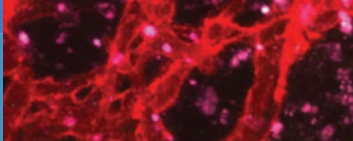
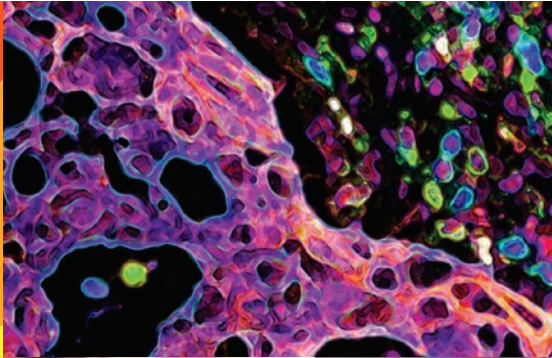
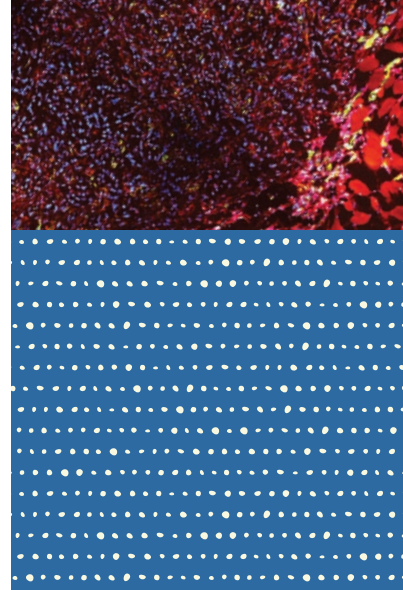


# AACR CANCER DISPARITIES PROGRESS REPORT 2024



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ACHIEVING THE  
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# Survivor Spotlights



**Phuong Ho, MD • 48 • Pleasanton, California** ..... 23

**Diagnosis: Non-Small Cell Lung Cancer**

“I consider myself a healthy person. I exercise regularly. I don’t smoke. So, when I was diagnosed with lung cancer, it was a shock. I was able to share with my husband, but I had a very difficult time explaining to my young children.”



**Katrece Nolen • 49 • Ashburn, Virginia** ..... 25

**Diagnosis: Inflammatory Breast Cancer**

“When you’re in the doctor’s office, that’s probably going to be the highest chance that someone’s going to participate in a clinical trial. And I think in many instances, we as patients, don’t feel like we’re recruited enough to participate.”



**Oya Gilbert • 54 • Waynesboro, Pennsylvania** ..... 43

**Diagnosis: Multiple Myeloma**

“I live in a rural area—predominantly White. It’s difficult for doctors to know anything about African Americans if you rarely see them, or maybe have some prejudices about them.”



**Daniel West • 53 • Houston, Texas** .....71

**Diagnosis: Non-Small Cell Lung Cancer**

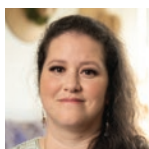
“My doctor is understanding of John and my relationship. He understands that we’re a team and that we make decisions about my treatment together. And that was important for us.”



**Anibal Torres • 66 • Humacao, Puerto Rico** ..... 99

**Diagnosis: Liver Cancer**

“I said I’m going to go for it. I signed the papers [for the clinical trial] quickly. I told them I want to stay alive and start as soon as possible.”



**Melissa Adams • 45 • Waipahu, Hawai‘i** ..... 109

**Diagnosis: Breast Cancer**

“The unfortunate thing for us here in Hawai‘i is that when it comes to clinical trials, most of them are on the mainland.”



**Todd Gates • 62 • Cattaraugus Territory of the Seneca Nation** ..... 111

**Diagnosis: Prostate Cancer**

“To make more progress against cancer, there are three things you need: The first one is funding. The second one is funding. And the third one is funding.”



**Darlene Pruess • 67 • Tampa, Florida** ..... 135

**Diagnosis: Multiple Myeloma**

“It is wonderful that, even though I continue to go back and forth in remission, they have individual treatment recipes just for me that work. So just keep it [the research] going.”



**Irasema Partida Chavez • 43 • Glendora, California** ..... 137

**Diagnosis: Gastric Cancer and Breast Cancer**

“I like sharing my story and hope that somebody who is just starting their journey can find some strength in mine.”



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## About the American Association for Cancer Research

**Founded in 1907, the American Association for Cancer Research® (AACR) is the world's first and largest professional organization dedicated to advancing cancer research and its mission to prevent and cure cancer.**

AACR membership includes more than 58,000 laboratory, translational, and clinical researchers; population scientists; other health care professionals; and patient advocates residing in 141 countries and territories around the world. Presently, 32% of members live outside the United States and 22% of AACR's international members are located in countries with emerging economies. The AACR marshals the full spectrum of expertise of the cancer community to accelerate progress in the prevention, diagnosis, and treatment of cancer by annually convening more than 30 conferences and educational workshops, the largest of which is the AACR Annual Meeting. The AACR publishes 10 prestigious, peer-reviewed scientific journals. Other AACR

publications include *Cancer Today*®, a magazine for cancer patients and caregivers; the annual *AACR Cancer Progress Report*; *AACR Cancer Disparities Progress Report*; *AACR Annual Impact Report*; *Leading Discoveries*, the AACR's awareness and donor magazine; and the blog, *Cancer Research Catalyst*. In addition, the AACR funds meritorious research directly as well as in cooperation with numerous cancer organizations. As the Scientific Partner of Stand Up To Cancer, the AACR provides expert peer review, grants administration, and scientific oversight of team science and individual investigator grants in cancer research that have the potential for near-term patient benefit. The AACR actively communicates with legislators and other policymakers about the value of cancer research and related biomedical science in saving lives from cancer. For more information about the AACR, visit **AACR.org**.

# A Message from AACR

**W**e are now witnessing spectacular progress against cancer in the United States, with more people living longer and fuller lives after a cancer diagnosis than ever before. This is the result of unprecedented advances in our understanding of cancer biology and in cutting-edge technologies that are allowing us to target the molecular drivers of the disease with increasing precision. Unfortunately, large segments of the US population have not benefited from these advances and continue to shoulder a disproportionate cancer burden. Cancer disparities in the United States stem from a long history of systemic inequities and are perpetuated by a range of structural and social factors that adversely impact human health. Also contributing to the disparities is the serious lack of diversity in the cancer research and care workforce attributable to the same institutional and societal injustices that limit opportunities for higher education among minoritized communities.

Launched in 2020, the Cancer Disparities Progress Report to Congress and the American public is a cornerstone of AACR's educational and advocacy efforts to achieve health equity. The *AACR Cancer Disparities Progress Report 2024* highlights areas of recent progress in understanding and reducing cancer disparities. It also emphasizes the vital need for continued transformative research and for increased collaborations to ensure that advances against cancer benefit all patients, regardless of their race, ethnicity, age, sexual orientation, gender identity, socioeconomic status, or geographic location.

Racial and ethnic minority population groups in the United States have long experienced cancer disparities. As one striking example, although the overall cancer incidence rates among Black and American Indian or Alaska Native (AI/AN) people are lower compared to the White population, Black and Indigenous individuals have the highest overall cancer death rates of all US racial or ethnic groups. Alarming disparities also exist for sexual or gender minority (SGM) populations, individuals residing in rural areas, and/or those living under persistent poverty. Additionally, it is concerning that we do not have a precise understanding of the true burden of cancer disparities for many of the vulnerable populations because of a lack of comprehensive, disaggregated health data. For example, most cancer databases lack information about sexual orientation or gender identity making it difficult to discern the true burden of cancer in SGM populations. In addition, health records for Native Hawaiian and other Pacific Islander populations are often combined

with those of Asian populations, thus masking the true extent of health disparities in this population group.

Encouragingly, some progress has been made in reducing cancer disparities. As one example, the disparities in overall cancer mortality between Black and White populations have narrowed significantly over the past two decades. Additionally, several clinical studies have demonstrated that racial and ethnic disparities in outcomes for many cancer types can be drastically reduced if all patients have equal access to standard treatments. However, the goal of achieving health equity for all medically underserved populations has yet to be realized.

As a scientific organization focused on preventing and curing all cancers, the AACR's principle focus has been and will remain diversity, equity, inclusion, and access. AACR is fiercely committed to advancing the science of cancer disparities by catalyzing discoveries in basic, translational, and clinical research as well as by underscoring the critical importance of population sciences, all of which are vital to identifying the systemic roots of health disparities. As highlighted throughout this report, an integrated approach that accounts for the interplay of an individual's living environments and exposures with biology and cancer risks is critical to cancer disparities research.

Cancer represents genetic aberrations at its root. Research has shown that these aberrations are driven by a range of factors and may differ by patients' ancestral backgrounds. Therefore, a comprehensive understanding of cancer relies on biospecimen and research models that represent diverse populations. As we look into the future, we strongly believe that a deeper understanding of the differences in cancer biology related to patients' ancestral backgrounds is key if we are to achieve health equity for all patients. Data repositories, such as the AACR Project Genomics Evidence Neoplasia Information Exchange® (AACR Project GENIE®), are providing novel insights into this very issue.

Cancer disparities are a complex and multifaceted problem necessitating multidisciplinary and collaborative approaches to identify effective solutions. AACR continues to be a trailblazer for the cancer disparities research community by catalyzing collaborations, bringing together all sectors in public health, and disseminating critical knowledge to the relevant stakeholders. One outstanding example is the pioneering AACR Conference

on The Science of Cancer Health Disparities in Racial/Ethnic Minorities and the Medically Underserved, the 17th edition of which will be held in September 2024. More recently, AACR has formed the AACR Cancer Centers Alliance, a collaborative initiative with US cancer centers. One of the major goals of the Alliance is to create new and inclusive opportunities for the next generation of cancer researchers and clinicians and thereby create a workforce that is reflective of the diverse communities that the cancer centers serve.

Research has shown that teams that are diverse in terms of race, ethnicity, opinions, experiences, and other sociodemographic characteristics are more innovative. We believe that increasing diversity in the cancer workforce and nurturing the professional development of underrepresented researchers will make future cancer research more equitable. For more than two decades, the AACR Minorities in Cancer Research and AACR Women in Cancer Research constituency groups have been leading the way in increasing the number, participation, visibility, and recognition of minority and women scientists. Additionally, AACR supports cancer disparities research and cancer researchers from underrepresented backgrounds through a wide range of national and international grant mechanisms.

Clinical trials are an integral extension of quality cancer care. To achieve the full potential of precision cancer medicine, an approach to treatment that harnesses our growing knowledge of the specific characteristics of individual patients and their cancers, it is essential that all segments of the population are adequately represented in cancer clinical trials. However, as underscored in this report as well as in past editions, participation in cancer clinical trials continues to be low, and there is a serious lack of diversity among those who do participate. In this regard, AACR has partnered with Bristol Myers Squibb Foundation to launch the Robert A. Winn Diversity in Clinical Trials program, which is designed to train early-stage physician scientists in the fundamentals of clinical trial design and the science of community outreach and engagement. These physician-scientists are from underrepresented backgrounds and have demonstrated a commitment to increasing diversity in clinical research.

Clearly, we are in an era of extraordinary scientific progress against cancer. Thanks to the new wave of scientific discoveries and technological innovations, the overall cancer death rate in the US is declining steadily, and we are now poised to deliver even more transformative breakthroughs for our patients. But along with these advances in cancer science and medicine, we must be equally committed to ensuring that no populations or communities are left behind. As powerfully described by the Reverend Dr. Martin Luther King, Jr., during the Medical Committee for Human Rights 1966 meeting in Chicago: "Of all the forms of inequality, injustice in health is the most shocking and inhuman because it often results in physical death." AACR is committed to working with policymakers to ensure that health equity is a national priority. By providing robust, sustained, and predictable funding for innovative research, Congress will continue to be of enormous assistance in eliminating cancer disparities and achieving the vision of health equity for all patient populations.



A handwritten signature in black ink that reads "Robert A. Winn, MD, FAACR".

**Robert A. Winn, MD, FAACR**  
CHAIR  
*AACR Cancer Disparities Progress Report 2024 Steering Committee*



A handwritten signature in black ink that reads "Margaret Foti, PhD, MD (hc)".

**Margaret Foti, PhD, MD (hc)**  
CHIEF EXECUTIVE OFFICER  
American Association for  
Cancer Research®





# Executive Summary

This is an exciting time in cancer science and medicine. Thanks to research, we are making unprecedented progress against the many diseases we call cancer. However, these advances have not benefited everyone equally. Because of a long history of structural inequities and systemic injustices in the United States, many segments of the US population continue to shoulder a disproportionate burden of cancer. Disparities in health care are among the most significant forms of inequity and injustice, and it is imperative that everyone plays a role in eliminating the barriers to health equity, which is one of the most basic human rights.

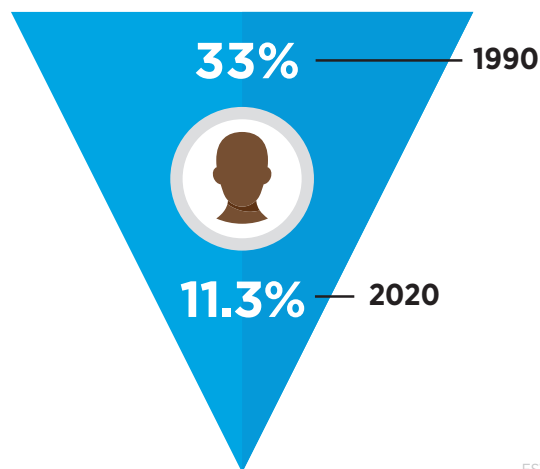
As the first and largest professional organization in the world dedicated to preventing and curing all cancers for all populations, the American Association for Cancer Research® (AACR) is committed to accelerating the pace of research to address the disparities across the cancer continuum. AACR is also dedicated to increasing public awareness of cancer disparities and underscoring the importance of cancer disparities research in saving lives, as well as to advocating for increased annual federal funding for the government entities that fuel progress against cancer disparities, in particular, the National Institutes of Health (NIH), National Cancer Institute (NCI), and Centers for Disease Control and Prevention (CDC).

The AACR *Cancer Disparities Progress Report 2024* to Congress and the American public is a cornerstone of AACR's educational and advocacy efforts to achieve health equity. This report highlights areas of recent progress in reducing cancer disparities. It also emphasizes the vital need for continued transformative research and for increased collaborations to ensure that research-driven advances benefit all people, regardless of their race, ethnicity, age, gender, sexual orientation, socioeconomic status, or geographic location.

## The State of US Cancer Disparities in 2024

Even though we are making great progress against cancer in the United States, as illustrated by the declining overall cancer death rate and the increasing number of cancer survivors, it is projected that there will still be 2,001,140 new cases diagnosed in 2024 and 611,720 deaths from the disease. The burden of cancer is disproportionately higher among certain segments of the US population.

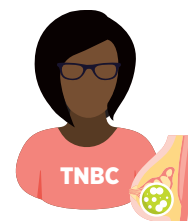
### NARROWING DISPARITY IN OVERALL CANCER DEATH RATE BETWEEN WHITE AND BLACK POPULATIONS



ESW1

Racial and ethnic minority population groups in the United States have long experienced cancer disparities. Despite promising trends in narrowing disparities in some instances, cancer disparities remain a serious challenge to public health and a significant barrier to achieving health equity. As discussed in this report, compared to White people, incidence rates for colorectal and cervical cancers are higher among American Indian and Alaska Native (AI/AN) people and for cervical cancer among Hispanic women. Compared to the White population, the overall cancer death rate is higher among Black and AI/AN populations. Furthermore, all racial and ethnic minority groups have a lower 5-year relative survival compared to the White population. Other concerning trends include the increasing burden of certain cancers such as the rising incidence rates of cancer among adults younger than 50 years, also called early-onset cancers. Two examples of this trend include rising incidence of early-onset colorectal cancer in AI/AN people, and of lung cancer in Asian women who have never smoked.

Non-Hispanic **Black women** living in **low-income neighborhoods** were **twice as likely to be diagnosed** with the **highly aggressive triple-negative breast cancer** as those living in high-income neighborhoods.



ESW2

In addition to racial and ethnic minority groups, many segments of the US population shoulder a disproportionate burden of cancer. These groups include rural residents, people living under poverty, and individuals who belong to sexual and gender minority (SGM) communities. The decline in the overall cancer death rates has been slower in rural residents compared to those living in urban counties. Counties with persistent poverty have a 7 percent higher death rate from all cancers combined compared to non-persistent poverty counties. Additionally, population-level cancer data on members of SGM communities are lacking, making it difficult to understand the true burden of cancer in this population.

It is increasingly evident that each of the US population groups is diverse, and collecting comprehensive, disaggregated cancer data for subgroups is critical to fully understand the extent of cancer disparities within and among these populations. As one example, combining Native Hawaiian and Other Pacific Islander (NHOPI) with Asian populations can hide significant cancer disparities experienced by the NHOPI population as well as by the Asian subgroups. The impact of cancer disparities is felt not only by the patient populations, but also by the US economy. The economic cost of racial and ethnic health disparities in 2018 alone was \$451 billion, a majority of which was disproportionately borne by AI/AN, Black, and NHOPI populations. As outlined in the AACR Call to Action, the bold vision of health equity can only be realized if the US Congress continues to provide sustained, robust, and predictable increases in funding for the federal agencies that are spearheading efforts to address and eliminate cancer disparities.

## Understanding and Addressing Drivers of Cancer Disparities

Health disparities, including cancer disparities, adversely impact racial and ethnic minorities and medically underserved populations. These disparities have stemmed from a long history of structural racism and contemporary injustices in the US and continue to have lasting, multigenerational adverse effects on marginalized populations in all aspects of life, including on health outcomes. Researchers have proposed many frameworks to understand and address influences that determine health outcomes and contribute to cancer disparities. These frameworks are based on a complex network of interrelated factors, called social drivers of health (SDOH), also referred to as social determinants of health.

According to NCI, SDOH are the social, economic, and physical conditions in the places where people are born and

where they live, learn, work, play, and get older that can affect their health, well-being, and quality of life. Social drivers of health include factors such as education level; income; employment; housing; transportation; and access to healthy food, clean air, water, and health care services. The interplay between SDOH, biological, and environmental factors impacts all aspects of a person's lived experiences, including health outcomes across the lifespan. Emerging technologies such as artificial intelligence, digital health, and liquid biopsies, also have the potential to influence health outcomes, and inequitable utilization can drive cancer disparities.

Ongoing research is identifying the multilevel and multifaceted impacts of SDOH on the health of individuals, communities, and populations. It is increasingly evident that SDOH impact cancer incidence and outcomes. Thus, addressing SDOH can not only improve overall health, but also help reduce the cancer disparities which are deeply rooted in social and economic disadvantages experienced by racial and ethnic minority groups and medically underserved populations. Constituents across the continuum of cancer care are taking multipronged approaches to address SDOH at various levels, with the overarching goal of achieving health equity for everyone.

Evidence-based interventions and policies implemented at the population level have the potential to not only improve the nation's health, but also strengthen the economy. The federal government has implemented numerous programs that are focused on providing stable and safe housing, nutrition and food access, and economic mobility. Similarly, NIH, NCI, CDC, and cancer-focused organizations are collaborating with each other and with institutes across the nation to investigate, develop, and implement interventions that are meaningful to the communities that they serve. Research has shown that racial and ethnic minority groups and medically underserved populations substantially benefit from community engagement and patient navigation that can enhance participation in healthy behaviors; increase adherence to cancer screening; and improve participation in clinical trials and receipt of treatment. Ongoing evaluation of the implemented strategies is essential to fully understand the impact of such efforts on addressing cancer disparities.

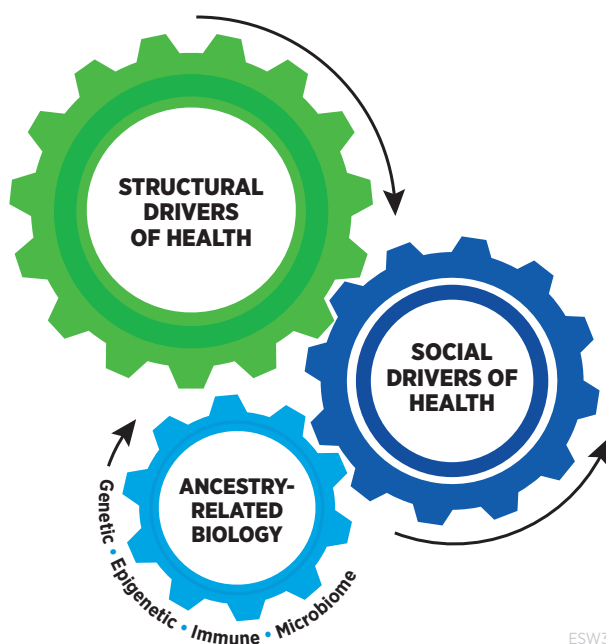
## Understanding Cancer Development in the Context of Cancer Disparities

Cancer is a collection of diseases characterized by uncontrolled cell multiplication. Cancer initiation, progression, and metastasis—the spread of cancer cells from primary sites to distant organs—are all complex, multistep processes that are influenced by alterations both inside and outside the cell.

Cancer-driving changes inside the cell include alterations in the DNA, RNA, and/or protein. Research has also shown that tumor initiation and progression are largely dependent upon complex interactions between cancer cells and the surrounding tissue, known as the tumor microenvironment. Among the key components of the tumor microenvironment are immune cells and blood vessels. While immune cells can identify and eliminate cancer cells under normal circumstances, in many cases, the immune system is suppressed, permitting the formation and progression of tumors. The blood and lymphatic networks are the primary conduits for the process of metastasis. Additionally, emerging evidence indicates that the microbiome, which is the collection of all microorganisms (e.g., bacteria, fungi) living in the body, can also influence cancer development.

Research has shown that there are ancestry-related differences in cancer-driving cellular and molecular alterations, such as those occurring in tumor and immune cells. Cancer disparities among racial and ethnic minority groups are driven by a complex interplay between structural and social drivers of health as well as biological factors that are attributable to ancestral differences between population groups. A major challenge in cancer science is the fact that most currently available data on cancer etiology are based on studies of individuals that are of European ancestry. Researchers are addressing this challenge through ongoing efforts to increase racial, ethnic, and ancestral diversity in cancer biology research investigations. Notably, biological differences among cancers in patients of different ancestries could provide novel targets for therapies and improve precision medicine.

### INTERCONNECTED CONTRIBUTORS TO CANCER DISPARITIES



ESW3

## Disparities in the Burden of Preventable Cancer Risk Factors

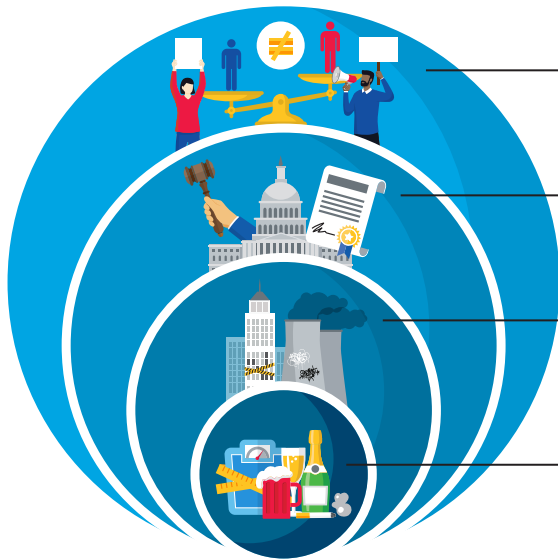
Research in basic, translational, and population sciences has broadened our understanding of the factors that increase an individual's risk of developing cancer. Modifiable risk factors, including tobacco use, poor diet, physical inactivity, UV exposure, alcohol consumption, pathogenic infections, and obesity, contribute to 40 percent of all cancer cases. Because several of these risks can be modified, many cases of cancer could potentially be prevented.

Environmental risk factors, such as air pollution, water contamination, and naturally occurring radon gas, among others, can also increase a person's risk of certain types of cancer. Furthermore, occupations such as firefighting and night shift work can expose individuals to factors that increase their cancer risk.

Individuals can reduce their risk of developing cancer through behavioral and lifestyle changes. However, long-standing inequities in numerous SDOH contribute to significant disparities in the prevalence of modifiable cancer risk factors among socially, economically, and geographically disadvantaged populations. These disparities stem from decades of structural, social, and institutional injustices, placing disadvantaged populations in unfavorable living environments that contribute to behaviors that increase cancer risk.

Individual behaviors are strongly influenced by the surrounding environment. Unfortunately, neighborhoods where socioeconomically disadvantaged populations reside are often characterized by low walkability, reduced availability of healthy food options, including fresh fruits and vegetables, and limited outdoor space for recreation and exercise. Socioeconomically vulnerable populations are also more likely to reside in less favorable locations such as near highways, near busy roads, or near industries, which increases their exposure to environmental pollutants to a greater degree, thereby increasing cancer risk. Additionally, occupations that increase exposure to cancer risk factors are also more likely to be staffed by minoritized populations.

Risk factors can intersect with other population characteristics, such as race, ethnicity, sexual orientation, gender identity, and disability status among others, to drive cancer disparities. As one example, individuals with disabilities, who may have fewer occupational opportunities and lower income, also have higher prevalence of smoking, obesity, and physical inactivity. It is imperative that public health experts prioritize cancer prevention efforts that account for the complex and interrelated factors across institutional, social, and



**Structural Inequity and Social Injustice**  
(marginalization, discrimination)

**Inequities in Institutional Environments**  
(laws, regulations, policies)

**Inequities in Living Environments**  
(pollution; lack of green spaces, sidewalks, fresh food, and neighborhood safety)

**Disparities in the Burden of Preventable Cancer Risk Factors**  
(tobacco use, poor diet, physical inactivity, alcohol use, obesity)

ESW4

individual levels influencing personal risk exposure and disparate health outcomes. There is an urgent need for all members of the medical research community to come together and develop strategies that enhance the dissemination of our current knowledge of cancer risk reduction and implement evidence-based interventions for reducing the burden of cancer for everyone.

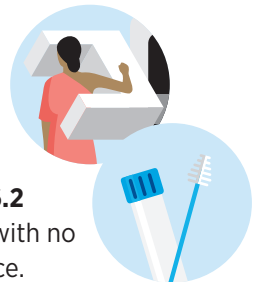
## Disparities in Cancer Screening for Early Detection

Cancer screening means finding precancerous lesions and cancers at their earliest stage when they are easier to treat and potentially curable. In the United States, government-affiliated agencies or other professional societies convene independent panels of experts in preventive medicine to develop population-level screening guidelines; the US Preventive Services Task Force (USPSTF) is one such panel. USPSTF recommends screening for breast, prostate, cervical, and colorectal cancers for individuals who are at an average risk of being diagnosed with these cancer types. In addition, USPSTF also issues screening guidelines for individuals who are at an increased risk of being diagnosed with certain cancers, e.g., lung cancer screening guidelines for current or former smokers.

Many of the disparities in cancer screening experienced by racial and ethnic minority populations and medically underserved groups stem from systemic and structural barriers. For example, residents of low-income neighborhoods have less access to affordable and quality health care facilities that can perform cancer screening tests. Deeply rooted mistrust of the health care system,

originating from a history of injustices committed by the health care establishment of the time, also contributes to cancer screening disparities. In some population groups, cultural beliefs, as well as lack of knowledge about cancer screening, play a role in exacerbating disparities in cancer screening. Another major source of disparities in cancer screening is barriers to follow-up exam(s) if the initial screening test indicates that the individual may have cancer. Further contributing to the disparities is the lack of participant diversity in the clinical studies that were used to develop the current cancer screening guidelines.

Since 1991, **CDC’s National Breast and Cervical Cancer Early Detection Program** has provided more than 16.1 million **breast and cervical cancer exams** to more than **6.2 million low-income women** with no or suboptimal health insurance.



ESW5

Researchers are taking multilevel approaches to address disparities in cancer screening and follow-up exams. Many of the approaches have been effective and provide a blueprint to effectively reach racially and ethnically minoritized communities and medically underserved populations. These strategies include developing comprehensive public health campaigns for eligible individuals to receive cancer screening; reducing mistrust in the health care systems; increasing access to health insurance to minimize out-of-pocket costs for certain types of screening tests; and developing culturally tailored interventions through patient navigation and community engagement.



## Disparities in Clinical Research and Cancer Treatment

The dedicated efforts of individuals working in medical research are constantly translating new research discoveries into advances in cancer treatments that are improving survival and quality of life for people in the United States and around the world. Clinical trials are a vital part of medical research because they establish whether new cancer treatments are safe and effective. Therefore, it is imperative that participants in clinical trials represent the entire population who may use these treatments if they are approved. Despite this knowledge, participation in cancer clinical trials is low, and there is a serious lack of sociodemographic diversity among those who do participate. Recent data indicate that community outreach and patient navigation can enhance participation of racial and ethnic minority population groups in clinical trials. It is imperative that researchers and policymakers work together to address the many barriers to clinical trial participation.

Remarkable advances in novel and innovative approaches to surgery, radiotherapy, chemotherapy, molecularly targeted therapy, and immunotherapy—the five pillars of cancer treatment—are saving and improving lives. Despite these advances, racial and ethnic minority groups and medically underserved populations continue to experience more frequent and higher severity of multilevel barriers to quality cancer treatment, including treatment delays, lack of access to guideline-adherent treatment, undertreatment, refusal or early termination of treatment, treatment receipt at low-volume hospitals and community settings rather than comprehensive cancer centers, and higher rates of treatment-related and/or financial toxicities. Patients from disadvantaged population groups may also experience overt discrimination and/or implicit bias during the receipt of care.



**Black and Hispanic patients with triple-negative breast cancer** are 18 percent and 13 percent **less likely**, respectively, to **receive guideline-adherent treatment** (including surgery, radiation, and/or chemotherapy) compared to White patients.

ESW6

Encouragingly, recent data show that racial and ethnic disparities in cancer outcomes can be eliminated if every patient has equitable access to guideline-adherent care. In fact, researchers have shown that certain patients



**Robert A. Winn, MD, FAACR**  
Chair, AACR Cancer Disparities Progress Report 2024 Steering Committee



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“The standard of care for cancer in the 21st century is to offer clinical trials. I, for one, believe that it’s not a trial as much as it is an extension of care. Therefore, we must come up with new and better ways to make our trials, i.e., our extension of health care, much more accessible to all people that are suffering from cancers.”



Scan the QR code

to watch Dr. Winn’s full interview.

with cancer from racial and ethnic minority populations may respond better to select treatments compared to White patients and have better outcomes when offered similar access to standard and quality care. All sectors must work together to urgently address the challenges of disparities in cancer treatment. In this regard, it should be noted that clinical studies, including the Accountability for Cancer through Undoing Racism and Equity (ACCURE) program, have shown that multilevel interventions that include addressing system-level barriers to care, connecting to resources, and providing psychosocial support through patient advocacy and navigation can address the current disparities in cancer treatment and improve outcomes for all patients.

## Disparities in Cancer Survivorship

According to NCI, a person is considered a cancer survivor from the time of cancer diagnosis through the balance of the person’s life. With 18.1 million cancer survivors in the United States as of 2022, many more people are living through and beyond their cancer diagnosis. While these numbers are promising, medically underserved populations have higher rates of morbidity and mortality for many types of cancers. With the number of US individuals over the age of 65 and the diversity of the US population increasing, the number of cancer survivors who belong to racially and ethnically minoritized groups is projected to grow over the next few decades. Unless more equitable cancer control efforts are put in place, disparities across the cancer continuum, including survivorship, will widen, potentially increasing the future cancer burden.

Cancer treatments can be difficult for a patient's physical and mental health and can contribute to potentially adverse side effects during or after cessation of treatment. Individuals from racial and ethnic minority groups and other medically underserved populations experience side effects at higher rates than those who are White. The adverse physical effects, coupled with worsened functional, psychological, social, and financial challenges, contribute to inferior health-related quality of life (HRQOL), an increasingly important consideration in cancer care, US Food and Drug Administration (FDA) drug approvals, and long-term survival predictions. It has long been recognized that HRQOL is lower in cancer survivors compared to individuals who have never been diagnosed with cancer. Furthermore, cancer survivors from medically underserved populations are at an increased risk of experiencing worse HRQOL.

Healthy behaviors, such as increasing physical activity, eating a healthy diet, reducing alcohol consumption, and not smoking, can significantly improve both health outcomes and HRQOL for cancer survivors. Unfortunately, many of the same barriers to participating in healthy behaviors discussed earlier in the context of cancer prevention also exist for cancer survivors. As one example, lack of access to exercise facilities and other types of recreational activity for racially and ethnically minoritized and medically underserved cancer survivors reduces participation in physical activity.

A key to charting an equitable path forward for cancer survivors who belong to disadvantaged populations is to implement community-based, culturally tailored solutions that include patient advocates and patient navigators as key partners to meet the specific needs of every patient. Such strategies can address the specific social, psychological, medical, and physical needs of the patient while tying in cultural norms and perceptions, and ultimately increasing HRQOL; bolstering adherence to follow-up survivorship care; identifying financial concerns; providing equitable health care; and reducing the overall cost of cancer care.

**Patients with hematologic cancer** and their caregivers who **participated in a financial navigation program** saved an average of about \$2,500 per participant.



ESW7

## Overcoming Cancer Disparities Through Diversity in Cancer Training and Workforce

A diverse cancer research and patient care workforce includes individuals who represent a wide range of

backgrounds, life experiences, and demographic groups, including differences in race, ethnicity, sexual orientation and gender identity, disability status, and socioeconomic background. A cancer care workforce that reflects the diversity of the US population enhances cultural competence and humility in delivering care to a diverse patient population, fosters innovation by integrating different perspectives and approaches, and elevates role models and mentors to inspire and support the next generation of historically underrepresented professionals in the cancer research and patient care workforce.

Some key strategies to increase diversity in the cancer research and care training pathway and workforce include ensuring early exposure to cancer research among students from underrepresented backgrounds; strengthening partnerships with minority-serving institutions; providing scholarships, grants, and loan repayment programs to help students from underrepresented groups overcome financial barriers to pursuing careers in cancer science and medicine; developing tailored recruitment programs to attract underrepresented minorities to cancer-related fields; implementing support systems and mentorship programs to retain the cancer workforce; and ensuring that leadership at cancer centers and research institutions is committed to diversity and health equity.

While there have been efforts to increase diversity in the cancer workforce, progress has been slow compared to the overall health care field. The underrepresentation of women, as well as racial and ethnic minority populations, in cancer science and medicine, remains a significant concern and may contribute to cancer disparities. In June 2023, the Supreme Court banned affirmative action in college admissions, striking down the use of race as an admissions factor. With affirmative action severely curtailed nationwide, substantial additional drops in historically underrepresented student admissions are expected, thus threatening diversity gains. Therefore it is vital that all constituents in the medical research and public health community work with policymakers to identify new and improved strategies that ensure continued progress toward a diverse and representative cancer care workforce.

## Overcoming Cancer Disparities Through Science-based Public Policy

Public policy is instrumental in addressing systemic barriers and promoting health equity to improve cancer outcomes for historically marginalized populations. Evidence-based policymaking can increase access to high-quality health care, enhance diverse representation

in clinical studies, and remove barriers to facilitate access to cancer screening and preventive services.

Historically, the tobacco industry has aggressively targeted racial, ethnic, sexual, and gender minority groups. Increased tobacco regulation is urgently needed to mitigate the disproportionately high disease burden from tobacco use among these populations.

Several government agencies, including NIH, FDA, and CDC, have developed policies and implemented programs to reduce disparities across the cancer care continuum. Sustained and meaningful collaboration across all branches of government is a promising strategy to reduce cancer disparities. Achieving long-term health equity in cancer outcomes will ultimately require intentional and multidimensional efforts from government, community organizations, health systems, researchers, nonprofit organizations, and all other stakeholders.

## AACR Call to Action

Economic inequities, social injustices, and systemic barriers continue to adversely affect all facets of cancer research and patient care leading to a disproportionate burden of cancer for many US population groups. These disparities are driven by exposure to environmental carcinogens, limited access to health care and clinical trials, policies that exacerbate modifiable risk factors, such as smoking and lack of access to healthy food, and impediments to the development of a research and health care workforce that is broadly representative of our society.

Many programs and initiatives, both public and private, have been undertaken to address these challenges, but additional efforts and investments are urgently needed.

### To make further progress toward eliminating cancer disparities, AACR calls on US policymakers to\*:

- **Provide robust, sustained, and predictable funding increases** for the US federal agencies and programs that are tasked with reducing cancer disparities.
- **Support data collection initiatives** to reduce cancer disparities.
- **Increase access** to and participation in clinical trials.
- **Prioritize cancer control initiatives** and increase screening for early detection and prevention.
- **Implement policies** to ensure equitable patient care.
- **Reduce cancer disparities** by building a more diverse and inclusive workforce.
- **Enact comprehensive legislation** to eliminate health inequities.

AACR has been a leader in advancing science to eliminate cancer disparities. The *AACR Cancer Disparities Progress Report 2024* showcases the progress that has been made to address these disparities, while it highlights the many challenges that must be overcome. To fulfill the aims of the Call to Action and further advance health equity, partnerships will be required among diverse stakeholders, including federal, state, and local governments; the biopharmaceutical industry; academic and medical institutions; patient-centric and community-based organizations; and professional organizations. These collaborations must synergize with broader efforts in society to overcome economic inequities, dismantle structural barriers, and rectify social injustices to ensure the health and well-being of all patient populations.

\*For a more comprehensive list of recommendations, see **AACR Call to Action** (p. 169).



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of the report.

# A Snapshot of US Cancer Disparities in 2024

**Cancer disparities are an enormous public health challenge in the United States. Examples of these disparities across the cancer continuum include the following:**

**HIGHEST overall**

**Black people** have the **highest overall cancer death rate** among all racial and ethnic groups.

**Significantly HIGHER**

Incidence and **mortality rates** for stomach and liver cancers are **significantly higher in AI/AN, API, and Hispanic populations.**

**21% more likely**

**NHOPI women** are 21 percent **more likely to die from breast cancer** compared to White women.

**38% more likely**

**Residents of rural counties** are 38 percent **more likely to be diagnosed with and die from lung cancer**, compared to those living in large metropolitan or urban counties.

**60% lower risk**

Compared to cisgender men, **transgender women** appear to be at a 60 percent **lower risk of developing prostate cancer**, but they are **nearly double the likelihood of dying** from it.

**22% higher mortality**

**Residents of disadvantaged neighborhoods** had a 22 percent **higher mortality rate for all cancers combined** compared to those living in advantaged neighborhoods.

## CANCER SCREENING

In 2021, only **64 percent of eligible Asian and AI/AN** individuals were **up to date** with USPSTF-recommended **cervical cancer screening** compared to 78 percent of White individuals.

**Women under the age of 65 without any insurance** were 50% **less likely to be up to date with breast cancer screening** compared to those who had private insurance.

## CANCER TREATMENT

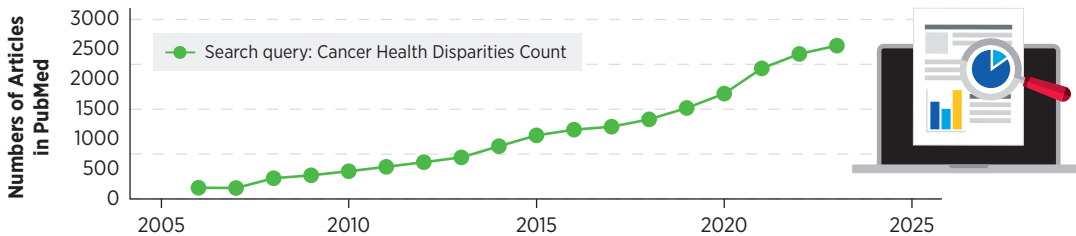
Of the **pivotal clinical trials** that supported FDA approvals of **82 novel therapeutics** during 2015–2021, **90 percent lacked adequate representation of Black patients**, and **73 percent** lacked adequate representation of **Hispanic/Latino patients.**

Compared to non-Hispanic (NH) White women, **NH Black women with breast cancer are less likely to receive curative surgery** and NH Black and Hispanic women are more likely to delay surgical procedures.

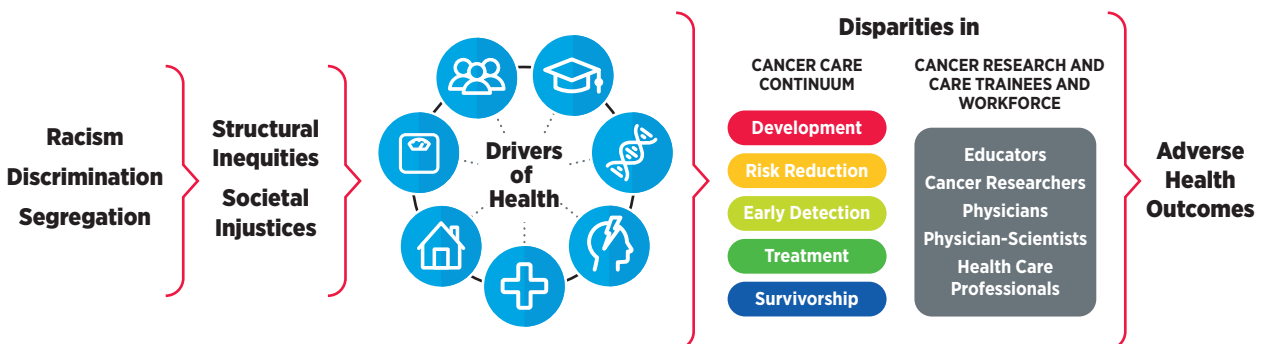
## CANCER SURVIVORSHIP

**Cancer survivors** who belong to **medically underserved populations** are at an **elevated risk of worse health-related quality of life**, which has been shown to **increase the likelihood of cancer recurrence and mortality.**

### RESEARCH ON THE SCIENCE OF CANCER DISPARITIES HAS GROWN EXPONENTIALLY OVER THE PAST DECADE

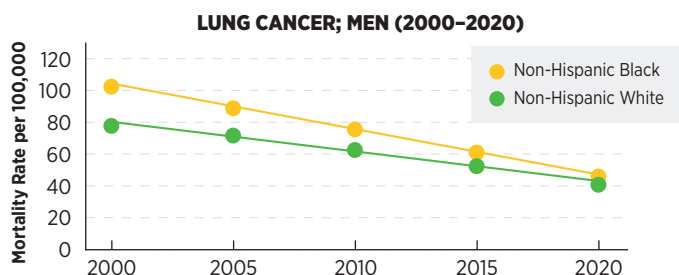


**Researchers have identified a range of complex and interrelated factors that drive cancer disparities in the United States; many of them have been perpetuated by a long history of structural inequities and societal injustices:**

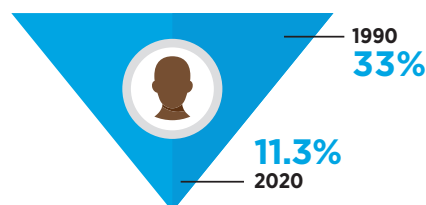




## There has been progress in our understanding of cancer disparities and in some cases reducing cancer disparities:



## NARROWING DISPARITY IN OVERALL CANCER DEATH RATE BETWEEN WHITE AND BLACK POPULATIONS



## Approaches that have been effective in reducing disparities in cancer care include:

**Building community trust and partnerships** in health care systems through public education and awareness

**Developing** culturally and linguistically tailored interventions

**Implementing patient navigation** to reduce the structural barriers

**Improving access to and coverage of health insurance** such as Medicaid expansion and minimizing out-of-pocket costs

**Enhancing communication** between providers and patients

**Transgender women** are 35 percent less likely to receive prostate cancer screening compared to cisgender men. **When providers recommend the PSA test and initiate a discussion of its advantages and disadvantages, the disparity is nearly eliminated.**

### PATIENT NAVIGATION

A navigation program that addressed insurance, food, housing, transportation, language, health literacy, social and clinical needs **increased participation in clinical research:**

	Before Navigation*	After Navigation*
<b>Rural</b>	19%	40%
<b>Black</b>	13%	41%
<b>Hispanic</b>	5%	33%

\* Participation (% of patients)

**Patient navigators** improved the rates of genetic testing for medically underserved patients with prostate cancer.

	7 Months Before†	7 Months After†
<b>Black</b>	19%	58%
<b>Low income</b>	20%	64%
<b>Medicare/Medicaid</b>	20%	69%
<b>Treated in a community setting</b>	6%	77%

† Referral rates for genetic testing (% of patients)

## Advancing policies to achieve health equity and build a diverse workforce:

**Funding for disparities research at NIH, NCI, and NIMHD** helps inform effective strategies to improve health equity.

**Federal investments in STEMM education programs** create pathways for students from diverse backgrounds to be part of an inclusive research and health care workforce.

**Ensuring diverse representation in basic and translational research studies and cancer clinical trials** are essential for reducing disparities in cancer treatment.

**Expanding cancer prevention and screening efforts**, such as addressing environmental exposures, unhealthy diet, physical inactivity, tobacco use, and suboptimal uptake of vaccines help address health disparities.

The health of all patients can be improved by **broadening access to equitable and affordable quality health care**, including access to telehealth for underserved populations.



# The State of US Cancer Disparities in 2024

## IN THIS SECTION, YOU WILL LEARN:

- Cancer disparities are adverse differences in the cancer burden that are experienced by, but not limited to, racially and ethnically minoritized groups, rural residents, citizens of sovereign Native Nations, those identifying as sexual and gender minorities, and those living under persistent poverty.
- In recent decades, disparities in the burden of certain cancer types have declined among racial and ethnic minority populations.
- Compared to the White population, Black people were 24 percent more likely to die from lung cancer in 1990, a disparity that has been drastically reduced in 2020. Similarly, gaps in cervical cancer deaths for Hispanic populations and in stomach cancer deaths for Asian and Pacific Islander populations have narrowed significantly over the past two decades.
- Despite some progress, substantial differences in cancer burden remain. Constituents across the cancer care continuum are working together to understand and reduce cancer disparities.
- Research is revealing that the aggregated cancer data that are currently available in most cancer registries and databases may mask underlying cancer disparities within subgroups of racial or ethnic populations, necessitating the collection of disaggregated cancer data.
- The cost of health disparities, including cancer disparities, to the US economy in 2018 alone was \$451 billion, the majority of which was disproportionately borne by racial and ethnic minority populations.

Major advances in cancer prevention, early detection, treatment and cancer survivorship care have accelerated the pace of progress against cancer in recent decades. The overall cancer death rate in the United States (US) declined by one-third from 1991 to 2021. During the same period, the number of individuals living with a history of cancer diagnosis more than doubled from 7.2 million in 1992 to 18.1 million in 2022 (1). Despite the overall progress against cancer, substantial challenges remain.

Cancer disparities are among the most significant public health challenges in the United States. Due to structural, social, environmental, and economic disadvantages, certain US population groups carry a disproportionately high burden of cancer. According to the National Cancer Institute (NCI), cancer disparities are differences in cancer-related measures that include number of new cases, number of deaths, cancer-related health complications, survivorship and quality of life after treatment, screening rates, and stage at diagnosis. Cancer disparities persist, and may even worsen, if improvements

are not observed equally in all population groups. Because research and medical advances thus far have not been applied equitably across all segments of the population, the burden of cancer continues to disproportionately impact racially and ethnically minoritized groups and medically underserved populations, including those identifying as sexual and gender minorities (SGM) and those living in rural areas and/or under persistent poverty.

In the United States, a long history of racism, segregation, and discrimination against marginalized population groups has resulted in structural inequities and societal injustices that cause and perpetuate many of the cancer disparities discussed in this report. Population groups who experience cancer disparities may be characterized by race, ethnicity, disability, gender and sexual identity, geographic residential location, income, education, and other characteristics (see **Sidebar 1**, p. 13), and disparities may be further compounded among those at the intersections of multiple minoritized identities.






### Important Notes

- The report covers disparities and progress against disparities that were reported in the 24 months between April 1, 2022, to March 31, 2024.
- Most of the cancer incidence data used in this report are from the NCI Surveillance, Epidemiology, and End Results (SEER) database. The November 2022 SEER data submission includes new cancer cases diagnosed in 2020, the first year of the COVID-19 pandemic when delays and reductions in cancer screening and diagnosis led to a decline in the incidence rates for most cancer sites. Because 2020 was an anomalous year caused by the pandemic, it can bias estimates such as cancer incidence trends that are of substantive interest. To address the bias, the 2020 incidence data is excluded from two cancer statistics: estimation of Joinpoint trends and risks of developing cancer.

**SIDEBAR 1**

## US Population Groups That Experience Cancer Disparities

According to the National Cancer Institute (NCI), cancer disparities are adverse differences in cancer-related measures, such as the number of new cases and deaths, cancer-related health complications, quality of life after cancer treatment, financial burden, screening rates, and stage at diagnosis that are shouldered by certain population groups including:

	<b>Individuals belonging to certain ancestry, racial or ethnic minority populations</b>		<b>Individuals of low socioeconomic status (SES), including low educational attainment</b>
	<b>Individuals who lack or have inadequate health insurance coverage</b>		<b>Individuals belonging to sexual and gender minority communities</b>
	<b>Individuals with disabilities</b>		<b>Adolescents and young adults (AYA)</b>
	<b>Individuals who are incarcerated</b>		<b>Immigrants, refugees, or asylum seekers</b>
	<b>Older adults</b>		<b>Citizens of Sovereign Native Nations</b>
	<b>Residents in certain geographic locations, including rural areas, or of certain types of neighborhoods, such as those with low access to resources</b>		

### Cancer Disparities Experienced by US Racial and Ethnic Minority Populations

According to the 2020 Census, racial and ethnic minority groups constitute 40 percent of the US population (see **Sidebar 2**, p. 14). The rapidly increasing diversity of the US population is of particular importance since the 2020 Census projects that racial and ethnic minority populations will become the majority population by 2045. As highlighted throughout this report, all racial and ethnic minority populations experience varying degrees of cancer disparities. During 2016–2020, the incidence rate for all cancers combined was higher among Black men, for colorectal and cervical cancers was higher among American Indian and Alaska Native (AI/AN) people, and for cervical cancer was higher among Hispanic women, compared to their respective non-Hispanic (NH) White counterparts (2). Similarly, the overall cancer mortality rate during 2016–2020 was 18 percent and 19 percent higher, respectively, among Black and AI/AN men and 16

percent and 12 percent higher, respectively, among AI/AN and Black women, compared to their NH White counterparts. During 2014–2020, patients with cancer from all racial and ethnic minority groups had a lower 5-year relative survival compared to their NH White counterparts (2).

Encouragingly, years-long work among multiple constituents across the cancer continuum has begun to reduce some cancer disparities. Over the past two decades, progress against certain cancer types in racial and ethnic minority populations has accelerated compared to the NH White population (see **Sidebar 3**, p. 15, and **Figure 1**, p. 16).

Despite some progress, much work remains to be done to eliminate cancer disparities, not only between the White population and other racial and ethnic populations, but also between distinct subgroups within each racial and ethnic population. In this section, we provide an overview of the current state of cancer disparities experienced by racial and ethnic minority groups and other medically underserved populations in the United States.

**SIDEBAR 2**

# US Racial and Ethnic Population Groups\*†

When collecting data that include race and ethnicity, federal agencies follow the Office of Management and Budget (OMB) Statistical Policy Directive No. 15, Race and Ethnic Standards for Federal Statistics and Administrative Reporting.‡ The broad and recently revised racial and ethnic OMB categories are as follows:



**American Indian or Alaska Native**<sup>§</sup> Individuals with origins in any of the original peoples of North, Central, and South America, including, for example, Navajo Nation, Blackfeet Tribe of the Blackfeet Indian Reservation of Montana, Native Village of Barrow Inupiat Traditional Government, Nome Eskimo Community, Aztec, and Maya.

**Asian** Individuals with origins in any of the original peoples of Central or East Asia, Southeast Asia, or South Asia, including, for example, Chinese, Asian Indian, Filipino, Vietnamese, Korean, and Japanese.

**Black or African American** Individuals with origins in any of the Black racial groups of Africa, including, for example, African American, Jamaican, Haitian, Nigerian, Ethiopian, and Somali.

**Hispanic or Latino**<sup>¶</sup> Includes individuals of Mexican, Puerto Rican, Salvadoran, Cuban, Dominican, Guatemalan, and other Central or South American or Spanish culture or origin.

**Middle Eastern or North African** Individuals with origins in any of the original peoples of the Middle East or North Africa, including, for example, Lebanese, Iranian, Egyptian, Syrian, Iraqi, and Israeli.

**Native Hawaiian or Other Pacific Islander** Individuals with origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands, including, for example, Native Hawaiian, Samoan, Chamorro, Tongan, Fijian, and Marshallese.

**White** Individuals with origins in any of the original peoples of Europe, including, for example, English, German, Irish, Italian, Polish, and Scottish.

\* We recognize that the categories described here refer to heterogeneous groups of people and are only relevant based on their use within official registries, health systems, and the decennial census. Furthermore, the OMB categories are socio-politically determined, and can change over time. In general, we consider race and ethnicity to be social and political constructs, not defined by genetic or biological differences.

† Throughout this report, we use terms and/or categories described here without intentional preference or prejudice.

‡ Data collected on race and ethnicity rely on self-reporting of this information and individuals can self-identify as belonging to multiple races. Therefore, identities may be fluid over time.

§ Indigenous populations in the United States throughout this report will include the following: American Indian, Native American, Native Hawaiian, and Alaska Native. Some referenced reports also include South American Indigenous Peoples and Asians as part of their American Indian datasets. Primarily, the term American Indian or Alaska Native (AI/AN) will be used in this report unless defined differently in studies being discussed. The AI/AN population may also include those maintaining tribal citizenship and/or records of descendency.

¶ Sometimes described in gender-neutral terms, Latinx or Latine. It is also important to note that Hispanic or Latino is not a race, but rather an ethnic population group.

## American Indian or Alaska Native (AI/AN) Population

### AT A GLANCE

#### American Indian or Alaska Native (AI/AN) Population in 2020\*

**Number and proportion of the US population<sup>†</sup>:**  
3.7 million people or about 1.1 percent

**New cancer cases<sup>‡</sup>:** 9,668      **Cancer deaths<sup>‡</sup>:** 3,385

**Most common cancers<sup>§</sup>:** Female breast, prostate, and lung and bronchus cancers

**Most common causes of cancer deaths<sup>§</sup>:** Lung and bronchus, female breast, and colorectal cancers

\* Most recent year/timeframe for which such data are available.

† Based on the Census 2020. Numbers shown are for those who identified as AI/AN alone, and not in combination with another race.

‡ Data indicate reported numbers for 2020 for non-Hispanic AI/AN population (4).

§ 2016–2020, most recent timeframe for which such data are available.

There are 574 federally recognized AI/AN tribes or people groups in the United States, spanning diverse customs, languages, and histories. The AI/AN population has significant racial misclassification in health data (5,6)—and an imprecise estimation of the disease burden—warranting a cautious approach when drawing conclusions about the accurate burden of cancer in the group (see **Sidebar 4**, p. 17). AI/AN individuals with cancer are also under-documented in cancer databases, such as the National Cancer Database, a cancer registry that is widely used in research. A recent study found that the percentage of AI/AN individuals diagnosed with breast, colorectal, lung, and prostate cancer who are captured in the National Cancer Database has doubled from 20.7 percent during 2004–2006 to 41.4 percent during 2017–2019 (7). This is encouraging because the representation of AI/AN patients in cancer databases that accurately reflects this population’s cancer burden is critical to fully understanding and addressing cancer disparities they face. Furthermore, new data analysis tools, such as Centers for Disease Control and Prevention (CDC)’s dashboard for the cancer incidence and mortality rates in the NH AI/AN populations, are expected to improve understanding of the cancer burden in these communities.



## SIDEBAR 3

## Progress Against Cancer in Racial and Ethnic Minority Populations

With an increased understanding of the root causes of cancer disparities, progress against certain cancer types has accelerated among US racial and ethnic minority groups. Although the burden of these cancers remains substantial for these groups, the declining rates are encouraging. Below are some examples of such recent trends:

**5X  
higher**

During 2016–2020, **mortality from prostate cancer declined** at a five times **higher rate in non-Hispanic (NH) American Indian or Alaska Native men**, compared to NH White men (1.5 percent versus 0.3 percent decline annually, respectively).

**MORE  
than double**

During 2015–2019, **stomach cancer incidence declined** at more than double the rate in the **aggregated NH Asian and Pacific Islander population**, compared to the NH White population (2.7 percent versus 1.2 percent decline annually, respectively).

**MORE  
than 7X**

During 2016–2020, **mortality from liver cancer declined** more than seven times **faster in NH Black individuals**, compared to NH White individuals (2.8 percent decline versus 0.3 percent increase annually, respectively).

**8X  
faster**

During 2011–2020, **mortality from cervical cancer declined** eight times faster in **Hispanic women**, compared to NH White women (1.6 percent versus 0.2 percent decline annually, respectively).

Developed from (3).

During 2016–2020, the overall incidence of all cancer types combined was about the same for the NH AI/AN and NH White populations (461.2 versus 455.1 per 100,000 cases, respectively) (see **Table 1**, p. 18). However, during the same period, the NH AI/AN population experienced varying degrees of disparity in incidence for cancers of the colon and rectum, kidney, liver, stomach, gallbladder, and cervix uteri when compared to the NH White population. Of these, the NH AI/AN population had 2.22, 2.49, 1.92, and 1.54 times higher incidence for cancers of gallbladder, liver, stomach, and kidney, respectively (see **Table 1**, p. 18). Furthermore, a recent study reported that AI/AN individuals residing in Alaska had the highest incidence of colorectal cancer between 2014 and 2018, compared to any other US racial population (8). The colorectal cancer incidence among AI/AN people in Alaska was also the highest in the world in 2018 (8).

During 2016 through 2020, the overall cancer death rate in the NH AI/AN population was about the same as in the NH White population (see **Table 1**, p. 18). However, deaths from cancers of the stomach, liver, and gallbladder were more than double in the NH AI/AN population compared to the NH White population. The AI/AN population also had 75 percent and 45 percent higher deaths rates from cancers of the kidney and cervix uteri, respectively (see **Table 1**, p. 18). Furthermore, AI/AN population is experiencing an increase in the incidence of early-onset cancers, i.e., incidence of cancer in adults between the ages of 18 and 49 years. For example, during 2009–2018, the incidence of early-onset colorectal cancer (EO-CRC) in AI/AN individuals aged 20 to 49 rose by 3.4 percent annually, while it increased by

1.7 percent annually in NH White individuals. Similarly, deaths from EO-CRC in the same age group during 2010–2019 increased by 3.0 percent annually in AI/AN individuals, compared to a 1.8 percent annual increase in NH White individuals (14).

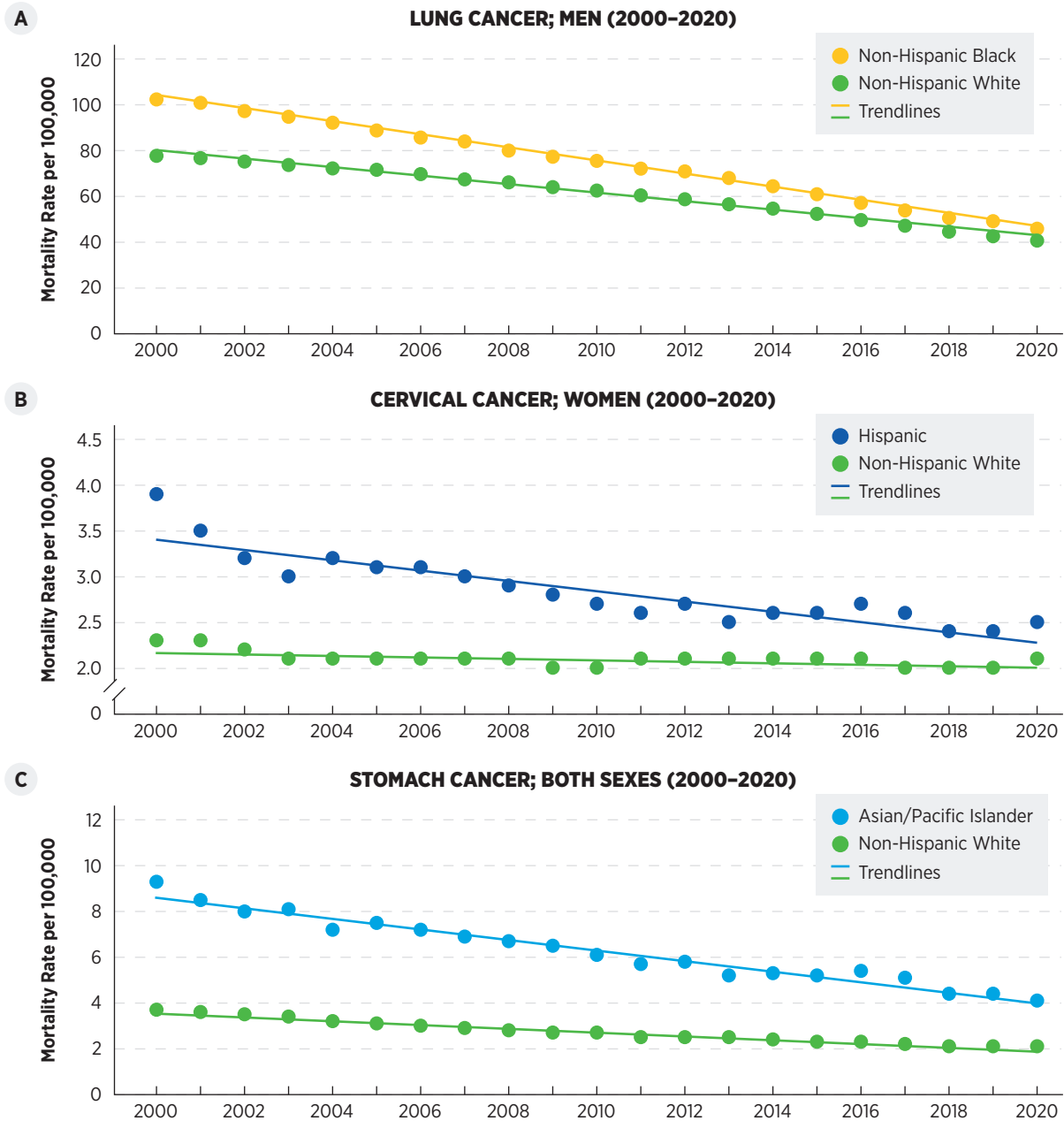
The Indian Health Service (IHS), within the Department of Health and Human Services (HHS), provides health services to the AI/AN populations in federally recognized tribes through facilities that are managed directly by IHS, by tribes or tribal organizations. As of 2021, there are 687 IHS and tribally owned or operated facilities located on or near reservations (15). If these facilities cannot provide needed health services, the IHS and tribes may contract private providers through the IHS Purchased/Referred Care program. Approximately two-thirds of the NH AI/AN population lives in tribal areas or surrounding counties, called Purchased/Referred Care Delivery Area (PRCDA) counties, that are covered by the program. These counties are located in six US regions: Alaska, East, Northern Plains, Pacific Coast, Southern Plains, and Southwest.

There are stark disparities in the risk of cancer incidence and outcomes within the AI/AN populations when cancer data are disaggregated by the PRCDA regions (see **Figure 2**, p. 19). As one example, the incidence of stomach cancer in the NH AI/AN population as a collective was roughly double during 2016–2020 when compared to the NH White population (see **Table 1**, p. 18). However, when disaggregated by the PRCDA region, the incidence rate of stomach cancer was the highest among NH

*continued on page 17*

**FIGURE 1**

# Narrowing Disparities in Cancer Mortality Rates Between Non-Hispanic White Population and Racial and Ethnic Minority Populations



The accelerated pace of progress against cancer in recent decades is contributing to narrowing disparities in the rates of mortality from certain cancer types between the non-Hispanic White (NHW) population and certain racial and ethnic minority groups. Examples shown are the declining mortality rates during 2000–2020 for (A) lung cancer in NHW and non-Hispanic Black men, (B) cervical cancer in NHW and Hispanic women, and (C) stomach cancer in NHW and Asian and Pacific Islander populations. In each of the examples shown, the trends have declined faster in racial and ethnic minority groups, resulting in narrowing of disparities in the indicated cancer types compared to the NHW population.

Graphs are developed using the NCI Surveillance, Epidemiology, and End Results Explorer application. Years are indicated on X-axes. Rates (Y-axes) are per 100,000 and are age-adjusted to the 2000 US standard population.

## SIDEBAR 4

## The Importance of Disaggregated Cancer Data

Collecting disaggregated cancer data is necessary in understanding the burden of cancers within the heterogeneous racial and ethnic minority populations. It is important to note that collection of disaggregated data itself is insufficient to realize equity in data representation. Additional considerations include developing ways to understand and address the burden of cancer in a meaningful manner in relatively small populations, such as American Indian, Alaska Native, Native Hawaiian and Other Pacific Islander populations, or the sexual and gender minority (SGM) community.

While US cancer registries collect relatively granular data on race and ethnicity, a major barrier for calculating cancer incidence and mortality rates for disaggregated racial and ethnic group is often lack of population denominator data, which is the size of the population.

Examples below from recent studies highlight the heterogeneity among racial and ethnic minority groups and underscore the necessity to collect and analyze disaggregated cancer data so that community-specific and/or population-specific strategies can be developed and implemented to address cancer disparities:

**American Indian or Alaska Native populations** American Indian or Alaska Native individuals living in the Southwest region were **56 percent more likely to be diagnosed with kidney cancer** compared to **those living in the East region**, but were **35 percent less likely to be diagnosed with kidney cancer** compared to **those living in the Southern Plains region** (9).

**Asian populations** Compared to non-Hispanic White men, **Laotian American men were 29 percent more likely**, but **Chinese American men were 27 percent less likely, to die from liver cancer** (10).

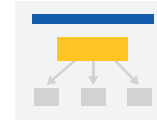
**Black/African American populations** Compared to non-Hispanic Black women born in Africa, the **incidence of all cancers combined was double in those born in the United States**, but **21 percent less** in those **born in Jamaica** (11).

**Hispanic populations** Compared to Hispanic women of South and Central American origin, **those of Mexican origin were 10 percent less likely**, but those of **Dominican origin were 18 percent more likely, to be diagnosed with aggressive forms of endometrial cancer** (12).

**Native Hawaiian or Other Pacific Islander populations** Compared to women living in American Samoa, the **incidence of breast cancer was 37 percent less in those living in the Republic of the Marshall Islands**, but **55 percent more in those living in Guam** (13).

AI/AN individuals living in the Alaska region and the lowest among those living in the East region (4.23 versus 1.26 times higher, respectively, compared to the corresponding NH White populations) (9). Similarly, NH AI/AN individuals living in Alaska, the Northern Plains, and the Southern Plains had at least double the incidence of kidney cancer compared to those living in the East region (9).

Reasons for disparities in cancer burden between the AI/AN and White populations, as well as those within the AI/AN populations residing in different PRCDA regions, stem from a long history of racism, discrimination, and systemic inequities in the United States that have substantially contributed to higher rates of tobacco and alcohol use, higher exposure to environmental carcinogens, higher rates of type 2 diabetes and chronic hepatitis C virus (HCV) infection, as well as lower access to quality health care (see **Disparities in the Burden of Preventable Cancer Risk Factors**, p. 66) (14).



### Asian Population

#### AT A GLANCE

#### Asian Population in 2020\*

##### Number and proportion of the US population†:

19.9 million people or about 6 percent

**New cancer cases‡:** 56,790      **Cancer deaths‡:** 19,869

**Most common cancers§:** Female breast, prostate, and lung and bronchus cancers

**Most common causes of cancer deaths§:** Lung and bronchus, female breast, and colorectal cancers

\* Most recent year/timeframe for which such data are available.

† Based on the Census 2020. Numbers shown are for those who identified as Asian alone and do not include the Native Hawaiian or Pacific Islander population.

‡ Data indicate reported numbers for 2020 for the aggregated non-Hispanic Asian and Pacific Islander (API) population (4).

§ 2016–2020, most recent timeframe for which such data are available.

**TABLE 1**

## Cancer Incidence and Mortality Among US Racial and Ethnic Minority Populations Compared to Non-Hispanic White Population

Cancer Site	NH AI/AN		NH API		NH Black		Hispanic (All races)	
	Incidence	Mortality	Incidence	Mortality	Incidence	Mortality	Incidence	Mortality
<b>All Cancer Sites Combined</b>	<b>0.89</b>	<b>1.02</b>	<b>0.64</b>	<b>0.61</b>	<b>0.96</b>	<b>1.13</b>	<b>0.74</b>	<b>0.70</b>
Anus, Anal Canal and Anorectum	0.78	1.00	0.17	0.33	0.91	1.00	0.57	0.67
Bones and Joints	0.91	0.80	0.73	0.60	0.82	1.00	0.82	0.80
Brain and Other Nervous System	0.66	0.57	0.51	0.45	0.54	0.55	0.69	0.61
Cervix Uteri	1.28	1.45	0.88	0.80	1.28	1.65	1.43	1.25
Colon and Rectum	1.30	1.31	0.80	0.69	1.15	1.34	0.90	0.82
Corpus and Uterus, NOS	1.04	0.98	0.82	0.76	1.07	1.98	0.95	0.93
Esophagus	1.12	0.88	0.45	0.35	0.71	0.67	0.55	0.44
Eye and Orbit	0.64	*	0.27	0.00	0.27	0.00	0.45	0.00
Female Breast	0.79	0.89	0.78	0.59	0.94	1.40	0.72	0.70
Gallbladder	2.22	2.00	1.33	1.20	2.00	1.80	2.22	1.60
Hodgkin Lymphoma	0.59	0.67	0.48	0.33	0.90	0.67	0.76	1.00
Kidney and Renal Pelvis	1.54	1.75	0.49	0.44	1.05	0.94	1.04	0.92
Larynx	0.83	1.11	0.34	0.33	1.24	1.67	0.69	0.67
Leukemia	0.82	0.67	0.54	0.53	0.73	0.83	0.72	0.67
Liver and Intrahepatic Bile Duct	2.49	2.07	1.59	1.42	1.43	1.41	2.01	1.56
Lung and Bronchus	0.84	0.90	0.60	0.52	0.95	0.98	0.46	0.41
Melanoma of the Skin	0.26	0.33	0.04	0.11	0.03	0.11	0.14	0.22
Myeloma	1.09	1.10	0.63	0.52	2.25	2.03	1.05	0.90
Non-Hodgkin Lymphoma	0.75	0.85	0.67	0.67	0.71	0.72	0.86	0.83
Oral Cavity and Pharynx	0.80	0.85	0.64	0.74	0.63	0.93	0.53	0.56
Ovary	1.08	0.96	0.89	0.66	0.85	0.85	0.95	0.73
Pancreas	0.99	0.92	0.73	0.67	1.18	1.21	0.88	0.79
Prostate	0.66	1.10	0.53	0.48	1.65	2.11	0.78	0.86
Small Intestine	0.80	1.00	0.52	0.75	1.64	1.75	0.76	0.75
Soft Tissue including Heart	0.82	0.92	0.79	0.69	1.03	1.15	0.94	0.85
Stomach	1.92	2.62	1.74	2.19	1.85	2.38	1.85	2.29
Testis	1.00	1.33	0.31	0.33	0.23	0.67	0.80	1.00
Thyroid	0.89	1.00	1.01	1.20	0.55	1.00	0.89	1.20
Urinary Bladder (Invasive and <i>in situ</i> )	0.56	0.61	0.38	0.37	0.50	0.74	0.45	0.50
Vagina	*	*	0.67	0.50	1.50	1.50	1.17	1.00
Vulva	0.77	0.57	0.33	0.29	0.63	0.57	0.60	0.43

\* Estimates based on fewer than 16 cases are suppressed and not shown.

AI/AN, American Indian or Alaska Native; API, Asian and Pacific Islander; NH, Non-Hispanic; NOS, Not otherwise specified.

Numbers indicate incidence and mortality rates for the cancer types shown in racial or ethnic minority populations, using corresponding rates for the NH White population as reference.

Sources: SEER Incidence Data, November 2022 Submission (1975–2020), SEER 22 registries [<https://seer.cancer.gov/registries/terms.html>]; US Mortality Data (1969–2020), National Center for Health Statistics, CDC.

Methodology: Rates are per 100,000 and are age-adjusted to the 2000 US Standard Population.

Race/Ethnicity Coding:

For more details on SEER race/ethnicity groupings and changes made to the grouping for this year's data release, please see Race and Hispanic Ethnicity Changes [[https://seer.cancer.gov/seerstat/variables/seer/race\\_ethnicity/](https://seer.cancer.gov/seerstat/variables/seer/race_ethnicity/)].

Rates for American Indians/Alaska Natives only include cases that are in a Purchased/Referred Care Delivery Area (PRCDA).

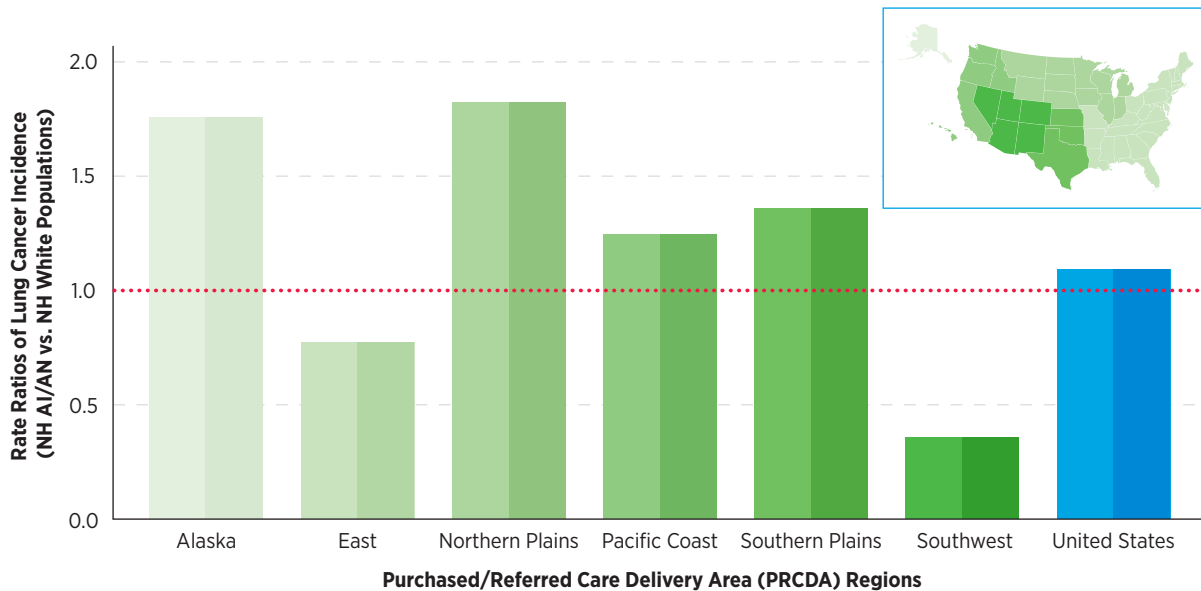
Incidence data for Hispanics and Non-Hispanics are based on the NAACCR Hispanic Latino Identification Algorithm (NHIA).

The Asian population is the fastest-growing racial group in the United States (16). The five largest groups constituting the Asian designation are Chinese, South Asian, Filipino, Vietnamese, Korean, and Japanese. Despite the remarkable

diversity of cultures, places of birth, migration histories, and other characteristics that distinguish Asian populations from the Native Hawaiian and Pacific Islander populations, health records from the two racial groups are either aggregated

**FIGURE 2**

## Disparate Burden of Lung Cancer in Non-Hispanic (NH) American Indian or Alaska Native (AI/AN) Populations Living in Different PRCDA Regions (2016–2020)



Cancers of lung and bronchus are the most commonly diagnosed cancer and have the highest mortality rate, in the NH AI/AN population. Compared to the NH White population, the NH AI/AN population as a collective has a slightly higher incidence of lung cancer (60.2 versus 54.8 per 100,000 cases, respectively). However, lung cancer incidence differs substantially among NH AI/AN subpopulations living in different PRCDA regions. Bar graphs show ratios of lung incidence rates for the NH AI/AN population living in the six PRCDA regions during 2016–2020, compared to the corresponding NH White population as a reference (shown by a red dotted line). The overall rate ratio for the entire United States is also included. The numbers above each bar graph show the number of new lung cancer cases per 100,000 for the AI/AN population in the indicated region. Data are age-adjusted to the 2000 US population.

or disaggregated data are not reported, thus masking the underlying differences within the population subgroups (see **Sidebar 4**, p. 17). In this report, we use the Asian and Pacific Islander (API) designation for some of the cancer incidence and mortality rates that are only available as aggregate data.

According to recent estimates, the NH API population has the lowest overall rates of cancer incidence and mortality compared to any other racial or ethnic population (2). However, according to the Centers for Disease Control and Prevention (CDC), NH API was the only racial or ethnic

population with cancer as the leading cause of death in 2021, the most recent year for which such data are available (18). The NH API population is disproportionately affected by cancers that are caused by infectious agents, such as hepatitis B virus (HBV) and *Helicobacter pylori* (see **Disparities in the Burden of Preventable Cancer Risk Factors**, p. 66) (19). As one example, when compared to the NH White population, the NH API population has a more than 70 percent higher probability of developing stomach cancer and double the likelihood of dying from it (see **Table 1**, p. 18); *H. pylori* causes up to 75 percent of all noncardia stomach cancer cases

Between 2015 and 2019, **the incidence of breast cancer among Asian and Pacific Islander (API) women increased 2.1 percent annually**, which was the highest increase during this time period observed in any racial and ethnic group, including non-Hispanic White women (0.5 percent increase annually). Concerningly, the increase in breast cancer **incidence is even higher among API women younger than 50** (3.4 percent annual increase) (3,17).



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worldwide (20). Similarly, NH API individuals have a 42 percent and 20 percent higher chance of dying from liver or gallbladder cancers, respectively (see **Table 1**, p. 18), both of which are caused primarily by HBV infection.

Recent studies analyzing disaggregated data have shown a unique cancer burden for subgroups within the Asian population. One study identified large disparities in the burden of human papillomavirus (HPV)-associated cancers (21). During 1990–2014, the time period covered by the study, NH API women had about a 30 percent lower likelihood of developing cervical cancer when compared to NH White women. However, there were stark differences within the Asian subgroups, with Laotian women having a four times higher risk of developing cervical cancer than Asian Indian and Pakistani women (21). Another study showed stark disparities in pancreatic cancer outcomes within the disaggregated API population (22). Based on the aggregated data of patients with pancreatic cancer, during 2010–2019, survival among API patients was higher than that among White patients (11.3 months vs. 8.9 months, respectively). However, when disaggregated by subgroups, Asian Indian patients had the highest and Japanese patients with pancreatic cancer had the lowest survival (14.3 vs. 7.6 months, respectively) (22).

A concerning trend contributing to cancer disparity in the API population is the disproportionately increasing cases of lung cancer, especially in women such as **Puong Ho, MD** (see p. 23), who have never smoked. One study evaluating 77,642 confirmed lung cancer cases between 2014 and 2018 in Florida found that the proportion of lung cancer cases among individuals with no history of smoking was four times higher in API women compared to White women, and more than twice as high in API men as in White men (23). Among lung cancer cases, 27.7 percent of men had no history of smoking compared to 59.9 percent of women who had never smoked. The study further showed that, among the population who never smoked, lung cancer was the second most common cause of death in API women, compared to 14th in White women (23). Another study also reported that the incidence of lung cancer among API women who had never smoked was higher compared to NH White women who had never smoked (17.1 versus 10.1 per 100,000 cases, respectively) (24). Furthermore, compared to NH White women who had never smoked, lung cancer incidence among women belonging to every API ethnic subgroup, except for the Japanese American population, was higher, and ranged from 66 percent greater among Native Hawaiian women to more than 100 percent greater among Chinese American women (24).

Studies have identified genetic and epigenetic alterations, as well as exposure to other risk factors, including occupational and environmental carcinogens, that are associated with an increased risk of developing lung cancer in individuals with no history of smoking. However, beyond the few established risk factors including exposure to secondhand and thirdhand smoke, radon, air pollution, and cooking oil fumes, additional

risk factors that explain the higher lung cancer risks in API women who have never smoked have not been identified (25). The Female Asian Never Smokers or FANS study aims to understand possible causes of lung cancer in this population, including secondhand smoke, genetics, environmental factors (e.g., air pollution and radon), and cultural factors (26).

## Black or African American Population

### AT A GLANCE

#### Black or African American Population in 2020\*

##### Number and proportion of the US population<sup>†</sup>:

Estimated 41.1 million people or 12.4 percent

**New cancer cases<sup>‡</sup>:** 174,757      **Cancer deaths<sup>‡</sup>:** 70,963

**Most common cancers<sup>§</sup>:** Prostate, female breast, and lung and bronchus cancers

**Most common causes of cancer deaths<sup>§</sup>:** Prostate, lung and bronchus, female breast cancers

\* Most recent year/timeframe for which such data are available.

† Based on the Census 2020. Numbers shown are for those who identified as Black alone, and not in combination with another race.

‡ Data indicate reported numbers for 2020 for non-Hispanic Black population (4).

§ 2016–2020, most recent timeframe for which such data are available.

Black or African American people constitute the third largest racial/ethnic population group in the United States. The US Black population is heterogeneous and includes US-born Black people, as well as those who have immigrated to the United States and trace their ancestry to any of the Black racial groups of Africa and the African diaspora. In 2021, about 10 percent of the US Black population was foreign-born (27). The burden of cancer varies substantially within the population subgroups (see **Sidebar 4**, p. 17).

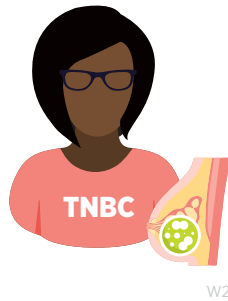
In recent decades, the disparity in age-adjusted overall cancer deaths between the Black and White populations has declined significantly, narrowing from 32 percent in 1991 to 11 percent in 2020, the most recent year for which such data are available (3). During 2016 through 2020, cancer mortality rates declined faster in Black men compared to White men (2.7 percent versus 2.1 percent decline per year, respectively), while cancer deaths declined at about the same rate in Black and White women (2.2 percent versus 1.9 percent decline per year, respectively).

In addition to the narrowing gap in overall cancer death rates, disparities in the burden of certain cancer types have also decreased significantly between the NH Black and White populations. As one example, the disparity between the two populations in mortality rates of colorectal cancer, the fourth highest cause of cancer deaths in the Black population in 2020 (4), has steadily narrowed from 40 percent in 2000 to 30 percent in 2020 (3). Furthermore, according to the latest trends, colorectal cancer mortality rates from 2016 to 2020 declined faster among Black people compared to White people (2.9 percent versus 1.8

percent annual decline, respectively). Mortality rates from lung cancer have also significantly declined in the Black population. In 1990, Black people were 24 percent more likely to die from lung cancer than White people (mortality rate: 72.1 versus 58.2 per 100,000, respectively). In 2020, this disparity has been drastically reduced (mortality rate: 32.3 versus 32.6 per 100,000, respectively) (3). Similarly encouraging trends are apparent for narrowing disparities in deaths attributed to prostate cancer among Black men and to cervical cancer among Black women.

Despite the progress, the Black population continues to shoulder a higher burden of cancer compared to the White population. Compared to any other racial or ethnic group, Black people have the highest incidence of cancer and the highest death rate for the disease (see **Table 1**, p. 18). During 2016–2020, the overall cancer mortality rates were 18 percent higher in Black men compared to White men, and 12 percent higher in Black women compared to White women (2). Compared to White individuals, in 2016–2020, Black individuals overall were at double or higher risk of dying from myeloma, stomach, and prostate cancers (3).

Black women are **two times more likely** than White women to be diagnosed with the **highly aggressive triple-negative breast cancer** and 30 percent more likely to die from it (28).



Concerning disparities in the burden of prostate cancer exist for Black men, who are at a 65 percent higher risk of developing prostate cancer and are at a more than double the risk of dying from it, compared to NH White men. Black women have a 6 percent lower likelihood of developing breast cancer but are at a 40 percent higher risk of dying from it, compared to NH White women. Compared to women of any other racial or ethnic background, Black women, such as **Katrece Nolen** (see p. 25), are also two times more likely to be diagnosed with inflammatory breast cancer, an aggressive form of breast cancer (29). Another stark disparity exists in the burden of uterine cancer, for which Black women have about the same incidence rate as White women but double the likelihood of dying from it (3).

The US Black population includes those born in the United States as well as those who have immigrated to the country and trace their ancestral roots to any of the Black racial groups of Africa and the African diaspora. Significant disparities in cancer burden exist within these subgroups, in part because of different exposure to cancer risk factors. A recent study found markedly different rates of lung cancer incidence in different subgroups within the Black population in Florida between 2012 and 2018 (30). Overall, lung cancer

incidence in Black men was more than three times higher among those born in the United States compared to those born in the Caribbean. The study also found that US-born Black women with lung cancer had more than twice and three times the diagnoses of highly aggressive squamous cell carcinoma and small cell carcinoma, respectively, compared to those who are Caribbean-born (30).

Cancer disparities faced by the Black population stem from a long history of structural racism, prejudice, and discrimination that have resulted in adverse social drivers of health (conditions within which people live, work, play), low socioeconomic status (SES), and inadequate access to quality health care (see **Understanding and Addressing Drivers of Cancer Disparities**, p. 36), thus impeding the upward economic mobility of Black people.

## Hispanic or Latino/a Population

### AT A GLANCE

#### Hispanic or Latino/a Population in 2020\*

**Number and proportion of the US population†:**  
62.1 million people or 19 percent

**New cancer cases‡:** 140,609      **Cancer deaths‡:** 43,942

**Most common cancers§:** Female breast, prostate, and colon and rectum cancers

**Most common causes of cancer deaths§:** Lung and bronchus, prostate, and female breast cancers

\* Most recent year/timeframe for which such data are available.

† Based on the Census 2020.

‡ Data indicate reported numbers for 2020 (4).

§ 2016–2020, most recent timeframe for which such data are available.

The Hispanic population is one of the fastest-growing and most diverse ethnic groups in the United States, representing many races, religions, languages, countries of origin, and cultural identities. Because most US cancer data for the Hispanic population are reported in the aggregate, descriptions of incidence and mortality rates do not account for important differences among diverse subgroups within the population (see **Sidebar 4**, p. 17). Furthermore, it is well known that Hispanic individuals in the United States have a higher life expectancy compared to NH White individuals despite having lower income, inadequate health care, and higher exposure to certain risk factors, a phenomenon called the “Hispanic Paradox” (31,32). Comprehensive and disaggregated health data on the population can help facilitate understanding the true burden of disparities, including cancer disparities (see **Sidebar 4**, p. 17).

During 2016–2020, Hispanic people had the second lowest overall rates of cancer incidence and mortality compared to

*continued on page 26*



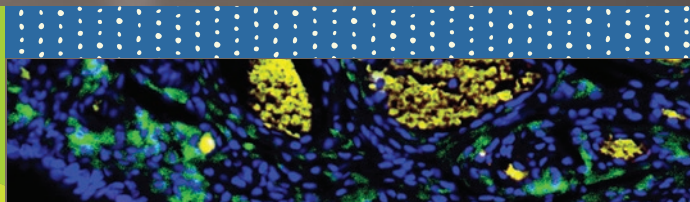


“I consider myself a healthy person. I exercise regularly. I don’t smoke. So, when I was diagnosed with lung cancer, it was a shock. I was able to share with my husband, but I had a very difficult time explaining to my young children.”



# Phuong Ho, MD, 48

## Pleasanton, California



In 2019, Dr. Phuong Ho started experiencing a mild cough and tightness in her chest. Being an emergency room physician who cared for many patients with similar conditions, Phuong thought she was developing asthma and treated herself with inhalers. Unfortunately, her symptoms persisted. “I felt worse when I got sick, even with a minor cold. So, by the time COVID-19 hit, I realized that I was putting myself at risk and could potentially develop a more serious condition than most patients,” Phuong said. She decided to seek medical care to find out whether she had underlying asthma, so she could better protect herself.

Phuong’s primary care physician ordered chest X-rays and pulmonary function tests, which came back fine. She continued using inhalers, but her symptoms did not improve. At this time, Phuong decided to consult a pulmonologist, who ordered a CT scan of her chest. The scan revealed an almost 2-centimeter mass on the upper lobe of her right lung. Then she underwent a lung biopsy. “I still remember the day when I received the phone call from my physician. I was told that I had stage IA lung cancer and the pathology report indicated adenocarcinoma,” Phuong recalled.

The diagnosis came as a shock. “I consider myself a healthy person. I exercise regularly. I don’t smoke. So, when I was diagnosed with lung cancer, it was a shock. I was able to share with my husband, but I had a very difficult time explaining to my young children,” she said. Phuong was also alarmed to learn about the rise in the incidence of lung cancer among Asian females who have never smoked.

Right after her diagnosis, Phuong met with her pulmonologist and an oncologist to decide on the next steps. She underwent a series of CT scans and PET scans to make sure that her cancer had not spread. Once the scans were completed, and it was confirmed that the cancer was localized, Phuong had a consultation with a surgeon. “The definitive treatment for stage IA lung cancer is either wedge resection, which is a partial lung resection, or removal of the entire upper lobe. After discussing with my thoracic surgeon and doing my own research, we made the decision to have the whole right upper lobe removed,” Phuong said. During her surgery, she also had her lymph nodes removed to confirm that there was no spread of cancer anywhere else in her chest.

Phuong’s surgery was successful. The cancer had not spread. Her oncologist recommended that her tumor be tested for biomarkers, which showed an alteration in the EGFR protein. “But based on my own research and discussion with my oncologist, there is no further treatment indicated,” she said. She wondered whether adding chemotherapy would prevent a potential future recurrence of the cancer. However, there is not enough evidence currently to support such treatments. “I don’t need to be on any chemotherapy.”

Phuong considers herself fortunate. “As a physician I understand my symptoms and was able to seek out

immediate medical attention and receive the screening test early. I understood the process of the diagnosis, treatment, and recovery, and everything went well. I am thankful that I did not encounter any of the barriers that other patients might encounter under the same situation,” said Phuong.

Phuong has been cancer free for the last 3 years. “I am doing great now,” she said. While she is still working on improving her lung capacity and overall health through regular exercise, Phuong is thankful. She feels fortunate to be able to work and spend time with her family cooking, eating out, playing in the yard, hiking, and traveling. “I enjoy every moment and realize that just to be able to be here around family is the best gift that I have now.”

Phuong’s experience with cancer has made her a passionate advocate for health education, especially for minority communities. She also feels strongly about raising awareness among physicians about the rise in lung cancer cases among Asian females who have never smoked. Her message to other providers is to provide screening when patients come in with similar symptoms like she did. “Keep in mind that lung cancer is a differential diagnosis even though the patient might not be smoking, and there is an increased risk for Asian female non-smokers.”

Phuong recognizes that language is a barrier for many Asian patients. “They might not be able to express their symptoms or even seek medical attention. Breaching that barrier would require health educators who speak in their native language.”

As an advocate for the Asian community, Phuong is participating in the Female Asian Never Smokers (FANS) study at the University of California San Francisco. The research aims to identify possible causes of lung cancer in non-smokers. “I do promote the study to the Asian communities through my friends and family, spreading the word to enroll because we need participation for this important research.”

Phuong urges policymakers to promote research that addresses disparities in cancer screening, especially for minority and underserved populations. “The Asian community, especially, might not have the awareness, health education, or access to medical care to have screening tests done, or even to seek out medical attention.”

Phuong also urges our lawmakers to continue to provide the support and funding for medical research. “We still need research to promote early detection for cancer and to bridge the gap of disparities in early cancer detection and treatment for racial and ethnic minorities and medically underserved populations. Continual support would improve health and save lives.”

Scan the QR code  
to watch Phuong’s video interview.







“When you’re in the doctor’s office, that’s probably going to be the highest chance that someone’s going to participate in a clinical trial. And I think in many instances, we as patients don’t feel like we’re recruited enough to participate.”



# Katrece Nolen, 49

Ashburn, Virginia



**K**atrece was diagnosed with stage III inflammatory breast cancer in February 2013. Her journey began one day when she was playing with her son. “I just happened to look down and thought, you know what, one of my breasts seems to be slightly larger than the other,” she said. The next morning, she called her doctor’s office. Even though her regular physician was unavailable, she made an appointment for the same day.

The doctor did a breast exam but did not feel any lumps. He did, however, notice some swelling and that the breast was warm to the touch. While unusual, since Katrece wasn’t breastfeeding, the doctor thought it could be mastitis—an infectious condition that occurs in women who are breastfeeding due to clogged milk ducts—and prescribed her antibiotics. He also suggested that she receive a mammogram.

Katrece got the mammogram right away. According to the radiologist, there was nothing suspicious. Within a couple of weeks, however, her left breast had swollen so much that she couldn’t button her shirt. “That’s when fear set in,” she recalled. When she tried to make an appointment with a breast surgeon, she was told it wouldn’t be for several months. But she advocated for herself and secured an appointment that week.

“I brought the mammogram CD they’d asked me to bring,” she said. But the receptionist called me up to the front and asked for the film. Katrece explained she had given them the CD, but was told, “the doctors require that you have the mammogram film. If you don’t have the film, we’re going to have to reschedule your appointment.”

Katrece insisted on seeing a doctor even if it meant she wouldn’t be covered by her insurance. She spoke with the office manager. “While we’re going back and forth, in walks a doctor. She has a folder underneath her arm, quickly introduces herself and says, ‘You know what? I went ahead and looked at your information. And now that I see you in person, I suspect that you might have inflammatory breast cancer.’”

The surgeon ordered a skin biopsy to test for cancer because inflammatory breast cancer can be present in the skin. The biopsy was done on a Friday and the following Monday Katrece received a call confirming that she had cancer. She quickly began chemotherapy followed by a mastectomy and radiation. “Scheduling all those things

seemed like the longest drawn-out process that you can imagine,” she said. One of the main challenges during treatment was getting the information she needed to make informed decisions. “The other challenge was being a mom of young kids,” Katrece said. She was terrified of introducing into their lives the fear of losing their mother.

Clinical trials are vital to progress against cancer. Katrece, however, was never given an opportunity to participate in a trial. “Because I had an aggressive cancer, I knew that clinical trials might be best suited for me. I remember talking to my local oncologist and her response was, ‘No, we do not have any clinical trials available for you at our practice,’” she recalled. Katrece did not realize until later that it was her responsibility to personally search for clinical trials outside the scope of the local oncology practice. “When you’re in the doctor’s office, that’s probably going to be the highest chance that someone’s going to participate in a clinical trial. And I think in many instances, we as patients don’t feel like we’re recruited enough to participate.” She thinks community oncologists should consider clinical trials that are external to the practice and actively aid in the search.

“I crossed the 10-year mark, which for the type of cancer I have is rare. I feel like I’ve won the lottery,” she said. She takes medication to reduce the likelihood of a recurrence. Navigating through her cancer journey made Katrece a passionate advocate for other patients. By sharing her experiences, Katrece has connected with a community of women who were fighting inflammatory breast cancer and with specialists in its treatment.

To empower other women and families dealing with cancer, especially Black women, with the knowledge and resources that she gathered during her journey, Katrece wrote a book. “I think it helps me advance advocacy by letting people know that our stories exist. Hopefully, my book can help shed light on the fact that there should be more of us who survive this disease,” she said. Katrece wants every patient to advocate for themselves. “You are worthy, and you need to make sure that the medical professionals understand that you are a priority. You must speak up.”

Scan the QR code  
to watch Katrece’s video interview.



any other race or ethnicity (3). A recent study showed that cancer deaths among Hispanic people declined by 1.3 percent every year between 1999 and 2020. The study also found that the decline rate in cancer deaths was faster in Hispanic men than Hispanic women (1.6 percent vs. 1.0 percent per year, respectively) (33).

Both **Hispanic men and women** are, respectively, more than **twice as likely** as White men and women to be **diagnosed with gallbladder cancer**. Hispanic women are more than twice as likely as White women, and Hispanic men are 50 percent more likely than White men, to die from it (3).



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The Hispanic population shoulders a significantly higher burden of cancers, especially those associated with infectious agents, such as liver and stomach cancer. For example, compared to the White population during 2016–2020, Hispanic people had an 85 percent higher likelihood of being diagnosed with stomach cancer and more than double the likelihood of dying from it (see **Table 1**, p. 18) (3). Hispanic people were also twice as likely as White people to be diagnosed with liver cancer and 56 percent more likely to die from it (see **Table 1**, p. 18) (3). Furthermore, the incidence of early-onset colorectal cancer between 2015 and 2019, while increasing for all racial and ethnic minority populations, has increased the most in the Hispanic population, with a 5.8 percent annual increase in incidence compared to a 1.6 percent annual increase in incidence in the White population (3).

Another concerning trend during 2016–2020 was the disparity in the burden of cervical cancer between Hispanic and White women (3). Compared to White women, Hispanic women are 43 percent more likely to be diagnosed with cervical cancer (see **Table 1**, p. 18). Further concerning are the trends showing that, compared to NH White women, Hispanic women are more likely to be diagnosed at advanced stages of cervical cancer that has spread to nearby (56 percent more likely) or distant (44 percent more likely) organs (3). Although the disparity in mortality from cervical cancer has narrowed in recent decades (see **Figure 1**, p. 16), Hispanic women are still 25 percent more likely to die from it, compared to NH White women (see **Table 1**, p. 18) (3).

Hispanic youths are another segment of the Hispanic population shouldering a disproportionate burden of cancer. For example, a recent study of children (ages 0–14) and adolescents and young adults (ages 15–30) with B-cell acute lymphoblastic leukemia (B-ALL) found that Hispanic patients with B-ALL were 41 percent more likely to have disease recurrence within 5 years of enrollment in the study

compared to NH White patients (34). Another study found that between 2001 and 2011, cancer deaths among Hispanic and White children and youth (ages 0 to 19) declined at about the same rate (14.7 percent versus 16.8 percent decline, respectively.) However, between 2011 and 2021, the decline in cancer deaths slowed by half for Hispanic youth compared to White youth (5.6 percent versus 12.3 percent decline, respectively), widening a disparity in death rates between the two populations (35).

The US Hispanic population comprises nearly two dozen subgroups based on country of origin and cultural heritage, among other factors. According to the US Census 2020, eight Hispanic groups reached a population of one million or more, with the Mexican population constituting the largest subgroup of Hispanic people. Cancer burden differs significantly within the Hispanic subgroups, largely attributable by country of origin, generation, and the length of time in the United States (36).

A recent study found that Hispanic men had a 16 percent higher likelihood of being diagnosed with advanced-stage prostate cancer compared to NH White men (37). However, there were stark differences in burden of prostate cancer among Hispanic subgroups. For example, when disaggregated by country of origin, Mexican Hispanic men were 26 percent more likely, while Cuban Hispanic men were 3 percent less likely, to be diagnosed with advanced-stage prostate cancer (37). As another example, the overall incidence of prostate cancer is 18 percent lower in Hispanic men compared to White men, but 44 percent higher in men residing in Puerto Rico, which is predominantly Hispanic (38).

Another example of differences in the burden of cancer within Hispanic populations is the incidence and mortality rates in women who reside in Puerto Rico (39). A recent study found that, during 2014–2018, women from Puerto Rico had the highest incidence of endometrial cancer (41.3 per 100,000 cases) across all racial and ethnic minority populations; in comparison, US Hispanic women had the lowest incidence rate (34.2 per 100,000 cases). Furthermore, mortality from endometrial cancer among Puerto Rican women increased 2.1 percent annually, second only to NH Black women, who had a 3.2 percent annual increase in mortality from endometrial cancer (39).

The reasons for disparities in cancer burden faced by the Hispanic population are manifold and arise from decades of systemic inequities and discrimination. Adverse social drivers of health (SDOH) have led to higher prevalence of infections from cancer-causing infectious agents, obesity, poor diet quality, sedentary lifestyle, lack of access to quality health care, all of which interact with ancestry-related biological differences, contributing to cancer disparities in the Hispanic populations (see **Understanding and Addressing Drivers of Cancer Disparities**, p. 36, and **Disparities in the Burden of Preventable Cancer Risk Factors**, p. 66) (40).

## Native Hawaiian or Other Pacific Islander (NHOPI) Population

### AT A GLANCE

#### Native Hawaiian or Other Pacific Islander Population

**Number and proportion of the US population\*:**  
Estimated 690,000 people or about 0.2 percent

#### State of Hawai'i (2014–2018)<sup>†‡</sup>

**New cancer cases:** 7,393 per year

**Cancer deaths:** 2,392 per year

**Most common cancers:** Female breast, prostate, and colorectal cancers

**Most common causes of cancer deaths:** Lung and bronchus, prostate, and female breast cancers

#### US-affiliated Pacific Islands (2007–2020)<sup>†§</sup>

**New cancer cases:** 7,652 total

**Cancer deaths<sup>¶</sup>:** Data not available

**Most common cancers:** Female breast, lung and bronchus, and colorectal cancers

**Most common causes of cancer deaths<sup>¶</sup>:** Data not available

\* Based on the Census 2020.

† Most recent year/timeframe for which such data are available.

‡ Data source: Report from Hawai'i Tumor Registry (41).

§ Data source: Report from Pacific Regional Central Cancer Registry (13).

¶ The report does not document cancer mortality rates due to ongoing challenges with reporting and recording of deaths in the US-affiliated Pacific Islands.

The Native Hawaiian or Other Pacific Islander (NHOPI) population includes more than 25 diverse groups with distinct variations in historical backgrounds, languages, immigration and colonization experiences, and cultural traditions. The NHOPI racial group includes individuals with origins in any of the original peoples of Hawai'i and the six US-affiliated Pacific Island jurisdictions: Guam, American Samoa, the Commonwealth of the Northern Mariana Islands, the Republic of the Marshall Islands, the Republic of Belau, and the Federated States of Micronesia.

In its 1997 mandate, the Office of Management and Budget (OMB) separated the Asian and Pacific Islander (API) populations into two distinct racial groups (see **Sidebar 2**, p. 14). Despite this classification, NHOPI populations continue to be aggregated with Asian populations for data reporting in most national resources documenting cancer burden. Because there are fewer NHOPI individuals than Asian individuals (0.2 percent versus 6 percent, respectively, of the US population in 2020), aggregated API data vastly mask cancer burden in the NHOPI population (see **Sidebar 4**, p. 17). For example, the incidence rate per 100,000 cases of all HPV-associated

cancers combined in men during 1990–2014 was 2.1 for Asian American men compared to 5.1 for NHOPI men; this difference was masked when Asian American and NHOPI men were combined (2.3 per 100,000 cases; (21)).

Researchers have uncovered cancer disparities between White, NHOPI, and Asian populations by analyzing disaggregated data. For example, aggregated data show API women are 22 percent less likely than NH White women to be diagnosed with, and 41 percent less likely to die from, breast cancer (see **Table 1**, p. 18) (3). However, a recent study evaluating rates of cancer mortality between 2018 and 2020 found that, compared to NH White women, Asian women were 42 percent less likely, but NHOPI women were 21 percent more likely, to die from breast cancer, unmasking a significant disparity (42). Similarly concerning trends exist for the burden of uterine cancer. Compared to NH White women, API women are 20 percent less likely to die from uterine cancer. However, disaggregated data show that Asian women are 30 percent less likely, but NHOPI women are three times more likely, to die from uterine cancer (3,42).

The Hawai'i Tumor Registry—which is a part of the NCI Surveillance, Epidemiology, and End Results (SEER) program—periodically provides an overview of the cancer burden shouldered by the Hawaiian people. According to its most recent report, *Hawai'i Cancer at a Glance 2014–2018*, released in 2022, Hawai'i rates of incidence and mortality from all cancers combined were significantly lower for both men and women when compared to corresponding rates from the contiguous United States (41). However, the burden of certain cancer types, such as stomach cancer, was substantially higher in the population of Hawai'i (see **Table 2**, p. 28). Compared to the contiguous US residents, women and men in Hawai'i are 32.6 percent and 27.5 percent more likely to be diagnosed with stomach cancer, respectively. Furthermore, mortality rates of stomach cancer for Hawaiian women and men are 32 percent and 25 percent higher, respectively, compared to residents of the contiguous United States (41). There is also substantial variation in the burden of breast cancer between Asian and NHOPI women living in Hawai'i. Breast cancer incidence is higher among Native Hawaiian and Japanese American women compared to Chinese, Filipino, White, other Asian, and women of other racial and ethnic groups. Native Hawaiian women also have higher mortality than Chinese, Filipino, Japanese, White, and other Asian women (41).

There are also considerable disparities based on the geographic location of residence and racial and ethnic origin among individuals living in the state of Hawai'i. For example, the overall cancer mortality is highest in Native Hawaiian individuals compared to other populations in the state. Similarly, Native Hawaiian women have the highest mortality from, and second highest incidence of, invasive breast cancer compared to Chinese, Filipino, White, and other Asian women living in Hawai'i (41). Another example is the disparate burden of cancer among residents

**TABLE 2**

## Burden of Cancer in the State of Hawai'i Compared to the Contiguous United States (2014–2018)

	Site	Hawai'i Rate	US Rate	Rate Ratio		
<b>Men</b>	<b>All Cancer Sites Combined</b>	<b>439.8</b>	<b>487.9</b>	<b>0.90</b>		
	<b>Incidence</b>	Bladder	24.9	34	0.73	
		Kidney and Renal Pelvis	18.8	23.2	0.81	
		Liver and Intrahepatic Bile Duct	16	13.1	1.22	
		Lung and Bronchus	54.5	65.8	0.83	
		Other Biliary	2.9	2.1	1.38	
		Other Digestive Organs	1.8	0.8	2.25	
		Prostate	95.6	106.4	0.90	
	<b>Mortality</b>	Stomach	11.1	8.7	1.28	
		<b>All Cancer Sites Combined</b>	<b>153.4</b>	<b>185.6</b>	<b>0.83</b>	
	<b>Women</b>	<b>Incidence</b>	Bladder	4.9	7.4	0.66
			Colon and Rectum	13.9	16.3	0.85
			Liver and Intrahepatic Bile Duct	11.9	9.7	1.23
			Lung and Bronchus	36.9	46.9	0.79
Prostate			14.8	19	0.78	
Stomach			5	4	1.25	
<b>All Cancer Sites Combined</b>			<b>402.1</b>	<b>423</b>	<b>0.95</b>	
<b>Mortality</b>	<b>Incidence</b>	Bladder	5.2	8.5	0.61	
		Kidney and Renal Pelvis	8.4	11.8	0.71	
		Liver and Intrahepatic Bile Duct	5.9	4.7	1.26	
		Lung and Bronchus	35.5	50.8	0.70	
		Myeloma	4	5.7	0.70	
		Other Digestive Organs	1	0.6	1.67	
		Other Female Genital Organs	3.1	1.7	1.82	
<b>Mortality</b>	<b>Incidence</b>	Stomach	6.1	4.6	1.33	
		<b>All Cancer Sites Combined</b>	<b>106.9</b>	<b>133.6</b>	<b>0.80</b>	
		<b>Mortality</b>	Breast	15.8	20.1	0.79
			Cervix	1.5	2.2	0.68
			Lung and Bronchus	22.3	32	0.70
			Ovary	4.5	6.7	0.67
			Stomach	2.9	2.2	1.32

Source: Data from Pacific Regional Central Cancer Registry (13) and Hawai'i Tumor Registry (41). Rates shown are 5-year average annual rates per 100,000 and are age-adjusted to the 2000 standard US population.

of different Hawaiian Islands. As one example, residents of Hawai'i County have the second lowest rate of overall cancer incidence, but the highest rate of cancer mortality, compared to those living in other counties (41).

According to a recent report *Cancer in the U.S. Affiliated Pacific Islands 2007–2020*, released in 2022 by the Pacific Regional Central Cancer Registry, the incidence rate for all cancers combined in the US-affiliated Pacific Islands population during 2007–2020 was 51 percent less than that of the US population during 2015–2019 (13). Nearly all major cancer types, including cancers of lung and bronchus,

female breast, and colon and rectum, had lower incidence rates in the US-affiliated Pacific Islands population. The only exception is liver cancer, which had a slightly higher incidence rate in the US-affiliated Pacific Islands population compared to the US population (10.7 versus 9.0 cases per 100,000, respectively) (13). Despite the overall lower incidence rates in the aggregated US-affiliated Pacific Islands population, there were substantial disparities among populations living in various US-affiliated Pacific Islands (see **Table 3**, p. 29).

*continued on page 30*



TABLE 3

## Incidence of the Five Most Common Cancers in US-affiliated Pacific Islands (2007–2020)

USAPI	Cancer Site	USAPI Rate	US Rate
<b>Guam</b>	<b>All Sites</b>	<b>299.5</b>	<b>449</b>
	Breast	87.1	128
	Prostate	84.5	110
	Lung and Bronchus	54.0	56
	Colon and Rectum	33.8	38
	Uterus	24.6	28
<b>American Samoa</b>	<b>All Sites</b>	<b>102.9</b>	<b>449</b>
	Uterus	55.9	28
	Breast	39.2	128
	Colon and Rectum	13.3	33
	Cervical Cancer, invasive	9.1	7.8
	Stomach	6.7	6
<b>The Commonwealth of Northern Mariana Islands</b>	<b>All Sites</b>	<b>129.8</b>	<b>449</b>
	Breast	38.1	128
	Prostate	21.5	110
	Lung and Bronchus	19.6	56
	Uterus	17.0	28
	Tobacco-related Oral Cavity and Pharynx	14.3	12
<b>The Republic of Marshall Islands</b>	<b>All Sites</b>	<b>185.5</b>	<b>449</b>
	Cervical Cancer, invasive	62.4	7.8
	Lung and Bronchus	30	56
	Breast	24.7	128
	Uterus	24.6	28
	Liver	11.8	9
<b>The Republic of Belau</b>	<b>All Sites</b>	<b>179.2</b>	<b>449</b>
	Prostate	43.3	110
	Breast	33.7	128
	Lung and Bronchus	31.8	56
	Liver	23.5	9
	Uterus	22.7	28
<b>Federated States of Micronesia</b>	<b>All Sites</b>	<b>141.6</b>	<b>449</b>
	Prostate	27.2	110
	Breast	25.5	128
	Cervical Cancer, invasive	23.2	7.8
	Lung and Bronchus	21.4	56
	Tobacco-related Oral Cavity and Pharynx	18.5	12

USAPI, US-affiliated Pacific Islands.

Cancer cases reported to Pacific Regional Central Cancer Registry (PRCCR) and Centers for Disease Control and Prevention (CDC) diagnosed in 2007–2020 are shown.

Source for US data: US Cancer Statistics Working Group. US Cancer Statistics Data Visualizations Tool, based on 2021 submission data (1999–2019); US Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute; <https://www.cdc.gov/cancer/dataviz>, released in November 2022.

Source: The *Cancer in the U.S. Affiliated Pacific Islands 2007–2020* report (13).

USAPI rates average-standardized to the 2000 US population.



**SIDEBAR 5**

## Disparate Burden of Cancer Among Medically Underserved Populations

Examples below underscore unique disparities in medically underserved segments of the US population that are not covered in depth in this report:

<b>22% vs. 19%</b>	<p><b>Veterans</b></p> <p>Unhoused veterans had a <b>higher likelihood of being diagnosed with colorectal cancer at an advanced stage</b> compared to those with housing (22 percent versus 19 percent, respectively) (43).</p>
<b>31% lower</b>	<p><b>Adolescents and young adults (AYA)</b></p> <p><b>Compared to children</b> (0 to 14 years old), AYA (15 to 39 years old) have a 31 percent <b>lower 5-year relative survival rate for acute lymphoblastic leukemia</b> (91.6 percent versus 63.2 percent, respectively) (44).</p>
<b>MORE likely</b>	<p><b>Individuals with disabilities</b></p> <p><b>Likelihood of dying from gastric cancer</b> was 18 percent <b>higher in patients with disabilities</b> and 62 percent higher in patients with severe disabilities, compared to individuals without disabilities (45).</p>
<b>78% more likely</b>	<p><b>Older adults</b></p> <p><b>Older adults</b> (age 65 or older) <b>with cancer living in rural areas</b> were 78 percent <b>more likely to die within 1 year of cancer diagnosis</b> compared to those living in urban areas (46).</p>
<b>39% higher</b>	<p><b>Incarcerated populations</b></p> <p>Compared to individuals who were never incarcerated, the <b>risk of cancer-related death at 5 years</b> was 39 percent higher <b>in those diagnosed with cancer while incarcerated</b>, and 82 percent higher in those recently released (47).</p>
<b>5X higher</b>	<p><b>Immigrants</b></p> <p><b>Among the residents of Olmsted County, Minnesota, during 2000–2020, Somali immigrants</b> had more than 5 times higher <b>the incidence of liver cancer</b> compared to the non-Somali population (48).</p>

The *Cancer in the U.S. Affiliated Pacific Islands 2007–2020* report does not document cancer mortality rates due to ongoing challenges with reporting and recording of deaths in the US-affiliated Pacific Islands. However, significant differences among various US-affiliated Pacific Island populations exist in 5-year relative survival rates for several cancer types. As one example, the 5-year relative survival rate for cervical cancer among women living in the Republic of Palau is about half that of those living in the Commonwealth of the Northern Mariana Islands (43 percent versus 82 percent, respectively), even though the age-standardized incidence of cervical cancer is almost similar (10 versus 11.4 cases per 100,000, respectively) (13).

The increasing prevalence of sedentary lifestyle, poor nutrition, and tobacco use among the NHOPI population is a key driver of cancer disparities. Furthermore, its geographic location and socioeconomic characteristics present unique structural barriers to accessing quality health care, which translates into underdiagnosis for most cancers and can further exacerbate the disproportionate cancer burden among the population.

### Cancer Disparities Experienced by Other Medically Underserved Populations

In addition to racial and ethnic minority groups, many segments of the US population remain medically underserved and shoulder a disproportionate burden of cancer. Factors that contribute to disparities in these populations include lack of access to quality cancer care, a higher prevalence of certain modifiable risk factors, residence in remote areas, barriers arising due to sexual orientation and gender identity, and persistent poverty. In addition, older adults, veterans, immigrants, individuals with disabilities, individuals who are incarcerated, adolescents and young adults all are medically underserved to varying degrees and face unique challenges in the burden of cancer (see **Sidebar 5**, p. 30).

#### Populations Residing in Rural Areas

Multiple criteria distinguish rural or nonmetropolitan areas from urban or metropolitan counties. Based on the 2023 Rural-

Urban Continuum Codes developed by the US Department of Agriculture Economic Research Services, an estimated 15 percent of the US population and 74 percent of US counties reside in rural or nonmetropolitan areas (49). Although less racially and ethnically diverse compared to urban or metropolitan counties, rural populations tend to have lower socioeconomic status and face unique challenges in access to quality cancer care, prevention, and screening. According to the National Health Interview Survey, 11.3 percent of individuals with a history of cancer were living in rural or nonmetropolitan areas of the United States in 2022 (50).

During 2016–2020, cancer incidence rates were slightly higher in residents of nonmetropolitan or rural areas, compared to those living in large (one million or more residents) and medium (fewer than one million residents) metropolitan or urban areas (460.8 versus 431.7 versus 446.9 cases per 100,000, respectively) (2). There are significant disparities between rural and urban residents in the burden of certain cancer types. For example, a recent study covering the 2000–2017 time period found that rural residents have 19 percent higher likelihood of dying from melanoma (51). Similarly, another study found that, between 1999 and 2020, mortality from all cancers combined decreased at a faster pace in urban residents compared to rural residents—1.96 percent versus 1.43 percent yearly decline among men living in urban versus rural areas, respectively, and 1.56 percent versus 0.93 percent yearly decline among women living in urban versus rural areas (52).

During the most recent 2016–2020 time period for which such data are available, residents of nonmetropolitan or rural counties were 38 percent more likely to be diagnosed with and die from lung cancer, compared to those living in large metropolitan or urban areas (2). Similarly, cervical cancer, which is potentially preventable, has a disparate burden among residents of rural areas. Women age 65 or younger, living in nonmetropolitan or rural areas, had 37 percent higher incidence of, and 39 percent higher mortality from, cervical cancer, compared to those living in urban or metropolitan areas (2), in part due to lower vaccination rates and lower screening rates (see **Disparities in the Burden of Preventable Cancer Risk Factors**, p. 66).

**PERCENT HIGHER LIKELIHOOD OF DYING WITHIN 5 YEARS OF COLORECTAL CANCER DIAGNOSIS (Compared to White Urban Residents)**

Reference point	White	Black
Urban residents	5%	16%
Rural residents	5%	26%

Data from (53).

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Intersectionality encompasses the complex ways in which the effects of multiple forms of discrimination (such as racism,

sexism, and classism) combine, overlap, or intersect especially in the lived experiences of marginalized individuals or groups, and is an important consideration when discussing the burden of cancer in medically underserved populations, including rural residents. For example, an individual residing in a rural area and belonging to a racially or ethnically minoritized group shoulders a disproportionate cancer burden attributable to multiple factors that adversely impact their lived experiences. According to the 2020 US Census, about 24 percent of rural residents belong to racially or ethnically minoritized groups who face unique cancer disparities such as higher rates of incidence and mortality for certain cancer types (see **Cancer Disparities Experienced by US Racial and Ethnic Minority Populations**, p. 13).

It is important to note that 85 percent of counties under persistent poverty are rural (54) (see **Populations Living Under Poverty**, p. 33). Because of these sociodemographic characteristics, people living in rural areas have fewer opportunities to improve their socioeconomic status; experience higher exposure to certain environmental and other cancer risk factors; face barriers in access to health care, particularly specialty cancer care; and have sparse access to high-speed Internet and state-of-the-art medical facilities (see **Understanding and Addressing Drivers of Cancer Disparities**, p. 36) (54).

**Populations Identifying as Sexual and Gender Minority**

Sexual and gender minority (SGM) is an all-inclusive term used by the National Institutes of Health (NIH) and includes those who identify as lesbian, gay, bisexual, transgender, queer, intersex, asexual, and/or Two-Spirit; those with same-sex or same-gender attractions or behaviors; those with a difference in sex development; and those who do not self-identify with one of these terms but whose sexual orientation, gender identity or expression, or reproductive development is characterized by nonbinary constructs of sexual orientation, gender, and/or sex. According to a 2022 Pew Research Center Survey, about 7 percent of the US population self-identifies as belonging to the SGM populations (55).

Comprehensive and population-level information about cancer incidence and mortality among SGM individuals is limited because sexual orientation and gender identity (SOGI) data historically have not been routinely collected and documented in national cancer registries and other health records. In the absence of population-level data, this report relies on relatively small studies that highlight cancer disparities experienced by SGM individuals (see **Sidebar 6**, p. 32).

Evidence suggests that the risk of breast cancer is higher among sexual minority women compared to heterosexual women (57,58). Transgender individuals are at a 76 percent higher risk of being diagnosed with advanced-stage lung cancer compared to cisgender individuals (59). However, specific findings to support

## SIDEBAR 6

## Recommendations of the 2020 National Academies of Sciences Engineering and Medicine Report *Understanding the Well-Being of LGBTQI+ Populations*

In October 2020, the National Academies of Sciences, Engineering, and Medicine issued a comprehensive report, *Understanding the Well-Being of LGBTQI+ Populations*, to evaluate deficits in sexual and gender minority (SGM) population research. Based on the available evidence, the report made several recommendations to all constituents, including federal, state, local, and tribal governments; public and private funders; and researchers, among others.



### These recommendations are summarized below:

- **Add measures** of sexual orientation and gender identity to all health data collected by federal, state, local, and tribal governments.
- **Fund and conduct research** to develop, improve, and expand measures that fully capture lived experiences of the SGM populations, such as discrimination in the health care system.
- **Fund and conduct studies** using a variety of methods and sampling techniques that, in particular, enhance understanding of small SGM population groups, such as transgender women belonging to racial or ethnic minorities and Native American Two-Spirit people.
- **Address significant problems**, such as removing barriers to accessing critical health and demographics information without compromising privacy and confidentiality, in linking data from different datasets to facilitate research on the health status and well-being of SGM populations.
- **Prioritize research** into the development, implementation, and evaluation of evidence-based services, programs, and interventions that promote the well-being of SGM populations.

Developed from (56).

higher incidence or risk of breast cancer among transgender relative to cisgender women are mixed (60-63). Similarly, the interplay between hormone therapy—an essential component of gender-affirming care for many transgender individuals (64)—and the likelihood of developing cancer is not clear.

A recent review of the current literature suggests that gay and bisexual men are at a higher risk of developing prostate cancer (65). Another study found that, compared to cisgender men, transgender women appear to be at a 60 percent lower risk of developing prostate cancer, but their likelihood of dying from it is nearly double (66). Studies have also found that men who have sex with men (MSM) are at a higher risk of HPV-associated anal cancer than their heterosexual counterparts (67). This risk is further increased among those infected with human immunodeficiency virus (HIV): HIV-negative MSM are 20 times more likely and HIV-positive MSM are 40 times more likely to have anal cancer, compared to heterosexual men (68).

Examples discussed above highlight the urgent need for comprehensive SOGI data collection for accurate estimation

of the cancer burden in the SGM populations. In recent years, constituents across the health care continuum have accelerated large-scale efforts to meet challenges posed by the absence of comprehensive health data from certain populations, including the SGM populations. One such effort is NIH's *All of Us* Research Program, which was launched in 2018 and aims to recruit one million participants from diverse backgrounds for medical research, with the goal to improve health outcomes for all patients (70). Findings of a recent study from the program that included more than 30,000 SGM participants, making up nearly 9 percent of the overall study sample, show that cisgender sexual minority men were 15 percent more likely, and cisgender sexual minority women were 12 percent less likely, to be diagnosed with cancer compared to their cisgender heterosexual counterparts (71). It is important to note that research initiatives, such as the *All of Us* Research Program, rely on primary data collection, whereas cancer registry data primarily come from medical records. Thus, collection of comprehensive cancer data on SGM populations, as well as additional research using such population-level data, is vital to fully understand the burden from all cancer combined, as well as from specific cancer types, in this population.

A recent study of 92 **sexual and gender minority (SGM) patients with breast cancer** found that SGM patients **experienced a 30-day delay in cancer diagnosis** from appearance of symptoms, compared to cisgender heterosexual patients with breast cancer (64 vs. 34 days from symptoms to diagnosis, respectively) (69).



Possible reasons for cancer disparities among SGM populations are numerous, including high prevalence of certain risk factors (such as tobacco and alcohol use), higher rates of HPV and HIV infections, suboptimal uptake of cancer screening, a lack of knowledge among health care providers about SGM individuals' health needs, and discrimination (72). For example, a 2023 survey of SGM cancer patients and survivors found that 37 percent of respondents faced discrimination in a health care setting due to their sexual orientation or gender identity (73).

## Populations Living Under Poverty

Populations who live under poverty experience a substantially disparate burden in cancer incidence, mortality, and outcomes. Areas of persistent poverty in the United States are geographic locations where 20 percent or more of the residents have lived below the federal poverty level over a 30-year period. Many of these regions emerged following racial and/or economic segregation and lack opportunities for residents to rise out of poverty, reflecting persistent disinvestment in the particular region.

### THE 2024 FEDERAL POVERTY LEVEL FOR A FAMILY OF FOUR IS EQUIVALENT TO AN ANNUAL INCOME OF:



≤ \$39,000  
ALASKA RESIDENTS



≤ \$35,880  
HAWAI'I RESIDENTS



≤ \$31,200  
48 STATES & DC RESIDENTS

Developed from (74).

W6

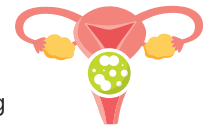
According to a 2023 US Census Bureau report, *Persistent Poverty in Counties and Census Tracts*, about 11 percent of US counties are under persistent poverty, and most of them are in the rural Southeast (75). It is important to note that persistent poverty neighborhoods are distinct from chronic poverty, which identifies individuals and families that are living in multi-generational poverty over many years, often over their entire lives.

Researchers have found a substantially higher cancer mortality in the US counties with persistent poverty (76). According to a recent study, during 2014–2018, deaths from all cancers combined were 7.1 percent higher in persistent poverty counties compared to nonpersistent poverty counties. Furthermore, compared to nonpersistent poverty counties, deaths from all major cancer types included in the study were higher in persistent poverty counties and ranged from

7.6 percent higher for lung cancer to 48.8 percent higher for cervical cancer (77). Similarly, children with cancer living in persistent poverty counties in Alabama during 2000–2016 were 30 percent more likely to die within 5 years of cancer diagnosis, compared to those not living in Alabama counties with persistent poverty (78).

Another study found significant differences in cancer incidence and mortality between high- and low-poverty counties—defined in the study as those above or below, respectively, the 5-year poverty rate of 14.8 percent—during 2014–2018 in Florida (79). While low- and high-poverty counties had similar incidence rates for all cancers combined, high-poverty counties had 22 percent higher mortality from all cancers combined. Furthermore, compared to low-poverty counties, high-poverty counties had higher incidence of cancers of the cervix (52 percent higher), liver (43 percent higher), larynx (41 percent higher), stomach (27 percent higher), and lung (22 percent higher), and higher mortality from cancers of the larynx (83 percent higher), cervix (64 percent higher), stomach (45 percent higher), liver (42 percent higher), and uterus (37 percent higher) (79).

During 2000–2019, **diagnosis of advanced-stage cervical cancer increased 4.4 percent annually** in non-Hispanic White women living in **low-income counties** (80).



W7

Populations living in persistent poverty areas are exposed to multifactorial structural and social drivers of health risks that contribute to a higher cancer burden. As a result, these communities comprise populations with less formal education; higher prevalence of certain cancer risk factors such as obesity, alcohol consumption, or cigarette smoking; higher exposure to environmental carcinogens; limited or no access to healthy food and/or quality health care; greater rate of unemployment; and larger proportion of racial and ethnic minority groups (75).

## Achieving Health Equity: A Vital Investment for the US Public Health and Economy

Adverse effects of cancer and cancer disparities are numerous, including the economic burden placed on individuals, families, communities, and society. Examining the economic burden of cancer and cancer disparities is an important aspect for developing and implementing evidence-based strategies so that health equity can be achieved for all.

**SIDEBAR 7**

**The Medical Research Community: Working Together to Eliminate Cancer Disparities**

Understanding and eliminating cancer disparities necessitates that all constituents dedicated to fundamentally changing the burden of cancer work together. Further increasing collaboration among key constituents will help in understanding and addressing complex and interrelated issues that contribute to and perpetuate cancer disparities. These constituents include:



Adapted from (1).

As cancer is the second leading cause of mortality in the United States, it is unsurprising that the cost of cancer care is among the highest of all diseases. According to the most recent estimates available, the patient economic burden associated with cancer care in 2019 was more than \$21 billion, about 80 percent of which was out-of-pocket costs for cancer patients. For example, total out-of-pocket costs for the four most common cancers in 2019 were \$3.14 billion (female breast

cancer), \$2.26 billion (prostate cancer), \$1.15 billion (colorectal cancer), and \$1.35 billion (lung cancer) (82). According to the most recent estimates available, cigarette smoking-associated cancers (such as lung cancer) were attributable to \$20.9 billion in lost earnings in 2019 (83).

Medically underserved populations, including racial and ethnic minority populations, share a disproportionate economic



burden associated with cancer. For example, a recent study evaluating years of life lost due to gynecologic cancer in the United States revealed that women from racially or ethnically minoritized populations had a substantially higher number of potential years of life lost compared to NH White women (84). Similarly, another recent report evaluating cancers diagnosed in 2019 in the US found that adolescents and young adults (ages 15 to 39)—who are often uninsured or underinsured and face unique challenges after cancer diagnosis—had significantly higher lifetime costs of cancer. The study estimated that the total lifetime cost of cancer care among this population was \$3.2 billion and the cost of lost productivity was \$18.03 billion (85).

According to a recent study, **the economic cost of racial and ethnic health disparities in 2018 was \$451 billion**, the majority of which was disproportionately borne by AI/AN, Black, and NHOPI populations (81).



w8

In recent years, there is increased recognition within the cancer community and the broader public health field that addressing cancer disparities is vital for achieving health equity, and constituents across the continuum of cancer care are working together to understand and address cancer disparities (see **Sidebar 7**, p. 34). The National Institute on Minority Health and Health Disparities (NIMHD), as well as NCI and its Center to Reduce Cancer Health Disparities (CRCHD), are playing a central role in understanding the burden of cancer disparities through several programs and funding opportunities (see **Overcoming Cancer Disparities Through Diversity in Cancer Training and Workforce**, p. 145, and **Sidebar 45**, p. 158).

Complex and multidimensional reasons drive cancer disparities and health inequities experienced by so many segments of the US population (see **Understanding and Addressing Drivers of Cancer Disparities**, p. 36).

Consequently, multipronged approaches are required to eliminate them. The bold vision of health equity can only be realized if the US Congress continues to provide sustained, robust, and predictable increases in funding for the federal agencies that are spearheading efforts to address and eliminate cancer disparities (see **AACR Call to Action**, p. 169).

# Understanding and Addressing Drivers of Cancer Disparities

## IN THIS SECTION, YOU WILL LEARN:

- Extensive research has shown that a long history of racism and contemporary injustices in the United States contributes to and perpetuates health inequities, including cancer disparities.
- Researchers are using a framework of complex and interrelated factors, called social drivers of health, to understand and address cancer disparities.
- Social drivers of health include socioeconomic status, social and built environments, and health care access, and interact with other factors such as mental health, modifiable risk factors, and biological factors to influence health outcomes.
- Drivers of health disparately and adversely affect racial and ethnic minority groups and medically underserved populations.
- Constituents across the medical research community are working together to implement strategies at the population, institution, and community levels to reduce cancer disparities and achieve health equity for all.

Disparities resulting from a long history of racism and contemporary injustices in the United States continue to have lasting, multigenerational adverse effects on marginalized populations in all aspects of life, including on health outcomes. The National Institute of Medicine, under mandate from the US Congress, produced the first major report on the topic in 2003 (86). The report, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, concluded that while socioeconomic factors such as poverty and lack of access to health care are key contributors, long-standing systemic racism is a major reason for the deeply entrenched health disparities in the United States (86).

Disparities stemming from structural racism (see **Sidebar 8**, p. 38), societal inequities, and contemporary injustices are abundant and apparent in racial and ethnic minority groups and medically underserved populations in overall health outcomes, as well as in the burden of cancer. In this section, we discuss some of the key drivers of cancer disparities in the United States and highlight selected initiatives and programs that are addressing cancer disparities, with the overarching goal of achieving health equity for all.

## Drivers of Health Disparities

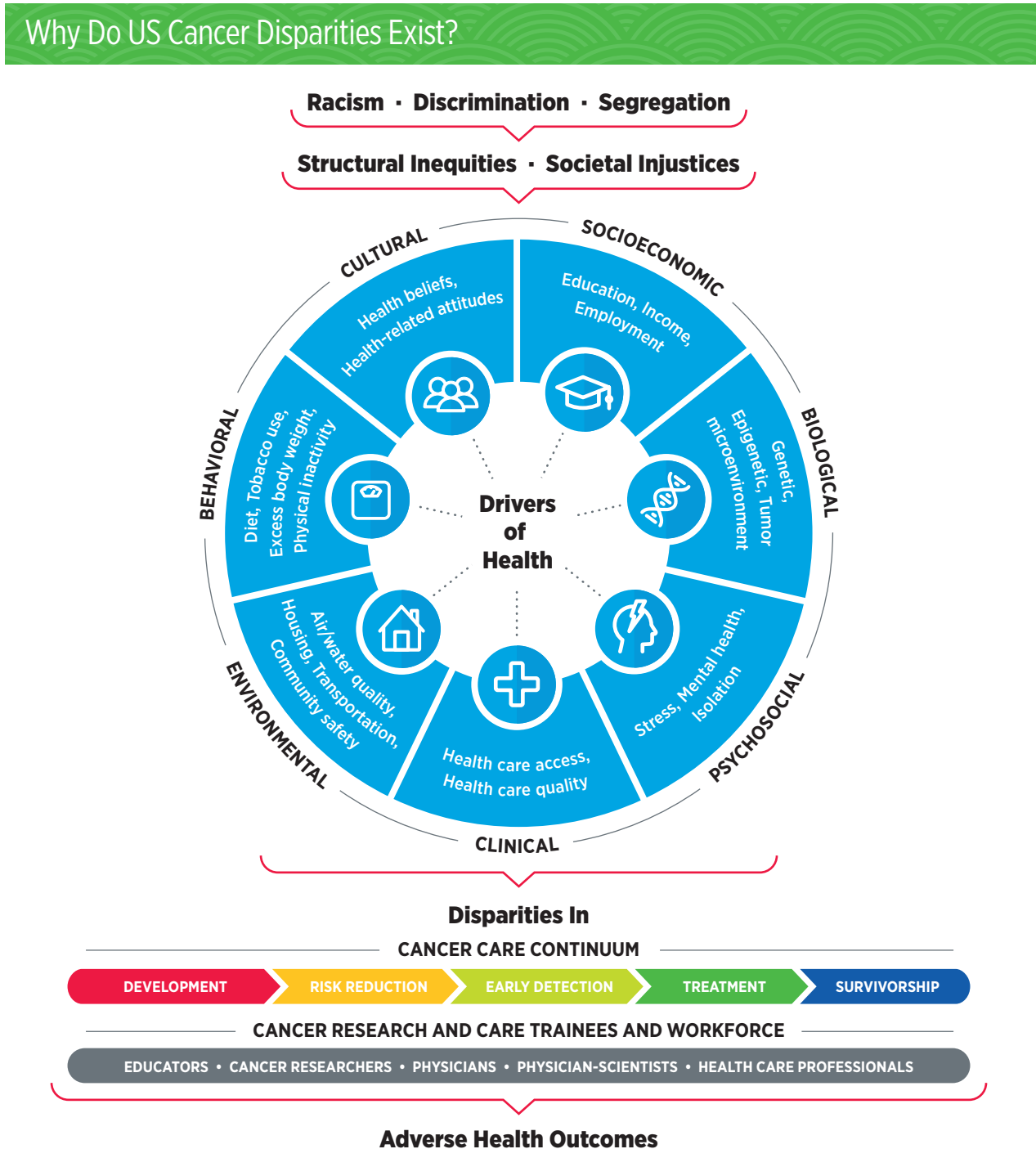
Researchers have proposed many frameworks to understand and address influences that determine health outcomes and contribute to health disparities, including cancer disparities. These frameworks are based on a complex network of

interrelated and interconnected factors that include biological factors, mental health, and modifiable risk factors as well as non-clinical factors called social drivers of health (SDOH) (87,88). According to NCI, SDOH, sometimes also called social determinants of health, are the social, economic, and physical conditions in the places where people are born and where they live, learn, work, play, and get older that can affect their health, mfactors such as socioeconomic status; housing; transportation; and access to healthy food, clean air and water, and health care services (see **Figure 3**, p. 37).

Social drivers of health interplay and, positively or negatively, impact all aspects of a person's lived experiences. For example, it is well known that balanced and healthy nutritional choices improve overall health and well-being (90). Conversely, lack of access to healthy nutrition increases the likelihood of developing health conditions, such as cancer, and contributes to cancer disparities (see **Disparities in the Burden of Preventable Cancer Risk Factors**, p. 66). In this regard, educational campaigns alone are insufficient to promote healthy choices in a neighborhood that does not have grocery stores with healthy food options, or whose residents cannot access grocery stores because of crime and violence or because they do not have the means to afford healthy foods. Instead, the intertwined nature of SDOH requires multiple sectors—education, health, labor, transportation, justice, and housing—to work together and improve access and affordability of healthy food as well as raise awareness of the health benefits of eating well among residents of the neighborhood (see **Figure 3**, p. 37). Ongoing research

*continued on page 39*

FIGURE 3



Complex and interrelated structural and social contextual factors, stemming from a long history of racism and discrimination against marginalized populations, drive cancer disparities. These factors include social drivers of health (SDOH) as well as biological factors, mental health and modifiable risk factors. The National Cancer Institute defines SDOH, sometimes also known as social determinants of health, as conditions in the environments in which people are born, grow, live, work, and age. Social drivers of health have a major influence on people’s health, well-being, and quality of life. In the United States, historical racism and contemporary injustices have perpetuated and exacerbated systemic inequities, resulting in adverse differences in SDOH for racial and ethnic minorities and medically underserved populations. The circle in the figure depicts key drivers of health and how they interconnect and intersect, both at societal and community levels and at the individual level. Selected examples of the multilevel factors that make up drivers of health are highlighted. Collectively, these factors impact every stage of the cancer continuum, leading to worse health outcomes for racial and ethnic minorities and other underserved populations (shown at the bottom).

**SIDEBAR 8**

# Key Concepts and Terms Related to Cancer Disparities

This report includes topics and terms that have defined descriptions, applicability, and/or purpose in the cancer disparities literature. Below is a brief list of key terms and their definitions to provide context and clarity to the topics discussed throughout this report.\*

**Cancer disparities** Adverse differences in cancer measures such as number of new cases, number of deaths, cancer-related health complications, survivorship and quality of life after cancer treatment, screening rates, and stage at diagnosis between certain population groups. These population groups may be characterized by race, ethnicity, disability, sexual orientation and gender identity, geographic location, income, education, and other characteristics.



**Lived experiences** According to the US Department of Health and Human Services, lived experience refers to representation and understanding of an individual's human experiences, choices, and options and how those factors influence one's perception of knowledge based on one's own life. A better knowledge of people's lived experiences can inform and improve systems, research, policies, practices, and programs.



**Discrimination** Actions, based on conscious or unconscious prejudice, that favor one group over others in the provision of goods, services, or opportunities. Structural and institutional factors can contribute to discriminatory behaviors, including being implicitly biased against other social characteristics such as class, age, race, ethnicity, immigration status, gender identity, and sexual orientation.



**Persistent poverty areas** A persistent poverty county is defined as one in which 20 percent or more of its population has lived in poverty over the past three-decade period.



**Diversity** The full range of human similarities and differences in group affiliation, including but not limited to gender, race and ethnicity, social class, role within an organization, age, religion, sexual orientation, physical ability, ideas, and other group identities.



**Redlining** Redlining is a form of illegal disparate treatment whereby a lender provides unequal access to credit, or unequal terms of credit, because of the race, color, national origin, or other prohibited characteristic(s) of the residents of the area in which the credit seeker resides or will reside or in which the residential property to be mortgaged is located.



**Health equity** Health equity is when all people are given the chance to live as healthy a life as possible regardless of their race, ethnicity, sex, gender identity, sexual orientation, disability, education, job, religion, language, where they live, or other factors.



**Rural and urban areas** The US Department of Agriculture categorizes rural and urban areas using the Rural-Urban Continuum codes, which distinguish US metropolitan or urban counties by the population size, and nonmetropolitan or rural counties by their degree of urbanization and adjacency to a metro area.



**Injustice** Injustice is the violation of the right(s) of other people.



**Socioeconomic status** A way of describing individuals or neighborhoods based on their education, income, housing, and type of job, among other indicators.



**Intersectionality** Coined in 1989 by legal scholar Kimberlé Crenshaw, the term intersectionality traces its roots in Black feminist thought and encompasses the complex, cumulative way in which the effects of multiple forms of discrimination (such as racism, sexism, and classism) combine, overlap, or intersect, especially in the lived experiences of marginalized individuals or groups.



**Structural racism** A system of organizational and institutional policies created over time that support a continued, unfair advantage for some people and unfair or harmful treatment of others based on their race or ethnicity. Structural racism comes from deep patterns of social, economic, and cultural differences that have developed over time between different groups of people. It affects the physical, social, and economic conditions of where people live, learn, work, and play.



\* These are not official definitions; federal agencies, organizations, and studies in the literature use slight variations to describe the same or similar concepts. Adapted from (89).

**TABLE 4**

**At a Glance:  
Key Social Drivers of Health and US Population Groups (2022)**

	<b>Percentage (%)</b>					
	<b>AI/AN</b>	<b>Asian</b>	<b>Black</b>	<b>Hispanic</b>	<b>NHOPI</b>	<b>White</b>
<b>Living under poverty</b>	25	8.6	17.1	17	14.8	9.5
<b>Health care status</b>						
Uninsured adults	21	6	11	19	11	7
No doctor or healthcare provider	24	19	18	34	21	16
Went without care due to cost	15	7	14	18	14	9
<b>With food insecurity</b>	25	4	12	8	22	4
<b>Living in crowded household</b>	16	12	8	18	28	3
<b>Educational attainment</b>						
Less than high school	14	12	11	27	12	6
High school or equivalent	34	14	31	28	35	26
Some college	35	17	32	25	34	29
Bachelor's degree or higher	17	57	26	20	19	39

AI/AN, American Indian or Alaska Native; NHOPI, Native Hawaiian or Other Pacific Islander. Source: (108).

impacts of SDOH on the health of a person, community, and population. In this section, we highlight, with recent examples, some of the key drivers of health, including SDOH, and their contributions to cancer disparities experienced by US racial and ethnic minority groups and medically underserved populations.

**Socioeconomic Status**

Socioeconomic status—also called SES and usually described as low, medium, and high—refers to the position of an individual in society based on education, income, and type of job, among other indicators. The overarching goal of determining SES is to understand the social health of a society, and to identify and address inequalities among various population groups. In addition to describing individuals, SES can also be used to categorize neighborhoods and other geographically defined areas. The neighborhood-level SES includes the SES of residents and how their social environment influences access to goods and services; crime levels, safety, and policing; and societal norms. For example, residents living in low-SES neighborhoods with limited transportation options, greater travel distances to stores, and fewer supermarkets can experience food insecurity, which is the lack of access to sufficient food or food of adequate quality to meet a person’s needs.

Socioeconomic status is a key driver of disparities, including cancer disparities, in people of all races and ethnicities. For example, findings from a recent study show that women with

low SES had worse survival compared to those who lived in neighborhoods with high SES, and this association was independent of the race of the patient (91). Many racially and ethnically minoritized and medically underserved populations live in conditions that perpetuate low SES. Compared to the White population, a higher proportion of nearly all racial and ethnic minorities were living below the federal poverty level in 2021, had food and housing insecurity, were uninsured, and had less educational attainment (see **Table 4**, p. 39).

Individuals or groups with low SES are more likely to experience disparate cancer burdens. One study evaluated the impact of SES on disparities in the outcomes of head and neck cancer in a diverse patient population (92). Findings showed that individuals with the lowest SES had a 45 percent higher mortality rate compared to those with the highest SES (92).

**! 44% HIGHER MORTALITY**

**Women diagnosed with breast cancer during 2007–2016 at a Florida cancer center who were living in the most disadvantaged neighborhoods had 44 percent higher mortality from breast cancer compared to those living in the most advantaged neighborhoods (93).**

W9



Two recent studies found that residents of neighborhoods with low SES had a higher burden of oral cavity cancers, compared to those living in high-SES neighborhoods (94,95). One study showed a significant difference in 5-year overall survival rates for residents of high and low neighborhood SES, respectively, i.e., 55 percent versus 45 percent for NH White; 36 percent versus 28 percent for NH Black; and 56.5 percent versus 20 percent for Pacific Islander patients (95). The second study found that the incidence of oral cavity cancers was 2.4 times higher in White individuals living in neighborhoods with low SES compared to Black individuals living in neighborhoods with high SES (2.86 versus 1.17 cases per 100,000, respectively; (94)).

Low SES contributes to a higher cancer burden due to many interconnected reasons. For example, individuals with low SES have limited access to quality cancer care services, which leads to delayed diagnosis and treatment. Neighborhoods with low SES have higher exposures to environmental carcinogens, which are cancer risk factors. Low SES also adversely impacts other aspects of lived experiences, such as mental health. This complexity requires the development of multipronged, effective approaches that provide individuals and neighborhoods with the means and resources to increase their SES.

## Social and Built Environments

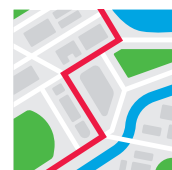
Racial and ethnic diversity, neighborhood SES, and residential distribution and segregation constitute the social environment of a neighborhood. The built or physical environment of a neighborhood is composed of transportation, public services, and policies and regulations. Together, social and built environments determine, among other attributes, a neighborhood's cultural norms, collective efficacy, availability of ethnic-serving resources, education quality, and crime, as well as its residents' access to food, medical facilities, fresh air, clean water, and environments that are free from toxic environmental exposures.

Researchers use several ways to determine the characteristics of a neighborhood. One commonly used metric is called the area deprivation index (ADI). Developed to inform health care delivery and policy, and regularly used in health disparities research to describe neighborhood characteristics, ADI reflects 17 measures across four SES indicators—income, education, employment, and housing quality—and is expressed from 1 (least disadvantaged neighborhood) to 100 (most disadvantaged neighborhood) (96). Decades of research have shown that health outcomes of people are influenced by their social and built environments. As such, the longer an individual resides in a high ADI environment, the more likely they are to experience a disproportionate burden of cancer.

Racial and ethnic minority populations are more likely to live in neighborhoods with poor social and built environments. The reasons for such residential segregation are deeply rooted in centuries of discrimination and structural racism in the United

States. One example of structural racism is the egregious practice of redlining, in which financial services are withheld from potential customers who reside in neighborhoods classified as “hazardous” for investment. Although currently illegal, *de facto* redlining and racial bias in mortgage lending continue to this day. Redlining has segregated many low-income people, often belonging to racially and ethnically minoritized populations, into neighborhoods with poor social and built environments. For example, current neighborhoods exposed to historic redlining have higher air pollution levels (97). There is extensive evidence that historic redlining is associated with adverse health outcomes, including a disparate burden of cancer (98-100).

Breast or colorectal cancer patients living in historically redlined neighborhoods in Indiana during 2010–2015 had a higher risk of being diagnosed with advanced-stage cancer (30 percent and 41 percent higher risk, respectively) compared to those living in non-redlined neighborhoods (101).



W10

Studies have shown that residents who live in redlined and disadvantaged neighborhoods share a higher burden of cancer. An analysis of US cancer deaths during 2015–2019 in relation to residential segregation found that residents of disadvantaged neighborhoods had a 22 percent higher mortality rate for all cancers combined compared to those living in advantaged neighborhoods (102). Findings of the study also revealed that residents of disadvantaged neighborhoods had higher mortality rates for 12 of 13 cancer types reported in the study, ranging from 6 percent higher for cancers of the brain and other parts of the nervous system to 49 percent higher for cancers of the lung and bronchus (102). Another study found that women older than 65 years who were living in redlined neighborhoods had a 26 percent higher chance of dying within 5 years of a breast cancer diagnosis compared to those living in non-redlined neighborhoods (103).

The intersection of race with poor social and built environments further exacerbates cancer disparities. As one example, a recent study evaluated the association of race and ethnicity with place of residence regarding the diagnosis of the highly aggressive triple-negative form of breast cancer (TNBC) (104). Findings show that women living in low-income neighborhoods were 33 percent more likely to be diagnosed with TNBC compared to women living in high-income neighborhoods. Furthermore, the likelihood of TNBC diagnosis was more than double for NH Black women living in low-income neighborhoods compared to those living in high-income neighborhoods (104). Another study of cancer incidence in metropolitan Detroit during 2012–2016 found that the incidence of prostate cancer among NH Black men was

44 percent lower if they lived in advantaged neighborhoods but was 27 percent higher if they lived in disadvantaged neighborhoods, compared to NH White men living in the corresponding neighborhoods. The study also found that Black adults were more likely to be diagnosed with lung cancer if they lived in a disadvantaged neighborhood, with the likelihood of lung cancer diagnosis increasing with increased disadvantage of the neighborhood (105).

Evidence presented here underscores how social and built environments can determine health outcomes, including cancer outcomes. Poor social and built environments can limit access and availability of healthy food, expose residents to environmental carcinogens and increase their risk of developing cancer, and/or can restrict access of residents to quality health care services and cause delays in cancer treatment. It is thus unsurprising that the US Department of Health and Human Services (HHS) department has included promoting healthier environments at home and workplaces as one of the five objectives of the Healthy People 2030 initiative. In addition to such initiatives, it is imperative that constituents across the health care continuum work together to eliminate discriminatory practices—such as modern-day denial of mortgage loans to specific applicants or to specific neighborhoods, also called contemporary redlining—that keep disadvantaged communities and populations under conditions that perpetuate cancer disparities.

## Health Care Access

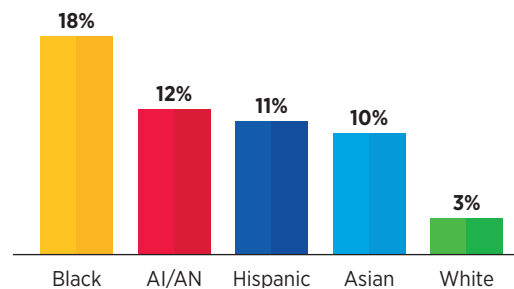
One of the most impactful SDOH is the access of a person to quality health care, which is the degree to which health care services increase the likelihood of desired health outcomes for individuals and populations. Lack of insurance is a key determinant of whether an individual will receive the needed health care. In 2021, nearly 27 percent of US adults ages 18 to 64 who were uninsured delayed or did not receive needed medical care due to cost, compared to a little over 7 percent of those who had either public or private insurance (2).

The disparities in access to quality health care are significant. A substantial proportion of racial and ethnic minorities and medically underserved populations in the United States either receive lower-quality health care or lack health care access altogether. For example, compared to White individuals, the proportion of uninsured NHOPI and Black adults in the United States during 2020–2021 was 1.6 times, and that of AI/AN and Hispanic individuals was about three times (see **Table 4**, p. 39) (106). In addition, racially and ethnically minoritized groups and medically underserved populations experience disparities at multiple levels in their interactions with health care systems (see **Sidebar 9**, p. 44).

Lack of access to quality health care has adverse effects across the cancer care continuum. Compared to those with private insurance, uninsured individuals are less likely to be up to date

with the recommended cancer screening and are more likely to be diagnosed with cancer at an advanced stage. For example, the number of uninsured women who were not up to date with breast cancer screening in 2021 was nearly double the number of those with public or private insurance (see **Disparities in Cancer Screening for Early Detection**, p. 83) (2). Similarly, a recent study found that being uninsured or insured by Medicaid accounted for more than half of the estimated disparity in advanced-stage cervical cancer diagnosis among all racial and ethnic minority groups compared to White women (113).

### PERCENTAGE OF ADULTS REPORTED TO HAVE BEEN TREATED UNFAIRLY OR WITH DISRESPECT BY HEALTH CARE PROVIDER DUE TO RACIAL OR ETHNIC BACKGROUND



Developed from (114).

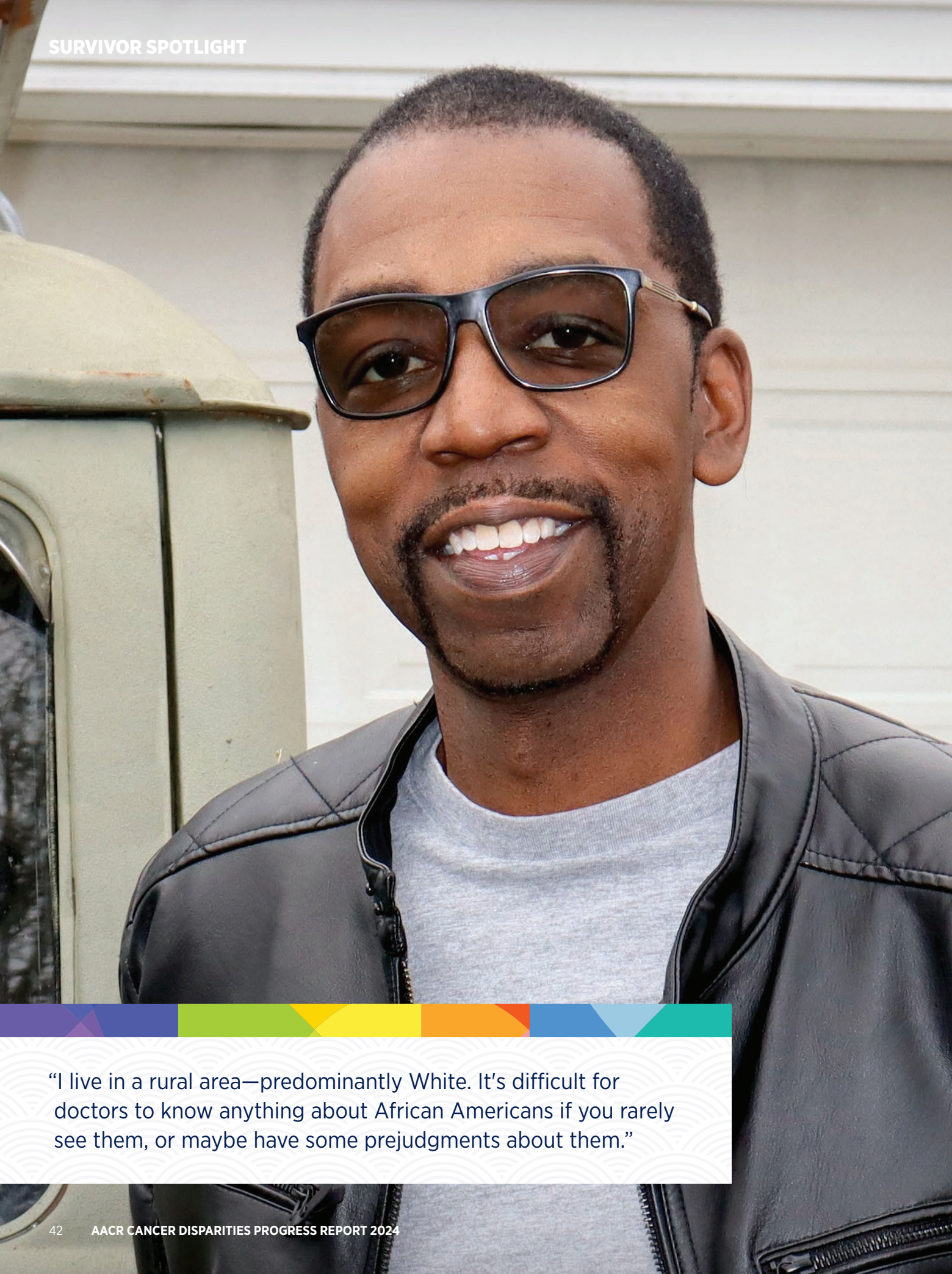
W11

Access to quality health care plays a pivotal role in improving health outcomes after a cancer diagnosis. For example, findings of a recent study of women with breast cancer who were active duty, veteran or medical beneficiaries and were treated at a military health care system suggest that disparities in survival outcomes between NH Black and NH White patients are virtually eliminated when equitable access to quality health care is provided (115). However, other important factors contribute to suboptimal interactions between racially and ethnically minoritized patients and health care systems, including distrust in medical research and health care. This distrust has deep roots in historical atrocities, such as experimental gynecologic surgeries performed in the 19th century on enslaved Black women by the Alabama physician James Marion Sims; the Tuskegee Study conducted in the early 20th century in Black people by the medical establishment of the time; and the 1950s development of the first cancer cell line, extensively used in medical research, without the consent of Henrietta Lacks, a Black woman with cervical cancer (89).

Research has shown that suboptimal communication and interaction between minority and medically underserved patients and their providers can lead to delayed diagnosis and cancer care, as was the case with **Oya Gilbert** (see p. 43). According to a recent nationwide survey, a large proportion of Black (60 percent), AI/AN (52 percent), Hispanic (51 percent),

*continued on page 44*



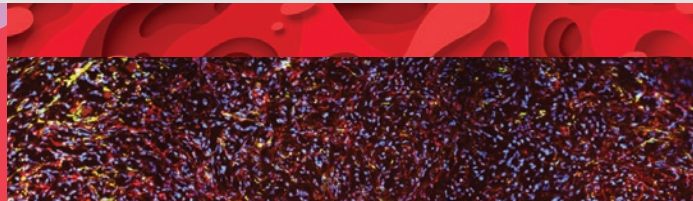


“I live in a rural area—predominantly White. It’s difficult for doctors to know anything about African Americans if you rarely see them, or maybe have some prejudgments about them.”



# Oya Gilbert, 54

Waynesboro, Pennsylvania



Oya Gilbert was diagnosed with multiple myeloma the day after Christmas, 2017.

“It wasn’t an easy road to diagnosis,” remembers Oya. It all started in 2015 when he experienced what he thought was a heart attack, but when he went to the hospital, he was told he was having an anxiety attack. Oya followed up with his primary care provider, who didn’t pay attention when he said he wasn’t experiencing anxiety and was sure something physical was causing his “episodes.”

“As the years progressed, I started having more of these episodes—they were more frequent, more violent—with shortness of breath, fatigue, and tremendous pain,” Oya recalled. This continued for several years, affecting his work, quality of life, and relationships. Oya went through a series of doctors, including specialists, looking for answers. “At some point, they just labeled me a hypochondriac and started prescribing me anxiety pills,” Oya said. As a result, the medication made him extremely tired (on top of the fatigue he was already experiencing from the not-yet-diagnosed blood cancer) and he ended up having a (minor) car accident.

“Eventually, I wound up feeling like I was just going to die because nobody was giving me an answer, so I tried to increase my life insurance policy to put my children in a better financial position,” Oya said. It was the insurance company’s doctors who discovered the protein markers in his blood and urine, which led to a bone marrow biopsy, and his diagnosis of multiple myeloma. While it was devastating news, Oya was relieved to finally know what was wrong. “It was validating. Two years of making me think I was going crazy, but I knew that these symptoms were real,” he said.

Oya reflects on his oncologist delivering the diagnosis. “I remember saying to myself, did this guy just say I have cancer? And then did he just say, it can’t be cured?” recalled Oya. “It was overwhelming. I did a little crying. I just wanted more time.” The doctor explained to Oya that, even though his disease was in stage I, they needed to get him started with treatment as quickly as possible. “I was diagnosed in December of 2017. I started treatment on February 1st, 2018.” Oya’s treatment included a combination of bortezomib (Velcade), lenalidomide (Revlimid), and dexamethasone (VRd). Within a month or so of starting treatment, his cancer markers were decreasing and he began to feel better.

As the next step of Oya’s clinical care, his oncologist discussed a stem cell transplant. It was explained to him that, while not a cure, the transplant could extend his life. “I told the guy, if this is something that could give me an opportunity to live longer, I want to discuss that further and pursue that.” Once he qualified for the procedure, Oya had to travel more than an hour away to a major medical center in Hershey, Pennsylvania, for the transplant.

Oya’s cancer is currently under control. Throughout his journey with multiple myeloma, Oya has never experienced full remission, but he feels a lot better now than he did prior to his diagnosis. He does experience neuropathy as well as shortness of breath and back pain at times. “My biggest challenge is trying to figure out if it is associated with cancer, chemo, or just getting old,” he said. “I’m alive, so that’s good news. And I am healthy-ish, which is also good news.”

He continues to receive Revlimid to keep the cancer under control. However, as he’s educated himself more about his disease and its treatments, Oya made the decision to minimize his treatments. “I decided not to pursue trying to reach zero for a disease that cannot be cured.” It didn’t make sense to Oya to continue with the harsh treatments because of the trauma they were causing to his body. “Let’s talk about that if the disease starts progressing again.”

Looking back at his journey with multiple myeloma, Oya sees many missed opportunities. “Just different things I discovered that were just not handled correctly. The communication wasn’t really that great. I was just given a pamphlet and left to figure it out on my own. Clinical trials were never discussed.”

When Oya learned about the higher rate of multiple myeloma in Black people, he was stunned. “I live in a rural area—predominantly White. It’s difficult for doctors to know anything about African Americans if you rarely see them, or maybe have some prejudgments about them. When I look at the disparity in my particular case, it leans to geography and the lack of education for the doctors,” Oya said. “This region is known for prescription addiction,” he added, “So, they were thinking that’s what I wanted. They just didn’t listen. If they’d listened, I think we could have gotten past a lot of those issues leading up to my diagnosis that just got brushed off.”

Because of the way Oya’s been treated during his journey and some unsupportive conversations he’s had with his medical care team, he’s had to replace several providers. He recognizes the importance of advocating for himself and for other patients like him who don’t know what they don’t know.

Drawn to make a bigger impact, Oya proudly launched a nonprofit in 2023—the Health, Hope, & Hip-Hop Foundation—to close the gaps and improve the medical mindset of our communities of color. His mission is to bring health education and equity to underserved communities across the US through honesty, transparency, and the uniquely connective power of hip-hop. This foundation will address health disparities at the grassroots level, driving them all the way to the White House.

“I don’t think you can have true sustainable change without policy changes.” He wants to remind our policymakers that people get late diagnoses, suffer, and die unnecessarily while new policies to reduce cancer disparities are debated.

“We now understand a lot more about cancer disparities. We also have the brightest minds and researchers from all over the world who are trying to address these disparities. But we are still here—still talking about it,” Oya said. “We must start acting. I come from an urban community—a horrible childhood—all the way to this point, trying to contribute to society, and raising my children. I’m talking to you as a multiple myeloma patient who happens to be African American—please get something done.”

Scan the QR code  
to watch Oya’s video interview.





## SIDEBAR 9

## Inequities in Access to Health Care Systems and Services

According to the US Department of Health and Human Services, **health care systems are organizations with at least one hospital and one group of physicians providing primary and specialty care under common ownership or joint management** (107). Many conceptual frameworks are used in literature and for policymaking to define access to, and measure the quality of, services provided by health care systems.

According to one commonly used framework, access to a health care system encompasses affordability; availability; accessibility; accommodation; and acceptability (108).

Selected recent examples below underscore how racially and ethnically minoritized individuals and medically underserved populations face disparities at one or more levels in their experiences with health care systems and services:



### Affordability

#### HOW AFFORDABLE IT IS

Uninsured cancer patients with a stage I cancer diagnosis were 2.5 times more likely to die than privately insured patients (109).



### Availability

#### HOW WELL EQUIPPED AND WELL STAFFED IT IS

A study of 4,400 US hospitals revealed that hospitals serving Black, Hispanic, and other racial and ethnic minority patients were significantly less likely than other hospitals to have access to essential cancer services, such as positron emission tomography and computed tomography, robotic surgery, and palliative care (110).



### Accessibility

#### HOW CLOSE IT IS TO THE PATIENTS' RESIDENCE

A 2022 survey of 102 cancer centers found that about 15 percent of US counties, or roughly 25 million people, mostly in rural Appalachia and the South where cancer burden is high, were not served by a cancer center (111).



### Accommodation

#### HOW WELL PREPARED IT IS TO WORK WITH SPECIFIC NEEDS OF PATIENTS

A small study of electronic health records found that breast cancer patients with mobility disability did not receive quality care because of the disability. For example, physical barriers prevented patients from receiving routine mammography. Furthermore, clinicians favored complete breast removal instead of breast-conserving surgery despite early-stage diagnosis because of physical barriers in receiving radiotherapy that is required after breast-conserving surgery (112).



### Acceptability

#### QUALITY OF CARE PROVIDED REGARDLESS OF PATIENTS' PERSONAL ATTRIBUTES, SUCH AS RACE

In a national survey of sexual and gender minority patients with cancer, 45 percent of Hispanic, 44 percent of Black, and 21 percent of White patients indicated that their sexual orientation or gender identity had presented a barrier to receiving health care (73).

and Asian (42 percent) individuals indicated that they mentally prepare for possible insults from providers or staff during their health care visits. Findings from the survey also show that Black, Hispanic, and Asian adults who had more health care visits with providers from their own racial and ethnic background had more frequent positive and respectful interactions (114). In another study focused on understanding the health needs of SGM individuals residing in the United States, 19.1 percent of transgender men and 16.3 percent of transgender women reported that they were denied health service within the past year or received lower-quality medical care (116).

Continued and concerted efforts to understand and address the root causes of cancer disparities are necessary to realize the bold vision of achieving health equity. Examples discussed here, as well as a large body of accumulating literature on the topic, underscore the responsibility of all constituents in the medical research community to take proactive and effective measures that include eliminating gaps in health insurance, increasing access to quality health care, and eradicating discrimination and bias across the cancer care continuum.

## Mental Health

Mental health includes a person's emotional, psychological, and social well-being and is an essential part of overall health. Social drivers of health contribute to poor mental health and the resulting stress, both of which are directly and indirectly linked to adverse physical health. Understanding a link between stress and cancer is an area of active research. Another area of ongoing investigation is the impact of early life stress on the cancer burden of the pediatric population. Research has shown that individuals under persistent stress can develop unhealthy behaviors, such as tobacco or alcohol use, both of which are associated with increased risk of cancer (see **Disparities in the Burden of Preventable Cancer Risk Factors**, p. 66) (117). Conversely, stress related to cancer diagnosis, treatment, and survivorship negatively impacts the mental and psychological well-being of patients with cancer. Furthermore, a cancer diagnosis also adversely affects the mental health of caregivers.

Individuals belonging to racial and ethnic minority populations and medically underserved groups experience higher chronic stress, which is associated with worse health outcomes (118,119). Furthermore, research has found links between chronic stress and the burden of cancer. A recent review of the literature found an increasing number of studies associating psychological stress with increased risk of developing cancer, including cancers of the breast, prostate, lung and bronchus, and colon and rectum (120). For example, one study found that women who had anxiety had a 67 percent higher risk of developing lung cancer (121). A study of Danish patients diagnosed with cancer between 1995 and 2011 found that, compared to patients who did not have a stress-related mental disorder diagnosis before their cancer diagnosis, patients with a preexisting stress-related diagnosis had a 1.3 times higher rate of overall cancer mortality; the mortality rate was even higher among patients with hematologic malignancies (1.9 times higher), or if the cancer was diagnosed at an advanced stage (1.7 times higher) (122).

In a qualitative, interview-based study, **SGM patients** with cancer reported **higher levels of anxiety, depression, and social isolation**, compared to cisgender heterosexual counterparts (123).



W12

Substantial evidence indicates that a cancer diagnosis adversely affects the mental and psychological health and well-being of a person. One study found that the likelihood of a mood disorder diagnosis, including depression, increased among patients with prostate cancer compared to the general population (124). Certain population groups are at a higher risk of developing mental health disorders after a cancer diagnosis. A recent study showed that veterans who received a

new cancer diagnosis were at a 47 percent higher suicide risk compared to veterans without a new cancer diagnosis (125). Findings further revealed that the suicide risk was even higher in veterans who received a diagnosis of esophageal cancer (six times higher), head and neck cancer (3.5 times higher), and lung cancer (2.4 times higher), or if the patient was diagnosed with cancer at stage III (2.4 times higher) or stage IV (3.5 times higher) (125).

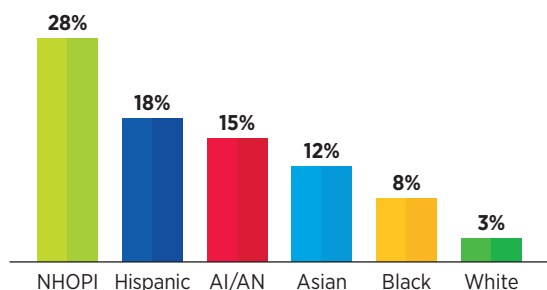
Studies have also reported that a cancer diagnosis negatively impacts the mental well-being of caregivers. Evidence suggests that siblings of childhood cancer survivors can also experience adverse health outcomes, including cancer risk concerns (126). It is unsurprising that several minoritized statuses and SDOH also intersect with and impact a person's mental health. Studies have linked poor mental health with having a low SES (127), living under persistent poverty (128), residing in disadvantaged neighborhoods (129), and belonging to the SGM community (130). The relationship between race and ethnicity and mental health is complex. Among adults with any mental illness who, in 2021, reported receiving mental health services in the past year, only 39 percent were Black, 36 percent were Hispanic, and 25 percent were Asian, compared to 52 percent who were White (106). More research is needed to comprehensively address the role of mental health in increasing cancer risk as well as its intersection with other factors, such as tobacco and alcohol use, that independently increase the risk of developing cancer.

## Modifiable Risk Factors

Modifiable risk factors refer to individual health behaviors that can be changed to decrease the likelihood of developing cancer, and are substantially influenced by SDOH. Tobacco use, poor nutrition, alcohol consumption, and insufficient physical activity are some of the modifiable behaviors that are linked with increased likelihood of developing several types of cancer. These behaviors are often shaped by multiple factors, including SES, social and built environments, and lived experiences of a person, and the extent to which they can be modified depends on the structural barriers faced by minoritized populations.

Several medically underserved populations live in conditions that increase their exposure to cancer risk factors and perpetuate unhealthy behaviors (see **Disparities in the Burden of Preventable Cancer Risk Factors**, p. 66). As one example, people who do not smoke and live under disadvantaged conditions (e.g., crowded living spaces without smoke-free policies) are exposed to secondhand smoke, which causes at least 3 percent of all lung cancer deaths each year (an estimated 3,600 deaths in 2023) (131). There are racial and ethnic disparities in exposure to secondhand smoke. During 2017–2020, 17 percent of White individuals were exposed to secondhand smoke. In comparison, 35 percent of Black, 21 percent of Asian, and 18 percent of Hispanic individuals were exposed to secondhand smoke (131).

### RACIAL AND ETHNIC MINORITY POPULATIONS LIVING IN CROWDED SPACES



Compared to White individuals, **a greater proportion of those belonging to racial and ethnic minority populations live in crowded spaces**, which can **potentially increase** their exposure to **cancer risk factors**, such as secondhand smoke.

Developed from (106).

W13

The burden of cancers associated with modifiable risk factors is disparate among racial and ethnic minority populations. In a study of nearly the entire US female population age 20 or older from 2001 to 2018, researchers found substantial racial and ethnic differences in the incidence trends of cancers associated with five major modifiable risk factors: tobacco use, excess body fat, alcohol consumption, insufficient physical activity, and HPV infection (132). For example, among women ages 20 to 49 years, obesity-associated cancers in Hispanic and NH API women rose at nearly twice the rate of NH White women (2.86 versus 2.19 versus 1.39 percent annual increase, respectively); this increase was the smallest in NH Black women (0.96 percent annual increase). NH API women also had the largest increase in alcohol consumption-associated cancers (1.33 percent increase every year) (132). Among women age 50 years or older, obesity-associated cancers decreased only among NH White women (0.60 percent annual decrease) and increased in all racial and ethnic minorities, with the largest increase observed in API women (0.62 percent annual increase). Similarly, cancers associated with insufficient physical activity decreased 0.74 percent annually in NH White women but increased 0.13 percent in NH Black women (132).

**Long-term residence in walkable neighborhoods reduced the risk of overall obesity-related cancers** by 11 percent among Black women in New York City; the risk reduction was strongest for multiple myeloma (32 percent) and among women living in high-poverty neighborhoods (133).



W14

As noted above, risk factor exposure of racial and ethnic minority groups and disadvantaged populations substantially depends on systemic factors (e.g., lacking the resources to move out of a crowded living space) that may be barriers in reducing their exposure. Moreover, cancer risk factors also contribute to other chronic conditions, such as diabetes and cardiovascular disease, for which there are similar disparities in burden. Together, the intersecting nature of minoritized statuses and disparate exposures to cancer risk factors because of systemic inequities highlight the complexity in understanding the causal relationship of race and ethnicity with the burden of cancers associated with modifiable risk factors and necessitate a comprehensive approach to investigating and mitigating the root causes of cancer disparities caused by modifiable risk factors.

### Biological Factors

Our knowledge of the molecular underpinnings of cancer development has increased tremendously in recent decades. Technological advances in sequencing the human genome with precision have revealed that certain genes and their expression patterns, as well as small changes in their sequences, can increase chances of cancer development (see **Understanding Cancer Development in the Context of Cancer Disparities**, p. 52). Studies have also shown that environmental factors as well as ancestral differences are associated with changes in sequences and expression of cancer-related genes that can potentially increase a person's risk of developing cancer (134-137). Furthermore, interplay between SDOH and biological factors directly influences health outcomes.

Researchers have investigated associations between ancestry-related differences in genetic sequences and cancer. According to findings from a recent study, among patients with endometrial cancer, those of African ancestry were 56 percent less likely and those of Ashkenazi Jewish ancestry were 62 percent more likely than those with European ancestry to have genetic changes known to cause cancer (138). A systematic review of the literature found that among patients with lung cancer, African and Hispanic ancestries were associated with mutations in epidermal growth factor receptor (EGFR) and tumor protein 53 (TP53), respectively (139); mutations in both genes are well-known drivers of lung cancer (140). It is important to note that because of reference datasets used in determining genetic ancestry in such studies, ancestry may reflect historic and structural drivers of health as much as genetic variations.

A key limitation of understanding the role of biological factors in cancer disparities is the fact that much of the genome-wide information on the burden of cancer is based on data from the White population (141). Researchers are continually working to overcome this shortcoming. For example, in a recent study, researchers reported the development of a computational approach to infer genetic ancestry from existing genomic data from cancer patients that lack such information. The approach

is anticipated to double the ability of researchers to investigate links between genetic ancestry and cancer (142).

Research initiatives, such as NIH's *All of Us* Research Program, the AACR Project GENIE® (see **AACR Initiatives Reducing Cancer Disparities and Promoting Health Equity**, p. 172), and others are beginning to address underrepresentation of racial and ethnic minority populations in genomic databases (see **Sidebar 15**, p. 64). As one example, researchers from the program recently released data from nearly 250,000 genome sequences, 77 percent of which are from communities that are historically underrepresented in medical research and 46 percent are individuals from underrepresented racial and ethnic minority populations. Importantly, *All of Us* researchers identified more than 1 billion genetic variants, including more than 275 million previously unreported genetic variants (143). Such studies have the potential to advance the promise of precision medicine (see **Figure 6**, p. 63) for all populations.

Recent decades have seen tremendous innovation in technologies and approaches researchers use to understand various aspects of cancer. These advances carry immense potential to help address some of the most intractable challenges in cancer science and medicine, including cancer disparities. However, some of the technologies and approaches may unintentionally worsen cancer disparities (see **Sidebar 10**, p. 48). It is vital that all constituents remain cognizant of the potential drawbacks of a rapidly evolving landscape of technological revolution in medicine and take necessary steps to ensure that these advances are equitable in implementation and access for all populations.

## Approaches to Address Drivers of Health and Reduce Cancer Disparities

As noted in the previous section, SDOH intersect with all aspects of life, impact lived experiences, and influence health outcomes of a person across the life span. Addressing SDOH can not only improve overall health but also help reduce cancer disparities that are deeply rooted in social and economic disadvantages experienced by racial and ethnic minority groups and medically underserved populations. Constituents across the continuum of cancer care are taking multipronged approaches to address SDOH at various levels, with the overarching goal of achieving health equity for all. In this section, we highlight how some of these approaches are helping us to understand and mitigate cancer disparities.

### Policy-focused Approaches

Evidence-based interventions and policies implemented at the population level have the potential not only to improve the nation's health but also strengthen the US economy. The National

Academies of Sciences, Engineering, and Medicine highlighted in its 2019 report, *Integrating Social Care into the Delivery of Health Care: Moving Upstream to Improve the Nation's Health*, that addressing social needs, such as transportation, housing, and education, at the government level can significantly improve health outcomes.

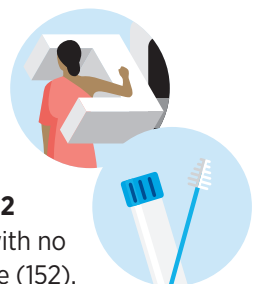
Several long-term initiatives are aimed at improving health outcomes at a population level. One such initiative is the US HHS department's Healthy People 2030 initiative. Addressing SDOH is a key focus of Healthy People 2030, which contains multipronged approaches to improve social and built environments in which people live (144). As another example of a population-level intervention, there is significant evidence that The Patient Protection and Affordable Care Act (ACA) has decreased the number of uninsured individuals, thus mitigating lack of access to health care, which is a key driver of health for a large proportion of the population (see **Health Care Access**, p. 41) (145). Consequently, the ACA-associated Medicaid expansion has been linked to an increase in adherence to routine cancer screening, cancer diagnosis at an early stage when it is easier to treat the disease, increase in utilization of cancer treatments, reduction in disparities, and improvements in survival rates (146).

There are also examples of evidence-based strategies being implemented at multiple levels to help improve one or more SDOH. For example, lack of transportation because of insufficient resources, also called transportation insecurity, can lead to delayed or missed cancer care and additional economic and health costs later in life (147,148). Centers for Medicare and Medicaid Services has developed the Non-Emergency Medical Transportation (NEMT) program, which provides eligible Medicaid beneficiaries rides to medical appointments and is the largest program addressing health care-related transportation needs (149). Another federal program addressing transportation insecurity as one of the ways to improve health outcomes is the Veterans Transportation Program, which offers veterans travel assistance to and from their Veteran Affairs health care facilities (150). Other constituents, such as health care systems, nonprofit organizations, and pharmaceutical agencies, are also addressing transportation insecurity (147). There is some evidence that such programs improve health outcomes for patients and increase savings for the health care system by reducing the number of missed appointments, among other benefits (151).

*continued on page 49*

Since 1991, **CDC's National Breast and Cervical Cancer Early Detection Program**

has provided more than **16.1 million breast and cervical cancer exams** to more than **6.2 million low-income women** with no or suboptimal health insurance (152).



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## SIDEBAR 10

## Technological Revolution in Medicine and Cancer Disparities

Technological advances in recent decades have revolutionized cancer science and medicine and have enhanced understanding of cancer etiology, early detection, treatment, and response. Below are examples of some of these advances, the promises they hold for advancing progress against cancer as well as potential drawbacks that may lead to increased disparities.



**ARTIFICIAL INTELLIGENCE (AI)** is the ability of a computer to perform tasks commonly associated with human intelligence, such as how to act, reason, and learn.

### Promise of AI

#### ARTIFICIAL INTELLIGENCE CAN HELP...

- **Accelerate cancer early detection** through speed and accuracy to detect existing cancers or to rule out that cancer is present.
- **Accelerate drug development** by identifying potential drug targets faster.
- **Accelerate treatment decisions** by reducing the time it takes to optimize a personalized course of treatment.
- **Monitor responses to cancer treatment** by quickly analyzing patient data, such as medical imaging (e.g., computed tomography [CT] scan).
- **Optimize treatment guidelines** by analyzing large amounts of clinical information, electronic health records, existing treatment protocols, and health outcomes data.

### Potential Drawbacks

#### ARTIFICIAL INTELLIGENCE MAY...

- **Perpetuate data biases** if datasets used to train AI algorithms do not include diverse populations.
- **Inherit algorithmic biases** if the design choices are made by teams of professionals who do not have diverse perspectives, voices, and experiences.
- **Promote cultural bias** if algorithms are not developed carefully to consider linguistic diversity and cultural norms, among other factors.
- **Increase cancer disparities** if not made equitably accessible to all populations as well as to all health care systems, including public hospitals.



**LIQUID BIOPSY** is a test that can detect cancers from a variety of materials (such as cells and small pieces of DNA, RNA, or proteins), shed by precancerous lesions and tumors, in blood, urine, or other body fluids.

### Promise of Liquid Biopsy

#### LIQUID BIOPSY TESTS CAN HELP...

- **Detect multiple cancers** early and simultaneously.
- **Reduce potential harms** associated with a medical procedure, because these tests are minimally invasive.
- **Overcome certain structural barriers**, such as geographic accessibility, because they do not require large-scale infrastructure and can be performed at a nearby clinic.
- **Inform** treatment decisions, because they can be used to quickly determine patient's response to a treatment regimen.
- **Monitor if cancer has returned** in patients who have already received cancer treatment.

### Potential Drawbacks

#### LIQUID BIOPSY TESTS MAY...

- **Lead to higher rates of false positive findings and unnecessary follow-up procedures** when used to detect multiple cancers. Follow-up procedures can be costly and invasive with their own side effects, and may increase anxiety for patients and strain for health care systems.
- **Not capture tumor heterogeneity fully**, potentially leading to incomplete or inaccurate representation of the tumor's genomic landscape.
- **Not yield the same benefits for all populations** if racial and ethnic minority populations are not well represented in the research leading to the development of such tests.
- **Be out of reach for many minoritized and medically underserved populations** because of costs and access.



**DIGITAL HEALTH** is a broad multidisciplinary area that involves the use of information technology, digital tools, and electronic platforms to improve the delivery of health care services and to enhance patient care and health outcomes. The nearly ubiquitous access to cell phones further highlights digital health intervention as a viable communication tool.

### Promise of Digital Health

#### DIGITAL HEALTH CAN HELP...

- **Overcome structural barriers** to accessing health care.
- **Monitor and manage symptoms** remotely.
- **Increase diversity** in clinical trials.

### Potential Drawbacks

#### DIGITAL HEALTH MAY...

- **Not be accessible** to all populations equitably.
- **Exacerbate disparities** in health and digital literacy.
- **Perpetuate biases** in clinical decision-making.

As with any technological innovations, these approaches also carry potential drawbacks and may exacerbate cancer disparities if not implemented with caution and care.

Many patients with cancer, especially those belonging to racial and ethnic minority populations and medically underserved groups, experience food insecurity, which is the condition of not having access to sufficient food or food of an adequate quality, to meet a person's basic needs (153). There are several programs and initiatives to address food insecurity among patients with cancer. The FOOD (Food to Overcome Outcome Disparities) program, launched in 2011 by a New York City comprehensive cancer center, is one such example (154). The FOOD program is a network of food pantries, coupled with cancer nutrition education and food navigators, that are embedded in 15 safety net hospitals and comprehensive cancer center clinics throughout the Greater New York metropolitan area. Once a patient with cancer is identified to have food insecurity, the FOOD pantries provide groceries with enough food for 10 meals for one person. A randomized controlled trial comparing FOOD interventions found that food insecurity among patients with cancer who participated in the program decreased significantly at 6 months of study enrollment (155). As another example of initiatives to address challenges faced by medically underserved populations, the Louisiana Department of Health and Louisiana Housing Authority partnered to provide a Permanent Supportive Housing program to Medicaid beneficiaries in an effort to prevent and reduce homelessness. Preliminary analysis reveals a 24 percent reduction in Medicaid costs and a significant reduction in hospitalization and emergency department utilization (156).

The federal government has implemented multiple programs providing stable and safe housing, nutrition and food access, social and economic mobility, and social services programs (157,158). Because of the scale of population-level interventions, additional research and routine evaluation of the implemented programs are necessary to fully understand the impact of such efforts on addressing cancer disparities.

## Research-focused Approaches

Approaches focused on understanding and addressing SDOH can help improve health outcomes and prevent disease in the long term. NIH, NCI, CDC, and cancer-focused organizations are collaborating with each other and with institutes across the nation to research, develop, and implement interventions that are meaningful to the communities they are serving. At NIH, the National Institute of Minority Health and Health Disparities (NIMHD) is leading research efforts to improve minority health and reduce health disparities. For example, NIMHD has partnered with NCI to launch the RESPOND (Research on Prostate Cancer in African American Men: Defining the Roles of Genetics, Tumor Markers, and Social Stress) study, one of the largest efforts to identify the environmental and genetic factors related to disproportionately high diagnoses of aggressive prostate cancer in Black men (159). The initiative has funded a national network of prostate cancer researchers

across 13 institutes to recruit over 12,000 Black men who were recently diagnosed with prostate cancer, with the aim to collect both biological and nonbiological information that will help researchers understand and address factors that contribute to the disproportional diagnosis of aggressive prostate cancer in Black men.

Similarly, NIH, NCI, and other constituents in the cancer care community have launched several research efforts to understand and address cancer disparities. Some examples include the NCI-funded Multiethnic Cohort Study, an epidemiological study that follows over 215,000 residents of Hawai'i and Los Angeles for development of cancer and other chronic diseases (160); the Southern Community Cohort Study, also funded by NCI, to understand the root causes of cancer disparities (161); and the Black Women's Health Study, to understand causes of chronic diseases, including breast cancer, among Black women (162) (see **Sidebar 15**, p. 64). One of NIH's major initiatives addressing cancer disparities is the *All of Us* Research Program (163). The program aims to gather health data, such as genetic information, electronic health records, lifestyle factors, and environmental exposures, from one million or more people for creating a diverse and representative research cohort that reflects the demographic, socioeconomic, and geographic diversity of the US population. As of February 2024, the program has recruited more than 763,000 participants, more than 80 percent of whom are underrepresented in biomedical research and about 45 percent are from racial and ethnic minorities (164). The program provides a template to initiate similar approaches focused on collecting cancer data for research purposes.

The number of **NCI-funded research grants focused on food insecurity, housing instability, or transportation-related barriers** among individuals

diagnosed with cancer **increased from 1 in 2010 to 7 in 2021**, underscoring the importance of addressing SDOH (165).



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NCI also plays a pivotal role in funding institute-level initiatives aimed to help reduce cancer disparities. The NCI Center to Reduce Cancer Health Disparities (CRCHD) plays an essential role in training a diverse cancer research and care workforce through a myriad of highly effective initiatives and programs (see **Overcoming Cancer Disparities Through Diversity in Cancer Training and Workforce**, p. 145). The NCI Community Oncology Research Program (NCORP) is another example of NCI's efforts to reduce disparities. NCORP brings cancer research studies and results to patients in their own communities across the United States. This

cross-institutional program focuses on increasing clinical trial participation, addressing social drivers of disparities, and evaluating differential outcomes in racially and ethnically minoritized populations and medically underserved groups (166). The program reported in 2020 that the proportion of racial and ethnic minority patients in NCI-funded clinical trials nearly doubled from 14 percent in 1999 to 25 percent in 2019 (167). Currently, the NCORP network includes seven research sites that develop and coordinate clinical studies and cancer care research for 32 community sites, as well as for 14 community sites that serve racial and ethnic minorities and medically underserved populations, to bring NCI-approved clinical studies to more than 1,000 locations at diverse, community-based hospitals and private practices across the United States (166).

Many of CDC's programs and initiatives are also focused on reducing racial and ethnic health disparities (see **Sidebar 46**, p. 159). For example, Racial and Ethnic Approaches to Community Health (REACH) is a national program that provides funds to state and local health departments, tribes, universities, and community-based organizations to build strong partnerships to guide and support the program's mission to reduce health disparities (168). As one example, in December 2023, the program awarded funds to the American Indian Cancer Foundation to improve health and prevent chronic diseases, including cancer, through encouraging healthy food choices, promoting safe and accessible physical activity, and implementing tobacco prevention and control policies in Native communities residing in Oklahoma (169).

It is well known that suboptimal recruitment of underrepresented populations in cancer research is a pervasive challenge that perpetuates disparities (see **Disparities in Cancer Clinical Trial Participation**, p. 97). To address this challenge, six institutions across the United States formed the Alliance to Advance Patient-Centered Cancer Care (AAPCCC). Each site identified opportunities within their cancer programs to increase their reach to underrepresented populations that ranged from racially and ethnically minoritized groups to rural residents. Member sites implemented four evidence-based interventions: patient navigation; culturally tailored community outreach; digital health; and addressing social needs, such as transportation insecurity. Preliminary findings from the collaborative showed an overall 38 percent recruitment of patients who were reflective of the diversity of the population the member sites intended to reach (170).

Research-focused approaches highlighted here are select examples of the ways constituents across the cancer care continuum are collaborating to accelerate progress against cancer disparities. There are many more initiatives at the levels of federal agencies, cancer centers, and other cancer-focused organizations, all with the ultimate goal to eliminate cancer disparities and achieve health equity.

## Community-focused Approaches

A community provides support and a sense of belonging during difficult times. Research has shown that individuals living in supportive communities experience improved mental and physical health (171,172). Furthermore, community engagement is a way to establish trust with health care providers and reach racial and ethnic minority populations and medically underserved populations. Community-based involvement may enhance healthy behaviors, increase adherence to cancer screening, encourage participation in clinical trials, and improve the receipt of treatment (173,174).

In the United States, numerous efforts have prioritized community-focused approaches to address health disparities. As one example, the Community Preventive Services Task Force (CPSTF), established by the US HHS department in 1996, develops evidence-based guidance for community-level interventions to promote health and prevent disease. Based on the available evidence, CPSTF recommended in the *2022 Annual Report to Congress* that patient navigation services should be provided to medically underserved communities to increase cancer screening (175). Considering the importance of engaging the community to improve health, NCI requires that community outreach and engagement spans all aspects of an NCI-designated Comprehensive Cancer Center's programs, including basic, clinical, translational, and population research (176).

Researchers are developing innovative ways to connect scientists with community members to inform and involve the general population in clinical research. Florida-California Cancer Research, Education and Engagement (CaRE2) Health Equity Center is one such program (177). The program, which encompasses three institutes located on the US East and West coasts, is designed to eliminate cancer disparities in Black and Hispanic populations living in California and Florida. The program, conducted virtually over 13 weeks, provides educational materials in English and Spanish for participants to learn more about prostate, lung, and pancreas cancers. A recent report from the program shows that the knowledge among participants about breast and prostate cancers substantially increased at the end of the 13-week course (177).

CDC also funds partnerships among constituents to increase community engagement in developing comprehensive cancer control strategies—state-level roadmaps to identify regional needs to reduce cancer burden and increase health equity. As one example, the Illinois Department of Public Health, with funding from CDC, partnered with its statewide coalition, the Illinois Cancer Partnership, to develop the 2022–2027 Illinois Comprehensive Cancer Control Plan. The partnership convened town halls and focus groups of diverse participants that included cancer survivors, caregivers, racial and ethnic minority groups, and rural residents. Based on feedback from participants, the partnership developed the 2022–2027 Illinois Comprehensive Cancer Control Plan, which was passed by the Illinois state legislature in March 2022 (178).

Community engagement plays an important role in addressing cancer disparities by engaging medically underserved communities in designing, implementing, and evaluating initiatives and interventions to address their cancer care needs (173). As one example, a systematic review and meta-analysis of 10 clinical trials revealed that interventions led by community health workers doubled the participation of all racial and ethnic groups in colorectal cancer screening programs compared to those receiving no interventions (179). Similarly, two systematic reviews of thousands of studies have found that interventions involving

patient navigation, especially those that are culturally tailored, significantly increase racial and ethnic minority patient engagement across the cancer care continuum and improve health outcomes (180,181).

Current evidence shows that community-level approaches not only increase engagement and participation of racial and ethnic minority populations and medically underserved groups in efforts to reduce cancer burden but also build trust in health care systems, inspire advocacy and policy changes, and develop long-lasting partnerships, all of which reduce cancer disparities.



# Understanding Cancer Development in the Context of Cancer Disparities

## IN THIS SECTION, YOU WILL LEARN:

- Cancer is a collection of diseases characterized by uncontrolled cell multiplication.
- Alterations both within a cell and its surrounding environment contribute to cancer initiation and progression.
- An important part of the cancer care decision-making process and the foundation of precision medicine is the identification of alterations in DNA, RNA, and proteins that drive cancer.
- There are ancestry-related differences in cancer-driving cellular and molecular alterations.
- The majority of currently available information on cancer development is based on studies of individuals that are of European ancestry. Researchers are addressing this challenge through ongoing efforts to increase racial, ethnic, and ancestral diversity in cancer biology research studies.
- The biological differences among cancers in patients of different ancestries could provide novel targets for therapies and improve precision medicine.

Decades of medical research have provided great insights into the underpinnings of cancer development. Knowledge gleaned from this research shows that cancer is not a single disease but a collection of diseases that arise when the processes that control normal cell growth, division, and life span go awry. As a result, cells start multiplying uncontrollably, fail to die when they should, and mobilize other cells and tissues, such as blood vessels and immune cells, all of which gives abnormal cells a growth advantage. In organs and tissues, the accumulating cancer cells form masses called tumors, whereas in the blood or bone marrow they crowd out normal cells.

During cancer development, abnormal or damaged cells acquire so-called “hallmarks” or characteristics that distinguish cancer cells from non-cancerous cells. Some of the hallmarks of cancer cells include their ability to multiply limitlessly by ignoring signals that tell normal cells to stop dividing or to die; sustain rapid growth by relying on nutrients that are different from those used by normal cells; accumulate multiple changes in their genetic material; evade the immune system responsible for eliminating abnormal or damaged cells; recruit blood vessels, thus increasing nutrients and oxygen supply to tumors; and leave the tissue of origin and spread to other tissues (182). Cancer that has spread to other parts of the body, which is called metastatic disease, is the main cause of most cancer-related deaths.

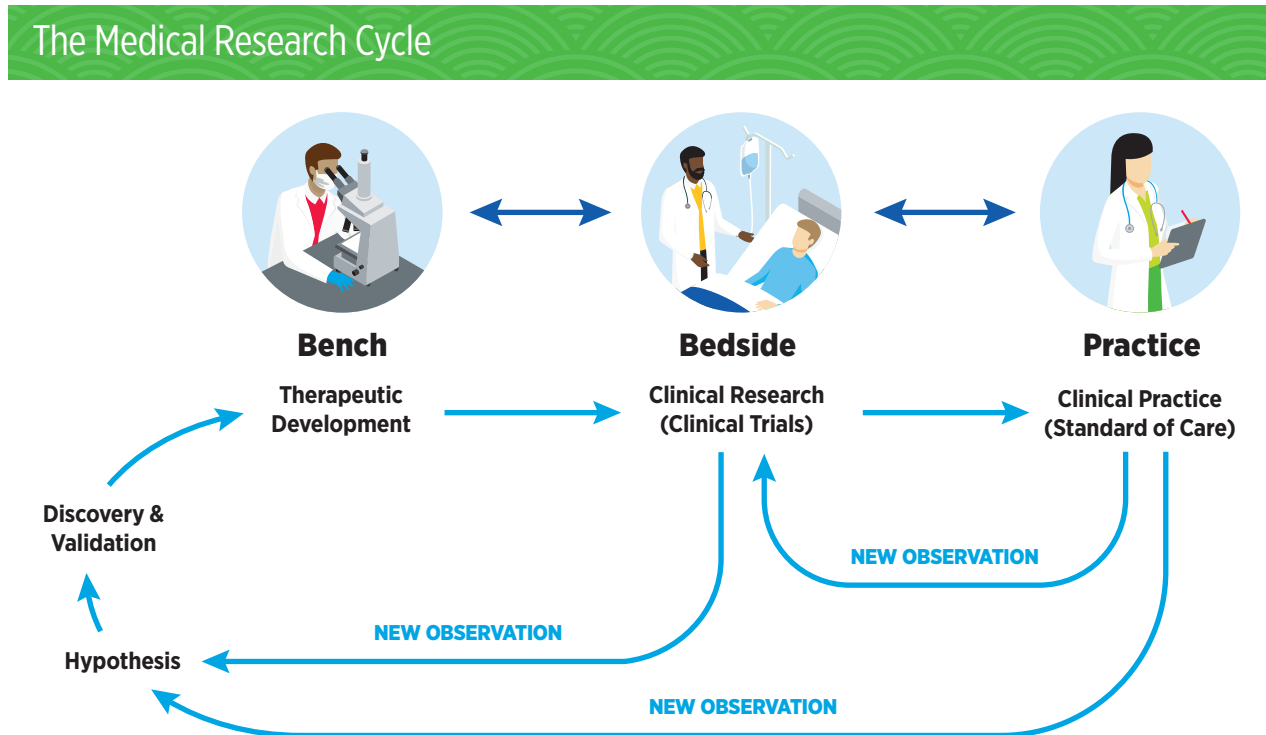
It is important to note that there are many factors, from biological to environmental to behavioral, that influence

cancer development. In the United States, centuries of systemic inequities and injustices have led to racial and ethnic minority groups and medically underserved populations being exposed to adverse social and built environmental factors, collectively referred to as structural and social drivers of health (SDOH), that contribute to the observed disparities in cancer burden among these population groups (see **Figure 3**, p. 37). Adverse differences in SDOH can contribute to a higher cancer burden both indirectly, for example, by impeding health care access and promoting poorer health habits such as smoking and alcohol consumption, and directly through complex biological interplay that is still not fully understood but includes epigenetic modifications (see **Epigenetic Changes**, p. 59), chronic inflammation, and altered metabolism (183).

## Cancer Development: Generating Knowledge

Medical research is the backbone of progress against cancer because it is the driving force behind every breakthrough that enhances survival and quality of life, and every new policy or program designed to improve public health. Discoveries across the major areas of cancer research, including basic, clinical, translational, and population sciences, provide the foundation for advances in cancer prevention, detection, diagnosis, treatment, and survivorship.

FIGURE 4



The medical research cycle is an iterative and self-driven process with a primary goal to save and improve lives. Findings from any type of research can lead to new questions and generate new hypotheses relevant to the practice of medicine. The discovery phase of the medical research cycle uncovers new targets for developing better and more effective treatments. Potential therapeutics first undergo preclinical testing to identify any harmful effects and determine initial dosing. The safety and efficacy of potential therapeutics are then tested in clinical trials. If an agent is safe for the patient and effective against the type of cancer for which it is designed, it is approved for use in the clinic by the US Food and Drug Administration (FDA). Importantly, observations made during the routine use of a new therapeutic can further improve its use or inform the development of others like it. Even for therapeutics that are not approved by FDA, the observations from preclinical and/or clinical testing can spur future research efforts.

Adapted from (1).

Much of the current knowledge of how cancer develops comes from basic research. Discoveries stemming from decades of basic research and population sciences have provided the foundational knowledge to drive preventive interventions and clinical breakthroughs, which have contributed to a 33 percent reduction in the overall US cancer mortality rate over the past three decades (38).

In the discovery phase of medical research (see **Figure 4**, p. 53), hypotheses generated through basic research from observations with medical relevance are tested in experiments performed using cell- and animal-based models that attempt to mimic healthy and disease conditions, such as cancer. Cancer research uses models that mimic specific characteristics of cancer (e.g., increased cell growth) or types of cancer (e.g., breast cancer). A major challenge in cancer research, and one of the main barriers to studying cancer disparities, has been the historical lack of representation of biospecimens from medically underserved populations among basic research models (see **Sidebar 11**, p. 54).

Cancer disparities among racial and ethnic minority groups are driven by complex interactions between adverse influences of SDOH (see **Figure 3**, p. 37) and genetic and epigenetic differences that may be attributable to ancestral differences between populations. Unfortunately, due to the convenience of researchers, most established cancer cell lines—models that have provided much of the fundamental knowledge of the underpinnings of cancer initiation and progression (see **Sidebar 11**, p. 54)—have been derived from patients with European ancestry (184,185).

Lack of diversity in genetic ancestry and/or lack of racial and ethnic representation while building research models and biorepositories leads to the generation of data that do not apply to all populations, thereby minimizing the applicability of research results. Diversity and inclusion in cancer research models is especially vital when investigating diseases that disproportionately impact patients from certain racial and ethnic minority groups and medically underserved populations. It is imperative that

**SIDEBAR 11**

# Lack of Diversity in Basic Research Models

To understand the biological underpinnings of a disease, researchers use a variety of models to mimic what happens in healthy and disease conditions.

**Below are some of the most commonly used models in cancer research.**

**CELL LINES** are cancer cells derived from different types of tumors and can be grown continuously in the laboratory.



**TISSUES** are entire pieces of cancerous or healthy biospecimens obtained from humans or animals through biopsies or surgery.



**PRIMARY CELLS** are cells that are obtained directly from healthy or cancerous tissues of either human or animal origin.



Many different **ANIMAL MODELS** are used in cancer research. Mice are the most commonly used models.



**ORGANOIDS** are engineered three-dimensional (3-D) structures generated from healthy or diseased components, which resemble an organ in cellular composition and organization.



**PATIENT-DERIVED XENOGRAPHS (PDX)** are generated by transplanting pieces of a patient's tumor into mice. A large number of therapeutics can then be tested for their ability to destroy the patient's tumor in mice before they are given to the patient.



**Historically, a major challenge in cancer science has been the lack of inclusion of biospecimens from racial and ethnic minority groups and other medically underserved populations in the research models. For example:**

Well-established cellular panels, such as the NCI-60 cancer cell lines, that have been used extensively in cancer drug development are **derived mostly (95 percent) from non-Hispanic White patients** (184,185).

Analysis of more than 1,000 cancer cell lines in the Catalog of Somatic Mutations in Cancer (COSMIC) database found **that >68 percent of cell lines were from non-Latino White patients; only 5.5 percent were derived from patients with African ancestry** (184,185).

Black men experience the highest mortality from lung cancer in the United States (3). A recent review of currently available lung cancer cell lines found that **cells derived from Black patients were significantly underrepresented; additionally, there were no identifiable cell lines from Hispanic, American Indian or Alaska Native, or Native Hawaiian or Pacific Islander patients** (186).

**Nearly half of the samples** in an NCI patient-derived model repository, which includes xenografts, organoids, and tumor cell cultures, **lack data on race and ethnicity** while most of the rest are derived from self-identified White/European patients (185).

the medical research community work together to promote the development of more diverse cancer research models that represent the populations affected by the diseases.

To enhance our knowledge of the biological and genetic contributors to cancer disparities, additional resources are needed, including cancer models and biospecimens derived from patients representing a diverse array of racial and ethnic groups. In this regard, it should be noted that NCI has established the PDX (see **Sidebar 11**, p. 54) Development and Trial Centers Research Network to accelerate translational research using patient-derived xenograft (PDX) datasets, and two of the six PDX Development and Trial Centers focus exclusively on developing minority PDXs.

Investigating the effects of changing or editing, the genetic material of a cell is an important part of cancer research.

**CRISPR is a revolutionary tool for gene editing** that has emerged recently, and it is currently being used to identify new targets for cancer treatment (187).



**!** In a recent study, CRISPR-based technology **failed to identify potential cancer targets more often in cell lines derived from people of African ancestry** (188).

## SIDEBAR 12

## Genetic and Epigenetic Control of Cell Function

The genetic material of a cell comprises strings of **deoxyribonucleic acid (DNA)**, a complex molecule composed of four units called bases that are designated A, C, G, and T.

DNA bases are organized into **genes**. The order, or sequence, of the bases provides the code used by the cell to produce **messenger ribonucleic acid (mRNA)**, which subsequently is used by cells to generate the various proteins that cells need to function.

The entirety of a person's DNA is called the **genome**. Almost every cell in the body contains at least one copy of the genome. The genome is packaged together with proteins known as **histones** into structures called **chromosomes**.

Special molecules, called **epigenetic marks**, can tag DNA or attach to histones. The presence or absence of these marks determines whether a gene is accessible for reading. The sum of these marks across the entire genome is called the **epigenome**.

**The accessible genes within each cell are read by specialized molecular machinery to produce the proteins that ultimately define the function of the cell and the tissue in which the cell resides.**



Adapted from (189).

## Cancer Development: Interpreting Knowledge

Cancer is a genetic disease caused by changes in genes that control vital functions, such as cell multiplication and cell growth. However, transformation of noncancerous cells into cancer cells, accumulation of cancer cells to form tumors, and spread of tumors to distant sites in the body are all complex, multistep processes that are influenced by alterations inside the cell as well as changes outside the cell.

### Changes That Contribute to Cancer Initiation

Cells of the human body rely on instructions from genetic material known as deoxyribonucleic acid (DNA) to function. DNA is made up of four types of building blocks called bases, that are designated A, T, C, and G (see **Sidebar 12**, p. 55). Anywhere from 50 million to 250 million of these bases link together to form individual strands, with two strands of the same length paired together to form a double-stranded, helical structure; the paired strands are packaged together with proteins known as histones into structures called chromosomes. Each chromosome contains hundreds to thousands of genes, which are segments of DNA that contain the code for a protein, the functional unit of the cell.

To make a protein, a cell reads a gene from the DNA to make another type of molecule called messenger ribonucleic acid (mRNA) in a process called transcription. The cell can make many copies of mRNA from a single sequence of DNA, increasing the amount of message in the cell. The cells then “translate” the information in the mRNA into proteins; therefore, usually the more mRNA present, the more protein is made.

All humans share roughly 99.9 percent sequence similarity in their DNA, with only 0.1 percent being different from one human to another; yet this 0.1 percent encompasses millions of changes and is what makes each of us unique. Many of the genetic differences found in DNA across groups with different genetic ancestries are a result of human migration out of continental Africa roughly 100,000 years ago to neighboring continents (collectively termed the human diaspora). The subsequent adaptations to new climates, diseases, and environments shaped human genetics, which results in the human diversity we see today (190).

Biological traits that arise from genetic differences can be positive, such as adaptation to unfavorable climates and altitudes, tolerance of particular food sources, or resistance to infections with parasites. However, genetic differences can also predispose certain population groups to genetic diseases like cancer. Recent migrations (forced or intentional) have led to genetic mixture of ancestral groups among most minority populations in the United States. The differences in genetic composition that result from this mixing are what make



measurements of ancestry important in cancer studies in human populations.

In the following sections, we describe the cellular and molecular alterations that lead to cancer initiation and progression. We also highlight some of the known ancestry-related differences in such alterations. It should be emphasized that US racial categories are sociopolitical constructs and the racial or ethnic disparities in cancer burden are driven largely by decades of systemic and structural inequities that directly and/or indirectly impact human biology and population health. However, the greater prevalence of advanced-stage disease and more aggressive cancers in certain population groups may indicate factors beyond socioeconomic and structural differences. The interactions of inherent genetic ancestry with environmental influences, such as systemic racism and SDOH, and the relative contributions of each on driving cancer disparities is an area of extensive research.

In a recent report outlining **a new framework for the use of population descriptors in genomic research**, the National Academies of Sciences, Engineering, and Medicine recommends:

**RESEARCHERS SHOULD NOT USE RACE AS A PROXY FOR HUMAN GENETIC VARIATION.**

In particular, researchers **should not assign genetic ancestry group labels** to individuals or sets of individuals **based on their race, whether self-identified or not** (191).

W18

## Genetic Alterations

Alterations in the DNA sequence, referred to as mutations, can disrupt or modify normal protein function and are among the hallmarks of cancer cells. Genetic alterations can change the sequence or amount of mRNA and the resulting protein that is produced, which in turn can contribute to cancer development (see **Sidebar 13**, p. 57). Genetic alterations can be inherited (called germline mutations) or acquired during a person's lifetime (called somatic mutations). In about 10 percent of cancer cases, the mutations are inherited.

To identify genetic alterations in cancer and other diseases, a patient's genome must be compared against the human reference genome. Unfortunately, the original reference genome that was used by researchers lacked the genetic diversity that naturally exists among different populations because it was derived from a very small pool of individuals, mostly of European ancestry. Therefore, a major advance in the field of genomic medicine has been the recent release of the updated human reference pangenome, which is built from a more diverse cohort of individuals (192).

Germline mutations are passed on from parents to children and become incorporated into the DNA of every cell in the body of the offspring and increase their risk of developing cancer. Not all germline mutations contribute to cancer development. Inherited genetic alterations that play a role in cancer development are among the pathogenic germline mutations.

Much of the research on pathogenic germline mutations has been conducted in individuals of European ancestry, limiting our understanding of many identified pathogenic variants in patients of other ancestries. Because of limited information from racial and ethnic minority individuals, there is often insufficient evidence to determine with confidence whether a mutation is truly cancer causing, and these mutations are often categorized as variants of undetermined significance (VUS). Consequently, genetic counseling for racial and ethnic minority individuals becomes less precise and less informative than it is for those of European ancestry. There is an urgent need to increase research on examining differences in inherited genetic alterations in people from different ancestral backgrounds because these differences can inform early detection, surveillance, and treatment decisions.

Thanks to a sharper focus on the science of cancer disparities over the past decade, along with rapid advances in technology, such as sophisticated DNA and RNA sequencing methods, we are beginning to understand ancestry-related differences in pathogenic germline mutations. African ancestry is a significant risk factor for prostate cancer, with mortality rates for patients across sub-Saharan Africa being nearly three-fold higher than global averages (193). In the United States, Black patients have disproportionately higher prostate cancer incidence and mortality compared to other racial and ethnic groups. Emerging data suggest that germline mutations may contribute to the increased prostate cancer risk among Black men and that prostate cancers from Black men exhibit higher rates of pathogenic germline mutations in *BRCA1* genes (183).

**Genetic markers are DNA sequences with a known location on a chromosome** and can be used to identify genetic ancestry. Specific markers are also strongly associated with cancer risk.

- One such marker resides on human chromosome 8 and is known as 8q24. **Individuals who carry specific genetic patterns at 8q24 have an increased risk of developing prostate cancer.**
- Research has shown that **the 8q24 marker is enriched in sub-Saharan Africa**, is indicative of African ancestry, and may, at least in part, be responsible for the prostate cancer disparities in African American men (183).



W19

## SIDEBAR 13

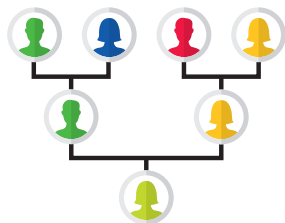
## Genetic Alterations

Genetic alterations or mutations are changes in the DNA sequence. While not all genetic alterations cause cancer, many can result in changes in the sequence or amount of mRNA and/or proteins produced, some of which can drive or contribute to cancer development. Genetic alterations are one of the hallmarks of cancer cells.

## How Are Genetic Alterations Acquired?

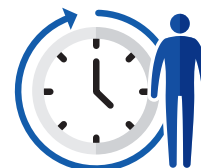
Cells can acquire genetic alterations in several ways, including:

## BY INHERITANCE FROM PARENTS



## DURING A PERSON'S LIFETIME

- From errors made during cell division.
- From exposure to modifiable cancer risk factors, for instance, toxicants in tobacco smoke or infectious pathogens that alter normal cellular machinery, such as human papillomavirus or *Helicobacter pylori* bacteria.
- Because of chronic medical conditions that are associated with inflammation, such as diabetes or Crohn's disease.



## What Types of Genetic Alterations Contribute to Cancer Development?

**SINGLE BASE CHANGES** refer to deletion, insertion, or substitution of a single base (designated A, T, G, C) in DNA that can result in new proteins, altered versions of normal proteins, loss of protein function, or changed amount of the protein produced, all of which can contribute to cancer.



**STRUCTURAL VARIATIONS** arise when two separate genes or pieces of chromosomes join to produce a new protein or a different amount of protein, thus contributing to cancer.



**GENE AMPLIFICATION** reflects extra copies of genes in the genome, causing higher quantities of certain proteins that can enhance cell survival and growth, thus contributing to cancer.



**DELETIONS** indicate loss of DNA, which can result in the loss of genes necessary to regulate the processes that control normal cell growth, multiplication, and life span, thus contributing to cancer.

**EPIGENOME-ALTERING MUTATIONS**

involve proteins that read, write, or erase epigenetic marks on DNA or histones. Mutations in the genes that produce these proteins can lead to cancer by altering the coordinated activation or silencing of genes needed to control cell growth and division processes.



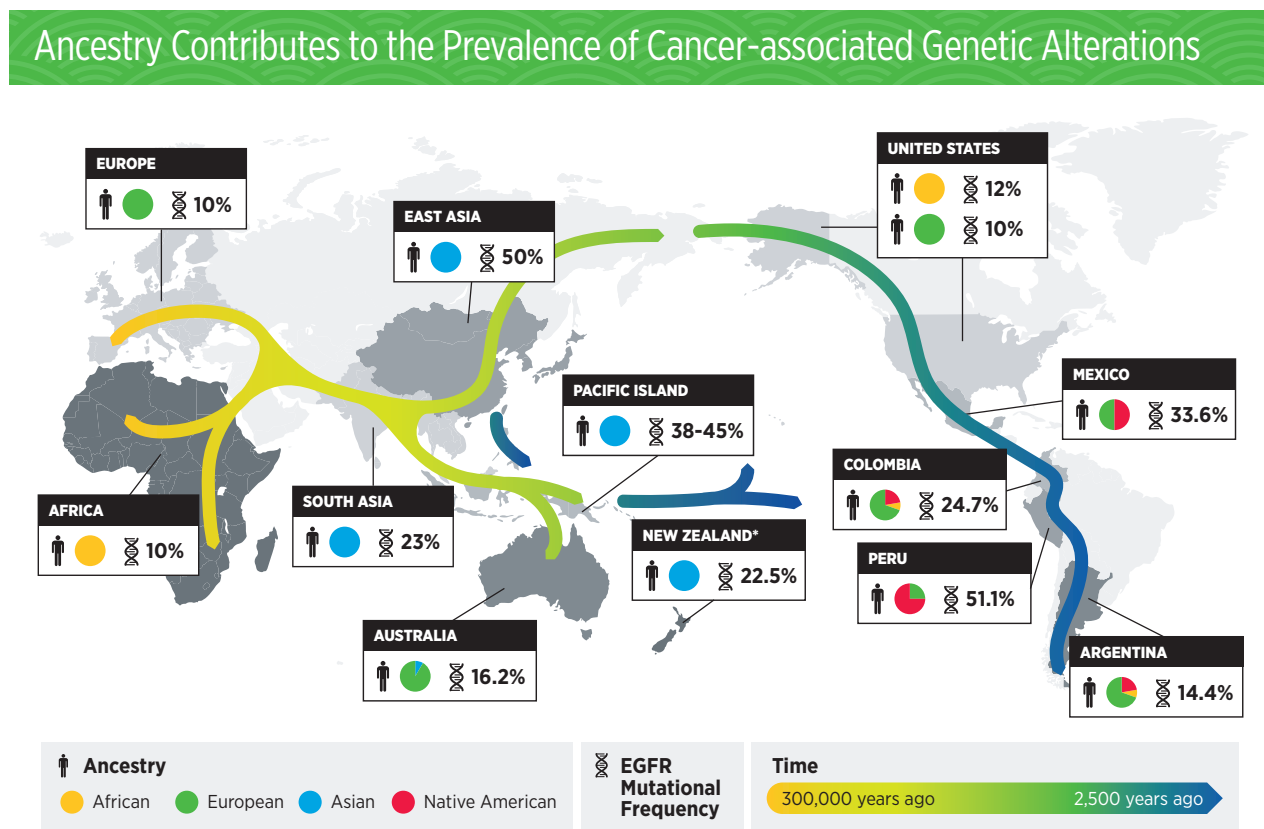
Adapted from (1).

Black women in the United States have a 40 percent higher mortality from breast cancer, attributable in part to advanced stage at diagnosis and more aggressive tumors such as the triple-negative subtype, a particularly intractable form of breast cancer. Studies show that breast cancer patients with West African ancestry have a higher prevalence of pathogenic mutations in *BRCA1* or *BRCA2* compared to women from Western Europe; the rate is even higher among patients from the Bahamas (194). Among women with endometrial cancer and epithelial ovarian cancer, higher rates of germline pathogenic mutations are found in patients from Ashkenazi Jewish ancestry compared to those with European ancestry (138,195). Hispanic children, adolescents, and young adults have a higher risk of acute lymphoblastic leukemia (ALL) compared to other US racial or

ethnic groups. Recent studies have identified a genetic alteration that is associated with Native American ancestry and increases the risk of childhood ALL. The genetic variant was detected among self-reported Hispanic/Latino individuals but not NH White individuals (196).

Somatic mutations or acquired genomic alterations occur over an individual's lifetime because of internal errors arising during cell multiplication or because of external influences such as environmental exposures and lifestyle factors (see **Disparities in the Burden of Preventable Cancer Risk Factors**, p. 66), or because of underlying health conditions such as Crohn's disease. Comprehensive analyses of cancer cell DNA have revealed numerous cancer-causing somatic mutations. The

**FIGURE 5**



\*This study exclusively profiled the EGFR mutational frequency in the native Māori population.

Somatic mutations of the *EGFR* gene are commonly observed in patients with lung cancer and represent a key target for molecularly targeted therapeutics. The overall mutational frequency of the *EGFR* gene differs based on ancestry of the patient with cancer, with the highest rates of mutation in East Asian groups (up to 50 percent) and the lowest rates observed in African (10 percent) and European (10 percent) populations. The frequency of this mutation follows patterns that are a result of the human diaspora out of Africa as well as more recent migration (forced or otherwise) of population groups to new geographic locations. For example, Peru has a high genetic admixture (i.e., inferring someone's geographic origins based on an analysis of their genetic ancestry) of Native American ancestry, while Argentina has more admixture of European ancestry (209).

Cancer Genome Atlas (TCGA), an initiative supported by NCI and the National Human Genome Research Institute, looked at the genetic content of about 11,000 tumors across 33 different cancer types. The data have provided a comprehensive map of the somatic mutational landscape across many cancer types.

Ancestry analysis of the TCGA samples has reported that only 9.8 percent of tumors are of African ancestry and only 0.4 percent are of Native or Latin American ancestry (184). The disparity becomes even more striking in certain cancer types, such as gastric cancer, which has a disproportionately higher burden among AI/AN, Asian, Black, Hispanic, and Native Hawaiian populations but for which data are underrepresented or completely lacking in TCGA (3,184,197). Additionally, lower-quality analysis of African ancestral samples, attributable to lower sequencing coverage—a metric that ensures reliability of DNA sequencing data—has led to underdetection of

mutations from these population groups, thereby deepening research gaps that perpetuate cancer disparities (198).

The evidence is mounting that there are considerable differences in somatic mutational profiles of most cancer types when comparing patients of different ancestries, with potential implications for therapeutic interventions (see **Figure 5**, p. 58) (137,199-202). As one example, a series of recent studies have interrogated the cancer genome in patients from diverse ancestries and compiled a comprehensive list of novel genetic mutations associated with prostate cancer risk, some with therapeutic implications, and the likelihood of aggressive disease among men of African ancestry (193,203-205). As another example, many recent reports indicate that there are unique somatic mutations among patients with early-onset colorectal cancers—colorectal cancer among individuals younger than 50 years—based on race, ethnicity, ancestry, and

geography (206-208). Notably, early-onset cancer incidence has been rising globally (35,36).

Encouragingly, these data highlight recent efforts among researchers to achieve equity in cancer genomics and ensure that benefits of precision medicine (see **Figure 6**, p. 63) are accessible to populations from all ancestral backgrounds. Another area of urgent need is to address the underrepresentation of rural patients in cancer genomic databases (210).

## RNA Variations

RNA is the transcript of the original genetic code embedded in the DNA and is used to make proteins, which are the molecules that perform important functions that dictate a cell's fate. Most human genes contain information for making proteins in fragments of DNA, called exons. Exons are interspersed by DNA sequences, called introns, that do not contain information necessary to make a functional protein. When a gene is transcribed into mRNA, the initial mRNA molecule contains a copy of both exons and introns. An intricate “cut and paste” process, called splicing, removes introns and joins exons together to produce an mRNA molecule that is subsequently translated into a functional protein by the cellular machinery. RNA splicing plays a pivotal role in maintaining normal cellular functions and aberration to normal splicing pathways can lead to cancer (211).

Ancestry-related differences in mRNA levels or processing in cancer have been demonstrated in many analyses (212,213). As one example, comparison of RNA data from patients with breast cancer versus healthy individuals of Asian and European ancestry led to the identification of new details of unique breast cancer risks across these population groups (214).

Of interest, research has shown that RNA may be spliced differently in people of different ancestry. One study found that the *PIK3CD-S* gene, which increases the aggressiveness of prostate cancer, was spliced differently in patients of African ancestry, compared to those of European ancestry. Researchers hypothesize that, because of this difference, response to common treatments targeted against the PIK3C protein may not be as effective in African American patients (215).

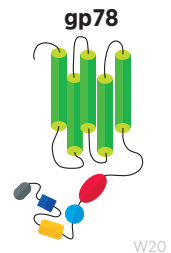
In contrast to mRNA, non-coding RNAs are a heterogeneous group of molecules that are not translated into proteins. Since their discovery, non-coding RNAs have emerged as important regulators of multiple biological functions across a range of cell types and tissues. Micro(mi)RNAs are one type of non-coding RNA that blocks the ability of mRNAs to be translated to proteins. Dysregulation of miRNAs has been implicated in cancer. Additionally, ancestry-related differences in miRNA levels and/or function that may contribute to cancer disparities have been identified (213,216,217). For example, recent studies indicate that ancestry-related differences in

the levels or function of miRNAs may mediate disparities in breast cancer survival and therapeutic outcomes among African American patients (218-220). Long non-coding RNAs are another type of non-coding RNA and their role in cancer as well as ancestry-associated expression in certain cancers are areas of active research (221).

## Protein Modifications

Proteins are vital for normal cellular functions. The human proteome—the complete set of proteins made by humans—contains about 20,000 unique proteins. After being produced from mRNA, proteins can undergo additional modifications, providing great versatility and variability in protein functions to meet cellular needs. Examining the proteome of cancer cells can unveil additional information about how cancer develops. For example, a recent study that evaluated proteomes of nearly 1,000 cancer cell lines identified common and unique cancer-related changes in levels of many proteins that were not detected at DNA or RNA levels (222).

The **protein gp78** is expressed at a higher level in breast cancers of women of African ancestry compared to those of European ancestry and **is predictive of tumor recurrence and poor survival in women of African ancestry** (223).



In the United States, NCI is playing a vital role in supporting research on proteomic alterations in cancer through the Clinical Proteomic Tumor Analysis Consortium (CPTAC) (224). CPTAC researchers are already generating data on how alterations in protein modifications play a role in cancer and discovering novel avenues for therapeutic intervention (225).

## Epigenetic Changes

DNA inside the cell's nucleus is tightly packaged around proteins called histones. Epigenetic alterations refer to modifications that do not involve a change in the DNA sequence. Epigenetic alterations occur when chemical marks are added to or removed from DNA or the histone proteins. Epigenetic modifications regulate how and when genes are turned on or off. Specialized proteins add or remove unique epigenetic modifications to and from DNA and histones (226). The complete set of all the epigenetic changes in a cell is called the epigenome. In contrast to genetic mutations, most epigenetic changes are reversible.

Epigenetic alterations are frequently observed in cancer cells. Because most epigenetic changes are reversible, they are



attractive targets for drug development. Cancer-associated epigenetic changes may be acquired with age and/or exposure to environmental factors (e.g., air pollution) or behavioral factors (e.g., cigarette smoking) or psychosocial stressors (e.g., systemic racism and discrimination) and may be passed from parent to child (227-229).

One area of research is ancestry-related epigenetic differences in tumors and how such differences may contribute to cancer disparities among different patient populations (230-232). There is increasing evidence suggesting that social and built environmental factors (such as redlining, segregation, or neighborhood deprivation) (see **Understanding and Addressing Drivers of Cancer Disparities**, p. 36) may drive cancer disparities through modulation of the tumor epigenome (233,234). For example, high neighborhood deprivation has been shown to be associated with epigenetic changes and differential gene expression in breast tumors among Black women (235). These alterations may lead to more aggressive tumors in Black women, highlighting the vital need for investments in public health interventions and policy changes at the neighborhood level.

## Systems That Enable Cancer Progression

A hallmark of cancer is the ability of tumor cells to break away from the primary tissue and travel to other parts of the body. Systems that enable cancer to spread from the primary tissue to other organs of the body include the circulatory system (blood and lymphatics) and the immune system. There is emerging evidence that cancer initiation or progression, as it becomes worse or spreads in the body, is also affected by the microbiome (microorganisms that live in our bodies).

### The Circulatory System

The blood and lymphatic systems form the roads and bridges that connect organs and tissues and help in the delivery of nutrients and oxygen and removal of waste such as dead cells or carbon dioxide. These circulatory networks are also the primary conduits for the process of cancer metastasis, whereby cancer cells leave their primary sites and form secondary tumors in distant organs. The ability to promote blood vessel formation toward and within a tumor is a hallmark of cancer. Because of the high demand of fuel and oxygen required to sustain the rapid growth of cancer cells, blood vessels connecting to tumors also grow quickly, making tumors highly vascularized. The degree to which tumors become vascularized can be an indicator of tumor aggressiveness and patient outcomes.

Interestingly, studies have shown increased vascularization in breast tumors of patients of African ancestry compared to those of European ancestry (236,237). In fact, a notable difference

between cancer patients of African and European ancestry is in the biology of tumor blood vessel formation (238).

### The Immune System

The immune system is composed of a variety of organs, tissues, cells, and molecules that work together to defend the body against external (virus, bacteria) and internal (cancer) threats. How the immune system responds to these threats depends on the types of exposures individuals encounter in their lifetime. Groups that share common ancestral history can also have comparable immune systems because of evolutionary shaping at both genetic and environmental levels. The immune cells found within a tumor can identify and eliminate cancer cells, although in many cases the immune system is suppressed, permitting the formation and progression of a tumor (239,240).

Recent studies have highlighted the role of circulating immune cells and proteins in cancer metastasis, potentially through protection of circulating tumor cells as well as the promotion of tumor cell implantation in distant sites (241). Understanding how and why immune systems in individuals from different ancestries are different can give us a better understanding of the biology of cancer disparities. Notably, the levels of immune molecules in the blood correlate with ancestry, suggesting a potential role in cancer disparities. Emerging data point to distinct ancestry-related immune and inflammatory markers in the circulation among patients with prostate cancer and lung cancer, among other diseases (241). Additionally, there is evidence that systemic inequities such as neighborhood deprivation can impact the immune system and may predispose African American men to aggressive prostate cancer (242).

Insights into the interplay between the immune system and cancer form the basis for developing immunotherapies, one of the most effective cancer treatment pillars available today; so far, immunotherapies have been approved to treat more than 20 different types of cancer (see **Figure 16**, p. 127). Despite this success, it must be noted that the development of immunotherapies has been primarily based on clinical samples from individuals of European ancestry, with limited data from minority populations. This is troubling, since immune function has been found to be different between different ancestral groups, indicating there cannot be a “one-size-fits-all” approach (see **Treatment With Molecularly Targeted Therapy and Immunotherapy**, p. 123) (239,240). Comprehensive analysis of the immune system of cancer patients from diverse racial and ethnic backgrounds is vital to develop precise interventions that are effective in these populations.

### The Microbiome

The human microbiome is the collection of all microorganisms (e.g., bacteria and fungi) and viruses that live in the gut,

skin, and mouth, among other sites in the body. Most microorganisms that make up the human microbiome are beneficial to our health, but some are potentially harmful. Accumulating evidence suggests that the balance between helpful and potentially harmful microorganisms in the gut microbiome contributes to overall health, and an imbalance can contribute to a number of diseases, including cancer (243). Research has also shown an association between a patient's microbial composition and their response to therapeutics, with implications that modulating the microbiome can boost the effectiveness of certain anticancer treatments such as immunotherapies (244).

The gut microbiome can be affected by SDOH, such as food insecurity, access to spaces for physical activity, and chronic stress, implying potential differences across racial and ethnic groups (245). The diversity of the gut microbiome within an individual and between different individuals, as well as the abundance of specific microbes within a person, could differ by race and ethnicity, and these differences may be relevant to cancer disparities (245). In fact, unique, race-specific associations of harmful microbes with colorectal cancer have been reported (245,246).

The microbiome in other sites in the body has also been associated with the risk of precancerous states or cancer. As one example, the interplay between vaginal microbiome and human papillomavirus (HPV) in cervical precancers and cancer development is an area of ongoing research (247,248). Emerging data suggest that the risk of cervical cancer associated with vaginal microbiome may differ by race (249). Future studies should examine whether early detection and manipulation of specific microbes may aid in cancer prevention or interception.

Research has shown that tumors themselves also harbor microorganisms and the type of microorganism present in tumors can predict health outcomes (250). Race-specific microbial associations have been identified in breast tumors with potential associations with genes involved in tumor aggressiveness, blood vessel formation, and metastasis (251).

Targeting the microbiome may hold promise for reducing racial and ethnic disparities in cancer. However, many outstanding questions remain before such interventions can become a part of routine clinical care (245,252). These include a better understanding of the influence of host genetics on the microbiome and vice versa, and how that interplay may lead to cancer development. Current and future

preclinical and clinical studies evaluating the microbiome as a driver of cancer and cancer disparities must recruit diverse participants and collect detailed data on SDOH to accurately ascertain the microbial contribution to cancer risk across races and ethnicities.

## Processes That Promote Cancer Progression

As cancer cells grow and divide, a mass of cells, or tumor, develops. The tumor is not just made up of cancer cells; rather, it is heterogeneous, and is made up of diverse cancerous and noncancerous cells. Research has shown that tumor progression and metastasis are largely dependent upon complex interactions between cancer cells and their surrounding tissue. Cancer metastasis refers to the spread of cancer cells from the tissue where they first originated to another part of the body. More than 90 percent of cancer-related deaths result from metastatic disease (254).

Researchers are continually uncovering complex processes that facilitate cancer metastasis. One area of investigation is the ancestry-related differences in inflammatory and immune biomarkers in the circulation and their contribution to disparities in cancer progression and treatment response.

## Tumor Heterogeneity

During the course of disease, as cancer cells divide, they continue to acquire new alterations in their genomes, epigenomes, transcriptomes, and proteomes in various combinations and become more heterogeneous. Researchers use the term “tumor heterogeneity” to describe the differences between cancer cells within a single tumor, the differences between tumors of the same type in different patients, or the differences between a primary (original) tumor and the metastatic tumor.

Tumor heterogeneity plays a crucial role in cancer development and influences how cancer spreads and how it responds to treatment. The heterogeneity of cancer cells in the primary tumor enables some tumor cells to acquire properties that facilitate their spread to other parts of the body. Tumor heterogeneity is also one of the major reasons for treatment resistance (255).

Evaluating ancestry-related differences in the genetic drivers of cancer and the differential patterns of cancer cell evolution over time is an area of ongoing research (256). For example, studies in gastrointestinal cancers such as stomach and liver cancer have aimed to characterize tumor heterogeneity and identify shared features of liver cancer across diverse populations to improve equitable utilization of precision cancer medicine (257,258). A recent report demonstrated population-specific patterns of tumor

**Race- and ethnicity-associated variation** in the human gut microbiome emerges **as early as 3 months of age** (253).



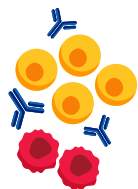
W21

## SIDEBAR 14

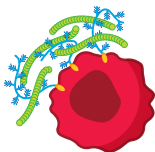
## Cancer Progression: Local and Systemic Influences

Solid tumors are much more complex than an isolated mass of proliferating cancer cells. Cancer initiation and progression are strongly influenced by interactions among cancer cells and numerous factors in their tissue environment known as the tumor microenvironment. Among the components of the tumor microenvironment are the following:

**Immune cells** can identify and eliminate cancer cells, although in many cases, the immune system is suppressed, permitting the formation and progression of a tumor. However, in some situations of chronic inflammation, the immune system can promote cancer development and progression.



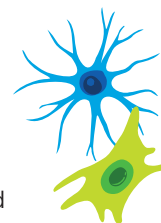
The **matrix of proteins** that surrounds the cancer cells can influence cancer formation, metastasis, and other processes.



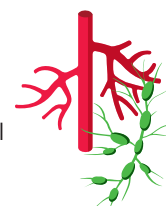
**Systemic factors** in the circulation, such as hormones and nutrients, influence the development and growth of cancer.



Other **tumor-associated cells**, such as pericytes, fibroblasts, and astrocytes, can support tumor growth through various mechanisms, including stimulating tumor cell multiplication, triggering formation of new blood vessels, and enhancing cancer cell survival.



Cancer cells can stimulate the growth of **blood and lymphatic vessel networks**, which supply the cancer cells with the nutrients and oxygen required for rapid growth and survival and provide a route for cancer cell escape to distant sites (metastasis).



A growing body of evidence suggests the presence of differential tumor microenvironment components among different racial and ethnic populations. These differences in the tumor microenvironment can put certain populations at a higher risk for developing more aggressive cancers and may affect clinical outcomes. A better understanding of differences in the tumor microenvironment is critical for novel therapeutic interventions to bridge the disparities in clinical outcomes for patients from different racial and ethnic groups.

Adapted from (89).

heterogeneity with a unique tumor mutational landscape among stomach cancer patients of Latino ancestry (258). The burden of stomach cancer is disproportionately higher among individuals of Latino ancestry, and the study found a higher frequency of a poor prognosis-associated molecular subtype in Latino patients.

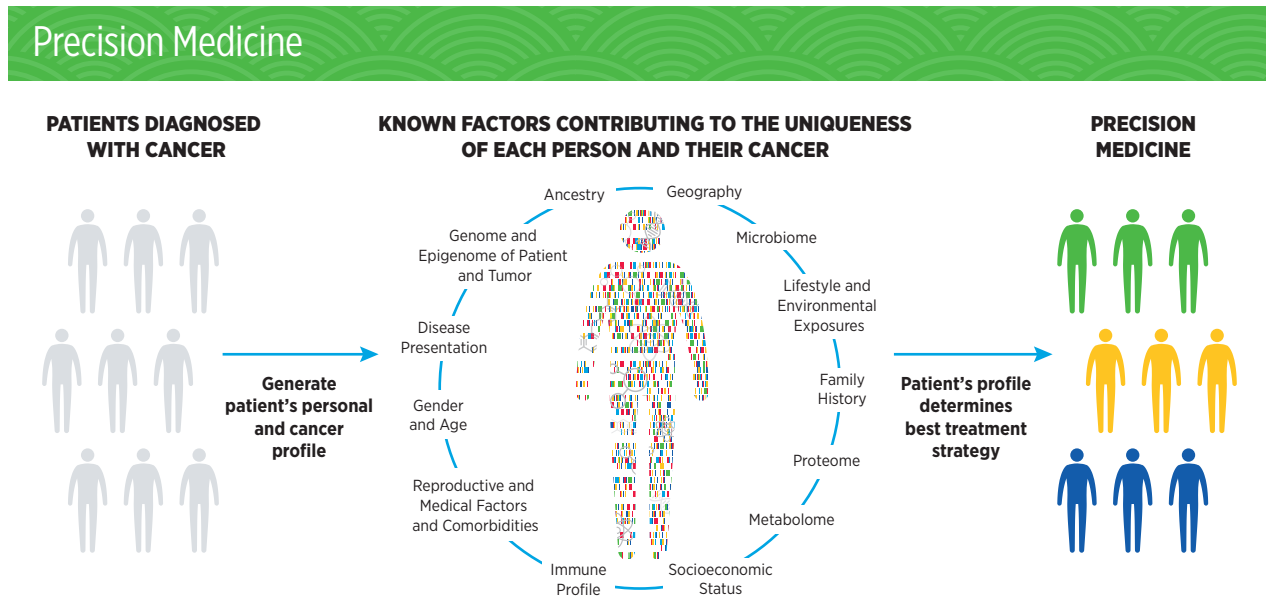
### Tumor Microenvironment

Research has shown that tumor initiation and progression are largely dependent upon complex interactions between cancer cells and the surrounding tissue, which is known as the tumor microenvironment (see **Sidebar 14**, p. 62). Bidirectional communication between cancer cells and the tumor microenvironment has a profound influence on cancer progression. Moreover, the tumor microenvironment can shelter cancer cells from the effects of some cancer treatments, including radiation, chemotherapy, and immunotherapy, thus modifying a patient's response to treatment (259,260).

Recent research suggests that several components of the tumor microenvironment could differ among different racial and ethnic patient populations (261-263). These differences may result from factors associated with inherited genetic ancestry, increased levels of chronic inflammation, innate differences in immune response, or a combination of these (264-266). As an example, several recent studies that have examined breast tumors have shown that patients of African ancestry have unique architecture and cellular composition within the tumor microenvironment (267,268). Additionally, a number of these studies reported a higher mobilization and greater abundance of immune cells within the breast tumor microenvironment in patients of African ancestry, albeit the cells exhibited an inactive or suppressed state indicative of a more aggressive disease (223,269,270).

A better understanding of how cancer cells and the tumor microenvironment—in particular, immune components—differ among diverse patient populations will help to better identify causes of cancer disparities, determine better treatment strategies such as immunotherapies, and provide information on how to eliminate cancer disparities.

FIGURE 6



Precision medicine, also called personalized medicine, is broadly defined as treating patients based on characteristics that distinguish them from other individuals with the same disease. As shown in the figure, the factors that contribute to the uniqueness of a patient and the patient's cancer include, but are not limited to, the person's inherited and tumor's genome, epigenome, transcriptome, proteome, microbiome, and metabolome, the immune characteristics of the person and the cancer, disease presentation, gender, ancestry, environmental exposures, lifestyle, and comorbidities.

Currently, genomics is the predominant factor influencing precision medicine, but as we learn more about the additional factors, such as epigenomics, tumor immune characteristics, microbiome, and so on, we have begun to integrate this knowledge to further refine the personalized approach to cancer treatment. Although genomic profiling of a patient and of the patient's tumor is becoming routine in the clinic, it is important to note that there are stark disparities in the utilization of these services with lower uptake among medically underserved populations (277).

## Epithelial-to-mesenchymal Transition

Epithelial cells tightly connect with each other to form the covering of all body surfaces and line body cavities and hollow organs. Roughly 90 percent of cancers develop in epithelial cells (271).

Cancers that develop in epithelial cells acquire properties of another type of cells, called mesenchymal cells, which form the connective tissue, blood vessels, and lymphatic tissue, and have the ability to migrate within the body. Cancer cells acquire the mesenchymal characteristic of moving within the body by hijacking pathways fundamental for epithelial-to-mesenchymal cell transition, or EMT, which is an essential process for the formation of organs during normal embryonic development (272). Hijacking of EMT pathways by cancer cells is one of the hallmarks of cancer. EMT plays a critical role in the ability of cancer cells to evade the immune system (273).

Recent studies have demonstrated ancestry-related differences in cellular and molecular pathways associated with EMT (274-276). Ongoing research is exploring whether therapeutically targeting EMT could improve clinical outcomes.

## Cancer Development: Integrating and Translating Our Knowledge

One of the most important insights gleaned from our current knowledge of the complexities underpinning cancer initiation and progression is that each patient's cancer is unique because of their distinct biological, lifestyle, environmental, and ancestral influences. The most effective cancer control efforts, therefore, must take a comprehensive look at multiple factors such as the person's inherited genome, the genome and epigenome of the cancer, family history, disease presentation, gender, exposures, lifestyle, microbiome, and other comorbidities and apply approaches tailored to each individual patient. In fact, in the past decade there has been a shift from a "one-size-fits-all" approach to cancer prevention, screening, and treatment to a more personalized approach called precision medicine (see **Figure 6**, p. 63).

The aim of precision medicine is to use information about an individual's biology as well as other factors to prevent, diagnose, and treat disease. Precision medicine has the potential to further revolutionize cancer care. While genomics is the predominant



## SIDEBAR 15

## Diversifying Cancer Data

Several ongoing efforts are underway to increase the inclusion of biospecimens from individuals of non-European ancestry and diversify cancer-related data. Selected examples of such efforts include the following:

### African Cancer Genome Registry

The African-Caribbean Cancer Consortium registry includes comprehensive lifestyle and behavioral data linked to banked biospecimens involving persons of African ancestry diagnosed with prostate or breast cancer. Participants are enrolled in the United States, the Caribbean, and Africa.

### Avanzando Caminos (Leading Pathways) Study

The Hispanic/Latino Cancer Survivorship Study is a 6-year observational study that will enroll 3,000 Hispanic/Latino cancer survivors in South Texas and South Florida.

### Black Women's Health Study (BWHS)

The study gathers information on many conditions that affect Black women such as breast cancer, lupus, premature birth, hypertension, colon cancer, diabetes, and uterine fibroids, among others. The BWHS is a follow-up study, which followed 59,000 women over time who enrolled in 1995.

### Cancer Prevention Project of Philadelphia

The project is a multi-ethnic registry of comprehensive epidemiological lifestyle and behavioral data linked to banked biospecimens involving persons of African ancestry with no known diagnosis of cancer. Participants are from Pennsylvania, New York, and New Jersey.

### International Registry for Men with Advanced Prostate Cancer (IRONMAN)

The registry collects information about a man's type of prostate cancer, its treatment, and side effects. This information will enable researchers to better understand the causes of prostate cancer, ways to stop or slow its progression, and how to provide the best possible care.

factor influencing current precision cancer medicine, researchers are rapidly accumulating data on additional cancer-associated measures, including immune, metabolic, microbial, and protein profiles, to better understand and tackle cancer. Furthermore, the role of additional biological factors, such as vitamins or lipids, that contribute to cancer development and may have ancestry-related differences is being identified (278,279).

### Multiethnic Cohort Study

The study consists of 215,000 men and women primarily of five ethnic groups (Non-Hispanic Whites, Japanese Americans, Native Hawaiians, African Americans, and Latinos) followed since 1993–1996. It is the most ethnically diverse epidemiologic study that investigates the roles of lifestyle, nutrition, genetics, and social drivers of health in cancer and other chronic diseases.



### Southern Community Cohort Study

The study is a unique ongoing prospective investigation tracking a population of approximately 85,000 adults, two-thirds African American, recruited in 12 Southern states to investigate various chronic disease outcomes, study disparities in cancer incidence and mortality, and disparities in the occurrence of other chronic diseases such as diabetes, hypertension, and heart disease.

### VOICES of Black Women

The study aims to understand how unique lived experiences of Black women impact their overall health and cancer risk. Participants provide health information, electronically, twice a year for at least 30 years. The goal of the study is to enroll at least 100,000 US Black women between 25 and 55 years.

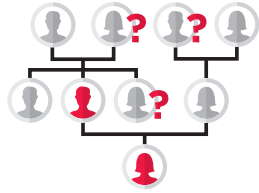
### Women's Circle of Health Study

The study aims to evaluate factors explaining the earlier age at diagnosis and the more aggressive nature of breast cancer among Black women compared to White women.

Unfortunately, much of the current information fueling precision medicine is derived from patients who are White and/or of European ancestry. Lack of relevant data from racial and ethnic minority groups and medically underserved populations, as well as a lack of diversity in cancer clinical studies undermines the true success of precision medicine. Collecting biospecimens from patients with different

sociodemographic backgrounds will create diverse datasets that researchers can use to better understand race-, ethnicity-, and ancestry-related differences in cancers. All constituents invested in public health must come together to ensure that institutions serving historically underserved populations and underresourced communities have the infrastructure, including access to advanced technologies such as the latest DNA and RNA sequencing techniques, that is needed for proper implementation of precision medicine.

Family health history including that of cancer can guide health care decisions for patients. However, information about **family history of cancer is either not available or is incomplete in patients from medically underserved populations** such as those who are Black, Hispanic, and Spanish speaking (280).



W22

Several private and federal initiatives are being undertaken to diversify cancer-related data (see **Sidebar 15**, p. 64). As one example, the AACR Project Genomics Evidence Neoplasia Information Exchange (GENIE) has sequenced tumors from over 172,000 patients across 19 leading cancer centers in the United States and Europe, nearly 12 percent of whom are from racial and ethnic minorities (281). Researchers are already using these databases to address gaps in knowledge about cancer biology and the genetic changes that occur specifically in underrepresented and underserved populations (282-284).

To advance the science of cancer disparities, it is imperative that researchers integrate biological data with structural and social drivers of health that contribute to cancer development and are known contributors to cancer disparities. In this regard it should be noted that the Research on Prostate Cancer in Men of African Ancestry: Defining the Roles of Genetics, Tumor Markers and Social Stress (RESPOND) is one such study that is looking at the underlying factors and reasons that put African American men at higher risk for prostate cancer. By using surveys and tumor characterization, RESPOND is evaluating how exposure to stress over a lifetime, inherited susceptibility (i.e., genes), and tumor characteristics contribute to the development of prostate cancer (285,286).

Precision medicine holds immense promise to deliver better outcomes with reduced toxicity for patients with cancer. However, many questions remain unanswered, such as the cost effectiveness of multidimensional profiling required for precision medicine, and the extent to which such profiling improves outcomes for individuals from diverse populations. Additionally, there are disparities in the access and utilization of these services, with lower uptake among racial and ethnic minority groups and underserved populations (see **Treatment With Molecularly Targeted Therapy and Immunotherapy**, p. 123) (277,287,288). It is vital that researchers across cancer science, medicine, and public health work together with policymakers to ensure that all patients with cancer can equitably benefit from the unprecedented breakthroughs being made in cancer care and that precision medicine approaches reduce and not further exacerbate cancer disparities.

# Disparities in the Burden of Preventable Cancer Risk Factors

## IN THIS SECTION, YOU WILL LEARN:

- In the United States, four out of 10 cancer cases are associated with modifiable risk factors.
- Decades of systemic inequities and social injustices have led to adverse differences in drivers of health causing a disproportionately higher burden of cancer risk factors among US racial and ethnic minority groups and medically underserved populations.
- Vaccinating against human papillomavirus and hepatitis B and not using tobacco are some of the most effective ways a person can prevent cancer from developing.
- Nearly 20 percent of US cancer diagnoses are estimated to be related to excess body weight, alcohol intake, unhealthy diet, and physical inactivity.
- Certain segments of the US population have higher than average exposure to occupational and environmental carcinogens, increasing their risk of cancer.

Research in basic, translational, and population sciences has broadened our understanding of the factors that increase an individual's risk of developing cancer. Modifiable risk factors, including tobacco use, poor diet, physical inactivity, ultraviolet (UV) light exposure, alcohol consumption, pathogenic infections, and obesity, contribute to the development of 40 percent of all cancers. Given that several of these risks can be avoided, such as eliminating tobacco use or receiving vaccinations against pathogenic infections, many cases of cancer could potentially be prevented (see **Figure 7**, p. 67). It is recognized, however, that some of these risk factors are less avoidable in some communities because of many structural barriers they face. Environmental risk factors, such as air pollution, water contamination, and naturally occurring radon gas, increase a person's risk for certain types of cancer, including common cancers like lung cancer. Furthermore, occupations such as firefighting and those involving night-shift work can expose individuals to factors that increase their risk of developing cancer.

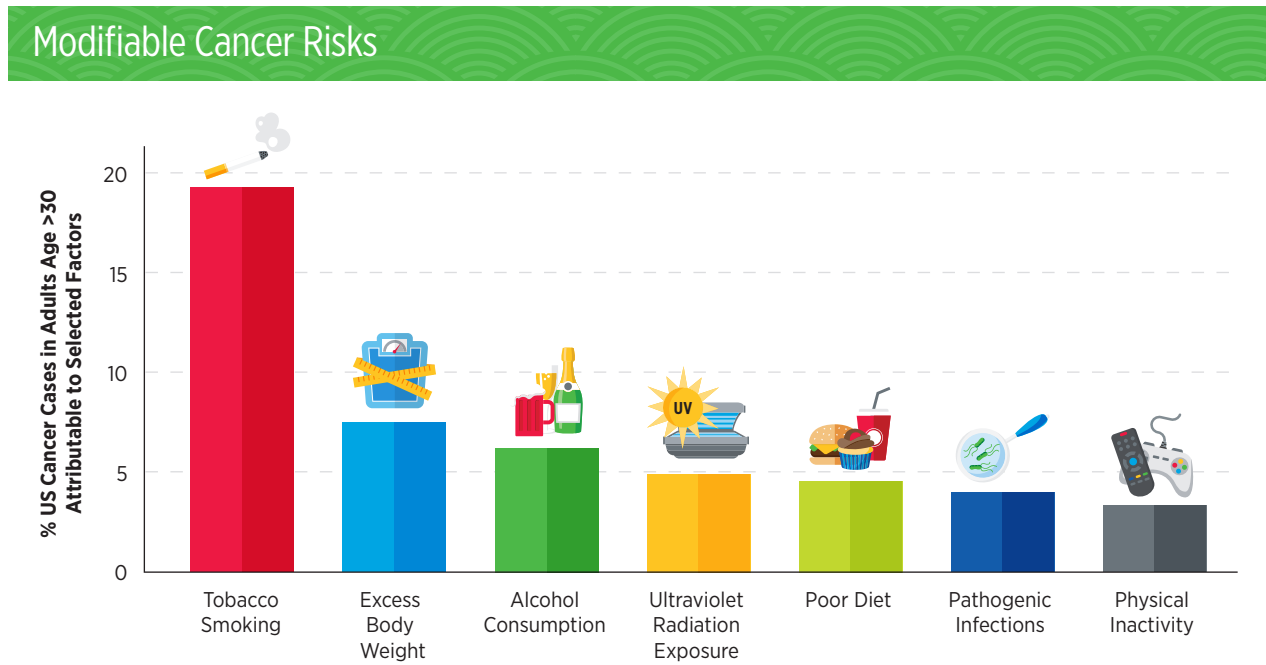
Emerging data indicate that certain cancer risk factors are also associated with worse outcomes after a cancer diagnosis, including development of secondary cancers. In addition, cancer risk factors contribute to other chronic diseases, such as cardiovascular and respiratory diseases and diabetes. Strategies that mitigate exposure to the wide range of avoidable cancer risk factors have the potential to reduce the burden of cancer and other debilitating conditions.

## Systemic Inequities and Social Injustices

Long-standing inequities in numerous social drivers of health (SDOH) (see **Understanding and Addressing Drivers of Cancer Disparities**, p. 36) contribute to significant disparities in the burden of preventable cancer risk factors among socially, economically, and geographically disadvantaged populations. These disparities stem from decades of structural, social, and institutional injustices, placing disadvantaged populations in unfavorable living environments and contributing to behaviors that increase cancer risk.

Public education and policies aimed at reducing the burden of cancer risk factors, such as tobacco cessation or physical activity-promoting interventions, are useful. For example, adherence to nutrition and physical activity guidelines led to a 28 percent to 42 percent reduction in the risk of obesity-related cancers in both Black and Latina women, respectively (290). However, it is important to note that individual behaviors are strongly influenced by the surrounding environment. Unfortunately, neighborhoods where socioeconomically disadvantaged populations reside are often characterized by low walkability, reduced availability of healthy food options including fresh fruits and vegetables, and limited outdoor space for recreation and exercise (291,292). These areas, often with historic redlining, have reduced tree canopy cover, which increases average temperatures (293).

FIGURE 7



Research has identified numerous factors that increase an individual's risk for developing cancer. The prevalence of many of these risk factors are higher among minoritized and medically underserved populations. By modifying behavior, individuals can assist in the elimination or reduction of many of these risks and thereby reduce their risk of developing or dying from cancer. Developing and implementing equitable interventions such as public health campaigns and policy initiatives can help further reduce the burden of cancers related to modifiable cancer risk factors.

Adapted from (289).

Socioeconomically vulnerable populations are also more likely to reside in less favorable locations such as near highways, busy roads, or industries, which increases their exposure to air pollution increasing cancer risk (97,294,295). Occupations that increase exposure to cancer risk factors are also more likely to be staffed by minoritized and underserved populations (296). For instance, Native Hawaiian and Other Pacific Islander (NHOPI) and Hispanic/Latino individuals are more likely to have permanent night-shift work, which has been shown to increase the likelihood of certain types of cancers (297).

Cancer risk factors can intersect with other population characteristics, such as race, ethnicity, sexual orientation, and disability status, among others, to drive cancer disparities. As one example, individuals with disabilities, who may have fewer occupational opportunities and lower income, also have higher prevalence of smoking, obesity, and physical inactivity. It is imperative that public health experts prioritize cancer prevention efforts that account for the complex and interrelated factors across institutional, social, and individual levels that influence personal risk exposure and disparate health outcomes. There is an urgent need for all members of the medical research community to come together and develop strategies that enhance the dissemination of our current knowledge of cancer

risk reduction and implement evidence-based interventions for reducing the burden of cancer for everyone.

## Tobacco Use

The use of tobacco products is the leading preventable cause of cancer and is associated with the development of 17 different types of cancer in addition to lung cancer. Nearly 20 percent of all cancer cases and 30 percent of all cancer-related deaths are caused by tobacco products (131). In the United States, between 80 percent and 90 percent of lung cancer deaths are attributable to smoking (298). On average, people who smoke die 10 years younger than those who have never smoked (299).

Research over the past 50 years has consistently demonstrated that byproducts released from smoking tobacco products, such as cigarettes, cause permanent cellular and molecular alterations, which lead to cancer (300-302). Furthermore, smoking causes many other chronic conditions, including chronic obstructive pulmonary disease (COPD), asthma, chronic bronchitis, emphysema, and many types of cardiovascular diseases.



Thanks to nationwide tobacco control initiatives, cigarette smoking among US adults has been declining. In fact, cigarette smoking rates among US adults have decreased from 42.4 percent in 1965 to 11.5 percent in 2021 (303). However, even in 2021, the most recent year for which such data are available, an estimated 46 million US adults reported using any tobacco product (e.g., cigarettes, cigars, pipes) (303). In the most recent decade between 2011 and 2020, there have been decreases in smoking among non-Hispanic (NH) White, NH Black, and Hispanic adults. However, during the same time period, there was an increase of 29,700 American Indian or Alask Native (AI/AN) individuals who smoked, even though rates of smoking among NH AI/AN adults remained the same (304).

There are striking sociodemographic disparities in the use of tobacco products as well as in exposure to secondhand smoke. Overall tobacco use is higher among US residents who live in rural areas and in the Midwest, those with lower levels of household income and educational attainment, those who are uninsured or insured by Medicaid, and those experiencing psychological distress or have a disability (303,305). Furthermore, US adults who identify as belonging to the SGM populations have higher rates of using tobacco products.

Exposure to secondhand smoke, which occurs when people inhale smoke exhaled by people who smoke or from burning tobacco products, has declined from 27.7 percent between 2009 and 2010 to 20.7 percent between 2017 and 2018 (306), the most recent time for which such data were available. Despite this decline, secondhand smoke is estimated to cause 41,000 deaths each year among adults in the United States, with 7,300 deaths attributed to lung cancer, the primary cancer associated with secondhand smoking (307).

Unfortunately, Black adults who do not smoke are consistently exposed to nearly twice as much secondhand smoke as Hispanic, NH White, and Asian adults (306). Black individuals are 16 percent less likely to survive 5 years after diagnosis with lung cancer compared to NH White individuals (308). Although the exact mechanisms are not known, increased exposure to secondhand smoke, comorbidities, and higher use of mentholated cigarettes among Black adults could contribute to this disparity (306).

Because lung cancer is often associated with smoking, patients with lung cancer without a history of smoking or very brief history of smoking, such as **Daniel West** (see p. 71), may experience societal stigma (309-312). It should be noted that about 12 percent of newly diagnosed lung cancer cases occur in individuals who have never smoked (313). There is an urgent need for more research to identify lung cancer risk factors among these individuals and to determine whether the incidence rate of lung cancer among those without a history of smoking is increasing.

There is strong evidence that smoking cessation has both immediate and long-term health benefits, especially when stopping at a younger age. Evidence from a large cohort study demonstrated that among individuals who stopped smoking before age 45, all-cause mortality was similar to that of a person who never smoked (314). Those who stop smoking reduce their risk of developing cancers of the larynx, oral cavity, and pharynx by half after 10 years of cessation (315,316). After 20 years, the risk of developing these cancers is lowered to the same level as someone who never smoked (315,316).

People who smoke often have difficulty stopping and, while more than half attempt smoking cessation every year, only 7.3 percent of smokers manage to successfully stop smoking (317). Using data from the National Health Interview Survey (NHIS), it was found that 63.4 percent of Black, 69.4 percent of Asian, and 69 percent of NHOPI people who smoke attempted to quit smoking within the previous year, compared to only 53.3 percent of NH White people (318).

Evidence-based interventions at local, state, and federal levels, including tobacco price increases, public health campaigns, marketing restrictions, cessation counseling, FDA-approved medications, and smoke-free laws, must be utilized to continue the downward trend of tobacco use. Unfortunately, while certain groups, including Black individuals, are more likely to report their willingness to stop smoking (28), there are disparities in access to tobacco cessation interventions. A large analysis of Medicaid beneficiaries across all 50 US states from 2009 to 2014 found that Black, Latino, Asian, and AI/AN individuals had lower rates of access to smoking cessation medication and counseling compared to White beneficiaries (319).

In a study of **1,610 rural adults** who smoke, **only 1 in 4 attempted to stop smoking** in 2023 (320).



W23

Over 70 percent of NH Black adults who smoke report that they want to stop; however, this population does not receive information to the same degree as NH White people (318). Only 56 percent of NH Black adults report receiving advice from their doctors about ways to quit smoking, and NH Black adults are 65 percent less likely to receive this advice compared to White people who smoke (318,321). The use of culturally tailored smoking cessation programs that incorporate individual-level counseling can significantly improve engagement and increase abstinence and rates of attempted cessation across many groups (322-325).

Flavored tobacco products, such as menthol cigarettes, pose a significant health risk because they lead to increased nicotine dependence and reduced smoking cessation compared to

nonmentholated cigarettes (326,327). Overall, 38.8 percent of Americans who smoke use menthol cigarettes (328). Use of menthol cigarettes is higher among certain racial and ethnic minority populations, particularly NH Black people, with 85 percent of Black individuals who smoke using menthol cigarettes (328). The disparity in menthol cigarette use can be attributed to tobacco industries aggressively marketing to these populations through advertisements, giveaways, price reductions, lifestyle branding, and event sponsorships. It has been estimated that between 1980 and 2018, 1.5 million NH Black individuals began smoking menthol cigarettes and 157,000 NH Black individuals died prematurely because of menthol cigarette smoking (329).

Evidence shows that young adults are more likely to try menthol cigarettes and those who do are more likely to continue smoking into adulthood (326). In addition, 40.4 percent of middle and high school students who smoke report using menthol cigarettes (305). This is greater than the percentage of adults who smoke menthol cigarettes. Use of menthol cigarettes is 20 percent higher in NH Black and 18 percent higher in Hispanic youth compared to NH White youth who smoke (330).

The use of other combustible tobacco products (e.g., cigars), smokeless tobacco products (e.g., chewing tobacco and snuff), and waterpipes (e.g., hookahs) is also associated with adverse health outcomes including cancer.

E-cigarettes, first introduced in 2006 in the United States, have gained popularity among those who have never smoked, with the long-term health consequences of these products still unknown. Therefore, it is concerning that in 2023, 10 percent of middle and high school students used e-cigarettes, with 25 percent of those using e-cigarettes daily (331). Of middle and high school students who used e-cigarettes daily, nearly nine out of 10 reported using flavored e-cigarette products (331).

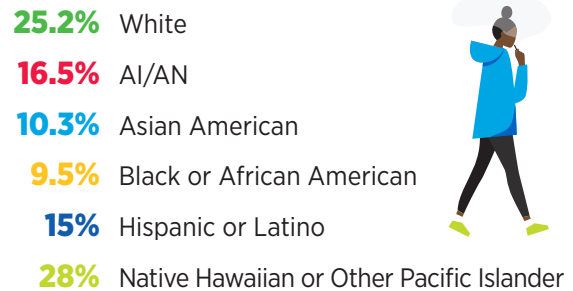
Fortunately, the use of e-cigarettes and other tobacco products among middle and high school students are declining, with a 10 percent reduction in the use of these products between 2022 and 2023 (331, 332). Despite the downward trends, these numbers are still of concern, as research shows that nine out of 10 adults who smoke cigarettes daily first try smoking by age 18 (333).

The landscape of e-cigarette devices has evolved over the years to include different types of products, such as prefilled pods (e.g., JUUL) or cartridge-based and disposable devices (e.g., Puff Bar), among others. E-cigarettes can deliver nicotine, a highly addictive substance that is harmful to the developing brain, at levels similar to those of traditional cigarettes (334). Unlike combustible cigarettes, e-cigarettes come in flavors, such as cotton candy and bubblegum, that appeal to youth and are key drivers of e-cigarette use among youth and young adults (335).

Recent estimates show that e-cigarette usage was highest among individuals ages 18 to 24 years, with 18.6 percent reporting current use (337). E-cigarette use is higher among bisexual individuals compared to heterosexual individuals, as well as among transgender individuals compared to cisgender individuals (337).

While e-cigarettes emit fewer carcinogens than combustible tobacco, they still expose individuals to many toxic chemicals, including metals that can damage DNA and trigger inflammation (338,339). Furthermore, people who use e-cigarettes (among other electronic nicotine delivery systems) are between 2.9 and 4 times more likely to ever smoke a combustible cigarette than people who have never used e-cigarettes (339). Further research is warranted on e-cigarettes and their long-term effects, especially in teens and young adults so that appropriate preventive interventions could be implemented.

### USE OF E-CIGARETTES AMONG MIDDLE AND HIGH SCHOOL STUDENTS IN 2019



Data from (336).

W24

Another area where more research is needed is the health consequences of smoking marijuana; for example, there is concern among public health experts that it could cause cancer because it involves the burning of an organic material, much like smoking tobacco (340). The need for this research is driven by the growing number of states that have legalized marijuana use for medical and/or recreational purposes. Currently in the United States, 74 percent of Americans live in a state where marijuana is legal for either recreational or medical use (341).

## Body Weight, Diet, and Physical Activity

Nearly 20 percent of new cancer cases and 16 percent of cancer deaths in US adults are attributable to a combination of excess body weight, poor diet, physical inactivity, and alcohol consumption (342,343). Following a healthier

*continued on page 72*

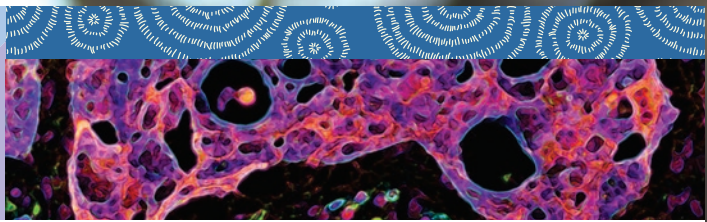


“My doctor is understanding of John’s and my relationship. He understands that we’re a team and that we make decisions about my treatment together. And that was important for us.”



# Daniel West, 53

Houston, Texas



**D**aniel has a family history of heart disease. In 2019, his dad died from a heart attack. So, in 2022, Daniel took up an opportunity he had through work to receive cardiac testing at an affordable price. “The results came back, and they said they saw two nodules on my lung that looked concerning.” Further testing through CT scans and a PET scan showed a nodule in the middle of the lobe of his right lung. His provider wanted to do a biopsy and ordered a bronchoscopy. Daniel still remembers getting the call from his physician while he was at a music convention in Chicago with his husband John. They set up an appointment with his doctor as soon as they got back to Houston. On December 22, 2022, Daniel received his diagnosis of non-small cell lung cancer (NSCLC).

Being a task-oriented person, Daniel immediately sought to figure out the next steps. His primary care network connected him with a surgeon who recommended resection to remove the nodules. Having some reservations, Daniel and John wanted a second opinion and reached out to the University of Texas MD Anderson Cancer Center. “That is how we ended up at MD Anderson, and I’m so thankful that we are here. I had so many questions. It is important to find someone that can be an advocate and help you navigate the steps that you need to take for treatment,” said Daniel. “I think the most important for us is communication with our doctor and trust. My doctor is understanding of John’s and my relationship. He understands that we’re a team and that we make decisions about my treatment together. And that was important for us,” Daniel added.

His initial treatment was lobectomy (a surgery performed to remove an entire lobe of the lungs) since his physician believed that the cancer was contained in the middle right lobe. The surgery was successful. During the procedure the surgeon also removed several lymph nodes around the tumor to determine if there were any cancer cells. The lymph nodes came back positive, revealing there had been some spread to the lymph nodes, particularly the ones immediately around the tumor. This led to a change of his diagnosis to a more advanced stage IIB NSCLC. As a result his care team recommended several rounds of chemotherapy following surgery.

During his discussion with the surgeon, Daniel was informed that his first hospital had done some biomarker testing of his nodules. The tests had shown that his tumor was positive for alteration in the EGFR protein, an aberration that is frequently linked to lung cancer among individuals who never or rarely smoked and is a target for many molecularly targeted

therapeutics. Since completion of his chemotherapy regimen in June 2023, Daniel has started receiving the EGFR-targeted treatment osimertinib (Tagrisso).

The chemotherapeutics took a toll on Daniel. He experienced neuropathy, sciatica, and stomach ulcers. He also developed deep vein thrombosis in his leg as well as pulmonary embolisms requiring him to be on blood thinners long-term. But the treatments are working. Daniel currently has no evidence of active cancer. His physicians are monitoring a couple of small nodules, but there has been no progression. “So, we’re very thankful for that,” Daniel said.

Daniel’s journey has taught him to be an advocate for his own health care. “It’s partly on me to be proactive in my treatment.” And he hopes that as a society we can learn to dispel the stigma and guilt associated with lung cancer. “Often, the first question that people ask when I share my diagnosis is, oh, I didn’t know you smoked, or did you smoke? I guess they’re looking for a reason why this otherwise seemingly healthy person would be diagnosed with lung cancer. And the bottom line is anyone with lungs can get lung cancer,” he said. Through his advocacy and meeting with other survivors, Daniel has gotten more comfortable talking about his cancer. “I don’t feel guilty. I feel focused on getting well and living my life.”

Key lessons that Daniel has gained along the way are that access to early detection and affordable screening are vital. Unfortunately, my light smoking history was outside of the USPSTF guidelines for screening and I would not have qualified for insurance covered testing. Additionally, trusting one’s care provider and having open lines of communication are key. “Being a gay man, what was important for me was being able to trust my doctor. It’s very important for anyone in my community to be comfortable with their physician. It’s okay to get a second opinion if you don’t feel like you’re getting the care that you need,” he said. His advice for other cancer patients from the sexual and gender minority community is to make sure that they trust their providers and have clear communication about their care plans. “We made decisions to be comfortable with our treatment plan. As a patient, it was important for me to have a provider that acknowledged the relationship I had with John and the fact that we were making this decision as a family.”

Scan the QR code  
to watch Daniel’s video interview.





lifestyle may reduce the risk of developing certain cancers as well as other adverse health outcomes. In the United States, decades of systemic and structural racism have contributed to adverse differences in SDOH in racial and ethnic minority groups and medically underserved populations (see **Understanding and Addressing Drivers of Cancer Disparities**, p. 36). Racial inequality in income, employment, and homeownership, stemming from structural racism, has led to built environments that limit opportunities to maintain a healthy weight, such as participating in physical activities and recreation, and eating a healthy diet.

## Obesity

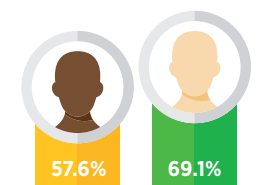
Among US adults, the rate of obesity was 41.9 percent from 2017 to 2020 (344). This is a 37 percent increase from the year 2000, when the rate was 30.5 percent (344). During the same time, severe obesity among US adults nearly doubled, with an increase from 4.7 percent to 9.1 percent (344). The rise in obesity rates has been observed in most racial and ethnic groups (see **Figure 8**, p. 72). As with smoking, adults who are obese have a higher risk of many chronic diseases, including diabetes, cardiovascular disease, stroke, and cancer (289).

Of increasing concern is the rise in obesity among children and teens (2 to 19 years of age), rising 300 percent in the past five decades, from 5 percent in the 1970s to approximately 19.7 percent during the period from 2017 to 2020 (346). Recent data show that being overweight or obese during childhood increases the likelihood of developing cancer as adults (347). As in adults, racial and ethnic minority children have higher rates of obesity, with 26.2 percent of Hispanic and 24.8 percent of NH Black children being obese compared to 16.6 percent of NH White children between 2017 and 2020 (348).

Concurrent with the rise in obesity, there has been a rise in obesity-related cancers in the United States (349). Almost one-tenth of cancers in the United States can be attributed to obesity (350). Increasing incidence of a subset of obesity-related cancers including kidney, pancreatic, gallbladder, endometrium, and colon or rectum, as well as multiple myeloma, has been more prominent in young adults (25 to 39 years of age) compared to adults 50 years of age or older (351). In young women, rates of obesity-associated cancers are increasing the most among Hispanic women when compared to NH Black and NH White women (132).

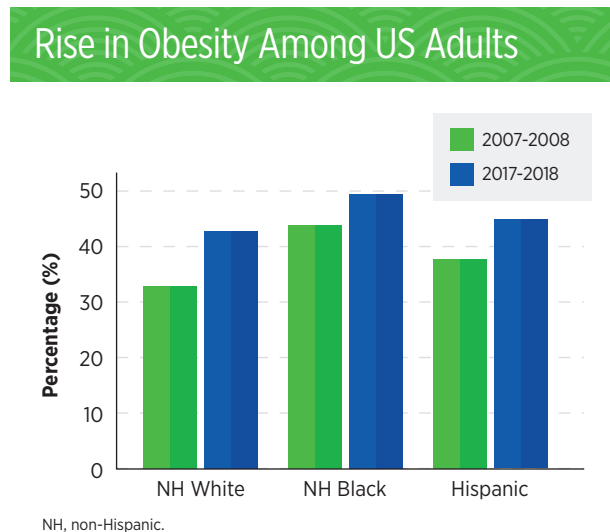
**5-YEAR SURVIVAL RATE OF PATIENTS IN BLACK AND WHITE POPULATIONS WITH EARLY-ONSET COLORECTAL CANCER**

Source: (355).



W25

**FIGURE 8**



Obesity rates have continued to rise among all racial and ethnic groups over the past decade. However, current rates of obesity are higher among certain populations compared to NH Whites.

Data adapted from (345).

Early-onset cancers are also rising globally, with a striking 79 percent increase in new cases of cancer among individuals under 50 over the past 30 years (352). It is estimated that in the next 10 years, 25 percent of rectal cancers and 11 percent of colorectal cancers will be diagnosed in individuals younger than 50 (353). Being overweight or obese increases the likelihood of developing early-onset colorectal cancer by 1.2 and 1.5 times, respectively, compared to maintaining a healthy weight (354).

Weight loss interventions have proven to be effective in reducing or eliminating the risk of cancers associated with obesity (356,357). Barriers exist in attaining weight loss among certain racial and ethnic minority groups. When participants in weight loss programs are not engaged, it leads to nonadherence and unsuccessful outcomes (358). Structural barriers including long work and commute hours, inconvenient class times and locations, and limited disposable income for weight loss activities result in disparities in the ability of Hispanic and NH Black people to lose weight (359).

Bariatric surgery, a term used to describe a collection of procedures that are done to help people who are obese lose weight, has been shown to lower the risk of developing and/or dying from certain obesity-associated cancers (360,361). However, it is important to note that compared to White patients, Black patients experience higher adverse events 30 days following surgery, including postoperative mortality, morbidity, readmission, and reoperation (362).

Eliminating disparities in obesity and obesity-related cancers necessitates further research to identify culturally tailored, community-based interventions that are scalable across settings including limited resource settings. Research shows that positive community support, more flexible or convenient work schedules, and low- or no-cost lifestyle resources such as gym memberships or one-on-one consultations can help reduce obesity among underserved groups (359). For example, Black women who participated in a 6 month weight loss program that was followed by a patient-centered, culturally sensitive weight loss maintenance intervention continued to lose weight compared to those who participated in a standard weight loss maintenance intervention (363).

## Diet

Complex and interrelated factors ranging from socioeconomic, environmental, and biological to individual lifestyle factors contribute to obesity. There is, however, sufficient evidence that consumption of high-calorie, energy-dense foods and beverages and insufficient physical activity play a significant role. Poor diet, consisting of processed foods and lacking fresh fruits or vegetables, is responsible for the development of about 5 percent of all cancers, with several studies demonstrating a link between consumption of highly processed foods and cancer incidence (364-366). Conversely, consumption of a diet rich in fresh fruits and vegetables, nuts, whole grains, and fish can help lower the risk of developing certain cancers and many other chronic conditions. One study of nearly 80,000 men from diverse backgrounds found that adherence to a healthy diet lowered risk for certain types of colorectal cancers (367).

### FOOD INSECURITY AMONG DIFFERENT RACES AND ETHNICITIES IN THE UNITED STATES IN 2022 (369)

**22.4%** Black  
**20.8%** Hispanic  
**9.3%** White



Data from (369).

W26

It is concerning that US adults consumed 7 percent more highly processed foods in 2017–2018 than they did in 2001–2002 (368). Consumption of fast food—food that can be prepared quickly and easily and is sold in restaurants and snack bars—is higher among racial or ethnic minority individuals, with 43 percent of NH Black adults versus 36 percent of NH White adults consuming fast food between 2013 and 2016, the most recent timeframe for which these data are available (368).

Disparities in diet quality among different segments of the US population can be attributed to socioeconomic and

geographic factors, which contribute to food insecurity. As defined by the United States Department of Agriculture (USDA), food insecurity is the lack of access by all people in a household at all times to enough food for an active, healthy life. Studies show that food insecurity is higher among racial or ethnic minorities and those who live in poverty (370). These communities are often located in neighborhoods considered “food deserts,” which are areas that have low availability of healthy foods like fresh fruit and vegetables and an abundance of fast-food options. Community-driven initiatives administered through key partners, such as faith-based organizations, schools, and local food retailers, are one mechanism to promote healthy eating among underserved populations.

Sugar-sweetened beverages are a major contributor to caloric intake among US youth and adults, and there are emerging data indicating that consumption of sugar-sweetened beverages may be associated with an increased risk of cancer (189,371). In certain rural areas—for example, the Appalachia region—local interventions have led to a reduction in consumption of sugar-sweetened beverages and increased consumption of vegetables (372). The Philadelphia Beverage Tax on sugar-sweetened beverages, implemented in 2017, increased the cost by 1.5 cents per ounce of sodas and juices that contain sugar. The tax led to significant reductions in the consumption of sugar-sweetened beverages (373,374), with one study indicating as much as a 42 percent drop in the sale of these types of beverages after 2 years (375). The tax revenue generated is used to fund early-education programs (including free universal pre-K), healthy messaging, and upgrades to playground equipment. Pilot initiatives like these are a step in the right direction and continuous evaluation will further determine their long-term health benefits and impact on diet, obesity, and cancer burden.

## Physical Activity





Engaging in regular physical activity can reduce the risk of nine different types of cancer, with research indicating that over 46,000 US cancer cases annually could potentially be avoided if everyone met the recommended CDC guidelines for physical activity (see **Sidebar 16**, p. 74) (376,377). People who engage in 4 to 5 minutes of vigorous physical activity daily can reduce their cancer risk by up to 32 percent (378).

There are many barriers that may prevent individuals from being physically active, including cost and access to fitness facilities, low neighborhood walkability, lack of green spaces, inadequate tree canopy cover, and family obligations (380-383). These barriers are exacerbated in racial and ethnic minority individuals and medically underserved populations (see **Figure 3**, p. 37). Based on recent data, physical inactivity is higher among Hispanic (31.7 percent) and NH Black (30.3 percent) populations, compared to

**SIDEBAR 16**

# Physical Activity Guidelines

Incorporation of regular physical activity into daily life is one of the most important things people can do to improve their health, including reducing cancer risk. The recommended level of physical activity varies depending on age and preexisting medical conditions.

 <p><b>Pre-school aged children</b> (3–5 YEARS)</p>	 <p><b>Adolescents</b> (UNDER 18 YEARS)</p>	 <p><b>Adults</b> (18–64 YEARS)</p>	 <p><b>Older adults</b> (65+ YEARS)</p>
<b>AEROBIC ACTIVITY</b>			
60 MINUTES PER DAY	150–300 minutes moderate intensity per week or 75–150 minutes vigorous intensity per week		
<b>STRENGTH TRAINING</b>			
3 days per week	2+ days per week	3 days per week	

**Aerobic Activity**

Cardiovascular exercise that gets your heart pumping

**MODERATE INTENSITY**

Includes activities in which one can still talk without pausing for breaths, such as:

- Walking
- Pushing lawnmower
- Water aerobics
- Pickle ball

**VIGOROUS INTENSITY**

Includes activities during which it is hard to speak more than a few words before catching breath, such as:

- Running
- Swimming fast
- Cycling fast or on hilly terrain



**Strength Training**

Includes activities that work muscles and core by doing repetitions or sets of movements, such as:

- Yoga
- Martial arts
- Tai chi
- Pilates
- Lifting weights
- Using resistance equipment



Developed from (379).

those who are NH White (23.4 percent) (384). There are also geographic disparities, with only 16 percent of people in suburban and rural areas meeting the recommended physical activity guidelines, compared to 27.8 percent of those living in urban areas (385).

## Alcohol Consumption

Alcohol consumption increases the risk for six different types of cancer (see **Figure 9**, p. 75) and is linked to more than 200 diseases. Nearly 4 percent of cancers diagnosed worldwide in 2020 were attributed to alcohol consumption and in the United States, it is estimated that from 2013 to

2016, 75,000 cancer cases and 19,000 cancer deaths were linked to alcohol (386,387). There are sociodemographic disparities in consumption of alcohol.

**BINGE ALCOHOL USE IN THE PAST MONTH IN THE UNITED STATES IN 2022, BY RACE/ETHNICITY**

- 25.5%** AI/AN
- 23.3%** Hispanic or Latino
- 22.5%** White
- 20.9%** Black or African American
- 10.3%** Asian

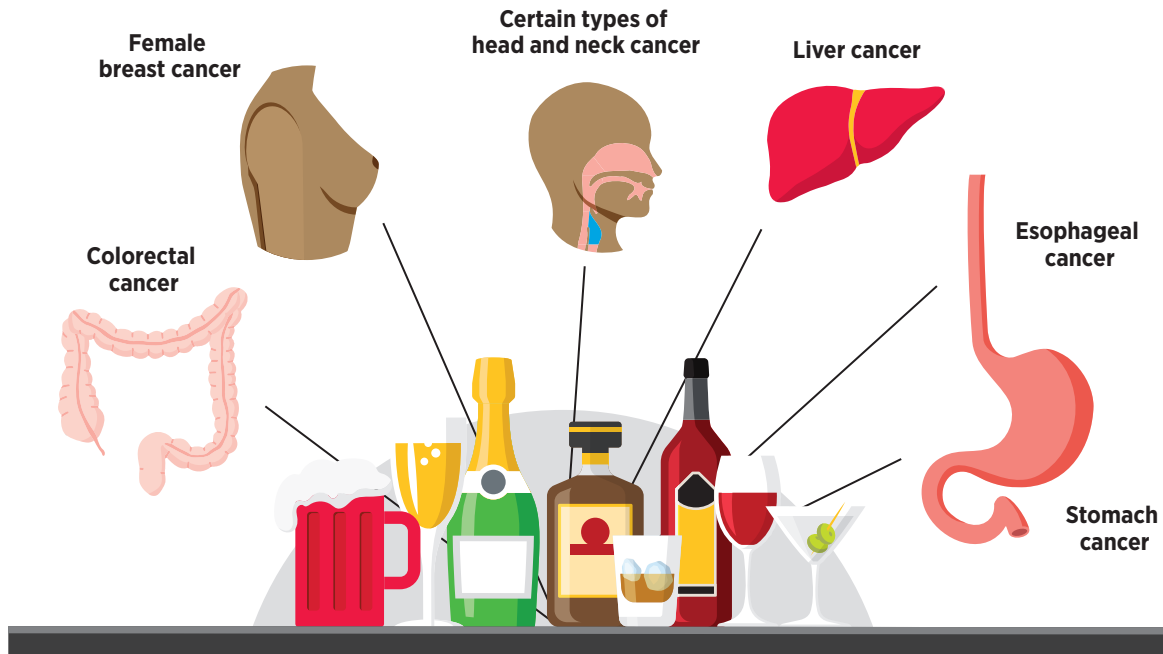


Data from (388).

W27

FIGURE 9

## Alcohol and Cancer Risk



Consumption of alcohol increases an individual's risk of developing six types of cancer—certain types of head and neck cancer, esophageal squamous cell carcinoma, female breast, colorectal, liver, and stomach cancers.

The greatest risks are associated with long-term alcohol consumption and binge-drinking, i.e., when large amounts of alcohol are consumed in a short period of time (389). Even light intake of alcohol can increase an individual's risk for certain cancers, while moderate drinking can increase the risk of developing certain cancers of the head and neck, breast, and colon and rectum (390-392).

Those who experience structural racism consume more alcohol. As one example, a recent study found that structural racism experienced by Black individuals increased the level of binge drinking frequency and smoking (393). Increasingly, studies show that exposure to or lived experiences with racism, micro-aggressive behavior, and stress leads to an increase in levels of alcohol consumption (393-395).

One study found that areas in North Carolina with **lower socioeconomic status had 65 percent more alcohol outlet stores** compared to areas with higher socioeconomic status (396).



W28

## UV Exposure

UV radiation is a type of light emitted primarily from the sun but also from artificial sources, such as tanning beds. Exposure to UV radiation can lead to the development of skin cancers, including basal cell carcinoma, squamous cell carcinoma, and melanoma, which is the most aggressive form of skin cancer. In fact, UV radiation accounts for 95 percent of skin melanomas and 6 percent of all cancers (342). This is because UV radiation can damage cellular DNA, with continued exposure leading to cancer. In the United States, 33,000 sunburns requiring emergency room visits are reported annually. Past sunburns are a strong predictor of future skin cancer, especially melanoma. One study reported that women who experienced at least five episodes of severe sunburns between the ages of 15 and 20 years were 80 percent more likely to develop melanoma later in life, compared to those who did not experience sunburns (397).

While those who are light skinned are more susceptible to sunburn, those with darker skin are also at risk. Black and Hispanic individuals, who typically have darker skin tones compared to NH White individuals, are less likely to engage in sun-safe habits, such as wearing long sleeves, seeking shade, and using sunscreen while outdoors (398). These behaviors are attributable to lack of information and education on how sunburn increases the risk of skin cancer. In a survey



of high school students in Texas, those from racial minority populations, and individuals of low socioeconomic status, showed poorer knowledge of melanoma and skin cancer risk (399). These groups are also less knowledgeable about the appearance of melanoma, understanding the importance of skin self-examinations, and less likely to be examined for skin lesions by a doctor (400). Exacerbating the lack of knowledge about skin cancer risk are “sunscreen deserts,” which are areas that have lower availability and lesser variety of sunscreen compared to other areas. One study found that sunscreen deserts were more prominent in majority Black areas compared to majority White areas (401).

The disparity in skin cancer preventive behavior is of public health concern because Black, Hispanic, and NHOPI people tend to be diagnosed at more advanced stages despite having a lower incidence of skin cancer (402,403). Patients from racial and ethnic minority populations also have distinct characteristics of skin cancer, differing clinical features, and unique genetic risk factors compared to NH White patients (404,405).

To address the disparities in skin cancer risk among racial and ethnic minority populations, developing a health equity framework for dermatologists and other constituents in the public health sector has been proposed (405). This framework addresses several barriers, including appropriate medical assessment, awareness concerning skin lesions and melanoma risk, and acceptance and adherence to treatment and/or follow-up recommendations (see **Figure 10**, p. 77).

Indoor tanning exposes individuals to the same harmful UV radiation of the sun but in an artificial setting. Fortunately, rates of indoor tanning have been declining over the past decade, particularly among US youth (406). Currently, 44 states and the District of Columbia either ban or regulate the use of indoor tanning devices by minors (407). All states should enact legislation banning indoor tanning for minors, to continue the downward trend of tanning bed usage, especially among youth.

**Indoor tanning salons** are twice as likely to be **located in areas where 10 percent or higher of households have male-male partners** compared to areas with less than 10 percent of households with male-male partners (408).



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## Infectious Agents

Cancer-causing agents or pathogens (bacteria, viruses, and parasites) increase a person’s risk for several types of cancer. Infection with these agents can change the way a cell behaves,

weaken the immune system, and cause chronic inflammation, all of which can lead to cancer. In the United States about 3 percent of all cancer cases can be attributed to infection with pathogens (342). Globally, an estimated 13 percent (2.2 million) of all cancer cases in 2018 were attributable to pathogenic infections, with more than 90 percent of these cases caused by four pathogens: human papillomavirus (HPV), hepatitis B (HBV), hepatitis C (HCV), and *Helicobacter pylori* (*H. pylori*) (409).

## Human papillomavirus (HPV)

HPV is a group of more than 200 related viruses that are responsible for almost all cervical cancers, 90 percent of anal cancers, and 70 percent of oropharyngeal cancers, as well as most penile, vaginal, and vulvar cancers. While most HPV infections do not cause cancer, those that are persistent and with high-risk strains of HPV can lead to cancer. These high-risk HPVs cause 2 percent and 3 percent of all cancers in men and women, respectively, in the United States. Globally, HPV-related cancers make up about 5 percent of all cancers (410).

Incidence of HPV is higher among certain racial and ethnic minority populations. Rates of HPV infection are higher in young Black women compared to young White women (411). Gay and bisexual men and men who have sex with men are twice as likely to have anal HPV infection compared to men who have sex with women due to lower rates of contraceptive use during intercourse (412,413). The higher rate of HPV infection among gay and bisexual men may partly explain why this population is 17 times more likely to develop anal cancer compared to heterosexual men (414).

The HPV vaccine is approved for males and females ages 9 to 45, with recommendations for the first doses beginning at age 11 to 12 (see **Sidebar 17**, p. 78). There are 13 different types of HPV that can cause cancers; the HPV vaccine currently used in the United States, Gardasil 9, can protect against nine of these HPV strains.

Despite the clear evidence of the HPV vaccine reducing cervical cancer incidence, the uptake of the HPV vaccine has been suboptimal in the United States (415). This stands in stark contrast to other countries such as the United Kingdom and Australia, which have very high rates of vaccination among adolescents and young adults. The United States does not require HPV vaccination to attend school. In 2021, 76.9 percent of adolescents ages 13 to 17 had received one dose of the HPV vaccine and only 61.7 percent had received the recommended two doses (416). While initial uptake of the HPV vaccine was extremely low among racial and ethnic minority populations, there have been significant improvements in the past decade, especially among Black adolescent girls. Disparities still exist, however, due to location, income level, and by educational attainment (411,417,418).

**FIGURE 10**

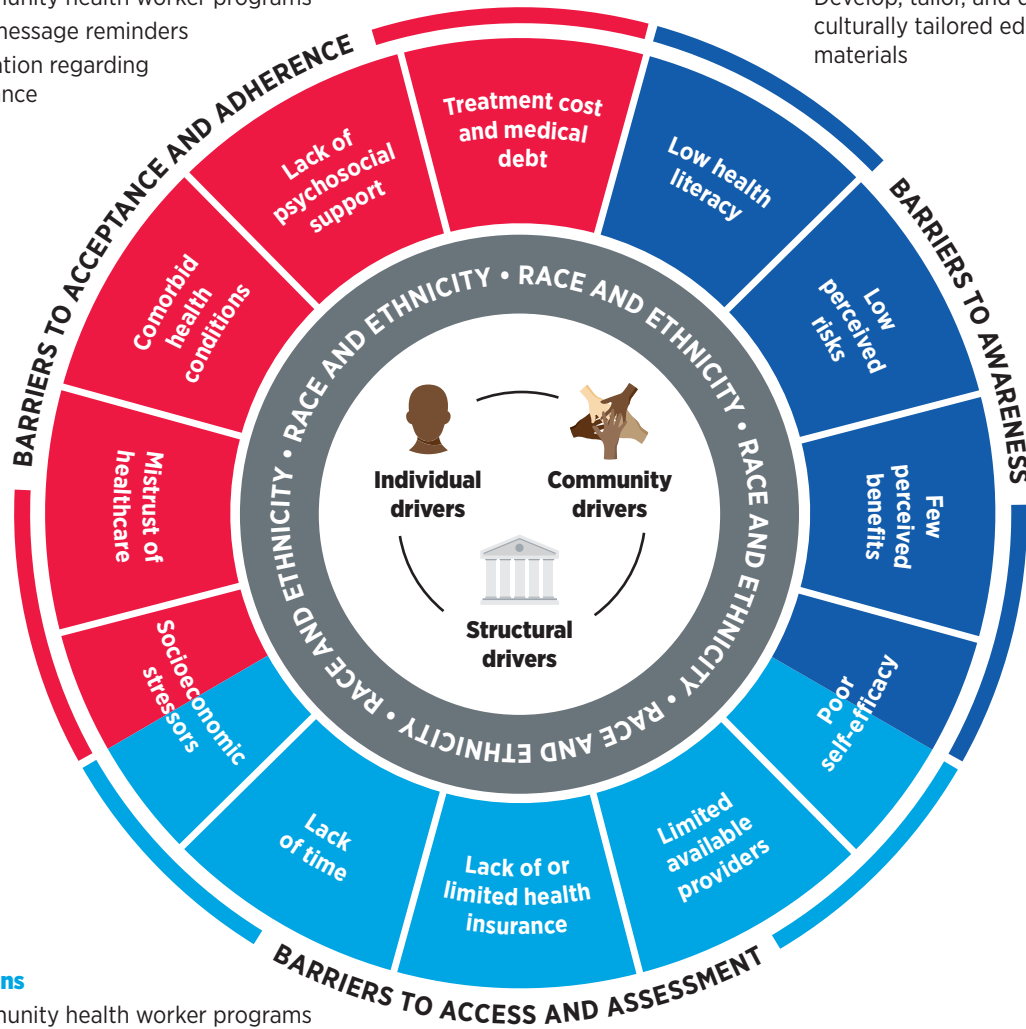
# A Melanoma Health Equity Framework

**Solutions**

- Community health worker programs
- Text message reminders
- Education regarding insurance

**Solutions**

- Develop, tailor, and distribute culturally tailored educational materials



**Solutions**

- Community health worker programs
- Telehealth platforms
- Improved access to healthcare

The melanoma health equity framework centers on race and ethnicity. The inner circle represents how the individual, community, and SDOH impact care. The outer circle represents barriers to awareness of skin lesions and melanoma risk (blue); access to medical assessment barriers (light blue); and accepting and adhering to treatment and/or follow-up recommendations (red). The slices between the inner and outer circles represent the barriers to achievable goals. Finally, solutions to reaching timely, equitable, and appropriate access to melanoma treatment are presented.

Developed from (405).

HPV vaccination for gay and bisexual men has been low among those eligible, with an estimated 63 percent of gay and bisexual men ages 18 to 26 having received any dose of the HPV vaccine (419).

The lack of HPV vaccination awareness can be explained by a lack of education and trust (i.e., “vaccine hesitancy”

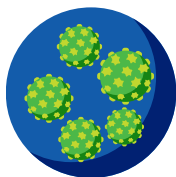
(420,421) about the importance of HPV vaccination and the risk of cancer from HPV infection (422). In a study of over 15,000 people, only 40.4 percent of those with less than a high school diploma, compared to 78.2 percent with a college degree or higher, had awareness of how vaccination against HPV would reduce HPV infection (417). Among those with HPV awareness, only 51.7 percent of those with less

## SIDEBAR 17

## HPV Vaccination Recommendations

**Thirteen strains of human papillomavirus (HPV) can cause cancer:**

HPV16, 18, 31, 33, 35, 39, 45, 51, 52, 56, 58, 59, and 66.

**US CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC) AND ADVISORY COMMITTEE ON IMMUNIZATION PRACTICES (ACIP) RECOMMEND:**

- **Two doses of HPV vaccine**, given at least 6 months apart, for adolescents **younger than age 15** (except immunocompromised persons).
- **Three doses of HPV vaccine** for adolescents and young adults **ages 15 to 26** and for people with weakened immune systems.
- **Shared decision-making** through discussion with health care providers for adults **ages 27 to 45**; if an individual chooses to be vaccinated, three doses of HPV vaccine.

Although there are **three FDA-approved HPV vaccines**—Gardasil (first approved in 2006), Cervarix (first approved in 2009), and Gardasil 9 (first approved in 2014)—only one (Gardasil 9) is currently being distributed in the United States.

**GARDASIL 9**

Protects against infection with HPV6, 11, 16, 18, 31, 33, 45, 52, and 58.

**FDA APPROVED FOR:**

- Preventing anal, cervical, head and neck, vaginal, and vulvar cancers and precancers, as well as genital warts.
- Vaccination of males and females ages 9 to 45.



Adapted from (1).

than a high school diploma knew that HPV causes cervical cancer, compared to 84.7 percent of adults with a college degree or higher (417). Developing evidence-based strategies to improve HPV vaccination uptake among all eligible individuals could have immense public health benefits.

**Hepatitis B Virus (HBV) and Hepatitis C Virus (HCV)**

Chronic infection from HBV and HCV can cause liver cancer and can be a risk factor for other malignancies such as non-Hodgkin lymphoma. Globally, the most common risk factor for liver cancer is chronic infection with HBV and

HCV. In the United States, after new reported cases of HBV remained stable from 2013 through 2019, there was an abrupt decrease of 32 percent in reported cases in 2020, with a further decrease of 14 percent between 2020 and 2021 (423). These decreases are potentially attributable to the COVID-19 pandemic, which may have led to reduced testing but not necessarily reduced infections (423). In contrast, cases of acute HCV have doubled during 2013–2020, with an increase of 7 percent between 2020 and 2021 (424).

Rates of HBV infection are highest among NH Asian adults (21.1 percent) and NH Black adults (10.8 percent) compared to White adults (2.1 percent) (425). Additionally, there are disparities based on place of birth: 11.9 percent of adults born outside the United States have past or present HBV infection compared to 2.5 percent of those born in the United States (425). Recent estimates show that HBV infections are likely higher than the 1.8 million as reported in 2020 because of imprecise tracking of infections in immigrant populations. Appropriate tracking of HBV infections is important to predict future incidence of liver cancer, which is expected to increase by 31 percent in the United States from 2019 to 2030 (426).

Compared to all other racial and ethnic groups, acute HCV infection is highest among AI/AN individuals, with 2.7 cases of HCV reported per 100,000 in 2021, the most recent year for which such data are available. The rate of newly reported chronic HCV cases was also highest among AI/AN persons compared to all other groups, with 68.9 cases per 100,000 population reported in 2021 (427). To reduce the burden of HCV, the Indian Health Service recommends universal screening of all AI/AN adults (428). Further, to eliminate viral hepatitis as a public health threat, US HHS department released the *Viral Hepatitis National Strategic Plan for the United States: A Roadmap to Elimination (2021–2025)* in 2022. The primary goals are to prevent new infections, improve health outcomes for infected individuals, reduce disparities and health inequities, increase surveillance, and bring together all relevant constituents in coordinating efforts to address the hepatitis epidemic.

***Helicobacter pylori (H. pylori)***

*H. pylori* is a type of bacteria that has been shown to cause gastric cancer if left untreated. Among those diagnosed with *H. pylori* infection, racial and ethnic minority populations (429) and those who smoked (430) were at a greater risk of gastric cancer. Fortunately, treatment of *H. pylori* infection decreases gastric cancer risk (430). Overall, *H. pylori*-associated gastric cancer has declined over the past two decades; however, rates of *H. pylori*-associated gastric cancer are not equal among all population groups (431).

Infection with *H. pylori* is higher among AI/AN communities. Among Navajo adults in Arizona, the *H. pylori* prevalence is 62 percent, while 75 percent of the Alaska Native population are reportedly infected with *H. pylori*, compared to 36 percent

In a study of over 371,000 US veterans, *H. pylori* infection **increased gastric cancer risk** by a factor of 2 in African American, 2.5 times in Asian, and 1.6 times in Hispanic or Latino populations compared to White populations (430).



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in the overall US population (432-434). This high incidence may explain why AI/AN populations experience higher rates of gastric cancer compared to the White population (435). The causes of high rates of infection are multifactorial and include genetics, environmental factors, and socioeconomic factors (436). While living conditions in the Navajo Nation have improved over the past decades, crowded and substandard housing, which relies on untreated well water, increases the likelihood of *H. pylori* transmission and infection (437).

## Environmental Exposures

Built environment describes the physical environment of a neighborhood in which people live, and includes transportation, infrastructure, clear air, buildings that abide by radon regulations and asbestos abatement procedures, clean water, healthy food access, community gardens, walkability, public services, and policies and regulations (see **Understanding and Addressing Drivers of Cancer Disparities**, p. 36). Environmental exposures are the substances people encounter in their built environment or occupations, including sunlight, chemical pollutants, social interactions, and/or stress, which can impact human health.

In this section, we focus on the physical environment and highlight the disparities in exposure to toxic substances, such as environmental carcinogens, which are also associated with increased risk for cancer and poorer cancer outcomes. It can be difficult for people to avoid or reduce their exposure to environmental carcinogens because modifying the amounts of most environmental exposures requires regulation by local, state, or national bodies.

Exposure to higher than acceptable levels of certain pollutants, without appropriate protection, can increase the risk of certain diseases. Environmental carcinogens, which are substances that can lead to cancer and are present in the environment, include arsenic, asbestos, radon, lead, radiation, and other chemical pollutants including heavy metals and endocrine disrupting chemicals. Coordinated efforts such as those being initiated by Cohorts for Environmental Exposures and Cancer Risks (CEEER) build collaborative infrastructure and facilitate integrated scientific research for enhancing the understanding of environmental exposures influencing cancer etiology, and the genetic, behavioral, and structural factors that modify risk across diverse populations.

Of increasing concern among public health experts is climate change, which refers to a change in temperature and weather patterns across the globe directly attributable to human activity. There is strong scientific evidence for climate change, which has the potential to worsen human exposure to carcinogens. For instance, wildfires in the western United States and Canada, which have increased in intensity in recent years due to climate change (438), have led to increased exposure to certain metal toxins, such as carcinogenic forms of chromium, known to increase cancer risk (439). Those living in rural communities or those who participate in firefighting activities may be at a higher risk of developing cancer as climate change continues to increase wildfire intensity.

## Radon

Radon, a naturally occurring radioactive gas that is produced from the breakdown of uranium in soil, rock, and water, is the second leading cause of lung cancer death in the United States. Although levels of naturally occurring radon vary widely based on geographic location, certain populations, such as the Navajo Nation, are situated on land rich in radioactive ores containing uranium (see **Sidebar 18**, p. 80).

## Pollutants and Endocrine-disrupting Chemicals

Living near industrial areas can increase exposure to toxic chemicals and metals. Most industries are usually adjacent to neighborhoods with low SES and with a high proportion of racially and ethnically minoritized populations (442,443). These exposures can increase the risk for certain types of cancer, such as hematologic malignancies and thyroid, lung, breast, and uterine cancers (444-448).

The endocrine system is made up of the glands and organs that make hormones and release them directly into the blood so they can travel to, and regulate functions of, body tissues and organs. Endocrine-disrupting chemicals can be natural or human-made, and may mimic, block, or interfere with the body's hormones. Endocrine-disrupting chemicals, such as per- and polyfluoroalkyl substances (PFAS), have been shown to increase the risk of certain cancers, such as thyroid and breast cancers (445,446). An emerging concern is the use of personal care products such as hair straightening products, which contain hazardous chemicals with hormone-disrupting properties and have been shown to increase the risk of uterine cancers (449). The use of chemical hair relaxers among Black women is shown to increase the risk of uterine cancer in postmenopausal women (450). The use of hair dye, relaxers, and other hair products have also been shown to be associated with breast cancer risk (451).

PFAS as well as other contaminants including asbestos, arsenic, radon, agricultural chemicals, and hazardous waste can be present in drinking water (452). AI/AN individuals are 19



## SIDEBAR 18

## Impact of Uranium Mining and Radon Exposure in the Navajo Nation

During the 1940s, mining of uranium for national defense and energy took place, ultimately generating 520 abandoned mines, with waste from these mines posing serious health risks. Several studies have demonstrated that homes located on the Navajo Nation have higher than average levels of radon, a naturally occurring radioactive gas that is produced from the breakdown of uranium in soil, rock, and water, compared to the rest of the United States (440). Several programs are addressing the impact of these environmental exposures in the Navajo Nation.

**The Navajo Nation Radon Program, developed in partnership with the Environmental Protection Agency (EPA), provides:**

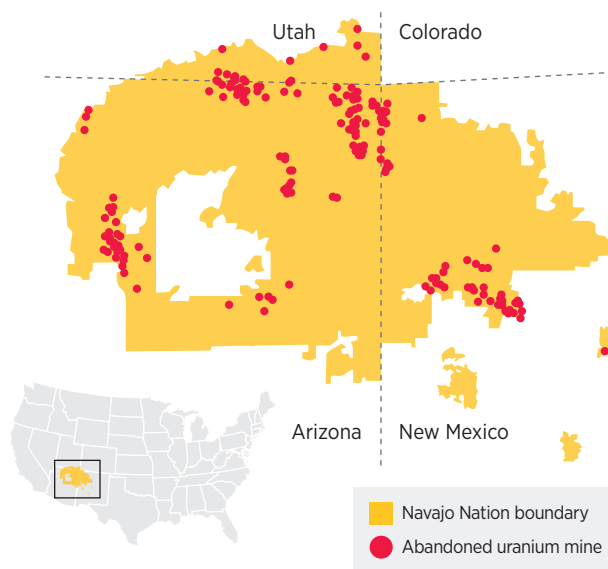
- Culturally tailored educational material about radon and air quality to relevant stakeholders;
- Testing of all homes and tribal offices for radon at least once, schools and daycare centers testing yearly; and
- The screening of all high-risk mines in the Navajo Nation.

**In February 2021, EPA issued the *Federal Actions to Address Uranium Contamination on Navajo Nation 2020–2029*, which totals over \$1.7 billion in agreements and settlements, aims to address impacts of uranium contamination on the Navajo Nation (441), including:**

- Cleaning up the remaining 230 mining sites;
- Increasing funding for Navajo Nation Agencies;
- Undertaking waste remediation projects; and
- Continued monitoring of groundwater.

times more likely than White individuals to live in a household without indoor plumbing, requiring them to source water from communal wells (453,454). These water sources are more prone to being contaminated with bacteria, arsenic, and uranium (436,454), all of which increase the risk of several types of cancer including gastric, liver, lung, bladder, and kidney cancer (436,452,455). Studies have also found that community water systems contaminated with PFAS are more likely to provide water to communities with greater proportions of Latino and NH Black populations (456). Evidence demonstrates that exposure to PFAS pollution is linked to these communities' proximity to polluting industries such as airports, industrial sites, wastewater treatment plants, and military fire training areas (456).

The International Agency for Research on Cancer (IARC), the specialized cancer agency of the World Health Organization (WHO), classifies outdoor air pollution as a potential cause of cancer in humans (457). One type of air pollution is called particle pollution, which refers to a mix of tiny solid and liquid particles that are in the air. In 2013, IARC concluded that particle pollution may cause lung cancer (458). Air



pollution also contains polycyclic aromatic hydrocarbons (PAHs) which have been associated with a number of cancers including cancers of the lung and breast (459,460). In 2023, 119.6 million people lived in places with unhealthy levels of particulate pollution and 63.7 million people living in the United States were exposed to daily, unhealthy spikes in particle pollution (461). Low-income populations and minority groups are among those who often face higher exposure to pollutants (462,463). Those who live in urban areas, particularly with low socioeconomic status, are exposed to higher levels of certain traffic-related air pollution risks, which have been shown to be associated with an increased risk of lung cancer (447,448).

### Occupational Exposures

Higher than normal levels of exposure to carcinogens have led IARC to classify certain occupations, such as firefighting and industrial painting, and work environments, such as iron and steel foundries or working around welding fumes, as class 1 carcinogens, meaning they are cancer-causing to humans.

## SIDEBAR 19

## Occupation and Cancer Risk in Firefighters

High levels of exposure to certain carcinogens without the use of respirators, protective equipment, and appropriate decontamination procedures increase the likelihood of developing several types of cancer. In 2022, the International Agency for Research on Cancer (IARC) characterized firefighting as a class 1 carcinogen because there is sufficient evidence that firefighters are more likely to develop many types of cancers.

**Firefighters are at a greater risk of developing several types of cancer because of the constant exposure to smoke and other hazardous materials (470,471).**

## The Risks

**All firefighters**, regardless of their status as a career or a volunteer firefighter, **are exposed to a wide range of carcinogenic compounds** due to the environmental conditions in which they work (472). Modern homes and furnishings are made of synthetic and plastic materials, which release more unburned particulates (i.e., smoke) compared to natural products made from wood and cloth. **Even after the fire is extinguished, carcinogenic particulates remain** on turnout gear and equipment, which can be brought back to the fire apparatus and fire station if appropriate decontamination procedures are not followed.



## The Cancers

Reports indicate that firefighters have a 9 percent higher risk of being diagnosed with, and a 14 percent higher risk of dying from, cancer compared to the general US population.

**Firefighters have a higher risk of being diagnosed with certain specific cancer types, including:**



**Thyroid cancer**  
2.1X greater



**Multiple myeloma**  
1.5X greater



**Brain cancer**  
1.31X greater



**Mesothelioma**  
2X greater



**Non-Hodgkin lymphoma**  
1.5X greater  
**Leukemia**  
1.14X greater



**Prostate cancer**  
1.28X greater



**Testicular cancer**  
2X greater



**Skin cancer**  
1.39X greater



**Colon cancer**  
1.21X greater

## Initiatives to Address Risks

In 2023, CDC launched the **National Firefighter Registry for Cancer (NFR)** in collaboration with the National Institute for Occupational Safety and Health (NIOSH) in response to the Firefighter Cancer Registry Act passed in 2018 by Congress. This registry is the **largest effort undertaken so far to understand cancer burden among US firefighters**. The NFR expands upon previous registries by including more women, diverse racial and ethnic groups, and volunteer firefighters, making the data more inclusive and representative. These data will pave the way for new health and safety measures for firefighters to protect them from developing cancer.



Racial and ethnic minority groups are more likely to work in jobs that have high levels of exposure to carcinogenic chemicals (464). One study found that among roofers and welders, who can be exposed to carcinogenic fumes, those who were African American had increased risk of adenocarcinoma and large cell lung cancer compared to other races and ethnicities (465). African American workers also have increased occupational exposures to silica and asbestos compared to White individuals, which can increase the risk of lung cancer (296). Mexican American individuals

are more than twice as likely to develop lung cancer caused by conventional and antimicrobial pesticide exposure compared to other groups, attributable to their employment in agricultural occupations (466,467). Studies show that firefighters are also at increased risk of multiple types of cancer because of exposure to smoke and other hazardous materials (see **Sidebar 19**, p. 81). Of interest, Hispanic and Black firefighters are at higher risk to develop these cancers compared to their White counterparts (468,469).

Other risk factors associated with a person's occupation, including lack of sleep and night-shift work, have also been shown to increase their risk of developing certain types of cancers. CDC reports that about 11 million adults in the United States frequently work night shifts, with certain groups, such as men, and Black and non-Hispanic individuals, more likely to do this type of work. In one recent study, researchers found that women age 50 or older who worked both day and night shifts were twice as likely to develop breast cancer as those who only worked day shifts (478).

Although the underlying mechanisms are not clear, researchers believe that disruption of the body's circadian rhythm (i.e., the internal clock) can alter biological processes that normally help prevent cancer development (479). Emerging research indicates that avoiding lighting that disrupts circadian rhythms, for example, lighting that is low in blue light, may help reduce cancer risk (480-482). Long-term research is needed to understand how avoiding exposure to certain light sources, particularly at night, may help regulate the circadian rhythms and thus may reduce cancer risk.

## Social and Behavioral Stress

Stress-inducing social and behavioral factors have been considered as possible cancer risk factors. Several studies link elevated psychosocial stress with biological changes associated with cancer such as increased epigenetic aging, which are reversible changes to the DNA and RNA (483,484). This is concerning because it has been reported that patients with cancer from racial and ethnic minority groups are more likely to report psychosocial stress compared to those who are White (485-487).

In a study of **overweight adults with high body mass index (BMI), those with a high allostatic load had a 39 percent increase in cancer mortality**, compared with those with a low allostatic load (494).



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One area of active investigation in cancer disparities research is understanding the contribution of the allostatic load—the combined influences of stresses, lifestyle, and environmental exposures—on the lifetime risk of cancer and other diseases (488-491). Heightened allostatic load due to stressors related to SDOH (see **Figure 3**, p. 37) is linked to worse cancer outcomes, particularly among racial and ethnic minorities and medically underserved populations (492,493). Researchers are evaluating interventions, including lifestyle factors, that may alleviate allostatic load in populations that are at an increased risk for cancer.

# Disparities in Cancer Screening for Early Detection

## IN THIS SECTION, YOU WILL LEARN:

- Screening for cancer means looking for cancer or abnormal cells that may become cancerous in people who do not have any signs of the disease.
- Routine cancer screening and follow-up care saves lives.
- Racial and ethnic minority groups and medically underserved populations experience disparities in adherence to routine cancer screening and follow-up care.
- A multitude of systemic factors contribute to disparities in cancer screening.
- Research has identified a series of evidence-based interventions that are proving successful in reducing disparities in adherence to recommended cancer screening and follow-up care.

Cancer screening refers to checking for cancer, or abnormal cells that may become cancerous, in people who do not have signs or symptoms of the disease. The purpose of screening is to detect abnormalities at the earliest possible phase when cancer can be more effectively treated and is potentially curable (see **Figure 11**, p. 84). Different kinds of tests are used for early detection, including laboratory tests that can detect cancer-related cellular or molecular changes in biospecimen samples, and imaging or endoscopic procedures that can look for cancer-specific abnormalities in the tissue (see **Sidebar 20**, p. 85). Information obtained from cancer screening tests helps health care providers decide whether to monitor or treat precancerous lesions or early-stage cancer before they progress to a more advanced stage.

## Eligibility for Cancer Screening

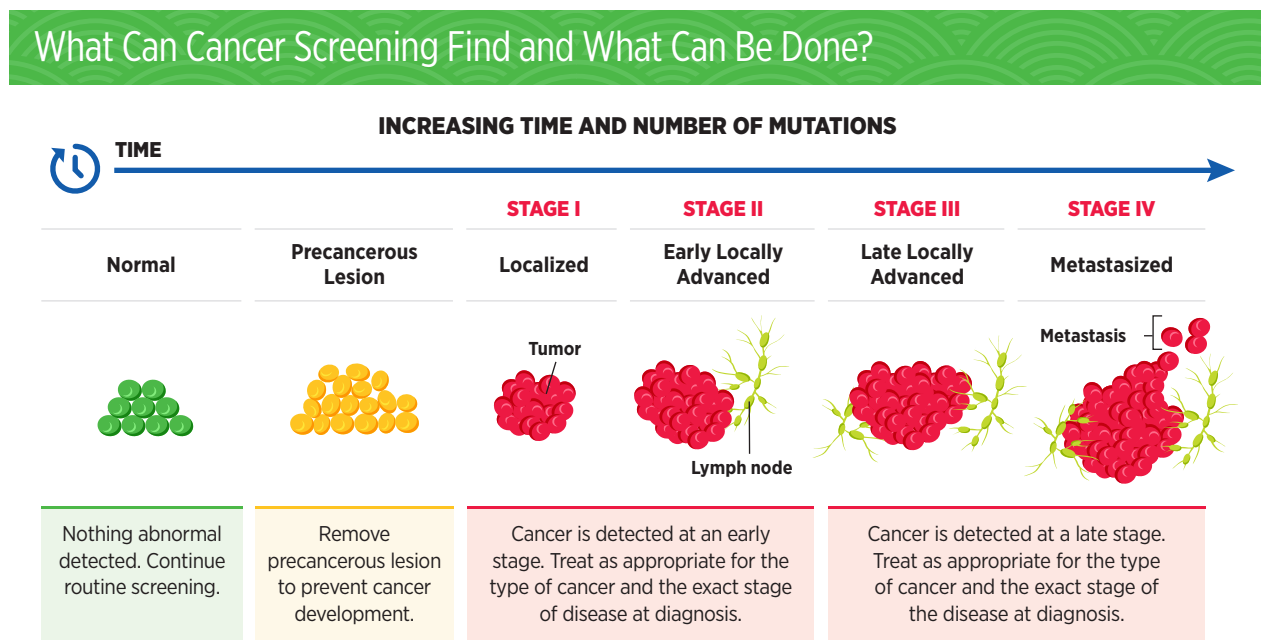
Guidelines for cancer screening are carefully developed by groups of subject matter experts convened by government agencies and some professional societies focused on public health. In this report, we use the US Preventive Services Task Force (USPSTF)—a congressionally mandated independent panel of experts convened by the Agency for Healthcare Research and Quality of the US Health and Human Services (HHS) department—and its process for developing guidelines as an example. USPSTF’s mandate includes making evidence-based recommendations that can be used in primary care settings to prevent disease, including cancer.

USPSTF guidance for cancer screening includes recommendations for screening certain individuals at certain intervals and recommendations against screening that has been shown to be harmful, as well as information that there is insufficient evidence to make a recommendation. For the finalized guidelines, USPSTF assigns a grade to its recommendations. The grade reflects confidence in the available evidence for the recommendation and also informs which services are covered without out-of-pocket costs under the Patient Protection and Affordable Care Act (ACA). USPSTF can also assign different grades to different population groups within the same cancer type as part of its screening guidelines (see **Sidebar 21**, p. 86). Throughout the process, USPSTF seeks input from the public. The finalized recommendations and review of the scientific evidence used to develop recommendations are published in a scientific journal and on the USPSTF website.

USPSTF develops cancer screening guidelines for individuals who are at an average risk of being diagnosed with cancer, as well as for those who are at a higher-than-average risk. Individuals at average risk of being diagnosed with cancer are those who do not have a family history of cancer or personal history of cancer, and do not have an inherited genetic condition that places them at a higher risk of developing cancer. Two key considerations for recommending screening in average-risk individuals are gender and age. Individuals at a higher-than-average risk of being diagnosed with cancer are those who have a strong family history of cancer, a personal history of cancer,



**FIGURE 11**



Results of cancer screening tests can be negative, positive, indeterminate, or incomplete. If the test does not indicate an abnormality, routine cancer screening should be continued as long as its benefits for the person continue to outweigh potential harms. If the test detects a precancerous lesion, the lesion can be treated, thus minimizing the likelihood of its progression into cancer. If the test finds early-stage cancer, for example, stage I or stage II for a solid tumor, the patient can be treated successfully and has a higher likelihood of a cure. If the test finds late-stage cancer, for example, stage III or stage IV for solid tumors, the likelihood of a cure decreases significantly. Treating a precancerous lesion or cancer at the earliest stage of development is called cancer interception, which is an area of active research for its potential to minimize the burden of cancer.

Adapted from (189).

certain tissue make-up, an inherited genetic condition, or who are exposed to one or more cancer risk factors, all of which place them at a higher risk of developing cancer. One example is individuals who smoke, which significantly increases their likelihood of developing lung cancer and dying from it (see **Disparities in the Burden of Preventable Cancer Risk Factors**, p. 66).

Another example of individuals at a higher-than-average risk of being diagnosed with cancer is women with extremely dense breast tissue. Density of the breast tissue in a mammogram is determined by the comparative amounts of fibrous, glandular, and fat tissues that make up the breast. The higher the amount of fibrous and glandular tissue, the denser the breast tissue appears in the mammogram. Having dense breast tissue is not considered abnormal, but it is one of the risk factors for developing breast cancer (495).

People with inherited cancer susceptibility syndromes, also called hereditary cancer syndromes, constitute another group of individuals who are at higher-than-average risk of being diagnosed with cancer. Hereditary cancer syndromes are caused by genetic mutations that can be passed on from

In a study that examined 2.6 million breast density measurements across the United States, the **prevalence of dense breast was 19 percent higher in Asian women, 8 percent higher in Black women, the same in Hispanic women,** and 4 percent lower in non-Hispanic White women, compared to the overall prevalence of dense breast (496).



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one generation to the next and can predispose an individual to develop certain types of cancer. For example, individuals who have Lynch syndrome, which is caused by mutations in genes important for repairing damaged DNA, have an increased risk of developing colorectal cancer, endometrial cancer, ovarian cancer, prostate cancer and several other types of cancer.

Some of the factors used to determine eligibility for cancer screening, such as exposure to cancer risk factors, are

*continued on page 86*

## SIDEBAR 20

## USPSTF-recommended Tests to Screen for Cancer

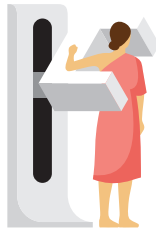
Mandated by Congress and convened by the Agency for Healthcare Research and Quality, the US Preventive Services Task Force (USPSTF) is an independent panel of experts in preventive care. USPSTF rigorously reviews the evidence on the benefits and harms of screening strategies, behavioral counseling, and preventive medications related to cancer.

Tests described below are a part of evidence-based recommendations by USPSTF\* to screen for four cancer types in individuals who are at an average risk of being diagnosed with cancer, and to screen for lung cancer in individuals who are at a higher-than-average risk of being diagnosed with lung cancer.

### Breast Cancer

#### DIGITAL MAMMOGRAPHY

Uses X-rays to generate two-dimensional images of the breast that are stored electronically and analyzed for signs of breast cancer.



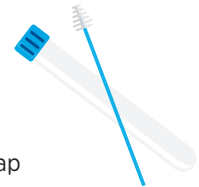
#### DIGITAL BREAST TOMOSYNTHESIS

Also called three-dimensional (3D) mammography, this screening method generates 3D images of the breast that are analyzed for signs of cancer. It must be accompanied by digital mammography.

### Cervical Cancer

#### CYTOLOGY

Samples cervical cells, which are analyzed under a microscope to look for abnormalities. It is also called a Pap test or Pap smear.



#### HIGH-RISK HUMAN PAPILLOMAVIRUS (HPV) TEST

Detects the presence of certain cervical cancer-causing types of HPV and identifies people for whom further testing is recommended. It does not directly detect precancerous or cancerous cervical lesions.

### Colorectal Cancer

#### STOOL-BASED TESTS



Some of these test for the presence of a product of red blood cells. Others test for both the presence of a product of red blood cells and certain genetic mutations linked to colorectal cancer. They do not directly detect precancerous lesions or cancers but identify people for whom further testing is recommended.

#### DIRECT VISUALIZATION TESTS

##### Flexible sigmoidoscopy and colonoscopy

Uses a thin, flexible, lighted tube with a small video camera on the end to examine the lining of the entire colon and rectum (as is the case with colonoscopy) or only certain parts (as is the case with flexible sigmoidoscopy).



##### Computed tomography (CT) colonography

(virtual colonoscopy) Uses X-rays to image the colon and rectum.



### Lung Cancer

#### LOW-DOSE CT SCAN

Uses a lower dose of X-rays to rapidly image the lungs and detect any abnormalities (e.g., nodules) suggestive of lung cancer. Suspicious lesions may be biopsied to examine for abnormal or cancer cells.



### Prostate Cancer

#### PSA TEST

Measures the level of a protein called prostate-specific antigen (PSA) in blood, which is often elevated in men with prostate cancer. Does not directly detect prostate cancer but identifies men for whom further testing is recommended.








\* It is noteworthy that clinicians sometimes use tests beyond those recommended by USPSTF to detect cancer. For example, magnetic resonance imaging (MRI), which is not a USPSTF-recommended test and is not typically used to screen for breast cancer, may be performed to further evaluate abnormal findings on mammograms under certain circumstances.

Adapted from (189).

## SIDEBAR 21

## USPSTF Guidelines for Cancer Screening

Cancer Type	USPSTF Guidelines*	USPSTF Grade <sup>†</sup>
<b>BREAST</b> 	<ul style="list-style-type: none"> <li>Screening mammography recommended every other year for women ages 40 to 74.</li> <li>Screening mammography not recommended for women age 75 or older.</li> </ul>	<b>B</b> <b>I</b>
<b>CERVICAL</b> 	<ul style="list-style-type: none"> <li>Cervical cytology recommended every 3 years for women ages 21 to 65; high-risk human papillomavirus testing alone, or in combination with cytology, every 5 years for women ages 30 to 65.</li> <li>Cervical cancer screening not recommended in women younger than 21 years, or older than 65 years.</li> </ul>	<b>A</b> <b>D</b>
<b>COLORECTAL</b> 	<ul style="list-style-type: none"> <li>Stool-based tests every 1 to 3 years; colonoscopy every 5 to 10 years; flexible sigmoidoscopy every 5 years or every 10 years with annual stool-based test recommended for all adults ages 50 to 75.</li> <li>Stool-based tests every 1 to 3 years; colonoscopy every 5 to 10 years; flexible sigmoidoscopy every 5 years or every 10 years with annual stool-based test recommended for all adults ages 45 to 49.</li> </ul>	<b>A</b> <b>B</b>
<b>LUNG</b> 	<ul style="list-style-type: none"> <li>Low-dose computed tomography (LDCT) every year recommended for all adults ages 50 to 80 who currently smoke or formerly smoked within the past 15 years, with a 20 pack-year smoking history. Screening should be discontinued once a person has not smoked for 15 years or develops a health problem that substantially limits life expectancy or the ability or willingness to have curative lung surgery.</li> </ul>	<b>B</b>
<b>PROSTATE</b> 	<ul style="list-style-type: none"> <li>Periodic prostate-specific antigen-based test, by making a shared decision with health care provider through an ongoing dialogue, recommended for men ages 55 to 69.</li> <li>PSA-based screening not recommended in men 70 years and older</li> </ul>	<b>C</b> <b>D</b>

USPSTF, United States Preventive Services Task Force

\* Only USPSTF recommendations are included here. Several other professional societies issue evidence-based screening guidelines for types of cancer listed here that may differ from those issued by USPSTF. Furthermore, guidelines have been simplified for brevity. Readers are advised to visit the USPSTF website for a complete description and more detailed information.

<sup>†</sup> Grade A: Screening recommended because of high certainty that net benefit is substantial.

Grade B: Screening recommended because of high certainty that net benefit is moderate.

Grade C: Selective screening recommended based on professional assessment and patient preferences because of moderate certainty that net benefit is small.

Grade D: Screening not recommended because of moderate to high certainty that screening has no net benefit, or that the harms outweigh the benefits.

I Statement: Insufficient evidence to assess the balance of benefits and harms of screening.

different for each person and may change throughout life. It is also noteworthy that cancer screening is a process and not a single test or scan. Depending upon the findings of the initial screening test, an individual may need follow-up exams and additional medical procedures. Therefore, it is important that people empower themselves with the most up-to-date information on cancer screening eligibility by having an ongoing dialogue with their health care providers and develop a personalized cancer screening plan that considers their specific risks and tolerance of potential harms from screening tests.

## Importance of Cancer Screening and Follow-up

The overall goal of cancer screening is to reduce the burden of cancer in the general population. There are several benefits of adherence to the recommended cancer screening. Studies using real-world observations or computer models have shown that screening for cancer in eligible individuals prevents cancer deaths. Recent findings from a large, international study revealed that routine screening detected

## SIDEBAR 22

## Benefits and Potential Harms of Cancer Screening

The US Preventive Services Task Force (USPSTF) or other professional societies focused on cancer care meticulously review the available scientific evidence to weigh benefits of screening for a specific cancer type against potential harms before issuing final screening guidelines. In the recommended screening guidelines, benefits of cancer screening outweigh its potential harms:

Benefits of Screening **REDUCED CANCER MORTALITY**

If a screening test detects precancerous lesions or cancer at an early stage of development, it may increase the likelihood that a patient can be successfully treated, thus reducing the risk of dying from cancer.

**REDUCED CANCER INCIDENCE**

If a screening test detects precancerous lesions, removing these lesions can reduce, or even eliminate, an individual's risk of ever developing the screened cancer.

**REDUCED LIKELIHOOD OF ADVANCED DISEASE**

If a screening test detects cancer at an early stage of development, it may reduce an individual's risk of being diagnosed with the screened cancer at an advanced stage, thus making treatment more successful and avoiding more complex treatment regimens.

Potential Harms of Screening\* **FALSE-POSITIVE TEST RESULTS**

Screening tests could give false-positive results in individuals who do not have the screened cancer, leading to additional unnecessary medical procedures, treatments, and anxiety.

**OVERDIAGNOSIS AND OVERTREATMENT**

Screening tests could sometimes overdiagnose, which is the detection of precancerous lesions or cancers that may not go on to cause symptoms and threaten life, leading to overtreatment (i.e., unnecessary treatment) with its own potential harms.

**INCIDENTAL FINDINGS**

Screening tests could find an unrelated medical issue—such as finding an unrelated heart problem—and may require follow-up tests or procedures, which also have risks.

**ADVERSE EVENTS**

Screening tests could carry risks of harm. For example, colonoscopy can potentially cause a cut in the wall of the colon in rare cases.

**ANXIETY**

Screening tests could cause fear, worry, and/or anxiety in individuals who are eligible for cancer screening and may not have the disease.

**FALSE-NEGATIVE TEST RESULTS**

Screening tests could sporadically give negative results in individuals who are not free from screened cancer, leading to missed opportunities for early treatment.

\* Harms from a cancer screening test are rare. Furthermore, the benefits-to-potential harms ratio can vary for different population groups, as well as for individuals based on age, gender, and existing medical conditions, among other factors.

stage I lung cancer in 81 percent of 1,257 study participants who were diagnosed for the first time; 81 percent of those detected with, and treated for, stage I lung cancer were living 20 years after diagnosis (497). A recent study using a mathematical model estimated that routine cancer screening has saved 12.2 to 16.2 million life-years, amounting to approximately \$6.5 to \$8.6 trillion in economic savings, since the introduction of USPSTF recommendations in 1996 (498). Another modeling study projected that just a 10-percentage point increase in adherence to the USPSTF-recommended cancer screening can prevent an estimated

15,580 additional deaths from lung, colorectum, breast, and cervix cancers combined (499).

While the benefits of routine cancer screening are many, cancer screening tests are medical procedures and do carry potential risks (see **Sidebar 22**, p. 87). Researchers use several ways to assess and describe harms from cancer screening tests. One such method assesses the harms from cancer screening tests in four broad categories: physical effects, psychological effects, financial strain, and opportunity costs (500). Experts carefully consider risks and benefits



**TABLE 5**

## Percentage of Eligible Individuals Up to Date With USPSTF Screening Guidelines in the United States in 2021

		Breast Cancer*	Cervical Cancer*	Colorectal Cancer*	Prostate Cancer†	Lung Cancer‡
<b>Overall Screening Uptake</b>		<b>75.6</b>	<b>75.5</b>	<b>71.6</b>	<b>36.3</b>	<b>16.4</b>
<b>Race and Ethnicity</b>	White	75.7	78.1	74	40.2	16.5
	Black	81.6	73.3	71.3	32.5	17.1
	Hispanic	73.8	68.7	62.1	26.7	15.7
	AI/AN	52.8	64	62.6	N/A	12.9
	Asian	66.6	63.6	60.9	17.6	23.1
<b>Place of Residence</b>	Large central metro	75.5	73.1	71.7	N/A	N/A
	Nonmetropolitan	72.2	72	69.3	N/A	N/A
<b>SOGI</b>	Straight	76	76	72.4	N/A	N/A
	Gay or lesbian	78.8	71.4	76.1	N/A	N/A
	Bisexual	60.6	69.4	70	N/A	N/A
<b>Income</b>	> 400 FPL	81.4	83.4	78.6	76.8	14.5
	≤ 138 FPL	64.8	67.4	60.3	8.9	17.5
<b>Education</b>	College degree	81.4	83.8	78.4	N/A	16.6
	Less than high school	63.6	57.7	59.2	N/A	13.9
<b>Disability</b>	No	77	75.8	72.3	N/A	N/A
	Yes	65.8	64	71.6	N/A	N/A

AI/AN, American Indian or Alaska Native; FPL, Federal Poverty Level; N/A, Not Available; SOGI, Sexual Orientation/Gender Identity; USPSTF, US Preventive Services Task Force. \* Source: (509).

† Source: Star et al. (2023) J Clin Oncol. 41:4352. Income thresholds are >200% of FPL and <100% of FPL.

‡ Source: Henderson et al. (2024) JAMA Netw Open. 7:e243190. Income thresholds are >\$100,000 and <\$25000. Data year for lung cancer screening is 2022. Numbers represent prevalence of lung cancer screening according to the 2021 USPSTF guidelines.

of cancer screening tests when developing screening recommendations. Thus, findings of a recent study that some cancer screening recommendations and guidelines did not include potential harms associated with the tests are concerning (501). It is critical that the information about benefits and potential harms of cancer screening is clearly and easily available so that people can make an informed decision in consultation with their health care providers.

### Disparities in Cancer Screening

Following the recommended cancer screening is one of the most important ways to reduce cancer burden at the population level. Unfortunately, adherence to cancer screening remains suboptimal. Furthermore, screening patterns vary for different types of cancer among racial and ethnic minority groups, citizens of sovereign Native Nations, and medically underserved populations (see **Table 5**, p. 88). Disparities in genetic testing for cancer risk are also

prevalent (502). Multiple barriers contribute to low rates of cancer screening and genetic testing, including social and structural barriers; bias and discrimination against minoritized populations in the health care system; mistrust of health care professionals among minoritized populations; lack of access to quality health insurance and coverage; low health literacy; and miscommunication between patients and providers (see **Sidebar 23**, p. 89). In this report, we discuss disparities in screening for five cancer types for which USPSTF currently has screening guidelines for individuals who are at an average risk of developing breast, cervical, colorectal, and prostate cancers, as well as for individuals who are at a higher risk of developing lung cancer. We also highlight some of the interventions that have helped close disparities in cancer screening.

### Breast Cancer Screening

Racial and ethnic minority populations and medically underserved communities experience substantial disparities

## SIDEBAR 23

## Factors Associated with Disparities in Cancer Screening

Racial and ethnic minority groups and medically underserved populations experience disparities in cancer screening uptake, as well as in receiving follow-up testing when the initial cancer screening test shows abnormality.

**Examples from recent studies presented here highlight factors that are associated with disparities in cancer screening and follow-up testing:**



### HEALTH INSURANCE

Compared to those with private insurance, uninsured individuals who underwent initial lung cancer screening were 56 percent less likely to receive subsequent recommended annual lung cancer screening (503).



### NEIGHBORHOOD VULNERABILITY

Compared to those living in counties with a low social vulnerability index (SVI)—a measure of the potential negative effects on communities caused by social factors such as poverty, lack of transportation, and crowded housing—residents in high-SVI counties were 28 percent less likely to undergo colorectal cancer screening (504).



### STRUCTURAL BARRIERS

Black patients were 27 percent less likely than White patients to adhere to annual screening in decentralized lung cancer screening programs. This disparity was not observed in centralized lung cancer screening programs where multiple needs of patients (e.g., eligibility, medical reporting, follow-up care, smoking cessation) were integrated in one place (505).



### DISABILITY STATUS

Compared to women without intellectual and developmental disabilities, those with intellectual and developmental disabilities were 33 percent less likely to undergo breast cancer screening (506).



### PATIENT-PROVIDER COMMUNICATION

Compared to non-Hispanic White adults, Asian adults who reported lower quality of patient-provider communication were 26 percent less likely to receive the recommended colorectal cancer screening (507).



### GEOGRAPHIC ACCESSIBILITY

Counties with persistent adult poverty in 594 federally recognized American Indian and Alaska Native tribes were 53 percent less likely to have a cancer screening center within 200 miles (508).

in receiving the recommended breast cancer screening, as well as in the follow-up care if the screening mammogram shows an abnormality. In 2021 in the United States, only 52.8 percent American Indian and Alaska Native (AI/AN) and 66.6 percent of Asian women were up to date with breast cancer screening, compared to 75.7 percent of non-Hispanic (NH) White women (see **Table 5**, p. 88). Similar disparities in the receipt of breast cancer screening were apparent based on education, income, and sexual orientation (see **Table 5**, p. 88). Furthermore, women under the age of 65 who had private insurance were about twice as likely to be up to date with breast cancer screening as those without any insurance (80.1 versus 42.3 percent, respectively) (509). One study found that in 2019 in the United States, the rate of NH Asian women who were eligible for breast cancer screening but never received it was 12.6 percent, the highest among racial and ethnic minority populations (510).

Researchers are continually working to improve screening guidelines to capture cancers early, particularly in populations that may be at an increased risk of developing breast cancer. One study of nearly half a million women who died of breast cancer between 2011 and 2020—recommended start age for breast cancer screening was 50 years during this time—found that screening guidelines could be tailored specifically for women belonging to different racial and minority groups. For example, the findings suggested that screening for breast cancer could start 8 years earlier for Black women (511). USPSTF is currently finalizing recommendations to start breast cancer screening at age 40, which is expected to save 19 percent more lives from breast cancer (512). Other professional societies are recommending that all Black women should undergo baseline assessment for future risk of breast cancer by a trained health care professional no later than age 25 years (513).

Compared to White women, **Black women** were more than **twice as likely to be diagnosed with cancer at the first mammogram** (514).



W33

A systematic review of the literature identified multiple barriers to adherence to breast cancer screening among vulnerable populations, including those with unemployment, lack of private health insurance, limited access to transportation, low income, and recency of immigration (515). One study found that Asian women who recently immigrated to the United States had low rates of breast cancer screening compared to long-term immigrants or US-born Asian women (516). Another review found that compared to their heterosexual counterparts, lesbian and bisexual women were less likely to participate in mammography. Furthermore, transgender individuals had lower rates of screening than cisgender individuals for all cancer types (517). The study found that better communication with health care providers was the strongest facilitator among SGM individuals to stay up to date with routine cancer screening.

Research has also identified disparities across the cancer screening continuum. For example, findings from a recent study show that Black women had lower rates of referrals for breast cancer screening by a provider, compared to White women (9 percent vs. 13 percent, respectively), and 15 percent to 26 percent lower likelihood of completing mammography (518). Another study found that Black and Hispanic women living in rural Texas were, respectively, 33 percent and 22 percent less likely to be regular users of mammography compared to their urban counterparts (519). The study identified the lack of primary care physicians as one of the major barriers to routine breast cancer screening.

## Cervical Cancer Screening

There are stark disparities in adherence to screening for cervical cancer. In 2021, only about 64 percent of eligible Asian and AI/AN individuals were up to date with USPSTF-recommended cervical cancer screening compared to 78 percent of White individuals. Additionally, significant disparities existed based on income level, educational attainment, disability, and insurance status (see **Table 5**, p. 88) (509). Studies have also found that older eligible women (ages 60 to 64) were less likely to be up to date with cervical cancer screening (520).

Many other vulnerable populations also experience disparities in receipt of cervical cancer screening. For instance, members of the SGM community, especially those identifying as transgender, experience substantial disparities in routine screening for cervical cancer. According to a recent study, between 2016 and 2018, nearly 25 percent of transgender individuals reported that they have never been screened for

cervical cancer in their lifetime, compared to 7 percent of cisgender individuals (521). Furthermore, 41.3 percent of Hispanic and 67.7 percent of API respondents who identified as transgender men indicated that they had never been screened for cervical cancer, compared to 20.5 percent of NH White respondents who identified as transgender men (521). Another study found that women with two or more disabilities were 12 percent less likely to receive cervical cancer screening than women who did not have any disabilities (522).

Research has identified multiple factors, such as access to, and accommodation by, health care systems, that can help increase adherence to cervical cancer screening. For example, racial and ethnic minority patients and individuals with low household income often seek care at community health centers, as these facilities offer services to everyone, regardless of factors such as health insurance status (523). One study investigated the association of ethnicity and preferred language with adherence to cancer screening at community health centers. Findings show that patients seen at clinics with higher concentrations of Spanish-speaking residents were significantly more likely to be up to date with cervical cancer screening, as were individuals residing in areas with higher percentages of Spanish-speaking residents. Compared to NH White adults, Spanish-speaking Hispanic adults were 53 percent more likely and English-speaking Hispanic adults were 14 percent more likely to be up to date with cervical cancer screening. Furthermore, adherence to cervical cancer screening increased with an increase in the Spanish-speaking staff at the community health care facility (524). It would be important to further examine how strategies that contribute to higher cervical cancer screening at community health centers can be implemented to other health care systems.

Another study found that having routine health care checkups was a strong predictor of being up to date with cervical cancer screening. The study compared a racially and ethnically diverse population of women who had a routine health care checkup within the past year with women who had a routine health care checkup more than 5 years ago or never had one (520). Findings revealed that women with a routine checkup within the year were significantly more likely to be up to date with cervical cancer screening, ranging from nearly nine times more likely for NH Asian women to 19 times more likely for NH Black women. Furthermore, women who received a mammogram for breast cancer screening were more than twice as likely to also be up to date with cervical cancer screening compared to women who did not receive a screening mammogram (520).

Immigration status also appears to play a significant role in adherence to the recommended cervical cancer screening. For example, immigrant NH Asian and Hispanic women were, respectively, 71 percent and 49 percent less likely to be up to date with cervical cancer screening compared to US-born NH White women. When adjusted for SES and access to care, the disparity was eliminated for immigrant Hispanic women, but not for immigrant Asian women (516).

## Colorectal Cancer Screening

The percentage of adults up to date with colorectal cancer screening in 2021 was 72.2 percent (509). However, significant disparities existed among various population groups. Compared to NH White adults, uptake of colorectal cancer screening was substantially lower in Hispanic, Asian, and AI/AN adults. Furthermore, those living 138 percent below the federal poverty level, as well as those with less than a high school education, were less likely to be up to date with colorectal cancer screening (see **Table 5**, p. 88). Similarly, compared to those with private insurance, uninsured individuals were 60 percent less likely to be up to date with colorectal cancer screening and 47 percent less likely to receive a follow-up colonoscopy (509,525).

Another study, evaluating data from more than 220,000 adults, reported that individuals from all racial and ethnic minority populations had significantly lower likelihood of being up to date with colorectal cancer screening, compared to NH White individuals. Importantly, accounting for certain SDOH, such as income and education; behavioral factors, such as smoking status, i.e., those who are currently smoking; and other demographics, such as age and sex; either eliminated or significantly reduced this disparity (526). For example, after accounting for these factors, the disparity in the receipt of colorectal cancer screening decreased by 21 percentage points for Black adults, 25 percentage points for Hispanic adults, and 20 percentage points for AI/AN adults, although it remained lower compared to NH White adults (526). These findings indicate that addressing SDOH can help decrease disparities in adherence to colorectal cancer screening and follow-up care.

Compared to White individuals, **Black individuals** were 38 percent less likely to have a colorectal cancer early detection test ordered on the same day as the initial appointment, and 50 percent less likely to have colonoscopy performed within 1 year of the initial health care visit (527).



W34

In 2021, USPSTF revised its recommendation to start colorectal cancer screening at the age of 45 (189). However, researchers have raised concerns that the implementation of revised recommendations can further increase colorectal cancer disparities, especially for Black and AI/AN populations. As one example, an estimated 10.7 million additional colonoscopies may be required as a result of the recommendation change, which can limit access among medically underserved populations unless the number of facilities with a capacity to perform colonoscopies are expanded (528).

Immigration status and length of stay in the United States is also an important determinant of adherence to colorectal

cancer screening. One study found that individuals who immigrated to the United States within the past 15 years were 21 percent less likely to be up to date with colorectal cancer screening compared to those who were born in the United States (529). The analysis showed additional variations among different racial and ethnic populations. Asian and Hispanic individuals who immigrated to the United States within the past 15 years were, respectively, 26 percent and 14 percent less likely to be up to date with colorectal cancer screening compared to those who were born in the United States (529).

Benefits of colorectal cancer screening are highlighted by a recent modeling study (530). Researchers used incidence rates of colorectal cancer among White and Black people from 1979 to 2018 to estimate the effect of colorectal screening on lifetime incidence rates. The model projected that routine colorectal cancer screening would decrease lifetime incidence rates for colorectal cancer and increase total life-years saved in both populations, but the benefit was greater for Black people (530).

## Lung Cancer Screening

Despite the evidence that adhering to screening reduces lung cancer-related deaths by more than 20 percent (531,532), only 5.8 percent of eligible individuals in the United States were up to date with low-dose computed tomography (LDCT) in 2021 (311). Furthermore, a recent study found that adherence to the recommended follow-up annual lung cancer screening after a positive LDCT finding was only 22.3 percent among more than one million patients who underwent initial screening between 2015 and 2019 (503). In addition to the overall low adherence rates for LDCT, significant disparities exist between White individuals and those belonging to racial and ethnic minority populations (see **Table 5**, p. 88).

In a study of one million people screened for lung cancer between 2015 and 2019, **Black, Hispanic, and Asian individuals** were, respectively, 16 percent, 27 percent, and 21 percent less likely to have at least one lung cancer screening following initial screening examination that showed a positive finding, compared to White individuals (503).



W35

A systematic review and meta-analysis of nine studies found that Black individuals were 33 percent less likely than White individuals to adhere to follow-up recommendations after the initial LDCT. Furthermore, compared to White individuals, Black individuals were 44 percent less likely to follow up after a positive LDCT finding (533). These findings are concerning



because Black people are more likely to be diagnosed with lung cancer at an advanced stage (2), highlighting the critical need for adhering to routine screening and follow-up.

Researchers are continually improving eligibility criteria for lung cancer screening. In March 2021, USPSTF revised its recommendation for lung cancer screening, which significantly increased the number of eligible people who are considered at high risk for lung cancer, including women and Black individuals. Initial evaluation suggested that revised guidelines have reduced eligibility disparities, especially for Black adults (534,535). However, recent studies have shown that the guidelines still fall short of accounting for all the racial and ethnic differences in lung cancer risk. For example, two recent studies compared the updated 2021 USPSTF guidelines, which are based on age and smoking history, with a risk-based criteria that accounted for additional factors, including family history and other health issues, such as previous cancer diagnoses (536,537). One study of nearly 6,000 lung cancer cases from a diverse patient population found that, compared to 2021 USPSTF guidelines, using the guidelines founded on a risk-based model has the potential to reduce the lung cancer screening disparity by more than half for Black adults, but increased it by more than double for Hispanic individuals compared to White adults (536). The second study used data from more than 100,000 adults from diverse racial and ethnic backgrounds with a history of smoking. Similar to the first study their findings also show that the risk-based guidelines have a greater potential to reduce lung cancer screening disparities between Black and White populations (537).

Disparities in adherence to lung cancer screening also exist in other racial and ethnic populations. As one example, a recent study from Hawai'i showed that there was a 14 percent to 15 percent gap in completion of lung cancer screening among various population groups (538). Findings from the study show that Asian individuals had the highest screening completion rate (86 percent), followed by Native Hawaiian (80 percent) and NH White individuals (80 percent), and Pacific Islander individuals (79 percent). Within Asian subpopulations, Korean (94 percent) and Japanese (88 percent) individuals had the highest completion rates followed by Chinese individuals (82) and Filipino individuals (79 percent) (538).

Evidence indicates that racial disparities in lung cancer screening are attributable to multilevel factors that include socioeconomic factors, such as cost, as well as structural barriers, such as transportation. However, a recent study found that disparities in the completion of lung cancer screening between White and Black patients persisted at a Veterans Affairs health care system, where health care system-related barriers are minimal. Of the 4,562 veterans who were referred for lung cancer screening, only 37 percent completed screening overall, and Black veterans were 34 percent less likely to complete screening compared to White veterans (539). Another study of individuals with a history of smoking found that the receipt of annual lung cancer screening was significantly less among Black patients compared to White

patients (23.6 percent vs. 33.6 percent, respectively) (540). The study also showed that as the neighborhood SES where patients lived improved, adherence to lung cancer screening for both White and Black patients also increased, eliminating half of the racial disparity. These findings further indicate that racial disparities in lung cancer screening are not fully explained by SES differences.

## Prostate Cancer Screening

According to the most recent estimates, in 2021, 40.2 percent of White men, 32.5 percent of Black men, and 26.7 percent of Hispanic men ages 55 to 69 years had a prostate-specific antigen (PSA) test to screen for prostate cancer within the past year (see **Table 5**, p. 88) (541). Recent evidence from the US Veterans Health Administration comparing PSA screening tests and prostate cancer diagnoses between 2005 and 2019 across 128 facilities suggests that facilities with higher PSA screening rates had lower rates of metastatic prostate cancer 5 years later (542).

Current USPSTF guidelines for individuals at an average risk of being diagnosed with prostate cancer recommend shared decision-making in which individuals should routinely discuss benefits and potential harms of receiving PSA testing with their health care provider (see **Sidebar 21**, p. 86). The guidance for a shared decision is because data are lacking to make a specific recommendation. As one example, even though Black men have an estimated 70 to 110 percent higher incidence and mortality rate for prostate cancer than White men (543), they were poorly represented in the screening studies that informed current guidelines (544). Researchers are suggesting that a discussion about prostate cancer screening between Black individuals and their health care provider should start at a younger age (e.g., 45 to 50 years) and at more frequent intervals compared to other racial and ethnic groups (545).

Although large-scale data remain sparse, there is accumulating evidence of significant disparities in prostate cancer screening for transgender individuals. Researchers have found that prostate cancer screening rates are significantly lower among eligible transgender women (546). One study found that transgender women were 35 percent less likely to have received prostate cancer screening compared to cisgender men (547). Importantly, when providers recommended the PSA test and initiated a discussion of its advantages and disadvantages, the disparity was nearly eliminated, and transgender women were 12 times more likely to have recently undergone screening (547).

Research has shown that shared decision-making between a patient and a provider is critical to increasing uptake in prostate cancer screening. One study found that, compared to men who received no information about PSA testing from their health care provider, men who received information about both benefits and harms were three times more likely to undergo PSA testing

(548). Similarly, another study of nearly seven million men who received PSA screening for prostate cancer in 2020 showed that shared decision-making more than doubled the likelihood of PSA screening (549). Unfortunately, Black and Hispanic men were less likely to report shared decision-making and were, respectively, 23 percent and 49 percent less likely to undergo PSA screening compared to White men (549).

## Eliminating Disparities in Cancer Screening Through Evidence-based Interventions

Disparate adherence to cancer screening and follow-up care contributes to disproportionately higher rates of advanced-stage cancer diagnoses and cancer-related deaths in racial and ethnic minority groups and medically underserved populations. However, eliminating disparities in cancer screening requires that the root causes of suboptimal uptake in screening and follow-up care are identified and addressed. All sectors must work in concert to develop and implement multipronged approaches to dismantle structural racism, discrimination, and other societal inequities that pose significant barriers in equitable access to all aspects of the cancer screening continuum. In the following sections, we highlight some of the evidence-based interventions that have proven to be effective in increasing cancer screening awareness, adherence, and follow-up in racial and ethnic minority groups and medically underserved populations. It is also important to note that not all evidence-based interventions are effective for all communities, and additional work is required to refine these approaches for specific populations.



According to a systematic review of the literature, **interventions that addressed one or more social drivers of health**—such as providing transportation and covering the cost of the procedure, among others—**increased screening** by 8.4 percentage points across cancer types (colorectal, cervical, breast, and lung) (550).

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### Public Health Campaigns

In 2015, CDC funded the Colorectal Cancer Control Program (CRCCP) with the goal of increasing CRC screening. The program provided funds to states, organizations, and institutes to develop partnerships with primary care clinics and implement four evidence-based interventions: patient reminders, provider reminders, reduction of structural

barriers, and provider assessment and feedback. In its current iteration, initiated in 2020, CRCCP has funded 35 awardees that include state public health departments, universities and institutes, and tribal organizations (551).

Since its launch, awardees of the CRCCP program have taken several approaches to increase CRC screening among populations they serve. For example, the *Iowa Get Screened: Colorectal Cancer Program*, which helps people with low income get screened for CRC, offered patients payment for gas if they had to travel to the clinic to drop off their fecal immunochemical test kit. The intervention increased CRC screening from about 33 percent in 2015 to 57 percent in 2020 (552).

As part of the intervention, a health center in Chicago trained medical assistants about CRC and how to educate patients about it; they sent reminder text messages to patients to get screened, and, on provider reports, included information about the number of patients who should have been offered a screening. As a result of this multipronged approach, the overall CRC screening nearly doubled in 4 years. During the same time, the number of tests ordered for Hispanic patients increased nearly three times (from 17 percent to 49 percent), while the returned completed test increased more than 10 times (from 3.5 percent to almost 37 percent) (552).

CDC also administers the National Breast and Cervical Cancer Early Detection Program (NBCCEDP), which provides those with low income and without adequate insurance access to breast and cervical cancer screening, among other services (e.g., patient navigation) to overcome structural barriers and get quality care (see **Funding Research and Supporting Innovative Programs to Address Disparities and Promote Health Equity**, p. 157). Currently in its 33rd year, the program provided more than 300,000 breast and cervical cancer screenings in 2022 alone, the most recent year for which such data are available (152).

### Access to Health Insurance

Access to, and quality of, health care insurance is a significant contributor to disparities in uptake of cancer screening. In a recent study, researchers used data from National Health Interview Surveys (2010, 2015, 2018, 2019, and 2021) to address the role of access to health insurance in adherence to cancer screening. The findings show that patients without health insurance coverage had the lowest screening rates (553). Furthermore, patients who had continuous private health insurance coverage had higher screening rates for breast cancer (80.5 percent), colorectal cancer (65.4 percent), and cervical cancer (80 percent). In contrast, patients who had gaps in health insurance coverage had lower screening rates (63.1 percent for breast cancer, 47.1 percent for colorectal cancer, and 73.1 percent for cervical cancer) (553).

The ACA and the associated expansion in Medicaid eligibility adopted by most states has positively impacted

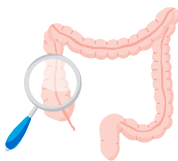
access of medically underserved populations to health care (see **Policies to Address Disparities in Cancer Screening and Follow-up Care**, p. 162) (554). One study found a 16 percent increase in colorectal cancer screening among low-income individuals living in states with expanded Medicaid eligibility compared to those living in states with no Medicaid expansion (555).

## Culturally Tailored Strategies

Researchers are also taking innovative approaches by engaging communities to increase awareness about the importance of undergoing routine cancer screening, participating in clinical trials, and reducing exposure to modifiable cancer risk factors. For example, researchers developed a culturally tailored approach—using bilingual community health workers to give presentations, develop educational materials, and follow up with participants—to promote the use of HPV self-sampling tests among low-income Asian women with low English proficiency. Among the 156 participants, HPV knowledge doubled and the comfort of participants with the HPV self-sample test increased significantly (556).

**Screen to Save: NCI Colorectal Cancer Outreach and Screening Initiative** is a national program launched by the NCI Center to Reduce Cancer Health Disparities.

The initiative **aims to increase colorectal cancer screening rates** among racially and ethnically diverse communities and in rural areas by **providing culturally tailored, evidence-based colorectal cancer information, education, and screening resources** through community health educators (557).



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A systematic review of studies evaluating interventions to increase cancer screening rates found that video interventions were particularly effective in increasing cervical and breast cancer screening, especially in low-income Black women. Furthermore, videos that included culturally tailored educational material were generally more effective than information-only videos (558). Another study combined culturally adapted education material with patient navigation to increase breast and cervical cancer screening among Muslim women in New York City. Between the start of the intervention and the 4-month follow-up, mammography increased from 16 percent to 49 percent, and cervical cancer screening increased from 17 percent to 42 percent (559).

Colorectal cancer adversely affects Indigenous populations (see **Table 1**, p. 18), further highlighting the needs for effective

and culturally tailored interventions to raise the awareness and utilization of colorectal cancer screening in these communities. In a recent study, Indigenous and rural community outreach teams partnered with a community advisory board to provide an indigenized/ruralized version of the NCI Screen to Save program to both Indigenous and rural/suburban communities (560). Findings show that Indigenous/rural participants who received the culturally tailored educational material successfully identified smoking and tobacco use, as well as physical inactivity, as risk factors for colorectal cancer. Importantly, participants reported that their cancer screening experiences have increased their likelihood, as well as the likelihood of their family and friends, to receive subsequent routine screening for colorectal cancer. This example further underscores that culturally tailored interventions are effective for increasing screening awareness and adherence among Indigenous and rural populations (560).

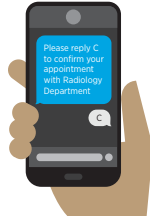
## Community Engagement and Patient Navigation

One of the key reasons that many people are not up to date with the recommended cancer screening is structural barriers, such as the lack of transportation and language barriers, among others. In an effort to improve adherence to cancer screening, constituents across the cancer care continuum are implementing a variety of interventions to reduce these barriers. For example, one cancer center in Florida implemented a multilevel strategy to improve uptake of lung cancer screening. The center alerted eligible patients about screening through electronic notifications, provided culturally competent patient navigators, arranged for interpreters to address language barriers, and held teaching sessions for providers about lung cancer and motivational communication skills (561). During the 1-year pilot program (January 2022 through December 2022), the overall lung cancer screening increased from 20 percent to 25 percent, and screening rates were higher among Hispanic and Black patients (12 and 8 percent, respectively), compared to NH White patients (6 percent) (561).

In another study, researchers implemented an innovative multidisciplinary strategy to improve access to cancer screening for the predominantly Black, medically underserved residents in West Philadelphia (562). A “one-stop-shop” health fair, held in the heart of the community, included eight core stations that provided various services from screening exams to financial counseling. The health fair was attended by 350 participants, and a total of 232 screening tests or assessments were completed. An additional 153 women underwent screening mammography during the subsequent 3 weeks at the mobile mammography unit (562).

Cancer screening rates are lower in populations with limited English proficiency, who experience additional barriers to care. Many of these populations are served by community health

Among 11,980 patients who had at least one abnormal breast, cervical, colorectal, or lung cancer screening test and enrolled in a clinical trial to evaluate the effectiveness of multilevel interventions,



**completion of follow-up for an abnormal cancer screening test result was higher among patients who received electronic health records-based reminders, outreach, and patient navigation** (31.4 percent) than those who received usual care (22.9 percent) (563).

W38

care centers, where uptake of cancer screening is low. For example, uptake of colorectal cancer screening at community health care centers is 43 percent compared to the national average of 80 percent (564). To overcome these barriers, one urban community health care center implemented patient navigation and culturally tailored education at one of its two sites; the other site was used as a reference point to examine the impact of the interventions. Findings show that patient navigation helped increase colorectal cancer screening from 31 percent to 59 percent between August 2016 and December 2018, with the most notable increase in patients with low

English proficiency (564). At the end of the pilot program in December 2018, compared to English-speaking patients, non-English-speaking patients were, respectively, two times and three times more likely to receive colorectal cancer screening by colonoscopy or a stool-based test (564).

## Improved Patient-Provider Communications

Research has shown that clear communication between patients and providers improves delivery of quality health care. One study evaluated the effectiveness of different communication methods after the initial LDCT for lung cancer screening showed a positive finding (565). Researchers found that patients whose communications mentioned “*benign*” findings were 46 percent less likely to receive recommended follow-up care compared to those whose communications did not mention “*benign*.” In contrast, patients whose communications mentioned “*abnormal*” or “*suspicious*” findings were 51 percent more likely to receive a follow-up exam. The study also found that patients who spoke to their health care providers about the initial findings by phone were three times more likely to receive follow-up care than those whose results were communicated by letter, voicemail, text, e-mail, or online portal (565).



# Disparities in Clinical Research and Cancer Treatment

## IN THIS SECTION, YOU WILL LEARN:

- Clinical trials establish whether new treatments are safe and effective; lack of sociodemographic diversity among clinical trial participants represents a major barrier to advancing cancer care for all patient populations.
- Improved diversity among clinical trial participants requires health care providers to equitably offer clinical trial options to all patients regardless of race, ethnicity, geography, or other sociodemographic factors such as health insurance.
- Improved diversity among clinical trial participants requires attention to trial design regarding accrual sites and outreach; involvement of a diverse workforce and patient navigators; use of culturally tailored patient education; and minimizing the costs associated with trial participation.
- Despite many advances in cancer treatment, patients from racial and ethnic minority groups and medically underserved populations are less likely to receive the recommended standard of care for their cancer.
- Recent studies have shown that racial and ethnic disparities in outcomes for several types of cancer can be eliminated if every patient has equitable access to guideline-adherent treatments.
- Patient navigation and community engagement can reduce disparities in cancer treatment among underserved groups and potentially improve outcomes for all patients with cancer.

Progress across the continuum of cancer research and patient care improves survival and quality of life for people in the United States and around the world. In the United States, the annual decline in the overall cancer death rate has accelerated over the past two decades (1). This progress is driven by the dedicated efforts of individuals working throughout the cycle of medical research (see **Sidebar 24**, p. 97).

## Clinical Research

The rapid pace of progress against cancer is attributable in part to the new and effective treatments that are available today, thanks to the discoveries made through decades of research in basic and translational sciences. These discoveries have deepened our understanding of the cellular and molecular underpinnings of cancer initiation and progression and have led to the identification of a range of molecular targets that drive cancer (see **Understanding Cancer Development in the Context of Cancer Disparities**, p. 52). After a potential therapeutic target is identified, it takes many more years of preclinical research before a candidate therapeutic is developed and ready for testing in

clinical research, also known as clinical studies or clinical trials (see **Sidebar 25**, p. 100).

Clinical trials evaluate the safety and efficacy of candidate agents before a preventive intervention or therapeutic can be approved by the US Food and Drug Administration (FDA) and used as part of patient care. All clinical trials are critically reviewed and approved by institutional review boards before they can begin and are monitored throughout their duration. Patient safety and understanding of the clinical trial are prioritized through the informed consent process, which involves a discussion between the clinical research team and the patient about the trial's purpose and what is expected of the patient, potential benefits and risks, alternative treatments, and the patient's right to withdraw at any time without consequences. There are many benefits to participating in a clinical trial, as highlighted in the personal experience of **Anibal Torres** (see p. 99). These include access to potentially more effective treatments before they are widely available, a direct contribution to lifesaving cancer research, and an active involvement in making health care decisions (567). Additionally, there is evidence that clinical trial participants often have improved outcomes compared to nonparticipants (568,569).

## SIDEBAR 24

## Medical Research

Medical research, as defined by the Organization for Economic Cooperation and Development (OECD), comprises:



**The study of specific diseases and conditions** (mental or physical), including detection, cause, prevention, and treatment of diseases, as well as rehabilitation of persons.



**The design of methods, drugs, and devices** used to diagnose, support, and maintain the individual during and after treatment for specific diseases or conditions.



**The scientific investigation** required to understand the underlying life processes that affect disease and human well-being, including areas such as the cellular and molecular bases of diseases, genetics, and immunology.

Any individual whose work falls within the definition of medical research is part of the medical research community. Thus, the medical research community is highly diverse. It includes, but is not limited to, basic and translational researchers working in a wide range of disciplines, including biology, chemistry, immunology, physics, engineering, statistics, and computer science; physician-scientists; health care providers; and population scientists.

Adapted from (566).

There are several types of cancer clinical trials, including prevention trials, screening trials, treatment trials, and supportive or palliative care trials, each designed to answer different research questions (see **Sidebar 26**, p. 101). Clinical studies in which participants are randomly assigned to receive experimental treatment or standard-of-care treatment are called randomized clinical trials and are considered the most rigorous.

Clinical trials that test candidate therapeutics for patients with cancer have traditionally been done in three successive phases (see **Figure 12**, p. 102). Observations made during the real-world use of a drug after it is approved by FDA can also be utilized to further enhance the use of that drug. The multiphase clinical testing process is extremely costly, requires many patients, and takes years to complete (570,571). Identifying and implementing more efficient clinical development strategies are areas of extensive investigation for all members of the medical research community.

## Disparities in Cancer Clinical Trial Participation

While researchers are continually identifying and implementing new ways of designing, reviewing, and conducting clinical trials that are yielding advances in patient care, there are still numerous opportunities for improvements. Two of the most pressing shortcomings that need to be addressed urgently are low participation in cancer clinical trials and a lack of sociodemographic diversity among those who do participate (see **Sidebar 27**, p. 103) (574-576). Low participation in clinical trials means that many trials fail to enroll enough participants to draw meaningful conclusions about the effectiveness of the anticancer therapeutic being tested. Lack of diversity in clinical studies means that the trial participant population is not reflective of the real-world demographics of the cancer burden—the population that is likely to receive the treatments if and when they are approved (577). Underrepresentation in clinical research compromises the generalizability of the research findings to the entire US patient population.

It is well established that many segments of the US population, such as racial and ethnic minority populations, sexual and gender minority (SGM) populations, individuals living in rural and poorer areas, adolescents and young adults, people with disabilities, and older adults are underrepresented in cancer clinical trials (584,586-593). Despite the enactment of the landmark NIH Revitalization Act by the US Congress in 1993 to improve representation of women and minority populations in clinical trials and numerous initiatives from FDA and NCI since then, lack of diversity as well as underreporting of race, ethnicity, and age of participants continues to be an ongoing challenge (see **Policies to Address Disparities in Clinical Research and Care**, p. 163). In fact, several recent reports point to a further worsening of disparities in clinical trial participation for minority populations over the past decade (583,586,594,595).

Analysis of FDA's Drug Trials Snapshots website, which was created to improve diversity and transparency of pivotal clinical trials of newly approved drugs, indicates that many of the recently approved therapeutics were based on trials with inadequate representation of racial and ethnic minority participants (see **Figure 13**, p. 104). A recent study that analyzed pivotal clinical trial data for 59 cancer therapeutics approved between 2012 and 2017 showed that only 40 percent of trials reported age and only 24 percent reported race and ethnicity of participants (596). At the level of clinical trial funders, all sponsors reported the sex of enrolled participants. However, only 56 percent of sponsors adequately represented women. Forty percent of sponsors were transparent in reporting the age of participants and only 24 percent adequately represented older adults; only 24

*continued on page 100*



“I said I’m going to go for it. I signed the papers [for the clinical trial] quickly. I told them I want to stay alive and start as soon as possible.”



# Anibal Torres, 66

Humacao, Puerto Rico

It was Cinco de Mayo (May 5), 2022. Anibal will never forget the day. He woke up with severe pain in his stomach. He could barely eat anything over the next three days. On Sunday, which happened to be Mother's Day, Anibal took his wife and daughter to celebrate at a seafood restaurant. "They were worried about me because they were eating, but I wasn't. I was still in pain. I made a promise to them. I was going to the hospital on Monday," Anibal said. After the checkup the doctor told Anibal to go to the hospital right away and get a CT scan. "I was there till about two o'clock in the morning and the doctor came out and said you have a big mass in your liver, and you have to go to a gastroenterologist as soon as possible," he remembers.

At the time, Anibal did not think much about his condition. He gave his daughter Michelle the CD with all the results. "And she called me crying. She said, 'Dad, how come you didn't tell me you have cancer?'" But he didn't know. While he was told that he had an 11.9 centimeter mass in his liver, Anibal did not realize that it was malignant. His doctor said that it was the biggest mass they had ever seen. Michelle took Anibal to a doctor at San Juan. They performed a biopsy of his liver, which confirmed his diagnosis of liver cancer.

Michelle assured her father that they would do everything they could to take care of him. "I promised him we are going to find the best doctors on the island." A referral from Dr. Marcia Cruz-Correa, the Director of University of Puerto Rico Comprehensive Cancer Center at the time, led Anibal to PanOncology Trials. After his doctor talked to him about a clinical trial that was evaluating immunotherapy for patients with hepatocellular carcinoma, a form of liver cancer, Anibal decided to participate. "I said I'm going to go for it. I signed the papers [for the clinical trial] quickly. I told them I want to stay alive and start as soon as possible," he recalled.

Anibal is aware of the high costs associated with his treatments. "It's very expensive. I cannot afford it without this clinical trial," he said, thanking all the researchers who are involved in the study. Michelle was happy that her father opted for the treatment. "I'm glad that he went for it because he was in denial, and he was tired. He would tell us that he was going to give up. I had a 10-year-old son at the time. He and my daughter love my dad. And I said, you must go to their graduation. We need you. And thank God he tried," Michelle said reflecting on her father's journey.

Even though the treatments caused several side effects including GI and kidney issues, Anibal has been feeling better since starting the clinical trial. "I'm eating better, I'm sleeping better, I'm doing everything better. I meditate every day, and I'm grateful for living every day. I tell everybody to be happy and thankful for every day," he said. Every 6 weeks he gets CT scans to monitor the mass. And his tumor has been shrinking. "They tell me how the liver mass is going down. And I'm very grateful that from 11.9 it is down to 4.3 centimeters this week. The treatment is working. Look at me. I'm living proof," he added.

Anibal's message to his community and friends is to eat well, exercise, and avoid unhealthy foods and alcohol as much as they can. To other cancer patients he wants to share hope and prayers. He urges researchers to continue working on clinical trials, especially those that can benefit minorities and those living outside mainland United States, "It is a challenge being a minority, especially living in Puerto Rico," Michelle said. She wants to thank the Congress and policymakers for funding the clinical trial program on the island. "We do advocate that this program keeps being funded because we have a lot of cancer in our communities in Puerto Rico."

Scan the QR code  
to watch Anibal's video interview.





## SIDEBAR 25

## Therapeutic Development



Adapted from (189).

percent of sponsors were transparent in reporting the racial and ethnic identity of participants for all pivotal trials and only 16 percent adequately represented patients from racial and ethnic minority populations (596).

Representative study populations in clinical trials are critical to accurately determine the efficacy as well as potential toxicities of new treatments. Diversity among participants is even more vital during evaluation of cancer types with a disparately higher burden in specific populations, such as certain racial or ethnic minority groups, as well as during evaluation of cutting-edge precision medicine, e.g., molecularly targeted therapeutics or immunotherapeutics, because these treatments are closely tied to the unique characteristics of an individual’s cancer, immune system, lifestyle, and family history, among other factors (see **Understanding Cancer Development in the Context of Cancer Disparities**, p. 52).

Enrollment of participants from all sociodemographic backgrounds, as well as race- and ethnicity-specific reporting

of the benefits and potential risks, can enable a comprehensive understanding of potential ancestry-related differences in cancer biology, disease biomarkers, or treatment responses including adverse events and ensure that newly approved anticancer agents can be safely used in the real-world setting.

## Barriers to Clinical Trial Participation

Numerous studies have investigated the existing barriers that limit participation of racial and ethnic minority groups and medically underserved populations in cancer clinical trials. Evidence indicates a range of structural barriers and societal injustices that operate at individual (patient and health care provider) and systemic (health care system) levels (see **Figure 14**, p. 105). It is important to note that the patient-level barriers are often unique for each underserved population. For example, racial and ethnic minority populations may experience participation barriers due to lack of clinical trial awareness; lack of trust; lack of racial, ethnic, or language

**SIDEBAR 26**

# Types of Clinical Trials

Clinical trials can be designed to address different research questions. Furthermore, many clinical trials can provide answers to multiple questions. As one example, treatment trials—designed to primarily determine clinical outcomes, such as efficacy of an anticancer drug—can also evaluate the impact of the treatment on quality of life. Cancer clinical trials include the following:



**Prevention** trials are designed to find out whether people without a cancer diagnosis can reduce their risk of cancer by proactively taking certain actions, such as increasing physical activity and eating healthily.



**Quality-of-life** trials are designed to examine whether patients with cancer can improve their quality of life by taking certain actions, such as attending support groups or exercising more. These trials are also known as supportive care or palliative care trials, and many evaluate the effects of certain cancer medications and treatments on quality of life.



**Screening** trials are designed to evaluate new tests to detect cancer before symptoms arise, with the goal of determining whether the screening test will reduce deaths from cancer.



**Natural history or observational** studies are designed to learn more about how cancer develops and progresses by following patients with cancer or individuals who are at high risk for developing cancer over a period of years.



**Diagnostic** trials are designed to test new ways to diagnose a certain type of cancer.

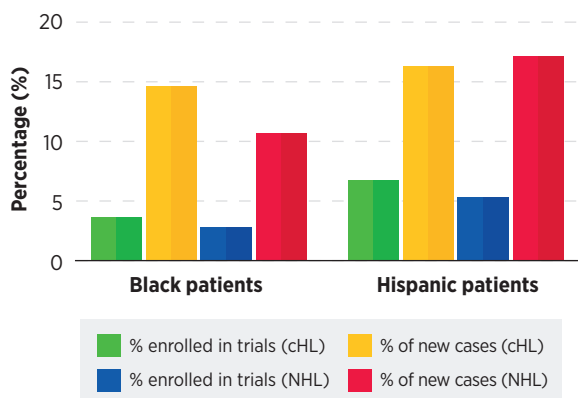


**Correlative** studies are designed to examine the efficacy of a candidate anticancer drug by using biomarkers, such as proteins, as indicators of the desired clinical outcome when the effects of the drug on key clinical outcomes, such as reduction in tumor size, may not be apparent.



**Treatment** trials are designed to determine whether new treatments or new ways of using existing treatments—alone or in combination—are safe for patients and effective in treating cancer.

Compared to their respective US burden of disease, **Black and Hispanic patients with lymphomas were significantly underrepresented in clinical trials** that were conducted between 2011 and 2021 and led to the approval of 18 lymphoma treatments. US counties with higher mortality from lymphomas and higher racial minority populations also had low access to the trials (599).



concordance with the clinical trial team; and pervasive systemic racism, while SGM groups may experience participation barriers primarily due to societal stigma and lack of standardized protocols and recruitment methods for this patient population (591,600). Additional complexities may result from the social and cultural differences among different racial, ethnic, sexual, and gender minority populations. Therefore, interventions to address barriers to clinical research must take into consideration the unique and specific experiences of the target population.

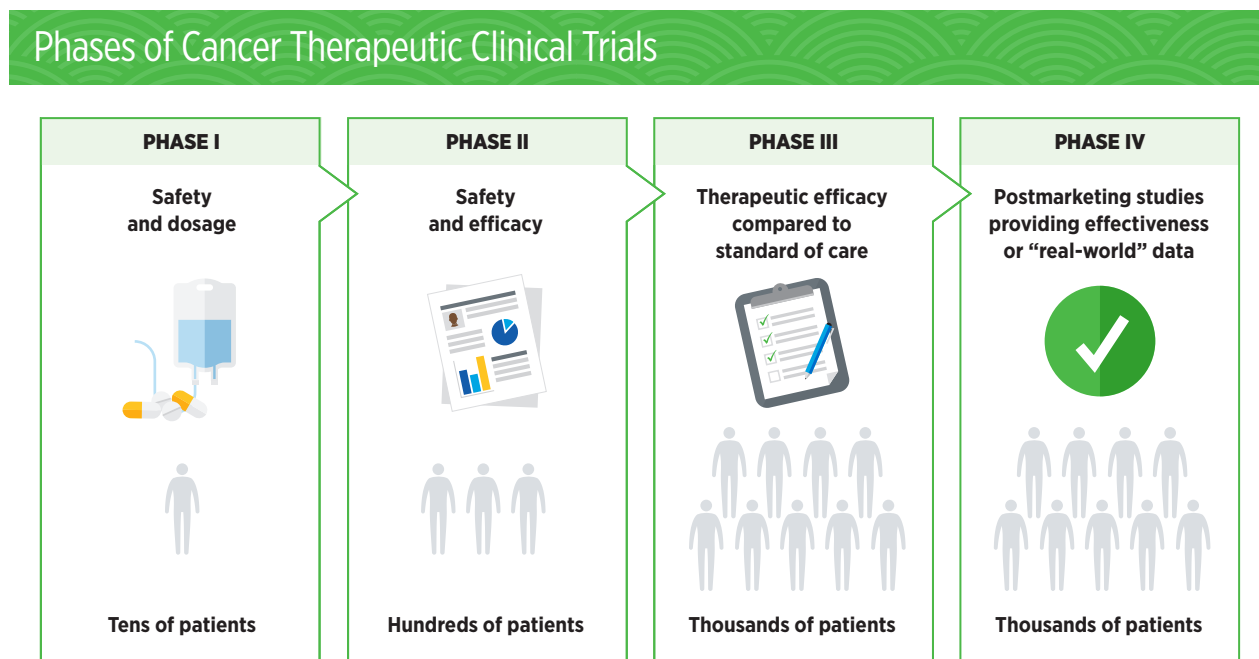
Individual-level barriers for patients include lack of understanding, awareness, or adequate information of clinical trials; limited health literacy; language barriers; mistrust of the health care system; and a fear of being placed in the control group, thereby not receiving the desired medical intervention (601). As one example, according to a recent study among Black patients with metastatic breast cancer, only 36 percent of patients said they received enough information from their health care team to make an informed decision about participating in a trial (602). Notably, more than 90 percent

cHL, Classic Hodgkin Lymphoma; NHL, Non-Hodgkin's Lymphoma

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*continued on page 104*

FIGURE 12



Clinical trials evaluating potential new therapeutics for treating patients with cancer have traditionally been done in three successive phases, each with an increasing number of patients.

**Phase I** studies are designed to determine the optimal dose of an investigational anticancer therapeutic, how humans process it, and potential toxicities. Historically, phase I trials were not designed to evaluate efficacy of a therapeutic in treating the cancer. However, thanks to rapid advances in our understanding of cancer biology and progress in clinical trial design and conduct, phase I trials are increasingly incorporating a preliminary evaluation of efficacy (572). Patient response rates in phase I studies have also nearly doubled over the past two decades (573).

**Phase II** studies are designed to determine the initial efficacy of an investigational therapy, in addition to continually monitoring for potential toxicities.

**Phase III** studies are large trials designed to determine therapeutic efficacy as compared to standard of care; when successful, the results of these trials can be used by the US Food and Drug Administration (FDA) to approve new therapeutics or new indications for existing therapeutics.

**Phase IV** studies are conducted after a therapy is provisionally approved by FDA and provide additional effectiveness or “real-world” data on the therapy. In recent years, researchers often combine different phases into one clinical trial (labeling depends on the phases combined, e.g., phase I/II or phase III/IV clinical trials), which allows research questions to be answered more quickly or with fewer patients.

Sometimes **phase 0** clinical studies are performed prior to traditional clinical trials wherein low doses of potential therapeutics are administered to a small number of patients to determine whether such treatments may have the desired effect.

Adapted from (566).

In May 2022, the National Academies of Sciences, Engineering, and Medicine released a **report outlining the barriers and opportunities in clinical research representation** (577). This report:

- **Highlights the significant adverse health and economic consequences** of underrepresentation in clinical trials.
- **Emphasizes** that Asian, Black, Latinx Americans, and American Indian/Alaska Native individuals are equally likely to participate in research if and when they are asked.
- **Stresses the urgency in increasing representation in clinical research** through substantial investments as well as accountability and transparency from all stakeholders that are committed to health equity.



## SIDEBAR 27

## Disparities in Clinical Trial Participation

To ensure that candidate anticancer therapeutics are safe and effective for everyone who will use them if they are approved, it is vital that the participants in the clinical trials represent the diversity of the patient population. Racial, ethnic, and other sociodemographic disparities in clinical trial enrollment are an injustice that hinders equitable progress against cancer. Examples of these disparities include the following:

### LACKED adequate participation

The US Food and Drug Administration (FDA) approved **82 novel therapeutics for cancer treatment** between 2015 and 2021. **Almost 90 percent** of the pivotal\* clinical trials supporting these **approvals lacked adequate† representation of Black patients; 73 percent lacked adequate representation of Hispanic/Latino patients** (578).

### LESS than 10%

Despite accounting for 23 percent of all liver cancer cases in the United States over the past 20 years, **Hispanic people have represented less than 10 percent of patients enrolled in clinical trials for liver cancer** in that same period (579).

### MORE likely to participate

Among **older Medicare beneficiaries** with newly diagnosed cancer in 2015, **those living in zip codes with a higher median income (\$60,000 to \$250,000) were more likely to participate in clinical trials** compared to those living in zip codes with a lower median income (\$47,000–\$60,000) (57 percent versus 23.4 percent, respectively) (580).

### LESS THAN 65 years old

A recent analysis of phase III clinical trials over the past decade that were **evaluating interventions for patients with acute myeloid leukemia (AML)** showed that **>70 percent of participants were less than 65 years old** (581), even though the incidence of AML is highest among those aged 65 years or older.

### ONLY 17%

Analysis of the largest multicenter clinical trial examining a **treatment regimen traditionally used in pediatric and adolescent and young adult (AYA) patients with acute lymphoblastic leukemia (ALL)** showed that **only 17 percent of participants with known ethnicity were Hispanic** (582), even though 46 percent of AYA patients newly diagnosed with ALL in the United States are Hispanic.

### 39% less likely

An evaluation of **cancer clinical trials before, during, and after the COVID-19 pandemic** showed that **prior to the pandemic (2017–2019), Black patients were 39 percent less likely to participate** compared to White patients; these disparities worsened post pandemic (2020–2022), with Black patients being 51 percent less likely to participate (583).

### ONLY 7% or less

Between January 2010 and August 2022, **FDA approved 92 immunotherapeutics**, alone or in combination, for the **treatment of >20 cancer types**. Analysis of 113 pivotal trials that led to these approvals show that **Hispanic, Black, Native American or Alaska Native, and Hawaiian or Pacific Islander patients represented only 7 percent, 2 percent, 0.5 percent, and 0.1 percent of the participants**, respectively (584).

### 30% less likely

Analyses of **clinical trial enrollment for women with endometrial, ovarian, or cervical cancer** from 2004 to 2019 showed that **Asian and Hispanic women were underrepresented** compared to the proportion expected based on US cancer incidence. Women living in **small metropolitan counties were 30 percent less likely** to participate compared to women living in large metropolitan counties (585).

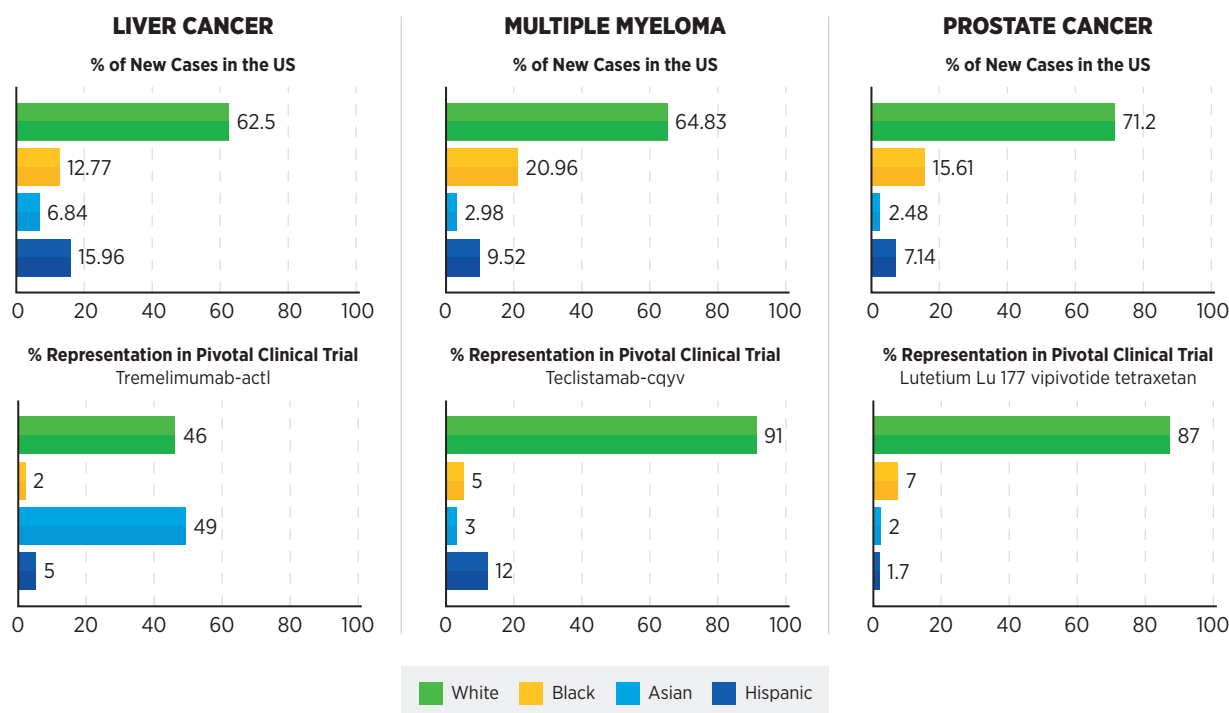
\* Pivotal clinical trials seek to demonstrate the efficacy of a new therapeutic to obtain its marketing approval by regulatory agencies such as FDA.

† Adequate representation was evaluated using participation to prevalence ratios (PPRs), by dividing the percentage of each demographic subgroup enrolled in the pivotal trial for a specific cancer type by the percentage of US patient population diagnosed with the same cancer type who belong to the same subgroup; PPRs of at least 0.8 indicate adequate representation.



**FIGURE 13**

## Underrepresentation of Racial and Ethnic Minority Patients in Recent Cancer Clinical Trials



The US Food and Drug Administration (FDA) Drug Trials Snapshots website was created to improve diversity and transparency of pivotal clinical trials supporting new drug approvals. In 2022, FDA approved the immunotherapeutics tremelimumab-actl (Imjudo) and teclistamab-cqyv (Tecvyli) for patients with certain types of liver cancer and multiple myeloma, respectively, and the radioconjugate lutetium Lu 177 vipivotide tetraxetan (Pluvicto) for patients with prostate cancer (597). Demographic data for participants indicate that the approvals were based on trials with inadequate representation of racial and ethnic minority patients (598). The percentage of Black patients enrolled in clinical trials for prostate cancer and multiple myeloma were substantially lower than their disease burden (proportion of new cases) in the United States. Similarly, Hispanic patients were underrepresented in the liver cancer clinical trial.

of patients indicated that they would be interested in learning about clinical trials and 83 percent were somewhat or very likely to consider participating.

Lack of health literacy, including limited understanding of clinical trials, has been reported as a barrier for participation in clinical trials (604). Evaluation of barriers among Hispanic patients indicates that poor understanding of the purpose

of a clinical trial, poor communication from health care providers, and fear of or uncertainty over experimental treatment may adversely affect their enrollment in clinical trials (605). Low health literacy has also been reported as a barrier for parents while making informed decisions for their child's participation in clinical research (606).

Additional patient-level barriers include financial and time-related burdens, such as costs of cancer treatment and medication, transportation, childcare, lost work, and inadequate insurance or complete lack of it. These barriers are heightened in patients from racial and ethnic minority populations, who frequently report being the primary caregivers to family members and not having the time to participate in clinical trials; working in service occupations where it is difficult to get paid time off from work; and having more difficulties paying for health care, transportation, and other costs related to trial participation (607). Financial and













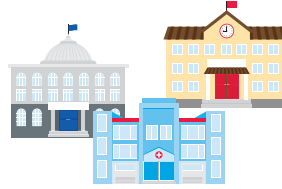




**Black patients participated at similar rates (58 percent) compared to White patients (55 percent) in cancer clinical trials when offered the opportunity (603).**



W41

FIGURE 14

# Barriers and Facilitators of Diverse Participation in Cancer Clinical Trials

	Barrier	Solution
<p><b>Individual level</b></p> 	<p><b>PATIENT</b></p> <ul style="list-style-type: none"> <li> Transportation. . . . .</li> <li> Cost. . . . .</li> <li> Caregiver burden . . . . .</li> <li> Time toxicity . . . . .</li> <li> Language. . . . .</li> <li> Education. . . . .</li> <li> Health literacy. . . . .</li> <li> Lack of awareness . . . . .</li> </ul> <p><b>DOCTOR</b></p> <ul style="list-style-type: none"> <li> Lack of awareness . . . . .</li> <li> Implicit bias . . . . .</li> <li> Cultural insensitivity. . . . .</li> </ul>	<p><b>PATIENT</b></p> <ul style="list-style-type: none"> <li>Transportation vouchers, decentralized trials</li> <li>Financial navigation, decentralized trials</li> <li>Support system, decentralized trials</li> <li>Extended clinic hours, decentralized trials</li> <li>Use of translators</li> <li>Patient education</li> <li>Patient education</li> <li>Patient education</li> </ul> <p><b>DOCTOR</b></p> <ul style="list-style-type: none"> <li>Education and training</li> <li>Education and training</li> <li>Cultural competence</li> </ul>
<p><b>Institutional/ Structural level</b></p> 	<ul style="list-style-type: none"> <li> Lack of clinical trial sites . .</li> <li> Complicated informed . . . consent process</li> <li> Eligibility criteria. . . . .</li> <li> Medical distrust. . . . .</li> </ul>	<p style="writing-mode: vertical-rl; transform: rotate(180deg); color: green; font-weight: bold;">GREATER DIVERSITY IN THE CLINICAL RESEARCH WORKFORCE</p> <ul style="list-style-type: none"> <li>Increase clinical trial site locations</li> <li>Patient navigation</li> <li>Expand criteria based on real world data</li> <li>Patient navigation and community outreach and engagement</li> </ul>

Patients from racial and ethnic minority groups and medically underserved populations experience multilevel barriers to participating in cancer clinical trials. Some of these barriers operate at an individual level for patients as well as health care providers, but many operate at the systemic or institutional level.

time burdens of trial participation for minoritized and medically underserved patients must be considered during the design and implementation of clinical studies if we are to achieve equitable participation for all patients.

Many barriers exist at the provider level, including lack of knowledge of clinical trials and implicit biases such as health care providers perceiving minoritized patients as being less interested in participating compared to White patients (600,608). Implicit biases among health care staff and discrimination by providers who are responsible for recruiting patients in clinical trials can contribute to the exclusion of medically underserved populations (609). Evaluation of the impact of implicit bias on clinical trial recruitment and the

utility of intervention strategies such as training curricula for addressing implicit bias in clinical research are areas of active investigation (610).

Lack of dedicated staff to engage with and serve minority patient populations, time constraints for clinicians, and lack of cultural competence and effective communication skills are among the other provider-level factors that hinder diversity in clinical trial participation. A recent study evaluating the accrual of cancer patients in a molecularly targeted therapeutic clinical study showed that despite multiple notifications to physicians regarding patient eligibility based on tumor mutations, many patients were never informed of trial availability (611). Considering that physicians are the most trusted source of

clinical trial information for most racial and ethnic minority patients (575), identifying ways to enhance physician motivation is vital for patient recruitment in clinical studies.

While evaluating clinical trial barriers and facilitators, researchers must give careful consideration to the adverse influences of all social drivers of health (SDOH), including poverty, food insecurity, housing insecurity, and psychosocial stressors throughout a patient's life experience, even beyond clinical trial participation (see **Understanding and Addressing Drivers of Cancer Disparities**, p. 36). Such considerations are vital because research has shown that participation in clinical trials alone may not be enough to eliminate disparities in cancer outcomes (612). According to a recent analysis, even among patients with breast cancer who participated in clinical trials, there were disparities in outcomes among certain groups, including young Black and Hispanic patients compared to their White counterparts (613). Future research should examine how to eliminate additional sources of disparities that may be introduced through barriers or hardships prior to or following participation in clinical trials.

Beyond individual-level factors, there are barriers that operate at the level of the health care systems, as well as at the levels of the community and/or society. Many of these barriers are driven by structural inequities and social injustices (see **Understanding and Addressing Drivers of Cancer Disparities**, p. 36). Some of the major system-level and structural barriers include lack of trial availability, such as for patients like **Melissa Adams** (see p. 109) who live in states or US territories that are far from mainland United States. Additional structural barriers include complexity of the clinical trials; time constraints for proper informed consent and clinical trial paperwork; complexities of consent documents; patient exclusion due to narrow eligibility criteria; medical distrust; lack of facilitators, such as translators or patient navigators; and lack of community engagement in low-resource settings.

Restrictive eligibility criteria often lead to exclusion of racial and ethnic minority patients from cancer studies (614). A recent analysis of clinical trials submitted to FDA between 2006 and 2019 to support the approval of treatments for multiple myeloma showed that the ineligibility rates were higher for Black patients (24 percent) compared to White patients (17 percent) even though multiple myeloma incidence and mortality are highest among the US Black population (615). Research also shows that despite FDA's efforts to expand certain eligibility criteria to improve diversity in patient enrollment, compliance with revised criteria remains poor (616).

Research has shown that patients living in areas of higher disadvantage, characterized by lower income, education, employment, and housing quality, have a lower likelihood of enrollment in clinical trials (see **Social and Built Environments**, p. 40) (617). Areas with high levels of deprivation tend to have a higher proportion of underrepresented racial and ethnic minority residents. Lack of trial availability in areas

with a high proportion of racial and ethnic minorities restricts access to clinical studies. As one example, a recent analysis of 69 multiple myeloma clinical trials evaluating two different types of immunotherapies, chimeric antigen receptor (CAR) T-cell therapy and bispecific antibodies, showed limited trial availability in states with the highest percentage of Black residents (618). Three out of 10 states with the highest proportion of Black residents had no clinical trial openings.

According to a survey of clinical researchers, structural barriers such as distance to study sites and lack of involvement of community sites are the greatest barriers to diverse enrollment (584). Most clinical studies are conducted at large academic cancer centers located in major metropolitan areas rather than smaller community-based cancer centers where nearly 85 percent of US patients receive their care (619). These system-level barriers make clinical studies inaccessible to many populations, including patients living in rural and suburban parts of the country. As one example, despite the known efficacy of immunotherapeutics to improve outcomes for patients with metastatic melanoma, geographic access to clinical trials investigating these therapies remains a significant challenge for rural and Southern regions of the United States (620).

**Enrollment rates of pediatric cancer patients from racial and ethnic minority groups in clinical trials supporting FDA**



approval of cancer treatments are **higher than that of adult patients** (621). These differences are partly attributable to the fact that most children with cancer are treated at specialized pediatric cancer centers that offer access to clinical trials.

W42

Another known barrier to clinical trial enrollment for medically underserved patients, such as those from racial or ethnic minority populations, particularly those with limited English proficiency, is the informed consent process. Research shows that physicians may omit important information, including key specifics of the trial and the right to withdraw from a trial, during informed consent discussions with patients who do not speak English (622). While consent forms translated into a patient's native language can, in part, improve patient satisfaction and facilitate the enrollment process, many studies do not have the financial resources for such services (623,624). Limited health literacy can further compromise the consent process and prevent patients from making fully informed decisions about clinical study participation (625). Evidence-based interventions to enhance communication and reduce bias with patients from historically marginalized groups during informed consent discussions are needed to address the current inequities.

## Facilitating Equity in Clinical Cancer Research

Overcoming barriers to clinical trial participation will require all constituents of the cancer research and care community to come together and develop multifaceted approaches that include the implementation of newer and more effective education and policy initiatives. Intervention strategies need to address barriers across all levels, from dismantling structural racism to catering to the individual needs of cancer patients. Ongoing research from academia, biopharmaceutical industry, nonprofit organizations, and federal agencies has identified many approaches that can facilitate enrollment of participants from diverse sociodemographic backgrounds (see **Figure 14**, p. 105) (626-629). The goals of these strategies are to improve access to clinical trials for diverse populations in the community, increase patient awareness and understanding of clinical research, build trust in communities, improve support of clinical trial sites and their health care staff, and report race/ethnicity-related information while publishing clinical trial data. These goals align with the lifelong efforts of A. William Blackstock Jr., MD, Edith P. Mitchell, MD, and Wortia McCaskill-Stevens, MD (see **In Memoriam**, p. 115).

These interventions focus on a range of issues that include addressing SDOH (see **Figure 3**, p. 37); decentralizing many of the trial activities to ease patient participation; expanding eligibility criteria; improving the efficiency of data collection, including patient-reported outcomes; enhancing community outreach and patient navigation efforts to raise awareness of trials; and improving patient-provider communication. One critical area of focus for the medical research community is fostering greater diversity, equity, and inclusion within the clinical research workforce so that the workforce will resemble the patient populations it serves (see **Cancer Care Workforce Landscape**, p. 151). These efforts are vital because research shows that racial concordance between patients and health care providers can improve communication, trust, and adherence to medical advice and lead to better care (630,631).

### Community Engagement and Patient Navigation

Research has shown that community outreach and patient navigation can enhance awareness of clinical trials and increase participation for racial and ethnic minority patients (180,632,633). Clinical researchers and institutions must implement strategies to include community-based partners in the design and execution of clinical trials and integrate patient and community feedback into clinical research design (626,627). These efforts can build trust and credibility and facilitate relationship building and bidirectional communication, especially for populations that experience systemic injustices and discrimination and do not trust the clinical system.

It is also critical that research teams disseminate clinical trial results back to the communities. Policies to integrate community-based clinical partners such as local health care providers who may not traditionally participate in clinical research can further improve access to studies at the population level in underserved areas. Clinical institutions, sponsors, and researchers must support an infrastructure that sustains long-standing partnerships with the community, patients, and patient advocates (628). These actions can lead to fundamental changes to the clinical research landscape and ensure equitable participation.

Community engagement is particularly important for the inclusion of Indigenous populations and patients from tribal nations in clinical research. Research shows that AI/AN patients have the lowest representation in clinical trials among all racial and ethnic groups (634). The role of the community is central to the AI/AN culture as highlighted in the personal story of **Todd Gates** (see p. 111). Research shows that incorporating the community perspective in a manner that considers cultural safety and humility may facilitate recruitment and retention in clinical research (634). In this regard, a new framework, known as “Circle of Trust,” has been developed by AI/AN researchers who work with their communities for recruitment in clinical research. The model proposes interdependent and reciprocal relationships between patients, researchers, the communities, and trusted entities within the communities such as cultural leaders, elders, religious or spiritual leaders, traditional healers, tribal leaders, community leaders, traditional birth workers, community health workers, community health representatives, and tribal board members.

**Following intentional engagement strategies** such as culturally tailored messaging, partnerships with trusted community outreach organizations, and patient advocacy groups, **11 percent more Black men enrolled in prostate cancer clinical trials** (631).



W43

Patient navigators can provide social, emotional, and logistical support and act as a potential facilitating factor for clinical trial participation. As one example, a population health navigation program designed to address common barriers to cancer care for medically underserved populations, including insurance needs, food, clothing, housing, transportation, language, health literacy, social support, and missed appointments, was able to increase participation in clinical research (635). Prior to the initiation of the navigation program, only 19 percent of rural patients, 13 percent of Black patients, and 5 percent

*continued on page 112*



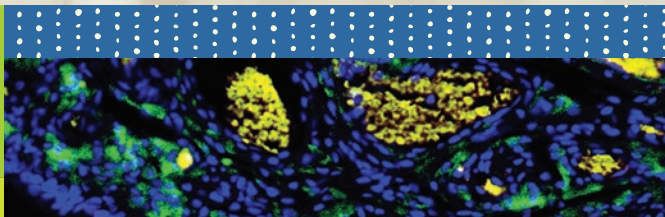


“The unfortunate thing for us here in Hawai’i is that when it comes to clinical trials, most of them are on the mainland.”



# Melissa Adams, 45

Waipahu, Hawai'i



In 2017 Melissa Adams was enrolled in graduate school working to complete her master's degree in planetary geology. One day after taking a shower she looked up in the mirror and noticed that her right breast looked abnormal. She went to the school nurse, who thought that the abnormality was linked to her menstrual cycle and suggested that she follow up in a month. "I went back in a month and the issue had persisted. It was quite a large lump of dense tissue," Melissa said. She was referred to a specialist but was apprehensive. She was about to graduate and lose her existing insurance. "I didn't want to have this preexisting condition and not be able to get new insurance," she said. However, her nurse explained the seriousness of the situation and insisted that she get care immediately. "All in one day I had an ultrasound, a mammogram, and a biopsy. And then a week later, the Friday before Mother's Day, I was diagnosed with invasive lobular carcinoma."

Melissa recalled: "From getting diagnosed it was just a whirlwind of appointments until I got my surgery." While many patients receive chemotherapy to shrink their tumors before surgery, Melissa had to have surgery right away since her tumor was massive. In addition to the cancer on her right breast, an MRI showed some abnormality on the left breast. "I did not want to go through surgery again and decided to get a double mastectomy," she said.

After her surgery Melissa wanted to get a second opinion to decide on the next course of action. It was a challenge. "Since we live in Hawai'i, it is extremely hard for us. I had to buy plane tickets to go to the mainland. I still had drains in from my surgery and could not lift anything over my head. I needed help. My boyfriend had to take time off from work. That was a huge burden timewise, financially, and physically."

Melissa also highlighted the barriers that prevent patients from Hawai'i and other Pacific Islands from participating in clinical trials. "We discussed clinical trials and I actively searched for clinical trials. But the unfortunate thing for us here in Hawai'i is that when it comes to clinical trials, most of them are on the mainland. And I cannot afford to go and stay in a hotel for however many weeks the clinical trials entail," she said. Additionally, Melissa urges health care providers to identify better ways to communicate with patients and explain clinical trials in a manner that encourages patients to participate.

Melissa did travel to the University of Texas MD Anderson Cancer Center for her second opinion. After the

consultation, she received many rounds of chemotherapy and radiation therapy. Following these treatments, she had a PET scan that did not show any evidence of disease. "But with stage III cancer I knew that it was only a matter of time." Melissa went on to receive maintenance treatment with hormone therapy and continued until her cancer progressed and was reassigned as stage IV.

The treatments have taken a toll on Melissa. She does not have the level of energy that she used to. "It frustrates me" she said. "I also have what they call 'chemo brain'. It is hard for me to retain information. And that has taken a big hit to my mental health. Unfortunately, the current medicine available is not able to cure me. It is now a point of how much we can keep the cancer at bay. That is why we need more research for stage IV cancer patients. I feel very lucky to live in this day and age because with all the new medicines that are being developed, they are able to prolong our lives. I am hopeful that a cure will be found one day soon," she said.

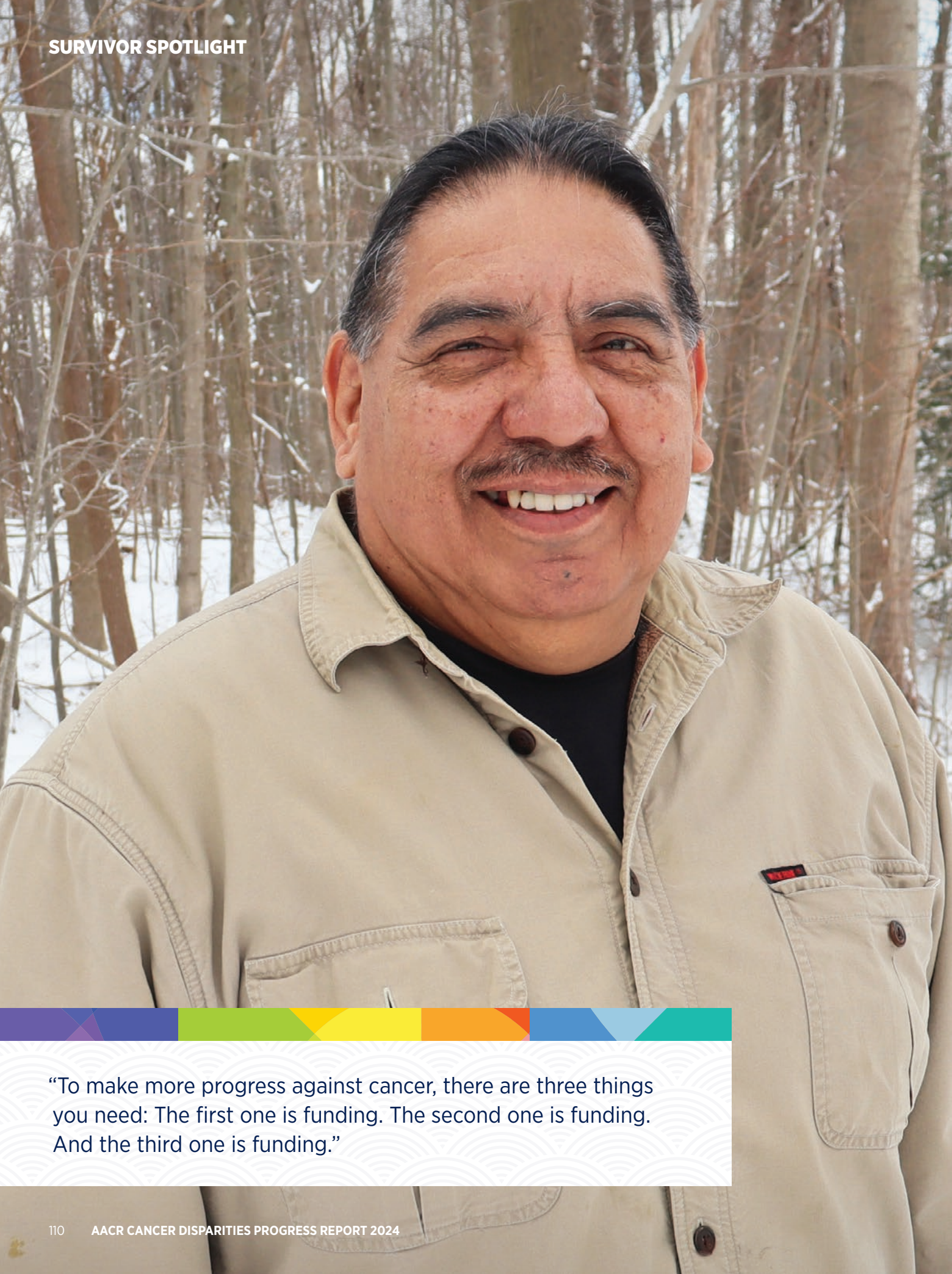
Despite all the challenges, Melissa has been doing better. "I am not caged by fear anymore. I went back to church, which helped tremendously. I am volunteering with Breast Cancer Hawaii. Connecting with people who are like myself has been a great comfort." As part of her volunteer work Melissa participates in a lot of outreach efforts. "For breast cancer awareness month, we were able to visit our local prison and we talked about early detection. This work is important, and very fulfilling."

Her diagnosis has Melissa rethinking her legacy. Her perspective on life has shifted dramatically. While it was vital for her to pursue a graduate degree prior to the diagnosis she is now more focused on her relationships. "It is more important to be kind and show love to one another. What really matters is being there for the people that are in your life. Keep them close. Be kind and forgive. If people can be kind, forgiving, and love each other and perpetuate that love it can go far beyond us. It is like the waves that propagate from one small drop of water. A small act of kindness can go far beyond that person." That is how she wants to be remembered. "That's a legacy," she said.

Scan the QR code  
to watch Melissa's video interview.







“To make more progress against cancer, there are three things you need: The first one is funding. The second one is funding. And the third one is funding.”



# Todd Gates, 62

## Cattaraugus Territory of the Seneca Nation

**T**odd knew his PSA levels were high. So, last year, when he started having trouble going to the bathroom, he went to see his doctor right away. In late July 2023, after undergoing tests, he was diagnosed with prostate cancer. “I was suspecting it. But I was worried about what was going to happen to my family,” Todd said. He was also worried about his treatment. Thankfully, Todd had a great relationship with his doctors as well as with Roswell Park Comprehensive Cancer Center even before his diagnosis. Todd’s wife had been diagnosed with breast cancer in 2019 and received care at the cancer center.

Todd discussed his treatment options with his care team. “We went through several options about how to treat the cancer. They talked about surgery, radiation, chemotherapy, and some other things. I elected the operation.” Todd remembers being informed of clinical trials but preferring surgery. “I had friends of mine who had gone through it and they seemed to be doing fine,” he said. After discussing his options, Todd decided to have a prostatectomy, which is a procedure in which the surgeon removes the entire prostate gland plus some of the tissue around it.

Todd’s recovery has been slow. He experienced some side effects from his procedure, including urinary incontinence. It has been difficult to sleep through the night. As a result, he feels tired and fatigued more easily. “It seems like I have not gotten any rest since my diagnosis. I have to get up to go to the bathroom frequently and am not sleeping well at night. And by the end of the week, I am exhausted.”

One of the barriers Todd faced during his care was related to his health insurance coverage. “They didn’t want to pay for the MRI,” he recalled. As a result, his surgery got delayed. “And then, when it came time for my scheduled surgery, I came down with COVID, and that pushed everything back over a month,” said Todd. “I am a patient guy and, you know, finally got my operation, and here we sit today.”

A former president of the Seneca Nation, Todd said there is an urgent need for patient education among members of his tribe. Increasing awareness of the signs and symptoms that individuals should pay attention to and seek medical care for is vital. Remembering a friend who passed away from cancer, Todd said, “Me and my buddies tried to tell him, you need to get treated, there is something wrong. He did not, and it developed into stage IV cancer. By the time he started treatment, it was too late.”

Additionally, Todd believes that more patients in his Nation and other Indigenous communities need to be made aware of clinical trials. “It should be more available to everybody.” Todd also highlighted the community-based services and

educational programs at the Roswell Park Comprehensive Cancer Center. “They help people by making it easier for them to even go to treatment. Some people do not have rides. For someone to take them there or even to sit with them through the whole process would be helpful.” Todd emphasized the logistical problems experienced by many patients in his community and the vital role of patient navigators. “Help with making appointments, keeping appointments, and having someone walk you through what your next steps are can help, because many people just don’t know enough about it.”

As the former elected tribal president, the former tribal treasurer, and the former tribal council leader, Todd is fully aware of the challenges, including financial strains and economic barriers, experienced by his community. Addressing those barriers requires building relationships and collaborating with all partners in the community. “When I was part of the [the leadership of the] Nation, I was always trying to develop relationships with educational institutions, medical institutions, and health organizations because I knew those relationships would create opportunities for our younger people and help our nation. Those are some of the biggest issues, health and education. And when you take care of that, even the sky is not the limit.”

Todd highlighted the vital importance of funding the Indian Health Service (IHS), which cares for all the tribes, nationwide. “It is still discretionary funding through the federal government. That is one of the treaty related items. They need to take care of our health, education, and welfare and make that mandatory funding at the federal level. But also appropriate the dollars carefully,” said Todd. He further emphasized the value of relationships with the local institutions and partners. “The better relationship we have with people and their communities the better cooperation we will receive and that will help their members.”

Todd also highlighted the importance of funding medical research. “Because of all the research prostate cancer has become one of the more treatable diseases,” he said. Todd attended a conference recently where he spoke about what is needed to make more progress against cancer. “There are three things you need. The first one is funding. If you are going to get serious about it, provide the funding. The second one is funding, money for the research programs, and the third one is funding. The research and all that stuff takes money.”

Scan the QR code  
to watch Todd’s video interview.





of Hispanic patients participated in clinical cancer studies. Among the navigated patient population, accrual in clinical trials rose to 40 percent, 41 percent, and 33 percent for rural, Black, and Hispanic patients, respectively (635).

Researchers are evaluating whether tailored education and socioeconomic support using navigation can improve access to clinical trials. Patients who are Hispanic, Spanish-speaking, or publicly insured have limited access to facilities that deliver cell therapy for cancer (636). A collaborative effort between a comprehensive cancer center and a safety net hospital system is using a multipronged approach including community outreach and patient navigation to guide patients, many of whom have low income, are uninsured, and are from racial and ethnic minority populations, through the process of enrolling in early-phase cell therapy trials and connecting them with relevant resources to address SDOH (637). While it remains to be seen whether this approach is able to expand cutting-edge clinical trials to medically underserved populations, researchers are hopeful that the program, if successful, could serve as a national model for enhancing health equity in cancer care.

### Addressing System-level and Structural Barriers

While certain system-level barriers to clinical trial participation may require long-term strategies and effective policies, some could be addressed in the short term. One immediate approach could be to conduct clinical trials at facilities that treat a high percentage of racial and ethnic minority groups and medically underserved patient populations. Currently, many late-phase clinical trials are conducted outside the United States, and those within the United States are often limited to the high-volume cancer centers—facilities that treat higher numbers of patients, have specialty surgeons, and perform greater numbers of procedures—where patients from racial and ethnic minority groups rarely receive care (638). It is, therefore, crucial that clinical studies be available to Minority-Serving Institutions (MSIs), including at safety net hospitals, which often operate in inner-city communities and provide a larger share of care to low-income and uninsured populations. In fact, research has shown that more non-White patients enroll in clinical research sites in counties with higher proportions of non-White residents (631,639).

#### An **intervention aimed to build patient trust and foster communication**

improved communication quality and clinical trial invitation rates, especially for eligible Black patients with prostate cancer (640).



W44

It is vital that researchers define adequate representation and set enrollment goals prior to the initiation of clinical studies (641,642). Equitable representation of a population group in a clinical trial should, at a minimum, match their disease

burden rather than their proportion in the US population, but should ideally aim to represent groups in adequate numbers for subgroup-specific analyses (643). For instance, a multiple myeloma clinical trial should enroll at least 21 percent Black patients, based on the US disease burden—Black patients account for one-fifth of all new cases of multiple myeloma—instead of 12 percent of Black patients, based on the US Census—Black people make up 12.4 percent of the US population. Appropriate enrollment goals must also be justified prior to the recruitment process. This approach is vital, since a low enrollment of participants from a population subgroup may hinder accurate analyses of the safety and efficacy of a therapeutic in that group.

Additionally, clinical trial infrastructures must be set up to address social needs and alleviate common barriers such as food and housing insecurity, out-of-pocket costs, time off from work, and child and elder care. To encourage patients with cancer to participate in clinical studies, research teams need to reach out to and work with minority patient populations. Federal funding is critical to support infrastructures that enhance the accrual of minority patients on clinical trials.

The NCI Community Oncology Research Program (NCORP) is one example of federal efforts to reduce structural barriers for patients. NCORP is a national network that is successfully bringing cancer clinical trials and care delivery studies to people in their own communities in diverse settings. The program focuses on increasing clinical trial participation by addressing the structural and social drivers of disparities and evaluating differential outcomes in racial and ethnic minority groups and medically underserved populations (170). The participation of Chinese, Filipino, Japanese, and Native Hawaiian patients in cancer clinical studies at least as often or more frequently compared to White patients in an NCORP-affiliated center in Hawai'i that obtains federal funding to enhance enrollment and provide all patients the same clinical trial opportunities highlights the importance of NCORP strategies (639).

Another key strategy to diversify clinical trial participants is to simplify and expand eligibility criteria that often lead to exclusion of racial and ethnic minority patients. These criteria need to keep up with scientific innovation; be pragmatic, inclusive, and influenced by real-world evidence; and allow flexibility for patients with clinical or physical limitations (644). If candidate anticancer therapeutics are to be given to a broad range of patients once approved, they should be tested in a broad range of patients, including those who may have coexisting medical conditions. In this regard, a recent study showed that expanding eligibility criteria for a pancreatic cancer clinical trial using real-world data derived from electronic health records and administrative claims equalized eligibility rates between Black and White patients (614). Notably, traditional eligibility criteria differentially excluded Black patients from participating in such trials (614).

US policymakers and FDA are working on legislation and guidelines intended to increase the diversity of clinical trial

participants (see **Overcoming Cancer Disparities Through Science-based Public Policy**, p. 157). These include a diversity action plan that would require researchers and funders of clinical trials to submit concrete goals and needed steps for enrolling specific demographic groups in pivotal studies of new drugs (645,646). Continual monitoring of diversity plan submissions is required to benchmark whether ongoing and new clinical studies are consistently and adequately meeting their enrollment goals (647). COVID-19, despite its adverse effects on all aspects of cancer research and patient care, provided an opportunity to decentralize clinical trial designs, so that lifesaving therapeutics could be brought quickly to as many patients as possible (648).

Based on a recent analysis of clinical trials conducted by the SWOG Cancer Research Network, **socioeconomically vulnerable patients with cancer had better access to trials after implementation of the Affordable Care Act Medicaid expansion.** The study shows an annual 19 percent increase in Medicaid-insured cancer patients participating in publicly funded clinical trials after this policy change (649).



W45

Adaptations implemented by NCI and FDA during the pandemic to decentralize trials, including consenting patients remotely, permitting telehealth for routine clinical assessments, delivering experimental drugs to patients, and allowing the use of local laboratory or imaging facilities accessible to patients, have offered a blueprint of success to further revise and reform clinical research. Further efforts to build strong and sustainable partnerships between clinical research centers and local community practices and hospitals will be critical to ensure successful equitable implementation of decentralized clinical trials as well as continuity of care beyond clinical trial participation (619).

It is important, however, to rigorously examine whether decentralized clinical trials can ensure equal access to trial participation for all population groups to avoid widening of existing inequities. For example, it is possible that by eliminating the barriers to participation such as transportation and geographic constraints, those groups who already participate in clinical research may enroll at higher rates, making trial participants even less diverse and representative of the real-world disease burden (650).

## Inequities in Cancer Treatment

The dedicated efforts of individuals working throughout the medical research cycle (see **Figure 4**, p. 53) are constantly

translating new research discoveries into advances in cancer treatment that are improving survival and quality of life for people in the United States and around the world. Much of the recent progress, including many new cancer treatments approved by FDA, was highlighted in the *AACR Cancer Progress Report 2023* (1).

Despite these advances, racial and ethnic minority groups and medically underserved populations continue to experience more frequent and higher severity of multilevel barriers to quality cancer treatment, including treatment delays, lack of access to guideline-adherent treatment, undertreatment, refusal or early termination of treatment, treatment receipt at low-volume and community settings rather than comprehensive cancer centers, and higher rates of treatment-related and/or financial toxicities (see **Sidebar 28**, p. 114) (651-655). As one example, based on a recent analysis, Black and Hispanic patients with triple-negative breast cancer are 18 percent and 13 percent less likely, respectively, to receive guideline-adherent treatment (including surgery, radiation, and/or chemotherapy) compared to White patients (651).

Patients from racial and ethnic minority groups and medically underserved populations report experiences of overt discrimination and/or implicit bias during the delivery of care, including negative experiences with their health care providers (656). Better experiences while accessing care may mitigate racial and ethnic disparities in the receipt of guideline-adherent treatment (657). Unfortunately, oncologists rarely perceive racial anxiety or unconscious bias as adversely influencing clinical care or survival outcomes for minoritized patients (657). Implementing health system interventions to increase institutional awareness of the current challenges and ensuring that the cancer care workforce is cognizant of their own perceptions surrounding racial disparities and biases is vital to achieving health equity.

Many of the inequities in cancer care can be attributed to adverse differences in SDOH, including low income, lack of health insurance, and limited access to health care facilities (see **Understanding and Addressing Drivers of Cancer Disparities**, p. 36). Research shows that patients with high household income deem cure as a priority when choosing treatment options, whereas those with lower income prioritize additional factors beyond cure such as cost, duration, effect on daily activities, and burden on family and friends (669).

Barriers to quality cancer treatments are compounded for Indigenous populations and those living in remote or rural areas, as well as for patients who lack health literacy or have language barriers (655,663,670,671). Evidence suggests that receiving health care from a provider who is of the same race and/or ethnicity or speaks the same language as the patient can

*continued on page 117*

## SIDEBAR 28

## Multilevel Barriers to Quality Cancer Treatment

Cancer patients from racial and ethnic minority groups and other underserved populations experience numerous barriers to quality cancer care. As one example, compared to White patients, **Black and Hispanic patients with liver cancer are 26 percent and 21 percent less likely, respectively, to receive curative treatments that can improve survival** (658). Treatment disparities can be attributed largely to structural and systemic inequities and were exacerbated by COVID-19. Some recent examples of the multifaceted barriers to cancer care are cited below.

**MORE  
likely**

**Black and Hispanic cancer patients and caregivers** are more likely **to report not having their questions answered in an easy-to-understand manner** by their health care team, **not feeling comfortable discussing their questions** with their care team, and receiving poorer quality of care based on their race or ethnicity (659).

**6%  
lower**

Cancer patients living in **areas with lower socioeconomic status (SES)** are more likely to be Black or Latinx and have a **6 percent lower rate of initiating treatments** compared to those living in areas of high SES (659).

**83% vs. 48%**

**Black men with metastatic prostate cancer** who are Hispanic or from South/Central America are 83 percent and 48 percent, respectively, **more likely to experience treatment delays** compared with Non-Hispanic White men (660).

**LESS  
likely**

**Patients with pancreatic cancer** who receive care at **minority-serving hospitals** are significantly **less likely to receive guideline-compliant care** compared to those receiving care at non-minority-serving hospitals (661,662). Guideline-compliant care is associated with improved survival.

**LONGEST  
times**

**Travel times** to the nearest pediatric oncologist were **longest for the American Indian or Alaska Native** pediatric population, residents of rural areas, and those living in areas with high levels of socioeconomic deprivation (663).

**28% and 38%  
vs. 94%**

**Fewer non-English-speaking patient callers** at 144 hospitals across 12 states were **provided with the next steps** in their colon, lung, or thyroid **cancer care** (28 percent of Mandarin-speaking callers and 38 percent of Spanish-speaking callers versus 94 percent of English-speaking callers) (664).

**39%  
increase**

Among **patients with early-stage lung cancer living in neighborhoods with the lowest socioeconomic status**, a 15-minute increase in public transit time was associated with a 39 percent increase in the **risk of undertreatment** (665).

**MORE  
likely**

Following SARS-CoV-2 infection, **non-Hispanic Black and Hispanic patients with cancer** were more likely to **experience treatment delays** of at least 2 weeks and **treatment discontinuation** compared to non-Hispanic White patients, attributable to adversities in social drivers of health (666).

**Substantial  
DELAYS**

During the COVID-19 pandemic, **rural residents in Hawai'i** experienced **substantial delays in cancer treatment initiation** (667).

**CANCELED  
appointments**

A survey of **American Indian patients living in California and Oklahoma** showed that 42 percent of patients **canceled cancer-related appointments**, and 24 percent of patients were **unable to access prescription medications** due to COVID-19 (668).

## In Memoriam



### A. WILLIAM BLACKSTOCK, JR., MD

(April 29, 1963–June 18, 2023)

A. William Blackstock Jr., MD, a radiation oncologist and cancer center leader, was a passionate advocate for innovative and inclusive cancer research and workforce diversity.

Dr. Blackstock was born April 29, 1963, in Eden, North Carolina. He earned a bachelor's degree in biology from Wake Forest University and a medical degree from East Carolina University Brody School of Medicine. He completed his residency and a fellowship at University of North Carolina School of Medicine at Chapel Hill, where he won a national award for best research by a resident in radiation oncology.

Dr. Blackstock began his career as an instructor at the UNC School of Medicine and a member of the Lineberger Comprehensive Cancer Center. In 1996, Dr. Blackstock joined the Department of Radiation Oncology at Wake Forest Baptist Health (known today as Atrium Health Wake Forest Baptist) as a clinician and a professor of radiation oncology and cancer biology. From 2008 until his death, he served as department chairperson,

becoming one of the first Black scientists to chair a department of radiation oncology. From 2022 to 2023, he also served as interim director of the Atrium Health Wake Forest Baptist Comprehensive Cancer Center.

Dr. Blackstock's clinical practice focused primarily on patients with gastrointestinal and lung cancer. As a researcher, he led numerous Phase I and Phase II clinical trials that examined novel drugs and treatment approaches in combination with radiation therapy. His research on esophageal cancer and the prognostic value of PET-based response led to changes in the assessment of treatment response.

Dr. Blackstock published more than 100 academic journal articles and book chapters. He served on councils for the National Institutes of Health and the National Cancer Institute. He was also a passionate advocate for health equity, publishing research on social determinants of health for African Americans with lung cancer.

Dr. Blackstock became a member of the AACR in 2001. He served on the committee for the AACR Distinguished Lectureship on the Science of Cancer Health Disparities from 2012–2013, and on the Research Grant Review Committee from 2014–2015. He was a member of Minorities in Cancer Research and the Radiation Science and Medicine Working Group.



### WORTA MCCASKILL-STEVENS, MD

(July 26, 1949–November 15, 2023)

Worta McCaskill-Stevens, MD, former chief of the National Cancer Institute (NCI) Community Oncology and Prevention Trials Research Group and former director of the NCI Community Oncology Research Program, was a tireless champion of addressing cancer disparities.

Born on July 26, 1949, in Louisburg, North Carolina, Dr. McCaskill-Stevens attended Washington University in St. Louis and the Georgetown University Medical School, graduating in 1985. At Georgetown, she received the Sarah E. Steward Award for Leadership in Medicine and the Kaiser Family Fund Award for Excellence in Academic Achievement. She trained in internal medicine at Georgetown and completed a fellowship in medical oncology at the Mayo Clinic in 1991.

Dr. McCaskill-Stevens worked as a breast cancer oncologist before joining NCI in 1998 in the Community Clinical Oncology Program. She also served as program director for

*continued on page 116*



the Study of Tamoxifen and Raloxifene, which involved nearly 20,000 postmenopausal women at increased risk of breast cancer, and she helped plan the Tomosynthesis Mammographic Imaging Screening Trial (TMIST), an ongoing, international breast cancer screening trial of nearly 130,000 women ages 45 to 74. She herself participated in TMIST.

Monica Bertagnolli, MD, then director of NCI and now director of the National Institutes of Health, announced in August 2023 the creation of a training award named in her honor, the NCI Wortz McCaskill-Stevens Career Development Award for Community Oncology and Prevention Research. McCaskill-Stevens worked for NCI for 25 years.

In 2017, Georgetown University awarded Dr. McCaskill-Stevens an honorary doctorate in science. She also received the David King Community Clinical Scientist Award from the Association of Community Cancer Centers in 2020.

A member of the AACR since 2007, she was chair of the Women in Cancer Research Council from 2012–2013 and was a member of the Minorities in Cancer Research (MICR) Council. In 2016, she received the AACR-MICR Jane Cooke Wright Memorial Lectureship.



## **EDITH P. MITCHELL, MD**

**(November 20, 1947–January 21, 2024)**

Edith P. Mitchell, MD, an oncologist, the enterprise vice president for cancer disparities at the Sidney Kimmel Cancer Center (SKCC) in Philadelphia, Pennsylvania, and a retired brigadier general in the United States (US) Air Force had a lifelong commitment to health equity.

Dr. Mitchell joined Jefferson Health in 1995 and held several positions, including director of the Center to Eliminate Cancer Disparities and clinical professor of medicine and medical oncology. She became enterprise vice president for cancer disparities at Jefferson's SKCC in 2023.

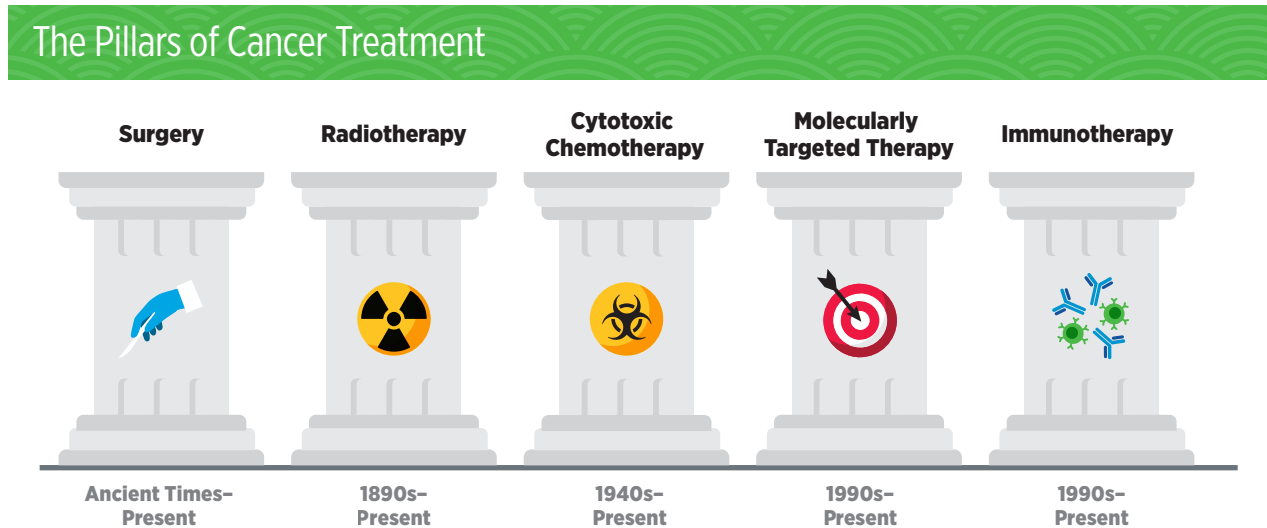
Raised on a farm in West Tennessee, Dr. Mitchell received her bachelor's degree in biochemistry from Tennessee State University in Nashville, Tennessee, in 1969. She completed medical school at the Medical College of Virginia in Richmond in 1974. She was commissioned in the US Air Force through its Health Professions Scholarship Program and entered active service after completing an internship and residency at Meharry Medical College in Nashville and a fellowship at Georgetown University in Washington, DC.

She became a senior flight surgeon and served in the Air Force and Air National Guard for 36 years. She was the first woman physician to rise to the rank of brigadier general, a rank to which she was promoted in 2001 after completing flight training and earning her wings.

In 2015, she was named the 116th president of the National Medical Association. She was a member of the President's Cancer Panel from 2019-2023, and she served on the National Cancer Institute's Blue Ribbon Panel to advise the National Cancer Advisory Board on then-Vice President Joe Biden's National Cancer Moonshot Initiative.

An AACR member since 2016, Dr. Mitchell was a member of the steering committee for the *AACR Cancer Disparities Progress Report 2022* and served on the program committee for the 15th AACR Conference on the Science of Cancer Health Disparities in Racial/Ethnic Minorities and the Medically Underserved, held in Philadelphia, Pennsylvania, in 2022. She received the AACR Minorities in Cancer Research Jane Cooke Wright Lectureship in 2021. She was also a member of the AACR Women in Cancer Research and AACR Minorities in Cancer Research constituency groups.

FIGURE 15



The cancer treatment paradigm is built upon what physicians often refer to as the “pillars” of cancer treatment. For centuries, surgery was the only treatment for cancer. In 1896, treatment of a patient with breast cancer with X-rays added radiotherapy as the second pillar. The foundations for the third treatment pillar—cytotoxic chemotherapy—were established in the early 1940s when a derivative of nitrogen mustard was explored as a treatment for lymphoma. These three pillars—surgery, radiotherapy, and cytotoxic chemotherapy—continue to be critical components of cancer treatment. The introduction of the first molecularly targeted therapeutics in the late 1990s led to the fourth pillar, molecularly targeted therapy. Also, in the late 1990s, decades of discovery science laid the groundwork for the fifth treatment pillar, immunotherapy. The number of anticancer agents that form the two most recent pillars of treatment continues to increase every year.

Adapted from (1).

improve patient satisfaction and quality of care (630,672,673). However, fewer individuals from racial and ethnic minority groups report having the same race and/or ethnicity or language preference as their provider (114).

Dissatisfaction with their health care due to experiences of discrimination and cultural incompetency is a major barrier for patients from SGM populations and often leads to avoidance of care (674,675). Based on a recent report, patients with breast cancer from SGM groups are more than twice as likely to decline an oncologist-recommended treatment modality compared with cisgender heterosexual patients (67). There is also serious lack of data on the quality of the cancer care received by SGM patients, making it difficult to accurately assess the disparities in cancer treatment and continuity of care among these patients (676).

Patients with breast cancer who are **Spanish-speaking** experience an **80 percent higher likelihood of delay in the initiation of cancer treatment** compared to patients who are English-speaking (655).



W46

It should be noted that patients with intersectional identities often experience multilevel barriers to cancer care that adversely impact screening, diagnosis, treatment, and survivorship. As one example, recent data show that Black and AI/AN populations living in rural areas experience greater poverty and lack of access to quality care, both of which expose them to a greater risk of experiencing poorer cancer outcomes (677). There is a critical need for additional research to understand the intersections of geography, race/ethnicity, socioeconomic, sexual orientation, and gender identity and their effects on disparities in cancer treatment and to mitigate these disparities through reduced structural and interpersonal biases, increased access, and implementation of evidence-based interventions.

In the following sections, we highlight recently documented inequities among cancer patients from racial and ethnic minority groups and medically underserved populations in the use of the main pillars of cancer treatment (see **Figure 15**, p. 117) and highlight areas where advances have been made in achieving equity in cancer treatment. Importantly, several recent studies have pointed out that disparities in the receipt of care, as well as outcomes for many cancers, can be eliminated if every patient has equitable access to quality health care services (115,678,679).

## SIDEBAR 29

## Using Surgery for Cancer Treatment

Surgery can be used in several ways during the care of a patient with cancer:

**Surgery to diagnose cancer** is performed to obtain a tumor sample for diagnosing cancer.

**Surgery to stage cancer** is performed to determine how far the cancer has spread from the site of origin so that the best treatment plan can be developed for the patient.

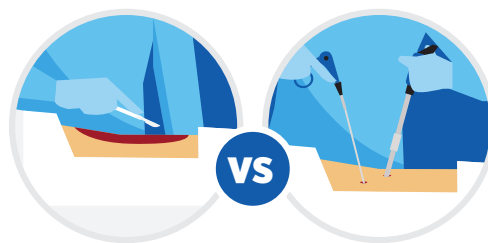
**Surgery to cure cancer** is performed to remove the entire tumor if cancer is confined to one area of the body.

Cancer tissue obtained during surgery can be utilized as experimental models for functional screening of the best therapeutic options for the patient.

### Surgery for patients with cancer can be open or minimally invasive.

**OPEN SURGERY** is when a surgeon makes one or more large cuts to remove the tumor, some surrounding healthy tissue, and maybe some nearby lymph nodes.

**MINIMALLY INVASIVE SURGERY** is when a surgeon makes one or more small cuts, inserting a long, thin tube with a tiny camera, called a laparoscope, into one of the small cuts. The camera projects images from the inside of the body onto a monitor, which allows the surgeon to see what is happening. Special surgery tools are inserted through other small cuts to remove the tumor and some healthy tissue. **Robotic platforms** can be used to perform minimally invasive surgeries. This approach provides a magnified stereoscopic vision of the tumor and internal organs and a better ability for surgeons to work within confined spaces.



Adapted from (1).

## Treatment With Surgery

Surgery, radiotherapy, and cytotoxic chemotherapy are three pillars of cancer treatment (see **Figure 15**, p. 117) that form the foundation of initial clinical care for almost all patients with cancer. Surgery is the foundation of treatment for many cancer types (see **Sidebar 29**, p. 118) for which there are significant disparities in mortality and morbidity experienced by racial and ethnic minority groups and medically underserved populations.

For cancers associated with high mortality, such as lung, liver, and pancreatic cancers, surgical resection is key to survival when these tumors are detected at an early stage. For cancers with better prognosis, specialty surgeries are necessary to optimize quality of life after the treatment, such as minimally invasive surgery for gastrointestinal cancers, reconstruction surgery for certain breast cancer patients requiring mastectomy, and sphincter-preserving surgery for rectal cancer patients. Researchers are continuously innovating new and improved strategies to maximize the benefit and minimize harms from surgery for cancer patients. Thanks to

such efforts, overall mortality rates after surgery for all patients with many common types of cancer have declined over the past decade (680). However, the mortality gap between Black and White patients after surgery, overall, or for individual cancer procedures, has not narrowed (680).

Racial and ethnic minority groups and medically underserved populations often experience disparities in surgical management of cancer, including treatment delays or refusals and lack of guideline-adherent care (see **Sidebar 30**, p. 119). These disparities are seen across many cancer types, including the most diagnosed cancers in the United States, and may contribute to worse outcomes. As one example, NH Black women with breast cancer are less likely to receive curative surgery and NH Black as well as Hispanic women with breast cancer have higher odds of delayed surgery compared to non-Hispanic White women (681,682). Among patients with colorectal cancer, NH Black patients are more likely to undergo emergency surgery compared to NH White patients (683). Undergoing emergency surgery is indicative of barriers to timely screening and evaluation and is associated with increased likelihood of postoperative complications, including mortality.

## SIDEBAR 30

## Disparities in Cancer Surgery in the United States

**TWICE**  
as likely

**Black patients with kidney cancer** are 24 percent **less likely to receive potentially lifesaving surgery** compared to White patients; **Black patients and American Indian and Alaska Native patients with kidney cancer** are nearly twice as **likely to refuse recommended surgery** compared to White patients (684).

**26%**  
less likely

**American Indian and Alaska Native patients with stage I non–small cell lung cancer** are 26 percent **less likely to undergo guideline-concordant surgery** compared to White patients (685).

**MORE**  
likely

**Chinese, Japanese, Filipino, Korean, and Vietnamese patients with colon cancer** are 27 percent, 23 percent, 36 percent, 16 percent, and 55 percent **more likely, respectively, to experience delay before receiving surgery** compared to White patients (686).

**48%**  
less likely

**Melanoma patients from rural areas** are 48 percent **less likely to receive recommended surgery** and have nearly **20 percent higher melanoma-specific mortality** compared to patients from urban areas (51).

**18%**  
lower

Among **patients with colorectal cancer who have liver metastases**, the likelihood of **receiving liver surgery** to remove metastases is 18 percent lower **for those living in counties with high poverty** (687).

For cancers associated with high mortality, such as glioblastoma multiforme (an aggressive form of brain tumor) or pancreatic cancer, surgical resection is key to survival. Unfortunately, research shows that US counties with a higher percentage of Black patients have delays in surgical care, attributed to lack of neurosurgeons, as well as lower overall rates of surgery for glioblastoma (688). Cancer patients from racial and ethnic minority populations are often treated at community and minority-serving hospitals. Patients with pancreatic cancer treated at minority-serving hospitals have lower rates of surgical resection, a decreased likelihood of undergoing curative surgery, and increased mortality (689).

Despite the immense benefits of surgery in cancer, complications are common and can negatively affect a patient's quality of life. One approach to reducing the complications during and after surgery and improving quality of life post procedure is to perform minimally invasive surgeries, such as robotic surgeries, that are performed by highly specialized surgeons.

Unfortunately, there are disparities in the use of these cutting-edge procedures and in the access to specialized surgeons. As one example, patients with lung cancer who are Black, have Medicaid insurance, are treated at smaller hospitals, or are from rural areas, are less likely to be treated by a specialized thoracic surgeon (690). A recent review that evaluated the use of robotic and minimally invasive surgeries in patients with prostate, endometrial, bladder, or rectal cancer found that 70

percent of current studies reported lower use of these state-of-the-art procedures among Black patients and 50 percent of all studies reported lower use among Hispanic patients compared to White patients (691). According to another analysis, among patients with non–small cell lung cancer (NSCLC), those who live in low-income neighborhoods or receive care at community hospitals are significantly less likely to undergo minimally invasive surgeries (692). Additionally, patients without private health insurance are less likely to receive robotic surgeries (693).

Lack of or limited access to surgical facilities is a major barrier in seeking cancer surgery. It is known that a greater distance to a surgical facility is associated with a decreased likelihood of treatment (694). Patients from the rural United States are particularly vulnerable, since they must travel significantly longer distances for care (695). This may result in delay or lack of needed surgeries (671,696). As one example, patients with pancreatic cancer from rural areas are 12 percent less likely to undergo pancreatectomy and have a 25 percent higher 1-year mortality compared to metropolitan residents (697). These disparities are driven largely by socioeconomic factors and could be exacerbated in patients from racial and ethnic minority populations living in rural areas. According to a recent study, patients with colon cancer from racial and ethnic minority groups who resided in rural areas experienced higher odds of postoperative surgical complications and mortality, with Black patients from rural areas experiencing 86 percent



higher odds of postoperative mortality compared to their metropolitan counterparts (698).

Many of the inequities in cancer surgery are driven by centuries of structural and systemic injustices. As one example, research has shown that women with breast cancer living in historically redlined areas are less likely to receive surgery and have higher breast cancer–specific mortality compared to those not living in such areas (103). It has been demonstrated that receiving specialized treatments such as complex cancer surgeries at high-volume hospitals is associated with better outcomes compared to low-volume hospitals (699,700). Patients living in redlined areas are less likely to receive surgery at high-volume hospitals because of socioeconomic challenges (701).

**Black Medicare beneficiaries with prostate cancer** are more likely to receive care from low-volume hospitals and **less likely to receive care at NCI-designated cancer centers** compared to their White counterparts. Black men receiving surgery at a low-volume facility had a 61 percent increased risk of prostate cancer mortality (702).



W47

Inequities in quality surgical care can be attributed to adverse influences of SDOH, including low income or education levels, lack of health insurance, and transportation challenges. A retrospective analysis identified lower median household income and nonprivate health insurance as two of the factors associated with not undergoing surgery for patients with rectal cancers (703). Similar results have been found among patients with lung cancer (704). Another study looking at the receipt of surgery among women with certain gynecologic cancers found higher rates of treatment refusal among patients who were uninsured, lived in regions with low rates of high school graduation, or were treated at a community hospital (705). Notably, overall survival rates are lower among patients who refuse surgery.

Taken together these studies highlight the need for multilevel interventions to ensure equitable delivery of guideline-recommended surgery for all cancer patients. All constituents must work together to improve access to quality health care resources for all patients while continuing further research into the mechanisms that perpetuate disparities. In this regard, an urgent unmet need is to capture and integrate SOGI data in the surgical literature to understand the extent of perioperative disparities these patients may experience (706). Furthermore, concerted efforts from the medical research community and policymakers are needed to diversify the current surgical oncology workforce, which significantly lacks representation from minoritized groups and women (707).

## Treatment With Radiation Therapy

Radiotherapy is the use of high-energy rays (e.g., gamma rays and X-rays) or particles (e.g., electrons, protons, and carbon nuclei) to control or eradicate cancer. The discovery of X-rays in 1895 allowed visualization of internal organs at low doses, and the effective use of X-rays at high doses to treat a patient with breast cancer a year later established radiotherapy as the second pillar of cancer treatment (see **Figure 15**, p. 117). Radiotherapy plays a central role in the management of cancer and works primarily by damaging DNA, leading to cancer cell death. The use of radiotherapy in the treatment and management of cancer continues to increase, as indicated by a 16.4 percent increase in radiation facilities across the United States between 2005 and 2020 (708).

There are many types and uses of radiotherapy (see **Sidebar 31**, p. 121). Approximately 50 to 60 percent of patients with cancer receive radiotherapy at some point during their disease course (709,710). However, it is important to note that radiotherapy may also have harmful side effects, partly because of the radiation-induced damage to healthy cells surrounding the tumor tissue.

Researchers are continuously working on making radiotherapy safer and more effective. As one example, stereotactic ablative radiotherapy is an advanced approach to radiotherapy that can more precisely target radiation to tumors than conventional forms of external beam radiotherapy (see **Sidebar 31**, p. 121). As a result, higher doses of radiation can be used without damaging healthy tissues surrounding a tumor, which reduces the long-term adverse effects of radiotherapy. Recent clinical trials have shown that stereotactic ablative radiotherapy targeted to certain metastatic tumors can reduce the chances of disease progression and increase survival for patients who have solid tumors, such as prostate cancer, lung cancer, and gastrointestinal tumors (711). Researchers are also designing novel radiotherapeutics, such as molecularly targeted radioconjugates, to be used alone or in combination with other treatments, to target more cancer types and benefit more patients (89,712).

Another area of active investigation is identifying when radiotherapy can be reduced or avoided without affecting the chances of survival for patients. In this regard, a recent clinical trial showed that for patients with early-stage prostate cancer, active monitoring of their disease is a safe alternative to receiving immediate surgery or radiotherapy (713). The study directly compared the long-term outcomes of three approaches, prostate removal surgery, radiotherapy, or active monitoring, and found that there was no difference in prostate cancer mortality at the 15-year follow-up between the three groups. These data provide hope for patients with prostate cancer who opt for active monitoring to avoid treatment-related adverse effects, such as sexual and incontinence problems. Recent findings show that uptake of active monitoring has increased nationally but remains suboptimal, with wide disparities across health care practices (714).

## SIDEBAR 31

## Using Radiation in Cancer Treatment

## There are two major applications of ionizing radiation in cancer care:

## TREATMENT OF CANCER

**Radiotherapy**, or radiation therapy, uses high-energy radiation to control and eliminate the disease.



## DETECTION OF CANCER

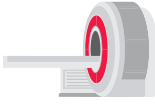
**Radiology** largely uses low-energy radiation to image tissues to diagnose the disease.



## Types of Radiotherapy

## EXTERNAL BEAM RADIO THERAPY

delivers radiation, usually photons (X-rays) or electrons, to the tumor from outside the body; it is the most common form of radiotherapy.



## There are several types of external beam radiotherapy:

- **Conventional external beam radiation therapy** delivers a high-energy X-ray beam from one or more directions and is primarily used when high precision is not required.
- **Three-dimensional conformal radiotherapy (3DCRT)** delivers high-energy X-rays via multiple beams that, with the help of computed tomography and/or magnetic resonance imaging, enable more precise planning to best target the shape and size of the tumor.
- **Hypofractionated radiation therapy** is a treatment in which the total dose of radiation is divided into large doses and given over a shorter period of time (fewer days or weeks) than standard radiation therapy.
- **Intensity-modulated radiotherapy** is a refinement of 3DCRT; it delivers radiation by dividing each beam into many “beamlets,” each of which can have a different intensity, to achieve improved conformality.
- **Intraoperative radiation therapy** delivers electron beam (superficial) radiation directly on tumors that have been exposed during surgical procedures, or to

the tumor cavity immediately after cancer removal.

- **Stereotactic radiotherapy** delivers radiation to very well-defined smaller tumors, typically using more than eight beams with the help of a highly sophisticated immobilization and imaging system. It is used in both stereotactic radiosurgery (to treat tumors of the brain and central nervous system) and stereotactic body radiotherapy (to treat small tumors within the rest of the body).

**PARTICLE THERAPY** delivers radiation doses by protons or carbon ions, instead of X-rays, to the tumor with a dose distribution that better spares the exposure of surrounding tissue because these particles deposit most of their energy in the target. Although of great interest, proton facilities are much more expensive than traditional facilities, and the overall benefit to patients remains to be defined.



**BRACHYTHERAPY** delivers radiation by placing small radioactive sources in or next to the tumor either temporarily or permanently.



**RADIOISOTOPE THERAPY** delivers radiation to the tumors via systemic ingestion or infusion of radioisotopes.



## Uses of Radiotherapy

**CURATIVE RADIO THERAPY** is used to eliminate cancers, often in combination with systemic therapy.

**NEOADJUVANT RADIO THERAPY** is used to shrink a tumor so that it can be subsequently treated by a different method such as surgery.

**ADJUVANT RADIO THERAPY** is used to eliminate any remaining cancer, often directed to the tumor cavity following prior surgical removal.

**PALLIATIVE RADIO THERAPY** is used to reduce or control symptoms of disease when cancer is considered incurable.

**SALVAGE RADIO THERAPY** is used to treat cancer after the cancer has not responded to other treatments but could be successfully controlled by radiotherapy.

Unfortunately, reduced access to and utilization of radiation therapy, including as curative treatments, have been well documented among patients from racial and ethnic minority

populations in the United States (715-717), which contributes to disparities in cancer outcomes. As one example, a retrospective analysis of the National Cancer Database showed

that Black women with cervical cancer and NHOPI women with endometrial cancer were significantly less likely to receive brachytherapy compared to NH White women and that for both Black and NHOPI women, treatment at community cancer centers was associated with a decreased likelihood of brachytherapy (718). Another study evaluating patients with head and neck cancer showed that racial and ethnic minority patients were more likely to experience delays in the receipt of adjuvant radiation (719). Additionally, non-English-speaking patients and those from low SES were more likely to experience such delays. The likelihood of missing radiation therapy appointments has been shown to be nearly three times higher among Black, Hispanic, and low-income patients (715).

A recent advance in radiation oncology is the emergence of hypofractionated radiotherapy, whereby patients receive fewer but higher doses of radiotherapy compared with the traditional course. Hypofractionated radiotherapy is increasingly being used in the treatment of breast cancer and prostate cancer because it has shown similar efficacy in improving long-term outcomes as traditional courses of radiotherapy (721-723). Patients who have hypofractionated radiotherapy complete their treatment over a shorter period and in fewer sessions.

**American Indian and Alaska Native, Black, and Hispanic patients with breast cancer report substantially worse long-term quality of life after radiation therapy (720).**



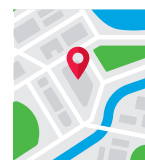
W48

Hypofractionated regimens could potentially benefit underserved patients by reducing travel-related financial and time burdens. In fact, recent studies indicate that across racial and socioeconomic populations, timely completion of radiation therapy is greater for patients with breast cancer receiving hypofractionated radiation compared to those receiving traditional radiation (724). Additionally, racial disparities in treatment noncompletion between Black and White patients with breast and prostate cancer were drastically reduced with shorter radiation regimens (725). It is also encouraging that over the past two decades, there has been an increase in the utilization of shorter radiation regimens, such as hypofractionated radiotherapy and stereotactic body radiotherapy, across all populations (726,727). However, treatment disparities persist, with evidence that Black patients are less likely to receive hypofractionated radiation (725,727,728).

Researchers have identified a range of barriers, including socioeconomic status, geographic location, insurance status, language, and health care facility characteristics, that contribute to the disparities in radiation therapy access and utilization. Based on a recent report, hospitals serving racial and ethnic minority groups are significantly less likely to offer many core cancer services, including diagnostic radiology for cancer detection, many radiotherapy modalities, and other treatment modalities (110).

One of the most prominent barriers to receiving radiation therapy lies in geographic location and access (or lack thereof) to clinical facilities. Regions with greater geographic access to radiation therapy tend to have residents who are of higher socioeconomic status and are better insured (708). Increasing travel distances to treatment facilities are associated with lower receipt of radiation treatment (729,730). Greater distance to radiation therapy facilities and fewer radiation oncologists in an area have been shown to be associated with higher cancer mortality (729,731). Patients from Indigenous populations and rural areas are at a particularly higher risk of living farther away from radiation facilities and not receiving needed treatments (732).

A recent study found that travel distances to radiation therapy for AI/AN population-majority areas were **39 to 41 miles longer** than in areas with non-AI/AN majorities (733).



W49

Overall, these findings call for new evidence-based strategies to improve access to radiotherapy services for patients with cancer from all medically underserved populations. It is imperative that all constituents in medical research and public health come together to identify populations and areas with the greatest barriers to radiation care, investigate the underlying barriers, and develop tailored interventions with the goal of reducing health inequities in radiotherapy.

## Treatment With Chemotherapy

Cytotoxic chemotherapy is the use of chemicals to kill cancer cells and was first introduced as a pillar of cancer treatment in the early to mid-20th century (734). Chemotherapy can be extremely effective in systemic treatment of cancer. It remains a backbone of cancer treatment, and its use is continually evolving to minimize potential harm to patients with cancer, while maximizing its benefits.

Treatment with cytotoxic chemotherapeutics can have adverse effects on patients. These effects can occur during treatment and continue in the long term, or they can appear months or even years later. Health care providers and researchers are investigating different approaches to make chemotherapeutics safer for patients. Areas of ongoing investigation include designing modifiable chemotherapeutics, e.g., with “on” and “off” switches, that are selectively delivered to tumors while sparing healthy tissue; evaluating less aggressive chemotherapy regimens that can allow patients the chance of an improved quality of life without compromising survival; and identifying specific molecular characteristics in tumors called biomarkers to correctly predict which patients will or will not benefit from chemotherapy (735-737).

## SIDEBAR 32

## Disparities in the Use of Chemotherapy

**LESS  
likely**

Among patients with stage III colon cancer ages 18 to 65, the use of adjuvant chemotherapy was less likely among those who are **non-Hispanic Black and Hispanic, travel  $\geq$  50 miles, have a yearly income  $<$  \$40,000, and are uninsured** (742).

**MORE  
likely**

Among patients undergoing surgery for pancreatic cancer, those living in counties with **low socioeconomic status** had a 22 percent higher likelihood of delay and a 30 percent **higher likelihood of not receiving adjuvant chemotherapy** (743).

**LESS  
likely**

Among Asian American women with cervical cancer, **Southeast Asian patients were less likely to receive guideline-concordant chemotherapy** compared to South Asian patients (744)

Unfortunately, many reports have documented that cancer patients from racial and ethnic minority groups and medically underserved populations are less likely to receive recommended chemotherapy (see **Sidebar 32**, p. 123). Medically underserved patients are also more likely to decline physician-recommended chemotherapy (738). These disparities arise due to a range of socioeconomic disadvantages, including low income, lack of health insurance, being treated at community hospitals, language barriers, and clinical factors such as advanced age.

colorectal cancer tend to have worse outcomes compared to White patients. Understanding the reasons behind rising cases of early-onset colorectal cancer and addressing this trend for all populations are areas of intensive research.

While it is vital for the medical research community to address the inequities in access to cancer chemotherapy for racial and ethnic minority patients, it is also critical to carefully evaluate the disparities in chemotherapeutic responses, including differences in toxicities that have been reported in the literature, since they impact patient outcomes and quality of lives (745,746).

**NEOADJUVANT  
CHEMOTHERAPY**

Chemotherapy **administered BEFORE surgery** to reduce the tumor size.

**ADJUVANT  
CHEMOTHERAPY**

Chemotherapy **administered AFTER surgery** to eradicate as many residual cancer cells as possible.

W50

As one example, a recent study that examined racial disparities in treatment among Black and White patients ages 18 to 49 with colorectal cancer found that Black patients were more likely to not receive guideline-adherent care in part because of lack of health insurance (739). Compared to White patients, Black patients with colon cancer were 22 percent more likely to not receive chemotherapy, while Black patients with rectal cancer were 68 percent more likely to not receive chemotherapy. Black patients also experienced greater delays before receiving the needed chemotherapy. These findings are concerning considering the rising incidence of colorectal cancer among individuals younger than 50 years (early-onset colorectal cancer) (740,741) and evidence that Black patients with early-onset

For patients with breast cancer, the presence or absence of three tumor biomarkers, two hormone receptors (HR) and the protein HER2, determines what treatment options should be considered. About 70 percent of breast cancers diagnosed in the United States are characterized as HR-positive and HER2-negative. Based on recent reports, Black patients with nearly every subtype of breast cancer tended to have worse responses to neoadjuvant chemotherapy (747,748); the disparity was most pronounced in patients with HR-negative, HER2-positive tumors. Researchers found biological differences in the tumors from Black patients that rendered them resistant to chemotherapeutics. These findings highlight the importance of identifying appropriate biomarkers in making treatment decisions. It is imperative that cancer biomarkers are evaluated in patients from all sociodemographic backgrounds, considering the evidence that certain biomarker-driven tests currently used to measure breast cancer aggressiveness and make decisions on chemotherapy treatment are less accurate for Black women than for White women (749,750).

**Treatment With Molecularly Targeted  
Therapy and Immunotherapy**

Remarkable advances in our understanding of the biology of cancer, including the identification of numerous genetic



## SIDEBAR 33

## The Increasing Precision of Molecularly Targeted Therapeutics

Research has increased the understanding of the factors most associated with cancer. As this knowledge has grown, anticancer therapeutics have become more precisely targeted to those factors, meaning they cause less damage to normal cells. Here we list the major categories of molecularly targeted therapeutics with selected examples that have been approved by the US Food and Drug Administration:

**Angiogenesis inhibitors** Block new blood vessel formation, which is vital for tumor growth and metastasis, e.g., bevacizumab (Avastin).



**Cell-lysis mediators** Cause cancer cell death via different mechanisms, e.g., antibody drug conjugates, such as trastuzumab deruxtecan-nxki (Enhertu), that deliver anticancer drugs specifically to cancer cells.



**Cell-signaling inhibitors** Block cell-signaling pathways that drive cancer initiation and progression, e.g., receptor tyrosine kinase inhibitors, such as the epidermal growth factor receptor (EGFR)-targeted therapeutic osimertinib (Tagrisso).



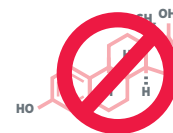
**DNA-repair inhibitors** Prevent cancer cells from repairing their damaged DNA, causing them to die, e.g., poly (ADP-ribose) polymerase (PARP) inhibitors, such as olaparib (Lynparza).



**Epigenome-modifying agents** Block proteins that epigenetically modify DNA, e.g., panobinostat (Farydak).



**Hormones/Antihormones** Block hormones such as estrogen or testosterone that drive cancer development, e.g., apalutamide (Erleada).



**Proteasome inhibitors** Block the action of proteasomes, which are part of the normal cellular machinery for breaking down proteins. This may prevent cancer cells from growing and may kill them, e.g., bortezomib (Velcade).



**Radiation-emitting therapeutics/ Radioconjugates** Deliver high doses of radiation to cancer cells leading to cancer cell death, e.g., lutetium Lu 177 dotatate (Lutathera).



These therapeutics have revolutionized cancer treatment in recent decades and the greater precision of these molecularly targeted treatments tends to make them more effective and less toxic than chemotherapeutics.

mutations that fuel tumor growth, set the stage for a new era of precision medicine, an era in which the standard of care for many patients is changing from a one-size-fits-all approach to one in which greater understanding of the individual patient and characteristics of their cancer dictates the best treatment option for the patient. Therapeutics directed to the molecules influencing cancer cell multiplication and survival target the cells within a tumor more precisely. The greater precision of these molecularly targeted therapeutics tends to make them more effective and less toxic than chemotherapeutics (see **Sidebar 33**, p. 124). Molecularly targeted therapeutics have become the fourth pillar of cancer care and are not only saving the lives of patients with cancer but are also allowing these individuals to have a better quality of life.

Groundbreaking basic research in the field of immunology—the study of the immune system—has laid the foundation of modern immunotherapy. Cancer immunotherapeutics leverage the natural ability of the immune system to

fight cancer. There are various ways in which different immunotherapeutics unleash the immune system to fight cancer (see **Sidebar 34**, p. 125).

In recent years, immunotherapy has emerged as the fifth pillar of cancer care and as one of the most exciting new approaches to cancer treatment along with molecularly targeted therapeutics. This is, in part, because many patients with metastatic cancer who have been treated with these revolutionary treatments have had remarkable and durable responses. In fact, the rapid advances in the field of molecularly targeted therapeutics and immunotherapeutics have transformed the treatment landscape for patients with formerly intractable cancers such as NSCLC or metastatic melanoma, the deadliest form of skin cancer. As reported in the *ACR Cancer Progress Report 2023*, dramatic reductions in lung cancer and melanoma death rates in recent years, due in part to molecularly targeted therapeutics and immunotherapeutics, are largely responsible for the steady decline in overall age-adjusted US cancer death rates (1).

## SIDEBAR 34

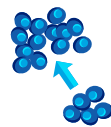
## How Immunotherapeutics Work

The way in which different immunotherapeutics unleash a patient's immune system to fight cancer varies:

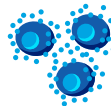
Some **release the brakes** on the natural cancer-fighting power of the immune system, for example, nivolumab (Opdivo) and pembrolizumab (Keytruda). These therapeutics are commonly known as checkpoint inhibitors.



Some **amplify the killing power of the immune system** by providing more cancer-targeted immune cells called T cells, for example, chimeric antigen receptor (CAR) T-cell therapies such as axicabtagene ciloleucel (Yescarta) and tisagenlecleucel (Kymriah).



Some **increase the killing power of the immune system** by enhancing T-cell function, for example, interleukin-2 (Aldesleukin).



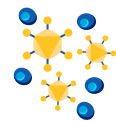
Some **enhance the cancer-killing power of the immune system** by triggering cancer-fighting T cells; these are called therapeutic cancer vaccines, for example, sipuleucel-T (Provenge).



Some **flag cancer cells for destruction** by the immune system, for example, daratumumab (Darzalex).



Some **comprise a virus that preferentially infects and kills cancer cells**, releasing molecules that trigger cancer-fighting T cells; these are called oncolytic virotherapeutics, for example, talimogene laherparepvec (T-VEC; Imlygic).



Adapted from (1).

The effective use of molecularly targeted therapeutics and immunotherapeutics often requires tests called companion diagnostics. Companion diagnostics detect specific molecular abnormalities, e.g., genetic mutations within tumors, often referred to as biomarkers, to identify patients who are most likely to benefit from the corresponding targeted therapy. This also allows patients identified as very unlikely to respond to forgo treatment and thus be spared any adverse side effects.

Unfortunately, there are striking inequities in the utilization of molecularly targeted therapeutics and immunotherapeutics which form the foundation of cancer precision medicine (652). These disparities are observed for most cancers, including those with a disparate burden among patients from racial and ethnic minority groups and medically underserved populations. Black women with breast cancer have a 40 percent higher mortality, while Black men with prostate cancer have a nearly two-fold higher mortality compared to their White counterparts (see **Cancer Disparities Experienced by US Racial and Ethnic Minority Populations**, p. 13). While differences in tumor molecular characteristics may contribute to some of these disparities, there are known inequities in the receipt of molecularly targeted therapeutics, that also play a significant role.

Patients with HR-positive and HER2-negative breast cancers are treated with a class of molecularly targeted therapeutics known as hormone therapies or endocrine therapies, which work by lowering the levels or preventing the function of the hormone estrogen. Hormone therapies can be used prior to initial breast cancer surgery (neoadjuvant), as initial treatment, or following surgery to be continued for 5 years or longer (adjuvant), depending on a patient's tumor characteristics.

Based on a recent analysis of patients with breast cancer who are 18 years or older, NH Black patients have a 17 percent lower likelihood of being prescribed endocrine therapy and have a significantly longer delay to initiation of endocrine therapy when prescribed, compared to White patients (681). NH Black patients also have lower odds of adhering to recommended treatments and continuing adjuvant endocrine therapy compared with NH White patients (751). Higher severity in adverse physical and psychological symptoms from adjuvant endocrine therapy may contribute to lower treatment adherence among Black women with breast cancer (752).

**AI/AN women** ages 66 and older with hormone receptor–positive breast cancer were **8 percent less likely** to use hormone therapy compared to non-Hispanic White patients (753).



W51

Another treatment option for patients with HR-positive and HER2-negative breast cancer is a molecularly targeted therapeutic that works by blocking the function of two specific proteins that play a role in driving cell multiplication—cyclin-dependent kinase (CDK) 4 and CDK6. There are three CDK4/6-targeted therapeutics that are approved by FDA to be used in combination with hormone therapy for treatment of patients with breast cancer. Long-term follow-up of these patients has shown that this combination approach improves overall survival (754,755). Unfortunately, there is evidence that the use

## SIDEBAR 35

## Disparities in the Utilization of Diagnostic Testing for Cancer Precision Medicine

Genetic testing to identify targetable alterations in tumor cells forms the basis of cancer precision medicine. Additionally, genetic testing of patients at risk for inherited mutations benefits their own care and potentially that of other family members. Unfortunately, there are disparities in the utilization of diagnostic testing attributable to a range of socioeconomic and structural factors, including lack of awareness, inadequate insurance, poverty, and treatment at community hospitals, among others (287). Some recent examples of these disparities include:

**65%**  
less likely

Black men with prostate cancer were **65 percent less likely** to complete genetic testing for inherited genetic alterations compared to White men (761).

**76% vs.**  
**10% and 9%**

**An analysis of tumor specimens submitted for genetic testing** from April 2013 through September 2022 showed that 76 percent of specimens came from patients with predominantly European ancestry; **only 10 percent of patients had African ancestry, and 9 percent had admixed American ancestry** (a proxy for the Hispanic population) (759). The data indicated that the use of genetic testing among those who had predominantly African ancestry increased by half a percentage point each year over the 10-year period.

**23% vs. 47%**

According to a recent analysis of patients diagnosed with ovarian cancer, **only 30 percent of patients completed genetic testing**. Rates of testing differed by race and testing was completed by 40 percent of White patients, **26 percent of Black patients, and 14 percent of Asian patients** (762). Patients without health insurance were significantly less likely to complete genetic testing compared to those with private insurance (23 percent vs. 47 percent).

Considering the steep rise in emerging technologies that aid tumor genetic testing and the rapid integration of genetic data and artificial intelligence to make individualized treatment strategies, it is imperative that all constituents invested in public health work together to prevent any widening of the current inequities in precision diagnostic testing. Investments in robust infrastructures, including virtual molecular tumor boards, provider and patient education, electronic health record-based interventions, and clinical decision-making support tools are vital to extend the promise of precision oncology to all patients (287).

of CDK4/6-targeted therapeutics is lower among patients who are Black and from lower SES (756). Use of CDK4/6-targeted therapeutics is twice as high among patients treated at academic cancer centers compared to those treated at community centers, where the majority of underserved patients receive care.

The growth of most prostate cancers is fueled by hormones called androgens. This knowledge led researchers to develop molecularly targeted therapeutics that lower androgen levels in the body or prevent its function. This approach to prostate cancer treatment is another type of hormone therapy called androgen-deprivation therapy. Unfortunately, most prostate cancers that initially respond to androgen-deprivation therapy eventually begin to grow again. To address this challenge, researchers have developed a new generation of hormone therapeutics that more effectively deprive prostate cancer of androgens. These treatments have been shown to prolong overall survival for patients with advanced prostate cancer. However, recent data indicate that the use of these novel hormone therapeutics is not similar across all populations, with decreased utilization observed in Black patients compared

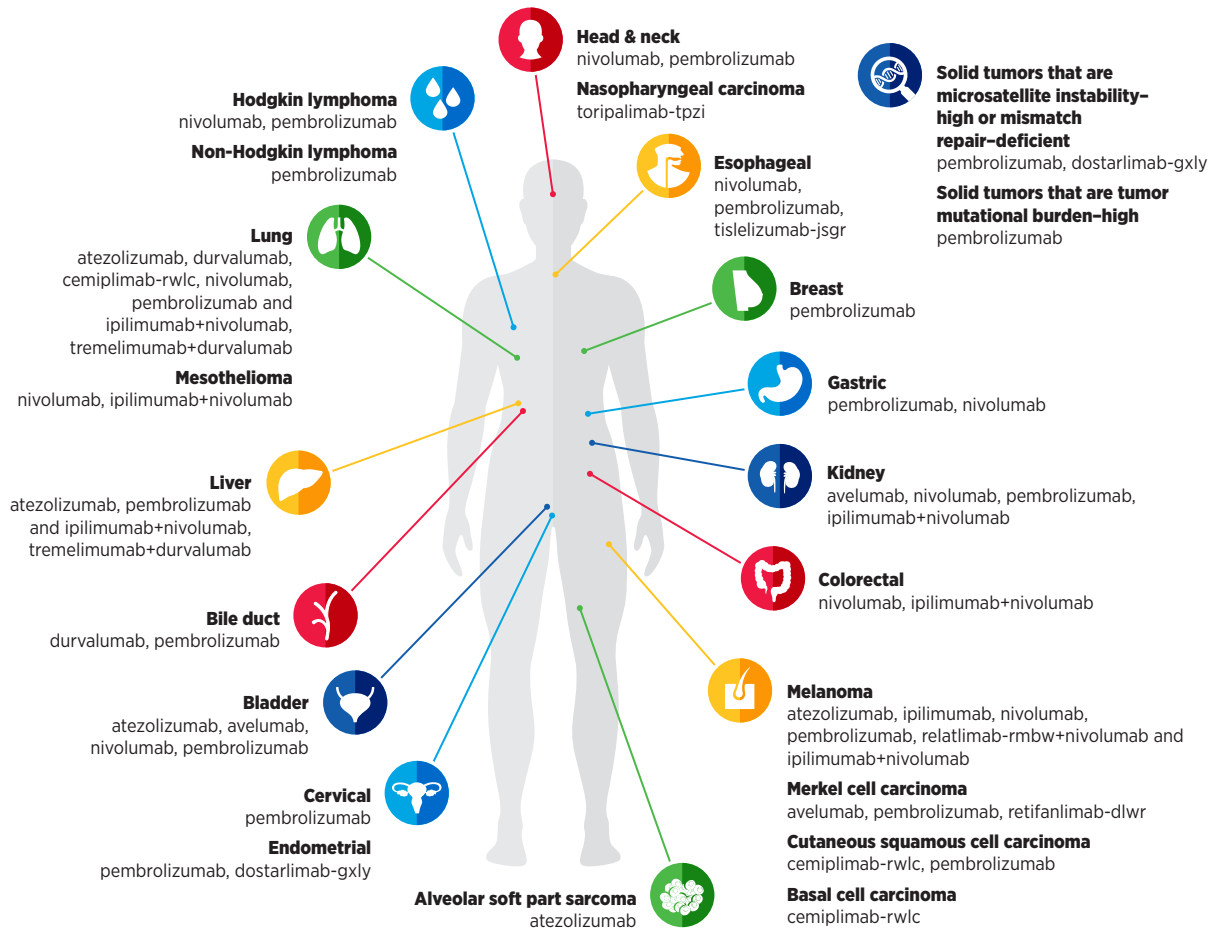
with other racial and ethnic groups, likely due to multilevel barriers, including adverse SDOH (757).

Genetic testing of tumors to detect cancer-causing mutations is a critical step before receiving treatment with matching molecularly targeted therapeutics. Patients who are at high risk for inherited cancers, as well as their family members, may also benefit from genetic testing. Unfortunately, recent reports indicate that the utilization of tumor genetic testing is suboptimal and particularly low among medically underserved populations, including racial and ethnic minorities (see **Sidebar 35**, p. 126). Encouragingly, tumor genetic testing rates have been increasing, including among medically underserved populations (758,759). As one example, within a large regional health system, tumor genetic testing rates in both Black and White patients with metastatic colorectal cancer increased significantly between 2008 and 2018 following clinical guideline changes (758).

In addition to guiding treatment decisions, genetic tests are being developed to help researchers predict the likelihood of cancer metastasis or recurrence. It is vital that the research on

FIGURE 16

## Expanding Scope of Immune Checkpoint Inhibitors



Immune checkpoint inhibitors (ICIs) are cancer immunotherapeutics that work by releasing certain “brakes” on the surface of immune cells called T cells, which are naturally capable of destroying cancer cells. The first ICI to be approved by the US Food and Drug Administration (FDA) was ipilimumab (Yervoy), in March 2011, for metastatic melanoma. Three-and-a-half years passed before the second ICI was approved, pembrolizumab (Keytruda), also for metastatic melanoma. Since then, over the past decade, 11 additional ICIs have been approved by FDA. In addition, FDA has expanded the number of cancer types for which there is at least one ICI approved. The broad utility of these groundbreaking immunotherapeutics is highlighted by the fact that as of March 31, 2024, there was at least one ICI approved for treating more than 20 cancer types. In addition, with many ICIs approved for treating multiple cancer types, there are several diseases for which a deep selection of ICIs is available as a treatment option.

Adapted from (1).

the development and evaluation of these genetic tests involve patients from all sociodemographic backgrounds and that all patients benefit from these tests once they become available in the clinic. In this regard, a recent study, which compared the efficacy of a genetic test to conventional cell and protein-based tests in identifying aggressive prostate cancers, found that Black patients were more than twice as likely as men from other races to have their cancers recategorized as high risk based on the genetic test, even though conventional tests had characterized them as lower risk (760).

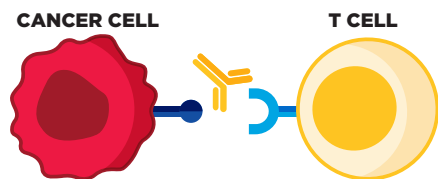
Decades of research have revealed that some tumor cells have increased levels of certain proteins on their surface that attach to and activate “brakes” on immune cells called T cells, thus stopping them from attacking cancer cells. These brakes are proteins on the surface of T cells and are called immune checkpoint proteins. Immune checkpoint inhibitors (ICIs) are a class of transformative new immunotherapeutics that can release the brakes on T cells and trigger T cells to destroy cancer cells (763).



The use of ICIs in the treatment of cancer has rapidly expanded over the past decade, and these therapeutics are considered one of the most exciting approaches to cancer treatment (see **Figure 16**, p. 127). This is in part because some patients with metastatic disease who have been treated with these therapeutics have had remarkable and durable responses. As one example, long-term results from a clinical trial testing the ICI pembrolizumab for patients with advanced NSCLC showed that 23 percent lived 5 or more years, which stands in stark contrast to the historical 5-year relative survival rate for patients with advanced NSCLC of about 5 percent (764). Evaluation of the efficacy of ICIs among NH Black, Hispanic, and NH White patients with NSCLC has shown similar survival benefits across racial and ethnic groups, with some reports indicating even higher survival among NH Black patients compared to NH White patients (765-767).

As documented in 13 editions of the annual *AACR Cancer Progress Report*, ICIs have transformed the clinical care of patients with a diverse array of cancer types, including historically intractable diseases such as metastatic melanoma, lung cancer, and kidney cancer. Despite the high efficacy, there are sociodemographic disparities in the receipt of ICIs. For example, based on a recent study, among patients with advanced-stage NSCLC, those living in neighborhoods with the lowest education or income levels were 29 percent less likely to receive immunotherapy compared to those living in the most educated or highest income areas (768). Another study showed a 40 percent lower likelihood of receiving ICI treatment for Black patients with late-stage NSCLC (766). Yet another study reported that patients with metastatic melanoma living in counties with a higher proportion of racial and ethnic minority populations, particularly of Hispanic population, are more likely to experience delays in ICI treatment (769).

A retrospective study of patients 65 years or older diagnosed with certain types of head and neck cancers showed that **White patients had an 80 percent greater likelihood of receiving ICI treatment** compared to patients from racial and ethnic minority groups (770).



W52

Access to therapeutics prior to their FDA approval is limited to clinical trials or through some additional rare considerations from the agency, such as the expanded access program (771). FDA approval potentially expands access to treatments. A recent study evaluated the use of ICIs for patients with different cancer types before and after FDA approval of ICIs for their

respective diseases (772). The results showed many disparities prior to FDA approval: Black patients with NSCLC were 22 percent less likely to receive ICIs compared to White patients; uninsured patients with kidney cancer were 69 percent less likely to receive ICIs than privately insured patients; and Hispanic patients with NSCLC and melanoma were 21 percent and 72 percent less likely, respectively, to receive ICI treatments. Following FDA approval, receipt of ICIs increased by 9 percentage points among Black patients with NSCLC and 29 percentage points among uninsured patients with kidney cancer, and the disparity in ICI use among Hispanic patients with melanoma was eliminated. However, many of the disparities in ICI use persisted and new gaps emerged after FDA approval.

**Adoption of immunotherapy is lower at rural practices** compared to urban practices, lower at practices with 1 to 5 physicians compared to practices with 6 or more physicians, and lower at independent practices and nonacademic settings compared to academic settings (773).



W53

It is critical that ongoing research continue to evaluate the utilization, as well as safety and efficacy, of ICIs among all patient populations through increased accrual in clinical trials as well as from assessing data in real-world practice. In addition, there is a critical need for additional basic and translational research into the ancestry-related differences in tumor biology and immune system, which are key contributing factors in determining efficacy of cancer immunotherapies.

Research has shown that tumors with many mutations, a phenomenon often referred to as high tumor mutational burden (TMB), respond well to ICIs. A study that evaluated the presence of TMB in patients with advanced NSCLC found that the levels of TMB varied significantly across ancestry groups (774). Patients of African ancestry had the highest level of TMB. However, recent studies have highlighted that the conventional methods of evaluating TMB only work for those with European ancestry. For patients of non-European ancestry, such as those of African or Asian ancestry, the estimated TMB is erroneously inflated to appear more than twice their actual TMB (775). As a result, patients from non-European ancestries may not respond favorably to ICIs despite seemingly high TMB and may even experience disease worsening. TMB calculation involves comparison of genetic mutations between tumor and normal healthy tissue that is used as a reference. Unfortunately, the reference data come mostly from individuals of European ancestry, thereby introducing errors in TMB calibration. Ancestry-informed quantification of TMB is vital to mitigate these biases and improve outcomes for patients after use of ICIs.

Currently, there are many barriers to the equitable use of cancer immunotherapies in the clinic, including high costs of these new therapeutics as well as other socioeconomic and geographic factors. It should be noted that immunotherapies can cause serious and life-threatening adverse events, which necessitate administration at specialized high-quality health care facilities with adequate resources to manage symptoms. Therefore, it is likely that lack of trained and experienced health care personnel, including but not limited to, medical oncologists, palliative care specialists, social workers, mental health care clinicians, and other cancer subspecialists, may be a barrier to receiving immunotherapies. Such barriers may be particularly prominent for patients in community settings, rural regions, and those who must travel long distances to access specialty clinics delivering immunotherapies.

As more of these transformative anticancer agents make their way from the bench to the clinic, it is imperative that the medical research community addresses the current disparities in the use of immunotherapies among medically underserved populations while also advocating for increased participation of some of the same populations in cancer immunotherapy clinical trials. Ensuring equitable use of immunotherapies must also be a top priority for our policymakers considering evidence that patients diagnosed in states with Medicaid expansion have a greater likelihood of receiving immunotherapies (776).

## Equity in Quality Cancer Care

There is increasing evidence that racial, ethnic, socioeconomic, and geographic disparities in cancer outcomes could be reduced or even eliminated if every patient has access to quality cancer treatments (777-779). As one example, Black patients with prostate cancer have worse outcomes compared to White patients, attributable in large part to inequitable treatment. A recent analysis of the survival outcomes of Black and White patients with metastatic prostate cancer who participated in a phase III clinical trial evaluating a new hormone therapy found no statistically significant difference (780), suggesting equitable access to health care may eliminate disparities in outcomes from advanced prostate cancer. Similar trends have emerged in data from the Veterans Affairs Health Care System where comparable access to care leads to reduction and, in some cases, elimination of cancer disparities (781,782).

In the United States, Black patients with lung cancer have poorer survival compared to White patients (3). Multiple factors contribute to these disparities, including inadequate health insurance and lack of access to quality cancer care. Black patients with NSCLC are less likely to undergo surgery or receive high-quality surgical procedures compared to White patients (782). A recent study that analyzed treatment patterns and outcomes of nearly 19,000 veterans with NSCLC between 2006 and 2016 found that Black patients received

comparable care at the Veterans Affairs Health Care System and had similar or superior outcomes compared to White patients (782). These data are encouraging and suggest that an equitable health care system such as the Veterans Affairs Health Care System—which also provides SDOH support like transportation, housing and employment assistance, and mental health care—can address many of the socioeconomic barriers that lead to cancer disparities.

Researchers have also shown that for many cancers, racial and ethnic minority patients may respond better to treatments and have better outcomes compared to White patients when offered similar access to guideline-adherent care. A recent analysis of patients with stomach cancer undergoing surgery with or without neoadjuvant and adjuvant treatments found that Asian and Hispanic patients had better overall survival compared to White patients. Additionally, the study showed that Black patients who received neoadjuvant therapy had better overall survival than their White counterparts (779). Recent studies have indicated that Asian patients with several cancer types may experience superior survival benefits when treated with immunotherapies such as ICIs, compared to other races and ethnicities (783,784). These exciting new data suggest that implementation of policies and SDOH-based interventions that ensure equitable access to quality cancer treatment may be able to address many racial or ethnic differences in cancer outcomes.

Several recent clinical studies have demonstrated that while **Black patients with prostate cancer** may enroll in clinical trials with more advanced disease, they **respond better to treatments** such as immunotherapy, molecularly targeted therapy, chemotherapy, and radiotherapy and **have better outcomes** compared to White patients (679).



W54

Delays in cancer treatment initiation are associated with adverse outcomes. Patients from racial and ethnic minority populations are more likely to experience treatment delays leading to cancer disparities. Medicaid expansion through the Patient Protection and Affordable Care Act (ACA) has been shown to increase insured status, early diagnosis, and timely cancer treatment, and improve outcomes leading to reduced cancer disparities (see **Improving Access to High-quality Cancer Care**, p. 165). As one example, a recent study that evaluated the association between Medicaid expansion and time to breast cancer surgery showed that Medicaid expansion led to a significant reduction of disparity in surgery delays between White patients and patients from racial and ethnic minority populations (785). Additionally, Medicaid expansion has been shown to reduce racial disparities in time

to chemotherapy initiation between White patients with early-stage breast cancer and those belonging to racial and ethnic minority groups (786).

A multidisciplinary care approach to cancer treatment has been associated with improved outcomes, especially in medically underserved populations. Traditionally, multidisciplinary teams comprise specialists in many areas, such as surgery, medical oncology, radiotherapy, palliative care, and genetic counseling, among others. Research shows that patients from low SES are less likely to receive care at multidisciplinary clinics. However, based on a recent study, when treated at a multidisciplinary care clinic, patients with pancreatic cancer from low SES received all the needed treatments and the disparity in outcomes for patients from low versus high SES was eliminated (787,788). Notably, access to multidisciplinary cancer care can overcome socioeconomic disparities in timely treatment even in low-resource settings such as safety net hospitals, leading to equitable outcomes for all patients (789).

**Receiving guideline-adherent chemotherapy, radiation, and hormone therapy from the same breast cancer clinical teams resulted in similar overall survival for patients** treated at a safety net hospital and those in an academic cancer center (790).



W55

## Vital Role of Patient Navigation

Considering accumulating evidence that disparities in cancer outcomes can be reduced and sometimes eliminated when all patients receive guideline-adherent quality care, it is important that researchers devise innovative strategies to ensure that medically underserved patient populations have access to standard treatments and cutting-edge clinical trials. These strategies must simultaneously address many of the complex and interrelated structural and social drivers that contribute to disparities in cancer care. Having patient navigators at the front line of cancer care plays an essential role in reducing barriers to care and improving cancer outcomes (181).

The vital importance of patient navigation across the continuum of cancer care was highlighted in a recent review, which found strong evidence that patient navigation can be effective in reducing time to cancer diagnosis, reducing hospital readmissions during treatment, increasing adherence to follow-up appointments, and improving treatment knowledge and patients' satisfaction with care (181). Research has shown that patient navigation can address numerous barriers related to SDOH, including transportation, food insecurity, language, literacy, and health insurance, among others (791).

One example of a multipronged intervention utilizing patient navigation and aimed at mitigating disparities in cancer treatment among underserved patients is the ACCURE (Accountability for Cancer Care through Undoing Racism and Equity) program (792). The goal of this comprehensive program is to proactively identify and address structural and cultural barriers to cancer treatment (793). A recent analysis of the program identified the different ways through which patient navigators enhanced accountability in cancer care. There were six main approaches: patient-centered advocacy, addressing system-level barriers to care, connecting to resources, reengaging patients after lapsed treatment, addressing symptoms and side effects, and providing emotional support (794).

This multipronged intervention was associated with timelier surgery for early-stage NSCLC and reduction of the disparity in timely surgery between Black and White patients (795). Notably, timely cancer surgery is a metric of high-quality care and improves survival for patients with early-stage lung cancer. Preliminary evidence indicates that the approach has the potential to narrow the disparities in 5-year survival between Black and White patients with early-stage lung and breast cancer (793). Notably, the ACCURE program not only eliminated racial disparities but also improved cancer care and outcomes for all patients. While additional work is needed to ascertain definitively whether ACCURE intervention can eliminate disparities in cancer outcomes, the model can guide future efforts to implement equitable care in new settings and patient populations (796). It is important that health care organizations invest in navigator education and support so that they can provide guideline-adherent care to their patients (797).

In medically underserved patient populations with prostate cancer, **genetic testing referral rates increased** in the 7 months **after introduction of a precision medicine patient navigator**, compared to referral rates 7 months prior to introduction (798).



### INCREASE IN REFERRAL RATES

- 19%** → **58%** Black
- 20%** → **64%** Low-income
- 20%** → **69%** Medicare/Medicaid
- 6%** → **77%** Community setting treatment

W56

# Disparities in Cancer Survivorship

## IN THIS SECTION, YOU WILL LEARN:

- Cancer survivorship encompasses the physical and mental health–related issues, as well as the social and financial challenges, encountered by anyone who has received a cancer diagnosis.
- Patients belonging to racial and ethnic minority groups and medically underserved populations experience higher rates of adverse side effects, poorer quality of life, and higher financial toxicity from a cancer diagnosis.
- To improve the survivorship experience for racial and ethnic minority groups and medically underserved populations, patient navigators, patient advocates, and culturally sensitive intervention/navigation programs need to be used.

According to the NCI, a person is considered a cancer survivor from the time of cancer diagnosis through the balance of the person's life. With 18.1 million cancer survivors in the United States as of 2022, many more people are living through and beyond their cancer. While these numbers are promising, medically underserved populations have higher rates of morbidity and mortality for many types of cancers (42,799). With the number of US individuals over the age of 65 and the diversity of the US population increasing, the number of cancer survivors who belong to racially and ethnically minoritized groups is projected to grow over the next few decades. Unless more equitable cancer control efforts are put in place, disparities across the cancer continuum, including survivorship, will potentially widen.

As more people are living longer and fuller lives after a cancer diagnosis, thanks to improved diagnosis and treatment options, greater attention is needed to understand survivorship experiences. These experiences include the physical, psychosocial, and economic adversities caused by a cancer diagnosis. Cancer survivors are at risk for late effects or secondary health problems due to their cancer treatment and therefore require long-term follow-up care, that includes screening for these late effects (see **Sidebar 36**, p. 132). Survivorship care should include cancer prevention counseling and assessment for late effects including the increased risk of secondary cancers.

While all survivors of cancer have unique experiences, it is becoming clear that those belonging to medically underserved populations shoulder a disproportionate burden of the adverse effects of cancer survivorship. Understanding the challenges faced by these groups will help inform cancer care strategies and personalized recommendations for those who are more vulnerable, leading to a better quality of life. A cancer diagnosis also impacts family members, caregivers, and friends who are often the main support network for the survivor. This fact necessitates widening the focus of research, support, and care

beyond the cancer patient and survivor to include individuals who make up the support system.

The following sections highlight the challenges in health-related quality of life and survivorship faced by cancer survivors and their support network, strategies to improve quality of life, and approaches that have been shown to deliver care most effectively.

## Challenges Faced by Cancer Survivors

Cancer survivors often face challenges throughout their survivorship journey (see **Sidebar 36**, p. 132). The number of cancer survivors living with a functional limitation, defined as difficulty in performing any of 12 routine physical or social activities without assistance (e.g., sitting for more than 2 hours or participating in social activities), more than doubled from 3.6 million in 1999 to 8.2 million in 2018 (800). The functional limitations can vary based on the type of cancer diagnosed and were highest among survivors of pancreatic (80.3 percent) and lung cancer (76.5 percent) and lowest for those who had melanoma (62.2 percent) or breast (61.8 percent) and prostate cancers (59.5 percent) (800).

### Physical Challenges

Survivors experience a wide range of short- and long-term symptoms caused by cancer or its treatments (see **Sidebar 36**, p. 132) as highlighted in the personal stories of **Darlene Pruess** (see p. 135) and **Irasema Partida Chavez** (see p. 137). Short-term effects include hair loss, pain, nausea, vomiting, and loss of smell and appetite with varying severity of symptoms,

*continued on page 133*

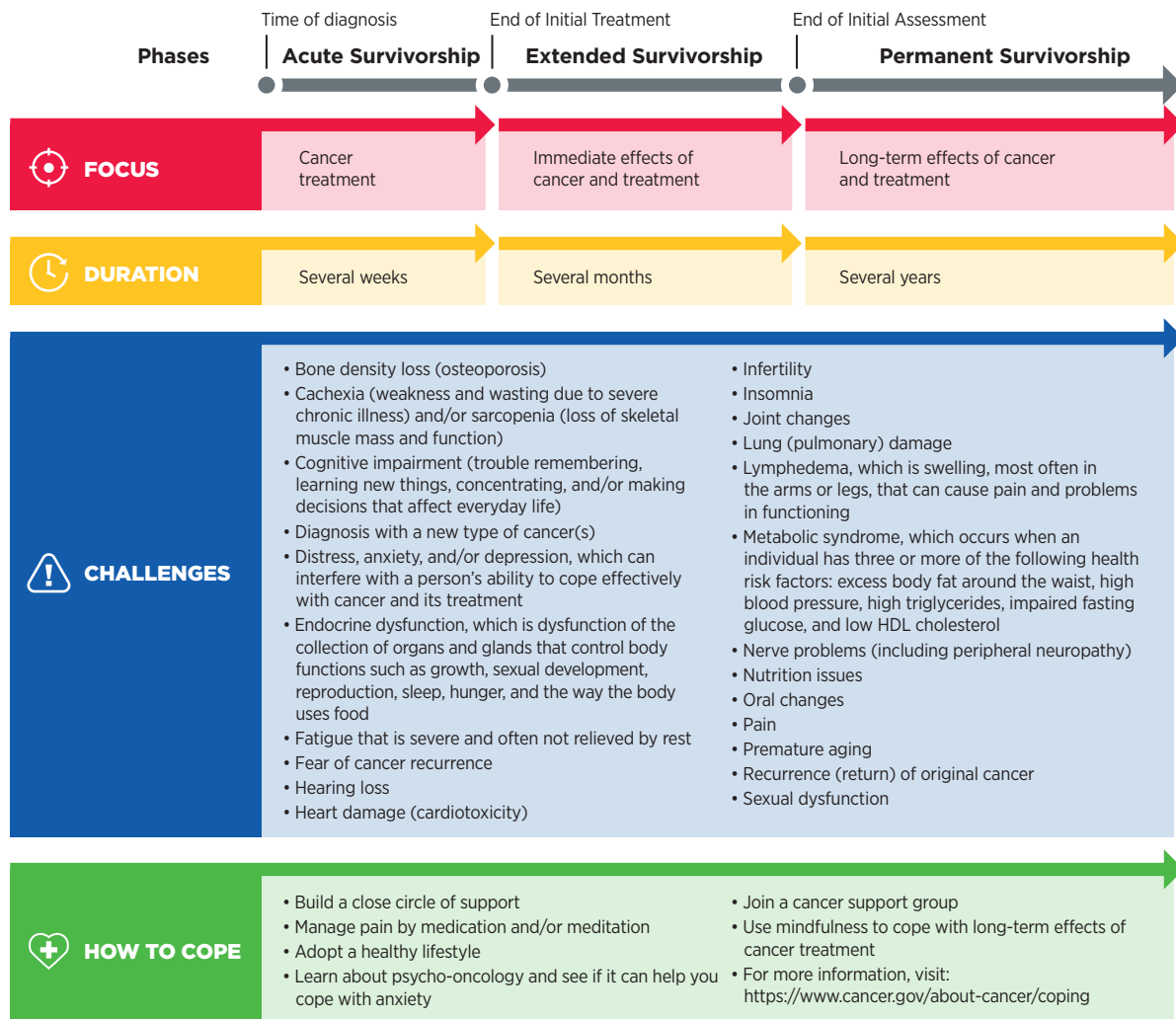


**SIDEBAR 36**

# Phases of Cancer Survivorship

**Survivorship is a continuum that can be broken down into three phases, as shown below.**

Which phase a survivor belongs to depends on the treatment received, type and stage of cancer, and goal of care as determined by patient and care provider. It is important to note that some survivors of metastatic cancer continue to remain on active treatment for the rest of their lives to keep their cancer under control.



Although cancer survivors may face challenges, some groups are at higher risk for severe long-term and late effects. These include those patients diagnosed during childhood, adolescence, and young adulthood (from ages 0 to 39). Several organizations have established guidelines specifically for adolescent and young adult patients, including National Comprehensive Cancer Network's (NCCN) "Adolescents and Young Adults with Cancer" and The Children's Oncology Group's "Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers." These guidelines were developed to help standardize and enhance the lifelong follow-up care of individuals who were diagnosed with cancer as children, adolescents, or young adults. For more information, see <http://survivorshipguidelines.org/>.

These groups also include older adults (age 65 and older). The NCCN's "Guidelines for Older Adult Oncology" address specific issues of cancer in older adults, including screening and comprehensive geriatric assessment, treatment risk and benefits, and management of complications from therapies.

depending on the person, cancer type, and treatment. As cancer survivors are living longer because of better therapies, the development of long-term side effects such as heart damage (cardiotoxicity), lung damage, loss of bone density, and cognitive decline is becoming more common. Increasing evidence shows disparities in both long-term and late effects of cancer treatments in medically underserved populations (see **Sidebar 36**, p. 132). As evident from such studies, there are population-specific differences in the rates of cardiovascular complications, lymphedema, peripheral neuropathies, metabolic disorders, diabetes, recurrence of cancer, and development of new, secondary cancers.

Many common cancer treatments damage the cardiovascular system, further exacerbating complications in cancer survivors. Research has shown that cancer survivors have an “excess heart age”—a measure of cardiovascular damage and risk factor for a heart attack—of eight and a half years in men and six and a half years in women compared to those individuals who have never received a cancer diagnosis (801). Average excess heart age was shown to be higher in cancer patients who are NH Black, have low educational attainment, live in rural areas, and have lower income (802,803). Accelerated aging in cancer survivors has also been associated with experiences of racism. Black cancer survivors who experienced major discrimination had higher levels of functional deficits associated with age-related disease (804).

**Sexual and gender minority (SGM) cancer survivors** were 2.5 and 2.2 times **more likely to report chronic health conditions** compared to SGM individuals without a history of cancer and heterosexual cancer survivors, respectively (805).



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Lymphedema results from damage to the lymphatic system after cancer surgery and is a common long-term side effect among survivors of colorectal, endometrial, and breast cancer (806). Lymphedema disrupts normal draining of the lymphatic fluid, leading to accumulation in the surrounding tissue and resulting in painful swelling, most commonly in the arms and legs (806-808). Research shows that Black and Hispanic women are more likely to develop breast cancer–related lymphedema compared to White women (809,810). Minoritized populations, who often have limited access to medical resources, including surgery, physical therapy, and medical equipment, coupled with barriers to maintaining a healthy diet and exercising to reduce swelling, are at an increased risk for lymphedema occurrence and severity, and worse quality of life (809-813).

As cancer survivors continue to thrive and live longer, their risk of secondary cancers increases. Younger adult cancer

survivors are 1.4 to 2 times more likely to develop secondary cancers than older cancer survivors (814). It is critical to ensure access for survivorship care that can screen for the development of secondary cancers and provide counsel, including cancer prevention and control strategies such as regular exercise, tobacco cessation, and limited alcohol consumption and sunscreen use. According to a recent study, NH Black female breast cancer survivors are at the highest risk of developing secondary cancers among all minority groups (814). Many factors can contribute to racial and ethnic differences in secondary cancer risk, including geography, cultural differences, language barriers, insurance coverage, genetics, and lifestyle factors (670,759).

Another common side effect related to treatment is chemotherapy-induced peripheral neuropathy (CIPN). CIPN is caused by chemotherapy drugs damaging nerves that control the sensations and movements of the arms, legs, hands, and feet, thus leading to pain; abnormal reflexes, abnormal sensations, such as buzzing or tingling; and inability to control certain bodily functions, such as excessive sweating or loss of bladder control. CIPN is common in Black cancer survivors, with 68 percent of survivors experiencing this side effect (815). Studies have shown that a lack of vitamin D is associated with increased CIPN. Black individuals in general, and cancer survivors in particular, have higher rates of vitamin D insufficiency, which partially explains the higher rates of CIPN in this population (816,817).

## Unique Challenges Faced by Pediatric and Adolescent and Young Adult (AYA) Cancer Survivors

Pediatric cancer survivors are those diagnosed between ages less than 1 year to 14 years, while AYAs are diagnosed between ages 15 and 39 years. With tremendous advances in treatments, 85 percent of AYA and pediatric survivors are alive at least 5 years after diagnosis in 2019 compared to only 58 percent of pediatric and 68 percent of AYA survivors 40 years ago (818).

Unique challenges experienced by these groups include greater risk of chronic health problems that arise later in life but are attributable to cancer treatment at a young age, which are termed late effects, employment difficulties, financial toxicities, psychological challenges, secondary cancers, and worse quality of life (819). These challenges are further compounded if pediatric/AYA survivors belong to a racial or ethnic minority or a medically underserved group (see **Sidebar 37**, p. 138). To improve long-term follow-up care and optimize quality of life, it is essential to understand how disease burden in these vulnerable patient populations differs by race/ethnicity, sexual orientation and gender identity, and geographic location.

*continued on page 138*



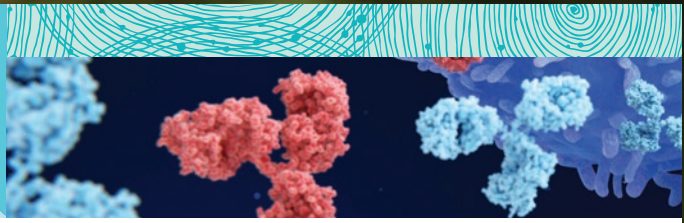


“It is wonderful that, even though I continue to go back and forth in remission, they have individual treatment recipes just for me that work. So just keep it [the research] going.”



# Darlene Pruess, 67

Tampa, Florida



In April 2020, Darlene went to see the doctor for severe pain in her ribs. Initially, her doctor thought it was a problem with her gallbladder. And because this occurred at the start of the COVID-19 pandemic, she was sent to the emergency room for a full checkup, which ultimately led to her diagnosis of multiple myeloma. “It was quite a shock, especially hearing multiple myeloma,” she said. She was worried that the blood cancer had limited treatment options and, currently, no cure.

Darlene received care at the Moffitt Cancer Center in Tampa, Florida. The doctors started her on a treatment regimen right away. She received six cycles of cyclophosphamide (Cytoxan), bortezomib (Velcade), and dexamethasone, also referred to as the CyBorD regimen. This was followed by a bone marrow transplant. Since the transplant, Darlene has been on many different treatment regimens. “I’ve been back and forth in and out of remission on different recipes, so to speak.” She is currently receiving cyclophosphamide, pomalidomide (Pomalyst), and dexamethasone.

Darlene experienced some financial stress during her cancer journey. She was diagnosed right around the time as she was planning to retire. “That kind of answered that as far as working, but it still was stressful. Now I’ll be on Social Security and how am I going to make a living? It was kind of one foot in front of the other,” Darlene recalled. She is grateful that she had health insurance coverage for most of her treatments. She also received some foundation support for her care.

Even though Darlene has experienced several side effects from her treatments, she is currently doing well. She is living her life, enjoying her favorite activities, swimming, biking, walking, and staying active. “I feel great. I may be in remission again, as we speak,” she said.

Darlene feels very fortunate that her health care providers communicated effectively with her, keeping her fully informed about next steps along her treatment path. “The oncologist who diagnosed me, I still see her today. They’re just very responsive. They answer all my questions and explain things to me. I understood the steps, what we were doing, and why we were doing them,” she said.

It was, however, difficult navigating cancer by herself. “The hard part was managing all of that. It is like a full-time job, especially being single,” she added. “However, I did have a lot of friends both from my local LGBTQ community as well as outside the community.” She is extremely grateful for the tremendous help she received from her friends. “Everybody was just wonderful and helpful. It’s hard to ask for help, but essential when you’re going through this, and they made it very easy.” Her experience with cancer has also made Darlene a strong advocate for other patients who might be going through the same journey as she did.

Darlene’s message to cancer researchers is to continue to work on better new treatments. “It is wonderful that, even though I continue to go back and forth in remission, they have individual treatment recipes just for me that work. So just keep it going,” she said. She also wants more research in the sexual and gender minority population. “I would be very comfortable and happy to be part of that data,” she said. Additionally, she wants policymakers to continue supporting cancer research. “Definitely more money for research. That is a big thing.”

Scan the QR code  
to watch Darlene’s video interview.







“I like sharing my story and hope that somebody who is just starting their journey can find some strength in mine.”



# Irasema Partida Chavez, 43

Glendora, California

Irasema Partida Chavez was diagnosed with stomach cancer in 2015, at the age of 34. Irasema remembers dealing with months of persistent heartburn, indigestion, nausea, and fatigue. She had also lost some weight. “I took over-the-counter pain medications to help with the symptoms so I could perform my daily functions,” she said. After a particularly bad episode at work, Irasema and her girlfriend, now wife, ended up in urgent care. Unfortunately, the providers at the urgent care facility did not give much attention to the situation and recommended that she follow up with her primary care physician. The pain persisted and the next morning her wife made a same day appointment with a gastroenterologist.

“The gastroenterologist just said, ‘I do not like it. I do not think that you should be in this much pain,’” she recalled. They performed an endoscopy, which revealed an ulcer. While they thought that the ulcer was the main cause of Irasema’s symptoms, her gastroenterologist had also taken some biopsies. “When my biopsy results came back, we got a call. I ignored my phone.” Irasema’s wife also received a call asking them to go back to the doctor’s office right away. Irasema’s hemoglobin counts were extremely low. “They wanted to admit me to the hospital to give me some blood transfusions.”

However, when Irasema and her wife arrived at the doctor’s office, her gastroenterologist informed them there was something else that he needed to discuss. “My biopsies had come back, and they were positive for stomach cancer,” she said. “My wife and I sat in that office. It felt like we were just hit by a train. We were in shock and really did not know what that meant. You hear the word cancer, and the first thought that comes to your brain is death. I was 34, my daughter was 13 and our son was four at the time. We did not know what to expect.”

Looking back, Irasema feels fortunate to have a gastroenterologist who guided her through her treatment path. “He had already called a surgeon who he had worked with in the past to get me a consultation.” Initially she underwent a partial gastrectomy where 80 percent of her stomach was removed. The surgery also revealed cancer in the nearby lymph nodes, which led to Irasema’s cancer being assigned as stage IIB. After she healed for about six weeks, she underwent chemotherapy and radiation.

Life after a partial gastrectomy was challenging. “I was learning how to reintroduce food into my system. Trying to go through chemo as well was very debilitating. It was very challenging maintaining my weight and we had to do a peripherally inserted central catheter

(PICC) line to help with nutrition intravenously. Irasema had no evidence of disease (NED) for eight months. However, a follow-up endoscopy and biopsies in September of 2016 showed signs of recurrence. Even though it was localized, Irasema had to undergo a total gastrectomy, to surgically remove her entire stomach.

She does not recall clinical trials being part of the discussion during her initial treatments. However, from her work in the patient advocacy space in recent years, she has gained a deep knowledge about clinical trials and their importance. “I do not know if I would have been open to it in 2015, but if it were now, I would have participated. Because I understand how important my voice is and me being in a trial would be for other patients.”

Then, after having no evidence of stomach cancer for three and a half years, in September of 2020, Irasema was diagnosed with breast cancer. Her routine scans showed abnormality in the right breast, which led to a mammogram followed by biopsy that revealed invasive ductal carcinoma in situ (DCIS). “It felt like an eternity before the biopsies came back and all of it was cancer. They found 13 centimeters of cancer in my right breast.” She decided to have a double mastectomy to maximize the extent of cancer removal. Molecular testing had shown that the cancer was HER2 positive. As a result, she received a molecularly targeted treatment against HER2 for a year.

Fortunately, Irasema has been healthy since. “I am doing well. I have been NED for three years for breast cancer and about eight years for stomach cancer. I am happy that I am here and that everything worked well,” she said.

Irasema’s wife has been a pillar for her throughout the entire cancer journey. “My wife was with me at every single appointment. I had an amazing team of doctors, who nine times out of ten reached out to my wife first. I never experienced any kind of discrimination for my orientation.”

Her experience has made her a passionate advocate for patients with stomach cancer. Her message to other patients is to not lose hope while going through their cancer journey. I like sharing my story and hope that somebody who is just starting their journey can find some strength in mine. I want them to know that living without a stomach is possible. It is hard but you can live a good, healthy, and very fulfilling life.

Scan the QR code  
to watch Irasema’s video interview.



**SIDEBAR 37****Survivorship Disparities in Pediatric, Adolescent and Young Adult Cancer Patients**

Pediatric, adolescent and young adult (AYA) cancer survivors face unique challenges compared to their peers who have never had a diagnosis of cancer. These challenges can be exacerbated in minoritized groups.

**Financial toxicity**

Due to younger age at diagnosis, rising costs of health care, and lower enrollment in insurance, AYA cancer survivors are at a greater risk of experiencing financial toxicity compared to survivors 40 years or older, who have had more time to establish a career and build financial assets (820-822). A study of young Black cancer survivors found that this population was more likely to have financial hardship compared to older Black survivors (823).

**Side effects**

Adverse social, physical, and psychological side effects after a diagnosis of cancer are increased in AYA populations compared to their healthy counterparts. These side effects are experienced differently by medically underserved populations who are AYA. For example, compared to non-Hispanic White cancer survivors, Hispanic survivors had poorer health (824).

**Follow-up care**

Compared to White individuals with pediatric cancer, individuals who were Black or other races were twice as likely to not attend follow up visits or survivorship clinics within 32 months (825).

**Health behaviors**

Self-reported data from 4,766 AYA cancer survivors found that those AYA cancer survivors who were Black participated less in physical activity than those who were White (826). Lower household income, lower education, and current smoking status were also associated with reduced physical activity in AYA cancer survivors (826).

**Preventing Secondary Cancers**

Skin cancer is the most common secondary cancer among young adult survivors of childhood cancer. Self- or physician-based skin examinations to detect cancer early are recommended for this group, especially for those young adults who receive radiotherapy (827). One study found that consistently examining oneself for skin cancer was low in this population with Latino individuals less likely to engage in physician- or self-skin exams than non-Latino individuals (828).

**Health-related Quality of Life**

Health-related quality of life (HRQOL) offers a comprehensive view of the impact a disease and its treatment can have on a patient's physical, functional, psychological, social, and financial well-being. Cancer survivors who belong to medically underserved populations are at an elevated risk of worse HRQOL, which has been shown to increase the likelihood of cancer recurrence and mortality (829-831). One study found that compared to NH White cancer survivors, survivors who were AI/AN, Cuban, Dominican, and Puerto Rican, as well as those from the Caribbean, were more likely to experience worse HRQOL (832). Lower HRQOL is associated with being unemployed, having other comorbidities, eating an unhealthy diet, and experiencing a high fear of cancer recurrence (833).

A diagnosis of cancer can pose serious challenges to a person's mental and emotional health. Many survivors experience anxiety (7 percent to 10 percent of patients), depression (8 percent to 24 percent of patients), and distress (25 percent to 41 percent of patients) following the completion of cancer treatment (289,834-836). A study in patients with 26 different cancer types found that 98 percent of patients with testicular cancer, 78 percent of patients with cervical cancer, and 69 percent of patients with Hodgkin lymphoma experienced a depressive event (836). Many of the adverse influences of SDOH can lead to greater negative mental health outcomes among survivors who experience health disparities. For instance, poor access to mental health care, housing instability, and food insecurity, which are higher in certain populations, can worsen mental health (837-842).

Even when survivors are treated at NCI-designated cancer centers, there are identified gaps and poor access to services for cancer

survivors, including those for mental health (843). One study of NCI-designated cancer centers found that while main hub hospitals, which are often located in large metropolitan areas, adequately provided services for cancer survivors, including support for treatment side effects, health behavior information, and mental health services, the affiliated satellite locations, which are often located in less dense, rural areas, provided these services less than one-quarter of the time (843).

AI/AN groups, which are comprised of 574 federally recognized tribes or people groups and are highly diverse communities, experience disparities in cancer survival rates and social and physical quality of life and have the poorest 5-year survival rate from cancer of any racial group (see section on **American Indian or Alaska Native (AI/AN) Population**, p. 14) (844,845). AI/AN cancer survivors have higher spiritual quality of life compared to those who belong to other races and ethnicities. Further, because of the diversity among AI/AN tribal groups, spirituality characteristics are highly individualistic (845). Studies looking at quality of life among American Indian cancer survivors in South Dakota found that spirituality and social support were strong predictors for positive outcomes (846). Further research has shown that the best way to support AI/AN cancer survivors is a systematic approach that leverages community strengths and partnerships to support all factors influencing a survivor's quality of life, including physical, spiritual, mental/emotional, and social aspects (844). Researchers must ensure that interventions for Indigenous populations align with the cultural values of cancer survivors from these populations (844).

Asian cancer survivors are highly diverse, representing a wide range of race and ethnicities (see **Sidebar 2**, p. 14). Some segments of this population, however, experience worse HRQOL. Asian survivors are also less likely to be screened for psychological distress by health care providers, compared to survivors from other races and ethnicities (847).

Compared to patients who are not Black, **Black patients undergoing radiation therapy** had higher levels of unmet needs regarding:

- **Pain** (67% vs. 39%)
- **Stress management** (64.7% vs. 43.3%)
- **Transportation** (64% vs. 19%)
- **Smoking cessation** (35% vs. 8.7%) (848).



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Studies of breast, prostate, or colorectal cancer survivors who are Black report poorer quality of life and physical and mental health, compared to cancer survivors who are White (849-852). One way to improve psychological outcomes among Black cancer survivors is to make use of psycho-oncologic services, which use health care professionals to address the behavioral, emotional, psychological,

and social challenges faced by cancer survivors and their caregivers (853,854). Unfortunately, Black survivors often do not get the psycho-oncological help they need. For instance, one study of Black cancer patients found that Black women were referred to psycho-oncology services only 2 percent of the time compared to 10 percent for White women (855).

Hispanic/Latino cancer survivors experience lower HRQOL and mental health compared to other racial and ethnic groups (856). Mental and HRQOL disparities might be exacerbated due to the fact that Hispanic/Latino survivors are not screened for psychological distress as often as survivors who belong to other racial and ethnic populations (847). Emerging data demonstrate some important strategies to improve mental health among this population. First, positive family functioning (e.g., family cohesiveness) was correlated with higher quality of life, which consequently was associated with lower levels of anxiety, depression, and hopelessness (857,858). Evidence shows that the use of culturally appropriate, bilingual interventions was also beneficial in improving psychosocial outcomes for both patients and caregivers who are Hispanic/Latino (859).

Patients from SGM populations are susceptible to worse psychosocial and HRQOL compared to heterosexual patients (860-863). In part, this can be attributed to lack of trust in health care systems and non-inclusive health care environments experienced by this population across the cancer care continuum. SGM cancer survivors treated at a hospital that had a more inclusive environment were six times more likely to be satisfied with the care they received for their cancer than those who had been treated in an environment that was not welcoming to SGM individuals (864). Those who reported feeling satisfied with their care felt they had improved physical and mental health (864,865).

## Financial Toxicity

Financial toxicity refers to the financial hardship associated with cancer treatment and its management. Evidence indicates that cancer survivors who experience financial toxicity, such as difficulty in paying for prescriptions, mental health care, and other health services, and/or who delay medical care due to cost, are also at greater risk of mortality, regardless of insurance status (866).

Financial toxicity is pervasive and is, in part, exacerbated by the rising costs of cancer care (867). For instance, between 2009 and 2016, the average cost of treatment increased 29 percent for breast cancer, 11 percent for lung cancer, and 4 percent for prostate cancer. In addition, out-of-pocket costs have also increased by 15 percent for all patients with cancer (867).

The burden of cancer disproportionately affects those who are living in poverty (see section on **Populations Living Under Poverty**, p. 33). Additionally, chronic diseases such as cancer have consistent high costs of care that unfairly impact populations from low SES, pushing them deeper into poverty. Low-income Americans have difficulty in paying for cancer care,



## SIDEBAR 38

## Integrating Culturally Tailored Physical Activity Interventions Among Minoritized Populations

Being physically active has been shown to increase survival and lower recurrence of cancers (290,870).

### Selected examples of interventions that promote healthy behavior in medically underserved cancer survivors include the following:



#### LATINO/HISPANIC SURVIVORS

**Participation in aerobic and resistance training** has been shown to reduce the risk of cardiovascular disease among Hispanic and Latina breast cancer survivors (871).



#### NATIVE AMERICAN SURVIVORS

A 12-week clinical trial involving Native American cancer survivors and their caregivers, representing 10 different tribes, that aimed to boost exercise using culturally tailored exercises was shown to **improve cardiorespiratory fitness and physical function**. These included certified fitness trainers who were Native American, free exercise equipment, and use of local community centers and churches. Their familial support persons also had significantly improved blood pressure and blood sugar levels (872).



#### BLACK SURVIVORS

Long-term breast cancer survivors with chronic conditions have reported the **importance of spirituality** in their lives. One study of 323 Black survivors of breast cancer found that those who were **more spiritual were more likely to participate in physical activities** and meet physical activity guidelines (873).



#### CANCER SURVIVORS WHO LIVE IN RURAL AREAS

**Use of technology, like wearable trackers**, among rural cancer survivors can positively impact this population in ways not previously possible. In a randomized controlled trial of remote cancer survivors, participants who were given wearable activity trackers and counseling via telehealth increased their physical activity by 50 minutes per week (874).

even when insured. With increasing enrollment of many US workers in high-deductible health insurance plans (868), which offer lower up-front costs in exchange for high deductibles (from \$2,500 up to \$5,000) (869), even insured patients with cancer may struggle with debt related to treatment and follow-up care. In fact, roughly 50 percent of Americans cannot afford to pay for their deductibles (869). Cancer patients who are uninsured are more likely to be Black and Hispanic, and even when insured, Black and Hispanic patients are more likely to experience financial toxicity (875). Unfortunately, the inability to afford treatments or the accumulation of debt leads to an increased likelihood of bankruptcy among cancer survivors.

Low-income cancer survivors also experience worse cancer outcomes because of barriers in maintaining and receiving support after treatment (876-878). Patients and survivors who have low income are more likely to miss their appointments. Those who are Black or Latino also have higher odds of missed appointments (715).

Survivors can face challenges in maintaining a job or going back to a previous job after the conclusion of cancer treatment. This is troubling because having a job decreases the likelihood of financial toxicity and improves HRQOL (879). Based on

a recent study, cancer survivors between the ages of 50 and 64 years were more likely to have a work-limiting disability and less likely to be employed than those without a history of cancer, equating to 505,768 fewer employed individuals between 2010 and 2016 (880).

Several programs have been shown to mitigate the damaging effects of financial toxicity (see **Sidebar 41**, p. 143). Programs that provide monetary assistance to help offset the cost of treatment can help mitigate high out-of-pocket spending (881). However, these programs do not work for those who have extremely high costs associated with their cancer treatment (881). Furthermore, non-White patients and those who speak English as a second language are half as likely to receive financial assistance as White and English-speaking patients, respectively (881).

## Promoting Healthy Behaviors

Healthy behaviors, such as increasing physical activity, eating a healthy diet, reducing alcohol consumption, and not smoking, can significantly improve both health outcomes and HRQOL

for cancer survivors (see **Sidebar 38**, p. 140). In fact, it is increasingly appreciated that adopting healthy behaviors after a diagnosis of cancer, but prior to beginning cancer treatment, can significantly improve outcomes for patients (882,883). A patient who is healthy at the start of treatment can undergo treatment with higher doses of drug, is less susceptible to certain side effects, and has an immune system that is primed to fight cancer better (884).

Many of the barriers to participating in healthy behaviors discussed earlier (see **Disparities in the Burden of Preventable Cancer Risk Factors**, p. 66) also exist for cancer survivors. Lack of access to exercise facilities and other types of recreational activity for racially and ethnically minoritized and medically underserved cancer survivors reduces participation in physical activity (885). As one example, rural cancer survivors who had low access to fitness facilities and outdoor space for activities (like biking trails) were less active and did not participate in physical activity compared to those who did have access (886).

## Integrating Palliative Care

Palliative care is an approach to prevent or treat the symptoms and side effects of any disease, including cancer, by addressing the physical, psychological, financial, social, and spiritual needs that arise from the disease and associated treatments (see **Sidebar 39**, p. 141). Palliative care is facilitated by a multidisciplinary team of doctors, nurses, dietitians, pharmacists, therapists, spiritual leaders, and social workers and has been shown to improve quality of life for patients, families, and caregivers (887).

Despite the advantages of palliative care, there are disparities (888,889) in and barriers to utilization by racial and ethnic minorities (890), SGM populations (891,892), and those living in geographically remote areas (893,894). As one example, in a survey of nurses, physicians, social workers, and chaplains, 23 percent observed discriminatory care to transgender patients with cancer (895).

## Improving Mental Health

The psychological challenges faced by survivors of cancer necessitate approaches that improve the mental well-being of this population. There are several approaches that can be utilized, including mind-body interventions, support groups, improved mental health screening, physical activity, and community engagement (896-899).

In one meta-analysis that analyzed mind-body exercises (e.g., meditation, yoga) in Black individuals found that these exercises are viewed as acceptable ways to improve quality of life, pain

### SIDEBAR 39

## Palliative Care and Cancer Survivorship

**Palliative care is specialized care** that provides, if needed, an extra layer of support to patients and survivors of serious illnesses, such as cancer, as well as to their families and caregivers.



**Palliative care is given throughout a person's experience with cancer**, beginning at diagnosis and continuing through treatment, follow-up, survivorship, and end-of-life care. Palliative care given near the end of life when curative treatment has stopped is usually referred to as hospice care.

**Palliative care can be given in addition to cancer treatment** or to those with no curative treatment options. It addresses many of the challenges that can affect quality of life after a cancer diagnosis, including:

- Emotional challenges, such as anxiety and depression.
- Physical symptoms and adverse effects of the disease and its treatment, such as pain, nausea, vomiting, fatigue, difficulty in sleeping, and loss of appetite.
- Practical challenges, such as navigating the health care system.
- Spiritual challenges.

Adapted from (711).

interference, fatigue, anxiety, depression, and physical health among participants (897). Unfortunately, these interventions can be inaccessible for the Black population due to cost or geographic location (897).

Research shows that a cancer diagnosis can promote “post-traumatic growth,” which describes the positive life changes that can develop from traumatic, stressful experiences, such as a diagnosis of cancer (see **Sidebar 40**, p. 142). Posttraumatic growth may lead to perceptions of new possibilities, closer relationships with family and friends, development of personal strength, spiritual development, and a greater appreciation for life. Although the concept of posttraumatic growth is not new, its potential is just beginning to be appreciated within the cancer care community.

## Supporting Caregivers

Caregivers comprise family members or friends who help patients with long-term chronic illness and manage any and all aspects of their care. One in five US adults (ages 18 to 64), accounting for over 53 million people, provided care for another person in 2020, a significant increase from 43.5 million in 2015

## SIDEBAR 40

## Cancer Survivorship Experience and Personal Growth

Both quantitative and qualitative data demonstrate that most cancer survivors experience post-traumatic growth, which is described as the personal growth that comes from experiencing a stressful, traumatic event (900-902). Post-traumatic growth is not necessarily a consequence of a traumatic event and to experience post-traumatic growth, survivors need to cultivate these feelings through personal development (903). Post-traumatic growth is being more appreciated as an approach to improve a survivor's mental well-being and recovery. Components of post-traumatic growth include:

**Relating to Others**

Some survivors may find that their cancer diagnosis has helped them prioritize and improve relationships and build stronger connections with those who are important to them. These experiences are attributed to increased willingness to express feelings, understand complex emotions, and empathize better with those struggling with similar challenges.

**New Possibilities**

Some survivors may adopt a completely new lifestyle after cancer diagnosis, and may reevaluate their career or life path and choose to spend more time with family and friends. Change of lifestyle can often lead to healthier behaviors such as smoking cessation, engaging in a healthful diet, and exercising.

**Personal Strength**

Some survivors may experience a belief that if they are able to defeat cancer, they can possibly manage any future challenge. This can prompt positive attitudes during times of stress or anxiety.

**New Appreciation of Life**

Some survivors may reevaluate feelings of appreciation for good health as a second chance at life and may feel grateful for the beauty in the world and the importance of the small victories in life. Others may report having the perspective of living in the moment.

**Spiritual Changes**

Some survivors may find or strengthen spiritual beliefs and deepen their faith. Spiritual growth has also been shown to help survivors with their recovery and the ability to manage day-to-day challenges.

Adapted from (900).

(904). It is further estimated that four million of these caregivers are caring for an adult cancer patient. More evidence of the challenges faced by caregivers is becoming clear, and there are many opportunities to assist this vulnerable population.

Survivors require many resources that are often provided by their caregivers, including arranging transportation, helping with day-to-day activities such as doctor visits, providing medical care or other clinical tasks, coordinating care,

and giving emotional support. This support often leads to caregivers deferring their own health care. One report shows that caregivers who are actively taking care of a family member are less likely to seek medical care, including physician and emergency room visits. Caregivers of individuals with cancer also had an elevated risk of cardiovascular disease (905). This is especially concerning among Black and Hispanic caregivers, who spend more time caregiving compared to their White counterparts, potentially exacerbating health disparities in these communities (906).

**TWO-THIRDS (64 PERCENT) OF BLACK CAREGIVERS IN DETROIT REPORTED COSTS ASSOCIATED WITH CAREGIVING, INCLUDING:**

**58%**  **Logistical** (transportation, etc.)

**35%**  **Medication costs** for patient

**17%**  **Medical bills** for patient (907).

Caregivers are also susceptible to financial toxicity, and this is prevalent among those who support individuals with cancer. These caregivers often delay their own care as cost-related coping mechanisms. These coping mechanisms are more common among those who are poor and lack health insurance. Among a survey of nearly 1,000 African American caregivers in Detroit, 52 percent experienced financial toxicity (907). Similarly, Hispanic caregivers of children with cancer reported having household material hardship and financial toxicity nearly twice as often as NH White and Asian caregivers (908).

W59

## SIDEBAR 41

## Patient Navigation for Cancer Survivors

The first patient navigation program in the United States was designed specifically to address racial disparities in breast cancer screening and follow-up for Black women. Implementation of this program led to a 70 percent increase in 5-year survival in this group (910). While patient navigation is being increasingly recognized as a potent resource for helping cancer survivors, challenges in implementation remain.

### Benefits

#### Patient navigation bridges a variety of gaps and addresses diverse needs across the cancer care continuum:

- Patient navigation improves access to screening, patient care coordination, symptom management, and follow-up care (799,916,917).
- Patient navigation reduces the cost of health care by reducing emergency room visits and missed appointments (918-920).
- Patient navigation can reduce financial toxicity for patients with cancer (920).



### What Has Been Done?

#### In recognition of the benefits of patient navigators, legislative efforts have been made to increase access to patient navigation, including:

- The Patient Protection and Affordable Care Act in 2010, which helped increase access to patient navigation programs for cancer patients and survivors.
- In support of the White House's Cancer Moonshot initiative, the Centers for Medicare and Medicaid Services changed billing codes to allow oncologists to bill and receive Medicare payment for connecting patients to patient navigators as of January 1, 2024.

Additionally, the American College of Surgeons' Commission on Cancer requires all accredited organizations to have a patient navigation program. The Community Preventive Services Task Force (CPSTF) also recommends the use of patient navigation services to increase cancer screenings among historically disadvantaged racial and ethnic populations and people with lower incomes.

### Challenges

#### Despite the benefits of patient navigators, challenges remain:

- There is often high variability in the organization and training of patient navigators in the United States. Lack of standardization can lead to different experiences for survivors.
- There is often confusion about coverage and financial benefits of patient navigator services through Medicare, Medicaid, The Indian Health Service, and private/commercial insurers.
- Patient navigation services are not well integrated into the Health Information System, which simplifies care coordination by improving access to patient history and health information in health care settings. This results in poor coordination and delayed information sharing among patient navigators.

## Paving the Way for Health Equity in Cancer Survivorship

The disparities in various aspects of cancer survivorship as highlighted in this section necessitate a comprehensive multidisciplinary approach to address the deficiencies experienced by medically underserved groups. It is imperative that researchers, health care systems, professional organizations, insurance groups, and care

teams work together to meet the specific needs of the community and the patient.

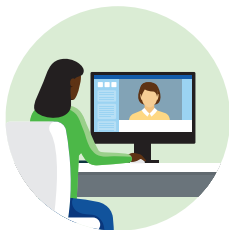
Community-centered approaches are required to better understand the challenges faced by cancer survivors who belong to racial and ethnic minority groups and medically underserved populations (909). Patient advocates are uniquely positioned to bridge a critical gap between survivors and researchers. Patient advocates have immense influence within their communities because they understand the unique needs and challenges within the community; partnering with patient



advocates can help inform research questions and clinical study designs. Patient advocates can also help disseminate new information gleaned from research studies into the community so that it is readily accessible and favorably received.

**Project Extension for Community Healthcare Outcomes (ECHO)** helps increase workforce capacity and enhance knowledge about cancer survivors who live in rural areas by hosting

**telemedicine sessions for patient navigators.** The program trained 16 patient navigators, leading to 164 rural cancer survivors being helped (911).



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Patient navigators are individuals dedicated to assisting patients with cancer, survivors, family, and caregivers by facilitating and navigating through the health care system for access to timely and quality care. Utilization of patient navigation has been shown to benefit patients across the cancer care continuum, especially in medically underserved population groups, and to reduce the overall costs associated with cancer (see **Sidebar 41**, p. 143). In 2024, in response to the White House's Cancer Moonshot Initiative, seven leading health insurance companies committed to expanding coverage to patient navigation services for cancer patients and those with other serious illnesses, which were previously not covered by insurance. The expanded coverage includes covering and reimbursing navigation services, capturing utilization of navigation services across patient demographics, and tracking health outcomes of patients who utilize patient navigation services. Additionally, these insurance providers

have committed to supporting standardization of patient navigation services to align with the Oncology Navigation Standards of Professional Practice, which sets out knowledge and practices navigators should provide in order to deliver standardized, high-quality services. Finally, these health plans have pledged to educate providers, including payers and cancer centers, which service millions of Americans, on how to cover these navigation services (910).

In the wake of the COVID-19 pandemic, there was increased reliance on the use of telehealth, which uses digital information and communication technologies to access health care services remotely and manage a patient's health care. Utilization of telehealth services among cancer survivors in rural settings increased by 70 percent compared to pre-pandemic levels (912). Telehealth has helped cancer patients in rural settings receive survivorship care and patient navigation services (913,914); however, utilization among rural survivors is still much lower than among cancer survivors who live in urban settings and are closer to major hospital centers (915). Further investigation into how to best utilize telehealth strategies among rural cancer survivors is warranted to help bring these essential services to this vulnerable population.

A key to charting an equitable path forward for cancer survivors who belong to medically underserved populations is the use of community-based, tailored solutions that meet the specific needs of every patient and include patient advocates and patient navigators as key partners. Such approaches will help implement strategies that address the specific social, psychological, medical, and physical needs of the patient while tying in cultural norms and perceptions, ultimately increasing quality of life, bolstering adherence to follow-up care, identifying financial concerns, providing equitable health care, and reducing the overall cost of cancer care (920-922).

# Overcoming Cancer Disparities Through Diversity in Cancer Training and Workforce

## IN THIS SECTION, YOU WILL LEARN:

- Certain demographic groups such as women, disabled individuals, some racial and ethnic minority groups, and sexual and gender minority groups are considerably underrepresented in the cancer research and care workforce.
- It is imperative to prioritize investment in early-career researchers to enhance diversity and improve equity in the workforce.
- Diversity-focused training has improved inclusion within the cancer research and care workforce; however, gaps remain throughout the cancer research training path and workforce.
- Improved support from medical research mentors and peer groups is needed to support diverse researchers and address cancer disparities.
- The Supreme Court's ruling on race neutrality may negatively impact equitable representation in cancer science and medicine.

A diverse cancer research and patient care workforce includes individuals who represent a wide range of backgrounds, lived experiences, and demographic groups, including differences in race, ethnicity, sexual orientation and gender identity, disability status, and socioeconomic backgrounds (923,924). Diversity, equity, inclusion, and accessibility fundamentally strengthens cancer care and research by harnessing talent, overcoming systemic biases, delivering patient-centered care, and fostering collaboration.

A diverse cancer care workforce that reflects the diversity of the US population is critically important for several reasons. For example, it enhances cultural competence and humility in delivering care to a diverse patient population. Furthermore, a diverse workforce is better equipped to understand and meet the needs of all patients. It also builds public trust and participation in cancer research by having representative stakeholders involved in research and institutional processes (925).

Studies show that patients tend to have more positive health care experiences when their provider shares a similar racial or ethnic background (114). Diversity in cancer care workforce fosters innovation and problem-solving by integrating different perspectives, insights and approaches to cancer research and clinical care. For instance, women remain underrepresented in medicine (926), but they are more likely than male physicians to follow evidence-based practice (927) and to engage in more preventive services (e.g., cancer screening) and communication (e.g., information-giving, partnership-building) (928). Therefore, a medical workforce that mirrors the US gender distribution is vital. Finally, efforts to enhance workforce

diversity elevates role models and mentors to inspire and support the next generation of historically underrepresented professionals in the cancer research and patient care workforce.

The scientific community must acknowledge and mitigate discriminatory practices and policies that prevent promising and talented scientists, researchers, and clinician-scientists from underrepresented populations from fully contributing to the scientific community.

## Science, Technology, Engineering, Mathematics, and Medicine Educational Landscape

STEMM, which stands for Science, Technology, Engineering, Mathematics, and Medicine, serves as an umbrella term for a number of fields that lay the foundation for entry into the health care professions (929).

Most STEMM disciplines and occupations lack diversity. In 2023, the National Center for Science and Engineering Statistics released a report on diversity trends in STEMM employment and education. The report found that various population groups are underrepresented in STEMM fields. These groups include racial and ethnic minority populations, women, individuals from low SES backgrounds, people who reported a disability, those belonging to the sexual and gender minority community, and those who are the first in their families to attend college (930).

One major driver for lack of diversity in STEM is rooted in the educational system. Students who attend underresourced pre-K–12 schools often face obstacles that can severely restrict their ability to pursue STEM careers. Studies show that exposure and access to STEM experiences in the early years are especially effective for increasing interest in STEM careers. However, these opportunities are often not easily accessible to students from disadvantaged backgrounds, particularly those attending schools in low-income communities (931).

People from racial and ethnic minority groups are underrepresented in STEM fields. According to a recent Pew Research Center report, while 62 percent of White students have a STEM degree, just 2.2 percent of Hispanic or Latino/a students, 2.7 percent of Black students, and 3.3 percent of AI/AN students have earned a university degree in STEM fields. Furthermore, 52 percent of those surveyed believed this lack of representation was due to a lack of educational opportunities for people from racial and ethnic minority groups, and 45 percent believed the cause was lack of encouragement at an early age to pursue STEM-related subjects (932). Finally, about one-third of those surveyed also attribute this underrepresentation to a lack of belief in their ability to succeed in these fields, the lack of diverse role models in these fields, and discrimination in recruitment, hiring, and promotions.

Diversifying the future cancer research workforce requires that students choose paths toward STEM fields and engage in cancer research (933). In recognition of the challenges faced by students from underrepresented groups, the Center to Reduce Cancer Health Disparities (CRCHD) CURE program offers unique training and career development opportunities to enhance and increase diversity in the cancer and cancer disparities research workforce. The CURE program supports promising candidates from middle school through junior investigator levels and provides them with a continuum of competitive funding opportunities. One of the goals of the CURE program is to support middle school, high school, and undergraduate students interested in cancer and cancer disparities research to enter the research field, work directly with scientists and community leaders, gain laboratory experience, and develop research skills (934).

The federal government has established or expanded initiatives to enable participation in STEM education programs and created pathways for people from diverse backgrounds to pursue careers in STEM fields. The National Science Foundation (NSF) leads many programs and initiatives aimed at broadening participation, including programs in informal STEM learning, pre-K–12 science education, undergraduate and graduate training in the sciences and engineering, and career support mechanisms for early-career academic researchers (935). Many of these programs were created or expanded through provisions of the 2022 Creating Helpful Incentives to Produce Semiconductors (CHIPS) and Science Act (936). The CHIPS and Science Act aims to

support historically underserved students and communities by providing new initiatives and funding to Historically Black Colleges and Universities (HBCUs), minority-serving institutions (MSIs), and other academic institutions. The CHIPS and Science Act also focuses on increasing the geographic diversity of research and innovation funding, combating sexual and gender-based harassment in the sciences, and supporting learners, educators, and researchers at minority-serving and emerging research institutions in rural communities. These investments and initiatives are designed to create a more inclusive STEM environment that represents and benefits all Americans, regardless of their background or experience (937,938).

The federal strategy to improve STEM career pathways also includes building capacity at MSIs and other underresourced colleges and universities. These include programs managed by the Department of Education, NSF, and other federal agencies to expand educational and research opportunities at HBCUs, Tribal Colleges and Universities, Hispanic-Serving Institutions, and Asian American and Native American or Pacific Islander-Serving Institutions.

One of the nation's leading advocates for the importance of minority education and community engagement in STEM is the United Negro College Fund (UNCF). UNCF awards more than 7,000 student scholarships, worth more than \$83 million, each year, and provides financial support to 37 HBCUs. Since 1944, UNCF has helped to more than double the number of students from minority groups attending college. The 6-year graduation rate for UNCF Black scholarship recipients is 70 percent; this is 11 percent higher than the national average and 31 percent higher than the national average for all Black students (939). Another organization is the National Action Council for Minorities in Engineering (NACME). NACME provides scholarships, resources, and opportunities for high-achieving, underrepresented college students pursuing careers in engineering and computer science (see **Sidebar 42**, p. 147) (940-944).

Within the National Cancer Institute (NCI), the R25 Youth Enjoy Science (YES) Research Education Program funds nonprofit- and government-based research programs for high school and undergraduate students with the dual goal of increasing cancer knowledge and awareness among underrepresented students while also preparing these students to participate in careers in medical research (945). These programs have primarily focused on promoting cancer research training to underrepresented racial and ethnic minority youth populations (946-948). Some examples of programs designed to increase diversity in STEM fields are summarized in **Sidebar 43** (p. 157).

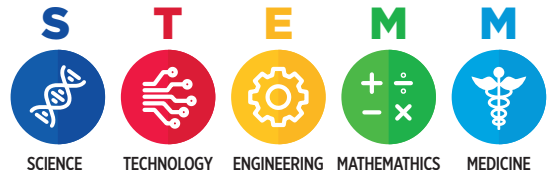
The Diversity in Cancer Research (DICR) is a collaborative program engaging historically black medical schools to

*continued on page 149*

**SIDEBAR 42**

## Organizations and Programs Focusing on Participation of Specific Minority Populations in STEMM

Many organizations and initiatives aim to promote diversity in Science, Technology, Engineering, Mathematic, and Medicine (STEMM) by specifically enhancing representation of minority populations. A selection of such organizations and programs is listed below:



### American Indian Science and Engineering Society (AISES)

AISES aims to increase the representation of American Indian, Alaska Native, Native Hawaiian, and Pacific Islander individuals; First Nations; and other Indigenous peoples of North America in STEMM studies and careers.

### Asian American and Native American Pacific Islander–Serving Institutions Program

This program provides grants and related assistance to Asian American and Native American Pacific Islander–Serving Institutions to enable such institutions to improve and expand their capacity to serve Asian Americans and Native American Pacific Islanders and low-income individuals.

### The Hispanic-Serving Institutions Program

This program aims to enhance the quality of undergraduate STEM\* education and to increase the recruitment, retention, and graduation rates of students pursuing an associate's or bachelor's degree in STEM.

### The National Academies of Sciences, Engineering, and Medicine

The National Academies of Sciences, Engineering, and Medicine appoints an interdisciplinary committee tasked with reviewing literature on bias and racism in STEMM workplaces, and approaches to increasing racial and ethnic diversity, equity, and inclusion (DEI) in STEMM organizations (e.g., universities, nonprofit organizations, hospitals, and industry). This committee also offers best policies and practices for DEI and anti-racism initiatives, as well as outlining goals for relevant, future research and for organizational strategic planning.

### National Action Council for Minorities in Engineering (NACME)

NACME's mission is to enrich society with an American workforce that champions diversity in STEM by increasing the number of underrepresented minority (URM) groups in engineering and computer science.

### Society for the Advancement of Chicanos/Hispanics and Native Americans in Science (SACNAS)

SACNAS is an inclusive organization dedicated to fostering the success of Chicanos/Hispanics and Native Americans, from college students to professionals, in attaining advanced degrees, careers, and positions of leadership in STEMM.

### The Tribal Colleges and Universities Program (TCUP)

This program provides awards to federally recognized Tribal Colleges and Universities, Alaska Native–Serving Institutions, and Native Hawaiian–Serving Institutions to promote high-quality STEM education, research, and outreach.

### United Negro College Fund (UNCF)

UNCF awards more than 7,000 student scholarships, worth more than \$83 million each year and provides financial support to 37 Historically Black Colleges and Universities (HBCUs).

These organizations and programs aim to increase the representation and success of underrepresented groups, such as women, racial and ethnic minority groups, and individuals from disadvantaged backgrounds.

\* STEM, Science, Technology, Engineering, and Mathematics.



**SIDEBAR 43**

## Programs and Initiatives Aimed at Improving Diversity in STEMM

Several programs and initiatives work to increase access, support, and opportunities for underrepresented groups in STEMM fields through scholarships, mentorship and research experiences.



### American Society for Microbiology Undergraduate Research Fellowship

Example of one of several fellowships offered by professional societies that are open to all undergraduates who are a member of the society; fellowships typically offer field-specific funding to work in a laboratory as well as travel funds to attend annual conferences.

### Appalachian Career Training in Oncology (ACTION) Program

A National Cancer Institute (NCI) Youth Enjoy Science (YES) research education grant program that recruits and trains early-career undergraduate and high school students from underrepresented, socioeconomically distressed areas of Appalachian Kentucky in cancer research and outreach.

### Initiative for Maximizing Student Development (IMSD)

National Institutes of Health (NIH)/National Institute of General Medicine Sciences (NIGMS)-funded program to fund underrepresented PhD students and offer financial support, an individualized development plan, mentored research experiences, and professional development to promote persistence in biomedical research careers.

### Louis Stokes Alliance for Minority Participation (LSAMP)

LSAMP is a US National Science Foundation (NSF) initiative that takes a comprehensive approach to impacting student development and retention and increasing diversity in STEM\*. LSAMP provides higher education institutes funding to work together and implement comprehensive and evidence-based strategies that help increase the number of STEM bachelor's and graduate degrees awarded to persons from LSAMP populations, which include Blacks and African Americans, Hispanic and Latino Americans, American Indians, Alaska Natives, Native Hawaiians, and Pacific Islanders.

### Maximizing Access to Research Careers (MARC)

The goal of the MARC research training program is to develop a diverse pool of undergraduates who complete their bachelor's degree, and transition into and complete biomedical, research-focused higher degree programs (e.g., PhD or MD/PhD). Training grants offset the cost of stipends, tuition and fees, and training related expenses, including health insurance, for the appointed trainees in accordance with the approved NIH support levels. Training grants are usually awarded for 5 years and are renewable. Full details are found in the Notice of Funding Opportunity (NOFO) PAR-21-147.

### Research Experience for Undergraduates (REU)

NSF-funded summer programs at a variety of institutions with varied formats, but generally focused on research across 8-week periods. Effective in improving students' understanding of research and students' interest in science.

### Research Training Initiative for Student Enhancement (RISE)

Funded by NIH/NIGMS with annual costs of around \$30 million per year. Mixture of direct mentoring, laboratory research experiences, and professional development training for undergraduates across the year.

### Student-centered Pipeline to Advance Research in Cancer Careers (SPARCC)

SPARCC uniquely prepares underrepresented minority students to quickly transition into the clinical research workforce and seek advanced graduate degrees.

### Summer Clinical Oncology Research Experience (SCORE)

Designed in 2010 to engage undergraduate (U) and post-baccalaureate (PB) students from diverse backgrounds in cancer research, SCORE is an 8-week summer program pairing a U or PB student with a faculty mentor to conduct cancer research.

### Undergraduate Research Opportunity Program (UROP)

Program run by select institutions including University of Michigan and MIT, offering credit or pay for students to work in a laboratory with principal investigators in a broad program that is typically targeted specifically at racial minorities.

\* STEM, Science, Technology, Engineering, and Mathematics.

improve diversity, equity, and inclusion in cancer research. The program aims to build a more inclusive research community, address health disparities, and provide support for minority cancer researchers through institutional development grants, mentorship, and career development opportunities. The initiative is expected to contribute to the advancement of health equity and the improvement of cancer care outcomes for underrepresented populations.

In December 2022, the White House Office of Science and Technology Policy outlined five action areas for STEMM equity and excellence. Those areas are the following: ensuring adequate support for students, teachers, workers, and communities to participate in and contribute to STEMM in their lifetime; addressing the STEMM teacher shortage by expanding and enhancing pathways for the training, hiring, and professional success of a diverse teacher workforce; closing the funding gap and developing long-term investment plans for historically underfunded communities; creating solutions to address bias, discrimination, and harassment in classrooms, labs, and workplaces; and promoting accountability in STEMM (949).

## Basic and Translational Cancer Research Workforce Landscape

Basic and translational cancer research are two interconnected areas of research that aim to improve our understanding of cancer biology and develop new strategies for cancer prevention, diagnosis, and treatment. Basic cancer research focuses on understanding the fundamental mechanisms and processes that underlie cancer development, progression, and spread. Translational cancer research, on the other hand, aims to “translate” the findings from basic cancer research into clinical applications that can benefit cancer patients. This type of research serves as a bridge between basic science discoveries and clinical practice. Promoting diversity in cancer research ensures that findings reflect the diverse populations affected by cancer and contributes to the development of more effective and equitable interventions. Diversifying the research workforce applies to higher education, researchers from academic institutions, editorial boards of peer-reviewed scientific journals, and conference speakers and participants (950). In higher education, for instance, a diverse learning environment promotes students’ exploration of diverse perspectives, reduces racial prejudice, and increases understanding of alternative points of view and other human differences (951).

New and junior underrepresented cancer researchers and clinician-scientists encounter persistent challenges rooted in systemic racism along their career paths, which Black students and scientists disproportionately experience. According to the Advisory Committee to the Director Working Group

on Diversity of National Institutes of Health (NIH), Black scientists make up 7.7 percent of the scientific workforce despite representing 12.4 percent of the US population. Moreover, only 1 percent of postdoctoral awards go to Black applicants. While the number of R01 grants awarded to Black researchers increased between 2013 and 2018, only 2 percent of all R01 grants were awarded to Black researchers or clinical scientists in 2018 (952). Data from 2013 to 2020 show that, compared to White applicants, Black applicants had a lower likelihood of receiving R01 funding (10.7 percent vs. 17.7 percent) and were less likely to resubmit unfunded applications (37.4 percent versus 50.0 percent) (953).

The lack of diversity in basic and translational cancer research may be reflective of the underrepresentation of racial and ethnic minority groups in health care overall. This underrepresentation may be attributed to disparities in the application, matriculation, and completion of professional and graduate school among these individuals. Multiple barriers contribute to the underrepresentation of certain racial and ethnic groups in health care, including differences in parental educational level, ineffective evaluation and metrics of performance and scientific potential, social and cultural factors, financial barriers, systemic racism (954), and differences in the networks and other extracurricular educational opportunities valued in the medical school application process (955).

Lack of diversity in academic medicine overall is another factor contributing to inequities in the matriculation of students who are underrepresented in medicine. Data from the Association of American Medical Colleges (AAMC) show that over 83 percent of the medical school faculty is White or Asian (956). This lack of faculty diversity could potentially lead to admissions committees that are prone to unconscious racial bias (957). In 2023, representation of groups based on race or ethnicity was uneven relative to the proportion of these groups in the US population. Persons from many racial and ethnic minority groups—such as Hispanic or Latino, Black, and AI/AN populations—are underrepresented in medical schools when compared to their proportion of the total population. In 2023, Black people made up 12.4 percent of the total population, but only 8 percent of medical school applicants and matriculants were Black. Hispanic or Latino/a people made up 18.7 percent of the total population, but only 6 percent of medical school applicants and matriculants were Hispanic or Latino/a. AI/AN individuals made up 1.1 percent of the total population, but only 0.17 percent of medical school applicants and matriculants were AI/AN individuals (956) (see **Table 6**, p. 150).

Although the diversity of medical school applicants, matriculants, and graduates has increased during the past 10 years, these increases are not translating to a better representation at the faculty level or at higher levels of leadership in medicine (958). The cancer science and medicine faculty at academic medical centers plays an important role

**TABLE 6**

## Applicants and Matriculants to US Medical Schools by Race/Ethnicity (2023–2024)

Applicant Race/ Ethnicity Responses	Percentage (%)	
	Applicants	Matriculants
American Indian or Alaska Native	0.17	0.16
Asian	23.96	25.68
Black or African American	8.89	8.03
Hispanic, Latino, or of Spanish Origin	6.04	6.5
Native Hawaiian or Other Pacific Islander	0.11	0.08
White	40.19	41.49
Other	2.4	2.1
Multiple Race/Ethnicity	11.43	11.86
Unknown Race/Ethnicity	3.22	2.86
Non-US Citizen and Non-Permanent Resident	3.59	1.25

Source: <https://www.aamc.org/data-reports/topic/admissions#data>

in training the next generation of researchers and clinicians. It is important that the faculty is fully reflective of the US population to adequately train future oncologists who will provide care to a diverse patient population.

Affirmative action relates to procedures that seek to eliminate discrimination and to support people who have been historically discriminated against (959). In June 2023, the Supreme Court invalidated admissions programs at Harvard University and the University of North Carolina (UNC) system that took race into consideration as a specific basis in admissions. The Court held that Harvard and UNC’s admissions programs, which account for race at various stages in the process, violate the Equal Protection Clause of the Fourteenth Amendment to the US Constitution. State bans on affirmative action previously caused minority

**Black, Hispanic, and AI/AN individuals** represent 31 percent of the population but **only about 5 percent of faculty in radiation oncology and medical oncology. Initiatives to ensure successful recruitment and retention** of URM individuals throughout the academic pathway are urgently needed (962).



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student enrollment to drop 5 percentage points (960). In addition to disproportionate underrepresentation of minority groups in medical schools, in the years since state-level bans on affirmative action were implemented, public medical schools in ban states had significant drops in the proportion of historically underrepresented students compared to the years prior to the ban (960). The recent Supreme Court ruling has the potential to amplify this effect on the enrollment of historically underrepresented groups nationally (961).

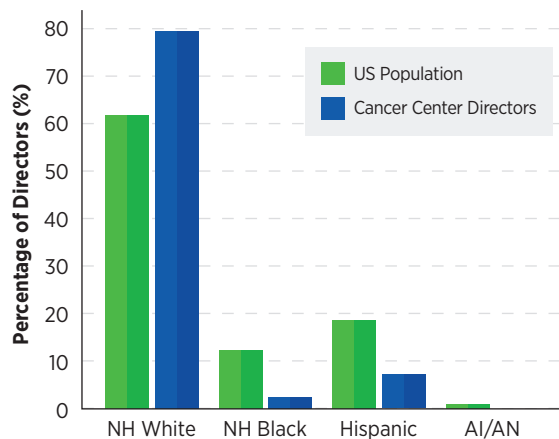
The largest bottleneck in the academic scientist training pathway is securing and maintaining a tenure-track faculty position, which is widely seen as the most challenging step for academic scientists looking to establish independent research careers. A postdoctoral research position is a transition path between graduate school and becoming an independent investigator. Unfortunately, low salaries not only are a deterrent for graduate students to apply for postdoctoral fellowships, but also result in burnout and lack of research productivity. A key advisory group at NIH has recommended raising the minimum salary for postdoctoral researchers. However, the plan faces uncertainty, as it requires approval by NIH leadership. If implemented, the postdoctoral pay boost may improve both recruitment and retention of talented early-career scientists at NIH-funded labs across the country (963). Policymakers seeking to address this issue and ensuring that the next generation of scientists have viable career options should focus on measures to increase federal research budgets and incentivize universities to expand their available faculty positions.

Intentional, unrelenting, and multilevel interventions are urgently needed to course-correct the systematic, institutionalized, and persistent barriers that prevent people from minoritized communities from thriving in medical research. NIH has embarked on an agency-wide effort to enhance diversity and dismantle structural racism in the medical research community. A central part of this is the UNITE initiative, focused on enhancing health disparities research, and promoting inclusion and diversity within both intramural NIH programs and the extramural medical and behavioral research workforce (964). Though much work remains to be done, through the UNITE framework, NIH has begun to allocate funds for research, share data regarding funded researchers, develop new science education programs, and enhance grant programs to help diversify the biomedical workforce (965).

Racial and ethnic minority groups, women, or individuals from sexual or gender minority groups face systemic barriers to leadership positions in higher education and health care. The lack of diversity among senior leadership limits the range of perspectives and experiences guiding journal policies, peer review, and conference agendas. Leadership at cancer centers remains predominantly White. According to a recent survey, among 82 cancer centers, including 64 National Cancer Institute (NCI)–designated and 18 emerging centers, 79

FIGURE 17

## Race and Ethnicity of US Cancer Center Directors



AI/AN, American Indian or Alaska Native; NH, non-Hispanic.

A recent survey that examined the diversity among cancer center directors, showed that the oncology leadership workforce does not reflect the diversity of the US population. Among 82 cancer centers, including 64 National Cancer Institute–designated and 18 emerging centers, 79.3 percent of director positions were held by non-Hispanic White individuals, while only 2.4 percent were Black individuals, 0 percent were AI/AN individuals, and 7.3 percent were Hispanic individuals (966).

percent of director positions were held by non-Hispanic White individuals (see **Figure 17**, p. 151). This underrepresentation of racial and ethnic minority groups may result in a lack of diverse perspectives when major decisions are made about cancer research priorities and resource allocation (966).

In 2022, the NCI introduced a new requirement for all NCI-designated cancer centers to develop and implement a Plan to Enhance Diversity. This plan aims to promote diversity, equity, and inclusion in the cancer research workforce and address disparities in cancer prevention, diagnosis, and treatment. The requirement is part of the Cancer Center Support Grant (CCSG) application process and emphasizes the importance of fostering a diverse and inclusive environment within NCI-designated cancer centers. Centers are expected to outline strategies to recruit, retain, and support individuals from underrepresented backgrounds in cancer research and patient care.

Within NCI, the Center to Reduce Cancer Health Disparities (CRCHD) is leading the initiatives to train students, researchers, and clinician-scientists from underrepresented communities in cancer and cancer disparities research. CRCHD addresses career development gaps through a holistic and multilevel approach to increase the number of underrepresented researchers and

clinician-scientists by offering various pathways across the academic cancer research continuum, which has proven effective (see **Sidebar 44**, p. 152).

## Cancer Care Workforce Landscape

### Physicians

Despite many diversity initiatives over the past 10 years, underrepresentation of racial and ethnic minority groups, sexual and gender minority groups, and individuals from low socioeconomic status continues in the oncology workforce (see **Table 7**, p. 153 and **Table 8**, p. 154). In 2023, on average, just 4.1 percent of cancer-focused medical residents were Black. For those of Hispanic ethnicity, the percentage was 5.3 percent. AI/AN individuals represented 0.46 percent of the cancer-focused residents and only 0.17 percent were NHOPI residents (967).

Similarly, a 2022 survey of 80,299 cancer-focused physicians found that 3.93 percent identified as Black, and 0.23 percent were AI/AN individuals. Only 5.6 percent were Hispanic or Latino/a individuals and 0.09 percent were NHOPI individuals (968). The Association of American Medical Colleges (AAMC) *2022 Physician Specialty Data Report* indicated that the share of medical students who are women; Black; or Hispanic, Latino/a, or of Spanish origin has grown in the 2022–2023 school year. Additionally, the report found that 37.1 percent of active physicians in the United States were women in 2021, up from 28.3 percent in 2007.

Diversity in the medical workforce may improve outcomes and access to care for patients from minority groups. Research shows that having more Black doctors is associated with better survival-related outcomes, lower all-cause mortality rates, and fewer mortality rate disparities for Black individuals (969). Although Black physicians make up less than 5 percent of all US physicians, they care for 25 percent of Black patients (970). Within oncology, the number of Black physicians is just 3 percent with minimal increase in fellowship applications for Black trainees over the past decade (971). To increase the number of Black physicians, medical schools must recognize and address the systemic challenges associated with these goals. These challenges are structural, faced by racial and ethnic minority groups, and are endured for generations. A strong educational pathway must be developed, including working alongside undergraduate institutions, particularly HBCUs, to identify and help develop promising potential Black medical students (972).

The issue of underrepresentation also persists among the Hispanic population. Oncologists who identify as Hispanic/

*continued on page 153*



## SIDEBAR 44

## National Cancer Institute (NCI) Programs Promoting a Diverse Scientific Workforce

**NCI's Center to Reduce Cancer Health Disparities (CRCHD)**

is committed to a cancer research workforce representative of the communities that experience disproportionate risk for and burden across the cancer continuum. NCI takes a holistic and multilevel approach to address the systemic and persistent barriers faced by underrepresented students, researchers, and clinician-scientists in cancer research. Programs and initiatives across the NCI, including CRCHD-lead efforts to support a diverse cancer research workforce, include the following:

**THE ADMINISTRATIVE SUPPLEMENT TO PROMOTE DIVERSITY**

is designed to support candidates from underrepresented backgrounds in cancer research. It offers financial assistance to students and research scientists seeking practical experience with established researchers or clinician-scientists who serve as mentors.

**BLACK CANCER RESEARCHERS (BCR)** was established to build community among the three campuses and create a safe informal space for Black scientists within NCI. The group helps participants build collaboration (both scientific and professional), provide peer mentoring, and grow their scientific network.

**CANCER MOONSHOT SCHOLARS PROGRAM** was launched in 2022, with the aim to enhance the diversity of the cancer research workforce while bringing new ideas and perspectives to cancer research and helping achieve the Biden-Harris Administration Cancer Moonshot initiative's goals; the program seeks to inspire and support world-class early-stage investigators from diverse backgrounds.

**THE CANCER RESEARCH INTERNS (CRI) SUMMER PROGRAM** provides a training opportunity for students looking for initial research training.

**THE CANCER RESEARCH POSTBAC (CRP) PROGRAM** (formerly known as the Introduction to Cancer Research Careers) provides up to 2 years of postbaccalaureate training to explore opportunities in basic and clinical research, cancer epidemiology and genetics research, cancer control science, and global health.

**THE CONTINUING UMBRELLA OF RESEARCH EXPERIENCES (CURE) PROGRAM** offers unique training and career development opportunities to enhance and increase diversity in the cancer disparities research workforce. The CURE program supports promising candidates from middle school through junior investigator levels and provides them with a continuum of competitive funding opportunities. Several other CRCHD programs and initiatives, including Partnerships to Advance Cancer Health Equity (PACHE), focus on promoting diversity in the cancer research workforce.

**THE DIVERSITY CAREER DEVELOPMENT PROGRAM (DCDP)** provides current NCI postdoctoral fellows with the tools necessary to develop as leaders in academic independent research careers.

**THE EARLY INVESTIGATOR ADVANCEMENT PROGRAM (EIAP)**

is a cross-NCI initiative managed by CRCHD, with a goal of enhancing diversity in the cancer research workforce. The EIAP was established in 2021 and recruited its first cohort in 2022 to provide in-kind grantsmanship training, individualized grantsmanship coaching, career navigation, mentorship from NCI-funded established investigators, peer networking opportunities, access to professional development workshops (PDWs), and professional development webinars. In 2 years, 45 competitive cancer researchers and clinician-scientists from diverse backgrounds have completed the program, resulting in a 29 percent success rate in obtaining RO1s, three of whom are CURE awardees, with many applications pending review.

**THE FREDERICK DIVERSITY COMMITTEE (FDC)** provides current NCI fellows with opportunities to promote diversity and inclusivity at the Frederick campus.

**THE INTRAMURAL CONTINUING UMBRELLA OF RESEARCH EXPERIENCES (ICURE) PROGRAM** provides mentored research experiences for underrepresented students and scientists from diverse backgrounds in the multidisciplinary research environment of NCI campuses in Bethesda, Rockville, and Frederick, Maryland. Over the past 24 years, CURE and iCURE have trained over 5,000 underrepresented students and research scientists.

**NCI POSTDOC RECRUITMENT EVENT (PRE)** (formerly known as the Graduate Student Recruiting Program) provides doctoral candidates with the opportunity to explore postdoctoral opportunities at NCI.

**R25 YOUTH ENJOY SCIENCE PROGRAM (YES)** is the only early-intervention program at NCI that supports research education activities in the mission areas of NIH. The overarching goal of this R25 program is to support educational activities that encourage individuals from diverse backgrounds, including those from groups underrepresented in the biomedical and behavioral sciences, to pursue further studies or careers in research. This program is critical in addressing NCI's priority of enhancing the diversity of the cancer research workforce, a strategic goal of NCI's National Cancer Plan.

**TRANSFORMATIVE EDUCATIONAL ADVANCEMENT AND MENTORING (TEAM) NETWORK** was implemented in 2023 to address institutional barriers by piloting the use of training champions (TCs) at Minority-Serving Institutions (MSIs) to promote education and career development opportunities for diverse scholars.

TABLE 7

## Active MD Residents by Specialty and Race/Ethnicity (2022–2023)

	Percentage (%)							
	Asian	Black or African American	Hispanic, Latino, or of Spanish Origin	NHOPI	White	Other	Unknown	Non-US Citizen or Non-Permanent Resident
Gynecologic Oncology (Obstetrics and Gynecology)	18.9	5.9	10.5	0.4	66.8	3.8	0	5.9
Pediatric Hematology/Oncology (Pediatrics)	18	4.6	6.1	0	53.4	4.1	0.5	18.7
Hematology and Oncology (Internal Medicine)	29.4	3.5	3.7	0.2	36.8	3.2	0.2	27.3
Molecular Genetic Pathology (Medical Genetics and Genomics)	25	0	3.6	0	42.9	1.8	0	28.6
Hematology (Pathology)	19.8	3.4	6	0	45.7	3.4	0.9	26.7
Oncology (Internal Medicine)	63.6	0	18.2	0	0	9.1	0	9.1
Musculoskeletal Oncology (Orthopedic Surgery)	7.7	0	7.7	0	61.5	0	0	23.1
Radiation Oncology	29.2	5.9	5	0.3	49.2	4.1	0	11.9
Complex General Surgical Oncology (General Surgery)	18.3	4	7.1	0.8	61.9	3.2	0	14.3
Nuclear Medicine	18.1	2.8	8.3	0	19.4	6.9	0	50
Cytopathology (Pathology)	27.3	5.7	6.8	0	36.4	3.4	0	27.3
Radiology, Interventional: Integrated	27.1	3.8	6.6	0.1	56.8	4.4	0.1	8.5
Thoracic Surgery	15.2	6.5	6.1	0	56.5	7	0	13.5
Diagnostic Radiology/Nuclear Medicine/Nuclear Radiology	25	8.3	0	0	25	0	8.3	33.3
Internal Medicine/Medical Genetics	36.4	0	18.2	0	36.4	0	0	27.3
Pediatrics/Medical Genetics	7.9	5.3	3.9	0	67.1	2.6	0	19.7

NHOPI, Native Hawaiian or Other Pacific Islander; NH, Non-Hispanic.

The sum of the race/ethnicity categories may not add up to 100 percent since a resident could designate multiple race/ethnicity categories.

Source: <https://www.aamc.org/data-reports/students-residents/report/report-residents>

Latino remain highly underrepresented in the workforce (973). While the Latino population is the largest minority group in the United States, constituting 18.7 percent of the total population, less than 5 percent of practicing oncologists in the United States self-identify as Hispanic or Latino, and only 7 percent of matriculating medical school students self-identify as Hispanic or Latino, of which only a fraction will go on to pursue oncology training (974). Physicians of Black, AI/AN, and Latino origin are more likely to practice in areas federally designated as medically underserved (975). Furthermore, a shortage of Spanish-speaking physicians could negatively impact the health care quality and access for Hispanic or Latino patients whose preferred language is Spanish (976).

Besides oncologists, obstetrician-gynecologists (Ob-Gyns) and urologists play pivotal roles in prevention, detection, diagnosis, supportive services, and survivorship care for patients with cancer. A recent study shows higher proportions of Ob-Gyn residents who identified as Black (10.2 percent) or Hispanic (9.6 percent) compared with surgical and nonsurgical

specialties. While Ob-Gyns do have a higher proportion of Hispanic and Black medical residents compared to other specialties, their numbers still fall below that of the general population (977). According to statistics published in the 2021 Census Reports from the American Urological Association (AUA), the following is a current breakdown of the racial landscape in this field: Out of 13,790 practitioners, 83 percent are White, 2.4 percent are Black, and 4.4 percent are Hispanic individuals. The AUA recommends including educational efforts that inform our diplomates and committee members about the benefits of diversity (978).

Medicare is the largest funder of graduate medical education (GME) in the United States, supporting over 98,000 residency positions through payments to teaching hospitals (979,980). In 1997, Congress passed the Balanced Budget Act, which froze the number of Medicare-funded residency positions at 1996 levels (981). This cap remains and has created a bottleneck that limits the number of new physicians who can enter the workforce each year.

TABLE 8

## Cancer-focused Physicians by Specialty and Race/Ethnicity (2022)

	Percentage (%)						
	AI/AN	Asian	Black or African American	Hispanic, Latino, or of Spanish Origin	NHOPI	White	Other
Anatomic/Clinical Pathology	0.13	17.99	3.1	6.14	0.11	70.53	2.01
General Surgery	0.44	15.07	6.14	6.92	0.12	69.03	2.28
Hematology and Oncology	0.08	32.08	3.5	5.4	0.1	56.47	2.36
Radiation Oncology	0.28	25.87	3.54	3.88	*	64.46	1.97
Radiology and Diagnostic Radiology	0.21	17.81	2.68	4.59	0.09	73.2	1.42
Pediatric Hematology/Oncology	*	20.35	3.83	6.13	*	66.86	2.82

\* Fewer than 10 physicians, data not shown

AI/AN, American Indian or Alaska Native; NHOPI, Native Hawaiian or Other Pacific Islander.

Source: <https://www.aamc.org/data-reports/workforce/report/physician-specialty-data-report>.

Race and ethnicity are obtained from a variety of AAMC sources, including DBS, ERAS, APP, MCAT, SMDEP, GQ, MSQ, PMQ, FACULTY, GME, and STUDENT, with priority given to the most recent self-reported source.

Rural and urban underserved community programs rely more heavily on Medicare funding for residency positions, which has made practicing in underserved areas challenging. In 2020, only 2 percent of Medicare-funded residency training occurred in rural areas (982). Studies have also shown that rural background among trainees and rural exposures during medical school were associated with higher rural practice uptake (983-985), and physicians often practice within 100 miles of where they completed residency. Therefore, training residents where they are needed in practice is one promising strategy to increase the supply of rural physicians (986,987).

A 2023 study found that less than 30 percent of medical students planned to practice in underserved areas between 2019 and 2021; those who did were more likely to be women, belong to minoritized populations, or identify as a member of the SGM community (988). The lack of residency training in rural and underserved areas worsens the uneven distribution of physicians. Congress recently took steps to support several programs supporting GME funding by adding 1,000 new Medicare-funded positions for the first time since 1997 (989). Advocacy efforts continue for lifting the cap on Medicare GME funding and expanding physician workforce capacity.

In summary, diversity brings valuable new perspectives and ways of thinking that benefit research, education, and care delivery. A physician workforce that adequately represents the diversity of the general population has the potential to improve patient outcomes, experiences, and access to high-quality care. A concerted effort is needed to attract, support, and retain a diverse medical workforce.

## Physician-Scientists

Physician-scientists with combined MD and PhD training play a vital role in medical research. While only 4 percent of medical

school graduates are MD-PhDs, almost half of NIH research funding distributed to physicians is allocated to MD-PhD researchers (990). MD-PhD physician-scientists can seamlessly transition between bench and bedside, conducting impactful research while keeping the focus on serving patients (991).

During the past decade, diversifying efforts have resulted in a consistent and sustained increase in the share of female and underrepresented minority (URM) in medicine matriculants to MD-PhD programs. Yet, there is much room for improvement to include more women, Black, Hispanic, AI/AN, and NHOPI individuals in the MD-PhD population in the United States (see **Table 9**, p. 155). Both NIH and Congress have cited this stark lack of gender and racial and ethnic diversity among MD-PhDs as an issue of concern that needs to be addressed urgently (992).

Attrition rates among URM MD-PhD students, including those who identify as Black, Hispanic or Latino(a), and AI/AN, are disproportionately high (993). Studies indicate that about 25 percent of URM students withdraw from combined degree programs, compared to less than 10 percent of non-URM students. According to a recent study, among more than 4,700 students enrolled in combined MD-PhD programs, overall 84 percent of students completed their training. However, compared to 17 percent of White students, 29 percent of Black students did not complete their MD-PhD training. Furthermore, Black students were more likely than their White counterparts to leave medical school (994).

Factors contributing to high rates of attrition likely include a lack of mentors with shared backgrounds, feelings of isolation, imposter syndrome, and insufficient research funding for URM trainees (991). The high attrition of minority MD-PhD students is an unacceptable loss of talent and perpetuates inequities in representation within academic medicine and medical research. Proactive measures to boost enrollment, provide funding, and retain URM MD-PhD

TABLE 9

## MD-PhD Students by Specialty and Race/Ethnicity (2021)

	Percentage (%)				
	2018	2019	2020	2021	2022
American Indian or Alaska Native	0.8	0.45	0.55	0.54	1.02
Asian	26.05	27.4	28.22	24.83	28.16
Black or African American	4.98	4.04	4.29	6.07	4.93
Hispanic, Latino, or of Spanish Origin	4.98	5.09	7.61	7.56	5.08
Native Hawaiian or Other Pacific Islander	0	0.3	0.14	0.54	0
White	57.07	58.68	53.11	54.39	52.39
Other	3.05	2.1	3.46	2.7	5.22
Non-U.S. Citizen and Non-Permanent Resident	3.05	1.95	2.63	3.37	3.19

Source: <https://www.aamc.org/data-reports/students-residents/data/report-residents/2021/table-b3-number-active-residents-type-medical-school-gme-specialty-and-sex>

students through graduation are essential for diversifying the physician-scientist workforce.

In a 2023 Consensus Report published by the National Academies of Sciences, Engineering, and Medicine, national experts in STEM industries recommended that leaders systematically interrogate the causes perpetuating disparities in educational and career outcomes. The report serves as a roadmap for government, educational institutions, and other stakeholders to acknowledge and address the historical underpinnings of today's injustices (995).

Policy changes at institutional, funding agency, and federal levels are needed to drive meaningful improvements in participation of underrepresented groups in cancer research. Some solutions include the following: offering focused scholarship programs to incentivize and support URM students in pursuing MD-PhD programs to help lower financial barriers to entry; providing dedicated research funding opportunities for early-career physician-scientists from diverse backgrounds to promote retention and career development; setting clear diversity goals and collecting data on demographics to monitor representation in MD-PhD programs, faculty appointments, and leadership roles; expanding mentoring and networking programs to connect URM physician-scientists with senior researchers who can advise on career progression; and increasing exposure to research careers for minority undergraduate and high school students via pathway programs and partnerships with Minority-Serving Institutions (996,997).

In 2020, as a collaborative effort, the AACR and the Bristol Myers Squibb Foundation and National Medical Fellowships created an initiative named the Robert A. Winn Diversity in Clinical Trials Award Program (Winn CDA). The Winn CDA is a 2-year program designed to train early-stage physician scientists in the fundamentals of clinical trial design and the science of community outreach and engagement. These physician-scientists are from underrepresented backgrounds

and have demonstrated a commitment to increasing diversity in clinical research. To date, the Winn CDA has trained 179 early-stage investigators, with an additional 67 scheduled for 2024.

## Other Health Care Professionals

While physicians have a central role in cancer care, they rely on the expertise and support of many other team members involved in caring for cancer patients, including nurses, physician assistants, pharmacists, radiation therapists, social workers, nutritionists, rehabilitation therapists, psychologists and counselors, and patient navigators.

Despite decades of effort, the nursing workforce remains mostly female and White. According to a 2022 survey, the nursing workforce lacks diversity, with 80 percent identifying as non-Hispanic White (998). The number of Hispanic or Latino(a) registered nurses (RNs) increased from 3.6 percent in 2015 to 6.9 percent in 2022; 6.3 percent of RNs were Black, and AI/AN and NHOPI individuals both represented 0.4 percent of the nursing workforce. Male nurses accounted for 11.2 percent of the registered nurse workforce in 2022, with an increase of 1.8 percent since 2020 (998).

*The Future of Nursing 2020–2030* report by the National Academy of Medicine emphasizes diversifying the nursing workforce as a key priority. Specifically, the report calls for expanding pathways and creating more seats for students from minority and disadvantaged backgrounds to access nursing schools, tailoring recruitment, and establishing retention strategies toward nurses from minority groups, including underrepresented racial and ethnic groups, men, sexual and gender minority individuals, immigrants, people with disabilities, veterans, and those living in rural areas (999).

Similar to the nursing workforce, the physician assistant (PA) workforce falls short of mirroring national demographics,



mainly due to a lack of diversity in student enrollment. An analysis of PA programs in the United States in 2022 showed that during 2014–2018, PA programs had difficulty in recruiting and graduating a diverse group of students: out of 34,625 graduates, only 6.4 percent were of Hispanic ethnicity and 3.5 percent were from URM groups. Furthermore, diverse graduates came from a few top-performing programs (1000). As part of the efforts to diversify the PA workforce, the Physician Assistant Higher Education Modernization Act was introduced in Congress in January 2021 to help enhance diversity among PAs by allocating more federal resources and funding to PA programs and initiatives aimed at recruiting and graduating more students from minority, disadvantaged and underserved backgrounds. The bill is currently in the early phases of being considered by Congress (1001).

While not directly administering cancer therapies, dentists play a key role in certain aspects of cancer care by detecting abnormalities in the mouth and throat during routine oral examinations that could lead to a diagnosis of cancer (1002). Among 202,304 dentists in the United States in 2023, 3.8 percent were Black individuals, 6 percent were from Hispanic groups, 0.3 percent were AI/AN people, and 0.2 percent were NHOPI individuals (1003).

Oncology pharmacists are crucial members of the cancer care team, ensuring safe and effective use of complex medications. They collaborate with health care professionals to optimize treatment, monitor patients, and educate patients and caregivers. Recent studies have highlighted disparities within the oncology pharmacy workforce, particularly in terms of representation, leadership opportunities, and access to specialized education and training. For instance, a 2019 survey by the Hematology/Oncology Pharmacy Association (HOPA) found that while women made up 63 percent of HOPA's membership, they held only 56 percent of leadership positions within the organization (1004); additionally, only 3.9 percent of pharmacists were Black, and 3.6 percent were Latino, compared to 76.9 percent who identified as White (1005). These disparities extend to education and training, with a 2018 study finding that non-White oncology pharmacists were less likely to have completed a postgraduate year 2 (PGY2) oncology pharmacy residency, a training program for pharmacists who wish to specialize in the field of oncology pharmacy, compared to their White counterparts (20.3 percent versus 33.7 percent) (1006). These findings highlight the need for targeted efforts to increase diversity and inclusion within the oncology pharmacy workforce.

# Overcoming Cancer Disparities Through Science-based Public Policy

## IN THIS SECTION, YOU WILL LEARN:

- Federal funding through NIH, FDA, CDC, CMS, and other agencies is fundamental to addressing many of the issues that perpetuate cancer disparities.
- Policies that are aimed at improving cancer prevention and early detection will help reduce cancer disparities.
- A recently enacted law to require clinical trial sponsors to submit Diversity Action Plans to the FDA as part of their clinical study protocols will increase enrollment of underrepresented populations in clinical trials, thereby improving access to innovative cancer therapies for all patients.
- With the growing use of telemedicine, universal access to high-speed broadband Internet is vital to health equity.

Disparities in cancer research, prevention, and care continue to disproportionately affect historically marginalized populations. Achieving cancer health equity will require focused and multidirectional efforts from government, communities, health systems, researchers, nonprofit organizations, and all other stakeholders in the cancer care ecosystem. This section focuses on federal initiatives and science-based policy solutions to reduce cancer disparities and promote health equity.

## Funding Research and Supporting Innovative Programs to Address Disparities and Promote Health Equity

Federal funding for the National Institutes of Health (NIH), Food and Drug Administration (FDA), Centers for Disease Control and Prevention (CDC), and Centers for Medicare and Medicaid Services (CMS) and other agencies is crucial for advancing our understanding of cancer disparities and developing effective strategies to address them. In recent years, federal agencies have augmented existing research programs and created new research initiatives designed to expand our knowledge of diverse populations and the health challenges they face.

The NIH-wide UNITE Initiative seeks to address structural racism at NIH and in the broader medical community research and promote health equity research (964). As part of this initiative, the agency has created new sources of support to study and reduce

health disparities across populations, such as the NIH Common Fund Transformative Research to Address Health Disparities and Advance Health Equity program (1007). The NIH UNITE initiative has also led to the creation of the NIH Community Partnerships to Advance Science for Society (ComPASS) initiative, which seeks to develop, implement, and evaluate structural interventions to improve health equity through community-driven partnerships. NIH intends to budget approximately \$400 million over 10 years for ComPASS activities (965,1008).

The National Institute on Minority Health and Health Disparities (NIMHD) is a leader of these initiatives and a locus for federal health equity research. With a fiscal year (FY) 2023



**THE HONORABLE**  
**Deb Fischer**  
US Senator for Nebraska



“Even as we continue to see rapid advances in cancer treatment and prevention, I’m concerned about the disparities in health care across this country—especially in our rural areas. As I travel the state, I’ve seen firsthand the significance of our rural hospitals and the need to expand access to care for rural Americans. In the Senate, I fought to reauthorize and increase funding for the National Firefighter Cancer Registry, and I voted for sustained increases in research funding to help us end cancer. Working together, I know we will find a cure.”

**SIDEBAR 45****NCI Programs That Address Disparities in Cancer Care and Prevention**

NCI supports several programs to improve cancer prevention and care across the United States.



**The NCI Center to Reduce Cancer Health Disparities (CRCHD)** was founded in 2001 to help reduce the unequal burden of cancer among diverse populations. The center supports basic, clinical, translational, population research and science; provides expert advice on policy and participates in strategic planning to strengthen cancer disparities research; and leads NCI's training efforts to increase diversity and representation in the cancer research workforce.

**Partnerships to Advance Cancer Health Equity (PACHE)**, lead by CRCHD, grants institutional awards to support research, training, and community engagement partnerships between NCI-designated cancer centers and institutions that serve underserved health disparity populations and underrepresented students (ISUPS). PACHE currently funds 15 partnerships across the country that continue to expand cancer disparities research, train undergraduate and graduate students from diverse backgrounds for careers in the life sciences, and conduct community outreach to promote cancer prevention and participation in clinical trials.

**The NCI Community Oncology Research Program (NCORP)** is a national network designed to bring cancer clinical trials and care studies closer to people in communities across the country. Encompassing seven research bases and 46 community sites across the nation, the NCORP network members are conducting clinical trials across many areas, including cancer screening and prevention, care delivery, and supportive care, symptom management, and patient quality of life. To increase access to these clinical trials, 14 of the community sites are medical centers or practices where at least 30 percent of the patient population come from racial/ethnic minority groups or live in rural areas (166).

budget of approximately \$524 million, NIMHD funds both intramural and extramural research projects organized around major themes, including clinical and health services research, integrative biological and behavioral research, and community health and population sciences (1009).

Each of the NIH Institutes and Centers, including NCI, has also expanded its research programs to address disparities (see **Sidebar 45**, p. 158). For example, NCI recently coordinated a new \$50 million Persistent Poverty Initiative. This program entails the creation of five new Centers for Cancer Control Research in Persistent Poverty Areas that will implement and study interventions for cancer prevention (1010).

The NCI Center to Reduce Cancer Health Disparities (CRCHD) remains a key part of NCI's research efforts to address the unequal burden of cancer across the United States (1011). CRCHD runs many programs that facilitate the expansion of scientific partnerships between institutions serving underserved communities and NCI-designated cancer centers, broaden opportunities for scientific training, and build community partnerships to improve cancer screening.

Federal funding is also helping to reduce disparities in personalized medicine research. Breakthroughs in genomic sequencing are unlocking the potential for personalized medicine based on a deeper understanding of an individual's genetics. However, racial and ethnic minorities are

underrepresented in genomics studies and databases. To address these gaps, programs such as the NIH *All of Us* Research Program are building genomic and other health research resources across populations (1012).

CDC operates many public health programs to reduce cancer disparities and improve health equity (see **Sidebar 46**, p. 159). CDC's Division of Cancer Prevention and Control (DCPC) works to improve equity in cancer control, including through grants to state and local health departments. Its public health strategies include studying awareness of cancer risk among diverse groups, providing access to cancer screening to medically underserved populations, and identifying other barriers to cancer prevention and treatment (1013). DCPC is playing a central role in the CDC-wide CORE Health Equity Science and Intervention Strategy, which seeks to embed health equity in all the agency's projects to improve public health (see **Sidebar 47**, p. 161) (1014).

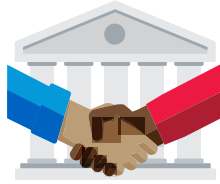
## Collaborative Resources to Advance Research for Health Equity

Present-day disparities in cancer risk and outcomes often stem from underlying policies, laws, structures, and

## SIDEBAR 46

## CDC Funding Partnerships to Reduce Cancer Disparities

The Centers for Disease Control and Prevention (CDC) awarded funds to three research organizations to help advance health equity in cancer. These CDC-funded projects are among the first to address cancer disparities that are deeply rooted in systemic racism. CDC researchers will partner with researchers from the funded organizations to study novel ways to achieve health equity in cancer prevention and treatment.



**Project BAT (Black People Against Tobacco)** is a community-based intervention that intends to reduce tobacco use among Black residents of Jackson, Mississippi. This project will implement strategies to address social drivers of health that impact tobacco use, including:

- Provide educational resources for smoking cessation;
- Encourage community engagement; and
- Inform policymakers about legislation that can help reduce tobacco use.

**NYC CONNECT (New York City Cancer Outreach Network in Neighborhoods for Equity and Community Translation)** builds on a patient navigation program at New York University to increase accessibility of cancer screening for residents in New York City. NYC CONNECT intends to:

- Reduce systemic racism and study its effect on community clinical care screening interventions;
- Lead a research initiative to learn how well patient navigator programs increase screening for breast, cervical, and colorectal cancers; and
- Share successful strategies with other communities.

**The MedStar Health Research Institute** is partnering with local universities in Washington, DC, to improve cancer survivors' health and well-being through a patient navigation project. The project intends to:

- Create one screening and referral process across three cancer centers to coordinate care;
- Learn how community health workers can identify and help Black individuals who have survived breast and prostate cancer and need support and additional resources; and
- Provide training for health care professionals to help them recognize and avoid racism (1015).

beliefs ingrained in our society. Some of these policies are or were intentionally discriminatory toward racial and ethnic minority communities and continue to produce broad negative impacts on opportunities for education, employment, housing, and access to healthy nutrition (see **Figure 18**, p. 160). These negative impacts resulting from centuries of race-based policies are commonly known as structural or systemic racism. For example, redlining (see **Sidebar 8**, p. 38) is a racist practice stemming from the Homeowners Loan Corp and the Federal Housing Administration's use of color-coding maps to indicate where it was perceived as "safe" to insure mortgages. Anywhere Black individuals lived was marked as red to denote these places were "risky" neighborhoods, and these designations have had lasting effects on health disparities (see **Sidebar 8**, p. 38). Redlining prevented Black individuals from building home equity and has furthered health disparities associated with less resourced schools, increased environmental hazards, reduced air quality, decreased availability of health care facilities, and increased risk of low birth weight (701,1016). Addressing and combating ways patients are impacted by social drivers of health, including racist policies like redlining, are essential in achieving health equity (see **Understanding and Addressing Drivers of Cancer Disparities**, p. 36).

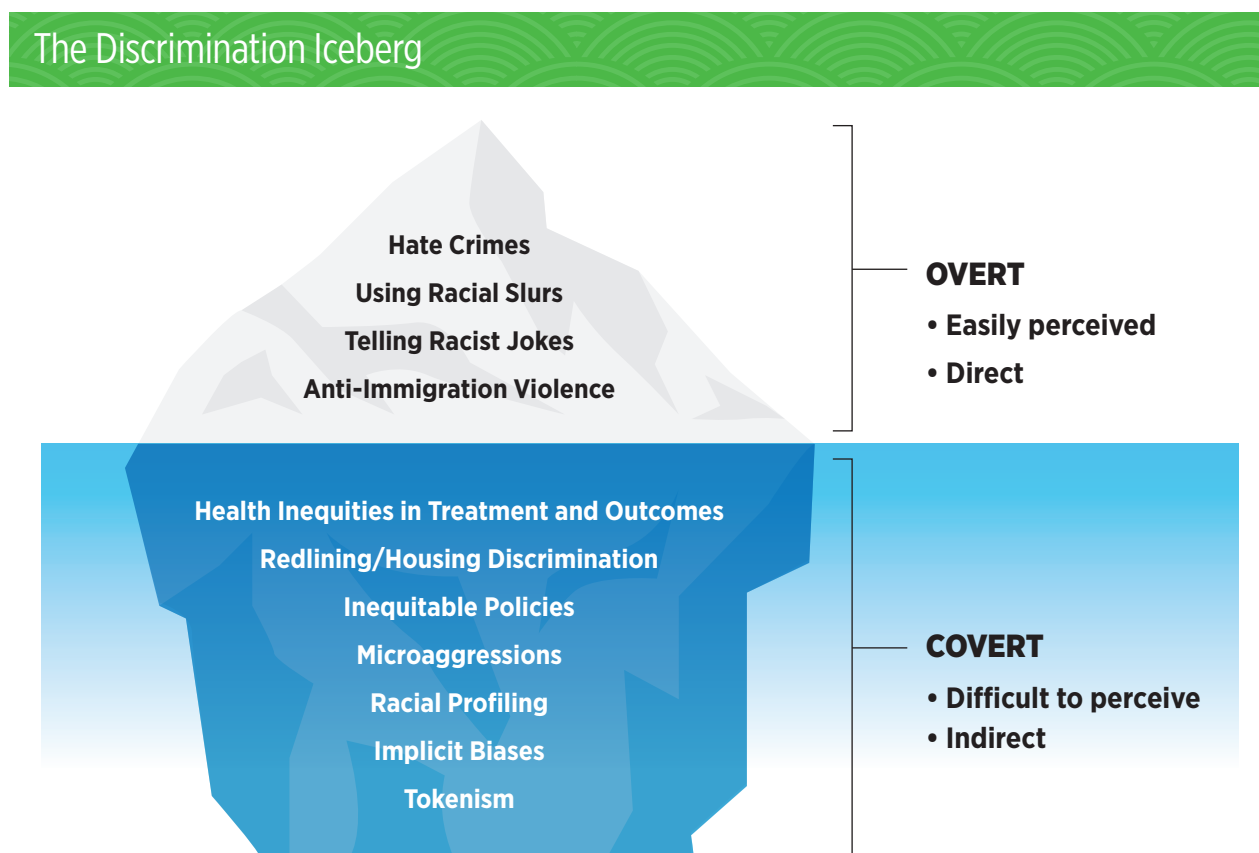
## Policies to Address Disparities in Cancer Prevention

### Regulations to Reduce the Disparate Harms of Tobacco Products

Scientific evidence demonstrates that tobacco smoking causes 18 different types of cancer and is the top modifiable risk factor for cancer-related deaths (see **Disparities in the Burden of Preventable Cancer Risk Factors**, p. 66). Over the past 60 years, the percentage of US adults who currently smoke has been reduced from 42.4 percent to 11.5 percent through policies such as smoke-free laws, tobacco taxes, advertising restrictions, evidence-based smoking cessation programs, and awareness campaigns. However, predatory marketing practices from the tobacco industry toward racial and ethnic as well as sexual and gender minority individuals have resulted in persistently higher smoking rates compared to NH White individuals, especially among youth (1017).

The tobacco industry has aggressively targeted racial and ethnic minority communities with menthol cigarettes for decades. Overall, 38.8 percent of Americans who smoke use menthol cigarettes, and largely due to predatory marketing practices, 85 percent of Black individuals who smoke use menthol cigarettes (331). Extensive evidence indicates that menthol cigarettes increase smoking initiation, progression to



**FIGURE 18**

Discrimination exists at multiple social levels. Using an iceberg as a metaphor, hate crimes and other overt acts are the tip of the discrimination iceberg, as they are easily seen. More subtle acts of discrimination, such as stereotyping groups and treating a particular group with less respect, are difficult to discern and are below the waterline. The base of the iceberg represents systemic racism, which is an underlying cause of health disparities.

frequent smoking, exposure to nicotine, and reduce smoking cessation success (1018-1020). The 2009 Family Smoking Prevention and Tobacco Control Act (TCA) prohibited most flavors of cigarette products but allowed the tobacco industry to continue marketing menthol cigarettes and flavored cigars. However, the TCA asked FDA to determine if continued availability of menthol cigarettes was “appropriate for the protection of public health.” In 2013, FDA concluded that “menthol cigarettes pose a public health risk above that seen with nonmenthol cigarettes” (1021).

AACR and many other public health–focused organizations have consistently advocated for FDA to prohibit menthol cigarettes, including through a formal Citizen Petition in 2013 (1022). In April 2022, FDA responded to the Citizen Petition with a draft product standard to prohibit the manufacture, distribution, or sale of menthol cigarettes (1023), which received hundreds of thousands of public comments. As of the writing of this report, the menthol rule has not been finalized. Scientific studies estimate that between 25 and 64 percent of adults who smoke menthol cigarettes would quit if menthol cigarettes were not available

(1024). Additionally, a federal menthol ban is estimated to save 650,000 lives by 2060, with a large proportion of those lives saved among Black individuals (1025). In November 2022, California residents voted in favor of Proposition 31, which banned nearly all flavored tobacco products including menthol cigarettes (1026). However, tobacco companies have effectively circumvented the flavor ban by using synthetic chemicals that provide a cooling sensation without a “flavor” (1027). It is important that a comprehensive ban on menthol cigarettes closes this loophole by banning any additives that provide a cooling sensation to mask the harshness of smoke. Furthermore, increased support for evidence-based smoking cessation resources and programs is critical to maximize the public health benefits of banning these extremely addictive products.

Similar to menthol, all flavored tobacco products significantly increase smoking initiation (1028-1030). Two-thirds of adults who currently use “little cigars” or “cigarillos” have smoked these products with flavors other than tobacco (1028). Additionally, Black and Hispanic adults are more than twice as likely as White adults to smoke little cigars or cigarillos. In

## SIDEBAR 47

## CDC Programs to Promote Cancer Health Equity

### Racial and Ethnic Approaches to Community Health (REACH)

is a national program that demonstrates how local and culturally tailored solutions can be effective in reversing the health disparities of diverse communities in urban, tribal, and rural areas. REACH funds community programs that encourage preventive behaviors foundational to cancer prevention, such as physical activity, obesity reduction, healthy eating, smoking cessation, and cancer screening.



### The National Breast and Cervical Cancer Early Detection Program,

since its inception in 1991, has helped low-income, uninsured, and underinsured women gain access to screening, diagnostic, and treatment services. In 2022, it provided breast cancer screening and diagnostic services to 263,134 women and diagnosed 2,168 invasive breast cancers and 627 premalignant breast lesions. This program also provided cervical cancer screening and diagnostic services to 121,197 women and diagnosed 99 invasive cervical cancers and 5,732 premalignant cervical lesions, of which 35 percent were high-grade (152).



**The Colorectal Cancer Control Program** was established in 2015 to increase colorectal cancer screening rates. It currently includes 541 clinics that serve nearly 1 million individuals ages 50 to 75, including many who are uninsured. Clinics that have participated since the program's inception have increased screening rates by 8.3 percent.



April 2022, FDA proposed a draft product standard banning the manufacture, distribution, or sale of flavored cigars (1031), but as of writing has not been finalized. This policy is estimated to prevent 112,000 youth and young adults from initiating cigar smoking every year, and therefore decrease premature deaths from cigar smoking by 21 percent (1032).

Smoking-related health disparities are exacerbated by inconsistent insurance coverage for evidence-based smoking cessation therapies. Among US adults who attempted to stop smoking in 2015, 34.3 percent of non-Hispanic White (NHW) adults used evidence-based medication or counseling (321). In comparison, 28.9 percent of Black adults, 20.5 percent of Asian

adults, and 19.2 percent of Hispanic adults used evidence-based cessation methods. Lack of health insurance was a key reason for these disparities; only 21.4 percent of adults without health insurance used evidence-based methods. Expanding Medicaid, improving cessation benefits within Medicaid and Medicare, and eliminating other barriers could greatly improve the use of evidence-based cessation methods that reduce overall health care costs (1033,1034). Additionally, increased funding for federal awareness campaigns and cessation support services, such as SmokeFree.gov and CDC's "Tips from Former Smokers," with focused initiatives for racial and ethnic and/or sexual and gender minority (SGM) populations could help address tobacco-related disparities (1035,1036).

### HOW THE TOBACCO INDUSTRY TARGETED BLACK COMMUNITIES

Several **periodicals that focus on Black audiences**, like *Ebony* magazine, financially **depend on tobacco advertising**, which has allowed tobacco companies to disproportionately target Black consumers. These practices, including free distribution of menthol cigarettes in Black communities, have **resulted in 85 percent of Black adult smokers using menthols** (1037).



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## Policies to Promote Environmental Justice

The term "environmental justice" refers to efforts that advance the just treatment of all people by ensuring they are protected from disproportionate environmental health risks and can live in a healthy, sustainable environment (1038). Racial and ethnic minorities and other marginalized groups are disproportionately harmed by exposures to environmental carcinogens, including radon, petrochemicals, per- and polyfluoroalkyl substances (PFAS), and pesticides (442,443). In turn, these exposures lead to higher cancer rates and mortality (102). These outcomes are the result of discriminatory policies, including redlining and the construction of polluting industrial facilities and waste disposal sites in marginalized communities (98-100).

As part of the Cancer Moonshot, the Environmental Protection Agency (EPA) has undertaken and expanded a series of initiatives to prevent exposure to environmental carcinogens and promote environmental justice (1039). The National Radon Action Plan (NRAP), an EPA-led public-private partnership between government, industry, and not-for-profit organizations, is continuing its efforts to eliminate preventable, radon-induced lung cancer (1040). First established in 2015, the NRAP has saved approximately 2,000 lives annually through increased radon testing

requirements in the home finance and insurance sectors, updated building codes, improved radon detection and mitigation strategies, and better public education of radon risks (1041). The current NRAP from 2021 to 2025 seeks to build on these successes by expanding risk reduction in building codes and real estate transactions, providing financial support for radon mitigation to low-income and other historically marginalized communities, and growing the workforce of certified radon mitigation professionals, among other strategies (1042).

EPA has a central role in the regulation of harmful synthetic chemicals under the authorities granted to the agency by the Toxic Substances Control Act (TSCA) (1043). The agency has recently pursued regulatory activities to curtail the manufacture and use of environmental carcinogens including trichloroethylene and methylene chloride (1044,1045).

The agency has also recently pursued a series of regulatory actions to regulate PFAS. In September 2022, EPA proposed to designate two PFAS (PFOA and PFOS) as hazardous substances under the Comprehensive Environmental Response, Compensation, and Liability Act (CERCLA) also known as Superfund (1046). Such action would increase reporting requirements and enable enforcement related to the release of these chemicals into the environment. In March 2023, EPA proposed a set of legally enforceable levels for six types of PFAS in drinking water (1047).

Many of EPA's activities to advance environmental justice are coordinated through the Office of Environmental Justice and External Civil Rights (OEJECR). OEJECR creates tools such as EJScreen to provide consistent information to the public about the burden of environmental hazards on communities to help enable action, including reduction of exposure to carcinogens (1048). The Office also provides grants and technical assistance to communities and multi-stakeholder partnerships to improve environmental health in marginalized communities, including the Environmental Justice Collaborative Problem-Solving Cooperative Agreement Program and the Environmental Justice Government-to-Government Program (1049).

## Policies to Address Disparities in Cancer Screening and Follow-up Care

Addressing disparities in cancer screening and follow-up care will require patient centricity when navigating the health care system (1050). While policy measures like the Patient Protection and Affordable Care Act (ACA) have greatly reduced some financial barriers to cancer screenings, cost remains a major factor. Colonoscopy screenings are essential for addressing colorectal cancer; however, there can be gaps



**THE HONORABLE**  
**Mark Pocan**  
US Representative for  
Wisconsin's 2nd District,  
Chair of the Congressional  
Equality Caucus



“The LGBTQI+ community experiences ongoing issues in healthcare, including discrimination, inadequate insurance, and refusals of care, ultimately resulting in far worse health outcomes. In addition, our community faces significant barriers to accessing essential preventive care and cancer treatments, which worsens cancer disparities. Congress must prioritize funding for research to understand and improve LGBTQI+ health outcomes and advance legislation to address challenges throughout the spectrum of cancer care, including by explicitly prohibiting discrimination against LGBTQI+ people. Ultimately, prioritizing equitable cancer treatments is necessary to both improve people's health and create a more just and inclusive healthcare system for all.”

in what insurance covers. While stool-based tests can be fully covered under insurance, subsequent colonoscopies can be subject to a deductible or copay, as they are no longer considered preventive (1051). One way to address this financial barrier to care is to support bills like The Colorectal Cancer Payment Fairness Act (H.R.3382), introduced by Representative Donald Payne, Jr. (1052). This bill would eliminate the coinsurance requirement for diagnostic colorectal cancer screening tests under the Medicare program (1053). Black individuals have a 20 percent higher chance of getting colorectal cancer and colorectal cancer is the second leading cancer death in AI/AN communities (1054), so enacting policies like H.R.3382 is a step towards addressing these disparities.

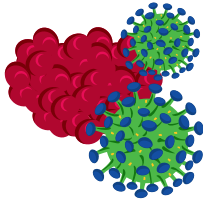
Many societal factors have resulted in mass incarceration that disproportionately affects racial and ethnic minority groups (1055). There is a lack of data on whether incarcerated individuals receive cancer screenings when needed (1056). Incarcerated individuals also face numerous elevated cancer risk factors, including higher infection rates with HPV (1057), hepatitis B and C viruses, and HIV (1058). Lack of screening for incarcerated individuals also leads to diagnoses at later stages, which can be more difficult to treat.

Community outreach and engagement are crucial to understand the needs of the local community, navigate the health care system, build trust in research, and ultimately address disparities. Funding for short-term housing near cancer treatment centers, transportation assistance, flexible appointment hours, and Medicaid expansion are potential

solutions to address these difficulties. In addition, supporting community health workers in the Latin community, sometimes referred to as “promotoras de salud,” addresses the need for culturally competent support systems and can be essential in establishing trust with their community (1059). These challenges and opportunities will require complex and unified efforts by providers, policymakers, and communities, but are essential to dismantle health care disparities.

### HIV AND CANCER

- **Anti-retroviral therapy** (ART) is helping people living with HIV (PLWH) live longer and healthier lives.
- HIV can still **cause the immune system to weaken**, increasing the risk of cancer.
- **PLWH have increased mortality** for several cancer types.
- **Stigmas** around HIV might **prevent PLWH from seeking necessary screenings** essential for their health.



Further research as well as collaboration between oncologists and HIV specialists is needed to address any potential changes to ART, discuss additional medicines needed during treatment, and increase the overall chance of survival.

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## Policies to Address Disparities in Screening and Surveillance for Hereditary Cancer Syndromes

Early diagnosis of hereditary cancer syndromes is critical to reducing cancer risk (1060). There are over 50 known hereditary cancer syndromes, but prevention testing remains underutilized due to cost, geographic location, and lack of awareness (1061). To improve the availability and use of testing, many research projects, tools and initiatives have been developed to identify and improve care for individuals and families with hereditary cancer syndromes. For example, genetic testing using next-generation sequencing technologies (e.g., companion diagnostics) to detect hereditary cancer syndromes is increasing in clinical settings. Many sponsor companies are developing cancer therapies in conjunction with companion diagnostics to identify individuals who are most likely to receive benefit from treatment and improve survival outcomes (1062). To support early detection and treatment of hereditary cancer syndromes, it is critical to increase the accessibility of diagnostic testing for individuals and families at high-risk for cancer.

### MYLYNCH: AN ELECTRONIC CLINICAL DECISION SUPPORT TOOL FOR LYNCH SYNDROME

MyLynch is a **patient-facing clinical decision support web application** that applies genetically guided personalized medicine for individuals with Lynch syndrome. This tool **informs patients of their personal cancer risks, educates on relevant interventions, and provides adjusted risk estimates**, depending on the interventions chosen (1063).



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## Policies to Address Disparities in Clinical Research and Care

### Diversifying Representation in Clinical Trials by Addressing Barriers in Trial Design

There is growing awareness that diversity in cancer clinical trials is key to assessing differential efficacy of molecularly targeted therapeutics in various populations and maximizing the generalizability of treatment outcomes (1064). Despite stakeholder efforts to improve representation in cancer research, clinical studies do not reflect the racial and ethnic diversity of the US population. While the barriers to improve diverse representation in cancer research are complex, many can be addressed at the trial level (628). FDA has published several guidance documents to improve clinical trial diversity during study design that address various topics including measures that increase diversity in clinical trials; post-marketing approaches to obtain safety and efficacy data for historically underrepresented populations; the modernization of eligibility criteria when scientifically appropriate; and the collection and analysis of racial and ethnic data. In January 2024, the agency issued guidance that outlines a standardized approach for collecting and reporting on race and ethnicity data in clinical trials (1065). In the guidance, FDA recommends:

- study sponsors use a two-question format that asks for information about ethnicity before asking about race;
- avoiding the term “non-White” when collecting information on race and ethnicity;
- including more detailed race and ethnicity information for trials outside of the United States where these categories may not adequately describe racial and ethnic groups in other countries; and
- providing study participants with the opportunity to self-report their race and ethnicity.



The Food and Drug Omnibus Reform Act (FDORA) was signed into law in December 2022 and outlines the need for greater diversity in clinical trials and authorizes the use of diversity action plans. Legislation within FDORA requires FDA to issue draft guidance for clinical study sponsors to develop a Race and Ethnicity Diversity Plan, which was published in April 2022. In addition to race and ethnicity, the plan recommends inclusion of other underrepresented populations based on sex, gender, age, socioeconomic status, disability, pregnancy and lactation status, and comorbidities. When designing clinical studies, the plan should include:

- a community engagement and patient outreach strategy;
- enrollment goals for diverse participation and the rationale for selecting those goals;
- the plan of action to enroll and retain diverse participants; and
- the status of meeting enrollment goals throughout the duration of the study.

FDA's continuous efforts along with guidance documents and enactment of the DEPICT Act (H.R. 6584) in 2022 underscore the urgent need to improve the representativeness in clinical studies, but more is needed to holistically design equitable trials (1066,1067). Increasing diversity in genomic trials for targeted and immunotherapies, integrating the patient's voice in the study protocol, and establishing meaningful community partnerships will achieve long-lasting progress in addressing cancer disparities (1068).

#### NIH CLINICAL TRIAL DIVERSITY ACT OF 2023

NIH Clinical Trials Diversity Act of 2023 (H.R. 3503) aims to enhance the inclusion of women, racially and ethnically diverse individuals and people of all ages in all NIH-funded trials (1069).



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### Diversifying Representation in Clinical Trials by Addressing Barriers for Patients

There are many challenges to recruit and retain diverse volunteers to participate in cancer clinical studies. Many factors impede clinical study participation, including access, awareness, fear and distrust, which disproportionately impact certain groups depending on age, race/ethnicity, gender, geographic location, disease burden, and socioeconomic status (607). These multidimensional barriers affect an individual's capacity to participate in clinical studies.

Limited access to clinical research and health care is a major barrier to recruit and retain a diverse set of study participants, which can be attributed to lack of transportation, caregiver burden, employment, and financial constraints (607). Furthermore, clinical research sites are often located in areas that are far from potential participants, particularly in rural communities (601). The Improving Access to Health Care in Rural and Underserved Areas Act (H.R. 7383) introduced in 2022 calls for increased funding to expand access to care in rural communities by establishing a 5-year pilot program that increases capacity through enhanced training and clinical support for primary care providers. Focused structural solutions including decentralization of clinical studies, reimbursing for costs associated with trial participation, and extending clinic hours are needed to increase the availability and accessibility of cancer clinical trials (1070).

Lack of awareness and knowledge of clinical studies limits participation in cancer studies. Most study participants learn about clinical trials through their primary care provider, but research has shown that many underrepresented groups do not have a routine source of care (1071) due to disproportionately fewer primary care clinics within racial and ethnic communities (1072). Communities historically underrepresented in clinical trials may benefit from tailored educational campaigns to increase their awareness of clinical trials and encourage informed decision-making, which can include culturally adapted materials and engaging informational videos (180). FDA's Enhance Equity Initiative and Project Community encourage increased communication between underserved populations and health care professionals to foster understanding, reduce cancer risk, and increase survival (1073).

#### HEALTH DISPARITIES IN INDIGENOUS COMMUNITIES

Laws enacted since 2021 such as the Bipartisan Infrastructure Law are seeking to address Indigenous health disparities by increasing access to high-speed broadband Internet in Native American communities (1074).



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Effective and intentional recruitment strategies are crucial to improve representation in clinical studies. Additional legislation to implement solutions that address patient barriers is needed to improve equitable clinical trial enrollment. Only through a coalition of patients, community stakeholders, academia, policymakers, industry, and nonprofit organizations can there be indelible progress to build a clinical trial ecosystem that represents real-world patients.

## Improving Access to High-quality Cancer Care

Proper insurance coverage is vital to accessing high-quality cancer care. Over the past 15 years, the United States has made enormous strides in expanding insurance coverage. Following enactment of the ACA in 2009, the uninsured rate has declined from 17.8 percent in 2010 to 9.6 percent in 2022. This historic expansion in coverage was made possible by the creation of state-based and federal insurance marketplaces that offered new competitive markets for consumers to shop for commercial insurance plans, as well as incentives that have expanded Medicaid coverage to 41 states and the District of Columbia. Medicaid expansion has been especially crucial in addressing health disparities, as Medicaid remains a major source of coverage for patients from racial and ethnic minority groups. In Medicaid expansion states, rates of insured individuals have increased among Black, Hispanic, and rural populations compared to their counterparts in non-expansion states. Furthermore, Medicaid expansion has been connected to earlier diagnoses, more prompt treatment, and a higher number of treatment options for patients with cancer (1075). The Biden administration has also taken steps to roll back guidelines on work requirements in Medicaid, which has the potential to reserve coverage losses in states that initially implemented work requirements. Known for their complex administration and documentation requirements, Medicaid work requirements disproportionately impact racial and ethnic minorities. However, efforts remain underway to pursue work requirements in several states like Idaho, Louisiana, and South Dakota.

Despite historic gains in coverage through ACA marketplaces and Medicaid expansion, coverage challenges remain, particularly for vulnerable communities. For many Americans with low-quality insurance coverage, high premiums and high out-of-pocket costs make health care services unaffordable. According to the Commonwealth Fund Biennial Health Insurance Survey, 46 percent of respondents reportedly delayed or skipped care due to high costs (1076). Geographic disparities on forgone care are particularly prevalent. A 2023 study found one in four rural cancer survivors in seven Appalachian counties in North Carolina reported delayed or missed medical treatment due to high cost, with rates nearing 50 percent among survivors aged greater than 65 years (1077). This trend is especially concerning given the strong link between delayed cancer treatment and higher mortality rates (1078).

The resumption of the Medicaid redetermination process also threatens to exacerbate existing health disparities. Initially paused due to the COVID-19 pandemic, Medicaid determination refers to the process by which state Medicaid offices determine whether current Medicaid enrollees are still eligible for coverage (1079). However, over seven million people have lost Medicaid coverage since states began to resume redeterminations in April 2023 (1080). Many of these coverage losses were due to procedural reasons (1081), which prompted the Biden administration to pause Medicaid redetermination in

30 states (1082) and subsequently issue new flexibilities for state Medicaid offices to limit coverage losses (1083).

Special types of health care facilities such as safety net hospitals are also vital to providing members of underserved communities access to cancer care, particularly residents of low-income and rural communities. Safety net hospitals are disproportionately more likely to face financial challenges due to the fact that their patients are more likely to be enrolled in Medicare or Medicaid, which have lower reimbursement than commercial insurance plans. Furthermore, safety net hospitals have higher levels of uncompensated care (1084), which refers to care for which a provider receives no payment from a patient or insurer (1085). These financial challenges are the primary reason why nearly 70 rural hospitals have closed between 2018 and 2023. Additionally, the combination of a higher proportion of uninsured or underinsured patients means safety net hospitals experience lower quality of care measures (1086). Fortunately, higher levels of government assistance and guidance can help ensure that safety net hospitals have sufficient resources and tools to provide better cancer care to underserved communities. Specific policies that could provide more sufficient levels of support for safety net hospitals include increasing Medicaid reimbursement rates for hospitals with a higher proportion of Medicaid and uninsured patients and tying rate increases to quality metrics to incentivize higher-quality care.

Another challenge for safety net hospitals in rural areas is a shortage of health care practitioners. Despite being home to one-fifth of the US population, rural hospitals only contain 10 percent of the nation's physicians (1087). For physician specialties involved in cancer treatment, shortages are particularly acute in rural areas. Since 2012, the proportion of radiation oncologists in rural areas declined from 16 to 13 percent due to a combination of rural physicians leaving the workforce and fewer new physicians opting to practice in rural areas (1088). Additionally, less than 24 percent of hematology and medical oncology practices have sites in rural areas (1089). Workforce shortages have long plagued rural areas due to the difficulty of recruiting clinicians.

Since physicians who train in rural areas are more likely to practice in rural areas (1090), one way to address the workforce shortage is to increase the number of Medicare-funded residency slots, thereby creating more slots that can be directed to rural hospitals (982). Additionally, expansion of a visa waiver program that requires foreign physicians to practice in medically underserved communities shows great promise in addressing rural health care workforce shortages (1091). Another solution is to utilize telehealth services to connect rural patients with specialists located in urban or suburban areas (1092). To boost telehealth utilization in rural areas, lawmakers should consider policies that would increase access to high-speed broadband Internet (see **Advocacy for Universal Access to High-speed Broadband Internet**, p. 166).



### THE HONORABLE Joaquin Castro

US Representative for Texas'  
20th District



“As a legislator, I’ve always been supportive of fighting cancer, but the idea of getting cancer hadn’t crossed my mind much until a surprise diagnosis in the summer of 2022. I’m lucky to have good insurance, but millions of uninsured Americans can’t afford the basics of cancer treatment. In my state of Texas, cancer is the leading cause of death among Latinos, many of whom don’t get screened until it’s too late. America is a rich country—and watching our people go bankrupt, suffer, or die because of the cost of care should be unconscionable. I’m hopeful for President Joe Biden’s Cancer Moonshot and all the promising research that is taking place, and I’ll keep pushing for universal health care so everyone can get the cancer care they need.”

## Sustainably Supporting Patient Navigators and Community Health Workers

Patient navigation is a strategy to address disparities in cancer detection, treatment, and outcomes in underrepresented populations (1093). Patient navigators and community health workers can assist in alleviating the socioeconomic and structural barriers to clinical trial participation as discussed throughout this report. Since the first patient navigation program in the United States was created in 1990, many organizations have recognized the unique role of patient navigators and community health workers across the cancer care continuum (1093,1094). These programs have historically been supported by grants, but financial compensation continues to challenge their sustainability (1095). In 2023, the Center for Medicare and Medicaid Services (CMS) finalized a rule to offer reimbursement for oncology patient navigation in its

### INVESTMENTS IN COMMUNITY HEALTH WORKER INITIATIVES

To meet the needs of medically underserved populations, President Biden signed into law the **Consolidated Appropriations Act of 2023** that authorizes \$50 million annually **to build Community Health Workers workforce** capacity from FY 2023 through FY 2027 (1096).



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Calendar Year 2024 Medicare Physician Fee Schedule (1095). This means that certified patient navigators can now be directly reimbursed for services provided to patients. Continued investment in patient navigators and community health workers from the federal government is essential to reduce many logistical barriers that impact the provision of high-quality, patient-centered care for historically marginalized populations.

## Advocacy for Universal Access to High-speed Broadband Internet

The COVID-19 pandemic necessitated the use of telemedicine in many facets of health care, including cancer care. Patient access to high-speed broadband Internet is essential to telehealth utilization (1097), which has become significantly more prevalent in cancer care since the start of 2020 (1098). Examples of telemedicine in oncologic care and clinical trials include remote monitoring devices such as wearable technology and video conferencing.

Unfortunately, significant disparities exist along racial, ethnic, socioeconomic, and geographic lines in accessing broadband Internet. Low-income areas are less likely to have reliable broadband access than high-income areas. When controlling for income, broadband access in majority Black and Hispanic neighborhoods is lower than in majority White or Asian neighborhoods (1099). Furthermore, rural residents are nearly 9 percent less likely to have broadband access than their urban and suburban counterparts.

Disparities in access to broadband represent a major technological barrier to cancer care and clinical trials that increasingly utilize telemedicine (1100). This barrier threatens to exacerbate existing health disparities since underutilization of telemedicine is associated with higher mortality rates in oncologic care (1101). With most cancer patients expressing their comfort with using telehealth in oncologic care (1102), those without access to high-speed Internet risk receiving delayed or suboptimal cancer care.

To ensure all communities can benefit from cancer clinical trials in the new era of increased telehealth use, it is paramount to advocate for policies that will provide universal access to high-speed broadband Internet. Successful policy proposals must target the underlying issues behind limited access to broadband Internet, including a lack of infrastructure in low-density communities and a lack of competition among Internet service providers that result in higher prices for consumers (1103).

In recent years, Congress and the Biden administration have increased access to broadband Internet. Both the American Rescue Plan Act and the Infrastructure Investment and Jobs Act provide \$25 billion and \$65 billion, respectively, to expand broadband infrastructure and provide financial

assistance for certain underserved households (1104). To help further efforts to achieve universal broadband, some bipartisan legislative proposals in the 118th Congress would boost investments in programs that subsidize broadband costs for rural Americans (1105) and ensure that grants awarded to improve broadband infrastructure are not subject to taxation (1106). These proposals to grow broadband infrastructure and assist underserved households with paying for the high cost of high-speed Internet have the potential to allow more patients with cancer from various communities and backgrounds to participate in an increasingly telehealth-driven oncologic care and clinical trial environment.

## Coordination of Health Disparities Research and Programs Within the Federal Government

As described throughout this report, cancer disparities are caused by many intersecting social, economic, and environmental factors. There are several initiatives within the federal government that support multilayered interventions to reduce health disparities in cancer care (see **Sidebar 48**, p. 167 and **Understanding and Addressing Drivers of Cancer Disparities**, p. 36). To address the unequal burden of cancer and dismantle centuries of health care inequities, continued and deliberate investment in research and programs across all branches of government will be vital.

### SIDEBAR 48

## Broader Support Across Federal Agencies to Promote Health Equity

### The Center for Medicare and Medicaid Innovation

released the Enhancing Oncology Model, which outlines health equity strategies that require participating oncology practices to screen for health-related social needs and introduces data reports on expenditure and utilization patterns of each participant's patient population to help identify and address health disparities. The model performance period began in July 2023 and will end in June 2028 (1107).



**The Office of Minority Health** released the 2022–2032 CMS Framework for Health Equity, which includes five priorities related to expanding the collecting, reporting, and analysis of standardized data on demographics and social drivers of health: assessing the causes of disparities within CMS programs and addressing inequities in policies and operations; building capacity of health care organizations and the workforce to reduce disparities; advancing language access, health literacy, and the provision of culturally tailored services; and increasing all forms of accessibility to health services and coverage (1108).



# Conclusion

Over the last decade, the field of cancer disparities research has grown exponentially. The American Association for Cancer Research® (AACR) launched the *AACR Cancer Disparities Progress Report* to Congress and the American public in 2020 with the overarching goal of increasing awareness of cancer disparities and emphasizing the vital importance of cancer disparities research to saving lives. This third edition of the biennial report captures the progress that has been made to understanding and addressing cancer disparities and highlights the areas that need more work to achieve health equity.

As comprehensively covered in the report, the increased focus on the science of cancer disparities is helping to bridge gaps in our knowledge of the causes of cancer disparities. We are also gleaning better insights into the burden of cancer in various US population groups who experience cancer disparities. Evidence presented in the report paints a complex picture of factors that drive cancer disparities and underscores how multipronged approaches are vital to address cancer disparities.

It is abundantly clear that racism, discrimination, and injustices perpetuated against marginalized US population groups over centuries are key causes of cancer disparities. Dismantling of systemic and societal inequities is essential to ensure that everyone has equitable opportunities for upward economic mobility, regardless of race, ethnicity, sexual orientations, gender identities, geographic location, and/or socioeconomic statuses. As the world's first and largest organization focused on preventing and curing all cancers and whose core values include diversity, equity, and inclusion, AACR stands in solidarity with the medical research community in the fight against racism, privilege, and discrimination in all aspects of life.

It is also clear that equitable access to quality health care can help mitigate many of the disparities that exist across the cancer care continuum. The report also identifies evidence-based interventions that incorporate culturally sensitive community engagement and patient navigation as some of the most effective approaches to addressing cancer disparities. Strategies that improve communications and build trust between patients and providers are additional ways that are proving helpful in reducing cancer disparities. Finally, a key takeaway from the report is that documenting comprehensive sociodemographic data as well as disaggregated health records is essential to fully capturing the extent of cancer disparities in various US population groups.

Based on the evidence presented, and as underscored by cancer survivors from all walks of life who shared their experiences for the report, continued transformative research and increased collaborations across the medical research community are key strategies for addressing cancer disparities. To this end, the AACR Call to Action lays out a comprehensive framework and offers the organization's unequivocal support to our policymakers to develop policies that maintain a sharp focus on prioritizing cancer disparities research. Much of the progress made against cancer disparities has stemmed from the steadfast and bipartisan support from Congress. By continuing to provide robust, predictable and sustainable funding for innovative cancer disparities research, Congress can ensure that we achieve the bold vision of health equity.

# AACR Call to Action

Economic inequities, social injustices, and systemic barriers continue to adversely affect all facets of cancer research and patient care leading to a disproportionate burden of cancer for many US population groups. These disparities are driven by exposure to environmental carcinogens, limited access to health care and clinical trials, policies that exacerbate modifiable risk factors such as smoking and lack of access to healthy food, and impediments to the development of a research and health care workforce that is broadly representative of our society. Many programs and initiatives, both public and private, have been undertaken to address these challenges, but additional efforts and investments are urgently needed.

To make further progress in reducing cancer disparities, federal agencies and Congress must continue to play a central role in setting policies and making key investments to achieve health equity.

## **Because of the overlapping and intersecting causes of cancer disparities, concerted efforts in many areas of policy are needed, including:**

- Increasing federal funding for medical research and public health initiatives designed to reduce cancer disparities.
- Increasing federal investments in STEMM education programs to create pathways for students from diverse backgrounds to be part of an inclusive research and health care workforce.
- Improving the collection of disaggregated cancer-related data for all racial, ethnic, and sexual and gender minority groups.
- Continuing efforts to ensure diverse representation in basic and translational research studies and oncology clinical trials, including support for community partnerships.
- Expanding cancer prevention and screening efforts, such as addressing environmental exposures (including those related to the climate crisis), obesity, unhealthy diets, physical inactivity, tobacco use, and suboptimal uptake of vaccines.
- Broadening access to equitable and affordable quality health care, including access to telehealth for underserved populations in rural areas.

## **To make further progress on all these fronts, AACR recommends the following actions:**

### **1 Provide robust, sustained, and predictable funding increases for the US federal agencies and programs that are tasked with reducing cancer disparities.**

- Congress should appropriate at least \$51.3 billion for NIH in fiscal year 2025 to continue progress in medical research and expand initiatives across NIH and the extramural research community to study health disparities and help achieve health equity.
- Congress should provide higher appropriations for the National Institute on Minority Health and Health Disparities (NIMHD) to continue its pioneering scientific work on these issues and coordinate health disparities research across NIH.
- Congress should appropriate at least \$7.9 billion for NCI in fiscal year 2025—including funding for the NCI Center to Reduce Cancer Health Disparities (CRCHD), the NCI Community Oncology Research Program (NCORP), and other NCI and cross-NIH programs studying cancer disparities to expand research on cancer disparities, create an inclusive cancer workforce, and implement new prevention, screening, and health care access strategies.

### **2 Support data collection initiatives to reduce cancer disparities.**

- Data collection efforts through federal programs should include detailed demographic information, including sexual orientation and gender identity data to better elucidate the burden of cancer on specific populations, and the intersection of cancer burden with other health inequities.
- NIH should fund large multi-ethnic prospective studies with biorepositories as resources for exploring current and future research questions related to cancer disparities.
- NCI should expand cancer center partnerships to enhance collaboration with underserved communities, including with US Native populations, Native Hawaiians, and Alaska Natives.

### 3 Increase access and participation in clinical trials.

- NCI should expand the NCI Connecting Underrepresented Populations to Clinical Trials (CUSP2CT) program to address lack of participation and diversity in cancer clinical trials.
- FDA should fully implement the Clinical Trial Diversity and Modernization provisions of the Food and Drug Omnibus Reform Act (FDORA) of 2022, including requiring trial sponsors to utilize diversity action plans.
- FDA should continue to work with the biopharmaceutical industry to expand participation in clinical trials, including through decentralized clinical trials and expansion of eligibility criteria when scientifically appropriate.

### 4 Prioritize cancer control initiatives and increase screening for early detection and prevention.

- Congress should appropriate \$472.4 million for the CDC Division of Cancer Prevention and Control and provide resources to enable CDC's CORE Health Equity Science and Intervention Strategy.
- Congress should robustly support EPA Cancer Moonshot Activities, including the Office of Environmental Justice and External Civil Rights (OEJECR).
- Congress should provide increased funding for federal programs such as the Alcee Hastings Program for Advanced Cancer Screening in Underserved Communities, which aims to close disparity gaps in cancer screening by reaching individuals in geographically remote, rural, and underserved communities through community partnerships and patient navigators.
- FDA should finalize the Tobacco Product Standard for Menthol in Cigarettes and the Tobacco Product Standard for Characterizing Flavors in Cigars, thereby banning menthol in cigarettes and characterizing flavors in cigars.

### 5 Implement policies to ensure equitable patient care.

- States should expand Medicaid to improve health care access among lower income communities, reduce financial burdens on patients, and ensure coverage for necessary medical tests and follow-up care.

- Through federal legislation or regulatory action, Congress and the federal government should ensure that Medicaid and private insurance comprehensively cover tobacco cessation services.
- Congress should appropriate additional funds for HHS programs to expand and diversify the community health care workforce to guide patients with cancer from diagnosis through treatment and survivorship, improve patient satisfaction, and reduce disparities in cancer outcomes.
- Congress should increase appropriations for the Indian Health Service, which provides critical health care services to millions of American Indian and Alaska Native individuals.

### 6 Reduce cancer disparities by building a more diverse and inclusive cancer research and care workforce.

- NIH should continue the UNITE initiative in its efforts to address structural racism at NIH and in the broader medical research community.
- Congress should fully fund the education and training programs of the CHIPS and Science Act to create more pathways for underrepresented groups to pursue STEM careers.
- NCI should continue key initiatives within the NCI CRCHD that support pathways into the cancer research workforce, including the following programs: Continuing Umbrella of Research Experiences (CURE), the Administrative Supplement to Promote Diversity, F32 National Research Service Awards and Fellowships, R21 Exploratory Grant Awards to Promote Workforce Diversity in Basic Cancer Research, R01 Cancer Moonshot Scholars, and the Transformative Educational Advancement and Mentoring (TEAM) Network.

### 7 Enact comprehensive legislation to eliminate health inequities.

We also strongly support recent Congressional efforts to enact comprehensive legislation to help eliminate systemic health inequities, such as the Health Equity and Accountability Act (HEAA), which addresses several crucial areas. Here are some of the priorities from the HEAA Act.

- Expansion of Medicaid and the coverage of comprehensive tobacco cessation services.

- Establishment of rural health programs, including a rural community hospital program to expand federal payments for healthcare services in rural areas.
- Additional support to Historically Black Colleges and Universities and other Minority Serving Institutions to train a diverse and inclusive health care workforce.
- Investments in health IT infrastructure for underserved communities.
- New programs to address cancers that disproportionately affect minority communities and marginalized groups.

It is clear that while some progress has been made in reducing cancer disparities, there is much more work to be done to eliminate the health inequities. Fulfilling the aims of this Call to Action will require not only the commitment from the public sector, but also partnerships with many other stakeholders, including the biopharmaceutical industry, academic and medical institutions, patient-centric organizations, community-based organizations, and professional organizations, to achieve the vision health equity. These collaborations must be integrated with other efforts across our society to address the broader challenges of overcoming economic inequities, dismantling structural barriers, and rectifying social injustices to ensure the health and well-being of all patient populations.



# AACR Initiatives Reducing Cancer Disparities and Promoting Health Equity

As an organization whose core values include diversity, equity, and inclusion, the American Association for Cancer Research® (AACR) is deeply committed to achieving the bold vision of cancer health equity for all. Through a wide range of programs and initiatives, AACR fosters cancer health equity and advances its mission to prevent and cure all cancers—for all patients.



## **AACR CANCER CENTERS ALLIANCE**

In 2022, AACR formed the AACR Cancer Centers Alliance, a collaborative initiative with US cancer centers. A major goal of the Alliance is to create new and inclusive opportunities for the next generation of cancer researchers and clinicians and create a workforce that is reflective of the diverse communities that the cancer centers serve.



## **AACR CANCER DISPARITIES PROGRESS REPORT**

Currently on its third edition, this pioneer AACR report focuses on the science of and progress against cancer disparities. It is central to AACR's educational efforts to increase public understanding of cancer disparities, and highlights the vital importance of cancer disparities research in achieving the bold vision of health equity.



## **AACR CONFERENCE ON THE SCIENCE OF CANCER HEALTH DISPARITIES IN RACIAL/ETHNIC MINORITIES AND THE MEDICALLY UNDERSERVED**

Launched in 2007, this trailblazing AACR conference has established and expanded the critical field of cancer disparities. The 16th edition of the conference, held in Orlando in September 2023, convened more than 750 scientists, clinicians, health care professionals, cancer survivors, and patient advocates to share the latest cutting-edge research on cancer disparities.



## **AACR CLINICAL ONCOLOGY RESEARCH (CORE) TRAINING FELLOWSHIPS**

These fellowships provide \$100,000 over one year for clinical research fellows to work onsite at the facility of our industry partner, Johnson & Johnson. Applicants must be female or belong to an underrepresented group per NIH guidelines.



## **AACR DISTINGUISHED LECTURESHIP ON THE SCIENCE OF CANCER HEALTH DISPARITIES**

Since 2010, this AACR award has elevated the field of disparities research by honoring an investigator whose novel and significant work has had or may have a far-reaching impact on the etiology, detection, diagnosis, treatment, or prevention of cancer disparities.



## **AACR MINORITIES IN CANCER RESEARCH (MICR)**

MICR is a membership group within AACR that is committed to meeting the professional needs and advancing the careers of minority scientists by increasing the number, participation, visibility, and recognition of minority scientists in cancer research.

**AACR MINORITY SCHOLAR AWARD or a MINORITY-SERVING INSTITUTION FACULTY SCHOLAR IN CANCER RESEARCH AWARD**

With the generous support of the NCI Center to Reduce Cancer Health Disparities, AACR offers grants to enable full-time minority faculty members and faculty members of Minority-Serving Institutions to participate in the AACR Annual Meeting. For more than 25 years, the program has provided the education and training that are critical to sustaining a diverse pipeline of cancer scientists.

**AACR PROJECT GENIE®**

AACR Project GENIE® is an open-source, international, pancancer registry of real-world data assembled through data sharing between a cohort of leading international cancer centers. The registry leverages clinical sequencing efforts at participating cancer centers by pooling their data to create a collective evidence base.

**AACR WOMEN IN CANCER RESEARCH (WICR)**

WICR is a membership group within AACR that is committed to recognizing women's scientific achievements and fostering their career development and advancement in cancer research. The WICR Council acts as an advisory body to AACR leadership on issues of concern to women investigators.

**FUNDING MERITORIOUS UNDERREPRESENTED INVESTIGATORS**

The AACR Grants Program funds meritorious scientists from diverse backgrounds that are underrepresented in the cancer research community—including women, individuals working in low- and middle-income countries, and members of racial or ethnic minority groups.

**LUSTGARTEN FOUNDATION-AACR CAREER DEVELOPMENT AWARDS FOR PANCREATIC CANCER RESEARCH In Honor of Ruth Bader Ginsburg and John Robert Lewis**

Female and ethnic or racial minorities who are underrepresented in biomedical research and are early-career investigators at institutions worldwide are invited to apply for these three-year, \$300,000 grants.

**ROBERT A. WINN DIVERSITY IN CLINICAL TRIALS AWARD PROGRAM**

Established in 2021, the Robert A. Winn Diversity in Clinical Trials Award Program is implemented by AACR and Virginia Commonwealth University and funded by the Bristol Myers Squibb Foundation to train 250 community-oriented clinical trial investigators by 2025.

## AACR-funded Young Research Scientists Addressing Cancer Disparities

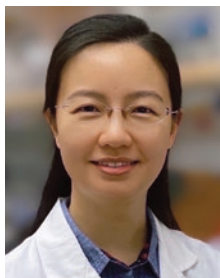


### 2022 AACR-MERCK CANCER DISPARITIES RESEARCH FELLOWSHIP

#### Roy Xiao, MD, MS

Resident Physician and Clinical Research Fellow  
Harvard Medical School • Boston, Massachusetts

My research studies financial toxicity in medically underserved populations that results from less than transparent treatment pricing at hospitals. Understanding how to not only better control healthcare costs but also financially inform patients can help empower them as they make decisions regarding their health. Our underserved patients are not only less privileged but also oftentimes the sickest populations, and I believe it is important to support them not only with high-quality care, but also in an informed and financially sustainable fashion. I hope everyone, whether underrepresented or not, can picture themselves pursuing and achieving important work to advance the care of our cancer patients, and I hope that seeing the work that we've been able to achieve can help inspire future researchers to continue to pursue their passions.



### 2022 AACR-MERCK CANCER DISPARITIES RESEARCH FELLOWSHIP

#### Yuanyuan Fu, PhD

Postdoctoral Fellow  
University of Hawai'i • Honolulu, Hawai'i

My research identifies differences in gene expression profiles between Native Hawaiian and White colorectal tumors, which can help identify population-specific genetic variations between these two groups. This research helps resolve one of the most critical and pressing issues in disparities research, which is the lack of diverse genomic data. The underrepresentation of genetic samples from diverse populations has led to a gap in our understanding of how genetic factors influence health and disease. This type of research can fuel innovation in healthcare by uncovering new insights into the intersection of genetics, environment, and social determinants of health and advance personalized medicine to tailor healthcare to meet the unique needs of diverse populations. I call on our lawmakers and Congress to make health equity research a national priority—reducing health disparities is not just a healthcare issue, but a fundamental aspect of social justice and equity. Health disparities undermine our national values of fairness and equality. By investing in disparities research, we are committing to a healthier, more equitable future for all citizens.



### 2021 AACR-GENENTECH CANCER DISPARITIES RESEARCH FELLOWSHIP

#### Francisco Cartujano, MD

Research Assistant Professor  
University of Rochester Medical Center • Rochester, New York

I assessed the feasibility and acceptability of Activatexto, a mobile intervention that promotes smoking cessation and physical activity among Latino adults. This intervention led to a 70 percent cessation rate and increased levels of moderate to vigorous physical activity among enrolled patients. This award is grounded in principles of community-based participatory research (CBPR). CBPR is a partnership approach that involves community members across all phases of research. Through this grant, I was able to continue working with an experienced, talented, and multidisciplinary community advisory board (CAB) to address smoking cessation and physical activity in the Latino community. The CAB has ensured that our research is appropriate, relevant, and meaningful to the Latino community. Additionally, as a Research Assistant Professor, mentoring and uplifting other underrepresented researchers is one of my personal and professional commitments. I am proud to say that the AACR-Genentech Cancer Disparities Research Fellowship has been a key element to the overall professional growth of other underrepresented individuals interested in pursuing a career in healthcare, helping them to continue their upward career trajectory in research and medicine.

# Glossary

**Biospecimen** A sample of material, such as urine, blood, tissue, cells, DNA, RNA, or protein, from humans, animals, or plants. Biospecimens may be used for a laboratory test or stored in a biorepository to be used for research.

**BRCA1/2 (Breast Cancer Resistance Genes 1 and 2)**

Genes that produce proteins that are involved in repairing damaged DNA. Females who inherit certain mutations in a *BRCA1* or *BRCA2* gene are at increased risk of developing breast cancer, ovarian cancer, and some other types of cancer. Males who inherit certain *BRCA1* or *BRCA2* mutations are at increased risk of developing breast cancer, prostate cancer, and some other types of cancer.

**Breast cancer** Cancer that forms in tissues of the breast. The most common type of breast cancer is ductal carcinoma, which begins in the lining of the milk ducts (thin tubes that carry milk from the lobules of the breast to the nipple). Another type of breast cancer is lobular carcinoma, which begins in the lobules (milk glands) of the breast. Invasive breast cancer is breast cancer that has spread from where it began in the breast ducts or lobules to surrounding normal tissue. Breast cancer occurs in both men and women, although male breast cancer is rare.

**Cancer** A term for diseases in which abnormal cells divide without control and can invade nearby tissues. Cancer cells can also spread to other parts of the body through the blood and lymph systems. There are several main types of cancer. Carcinomas begin in the skin or in tissues that line or cover internal organs. Sarcomas begin in bone, cartilage, fat, muscle, blood vessels, or other connective or supportive tissue. Leukemias arise in blood-forming tissue, such as the bone marrow, and cause large numbers of abnormal blood cells to be produced and enter the blood. Lymphomas and multiple myeloma originate in the cells of the immune system. Central nervous system cancers arise in the tissues of the brain and spinal cord. Also called malignancy.

**Carcinogen** Any substance that causes cancer.

**Center to Reduce Cancer Health Disparities (CRCHD)**

The center established by the National Cancer Institute (NCI) in 2001 to help reduce the unequal burden of cancer in the United States. One key goal of the CRCHD is to diversify the cancer research workforce by training students and investigators from diverse backgrounds.

**Centers for Disease Control and Prevention (CDC)**

A federal agency, within the US Public Health Service of the Department of Health and Human Services, whose mission is to protect public health by preventing and controlling disease, injury, and disability. The CDC promotes healthy behaviors and safe, healthy environments. It keeps track of health trends, tries to find the cause of health problems and outbreaks of disease, and responds to new public health threats.

**Cervical cancer** Cancer that arises in the cervix (the area where the uterus connects to the vagina). The two main types of cervical cancer are squamous cell carcinoma and adenocarcinoma. Most cervical cancers are caused by persistent infection with certain strains of human papillomavirus (HPV). Normal cells of the cervix do not suddenly become cancerous; they first gradually develop precancerous changes, then later turn into cancer. These changes can be detected by the Papanicolaou (Pap) test and treated to prevent the development of cancer.

**Chemotherapy** The use of drugs to kill or slow the growth of cancer cells.

**Chromosome** Structure within the nucleus of a cell that contains genetic information (DNA) and its associated proteins. Except for sperm and eggs, nearly all nondiseased human cells contain 46 chromosomes.

**Clinical trial** A type of research study that tests how well new medical approaches work in people. These studies test new methods for screening, preventing, diagnosing, or treating a disease. Also called clinical study.

**Colonoscopy** Examination of the inside of the colon using a colonoscope that is inserted into the rectum. A colonoscope is a thin, tube-like instrument with a light and a lens for viewing. It may also have a tool to remove tissue to be checked under a microscope for signs of disease.

**Colorectal cancer** Cancer that forms in the colon or the rectum. More than 95 percent of colorectal cancers are adenocarcinomas that arise in cells forming glands that make mucus to lubricate the inside of the colon and rectum. Before a colorectal cancer develops, a growth of tissue or tumor usually begins as a noncancerous polyp on the inner lining of the colon or rectum. Polyps can be found—for example, through colonoscopy—and removed before they turn into cancer.



**Computed tomography (CT)** A series of detailed pictures of areas inside the body taken from different angles. The pictures are created by a computer linked to an X-ray machine. Also called CAT scan, computerized axial tomography scan, and computerized tomography.

**Cytotoxic** An agent or substance that is toxic to living cells.

**Death rate/mortality rate** The number of deaths in a certain group of people in a certain period of time. Death rates may be reported for people who have a certain disease; who live in one area of the country; or who are of a certain gender, age, or ethnic group.

**Deoxyribonucleic acid (DNA)** The molecules inside cells that carry genetic information and pass it from one generation to the next. DNA is composed of bases designated A, T, C, and G.

**Discrimination** Actions, based on conscious or unconscious prejudice, which favor one group over others in the provision of goods, services, or opportunities. Structural and institutional factors can contribute to discriminatory behaviors including being implicitly biased against other social characteristics such as class, age, immigration status, gender identity and sexual orientation.

**Diversity** The full range of human similarities and differences in group affiliation including gender, race and ethnicity, social class, role within an organization, age, religion, sexual orientation, physical ability, and other group identities.

**EGFR (Epidermal Growth Factor Receptor)** A protein found on certain types of cells that binds to a substance called epidermal growth factor. The EGFR protein is involved in cell signaling pathways that control cell division and survival. Common mutations in this gene can lead to increased levels of protein and occur in several cancers such as non-small cell lung cancer; this results in increased cellular proliferation and survival.

**Epigenetic mark** A chemical modification of DNA and/or histones that can control the accessibility of genes. The collection of epigenetic marks across the entire genome is referred to as the epigenome.

**Epigenetics** The study of heritable changes in gene expression or cellular phenotype caused by mechanisms other than changes in DNA sequence. Examples of such changes might be DNA methylation or histone deacetylation, both of which serve to suppress gene expression without altering the sequence of the silenced genes.

**Financial toxicity** The financial challenges a patient faces as a result of the cost of medical care. These challenges can lead to debt, bankruptcy, lower quality of life, and reduced access to medical care.

**Five-year survival rate** The percentage of people in a specific group, for example, people diagnosed with a certain type of cancer or those who started a certain treatment, who are alive 5 years after they were diagnosed with or started treatment for a disease, such as cancer. The disease may or may not have come back.

**Follow-up care** Care given to a patient over time after finishing treatment for a disease. Follow-up care involves regular medical checkups, which may include a physical exam, blood tests, and imaging tests. Follow-up care checks for health problems that may occur months or years after treatment ends, including the development of other types of cancer. Follow-up care is given after positive screening test results, such as a positive Pap test result. In cancer patients, one purpose of follow-up care is checking to see if the cancer has come back or has spread to other parts of the body.

**Food and Drug Administration (FDA)** An agency in the US federal government whose mission is to protect public health by making sure that food, cosmetics, and nutritional supplements are safe to use and truthfully labeled. The FDA also makes sure that drugs, medical devices, and equipment are safe and effective, and that blood for transfusions and transplant tissue are safe.

**Gastric cancer** Cancer that arises in cells lining the stomach. Cancers starting in different sections of the stomach may cause different symptoms and often have different outcomes. Infection with the bacterium *Helicobacter pylori* is a major cause of gastric cancer, except for gastric cancers arising in the top portion of the stomach, called the cardia.

**Gene** The functional and physical unit of heredity passed from parent to offspring. Genes are pieces of DNA and most genes contain the information for making a specific protein.

**Genetic ancestry** A person's genetic line of ethnic descent. Examination of DNA variations can provide clues about a person's ethnicity because certain patterns of genetic variation are often shared among people of particular ethnic backgrounds.

**Health equity** When all people are given the chance to live as healthy a life as possible regardless of their race, ethnicity, sex, gender identity, sexual orientation, disability, education, job, religion, language, where they live, or other factors.

**Health-Related Quality of Life (HRQOL)** A multi-dimensional concept that includes domains related to physical, mental, emotional, and social functioning. It goes beyond direct measures of population health, life expectancy, and causes of death, and focuses on the impact health status has on quality of life.

**Hormones** A hormone, often referred to as a chemical messenger, is a chemical that is made in special tissues such as the endocrine gland, where it is released into the bloodstream to send a message to another part of the body. Hormones provide an internal communication system between cells located in distant parts of the body. Hormones can influence tumor development and growth.

**Human papillomavirus (HPV)** A type of virus that can cause abnormal tissue growth (e.g., warts) and other changes to cells. Infection for a long time with certain types of HPV can cause cervical cancer. HPV also plays a role in some other types of cancer, including anal, oropharyngeal, penile, vaginal, and vulvar cancers.

**Immune system** A diffuse, complex network of interacting cells, cell products, and cell-forming tissues that protects the body from invading microorganisms and other foreign substances, destroys infected and malignant cells, and removes cellular debris. The immune system includes the thymus, spleen, lymph nodes and lymph tissue, stem cells, white blood cells, antibodies, and lymphokines.

**Immunotherapy** Treatment designed to produce immunity to a disease or enhance the resistance of the immune system to an active disease process, such as cancer.

**Implicit bias** Also known as unconscious or hidden bias, implicit biases are negative associations that people unknowingly hold based on race, gender, sexual orientation, age, religion, and other characteristics. They are expressed without conscious awareness.

**Incidence rate** The number of new cases per population at risk in a given time period.

**Intersectionality** Intersectionality encompasses the complex, cumulative way in which the effects of multiple forms of discrimination (such as racism, sexism, and classism) combine, overlap, or intersect especially in the lived experiences of marginalized individuals or groups.

**Lymphatic vessels** The thin tubes that carry lymph and white blood cells. Lymphatic vessels branch and grow, like blood vessels, by a process called lymphangiogenesis into all the tissues of the body. Lymphatic vessels are an important part of the metastatic process.

**Lymphedema** Build-up of fluid in soft body tissues when the lymph system is damaged or blocked. Lymphedema occurs when lymph is not able to flow through the body the way that it should.

**Mammogram** An X-ray of the breast that is used to look for early signs of breast cancer.

**Medicaid** A health insurance program for people who cannot afford regular medical care. The program is run by US federal, state, and local governments. People who receive Medicaid may have to pay a small amount for the services they get.

**Medically underserved populations** Segments of the population that have little or no access to effective health care.

**Medicare** A US federal health insurance program for people aged 65 years or older and people with certain disabilities. Medicare pays for hospital stays, medical services, and some prescription drugs but people who receive Medicare must pay part of their health care costs.

**Metastasis** The spread of cancer from one part of the body to another. A tumor formed by cells that have spread is called a metastatic tumor or a metastasis. The metastatic tumor contains cells that are like those in the original (primary) tumor. The plural form of metastasis is metastases.

**Molecularly targeted therapy** A type of treatment that uses therapeutics to target specific molecules involved in the growth and spread of cancer cells.

**Morbidity** Refers to having a disease, a symptom of disease, the amount of disease within a population, or the medical problems caused by a treatment.

**Multiple myeloma** A type of cancer that begins in plasma cells (white blood cells that produce antibodies). Also called Kahler disease, myelomatosis, and plasma cell myeloma.

**Mutation** Any change in the DNA of a cell. Mutations may be caused by mistakes during cell proliferation or by exposure to DNA-damaging agents in the environment. Mutations can be harmful, beneficial, or have no effect. If they occur in cells that make eggs or sperm, they can be inherited; if mutations occur in other types of cells, they are not inherited. Certain mutations may lead to cancer or other diseases.

**National Cancer Institute (NCI)** The largest of the 27 institutes and centers of the National Institutes of Health. The NCI coordinates the National Cancer Program, which conducts and supports research, training, health information dissemination, and other programs with respect to the cause, diagnosis, prevention, and treatment of cancer; rehabilitation from cancer; and the continuing care of cancer patients and their families.

**National Institute of Minority Health and Health Disparities (NIMHD)** One of the 27 Institutes and Centers of the National Institutes of Health (NIH). NIMHD's mission is to lead scientific research to improve minority health and reduce health disparities and its work impacts millions across the US who are burdened by disparities in health status and health care delivery, including racial and ethnic minority groups, rural populations, populations with low socioeconomic status, and other population groups.

**National Institutes of Health (NIH)** The primary US federal agency for conducting and supporting medical research.

**Non-Small Cell Lung Cancer (NSCLC)** A group of lung cancers that are named for the kinds of cells found in the cancer and how the cells look under a microscope. The three main types of NSCLC are squamous cell carcinoma, large cell carcinoma, and adenocarcinoma. NSCLC is the most common kind of lung cancer.

**Oncology** The branch of medicine that focuses on cancer diagnosis and treatment.

**Palliative care** Care given to improve the quality of life and help reduce pain in people who have a serious or life-threatening disease, such as cancer. The goal of palliative care is to prevent or treat, as early as possible, the symptoms of the disease and the side effects caused by treatment of the disease. It also attends to the psychological, social, and spiritual problems caused by the disease or its treatment. For cancer, palliative care may include therapies, such as surgery, radiation therapy, or chemotherapy, to remove, shrink, or slow the growth of a tumor that is causing pain. It may also include family and caregiver support. Palliative care may be given with other treatments from the time of diagnosis until the end of life.

**Pathogen** A bacterium, virus, or other microorganism that can cause disease. Also referred to as an infectious agent.

**Patient advocate** A person who helps guide a patient through the health care system. This includes help going through the screening, diagnosis, treatment, and follow-up of a medical condition, such as cancer. A patient navigator helps patients communicate with their health care providers, set up appointments for doctor visits and medical tests, and get financial, legal, and social support. They may also work with insurance companies, employers, case managers, lawyers, and others who may have an effect on a patient's health care needs. Similar to a patient navigator.

**Patient navigator** See Patient Advocate.

**Persistent poverty areas** A persistent poverty county is defined as one in which 20 percent or more of its population has lived in poverty over the past 30 years.

**Physician-scientist** An individual who cares for patients and also works in a laboratory.

**Precision medicine** In oncology, precision medicine refers to the tailoring of treatments to the individual characteristics—in particular, the genetics—of patients and their cancer.

**Prostate cancer** Cancer that starts in tissues of the prostate (a gland in the male reproductive system found below the bladder and in front of the rectum). In men, it is the most frequently diagnosed cancer and the second most common cause of death from cancer.

**Prostate-Specific Antigen (PSA)** A protein secreted by the prostate gland, increased levels of which are found in the blood of patients with cancer of the prostate.

**Protein** A molecule made up of amino acids that is needed for the body to function properly.

**Radiation** Energy released in the form of particle or electromagnetic waves. Common sources of radiation include radon gas, cosmic rays from outer space, medical X-rays, and energy given off by a radioisotope (unstable form of a chemical element that releases radiation as it breaks down and becomes more stable).

**Radiotherapy** The use of high-energy radiation from X-rays, gamma rays, neutrons, protons, and other sources to kill cancer cells and shrink tumors.

**Ribonucleic Acid (RNA)** A copy of the DNA that contains the code for a protein.

**Rural and urban areas** The US Department of Agriculture categorizes rural and urban areas using the rural-urban commuting area codes, which classify US census tracts—small, relatively permanent statistical subdivisions of a county or statistically equivalent entity—using measures of population density, urbanization, and daily commuting.

**Social drivers of health** The social, economic, and physical conditions in the places where people are born and where they live, learn, work, play, and get older that can affect their health, well-being, and quality of life. Social drivers of health include factors such as education level, income, employment, housing, transportation, and access to healthy food, clean air and water, and health care services.

**Sociodemographic** Relating to, or involving a combination of social and demographic factors

**Socioeconomic status** A way of describing individuals or neighborhoods based on their education, income, housing and type of job, among other indicators.

**Standard of care** The intervention or interventions generally provided for a certain type of patient, illness, or clinical circumstance. The intervention is typically supported by evidence and/or expert consensus as providing the best outcomes for the given circumstance.

**Structural racism** A system of organizational and institutional policies created over time that support a continued unfair advantage for some people and unfair or harmful treatment of others based on their race or ethnic group. Structural racism comes from deep patterns of social, economic, and cultural differences that have developed over time between different groups of people. It affects the physical, social, and economic conditions of where people live, learn, work, and play.

**Survivorship** Health and well-being of a person with cancer from the time of diagnosis until the end of life. This includes the physical, mental, emotional, social, and financial effects of cancer that begin at diagnosis and continue through treatment and beyond. The survivorship experience also includes issues related to follow-up care (including regular health and wellness checkups), late effects of treatment, cancer recurrence, second cancers, and quality of life. Family members, friends, and caregivers are also considered part of the survivorship experience.

**Systemic therapy** Treatment using substances that travel through the bloodstream, reaching and affecting cells all over the body. This treatment includes chemotherapy, targeted drugs, and immunotherapy.

**Transcriptome** The collection of transcribed RNA molecules present in a cell, tissue, or tumor.

**Triple-Negative Breast Cancer (TNBC)** A type of breast cancer in which the cancer cells do not have estrogen receptors, progesterone receptors, or large amounts of HER2/neu protein. Also called ER-negative, PR-negative, HER2-negative breast cancer.

**Tumor** An abnormal mass of tissue that results when cells divide more than they should or do not die when they should. Tumors may be benign (not cancer) or malignant (cancer). Also called neoplasm.

**Tumor microenvironment** The cells, molecules, and blood vessels that surround and feed a cancer cell. A cancer can change its microenvironment, and the microenvironment can affect how a tumor grows and spreads.

**US Preventive Services Task Force (USPSTF)** An independent, volunteer panel of experts in prevention and evidence-based medicine.



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