

AACR CANCER DISPARITIES PROGRESS REPORT 2022

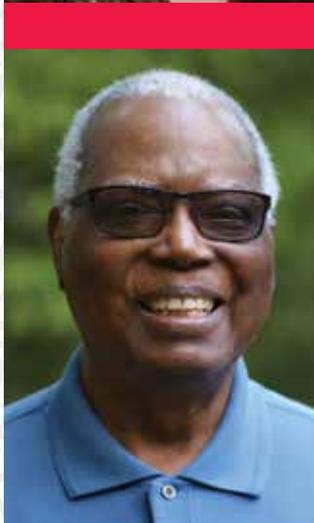
Achieving the Bold Vision of Health
Equity for Racial and Ethnic Minorities
and Other Underserved Populations

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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 50,000 laboratory, translational, and clinical researchers; population scientists; other health care professionals; and patient advocates residing in 129 countries. 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. In addition,

the AACR publishes 10 prestigious, peer-reviewed scientific journals and a magazine for cancer survivors, patients, and their caregivers. 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

We have witnessed remarkable advances against cancer in the United States over the past decade. Transformative research and technological innovation enabled by federal investments have led to steady declines in overall cancer incidence and death rates and a significant increase in the number of individuals who are living longer and fuller lives after a cancer diagnosis. Despite this spectacular progress, much of which has been documented in the annual *AACR Cancer Progress Reports* since 2011, large segments of the U.S. population continue to shoulder a disproportionate cancer burden. Disparities across the cancer continuum stem from a long history of systemic inequities and lead to adverse differences in social determinants of health for racial and ethnic minorities and other medically underserved populations. These same institutional and societal injustices impair the rate of progress in oncology outcomes because the reduced opportunities for higher education among minority communities result in a lack of diversity in health care professions. The oncology workforce is weakened by limiting the pool of creative and brilliant minds that can potentially contribute to cancer research and patient care.

Launched in 2020, the Cancer Disparities Progress Report to Congress and the American public is a cornerstone of the AACR's educational and advocacy efforts to achieve health equity. The *AACR Cancer Disparities Progress Report 2022*, highlights areas of recent progress in reducing cancer health disparities. It also emphasizes the vital need for continued transformative research and for increased collaborations if we are 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 populations in the United States have long experienced cancer health disparities. As one striking example, while the overall cancer incidence rate is lower in Black individuals compared to White individuals, the Black population has the highest overall cancer death rate of any racial or ethnic group. Alarming disparities also exist related to the cancer burden faced by populations living in rural areas, experiencing persistent poverty, and/or belonging to sexual or gender minorities. Clearly, we are not reaching our robustly diverse population with all the advances that have been made. Inequities in the U.S. health care system have drawn renewed attention and concern in the face of the ongoing COVID-19 pandemic, which according to experts may further exacerbate cancer health disparities. As a scientific organization focused on preventing and curing all cancers, diversity, equity, and inclusion have been and will remain at the foundational core of AACR's work. We are fiercely committed to understanding and addressing the biological and systemic roots of cancer health disparities.

Research has fueled progress in identifying, quantifying, and understanding the causes of cancer health disparities, which are

vital steps toward developing and implementing strategies to eliminate disparities. Encouragingly, differences in the overall cancer death rates among racial and ethnic groups in the United States have narrowed over the past two decades. Additionally, clinical studies have demonstrated that racial and ethnic disparities in outcomes for several types of cancer could be minimized if all patients had equal access to standard treatment. However, the goal of eliminating disparities in the burden of cancer for racial and ethnic minorities and other underserved populations has yet to be realized. Cancer represents a genetic aberration at its root cause; we will not be able to eradicate this disease until we understand the complete spectrum of environmental, behavioral, and socioeconomic as well as ancestral factors that can result in carcinogenic alterations. This comprehensive understanding of cancer therefore depends upon research involving diverse communities as well.

As we look to the future, we strongly believe that a deeper understanding of the ancestry-related differences in cancer biology is key if we are 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. Novel initiatives, such as the AACR Project Genomics Evidence Neoplasia Information Exchange (GENIE)*; the National Institutes of Health's All of Us Program; and the Research on Prostate Cancer in Men of African Ancestry: Defining the Roles of Genetics, Tumor Markers, and Social Stress study, to name a few, will provide insights into the biological and genetic factors that are associated with cancer in racial and ethnic minorities. In addition, it is vital that all stakeholders in medical research work together to eliminate systemic- and individual-level barriers to cancer clinical trial participation. Sociodemographic diversity among clinical trial participants is fundamental in driving transformative improvements in cancer outcomes for diverse patients. We believe that enhancing diversity in the cancer science and medicine workforce and making clinical trials available across the spectrum of health care facilities, including at community and safety-net hospitals, will make future clinical research more equitable.

Cancer health disparities are a complex and multifaceted problem. Therefore, addressing disparities will require a multidisciplinary and collaborative approach. By combining diverse and distinct domains of expertise, we will achieve a greater understanding of the confluence of factors associated with this public health challenge, the underlying causes, and best approaches for intervention. AACR continues to be a trailblazer for the cancer health disparities research community in catalyzing collaborations by 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 15th edition of which will be held in September 2022. AACR has also long fostered training and educational initiatives that address the gaps in cancer research and care. For more than two decades, the AACR Minorities in Cancer Research constituency group has been leading the way in increasing the number, participation, visibility, and recognition of minority researchers. More recently, AACR collaborated with the Bristol Myers Squibb Foundation and National Medical Fellowships on an initiative to train 250 community-oriented clinical trial investigators who are underrepresented in medicine or have demonstrated a commitment to increasing diversity in clinical trials; named Robert A. Winn Diversity in Clinical Trials Award Program, this new initiative is a testament to our commitment to eliminating cancer health disparities by propelling tangible improvements in cancer workforce diversity.

Every American must have equitable access to life, liberty, and the pursuit of happiness. Health care is a critical component of these “unalienable rights,” 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 inhumane.” AACR is committed to working with our policy

makers to ensure that we maintain a sharp focus on prioritizing cancer health disparities research. By providing adequate funding for innovative research, Congress can be of enormous assistance in eradicating cancer health disparities and ensuring that we achieve the bold vision of health equity for racial and ethnic minorities and other medically underserved populations.



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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. More people than ever before are living longer and fuller lives after a cancer diagnosis. However, the grim reality is that advances against cancer have not benefited everyone equally. Because of a long history of structural inequities and systemic injustices in the United States (U.S.), certain segments of the U.S. population continue to shoulder a disproportionate burden of adverse health conditions, including cancer. The same socially, economically, and geographically disadvantaged populations have also experienced a greater negative impact from the Coronavirus Disease 2019 (COVID-19) pandemic. Disparities in health care are among the most significant forms of inequity and injustice, and it is imperative that everyone play a role in eradicating the social injustices that are barriers to health equity, which is one of our most basic human rights.

As the first and largest professional organization in the world focused on preventing and curing all and cancers whose core values include diversity, equity, and inclusion, the American Association for Cancer Research (AACR) is committed to accelerating the pace of research to address the disparities across the cancer continuum faced by racial and ethnic minorities and other medically underserved populations. It is also dedicated to increasing public understanding of cancer health disparities and the importance of cancer health disparities research for saving lives, and to advocating for increased annual federal funding for government entities that fuel progress against cancer health 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 2022* to Congress and the American public is a cornerstone of AACR's educational and advocacy efforts to achieve health equity. The report highlights areas of recent progress in reducing cancer health disparities. It also emphasizes the vital need for continued transformative research and for increased collaborations among all stakeholders working toward the bold vision of health equity if we are 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 Cancer Health Disparities in 2022

In the United States, we have experienced tremendous progress against cancer in recent decades. As a result, overall cancer incidence and mortality are declining steadily across all

Disparity in overall cancer mortality between Black and White populations has **narrowed by half** during the last two decades.



population groups. Further encouraging is the evidence that the differences in overall cancer incidence and death rates are decreasing between racial and ethnic groups.

Despite these encouraging trends, disparities across the cancer continuum remain a major public health challenge in the United States. Compared to the White population, racial and ethnic minorities and other medically underserved populations continue to share a disproportionate burden for certain types of cancer. As one example, although disparity in cancer-related deaths between Black and White populations has been narrowing, the Black population still has the highest rate of overall cancer mortality. Other racial and ethnic minorities continue to experience disproportionate burdens for certain types of cancer. Similarly, those living under persistent poverty or in rural areas continue to face serious structural barriers and/or systemic inequities in their access to quality health care.

A long history of racism in the United States has resulted in discriminatory policies, systemic inequities, and structural barriers that cause and perpetuate cancer health disparities. Researchers are using a framework of interrelated and overlapping factors, called social determinants of health (SDOH), to understand and address cancer health disparities. Among the key SDOH are socioeconomic factors such as education and income; modifiable factors such as tobacco use and physical inactivity; psychological factors such as stress and mental health; environmental factors such as housing and transportation; health care access and experiences; and biological and genetic factors. SDOH operate at individual, community, and population levels to drive health outcomes.

Cancer health disparities not only adversely affect the lives of millions of Americans, but they also carry an immense economic toll. According to one estimate examining the direct cost of cancer health disparities during 2002-2007, eliminating racial disparities in incidence of the four most common types of cancer—lung, colorectal, breast, and prostate—would have resulted in \$2.3 billion in savings in annual medical expenditures by patients with cancer. Another study found that, compared to White individuals, the rate of lost earnings for Black individuals was more than double because of premature deaths related to prostate and stomach cancers and multiple myeloma.

Given the significant personal, societal, and economic impact of cancer health disparities, there is an increased urgency within the cancer community to understand and address these disparities. It is increasingly evident that COVID-19 has exacerbated many of the existing cancer health disparities. Therefore, funding research to understand and address the public health challenge of cancer health disparities is a vital national investment to achieve an equitable future for all populations.

Understanding Cancer Development in the Context of Cancer Health Disparities

Understanding of the hallmarks that define how cancer develops has increased tremendously in the past two decades, thanks to major advances in medical research. We now know that cancer is not a single disease but a collection of disorders broadly characterized by the inability of a cell to respond to normal biological cues related to cell division, growth, and death.

Cancer development occurs through fundamental changes to the genetic material inside the cell, as well as in the surrounding cellular and molecular environment. Reciprocal interactions between the cancer cell and the tumor microenvironment—cells, molecules, and blood vessels that surround a cancer cell—influence tumor progression and spread into other tissues, a process called metastasis. Gaining an understanding of the changes that occur internally and externally and how these changes drive cancer initiation and progression is essential for cancer diagnosis, prognosis, and development of effective treatments.

Historically, research studies on the genetic and microenvironmental changes of the tumor have been performed primarily in individuals of European ancestry. Lack of representation in these studies of racial and ethnic minorities and other underrepresented groups has severely limited our understanding of genetic predispositions that lead to higher incidence and mortality or increased aggressiveness of cancer in these individuals. Identification of alterations that lead to cancer using diverse laboratory research models while creating large and inclusive databases will increase our knowledge surrounding the cancer-related genetic, epigenetic, and other changes that occur in patients from different ancestral groups. As one example, recent data show that the frequency of alterations in the *EGFR* gene differs based on ancestry of the patient, with the highest rates of alteration observed in East Asian groups and the lowest rates observed in patients of African and European descent. Many initiatives such as NIH's All of Us Research Program or AACR Project GENIE® are beginning to shed light on different genetic changes associated with cancer in different racial and ethnic populations, but there is an urgent need to significantly increase research into this important factor influencing cancer health disparities.

Disparities in the Burden of Preventable Cancer Risk Factors

Decades of research have led to the identification of numerous factors that increase a person's risk of developing cancer. Many of these factors, which are often referred to as cancer risk factors, are potentially modifiable. In the United States, the major potentially modifiable cancer risk factors are tobacco use; obesity; lack of physical activity; alcohol consumption; exposure to UV light from the sun or tanning devices; infection with certain pathogens, such as cancer-causing strains of human papillomavirus (HPV), and environmental exposure to carcinogens.

Individuals can reduce their risk of developing certain types of cancer through behavioral changes. However, long-standing inequities in numerous SDOH contribute to significant disparities in the burden of preventable cancer risk factors among socially, economically, and geographically disadvantaged populations. These disparities stem from a long history of structural, social, and institutional injustices, and not only place disadvantaged populations in unfavorable living environments (e.g., with higher exposure to environmental carcinogens), but also contribute to their increased risk behaviors (e.g., smoking, alcohol consumption, or unhealthy diet).

It must be noted that an individual's behavior and exposures are strongly influenced by the individual's living environment. For example, lack of quality housing may expose residents, such as those living in disadvantaged communities without comprehensive smoke-free policies, to high levels of secondhand smoke, a known risk factor for lung cancer. Moreover, disadvantaged populations may not be able to maintain behaviors that are key to lowering cancer risks, such as maintaining a healthy weight, eating a healthful diet, and being physically active, because of factors beyond their control, e.g., the unavailability of healthy food options and/or lack of safe

Percentage of adults age 18 and older who reported cigarette use in 2020:

- **27.1%** American Indian or Alaska Native
- **14.4%** Black
- **13.3%** White
- **8.0%** Asian
- **8.0%** Hispanic
- **19.0%** Rural residents
- **11.4%** Urban residents
- **20.2%** Annual household income of <\$35,000
- **6.2%** Annual household income of >\$100,000
- **16.1%** Sexual and gender minority
- **12.3%** Heterosexual/straight



greenways and parks for recreation and physical activity in the neighborhood. It is also important to note that socioeconomic and geographic disadvantages intersect with other population characteristics, such as race, ethnicity, sexual orientation, and disability status. It is imperative that public health experts prioritize cancer prevention efforts that account for the complex and interrelated factors at institutional, social, and individual levels, all of which influence personal risk behavior and disparate health outcomes.

Disparities in Cancer Screening for Early Detection

The aim of cancer screening is to find precancerous lesions and cancers at their earliest possible stage when it is easier to treat them successfully. In United States, the U.S. Preventive Services Task Force (USPSTF), as well as other professional societies, carefully weighs benefits and potential harms of screening for certain types of cancer to issue population-level screening guidelines. USPSTF recommends that individuals who are at an average risk of developing cancer should receive screening for breast, prostate, cervical, and colorectal cancers. USPSTF also issues guidelines for certain individuals who should be screened for other types of cancer only if they are at an increased risk of developing these cancers; e.g., current or former smokers should be screened for lung cancer.

Routine cancer screening is one of the most effective ways to reduce the burden of cancer at the population level. Yet, many disparities in cancer screening exist for racial and ethnic minorities and other medically underserved populations. Some of these disparities are a result of screening guidelines that are based on studies with predominantly White participants. USPSTF and other cancer-focused professional organizations routinely evaluate newly available evidence and adjust their guidelines accordingly. Some cancer screening disparities stem from systemic and structural barriers. For example, residents who live in remote areas have less access to health care facilities with capabilities to perform certain cancer screening tests. Yet, some other disparities in cancer screening exist because of the deeply rooted mistrust of the health care system. Cultural beliefs as well as lack of knowledge about cancer screening also play a role in cultivating disparities in cancer screening. Another source of disparities is the lack of follow-up exam(s) if the initial cancer screening test indicates that the individual may have cancer.

In February 2022, the President's Cancer Panel released the ***Closing Gaps in Cancer Screening: Connecting People, Communities, and Systems to Improve Equity and Access Report***. The report was presented to President Biden and **outlined barriers and provided recommendations to improve cancer screening and follow-up care in the United States.**



Researchers are taking innovative and multipronged approaches to raise awareness and increase knowledge of the importance of cancer screening among racial and ethnic minorities. Many approaches have been successfully applied at local or state levels and provide a blueprint to effectively reach racial and ethnic minorities and other medically underserved populations across the nation for increased adherence and follow-up to cancer screening. These strategies include developing comprehensive public health campaigns that not only raise the awareness, but also make it easier for eligible individuals to adhere to cancer screening; increasing access to health insurance to minimize out-of-pocket costs for certain types of screening tests; developing culturally tailored interventions through community engagement to alleviate any concerns about cancer screening in a culturally sensitive manner; reducing structural barriers by providing at-home screening tests where possible; and reducing mistrust in the health care system by improving communications between patients and providers.

Disparities in Clinical Research and Cancer Treatment

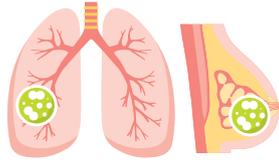
Researchers working across the continuum of cancer science and medicine are constantly powering the translation of new discoveries into advances in cancer treatment that are improving survival and quality of life for U.S. adults and children. Clinical trials are a vital part of medical research because they establish whether new cancer treatments are safe and effective. Therefore, it is imperative that participants

Between 2012—the last year before expansion of the Affordable Care Act coverage was implemented—**and 2020**, the share of **Hispanic women** who were **eligible but did not receive a recent mammogram declined from 32 percent to 21 percent**, eliminating a disparity between them and White women, 24 percent and 22 percent of whom were without a recent mammogram in 2012 and 2020, respectively.



The **Accountability for Cancer through Undoing Racism and Equity (ACCURE) program**

reduced the racial disparity in timely surgery and treatment completion between Black and White patients with lung cancer. Emerging preliminary data suggest that the approach **may reduce disparities in 5-year survival rates between Black and White patients** with breast or lung cancer.



in clinical trials testing new cancer treatments represent all population groups who may use these therapeutics if they are approved. Despite this knowledge, enrollment in cancer clinical trials is extremely 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 minorities in clinical trials. It is vital that all stakeholders in the medical research community work together to identify interventions which ensure equitable participation of all population groups in clinical studies since it is the only way to guarantee that all segments of the U.S. population benefit from the unprecedented advances against cancer.

Most patients with cancer are treated with a combination of treatment options across the five pillars of cancer treatment—surgery, radiotherapy, cytotoxic chemotherapy, molecularly targeted therapy, and immunotherapy. Despite major advances in these treatments in recent years, racial and ethnic minorities and other medically underserved populations frequently experience severe and multilevel barriers to quality cancer treatment, including delays in or lack of access to standard of care treatments, as well as higher rates of treatment-related financial toxicities. Many patients from disadvantaged population groups also experience overt discrimination and/or implicit bias during the receipt of care.

Encouragingly, recent data show that racial and ethnic disparities in cancer outcomes can be eliminated if every patient has equitable access to standard of care treatments. In fact, researchers have shown that racial and ethnic minority patients respond better to treatments against many cancers compared to White patients, and have better outcomes when offered similar access to standard and quality care. Therefore, it is imperative that all sectors work together to address the challenges of disparities in cancer treatment, a necessity to achieve health equity. In this regard, it should be noted that several clinical studies, including the Accountability for Cancer through Undoing Racism and Equity (ACCURE) program, have shown that multilevel interventions that utilize patient navigation can address the current disparities in cancer treatment and also improve outcomes for all patients.

Disparities in Cancer Survivorship

Any person who has been diagnosed with cancer may be referred to as a cancer survivor from the time of initial diagnosis until the end of life. As more people are living longer and fuller lives after a cancer diagnosis—thanks to improved detection and treatment options—greater attention is needed to understand the survivorship experience. While every cancer survivor has a unique experience, 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 to support those who are more vulnerable and lead to better quality of life.

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 minorities and other medically underserved populations have been shown to 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, an increasingly important consideration in cancer care, drug approvals, and long-term survival predictions. It has long been recognized that health-related quality of life is lower in cancer survivors compared to individuals who have never had a cancer diagnosis. Furthermore, cancer survivors from medically underserved groups are at an increased risk of experiencing worse health-related quality of life.

A major contributing factor to poor health-related quality of life is financial toxicity, which refers to the detrimental effects experienced by cancer survivors and their family members caused by the financial strain after a cancer diagnosis. Out-of-pocket costs for cancer care are higher than any other illness and often result in coping behaviors, such as skipping medications and follow-up visits, and/or taking on debt. Financial toxicity is more prevalent in individuals from disadvantaged groups such as those from low socioeconomic status, further exacerbating their poverty.

A key to charting an equitable path forward for cancer survivors who belong to medically underserved populations is the use of

Black and Hispanic patients with cancer have increased use of financial coping behaviors, such as skipping medications, because they **experience adverse financial impact twice as often as White patients.**



community-based and culturally tailored solutions that meet the specific needs of the patient and the particular population group. These interventions include involving patient advocates and patient navigators as key partners and addressing the specific social, psychological, medical, and physical needs of the patient while taking into account cultural norms and perceptions. Such comprehensive approaches are key to improving quality of life; bolstering adherence to follow-up care; identifying financial concerns; providing equitable health care; and reducing the overall cost of cancer care.

Overcoming Cancer Health Disparities Through Diversity in Cancer Training and Workforce

Diversity can be defined as 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. The overall health care workforce has become more diverse in recent years. However, representation of racial, ethnic, sexual, and gender minorities in the cancer research and care workforce has not kept pace with trends in the U.S. population and contributes to cancer health disparities. A key strategy to eliminate cancer health disparities and achieve health equity is to increase diversity along the science, technology, engineering, mathematics, and medicine training pipeline and support the entire cancer research and care workforce. A diverse cancer research and care workforce would enhance the quality of care; improve patient satisfaction; strengthen trust in the medical research community; increase enrollment in clinical trials of underrepresented and underserved community members; and expand access to jobs in health care. Continued, intentional efforts to increase diversity across the cancer care and research workforce are needed to achieve health equity.

Overcoming Cancer Health Disparities Through Science-based Public Policy

Strong public health policies have contributed to the progress that has been made in reducing cancer health disparities over the past two decades. Evidence-based public policies have the potential to address disparities by improving prevention and early detection of cancers, improving diversity in clinical trial enrollment, increasing access to health care for racial and ethnic minorities and other underserved populations, and improving the quality of care they receive.

Improved tobacco control regulations, such as prohibiting menthol cigarettes and improving smoking cessation support, especially among racial and ethnic minorities and other

disadvantaged groups who are specifically targeted by the tobacco industry through advertisements, could greatly reduce disparities in tobacco-related illnesses. Legislation to increase awareness of HPV vaccination and cancer screening could decrease disparities in cancer incidence and mortality, and eliminate cervical cancer in the United States. It is evident that a complex interplay between social and environmental factors drives cancer health disparities. This interaction provides several opportunities for implementing policies to prioritize environmental justice, cancer equity research, and improved access to cancer care. Federal support of collaborative initiatives with academic institution- and community-based organizations has resulted in strengthening equitable partnerships at the community level. Continued meaningful collaborations across all branches of government are needed to address the health care needs of historically underserved groups and improve cancer outcomes for all populations.

AACR Call to Action

Systemic inequities and social injustices have adversely impacted every aspect of cancer research and patient care, including limited participation in clinical trials and differences in cancer incidence and outcomes among underserved populations. In addition, these inequities have created barriers to career advancement for underrepresented minorities. While new research and initiatives are closing these gaps, progress has been slow, and the cost of cancer health disparities remains monumental. To reduce cancer health disparities, the structural barriers that lead to these outcomes must be addressed.

Therefore, AACR calls on policy makers and other stakeholders committed to eliminating cancer health disparities to:

- Provide robust, sustained, and predictable funding increases for the federal agencies and programs that are tasked with reducing cancer health disparities, including the National Institutes of Health, National Cancer Institute, National Institute on Minority Health and Health Disparities, and the Centers for Disease Control and Prevention.
- Ensure that cancer-related, disaggregated data are collected and analyzed for sexual, gender, racial, and ethnic minority populations.
- Improve representation in clinical trials by reducing barriers to patient enrollment and requiring enhanced data reporting and community engagement, as included in the Diverse and Equitable Participation in Clinical Trials (DEPICT) Act.
- Prioritize cancer control initiatives, including increased HPV vaccination and awareness, and improved access to cancer screening.
- Expand Medicaid and access to quality, affordable health care coverage, and provide greater support for patients and health care providers.

- Implement concrete steps to increase diversity in the cancer research and care workforce.
- Enact provisions of the Health Equity and Accountability Act (HEAA), comprehensive legislation that aims to eliminate racial and ethnic health inequities.

AACR has been a pioneer and a leader in advancing the science of cancer health disparities with the goal of eliminating cancer health disparities. We are proud to share the latest effort, the *AACR Cancer Disparities Progress Report 2022*, to achieve this important goal. The second edition of the *AACR Cancer Disparities Progress Report* builds on the inaugural report released in 2020, which

brought to the forefront many of the key actions needed to overcome the enormous public health challenges posed by cancer health disparities. Fulfilling the recommendations included in our Call to Action demands ongoing and active participation from a broad spectrum of stakeholders. These efforts must be coupled with actions to eradicate the systemic inequities and social injustices that are barriers to health equity, which is one of our most basic human rights. This is why AACR stands in solidarity against racism, privilege, and discrimination in all aspects of life and actively supports policies that guarantee equitable access to quality health care and thereby eradicate all barriers to achieving the bold vision of health equity.

A Snapshot of U.S. Cancer Health Disparities in 2022

Cancer health disparities are an enormous public health challenge in the United States. Examples of these disparities include:

- Compared to the **White** population:

80% higher	AI/AN population has 80 percent higher incidence rate of kidney cancer
HIGHER incidence	Asian population has higher incidence of cancers caused by infectious agents
More than DOUBLE	Black population has more than double the mortality rate of multiple myeloma
More than DOUBLE	Hispanic population has more than double the mortality rate of liver cancer
3X mortality	NHOPI population has nearly 3 times the mortality rate of stomach cancer .

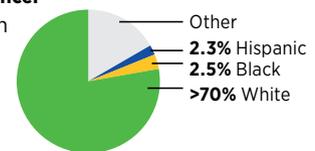
- Individuals **living under persistent poverty** have 43.2 percent higher mortality rate of stomach cancer.
- 77 percent of tumor samples** in *The Cancer Genome Atlas* are **from White populations**.



- Compared to cisgender individuals, individuals **transitioning from female to male** are 58 percent **less likely** to adhere to **cervical cancer screening**.

- Between 2009 and 2019, **FDA approved 81 oral anticancer chemotherapeutics**, based on data from 142 clinical trials. **Only 52 percent of these trials reported on race/ethnicity.**

CLINICAL TRIAL PARTICIPANTS



- Two thirds of rural cancer survivors** from the Appalachian region **report financial distress**.

- Liver cancer patients living in rural communities** at the time of diagnosis are 12 percent **less likely to receive treatment** and have nearly 10 percent **higher mortality** compared to patients living in urban communities.

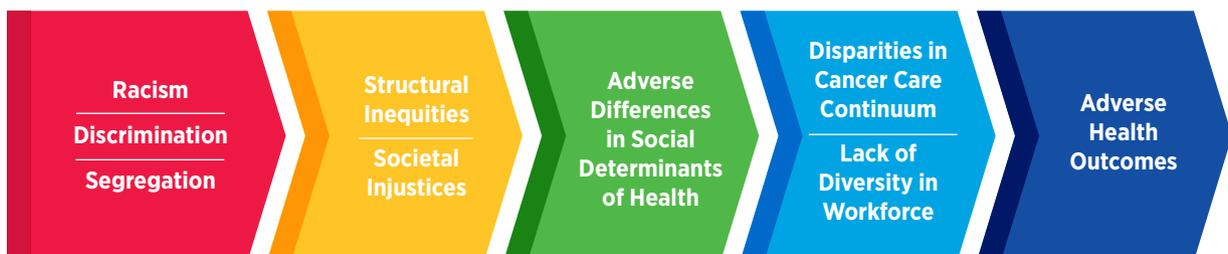


- Individuals **living in rural areas** have 17 percent **higher death rate** from all cancers combined.

- Elderly Native Hawaiian or Other Pacific Islander patients** are **less likely** to be able to **pay medical bills** associated with cancer treatments and **more likely to delay or forgo medical care** compared to non-Hispanic White patients.



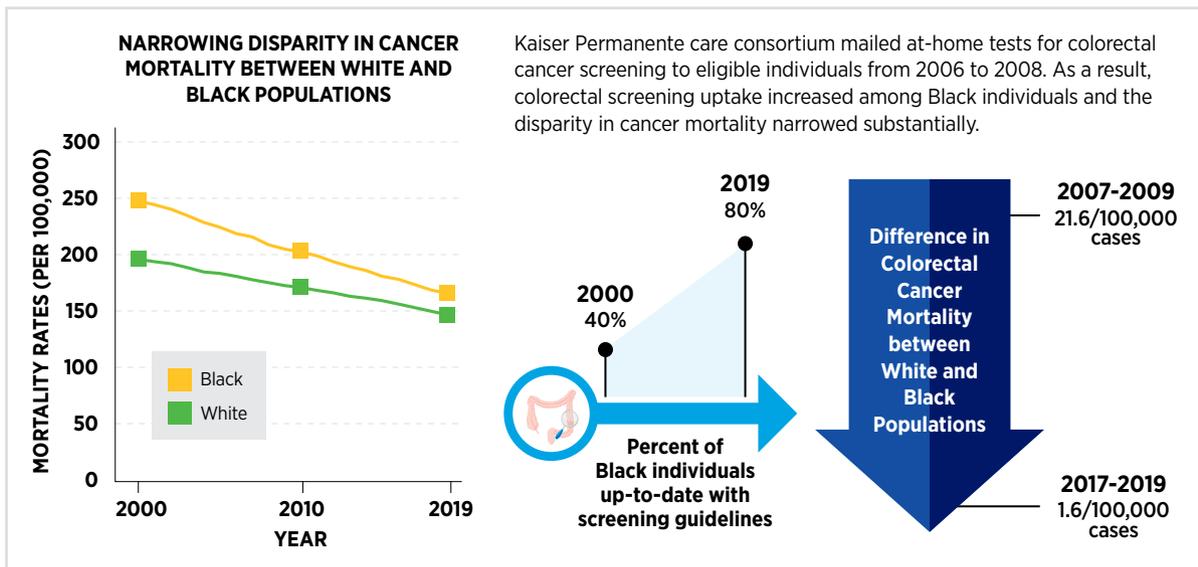
Researchers have identified many factors that contribute to U.S. cancer health disparities. These factors are complex and interrelated and many of them have been perpetuated by a long history of structural inequities and societal injustices:



There has been progress in our understanding of cancer health disparities and in some cases reducing or eliminating cancer health disparities:

Many new initiatives have the potential to provide deep insight into the biological factors that contribute to cancer health disparities.

- NIH's All of Us project has enrolled 100,000 people; 50 percent are from underrepresented groups.
- AACR Project GENIE® has sequenced tumors from over 121,000 patients; 16,000 (13.4 percent) are from racial and ethnic minorities.



Disparities in outcomes for several types of cancer can be eliminated if every patient has equitable access to standard treatment.

- Black patients with prostate cancer may enroll into clinical trials with more advanced disease, but respond better to radiotherapy, chemotherapy, molecularly targeted therapy, or immunotherapy and have better outcomes compared to White patients.
- A multipronged intervention comprising **patient navigation**, a real-time **warning system to track patient care**, and **race-specific feedback** to clinical teams on treatment completion rates was not only able to eliminate treatment disparities among Black and White patients with lung cancer, but also **improved care for all patients** regardless of race.

Advancing policies to build a diverse workforce and health equity

- The **UNITE** initiative and other NIH programs are increasing support for a more diverse workforce.
- Funding for disparities research at **NIH**, **NCI**, and **NIMHD** helps inform effective strategies to improve health equity.
- **New policies** to ban menthol cigarettes, promote environmental justice, and increase diversity in clinical trials will **help address cancer health disparities**.
- **Improving access to health care**, including cancer screenings and follow-up care, is critical to achieve health equity.



The State of Cancer Health Disparities in 2022

IN THIS SECTION, YOU WILL LEARN:

- ▶ Cancer health disparities are adverse differences in cancer burden experienced by racial and ethnic minorities and other medically underserved populations that include those living in rural areas; individuals from sexual and gender minorities; and those living in persistent poverty.
- ▶ In recent decades, overall cancer incidence and mortality rates have declined for all racial and ethnic minorities in the United States. The disparity in overall cancer mortality rates between Black people and White people has narrowed from 26 percent in 2000 to 13 percent in 2019.
- ▶ There is a growing recognition of the heterogeneity among individuals within each of the racial and ethnic minority groups, highlighting the need for disaggregated cancer data to develop effective strategies for achieving health equity.
- ▶ Research has identified complex factors, such as socioeconomic, cultural, social, and environmental factors, that influence each other to drive and perpetuate cancer health disparities.
- ▶ The economic burden of health disparities, including cancer health disparities, is enormous, as illustrated by an estimated loss of \$3.2 billion in earnings in 2015 because of disparities in premature cancer deaths between Black and White individuals.

Breakthrough discoveries and technological innovations that bring lifesaving anticancer treatments to the clinic have resulted in unprecedented progress against cancer in recent decades. The age-adjusted overall U.S. cancer death rate has declined by 32 percent from 1991 to 2019 (1), due to major advances in prevention, early detection, and treatment including treatment of aggressive tumors, such as lung cancer and melanoma. During the same period, the number of cancer survivors living in the U.S. has more than doubled from 7.2 million in 1992 to 16.9 million in 2019 (2).

Despite the significant overall progress, cancer continues to pose a major public health challenge, and certain segments of the U.S. population continue to experience a disproportionate burden of cancer (see sidebar on **Which U.S. Population Groups Experience Cancer Health Disparities?**, p. 12). A long history of racism has resulted in discriminatory policies, systemic inequities, and structural barriers that cause and perpetuate many of these health disparities (see **Factors That Drive Cancer Health Disparities**, p. 29).

The exact measures of cancer burden when discussing health disparities often vary. Throughout this report, we use the NCI definition of cancer health disparities, i.e., adverse differences between certain population groups in cancer measures that include: 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. These

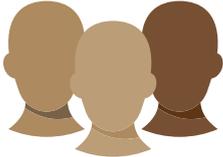
population groups may be characterized by race, ethnicity, disability, gender and sexual identity, geographic location, income, education, and other characteristics (see sidebar on **Which U.S. Population Groups Experience Cancer Health Disparities?**, p. 12) (3).

The *AACR Cancer Disparities Progress Report 2022* aims to increase awareness of the progress in understanding and addressing disparities across the cancer care continuum, and to emphasize the vital importance of cancer health disparities research in saving lives. The report underscores the need for robust, sustained, and predictable annual federal funding increases for the entities that fuel progress against cancer health disparities, in particular, NIH, NCI, and CDC.

In this opening chapter, we provide an overview of the current state of disparities experienced by certain U.S. population groups in cancer incidence rates (i.e., the number of new individuals diagnosed with cancer per 100,000 people) and cancer death rates (i.e., the number of individuals who die from cancer per 100,000 people). We discuss the multifactorial, deeply rooted, and interconnected causes of cancer health disparities. The chapter concludes with the far-reaching and multifaceted adverse impacts of continued cancer health disparities on U.S. health and economy, and how addressing cancer health disparities through research funding can catalyze equitable access to health care.

Which U.S. Population Groups Experience Cancer Health Disparities?

According to the National Cancer Institute (3), cancer health disparities in the United States are 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 that exist among certain population groups including:

<p>Individuals belonging to different ancestry, race, or ethnicity</p> 	<p>Individuals of low socioeconomic status</p> 	<p>Individuals who lack or have limited health insurance coverage</p> 
<p>Residents in certain U.S. geographic locations, such as rural areas, or territories, such as Puerto Rico and Guam</p> 	<p>Members of the sexual and gender minority communities</p> 	<p>Certain immigrants, refugees, or asylum seekers</p> 
<p>Individuals with disabilities</p> 	<p>Adolescents and young adults</p> 	<p>Elderly</p> 

It is important to note that some populations may carry even a higher burden of cancer because they simultaneously fall into more than one of these categories.

Adapted from (2).

Cancer Health Disparities Among Racial and Ethnic Minority Populations

According to the 2020 Census, racial and ethnic minorities (see sidebar on **U.S. Racial and Ethnic Population Groups**, p. 13) comprise nearly 40 percent of the U.S. population (see **Figure 1**, p. 14). It is encouraging that both the overall cancer incidence and cancer mortality—two key measures of cancer burden—have

been steadily decreasing among all racial and ethnic minorities in the U.S. in recent decades (see **Figure 2**, p. 14). In some instances, the disparity in cancer incidence and mortality is narrowing between White population and certain racial and ethnic minorities. For example, overall cancer incidence rates between 2013 and 2018 decreased the most among Black individuals compared to White individuals (eight percent versus five percent decline, respectively) (4).

Despite some promising trends, disparities across the cancer control continuum remain, and in some cases, continue to

U.S. Racial and Ethnic Population Groups*

When federal agencies collect data that include race and ethnicity[§], the agencies follow the Office of Management and Budget (OMB) Statistical Policy Directive No. 15, Race and Ethnic Standards for Federal Statistics and Administrative Reporting (5). The basic racial and ethnic OMB categories[†] are:



American Indian or Alaska Native

A person having origins in any of the original peoples of North and South America (including Central America), and who maintains tribal affiliation or community attachment.

Asian

A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam.

Black or African American

A person having origins in any of the Black racial groups of Africa and the African Diaspora.

Hispanic or Latino[#]

A person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race.

Native Hawaiian or Other Pacific Islander

A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.

White

A person having origins in any of the original peoples of Europe, the Middle East, or North Africa.

* 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.

§ Data collected on race and ethnicity rely on individuals self-reporting this information. Therefore, the data may be influenced by sociopolitical constructs and may not fully reflect the individual's genetic ancestry.

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

Sometimes described in gender-neutral terms, Latinx or Latine.

widen, as discussed throughout this report. As an example, although Black people experienced the largest decrease in cancer mortality rates between 2013 and 2018, cancer death rates were still the highest in this population group in 2018 (4). Furthermore, the burden of cancer among various racial and ethnic minorities varies substantially by cancer type as discussed in sections below.

It is also important to note that the latest years for which much of the cancer incidence and mortality data are presented in this report precede the onset of the COVID-19 pandemic. Thus, discussions and descriptions of cancer burden among racial and ethnic minorities in this report do not reflect the impact of COVID-19, which according to experts has worsened health disparities. For instance, because the adverse effects of COVID-19 were disproportionately higher among Black and Hispanic populations (7), there is a greater possibility that individuals from these communities will experience additional delays in resuming routine cancer screening. It is therefore likely that the adverse impact of COVID-19 on disparities in the stage at which cancer is diagnosed, as well as the health outcomes for patients with cancer, will continue to evolve over the next several years.

AMERICAN INDIAN OR ALASKA NATIVE (AI/AN) POPULATION

According to the Census 2020, an estimated 9.7 million people identified as American Indian or Alaska Native (AI/AN)—alone or in combination with another race—accounting for 2.9 percent of the U.S. population (8). The AI/AN population is incredibly diverse, with 574 federally recognized tribes and more than 200 that remain unrecognized, encompassing many distinct customs, languages, and histories. It is important to note that the AI/AN population has the highest racial misclassification in health data of any racial or ethnic group in the U.S., likely contributing to an underestimation of the burden of cancer in the group (9).

Approximately two-thirds of the AI/AN population live in tribal areas or surrounding counties, called **Purchased/Referred Care Delivery Area (PRCDA) counties. There are six PRCDA regions: Alaska, East, Northern Plains, Pacific Coast, Southern Plains, and Southwest (6).**

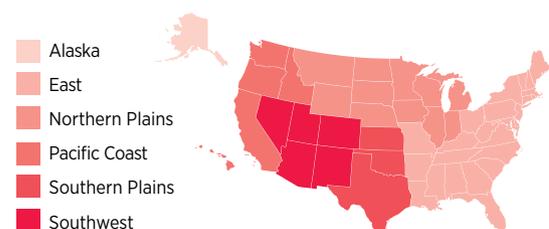
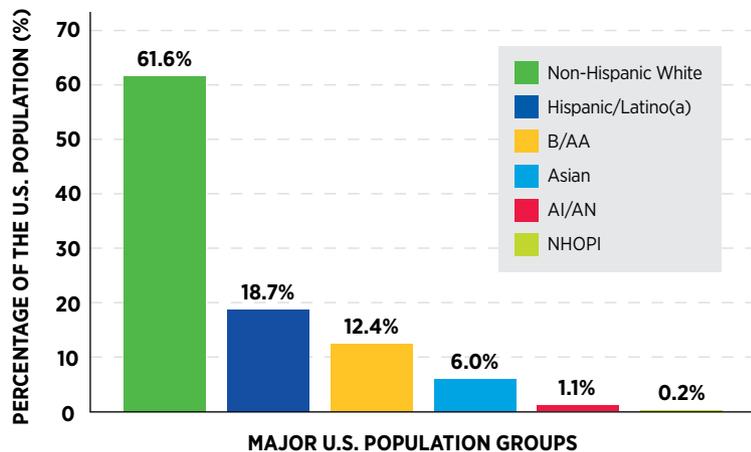


FIGURE 1

Percent Representation of Racial and Ethnic Minorities in the U.S. Population



The major population groups are shown as percent of the U.S. population based on the U.S. Census 2020. Numbers represent percent of the U.S. population: non-Hispanic White, 61.6; Hispanic or Latino^a, 18.7; Black or African American (B/AA)^b, 12.4; Asian^b, 6.0; American Indian or Alaska Native (AI/AN)^b, 1.1; and Native Hawaiian or Other Pacific Islander (NHOPI)^b, 0.2.

^a Hispanic people may be of any race, so are also included in applicable race categories.

^b Includes persons reporting only one race.

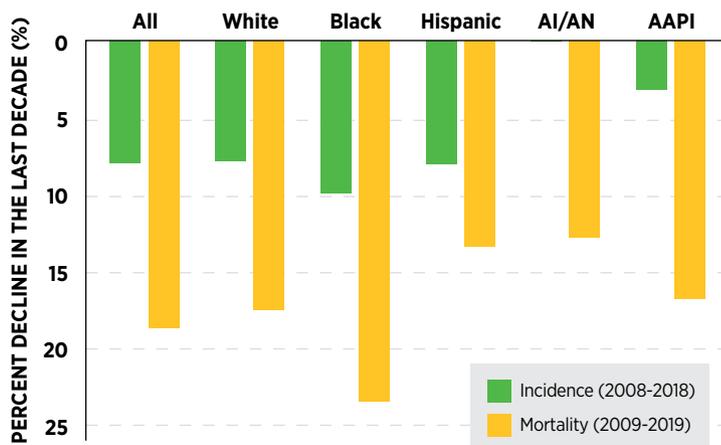
Compared to White people, AI/AN people had higher incidence rates during 2014–2018 for lung, colorectal, and kidney cancers, as well as liver, stomach, and cervical cancers that are caused by infectious agents (see **Figure 3**, p. 15). Furthermore, AI/AN populations living in different Purchased/Referred Care Delivery Area (PRCDA) regions have substantially different cancer risk and disparities compared to each other and to the White population. When compared to the White population, the incidence rate for all cancers combined is 23 percent lower in the AI/AN population living in the Southwest but 49 percent higher in those living in the Southern Plains (1). Similar patterns extend to individual cancer types. As one example, AI/AN individuals living in

the Northern Plains PRCDA region have five times higher incidence of lung cancer—the most diagnosed cancer in the AI/AN population—than those living in the Southwest PRCDA region (1). When compared to White individuals, the lung cancer incidence is 80 percent higher among AI/AN individuals living in the Northern Plains, but 64 percent lower in those living in the Southwest (1).

An example of the burden of cancer for the AI/AN population is the disparity in kidney cancer. Compared to the White population, kidney cancer incidence rates are about 80 percent higher in the AI/AN population across all PRCDA regions except for the East region (1). Alarming, these rates have been rapidly

FIGURE 2

Declining Overall Cancer Incidence and Mortality Across U.S. Racial and Ethnic Population Groups

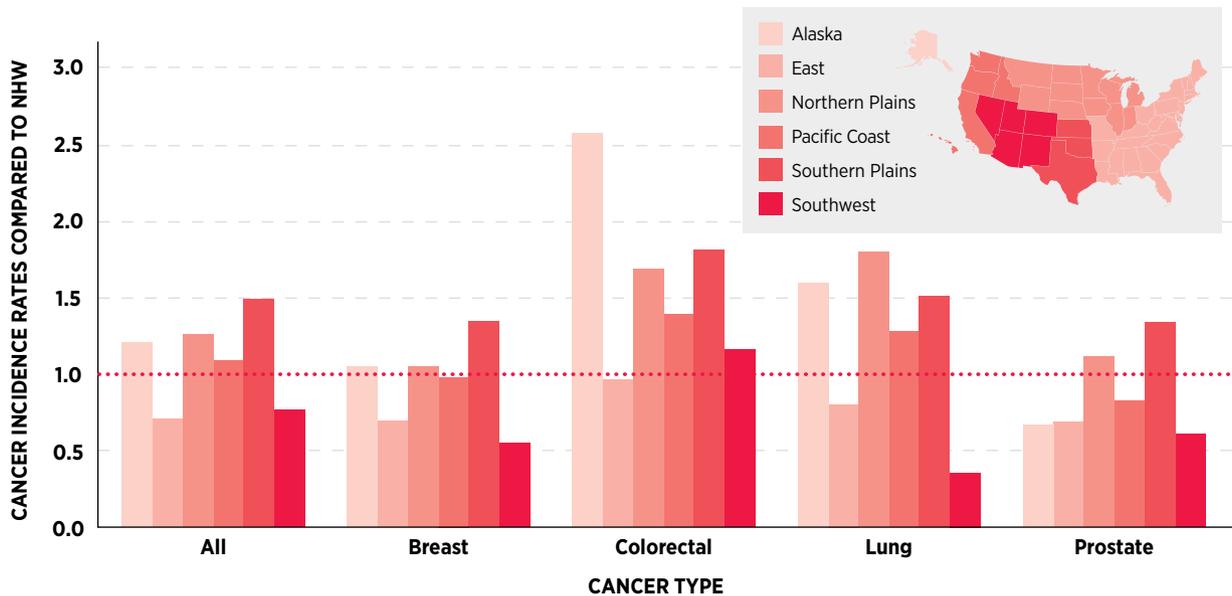


Since the early 1990s, cancer incidence and deaths have declined across all population groups. The x-axis shows the entire U.S. population (All) as well as major U.S. population groups [White; Black; Hispanic; American Indian or Alaska Native (AI/AN); and Asian American and Pacific Islanders (AAPI)]. The y-axis represents percent decline during the most recent 10 years for which cancer incidence (2008–2018; green bars) and cancer mortality (2009–2019; yellow bars) data are available.

Data source: NCI SEER

FIGURE 3

Ratios of Incidence Rates for the Four Most Common Cancer Types Within the American Indian or Alaska Native Population



Incidence of the four most common cancer types—female breast, colorectal, lung, and prostate—vary substantially within the AI/AN populations living in different Purchased/Referred Care Delivery Area (PRCDA) regions and between AI/AN and non-Hispanic White (NHW) populations. Bar graphs show ratios of incidence rates

between the White population (set at 1.0 and shown by the horizontal dotted line) and the AI/AN population living in the six PRCDA regions during the 2014-2018 period. Ratios of incidence rates for all cancer sites combined are shown as a reference. Data are age-adjusted to the 2000 U.S. population.

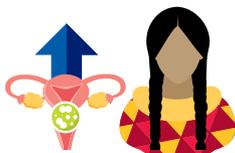
Data from (1).

increasing in the AI/AN population over the last two decades (2.8 percent annual increase from 2009 to 2018) compared to the White population (1.1 percent increase during the same time) (10). In addition to smoking, another reason for a higher incidence of kidney cancer is the higher rates of type 2 diabetes among AI/AN people (11), which increases kidney cancer risk (12). During 2014-2019, the most recent period for which such data are available, AI/AN men and women had 75 percent and 64 percent higher death rates from kidney cancer compared to White men and women, respectively (13). This disparity is likely attributed also to poor access to quality health care.

Liver cancer represents another example of notable disparities in the burden of cancer between AI/AN and White populations. AI/AN people have the highest liver cancer incidence of any major racial or ethnic group in the U.S. (1). Both the liver cancer incidence (most recent 5-year data time period: 2014-2018) and mortality (most recent 5-year data time period: 2015-2019) were nearly double in the AI/AN population compared to White individuals (10). This is likely due in large part to higher prevalence of risk factors in the AI/AN population, such as chronic hepatitis C virus (HCV) infection, obesity, diabetes, and cigarette smoking (1).

Examples presented in this section underscore the heterogeneity of the AI/AN population which indicate differences in exposures to risk factors as well as access to health care in different PRCDA regions (see sidebar on **Why Is Disaggregated Cancer Data Needed?**, p. 16). This highlights the importance of understanding region-specific needs and developing and implementing region-appropriate strategies to eliminate cancer health disparities in the AI/AN population.

Cervical cancer incidence rates are 56 percent higher in AI/AN women than White women (1).



Why Is Disaggregated Cancer Data Needed?

Recognizing the complex multilevel approaches necessary to address health disparities, the U.S.

Department of Health and Human Services in April 2011 released the first strategic plan to eliminate health disparities. A part of the

plan is to enhance data collection and research because incomplete and poor-quality data on race, ethnicity, and language prevent a comprehensive and accurate assessment of the health disparities (14).

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



American Indian or Alaska Native

Compared to the American Indian or Alaska Native individuals living in the Northern Plains region, those living in Alaska were more than twice as likely to be diagnosed with colorectal cancer, but 45 percent less likely to be diagnosed with prostate cancer (1).

Asian

Compared to non-Hispanic White males, the risk of dying from stomach cancer was more than double for Chinese American males, but less than half for South Asian American males (15).

Black/African American

Compared to Black men born in the U.S., Black men who recently migrated from Africa were 76 percent less likely to die from lung cancer but 64 percent more likely to die from liver cancer (16).

Hispanic/Latino/a

Compared to the Hispanic women living in the continental U.S. and Hawaii, those living in Puerto Rico had a similar incidence rate of breast cancer, but 28 percent higher likelihood of dying from breast cancer (17).

Native Hawaiian or Other Pacific Islander

Compared to Native Hawaiian males, Samoan males were 66 percent more likely to be diagnosed with prostate cancer, but 34 percent less likely to be diagnosed with colorectal cancer (18).

ASIAN POPULATION

The Asian population constitutes the fastest-growing racial group in the United States. In the 2020 U.S. Census, the Asian American population accounted for six percent of the U.S. population, a 35.5 percent increase since the 2010 Census (19). With ancestry in numerous countries of origin, remarkable heterogeneity exists within the Asian population. The five largest groups constituting the Asian American designation are Chinese, South Asian, Filipino, Vietnamese, Korean, and Japanese. Differences in culture, nativity, migration history, and socioeconomic and behavioral factors impact the overall health as well as cancer-specific risk factors within these groups.

Compared to individuals from any other racial or ethnic groups, Asian individuals have the lowest rate of developing any type of cancer (20). However, cancer is the leading cause of death for the Asian population in the United States (21). Asian people are disproportionately impacted by cancers that are caused by infectious agents (18). As one example, the higher burden of liver cancer due to chronic hepatitis B virus (HBV) infection among Asian individuals can be attributed to high HBV prevalence in the country of origin (22). However, liver cancer mortality varies greatly within the Asian population. A recent study examined nationwide death records of Americans from the years 2003 to 2017 and found that Vietnamese Americans were nearly three times more likely to die from liver cancer compared to non-Hispanic White (NHW) Americans; the likelihood of death from liver cancer was 35 percent less among Indian Americans compared to NHW Americans (23). Similar variations in the burden among Asian Americans exist for cervical (caused by HPV), nasopharyngeal [caused by Epstein-Barr virus (EBV)], and stomach (caused by *Helicobacter pylori*) cancers (see **Figure 4**, p. 17) (24).

Of the cancer types common in the overall U.S. population, lung cancer is the leading cause of cancer-related deaths in the Asian population (18). Furthermore, Asian individuals, particularly women without a history of smoking, have a uniquely high burden of lung cancer among never-smokers (25). Notably, more than 30 percent of lung cancer patients in Asia, including more than half of female patients with lung cancer, are never-smokers. This observation has been attributed to a markedly increased rate of epidermal growth factor receptor (EGFR)-mutant lung cancer in Asian female nonsmokers (see **Figure 6**, p. 43) (26).

Compared to non-Hispanic White women who have never smoked, the age-adjusted rate of **lung cancer incidence is more than double in never-smoking Chinese American women** (25).

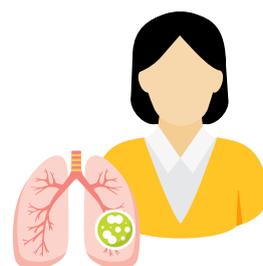
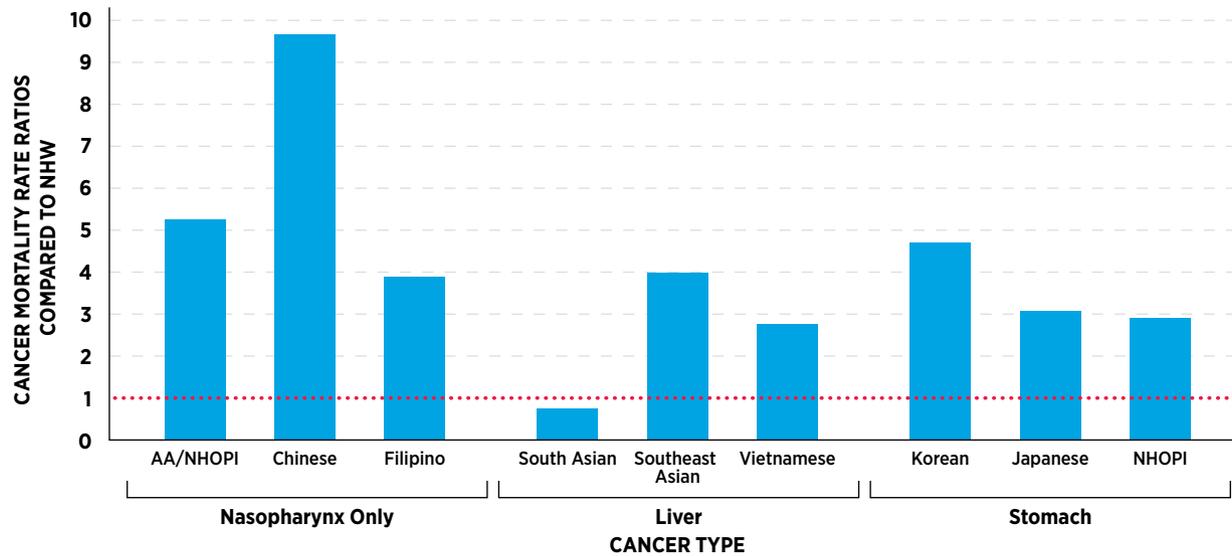


FIGURE 4

Varied Burden of Cancer Within the Asian American, Native Hawaiian or Other Pacific Islander (AA/NHOPI) Population



The Asian American and NHOPI population groups are highly distinct and diverse, and represent individuals from different countries of origin, cultures, races and/or ethnicities. However, data related to the cancer burden in the two groups are often aggregated in most cancer databases and registries, making it difficult to accurately

ascertain the burden of cancer within the two population groups. The bar graph shows ratios of mortality rate for the most common cause of cancer-related deaths in various subgroups within the two populations compared to the non-Hispanic White population (shown as the horizontal red dotted line) in California during 2012-2017.

While smoking cessation remains key to reducing the overall lung cancer incidence and mortality, this example underscores the importance of understanding the disease in broader contexts of biology and country of origin, among other factors, to develop effective and population-specific interventions for eliminating cancer health disparities.

It is becoming evident that the aggregated reporting of cancer statistics for the Asian population results in underestimating the overall cancer burden as well as that of specific cancer types for specific subgroups within the Asian population—as it does for other racial and ethnic minorities (see sidebar on **Why Is Disaggregated Cancer Data Needed?**, p. 16). Furthermore, it has been demonstrated that inaccuracies and deficiencies in data collection on cancer deaths for Asian individuals result in a misleading inflation of survival statistics for this population (27). Because of the heterogeneity of the Asian population, cancer researchers have been advocating for collection of disaggregated cancer data to accurately reflect the burden of cancer in this population and devise tailored strategies to close the disparities gap (21,28).

THE HONORABLE **Jeff Merkley** U.S. Senator for Oregon

“If we believe in equality for all, we cannot allow health disparities and inequality in treating patients to continue. All of us want to know that we and our loved ones will get the best care available when illness strikes, but this report shows, yet again, that Black Americans get lower standard care than similarly situated White people. For everyone to get equal health care, we have to make it a priority to understand how these racial disparities in care occur and take intentional action to attack them.”



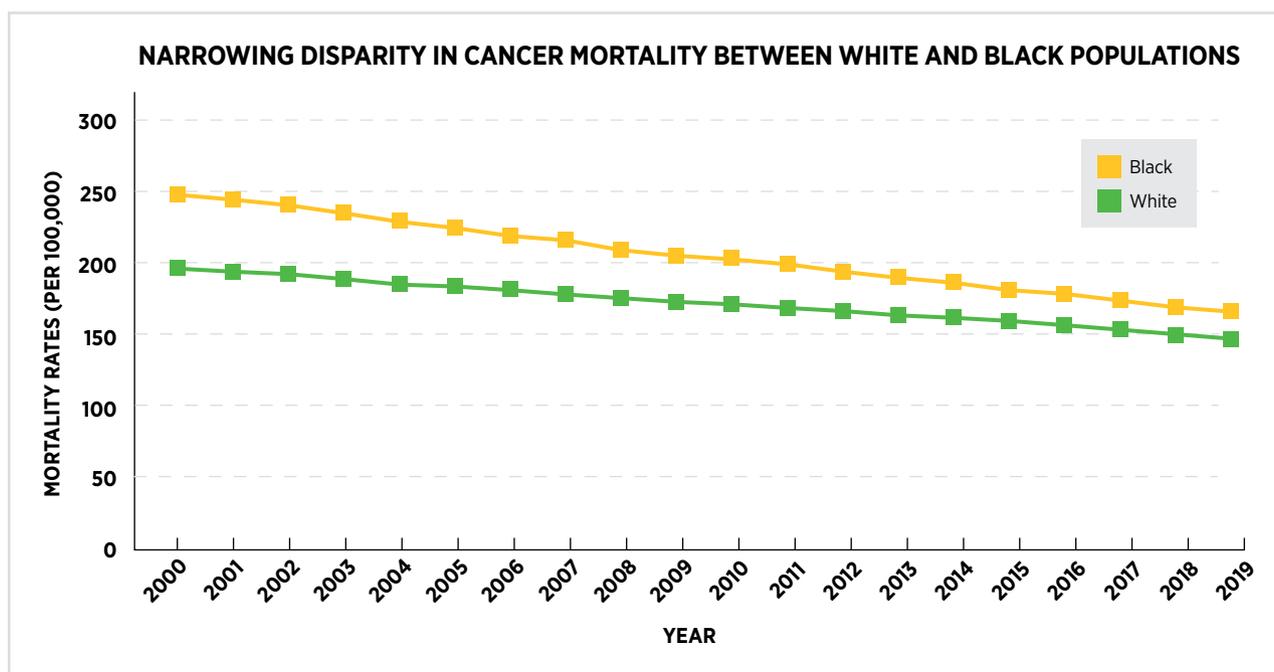
BLACK OR AFRICAN AMERICAN POPULATION

In 2020, nearly 47 million African American or Black individuals—including those who identified as African American or Black in combination with at least one additional race—were living in the U.S., constituting the third largest racial/ethnic population group (8). Recent estimates indicate that 111,990 new cancer diagnoses and 36,340 cancer deaths are expected in Black men in 2022. These projections are slightly higher—112,090 new cancer diagnoses and 37,250 cancer deaths—for Black women (1). Prostate cancer is the most common cancer type in Black men and accounts for 37 percent of all new cancer diagnoses, while breast cancer is the most commonly diagnosed cancer in Black women and accounts for 32 percent of all new cancer diagnoses. Lung and colorectal cancers are the second (11-12 percent) and third (nine percent) most commonly diagnosed cancer types, respectively, in both Black men and Black women. The four cancer types are also the deadliest among the Black population and account for half of all cancer deaths in Black men and 44 percent of all cancer deaths in Black women (1).

The Black population in the U.S. experienced the largest decline in cancer incidence and mortality between 2013 and 2018 compared to any other racial population group (4). Despite recent progress toward reducing disparities in the burden of cancer, Black individuals continue to experience a disproportionate burden of cancer. Compared to White men, cancer incidence in Black men is six percent higher and cancer mortality is 19 percent higher. This disparity is even more notable in Black women who have eight percent lower cancer incidence than White women, but 12 percent higher cancer mortality (1). Among the specific cancer types, stomach and prostate cancers and multiple myeloma show the largest racial disparities in incidence and mortality, with death rates more than two-fold higher in Black people than in White people.

Breast cancer is the most common cancer among Black women, with an estimated 36,260 new cases expected to be diagnosed in 2022. During 2014-2018, the overall breast cancer incidence rate was slightly lower in Black women compared to White women (127 versus 132 per 100,000 cases, respectively). However, it is concerning that, among women who are younger than 40 years, the breast cancer incidence rates are higher among Black women compared to White women. Furthermore, there are key differences in distribution of various breast cancer subtypes between Black and White women. For example, Black women are twice as likely as women of other racial and ethnic groups to be diagnosed with triple-negative breast cancer (TNBC) and 41 percent more likely to be diagnosed with inflammatory breast cancer, two aggressive subtypes of breast cancer (29). Reasons for these differences are not yet clear. Unfortunately, these disparities in incidence are reflected in breast cancer mortality rates: Black women are 40 percent more likely to die from breast cancer compared to White women, despite a slightly lower overall breast cancer incidence rate (1). Research indicates that the higher breast cancer mortality rate in Black women is multifactorial in etiology, explained, in part, by cancer diagnosis at an advanced stage; higher prevalence of aggressive subtypes of the disease; and more limited access to treatment options (29). Socioeconomic disadvantages that are more prevalent in the Black community significantly contribute to this disparity, but the increased risk for biologically aggressive tumor subtypes is likely explained by genetic factors as well.

Although rare in U.S., 2,710 new cases of invasive male breast cancer will be diagnosed and 530 men will die from it in 2022 (13). Breast cancer has a higher prevalence among Black men, as experienced by **Mr. Mathew Knowles** (see p. 20). Overall, Black men have 44-52 percent higher risk of developing breast cancer compared to White men (13,30). Black men are also more than twice as likely as White men to develop highly aggressive



Incidence of **breast cancer is higher in Black men**

compared to White men, including a two-fold higher risk of the aggressive triple-negative breast cancer subtype (30).



forms of breast cancer, such as triple negative breast cancer (30). Well-known risk factors for male breast cancer include family history of breast and/or ovarian cancers, mutations in *BRCA2* gene, radiation exposure, certain conditions that alter hormonal balance, and obesity, and diabetes (13).

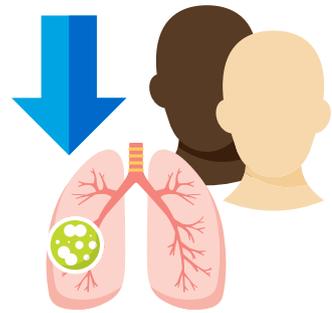
Prostate cancer is projected to account for 37 percent (or 41,600 cases) of all new cancer diagnoses in Black men in 2022, making it the most common cancer among Black men. The rate of prostate cancer incidence during 2014-2018 was 73 percent higher in Black men compared to White men, a disparity that has persisted for decades (1,10). During 2015-2019, the most recent years for which such data are available, prostate cancer death rates declined every year by 1.3 percent for Black men compared to 0.7 percent for White men. This favorable trend indicates a narrowing of the disparity between the two populations, but much remains to be done. Black men continue to have the highest death rate for prostate cancer compared to any racial or ethnic group in the U.S.; during 2015-2019, Black men were twice as likely to die from prostate cancer compared to White men (1,10). The reasons for disparities in the burden of prostate cancer among Black men are complex and multifactorial. Research has shown that biological factors (such as ancestry-related genetic differences) (31), as well as socioeconomic factors (such as lack of access to best available treatment options and/or suboptimal treatment for prostate cancer) contribute to the disparity in prostate cancer mortality among Black men (32,33). Researchers are currently working on understanding the biological and genetic features of tumors that contribute to disparities in the burden of prostate cancer.

Lung cancer is the third most common cancer in Black people and will account for more than 11 percent of all new cancer diagnoses (25,690 cases) in the population group in 2022. Effective smoking cessation campaigns over the past five decades have resulted in a

Stomach cancer incidence is roughly **two times higher** and **death rates are more than two-fold higher** in **Black individuals** than White individuals (1).



Disparity in lung cancer mortality between Black men and White men was reduced from more than 40 percent in 1990-1992 to 15 percent in 2015-2019 (1).



steady decline in the overall lung cancer incidence with a steeper decline among Black adults, greatly reducing the disparity in lung cancer incidence between Black and White populations (1).

Despite the narrowing disparities, lung cancer incidence rates in Black men were 12 percent higher than those in White men during 2014-2018 (1). Furthermore, an estimated 14,160 Black individuals are expected to die from lung cancer in 2022. Lung cancer is also the leading cause of cancer-related mortality in Black men and the second-leading cause of cancer deaths in Black women. Encouragingly, the lung cancer-related mortality has declined at a faster pace in Black individuals than in White individuals over the past two decades. During 2015-2019, the most recent period for which such data are available, the lung cancer death rate declined by about six percent every year in Black men compared to five percent in White men, and four percent in Black and White women. These trends reflect a steep decline in smoking rates over the past five decades, thanks to effective public health policies (see **Regulations to Reduce the Disparate Harms of Tobacco Products**, p. 138) (2).

An estimated 20,700 Black individuals are expected to be diagnosed with colorectal cancer in 2022, making it the fourth most common cancer in the Black population. During 2014-2018, Black people had the highest incidence of colorectal cancer in the U.S. compared to any other racial or ethnic minority group, and the incidence was nearly 15 percent higher compared to White people (10). Historically, colorectal cancer was more common in White populations until the early 1990s, when the colorectal cancer incidence became higher in Black populations due to an increase in the associated risk factors as well as lower screening rates for colorectal cancer (1,34). Even though the incidence rates are declining at a faster pace among the overall Black population compared to the overall White population (three versus two percent annual decline from 2009 to 2018, respectively), it is concerning that among individuals who are younger than 50 years of age the yearly decline for the same period was four times lower in Black people compared to White people (1). Furthermore, there is a major disparity between Black and White populations in mortality rates for colorectal cancer, which are 44 and 31 percent higher in Black men and women, respectively, compared to White men and women (1). Research indicates that many biological and socioeconomic factors contribute to disparities

Continued on page 22



“

If you find cancer early, you've got a shot at being OK. And if we can give the tools that physicians need, which only come from research, it makes it even better.”

Speaking Out About Male Breast Cancer

In July 2017, Mathew Knowles, a music industry executive, businessman, and university lecturer, noticed that his new white T-shirts had little dots of blood. When he mentioned this to his wife, she said that she herself had noticed that the sheets on his side of their bed had some small spots of blood.

Knowles recalled a seminar he had attended years ago, when he was selling radiology equipment for Xerox, that talked about small blood spots in the chest area as a possible sign of breast cancer.

“And at that time, I knew it might be breast cancer. I knew that because I have a family history of breast and prostate cancer,” he said.

When he spoke to his primary care physician about his concerns, he was met with skepticism. His doctor told him he had only encountered one case of male breast cancer in 40 or 50 years of practice. Mr. Knowles had extensive experience in the medical imaging field, so despite the skepticism from his physician, he insisted on getting a mammogram, which led to his diagnosis of stage IA breast cancer.

A diagnosis of breast cancer in men is more common than people realize, with more than 2,700 cases per year. Compared to White men, Black men are 50 percent more likely to be diagnosed with breast cancer, and twice as likely to be diagnosed with triple-negative breast cancer, the most aggressive form of the disease.

“No one wants to hear the words that you have cancer,” Mr. Knowles said, “For me, it was a moment of silence, because it just takes the breath away. And anyone who has heard those words has had those moments of silence where the brain is processing a mile a minute and asking, ‘Why me?’”

Quickly, Mr. Knowles consulted with oncologists in Philadelphia and Houston. After those discussions he decided to undergo a mastectomy just days after his diagnosis. Following his surgery, his breast tissue was tested for mutations in genes that are associated with a family history of cancer. His care team found that Mr. Knowles had a mutation in *BRCA2*, a gene commonly associated with causing breast cancer when a mutation in it is inherited from one or both parents. Knowing that he has a *BRCA2* mutation, Mr. Knowles has increased his adherence to surveillance testing for breast and other types of cancer.

“I have an annual mammogram. I also get an annual PSA for prostate cancer, a dermatologist visit, and an MRI for pancreas cancer,” he said.

Unfortunately, genetic testing for cancer in the United States is suboptimal, with rates even lower in the Black population. As a result, many people are unaware of their genetic risks for cancers and other diseases, leading to lower rates of active prevention and early detection.

Policy makers, Knowles said, should understand the importance of making genetic testing and other technologies more affordable and accessible to everyone to increase the use of these potentially lifesaving technologies.

“The first thing that I would say to policy makers is, ‘You might be saving your own life, or saving your son’s or your daughter’s life,’” he said. “Because when you’re talking about your family, it hits differently. The more progress we make, the more lives we save.”

And, Mr. Knowles explained, addressing the accessibility and cost of lifesaving technology is critical to reducing health disparities in the country.

“The percentage of deaths is much greater if cancer is not found early,” he noted.

Another challenge men in general, and Black men in particular, face is the stigma associated with being diagnosed with a type of cancer typically associated with women.

“No man wants to say he has breast cancer,” he said. “Words matter. The fact that medical centers say ‘women’s breast cancer center’ instead of ‘women’s and men’s breast cancer center’ or just ‘cancer center,’ makes a difference,” he said.

“The phrase that I use is male ‘chest’ cancer,” he said. “It might not be the accurate description but that’s not what we’re trying to do; we’re trying to save men’s lives, and if male chest cancer makes it more comfortable, then maybe we should consider it. Whatever gets us the greatest results.”

Since his diagnosis, Mr. Knowles has adopted a healthier lifestyle, exercising regularly, decreasing his intake of alcohol, and reducing the amount of meat he eats.

“I’m just grateful for my health,” he said. “I feel better today than before my diagnosis. A lot of that had to do with my lifestyle change,” which has resulted in the loss of 37 pounds.

And he’s grateful that his cancer was caught early—at stage IA.

“If you find cancer early, you’ve got a shot at being OK. And if we can give the tools that physicians need, which only come from research, it makes it even better.”

in colorectal cancer mortality for Black people, such as: obesity, malnutrition, and physical inactivity (see **Disparities in the Burden of Preventable Cancer Risk Factors**, p. 50); lower rates of screening for early detection (see **Disparities in Cancer Screening for Early Detection**, p. 71); and lower stage-specific survival (34,35).

Another cancer type with a significant racial disparity for Black people is multiple myeloma. In 2022, an estimated 7,810 new myeloma cases and 2,530 myeloma deaths are expected among Black individuals (1). Death rates for myeloma declined by three percent every year for Black women and one percent for Black men and White men during 2015-2019 (1), thanks to rapid advancements in effective therapeutics. However, both the incidence and mortality rates for myeloma in Black people remain at least twice as high as in White people, in part, due to disparities in access to quality health care and newer treatment options. From 2009 to 2018, there was also a concerning two percent yearly increase in the incidence of myeloma in Black women (1). Reasons for an increase in multiple myeloma incidence among Black women are multifactorial and may include higher rates of obesity (36); and a potential increase in the incidence of monoclonal gammopathy of undetermined significance, a blood condition that can progress to multiple myeloma (37,38), among other factors.

The U.S. Black population is heterogeneous and includes Black individuals who were either born in the U.S. or emigrated to the U.S. and trace their ancestry to any of the Black racial groups of Africa and the African Diaspora (see sidebar on **U.S. Racial and Ethnic Population Groups**, p. 13). It is important to underscore this heterogeneity because the burden of cancer varies substantially within the population subgroups (see sidebar on **Why Is Disaggregated Cancer Data Needed?**, p. 16). A recent study found large variations in age-adjusted cancer incidence rates across non-Hispanic Black (NHB) subgroups (39). For example, age-adjusted cancer incidence was >32 percent lower among NHB individuals born outside the U.S. compared to those born in the U.S. Furthermore, females born in Jamaica and other Caribbean islands had lower rates of cancer incidence (114.6 and 128.8 per 100,000, respectively) than those born in Africa and Haiti (139.4 and 149.9 per 100,000, respectively). No significant differences in age-adjusted cancer incidence were observed by birthplace among the immigrant NHB males.

HISPANIC OR LATINO(A) POPULATION

The Hispanic population—one of the fastest growing ethnic groups in the U.S.—accounted for 18 percent of the total U.S. population in the 2020 U.S. census (see **Figure 1**, p. 14). It is a diverse community of individuals from many races, religions, languages, and cultural identities. It is important to note that, because most U.S. cancer data are reported in the aggregate, the descriptions of incidence and mortality rates in the population do not account for the important differences among the diverse subgroups within the Hispanic population. (see sidebar on **Why Is Disaggregated Cancer Data Needed?**, p. 16). Furthermore, it has been demonstrated that inaccuracies and deficiencies in data collection on cancer deaths for Hispanic individuals results in a misleading inflation of survival statistics for this population (27).

In 2018, **gallbladder cancer** incidence rates in **Hispanic individuals** were **more than double** those in non-Hispanic White individuals (10).



Overall, Hispanic individuals are less likely to be diagnosed with cancer than NHW individuals, but have higher incidence of specific cancer types. In 2021, more than 1.7 million Hispanic individuals in the U.S. were diagnosed with cancer and nearly 50,000 died from the disease, making cancer the leading cause of death in this population group. Compared to the NHW population, the Hispanic population has lower rates of breast, colorectal, lung, and prostate cancers, but higher rates of gallbladder cancer as well as liver, stomach, and cervical cancers (1). However, as in the overall U.S. population, prostate and breast cancers are the most common cancers in Hispanic men and women, respectively. In recent years, the reduction in the burden of cancer in the Hispanic population has closely followed the trends in the NHW population, i.e., 0.5 percent yearly decline in overall incidence for both populations during 2009-2018, and 1.2 percent and 1.6 percent yearly decrease in overall mortality during 2010-2019, respectively (10).

Because of the heterogeneity of the Hispanic population, the risk for different cancer types varies widely depending upon country or region of ancestral origin (e.g., Mexican Americans versus Cuban Americans); nativity (e.g., U.S.-born versus foreign-born); and ancestral race (e.g., Indigenous Americans, Europeans, and Africans) (1,40). As an example, the lung cancer incidence rates during 2014-2018 among Hispanic individuals in Puerto Rico were 44 percent lower than among Hispanic individuals in mainland U.S. (16.1 versus 29.0 per 100,000, respectively) (10,41). In contrast, prostate cancer incidence rates among men in Puerto Rico were nearly 70 percent higher than among Hispanic men in mainland U.S. (144.3 versus 94.1 per 100,000, respectively) (1). As another example, genetic ancestry studies have demonstrated that risk of breast cancer is lower in Hispanic women if more of their genetic makeup comes from a higher proportion of Indigenous American

Compared to non-Hispanic White individuals, **lung cancer incidence and mortality rates among Hispanic individuals** in 2019 were 63 percent and 69 percent **less**, respectively (10).

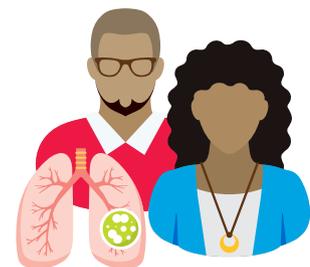


TABLE 1

Cancer Burden Disparities for Racial and Ethnic Minority Groups in the United States*

	AI/AN	API [§]	HISPANIC (ALL RACES)	NHB
Incidence Rate Ratio[¶]				
All Sites	0.73	0.65	0.73	1.00
Breast	0.69	0.77	0.70	1.00
Cervix uteri	1.23	1.02	1.47	1.48
Colon and rectum	0.96	0.82	0.82	1.22
Kidney and renal pelvis	1.20	0.53	0.99	1.13
Liver and intrahepatic bile duct	2.14	2.22	2.03	1.57
Lung and bronchus	0.72	0.58	0.47	1.05
Myeloma	0.97	0.65	1.06	2.29
Prostate	0.55	0.53	0.80	1.50
Stomach	1.64	1.99	1.88	1.93
Thyroid	0.70	0.95	0.84	0.57
Mortality Rate Ratio[#]				
All Sites	0.90	0.64	0.78	1.22
Breast	0.82	0.53	0.71	1.39
Cervix uteri	1.45	1.05	1.20	2.26
Colon and rectum	1.03	0.72	0.81	1.37
Kidney and renal pelvis	1.46	0.50	1.02	1.22
Liver and intrahepatic bile duct	2.31	2.18	2.10	1.65
Lung and bronchus	0.77	0.56	0.47	1.10
Myeloma	1.07	0.64	1.10	2.35
Prostate	0.81	0.55	0.89	1.90
Stomach	1.86	1.90	1.91	2.01
Thyroid	1.10	1.02	1.13	1.03

* Source: NCI Surveillance Epidemiology, and End Results Program SEER*Stat Database. Incidence and mortality data were analyzed using the Surveillance Research Program, National Cancer Institute SEER*Stat software. Data are shown as rate ratios between the White population and population groups shown in columns. Rates are per 100,000 and age-adjusted to the 2000 U.S. population. Rows indicate all cancer sites combined or individual cancer types. NHB, non-Hispanic Black; AI/AN, American Indian or Alaska Native; API, Asian or Pacific Islander.

§ Aggregated cancer mortality and incidence data are shown for Asian and Pacific Islander population here. See Tables 2 (p. 24) and 3 (p. 26) for disaggregated data for the population groups.

¶ Incidence rate ratio data shown are for 2018, the most recent year for which such data are available.

Mortality rate ratio data shown are for 2019, the most recent year for which such data are available.

ancestry but increases if more of their genetic makeup comes from European ancestry (42).

The three cancer types for which the Hispanic community shoulders a high burden of incidence and mortality compared to the NHW population are liver, stomach, and cervical cancers (see **Table 1**) (1). Hispanic men and women have nearly double the incidence and mortality rates for liver and stomach cancers compared to NHW men and women, while Hispanic women have an approximately 47 percent higher risk of cervical cancer incidence and 20 percent higher risk of death compared to NHW women (10,43). Reasons of the disproportionate burden of these three cancer types in the Hispanic population are multifactorial but

can be largely attributed to exposure to known risk factors, such as smoking, obesity, and pathogenic infections, all of which are highly prevalent within the Hispanic population subgroups (44,45).

Chronic infection with the bacterium, *Helicobacter pylori*—the strongest known risk factor for stomach cancer—remains high in Hispanic individuals compared to the NHW population (46). Chronic infection with HBV or HCV is the strongest risk factor for liver cancer and accounts for most liver cancer cases among Hispanic individuals in the United States (47). Other contributing factors to rising incidence of liver cancer among Hispanic populations include obesity and fatty liver disease (43). Furthermore, Hispanic individuals from Mexico may also be

Hispanic children and adolescents have the **highest rates of acute lymphocytic leukemia** of any racial and ethnic groups in the U.S., nearly double those of non-Hispanic Black children, who have the lowest rates (1).



exposed to aflatoxin—a carcinogen produced by a fungus that can grow in foods stored in moist, warm conditions—which is an important independent risk factor for liver cancer (48).

Cervical cancer is caused by persistent infection with certain strains of HPV. These carcinogenic strains of HPV have a higher prevalence among Hispanic women (1). Other factors contributing to higher cervical cancer incidence and mortality in Hispanic women include structural barriers in access to screening as well as significantly lower HPV and HPV vaccine awareness and knowledge within the Hispanic population. According to a recent study, more than 50 percent of foreign-born U.S. Hispanic adults are unaware of HPV and the preventive vaccine (49). These examples not only highlight the heterogeneity of the Hispanic population, but also underscore the need for disaggregated cancer and risk prevalence data in heterogeneous ethnic minorities in the U.S. so that evidence-based and population-specific interventions and policies can be devised to reduce and ultimately eliminate cancer health disparities (see **Policies to Address Disparities in Cancer Prevention**, p. 138).

NATIVE HAWAIIAN OR OTHER PACIFIC ISLANDER (NHOP) POPULATION

The Native Hawaiian or Other Pacific Islander (NHOP) racial group refers to individuals having origins in any of the original peoples of Hawaii and the six U.S.-associated Pacific Island jurisdictions: Guam; American Samoa; the Commonwealth of the Northern Mariana Islands; the Republic of the Marshall Islands; the Republic of Palau; and the Federated States of Micronesia. The NHOP population is comprised of more than 25 diverse subgroups with distinct variations in historical backgrounds, languages, and cultural traditions and, according to the 2020 U.S. Census Bureau, makes up roughly 0.2 percent of the U.S. population (19).

The overall cancer incidence in 2019 was 40 percent less in the NHOP population compared to the NHW population (50). While many major registries aggregate cancer data from NHOP and Asian American populations, the Hawaii Tumor Registry—funded by the NCI SEER—provides some cancer data for the state of Hawaii. According to its most recent *Hawaii Cancer at a Glance 2012-2016 Report*, the overall cancer mortality in the state was the highest in Native Hawaiians compared to the other major racial/ethnic groups [Chinese, Filipinos, Japanese, Whites, and Others

Annual Burden of Cancer in the State of Hawaii (2012-2016)

TABLE 2

NATIVE HAWAIIAN*		
	Incidence	Mortality
MALES		
All Sites	426	157.5
Colon and rectum	48.1	15.3
Esophagus	5.9	4.3
Leukemia	13.4	5.6
Liver	16.9	11.9
Lung and bronchus	57.2	38.5
Oral cavity and pharynx	18.8	4.1
Pancreas	15.1	12
Prostate	84.9	13.5
Stomach	11.2	5.5
Thyroid	7.8	NA**
FEMALES		
All Sites	399.9	110
Breast	137.5	15.8
Cervix	7.3	1.8
Colon and rectum	35.5	10.3
Esophagus	1.2	1.2
Leukemia	8.4	3.3
Liver	6.2	5
Lung and bronchus	36.4	23.5
Oral cavity and pharynx	8.2	1.6
Ovary	10	4.6
Pancreas	12	9.6
Stomach	6.7	3.5
Thyroid	22.6	NA
Uterus	30.8	4.2

*Data from *Hawaii Cancer at a Glance 2012-2016 Report*. Hawaii Tumor Registry, University of Hawaii Cancer Center. Shown here are 5-year average annual rates per 100,000 persons and age-adjusted to 2000 U.S. standard population.
**Rate was not calculated because of insufficient number of cases.

(includes all other races and ethnicities)] (see **Table 2**) (51). During 2012-2016, the most recent period for which such data are available, Native Hawaiian men had the lowest incidence of but the highest mortality from prostate cancer, while breast cancer incidence and mortality were highest among Native Hawaiian women compared to any other racial or ethnic group. Native Hawaiian women also had the highest mortality from multiple myeloma compared to any other

racial or ethnic group in the state (51). Although Hawaii had among the lowest rates of lung cancer in the United States in 2012-2016, lung cancer incidence was highest among Native Hawaiian men and women, and lung cancer mortality was highest in Native Hawaiian women compared to the other population groups in the state (51). Another cancer type with the highest mortality rate among Native Hawaiian men is cancer of the liver and intrahepatic bile duct compared to men from other population groups in the state (51).

Cancer incidence and mortality data for the U.S.-affiliated Pacific Islands remain sparse. A recent report, which evaluated the cancer incidence and mortality data from the Pacific Regional Central Cancer Registry captured during 2008-2013, provides some insights into the burden of cancer among Pacific Islanders (52). Incidence-based cancer mortality rates—a metric that allows calculation of mortality rates by stage at diagnosis, age at diagnosis and year of diagnosis—among males were highest in Palau (151 per 100,000) and lowest in American Samoa (22 per 100,000). Among females, rates were highest in the Republic of the Marshall Islands (120 per 100,000) and lowest in the Commonwealth of the Northern Mariana Islands (19 per 100,000) (see **Table 3**, p. 26) (52). Overall, Pacific Islanders had the highest incidence-based mortality rates for cancer types (lung, liver, cervical, oral cavity, and pharynx) that are either preventable through reduction of risk factors, or can be detected through effective screening tests at an early stage when treatments are most effective (52). Pacific Islanders also have a unique burden for certain cancer types. For example, women in the Republic of the Marshall Islands have eight times the U.S. incidence of invasive cervical cancer, making this the highest incidence of cervical cancer in the world (53). In addition, Pacific Islands were also the sites for nuclear bomb testing programs of many nations during the Cold War. Despite mixed evidence that radioactivity from the testing affected thyroid cancer rates among Pacific Islanders, the cultural context, perspectives, and fears related to radiation remain (54).

Because of its geographical location, racial and ethnic heterogeneity, and socioeconomic characteristics, the NHOPI population faces unique structural barriers to accessing quality health care, which can further exacerbate the disproportionate burden of certain types of cancer among the population. As evident from examples discussed throughout this section, disaggregated cancer data for the population group are sparse and not up to date with the mainland U.S. cancer data, underscoring the urgent need for collecting high-quality cancer data of the population so that effective and evidence-based strategies can be developed to address cancer health disparities in this population (see sidebar on **Why Is Disaggregated Cancer Data Needed?**, p. 16).

Cancer Health Disparities Among Other Medically Underserved Populations

In addition to racial and ethnic minorities, many other segments of the U.S. population shoulder a disproportionate burden of

Disparities in Cancer Incidence and Mortality in Medically Underserved Populations in the United States

In addition to race and ethnicity, other factors, such as residence in a remote area; discrimination based on gender identity and/or sexual orientation; and living under persistent poverty, contribute to cancer health disparities among certain segments of the U.S. population.

Examples below underscore the disproportionate burden of cancer among medically underserved populations:



Those Living in Persistent Poverty

Overall cancer mortality rate in persistently poor counties was 12 percent higher compared to non-persistently poor counties (55).



Those Belonging to Sexual and Gender Minorities

Transgender men are more than twice as likely as cisgender men to be diagnosed with cancer (56).



Those Living in Rural Areas

Incidence of hepatocellular carcinoma increased at a rate of 5.7 percent annually in rural areas from 1995 to 2016 compared to 3.9 percent in urban areas during the same period (57).

cancer (see sidebar on **Which U.S. Population Groups Experience Cancer Health Disparities?**, p. 12). These population groups are often racially and ethnically diverse, but are disadvantaged in their access to quality cancer care and may also have a higher prevalence of modifiable risk factors because of a myriad of factors including: residence in a remote area that lacks access to cutting-edge cancer treatments and/or state-of-the-art health care facilities (e.g., rural populations); gender and/or sexual orientation that may invoke implicit bias and discriminatory behavior (e.g., sexual and gender minorities); and persistent poverty that prevents a person from accessing the needed health care (e.g., low-income households) (see sidebar on **Disparities in Cancer Incidence and Mortality in Medically Underserved Populations in the United States**).

TABLE 3

Annual Burden of Cancer in the U.S.-affiliated Pacific Islands (2008–2013)*

	AMERICAN SAMOA	GUAM	COMMONWEALTH OF THE NORTHERN MARIANA ISLANDS	FEDERATED STATES OF MICRONESIA	MARSHALL ISLANDS	PALAU
IBM[§] Rate						
MALES						
All Sites	21.7	133.2	22.7	28.9	142	151.5
Colon and rectum	2.4	12.3	NA	3.6	2.7	11.4
Esophagus	NA [¶]	3.4	NA	NA	NA	5.8
Leukemia	0.7	1.7	2.1	1	1	6.1
Liver	2	20.7	5.7	5.1	24.5	28
Lung and bronchus	4.4	50	4.8	6	35	35.6
Oral cavity and pharynx	NA	4.6	NA	5	9.3	16.8
Pancreas	1.2	5.6	0.7	0.5	1.5	NA
Prostate	3.7	8.5	NA	1	9.4	26.9
Stomach	4.1	4.5	1	1.4	1.1	11.6
Thyroid	NA	1.2	NA	NA	NA	2.6
FEMALES						
All Sites	42.8	72.2	19	23.2	120.3	107.7
Breast	11.2	7.6	0.6	4.1	12.9	5.8
Cervix	4.2	1.9	NA	3.2	34	11.7
Colon and rectum	NA	5.2	NA	1.9	NA	4.7
Esophagus	NA	0.3	NA	NA	NA	3.1
Leukemia	0.3	1.9	NA	0.5	3.9	2
Liver	NA	3.9	NA	2.2	6.9	15.2
Lung and bronchus	NA	22.5	NA	3.2	23	19.4
Oral cavity and pharynx	2.7	1.9	3.2	0.5	5	5.2
Ovary	4.7	2.7	NA	0.5	5	7.3
Pancreas	NA	3.2	NA	0.5	6.8	6.3
Stomach	4.9	4	8.9	0.5	5.6	2
Thyroid	0.9	1	NA	NA	4.5	3.1
Uterus	8.8	3.4	4.8	3.6	3.5	8.9

* Data from Pacific Regional Central Cancer Registry Cancer Council of the Pacific Islands, based on vital status 'deceased,' reported with a cause-specific death classification attributable to cancer diagnosis, year of death January 1, 2008–December 30, 2013.

§ Shown for all U.S.-affiliated Pacific Islands are incidence-based mortality (IBM) rates per 100,000 persons and age-adjusted to 2000 U.S. standard population. Rank represents prevalence of the cancer types in the indicated island.

¶ Rate was not calculated because of insufficient number of cases.

POPULATIONS RESIDING IN RURAL AREAS

Rural and urban areas in the U.S. represent populations that are racially and ethnically diverse and have overlapping as well as distinct socioeconomic and sociodemographic patterns (58). Researchers and policy officials employ many definitions to distinguish rural from urban areas. NCI's Division of Cancer Control and Population Sciences uses the United States

Department of Agriculture (USDA) Economic Research Services' 2013 Rural-Urban Continuum Codes to define rural areas.

Based on this classification, an estimated 15 percent of the U.S. population and approximately 74 percent of the U.S. geographical areas are considered rural (59).

Rural counties have lower cancer incidence rates but higher death rates for all cancer sites combined compared to urban

THE HONORABLE
Shelley Moore Capito
U.S. Senator for West Virginia

“It is crucial we look at the impact health disparities play on cancer research, care, and our health care workforce. I have seen firsthand the impact health disparities have had and continue to have on the rural areas of my state of West Virginia, as well as in rural areas around the entire country. Access to high-quality cancer screening and care is essential for these communities, which are too often at the top of cancer prevalence and mortality lists, and at the bottom of the lists showing access to and utilization of cancer screening. During my time in the House, and now as a member of the Senate, I have worked to highlight this disparity, and I will continue to work to provide the funding needed to eliminate it through my role on the Senate Appropriations Committee.”



counties. It is of concern that differences in death rates between rural and urban areas are increasing over time (60). Additionally, while a recent study shows that the cancer incidence rates are declining among both rural and urban populations, the rate of decline in urban areas between 1995 and 2013 was more than double that of rural areas (10.2 versus 4.8 percent, respectively) (61).

Evidence suggests that some cancers are more common in rural areas while others are more common in urban areas. Among the four most common cancers in the U.S., lung and colorectal cancers occur more often in rural populations (59). Notably, lung cancer incidence rates in rural areas declined at nearly one third the pace of urban counties during the 1995-2013 period (6.95 versus 18.4 percent, respectively) (61). The slower decline in incidence rates of lung cancer in rural areas is mostly attributed to higher rates of tobacco use and lower rates of low-dose computed tomography (LDCT)—a screening exam for lung cancer (see **Ways to Screen for Cancer**, p. 71). Elevated incidence of colorectal cancer rates is likely because of higher prevalence of obesity and lower adherence to screening. Conversely, breast cancer and prostate cancer incidence rates tend to be higher in urban areas, likely because of higher uptake in breast cancer screening (62) and better access to quality health care.

Compared to those living in urban areas, individuals living in rural areas have 17 percent higher death rates from all cancers

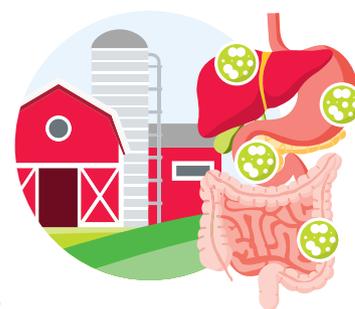
combined, although disparities in deaths from prostate and breast cancers have narrowed substantially in recent years (63). However, disparities in death rates for lung and colorectal cancers remain large, with 34 and 23 percent higher death rates in rural residents, respectively (63). Evidence suggests that progress in reducing cancer death rates for all cancers combined and for most common cancers has been slower in rural than in urban areas, further widening the disparities in mortality.

Reasons for rural-urban disparities are multidimensional. Compared to those living in urban areas, rural residents face many disadvantages that place them at an increased risk of cancer such as: restricted means to enhance socioeconomic status; higher exposure to certain cancer risk factors; and limited access to quality health care. Rural communities also tend to have limited access to high-speed Internet resources, a phenomenon known as the “digital divide.” In the wake of the COVID-19 pandemic, the cancer care community has become even more reliant upon electronic health and telemedicine (see sidebar on **What Is Telemedicine?**, p. 112), thus making the digital divide yet another cause for cancer disparities associated with rural residence. Cancer health disparities are further exacerbated, in part, by the lack of health insurance among some rural residents and shortages of primary care physicians, oncologists, and other cancer care specialists, as well as by limited access to state-of-the-art medical facilities. Furthermore, certain rural areas, especially in the Southeast, have disproportionately higher racial and ethnic minority populations. Due to historic and modern injustices these communities often live in persistently poor counties (see **Populations That Live Under Persistent Poverty**, p. 28), thus further exacerbating and compounding cancer health disparities.

INDIVIDUALS WHO BELONG TO SEXUAL AND GENDER MINORITY POPULATIONS

According to NIH, the sexual and gender minority (SGM) populations include, but are not limited to, individuals 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

During 1999-2019, the percent annual decline in mortality rates from gastrointestinal cancers in rural areas was about half that of urban areas (0.6 percent versus 0.8-1.2 percent, respectively) (64).



THE HONORABLE Terri A. Sewell

U.S. Representative for Alabama's 7th District

“The COVID-19 pandemic put a spotlight on health disparities in this country, but we didn’t need a pandemic to know they existed. Cancer disproportionately impacts rural and underserved communities resulting in worse and costlier outcomes.



Thanks to extraordinary scientific progress, we have more tools than ever to prevent, detect, and diagnose cancer, including emerging early detection screening tools, which have the potential to significantly reduce these glaring disparities. As cochair of the Ways and Means Committee’s Racial Equity Initiative, I take seriously my responsibility to bring equitable access to health care to the forefront of our policy agenda and I am committed to ensuring that rural and underserved communities like the ones I represent can access these new technologies as they become available.”

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 (63). According to the 2021 Gallup poll, about 5.6 percent of the U.S. population self-identifies as belonging to the SGM population (65).

There are limited data on the prevalence and incidence of cancer among SGM individuals, such as **Simone Saint Laurent** (see p. 30), with only a handful of studies documenting the cancer disparities that exist in this population (66). As noted in the 2011 Institute of Medicine report on lesbian, gay, bisexual, and transgender (LGBT) health—the first comprehensive effort by a federal body to understand the state of SGM health—there are critical gaps in understanding the burden of cancer in this diverse population, many members of which also belong to one or more medically underserved communities (e.g., a person may simultaneously belong to a racial or ethnic minority; identify as a member of the SGM community; and live in a medically underserved remote area) (67).

Since the publication of the report, many studies and surveys have evaluated aspects of cancer burden in the SGM community, such as experiences of SGM individuals within the health care system (68). It has been documented that potentially modifiable causes of cancer disparities related to SGM identity include

implicit biases and discriminatory health care provider behaviors (see **Figure 11**, p. 69). One important area warranting further research attention includes breast and cervical cancer screening guidelines for transgender individuals.

A follow-up report in 2020 from the National Academy of Sciences, Engineering, and Medicine indicated that some of the goals of the 2011 Institute of Medicine report have been met, but many challenges remain (69). In particular, comprehensive data on rates of cancer incidence and mortality in the SGM population remain sparse and mostly come from small observational studies (70), making it difficult to evaluate the true burden of cancer in this population. It is imperative that health care providers collect information on sexual orientation and gender identity from patients with cancer, as **Simone Saint Laurent** emphasized (see p. 30). Cancer incidence and mortality data for the SGM populations in disaggregated form, for example, by sexual orientation and gender identity, as well as among sexual minorities (e.g., lesbian versus bisexual) and gender minorities (e.g., transgender versus nonbinary) will help researchers accurately capture the true burden of cancer in these heterogeneous and diverse populations. The NIH Sexual and Gender Minority Research Office is leading several research and educational efforts to close the gap in understanding the health needs, including the burden of cancer, among SGM individuals (71).

POPULATIONS THAT LIVE UNDER PERSISTENT POVERTY

According to USDA, areas of persistent poverty in the U.S. are places where 20 percent or more of the residents have lived below the federal poverty level during a four-decade period. Many of these regions emerged following racial and/or economic segregation and lack opportunities for residents to rise out of poverty. About 10 percent of U.S. counties fall into this category, and most of them are in the rural Southeast (72).

Areas with low household income share a disproportionate burden of cancer incidence. As one example, a decrease in prostate cancer screening over the past decade, likely because of the USPSTF recommendation in 2012 against routine PSA screening for men between ages 55 and 69 (73), raised concerns of an increase in new cases of metastatic prostate cancer. A recent study found that the overall incidence of metastatic prostate cancer increased by 18 percent from 2008-9 to 2014-16. Alarming, the increase in diagnoses of metastatic prostate cancer was substantially higher—31 percent during the same period—in U.S. counties where residents were living 20 percent below federal poverty levels (74). Even though USPSTF revised its prostate cancer screening guidelines in 2018 and now recommends discussing the potential benefits and harms of routine screening with health care providers (75), it remains to be seen whether this change in guidelines will lead to narrowing of the disparity.

Residents of low-income areas also share a disproportionate burden of cancer deaths. In a landmark study, researchers from NCI presented evidence that persistent poverty is linked with increased rates of cancer deaths. Compared to the counties

Disproportionate Burden of Cancer and COVID-19 in Disadvantaged Segments of the U.S. Population

Cancer patients belonging to racial and ethnic minorities and other medically underserved populations in the U.S. also experience a disparate burden of COVID-19, largely because of the same complex and interconnected factors that drive cancer health disparities.



Examples below underscore concerns among researchers that the adverse effects of the COVID-19 pandemic on cancer patients from disadvantaged segments of the U.S. population, if left unchecked, will likely compound cancer health disparities:

COVID-19 Infections

Black patients with multiple myeloma had more than a four times higher likelihood of COVID-19 infection compared to White patients with multiple myeloma (77).

Severe Symptoms

Hispanic patients with cancer were 38 percent more likely to develop severe symptoms from COVID-19 infection compared to non-Hispanic White patients with cancer (78).

Worse Illness

Despite the similar distribution of cancer type, cancer status, and anticancer therapy at the time of COVID-19 diagnosis, Black patients presented with worse illness and had significantly worse COVID-19 severity (79).

that do not fall into the persistent poverty category, mortality rates were higher in the persistent-poverty counties for all cancer types (12.3 percent higher), as well as for cancers of lung and bronchus (16.5 percent higher); colon and rectum (17.7 percent higher); stomach (43.2 percent higher); and liver and intrahepatic bile duct (27.6 percent higher) (55).

The reasons for higher cancer incidence and mortality in low-income areas are multidimensional and are influenced by adverse differences in SDOH (see **Factors That Drive Cancer Health Disparities**). Persistent-poverty counties are characterized by larger populations of racial and ethnic minorities; less formal education; limited access to quality health care; and greater

unemployment. People living in persistent-poverty counties are also more likely to have higher prevalence of cancer risk factors such as obesity or cigarette smoking (72).

Impact of COVID-19 on Cancer Health Disparities

The COVID-19 pandemic has disrupted the everyday lives of billions of people, exhausted the health care infrastructure and workforce, upended societal norms, and shattered economies worldwide. As of March 31, 2022, the U.S.—which makes up 4.25 percent of the world’s population—accounted for 16.4 percent of global COVID-19 cases and 16.0 percent of global COVID-19 deaths (76). Unfortunately, many of the same complex and interrelated factors that contribute to U.S. cancer health disparities have also contributed to a disproportionate burden of the disease among racial and ethnic minorities and other medically underserved populations (see sidebar on **Disproportionate Burden of Cancer and COVID-19 in Disadvantaged Segments of the U.S. Population**) (7).

Factors That Drive Cancer Health Disparities

Root causes of cancer health disparities are multidimensional and multifactorial. Over the past few decades, researchers have proposed many models to understand and address health inequities, including cancer health disparities (80,81). A key component of these models is the framework of SDOH (see sidebar on **Key Terms Related to Cancer Health Disparities**, p. 34). 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 (82). SDOH have a major positive or negative impact on people’s health, well-being, and quality of life (see **Figure 5**, p. 32). It is increasingly evident that, structural racism and systemic injustices are key contributors to adverse SDOH, creating conditions that perpetuate health inequities, including cancer health disparities, for racial and ethnic minorities and other medically underserved populations (80).

Notably, the overall health outcomes of a person, community, or society are determined by the overlapping as well as intersecting nature of SDOH. Thus, SDOH must be examined at individual, communal, and societal levels to comprehensively understand and address health inequities(83). As one example, people who do not have access to grocery stores with healthy foods, or those who have access but cannot afford healthy foods, are less likely to have good nutrition. Lack of good nutrition, in turn, can increase the likelihood of developing health conditions, such as obesity and diabetes, that are major risk factors for cancer and other chronic diseases. Because SDOH are interconnected (see **Figure 5**, p. 32), promoting healthy choices alone will be insufficient to

Continued on page 32

Combating Breast Cancer, Thanks to Support from the LGBTQIA+ Community

The Monday before Thanksgiving of 2021, Simone Saint Laurent, a proud New Yorker from Brooklyn, received a phone call from her health care provider letting her know that she had breast cancer and that she needed a mastectomy.

The diagnosis stunned Simone. After getting over her initial shock, her next thought was, “Am I going to die? And my third thought was, how am I going to tell my wife this news?” recalled Simone.

She was 51 years old.

“As a lesbian, and a member of the LGBTQIA+ community, I came from a place of low self-worth, where the larger culture tells me that it’s not all right to be who I am. For a long time, I didn’t treat myself very well because of that. But in the last 10 years things had changed. I felt more supported in the culture, and I was taking better care of myself. I was eating well; I did not drink or smoke; I worked out five days a week. So, I was shocked to be diagnosed with breast cancer,” she said.

After turning 40, Simone received routine mammograms once every two years. Unfortunately, because of the pandemic and the resulting backlogs in screening, her latest appointment was delayed by almost a year. In late 2021, she received a mammogram that showed suspicious calcifications in her breast. She was immediately referred to a specialist for a biopsy, which led to her diagnosis of ductal carcinoma in situ (DCIS), also known as stage 0 breast cancer.

Even though the cancer was DCIS, biopsies revealed that she had an aggressive form of the disease. To ensure the best outcome and prevent future recurrence, her doctor recommended surgical removal, also known as mastectomy, of both breasts and testing of nearby lymph nodes to check if her cancer had spread.

“Hearing that I had stage 0 and then to be told in the same breath that I needed a mastectomy was shocking, to say the least,” Simone said. “I had to decide whether to undergo one mastectomy or both, or to take sentinel nodes or not, or to reconstruct my breast or not. That was an overwhelming amount of information to receive, and I didn’t have a lot of time to make these decisions, which was the hardest part of this experience.”

What helped Simone the most was reaching out to her LGBTQIA+ community and, especially, talking to her transgender friends about their experiences with breast surgeries.

When Simone’s physicians recommended the mastectomy, they also recommended reconstructive surgery. Her providers assumed she would want breast implants. She did not.

“I didn’t know that there was an option of going flat. It was an assumption that I would have implants. That was difficult for me because I didn’t want a foreign object in my body,” Simone recalled. Ultimately, she chose a procedure called deep flap which used her own tissue to reconstruct her breasts. Throughout her decision-making process, she benefited from talking with transgender friends about their experiences with breast surgery, and she wishes her providers had discussed all options with her.

Simone did not feel comfortable discussing her sexual orientation or gender identity with her providers.

“I never felt discriminated against by doctors, but I did think that this was information I had to reveal throughout the process, by me referring to my wife. It was never asked of me, and I think medical intake forms should ask specific questions on gender identity, sexual orientation, and preferred pronouns, how they are partnered or married,” she said. “It would be amazing if providers could get that information before they met the patient and put it into consideration while recommending treatments. I think it would give more understanding and ability to empathize with the patient and improve quality of care.”

Simone was also apprehensive about her cancer being associated with a “genderized” color.

“I thought, oh no, everything’s going to be pink. It forced me to be a part of a culture that rejects me,” she said. “I also think that calling it breast cancer survivor group, instead of women’s breast cancer survivor group, would be more encompassing and more inclusive,” she added.

For Simone, the next steps of treatment involve ensuring that she is fully satisfied with her breast reconstruction. Once her breasts have healed, she will decide with her surgeon whether she needs further revisions. While she may need yearly exams, Simone is now considered someone with a “past history” of cancer.

“I never thought I would say I was grateful to cancer, but I am. Facing difficult situations helps you find out about qualities that you didn’t know you had. I had no idea that I could persevere. I didn’t know I had the strength to go through this experience. It has given me an opportunity to share my feelings with friends and family. I have a stronger family and relationships with my friends,” she said. “I can speak and advocate for my community and be a voice that says we need to change things and that we’re worth it. We are worth it to survive so that we can share this message and help generations to come.”

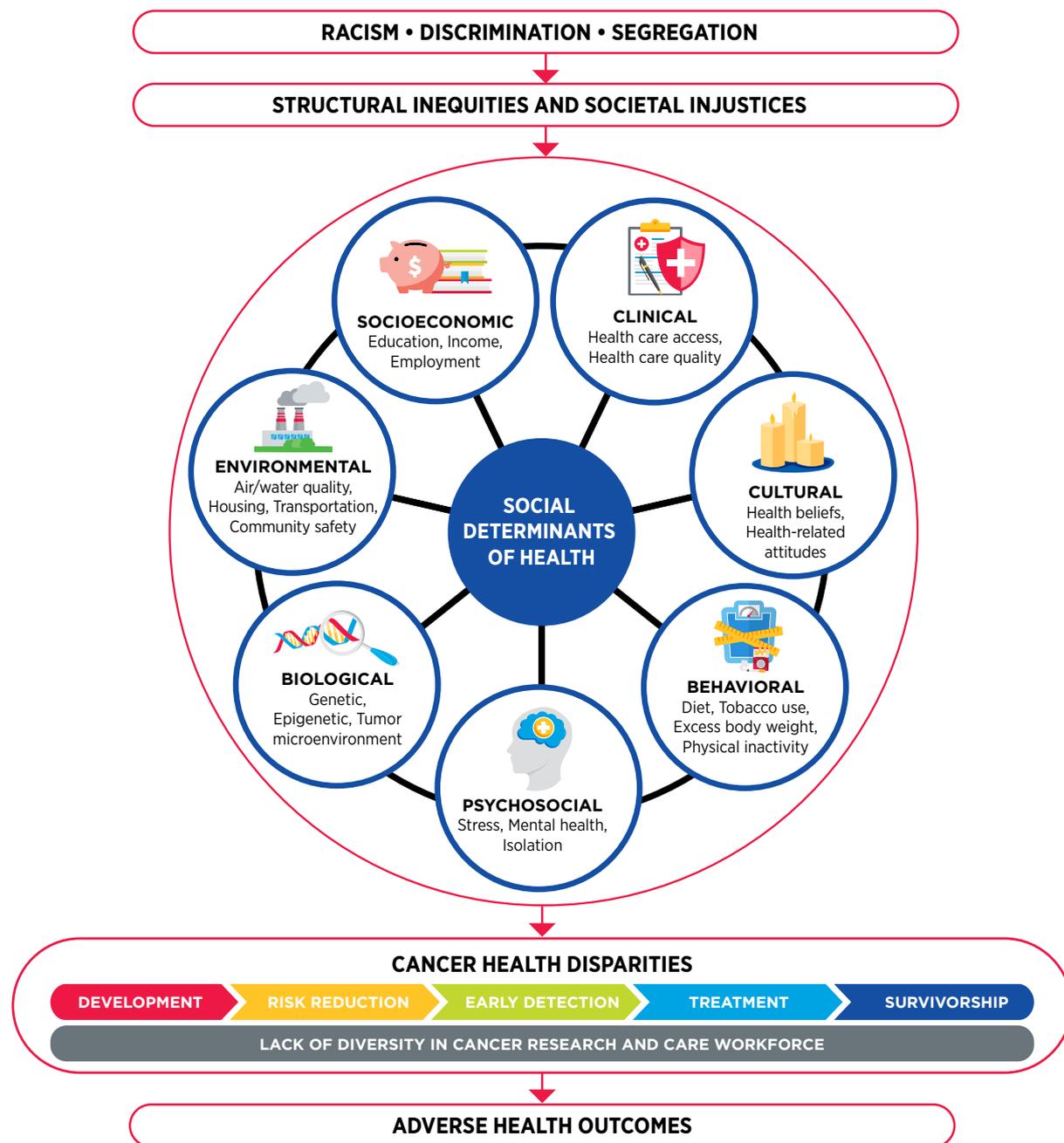


“

Medical intake forms should ask specific questions on gender identity, sexual orientation, and preferred pronouns.”

FIGURE 5

Why Do U.S. Cancer Health Disparities Exist?



Complex and interrelated factors—called social determinants of health (SDOH)—drive cancer health disparities. The National Cancer Institute defines SDOH as 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. SDOH have a major influence on people’s health, well-being, and quality of life. In the United States, centuries of structural racism and systemic inequities have perpetuated and exacerbated adverse

differences in SDOH for racial and ethnic minorities and other medically underserved populations. The circle in the figure depicts key SDOH and how they interconnect and intersect, both at societal and community levels and at the individual level. Selected examples of the multilevel factors comprising SDOH 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).

THE HONORABLE

Cheri Bustos

U.S. Representative for Illinois' 17th District

“Before I came to Congress, I lost my brother Danny to a battle with neurotropic melanoma, a rare form of skin cancer. During his battle, his insurance refused to cover his treatment because it was considered an experimental drug.



His experience reflects the story of too many Americans who've struggled to access care when it was needed most. In my time in office, I've focused my work on ensuring that every American has access to affordable, quality health care—and on addressing the social determinants of health driving disparities in research, treatment, care, and health outcomes nationwide. By tackling these challenges, such as through localized grants in line with my Social Determinants Accelerator Act, we can ensure that fewer of our loved ones are taken from us by cancer.”

eliminate health disparities in this context. Instead, stakeholders from multiple sectors, such as education, health, labor, transportation, and housing, will need to take collective and coordinated action to improve access and affordability of healthy food and safe green spaces and gyms for physical activity, as well as to raise awareness of health benefits of eating well.

In recent years, there has been an increased focus on incorporating SDOH in public health programs. For example, addressing various aspects of SDOH is one of the five key objectives of the Healthy People 2030 Framework—a program by the United States Department of Health and Human Services (HHS) to promote, strengthen, and evaluate the nation's efforts to improve the health and well-being of all people (87). The National Institute of Minority Health and Disparities (NIMHD) Research Framework organizes SDOH in five domains of influence—biological, behavioral, physical/built environment, sociocultural environment, and health care system—whereby each domain can be influenced at four distinct levels—individual, interpersonal, community, and societal (83). Researchers are also applying multilevel and transdisciplinary approaches to move the field of cancer health disparities research from simply describing different outcomes among populations into an established field of convergence science—the research that explores how social, lifestyle, structural, and biological determinants of health can impact each other to either exacerbate or mitigate disparities and either thwart or promote health equity (91). The

overarching goal of such efforts is to identify and address knowledge gaps relevant to understanding and improving health and to the understanding and reduction of health disparities so that informed policy decisions can be made to achieve health equity for all.

In this section, we discuss key factors that overlap and intersect and, independently as well as collectively, contribute to cancer health disparities. It is important to note that the same SDOH that drive cancer health disparities also contributed to COVID-19 pandemic-related health inequities, as discussed in the *AACR Report on the Impact of COVID-19 on Cancer Research and Patient Care*, released early in early 2022 (7).

SOCIOECONOMIC STATUS

Socioeconomic status (SES) is the social standing of an individual or a group. SES can be measured at the individual or neighborhood level. At the individual level, it is typically based on a person's income, education level, occupation, and other factors. SES at the neighborhood level includes the SES of the residents and also captures influences of the social environment on access to goods and services; levels of crime, safety, and policing; and social norms (3). SES is one of the most important factors that contribute to cancer health disparities in people of all races and ethnicities (92-95). For example, a low SES substantially increases the likelihood of exposures to environmental (e.g., living in areas with high levels of air pollutants); behavioral (e.g., excessive alcohol intake); and clinical (e.g., lack of access to health insurance) risk factors, all of which can lead to adverse cancer outcomes.

It is known that many racial and ethnic minorities and other medically underserved populations live in conditions that perpetuate low SES. According to the 2020 U.S. Census, 19.5 percent of the Black and 17 percent of the Hispanic populations were living below the federal poverty level compared to 8.2 percent of the NHW population (96). Those living in poverty lack access to healthy food; stable employment; suitable housing; formal education; and quality health care, all of which contribute to unhealthy behaviors and not only increase the risk of developing cancer and other chronic diseases, but also result in adverse health outcomes (see **Populations That Live Under Persistent Poverty**, p. 28).

Patients living in **low-income neighborhoods with higher proportions of non-Hispanic Black and Hispanic populations** in South Florida during 2005-2017 had **double the risk of breast cancer-related mortality** compared to those living in non-Hispanic White high-income neighborhoods (97).



Key Terms Related to Cancer Health Disparities

This report includes topics and terms that have defined descriptions, applicability, and/or purpose in the cancer health 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 Health 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, gender and sexual identity, geographic location, income, education, and other characteristics (3).



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, immigration status, gender identity, and sexual orientation (90).



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 (90a).



Health Equity

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 (3).



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 (84).



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 four-decade period (85).



Rural and Urban Areas

The U.S. Department of Agriculture categorizes rural and urban areas using the rural-urban commuting area codes, which classify U.S. census tracts—small, relatively permanent statistical subdivisions of a county or statistically equivalent entity—using measures of population density, urbanization, and daily commuting (86).



Social Determinants 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 determinants 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 (87).



Socioeconomic Status

A way of describing individuals or neighborhoods based on their education, income, housing, and type of job, among other indicators (88).



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 (89).

A recent study found that women residing in the lowest-SES neighborhoods of New York City were 73 percent more likely to develop cervical cancer than those in the highest-SES neighborhoods (98). Another example of how SES impacts health outcomes is the finding that overall cancer mortality rates among individuals with 12 or fewer years of formal education are more than double of that among individuals with at least 16 years of formal education (13). An emerging and important factor with potential to widen the disparities gap for individuals with low SES is access to digital services, such as reliable Internet connection and computers. Based on recent data, only 69 percent of Black adults and 67 percent of Hispanic adults reported owning a desktop or laptop computer compared to 80 percent of White adults (99). The essentiality of digital services—especially in providing remote care through telemedicine to patients with cancer among other diseases—is underscored by the COVID-19 pandemic, raising concerns among researchers that the “digital divide” will further exacerbate cancer health disparities (see sidebar on **What Is Telemedicine?**, p. 112) (7).

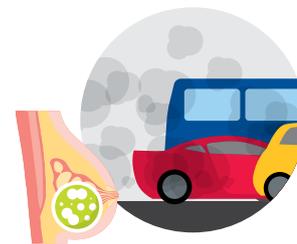
SOCIAL AND BUILT ENVIRONMENTS

Neighborhoods where people live and work can be broadly described in terms of their social and built characteristics that intersect and overlap with each other to influence health outcomes. Social environment of a neighborhood is determined by the racial and ethnic composition of the community; SES of individuals and the neighborhood (see **Socioeconomic Status**, p. 33); and residential segregation and distribution. These broad categories, in turn, determine cultural norms, quality of education, and crime, among other characteristics of a neighborhood.

Built or physical environment of a neighborhood contains transportation; public services; and policies and regulations, all of which influence the availability of and access to food, medical facilities, and green spaces, among other attributes of a neighborhood. In addition to the individual SES, social and built environments of a neighborhood independently influence the cancer continuum (100).

Decades of research have shown that the physical environments and surroundings in which people live and work are key determinants of exposure to risk factors that can adversely affect health outcomes (101). This knowledge has prompted HHS to include promoting healthier environments at home and workplaces as one of the five objectives of the Healthy People 2030 initiative (102). Due to a long history of racial segregation in the U.S., racial and ethnic minorities are more likely to live in poor neighborhoods. Although the number of individuals belonging to racial and ethnic minorities who live in poor neighborhoods has dropped by 10 percentage points between 1990 and 2019, more than 16 percent still live in poor neighborhoods compared to about 4 percent of the White population (103), increasing their likelihood of exposure to cancer risk factors. As noted above, these neighborhoods are also characterized by financially constrained public school systems, resulting in more limited higher education and future employment prospects, thereby perpetuating a legacy of generations that are trapped in poverty. This residential racial

During 1993-2010 in California, an **increased exposure to air pollution** caused by fuel burning was associated with a **26 percent and 42 percent increased risk of breast cancer in Black and Japanese American women** living in neighborhoods close to major roads, respectively (104).



segregation contributes to the lack of diversity in the health care workforce (see **Diversity in the Cancer Care Workforce**, p. 131), yet another source of cancer health disparities.

Historic and egregious housing policies such as redlining—a discriminatory practice in which financial and other services are withheld from potential customers who reside in neighborhoods classified as “hazardous” for investment—have resulted in residential segregation of many low-income people, often belonging to racial and ethnic minorities, into neighborhoods with industrial facilities and high air pollution. Although not legally supported, redlining and racial bias in mortgage lending continue to this day. A recent study found that women with breast cancer living in contemporary redlined areas were at a 58 percent increased risk of breast cancer mortality (105). Furthermore, a 2019 report by the U.S. Environmental Protection Agency (EPA) found that the Black and Hispanic individuals were consistently at a higher risk of exposure to air pollutants, as well as pollution-related adverse health effects, compared to White individuals (103). Another example of the impact of environmental pollutants on the health of workers comes from the exposure of Latino migrants, who account for nearly 75 percent of farmworkers in the U.S., to pesticides that are known to cause cancer (106). Concerningly, a recent study in California found that adolescent Latino boys whose mothers have been exposed to a commonly used pesticide are at a higher risk of developing testicular cancer (107).

MENTAL HEALTH

Mental health encompasses the emotional, psychological, and social well-being of a person and affects how one thinks, feels and acts (108). Negative mental health and the resulting psychological stress can directly or indirectly cause several physical health problems. While it is unclear whether the psychological stress is a direct cause of cancer, a growing body of knowledge suggests a reciprocal link between cancer and psychological and mental health of a person (109). A recent study found that increased psychological distress was associated with increased cancer mortality (110). Furthermore, studies have shown that individuals who are under persistent stress, as well as those who have experienced adverse childhood

According to the National Survey on Drug Use and Health, **smoking prevalence** in 2016 was **nearly 41 percent in people who reported having serious psychological stress** compared to 19.5 percent in those who did not report any psychological stress (114).



experiences, can develop certain behaviors, such as tobacco smoking, that can increase the risk of developing cancer. A cancer diagnosis substantially impacts the mental and psychological health and well-being of a person (111). For example, a recent study found that more than eight percent of individuals received a mental health diagnosis within 200 days of being diagnosed with cancer (112). There are also indications that psychological stress is moderately linked to cancer recurrence (113).

A large recent study examined the likelihood of psychological distress as a risk factor for U.S. cancer mortality between 1997 and 2014. Researchers found that cancer mortality risk was 33 percent higher in adults with serious psychological distress compared to adults without psychological distress (115).

Mental health intersects with other SDOH: low SES is associated with more frequent mental health problems (117); persistent poverty adversely impacts mental health of adolescents (118); living in more urban environments is linked with negative mental health outcomes (119); and, while the link between race/ethnicity and mental health is more complex, those belonging to racial and ethnic minorities report consistently higher psychological stress and mental trauma compared to White people (120).

MODIFIABLE RISK FACTORS

Modifiable risk factors are aspects of behavior that can be changed to decrease the risk of developing cancer. These individual health behaviors include smoking, malnutrition, alcohol consumption, exposure to carcinogenic pathogens, and limited physical activity, and are often shaped by a person's

Black women who suffered from childhood sexual abuse and trauma were more than four times as likely to develop certain types of breast cancer (116).



SES as well as the social and built environments. It is thus not surprising that racial and ethnic minorities and other medically underserved populations experience disparities in the burden of many modifiable cancer risk factors (see **Disparities in the Burden of Preventable Cancer Risk Factors**, p. 50). It is noteworthy that most cancer risk factors also contribute to other chronic diseases, such as diabetes and chronic renal disease, which are also more common in racial and ethnic minorities and may influence disparities in cancer survival and treatment outcomes (43). Moreover, foreign-born people may face an increased risk for specific cancers associated with infection with cancer-associated pathogens that have higher incidence in their countries of origin (see **Infectious Agents**, p. 64).

According to one estimate, 42 percent of cancer cases and 45 percent of all cancer deaths in the U.S. in 2014 were attributable to modifiable risk factors (121). Many of the modifiable cancer risk factors—smoking, physical inactivity, excess alcohol consumption, obesity—are also more prevalent in racial and ethnic minorities and other medically underserved populations (see sidebars on **Disparities in the Prevalence of Tobacco Use in the United States**, p. 54; and **Racial and Ethnic Disparities in Obesity, Diet, and Physical Activity in the United States**, p. 58). There are only a few studies, especially those with racially and ethnically diverse study populations, that are directly examining the effects of changing or reducing risky health behaviors on decreasing the cancer risk. Most studies have primarily focused on Black women at high risk for breast cancer (122). As an example, one study reported a marked reduction in signs of metabolic syndrome—a collection of conditions that include high cholesterol and excess body fat around the waist—following a 6-month light-to-moderate exercise program in Black women with unhealthy weight (123).

Because modifiable behaviors affect the risk of developing cancer over longer periods of time, researchers are evaluating various multipronged and long-term interventions in medically underserved populations, including: increasing awareness of cancer risk factors among middle and high school students in the Appalachian Kentucky region (124); implementing evidence-based obesity education curricula that are specifically tailored for the Mexican Hispanic community, which has high prevalence of obesity (125); utilizing the reach of faith-based organizations for weight loss interventions to reduce cancer risk in Black men (126); developing interactive cancer risk-reduction education tools (127); using narrative approaches to educate Hispanic women about the importance of screening for cervical cancer (128,129); and employing smartphone-based interventions to promote smoking cessation among Alaska Native women (130). Findings of these and other ongoing efforts will provide a clearer understanding of which interventions are successful in modifying unhealthy behavior to reduce cancer risk. Furthermore, it will be equally important to create interventions that are culturally tailored and inclusive, i.e., the study design, materials, and other components of the intervention reflect cultural needs and preferences of the community (131).

BIOLOGICAL FACTORS

Since the decoding of the human genome more than two decades ago, research has increased our knowledge and understanding of the biological mechanisms that can lead to cancer development tremendously (see **Understanding Cancer Development in the Context of Cancer Health Disparities**, p. 40). We now know that subtle changes in DNA sequence of certain genes, as well as changes in the patterns of expression of cancer-related genes, have the potential to increase the risk of cancer development. Research further shows that a combination of genetic changes and environmental influences can potentially contribute to racial disparities in cancer incidence and progression. It is important to note that, despite an explosion in our knowledge of the genetic basis of cancer development, much of the genome-wide information on the burden of cancer has been gleaned from studies in populations of primarily European ancestry, with substantial underrepresentation of racial and ethnic minorities.

As an example of the link between genetic ancestry and burden of cancer, Black women in the U.S. have a disproportionately higher rate of developing TNBC, a particularly aggressive type of breast cancer, compared to White women (132). Researchers have found that TNBC is more prevalent in Black women who trace their ancestry to West Africa, and more specifically to Ghana (133,134). Similar links have been identified between ancestry and risk of developing prostate cancer in Black men (31,135). Studies linking certain genetic variations with risk of developing specific cancer types carry the enormous potential of developing precise screening and/or treatment strategies (see **Integrating and Translating our Knowledge**, p. 48). However, a key limitation of these studies is not only the lack of sufficiently diverse populations, but also the low number of racial and ethnic minority individuals who do participate. It is imperative to include racially and ethnically diverse populations in genomic research studies so that the promise of precision medicine can be fully realized.

HEALTH CARE ACCESS AND EXPERIENCES

The lack of access to quality health care, often associated with low SES, is a key driver of health disparities, including disparities in cancer care. According to the National Academy of Medicine, the quality of health care is the degree to which health care services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge. It is well known that racial and ethnic minorities and other medically underserved populations receive lower quality care compared to White individuals (95). In the U.S., the only industrialized nation without universal health coverage for all citizens (136), a key contributor to these access inequities is the lack of universal health insurance coverage.

In the U.S., a higher proportion of individuals belonging to racial and ethnic minorities and other medically underserved populations are without health insurance. Among those older than 65 years of age in 2019, 30.2 percent of Hispanic, 25.9

In 2019, more than 32 percent of **uninsured individuals** either **delayed or did not receive the needed medical care due** to the associated financial costs (13).



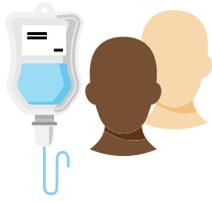
percent of AI/AN, and 14.3 percent of Black people were without insurance compared to 10.2 percent of White or 7.1 percent of Asian people (13). Lack of insurance often dictates whether an individual will receive the needed health care. Furthermore, compared to those with private insurance, uninsured 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. It is noteworthy that insurance alone does not guarantee access to quality health care. For example, the distance between the place of residence and a well-equipped health care facility with highly trained staff can be a barrier to receiving quality health care (137,138). One study found that the racial and ethnic disparities in treatment of colon cancer persisted even with comparable insurance status; among privately insured individuals, Black patients were 24 percent less likely to undergo surgical removal and 23 percent less likely to receive chemotherapy, and Hispanic patients were 24 percent less likely to undergo surgical removal compared to NHW patients (139). In addition, not all health insurance plans are the same, as some may carry high deductibles and copays that can become financially prohibitive for cancer patients. Financial toxicity, or the financial strain associated with a cancer diagnosis, can affect the quality of care that a patient receives, as well as their psychosocial distress (see **Financial Toxicity**, p. 118). It must be noted that the COVID-19-related economic recession was disproportionately severe for racial and ethnic minorities, resulting in the loss of employment and employment-based insurance for individuals as well as their families (140). Recovery from the recession has lagged for marginalized communities, further compounding the existing cancer health disparities.

Lack of comprehensive health insurance or any insurance at all disproportionately and adversely affects patients with cancer. The reason is that patients with cancer often receive a combination of different types of treatment—surgery, radiotherapy, chemotherapy, molecularly targeted therapy, and immunotherapy—each of which

In 2018, **only 30.2 percent of women without health insurance were up to date with the recommended breast cancer screening** compared to 68.2 percent of those with any private insurance (13).



Expansion of Medicaid under the Affordable Care Act 2010 has **nearly eliminated the disparity between Black patients and White patients in receiving chemotherapy**



within a month of cancer diagnosis from a 4.8 percentage point difference to a 0.8 percentage point difference (144).

is costly, even with health insurance. A recent study found that, compared to the privately insured, the risk for advanced breast cancer diagnosis and death from breast cancer was more than double in uninsured women (141). Combined with the higher proportion of uninsured individuals among racial and ethnic minorities and other medically underserved populations, a cancer diagnosis can lead to debilitating financial hardship and adverse health outcomes, further contributing to cancer health disparities (see **Financial Toxicity**, p. 118) (139,142,143).

In addition to the lack of access to quality health care, there are other factors associated with interactions of minority individuals with the health care system that contribute to cancer health disparities. For example, a 2020 survey of 1,769 U.S. adults found that Black and Hispanic adults were more likely to report some negative experiences with health care providers, including providers not believing they were telling the truth or refusing to provide pain medication or other treatments they thought they needed (145). Furthermore, historical atrocities, such as experimental gynecological surgeries performed by the Alabama physician James Marion Sims on enslaved Black women in the nineteenth century (146); the Tuskegee Study in the early twentieth century conducted in Black people by the medical establishment of the time (147); or in the 1950s, the development of the first cancer cell line, extensively used in biomedical research, without the consent of a Black woman with the name of Henrietta Lacks (148), all collectively provide important context for understanding the present-day mistrust of the health care system among racial and ethnic minorities. Thus, it is the responsibility of the medical research community and the health care establishment to take proactive and effective measures to alleviate mistrust in the health care system among racial and ethnic minorities. Research also indicates that communication and interaction barriers, such as limited health literacy and limited English language proficiency, contribute to cancer disparities. Racial and ethnic minorities and other medically underserved populations are also underrepresented in clinical studies evaluating the efficacy of anticancer treatments (see **Disparities in Cancer Clinical Trial Participation**, p. 88), which can potentially contribute to higher cancer mortality and morbidity. Among the many reasons for low participation—fear of taking an experimental drug, time commitment, travel to the site where study is taking place, out-of-pocket costs—researchers have found that physicians are less likely to discuss clinical studies with minority patients (149). When

offered, Black patients participate in clinical studies at similar rates compared to White patients (150).

Continued and concerted efforts to understand and address the root causes of cancer health disparities are pivotal to realize the bold vision of achieving health equity for all. At the level of the health care system, these efforts must include eliminating gaps in health insurance, increasing access to quality health care, and eradicating discrimination and bias across the cancer care continuum. At the population level, these efforts must include addressing broader structural and socioeconomic factors (151).

Achieving Health Equity: A Vital Investment for the U.S. Public Health and Economy

Cancer takes its toll on individual patients, communities, and the society as a whole. It is instructive to examine the economic burden of cancer and cancer health disparities so that evidence-based strategies can be developed and implemented.

In 2020, the U.S. spending on cancer-related health care was \$200.7 billion, accounting for nearly five percent of all health care spending that year (152,153). The cost of cancer care is projected to reach \$246 billion by 2030 (152). These costs are paid by many entities and people including employers, insurance companies, taxpayers, and cancer patients and their families and do not include the indirect cost of lost productivity. According to NCI's *2021 Annual Report to the Nation on the Status of Cancer*, the

THE HONORABLE

Andy Kim

U.S. Representative for New Jersey's 3rd District

"Cancer has touched everyone; we all know family members, friends, and coworkers who have had or been close to someone who has had cancer. My Dad spent his career in New Jersey trying to cure cancer and Alzheimer's, so



this research is deeply personal to me. Incredible progress has been made in cancer research, but there's always more to do and I applaud AACR's work to decrease health disparities in cancer research. In Congress, I will continue supporting cancer research, working to eliminate health disparities, and fighting to ensure every American has access to quality, affordable health care."

economic burden associated with cancer care on patients in the U.S. in 2019 was an estimated \$21.09 billion, including \$16.22 billion in out-of-pocket costs and \$4.87 billion in time costs, i.e., the value of time patients spent traveling to and from health care facilities, and waiting for and receiving care (154).

Not surprisingly, racial and ethnic minorities and other medically underserved populations also share a disproportionate economic burden associated with cancer. According to one estimate examining the direct cost of cancer health disparities during 2002-2007, eliminating racial disparities in incidence of the four most common types of cancer—lung, colorectal, breast, and prostate—would have resulted in \$2.3 billion in savings on annual medical expenditures by patients with cancer (155). Compared to NHW individuals, racial and ethnic minorities also suffer substantially higher person-years of life lost, which is an estimate of the average years a person would have lived if they had not died prematurely. Person-years of life lost is often used by public health experts to determine the economic cost of premature mortality because of a disease or another cause. One study found that lost earnings from cancer deaths in the U.S. in 2015 were \$94.4 billion (156). Findings from another study indicate that, compared to NHW individuals, person-years of life lost and rates of lost earnings for Black individuals were more than double because of premature deaths related to prostate and stomach cancers and multiple myeloma (157).

In the past decade, there has been some promising progress toward reducing cancer health disparities among racial and ethnic minorities and other medically underserved populations, as is evident by the narrowing gaps in overall cancer incidence and deaths among different populations (see **Figure 2**, p. 14). It is also reassuring that there is an increased urgency within the cancer community to understand and address cancer health disparities. Among the many federal agencies addressing the health disparities, National Institute on Minority Health and Health Disparities (NIMHD) and NCI, specifically its Center to Reduce Cancer Health Disparities (CRCHD), are key institutes primarily focused on reducing disparities in the burden of cancer. Both institutes and CRCHD spearhead numerous programs and offer many funding opportunities to address cancer health disparities (see sidebar on **NCI Programs That Address Disparities in Cancer Prevention and Care**, p. 136). These

THE HONORABLE
Mike Thompson

U.S. Representative for California's 5th District

“Federal investment in cancer research and prevention is essential to reduce cancer rates in America. By developing the next generation of cancer prevention technology and medicine, millions of Americans affected by cancer can live longer, healthier lives. However, this can only be achieved if cancer research and those who conduct it are as diverse as our nation. Our diversity is one of our greatest strengths, and I am grateful to work with organizations like the American Association for Cancer Research to make medical diversity a priority and strive to end cancer as we know it.”



include basic research on the biology behind disparities; large studies examining the factors that contribute to disparities; programs at the community level that are aimed at overcoming barriers to cancer care; and population-based registries that help to document the extent of the problem and highlight areas for further research.

Cancer health disparities stem from complex and intersecting factors, and thus require comprehensive and multidisciplinary strategies to eliminate them. With the accruing evidence that the COVID-19 pandemic has further exacerbated many of the existing cancer health disparities (7), it is all the more important that Congress continue to provide sustained, robust, and predictable increases in funding for the federal agencies, such as NIH, NCI, CDC, and NIMHD, that are at the forefront of addressing the menace of cancer health disparities so that the bold vision of health equity can be realized (see **AACR Call to Action**, p. 149).

Understanding Cancer Development in the Context of Cancer Health Disparities

IN THIS SECTION, YOU WILL LEARN:

- ▶ Cancer is a highly diverse group of diseases characterized by uncontrolled cellular growth.
- ▶ Biological determinants of cancer development include changes within and outside the cell.
- ▶ Pathogenic germline mutations predispose individuals to diseases such as cancer. These mutations can be more common in groups that share genetic ancestry.
- ▶ Identification of genetic, epigenetic, transcriptomic, and protein alterations that drive cancer are an important part of the cancer care decision-making process and form the foundation of precision medicine. The majority of currently available cancer treatments are based on studies of individuals that are of European ancestry and have consequently benefited these populations more compared to groups of non-European ancestry.
- ▶ To equitably treat cancer, continued research is needed to deepen our understanding of cancer biology in racial and ethnic minorities and other underserved populations.

Cancer is not a single disease but rather a collection of disorders broadly characterized by the inability of a cell to respond to normal biological cues related to proliferation, growth, and death. As a result, uncontrolled division leads to a mass of cells called a tumor. The development of cancer is extremely complex, and the field of cancer research is rapidly evolving. Our understanding of the hallmarks that define cancer development has increased tremendously in the past two decades, thanks to major advances in medical research resulting from generous federal investments.

If detected early, small tumors are treatable with surgery, radiation, or systemic therapies. However, if undetected, tumors continue to grow and crowd out the surrounding healthy cells within organs, disrupting normal function and leading to organ failure. Cancer cells can continue to divide, acquiring changes that allow them to grow faster, and eventually use the blood and lymphatic systems to move to distant organs. Growth of cancer cells in another organ distant from its original site is called metastasis and is the primary cause of death from most cancers. Many cancers have already metastasized through the bloodstream to other organs even when the primary tumor is detected early (158). The aggressiveness of a cancer often refers to the speed at which a single cancer cell progresses to form a tumor and metastasizes throughout the body. This process is highly dependent on the site of cancer, the health of the patient, lifestyle, and environmental factors. Survival rates from cancers will therefore depend upon equitable access to the main pillars of cancer treatment (see **Figure 16**, p. 102) at the time of diagnosis.

Centuries of systemic racism and discrimination in the United States have led to many racial and ethnic minorities and underserved groups being disproportionately exposed to detrimental social and built environmental factors that directly or indirectly contribute to increased incidence, advanced-stage diagnoses, and higher mortality from cancer (33,159-163). These factors, collectively referred to as SDOH, contribute to a greater burden of many types of cancers in racial and ethnic minorities and other medically underserved populations (see **Factors That Drive Cancer Health Disparities**, p. 29) (43,164).



Race and ethnicity are terms embedded with **historical and social meaning** and can often misrepresent an individual's true genetic ancestry (165). The use of **ancestry informative markers** is more accurate because these **identify individuals by their genetics** and give context of shared genetic backgrounds among populations. This is important for accurately categorizing tumor samples in cancer research and genetic registries (165).

Genetic and Epigenetic Control of Cell Function

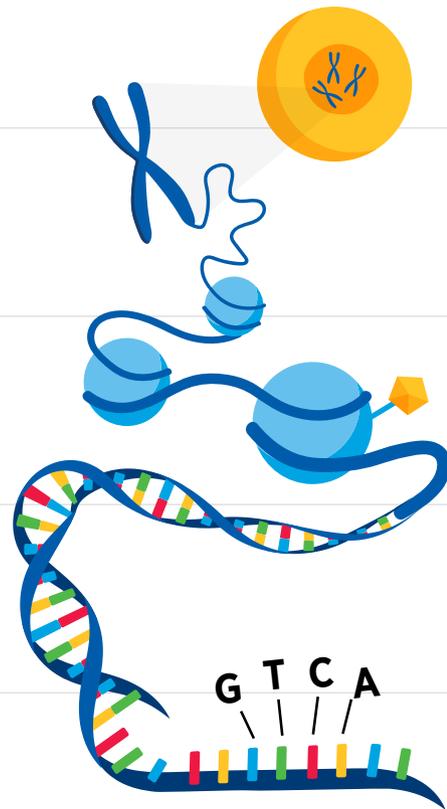
The genetic material of a cell comprises strings of **deoxyribonucleic acid (DNA)**, a complex molecule comprised of four units called bases which are designated A, C, G and T.

DNA bases are organized into **genes**. The order, or sequence, of the bases provides the code used by the cell to produce **ribonucleic acid (RNA)**, 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 factors, called **epigenetic marks**, can tag DNA or attach to histones. The presence or absence of these factors 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 (2).

While SDOH individually and collectively play an undeniable role in driving cancer health disparities, it must be noted that research has uncovered ancestry-related biological differences in cancers among patients from different populations. These differences may help explain the higher incidence or aggressiveness of certain cancers and differential responses to therapy that persist even after accounting for SDOH.

Influences Inside the Cell

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 which are designated A, T, C, and G (see sidebar on **Genetic and Epigenetic Control of Cell Function**, p. 41). Anywhere from 50–250 million of these bases are linked together to form individual strands, with two strands of the same length paired together to form a double-stranded, helical structure; these pairs of 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 copies a gene from the DNA to make another type of molecule called ribonucleic acid (RNA) in a process called transcription. The cell can make many copies of RNA from a single sequence of DNA, increasing the amount of message in the cell. The cells then “translate” the information in the RNA into proteins; therefore, the more RNA present, the more protein that is made.

The human species shares roughly 99.9 percent sequence similarity in its 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 (see **Figure 6**, p. 43) (166). Biological traits that arise from genetic differences can be positive,

Africa has the most genetically diverse population of any continent.

This is primarily because the genetic variation outside of Africa is a subset of genetic variation within Africa corresponding to the movement of humans to other continents roughly 100,000 years ago (167).



such as adaptability to unfavorable climates and altitudes, tolerance of particular food sources, or being more resistant to infections by parasites. However, these genetic differences can also predispose certain groups to genetic diseases like cancer. Recent migrations (forced or otherwise) have led to further genetic mixture, which is the reality of most minority populations in the U.S. The differences in genetic composition that result from this mixing are what make measurements of ancestry important in comparative tumor studies.

GENETIC CHANGES IN CANCER

Genetic mutations are changes that occur to the sequence of bases in the DNA. These include single base changes such as substitution, losing, or gaining of a base. Mutations can also be changes to a larger number of bases such as deletions, amplifications, and exchange within and between chromosomes (168). In fact, even within a single tumor, there can be subpopulations of cancer cells with different mutations, a phenomenon known as intratumor heterogeneity, which helps cancer cells evade anticancer therapies.

Most cancer-causing mutations are acquired over an individual's lifetime due to errors arising during normal cell duplication or because of environmental exposures, lifestyle factors, or health conditions that fuel chronic inflammation. These acquired mutations are referred to as somatic mutations. About 10 percent of cancer-causing mutations are inherited. When multiple individuals in a family carry a mutation in a gene that is important in cancer-causing processes, and there is strong evidence that the mutation significantly increases risk of cancer,

Of 78 genetic mutations identified to predict breast cancer risk in women of European ancestry, only 44 mutations were present in women of East Asian ancestry (169).



these types of inherited mutations are called “pathogenic” as experienced by **Alejandro Mirazo** who has lynch syndrome, an inherited condition which dramatically increases the risk of certain cancers (see p. 44). Decades of research have led to the identification of numerous genes that are associated with cancers as well as specific inherited mutations that are pathogenic.

Unfortunately, much of the research studies to understand these genetic predispositions have been done primarily in groups of European ancestry, limiting our understanding of many identified pathogenic variants in other groups, such as those from African, Native American, Asian, and Hispanic ancestries. Research studies focused on examining differences in genetic predispositions in people from different ancestries are vital because they can inform early detection, surveillance, and treatment decisions.

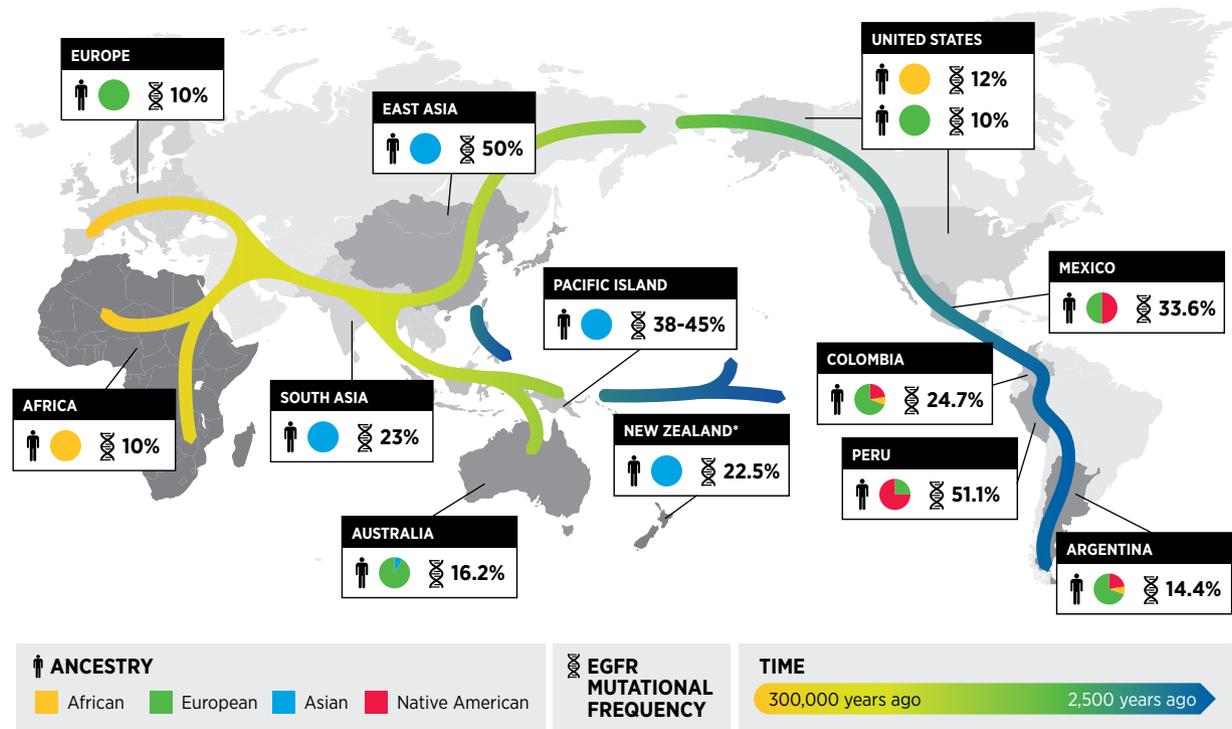
EPIGENETIC CHANGES IN CANCER

DNA inside the cell is tightly packaged around proteins called histones. This packaging serves many purposes, the most important of which is to control access to the genes that are encoded in the DNA. To regulate access to the genetic code, cells make small changes to the DNA and/or the histones. These changes, called epigenetic modifications, do not alter the DNA sequence and can be reversible, but they can still be passed on to children. The “epigenome” describes all of the epigenetic modifications to the DNA in a single cell. A key function of epigenetic modifications is to grant access to the genetic code when cells need to generate a specific protein and restrict access to it when cells do not need the protein. In cancer cells, the epigenetic processes that grant or restrict access to the genetic code can become aberrant, leading to cancer (171). Emerging evidence shows that environmental influences such as diet, stress, and exposure to pollutants can result in epigenetic changes to the DNA. This is especially relevant to racial and ethnic minorities and other underserved populations, who continue to be disproportionately negatively affected by environmental influences, potentially experiencing epigenetic changes that can aid cancer development.

The study of how social experiences can lead to epigenetic changes in DNA is known as social epigenomics. Individuals and their communities are exposed to these societal risks to varying degrees. Understanding how SDOH affect biology therefore represents an important area for developing intervention strategies to combat cancer disparities (see **Factors That Drive Cancer Health Disparities**, p. 29). While the exact mechanisms by which these factors influence biology are multifaceted, it has been shown that the epigenetic regulation of genes that cause breast and prostate cancers is different between African American and Caucasian patients (172,173). One area of active investigation is understanding allostatic load, which refers to the cumulative lifetime effects of stressors such as racism on epigenomics and the body's stress response system, and how these interactions influence cancer risk and development. Because epigenetic modifications are potentially reversible, intervention strategies that remove adverse environmental and social risks may provide effective approaches for improving outcomes.

FIGURE 6

Ancestry Contributes to the Prevalence of Cancer-associated Genetic Alterations



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

Acquired mutations of the *EGFR* gene are commonly observed in patients with lung cancer and represent a key target for molecularly targeted therapeutics. The frequency of overall somatic mutations in the *EGFR* gene differ based on ancestry of the patient, with the highest mutation rates observed in East Asian groups (50%) and the lowest rates observed in African (10%) and European (10%) 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 geographical origins based on an analysis of their genetic ancestry) of Native American ancestry while Argentina has more admixture of European ancestry (170).

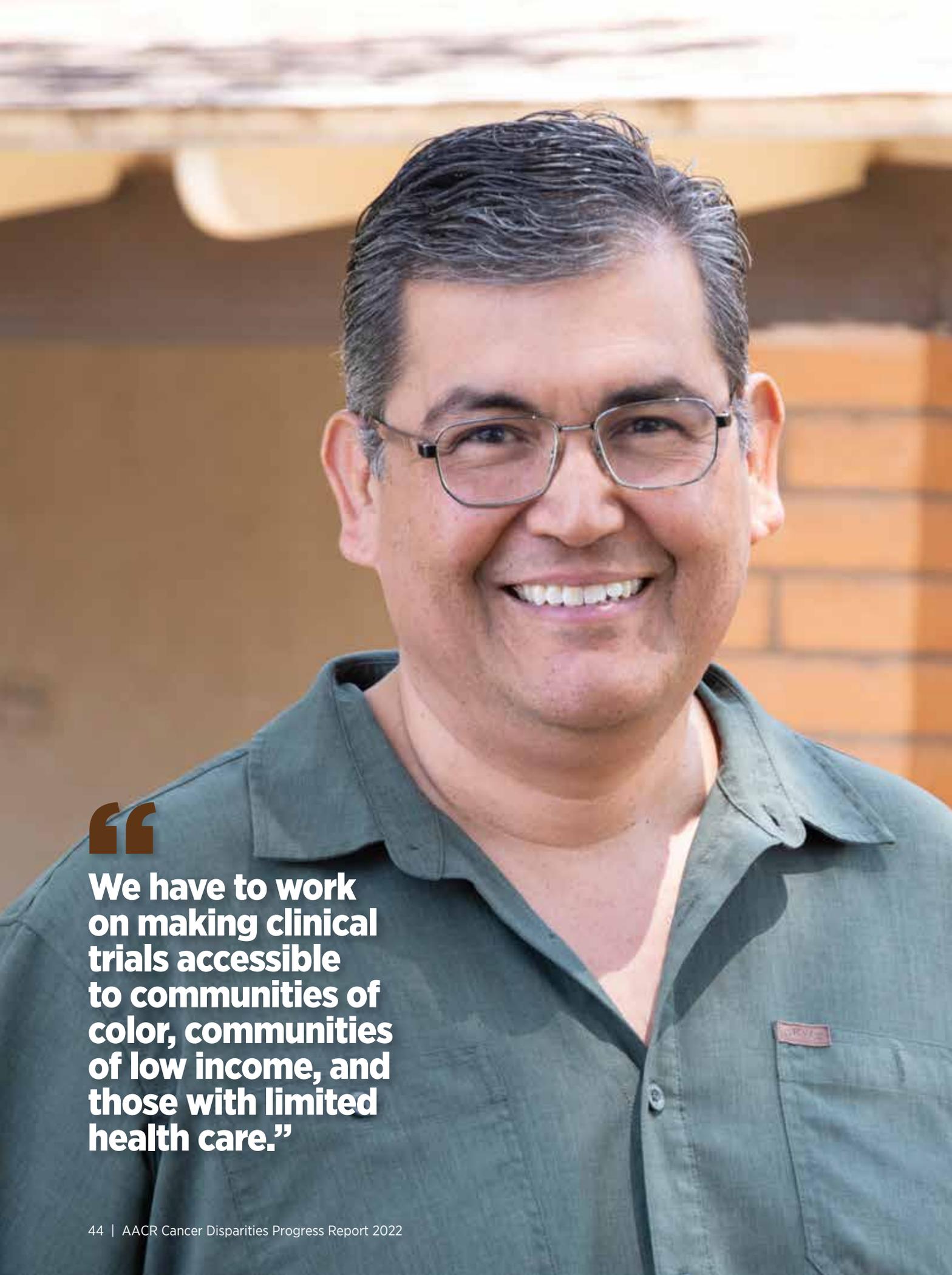
THE TRANSCRIPTOME

As described earlier in this chapter, when a cell “reads” a gene, it copies the information from the DNA and makes it into RNA. By changing the number of times the DNA is copied into RNA, the cell can increase or decrease the level of the RNA present in the cell, which helps regulate the amount of protein a cell generates; how much protein is made can drastically affect cell function. By changing the levels of RNA, a cell can adapt to changes that occur in the body. Because a cell is usually making copies of RNA from hundreds to thousands of genes at once, determining the RNA levels of each of these genes can help create a molecular profile, which often matches with the function of the cell. Researchers compare these profiles from tumor and normal cells to identify specific characteristics that drive a cancer cell or a tumor and

aid clinicians in making treatment decisions. To date, there are limited studies that have compared tumor signatures of people from diverse genetic ancestries. However, emerging evidence shows different RNA expression patterns in triple-negative breast tumors of African Americans compared to European Americans (174). Studies such as these highlight the contributions of ancestry to the unique genetic and molecular profiles of tumors. Understanding these different profiles across groups will be key to understanding why certain cancers are more aggressive in certain ancestral groups and, more importantly, to determining the best type of diagnostic or treatment.

After RNA is copied from DNA, a process called RNA splicing helps complete the message by removing those bases from the

Continued on page 46



“

We have to work on making clinical trials accessible to communities of color, communities of low income, and those with limited health care.”

Managing Inherited Cancer Risk, Thanks to Genetic Testing

In 2021, Alejandro Mirazo received an invitation from Mayo Clinic to participate in a clinical trial seeking to understand how an individual's genetic information could impact health care delivery. Having had terrific experiences with medical care for himself and members of his family at the Mayo Clinic in Phoenix, Arizona, Alejandro was happy to join the study.

"I have a lot of confidence in Mayo Clinic. When they came to me and said, 'Would you like to participate in a study to expand our knowledge about the relationship between genetic variations and cancer and other illnesses?' I didn't think twice. I said, 'I want to help,'" Alejandro said.

Going into the Mayo Clinic Tapestry DNA Sequencing Research Study, Alejandro thought he would serve as a "data point" to help advance medical science, not that he would directly benefit from the results. So, in November 2021, he sent his samples for genetic sequencing.

Soon after, he received preliminary information that he carried a possible genetic variant tied to an inherited condition known as Lynch syndrome which dramatically increases an individual's risk of many types of cancer, including colon cancer.

"I was advised by the study team to get a clinical confirmation of the diagnosis. We went through that in December," Alejandro said. After confirming that he had Lynch syndrome, Alejandro was scheduled for a colonoscopy, which led to his diagnosis with early-stage colon cancer.

Following his diagnosis, Alejandro underwent a series of tests to prepare for colon surgery. His health care team wanted to make sure that his cancer had not spread beyond the colon. On March 2, 2022, Alejandro had a surgical resection.

"It took like four hours. So, I assume it was very complex and difficult, but at the end the surgery was very successful," he said. "I left the hospital the next day, and I never felt any pain other than the first three or four days. I went back to work within five days."

While his surgery was considered a success, to reduce the chances of a recurrence, Alejandro's oncologist recommended chemotherapy. He completed the first for four cycles of chemo in May 2022.

"I'm feeling well compared to all the things that I could be feeling, other than a little bit of fatigue," he said.

Alejandro is grateful to have participated in the study because it led to the detection of his cancer at an early stage, when the likelihood of successful treatment is better.

"I'm a very healthy person. I have a lot of energy. I would never have guessed. Even though I have regular checkups, I never had a colonoscopy. So, I'm happy to have participated in Tapestry," he said.

Participation in the study has also brought into focus the inherited cancer risks within Alejandro's family. He remembers his grandmother being diagnosed with colon cancer in her 70s. More recently, one of his sisters who is in her 40s was diagnosed with ovarian cancer. Alejandro had not thought about a family connection of cancer until that happened.

More members of his family are going through the process of testing right now. Two of his children have tested negative, which was a great relief for the family. His youngest son will be tested when he turns 18.

"I had never heard of Lynch syndrome. So, it was a bit scary in the beginning. Now that we understand, we're better informed," Alejandro said. "We're glad that we can look for symptoms and that there's a path forward. We will be tracking any possible recurrence or occurrence of new symptoms that come from Lynch syndrome."

Alejandro's personal experience has increased his belief in the importance of clinical research. He recognizes the lack of awareness of clinical research in the general population and particularly in racial and ethnic minorities.

"This is not common knowledge," he said. "And in communities that have recently immigrated to the U.S., it is not going to be as easy to get that information."

While the level of education can sometimes be a barrier to awareness, Alejandro said he has realized that many of his classmates from high school and college are not aware of genetic testing or clinical trials.

"We need to communicate this broadly, but then we have to work on making it accessible to everyone, for example, to communities of color, communities of low income, and those with limited health care," Alejandro said.

His ardent request is for Congress to invest heavily in clinical research to improve public health.

"I believe that Congress has to be a big part of this, going forward," he said.

RNA that are not needed to make a protein. In cancer cells, this process can be altered to generate abnormal proteins, which can fuel uncontrolled cell proliferation and growth (see sidebar on **The Cancer Cell: Changes that Lead to Cancer**, p. 47). Research has shown that RNA may be spliced differently in people of different genetic ancestry. One study found that the PIK3CD-S gene, which increases the aggressiveness of prostate cancer, was spliced differently in African American patients, compared to European American patients. Researchers theorized that, because of the function of the gene involved, response to common treatments targeted against PIK3C may not be as effective in African American patients (175).

Influences Outside the Cell

Genetic mutations, epigenetic modifications, and RNA splicing are factors that influence cancer development from inside the cell. However, the environment surrounding the cell is equally important in cancer initiation and progression. Cross talk between the cancer cell and its surroundings (also known as the tumor microenvironment) is a key contributor to tumor growth and metastasis (see sidebar on **The Tumor Microenvironment: External Influences on Cancer Development and Progression**, p. 48). Cancer cells can release molecules that shape their surrounding environment to provide them with nutrients, oxygen, and a supportive structure. This reorganization also aids in the process of metastasis, where cancer cells leave the tumor through blood and lymphatic systems. In turn, the microenvironment can influence the tumor by promoting or suppressing its growth.

SUPPORTING THE TUMOR CELLS

Directly surrounding the tumor is the extracellular matrix, a platform of noncellular components on which cancer cells grow. During proliferation, cancer cells instruct the surrounding matrix to support their growth and in turn the matrix provides cues to the tumor that influence cancer progression and metastasis (186). Because some cancer types are more aggressive in patients of certain genetic ancestry, there is an interest in understanding if the tumor matrix is different across populations, whether this difference drives tumor aggressiveness, and if the matrix could be targeted therapeutically (187).

The blood and lymphatic networks form the roads and bridges that connect the body's organs and tissues and help in the delivery of nutrients and oxygen and removal of waste such as dead cells or carbon dioxide. These networks also make an important component of the tumor microenvironment. Because a lot of fuel and oxygen is 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, some studies have shown increased vascularization in breast tumors of patients of African ancestry compared to those of European ancestry (183,188). Although data are still emerging, the difference in tumor

vascularization between the two populations may explain in part why, despite having lower incidence of breast cancer, African American patients continue to have a 40 percent higher risk of breast cancer-related death.

Hormones are molecules that travel in the bloodstream and are naturally produced by organs. The main function of hormones is to act as communication signals that relay information from one place in the body to another. Notably, hormones also play a key role in the development of several cancers including breast, prostate, uterine, ovarian, testicular, thyroid, and bone. Often, the primary treatment for these cancers is limiting the levels of hormones using hormone therapy. While hormone therapy is a useful cancer treatment, hormones can also be used in gender-affirming therapy by members of the SGM community. How, under these circumstances, hormones could contribute to cancer development is an area of active investigation. Notably, studies suggest that hormone therapies may promote cancer development in individuals using these treatments for cancer- or non-cancer-related purposes (181,182) (see sidebar on **The Tumor Microenvironment: External Influences on Cancer Development and Progression**, p. 48).

THE IMMUNE SYSTEM

The immune system is composed of a variety of organs, tissues, cells, and molecules that all work together to defend the body against external (virus, bacteria) and internal (cancer) threats by recognizing and eliminating them. 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 (160,189). Understanding how and why immune systems in individuals from different ancestry are different can give us a better understanding of how cancers develop and the unique role the immune system plays.

Insights into the interplay between the immune system and cancer form the basis for developing immunotherapies, which are some of the most effective cancer treatments available today; so far, immunotherapies have been approved for the treatment of more than 26 different types of cancer.

African American men showed increased survival by an average of 4.5 years compared to White men from the most aggressive form of prostate cancer when treated with the cancer vaccine sipuleucel-T (190,191).



The Cancer Cell: Changes That Lead to Cancer

Myriads of molecular changes occur inside of a cell that result in the initiation and progression of cancer. These changes can occur in the genetic material, but also in how that material is copied and read. In order to understand how to treat cancer, researchers seek to understand what these changes are, how they come about, and how they affect cellular function. Emerging studies such as those listed below highlight how these changes can be different in population groups with different genetic ancestries.

STUDY

EXAMPLE OF ANCESTRY-RELATED DIFFERENCE



DNA Mutations

Alterations in the DNA sequence, referred to as mutations, alter the message that is read by the cell to make proteins, and result in new proteins, altered versions of normal proteins, or loss of protein function, which can lead to cancer.

Fifty percent of patients with **lung cancer** who were of Asian ancestry had a **mutation in the EGFR gene** compared to only 10 percent of patients who were of European or African ancestry (170).



Epigenetic Modifications

Epigenetic modifications determine whether a gene is accessible for reading but do not alter the genetic message itself. These modifications can be influenced by factors such as stress, diet, and pollution.

Among patients with a specific subtype of **breast cancer**, those who were of African ancestry had **different epigenetic marks on several genes** important for slowing down cell replication as compared to those who were of primarily European ancestry (172,173).



Genetic/Chromosomal Aberrations

Unlike base changes, larger parts of a gene or chromosome, including the gene or chromosome itself, can be duplicated, multiplied, rearranged, or deleted. Genetic/chromosomal aberrations can generate increased quantities of proteins, entirely new proteins, or loss of proteins and change how a cell grows and divides leading to cancer.

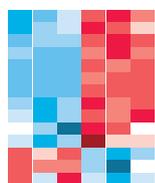
Hispanic/Latino/a individuals have higher incidence and mortality of **acute lymphoblastic leukemia (ALL)** compared to all other racial groups (10) (excluding American Indians/Alaska Natives). A key genetic aberration called **the IGH-CRLF2 fusion** is associated with poor prognosis in ALL (176). This arises when two normal genes (IGH and CRLF2) are rearranged and the alteration occurs four times more often in Hispanic patients than in non-Hispanic White patients (168). This may explain why ALL occurs more often in this population.



Cancer-Related Alternative Splicing

Normal cells copy the information from DNA in pieces of RNA that are assembled in a process called splicing to complete the message. In cancer cells, this process can be altered to generate abnormal proteins which fuel uncontrolled cell proliferation and growth.

In **prostate cancer** patients **“skipping” of certain parts of the PIK3CD gene** promotes this cancer’s aggressiveness; this phenomenon occurs more often in those of African ancestry than in European American patients with prostate cancer (175).



Changes in RNA Levels

Comparing the levels of thousands of RNA molecules within a tumor or even a single cancer cell can help researchers build a molecular profile of the cancer. This profile can be compared to profiles that have been documented in other cancers or normal cells. This comparison can inform the health care team about prognosis and best course of treatment.

In an analysis of 1,152 U.S. patients with **prostate cancer**, substantial gene expression differences were found between men of African and European ancestries, with a **reduced expression of genes that prevent DNA damage** seen more frequently in those of African ancestry. These observed differences could explain why this group experiences higher rates of aggressive prostate cancer and could prove useful in tailoring treatments to patients of African ancestry (177).

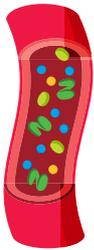
The Tumor Microenvironment: External Influences on Cancer Development and Progression

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



Tumor Matrix

The matrix is the platform upon which tumor cells grow, and components of the matrix can influence the aggressiveness of a cancer.



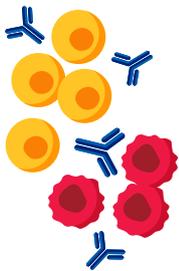
Hormones

Hormones are chemicals that circulate throughout the body and can influence tumor growth and development. While hormones have been shown to be a cause of differential cancer risks between males and females (178,179), their role in cancer development among individuals receiving gender-affirming hormonal therapy is just beginning to be understood (180). Differences in cancer development have been shown in breast (181) and prostate (182) of transgender people that were receiving hormone therapy compared to cisgender individuals not receiving hormone-based, gender-affirming therapy.



Tumor Blood and Lymphatic Networks

Tumors can grow blood vessels by releasing chemicals into their microenvironment, which, in turn, aids in tumor growth. The degree to which this occurs differs across ancestral groups, and may explain why cancers are more aggressive in one population versus another (183).



Immune Cells

The immune system is a large network of organs, tissues, cells, and the substances they produce that helps keep the body safe from harmful substances, pathogens, and cellular changes, including cancer. Immune cells 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. Targeting of cancer by unleashing the immune system is an exciting area of research. Cancer immunotherapies have demonstrated efficacy against multiple cancers including in patients with triple-negative breast cancer (TNBC), with some studies showing particular effectiveness of these therapies in certain racial/ethnic groups (184). For instance, it has been observed that there was a distinct signature in the T cells (one type of immune cell) of African American women compared with women of European ancestry with TNBC. These immunobiological differences indicate that Black women may have better responses and provide rationale for the use of checkpoint inhibitors in this group compared to White patients (185).

Despite this success, it must be noted that the development of immunotherapies has been primarily based on clinical trials involving 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 (160,189). Comprehensive analysis of the immune system of cancer patients from diverse racial and ethnic backgrounds is vital to develop precise therapeutic interventions that are effective in these populations.

Integrating and Translating Our Knowledge

In this chapter we have highlighted how cancer is a complex, multifaceted collection of diseases. The most effective cancer control efforts must take a comprehensive look at the genetic, epigenetic, lifestyle, and environmental influences and apply approaches tailored to each individual patient. In fact, in recent years 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. 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. However, collection of relevant data from racial and ethnic minorities and other underserved populations including recruitment of diverse population groups in clinical studies is vital if we are to improve patient outcomes in an equitable manner.

Collecting biospecimens from people with different backgrounds will create diverse datasets that researchers can use to better understand the ancestry-related differences in cancers. Currently, many of the large cancer datasets including The Cancer Genome Atlas, an NIH-supported collaborative effort to genetically profile cancers based on patient tumors, contain samples largely from White people (77 percent of all samples), reducing the likelihood of discovering cancer-causing alterations in underrepresented population groups. As one such example, in a recent study among Black patients with prostate cancer, tumor sequencing identified a genetic mutation in a tumor suppressor gene that was more common in Black men (five percent) compared to White men (only one percent) (192). Recent reports have also shown that tumors sequenced from African American patients were of lower quality and reduced coverage, leading to lower detection of possible variants (193). To accelerate progress in this area, data integration and sharing across institutions, companies, and countries worldwide is critical. A main focus of these research endeavors must be to build a highly diverse reference genome, which can increase our understanding of genetic alterations found in underrepresented groups (194,195).

Several initiatives are being spearheaded by private and public organizations to facilitate the expansion of diverse biospecimens. As one example, in 2018, the All of Us research program was launched by the NIH to enroll 1 million people in the United States and “build a diverse database that can inform thousands of studies on a variety of health conditions.” In March 2022, this project had sequenced the entire genomes of 100,000 people, 50 percent of whom self-reported as being racially or ethnically diverse (196). Additionally, the AACR Project Genomics Evidence Neoplasia Information Exchange® (GENIE) has sequenced tumors from over 121,000 patients across 19 leading cancer centers in the U.S. and Europe, nearly 13.4 percent of which are from racial and ethnic minorities. Researchers are already using these databases to address gaps in our knowledge about cancer biology and the genetic changes that occur specifically in minority groups (197-199).

Researchers use a variety of model systems to understand how genetic alterations result in cancers. Establishment of research models that better represent genetic diversity for biomedical research is paramount to developing treatments that are safe and effective for all populations. Emerging studies are beginning to utilize “patient-derived xenografts,” tumor cells surgically resected from a patient and grown in immunosuppressed mice. These models are often used to evaluate personalized cancer treatments (200,201). Diversifying these preclinical cancer research tools will be key to the success of precision medicine in treating disease for diverse populations.

Discoveries in cancer genomics have led to the development of numerous therapeutics which target the cellular changes that arise due to mutations. Unfortunately, most of these therapies have been developed in patients with cancer who are of primarily European ancestry. To develop new therapies for diverse groups, studies that incorporate the tumor and patient genetic factors as well as SDOH will need to be utilized. One such study is the Research on Prostate Cancer in Men of African Ancestry: Defining the Roles of Genetics, Tumor Markers and Social Stress (RESPOND), which is “one of the largest studies ever to look at the underlying factors and reasons that put African American men at higher risk for prostate cancer.” By using surveys, current DNA sequencing, and tumor samples, RESPOND will “study how exposure to stress over a lifetime, inherited susceptibility (i.e. genes), and tumor characteristics contribute to the development of prostate cancer” (202,203)

The use of molecularly targeted therapeutics relies on genetic tests that detect mutations. Currently, only a fraction of patients with cancer have their tumors tested (204,205), with disparities in who gets tested (206). For instance, following the expansion of Medicare to cover tumor sequencing, compared to NHW individuals, use of tumor sequencing was 14 percent lower in African Americans and 23 percent lower in Hispanic/Latinos (207). Current disparities in the implementation of precision medicine (205,208) can be attributed to lack of information given to patients, lower recruitment into clinical trials, implicit bias, insurance disparities, and financial cost (209).

Overall, reducing disparities in treatment and understanding of cancer across different groups will require a multilevel approach. Identification of mutations that lead to cancer through the use of large and inclusive genomic databases as well as studying them in diverse research models will increase our knowledge surrounding the genetic and other changes that occur in different ancestral groups. Translating this knowledge into the clinic will require sequencing of tumors from individuals to understand the mutations that have occurred in that tumor; these mutations will then allow clinicians to select the most appropriate therapy for the patient.

Disparities in the Burden of Preventable Cancer Risk Factors

IN THIS SECTION, YOU WILL LEARN:

- ▶ Decades of systemic inequities and social injustices have led to adverse differences in social determinants of health causing a disproportionately higher burden of cancer risk factors among U.S. racial and ethnic minorities and other underserved populations.
- ▶ In the United States, four out of 10 cancer cases are associated with preventable risk factors.
- ▶ Not using tobacco is one of the most effective ways a person can prevent cancer from developing.
- ▶ Nearly 20 percent of U.S. cancer diagnoses are related to excess body weight, alcohol intake, unhealthy diet, and physical inactivity.
- ▶ Nearly all cases of cervical cancer, as well as many cases of head and neck and anal cancers, can be prevented by HPV vaccination.

Factors that increase a person's chances of developing cancer are referred to as cancer risk factors. Decades of research have led to the identification of numerous cancer risk factors (see **Figure 7**, p. 51) such as tobacco use, poor diet, physical inactivity, obesity, infection with certain pathogens, and exposure to ultraviolet (UV) radiation. Given that several of these risks can be avoided, many cases of cancer can potentially be prevented. In the United States, the most recent data available indicate that more than 40 percent of all new cancer cases diagnosed in 2014 were attributable to preventable risk factors (210). Emerging data indicate that certain cancer risk factors are also associated with worse outcomes after a cancer diagnosis, including development of secondary cancers (211,212). In addition, many cancer risk factors contribute to other chronic diseases, such as cardiovascular disease, respiratory diseases, and diabetes. Therefore, reducing or eliminating exposure has the potential to reduce the burden of cancer as well as several other diseases.

Systemic Inequities and Social Injustices

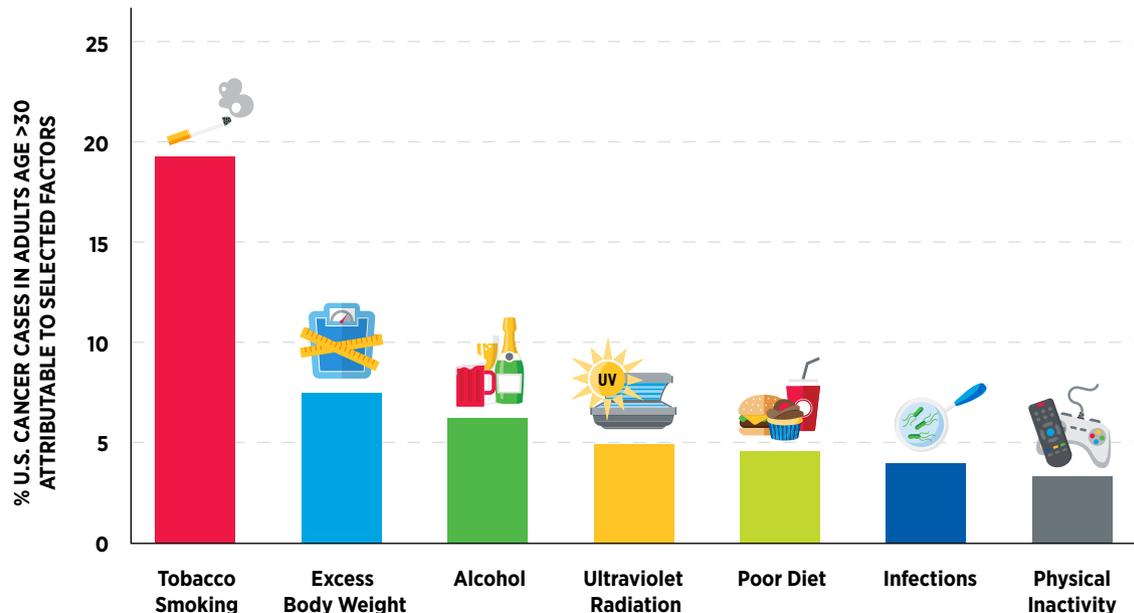
In the United States, many of the greatest reductions in cancer morbidity and mortality have been achieved through implementation of effective public education and policies in cancer prevention. For example, such initiatives have helped reduce cigarette smoking rates among U.S. adults by 70 percent from 1965 to 2020 (213,214), which has contributed significantly to the dramatic decline in overall U.S. cancer mortality rates (1). However, long-standing inequities in numerous SDOH (see **Factors That Drive Cancer Health Disparities**, p. 29; and **Figure 5**, p. 32) 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 and not only place disadvantaged populations in unfavorable living environments (e.g., with higher exposure to environmental carcinogens) (see **Social and Built Environments**, p. 35) but also contribute to behaviors that increase cancer risk (e.g., smoking, alcohol consumption, or unhealthy diet) (215).

It must be noted that an individual's personal behaviors and exposures are strongly influenced by living environments. For example, lack of quality housing (e.g., those without smoke-free policies) may expose disadvantaged communities to high levels of secondhand smoke, a known cause of lung cancer. Moreover, the neighborhoods where socioeconomically disadvantaged populations reside are often characterized by food deserts with reduced availability of healthy food options such as fresh fruits and vegetables, and limited outdoor space for recreation and/or exercise. These living environments create barriers to behaviors that are important in lowering cancer risk, such as maintaining a healthy weight, eating a balanced diet, and being physically active. Socioeconomically disadvantaged neighborhoods are also more likely to be in less favorable locations such as in close proximity to highways and busy roads, which increase exposure of residents to air pollution (see **Social and Built Environments**, p. 35). It is also important to consider that socioeconomic and geographic disadvantages intersect with other population characteristics such as race, ethnicity, sexual orientation, disability status, among others. As one example, individuals with disabilities, who may have fewer occupational opportunities and lower income, also have a higher prevalence of smoking, obesity, and physical inactivity (13). It is imperative that public health experts prioritize cancer prevention efforts that account for the

FIGURE 7

Increasing Cancer Risk



Research has identified numerous factors that increase an individual's risk for developing cancer. The higher prevalence of many of these risk factors among racial and ethnic minorities and other medically underserved populations can be attributed to adverse differences in

social determinants of health. Developing and implementing comprehensive and integrated cancer control efforts, including public education and policy initiatives, could help reduce the burden of cancers related to disparate exposure to preventable cancer risk factors.

Adapted from (2).

complex and interrelated factors across institutional, social, and individual levels, which influence personal risk behavior and disparate health outcomes. Furthermore, there is an urgent need for all stakeholders in the medical research community to come together and develop better strategies which enhance the dissemination of our current knowledge of cancer prevention and implement evidence-based interventions for reducing the burden of cancer for everyone.

Tobacco Use

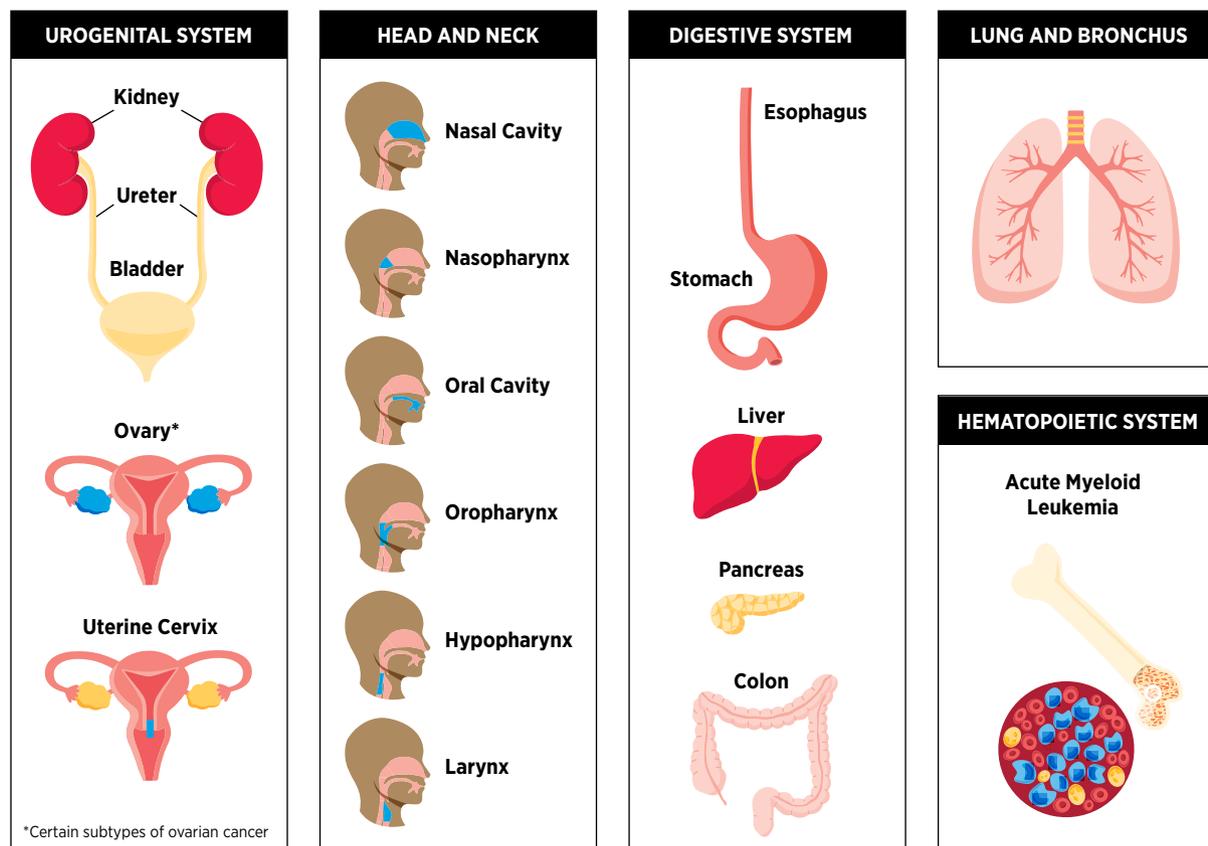
Tobacco use is the leading preventable cause of cancer. Smoking increases the risk of developing at least 17 different types of cancer in addition to lung cancer (see **Figure 8**, p. 52), because it exposes individuals to many harmful chemicals that cause genetic and epigenetic alterations leading to cancer development (2). Fortunately, quitting at any age reduces the risk of cancer occurrence and cancer-related death. In addition, smoking cessation also reduces risk for many adverse health effects including cardiovascular diseases and chronic obstructive pulmonary disease (COPD), among others (216). Thus, one of

the most effective ways a person can lower the risk of developing cancer and other smoking-related conditions is to avoid or eliminate tobacco use.

Thanks to the implementation of nationwide comprehensive tobacco control initiatives, cigarette smoking among U.S. adults has been declining steadily. In 2020, the most recent year for which such data are available, 12.5 percent of U.S. adults age 18 and older smoked cigarettes, a significant decline from 42.4 percent of adults in 1965 (213,214). Exposure to secondhand smoke, which increases the risk of lung cancer among nonsmokers, has also dropped substantially over the past three decades (217). Despite these positive trends, more than 47 million adults in the United States reported using a tobacco product in 2020 (213). It has been documented that most adult users initiate smoking in their youth. Therefore, it is concerning that 5.2 million high school students and 1.34 million middle school students in the United States used some type of tobacco product in 2021 (218). Notably, there are striking sociodemographic disparities in the use of tobacco products as well as in the exposure to secondhand smoke (see sidebar on **Disparities in the Prevalence of Tobacco Use in the United States**, p. 54). Overall,

FIGURE 8

Beyond the Lungs: Cancers Caused by Smoking Tobacco



Smoking tobacco increases an individual's risk of developing not only lung cancer, but also 17 other types of cancer. No level of exposure to tobacco smoke is safe, including exposure to secondhand smoke.

Adapted from (2).



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, alcohol, obesity)

tobacco use is higher among residents of the U.S. Midwest and South compared to the rest of the country; among individuals with lower levels of household income; among adults who lack private health insurance; and among individuals with disabilities or serious psychological distress (213). In addition, tobacco use is higher among American Indian or Alaska Native (AI/AN) adults compared to any other racial or ethnic groups. The prevalence of cigarette smoking among AI/AN adults varies by geographic region, which leads to geographic variation in lung cancer incidence rates among these populations (219).

Although Black adults smoke at comparable levels to NHW adults, tobacco-related cancer morbidity and mortality rates are disproportionately higher among this population (220). According to a recent report, even at relatively low levels of smoking intensity, Black as well as Native Hawaiian adults who smoke have significantly higher risk of lung cancer compared to Japanese Americans, Hispanic, and White adults (223). The reason for the differential risk is not fully understood and is likely to be multifactorial, including socioeconomic differences impacting access to quality care, prevalence of additional risk factors such as obesity, exposure to secondhand smoke, and prevalence of mentholated cigarette use. In addition, there is emerging evidence that current measures of nicotine intake and dependence and smoke exposure may underestimate the risk to Black adults who smoke (224). According to recent data, tobacco-related cancer mortality in the U.S. is declining rapidly because of significant reductions in smoking over the past five decades (1). The steeper reductions in smoking initiation in recent years, especially among Black men, have led to a faster decline in tobacco-related cancer mortality among Black people compared to White people (220).

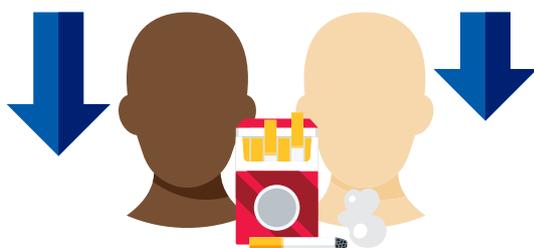
Smoking cessation through medications or counseling can lower risk for cancer development or death from cancer (226). Unfortunately, the rate of successful smoking cessation is lower among Black and AI/AN adults compared to White adults (227), even though Black adults are more likely to report their willingness to stop smoking compared to other racial and ethnic groups (220). Similarly, despite a higher prevalence of smoking in rural areas compared to urban areas, a recent study reported

that rural smokers were nearly three times less likely than their urban counterparts to receive any smoking cessation treatment (228). Another study which examined the role of health care access in the receipt of smoking cessation advice from health care providers found that among those with limited access to health care, Hispanic smokers had significantly lower odds of being advised to stop smoking compared to NHW smokers (229). Therefore, increasing health insurance coverage and reducing additional health care access barriers may facilitate provider-patient discussion and promote tobacco cessation among minority populations. Further progress in reducing smoking and smoking-related cancer burden will require the implementation of culturally tailored, evidence-based, and equitably accessible smoking cessation interventions. It is vital for these interventions to be available to all populations irrespective of their geographic location or socioeconomic status.

Flavored tobacco products, such as mentholated cigarettes, pose a significant public health risk. People who smoke menthol cigarettes report increased nicotine dependence and reduced smoking cessation compared to those who smoke nonmenthol cigarettes (230). The prevalence of menthol cigarette use is higher among individuals who are Black, from the SGM population, or from low socioeconomic background (220,231,232). For example, based on a recent report, lesbian and bisexual females are 27 percent more likely to initiate smoking with a menthol cigarette and 24 percent more likely to report menthol cigarette use compared to heterosexual females (231). In addition, certain medically underserved populations not only use menthol cigarettes at a disproportionately higher rate, but also exhibit dual menthol cigarette and other tobacco product use (232). Among people who smoke menthol cigarettes, Black individuals have lower odds of smoking cessation compared to White or Hispanic individuals. Furthermore, Black and low-income communities are at a higher risk of being exposed to targeted advertisements, including storefront ads and price promotions, specifically for menthol cigarettes (233,234). Thus, tobacco control policies that restrict menthol cigarette sales including restrictive laws and menthol bans are a potential policy target for reducing tobacco-related health disparities. As one example, a comprehensive flavor ban on tobacco products in Massachusetts was associated with a significant reduction in state-level menthol- and all- cigarette sales (235). Therefore, it is encouraging that FDA has proposed a nationwide menthol ban that will restrict the manufacturing, marketing, and sale of menthol cigarettes (see **Policies to Address Disparities in Cancer Prevention**, p. 138) (236). Ongoing research is needed to monitor the effectiveness of such policies and to address potential limitations (e.g., menthol smokers switching to unflavored cigarettes) that can undermine the effectiveness of the policies.

Historically, tobacco companies have marketed their products more heavily to minority and low-income populations. Tobacco retailer densities are highly concentrated in neighborhoods with more Black and Hispanic residents (237), and these sociodemographic disparities in marketing contribute to inequities in smoking and the burden of smoking-related

Between 1965 and 2019, **the prevalence of cigarette smoking declined** by 58 percent among Black adults compared to less than 50 percent among White adults (213,225).



Disparities in the Prevalence of Tobacco Use in the United States

There are striking disparities in the prevalence of tobacco use with significantly higher use among certain racial and ethnic minorities and other medically underserved populations:

**35% vs 12%
vs 21%**

The **prevalence of tobacco product use is higher among American Indian/Alaska Native adults** (35 percent) and **lower among Asian* adults** (12 percent) compared to White adults (21 percent) (213).

**More than
TWICE**

Among adults who do not smoke, the **prevalence of secondhand smoke exposure is more than twice as high among Black people** compared to White people (220).

10% vs 3%

The **prevalence of smoking is more than twice as high among U.S.-born Hispanic women** (10 percent) compared to foreign-born Hispanic women (3 percent) (17).

25% vs 9%

Cigarette smoking rates are higher in adults with less than a high school education (25 percent) compared to those with a graduate degree (9 percent) (213).

29% vs 18%

Prevalence of cigarette smoking is highest among those living in rural areas (29 percent) and lowest among those living in large metropolitan areas (18 percent) (221).

25% vs 19%

The **use of any tobacco product is higher among those who identify as lesbian, gay, or bisexual** (25 percent) compared to those who identify as heterosexual or straight (19 percent) (213).

25% vs 14%

Cigarette smoking rates are 25 percent among those with less than \$35,000 annual household income compared to 14 percent among those with annual household income of \$100,000 or more (213).

* It should be noted that prevalence of tobacco use among subgroups of Asian Americans varies considerably (222).

diseases. Therefore, identifying communities that need to be prioritized for tobacco-restrictive policies and regulation and rapidly implementing evidence-based interventions are urgent public health needs. Increasing cigarette prices via tobacco tax increases is another approach to reduce tobacco use and prevent smoking initiation (214). A recent analysis reported that a one dollar increase in cigarette pack price corresponded with a 72 percent decrease in smoking initiation and a 70 percent

decrease in progression to daily smoking (238). Whether such interventions can reduce the sociodemographic disparities in smoking rates and related illnesses needs to be evaluated (239). Nonetheless, these data clearly highlight the urgent need for all stakeholders to work together to develop and implement evidence-based, population-level interventions to reduce the burden of tobacco use for racial and ethnic minorities and other underserved populations.

NIŁCH' ÉÍ BEE ÍÍNÁ – AIR IS LIFE ACT OF 2021

On November 6, 2021, the **Navajo Nation enacted the first comprehensive ban on commercial tobacco products on American Indian tribal lands**. The prohibition went into effect on February 5, 2022, and includes casinos, other businesses, and public Navajo buildings and lands. The act covers conventional cigarettes, e-cigarettes, cigars, and similar products but excludes tobacco used for ceremonial purposes and use of any tobacco product in a person's home (240).



The use of other combustible tobacco products (e.g., cigars), smokeless tobacco products (e.g., chewing tobacco and snuff), and waterpipes (hookahs) is also associated with adverse health outcomes including cancer (241). The use of electronic cigarettes (e-cigarettes) has increased dramatically in the past ten years, and their long-term health impacts are unknown (242). While promoted by manufacturers as a smoking cessation tool, the benefit of e-cigarettes in cessation is currently unclear (2). It is known, however, that in addition to nicotine, a highly addictive substance, e-cigarettes contain and emit numerous potentially toxic chemicals including heavy metals and volatile organic compounds. Therefore, an alarming trend in recent years is the growing popularity of e-cigarettes among U.S. youth and young adults. These trends are concerning because the use of e-cigarettes increases the probability of youth or young adults transitioning to conventional cigarettes (2). Additionally, there are emerging data showing that the use of e-cigarettes may cause inflammation and disease (243). Currently the NHW population has higher use of e-cigarettes compared to other racial and ethnic groups (213,218). Continuing research on the health effects of e-cigarettes and their use across different population groups is necessary to ensure that use of e-cigarettes does not increase existing disparities in smoking behavior and health outcomes. Additionally, any potential efficacy of these products for supporting smoking cessation must be investigated in randomized clinical trials with diverse representation of participants.

Adverse influence of SDOH (see **Figure 5**, p. 32) (see **Factors That Drive Cancer Health Disparities**, p. 29) including lack of homeownership, lower income, and greater neighborhood problems may significantly contribute to racial disparities in smoking cessation (245). Additional factors such as dwellings with higher population density, increased volume of tobacco retailers, and lack of smoke free housing laws, increase smoking initiation and exposure to secondhand smoke in underserved neighborhoods. These factors also make it more challenging for residents to quit smoking. Lack of quality health care coverage can reduce access to FDA-approved medications or evidence-based counseling, both of which are known to help with smoking cessation. Collectively, these challenges highlight the need for multilevel (institutional, community, and individual) interventions to address disparities in tobacco use. Policy interventions can reduce tobacco-related cancer disparities by preventing people from starting to smoke, helping people quit smoking, and reducing exposure to secondhand smoke. This can be accomplished through enacting comprehensive smoke-free laws, increasing taxes on tobacco products, reducing predatory advertising, and offering comprehensive and evidence-based cessation services. Going forward, it is vital that tobacco-related

Compared to White adults, **Black adults are more than twice as likely to smoke cigars** on a daily basis (244).



policies provide equal benefit to everyone, particularly to vulnerable populations including racial and ethnic minorities and other underserved population groups. For instance, smoking cessation clinical trials must implement strategies to recruit a sociodemographically diverse cohort of participants to ensure that the interventions are effective in diverse populations (246). It is also vital that the interventions be culturally sensitive. Two recent studies showed that tailored interventions were effective in discouraging smoking among urban American Indian youth and encouraging smoking cessation among Spanish-speaking Hispanics in the United States (247,248). Notably, the NCI's Cancer Center Cessation Initiatives is evaluating numerous innovative approaches to reduce the disproportionate tobacco-related burden and eliminate tobacco-related cancer disparities (249,250).

Body Weight, Diet, and Physical Activity

Nearly 20 percent of new cancer cases and 16 percent of cancer deaths in U.S. adults are attributable to a combination of excess body weight, lack of healthful diet, physical inactivity, and alcohol consumption (210). Therefore, maintaining a healthy weight, being physically active, consuming a balanced diet, and avoiding alcohol are effective strategies for individuals to lower their risk of developing or dying from cancer (see sidebar on **Guidelines to Reduce Cancer Risk**, p. 56). In the United States, decades of systemic and structural racism have contributed to adverse differences in SDOH in racial and ethnic minorities and other underserved populations (see **Factors That Drive Cancer Health Disparities**, p. 29). Racial inequality in income, employment, and homeownership, stemming from structural racism, in turn, has been associated with obesity (251,252). SDOH can shape an individual's education, employment, financial security, and available choices around healthful diet and physical activity through psychosocial influences such as stress as well as environmental influences such as the availability of fresh food and green spaces in the community. Collectively, these factors may impact body weight and subsequent health outcomes.

Being overweight or obese as an adult increases a person's risk for 15 types of cancer; being physically active reduces risk for nine types of cancer (see **Figure 9**, p. 57). Identifying the underlying mechanisms by which obesity, unhealthy diet, alcohol, and physical inactivity increase cancer risk and quantifying the magnitude of such risks are areas of active research. Accumulating evidence indicates a role of chronic inflammation and the immune system in mediating the effects of obesity on cancer development (262,263).

There are significant differences in the quality of diet, prevalence of obesity, physical activity, and alcohol consumption among different populations (see sidebar on **Racial and Ethnic Disparities in Obesity, Diet, and Physical Activity in the United States**, p. 58) and several cancers with a higher burden among racial and ethnic

Guidelines to Reduce Cancer Risk

Research shows that about one-fifth of all cancers diagnosed in the United States are attributed to being overweight or obese, being physically inactive, eating poorly, and drinking excessively. Based on current evidence, experts from the World Cancer Research Fund International recommend people:

Maintain a healthy weight because 15 types of cancer have been causally linked to being obese or overweight*.



Limit consumption of “fast foods” and other processed foods high in fat, simple starches, or added sugars because these contribute to weight gain without providing other nutrients.



Eat at least 30g of fiber and at least 400g of fruit and vegetables each day. One way to achieve this is to include in most meals foods containing whole grains, nonstarchy vegetables, fruit, and pulses (legumes), and to make sure to eat at least five portions or servings of nonstarchy vegetables and fruit every day (253). A diet rich in vegetables, fruits, whole grains, and beans has a low energy density and, therefore, promotes healthy weight.



Limit intake of red meat (beef, pork, lamb) to no more than three servings a week (12-18 ounces a week) and **consume very little or avoid processed meats** (e.g., hot dogs, bacon, and salami) because these foods can increase risk for colorectal and perhaps other cancers (254,255).



Be physically active as part of everyday life; regular physical activity can decrease risk for nine types of cancer (see sidebar on **Physical Activity Guidelines**, p. 63 for details) .



Limit alcoholic drinks, if consumed at all, because alcohol consumption can increase risk for six types of cancer.



For mothers, **breastfeeding** after pregnancy (when feasible) can reduce breast cancer risk.



Limit intake of sugar-sweetened drinks because these lead to weight gain; drink mostly water.



* Overweight and obesity are often assessed using body mass index (BMI): BMI between 18.5 and 24.9 is considered healthy weight. However, it must be noted that the use of BMI has limitations as it is not an accurate measure of obesity or body fatness for all individuals. Researchers are currently investigating novel biomarkers that are better indicators of body fatness and predictive of cancer risk.

Adapted from (2).

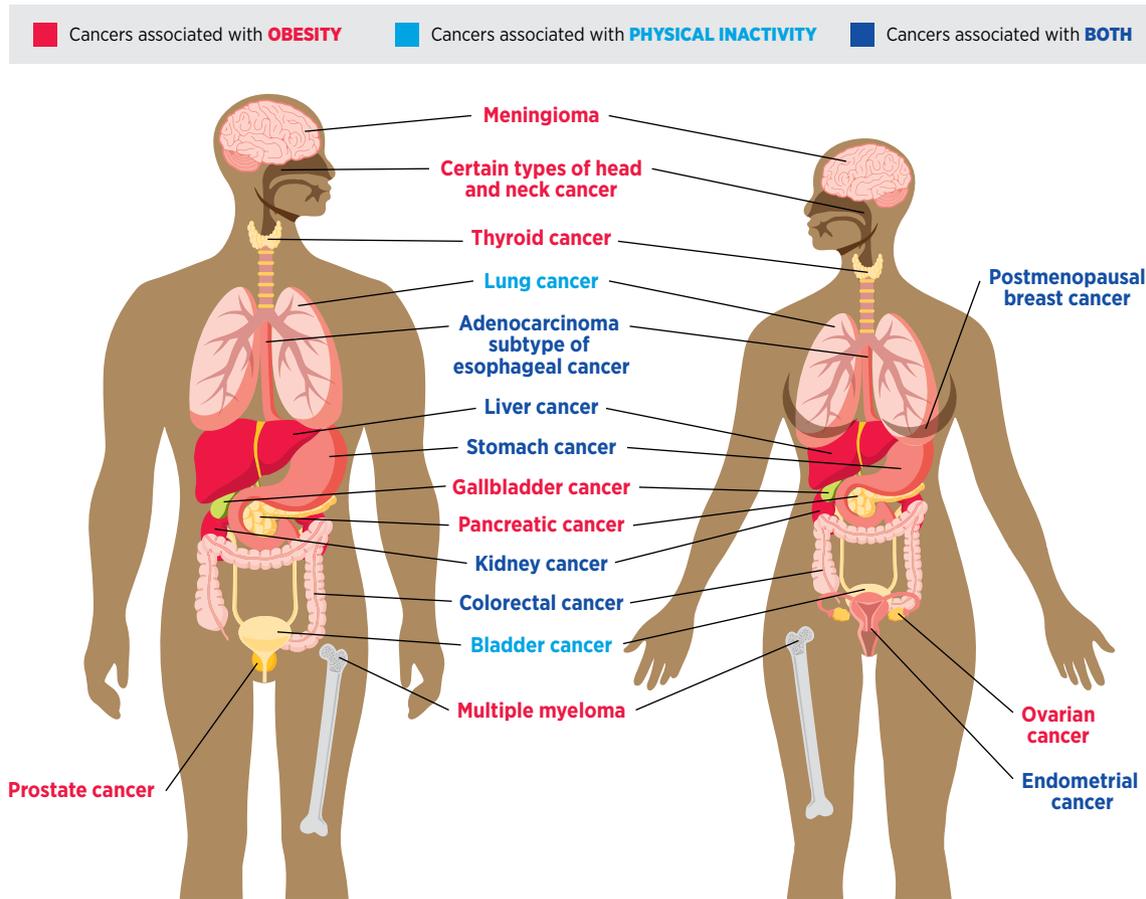
minorities and other underserved populations are associated with obesity and physical inactivity. Emerging data indicate that the association between obesity and cancer risk may vary among different racial and ethnic groups (264,265). Furthermore, the distribution of body fat can vary by racial or ethnic group, and this distribution may also affect cancer risk. Although the increased cancer risk associated with excess body weight and weight gain is clear, mechanisms underlying the variation in risk among different populations are not fully understood. Ongoing research is investigating the biological underpinnings including ancestry-related genetic alterations that may contribute to the differential

susceptibility of racial and ethnic groups to obesity-related diseases such as cancer (266).

The prevalence of obesity has been rising steadily in the United States. In 2018, which is the most recent year for which data are available, 21 percent of youth ages 12 to 19, and 42 percent of adults ages 20 and older were considered obese (272,273). There are, however, notable disparities based on geography and levels of income, as well as race/ethnicity (see sidebar on **Racial and Ethnic Disparities in Obesity, Diet, and Physical Activity in the United States**, p. 58). Studies have shown that socioeconomic inequalities,

FIGURE 9

Reasons to Maintain a Healthy Weight and Stay Active



Fifteen types of cancer—the adenocarcinoma subtype of esophageal cancer; certain types of head and neck cancer; advanced prostate cancer; meningioma; multiple myeloma; and colon, rectal, endometrial, gallbladder, kidney, liver, ovarian, pancreatic, stomach, thyroid, and postmenopausal breast cancers—have all been directly linked to being overweight or obese. Being physically active lowers the risk of nine cancers—bladder, breast

(postmenopausal), colon, endometrial, esophageal, kidney, liver, lung, and stomach. There is growing evidence that physical fitness may also reduce the risk of developing additional types of cancer. Cancers associated with obesity are shown in red; cancers associated with physical inactivity are shown in light blue; cancers that are associated with both are shown in dark blue.

Data from (256-261). Adapted from (2).

which are driven largely by structural and social inequities, are associated with obesity (274). For example, according to a recent study, favorable social and built environment in a neighborhood can promote healthy weight maintenance during adolescence and young adulthood (275). It should be noted that focusing on obesity in early life is key to reducing disparities in obesity and cancer because risk of adult obesity is greater among individuals who were obese as children. Another recent report indicated that among U.S. adults, long-term improvement in neighborhood socioeconomic status is associated with lower risk while long-term decline in neighborhood socioeconomic status is associated

with higher risks for excessive weight gain among residents (276). A variety of factors such as absence of grocery stores and prevalence of fast-food restaurants in the neighborhood, as well as social contexts, such as chronic stress, may contribute to the environment-induced effect on obesity (274).

One major concern among U.S. public health experts is the significantly higher prevalence of obesity among rural adults. There are complex and interrelated factors that contribute to this disparity (277). Rural residents are less likely to be physically active and eat healthily compared to urban residents. Rural

Racial and Ethnic Disparities in Obesity, Diet, and Physical Activity in the United States

In the United States, decades of structural inequities and social injustices have contributed to adverse differences in social determinants of health, such as education, housing, employment, and financial security, all of which are factors that influence a person's behaviors related to diet, physical activity, and general wellness. As a result, there are considerable disparities in the quality of diet, physical activity, and obesity* among certain segments of the U.S. population:

OBESITY

- Among adults, **prevalence of obesity is higher among Black women** (57 percent) compared to White women (40 percent) (267).
- Among **youth ages 10 to 17**:
 - **Obesity rates are significantly higher for those who are non-Hispanic Black** (23.8 percent), **Hispanic** (21.4 percent), or **non-Hispanic American Indian/Alaska Native** (28.7 percent), compared to those who are non-Hispanic White (12.1 percent) or non-Hispanic Asian (8.1 percent);
 - **Obesity rates** were 8.6 percent in the highest income group versus **23.1 percent in the lowest income group** (268).
- The **prevalence of obesity is significantly higher among U.S. adults living in rural counties** (34.2 percent) compared to those living in urban counties (28.7 percent) (221).



DIET

- In **Philadelphia, PA**, the sixth most populous city in the United States, neighborhoods with the lowest median income have **28 percent fewer stores with healthier foods per capita** compared to places with the highest median income; more people living in areas with an overabundance of unhealthy food are Black (45 percent) compared to White (27 percent) (269).
- Between 2013 and 2016, **consumption of unhealthy “fast food” was higher among Black adults** (42 percent) compared to White (37 percent), Hispanic (36 percent) and Asian (31 percent) adults (121).



PHYSICAL ACTIVITY

- The **prevalence of physical inactivity is higher among people with less than a high school education** (48.2 percent) compared to those who are college graduates (14.5 percent) (270).
- **Hispanic adults** (32.1 percent) have the **highest prevalence of physical inactivity**, followed by non-Hispanic Black adults (30 percent) compared to non-Hispanic White adults (23%) (271).



* Overweight and obesity are often assessed using BMI: BMI between 18.5 and 24.9 is considered healthy weight. However, it must be noted that the use of BMI has limitations as it is not an accurate measure of obesity or body fatness for all individuals. For example, Asian individuals may have increased health risks at a lower BMI.

Americans may also have lower income and lack access to resources such as healthy food or recreational facilities to assist them in weight reduction compared to urban residents (277). Further research to gain a comprehensive understanding of the major contributors of obesity among rural residents is needed to develop interventions and policies that can effectively reduce cancer risks and cancer health disparities among rural residents, who account for 15 percent of the U.S. population (221).

There are emerging data showing that weight loss interventions may lower the future risk of certain obesity-related cancers (278-280). Eliminating disparities in obesity and obesity-related cancers necessitates further research to identify culturally tailored, community-based interventions that can be implemented at population levels, especially in low-resource and diverse settings. In this regard, a lifestyle-based obesity intervention delivered in an underserved, low-income primary

THE HONORABLE

Jeanne Shaheen

U.S. Senator for New Hampshire

“Cancer is one of the leading causes of death across America—every family and community has been affected by this disease. It’s unacceptable that rural and marginalized communities don’t have equal access to lifesaving care and treatments for cancer. We need an all-hands-on-deck approach to eliminate these disparities by expanding access to tools to manage and treat this disease. In the Senate, I’ve fought to secure funding to boost research and outreach to communities affected by high rates of cancer, and I’ll keep working to eliminate health care disparities as we work towards a cure.”



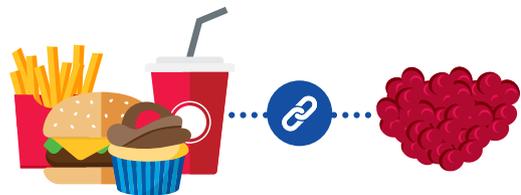
care population resulted in clinically significant weight loss among participants within 24 months (281). Yet another lifestyle program addressing obesity among U.S. Mexicans identified family as a primary motivator for behavior change while barriers to intervention adoption included time and workplace-related factors (282). There is evidence that weight control programs need to be designed with population-specific incentives to maximize population reach and reduce health disparities (283). To reduce the burden of cancer in racial and ethnic minorities and other underserved populations, implementation of evidence-based interventions to address obesity must be a top priority among U.S. public health efforts. Such interventions must also address weight-based discrimination, especially within health care settings. Weight stigma has been related to avoidance or delay in receiving health care (284) and negative health outcomes (285,286).

One key public policy aimed at reducing obesity is the introduction of taxes on sugar-sweetened beverages in several local jurisdictions in the United States (121). Sugar-sweetened beverages are a major contributor to caloric intake among U.S. youth and adults, and there are some emerging data indicating that consumption may be associated with an increased risk of cancer incidence and mortality (287-292). Thus, it is encouraging that the prevalence of heavy sugar-sweetened beverage intake (consumption of 500 kcal or more from sugar-sweetened beverages per day) has declined among U.S. children and adults in recent years (293,294). However, there are persistent disparities in consumption across racial and ethnic populations, with Black, Mexican American, and other Hispanic

adults and children being more likely to drink sugar-sweetened beverages than their White counterparts (293,295,296). Researchers estimate that sugar-sweetened beverage taxes can be cost effective and can potentially result in significant health gains as well as economic benefits for all populations including those who experience cancer health disparities (297). Continued research is necessary to identify effective policies related to food and nutrition that maximize health benefits and to evaluate the long-term effects of these policies on obesity and obesity-related health outcomes such as cancer.

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 (274). To achieve and maintain good health, USDA and HHS, in *Dietary Guidelines for Americans, 2020-2025*, recommend that individuals follow a healthy dietary pattern at every stage of life (298). According to the guidelines, all individuals should fulfill their nutritional needs by consuming nutrient-dense food and beverages including fruits, vegetables, whole grains, low-fat dairy products, lean meat, eggs, seafood, beans, legumes, nuts, and vegetable oil, and limit foods and beverages that are high in added sugars, saturated fat, and sodium, as well as alcoholic beverages (298).

In the United States, more than 5 percent of all newly diagnosed cancer cases among adults are attributable to eating a poor diet (300). Research shows that daily intake of five servings of fruit and vegetables is associated with a 10 percent reduction in overall cancer mortality when compared to intake of two servings per day (301). Higher intake of red meat is associated with increased risk, whereas higher intake of dietary fiber and whole grains is associated with reduced risk of colorectal cancer incidence (121,302,303). Unfortunately, racial and ethnic



Poor diet is estimated to contribute to **3 million new cancer cases, 1.74 million cancer deaths, and \$254 billion in economic costs** among U.S. adults age 20 years or older over their lifetime.

Burden of **diet-attributable cancers** is **higher among those who are Black** and with lower education and income.

Data from (299).

The **Special Supplemental Nutrition Program for Women, Infants, and Children** has been **effective in increasing the consumption of healthy food** and lowering the rates of obesity among children from low-income families.



Data from more than **12 million children ages 2 to 4** whose families are **enrolled in the program** show that **obesity rates declined** from 16 percent (2010) to less than four percent (2016).

A recent report from **Latin American immigrant families in New York** showed that **among eligible families 49 percent had no child enrolled**. Reasons included fears of repercussion arising from misinformation (e.g., payback obligation, college aid ineligibility, child removal, noncitizen family member penalties) and logistical barriers.

Data from (307-309).

minorities and other underserved populations are at a higher risk of poor dietary habits. For example, consumption of whole grains is lower among Hispanic (11 percent) and Black (14 percent) adults compared to White (17 percent) and Asian (18 percent) adults (121); federal guideline-concordant vegetable intake is lower among Black adults (seven percent) compared to White (10 percent) or Hispanic adults (11 percent)(304). It is concerning that, according to a recent analysis, there was a greater increase in the consumption of unhealthy ultraprocessed foods between 1999 and 2018 among Black and Mexican American youths compared to White youths (305). Unfortunately, while overall dietary patterns in the U.S. have improved over the past two decades, the progress has been uneven across different populations (121). As one example, according to a recent analysis, diet quality has improved over the past two decades for Black and White young adults (ages 18-39), while remaining the same for Mexican Americans. The data further indicate that even though individuals from all income levels experienced some improvement in diet quality, the disparity between low- and high-income groups increased considerably (306). There are also regional differences in dietary patterns. For instance, consumption of recommended fruits and vegetables is lower in Puerto Rico compared to the continental U.S. (121). Intensive efforts by all stakeholders are needed if we are to increase the number of people who consume a balanced diet such as that recommended by the *Dietary Guidelines for Americans, 2020-2025*.

A major barrier to a healthy diet is food insecurity, defined by the USDA as the lack of access by all people in a household at all times to enough food for an active, healthy life. Many studies have found an association between food insecurity and excess body weight (274). It is concerning that the prevalence of food insecurity has increased from approximately nine percent to 18 percent between 2000 and 2016, and that racial and ethnic minorities and individuals living in poverty have significantly higher likelihood of living with food insecurity (310). Notably, low-income and racially and ethnically diverse neighborhoods are often located in “food deserts,” lacking access to healthy food retail such as supermarkets, while having an overabundance of convenience stores with unhealthy, highly processed, and fast-food options (274,311). Higher food insecurity rates are associated with increased likelihood of late-stage cancer (312). There is growing recognition that systemic inequities and social injustices contribute to food insecurity (313). It is imperative that all sectors work together to identify evidence-based public policies and programs that address structural racism and discrimination and alleviate disparities in access to healthy food options. Public education to improve nutritional knowledge must be a key component of such policies considering recent observations that the association between greater access to grocery stores and increased fruit and vegetable consumption varies widely by race/ethnicity and that high educational attainment rather than high income or access to grocery stores has the strongest association with healthy eating behavior in racially and ethnically diverse neighborhoods (314).

Alcohol consumption increases the risk for six different types of cancer (260) (see **Figure 10**, p. 61), and emerging evidence suggests that there may be increased risks for additional cancer types (315). Even modest use of alcohol may increase cancer risk, but the greatest risks are associated with excessive and/or long-term consumption (316-319) (see sidebar on **Guidelines for Alcohol Consumption**, p. 62). In the United States, alcohol consumption accounted for greater than 75,000 cancer cases and nearly 19,000 cancer deaths annually between 2013 and 2016 (320). Consumption is higher among men with lower education and income compared to men who are college graduates and have higher income, as well as among certain SGM individuals compared to those who identify as straight (270).

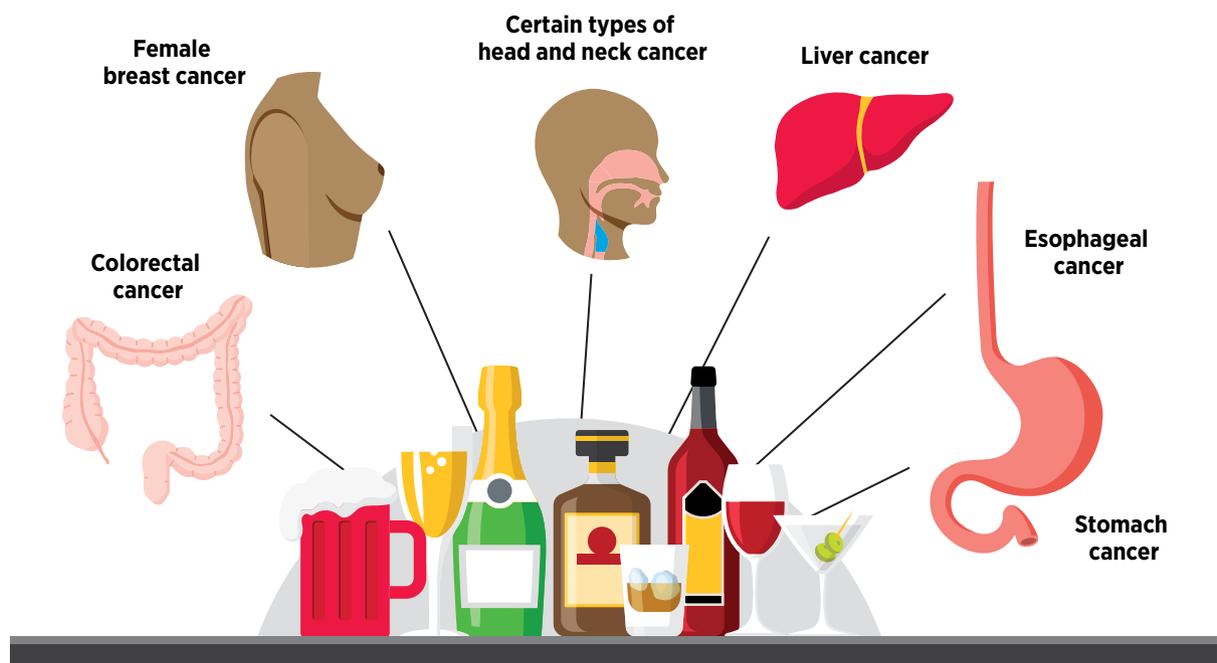
Despite generally lower alcohol consumption, **American Indian/ Alaska Native adults** have the **highest alcohol-related death rates**



among all racial and ethnic groups (322).

FIGURE 10

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, and breast, colorectal, liver, and stomach cancers.

Adapted from (2).

Ongoing efforts focused on public education, evidence-based policy interventions such as regulating alcohol retail density, taxes, and prices, along with clinical strategies are being evaluated to reduce the consumption of alcohol and the burden of alcohol-related cancers. There is compelling evidence that racial and ethnic discrimination is associated with depression and social anxiety leading to hazardous drinking among Black and Hispanic adults (323). Prevention and treatment efforts must therefore consider the psychosocial and cultural factors that play a role in alcohol-related health problems in minorities and underserved populations.

Three percent of overall cancer cases in the United States can be attributed to physical inactivity (210). Engaging in recommended amounts of physical activity (see sidebar on **Physical Activity Guidelines**, p. 63) can lower the risks for developing nine types of cancer (see **Figure 9**, p. 57), and there is emerging evidence that there may be risk reduction for even more cancer types (257-259). Considering this evidence, it is concerning that more than a quarter of U.S. adults reported no physical activity in 2018 (270). There are also striking sociodemographic disparities among those who are physically active with a higher prevalence of activity recorded among adults who are White, have a graduate level education, higher income, and private health insurance (13).

Living in low-income neighborhoods, which are more likely to lack safe and affordable options for physical exercise, such as gyms, biking and hiking trails, and biking and walking paths, contributes to disparities in the burden of obesity-related diseases in minorities and other underserved populations. Studies have shown that living in neighborhoods that are perceived to be safe and have attributes of walkability is associated with higher levels of physical activity among low-income and racial and ethnic minority populations (324,325). It is imperative that health care professionals and policy makers work in concert to increase awareness of the benefits of physical activity and support programs and policies that facilitate an active lifestyle for all individuals in the United States.

It is equally important to include racially, ethnically, and geographically diverse populations in clinical trials on cancer prevention. Identifying social, cultural, behavioral, technological, and health care-related factors that encourage adherence to an active lifestyle in minorities and other medically underserved populations is critical to achieving health equity in cancer and other chronic diseases. In this regard, recent clinical trials provide valuable insights into strategies that may promote healthy behaviors in underserved populations as observed in rural Hispanic women in the state

Guidelines for Alcohol Consumption

The U.S. Department of Agriculture and U.S. Department of Health and Human Services, *Dietary Guidelines for Americans, 2020-2025*, recommends (298):

If alcohol is consumed, **it should be done in moderation.**

MODERATE DRINKING



≤ 1 drink per day for women



≤ 2 drinks per day for men

Only by **adults of legal drinking age.**

One drink is described as containing **14 g (0.6 fl oz) of pure alcohol.**

The following are reference beverages that are **one alcoholic drink-equivalent:**

12 fl oz of regular beer
(5% alcohol)



5 fl oz of wine
(12% alcohol)



1.5 fl oz of 80 proof distilled spirits
(40% alcohol)



According to the National Institute on Alcohol Abuse and Alcoholism:

HEAVY DRINKING



≥ 3 drinks on any day or ≥ 7 drinks per week for women



≥ 4 drinks on any day or ≥ 14 drinks per week for men

BINGE DRINKING



≥ 4 drinks within 2 hours for women



≥ 5 drinks within 2 hours for men

Excessive alcohol consumption includes binge drinking, heavy drinking, and any drinking by pregnant women or those under 21 years of age.

The U.S. Preventive Services Task Force recommends that clinicians screen adults age 18 and older for alcohol misuse and provide individuals engaged in excessive drinking with brief behavioral counseling interventions. However, according to a recent survey, while many of the survey respondents report being asked by their health care provider about alcohol consumption and binge drinking, during checkups, 80 percent of these individuals received no advice to reduce their drinking (321).

Adapted from (2).

of Washington, residents in Alabama's rural Black Belt region, and Hispanic adults along the Texas/Mexico border, among others (327-329). The data from these trials identify positive influences on physical activity such as emotional and social support from promotoras (community health workers) or a romantic partner as well as technologies such as the interactive voice response system (327,328,330).

UV Exposure

Exposure to UV radiation from the sun or indoor tanning devices poses a serious threat for the development of all three main types of skin cancer—basal cell carcinoma, squamous cell carcinoma, and melanoma, which is the deadliest form of skin cancer. Thus, one of the most effective ways a person can reduce the risk of skin cancer

is by practicing sun-safe habits and not using UV indoor tanning devices (see sidebar on **Ways to Protect Your Skin**, p. 64).

Overall, exposure to UV light accounts for 4-6 percent of all cancers and is responsible for 95 percent of skin melanomas (210). Disparities have been reported in the level of knowledge about the dangers of sun exposure and importance of using sunscreen, with Black and Hispanic individuals having less knowledge and being less likely to use sunscreen than White individuals (331,332). A recent survey indicated that greater than 80 percent of Native Americans report experiencing sunburns, while only 11 percent and 36 percent regularly use sunscreen on their bodies and faces, respectively (333). Another study showed that only six percent of Black and 24 percent of Hispanic fifth graders reported using sunscreens compared to 45 percent of their NHW counterparts (334). These data are particularly concerning because

Physical Activity Guidelines

The U.S. Department of Health and Human Services recommends the following minimum physical activity levels to improve the nation's health (256).

For preschool-age children

- Physical activity throughout the day to enhance growth and development
- Three hours per day of activity of all intensities



For school-age children and adolescents

- Sixty minutes or more of physical activity (for example, running) daily
- Muscle- and bone-strengthening exercises such as push-ups at least three days per week



For adults

- All adults should avoid inactivity; some physical activity is better than none.
- At least 150 minutes per week of moderate-intensity activity such as a brisk walk or 75 minutes per week of vigorous-intensity activity such as running
- Moderate- or high-intensity muscle-strengthening activities two or more days per week



For specific populations

- Older adults, those who are pregnant, and/or those with chronic health conditions and disabilities should consult their physicians and follow modified guidelines.
- Cancer survivors should consult their physicians and follow modified guidelines adapted for their specific cancers and treatment (326).



Adapted from (2).

sunburns—clear indicators of overexposure to UV radiation—during childhood pose one of the greatest risks for developing skin cancer later in life (335). Recent studies show that sun safety interventions, such as those being evaluated in school settings and utilizing ethnically and racially tailored lessons on protective behaviors from trained health educators, can improve risk reducing behavior among children from diverse backgrounds (336).

The level of knowledge about skin cancer risks among Black and Hispanic populations is influenced by the level of education (337). Overall, the disparity in skin cancer preventive behavior among these populations is of public health concern because Black and Hispanic people tend to be diagnosed at more advanced stages despite having a lower incidence of skin cancer (338,339). There are distinct characteristics of skin cancers in racial and ethnic minorities, e.g., places on the body where skin cancers tend to occur are often in less sun-exposed areas, making early detection more difficult (338,339). More research is needed to understand the association between UV

exposure and the risk of melanoma as well as novel risk factors for skin cancer in racial and ethnic minorities (340,341). Data from such investigations will help identify and implement more effective interventions to reduce the burden of skin cancers among racial and ethnic minorities.

Use of indoor UV tanning devices increases a person's risk for melanoma. Sexual minority men have been shown to have increased rates of indoor tanning compared with heterosexual men indicating that they may be at higher risk for skin cancer due to differential risk behaviors(342). Laws prohibiting tanning can be effective in reducing tanning practice and may reduce the incidence of future melanoma cases (343,344). However, as of January 1, 2021, in the U.S., only 20 states and the District of Columbia have laws prohibiting tanning for minors (under the age of 18) (121). It is vital that all stakeholders in public health continue to work together to develop and implement more effective policy changes and public education campaigns to reduce indoor tanning practice, especially among high-risk populations.

Ways to Protect Your Skin

To reduce risk of the three main types of skin cancer—basal cell carcinoma, squamous cell carcinoma, and melanoma—the Centers for Disease Control and Prevention recommends the following measures:

Seek shade and limit time in the sun, especially during peak sun hours (10:00 a.m. to 4:00 p.m.).



Wear clothing that covers arms and legs; some clothing is designed to provide protection from the sun.



Wear a **wide-brimmed hat**.



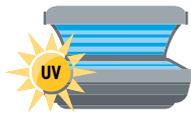
Wear **wrap-around sunglasses**.



Apply the recommended amount of a sunscreen before going outside (even on slightly cloudy or cool days); **use sunscreen that provides protection against UVA and UVB rays** and that is rated sun protection factor (SPF) **15 or higher**, at least every 2 hours and after swimming, sweating, and toweling off.



Avoid indoor tanning with UV devices such as sunlamps, sunbeds, and tanning booths.



Adapted from (2).

Infectious Agents

Persistent infection with several pathogens—disease causing bacteria, viruses, and parasites—increases a person’s risk for several types of cancer (see **Table 4**, p. 66). Globally, an estimated 13 percent of all cancer cases in 2018 were attributable to pathogenic infections, with more than 90 percent of these cases attributable to four pathogens: HPV, HBV, HCV, and *Helicobacter pylori* (345,346). In the United States, about three percent of all cancer cases are attributable

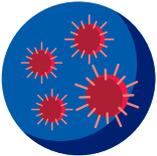
to infection with pathogens (210). Individuals can significantly lower their risks by protecting themselves from the infection or by seeking treatment, if available, to eliminate an infection (see sidebar on **Preventing or Eliminating Infection with the Four Main Cancer-causing Pathogens**, p. 65). It is important to note that even though strategies to eliminate, treat, or prevent infection with *Helicobacter pylori*, HBV, HCV, and HPV can significantly lower an individual’s risks for developing cancers, these strategies are not effective at treating infection-related cancers once they develop.

Helicobacter pylori is a type of bacterium that has been shown to cause gastric cancer. Among U.S. adults, *H. pylori* prevalence is two to three times higher among Mexican American and Black persons compared to White persons (121), which may contribute to the higher rates of gastric cancer in these populations. Prevalence is also greater among non-U.S.-born individuals and varies by Hispanic/Latino background (46). Declining rates of *H. pylori* infection have been reported recently, which may be due in part to improved access to health care and healthier living (347).

Chronic infection with HBV and HCV can cause liver cancer and is increasingly recognized as a risk factor for additional malignancies such as non-Hodgkin lymphoma. The rates of HBV infection decreased among all racial and ethnic groups during 2004 and 2014 with a steeper decline observed among minorities compared to White people (348). Unfortunately, after decades of progress, the number of new HBV infections is now rising among adults despite the availability of a safe and effective vaccine. HBV infection is also higher among certain populations who emigrated from outside the U.S. As one example, the higher burden of liver cancer due to chronic HBV infection among Asian individuals can be attributed to high HBV prevalence in the country of origin and recent immigration (22). CDC recently recommended that all adults ages 19-59 years receive a vaccination for HBV (349). Additionally, CDC recommended that adults age 60 years and older without known risk factors for HBV also get vaccinated. Current evidence suggests significant gaps in the perception, evaluation, and treatment of HBV especially among racial and ethnic minorities, highlighting the need for community-based, culturally appropriate interventions to mitigate the disproportionate impact of the virus in these populations (350,351).

Acute infection with HCV is often asymptomatic but more than half of these cases progress to chronic infection. Therefore, it is extremely concerning that the rate of reported acute HCV cases in the United States increased by 89 percent between 2014 and 2019 with most cases occurring among individuals ages 20-39 years (348). There are disparities in the rates of acute HCV infection among racial and ethnic groups with the highest rate of 3.6 cases per 100,000 reported among AI/AN persons. Liver cancer incidence and mortality rates are also higher among AI/AN populations compared to White people (see **Table 1**, p. 23; and **American Indian or Alaska Native (AI/AN) Population**, p. 13). Among AI/AN, HCV infections occur earlier than in other racial and ethnic groups and HCV-related deaths are double the

Preventing or Eliminating Infection with the Four Main Cancer-causing Pathogens

PATHOGEN	WAYS TO PREVENT INFECTION	WAYS TO ELIMINATE OR TREAT INFECTION	U.S. RECOMMENDATIONS
<p><i>Helicobacter pylori</i></p> 	<p>Avoid exposure through good hygiene and sanitation</p>	<p>Treatment with a combination of antibiotics and a proton-pump inhibitor can eliminate infection</p>	<p>CDC recommends testing and treatment for people with active or a documented history of gastric or duodenal ulcers, low-grade gastric MALT lymphoma, or early gastric cancer that has been surgically treated.</p>
<p>Hepatitis B virus (HBV)</p> 	<ul style="list-style-type: none"> • HBV vaccination • Avoid behaviors that can transmit infection (e.g., injection drug use and unsafe sex) 	<p>Treatment of those chronically infected with antiviral drugs rarely eliminates infection but does slow virus multiplication; this slows the pace at which liver damage occurs and thereby reduces risk for liver cancer</p>	<ul style="list-style-type: none"> • Vaccination has been part of the childhood immunization schedule since 1991. In March 2022, CDC updated its recommendation suggesting all adults ages 19-59 years receive a vaccination. • CDC and USPSTF recommend screening high-risk individuals—those from countries with high rates of HBV infection, HIV-positive persons, injection drug users, household contacts of HBV-infected individuals, and men who have sex with men—for HBV infection.
<p>Hepatitis C virus (HCV)</p> 	<p>Avoid behaviors that can transmit infection (e.g., injection drug use and unsafe sex)</p>	<p>Treatment with any of several antiviral drugs can eliminate infection</p>	<p>There is consensus in recommendations from CDC and USPSTF for universal screening of all adults ages 18 to 79.</p>
<p>Human papillomavirus (HPV)</p> 	<ul style="list-style-type: none"> • Three FDA-approved vaccines • Practice safe sex, although this may not fully protect against infection 	<p>None available</p>	<p>CDC recommends HPV vaccination for boys and girls age 11 or 12; recommendations for other groups can be found in sidebar on HPV Vaccination Recommendations, p. 67).</p>

CDC, Centers for Disease Control and Prevention; MALT, mucosa-associated lymphoid tissue; USPSTF, U.S. Preventive Services Task Force. Adapted from (2).

TABLE 4

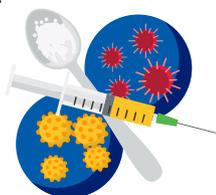
Cancer-causing Pathogens

PATHOGEN	CANCER TYPES CAUSED BY THE PATHOGEN	NUMBER OF GLOBAL CANCER CASES
Bacteria		
<i>Helicobacter pylori</i>	Stomach cancer and non-Hodgkin lymphoma	810,000
Parasites		
<i>Clonorchis sinensis</i> and <i>Opisthorchis viverrini</i>	Cholangiocarcinoma	3,500
<i>Schistosoma haematobium</i>	Bladder cancer	NA
Viruses		
Epstein-Barr Virus (EBV)	Hodgkin lymphoma, certain types of non-Hodgkin lymphoma, and nasopharyngeal cancer	156,600
Hepatitis B Virus (HBV)	Hepatocellular carcinoma	360,000
Hepatitis C Virus (HCV)	Hepatocellular carcinoma and non-Hodgkin lymphoma	156,000
Human Herpesvirus type 8 (HHV-8; also known as Kaposi sarcoma herpesvirus)	Kaposi sarcoma	42,000
Human Immunodeficiency Virus (HIV)	Kaposi sarcoma and non-Hodgkin lymphoma	NA
Human Papillomavirus (HPV)	Anal, cervical, head and neck, larynx, oral, oropharyngeal, penile, vaginal, and vulvar cancers	690,000
Human T-cell Lymphotropic Virus, type 1 (HTLV-1)	T-cell leukemia and lymphoma	3,600
Merkel Cell Polyomavirus (MCV)	Skin cancer	NA

NA, Not applicable.
Data from Ref. [https://www.thelancet.com/journals/langlo/article/PIIS2214-109X\(19\)30488-7/fulltext#seccetitle10](https://www.thelancet.com/journals/langlo/article/PIIS2214-109X(19)30488-7/fulltext#seccetitle10)

national rate (352). To reduce the burden of HCV, the Indian Health Service (IHS) recommends universal screening of all AI/AN adults (353). While rates of infection among Black and Hispanic persons are lower compared to White persons, Black and Hispanic populations have recorded the greatest increases in infection between 2010 and 2019 (348). To eliminate viral hepatitis as a public health threat, HHS recently released the *Viral Hepatitis National Strategic Plan for the United States: A Roadmap to Elimination (2021–2025)* (354). The primary goals listed in the report are to prevent new infections, improve hepatitis-related health outcomes for infected individuals, reduce disparities and health inequities related to hepatitis, improve surveillance of viral hepatitis, and bring together all relevant stakeholders in coordinating efforts to address the hepatitis epidemic.

- Among the **reported cases of hepatitis B (HBV) and hepatitis C (HCV)** where injection drug use information is available, 35 percent of HBV and 67 percent of HCV **cases report drug use by injection** (348).
- CDC recommends that people who inject drugs **should be vaccinated against HBV and tested for HBV and HCV.**



Persistent infection with HPV is responsible for almost all cervical cancers, 90 percent of anal cancers, about 70 percent of oropharyngeal cancers, and more than half of all vaginal, vulvar, and penile cancers (355). This knowledge has driven the development of vaccines that prevent infection with most cancer-causing strains of HPV. 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 (355). Higher prevalence of HPV infection has been reported both in females and males in certain racial and ethnic minorities (356,357). There is emerging evidence that the receipt of recommended HPV vaccination (see sidebar on **HPV Vaccination Recommendations**, p. 67) significantly lowers the risk of infection with HPV types that are covered by the vaccines, and dramatically reduces the incidence of cervical cancers among the vaccinated individuals (358–360). Until recently, cervical cancer was the most common HPV-related cancer in the United States. However, the incidence of HPV-related oropharyngeal and anal cancers has been increasing and oropharyngeal squamous cell carcinoma was recently reported to have become the most common HPV-associated cancer in the United States (361,362). Notably, HPV infection is a particular concern for gay, bisexual, and other men who have sex with men because they are at a significantly higher risk for anal cancer than heterosexual men (363). There are, however, no formal screening tests for oropharyngeal or anal cancers. Developing effective strategies to increase the uptake of HPV vaccines among eligible adolescent boys could have immense public health benefits.

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.



Although there are **three FDA-approved HPV vaccines**, only one (Gardasil 9) is currently 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.

U.S. 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.



Adapted from (364).

Despite the known benefits, the uptake of HPV vaccines has been suboptimal in the United States. While there has been some progress in recent years, only 56 percent of boys and 61 percent of girls who are eligible were up to date on their vaccination regimen in 2020 (365). Vaccination is significantly lower among adolescents in rural areas in comparison to urban communities (49 percent vs. 60 percent respectively) (365). There are also disparities based on sociodemographic characteristics. Recent reports indicate that vaccination is lower among U.S. adolescents and young adults who are not born in the country, live in disadvantaged neighborhoods, are without private health insurance, and/or belong to racial and ethnic minorities (366,367). Common barriers to HPV vaccination identified in racial minorities, e.g., among American Indian/Alaska Native and Native Hawaiian or Other Pacific Islander populations include health care-, community-, and individual-level factors such as inadequate knowledge about the vaccine, misconceptions about its safety, and lack of provider recommendation (368-370).

All stakeholders must work together and develop evidence-based interventions to increase the uptake of HPV vaccination in the United States. These strategies must increase health care provider recommendations to eligible adolescents and their parents, improve

provider-parent communication, increase parental awareness, build trust in medical research, and remove structural and financial barriers to increase access to vaccination. Systematic review of the published literature indicates that among minority populations, interventions that provide culturally tailored messages, address misconceptions, engage parents as well as community members, and utilize education and appointment reminders can improve

During 2013-2017, an estimated 1,030 cases of HPV-associated cancers were reported in American Indian/Alaska Native populations. Of these, 72 percent were attributable to HPV

types covered by the vaccine (Gardasil 9); most cancers reported were cervical cancers (female) and oropharyngeal cancers (male) (371).



vaccination uptake (372,373). It is critical to address SDOH through public policies, considering the stark disparities in the burden of HPV based on poverty and education (374). In this regard, the Affordable Care Act's 2010 provisions and 2014 insurance expansions were associated with increases in HPV vaccination completion among 9- to 26- year-old females and males (375).

Exposure to Environmental Carcinogens

HHS recognizes that a person's physical environment influences health (see **Social and Built Environments**, p. 35) (376). As described in earlier sections of this chapter, the physical design of an individual's neighborhood—built environment—determines access to healthy foods, spaces for physical activity, and exposure to secondhand smoke which are linked to cancer. There is clear evidence that individuals living in disadvantaged neighborhoods are more likely to be diagnosed with cancer and to have poorer survival compared with individuals in more advantaged neighborhoods (377-381). 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, and not every exposure will lead to cancer. The intensity and duration of exposure, combined with an individual's biological characteristics such as genetic makeup and lifestyle factors, determine each person's chances of developing cancer over his or her lifetime. In addition, when studying environmental cancer risk factors, it is important to consider that exposure to several environmental cancer risk factors may occur simultaneously.

Environmental exposures to pollutants and certain occupational agents can increase a person's risk of cancer. For instance, radon, a naturally occurring radioactive gas that comes 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 (382,383). Unfortunately, there are significant gaps in the knowledge about the cancer risks from radon, especially among minorities and other underserved populations (384). Other examples of environmental carcinogens include arsenic, asbestos, lead, radiation, and benzene (385). Increasing knowledge of the presence of environmental pollutants in certain geographic regions emphasizes the need for more research to inform the future development and implementation of education and policy initiatives. For example, researchers recently found elevated levels of arsenic, uranium, and other heavy metals near abandoned mines in the western United States and are now investigating how this might affect the health of nearby American Indian communities (386-388).

Outdoor air pollution is classified by the International Agency for Research on Cancer (IARC), the specialized cancer agency of

WHO, as a potential cause of cancer in humans (389). Two types of air pollution are most common in the United States: ozone and particle pollution. Particle pollution refers to a mix of tiny solid and liquid particles that are in the air we breathe, and in 2013, IARC concluded that particle pollution may cause lung cancer (385). Therefore, it is concerning that nearly 21 million people in the United States were exposed year-round to unhealthy levels of particle pollution between 2017 and 2019 (385). Racial and ethnic minorities and people living in poverty were at an increased risk of being exposed to polluted air (385,390). According to a recent report, historical redlining has been associated with substantial disparities in the exposure to air pollution, leading to racial and ethnic minorities who are frequently overrepresented in the most disadvantaged neighborhoods being exposed to greater levels of air pollutants such as nitrogen dioxide and fine particulate matter, which are significant causes of premature mortality (391). Therefore, new policies to reduce the release of pollutants into the atmosphere, especially in historically disadvantaged regions, are urgently needed to combat the adverse health effects of air pollution.

Chemical compounds that are used in agriculture, in the house, in some occupations such as to combat pests or weeds, and to protect us from fires, such as fire-retardants, may cause cancer. The National Toxicology Program (NTP), a collaborative effort between HHS, and IARC, has developed lists of substances that are known or are reasonably anticipated to be human carcinogens based on the available scientific evidence (394,395). Among these substances are pesticides and other products that can disrupt the function of hormones, which are produced by a body's endocrine system, and some of these endocrine-disrupting chemicals have been linked to cancer (396). Involuntary exposures to many of

Data from a **U.S. Environmental Protection Agency (EPA)-based model called Risk-Screening Environmental Indicators** were used in a recent effort to create a detailed map to **visualize the cumulative cancer risk from toxic industrial air pollution** across the United States (392). The map identified many cancer “hot spots”—areas where the estimated cancer risk over a lifetime averaged for five years is at or above 1 in 100,000 (393).

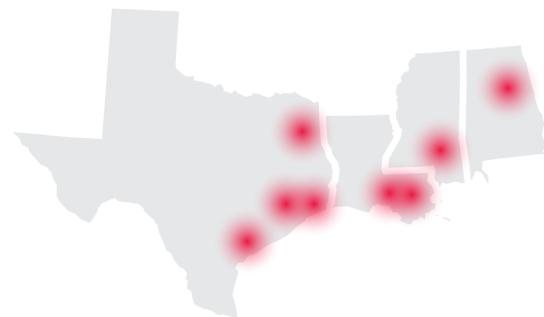
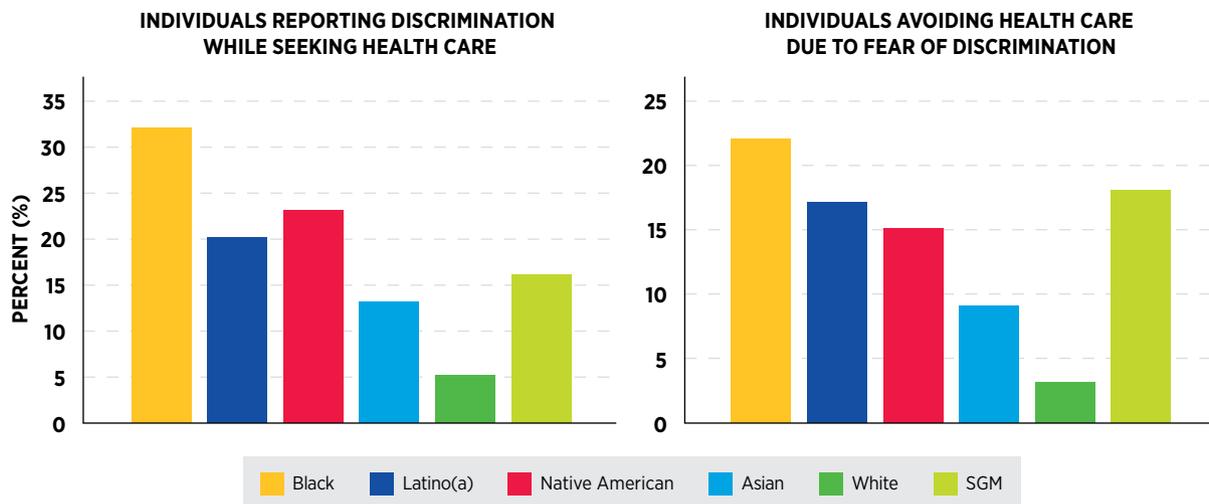


FIGURE 11

Discrimination Is a Major Barrier to Receiving Quality Health Care



According to a recent survey, racial and ethnic minorities and other underserved populations experience discrimination frequently when seeking medical care. In fact, 32 percent of Black, 23 percent of Native American, 20 percent of Hispanic, and 13 percent of Asian respondents experienced discrimination when going to a health care provider because of their race or ethnicity. Sixteen percent of sexual and gender minority (SGM) respondents reported discrimination based on their sexual orientation. Furthermore, 22 percent of Black, 17 percent of Hispanic, 15 percent of Native American, and 9 percent of Asian respondents reported that they have avoided

seeking medical care for themselves or a family member out of concern that they would be discriminated against because of their race, compared to only three percent of White respondents who report this behavior. Nearly one in five (18 percent) SGM individuals say they have avoided seeking medical care due to concern that they would be discriminated against because of their sexual orientation and/or gender identity. Although not shown in this figure, individuals who are overweight or obese and those with disabilities report experiencing discrimination at health care settings and delaying or avoiding medical care because of such experiences.

Data from (434).

the environmental pollutants are usually higher in subgroups of the population, such as workers in certain industries who may be exposed to carcinogens on the job; racial and ethnic minorities; or individuals from a low socioeconomic level (397-401). As one example, the most recently updated NTP report on carcinogens reports higher urinary levels of antimony trioxide, a compound newly listed as a carcinogen, in lower-income individuals living in economically deprived neighborhoods compared to those in more affluent neighborhoods (394). One area of ongoing research is to determine whether exposure to certain chemicals in personal care products e.g., hair products, can increase the risk of breast cancer especially among minority women (402,403). There are disparities in the burden of cancers caused by environmental exposures based on geographic locations and socioeconomic status (404). As we learn more about environmental and occupational cancer risk factors and identify segments of the U.S. population that are exposed to these factors, new and/or more effective policies

need to be developed and implemented for the benefit of all populations, especially the most vulnerable and underserved.

Social and Behavioral Stress

Stress-inducing social and behavioral factors have been considered as possible cancer risk factors. For example, it has been suggested that having a stress-prone personality and poor coping skills, as well as trauma-induced distress, can affect incidence, mortality, and survival for various types of cancer (405-407). According to a recent report, individuals who consistently experience high-stress levels for a long time have an 11 percent greater risk of developing cancer than those with consistently low stress levels (408). It is not clear whether the effects of stress on cancer are due to an increase in risk-enhancing lifestyles, such as smoking, alcohol consumption, poor diet, and physical inactivity,

or due to direct effects on our biological processes that play a role in cancer initiation and progression. Evidence is accruing that stress can directly affect hormones and/or cellular processes including those that regulate our immune function, which in turn may contribute to cancer incidence or outcomes (109,409-411).

There is emerging evidence that structural racism leads to disparities in the burden of cancer (412-414). Unfortunately, many psychological and social stressors stem from systemic inequities and social injustices (e.g., structural racism, marginalization, discrimination), which are disproportionately experienced by minority and underserved populations over the course of their lives (415-418) (see **Figure 11**, p. 69). Among the various psychosocial risk factors that may induce stress are social isolation (419), which has been shown to contribute to increased morbidity and mortality, particularly among underserved population (420-422), and racial discrimination (perceived or experienced), which can contribute to poor physical and mental health among minorities (97,423,424). Social isolation and lack of social support may mediate cancer disparities (425,426). Moreover, gentrification, segregation, and discrimination have been linked to chronic health conditions and worse cancer outcomes (97,427-431). Patients with cancer from racial and ethnic minorities are more likely to report psychosocial stress compared to those who are White (432,433). It is imperative that additional studies on different cancers, populations, and environmental settings be undertaken to fully elucidate the role of psychosocial factors on cancer risk, and that appropriate interventions including community-level supports be deployed to prevent these factors and minimize their contribution to cancer health disparities.

One area of active investigation in cancer health 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 (435,436). Heightened allostatic load due to stressors related to

SDOH (see **Figure 5**, p. 32) is linked to worse cancer outcomes, particularly among racial and ethnic minorities and other medically underserved populations (437,438). Allostatic load may contribute to cancer burden through effects on stress hormones and/or epigenetics. Researchers are evaluating interventions including lifestyle factors which may improve allostatic load in populations that are at an increased risk for cancer (439).

It is clear that COVID-19 has had a significant negative impact on the mental health. Individuals from racial and ethnic minorities and other medically underserved populations have been especially vulnerable. Data also indicate worse impact among cancer patients, survivors, and their caregivers, arising from social isolation, financial stress, food insecurity, concerns about timely access to cancer treatments, and disease recurrence (7). Ongoing research is needed to monitor and address the long-term impact of pandemic-related stress on cancer burden, overall, and on cancer health disparities.

Night Shift Work and Sleep

There is accumulating scientific evidence that qualitative and quantitative sleep disturbances may increase a person's risk for developing cancer. Research has shown that working at night or working in airplanes that cross many time zones can lead to the disruption of the regular circadian cycle and have possible implications in cancer formation, mainly for breast, gastrointestinal, and skin cancers (440,441). Research into the role of circadian rhythms in diseases including cancer is an active area of investigation. Both Black and Hispanic people have been found to have higher prevalence of short sleep duration, including night shift work, compared with White people (393,442,443). However, more research is needed to completely understand the causes and develop potential interventions for this underappreciated cancer risk factor as well as to identify its role in cancer health disparities.

Disparities in Cancer Screening for Early Detection

IN THIS SECTION, YOU WILL LEARN:

- ▶ Cancer screening aims to find precancerous lesions and cancers at their earliest stage when it is easier to treat them.
- ▶ Population-based screenings are performed based on age and sex for those at an average risk of developing cancer, and based on behavioral factors or family history for those at a higher risk of developing cancer.
- ▶ Professional organizations and government-affiliated agencies carefully evaluate the benefits and harms of cancer screening to make evidence-based recommendations for its use in the clinic.
- ▶ Adherence to routine cancer screening reduces mortality from the cancer for which individuals are screened.
- ▶ Socioeconomic and structural barriers are primary contributors to cancer screening disparities for racial and ethnic minorities and other medically underserved populations.
- ▶ Stakeholders across the cancer control continuum are developing and implementing multipronged strategies that are culturally and linguistically tailored to raise cancer screening awareness, access, and adherence among the underscreened populations.
- ▶ Research regarding genetics of ancestry and its impact on cancer risk may improve the precision of personalized screening for patients in the future.

Cancer screening is defined as looking for precancerous lesions, or early cancers before a person develops any signs or symptoms. While modifying certain behaviors can reduce the risk of developing cancer, routine screening for cancer can help find an aberration at the earliest possible time during cancer development. Health care providers use the information gleaned from a cancer screening test to make an informed decision on whether to monitor or treat, or surgically remove precancerous lesions or early-stage cancer before either progresses to a more advanced stage (see **Figure 12**, p. 72).

Ways to Screen for Cancer

There are different kinds of cancer screening tests and exams that include visual examination to check for unusual features such as lumps or discolored skin; medical and family history analyses to review an individual's genetic, behavioral, and environmental risks; laboratory tests to determine the changes in cancer biomarkers in samples of tissues or fluids in the body; and imaging procedures to look for abnormalities inside the body (see sidebar on **Tests for Cancer Screening**, p. 73).

Cancer screening has the potential to save lives by detecting cancer early when it is easier to treat and when chances of

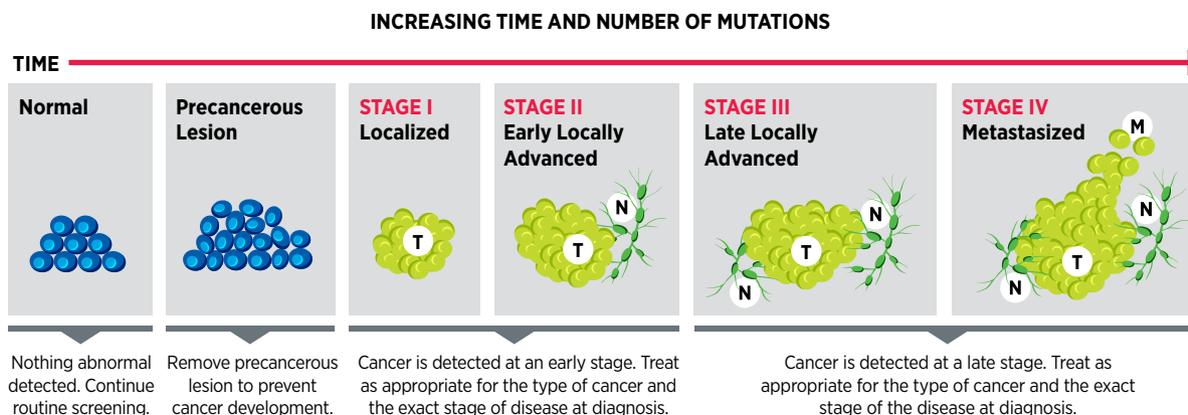
survival are the highest. For example, researchers evaluating the benefits of lung cancer screening recently reported a 25 percent decline in lung cancer deaths at a 10-year follow-up of more than 6,000 participants who underwent lung cancer screening from December 2003 to July 2006 (444). Another recent study found that the routine screening for breast cancer in eligible women reduced the risk of dying from breast cancer within 10 years after the initial diagnosis by 41 percent and decreased the risk of developing advanced breast cancer by 25 percent (445). However, it is important to note that some screening tests are invasive medical procedures that can potentially cause harm (see sidebar on **Benefits and Potential Harms of Cancer Screening**, p. 74). Because of the potential harms, the risks and benefits of cancer screening are carefully considered for everyone.

Cancer Screening Guidelines

Guidelines for cancer screening are meticulously developed by professional societies focused on public health. The key objective is to help individuals decide whether they should be screened for cancer, at what age they should start and stop screening, how frequently they should get screened, and by

FIGURE 12

Cancer Screening: What Can Be Found? What Can Be Done?



In general, cancers are progressive in nature. In the example depicted here, a normal cell contains an inherited genetic mutation or an acquired one. At this juncture in cancer progression, cancer screening tests are not able to detect the alterations even though the cell is predisposed to becoming cancerous. As the cell multiplies and acquires more genetic mutations, it gains precancerous characteristics (such as uncontrollable cell growth), and an increasingly abnormal precancerous lesion becomes detectable. Without treatment, additional mutations accumulate over time, and the precancerous lesion evolves into a cancerous lesion (tumor; T) that spreads to nearby lymph nodes (N) and ultimately metastasizes (M) to other organs in the body. Solid tumors are usually staged using the TNM staging system. Because blood cells circulate throughout the body, cancers originating from different types of blood cells are staged differently from those that originate from solid tissues.

When a person is screened for a given cancer, different outcomes can be predicted based on the finding. For example, the screening test may show that there is no

abnormality present; if this is the case, the person should continue routine screening. If the test detects a precancerous lesion, the lesion can be removed or treated, thus preventing its progression into cancer. If the test finds a cancer at an early stage of development, for example stage I or stage II for a solid tumor, the patient can be treated successfully with prevention medication or risk-reducing surgery and has a higher likelihood of survival. If the test identifies a genetic mutation that increases the risk of developing cancer, the individual may receive preventive medication and/or genetic counseling. If the test detects cancer at an intermediate stage, there is still a chance of cure, albeit lower than if the cancer was detected at stage I or II. Treatment is less likely to be curative if the test detects cancer at a later stage of development, i.e., stage III or stage IV. Treating or surgically removing 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 for all populations.

Adapted from (2).

which method. In the United States, an independent group of experts convened by the Agency for Healthcare Research and Quality of HHS carefully evaluates data regarding the benefits and potential harms of different approaches to disease prevention, including cancer screening tests, genetic testing, and preventive therapeutics, to make evidence-based recommendations about the use of these in the clinic. These volunteer experts form USPSTF (see **Figure 13**, p. 75).

USPSTF recommendations for cancer screening tests fall into four categories, including recommendations for screening

certain individuals at certain intervals (see sidebar on **Characteristics That Determine Eligibility for Cancer Screening**, p. 76), recommendations against screening, and deciding that there is insufficient evidence to make a recommendation. In addition to considering evidence regarding potential new screening programs, USPSTF reevaluates existing recommendations as new research becomes available and can revise the recommendations if necessary (see **Figure 13**, p. 75). Occasionally, other professional societies focused on cancer care also issue screening guidelines.

Tests for Cancer Screening

Highlighted below are some cancer screening tests used in the clinic for the five most common cancer types for which there are evidence-based screening guidelines from the United States Preventive Services Task Force. Unless indicated otherwise, many of the procedures listed here can detect cancer at any stage of development, but the aim of using them for screening purposes is to find the cancer at the earliest possible stage.

BREAST CANCER

Mammogram

Uses X-rays to generate 2-dimensional images of the breast that can be stored on film (a conventional mammogram) or electronically (a digital mammogram) for further analysis. Some machines can generate 3-dimensional images in a process called breast tomosynthesis.



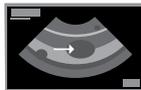
Breast Magnetic Resonance Imaging (MRI)

Uses radio waves and a powerful magnet linked to a computer to create a detailed image of the breast.



Whole Breast Ultrasound

Uses ultrasonography to scan the entire breast, looking for lumps or nodules.



CERVICAL CANCER

Pap Test

Samples cervical cells, which are analyzed under a microscope to look for abnormalities.



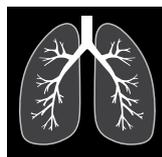
HPV Test

Detects the presence of certain cervical cancer-causing types of human papillomavirus (HPV) and identifies people for whom further testing is recommended. Does not directly detect precancerous or cancerous cervical lesions.

LUNG CANCER

Low-Dose Spiral CT Scan

Uses low doses of X-rays to rapidly image the lungs and detect any structural abnormalities suggestive of lung cancer. Suspicious lesions are then biopsied for diagnosis.



COLORECTAL CANCER

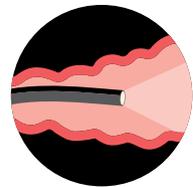
Stool Tests

Some of these test for the presence of red blood cells in stool samples. Others test for both red blood cells and certain genetic mutations linked to colorectal cancer. These tests do not directly detect colorectal precancerous lesions or cancers but identify people for whom further testing is recommended.



Flexible Sigmoidoscopy and Colonoscopy

Use a thin, flexible, lighted tube with a small video camera on the end to allow physicians to look at the lining of certain parts of the colon and rectum.



Computed Tomography (CT) Colonography (Virtual Colonoscopy), and Double-contrast Barium Enema

Use X-rays to image the colon and rectum.



Blood Test

Detects epigenetic abnormalities linked to colorectal cancer in blood. Does not directly detect colorectal precancerous lesions or cancers but identifies people for whom further testing is recommended.



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.



Adapted from (2).

Benefits and Potential Harms of Cancer Screening

The U.S. Preventive Services Task Force or professional societies focused on cancer care meticulously review the available scientific evidence to weigh potential risks of screening for a specific cancer type against benefits of screening for it before the cancer screening guidelines are issued. Review of the scientific evidence includes, but is not limited to, the type(s) of screening test(s) that should be used for screening for a specific cancer type, as well as which individuals should be screened and at what age (see **Figure 13**, p. 75). Benefits of routine cancer screening are substantial and typically outweigh potential harms from the procedure, as described below:

BENEFITS OF SCREENING



Reduced Cancer Incidence

If a screening test detects precancerous lesions, removing these lesions can reduce, or even eliminate, an individual's risk of developing the screened cancer.

Reduced Likelihood of Advanced Disease

If a screening test detects cancer at an early stage of development, it can reduce an individual's risk of being diagnosed with the screened cancer at an advanced stage.

Reduced Cancer Mortality

Diagnosis of cancer at an early stage can increase the likelihood that a patient can be successfully treated. Screening can also indicate that making behavioral changes—for example, eliminating exposure to cigarette smoke if a screening test finds early signs of lung cancer—will reduce the chances of developing cancer. Both of these possibilities increase quality of life and reduce an individual's risk of dying from the screened cancer.

POTENTIAL HARMS OF SCREENING



Adverse Events

Screening tests are medical procedures, and they carry minimal but measurable risks of side effects.

Anxiety

Screening individuals who are not at risk of disease can cause unnecessary anxiety during the waiting period for the test results.

False-positive Test Results

It is possible that some individuals who receive a positive screening test result do not have the screened cancer. A false-positive test result can result in additional unnecessary medical procedures, treatments, and anxiety.

False-negative Test Results

It is also possible that some individuals who receive a negative screening test result are not free from the screened cancer. A false-negative test result can lead to missed opportunities for early treatment and/or behavioral changes to minimize the risk of dying from cancer.

Overdiagnosis and Overtreatment

Not all precancerous lesions or cancers detected by screening will progress to cause symptoms and threaten life. Detection of indolent tumors is called overdiagnosis and can lead to overtreatment, which carries its own potential harms and costs.

Adapted from (2).

Disparities in Cancer Screening

Early detection of cancer through routine screening saves lives by catching the disease early; minimizing risk of cancer progressing to an advanced, harder-to-treat stage; and thus improving both the survival and quality of life. According to one recent estimate, increasing the use of screening for breast, cervical, and colorectal cancers to 100 percent from its levels in 2016 would prevent an additional 2,821, 6,834, and 35,530 deaths, respectively (446).

Unfortunately, not all segments of the U.S. population equitably benefit from routine cancer screening (see sidebar on **Guidelines for and Disparities in Screening for Five Cancer Types**, p. 78). Research shows that cancer screening rates are substantially lower among those from racial/ethnic minorities compared to White individuals (447). Furthermore, screening patterns vary for different types of cancer and/or screening tests among racial and ethnic minorities and other medically underserved populations (4). Barriers such as lack of access to health insurance, low health literacy, and miscommunication between patients and providers

FIGURE 13

How Are Cancer Screening Guidelines Developed?



Review Topic Nominations

Anyone can nominate a new topic for review at any time. U.S. Preventive Services Task Force (USPSTF) reviews, selects, and prioritizes nominated topics based on relevance to and impact on disease prevention, primary care, and public health.



Develop Draft Research Plan

USPSTF and Evidence-based Practice Center (EPC) develop a research plan and seek expert input on the prioritized topic. USPSTF posts the draft research plan to website for public comments.



Review Public Comments and Finalize Research Plan

USPSTF and EPC carefully review public comments and revise research plan as needed. USPSTF posts the final research plan to website.



Review Evidence and Develop Draft Recommendation

USPSTF assesses EPC-gathered evidence, weighing effectiveness and benefits/harms and develops a draft recommendation statement, which is posted to the website, along with EPC evidence review, for public comments.



Review Public Comments & Finalize Recommendation

Both the draft recommendation and evidence review are revised and finalized based on public comments and published in peer-reviewed journals and on the USPSTF website.

Panels of subject matter experts convened by professional organizations and government agencies, such as the U.S. Preventive Services Task Force (USPSTF) assembled by U.S. Department of Health and Human Services, meticulously review the available evidence and carefully weigh benefits of cancer screening against any potential harms before recommending at what age a person should be screened, for which cancer type, how frequently, and by which method. Summarized here as an example is the recommendation process followed by USPSTF.

During the development of cancer screening guidelines, USPSTF is supported by researchers from the Evidence-based Practice Center (EPC) program, a U.S. Agency for Healthcare Research and Quality initiative. Institutions in the United States and Canada are awarded 5-year contracts to serve as EPCs. Once USPSTF decides that a screening guideline merits consideration (cancers for which there are currently no screening guidelines) or revision (for existing guidelines) as new scientific evidence becomes available, the researchers from the EPC produce a draft evidence review. The draft evidence

review is based on evaluation of all the relevant scientific literature on the potential benefits and harms of screening, optimal method for screening, and the optimal age for screening initiation. USPSTF uses the draft evidence review to develop a draft recommendation statement. Both documents are made publicly available on USPSTF website for various stakeholders to provide their feedback. The EPC researchers and USPSTF review the feedback on the draft evidence review and the draft recommendation statement, respectively, and revise the documents if necessary. The final recommendation statement, outlining the new and/or revised guidelines, and the final evidence summary, outlining the reviewed evidence, are posted on the USPSTF website and are published in a peer-reviewed scientific journal.

There are minor differences in the processes that are used by different organizations to develop screening guidelines, but the overall rigor that is put in place to ensure maximal benefit and minimal harms to public health and safety is the same.

Adapted from (2).

Characteristics That Determine Eligibility for Cancer Screening

Many factors can contribute to an individual's risk of developing cancer, and each person has his or her unique cancer risks. Thus, the decision of whether someone should be screened for cancer, at what age, and for which cancer type(s) is different for each person. It is important that people consult with their health care providers to develop a personalized cancer screening plan that considers their risk of developing a cancer and their tolerance for the potential harms of a screening test. Broadly speaking, individuals fall into two categories for cancer screening:

INDIVIDUALS AT AVERAGE RISK OF DEVELOPING CANCER

Individuals are considered at an average risk of developing cancer if they do not have a family or personal history of cancer and are without any known risk factors that can cause cancer. Health care providers consider two key characteristics—age and gender—when recommending a cancer screening test to a person who is at an average risk.

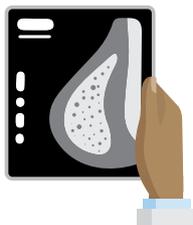
INDIVIDUALS AT HIGH RISK OF DEVELOPING CANCER

Individuals are considered at a higher risk for developing certain type(s) of cancer if they have an increased exposure to one or more cancer risk factors, unique tissue makeup, a family history of cancer, and/or belong to certain racial and ethnic minorities:



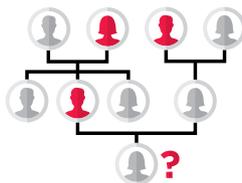
Individuals with increased exposure to one or more cancer risk factors:

For example, individuals who smoke tobacco are at a higher risk for developing cancer (see **Figure 8**, p. 52). According to CDC, people who smoke cigarettes are 15 to 30 times more likely to develop lung cancer or die from it than people who do not smoke.



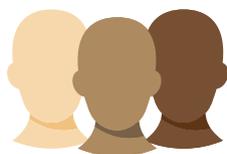
Individuals with a unique cellular or tissue makeup:

For example, women who have extremely dense breasts have an increased risk of developing breast cancer compared to women with less dense breasts. This is because dense breast tissue, like breast cancer, appears white on mammograms, thus reducing their effectiveness in distinguishing tumor from normal tissue. As another example, women found to have certain patterns of “overactive” breast tissue in an otherwise benign breast biopsy (e.g., atypical cells or lobular carcinoma in situ) are also at increased risk for developing breast cancer.



Individuals with inherited cancer susceptibility syndromes:

Also called hereditary cancer syndromes, inherited cancer susceptibility syndromes are caused by inherited genetic mutations that can predispose an individual to develop certain types of cancer. As one example, women who have certain mutations in the *BRCA1/2* genes and a family history of breast cancer are at a higher risk of developing breast cancer. If an individual thinks that he or she is at a high risk for inheriting a cancer-predisposing genetic mutation, he or she should consult a health care provider and consider genetic testing and genetic counseling.



Individuals from certain racial and ethnic minorities:

Individuals belonging to certain racial and ethnic minorities are at a higher risk of developing certain types of cancer and at an earlier age compared to the White population (see **Cancer Health Disparities Among Racial and Ethnic Minority Populations**, p. 12). For example, accruing evidence shows that a breast cancer diagnosis at a younger age is more common in Black women compared to White women. Furthermore, Black women are more likely to be diagnosed with biologically aggressive forms of the disease at all ages.

contribute to low screening rates among minority adults (447). As detailed in the *AACR Report on the Impact of COVID-19 on Cancer Research and Patient Care* released in February 2022, severe interruptions in routine cancer screening, especially during the initial months of the pandemic, may have exacerbated the existing disparities (7). Here, we focus our discussion on the disparities in screening for five cancer types for which USPSTF currently has population-based screening guidelines and discuss some of the interventions that have helped close the disparity gap in cancer screening.

BREAST CANCER

The overall screening rates for breast cancer are mostly similar between White women and women from racial and ethnic minorities (451). However, there are substantial variations in different aspects within the cancer screening process—such as provider–patient communication on the benefits and potential harms of screening; referral for a screening exam; follow-up if the results of a screening exam are positive, among others—that lead to persistent disparities. For example, even though the overall screening rates among Black women are similar to those for White women, researchers have found that Black women receive suboptimal methods of screening for breast cancer. One study evaluated imaging data from nearly 400,000 women who received breast cancer screening between 2015 and 2019 and found that, compared to 60.5 percent of White women, only 44 percent of Black women were screened by digital breast tomosynthesis, considered to be technologically superior in identifying invasive breast cancer (452). Studies have also found that, compared to NHW women, Black women are 31 percent more likely to have extremely dense breasts (453)—a known risk factor for breast cancer. Yet, Black women with dense breasts are less likely to receive supplemental breast imaging to confirm the results of the initial screening test compared to NHW women (15 percent versus 45 percent, respectively) (454). Since Black women face higher risks of breast cancer at younger ages compared to White women, and higher risk of biologically aggressive breast tumors at all ages (see **Black or African American Population**, p. 18), many disparities researchers advocate in favor of screening mammography beginning at age 40 years as a strategy to mitigate breast cancer disparities.

Similar variations in aspects of breast cancer screening are also prevalent among women from other ethnic and racial minorities. One study found that Hispanic women were 12 times less likely to be screened for breast cancer more than once in a 5-year period compared to White women (452). There are also significant differences in breast cancer screening rates within minority populations who represent a diverse group of individuals with unique cultural identities and behavioral habits. For instance, within the Asian American population, women who immigrated from Korea had the lowest screening rates (55 percent), while those from China had the highest rate (72 percent) (455).

Research has shown that the largest disparities in receiving the recommended screening for breast cancer are determined by socioeconomic status (SES), level of education, and access to

THE HONORABLE

Debbie Wasserman Schultz

U.S. Representative for Florida's 23rd District

“As a breast cancer survivor, I know firsthand that early detection saves lives, especially for rural and underserved populations, so my mission is to champion policies that ensure access to cancer screenings. Equally important to preventive care are education and awareness. We must provide individuals, their families, and providers with tools to help navigate the unique challenges of a cancer diagnosis. With nearly 17 million survivors in the U.S., and 20 million expected by 2026, we know that robust investments at the NIH and NCI in cancer research, high-quality screenings, and treatments will bring hope to millions of families who face this heartbreaking disease. I am proud that President Biden reignited the Cancer Moonshot initiative, and I work hard to combine my experiences as both a survivor and a Member of Congress to make real change that helps more Americans survive cancer and more survivors thrive.”



health care, all of which also intersect with racial and ethnic identities to exacerbate breast cancer screening disparities (see **Factors That Drive Cancer Health Disparities**, p. 29). For example, the rate of breast cancer screening was 10 percentage points less among women with a high school diploma compared to those with a college degree (451). Access to health insurance was the biggest determinant of disparity in meeting the USPSTF guidelines for breast cancer screening. In 2018, there was a difference of 26 percentage points in breast cancer screening between women who had some form of health insurance (80.5 percent) versus those without any health insurance (54.5 percent) (451).

Successful breast cancer screening relies on timely follow up if the exam shows any abnormalities, as it did for **Sandra Morales** (see p. 82). Delaying or failing to follow up on a screening exam undermines the potential benefits of screening and is associated with poorer outcomes. Researchers are finding that women from racial and ethnic minorities and other medically underserved populations often do not receive follow up care (456). The reasons for failure to follow-up include lack of access to health insurance, fear of cost, lack of health literacy, and/or miscommunications between patient and provider.

Disparities in routine breast cancer screening are also apparent for transgender individuals, who are at an increased risk

Guidelines for and Disparities in Screening for Five Cancer Types

The U.S. Preventive Services Task Force (USPSTF) is an independent volunteer panel of experts in prevention and evidence-based medicine. The panel carefully reviews the available data and weighs the risks and benefits for the broader population before issuing cancer screening guidelines (see **Figure 13**, p. 75). Currently, there are USPSTF guidelines for five types of cancer, four of which apply to individuals who are at an

average risk of developing breast, colorectal, prostate, or cervical cancer. Guidelines for lung cancer apply to former or current smokers, individuals who are at a high risk of developing the disease because of tobacco use. Screening rates for all five cancers declined significantly during the peaks of COVID-19, although more recent data suggest that screening rates for some cancer types are returning to prepandemic levels.

BREAST CANCER



USPSTF Recommendation: Mammogram every other year for women ages 50-74. Women ages 40-49 should discuss with their health care provider to make an informed and shared decision whether they should receive breast cancer screening.*

Example of Disparity: In 2018, only 63.0 percent of women with less than a high school education were up to date with breast cancer screening compared to 80.4 percent of those with a college degree (448).

CERVICAL CANCER



USPSTF Recommendation: Cervical cytology every three years for women ages 21-65; high-risk human papillomavirus testing alone, or in combination with cytology, every five years for women ages 30-65.

Example of Disparity: In 2018, only 64.7 percent of gay or lesbian women were up to date with cervical cancer screening compared to 83.4 percent of straight women (448).

COLORECTAL CANCER



USPSTF Recommendation: Stool-based tests every 1-3 years, and/or colonoscopy/flexible sigmoidoscopy every 5-10 years, for all adults ages 45-75.

Example of Disparity: Women living in rural areas between 2017 and 2020 were 19 percent less likely to be up to date with colorectal cancer screening than those living in urban areas (449).**

LUNG CANCER



USPSTF Recommendation: Low-dose computed tomography (LDCT) every year for all adults ages 50-80 who are current smokers or who quit within the past 15 years, with a 20 pack-year smoking history.

Example of Disparity: Compared to eligible non-Hispanic White individuals, eligible non-Hispanic Black individuals were 53 percent less likely to report that they have completed LDCT in the past one year (450).**

PROSTATE CANCER



USPSTF Recommendation: Periodic prostate-specific antigen-based test, as recommended by the health care provider, for men ages 55-69.

Example of Disparity: In 2018, only 8.9 percent of uninsured men age 65 and above were up to date with prostate cancer screening compared to 34.4 of those who had any private insurance (13).

* Only USPSTF guidelines are included in this sidebar. Many other professional societies issue evidence-based screening guidelines for certain types of cancer that may differ from those issued by USPSTF. For example, certain organizations recommend that women should undergo screening mammography beginning at age 40 years.

**Note: Findings of these studies predate the revised 2021 USPSTF guidelines. Future studies will delineate the impact of the revised guidelines on cancer screening disparities.

of developing breast cancer. A recent study showed that, compared to individuals whose gender identity aligns with the one associated with the sex assigned to them at birth (cisgender), only 32 percent of individuals transitioning from female to male and just two percent of those transitioning from male to female had undergone breast cancer screening (457). In addition to better quality data to develop cancer screening guidelines that are specific to the needs of SGM populations, culturally sensitive interventions are urgently needed to close gaps in provider and patient knowledge about cancer screening and improve health care experiences of gender minorities in the United States (458,459).

CERVICAL CANCER

According to the most recent estimates available, the overall cervical cancer screening rate was more than 80 percent in the U.S. in 2018 (460). However, there are disparities in screening rates based on sociodemographics. Compared to the White population, incidence of cervical cancer is higher among all racial and ethnic minorities (see **Table 1**, p. 23). The disparate rates of cervical cancer incidence are particularly alarming because medically underserved and underscreened populations account for more than 60 percent of cervical cancer diagnoses (461).

In recent years, the percentage of women in the U.S. who are overdue for cervical cancer screening has been growing (462). It is important to note that this increase predates the COVID-19 pandemic and is independent of the severe interruptions in overall cancer screening during the first half of 2020 (7), which may further worsen these trends. Researchers found that the number of women overdue for cervical cancer screening increased overall between 2005 and 2019. For example, the proportion of women ages 21 to 29 years without up-to-date screening doubled from 14.2 percent in 2005 to 29.1 percent by 2019 (462). A significant proportion of Hispanic women (64.4 percent), who have the highest incidence of cervical cancer among racial and ethnic minorities (see **Table 1**, p. 23), were overdue for cervical cancer screening; it is alarming that the reason for this disparity was because they did not know they needed to be screened for cervical cancer. Conversely, access to health care was a major source of disparity among NHW women; 10.4 percent indicated lack of access as the reason for not receiving cervical cancer screening compared to only 3.2 percent of Asian women—the population group with the highest proportion of overdue cervical cancer screening (462).

In 2019, **31.4 percent of eligible Asian women were overdue for cervical cancer screening** compared to 20.1 percent of eligible non-Hispanic White women (462).



In the 12-month period **during the COVID-19 pandemic** (April 2020 to March 2021), the **decline in cervical cancer screening** using Pap test was **2.6 fold higher in women residing in rural areas** of Washington state compared to those residing in urban areas of the state (464).



Disparities in cervical cancer screening are also persistent in other medically underserved populations. According to a recent study, women who identified as lesbian were 22 percent less likely to be up to date with their cervical cancer screening in 2018 (448). Findings from another recent study highlight the disparities in routine cancer screening for transgender individuals despite their increased risk for cervical cancer. Compared to cisgender individuals, individuals transitioning from female to male were 58 percent less likely to adhere to cervical cancer screening (457).

Place of residence also plays an important role in staying up to date with cervical cancer screening. In 2018, women living in rural areas were 34 percent less likely to be up to date with cervical cancer screening compared to those living in urban areas. Researchers identified the lack of access to health care as a significant contributor to this disparity (463). Another study found that women without any health insurance in 2018 were 17 percent less likely to have received cervical cancer screening compared to those who had some form of health insurance (451).

COLORECTAL CANCER

In recent years, the rate of colorectal cancer (CRC) diagnoses in individuals who are younger than 50 years of age—a diagnosis that is considered an early-onset colorectal cancer (EOCRC)—has increased by 2.2 percent every year (465), prompting USPSTF in 2021 to lower the recommended age for initiating CRC screening from 50 to 45 years (466). According to a recent report, the alarming increase in EOCRC is disproportionately high in Black and Hispanic individuals compared to White individuals (12.7 percent versus 16.5 percent versus 8.7 percent) (467). The reasons for EOCRC are not clear.

There has been some progress toward reducing disparities in colorectal screening in recent years. Researchers have observed that the proportion of individuals who were not up to date with CRC screening decreased for most racial and ethnic minorities between 2012 and 2020; compared to White individuals, the decrease was the largest for NHOPI (from 46 percent in 2012 to 28 percent in 2020), followed by Hispanic people (from 47 percent in 2012 to 37 percent in 2020) (4). Despite the narrowing disparity in staying up to date with the CRC screening, Hispanic, Asian, and AI/AN people were still more likely than White people not to be up to date with CRC screening tests in 2020 (4).

Disparities in CRC screening are complex and multidimensional. For example, a similar proportion of Black and White individuals were up to date with CRC screening in 2018 (65.3 percent versus 67.9 percent, respectively) (448). However, evidence is accruing that population-specific guidelines may be necessary to ensure that individuals at a disproportionately higher risk of developing certain types of cancer receive screening starting at the age and using tests that will increase the chances of diagnosing cancer early when it is easier to treat. As one example, one study found that Black individuals, especially Black females, were more likely to be diagnosed with advanced stage EOCRC, and that the cancer was likely to be present in areas of the colon that are harder to image by sigmoidoscopy (467), indicating that specific CRC screening guidelines may be needed for younger Black women.

For Hispanic individuals, there are significant disparities in being up to date with the recommended CRC screening, and these disparities vary by population subgroup. In 2018, for instance, Puerto Rican individuals were more likely to be up to date with the recommended CRC screening compared to non-Hispanic individuals (76.6 percent versus 68.2 percent, respectively). In comparison, Mexican American individuals were significantly less likely to be up to date with CRC screening (52.3 percent) (448). Other studies have shown CRC screening disparities among Hispanic populations also vary by state and are primarily determined by the lack of adequate health insurance and lack of access to care (468).

THE HONORABLE

Donald M. Payne, Jr.

U.S. Representative for New Jersey's 10th District

“One of the most significant problems with the health care disparities that exist in America is that American minorities are dying from diseases that could be treated and possibly cured with early detection. We know that many cancers disproportionately affect ethnic and racial minorities and that the rates of cancer screenings in these communities are too low to detect and diagnose a variety of cancers until the later stages. I am working to encourage more people in underserved communities to get screened for cancer, particularly colorectal cancer. It is our responsibility to create the awareness necessary to support investments in cancer research to ensure the availability of high-quality cancer screening tests in underserved and rural communities across the nation.”



Researchers have found that rural residence adversely affects adherence to the recommended CRC screening. Findings from a recent study of nearly 3,000 women across 11 U.S. states revealed that those living in rural areas were 19 percent less likely to be up to date with CRC screening compared to women living in urban areas (449). In 2018, the recommended CRC screening was also significantly lagging among individuals with less than a high school education (54.2 percent compared to 73.5 percent among college graduates); among uninsured individuals (30.2 percent compared to 69 percent among those with private insurance); and among immigrants who had been in the U.S. fewer than ten years (32.8 percent compared to 69.2 percent among those born in U.S.) (448). The prevalence of CRC screening also varies substantially among U.S. states and territories.

There are many barriers to the CRC screening adherence among ethnic and racial minorities and other medically underserved populations. Low SES, lack of access to health care, lack of knowledge about CRC screening, and mistrust in the health care system all contribute to low adherence to CRC screening (469). Researchers have found that sociocultural attitudes such as perceptions of masculinity among Black men are additional barriers to meeting CRC screening recommendations (470).

LUNG CANCER

Less than five percent of all eligible individuals were up to date with low-dose computed tomography (LDCT) in 2016-2017 (471), even though adhering to screening guidelines reduces lung cancer-related deaths by more than 20 percent, according to the findings of two landmark studies (444,472). In addition to the overall low adherence rates for LDCT, significant disparities exist between White individuals and those belonging to racial and ethnic minorities.

One key example of the disparity is the LDCT eligibility for Black individuals. Research shows that Black people are at a higher risk of lung cancer at a younger age even if they smoke less over time (473), and yet they were 36 percent less likely to be eligible for LDCT under the previous USPSTF guidelines (474). USPSTF lowered the age to begin screening for lung cancer from 55 to 50 years of age in 2021, in part to mitigate disparities in eligibility criteria for LDCT, and greatly expanded the proportion of individuals eligible for LDCT. However, initial findings suggest that additional changes to the guidelines may be necessary to further decrease the gap in LDCT eligibility of Black individuals. One study examined the LDCT eligibility of the participants of the Black Women's Health Study, which includes nearly 60,000 Black women from across the U.S. Researchers found that the LDCT eligibility of at-risk Black women in the study increased from 22.7 percent under the previous guidelines to 33.9 percent under the revised guidelines, amounting to a 50 percent increase. However, the study also found that removing the restriction from the revised guidelines that former smokers must have stopped smoking within the past 15 years to be eligible for LDCT could have further increased the proportion of eligible Black women from 33.9 percent to 48.2 percent (475). Additional

studies will further help inform evidence-based adaptations to the guidelines ensuring that everyone benefits equally from lifesaving cancer screening recommendations. Racial and ethnic minorities and other medically underserved populations also experience disparities in the follow up visits if the screening results are positive for abnormalities. An analysis of nine studies comprising thousands of individuals who underwent LDCT found that only 67 percent of Black individuals followed up after the initial screening regardless of the stage at which lung cancer was diagnosed (476). Lack of access to quality health care is also a major contributor to the low LDCT adherence rates (477). One study found that individuals on a fee-for-service Medicare plan—a type of Medicare plan offered by a private insurance company where the plan determines how much the insurer must pay for care—were more than 50 percent less likely to undergo LDCT compared to those with private health insurance (478). Similarly, place of residence can dictate access to state-of-the-art health care facilities. For example, individuals residing in urban areas were more than twice as likely to undergo LDCT compared to those living in rural areas (478).

Researchers have found that many additional reasons contribute to disparities in LDCT. For patients, reasons include unawareness of screening programs; fear of cancer diagnosis and perceived stigma; and cost concerns. For health care providers, reasons include unfamiliarity with eligibility criteria and insurance coverage; difficulty identifying eligible patients; insufficient time or knowledge to conduct shared decision-making; need for guidance with management of lung cancer screening results; and skepticism about the benefits of screening (479).

PROSTATE CANCER

Current USPSTF screening guidelines for prostate cancer recommend that men at an average risk of developing prostate cancer should start discussing potential benefits and harms of prostate cancer screening with their health care providers at the age of 55 (75). Black men share a disproportionate burden of prostate cancer compared to any other racial or ethnic group in the U.S. (see **Cancer Health Disparities Among Racial and Ethnic Minority Populations**, p. 12). There is also a consensus that Black men were poorly represented in the screening studies that informed most current guidelines for prostate cancer (480). Notably, recent findings indicate that screening Black men for prostate cancer at a younger age can decrease the likelihood of diagnosis with metastatic disease

by 39 percent, and reduce the probability of dying from prostate cancer by 25 percent (481). Some cancer-focused organizations now recommend that Black individuals start a dialogue with their physicians at the age of 45 to make an informed and shared decision about screening for prostate cancer (482). Similar disparities in PSA-based prostate cancer screening exist among men who belong to other racial or ethnic populations (483).

One persistent disparity in prostate cancer screening is the adherence to follow-up if elevated blood levels of PSA are detected, an indication that the individual may have prostate cancer and should undergo additional imaging-based tests for confirmation (see sidebar on **Tests for Cancer Screening**, p. 73). A recent study found that, compared to White patients, Black patients with elevated PSA blood levels were 24-35 percent less likely to undergo subsequent prostate imaging. Researchers also noted that the likelihood of Black patients to undergo follow-up exams was less among those with higher levels of PSA and those between ages 65 and 74 years (483). Cost of medical care is another significant contributor to disparities. One study found that 11 percent of those who decided not to get screened for prostate cancer with a PSA test did so because of the concern for the cost of the test (485).

Researchers have also identified the need for effective communication between patients and physicians to alleviate disparities in prostate cancer screening. For example, only 38.6 percent of those who responded to a survey about the PSA test indicated that their doctor had discussed the advantages of a PSA test. The study also found that Asian men, or those without any form of health insurance, were less likely to be told about the benefits and potential harms of a PSA test (486).

Eliminating Disparities in Cancer Screening

Disparities in early detection of cancer lead to increased cancer diagnoses at an advanced stage when cancer is harder to treat and thus substantially contributes to the disproportionate burden of cancer-related deaths in racial and ethnic minorities and other medically underserved populations (see **The State of Cancer Health Disparities in 2022**, p. 11). During the early months of the COVID-19 surge in 2020, elective clinical care (including cancer screening) was shut down in order to divert medical resources to COVID care and to comply with shelter-in-place mandates. After lifting of the hiatus, ongoing social distancing policies placed limits on availability of cancer screening appointments. The pandemic-related recession has been disproportionately severe among Black and Hispanic population groups, resulting in these groups experiencing even greater barriers to cancer screening. Lastly, the costs of COVID care disproportionately devastated many safety-net hospitals, leaving these facilities even more financially constrained when attempting to resume cancer screening programs for socioeconomically disadvantaged

Continued on page 84

Following the 2012 **USPSTF recommendation against routine prostate-specific antigen screening**, incidence of **metastatic prostate cancer more than doubled** during 2012-2017 among non-Hispanic Black men ages 50-69 compared to non-Hispanic White men (484).





“

**Don't be a witness
in your experience
with cancer; play
an active role.”**

Helping Latina Women with Cancer by Overcoming the Language Barrier

In 2008, Sandra Morales felt a very uncomfortable sensation in her left breast. But as a 38-year-old woman with no known breast cancer risk factors, she was told that there were no mammograms recommended for women under 40. Two years later, Sandra felt something again in her left breast, and this time, she was able to schedule an appointment for a mammogram.

“I literally did have my first mammogram the day of my birthday,” Sandra remembered. The test found a suspicious mass in her left breast, which led to a biopsy and ultimately to the diagnosis of stage III breast cancer in May 2010. Sandra’s doctor told her that she had an aggressive form of cancer and recommended that she have a mastectomy as soon as possible. The news took Sandra through an emotional roller coaster.

“It was the worst experience of my life. When you hear the word ‘cancer,’ you associate it with death, right away,” she said. “I just wanted to cry. I thought I wasn’t smart enough to listen to my body. I thought maybe I did not have the right doctor or the right attitude. But I remembered my daughter and thought, if I break down, she’s going to break, too. And a mother’s instinct came over me. I felt OK and I asked my doctor, ‘So, what is the next step?’”

Sandra went to see an oncologist for a second opinion. After additional screening and genetic tests that confirmed her cancer, she started her chemotherapy. Even though her oncologist spoke some Spanish, it was Sandra’s husband who helped translate complex medical terminology for her. Sandra’s experience and interaction with the health care and insurance systems got her thinking about other women who do not have someone helping them understand their disease, the treatment options and side effects, and how to navigate the financial aspects of cancer care.

“It’s very complicated to understand how insurance works, or if you have the right insurance, or why you have so many copayments, or the financial stress you feel over having to choose between going to your treatment or going to work,” Sandra said. “I know a lot of Latina women who have been diagnosed but they are the breadwinners of their families. If they go for their treatment, they don’t work enough hours to have their insurance. And if they don’t keep on paying the rent, how can they continue living? It’s very hard.”

Cancer treatments and the financial burden of her disease were not the only stresses Sandra faced. She was also grappling with cultural barriers and perceptions about a cancer diagnosis that

are all too common in her community. She only told her sister and an aunt to whom she was particularly close.

“She said to me, ‘I don’t understand why this is happening to you. You are such a good person. What did you do that was so wrong that you got cancer?’” Sandra recalled of her aunt’s reaction. “And I know that she didn’t mean anything bad; I know she loves me, but it was a real concern she had.”

It took her some time to realize that illness is a part of life. Through her experience, Sandra has become an impassioned voice for those diagnosed with cancer, especially those who face language, financial, cultural, and other structural barriers in accessing the health care they need.

She has become a certified clinical interpreter, explaining to patients—step by step—the type of cancer they have, their treatment options, and their health insurance. In the six years that she has been helping patients, she has now developed contacts within the clinical system, as well as within the community, to get patients the care they need, whether it’s changing an appointment so their treatment plan can start sooner or connecting patients with support groups who can provide transportation services or other assistance.

“I say this position is important for everybody, something that should be available in the hospital. Patients are very thrilled when they see that there is a patient navigator who is going to be involved in their care,” Sandra said. “I also visit policy makers and legislators and advocate for more funding for cancer research and cancer treatments, especially for the vulnerable individuals.”

Sandra is currently doing well. She sees her oncologist twice a year and is receiving hormone blocking therapy to prevent a recurrence. And she gets great satisfaction from her work and advocacy.

“I am very lucky to have the life I have now. And I never imagined that I would be helping other women going through the same illness I had,” she said. “I feel very fortunate. I am very happy that with my experience and my knowledge, now I can help other women overcome all the barriers they have to getting treatment.”

Her advice for people is to be proactive regarding their health; to go for annual checkups so if something is going on, it’s caught sooner; to get all the information they can; and “Don’t be a witness in your experience with cancer; play an active role.”

individuals. For all of these reasons, disparities experts fear that the pandemic may not only cause an increase in advanced-stage cancer diagnoses in all population groups, but it may also exacerbate the existing disparities in cancer screening.

Eliminating inequities in cancer screening requires more than increasing adherence among eligible individuals. All sectors must work in concert to develop and implement multipronged approaches that include dismantling structural racism, discrimination, and other societal inequities that pose significant barriers in access to cancer screening; raising the awareness of cancer screening among eligible individuals, especially those belonging to racial and ethnic minorities and other medically underserved populations; communicating its benefits and potential harms; developing culturally tailored interventions that address the lack of health literacy and cancer screening knowledge among certain populations; making cancer screening accessible to all—both in availability and cost; and conveying the importance of follow-up visits if the initial screening exam indicates the possibility of cancer. Stakeholders across the cancer care continuum—cancer researchers, physicians, federal regulatory and funding agencies; cancer-focused professional organizations; patient advocates and navigators—are working together to achieve this goal, and many established as well as innovative interventions are being tested across the nation.

In February 2022, the President’s Cancer Panel released the *Closing Gaps in Cancer Screening: Connecting People, Communities, and Systems to Improve Equity and Access Report*. The report was presented to President Biden and outlined barriers and provided recommendations to improve

cancer screening and follow-up care in the United States (488a). In this section, we are highlighting some of the approaches that have proven to be effective not only in increasing the cancer screening awareness, adherence and followup in racial and ethnic minorities, but also reducing or, in some cases, eliminating disparities in cancer mortality.

BY IMPLEMENTING COMPREHENSIVE PUBLIC HEALTH CAMPAIGNS

In 2003, the New York City (NYC) Department of Health and Mental Hygiene launched a comprehensive campaign to increase colonoscopy uptake among NHB and Latino individuals as the primary test to screen for colorectal cancer. As a result of the campaign, disparities in colonoscopy were eliminated for these population groups in NYC by 2014.

The proportion of NHB individuals who had received colonoscopy within the last 10 years prior to the launch of the campaign in 2003 was 35 percent compared to White individuals, for whom the proportion was 48 percent. As one example of the effectiveness of the campaign, by 2016, proportions of eligible NHB and White individuals receiving timely colonoscopy were 72 percent and 67 percent, respectively (488). Importantly, the overall CRC incidence and mortality rates were significantly decreased for White, NHB, and Latino populations in New York City between 2003 and 2016 (488).

BY INCREASING ACCESS TO HEALTH INSURANCE

The United States is the only industrialized economy without a universal health care model, making access to quality health

CITYWIDE COLON CANCER CONTROL COALITION: A STEP TOWARD ELIMINATING COLORECTAL CANCER DISPARITIES IN NEW YORK CITY

In 2003, the Citywide Colon Cancer Control Coalition and New York City (NYC) Department of Health and Mental Hygiene launched a comprehensive campaign to promote colonoscopy to screen for colorectal cancer. The campaign included:

Public education—Using celebrity spokespersons, as well as culturally and linguistically tailored educational segments on selected ethnic radio stations and poster campaigns in public transport.

Professional education—Using the *City Health Information* newsletter for outreach to health care providers.

A detailing initiative—Using trained Department of Health and Mental Hygiene representatives to deliver evidence-based messages and materials to primary care offices, and distribute action kits for providers and patients.

Adapted from (487).

A patient navigator program—Using trained health care staff to help minority populations resolve abnormal screening test findings in a timely and culturally appropriate manner.

A direct referral initiative—Using a streamlined colonoscopy referral process that eliminated the need for eligible patients to have a consultation before colonoscopy; and an NYC colonoscopy quality initiative to ensure that the colonoscopies being conducted were of high quality.



care one of the most significant barriers in adherence to recommended cancer screening. In 2018, uninsured women were 26 percent less likely to undergo breast cancer screening compared to those with some form of health insurance, and 15 percent of women avoided medical care because of cost (451). Another study found that NHB, AI/AN, or Hispanic women were more likely to be diagnosed with locally advanced breast cancer compared to White women and that nearly half of the differences were associated with lack of health insurance among women from minority populations (142).

Research has shown that equitable access to health care eliminates disparities. According to recent findings, between 2012—the last data year before expansion of the Affordable Care Act coverage was implemented—and 2020, the share of Hispanic women who were eligible but did not receive a recent mammogram fell by 11 percentage points from 32 percent to 21 percent, reversing a disparity between them and White women, 24 percent and 22 percent of whom were without a recent mammogram in 2012 and 2020, respectively (4).

BY DEVELOPING CULTURALLY TAILORED INTERVENTIONS THROUGH COMMUNITY ENGAGEMENT

Lack of information about screening recommendations, cultural beliefs, and patient attitudes and behaviors regarding health care visits and cancer screening measures can be significant contributors to lack of or hesitation in getting screened for cancer. Multiple studies have found that culturally and linguistically tailored interventions to enhance uptake of cancer screening among racial and ethnic groups have a high degree of success. In one study, researchers developed a multicomponent intervention to increase cervical cancer screening among Hispanic women along the U.S.-Mexico border. The approach—De Casa en Casa—combined previously successful screening strategies (comprised of reminders, incentives, one-on-one education, and out-of-pocket cost reduction) with a bilingual, culturally tailored educational component (which included community member engagement, culturally tailored material, and culturally tailored method of delivery) and a navigation component (which facilitated screening and diagnostic testing through dedicated patient navigators who helped with making appointments for screening tests, placed reminder calls, and provided transportation if needed). According to the study's findings, individuals who received intervention were 14 times more likely to be screened compared with those who did not receive the intervention (489). Researchers have also found other innovative approaches, such as using narrative short films to convey the importance of cervical cancer screening to Spanish-speaking women, to be effective in increasing the uptake of cervical cancer screening in the study populations (128,129).

Research shows that interventions which actively engage community members are often more effective. For example, the Pitt County Breast Wellness Initiative-Education provided

culturally tailored breast cancer education and navigation for uninsured and underinsured Black and Latina women in two rural counties in North Carolina (490). This program trained community members and undergraduate students majoring in public health to educate participating women about breast health and the importance of screening using informational material developed for lay audiences. Sixty-eight percent of women who were eligible but never received a mammogram before received one through the program (490).

BY REDUCING STRUCTURAL BARRIERS

Collecting biospecimens (for example, blood) and/or images for most screening tests require specialized instruments and/or trained health care staff and a visit to a health care facility (see sidebar on **Tests for Cancer Screening**, p. 73) and thus present potential structural barriers to adhering to cancer screenings. Researchers are testing strategies to minimize structural barriers to cancer screening. As one example, Kaiser Permanente Northern California—an integrated managed care consortium of eight states and the District of Columbia—initiated an organized, population-based colorectal cancer screening program from 2006 through 2008. The program, which is still in effect, proactively mailed fecal immunochemical (a stool-based CRC screening) tests (FIT) to use at home annually and allowed eligible individuals to request a colonoscopy. Recent findings from the program show that the proportion of individuals who were up to date with screening increased from 42 percent in 2000 to 79-80 percent during the period from 2015 through 2019 among Black persons and from 40 percent in 2000 to 82-83 percent during the period from 2015 through 2019 among White persons. Importantly, the disparity in colorectal cancer-specific mortality between the two groups was nearly eliminated from a difference of 21.6 cases per 100,000 people during 2007-2009 to 1.6 cases per 100,000 people during 2017-2019 (491).

Another study found that combining text messaging with mailing free, at-home test kits can help boost the number of people who get screened for colorectal cancer. A nearly 10-fold increase in screening completion was observed among those who received a series of reminder texts and a free FIT to use at home compared to those who only received a single text message reminding them that they were overdue for colorectal cancer screening (492).

Expanding clinic hours and/or offering weekend appointments for cancer screening is another potential strategy for facilitating screening among socioeconomically disadvantaged populations. Individuals belonging to these population groups may seek health maintenance appointments that allow them to avoid taking unpaid time off from work or at times when they have additional childcare options. Patient navigators, such as **Sandra Morales** (see p. 82), are also drawing on their personal experiences with health care system and playing a pivotal role in helping cancer patients from racial and ethnic minorities with overcoming structural barriers that can otherwise pose serious obstacles to navigating and accessing quality health care.

BY IMPROVING COMMUNICATION BETWEEN PATIENTS AND PHYSICIANS

Effective communication about health-related information and advice between patients and their providers is pivotal for making informed and shared decisions as well as for receiving quality health care (493). Research has shown that the patient-provider communication regarding cancer screening is influenced by several factors, such as whether the provider is current with knowledge of screening guidelines; whether the patient trusts the provider and the health care system in general; and whether the patient and provider speak the same language. A recent study found that Asian Americans with limited English proficiency

were more than 50 percent less likely to be up to date with breast, cervical, or colorectal cancer screening compared to those proficient in English (494).

Harnessing data from electronic health records is one way to promote quality, safety, and efficiency; reduce health disparities; engage patients and families; improve care coordination; and maintain patient health information privacy and security. However, it is equally important to ensure that medically underserved populations have equitable access to the digital services and tools, and computers with high-speed Internet connections, to effectively benefit from new and emerging technologies.

Disparities in Clinical Research and Cancer Treatment

IN THIS SECTION, YOU WILL LEARN:

- ▶ Clinical trials establish whether new cancer treatments are safe and effective for everyone who will use them if they are approved; the substantial lack of sociodemographic diversity among clinical trial participants represents a major barrier to advancing cancer care for the entire patient population.
- ▶ Achieving cancer health equity necessitates equitable access to participation in clinical research opportunities. Physicians must play an active role in this effort, by ensuring that all patients are offered appropriate clinical trial options, regardless of race/ethnicity or socioeconomic status.
- ▶ Improved diversity among clinical trial participants requires attention to study design regarding accrual sites and outreach; involvement of a diverse trial workforce and patient navigators; use of culturally tailored patient education materials; and minimizing the costs associated with trial participation, such as those related to frequency of clinic visits.
- ▶ Despite many advances in the main pillars of cancer treatment, patients from racial and ethnic minorities and other underserved populations are less likely to receive the standard of care recommended for the type and stage of cancer with which they have been diagnosed.
- ▶ Several 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 standard treatment.
- ▶ Clinical interventions that utilize patient navigation and community engagement can reduce disparities in cancer treatment among underserved groups and potentially improve outcomes for all patients with cancer.

Medical research is an iterative process that is set in motion when a discovery with the potential to affect the practice of medicine or public health is made in any area of research or clinical practice (see **Figure 14**, p. 88). One way that researchers build on a discovery is by asking questions that can be tested through experiments in a wide range of models that mimic healthy and diseased conditions. Results from these experiments can lead to the identification of potential therapeutic targets, or biomarkers—cellular and molecular characteristics measurable in tissue and/or bodily fluid by which normal and/or abnormal processes can be recognized and/or monitored. They also can feed back into the medical research cycle by providing new discoveries that lead to more questions or hypotheses.

Once 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 trials. During this time, several drug candidates are rigorously tested to identify any potential toxicity and to determine the appropriate doses and dosing schedules for testing in the first clinical trial. There are many types of clinical trials, each designed to answer different

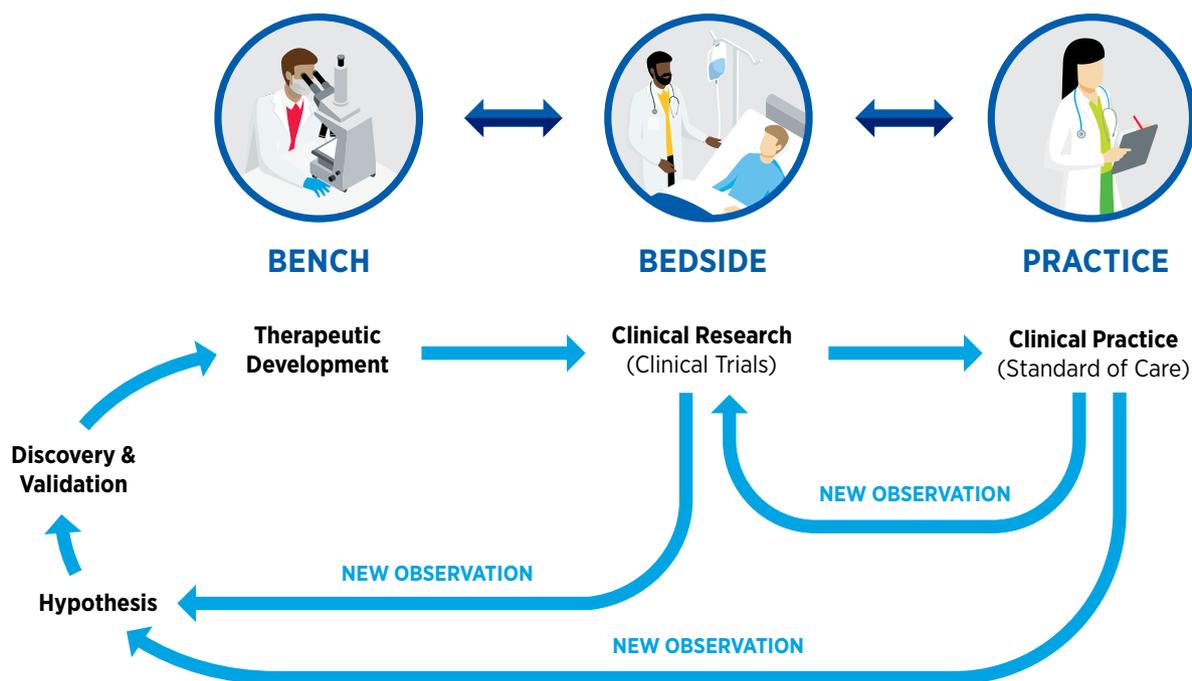
THE HONORABLE **Alex Padilla** U.S. Senator for California

“To address inequity in cancer care, we need an all-hands-on-deck approach. Congress must fund better cancer screening for underserved communities, invest in clinical trials that reflect patient diversity, and support the next generation of scientists who will continue to close the gap on health disparities. I’m proud to lead the Equal Health Care for All Act, which would make medical equity a civil right, and to advocate for critical community providers like Urban Indian Organizations.”



FIGURE 14

The Medical Research Cycle



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

Adapted from (2).

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 U.S. 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.

research questions (see sidebar on **Types of Clinical Studies**, p. 89). All clinical trials are reviewed and approved by institutional review boards before they can begin and are monitored throughout their duration. Clinical trials testing the safety and efficacy of candidate anticancer therapeutics have traditionally been done in three successive phases (see **Figure 15**, p. 90).

Disparities in Cancer Clinical Trial Participation

While researchers are continually identifying and implementing new ways of designing, conducting, and reviewing clinical trials that are yielding advances in patient care, there are still numerous opportunities for improvements. The most pressing challenges

that need to be urgently addressed are low participation in clinical trials, in particular, among individuals living in rural areas, adolescents and young adults, and the elderly, as well as the lack of representation from racial and ethnic minorities (see sidebar on **Disparities in Clinical Trial Participation**, p. 92). Participation of racial and ethnic minorities and other underserved populations in clinical trials is critical to accurately determine the efficacy as well as potential toxicities of new treatments in these populations. Diversity among participants is even more vital during evaluation of cancer types with a disparately higher burden in racial or ethnic minorities, 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, and lifestyle, among other factors. Enrollment of diverse

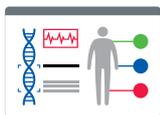
Types of Clinical Studies

There are multiple types of clinical studies (also called clinical trials). Although each clinical trial is designed to address specific research questions, many clinical studies can also provide answers to additional questions. For example, treatment trials, which primarily determine clinical outcomes such as efficacy of a drug for treating the cancer type for which the drug has been developed, can also evaluate measures to assess the impact of the treatment being tested on quality of life. In cancer research, the types of clinical trials include:



Prevention Trials

Designed to find out whether healthy people can reduce their risk of cancer by preemptively taking certain actions, such as by smoking cessation; by taking certain therapeutics, vitamins, minerals, or dietary supplements; or by having certain risk-reducing surgeries.



Screening Trials

Designed to evaluate new tests to detect cancer in individuals before symptoms arise, with the goal of determining whether the screening test can reduce deaths from the cancer being screened for.



Diagnostic Trials

Designed to test new ways to diagnose a certain type of cancer.



Treatment Trials

Designed to determine whether new treatments or new ways of using existing treatments are safe and effective for people who have cancer. These trials can test any type of treatment, including surgery, radiotherapy, cytotoxic chemotherapy, molecularly targeted therapy, and immunotherapy, alone or in combination with another treatment(s).



Quality of Life Trials

Designed to examine whether people who have cancer can improve their quality of life by taking certain actions, such as attending support groups or exercising more; or by taking certain therapeutics, such as those to treat depression or nausea. These studies are also known as supportive care or palliative care trials.



Natural History or Observational Studies

Designed to learn more about how cancer develops and progresses by following people who have cancer or people who are at high risk for developing cancer over a long period of time.



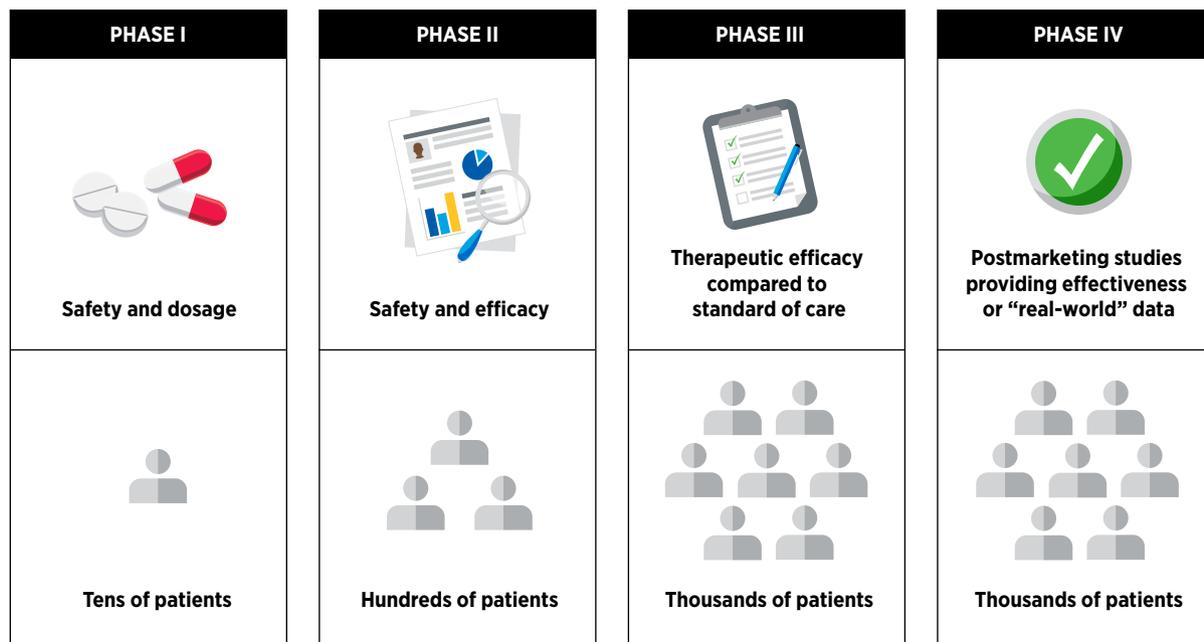
Correlative Studies

Designed to examine the relationship between potential efficacy of candidate anticancer therapeutics and positive clinical activity as determined by biomarkers. Correlative studies are an integral part of early-stage clinical trials when the effects of a candidate anticancer therapeutic on key clinical outcomes, such as reduction in tumor size, may not be apparent. Data obtained from correlative studies can provide important guidance on the design and ultimately successful evaluation of anticancer therapeutics in later-stage trials.

Adapted from (2).

FIGURE 15

Phases of Clinical Trials



Oncology Clinical Trials—the types of clinical studies that evaluate the efficacy and safety of potential new therapeutics for treating cancer patients—have traditionally been conducted in three successive phases, each with an increasing number of patients. Phase I studies determine the optimal dose of an investigational anticancer therapeutic, how humans metabolize it, and any potentially harmful side effects. Phase II studies determine the initial efficacy of an investigational therapy in humans while continually

monitoring for potential toxicities. Phase III studies are large trials designed to determine therapeutic efficacy of the new drug in comparison to standard of care. When successful, the results of these trials can be used by the U.S. 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.

Adapted from (2).

participants in clinical trials, as well as the race- and ethnicity-specific reporting of the benefits and potential risks, can enable a comprehensive understanding of 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 patient population for whom these treatments are ultimately intended.

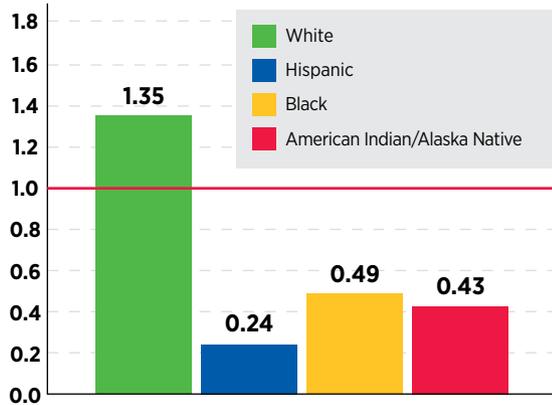
The NIH Revitalization Act was implemented in 1993 to improve the representation of women and minority populations in clinical trials. Since then, additional initiatives have been put forward by federal organizations including FDA and NCI to address the lack of diversity in clinical trials. Unfortunately, despite these efforts, minority participation in clinical trials and race and ethnicity reporting have improved only minimally (496-498), and certain segments of the U.S. population continue to be severely underrepresented in clinical research. A recent analysis

of FDA’s Drug Trials Snapshots website, which was created to improve diversity and transparency of pivotal clinical trials of newly approved drugs, indicated that since the implementation of the initiative fewer than 20 percent of therapeutics included data regarding benefits or side effects among Black patients (499). A separate assessment of patient enrollment in clinical trials that led to FDA approvals of 75 new anticancer agents between 2014 and 2018 indicated that Black patients were significantly underrepresented in breast, prostate, lung, and blood cancer clinical trials relative to their disease burden in the U.S. while White patients were overrepresented (500). Similar trends have been noted among early-phase clinical trials (501).

BARRIERS TO CLINICAL TRIAL PARTICIPATION

Numerous studies have investigated the existing barriers that limit participation of racial and ethnic minorities and other

In a recent **analysis of 93 precision oncology clinical trials** with 5,867 participants, **representation of racial and ethnic minorities** was calculated using the **ratio of the actual number of enrolled cases to the expected number of cases** based on their corresponding U.S. population (495).



Ratio >1 signifies overrepresentation
Ratio <1 signifies underrepresentation

medically underserved populations in cancer clinical trials. These data indicate a range of structural barriers and societal injustices that operate at individual (patient and health care provider) and systemic (health care system) levels (512).

The individual-level barriers for patients include lack of awareness of clinical trials, limited health literacy, and mistrust of the health care system, as well as financial barriers such as costs of cancer treatment and medication, transportation, child care, lost work, and inadequate or complete lack of insurance, among others. A recent study that assessed the clinical and nonclinical barriers to participation of Black patients in cancer clinical trials at a safety-net hospital identified lack of understanding of cancer clinical trials and perceptions and fears of cancer clinical trials as two prominent themes (513). Most participants stated that their health care providers never informed them of clinical trials, and many reported fear and mistrust of the health care system as a barrier to clinical trial participation. It is important to note that safety-net practices provide a disproportionately larger share of care to racial and ethnic minorities, as well as low-income and/or uninsured individuals, among other medically underserved populations. Thus, addressing barriers to clinical trial participation at these facilities is vital if we are to reduce cancer health disparities. Careful consideration must be given to the adverse influences of SDOH, including poverty, food insecurity, housing insecurity, and psychosocial stressors (see **Factors That Drive Cancer Health Disparities**, p. 29), while approaching interventions for patients receiving care at safety-net hospitals. In this regard, it should be noted that among cancer patients participating in clinical trials, those living in areas with high

A recent **analysis of phase I clinical trials** for anticancer agents developed by biopharmaceutical companies, showed **extremely low participation of patients from racial and ethnic minorities** compared to their proportion in the U.S. population (501).

RACE/ETHNICITY	PERCENTAGE OF PATIENTS	PERCENTAGE OF U.S. POPULATION
White	84.2	76.5
Black	7.3	13.4
Asian	3.4	5.9
Native Hawaiian or Other Pacific Islander	0.1	0.2
American Indian or Alaska Native	0.1	1.3
Hispanic	2.8	18.3

socioeconomic deprivation are still at an increased risk of worse outcomes (514). Future research should examine how to eliminate additional sources of disparities that are not mitigated even after equal access to clinical trials.

Lack of health literacy including limited understanding of clinical trials has been reported as a barrier for participation in clinical trials (513). Evaluation of barriers among Hispanic patients

THE HONORABLE **Tony Cárdenas**

U.S Representative for California's 29th District

"It is essential that clinical trial participants mirror the diversity of this country. People of color are dramatically underrepresented in cancer trials. This has life-and-death consequences for some of our communities. I believe that a rising tide lifts all boats, and ensuring that therapies are evaluated with all patient communities in mind will make our science stronger, our therapies safer and more effective, and our communities healthier across the board. I am grateful to the AACR for releasing this report which illuminates these urgent disparities, and I am eager to continue my work championing these issues in Congress."



Disparities in Clinical Trial Participation

To fully ensure the safety and efficacy of anticancer therapeutics for everyone who will use them once approved, it is vital that the participants in the clinical trials represent the diversity of the patient population. Unfortunately, several segments of the population continue to be underrepresented in cancer clinical trials relative to their proportion in the overall U.S. population and/or the relevant disease population. Selected examples of these disparities are listed here:

90%
vs
<25%

According to data from a biopharmaceutical company, 90 percent of their cancer clinical trials achieved **representation of non-Hispanic White participants at or above U.S. census levels** while only **24 percent, 16 percent, 8 percent, and 7 percent of trials achieved proportional representation of Asian, Black, Native Hawaiian or Other Pacific Islander, and Hispanic/Latino** participants, respectively. None achieved census level representation of American Indian or Alaska Native participants (502).

HIGHEST
incidence and
mortality

Analysis of demographic data from **207 pancreatic cancer clinical trials** reported between 2005 and 2020 indicated that White patients (85 percent) were overrepresented while Black (8 percent), Hispanic (6 percent), American Indian/Alaska Native (0.3 percent), and Asian or Pacific Islander patients (2 percent) were underrepresented compared to their disease incidence in the U.S. population (497). Research has shown that **restrictive eligibility criteria contribute to low participation** of Black patients in pancreatic cancer clinical trials (503). Notably, **Black patients have the highest incidence and mortality from pancreatic cancer** among all U.S. racial and ethnic population groups (504).

>70%
vs
<3%

Between 2009 and 2019, 81 oral chemotherapeutic agents were approved by the U.S. Food and Drug Administration based on data from 142 clinical trials. **Only 52 percent of these trials reported on race/ethnicity**. Among the participants, **greater than 70 percent were White** while only **2.5 percent and 2.3 percent were Black and Hispanic**, respectively (505).

LOW
enrollment

An evaluation of **53 cancer immunotherapy clinical trials** indicated that **enrollment of Black patients** was **32-fold lower** (for ovarian cancer trials), **19-fold lower** (cervical), **15-fold lower** (uterine), and **11-fold lower** (breast) than expected if accrual rates were equal across all races. **Enrollment of Asian patients** was **3-fold lower** (ovarian), **10-fold lower** (cervical), **15-fold lower** (uterine), and **2.5-fold lower** (breast) than expected (506).

>65 YO
low enrollment

Fifty-seven percent of **people diagnosed with cancer in the U.S. are 65 years of age or older** (1). Yet, according to a recent analysis of demographic data from a cancer registry in Wisconsin, **patients older than 65 are 43 percent less likely to participate** in clinical trials compared to those who are younger than 65 (507).

AYA
low enrollment

Cancer is a leading cause of death among adolescent and young adult (AYA) patients. While evidence suggests that AYA patients were better represented and more diverse than older participants in certain **National Cancer Institute-sponsored clinical trials** conducted over the past two decades (508), **enrollment of Black participants continues to be low** (509).

11% vs 24%

Among patients with blood cancer, **those who reside in rural counties are less likely to enroll in clinical trials** compared to those in urban counties (11 percent versus 24 percent) (510).

It should be noted that U.S. cancer incidence is from SEER data, which are often used as a comparator in studies evaluating racial and ethnic representation in clinical trials, and are collected from regions that overrepresent certain population groups and thus may not be an accurate estimate of the overall U.S. cancer incidence. Given the vital importance of these analyses in evaluating and ensuring racial and ethnic representativeness of past and ongoing clinical studies, researchers are working to identify better datasets for comparison, such as cancer incidence from the geographical areas from which the trial cohort was recruited or data from the North American Association for Central Cancer Registries (NAACR) (511).

indicates that poor understanding of the purpose of a clinical trial, poor communication with health care providers, and fear of uncertainty over experimental treatment may adversely affect their enrollment in clinical trials (515). Low health literacy has also been reported as a barrier to parents in making informed decisions for their child's participation in clinical research (516).

Financial costs are another key patient-level barrier to clinical trial enrollment. According to a recent survey of 213 cancer patients enrolled in early-phase clinical trials, half of the respondents reported out-of-pocket costs of at least 1,000 US dollars every month (517). More than half of participants reported unanticipated medical and nonmedical expenses including for travel and housing. Racial and ethnic minority individuals as well as those with lower income experienced disproportionately higher unanticipated medical costs (517). Transportation difficulties including lack of free parking in urban locations are a known barrier to minority participation in clinical research (518). It has been reported that cancer patients may face substantial nonmedical costs through parking fees at NCI-designated cancer treatment centers, especially in cities with a high cost of living (519). The high financial burden for patients, especially those from minority and underserved populations, may deter these patients from participating in clinical research and must be addressed during the design and implementation of these studies.

Many barriers exist at the provider level including lack of knowledge of clinical trials; implicit biases among health care providers; lack of dedicated staff to serve minority populations; and lack of cultural competence and appropriate communication skills, among other factors. Patients ages 15 to 39, who are collectively referred to as adolescents and young adults (AYA), are an underserved population who often experience unfavorable cancer outcomes. Cancer is a leading cause of death in this population and AYA patients remain especially vulnerable, given their predisposition to certain cancer types, distinct cancer biology, and unique physical and mental health needs during survivorship (see sidebar on **Survivorship Disparities in Pediatric, Adolescent, and Young Adult Cancer Patients**, p. 119). Recent studies that evaluated the barriers to enrollment of AYA patients identified limited research staff and resources, lack of awareness of available trials among health care staff, and lack of communication between pediatric and medical oncologists as frequent reasons for not enrolling in cancer clinical trials (520,521). Implicit biases among health care staff who are responsible for recruiting patients on clinical trials can contribute to exclusion of minority groups. In a recent study, researchers interviewed 91 individuals (from research staff to cancer center leaders) across five major U.S. cancer centers (522). Prominent themes emerging from these interviews included perceptions that minority participants are less knowledgeable about clinical trials and therefore more difficult to communicate with; that minorities wouldn't follow trial protocols; and that race should not be a consideration when recruiting for trials. A framework for addressing such biases is urgently needed, including diversification of the cancer research and care workforce.

According to a recent systematic review and meta-analysis, **cancer patients irrespective of race and ethnicity do participate in clinical trials more than half the time when they are offered the opportunity.** Black patients participate at similar rates (58 percent) compared to White patients (55 percent) (150).



Beyond individual-level factors, there are barriers that operate at the level of the health care system, as well as the community and/or society. Many of these barriers are driven by structural inequities and social injustices and negatively impact SDOH (see **Factors That Drive Cancer Health Disparities**, p. 29). Some of the major system-level and structural barriers include lack of trial availability; complexity of clinical trials; time constraints for proper informed consent and clinical trial paperwork; patient exclusion due to narrow eligibility criteria; medical distrust; and lack of facilitators, such as translators or patient navigators and community engagement in low-resource settings (512,523). Lack of trial availability in areas with a high proportion of racial and ethnic minorities can significantly limit their enrollment in clinical research. While Black men have a disproportionately higher incidence and mortality from prostate cancer, a recent study showed that U.S. counties with a higher proportion of Black residents were 15 percent less likely to have cancer care facilities (524). Additionally, among counties with cancer care facilities, those with a higher proportion of Black residents had significantly fewer prostate cancer trials available. It should be noted that many clinical trials enroll participants from outside the United States. According to a new study, underrepresentation of Black patients in cancer clinical trials may be exacerbated with increasing globalization of clinical research (525). When clinical trials are conducted in other countries, Black patients are enrolled at less than half the rate of U.S. studies. Between 2015 and 2018, 64 percent of patients in 21 clinical trials that led to FDA approvals of 18 anticancer drugs were enrolled outside the U.S., and Black patients accounted for only three percent of participants. As a result, researchers are concerned about the effectiveness of these therapeutics in Black patients. These data highlight the importance of adequate availability of enrollment sites in locations with a higher proportion of racial and ethnic minority residents.

ACHIEVING EQUITY IN CLINICAL CANCER RESEARCH

Overcoming barriers to clinical trial participation for all segments of the population will require all stakeholders in the cancer research and care community to actively come together and develop multifaceted approaches that include the

implementation of new, 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, and federal organizations has identified many approaches that can facilitate enrollment of participants from diverse sociodemographic backgrounds (512,526-528). 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.

Community Engagement and Patient Navigation

Research has shown that community outreach and patient navigation can enhance minority participation in clinical trials. As one example, a culturally tailored educational intervention that used trained community health educators to deliver presentations at town halls held at local churches, community health clinics, and other community centers, was able to increase knowledge about clinical trials, trust in medical researchers, and intent for clinical trial participation among Black and Hispanic participants (529). Connecting with the community and building trust are particularly important when engaging with racial and ethnic minorities who may distrust research and the health care system due to historical injustices. For instance, researchers have indicated that community based participatory research utilizing tribal and academic collaboration is a promising approach when collecting genetic data from AI/AN populations (530). Specifically, the investigators recommended becoming familiar with tribal governance and its structure, building trust with the AI/AN community, being clear about expectations and ideal communication strategies, developing a research agreement and plan for using and sharing genetic data with participants, and ensuring appropriate review by the tribe for ethical and cultural considerations. In another study, a focus group conducted at a safety-net hospital identified fear of clinical trials as a major barrier to clinical trial participation for Black patients and recommended patient navigation to provide social, emotional, and logistical support as a potential facilitating factor (513). Trust-based interventions that promote relationships between investigators, minority-serving physicians, and their minority patients have been shown to increase minority recruitment to clinical trials (531).

The vital role of community engagement and patient navigation was highlighted in a recent study that evaluated the impact of a multifaceted intervention on enrollment of Black patients in clinical trials (532). The intervention included culturally tailored marketing, partnerships with faith-based organizations serving Black communities to conduct educational events, collaboration with Lyft and Ride Health to address transportation barriers, and patient education by nurse navigators regarding cancer clinical trials (532). While Black residents comprise 19 percent of the population and 17 percent of cancer cases in the study's catchment area, only 11 percent of patients were Black prior to the intervention. Furthermore, only 12 percent and eight percent of Black participants accrued onto treatment and nontherapeutic

THE HONORABLE

Bennie G. Thompson

U.S. Representative for Mississippi's 2nd District

"During my years in Congress, I have been an advocate for reducing health disparities in cancer research, treatment, and care. We must continue to fight for a better outcome regarding cancer research. There are still minorities who have not received the resources that they need. We should be fighting this battle every day to improve the needs of cancer research. This report will identify and help each person understand the causes of cancer health disparities in the United States."



interventional clinical trials, respectively. After implementation of the community outreach and engagement intervention these numbers increased to 24 percent and 33 percent respectively. The initiative utilized community venues including churches, neighborhoods, parks, and health centers with formats ranging from educational forums to wellness fairs and reached over 10,000 individuals.

Addressing the System-Level and Structural Barriers

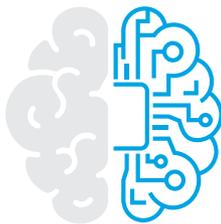
While certain system-level barriers to clinical trial participation may be more difficult to tackle, some could be addressed in the short term. One immediate approach could be to conduct clinical trials at facilities that treat a high percentage of racial and ethnic minorities and other medically underserved patients. 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 where minority patients are underrepresented (533). However, nearly 85 percent of cancer patients are treated in community centers, compared with only about 15 percent in larger, academic centers (534). It is, therefore, crucial that these studies be available to Minority-Serving Institutions 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. Additionally, the 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 work, child and elder care, etc. To encourage cancer patients to participate in clinical studies, research teams need to reach out and to work with minority patient populations. As one example, the NCI's Community Oncology Research Program (NCORP) is successfully bringing cancer clinical trials into diverse community settings .

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, and allow flexibility for patients with medical or physical limitations other than their cancer. 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. Furthermore, clinical trials should include collection of real-world data and evidence in the form of patient-reported outcomes, to help us better understand the patient experience from diverse populations.

Data from recent studies indicate that cutting edge technologies such as Artificial Intelligence (AI) platforms can play a critical role in these efforts. A new report, which used an AI platform to harness data from electronic health records from more than 60,000 lung cancer patients and publicly available trial eligibility criteria from clinicaltrials.gov to evaluate the real-world impact of eligibility criteria on patient recruitment and outcomes, found that many patients who were excluded from certain trials due to restrictive criteria could have benefited from treatments provided in the trials (535). In fact, when the researchers broadened the eligibility criteria using the AI-guided approach, the estimated number of eligible patients more than doubled. In addition, the study also concluded that trials with broader eligibility may not have any more adverse event-related treatment withdrawals compared to trials with strict eligibility criteria. These data highlight the need for innovation in the future design of more inclusive clinical trials while still maintaining patient safety.

FDA has prioritized improving representation of racial, ethnic, and gender minority populations in oncology clinical trials (see

According to NCI, **artificial intelligence (AI)** is defined as the **ability of a computer to perform functions that are usually thought of as intelligent human behavior, such as learning, reasoning, problem solving, and decision-making**. As researchers accumulate large quantities of cancer-related data ranging from tumor images to tumor sequencing, electronic health records, and clinical outcomes, AI can analyze this information to derive meaningful insights that previously could not have been realized. It is, however, **critical to ensure that the cancer-related data analyzed by AI come from diverse populations to prevent potential biases** associated with AI-driven analyses.



Diversifying Representation in Clinical Trials by Addressing Barriers for Patients, p. 143). The Center for Drug Evaluation and Research (CDER) and the Center for Biologics Evaluation and Research (CBER) at FDA released a guidance in November 2020 to encourage clinical trial sponsors to implement strategies that would increase representation of racial and ethnic minorities (527). Among the recommendations included in the guidance are broadening eligibility criteria for late-stage efficacy trials when more patients with comorbidities can be safely included; encouraging trials or follow-up studies to include representation of racial and ethnic minorities, when possible, to definitively determine differences in safety and efficacy; conducting trials at decentralized local health facilities while maintaining data integrity and patient safety; and advancing the appropriate use of real-world evidence to fill evidence gaps where randomized clinical trials may not be feasible. It must be noted that the COVID-19 pandemic, despite its adverse effects on nearly all aspects of cancer science and medicine, also offered a blueprint of success to further revise and reform the clinical trial enterprise and the drug approval process (see the sidebar on **Lessons from COVID-19 to Streamline Cancer Clinical Trials**, p. 100). Guidance issued by FDA and NCI during 2020 to minimize the adverse effects of the pandemic on the conduct of cancer clinical trials offers valuable lessons that can be implemented to streamline future oncology clinical trials, increase participation from racial and ethnic minorities and other historically underrepresented populations by eliminating system-level and structural barriers, and accelerate the pace of progress against cancer.

Disparities in Cancer Treatment

The dedicated efforts of individuals working throughout the medical research cycle are constantly powering the translation of new research discoveries into advances in cancer treatment that are improving survival and quality of life for patients in the United States like **Faye Belvin** (see p. 96) and **Ray Spells** (see p. 98) and around the world. Much of the most recent progress was highlighted in the *AACR Cancer Progress Report 2021*, which documented many new cancer treatments approved by FDA in the 12 months covered in this eleventh edition of the annual report (2). Despite these advances, racial and ethnic minorities and other 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-concordant treatment, and higher rates of treatment-related financial toxicities. The same population groups may also experience overt discrimination and/or implicit bias during the delivery of care (536,537).

Most of the disparities in cancer care can be attributed to adverse differences in SDOH (see **Factors That Drive Cancer Health Disparities**, p. 29). According to a recent survey of 165 cancer physicians practicing in community- or hospital-based settings, 93 percent of respondents agreed that SDOH negatively impacted their patients' outcomes (538). Financial insecurity, lack of health

Continued on page 100

Living a Healthy Life, Thanks to a Phase I Clinical Trial

In November 2019, Faye Belvin, 58, of Jacksonville, Florida, was diagnosed with breast cancer and immediately began treatment which included radiation therapy. She was able to continue her treatments when the COVID-19 pandemic began. Faye, who is a legal assistant at a law firm and comes from a close-knit family, experienced the impact of the pandemic like everyone else.

“It pretty much affected me just like it affected everybody. I was basically home, I had to social distance, and wear a mask,” she said. “The most I did was get in my car if I felt like it and take a drive.”

As her radiation therapy regimen was ending in late 2020, Faye began to experience a pain in her side. Then, at her regular oncology checkup, a blood test showed a tumor marker. She was referred to the Mayo Clinic in Jacksonville for follow-up tests and care.

In February 2021, after a series of scans and biopsies, Faye was diagnosed with ovarian cancer.

The next month, she began chemotherapy for that cancer.

Throughout her experience with cancer, Faye has felt deeply grateful. She was surrounded by a loving family that made it easier for her to deal with common barriers, such as traveling for medical appointments, that many other patients face when receiving cancer care.

“I know that a lot of people have challenges, but my experience is different. I had my family surrounding me. And they were there from day one,” she said. “I never drove. My sisters took me back and forth to the doctor for all of my appointments and treatments. They were there with me the whole time.”

And Faye had an outstanding cancer care team, led by Gerardo Colon-Otero, MD.

“He is so personable. He’s a great doctor,” Faye said. “He talked about everything in layman’s terms, so I never had a problem understanding what was going on. From the

beginning, we had a great relationship. I had confidence that what he said was good for me, and I would just follow his advice. It was a good experience.”

Following several rounds of chemotherapy and a surgery, Faye decided to participate in a phase I clinical trial upon Dr. Colon-Otero’s recommendation. The study was evaluating a combination of two molecularly targeted anticancer therapeutics, trastuzumab deruxtecan (Enhertu) and olaparib (Lynparza).

The first time she received the combination therapy, she said it was rough, but her team quickly adjusted the dosage, and it has been easier for her. Faye is still receiving the combination therapy and is doing well. The most common side effect she experiences is nausea.

As a person of faith, Faye is deeply grateful for the strength her beliefs have given her during both cancer diagnoses and various treatments. That faith in God, she said, has helped her remain steadfast through the ups and downs.

She is also very thankful for her care team and for the clinical trial.

“I’m living healthy. The clinical trial is working. I feel better now than I felt in the last two years,” she said.

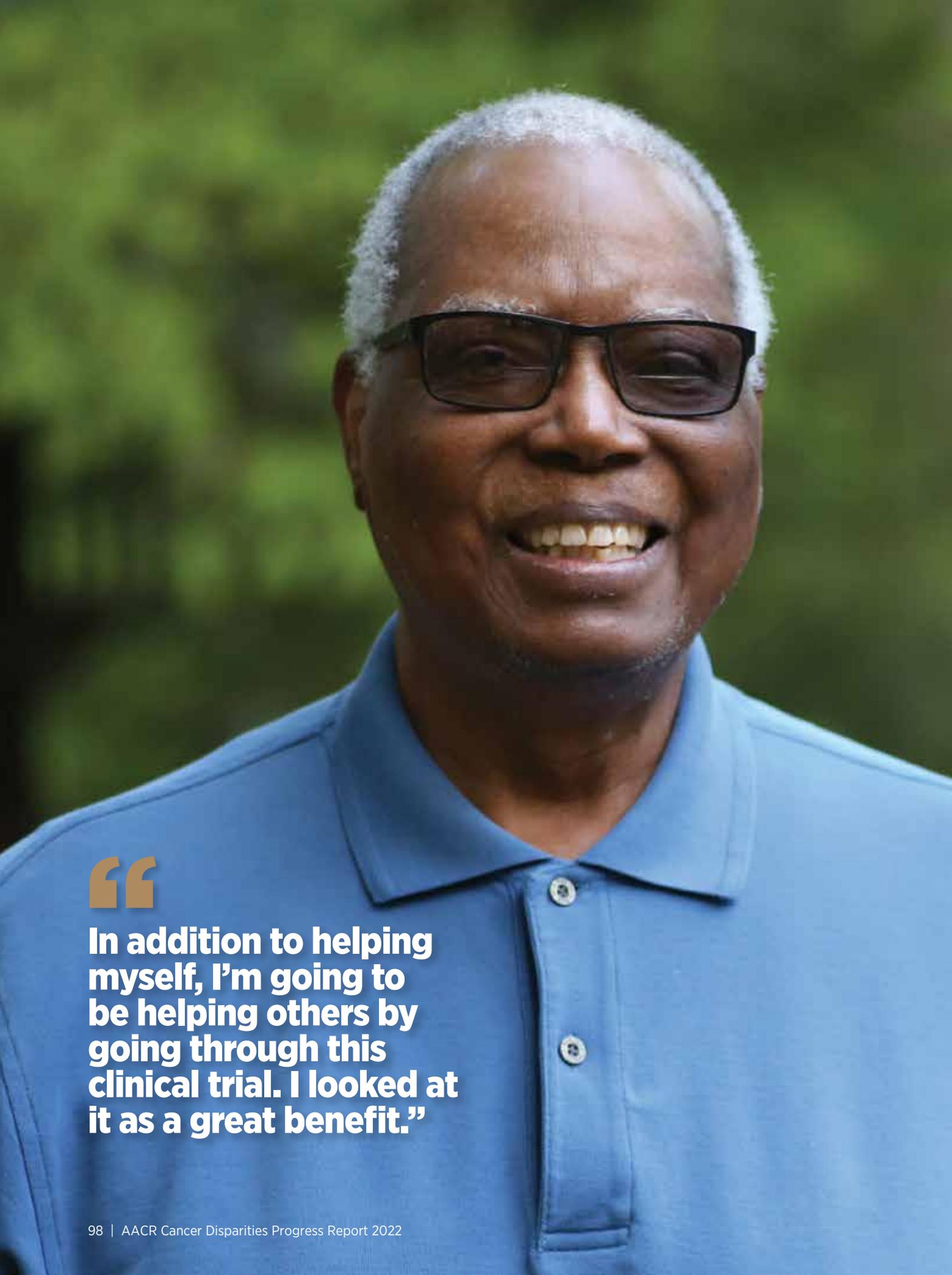
Faye’s experience has made her a huge believer in clinical trials.

“My message to the doctors and researchers is that, if you can, have a clinical trial available for your patients. My message to other patients is, don’t be apprehensive about participating in a clinical trial. It has definitely proven to be a blessing for me,” Faye said. “And my message to policy makers is that clinical trials work. So, I would encourage them to fund clinical trials.”

Faye has had a passion for helping children with cancer. That passion, combined with her own experiences with the disease, has led Faye to seriously consider becoming a patient advocate for children with cancer.



My message to policy makers is that clinical trials work. So, I would encourage them to fund clinical trials.”



“

In addition to helping myself, I'm going to be helping others by going through this clinical trial. I looked at it as a great benefit.”

Maintaining a Positive Attitude for Life Despite a History of Prostate Cancer

In December 2010, Ray Spells, a 75-year-old native of Asheville, North Carolina, went for what he thought would be a routine annual checkup with his primary care physician. A simple blood test during that appointment found that Ray's prostate-specific antigen (PSA) level, a marker for prostate cancer, had risen, indicating the possibility of prostate cancer.

Ray's doctor sent him for a biopsy, which confirmed his cancer diagnosis. At the time, Ray was 63 years old. Ray had already seen the devastating effects of cancer firsthand, when his mother was diagnosed with bone cancer.

"It was quite challenging for me to experience because of the way she suffered," he said.

So, when he received his own diagnosis, Ray was horrified. "It was very shocking. I considered myself a healthy individual and that announcement shook me up psychologically. I figured I was in for a rough ride, but I was going to ride it," he said.

After the diagnosis, Ray met with a urologist and an oncologist to discuss various options for managing his prostate cancer. Because his cancer was caught early on, one option was to watch and monitor his disease to check for any progression. Another option was a type of radiation therapy known as brachytherapy, in which tiny radioactive seeds are placed in or close to tumors.

Ray opted for brachytherapy. Initially, he did well.

A subsequent checkup, however, showed that his PSA level was rising again. "So, at that point, my oncologist suggested that I go to Duke Cancer Center," Ray continued.

After undergoing a series of tests at Duke, he began treatment with an antihormone therapy known as leuprolide (Lupron), every six months. Ray responded well to the treatment. His PSA declined steadily for several years.

"Things were going pretty well, but when I went back for my checkup in 2018, they found out my PSA had risen," Ray said.

Laboratory tests and MRI revealed that the cancer had spread to Ray's ribs. At this time, Ray's health care team recommended that he participate in the PANTHER clinical trial, which was evaluating a combination of antihormone treatments, abiraterone acetate (Zytiga) and apalutamide (Erleada). Ray was a good candidate for the trial and started receiving his treatments in April 2019.

Ray completed the trial in March 2021 but continues to receive abiraterone upon his physician's recommendation.

"I'll be taking it pretty much for the rest of my life. And, overall, I'd say I have done well. My doctor tells me that I've pretty much beaten the odds on this," Ray said. "It has been quite a journey. I'm just glad to still be above ground and moving. Having this disease and going through these treatments can really get to you psychologically, because it's constantly on your mind. What's going to happen next? Will I be able to maintain this level of health? Will things get worse? The psychological aspects of this were very challenging," Ray said. "But I tried to keep a positive mind about the whole process."

Ray believes he benefited from his active lifestyle. Before the COVID-19 pandemic, he exercised regularly at the gym, and he continues to chop wood and do other activities around his house. He also maintains a positive attitude toward life.

"I'm an active individual. And even with medication, I can still do most of my normal things. I always felt that having a positive mind would be a help for me. So, even to this day, I think in a positive way," Ray added.

Based on his personal experience, Ray tells other patients to do their due diligence and find a health care team that they are comfortable with.

"Once you feel like you got a good medical team, follow their advice, because they want you to get better," said Ray.

Also, he strongly believes that clinical trials are a great way to improve the quality of life for patients while also advancing cancer research.

"And that's one of the things that I looked at. In addition to helping myself, I'm going to be helping others by going through this clinical trial," he said. "I looked at it as a great benefit. That's how a lot of things are improved on, and I wanted to be a part of the process."

Ray tries to convince his friends and fellow Black men to seek out medical care and get regular physical examinations.

"That's one of the things that I do religiously. It's one of my top priorities and it has worked for me. I can say that today. It has worked because I'm still here," Ray concluded.

Lessons from COVID-19 to Streamline Cancer Clinical Trials

The guidance issued by FDA and NCI during 2020 to minimize the adverse effects of the pandemic on the conduct of cancer clinical trials offers valuable lessons that can be implemented to streamline future oncology clinical trials, increase participation from diverse groups, and accelerate the pace of progress against cancer. These lessons include:

Consenting remotely, using electronic means, to participate in a clinical trial.

Currently, in-person consent is required to participate in a cancer clinical trial.



Allowing the use of any laboratory and imaging centers that meet the specifications required for participation in a clinical trial.

Currently, individuals are required to use a clinical trial-specified laboratory or imaging center.



Permitting telehealth approaches for routine clinical assessments, such as safety of the experimental treatment.

Currently, individuals are required to visit clinics in person for these evaluations.



Increasing the engagement of community-based network sites in conducting a clinical trial.

Currently, experimental therapeutics are only available at the institutes where clinical trials are being conducted.



Allowing home delivery of investigational oral drugs directly to patients and concomitant medication reporting via digital tools.

Currently, an in-person visit is required to receive experimental drugs.



Making clinical trials more accessible to rural areas and underserved populations.

Currently, underserved populations have limited access to clinical trials for a variety of reasons.



Adapted from (7).

insurance, and access to transportation were identified as the greatest obstacles in accessing quality health care services. These obstacles can be compounded for those living in remote or rural areas with limited access to health care facilities, as well as for patients who lack health literacy and have language barriers (see sidebar on **Multilevel Barriers to Quality Cancer Treatment**, p. 101). Notably, while 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 improve patient satisfaction and quality of care (539), fewer Black adults (22 percent) report having providers who are of the same race compared to White adults (74 percent) (527). Among Hispanic/Latino adults, only 23 percent report having the same race and/or ethnicity or language preference as their provider. Fear of discrimination and cultural incompetency are major barriers for patients from SGM populations and often leads to avoidance of care and nondisclosure of sexual orientation and gender identity (540). Therefore, it is encouraging that a recent survey that assessed

patient services, support, patient and community engagement, and policies at leading health care facilities across the United States, reported significant improvement in the adoption of SGM-inclusive policies and practices (541).

The multilevel barriers result in racial and ethnic minorities and other medically underserved populations experiencing greater incidence, mortality, and morbidity from several types of cancers due to delayed diagnosis, a more advanced stage of disease at diagnosis, more rapid progression to aggressive disease, increased rates of development of treatment resistance, higher cancer-specific and cancer-related mortality rates, and worse survival. 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 have shown that Black and AI/AN populations living in rural areas experience greater poverty and lack of access to quality care, which expose them to greater risk of experiencing poorer cancer outcomes

Multilevel Barriers to Quality Cancer Treatment

Cancer patients from racial and ethnic minorities and other medically underserved populations experience numerous barriers to quality cancer care. Many of these barriers can be attributed to systemic inequities and societal injustices. Some recent examples of the multifaceted disparities in cancer care are cited below.

TWICE as frequent	Black women with breast cancer experience delay in surgery beyond 90 days almost twice as frequently as White women (542); Black men age 55 or younger with prostate cancer experience treatment delays beyond six months almost twice as frequently as White men of the same age (543).
LONGER delays	Non-English-speaking Latina patients with breast cancer experience longer delays between initial clinical or radiographic findings and diagnostic mammogram , and between tumor biopsy and resection compared to English-speaking Latina or White patients (544).
47% more likely	Asian patients with prostate cancer are 47 percent more likely than White patients to refuse potentially survival-prolonging treatment , including radiotherapy and surgery, despite provider recommendation (545).
INCREASED risk	Hispanic and Black patients with colorectal cancer are at an increased risk for undertreatment compared to White patients, partly attributable to the neighborhood socioeconomic status of the patients (546).
INCREASED rates	Compared to White patients, Black and Hispanic patients with kidney cancer have increased rates of treatments that are not based on standard guidelines (547).
LESS likely	Liver cancer patients living in rural and suburban communities at the time of diagnosis are less likely to receive treatment and have higher mortality compared to urban residents (548).
31% less likely	Patients with gastric cancer who live along the U.S.-Mexico border counties are 31 percent less likely to receive guideline-based treatments and have 11 percent higher all-cause mortality compared to patients from nonborder counties (549).
50% and 40% less likely	Among patients with acute promyelocytic leukemia , those who are treated at community cancer centers are 50 percent less likely to receive multi-agent therapy compared to those treated at academic cancer centers; patients without health insurance are 40 percent less like to receive multi-agent therapy compared to those with private health insurance (550).

(551). There is a critical need for additional research to understand the intersections of geography, race/ethnicity, socioeconomics, sexual orientation, and gender identity on disparities in cancer treatment and mitigate these disparities through reduced structural barriers and interpersonal biases in cancer care, increased access, and implementation of evidence-based interventions.

In the following sections, we discuss major disparities among racial and ethnic minorities and other medically underserved populations in the use of the main pillars of cancer treatment (see **Figure 16**,

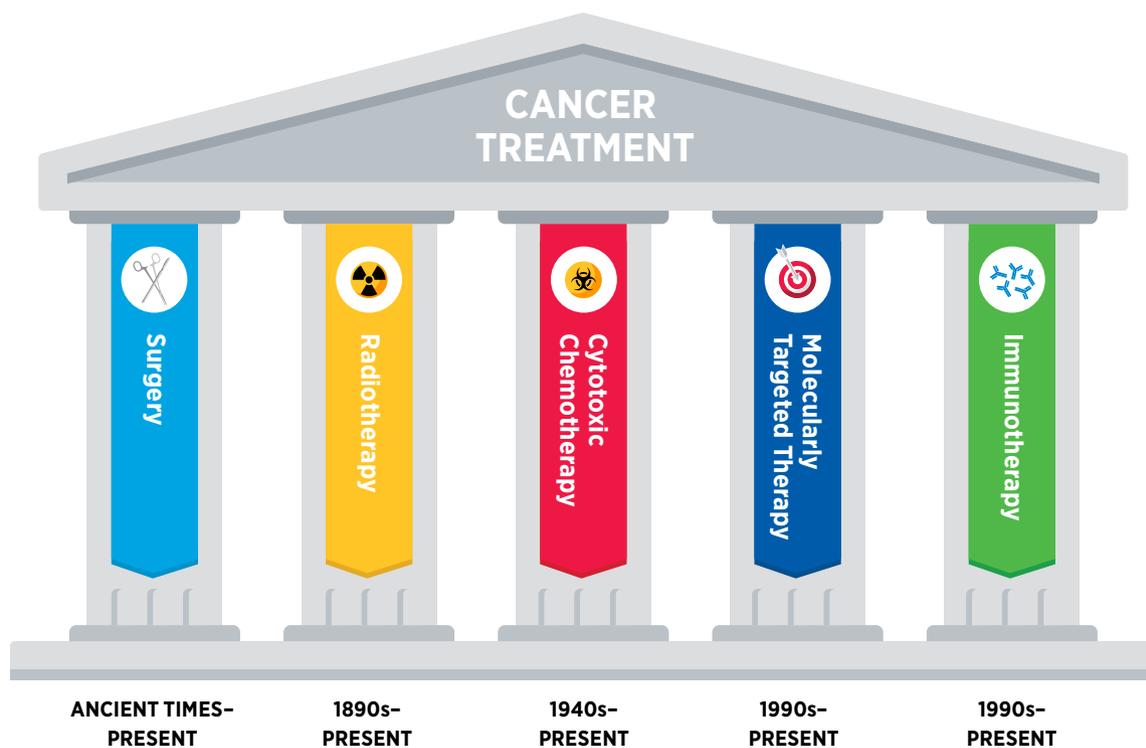
p. 102) and highlight areas where advances have been made in achieving equity in cancer treatment. Importantly, several recent studies have pointed out that disparities in the receipt of care as well as outcomes for many cancers can be eliminated if every patient has equivalent access to quality health care services (553-557).

TREATMENT WITH SURGERY, RADIOOTHERAPY, AND CHEMOTHERAPY

For many decades, surgery was the only pillar (see **Figure 16**, p. 102) of cancer treatment and remains an important treatment option for

FIGURE 16

The Pillars of Cancer Treatment



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 breast cancer patient 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. 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 (2).

The **Women’s Health Check (WHC) Program** in Idaho **serves underinsured and uninsured women**, largely from racial and ethnic minorities, living in poorer census tracts, who are often diagnosed with late-stage cancers. For women enrolled in the program there are no disparities in the interval from definitive breast cancer diagnosis to treatment initiation compared to other Idaho women (552).



many patients (see sidebar on **Using Surgery for Cancer Treatment**, p. 103). Surgery is the foundation of treatment for many cancer types for which there are significant disparities in mortality and morbidity experienced by racial and ethnic minorities and other medically underserved populations. For cancers associated with high mortality, such as lung 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 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

Using Surgery for Cancer Treatment

Surgery can be used in several different ways during the care of a patient with cancer:

- **Surgery to diagnose cancer:** In some cases, surgery is performed to obtain a tumor sample, or biopsy, for diagnosing cancer.
- **Surgery to stage cancer:** Some cancer patients require surgery to determine how far the cancer has spread from the site of origin. This information is vital for establishing the best treatment plan for a patient.
- **Surgery to cure cancer:** If cancer is confined to one area of the body, sometimes surgery can be performed to remove the entire tumor.
- **Surgery to debulk a cancer:** If a tumor is extremely large and/or located very close to important organs or tissues, surgery may be recommended to remove only part of the tumor.
- **Surgery to ease problems caused by a cancer:** For patients with advanced cancer, surgery can sometimes be performed palliatively to remove tumors that are causing pain, pressure, or blockages.

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 healthy tissue, and maybe some nearby lymph nodes.



Minimally invasive surgery is when a surgeon makes a few small cuts instead of one or more large ones. A long, thin tube with a tiny camera is inserted into one of the small cuts, allowing the surgeon to see what is happening, and special surgery tools are inserted through the other small cuts to remove the tumor and some healthy tissue surrounding the tumor.



Adapted from (2).

maximize the benefit and minimize harms from surgery for cancer patients. Thanks to such efforts, overall mortality rates after surgery for many common types of cancer have declined over the past decade (558). Post surgery mortality rates have improved for both White and Black patients. However, the mortality gap between Black and White patients, overall, or for individual cancer surgery procedures, has not narrowed (558).

Racial and ethnic minorities and other medically underserved populations often experience disparities in surgical management of cancer including treatment delays or refusals and lack of guideline-concordant care (see sidebar on **Disparities in Cancer Surgery in the United States**, p. 104). These disparities are seen across many cancer types including the most diagnosed cancers in the U.S. and may contribute to worse outcomes (559-561). As one example, Black women with nonmetastatic TNBC have a 28 percent higher risk of breast cancer mortality compared to White women, partly attributable to their disparities in the receipt of surgery and chemotherapy (561).

The most prominent barriers to cancer surgery include adverse SDOH such as lack of health insurance, lack of social support, and poverty, among other factors (see **Factors That Drive Cancer Health Disparities**, p. 29). According to a recent report, Black patients with non-small cell lung cancer (NSCLC) are almost twice as likely to delay surgery compared to White patients and 26 percent of the racial disparity can be attributed to SDOH (569). NSCLC patients experiencing adverse SDOH are also likely to have worse long-term survival (559). A recent study showed that Black and Hispanic liver cancer patients residing in counties with a high level of social vulnerability (a composite measure for SDOH) were significantly more likely not to have received surgical intervention for their cancer compared to those living in less vulnerable counties (567). Racial and ethnic minority patients are less likely to travel long distances to seek surgical treatment and are more likely to receive their cancer care in safety-net and public hospitals, which often lack multidisciplinary programs that can support complex cancer perioperative needs compared with academic hospitals or specialty cancer centers (570,571). In this regard, it should

Disparities in Cancer Surgery in the United States

MORE likely	Black patients with colon cancer are more likely to refuse recommended surgery compared to White patients (562).
BETTER survival	Black patients with early-stage lung cancer receiving surgery at academic facilities have better 5-year overall survival compared to those treated at community medical facilities (563).
INCREASED likelihood	Hispanic and Black women have an increased likelihood of needing an emergency department visit within 90 days of breast cancer surgery compared to White women (564).
66% more likely	According to data from the Arizona Cancer Registry, from 2007 to 2016 Mexican American patients with kidney cancer were 66 percent more likely not to receive surgery compared to White patients (565).
LESS likely	Indian, Pakistani, and Chinese American women with breast cancer are more likely, while Filipino and Vietnamese American women are less likely to receive surgery within 30 days of diagnosis compared to White women (566).
18% more likely	Liver cancer patients living in counties with low socioeconomic status, housing and language vulnerabilities are 18 percent more likely not to receive surgical interventions that can improve outcomes (567).
HIGHER mortality	Lower levels of neighborhood income and education are independently associated with higher 30-day and 90-day mortality among patients undergoing surgical treatment for gastric cancer (568).

be noted that even at safety-net settings, multidisciplinary cancer care and appropriate initiation of treatment can lead to equitable outcomes (572).

Implicit biases among health care providers may also contribute to disparities in cancer surgery. As one example, Black women with breast cancer undergoing mastectomy surgery were less likely to be referred for breast reconstruction compared to White patients. Additionally, even when referred to a plastic surgeon, Black patients were less likely to be offered reconstruction (573).

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 (574). Patients from the rural U.S. are particularly vulnerable. Recent data show that density of surgical specialists is considerably lower in rural areas compared to urban areas and the rural-urban gap has been exacerbated between 2004 and 2017 with the largest increase in disparity being among colorectal surgeons (575). The remote location of many AI/AN reservations is a contributing factor to the surgical disparities among these populations. In a recent study, researchers found that, compared to White women, AI/AN women with

early-stage breast cancer had higher rates of mastectomies (41 percent versus 34 percent) and lower rates of lumpectomies (59 percent versus 66 percent) (576), albeit with significant regional variations. These data are concerning because lumpectomy followed by radiation can decrease complications and pain post surgery with similar survival compared to mastectomy. Lack of knowledge of available treatment options as well as distance and transportation to medical centers can contribute to these disparities. Higher use of mastectomy in certain vulnerable populations may also stem from mistrust of the health care system since mastectomy is more definitive and may reduce the need for follow-up encounters with the health care system.

Taken together these data highlight the need for multilevel interventions to ensure equitable delivery of guideline-recommended surgery for all cancer patients. All stakeholders must work together to improve effective communication and access to health care resources for patients while continuing further research into the mechanisms that perpetuate disparities. The vital importance of access to surgical treatment is highlighted by studies showing that disparities in survival between Black and White patients are eliminated in health care setting where all patients receive guideline-concordant

The **COVID-19 pandemic necessitated many adaptations to the delivery of anticancer treatment regimens**, ranging from cancelled surgeries and radiotherapy to modified schedules and/or dosing for patients receiving chemotherapy, molecularly targeted therapy, and/or immunotherapy (577). The pandemic has also brought a **sharper focus on cancer health disparities**.

According to a recent study, a **90.9 percent lower rate of prostatectomies**—surgery to remove the prostate gland completely or partially—was **observed among Black patients with prostate cancer**, compared to a 17.4 percent lower rate of prostatectomies among White patients, during the initial wave of the COVID-19 pandemic (578).



treatment (579,580). Furthermore, concerted efforts from all stakeholders are needed to diversify the current surgical oncology workforce which significantly lacks representation from minorities and women (581).

Radiotherapy uses high energy rays or particles to control the growth of and/or eradicate cancer cells. Discovery of X-rays in 1895 allowed visualization of internal organs at low doses. A year later, the effective use of X-rays at high doses to treat a breast cancer patient firmly established radiotherapy as the second pillar of cancer treatment. Today, about 50 percent of all cancer patients in the United States receive radiotherapy as part of their treatment regimens. There are many types and uses of radiotherapy (see sidebar on **Using Radiation in Cancer Treatment**, p. 106). It is important to note that radiotherapy may also have adverse side effects, partly because of the radiation-induced damage to healthy organs surrounding the tumor tissue. Researchers are continuously refining the use of radiotherapy to make it safer and more effective while designing novel radiotherapeutics (to be used alone or in combination with other types of treatments) to target more cancer types.

Unfortunately, reduced access to and utilization of radiation therapy have been well documented among U.S. racial and ethnic minorities and other medically underserved populations and contribute to cancer health disparities. A recent analysis, which examined the receipt of more than 250,000 treatments using Medicare claims and beneficiary data between 2016 and 2018, found that failure to initiate radiation treatment was 29 percent greater for Black, Hispanic, and AI/AN patients compared to White patients (582). Even when radiation treatment was initiated, Black and Hispanic

patients required significantly more days for completion of the treatment compared to White patients. Additionally, studies have shown that interruptions to radiation treatment disproportionately affect financially and socially vulnerable patients and can be mapped to disadvantaged neighborhoods such as urban, majority Black, low-income neighborhoods as well as rural, majority White, low-income regions (583).

Disparities in the utilization of radiation therapy are evident across cancer types. Lack or underutilization of the treatment among the disadvantaged population groups is also evident for state-of-the-art treatment regimens such as stereotactic body radiotherapy, hypofractionated radiotherapy, and intensity-modulated radiotherapy, all of which have been shown to improve outcomes for patients while reducing the adverse side effects of radiation (574,584,585). As one example, a recent advance is the emergence of hypofractionated radiotherapy, whereby patients receive fewer but higher doses of radiotherapy compared with the traditional course and complete treatment over a shorter period. In 2018, new guidelines were introduced which recommended expanding the use of hypofractionated radiotherapy for treating breast cancer (586). This change was spurred by research showing that hypofractionated radiotherapy is as effective as the traditional course of radiotherapy and has fewer adverse effects (587,588). While use of hypofractionated radiotherapy has increased in recent years, the likelihood of receiving treatment is greater among patients with higher median income, those with private insurance, and those being treated at an academic center (584). Additionally, a recent analysis indicated that after undergoing breast-conserving surgery, Black and Asian patients receive hypofractionated radiation therapy less often than White patients, and these disparities are driven by variations in treatment facility-specific hypofractionation use (585).

Adverse differences in SDOH as well as clinical factors are associated with disparities in timely radiation treatment. Research has shown that lack of or inadequate health insurance, low socioeconomic status, limited access to care facilities, and having additional comorbidities, are among the prominent drivers of inequities in the utilization of radiation treatment (584,589,590). Disparities in access to radiation therapy facilities have been identified as a major barrier to receiving treatment for racial and ethnic minorities and other medically underserved populations. For instance, research has identified significant disparities in access to radiation therapy facilities in Washington State specifically for AI/AN and rural residents (591). Notably, regions with greater geographic access to radiation therapy tend to be of higher socioeconomic status and better insured (592) and increasing distance from treatment facility is known to be associated with lower receipt of radiation treatment (593). Rural residents are at a particularly higher risk of living farther away from radiation facilities, specifically those offering emerging treatment options such as stereotactic body radiotherapy or particle therapy (see sidebar on **Using Radiation in Cancer Treatment**, p. 106) (574).

Overall, these findings call for new evidence-based strategies to improve access to radiotherapy services for cancer patients from

Using Radiation in Cancer Treatment

There are two major uses of ionizing radiation in the diagnosis and treatment of cancer:

HIGH
=====



Radiotherapy, or radiation therapy, uses high-energy radiation to control and eliminate cancer.

HIGH
=====



Radiology largely uses low-energy radiation to image tissues to diagnose disease.

RADIOTHERAPY

- 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.
- Radiotherapy works primarily by damaging DNA, leading to cancer cell death with relative sparing of normal tissues, a feat achieved by using sophisticated approaches, such as computer analytic programs that optimize the delivery of the radiation to the tumor while minimizing exposure of normal tissues.



USES OF RADIOTHERAPY

Curative radiotherapy seeks to eliminate cancers, particularly small and locally advanced cancers; it is often used in combination with systemic therapy.

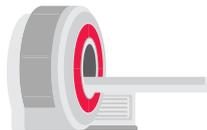
Neoadjuvant radiotherapy is used to shrink a tumor before the main treatment, which is usually surgery.

Adjuvant radiotherapy seeks to eliminate any remaining cancer following primary treatment, such as surgery.

Palliative radiotherapy is used to reduce or control symptoms of disease when cure by another method is not possible.

TYPES OF RADIOTHERAPY

External beam radiotherapy, usually photons (X-rays) or electrons, delivers radiation to the tumor from outside the body; it is the most common form of radiotherapy.



- Conventional (2-D) external beam radiation therapy delivers a high-energy X-ray beam from one or more directions. Imaging of the treatment area is typically performed using low-energy diagnostic X-rays. It is primarily used in settings where high precision is not required, such as in the treatment of bone metastases.
- 3-D conformational radiotherapy (3DCRT) uses specialized imaging, usually computed tomography (CT) and/or magnetic resonance imaging (MRI) and planning software to deliver high-energy X-rays via multiple beams that more precisely target the shape and size of the tumor.
- Intensity-modulated radiotherapy (IMRT) is a refinement of 3DCRT that more precisely focuses and shapes the radiation by dividing each beam into many “beamlets,” each of which can have a different intensity.
- Intraoperative radiation therapy uses electron beam (superficial) radiation directly on tumors that have been exposed during surgical procedures.

- Stereotactic radiotherapy is used in both stereotactic surgery (SRS) and stereotactic body radiotherapy (SBRT). It uses typically more than eight beams with a highly sophisticated imaging system to direct radiation to very well-defined smaller tumors. Usually, SRS is used to treat tumors of the brain and central nervous system, whereas SBRT can be used on small tumors within larger organs of the body.

Particle therapy refers to protons or carbon ions rather than X-rays as the source of energy. In contrast to X-rays that cause damage to the noncancerous tissues through which they pass, these heavier particles deposit most of their energy in the target. In this manner, particle therapy can deliver higher doses with less damage to surrounding tissue. Although of great interest, proton facilities are much more expensive than traditional facilities, and the overall benefit to selected patients is still being determined.



Brachytherapy places small radioactive sources in or next to the tumor either temporarily or permanently.



Radioisotope therapy involves systemic ingestion or infusion of radioisotopes, for example, iodine-131 to treat thyroid cancer or lutetium Lu 177 dotatate (Lutathera) to treat gastroenteropancreatic neuroendocrine tumors.

Adapted from (2).

NEOADJUVANT THERAPY

Anticancer therapy administered **before surgery** to reduce the tumor size.

SURGERY



ADJUVANT THERAPY

Anticancer therapy administered **after surgery** to eradicate as many residual cancer cells as possible.

all medically underserved populations. When developing such interventions, health care providers must consider not only clinical factors but also the adverse influences of SDOH. For maximal benefits in cancer outcomes there must be structural changes in public health and health care delivery to promote equitable access to care for all. Encouragingly, it has been shown in many settings that equitable use of standard of care radiotherapy can overcome the racial and ethnic disparities seen in cancer outcomes (590).

Chemotherapy remains the backbone of cancer treatment for many patients. First introduced as a pillar of cancer treatment in the early to mid-20th century, use of chemotherapy is continually evolving to minimize its potential harms to cancer patients, while maximizing its benefits.

Unfortunately, many reports have documented that patients with cancer from racial and ethnic minorities and other medically underserved populations are less likely to receive recommended chemotherapy (see sidebar on the **Disparities in the Use of Chemotherapy**). These disparities arise due to a range of issues from socioeconomic disadvantages including poverty, lack of health insurance, being treated at community hospital setting, and language barriers to clinical factors such as advanced age. Results from recent studies suggest that even among those with private health insurance, Black and Hispanic patients are still less likely to receive chemotherapy, highlighting the need for additional research to identify factors beyond health insurance that are preventing underserved patients from receiving the standard of care for their cancers (594). There is also evidence suggesting clinical differences in the response to chemotherapy for patients from different racial

and ethnic backgrounds, with minority patients benefiting less from the chemotherapy exposure (595). These data underscore the importance of diversifying accrual in cancer clinical trials to ensure the safety and efficacy of therapeutics for patients from all sociodemographic backgrounds.

Treatment with chemotherapeutics can have adverse effects on patients. These effects can arise during treatment and continue in the long term, or they can appear months or even years later. As a result, researchers are investigating ways to identify patients who may benefit most from these treatments (599). Researchers use a test known as the Oncotype DX score to measure how aggressive a woman's breast cancer is and to decide whether she needs chemotherapy after surgery (600). The test works by looking at the activity of 21 genes within the tumor and calculating a score between 0 and 100. Oncotype DX scores fall into three categories that reflect the risk of breast cancer recurrence. Scores under 10 indicate a low risk, between 11 and 25 are intermediate risk, while 26 and above are considered high risk. Most patients with low and intermediate risk scores get hormone therapy after surgery, whereas those with high scores get chemotherapy in addition to hormone therapy. Recent data suggest that, in addition to recurrence scores, menopausal status of the patient should be taken into consideration while making decisions on chemotherapy (601). Oncotype DX testing followed by guideline-concordant treatment is associated with improved outcomes. Unfortunately, among breast cancer patients who are recommended chemotherapy following a high Oncotype DX score, many refuse treatment and the rates of refusal are higher among women who are Black, older, and lack private health insurance (602).

Disparities in the Use of Chemotherapy

LESS
likely

Among **patients with bladder cancer** those who are **uninsured** (versus privately insured), **live in rural areas** (versus urban areas), and are **treated at community settings** (versus academic/research setting) are 53 percent, 30 percent, and 28 percent **less likely**, respectively, **to receive neoadjuvant chemotherapy** (596).

GREATER
delays

A review of patients with breast cancer who received treatment at a safety-net hospital indicated that **non-English-speaking and older patients** experienced **significantly greater delays in receiving adjuvant chemotherapy** (597).

MORE
likely

Among **patients with endometrial cancer**, **Black women** are 26 percent **more likely to refuse chemotherapy** than White women; this difference contributes to about two months of the overall 3.2-year survival disparity observed between White and Black women (598).

While there are some variations in the published data, some recent studies have indicated that the Oncotype DX test may be less accurate at predicting the risk of breast cancer death for Black women compared to White women (603,604). Specifically, the researchers found that overall, Black women had higher Oncotype DX scores than White women and even among women with similar scores, Black patients were more likely to die of breast cancer compared to White women. These data highlight the importance of additional research into the cellular and molecular characteristics within tumors and/or other treatment-related factors that are not captured by Oncotype DX tests and may be driving racial disparities in breast cancer. Furthermore, these results reinforce the need for greater racial diversity in clinical trial populations as researchers develop new tests such as the Oncotype DX, because there can be ancestry-related biological differences among patients from different population groups that influence the performance of these tests.

TREATMENT WITH MOLECULARLY TARGETED THERAPY AND IMMUNOTHERAPY

Therapeutics directed to the molecules influencing cancer cell multiplication and survival target the cells within a tumor more precisely than cytotoxic chemotherapeutics that target all rapidly dividing cells, thereby limiting damage to healthy tissues. The greater precision of these molecularly targeted therapeutics tends to make them more effective and less toxic than cytotoxic chemotherapeutics. Molecularly targeted therapeutics have become the fourth pillar of cancer care and are not only saving the lives of patients with cancer, but also allowing these individuals to have a higher quality of life. The effective use of molecularly targeted therapeutics 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 those 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. The use of molecularly targeted therapeutics has ushered in a new era of precision medicine in which patients are treated based on their disease characteristics.

Unfortunately, many recent reports have highlighted striking disparities in the utilization of molecularly targeted

treatments among patients from racial and ethnic minorities. For example, among women with stage III HER2 positive breast cancer, only 56 percent of Black patients compared to 74 percent of White patients received the HER2-targeted therapeutic trastuzumab (Herceptin) (605). According to another recent study, among women with hormone receptor-positive breast cancer who are eligible for adjuvant endocrine therapy, 71 percent of AI/AN, 70 percent of Black, and 63 percent of Hispanic patients underutilize (i.e., fail to initiate or adhere to) treatment compared to 59 percent of White patients (606). Yet another study reported that Black patients with NSCLC, are less likely to be tested to determine whether their cancer has an EGFR mutation compared with White patients and are less likely to be treated with the EGFR-targeted therapeutic erlotinib (Tarceva) (607).

Genetic testing of tumors to detect cancer-causing mutations is a critical step before receiving treatment with molecularly targeted therapeutics. Patients who are at high-risk for inherited cancers may also benefit from genetic testing. Unfortunately, recent reports indicate that the utilization of tumor genetic testing, overall, is suboptimal (608). Rates of testing are particularly low among medically underserved populations, including racial and ethnic minorities. For example, a recent analysis of genetic testing rates among lung cancer patients showed that only 14 percent of Black patients received testing compared with 26 percent of White patients (204). Similar trends have been noted in other types of cancer, including ovarian cancer (609). Black women with ovarian cancer who report low income or discrimination at their place of work are significantly less likely to receive genetic testing (610). Reducing financial barriers and providing credible assurances that health information will not be disclosed and will not affect socioeconomic factors, such as employment, may increase uptake of genetic testing among these women. Additionally, educational interventions are needed to address biases among physicians' perceived barriers to genetic testing among minority patients (611).

Recent data indicate that there are racial and ethnic differences in the patterns of cancer-associated genetic alterations (see **Figure 6**, p. 43). As one example, among patients with colorectal cancer age 50 and younger (often referred to as early-onset colorectal cancer), Black patients have higher rates of mutations in the KRAS gene (612). This information can be critical in making treatment decisions, since many KRAS-targeted therapeutics are currently being evaluated in clinical trials and one therapeutic has recently received FDA approval (2). Equally important among early-onset colorectal cancer patients is the detection of inherited mutations which may guide their treatment and/or future surveillance options. Unfortunately, a recent analysis of a diverse population of early-onset colorectal cancer patients indicated racial/ethnic differences in referral to and receipt of genetic testing (207,613). It is also concerning that disparities in genetic testing rates have worsened in recent years, particularly between patients with and without private health insurance (207,613). Receiving care at equal-access health care systems, for instance the Veterans Health Administration, the U.S. military health care system, has been

The **TAILORx** clinical trial involved nearly ten thousand breast cancer patients undergoing **Oncotype DX testing**. The study found that among patients with intermediate-risk scores, **outcomes were substantially worse for the Black patients**, suggesting possible differences in primary tumor biology (150).



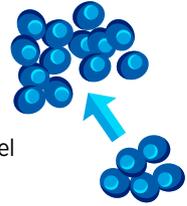
How Immunotherapeutics Work

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.



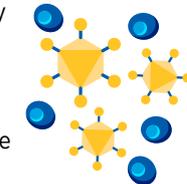
Some amplify the killing power of the immune system by providing more cancer-targeted immune cells called T cells, for example, axicabtagene ciloleucel (Yescarta) and tisagenlecleucel (Kymriah).



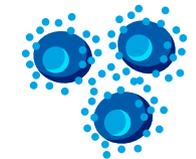
Some enhance the cancer-killing power of the immune system by triggering cancer-fighting T cells; these are called therapeutic cancer vaccines, for example, sipuleucel-T (Provenge).



Some 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).



Some increase the killing power of the immune system by enhancing T-cell function, for example, interleukin-2 (Aldesleukin).



Some flag cancer cells for destruction by the immune system, for example daratumumab (Darzalex).



Adapted from (2).

shown to reduce disparities in genetic testing among underserved populations (614). Therefore, future public health policies must aim at equitable access to the benefits of precision medicine including tumor genetic testing and the receipt of molecularly targeted therapeutics for all patients.

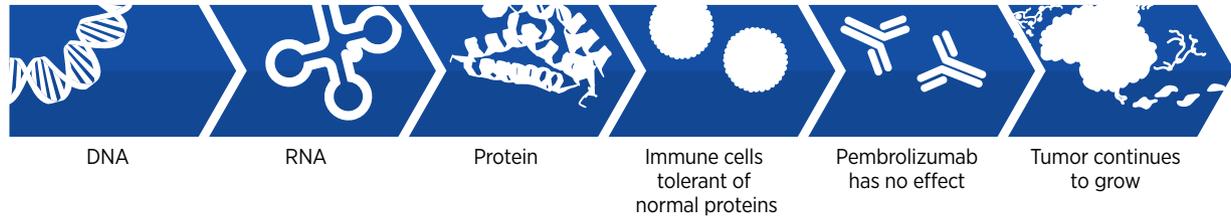
Cancer immunotherapeutics work by unleashing the power of a patient's immune system to fight cancer the way it fights pathogens like the virus that causes flu and the bacterium that causes strep throat. There are many ways by which immunotherapeutics can eliminate cancer (see sidebar on **How Immunotherapeutics Work**, p. 109). Immunotherapy has emerged as the fifth pillar of cancer care and as one of the most exciting new approaches to cancer treatment. 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 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 *AACR Cancer Progress Report 2021*, 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 U.S. cancer death rates (2).

Despite the high efficacy of immunotherapies, less than half of all patients with advanced melanoma and less than 10 percent of patients with NSCLC receive treatment with these lifesaving therapeutics (615). There are sociodemographic disparities in the utilization of immunotherapies. For example, according to a recent analysis, patients with metastatic melanoma are less likely to receive immunotherapy if they are older, uninsured or lack private insurance, receive treatment at a community setting, or live in zip codes with low level of education (616,617). Additionally, data show that Black patients with melanoma may experience a longer time to immunotherapy initiation compared to White patients (618). Similarly, NSCLC patients who are Black, live in less-educated areas, or are uninsured or lack private health insurance are less likely to receive immunotherapy (208). It should be noted that treatment responses and toxic side effects from immunotherapies might differ among patients from different racial and ethnic populations (619,620). It is critical that ongoing research continue to evaluate the safety, efficacy, and utilization of these therapeutics among racial and ethnic minorities and other medically underserved patient populations through increased participation in clinical trials as well as from assessing data in real-world practice (see **Achieving Equity in Clinical Cancer Research**, p. 93).

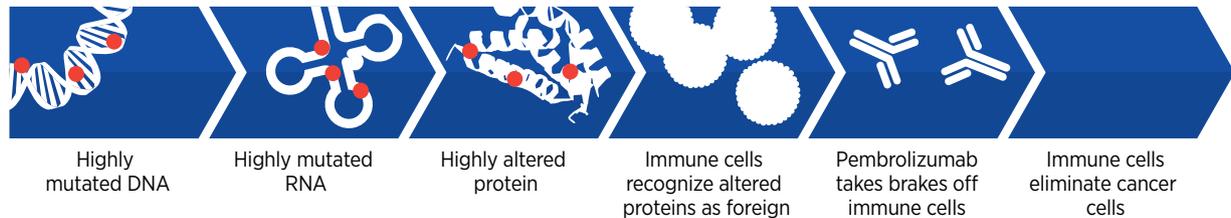
FIGURE 17

More Precisely Identifying Tumors Likely to Respond to Immunotherapy

TUMOR DOES NOT HAVE “HIGH MUTATIONAL BURDEN”



TUMOR IS “TUMOR MUTATIONAL BURDEN (TMB)-HIGH”



Precision medicine is broadly defined as treating a patient based on characteristics that distinguish that patient from other patients with the same disease. The U.S. Food and Drug Administration approval of pembrolizumab (Keytruda), a type of therapeutic known as a checkpoint inhibitor, for the treatment of any solid tumor identified to be tumor mutational burden–high is an example of precision immunotherapy. The scientific rationale underpinning this approval was the result of the dedicated researchers integrating scientific discoveries in the fields of immunology and cancer biology to develop an understanding of why tumor mutational burden–high is an effective biomarker for the use of pembrolizumab. Cancer cells with this biomarker have a much higher

number of mutations in their DNA compared with other cancer cells (in the case of this approval, tumor mutational burden–high was measured using a defined test as 10 or more mutations per megabase of DNA). These mutations give rise to altered proteins, which are recognized as abnormal, or foreign, to cancer-fighting immune cells called T cells. These T cells are spurred into action when the PD-1 brake that is preventing them from eliminating cancer cells is released by pembrolizumab. In cancer cells that are not tumor mutational burden–high, the dramatically fewer DNA mutations mean fewer altered proteins. The immune cells in this situation accept the protein landscape in the tumor as normal and are unlikely to be spurred into action by pembrolizumab.

Adapted from (2).

In addition, there is a critical need for additional basic and translational research into the ancestry-related differences in the immune system and tumor immune microenvironment, which are key contributing factors in determining efficacy of cancer immunotherapies. A recent analysis that evaluated the presence of a specific molecular characteristic or biomarker, called tumor mutational burden (TMB), in the tumors of patients with advanced NSCLC found that the levels of TMB varied significantly across ancestry groups (621). Patients of African ancestry had the highest level of TMB. These data are critical for making treatment decisions since high TMB is associated with greater benefit, including improved overall survival, from certain immunotherapeutics known as checkpoint inhibitors (see **Figure 17**).

Currently, there are many barriers to 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 barriers to receiving immunotherapies (see **Overcoming Cancer Health Disparities Through Diversity in Cancer Training and Workforce**, p. 125). These barriers may be particularly prominent for patients in rural

regions who must travel long distances to access specialty clinics delivering immunotherapies as well as those receiving care at safety-net settings in urban areas. As more of these transformative anticancer agents make their way from the bench to the clinic it is imperative that the medical research community address 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 (see **Achieving Equity in Clinical Cancer Research**, p. 93). Ensuring equitable use of immunotherapies must also be a top priority for our policy makers considering evidence that patients diagnosed in states with Medicaid expansion have a greater likelihood of receiving immunotherapies (615).

While molecularly targeted therapeutics and immunotherapeutics have transformed cancer care for many patients, they have also brought to attention the lack of racial and ethnic diversity in human genomic studies. Our limited knowledge of inherited cancer predisposition, and genomic and other underpinnings of cancer initiation and progression, in racial and ethnic minorities and underserved populations greatly diminishes the potential of precision medicine. Disparities in the current application of these highly effective therapies mandate further research to identify current barriers to the use of precision cancer medicine among underserved cancer patients and address those barriers at the earliest possible time.

Achieving Equity in Quality Cancer Care

There is increasing evidence that disparities in cancer outcomes could be reduced or even eliminated when every patient has equitable access to quality cancer treatments. As one example, Black patients with colorectal cancer are known to have worse outcomes compared to White patients (10). However, a recent clinical trial which evaluated certain molecularly targeted therapeutics (alone or in combination) in patients with advanced colorectal cancer found no difference in treatment responses or overall survival between Black and White patients who received equal treatments (622). Researchers have also shown that for many cancers, racial and ethnic minorities may respond better to treatments and have better outcomes compared to White patients when offered similar access to guideline-concordant quality care. A recent meta-analysis of data from seven prostate cancer clinical trials evaluating radiation therapy along with other types of treatments indicated that even though Black men enrolled in these trials with more aggressive disease, they experienced better outcomes compared to White men (623). Similar observations have been made by other researchers who evaluated the outcomes of Black versus White patient with prostate cancer treated with a hormone-targeted therapy (624). Yet another analysis showed that among advanced NSCLC patients who received immunotherapy, Black patients experienced higher survival compared to White patients (625). These exciting new data

Several **recent clinical studies** have demonstrated that while **Black patients with prostate cancer** may enroll in the 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 (190,630-632).



suggest that implementation of policies and interventions that ensure equitable access to cancer treatment may be able to address racial or ethnic differences in cancer outcomes. In this regard, Medicaid expansion through the Affordable Care Act (ACA) has been shown to increase insured status, early diagnosis, and timely cancer treatment, and to improve outcomes and reduce cancer disparities (626-629) (see **Improving Access to High Quality Clinical Care**, p. 146).

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. A recent report indicated that treatment at a multidisciplinary care clinic eliminated the disparity in outcomes for patients with pancreatic cancer from low versus high socioeconomic status (579). Notably, access to multidisciplinary cancer care can overcome socioeconomic disparities in timely treatment even in low-resource settings such as safety-net hospitals and deliver equitable outcomes for all patients (572).

VITAL ROLE OF PATIENT NAVIGATION

Considering accruing evidence that disparities in cancer outcomes can often be mitigated when patients from racial and ethnic minorities and other medically underserved populations receive the same care, it is important that researchers devise innovative strategies to ensure that all patients receive standard treatments and participate in cutting-edge clinical trials. These strategies must simultaneously address many of the complex and interrelated factors contributing to disparities in cancer treatment. Having patient navigators at the front line of cancer care plays an essential role in improving the quality of care and reducing cancer health disparities (633). The importance of nurse navigators was highlighted in a recent study showing that racial and ethnic minority patients with aggressive large B-cell lymphoma were just as likely as White patients to receive standard treatments, participate in clinical trials, and complete treatment when they received care at a health care facility with an

What Is Telemedicine?

According to the National Cancer Institute, telemedicine, also called telehealth, is the delivery of health care from a distance using electronic information and technology, such as computers, cameras, videoconferencing, satellites, wireless communications, and the Internet.

TYPES OF TELEMEDICINE

Teleconsultation Presentation of a patient's health report by the primary health care provider(s) to an expert in another institution.

Telediagnosis Remote or concurrent transmission of results from physical exams, scans and/or lab tests to a specialist, such as a pathologist, for diagnostic purposes.

Teleinterpretation Interpretation of a patient's test results, such as images obtained from a full-body scan, remotely.

Telemonitoring Signs or symptoms, as well as health records, of a patient communicated to a health care team by an electronic communication platform that is compliant with the Health Insurance Portability and Accountability Act (HIPAA).

Telesupervision Presentation of a patient's information via shared screen electronically—either recorded or with the patient present in person—to a senior clinician by a medical trainee (e.g., medical student) or other health care worker (e.g., nurse) using electronic means, such as PowerPoint slides.

Televisit Usual visit of a patient with his or her health care provider, but using videoconferencing software.



POTENTIAL BENEFITS OF USING TELEMEDICINE

- **Increased access to health care** Allows access to health services that may not be available to patients locally.
- **Improved health care outcomes** Promotes continuity of care regardless of the location of the patient and the provider, thus improving overall health outcomes.
- **Decreased infectious exposure** Helps avoid exposure to infectious viruses, bacteria, and other pathogens.
- **Reduced costs and/or work-related adjustments** Saves time and money by eliminating the need to travel to the health care facility or to take too much time off work or to arrange for elder and/or childcare.
- **Facilitated caregiver and family engagement** Allows caregivers and other family members to join, which can facilitate patient care.

POTENTIAL DRAWBACKS OF USING TELEMEDICINE

- **Widened health care disparities** Infrastructure that enables electronic communications, such as broadband Internet, computer, or smartphones, as well as digital literacy, are two key requirements for implementing telemedicine effectively. However, lack of access to both is disproportionately experienced by patients from medically underserved populations and may widen already existing disparities.
- **Rapidly changing policies and reimbursement rules** The fast-paced nature of telemedicine may make it harder for health care providers to keep up with health care laws, reimbursement policies, and privacy protections.
- **Costly initial implementation** Implementing telemedicine at a health care facility, including restructuring information technology staff, purchasing necessary equipment, and training clinicians and support staff, takes time and costs money.
- **Security of personal health data** The security of personal health data transmitted electronically is also a concern, which can be mitigated by employing a HIPAA-compliant telemedicine platform.

Adapted from (7).

extensive nurse navigator program (634). The nurse navigators helped disadvantaged patients access care by guiding them through treatment, helping them with their social needs such as lodging, and providing other nonmedical support. Most importantly, the study found similar survival between White and minority patients, which was likely due to equal access to guideline-concordant therapy.

Another example of a multilevel intervention aimed to mitigate disparities in cancer treatment among underserved patients is the ACCURE (Accountability for Cancer Care through Undoing Racism and Equity) program (635). The goal of this comprehensive program is to proactively identify and address structural and cultural barriers to cancer treatment (636). ACCURE uses three main strategies to improve the rate of treatment completion. First, nurse navigators meet with patients regularly to understand and address their challenges, such as medical mistrust, miscommunication with health care providers, limited access to transportation, financial hardships, and difficulties taking time off work. Second, a real-time, electronic health record-based warning system alerts nurse navigators if patients miss an appointment or do not reach an expected care milestone (e.g., surgery within 90 days of their first appointment). In such cases, nurse navigators try to address any issues patients are facing using available resources like free transportation, rescheduling appointments, telehealth visits, and/or financial assistance for utilities, rent, or gas. Finally, to enhance accountability, clinical teams are updated regularly on the race-specific rates of treatment completion. Researchers showed that this multipronged intervention led to the elimination of disparities in the likelihood of receiving curative treatment for Black and White patients with NSCLC (555). Data further indicated that Black and White patients completed their treatment at equal rates (637) and a recent analysis indicated that the intervention reduced the racial disparity in the timeliness of receiving lung cancer surgery after diagnosis (638). While additional larger studies are needed to elucidate whether ACCURE intervention can eliminate the disparities in cancer outcomes, 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 (636). Importantly, the ACCURE program was not only able to eliminate disparities among Black and White cancer patients, but also improved care and outcomes for all patients regardless of race.

Whether multifaceted interventions like ACCURE could be widely implemented across health care systems in the U.S. and utilized for different cancer types, and whether they can be effective in achieving health equity for all underserved

Fifty-four percent of non-Hispanic White patients with cancer **used video-based telehealth visits** from March to December 2020, compared to **38 percent of Black patients with cancer** (641).



populations, needs to be evaluated. However, the findings from ACCURE and other similar studies strongly support the importance of conducting innovative translational and clinical cancer research to determine how to eliminate disparities in cancer treatment and improve outcomes for all patients. Moving forward, all sectors must work together to ensure that everyone and not just a handful of patients benefits from the scientific and technological breakthroughs against cancer.

COVID-19 has led to a significant increase in the uptake of telehealth or telemedicine across health care including in cancer care (see sidebar on **What Is Telemedicine?**, p. 112) (7). The use of telemedicine by the elderly and patients with cancer has already had a widespread positive effect on the delivery of oncology services during the pandemic and has allowed patients to continue receiving cancer care, even when they are unable to visit a health care facility in person. However, studies have highlighted disparities in telehealth use for cancer care, indicating lower uptake or user satisfaction among those who are older, have low income, lack private insurance, or belong to racial or ethnic minorities (639,640). It is imperative that all stakeholders work together to ensure equitable access and uptake of telemedicine for all populations.

In summary, it is imperative that cancer researchers and physicians move past simply describing disparities to developing a more in-depth understanding of the interrelated factors that are associated with disparate cancer treatments and outcomes. A greater understanding of the underlying factors will lay the foundation for comprehensive, sustainable, population-based interventions that can potentially narrow treatment differences among different populations and improve outcomes for all patients. Furthermore, all scientific endeavors must be complemented with evidence-based policy initiatives that aim toward delivering guideline-concordant quality care for every cancer patient. All stakeholders committed to fundamentally changing the face of cancer must work together to address the challenges of disparities in cancer treatment and lead us toward a brighter future with health equity.

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 minorities and other medically underserved populations experience higher rates of adverse side effects, poorer quality of life, and higher financial toxicity resulting from a cancer diagnosis.
- ▶ Pediatric, adolescent, and young adult cancer survivors who belong to medically underserved populations experience increased financial toxicity, adverse side effects, and differences in the types of palliative care services they receive.
- ▶ To improve the survivorship experience for racial and ethnic minorities and other underserved populations, patient navigators, patient advocates, and culturally sensitive intervention/navigation programs need to be used.

A cancer survivor is anyone who has been diagnosed with any cancer. Cancer survivorship includes the time from initial diagnosis (often called the acute phase) until end of life (also called the chronic phase). With nearly 17 million cancer survivors in the United States as of 2019, many more people, such as **Lillian Frances Bernadette Kehaunani (Kehau) Matsumoto** (see p. 144), are living through and beyond their cancer. While these numbers are promising, medically underserved populations have higher rates of incidence and mortality for many types of cancers (17,642). With the projected increase in cancer survivors who belong to racial and ethnic minorities, disparities across the cancer continuum will potentially

widen, because both the numbers of U.S. individuals over the age of 65 and the diversity of the U.S. population are increasing (643-646).

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 the survivorship experience. These experiences include the physical, psychosocial, and economic adversities caused by a cancer diagnosis, such as the need for long-term follow-up care and the increased risk of secondary cancers, among others. 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. Outlining the challenges faced by these groups will help inform cancer care strategies and personalized recommendations for those who are more vulnerable, leading to better quality of life.

THE HONORABLE **Earl L. “Buddy” Carter**

U.S. Representative for Georgia’s 1st District

“As a pharmacist and cochair of the Cancer Survivors Caucus, I know how important it is to ensure that everyone has access to high-quality medical care. That’s why I fiercely advocate for rural and underserved communities, who face worse health outcomes due to a lack of preventative care. AACR is a great partner in the fight to increase cancer research and screenings, which will decrease these health disparities and save lives.”



Long-Term and Late Effects of Cancer Treatment

Cancer treatments can impact a patient’s physical and mental health. When a cancer survivor experiences adverse side effects that begin during treatment and continue afterward, these are called long-term side effects; nearly one-third of cancer survivors experience long-term side effects (647). Late-term side effects happen after the conclusion of treatment and can occur for the lifetime of the survivor. Side effects are unique to each individual and are dependent on multiple factors such as cancer type, treatment, physical health, and mental well-being. Recent studies are highlighting the disparities in both long- and late-term effects of cancer treatments in medically underserved populations. As evident from such studies, these groups experience lower rates

of fertility preservation (648), neurological challenges such as anxiety and post-traumatic stress disorder (PTSD) (433,649), lymphedema (650), metabolic disorders (651), diabetes (652), heart failure (653), cardiac dysfunction (654,655), recurrence of cancer (656,657), and development of new, secondary cancers (658,659) (see sidebar on **Phases of Cancer Survivorship**, p. 116).

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 for a heart attack—of eight and a half years in men and six and half years in women compared to those individuals who have never received a cancer diagnosis (660). Average excess heart age was shown to be higher in cancer patients who are NHB, less educated, and have lower income. Other cardiovascular conditions like thrombosis, which is a result of blood clots in veins and arteries, are more common in patients who are Black, regardless of cancer type (except myeloma) and can lead to pain and swelling as well as stroke and heart attack (661). Furthermore, several studies have shown disproportionately higher rates of cardiovascular disease in Black cancer patients (655,662-664), with one study of over 400,000 patients with breast cancer showing mortality related to cardiovascular disease occurring in 13.3 percent of NHB patients compared to only 8.9 percent of NHW patients (665). Further concerning are data indicating that NHB breast cancer survivors were 15 percent more likely to not adhere to cardiovascular medication schedules after treatment, increasing the likelihood of having a cardiac event (666).

One challenge faced by cancer survivors is infertility or the inability to conceive a child that can be a consequence of cancer treatments. This can occur in both men and women as a result of surgery on reproductive organs or effects of cancer medications on reproductive cells. In anticipation of impaired reproductive abilities, patients may choose to store reproductive material in a process called fertility preservation prior to cancer treatment. Rates of fertility preservation among patients with cancer is an area of active investigation, but emerging data show that rates vary among men and women, cancer type, treating institution, and age (667-669). Trends show, however, that women cancer survivors who were Black, poor, or lived in rural areas, had decreased rates of fertility preservation (648,670). Currently, cancer-focused organizations have guidelines that discuss fertility preservation and sexual health as an essential part of cancer management, especially in AYA populations (671). Furthermore,

Excess heart age, which is a measure of cardiovascular damage and the risk for a heart attack, was **9.2 years higher** among **women cancer survivors ages 50 to 59 who were non-Hispanic Black** compared to those who were non-Hispanic White (660).



THE HONORABLE Mark DeSaulnier

U.S. Representative for California's 11th District

“I am alive because of U.S. federal investments in cancer research. Thanks to this funding, the women and men who dedicate their lives to discovering and developing the kind of lifesaving cancer treatment I rely on can continue their critical work.



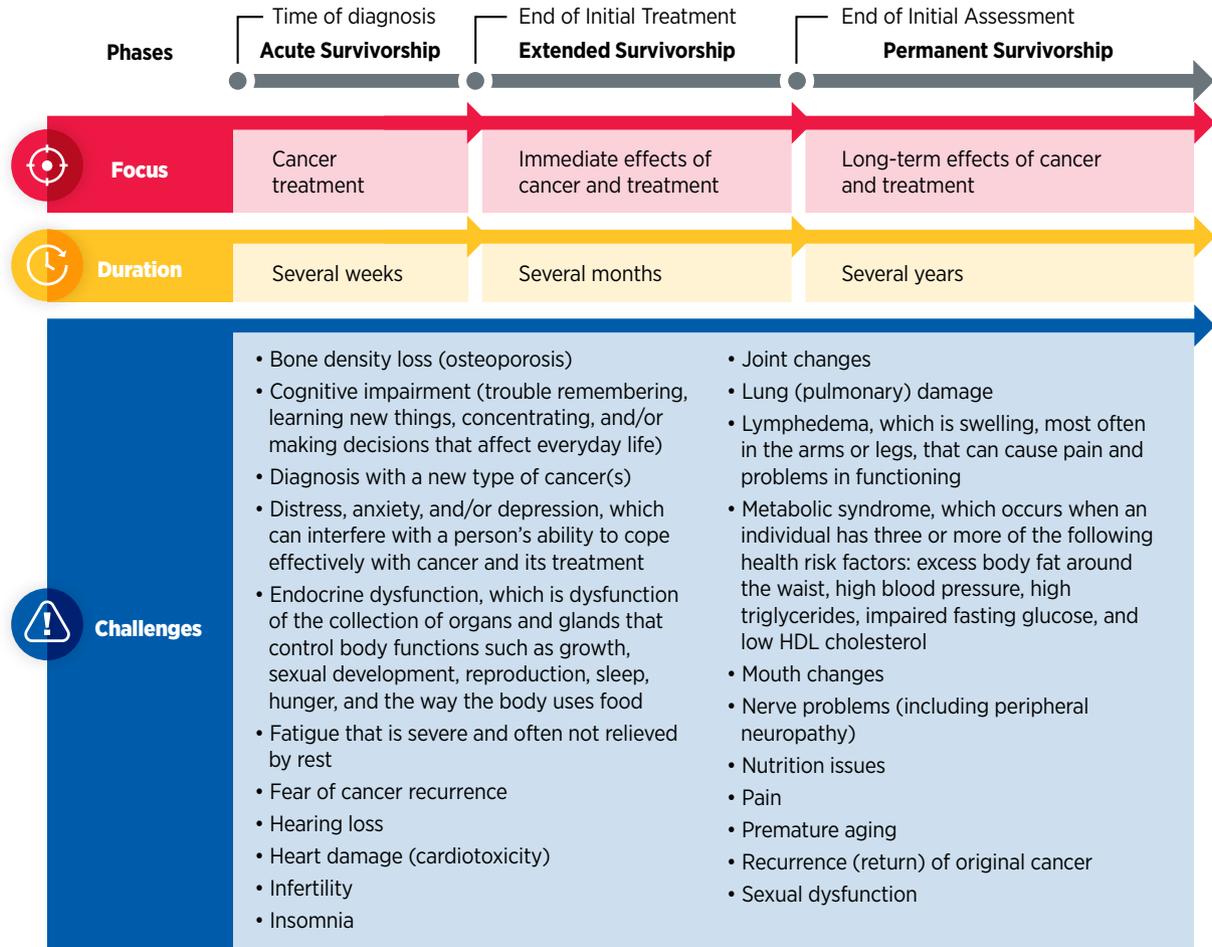
But we need to do more to address the disparities in our health care system and improve diversity in clinical trials, specifically, to ensure that new cancer treatments are effective across racial and ethnic groups. As a survivor and a Member of Congress, I'm proud of the progress we've made and look forward to continuing these efforts with the American Association for Cancer Research.”

as of February 2022, 10 states have mandates, and 12 more have active legislation, requiring insurance coverage of fertility preservation for patients facing infertility due to treatments such as anticancer therapies (672).

Lymphedema is a common long-term side effect among survivors of colorectal, endometrial, and breast cancer that results from damage to the lymphatic system after cancer surgery (673). This damage disrupts normal draining of lymphatic fluid, leading to accumulation in the surrounding tissue, resulting in painful swelling most commonly in the arms and legs (673-675). Black women, such as **Marlena Murphy** (see p. 120), are 3.85 times and Hispanic women 1.47 times more likely to develop breast cancer-related lymphedemas compared with White women (676,677). Limited access to medical resources including surgery, physical therapy, and medical equipment, coupled with barriers to maintaining a healthy diet and exercise to reduce swelling, increase lymphedema occurrence and severity and reduce quality of life (326).

Implementation of behavioral strategies that reduce the risk of developing adverse health conditions by promoting risk reduction strategies (e.g., smoking cessation and maintaining a healthy weight) in patients with cancer are important for reducing side effects of cancer treatment. Lifestyle programs to reduce obesity such as the obesity-related behavioral intervention trials (ORBIT) can help combat these risks and are being evaluated in specific vulnerable populations (678). Furthermore, activities such as walking have been shown to reduce obesity and improve health outcomes in cancer survivors (679). For example, one study has shown that exercise benefited the physical well-being of Black breast cancer survivors to a greater degree than White breast cancer survivors

Phases of Cancer Survivorship



Although all cancer survivors face challenges, survivors of cancer diagnosed during childhood, adolescence, and young adulthood (from ages <1 to 39) are particularly at risk for severe long-term and late effects. The Children's Oncology Group's "Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers" 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/>. Adapted from (2).

(680). Unfortunately, neighborhood walkability, (i.e. how much a neighborhood supports walking) is much lower in neighborhoods that are majority Black or have high poverty compared to those that are White and highly affluent, reducing opportunities for exercise among minority and underserved populations. (681). Because of the importance of the built environment to improving outcomes for patients with cancer, equal access to outdoor spaces is essential to improve health for everyone.

Health-related Quality of Life

Adverse physical effects are only a part of the impact that a cancer diagnosis can have on cancer survivors. Health-related quality of life (HRQOL) offers a comprehensive view of the

impact a disease and its treatment have on a patient's physical, functional, psychological, social, and financial well-being (682). HRQOL is becoming an important consideration in cancer care, the approval of new drugs, and prediction of long-term survival (683-685). Research has shown that HRQOL is lower for cancer survivors than individuals who have never had a cancer diagnosis or other type of chronic condition. Low HRQOL is exacerbated in cancer survivors who are pediatric (under 1 to 14 years of age) or adolescent and young adult (15-39 years of age) due to a range of factors (see sidebar on **Survivorship Disparities in Pediatric, Adolescent, and Young Adult Cancer Patients**, p. 119). Cancer survivors that 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 (686-688).

Women cancer survivors who identify as lesbian, gay, or bisexual report increased depression, anxiety, and PTSD compared to heterosexual women (689,690). A similar trend has been observed in gay men with prostate cancer, who reported worse mental health, greater fear of cancer recurrence, and general dissatisfaction with their medical care (691). The disparity widens if the individuals are also Black or Hispanic, who experience poor overall health and physical health, and poor activity, explained by sociodemographic and access-to-care factors, further highlighting the key influence of intersectionality in cancer health disparities (692). Sexual orientation is not a routinely discussed topic between physicians and survivors, which limits the ability to understand the cancer care needs of this population. There is increased interest in implementing standards to collect information on sexual and gender minorities (693). Routine assessment of sexual orientation would establish the need for sensitive and culturally appropriate health care discussions, foster healthy behaviors, and strengthen patient-physician relationships in addition to gathering data to assess cancer outcomes in sexual minorities (690). Research into the health of SGM populations is necessary to improve outcomes, with nationally funded offices such as the NIH Sexual and Gender Minority Office launched in 2016 (694) providing resources to more clearly understand these needs.

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 (695-698). Even when sociodemographic and psychosocial factors are accounted for, disparities in survivors' mental health remain (698). Continued evaluation of quality of life in medically underserved populations and assessment of the contributing factors such as income, education, and stress are important to identify avenues for intervention. For instance, Black cancer survivors report increased social support and spirituality (697) as well as communication among family members (699) compared to those who are White. These data underscore the importance of culturally targeted regimens to improve quality of life for cancer survivors (698,700). To understand the myriad factors that contribute to these disparities, the NCI funded the Detroit Research on Cancer Survivors (ROCS) study which will look at cancer progression, recurrence, mortality, and quality of life of 5,560 African American cancer survivors across three counties surrounding Detroit, Michigan. The study seeks to

identify how cancer type, genetics, social, psychological, and racial discrimination influence cancer survivorship in this group through interviews, medical records, and biospecimen collection; the study will also include survivors' family members, to understand how a cancer diagnosis affects caregivers (701).

Hispanic/Latino cancer survivors experience lower HRQOL compared to other racial and ethnic groups (702,703). Worse survival rates of colorectal, prostate, and breast cancers lead to this population experiencing higher psychosocial burden compared to NHW individuals (704,705). Furthermore, side effects of cancer treatment such as lymphedema may lower the physical and mental quality of life among these patients (706). Finally, food insecurity, a household-level economic and social condition of limited or uncertain access to adequate food is experienced by 26 percent of Hispanic/Latino households and is more prevalent in Hispanics/Latinos as well as other underserved minorities with cancer (707). Higher rates of food insecurity experienced by patients and survivors of cancer that are Hispanic/Latino as well as other underserved groups have been shown to lead to lower HRQOL compared with other races or ethnicities. Other research has shown that persistent food insecurity in cancer patients has led to lower treatment adherence (708). It is important for providers to screen for food insecurity in highly vulnerable groups in order to increase adherence to treatment, increase HRQOL, and improve patient outcomes.

Intervention strategies that address HRQOL in Hispanic/Latino populations, such as The National Latino Cancer Research Network and LIVESTRONG cancer navigation services patient navigation program, demonstrate the importance of providing culturally relevant patient navigation to improve quality of life in cancer survivors (705). Avanzando Caminos (Leading Pathways): The Hispanic/Latino Cancer Survivorship Study is a 6-year study that aims to recruit 3,000 survivors of breast, colorectal, kidney, lung, prostate, stomach, and cervical cancers to understand the social, cultural, behavioral, psychosocial, biological, and medical influences during cancer survivorship. Studies like these are important in understanding recovery, disease burden, and quality of life after treatment and the unique biological and social burdens experienced by Hispanic/Latino cancer survivors (709).

American Indian or Alaska Native (AI/AN) groups, which represent highly diverse communities with 560 federally recognized and 100 state tribes in the U.S., 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 (710-712). Due to diversity among AI/AN tribal groups, spirituality characteristics are highly individualistic, and AI/AN cancer survivors have higher spiritual quality of life compared to those who belong to other races and ethnicities (711). In one study of AN cancer survivors insight into navigating life after cancer, common themes pointed to the unique challenges survivors faced, such as balancing their responsibility to care for themselves while simultaneously embracing cultural values of selflessness (710), which necessitates the study and use of culturally relevant approaches to cancer care and patient

LGBT individuals with a history of gynecological cancers reported **increased depression** (31 percent versus 10 percent), **anxiety** (25 percent versus 7 percent), and **post-traumatic stress disorder** (13.6 percent versus 3.5 percent) compared to heterosexual individuals (690).



navigation such as those utilized by the Native American Cancer Survivors' Support Network (NACES) (712-714).

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 on **What Is Palliative Care?**). 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 (715). Despite the advantages of palliative care, there are disparities (716) in utilization by racial and ethnic minorities, SGM populations (717), and those living in geographically remote areas (718,719). Unfortunately, most studies examining palliative care in medically underserved populations focus on the end-of-life care and not care during cancer treatment or survivorship. Additional focus needs to be given to identifying the unique needs of cancer patients from medically underserved groups, developing innovative methods to overcome barriers, and implementing policies that provide equitable care (720) during the chronic phase of cancer survivorship (see sidebar on **Phases of Cancer Survivorship**, p. 116).

End-of-life care is one component of palliative care that places emphasis on improving patient comfort and quality of life through management of pain, psychological burden, and medical events. Unfortunately, there are disparities in access to appropriate end-of-life care services. For instance, over 70 percent of patients with multiple myeloma who are in the final stages of the disease develop bone lesions and related skeletal events, leading to pain. Palliative radiotherapy is an effective treatment to reduce pain. However, based on a recent study, Black patients were 13 percent less likely to receive this treatment compared to NHW patients (721). Management of care during terminal stages of cancer comes with tremendous mental and physical challenges for patients, caregivers, family, and friends. Current guidelines during end-of-life care favor highest quality of life over intense treatment interventions, which can be aggressive, invasive, and expensive (722-724). Unfortunately, it has been shown that patients from racial and ethnic minorities and those on Medicare or Medicaid that have metastatic cancers and are receiving end of life care are more likely to receive more aggressive, higher cost medical interventions that are not beneficial (724). More research is needed to understand why patients belonging to these groups are more likely to receive this type of care and to develop prospective interventions that can be implemented in the future.

Financial Toxicity

Financial toxicity refers to the detrimental effects experienced by cancer survivors and their family members caused by the financial strain after a cancer diagnosis. Estimates indicate that out-of-pocket

What Is Palliative Care?

Palliative care is specialized care that provides, if needed, an extra layer of support to patients with and survivors of serious illnesses, such as cancer, and their families and caregivers.



Palliative care is not the same as hospice care, because it can be 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 can be given in addition to cancer treatment or to those with no curative treatment options; palliative care given near the end of life when curative treatment has stopped is usually referred to as hospice care.

Palliative care 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 sleeping, and loss of appetite;
- practical challenges, such as navigating the health care system; and
- spiritual challenges.

Adapted from (2).

costs for cancer care are higher than for any other chronic illness (743), and at least 50 percent of patients with cancer report financial difficulties irrespective of cancer type or treatment regimen (744,745). These financial strains lead to financial coping behaviors including taking medications less frequently (e.g. skipping doses, taking less medication than prescribed, or not filling a prescription); taking on debt; reduced follow-up care; and decreased preventative services, all of which increase cancer-related mortality (746-750).

The burden of cancer disproportionately affects those who are poor or are living in poverty (see **Cancer Health Disparities Among Other Medically Underserved Populations**, p. 25). Additionally, chronic

Continued on page 122

Survivorship Disparities in Pediatric, Adolescent, and Young Adult Cancer Patients

Pediatric cancer survivors are those diagnosed with any cancer between ages less than one year to 14 years, while adolescent and young adults (AYA) are ages 15 to 39 years. With tremendous advances in treatments, 85 percent of AYA and pediatric survivors are alive at least five years after diagnosis in 2019 compared to only 58 percent of pediatric and 68 percent of adolescent survivors 40 years ago (725). Unique challenges faced by these groups include greater risk of late-term side effects, employment difficulties, financial toxicities, psychological challenges, secondary cancers, and reduced quality of life (726). These challenges are further compounded if children/AYA belong to a racial or ethnic minority or a medically underserved group. To improve long-term follow-up care and optimize quality of life it is essential to understand how disease burden differs by race/ethnicity, sexual orientation and gender identity, and geographic location.



Quality of Life

The disruptive nature of a cancer diagnosis on social development, psychological health, career development, and finances results in a lower reported quality of life among AYA cancer survivors compared to those who have never received a cancer diagnosis (731).

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 over the age of 40 years old, who have had more time to establish a career and build financial assets (738-740). Poverty in AYA survivors was associated with worse survival (741) while racial and ethnic minorities reported experiencing financial toxicity more often than Whites (742).

Palliative Care

Assessment of the multifactorial impact of cancer treatments on the psychosocial, physical, and financial challenges faced by AYA groups is important to identify areas of intervention (734). The unique needs of AYA cancer survivors come from their early stage of life and social development compared to older survivors, and present challenges for patient and provider (735).

Determinants of end-of-life care include many interrelated factors that are determined by location (treatment center, local resources, provider characteristics, and patient/caregiver preferences) and treatment (intensity of intervention, pain control, and timely referral), which contribute to patient well-being. One study that looked specifically at treatment intensity found that in AYA cancer patients, there was increased frequency of intense interventions, such as the use of mechanical ventilation or admittance to intensive care units, in racial minorities compared to non-Hispanic Whites (736,737). Current guidelines during end-of-life care favor highest quality of life over intense treatment interventions, which can be aggressive, invasive, and expensive, so understanding why these groups receive this type of care needs to be assessed to enhance quality of life and reduce overtreatment.

Side Effects

Experiencing cancer therapies early in life increases the likelihood of survivors developing late-term side effects including stroke, secondary cancers, neurodegenerative defects, cardiovascular disease, diabetes, and other pulmonary diseases compared to those without a cancer diagnosis (727-729). In a study examining childhood cancers, compared to non-Hispanic White patients, non-Hispanic Black and Hispanic patients had higher prevalence of obesity and diabetes, although these risks were not significant after adjusting for socioeconomic status and other factors (730). Studies such as this demonstrate how the social determinants of health impact survivors and influence different experiences of side effects.

Follow-Up Care

After conclusion of treatment, continuing to screen for subsequent cancers, managing side effects, and maintaining healthy behaviors like not smoking and staying physically fit, are important for health and well-being among survivors. There are differences in follow-up and long-term care observed depending on race/ethnicity. For instance in AYA cancer survivors, Black women are more likely to have a Pap smear and breast self-exam compared to White women, while Hispanic women were less likely to have a Pap smear even when adjusting for income, education, and health insurance status (732). Data also indicate that both Black and Hispanic adult survivors of pediatric cancer are less likely to smoke, and Black survivors are less likely to binge drink than their White counterparts (732).

An important component to accurate follow-up care and continuity of care is having a comprehensive knowledge regarding previous care. Survivors of childhood cancers who had less than a high school education were 6.7-fold less likely to accurately report their diagnosis or treatment (733). This deficit reduces a survivor's ability to seek and receive appropriate follow-up care and highlights the need for long-term solutions. For instance, the national implementation of an electronic health record is a secure way for a patient's medical history to be accessed by a qualified health care professional throughout the life of a survivor and reduces the risk of lost health data.



“

**Black people
love education.
That’s our
way to move
past so many
different
barriers.”**

Bringing Cancer Education to the Community as a Patient Advocate

In 2018, during her regular, monthly self-exam, Marlena Murphy felt a lump in her left breast. It was a wake-up call for the then 40-year-old mother from Union City, Georgia, near Atlanta. She then was scheduled for a mammogram, which was quickly followed by an ultrasound and biopsy and ultimately a breast MRI.

She was diagnosed with stage III triple-negative breast cancer—an aggressive subtype of breast cancer with twice the incidence rate in Black women compared to White women. Marlena’s cancer had spread into the surrounding lymph nodes.

“They said it was an aggressive form of cancer and things needed to be done pretty quickly,” she said. “It was shocking. I didn’t even know there were multiple types of breast cancer.”

Marlena began chemotherapy to shrink the tumor before undergoing lumpectomy to remove the tumor and lymphadenectomy to remove cancer-containing lymph nodes to prevent metastasis. To keep cancer from recurring, she underwent radiation therapy and began taking a different chemotherapeutic called capecitabine (Xeloda).

During treatment, Marlena was unable to work because of the side effects of her medications, the rigorous treatment schedule, and the development of neuropathy, a condition that causes weakness and pain in the hands and feet; this also made it hard for her to travel to and from medical appointments.

In addition to the physical impact, Marlena experienced a psychological toll.

“It was just mentally and emotionally draining, and you don’t even realize it’s going to take that toll. And it affected not just me; I have a daughter, so it definitely had an effect on her as well,” she said.

The treatments have also led to lasting side effects for Marlena, including lymphedema—the fluid build-up in soft body tissue from a blocked or damaged lymph system in the arms, as well as “chemo brain”—a term used to describe mental cloudiness and memory difficulties that may occur because of chemotherapy. Despite these challenges, Marlena is currently enrolled in graduate school. She says, “It’s funny because I didn’t even think I would be able to succeed in grad school because of the chemo brain, but I was determined. I’ve been doing really great.”

During her treatment, Marlena began to volunteer as an advocate, supporting other cancer patients in managing their illnesses. Following the conclusion of her treatment, Marlena became a patient advocate with two organizations to help educate her community about cancer incidence, research, and screening.

“Black people love education. That’s our way to move past so many different barriers. It’s also important that information comes from a trusted source,” Marlena said. “If a person is coming into our community that looks like us, which is key, telling us about the statistics regarding triple-negative breast cancer, we’ll listen.”

Marlena’s experiences as a patient and an advocate have shown her where gaps exist in community support, and sparked ideas about how policy makers can help.

“Funding toward education, funding to get out there in the community, educational workshops, providing money for transportation, and also protections for missed work. If a woman needs to go and get a mammogram, she should not be punished for missing work, because a lot of people might fear their job is on the line,” Marlena said. Marlena’s experience has also led her to talk to Black friends and community members about the importance of participating in clinical trials. Only about 7.3 percent of participants in U.S. phase I cancer clinical trials are Black, compared with 84.2 percent who are White. This long-standing disparity stems from a history of exploitation of minorities by the medical community.

“Often Black people think they’re going to put something that’s not supposed to be in us or take our blood or samples and make all of this money and not pay us,” Marlena said of the medical establishment. “Talking with people about clinical trials and showing them that there is a benefit, you’ll find more people wanting to get educated and participate in clinical trials. But it’s going to take a person who looks like us to say, ‘This is why you should do a clinical trial.’”

Currently, Marlena receives follow-up care that includes mammograms twice a year and routine visits with her oncologist. Recently, after feeling a small bump under her right arm—the opposite side of her original cancer—she utilized telehealth to contact her doctor. Ultimately, tests detected cancer cells.

“Hopefully I caught it fast enough and will not have to go through the extensive treatment that I had to do before,” she said.

Marlena has a powerful message for others: “When people hear cancer, they automatically think death sentence. It’s not, and I’m a firm believer in that.

“Keep fighting. I would say to patients and survivors to keep pushing forward; don’t just hear cancer diagnosis and think, oh, my life is over. No, it is not over. Your life may be just beginning; this may be just like me. It might be the thing that needs to push you forward to move toward your purpose.”

diseases such as cancer have consistently high costs of care and unfairly impact populations from low SES pushing them deeper into poverty. To that end, low-income Americans have difficulty paying for cancer care, even when insured. With increasing enrollment of many U.S. workers in high-deductible health insurance plans (751), which offer lower up-front costs in exchange for high deductibles (anywhere from \$2,500 to \$5,000) (752), even insured patients with cancer may struggle with debt related to treatment and follow up care. In fact, roughly 50% of Americans are not able to afford to pay their deductibles using savings (752). Unfortunately, the inability to afford treatments or accumulation of debt leads to the increased likelihood of bankruptcy among cancer survivors. Furthermore, finding a new job or returning to a previous job is more difficult after any cancer diagnosis (753,754), further straining survivors financially (755). Those who experience financial toxicity are also less likely to enroll in clinical trials (756,757), preventing access to potentially lifesaving treatments and furthering the low participation of medically underserved populations (see **Disparities in Cancer Clinical Trial Participation**, p. 88).

Individuals who belong to medically underserved groups including racial and ethnic minorities, those who live in rural areas, and/or those who are elderly are at a higher risk of experiencing financial toxicity as a result of a cancer diagnosis (143,759-761). Compared to 44.5 percent of NHWs, 68 percent of African Americans and 58 percent of Hispanics reported experiencing financial hardships one year after cancer diagnosis (762). In a study that examined the effects of cancer on financial wellness, both Black and Hispanic groups reported being negatively impacted financially twice as often as White individuals (759). This led to increased use of financial coping behaviors like skipping medications (747). Among rural populations, such as those residing in the Appalachian region of the eastern United States, two thirds of cancer survivors reported financial distress (763). Compared to NHWs, elderly Native Hawaiian or Other Pacific Islander were less likely to be able to pay medical bills, more likely to experience psychological distress about paying bills, and more likely to delay or forgo medical care due to cost (764).

Even after treatment, cancer survivors especially those from racial and ethnic minorities, experience difficulties in obtaining health and life insurance. Compared to NHWs, Black cancer survivors were three to five times more likely to be denied health insurance (765), while Hispanic cancer survivors were twice as likely to be denied health insurance (766). Lack of, or insufficient, health insurance coverage can further increase mortality among racial and ethnic minorities from side effects of cancer, such as cardiovascular disease, which is increased in NHB cancer survivors (767).

Cancer patients experience an **increase of anywhere from 100-2,400 percent** in their **out-of-pocket costs after diagnosis** compared to before diagnosis (758).



Thirteen percent of nonelderly patients with cancer pay **at least 20 percent of their income** on **out-of-pocket cancer expenses** (752).



Combating financial toxicity for cancer survivors must occur at multiple levels such as lowering of drug prices, implementation of financial planners, evaluation of high-deductible insurance plans, and practical decision-making about what treatments are necessary such as through the American Board of Internal Medicine's Choose Wisely campaign. This campaign helps patients choose treatment that has been proven to be effective and avoid unnecessary medical tests, treatments, and procedures. In order to navigate the financial burdens of cancer care, the use of patient navigators and patient advocates, and discussions with the health care team, will be necessary to reduce financial toxicity, which disproportionately affects medically underserved groups.

Adherence to Follow-up Care

The cancer experience does not end at the completion of the initial treatment plan, as 60 percent of adults diagnosed with cancer are expected to become long-term cancer survivors (768). Follow-up care for cancer survivors includes developing a survivorship care plan with the health care team, monitoring for signs of cancer recurrence, managing the long- and late-term side effects of treatments, and monitoring overall health. Due to the uniqueness of each individual, their cancer, and their treatment, the needs of each survivor are highly complex and variable, which creates challenges to effective follow-up care.

Following completion of the treatment, continuity of care is an important component of a successful transition to living with and beyond cancer. This includes the coordinated and uninterrupted care of a patient's physical, mental, and social needs. Fragmentation of care can lead to duplicated services which can increase costs; reduce patient-clinician trust and communication; and decrease a patient's satisfaction with care

Data show that **after a cancer diagnosis, only 40 percent of survivors go back to work.** Those more likely to go back to work are White, male, younger, and have a higher level of education (750).



and quality of life (769-771). As one example, a higher continuity of care benefited Black prostate cancer survivors over two years after the conclusion of treatment and was associated with fewer emergency room visits, lower cost, and lower all-cause mortality compared to White cancer survivors (772). The success of continuity of care immediately following treatment in improving outcomes, especially in medically underserved groups, highlights the importance of incorporating such regimens into the current standard of care.

Follow-up care can be delayed because of lack of insurance and out-of-pocket costs, transportation and language barriers, scheduling challenges, and childcare issues, especially in groups at risk of experiencing difficulties related to these factors such as those in rural communities or immigrants (774-776). Notably, breast cancer survivors who were Black reported increased difficulty in accessing follow-up care due to one or more of these factors at a higher rate than survivors who were White (777).

Those living in rural areas are less likely to continue follow-up care because of greater distance from large research hospitals, which are usually located in metropolitan areas. This creates barriers for rural residents, such as those living in Appalachia, Mississippi Delta, and Rocky Mountain regions of the United States; for AI/AN communities that live on reservations; or for those in rural communities with limited transportation options. Long travel times compounded by financial strains lead to a reluctance to travel to specialists, opting for local primary care providers who may lack experience and/or access to state-of-the-art facilities and adequate knowledge about frequency of surveillance testing for cancer recurrence (778). Transfer of care to primary care physicians from oncologists can often create gaps in follow-up care for doctors and patients (779,780). Recommendations to improve transfer of care among patients living in remote areas include the use of telehealth strategies. Although telehealth is highly effective, lack of access to high-speed Internet and computers can limit access to telehealth for medically underserved groups and could exacerbate disparities. Recruitment and retention of oncology providers in rural hospitals



In a study of **lung cancer survivors**, only **71 percent of non-Hispanic Black survivors were informed of the need for follow-up care** compared to 94 percent of non-Hispanic White survivors (773).

THE HONORABLE John P. Sarbanes

U.S. Representative for Maryland's 3rd District

"Cancer touches the lives of millions of Americans but many individuals, particularly people of color, do not have equal access to lifesaving cancer screenings, diagnoses, and treatments. COVID-19 underscored the dangers of a health care system that fails to address pervasive racial inequities. It is time for Congress to increase federal funding for research around cancer health disparities and advance legislation that addresses challenges across the continuum of cancer care for all communities."



through incentives, including loan repayments are also important ways to improve care in rural areas for patients after treatment (781).

Impact of COVID-19 on Disparities in Cancer Survivorship

The COVID-19 pandemic has had a more severe impact on mental and physical health of cancer survivors compared to those without a history of cancer (782-785). The pandemic has increased social isolation, financial stress, and food insecurity, as well as timely access to routine follow-up care. As many of these factors are commonly known mechanisms for disparities in cancer survivorship, COVID-19 has disproportionately affected cancer survivors belonging to racial and ethnic minorities and other underserved populations. Furthermore, Black, Hispanic, and AI/AN individuals have experienced a higher burden of COVID-19 compared to NHW individuals. These compounding factors place racial and ethnic minority survivors at risk of negative outcomes necessitating increased support for these groups through and beyond the pandemic. AACR has outlined many of these challenges in the *AACR Report on the Impact of COVID-19 on Cancer Research and Patient Care* with a Call to Action to bolster access to health care services, like telehealth, which has been less accessible to minorities but can potentially address health care disparities (786,787).

Paving the Way for Health Equity in Cancer Survivorship

The disparities in various aspects of cancer survivorship as highlighted in this chapter necessitate a comprehensive

In a study of **rural cancer survivors in Missouri**, **62 percent** of survivors reported receiving **advice about follow-up care** vs. 78 percent of urban survivors (779).



multidisciplinary approach to address the deficiencies experienced by underserved groups. This includes researchers, health care systems, professional organizations, insurance groups, and care teams working together to meet the specific needs of the community and the patient.

Community-centered approaches that meet patients where they are, are required if we are to better understand the challenges faced by cancer survivors who belong to racial and ethnic minorities and underserved populations. Patient advocates such as **Sandra Morales** (see p. 82), **Marlena Murphy** (see p. 120) and **Lillian Frances Bernadette Kehaunani (Kehau) Matsumoto** (see p. 144), who themselves are often cancer survivors and support those living with and through cancer, are uniquely positioned to bridge a critical gap between survivors and researchers. Patient advocates have immense social capital within their communities because they understand the unique needs and challenges within the community; this 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. Organizations such as Turning Point and Guiding Researchers and Advocates to Scientific Partnerships (GRASP) bridge the gap by bringing together all stakeholders including researchers, advocates, and survivors. Utilization of patient advocates is necessary to reduce health disparities, voice community concerns, increase research of underserved groups, increase survival, increase quality of life, and reduce financial strain on survivors.

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 (788-790). In fact, the first patient navigation program in the U.S. was designed specifically to address racial disparities of breast cancer screening and follow-up in Black women, which led to a 70 percent increase in 5-year survival in this group (791,792). Recognition of the benefits of patient navigators on health outcomes has led to legislative efforts to increase access to patient navigation including the Patient Navigation Outreach and Chronic Disease Prevention Act in 2005 and the Patient Protection and Affordable Care Act in 2010, the latter of which requires each state health insurance exchange to establish a navigator program.

To further increase the use of patient navigators, the American College of Surgeons' Commission on Cancer (CoC) required all organizations accredited by the CoC to have a patient navigation program by 2015. Despite this requirement, there is high variability in the organization and training of patient navigators in the United States, leading to heterogeneous navigation (793); for instance, navigators can be classified as either health care or non-health care workers leading to confusion surrounding their credentials. Additionally, there is often confusion about coverage and financial benefits of patient navigator services through Medicare, Medicaid, and private/commercial insurers (794). Broad implementation of patient navigators to assist all patients with cancer will require standardization guidelines and population-specific training, support from government and health care providers, and more universal access through implementation of telehealth (see **Sustainably Supporting Patient Navigators and Community Health Workers**, p. 147).

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 an approach 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 (795).

Overcoming Cancer Health Disparities Through Diversity in Cancer Training and Workforce

IN THIS SECTION, YOU WILL LEARN:

- ▶ Racial and ethnic minorities 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.
- ▶ Improved support from medical research mentors and peer groups is needed to support diverse researchers and address cancer health disparities.

Complex, interrelated factors contribute to cancer health disparities (see **Factors That Drive Cancer Health Disparities**, p. 29). Although the overall health care workforce has become more diverse (796), diversity in the cancer research (797) and care workforce (798)

still lags behind trends in the general U.S. population. A proposed strategy to overcome cancer health disparities and achieve health equity is to diversify and support the cancer research and care workforce (799). Diversity is generally defined as 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 (90a). In June 2021, Executive Order 14035 “Diversity, Equity, Inclusion, and Accessibility (DEIA) in the Federal Workforce” established a working DEIA framework for the federal government (800). The identified DEIA priorities and guidance seek to increase representation and promote fair treatment of people regardless of race, ethnicity, sexual orientation, gender identity, physical ability, religious beliefs, or community background. This federal initiative can be applied to the Science, Technology, Engineering, Mathematics, and Medicine (STEMM) career pathway that prepares current and future students and health care trainees for successful careers in cancer research and care. This chapter details the changing landscape of training and workforce diversity; describes efforts to sustain the cancer research training pool; and discusses approaches to develop a supportive health care workforce that reflects community diversity.

THE HONORABLE **Marilyn Strickland** U.S. Representative for Washington’s 10th District

“Every stage of our research process is in need of expanded diversity, from more scientists and researchers of color to increased representation in clinical trials to ensuring that all communities have access to critical cancer screening technology. I am proud to cosponsor the Medicare Multi-Cancer Early Detection Screening Coverage Act to ensure that Medicare beneficiaries will have access to this potentially lifesaving technology, and have urged the Administration to make it more affordable and accessible to minority populations. I am also proud to cosponsor Rep. Payne’s bill to allow Medicare to cover approved blood-based tests for colorectal cancer and increase screening in underserved communities.”

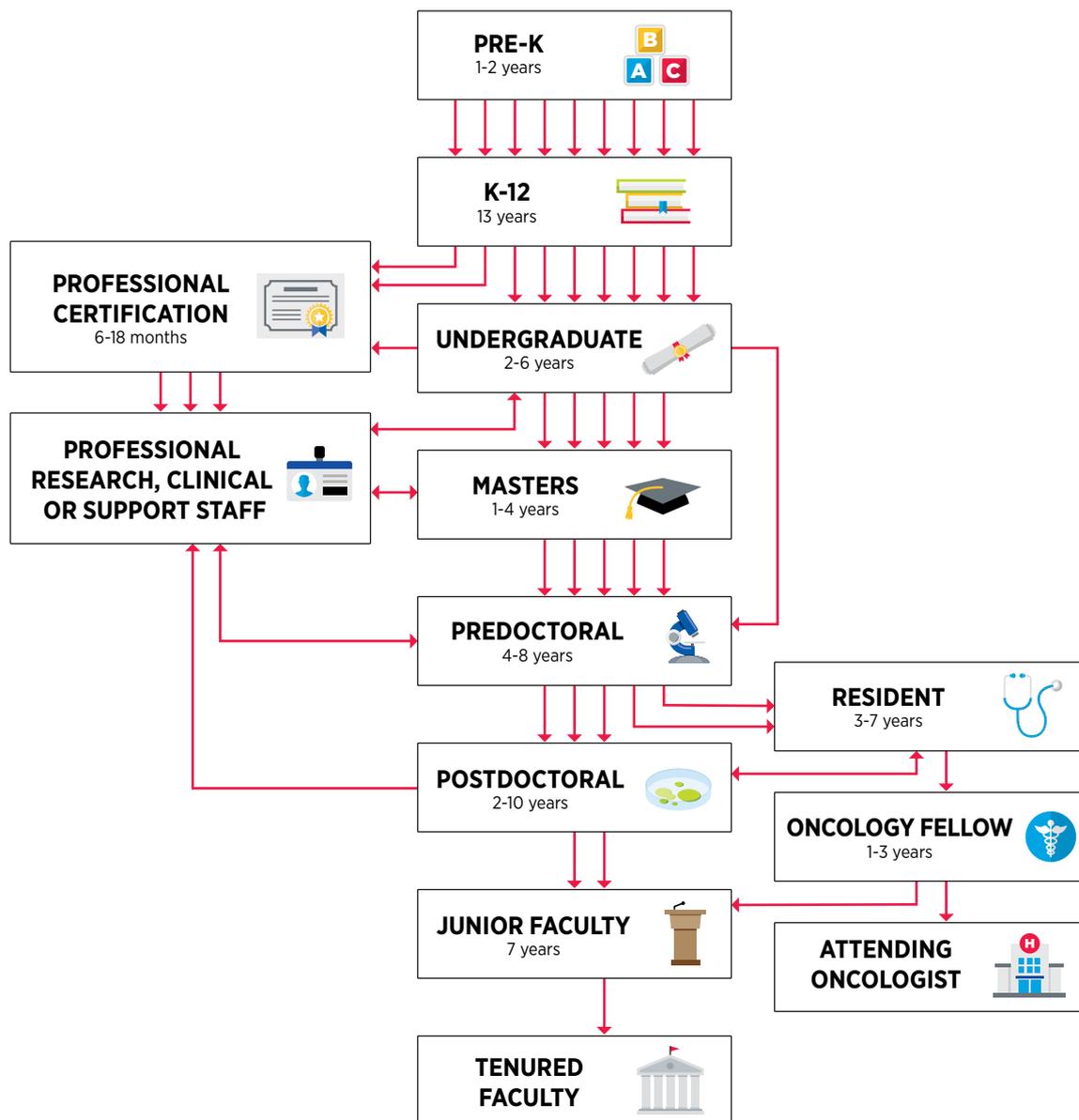


Science, Technology, Engineering, Mathematics, and Medicine Educational Landscape

The traditional academic pipeline—starting with K-12 education, through undergraduate and graduate programs, followed by postdoctoral or clinical training, and leading to an independent

FIGURE 18

STEMM pathway



There are variations in experiences and reasons for entering the STEMM workforce. Expanding the traditional academic pipeline (K-12 education, undergraduate and graduate programs, postdoctoral or clinical training,

independent investigator or attending oncologist) provides opportunities to address student needs and understand the decision to continue or depart from the STEMM pathway.

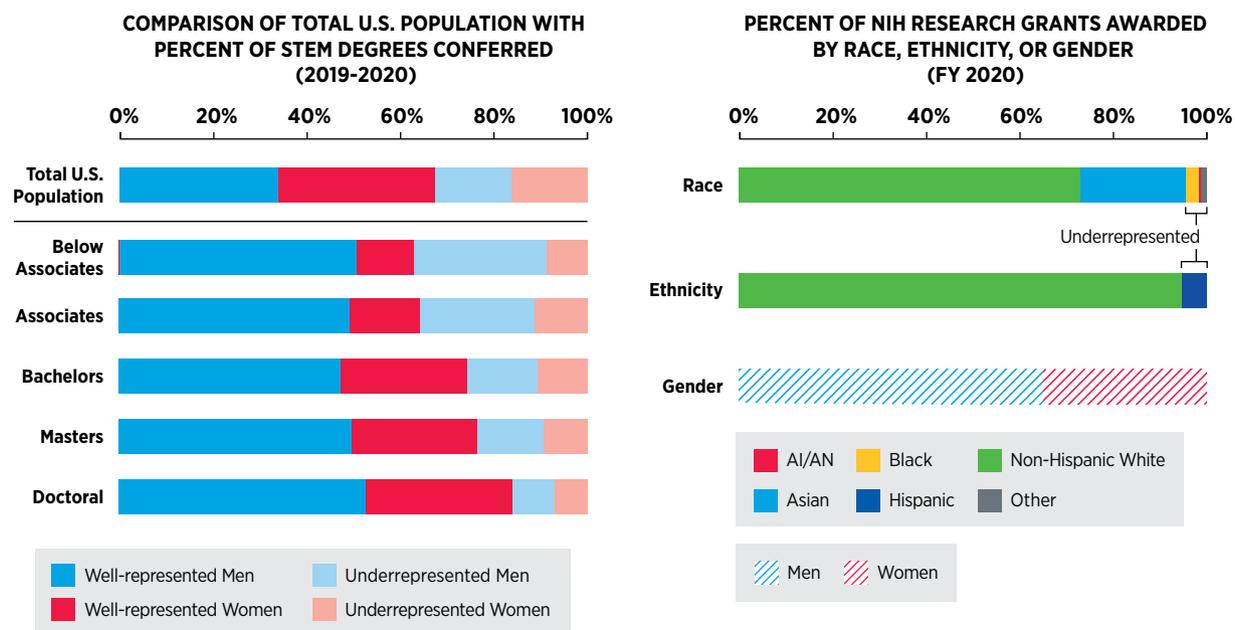
investigator (including physician-scientist) position—is not linear. For many, there are different pathways that lead them to join the cancer research and care workforce (see **Figure 18**).

A diverse cancer research and care workforce provides many benefits, including: increased quality of care and patient satisfaction for medically underserved groups (801); enhanced

communication between patients and providers (802,803); greater trust and enrollment in clinical trials (522,804); and high-quality jobs for a larger proportion of the population. For example, Black and Hispanic women working with patient navigators who spoke the same language and were from similar racial and ethnic backgrounds received official cancer diagnoses

FIGURE 19

Representation in the Biomedical Sciences



(Left) Bar graphs indicate percent of the U.S. population and postsecondary degree graduates in the 2019-2020 academic year from Well-represented or Underrepresented races and ethnicities among men and women. Well-represented groups include non-Hispanic White and Asian individuals; Underrepresented groups include Black/African American, Hispanic, Native American and Alaska Native, Pacific Islander, and multiracial individuals. Degree award data were

compiled from the U.S. Department of Education, National Center for Education Statistics, Integrated Postsecondary Education Data System. Total U.S. population data were compiled from the 2020 Census.

(Right) Bar graphs indicate the percent of principal investigators awarded NIH research grants in FY 2020 who self-identified as the indicated races, ethnicities, and genders. Data were compiled from the *NIH Research Portfolio Online Reporting Tools, NIH Data Book*.

sooner following an abnormal breast or cervical cancer screening (805). However, achieving diversity and promoting fair treatment regardless of identity are persistent challenges across the cancer research and care workforce, especially at senior leadership levels (see **Figure 19**) (806,807).

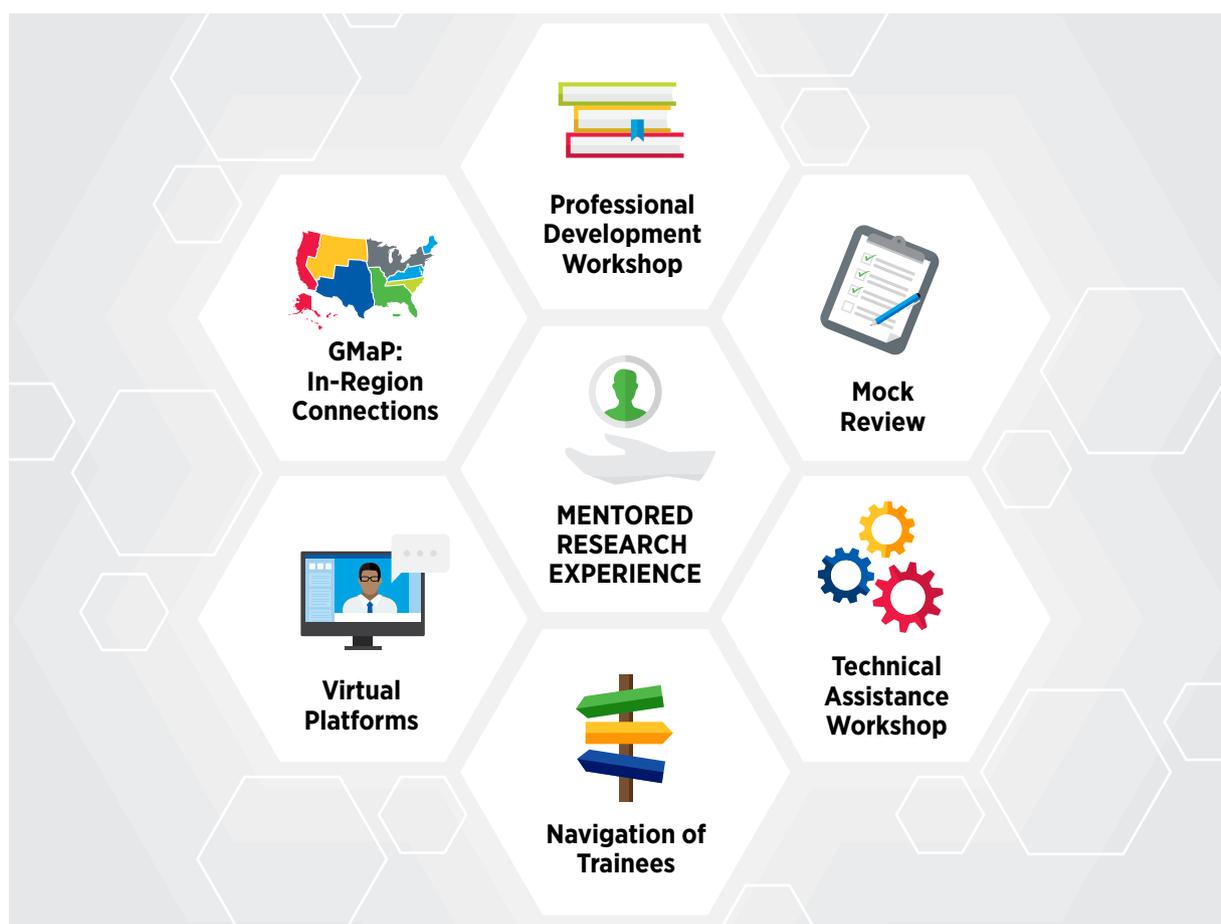
Exploring underlying causes for the loss of a significant number of underrepresented minorities (URM: Black, Hispanic, Native American and Alaska Native, Pacific Islander, and multiracial individuals) from the STEM career pathway and identifying effective strategies to mitigate these factors are essential for creating a more inclusive cancer research workforce (see **Figure 18**, p. 126). Every step along the STEM career pathway poses different structural challenges that disproportionately impact trainees. For example, some of the greatest predictors of scientific achievement disparities for Black and Hispanic children in grades three through eight in the United States are (808,809): gaps in general knowledge in kindergarten and first grade; low socioeconomic status; and attending schools with

limited resources. Native Hawaiian or other Pacific Islander children face unique challenges with the STEM career pathway due to geographical isolation, scarcity of STEM educators, and a cultural focus on fulfilling the immediate needs of their families and communities (810). Decades of underinvestment in K-12 education within predominantly racial and ethnic minority communities have contributed to lower graduation rates, lower availability of college-level classes in high school, and lower standardized test scores (811-813). These factors contribute to fewer URM students enrolling in undergraduate STEM programs.

Recognizing these challenges and cultivating early childhood interests in STEM establish a strong educational foundation. This supports the feasibility of becoming a productive and impactful cancer researcher or health care provider in the future. Tailored approaches to increase diversity and promote fair treatment are needed as structural challenges associated with early childhood STEM education differ between specific

FIGURE 20

CURE and iCure Provide an Ecosystem of Support



The CURE and iCURE programs provide holistic support to underrepresented students and scientists along their career pathways. Successful career progression requires multifaceted efforts from mentors, region-based outreach, resource sharing, and trainee engagement.

groups and settings. These examples highlight the importance of introducing STEM concepts and training in early childhood and supporting the professional development of K-12 teachers in low-resource areas (814).

A robust ecosystem of flexible, inclusive, and individualized support is needed to foster diversity in STEM pathways beyond high school. There are disproportionately fewer STEM bachelor's degrees earned by racial and ethnic minorities (see **Figure 19**, p. 127), which can be attributed to educational inequality, reported/perceived discrimination, disenchantment with the original career plan, or changing career plans but remaining in biomedical science (815).

The NCI CRCHD supports URMs from middle school through the junior tenure-track faculty positions with the Continuing Umbrella of Research Experiences (CURE) program (see sidebar

on **NIH and NCI Initiatives to Promote Workforce Diversity**, p. 130). CURE invests in trainees and scientists from groups typically underrepresented in biomedical research by employing a holistic approach that promotes mentoring, professional support, and career skills building, all surrounding the centerpiece of individually mentored research experience. In addition, the Intramural Continuing Umbrella of Research Experiences (iCURE) brings undergraduate students, postbaccalaureate and post-masters degree individuals, graduate students, and postdoctoral fellows into the NCI research community and supports mentored research experiences. iCURE particularly encourages the participation of individuals from underrepresented populations and aims to further NCI's interest in diversity (see **Figure 20**).

Additional programs, such as the Science, Education, Partnership Awards (SEPA) Program from NIH's National

Institute of General Medical Sciences, facilitate collaborations between K-12 teachers and medical researchers to provide early opportunities to engage with medical research (816). A SEPA program at the University of Arizona, Q-Cubed, included 787 high school students from a historically underserved community and 98 percent of the participants went on to attend college between 1987-2021. In comparison, approximately half of high school graduates in Arizona went on to attend college in 2018 (817). Expanding upon these excellent initiatives carries the potential to improve equity in early-life educational opportunities. However, additional large structural changes are necessary to fully develop the potential of children from historically marginalized communities.

Diversity in the Basic and Translational Cancer Research Workforce

Building a diverse workforce requires understanding and addressing the underlying structural challenges that continue to perpetuate inequity in STEM training and career progression. PhD students and postdoctoral fellows are the foundation of the cancer research workforce, as they conduct the vast majority of basic and translational experiments. Recruiting diverse graduate school applicants from Minority-Serving Institutions has the potential to promote a diverse graduate student body (818). Retaining URM scientists is also critical. Studies show that URM graduate students and scientists receive less mentoring support than well-represented peers (819,820). While academia primarily incentivizes scientists who propose innovative grants and succeed in publishing scientific articles, many successful senior scientists may benefit from additional training in mentorship which would subsequently help support the professional development of their trainees. In fact, incentives and compensation for excellence in mentorship as well as formal training programs have been shown to increase retention of URM scientists (820). Providing additional institutional supports, such as mental health and childcare services, can also improve retention of graduate students and postdoctoral fellows in academia (821,822). Less than 15 percent of life science PhD graduates receive a tenure-track research position within five years of graduation (821), which emphasizes the need to reform graduate education to support and prepare students for a variety of fulfilling career options. The challenge of finding a tenure-track position has been made even more difficult by the COVID-19 pandemic forcing many universities to freeze hiring new faculty members (7). While these general issues affect all scientists, URM scientists navigate structural racism (see **Collaborative Resources to Build Health Equity Partnerships**, p. 135), have a greater likelihood of being first-generation college students, and infrequently receive financial support from family members during tenuous career transitions. These hurdles exacerbate difficulties inherent within the academic job market.

A key milestone that establishes a scientist as an independent investigator is attaining a NIH Research Project (R01) grant. It is concerning that the challenges described in this chapter hinder DEIA efforts and independence across STEM pathways (see **Science, Technology, Engineering, Mathematics, and Medicine Educational Landscape**, p. 125). Early-stage women and/or URM researchers received a disproportionately low number of R01 grants in fiscal year (FY) 2020 when compared to male scientists from well-represented groups (823). A key contributing factor is that start-up packages—money and resources provided by institutes to new faculty for starting their own laboratories—offered to women scientists are on average 60 percent less than those offered to men (824). Furthermore, disproportionate dependent-care responsibilities, greater time spent mentoring trainees, and lower pay contribute to female scientists leaving academic research positions more frequently than men (825,826). These issues highlight the need for focused efforts and funding mechanisms to support women and URM scientists in order to increase diversity in the workforce (826a).

NIH and NCI have recently created several initiatives to support URM scientists in the research workforce (see sidebar on **NIH and NCI Initiatives to Promote Workforce Diversity**, p. 130). As one example, the UNITE initiative was established with the goal of ending structural racism across NIH and the NIH-supported scientific community. To improve equity, there needs to be continued focus on retaining every promising scientist, addressing bias in the grant review process, offering flexibility in career status and grant timelines, fostering innovation in recruitment strategies, and using formalized mentor training programs to improve mentorship skills and interaction with mentees (806,827).

NCI and NIH have created several funding mechanisms to directly support URM ESIs. For example, the K01, K99/R00, and R21 grant mechanisms support postdoctoral early-career scientists in gaining their independence. Some K01 and R21 grants in particular are focused on supporting URM scientists (828,829). This year, NIH also announced new administrative supplements for mentors committed to training URM scientists (830). Starting in 2022, scientists with current NIH-funded grants supporting mentorship and training activities can apply for up to \$250,000 in direct cost support to fund research projects and career development for trainees. In addition, NIH institutes and centers issued 171 student loan repayment awards in FY 2020 totaling almost \$13 million for investigators involved in health disparities research (831). Focused approaches to fund ESIs and women researchers from underrepresented groups should be a priority, as this could improve recruitment and retention within the cancer research workforce (see sidebar on **NIH and NCI Initiatives to Promote Workforce Diversity**, p. 130). Robust, sustained, and predictable funding increases for NIH and NCI are critical to ensure that these programs continue.

NIH and NCI Initiatives to Promote Workforce Diversity



NCI EQUITY AND INCLUSION PROGRAM (EIP)

The EIP, which is overseen by the NCI Equity Council and five working groups, strives to:

- Increase the diversity of the cancer research workforce.
- Build a more equitable and inclusive NCI community.
- Address cancer disparities and advance health equity.

EARLY INVESTIGATOR ADVANCEMENT PROGRAM (EIAP):

With the support of its Equity Council, in December 2021, NCI launched EIAP to facilitate the advancement of scientists from diverse backgrounds to become independent investigators.

The cancer research enterprise needs a continuous flow of talent through the research career pipeline to thrive. One critical juncture is the transition from junior investigator to independent investigator. EIAP aims to enhance professional skills, guide preparation of an R01 grant application, provide access to a mentoring and peer network, and grow a community of emerging independent investigators from diverse backgrounds.

Each year, EIAP will support the professional and career development of a cohort of eligible and qualified Early-Stage Investigators (ESIs) and New Investigators from institutions across the country. Cohort members will provide peer support for each other both during and beyond their participation in the program.

FACULTY INSTITUTIONAL RECRUITMENT FOR SUSTAINABLE TRANSFORMATION (FIRST):

NIH launched the FIRST program with the goal of developing cultures of inclusive excellence—scientific environments that can cultivate and benefit from a full range of talents—at NIH-funded institutions. Inclusive excellence hinges on enhancing diversity and inclusion, as well as institutional culture change. Fostering inclusive environments that cultivate and benefit from a full range of talents is not only essential for the quality and impact of science, but also improves stewardship of federal funds to ensure that the most talented researchers are recruited, supported, and advanced to become competitive research investigators.

CONNECTING UNDERREPRESENTED POPULATIONS TO CLINICAL TRIALS (CUSP2CT)

The CUSP2CT program will implement and evaluate multilevel and culturally tailored outreach and education interventions with the primary goal of increasing referral and, ultimately, accrual of underrepresented racial and ethnic minority populations to NCI-supported clinical trials. CUSP2CT will address cancer health disparities through a network of local multidisciplinary and integrated partners that include community health educators, lay health advisors, community members, health care providers, and researchers working in coordination to educate and refer racial and ethnic minority populations to NCI-supported clinical trials and increase provider awareness about racial and ethnic minority participation in NCI clinical trials.

PROFESSIONAL ADVANCEMENT VIRTUAL ENGAGEMENT SERIES (PAVES)

Launched during the pandemic, this CRCHD-hosted seminar series is held monthly and offers professional development for both intramural and extramural grantees and trainees. From networking with each other to learning about cancer systems biology or transitioning to faculty positions, the experiences and information are fruitful.

TRAINING NAVIGATION

CRCHD uses a Training Navigation model to facilitate and increase the successful entry of underrepresented scholars into the **Continuing Umbrella of Research Experiences (CURE)** training pipeline and to transition existing CURE scholars through the CURE pipeline to career independence. Training Navigation also aims to provide career development support for the advancement of early to mid-career and tenured investigators to develop the skills necessary to obtain R-type funding and achieve career advancement.

The Training Navigation model has also been leveraged by the **Geographic Management of Cancer Health Disparities Program (GMaP)**. GMaP is a national program designed to enhance the recruitment and career/professional development of underrepresented investigators, trainees, and students; communication and dissemination; and evaluation, as part of building region-based “hubs” for the support and efficient management of cancer health disparities research, training, and outreach. GMaP-supported activities include addressing questions from potential applicants and GMaP Regional Coordinating Directors, performing NCI outreach activities, promoting new and existing funding opportunities, hosting/supporting webinars and workshops, connecting scholars with potential mentors and regional training opportunities, and identifying existing NIH career development/grantsmanship resources and available tools. Tracking investigators as they mature professionally is important for career progression and growth.

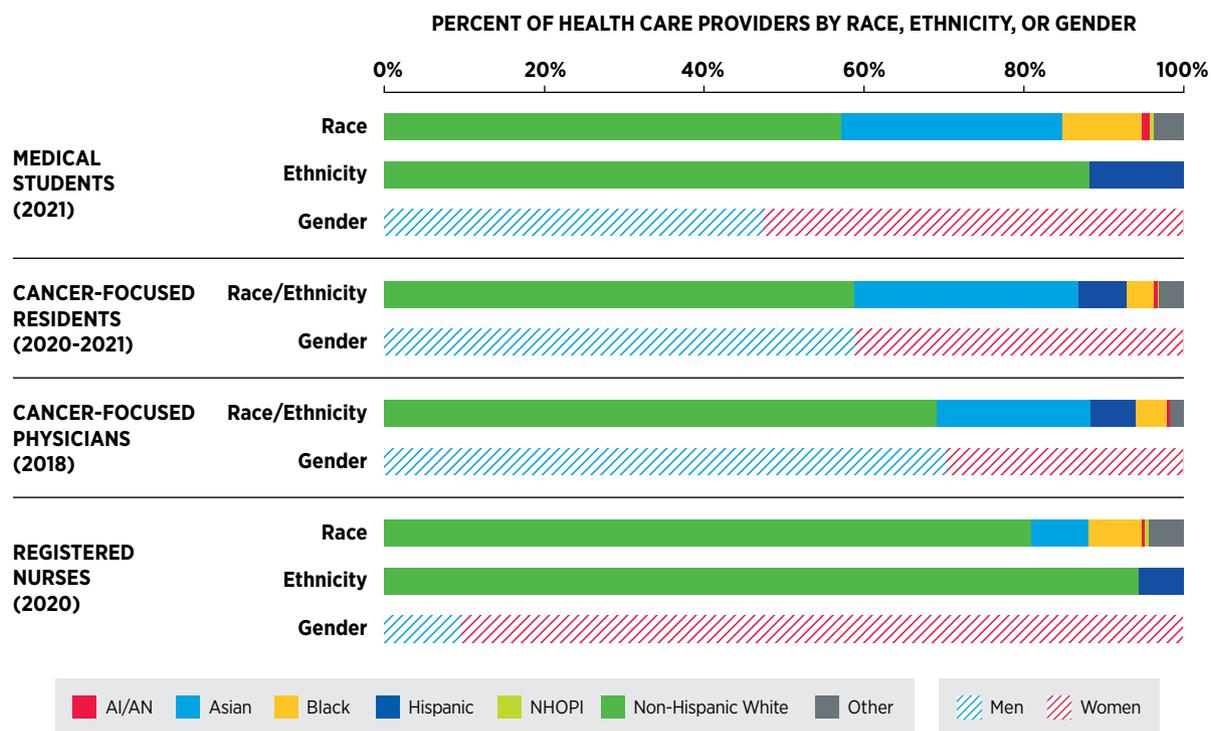
UNITE INITIATIVE

UNITE is comprised of five committees with separate but coordinated objectives on tackling the problem of racism and discrimination in science, while developing diversity and inclusion across the biomedical enterprise:

- **Committee U:** Understanding stakeholder experiences through listening and learning
- **Committee N:** New research on health disparities, minority health, and health equity
- **Committee I:** Improving NIH culture and structure for equity, inclusion, and excellence
- **Committee T:** Transparency, communication, and accountability with our internal and external stakeholders
- **Committee E:** Extramural research ecosystem changing policy, culture, and structure to promote workforce diversity

FIGURE 21

Representation in Cancer Care



Bar graphs represent percent of medical students, cancer-related medical residents, cancer-related physicians, and registered nurses who identified as the indicated races, ethnicities, and genders.

Medical student data were compiled from the *Association of American Medical Colleges (AAMC), 2021 Fall Applicant, Matriculant, and Enrollment Data Tables*.

Resident data were compiled from the *AAMC 2021 Report on Residents*, and include residents who self-identified as training in the following specialty categories: Colon and Rectal Surgery, Hematology, Hematology and Oncology, Oncology, Molecular Genetic Pathology, Nuclear Medicine, Gynecologic Oncology, Musculoskeletal Oncology, Cytopathology,

Hematology (Pathology), Pediatric Hematology/Oncology, Radiation Oncology, Independent or Integrated Interventional Radiology, Complex General Surgical Oncology, Thoracic Surgery, Diagnostic Radiology/Nuclear Medicine/Nuclear Radiology, Internal Medicine/Medical Genetics, Pediatrics/Medical Genetics.

Physician data were compiled from the *AAMC Diversity in Medicine: Facts and Figures 2019* report, and include the following specialty categories: Anatomic/Clinical Pathology, General Surgery, Hematology and Oncology, Radiation Oncology, and Radiology.

Registered nurse data were compiled from the *2020 National Nursing Workforce Survey*.

Diversity in the Cancer Care Workforce

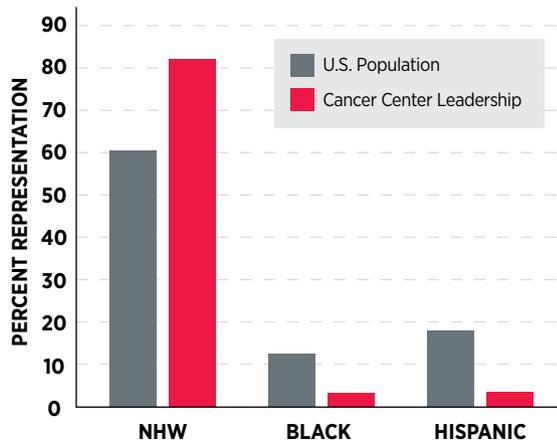
PHYSICIANS

Similar to the cancer research workforce, diversity in the cancer care workforce does not reflect the patient population, especially at higher career stages (see **Figure 21**). Failure to retain diverse physicians in the training pathway contributes to staffing

shortages. It is estimated that the United States will have 2,250 fewer oncologist physicians in 2025 than needed to maintain the same ratio of providers to patients as there was during 2014 (832). Approximately 21 percent of 13,146 U.S. oncologists were over the age of 64 years in 2021 (833), suggesting a significant proportion may soon retire. It is concerning that only 577 new oncologists graduated U.S. oncology fellowship programs in 2021 (833). This shortage of oncologists has an immediate impact on the ability to access and deliver cancer care in underserved communities, particularly in rural areas; 32 million Americans live in rural



A recent assessment of **racial and ethnic representation in leadership positions at National Cancer Institute-designated Cancer Centers** indicated **significant underrepresentation of minorities** compared to their census populations (838).



counties that do not have any oncologists, which is an important missing aspect of geographical diversity in the workforce (834). These shortages lead to long working hours and high burnout rates (835), which impact access to care as well as quality of care. One of the most significant predictors of where physicians will start their careers is where they train; almost half of physicians continue to practice in the state where they conducted a residency, and more than two thirds of physicians continue to practice in the state if they attended medical school and conducted a residency in that state (836). Therefore, providing increased residency and fellowship positions in rural areas is critical to grow the rural workforce, as well as establishing new medical schools in historically underserved areas. It is notable that Alaska, Montana, and Wyoming do not have medical schools to train physicians. Enhancing federal student loan repayment programs or other financial incentives for physicians to work in rural areas or urban communities that are medically underserved could also improve access to health care by building the local workforce (837).

It is encouraging that the matriculating class of medical students in 2021 was the largest and most diverse ever (839), with Black first-year medical students comprising 11.3 percent, Hispanic students comprising 12.7 percent, and Asian students comprising 26.5 percent of the matriculating class. Additionally, women comprised 55.5 percent of the matriculating class. The increase

of first year medical students from diverse populations aligns with the lifelong efforts of **LaSalle D. Leffall, Jr., MD** (see p. 134). Mentoring and training future physicians from diverse backgrounds is key to addressing cancer health inequities. However, a critical bottleneck in training more physicians is the congressionally mandated limit on the number of Medicare-funded medical residency positions following medical school (840,841). While some states and universities fund a few medical residencies, Medicare funds the vast majority. This means that thousands of highly capable medical school graduates may not be able to ultimately practice medicine and must find nonclinical jobs (842,843). As part of the FY 2021 federal appropriations package, Congress provided funds for 200 additional residency spots per year for five years, with a focus on areas with physician shortages (844); this was the largest increase to Medicare-funded residency spots in 25 years. Further lifting the cap on Medicare-funded residencies would enable the training of additional oncologists and other physicians, including URM physicians. In addition, continued efforts from all stakeholders are needed to ensure a diverse and representative oncology residency workforce, considering recent evidence of continued disparities in URM representation within oncology training programs (798).

Efforts from professional societies are also important for diversifying the health care workforce. The National Medical Association provides scholarships for African American students to attend medical school (845). In 2021, the American Medical Association (AMA) unveiled a new strategic plan to build equity and reconcile the organization's own history with policies that exacerbated structural racism throughout health care (846). AMA's plan includes working with medical schools to develop more inclusive recruitment policies and advocating for funds to create new medical schools at Historically Black Colleges and Universities (HBCUs), Hispanic-Serving Institutions, and Tribal Colleges and Universities.

PHYSICIAN-SCIENTISTS

Physician-scientists fill a unique niche in cancer research and care due to their dual training in both science and medicine. However, this valuable skill set means that physician-scientists have great

Racial and ethnic diversity of the U.S. radiation oncology and medical oncology faculty has increased over the past



five decades. However, this growth has **not kept pace with that of the U.S. population**, particularly for individuals designated as underrepresented in medicine (847).

demands on their time and may not have adequate room in their schedules to conduct research to develop successful grant proposals. Due to similar issues facing women in basic cancer research described earlier, women physician-scientists are 30 percent less likely than male physician-scientists to receive an R01-equivalent grant within eight years of joining a postdoctoral program. Furthermore, URM physician-scientists are 17 percent less likely than NHW or Asian physician-scientists to receive an R01-equivalent grant (848). Receiving an NIH K award, such as a K08 or K23, to protect research time in the clinical postdoctoral setting was associated with a 10-fold greater likelihood of receiving an R01-equivalent grant. Therefore, K awards or other support to protect research time focused on female and other underrepresented physician-scientists could greatly help improve the diversity of physician-scientists. More recently, AACR collaborated with the Bristol Myers Squibb Foundation and National Medical Fellowships on an initiative to train 250 community-oriented clinical trial investigators who are underrepresented in medicine or have demonstrated a commitment to increasing diversity in clinical trials; named Robert A. Winn Diversity in Clinical Trials Award Program, this new initiative is a testament to our commitment to eliminating cancer health disparities by propelling tangible improvements in cancer workforce diversity (849,850). Increasing the diversity of physician-scientists is crucial to build trust in medical research and stimulate innovation.

OTHER HEALTH CARE PROFESSIONALS

Comprehensive cancer care teams consist of additional professionals, such as physician assistants, nurse practitioners, registered nurses, dietitians, community health workers, patient

navigators, and other care partners, who play an important role in cancer care; yet many of these professions do not reflect the patient populations they serve. For example, in 2020, 7.2 percent of U.S. registered nurses identified as Asian, 6.7 percent identified as Black, 5.6 percent as Hispanic, and 0.5 percent as AI/AN (851). A 2018 analysis estimated that the United States would have a shortage of 154,018 registered nurses by 2020 and 510,394 by 2030 (852). The COVID-19 pandemic has made this shortage dramatically apparent and has further exacerbated it (853,854). A key bottleneck in training additional registered nurses is the lack of nurse instructors and the related capacity of undergraduate programs (855). Supporting larger nursing programs, especially at Minority-Serving Institutions, could significantly increase the diversity of registered nurses. As discussed in the following chapter (see **Policies to Address Disparities in Clinical Research and Care**, p. 143), community health workers and patient navigators help connect racial and ethnic minority patients with the health care system and other resources that build health equity and reduce health care costs by promoting disease prevention (856-859). Community health workers are more likely than other types of health workers to reflect the demographic makeup of the patients they serve (860), partly due to less expensive education requirements that lower barriers to entering the profession. Community health workers also provide net health care cost savings by reducing the amount of emergency care their patients require (858). However, funding sources for community health workers and patient navigators are often not sustainable. Facilitating and incentivizing the training of more health care providers from medically underserved communities would not only benefit patients in those communities, but also provide stable, high-quality jobs for local economies that are historically disadvantaged.

LaSalle D. Leffall, Jr., MD (1930-2019)



LaSalle D. Leffall, Jr., MD (1930-2019) was an esteemed surgical oncologist and a beloved educator. Dr. Leffall was born in Tallahassee, Florida, on May 22, 1930. His brilliance was evident early in life as he was only 15 when he completed high school and 18 years old when he graduated summa cum laude from the historically Black Florida Agricultural and Mechanical College in Tallahassee, Florida. After earning a medical degree from Howard University Medical School in Washington, D.C., in 1952, Dr. Leffall completed his residency at Freedmen's Hospital, known today as Howard University Hospital, followed by a surgical oncology fellowship at the Memorial Sloan Kettering Cancer Center in New York City. Dr. Leffall served as a captain in the U.S. Army Medical Corps and was the chief of general surgery at the U.S. Army Hospital in Munich, Germany.

Dr. Leffall returned to Howard University Hospital to join the surgery faculty in 1962, and served as chairman of its Department of Surgery from 1970 to 1995. During his illustrious career, Dr. Leffall served the cancer research community in many capacities. He was the first Black president of both the American Cancer Society and the American College of Surgeons. He served as the president of the Society of Surgical Oncology and the Society of Surgical Chairs. Dr. Leffall was also the chairman of the board for the Susan G. Komen Breast Cancer Foundation, and in 2002, he was appointed the chair of the President's Cancer Panel by the 43rd U.S. president, George W. Bush.

His autobiography, *No Boundaries: A Cancer Surgeon's Odyssey*, chronicles his experiences with battling overt racism in medical services delivered under the egregious doctrine of "separate but equal" clinical care, as well as his efforts to strengthen the health care workforce by increasing the diversity of surgeons through his enormous mentorship platform. When discussing the inequities in educational opportunities that prevented many Black individuals from pursuing careers in medicine, Dr. Leffall was fond of quoting one of his mentors, Dr. Charles Drew, another Black surgeon, a blood banking pioneer, and the first medical director of the American Red Cross, "Excellence in performance will transcend artificial barriers created by man." Dr. Leffall proudly shared this quote as a source of inspiration to his mentees and as a testimony to his own incredibly strong work ethic.

Dr. Leffall was well aware of the unique obstacles faced by Black individuals because of systemic racism in the health care professions. He was a passionate advocate for providing mentorship and sponsorship to diverse trainees. His commitment to diversity, equity, and inclusion was embodied by his career-long dedication to Howard University Medical School, which remains one of the most prolific schools in the United States in graduating Black physicians.

Dr. Leffall had a distinguished affiliation with AACR. In 1993, AACR partnered with the Kellogg Company and the organizers of

the Biennial Symposium on Minorities, the Medically Underserved and Cancer to sponsor the LaSalle D. Leffall Jr./Jack E. White Award for Cancer Prevention and Control. The award—created in 1987 to honor Leffall—was given jointly in the 1990s by AACR and fellow sponsors to recognize researchers who had addressed cancer disparities in minority and medically underserved communities.

Dr. Leffall became an active member of AACR in 2002, participated in the AACR initiative, Minorities in Cancer Research, and was granted Emeritus Member status in 2011. In 2007, he was awarded the AACR Public Service Award in recognition of his leadership in the fight against cancer health disparities through excellence in teaching, research, scholarship, patient care, and public service.

"The health care system we have today, one that, in many ways, is striving to better serve underprivileged and underresourced communities, would not have been possible without Dr. Leffall's ability to recognize the truth and his insistence on serving his patients to whatever degree necessary, including revolutionizing and reorienting the entire health care system around greater justice and equity."

Wayne A. I. Frederick, MD, MBA

President, Howard University

"I am incredibly proud to be able to count myself as one of the many black surgeons that benefited from Dr. Leffall's mentorship; the opportunity to interact with him and learn from him was one of the most impactful highlights of my career."

Lisa A. Newman, MD, MPH

Chief, Section of Breast Surgery,
Weill Cornell Medical Center

"Dr. Leffall was a titan. He made a difference in the lives of so many. I'm proud to have known and been personally mentored by Dr. Leffall, who was instrumental in my attending Howard University when he was dean of its Medical School. I will always cherish the time I spent with him and the invaluable lessons I learned from him."

Sanya A. Springfield, PhD

Director, NCI Center to Reduce Cancer Health Disparities

Overcoming Cancer Health Disparities Through Science-based Public Policy

IN THIS SECTION, YOU WILL LEARN:

- ▶ Funding for research and programs at NIH, NCI, NIMHD, CDC, and FDA is critical for addressing cancer health disparities.
- ▶ Policies that increase access to early detection and promote cancer prevention help reduce cancer health disparities.
- ▶ New FDA guidelines bring promise to increasing diversity of clinical trials, but additional enforcement authorities could help implement the voluntary recommendations.
- ▶ Improving insurance coverage and access to high-quality clinical care will help bring new advances to all patients and reduce disparities.

Achieving health equity by eliminating disparities in SDOH and access to care is a bold yet achievable goal and central to the AACR's mission of preventing and curing all cancers. Creating equitable cancer care will require a multipronged approach to support individuals, communities, health systems, and local, state, and federal governments to eliminate structural racism and systemic barriers to cancer prevention, screening, treatment, and survivorship care. This chapter presents science-based policy solutions to make meaningful progress in addressing cancer health disparities.

Funding for Research and Programs That Address Disparities and Promote Health Equity

Federal investment in NIH, NCI, NIMHD, and CDC is critical for understanding cancer disparities and developing evidence-based strategies to address them. For example, racial and ethnic minorities have been chronically underrepresented in genomic sequencing databases and studies, which harms the ability to leverage precision therapies targeting specific cancer mutations. In an effort to diversify genomic sequencing databases and improve precision medicine, NIH has utilized the All of Us initiative to conduct outreach and gene sequencing for historically underrepresented demographics.

NCI has many initiatives that focus on reducing cancer disparities (see sidebar on **NCI Programs That Address Disparities in Cancer Care and Prevention**, p. 136). For example, the NCI Community Oncology Research Program (NCORP) engages communities across the United States in clinical research to actively recruit medically underserved patients so clinical trials

reflect the patient population intended to be treated. In addition to funding cancer disparities research, the NCI CRCHD helps train a diverse cancer research workforce (see **Overcoming Cancer Health Disparities Through Diversity in Cancer Training and Workforce**, p. 125). NIMHD also supports research on how SDOH influence health risks. Robust, sustained, and predictable, and robust federal funding for these programs at NCI, NIMHD, and other NIH Institutes and Centers is vital to better understand which policy changes help promote health equity; recruit underrepresented patients in cancer research; and support a diverse workforce.

CDC's many disease prevention programs provide access to cancer care and build health equity, such as the National Program of Cancer Registries (NPCR), the National Breast and Cervical Cancer Early Detection Program (NBCCEDP), Racial and Ethnic Approaches to Community Health (REACH), and the Colorectal Cancer Control Program (see sidebar on **CDC Programs to Promote Health Equity**, p. 137). Federal investment in these programs enables CDC and local partners to collect data, share public health messages, and provide hundreds of thousands of cancer screenings annually for patients in communities with limited access to screening facilities. AACR advocates for additional investments for CDC to expand the work of the agency in these important areas.

Collaborative Resources to Build Health Equity Partnerships

Structural racism is a form of racism that is pervasive throughout systems, laws, practices, and beliefs that reinforce and maintain racial group inequities (861). Structural racism has been

NCI Programs That Address Disparities in Cancer Care and Prevention

NCI funds and coordinates a number of programs aimed at increasing cancer prevention activities across the country.



A program of the National Cancer Institute
of the National Institutes of Health

One such program is the **NCI Community Oncology Research Program (NCORP)** which is a national network that aims to increase access to clinical trials and cancer care (including cancer prevention, screening, and surveillance) to people in their own communities. NCORP consists of 53 institutions including 7 research bases and 46 community sites that each coordinate clinical trials and cancer care delivery in locations accessible to patients. One mission of NCORP is to reduce cancer disparities through increasing access to cancer care services at these sites. Fourteen of NCORP's community sites serve minority communities with patient populations of at least 30 percent minorities and/or rural residents who cannot travel long distances to NCI-designated cancer centers. NCORP focuses on increasing access to cancer care and prevention services for people in their local communities.



The **NCI Center to Reduce Cancer Health Disparities (CRCHD)** was established in 2001 to help reduce the unequal burden of cancer in our society through strengthening NCI's research portfolio in disparities research, building interinstitutional partnerships and regional networks to foster collaboration to address cancer health disparities, providing technical advice and expertise to NCI leadership, and leading NCI's efforts in workforce diversity.

CRCHD's **Partnerships to Advance Cancer Health Equity (PACHE)** program seeks to build research, education, and community outreach capacity between NCI-designated

cancer centers (CCs) and institutions serving underserved health disparity populations and underrepresented students (ISUPS). In 2019, CRCHD supported 16 partnerships between 16 NCI-designated CCs and 20 ISUPS that aim to increase access to cancer advances (including in cancer prevention, screening, and treatment) in underserved communities across the nation. CRCHD also houses two network-based programs: **Geographic Management of Cancer Health Disparities Program (GMAP)** and the **National Outreach Network (NON)**.

PACHE LOCATIONS IN GMAP REGIONS



GMAP fosters collaboration, resource-sharing, training, and capacity-building among cancer disparities researchers and trainees from underrepresented backgrounds. GMAP coordinates these activities through six administrative hubs that serve specific regions across the country. The program also builds strong relationships between cancer care sites and NON-supported community health educators (CHEs). NON, working through CHEs, develops and disseminates culturally tailored, evidence-based cancer prevention and control resources within the underserved communities served by NCI-designated CCs. NON and GMAP work in concert to increase awareness, knowledge, and access to NCI cancer prevention, screening, and treatment information among underserved populations.

Adapted from (90a).

described as the hidden base of the “discrimination iceberg” as it supports underlying stereotypical beliefs, overt racism, and discrimination (see **Figure 22**, p. 138) (862). For example, redlining is a discriminatory practice in which financial and other services are withheld from potential customers who

reside in neighborhoods classified as ‘hazardous’ for investment based on race/ethnicity. A growing body of evidence shows that community disinvestment and residing in historically redlined neighborhoods negatively impact physical and mental health (see **Figure 23**, p. 139) (863-866). Alarming, residing in historically

CDC Programs to Promote Health Equity

CDC's **Racial and Ethnic Approaches to Community Health (REACH)** is a grant-



making 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 preventative behaviors that are foundational to cancer prevention, such as physical activity, obesity reduction, healthy eating, smoking cessation, and cancer screening.

Since its inception in 1991, **CDC's National Breast and Cervical Cancer Early Detection Program** has helped low-income, uninsured, and underinsured women gain access to screening, diagnostic, and treatment services. In 2017, the program provided breast cancer screening to nearly 286,000 women, diagnosing about 2,500 invasive breast cancers and 765 premalignant lesions before they turned into cancer. The program also provided cervical cancer screening to nearly 139,000 women, diagnosing around 170 invasive cancers and 6,000 premalignant lesions.



The **CDC Colorectal Cancer Control Program** was established in 2015 to increase colorectal cancer screening rates. It currently includes 541 clinics that serve nearly 1 million patients ages 50 to 75, including many uninsured patients. Clinics that have participated since the program's inception have increased screening rates by 8.3 percent.



The **NCI Screen to Save: National Colorectal Cancer Outreach** initiative aims to increase awareness and knowledge about colorectal cancer screening and screening rates among racially and ethnically diverse and rural communities through community health educator-conducted community outreach and education.

redlined neighborhoods is also associated with late-stage breast cancer diagnosis and increased rates of mortality in Black women (867) (see **Social and Built Environments**, p. 35). The complex interplay between social and environmental factors presents several opportunities for government agencies, private funders, and the research community to prioritize cancer equity research.

Cancer health equity would be achieved only when everyone has equal opportunities and capabilities to prevent cancer, detect cancer early, and receive appropriate treatment and survivorship care (868). Health equity cannot be achieved, however, without considering SDOH, which are conditions in the environments where people are born, live, learn, work, play, worship and age that affect quality of life outcomes and health risks (87) (see **Factors That Drive Cancer Health Disparities**, p. 29).

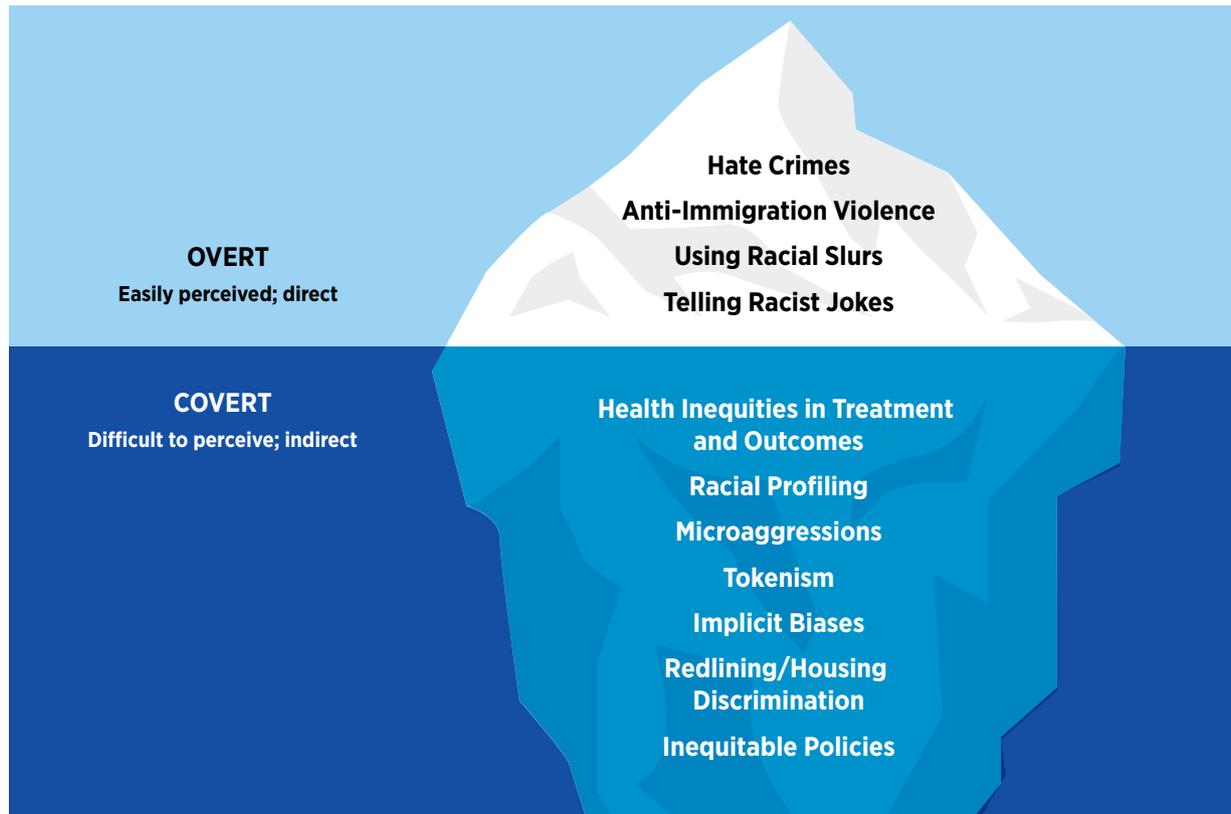
As described in **Understanding Cancer Development in the Context of Cancer Health Disparities** (p. 40), biological vulnerabilities at the individual level need to be considered when investigating cancer risks between and across racial and ethnic minorities. Equally important to reaching cancer equity is supporting collaborative efforts among communities, educators, scientists, academic institutions, and federal agencies. Several NIH programs and funding opportunities seek to address disparities and strengthen the cancer workforce pipeline via community engagement.

More than 20 years ago, the NCI CRCHD initiated the Partnerships to Advance Cancer Health Equity (PACHE) program, which provides institutional awards that support partnerships between institutions serving underserved populations and NCI-Designated Cancer Centers (869). A promising example of PACHE investment in community-based efforts occurs in Illinois, one of the top states for breast cancer-related deaths among Black and Hispanic women (870-872). The Chicago Cancer Health Equity Collaborative (ChicagoCHEC) is a PACHE supported, tri-institutional partnership between Northwestern University, Northeastern Illinois University, and the University of Illinois at Chicago seeking to achieve cancer health equity and support the STEM workforce (873). The shared governance model and a community engagement core are bridging the gap between academic institutions, researchers, community residents and leaders, and health care providers to improve cancer health equity (874).

Similar efforts are underway at Duke Cancer Institute (DCI) in North Carolina, a state with a diverse populace at high risk for cancer and limited access to cancer prevention and treatment resources (875). Within the DCI patient serving area, the extensive NCI-funded community and academic health assessment, called Project PLACE (Population Level Approaches to Cancer Elimination), was distributed to diverse community partners and collaborators. Respondents included representation from racial and ethnic communities, faith-based organizations, sexual and gender minority community centers, Minority-Serving Institutions, Panhellenic organizations, senior centers, and health clinics. As a result, a five-step blueprint for proactively engaging

FIGURE 22

Discrimination Iceberg



Discrimination exists at multiple social levels. 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 structural racism, which is an underlying cause of health disparities.

underserved communities has been designed, with the potential to improve the quality of patient care received at DCI (876). Federal investments that encourage and strengthen collaboration between NCI, academic institutions, and community-based organizations are imperative to address cancer disparities.

Policies to Address Disparities in Cancer Prevention

REGULATIONS TO REDUCE THE DISPARATE HARMS OF TOBACCO PRODUCTS

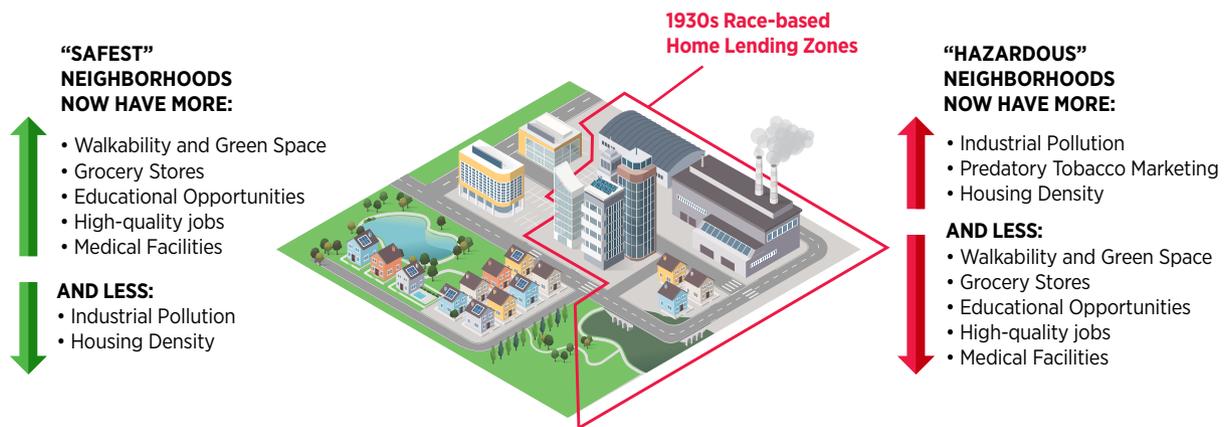
Tobacco use is known to cause 18 different cancers and is the top preventable cause of cancer and cancer-related deaths (see **Disparities in the Burden of Preventable Cancer Risk Factors**, p. 50). Policies such as smoke-free laws, tobacco taxes, advertising restrictions, evidence-based smoking cessation programs, and awareness campaigns have successfully reduced the national

cigarette smoking rate from approximately 40 percent to 12.5 percent the past 60 years (213). 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 NHW individuals, especially among youth (877,878).

The tobacco industry has used menthol-flavored cigarettes to aggressively target minority communities (see **Figure 24**, p. 140). Overall, 38.8 percent of Americans who smoke use menthol cigarettes, and largely due to predatory marketing practices, 85 percent of African Americans who smoke use menthol cigarettes (878). Extensive evidence indicates that menthol cigarettes increase smoking initiation, progression to frequent smoking, and exposure to nicotine, and reduce smoking cessation success (230,879,880). Yet the 2009 Family Smoking Prevention and Tobacco Control Act (TCA) allowed the tobacco industry to continue marketing menthol cigarettes, while asking FDA to determine if this was “appropriate for the protection of public health.”

FIGURE 23

How Redlining Underlies Cancer Disparities



In the 1930’s, neighborhoods were classified on how “safe” they were for investment based on the race and ethnicity of residents. This made it harder for racial

and ethnic minorities to receive mortgages in order to buy homes and has led to numerous inequalities in educational, economic, and health outcomes.

In 2013, FDA concluded that “menthol cigarettes pose a public health risk above that seen with nonmenthol cigarettes” (881). AACR and other public health-focused organizations have consistently urged FDA to prohibit menthol cigarettes, including through a formal Citizen Petition in 2013 (882). In April 2022, FDA responded to the Citizen Petition with a draft product standard to prohibit the manufacture, distribution, or sale of menthol cigarettes (883). Several studies suggest that between 25 and 64 percent of adults who smoke menthol cigarettes would stop if menthol cigarettes were not available (884). It is estimated that a federal menthol ban can save 650,000 lives by 2060, with a large proportion of those lives saved among Black individuals (327). Concurrent with any ban on menthol, it would be important to increase evidence-based smoking cessation resources and programs to support these new cessation attempts.

In addition to menthol, all flavored tobacco products significantly increase smoking initiation (885-887). While the TCA prohibited flavored cigarettes, it exempted other tobacco products like flavored little cigars and cigarillos. Two thirds of adults who currently use these products have smoked cigars with flavors other than tobacco (885). Additionally, Black and Hispanic adults are more than twice as likely as White adults to smoke little cigars or cigarillos. In April 2022, FDA proposed a draft product standard banning the manufacture, distribution, or sale of flavored cigars (888). 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 (889).

AI/AN adults are nearly 40 percent more likely to smoke cigarettes compared to any other population groups in the United States (890), partly due to predatory marketing practices from the

tobacco industry (891). In 2022, the Navajo Nation took bold action to reduce tobacco-related health disparities among Navajo communities by implementing a comprehensive ban on commercial tobacco products on tribal lands, except for private use in the home or traditional tobacco for ceremonial purposes (892).

Lack of health insurance and inconsistent coverage of evidence-based smoking cessation therapies also contribute to smoking-related health disparities. Among U.S. adults who attempted to stop smoking in 2015, 34.3 percent of NHW adults used evidence-based medication or counseling (893). 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. A key reason for these disparities was the lack of health insurance; 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 (894,895). 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 SGM populations could help address tobacco-related disparities (896,897).

ELIMINATING CERVICAL CANCER AND REDUCING THE BURDEN OF OTHER HPV-DRIVEN CANCERS

HPV is known to cause six different types of cancer among men and women, including nearly all cases of cervical cancer (see **Infectious Agents**, p. 64). Fortunately, HPV vaccines significantly reduce the risk of developing an HPV infection and related cancers

FIGURE 24

How Flavored Tobacco Products Contribute to Disparities



Masks Harsh Taste



Menthol Increases Nicotine Receptors



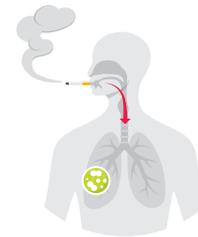
Youth More Likely to Try



Cooling Effect of Menthol Hides Smoke Irritation



Predatory Marketing



Tobacco Smoke Causes 17 Types of Cancer Beyond Lung

The tobacco industry has used flavored products and predatory marketing practices, such as providing free samples of menthol cigarettes from vans, to addict racial and ethnic minority communities to nicotine for

decades. These aggressive campaigns were intentional business strategies to preserve market share as overall smoking rates dropped across the United States.

when administered before the age of 17 years (884,898,899). However, only 58.6 percent of Americans ages 13 to 17 years were fully vaccinated against HPV in 2020 (365), and NHW adolescents, particularly those living in rural areas, persistently experience the lowest vaccination rates (900).

The Patient Protection and Affordable Care Act (ACA) requires health insurance plans, including Medicaid expansion plans, to cover all vaccines recommended by the CDC Advisory Council on Immunization Practices without a copayment (901). State-level vaccination requirements to attend public schools for other deadly diseases, like measles and polio, have been effective strategies to nearly eradicate those viruses (902). However, only Hawaii, Rhode Island, Virginia, Puerto Rico, and the District of Columbia have such requirements for HPV vaccination (903). Also, tailored and culturally sensitive communication is critical to improving vaccination rates.

In addition to HPV vaccines, cervical cancer can be effectively prevented with routine cancer screenings and minor surgical

removal of precancerous or early-stage cancerous lesions. By utilizing vaccines, early detection, and follow-up care, the World Health Organization has called on public health authorities around the world to eliminate cervical cancer globally by 2030 (904). More than 80 U.S.-based public health organizations, including AACR, have signed on to related recommendations to eliminate cervical cancer within the United States (905). As described earlier, low access to screening and especially follow-up treatment services for racial and ethnic minority women, and uninsured women, drives disparities in cervical cancer incidence and mortality in the United States (see **Disparities in Cancer Screening for Early Detection**, p. 71). Increased funding for CDC's NBCCEDP, as well as mobile screening units organized by cancer centers, is critical for improving access to cervical cancer screening in medically underserved communities (see sidebar on **Guidelines for and Disparities in Screening for Five Cancer Types**, p. 78). Legislation such as the PREVENT HPV Cancers Act (H.R. 1550) would enhance awareness efforts by authorizing \$25 million to support national awareness campaigns about HPV vaccinations and early detection, with a focus on rural areas and communities with lower rates of vaccination or screening.

THE HONORABLE

Kathy Castor

U.S. Representative for Florida's 14th District

"If the NIH called a press conference to announce that we had cured cancer, it would be a cause for celebration. Well, since 2006, there has been a safe and effective vaccine that prevents cancer caused by the human papillomavirus (HPV)—one of only two cancer-preventing vaccines we have, and the only one that helps prevent six types of cancer. People are dying from cervical cancer and other HPV-related cancers when they shouldn't be. My PREVENT HPV Cancers Act would expand upon the work that the CDC is already doing to raise awareness about gynecological cancers, place an emphasis on equity, and include HPV and HPV-related cancers in a national public awareness campaign to educate providers, parents, and the general public about the lifesaving HPV vaccine. We need a strong commitment from all stakeholders, including Congress, to increase HPV vaccination rates and save lives."



ADDRESSING OBESITY, MALNUTRITION, AND PHYSICAL INACTIVITY

When the interconnected impacts of obesity, malnutrition, and physical inactivity on cancer risk are combined, these factors are associated with increased risk of 15 types of cancer and cause nearly as many cases of cancer as smoking tobacco (906). Obesity promotes cancer by elevating growth signals and increasing the availability of nutrients that collectively enable cancer cells to grow more rapidly. Obesity also poses unique challenges for patients with cancer undergoing active treatment, such as surgical complications and restrictions on chemotherapy options (907). There are many social, cultural, and economic factors that contribute to disparities in obesity rates, including: economic and educational discrimination that results in lower incomes; lack of green spaces to safely exercise outdoors; absence of grocery stores in a community (areas that are considered "food deserts"); overabundance of fast foods in a community (areas that are considered "food swamps"); lack of education on healthy nutrition; inability to walk or bike around a neighborhood; discrimination in housing through practices such as redlining; ongoing and historic injustices against racial and ethnic minorities; and many others. Since factors driving obesity are multifaceted and often driven by structural racism and wide-ranging policies, reducing obesity and eliminating disparities will require broad policy changes at

all levels of government, private industry, and health systems (see **Body Weight, Diet, and Physical Activity**, p. 55).

With devastating job losses during the COVID-19 pandemic disproportionately affecting racial and ethnic minorities (908), there was a concern that the ability to afford healthy food could decrease and thus worsen disparities. In response, Congress increased nutritional and unemployment benefits in several COVID-19 relief bills in 2020 and 2021 (909,910). Additionally, USDA revised the federal "Thrifty Food Plan" benchmark for nutrition programs to reflect the growing cost of healthy foods in August 2021 (911). This action increased Supplemental Nutrition Assistance Program (SNAP) benefits by \$36.24 per month per beneficiary, the largest increase in the program's history. This increase particularly benefited children, who comprised 43 percent of SNAP beneficiaries in 2019, as well as African American and Hispanic residents who comprised 30.8 percent and 19.1 percent of beneficiaries, respectively (912). Before and during the COVID-19 pandemic, CDC programs, such as REACH, supported community partners to promote physical activity and access to fresh fruit and vegetables in underserved communities (913).

To comprehensively address the obesity epidemic, policies to address SDOH, like housing affordability, availability of healthy food, walkable neighborhoods, educational opportunities, and green spaces for physical activity, must be considered (914). These efforts will require collaboration with a wide variety of stakeholders outside the health sector.

POLICIES TO PROMOTE ENVIRONMENTAL JUSTICE

As detailed earlier in the report (see **Exposure to Environmental Carcinogens**, p. 68), exposure to environmental carcinogens disproportionately impacts racial and ethnic minorities (391). For example, radon exposure was estimated to cause approximately 10 percent of all lung cancers in the United States during the 1990s (915). Families with lower incomes and/or those who rent their homes are less likely to have their properties tested for radon or have mitigating technology installed if high radon levels are found (916,917). In 2015, EPA launched a public private partnership with nonprofit and industry organizations to create the National Radon Action Plan (NRAP), which has saved an estimated 2,000 lives per year (196,918,919). NRAP has improved building codes to become more radon-resistant; increased testing requirements in the mortgage process; created and shared technical standards; and raised awareness. In partnership with EPA, Kansas State University operates the National Radon Program Services, which provides low-cost radon test kits (920), and many states have programs to provide free or low-cost radon testing and mitigation services. The U.S. Department of Housing and Urban Development announced a new \$4 million pilot grant program in January 2022 to provide radon testing and mitigation for low-income families (921). These programs have greatly helped mitigate radon exposures, and necessitate new research to update estimates for the impact of radon on lung cancer rates.

Since 1990, EPA has regulated 188 hazardous air pollutants under the Clean Air Act to protect public health (922). Unfortunately, elevated rates of cancer incidence as well as severe respiratory and neurological health complaints in heavily polluted communities have persisted over the past three decades (923-926). Partly due to housing discrimination and low incomes preventing residents from leaving, many of the areas most impacted by heavy industrial pollution are predominantly racial and ethnic minority communities. In early 2022, EPA announced the Environmental Justice initiative (927), which included some of the strongest actions ever taken to reduce industrial air pollution, primarily in Texas, Louisiana, and Mississippi. These are as follows:

- Create a new Pollution Accountability Team to increase unannounced inspections.
- Utilize \$20 million of grants from the 2021 American Rescue Plan to increase air pollution monitoring capabilities in historically polluted communities.
- Require some heavily polluting sites to install new monitoring systems or pollution reduction devices.
- Reduce allowable emissions of the carcinogen, ethylene oxide, by 2,000-fold.
- Appoint a Senior Advisor for Environmental Justice.
- Reinstate regulations for power plant emissions of hazardous air pollutants from 2016.

In October 2021, EPA also announced the first-ever agency-wide strategic plan to address pollution from poly- or perfluorinated alkyl substances (PFAS) (928). PFAS are carcinogens known for their long-lasting stability in nature and human bodies. Emerging evidence suggests racial and ethnic minorities are disproportionately impacted by PFAS pollution from industrial, military, and food packaging sources (929,930). Rural areas in Michigan that use PFAS-contaminated biosolid waste from water treatment plants as agricultural fertilizer have dangerously high levels of PFAS in the soil, water, and livestock (931). A key provision of EPA's new plan is to create an enforceable safe drinking water standard that will require routine testing for the two most common PFAS chemicals in tap water systems. Other plans include new regulations to limit discharge of PFAS into waterways; requiring polluters to pay for decontaminating PFAS within the Superfund program; leveraging \$10 billion from the bipartisan infrastructure law to clean up PFAS in drinking water; and researching additional types of PFAS and emissions sources to inform future actions. In addition to these bold new actions, the House-passed PFAS Action Act will provide greater regulatory authority to EPA over PFAS pollution if it becomes law.

Policies to Address Disparities in Cancer Screening and Follow-up

As described in **Collaborative Resources to Build Health Equity Partnerships** (p. 135), structural racism is an underlying driver for

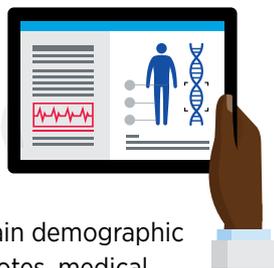
cancer health disparities (see also **Figure 5**, p. 32; and **Factors That Drive Cancer Health Disparities**, p. 29). Routine cancer screenings are necessary to detect precancerous lesions as early as possible in cancer development; however, variability along the cancer screening continuum presents challenges to improving equity (see **Disparities in Cancer Screening for Early Detection**, p. 71). For example, cancer screenings for cervical (932), breast (933), colorectal (932), and lung (934) cancer are equally or more likely to occur in minority communities at health centers when compared to NHW populations. Follow-up care, however, is less likely to occur in minority populations for several reasons including being uninsured or underinsured, decreased access to care, healthcare system bias, and miscommunication with health care providers (4). For sexual and gender minorities, cancer screening data are limited because national cancer screening programs do not collect sexual orientation or gender identification data (935) (see **Cancer Health Disparities Among Other Medically Underserved Populations**, p. 25). Self-reported concerns regarding discrimination are an additional barrier to cancer screenings for sexual and gender minorities (935). These knowledge gaps, screening eligibility criteria, concerns about discrimination, and variable screening data among racial, ethnic, sexual, and gender minorities present opportunities for policies that increase insurance coverage for low-income individuals. Collecting disaggregated cancer data (see sidebar on **Why Is Disaggregated Cancer Data Needed?**, p. 16), providing opportunities to report sexual orientation, and improving cultural competency across the health care system are viable approaches to improving equity.

Inadequate health insurance coverage is more prevalent among racial and ethnic minorities and is associated with not completing recommended care (936). Addressing cancer screening needs of the underinsured and those that are low income is a priority of the CDC's NBCCEDP and the Colorectal Cancer Control Program (CRCCP). However, funding challenges prevent servicing all program-eligible individuals (937). Increased federal investment is needed to achieve equity in cancer screening and follow-up. There is growing evidence that expanding Medicaid is associated with detecting breast cancer at an earlier stage (938), demonstrating that expanding Medicaid coverage to historically underserved populations is another substantive approach to achieving health equity.

Community health centers are patient-directed organizations that deliver comprehensive, culturally and linguistically competent, and high-quality care and that accept patients without insurance (939). Community health centers receive Health Center Program federal grant funding to improve the health of underserved populations, but cancer prevention services vary due to underfunding, high staff turnover, and differences in the meaningful use of electronic health records (EHRs) (940). A March 2022 workshop held by the National Cancer Policy Forum and the Computer Science and Telecommunications Board discussed opportunities to redevelop the use of EHRs in oncology care, research, and surveillance as the first generation EHRs were intended for medical billing and not health care research (941). Transforming EHRs has the potential to standardize cancer

Electronic health records (EHRs) are digital versions of a patient's paper chart

that are a real-time, patient-centered record. EHRs may contain demographic information, progress notes, medical history, laboratory data, and radiology reports.



management pathways, collect data for evidence-based care, and minimize provider burden. This will require coordinated efforts between the federal government, state, tribal, local, and territorial health professionals, and EHR vendors.

Policies to Address Disparities in Clinical Research and Care

DIVERSIFYING REPRESENTATION IN CLINICAL TRIALS BY ADDRESSING BARRIERS IN TRIAL DESIGN

Participating in clinical trials often improves outcomes for patients with cancer (942-944) and drives improvements in overall survival rates (945). Historically, racial and ethnic minority populations have been underrepresented in clinical trials, resulting in FDA-approved medical products that have not been adequately tested in a diverse sampling of patients that reflects how the products will be used in clinical practice (see **Disparities in Clinical Research and Cancer Treatment**, p. 87). Unfortunately, more than 75 percent of patients with cancer are ineligible to participate in clinical trials because either a trial is unavailable for their disease or strict eligibility criteria exclude them from studies (534).

In November 2020, FDA issued voluntary guidance to encourage trial sponsors to increase representation of historically underserved minorities in clinical trials (527). Some key provisions are:

- Expand eligibility criteria for large clinical trials when safety data for the new therapies should be well established;
- Propose strategies to ensure the intended patient population is adequately represented in clinical trials;
- Recommend studies to include sufficient numbers of participants from key demographics, when possible, to conclusively identify differences in safety and efficacy;
- Decentralize clinical trials by collaborating with local health facilities; and
- Leverage real-world evidence to fill in knowledge gaps when randomized clinical trials may not be possible.

Guidance from federal agencies represent important first steps in loosening eligibility criteria and improving clinical trial design. However, enforcement mechanisms could greatly accelerate change. It is critical to engage stakeholders in the policy-making process to help identify solutions to change traditional patterns and increase access to clinical trials for all patients. As stated in the **AACR Call to Action** (p. 149), Congress should pass the **Diverse and Equitable Participation in Clinical Trials (DEPICT)**, H.R. 6584) Act to provide FDA with the authority to require diverse representation in clinical trials (946).

DIVERSIFYING REPRESENTATION IN CLINICAL TRIALS BY ADDRESSING BARRIERS FOR PATIENTS

When offered, 58.4 percent of Black patients with cancer and 55.1 percent of White patients with cancer choose to join a clinical trial (150). However, many patients are never asked by their health care providers. Additional barriers such as the absence of clinical trial sites in the community, financial costs associated with trial participation, dependent care responsibilities, lack of paid leave from work, and many other factors reduce clinical trial participation (150,534,947,948).

Financial barriers to clinical trial participation include medical costs, transportation costs, lodging costs, and loss of wages. The ACA required Medicare and private insurance plans to cover routine medical costs related to clinical trial participation, but deductibles and other out-of-pocket costs can still pose significant challenges. Following passage of the **CLINICAL TREATMENT Act** in December 2020, all Medicaid programs are also required to cover medical costs of clinical trial participation. As included in FDA's 2020 guidance, further decentralization of clinical trials and

Continued on page 146

The **Diverse and Equitable Participation in Clinical Trials (DEPICT) Act** (H.R. 6584) would provide FDA with new authorities to **improve representation of racial and ethnic minorities**

in clinical trials, so new therapies are studied in populations that reflect real-world use.

The **Diversifying Investigations Via Equitable Research Studies for Everyone (DIVERSE) Trials Act** (H.R. 5030/S. 2706) would provide **additional support for decentralizing clinical trials** and decrease burdens associated with trial participation. This would be accomplished in part by supporting the use of telehealth and remote monitoring, and allowing reimbursement for travel expenses.



Helping the Hawaiian Community Get the Cancer Care Resources They Need

Lillian Frances Bernadette Kehaunani (Kehau) Matsumoto is a 78-year-old patient advocate, a five-time cancer survivor, and a grandmother, who was born in Hawaii and currently lives in Honolulu on the island of Oahu. Kehau was first diagnosed with breast cancer in 1993 after a routine mammogram.

“When I heard this news,” Kehau said, “my first question to the doctor was, ‘Am I going to die?’ I was very afraid.”

After that initial diagnosis, Kehau did not want to have surgery and opted for radiation therapy.

“I didn’t think I could have breast cancer more than once. Unfortunately, I had it three more times and now I laugh about it because to me it was a hip hop left, right, left, right,” she said.

The second time and third times she was diagnosed, the cancer was treated with lumpectomies, and then in 2006 she underwent more radiation.

“I had cancer. Cancer never had me. I still kept on with my life. I went to my kids’ sporting events, business meetings; I kept my life going. Cancer was not going to stop me,” Kehau reflected on what kept her going through those difficult times. Kehau’s third recurrence in 2006 necessitated a mastectomy of her left breast. Following the surgery, Kehau had five years without recurrence and felt a wave of relief. “When I got to the fifth year, I was so happy. I’m going to live now because I passed my five years,” she said.

But then, in 2016, Kehau was diagnosed with leukemia. “I was devastated,” she said.

For her leukemia, Kehau received oral chemotherapies until 2019 when her doctor said she no longer needed treatment.

“And that was my Christmas present and that was the best Christmas I have had,” she said.

Currently, Kehau is living with minimal side effects from her cancer treatment and has no signs of cancer.

“My numbers are great. It’s a blessing,” she said.

During her treatments, Kehau did not have adequate information about her diagnosis and treatment options.

“So in order to navigate, I had to do my own education, my own inquiries,” she said. “I wish at that time I had a [patient] navigator.”

Seeing the need and still wanting to “pay it forward” as she and her husband had discussed, Kehau became an advocate and worked with other cancer patients to help them navigate their care.

“I found people still had questions. They didn’t know which doctors to look for. They didn’t have transportation or insurance,” she said. Kehau has focused on patients from rural parts of Hawaii.

“They have to come to Honolulu, and they don’t have transportation, they don’t have finances, and the insurance coverage is very limited,” she said, highlighting some of the challenges faced by rural Hawaiians. As an advocate, Kehau is especially proud that she helped others secure these resources. “I can still help and direct people and that is my biggest joy.”

Cultural and family values held by native Hawaiians necessitate careful consideration of cancer screening, treatment, and survivorship care. “Hawaiians are very private and would say, ‘Oh no, I’m fine, I don’t need to get examined. I have to take care of my mo’opuna—grandchildren—and—land—and I would always say, ‘āina will always be here. Your mo’opuna will grow up. If you die, your mo’opuna won’t see you anymore,’” Kehau said, recalling how it was often difficult to convince other native Hawaiian women to get routine mammograms.

“I’m proud to be Hawaiian, but I want Hawaiians to live and learn more about cancer, so they would get their [screenings] done,” Kehau added. “Hawaiians in general are strong and proud people who believe they can get food from the ocean, learn how to plant [food] in the ground and bring it to the table for their family. They want to be their own resources. They want to be their own people.”

This often creates a distrust of modern medicine.

“Hawaiians have their own ways of healing themselves, but they do not work all the time, so they have to use the Americanized ones,” she said.

Kehau recognizes that the work she did as an advocate helped many patients. “I don’t want pats on the back. I just want a cure,” she said. “One of the most important things is never do cancer alone. Get your family involved or someone special, but you can never, ever walk alone with cancer. You should always have someone with you.”



“

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use of telemedicine could be powerful tools to reduce the time and financial burdens of participating in trials (see **Achieving Equity in Clinical Cancer Research**, p. 93) (527,949). The Diversifying Investigations Via Equitable Research Studies for Everyone (DIVERSE) Trials Act (H.R. 5030/S. 2706) would further support decentralization of trials through telemedicine and remote data collection, as well as allow trial sponsors to help offset the costs of transportation and other expenses related to participation (950).

Engaging community partners to raise awareness about clinical trials is a powerful tool to increase diversity. For example, in April 2019, FDA Oncology Center of Excellence created Project Community to promote the benefits of clinical trials participation in historically underserved areas(951). Furthermore, research networks like NCORP conduct clinical trials at sites outside of large research centers—the traditional sites for clinical trials—and have developed strong partnerships with the communities served. Numerous studies have shown that trusted patient navigators, community health workers, and patient advocates can effectively support enrollment and retention of racial and ethnic minority patients in clinical trials, as well as educating patients about their disease and the trial process. However, funding streams for these crucial workers are often temporary and unsustainable. The Centers for Medicare and Medicaid Services and/or Congress should support routine reimbursement for these essential members of the health care workforce.

IMPROVING ACCESS TO HIGH-QUALITY CLINICAL CARE

Insurance coverage is well-demonstrated to increase patient access to health care services, including for treatment and management of cancer. Following passage of the ACA, roughly 20 million people who lacked insurance gained coverage through ACA marketplaces or Medicaid expansion (931). In 2020, an estimated 70 percent (232 million) of Americans were covered by private or public health plans included in the ACA provision that requires coverage of preventive services, such as most cancer screening recommended by the USPSTF, without any out-of-pocket expenses (952). The largest gain in access to cancer treatment was found in states that chose to expand Medicaid under the ACA; in expansion states the percentage of low-income patients with cancer who lacked health insurance decreased from 9.6 percent to 3.6 percent between 2011 and 2013, compared to a decrease from 14.7 percent to 13.3 percent in states that did not expand Medicaid (953). The ACA and Medicaid expansion were also correlated with increased detection of early-stage colorectal, lung, breast, melanoma, and pancreatic cancers and increased access to cancer surgeries (954). Other studies found that Medicaid expansion increased access to cancer survivorship care (955), and nearly eliminated racial disparities related to timely cancer treatment (955).

The ACA and Medicaid expansion have also decreased the rates of patients with cancer who delayed care or were unable to afford prescriptions or services, especially women and NHB patients (956-959). However, patients with high-deductible plans or

limited provider networks, known as undersinsured, may still face financial challenges with health care (960-962). Therefore, underinsurance can continue to exacerbate health disparities by incentivizing patients to wait to seek medical care until they can no longer tolerate their symptoms. This leads to more advanced cancers being diagnosed that entail more expensive procedures and medications. It is important to address gaps in access to care that ultimately drive up overall health care costs and premiums. Additionally, states that have not yet expanded Medicaid could significantly decrease cancer disparities and improve access to care by choosing to expand.

Furthermore, IHS provides comprehensive health care services for 2.6 million AI/AN (963). Unfortunately, chronic underfunding of IHS has contributed to severe health disparities and dangerously outdated health care facilities that have an average age of 40 years, compared to the national average of 10.6 years (964,965). Additionally, IHS spends less than \$4,000 per year per beneficiary on health care, compared to more than \$13,000 per Medicare beneficiary (3.5-fold greater) or \$9,500 for veterans (2.5-fold greater) in the Veterans Affairs health system. IHS is in desperate need of additional investment from Congress to adequately serve the health needs of AI/AN, especially those living in remote rural areas without other options for health care services.

Special categories of hospitals, such as Safety Net Hospitals, Critical Access Hospitals, and Sole Community Hospitals, are essential for providing access to health care for their respective patient populations and addressing cancer disparities (966,967). These types of hospitals provide the majority of uncompensated care to uninsured and underinsured patients, as well as disproportionately care for patients who live in rural and underserved urban areas (967a). It is estimated that nearly thirty million adults in the United States were uninsured in 2019 (967b). Since poverty, unemployment, and uninsured rates are disproportionately high among racial and ethnic minority populations, the safety net system provides care to a disproportionately high volume of these patients (967c). Safety net institutions by definition have fewer per capita dollars available for health care, and are therefore less likely to have the financial resources available to support clinical trials infrastructure or remain operational during times of crisis and financial strain. As a consequence, inadequate funding of public hospitals contributes to the underrepresentation of minorities in cancer clinical research.

The costs of caring for patients with COVID-19 devastated Safety Net Hospitals, because of the pandemic severity and resulting economic losses among racial and ethnic minority groups. As the safety net institutions resumed routine health maintenance practices following the pandemic shutdown, they were faced with the burden of catching up with cancer screening and treatment for an even larger population of uninsured and underinsured patients, but with even more constrained budgets (967d). Partnering with cancer centers is one effective strategy to increase capacity to care for patients with cancer and conduct cancer screenings (967e). Additionally, the ACA authorized Medicare

and Medicaid to provide reimbursement adjustment bonuses to help subsidize uncompensated care at safety net hospitals (968). The federal 340B Drug Pricing Program also allows eligible facilities to buy prescription drugs at a discount from pharmaceutical companies and then be reimbursed at the full cost through private and public insurance plans (969). Despite these subsidies, more than 100 rural hospitals closed between 2013 and February 2020 (970), and several dozen more closed or declared bankruptcy during the pandemic (971). Increased investment in these critical medical facilities is vital to ensure underserved communities continue to have local access to health care.

SUSTAINABLY SUPPORTING PATIENT NAVIGATORS AND COMMUNITY HEALTH WORKERS

As described throughout this report, patient navigators and community health workers can greatly assist health prevention initiatives and help connect patients to health systems, clinical trials, and community resources (859). Furthermore, patient navigators and community health workers are instrumental in addressing health disparities by connecting patients with health care and community resources (638,856,858). However, funding for these vital health care workers is often short-term and unsustainable. A crucial step to increase the sustainability of patient navigation is the recognition of the profession by creation of a Payroll-Based Journal job title code by the Centers for Medicare and Medicaid Services, which would enable reimbursement. Currently, 15 states reimburse community health workers through Medicaid programs, and another 10 hire community health workers through Medicaid Managed Care Organizations (972). Expanding sustainable reimbursement models within Medicare and private insurance plans for community health workers and patient navigators could greatly improve the health status of historically medically underserved communities while reducing costs.

ENHANCING COVERAGE OF LYMPHEDEMA MAINTENANCE TREATMENTS

As described earlier (see **Disparities in Cancer Survivorship**, p. 114), disparities in lymphedema contribute to worse outcomes in quality of life for cancer survivors who are racial and ethnic minorities and patients without private health insurance. The standard to treat lymphedema is “comprehensive decongestive

therapy,” delivered in two phases (973-975): 1) acute therapy with trained providers performing manual lymph drainage, assisting with exercises, and applying compression bandages; 2) maintenance therapy at home with manual lymph drainage, exercises, and compression garments. While Medicare covers acute therapy (976), it is not allowed by law to cover compression bandages because they fall into a grey zone of nondurable medical equipment (977). The Lymphedema Treatment Act was originally introduced to Congress in 2010 with the goal of requiring Medicare coverage of compression garments; the current version of the bill has bipartisan cosponsors representing strong majorities of both the Senate and the House (978,979), but has not yet been enacted. Addressing this gap in coverage would greatly improve the affordability and access to lymphedema-related garments to reduce disparities in cancer survivorship.

ADVOCACY FOR UNIVERSAL ACCESS TO HIGH-SPEED BROADBAND INTERNET

The COVID-19 pandemic and widespread adoption of telehealth have highlighted the importance of reliably fast Internet speeds in the modern era. However, an estimated 42 million Americans do not have access to broadband Internet with download speeds of at least 25 Mbps needed to stream video (980). Rural communities and historically marginalized urban communities are disproportionately impacted by limited Internet access. Lack of high-speed Internet harms many aspects of the communities affected, including the ability to receive telehealth, attend school remotely and do homework, start businesses, and work from home (981,982).

Through the Telecommunications Act of 1996, Congress and the Federal Communications Commission created a nonprofit organization, Universal Service Administrative Co. (USAC), to oversee federal programs to expand high-speed Internet access to underserved areas. USAC now leverages more than \$8 billion per year in federal funds to support Internet infrastructure and telehealth (983). Additionally, the 2021 Bipartisan Infrastructure law provided \$65 billion to further support broadband access and lower costs for low-income families (984). Several local governments, mainly in rural areas, have also created their own broadband and fiber Internet networks that effectively and affordably connect their communities with some of the highest Internet speeds in the country (985). Unfortunately, 18 states restrict or prohibit municipal Internet projects (986). Federal and local support for Internet access will be vital for bridging the digital divide and creating equity in health care and in educational and economic opportunities.

Coordination of Health Disparities Research and Programs Within the Federal Government

As described throughout this chapter, the negative impact of structural racism is pervasive throughout the cancer care continuum. There are several initiatives across all branches of

On average **every dollar invested in community health worker initiatives saves Medicaid programs \$2.47** by shifting the focus from emergency care to less expensive primary care services (858).



the U.S. federal government aimed at addressing the impact of structural racism on perpetuating cancer disparities. CRCHD manages and coordinates several disparities-related research and training programs; NCORP engages communities across the United States in clinical research to actively recruit minority and underserved patients to clinical trials; and NIMHD supports research on the influence of SDOH on disease risks.

Within the judicial and legislative branches, there are also increased efforts to reduce the impact of structural racism on health outcomes. As of October 2021, the Department of Justice announced the launch of the “Combating Redlining Initiative,” its most powerful initiative to address lending discrimination in the past 50 years (987). Concurrently, there are hundreds of introduced bills in Congress that have the potential to promote health equity. In addition to increasing coordination between these programs across all branches of government, it is necessary to recognize the importance of disaggregating racial and ethnic demographics data. Underrepresented minorities and historically underserved groups are not monolithic. It will take concerted efforts to understand the diversity that lies within each group to address and remedy cancer disparities. To intentionally address the health care needs of historically underserved groups and improve cancer outcomes, continued, meaningful collaboration across all branches of government and sustained, robust, and predictable funding for CDC and NIH, specifically NCI, are needed.

THE HONORABLE

Tom Cole

U.S. Representative for Oklahoma’s 4th District

“I am proud to be Ranking Member on the House Appropriations subcommittee responsible for funding increases in cancer research through the National Cancer Institute, whose budget increased 36 percent since I first became chairman of the subcommittee. Because of these consistent and incremental funding increases, significant advancements have been made in cancer prevention, detection, diagnosis, and treatment that have led to saving thousands of lives.”



AACR Call to Action

TO REDUCE CANCER HEALTH DISPARITIES,
AACR CALLS UPON POLICY MAKERS TO IMMEDIATELY
ADDRESS THE FOLLOWING:

- ▶ Increase federal funding for medical research and public health initiatives that are tasked with reducing cancer health disparities.
- ▶ Improve collection of disaggregated data for racial, ethnic, sexual, and gender minority groups.
- ▶ Increase diversity in clinical trial participation.
- ▶ Enhance cancer prevention and screening efforts to reduce the burden of cancer among all medically underserved populations.
- ▶ Expand access to equitable and affordable quality health care.
- ▶ Build a more diverse STEM trainee pipeline and cancer research and health care workforce.

Systemic inequities and social injustices have adversely impacted every aspect of cancer research and patient care, including limited participation in clinical trials and disparities in cancer incidence and outcomes. In addition, these inequities have created barriers to career advancement for underrepresented minorities. While new research and other initiatives are being developed and implemented to close these gaps, progress has come too slowly, and the cost of cancer health disparities remains monumental. To reduce cancer health disparities, the structural factors that lead to these outcomes must be eliminated.

Therefore, AACR calls on policy makers and other stakeholders committed to eradicating cancer health disparities to:

Provide Robust, Sustained, and Predictable Funding Increases for the U.S. Federal Agencies and Programs That are Tasked with Reducing Cancer Health Disparities

AACR recommends that Congress:

- Support NIH's important research initiatives to reduce cancer health disparities. To continue this important work and support NIH's invaluable contributions to the medical research enterprise, AACR calls on Congress to provide \$49 billion for NIH's base budget in Fiscal Year (FY) 2023, as well as to increase funding for the National Institute on Minority Health and Health Disparities.
- Fund NCI at \$7.766 billion in FY 2023 to provide additional research opportunities for more diverse applicants and early-stage researchers, support comprehensive studies to examine differences in cancer incidence between population groups, and continue the important work of the Center to Reduce Cancer Health Disparities.

- Increase investments in CDC in FY 2023 to enhance initiatives such as the Social Determinants of Health Community Pilots, the National Breast and Cervical Cancer Early Detection Program, and the Racial and Ethnic Approaches to Community Health program, among others.
- Address the underfunding of Indian Health Service, which provides health care services for 2.6 million American Indian or Alaska Native individuals, many of whom live in remote rural areas with fewer health care options.

Support Research and Data Collection Initiatives to Reduce Cancer Health Disparities

Investing in research and recording quality, disaggregated data for racial and ethnic groups are imperative to inform policy decisions to reduce cancer health disparities. For accurate and fully reflective data collection and analysis, AACR recommends researchers and policy makers to:

- Ensure collection and reporting of disaggregated data on cancer incidence, outcomes, survival, drug safety, and efficacy within racial, ethnic, sexual, and gender minorities to increase understanding of health disparities among these populations.
- Support the NIH UNITE Initiative, which facilitates inclusivity and diversity, and addresses structural racism within the scientific community, including at NIH.
- Continue to fund NIH's All of Us Research Program with the goal of building a diverse database of one million volunteers that accounts for each participant's environment, lifestyle, family medical history, and genetics to advance the field of precision medicine and improve health outcomes for human diseases including cancer.

Increase Representation of Underserved Communities in Clinical Trials

Racial and ethnic minorities and other medically underserved populations are historically underrepresented in clinical trials. Clinical trial design should be modified to require inclusivity, reduce barriers for patient enrollment, and reach a broader patient population. To ensure racially and ethnically diverse clinical trial participation, AACR recommends the following:

- Require clinical trial sponsors and clinical investigators to:
 - Submit a specific, prospective study plan that outlines how a clinical trial will recruit participants reflective of the patient population affected by the disease intended to be treated;
 - Provide detailed strategies on how such goals will be met including approaches to overcome cultural barriers; and
 - Set prospective plans for how to meet goals in the post market setting if demographic representation goals are not achieved prior to FDA approval of anticancer agents.
- Appoint diversity officers for phase II and III clinical trials to assist with trial design, community engagement, and recruitment strategies for achieving inclusion goals. The diversity officer's role and responsibilities should be clearly defined, and training should be offered to sponsors and investigators on the desired qualifications of a diversity officer.
- Educate clinical investigators and physicians who refer patients to clinical trials on the importance of representation and inclusion in trials and provide training in the importance of cultural humility and the need to address implicit bias.
- Encourage U.S. federally funded trials to create site infrastructure that includes certified navigation, community health workers, and patient advocate networks to ensure diverse enrollment.
- Require that authors of clinical research studies provide background information on the representativeness of the patient sample and the generalizability of the research findings.
- Support passage of H.R. 6585, the Diverse and Equitable Participation in Clinical Trials (DEPICT) Act, which would provide FDA with the authority to require diverse representation in clinical trials, require enhanced data reporting on clinical trial demographics, and increase community engagement by providing grants to Community Health Centers to increase their capacity to participate in clinical trials.
- Support passage of H.R. 5030/S. 2706, the Diversifying Investigations Via Equitable Research Studies for Everyone (DIVERSE) Trials Act, which would allow the U.S. Department of Health and Human Services to

issue grants or contracts to support education, outreach, and recruitment for clinical trials aimed at diseases with a disproportionate impact on underrepresented communities, and to reduce financial barriers associated with clinical trial enrollment by decentralizing clinical trial participation through the use of telehealth.

Prioritize Cancer Control Initiatives and Increase Screening for Early Detection and Prevention

To best utilize evidence-based interventions for prevention, early detection, diagnosis, and treatment to reduce the incidence, morbidity and mortality of cancer, AACR recommends that policy makers:

- Close the disparity gaps in cancer screening using community outreach initiatives and patient navigators to connect individuals with screening and other resources, and using innovative tools such as bundled screenings and mobile screening vans to reach geographically remote underserved and rural communities.
- Fund programs such as the Health Resources and Services Administration Alcee L. Hastings Program for Advanced Cancer Screening in Underserved Communities to assist health centers in increasing access and removing barriers to cancer screening through patient education, outreach, and other community services.
- Support the World Health Organization's Cervical Cancer Elimination Initiative by increasing HPV vaccination, screening, and treatment. In addition, enact H.R. 1550, the PREVENT HPV Cancers Act of 2021, which would enhance CDC efforts through national public awareness campaigns for HPV vaccines and HPV-associated cancers.
- Ensure that USPSTF cancer screening guidance considers race-associated differences in risk and health outcomes.

Ensure Equitable Patient Care and Assist Health Care Providers

It is imperative that all Americans have access to affordable, high-quality health care regardless of their income or where they live. To reduce cancer health disparities in access to care, AACR recommends that policy makers and health care providers:

- Expand Medicaid to ensure that low-income Americans have access to health coverage, reduce underinsurance that poses financial burdens on patients, and ensure that health insurance covers follow-up care and medically necessary tests.
- Relieve the financial burden on safety-net hospitals by preventing cuts to the 340B Drug Pricing Program, which reduces costs of prescription drugs for hospitals serving vulnerable communities.

- Utilize patient navigators and community health care workers to guide patients with cancer from diagnosis through treatment and survivorship, improve patient satisfaction, and reduce disparities in health outcomes.
- Support cancer survivors by providing health coverage for common and effective tools, such as compression garments for lymphedema.
- Provide grants and financial support to expand high-speed Internet to reach underserved areas and reduce the digital divide.

Reduce Cancer Disparities by Building a More Diverse Workforce

To combat structural racism by ensuring that historically underrepresented groups have access to training, mentorship, and career progression in the cancer research and care workforce, AACR recommends that policy makers and the medical research community:

- Improve the medical school curriculum to educate a new generation of health care professionals and researchers in health disparities, social determinants of health, implicit bias, cultural humility, and community engagement.
- Increase the diversity of the cancer research and care workforce so that it reflects the population of patients with cancer in the United States.
- Support student loan repayment programs to make health care careers more accessible for historically underrepresented communities and provide student loan assistance to researchers who focus on racial and ethnic disparities in health.
- Create a network of skilled patient advocates from underrepresented communities and populations.
- Utilize mentorships and peer networks to increase career and financial security for researchers from underrepresented minority populations.

Enact Comprehensive Legislation to Eliminate Racial and Ethnic Health Inequities

The Health Equity and Accountability Act (HEAA), which is a comprehensive legislation introduced on behalf of the Congressional Tri-Caucus comprised of the Congressional Black Caucus, Congressional Asian Pacific American Caucus, and the Congressional Hispanic Caucus, aims to eliminate racial and ethnic health inequities and expand access to high-quality and affordable health care. AACR recommends passage of provisions of the HEAA that would:

- Expand Medicaid under the Affordable Care Act to the remaining states that are yet to implement expansion.
- Increase diversity within the health care workforce by providing grants to HBCUs and Minority-Serving Institutions for counseling, mentoring, and providing financial assistance to recruit underrepresented minority individuals within graduate programs in health care and related fields.
- Implement a Lung Cancer Mortality Reduction Program aimed at reducing lung cancer mortality by at least 25 percent; establish an Interagency Prostate Cancer Coordination and Education Task Force across federal agencies to expand prostate cancer research, screening, awareness, and testing; and require the U.S. Department of Health and Human Services to evaluate disparities in the quality of cancer care within Medicare.
- Reduce the prevalence of tobacco use by expanding coverage for tobacco cessation services under Medicaid and private health insurance plans, increase the excise tax on cigarettes, and create tax parity for other tobacco products.

Fulfilling the recommendations included in our Call to Action demands ongoing, active participation from a broad spectrum of stakeholders. These efforts must be coupled with actions to eradicate the systemic inequities and social injustices that are barriers to health equity, which is one of our most basic human rights.

Conclusion

The *AACR Cancer Disparities Progress Report* to Congress and the American public is a cornerstone of AACR's educational and advocacy efforts in the field of health equity. This second edition of the report is a timely update on the state of knowledge and recent progress against disparities across the continuum of cancer science and medicine.

There has been great progress against cancer in the United States in recent decades, as illustrated by the declining overall cancer mortality rate and the increasing number of cancer survivors. Furthermore, differences in the overall cancer death rate among U.S. racial and ethnic groups are less pronounced now than they have ever been. Despite this progress, marginalized populations continue to shoulder a disproportionate burden of cancer. For example, Black Americans have the highest overall cancer death rate among all racial and ethnic populations, and the burden of many common cancers of the digestive tract or the respiratory system is disproportionately higher in racial and ethnic minorities and other medically underserved populations. The immense toll of U.S. cancer health disparities is also felt through their significant adverse economic impact. According to one estimate, eliminating racial disparities in the incidence of just the four most common types of cancer in the U.S.—lung, colorectal, breast, and prostate—during 2002–2007, would have saved \$2.3 billion in annual medical expenditures.

As discussed in the report, the reasons for cancer health disparities are complex and multifactorial. It is undeniable that a long history of structural racism and other social and institutional injustices have contributed to adverse social determinants of health, which in turn continue to perpetuate inequities, including cancer disparities, for racial and ethnic minorities and other medically underserved populations. From a cancer research and patient care standpoint, many gaps in our knowledge of cancer health disparities remain. As one example, racial and ethnic minorities continue to be underrepresented in clinical trials and cancer genomic data repositories, thus presenting challenges in realizing the full potential of precision medicine for all populations. The report emphasizes the vital need for continued transformative research and for increased collaboration among all stakeholders working toward the bold vision of health equity if we are to ensure that research-driven advances benefit all people, regardless of their race, ethnicity, age, gender, sexual orientation, socioeconomic status, or the community in which they live.

The report highlights several strategies across the cancer continuum that have shown promise in mitigating, and in some cases eliminating, cancer health disparities. For instance, recent clinical studies have shown that disparities in outcomes for several types of cancer can be eliminated if every patient has equitable access to standard treatment. Furthermore, clinical interventions that utilize patient navigation and community engagement have shown promise for improving the diversity of clinical trial participants

and narrowing racial disparities in cancer treatment. Similarly, culturally tailored strategies and community outreach have been effective in increasing the adherence to cancer screening among racial and ethnic minorities. Many initiatives, such as AACR Project GENIE® and NIH's All of Us Program are beginning to provide deep insight into the ancestry-related differences in genetic factors that may contribute to cancer health disparities. To fully realize the collective impact of these approaches, it is imperative that all sectors in medical research continue to work together to eliminate the structural barriers to equitable care so that the advances against cancer can reach all populations.

As the first and largest professional organization in the world focused on preventing and curing all cancers, whose core values are diversity, equity, and inclusion, AACR stands in solidarity in the fight against racism, privilege, and discrimination in all aspects of life. The organization is fiercely committed to accelerating the pace of research to address the disparities in cancer burden faced by racial and ethnic minorities and other underserved populations. One outstanding example is the pioneering AACR Conference on the Science of Cancer Health Disparities in Racial/Ethnic Minorities and the Medically Underserved. Now in its 15th year, this international conference brings together scientists, physicians, and other professionals from academia, industry, and government, as well as patient advocates and members of the community, to stimulate innovative approaches to research on cancer health disparities.

AACR has also long fostered training and educational initiatives that address the gaps in cancer research and care. For more than two decades, the AACR Minorities in Cancer Research constituency group has been leading the way in increasing the number, participation, visibility, and recognition of minority researchers. More recently, AACR has collaborated with the Bristol Myers Squibb Foundation and National Medical Fellowships on an initiative to train 250 community-oriented clinical trial investigators who are underrepresented in medicine or have demonstrated a commitment to increasing diversity in clinical trials; named Robert A. Winn Diversity in Clinical Trials Award Program, this new initiative is a testament to AACR's commitment to eliminating cancer health disparities by propelling tangible improvements in cancer workforce diversity.

Every American must have equitable access to life, liberty, and the pursuit of happiness. Health care is a critical component of these “unalienable rights,” and disparities in health care are among the most significant forms of injustice. AACR is committed to working with our policy makers to ensure that we maintain a sharp focus on prioritizing cancer health disparities research. By providing adequate funding for innovative research, Congress can be of enormous assistance in eradicating cancer health disparities and ensuring that we achieve the bold vision of health equity for racial and ethnic minorities and other medically underserved populations.

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Glossary*

A

Ancestry Informative Markers Ancestry informative markers are sets of polymorphisms for a particular DNA sequence that appear in substantially different frequencies between populations from different geographical regions of the world. Ancestry informative markers can be used to estimate the geographical origins of the ancestors of an individual typically by continent of origin (Africa, Asia, or Europe).

B

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.

C

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 U.S. 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.

*This list contains some of the specialized terms pertinent to the AACR Cancer Disparities Progress Report 2020.

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.

D

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.

E

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.

F

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 U.S. 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.

G

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.

H

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.

I

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.

L

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.

M

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 U.S. 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 U.S. 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 healthcare 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.

N

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 U.S. 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 United States Federal agency for conducting and supporting medical research.

Non-Hispanic Black (NHB) A person who identifies as racially Black or African American (which means having origins in any of the Black racial groups of Africa) and not of Hispanic ethnicity (which means being not of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin).

Non-Hispanic White (NHW) A person who identifies as racially White (which means having origins in any of the original peoples of Europe, the Middle East, or North Africa) and not of Hispanic ethnicity (which means being not of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin).

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.

O

Oncology The branch of medicine that focuses on cancer diagnosis and treatment.

P

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 healthcare 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 healthcare 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 healthcare needs. Similar to a Patient navigator.

Patient Navigator See Patient Advocate.

Patient Protection and Affordable Care Act The first part of the comprehensive health care reform law enacted on March 23, 2010. The law was amended by the Health Care and Education Reconciliation Act on March 30, 2010. The name "Affordable Care Act" is usually used to refer to the final, amended version of the law (It's sometimes known as "PPACA," "ACA," or "Obamacare."). The law provides numerous rights and protections that make health coverage more fair and easier to understand, along with subsidies to make it more affordable. The law also expanded the Medicaid program to cover more people with low incomes.

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.

R

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 U.S. Department of Agriculture categorizes rural and urban areas using the rural-urban commuting area codes, which classify U.S. census tracts—small, relatively permanent statistical subdivisions of a county or statistically equivalent entity—using measures of population density, urbanization, and daily commuting.

S

Social determinants 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 determinants 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. They include chemotherapy, targeted drugs, and immunotherapy

T

Transcriptome The collection of transcribed RNA molecules present in a cell, tissue, or tumor.

Triple-negative breast cancer 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.

U

U.S. Preventive Services Task Force (USPSTF) An independent, volunteer panel of experts in prevention and evidence-based medicine.

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