Too Many Cases, Too Many Deaths:
Lung Cancer in African Americans

AMERICAN LUNG ASSOCIATION®
Fighting for Air

Preface

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The American Lung Association document you are about to read provides a comprehensive discussion defining the impact of cancer-causing agents, primarily, but not limited to, inhaled tobacco on the development of lung cancer and its disproportional impact on the lives of African Americans. The effect of lung cancer on men and women of all races is undeniable. The loss of productivity and potential years of life lost as measured by an estimated 159,000 deaths in 2009 is staggering and greater than the number of deaths attributed to prostate, colon and breast cancers combined. The overwhelming case for a racial difference in the burden of lung cancer, which is the greatest cause of preventable cancer deaths in the United States and worldwide, is presented with undeniable clarity. Delineating the origin of the disparity is undertaken with the acknowledgement that precise attributions of cause are difficult, but all are worthy of systemic attempts for further documentation and remediation.

Although there has been a decrease in the overall lung cancer death rates for African Americans and others, the disparity by race persists. Progress in overcoming the disparity and lowering the lung cancer death rate has been made. Cooperative work, however, is yet to be done. As we move into an era of healthcare reform and health equity, *Too Many Cases, Too Many Deaths: Lung Cancer in African Americans* can provide a stimulus for revitalized efforts among individuals, healthcare providers, researchers, community-based organizations, the business community and all levels of government.

The movement to make lung cancer, a disease that was rarely encountered before the 20th century, another example of man's ability to overcome a public health threat is foretold in this effort. Returning lung cancer to simply a medical curiosity is a goal we can all share.

The numbers say a lot in this report, but lung cancer affects individual people and their friends and families:

Diane B.K.'s Story

In 2004, Diane, an otherwise healthy 49-year-old wife, mother, sister, daughter and friend, was diagnosed with lung cancer. At MD Anderson Cancer Center, Diane found answers, hope and her doctor, Dr. Martin Raber, a cancer survivor himself.

While Diane is clearly a survivor with a positive attitude and strong support from her husband, she faced numerous challenges along the way – some that she does believe are specific to the African American community.

"I want to use my PhD in clinical psychology to work with families and caregivers who are going through cancer, because I have been there. While it wasn't the best thing that happened to me in my life, it was actually a blessing for me to learn about what survivorship really means. I feel like you can either grow from this kind of experience or be destroyed. I chose to grow."

Michael R.'s Story

Michael was diagnosed with lung cancer in 2006. At Ohio State Medical Center, Michael's treatment has included surgery, radiation and chemotherapy. His physician, Dr. William Hicks, has been the honorary chair of the National Black Leadership Initiative on Cancer since 1998.

While Michael's primary tumor could not be removed, he has refused to yield to hopelessness. He is living in the present, thankful for all that he can do, and continues to maintain a positive attitude.

"I'm ex-military and have a pretty decent inner drive and self-discipline." He also feels lucky to have family around that he can talk to and that support him.

"Miracles happen. In the back of your mind, you think maybe they'll find a cure. Statistics don't show those miracles."

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Introduction

African Americans suffer from lung cancer more than any other population group in the United States. They are more likely to get it, and more likely to die from it. African American men in particular are at increased risk; they are 37 percent more likely to develop lung cancer than white men, even though their overall exposure to cigarette smoke – the primary risk factor for lung cancer – is lower.[1]

The reasons for this unequal burden are not entirely clear. Over the years, researchers have examined smoking behavior, workplace exposures, genetics, access to health care, discrimination and social stress, as well as other possible contributors. The answer appears to be that this terrible disparity is caused by an intricate interaction of biological, environmental, political and cultural factors.

Fixing the problem will not be easy. Some progress has been made, especially in reducing smoking rates and exposure to secondhand smoke. Government agencies and healthcare systems are focusing increased attention on eliminating health disparities of all kinds. And lung cancer advocacy groups are becoming more vocal about reducing the toll of this dreaded disease. Much remains to be done, and governments, healthcare providers, community leaders and individuals all have an important role to play.

"The real challenge lies not in debating whether disparities exist, but in developing and implementing strategies to reduce and eliminate them."
– Alan R. Nelson, MD, Chair,
IOM Committee on Understanding and Eliminating
Racial and Ethnic Disparities in Health Care

Health Disparities in the United States

Health disparity is defined by the National Partnership for Action to End Health Disparities as "a particular type of health difference that is closely linked to social or economic disadvantage."

The reasons for specific health disparities in any population group are complex. They may include lack of easy access to health care, access to and ability to afford health insurance and levels of income and education. Other factors that have been identified include living in poor environmental conditions, inadequate availability of healthy foods, limited personal support systems and limited language proficiency.[2]

Some causes are hard to measure and even harder to talk about. In its groundbreaking 2002 report *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare*, the Institute of Medicine (IOM) concluded that "(al)though a myriad sources contribute to these disparities, some evidence suggests that bias, prejudice, and stereotyping on the part of healthcare providers may contribute to differences in care."[3] While this is unsettling to healthcare providers and patients alike, the bottom line is clear: Inequalities in health exist and must be addressed on many fronts.

In 2008, Margaret Chan, Director General of the World Health Organization, declared that, "Health inequity really is a matter of life and death."[4] For African Americans in the United States, it unfortunately tends to be a matter of death. Overall, the African American population experiences higher rates of death from heart disease, cancer, cerebrovascular disease and HIV/AIDS than any other racial or ethnic group.[2]

When it comes to the issue of cancer, race and ethnicity truly determine who lives or dies. Although cancer deaths have declined for both whites and African Americans living in the United States, African Americans continue to suffer the greatest burden for each of the most common types of cancers. For example, white women have the highest occurrence of breast cancer, but African American women are more likely to die from it. African American men are more likely to get prostate cancer and more than twice as likely as white men to die from it. For all cancers combined, the death rate is 25 percent higher for African Americans than for whites.[5]

Too Many Cases

In every community, lung cancer cases, because they are so deadly and so preventable, are a tragedy. But in African American communities the tragic toll is especially high. African Americans have a higher occurrence of lung cancer than any other racial or ethnic group in the U.S. (Figure 1) Black men are 37 percent more likely to get lung cancer than white men. For black women, the occurrence of lung cancer is roughly equal to that of white women.[1]

Most people's immediate assumption is that lung cancer rates are higher in populations that smoke more. The picture is more complicated than that. Smoking rates are almost the same for African American and white men – 25.5 percent compared to 23.6 percent, respectively. However, American Indian and Alaska Native men smoke at higher rates than any other group – 42.3 percent – and they are less likely to get lung cancer.[1,14] (Figure 2) Data from the mid-80s showed that white men consumed 30-40 percent more cigarettes than African American men, which should mean their exposure to the carcinogens in cigarette smoke is higher.[15] Still, more African American men develop lung cancer.

About Lung Cancer

Lung cancer is the number one cancer killer in the nation. It has been the leading cause of cancer death among men since the early 1950s, and in 1987 it surpassed breast cancer as the leading cause of cancer deaths among women.[6]

Definition
Lung cancer is the uncontrolled growth of abnormal cells in one or both of the lungs. While normal cells reproduce and develop into healthy lung tissue, these abnormal cells reproduce faster and never grow into normal lung tissue. Lumps of cancer cells (tumors) then form and grow. Along with interfering with how the lung functions, cancer cells can spread from the tumor into the bloodstream or lymphatic system where they can spread to other organs.

Causes
Cigarette smoking is by far the leading cause of lung cancer, and the risk increases with the number of cigarettes smoked and the number of years spent smoking.[7] The U.S. Surgeon General estimates that 90 percent of lung cancer deaths in men and 80 percent in women are caused by smoking. Nonsmokers have a 20-

30 percent greater chance of developing lung cancer if they are exposed to secondhand smoke at home or work, and exposure to secondhand smoke causes approximately 3,400 lung cancer deaths among nonsmokers each year. [8,9]

Radon is a naturally occurring radioactive gas that seeps into homes from the soil. The Environmental Protection Agency estimates that radon causes between 7,000 and 30,000 lung cancer deaths per year in the United States, making it the leading cause of lung cancer in nonsmokers, and the second leading cause of lung cancer overall.[10] Other recognized causes of lung cancer include some occupational chemicals and pollutants like asbestos, benzene and formaldehyde, and air pollutants like diesel exhaust.[11,12,13]

> **"Everyone assumes I'm a breast cancer survivor because I am a woman. Then, when I say lung cancer, the person's expression changes and they are either shocked or say something like, 'you don't look like a smoker' or 'you don't look like the type that would have lung cancer.'"**
>
> *– Diane B.K.*

Types
There are two major types of lung cancer: non-small cell lung cancer (NSCLC) and small cell lung cancer (SCLC). Non-small cell lung cancer is much more common and accounts for 85 percent of all lung

cancer cases. It usually spreads to different parts of the body more slowly than small cell lung cancer. Small cell lung cancer accounts for 14 percent of all lung cancers. This type of lung cancer grows more quickly and is more likely to spread to other organs in the body.[1]
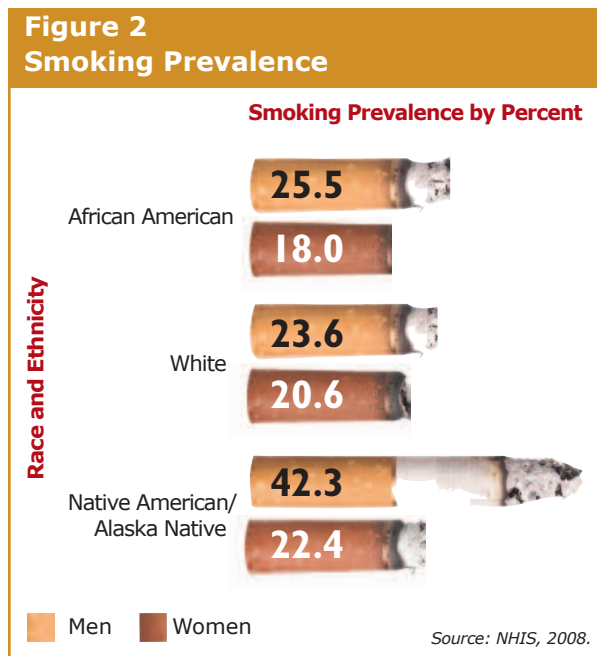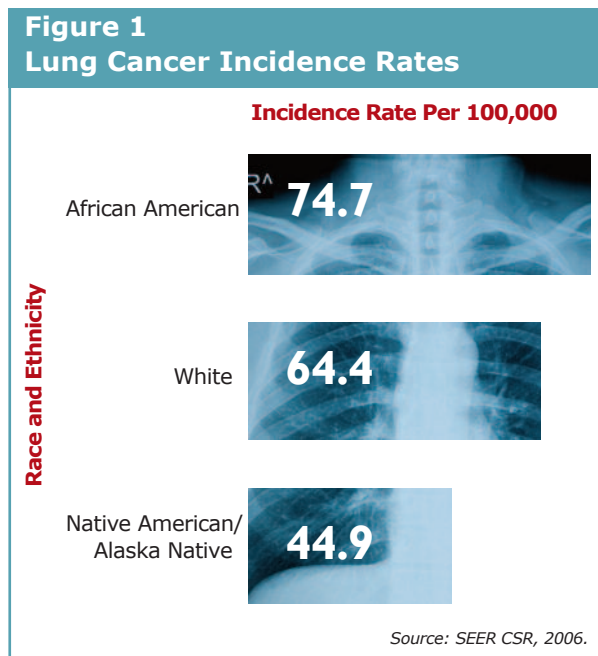
Diagnosis and Treatment
Symptoms of lung cancer include persistent cough, shortness of breath, wheezing, coughing up blood, chest pain and recurring pneumonia or bronchitis. Unfortunately, early stages are often symptomless, and most lung cancers are not diagnosed until already well advanced. If non-small cell lung cancer is caught in time, treatment using surgery, radiation therapy, chemotherapy or a combination of these approaches is often effective. The choice of treatment and prognosis generally depend on the specific type and stage of the lung cancer.

Survival rates for lung cancer tend to be much lower than those of most other common cancers. The five-year survival rate for all patients in whom lung cancer is diagnosed is approximately 15 percent, compared to approximately 64 percent for colon cancer, 89 percent for breast cancer and 99 percent for prostate cancer.[1]

Stigma
A major barrier to addressing the needs of persons diagnosed with lung cancer is the stigma associated with the disease because of its link to smoking. Stigma impacts how lung cancer is viewed by patients, their family members and caregivers, health providers and the public in general. It can lead to unnecessary harm and pain for patients and their families, and can influence the way lung cancer is approached by healthcare professionals and policymakers.

Figure 1
Lung Cancer Incidence Rates

Incidence Rate Per 100,000

Race and Ethnicity	
African American	74.7
White	64.4
Native American/ Alaska Native	44.9

Source: SEER CSR, 2006.

Figure 2
Smoking Prevalence

Smoking Prevalence by Percent

Race and Ethnicity	Men	Women
African American	25.5	18.0
White	23.6	20.6
Native American/ Alaska Native	42.3	22.4

Men   Women

Source: NHIS, 2008.

This disparity does not just relate to smoking. A 2008 study of self-reported never-smokers – representing more than 1.8 million people – found that the lung cancer mortality rate among African Americans was higher in this group of never-smokers for both women and men age 40 to 84 compared to that of individuals of European descent.[16] Clearly, something else is going on.

The driving factors that contribute to health inequalities can be categorized as behavioral, social, environmental and biological. In the context of the rate of occurrence of lung cancer cases among African Americans, these factors have been shown to contribute to the lung cancer disparity:

- Tobacco use
- Preventive behavior
- Socioeconomic status
- Environmental exposures
- Genetics

Tobacco Use

Smoking is a well-documented risk factor for lung cancer among all races and ethnicities, but there are specific tobacco-related factors that especially impact the African American community. These include decades of targeted marketing by the tobacco industry, brand choice and difficulties with quitting smoking.

The tobacco industry has been creating marketing targeted to the African American community since the 1960s. In fact, this targeted campaign has been called the "African American-ization of menthol cigarettes" by some researchers.[17] Menthol cigarettes were historically marketed toward African Americans as "smooth," "cool" and "healthier" alternatives to non-menthol cigarettes. Early on, the tobacco industry used advertising with tailored images and messages, while also promoting themselves as good corporate citizens by donating heavily to African American cultural organizations.

Four decades later, in 2002, a review of cigarette advertising showed that magazines targeted to the black community were nearly 10 times more likely to have cigarette ads than more general audience magazines. And nearly 70 percent of all the cigarette ads in those targeted magazines were for menthol brands.[18] Overall, African Americans are exposed to a higher volume of pro-tobacco advertising in both concentration and density, with money spent on magazine advertising of menthol cigarettes increasing from 13 percent in 1998 to 49 percent in 2005.[19]

"The tobacco industry has done a lot to court the black community, including buying good will at all levels."
– William Robinson, Executive Director,
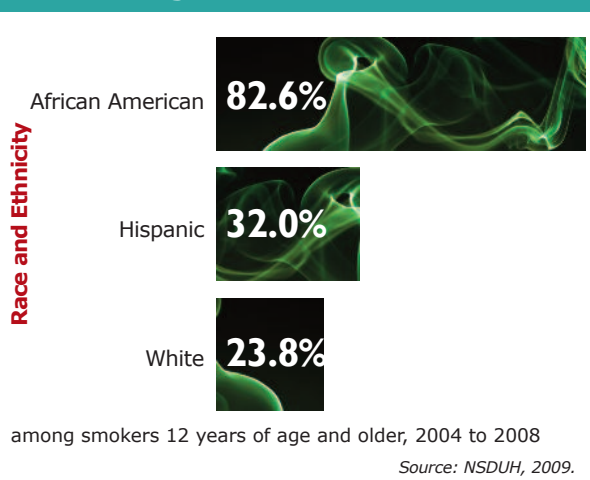*National African American Tobacco Prevention Network*

The tobacco industry's efforts have been wildly successful. According to a November 2009 report from the Substance Abuse and Mental Health Services Administration, nearly 83 percent of African American smokers aged 12 and older choose menthol cigarettes. This compares to 32 percent of Hispanic smokers, and only 24 percent of white smokers.[20] (Figure 3)

It has been suggested that this difference in the use of menthol cigarettes may contribute to the health disparity between black and white smokers. The health effects of menthol itself, and how it alters smoking behavior and severity of addiction, are not yet well understood. Research suggests that:

• Menthol smokers have higher levels of cotinine, a byproduct of nicotine, in their blood than non-menthol smokers.[21] These increased levels of cotinine have been related to higher nicotine exposure and may be associated with more severe levels of addiction.

Figure 3
Menthol Cigarette Smokers

Race and Ethnicity

African American **82.6%**

Hispanic **32.0%**

White **23.8%**

among smokers 12 years of age and older, 2004 to 2008

Source: NSDUH, 2009.

5

- Menthol smokers are less likely than non-menthol smokers to feel confident in their ability to quit smoking.[22]

- Menthol smokers are less likely to attempt cessation, more likely to relapse after successfully quitting and less likely to report sustained smoking cessation than non-menthol smokers.[23,24]

Preventive Behavior

African Americans are more likely than whites to hold beliefs that can interfere with the health behaviors that reduce the risk of lung cancer. An analysis of the *2005 Health Information National Trends Survey* found that while all races grossly underestimate the lethality of lung cancer, black patients appear to be more confused about prevention recommendations, to doubt the association of cancer with smoking and lifestyle and to be reluctant to seek preventive care because of fear of the disease.[25]
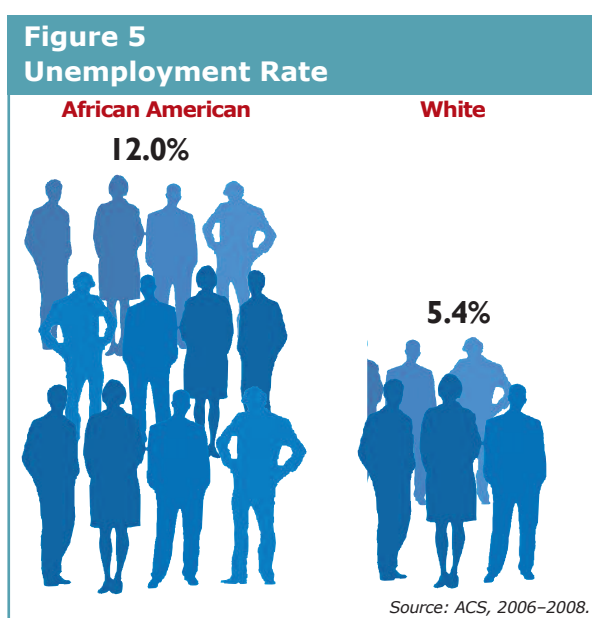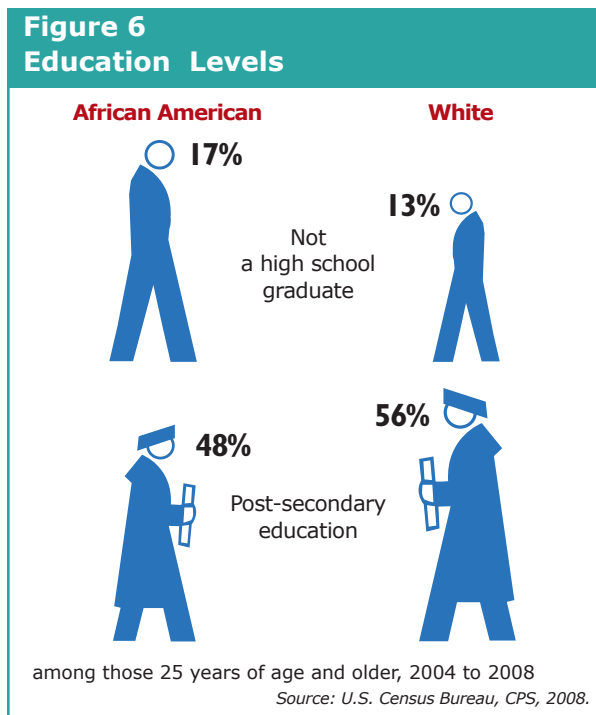
Socioeconomic Status

Socioeconomic status is the catch phrase for a combination of factors that affect one's place in society, including education, income and employment. African Americans in the U.S. do less well by most measures of socioeconomic status than do whites. Approximately 40 million people, or 13 percent of the U.S. population, live in poverty.[26] Compared with 8 percent of whites, 24 percent of African Americans live below the federal poverty threshold.[27] Poverty is closely associated with living arrangements, education and disability. Those without a high school education are not only more likely to experience poverty, they are less likely to find employment that includes health insurance.[2] (Figures 4, 5 and 6)

Socioeconomic status plays a significant role in achieving access to health insurance and health care, quality of health services, healthy lifestyle and health literacy.[2] In fact, studies suggest that the increase in health disparities tracks closely along socioeconomic lines, with health gains in those at higher socioeconomic levels and poorer health among those in lower socioeconomic groups.[28]

Socioeconomic status is highly correlated with cancer rates, as well as the progression of the disease. For lung, colorectal and prostate cancers combined, death rates among both African American and white men with 12 or fewer years of education are more than twice those of men with higher levels of education. People of lower socioeconomic status are more likely to engage in behaviors that increase cancer risk, such as tobacco use, physical inactivity and lower consumption of fresh fruits and vegetables. Low socioeconomic status is also associated with inadequate health

Figure 4
Median Household Income 2007

African American   White
                    $52,115
$33,916

Source: U.S. Census Bureau, 2008.

Figure 5
Unemployment Rate

African American   White
12.0%

                            5.4%

Source: ACS, 2006–2008.

Figure 6
Education Levels

African American   White

○ 17%

13% ○

Not
a high school
graduate

56%

48%

Post-secondary
education

among those 25 years of age and older, 2004 to 2008
Source: U.S. Census Bureau, CPS, 2008.

insurance, and reduced access to recommended preventive care and treatment services.[29]

Environmental Exposures

Race and income affect people's ability to choose where they live and work, and impact the likelihood that they will have dangerous pollution sources located in their communities. African Americans have historically faced higher exposures because of racial segregation that limited choices,[30,31] a lack of political power to keep new pollution sources away,[32] the deliberate location of polluting sources nearer racially concentrated areas and the lack of income to move away once these sources arrived.[33] In addition, lower income people, a group disproportionately African American, have often found lower housing costs in highly polluted neighborhoods.[34]

Much of the research about pollution and race at the neighborhood level has looked at air toxics, a group of almost 200 different air pollutants, including diesel exhaust and benzene. According to a recent review, African American neighborhoods face an average 1.5 times higher levels of air toxics than other communities, and the level of pollution goes up as the income level

of the residents goes down.[34] Only some air toxics cause cancer – and not all cause lung cancer – but there is ample evidence that overall cancer risk increases the more segregated an African American community is from other communities.[30] One study in Maryland found that the risk of cancer related to air toxics was greatest in areas with the largest African American population and lowest among those with the smallest African American population.[35]

Breathing particulate matter may also impact lung cancer.[36] Particulate matter pollution comes from many sources, including diesel exhaust, coal-fired power plants, wood-burning, even from agricultural practices. In its most recent review, the U.S. Environmental Protection Agency concluded that the available evidence suggests that particulate matter pollution increases the risk of dying from lung cancer, and may cause lung cancer. In the eastern half of the nation, coal-fired power plants are one of the major sources of particulate matter.[37] Sixty-eight percent of African Americans live within 30 miles of a coal-fired power plant, compared to only 56 percent of whites.[38]

Air pollution inside homes, most notably secondhand smoke and radon, can also cause lung cancer. Secondhand smoke causes an estimated 3,400 lung cancer deaths in the U.S. each year,[39] and African Americans have significantly higher rates of exposure to secondhand smoke than any other group.[8] An extensive study of indoor particulate matter in the homes of lower-income African American families in Baltimore found indoor concentrations of the pollutant were more than twice as high as outdoor levels. This was attributed primarily to smoking.[40]

Radon is the leading cause of lung cancer in non-smokers and the second leading cause of lung cancer overall. Information is lacking that could link household radon levels to the race and ethnicity of the residents, so it is not possible to identify radon's contribution to lung cancer disparities. But there have been inequalities in how radon problems in homes are identified and fixed, with most of the state and federal resources going to educate and support people buying single-family homes, and to new home construction. Urban dwellers and low-income families,

which are disproportionately African American, are more likely to live in rental housing.[41]

Occupational exposure to smoke, dust and chemicals in the workplace is an important contributor to lung cancer overall, but the role of the workplace in the disparity in African Americans is not well defined. There have been few studies that address lung cancer risk from workplace exposures, and how it differs by race. Much of the original research done on occupational lung cancer in the '70s and '80s looked only at white workers. More recent studies that have looked at racial differences have not brought any strong, clear disparities to light.[42,43] However, it is clear that many African Americans are exposed to cancer-causing agents on the job. Blacks are disproportionately employed in transportation jobs, where they are exposed to diesel exhaust, which EPA has linked to a 40 percent higher relative risk of lung cancer than for those who do not experience such exposure.[13] Additionally, millions of service workers – of all races – are still exposed to high levels of secondhand smoke, with deadly consequences.

"Initially they were not able to identify where my cancer originated. I knew that there was a long history of cancer in my family and I knew I had to do something about the fact that I didn't feel well and, once diagnosed, do something about the cancer."

– Diane B.K.

Genetics

While the study of genetics in cancer risk, detection and treatment has made headway in the past decade, it is still an emerging area. Researchers continue to look at whether a specific type of gene signals cancer risk in one human or if there are classes of genes that vary with particular races or ethnicities. Several recent studies illustrate some findings about the role that genetics may play in lung cancer.

Recent research has identified two particular genes that appear to be associated with nicotine dependence and an increased risk of lung cancer. African Americans are less likely to carry these genes than whites, but the risk for lung cancer is greater in African Americans than whites when the genes are actually present. The mechanism of how that might work is unclear at this time.[44]

Researchers have also looked at cotinine, a byproduct of nicotine that stays in the bloodstream after smoking, to see what they can learn about biological differences in African Americans that might affect lung cancer rates. Black smokers tend to have higher levels of cotinine in their blood than whites, probably due at least in part to differences in the way nicotine is metabolized in the body. The higher levels of cotinine in African Americans might also suggest higher exposure to nicotine and other tobacco carcinogens. Recently a specific gene was found that is linked to cotinine levels – and it occurs with higher frequency in African Americans.[45]

Genetic differences have also been shown to affect how an individual responds to lung cancer treatment. Some of the newer, more promising lung cancer drugs have been developed to target specific characteristics of lung cancer cells. In a recent study, researchers discovered that African Americans with lung cancer are often missing the cellular characteristic that is targeted by one of the common cancer drugs, meaning that they are less likely to benefit from that treatment.[46]

Unfortunately, progress in understanding and using genetics in improved treatments has been hampered by the low levels of African American patients participating in clinical trials.[47] A recent study among African American women found that a combination of experiences and beliefs influenced their decisions to participate in clinical trials. These include perceptions of cancer prevention and detection, the experience of having a loved one with cancer, knowledge of and experience with clinical trials and beliefs regarding the benefits and risks of clinical trial participation.[48]

Too Many Deaths

Not only do African Americans get lung cancer at higher rates than other groups, they are also more likely to die from it. African American men, who are the most at risk of any group, are 22 percent more likely to die from lung cancer than white men.[49] (Figure 7) The average length of time that African Americans survive after a lung cancer diagnosis is also lower: only 12 percent live longer than five years, compared to 16 percent of whites.[1] (Figure 8)

Studies have shown that equal treatment yields equal outcome among equal patients. But the sad truth is that not all patients are equal. African Americans:

• get diagnosed later, when their cancer is more advanced

• wait longer after diagnosis to receive treatment

• are more likely to refuse treatment

• are more likely to die in the hospital after surgery

The social and genetic factors that contribute to the higher numbers of African Americans getting lung cancer may also increase the likelihood that they will die from the disease. But there are other causes as well, including unequal access to health care, unequal quality of health care, racism and social stress.
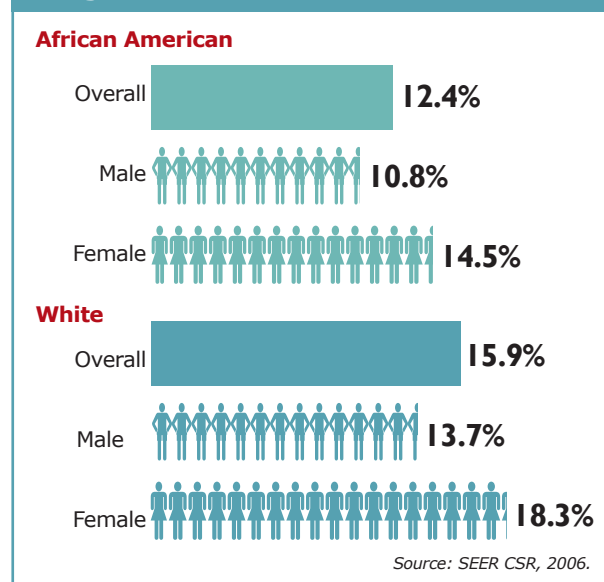
Figure 7
Lung Cancer Age-Adjusted Death Rates

African American **White**

| 85.4 | 39.8 | 69.7 | 43.5 |

Death Rate Per 100,000

Source: NCHS, 2006.
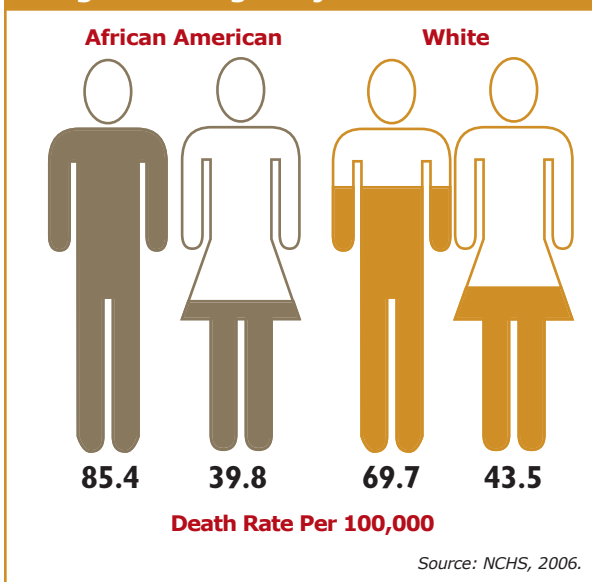
Figure 8
Lung Cancer 5-Year Survival Rates

African American

Overall — 12.4%
Male — 10.8%
Female — 14.5%

White

Overall — 15.9%
Male — 13.7%
Female — 18.3%

Source: SEER CSR, 2006.

"Access does not equal utilization. Like the layers of an onion, there are a myriad of reasons why a person may not use a healthcare system – stress, discrimination, health status. If someone believes they are not going to get good care, then they won't. It is this utilization that will make a difference in health outcomes."

– Dr. Lovell Jones, MD Anderson Cancer Center

Unequal Access to Care

Having access to care means that a patient has a healthcare provider or facility available, has the transportation and other support needed to get there, and has the ability to somehow cover the costs of visits and treatments needed. The importance of access, or lack thereof, in lung cancer disparities is poignantly illustrated by the findings of a recent study of lung cancer cases in the military healthcare system: Where access to medical care was unlimited, there were no racial disparities in survival rates.[50] Unfortunately, most of our current healthcare system does not get the same results, especially in disadvantaged communities.

The healthcare system and its infrastructure play a major role in the health disparities seen in the U.S. Historically, all minority populations are less likely than whites to have health insurance, have more difficulty getting health care and have fewer choices in where they receive care. African American patients are more likely to receive care in hospital emergency rooms and less likely than whites to have a regular primary care physician.[3]

There is little debate that lack of insurance and lower income level are important contributors to disparities in health care.[51] Twenty-one percent of African Americans are uninsured and approximately 38 percent of uninsured African American patients report an unmet health need and inability to see a physician when needed due to cost.[30,52] Individuals with no health insurance and those with Medicaid coverage are more likely to be diagnosed with advanced cancer.[53]

Lack of health insurance affects where people go for treatment, which has been shown to affect

"I'm sure economics comes into play ... whether you have a decent job or a job at all, and that could affect your treatment."
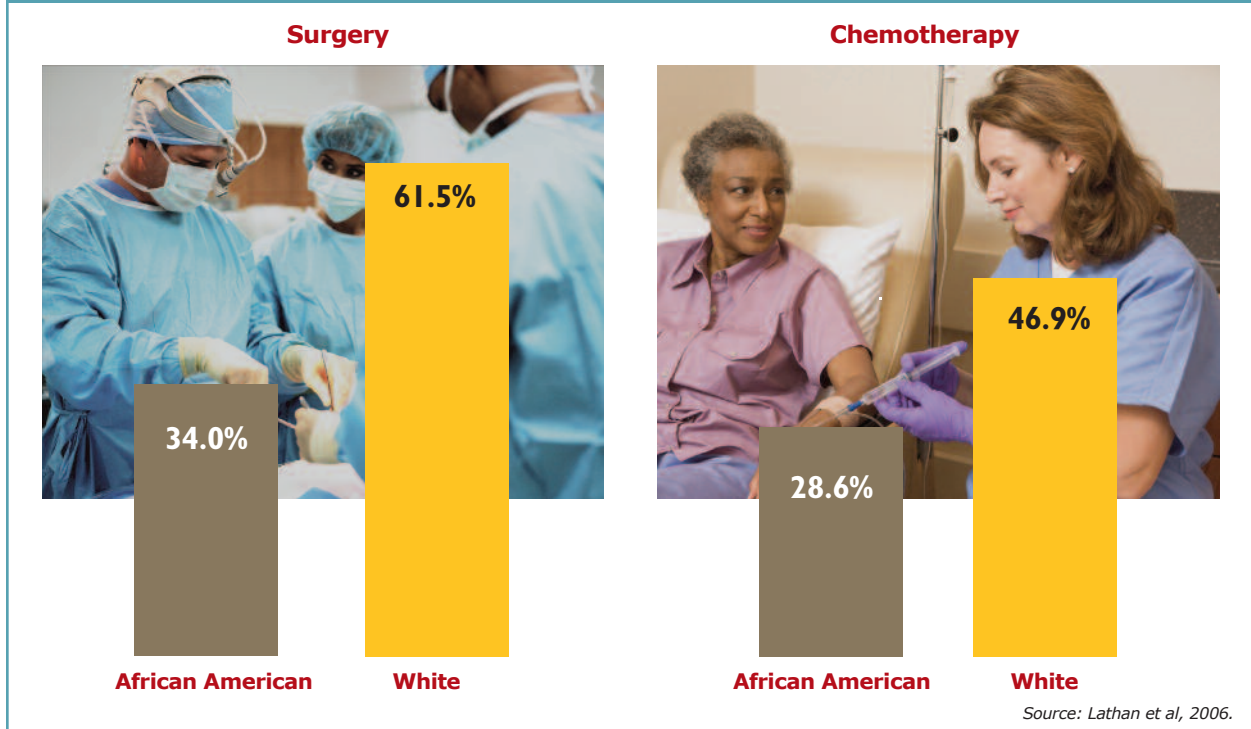
– Michael R., who retired two years ago because his lung cancer interfered with his ability to work. With his income cut in half, he worries about the future and being able to afford ongoing care.

health outcomes. Public hospital systems typically provide health care for the uninsured, those with lower income levels and those with lower levels of formal education. With a rising number of uninsured patients and uncompensated healthcare costs, these hospital systems have had limited resources that affect their ability to provide standard-of-care medical therapy.[52] In a recent review of lung cancer cases in Texas, researchers found that the patients who were receiving their care at public hospitals were waiting 40 percent longer to start treatment than patients attending private hospitals. The public hospital patients were more likely to be black, and less likely to have private insurance.[54]

But insurance coverage is only part of the access issue. There are many socioeconomic factors that affect a person's ability to choose where they get their care, including where they live, whether they have transportation and even if they can get paid time off from work to travel to a specialty cancer center. Research has shown that, across health issues, there are differences between the providers and facilities that treat black patients and those that treat white patients. In one study, African Americans were seen by a small subgroup of doctors who were less likely to be board certified, and more likely to report facing obstacles in gaining access to high-quality services for their patients.[55] Similarly, just a small number of hospitals care for the vast majority of elderly African American patients, and these facilities have been found to provide a somewhat lower quality of care.[56] In one study of why African Americans

Figure 9
Disparities in Treatment

Surgery

61.5%

34.0%

African American · White

Chemotherapy

46.9%

28.6%

African American · White

Source: Lathan et al, 2006.

For many African Americans, doubts about the trustworthiness of physicians and healthcare institutions spring from collective memory of the Tuskegee experiments and other abuses of black patients by largely white health professionals.

– Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care IOM 2003

with lung cancer are more likely to die in the hospital after surgery, researchers found that blacks are more likely to go to hospitals that have less experience with lung cancer resection surgery, because they do them less often.[57]

"Lung cancer, breast cancer and prostate cancer, you don't like to talk about them. You don't like to think about cancer and try to keep it out of your mind."
– Michael R.

Unequal Quality of Lung Cancer Care

African Americans with lung cancer do not get the same treatment for their disease as their white counterparts. They are less likely to undergo staging and, once staged, are less likely to have surgery. They are also less likely to receive chemotherapy. (Figure 9) Sadly, a recent study of over 83,000 Medicare patients found that the profundity of this disparity was relatively unchanged over the 12-year course of the study.[58,59] The reasons for this are many. Some of them stem from failures of the healthcare system, and others are deeply rooted in history, culture and beliefs.

African Americans across all health conditions are much more likely to report discrimination in healthcare settings than are whites.[60] The experience of discrimination has been associated with delays in seeking medical care, and poor acceptance of treatment recommendations.[61] Researchers have identified a sense of helplessness and hopelessness among African Americans about cancer – that it is a certain death sentence – that contributes to a reluctance to get diagnosed and treated.[62] Providers have also been found to settle into a kind of fatalism that can affect the care they give. They are less likely, for example, to refer black

Diane's sisters were not in favor of chemotherapy or radiation, because of the pain and suffering they had heard it caused. But while her sisters were focused on radiation burning the skin and chemotherapy poisoning the body, Diane knew she had to follow her medical experience, education and her doctor's recommendations.

patients to specialists for treatment, which limits available treatment options and quality.[52]

Even when offered optimum treatment, African Americans are more likely than whites to refuse it. They are more reluctant to accept physician recommendations and more likely to decline invasive procedures, including surgery to remove the cancer. One study found a 14 percent difference between the proportion of black patients and white patients who underwent lung resection surgery after it had been recommended.[63] This seems to be largely a problem of trust.

Distrust has proven to have a deadly impact on the beliefs and decision-making of black pa-

Figure 10
Physician Workforce

African American 12%
Asian 4%
White 65%
4%
13%
Other 19%
75%
8%
Physicians
Overall Population
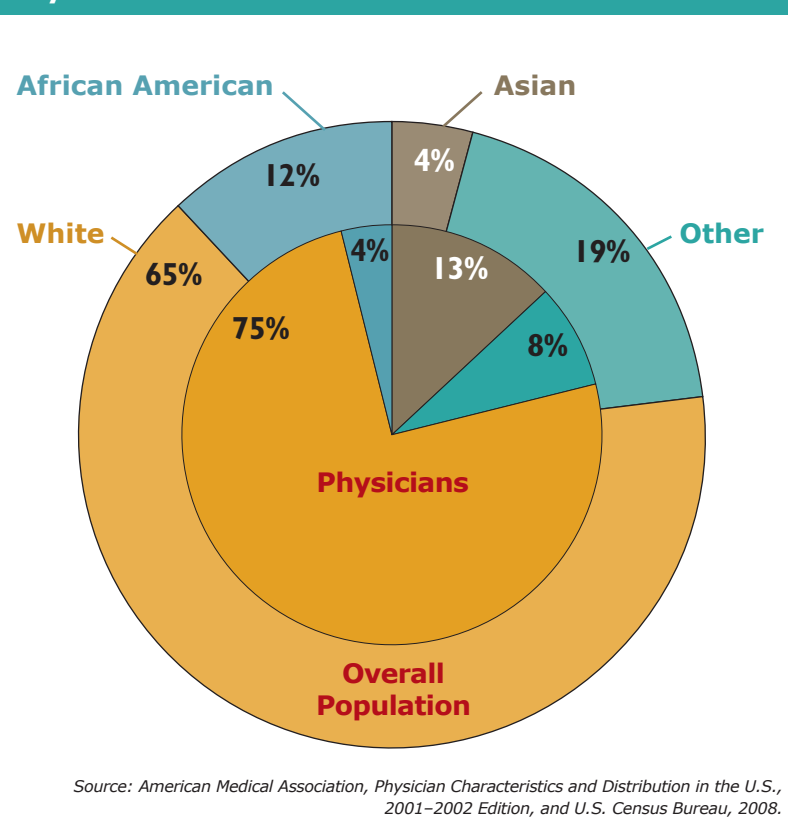
Source: American Medical Association, Physician Characteristics and Distribution in the U.S., 2001–2002 Edition, and U.S. Census Bureau, 2008.

tients with lung cancer. One of the more common misperceptions about lung cancer in the African American community is that exposure to air during surgery causes the tumor to spread. When one group of patients was questioned about this belief by researchers, 61 percent of African Americans believed this was true, 19 percent were opposed to having surgery on the basis of this belief, and 14 percent would not believe their doctor when told the belief was false.[64]

Overall, the provider-patient relationship is strengthened when patients see themselves as similar to their physicians in personal beliefs and values. Patients who feel a rapport with their physician are more likely to trust them, feel satisfied with their care and make a commitment to adhere to treatment recommendations. Being of the same race is a primary indicator of this perceived similarity.[65] Unfortunately, in many communities it is not easy to find an African American doctor, let alone a lung cancer specialist. According to the U.S. Health Resources and Services Administration, African Americans are significantly underrepresented in the physician workforce, at less than 4 percent.[66] (Figure 10)

Poor communication between physicians and patients is another part of the trust problem. In one study, researchers surveyed patients before and after their first visit for suspected lung cancer. Before the visit, African American and white patients expressed similar levels of trust in the physician they were about to see. But after the visit, the black patients' levels of trust went down, and the white patients' trust increased. When asked about the encounter, the African Americans perceived their doctors as less supportive, less partnering

"While I believe in prayer more than anything else in life, I believe God places doctors and researchers in this world to help us survive, in addition to prayer. I'm not saying I don't believe in miracles, because they do exist, but we each must be our own advocate."

– Diane B.K.

"I feel like the people at the James Cancer Clinic really have a concern for me, personally, and my well-being."

– Michael R.

and less informative.[67] These findings are consistent with other studies that have found that white physicians talk less, and engage in less shared decision-making with black patients than with white. It is important to note that this does not appear to be discrimination so much as a failure to communicate. In one study, the physicians initiated conversation with all patients with equal frequency. But the black patients were less likely to respond in ways that continued the information exchange.[68]

Fortunately, it is possible for healthcare providers who are skilled in patient-centered communication to transcend racial differences and increase patients' perceptions of similarity. Black patients are more likely to trust doctors of a different race when they are treated with respect and concern, and are encouraged to be involved in treatment decision-making.[66]

Cultural competence – the ability to interact effectively with people of different cultures – is a critical component of patient-centered care. For many African Americans that means, in part, being able to understand the role of religion and spirituality in their lives. The Institute of Medicine lists spiritual well-being as one of six domains of quality supportive care for those affected with cancer and other terminal diseases.[69] Cancer researchers have identified the reliance on prayer and spiritual healing as a factor in treatment disparities in the African American community.[70] The challenge for healthcare providers is to accept faith as a key factor for establishing a strong patient-physician relationship with their African American patients, and to work with it rather than against it in treatment.

Racism and Social Stress

For people of color in the U.S., race and discrimination are facts of everyday life. Over 30 percent of African Americans think about their race at least once a day, compared with only 5 percent of whites. This constant vigilance takes a toll. There is strong evidence that people who perceive more discrimination directed at themselves or other members of their group are at greater risk for poor mental and physical health.[60] According to the *2003 California Health Interview Survey*, 56 percent of African Americans in California reported experiencing racism, compared to 12 percent of whites. Those who reported experience with racism were more likely to smoke and less likely to be up-to-date with cancer screenings.[71]

How discrimination affects health – what biological mechanisms are at work – is not clearly understood. The experience of discrimination appears to bring on a physiological and psychological "fight or flight" stress response. And in fact, the impact of discrimination on health appears to be consistent with what we know about how stress has long-term consequences on health and well-being.[72] Kaiser Permanente and the Centers for Disease Control and Prevention recently re-

"If you feel like you're under life's pressures, you might resort to bad habits at the time. My problem was smoking cigarettes. It relaxed me and I enjoyed doing it even though I knew it was bad for me. Black men are probably more susceptible to coping with stress by smoking because racism causes stress and carries a lot of weight. Our African American history here has been a factor. It is tremendously better for African Americans in general, but we still have a long way to go."

– Michael R.

leased findings that stressful and traumatic childhood experiences may be associated with an increased risk of lung cancer and premature death from lung cancer. According to the researchers, this increased risk is only partly explained by smoking, and other causative pathways linking stress and health should be explored.[73]

Dr. Camara Jones, Research Director on Social Determinants of Health and Equity at the Centers for Disease Control and Prevention (CDC), has talked about the need to name the proverbial "elephant in the room" – racism – and how we must accept the fact that racism in this country contributes to poor health, in order to begin to make changes.[74] Efforts to reduce lung cancer disparities cannot wait until problems of racism and discrimination in the country are eliminated. But those problems must not be denied if we are to move forward.
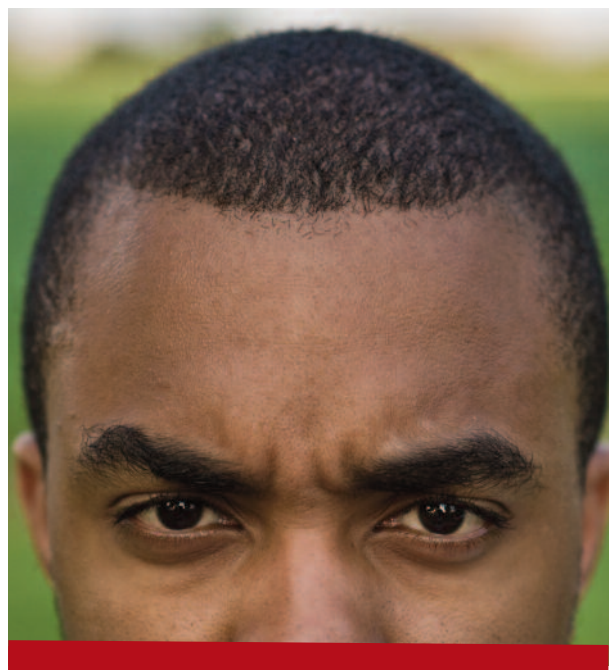
Progress Made

Lung cancer remains a terrible burden for all patients, families and communities. But in recent years there has been some progress in preventing and treating the disease. This progress has for the most part been population-wide: Like the rising tide, it floats all boats. Thanks to the work of advocates and researchers, in the future we expect fewer people of all races and ethnicities will be getting lung cancer, and there will be better treatments available for those who fall ill.

Tobacco Control

Over the last several decades, tobacco control measures have decreased the number of Americans who smoke and protected others from exposure to secondhand smoke. Successful policies have included comprehensive state and local smoke-free air laws, increased cigarette excise taxes, granting the U.S. Food and Drug Administration regulatory control over the manufacturing, distribution and advertising of tobacco products and increased funding for comprehensive tobacco control and cessation programs. In fact, decreased tobacco use by young African Americans has lowered lung cancer rates.[75]

Healthy Air

By strengthening and enforcing the Clean Air Act, including cleaning up diesel engines, outdoor air pollution has decreased in many parts of the U.S. Public places and individual homes are increasingly smoke-free.

Research Funding

In fiscal year 2010, the National Institutes of Health (NIH) spent more than $6 billion on cancer research, but only $203 million of that was spent on lung cancer.[76] The American Lung Association Research Program supports clinical, laboratory and epidemiological research on lung cancer. Along with other advocacy organizations, the Lung Association continues to fight for increased funding on prevention and treatment of lung cancer with the goal of increasing five-year survival rates and reducing death and disease.

Improved Treatments

Although the prognosis for patients with lung cancer remains poor, early-stage lung cancer is curable. There are effective treatments for locally advanced lung cancer and palliative treatments for later-stage disease that can extend and improve quality of life.[77] Researchers are working hard to develop tests that can detect lung cancer in its early stages, when it can be treated more successfully. Researchers are also seeking new treatments to increase the survival time and even cure lung cancer.

Areas for Improvement

Focus on Disparities

The advances we have already made will not close the lung cancer disparities gap on their own. That will require special attention and dedicated resources. In the last decade or so, a broader focus on health disparities has yielded some successes that can be used as models for improvement in data collection, systems-change and interventions that are specific to lung cancer.

It is essential to **collect better data** on race, socioeconomic status and cultural barriers to care. However, most hospitals, providers and insurers do not routinely collect that information, nor are these data linked to quality measures or used for quality improvement. Among the many large-scale efforts to improve data collection:

- The Agency for Healthcare Research and Quality (AHRQ) National Health Plan Collaborative, which includes 10 health plans with a total of 87 million enrollees.
- The Center for Healthcare Strategies Disparities Health Plan Collaborative, which includes 12 Medicaid health plans covering 3.2 million enrollees.
- The Health Education Research and Education Trust created a Disparities Toolkit to aid providers and health systems to collect accurate data from their patients or caregivers.

The National Business Group on Health has developed **systems-change strategies** to engage employers in eliminating health disparities by changing workplace practices but also in recognizing their power as healthcare purchasers. Employers are encouraged to require changes to their health plans' structure. They should consider the recruitment and training of health professionals, including cultural competency. Data collection should be used to design programs and improve case management. Customer service and communications are also critical.

Private and public organizations are undertaking national, regional and local efforts to identify and replicate **effective interventions** to reduce healthcare disparities:

- The Health Resources and Services Administration (HRSA) administers a national program of health disparities collectives that are developing evidence-based systems for quality improvement.
- The National Quality Forum identified addressing healthcare disparities as a national imperative. Included in the set of disparities-sensitive measures suggested for improvement at the practice level are tobacco use assessment and cessation intervention.
- The National Medical Association and the Cobb Institute are partnering to implement a program that supports increased involvement of minority physicians and patients in clinical research, as well as the dissemination of research findings for the better care of patients.
- Public and private health organizations are partnering with faith communities to develop community programs such as the University of California San Francisco Abundant Life Initiative and the Washington State African American Reach and Teach Health (AARTH) Ministry.

Taking Action

The problem of lung cancer disparities in African Americans has developed over the course of the history of the United States and will not be eliminated without the commitment of time, resources and the passion to make a difference. The American Lung Association calls on government agencies, health-care systems, community leaders and patient advocates to take the following actions to end the tragedy of too many cases and too many deaths:

- **The FDA Tobacco Product Scientific Advisory Committee** should complete its review of the impact of the use of menthol in cigarettes on the public health, including such use among children, African Americans, Hispanics and other racial and ethnic minorities, and issue its recommendations for the FDA on time.
- **The Food and Drug Administration** must, as required by statute, convene key stakeholders, including local and community-based organizations, in order to develop an action plan to enforce restrictions on the promotion and advertising of menthol and other cigarettes to youth, and to provide assistance to prevent underage tobacco use in communities with a disproportionate use of menthol cigarettes by minors.
- **States** should continue to pass comprehensive laws prohibiting smoking in all public places.
- **Health plans and Medicaid** should ensure availability of tobacco cessation programs, especially those tailored to African Americans or cessation from menthol cigarettes.
- **Federal agencies,** including the Department of Housing and Urban Development and the Department of Defense, should test and correct radon health hazards in housing that they own and manage.
- **The National Institutes of Health** should increase funding for lung cancer research. Additional research on health disparities, including lung cancer in African Americans, is needed.
- **The Health Care Education Reconciliation Act of 2010** should be implemented to ensure access for all to affordable health care.
- **Medical education programs** nationwide should recruit minority populations into the health and medical field, including specialty fields such as oncology.
- **Medical education programs** nationwide should educate physicians and other healthcare providers on successful ways to overcome communication barriers and deliver optimal care in a culturally competent way.
- **African American community and spiritual leaders** should speak up about lung cancer, and the importance of hope and trust in getting good care.

Concluding Thoughts from Diane and Michael

"We have to stop blaming the victim. We have to educate people – know your family history, advocate for your health, ask questions, find the answers, even if it's uncomfortable for you or your family in the short term. You don't ever know what it feels like until you've walked in that person's shoes and then you'll know what you would do in that situation. Trust in God, yourself and your doctors, but ultimately get treatment because diagnosis does not mean death. But doing nothing or giving up because you don't want to know is the wrong approach."

– Diane B.K.

"Find a healthier way to relieve stress from your life – eat healthy, exercise, don't smoke and don't even start. It is definitely addictive. You definitely have to have a positive attitude, as best as possible, and enjoy each moment that you can."

– Michael R.

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