

Current Challenges Facing Cancer Survivors

May 2021 Survey Findings Summary



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 patients' and survivors' experiences and perspectives, through efforts such as our [Survivor Views](#) research panel. The panel is a group of cancer patients and survivors who respond to regular surveys on their perspectives and experiences to provide important insights to support ACS CAN's public policy work at all levels of government.

Fielded March 30 to May 14, 2021, the latest survey gathered input on important current issues including the impact of the COVID-19 crisis on survivor cancer screening, disparities in accessing health care, and the public policy priorities with the greatest opportunity to impact their lives. The web-based survey was completed by 1,280 patients and survivors diagnosed with or treated for cancer in the last seven years. This sample provides a margin of error +/-3% at a 96% confidence level. The research provides important insights into the experiences and opinions of cancer patients and survivors in accessing care for their cancer in the midst of the pandemic.

Key Findings:

Key findings from the survey include:

- Regular cancer screening is a critical component of care for cancer patients and survivors, but nearly one in six respondents (16%) reported a delay or interruption to their recommended cancer screening within the last three months. These disruptions have impacted both screening for their primary cancer (11%) and additional cancers for which they require monitoring (5%). Screening disruptions are in most cases attributable to the impact of COVID-19, including logistical issues such as staffing shortages or lack of available appointments (26%) and patient concern about contracting COVID-19 (22%). However, nearly half of all cancer patients and survivors surveyed have not talked to their providers about what modifications, if any, they should make to cancer screening during the pandemic.
- More than one third of cancer patients and survivors report difficulty accessing care during the COVID-19 pandemic (35%). Younger patients are more likely to have encountered difficulty accessing care (44% of those under age 50), and those who indicated their race as American Indian and Asian or Pacific Islander (44%) were far more likely to have encountered challenges accessing care.
- The overall cost of health care was identified by over one third of cancer patients and survivors (36%) as the most important challenge to address in order to help people with cancer. This issue is critical because it affects the ability to afford all of the treatments and services needed by cancer patients and survivors. Further, nearly one in ten respondents (8%) believe that providers' perceptions of their ability to pay for care limits the treatment options offered. This belief is stronger among racial and ethnic minority respondents, 11% of whom believe this to be true.

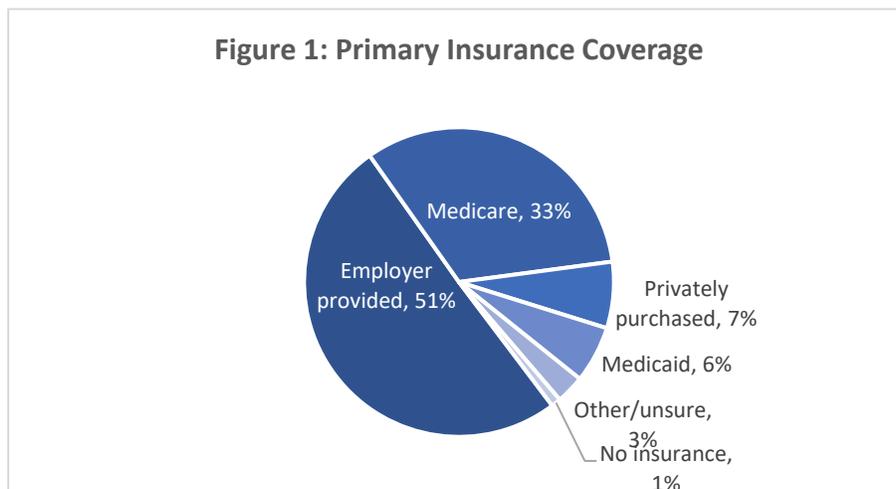
Current Challenges Facing Cancer Survivors

May 2021 Survey Findings Summary



Detailed Survey Findings:

The survey included a wide range of US cancer patients and survivors diagnosed with or treated for cancer within the last seven years. Nearly a third (32%) were currently in treatment for their cancer at the time of the survey and another 36% completed treatment in the last three years. A majority have employer-provided health care coverage, while a combined 39% have Medicare or Medicaid.



It's important for cancer survivors to have a clear understanding of the preventive care and ongoing cancer screenings they need. Nearly three quarters of respondents (73%) agree that their providers offered information and recommendations to inform their preventive care. However, younger cancer survivors were less likely to feel this is the case, with only 66% of those under the age of 40 and 68% of those between 40-49 agreeing their providers had shared this information. Similarly, younger respondents were more likely to report difficulty getting the preventive services needed as a cancer survivor, with 29% of those under the age of 40 indicating it is not easy, compared to 18% of all respondents, a difference that is statistically significant.

With regard to cancer screenings, more than three in four respondents (77%) agree or strongly agree with the statement "My health care providers have clearly communicated what cancer screenings I should have as a cancer survivor (including monitoring for recurrence and screening for new or additional primary cancers)." Respondents of Hispanic, Latino/a, or Spanish origin were less likely to agree (73%) as were Black respondents (69%).

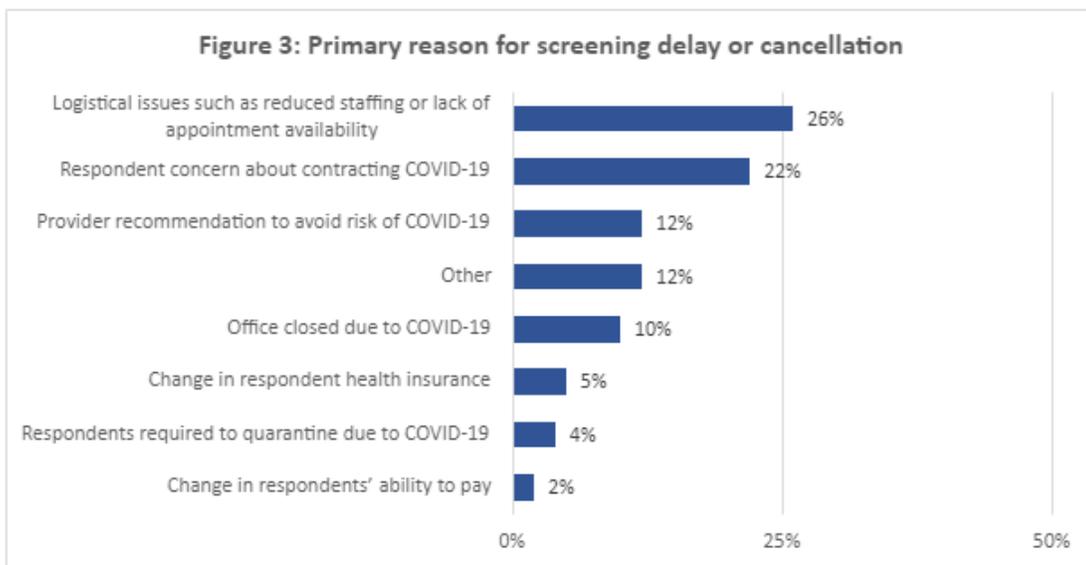
The COVID-19 pandemic has substantially disrupted access to health care, including the ability for cancer patients and survivors to maintain their regular screenings. While most reports indicate that these disruptions have improved since the early days of the pandemic, these data confirm that screening disruptions continue. In the last three months, nearly one in six (16%) of cancer patients and survivors report having experienced a delay or disruption to cancer screenings. These disruptions have impacted both screening for their primary cancer (11%) and additional cancers for which they require monitoring (5%).

Current Challenges Facing Cancer Survivors

May 2021 Survey Findings Summary



The most commonly cited reasons for those delaying or cancelling cancer screenings were logistical issues such as staffing shortages or lack of appointments (26%) and patient concern about contracting COVID-19 (22%), and Other (20%). The other category included a variety of reasons for screening disruptions, some COVID-related (such as the need to properly space screening procedures from vaccine administration and outbreaks in provider offices) and others related to the respondent's individual health or insurance situation (such as coordinating with more pressing treatment needs and issues with insurance coverage).



Among those whose cancer screenings were disrupted in the last three months, just over half have since rescheduled or completed the screenings (53%), while another 15% have rescheduled or completed some, but not all. As more of the US population becomes vaccinated for COVID-19, we can expect that some of the screening impact should abate. However, it is worth noting that 18% of respondents had not yet been vaccinated (partially or fully) at the time of the survey. Nearly one in five (17%) of those who have not been vaccinated indicated that they cannot receive the vaccine due to health issues.

To accommodate disruptions to cancer screenings, it's important that cancer survivors communicate with their health care providers. However, only 55% of respondents report having talked to their providers about what modifications, if any, they should make to cancer screenings during the pandemic. Patients who completed treatment 5 or more years ago were least likely to have discussed potential modifications needed (37%), while those currently in treatment or who recently completed treatment had better guidance.

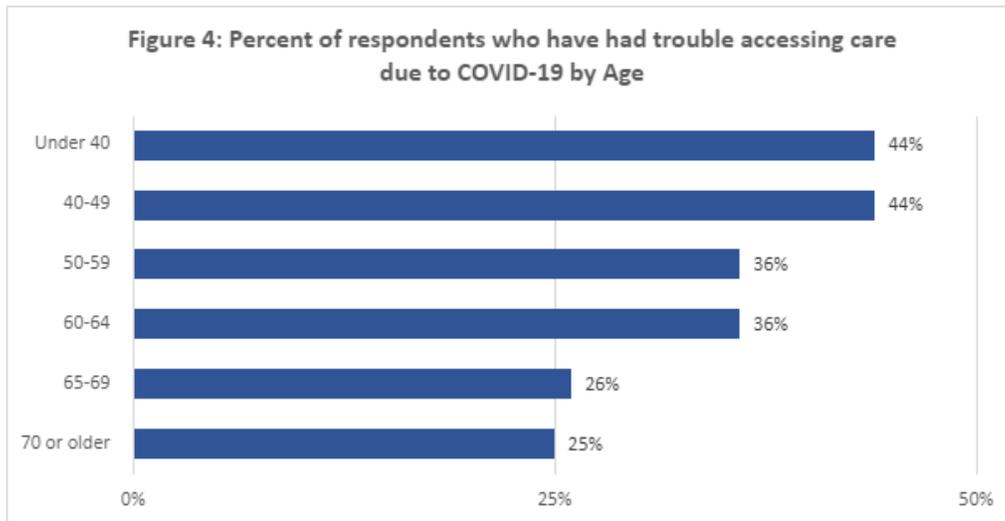
Previous ACS CAN surveys have documented the difficulty cancer patients and survivors experienced accessing care during the COVID-19 pandemic. In this survey, we asked respondents to characterize the

Current Challenges Facing Cancer Survivors

May 2021 Survey Findings Summary



degree of difficulty they are currently having compared to earlier stages of the pandemic. Over a third of respondents (35%) reported some degree of difficulty accessing care. While many of these (21% overall) indicated that the difficulty they experienced in the early stages of the pandemic has improved, 9% report that it is even more difficult now. Four percent indicated no change, saying it was difficult earlier in the pandemic and continues to be difficult now.



Also of note, respondents who reported their race as American Indian or Asian or Pacific Islander were more likely to report trouble accessing care due to COVID-19 (44%) as were those insured through Medicaid (44%). Both of these results are statistically significant differences.

More than a third of survey respondents (36%) identified the overall cost of health care as the most important challenge to address in helping people with cancer. This priority is even higher in importance for respondents whose annual household income is below \$35,000 (40%) and those insured through a privately purchased or employer-sponsored plan (39%). However, access to high quality care regardless of where one lives or receives care was the most commonly selected priority for respondents of Hispanic, Latino/a, or Spanish origin (33%) and Black respondents (39%).

Figure 5: Most important challenge to address to help people with cancer

Priority	All respondents	Black respondents (n=66)	Hispanic, Latino/a, or Spanish origin respondents (n=78)
The overall cost of health care	36%	26%	31%
The ability for all cancer survivors to get high quality health care, regardless of location	26%	39%	33%
Ongoing research to develop more effective treatments for cancer	17%	17%	18%

Current Challenges Facing Cancer Survivors

May 2021 Survey Findings Summary



Information and support to navigate cancer treatment and survivorship	16%	17%	12%
Other	4%	2%	6%

Addressing the cost of health care is an important priority because it improves the accessibility of services and treatments to prevent, detect, and treat cancer. However, respondents to our survey also noted the perceived impact of affordability on the quality of care and treatment received. Nearly one in ten respondents (8%) agreed or strongly agreed with the statement “The treatment options offered to me by my provider are limited by what he or she thinks I can afford.”

This perception was stronger among respondents whose annual household income is less than \$35,000 (16%), those insured by Medicaid (21%), and those whose highest education level is a high school degree or less (13%); all of these differences are statistically significant. Lower income respondents were also less likely to feel confident that they received the very best treatment available for their cancer (81% believe this to be true, compared to 88% of all respondents, a difference that is statistically significant).

Notably, racial and ethnic minority respondents (including all non-white respondents and respondents of all Hispanic origins) were also more likely to believe their treatment options are limited by providers’ perceptions of their ability to pay, with 11% agreeing or strongly agreeing that this is true. Similarly, 15% of Hispanic respondents and those whose race is American Indian, Asian or Pacific Islander responded no to the question “Did your health care provider ask you what you wanted from your care and make you an active participant in your treatment decisions?” (compared to 13% of all respondents).

Methodology:

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

Current Challenges Facing Cancer Survivors

May 2021 Survey Findings Summary



inform analysis as well as topical questions as discussed in this document. The data were collected between March 30 and May 14, 2021. A total of 1,280 participants responded to the survey, providing a margin of error +/- 3% and 96% confidence level.

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.