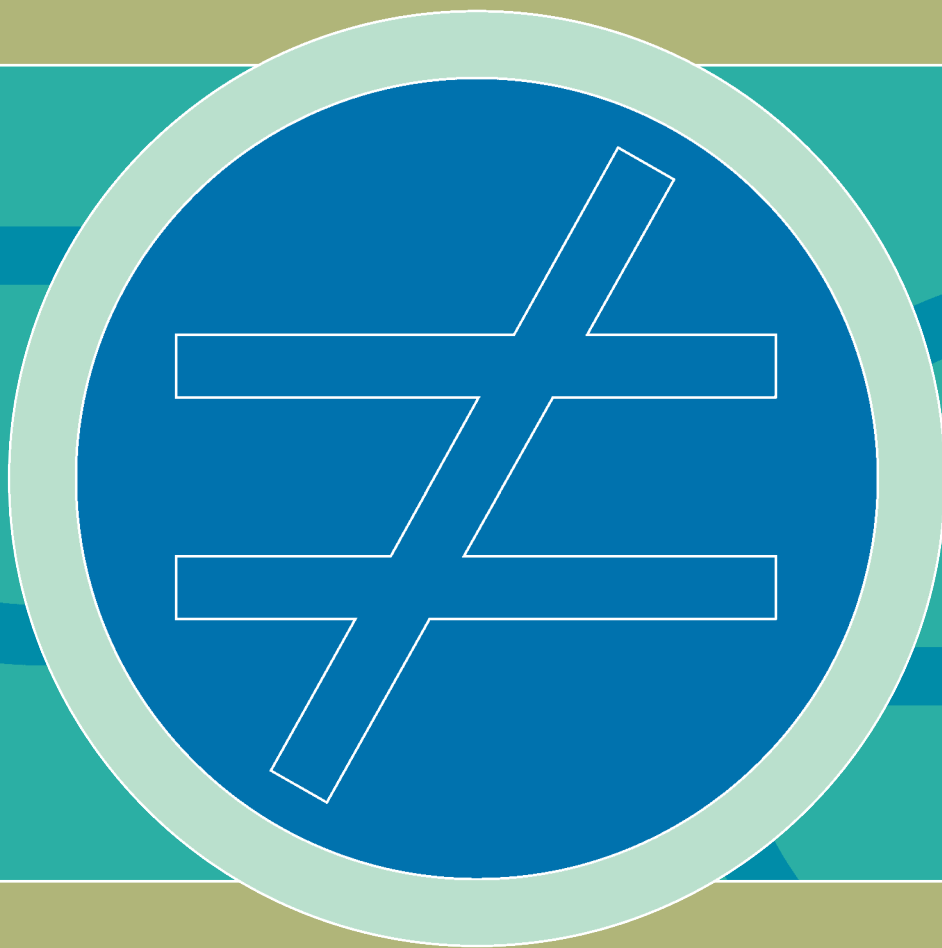


an insight into *Inequalities*



DISPARITIES IN CANCER INCIDENCE
AND MORTALITY IN DELAWARE

FEBRUARY 2007

A COMPREHENSIVE REVIEW

Cancer is a major public health burden in the United States. In Delaware, as in other states, this burden is not distributed equally across demographic lines. Cancer incidence and mortality vary by race/ethnicity, sex, age and socioeconomic status.

Although more is known about cancer prevention, detection, and treatment than ever before, there are still segments of our community that have not benefited from these advances. Some ethnic minorities experience more cancer than the majority population, and poor and uneducated people—regardless of race or ethnicity—often lack access to adequate cancer care.

When the Delaware Advisory Council on Cancer Incidence and Mortality formed in 2001, members knew that certain populations were more likely to be affected by cancer than others and therefore put significant emphasis on eliminating the inequity. To reach that goal, the Council focused on gathering and analyzing data to learn who shoulders an unequal burden of cancer in Delaware and to identify the factors that contribute to these disparities.

The final report, *Disparities in Cancer Incidence and Mortality in Delaware**, offers a comprehensive review of data gathered between 1998 and 2002. It also looks at the trends in cancer incidence and mortality by race and sex, the role of geographical location, differences in access to quality health care, and behavioral cancer risk factors.

In Summary: What We Now Know

- No racial/ethnic disparities were observed in the use of cancer screening tests.
- African-American men are more likely to die from prostate cancer than Caucasian men.
- African-American women are more likely to die from colorectal cancer than Caucasian women.
- Caucasian women are more likely to be diagnosed with breast cancer but African-American women are more likely to die from breast cancer.
- Only minimal differences were observed between African Americans and Caucasians in the stage at which cancer is diagnosed.
- The data indicates that the strongest predictor of lack of health insurance was lack of education. Overall, lack of access to health care was greatest for African Americans and Hispanics.

*The complete report is available at www.delawarecancerconsortium.com.

Defining disparities

Disparities—or inequalities—occur when members of certain population groups do not enjoy the same health status as other groups. Four health statistics are used to measure disparities: screenings—the number of cancer tests performed; incidence—the number of new cancers; mortality—the number of cancer deaths; and survival rates—the length of survival following diagnosis of cancer. Health disparities are indicated when one group of people has a higher incidence or mortality rate than another, or when survival rates are lower for one group than for another.

DISPARITIES IN THE CANCER BURDEN IN THE UNITED STATES

U.S. data from 1997 to 2001 found:

Compared to Caucasian men, African-American men are—

- 22 percent more likely to be diagnosed with cancer of any kind
- 60 percent more likely to be diagnosed with prostate cancer
- 44 percent more likely to be diagnosed with lung and bronchus cancer
- 16 percent more likely to be diagnosed with colorectal cancer
- 40 percent more likely to die of cancer

Compared to Caucasian women, African-American women are—

- 7 percent less likely to be diagnosed with cancer of any kind
- 21 percent more likely to be diagnosed with colorectal cancer
- 8 percent more likely to be diagnosed with lung cancer
- 17 percent less likely to be diagnosed with breast cancer
- 18 percent more likely to die of cancer

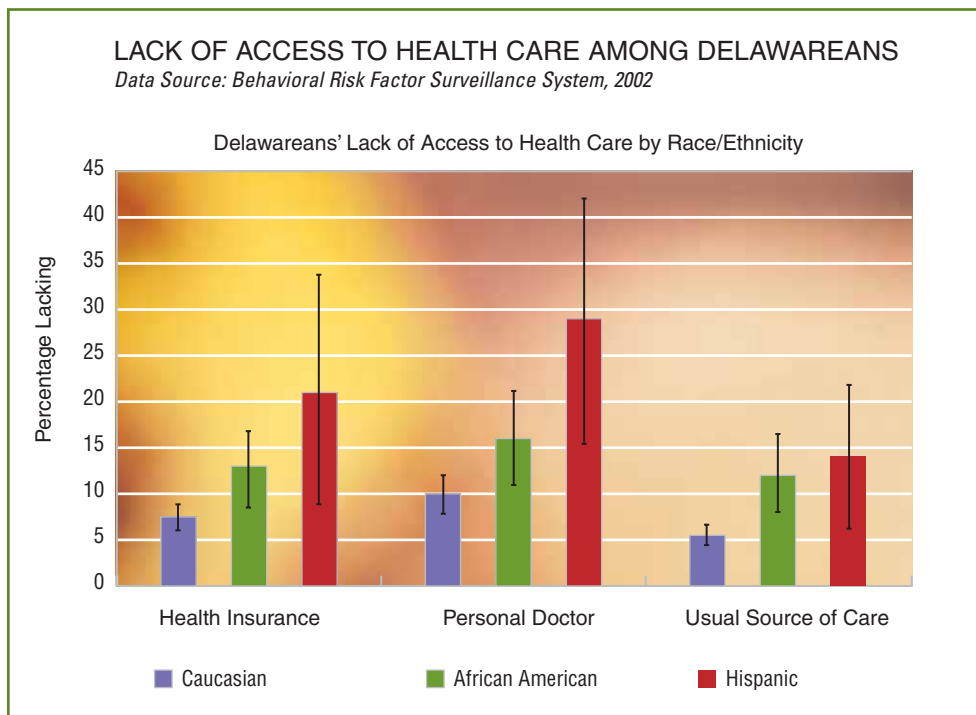
KEY FINDINGS

Cancer disparities in Delaware

The Division of Public Health and the Council learned a great deal about cancer disparities in Delaware when the data were examined. Some of our suppositions were correct. Sometimes what was thought to be true was not. In some cases there were obvious gaps. Frequently it was learned that disparities arose from complex issues. The data reviewed primarily compared African Americans and Caucasians because Hispanic and Asian populations in Delaware are not large enough to be used for analysis.

While disparities are most often identified along racial and ethnic lines—showing that African Americans or Hispanics and Caucasians, for example, have different disease and survival rates—significant health disparities extend beyond race and ethnicity. Cancer health disparities can involve biological, environmental, and behavioral factors, as well as differences noted on the basis of income and education.

The data indicates that the strongest predictor of lack of health insurance was lack of education. Overall, lack of access to health care was greatest for African Americans and Hispanics.



Racial disparities in Delaware

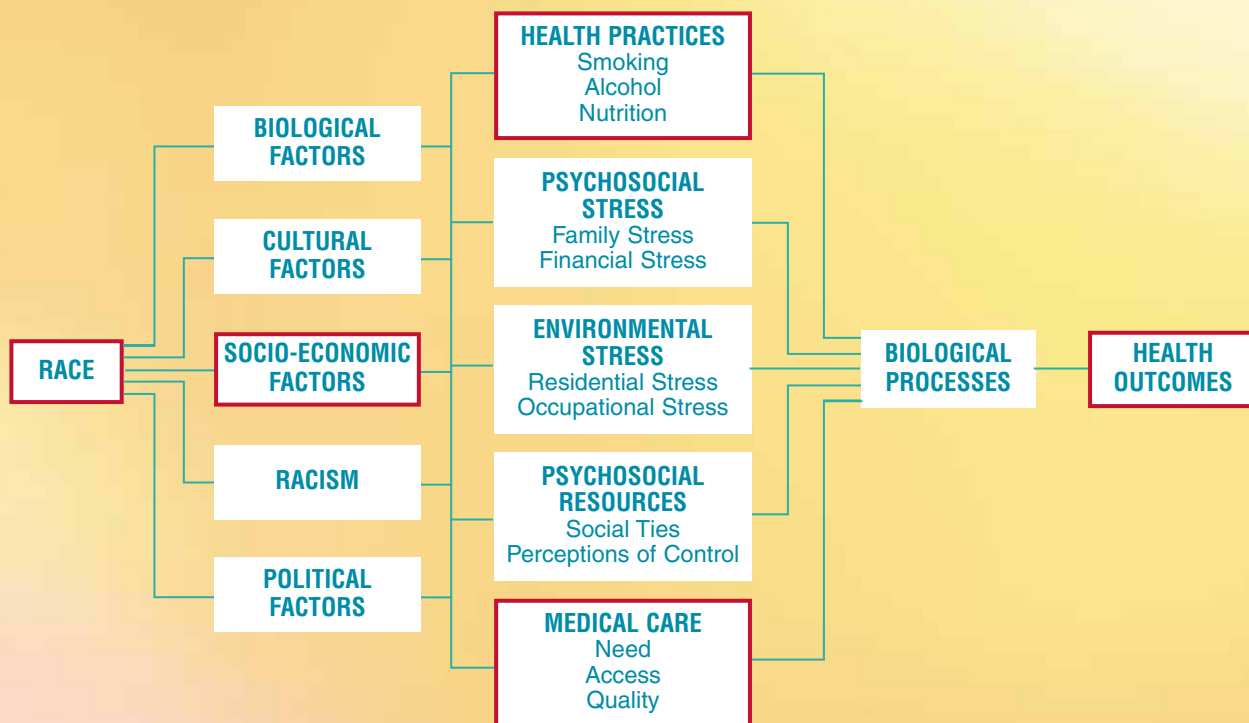
In Delaware, no major differences were observed between Caucasians and African Americans regarding screening rates. Only minimal differences were observed in the stage at which cancer is diagnosed, yet African Americans had a higher cancer incidence than Caucasians for all cancer sites combined. Most significant was that African-American men had a higher incidence of prostate cancer than Caucasian men. Cancer mortality was also higher among African Americans than among Caucasians in Delaware. Both of these patterns were consistent with the pattern observed in the United States.

Understanding the factors that contribute to racial disparities

There is no single reason for the higher incidence of cancer in certain ethnic and racial groups. A 2002 report by the Institute of Medicine proposed that health disparities are a result of a complex relationship between social, economic, and cultural factors (1, 2). Exposure to cancer risk factors, socioeconomic status, and even access to early detection and quality medical care could explain why and how disparities occur.

MULTIFACTORIAL BASIS OF RACIAL DISPARITIES

Society and Health, Oxford University Press, 1995



This model was created by the National Center on Minority Health and Health Disparities (NCMHD), a department within the National Institutes of Health (NIH). It shows the complex interaction of factors thought to create health disparities (3). The items highlighted in red are addressed in this report.

(1) Institute of Medicine. *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. 34. 2002. Washington, DC, National Academy Press.

(2) Institute of Medicine. *The Unequal Burden of Cancer: An Assessment of NIH Research and Programs for Ethnic Minorities and the Medically Underserved*. 1999. Washington, DC, National Academy Press.

(3) National Institutes of Health. *Strategic Research Plan and Budget to Reduce and Ultimately Eliminate Health Disparities*. 2002.

Education and health disparities

Lack of education is a significant barrier to health care equality in Delaware. Race and a lack of education are factors in health care access and behavioral risks. Delawareans who have less than a high school education and lack health care access (insurance, personal doctor, etc.) are less likely to have routine cancer screenings.

African Americans, Hispanics and people with less than a high school education are more likely to lack access to health care.

	Insurance	Personal Doctor	Usual Source of Care
African American	X		X
Hispanic		X	X
No High School Diploma	X	X	X

African Americans, people with less than a college education and those age 50–79 are more likely to exhibit behavioral risks.

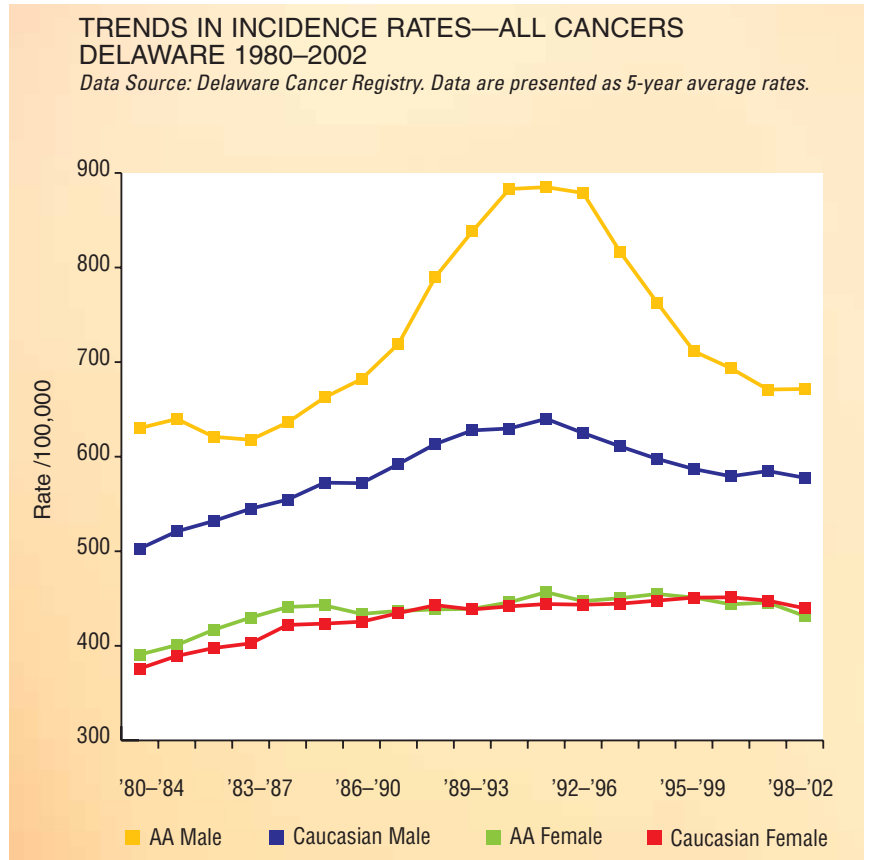
	No Exercise	Smoking	Obesity	Poor Diet
African American	X		X	X
Hispanic	X	X	X	X
No High School Diploma	X	X	X	X
High School Graduate	X	X	X	X
Age 50–64	X	X	X	
Age 65–79	X	X	X	

People with less than a high school education, those who lack health insurance, and those who lack a personal doctor are less likely to undergo routine screenings.

	Fecal Occult Blood Test	Sigmoidoscopy/Colonoscopy	Prostate-Specific Antigen Test	Digital Rectal Exam	Mammogram	Clinical Breast Exam
No High School Diploma		X		X	X	X
No Health Insurance		X	X	X	X	X
No Personal Doctor	X	X	X	X	X	

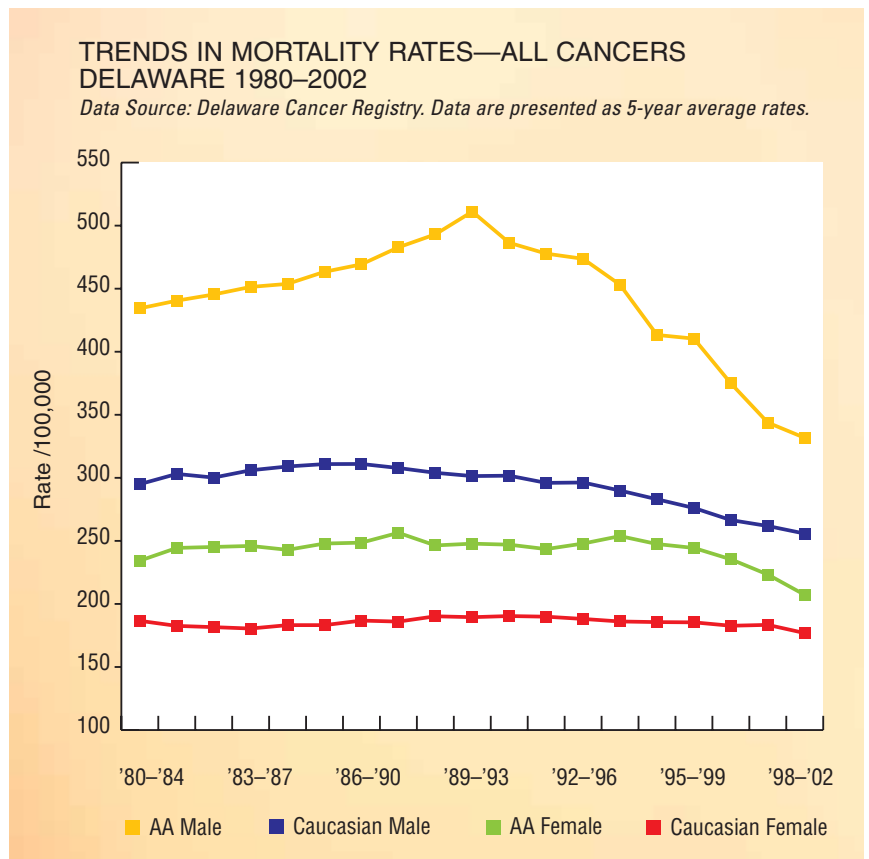
Trends in cancer incidence rates in Delaware

Cancer incidence rates among Caucasian men were consistently lower than those of African-American men and the rates started to decline earlier. The incidence rate for Caucasian men peaked between 1991 and 1995 at 640/100,000, and the rate for African-American men peaked between 1991 and 1995 at 640/100,000, and the rate for African-American men peaked between 1992 and 1996 at 878/100,000. The five-year average rate for African-American men began declining sharply from 1993 to 1997. There was little difference between Caucasian and African-American women, whose incidence rates were lower than for men and remained stable over time.



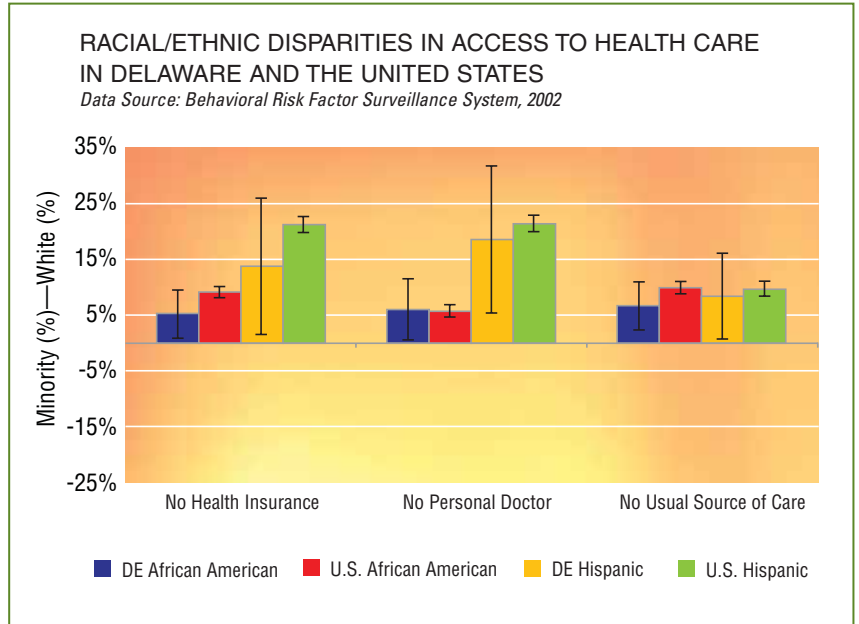
Trends in cancer mortality rates in Delaware

Cancer mortality was higher among men than among women, and for both sexes mortality was greater for African Americans than for Caucasians. Mortality rates for African-American men peaked between 1989 and 1993 and have been declining steadily since. For Caucasian men and all women, rates declined slightly over time. And in Caucasian women less than a 10/100,000 difference in mortality was seen over the 20 years examined.



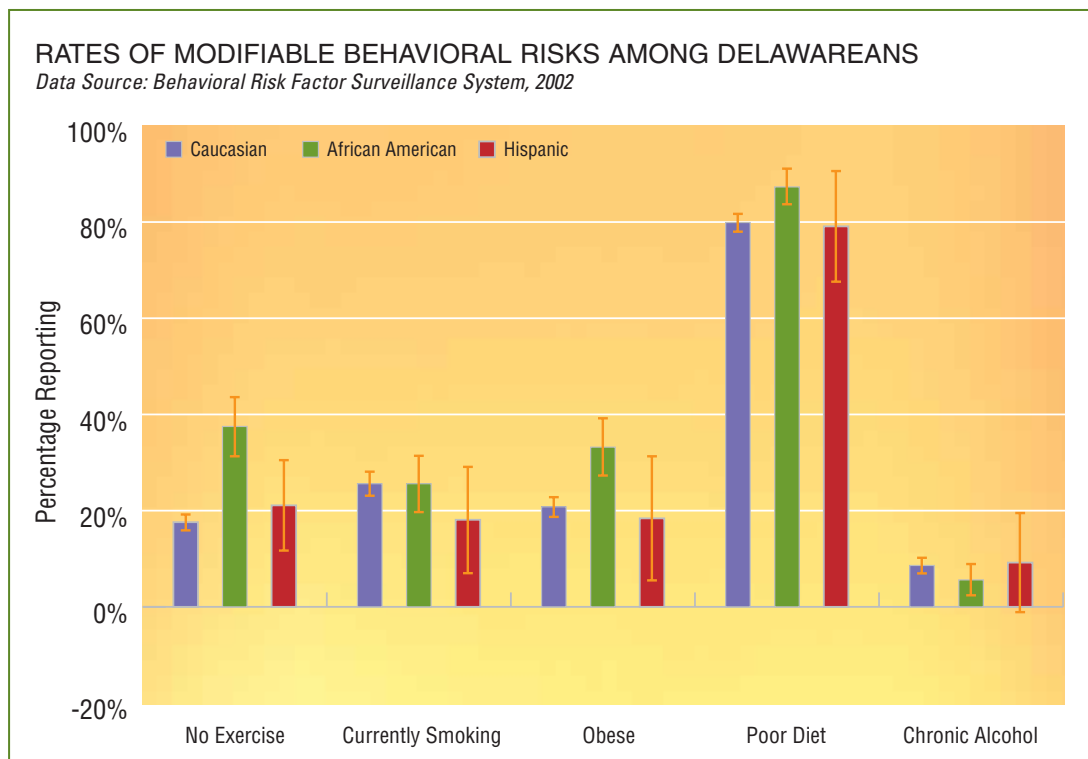
Lack of access to health care among Delawareans

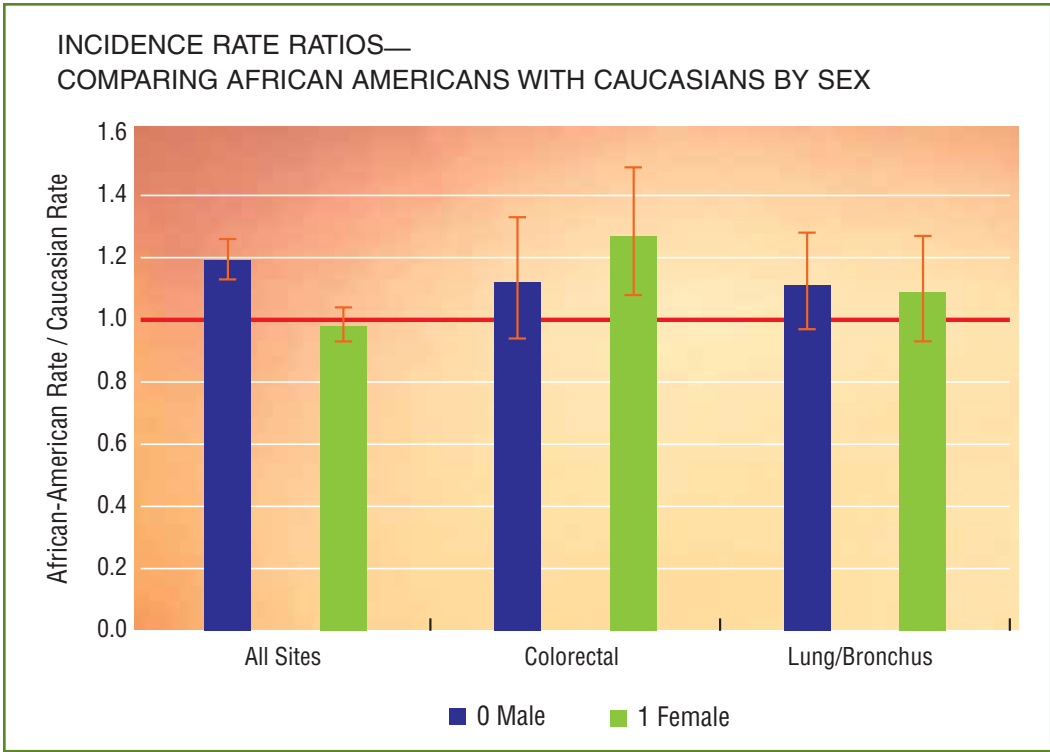
The data indicated that Hispanics were less likely than Caucasians to have health insurance, a personal doctor, and a usual source of care. The data also suggest that in Delaware, African Americans were less likely than Caucasians to have health insurance, a personal doctor, and a usual source of care—the only statistically significant difference was in having a usual source of care. The strongest predictor of not having each of the measures of access to health care was having less than a high school education.



Rates of modifiable behavioral risks among Delawareans

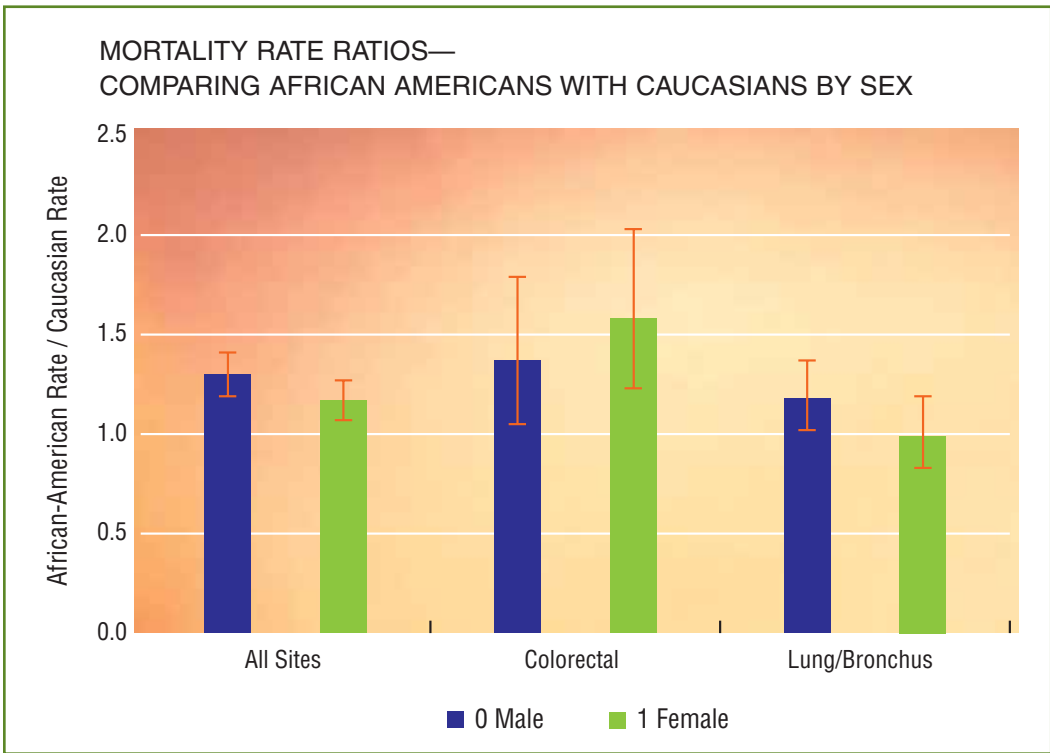
The study also examined the proportion of study respondents who never exercised, had ever smoked, had a body mass index greater than 25 (which corresponds to being roughly 10 percent over ideal body weight), ate fewer than five fruits and vegetables per day, and were chronic alcohol drinkers. The largest disparities for African Americans were in exercise and obesity. African Americans were less likely to have ever smoked than were Caucasians.





Disparities between men and women

For all cancer sites combined, incidence was higher among African-American men than among Caucasian men. Colorectal cancer incidence was higher for African-American women than for Caucasian women. Cancer mortality across all sites combined and also for colorectal cancer was higher among African-American men and women than among Caucasian men and women. Breast cancer incidence was higher for Caucasian women than for African-American women. However, mortality from breast cancer was higher for African-American women than for Caucasian women. There was no significant difference between the sexes for incidence or mortality for lung and bronchus cancer.



Female breast cancer, colorectal cancer, and prostate cancer cases by stage at diagnosis and race

Female breast cancer

A larger proportion of Caucasian women were diagnosed at the local stage than African-American women, while more African-American women were diagnosed with regional disease. African-American and Caucasian women were equally likely to be diagnosed with distant disease. African-American women age 79 or younger were more likely to be diagnosed with advanced disease. In Caucasian women, the likelihood of advanced-stage diagnosis decreased until age 70, after which it stabilized. County of residence had no bearing on the stage of diagnosis disparity.

No racial/ethnic disparities were observed in the use of cancer screening tests.

Colorectal cancer

African Americans and Caucasians were equally likely to be diagnosed at the local stage of disease. Caucasians may be slightly more likely to be diagnosed with regional disease, and African Americans with distant disease. The proportion of Caucasians diagnosed with advanced-stage disease may decrease with age until after age 80 when it increases. For African Americans, age had no effect on the proportion diagnosed with advanced-stage disease. For all races the proportions diagnosed at advanced stage were highest in New Castle County and lowest in Sussex County.

Prostate cancer

There were only minimal differences between Caucasians and African Americans in the stage of disease at diagnosis. Approximately 90 percent of prostate cancer cases were diagnosed at the local stage. Men of both races aged 80 or older were most likely to be diagnosed with advanced-stage disease. County of residence does not appear to affect the proportion diagnosed at advanced stage.

TREATMENT AND ITS IMPACT ON DISPARITIES

The difference in cancer mortality between African Americans and Caucasians is unacceptably high. As analysis of factors such as behavioral risks and receipt of cancer screening did not explain that difference, further examination was done to determine whether the cancer treatment received differed between races. Initial analysis of data from the Delaware Cancer Registry revealed marked differences between African Americans and Caucasians in the receipt of treatment considered by health care professionals to be appropriate for a given cancer. To ensure these findings were correct, a team of three physicians reviewed original treatment records for over 300 clients diagnosed with cancer and treated in Delaware. The review revealed that the treatment data recorded in the central registry were not complete; many clients had received treatments that were not reported to the central registry. Once the additional, more complete data were added to the information in the registry, analysis revealed no disparity in the first course of treatment between African Americans and Caucasians for a limited number of cancers. Looking only at registry data was not enough to provide a complete picture of treatment for cancer patients.

This validation study revealed:

- Crucial quality-related questions—such as whether the provision of cancer treatment differs by race—can be *asked* and *answered*.
- The difference in cancer mortality *does not* lie in the receipt of the first course of cancer treatment.

The next step is to ask whether there are differences in the provision of chemotherapy to patients with stage III colorectal cancer.

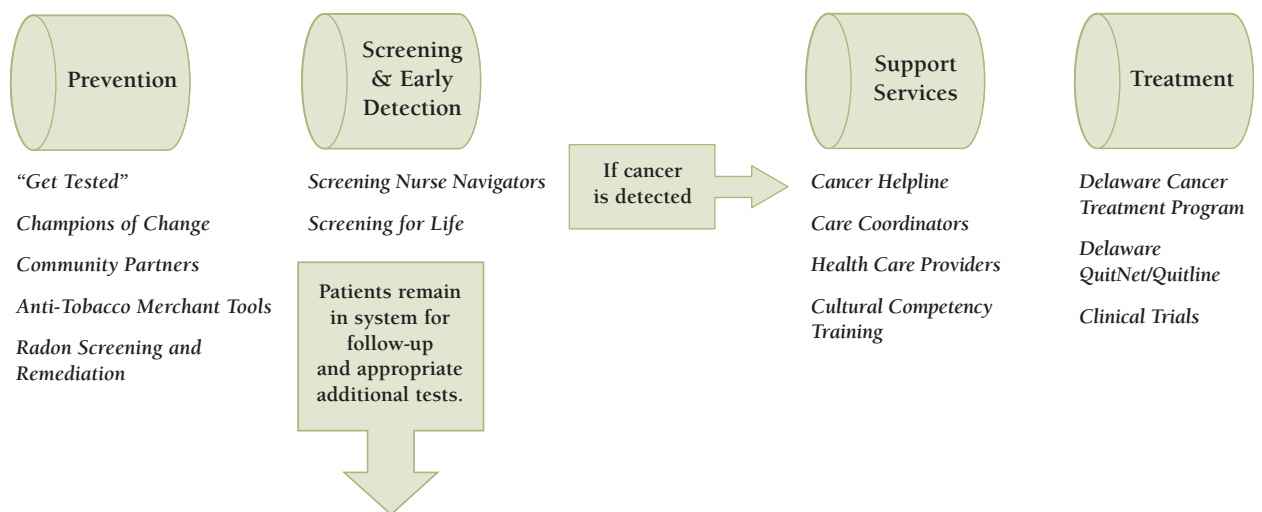
Further research will be conducted to identify sources of racial disparities and implement interventions to eliminate them.

INITIATIVES FOR HEALTHY COMMUNITIES

Removing the barriers

The disparities report has provided valuable insight about which populations are medically underserved in Delaware, supplied crucial information about why that is, and helped clarify the complex cancer disparities in Delaware.

The programs and initiatives described below are available to Delawareans of all racial and ethnic backgrounds. Providing a comprehensive set of cancer prevention, screening and early detection, support services, and treatment programs will have the highest impact on the most vulnerable among us. Those who are more likely to experience poorer health outcomes, have increased barriers to care, and have reduced access will benefit from the continuum of care our services provide. This comprehensive set of programs will ensure that they don't fall through the cracks of the health care system.



Prevention Outreach Efforts

The first step in the continuum begins by delivering information about the importance of prevention and early detection as well as providing the means to facilitate testing for at-risk populations. Several programs have been put into place that have increased Delaware's screening rates.

"Get Tested"

A culturally appropriate version of the overall marketing campaign, "Get Tested," was initiated. Media placement was targeted to elevate the level of awareness about colorectal cancer, the second-leading cause of cancer death in Delaware, among high-risk communities.



There was a 38.1 percent increase in the number of African Americans who reported ever having a colorectal cancer screening, from 39.6 percent in 1999 to 64 percent in 2005. It is encouraging to note that 42 percent of African Americans who reported ever having had a colonoscopy had done so within the last year.

Champions of Change

A user-friendly tool kit is being used to reach out to the community and deliver a peer-to-peer message about the importance of getting screened for colon cancer. Although available to anyone, the program offers a focused message to African Americans, who have a greater incidence of colorectal cancer in Delaware. More than 600 kits that include marketing materials and recommendations have been distributed to faith-based and neighborhood organizations, as well as social and service clubs.



Community Partners

Through collaboration with community partners throughout the state, people who may not have been reached through mainstream outreach efforts have received information and support. In FY '06 259 Delawareans pledged to get tested for colon cancer as a result of the intervention of 10 community partners, representing, on average, approximately 10 percent of the patient referrals for our CRC screening nurse navigators.



Anti-Tobacco Merchant Tools

Tools have been created to help merchants deal with requests for cigarettes from our young residents. The materials are user-friendly for every community and available in nine languages.



Radon Screening and Remediation Programs

Steps have been taken to educate all Delawareans about the importance of testing for radon, the second-leading cause of lung cancer. Free radon testing and remediation is available for residents who fall within income guidelines.



Screening and Early Detection

Delaware funds and manages CRC nurse navigators and community advocates to ensure that every Delawarean—especially those most at risk—have access to the information and screening services they need to be cancer-free. The navigators and advocates work out of five Delaware hospitals covering each county to ensure that citizens 50 and older, and high-risk patients, get screened for colon cancer.



Since the program's inception, nurse navigators have facilitated screenings for 753 Delawareans.

More than 13,000 uninsured and underinsured Delawareans have received cancer tests through Screening for Life.

Screening for Life

The financial barrier can play a major role in whether someone gets screened for cancer. To eliminate that barrier, Delaware's Screening for Life program provides free mammograms, Pap tests, pelvic exams, and colorectal screenings for residents who fall below 250 percent of the Federal Poverty Level. More than 13,000 Delawareans have been screened. The program has had an especially positive impact on Hispanic women; the number getting screened has increased by 48 percent since 1998.



Support Services

An infrastructure has been built to support patients when cancer is detected. These programs provide clinical assistance as well as quality-of-life help for cancer patients regardless of their resources.

Cancer Care Coordinators

Every Delaware resident, regardless of income level, insurance status, education, race, or ethnicity, can receive free guidance from a cancer care coordinator. Operating out of five Delaware hospitals, this team of dedicated professionals helps patients who have been diagnosed with cancer, and their families, navigate the sometimes daunting health care system. As of September 2006, the care coordinators have steered 11,086 patients and their families through the system and have participated in at least 15,000 personal interventions providing medical referrals, psychosocial services, financial assistance, and support.



Our statewide care coordinators have served more than 11,000 cancer patients and their families.

Between July 2004 and June 2006, 220 residents received treatment through our groundbreaking Delaware Cancer Treatment Program

The Cancer Helpline

Each and every Delawarean who is dealing with cancer can receive free quality-of-life services from specially trained counselors at the Cancer Helpline. No matter what the issue—financial assistance, transportation, legal services, or mental health—the Cancer Helpline will help lighten the burden.



Health Care Provider Cultural Competency Training

To make sure medically underserved residents have access to health care services, health care providers have received special training from the National Cancer Institute. This training provides insight on cultural issues and concerns and gives participants tools to deal with those issues.

Treatment

Money is a major obstacle that prevents those most at risk from seeking treatment. Concerns about the ability to pay for treatment have made some uninsured residents reluctant to get screened in some cases. Resources to pay for treatment during the first year of diagnosis, which is generally the most expensive treatment increment, have been made available to counter this obstacle. Free counseling services also are available to help eliminate the number-one cause of lung cancer, and clinical trial opportunities for those most at risk continue to be pursued.

Delaware Cancer Treatment Program

The unparalleled Delaware Cancer Treatment Program, instituted in 2004, has made it possible for more than 220 First State residents to receive cancer treatment. The service is available to any uninsured Delawareans who have been diagnosed with cancer and are at or below 650 percent of the Federal Poverty Level.

Patients who have received treatment through the Delaware Cancer Treatment Program	
By County	
New Castle County	124
Kent County	30
Sussex County	66
By Gender	
Females	115
Males	105
By Race/Ethnicity	
Asian	1
African American	56
Hispanic	25
Other	4



Tobacco Cessation Programs

Whether they choose one-on-one counseling, a combination of telephone counseling and a workbook program, or a web-based program, all Delaware residents 18 and older can receive free help to quit using tobacco. In FY '06 15 percent of the residents who used the service were African American and 2 percent were Hispanic. The number of Delawareans who smoke is now at the lowest rate since measurement began in 1982.



Adult smoking prevalence is down to 20.7 percent—the lowest since Delaware began tracking prevalence in 1982.

Clinical Trials

The Delaware Cancer Consortium continues to promote and monitor patient enrollment in clinical trials and is working with all seven major hospital systems in the state to establish a statewide Cooperative Oncology Group in keeping with the American Cancer Society and the Coalition of National Cancer Cooperative Groups: A Partnership for Cancer Clinical Trials.

Cancer disparities in Delaware: closing the gap

There are more significant factors than the obvious ones when it comes to how, when, and why people do or do not receive a timely cancer diagnosis and adequate care. The trends observed may be as much the result of societal and physical barriers as they are of health policy and health system factors. Even in a perfect world, where all communities are educated about cancer health, recommendations may not be acted upon appropriately because of embarrassment, discomfort, or confusion.

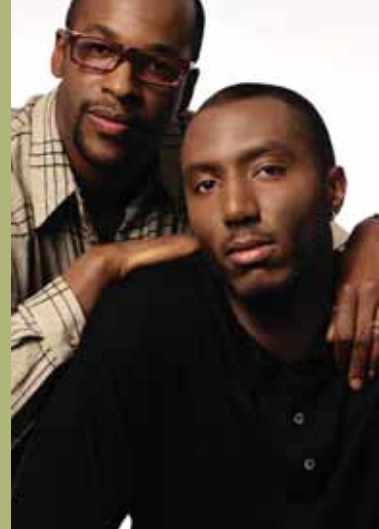
Legislation has been passed to help all individuals in Delaware get the cancer care and treatment they need. But more steps must be taken to close the gap. Disparities continue to affect cancer incidence and mortality. Initiatives have been and will continue to be developed to give residents effective tools to eliminate the barriers observed.

Some challenges and questions still need to be addressed.





Many questions remain. The collection of data will continue and every effort will be made to refine collection systems to ensure accuracy. The data will be studied and analyzed until all Delawareans receive equal cancer treatment and care.





DELAWARE
CANCER
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DELAWARE HEALTH AND SOCIAL SERVICES

Division of Public Health

Comprehensive Cancer Control Program