New Report Examines Causes and Solutions for Disparities in Cancer Research

Minority patients are more likely to report negative experiences about their cancer treatment.

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A new report from the American Cancer Society Cancer Action Network (ACS CAN) takes an in-depth look at disparities across all areas of cancer research and suggests immediate policy solutions that could help address such gaps in the years to come.

The report, Cancer Research and Disparities: Understanding and Addressing the Issues, finds that different types of research can either exacerbate or minimize cancer disparities as can the makeup of the cancer care and research workforce.

For instance, while racial and ethnic minority groups and older patients are equally willing to participate in clinical trials as other groups, they are often underrepresented in clinical trials. Reasons for this disparity in enrollment include everything from insurance status and trial location to the trial designs themselves; most of which are not designed to specifically identify, understand, or address disparities in cancer outcomes.

Also, research to identify and address disparities in outcomes has to be deliberate and specifically designed. This research often requires significant over-representation of certain populations and the inclusion of information from a wide array of clinical and social science work. Without such an approach research may miss why cancer outcomes are often worse for patients with limited access to care, lower SES and other factors.

“Addressing disparities in all areas of cancer research is essential to tackling the disproportionate cancer burden communities of color and people living in under-resourced areas too often experience,” said Lisa Lacasse, president of ACS CAN. “No one should be disadvantaged in their fight against cancer because of how much money they make, the color of their skin, their sexual orientation, their gender identity, their disability status, or where they live.”

Yet preliminary results from a forthcoming ACS CAN Survivor Views survey, finds Hispanic and non-white respondents were more likely to report a negative experience when asked about different aspects of their treatment, including whether they were confident they had access to the best and most effective treatment, if they were an active participant in their care and whether they were able to get the preventive care needed as a survivor. And more than 1 in 8 respondents whose annual household income is $35K or less reported that it is not easy to receive preventive care like check-ups and regular cancer screening.

Policy measures that would address research disparities were discussed during ACS CAN's National Policy Forum on the Future of Health Care earlier this month and included in the report entail:

- 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.
- 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.
- Issue permanent guidance on the conduct of decentralized clinical trials: During the COVID-19 pandemic the U.S. Food and Drug Administration (FDA) significantly expanded opportunities for the use of decentralized trial practices like telemedicine, which could allow greater participation of underrepresented groups in clinical trials. These flexibilities are set to expire with the end of the public health emergency.
- Address genetic variation leading to disparate responses to cancer therapeutics: Ancestry and genetic inheritance can have a direct effect on how a drug is metabolized, thus affecting the safety and efficacy of the treatment. FDA should collect evidence regarding differential safety and efficacy of therapies based on ancestry and ensure drug labeling accurately reflects these differences. Congress could also give FDA the authority to require sponsors to design clinical trials with appropriate demographic representation when prior evidence points to likely ancestral disparities in safety or efficacy.
- 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.

“Cancer research needs to reflect the people and communities it is meant to serve,” said Lacasse. “We cannot afford to ignore or neglect the critical role of diversity in advancing medical science. We need to take decisive action to eliminate cancer disparities in all areas of cancer care, including in cancer research.”

The full report, including all of the detailed policy provisions, and a recording of the National Policy Forum, where the report and other cancer equity issues are discussed, are both available online.

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