



National Comprehensive
Cancer Network®



Elevating Cancer Equity: Recommendations to Reduce Racial Disparities in Guideline Adherent Cancer Care

February 22, 2021

Elevating Cancer Equity Convening Organizations



The American Cancer Society Cancer Action Network (ACS CAN) empowers advocates across the country to make their voices heard and influence evidence-based public policy change as well as legislative and regulatory solutions at every level of government that will reduce the cancer burden.



National Comprehensive
Cancer Network®

The National Comprehensive Cancer Network® (NCCN®) is a not-for-profit alliance of 30 leading cancer centers devoted to patient care, research, and education. NCCN is dedicated to improving and facilitating quality, effective, efficient, and accessible cancer care so patients can live better lives.



Founded in 1998, the National Minority Quality Forum (NMQF) is a non-profit Washington, D.C.-based, health care research and education organization whose mission is to reduce patient risk by assuring optimal care for all.

ACS CAN, NCCN and NMQF Appreciates and Recognizes the Following Supporters for this Summit:

Supported by: **AbbVie; bluebird bio; Genentech; GSK; Janssen Oncology; Pharmaceutical Companies of Johnson & Johnson; Merck; MorphoSys US, Inc.; Pfizer, Taiho Oncology**

Sponsored by: **Bristol-Myers Squibb**

Thank You!

Agenda

12:30 – 12:35 PM	Welcome and Background on Racial Disparities in Guideline Adherent Cancer Care Robert Carlson, MD CEO, National Comprehensive Cancer Network
12:35 – 12:45 PM	Overview of Patient, Caregiver, and Physician Survey Results Lisa Lacasse, MBA President, American Cancer Society Cancer Action Network
12:45 – 1:20 PM	Review of Working Group Recommendations Shonta Chambers, MSW, Executive Vice President of Health Equity Initiatives and Community Engagement, Patient Advocate Foundation Robert Winn, MD, Director, VCU Massey Cancer Center
1:20 – 1:30 PM	Questions and Answers

Racial Disparities in Cancer Care

- People of color are less likely to receive optimal care, even when accounting for insurance status.
- Guideline adherent care improves outcomes for all and reduces racial disparities in cancer outcomes.
- Root causes of these disparities are multifactorial and may include:
 - Implicit and explicit bias in care delivery
 - A dearth of appropriate representation of people of color in oncology
 - Homogenous research populations not reflecting diverse communities
 - Lower rates of comprehensive insurance
 - Cost of care challenges
 - Social determinants of health

It's time for meaningful, actionable change.

© National Comprehensive Cancer Network, Inc. 2020, All rights reserved.



American Cancer Society Cancer Action Network (ACS CAN)



*Lisa A. Lacasse, MBA
President*



National Comprehensive
Cancer Network®



National Surveys: Key Findings

February 22, 2021

PREPARED BY:


PUBLIC OPINION
STRATEGIES
turning questions into answers

Methodology/Research Objectives

POS

- On behalf of the NCCN, ACS CAN, and NMQF, Public Opinion Strategies conducted two national online surveys:
 1. N=600 cancer patients/survivors (N=300) and family caregivers of cancer patients (N=300) - December 14-29, 2020
 - Oversamples were conducted to reach N=227 African Americans and N=238 Hispanics across these audiences.
 2. N=208 oncologists - December 14-21, 2020
- The objectives of the surveys were to assess perceptions about health disparities and racial bias in cancer care, explore oncologists' cancer care practices and explore cancer patients' and caregivers' experiences in receiving cancer care and treatment.

8



Key Findings – Cancer Patients/Caregivers

POS

- In order to have a better understanding of patients and caregivers' experiences with their oncologists care and treatment practices, we asked respondents about 14 things that their oncologist could do. For the most part, patients and caregivers report higher levels of their oncologists doing these individual care practices than oncologists' report doing themselves. But when combined together, only 19% of patients and caregivers report their oncologist doing all 14 care and treatment practices with them.
- African American and Hispanic patients and caregivers report experiencing negative situations (such as receiving poorer quality care because of their financial circumstances) with their oncologist and cancer care team at higher levels than white respondents.
- Significant majorities of African American and Hispanic patients and caregivers believe racial bias is occurring today in cancer care.

10

Key Findings - Oncologists

POS

- Majorities of oncologists report racial bias is happening “often” in our health care system.
- More than 4 in 10 oncologists say it is possible that they have unintentionally had racial bias in treating cancer patients of different racial or ethnic backgrounds.
- More than 6 in 10 oncologists agree with the premise that non-white cancer patients are more likely to receive poor quality care than white cancer patients.
- Only just over a third (35%) of oncologists report that on average they do all 14 care and treatment practices (that we tested) “*Nearly Always/Often*” with their cancer patients.
- Significant majorities of oncologists believe use of NCCN guidelines has a positive impact on patients’ clinical outcomes, quality of care, and quality of life as well as physician clinical recommendations and decision-making. There is less of a positive impact on the guidelines addressing racial disparities.

11



12

For the most part, patients and caregivers report higher levels of their oncologists doing these individual care practices than oncologists' report doing themselves.

Showing % Yes for Patients/Caregivers & % Nearly Always for Oncologists
Ranked by %Yes – All Patients

	All Patients/Survivors (% Yes)	All Caregivers (% Yes)	Oncologists* (% Nearly Always)
Explain results of cancer treatment in a way that is easy to understand	87%	81%	74%
Involve in decisions about cancer treatment	82%	87%	67%
Explain how cancer treatment could affect normal daily activities	80%	84%	64%
Explain how cancer could affect normal daily activities	78%	84%	65%
Explain in detail the advantages of each choice of cancer treatment	74%	80%	62%
Discuss more than one way to treat the cancer	74%	73%	58%
Explain in detail the disadvantages of each choice of cancer treatment	73%	72%	58%
Talk about all of the different treatment options available	72%	79%	69%
Use patient handouts, brochures, pamphlets, or other tools in discussions	72%	71%	41%
Ask patient what is best for them	69%	76%	47%
Ask patient for opinion about different cancer treatments	65%	72%	44%
Discuss clinical practice guidelines	64%	72%	45%
Discuss the cost of treatments or what is or is not covered by insurance	49%	65%	31%
Tell about any clinical trials available	39%	47%	42%

*Different Question Language, Statement Language, and Different Scale. Showing %Nearly Always Do Among Oncologists.



Thinking now about (your / your loved one's) cancer care... Please indicate whether or not (your / your loved one's) oncologist did each of the following. Did your oncologist...

13

Negative Experiences With Oncologist or Cancer Care Team:

Ranked by %Yes – All Patients and Caregivers

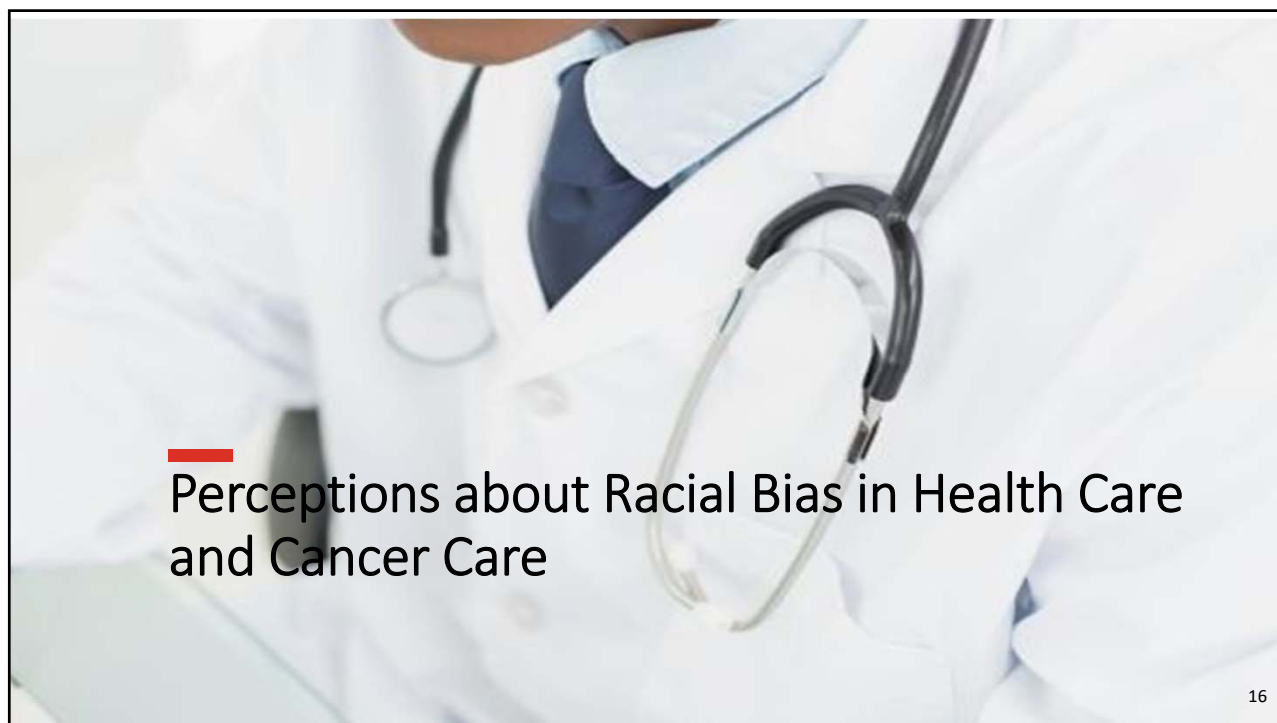
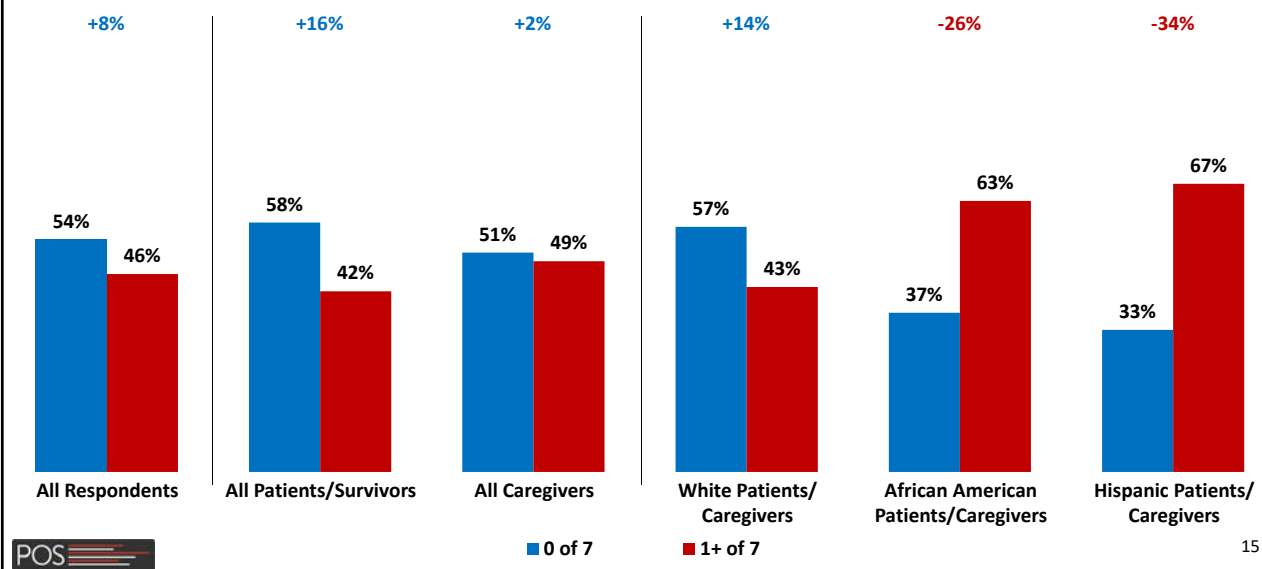
	%Yes
Did (you/your loved one) ever experience a situation where (your/their) questions were not answered in a way that was easy to understand by the oncologist or cancer care team?	30%
Did you ever feel (your/your loved one's) oncologist or cancer care team made assumptions about (you/your loved one) because of your financial circumstances?	25%
Did (you/your loved one) ever not ask questions about (your/their) cancer care or treatment because (you/your loved one) didn't feel comfortable talking with the oncologist or cancer care team about (your/their) questions?	25%
Did you ever feel (you/your loved one) received lesser or poorer quality cancer care because of your insurance status or the type of insurance (you/your loved one) had?	22%
Did you ever feel (you/your loved one) received lesser or poorer quality of cancer care because of your financial circumstances?	22%
Did you ever feel (your/your loved one's) oncologist or cancer care team made assumptions about (you/your loved one) because of race or ethnic background?	17%
Did you ever feel (you/your loved one) received lesser or poorer quality of cancer care because of race or ethnic background?	15%



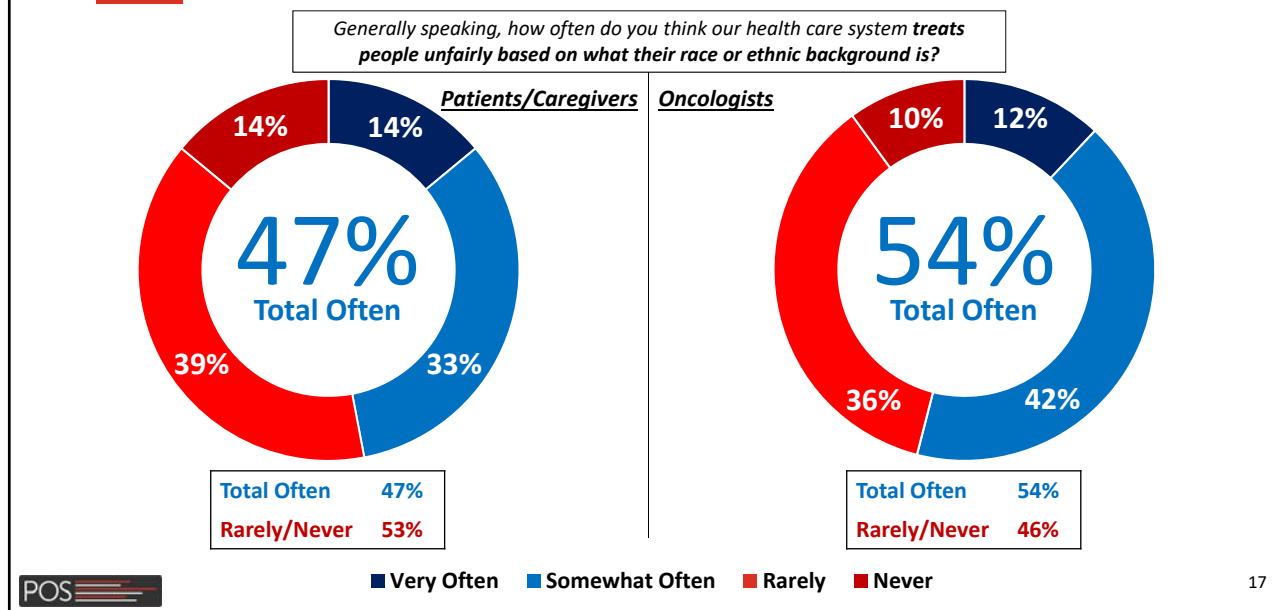
Thinking now specifically about (your / your loved one's) cancer care from your oncologist and cancer team... Please respond yes or no to each of the following questions.

14

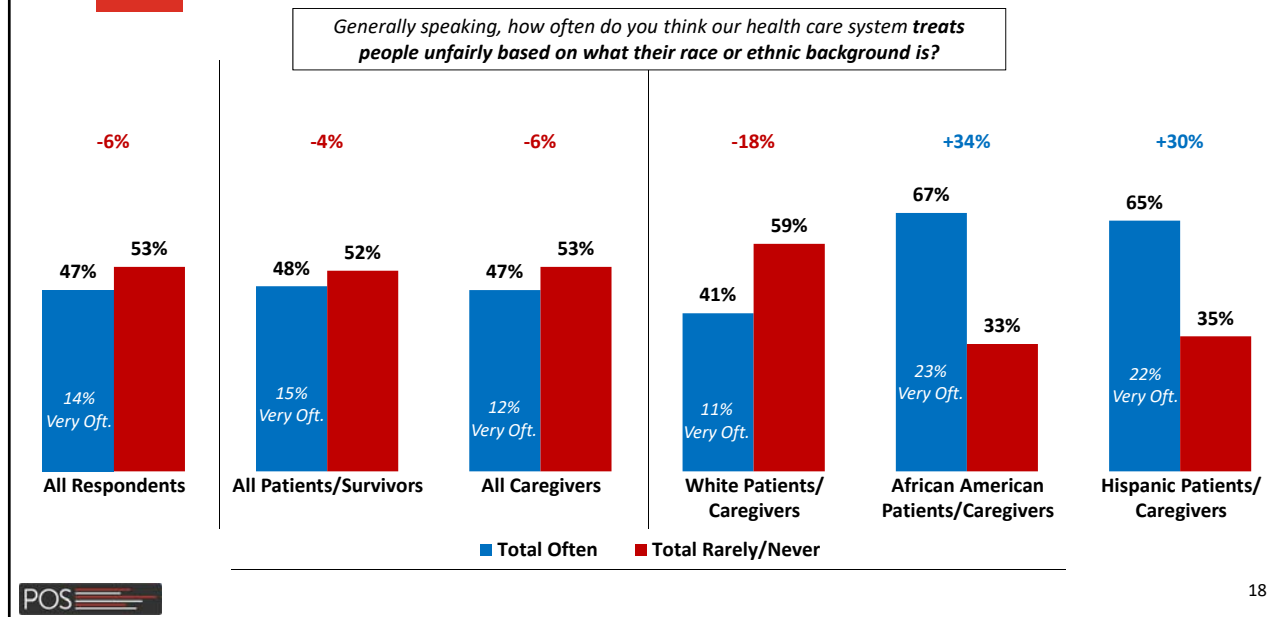
Nearly half of respondents' report experiencing at least one of these negative situations. African American and Hispanic patients and caregivers are much more likely to have experienced these negative situations with their oncologist/cancer care team than whites.



Overall, patients and caregivers are divided in their views about the health care system treating people unfairly based on race.

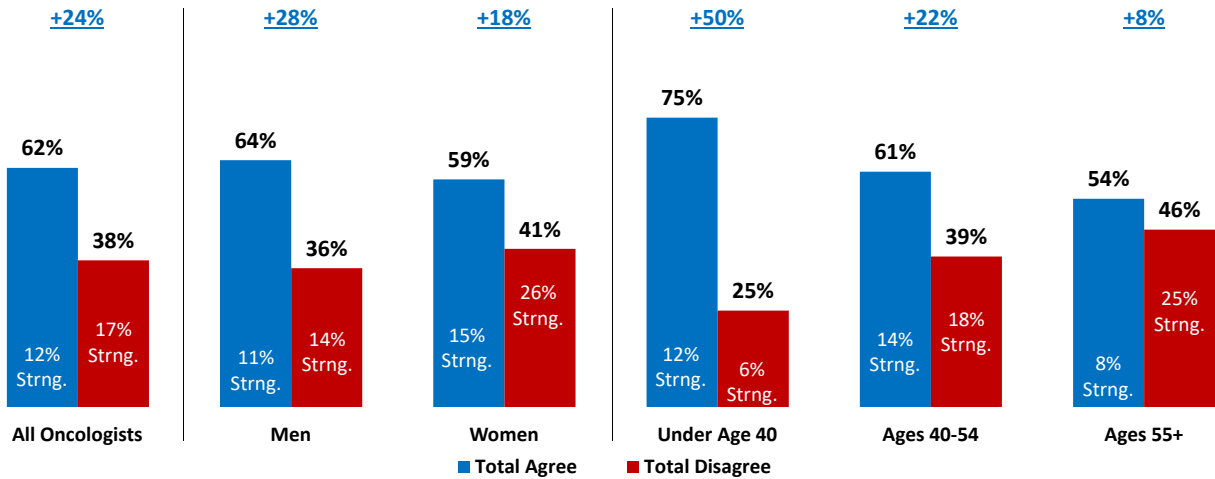


However, there is a clear divide in perceptions about whether this is happening by ethnicity. Significant majorities of African Americans and Hispanics believe this to be the case today.



Men are more likely than women and younger oncologists are more likely than older oncologists to believe this premise to be true.

Non-white cancer patients are more likely than white cancer patients to receive poor quality care.

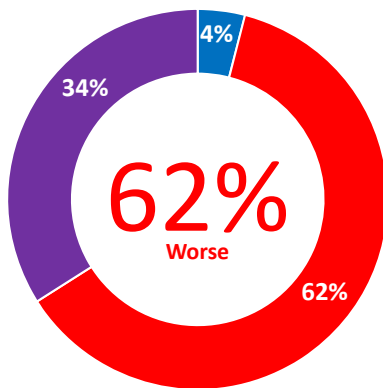


Please record whether you strongly agree, somewhat agree, somewhat disagree, or strongly disagree with the statement below.

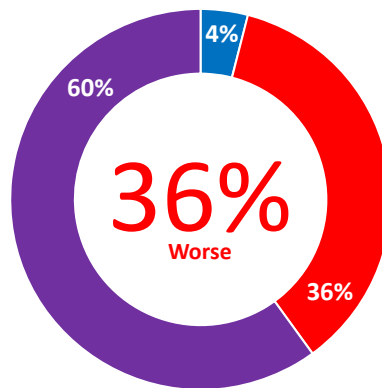
19

More than a third of oncologists say non-white cancer patients receive worse medical care and communication from their oncologist compared to white cancer patients. A majority say non-white cancer patients have worse health outcomes than white cancer patients.

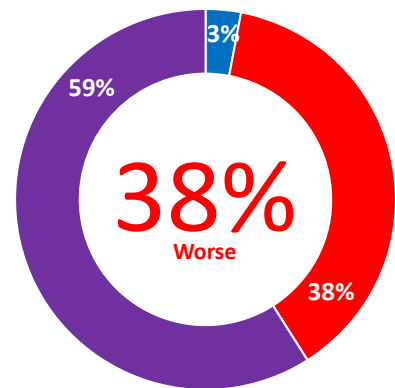
Non-white cancer patients have the same, better, or worse **health outcomes** as white cancer patients?



Non-white cancer patients receive the same, better, or worse **medical care** as white cancer patients?



Non-white cancer patients receive the same, better, or worse **communication from their oncologist** and cancer care team as white cancer patients?



■ Better ■ Worse ■ Same



Thinking now about differences and similarities in cancer care between different racial groups... On average, do you think...

20

Working Group Overview

Shonta Chambers, MSW

Robert Winn, MD

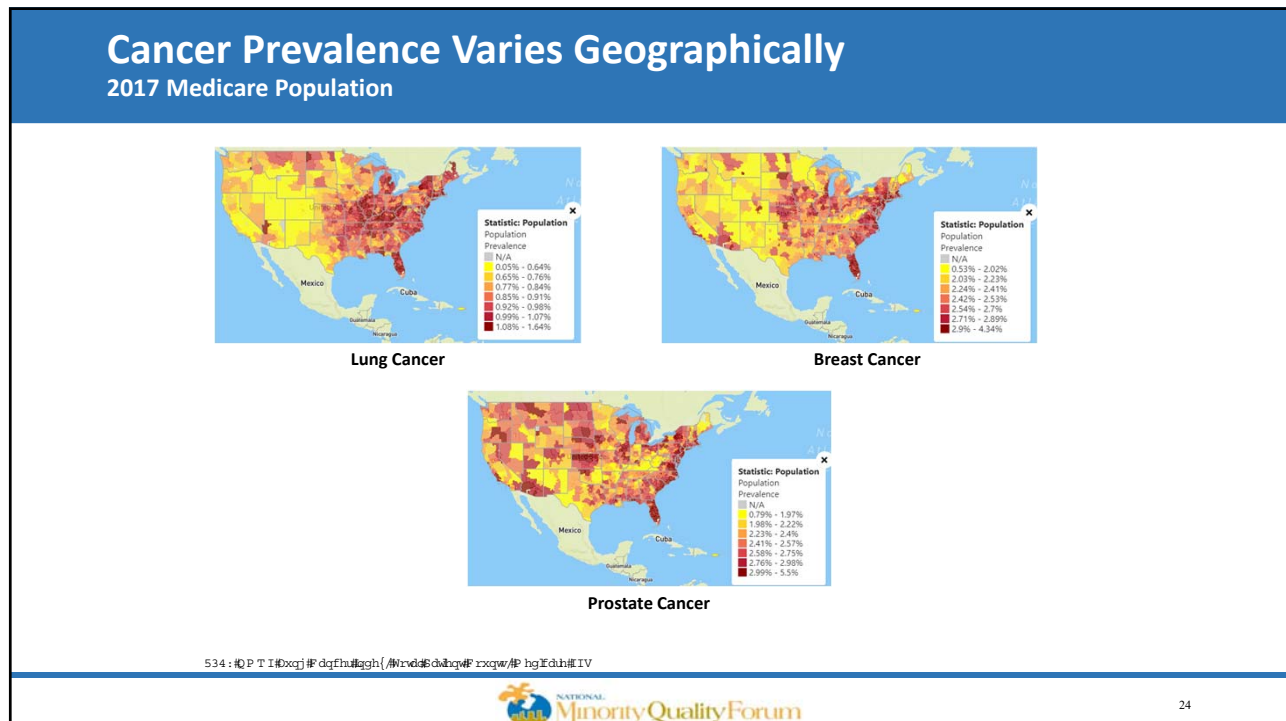
Chairs of the Elevating Cancer Equity Working Group

Working Group Overview

- The Elevating Cancer Equity Working group was convened to:
 - Explore the root causes of racial disparities in access to guideline adherent cancer care and discrimination in care delivery.
 - Develop recommendations for short-term and long-term actionable policy and practice strategies to address historic injustices in care access and quality and improve racial equity in access to guideline adherent cancer care.
- In advance of the meeting, the working group received the results of the surveys and discussion guides to inform the work.
- The working group met over the course of two days and held two follow up calls to further refine recommendations.
- The working group was comprised of 17 national experts representing physicians, patients, caregivers, researchers, and industry.

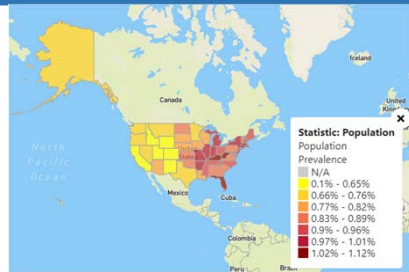
Elevating Cancer Equity Working Group Members

- **Chair:** Shonta Chambers, MSW, Patient Advocate • Chanita Hughes-Halbert, PhD, Medical University of South Carolina Foundation
- **Chair:** Robert Winn, MD, VCU Massey Cancer Center • Marjorie Kagawa Singer, PhD, UCLA Fielding School of Public Health
- Zeke Aguilera, ACT Lead, ACS CAN • Mel Mann, MBA M.Ed, Patient Advocate
- Nadine Barrett, PhD, Duke University School of Medicine • Regina Martinez, Volunteer, ACS CAN
- Linda Burhansstipanov, DrPH, MSPH, Native American Cancer Research Corporation • Kris Rhodes, MPH(Anishinaabe), Retired Founding CEO, American Indian Cancer Foundation
- Christina Chapman, MD, MS, Michigan Medicine • Brian Rivers, PhD, MPH Cancer Health Equity Institute, Morehouse School of Medicine
- Moon Chen, MPH, PhD, UC Davis Health • Gerren Wilson, PharmD, Genentech
- Thomas Farrington, Prostate Health Education Network • Karen Winkfield, MD, PhD, Meharry-Vanderbilt Alliance
- Carmen Guerra, MD, MSCE, Penn Abramson Cancer Center

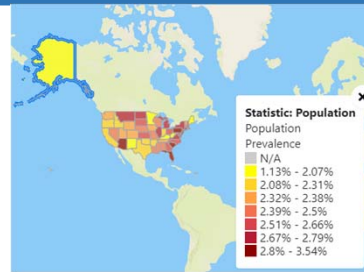


Cancer Prevalence Varies Geographically

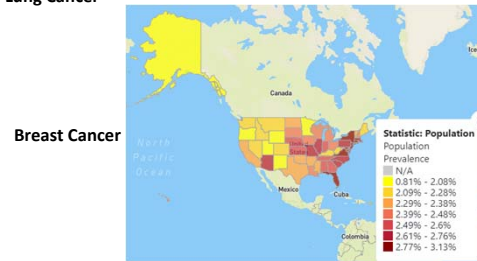
2017 Medicare Population



Lung Cancer



Prostate Cancer



Breast Cancer



Equity Report Card

Equity Report Card

- The Equity Report Card is intended to serve as a tool for providers, payers, and accreditation entities working to advance racially equitable practices in cancer care.
- The Report Card Includes 17 practices to advance equitable care delivery. The practices are divided into the following categories:
 - Community Engagement
 - Accessibility of Care and Social Determinants of Health
 - Addressing Bias in Care Delivery
 - Quality and Comprehensiveness of Care

Equity Report Card

Community Engagement
Incorporates meaningful community involvement in practice leadership through a community/patient advisory committee or designated board position that is reflective of: <ul style="list-style-type: none"> • the community the health care systems serves or • that is reflective of the community where the healthcare system resides or • is reflective of the demographics identified through the community needs assessment.
Marketing and educational materials use messaging that is linguistically and culturally appropriate for the community served.
Contracts with or has formal and equitable partnership with community providers, community-based organizations, and/or faith-based organizations (when mutually appropriate and not harmful) for community engagement and/or patient navigation.
Demonstrates the results of the community health needs assessments are used as a tool for program development through documented action plan tied to results.

Equity Report Card

Accessibility of Care and Social Determinants of Health

Facilitates access to government, commercial, or community-based non-emergency transportation services or financial support for public transportation where available.

Collects Social Determinants of Health data at intake and throughout the continuum of care. Population-level data collected (z-codes) helps to guide patient care and population-level health management as documented through the medical record or meeting notes.

Offers flexible hours for screening and treatment appointments.

Offers culturally and linguistically representative patient navigators or community health workers through internal hiring or contracting with community-based organizations.

Establish a process to navigate patients with identified social needs to local and or national resources.

Training is provided to staff on barriers to clinical trial participation and there are targeted efforts to reduce barriers to clinical trial participation through connection to appropriate services.

Equity Report Card

Addressing Bias in Care Delivery

Diversity, inclusion, and equity is embedded into the practice, institution, or health system policies (Examples: recruitment, hiring, and promotion policies, resource allocation standards).

Adopts measures related to the recruitment, retention, and promotion of minority researchers and practitioners.

Implements Health Information Technology or other workflow processes to identify critical moments in shared decision making and care planning when disparate care can occur.

Incorporates disparities and equity framework into quality improvement activities.

Provides and requires annual implicit bias training for all employees.

Equity Report Card

Quality and Comprehensiveness of Care

When appropriate, patients are offered or referred to appropriate preventive and supportive care services (e.g. smoking cessation and weight management programs, reducing exposure to environmental hazards).

Clinical trial options are discussed with all patients as documented through medical records.

Offers culturally and linguistically representative patient navigators or community health workers through internal hiring or contracting with community-based organizations.

Policy Change Recommendations

Policy Change Recommendations

- In addition to disparities stemming from bias in care delivery, structural and systemic contributors to disparities must also be addressed.
- The working group developed a total of 16 policy change recommendations for action by Congress, payers including CMS, and other federal agencies.
- ACS CAN, NCCN, and NMQF will work to put the policy change recommendations into place through advocacy and outreach to Congress, CMS, and other federal agencies as relevant.



Policy Change Recommendations

Congressional Recommendations

<p>Clinical Trial Diversity: Congress should pass legislation requiring the FDA to consider clinical trial diversity as an element of the drug approval process in a way that is proportionate to the intended patient population.</p>
<p>Supporting Cancer Prevention: Congress should allocate funds for public awareness campaigns of lifestyle factors impacting cancer risk that are linguistically and culturally reflective.</p>
<p>Supporting Cancer Prevention: Congress should pass legislation allocating funds for public education on the importance of the Human Papillomavirus(HPV) vaccine.</p>
<p>Supporting Access to Screening: Congress should allocate additional funding for CDC screening programs including the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) and the Colorectal Cancer Control Program (CCCP). Congress should also allocate funds for screening that prioritizes cancers where disparities are particularly prevalent.</p>
<p>Supporting Access to Screening: Congress should allocate funds to be granted to community-based organizations to connect people with screening, early detection and treatment support. Congress should restore funds for the National Comprehensive Cancer Control Program.</p>
<p>Supporting a Diverse Healthcare Workforce: Congress should allocate funds to Historically Black Colleges and Universities (HBCUs), tribal colleges, and other minority serving institutions (MSIs) because they excel at care, practice, education, and community engagement.</p>
<p>Supporting Patient Navigation: Congress should pass legislation ensuring reimbursement of patient navigators and community health workers in Medicare/Medicaid/Private Insurance markets.</p>
<p>Social Determinants of Health: Congress should allocate funds for the reconnect loan and grant program and eliminate the household threshold requirement. Access to basic infrastructure like electricity has a critical impact on health.</p>

Policy Change Recommendations

CMS and Commercial Payer Recommendations

Ensuring Equitable Access to Genetic Testing and Cancer Risk Reduction: All payers should cover appropriate genetic counseling and testing for individuals at high risk of cancer as well as related risk reduction services.

Addressing Clinical Trial Participation Barriers: CMS should ensure Medicare, Medicaid, CHIP, and exchange plans offer coverage of the costs of clinical trial participation including parking, transportation, and lodging.

Patient Navigation: CMMI and commercial payers should include reimbursement for patient navigators, community health workers, care coordination, and connection to social support services in alternative payment models.

Policy Change Recommendations

Federal Agency Recommendations

Data Collection: The Office of Management and Budget should revise their regulations dictating the collection and reporting of federal data on race and ethnicity. Data should be disaggregated from existing methods that fail to recognize the heterogeneity of African Americans, Pacific Islanders, Asians, Hispanics, American Indians and Alaska Natives.

Research: The Department of Health and Human Services should prioritize funds and resources for interdisciplinary research in SDOH and health disparities research. HHS should require health care systems to partner with community-based organizations to conduct research.

Cancer Prevention: The CDC should make the HPV vaccine an opt-out instead of an opt-in vaccine.

Patient Navigation: Create a Department of Labor code for Patient Navigators

Policy Change Recommendations

State Policymaker Recommendations

Medicaid Expansion: State governors and legislatures should expand their state Medicaid programs to increase access to screening, early detection and care.

Clinical Practice Guideline Recommendations

Guideline Change Recommendations

Clinical Practice Guideline Recommendations

Clinical practice guidelines should be reviewed for disparity issues within guidelines that could eliminate or reduce disparity. Additionally, clinical practice guidelines should incorporate language recognizing the existence of bias in care.

Clinical practice guidelines should incorporate a framework to account for health disparities into the panel processes. Panels should also consider adding a health equity expert representative.

Clinical Practice Guidelines should consider incorporating age adjustments on screening recommendations for specific populations that may have earlier manifestations.

Next Steps

Shonta Chambers, MSW

Next Steps

- Practice change recommendations will be presented at the NCCN Annual Conference on March 19th
- Policy change recommendations will be presented in Congressional briefings taking place in the spring
- Peer reviewed publication anticipated
- ACS CAN, NCCN, and NMQF will work to ensure the recommendations are realized through advocacy and outreach
- If you'd like to learn how you or your organization can help advance these recommendations, please fill out the form in chat and being sent following the call for more information!