Overview:
The American Cancer Society Cancer Action Network (ACS CAN) gives voice to cancer patients and survivors on critical public policy issues that affect their lives. As part of this effort, ACS CAN deploys surveys to better understand cancer patient and survivor experiences and perspectives, through our Survivor Views research panel. The panel is a group of cancer patients and survivors who respond to regular surveys and provide important insights to support ACS CAN’s advocacy work at all levels of government.

Fielded May 16-26, 2022, the latest survey explores cancer patients’ and survivors’ experiences and perspectives on copay assistance. The web-based survey was conducted among 1,241 patients and survivors nationwide diagnosed with or treated for cancer in the last seven years, along with oversamples of 1,370 targeted interviews (see methodological note at end). The margin of sampling error associated with a sample of this size is +/-2.8% at a 95% confidence level.

Key Findings:
• Cancer care is expensive and prescription drug costs are a challenge for nearly one-third of cancer patients and survivors (31%), with one-fifth having skipped or delayed taking prescribed medications due to costs. The number of patients who have skipped or delayed treatment because of costs is higher among Black, Hispanic, Asian, and lower income patients.
• About half have heard of copay assistance programs but just one-quarter have applied to one. Those who have enrolled agree that the assistance provides access to medication through the program that they otherwise couldn’t afford (83%), while some who were unable to enroll reported declining treatment (8%) or going into debt to cover their prescription drug costs (18%).
• These negative impacts are even greater among some patient populations, with over one-quarter of Black, Hispanic, and Asian cancer patients and survivors reporting they have declined treatment due to cost after finding they were unable to enroll in a copay assistance program.

Detailed Survey Findings:
Prescription Drug Costs are a Challenge for Nearly a Third of Cancer Patients and Survivors
Thirty-one percent of cancer patients and survivors find it difficult to afford their prescription drug costs. Among patients with annual household income below $35,000, 45% find prescription drug costs difficult and one-in-five say it is very difficult to afford them. One-fifth report having skipped or delayed taking a prescribed medication due to difficulty paying the cost, with significantly higher rates of missed medication reported by lower income (44%), Asian/Pacific Islander (40%), Black (44%), and Hispanic (58%) patients and survivors.
Copay Assistance Programs Help Ensure Patients Receive Needed Medications

Although 51% have heard of copay assistance programs, most have not tried to enroll: 20% have applied and enrolled while 5% report applying but not ultimately enrolling. Over a quarter (27%) of those who enrolled report that the assistance they received was not applied to their deductible or other out-of-pocket cost requirements and another 22% were unsure. Among those who were unable to enroll in a copay assistance program they applied to, 18% ultimately borrowed money or went into debt to cover their prescription drug copayment costs while 15% declined the treatment (8%) or sought a less expensive treatment than their doctor had prescribed (7%).

For some populations, the negative impacts of not being able to enroll in copay assistance programs are more pronounced. Over a quarter of Black (29%), Hispanic (29%), and Asian (28%) patients and survivors reported declining the treatment due to cost after being unable to enroll in a copay assistance program, along with 23% of lower income respondents. These groups report even higher rates of borrowing money or accumulating debt in order to cover the costs of their prescription drugs after finding they were unable to enroll upon applying to a program.

Among cancer patients and survivors who have enrolled in copay assistance programs, the benefits are clear. Eighty-five percent agree that the assistance they receive provides significant savings, making their prescription drug costs much more affordable, while 83% say it helps them access medication they otherwise could not afford, and allows them to take their medication as prescribed. While 78% agree the copay assistance program they used was simple and easy to understand (41% strongly agree), 97% say it is important for programs like copay assistance to be as simple and easy to use as possible for cancer patients (92% strongly agree).
ACS CAN’s Survivor Views research initiative was designed to enhance the organization’s mission to end suffering and death from cancer. Data provided by cancer patients and survivors as part of this project allows for a greater understanding of their experiences and opinions on cancer-related issues and gives voice to cancer patients and survivors in the shaping and advocating of public policies that help prevent, detect, and treat cancer and promote a more positive quality of life for those impacted.

To ensure the protection of all participants in this initiative all research protocols, questionnaires, and communications are reviewed by the Morehouse School of Medicine Institutional Review Board. The survey population is comprised of individuals who meet the following criteria:

- Diagnosed with and/or treated for cancer within the last seven years
- Over the age of 18 (parents of childhood cancer survivors were invited to participate on behalf of their minor children)
- Reside in the US or US territories

Potential Survivor Views participants were invited to participate through email invitations, social media promotion, and partner group outreach. Those who agreed to participate after reviewing the informed consent information completed a brief survey including demographic and cancer history information to inform analysis as well as topical questions as discussed in this document. The data were collected between May 16-26, 2022. A total of 1,241 cohort participants responded to the survey, providing a margin of error of +/- 2.8 percentage points at a 95% confidence level.

In addition to interviews conducted among the Survivor Views cohort, another 1,370 interviews were conducted among demographic groups that are often not included at sufficient numbers to allow for in-depth statistical analysis even when they are sampled at representative levels compared to the national cancer survivor population. This report summarizes the results of the cohort survey sample for consistency with other Survivor Views surveys, and includes the findings of our analysis of the oversamples where significant differences are observed among these groups.

The demographics of the cohort include:
- 16% Black/African American
- 9% Hispanic/Latino
- 3% Asian/Pacific Islander
- 17% Lower income households

The oversample interviews include:
- 589n Black/African American
- 497n Hispanic/Latino
- 229n Asian/Pacific Islander
- 524n Lower income households

About ACS CAN
The American Cancer Society Cancer Action Network (ACS CAN) is making cancer a top priority for public officials and candidates at the federal, state and local levels. 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 that will reduce the cancer burden. As the American Cancer Society’s nonprofit, nonpartisan advocacy affiliate, ACS CAN is critical to the fight for a world without cancer. For more information, visit www.fightcancer.org.