, but can speak in a way that can bring about a change."
- "An advocate is someone who stands up for an issue or cause, willing to be educated and informed, and is willing to take on the tough task of being challenged on an issue or cause."
- "An advocate for prostate cancer is a person who will address the disease and the patient and is constantly learning and updating him or herself so that they could meet the ever changing needs of the patient. It is not something that is stagnant. You cannot be one who is not sensitive to the cultural differences that exist with men of highest risk."

Advocacy Definitions from Different Organizations

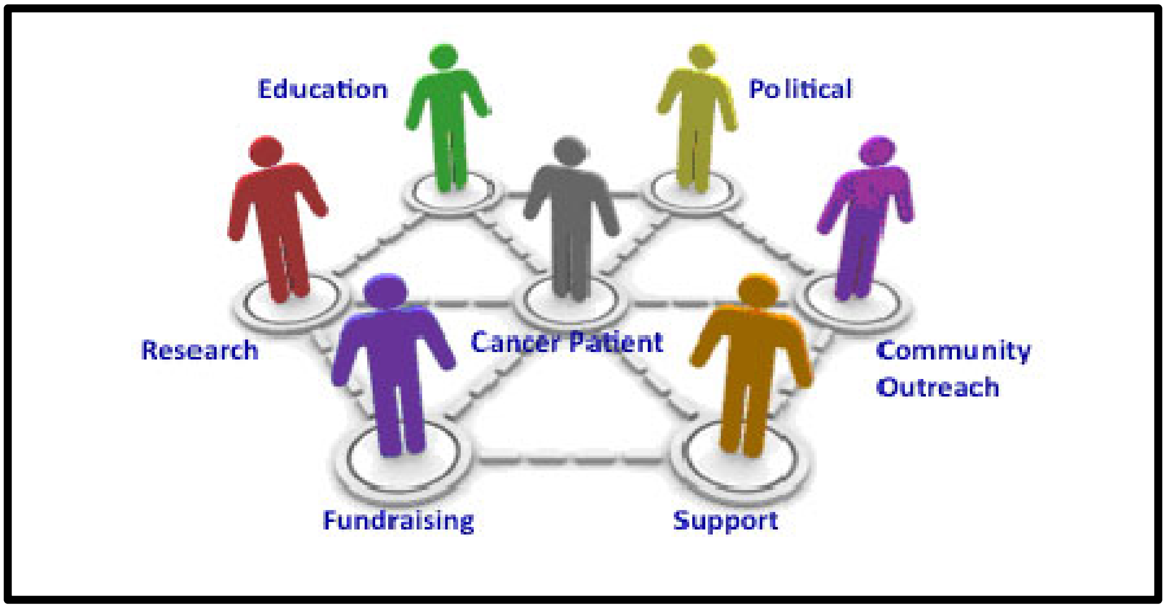
1. **National Coalition of Cancer Survivorship (NCCS) - Stages of advocacy**

Self-advocacy is characterized by becoming an empowered patient and taking control of one's own experiences, including but not limited to: independent research about the disease and the diagnosis, seeking second opinions from other providers, locating resources for identifying and obtaining support, and knowing how to ask the right questions (NCCS).

Advocacy for others, or **community advocacy**, is when cancer survivors go on to share their experiences through involvement with the community. Some examples include participation in charity runs and walks for cancer awareness and research, and enrollment in advocacy training courses.

The final stage is **public advocacy**, which deals with public policy activities at the national level in attempts to seek change on larger levels, often working with state and local government to create change for cancer awareness, treatment, and policies.

2. The Cancer Information & Support Network (CISN) Advocacy Categories



i. **Education advocacy** has goals of informing and educating cancer patients and their family and friends, including information about cancer, survivorship issues and even financial and insurance information.
ii. **Political advocacy** seeks to impact public policy through lobbying at the local, state and/or federal level.
iii. **Research advocacy** works to ensure that high quality research is sensitive to the priorities of cancer patients, including issues of quality of life, and causes and prevention of cancer; assist with strategies to increase patient recruitment, compliance and retention for clinical trials.
iv. **Support advocacy** provides support to cancer patients and their families in a variety of forms including emotional, financial, nutritional, and/or physical assistance.
v. **Fundraising advocacy** obtains funding for cancer research, support services, patient education and community outreach.
vi. **Community outreach advocacy** reaches into the community in a manner that encourages a two-way dialogue that often partners with a local health organization or professional group (CISN, 2014).

> REMEMBER! Advocates are bridges for their communities to connect them to the healthcare system and providers. Advocates are not replacing medical doctors, or the need to make regular visits – rather advocates encourage individuals in the community to see and talk with their doctor about their health, especially prostate health.

Can I be an Advocate?

Regardless of how you define advocacy and advocates, almost anyone can be an advocate.

- Prostate cancer survivors
- Friends and family members of prostate cancer survivors
- men and women
- Retirees and volunteers
- medical professionals and researchers
- Religious leaders

Traits of Successful Advocates

There are three common traits seen in successful advocates: passion; dedication; and desire to constantly improve.

1. Passion

Passion is what motivates individuals to get involved in prostate cancer advocacy at first. Some men get involved because they are survivors of prostate cancer, and feel obligated to share their experiences with other men, both positive and negative. Other advocates are passionate because they know the statistics of the health disparities when it comes to prostate cancer for black men. They have a sense of social justice that encourages them to make a difference in their own communities.

2. Dedication

Dedication is related to passion; dedication is what keeps people motivated over time and through challenges. Perseverance is what allows them to continue their efforts to achieve their goals in the face of hardship. There are times when advocacy will not be easy and may feel overwhelming. Having this dedication and perseverance is what maintains advocates.

3. Desire to Improve

A desire to constantly learn and improve is vital to being an effective advocate. Prostate cancer is dynamic – there is always new research coming out about prostate cancer: new treatments, new tests, and effectiveness of old tests. In order to be an effective advocate, you need be able to share this information with your community. You want to be well informed and up to date so you can share that information with your community.

As you begin (or continue) your journey to becoming advocate, reflect on your motivations, your level of dedication, and your desire to constantly learn and improve.

Personal Reflection

My motivations are:

I am dedicated because:

My plan to constantly learn and improve are:

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**** End of Chapter 3****

Chapter 4

Education Advocacy

Mary (Dicey) Jackson Scroggins

An Overarching Category

Education advocacy is a specific form of advocacy that focuses on providing awareness and educating cancer patients and families, the public, policy makers, researchers and clinicians, and others about issues related to cancer. In fact, education advocacy broadly overlaps or crosscuts every other form of advocacy, being encompassed in community outreach, political, research, and support advocacy and even fundraising advocacy and self-advocacy. The specific desired outcome of education advocacy might be different in the context of these different categories, but the essential overlapping goal is the same: to provide accurate, current information so that someone or something (e.g., an organization) will be able to or encouraged to act in an informed manner. Ultimately, education advocacy works to motivate people and institutions toward change and/or action.

Advocates focused on prostate cancer, like others engaged in education advocacy, provide other stakeholders—but especially the patients, families, and caregivers—with the informational tools and facts on which they can act and motivate others to act.

Spreading the Word

With prostate cancer being the second leading cause of cancer deaths in American men and Black men having the highest incidence of the disease, it is extremely important for prostate cancer-focused advocates to engage in research, especially Black men, who have a 200% higher death rate than Caucasians. Participation in education advocacy:

- Creates focused awareness (and thus potentially saves lives as well as supports the missions of other types of advocacy).
- Helps individuals and families understand and cope with the business side of cancer (e.g., insurance and financial concerns).
- Highlights the importance of survivorship (how well you live), the companion of survival (how long you live).
- Nurtures change in thinking and actions.
- Assists decision makers in focusing attention and resources on prostate cancer.

Empowering Individuals and Communities

As individuals and families become more actively involved in education advocacy, there is a health and health care ripple effect that promotes the health of everyone in the process and in the community. In addition, in the course of education advocacy, the roles of educator and student may shift as topics and needed expertise change. With every education advocate in a continuous learning mode, this advocacy:

- Empowers men, their wives or significant others, and caregivers to be more participatory and act more decisively in terms of their own care—cancer related and not.
- Empowers communities to act in the best interest of the health of the collective community.
- Promotes the health of the community through focused strategies that call upon the resources of the community (and encourage a holistic consideration of health, not just a focus on cancer).
- Changes lives.

Influencing All

As education advocates interact with the various stakeholders, influencing patients, the general public, researchers, clinicians, and individuals with little previous understanding of prostate cancer and no commitment to activism around cancer of any kind, they:

- Tailor messages to fit the needs, level of expertise and learning style/preferences of the recipients of the message; the specific situation, and community norms—with respect for cultural sensitivities.
- Facilitate discussions, community talk-backs, and shared decision-making.
- Delineate barriers to care, research study participation, and other issues specific to the particular population…and jointly pursue solutions.
- Make a tangible difference in their communities…and the world (Knowledge truly is power!).

Conclusion

Education advocacy, this broad and overarching form, is built into all other forms of advocacy and thus is a powerful tool for all those seeking to influence the conversation and needed interventions around prostate cancer, the quality and breadth of care, and the dire statistics particularly related to Black men (translated, “to save lives”). A continuous pool of dedicated advocates willing and able (through preparation and continuous learning) to take the message to the people—literally—is required. In addition, if you are interested in joining the pool and becoming a prostate education resource in your community, first, know that you can. The will to do so is essential; it is magic.

To get started or as a refresher, perhaps join (or re-engage with) a local organization with a health or cancer focus and work collaboratively within the organization to promote the idea of education advocacy, with specific strategies and goals. In addition, find a mentor—someone engaged in the field whom you admire. Understand that you are beginning a journey of ongoing preparation, training, learning, interacting with community at all levels, creating change, and/or planting the seeds of change in others.

You can help to shape the prostate cancer landscape within your community and beyond. You will be joining a growing family of dedicated advocates answering the call.

**** End of Chapter 4****

Chapter 5

Support Advocacy
Virgil Simons, MPA

Maintaining Community Credibility

A major aspect in the management of prostate cancer, and men's health deficiencies in general, has been three key impediments to achieving optimal patient care:

1 Lack of interdisciplinary evaluation as a benchmark of patient-centered care.
2 Lack of evidence-based clinical management recommendations by initial patient staging or disease progression.
3 Disparate access to care, e.g. facilities, insufficiency of time with a physician, socio-economic barriers, etc.

Historic patient interventions have focused around support groups, educational meetings, brochures and newsletters, webinars, as well as telephone or web-based help lines. Emerging technologies have seen some elemental web interactivity, video communications and smart-phone applications to educate consumers and patients and to provide access to patient health information. The core deficiency is that there is a lack of focus on target audiences, vehicle implementation, resource capabilities and ability to engage the communities of patients, professionals and stakeholders. There is a need for the creation of community-based leadership entities with broad skill sets and a history of successful interventions that can:

1. Partner synergistically to effectively re-position the conversation on disease risk awareness.
2. Inform and educate the at-risk consumer population.
3. Create a necessary stakeholder network of on-going intervention.
4. Develop a sustainable model of patient advocacy in their communities.

The Edelman Trust Barometer reported that only 18% of the public worldwide trusted business leaders to tell them the truth. The public (> 50%) was more likely to believe non-governmental organizations (NGOs) than companies - even when the companies had a stronger argument.

Model Project

A model for effective support advocacy has been The Prostate Net's CADRE Project (see: http://theprostatenet.org/knowledge.html) which is the first-in-principle prostate cancer patient advocate training initiative. This cadre builds effective partnerships with medical centers, public health agencies, research centers, complementary patient advocate organizations and corporations with investment in their local communities to significantly advance the fight against prostate cancer and other men's health issues.

Before you can begin to implement programs of community involvement and/or disease engagement, you must first move to undertake a needs analysis of the community that you plan to engage with and/or serve. Too often, many advocacy groups develop initiatives or programs for an audience without understanding from where the community receives information about cancer and how they act upon it. Effective advocacy, and the programs to engage it, must be derivative of what the community really needs understand what they need to know and analyzing the current situation under which the community is being informed.

The basics of a sound informational media analysis will include the following minimum information:

- ❖ Current service agencies operating in the community - public and private
- ❖ How are they communicating with the community
- ❖ Reception of those services
- ❖ Competitive advocacy groups that offer programs similar to those planned
- ❖ Prevalent use of media to serve the community

- Capability to develop appropriate media channels to communicate with your audiences:
    - Symposiums, educational conferences
    - Website resources
    - YouTube channels
    - Social media outlets: Facebook, Twitter, Instagram, LinkedIn, etc.
    - support groups

From these needs analysis, you should be able to determine exactly:

1. Who the target audiences for your programs should be.
2. The type of initiative that will be most effective in delivering the services you will provide.
3. The timeliness of the programs.
4. Those potential funders for your organization and programs.
5. The criteria of success measurement that will aid in developing on-going stratagems. Most importantly, it will guide you in developing the business plan for your entity.

The initial six advocates selected for the CADRE program came from regions with a disproportionate incidence and/or mortality from prostate cancer, were evaluated based on their current or previous advocacy efforts, and were trained to understand the etiology of prostate cancer from diagnosis to the advanced stages of the disease. They are returning to their communities in partnership with The Prostate Net to change the negative impact of prostate cancer. The synergy of the CADRE Project is the creation of team leaders who can coalesce their community's singular capabilities and provide a framework to execute initiatives that no one group could achieve alone.

From this essential proof-of-concept, we have extended the reach of the program, in partnership with the African Organization for Research and Training in Cancer (AORTIC), to undertake the creation of more than 1,500 trained patient advocates who can build sustainable programs of education and intervention across all disease sites within their communities.

Roadmap for Success

An absolute imperative for a successful organization is that its leadership possesses a Vision of what that organization intends to represent itself as, to what audience it intends to serve, of what its over-arching challenge is, how it will be met, and how it will evolve. The essential mandate is that everything changes and situations evolve; what was successful last year may no longer be effective or appropriate two years into the cycle. It is critical that the organization on a regular basis evaluate itself on its programmatic effectiveness and determine if changes are needed, how to implement them and to continue their relevancy.

The World Health Organization (WHO) has defined advocacy as, *"the effort to influence people…to create change, which in the context of cancer control results in comprehensive policies and effective program implementation, through various forms of persuasive communication."* Concurrently The United States Institute of Medicine has defined Patient Centricity as, "*Providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions."*

Both of these guidelines must form the structure and implementation for an effective patient advocacy organization, and will lead to an obvious plan for structuring the necessary community outreach objectives. Paramount in your mind as a leader of an advocacy organization is not only the "what" of your goals and objectives, but the "how" of your integrated initiatives to achieve your mission of serving the communities for whom you are giving voice. You cannot represent if you are not representative!

Fundraising Advocacy Case study: The Prostate Net's "Gentlemen Check Your Engines"

The President's Cancer Panel of the National Institutes of Health in 2001 clearly stated, "Lack of accurate cancer-related information that is readily available, understandable, clear and delivered in a sensitive and culturally acceptable manner is a major contributor to the inability of patients and the public to obtain the most appropriate cancer prevention, treatment and supportive care." One way to at least partially address this situation is to create

successful outreach programs, which educate men in order for them to make informed decisions about their personal risk of the disease as well as other conditions affecting their health.
Gentlemen Check Your Engines™ educational and health testing programs address these areas of concern and negative impact within the targeted communities and serves to position those conditions of co-morbid disease conditions relating to policies that de-emphasize screening and early detection.

Gentlemen Check Your Engines™ workshops, seminars, conferences and other events facilitate obtaining information on how best to manage men's prostate health and other medical options, and enhance communications between men and their healthcare providers using the Harley-Davidson dealerships as a network of trust. Additionally the on-site screening and educational programs provide better initial access to and participation in the health care system.

The basic concept behind this initiative is that men pay more attention to their cars, motorcycles and other toys than to their personal health. Gentlemen Check Your Engines™ educational program focuses on utilizing a credible environment that is safe and comfortable, the Harley-Davidson dealership, and motivating men to come there for health information and screenings. The key innovative factors are found in the unique corporate partnership with Harley-Davidson dealers, healthcare providers and public health agencies to promote men's health in a unique way.

An important tangent to the basic core promotional effort has been the involvement of a women's initiative to encourage greater male participation in the educational and health screening activities. The experience from 2010's event in New Jersey, done in conjunction with the "St. Valentine's Day" promotion period, served to increase the numbers of men participating in the health event through the use of incentive items suitable for the women in their lives. As a result, we have expanded our focus to include women's health as part of the overall mission.

The Prostate Net® piloted this initiative in February 2008 as part of the Bergen County Cancer Coalition and in partnership with the local Harley-Davidson dealership. The initial effort brought almost 80 men and women into the showroom where they circulated through health stations and a mobile health van provided by the North Hudson FQHC, received a custom bandanna from The Prostate Net® and socialized in the dealership during the event.

The program continued into 2009 with a return to the Bergen County dealership as well as into Chicago and Atlanta. Participation increased to 2,861 men, as well as a surveyed increase in participation satisfaction with the event and a desire for continued efforts of its kind. In 2010, the program expanded further and we saw our first documented case wherein the educational effort resulted in the diagnosis of, several previously undiscovered cases, prostate cancer.

Additionally one of our World Wide Prostate Cancer Coalition partner organizations, the Prostate Cancer Foundation of Australia, tested the concept in two major communities in Australia with comparable success in education and on-going involvement with their prostate cancer support organizations. The concept was extended into Spain for a first-in-Europe effort in 2014; details can be seen at http://www.theprostatenet.org/espanol/

The experience gained from the execution of this program over the past six years and in multiple markets has shown that information coming from a trusted source has a very significant impact on increasing awareness and education among men as well as motivating them to utilize the access to care afforded by the program.

**** End of Chapter 5 ****

Chapter 6

Community Outreach Advocacy

Angela Adams, PharmD, MPH

Community outreach advocacy can be defined as individuals or groups that advocate reaching out into the community to meet their needs. There can be several approaches to community outreach advocacy.

1. **Bottom-up approach:** Community outreach efforts that are based on needs or goals that have been identified by individuals or groups that are indigenous to the community may also be considered as "Grassroots".
2. **Top- down approach:** The identification of needs or goals have been identified by experts outside of the community.

Collaborative partnerships are essential and critical to the success of community outreach advocacy. The participation and buy-in from the community is an indicator for "readiness" of the community to support the outreach advocacy. Community outreach has been identified by the Cancer Information Support Network (CISN) as one of six distinct categories of cancer advocacy. However, community outreach can easily be viewed as a subset and an essential element for the other five categories of cancer advocacy (education, research, political, support, and fundraising).

Community outreach advocates (COA) must be included as partners or collaborators in prostate cancer education, research, political, and fundraising advocacy programs in order to maximize their potential for successful outcomes. The indigenous Community outreach advocate can work closely with all stakeholders in their community to help ensure that needs are met. They can also break down barriers to prostate cancer education, prevention, early detection, and treatment. Community outreach is an essential and necessary partner for academic and research institutions to accomplish the mission of identifying and eliminating health disparities.

Getting Started

"If There Is a Problem in a Community,
There Is a High Probability That the Solution Is There Also"

Needs Assessment

A key element of prostate cancer community outreach advocacy is not only assessing the impact of prostate cancer on the men in the community and their unmet needs but also identifying the problems and unmet needs as ***perceived*** by the community. A community needs assessment survey will allow you to understand what is needed for the community that you want to serve. Each community or neighborhood will have differences so do not assume that if the racial or ethnic group is the same the needs will be the same or similar. A prostate cancer needs assessment can be created for the community you want to serve or you can assess an existing template that had been previously used by your local or state health department. The Community Tool Box Work Group for Community Health and Development (University of Kansas - www.ctb.ku.edu) is an excellent resource for templates and information for conducting needs assessment surveys.

How to Get Started

Once you have completed the needs assessment, you will need to consider the following:

- What are the results of needs assessment for the community?
- What needs immediate attention?
- What are the long-term issues that need to be addressed?
- Development of an action plan to include time lines.
- The objectives for the community outreach.

- What do you hope to accomplish?

Accomplishing Your Objectives

You must have knowledge about your community outreach objectives that you have chosen to accomplish and they should be specific, realistic, measurable, achievable, realistic, and time based (SMART).

Plan

- **Avoid Overreach**: This is a common challenge but can be avoided by determining several intermediate objectives that collectively ensure the accomplishment of the ultimate objective.
- **Identify Community Health Assets**: There are resource organizations in the community that execute community outreach activities and events to reach specific target populations. Examples include Community Health Centers, Hospitals, Medical, Nursing, & Allied Health Schools, Professional Health Organizations, Faith Based Organization (Health Ministries), Disease Prevention Groups
- **Collaborate:** In a true collaboration, organizations help enhance each other's capacity to do their jobs, beyond just cooperating. Collaboration is a force multiplier, which will increase your organization's efforts to effectively accomplish your goals and objectives.

Prepare

- **Recruit Advocates:** Find and attract talented people and make sure opportunities are available for advocates to apply their talents. Provide meaningful projects in which people can work together and make sure that the right people are in the right jobs. A climate of optimism should be maintained making it fun to be part of the group.
- **Train**: Provide advocate orientation and training. To become a community outreach advocate in the area of prostate cancer, individuals should first be educated about the disease. The information presented should be from good, reliable resources whose information represents the latest evidence-based information available. Pair the new advocates with mentors or individuals that have experience in advocacy.
- **Build leadership**: Leadership is the art of helping people work together in common purpose. This is a critical factor in the work of advancing prostate cancer community outreach advocacy. Specify what leadership skills and core task that are needed to help accomplish the objectives. Identify and indicate how many leaders are needed and who needs to be included to reflect the advocacy and its interests.
- **Collaborate**: In a true collaboration, organizations help enhance each other's capacity to do their jobs, beyond just cooperating. Collaboration is a force multiplier, which will increase your organization's efforts to effectively accomplish your goals and objectives.
- **Funding:** Create a budget to determine the immediate and future resources that will be needed. Identify potential sources of funding and support, including in-kind support from members' organizations.

Execute

"A Community Responds When Invited To Wellness by People They Know & Trust"

Community Outreach Case Study 1: Black Men's Health Summit

In 1996, the Central Florida Pharmacy Council (CFPC) a professional volunteer community (grass roots) organization sponsored its First Black Men's Health & Wellness Summit in Orlando. The Summit a one-day health education conference was a response to the unmet need for providing culturally appropriate prostate cancer health education and screenings to Black men. Annually the Summit attracts more 3,000 men. There is no cost for the participants to attend the Summit's health education program and screenings for prostate cancer, diabetes, hypertension, cholesterol, HIV, kidney disease, stomach ulcers, oral cancer, mental health and lung function. Founded in 1996 by a pharmacist, the mission of the CFPC is to improve the health and wellness of African Americans and minorities through the presentation and development of culturally appropriate health education programs. The purpose of CFPC's community health education programs is to improve the health status and empower African Americans and minorities to take a proactive approach in the management of their health.


FREE MEN'S HEALTH SUMMIT!
SCREENINGS · WORKSHOPS · EXHIBITS

Father's Day Weekend
Saturday
June 18, 2016
Orange County Convention Center West Concourse
Orlando, FL
8am - 1pm

Register Online: www.BLACKMENSHEALTHSUMMIT.com

Community Outreach Case Study 2: Health Outreach and Promotion Education (HOPE) Training Academy

Health Outreach and Promotion Education (HOPE) Training Academy was established in 2011 by the Central Florida Pharmacy Council. The Hope Academy's mission is to increase a community's capacity to develop and successfully organize community-centered men's health and wellness programs that will successfully address the health disparities in targeted communities. The HOPE Academy has trained forty health advocates in five counties in Florida on how to engage their communities, develop and implement health outreach programs for men.

The Hope Training Academy curriculum included information for community outreach advocates on how to develop and maintain collaborations, increase access to care and reduce the prevalence and severity of chronic diseases among minority men. The training program also discussed and presented benchmarks and targets for improvements in health outcomes among minority men who are at risk for or diagnosed with prostate and colorectal cancer, diabetes, obesity, hypertension, HIV, and cardiovascular disease.

"He who has health, has hope. And he who has hope, has everything."
-Arabian Proverb

Community Outreach Advocacy Helpful Charts

Community Outreach Advocacy Approaches	Examples
Bottom-Up	Neighborhood Health Equality Coalition Local Native American Health Council Faith Based Organization- Health Ministry Local Prostate Cancer Support Groups
Top- Down	Health Department with Men's Health Initiatives Cancer Center Health Disparities Committee
Collaborative	Local Hospitals, Health Departments partnering with Neighborhood Health Equality Coalitions Local Native American Health Councils Faith Based Health Organizations, and local prostate cancer support groups

Potential Prostate Cancer Advocates

- Patients/Caregivers
- Local Health Associations
- Physicians/ Nurses/Pharmacists
- Allied Health Professionals
- Community/Political Activists
- Fraternities/Sororities/ Social Clubs
- Community Leaders (Formal & Informal)
- Faith Based Organizations
- Community Businesses
- Neighborhood Associations

Essential Factors For A Successful Prostate Cancer Community Outreach Advocacy

- Leadership
- Collaboration
- Forces Advocate Recruitment)
- Funding

Why Collaborate?

- Your organization's efforts cannot effectively accomplish its goal alone.
- The problem or goal is complex and is influenced by multiple factors.
- Prevent duplicate efforts and the desire for resources to be used to their full potential.

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Chapter 7

Political Advocacy

Former Senator Anthony Hill, Sr. & Ernest Kaninjing, DrPH

Political advocacy seeks to create change or influence public policy regarding an issue or social problem. Political advocacy incorporates practices and behaviors such as voting, contacting elected officials at the federal or local levels, protesting or demonstrating, signing a petition or persuading other citizens to vote for a certain issue (Weerts et al., 2010). Essential ingredients for a successful political advocacy include knowledge, ideas, skills, mobilization, technology, money and people.

In the United States system of government, responsibility for writing and debating laws rest with the legislative branch of government. At the federal level, once a bill is voted and passed by both houses of congress (House of Representatives and Senate) it goes to the President's desk for signature. When the president signs a bill, it becomes law. Advocates for policies that protect and advance the welfare of the population, need to be informed about the policy making process and the political process at the state and federal levels and work within that framework to make their cause part of the public agenda.

What is Advocacy?

Advocacy refers to the set of skills that can be used to shape public opinion on a given subject and to mobilize community resources in support of a policy or issue. According to VeneKlasen & Miller (2007), "**Advocacy is a continuous process which leads to positive change in attitudes, behavior, and relationships within the family, workplace, and community, and state and society, i.e. all social institutions**." The focus of advocacy is to increase public awareness of an issue of concern and to influence policy to address that issue. To change attitudes about a subject or shape perceptions on an issue, the public needs to be adequately informed. Therefore, a key component in advocacy is educating various audiences about the issue of concern by drafting position papers, helping to draft legislation and using the media to frame the issue in a way that is favorable to your cause.

Advocacy efforts are often directed at more than one audience and require different strategies to achieved desired goals. Consequently, it requires a variety of leaders, activities and organizations with different skills and talents (VeneKlasen & Miller, 2007).

Why is Advocacy Important?

Advocacy is often associated with social justice or the desire to address social imbalances through laws and policies. In essence, advocacy is a tool for changing policies and practices at the local, national or international levels. Advocacy also advances the well-being of individuals or groups who share similar problems (UN Women, 2016).

Advocacy provides opportunity for ordinary citizens to take active part in shaping decisions that affect their lives. In a democracy, citizens have the right to participate in policy formulation by contacting their legislative representatives to make their opinion known, participate in advocacy or interest groups and utilize other communication outlets to inform and persuade others to their cause.

What does Political Advocacy Entail?

Strategy and action steps are necessary to achieve desired objectives in political advocacy. While the goals are the same (organizing citizen participation and influencing policy adoption) at every level, different strategies may be employed to influence decision makers at the local level than say at the global level. Here are some strategies that could be employed.

Policy advocacy

To successfully influence decision makers about the merit of their cause, advocates use policy analysis, to evaluate alternative courses of action (Simon-Morton, Greene & Gottlieb, 1995). Policy analysis highlights the pros and cons of alternative policies in the areas of cost, effectiveness and outcomes. Another purpose of policy analysis is to illustrate the feasibility of implementing a proposed policy or regulation. Providing decision makers with draft legislation or a position paper that outline implementation steps can be influential.

Grass roots participation

Mobilizing the support of concerned citizens sympathetic to your cause is critical for sustained efforts to reach the desired goals. Advocacy is a continuous process that takes time to yield results. To exert sustained pressure on decision makers to act in favor of a draft legislation or adopt a position, requires the participation of concerned citizens who are ready to make phone calls, participate in public demonstrations or write letters to their elected representative urging them to take action. Technology provides important tools such as social media that offer creative ways to organize and reach people for social change. For example, Face Book, Twitter and Instagram are platforms where messages about the issue of concern could be communicated to create awareness, change attitudes and persuade other like-minded citizens to join the cause.

Coalition Building

Organizing constituency groups is an important part of political advocacy. Coalitions comprise of two or more groups or organizations that combine efforts and resources towards a shared goal. Coalitions provide political muscle behind advocacy to address a social problem. When policy makers receive multiple phone calls or multiple letters from several constituent groups in favor of a certain proposal, they pay attention to that issue. It is therefore important for political advocates to always seek to build and maintain organizations or pressure groups that support the policy prescriptions that they advocate.

Some of the direct and indirect benefits of coalitions (Butterfoss, 2007) include:

- Mobilizing diverse populations, talents, resources, and strategies.
- Sharing cost and associated risks.
- Serving as effective and efficient vehicles for exchanging knowledge and ideas.

Developing leadership among citizens

The sustainability of an advocacy effort relies not just on grassroots participation and coalition building, but also on the development of a cadre of citizens who will become future leaders. The core of advocacy is citizen participation in activities to improve a social problem or condition. Future leaders need to be trained in the advocacy planning process, how to build and sustain coalitions, how to influence policy makers and how to use the media to frame the issue in a way that is sympathetic to their cause. It is incumbent on those involved in political advocacy to mentor others who will learn and gain the experience to become future leaders.

Personal contact with policy makers

Legislators at the state and federal levels have a busy schedule. The issues that come before them for a decision, whether enacting a new law, making changes to existing law or implementing a law are often complex with pressure groups from opposite sides of the issue seeking to influence their decision. An advocate who has established contacts with an elected leader or her/his staff has an advantage that can be used to inform and educate the policy maker with position papers or draft legislations. Frequent contact with city or county managers and department heads, legislators, and their staff is essential for advocates (Johnson & Beckon, 2007).

Conducting Research

It is not enough for political advocates to be informed about their cause. They also need to be persuasive. Conducting research on the social problem will provide advocates with critical information to make the case for the solutions and policy proposals that they advance. For health related matters, two reliable web sites that can be used for research on the health conditions include www.cdc.gov and www.nih.gov. Statistical data can be very effective to compare and contrast similar social problems and help advocates explain why their issue of concern is worthy of attention by policy makers. Moreover, statistical data provide an objective quantifiable way to expose the scope and scale of a social problem such as disparities in health outcomes. For example, statistics from the Centers for Disease Control and Prevention (CDC, 2016) website shows that in 2013, Black men in America had the highest rate of getting prostate cancer and were more likely to die of it than any other group. This statistic can help advocates frame the conversation and better tell the story about the social problem for their advocacy.

Media advocacy

The media is an invaluable tool that can be used to influence policy makers, change societal attitudes and behavior and ensure the implementation of policies. The term media is used here to refer to electronic, print, radio, television and other mediums of personal or mass communication. Advocates need to create a media strategy on the social problem they are involved with by addressing the following questions:

1. What is the social problem or issue we are dealing with?
2. What are the possible solutions or proposed policy that can address this issue?
3. Who is the decision maker who can address this issue?
4. Who needs to be mobilized to apply pressure on decision makers?
5. What do our target audiences (policy makers, citizens) need to hear about this issue?

A message needs to address three items: identify the problem, propose a solution and provide a value statement. It is important to use language in any message that is easy for lay people to understand.

Political Advocacy Case Study: Positively Staying Alive (PSA)

In 2006, a coalition of concerned citizens, advocacy groups and community organizations in the state of Florida came together to address the growing disparities in health outcome for Black men in regards to prostate cancer. Statistics for the year 2003 indicated that Florida was second only to California in terms of incidence rates and fatalities from prostate cancer. The goal of this coalition was to address this health issue through legislation that would mandate health insurance companies to cover preventive screening for prostate cancer among all men aged 40 or older in Florida. Coalition members included the National Comprehensive Cancer Network (NCCN), 100 Black Men of Jacksonville, fraternity organizations and faith-based organizations.

On the opposing side of this campaign were some strong corporate interests, especially as the proposed legislation was to require health insurance policies, group health insurance policies and health maintenance contracts to provide coverage for annual screening for prostate cancer for men aged 40 and older. These groups spared no effort to lobby policy makers not to pass the proposed legislation.

One of the main aspects of this campaign was to educate men about the risks associated with prostate cancer and the steps that could be taken to minimize those risks. The importance of regular screening which could potentially lead to early detection was emphasized. One of the communication messages used in this campaign was "**early detection leads to direction**." Another message encouraged men 40 years and older to talk to their doctor about checking their prostate specific antigen (PSA) level as a way to "**Positively Staying Alive**".

Cognizant of the important role of research in the prevention, care and treatment of cancer, this proposed legislation had provisions addressing cancer research. For example, it authorized the University of Florida prostate disease center to work with other organizations and institutions in cancer research and to create a systematic focus on increasing community education and awareness of prostate cancer.

The outcome of this campaign was the passing of Senate Bill 110 by the Florida Senate in 2007. Similar efforts to pass a bill in the House failed leading to a defeat of the measure to mandate insurance companies to provide preventive screening for men 40 years and older in Florida. Important lessons can be learned from this advocacy campaign. First, communication messages used in this campaign were deliberately targeted at Black Men, increasing their awareness about this important issue in a way that they could understand and relate. For example, one campaign message stated, "**Real men don't fear the finger**" in reference to the Digital Rectal Examination (DRE) for screening. Secondly, the importance of having champions within the policymaking circles who could talk to their colleagues and advocate on behalf of the cause. Lastly the effectiveness of prostate cancer survivors who through testimonies give voice to the fear and hope that others may be feeling about this disease, and provide encouragement for other men to get screened for the disease. To reduce or eliminate the health disparities in prostate cancer among Black men, we need to use advocacy as a tool to raise awareness about this disease and encourage men to talk to their doctor about being screened. Remember, "**Early detection leads to direction**".

Take away points

Political advocacy is the process whereby ordinary citizens seek to change a social problem or issue through the democratic process. It involves identifying the issue of interest, finding out possible solutions and working with other like-minded citizens to influence policy makers to act in favor of the issue that you are advocating. The statistics in Florida speak for themselves. It is now time for us as men in Florida to speak to the policy makers. PSA = **P**ositivity **S**taying **A**live. DRE = **D**ecision **R**espect **E**ducation. It is time we eradicate this disease. This is a good fight and we, as men need to be in it.

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Chapter 8

Research Advocacy

Mary (Dicey) Jackson Scroggins

What is Research Advocacy?

The advocacy movement is alive and well in the United States and growing in strength and significance globally, with research advocacy—an influential subspecialty—firmly taking hold throughout the cancer research enterprise. Research advocacy can loosely be defined as the meaningful engagement of patient advocates and their representatives in the research system by:

- Putting faces on the disease and keeping patients at the center.
- Giving voice to all patients and survivors (These voices are unique, experience-based, and indispensable).
- Asking questions specific to the authentic experience of cancer journeys.
- Creating a sense of urgency—by your very presence.
- Elevating the importance of survivorship (how well you live), the companion of survival (how long you live).
- Forming mutually respectful and beneficial partnerships with researchers.
- Providing Hope.

All of these factors result in research studies that are more focused on issues important to patients, more patient-friendly, and more likely to accrue participants. Therefore, with patient engagement, research is more likely to lead to benefits for patients.

What Research Advocacy Is, Is Not and Requires

Is	Is Not	Requires
A partnership between advocates and researchers	Easy, for the faint of heart or for the easily discouraged	Dedicated advocates—a volunteer workforce (not necessarily synonymous with uncompensated)
A natural alliance of individuals with like goals and differing but complementary experience	A short-term project (It is a long-term commitment.)	A supportive advocacy network and research system
Necessary for the most patient-focused, patient-accruable research	Free of costs—financial and other	Mutual acceptance and respect between advocates and researchers (and an acknowledgment of different but equally important contributions)
		Ongoing training/preparation—advocates, researchers, the public
		Commitment—individual, private, public, time, financial, logistical

The Necessary for Prostate Cancer Research Advocacy

Research advocacy strengthens the research process, changes the way researchers see patients and patient needs, and keeps patients at the center of research thinking and conduct. In addition, it empowers patients, families, and caregivers to be active in all parts of health care—from discovery to delivery—not simply to be passive recipients of research results. With prostate cancer the second leading cause of cancer deaths in American men and Black men having the highest incidence of the disease, it is extremely important for prostate cancer-focused advocates to engage in research, especially Black men, who have a 200% higher death rate than Caucasians. Participation in the research process

- Can shift research focus
- Reset research strategies and portfolios
- Otherwise direct research to the benefit of all patients and survivors.

A Wide Swath of Participants

The prostate cancer community typically includes wide swaths of participants in patient care, including wives, significant others, caregivers, and children, and this is the case for active, meaningful research advocacy. Like others engaged in cancer site-focused advocacy, prostate cancer research advocates can come from any or many of the following categories:

- Patients, survivors, family members, caregivers—everyday citizens.
- Curious, willing learners—with or without a science background.
- Clear communicators with the ability to read, write, and/or speak in the language of the populations represented or served.
- Members of health advocacy groups or other types of community activism.
- Scientists and clinicians.
- Other interested individuals with the time, lifestyle ability, and commitment to ongoing training and continuous education in the name of change.

Numerous Training Grounds

Many people are drawn to health advocacy and specifically research advocacy through personal or family experience with cancer, but no matter what the initial motivation is, all involved must commit to training and ongoing education to prepare to be effective research advocates. Advocates focused on the pressing need to change the statistics for all prostate cancer patients (that is, reduce suffering and save lives) and specifically for the most heavily burdened—Black patients—can train/prepare through:

- Full participation in their care or that of others.
- Self-advocacy (that is, being an empowered patient who, for example, researches all-things cancer and becomes an "educated" consumer).
- Advocacy group interaction and sponsored training.
- Local, national, and international programs focused on research training and networking (e.g., the Scientist↔Survivor Program of the American Association for Cancer Research).
- Online resources.
- The example and mentorship of a neighbor, community activist, or others engaged in the process.

There are many ways of preparing to be and continuing to grow as a research advocate, which include increasing your competence and knowledge base. National and international organizations such as Prostate Health Education Network (www.prostatehealthed.org), The Prostate Net (www.prostatenet.org), and Us TOO Prostate Cancer Education & Support (www.ustoo.org) are good sources of information and guidance, and small local organizations are also valuable resources.

Almost Unlimited Ways to Serve

Almost unlimited opportunities to participate in research advocacy exist through which advocates can influence and even drive the research process through their passion, perseverance, preparation, unique perspectives, and lived knowledge. Research advocates serve, for example, on:

1. Research grant review panels.
2. Institutional Review Boards (which are required for research involving humans and must have community membership).
3. National Cancer Institute Steering Committees, Task Forces, panels, and boards.
4. Department of Defense Research Programs.
5. Research studies (as study participants or research team members).
6. They also serve as community representatives for local research sites and in numerous other capacities.

Members of the prostate cancer community must prepare for full participation in such opportunities to make a difference in the lives of men and families nationwide and beyond. No one and no group can represent your interests and the urgency of your needs as well, as authentically, or as persuasively as those touched by prostate cancer and motivated to act.

Conclusion

The need for prostate cancer-focused advocates to engage in research advocacy is clear. In bringing your unique perspectives and urgent needs to the research process, you have the potential to change the landscape for prostate cancer patients and survivors everywhere. Therefore, as you prepare to be a research advocate, remember that you do not have to reinvent the wheel; you can actively pursue existing avenues of training (including self-motivated and self-directed learning) and the almost unlimited avenues through which you can serve. And, if a mechanism that you believe is needed does not exist in your immediate environment, work with others to establish that missing link, structure, or organization.

Research advocacy is developing a rich history of accomplishments all to benefit patients. As a research advocate, you can help to push the needle toward improved survival and survivorship because you are uniquely positioned to do so.

Therefore, if you are considering becoming a research advocate or honing your research advocacy skills, remember that you are not a researcher but the voice of the patient throughout the research process; your training and your contribution will be different but equally as valuable and necessary.

Your next step might be to develop a plan (why, who, what, when, where, and how) for entering the field or for honing skills. Once you have a plan, perhaps answer a few questions to test its feasibility and completeness:

- What will you need to succeed?
- Who and/or what will benefit from the plan. How?
- What are the major strengths of the plan?
- What are the major challenges of the plan?
- Is anything missing?
- Is your plan realistic, doable, flexible, feasible?

Patient advocates and researchers are natural and necessary partners in research and discovery. Join the partnership and strengthen the pipeline of prostate cancer-focused research advocates.

**** End of Chapter 8 ****

Chapter 9

Fundraising Advocacy

Virgil Simons, MPA

Creating Sustainability for the Mission

Commitment to the cause of being an advocate for those impacted by a diagnosis of cancer goes beyond just verbalizing a wish, belief, or desire to help; it mandates a professional implementation of a strategy that meets the explicit, and often implicit, needs of those targeted for support of the organization. That strategy goes well past the concept of 20th Century advocacy that stated: “***We’re good people, doing good things, give us money!***” In today’s world wherein transparent measures are expected, the advocacy group must emulate the execution of business to justify their existence and the credibility of their mission. Essential to success is understanding that, if they are truly to serve their constituency, they must have a plan of sustainability to insure that the advocacy will continue to be a positive factor within the community.

However, before you can embark on a plan for funding the initiative, there must be certainty that the structure you establish for implementation is consistent with the Mission of service of the organization. Depending on what type of services you plan to deliver, e.g. education, disease care, insurance supplementation, research, etc., you will need an organizational infrastructure that legally and effectively is consistent with the stated activities. You may need to be a non-profit corporation (501c.3), a NGO (non-governmental organization), or a public or private foundation. Each of these entities provide differing frameworks for fundraising and/or revenue generation; consultation with the attorney and accountant (absolutely necessary!) for the organization will help you to choose the appropriate infrastructure for your mission.

As you think about the structure of the organization, it is absolutely critical to understand the needs infrastructure of the group. Too often, a starting group invests a disproportionately high amount of their funds in offices or employees, which leads them to make fundraising decisions based on the economics of supporting the structure versus funding the mission. In this Internet-driven business environment, it is possible to initially present a global presence from a home office, a rented office space, or a business incubator, which will conserve funds until a desired revenue stream is achieved and a plan of implementation is structured around that revenue stream. You must think creatively about your social presence within the framework of what you can actually achieve versus mission objectives. It is important that, initially, the group make “small wins” of easily attained goals that enhance its credibility among the service group, potential stakeholders, and targeted funders.

Needs Analysis

After you have determined the structure under which you will operate, you must then move to undertake a needs analysis of the community that you plan to engage with and/or serve. Too often, many advocacy groups develop initiatives or programs for an audience without probing that audience to determine if the proposed initiatives are really needed or desired. Effective advocacy, and the funds to sustain it, must be derivative of what the community really needs to mitigate against the negative impacts of cancer on it, and that can only be determined by analyzing the current situation under which the community is being served. The basics of a sound needs analysis will include the following minimum information:

- ❖ Cancer incidence and mortality rates; trending profile.
- ❖ Variances in rates by race, ethnicity, socio-economics, geography, etc.
- ❖ Current service agencies operating in the community - public and private.
- ❖ How are the services delivered to the community?
- ❖ Access to those services based on availability, cost, education, etc.
- ❖ Risk profile by patient group.
- ❖ Competitive groups that offer programs similar to those planned by your group.
- ❖ Prevalent use of media to serve the community.
- ❖ Current or potential sources of program funding:

  - foundations
  - government
  - corporate
  - private
  - range of funding dollars provided by each sector
  - compatibility of your group funding request with that supported by each sector
  - appropriateness of funder to the initiative proposed
  - timeline of funding request to approval and funds distribution

From this needs analysis you should be able to determine exactly:

1. Who the target audiences for your programs should be.
2. The type of initiative that will be most effective in delivering the services you will provide.
3. The timeliness of the programs.
4. Those potential funders for your organization and programs.
5. The criteria of success measurement that will aid in developing on-going funding stratagems.

Most importantly, it will guide you in developing the business plan for your entity.

Creating the Vision

An absolute imperative for a successful organization is that its leadership possesses a Vision of what that organization intends to represent itself as, to what audience it intends to serve, of what its over-arching challenge is, how it will be met, and how it will evolve. The essential mandate is that everything changes and situations evolve; what was successful last year may no longer be effective or appropriate two years into the cycle. It is critical that the organization on a regular basis evaluate itself on its programmatic effectiveness and determine if changes are needed, how to implement them and to fund them. Consistent with this is establishing and regularly updating a “report card” of your activities, e.g. website, social media postings, direct electronic mailings, newsletters, etc. At minimum, each year you have to review the program put forth, the costs of implementation, measurement of the success as determined by initial goals versus the resulting market engagements, the evolution of the patient awareness and involvement, and whether or not your primary mission is still relevant. From this, changes should be obvious and actionable.

Funding Targets

Potential funding targets should be those corporations with a stake in having healthy communities based on their business focus, such as:

- Pharmaceutical communities producing drugs for treatment of relevant disease.
- Medical device companies with the same objectives.
- Private foundations with established records of supporting healthy community programs.
- Corporations deriving significant retail revenues from the targeted communities, such as food chains, drug chains, food service outlets, etc.
- Charitable private donors.

The World Health Organization (WHO) has defined advocacy as, *“the effort to influence people…to create change, which in the context of cancer control results in comprehensive policies and effective program implementation, through various forms of persuasive communication.”* Concurrently The United States Institute of Medicine has defined Patient Centricity as, “*Providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions.”* Both of these guidelines must form the structure and implementation for an effective patient advocacy organization, and will lead to an obvious plan for structuring the necessary fundraising and/or revenue generation objectives. Paramount in your mind as a leader of an advocacy organization is not only the “what” of your goals and objectives, but the “how” of your integrated initiatives to achieve your mission of serving the communities for whom you are giving voice. You cannot represent if you do not exist!

Fundraising Advocacy Case Study: The Prostate Net’s “Barbershop Initiative”

The BarberShop Initiative® addresses the lack of readily available, understandable and accurate cancer-related information in areas with significant high-risk, and/or racial minority populations. Through the BarberShop Initiative®, The Prostate Net® has forged partnerships between barbers and medical centers to directly deliver crucial information about prostate cancer prevention, treatment and supportive care in a sensitive and culturally acceptable manner.

Historically, educational and outreach efforts to Black communities for health screening or clinical trials have not been particularly successful, due to limited community and individual participation. Within minority communities, the barber and his shop have an important position as a place for social interaction and where free and open discourse occurs. Tapping into the barber's leadership to inform and influence his/her clients and neighbors has been an effective way to reduce and/or eliminate cultural barriers encountered when health care messages come from the traditional health care establishment.

Starting in 2004, the program targeted selected medical centers serving certain minority communities, then recruited and trained local barbers from the affected service area to function as lay health educators and patient navigators who motivate their constituencies to be screened and treated for prostate cancer. The medical centers found that this program enabled them to achieve a higher level of community and patient service - and to save lives. In the first year, more than 30,000 men received prostate cancer screening tests, and more than 400 prostate cancers were discovered, along with other co-morbidities such as colorectal cancer, diabetes, etc.

The program evolved through expansion of the concept to more medical centers in the United States that focused on the initiative to:

1. Increase prostate cancer clinical trial participation.
2. Increase patient access to their services.
3. Provide a channel of dialogue with the communities to address disparities in other disease areas, such as obesity/diabetes, colorectal cancer, etc.

Building on our "Knowledge Net" program's technology, the BarberShop Initiative® placed computer terminals in selected barbershops. These terminals were used exclusively to provide current information about prostate cancer detection and treatment through the Prostate Net website. Data reflecting the number of Knowledge Net users and the type of information accessed was also gathered and used by the initiative to better understand the needs of the populations served. The program was used by public health agencies in New Jersey, Chicago, Atlanta, Philadelphia, and New York City as part of epidemiological research studies to better target the needs of racially disproportionately impacted communities and to identify interventional tools that could improve disease specific risk and educational needs.

An outgrowth of the U.S. program has been implementation of the initiative in Orissa Province in India as part of a prostate cancer awareness and tobacco cessation program, in Australia as an initiative supported by the Prostate Cancer Foundations of Australia and New Zealand, and planned for Switzerland in 2017.

From this point, the BarberShop Initiative® evolved to its present form wherein it functions as a partnering agency with the Centers for Disease Control’s Comprehensive Cancer Control Centers in 16 city/state locations that have existing programs of cancer education, intervention and/or screening. The objective is to utilize a local network of barbers and barbershops as channels of information dissemination and motivators for participation in the local CCCC programs to reduce the incidence and mortality of prostate cancer within the identified target communities. Program managers from The Prostate Net will work with the local public health agency staff in recruiting and training barbers, training the local agency staff in how to establish effective networks of engagement, establishing performance measures, and in providing on-going support for the initiatives.

When the funding strategy was developed in 2005 for the national launch, conventional product management protocols suggested that a minimum of $500,000 would be needed. That was a level we quickly realized was not readily attainable, so the Director and Board made the situation to move forward with whatever funding could be generated under the premise that, if we could register the concept as being a product of The Prostate Net, then only the “what” of achievement would be recognized and less attention on the “how”. We employed a broad-based media strategy that included mentions on the “Tonight Show with Jay Leno” and hundreds of newspapers across the country.

Funds were generated from programmatic partners such as, American Airlines, MGM Studios, Sanofi Pharmaceuticals, The Healthcare Foundation of New Jersey, Popeye Chicken, and many other diverse stakeholders for a healthy community. The program continues today through the contract relationships with the local CDC agencies and licensing of the Initiative name to university medical centers targeting minority communities for health access and/or clinical cancer research efforts.

**** End of Chapter 9 ****

Chapter 10

Health Communications and Literacy Issues in Advocacy

Jennifer Nguyen, PhD, MPH

Communication as an advocate can be very tough. In today's changing world, it can be hard to know whether your message is effective or reaching the right audience. This chapter will introduce you to concepts such as health communication and health literacy to help you create your message efficiently and effectively.

What is health communication?

> Health communication: "The study and use of communication strategies to inform and influence individual and community decisions that enhance health." (Office of Disease Prevention and Health Promotion, 2010)

Effective and efficient health communication can influence both individuals and the community.

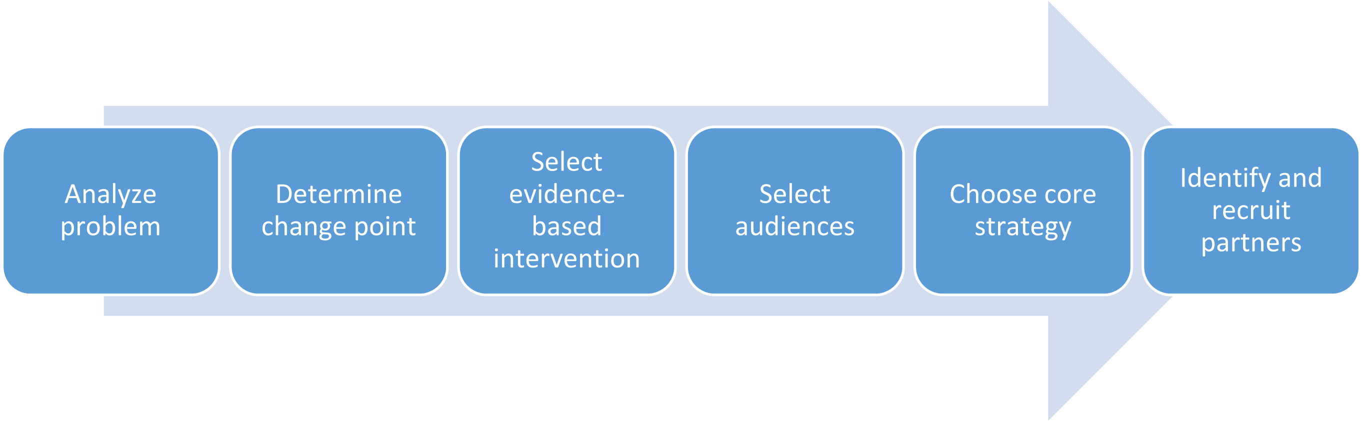
AT THE INDIVIDUAL LEVEL:	AT THE COMMUNITY LEVEL:
Raise awareness of prostate cancer	Influence public agenda
Provide motivation to reduce prostate cancer risk	Advocate for policies
Provide motivation for prostate cancer screening	Advocate for screening program
Help find support for those in similar situations	Promote positive community-level changes
Increase demand for appropriate services	Improve the delivery of health care
Make information available to assist in complex choices (for treatment, providers, etc.)	Encourage social norms that benefit health and quality of life

There are five key questions you should ask:

1. Have you correctly defined the behavior (e.g. screening, treatment choices)?
2. Is the strategy appropriate to the task, the audience, and what you are asking them to do?
3. Is the message appropriate to the task, the audience, and what you are asking them to do?
4. Is the channel (radio, television, blogs) appropriate to the task, the audience, and what you are asking them to do?
5. Is the medium (print, audio) appropriate to the task, the audience, and what you are asking them to do?

In order to make sure that you can answer the five key questions comprehensively, all advocates should plan at the beginning of your advocacy communication campaign.

Here are the steps you should take to comprehensively plan your communication campaign:



Analyze problem

Determine change point

Select evidence-based intervention

Select audiences

Choose core strategy

Identify and recruit partners

STEP 1: Analyze the Problem

Many times, we fail to realize that the root of the problem or issue is multi-faceted. For example, an individual may not go get a screening because of a) the stigma of prostate screening, b) the lack of awareness and understanding of prostate health, and c) the inability to receive paid time off to get the screening. The social ecological model (see image) is a framework to understand the dynamic relationships between society, communities, and the individual.

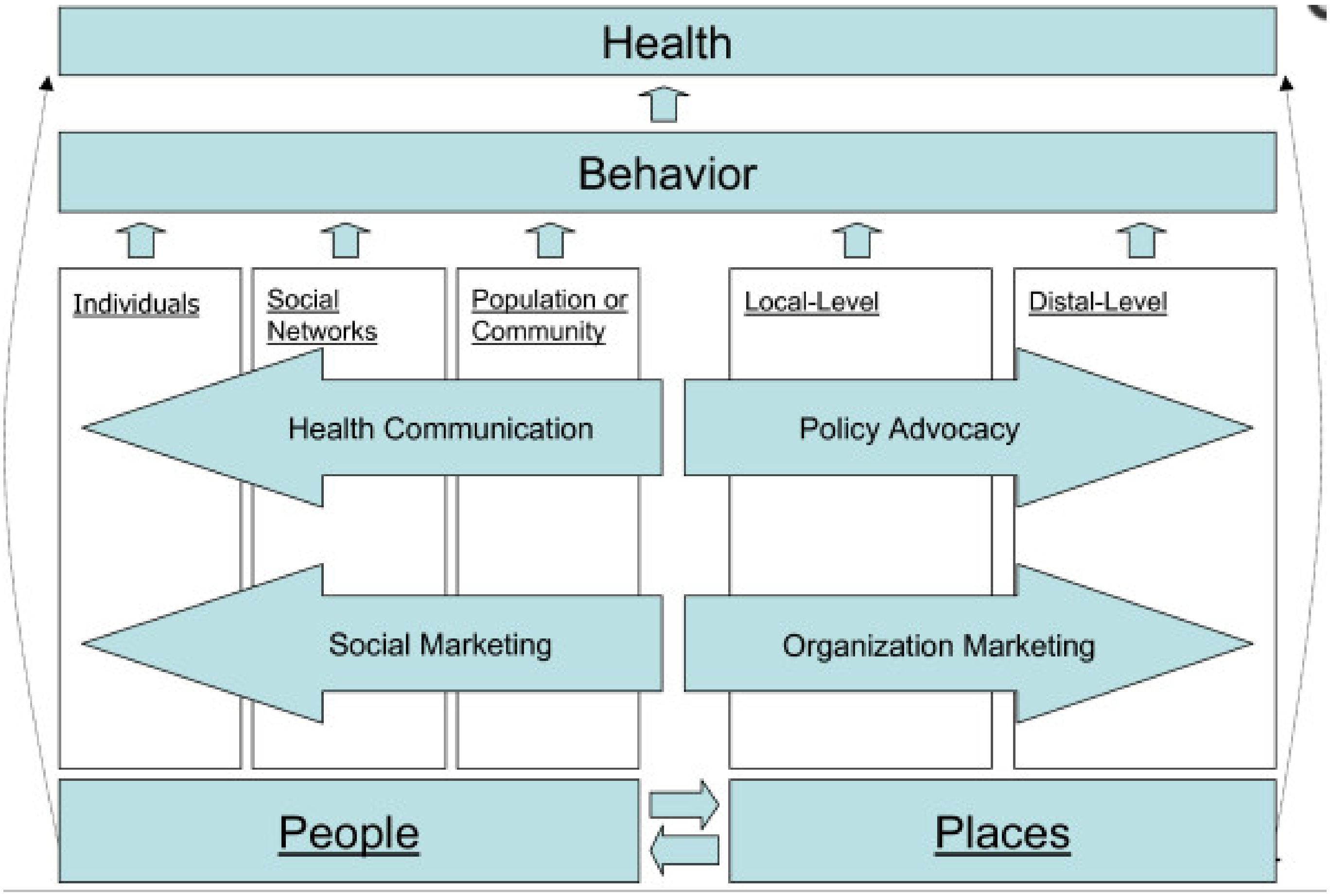
Below is a table (Parvanta, 2010) that outlines a level within the ecological model, the primary intervention that can be undertaken to address the issues within the level, and provides examples of communications support. Note that these communication support interventions or actions can be modified to fit your advocacy work.

Ecological Model Level	Primary Intervention	Communication Support
State, National, Global	Policies, laws, treaties, emergencies Example: Health care coverage	Advocacy to create or maintain policy or law
Living and Working Conditions	Hours and policies Example: time off and sick days	Awareness and promotional campaigns at work
Social, Community, Family	Social norms, community health programs Examples: Church ministries of health, volunteers	Grass roots campaigns, radio, TV, print, church-based marketing, health fairs
Individual behavior	Attitudes, acquisitions of beliefs, self-efficacy Examples: Ability to find a provider for screenings	Education materials, healthcare providers, decisional aids
Individual biology, Physiology	Prevention or treatment Example: healthcare provider visits, screenings	Reminders for screenings, healthcare provider communication during visits

STEP 2: Determine the Change Point

Think about who and where you would like to create this environment of change. To think about creating change in places, consider the follow fields of influence: organizations, businesses, advocacy organizations, and communities. To create change when considering "people" as your field of influence, think about social marketing, self-efficacy, and other psychological processes.

See the graphic (Maibach, Abroms, & Marosits, 2007) below to visualize the specific roles of communication and marketing can have in both spectrums of people and places. They all work together to change behavior in hopes of better health. These ideas and strategies (such as health communication, policy advocacy) work together to move towards a common goal and will not be effective on their own.



STEP 3: Evidence-Based Intervention

This step is extremely important so you can accurately estimate the impact, resources, and needs of the intervention. This step should include a review and evaluation of the scientific literature, including communication campaigns you are proposing. For instance, if you are interested in creating a campaign that encourages men who are undergoing treatment to get a second opinion, consider other campaigns that have tried to do the same in other cancers or in similar target populations. You should also discuss and consult with the target population. At this step, consider discussing your ideas and plans with the stakeholders in your community. Create a community advisory board and make sure that the members of the board are diverse and reflective of your community.

STEP 4: Identify the Relevant Audiences

There are three types of audiences for you to think about: primary, secondary, and tertiary.

Primary

Most affected by the problem

Hope to change their behavior

Secondary

Great deal of influence over behavior of primary audience

Example: Spouses, Providers

Tertiary

Group that affects behavior of secondary and primary audiences

Example: Children, Community Members

It is important to identify and understand your audience so you know how to tailor your message. Consider an intervention to encourage men to get their prostate screened. You should consider a complementary campaign to target their wives to encourage their husbands to go get their screenings. Health care and health care decision making rarely occurs in a singular vacuum and your secondary, or even tertiary, audiences may carry a lot of influence over your primary audience.

STEP 5: Choose a Core Strategy – inform vs persuade

In an ideal world, advocates would be able to change behavior easily and instantly with interventions that inform and persuade. However, it is most effective to decide whether the intervention focuses on informing or persuading. Think about your primary audience and what core strategy will be most effective for that audience.

For **informing**, you are answering questions, your content is meaningful to person asking the question, and you are providing tools to enhance health literacy, numeracy, and cultural competency.

Health Literacy: degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.

For **persuasion**, you are taking the evidence-based theories about decision-making to effect behavioral change. When choosing a strategy, please keep in mind health literacy. Many years of research has shown that the majority of health information is not usable or understood by most Americans. In fact, approximately 9 out of 10 adults have trouble using everyday health information from their doctors or the media. Without a clear understanding of the information, patients are more than likely to skip necessary tests, appointments, or fail to engage in preventive care. Patients with lower health literacy tend to make less informed health decisions that can result in poorer health outcomes. As part of your advocacy, it is important to keep in mind that everyone's health literacy level will be different, no matter his or her income, education level, or socio-economic status. For example, someone with a PhD in Physics may have no knowledge about prostate cancer but a patient care technician with a high school diploma may be more aware of prostate cancer. **It is better not to assume**. It is best that you ensure your message will be clear and understood by all.

In the case that you would like to identify how comfortable your audience is with health information, you can ask the following four questions (adapted from Haun et al., 2009).

1. How often do you have someone help you read medical materials?
    a. Always (1) – Often (2) – Sometimes (3) – Occasionally (4) – Never (5)
2. How often do you have a problem understanding the written materials about your medical condition?
    a. Always (1) – Often (2) – Sometimes (3) – Occasionally (4) – Never (5)
3. How often do you have a problem understanding what is told to you about your medical condition?
    a. Always (1) – Often (2) – Sometimes (3) – Occasionally (4) – Never (5)

4. How confident are you filling out medical forms by yourself?
    a. Not at all (1) – A little bit (2) – Somewhat (3) – Quite a bit (4) – Extremely (5)

To score, add up the numbers in the parentheses. Note that these four questions only assess a person's perceived health literacy level. Individuals' actual health literacy level are not being scored, rather, the scores indicate how comfortable the person is around medical/health information.

Score Range: 4-20

4-12 = Inadequate

13-16 = Marginal

17-20 = Adequate

STEP 6: Identify and Recruit Partners

Consider the mantra, "work smarter, not harder." Many campaigns and/or organizations out there may have similar messages or are targeting the same population. Identify these campaigns and organizations. They may be helpful in your advocacy work by collaborating with you during events or to reduce costs. They may also be able to share their difficulties or their successful strategies. Your work does not have to occur in a vacuum. Your work could be complementary to the ongoing efforts that currently exist.

Conclusion

Without the proper considerations, your advocacy work may not be impactful as it should be. By understanding the tools behind effective and efficient health communication, you can better plan your advocacy outreach. Remember that health literacy changes based on the situation, setting, etc. Do not be discouraged if your immediate outcome is not as successful as you thought it would be. Revisit the steps and evaluate what could be improved. Health communication and health literacy can be very complicated but it can definitely improve your advocacy efforts.

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**** End of Chapter 10 ****

Chapter 11

Public Health Consideration in Advocacy

Ernest Kaninjing, DrPH

The World Health Organization (WHO) defines advocacy as the “effort to influence people, primarily decision-makers, to create change, which in the context of cancer control results in comprehensive policies and effective program implementation, through various forms of persuasive communication.” Advocacy is an integral part of public health. It is used to increase public awareness about a specific public health issue such as disparities in the burden of prostate cancer across different populations, and seeks to influence stakeholders to take action. It is a tool used to ensure and sustain the health and well-being of the public at large. Advocacy seeks to change laws, regulations, policies and institutional practices that influence personal health choices (Chapman, 2001).

Background

In the United States, advocacy to improve the health of populations could be traced to the Progressive era (1890-1920) when there was an increase in demand for factory workers in urban areas. The limited housing available in these urban areas led to slums where factory workers lived in unhealthy conditions. Communities mobilized and advocated for better housing conditions and services for immigrant workers and poor citizens (Minkler, 2012). Advocacy in public health also resulted in laws that regulate motor-vehicle safety and mandated seat belts in cars. This led to reduced fatalities from automobile accidents and advanced the well-being of the population (CDC, 2016).

Certain elements are essential in order for advocacy to be an effective tool to address public health issues.

1. Advocates need to be **well informed** about the subject matter they are trying to address. In the case of prostate cancer, advocates need to have good knowledge of the signs, symptoms and risk factors for this disease and whom the disease affects. Knowledge about screening tests and treatment options is essential for advocates who can use this information to educate policy makers about this disease and seek to influence them in creating policy that could help reduce the impact of this disease.

2. Advocates need to be **engaged** within their own community and create conditions that will cause members of their community to be more receptive to health related information. Being active in community organizations like 100 Black Men that is engaged in mentoring, education, health and wellness, and economic development programs helps to engender goodwill within the community. This creates an environment whereby community members are willing and open to health related information coming from this organization because it is associated with good philanthropic gestures within the community.

3. **Planning effective strategies**. Besides being informed and active in the community, successful advocacy efforts entail careful planning. A key element in planning is framing the issue that needs to be address. For instance, men of African ancestry are disproportionately impacted by prostate cancer in terms of incidents and mortality of this disease (American Cancer Society). Having this knowledge can help during planning of an advocacy effort to frame this as an effort to redress the disparities that exist in the burden of prostate cancer. Another key element in planning is to know who to mobilize in your advocacy efforts. In other words, who are your allies and what resources could they bring to bear in your advocacy efforts. Thirdly, you need to know the key decisions makers and make a strategic plan on how to approach them. Policy makers such as legislators typically have a busy schedule so it is important for public health advocates to **be prepared** to summarize the message they want to get across and also demonstrate how the proposed policy they are advocating for, will also be of interest to the policy maker. Persuasive documented materials on the subject matter could enhance communication of the desired message.

There are several approaches and methods to advocacy. Here we present three approaches that are pertinent to public health advocacy.

Legislative advocacy

This approach to advocacy involves working with lawmakers to effect positive changes in government health policy. Individual citizens can get involved in legislative advocacy by writing letters or e-mail to their legislators expressing their views on certain public health topics and urging their legislators to adopt certain positions or vote in a certain way on pending legislation. It also entails education of the legislator on the health issue at hand, so that they are informed to make the right decision that advance the health of the public.

Policy advocacy

This approach aims to organize community participation with the goal of influencing the government to change or improve its health policy. Policy advocacy sometimes seeks to promote social change and redress social injustice. In this case, it is critical for advocates to form coalitions with other like-minded organizations or communities concerned or affected by the policy they are seeking to change. Multiple expression of the same view can cause elected officials to pay more attention to that view (Johnson & Breckon, 2007).

Media advocacy

Media advocacy is the use of the media to focus attention on a public health issue and apply pressure for policy change. The main goal of media advocacy is to influence public opinion, influence policy makers and influence policy. It may include the use of full-scale mass media campaign with advertising to gain public support for a specific policy or to influence policy makers to vote in a certain way (Edburg, 2007). Two key components of media advocacy include:

- ***Agenda setting***: This entails gaining access to the media and ensuring maximum coverage of the public health issue you are concerned about. This is designed to provide high visibility of the public health issue and to influence decision makers. A related aspect of this is using the media to gain access to key decision makers like politicians, regulators or business leaders to advocate for your public health issue.
- ***Framing the debate****:* This involves influencing the media coverage in a way that is beneficial to your cause. The use of simple messages that can be described in a short format and understood by non-experts can help to shape public opinion positively towards your cause.

Examples of materials/activities used in a media advocacy	**Examples of tools used in advocacy in general**
Press or news release	Electronic communication
Letters to the editor	Websites
Opinion (Op-Ed) pieces	List serve
Making presentation to an editorial board	Phone calls to legislators
Interviews	Newsletters

Public Health Consideration Case Study

Paul Hensaw grew up in a rural county in Michigan and followed in his father's footsteps working for an automobile company upon completing High School. Paul made a decent income and was able to support his family and raise two children. The automobile industry was the main source of employment in this area and provided steady jobs with benefits to its employees. The local economy flourished because of the success of this industry.

When the recession hit the U.S. economy in 2007-2008, the drop in consumer spending lead to a decline in new car sales and significantly affected the financial viability of the automobile industry. As a result, there was mass lay-offs in this industry that affected Paul and many of his colleagues. The local economy was in decline with high unemployment and few economic resources. The county also experienced some health problems such as high rates of alcohol abuse and drunk-driving accidents. The county health department commissioned an inquiry to identify the scope and scale of the health problems, who was affected and if there were any patterns. One of the main findings of this inquiry indicated that alcohol abuse problem was connected with the high unemployment in the county.

To address this issue, the county health department developed a health education program to educate citizens about the risk of excessive alcohol consumption and the consequences of driving while intoxicated. They worked with the local police department to tape public service announcements raising awareness about this issue in the community and educating the public about the negative effects of a bad driving record on employment prospects. Unable to find work for nine months, Paul Hensaw at the urging of his wife considered enrolling in college to pursue a degree in business hoping that it will help his employment prospects. However, the cost of this education and the time to complete it were prohibitive. Paul and two of his unemployed colleagues decided to lobby the mayor and state legislators to set up a job-retraining program in the county to train laid-off workers from the automobile industry with new skills that could be used in different industries. They did some research on the employment rate in the county over the past five years as well as the declining tax revenue that the cities and state were receiving over the past five years.

Armed with compelling statistics from their research, Paul and his colleagues were able to set an appointment with the mayor of their city where they advocated for an investment in a jobs retraining program to help unemployed citizens be trained for skills and jobs in other industries thereby improving their employment prospects. They argued that by investing in this retraining program, the city would benefit from increased tax revenue once the trained citizens become gainfully employed. With the support of the mayor, Paul and his colleagues lobbied their state legislators and requested their support in creating a job-retraining program that will benefit citizens across the state. With the help from the Chamber of Commerce, faith-based organizations and other community organizations, pressure was brought to bear on the state legislator and it eventually passed a job-retraining bill and sent to the Governor for signature. The health problems facing this community was linked to economic factors. Addressing both was essential for the long-term health of the community.

Take away points

At the core of advocacy is education in conjunction with elements of influence and power. Policy makers need to be informed about the public health issue for their advocacy. Effective advocacy efforts are borne out of careful planning and preparation, which helps to clarify the issue of interest and galvanize resources in support of advocacy issue. Personal contacts are helpful in gaining access to decision makers and those who can effect change.

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Chapter 12

Evaluating Cancer Advocacy Programs

Richard Segal, PhD

Advocacy defined as “a wide range of activities conducted to influence decision makers at various levels” requires careful and at least periodic evaluation to assist advocates in understanding their progress toward their goals. It further generates information that may be used to make adjustments in the pathway originally planned for reaching advocacy goals. Advocacy evaluation can be similar to the concept of “program evaluation,” which has been described as “the systematic collection of information about the activities, characteristics, and outcomes of programs to make judgments about the program, improve program effectiveness, and/or inform decisions about future program development (Patton, 1997). We evaluate advocacy-related programs for many reasons, including: (1) monitoring progress toward program goals; (2) identifying opportunities for program improvement; (3) identifying problem areas before significant resources are wasted and identifying what is working well; and (4) justifying the need for further funding and support.

Framework for Conducting Advocacy Evaluation

Among the types of advocacy evaluations are “process” and “outcomes” evaluations, both of which are considered necessary in evaluations of advocacy programs. *Process evaluations* are conducted to assess whether a program has been implemented as intended; while *Outcome evaluations* are conducted to assess whether a program is making progress toward its short-term, intermediate, and long-term outcomes. Having a conceptual understanding for the process for conducting advocacy evaluations is always useful. The U.S. Department of Health and Human Services Centers for Disease Control and Prevention (CDC) developed a framework which consists of six steps and four groups of standards for conducting evaluations of public health programs (CDC, 2005), which is applicable for evaluating advocacy programs. The six steps of the framework are presented in the outer ring of Figure 1 (CDC, 2015) and described below:

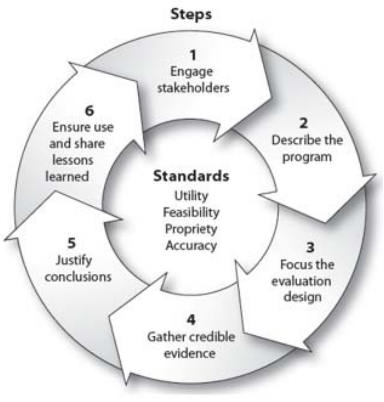

Figure 1. Evaluation Framework

1. Engage stakeholders who are invested in the advocacy program, are interested in its results and who have a stake in what will be done with the results of the evaluation.
2. A detailed description of the program helps to clarify all the parts of the program and its intended outcomes, thus helping to focus the evaluation on the most important questions that should be addressed as described in the next step.
3. Focus on the most important evaluation questions and identify the most appropriate design for the evaluation.
4. Credible evidence must be gathered to address the selected evaluation questions. Among the parts of this step are developing indicators or metrics and determining data collection methods and sources.
5. Analyze the evidence collected in Step 4 to show program effectiveness, help improve the program, or demonstrate accountability and justify the results from the analysis by comparing the evidence against stakeholder values.
6. Share evaluation findings with stakeholders in a timely, consistent, and unbiased manner.

Each of the evaluation steps in the CDC framework are intended to be influenced by a set of four standards shown in Figure 1, which include:

- ➢ *Utility,* specifically who needs the evaluation results and will the evaluation provide useful information in a timely fashion to stakeholders.
- ➢ *Feasibility,* will each of the planned evaluation activities be realistic given available resources.

- *Propriety,* will the undertaken evaluation protect the rights of individuals and protect the welfare of those involved and will it engage those most directly.
- *Accuracy,* are the findings valid and reliable (CDC, 2005).

Creating a well-developed plan for the evaluation process is critical for ensuring its efficient implementation and proper management. Prior to its implementation, the individuals responsible for conducting the evaluation should consider a number of practical issues, which are described below.

- ***Who will conduct and lead the advocacy evaluation****?* Often the availability of funding is a significant consideration when determining who will lead the evaluation process. Depending on circumstances, the following are options for consideration:
  - i. Using external evaluation contractors, such as individuals from universities or research firms or consultants.
  - ii. Using an internal evaluation team from within your own organization.
  - iii. Creating an evaluation team who may be available to all organizations in your region with a similar mission.
  - iv. Creating an evaluation team by using available public health personnel who have expertise in various areas of evaluation, such as designing an evaluation methodology, data collection, and analysis of data.

- ***How we will pay for the advocacy evaluation?*** Depending on who will be leading the advocacy evaluation process, funding may be required to pay for labor costs of the staff conducting the evaluation. Regardless of whether labor costs are required, funds are often needed to collect data and disseminate the findings. Sometimes funds are also needed to analyze the data as well. One source for funding the evaluation is to apply for funding to agencies with an interest in understanding the effectiveness of cancer control programs, such as from the U.S. National Institutes of Health. Another way to help pay for advocacy evaluation is to explore the possibility of engaging students from a university who are trained in evaluation methods and are looking for opportunities to fulfil practicums or thesis requirements that are part of a graduate or professional program. Collaborating with faculty advisors and students can provide a way to attract state-of-the-art methodological expertise to your organization and an opportunity to bring outside credibility to the findings of the program's effects. Understanding that the time committed by faculty and students is valuable, one should consider offering these individuals low-cost, but meaningful, rewards such as co-authorship of abstracts for presentation at professional meetings and co-authorship of manuscripts for publication in the peer-reviewed literature. When possible, providing travel reimbursement, meals, and housing, when needed, to students who are volunteering encourages their participation in the process.

- ***How do we develop an advocacy evaluation plan?*** All organizations involved in advocacy should create a formal evaluation plan that is updated annually. Four areas should be included in the plan at the minimum:
  - i. Identify stakeholders for participation in the evaluation process itself
  - ii. Program background and description
  - iii. Evaluation design and methods
  - iv. Approach for dissemination and utilization of findings

Each of these areas are discussed below.

Program Evaluation Case Study: Developing an Advocacy Evaluation Plan

I. Identify Stakeholders for Participation in the Evaluation Process

Stakeholders are the key individuals, organizations, or agencies that have a stake in the advocacy activities of your organization. They may be individuals that are directly affected by the outcomes of the cancer advocacy program; for example, cancer patients, survivors, clinicians, or public health workers. Organizations or agencies, including current or future funding agencies, academic institutions, and health departments may also be stakeholders due to their interest in the results of the evaluation and what will be done with the findings from the evaluation. They can even serve as data collectors or data analysts, although steps should be taken to ensure the accuracy and integrity of the data management process when those with a stake in the results of the advocacy program are involved. Stakeholders often will have a role in helping to interpret the findings from the evaluation and designing strategies for disseminating the findings.

Attention should be given to how stakeholders are identified and engaged during the advocacy evaluation process itself. In designing the evaluation process, stakeholders should be active participants in all the stages of evaluating advocacy programs. Their activities in the evaluation process can be considerable and varied. They can help to develop thoughtful questions to be addressed from the evaluation that, when answered, can address the most meaningful and impactful implications of the work performed by those conducting the advocacy activities. Involving stakeholders at the beginning of the evaluation planning process is invaluable and will help to determine whose voices should guide the evaluation process. Further, stakeholders may be invaluable in helping the evaluation team to gain access to the data sources needed to answer the evaluation questions.

Factors that are important when selecting which stakeholders shall participate in the evaluation process include:

1. Selecting stakeholders who are influential in the advocacy space of your organization such as those with influence at funding agencies and those who know the communities where advocacy efforts will be implemented well.
2. Selecting stakeholders that represent diverse perspectives and even those who may be critical of your advocacy goals and objectives. These individuals may help to shape the evaluation process to include metrics that are more discriminating by identifying the negative impacts of the advocacy process that may be otherwise ignored by stakeholders who are excited by the advocacy efforts and possibly blind to unintended negative consequences.
3. Including a reasonable number of stakeholders in the evaluation process so their expertise and talents can be managed effectively by the evaluation leader.
4. Selecting stakeholders who can commit the necessary time and effort to the evaluation process.

II. Program Background and Description

Paying attention to this step allows one to focus the design of the evaluation methodology. Involving the stakeholders in describing the core activities of the advocacy program and its intended outcomes is strongly encouraged as the evaluation team prepares the program background and description. Many advocacy programs have already created descriptions of their work for various purposes, and it is seldom necessary to recreate from scratch a program description, but often its necessary to add to the existing descriptions to ensure that it is detailed enough to serve the needs of the program evaluation.

One technique for displaying the description of an advocacy program is by using logic models in contrast to more traditional approaches such as providing a program description in narrative form or by using a table. Logic models are graphical displays of the relationships between a program’s resources, activities, and intended outcomes. The main components of a logic model are:

1. *Resources/inputs*, which are the resources invested in a program and can include financial and personnel resources for example.
2. *Activities*, which are actions undertaken by the program to achieve its outcomes.
3. *Outputs*, which are the direct results of program activities.
4. *Outcomes*, the desired results of the program, which may be short-term, intermediate or long term.
5. *Impacts* of the advocacy program.

Figure 2 displays the basic logic model (Kellogg Foundation, 2004).

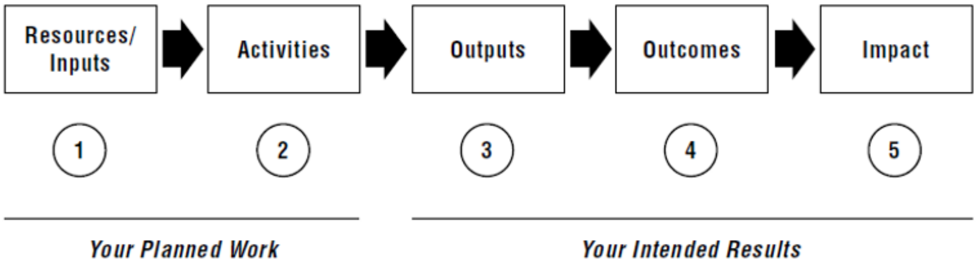

Figure 2. The Basic Logic Model[3]

Figure 3 is an example of a well-developed logic model built by the Alabama (USA) colorectal cancer prevention program (The FITWAY Alabama CRC Prevention Program).

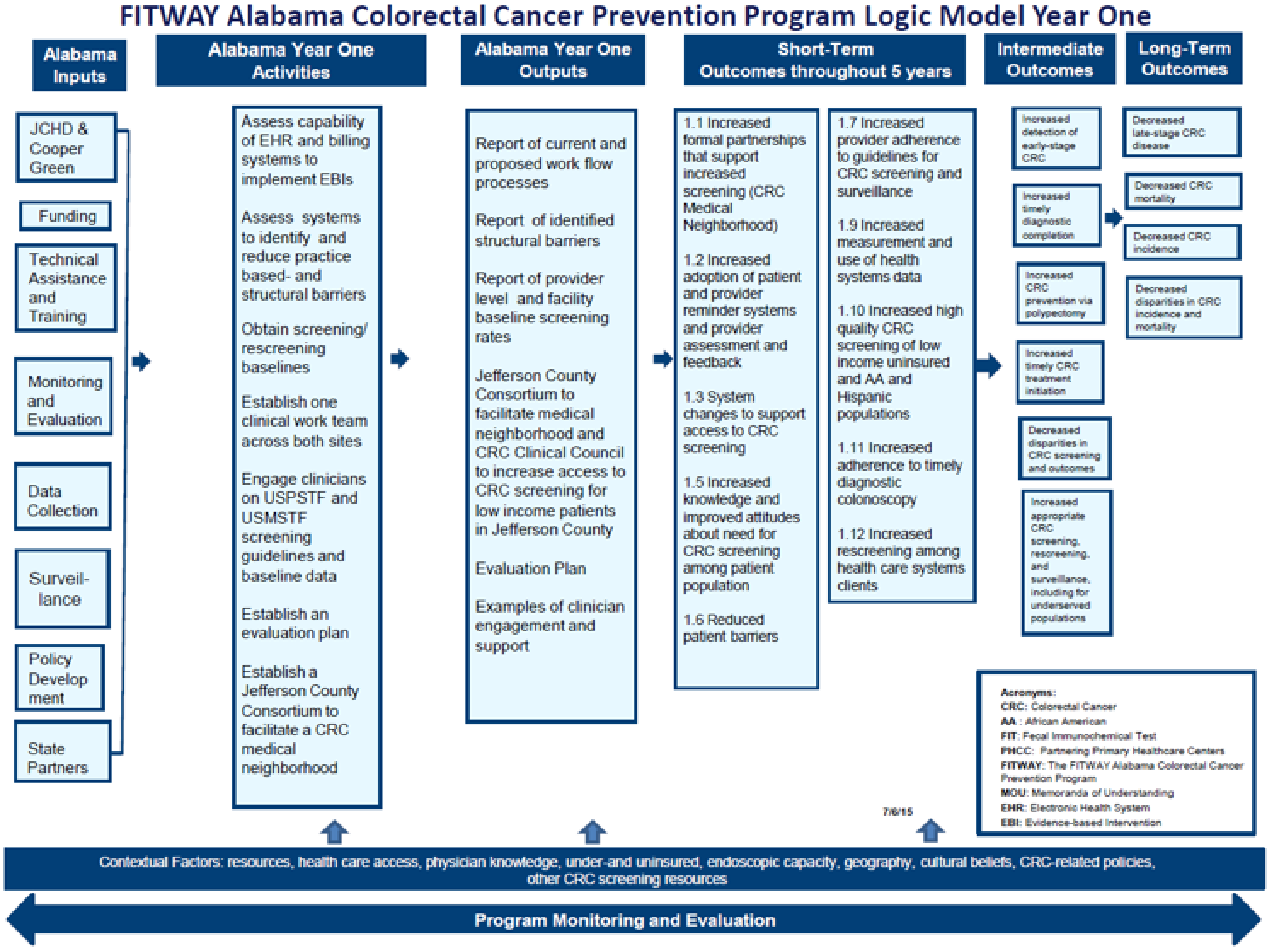

Figure 3. Developed Logic Model

III. Evaluation Design and Methods

This section of the advocacy evaluation plan builds on the prior efforts to engage the stakeholders in the evaluation process and on the logic model developed in the prior step. The evaluation design and methods section focuses on components of the advocacy program to be evaluated and associated questions to be answered, as well as the data collection, and analysis. Examples of focus areas for evaluating an advocacy program, recommended by the CDC, include:

1. *Products*, referring to the quality of resource material produced by the advocacy program.
2. *Training*, referring to the quality and impact of training programs provided by the advocacy program.
3. *Integration*, referring to the extent to which the advocacy program is integrated with related cancer control programs in the geographic areas of interest.
4. *Efficiency*, referring to the value and volume of outputs created by the resources that are invested into the advocacy program (CDC, 2005).

The advocacy goals and objectives must be clearly defined and the process of doing so will likely require wrestling with the questions, "What changes does the advocacy program want to bring about?" and "What must change and what alternative solution should be adopted?" (INTRAC, 2009).

Once having selected the focus area(s) and questions to be addressed by the evaluation, one should then turn their attention to metrics or indicators, which refer to the type of data and the measures required to answer an evaluation question. Indicators are intended to be measurable signs of the advocacy program performance and should be reflected in the outputs and outcomes developed in a logic model. Indicators are really what we observe to show the extent to which progress is being made towards goals. Indicators can also help by serving as a reference point for where we were performing at the start of a new advocacy program or before a new initiative in an existing advocacy program is implemented. Thus, indicators, if selected well, will show the evaluation team whether change has occurred and tell us when things are going well or when the advocacy program is failing. We should keep in mind that indicators only indicate and they do not really tell us why change has occurred.

The key to good indicators lies in its credibility. Quantitative indicators are not necessarily more credible than a qualitative observation. Different types of indicators are often needed to assess progress towards results. Three examples of indicator types are:

1. *Situational indicators*, which provide a broad picture of whether developmental changes, such as prevalence rates or mortality rates for prostate cancer for a country, have changed.
2. *Output indicators*, which assess progress against specific operational activities and are intended to be delivered within a short timeframe, such as the number of people trained to be cancer advocates in a region within a period of a year.
3. *Outcome indicators*, which assess progress against specified outcomes, such as the number and proportion of the relevant population being screened for prostate cancer or the proportion of the poor covered by insurance schemes for treatment of a diagnosed prostate cancer.

No one type of indicator is necessarily better than another; the choice of an indicator type depends on how it relates to the evaluation result we wish to measure (Sandhu-Rojon, 2016).

Evaluations of advocacy programs will often rely, at least in part, on the use of qualitative indicators. Numerical systems can be created for qualitative indicators to show magnitude of change, for example, whether the proportion of people who perceive and rate the government as being "responsive" to their need for access to cancer screening increases from 10% to 30% over a certain period of time. Such an increase provides a measure of the degree of qualitative change. In cases where an advocacy program has a goal of impacting policy results, qualitative observations may take the form of indicators such as a change in the composition of national budget devoted to cancer control or passage or enactment by a legislative body of a law legislation relevant to the advocacy initiative. Indicators for some of the evaluation questions are likely obvious, but the selection of indicators for some evaluation questions may not be straightforward. In the end, a good indicator is specific, measurable, attainable, relevant and trackable.

Data sources for indicators will vary based on the questions asked in the evaluation, data access, and funding. Examples of data sources include surveys and surveillance systems, cancer registries, vital statistics systems, interviews with key informants, observation, and documents associated with the program itself. Stakeholders can often help to identify the broad mix of data sources that may be necessary for evaluating an advocacy program, especially external data sources.

Data analysis methods should receive considerable attention to ensure that they are rigorous enough to address the evaluation questions and can withstand scrutiny by others who are external to the advocacy program and especially those for whom the advocacy program is intended to impact. While many evaluation questions may be analyzed using straightforward statistical analyses, other will require the use of more sophisticated analyses to adjust for biases that may have been introduced into the design of the evaluation.

IV. Approach for Dissemination and Utilization of Findings

The approach for dissemination and utilization of the advocacy evaluation findings builds on earlier efforts to engage stakeholders and focus the evaluation design on relevant questions to be investigated. The first step toward dissemination is effective reporting, which can take many forms such as radio or television spots, a newspaper article, website, briefing, detailed evaluation report with an executive summary, and a brochure. In reflecting on the dissemination approach, considerations should be given to carefully defining which target audiences or stakeholder groups will you share findings, what formats and channels are to be used to share findings, when and how often should findings be shared, and who is responsible for carrying out the dissemination strategies. The effectiveness of dissemination strategies is reflected in the extent to which the findings are utilized by stakeholders and other targeted populations. Steps that may be taken to increase utilization of findings may include holding regular meetings with stakeholder groups and asking them to help create recommendations for program improvement and for how best to operationalize the recommendations coming from the evaluation process and to influence change (CDC, 2013).

Conclusion

Each organization will have its own nuanced definition of advocacy, but common among all is an understanding that a program of advocacy requires careful and at least periodic evaluation to assist advocates in understanding their progress toward their goals. This chapter illustrates why it is important that every advocacy project be monitored continuously over its lifetime to show the extent to which the advocacy strategy is successful, to offer opportunities for building relationships with stakeholders, to describe the advocacy program and to document the evaluation process to learn from the experience to improve the future of the advocacy program, and finally, to demonstrate the results to funding agencies, policy-makers and other relevant stakeholders.

Chapter 12 References

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