

# PROSTATE CANCER INCIDENCE AND MORTALITY IN CALIFORNIA 1999-2000

Mark S. Litwin, MD, MPH  
Program Director, IMPACT

James R. Orecklin, MD, MPH  
Medical Director, IMPACT

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*“Our goal with IMPACT is to improve the health of underserved men in California who develop prostate cancer. This program is providing much needed care to many of the state’s neediest patients. And IMPACT is unique in the United States. It is the largest state-funded effort to provide comprehensive prostate cancer care to low income uninsured men, many of whom are from communities of color who have been medically underserved and disenfranchised.*”

*The approach we are taking in IMPACT is to address the whole patient, not just the prostate cancer. We are providing education, nursing interventions, counseling and nutritional support in addition to free prostate cancer care. IMPACT is designed to address not only patients’ acute treatment needs, but also their longer term needs to help them return to healthy, fulfilling lives after prostate cancer.”*

Mark S. Litwin, MD, MPH  
Program Director of IMPACT

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**PROGRAM MISSION**

The mission of *IMPACT: Improving Access, Counseling and Treatment for Californians with Prostate Cancer* is to provide high quality prostate cancer treatment and related medical care for indigent Californians who are uninsured or underinsured.

**EXECUTIVE SUMMARY**

IMPACT is a state-funded program whose mission is to provide free high quality prostate cancer treatment low-income California men with little or no health insurance. The program is administered by the UCLA Department of Urology under the direction of Dr. Mark S. Litwin and Dr. James R. Orecklin.

IMPACT understands the financial burden that prostate cancer may place on a man and his family. IMPACT understands that there are few options for a man who lacks the healthcare coverage or financial means to seek treatment. IMPACT is the first program of its kind dedicated to improving access to free quality prostate care and treatment for Californians living in all areas of the state. Full prostate cancer treatment and services are available at no cost to eligible patients and include a wide variety of options provided by high quality community physicians and health care facilities. The program funds prostate cancer-related treatments including surgery, 3D Conformal Radiation Therapy, palliative radiation therapy, hormone therapy, watchful waiting, and chemotherapy. Enrolled patients enlist the care of an experienced IMPACT Nurse Case Manager who provides individualized guidance and care management. Other IMPACT services include short-term personal and family counseling, nutrition education, and access to culturally competent, literacy sensitive prostate cancer educational materials and other resources to empower the patient with the knowledge to participate in his own treatment and recovery.

IMPACT partners with community providers, local health departments and other community based health organizations to bridge gaps in the detection, diagnosis, and treatment of prostate cancer. Through these partnerships, IMPACT has established a growing network of health care facilities statewide to evaluate and treat the men within their own local communities. IMPACT has also developed an extensive referral list of organizations providing prostate cancer screening and other support services for populations at risk.



## **CURRENT STATISTICS**

*Prostate Cancer in California – Special Report: Searching for Causes & Cures by the Public Health Institute* noted that between 1991 and 1995 the cumulative lifetime risk of being diagnosed with prostate cancer, by age and race/ethnicity in California was as follows:

<b>Cumulative Risk From Birth of Being Diagnosed with Prostate Cancer, by Age and Race/Ethnicity, California, 1991-1995</b>					
Birth to Age	All Races	Black	White	Hispanic	Asian/PL
	one in:	one in:	one in:	one in:	one in:
40	52,632	34,483	43,478	76,923	71,429
45	7,634	4,065	6,494	11,765	33,333
50	1,258	673	1,072	2,364	4,310
55	265	143	232	471	833
60	80	45	72	135	249
65	33	20	30	50	91
70	16	12	15	22	35
75	10	8	10	13	19
80	8	7	7	10	13
85	7	6	6	8	10
Lifetime	6	6	6	7	8

Race ethnicity categories are mutually exclusive. Persons of Hispanic ethnicity are identified by medical records and/or surname and may be of any race.

It was also noted that African American and Latino men in California are up to 1.5 times more likely to be diagnosed with advanced stages of the disease. Prostate cancer is incurable at the advanced stage, but if caught early it can be effectively treated and often cured while preserving quality of life.

Current American Cancer Society statistics note the following for 2003

- Approximately 20,500 new cases of prostate cancer will be diagnosed in California
- 2,700 Californians will die from prostate cancer
- The average annual age-adjusted mortality rates for prostate cancer (deaths per 100,000 men) by race, 1994-1998, are:

	California	National
Overall	20.8	23.7
Black	43.0	52.1
White	20.7	21.7
Hispanic	14.4	15.5
Asian/PI	8.8	9.5
American Indian/Alaska Native	6.7	13.4

## **THE PROBLEM**

Prostate cancer is the second leading cause of cancer death in California. One in six men and their families will have to deal with this disease and its treatment, which may result in any number of side effects that can potentially impact quality of life. Prostate cancer is thought by many to be more aggressive in minority patients, especially African American men. In addition, individuals in

communities of color may be inherently reticent to approach large health care organizations. Due to disparities of delivery of healthcare options and the bias against disenfranchised people.

Furthermore, there is a lack of low literacy and culturally sensitive educational materials that inform men about their treatment options and the impact high quality prostate cancer treatment can have on lengthening and improving their lives. Low literacy and lack of knowledge about prostate cancer are significant barriers to underserved populations. These barriers affect detection, diagnosis and treatment of the disease. Hence, these men constitute a primary target group with a great need for outreach, education, and treatment services for prostate cancer.

Prostate cancer is the most common solid malignancy diagnosed in California men. More than half of the new cases identified each year are clinically localized, an early stage of the disease in which the tumor is confined to the prostate. The usual approach to localized prostate cancer includes radical prostatectomy, radiation therapy, or watchful waiting. Unfortunately, clear evidence about the comparative efficacy of these treatments options is lacking.

The most common potential long-term complications after treatment for early stage prostate cancer may include urinary incontinence, impotence, and bowel dysfunction. The rates of these complications reported in the scientific literature by different researchers and institutions vary substantially. Although this variability may simply reflect differences in the patients included (case-mix) or in the ways in which the data were collected, it does raise concern that widespread variation exists in the quality of treatment provided for men with prostate cancer across the state of California.

### *Consequences of Being Uninsured*

Lack of health insurance is a serious problem for all Californians. It has been found to have strong associations with age, low income level and minority status. The uninsured may obtain basic health care services through “safety net providers” such as community health centers, hospital clinics, and free health clinics. However these facilities typically have limited hours, long waiting periods, and are not equipped to provide medicines or treatments for complicated illnesses such as cancer.

Not having health insurance has serious consequences for men. Men account for more than 50 percent of the uninsured in California. When men lack health insurance, they delay seeking needed health care, do not seek prostate cancer treatment, and die younger. Men without health insurance are more likely to be diagnosed with prostate cancer at a later, more advanced stage than those with health insurance. If prostate cancer is detected earlier through prostate cancer screening – an option usually unaffordable and not accessible to the uninsured – the likelihood of 5-year survival is higher.

In addition, men without health insurance and financial means often fall through the “safety net providers”. This means that the men’s income is too high for MediCal insurance yet they don’t have an ability to pay for prostate cancer treatment even on a sliding scale arrangement.

### **PROSTATE CANCER’S COST**

To understand the social implications of prostate cancer in California, it is important to examine the direct and indirect costs of the disease. A recent study published by Dr. Wendy Max et al. found that prostate cancer direct health care costs in California were estimated at \$180 million. Lost productivity from premature death was estimated at another \$180 million for a total cost of \$360 million in 1998. However, there are other costs (i.e. psychosocial and economic) associated with prostate cancer such as: decreased quality of life, loss of workplace productivity for the individual or his family members, increased household expenses, decreased tax base, and decreased spending power of the family. These human costs are often overlooked because the data is not kept or incomplete. Costs for prostate cancer are likely to increase as life expectancy increases, as improvements in prostate cancer treatment continue. At any given time, 105,900 California men are living with prostate cancer, which translates into increased costs for monitoring and management of morbidity, such as incontinence, erectile dysfunction, bowel dysfunction, and psychological issues related to changes in self-worth.

IMPACT recognizes the economic and psychosocial costs that prostate cancer has on Californians. Therefore, IMPACT has and continues to work to develop partnerships with medically and community-based organizations which provide detection, diagnosis, and treatment of prostate cancer. IMPACT strives to bridge the gaps and eliminate the barriers faced by low income, uninsured or underinsured men so that their disease is diagnosed and treated early resulting in improved quality of life, better treatment outcomes, increased 5-year survival rate, the ability of men to return to work, and lower economic and psychosocial costs.

The historical economic burden of prostate cancer

<b>Historical Prostate Cancer Expenses 1998</b>	
Direct Costs	Indirect Costs
<ul style="list-style-type: none"> <li>• Hospital care</li> <li>• Physician services</li> <li>• Prescription medications</li> <li>• Emergency room visits</li> <li>• Home health care</li> </ul>	<ul style="list-style-type: none"> <li>• Lost productivity resulting from premature death</li> </ul>
<b>Average Direct Cost per person = \$19,938</b>	<b>Average Indirect Cost per person = \$61,084</b>

Programs like IMPACT, provide substantial cost savings to the state, by reducing the direct and indirect costs of prostate cancer.

## **Prostate Cancer Incidence and Mortality in California, 1999-2000**

The focus of this evaluation is to facilitate understanding the issue of disparities among population subgroups and how the program IMPACT can help reduce racial and ethnic disparities in prostate cancer morbidity and mortality in California. For this analysis, we compared prostate cancer (CaP) incidence and mortality rates between 1999 and 2000 and between 5-yr period from 1991-1995 and 1996-2000 in all men and in four ethnic groups: Asian/Pacific Islanders, African Americans, Hispanics and Non-Hispanic whites. The reduction for California CaP incidence and mortality rates in 2000 from 1999 may be explained by any of the following:

1. The aggressive and comprehensive effort in the California public health sector in promoting CaP education, awareness of risk factors, and cancer prevention and control in an effort to reduce the burden of prostate cancer.
2. Better public health monitoring and surveillance of prostate cancer from screening, and of provider and public knowledge about prostate cancer and its prevention, such as identifying population at high risk, preventive measures that include identifying risk factors, environmental agents and dietary factors that affect risk for CaP.
3. Better CaP screening, diagnosing and treatment methods.

Highlights of CaP incidence rate results **Table 1** and **Figures 1A & 1B**.

1. Overall, incidence rates **decreased** for all race/ethnicities (**2-8%**) in 2000 from 1999. The largest decrease occurred in Asian/Pacific Islanders. Significant **decreases (13-19%)** in CaP incidence occurred for all race/ethnic groups in 1996-2000 from 1991-1995 (P<0.02).
2. The African American incidence rate is about **1.6-fold higher** than for all men, **~3-fold higher** than Asian/Pacific Islanders and **~2-fold higher** than Hispanics, with **3.2%** increase in 2000 from 1999, with a significant decrease of **13%** (P<0.02) between 1991-1995 and 1996-2000. The difference between incidence rates for African American and all men increased **3% increase** in 2000 from 1999, with a **6% increase** in 1996-2000 from 1991-1995.
3. The Hispanic incidence rate is about **20-22% less** than all men and **~1.3-fold higher** than Asian/Pacific Islanders. While the difference between 2000 and 1999 is minimal (**2% reduction**), in 1996-2000 from 1991-1995 there is a significant **decrease of 15%** (P<0.02). As for the rate difference between Hispanics and all men, **about 3% increase** in 2000 from 1999 and in 1996-2000 from 1991-1995.
4. The Asian/Pacific Islander incidence rate is about **42-43% less** than all men, with a **decrease of 8%** in 2000 from 1999, and a significant **decrease of 14%** (P<0.02) in 1996-2000 from 1991-1995. The rate difference between Asian/Pacific Islanders and all men saw a **2% decrease** in 2000 from 1999, and **5% increase** in 1996-2000 from 1991-1995.
5. There was no significant change in incidence rate for men between 18-64 years old, but there was a **~9% decrease** for men 65+ years old between 1999 and 2000. However, for the 5-yr incidence rates comparisons between 1991-1995 and 1996-2000, there is significant **increase** for men 18-64 (**100% for men <45, 21% for men 46-64, p<0.002**), and a **reduction of 27%** for men 65+ yrs (P<0.009).

Highlights of CaP mortality rate results in **Table 2** and **Figure 2**.

1. Overall, the mortality rate **decreased** for all race/ethnicities (**4-8%**) in 2000 from 1999, with highest in Asian/Pacific Islanders; and for the 5-yr mortality rates comparisons between 1991-1995 and 1996-2000, **reductions** ranged from **14-29%**, with highest in Asian/Pacific Islanders and Hispanics (P<0.002).
2. The African American mortality rate is about **2.2-fold higher** than for all men, **~5-fold higher** than Asian/Pacific Islanders and **~3-fold higher** than Hispanics with a **~6% decrease** in 2000 from 1999. and a **14% decrease** (P<0.02) for the 5-yr rates between 1991-1995 and 1996-2000. The rate difference between African American and all men saw a **3% decrease** in 2000 from 1999 and an **8% increase** in mortality rate in 1996-2000 from 1991-1995.
3. The Hispanic mortality rate is about a **one-third less** than for all men and **~1.5-fold higher** than Asian/Pacific Islander group. Whereas between 2000 and 1999 the mortality rate **reduced about 5%**, the 5-yr mortality rates between 1991-1995 and 1996-2000 **decreased substantially to 23%** (P<0.0005). For the rate difference between Hispanics and all men, **2% decrease** in 2000 from 1999, and about **4% decrease** for the 5-yr period comparisons.
4. The Asian/Pacific Islander mortality rate is about **60% less** than for all men. Between 2000 and 1999, the mortality rate **decreased 8%**, the 5-yr rates between 1991-1995 and 1996-2000 **decreased significantly to 29%** (P<0.0005). For the rate difference between Asian/Pacific Islanders and all men, **5% decrease** in 2000 from 1999, and about **12% decrease** in 1995-2000 from 1991-1995.

Highlights of IMPACT patient pre-enrollment and contacted data on ethnicity are summarized in **Table 3** and in **Figure 3**.

1. Statewide, about **19%** of African American men contacted IMPACT program from referrals, and **20%** from the eligible group, based on patient's self-reported information.
2. Statewide, about **41%** of Hispanic men contacted IMPACT program from referrals, and **43%** from the eligible group, based on patient's self-reported information.
3. Statewide, about **7%** of Asian/Pacific Islander men contacted IMPACT program referrals, and **9%** from the eligible group, based on patient's self-reported information.

**Table 1 - Incidence rate by ethnicity per 100,000 men in California**

Comparison Groups	1999	2000	% Change Between 99-00	Rate Difference Between Race/Ethnic Group & All Men in 1999	Rate Difference Between Race/Ethnic Group & All Men in 2000	% Change Between 99-00 for Rate Difference Between Race/Ethnic & All Men	1991-1995 (Mean ± SD)	1996-2000 (Mean ± SD)	% Change Between 91-95 & 96-00	Rate Difference Between Race/Ethnic Group & All Men for 91-95	Rate Difference Between Race/Ethnic Group & All Men for 96-00	% Change Between 91-95 & 96-00 for Rate Difference Between Race/Ethnic & All Men
All Men	157	148	-6%	□	□		187 ± 26	154 ± 4	-18%	□	□	
Asian/Pacific Islander	91	84	-8%	0.58	0.57	-2%	102 ± 11	88 ± 3	-14%	0.55	0.57	5%
African American	256	249	-3%	1.63	1.68	3%	285 ± 24	248 ± 5	-13%	1.52	1.61	6%
Hispanic	122	119	-2%	0.78	0.80	3%	140 ± 12	119 ± 5	-15%	0.75	0.77	3%
Non-Hispanic (White)	157	147	-6%	1.00	0.99	-1%	190 ± 32	153 ± 4	-19%	1.02	0.99	-2%
All Men < 45	0.9	0.9	0%				0.4 ± 0.05	0.72 ± 0.2	100%			
All Men 46-64	196	196	0%				156 ± 17	189 ± 10	21%			
All Men 65+	897	819	-9%				1,206 ± 213	883 ± 37	-27%			

**Table 2. Mortality rate by ethnicity per 100,000 men in California**

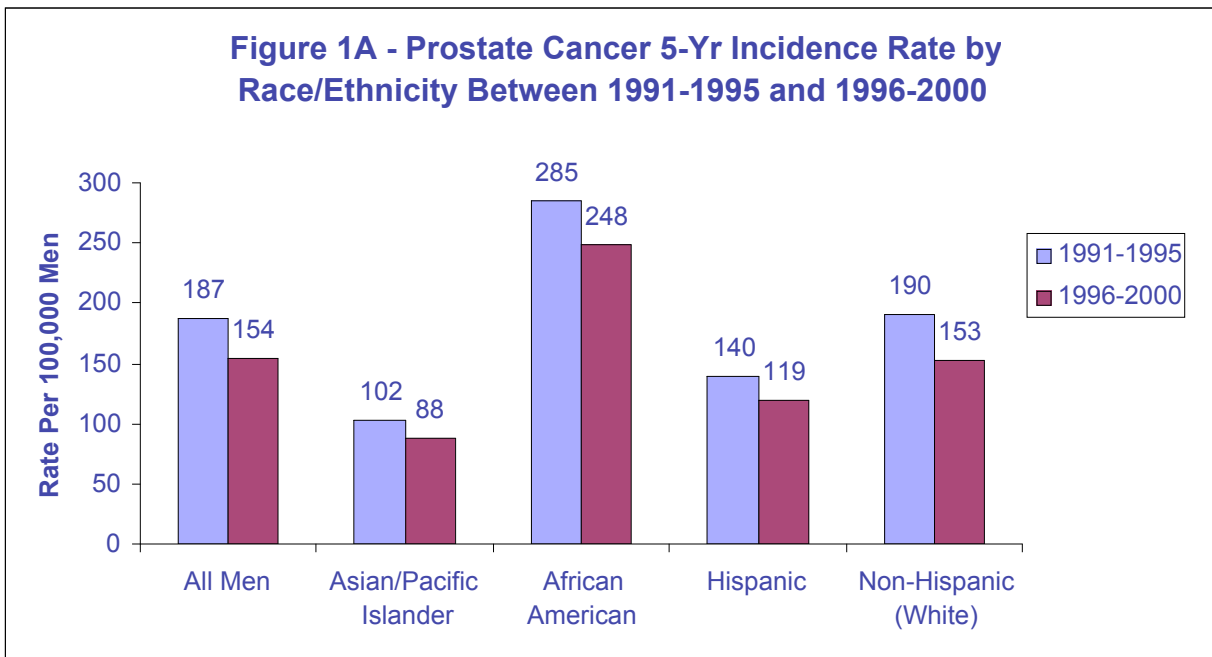
Comparison Groups	1999	2000	% Change Between 99-00	Rate Difference Between Ethnic Group & All Men in 1999	Rate Difference Between Ethnic Group & All Men in 2000	% Change Between 99-00 for Rate Difference Between Ethnic & All Men	1991-1995 (Mean ± SD)	1996-2000 (Mean ± SD)	% Change Between 91-95 & 96-00	Rate Difference Between Ethnic Group & All Men for 91-95	Rate Difference Between Ethnic Group & All Men for 96-00	% Change Between 91-95 & 96-00 for Rate Difference Between Ethnic & All Men
<b>All Men</b>	28	27	-4%	□	□		36 ± 2	29 ± 2	-20%	□	□	
<b>Asian/Pacific Islander</b>	12	11	-8%	0.43	0.41	-5%	17 ± 3	12 ± 1	-29%	0.472	0.416	-12%
<b>African American</b>	64	60	-6%	2.29	2.22	-3%	73 ± 3	63 ± 4	-14%	2.03	2.18	8%
<b>Hispanic</b>	19	18	-5%	0.68	0.67	-2%	26 ± 2	20 ± 2	-23%	0.72	0.69	-4%
<b>Non-Hispanic (White)</b>	30	28	-7%	1.07	1.04	-3%	37 ± 2	31 ± 2	-17%	1.03	1.06	3%

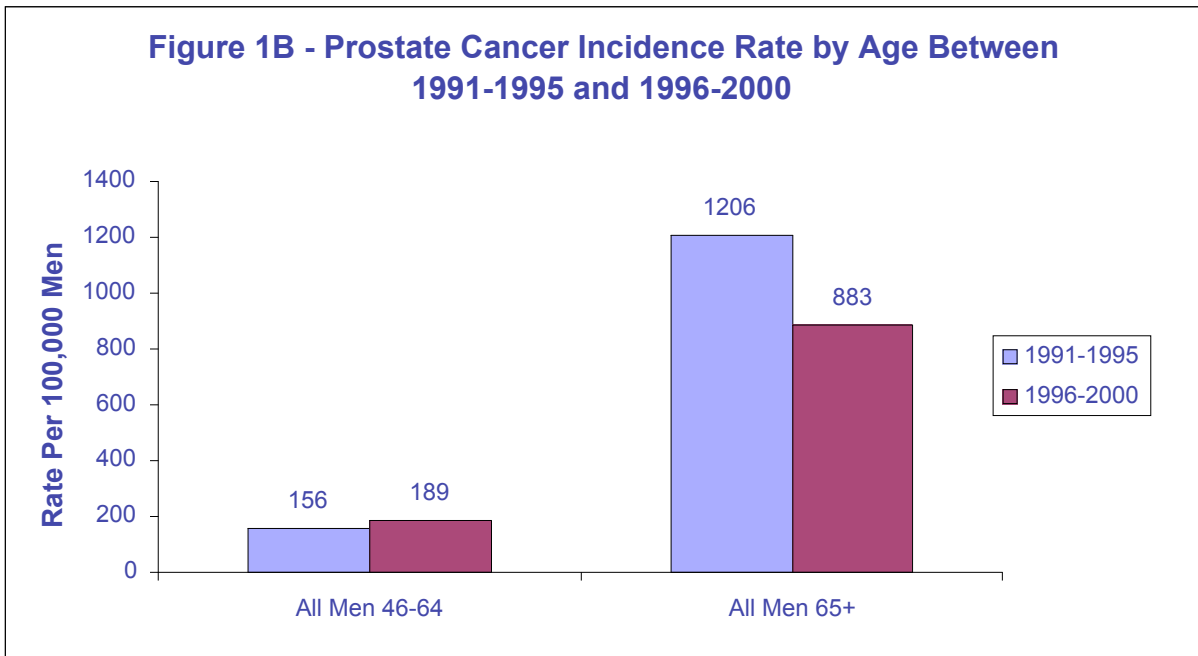
**Table 3. IMPACT patient pre-enrollment and contacted data by ethnicity**

IMPACT Eligible Patients	IMPACT Eligible Patients	% Distribution of Race/Ethnic Groups to All Men	Total Patients Contacted IMPACT	% Distribution of Race/Ethnic Groups to All Men
All Men	412	□	536	□
Asian/Pacific Islander	38	9%	38	7%
African American	83	20%	104	19%
Hispanic	179	43%	219	41
Non-Hispanic (White)	108	26%	156	29%

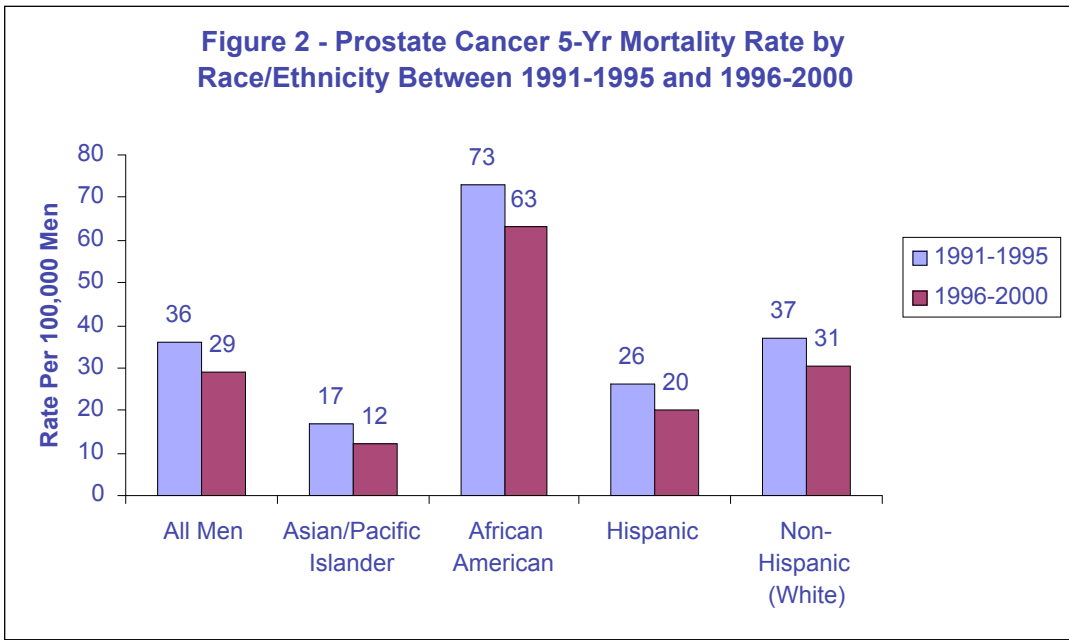
*Eligible* = Based on patient's self-reported information

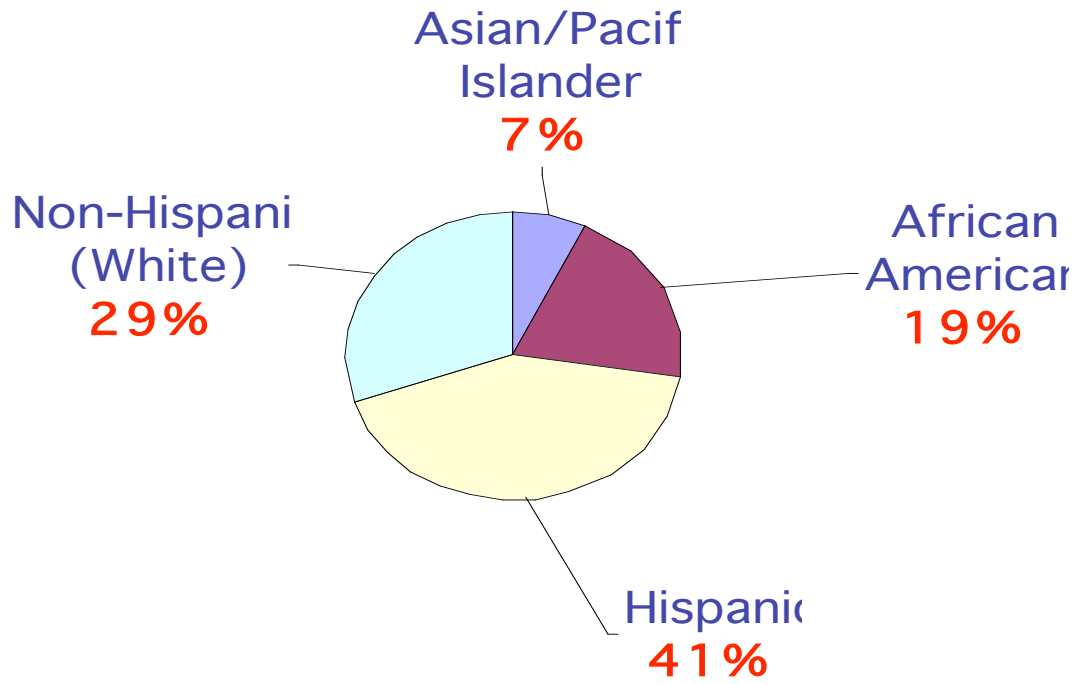
*Contacted* = including ineligible potential patients who received IMPACT referral services.





**Figure 3. Percent Distribution of IMPACT Patient by Race/Ethnicity**





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## **COMPONENTS OF THE IMPACT PROGRAM**

### *Nurse Case Managers*

The cornerstone of the IMPACT program is the Nurse Case Manager (NCM) care provided to every enrolled patient. At the inception of IMPACT, it was decided that each patient would be assigned a Nurse Case Manager (NCM) to ensure that patients did not become lost in the health care system. The primary goal of IMPACT NCMs is to empower patients through enhancement of self-efficacy. In addition, the NCM facilitates the patient's prostate cancer care and works collaboratively with health care provider to coordinate quality and timely prostate cancer care services. The NCMs role in the program has evolved as the program has evolved.

Low-income individuals face multiple barriers to feeling empowered including poor access to care, lack of resources, low literacy, and distrust of the health care system. Throughout the treatment process, men need to be able to interact with the health care system to have their health care needs met. This system is not always "user friendly," especially for uninsured, low-income men. Thus, intervening with men as they are being treated for prostate cancer provides opportunities to model problem-solving approaches, minimize barriers to promote successful interaction, and encourage self-initiated activities to optimize health care.

The NCMs utilize a wide range of strategies, which are individualized to each patient to remove these barriers. By educating, bridging gaps, promoting self-efficacy, enhancing of self-care capabilities, coordinating care across settings, brokering services, and serving as the patient's advocate, the NCMs empower the patient by enhancing his self-efficacy and diminishing his belief in his powerlessness. This increased self-efficacy empowers the patient to be a more active participant in his treatment decision-making, enhances his ability to cope during and after treatment, and increases his satisfaction with his treatment choice. It also decreases the patient's anxiety and facilitates communication with his healthcare providers.

The skillful tailoring and execution of these intervention strategies are dependent on the knowledge, experience, and skill that each NCM brings to the clinical situation. Without NCMs, the complex level of assessment and intervention required to manage the care of low-income, uninsured men with prostate cancer enrolled in IMPACT would not be possible. Furthermore, it would be difficult to strive for the goal of empowering patients through enhancement of self-efficacy.

### The IMPACT Nurse Case Manager Patient Empowerment Model

Patient Intervention Category	Definition	Strategies Menu	Individualized Patient Intervention
Assessment	NCM identifies patient needs and understanding of disease and selects strategies to meet these needs.	<ul style="list-style-type: none"> <li>• Review of patient’s current health status</li> <li>• Obtain medical and family history of patient</li> <li>• Assess available resources and support structure</li> <li>• Identify patient’s understanding of prostate cancer &amp; its treatment</li> <li>• Identify patient’s concerns &amp; worries about the disease</li> <li>• Asses patient’s emotional status</li> <li>• Identify patient preference for care &amp; treatment</li> </ul>	Strategies are individualized to each patient and are designed with input from the patient, health care providers, and family.
Facilitation	NCM assists patient with all aspects of the prostate cancer disease trajectory.	<ul style="list-style-type: none"> <li>• Expedite movement within the health care system</li> <li>• Provision of information/supplies to assist patient in self-management of disease</li> <li>• Encourage &amp; assist patients to voice their preferences and concerns to healthcare provider</li> <li>• Facilitate patient discussion of treatment options with healthcare provider &amp; family</li> </ul>	Strategies are individualized to each patient to promote successful self-action.
Advocacy	NCM provides support to patient throughout disease trajectory.	<ul style="list-style-type: none"> <li>• Obtain patient records or other clinical information the patient feels unable to obtain</li> <li>• Represent patient needs &amp; preferences to health care providers</li> <li>• Resolve medication and service payment issues</li> </ul>	Strategies are selected when the patient needs someone to act on his behalf.
Coordination	NCM assists in management of patient’s care across providers.	<ul style="list-style-type: none"> <li>• Contact agencies, health care providers, patients and family to coordinate treatment</li> <li>• Obtain patient clinical records</li> <li>• Make healthcare and social referrals</li> <li>• Arrange for medical supplies and medication</li> <li>• Identify barriers to treatment</li> <li>• Assist with transportation</li> <li>• Assist with translation services</li> </ul>	Strategies are utilized to provide a coordinated system of care individualized to the needs and preferences of the patient.
Teaching	NCM provides information to fill gaps in information or understanding of patient regarding disease trajectory.	<ul style="list-style-type: none"> <li>• Deliver culturally sensitive and literacy appropriate healthcare education about the disease and treatment options</li> <li>• Referral to clinical experts</li> <li>• Answer patient and family questions regarding disease and treatment</li> <li>• Refer patient and family to support group</li> </ul>	Teaching methods are individualized to reinforce patient’s capabilities and his learning of problem-solving skills.
Support	NCM provides continuous care throughout patient’s enrollment in program.	<ul style="list-style-type: none"> <li>• Provide contact information to patient and encourage its use</li> <li>• Follow-up calls to patients</li> <li>• Reassure patient and family about treatment progress</li> <li>• Support patient decisions</li> <li>• Keep patient and family informed about all aspects of healthcare</li> </ul>	Supportive actions are individualized to the needs and preferences of the patient and his family.
Collaborative Problem-Solving	NCM guides patient through a problem-solving process.	<ul style="list-style-type: none"> <li>• Active listening</li> <li>• Purposeful questioning</li> <li>• Identification of patient, family, and social resources and clinical actions needed to accomplish solutions</li> </ul>	Individualized actions are taken to reinforce the patient’s capabilities and learning of problem-solving skills.
Keeping Track	NCM tracks patients progress through the prostate cancer disease trajectory to prevent patients from “falling between the cracks” of the health care system.	<ul style="list-style-type: none"> <li>• Monitor patients progress through:                             <ul style="list-style-type: none"> <li>• Physician follow-up</li> <li>• Follow-up calls to patients, family members, other healthcare providers</li> <li>• Ascertain results of appointments or tests</li> <li>• Review of healthcare reports</li> </ul> </li> </ul>	Tracking efforts are utilized throughout patient’s enrollment in program to ensure patient is receiving necessary and appropriate care.

#### *Patient Education*

Early on, IMPACT undertook the development of a complete set of culturally competent, literacy sensitive, consistent, organized informational materials specific to the needs of underserved populations for a full disease course with multiple treatment approaches. Providing culturally sensitive education that is easy to understand for underserved men (1) enables them to be more informed participants in medical

decision-making, (2) assists them in regaining a sense of control over their lives, (3) enables them to manage both disease- and treatment-related symptoms competently and confidently, and (4) decreases anxiety related to uncertainty. Treatment modalities covered in the educational materials include hormone therapy, external beam radiation, radical prostatectomy, watchful waiting, chemotherapy, urinary incontinence, impotence, bowel dysfunction, and a variety of other related topics.

Of particular relevance to the IMPACT program is the notion of health literacy. Health literacy refers to a person's ability to comprehend patient education materials, physical care instructions, medication directions and other health-related materials. Millions of Americans are functionally illiterate or marginally illiterate with nearly half of those with the lowest literacy levels living in poverty.<sup>51</sup> Older adults tend to have lower levels of health literacy and that this is more pronounced in African Americans, Hispanics and those with less formal education.

Low literacy and lack of knowledge about prostate cancer are significant barriers to underserved populations. These barriers affect detection, diagnosis and treatment of the disease. Each of the treatment modalities for prostate cancer has significant side effects that patients and their families must manage in order to receive maximum benefit from the therapy and regain a sense of control over their lives. Without adequate information that is understandable and relevant, this is not easily accomplished. Furthermore, when treatment decisions are faced, patients need to be well-informed in order to be able to participate more knowledgeably in the decision-making process. This includes knowing and understanding the implications of each of the options under consideration, especially when effects may include bowel dysfunction, urinary incontinence and erectile dysfunction. Additionally, it is critical incorporate the cultural beliefs of the target audience if it is to be received, understood and used. Cultural sensitivity is even more imperative when dealing with sensitive topics such as sexual, bowel and urinary functions as is necessary when assisting people to deal with prostate cancer and its treatments over time. IMPACT has succeeded in overcoming many traditional barriers through its specially developed culturally competent, literacy sensitive prostate cancer educational materials.

### *Community, Patient, and Provider Education*

Utilizing a team approach, the IMPACT Education Team works to raise awareness of our program among our target populations, enhance our credibility with community-based organizations and establish relationships with medically-based organizations. Our education and outreach approach is aimed at socio-economically disadvantaged segments of the broader community and at the health professional community servicing low-income populations. These outreach efforts are focused on generating referrals of African-American and Latino men, the ethnic groups with the highest rates of prostate cancer in California.

IMPACT Education strategies include:

- Utilizing current United States Census and Department of Health Services data to target communities with greatest potential need of our program's services.
- Providing the public with language-specific and easy to understand materials
- Developing media contacts throughout the state to assist with placement of print, radio and television stories to raise awareness of the IMPACT program.
- Developing relationships with local and statewide agencies serving our target population, including: Cancer Care, Salvation Army, Real Men Cook, 100 Black Men, California Latino Medical Association and the American Cancer Society.
- Assisting with patient recruitment/enrollment in the County Hospital setting and making presentations to the medical directors and staffs of community-based clinics throughout California to raise awareness about IMPACT and prostate cancer.
- Attending community and cultural events that are visited by the IMPACT target population such as the African Market Place, Honoring Our Elders, Cesar Chavez Day Events, and the Black Business Expo.

Through these efforts, IMPACT enables men in our target population to exercise more control over their own health and environments to make choices conducive to better health.

### *Evaluation*

IMPACT has developed and implemented a comprehensive program evaluation plan. This evaluation plan systematically investigates IMPACT's success in providing high quality care to underserved men in California. Evaluation of IMPACT involves not only the creation of criteria or standards by which to judge the Program's performance but also the development of the tools necessary to determine how well these standards were met.

IMPACT Evaluation strategies include:

- *Developing Quality Of Care Indicators For Services Provided To Patients.* IMPACT will develop and conduct a survey of men participating in the Program to determine if the Program is meeting their needs. After an extensive review of existing instruments and questionnaires, their reliability, validity, and applicability to IMPACT's population, as well as the burden related to answering these items a comprehensive survey was developed and is currently underway. The

survey covers such topics as anxiety, cancer interference, comorbidity, distress, knowledge, quality of life, regret, self-efficacy, spirituality, and nutrition.

- *Analysis and Development of Educational Materials.* IMPACT is in the process of conducting an extensive review of available prostate cancer patient education materials. This review includes written materials, audio-visual tapes and prostate cancer websites. These materials will be reviewed and evaluated against the criteria for topic, target audience, completeness, accuracy, reading level, and cultural sensitivity for intended audience. Preliminary findings show that the available prostate cancer education materials are not written at an appropriate reading level, are not culturally sensitive, and are often incomplete. This review is leading IMPACT to develop its own patient education materials that are targeted to underserved men with prostate cancer.
- *Developing Quality of Care Indicators for Nursing Care Delivered by Impact Nurse Case Managers.* As part of the evaluation component of IMPACT, a tool to assess the quality of care delivered by the Nurse Case Manager needed to be developed. A literature review did not identify a specific tool for our population or for the responsibilities that the Nurse Case Manager has within this state funded program. Therefore, IMPACT has undertaken the process of developing such an instrument starting with the identification of quality indicators. This effort will make an essential contribution to the field of nursing including but not limited to the specialties of public health nursing, oncology nursing and to urological nursing.
- *Development of Quality of Care Indicators For Providers.* Studies have shown that patients perceive quality of care as logistical aspects of the process of encounter (e.g. waiting time in the doctor's office) rather than the providers' technical or professional abilities. Since it is difficult for patients to assess the quality of care they receive from their provider, IMPACT will not ask patients to assess their providers in this manner. Instead, we will utilize a series of quality of care indicators that can be implemented by the provider in order to assess the quality of care they provide to the patient. These indicators were taken from a RAND study conducted by Dr. Mark S. Litwin whose purpose was to "develop the infrastructure necessary to begin evaluating the quality of care provided to men with early stage prostate cancer".<sup>64</sup> This study involved a comprehensive review of current medical literature regarding treatment of localized prostate cancer, interviews with physician experts, focus groups with patients and spouses, and the convening of an expert consensus panel. The consensus panel reviewed and endorsed a list of quality of care indicators developed from the study. These indicators include measures of structure (i.e. the human, technical, and financial resources needed to provide medical care), process (i.e. the set of activities that goes on between patients and practitioners), and outcome (i.e. changes in patients' current and future health status, including health-related quality of life, as well as patient satisfaction).<sup>64</sup>
- *Quality Assurance in Impact Regional Offices.* As a statewide program, IMPACT recognizes the importance of creating a systematic method of implementing the program. Towards this end, a

standardized method for training regional office staff, data collection, and enrollment procedures has been created. Each staff member will take part in a comprehensive training program, which will include such areas as: enrollment, use of data tools, nutrition, and outreach. The regional offices will also receive regular updates and training as necessary regarding changes in the program. Quarterly reports from the regional offices will assist in monitoring their activities and the progress they have made in enrolling and treating patients.

- *Protection of Program Participants.* Although IMPACT is not a research study, the Program's affiliation with the University of California requires us to interface with the University of California, Los Angeles Office for Protection of Research Subjects (OPRS). OPRS defines program evaluation as a research activity. Therefore, IMPACT will work closely with OPRS to ensure that the dignity and welfare of individuals taking part in our program are protected. In addition to working with OPRS, IMPACT will also make certain that all materials produced for patients enrolled in the program are adapted for low literacy and translated into Spanish or other languages as necessary. This will allow economically and educationally disadvantaged participants to fully understand the information they receive and participate in the program.

#### **WHAT IMPACT PARTICIPANTS HAVE TO SAY**

- “Do you personally realize if IMPACT wasn't there, I couldn't have had this work? I mean...you may very easily have saved my life. I don't know if IMPACT realizes this because if you go to any of the public assistance program, they're very, “You do it my way, this is where you go, etc.” Where IMPACT gave me the choice of what treatment I wanted and...you even included my own urology doctor, who is wonderful, and you brought him into the study. You know, you actually probably saved my life.”
- A 59-year old Oxnard resident with eight children says that thanks to IMPACT he knows “that there are people that care for me.”
- One gentleman said that had it not been for the IMPACT program he would have had to sell his house in order to pay for prostate cancer treatment. He also said that as far as his treatment was concerned he “received cutting edge technology” from the IMPACT program.
- Another IMPACT patient said that the program “saved me from a nightmare.”
- “One of the worthwhile things I got from IMPACT was the repeated access I had to the professionals that helped me reach my (treatment) decision. The fact that you can keep going back to these radiologists, back to these surgeons with sometimes these stupid questions, these little things nag at you but it's really important and it gave me a peace of mind.”
- “I am very satisfied with the treatment I received. You have a good program going. Excellent doctors and nurses, very respectful of my wishes and that's why I feel I want to do all I can to help

the program. I am very happy with the program, matter a fact, I have recommended it to friends that I know that are in the process of being tested. Me, my wife, and my whole family have been very pleased. I commend you for your work.”

- “The program is wonderful. It’s an outstanding program. Treatment and doctors and everyone have been fabulous.”