



AACR CANCER DISPARITIES PROGRESS REPORT 2020

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

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Table of Contents

A Message from the AACR	1	Understanding Cancer Development in the Context of Cancer Health Disparities ...	34
Executive Summary	2	Cancer Initiation: DNA at the Core of Cancer	35
The State of Cancer Health Disparities in 2020	8	Genetic Changes: DNA Mutations in Cancer	35
Disparities in the Burden of Cancer among U.S. Racial and Ethnic Population Groups	11	Epigenetic Changes: DNA's Third Dimension	38
Cancers with a Disproportionate Burden in African Americans	11	Cancer Progression: Role of the Tumor Microenvironment	40
Cancers with a Disproportionate Burden in Hispanics	15	Cancer and the Immune System	41
Cancers with a Disproportionate Burden in Asians/Pacific Islanders	17	Cancer Metastasis	41
Cancers with a Disproportionate Burden in American Indians/Alaska Natives	18	Integrating Our Knowledge: Charting the Path Forward	41
Why Do Cancer Health Disparities Exist?	20	Disparities in the Burden of Preventable Cancer Risk Factors	43
Social Factors Contributing to Cancer Health Disparities	20	Tobacco Use	45
Clinical Factors Contributing to Cancer Health Disparities	21	Obesity	48
Behavioral and Cultural Factors Contributing to Cancer Health Disparities	22	Dietary Factors	50
Psychological Factors Contributing to Cancer Health Disparities	22	Physical Activity	53
Environmental Factors Contributing to Cancer Health Disparities	23	UV Exposure	54
Biological and Genetic Factors Contributing to Cancer Health Disparities	23	Infectious Agents	55
Health Disparities: A Costly Public Health Challenge; Health Equity: A Vital Investment	25	Social and Behavioral Stressors	57
Special Feature on Disparities in COVID-19 and Cancer	27	Other Cancer-causing Factors	57
Why Do COVID-19 Disparities Exist?	27	Outdoor Air Pollution	58
Disparities in SARS-CoV-2 Testing	30	Pesticides and Endocrine-disrupting Chemicals	58
COVID-19 and Cancer Health Disparities	31	Night Shift Work	58
COVID-19 Disparities: A Window of Opportunity to Achieve the Bold Vision of Health Equity?	32	Disparities in Cancer Screening for Early Detection	59
Special Feature References	33	How Can We Screen for Cancer and What Are the Screening Recommendations?	59
		Cancer Screening among U.S. Racial and Ethnic Groups	60
		Breast Cancer Screening	62
		Cervical Cancer Screening	64
		Colorectal Cancer Screening	65
		Lung Cancer Screening	71

Prostate Cancer Screening.....	71	Cancer Workforce Landscape.....	110
Increasing Cancer Screening Rates among Racial and Ethnic Minorities.....	71	<i>Research Scientists</i>	110
Disparities in Cancer Treatment.....	73	<i>Physicians</i>	111
Disparities in Treatment with Surgery.....	75	<i>Other Health Care Professionals</i>	111
Disparities in Treatment with Radiotherapy.....	76	Achieving Health Equity through a Strong and Diverse Future Workforce.....	112
Disparities in Therapeutic Cancer Clinical Trials.....	80	Overcoming Cancer Health Disparities through Science-based Public Policy	114
Lack of Diversity among Clinical Trial Participants.....	80	Funding for Research and Programs That Address Disparities and Promote Health Equity	115
How Can We Overcome the Current Barriers to Trial Participation?.....	82	Collaborative Resources to Advance Research for Health Equity.....	116
Disparities in Treatment with Systemic Therapeutics.....	83	Public Health Policies to Regulate and Reduce the Use of Tobacco Products.....	117
Achieving Equity in Quality Cancer Care.....	89	Achieving the Elimination of Cervical Cancer in the U.S. by Addressing Disparities	118
Disparities in Cancer Survivorship.....	93	Policies to Address Obesity, Poor Diet, and Physical Inactivity	119
Disparities in Long-term and Late Effects of Cancer Treatment.....	94	Policies to Address Disparities in Cancer Screening	119
Disparities in Health-related Quality of Life.....	95	Diversifying Representation in Clinical Trials by Addressing Barriers in Trial Design.....	122
Disparities in Financial Toxicity	96	Diversifying Representation in Clinical Trials by Addressing Barriers for Patients.....	123
Paving the Way for Health Equity for Racial and Ethnic Minority Cancer Survivors	96	Improving Access to High-Quality Clinical Care	124
Imprecision of Precision Medicine.....	100	Coordination of Health Disparities Research and Programs within the Federal Government.....	124
Precision Medicine: The Promise.....	100	The AACR Call to Action.....	125
Precision Medicine: The Challenges.....	101	References.....	127
Precision Medicine: The Future Provides Opportunities to Achieve Health Equity	102	Glossary.....	140
Overcoming Cancer Health Disparities through Diversity in Cancer Training and Workforce	105	Index	144
Diversity in Cancer Training	106		
Cancer Training Landscape.....	107		
Diversity in the Cancer Workforce	108		

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University of Southern California
Los Angeles, California



ELAINE R. MARDIS, PhD, FAACR
The Steve and Cindy Rasmussen Nationwide Foundation Endowed Chair in Genomic Medicine; Co-Executive Director, The Steve and Cindy Rasmussen Institute for Genomic Medicine Nationwide Children's Hospital
Professor of Pediatrics
The Ohio State University College of Medicine
Columbus, Ohio



JOHN M. CARETHERS, MD, MACP
C. Richard Boland Distinguished University Professor; John G. Searle Professor and Chair, Internal Medicine; Professor, Human Genetics
University of Michigan
Ann Arbor, Michigan



GRAHAM A. COLDITZ, MD, DrPH
Associate Director of Prevention and Control, Siteman Cancer Center
Washington University School of Medicine
St. Louis, Missouri



MARCIA R. CRUZ-CORREA, MD, PhD, AGAF, FASGE
Executive Director, UPR Comprehensive Cancer Center; Professor of Medicine & Biochemistry, Medical Sciences Campus
University of Puerto Rico
Director of GI Oncology Program
Oncologic Hospital
San Juan, Puerto Rico



MARGARET FOTI, PhD, MD (hc)
Chief Executive Officer
American Association for Cancer Research
Philadelphia, Pennsylvania



CHANITA HUGHES-HALBERT, PhD
Associate Dean for Assessment, Evaluation, and Quality Improvement, College of Medicine; Professor, Department of Psychiatry and Behavioral Sciences; Distinguished AT&T Endowed Chair for Cancer Equity, Hollings Cancer Center
Medical University of South Carolina
Charleston, South Carolina



RICK A. KITTLES, PhD
Professor and Founding Director, Division of Health Equities
City of Hope Comprehensive Cancer Center
Duarte, California



WILLIAM G. NELSON, MD, PhD
Professor and Director, Sidney Kimmel Comprehensive Cancer Center
Johns Hopkins University
Baltimore, Maryland



LISA A. NEWMAN, MD, MPH
Chief, Section of Breast Surgery; Chief, Breast Cancer Disease Management Team; Chief of the Breast Surgical Oncology Programs of the NYP-WCM Network
Weill Cornell Medicine
New York, New York



BRIAN M. RIVERS, PhD, MPH
Professor and Director, Cancer Health Equity Institute
Morehouse School of Medicine
Atlanta, Georgia



MARY (DICEY) J. SCROGGINS, MA
Founding Partner/Co-Founder
Pinkie Hugs, LLC/In My Sister's Care
Director of Global Outreach & Engagement
International Gynecologic Cancer Society
Washington, DC



SANYA A. SPRINGFIELD, PhD
Director, Center to Reduce Cancer Health Disparities
National Cancer Institute
Rockville, Maryland



MARIANA C. STERN, PhD
Professor of Preventive Medicine and Urology; Ira Goodman Chair in Cancer Research; Associate Director of Population Sciences
University of Southern California, Keck School of Medicine, Norris Comprehensive Cancer Center
Los Angeles, California



ROBERT A. WINN, MD
Director, Massey Cancer Center
Virginia Commonwealth University
Richmond, Virginia

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THE FOLLOWING INDIVIDUALS FOR THEIR HELP
WITH THE DEVELOPMENT OF THIS REPORT.

LUCILE L. ADAMS-CAMPBELL, PhD

Professor of Oncology, Associate Dean for Community
Health and Outreach
Georgetown Lombardi Comprehensive Cancer Center
Washington, DC

KIMLIN TAM ASHING, PhD

Professor
Beckman Research Institute,
City of Hope Comprehensive Cancer Center
Duarte, California

ONYINYE BALOGUN, MD

Assistant Professor, Radiation Oncology
Weill Cornell Medicine
New York, New York

NADINE J. BARRETT, PhD, MA, MS

Associate Director, Community Engagement
and Stakeholder Strategy
Duke Cancer Institute and Duke Clinical and
Translational Science Institute
Duke University School of Medicine
Durham, North Carolina

BRIAN C. DAVIS

Senior Health Communications Specialist
Center to Reduce Cancer Health Disparities
National Cancer Institute
Rockville, Maryland

MELISSA B. DAVIS, PhD

Assistant Professor, Surgery
Weill Cornell Medicine
New York, New York

LAURA FEJERMAN, PhD

Associate Professor, Institute of Human Genetics,
Helen Diller Family Comprehensive Cancer Center
University of California San Francisco
Berkeley, California

KEVIN L. GARDNER, MD, PhD

Professor of Pathology and Cell Biology and Senior
Vice Chair, Department of Pathology and Cell Biology
Columbia University
New York, New York

DANIEL J. GEORGE, MD

Professor of Medicine
Professor in Surgery
Duke Cancer Institute
Durham, North Carolina

MARÍA DEL MAR GONZÁLEZ-PONS, PhD

Assistant Professor, Division of Cancer Biology
University of Puerto Rico Comprehensive Cancer Center
San Juan, Puerto Rico

SUSAN HONG, MD, MPH

Director of Cancer Survivorship
University of Illinois Cancer Center
Chicago, Illinois

ALISON LIN, PhD

Deputy Chief, Diversity Training Branch
Center to Reduce Cancer Health Disparities
National Cancer Institute
Rockville, Maryland

JULYANN PÉREZ MAYORAL, PhD

Division of Cancer Biology
University of Puerto Rico Comprehensive Cancer Center
San Juan, Puerto Rico

LORNA H. MCNEILL, PhD, MPH

Chair and Associate Professor
University of Texas MD Anderson Cancer Center
Houston, Texas

STEVEN R. PATIERNO, PhD

Deputy Director
Duke Cancer Institute
Durham, North Carolina

AMELIE G. RAMIREZ, DrPH, MPH

Chair ad Interim and Professor
University of Texas Health San Antonio/
Institute for Health Promotion Research
San Antonio, Texas

BODOUR SALHIA, PhD

Assistant Professor
Keck School of Medicine, University of Southern California
Los Angeles, California

MARY ANN S. VAN DUYN, PhD, MPH

Associate Deputy Director for Integration
Center to Reduce Cancer Health Disparities
National Cancer Institute
Rockville, Maryland

TIFFANY A. WALLACE, PhD

Program Director
Center to Reduce Cancer Health Disparities
National Cancer Institute
Rockville, Maryland

KEVIN P. WILLIAMS, PhD

Professor, Pharmaceutical Sciences/Principal Investigator at BRITE
North Carolina Central University
Durham, North Carolina

JELANI C. ZARIF, PhD, MS

Assistant Professor of Oncology, Prostate Cancer Program
Member, Bloomberg-Kimmel Institute for Cancer Immunotherapy
Sidney Kimmel Comprehensive Cancer Center
Johns Hopkins School of Medicine
Baltimore, Maryland

AACR Staff

RAJARSHI SENGUPTA, PhD

Senior Editor and Scientific Advisor
Philadelphia, Pennsylvania

KAREN HONEY, PhD

Lead Science Writer, Cancer Progress Report
Philadelphia, Pennsylvania

JENNA M. BACHEN

Associate Creative Director, Marketing and
Creative Services
Philadelphia, Pennsylvania

HEATHER CLARK

Designer, Marketing and Creative Services
Philadelphia, Pennsylvania

GREGORY L. COSBY

Senior Production Editor
Philadelphia, Pennsylvania

PAUL J. DRISCOLL, Jr.

Senior Director, Marketing and Creative Services
Philadelphia, Pennsylvania

JOSHUA F. GOLDSTEIN

Director, Brand Strategy Communications
Philadelphia, Pennsylvania

STEPH GUERRA, PhD

Summer Intern, Science and Health Policy
Washington, DC

AUDREY F. JACKSON, PhD

Director, Science and Health Policy
Washington, DC

MARC JOHNSON, MPP

Senior Manager, Congressional Relations
Washington, DC

CARMINE LEGGETT, PhD

Assistant Director, Science and Health Policy
Washington, DC

BRANDON L. LEONARD, MA

Associate Director, Congressional Relations
Washington, DC

SARAH MARTIN, MS, PhD

Director, Regulatory Science and Policy
Washington, DC

MARY ANNE MENNITE

Executive Editor and Senior Liaison to the CEO
Philadelphia, Pennsylvania

JON G. RETZLAFF, MBA, MPA

Chief Policy Officer and Vice President
Washington, DC

SHAWN M. SWEENEY, PhD

Director, AACR Project GENIE Coordinating Center
Philadelphia, Pennsylvania

CARRIE TREADWELL, MBA

Director, Patient Advocacy and Engagement
Washington, DC

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 47,000 laboratory, translational, and clinical researchers; population scientists; other health care professionals; and patient advocates residing in 127 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, with more than 100,000 attendees for the 2020 virtual meetings and more than 22,500

attendees for past in-person meetings. In addition, the AACR publishes nine 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](https://www.aacr.org).

A MESSAGE FROM THE AACR

This is a time of extraordinary promise in cancer science and medicine. As highlighted in our *AACR Cancer Progress Report 2020*, in the United States, overall cancer death rates are steadily declining, and the number of survivors living with cancer has reached a record high. The unparalleled progress against cancer is being driven by transformative science that is spurring advances in public health and breakthroughs across the continuum of cancer research and care. However, progress against cancer has not benefited everyone equally, and certain segments of the U.S. population shoulder a disproportionate burden of the disease.

Racial and ethnic minorities and other underserved populations are among the groups in the United States that have long experienced cancer health disparities. A glaring example of these disparities is that African Americans have the highest overall cancer death rate of any other racial or ethnic group in the United States. The stark inequities in cancer burden have drawn renewed attention and concern in the face of the ongoing COVID-19 pandemic as well as the recently witnessed inhumanities against people of color. The significant social and health inequities experienced by racial and ethnic minorities are a result of decades of structural and systemic racism. Therefore, as a scientific organization focused on the conquest of all cancers whose core values include equality, diversity, and inclusion, the AACR is deeply committed to realizing the vision of social justice and equality for all racial and ethnic minorities, both nationally and globally.

Research has fueled progress in identifying, quantifying, and understanding the causes of cancer health disparities in the United States, which is a vital step toward developing and implementing strategies to eliminate cancer health disparities. Encouragingly, differences in the overall cancer death rates among racial and ethnic population groups in the United States have narrowed over the past two decades, and several studies have shown that racial and ethnic disparities in outcomes for several types of cancer, including prostate cancer and multiple myeloma, could have been eliminated if all patients had equal access to standard treatment. Despite this progress, the goal of eliminating racial and ethnic disparities in the burden of cancer has yet to be realized.

As we look to the future, we strongly believe that a deeper understanding of the biology of cancer in racial and ethnic minorities is essential if we are to ensure that all population groups benefit from precision medicine, which is a new approach to cancer treatment that harnesses our growing knowledge of individual patients and the specific characteristics of their cancers to make informed decisions about their best treatment options. Novel initiatives, such as AACR Project Genomics Evidence Neoplasia Information Exchange (GENIE); the African American Breast Cancer Epidemiology and Risk Consortium; and the Research on Prostate Cancer in Men of African Ancestry: Defining the Roles of Genetics, Tumor Markers, and Social Stress study, are beginning to provide insights into the biological and genetic factors that are associated with cancer in racial and ethnic minorities. To accelerate the pace of this progress and deliver innovative breakthroughs for all people, it is crucial that the cancer health disparities research community develop research models and biospecimens that are representative of all populations. Further, the participation of racial and ethnic minority patients in cancer

clinical trials must be increased as it will provide vitally important data for the improvement of clinical outcomes in these patients.

The AACR has been a longtime leader in advancing the science of cancer health disparities. Our organization has convened scientific conferences on the topic of cancer health disparities for over a decade, bringing together scientists, physicians, and other professionals from academia, industry, and government, as well as patient advocates and members of the community, to discuss the latest developments in the cancer field, and stimulate innovative approaches to research on cancer health disparities. This year, we are celebrating the 20th anniversary of the AACR Minorities in Cancer Research membership group, which is dedicated to supporting the careers of minority scientists and fostering the field of cancer health disparities research.

The *AACR Cancer Disparities Progress Report 2020* is an exciting new initiative with the overarching goal of increasing public understanding of cancer health disparities and of the vital importance of cancer health disparities research to saving lives. The report underscores the need for increased annual federal funding for the 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).

Every American is entitled to 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 inequality and injustice. The AACR will work together with all stakeholders to galvanize the momentum that has been created by the current movement against racial inequality to effect long-term positive changes in cancer research and care for the benefit of all. We will continue to actively promote high-quality, impactful science and policies that benefit everyone equally, and at the same time dedicate our efforts to the elimination of cancer health disparities and the inclusion and recognition of the contributions of minority investigators in cancer research. Furthermore, the AACR is committed to working with policy makers to ensure that cancer health disparities research becomes a national priority. By providing adequate funding for such innovative research, Congress can be of enormous assistance in unraveling the complexities of cancer health disparities and ensuring that we achieve the bold vision of health equity in racial and ethnic minorities and other underserved populations.



Margaret Foti, PhD, MD (hc)
AACR Chief Executive Officer



John D. Carpten, PhD
Chair, AACR Cancer
Disparities Progress Report
2020 Steering Committee

Executive Summary

IN THIS REPORT, YOU WILL LEARN:

- ▶ Cancer health disparities are an enormous public health challenge in the United States.
- ▶ Racial and ethnic minority populations are among the U.S. population groups that have long experienced cancer health disparities.
- ▶ Many of the U.S. population groups that experience cancer health disparities are also experiencing disparities related to the Coronavirus Disease 2019 (COVID-19) pandemic.
- ▶ There has been progress in reducing cancer incidence and health disparities, as illustrated by the fact that disparities in the overall cancer death rates among racial and ethnic groups are less pronounced now than they have been in the past two decades.
- ▶ Striking disparities in exposure to preventable cancer risk factors, rates of cancer screening for early detection, receipt of standard of care cancer treatment, and the burden of adverse effects of cancer and cancer treatment persist for racial and ethnic minorities and other underserved populations in the United States.
- ▶ Researchers have identified many factors that contribute to cancer health disparities and learned that these factors are complex and interrelated.
- ▶ Many studies and initiatives are beginning to provide deep insight into the biological and genetic factors that contribute to cancer health disparities.
- ▶ Enhancing diversity in the pool of trainees, researchers, and health care workers, and developing science-based public policies that advance cancer prevention and early detection for individuals, families, and communities will allow us to overcome cancer health disparities.

This is a time of great excitement in cancer science and medicine because research discoveries are continually being translated to new and better approaches to cancer prevention, detection, diagnosis, treatment, and survivorship. However, the grim reality is that progress against cancer has not benefited everyone equally, and certain segments of the U.S. population shoulder a disproportionate burden of cancer. The adverse differences in the burden of cancer that exist among certain population groups are referred to as cancer health disparities.

Racial and ethnic minorities are among the population groups in the United States that have long experienced cancer health disparities. They are also shouldering a disproportionate burden of the ongoing Coronavirus Disease 2019 (COVID-19) pandemic, further highlighting stark inequities in health care. Disparities in health care are among the most significant forms of inequality 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.

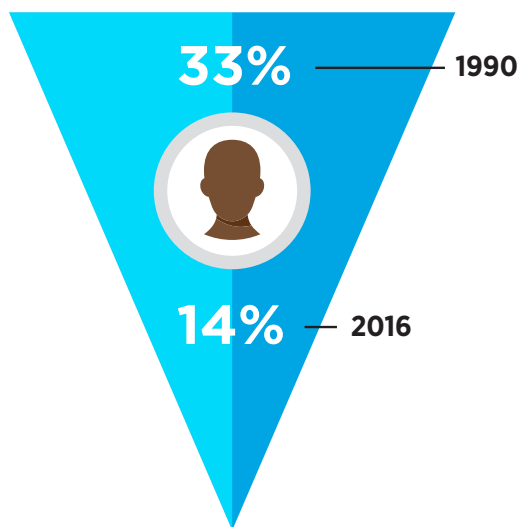
As the first and largest professional organization in the world focused on the conquest of cancer whose core values include equality, diversity, and inclusion, the American Association for Cancer Research (AACR) stands in solidarity in the fight against racism, privilege, and discrimination in all aspects of life. The organization is committed to accelerating the pace of research to address the disparities in cancer incidence and mortality faced by racial and ethnic minorities and other 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 inaugural AACR Cancer Disparities Progress Report to Congress and the American public is a cornerstone of the AACR's educational and advocacy efforts in the field of cancer health disparities. The report highlights areas of progress in reducing cancer health disparities. It also 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 communities in which they live.

The State of Cancer Health Disparities in 2020

Even though we are making great progress against cancer in the United States, as illustrated by the declining overall cancer death rate and the increasing number of cancer survivors, it is projected that there will still be 1,806,590 new cases of cancer diagnosed in 2020 and 606,520 deaths from the disease. The immense burden of cancer is not shouldered equally by all segments of the U.S. population. The adverse differences in cancer burden that exist among certain population groups, are one of the most pressing public health challenges that we face in the United States.

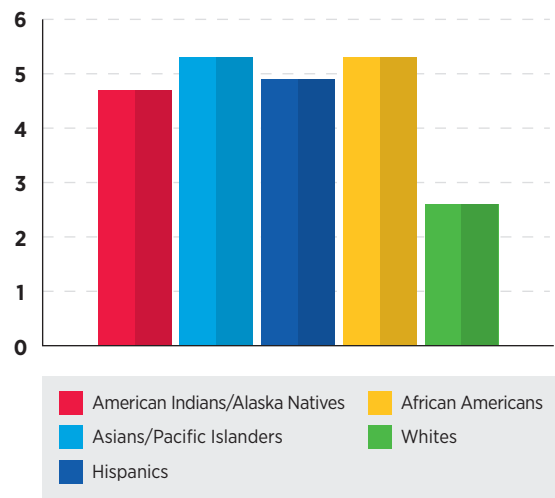
DECLINE IN DISPARITY FOR OVERALL CANCER DEATH RATE BETWEEN AFRICAN AMERICANS AND WHITES



Racial and ethnic minority populations are among the U.S. population groups that have long experienced cancer health disparities. For example, African Americans have had the highest overall cancer death rate of any racial or ethnic group in the United States for more than four decades. Encouragingly, differences in the overall cancer death rate among racial and ethnic groups are less pronounced now than they have ever been. Despite this progress, however, striking disparities in cancer incidence and death persist for racial and ethnic minority groups in the United States.

Thanks to research, we have identified many factors that contribute to cancer health disparities and learned that these factors are complex and interrelated. Among the most important factors are social factors such as education and income; clinical factors such as access to health care; behavioral factors such as tobacco use, obesity, and physical inactivity; cultural factors such as cultural health beliefs;

STOMACH CANCER DEATH RATES PER 100,000 FOR BOTH SEXES, ALL AGES



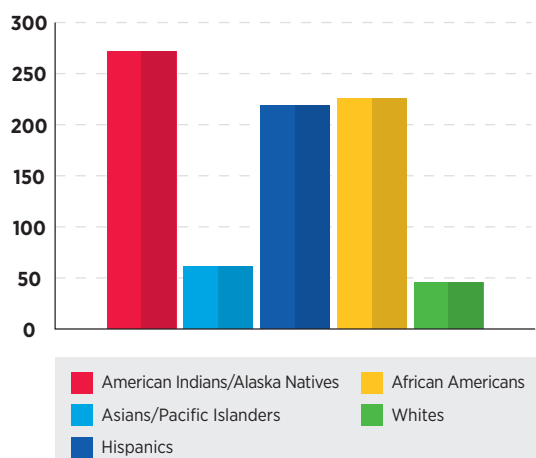
psychological factors such as stress and mental health; environmental factors such as housing and transportation; and biological and genetic factors. Increasing our understanding of the relative contributions of different factors is an area of intensive research investigation because this knowledge is vital if we are to develop and implement interventions that will eliminate cancer health disparities.

The immense toll of health disparities, including cancer health disparities, is felt through the number of lives it affects each year and through its significant economic impact. For example, it is projected that eliminating all health disparities for racial and ethnic minorities would have reduced direct medical costs by about \$230 billion and indirect costs associated with illness and premature death by more than \$1 trillion from 2003 to 2006. Given the tremendous personal and economic burden of health disparities, it is clear that health disparities research, including cancer health disparities research, is a vital national investment if we are to achieve the bold vision of health equity.

Special Feature on Disparities in COVID-19 and Cancer

On March 11, 2020, the World Health Organization (WHO) declared the global health crisis caused by the rapid spread of Coronavirus Disease 2019 (COVID-19), which is caused by infection with severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), a pandemic. As of July 31, 2020, almost 4.6 million people in the United States had been diagnosed with COVID-19 and more than 150,000 people in the country had died from the disease. These figures were about 25 percent of the global numbers on that same day.

COVID-19-ASSOCIATED HOSPITALIZATION RATES, PER 100,000 POPULATION, MARCH 1 – JULY 4, 2020



Source: CDC COVID-NET

Racial and ethnic minorities, in particular African Americans and Hispanics, have shouldered a disproportionate burden of COVID-19 in the United States. There are several complex and interrelated factors that contribute to the COVID-19 disparities experienced by racial and ethnic minorities. Some of these factors overlap with the factors that contribute to cancer health disparities, including social and clinical factors. In addition, racial and ethnic minorities are more likely to have one or more of the health conditions discovered to increase a person's chance of severe COVID-19.

The COVID-19 pandemic has created many challenges across the continuum of cancer care, with concern about the effects that delays in cancer screening, diagnosis, and treatment will have on outcomes for patients with cancer, in particular racial and ethnic minorities because these population groups have shouldered a disproportionate burden of COVID-19. Experts predict that the COVID-19 pandemic will exacerbate existing health disparities, including cancer health disparities. Therefore, it is imperative that all stakeholders work together to galvanize the momentum that has been created by the pandemic and by the current movement against racial inequality to reduce the unequal burden of all diseases, including COVID-19 and cancer.

Understanding Cancer Development in the Context of Cancer Health Disparities

Discoveries across the breadth of biomedical research have led to our current understanding of how cancer arises and develops.

We know that cancer is not one disease but rather a collection of diseases that arise when the processes that control the growth, division, and life span of normal cells go awry. This happens primarily because of changes, or mutations, in the genetic material of normal cells. However, epigenetic abnormalities, as well as interactions between cancer cells and their environment—known as the tumor microenvironment—also play an important role.

Even though most mutations are acquired over an individual's lifetime due to errors arising during normal cell division or because of exposure of the cell to external factors, such as toxicants in tobacco smoke and ultraviolet (UV) light from the sun, inherited mutations are linked to about 10 percent of cancer cases. Unfortunately, data on acquired and inherited cancer-associated mutations come predominantly from mostly white individuals of Western European ancestry. Many studies and initiatives are beginning to provide insight into the genes and specific mutations that are associated with cancer in racial and ethnic minorities who may have lower amounts of European genetic ancestry, such as many African Americans and Hispanics, but there is an urgent need to significantly increase research into this important factor influencing cancer health disparities.

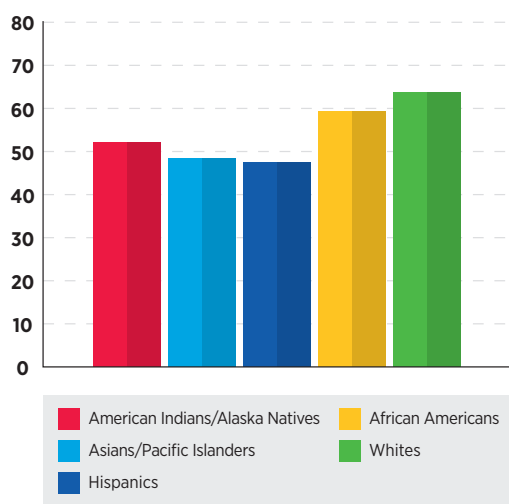
Disparities in the Burden of Preventable Cancer Risk Factors

Decades of research have led to the identification of numerous factors that increase a person's chance of developing cancer. Many of these factors, which are often referred to as cancer risk factors, are related to lifestyle. Therefore, a person can reduce his or her risk of developing certain types of cancer by modifying behaviors.

The major potentially modifiable cancer risk factors are tobacco use, excess body weight, lack of physical activity, alcohol consumption, exposure to UV light from the sun or tanning devices, and failure to use interventions that treat or prevent infection with cancer-associated pathogens, such as cancer-causing strains of human papillomavirus (HPV).

Despite knowledge that exposure to many cancer risk factors can be modified, it is estimated that more than four out of 10 cancer cases diagnosed among U.S. adults age 30 and older are attributable to potentially modifiable causes. Moreover, exposure to many of the major cancer risk factors continues to occur particularly among segments of the U.S. population that experience cancer health disparities, including racial and ethnic minorities. Therefore, there is an urgent need for new strategies to enhance the dissemination of our current knowledge of cancer prevention and to implement evidence-based interventions to reduce the burden of cancer for all populations.

PERCENT OF ADULTS UP TO DATE WITH COLORECTAL CANCER SCREENING BY RACE AND ETHNICITY



Disparities in Cancer Screening for Early Detection

Cancer screening means checking for precancerous lesions or for cancer in people who have no signs or symptoms of the cancer for which they are being checked. Finding precancerous lesions or cancer at an early stage of development makes it more likely that a cancer can be intercepted, and a patient treated successfully.

Breast, cervical, colorectal, and prostate cancers are the four types of cancer for which screening tests have been developed and used to screen people who are generally healthy and at average risk for the cancers being screened for. Tests to check for other types of cancer, such as lung and liver cancers, are used only for screening people who are at increased risk for developing the cancers being screened for.

Screening for cancer has many benefits, but it also has the potential to cause unintended harms, which is why cancer screening is not recommended for everyone. Therefore, individuals should regularly consult with their health care providers to develop a cancer screening plan that is tailored to their own unique cancer risks, general health, and tolerance for the potential harms of a screening test.

Even though the benefits of cancer screening outweigh the potential risks for defined groups of individuals, many people for whom screening is recommended do not get screened. Individuals who are not up to date with cancer screening recommendations are disproportionately found among segments of the U.S. population that experience cancer health

disparities, including racial and ethnic minority groups. Developing targeted strategies for each type of screening and for each racial and ethnic minority group is an area of active research investigation.

Disparities in Cancer Treatment

The dedicated efforts of individuals working throughout the cycle of biomedical research are constantly powering the translation of new research discoveries into advances in cancer treatment that are improving the survival and quality of life for U.S. adults and children like **Fernando Whitehead** (see p. 87).

Clinical trials are a vital part of the biomedical research cycle because they establish whether or not new cancer treatments are safe and effective for the patients who need them. Therefore, it is imperative that participants in clinical trials that are testing new cancer treatments represent the entire population who may use them if they are approved. Despite this knowledge, participation in cancer clinical trials is low, and there is a serious lack of racial and ethnic diversity among those who do participate, as **Karen Peterson** discovered when she enrolled in a new combination immunotherapy clinical trial (see p. 85). It is imperative that we overcome the many barriers to clinical trial participation if we are to ensure that all segments of the population benefit from progress against cancer.

Research discoveries made as a result of innovative cancer science are continually being converted to lifesaving advances in cancer treatment. It is important to note, however, that new FDA-approved cancer treatments are being used in addition to those already in use. Consequently, most patients with cancer are treated with some combination of surgery, radiotherapy, cytotoxic chemotherapy, molecularly targeted therapy, and immunotherapy.

Despite the advances in cancer treatment, patients from certain population groups, including racial and ethnic minorities and other underserved populations, are often 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, including prostate cancer and multiple myeloma, can be eliminated if all patients have equal access to standard treatment. Therefore, it is imperative that stakeholders work together to address the challenge of disparities in cancer treatment and achieve the goal of health equity.

Disparities in Cancer Survivorship

Research-fueled advances in cancer care are helping more and more people to survive longer after a cancer diagnosis. According to the latest estimates, more than 16.9 million cancer survivors were living in the United States on January 1, 2019.

Despite this progress, life after a cancer diagnosis can be challenging not only for those diagnosed with the disease, but also for their caregivers. Many of the challenges, which include physical, emotional, psychosocial, and financial challenges, begin during cancer treatment and continue in the long term, but others can appear months or even years later. The challenges faced by each patient and survivor are unique, but individuals who are part of U.S. population groups that experience cancer health disparities shoulder a disproportionate burden of the adverse effects of cancer and cancer treatment.



An interdisciplinary team science approach to cancer survivorship research is important for addressing the disparities in cancer morbidity, mortality, and quality of life experienced by racial and ethnic minority cancer survivors. However, this research must be informed by the voices of community members like patient advocate **Ghecemy Lopez** (see p. 99). Patient advocates are uniquely positioned to represent their own communities as partners in research projects, and the effective engagement of these community

members will result in improved health care and health status in underserved populations.

Imprecision of Precision Medicine

In recent years, we have made remarkable progress in understanding the biology of cancer, including learning that each person's cancer is unique because it is influenced by the individual's biological characteristics, environmental exposures, and lifestyle. This knowledge set the stage for the new era of precision medicine, an era in which the standard of care for many patients is changing from a one-size-fits-all approach to one in which greater understanding of individual patients and the specific characteristics of their cancer dictates the best treatment options for the patient.

Currently, our limited knowledge of cancer biology in racial and ethnic minorities, including their inherited cancer predisposition and the genomic underpinnings of cancer initiation and progression, diminishes the potential of precision medicine in these populations. However, research initiatives like AACR Project Genomics Evidence Neoplasia Information Exchange (GENIE) are beginning to provide more information about cancer in all populations. Such initiatives, together with new insights obtained through investigations that incorporate research models and biospecimens that are representative of all populations and the inclusion of all segments of the U.S. population in cancer clinical trials will allow us to develop and implement precision medicine for all patients with cancer.

Overcoming Cancer Health Disparities through Diversity in Cancer Training and Workforce

A lack of diversity in the pool of well-prepared trainees and well-trained researchers, and a lack of diversity in the health care workforce, contribute to cancer health disparities.

Enhancing diversity in training and in the cancer workforce will enhance the perspectives included and represented, fuel creativity, and make the training pipeline and workforce more reflective of our increasingly diverse nation and the populations bearing the unequal burden of cancer. Given that diversity can be defined as the full range of human similarities and differences including gender, race and ethnicity, social class, role within an organization, age, religion, sexual orientation, physical ability, and other group identities, it is clear that all stakeholders must work together to achieve the bold vision of health equity.

Overcoming Cancer Health Disparities through Science-based Public Policy

There has been some progress to date in reducing cancer health disparities, as evidenced by the narrowing of racial and ethnic disparities in the overall cancer incidence and death rates over the past two decades. This progress is a result of the concerted efforts of all stakeholders committed to eliminating cancer health disparities.

To deepen our understanding of cancer health disparities and take significant strides toward achieving health equity, it will be necessary for Congress to provide robust, sustained, and predictable annual budget increases for the NIH and the NCI. We must also continue our nation's commitment to supporting the cancer prevention and control programs at the CDC. These vital investments will help support a diverse research workforce and allow us to pursue policies that advance cancer prevention, early detection, and control for individuals, families, and communities.

The AACR Call to Action

Research is driving tremendous progress against cancer, but the grim reality is that the progress has not benefited everyone equally. The adverse differences in the burden of cancer that exist among certain population groups are among the most pressing public health challenges that we face in the United States.

In recent years, some strides have been made in combating cancer health disparities, as illustrated by narrowing of racial and ethnic disparities in the overall cancer incidence and death rates. However, progress has come too slowly, and the cost of all health disparities, including cancer and COVID-19 health disparities—in terms of premature deaths, lost productivity, and the impact on communities—remains monumental and must be addressed.

Therefore, the AACR urges policy makers and all 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.

- Implement steps to ensure that clinical trials include a diverse population of participants.
- Support programs to make sure that the health care workforce reflects and appreciates the diverse communities it serves.
- Prioritize cancer control initiatives.
- Work with members of the Congressional Tri-Caucus—comprised of the Congressional Asian Pacific American Caucus, Congressional Black Caucus, and Congressional Hispanic Caucus—to pass the provisions included in the Health Equity and Accountability Act (HEAA).

By making sure that cancer health disparities research is a national priority, Congress can help us transform cancer care for all people, regardless of their race, ethnicity, age, gender, sexual orientation, socioeconomic status, or the communities in which they live. When this support is coupled with increased collaboration among all stakeholders, achieving the bold vision of health equity will become a reality.

The AACR has been a longtime leader in advancing the science of cancer health disparities and working toward the elimination of cancer health disparities, and we are proud to share this latest effort, the *AACR Cancer Disparities Progress Report 2020*. This inaugural annual report raises awareness of the key actions that are required to overcome the enormous public health challenge posed by cancer health disparities in racial and ethnic minorities. These actions include enhancing minority participation in clinical trials, prioritizing cancer control efforts, increasing the number of minority researchers in the cancer workforce, and ensuring robust and sustained funding for federal agencies that conduct research that drives progress against cancer health disparities. 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 action to eradicate the social injustices that are barriers to health equity, which is one of our most basic human rights. This is why the AACR stands in solidarity in the fight against racism, privilege, and discrimination in all aspects of life and actively supports policies that guarantee equitable access to quality health care to eradicate all barriers to achieving the bold vision of health equity.

The State of Cancer Health Disparities in 2020

IN THIS SECTION, YOU WILL LEARN:

- ▶ Cancer health disparities are adverse differences in cancer burden experienced by certain groups, including racial and ethnic minorities, individuals of low socioeconomic status, and members of the lesbian, gay, bisexual, and transgender community.
- ▶ Progress in reducing cancer health disparities is being made, as illustrated by the narrowing of the disparity in the overall cancer death rate for African Americans compared with whites from 33 percent higher in 1990 to 14 percent higher in 2016.
- ▶ Research has identified several complex and interrelated factors which contribute to cancer health disparities, including social, clinical, behavioral, cultural, environmental, and biological and genetic factors.
- ▶ The economic burden of health disparities, including cancer health disparities, is enormous.
- ▶ We can accelerate the pace of progress by enhancing collaboration among stakeholders committed to eliminating cancer health disparities.

Cancer is an enormous public health challenge in the United States and around the world. In the United States alone, it is projected that 1,806,590 new cases of cancer will be diagnosed in 2020 and that there will be 606,520 deaths from the disease (1). These numbers translate into 206 new cancer cases and 69 cancer deaths every hour of every day.

The grim reality is that the burden of cancer is not shouldered equally by all segments of the U.S. population (see sidebars on **Which U.S. Population Groups Experience Cancer Health Disparities?**, p. 9, and **U.S. Cancer Health Disparities at a Glance**, p. 10). Adverse differences in the burden of cancer

that exist among certain population groups are referred to as cancer health disparities. The exact measures of cancer burden that are considered when discussing cancer health disparities can vary. Throughout this report, we use the National Cancer Institute (NCI) definition of cancer health disparities:

- Cancer health disparities are adverse differences between certain population groups 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 (2).



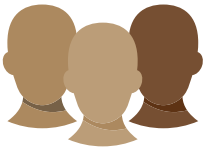










U.S. SENATOR FOR SOUTH CAROLINA

The Honorable Tim Scott

“While the past decade has seen tremendous advances in cancer research, troubling disparities in incidence, prevalence, and mortality remain. We need to address cancer disparities comprehensively, recognizing the complexity of the challenges at hand and enhancing efforts to better proactively prevent, efficiently detect, and effectively target and treat all cancer types. I commit to continuing to work with my colleagues on both sides of the political aisle to craft new pathways for novel diagnostic tools that will accelerate and improve disease detection, to leverage technology and innovative payment models to reduce access barriers, and to protect and bolster the incentives for innovation that will usher in new waves of groundbreaking therapeutic options.”

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

According to the National Cancer Institute (2) 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>racial and ethnic minority groups;</p> 	<p>individuals of different ancestry;</p> 	<p>individuals of low socioeconomic status;</p> 	<p>individuals with disabilities;</p> 
<p>individuals who lack or have limited health insurance coverage;</p> 	<p>residents in certain geographic locations, including rural areas;</p> 	<p>members of the lesbian, gay, bisexual, and transgender community;</p> 	<p>immigrants;</p> 
<p>refugees or asylum seekers;</p> 	<p>adolescents and young adults; and</p> 	<p>the elderly.</p> 	

Adapted from (3)



U.S. REPRESENTATIVE FOR OHIO'S 3RD DISTRICT

The Honorable Joyce Beatty

Vice-Chair, Congressional Black Caucus

“Throughout my time in Congress, I have been an outspoken advocate on the critical need to reduce health disparities in communities of color. Still today, we know that far too many men and women of color don’t receive the care and treatment they deserve—even when access to health care is available. The Cancer Disparities Progress Report will identify and address these obstacles so that we can ultimately improve health outcomes for all Americans.”

In this opening chapter of the inaugural AACR Cancer Disparities Progress Report, we provide an overview of the current status of disparities in cancer incidence rates (the number of new individuals diagnosed with cancer per 100,000 people in the population of interest) and cancer death rates (the number of individuals who die from cancer per 100,000 people in the population of interest) in the United States with

a focus on the disparities experienced by the major racial and ethnic minority groups in the United States—African Americans, Hispanics, Asians/Pacific Islanders, and American Indians/Alaska Natives (see sidebar on **U.S. Racial and Ethnic Population Groups**, p. 11). Other chapters of the report highlight disparities in other measures of cancer burden with an emphasis on African Americans and Hispanics.

U.S. Cancer Health Disparities at a Glance

Adverse differences in numerous measures of cancer burden exist among certain population groups in the United States. Examples of such disparities include:

111% and 39%
HIGHER RISK

African American men and women have a **111 percent and 39 percent higher risk of dying from prostate cancer and breast cancer**, respectively, compared with their white counterparts (4).

20% and 38%
MORE LIKELY

Hispanic children and adolescents are **20 percent and 38 percent more likely to develop leukemia** than non-Hispanic white children and adolescents, respectively (5).

TWICE
AS LIKELY

Asian/Pacific Islander adults are **twice as likely to die from stomach cancer** as white adults (6).

TWICE
AS LIKELY

American Indian/Alaska Native adults are **twice as likely to develop liver and bile duct cancer** as white adults (6).

3.5X
HIGHER

Men living in Kentucky have **lung cancer incidence and death rates that are about 3.5 times higher** than those for men living in Utah (7).

<HALF
AS LONG

Patients with localized hepatocellular carcinoma, the most common type of liver cancer, who have no health insurance have **overall survival that is less than half as long** as those who have private health insurance (8 months versus 18 months) (8).

35%
HIGHER

Men living in the poorest counties in the United States have a **colorectal cancer death rate that is 35 percent higher** than that for men living in the most affluent counties (6).

70%
MORE LIKELY

Bisexual women are **70 percent more likely to be diagnosed with cancer** than heterosexual women (9).



U.S. REPRESENTATIVE FOR NEW YORK'S 5TH DISTRICT

The Honorable Gregory W. Meeks

"Whether you're looking at new diagnoses or death rates, it is clear that cancer health disparities is a serious issue for the African American community in particular. For prostate cancer alone, Black men are twice as likely to die from that disease as their white counterparts. We need to redouble our investments into researching why these disparities exist and increase awareness to vulnerable communities about the importance of lifesaving early detection. Meanwhile, as Congress begins its appropriations for the next fiscal year, I will work to ensure that Congress is doing its part in providing funding for NIH and DOD to conduct research that will hopefully save lives."

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 (10). 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 Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam.

Native Hawaiian or Other Pacific Islander

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

*Hispanic or Latino/a

A person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race. The term "Spanish origin" can be used in addition to "Hispanic or Latino/a."

*African American or Black

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

White

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

When using race and ethnicity in record-keeping and reporting, including in the cancer statistics collected and reported by the National Cancer Institute's Surveillance, Epidemiology, and End Results Program, Asians and Native Hawaiians or other Pacific Islanders are often considered together and referred to as Asians/Pacific Islanders.

It is important to note that data collected on race and ethnicity relies on individuals self-reporting this information. Therefore, it may be influenced by sociopolitical constructs and may not fully reflect the individual's genetic ancestry.

*In this document, we use the terms African American and Hispanic without preference or prejudice.

Identifying, quantifying, and understanding the causes of cancer health disparities is a vital step toward developing and implementing strategies to eliminate the disparities and achieve cancer health equity. According to the World Health Organization, health equity is the idea that all people should have a fair opportunity to attain their full health potential regardless of demographic, social, economic, or geographic strata (11).

Health equity is one of our most basic human rights. Unfortunately, for most racial and ethnic minorities, including African Americans and Hispanics, racism, discrimination, prejudice, and inequality limit, if not prevent, full access to this right. As we celebrate the legacy of the late **Congressman John Lewis**, a leader on civil rights issues, including health disparities, it is vital that all stakeholders come together to eradicate the social injustices that are barriers to health equity (see p. 12).

Disparities in the Burden of Cancer among U.S. Racial and Ethnic Population Groups

It has long been recognized that the burden of cancer, as measured by cancer incidence and death rates, is not equivalent among the different racial and ethnic groups in the United States. For example, when considering all cancers combined, African Americans have the highest cancer death rate followed by whites, American Indians/Alaska Natives, Hispanics, and Asians/Pacific Islanders (4).

Differences in the overall cancer incidence and death rates among racial and ethnic groups in the United States are less pronounced now than they were in the early 2000s (4) (see **Figure 1**, p. 13). For example, the disparity in the overall cancer death rate has narrowed from 33 percent higher for African Americans compared with whites in 1990 to 14 percent higher for African Americans in 2016. The reduction in the disparity in the overall cancer death rate occurred because the overall cancer death rate decreased more rapidly among African Americans than it did among whites during this period. Even more encouragingly, the disparity in the overall cancer death rate between African Americans and whites has been nearly eliminated among men younger than 50 and women ages 70 or older (12).

Despite the progress, the African American population still shoulders a disproportionately high burden of overall cancer mortality compared with other racial and ethnic groups. In addition, racial and ethnic minority groups in the United States experience striking disparities in incidence and death rates for various types of cancer.

CANCERS WITH A DISPROPORTIONATE BURDEN IN AFRICAN AMERICANS

African Americans are the second-largest racial or ethnic minority group in the United States, comprising about



John R. Lewis

"Never, ever be afraid to make some noise and get in good trouble, necessary trouble."

Former U.S. Representative John R. Lewis, who sadly passed away on July 17, 2020, six months after being diagnosed with stage IV pancreatic cancer, dedicated his life to fighting against racial and social injustice. He served Georgia's 5th Congressional District since 1986. During his tenure in Congress, he served on the House Ways and Means committee, which set national tax policy, and in the Democratic Leadership as a Chief Deputy Whip.

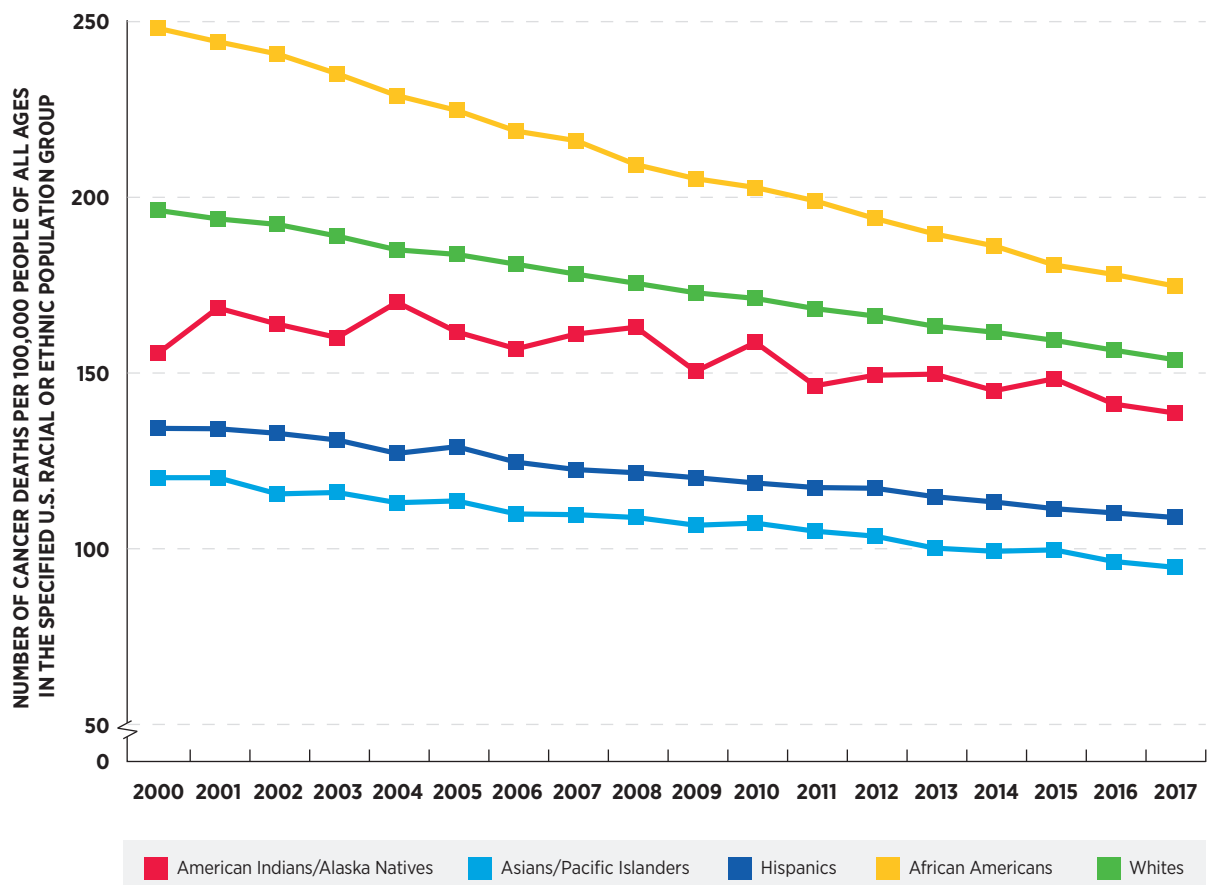
Lewis was a lifelong champion for equal and human rights who had met Rosa Parks and Dr. Martin Luther King, Jr., by the time he turned 19. As a student activist at Fisk University, and as one of the original "Freedom Riders" protesting segregation on public buses, Lewis continued to push forward in the quest for racial equality. In August 1963, at age 23, Lewis was the youngest speaker at the March on Washington. He is best known for leading a group of 600 marchers across the Edmund Pettus Bridge in Selma, Alabama, in 1965, where a large contingent of state troopers viciously beat the marchers, including Lewis himself, who bore scars from that day for the rest of his life.

John Lewis drew upon his experiences in the Civil Rights Movement and transitioned

into public service. As a member of the Congressional Black Caucus, Congressman Lewis continued to be a champion for the marginalized and unheard. He was a leader on civil rights issues, especially on issues concerning health disparities. He was an original cosponsor of the Minority Health and Health Disparities Research and Education Act of 2000, which established what is now the National Institute on Minority Health and Health Disparities. The bill was signed into law by President Clinton in November 2000, with the main purpose of enhancing biomedical research on minority health and health disparities. Congressman Lewis was an ardent supporter of the Affordable Care Act, supported Medicaid expansion in Georgia, and supported robust funding of the National Institutes of Health. In a May 2020 statement during a Ways and Means committee hearing on COVID-19's disproportionate impact on communities of color, Congressman Lewis stated that *"...if we put ego and ideology to the side, we will find a way to fix the underlying flaws in our health system that result in communities of color bearing the disproportionate burden of a global health crisis."*

Overall Cancer Death Rate Differences Are Narrowing

The age-adjusted overall cancer death rate for each of the racial and ethnic groups for which cancer statistics are collected by the National Cancer Institute’s Surveillance, Epidemiology, and End Results Program has been declining steadily since 2000. The extent of the decline has varied among the different groups, with the greatest overall cancer death rate decline (30 percent) occurring among African Americans (yellow line) and the least (11 percent) occurring among American Indians/Alaska Natives (red line). The declines in the overall cancer death rates for whites (green line), Hispanics (dark blue line), and Asians/Pacific Islanders (light blue line) were all about 20 percent.



Data from (4)

13 percent of the U.S. population (13). For more than four decades, African Americans have had a higher overall cancer death rate than all other racial and ethnic groups in the United States. An estimated 202,260 African Americans were diagnosed with cancer and 75,030 died from the disease in 2019 alone (12).

For many of the most common types of cancer, including breast, lung, prostate, and colorectal cancers, incidence and/or death rates are higher among African Americans than

other racial and ethnic groups (see **Table 1**, p. 14). One of the most striking examples of cancer-specific disparities is that African American men have prostate cancer incidence and death rates that are more than 1.5 times and more than 2 times those for men of any other race or ethnicity, respectively (12). The disparity in prostate cancer mortality between African American men and men of any other race or ethnicity was recently shown to be greatest for those diagnosed with low-grade prostate cancer (14). There are many factors that contribute to the high burden of

TABLE 1

Disparities in Incidence and Death Rates between African Americans and Whites for Selected Cancer Types

INCIDENCE RATES*			
Cancer Type	African Americans	Whites	Rate Ratio
Multiple myeloma	14.3	6.4	2.23
Prostate, males	172.8	102.0	1.69
Stomach	9.6	5.7	1.68
Liver and intrahepatic bile duct	11.9	7.4	1.61
Colorectal	45.5	36.5	1.25
Pancreas	15.7	12.7	1.24
Kidney and renal pelvis	19.2	15.7	1.22
Cervix uteri, females	7.4	6.3	1.17
Lung and bronchus	57.4	51.0	1.13
Breast, females	128.2	132.7	0.97
DEATH RATES*			
Cancer Type	African Americans	Whites	Rate Ratio
Prostate, males	38.4	18.2	2.11
Stomach	5.3	2.6	2.04
Multiple myeloma	6.0	3.0	2.00
Cervix uteri, females	3.1	2.2	1.41
Breast, females	27.3	19.6	1.39
Colorectal	18.3	13.4	1.37
Liver and intrahepatic bile duct	8.5	6.3	1.35
Pancreas	13.3	11.0	1.21
Lung and bronchus	40.2	39.3	1.02
Kidney and renal pelvis	3.4	3.7	0.92

*Both sexes unless otherwise specified

Data from: SEER Cancer Statistics Review 1975-2016 (Howlander N, Noone AM, Krapcho M, Miller D, Brest A, Yu M, Ruhl J, Tatalovich Z, Mariotto A, Lewis DR, Chen HS, Feuer EJ, Cronin KA (eds). SEER Cancer Statistics Review, 1975-2016, National Cancer Institute. Bethesda, MD, https://seer.cancer.gov/csr/1975_2016/, based on November 2018 SEER data submission, posted to the SEER website, April 2019.

prostate cancer mortality among African American men, including higher prostate cancer incidence rates among this population group. In addition, research has shown that prostate cancer in African American men is more likely to be aggressive (fast growing) and that African American men are less likely to receive cutting-edge treatment after a prostate cancer diagnosis (12).

Multiple myeloma and stomach cancer are two other types of cancer for which African Americans have a death rate that is at least double that for whites (see **Table 1**, p. 14). The incidence rates for these two types of cancer are also much higher among African Americans than among whites. One factor that may contribute to the higher burden of stomach cancer among African Americans is that infection with the cancer-causing bacterium *Helicobacter pylori* is more than twice as common among African Americans compared with whites (15) (see **Disparities in the Burden of Preventable Cancer Risk Factors**, p. 43). For multiple myeloma, among African Americans higher rates of obesity, which is a risk factor for the disease (see **Figure 5**, p. 49), and monoclonal gammopathy of undetermined significance, which is a blood condition that can progress to multiple myeloma, may contribute to incidence rate disparities (12). In addition to higher incidence rates, poorer access to new, cutting-edge treatments may contribute to the higher multiple myeloma death rates among African Americans (16).

Substantial disparities in colorectal cancer incidence and death rates between African Americans and whites have existed for many years (12)(17). Among the factors that contribute to the colorectal cancer incidence rate disparity between African Americans and whites are higher rates of obesity, which is a risk factor for the disease (see **Figure 5**, p. 49), and lower rates of colorectal cancer screening among African Americans (18). One study estimated that 42 percent of the incidence rate disparity and 19 percent of the death rate disparity were attributable to differences in colorectal cancer screening rates (19). Other factors contributing to the disparity in the colorectal cancer death rate include differences in where the tumor is located, with African Americans being four times more likely to be diagnosed with right-sided colon cancers, which are more aggressive than left-sided colon cancers, and African Americans having poorer access to new, cutting-edge treatments (20)(21).

Breast cancer is the most commonly diagnosed cancer among African American women, with 33,840 new cases estimated to have been diagnosed in 2019 alone (12). The breast cancer incidence rate has been lower among African American women than it has among white women for several decades (4). However, the incidence rate among African American women has been rising steadily during that time while it has fluctuated among white women. As a result of the disproportionate increase in the breast cancer incidence rate among African American women, incidence rates for this type of cancer are now very similar for African American and white women. In addition, when considering women under the age of 40, the breast cancer incidence rate is higher among African Americans than it is for any other racial or ethnic group (22). In contrast to the incidence rate, the breast cancer death rate is 39 percent higher for African American women

compared with white women. Many factors contribute to the breast cancer death rate disparity, including African American women being more likely to be diagnosed at a later stage of disease, when treatment is less likely to be successful, and being more likely to be diagnosed with triple-negative breast cancer, which is a biologically aggressive form of breast cancer with a poor prognosis (22).

Overall, disparities in lung cancer incidence and death rates between African Americans and whites are not striking (see **Table 1**, p. 14). However, dramatic disparities are evident when men and women are considered separately. The lung cancer incidence rate is 13 percent higher among African American men compared with white men, and it is 14 percent lower among African American women compared with white women (12). Similar trends are seen for the lung cancer death rate, which is 18 percent higher among African American men compared with white men and 12 percent lower among African American women compared with white women (12). These differences in lung cancer incidence and death rates are in large part due to differences in tobacco exposure among these different population groups. The most recent data show that African American men smoke cigarettes at a higher rate than white men, while African American women smoke cigarettes at a lower rate than white women (12). This knowledge is vital if we are to develop targeted approaches to tobacco control that will help eliminate disparities in lung cancer for African American men.

CANCERS WITH A DISPROPORTIONATE BURDEN IN HISPANICS

Hispanics comprise about 18 percent of the U.S. population and are the largest racial or ethnic minority population group in the United States (13). An additional 3.1 million Hispanic U.S. citizens live in Puerto Rico (23).

The overall cancer incidence and death rates are 25 percent and 32 percent lower among Hispanics in the continental United States and Hawaii than among whites (24). Hispanics also have lower incidence and death rates compared with whites for the types of cancer most commonly diagnosed in the United States including the five most common types of cancer—breast cancer, lung cancer, prostate cancer, colorectal cancer, and melanoma (4)(24). However, incidence and death rates for numerous other types of cancer are significantly higher among Hispanics (24) (see **Table 2**, p. 15).

It is important to note that the Hispanic population in the continental United States and Hawaii is highly diverse. For certain types of cancer, differences in incidence and death rates have been reported by country or region of origin, and for populations with differing degrees of ancestry from Indigenous Americans, Europeans, and Africans (25)(26) (27). There are also differences between U.S.-born and foreign-born Hispanics (28), and between Hispanics in the

TABLE 2

Disparities in Incidence and Death Rates between Hispanics and Whites for Selected Cancer Types

INCIDENCE RATES*			
Cancer Type	Hispanics	Whites	Rate Ratio
Liver and intrahepatic bile duct	12.6	7.4	1.7
Stomach	9.9	5.7	1.7
Cervix uteri, females	9.6	6.3	1.5
Childhood cancer	18.4	19	1.0
Gallbladder	1.1	1.1	1.0
Thyroid	14	15.3	0.9
Colorectal	32.9	36.5	0.9
Prostate, males	84.6	102.0	0.8
Breast, females	98	132.7	0.7
Lung and bronchus	27.7	51.0	0.5
DEATH RATES*			
Cancer Type	Hispanics	Whites	Rate Ratio
Stomach	4.9	2.6	1.9
Liver and intrahepatic bile duct	9.5	6.3	1.5
Thyroid	0.7	0.5	1.4
Cervix uteri, females	2.7	2.2	1.2
Gallbladder	0.6	0.5	1.2
Childhood cancer	2.4	2.4	1.0
Prostate, males	15.6	18.2	0.9
Colorectal	10.7	13.4	0.8
Breast, females	13.9	19.6	0.7
Lung and bronchus	16.8	39.3	0.4

*Both sexes unless otherwise specified

Data from: SEER Cancer Statistics Review 1975-2016 (Howlader N, Noone AM, Krapcho M, Miller D, Brest A, Yu M, Ruhl J, Tatalovich Z, Mariotto A, Lewis DR, Chen HS, Feuer EJ, Cronin KA (eds). SEER Cancer Statistics Review, 1975-2016, National Cancer Institute. Bethesda, MD, https://seer.cancer.gov/csr/1975_2016/, based on November 2018 SEER data submission, posted to the SEER website, April 2019.

continental United States and Hawaii and those in Puerto Rico (24). One powerful example of the difference in cancer burden between Hispanics in the continental United States and Hawaii and those in Puerto Rico is that the prostate cancer incidence rate among Hispanic men in Puerto Rico is 60 percent higher compared with Hispanic men in the continental United States and Hawaii (24).



U.S. REPRESENTATIVE FOR TEXAS'S 20TH DISTRICT

The Honorable Joaquin Castro

Chair, Congressional Hispanic Caucus

“The importance of addressing disparities in cancer prevention, early detection, treatment, and funding research will be our biggest bulwark in the fight against cancer and the fight for comprehensive health care. In Congress, as chairman of the Hispanic Caucus, I’ve worked on reducing the price of and expanding access to insulin directly with the companies who control the market. Through the Hispanic Caucus, I am also working on comprehensive legislation to eliminate health disparities among minority communities, including addressing cancer disparities among Hispanics. Hispanics have the highest rate for cancers associated with infection. This is a personal fight for me. My grandmother died from complications associated with diabetes and my mother suffers from the disease. Their suffering is mine, and the only way we will combat the all-encompassing impact of cancer, and of all diseases, is by working together.”



U.S. REPRESENTATIVE FOR CALIFORNIA'S 44TH DISTRICT

The Honorable Nanette Diaz Barragán

Vice-Chair, Congressional Hispanic Caucus

“There are profound racial disparities that exist regarding cancer, both in the prevalence of cancer diagnoses and in higher rates of death. We must get to the bottom as to why these disparities exist and do all we can to enact policies that ultimately eliminate them. This report is a good step to achieving that goal.”

Liver cancer is one of the types of cancer with the most striking disparities in incidence and death rates between Hispanics and whites in the continental United States and Hawaii (see **Table 2**, p. 15). Several studies have shown that among Hispanic men in the continental United States and Hawaii, those born in the United States have a liver cancer incidence rate that is nearly double that of those born outside the United States (28)(29); rates are comparable between U.S.- and foreign-born Hispanic women. In addition, Puerto Rican Hispanic men living on the U.S. mainland have a higher liver cancer incidence rate than those living on the island of Puerto Rico (30). Disparities in liver cancer incidence rates are in large part attributable to higher rates of exposure to risk factors for liver cancer—such as hepatitis B virus (HBV) infection, hepatitis C virus (HCV) infection, obesity, alcohol consumption, smoking, and diabetes (see **Disparities in the Burden of Preventable Cancer Risk Factors**, p. 43)—among the populations disproportionately shouldering the burden of this devastating disease. However, not all the disparities seem to be explained by higher rates of known risk factors, suggesting that additional risk factors need to be identified (28)(29).

Stomach cancer is another type of cancer with dramatic disparities in incidence and death rates between Hispanics and whites in the continental United States and Hawaii (see **Table 2**, p. 15). Hispanic women experience greater disparities in stomach cancer incidence and death rates than Hispanic men, with both rates more than twice as high for Hispanic women compared with white women while stomach cancer incidence and death rates are 61 percent and 98 percent higher, respectively for Hispanic men compared with white men (24). One study also reported differences in stomach cancer death rates among different groups of Hispanics living in Florida, with rates among Hispanics from Spanish-speaking countries in Central America and South America more than double the rate among Hispanics from Cuba (31). The disparities in stomach cancer incidence rates are in large part attributable to differences in rates of exposure to risk factors for the disease, in particular, chronic infection with *H. pylori* and obesity (24).

Cervical cancer incidence and death rates have been substantially higher among Hispanic women than they have among white women for the past two decades (4)



U.S. REPRESENTATIVE FOR CALIFORNIA'S 27TH DISTRICT

The Honorable Judy Chu

Chair, Congressional Asian Pacific American Caucus

"I'm grateful for this report for shedding light on the health care disparities in our country, particularly facing communities of color. Especially for issues like cancer, early screening and detection is a life-or-death difference. But due to lack of insurance, lack of information, lack of in-language care, or other obstacles, many Asian Pacific Islanders and other communities of color do not have this option. That leads to higher than average rates of cancer and death that could be avoided. With this report, I hope we can move forward the conversation on how to ensure quality and equal health care for all."



U.S. REPRESENTATIVE FOR OKLAHOMA'S 2ND DISTRICT

The Honorable Markwayne Mullin

Vice-Chair, Congressional Native American Caucus

"Cancer is the second leading cause of death for Native Americans and rates of stomach, liver, kidney, and gallbladder cancers are higher than in any other population. Rural communities and tribes face unique challenges when it comes to health care which can contribute to the disparities they face. Prevention and early detection are the keys to increasing positive outcomes and ensuring these communities have access to quality health care to address these disparities. As a member of the Energy and Commerce Committee, I will continue to fight for quality health care for rural communities and adequate funding for the Indian Health Service."

(see **Table 2**, p. 15). One key factor contributing to these disparities is the fact that the rate of cervical cancer screening is lower among Hispanic women compared with white women (18). As we look to the future, there is hope that disparities in cervical cancer incidence and death rates can be eliminated because rates of human papillomavirus (HPV) vaccination, which can prevent infection with the virus that causes nearly all cases of cervical cancer, are higher among Hispanic adolescents compared with white adolescents (32).

The overall incidence rates for childhood cancer (cancer diagnosed from ages 0 to 14) and for adolescent cancer (cancer diagnosed from ages 15 to 19) are very similar among Hispanic children and adolescents compared with white children and adolescents, respectively (5). However, Hispanic children and adolescents have the highest leukemia incidence rate of any racial and ethnic group in the United States (5). Five-year relative survival is also lower for Hispanic children diagnosed with leukemia, compared with white children. Differences in disease biology, access to treatment, and treatment efficacy are all factors that may contribute to this disparity in survival (5).

CANCERS WITH A DISPROPORTIONATE BURDEN IN ASIANS/PACIFIC ISLANDERS

The Asian American population, which encompasses people living in the United States who have origins in the Far East, Southeast Asia, or the Indian subcontinent, comprises about 6 percent of the U.S. population (13). Cancer statistics for the Asian American population are aggregated with those for the Pacific Islander population, even though these two populations are distinct racial groups. The Pacific Islander population, which encompasses people living in the United States who have origins in Hawaii, Guam, Samoa, or other Pacific Islands, comprises about 0.4 percent of the U.S. population (33).

The Asian/Pacific Islander population has the lowest overall cancer incidence and death rates of any racial or ethnic group in the United States (4)(34) (see **Figure 1**, p. 13). When compared with whites, the overall cancer incidence and death rates for Asians/Pacific Islanders are 34 percent and 38 percent lower, respectively. Asians/Pacific Islanders also have lower incidence and death rates compared with whites for the types of cancer most commonly diagnosed in the United States, including the five most common types of

TABLE 3

Disparities in Incidence and Death Rates between Asians/Pacific Islanders and Whites for Selected Cancer Types

INCIDENCE RATES*

Cancer Type	Asians/ Pacific Islanders	Whites	Rate Ratio
Nasopharyngeal†	2.3	0.3	7.7
Stomach	10	5.7	1.8
Liver and intrahepatic bile duct	12	7.4	1.6
Cervix uteri, females	6.1	6.3	1.0
Thyroid	15	15.3	1.0

DEATH RATES*

Cancer Type	Asians/ Pacific Islanders	Whites	Rate Ratio
Nasopharyngeal††	0.7	0.1	7
Stomach	5.3	2.6	2.04
Liver and intrahepatic bile duct	8.7	6.3	1.38
Thyroid	0.6	0.5	1.20
Cervix uteri, females	1.6	2.2	0.73

*Both sexes unless otherwise specified
Data from:

†Surveillance, Epidemiology, and End Results (SEER) Program (www.seer.cancer.gov) SEER*Stat Database: Incidence - SEER 13 Regs Research Data, Nov 2018 Sub (1992-2016) , National Cancer Institute, DCCPS, Surveillance Research Program, Surveillance Systems Branch, released April 2019, based on the November 2018 submission.

††Surveillance, Epidemiology, and End Results (SEER) Program (www.seer.cancer.gov) SEER*Stat Database: Mortality - All COD, Aggregated With State, Total U.S. (1990-2016) , National Cancer Institute, DCCPS, Surveillance Research Program, Surveillance Systems Branch, released April 2019. Underlying mortality data provided by NCHS (www.cdc.gov/nchs).

cancer—breast cancer, lung cancer, prostate cancer, colorectal cancer, and melanoma (4)(34).

However, incidence and death rates for some types of cancer are significantly higher among the Asian/Pacific Islander population (see Table 3, p. 18). For example, incidence and death rates for nasopharyngeal cancer, which is frequently caused by infection with Epstein-Barr virus, are about seven-fold higher among Asians/Pacific Islanders compared with whites.

It is important to note that the Asian/Pacific Islander population is very diverse and differences in cancer-specific incidence and death rates have been reported by country or

TABLE 4

Disparities in Incidence and Death Rates between American Indians/Alaska Natives and Whites for Selected Cancer Types

INCIDENCE RATES*

Cancer Type	American Indians/ Alaska Natives	Whites	Rate Ratio
Liver and intrahepatic bile duct	14.5	7.4	2.0
Kidney and renal pelvis	18.1	15.7	1.2
Colorectal	38.4	36.5	1.1
Stomach	6	5.7	1.1
Cervix uteri, females	6	6.3	1.0

DEATH RATES*

Cancer Type	American Indians/ Alaska Natives	Whites	Rate Ratio
Stomach	4.7	2.6	1.8
Liver and intrahepatic bile duct	10.6	6.3	1.7
Kidney and renal pelvis	5.3	3.7	1.4
Cervix uteri, females	2.8	2.2	1.3
Colorectal	14.4	13.4	1.1

*Both sexes unless otherwise specified

Data from: SEER Cancer Statistics Review 1975-2016 (Howlader N, Noone AM, Krapcho M, Miller D, Brest A, Yu M, Ruhl J, Tatalovich Z, Mariotto A, Lewis DR, Chen HS, Feuer EJ, Cronin KA (eds). SEER Cancer Statistics Review, 1975-2016, National Cancer Institute, Bethesda, MD, https://seer.cancer.gov/csr/1975_2016/, based on November 2018 SEER data submission, posted to the SEER web site, April 2019.

region of origin for selected cancers (35). For example, lung cancer incidence rates are four times higher among men and women of Samoan origin compared with men and women of Asian Indian/Pakistani origin, and these differences reflect differences in smoking rates among the population groups. In addition, the stomach cancer incidence rates among men and women of Korean origin are almost double those among men and women of Japanese origin who have the second highest rates among Asian/Pacific Islander populations.

CANCERS WITH A DISPROPORTIONATE BURDEN IN AMERICAN INDIANS/ALASKA NATIVES

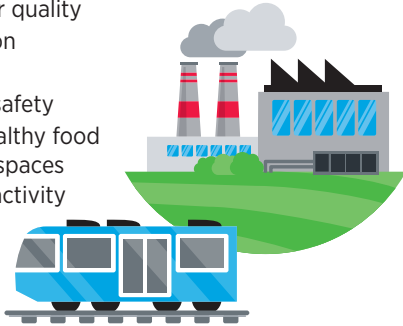
The American Indian/Alaska Native population comprises about 1.7 percent of the U.S. population (33). When compared with whites, the overall cancer incidence and

Why Do U.S. Cancer Health Disparities Exist?

Complex and interrelated factors contribute to cancer health disparities in the United States. Adverse differences in many, if not all, of these factors are directly influenced by structural and systemic racism. The factors may include, but are not limited to, differences or inequalities in:

ENVIRONMENTAL FACTORS

- Air and water quality
- Transportation
- Housing
- Community safety
- Access to healthy food sources and spaces for physical activity



BEHAVIORAL FACTORS

- Tobacco use
- Diet
- Excess body weight
- Physical inactivity
- Adherence to cancer screening and vaccination recommendations



SOCIAL FACTORS

- Education
- Income
- Employment
- Health literacy



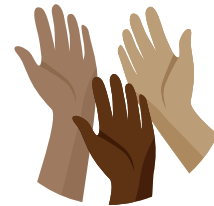
CLINICAL FACTORS

- Access to health care
- Quality of health care



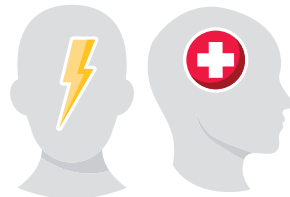
CULTURAL FACTORS

- Cultural beliefs
- Cultural health beliefs



PSYCHOLOGICAL FACTORS

- Stress
- Mental health



BIOLOGICAL AND GENETIC FACTORS



death rates for American Indians/Alaska Natives are 14 percent and 10 percent lower, respectively (34). However, incidence and death rates for some types of cancer are significantly higher among American Indians/Alaska Natives compared with whites (see **Table 4**, p. 18). Disparities in liver cancer incidence and death rates between American Indians/Alaska Natives and whites are particularly striking and are in large part due to American Indians/Alaska Natives having higher rates of exposure to risk factors for liver cancer such as HBV infection, HCV infection, chronic liver disease, obesity, alcohol consumption, smoking, and diabetes (36).

It is important to note that cancer incidence and death rates vary among American Indians/Alaska Natives living in different Indian Health Service regions (37). For example, American Indians/Alaska Natives in three of the six Indian Health Service regions—Alaska, Northern Plains, and Southern Plains—have higher overall cancer death rates compared with whites, those in the Pacific Coast region have a comparable overall cancer death rate, and those in the East or Southwest regions have lower overall cancer death rates compared with whites. There are also differences in incidence and death rates for specific types of cancer among American Indians/Alaska Natives in the different Indian Health Service



The **National Cancer Institute Health Disparities Calculator (HD*Calc)** is a statistical software tool to evaluate and monitor health disparities using data from multiple data sets such as the Surveillance, Epidemiology, and End Results Program, the National Health Interview Survey, and the National Health and Nutrition Examination Survey (44).

regions. For example, while the breast cancer death rate for all American Indian/Alaska Native women combined is lower than that for white women, the breast cancer death rates for American Indian/Alaska Native women in Alaska and the Southern Plains are 26 percent and 18 percent higher, respectively, compared with those for white women. In addition, lung cancer incidence rates among American Indian/Alaska Native men in Alaska and the Northern Plains are 45 percent and 54 percent higher, respectively, compared with those for white men but American Indian/Alaska Native men in the Southwest have a 65 percent lower lung cancer incidence rate compared with white men. Cancer disparities between Indian Health Service regions reflect different exposures to risk factors and access to care and understanding what these disparities are is important for developing and implementing region-appropriate strategies to eliminate the disparities.

Why Do Cancer Health Disparities Exist?

Decades of research have identified many factors that contribute to cancer health disparities. These factors are

complex and interrelated (see sidebar on **Why Do U.S. Cancer Health Disparities Exist?**, p. 19). Among the most important factors are social determinants of health, which are defined by the NCI as the conditions in which people are born, grow, live, work, and age, including the health system (38). Social determinants of health, which can be considered at the level of individuals, groups, communities, or societies (39), are the factors that provide the context within which cancer is prevented, detected, and treated (40) (17). Structural and systemic racism is a driver of adverse differences in the social determinants of health experienced by racial and ethnic minorities.

Increased realization of the importance of social determinants to the health of the nation led the United States Department of Health and Human Services (HHS) to include “Create social and physical environments that promote good health” as one of the four overarching goals of the Healthy People 2020 initiative (41). There are also efforts to develop standardized tools to obtain information from patients about social determinants of health and to develop standardized measures of contextual factors, such as social, cultural, and physical environment (42) (43). Information on social determinants of health from patients has the potential to help clinicians better care for and support the patients, and when combined with information on contextual factors, patient information can be used by cancer health disparities researchers to gain a more integrated and comprehensive understanding of the interrelationship of the various factors, which is vital if we are to achieve health equity.

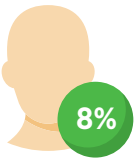
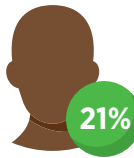
SOCIAL FACTORS CONTRIBUTING TO CANCER HEALTH DISPARITIES

Inequalities in socioeconomic status, at the level of individuals, neighborhoods, and regions, are among the most important social factors contributing to cancer health disparities in the United States (6). One recent study estimated that eliminating socioeconomic disparities could prevent 34 percent of cancer deaths among all U.S. adults ages 25 to 74 (45).

Socioeconomic status is most often determined based on income, education level, and occupation, and each of these components contributes to cancer health disparities among individuals of all races (6)(45). For example, the colorectal



34% of cancer deaths among all U.S. adults ages 25 to 74 could be **prevented if socioeconomic disparities were eliminated** (45).



21% of African Americans, 18% of Hispanics, and 8% of non-Hispanic whites were **living below the federal poverty level in 2018** (46).

cancer death rate among men living in the poorest counties in the United States is 35 percent higher than that for men living in the most affluent counties (6) and the lung cancer death rate among U.S. adults who have 12 or fewer years of education is almost four times higher than that for those who have 16 or more years of education (45).

Inequalities in socioeconomic status and its components are also factors that contribute to racial and ethnic cancer health disparities because socioeconomic disadvantages are disproportionately more common among racial and ethnic minority groups. For example, 21 percent of African Americans and 18 percent of Hispanics were living below the federal poverty level in 2018 compared with 8 percent of whites who are not of Hispanic ancestry (non-Hispanic whites) (46). In addition, just 25 percent of African Americans and 18 percent of Hispanics have attained a bachelor's degree or higher educational qualification compared with 35 percent of all whites (46).

The socioeconomic status of individuals and neighborhoods can affect clinical, environmental, psychological, behavioral, and cultural factors that influence health, including access to healthy foods, spaces for physical activity, the Internet, and transportation, as well as exposure to crime, violence, and social disorder. Establishing how much each factor contributes to racial and ethnic cancer health disparities is vital if we are to engage new sectors, such as education, housing, transportation, agriculture, and environment, in efforts to achieve cancer health equity.

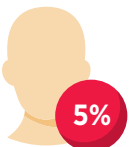
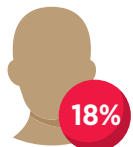
CLINICAL FACTORS CONTRIBUTING TO CANCER HEALTH DISPARITIES

Inequalities in access to clinical care and the quality of care received are important modifiable clinical factors that contribute to cancer health disparities. Quality is often measured based on whether individuals receive guideline-recommended care and whether they are treated at a

facility that has the experience and infrastructure to care for cancer patients. Research has shown that racial and ethnic minorities often receive lower quality care compared with whites (47)(16)(48). For example, African Americans and Hispanics with intrahepatic cholangiocarcinoma are 50 percent and 41 percent less likely to have surgery, respectively, compared with whites (47), and patients with multiple myeloma who are African American are 21 percent less likely to receive the molecularly targeted therapeutic bortezomib compared with whites (16).

Health insurance status is one of the most important factors determining access to quality cancer care. Individuals who lack health insurance have a higher risk of poor outcomes from cancer compared with those who are insured (49-53). For example, one study found that cancer patients who were uninsured were 45 percent more likely to die from their cancer compared with those who had non-Medicaid insurance, which includes private insurance, Medicare, and military coverage (49). Among the reasons that a lack of health insurance contributes to cancer health disparities is that compared with individuals who have private insurance, those who are uninsured are more likely to be diagnosed at an advanced stage of disease, which decreases the likelihood of treatment being successful, and are less likely to receive standard treatments (51-53). For example, patients with limited-stage small cell lung cancer who were uninsured were 35 percent less likely to receive chemotherapy and 25 percent less likely to receive radiotherapy compared with those who had private or managed care health insurance, and not receiving these treatments was, in turn, associated with poor survival (53).

Racial and ethnic minorities are more likely to be uninsured or receive Medicaid compared with whites, and health insurance status is a key factor contributing to racial and ethnic cancer health disparities (54). One recent study showed that African American, American Indian/Alaska Native, and Hispanic women were more than 30 percent more likely to be diagnosed with advanced stage breast cancer compared with white women and that nearly half of this disparity was a result of



10% of African Americans, 18% of Hispanics, and 5% of non-Hispanic whites were **uninsured in 2018** (54).

these women being uninsured or receiving Medicaid (55). Although these data and results from other studies show that addressing health insurance status will not completely mitigate cancer health disparities, providing equal insurance coverage has the potential to substantially reduce the burden of cancer for racial and ethnic minorities (49).

The complexity of the issue of access to quality cancer care is not only influenced by health insurance status, but is also influenced by factors such as whether an individual will accept or decline to use cancer care services and treatment; if the services are easy or difficult to use; if individuals can get to the facilities where care is being offered; language barriers or fear of discrimination; and whether individuals have enough health literacy to make the best decisions for their care (56).

BEHAVIORAL AND CULTURAL FACTORS CONTRIBUTING TO CANCER HEALTH DISPARITIES

In the United States, it is estimated that four out of 10 cancer cases and almost half of all cancer-related deaths are caused by potentially modifiable risk factors (57). Among the potentially modifiable factors with the biggest impact on cancer risk are tobacco use, poor diet, alcohol intake, physical inactivity, obesity, infection with cancer-causing pathogens, and exposure to ultraviolet (UV) radiation (see **Figure 2**, p. 44). There are striking racial and ethnic disparities in the burden of many of the potentially modifiable cancer risk factors, as discussed in **Disparities in the Burden of Preventable Cancer Risk Factors** (p. 43), and these are important behavioral factors contributing to cancer health disparities. Other behavioral factors, which are also influenced by clinical, cultural, and social factors, include racial and ethnic disparities in adherence to cancer screening recommendations and in rapidly obtaining cancer treatment (see **Disparities in Cancer Screening for Early Detection**, p. 59).

Given our knowledge of the behavioral factors related to cancer health disparities, it is clear that strategies that promote behavior modification, for example, eliminating tobacco use, increasing consumption of a healthy and balanced diet, and participating regularly in physical exercise, could help eliminate or reduce some racial and ethnic cancer health disparities. One statewide initiative designed to address this is Double Up Food Bucks (DUFB) in Michigan, which matches Supplemental Nutrition Assistance Program (SNAP) funds spent at farmers' markets. Uptake of DUFB was initially low, but a brief intervention, explaining the initiative to those eligible, resulted in a fourfold increase in uptake, as well as significant increases in fruit and vegetable consumption in a low-income, racially and ethnically diverse community in Michigan (58).

An important component of developing strategies to foster behavior modification is identifying and understanding

cultural factors, including cultural health beliefs, that influence behavior. For example, a recent study showed that a single-session educational intervention designed and tailored to the Pacific Islander community in Southern California increased cervical cancer screening by Pap testing in that community (59).

PSYCHOLOGICAL FACTORS CONTRIBUTING TO CANCER HEALTH DISPARITIES

There is growing evidence that psychological stress and stress responses are associated with higher overall cancer incidence and mortality, as well as poorer overall cancer survival (60). For example, psychological distress, such as ongoing depression and anxiety-related symptoms, is associated with a 97 percent increased risk for cancer mortality in people with a history of cancer (61).

The extent to which psychological factors are associated with cancer burden varies for different types of cancer. For example, one factor that influences cervical cancer incidence is adherence to screening recommendations, and research has shown that women who report having had a greater number of major traumatic or stressful life events, or having greater feelings of discrimination, were 85 percent and 17 percent more likely not to be up to date with cervical cancer screening recommendations, respectively (62). With regard to cancer type-specific outcomes, stress has been linked to poorer outcomes for patients with breast, lung, head and neck, hepatobiliary, and lymphoid or hematopoietic cancers (60). For example, women with breast cancer who report no traumatic or stressful life events have been found to have a disease-free interval that is twice as long as those who have experienced one or more stressful or traumatic life events (63). In addition, cancer patients whose marital status is separated at the time of diagnosis have a 10-year relative survival rate that is 36 percent lower than that for those who are married at the time of diagnosis (64).

Psychological stress is also emerging as an important factor in cancer health disparities, with researchers finding that levels of emotional distress are significantly higher among African American cancer survivors compared with cancer survivors from other racial and ethnic groups (65). Psychosocial stressors have also been shown to contribute to the increased risk of certain aggressive types of breast cancer among African American women (66).

Identifying how psychological factors, including experiences of stress, influence cancer progression is an area of intensive research investigation because this knowledge has the potential to help researchers develop prevention and intervention strategies. These, in turn, could be used to help eliminate cancer health disparities.

ENVIRONMENTAL FACTORS CONTRIBUTING TO CANCER HEALTH DISPARITIES

The HHS recognizes that a person's physical environment influences health (41). For example, an individual's physical environment determines access to healthy foods and spaces for physical activity, which are linked to improved health, including decreased risk for cancer and improved cancer outcomes; it determines access to transportation, which individuals may need to obtain clinical cancer care; it determines proximity to quality cancer care facilities; and it determines exposure to toxic substances, crime, violence, and social disorder, which are all associated with poorer health, including increased risk for cancer and poorer cancer outcomes.

Research has shown that individuals living in disadvantaged neighborhoods are more likely to be diagnosed with late-stage cancer and to have poorer survival compared with individuals in more advantaged neighborhoods (67-69). For example, women in disadvantaged urban neighborhoods are significantly more likely to be diagnosed with late-stage breast cancer and men in disadvantaged neighborhoods who are diagnosed with prostate cancer have poorer survival (67-69).

Disparities in physical environment contribute to racial and ethnic cancer health disparities. For example, one study found that African American women were significantly more likely to live in disadvantaged neighborhoods than white women and that this was an important factor contributing to disparities in triple-negative breast cancer stage at diagnosis and survival between African Americans and whites (70). In other studies, living in a disadvantaged neighborhood has been shown to contribute to disparities between African Americans and whites in liver cancer incidence and prostate cancer survival (69)(71).

Given the important contribution of physical environment to cancer health disparities, we must engage new sectors, such as education, housing, transportation, agriculture, and environment, in efforts to achieve cancer health equity.

Eliminating health disparities for racial and ethnic minorities from 2003 to 2006 would have reduced

Direct medical costs by:
\$230 BILLION

Indirect costs associated with illness and premature death by:
>\$1 TRILLION



BIOLOGICAL AND GENETIC FACTORS CONTRIBUTING TO CANCER HEALTH DISPARITIES

Following completion of the Human Genome Project there has been significant interest in understanding the association between biological and genetic factors and cancer health disparities. However, genetic studies that include minority populations are still significantly underrepresented compared with studies that include individuals of European descent (see **Understanding Cancer Development in the Context of Cancer Health Disparities**, p. 34). Nevertheless, emerging evidence supports a role for biological and genetic differences among populations as factors associated with cancer health disparities. For example, numerous studies have uncovered ancestry-related differences in prostate cancers and breast cancers from African Americans and whites at the level of DNA, RNA, and



U.S. REPRESENTATIVE FOR NEW MEXICO'S 1ST DISTRICT

The Honorable Deb Haaland

Cochair, Congressional Native American Caucus

"An important part of addressing cancer is fully understanding the disparities caused by generations of oppression and lack of access to quality health care. However, oftentimes, information is siloed, and not readily available for those of us who have a goal of finding solutions and increasing research for cures. I'm impressed with the work AACR did to ensure policy makers have the information we need to work on early prevention, understanding risk factors, and treatment for all our communities."

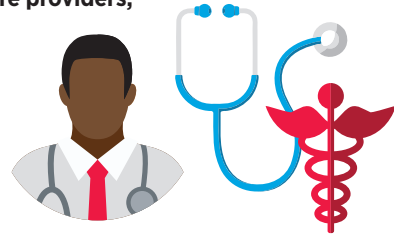
Driving Progress against Cancer Health Disparities Together

Progress in reducing cancer health disparities occurs when all stakeholders committed to achieving this goal work together. Further increasing collaboration will accelerate the pace of progress in the future. The key stakeholders are:

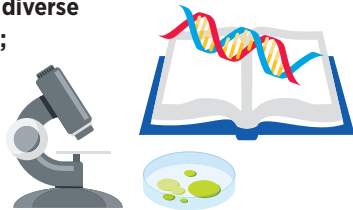
patients, survivors, and their caregivers, family members, and friends;



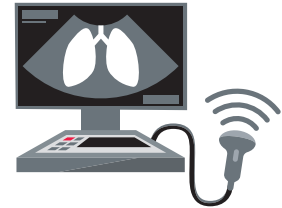
health care providers;



academic and government researchers from a diverse array of specialties;



biotechnology, pharmaceutical, diagnostics, and medical device companies;



individual citizen advocates and members of advocacy groups;



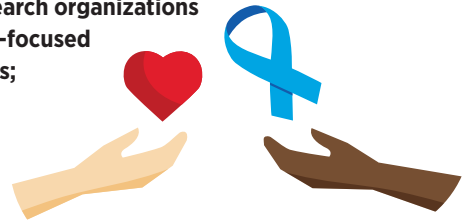
policy makers;



regulators;



philanthropic organizations, cancer research organizations and cancer-focused foundations;



federal funding organizations; and



payers.



Adapted from (3)



U.S. REPRESENTATIVE FOR OHIO'S 11TH DISTRICT

The Honorable Marcia L. Fudge

“Dr. Martin Luther King, Jr., once said, ‘Of all the forms of inequality, injustice in health care is the most shocking and inhumane.’ His words resonate today, as racial disparities in health care and outcomes continue to plague communities of color. Cancer is one of the many diseases that disproportionately affect people of color, and impact the uninsured and our most vulnerable citizens. Throughout his life, my friend and colleague, Congressman Elijah Cummings worked tirelessly to help eliminate these disparities. His passing reminds us of our shared responsibility to continue his pursuit of justice by working to eliminate health disparities and improve research to better prevent, detect, and treat cancer.”

proteins (72-77). Ancestry-related genetic differences have also been associated with differences in risk for breast cancer among African Americans, Hispanics, and whites (28)(78) (79). How and to what extent these biological and genetic factors contribute to racial and ethnic cancer health disparities is an area of intensive research investigation, as is the interplay between these factors and social determinants of health.

Health Disparities: A Costly Public Health Challenge; Health Equity: A Vital Investment

The immense toll of cancer in the United States is felt through both the number of lives it affects each year and its economic impact. One study projected that the direct medical costs of cancer care will be more than \$157 billion in 2020, an increase of 27 percent since 2010 (80). This number does not include the indirect costs of lost productivity due to cancer-related morbidity and mortality, which are also extremely high. In fact, a recent analysis estimated that cancer deaths among Americans ages 16 to 84 resulted in \$94.4 billion in lost earnings in 2015 alone (81).

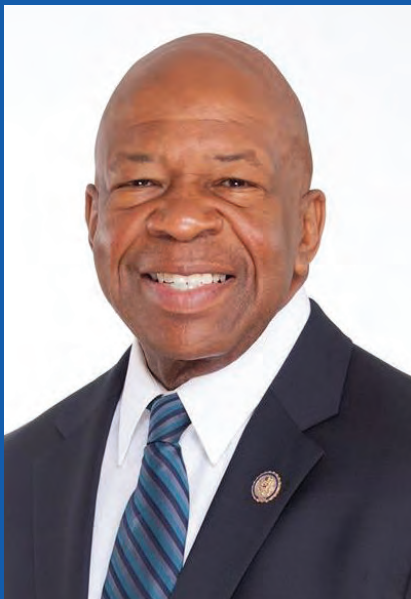
Importantly, racial and ethnic health disparities, including cancer health disparities, exert enormous direct medical costs and indirect costs through loss of productivity (82)(83). One study projected that eliminating health disparities for racial and ethnic minorities would have reduced direct medical costs by about \$230 billion and indirect costs associated with illness and premature death by more than \$1 trillion from 2003 to 2006 (82). In another study, it was estimated that disparities in premature deaths from cancer between African Americans and whites cost \$3.2 billion in lost earnings in 2015 (83a).

Fortunately, there has been some progress in reducing cancer health disparities, as evidenced by narrowing of racial and ethnic disparities in the overall cancer death rate over the past few years (see **Figure 1**, p. 13). This progress

is a result of the efforts of all stakeholders committed to eliminating cancer health disparities (see sidebar on **Driving Progress against Cancer Health Disparities Together**, p. 24). However, we cannot escape the reality that there is a vital need for more collaboration among the various stakeholders and more cancer health disparities research, which were positions championed by the late **Congressman Elijah Cummings** (see p. 26).

The field of cancer health disparities research has evolved from simply describing different outcomes among populations into an established multidisciplinary field of research. The increase in the representation of research from diverse disciplines, including anthropology, biology, clinical practice, engineering, education, psychology, and public health, has increased our understanding of the unique interplay between biology, behavior, the environment, and cancer outcomes. As more transdisciplinary approaches are applied in cancer health disparities research, we can expect greater understanding of the confluence of factors associated with this public health challenge, the causal pathways, and best approaches for intervention.

Much of the work of cancer health disparities researchers is supported by investments from the federal government, most of which are administered through the 27 institutes and centers of the National Institutes of Health (NIH). The NCI, which is the federal government's principal agency for cancer research and training, and the National Institute on Minority Health and Health Disparities (NIMHD) are two of the most important institutes of the NIH for accelerating the pace of progress toward cancer health equity. Within the NCI, the Center to Reduce Cancer Health Disparities (CRCHD) is central to the institute's efforts to reduce the unequal burden of cancer in the United States. It is imperative, therefore, that Congress continue to provide sustained, robust, and predictable increases in funding for the NIH if cancer health disparities research is to remain a top public health priority and we are to achieve the bold vision of health equity.



Elijah E. Cummings

"We've got to keep working (together) until there are no more disparities."

Former U.S. Representative Elijah Cummings, who sadly passed away on October 17, 2019, dedicated his career to public service, beginning with his election to the Maryland House of Delegates, where he served for 14 years and became the first African American in Maryland history to be named Speaker Pro Tempore. He served as the U.S. Representative for Maryland's 7th Congressional District since 1996 and was chairman of the House Committee on Oversight and Reform.

During his brilliant career, Representative Cummings was dedicated to improving the health of his constituents and all Americans, and he was a consistent champion for medical research. He was also especially committed to addressing disparities in health and health care. In fact, during his tenure as chair of the Congressional Black Caucus, Representative Cummings was the first member of Congress to develop and introduce comprehensive legislation on behalf of the Tri-Caucus—which represents over half of the Democratic Caucus and includes the Congressional

Hispanic Caucus, Congressional Black Caucus, and Congressional Asian Pacific American Caucus—that was aimed at tackling health disparities in the United States. Many portions of this legislation, the Healthcare Equality and Accountability Act, were eventually included in the Affordable Care Act and still operate to protect our most vulnerable populations today.

In 2010, Representative Cummings joined the AACR for an interview on health care, disparities, and cancer research. In the video, the Congressman talked about the importance of cancer researchers spending time on Capitol Hill to help inform members of Congress about research, and specifically how that research is making a difference in improving peoples' lives. In terms of his specific message to researchers who are working to eliminate cancer health disparities, he said, "We've got to keep working (together) until there are no more disparities. Sadly, I don't know if that day will come during my lifetime, but I'm going to work until I die to make sure that I help end the disparities that exist today."

Special Feature on Disparities in COVID-19 and Cancer

IN THIS SECTION, YOU WILL LEARN:

- ▶ On March 11, 2020, the World Health Organization (WHO) designated Coronavirus Disease 2019 (COVID-19), which is caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), a global pandemic.
- ▶ As of July 31, 2020, there were 17,622,478 confirmed cases of COVID-19 and 680,165 deaths from the disease globally; there were 4,566,275 cases and 153,391 deaths in the United States.
- ▶ Older adults, males, and individuals of any age with certain underlying medical conditions are at an increased risk for severe COVID-19 illness.
- ▶ Racial and ethnic minorities have been disproportionately impacted by COVID-19 for many of the same reasons that they shoulder a disproportionate burden of cancer.
- ▶ The COVID-19 pandemic has disrupted cancer care for many people, causing concern that the delays in screening, diagnosis, and treatment will exacerbate cancer health disparities in the future.
- ▶ All stakeholders need to work together to identify innovative mechanisms to reduce COVID-19 disparities and make strides in the future toward eliminating all health disparities, including cancer health disparities.

In 2020, a disease termed Coronavirus Disease 2019 (COVID-19), which is caused by infection with severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), spread rapidly around the world. On March 11, 2020, the World Health Organization (WHO) declared the ensuing global health crisis a pandemic.

As of July 31, 2020, more than 17 million people worldwide were diagnosed with COVID-19 and more than 680,000 people died from the disease, which affects many organs of the body in addition to the lungs (SF1)(SF2) (see **COVID-19 Figure 1**, p. 28). Beyond this personal toll, the COVID-19 pandemic has overwhelmed health care systems, devastated societal norms, and shattered the economies of U.S. households as well as those of other nations.

In the United States, which accounts for more than one in every four recorded cases of COVID-19 and almost one in every four recorded deaths from the disease (SF1), the burden of the disease has not been shouldered equally by all segments of the population (see sidebar on **Disparities in the Burden of COVID-19 in the United States**, p. 29). As with cancer, a disproportionate burden of COVID-19 has fallen on racial and ethnic minorities, in particular, African Americans and Hispanics (SF4)(SF5).

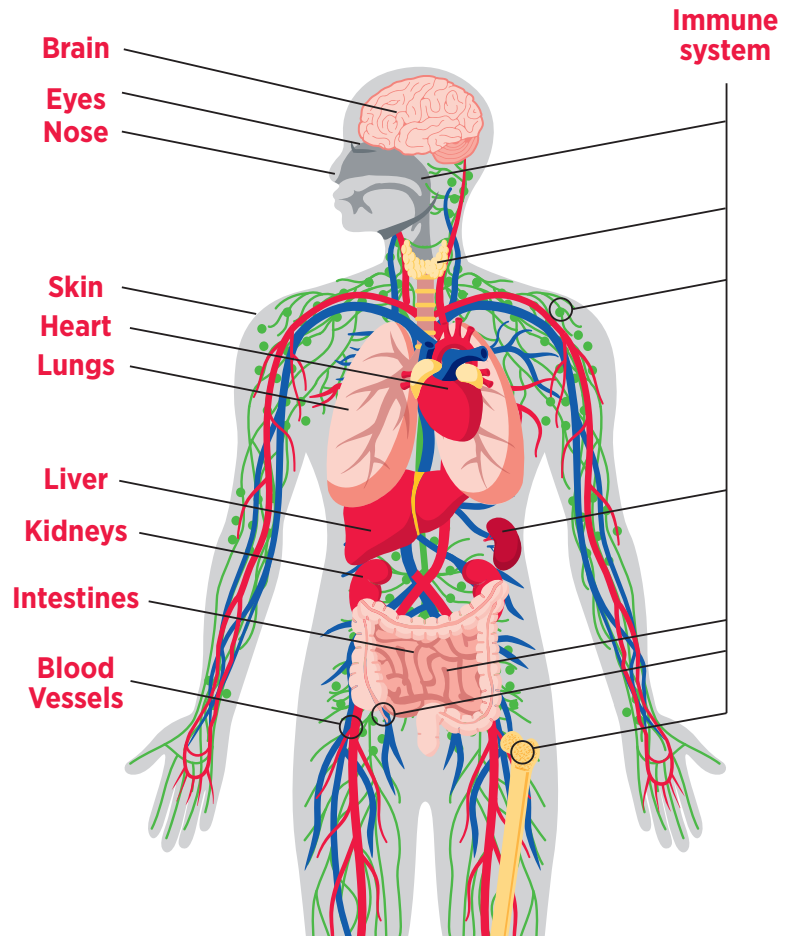
Why Do COVID-19 Disparities Exist?

Researchers are actively working to identify the specific factors contributing to the disproportionate burden of COVID-19 among racial and ethnic minorities. Early data suggest that there are several complex and interrelated factors, some of which overlap with the factors that contribute to cancer health disparities (SF10)(SF11) (see **Why Do Cancer Health Disparities Exist?**, p. 20).

Social determinants of health, defined by the NCI as the conditions in which people are born, grow, live, work, and age, are emerging as some of the most important factors contributing to racial and ethnic COVID-19 disparities (SF10-12). People in racial and ethnic minority groups are more likely to live in conditions that pose challenges for social distancing, which is one of the main strategies for reducing infection with SARS-CoV-2. For example, they are more likely to live in lower-income apartment complexes, with higher numbers of occupants per unit, and more likely to live in multigenerational family units. The same people are also more likely to work in occupations considered essential for society to function—such as staffing grocery stores, hospitals, and nursing homes; building maintenance; public transportation; and delivery services—which increases their chances of being exposed to SARS-CoV-2 because they are unable to shelter at home

Beyond the Lungs: COVID-19 Affects Many Parts of the Body

COVID-19 is best known as a disease of the lungs. In severe cases it can cause pneumonia and acute respiratory distress syndrome (ARDS), which is associated with difficulty breathing and low blood oxygen levels. If unchecked, ARDS can progress to respiratory failure, which is the cause of death in many fatal COVID-19 cases. As physicians and researchers learn more about COVID-19, an increasing number of organs and organ systems beyond the lungs are being found to be affected by the disease. Among the parts of the body most frequently affected by COVID-19 are the heart, brain, kidneys, intestines, blood vessels, blood, and immune system. Understanding the effects on blood vessels, blood, and the immune system is a particularly active area of research investigation because an overactive inflammatory response and abnormal blood clotting are emerging as important factors in severe disease. Effects of COVID-19 on the skin, liver, eyes, and nose have also been reported in some patients.



Data from (2)(3).

(SF13-15). In addition, people in racial and ethnic minority groups are more likely to have jobs that may not provide a secure income, only paying if the individual shows up to work, which means that they are more likely to leave their home, increasing the chance of exposure to SARS-CoV-2.

Another important factor contributing to racial and ethnic COVID-19 disparities is that many people in racial and ethnic minority groups are more likely to have one or more of the health conditions discovered to increase a person's chance of severe COVID-19 compared with non-Hispanic whites (SF10-12)(SF16). Among the health conditions that can increase a person's risk of severe illness from infection with SARS-CoV-2 are chronic kidney disease, chronic obstructive pulmonary disease (COPD), obesity, heart failure, coronary artery disease, sickle cell disease, diabetes, and having a weakened immune system (SF17). Other health conditions, including asthma and high blood pressure, have

also been linked to an increased risk of severe COVID-19, but additional research is needed to confirm these associations.

Inequity in access to quality health care is a key factor contributing to the higher levels of underlying health conditions that increase risk of severe COVID-19 among people in racial and ethnic minority groups. It is anticipated that we will find that disparities in access to quality health care are also directly contributing to the higher COVID-19 mortality among people in racial and ethnic minority groups, but additional research on this topic is needed (SF10). In addition, there is deep concern that undocumented immigrants will experience adverse differences in COVID-19 measures, in large part because of a lack of access to quality health care (SF18).

Researchers are actively investigating whether there are biological and/or genetic factors contributing to racial and ethnic COVID-19 disparities. To conduct this research,

Disparities in the Burden of COVID-19 in the United States

Not all segments of the U.S. population have shouldered the burden of Coronavirus Disease 2019 (COVID-19) equally. Examples of such disparities include:

Hispanics

Hispanics account for about **18 percent of the U.S. population**, but **34 percent of COVID-19 cases** (SF4) (SF6).

African Americans

African Americans account for about **13 percent of the U.S. population**, but **20 percent of COVID-19 cases** and **23 percent of deaths** from the disease (SF4)(SF6).

American Indians/Alaska Natives

American Indians/Alaska Natives have a **rate of hospitalization for COVID-19 that is five times higher** than the rate of hospitalization for COVID-19 among whites (SF7).

Men

Men account for about **49 percent of cases of COVID-19 in the United States**, but **55 percent of deaths** from the disease (SF8).

Age 75+

People age 75 and older account for **10 percent of COVID-19 cases**, but **58 percent of deaths** from the disease (SF4).

Medicare Recipients in Urban vs Rural Areas

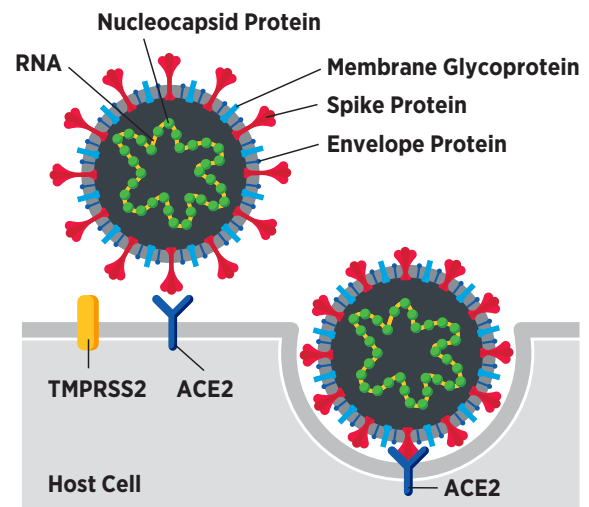
Medicare recipients in **urban areas** have a **rate of hospitalization for COVID-19 that is more than three times higher** than Medicare recipients in **rural areas** (SF9).

it was first necessary to study the biology of SARS-CoV-2 and COVID-19 (see sidebar on **The Biology of SARS-CoV-2 Infection and COVID-19**, p. 29). The knowledge gained from these studies has focused disparities research on two proteins

The Biology of SARS-CoV-2 Infection and COVID-19

A virus is composed primarily of genetic material, either DNA or RNA, encased in a protein “shell” called a capsid or nucleocapsid, which may or may not be enclosed in an envelope. To multiply, a virus must attach to and enter an appropriate host cell, where it hijacks the host’s genetic material and cellular machinery to produce more copies of the viral genetic material and capsid and envelope proteins.

SARS-CoV-2 uses RNA as its genetic material. This RNA encodes four major proteins: the spike, nucleocapsid, membrane, and envelope proteins. The spike protein can attach to proteins called angiotensin-converting enzyme 2 (ACE2), which are found on the surface of certain human cells in the nasal passages, lungs, and gastrointestinal tract. To enter these human cells, the virus needs another protein, called TMPRSS2, to be present on the cells. TMPRSS2 is naturally found in several tissues of the human body including the prostate, lung, gastrointestinal tract, and urinary tract, and it is frequently found together with ACE2 in cells in the nasal passages and lungs.

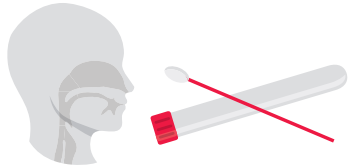


that are critical for SARS-CoV-2 infection of human cells—angiotensin-converting enzyme 2 (ACE2) and TMPRSS2—and on the immune response that is thought to cause the severe lung disease seen in patients with COVID-19 (SF19). One study found that among people with asthma, those who are African American have higher levels of ACE2 and TMPRSS2 on cells in their lungs compared with those who are from other racial and ethnic groups (SF20). Additional research is needed to determine whether these observations are also true

How Can We Test for SARS-CoV-2?

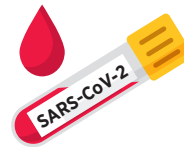
There are two types of SARS-CoV-2 tests: viral tests and antibody tests.

Viral Test



- Determines if a patient is currently infected with SARS-CoV-2; cannot determine if a person was previously infected.
- The samples tested are nasal or throat swabs, or saliva samples.
- The sample is tested either using a technique called PCR to determine whether the virus' genetic material is present or using other techniques that determine whether specific viral proteins, or antigens, are present.
- Antigen tests produce results more quickly than PCR tests, but they may be less sensitive.

Antibody Test



- Determines if a patient was previously infected with SARS-CoV-2; cannot determine if a person is actively infected.
- The samples tested are blood samples.
- The sample is tested to determine whether proteins called antibodies that the patient's immune system would have made during a previous infection with SARS-CoV-2 are present.

in individuals who do not have asthma and whether they are linked to differences in the severity of COVID-19 in different population groups. In addition, cancer research has shown that the *TM6SS2* gene is altered in a high proportion of prostate cancers, and that there are racial and ethnic differences in the frequency of these genetic alterations (SF21). Establishing whether this has any relation to disparities in COVID-19 and whether it might be possible to harness knowledge of *TM6SS2* gained through cancer-focused research to reduce COVID-19 disparities are areas of interest to researchers.

Only with increased understanding of the factors that contribute to COVID-19 disparities will we be able to address the devastating impact of COVID-19 among racial and ethnic minorities.

Disparities in SARS-CoV-2 Testing

Timely testing to identify those who are or have been infected with SARS-CoV-2 is a crucial step in understanding and controlling the COVID-19 pandemic (see sidebar on **How Can We Test for SARS-CoV-2?**, p. 30). Without knowledge of who is infected, it is challenging to implement appropriate measures to prevent further spread of the virus and to understand when such measures can be eased.

In the United States, SARS-CoV-2 testing was not readily available to anyone during the early stages of the COVID-19 pandemic (SF22)(SF23). Even as things have slowly improved, evidence suggests that many people in racial and ethnic minority

groups have had less access to testing compared with whites. Fortunately, efforts to increase access are underway. One of the barriers to testing for people in racial and ethnic minority groups has been that testing sites were often located in neighborhoods in which the majority of residents are white, although recognition of this is growing and many states and cities, including Chicago, New York, and Philadelphia, are actively working to address this issue (SF24)(SF25). Another barrier is that in some places, individuals initially needed a referral from a health care provider to be tested for SARS-CoV-2, and people in racial and ethnic minority groups are less likely to have a regular health care provider. Fortunately, recognition of this issue is growing and criteria for testing are being relaxed in some areas. For example, initially, the citywide testing that was made available in Detroit at the State Fairgrounds was limited to those who had a physician's order; later, as testing capacity improved, testing became available to those without such an order (SF26). Other barriers to access to SARS-CoV-2 testing are harder to address as they include social and behavioral factors such as distrust in the health care system, fear of medical costs, language barriers, and lack of paid sick leave if a test indicates SARS-CoV-2 infection (SF11).

Addressing disparities in SARS-CoV-2 testing is critical to control the spread of the virus in racial and ethnic minority communities. However, there is also an urgent need for resources to support individuals in these communities who test positive for SARS-CoV-2 because such a diagnosis would make these individuals vulnerable to subsequent social and health care disparities.

COVID-19 and Cancer Health Disparities

The COVID-19 pandemic has created many challenges across the continuum of cancer care, with deep concern about the consequences that delays in cancer screening, diagnosis, and treatment will have on outcomes for patients with cancer (SF27)(SF28). Data from electronic medical records from 190 hospitals spanning 23 states show that the number of screening tests for early detection of cervical, breast, and colon cancer conducted in the United States plummeted by 85 percent or more after the first COVID-19 case was reported in the United States on January 20, 2020 (SF29), and a recent survey of patients with cancer found that 79 percent of those who are actively undergoing treatment had to delay some aspect of their care as a result of COVID-19, including 17 percent who reported delays to their cancer treatment (SF30). It will take years to determine the consequences of all these delays, but researchers at the NCI have estimated that there will be at least 10,000 additional deaths from breast cancer and colorectal cancer over the next decade in the United States as a result of the negative impact that the COVID-19 pandemic has had on screening and treatment for these two types of cancer (SF27).

There are many reasons for the delays in cancer screening, diagnosis, and treatment that have been reported, including the need to focus health care resources on COVID-19–related emergency medicine and critical care services, the need to support shelter-in-place and social distancing policies implemented to contain the spread of SARS-CoV-2, and fear of becoming infected with SARS-CoV-2 when leaving the home to receive health care. In addition, for cancer treatment, many delays were the result of efforts to reduce the risk of patients with cancer becoming infected with SARS-CoV-2 as they go to a health care provider to receive treatment. This is a concern because early data from China and the United States indicate that patients with cancer are more likely to die from COVID-19 if they become infected with SARS-CoV-2 compared with individuals who do not have cancer

(SF31-33). Another report on outcomes following surgery found that lung complications occurred in 50 percent of all patients undergoing surgery who were infected with SARS-CoV-2 around the time of the surgery and that 24 percent died within 30 days of surgery (SF34). These numbers are dramatically higher than normally expected, and have led to delays in surgery, including surgeries for cancer.

In response to the COVID-19 pandemic, most cancer centers have been testing all patients for active SARS-CoV-2 infection before surgery, radiation therapy, or systemic therapy. The logistics of cancer care have also been greatly affected. Caring for someone with cancer who has symptoms suggesting infection requires specialized facilities for the isolation of persons known or suspected to have COVID-19. These specialized facilities are needed both for COVID-19 testing and for the timely delivery of urgent care that might be needed to treat cancer or the adverse effects of cancer treatment. Even routine care for patients with cancer who do not have COVID-19 has changed dramatically. To accomplish social distancing, many in-person health care visits have been replaced by video visits and telemedicine.

There is an urgent need for rigorous studies investigating how the COVID-19 pandemic has affected cancer health disparities. However, experts predict that the pandemic will exacerbate existing disparities. People in racial and ethnic minority groups already experience inequalities in socioeconomic status that contribute to cancer health disparities (see **Social Factors Contributing to Cancer Health Disparities**, p. 20). The COVID-19 pandemic has caused U.S. unemployment rates to skyrocket, and people in racial and ethnic minority groups have been disproportionately represented among jobs that have been lost (SF13-15). In addition to loss of income, unemployment can lead to loss of health insurance and tends to make general health care a lower priority in comparison to other costs of living such as meals and housing. This has the potential to drastically reduce cancer screening for early detection among people in



U.S. REPRESENTATIVE FOR NEW JERSEY'S 6TH DISTRICT

The Honorable Frank Pallone

Chairman of the House Committee on Energy and Commerce

“The racial and ethnic disparities in COVID-19 infections and health outcomes are heartbreaking and exemplify the persistent inequities that pervade our national health care system. Unfortunately, the Administration has been slow to provide Congress with a comprehensive data report that could help shed light on the impact COVID-19 has had in communities of color. However, I’m hopeful that Congress, health care providers and the public health community will be able to come together to help prevent these inequities from being perpetuated going forward and to direct resources and support to address the disproportionate impact this crisis is having on communities of color nationwide.”

racial and ethnic minority groups which in turn increases the likelihood of any cancer being identified at an advanced stage, when it is less likely to be treated successfully. This also has the potential to intensify disparities in treatment and other aspects of cancer care.

Another factor that is likely to compound existing cancer health disparities is that the public hospitals that provide safety-net health care and general medical care, including cancer care, to a disproportionate volume of people in racial and ethnic minority groups have been hard hit by the COVID-19 pandemic (SF16). The economic impact of the pandemic on these already financially constrained health care systems has the potential to further compromise cancer care for racial and ethnic minorities. In addition, people in racial and ethnic minority groups are less likely to have the capability for using advanced communication technologies for telemedicine, further limiting access to health care.

The COVID-19 pandemic continues to have a negative impact on individuals, communities, and health care systems across the United States and around the world. In the post-COVID-19 era there will be an urgent need to ensure comprehensive health care and economic interventions for equitable recovery of cancer care, from prevention to early detection, diagnosis, and treatment, to survivorship care.

COVID-19 Disparities: A Window of Opportunity to Achieve the Bold Vision of Health Equity?

The COVID-19 pandemic has focused national attention on the issue of health disparities. Racial and ethnic minority groups within the U.S. population have shouldered a disproportionate burden of the disease, and there is immense concern that the pandemic will exacerbate other existing health disparities, including cancer health disparities. It is imperative that all stakeholders work together to galvanize the momentum that has been created by the pandemic and by the current movement against racial inequality to reduce the unequal burden of all diseases, including COVID-19 and cancer.

Currently, addressing health disparities related to the COVID-19 pandemic is one of the most urgent public health challenges in the United States. The many steps that need to be taken to reduce COVID-19 disparities are:

- Health insurance coverage opportunities such as expanded Medicaid programs should be made readily available to financially constrained individuals who lost their employment-based health insurance because of the COVID-19 pandemic and to undocumented immigrants.
- Public hospitals must be supported so that they can continue to meet the safety-net health care needs of communities that are disproportionately represented among the medically underserved, including racial and ethnic minorities.
- Public health and educational messages tailored to racial and ethnic minority groups must be developed and implemented to increase COVID-19 testing among these segments of the population.
- Clinical trials testing COVID-19 diagnostic tests, treatments, and vaccines must have adequate representation of racial and ethnic minorities.
- Basic research into COVID-19 should be designed a priori with disparities-related studies, such as understanding viral biology in diverse host environments in terms of inherited genetic architecture as well as relevant acquired phenotypes (e.g., metabolic syndrome) that result from exposure to different physical environments.

It is imperative that all stakeholders build upon the concerted efforts to address COVID-19 disparities and drive progress in eliminating all health disparities, including cancer disparities in the future. As the cancer research community recovers from the COVID-19 pandemic, it is vital that cancer health disparities research, including community outreach, education, and engagement efforts, is protected from any budget constraints that arise as a result of the adverse financial impact of the pandemic.



U.S. REPRESENTATIVE FOR MARYLAND'S 4TH DISTRICT

The Honorable Anthony G. Brown

“The COVID-19 pandemic has exacerbated decades old racial health disparities in our nation’s health care system. From diagnosis to treatment and ultimate medical outcomes—Black and Latino Americans face both explicit and implicit bias resulting in disproportionate infection rates and death. Our efforts must be judged on how we protect our most vulnerable. This is fundamentally a systemic issue, and we must confront inequities in health care, criminal justice, housing, education and economic opportunity through targeted investment and solutions in communities of color. The time to act is now.”

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Understanding Cancer Development in the Context of Cancer Health Disparities

IN THIS SECTION, YOU WILL LEARN:

- ▶ Research provides our understanding of the biology of cancer, which is not one disease, but a collection of diseases characterized by the uncontrolled growth of cells.
- ▶ Genetic mutations underpin cancer biology in most cases; the mutations are inherited in only about 10 percent of cases.
- ▶ Cancer biology is strongly influenced by interactions among cancer cells and numerous factors in their environment.
- ▶ Data on cancer biology comes predominantly from mostly white individuals of Western European ancestry.
- ▶ Initiatives such as AACR Project Genomics Evidence Neoplasia Information Exchange (GENIE) and NCI-funded projects such as the African American Breast Cancer Epidemiology and Risk (AMBER) Consortium are beginning to provide insight into cancer biology in racial and ethnic minorities.
- ▶ There is an urgent need to increase research into understanding cancer biology in racial and ethnic minorities.

Decades of biomedical research have given us great insight into cancer biology. As basic research has uncovered the processes that change a normal cell to become cancerous, translational and clinical research has harnessed this information to design new and better approaches to prevent, detect, diagnose, and treat many cancers. We have learned that cancer is a collection of diseases that arise when the processes that control normal cell growth, division,

and life span go awry. As a result, cells start multiplying uncontrollably, fail to die when they should, and mobilize other cells and tissues such as blood vessels, immune cells, and other types of normal cells to give the tumor a growth advantage over the surrounding tissue. In body organs and tissues, the accumulating cancer cells form masses called tumors, whereas in the blood or bone marrow they crowd out normal cells.



U.S. REPRESENTATIVE FOR FLORIDA'S 25TH DISTRICT

The Honorable Mario Diaz-Balart

"We all know someone who has been affected by cancer. This merciless disease has taken countless loved ones away from us far too early, forever changing our lives and leaving us only with memories. While we should be proud of the strides made in cancer research over the years, we must not be satisfied. It's imperative that we continue to support research, innovation, and technological advances so that we can defeat this terrible disease."

As the cancer grows certain cells within the cancer acquire specific changes that give them and their daughter cells the best chance to grow and survive. Those changes might include the ability to grow faster, to survive despite the presence of treatments, to invade adjacent tissues and organs, to evade the body's immune system, and to move into the blood stream and/or lymphatic system and spread to distant parts of the body. Most advanced cancers acquire several, if not all, of these features. Cancer that has spread to other parts of the body, which is often called metastatic disease, is the main cause of most cancer deaths.

It is important to note that there are many factors, from biological to environmental to lifestyle factors, that influence cancer initiation and progression. Complex interplay among these factors can drive cancer development and may contribute to the observed disparities in cancer burden among different population groups (see **Why Do Cancer Health Disparities Exist?**, p. 20). Therefore, understanding these interactions is especially important in the context of cancer health disparities, in particular, for those cancers that disproportionately affect racial and ethnic minorities.

Cancer Initiation: DNA at the Core of Cancer

The normal behavior of each cell in the human body is controlled by its genetic material. The genetic material comprises chains of deoxyribonucleic acid (DNA), a complex molecule made up of four building blocks called bases that is found in nearly all cells of higher organisms. In humans, the four bases that comprise DNA are organized in a very specific pattern to build two paired chains that each have 3 billion bases and represent what is often referred to as the human genome. Incredibly, the pattern of bases is 99.9 percent identical between any two individuals! However, the 0.1 percent difference is what gives each person individual characteristics. The genome is packaged together with proteins known as histones into structures called chromosomes inside the cell's nucleus. Each person gets 23 chromosomes from each parent; thus, each normal cell has 46 chromosomes.

The order, or sequence, of the DNA bases provides the code used by a cell to produce the various proteins it needs to function. This code is at the core of what is known as Central Dogma, whereby the genetic code in DNA is converted into another form of nucleic acid called ribonucleic acid (RNA). RNA is the transcript of the original code embedded in the DNA and is used to manufacture proteins, which are the molecules that perform important functions that dictate a cell's fate. Normal processes in cells that dictate their functions are programmed into each cell's genome. One can generally conclude that normal DNA leads to normal proteins, which

leads to normal cells, which create normal tissue. Conversely, changes in the DNA may disrupt normal protein function, which leads to altered cells, which create altered tissue and lead to cancer development. Therefore, at its basic level, cancer is a genetic disease because it is caused by some intrinsic or extrinsic factor(s) that alter the normal DNA.

GENETIC CHANGES: DNA MUTATIONS IN CANCER

Alterations in the DNA sequence, referred to as mutations, can disrupt normal protein function, and are the leading cause of cancer development (see sidebar on **Genetic Mutations**, p. 37). Each person's cancer has a unique combination of mutations, and as cancer cells divide, new mutations arise in the daughter cells. Thus, a tumor is made up of a collection of cancer cells with a wide range of genetic abnormalities. This variation in cell types, also known as heterogeneity, is an important part of a cancer's characteristics and fuels the cancer's ability to grow faster, escape therapy, evade the immune system, and metastasize to other organs.

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 (see sidebar on **Sources of Genetic Alterations**, p. 38). 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, there is strong evidence that the mutation significantly increases risk of cancer, and mutations like these are called "pathogenic." 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 (see **Table 5**, p. 36).

The inherited genome plays an important role in cancer risk. Each person's inherited genome is related to his or her genetic ancestry, which is defined by the history of his or her biological family (see sidebar on **Genetic Markers, Ancestry, and Cancer Risk**, p. 39). Among the major ancestry groups are sub-Saharan Africans, Europeans, and Native Americans (89-91). Much of the world's population is made up of subgroups that have high rates of a single major ancestral group, or subgroups that have a combination of these major ancestries. For example, many people in the United States who self-identify as non-Hispanic white have greater than 95 percent European ancestry. However, many people in the United States who self-identify as African American or Hispanic have varying degrees of ancestral contributions from any or all three of these major ancestral groups (89-91). Ultimately, there is growing recognition of the extensive genetic diversity across the human population.

Inherited Cancer Risk

CANCER	SYNDROME	ASSOCIATED GENE(S)
Leukemias and lymphomas	Ataxia telangiectasia	ATM
Basal cell carcinoma and medulloblastoma	Basal cell nevus syndrome	PTCH1, PTCH2, SUFU
All cancers	Bloom syndrome	BLM
Breast, ovarian, pancreatic, and prostate cancers	Breast-ovarian cancer syndrome	BRCA1, BRCA2
Breast, thyroid, and endometrial cancers	Cowden syndrome	PTEN
Breast and stomach cancers	Diffuse gastric and lobular breast cancer syndrome	CDH1
Colorectal, duodenal, stomach, and thyroid cancers	MYH associated polyposis	MYH
Colorectal cancer, medulloblastoma	Familial adenomatous polyposis	APC
Melanoma and pancreatic cancer	Familial atypical multiple mole-melanoma syndrome	CDKN2A
Glioblastoma and melanoma	Familial glioma-melanoma syndrome	CDKN2A
Retinal cancer, pineoblastoma, and bone and soft tissue sarcomas	Retinoblastoma predisposition syndrome	RB1
Leukemia and myelodysplastic syndrome (MDS)	Inherited bone marrow failure syndromes, such as Fanconi's anemia and telomere syndromes	FANCC, FANCF, FANCG, FANCD1, FANCD2, FANCD3, FANCD4, FANCD5, FANCD6, FANCD7, FANCD8, FANCD9, FANCD10, FANCD11, FANCD12, FANCD13, FANCD14, FANCD15, FANCD16, FANCD17, FANCD18, FANCD19, FANCD20, FANCD21, FANCD22, FANCD23, FANCD24, FANCD25, FANCD26, FANCD27, FANCD28, FANCD29, FANCD30, FANCD31, FANCD32, FANCD33, FANCD34, FANCD35, FANCD36, FANCD37, FANCD38, FANCD39, FANCD40, FANCD41, FANCD42, FANCD43, FANCD44, FANCD45, FANCD46, FANCD47, FANCD48, FANCD49, FANCD50, FANCD51, FANCD52, FANCD53, FANCD54, FANCD55, FANCD56, FANCD57, FANCD58, FANCD59, FANCD60, FANCD61, FANCD62, FANCD63, FANCD64, FANCD65, FANCD66, FANCD67, FANCD68, FANCD69, FANCD70, FANCD71, FANCD72, FANCD73, FANCD74, FANCD75, FANCD76, FANCD77, FANCD78, FANCD79, FANCD80, FANCD81, FANCD82, FANCD83, FANCD84, FANCD85, FANCD86, FANCD87, FANCD88, FANCD89, FANCD90, FANCD91, FANCD92, FANCD93, FANCD94, FANCD95, FANCD96, FANCD97, FANCD98, FANCD99, FANCD100
Kidney cancer and uterine fibroids	Hereditary leiomyomatosis and renal cell cancer	FH
Pancreatic cancer	Hereditary pancreatitis/familial pancreatitis	PRSS1, SPINK1
Leukemias, breast cancer, glioblastoma, choroid plexus carcinoma, adrenocortical carcinoma, and bone and soft tissue cancers	Li-Fraumeni syndrome	TP53
Low grade gliomas, neurofibromas, neurofibrosarcomas, meningiomas, and ependymomas	Neurofibromatosis type I and neurofibromatosis type II	NF1 and NF2
Glioblastoma, colorectal cancer, and endometrial cancer	Brain tumor polyposis type I	MLH1, PMS2
Medulloblastoma, abdominal desmoid tumors, and colorectal cancer	Brain tumor polyposis type II	APC
Colorectal and endometrial cancers	Lynch syndrome	EPCAM, MLH1, MSH2, MSH6, PMS2
Rhabdoid tumors of brain, kidney and extra-renal sites	Rhabdoid predisposition syndrome	hSNFS, INI1
Subependymal giant cell astrocytoma, renal angioliopomas, and cardiac rhabdomyomas	Tuberous sclerosis complex	TSC1 and TSC2
Leukemias, lymphomas, and MDS	Hereditary myeloid malignancy syndromes, such as familial MDS/Acute myeloid leukemias	RUNX1, GATA2, CEBPA, ETV6, DDX41, ANKRD26, ATG2B/GSKIP,
Pineoblastoma, pleuro-pulmonary blastoma, lymphoma and glioblastoma	DICER syndrome	DICER1
Pancreatic cancer, pituitary adenomas, benign skin and fat tumors	Multiple endocrine neoplasia 1	MEN1
Thyroid cancer and pheochromocytoma	Multiple endocrine neoplasia 2	RET, NTRK1
Pancreatic, liver, lung, breast, ovarian, uterine, and testicular cancers	Peutz-Jeghers syndrome	STK11/LKB1
Tumors of the spinal cord, cerebellum, retina, adrenals, and kidneys	von Hippel-Lindau syndrome	VHL
Kidney cancer	Wilms' tumor	WT1
Skin cancer	Xeroderma pigmentosum	XPD, XPB, XPA

This list is not meant to be exhaustive, but contains some of the more commonly occurring cancer syndromes

Source: <http://www.cancer.gov/about-cancer/causes-prevention/genetics/risk-assessment-pdq> and <https://rarediseases.info.nih.gov/diseases/diseases-by-category/1/rare-cancers>

Genetic Mutations

Types of genetic mutation known to lead to cancer include:

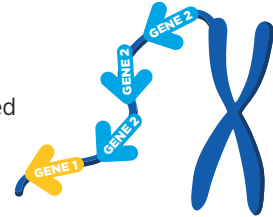
SINGLE BASE CHANGES

Deletion or insertion of a single base can result in new proteins, altered versions of normal proteins, or loss of protein function, which can lead to cancer.



EXTRA COPIES OF GENES (GENE AMPLIFICATION)

Higher quantities of certain proteins can result in enhanced cell survival and growth, leading to cancer.



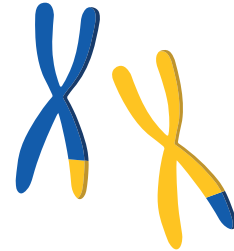
DELETIONS

Loss of DNA can result in loss of genes necessary to regulate the processes that control normal cell growth, division, and life span, leading to cancer development.



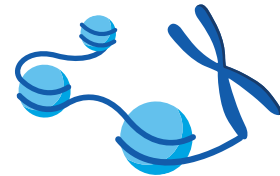
STRUCTURAL VARIATION

Exchange of DNA between chromosomes can alter multiple genes at once. It can sometimes lead to the fusion of two separate genes, generating entirely new proteins that can drive the development of cancer.



MUTATIONS THAT ALTER THE EPIGENOME

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



Of note, cells acquire mutations over time but not all mutations cause cancer. In addition, not all mutations found in a cancer cell contribute to cancer development.

Adapted from (3)

Unfortunately, the preponderance of research studies into inherited cancer risks have focused on individuals of high European genetic ancestry, namely, non-Hispanic whites in the United States. Thus, there is growing concern in the scientific community regarding the inadequate representation and lack of data from other racial and ethnic minorities who may have lower amounts of European genetic ancestry, such as many African Americans and Hispanics (92)(93). In other words, most data on the genetics of cancer risk is derived from mostly white individuals of Western European ancestry. Given these limitations, our current knowledge of cancer genetics cannot be applied to all populations, limiting our knowledge of inherited cancer risks in racial and ethnic minorities. For instance, because of limited information from racial and ethnic minorities, we often have insufficient evidence to determine with statistical strength whether a mutation is truly cancer causing, and these mutations are often categorized as variants of

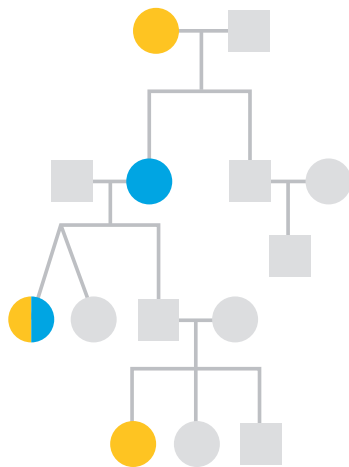
undetermined significance (VUS). Consequently, genetic counseling for racial and ethnic minority individuals becomes less precise and less informative than it is for those of high European ancestry. Therefore, there is an urgent need to increase research into understanding the genes and specific mutations that are associated with hereditary cancer in racial and ethnic minorities.

As mentioned earlier, most cancer mutations are not inherited, but rather are DNA changes that occur in cells during cell duplication or as a result of an assault on the cell by an extrinsic factor such as carcinogens or other environmental exposures. Comprehensive analyses of human cancer genomes (the DNA that is present specifically in cancer cells) over the past three decades have revealed numerous cancer-causing genetic alterations. For instance, The Cancer Genome Atlas (TCGA), an initiative supported by the NCI and National Human Genome Research

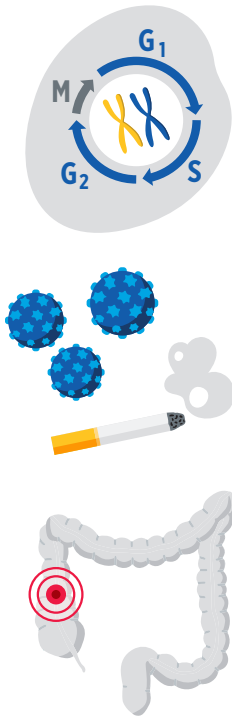
Sources of Genetic Alterations

Cancer initiation and progression are predominantly caused by the accumulation of alterations, or mutations, in the genetic material of a cell over time. The primary sources of genetic alterations are as follows:

About 10 percent of all new U.S. cancer cases are linked to inherited or de novo genetic mutations, which are present in each cell of the body from birth (84)(85).



Most alterations, however, are acquired during a person's lifetime.



- Some occur during normal cell division. Every time a cell divides it must make a full copy of its DNA. As there are 3 billion letters to copy, mistakes can happen during the process, leading to alterations in the DNA sequence. Cells have a specific machinery to fix most of these alterations to restore the DNA to a normal copy. However, sometimes these errors don't get fixed and a daughter cell acquires the mutation which may alter the cell's proteins and ultimately change the cell's control over functions such as growth.
- Many are caused by modifiable cancer risk factors, for instance, persistent exposure to substances that damage genetic material, such as toxicants in tobacco smoke, or to infectious pathogens that alter normal cellular machinery, such as human papillomavirus (HPV) or *Helicobacter pylori* bacteria (see **Disparities in the Burden of Preventable Cancer Risk Factors**, p. 43).
- Others occur as a result of medical conditions that are associated with chronic inflammation such as diabetes or Crohn's disease (86)(87).

These factors come together to determine the chance that an individual cell has of acquiring mutations over time, which, in turn, determines the overall risk that a person will develop cancer. The prevalence of many cancer-causing factors, such as smoking, HPV infection, and incidence of diabetes, are higher among racial and ethnic minorities, leading to a higher likelihood of cancer development among these populations. It is important to note that not all mutations lead to cancer.


Adapted from (88)

Institute, looked at the genetic content of about 11,000 tumors across 33 different cancer types. Notably, within the 11,000 tumors, racial and ethnic minorities are significantly underrepresented (99)(100). This is concerning because we know that the incidence and mortality of many cancers are higher among racial and ethnic minorities. It is extremely important to determine whether cancer patients from different racial and ethnic minority groups have different mutational patterns and if these patterns are associated with worse outcomes. In fact, there is mounting evidence that the cancer-associated mutation patterns may be different in racial and ethnic minority patients (101), but the overall body of data is still too limited to permit a true understanding of the actual magnitude of these differences.

Discoveries uncovering cancer-causing genetic alterations have also led to the development of a new class of therapeutics, molecularly targeted therapeutics, which aim to rectify the cellular changes that arise due to cancer-causing mutations. A better understanding of the mutational patterns in racial and ethnic minorities is critical for the development of such therapeutics that will be effective in treating racial and ethnic minority cancer patients.

EPIGENETIC CHANGES: DNA'S THIRD DIMENSION

Epigenetics refers to modifications to DNA that do not involve a change in the DNA base sequence. The epigenetically modified genome is referred to as the "epigenome". One major epigenetic process is involved in


 As of 2018, nearly **80 percent** of individuals included in genome-wide association studies—the most common type of research that detects genetic alterations that are associated with disease risk—**were of European descent; 10% were Asian, 2% African, 1% Hispanic, and less than 1% other population groups** (92).

packaging the DNA of a cell inside of a nucleus, which is a small compartment inside of the cell. The epigenetic process of packaging DNA in the nucleus involves the wrapping of DNA around proteins called histones. This process results in condensing DNA so that it can fit inside the nucleus. This condensed DNA, called chromatin, also functions to allow for proper cell division, protects the DNA strands from breaking, and controls how genes are turned on or off. A second epigenetic change, called DNA methylation, involves the chemical modification of adding a methyl molecule to a DNA base. This does not change the actual DNA sequence, but it does change the composition of the DNA.

Epigenetic modifications play a very important role in cells because they regulate how and when genes are turned “on” or “off” and they are made by specialized proteins that “add” or “erase” unique chemical modifications on DNA and/or histones (102). If the normal epigenetic processes go awry, there can be significant changes in the cell's normal growth machinery leading to cancer. In fact, epigenetic alterations of DNA repair genes or cell growth control genes are commonly seen in cancers (103)(104). Research has also led to the identification of a significant number of cancer-causing mutations in genes that control these epigenetic processes.

Epigenetic changes can be a part of normal development or may result from external or environmental factors such as chemical/biochemical/biological exposures, threats to food security, diet, exercise, and physiological and psychological stress (105)(106). In contrast to genetic mutations, epigenetic changes are often reversible, providing an opportunity for therapeutic intervention. Our understanding of the role of epigenetics in cancer and cancer health disparities is, however, incomplete, and continued research is needed to fulfill the real potential of the epigenome in cancer science and medicine.

Genetic Markers, Ancestry, and Cancer Risk

Genetic markers are DNA sequences with known location on a chromosome; they can be used to identify ancestry. Substantial research over the last 30 years has identified markers that are enriched in either sub-Saharan African, European, or Native American ancestral DNA, which allows researchers to determine the percentage of these different ancestries in a person's genome.



Although this type of genetic ancestry analysis is en vogue by commercial providers, we know that specific markers are also strongly associated with cancer risk.

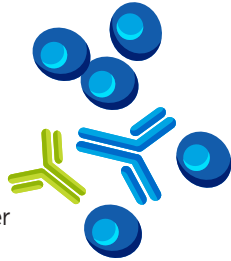
- One such marker resides on human chromosome 8 and is known as 8q24 (94)(95).
- Individuals who carry a specific genetic pattern at 8q24 have an increased risk of developing prostate cancer.
- Prostate cancer represents one of the most significant cancer health disparities, in that African American men are almost twice as likely to develop and die from this disease compared with whites.
- Research has shown that this marker at 8q24 is enriched in sub-Saharan Africa, is a marker of African ancestry, and may in fact be at least in part responsible for the prostate cancer disparities in African American men (96-98).

Other similar studies support an interesting link between race, genetics, ancestry, and cancer health disparities.

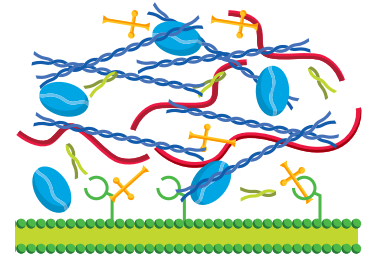
Cancer Progression: Local and Systemic Influences

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:

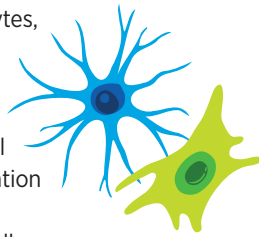
Immune cells can identify and eliminate cancer cells, although in many cases the immune system is suppressed, permitting the formation and progression of a tumor. However, in some situations of chronic inflammation, the immune system can promote cancer development and progression.



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



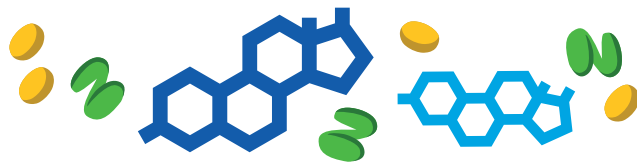
Other tissue-specific **tumor-associated cells**, such as pericytes, fibroblasts, and astrocytes, can support tumor growth through various mechanisms including stimulating tumor cell multiplication, triggering formation of new blood vessels, and enhancing survival of cancer cells.



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



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



A growing body of evidence suggests the presence of differential tumor microenvironment components among different racial and ethnic populations (111). These differences in the tumor microenvironment can put certain populations at a higher risk for developing aggressive types of cancer and may affect clinical outcomes. A better understanding of differences in the tumor microenvironment is critical for novel therapeutic interventions to bridge the disparities in clinical outcomes for patients from different racial and ethnic groups.

Adapted from (112)

Cancer Progression: Role of the Tumor Microenvironment

As cancer cells grow and divide in tissue, a mass of cells, or tumor, develops. The tumor is not just made up of cancer cells; rather, it is made up of both cancerous and noncancerous cells. Research has shown that the rate at which tumors grow and progress is largely dependent upon complex interactions between the cancer cells and the other cells and factors in their surrounding tissue, which is known as the tumor microenvironment (see sidebar on

Cancer Progression: Local and Systemic Influences, p. 40). Bidirectional communication between cancer cells and the tumor microenvironment has a profound influence on cancer progression (107-109). Moreover, the tumor microenvironment can shelter cancer cells from the effects of some cancer treatments, including radiation, chemotherapy, and immunotherapy, and thereby modify a patient's response to treatment (110).

Recent research suggests that several components of the tumor microenvironment are different among diverse racial

and ethnic patient populations. These differences among racial and ethnic populations may result from factors associated with inherited genetic ancestry, increased levels of chronic inflammation, innate differences in immune response, or a combination of these (74)(111)(113)(114). A better understanding of how cancer cells and the tumor microenvironment differ among diverse patient populations will help to better identify causes of cancer health disparities and, more importantly, provide information on how to eliminate them.

CANCER AND THE IMMUNE SYSTEM

One of the most significant advances in cancer research over the past two decades has been our increased understanding of the body's ability to mount an immune response against tumor cells, and the processes by which tumor cells suppress a patient's immune response. This knowledge forms the basis of one of the most exciting new approaches to cancer treatment—cancer immunotherapy—which utilizes patients' own immune systems to fight cancer. Cancer immunotherapy holds tremendous promise for improving outcomes for patients diagnosed with many types of cancer, including those types of cancer with a higher burden among racial and ethnic minorities. For instance, the incidence of triple-negative breast cancer, a particularly aggressive form of breast cancer, is twice as high among African American women compared with white women. In March 2019, the FDA approved an immunotherapeutic for the treatment of triple-negative breast cancer, bringing hope to many patients like Eva Joseph whose story was featured in the *AACR Cancer Progress Report 2019* (115).

Like genetic studies, however, research in cancer immunology has focused on individuals of largely European ancestry, with a significant lack of data from racial and ethnic minorities. Researchers are now beginning to understand the differences in immune biology among individuals with different ancestry. For example, studies have shown that the African genome has evolved over hundreds of generations to effectively combat infectious pathogens in the environment (116) (117). These evolutionary selections may have altered genes associated with inflammation, immune response, and wound repair. Genetic alterations that protect against infectious pathogens, however, are sometimes associated with inherited diseases. Early preclinical studies have also shown that genetic alterations that are specific to African ancestry correlate with distinct immune characteristics in tumors that may affect responses to immunotherapy. These data highlight the urgent need for comprehensive immune profiling of cancer patients from diverse racial and ethnic backgrounds in order to develop precise therapeutic interventions that are effective for these populations.

CANCER METASTASIS

Cancer metastasis is a multistep process in which the tumor cells break away from the original mass, gain access to the bloodstream and/or lymphatic system in nearby tissue, and travel to distant organs. One important question that remains to be answered about metastasis is why some cancers invade more often depending on the patient's race or genetic ancestry (118-120). This remains a complicated question to address, but the answer may lie in differences in the interactions of the tumor and the tumor microenvironment, which play a critical role in the cascade of steps that lead to metastasis (121)(122). Genetic ancestry-associated differences in intrinsic tumor biology and the immune microenvironment of tumors are expected to provide broader insights into factors that might influence steps in the metastatic cascade.

A current idea is that there may be subtle differences in how tissue repairs itself across different racial and ethnic groups (123-125). Other data suggest that cells derived from individuals of African ancestry might be more vulnerable to becoming cancerous and gaining invasive characteristics (126).

Integrating Our Knowledge: Charting the Path Forward

Over the past decade, we have made significant progress in how we understand and treat the complex group of diseases we call cancer. We have learned that cancer development is influenced by many factors including a patient's biological characteristics, social and environmental exposures, and lifestyle. Therefore, we are beginning to see a major 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 revolutionize cancer care. However, lack of relevant data from racial and ethnic minorities has really hampered the development and implementation of precision medicine for individuals from these populations (see **Imprecision of Precision Medicine**, p. 100).

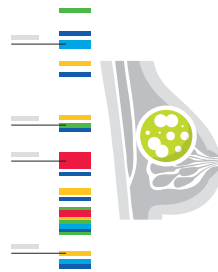
To further improve our understanding of cancer development in the broadest sense we must study the biological and genetic mechanisms that underpin cancer initiation and progression in all populations. Several studies and initiatives such as AACR Project Genomics Evidence Neoplasia Information Exchange (GENIE) and the NCI-funded African American Breast Cancer Epidemiology and Risk (AMBER) Consortium designed to address gaps in our knowledge about cancer biology in all populations are underway and complement those studies already conducted

Progress in Understanding Cancer Biology in Racial and Ethnic Minorities

There is growing recognition in the scientific community that more research into understanding cancer biology in racial and ethnic minorities is essential if we are to ensure that the new wave of scientific breakthroughs benefits all people. Here, we highlight a small number of the many studies that have recently been conducted:



Significant differences in mutation frequencies for important cancer genes between **multiple myelomas** from African Americans and whites have been detected using **comprehensive molecular profiling** (127).



Genetic markers for modeling and stratifying breast cancer risk in women of African ancestry were obtained using data from the **African American Breast Cancer Epidemiology and Risk (AMBER) Consortium** and two other consortia of breast cancer in women of African ancestry (129).



Genetic sequencing of a large dataset of **lung adenocarcinoma** in individuals of East Asian ancestry revealed that lung adenocarcinomas in East Asians have fewer mutations and fewer copy number alterations compared with lung adenocarcinomas in individuals of European ancestry (128).



Genome-wide association studies have found that individuals who carry a specific pattern at chromosome 6q25 have a **decreased risk of developing breast cancer** and that this marker is enriched in Hispanic women with a high proportion of Native American ancestry (130).



New cancer-associated genetic mutations were identified by **systematic genomic sequencing** of **prostate cancers** from African American men (131).

(see sidebar on **Progress in Understanding Cancer Biology in Racial and Ethnic Minorities**, p. 42). To continue enhancing our knowledge of biological and genetic contributors to cancer disparities additional resources are needed, including:

- biospecimens collected and analyzed from patients representing a diverse array of racial and ethnic groups;
- patient-derived cancer models generated from patients representing a diverse array of racial and ethnic groups, including both cell-based and animal models (for example, cell lines, organoids, and patient-derived xenografts);

- biological information that might be unique to patients from specific racial, ethnic, or ancestral populations; and
- racially diverse research consortia.

A concerted effort is needed from all sectors of the biomedical research community to ensure that the new wave of scientific breakthroughs benefits every cancer patient including individuals from racial and ethnic minorities and other underserved populations.

Disparities in the Burden of Preventable Cancer Risk Factors

IN THIS SECTION, YOU WILL LEARN:

- ▶ In the United States, four out of 10 cancer cases and almost half of all deaths from cancer are associated with preventable risk factors.
- ▶ Not using tobacco is the single best way a person can prevent cancer from developing.
- ▶ Nearly 20 percent of U.S. cancer diagnoses are related to excess body weight, alcohol intake, poor diet, and physical inactivity.
- ▶ About 3 percent of U.S. cancer diagnoses and deaths are related to infection with pathogens, including HPV, HBV, and HCV, for which there are treatments to eliminate infection or vaccines to prevent infection.
- ▶ Exposure to many of the major cancer risk factors continues to be high, particularly among racial and ethnic minorities and underserved populations.
- ▶ We need more effective strategies to disseminate our current knowledge of cancer prevention and implement evidence-based interventions to reduce the burden of cancer for everyone.

Decades of basic, epidemiological, and clinical research have led to the identification of several factors, known as cancer risk factors, that increase a person's chance of developing cancer (see **Figure 2**, p. 44). Researchers estimate that more than 40 percent of the cancer cases diagnosed in the United States in 2014 and nearly half of all the deaths from cancer in that year were caused by potentially avoidable cancer risk factors, including tobacco use, poor diet, alcohol intake, physical

inactivity, obesity, infection with cancer-causing pathogens, and exposure to UV radiation (57). While epidemiological studies have shown associations between exposure to high levels of some of these risk factors (for example, smoking) and the risk of developing cancer, basic research has been critical in identifying the underlying mechanisms of cancer development as a result of these exposures. Studies among immigrant populations have been instrumental in showing how cancer



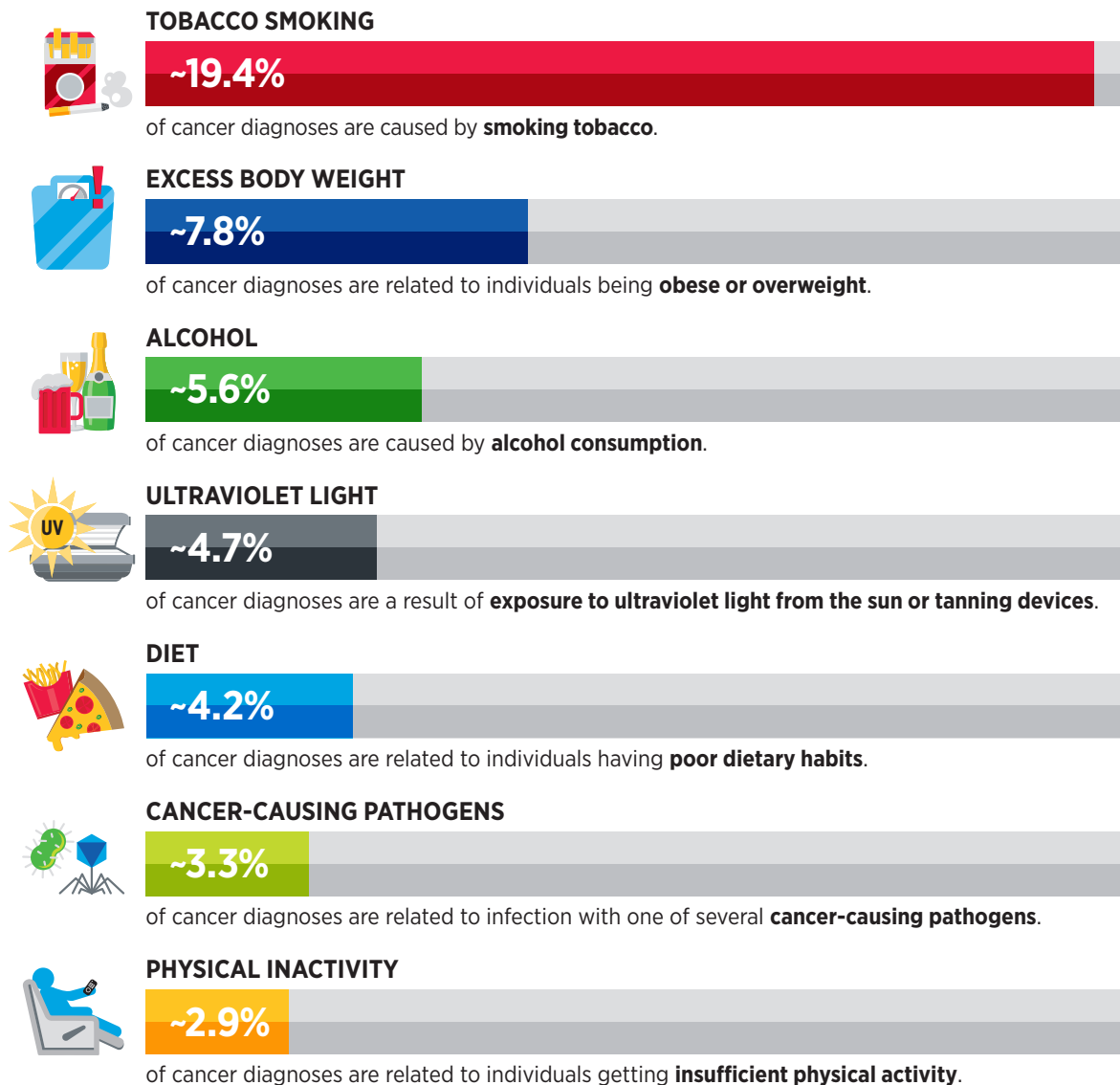
U.S. REPRESENTATIVE FOR NORTH CAROLINA'S 1ST DISTRICT

The Honorable G.K. Butterfield

"The statistics on cancer disparities are shocking and profoundly disturbing. According to the Office of Minority Health, African Americans have the highest mortality rate of any racial or ethnic group for all cancers combined, including for most major cancers. This alarming fact should be a call to arms. As a nation we must act now to reverse course and get serious about addressing disparities in our health care system—from focused cancer awareness and prevention programs that meet people where they are, to early detection and screening programs for at-risk groups, and funding critical research so that we can continue to learn how we can close the disparity gap, while improving the health of all."

Increasing Cancer Risk

Research has identified numerous factors that increase an individual's risk for developing cancer. By modifying behavior, individuals can eliminate or reduce many of these risks and thereby reduce their risk of cancer. Developing and implementing additional public education and policy initiatives could help further reduce the burden of cancers related to preventable cancer risk factors.



Data from (57)

incidence changes when populations move from one country to another, helping population scientists identify the risk factors most likely to be responsible for such changes. Together, these basic and population-based studies have allowed the classification of possible cancer-causing agents into different risk categories based on the level of evidence and the level of

risk. These classifications guide cancer prevention strategies and policies to reduce the burden of cancer in the population.

The development and implementation of public education and policy initiatives designed to eliminate or reduce exposure to preventable causes of cancer have reduced

cancer morbidity and mortality in the United States. For example, tobacco control efforts implemented since the 1960s have led to considerable reductions in smoking and smoking-related diseases, including lung cancer. Despite these measures, the prevalence of some of the major cancer risk factors continues to be high, particularly among segments of the U.S. population that experience cancer health disparities, such as racial and ethnic minorities, individuals from low socioeconomic backgrounds, and those with lower educational attainment (see sidebar on **Disparities in the Burden of Avoidable Cancer Risk Factors**, p. 45). Thus, we must identify more effective strategies to disseminate our current knowledge of cancer prevention and implement evidence-based interventions to reduce the burden of cancer for everyone.

Tobacco Use

Tobacco use is the leading preventable cause of cancer and cancer-related deaths (57). Tobacco use includes the use of cigarettes and other combustible tobacco products, such as cigars, as well as smokeless tobacco products (for example, chewing tobacco and snuff), and pipe tobacco. It causes cancer because tobacco or secondhand smoke exposes individuals to many harmful chemicals that damage DNA, causing genetic and epigenetic alterations that lead to cancer development (137)(138).

Smoking is linked to 17 different types of cancer in addition to lung cancer (see **Figure 3**, p. 46). Moreover, even though not proven to cause prostate cancer, cigarette smoking is associated with a higher risk of death from prostate cancer, a higher risk of advanced-stage prostate cancer, and a higher risk of prostate cancer progression (139). Exposure to secondhand smoke also can cause lung cancer (140). In cancer patients and survivors, cigarette smoking is associated with an increased risk of recurrence, poorer response to treatment, and increased treatment-related toxicity (139). Fortunately, cessation at any age can reduce the risk of cancer occurrence and cancer-related death (139). Thus, one of the most effective ways a person can lower his or her risk of developing cancer and lower his or her risk of other smoking-related conditions such as cardiovascular, metabolic, and lung diseases, is to avoid or eliminate tobacco use.

Use of tobacco in the United States differs widely by race and ethnicity (see **Figure 4**, p. 47 and sidebar on **Racial and Ethnic Differences in the Prevalence of Smoking**, p. 48).

Although African American adults smoke at comparable levels to non-Hispanic whites, tobacco-related morbidity and mortality rates are disproportionately higher among this population (12). The reason for this is not fully understood and is likely to be multifactorial including

Disparities in the Burden of Avoidable Cancer Risk Factors

There are considerable disparities in the exposure to avoidable cancer risk factors among certain segments of the U.S. population, such as:

TWICE
THE RATE

The **smoking rate** among individuals who have serious psychological distress is **twice** that among those who do not (132).

4
TIMES
LESS LIKELY

College-educated individuals are nearly **4 times less likely to smoke** than those with a high school education or less (133).

40%
HIGHER

Prevalence of adult tobacco use in southern states such as West Virginia, Kentucky, and Arkansas is **more than twice** that in California; incidence of invasive lung, bronchial, and tracheal cancers is **40 percent higher in the South** than in the West (134).

21%
VS
39%

Obesity prevalence among adults living in nonmetropolitan counties was **21 percent in Colorado compared with 39 percent in Louisiana** (135).

31.7%
VS
23.4%

The **prevalence of physical inactivity is higher among Hispanics** (31.7 percent), compared with non-Hispanic whites (23.4 percent) (136).

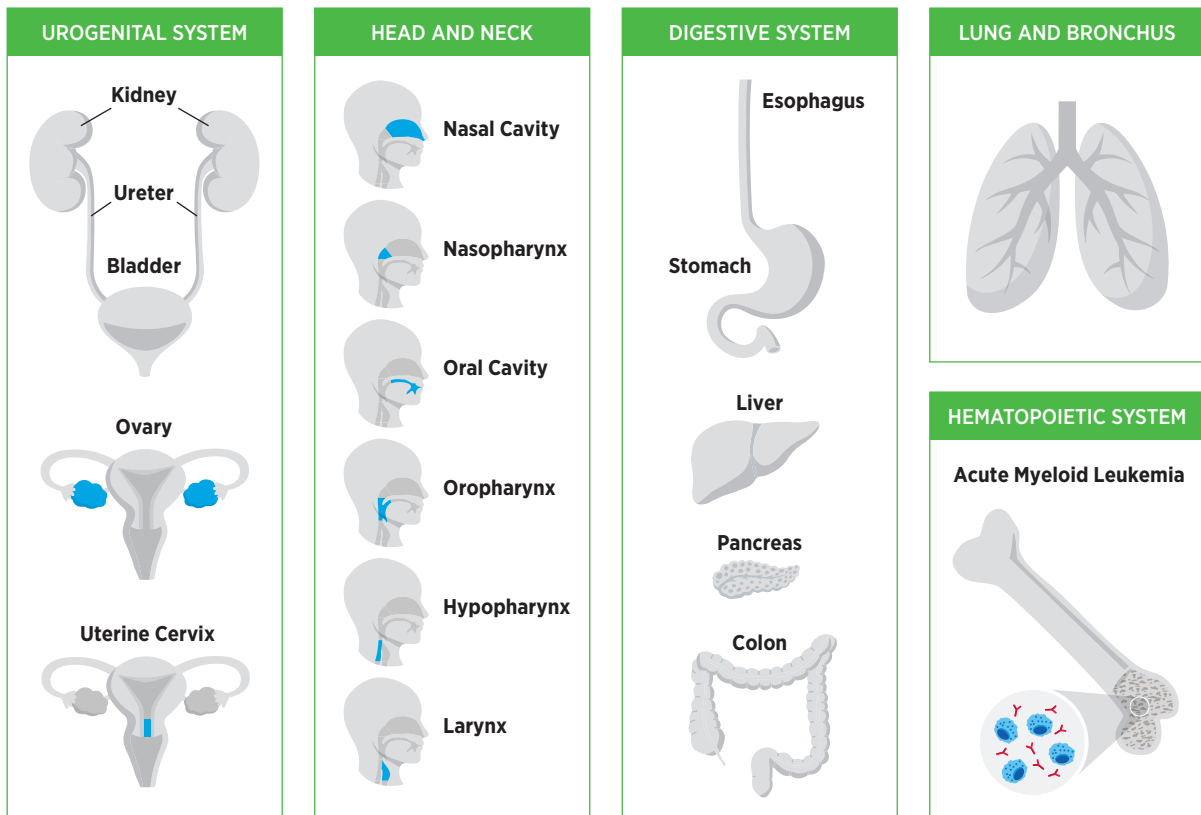
56%
VS
41%

Adolescents living in metropolitan areas are **more likely to be up to date with HPV vaccination** (56 percent) compared with those in nonmetropolitan areas (41 percent) (32).

Adapted from (115)

Beyond the Lungs: Cancers Caused by Smoking Tobacco

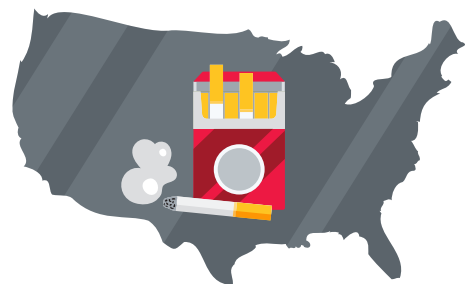
Smoking tobacco increases an individual's risk of developing not only lung cancer, but also 17 other types of cancer. No level of exposure to tobacco smoke is safe, including exposure to secondhand smoke, which is estimated to have resulted in more than 260,000 of the 5 million lung cancer deaths in the United States attributable to smoking from 1965 to 2014.



Adapted from (3)

In the United States, in 2014, it is estimated that (57):

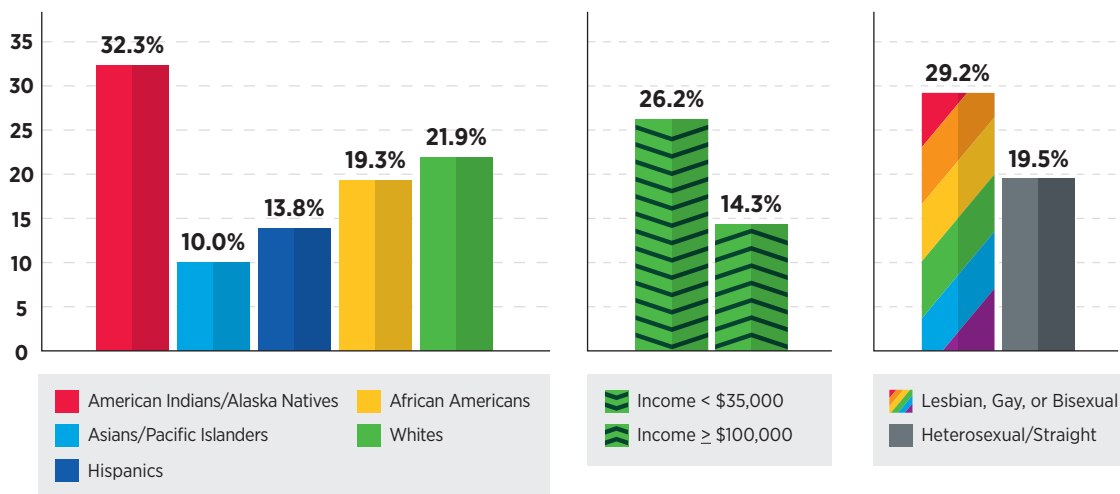
- 19.0% of cancer cases and 28.8% of cancer deaths were attributed to cigarette smoking, making it the **most significant potentially modifiable cause of cancer**;
- 2.7% of lung cancers were attributed to **secondhand smoke exposure**; and
- cigarette smoking accounted for **55.5% and 35.0% of all potentially preventable cancers** in men and women, respectively.



Disparities in Tobacco Product Use in the United States

Among adults age 18 and older the use of any tobacco product varies widely by race/ethnicity, annual household income, and sexual orientation, among other characteristics. Among the different racial/ethnic groups, use is highest among American Indians/Alaska Natives and lowest among Asians. Use is also higher among those with an annual household income of less than \$35,000 and lesbian, gay, or bisexual adults compared with those with an annual household income of \$100,000 or higher and heterosexual/straight adults, respectively.

PERCENTAGE OF ADULTS AGE 18 AND OLDER WHO REPORTED TOBACCO PRODUCT USE



Data from (132)

differences in socioeconomic status impacting access to quality care, prevalence of additional risk factors such as obesity, exposure to secondhand smoke, and higher use of mentholated cigarettes. Of note, menthol smokers report increased nicotine dependence and reduced smoking cessation compared with non-menthol smokers (144). Several cancers that are linked to tobacco use, including stomach, liver, pancreatic, colorectal, and cervical cancers, have higher burdens among African Americans (12). The continuing disparity in the overall cancer death rates between African Americans and non-Hispanic whites is driven by disparities in deaths from several cancers that are either caused by tobacco or are associated with worse disease among tobacco users and hence made more fatal by tobacco, specifically breast and colorectal cancer in women, and prostate, lung, and colorectal cancer in men (145).

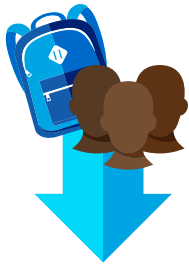
Quitting smoking can lower risk for cancer or death from cancer (139). Although African American adult cigarette smokers are more likely to report that they want to quit smoking and attempt to quit smoking as compared with smokers from other racial and ethnic groups, they are less successful at quitting than non-Hispanic white and Hispanic

smokers (146). This may be due to disparities in culturally tailored, evidence-based cessation strategies.

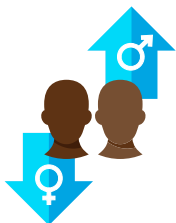
Policy interventions can reduce tobacco-related cancer disparities by helping people quit smoking, preventing people from starting to smoke, and reducing exposure to secondhand smoke. This can be done through comprehensive smoke-free laws, increasing taxes on tobacco products, reducing targeted advertising, and offering comprehensive and evidence-based cessation services (147). However, certain policies enacted in the past have not provided as much benefit to racial and ethnic minorities as they have to whites. For instance, the uptake of smoke-free laws across the United States has reduced overall exposure to secondhand smoke. However, African Americans have benefited less than other groups from these laws and continue to have higher rates of exposure to secondhand smoke. Differences in smoking rates, implementation of smoke-free laws, and knowledge about the harms of secondhand smoke may contribute to this disparity (140).

Increasing cigarette prices, such as via tobacco tax increases, reduces tobacco use and prevents initiation of use (139) and Hispanics and African Americans are more sensitive

Racial and Ethnic Differences in the Prevalence of Smoking



African American youth have lower smoking rates compared with Hispanic and non-Hispanic white youth and initiate smoking at older ages compared with non-Hispanic whites (141). However, the overall smoking rate among African American and non-Hispanic white adults is similar (133), although African Americans smoke fewer cigarettes per day (142).



The smoking rate is **higher among African American men** (19.1 percent) than non-Hispanic white men (16.9 percent) but **lower among African American women** (11.8 percent) than non-Hispanic white women (14.8 percent) (133).



The smoking rate is lower among Hispanics (9.8 percent) compared with whites (15 percent) and African Americans (14.6 percent) (132).



Among adult current tobacco users, there are differences in the tobacco products used by race and ethnicity. African Americans (5.8 percent) are **more likely to smoke cigars** compared with non-Hispanic whites (4.2 percent) (133).



African American current smokers are **significantly more likely to smoke mentholated cigarettes** compared with non-Hispanic whites (143).



African American adults and children are **more likely to be exposed to secondhand smoke** than adults and children from any other racial or ethnic group, with **50.3 percent of African American adults and children exposed to secondhand smoke** compared with **21.4 percent of non-Hispanic white adults and children** (140).

to tobacco prices than non-Hispanic whites. Tobacco companies have historically marketed their products more heavily to African Americans, particularly menthol cigarettes, and menthol cigarettes have in the past been exempt from stricter FDA regulations regarding flavored products (147). African American adult cigarette smokers are less likely to report receiving physician advice to quit smoking or using prescription smoking cessation medication (148). These data 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 especially for racial and ethnic minorities.

The use of electronic cigarettes (e-cigarettes) has increased dramatically in the past ten years, and their long-term health impacts are unknown (149). Currently non-Hispanics have higher rates of awareness and use of e-cigarettes as compared with other racial and ethnic groups (132). Adolescent and young adult e-cigarette users are two to four times more likely to begin using conventional tobacco products (149). Continuing research on the health effects of e-cigarettes and their use across different population groups is necessary to ensure that use of these devices does not increase existing disparities, and that their potential benefits (if any) for smoking cessation purposes are distributed equally across groups.

Obesity

In the United States, excess body weight is associated with nearly 5 percent of all cancers in men and 11 percent of all cancers in women (57). Being overweight or obese as an adult increases a person's risk for developing 15 types of cancer (see **Figure 5**, p. 49) (150)(151). There is evidence that obesity at the time of diagnosis is linked to increased risk of death from early-stage breast, colorectal, endometrial, and prostate cancer (150)(152)(153).

There are significant disparities in obesity rates among different racial and ethnic populations (see sidebar on **Disparities in Overweight and Obesity Rates in the United States**, p. 50 and **Figure 6**, p. 50) and several of the cancers that have higher burden among racial and ethnic minorities are associated with obesity (see sidebar on **Disparities in the Burden of Obesity-related Cancers**, p. 51).

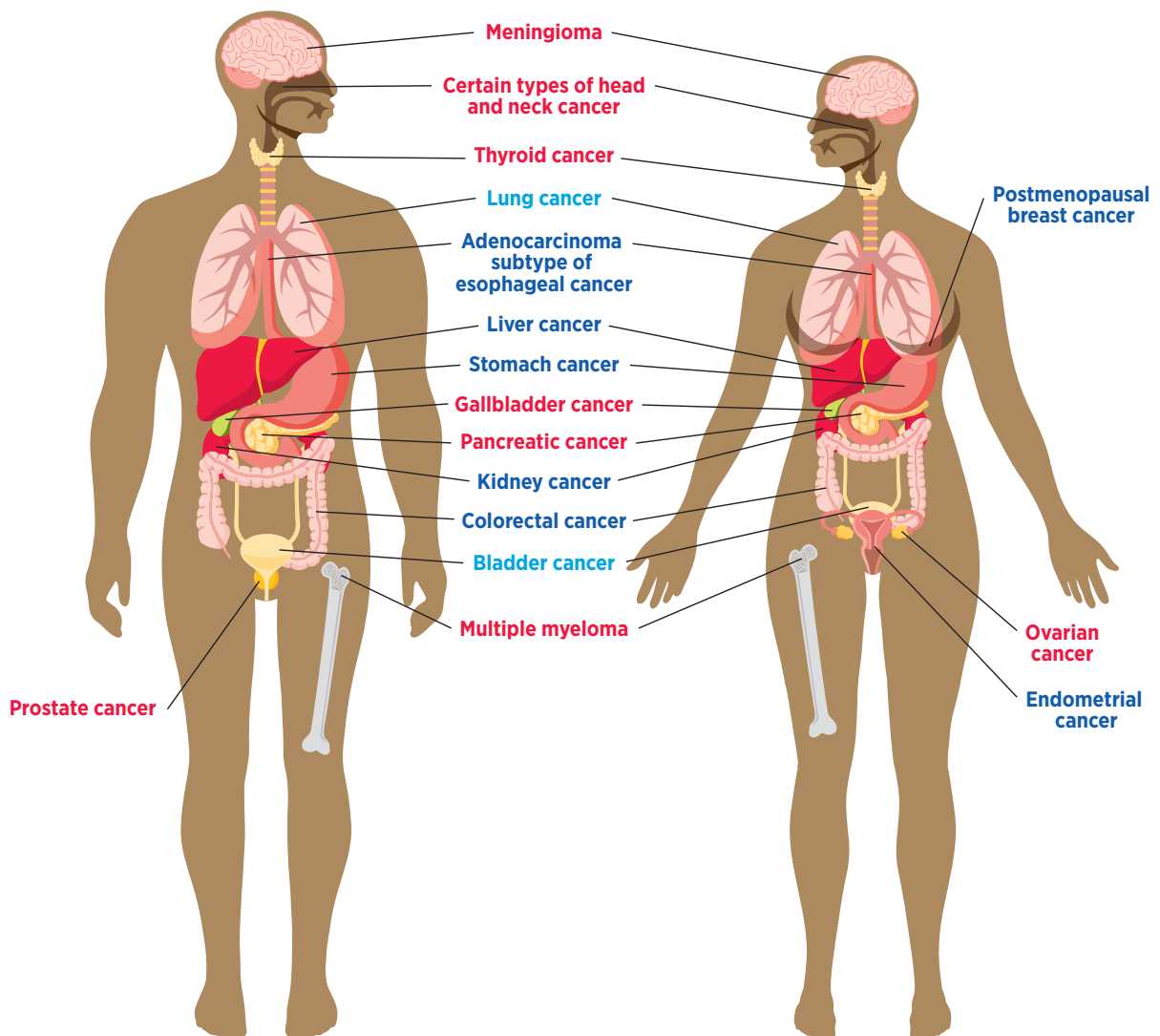
Focusing on obesity in childhood is key to reducing disparities in obesity and cancer because risk of adult obesity is greater among individuals who were obese as children, and overweight African American youth are more likely to become obese adults compared with non-Hispanic white obese youth (155).

Notably, the association between obesity and cancer risk may vary among racial and ethnic groups. For example, a stronger association between obesity and risk of prostate cancer is seen among African American men compared with non-Hispanic

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, colon and rectum, 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 types of cancer—esophageal, kidney, liver, lung, stomach, colon, breast (postmenopausal), endometrial, and bladder cancers. Cancers associated with obesity are shown in red, cancers associated with physical activity are shown in light blue, cancers that are associated with both are shown in dark blue.

■ Cancers associated with **OBESITY**
■ Cancers associated with **PHYSICAL ACTIVITY**
■ Cancers associated with **BOTH**



Data from 150, 151, 176, 177, 178, and 185. Adapted from (115)

Disparities in Overweight and Obesity Rates in the United States



Rates of overweight and obesity differ by race and ethnicity:

- Overall, **Hispanic (81.7 percent) and African American (75.1 percent) adults** have higher rates of overweight and obesity than non-Hispanic white adults (69.8 percent) (133). These differences are most pronounced among women.
- In 2017-2018, **nearly 57 percent of African American adult women and 44 percent of Hispanic adult women** were obese compared with 40 percent of non-Hispanic white adult women (133a).

Similar differences are seen among (ages 2 to 19):

- **25.8 percent of Hispanic and 22.0 percent of African American youth** are obese compared with 14.1 percent of non-Hispanic white youth (154).

white men (156). Although the increased cancer risk associated with excess body weight and weight gain is clear, the exact mechanisms underpinning this variation in risk are not fully understood. Further research to understand these mechanisms will lead to interventions and policies that can effectively reduce cancer risks and cancer health disparities among racial and ethnic minorities.

Dietary Factors

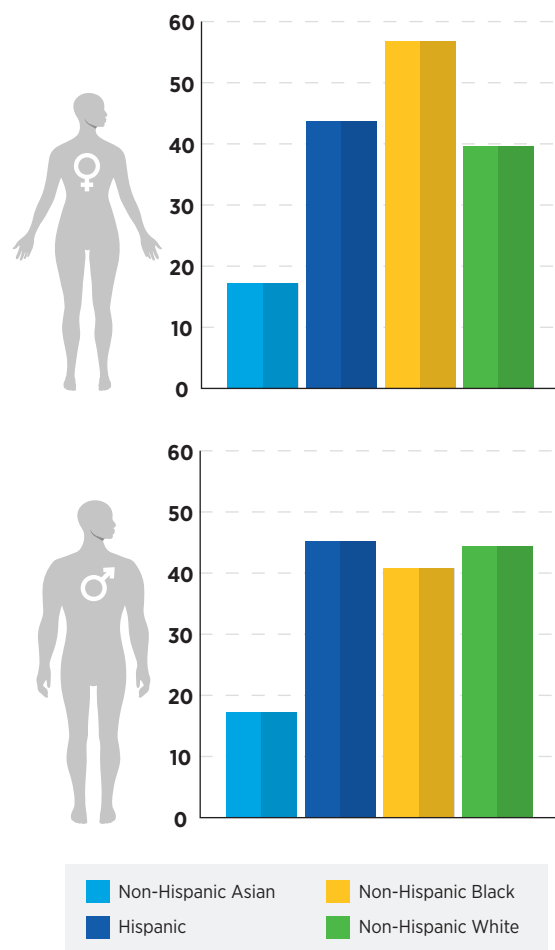
In the United States, nearly 5 percent of all cancer cases and deaths among adults age 30 and older are attributable to eating a poor diet (157). Low intake of healthy foods such as whole grains, fruits, nuts, and seeds combined with high intake of unhealthy foods such as sugar-sweetened drinks

FIGURE 6

Racial and Ethnic Disparities in Obesity Rates

There are significant disparities in obesity rates among different racial and ethnic populations. Among adults age 18 and older, obesity rates are highest among African American women and lowest among Asian men.

PERCENT OF ADULTS WITH OBESITY, 2017-2018



Adapted from (133a)

and high levels of red and processed meats are, in fact, responsible for one in five deaths globally (158).

The role that dietary factors play in determining cancer risk is greater for some types of cancers than it is for others. For example, it is estimated that more than 8 percent of colorectal cancer cases are caused by high intake of processed meats, and nearly 18 percent of oral/pharyngeal cancers are due to low

consumption of fruits and vegetables (57). Intensive efforts from all stakeholders are needed if we are to increase the number of people who consume a balanced diet and maintain a healthy lifestyle to minimize the risk of cancer development (see sidebar on **Guidelines to Reduce Cancer Risk**, p. 52).

Studies across the United States have shown that overall, Hispanics have better quality diets than African Americans, and of comparable quality to non-Hispanic whites; whereas African Americans have lower quality diets than whites, in particular for total vegetable and grain intake (159)(160). Among African Americans, the strongest barriers to consuming a high-quality diet are lack of time to prepare healthy food, the cost of healthy food, and the convenience of fast foods (161). Among Hispanics, dietary quality has been observed to vary considerably by country of origin; therefore, interventions tailored to Hispanics should consider these differences (162). For white and African American young adults (ages 18-39), diet quality has improved over the past two decades, while remaining the same for Mexican Americans. Notably, even though individuals from all income levels experienced an improvement in diet quality, the disparity between low- and high-income groups increased considerably (163). Overall, in the United States, diet quality improves with increased income level (160), which may contribute to cancer health disparities.

Sugar-sweetened beverages are a major contributor to obesity and excess body weight among U.S. youth and adults (165)(166). Reports indicate persistent disparities in the consumption of sugar-sweetened beverages across racial and ethnic populations, with African American, Mexican American, and other Hispanic adults and children being more likely to drink sugar-sweetened beverages than their white counterparts (167). A recent policy approach aimed at reducing obesity is the introduction of taxes on sugar-sweetened beverages in several local jurisdictions in the United States (168). It is encouraging that there is already some indication that there has been a reduction in consumption of sugar-sweetened beverages since the implementation of these taxes, especially in lower-income, racially and ethnically diverse neighborhoods (169)(170). However, ongoing research is needed to evaluate the long-term effects of these policies on obesity and obesity-related health outcomes such as cancer.

Disparities in the Burden of Obesity-related Cancers

There are significant disparities in obesity rates among different racial and ethnic populations. Obesity is one risk factor for many types of cancer with a higher burden among racial and ethnic minorities. Some examples include the following (145):

Multiple myeloma—African American men and women are greater than two times more likely to be diagnosed with the disease compared with non-Hispanic men and women.



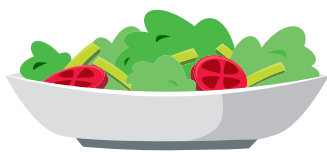
Stomach cancer—African American women are greater than two times more likely to be diagnosed and African American men and women are over two times more likely to die from the disease compared with their non-Hispanic white counterparts.



Colorectal cancer—African American men and women are more likely to be diagnosed and die from the disease compared with non-Hispanic men and women.



Prostate cancer—African American men are greater than two times more likely to die from prostate cancer than non-Hispanic white men, and advanced prostate cancer is linked to obesity.



Incorporating more salads into one's diet can be a practical approach to improving overall dietary quality. Across the U.S. population, **~26% of non-Hispanic whites, 18% of Hispanics, and ~13% of African Americans** reported being salad eaters, emphasizing the disparities in diet quality across racial and ethnic groups (159)

Guidelines to Reduce Cancer Risk

Research shows that about one-fifth of all cancers diagnosed in the United States can be 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 (body mass index [BMI] between 18.5 and 24.9) 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, starches, or sugars because these contribute to weight gain.



Be physically active as part of everyday life; regular physical activity can decrease risk for nine types of cancer.



Limit intake of red and processed meat (for example, hot dogs, bacon, and salami) because these foods can increase risk for colorectal cancer.



Eat a diet rich in vegetables, fruits, whole grains, and beans; at least 2/3 of the plate should contain these items.



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



Rely on healthy foods for vitamins and minerals over supplements.



If consumed at all, limit alcoholic drinks, because alcohol consumption can increase risk for six types of cancer; no more than 1 drink per day for women, and no more than 2 drinks per day for men.



For mothers: breastfeed your baby, if you can.

Source: <https://www.wcrf.org/dietandcancer/resources-and-toolkit>



>1 MILE



>10 MILES



The U.S. Department of Agriculture estimates that more than 23 million people live in low-income areas that are **more than a mile** (in the case of urban areas) **or 10 miles** (for rural areas) **away from the nearest supermarket** (166).

The burden of many diet-related diseases, including cancer, is disparately higher in low-income and racially and ethnically diverse neighborhoods (171). These neighborhoods are also often located in “food deserts,” lacking access to healthy food retail such as supermarkets, while having an overabundance of convenience stores with unhealthy and fast food options. However, even

when comparing communities with similar levels of poverty, studies show that African American and Hispanic neighborhoods have fewer supermarkets and more convenience stores than white neighborhoods (172). These findings underscore the need for evidence-based health improvement strategies to increase access to affordable and nutritious food for racial and ethnic minority populations.

For cancer survivors, the current recommendation is to follow the same guidelines for cancer prevention (see sidebar on **Guidelines to Reduce Cancer Risk**, p. 52). However, disparities have been reported, with research showing that African American survivors are less likely to adhere to dietary recommendations compared with non-Hispanic white survivors (173), and that being younger, less educated, having lower income, and higher body mass index are all determinants of low adherence to dietary recommendations (174)(175). These data emphasize the need for the implementation of evidence-based interventions that can mitigate such disparities to improve outcomes for African American cancer patients and survivors.

Physical Activity

An estimated 3 percent of all cancers, with up to 16 percent of colorectal cancers and 4 percent of breast cancers in the United States, can be attributed to lack of physical activity (57). Physical activity, which is any activity that involves our muscles and is different from resting, is known to have direct positive effects on the body, such as the immune system, hormones, and metabolism, which may decrease our risk of

cancer development. According to a recent report, physical activity can definitely reduce the risk of developing nine types of cancer (176) (see **Figure 5**, p. 49). There is growing evidence that physical fitness may also reduce the risk of developing additional types of cancer (177)(178). Furthermore, physical activity can dramatically lower rates of all causes of death after a diagnosis of certain types of cancer (179).

Considering the above evidence, it is concerning that four out of 10 U.S. adults are physically inactive and only a quarter of children and teenagers get the recommended hour of moderate-to-vigorous exercise a day (180-182). Racial and ethnic disparities have been reported in the proportion of individuals who are physically inactive, with Hispanics and African Americans having a higher prevalence of physical inactivity compared with whites, and these differences are not explained by socioeconomic status (133)(136)(183). Similar trends have been observed across the United States for various types of physical activity, with whites having a greater proportion of individuals who are physically active compared with African Americans and Hispanics (184).

Living in low-income neighborhoods, where there is a lack of safe and affordable options for physical exercise,

Physical Activity Guidelines

About 80 percent of U.S. adults and adolescents are insufficiently active. The U.S. Department of Health and Human Services recommends the following minimum physical activity levels to improve the nation's health (185).

For preschool-aged children (3 to 5 years)



- Physical activity throughout the day to enhance growth and development.

For school-aged children and adolescents



- Sixty minutes or more of physical activity such as 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.

Adapted from (3)

Ways to Protect Your Skin

To reduce your 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 your 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; and



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

Adapted from (112)

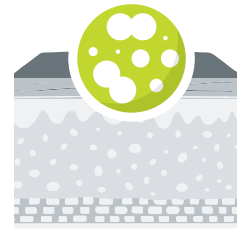
such as gyms, bike trails, and walking paths, contributes to disparities in the burden of obesity-related diseases in racial and ethnic minorities. Therefore, it is imperative that health care professionals and policy makers work together to increase awareness of the benefits of physical activity and support efforts to implement programs and policies to facilitate physical activity for all Americans (see sidebar on **Physical Activity Guidelines**, p. 53).

UV Exposure

Exposure to UV radiation from the sun or indoor tanning devices can cause genetic mutations and poses a serious

While less common than in whites, **individuals of other racial and ethnic backgrounds can get skin cancers** (191)(192). In fact, skin cancer represents approximately:

- **4 to 5 percent** of all cancers in Hispanics
- **1 to 2 percent** of all cancers in African Americans


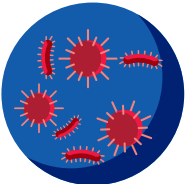

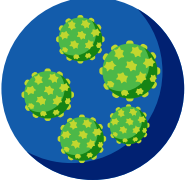


threat for the development of all three main types of skin cancer—basal cell carcinoma, squamous cell carcinoma, and melanoma, which is the deadliest form of skin cancer. Thus, one of the most effective ways a person can reduce his or her risk of skin cancer is by practicing sun-safe habits and not using UV indoor tanning devices (see sidebar on **Ways to Protect Your Skin**, p. 54).

Overall, UV light accounts for 4-6 percent of all cancers, and is responsible for 95 percent of skin melanomas (57). Disparities have been reported in the level of knowledge about the danger of sun exposure and importance of using sunscreen, with African Americans and Hispanics having less knowledge and being less likely to use sunscreen than whites (186)(187). According to a recent report, only 6 percent of African American and 24 percent of Hispanic fifth graders reported using sunscreens compared with 45 percent of their non-Hispanic white counterparts (188). These data are concerning given the fact that sunburns, a clear indication of overexposure to UV radiation, occurring in childhood pose one of the greatest risks for developing skin cancer later in life (189).

The level of knowledge about skin cancer risks among African Americans and Hispanics is influenced by level of education (190). Overall, the disparity in skin cancer prevention among these two minority groups is of public health relevance and is reflected in the fact that even though African Americans and Hispanics have lower incidence of skin cancer, they tend to be diagnosed at more advanced stages. Continued efforts from all sectors are necessary to identify and implement more effective interventions to promote sun-safe behaviors among racial and ethnic minorities and to reduce the burden of skin cancers for these population groups.

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> 	<ul style="list-style-type: none"> • Avoid exposure through good hygiene and sanitation 	<ul style="list-style-type: none"> • Treatment with a combination of antibiotics and a proton-pump inhibitor can eliminate infection 	<ul style="list-style-type: none"> • 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>HBV</p> 	<ul style="list-style-type: none"> • HBV vaccination • Avoid behaviors that can transmit infection (e.g., injection drug use and unsafe sex) 	<ul style="list-style-type: none"> • 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 	<ul style="list-style-type: none"> • Vaccination part of childhood immunization schedule since 1991 • 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>HCV</p> 	<ul style="list-style-type: none"> • Avoid behaviors that can transmit infection (e.g., injection drug use and unsafe sex) 	<ul style="list-style-type: none"> • Treatment with any of several antiviral drugs can eliminate infection 	<ul style="list-style-type: none"> • There is consensus in recommendations from CDC and USPSTF for universal screening of all adults ages 18 to 79
<p>HPV</p> 	<ul style="list-style-type: none"> • FDA-approved vaccine • Practice safe sex, although this may not fully protect against infection 	<ul style="list-style-type: none"> • None available 	<ul style="list-style-type: none"> • CDC recommends HPV vaccination for boys and girls age 11 or 12

CDC, Centers for Disease Control and Prevention; HBV, hepatitis B virus; HCV, hepatitis C virus; HPV, human papillomavirus; MALT, mucosa-associated lymphoid tissue; USPSTF, U.S. Preventive Services Task Force.

Adapted from (112)

Infectious Agents

Persistent infection with several pathogens including HPV, HBV, HCV, and *H. pylori* is known to cause cancer (see **Table 6**, p. 56). In the United States, in 2014, about 3 percent of all cancer cases and cancer deaths were attributable to infection with pathogens (57). Individuals, therefore, can significantly lower their risks by protecting themselves

from infection with these pathogens or by obtaining treatment, if available, to eliminate an infection (see sidebar on **Preventing or Eliminating Infection with the Four Main Cancer-causing Pathogens**, p. 55).

Although there are strategies available to eliminate, treat, or prevent infection with *H. pylori*, HBV, HCV, and HPV that can significantly lower an individual's risks for developing

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 and Opisthorchis viverrini</i>	Cholangiocarcinoma	3,500
<i>Schistosoma haematobium</i>	Bladder cancer	N/A
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 Herpes Virus type -8 (HHV-8; also known as Kaposi sarcoma herpes virus)	Kaposi sarcoma	42,000
Human Immunodeficiency Virus (HIV)	Kaposi sarcoma and non-Hodgkin lymphoma	N/A
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	N/A
* where known Data from Ref https://www.thelancet.com/journals/langlo/article/PIIS2214-109X(19)30488-7/fulltext#seccetitle10		

an infection-related cancer, it is important to note that these strategies are not effective at treating infection-related cancers once they develop. It is also clear that these strategies are not being used optimally. For example, even though the U.S. Preventive Services Task Force (USPSTF), an independent, volunteer panel of experts in prevention and evidence-based medicine, recommends one-time HCV testing for baby boomers, recent data show that only 14 percent of adults in this population group have been tested (193). Furthermore, even though HBV vaccination has been available for decades, disparities in access to vaccines remain for African Americans and Hispanics (194). This in turn contributes to the higher rates of liver cancer that occur in these racial and ethnic populations (see **Tables 1** and **2**, p. 14 and 15, respectively).

Given that in the United States, liver cancer incidence is increasing rapidly and that infection with HBV or HCV accounts for 65 percent of liver cancers, more effective implementation of vaccination, screening, and treatment is needed urgently to significantly reduce the burden of this disease (195). Notably, liver cancer incidence and mortality rates are higher among American Indians and Alaska

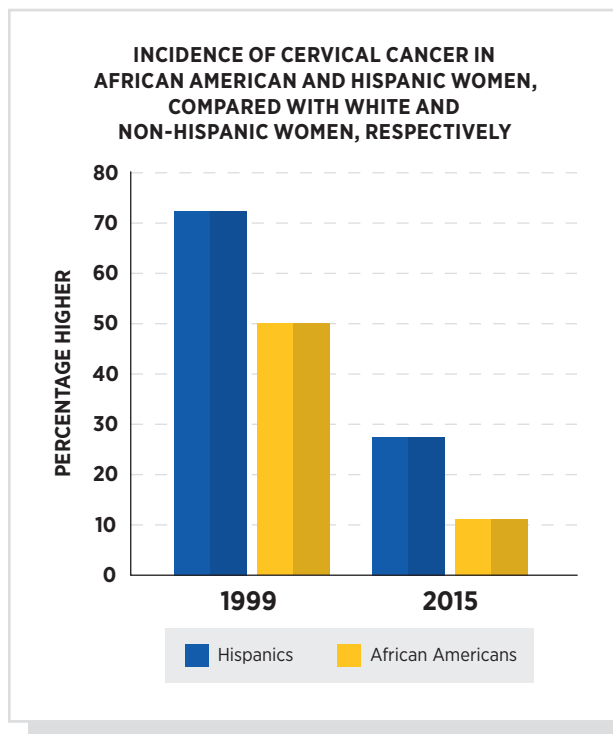
Natives compared with whites (4)(195). Among American Indians and Alaska Natives, HCV infections occur earlier than in the general population and HCV-related deaths are double the national rate (196). The Indian Health Service recently recommended universal screening of all American Indian and Alaska Native adults in an effort to reduce the burden of HCV infection and HCV-related deaths in this population group (<https://www.ihs.gov/ihtm/sgm/>).

H. pylori is a type of bacterium that has been shown to cause gastric cancer. Among U.S. adults, a higher prevalence of infection has been reported in Mexican Americans and non-Hispanic blacks compared with non-Hispanic whites (15), which may contribute to the higher rates of gastric cancer in these populations. Declining rates of *H. pylori* infection have been reported recently, which may be due in part to improved access to antibiotics, increased use of refrigeration, and decreased use of salted foods (197).

HPV is a known cause of many cancers as it can infect both the genitals and the oral cavity. It is estimated that in the United States, HPV infection accounts for nearly 34,000 cancer cases each year including almost all cervical and anal cancers as well

as the majority of vaginal, vulvar, penile, and oropharyngeal cancers (198). HPV vaccines are highly effective, and it has been estimated that if used as recommended they could prevent up to 90 percent of HPV-related cancers. Cervical cancer, moreover, can be detected at its very early stages, allowing treatment to eradicate early lesions and prevent the cancer from developing altogether, as discussed in **Disparities in Cancer Screening for Early Detection** (see p. 59).

In the United States, the prevalence of genital HPV infection and of any oral HPV infection is higher among African American adults ages 18 to 59 compared with their Hispanic and non-Hispanic white counterparts (199). Consequently, there are significant disparities in the burden of HPV-associated cancers in racial and ethnic minorities. For example, even though overall cervical cancer rates have decreased in the United States, African American and Hispanic women still have higher rates of HPV-associated cervical cancer compared with women of other races and non-Hispanic women respectively (200).



Currently, the coverage for HPV vaccination ranges widely across the United States, with only about 50 percent of adolescents ages 13 to 17 up to date with the recommended regimen (32). Unfortunately, disparities exist by race and ethnicity, with African American girls ages 13 to 17 being less likely than their white counterparts to have completed the recommended dose (201). This disparity does not seem to be explained by sociodemographic and health care access,

suggesting as yet unidentified additional barriers that need to be addressed (202). Therefore, there is a great need for programs designed to increase prevention, such as screening and vaccination, and reduce barriers in a culturally sensitive manner, in order to reduce cervical cancer incidence and mortality rates.

Social and Behavioral Stressors

Stress-related social and behavioral factors have been considered as possible cancer risk factors. For example, it has been found that having a stress-prone personality and/or poor coping skills, as well as emotional distress, can affect incidence, mortality, and survival for various types of cancer (60) and that having stressful life experiences can affect survival from multiple types of cancer. It is not clear if the effects of stress-related psychological factors on cancer are due to an increase in cancer risk behaviors, such as smoking, alcohol consumption, poor diet, and physical inactivity, or due to direct effects on our bodies. For example, stress can directly affect hormones and/or cellular processes, which in turn may contribute to cancer formation (60) (203). One area of intensive research investigation is understanding the contribution of the allostatic load, which describes the combined influences of stresses, lifestyle, and environmental exposures, on the lifetime risk of various diseases such as cancer (204)(205).

Among the various risk factors that may induce stress are social isolation, which has been shown to contribute to increased morbidity and mortality, particularly among minorities (206); and racial discrimination, even perceived discrimination, which can contribute to poor physical and mental health among minorities (207), and has been linked to breast cancer among African American women (208). Moreover, gentrification, segregation, and discrimination have been linked to stage at breast cancer diagnosis, cancer-specific mortality, and breast cancer incidence (66). Various studies have proposed that psychological and social factors may also contribute to the observed disparities for prostate cancer among African American men (209). It is therefore imperative that additional studies on different cancers, populations, and settings are undertaken in order to fully elucidate the role of psychosocial factors on cancer risk, and that appropriate interventions are deployed in order to prevent these factors and minimize their contribution to cancer health disparities.

Other Cancer-causing Factors

There are several other preventable cancer-causing factors with disparate burden among racial and ethnic minorities. For example, involuntary exposures to environmental

pollutants usually occur in subgroups of the population, such as workers in certain industries who may be exposed to carcinogens on the job or individuals living in low-income neighborhoods. Similarly, there are disparities in the burden of cancers caused by environmental exposures based on geographic locations and socioeconomic status.

OUTDOOR AIR POLLUTION

Outdoor air pollution has been found to be a cancer-causing agent, primarily for lung cancer, but possibly other cancers too. It is estimated that about 3 to 5 percent of lung cancer cases are due to outdoor pollution (210). Importantly, African Americans and Hispanics have been reported to be exposed to higher levels of outdoor air pollution than non-Hispanic whites (211). A study in California that integrated measures of air pollution as well as other environmental hazards concluded that African Americans and Hispanics were more likely than whites to live in proximity to multiple environmental health hazards (212).

PESTICIDES AND ENDOCRINE-DISRUPTING CHEMICALS

There are many chemical compounds that are used in agriculture, in the house, and in some occupations, to combat various pests, including weeds, and to protect us from fires, such as fire-retardant chemicals. It is a diverse group of chemicals, so each type needs to be studied separately. Several pesticides have been linked with cancer development, including lung, pancreatic, colorectal, prostate, brain, and bladder cancers, as well as leukemia, Non-Hodgkin lymphoma and multiple myeloma (213) (214). Pesticides and other products 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 (215). It has been estimated that African Americans and Mexican Americans suffer a higher burden of exposure to endocrine-disrupting chemicals than other racial and ethnic groups, primarily because of higher exposure to persistent pesticides and flame retardants among these two minority groups (216).

NIGHT SHIFT WORK

There is accumulating scientific evidence that qualitative and quantitative sleep disturbances increase a person's risk for developing cancer. Notably, 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, prostate, colon, and rectal cancers (217). Research into the role of circadian rhythms in disease including cancer is an active area of investigation. Both African Americans and Hispanics have been found to have higher prevalence of short sleep duration, including night shift work, compared with whites (218)(219). However, more work 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.

As we learn more about the various environmental, occupational, and other cancer risk factors and identify those segments of the U.S. population who are exposed to these factors, we need to develop and implement new and/or more effective policies and health care interventions that benefit everyone, including the most vulnerable and the underserved.

Disparities in Cancer Screening for Early Detection

IN THIS SECTION, YOU WILL LEARN:

- ▶ The goal of screening is to find precancer or cancer at the earliest possible time in development because this increases the chance for successful treatment.
- ▶ There are four types of cancer (breast, cervical, colorectal, and prostate) for which screening tests have been used to screen large segments of the U.S. population who are at average risk of developing the cancer being screened for.
- ▶ Many people for whom cancer screening is recommended do not get screened, including a disproportionate number of individuals who are part of U.S. population groups that experience cancer health disparities such as racial and ethnic minority groups and underserved populations.
- ▶ Research is identifying culturally tailored strategies to increase cancer screening awareness, access, and uptake among different population groups for whom screening is recommended.

Screening for cancer means checking for precancerous lesions or cancer in people who have no signs or symptoms of the cancer for which they are being checked. The aim is to find an abnormality at the earliest possible time in cancer development. If a cancer screening test shows a precancerous lesion is present, it can be treated or surgically removed before becoming cancer (see **Figure 7**, p. 60). If a test finds a cancer at an early stage of development, stage I or stage II, before it has spread, it is more likely that the patient can be treated successfully; for example patients diagnosed with colorectal cancer that is confined to the colon or rectum have a 5-year relative survival rate of 90

percent, while those diagnosed with colorectal cancer that has metastasized have a 5-year relative survival rate of 14 percent (4).

How Can We Screen for Cancer and What Are the Screening Recommendations?

Screening for cancer can be done in various ways, including by using imaging technologies to look for abnormalities inside the body, and by collecting tissue or fluid samples and then analyzing them for abnormalities characteristic of the



U.S. REPRESENTATIVE FOR CALIFORNIA'S 41ST DISTRICT

The Honorable Mark Takano

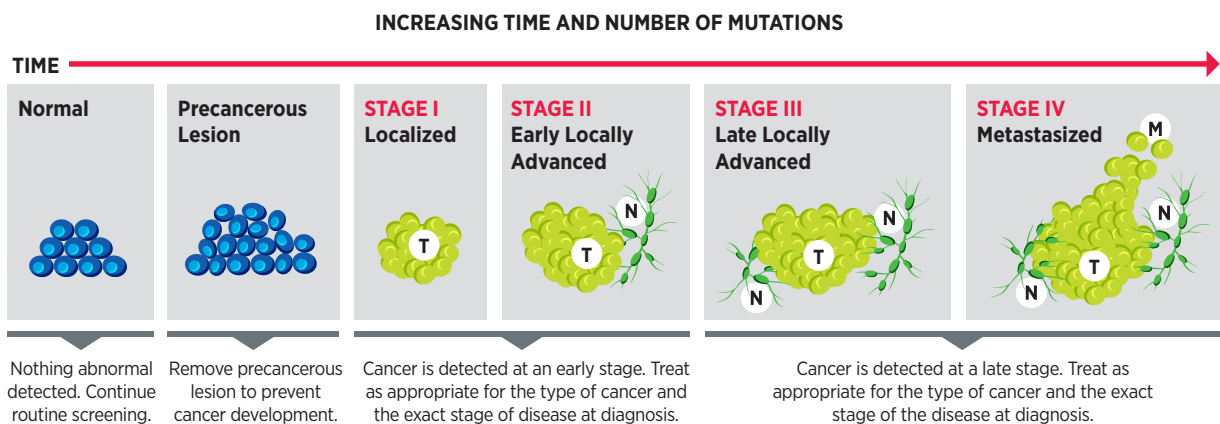
Vice-Chair, Congressional Asian Pacific American Caucus

“Health disparities among people of color continue to harm the health and well-being of our communities. Marginalized communities disproportionately suffer from a lack of access to critical care such as cancer screenings and life-saving treatment. It is essential we advance our understanding of ways to eliminate health disparities, which is why I will continue to support crucial federal funding for cancer research. The report released by AACR is an important step to effectively raise awareness to address the disparities in cancer incidence, treatment, and survival.”

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

Many 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, a precancer cannot be detected with cancer screening tests but the cell is predisposed to becoming cancerous. As the cell multiplies and acquires more genetic mutations, it gains precancerous characteristics, and an increasingly abnormal precancerous lesion becomes detectable. Without any treatment, additional mutations accumulate over time and the precancerous lesion evolves into a cancerous lesion (tumor; T), then it spreads to nearby lymph nodes (N), and, as it becomes more advanced, ultimately it metastasizes (M). When a person is screened for a given cancer, there are several different things that can be found, and different

outcomes predicted based on the finding. For example, the screening test may show that there is no abnormality present; in this situation, the person should continue routine screening. The test may detect a precancerous lesion which can be removed or treated; in this situation, the screen has led to the prevention of a cancerous lesion developing. The test may find a cancer at an early stage of development, stage I or stage II, before it has spread and at a point at which it is more likely that the patient can be treated successfully. It also may find a cancer at a late stage of development, stage III or stage IV, when treatment is less likely to be curative. Treating or surgically removing a precancerous lesion or treating early-stage cancer is called cancer interception.



Adapted from (112)

cancer being screened for. The tests used to screen for the five cancers for which screening is most commonly conducted are highlighted in **How Can We Screen for Cancer?** (p. 61).

Screening for cancer has many benefits, but it also has the potential to cause unintended harms (see sidebar on **Cancer Screening**, p. 62). Therefore, cancer screening is not recommended for everyone. The U.S. government and many professional societies and organizations convene panels of experts to carefully evaluate data regarding the benefits and potential harms of cancer screening tests. Although each panel creates its own evidence-based recommendations about the use of these tests, there is more consensus among recommendations than disagreement (see sidebar on **Consensus Cancer Screening Recommendations**, p. 63).

Cancer Screening among U.S. Racial and Ethnic Groups

Even though the benefits of cancer screening outweigh the potential risks for defined groups of individuals (see sidebar on **Consensus Cancer Screening Recommendations**, p. 63), many people for whom screening is recommended do not get screened (18)(220) (see sidebar on **Suboptimal Use of Cancer Screening Tests**, p. 65). Individuals who are not up to date with cancer screening recommendations are disproportionately found among segments of the U.S. population that experience cancer health disparities, including racial and ethnic minority groups (see **Table 7**, p. 70).

How Can We Screen for Cancer?

Highlighted here are some of the most commonly used cancer screening tests. When to use these tests and in whom is discussed elsewhere (see **Consensus Cancer Screening Recommendations**, p. 63).

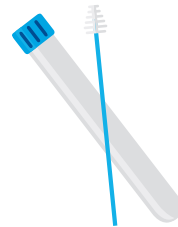
Breast Cancer



Screening mammogram:

- Uses X-rays to image the breast.
- The information generated by the procedure can be stored on film (a conventional mammogram) or electronically (a digital mammogram).
- In most cases, the image is 2-dimensional, but some machines generate 3-dimensional images in a process called breast tomosynthesis.
- Can detect breast cancers at any stage of development, but the aim of screening is to find them at the earliest possible stage.

Cervical Cancer



Pap test:

- Samples cervical cells, which are analyzed under a microscope to look for abnormalities.
- Can detect precancerous or cancerous cervical lesions, but the aim of screening is to find them at the earliest possible stage.

HPV test:

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

Colorectal Cancer



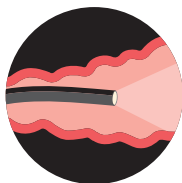
Stool tests:

- Some 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.
- Do not directly detect colorectal precancerous lesions or cancers, but identify people for whom further testing is recommended.



Computed tomography (CT) colonography (virtual colonoscopy) and double-contrast barium enema:

- Use X-rays to image the colon and rectum.
- Can detect colorectal precancerous lesions or cancers, but the aim of screening is to find them at the earliest possible stage.



Flexible sigmoidoscopy and colonoscopy:

- Both 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.
- Can detect colorectal precancerous lesions or cancers at any stage; the aim of screening is to find and remove them before cancer develops.



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.

Lung Cancer



Low-dose CT scan:

- Uses low doses of X-rays to image the lungs.
- Can detect lung cancers at any stage of development, but the aim of screening is to find them at the earliest possible stage.

Prostate Cancer



PSA test:

- Measures the level of a protein called prostate-specific antigen (PSA) in blood.
- Does not directly detect prostate cancer, but the blood level of PSA is often elevated in men with prostate cancer. Thus, the test identifies men for whom further testing is recommended.

Adapted from (112)

Cancer Screening



BENEFITS OF SCREENING

Reduced cancer incidence

Some screening tests can detect precancerous lesions. Removal of the precancerous lesions can reduce, or even eliminate, an individual's risk of developing the screened cancer at that site (see **Figure 7**, p. 60).

Reduced incidence of advanced disease

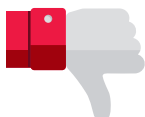
Screening tests that detect cancers at an early stage of development can reduce the individual's risk of being diagnosed with the screened cancer at a stage when it has spread to other parts of the body (see **Figure 7**, p. 60).

Reduced cancer mortality

Diagnosis at an early stage of disease can increase the likelihood that a patient can be successfully treated, which thereby reduces the individual's risk of dying from the screened cancer.

Reduced treatment-related toxicity

Diagnosis at an early stage of disease can reduce the likelihood of a patient's needing extensive surgery and/or chemotherapy to treat the cancer, which thereby reduces the individual's exposure to potential treatment-related toxicities.



POTENTIAL HARMS OF SCREENING

False-negative test results

Not all individuals who have a negative screening test result are free from the screened cancer. The rates of false-negative test results are generally low, but a false-negative test result can lead to missed opportunities for early treatment.

False-positive test results

Not all individuals who have a positive screening test result have the screened cancer. The rates of false-positive test results vary depending on the test but are generally low; a false-positive test result can result in additional unnecessary medical procedures, treatments, and anxiety.

Adverse events

Screening tests are medical procedures; thus, they carry some risk. However, the chance that an adverse event will occur during a screening test recommended by the U.S. Preventive Services Task Force or a professional society is low.

Anxiety

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

Overdiagnosis and overtreatment

Not all precancerous lesions or cancers detected by screening will go on to cause symptoms and threaten life. Overdiagnosis, as this is called, can lead to overtreatment, which carries its own potential harms and costs. The rates of overdiagnosis and overtreatment vary among cancer types. More longitudinal studies to elucidate and quantify the impact of overdiagnosis and overtreatment are required. Additional research is also needed to determine ways to identify which of the early-stage cancers detected through screening are most likely to go on to cause symptoms and threaten life.

Adapted from (3)

BREAST CANCER SCREENING

Even though the breast cancer screening rate—as defined by the percentage of women ages 50 to 74 who report having had a screening mammogram in the past 2 years—for African American women is very similar to that for white women, 9 percent of African American women are diagnosed with breast cancer when the disease is at an advanced stage compared with 5 percent of white

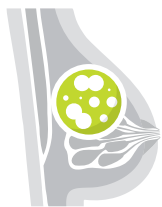
women (12). The disparity in advanced stage of diagnosis is one factor contributing to the striking disparity in the breast cancer death rates for African American and white women, which are 27.3 per 100,000 and 19.6 per 100,000, respectively (see **Table 1**, p. 14).

The disparity in advanced stage of diagnosis between African American and white women despite similar breast cancer screening rates is attributed to a complex interplay among

Consensus Cancer Screening Recommendations

The U.S. government and many professional societies and organizations have evidence-based recommendations about the use of the screening tests for the five cancers for which screening is most commonly conducted. Here, we highlight consensus, as of July 31, 2020, among these recommendations from the U.S. government's U.S. Preventive Services Task Force (USPSTF), the American Cancer Society (ACS), the National Comprehensive Cancer Network (NCCN), the American College of Physicians (ACP), the American College of Obstetrics and Gynecology (ACOG), the American Urologists Association (AUA), and the United States Multi-Society Task Force (MSTF) on colorectal cancer. Not all the professional societies and organizations have recommendations for every cancer screening test. In addition, very few of the professional societies and organizations have considered whether recommendations should vary by race and/or ethnicity, and this is an area of intensive research investigation.

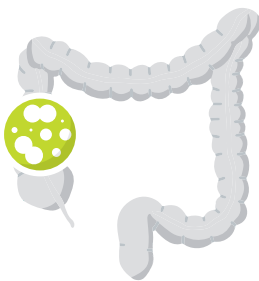
Breast Cancer Screening



There is consensus among the ACOG, ACP, ACS, and USPSTF that women ages 50 to 74 who are at **average risk** of developing breast cancer should have regular screening mammograms. However, there is variability about whether this screening should be done every year or every other year.

Some professional societies and organizations recommend women at average risk for developing breast cancer begin regular screening mammograms at either age 40 or age 45. It is important to note, however, that all the groups support women ages 40 to 49 having the opportunity to have regular screening mammograms if they decide it is right for them. Relevant to this decision is the fact that African American women are more likely to be diagnosed with breast cancer at a younger age than white women and are more likely to be diagnosed with biologically aggressive forms of the disease at all ages.

Colorectal Cancer Screening*



There is consensus among the ACS, ACP, NCCN, and USPSTF that adults ages 50 to 75 who are at **average risk** of developing colorectal cancer should be screened. How often a person should be screened depends on the screening test used (see sidebar on **How Can We Screen for Cancer?**, p. 61).

Some professional societies and organizations, including ACS, recommend starting regular screening at age 45 and some recommend certain screening approaches over others. The overall message, however, is that using any of the approved tests is better than not being screened and that average-risk adults should consult with their health care providers to decide when to start screening and to choose the test that is right for them.

Of note, the Department of Health of Puerto Rico recommends that colorectal cancer screening for average risk individuals commence at age 40 years.

Several groups of individuals, including African Americans, are at **increased risk** for colorectal cancer. Colorectal cancer screening recommendations vary for these different groups but all involve earlier and/or more frequent use of the screening tests used to screen average-risk individuals (see sidebar on **How Can We Screen for Cancer?**, p. 61).

For example:

- The ACS, NCCN, and MSTP on colorectal cancer recommend that individuals at **increased risk** because they have a first-degree relative who has been diagnosed with colorectal cancer should start screening with colonoscopy at age 40 or 10 years before the youngest case was diagnosed, whichever is earlier; and,
- the MSTP on colorectal cancer recommends that because African Americans are at **increased risk** for colorectal cancer they should begin screening at age 45.

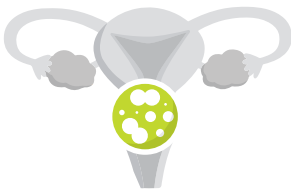
*USPSTF colorectal cancer screening guidelines are currently under review and will be updated in the near future. Some of the issues being reviewed are whether screening should begin at an earlier age for all average-risk individuals and whether recommendations should vary by race and/or ethnicity.

Adapted from (112)

Consensus Cancer Screening Recommendations *(continued)*

The U.S. government and many professional societies and organizations have evidence-based recommendations about the use of the screening tests for the five cancers for which screening is most commonly conducted. Here, we highlight consensus, as of July 31, 2020, among these recommendations from the U.S. government's U.S. Preventive Services Task Force (USPSTF), the American Cancer Society (ACS), the National Comprehensive Cancer Network (NCCN), the American College of Physicians (ACP), the American College of Obstetrics and Gynecology (ACOG), the American Urologists Association (AUA), and the United States Multi-Society Task Force (MSTF) on colorectal cancer. Not all the professional societies and organizations have recommendations for every cancer screening test. In addition, very few of the professional societies and organizations have considered whether recommendations should vary by race and/or ethnicity, and this is an area of intensive research investigation.

Cervical Cancer Screening



There is consensus among the ACOG, ACP, and USPSTF that:

- **average-risk** women younger than 21 should not be screened;
- **average-risk** women ages 21 to 29 should have a Pap test every 3 years;
- **average-risk** women ages 30 to 65 should have either a Pap test every 3 years, a Pap test and HPV testing every 5 years, or HPV testing alone every 5 years; and
- women older than 65 should not be screened if they are at **average risk** of the disease because they have previously had regular screenings with normal results and are not otherwise at high risk of developing cervical cancer.

Lung Cancer Screening



There is consensus among the ACS, NCCN, and USPSTF that annual screening with low-dose computed tomography should be limited to adults ages 55 to 80 who are at **high risk** for lung cancer because they have smoked at least one pack of cigarettes per day for 30 years, or the equivalent (two packs per day for 15 years, etc.), and who currently smoke or have quit within the past 15 years.

Prostate Cancer Screening



There is consensus among the ACS, ACP, AUA, and USPSTF that men ages 55 to 69 who are at **average risk** of developing prostate cancer talk to a physician about the benefits and potential harms of PSA testing before deciding if screening is right for them.

Adapted from (112)

various determinants of health related to socioeconomic status and access to quality cancer care (see **Why Do Cancer Health Disparities Exist?**, p. 20). The contributing social, clinical, and environmental factors include African American women overestimating screening mammogram utilization, having longer intervals between screening mammograms, experiencing less timely follow-up of abnormal results, being screened at lower resourced and nonaccredited facilities, and having reduced likelihood of receiving follow-up care at a comprehensive care center (12)(221).

CERVICAL CANCER SCREENING

Low rates of cervical cancer screening among Hispanics are a major factor contributing to the higher cervical cancer incidence rate experienced by this ethnic minority group

compared with whites (see **Table 2** and **Table 7**, p. 15 and p. 70, respectively). The disparity in cervical cancer screening rates between Hispanic and white women has been attributed to many social, clinical, cultural, psychological, and environmental factors, including a lack of health insurance, low levels of awareness about screening, distrust of the health care system, and cultural beliefs about sexual health (222).

Even though cervical cancer screening rates are similar for African American and white women, African American women have a higher cervical cancer incidence rate compared with white women (see **Table 1** and **Table 7**, p. 14 and p. 70, respectively). The reasons for this are not very clear but include social, clinical, and environmental factors that affect socioeconomic status and access to quality cancer care (12).

Suboptimal Use of Cancer Screening Tests

A substantial percentage of individuals for whom the U.S. Preventive Services Task Force (USPSTF) recommended breast, cervical, colorectal, and lung cancer screening were not up to date with screening in 2015, which is the last year for which these data are currently available (18)(220):

28.5%

28.5 percent of women ages 50 to 74 were not up to date with breast cancer screening.

17%

17 percent of women ages 21 to 65 were not up to date with cervical cancer screening.

38%

38 percent of adults ages 50 to 75 were not up to date with colorectal cancer screening.

96%

96 percent of adults ages 55 to 80 who have smoked at least one pack of cigarettes per day for 30 years, or the equivalent (two packs per day for 15 years, etc.), and who currently smoke or have quit within the past 15 years were not up to date with lung cancer screening.

Adapted from (115)

African American women are also more likely to be diagnosed with more advanced stage cervical cancer compared with white women, which may be because of differences in the quality of the facility at which the screening is conducted and timeliness of follow-up of abnormal results (12).

COLORECTAL CANCER SCREENING

Racial and ethnic disparities in cancer screening rates are particularly striking for colorectal cancer (18)(223) (see **Table 7**, p. 70). Disparities in colorectal cancer screening rates contribute substantially to disparities in colorectal cancer outcomes, with one study estimating that differences in colorectal cancer screening rates are responsible for 19 percent of the disparity between the colorectal cancer death rates for African Americans and whites (19).

Until recently, it was widely recommended that colorectal cancer screening for individuals at average risk for the disease begin at age 50 (see sidebar on **Consensus Cancer Screening Recommendations**, p. 63). After evidence emerged showing that the proportion of colorectal cancers diagnosed before age 50 was almost double for African Americans compared with whites (10.6 percent compared with 5.5 percent), the United States Multi-Society Task Force updated its colorectal cancer screening recommendations to advise that African Americans begin screening at age 45 (224). In addition, the Department of Health of Puerto Rico changed its recommendation in 2015 to advise that colorectal cancer screening for average risk individuals begin at age 40 (225). This change was made after it was shown that Hispanics living in Puerto Rico had a higher colorectal cancer incidence rate than Hispanics in the continental United States and Hawaii and that the U.S. colorectal cancer incidence rate among adults younger than 50 was increasing sharply (226)(227).

There are many social, clinical, cultural, psychological, and environmental factors that contribute to disparities in colorectal cancer screening among racial and ethnic minority groups. For African Americans, research has shown that poor knowledge of colorectal cancer risk, low perception of the benefits of screening, perceived invasiveness of colonoscopy, fear of pain, financial concerns, lack of insurance and access to care, and not having received a recommendation to undergo screening from a health care provider all contribute to low levels of colorectal cancer screening (228)(229). For Hispanics, cultural factors such as distrust in health care and having English as a second language have been shown to be particularly important drivers of disparities in colorectal cancer screening (230)(231).



U.S. REPRESENTATIVE FOR VIRGINIA'S 4TH DISTRICT

The Honorable A. Donald McEachin

"I am committed to removing barriers to routine cancer screenings because I know firsthand their importance—a colorectal cancer screening saved my life. Still, communities of color, low-income communities and the uninsured are too frequently excluded from access to these early-detection screenings, resulting in fewer treatment options and higher mortality rates. We must demand better and I will continue my fight on Capitol Hill to increase federal funding and awareness of lifesaving colorectal cancer research for all of our communities."



“I know that cancer researchers and participants in clinical trials have given me this opportunity for life that others before me did not have.”

Paying It Forward by Participating in a Prostate Cancer Clinical Trial

I was 62 when I was diagnosed with prostate cancer. It was detected after a routine test showed a rise in the level of PSA in my blood. Over the years, surgery, radiation, and treatment that I continue to take as a participant in a clinical trial have controlled my prostate cancer, and there has been no sign of the disease since December 2015. Two years later, however, I was diagnosed with multiple myeloma. Today that cancer is also under control. I'm doing well, and I do what I can to pay it forward—participating in the clinical trial and talking to my family and friends about the importance of asking their doctors about prostate cancer screening.

It was 2011 when I was diagnosed with prostate cancer. I had been having a routine PSA test as part of my annual checkup for several years, but this time, I received a call from the doctor a few days after my annual physical telling me there was a spike in my PSA level and that I needed to make an appointment with a urologist. The urologist recommended a prostate biopsy, which is how the cancer was found.

The oncologist discussed several options for treatment with me and my wife, Mona. After talking things over, we decided that I would have robotic surgery to remove the cancer. The surgery was a little more complicated than expected because the cancer had spread outside the capsule of the prostate, but it was successful. After about 10 days of discomfort, I went back to my normal life.

Following the surgery, my PSA level was checked every month and the numbers looked good for just over two years. During that time, and ever since, I have shared with family members and friends how my diagnosis came about, and I have encouraged them to talk about prostate cancer screening with their doctors. My brother listened and was diagnosed with prostate cancer about two years after me. His cancer was removed through surgery, and he's been cancer free ever since.

Unfortunately, in late summer of 2013, my PSA level started to rise. The cancer had returned. I underwent a series of radiation treatments over the course of several months, but they did not stop the PSA level from rising higher.

At this point, one of the options for treatment was to participate in a clinical trial. I jumped at the chance. I wanted to be involved in something that could not only help me, but also could help other patients down the road. I participated in the trial for about a year. I left the trial when my PSA level began to go up again.

I then entered a second clinical trial, through which I am still being treated today. I take bicalutamide once a day and have intramuscular injections of leuprolide quarterly. In the first six months after starting this trial, my PSA level fell from about 6.2 to undetectable, and it has remained that way ever since.

Even after the PSA became undetectable, I never felt that I was completely free of prostate cancer. It was going to be my challenge in life to live with the disease. Then, just over a year later, another challenge arose—I was diagnosed with multiple myeloma.

I know that there is no cure for multiple myeloma, but surgery and the standard treatment are controlling the disease. Part of the treatment is a drug called lenalidomide (Revlimid). A close friend of Mona's and mine participated in a clinical trial for this drug many years ago, and I am thankful to her and all the other people who participated in the trials that enabled me to have this drug as standard treatment.

Mona and I sometimes joke about my situation, saying, "Why have one type of cancer when you can have two?" But the reality is that I am blessed to be as healthy as I am; both cancers are under control. I know that cancer researchers and participants in clinical trials have given me this opportunity for life that others before me did not have.



“Advocacy has been an important part of my experience with cancer.”

Increasing Awareness of Colorectal Cancer among Hispanics in Puerto Rico

I was only 38 when I was diagnosed with metastatic colorectal cancer in 2016. Thanks to surgery, chemotherapy, and lots of self-care, I am blessed to be alive and without evidence of disease today. I enjoy life as much as I can; I recently got married and I'm writing a book to share how a cancer diagnosis and its treatment can impact the lives of patients and caregivers, and how gratefulness, hope, and active involvement in all this process create a more positive environment and better outcomes and quality of life. Although I am able to lead a very happy and productive life, the disease and its treatment have left me easily fatigued and in constant pain; this is one of the reasons I am sharing my story. Increasing awareness of the need for more research targeted to improving the quality of life for cancer survivors is one of the main goals of my advocacy efforts.

I was diagnosed with colon cancer in April 2016. I went to the emergency room (ER) because I had been in extreme pain for two weeks. I had postponed going to the doctor because of work, looking after the children, and all the other things I prioritized in my life. Since the pain didn't stop, I was worried I had appendicitis. In the ER an MRI showed a mass in my abdomen. I was admitted to the hospital, and a colonoscopy and biopsy a few days later showed that the mass was colon cancer.

My initial reaction was absolute shock. I was completely lost. But after a few days, I realized that the diagnosis explained the abdominal pain and general discomfort I had been suffering for more than 8 years, and I felt relief to finally have an answer. During that time, I had also been experiencing bloating, but the doctors believed it was related to gynecological issues. Despite these symptoms, none of the doctors I visited during those 8 years ordered me a colonoscopy. As a result of my experiences I am passionate about educating my community about the importance of listening to your body, going to the doctor when you need to, and not stopping to seek care until you have an answer.

Very soon after the initial diagnosis, which was stage I, I had surgery. But three months later, a PET scan revealed the cancer had spread to my lung. It was the first time I realized that I might not make it. I was devastated.

Fortunately, I was able to have surgery to remove the tumor in my lung. This was important for me because I just wanted to get the cancer cells out of my body. The surgery was followed by six cycles of a chemotherapy regimen called FOLFOX. The treatment was hard; there were days when I did not know if I would die of cancer or because of the treatment.

During chemotherapy, I made sure I ate healthily, exercised, rested, meditated, and prayed. I believe that taking the best care of my body and my mind gave me the best chance of the treatment working successfully.

I give thanks every day that I'm alive. I enjoy my life, but it is very different to the one I had before cancer. I get tired after only five hours of work and I'm always in pain. The long-term effects on me and my family are immense. More and more people are surviving cancer, and we need more research aimed at helping improve our quality of life.

After my treatment was over, my doctors recommended that I undergo genetic testing because I was diagnosed with colon cancer at such a young age and because my father had died from pancreatic cancer and my aunt had died from stomach cancer. I learned that I inherited a genetic mutation that causes a condition called MAP syndrome. People with this condition often develop lots of polyps [abnormal tissue growths] in their colon, which increases their risk of colon cancer. I am also participating in an observational clinical trial that is investigating inherited causes of colorectal cancer in Hispanics living in Puerto Rico.

Advocacy has been an important part of my experience with cancer. First, I had to advocate for myself, choosing a doctor and care team who understood me and taking care of myself. After I completed my treatment, I began serving as an advocate to patients newly diagnosed with cancer. I help them navigate the experience and provide support when they need it. More recently, I have begun being more broadly active in the Hispanic community here in Puerto Rico, increasing awareness about colorectal cancer and how screening can save lives.

Cancer Screening among Certain U.S. Population Groups

	BREAST CANCER SCREENING RATE*	CERVICAL CANCER SCREENING RATE*	COLORECTAL CANCER SCREENING RATE*	PROSTATE CANCER SCREENING RATE†
Race and ethnicity				
Whites	71.8	83.2	63.7	37.1
African Americans	74.3	85.3	59.3	30.7
Hispanics	72.1	78.6	47.4	25.5
American Indians/ Alaska Natives	56.7	76.9	48.4	N/A
Asians	66.1	75.8	52.1	17.4
Household income				
<139% of federal poverty threshold	58.7	75.2	46.9	N/A
>400% of federal poverty threshold	78.8	89.7	70	N/A
Education				
Less than high school	60.3	71.2	46.7	N/A
College graduate	78.9	89.5	70.7	N/A
Health care coverage				
Uninsured	35.3	63.8	25.1	10.2
Private insurance	76.7	86.8	65.6	29.8
Sexual orientation				
Gay	77.2	74.6	69.3	N/A
Straight	71.8	83.3	62.5	N/A

*Data from (18)
†Data from (223)



U.S. REPRESENTATIVE FOR INDIANA'S 7TH DISTRICT

The Honorable André Carson

“Cancer affects people of all backgrounds, but it’s clear that the disease doesn’t impact everyone equally. In fact, there are still wide racial and ethnic disparities when it comes to rates of cancer prevention, diagnosis, treatment, and survival. I’m working hard in Congress to address and erase these gaps for communities of color. For example, each year I urge the Appropriators to improve federal funding levels to help close persistent health disparities. I am also an original cosponsor of H.R. 5200, the Prostate-Specific Antigen Screening for High-Risk Men Act. This important bill waives deductibles, copayments and coinsurance costs for men who have a family history of prostate cancer or who are African American. Our health outcomes are linked to our unique backgrounds and our imperfect health care system, and as a result we must always take this fully into account in our efforts to create a cancer-free world.”

LUNG CANCER SCREENING

Lung cancer is the leading cause of cancer death in the United States (34). It is estimated that the lung cancer death rate could be reduced by 20 percent among all individuals eligible for lung cancer screening based on U.S. government recommendations—individuals ages 55 to 80 who still smoke or have quit within the last 15 years—if they were all to be screened (232).

Despite the benefits of lung cancer screening, it is estimated that only 3.9 percent of the 6.8 million individuals eligible for lung cancer screening in 2015 underwent screening (220). With such low rates of screening it is hard to determine whether there are racial and ethnic disparities. Therefore, the researchers considered just two groups, whites and nonwhites, and found that lung cancer screening rates for the two groups were 4.1 percent and 2.1 percent, respectively (220).

One reason for low lung cancer screening rates is that just 4.4 percent of whites and 5 percent of African Americans report that a physician has discussed screening with them (233). Identifying strategies to increase lung cancer screening rates among all eligible individuals, including by improving physician–patient discussion, is a priority for all stakeholders in the cancer research community.

It is particularly important to identify ways to increase screening among African American men because they are 15 percent more likely to develop lung cancer compared with white men and 18 percent more likely to die from the disease (12). This increased risk exists even though African American men who are smokers smoke fewer cigarettes each day compared with white men who are smokers, and begin smoking at an older age (234). The increased risk of lung cancer among African American men despite lower pack years of smoking has led to the suggestion that lung cancer screening recommendations may need to be tailored for individuals in different racial and ethnic groups (235)(236). Of relevance to this suggestion is the fact that the benefits of lung cancer screening were established in a clinical trial in which 90.9 percent of the participants were white and just 4.5 percent were African Americans (237).

PROSTATE CANCER SCREENING

The U.S. government and many professional societies and organizations recommend that men ages 55 to 69 who are at average risk of developing prostate cancer talk to a physician about the benefits and potential harms of screening before deciding if it is right for them. Some professional societies and organizations recommend that African American men like retired **U.S. Army Colonel Gary Steele** (see p. 67) begin this conversation at age 45 because the prostate cancer incidence rate is dramatically higher for African American men compared with men of any other race or ethnicity, which means that they are at increased risk for developing the disease (12).

Even though African American men have a higher risk for prostate cancer compared with white men, there is a striking disparity in prostate cancer screening rates (see **Table 7**, p. 70). There is also a marked disparity in prostate cancer screening rates between Hispanic and white men, which may contribute to the fact that Hispanic men are more likely to be diagnosed with advanced stage prostate cancer compared with white men (24). Of note, the disparity in prostate cancer screening between African American and white men exists even though African American men are more likely to report having been informed about prostate cancer screening than white men (238). Understanding the reasons for the low rates of prostate cancer screening among African American men informed about screening is vital if disparities in the burden of prostate cancer are to be eliminated. It will also be critical to determine whether there are differences in the benefits and harms of prostate cancer screening for men of different races and ethnicities, information that is currently lacking (239).

Increasing Cancer Screening Rates among Racial and Ethnic Minorities

Identifying strategies to increase cancer screening awareness, access, and uptake among those for whom screening is recommended is an important step toward achieving health equity. Strategies for increasing cancer screening rates among racial and ethnic minorities include increasing health literacy and awareness of cancer and cancer screening through culturally tailored community education and through the sharing of information by racial and ethnic minority patient advocates like **Tristana Vásquez** (see p. 69). It is also important to ensure that everyone has access to high-quality clinical care. In addition, more targeted strategies for each type of screening and for each racial and ethnic minority group need to be developed, and this is an area of active research investigation. Some of the approaches being assessed are described here.

Mobile mammography units are one approach showing promise for increasing breast cancer screening rates among underserved populations, including racial and ethnic minorities (240)(241). Mobile mammography units help eliminate transportation barriers to screening and, in some instances, screening is provided for free. However, some studies have found that patient retention and patient follow-up after an abnormal screening mammogram result are lower among women screened at mobile mammography units compared with those screened in fixed facilities, highlighting that greater patient education and patient navigation are needed if the mobile units are to improve their effectiveness at addressing disparities in breast cancer outcomes (240).

Numerous studies have shown that colorectal cancer screening rates can be significantly increased for all racial and ethnic

groups by actively reaching out to adults not up to date with screening, either by mailing them information about colorectal cancer risk and a stool test or by implementing patient navigation programs that provide individualized assistance to help patients overcome personal and health care system barriers, and to facilitate understanding and timely access to screening (242-245). One example of how effective patient navigation can be at reducing disparities in colorectal cancer screening and outcomes is the cancer control program that was established in 2003 in Delaware (246). A key component of this program was increasing colorectal cancer screening among racial and ethnic minorities. Through this program, colorectal cancer screening rates for African Americans rose from 48 percent in 2001 to 74 percent in 2009, which was equivalent to the screening rate for whites. During that time, disparities in the colorectal cancer incidence and death rates between African Americans and whites were almost eliminated (see sidebar **Eliminating Colorectal Cancer Disparities in Delaware**, p. 72). Unfortunately, substantial financial, infrastructure, and social challenges may prevent implementation of identical programs nationwide. As a result, other approaches to increasing colorectal cancer screening among racial and ethnic minorities are needed, with one focus group showing that culturally specific information and dissemination of colorectal cancer screening education through commercials and billboards could be effective for African Americans (228).

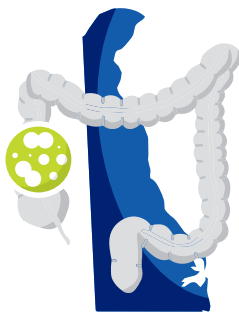
The most effective approaches to increasing cervical cancer screening among Hispanics involve culturally tailored interventions that address low levels of health literacy and issues rooted in cultural beliefs and fears (247)(248). Using

community-based participatory research approaches and lay health advisors are ways to ensure that interventions are culturally sensitive (222)(248). Lay health advisors are community members who provide help in many different ways, depending on the program that has been developed. For example, some serve as community role models by participating in mass media campaign messages; some distribute culturally tailored intervention materials such as community bulletins, flyers, educational pamphlets, and information about local providers and screening resources; some coordinate support such as childcare and transportation for women who need screening; and some serve as navigators and facilitators for women at screening facilities (222). Culturally tailored interventions have also been shown to increase cervical cancer screening among Vietnamese Americans (249).

Increasing cancer screening rates alone will not eliminate cancer health disparities. We need to ensure that individuals whose screening tests show an abnormality receive follow-up testing and care in a timely manner. Delayed follow-up can result in a later stage diagnosis and, therefore, a reduced chance that the patient can be treated successfully. Individuals who delay or who never return for follow-up care after a cancer screening test shows an abnormality are disproportionately found in the same population groups that experience disparities in other measures of cancer burden. For example, follow-up after cervical cancer screening detects an abnormality is lowest among women who are African American, who have low socioeconomic status, or who lack private health insurance (250-252).

Eliminating Colorectal Cancer Disparities in Delaware

The cancer control program was initiated in 2003 under the direction of the Delaware Cancer Consortium (246). As a result of this program:



- **Colorectal cancer screening among African Americans rose from 48 percent in 2001 to 74 percent in 2009**, which was almost equivalent to the 2009 screening rate among whites, which was 75 percent.
- **Disparities in the colorectal cancer incidence rates among African Americans and whites were almost eliminated** as a result of the equivalent screening rates between the two groups, falling from 15 percent higher among African Americans in 2001 to 3 percent higher in 2009.
- **Disparities in the colorectal cancer death rates among African Americans and whites were almost eliminated**, falling from 60 percent higher among African Americans in 2001 to 7 percent higher in 2009.

Disparities in Cancer Treatment

IN THIS SECTION, YOU WILL LEARN:

- ▶ Research is driving progress across all five pillars of cancer treatment: surgery, radiation, cytotoxic chemotherapy, molecularly targeted therapy, and immunotherapy.
- ▶ Clinical trials establish whether new cancer treatments are safe and effective for everyone who will use them if they are approved, so it is concerning that there is a serious lack of racial and ethnic diversity among clinical trial participants.
- ▶ Despite the advances in cancer treatment, patients from certain population groups, including racial and ethnic minorities, 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, including prostate cancer and multiple myeloma, can be eliminated if every patient has equal access to standard treatment.
- ▶ Researchers are working to identify innovative strategies to ensure that all patients can participate in cutting-edge clinical trials and receive standard treatments.

The dedicated efforts of individuals working throughout the cycle of biomedical research are constantly powering the translation of new research discoveries into advances in cancer treatment that are improving survival and quality of life for people in the United States and around the world (see **Figure 8**, p. 75). Much of the most recent progress was highlighted in the *AACR Cancer Progress Report 2019*, which documented a record number of new cancer treatments approved by the FDA in the 12 months covered in that edition of the annual report to treat several types of cancer (115). Despite these advances in clinical care, individuals from certain population groups including racial and ethnic minorities continue to experience more frequent and higher severity of multilevel barriers to quality cancer treatment including lack of access

to guideline-concordant treatment (223) (see sidebar on **Disparities in Cancer Treatment**, p. 74). The same population groups may also experience overt discrimination and/or implicit bias in the delivery of care (253). Disparities in cancer care among racial and ethnic minorities can be attributed to obstacles in accessing quality health care services, including cutting-edge cancer treatments. Among the obstacles are lack of or inadequate health insurance coverage, low socioeconomic conditions, transportation difficulties, and lack of health literacy (223).

These multilevel factors result in racial and ethnic minority populations experiencing greater incidence and mortality from a number types of cancers due to delayed diagnosis,



U.S. REPRESENTATIVE FOR NEW JERSEY'S 10TH DISTRICT

The Honorable Donald Payne, Jr.

“One of the biggest issues with health disparities is how doctors treat patients. Doctors are more likely to doubt the severity of pain in patients of color compared with white patients. So minority patients could have a cancerous growth that goes undetected and can cause more severe health issues and possibly become fatal. This report is critical to creating more awareness of these disparities so they can be addressed effectively.”

Disparities in Cancer Treatment

Research is constantly powering the development of new cancer treatments. However, several segments of the U.S. population have been found to be disproportionately less likely to receive standard recommended cancer treatments. Examples of these disparities include:

50%
LESS LIKELY

Patients with intrahepatic cholangiocarcinoma who are Black are **50 percent less likely to have surgery** compared with patients who are white (47).

29%
LESS LIKELY

Women with ductal carcinoma in situ who live in rural areas are **29 percent less likely to receive radiotherapy** after breast conserving surgery compared with women who live in urban areas (254).

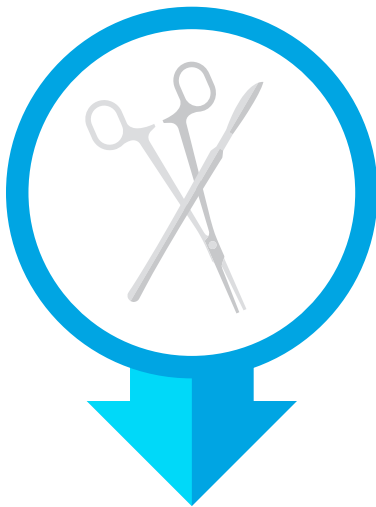
27%
LESS LIKELY

Among patients with locally advanced soft tissue sarcoma treated with limb sparing surgery, those without health insurance were **27 percent less likely to receive neoadjuvant or adjuvant radiotherapy** compared with those who had commercial insurance (255).

50%
LESS LIKELY

Patients with metastatic bladder cancer who are of low socioeconomic status are **50 percent less likely to receive chemotherapy** compared with those of high socioeconomic status (256).

Disparities in Cancer Surgery



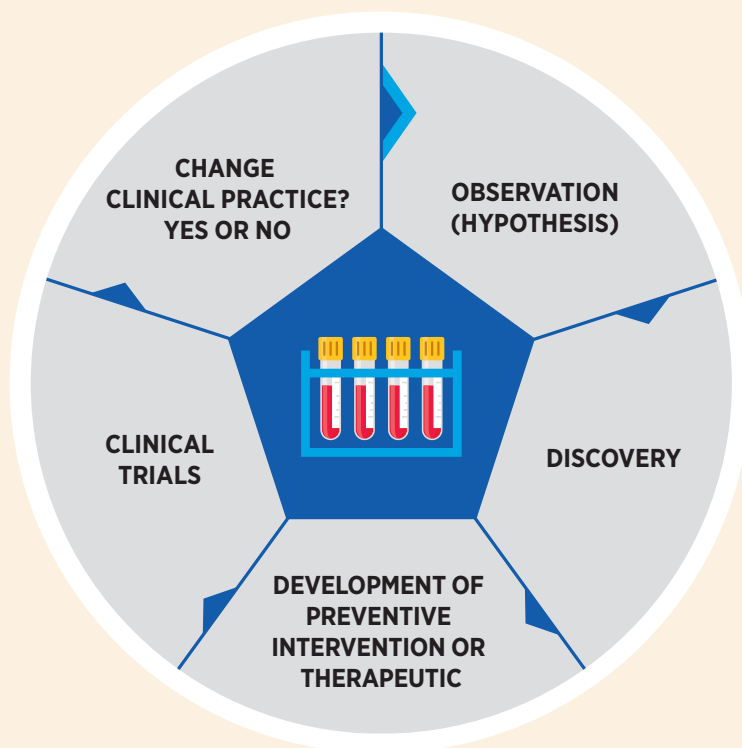
- African American breast cancer patients undergoing mastectomy surgery are **significantly less likely to have breast reconstruction** compared with white patients (267).
- African American and Hispanic patients with rectal cancer are **less likely to undergo sphincter-sparing surgery** compared with white patients (268).
- African American and Hispanic patients with early-stage cervical cancer are **more likely to forgo surgery**, which is the standard of care, compared with white patients (17% and 12% vs 9% respectively) (269).
- African American and Hispanic patients with early-stage lung cancer are **less likely to undergo curative-intent surgery** compared with white patients (270).
- Hispanic patients with potentially resectable esophageal cancer are **significantly less likely to receive surgery** compared with white patients (46% vs. 60%) (400).

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. Each of the potential drivers of disparity can also have a negative impact on responses to both standard treatment and/or novel agents being evaluated in clinical trials. Furthermore,

it has been consistently documented that racial and ethnic minorities are underrepresented in clinical trials of new anticancer therapeutics, even for trials that are aimed at cancer types with a disproportionately higher burden among those population groups (257)(258). Here, we highlight the major disparities among racial and ethnic minorities in clinical research participation as well as in the use of the main

Biomedical Research Cycle

Results from any type of research can fuel the biomedical research cycle by providing observations relevant to the practice of medicine, which lead to questions, or hypotheses, that are tested in experiments during the discovery phase of research. During the discovery phase, traits unique to a disease may be uncovered, leading to the development of a potential therapeutic. Before entering clinical testing, potential therapeutics undergo preclinical testing to identify any toxicities and help determine initial dosing. The safety and efficacy of potential therapeutics are then tested in clinical trials. If an agent is safe and effective and is approved for use by the U.S. Food and Drug Administration (FDA), it will enter clinical practice. Importantly, observations made during the routine use of a new therapeutic can feed back into the biomedical research cycle and further enhance the use of that agent or the development of others like it. If, however, a therapeutic is not safe or effective and fails to gain FDA approval, the observations from the clinical testing still feed back into the biomedical research cycle to spur future research efforts. Because the cycle is iterative, it is constantly building on prior knowledge, and research undertaken during any part of the cycle continually powers new observations.



Adapted from (88)

pillars of cancer treatment (see **Figure 9**, p. 76). It is important to note that several recent studies have pointed out that disparities in outcomes for many cancers can be eliminated if every patient has equivalent access to standard treatment (259-261).

Disparities in Treatment with Surgery

For many decades, surgery was the only pillar of cancer treatment (see **Figure 9**, p. 76). Today, it remains the foundation of treatment for many patients with cancer, including patients with breast cancer, such as **Shirley Dilbert** (see p. 79), and patients with colorectal cancer, which are two cancer types for which there are survival and overall death rate disparities experienced by racial and ethnic minorities. For cancer types associated with high mortality, such as lung and pancreatic cancer, surgical resection is a key to survival

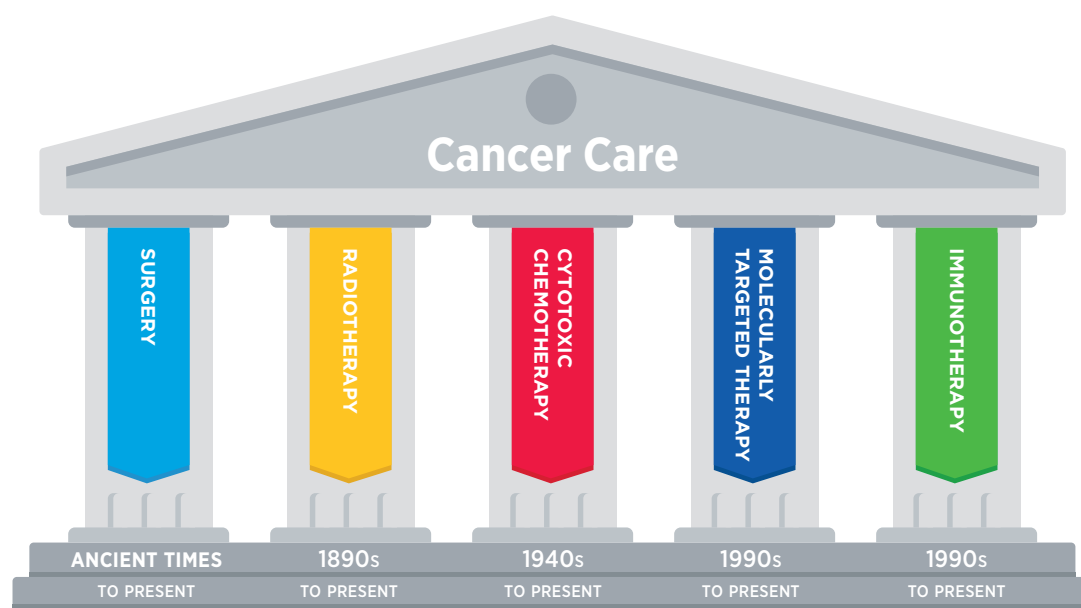
when these tumors are detected at an early stage. For other types of cancer, specialty surgical services are necessary to optimize quality of life after treatment, such as reconstruction surgery for breast cancer patients requiring mastectomy and sphincter-preserving surgery for rectal cancer patients.

Unfortunately, racial and ethnic minorities often experience disparities in surgical management of cancer (see sidebar on **Disparities in Cancer Surgery**, p. 74). These disparities are seen across cancer types and for a variety of reasons. For example, socioeconomic disadvantages that are more prevalent in racial and ethnic minority patients such as African Americans and Hispanics can result in diagnostic delays that render these patients less likely to be candidates for curative cancer surgery (262)(263). Racial and ethnic minority patients are also more likely to receive their cancer care in safety net and public hospitals, which are less likely to have surgical oncology

The Pillars of Cancer Care

Physicians often refer to the “pillars” of cancer treatment. For many years, there was one treatment pillar: surgery. In 1896, a second pillar, radiotherapy, was added. The foundations for the third treatment pillar, cytotoxic chemotherapy, were laid in the early 1940s when a derivative of nitrogen mustard was explored as a treatment for lymphoma. These three pillars—surgery, radiation, and cytotoxic chemotherapy—continue to

form the foundation of treatment for most patients with cancer. The first molecularly targeted therapeutics were introduced in the late 1990s, leading to the fourth pillar, molecularly targeted therapy, which continues to grow. Likewise, the late 1990s laid the groundwork for the fifth treatment pillar, immunotherapy. The number of anticancer therapeutics that form the most recent two pillars of cancer care continues to increase every year.



Adapted from (88)

programs that can support complex cancer perioperative needs compared with other hospitals and specialty cancer centers (264). Implicit bias and unconscious discriminatory practices on the part of health care providers can also have an adverse effect on communication regarding disease management (265)(266).

The inequities that exist in the receipt of guideline-recommended surgery for racial and ethnic minority patients mandate that all stakeholders work together to improve effective communication and access to health care resources that are important for patients while continuing further research into the mechanisms that perpetuate these disparities. The importance of access to high-quality surgical oncology in efforts to achieve cancer health equity is highlighted by studies showing that if African American and white patients who have colon cancer or early-stage lung cancer are treated with surgery

through the equal access Veterans Affairs health care system there are no disparities in survival between African Americans and whites (260)(271). These data stand in stark contrast to overall U.S. data showing that there are significant disparities between African Americans and whites in survival from colon cancer and early-stage lung cancer (12)(272).

Disparities in Treatment with Radiotherapy

Radiotherapy became the second pillar of cancer treatment in 1896 (see **Figure 9**, p. 76). Currently, about 50 percent of patients diagnosed with cancer have radiotherapy to shrink or eliminate tumors or to prevent local recurrence (273) (see sidebar on **Using Radiation in Cancer Care**, p. 77).

Using Radiation in Cancer Care

There are two major uses of ionizing radiation in the diagnosis and treatment of cancer:

HIGH



LOW



Radiology largely uses lower-energy radiation to image tissues to diagnose disease or treat disease via the minimally invasive techniques used in interventional radiology.

HIGH



LOW



Radiotherapy, or radiation therapy, uses high-energy radiation to control and eliminate cancer.

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 eliminate cancer.
- Radiotherapy works chiefly by damaging DNA, leading to cell death.

Uses of Radiotherapy

1

Curative radiotherapy seeks to eliminate cancers, particularly small cancers, as well as locally advanced cancers as part of combination therapy.

2

Neoadjuvant radiotherapy is used to shrink a cancer so that it can be subsequently treated by a different method such as surgery.

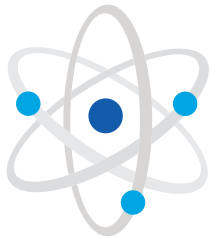
3

Adjuvant radiotherapy seeks to eliminate any remaining cancer following prior treatment.

4

Palliative radiotherapy is used to reduce or control symptoms of disease when cure by another method is not possible.

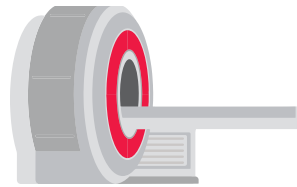
Types of Radiotherapy



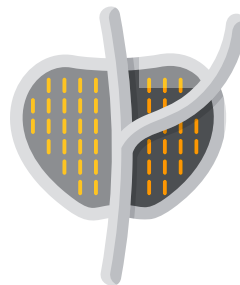
Particle therapy uses protons or carbon ions rather than X-rays as the source of energy. In contrast to X-rays that pass through the body, losing energy and causing damage to the noncancerous tissues through which they pass, these heavier particles deposit most of their energy in the target. In this 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 patients is still being determined.



Radioisotope therapy involves systemic ingestion or infusion of radioisotopes, for example, iodine-131 to treat thyroid cancer or lutetium-177 dotatate (Lutathera) to treat gastroenteropancreatic neuroendocrine tumors.



External beam radiotherapy encompasses several types of radiotherapy that direct radiation at the tumor from outside the body; it is the most common form of radiotherapy. Electrons and photons (X-rays) are the most common sources of radiation in external beam radiotherapy.



Brachytherapy places small radioactive sources in or next to the tumor either temporarily or permanently.

Adapted from (88)



"I...help other African American women diagnosed with breast cancer; I guide them through their experience and provide hope by telling them that I am a two-time survivor."

Surviving Breast Cancer Thanks to Support from My Community

I have been diagnosed with breast cancer twice, once in 2012 and then again in 2016. After my second diagnosis, I had trouble with insurance coverage and finding a doctor who would listen to my needs. I started to spiral downward. Support from my family, church, and a national African American breast cancer survivorship organization called Sisters Network Inc. helped me pay my medical bills, find a doctor whom I trusted, and discover the strength to get through the experience. Today, I keep a positive attitude, live a healthy life, and help other women navigate a breast cancer diagnosis.

It all started in January 2012. I was called back to the clinic a few days after my regular annual mammogram because it had shown that there was a tumor in my right breast. I was devastated. All I could think was that I was going to die and what would my daughter do without me? I turned to my oldest sister for support because she had survived a breast cancer diagnosis a few years earlier. She was able to calm me down and help me through the process.

After a number of tests, the doctors told me that the tumor was no bigger than a dime and that it was not the type of cancer that would spread through my body. My official diagnosis was stage I breast cancer. I had a lumpectomy followed by radiation treatment.

After the radiation was done, I went on with my life. I thought that I would be cancer free forever.

Then, four years later, my routine annual mammogram showed a tumor in my left breast. It was a shock, but I felt less traumatized than I had been by the first diagnosis.

Unfortunately, this is when things began to go wrong for me. First, my doctor recommended a mastectomy, but the idea of losing my breast

completely scared and upset me. I also ran into problems with my insurance; the doctor I was seeing performed surgery at a hospital that was not covered by my insurance. I tried to switch my care to another hospital and to change insurance, but the advice I received left me with no insurance coverage at all for several months, until open enrollment season. These two things put me under extreme stress, and I began to lose my hair, lose weight, and spiral down toward depression.

I reached out to my church for support. They not only gave me comfort when I needed it, but they also helped me with my medical bills by holding fundraisers. I also received support from a coworker who was a fellow cancer survivor. She was involved in the Sisters Network Inc. and connected me with an amazing doctor at another local cancer center. Dr. Lisa Newman called me and told me that the cancer was not aggressive and that I had plenty of time before I needed surgery, so I traveled to my granddaughter's graduation in South Carolina without worrying that I was wasting precious time in my fight against the cancer. Dr. Newman also reassured me that a lumpectomy, rather than a mastectomy, would be a good treatment option.

I had the lumpectomy in July 2016. This was followed by more radiation.

Fortunately, since then I have been cancer free and I feel wonderful. I love to play sports, dance, and work out. My friends call me the "Energizer Bunny."

I joined the Sisters Network Inc. and, through that, help to increase awareness of breast cancer in the African American community. I also help other African American women diagnosed with breast cancer; I guide them through their experience and provide hope by telling them that I am a two-time survivor.

Unfortunately, racial and ethnic minorities often experience disparities in treatment with radiotherapy. These disparities are seen across cancer types, including the three most commonly diagnosed cancers in the United States—breast, lung, and prostate cancer (34).

Radiotherapy is an important part of curing breast cancer, in addition to surgery and chemotherapy. For women with early-stage disease that has not spread outside the breast, delivering radiotherapy to the breast after surgery decreases the risk of breast cancer recurring. Radiotherapy is also important for more advanced stages of disease, when the cancer has spread outside of the breast. Research shows that racial and ethnic minority women with breast cancer are less likely to receive radiotherapy, which may contribute to a higher risk of dying from breast cancer. Compared with white women, African American women with early-stage breast cancer are half as likely to be treated with radiotherapy (274). African American and Hispanic women with breast cancer are also more likely to experience delays in beginning radiotherapy compared with white women (275).

Radiotherapy is part of the treatment for many patients with prostate cancer. Research has shown that among African American men with prostate cancer who receive radiotherapy overall survival is just as good as, if not better than, it is among their white counterparts (276). However, African American men with prostate cancer are less likely to receive radiotherapy compared with white men (277). Moreover, African American men with prostate cancer experience a longer time from diagnosis to the start of radiotherapy compared with white men (278). In addition, they are less likely to receive treatment with the intent of cure even when presenting with similar disease stage (279). These differences were present to a similar extent in both academic and community hospitals (280).

Radiotherapy can be used to cure early-stage lung cancer and is used in combination with chemotherapy with or without surgery in the treatment of advanced-stage lung cancer. Unfortunately, African American lung cancer

patients are 42 percent less likely to receive radiotherapy compared with their white counterparts (281).

Inequities in cancer radiotherapy must be addressed as part of the current efforts to eradicate cancer health disparities among racial and ethnic minorities. Many efforts are underway to understand why these inequities exist and some have provided useful insights into this issue. For example, patient populations that are overrepresented among the socioeconomically disadvantaged, such as African Americans and Hispanics, are more likely to rely on public transportation, and so disruptions or delays in service will impact their ability to attend daily radiotherapy. Continued research is needed to better understand the current barriers to the receipt of guideline-concordant radiation therapy for racial and ethnic minorities and to implement effective interventions to address those barriers.

Disparities in Therapeutic Cancer Clinical Trials

Before a candidate anticancer therapeutic can be used as part of patient care, its safety and efficacy must be rigorously tested in clinical trials. All clinical trials are reviewed and approved by an independent committee known as the institutional review board before they can begin and are monitored throughout their duration. If, after reviewing the clinical trial data, the FDA deems the therapeutic safe and effective it is approved for use and will enter clinical practice.

Clinical trials testing candidate therapeutics for patients with cancer have traditionally been done in three successive phases (see **Figure 10**, p. 81). The multiphase clinical testing process requires many patients and takes many years to complete.

LACK OF DIVERSITY AMONG CLINICAL TRIAL PARTICIPANTS

To ensure that candidate anticancer therapeutics are safe and effective for everyone who will use them if they are approved, it is vital that the participants in the clinical trials testing the

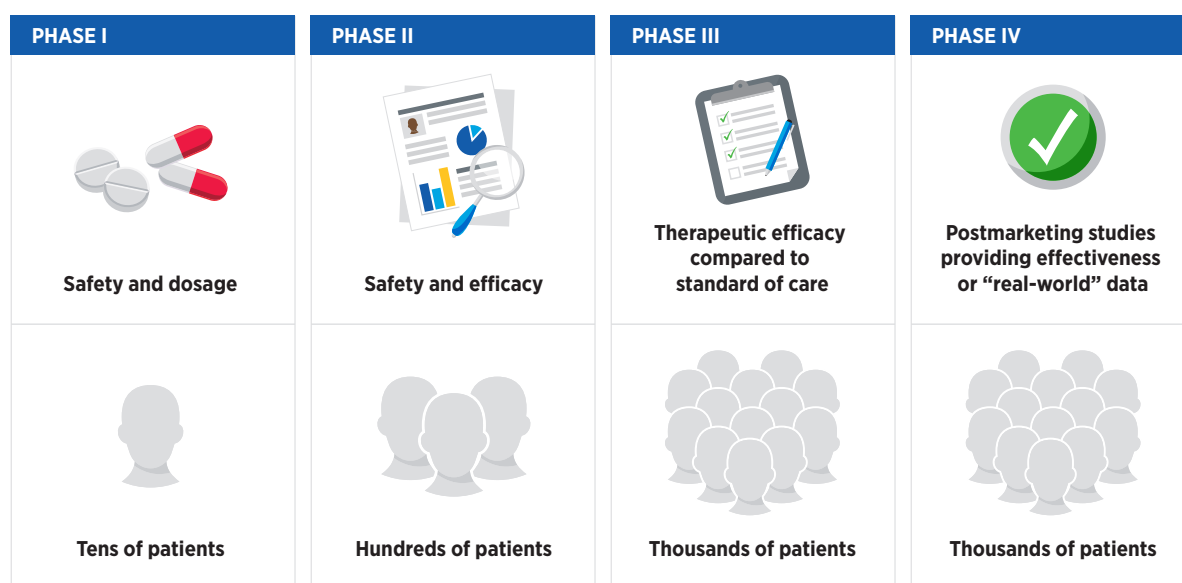
African Americans account for about 20 percent of new multiple myeloma cases, but **only constituted 10 percent of the participants in the clinical trials** that led to the approval of daratumumab (Darzalex), an immunotherapeutic for multiple myeloma (12)(282).

Hispanic children with cancer are **more than 50 percent less likely to enroll in clinical trials testing treatments** for childhood cancer compared with non-Hispanic white children (283).



Phases of Clinical Trials

Clinical trials evaluating potential new therapeutics for treating patients with cancer have traditionally been done in three successive phases, each with an increasing number of patients. Phase I studies are designed to determine the optimal dose of an investigational anticancer therapeutic, how humans process it, and its potential toxicities. Phase II studies are designed to determine the initial efficacy of an investigational therapy, in addition to continually monitoring for potential toxicities. Phase III studies are large trials designed to determine therapeutic efficacy as compared with standard of care. When successful, the results of these phase III 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 the FDA and provide additional effectiveness or “real-world” data on the therapy.



Adapted from (88)

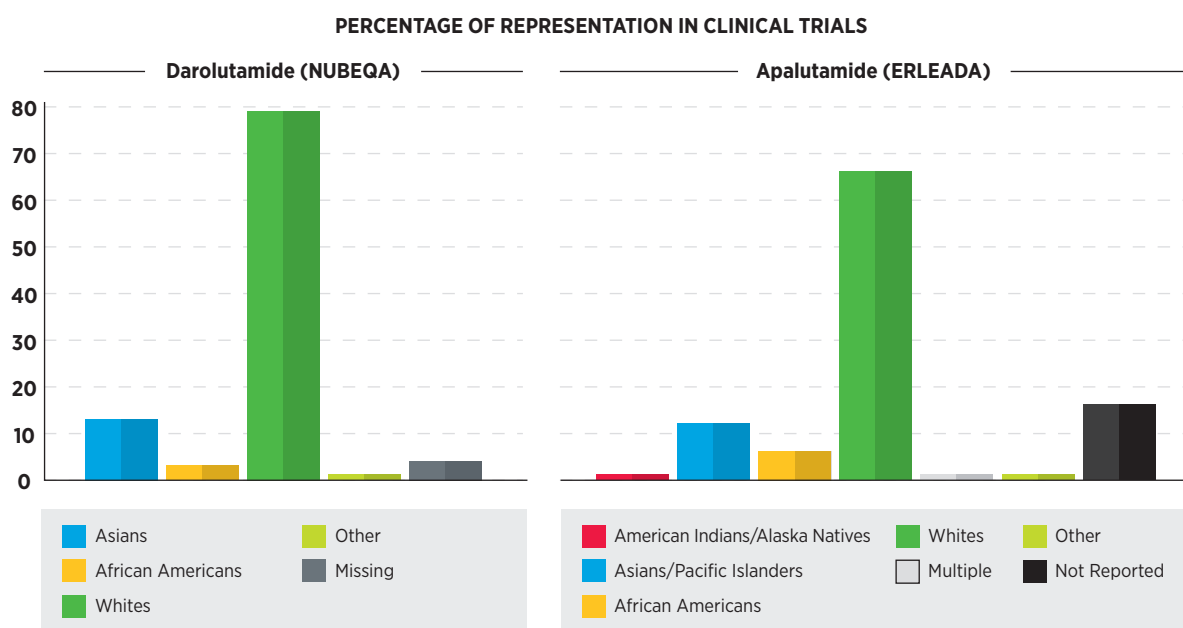
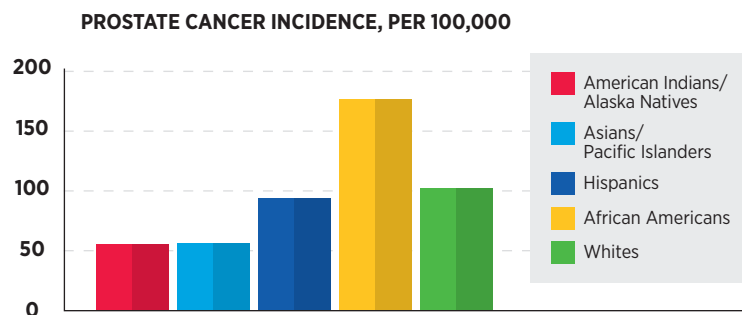
agents represent the entire population that may use them. Clinical trials also provide cancer patients the opportunity to receive the newest available treatments; therefore, access to clinical trials should be equitable for all patients. Despite this knowledge, low participation in clinical trials and lack of diversity among those who participate are some of the most pressing challenges in clinical research. It is well documented that racial and ethnic minorities are significantly underrepresented in clinical trials relative to their respective cancer burden in the United States (223)(257). For example, 13 percent of the U.S. population is African American and African American men are more than twice as likely to die from prostate cancer (12). However, fewer than 10 percent of participants in the clinical trials that led to the FDA approvals of apalutamide (Erleada) and darolutamide (Nubeqa), two recent new treatments for prostate cancer, were African American (282) (see **Figure 11**, p. 82).

Recruitment of racial and ethnic minorities in cancer clinical trials based on disease incidence rather than their proportion in the general population will allow researchers to obtain a deeper understanding of the biological determinants of cancer outcomes that may be enriched in one racial or ethnic group or another, but not exclusively so. In studying a proportionately appropriate racially and ethnically diverse population we can understand the genetic, epigenetic, metabolomic, and proteomic factors that correspond with response to therapy, regardless of race.

Identifying the subset of patients whose cancers are most likely to respond to immunotherapeutics, which are innovative new treatments for many types of cancer, is a pressing challenge in cancer care. Immunotherapeutics work by unleashing the power of a patient’s immune system to fight his or her cancer, but only about 30 percent of cancers

Underrepresentation of African Americans in Recent Prostate Cancer Clinical Trials

A striking example of cancer health disparities is that prostate cancer incidence among African American men is nearly 70 percent higher than among white men. Unfortunately, two recent clinical trials testing new therapeutics for the treatment of prostate cancer recruited fewer than 10 percent of patients who were African American.



Data from (4)

respond to these treatments. Since the ability of tumors to provoke an immune response in the body can differ by racial ancestry, it follows that the inadequate representation of racial and ethnic minorities in clinical trials is a missed opportunity to develop predictive biomarkers to identify responders across more diverse patient populations. Notably, racial and ethnic minority enrollment in pivotal clinical trials leading to FDA approval of immunotherapeutics called immune checkpoint inhibitors is exceedingly low (258).

HOW CAN WE OVERCOME THE CURRENT BARRIERS TO TRIAL PARTICIPATION?

While much work has been done to identify the numerous barriers to cancer clinical trial participation, rates of trial

participation for racial and ethnic minorities have not changed substantially over time (257). Some of the critical issues that have been identified through these studies include structural barriers such as trial availability, clinical barriers such as restrictive eligibility criteria, logistical barriers such as having to take time off work and needing to find and pay for transportation to and from the research site, and patient/physician-related factors including socioeconomic and cultural issues (284).

While certain barriers to clinical trial participation may be difficult to tackle, some could be addressed immediately. The first would be to conduct clinical trials at facilities that treat a high percentage of racial and ethnic minority patients. Many phase III clinical trials are conducted

- To increase enrollment in clinical trials and to ensure that participants are more reflective of real-world populations, the **NCI recently revised its eligibility criteria to expand access for previously excluded patients** (287).
- The revisions affect potential participants with preexisting conditions such as those with brain metastases, prior and current malignancies, HIV and hepatitis infections, and organ dysfunction.
- Ongoing efforts are underway to increase access to more patients who may be currently excluded due to the use of medications to manage their comorbidities.



outside the United States, and those within the United States are often limited to the high-volume cancer centers where minority patients are underrepresented (285). Notably, nearly 85 percent of cancer patients are treated in the community, compared with only about 15 percent in larger, academic centers. It is, therefore, crucial that these studies are available to minority communities. To encourage patients to participate, the clinical research team needs to reach out and work with minority patient populations. For example, the NCI's Community Oncology Research Program (NCORP) is successfully bringing cancer clinical trials into diverse community settings (286).

Another strategy to diversify clinical trial participants would be 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.

Increasing diversity among clinical trial participants is perhaps the most important aspect to understanding racial and ethnic differences in treatment outcomes but the effort to mitigate disparities in treatment should not begin or end there, as highlighted by **Karen Peterson** who participated in a combination immunotherapy trial in 2017 (see p. 85). Researchers need to increase minority participation in biobanking, tumor repositories, and genomic analyses, as well as to increase the racial and ethnic diversity of the model systems used to study cancer in order to begin to frame and predict possible effects of genetic and genomic diversity on treatment outcome. To diversify tissue and

blood biorepositories we must overcome educational gaps in awareness of the importance of biobanking and participating in clinical research through culturally appropriate and culturally sensitive community-facing education programs that engage and educate diverse populations, neighborhood by neighborhood. In addition, we need continued development of training programs to better enable health care professionals to overcome implicit bias.

Disparities in Treatment with Systemic Therapeutics

Systemic therapy is defined as treatment using therapeutics that travel through the bloodstream, reaching and affecting cells all over the body. Systemic therapeutics for cancer comprise three of the five pillars of cancer care, cytotoxic chemotherapeutics, molecularly targeted therapeutics, and immunotherapeutics (see **Figure 9**, p. 76). These treatments can transform lives by improving survival and quality of life for cancer patients, as illustrated by the experience of **Fernando Whitehead**, who received a cutting-edge immunotherapeutic (see p. 87). However, not all patients receive the treatments recommended for the type and stage of cancer that they have been diagnosed with. Therefore, it is imperative that all stakeholders committed to driving progress against cancer work together to address the challenge of disparities in cancer treatment with systemic therapeutics because these disparities are associated with serious adverse differences in survival.

Cytotoxic chemotherapy became the third pillar of cancer care in the early 1940s. While it remains the foundation of treatment for many cancers, researchers are also constantly developing newer and more sophisticated cytotoxic chemotherapeutics and identifying new ways to use existing cytotoxic chemotherapeutics to improve survival and quality of life for patients. Unfortunately, many reports have documented that African American and Hispanic patients are



“By sharing my story, I hope to inspire other African American women to...get involved in cancer research and clinical trials.”

Surviving Breast Cancer Thanks to a Clinical Trial

I was diagnosed with stage I triple-negative breast cancer in January 2015. Just over two years later, the cancer returned; this time it was stage IV. That's when I set to work educating myself about the latest research into the disease and its treatments. This knowledge empowered me to seek out a new clinical trial for immunotherapy, rather than accept standard treatment. Self-advocacy saved my life because there is currently no evidence of cancer in my body. By sharing my story, I hope to inspire other African American women to become educated about their health care and to get involved in cancer research and clinical trials.

Cancer runs in my family. I myself am a survivor of childhood cancer, I had a sibling who passed away from Wilms' tumor at 18 months, my uncle passed away from colorectal cancer at 48, and my grandmother passed away from breast and ovarian cancer at 44. Because of this, regular breast cancer screening was a deeply ingrained part of my health care routine.

It was after one of my mammograms that I was diagnosed with stage I triple-negative breast cancer. The diagnosis was made just weeks before my 50th birthday. As a survivor of childhood cancer, I was confident that I would be able to beat this diagnosis, and I postponed surgery until after my birthday.

I had a double mastectomy [surgery to remove all of both breasts] and then four rounds of an aggressive chemotherapy regimen. The chemotherapy made me extremely sick, but after it was over I was able to return to my normal life.

In April 2017, a CT scan showed that the cancer had returned. Worse still, it had spread to my lungs, ribs, spine, and pelvis. I realized that when I had first been diagnosed with breast cancer, I had simply accepted the advice of my oncologist. I decided that this time I had to become more educated and make informed decisions based on facts and science.

I scoured the Internet and read everything that I could about the latest research on triple-negative breast cancer and the latest clinical trials testing cutting-edge treatments for the disease. I also sought a second opinion from another oncologist who told me that tests showed that there were a lot of immune cells in my tumors. She suggested that immunotherapy might be a good treatment option for me because it might help boost the cancer-fighting power of those immune cells. She also suggested genomic testing of my cancer to help determine what treatment would be most effective for me.

When my original oncologist dismissed these ideas and suggested the standard treatment that she used for all her patients, I transferred my care to the other oncologist.

Genomic testing showed that my cancer had an elevated number of mutations, which is unusual for breast cancer but made me a candidate for immunotherapy. So I started calling researchers and clinical teams running immunotherapy clinical trials that I found on clinicaltrials.gov.

Eventually, one of the researchers returned my call. He told me that he did not have a trial at that time but that I should consider trying to enroll in a new combination immunotherapy trial that he knew would open soon.

Twelve weeks after my diagnosis with metastatic disease, I entered the trial. I received an infusion of a type of immunotherapy called interleukin-2 (IL-2) to build a more powerful army of cancer-fighting immune cells. I then received another type of immunotherapy, a PD1 inhibitor, to release brakes on this army of immune cells. I have received no treatments for my cancer since March 2019.

I was told at the start of the trial that there was a 4 percent chance of its working. Eight weeks later, scans showed that the tumors had shrunk by 72 percent. Over time they shrank further, and there has been no evidence of cancer in my body for more than a year.

Participating in a clinical trial was like getting the Rolls Royce of medicine. I had an entire team, from the researcher to the infusion nurses, receptionists, social workers, and business advocates, making sure that I was cared for in every way.

The treatment I received through the trial saved my life, and I'm doing everything I can to pay it forward—telling everyone that becoming educated, advocating for yourself, and participating in cancer research and clinical trials can save your life.

I understand the resistance within the African American community to participating in research studies, but if we do not participate how can we complain that researchers are not working on our behalf? We need to be willing to take a chance and to demand to be included, and researchers and oncologists must make an effort to bridge the gap and include African Americans in clinical trials.



“Since he received the treatment [CAR T-cell therapy], there has been no sign of Fernando’s leukemia.”

-Fernando’s mother, Natalie Whitehead

Overcoming Leukemia Thanks to CAR T-cell Therapy

A message from Natalie Whitehead, Fernando's mother

My son Fernando was 13 when he was diagnosed with acute lymphoblastic leukemia (ALL) in May 2017. After four months of aggressive chemotherapy failed to control the leukemia, his doctor suggested we consider a clinical trial testing a new type of treatment called CAR T-cell therapy. The treatment [now called tisagenlecleucel (Kymriah)] was a miracle for Fernando. He has been in complete remission with no evidence of the disease for more than two years, and he enjoys playing video games and hanging out with his friends.

I'll never forget the day that Fernando's experience with leukemia started; it was March 28, 2017. He loved playing sports; he played lacrosse and basketball, and he was thinking of starting to play soccer too. That day, when I picked him up from lacrosse practice, he was limping so badly that I took him to the pediatrician. An X-ray showed nothing concerning, so the pediatrician said he thought it was a sprain and that Fernando should take ibuprofen for the pain.

Over the next few days, Fernando's pain got worse and by the following week he couldn't walk. Neither the doctors at the emergency room we visited nor the orthopedic specialist I took him to could figure out what was wrong.

It was finally the rheumatologist that Fernando was seeing because he had an autoimmune disease called uveitis, which affects the eyes, who suggested the MRI that led to the leukemia diagnosis. The MRI showed some areas of concern and I was told to pack a bag and take Fernando straight to the emergency room.

Fernando was admitted to the hospital on May 1. He did not leave that hospital until August 24.

The initial blood work done at the hospital did not find signs of leukemia, but a bone marrow aspiration and biopsy showed that he had ALL.

When I told Fernando, he seemed almost relieved to have finally found out what was wrong. By this point he couldn't walk and was in so much pain that even morphine was not helping him.

Fernando's cancer was difficult to treat, so his oncologists put him on an aggressive chemotherapy regimen. It had lots of terrible side effects, including causing such severe lung and breathing issues that Fernando had to be admitted to the intensive care unit and stop the leukemia treatment.

Even though the chemotherapy was resumed after Fernando left the intensive care unit, he never went into remission. It was at this point that his oncologist suggested that we consider the CAR T-cell therapy clinical trial, which was being conducted at Children's Hospital of Philadelphia. I researched the trial. Everything I read about it was positive, and I felt that it would help Fernando.

Fernando was among the last group of patients to be part of the trial. He received the CAR T cells in December 2017. The difference between CAR T-cell therapy and chemotherapy was unbelievable. The chemotherapy had made Fernando so sick he could not leave the hospital. After receiving the CAR T cells, Fernando was bouncing around, like the Fernando before leukemia.

The CAR T-cell therapy was a miracle. Since he received the treatment, there has been no sign of Fernando's leukemia. He has a checkup every two months during which the doctors not only look to see if the leukemia is still gone, but also give him intravenous immunoglobulin because his immune system has still not recovered after the chemotherapy that he had to receive in order to get the CAR T cells.

Fernando does have long-term effects as a result of his chemotherapy treatment, including asthma, low bone density, and problems with his short-term memory. Because of the bone density issue Fernando hasn't been able to return to playing sports, but he is enjoying life and we are thankful for each and every day.

This process with Fernando's cancer has shown me how important it is to be joyful. I also feel that the treatment Fernando was able to get through the clinical trial in Philadelphia should be available to everyone. I don't think color, ethnicity, or money should be a factor.

less likely to receive recommended cytotoxic chemotherapy treatments compared with whites. For example, African American patients with colorectal cancer have been shown to be significantly less likely to be treated with cytotoxic chemotherapeutics compared with white patients and both Hispanic and African American patients with stomach cancer have been shown to be significantly less likely to receive presurgery cytotoxic chemotherapy compared with non-Hispanic whites (21)(289).

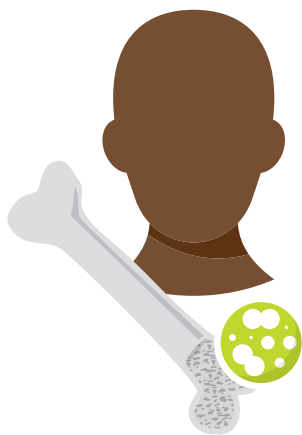
Systemic therapeutics directed to the molecules influencing cancer cell multiplication and survival target the cells within a tumor more precisely than cytotoxic chemotherapeutics, which target all rapidly dividing cells, thereby limiting damage to healthy tissues. The greater precision of these molecularly 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 in cancers to accurately match patients with the corresponding targeted therapy. This allows patients to receive a treatment to which they are most likely to respond, while allowing 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 particular disease characteristics.

Unfortunately, many recent reports have highlighted that there are striking disparities in the utilization of molecularly targeted treatments among racial and ethnic minority patients. For example, among women with stage III HER2-positive breast cancer, only 56 percent of African

American patients received the HER-targeted therapeutic trastuzumab (Herceptin) compared with 74 percent of whites (290). African American patients with non-small cell lung cancer (NSCLC), were less likely to be tested to determine whether their cancer was fueled by a mutation in the EGFR gene compared with white patients and were less likely to be treated with the EGFR-targeted therapeutic erlotinib (Tarceva) (291). The disparities in the receipt of these highly effective therapies mandates further research to identify current barriers to the use of molecularly targeted therapeutics among racial and ethnic minority 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. 89). In recent years, it 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. For example, recent long-term results from a clinical trial testing the immunotherapeutic pembrolizumab (Keytruda) as an initial treatment for patients with advanced NSCLC showed that 23 percent lived five or more years, which stands in stark contrast to the historical five-year relative survival rate of about 5 percent (292).

There are, however, confounding data on whether there are racial and ethnic disparities in the use of immunotherapeutics. For example, one study reported disparities in the use of immunotherapeutics based on health insurance status but not race, in patients with advanced melanoma, while a second report highlighted racial and socioeconomic disparities, with African American NSCLC patients consistently less likely to receive



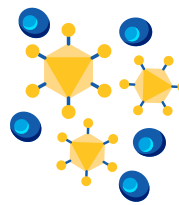
- **African Americans have a twofold higher incidence of and mortality** from multiple myeloma compared with whites (13).
- African American and Hispanic patients with multiple myeloma are **less likely to utilize stem cell transplantation and bortezomib treatment** compared with whites; they also receive novel treatments later after their diagnosis compared with whites (16)(283).
- Notably, a new study shows that African Americans **may have a higher survival rate** than whites when all patients have **equal access to novel treatments** (254).

How Immunotherapeutics Work

The way in which different immunotherapeutics unleash a patient's immune system to fight cancer varies:



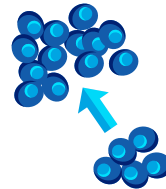
Some release the brakes on the natural cancer-fighting power of the immune system, for example, nivolumab (Opdivo) and pembrolizumab (Keytruda). These therapeutics are commonly known as checkpoint inhibitors.



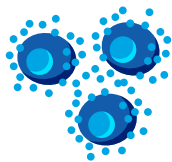
Some comprise a virus that preferentially infects and kills cancer cells, releasing molecules that trigger cancer-fighting T cells; these are called oncolytic virotherapeutics, for example, talimogene laherparepvec (T-VEC; Imlygic).



Some 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 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 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 mogamulizumab-kpkc (Poteligeo).

Adapted from (3)

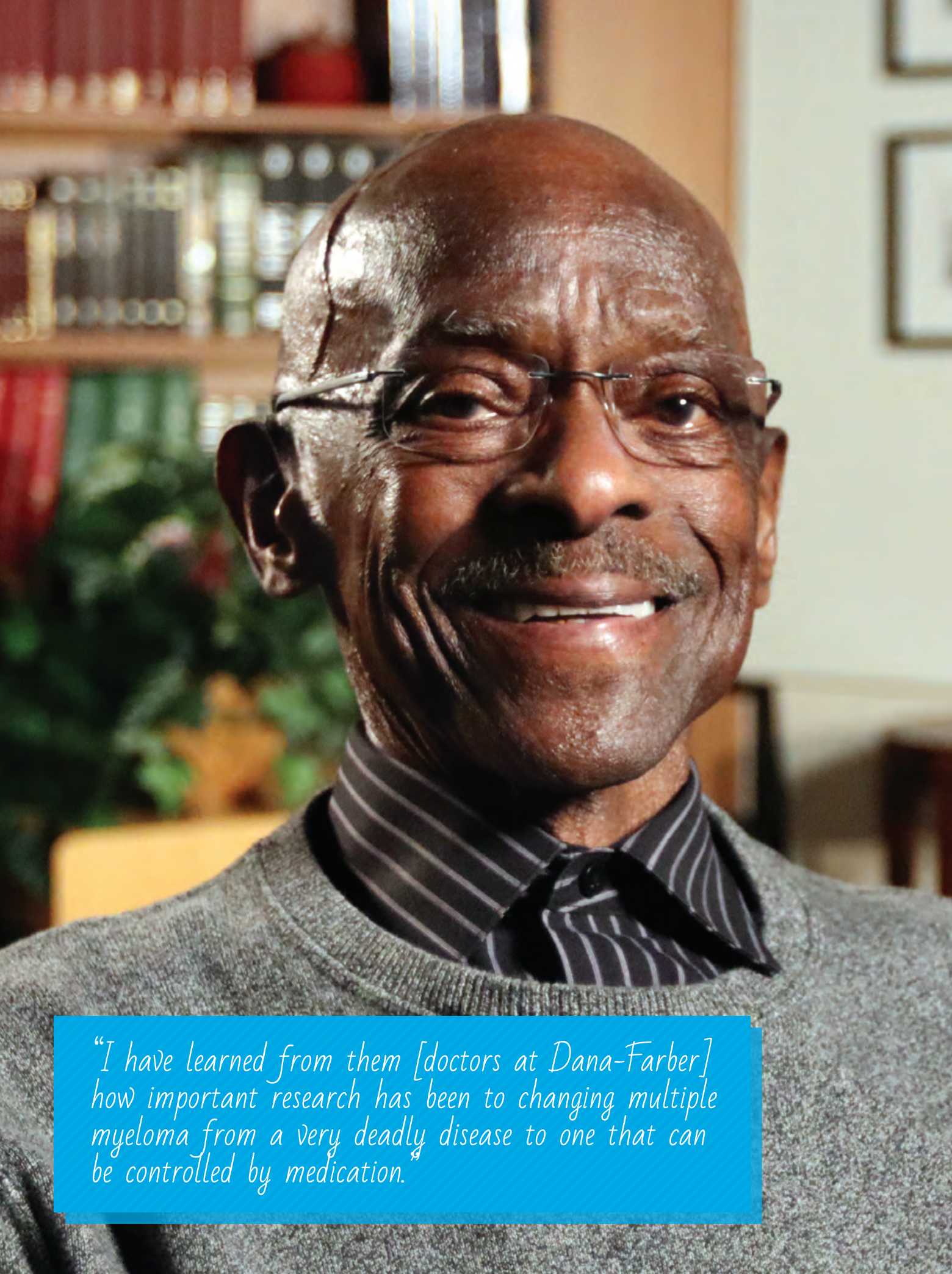
immunotherapeutics compared with whites (293)(294). Given these conflicting reports as well as ongoing concerns about racial disparities in access to clinical trials of novel cancer drugs, including immunotherapeutics, it is critical that ongoing research continue to evaluate the effectiveness and utilization rates of these therapeutics among minority patients in real-world practice.

Achieving Equity in Quality Cancer Care

Mounting evidence suggests that for many cancers, racial and ethnic minorities may respond better to treatments and have similar or better outcomes compared with white patients when offered similar access to quality clinical care. Four independent clinical studies in prostate cancer all indicated that although African American men entered into the trials with more advanced disease, they responded better to different types of treatment—cellular immunotherapy, hormone therapy, radiotherapy, and chemotherapy—with a 20 to 30 percent improvement in survival compared with white patients (276)(295-297). For example, a survival analysis of African American versus white men with prostate cancer treated with the cellular immunotherapeutic sipuleucel-T (Provenge) showed that the median overall

survival was 37.3 months among the African Americans compared with 28 months among the white patients. Similar trends were also reported in a study from the Veterans Administration health care system, where overall use of new treatments, such as the immunomodulatory drugs and proteasome inhibitors that **Alfred Johnson** was treated with (see p. 91), was the same across all multiple myeloma patient populations. The researchers showed that younger African American patients had better survival than whites. Specifically, the median overall survival for patients under 65 was significantly better (7.07 years) for African Americans compared with whites (5.83 years) (259).

Given the emerging evidence that disparities in outcomes can often be mitigated when patients from racial and ethnic minority groups receive the same treatments, it is important that researchers devise innovative strategies, including novel clinical trial designs, to ensure that all patients receive standard treatments and participate in cutting-edge clinical trials. These new strategies must simultaneously address more than one of the many complex and interrelated factors contributing to disparities in treatment. Multilevel interventions, including improved use of real-time signals from electronic health records, intensive training in overcoming implicit bias, and implementation



“I have learned from them [doctors at Dana-Farber] how important research has been to changing multiple myeloma from a very deadly disease to one that can be controlled by medication.”

Enjoying Family Life Thanks to Treatment for Multiple Myeloma

I was diagnosed with smoldering myeloma, which is a medical condition that is often a precursor to multiple myeloma, in 2009. For me, it was 8 years before the smoldering myeloma progressed to multiple myeloma. The main treatment I've received since then is a drug called lenalidomide (Revlimid). It is controlling the cancer, and I'm enjoying life with my family, my wife, sons, and grandchildren.

Ever since I was a young man, I had always made sure to get an annual checkup with my primary care doctor. For a number of years in the early 2000s, he and I would talk each year about back pain that I was experiencing, which would come and go. Finally, at my annual checkup in 2009, the doctor ordered a 24-hour urine test because he wanted to check whether the pain might be related to any problem with my kidneys.

The test showed that I had elevated levels of something called Bence Jones protein in my urine, and the doctor referred me to a hematologist. I knew that the referral meant that something was wrong with my blood and that scared me.

The hematologist did a bone marrow biopsy in which some cancer cells were found, which was even more scary.

At that point, I transferred my care to the Dana-Farber Cancer Institute. I knew it was a great place to be treated because my wife had been successfully treated there for ovarian cancer.

After my first visit to Dr. Munshi at Dana-Farber, I felt much better about my prospects. He told me that I had smoldering myeloma and that although

it often progresses to become a form of cancer called multiple myeloma, I would not need any treatment until I developed other symptoms of the disease. He also told me that there were a number of treatments available for multiple myeloma that could control the disease if it arose.

Over the next eight years, the only thing that I needed to do was have regular blood tests to check to see that the smoldering myeloma was not progressing. Then, in August 2017, the blood test showed that the smoldering myeloma might be progressing. A bone marrow biopsy confirmed that I did indeed now have multiple myeloma and that I needed to begin active treatment.

I started treatment with bortezomib (Velcade) injections and a steroid called dexamethasone. A few weeks later, lenalidomide was added to my treatment. After this treatment controlled the multiple myeloma, the bortezomib and steroid were discontinued. I have been treated with only lenalidomide ever since and the blood tests I have every three months show that the multiple myeloma remains under control.

I take lenalidomide daily for three weeks and then have a week off treatment. There are some side effects, but I have found that taking the medication in the evening limits some of these for me because I then go to sleep. I am not able to work as long in the yard as I used to be able, but I still enjoy life.

I am grateful to Dr. Munshi and his team for the great care I have received, and I have learned from them how important research has been to changing multiple myeloma from a very deadly disease to one that can be controlled by medication.

of patient navigation programs, can improve delivery of guideline-concordant care, help patients overcome barriers to care, improve participation in clinical trials, and mitigate disparities in therapy (298-300). For example, a recent clinical study conducted across five U.S. cancer centers showed that a multipronged intervention that included nurse navigators, a real-time warning system using data from electronic health records to alert nurse navigators if patients miss an appointment or do not reach an expected care milestone, and race-specific feedback to clinical teams on treatment completion rates was not only able to eliminate treatment disparities among African American and white patients with early-stage lung cancer, but also improved care for all patients regardless of race (298). The importance of nurse navigators was highlighted in another recent study showing that African American and Hispanic patients with diffuse large B cell lymphoma were just as likely as white patients to receive standard treatments and participate in clinical trials at a safety net hospital that has an extensive nurse navigator program to help disadvantaged patients access and complete treatment by guiding them through treatment, helping them with lodging, and providing other nonmedical support (300).

Whether similar multifaceted interventions could be implemented widely across multiple health care systems, for

different cancer types, and whether they can be effective in achieving health equity for all must be evaluated. However, these findings strongly support the importance of conducting innovative translational and clinical cancer research to determine how to eliminate disparities in cancer treatment and improve outcomes in diverse populations.

Moving forward, we need to ensure that everyone benefits from breakthroughs against cancer. Cancer researchers must 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-level interventions than 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. It is imperative that all stakeholders committed to fundamentally changing the face of cancer work together to address the challenges of disparities in cancer treatment and lead us toward a brighter future with health equity for all Americans.



U.S. REPRESENTATIVE FOR TEXAS'S 23RD DISTRICT

The Honorable Will Hurd

“Cancer is the second-leading cause of death in the United States. We must do all we can to find a cure for this devastating disease, which is why the American Association for Cancer Research’s (AACR) high-quality, innovative cancer research is vital for breakthroughs in this field. As we continue to make progress in finding innovative treatments, and ultimately a cure, we also have to make sure all patients have fair access to these resources. I thank the AACR for putting together this Disparities Progress Report so we can better educate ourselves on these issues and find ways to work together to fill these gaps. I’m proud to support bipartisan efforts in Congress to give patients more flexibility, transparency, and access to treatments such as the Cancer Drug Parity Act and the Lower Costs, More Cures Act, and I’ll continue to work with my colleagues to reduce cancer disparities and fight for patients across the nation.”

Disparities in Cancer Survivorship

IN THIS SECTION, YOU WILL LEARN:

- ▶ A record high number of cancer survivors are living in the United States.
- ▶ Each person diagnosed with cancer faces a unique set of challenges, but one in four survivors reports a poor physical quality of life and one in ten reports a poor mental health-related quality of life.
- ▶ Racial and ethnic minorities and other underserved populations shoulder a disproportionate burden of the adverse effects of cancer and cancer treatment, including physical, emotional, psychosocial, and financial challenges.
- ▶ An interdisciplinary team science approach to cancer survivorship research that is informed by the voices of community members such as patient advocates will result in improved health care and health status for racial and ethnic minorities and other underserved populations.

Advances in cancer detection, diagnosis, and treatment are helping more and more people to survive longer and lead fuller lives after a cancer diagnosis. According to the latest estimates, more than 16.9 million U.S. adults and children with a history of cancer were alive on January 1, 2019, compared with just 3 million in 1971, and this number is projected to rise to 22.1 million by January 1, 2030 (301)(302). The increase over the current number of cancer survivors is anticipated largely because the number of people being diagnosed with cancer each year is projected to rise sharply in the coming decades as a result of overall population growth, and because the segment of the U.S. population that accounts for the majority of cancer diagnoses—those age 65 and older (4)—is expected to grow

from 49 million in 2016 to 73 million in 2030 (303). Given that the proportion of individuals age 65 and older who are racial and ethnic minorities is projected to increase markedly, we need to better understand the needs of this population and to identify strategies to overcome the cancer-related challenges faced by this population (304)(305).

Cancer survivorship encompasses three distinct phases: the time from diagnosis to the end of initial treatment, the transition from initial treatment to extended survival, and long-term survival. Each phase of cancer survivorship is accompanied by a unique set of challenges (see sidebar on **Life after a Cancer Diagnosis in the United States**, p. 94). Importantly, the issues facing each cancer survivor vary.



U.S. REPRESENTATIVE FOR GEORGIA'S 6TH DISTRICT

The Honorable Lucy McBath

"As a two-time breast cancer survivor, I know firsthand the strain a cancer diagnosis can put on a person and their family. It breaks my heart to see disparities in cancer rates due to race and socioeconomic factors. Every day, Congress must come together and continue to fight for a more just and equitable health care system, and eliminating these disparities is an important part of that process. I am proud to support research to discover new treatments, improve access to health care, and work to ensure all of our families are kept healthy and whole."

Life after a Cancer Diagnosis in the United States



When an individual is diagnosed with cancer, his or her life is changed irrevocably. Cancer survivors often face serious and persistent adverse outcomes, including physical, emotional, psychosocial, and financial challenges as a result of the cancer diagnosis and treatment. Many challenges experienced by cancer survivors begin during cancer treatment and continue in the long term, but others can appear months or even years later. These long-term and late effects include, but are not limited to:

- bone density loss (osteoporosis);
- cognitive impairment (trouble remembering, learning new things, concentrating, and/or making decisions that affect everyday life);
- diagnosis with a new type of cancer(s);
- distress, anxiety, and/or depression, which can interfere with a person's ability to cope effectively with cancer and its treatment;
- endocrine dysfunction, which is dysfunction of the organs and glands that control body functions such as growth, sexual development, reproduction, sleep, hunger, and the way the body uses food;
- fatigue that is severe and often not relieved by rest;
- fear of cancer recurrence;
- hearing loss;
- heart damage (cardiotoxicity);
- infertility;
- insomnia;
- joint changes;
- lung (pulmonary) damage;
- lymphedema, which is swelling, most often in the arms or legs, that can cause pain and problems in functioning;
- metabolic syndrome, which occurs when an individual has three or more of the following health risk factors: excess body fat around the waist, high blood pressure, high triglycerides, impaired fasting glucose, and low HDL cholesterol;
- mouth changes, such as change in taste, mouth sores, dry mouth, jaw pain, and sensitive gums;
- nerve problems (peripheral neuropathy);
- nutrition issues;
- pain;
- premature aging;
- recurrence (return) of original cancer; and
- sexual dysfunction.

Although all cancer survivors face challenges, certain groups of people, including racial and ethnic minorities, shoulder a disproportionate burden of the adverse effects of cancer and cancer treatment. In addition, survivors of cancer diagnosed during childhood, adolescence, and young adulthood (from ages 0 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 (3)

Certain segments of the U.S. population, including racial and ethnic minorities and other underserved populations, shoulder a disproportionate burden of the adverse effects of cancer and cancer treatment, including physical, emotional, psychosocial, and financial challenges (see sidebar on **Disparities in Health and Quality of Life after a Cancer Diagnosis**, p. 95).

Disparities in Long-term and Late Effects of Cancer Treatment

Cancer survivors often face serious and persistent adverse outcomes as a result of the cancer diagnosis and treatment.

Many adverse outcomes experienced by cancer survivors begin during cancer treatment and continue in the long term; these are known as long-term effects of treatment. Other adverse outcomes can appear months or even years later; these are known as late effects of treatment.

Current knowledge indicates that there are racial and ethnic disparities in the late and long-term effects of cancer treatments, in particular among women who have been diagnosed with breast cancer (306)(309)(310). For example, African American women have been found to have a two-fold increased risk of breast cancer-related lymphedema (swelling in the arms that can cause pain and problems in

Disparities in Health and Quality of Life after a Cancer Diagnosis

Several segments of the population are disproportionately affected by cancer- and cancer treatment-related health complications that adversely affect health and quality of life after a cancer diagnosis. Examples of these disparities include the following:

**TWO-FOLD
INCREASED RISK**

African American women had a **two-fold increased risk of breast cancer-related lymphedema** (swelling in the arms that can cause pain and problems in functioning) compared with white women (306).

**23%
MORE LIKELY**

Cancer survivors who lived in rural areas were **23 percent more likely to report psychological distress** compared with those in urban areas (307).

**50%
MORE LIKELY**

Colorectal cancer survivors who had low socioeconomic status were **50 percent more likely to report clinically significant anxiety and depression** compared with those who had high socioeconomic status (308).

Adapted from (115)

functioning) compared with white women (306). In addition, African American women with breast cancer who were being treated with cytotoxic chemotherapeutics called taxanes were significantly more likely to have chemotherapy-induced peripheral neuropathy leading to a reduction in the dose of chemotherapy they received compared with white women (310). Treatment with HER2-targeted therapeutics has also been shown to cause more than twice the rate of heart damage (cardiotoxicity) among African American women with HER2-positive breast cancer compared with white women and therefore African American women had a significantly greater probability of not completing therapy (309).

Survivors of cancer diagnosed during childhood, adolescence, and young adulthood (from ages 0 to 39), are particularly at risk for severe long-term and late effects. To date, few studies have investigated racial and ethnic disparities in the late and long-term effects of cancer treatments for children, adolescents, and young adults. One study showed that African American adolescents and young adults surviving two or more years after a Hodgkin lymphoma diagnosis were 37 percent more likely to have endocrine diseases and 58 percent more likely to have circulatory system diseases than whites (311). In the same study, Hispanic adolescents and young adults were 24 percent more likely to have endocrine diseases than whites.

Disparities in Health-related Quality of Life

A cancer diagnosis and treatment for the disease can have a considerable impact on a person's quality of life. For cancer

patients and survivors, health-related quality of life is a multidimensional concept that goes beyond the person's cancer-related outcomes and considers the impact of cancer and cancer treatments on the person's overall physical, functional, psychological, social, and financial well-being (312)(313).

Health-related quality of life is often measured using patient-reported, subjective evaluations. Overall, cancer survivors report lower general health and quality of life compared with people without a history of cancer (314-316). For example, in one study, 25 percent of cancer survivors reported a poor physical quality of life and 10 percent reported a poor mental health-related quality of life compared with 10 percent and 6 percent of people without a history of cancer, respectively (314).

Several studies have shown that racial and ethnic minorities experience disparities in many measures of health-related quality of life after a cancer diagnosis, during cancer treatment, and after cancer treatment is completed (317-323). For example, African American cancer patients report significantly lower mental health-related quality of life, general health, and social functioning compared with white cancer patients (319). Among breast cancer survivors, Hispanic women report lower physical, mental health-related, and social health-related quality of life than women of any other racial or ethnic group (322). The disparities in health-related quality of life are often a result of factors such as age at diagnosis, cancer stage at diagnosis, and treatment type, as well as social, clinical, and environmental factors such as income, health insurance status, employment status, and education (317)(318)(320)(324)(325).

Even though racial and ethnic minorities experience disparities in most measures of health-related quality of life, several studies

show that African American cancer survivors report higher emotional and spiritual health-related quality of life compared with white cancer survivors (320)(326). This provides an opportunity for health care providers to recognize and reinforce these areas of strength and to use them to deliver culturally appropriate care and services that help reduce disparities in other measures of health-related quality of life.

Health-related quality of life for racial and ethnic minority cancer patients and survivors is influenced by social, clinical, cultural, behavioral, psychological, and environmental factors (317)(318)(320)(324)(325). Deeper understanding of the interplay between race and ethnicity and all these is vital to alleviate disparities in health-related quality of life. Improving health-related quality of life is also important because it is linked to cancer-related outcomes, including survival (327).

Disparities in Financial Toxicity

It is projected that direct spending on cancer care will exceed \$157 billion in 2020 (80). For cancer patients and survivors and their families, out-of-pocket medical costs are higher for cancer than for any other chronic disease (328). As a result of high cancer care costs, many patients experience financial hardship, or financial toxicity (329). One recent study showed that 25 percent of cancer survivors reported financial toxicity, as defined by borrowing money or going into debt, filing for bankruptcy, or being unable to cover their copayments (329).

Financial toxicity due to a cancer diagnosis and treatment is associated with lower rates of compliance to therapy, reduced likelihood of receiving follow-up care, skipping medications, and missing appointments (330). It is also associated with worse outcomes and poorer quality of life (331)(332). For example, the risk of death has been shown to be 79 percent higher among cancer patients who filed for bankruptcy compared with those who did not file for bankruptcy (331).

Unfortunately, the segments of the U.S. population that shoulder a disproportionate burden of the adverse effects of cancer and cancer treatment, including racial and ethnic minorities, are also at increased risk of experiencing financial toxicity because of the out-of-pocket expenditures caused by a cancer diagnosis and cancer treatment (329). For example, it has been reported that 31 percent of African American cancer survivors experience financial toxicity compared with 24 percent of white cancer survivors (329). In another study of lung and colorectal cancer survivors, about 68 percent of African Americans and 58 percent of Hispanics reported financial toxicity compared with 45 percent of whites (333).

Financial toxicity extends beyond out-of-pocket direct

medical costs and can be caused by indirect costs of lost productivity, such as days lost from work or disability days (334). For example, the likelihood of a cancer patient being employed has been shown to drop by almost 10 percentage points and hours worked decline by up to 200 hours in the first year after diagnosis (335). Among women who have been diagnosed with breast cancer, African American women living in urban areas are almost 50 percent more likely to lose a job or income after their diagnosis compared with white women living in urban areas (336). In addition, among women with breast cancer who were employed at the time of diagnosis, African Americans are significantly less likely to be employed when asked about this at 2 and 9 months after diagnosis compared with whites (337). Partners of breast cancer survivors also experience a worse financial and employment status as a result of the breast cancer diagnosis, with Hispanic partners significantly more likely to report worse financial and employment status compared with white partners (338).

Paving the Way for Health Equity for Racial and Ethnic Minority Cancer Survivors

Understanding the challenges faced by racial and ethnic minority cancer survivors is important to addressing the disparities in cancer morbidity, mortality, and quality of life that they face. Opportunities exist to refine the science of cancer survivorship by integrating the work of biological, health systems, and socioecological researchers, developing ways to assess multiple factors influencing disparities, and creating shared data repositories. Through this interdisciplinary team science approach to cancer survivorship research, we can strengthen existing resources and develop targeted interventions to achieve greater health equity.

In addition, to address cancer health disparities, the work of researchers must be informed by the voices of community members. Community-engaged research, which involves partnerships between community members and researchers, is important for catalyzing the translation of scientific knowledge into readily accessible and responsive community education, action, and interventions and for ensuring community receptivity (339). Patient advocates are uniquely positioned to represent their own communities as partners in research projects and will be instrumental in understanding the needs and priorities of the community, defining the research questions and study designs, implementing the studies, and disseminating the research results (see sidebar on **Patient Advocates Address Cancer Disparities**, p. 97). As such, there is a critical need for racial and ethnic minority patient advocates like **Ghecemy Lopez** (see p. 99) who can galvanize effective community-engaged

Patient Advocates Address Cancer Disparities

One of the many ways in which patient advocates are addressing cancer health disparities is by increasing community engagement in cancer research. Over the past two decades, patient advocates have expanded their partnership with cancer researchers to fund disparities research, improve awareness regarding cancer risks and prevention, enhance the participation of minorities in clinical trials, and work with Capitol Hill to develop novel policies to reduce cancer health disparities. Selected examples of the partnerships among patient advocates, cancer researchers, and legislators that aim to drive progress against cancer health disparities are highlighted here:



The **Prostate Cancer Foundation** partnered with the **National Cancer Institute** and the **National Institute on Minority Health and Health Disparities** to launch the largest coordinated research effort to study biological and nonbiological factors associated with aggressive prostate cancer in African American men. The project is called **Research on Prostate Cancer in Men of African Ancestry: Defining the Roles of Genetics, Tumor Markers, and Social Stress (RESPOND)**. Working together, patient advocates and investigators aim to enroll 10,000 African American men with prostate cancer into RESPOND to investigate environmental and genetic factors that will help us better understand why African American men disproportionately experience aggressive disease when compared with men of other racial and ethnic groups.



In the breast cancer community, the past two decades have brought about the formation of powerful national and local African American breast cancer advocacy organizations, such as **Sisters Network, Inc., Black Women's Health Imperative, African American Breast Cancer Alliance and African American Breast Cancer Coalition**. These organizations have been successful at raising public and political awareness, calling attention to improved accountability for quality care and policies, and elevating cancer health disparities as a public health priority. These awareness efforts have also encouraged new funding streams for breast cancer disparities research. The **Breast Cancer Foundation** and the **Susan G. Komen Foundation** have funded close to \$100 million in research programs to end breast cancer disparities and secure health equity for all breast cancer patients.



Colorectal patient advocates, minority health care organizations, and medical associations have been working with local and federal legislators to help address racial and ethnic disparities, with a focus on screening and outcomes. In 2002, seeking to address disparities in colorectal cancer among African Americans, the **Delaware Cancer Consortium**, which includes patient advocates, cancer researchers, oncologists, and representatives from government agencies, worked with state legislators to create a statewide colorectal cancer screening program that paid for screening and treatment and made patient navigators available to coordinate screening and cancer care. By 2009, this program had eliminated disparities in screening rates, reduced the percentage of African Americans diagnosed with advanced cancer, and almost completely abolished racial and ethnic differences in colorectal cancer incidence and mortality (see sidebar on **Eliminating Colorectal Cancer Disparities in Delaware**, p. 72).

research, resulting in improved health care and health status in these underserved populations.

Ultimately, cancer advocacy is about education and driving policy, practice, social, and funding progress toward the betterment of those affected by this illness. The scarcity of resources and services that are culturally salient for racial and

ethnic minorities, along with the growing number of racial and ethnic minority cancer patients and survivors makes a compelling case for their inclusion in advocacy efforts toward building cancer prevention and control systems and a health care system that is responsive to these communities, in order to reduce cancer disparities and bring about health equity.



“My experience...motivated me to become a survivor-advocate and patient navigator, and to pursue a doctorate in social work with a focus on closing gaps in health care access.”

Serving as an Advocate after Surviving Breast Cancer

I was diagnosed with triple-negative breast cancer in February 2011. Thanks to a combination of multiple surgeries and chemotherapy treatments, there has been no evidence of the breast cancer for more than eight years. My experience and talking with other cancer survivors motivated me to become a survivor-advocate and patient navigator, and to pursue a doctorate in social work with a focus on closing health gaps, especially in my community.

It all started just after my 30th birthday, in February 2011. My husband and I were at home watching TV when I felt a lump in my right breast. I was tempted to ignore it because we were preparing to go on a trip, but my husband insisted that I get it checked out. Within days, I had a mammogram, ultrasound, and biopsy. When I heard the news that I had breast cancer, I was shocked. A movie of my life went through my mind, but all I could think about were the things that I had not done yet; would I have time to accomplish my goals?

My doctor told me that I had a particularly aggressive type of breast cancer called triple-negative breast cancer. She also told me that there were no oral medications for this type of breast cancer; I would need surgery and chemotherapy.

My cancer was so aggressive that in the 18 days between the biopsy and first surgery, my diagnosis changed from stage I to stage II because the cancer had grown dramatically in size. The lumpectomy [surgery to remove the cancer and some normal tissue around it, but not the breast itself] was successful and fortunately, the cancer had not spread to my lymph nodes.

Because the cancer was so aggressive, the doctor recommended intensive chemotherapy with docetaxel and cyclophosphamide to make sure that I had a better chance of the cancer not recurring. The chemotherapy was brutal, but there has been no evidence of the breast cancer since.

Given how young I was, I went through genetic counseling and genetic testing. The results showed that I have a BRCA1 mutation. This helped me understand a little better why breast cancer had happened to me. It also made me decide to have a preventive bilateral mastectomy, which is a surgery to remove both breasts in order to reduce my

chance of the cancer recurring and to reduce my chance of having a second breast cancer.

I eventually found out that I inherited the BRCA1 mutation from my father. It has been very hard to explain to several members of my extended family in Mexico that this mutation may have caused several diagnoses and deaths in our family, because of limited health literacy and cultural taboos around cancer.

The experience with my extended family and encouragement from my genetic counselor, who told me that my community needed me when I was at a particularly low point in my journey, led me to my life as a survivor-advocate, patient navigator, and graduate student.

I started my advocacy by joining the USC Norris Survivorship Advisory Council, which works to promote cancer research, improve health outcomes, and provide a more satisfying patient experience. Not long after, I was fortunate to take part in a Project LEAD advocacy training program run by the National Breast Cancer Coalition and taught by extraordinary scientists from major research universities. As a result of everything I learned during the training about cancer research and the ways in which advocates can impact research, I have served as a programmatic grant reviewer for the Department of Defense Breast Cancer Research Program and for the California Breast Cancer Research Council.

In addition to the advocacy, I got involved in cancer education outreach in the most underserved communities in Los Angeles, many of which have a large population of Spanish speakers. Today, I work as a lay patient navigator at USC Norris Comprehensive Cancer Center. In this role, I have helped over 420 patients and caregivers who are facing social concerns that make their cancer treatment difficult, such as issues with housing, finances, and transportation. I sometimes go with patients to their appointments or interpret for them.

I am looking forward to graduating with a doctorate in social work this summer because it will help me pursue the new life goal I set after being diagnosed with breast cancer: to work to address the social issues that lead to gaps in health care.

Imprecision of Precision Medicine

IN THIS SECTION, YOU WILL LEARN:

- ▶ Precision medicine is a more personalized approach to medicine that uses information about a person's genes, proteins, and environment to prevent, diagnose, and treat disease.
- ▶ In cancer care, genomics is the predominant factor influencing precision medicine, but other biological factors, environmental exposures, and lifestyle also contribute to the uniqueness of each person's cancer.
- ▶ Research identifying the genetic mutations associated with certain cancers has led to numerous new treatments called molecularly targeted therapeutics; these treatments are the backbone of precision medicine in cancer care.
- ▶ Our limited knowledge of cancer biology in racial and ethnic minorities diminishes the potential of precision medicine in these populations.
- ▶ Research initiatives like AACR Project Genomics Evidence Neoplasia Information Exchange (GENIE) are beginning to provide more information about cancer in all populations, which will allow us to develop and implement precision medicine for everyone.

Over the past decade, we have made significant progress in how we understand and treat the complex group of diseases we call cancer. We have learned that each person's cancer is unique, in part because it is influenced by a patient's biological characteristics, environmental exposures, and lifestyle. As a result, we have seen a major shift from a "one size fits all" approach to cancer treatment to a more personalized approach called precision medicine. Precision medicine, also referred to as personalized medicine, is defined by the NCI as a form of medicine that uses information about a person's genes, proteins, and environment to prevent, diagnose, and treat disease (see **Figure 12**, p. 101). Precision medicine has the potential to revolutionize cancer care and if used optimally, it may help address the challenges of cancer health disparities.

Precision Medicine: The Promise

In cancer care, precision medicine aims to use genetic and other information about a patient and his or her tumor, to help diagnose the patient, plan that patient's treatment, determine how well the treatment is working, and/or make a prognosis. The factors that contribute to the uniqueness of a patient and his or her cancer include, but are not limited to, the person's genome, the genome and epigenome of the cancer, disease presentation, gender, exposures, lifestyle, microbiome, and other comorbidities. Currently, genomics is the predominant

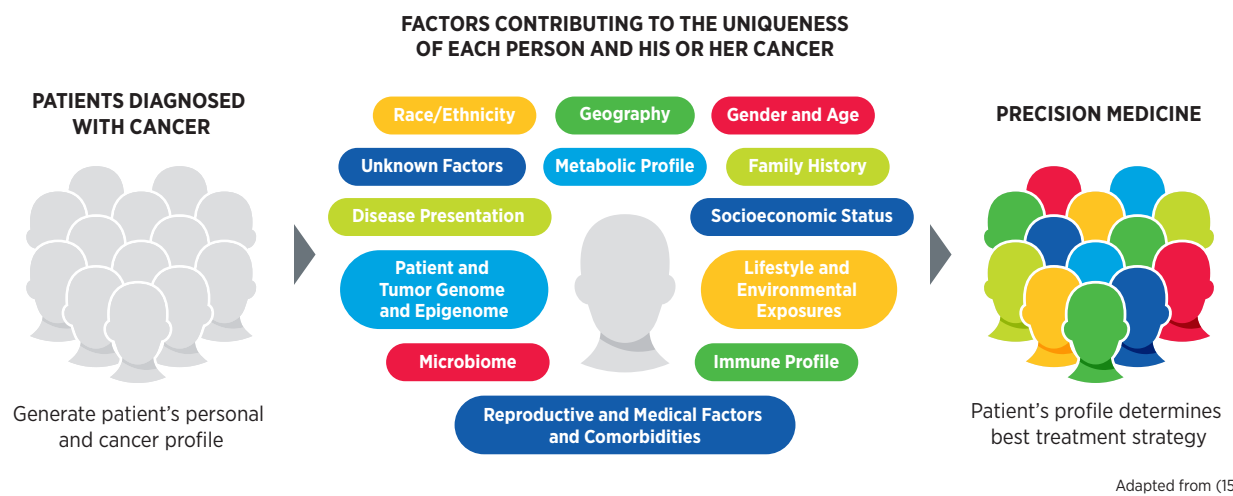
factor influencing precision oncology. Comprehensive analyses of cancer genomes have revealed numerous genetic mutations associated with various cancers. These discoveries have led to the development and FDA approval of numerous therapeutics targeted to specific molecules with the aim of rectifying the cellular changes that arise due to the mutations. For example, as of January 31, 2020, there are five therapeutics targeting ALK approved for use in the treatment of NSCLC driven by mutations in the ALK gene. Nevertheless, our current knowledge of cancer-causing genetic, lifestyle, and environmental risks is incomplete, and ongoing research will continue to uncover additional cellular and molecular alterations that lead to cancer development.

The development of molecularly targeted therapeutics often relies on the presence of specific biomarkers, such as a genetic mutation, within tumors to identify those patients who are most likely to benefit from these treatments. Genetic biomarkers are detected using tests that frequently utilize cutting-edge technologies such as next-generation sequencing techniques. Notably, recent reports show that using biomarkers, such as the presence of a specific mutation, can increase the efficiency of the clinical development of new therapeutics (340)(341). A study looking at anticancer therapeutics estimated that the chance of FDA approval was 10.7 percent for candidate agents that were matched to

Precision Medicine

Precision medicine is broadly defined as treating patients based on characteristics that distinguish them from other patients with the same disease. As shown in the figure, in oncology, the factors that contribute to the uniqueness of a patient and his or her cancer include, but are not limited to, the person's genome, the genome and epigenome of his or her cancer, disease presentation, gender, exposures, lifestyle, microbiome, and other comorbidities. Currently, genomics is the

predominant factor influencing precision oncology, but as we learn more about the additional factors, we can create an even more personalized approach to cancer treatment. It is important to note, however, that the cost-effectiveness of such profiling still needs to be evaluated alongside ongoing efforts that define which and to what extent such profiling improves outcomes for individuals.



patients using biomarkers, compared with merely 1.6 percent for unmatched candidates (340). These data emphasize the value of identifying cancer-specific alterations in the development of effective therapies.

The rapid expansion in our knowledge of the genetic mutations that drive individual cancers has led to a number of precision medicine clinical trials designed to streamline the clinical development of new molecularly targeted therapeutics by matching the right therapeutics with the right patients earlier. Among these clinical trials are the NCI's Molecular Analysis for Therapy Choice trial (NCI-MATCH), the NCI's Molecular Profiling-Based Assignment of Cancer Therapy trial (NCI-MPACT), and the Biomarker-integrated Approaches of Targeted Therapy for Lung Cancer Elimination (BATTLE) trial (342)(343). In NCI-MATCH and NCI-MPACT, patients with a wide array of cancer types are assigned to receive a certain treatment only if genomic sequencing and other tests on their cancers reveal the presence of the matching genetic abnormality. In BATTLE, a similar approach is used for patients with lung cancer. Early

data from these as well as other precision medicine trials indicate that patients benefit when treated with therapeutics chosen based on their tumors' specific genetic features, highlighting the promise of precision medicine (342-345).

Precision Medicine: The Challenges

To achieve the full potential of precision medicine every cancer patient's tumor should be tested for the presence of mutations for which there is a matching molecularly targeted therapeutic, and every patient with such a mutation should be treated with the matching anticancer therapeutic. Therefore, the delivery of precision medicine mandates that the right care is delivered to the right patient at the right time. Unfortunately, many recent reports indicate that in real-world settings, this is not the case and only a fraction of patients have their tumors tested for genetic mutations (346). Moreover, even among patients for whom genetic testing reveals biomarkers associated with a targeted therapeutic, not everyone receives treatment with the targeted therapeutic. For instance, only 64 and 70 percent of NSCLC patients with

There are racial and ethnic differences in the incidence of pathogenic mutations in genes for many cancer types (348):



BRCA1: Ovarian Cancer:

Whites (7.2%) versus
Hispanics (16.1%);



CHEK2: Breast Cancer:

Whites (2.3%) versus
African Americans (0.1%).

EGFR and ALK mutations, respectively, received one of the matching molecularly targeted therapeutics (347).

Challenges with suboptimal implementation of precision medicine are exacerbated in 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 African Americans received testing compared with 26 percent of white patients (346). Similar trends have been noted in other types of cancer, including ovarian cancer (348).

Taken together these data highlight the need to identify the current barriers to broad utilization of precision medicine as well as physician- and patient-education programs for effective dissemination of the current knowledge to ensure guideline-concordant care for every cancer patient.

While precision medicine has transformed cancer care for many patients, it has also brought attention to a lack of racial and ethnic diversity in human genomic studies. Our limited knowledge of cancer biology, including inherited cancer predisposition and the genomic underpinnings of cancer initiation and progression, in racial and ethnic minorities diminishes the potential of precision medicine in these populations. Some of the past efforts relied on investigators to obtain biospecimens from institutional or local biobanks, which fell short from the perspective of racial and ethnic diversity. While the cumulative benefits of these efforts have been important to developing resources such as TCGA, a recent report that examined the racial diversity of 5,729 samples in TCGA found that whites were overrepresented with respect to their proportion in the U.S. population while Asian and Hispanic patients were underrepresented (100). In addition, there were enough samples only from white patients to detect mutations present in a given type of cancer at a 5 percent frequency; there were insufficient samples from

any type of cancer in any racial and ethnic minority group to detect mutations present at that frequency. Other reports are consistent with these findings. Another recent analysis found that 81 percent of samples included in genome-wide association studies—a tool for discovering the genetic factors involved in common diseases such as cancer—have been from individuals of European ancestry and that individuals of other ancestries have been seriously underrepresented (93). Rectifying these issues is an area of active research investigation (see **Integrating Our Knowledge: Charting the Path Forward**, p. 41).

The underrepresentation of racial and ethnic minorities in cancer clinical trials and prevention research, and the documented challenges to enrolling these individuals into studies, pose another barrier for the implementation of precision medicine among these medically underserved populations. A consistent observation in some of the recent precision medicine trials mentioned above is the lack of diversity in patients. For example, it has been reported that in BATTLE, 82 percent of participants were white, and only 6 percent African American and 6 percent Hispanic (343). For the NCI-MATCH trial, preliminary numbers show that African Americans accounted for about 10 percent of patients who have had their tumors profiled, but only about 8 percent of those who have been treated on the study (342). Therefore, it should not be assumed that the response rates or clinical effectiveness of the therapeutics tested in these trials will generalize to all racial and ethnic groups. Collectively, these challenges can slow the pace of medical innovation, decrease the generalizability of research findings, lead to incorrect interpretations, and limit our full understanding of the effectiveness of precision medicine.

Precision Medicine: The Future Provides Opportunities to Achieve Health Equity

New insights obtained through investigations that incorporate research models and biospecimens that are representative of all populations and the inclusion of all segments of the U.S. population in cancer clinical trials are critical if we are to develop and implement precision medicine that will eliminate cancer for everyone. Many research initiatives are underway to tackle these challenges head-on. To enhance the potential for precision medicine to be effective at reducing disparities in health care and outcomes among minorities, strategic efforts and investments have been made by the NIMDH and NCI to fund centers in Precision Medicine and Minority Health. These transdisciplinary centers are working to understand the combined contribution of genetic, environmental, and lifestyle factors to racial and ethnic disparities in health care and outcomes. This approach is distinct from

previous efforts that examined these factors in isolation. The objectives are to advance the science of minority health and health disparities research by exploring the contribution of understudied determinants of minority health and establish the infrastructure to integrate basic, genomic, and population sciences within the context of health disparities research.

Funded by the NIH, the All of Us Research Program is another initiative to address the lack of racial and ethnic inclusivity in biomedical research. The scientific goals of these major prospective, retrospective, and cross-sectional analyses are to improve the understanding of health disparities, discover new disease biomarkers, support clinical trials, and develop new targeted therapeutics for a range of diseases including cancer. The program plans to enroll a diverse group of at least 1 million individuals in the United States with the aim of accelerating the pace of biomedical research and improving public health. The participants are asked to share their electronic health record data, donate biospecimens for genomic and other laboratory analyses, respond to surveys, and have standardized physical measurements taken. Participants can also contribute data from digital health devices. Researchers are currently developing tools to collect additional information that includes surveys regarding social and behavioral determinants of health as well as geospatial and environmental data such as air quality and pollutant levels.

Active community engagement has been one of the foundational pillars of the All of Us Research Program. All of Us has provided funding to health care providers and organizations (for example, federally qualified health centers) to identify best practices for recruiting and enrolling medically underserved patients into this precision medicine initiative. Similarly, organizations in the All of Us Engagement Partners are funded to motivate individuals from diverse communities to participate. As of July 2019, the program has enrolled more than 175,000 participants at more than 340 recruitment sites. More than half of the participants are nonwhite, and more than 80 percent are from groups that have been historically underrepresented in biomedical research (349).

Other clinical research initiatives that are aimed toward reducing cancer health disparities among minority patients and survivors include NCI-led studies such as the Research on Prostate Cancer in Men of African Ancestry: Defining the Roles of Genetics, Tumor Markers, and Social Stress (RESPOND) (350) and the Detroit Research on Cancer Survivors (ROCS) (323). These coordinated research efforts are designed to understand the role of environmental, genetic, social, and behavioral determinants of health that contribute to the higher burden among African American patients with prostate and breast cancer.

As we move deeper into the era of precision cancer medicine it is clear that the genomic characteristics of a patient's

cancer will need to be considered along with other factors, including the patient's epigenome, microbiome, metabolome, lifestyle, and environmental exposures, which are emerging as important influences on cancer initiation and progression. To deepen our understanding of these factors we need to first generate and gather real-world data, including patient history, results from diagnostic and genetic tests, treatment decisions, and measured and patient-reported outcomes from large numbers of cancer patients from all backgrounds including racial and ethnic minorities. One way to accelerate the pace at which we gather patient-derived information is through data sharing, and several cancer organizations as well as multi-institutional teams have already launched initiatives to catalyze these efforts. A few examples of these cross-institutional projects are AACR Project GENIE, ASCO CancerLinQ, BRCA Exchange, NCI Genomic Data Commons, and Oncology Research Information Exchange Network (ORIEN).

By using these "big data" sets researchers can answer many of cancer's most elusive questions. Physicians may be able to match existing FDA-approved molecularly targeted therapeutics to novel cancer types or identify subgroups of patients who are most or least likely to benefit from a certain treatment. Researchers may also be able to uncover important information related to cancer health disparities. For example, using the AACR Project GENIE database, which currently includes genomic and other information on nearly 4,000 African American cancer patients, we can infer that there are significant differences in the frequency of alterations in many genes between African American and white patients (**Figure 13**, p. 104). These data are invaluable regarding ongoing and future endeavors for the development of targeted therapeutics.

For precision medicine to be precise, we must increase the resolution of our measurements. Precision medicine must rely on accuracy for personalizing prevention, diagnosis, and treatment; however, with our current limitations in the diversity of patient cohorts in biomedical research, the precision and accuracy of this paradigm remain critically limited. As discussed throughout this report, most clinical trials as well as precision oncology studies are largely limited to patients of European descent. Because of the lack of diversity, the measurements and results do not describe the full story. We must ensure that the next wave of breakthroughs in cancer science and medicine is not limited to a select few, but benefits all patients. We also need to ensure that the latest tools in medical innovation, such as digital health or artificial intelligence, are racially unbiased and are used for the benefit of all patients (351)(352). It is therefore encouraging that efforts such as the All of Us and AACR Project GENIE are in progress. Nevertheless, there needs to be a stronger, concerted, and continued push from

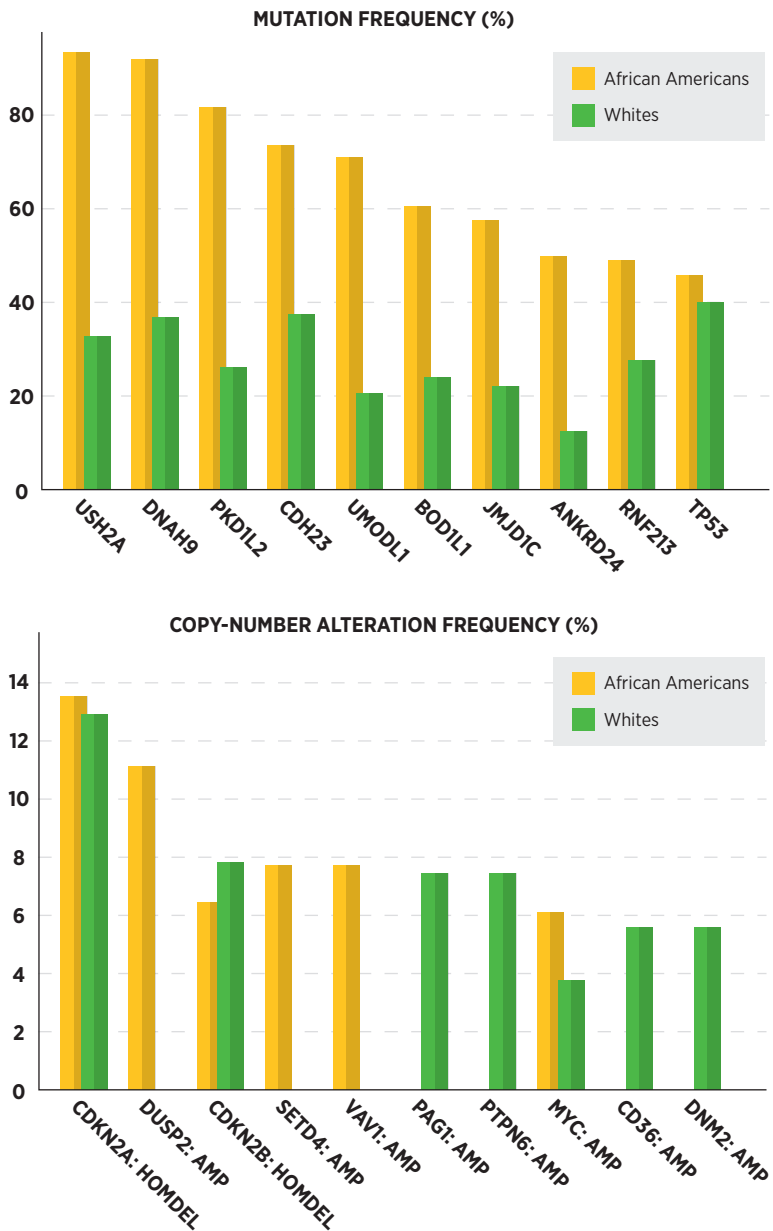
all stakeholders including the government, industry, and the community to develop new guiding principles and policies to understand why these limitations in racial and ethnic diversity persist, and what approaches can be developed to

promote and incentivize inclusion in studies and trials. Only when we make complete measurements of the etiology of cancer across all populations will we see precision medicine truly become precise.

FIGURE 13

Genetic Differences between Cancers from Individuals of Different Races

Most, if not all, cancers are caused by alterations (mutations) to the genetic material of a cell. There are numerous different types of genetic mutations that can lead to cancer, including single base changes, which involve deletion, insertion, or exchange of a single DNA base, and copy number alterations, which involve the deletion or duplication of long stretches of DNA. Knowledge of the genetic mutations that drive cancer has led to the development of molecularly targeted therapeutics that rectify the cellular changes that arise because of the mutations. Molecularly targeted therapeutics are the mainstay of precision medicine. It is increasingly clear that we have limited knowledge of the genetic mutations driving cancer in racial and ethnic minorities, which diminishes the potential of precision medicine in these populations. As shown here using data from the AACR Project Genomics Evidence Neoplasia Information Exchange (GENIE) database, there are differences in the frequency of single base changes (top) and copy number alterations (bottom) in selected genes among African American and white patients. This information is invaluable for future efforts to develop molecularly targeted therapeutics with the potential to benefit African Americans.



Data obtained from AACR PROJECT GENIE; 7.4-consortium; accession date 12/05/2019

Overcoming Cancer Health Disparities through Diversity in Cancer Training and Workforce

IN THIS SECTION, YOU WILL LEARN:

- ▶ A lack of racial and ethnic diversity in the pool of well-prepared trainees and well-trained researchers, and a lack of diversity in the health care workforce, contribute to cancer health disparities.
- ▶ Over the past two decades, diversity-focused training and career development programs have enhanced racial and ethnic diversity in cancer training, although gaps remain throughout the trajectory of the training path.
- ▶ Racial and ethnic minorities continue to be seriously underrepresented in the cancer research and cancer care workforce.
- ▶ Training and workforce diversity must remain a high priority if we are to eliminate cancer health disparities and, ultimately, realize the goal of achieving health equity.

The causes of cancer health disparities are complex and multifactorial, including interrelated biological, social, economic, cultural, environmental, behavioral, and clinical factors (see **Why Do Cancer Health Disparities Exist?**, p. 20). Another important factor that contributes to cancer health disparities is the lack of diversity in the pool of well-prepared

trainees and well-trained researchers, and the lack of diversity in the health care workforce. Given that 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 (353),



U.S. REPRESENTATIVE FOR CALIFORNIA'S 36TH DISTRICT

The Honorable Raul Ruiz, MD

“We need to ensure that we have a diverse cancer care workforce. If you have an oncologist who's from the community and speaks the language that the patient understands, then you have better health outcomes. You also have relief in the systematic bias of physicians going to more affluent communities, and you can promote the physicians going into the more rural underserved areas. In addition to that, we need to address the lack of diversity in the research workforce at the NIH and in other academic settings. If we want to understand the interplay of cancer and the lack of access leading to health disparities in underserved communities and communities of color and minorities, then we should do our research in those communities with those investigators.”

FIGURE 14

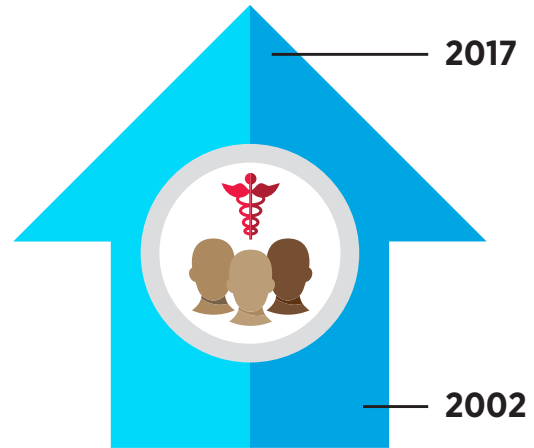
Interrelationships between Enhancing Diversity in Training and the Workforce and Reducing Cancer Health Disparities

Increasing diversity such that the training pipeline and the biomedical workforce are more representative both of our increasingly diverse nation and the populations enduring the unequal burden of cancer will, in turn, ensure that progress in cancer research will reach all populations.



it is clear that everyone must work together to achieve the bold vision of health equity.

Building a diverse cancer research community and biomedical workforce depends on a strong foundation in training and education. Diversity in cancer training, and by extension the workforce, helps ensure the inclusion of new viewpoints, enhances innovation and creativity, and has the potential to assist in addressing cancer health disparities (354-356). Many of the population groups that bear a disproportionate burden of cancer are also significantly underrepresented in the U.S. biomedical research and health care workforce. Increasing representation of racial and ethnic minorities will ensure that the training pipeline and biomedical workforce are more representative of our increasingly diverse nation and the populations enduring the unequal burden of cancer, and, by



Between 2002 and 2017, in the United States, the numbers of African American, Hispanic, and American Indian/Alaska Native medical school matriculants have increased.

However, these minority student populations are still underrepresented relative to their corresponding proportions in the U.S. population (362).

extension, that progress resulting from cancer research will reach all populations. Training and workforce diversity have a dynamic and bidirectional relationship that is required to ensure that disparities in cancer are reduced or eliminated (see **Figure 14**, p. 106). Moreover, a cancer research workforce that reflects its communities ensures an environment for advancing cancer health equity.

With at least 90 percent of the U.S. population growth between 2010 and 2050 expected to come from racial and ethnic minority groups, the issue of training and workforce diversity is more urgent than ever (357). Here, we focus on the disparities among African Americans and Hispanics in the cancer training pipeline and the workforce. We explore the current landscape of training and workforce diversity and provide recommendations that envision how we can best achieve a cancer research training pool and health care workforce that mirror the diversity of our communities.

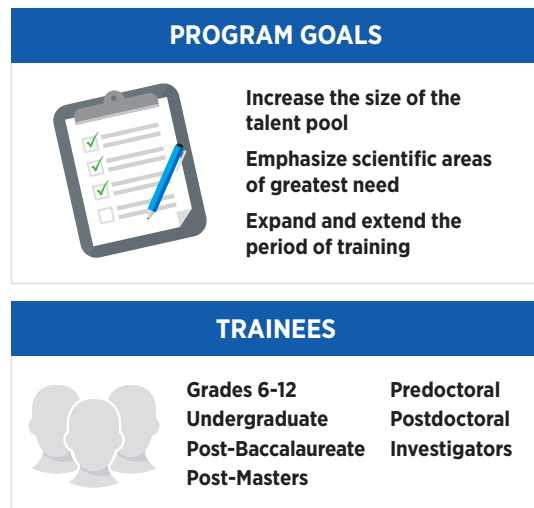
Diversity in Cancer Training

The traditional academic pipeline—starting with K-12 education, through undergraduate and graduate programs, followed by postdoctoral or clinician training, and leading to

FIGURE 15

CURE Program: Continuing Umbrella of Research Experiences (CURE)

The CURE program supports underrepresented students and scientists along their academic and research career pathway, with three primary goals: to increase the pool of well-prepared young students, to emphasize strategic and scientific areas of need, and to expand and extend the period of training so that the trainees are more competitive for achieving research independence.



an independent investigator (including physician-scientist) position—is far from linear.

CANCER TRAINING LANDSCAPE

In the current landscape, underrepresented racial and ethnic minority students do not have opportunities to engage and advance at pivotal points along the training path, from precollege education, through transitioning to and completing college, enrolling in graduate programs, and participating in postdoctoral and early investigator training (358)(359). Consequently, between 2000 and 2018, graduation rates for white and Asian students were higher than for African American students. In addition, the disparity between whites and African Americans in their late twenties who had attained a bachelor’s or higher degree widened over this time period, from 16 to 21 percentage points (360). These

persistent gaps throughout the trajectory of the training path culminate in low representation at the transition into the workforce (361)(360).

To promote cancer research training for diverse populations, CRCHD developed and implemented the Continuing Umbrella of Research Experiences (CURE) program (see **Figure 15**, p. 107). CURE, which supports underrepresented racial and ethnic minority trainees and scientists, employs a holistic approach that promotes mentoring, professional support, and career skills building, all surrounding the centerpiece of individually mentored research experience. To date, CURE has supported over 4,000 students and scientists from middle school to the early investigator level.

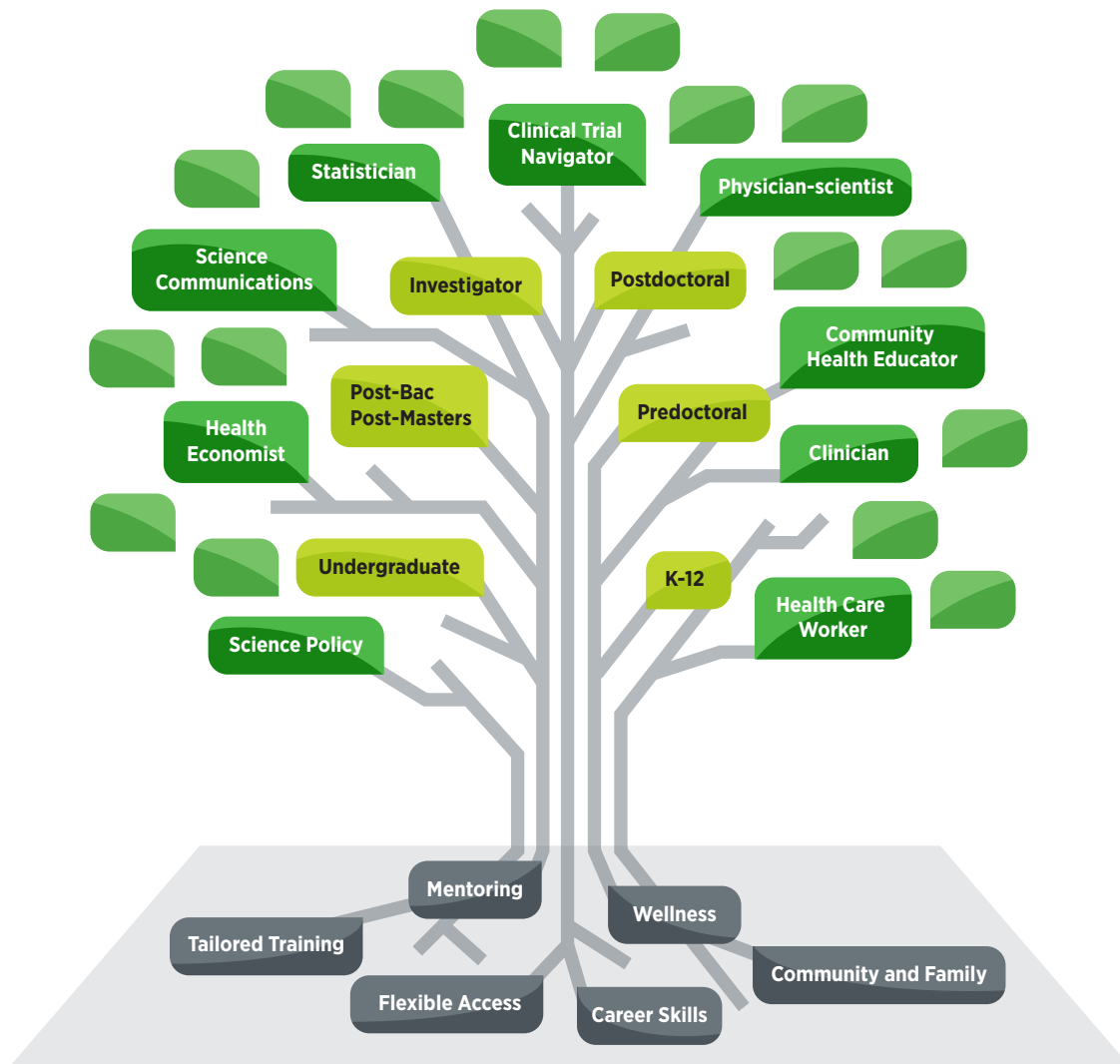
Over the past two decades, many diversity-focused training and career development programs (both federally and privately funded) have been instituted in response to the urgent need to enhance workforce diversity. These programs have been successful and impactful in advancing diversity in cancer training, while also identifying areas for improvement such as the following:

- Narrow academic and career-level focus: most programs focus on one part of the training path (e.g., undergraduate), with no clear strategies to connect students to subsequent career levels.
- Broad population approach: most programs seek to support all underrepresented minority populations, which may neglect to address the specific needs of a particular population.
- Inconsistent program access and support: many programs are concentrated in resource-rich geographic locations and institutions, whereas fewer are found in geographic areas and institutions accessible to underserved populations. Few programs offer intense support including mentoring, didactic courses, career skills building, and other professional development opportunities, while many only provide funding for research experiences.
- Lack of data evidence: evaluation of programs and tracking of trainees vary widely between programs. Almost all programs have anecdotal stories, but few have longitudinal and quantitative data to demonstrate impact.

Fostering racial and ethnic diversity among trainees requires a robust ecosystem of support that is flexible, inclusive, and individualized. Moving into the next decade, in place of the traditional pipeline, cancer research training can be envisioned as a tree in which a diverse cadre of scientists draws nourishment from strong support systems and flourishes into different branches of academic and career achievements (see **Figure 16**, p. 108). Taking the foregoing

Cancer Research Training Tree

Academic and career progression of diverse research trainees is not a linear process and thrives with a rich ecosystem of support forged and sustained by community, family, mentoring, and other enabling and empowering activities.



population- and program-level factors into consideration, several actions are needed to meaningfully strengthen diversity in training (see sidebar on **Recommendations for a Strong and Diverse Trainee Pipeline**, p. 109).

Diversity in the Cancer Workforce

The U.S. health care workforce comprises individuals with earned degrees employed in a variety of career sectors,

including research scientists working in colleges and universities, biotechnology and pharmaceutical industrial settings, and government laboratories; those caring for patients, including physicians, physician-scientists, nurses, nurse practitioners, promotoras, community health educators, and patient navigators; advocates and community-based organizations; and those in science policy and regulatory policy and science communications.

Recommendations for a Strong and Diverse Trainee Pipeline

Build connections and encourage formal partnerships across training programs and workforce entities.



This will allow trainees to recognize and learn to navigate connected pathways between their current positions and positions they wish to attain in the future.

Increase access to training for all trainees.



Using technology to explore alternative training methods may make training more accessible. Developing and widely disseminating research education tools can also enhance training.

Emphasize early interventions for research training.



Education outcome differences begin at a very early stage. It is important to improve K-12 education efforts to minimize disparities for underrepresented racial and ethnic minority individuals later in their education and in their careers.

Provide consistent professional and wellness support.



To maximize the positive impact of a training experience, it is important to institute consistent, holistic professional support for the trainee and nurture the trainee's physical and mental wellness. This is the foundation of a trainee's advancement in their research education and career.

Encourage approaches that are tailored to specific populations.



One size does not fit all in research education and training. Students and scientists from different backgrounds have different needs, and training programs that endeavor to address specific needs will improve recruitment and retention outcomes.

Require the tracking of trainees and evaluation of training programs.



To assess the impact of training efforts and to share best practices, tracking and evaluation standards need to be established and widely accepted. Importantly, evaluation needs to be integrated into program planning from the initial stages through implementation and completion.

Emphasize training in focused areas to address current gaps and anticipate future needs.



These may include cancer health disparities research that engages students in service-learning activities at the graduate and undergraduate levels and, for advanced trainees, special fellowships or additional training opportunities to support a concentration in health disparities and health equity. Additionally, training may emphasize the quantitative science disciplines, including but not limited to big data, -omics, imaging, mathematical modeling, bioinformatics, systems biology, and epidemiology. Strengthening training in these areas will increase the probability of a more diverse workforce in these areas of high potential.

Strengthen the mentoring infrastructure and grow a systematic network of mentors and mentor advocates.



Mentorship is a cornerstone of research training. Mentors offer support and encouragement and model and teach success. It is a priority to develop and broadly distribute evidence-based, culturally inclusive mentorship advocacy training. Mentor training should be part of all training programs so that good mentoring becomes part of the academic and research culture. Team mentoring should be encouraged to better provide diverse perspectives and expertise.

Influence of the Absence or Presence of Diversity

INFLUENCES	IN THE ABSENCE OF DIVERSITY	IN THE PRESENCE OF DIVERSITY
Implicit biases	Stereotyping may persist, directly affecting clinical, scientific, and managerial decision-making.	Diversity can prove the biases to be false and unreliable.
Lack of cultural competence	Cultural incompetence persists, compromising care across the spectrum, from prevention and screening, to treatment, and through survivorship or end of life.	Incompetence and one-size-fits-all care are challenged.
Systematic disparities	Disparities persist, becoming ingrained in the system and corrupting it.	Systematic discrimination and racism can be prevented, ameliorating or averting community- and population-level negative effects.
Creativity	The Center for Talent Innovation concluded that because more than half of leaders base decisions about the value of ideas on their personal experience, innovation can be stifled if leadership is homogeneous ("Diverse leaders unlock innovation"). ¹ The authors recommended that leaders be inclusive and be characterized by innate diversity (similarity to customer base) and acquired diversity (be communicative, suggest creative solutions, and advocate an open environment, accepting of unorthodox views). ²	Heterogeneity in small groups sparks creativity, with positive effects on solutions and ideas. ³ Other characteristics—differences in personality, abilities, and values—have also been defined as "deep-level" diversity. ⁴ McKinsey, the global consulting firm, argues that creating and sustaining a diverse and inclusive environment makes companies more creative, innovative, and profitable. ⁵
Discovery of relational similarity across racial and ethnic lines	Discovery of relational similarity is absent or less probable.	Discovery of relational similarity defies boundaries.

¹ Hewlett S, Marshall M, Sherbin L, Gonsalves T. Innovation, Diversity, and Market Growth. New York: Center for Talent Innovation; 2013.

² Hewlett S, Marshall M, Sherbin L. How diversity can drive innovation. Harvard Business Review [online]; 2013 <https://hbr.org/2013/12/how-diversity-can-drive-innovation>. Accessed June 10, 2019.

³ McLeod P, Lobel S, Cox T, Jr. Ethnic diversity and creativity in small groups. Small Group Research 1996;27:248-64.

⁴ Chamorro-Premusic T. Does diversity actually increase creativity? Harvard Business Review [online] <https://hbr.org/2017/06/does-diversity-actually-increase-creativity>. Accessed June 25, 2019.

⁵ Hunt V, Layton D, Prince S. Diversity Matters. New York: McKinsey and Company; 2014.

Enhancing racial and ethnic diversity in the health care workforce is critically important for many reasons. Such a diverse workforce increases the likelihood of better care for racial and ethnic minorities and other underserved groups, including Medicaid patients and the uninsured; improves patient-physician relationships through greater communication, linguistic concordance, and cultural competence; and results in greater patient adherence and satisfaction with care (363-365). For example, underrepresented racial and ethnic minority women resolved breast cancer and cervical cancer screening abnormalities in a timelier fashion when working with race-concordant and linguistically concordant patient navigators (366). Diversity in the workforce can also mean that implicit biases are less likely to persist, cultural incompetence is less likely to compromise care, and systemic disparities are less likely to become ingrained (see **Table 8**, p. 110). In the context of clinical research, workforce diversity can advance underrepresented minority participation by fostering credibility and making certain that research is culturally competent (367).

CANCER WORKFORCE LANDSCAPE

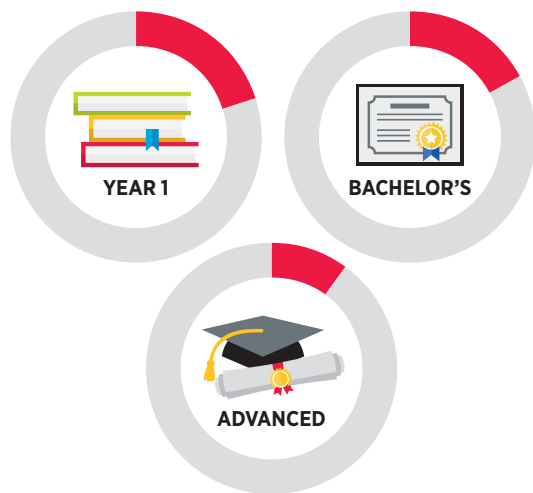
Today, racial and ethnic minorities continue to be seriously underrepresented in the cancer research and care workforce, yet they are the most rapidly growing segment of the U.S. population (368).

Research Scientists

The number of biomedical scientists in the United States grew from 27,500 in 1990 to 69,000 in 2014. However, this growth varied dramatically by race and ethnicity. The percentage of Asians among biomedical scientists, for example, grew from 12 to 34 percent; while the percentage of Hispanics grew from 2 to 6 percent and the percentage of African American biomedical scientists only grew from 1 to 2 percent (369).

Obtaining funding from the NIH, a milestone for promotion and tenure at many academic institutions where much of cancer health disparities research is performed, presents a further challenge. Minority applicants showed a persistent 7.5 percent lower funding rate compared with majority applicants from 2002 to 2016 (371). Of note, funding rates for the NIH's

Minority men and women comprise 20% of the 726,000 first-time freshmen in science and engineering, but only **17% of the 452,000 with bachelor's degrees** in science and engineering, and only **10% of the 145,000 with advanced degrees** in science and engineering (365).



most commonly used grant program, the R01, remained lowest for African American applicants, irrespective of whether they had an MD or PhD degree, with probabilities for funding at 16.6 percent for African Americans, compared with 26.6 percent, 25.3 percent, and 28.7 percent for Asians, Hispanics, and whites, respectively (372).

Physicians

Despite its importance, the diversity of the nation is not proportionately represented within the physician workforce. From 2011 to 2015, for example, the percentage of working age, non-Hispanic white physicians (67 percent) outpaced this group's percentage of the overall U.S. workforce (64 percent) compared with Hispanic (6.3 percent) and African American (4.8 percent) physician representation (see **Table 9**, p. 112). Practicing oncologists in 2016 had similar imbalances, with only 3 percent of these specialists identifying as Hispanic and an even smaller percentage—2.3 percent—identifying as African American (373).

These imbalances in racial and ethnic diversity extend to the academic level, beginning at the level of residents and clinical fellows. African Americans and Hispanics make up only 6 percent and 8 percent, respectively, of all residents and fellows, and 4 percent and 5 percent of

AACR-Minorities in Cancer Research (MICR) is a membership group within the AACR committed to:

- Preventing and curing cancer while **meeting the professional needs and advancing the careers of racial and ethnic minorities;**
- **Addressing the disparities in cancer incidence and mortality** faced by racial and ethnic minorities and other underserved populations; and
- **Advocating for relevant and effective legislation** pertaining to science and public policy.

medical oncology fellows, while constituting 13 percent and 18 percent of the U.S. population (373). At the assistant, associate, and full professor levels, African Americans and Hispanics were more underrepresented in 2016 than they were in 1990 relative to the proportions they constitute of the U.S. population (374).

Physician-scientists care for patients and conduct research. They have a special role to play in addressing cancer health disparities because the dual training provides a unique perspective on how to translate scientific knowledge into progress in health care and health policy. At present, underrepresented racial and ethnic minorities comprise only 10 percent of matriculants in MD-PhD programs (375) (376). Unfortunately, the opportunities for this dual training have lessened over time (377)(378). Issues contributing to the declining number of physician-scientists include increasing student debt, child and family responsibilities, inflexible family leave policies, increasing time to become independent and funded researchers, insufficient protected time for research, and stagnant funding growth (368)(373). The lack of diversity in the physician-scientist workforce is also leading to a corresponding lack of diverse role models and mentors (374).

Other Health Care Professionals

The underrepresentation of minorities extends beyond research scientist and physician occupations. According to one survey, African Americans, American Indians/Alaska Natives, and Hispanics make up only 6.4 percent, 0.4 percent, and 5.3 percent, respectively, of registered nurses in the United

Health and Social Services Occupations by Race and Ethnicity—2011–2015

	NON-HISPANIC		NON-HISPANIC				
	White	Hispanic	Black	Asian	American Indian/ Alaska Native	Native Hawaiian and Other Pacific Islander	Multiple/ Other Races
U.S. Workforce (%)	64.4	16.1	11.6	5.3	0.6	0.2	1.8
Health Diagnosing and Treating Practitioners Occupations							
Dietitians and nutritionists (%)	68.7	8.5	15.0	6.0	0.3	(0.1)	1.4
Nurses (%)							
Advanced practice	84.0	4.5	5.7	4.1	0.2	NR	1.3
Registered	73.5	5.7	10.4	8.4	0.4	0.1	1.5
Pharmacists (%)	70.4	3.7	5.9	17.9	0.2	0.1	1.8
Physicians (%)	67.0	6.3	4.8	19.6	0.1	0.0	2.1
Community and Social Services Occupations							
Social Workers (%)	60.6	12.0	21.5	3.0	0.8	0.1	2.0

Source: Adapted from Health Resources and Services Administration, Sex, Race, and Ethnic Diversity of U.S. Health Occupations (2011–2015) (Rockville, MD: Health Resources Services Administration; 2017).

Note: Populations are arranged from largest to smallest, left to right. Though we commonly associate the percentage of total population each group represents, in this table, because it considers the proportion of the population in the workforce, percentages of each group are somewhat lower than those values.

States (379). Furthermore, underrepresented racial and ethnic minorities comprise only 9 percent of dentists who are often at the front line of diagnosing oral cancers (380).

Urgent and immediate actions are necessary to strengthen diversity in the cancer workforce (see sidebar on

Recommendations to Enhance Racial and Ethnic Diversity in the Cancer Workforce, p. 113).

Achieving Health Equity through a Strong and Diverse Future Workforce

Enhancing diversity in training and the cancer workforce will expand the perspectives included and represented, fuel creativity, and make the training pipeline and workforce more reflective of our increasingly diverse nation and the populations bearing the unequal burden of cancer. Most importantly, enhancing diversity in cancer training and workforce is vital to effectively addressing cancer health disparities. Achieving a truly diverse and inclusive cancer research and care workforce is not only motivated by ethics and social justice, but also is essential to ensure top-quality scientific performance and cancer care. Succeeding

in this endeavor requires dedicated commitment and concerted efforts from all stakeholders, including private and academic institutions, training institutions, federal agencies, industry entities, professional organizations, and individuals from all backgrounds.

In this chapter, we have described the biomedical research training pipeline and biomedical research and health care workforce, examined the current landscapes, and offered recommendations for attracting and engaging a diverse pool of students and trainees and building a broad, skilled, and diverse workforce for the biomedical sciences—essential steps to reduce the burden of cancer for an increasingly diverse America.

Moving forward, it is critically important to provide more funding and create and support policies to ensure that we continue to advance training and workforce diversity in cancer. In addition, we must continue to evaluate whether these efforts are enhancing diversity in the biomedical and, in particular, the cancer workforce. Training and workforce diversity must remain a high priority if we are to realize the goal of eliminating cancer health disparities and, ultimately, achieving health equity.

Recommendations to Enhance Racial and Ethnic Diversity in the Cancer Workforce

ENHANCE DIVERSITY IN RECRUITMENT AND RETENTION PRACTICES.



To increase diversity in academia and industry, it will be important to develop environments where diverse candidates are hired and can advance at the same speed as nondiverse candidates. In academia, the opportunities for promotion must be equal across races and ethnicities; unconscious biases must be addressed systematically across an organization; and hiring committees should be of a diverse makeup, be able to develop a diverse pool of applicants, and utilize objective inputs for candidate selection. Industry should focus on diversity at the board of directors' level, build partnerships with academic institutions, and create or augment hiring policies/practices that are responsive to and accountable for diversity, including encouraging diversity in job candidates and deidentifying resumes in the review process.

INTERINSTITUTIONAL PARTNERSHIPS WITH MINORITY-SERVING INSTITUTIONS TO ENHANCE PIPELINE AND CAREER OPPORTUNITIES.



Many institutions, especially minority-serving institutions (MSIs), lack access to the expertise and facilities necessary to provide training in industry-relevant biotechnology skills. This limits underrepresented minority researchers' participation in the pharmaceutical/biotechnology workforce, hinders minority-led translational research, and reduces opportunities for MSIs to monetize technologies and generate minority-led start-up companies. Facilities are also needed that provide opportunities to learn and implement industry-related skills, understand drug discovery and its role in benefiting society, obtain data for and mentor the writing of Small Business Innovation Research/Small Business Technology Transfer grants, and potentially develop spin-off companies. Additionally, there is a need for more inter-institution level partnership programs, such as the NCI CRCHD Partnerships to Advance Cancer Health Equity (PACHE) program. PACHE promotes the development of partnerships between institutions serving underserved health disparity populations and underrepresented students (ISUPS) and NCI-designated Cancer Centers (CCs). Such partnerships build and strengthen the research infrastructure at ISUPS while expanding cancer health disparities research capacity at CCs, and in the process train diverse students and scientists at both institutions.

PROMOTE CONTINUAL PROFESSIONAL AND LEADERSHIP DEVELOPMENT WITH ACCESS TO MENTORS AND CAREER GROWTH OPPORTUNITIES.



Academic institutions can offer more mentoring and leadership training and/or professional development to prepare students, faculty, and employers for a broad array of careers, including in industry, as some graduates have difficulty identifying opportunities, many are not pursuing tenure-track positions, and others seek a private sector position after an initial foray into academia. It will also be important to support more interprofessional centers of excellence, with shared responsibilities for minority leadership and involvement.

PROVIDE OPPORTUNITY, MENTORSHIP, AND PROTECTED TIME FOR ALL RESEARCHERS.



There is a critical need to attract, train, and retain scientists in the biomedical enterprise. Key training components include exposure to solving a scientific problem, mentorship, and role models. This can be achieved initially at the graduate training level through funding opportunities. Protected time after required postdoctoral training for all researchers, and for physicians after clinical training, is also important, as is continued mentorship on initial publications and how to apply for grants. Additionally, loan repayment programs remain a big need due to the cost of graduate and medical school and the high debt burden. To further support the development of underrepresented minority researchers and leaders, it is necessary to create programs aimed at minorities toward the end of their training that can provide support in terms of research funding and guidance.

SHOWCASE ROLE MODELS AND THE SUCCESS OF CURRENT RESEARCH.



Diverse members of the biomedical workforce need to be visible as potential role models for students and trainees. Additionally, cancer health disparities research can showcase how it positively changes the approach to health care and the success of interventions for individuals and groups.

Overcoming Cancer Health Disparities through Science-based Public Policy

IN THIS SECTION, YOU WILL LEARN:

- ▶ Federal agencies including the NIH, NCI, CDC, and FDA play an important role in addressing cancer health disparities, and funding for vital research and innovative programs at these important government agencies is critical for making progress.
- ▶ Strong public health policies can help reduce cancer health disparities by improving prevention and early detection of many cancers.
- ▶ Recommendations exist for improving diversity in clinical trial enrollment, but actions are needed to make sure these recommendations are put into practice.
- ▶ Policy changes are needed to increase access to health care for racial and ethnic minorities and other underserved populations, as well as to improve the quality of care they receive.
- ▶ Promoting policies to encourage the collection and reporting of race/ethnicity data in clinical research will provide key information for future actions that are required to reduce cancer health disparities.

The efforts of the federal government are extremely important in our efforts to meaningfully reduce cancer health disparities (see sidebar on **Impact of Congressional Caucuses**, p. 115). However, achieving this goal will also require a multipronged approach that supports individuals, communities, health centers, and local, and state governments to resolve disparities in cancer prevention, screening, treatment, survivorship, and precision medicine.

In this chapter, policy-based solutions will be presented for Congress and federal departments and agencies, including HHS and its relevant operating units, the NIH, the NCI, the FDA, and the Centers for Disease Control and Prevention (CDC), among others. Federal coordination, program management, research prioritization, and funding are policy levers that can accelerate the reduction of health disparities across the cancer care continuum.



U.S. REPRESENTATIVE FOR OKLAHOMA'S 4TH DISTRICT

The Honorable Tom Cole

Cochair, Congressional Native American Caucus

“During my tenure in the House, I have recognized and promoted the importance of funding disease research in order to find more cures. While I was Chairman of the House Appropriations Committee which funds the Department of Health and Human Services, I was proud to help shepherd yearly increases for the National Cancer Institute. Since fiscal year 2016 while I was serving as Chairman, annual funding has increased from \$5.21 billion to nearly \$6.25 billion. This year, I am proud that the additional funding I fought for to increase NCI research grants and success rates was included in the final bill funding the National Institutes of Health.”

Impact of Congressional Caucuses

There are a number of Congressional Membership Organizations that bring members of Congress together around common interests and causes. These include the caucuses listed below, which each have a long history of promoting the interests of racial or ethnic minority communities through legislation, briefings, summits, and other activities. Each of these caucuses is actively engaged in reducing health disparities.

CONGRESSIONAL BLACK CAUCUS

The Congressional Black Caucus (CBC) was established in 1971 with a commitment to empower African Americans and other marginalized communities in the U.S. One of the policy priorities for the Caucus is to expand access to affordable, quality health care and eliminate racial health disparities. The CBC Health Braintrust serves as a platform for advancing legislative and policy solutions that will lead to greater health equity.

CONGRESSIONAL HISPANIC CAUCUS

The Congressional Hispanic Caucus (CHC) was founded in December 1976 to address issues and craft policies that impact the Hispanic community throughout the United States, Puerto Rico, and the Commonwealth of the Northern Mariana Islands. The Caucus has a Healthcare Task Force that focuses on issues including access to affordable care, promoting public health, and addressing health disparities for Hispanics.

CONGRESSIONAL ASIAN PACIFIC AMERICAN CAUCUS

The Congressional Asian Pacific American Caucus (CAPAC) was established in 1994 and is committed to promoting the well-being of the Asian American and Pacific Islander (AAPI) community. CAPAC works to establish and advance legislation and policies that reflect the needs of AAPI community members. The CAPAC Healthcare Task Force has a mission to eliminate health disparities and improve access to health care for Asian Americans and Pacific Islanders.

CONGRESSIONAL NATIVE AMERICAN CAUCUS

The Congressional Native American Caucus was founded in 1997 with a commitment to advancing the federal government's nation-to-nation relationship with tribal governments. The Caucus works to amplify the voices of American Indians, Alaska Natives, and Native Hawaiians across a broad range of policy issues, including health, by maintaining close relationships with tribal nations and their representatives, convening briefings, and sharing information on legislative proposals impacting Native Americans.

Funding for Research and Programs That Address Disparities and Promote Health Equity

Robust funding for key programs and initiatives at the NIH, NCI, FDA, and CDC is vital in our efforts to understand and address cancer health disparities. Research programs that incorporate a disparities focus can enhance our knowledge of factors that lead to poorer health outcomes in different populations. For example, the NIH's All of Us program, funded by the 21st Century Cures Act, emphasizes inclusion of historically underrepresented populations to improve precision medicine research. Additionally, the NIMHD, which is part of the NIH, is a global leader in supporting research on the many factors that lead to disparate health outcomes, including nonbiological variables such as socioeconomic, politics, discrimination, culture, and environment.

The NCI has many programs that aim to reduce cancer disparities (see sidebar on **NCI Programs That Address Disparities in Cancer Prevention and Care**, p. 116). Continued, robust funding for these programs is essential to reach patients who may often be underrepresented in cancer research and to build the capacity of researchers working to reduce cancer disparities. For example, the NCORP brings clinical research studies directly to individuals in communities across the country and actively seeks to include minority and underserved individuals in its programs. The NCI CRCHD plays an important role in supporting research on cancer disparities as well as providing training to the next generation of competitive researchers from diverse populations in cancer and cancer health disparities research.

The CDC also leads many programs that are critical to addressing cancer disparities, including the National Program of Cancer Registries (NPCR), the National Breast and Cervical Cancer Early Detection Program, Racial and

NCI Programs That Address Disparities in Cancer Prevention and Care

The 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 seven 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.

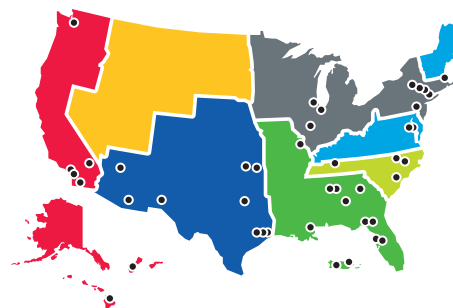


The **NCI Center to Reduce Cancer Health Disparities (CRCHD)** was established in 2001 to help reduce the unequal burden of cancer in our society through strengthening the NCI's research portfolio in disparities research, building interinstitutional partnerships and regional networks to foster collaboration 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.

Ethnic Approaches to Community Health (REACH), and the Colorectal Cancer Control Program. Federal funding for these programs allows the CDC and its local partners to collect data and reach individuals in diverse communities with key services and information.

Collaborative Resources to Advance Research for Health Equity

As discussed earlier in the report (see **Why Do Cancer Health Disparities Exist?**, p. 20), disparities in cancer health outcomes are due to a mix of social, clinical, biological, and environmental

REACH



CDC Racial and Ethnic Approaches to Community Health (REACH)

CDC's 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 (386).

factors, and there is ongoing research to investigate the complex interplay among these factors. Government agencies, private funders, and the research community have been collaborating on efforts to identify, prioritize, and generate resources that can support and advance such research.

Social determinants of health, including racial, ethnic, socioeconomic, and environmental factors, impact cancer care and outcomes. In the U.S., there is increasing recognition of the importance of documenting, analyzing, and improving the way social determinants of health impact individuals' health, as reflected in the HHS domestic health strategy document, *Healthy People 2020*. However, there are not yet consistent methods for defining and collecting data on social determinants of health. For example, most health researchers include demographic characteristics such as area of residence, education level, geographic origin, and genetic ancestry, while some researchers also include characteristics such as language fluency, health literacy, housing, and food security. At a recent workshop of the National Cancer Policy Forum of the National Academies, participants agreed that the most useful immediate action would be for the federal government to convene stakeholders to develop a consensus on standard language and definitions

for social determinants of health, as well as to create an efficient process to elicit and document these characteristics during patient care and in research studies. As methods are developed to collect this information from patients, for example through the electronic health record, it will be important to address patient privacy concerns through appropriate safeguards.

Precision medicine promises to transform medical care by creating tailored treatments for individual patients depending on their specific genetic background (see **Imprecision of Precision Medicine**, p. 100). To ensure that these new medical advances help to reduce cancer health disparities, it is critical that sample and data repositories include representation from individuals of diverse racial and ethnic backgrounds. Furthermore, patients from these groups should be provided appropriate genetic counseling in order to understand and make informed choices about their care based on their genetic information.

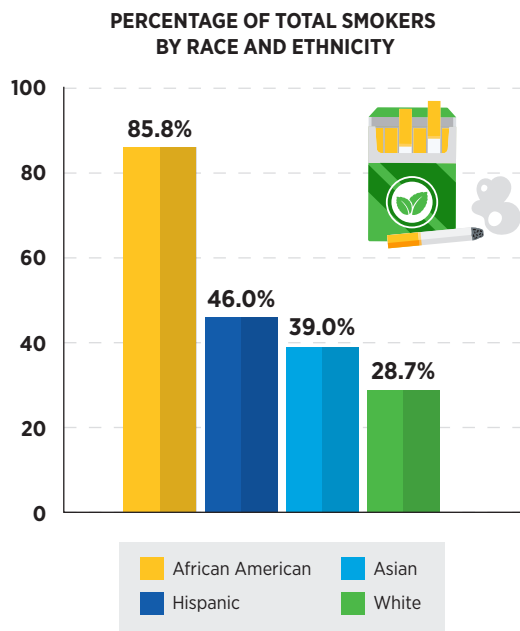
While TCGA and similar projects focus on genetic information from individuals with cancer, the NIH's All of Us Research Program is gathering information from the genomes of one million healthy individuals. The program was designed to recruit from groups historically underrepresented in biomedical research, and 80 percent of the initial cohort of 230,000 individuals come from such groups, including racial and ethnic minorities, rural residents, and sexual and gender minorities (349). The All of Us program will also provide genetic counseling to all of its participants, ensuring that it is a valuable resource for studying and narrowing health disparities.

Public Health Policies to Regulate and Reduce the Use of Tobacco Products

Tobacco use is the leading preventable cause of cancer and cancer-related deaths and has been linked to 18 different cancers (see **Disparities in the Burden of Preventable Cancer Risk Factors**, p. 43). Lung cancer is the leading cause of cancer death in the United States and a disproportionate number of racial and ethnic minorities die from this disease. Policy interventions such as smoke-free laws, added taxes on tobacco products, limitations on advertising for tobacco products, smoking cessation programs, and public health campaigns have succeeded in lowering the national smoking rate over the past 50 years. However, these policies have had limited benefits for racial and ethnic minority groups.

Differential tobacco product use by racial and ethnic minority groups is linked to differences in marketing and regulation of tobacco products used by minority groups. The prime example of this is the continued availability of menthol cigarettes—a tobacco product favored by African American

African Americans and other racial and ethnic minority groups are **more likely to smoke menthol cigarettes** (382).



smokers—following a federal ban on other flavored cigarettes. Menthol cigarettes constitute about one-third of the total cigarette market, and are preferred by African Americans, young people, women, Hispanics, and those with lower socioeconomic status. Insider documents from tobacco companies revealed that in order to maintain or increase market share for menthol cigarettes, African American and urban neighborhoods were specifically targeted with aggressive marketing and sales tactics (381).

Menthol cigarettes have been associated with numerous public health problems, including increased initiation of smoking and progression to habitual smoking particularly for young people, increased craving of and dependence on cigarettes, and reduced success in smoking cessation particularly for African American smokers (144). Menthol’s cooling and anesthetic properties mask the harsh taste of tobacco and feel of cigarette smoke. Yet when Congress banned flavored cigarettes through the 2009 Family Smoking Prevention and Tobacco Control Act (Tobacco Control Act), lawmakers allowed the popular menthol cigarettes to remain on the market and asked the FDA to determine the impact of menthol cigarettes on public health.

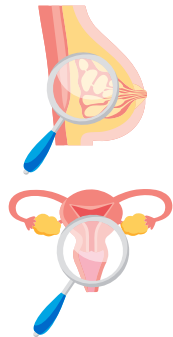
In 2011, the FDA Tobacco Products Scientific Advisory Committee (TPSAC) delivered its mandated report recommending that “removal of menthol cigarettes from the marketplace would benefit public health in the United

States” (383). Subsequently, the FDA was sued by tobacco companies and a judge ruled that the agency could not act on the advice of the TPSAC. The FDA appealed and the ruling was overturned in January 2016, allowing the agency to use the TPSAC report to inform rulemaking. The FDA also conducted its own independent evaluation of the public health effects of menthol cigarettes and similarly concluded that it was “likely that menthol cigarettes pose a public health risk above that seen with nonmenthol cigarettes (383).” Despite the 2016 court ruling and the consensus of internal and external experts on the negative public health impact of menthol cigarettes, the FDA has not issued any final regulation banning menthol cigarettes. The agency has issued several advanced notices of proposed rulemaking and made announcements that it intends to remove menthol cigarettes, but to date has not followed through on its intentions. The AACR and public health groups have repeatedly called on the FDA to remove menthol cigarettes from the marketplace, including through a formal Citizen Petition in 2013 (384).

The continued availability of menthol cigarettes in the marketplace contributes markedly to the national smoking rate and to disparities in tobacco use and subsequent disease. There are several policy mechanisms to address these disparities, including FDA regulatory action as well and Congressional legislation that directs the FDA to exercise its regulatory authority. Local governments have begun to consider banning menthol cigarettes within their localities, beginning with San Francisco in 2018. The debate over flavors in tobacco products heated up in 2019 in response to the epidemic rise in use of electronic cigarettes (e-cigarettes), which was sparked in part by flavored e-cigarettes. The federal government, states, and localities all have instituted or have considered instituting bans on flavored e-cigarettes. As public discourse, regulation, and legislation advance on flavored e-cigarettes, it is important to remember the role that menthol cigarettes continue to play in maintaining the national smoking rate.

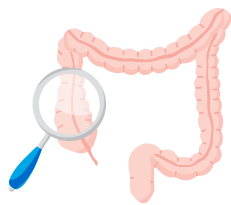
Some opponents of a federal ban on menthol cigarettes fear that it would result in enforcement actions on consumers, who are primarily minorities. A federal ban implemented by the FDA would set limits on menthol product content for cigarette manufacturers. States and localities are instituting bans on the sale of menthol cigarettes. Federal, state, and local policy actions should make it clear that compliance is directed at manufacturers and retailers, not consumers. From a public health perspective, surveys show that almost half of menthol smokers would quit if menthol cigarettes were not available. Menthol cigarettes continue to be a growing share of the cigarette market, so removing menthol cigarettes would contribute to further lowering the smoking rate. Given the fact that menthol makes it harder to quit smoking, it will be important to couple a ban on menthol cigarettes with

CDC and NCI Cancer Screening Programs



Since its inception in 1991, the 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

pre-malignant 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 pre-malignant lesions.



The CDC **Colorectal Cancer Control Program** was established in 2015 to increase colorectal cancer screening rates. It currently includes 679 clinics that serve more

than 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 10.1 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.

smoking cessation resources and programs to support those who are addicted, especially African Americans and those from other racial or ethnic minority groups.

Achieving the Elimination of Cervical Cancer in the U.S. by Addressing Disparities

Cervical cancer is one of the most highly preventable cancers because of effective vaccines for the causative agent, HPV, as well as available screening and treatment

methods for precancerous cervical lesions. Because of these preventative measures as well as available treatment for invasive cervical cancer, the elimination of cervical cancer as a public health concern (defined by the World Health Organization as an incidence of 4 or fewer cases per 100,000 women) is now an ambitious but feasible goal by 2030 in the United States. The public health strategy for cervical cancer elimination includes improved HPV vaccine coverage to 80 percent of eligible adolescents, increased screening and treatment of cervical precancer to 93 percent of eligible women, and prompt treatment of invasive cancers. But the elimination of cervical cancer as a public health concern cannot be achieved in the United States without addressing the current disparities in cervical cancer incidence and mortality rates. Although overall cervical cancer incidence and mortality in the United States have been decreasing, African American and Hispanic women still have higher rates of cervical cancer incidence and death than white women and non-Hispanic women, respectively (see **Tables 1 and 2**, p. 14 and p. 15).

Recent HPV vaccination rates are nearing parity between racial and ethnic minority groups, but HPV vaccination rates for all groups are still below the Healthy People 2020 goal of 80 percent of eligible adolescents. Long-standing racial and ethnic gaps in HPV vaccination have narrowed in recent years for young adolescents, in part due to insurance coverage through the Affordable Care Act and Medicaid expansion. In 2018, African American, Hispanic American, Asian American, and multiracial American adolescents were all vaccinated at the same rate or significantly higher rates than white American adolescents (32). Still, only 51.1 percent of adolescents ages 13 to 17 received the full course of HPV vaccination in 2018. Continued coverage of HPV vaccines by health insurance is important for patient access, and culturally sensitive and tailored communication between providers and parents or patients is critical to improving vaccination rates among minority groups.

There are ongoing disparities observed in cervical cancer screening and treatment. Lower cervical cancer screening rates are observed for Hispanic women, women who are less educated, and women living in poverty (see **Disparities in Cancer Screening for Early Detection**, p. 59). African American and Hispanic women are less likely than white women to receive the treatment that is recommended by clinical guidelines (385). To close the gaps in cervical cancer screening and treatment, expanded funding and implementation are needed for programs such as the CDC's National Breast and Cervical Cancer Early Detection Program, which currently provides nearly 139,000 low-income, uninsured, and underinsured women annually with access to screening, diagnostic, and treatment services (see sidebar on **CDC and NCI Cancer Screening Programs**, p. 119). As further discussed below, greater efforts are needed to provide underserved

minority patients with access to better quality care, which in this case means guideline-recommended treatment for invasive cervical cancer.

Policies to Address Obesity, Poor Diet, and Physical Inactivity

Addressing cancer prevention disparities in obesity, nutrition, and physical activity will require research to better understand the social determinants of health that impact these disparities. For example, the HHS and the U.S. Department of Agriculture (USDA) publish the Dietary Guidelines for Americans every five years as a source for Americans on nutrition. However, the 2015 Guidelines Advisory Committee was not able to address disparities in nutrition because of a lack of literature in this area. Future efforts would be supported by more funding of research on disparities in nutrition.

Community programs such as those funded by the CDC Racial and Ethnic Approaches to Community Health demonstrate how to encourage individual behaviors such as physical activity, nutrition, and obesity reduction. There

also needs to be an evaluation of how to impact structural determinants of health that affect communities, for example, factors such as food deserts, sidewalks and green space for activity, and noise and light exposure that disrupts sleep. This work will require input from and collaboration with sectors outside the health sector. Real progress will require prioritization at an interagency level or through legislative directives from Congress.

Policies to Address Disparities in Cancer Screening

Screening rates for several cancers are lower in racial and ethnic minority groups than in the general population (see **Disparities in Cancer Screening for Early Detection**, p. 59). Mechanisms to reduce screening disparities include funding research studies to define the biological and environmental differences in disease etiology between populations, improving tests and updating screening criteria for high-risk minority groups, and supporting patient access to and utilization of screening tests (see sidebar on **National Cancer Policy Forum Workshop on Cancer Screening**, p. 120).

National Cancer Policy Forum Workshop on Cancer Screening



A recent **National Cancer Policy Forum** workshop on “**Advancing Progress in the Development and Implementation of Effective, High-quality Cancer Screening**” brought together researchers from academia, industry, cancer research organizations and foundations, and federal agencies including the NCI, CDC, and FDA to discuss strategies that may improve cancer screening uptake within the U.S. population. A major goal of this workshop was to identify opportunities to reduce cancer health disparities by increasing access to quality cancer screening and timely follow-up among underserved populations.

Among the barriers to equitable cancer screening for underserved populations identified by the workshop participants were lack of access to health care due to factors such as hospital closures, living in remote rural areas, lack of insurance, and inability to afford care because of high deductibles; the presence of other co-existing health issues that prevent individuals from

seeking cancer screening; mistrust of the health care system; and disabilities. Barriers to timely follow-up of abnormal screening results included many of the same patient-related factors that pose barriers to screening, as well as clinical and/or organizational factors such as lack of awareness of abnormal screening results among physicians, lack of effective communication between health care providers and patients, and scheduling and other logistical challenges.

Addressing these challenges will require a better understanding of population-specific barriers from both patient and provider perspectives, followed by the development of evidence-based interventions. Potential steps to mitigate these challenges include enhancing existing public health programs such as those implemented by the CDC and FDA; a greater focus on rural health with utilization of new systems such as telemedicine and digital technologies; better use of electronic health records; and reinforcement of resources available at community health clinics. Continued research is also needed to identify ways to improve shared decision making for cancer screening, including the use of decision aids that may enhance patient knowledge about the potential risks and benefits of the tests and thereby actively engage patients in their health care.



U.S. REPRESENTATIVE FOR CALIFORNIA'S 37TH DISTRICT

The Honorable Karen Bass

Chair, Congressional Black Caucus

"The CBC has a long history of fighting against health disparities to improve outcomes in our communities. That is why we championed key provisions in the Affordable Care Act, like providing increased funding for community health centers. This landmark legislation allows people to access preventative screenings like colonoscopies and mammograms, which are often inaccessible to low income communities."

NIH Genetic Studies on Cancer Health Disparities



The **NCI Breast Cancer Genetic Study** is the largest study to investigate the biological and genetic factors that contribute to breast cancer in African American women. The study will compare the genomes of 20,000 African American women without breast cancer and 20,000 African American women with breast cancer to identify these factors and will also cross-compare to the genomes of white women (387).

The **NIH-Prostate Cancer Foundation RESPOND Study** will investigate the genetic and environmental factors, including social determinants of health, that influence prostate cancer development in African American men. Through the enrollment of 10,000 patients, the study will examine possible associations between aggressive disease and environmental and genetic factors (350).

There are gaps in current knowledge about how biological and environmental differences between groups contribute to the development and progression of specific cancers. There is a significant need for funding and infrastructure to investigate and identify the underlying genetics, biomarkers, and other factors that indicate advanced disease progression. The NCI coordinates two such research studies to examine differences in cancer etiology—the NCI Breast Cancer Genetic Study in African American women and the NIH-Prostate Cancer Foundation RESPOND study (see sidebar on **NIH Genetic Studies on Cancer Disparities**, p. 121). These two studies will provide valuable data that can be used to inform breast cancer and prostate cancer screening protocols for high-risk African Americans. It will be important to ensure that the results from these two studies are translated into guidelines and programs such as genetic testing and counseling. Increased funding and infrastructure are critical to support additional research studies in other cancers, as well as program implementation.

The USPSTF is responsible for reviewing evidence for clinical preventive services, reporting research gaps to Congress and the health community, and providing recommendations for screening and other preventive services. In its 2018 report, the USPSTF noted important research gaps in screening for

cervical cancer among diverse populations, including studies to identify and evaluate effective strategies to reach unscreened and inadequately screened women (388). The USPSTF also identified research gaps in screening for prostate cancer among African American men and men with a family history, including studies to develop and validate tools and tests to distinguish between slow-growing and aggressive prostate cancer. It is the responsibility of research agencies such as the NCI to prioritize and fund research to fill the gaps.

The research evidence base must be promptly translated into customized screening guidance for at-risk groups. A recent study found that the current USPSTF screening guidelines for lung cancer identified only 32 percent of African Americans with lung cancer in the study population, compared to 56 percent of whites (389). African Americans in the cohort study tended to develop lung cancer at earlier ages and after fewer pack-years of smoking. Researchers recommended that the USPSTF screening guidance account for race-related differences in risk and lower the age and smoking history criteria required to deem African American smokers eligible for lung cancer screening. It is also important to note that African Americans were underrepresented (4 percent) in the initial study population used for the development of the USPSTF lung cancer screening guidance (389).

Studies such as this highlight the importance of prioritizing research on disease etiology in minority populations and translating the resulting evidence into customized screening criteria for populations with different levels of risk. The Congressional Tri-Caucus has recognized this as an important issue, putting forth a legislative proposal in the Health Equity and Accountability Act of 2018 to direct the Secretary of HHS to convene experts to develop guidelines for disease screening in minority populations that have higher than average risk for chronic diseases including cancer.

Another mechanism for closing screening gaps is requiring public and private insurance to cover cancer screenings as essential health benefits for patients. For example, the Affordable Care Act requires Marketplace plans to provide without cost-sharing colorectal cancer screening for adults ages 50 to 75, tobacco use screening, and lung cancer screening for adults ages 55 to 80 who are at high risk for lung cancer (390). Research examining the effects of the Affordable Care Act and Medicaid expansion shows mixed impact on the utilization of cancer screening services in minority populations. The evidence suggests that insurance coverage may be necessary to provide access to these services, but other approaches are needed to promote utilization of screening tests.

Beyond providing minority populations with greater access to evidence-based screening tests, additional efforts including patient engagement, education, and local community outreach services are important to increase cancer screening rates. The NCI National Outreach Network and Screen to Save: National Colorectal Cancer Outreach and Screening Initiative (see sidebar on **CDC and NCI Cancer Screening Programs**, p. 119) help provide resources, materials, and infrastructure for outreach and education. The CDC works extensively to increase access to and utilization of cancer screening services through local and community programs funded by the National Breast and Cervical Cancer Early Detection Program and the Colorectal Cancer Control Program (CRCCP). The CRCCP currently funds clinics and health systems through 23 states, six academic centers, and one tribal grantee. Clinics that have been enrolled for the past three years of the program have increased screening rates by 10.1 percent. Increased funding would enable the program to expand to other states, where there is an ongoing need to address disparities in colorectal cancer screening. Continued funding support for these programs is critical, and similar programs for other cancers such as prostate and lung cancer should be considered.

Diversifying Representation in Clinical Trials by Addressing Barriers in Trial Design

Historically, clinical trial populations have been relatively homogeneous, leading to the approval of medical products

that have not been adequately tested in a real-world, representative sample of the patients who will use them (see **Disparities in Cancer Treatment**, p. 73). There are ongoing government and stakeholder initiatives to broaden clinical trial participation, but more must be done to prioritize these activities and consider how to incentivize or require the participation of academic and industry decision makers.

Eligibility criteria for clinical trials represent patient characteristics that are used to include and exclude patients for clinical trial enrollment. These criteria are intended to protect patient safety by limiting adverse events during testing of new investigational agents, but often exclusion criteria are used by default due to historical precedent. In 2018, the NCI broadened its recommended eligibility criteria for NCI-sponsored clinical trials, building on a stakeholder initiative begun by the American Society of Clinical Oncology and the Friends of Cancer Research (287). The NCI guidelines support greater inclusion of patients who were previously excluded due to brain metastases, HIV/AIDS status, organ dysfunction (that is, liver, kidney, and heart), prior and current malignancies, history of HBV or HCV, and pediatric status (391). While the NCI guidelines are a welcome first step, they do not address the exclusion of patients with common chronic conditions such as hypertension and diabetes, which leads to the exclusion of many underrepresented minority patients.

In 2019, the FDA issued a draft guidance for industry with its recommendations to enhance the diversity of clinical trial populations, developed following a public stakeholder workshop (see sidebar on **FDA Recommendations for Broadening Eligibility Criteria, Enrollment Practices, and Trial Design**, p. 123) (392). In addition to covering the issues raised in the NCI guidelines, the FDA guidance also addresses two primary reasons for the exclusion of patients with common chronic conditions: 1) concerns that patients may experience more adverse effects because the drug interacts with other medications the patient takes, and 2) concerns that these patients may add noise to the data, making it more difficult to determine the investigational drug's safety or effectiveness. Through the use of adaptive trial design, earlier or additional analysis of patients with comorbidities, and progressive relaxation of exclusion criteria, drug developers can broaden their clinical trial populations without reducing the chances of successfully measuring efficacy and safety. The guidance, while not legally enforceable, reflects the FDA's current thinking and presents recommendations for companies to consider during drug development.

Improving the workforce diversity of those who are designing clinical trials will provide an opportunity to bring in new ideas that could revolutionize the conduct and representation of clinical trials (see **Overcoming Cancer Health Disparities through Diversity in Cancer Training and Workforce**, p. 105). It will be important to include and

FDA Recommendations for Broadening Eligibility Criteria, Enrollment Practices, and Trial Design



- Examine each exclusion criterion and tailor it as narrowly as possible. For example, include patients with milder heart disease while excluding those with advanced heart failure.
- Eliminate or modify restrictive exclusion criteria as trials progress from phase II to III.
- Base exclusions on an appropriate measure of organ dysfunction that does not lead to unnecessary exclusion.
- Include children and adolescents in confirmatory clinical trials with adults.
- In early clinical development, characterize drug metabolism and clearance in populations that may metabolize or clear the drug differently, to prevent future exclusions.
- Consider utilizing adaptive clinical trials, which allow initiation with a narrow population and expansion to a broader population based on interim and external data.
- Consider including a broader participant group as part of secondary efficacy and safety analyses. This provides information on effectiveness and safety in a broader population (for example, across all disease stages or syndrome presentations) while not decreasing the chances of success on the primary endpoint with a particular stage of disease.

appreciate the insight from clinicians who are caring for patients with comorbidities and others who are routinely excluded from eligibility. Workforce diversity could come from recruiting investigators from minority-serving institutions, and historically Black colleges and universities, and minority investigators at both cancer centers and institutions that are not currently conducting clinical trials.

Guidance from the FDA, the NCI, and other federal government agencies represents an important first step in changing eligibility criteria and clinical trial design, but recommendations may not have much impact without incentives or mechanisms of enforcement. As this is a priority

issue that affects the development and availability of cancer therapeutics and continues to impact cancer health disparities, it is important for policy makers to engage with stakeholders to identify mechanisms that will change long-standing industry and academic patterns and make clinical trials more accessible to all patients. Government agencies could begin by requiring the reporting of criteria that lead to the exclusion of minority patients, which would help identify key criteria to be examined and expanded. The NCI funds cancer centers through competitive cancer center support grants. As part of the grant renewal process, cancer centers could be held accountable for the diversity metrics of trials in their centers. Cancer centers should strive for meaningful inclusion of minority populations in their center trials based on both the disease burden and diversity of the center's catchment area. Legislators could consider mechanisms that provide companies with FDA priority review or other incentives for meeting specified inclusion benchmarks in trials conducted in the United States.

Diversifying Representation in Clinical Trials by Addressing Barriers for Patients

Surveys demonstrate that while minority patients show a high willingness to participate in clinical trials, there are many barriers that prevent them from participating including geographic, financial, environmental, social, and cultural factors (393).

Many underrepresented minority patients do not even consider enrolling in a clinical trial because they do not live close to a trial site or are not provided information by their health care provider. In its draft guidance, FDA recommends that companies ensure clinical trial sites are in areas with high concentration of racial and ethnic minority patients. Research networks such as NCORP aim to expand access to clinical trials through community sites that are outside of large research centers. Patient navigators, community health workers, and patient advocates who have built trust within communities have been shown to be critical in improving the enrollment and retention of minority patients. These staff also help ensure that patients are adequately educated and informed about available trials. Congress should consider providing increased funding and support for patient navigation services at federally funded trial sites.

Patients experience financial barriers to participating in clinical trials that include related medical costs, out-of-pocket costs, transportation costs, and other incidental costs. Time off from work with loss of pay is an added barrier for those in the workforce. The Affordable Care Act required private insurance companies to cover routine medical costs of participating in clinical trials, but more comprehensive support is critical for patients. Medicare also covers routine costs for clinical trials, but not all state Medicaid programs do. The CLINICAL

TREATMENT Act would require Medicaid programs to provide that coverage. Other legislative proposals would require insurers to cover routine care costs at in-network rates, regardless of the provider's affiliation. Proposals such as these would help patients who may be enrolling in a clinical trial outside their standard provider network. In its draft guidance, the FDA also recommended a number of considerations to address financial barriers including reducing the frequency of study visits and making patients aware of financial reimbursements during the recruitment process.

Improving Access to High-Quality Clinical Care

A lack of access to quality clinical care is a critical element that contributes to cancer health disparities. Insurance coverage is an important factor that increases patient access to health care services across the cancer care continuum, including prevention, screening, treatment, precision medicine, and survivorship resources. With the passage of the Affordable Care Act, approximately 20 million people gained health insurance coverage through government exchanges or Medicaid expansion (394). The Affordable Care Act expanded Medicaid coverage to all individuals making less than 138 percent of the federal poverty line but some states refused federal funding for the expansion. In addition to expanding Medicaid, other changes that have been implemented as a result of the Affordable Care Act are also helping to address the issue of access to health care; these changes include ensuring that the recommended cancer screening and prevention interventions are now more widely available and affordable to a greater number of people than ever before.

Overall, the Affordable Care Act has increased an individual's ability to access diagnostic and treatment options for cancer (395). While it is still too early to examine long-term impacts, some research suggests that Medicaid expansion has had a positive effect on increasing access to cancer care for groups of lower socioeconomic status, including lower income individuals from racial and ethnic minority backgrounds (396). Some studies have shown that the Affordable Care Act and Medicaid expansion increased the rates of cancer diagnosis and led to enhanced access to cancer care surgery (397). Another study demonstrated that cancer survivors in Medicaid expansion states had better access to care than survivors in nonexpansion states (398). Additionally, a recent study showed that previous racial disparities in timely cancer treatment between African American and white patients practically disappeared in states where Medicaid access was expanded under the Affordable Care Act (399).

However, having insurance coverage is only the first step in ensuring access to high-quality clinical care. While more patients now have insurance coverage, patients with lower-tier insurance coverage may still not be able to get care at a given hospital because the hospital does not accept that insurance. Patients who are eligible for health care programs that serve the uninsured or underinsured may not be getting the minimum standard of quality care, which continues to exacerbate disparities. Other factors also impact access to quality care, including an individual's geographical residence, bias in the health care system, and similar factors. New policies are needed to ensure that patients are receiving access to at least the minimum standard quality of cancer care.

Coordination of Health Disparities Research and Programs within the Federal Government

As described throughout this chapter, there are several initiatives in different government agencies aimed at addressing cancer disparities. Efforts to increase coordination across these programs would help maximize impact and raise the visibility and awareness of these initiatives. The NCI CRCHD manages and coordinates a number of disparities-related research and training programs. There is further opportunity to break down silos that exist between NCI's clinical trial programs, including the broad NCI National Clinical Trials Network Program, the community-based NCORP, and the capacity-building Partnerships to Advance Cancer Health Equity and Geographic Management of Cancer Health Disparities Program. By creating a shared strategic plan, research framework, online portal, and other shared resources, the NCI would be able to better measure and leverage the programs' impact on cancer disparities research.

There are other opportunities to advance disparities research and health equity by creating innovative partnerships across government agencies. The NIH has already begun efforts to promote and support disparities research across institutes, including the NCI and the NIMHD. These efforts should continue to be prioritized. As the NCI seeks to address the complex issues of bias and other challenges in the health care workforce, there may be opportunities to create partnerships with the Health Resources and Services Administration (HRSA) and HRSA-funded community medical entities. Finally, as noted above, meaningfully addressing the impact of social determinants of health will require collaboration of the HHS with other relevant agencies, including the USDA, Department of Justice, and Department of Transportation.

The AACR Call to Action

Research is driving tremendous progress against cancer, but the grim reality is that these advances have not benefited everyone equally. The differences in the burden of cancer that exist among certain population groups, referred to as cancer health disparities, are among the most pressing public health challenges that we face in the United States.

In recent years, some strides have been made in combating cancer health disparities, as illustrated by the narrowing of racial and ethnic disparities in the overall cancer death rate. However, progress has come too slowly, and the cost of all health disparities, including COVID-19 and cancer health disparities—in terms of premature deaths, lost productivity, and the impact on communities of color—remains monumental and must be addressed.

Therefore, the AACR urges policy makers and all 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. Increased funding for the NIH, NCI, CDC, and numerous other federal agencies is absolutely necessary to support research and the federal initiatives that will allow us to eliminate cancer health disparities in the United States. This funding would stimulate research opportunities as follows:

- ▶ Further explore the role of biology and genetics in cancer health disparities. Recent scientific and technological innovations have provided a tremendous opportunity for us to better understand the biological and genetic factors that contribute to cancer health disparities. This information has much potential for both directly and indirectly reducing cancer health disparities.
- ▶ Fund additional clinical and translational longitudinal molecular profiling studies in large diverse cohorts of cancer patients, which will help us understand the natural history of cancers in racial and ethnic minority patients from both the clinical and biological standpoint.
- ▶ Build model systems, such as cell lines, organoids, and patient-derived xenograft models, from racial and ethnically diverse patients that can be shared and distributed to the scientific community. This will provide a better and broader understanding of cancer biology, which is necessary for developing new anticancer therapeutics for all cancer patients.
- ▶ Fund comprehensive studies that examine how the complex interplay of genetic, environmental, and social factors contributes to the differences observed in cancer incidence and mortality between various population groups. This knowledge will be useful for developing policy strategies to eliminate cancer health disparities.

Implement steps to ensure that clinical trials include a diverse population of participants. It is important to recognize that while many types of cancer disproportionately affect racial and ethnic minorities, the related clinical trials are often not representative of the populations most affected by the diseases. To ensure racially and ethnically diverse clinical trial participation, the AACR recommends:

- ▶ Requiring clinical trial sponsors and clinical investigators to:
 - Remove structural barriers to patient participation through innovative mechanisms such as telehealth, remote consenting and monitoring, convenient drug regimens (oral instead of intravenous; modified dosing that require fewer infusions).
 - Complete a specific, prospective “study plan” that outlines how an appropriately diverse population will be included in the clinical trial and set concrete targets for trial enrollment based on disease epidemiology/incidence.
 - Describe, with detailed strategies, how such targets will be met including approaches that will be employed to overcome cultural barriers.
 - Set prospective plans for how to meet targets in the postmarket setting if accrual goals are not achieved pre-FDA approval.
- ▶ Appointing a “diversity officer” to each phase II and phase III clinical trial to help design the trial and recruitment strategies for achieving the prespecified goals of representation and inclusion set forth in the study plan. The diversity officer role should be defined, and training offered to sponsors and investigators on what would constitute a qualified diversity officer.
- ▶ Educating clinical investigators and physicians who refer patients to clinical trials on the importance of representation and inclusion in trials and providing training on cultural competence toward that end.
- ▶ Encouraging federally funded trials to create a site infrastructure which includes certified navigation, community health workers/promotoras, and patient advocate networks, to ensure diverse enrollment.

- ▶ Urging journal editors and peer reviewers to inquire about the diversity of the patient population that participated in the clinical trial when a clinical study is submitted for consideration for publication.

Support programs to make sure that the health care workforce reflects and appreciates the diverse communities it serves.

According to the NIH, the groups that are now underrepresented in academic medicine include women, African Americans, Hispanics, and American Indians/Alaska Natives. Diversity in the workforce helps to form an environment of tolerance and teamwork, and it allows people from different backgrounds to come together to share innovative ideas. Therefore, the AACR recommends:

- ▶ Implement policies that remove structural barriers to professional development for racial and ethnic minorities.
- ▶ Increasing the diversity of the health care and public health workforce to ensure that the clinical research team members reflect the populations that they intend to study.
- ▶ Creating mechanisms to support networks of skilled patient advocates from underrepresented communities and populations.
- ▶ Educating a new generation of health care professionals and researchers to ensure that they have a comprehensive understanding of underserved populations.
- ▶ Ensuring that investigators and referring physicians are educated in cultural competence and the importance of community engagement.
- ▶ Improving the cultural and linguistic competency and diversity of the health-related workforce.

Prioritize cancer control initiatives. Cancer control aims to reduce the incidence, morbidity, and mortality of cancer and to improve quality of life for cancer patients and survivors through the implementation of evidence-based interventions for prevention, early detection, diagnosis, treatment, and palliative care. Therefore, the AACR recommends:

- ▶ Encouraging policy makers to approve H.R. 2339, the “Protecting American Lungs and Reversing the Youth Tobacco Epidemic Act of 2020” Among the provisions in the Act is the establishment of a demonstration grant program to develop strategies for smoking cessation among underserved communities.
- ▶ Closing the disparity gaps that exist in cervical cancer screening rates among different segments of the U.S. population.
- ▶ Ensuring that the USPSTF screening guidance accounts for race-related differences in risk.
- ▶ Supporting the USPSTF recommendation to lower the age and smoking history criteria required to deem African American smokers eligible for lung cancer screening.

Work with members of the Congressional Tri-Caucus—comprised of the Congressional Asian Pacific American Caucus, Congressional Black Caucus, and Congressional Hispanic Caucus—to pass the provisions included in the Health Equity and Accountability Act (HEAA). The Act builds on more than 10 years of Congressional action to combat health disparities, and it leverages the expertise and research of a 300-plus member community working group and endorsing organizations. Some of the recommendations included as part of the Act are:

- ▶ Expand Medicaid under the Affordable Care Act to the remaining states that have not implemented the initiative.
- ▶ Encourage federal agencies to award grants that expand existing opportunities for scientists and researchers and promote the inclusion of underrepresented minorities in the health professions.
- ▶ Establish a student loan reimbursement program to provide student loan reimbursement assistance to researchers who are focused on eliminating cancer health disparities.

The AACR has been a longtime leader in advancing the science of cancer health disparities and working toward the elimination of cancer health disparities, and we are proud to share this latest effort, the *AACR Cancer Disparities Progress Report 2020*. This inaugural annual report raises awareness of the key actions that are required to overcome the enormous public health challenge posed by cancer health disparities in racial and ethnic minorities. These actions include enhancing minority participation in clinical trials, prioritizing cancer control efforts, increasing minority researchers in the cancer workforce, and ensuring robust and sustained funding for federal agencies that conduct research which drives progress against cancer health disparities. 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 action to eradicate the social injustices that are barriers to health equity, which is one of our most basic human rights. This is why the AACR stands in solidarity in the fight against racism, privilege, and discrimination in all aspects of life and actively supports policies that guarantee equitable access to quality health care to eradicate all barriers to achieving the bold vision of health equity.

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A**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.

B**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.

Cancer patient navigator

A person who helps guide a cancer patient going through screening, diagnosis, treatment, and follow-up. Patient navigators can help patients communicate with their health care providers so they get the information they need to make the best decisions about their health care.

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.

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.

Chromosomal translocation

Genomic alteration in which a whole chromosome or segment of a chromosome becomes attached to or interchanged with another whole chromosome or segment. Chromosomal translocations can, in some cases, fuel cancer.

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.

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**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.

G**Gastric or stomach 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***

The idea that everyone should have a fair opportunity to attain their full health potential regardless of demographic, social, economic, or geographic strata.

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.

*The definition of health equity is based on the definition from the World Health Organization (11).

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.

Incidence rate

The number of new cases per population at risk in a given time period.

L

Leukemia

Cancer that starts in blood-forming tissue, such as the bone marrow, and causes large numbers of blood cells to be produced and enter the bloodstream.

Liver cancer

Cancer that forms in the tissues of the liver. The most common type of liver cancer is hepatocellular carcinoma.

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.

M

Mammogram

An X-ray of the breast that is used to look for early signs of breast cancer.

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.

Non-Hispanic Black

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

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.

GLOSSARY

O

Oncology

The branch of medicine that focuses on cancer diagnosis and treatment.

P

Pathogen

A bacterium, virus, or other microorganism that can cause disease. Also referred to as an infectious agent.

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. Radiation may come from a machine outside the body (external-beam radiation therapy), or it may come from radioactive material placed in the body near cancer cells (internal radiation therapy). Systemic radiotherapy uses a radioactive substance, such as a radiolabeled monoclonal antibody, that travels in the blood to tissues throughout the body. Also called irradiation and radiation therapy.

S

Social determinants of health

Social determinants of health are conditions in the environments where people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks.

Socioeconomic status

The social standing or class of an individual or group. It is often measured as a combination of education, income, and occupation.

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.

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

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

Underserved populations

Segments of the population that have little or no access to effective health care.

U.S. Preventive Services Task Force (USPSTF)

An independent, volunteer panel of experts in prevention and evidence-based medicine.

INDEX

A

Affordable Care Act (ACA), 12, 26, 121–24, 126
African Americans, 3–4, 8–11, 13–15, 21–23, 41–43, 47–48, 50–51, 53–54, 56–58, 62–65, 70–72, 74–75, 78–85, 88–89, 94–97, 102–4, 110–11, 117–19, 121
Alaska Natives, 11, 18, 20, 56, 70, 82, 112, 115
American Indian/Alaska Native, 10, 20–21, 106
American Indians, 11, 18, 20, 56, 70, 82, 112, 115
Asians, 18, 47, 70, 82, 110–11
Asians/Pacific Islanders, 9, 11, 13, 17–18

B

Biases, implicit, 32, 73, 76, 83, 89, 110
Biomarkers, 100–101, 121
Biomedical research, 4–5, 34, 73, 103, 106, 112, 117
BRCA1, 36, 102, 140
BRCA2, 36, 140
Breast cancer, 14–15, 22–23, 25, 41–42, 61–63, 78–80, 85, 94–96, 99, 102–3, 121, 140, 142–44
triple-negative, 15, 41, 85, 99, 143

C

Cancer biology, 6, 34, 41, 100, 102, 125
Cancer care, pillars of, 76, 83, 88
Cancer death rates, 1–3, 8–9, 11, 13, 19, 21, 25, 47, 125
Cancer deaths, 8, 13, 20, 25, 35, 46, 55, 71, 117
Cancer development, 35, 37–38, 40–41, 43, 45, 58–60, 100, 140
Cancer health disparities, 1–4, 6–11, 19–27, 31–32, 34–35, 39, 41, 50–51, 57–58, 97, 105, 114, 120–21, 124–26
Cancer health disparities research, 1–3, 7, 25, 32, 109–10, 113, 115
Cancer incidence, 2–3, 18, 22, 59, 111, 125
Cancer mortality, 11, 22
Cancer prevention, 2, 7, 16, 41, 53, 70, 114–17
Cancer risk, 22, 35, 37, 39, 48, 50, 57, 97
Cancer risk factors, 4, 14, 43, 45, 58
Cancer screening, 2, 4–5, 19, 22, 31, 57, 59–60, 62, 70–71, 117, 120, 122
breast, 62, 65, 119
cervical, 17, 64–65, 72, 119
colorectal, 5, 14, 63, 65, 72, 119, 122
lung, 64–65, 71, 121–22, 126
prostate, 64, 67, 71
tests, 59–61, 63–65, 72
Cancer survivors, 3, 6, 53, 93–96, 99, 124
Cancer survivorship, 6, 93, 96
Cancer treatment, 1–2, 5–6, 8–9, 31, 40–41, 73, 76, 88, 93–96, 99–101
disparities in, 5, 73–74, 83, 92, 122

Cancer workforce, 6–7, 108, 112–13, 126
Center to Reduce Cancer Health Disparities (CRCHD), 25, 107, 116, 140
Centers for Disease Control and Prevention (CDC), 1–2, 7, 54–55, 114–17, 119–20, 122, 125
Cervical cancer, 17, 47, 57, 61, 65, 119, 121, 140–41
Chemotherapy, 62, 69, 74, 76, 80, 85, 87, 89, 95, 99, 140, 143
Childhood cancer, 15, 17, 80, 85
Cigarettes, 45, 48, 64–65, 71, 118
mentholated, 47–48
Clinical trials, 1, 5–7, 66–67, 71, 73–75, 80–85, 87–89, 92, 97, 101–3, 116, 122–26
Colorectal cancer, 13, 15, 18, 36, 47, 49, 51–53, 59, 61, 63–65, 69, 85, 88, 141
Congressional Asian Pacific American Caucus, 7, 17, 59, 115, 126
Congressional Black Caucus (CBC), 7, 9, 12, 26, 115, 121, 126
Congressional Hispanic Caucus (CHC), 7, 16, 26, 115, 126
Congressional Native American Caucus, 17, 23, 114, 115
COVID-19, 2–4, 12, 27–32
COVID-19 disparities, 4, 27, 30, 32

E

Early detection, 2, 5, 7, 10, 16–17, 31–32, 57, 59, 114, 120, 126
E-cigarettes, 48, 118
Ethnic disparities, 1, 5, 7, 22, 25, 65, 70–71, 73, 94–95, 97
Ethnic groups, 1–3, 11, 13–14, 17, 22, 40–43, 47–48, 51, 58, 60, 95, 97, 102
Ethnicity, 2, 5–7, 11, 13, 45, 48, 50, 63–64, 70–71, 110, 112–13
Ethnic minority patients, 1, 38, 71, 75–76, 82–83, 88, 96, 123, 125
Ethnic populations, 40–41, 48, 50–51, 56

F

Financial toxicity, 96, 141

G

Genetic ancestry, 11, 35, 41, 117, 141
Genetics, 1, 35, 37, 39, 97, 103, 121, 125, 143

H

Hepatitis B virus (HBV), 16, 43, 55–56, 122
Hepatitis C virus (HCV), 16, 43, 55–56, 122
Health disparities, 2–4, 7–9, 11–12, 25–27, 32, 59, 103, 105, 114–15, 117, 121–22, 125
Health equity, 1–3, 5–7, 11, 25, 96–97, 106, 109, 115–16, 122, 124, 126, 141
Health-related quality of life, 95–96
Hispanics, 4, 9, 11, 15–16, 21, 47–48, 50–51, 53–54, 56–58, 64–65, 69–72, 102, 106, 110–12, 118, 126–27

INDEX

Human papillomavirus (HPV), 4, 17, 38, 43, 55–56, 61, 64, 119, 140–41

I

Immunotherapy, 5, 40–41, 73, 76, 85, 142–43
Implementation, 41, 44, 47, 51, 53, 72, 102, 109, 119–20, 126
Indian Health Service, 17, 19–20, 56

K

Kidney cancer, 36, 49

L

Liver cancer, 5, 10, 16, 19, 49, 55–56, 142
Lung cancer, 15, 18, 45–46, 49, 58, 61, 64, 71, 121–22, 142

M

Menthol cigarettes, 48, 118
Minorities, 57, 97, 102, 105, 111, 113, 115–16, 118
Minority patients, 73, 83, 89, 103, 120, 123
Minority-serving institutions (MSIs), 113, 123

N

NCI's Community Oncology Research Program (NCORP), 83, 115–16, 123

O

Obesity, 14, 16, 19, 22, 28, 43, 47–51, 120
Ovarian cancer, 49, 85, 91, 102, 140

P

Pacific Islanders, 11, 18, 22, 82, 112, 115
Pancreatic cancer, 12, 36, 49, 69, 75
Partnerships to Advance Cancer Health Equity (PACHE), 113, 116, 124
Pathogens, cancer-causing, 22, 43–44, 55–56
Patient navigation, 71, 72, 92, 123
Patient navigators, 97–99, 108, 123, 140
Physical activity, 19, 21, 23, 44, 49, 53–54, 117, 120
Physical inactivity, 3, 19, 22, 43–45, 53, 57, 120
Precision medicine, 1, 6, 41, 100–104, 114, 117, 124, 143
Preventable cancer risk factors, 2, 4, 22, 38, 43–44
Prevention, 2, 32, 54–57, 60, 110, 114, 124, 126, 142–43
Project Genomics Evidence Neoplasia Information Exchange (Project GENIE), 1, 6, 34, 41, 100, 104
Prostate cancer, 1, 5, 10, 14–15, 23, 48–49, 51, 61, 67, 70–71, 80–82, 89, 97
Prostate-specific antigen (PSA), 61, 64, 67, 70, 143

R

Racial disparities, 16, 25, 89, 124
Radiotherapy, 5, 21, 74, 76–77, 80, 89, 143
Rural areas, 9, 29, 52, 74, 95, 117

S

SARS-CoV-2, 3, 27–31
Secondhand smoke, 45, 47–48
Smoking, 16, 19, 38, 43, 45–46, 48, 57, 71, 118, 121
Social determinants of health, 20, 25, 27, 117, 120–21, 124, 143
Socioeconomic status, 2, 7, 20–21, 31, 53, 58, 64, 101, 143
Stomach cancer, 10, 14, 16, 36, 49, 51, 56, 69, 88, 141
Surgery, 31, 62, 67, 69, 73–77, 79–80, 85, 99
Survivors, 1, 6, 22, 24, 45, 53, 85, 94–97, 103, 124, 126
Survivorship, 2, 8–9, 110, 114

T

Tumor microenvironment, 4, 40–41, 143

U

Underserved populations, 1–2, 5–6, 42–43, 93–94, 97, 102, 107, 111, 114, 116, 120, 143

W

Weight, excess body, 4, 19, 43, 48, 50–51
Workforce, 6, 105–7, 110–12, 122–23, 126



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