

Cancer Research and Disparities: Understanding and Addressing the Issues



Executive Summary

The COVID-19 pandemic has made clear the significant disparities that exist in our health care system and the need to address their root causes, including in cancer care. Ensuring all individuals – regardless of age, race, ethnicity, socioeconomic status (SES), education, sexual orientation, insurance status, or zip code – have the same opportunities to prevent, detect, and treat cancer requires understanding what role research plays in potentially causing disparities as well as how research can help identify and address the causes of disparities. While disparities have been described in various domains of cancer research, each issue exists separately and has a different relationship to understanding and addressing disparities in clinical outcomes. The various domains of research disparities are explored in *Cancer Research and Disparities: Understanding and Addressing the Issues*.

Disparities in Cancer Clinical Trial Participation

Clinical trials are vital to advancing new and improved standards of care. They are intentionally conducted among a small portion of a population with a disease, but the intent is to apply the results to the larger population with disease.

Racial and ethnic minority groups, older adults, rural residents, and those with lower socioeconomic status (SES) tend to be underrepresented in cancer clinical trials, despite an increased burden of disease and an equal willingness to participate in clinical research. Representation of these groups varies significantly between the two primary types of sponsors of clinical trials – the federal government (e.g. National Cancer Institute) and the pharmaceutical industry. Broad health-system level barriers such as lack of insurance, lack of trials at sites serving underrepresented populations, the proportion of trials conducted in the U.S. versus globally, and clinical trial design are key drivers of underrepresentation.

Cancer clinical trials, especially those conducted for drug development, are not necessarily designed to identify, understand, or address disparities, even when a clinical trial's makeup is diverse and proportional to the broader population with a given cancer. Federal agencies and Congress have taken steps to address representation in both federal- and industry-sponsored trials, but there is no requirement for proportional representation.

DISPARITIES IN CANCER CLINICAL TRIAL PARTICIPATION

The makeup of cancer clinical trials does not represent the real-world population which limits the broader applicability of trial results, leading to social injustice.



RESEARCHING DISPARITIES IN CANCER OUTCOMES

Certain groups bear a disproportionate burden of cancer. Cancer disparities research investigates outcome differences between groups and the underlying factors driving the differences.

CANCER WORKFORCE DISPARITIES

The cancer care and research workforce does not represent the U.S. population demographically. A diverse workforce can help to reduce implicit biases and systemic disparities; however, structural barriers impede workforce diversity.



ACS CAN Policy Recommendations*

- **Maintain and expand access to Medicaid:** State Medicaid programs provide essential coverage for people with limited incomes including various populations likely to be underrepresented in clinical trials. States that have not already done so, should expand their Medicaid program pursuant to the provisions of the Patient Protection and Affordable Care Act.

* Additional policy recommendations for each section are included in the full report.

- **Shield patients from out-of-pocket ancillary costs of trial participation:** The U.S. Department of Health and Human Services' Office of the Inspector General should clarify policies to ensure reimbursement of ancillary costs such as travel, parking, and housing by clinical trial sponsors is not seen as undue influence and ensure awareness of allowable reimbursements.

Researching Disparities in Cancer Outcomes

Research to identify and address disparities in outcomes has to be deliberate and specifically designed. Such research often requires significant over-representation of sub populations. Disparities research is multi- and trans-disciplinary, spanning the fields of both clinical and social sciences which attests to the complex interaction of biological, structural, socioeconomic, and behavioral factors that influence disparities. Data informing this research are collected from a variety of sources and allow researchers to detect differences among subgroups within a population. Conclusions from this research can inform evidence-based solutions for alleviating disparities. Access to care, socioeconomic status (SES), and biology influence disparities in cancer outcomes and are primary areas of cancer disparities research. This research has shown that cancer outcomes are often worse for individuals who have limited access to care, lower SES, and among individuals that share certain genetic ancestries.

ACS CAN Policy Recommendations

- **Invest in biomedical and public health research at the National Institutes of Health (NIH), the National Cancer Institute (NCI), and the Centers for Disease Control and Prevention (CDC):** Not all people benefit equally from advancements in cancer prevention, screening, detection, and treatment which leads to disparities in cancer outcomes. Steady, significant funding increases to advance cancer disparities research at NIH, NCI, and CDC will help to identify, understand, and address the complex biological, structural, socioeconomic, and behavioral factors that prevent all people from benefitting from advancements in cancer care.

Disparities in the Cancer Care and Research Workforce

As racial and ethnic minority groups in the U.S. grow and increasingly make up a larger share of the population, addressing cancer disparities in these groups can be enhanced by increasing diversity within the cancer care and research workforce. The presence of a diverse workforce can contribute towards culturally competent care and help to reduce implicit biases and systematic disparities. However, the cancer care and cancer research workforce does not represent the U.S. population demographically, and many racial and ethnic minority groups – who often bear a disproportionate burden of cancer – are underrepresented. Issues contributing to lack of diversity are complex and include structural racism which has led to differences in achievement and opportunity to advance in the fields of medicine and medical research.

ACS CAN Policy Recommendations

- **Invest in a diverse cancer care and research workforce:** The National Institutes of Health (NIH), the National Institute on Minority Health and Health Disparities (NIMHD), and the National Cancer Institute (NCI) should expand existing opportunities and programs that support career development for scientists and researchers from underrepresented minority groups. Congress should allocate funds to Historically Black Colleges and Universities (HBCUs), tribal colleges, and other minority serving institutions (MSIs), for the purpose of increasing racial and ethnic minority representation across cancer research and care disciplines. Historically these institutions have succeeded in preparing students from underrepresented minority groups in these professions.