

Survivor Views: Biomarker Testing

Survey Findings Summary



Overview:

The American Cancer Society Cancer Action Network (ACS CAN) established *Survivor Views* in January 2019. The project has established a cohort of 3,057 cancer patients and survivors diagnosed with and/or treated for cancer within the last five years who are willing to share their opinions and experiences through a series of surveys focused on policy issues impacting cancer patients and survivors.

Two *Survivor Views* cohort surveys included questions related to genetic and biomarker testing. A survey from November-December 2019 collected data from 1,153 panelists (38% response rate; margin of error of +/- 3%; 95% confidence level) on topics including their understanding of the role of genetics in cancer and different types of genetic tests. A subsequent survey in May-June 2020 drew responses from 933 cohort members (31% response rate, margin of error +/- 4; 98% confidence level) on their personal experiences with biomarker testing, affordability and the role of testing in their course of treatment.

The research provides important insights into the experiences of cancer patients and survivors in navigating their cancer care.

Key Findings:

Key findings from the 2019 survey include:

- The majority of respondents (92%) reported having at least some understanding of genetics and their role in cancer.
- Nearly three-quarters (73%) reported knowing a little or a lot about tumor profile testing, while only 8% have never heard of this type of genetic test.

The 2020 survey provided additional details on tumor profile testing, specifically, henceforth referred to as “biomarker testing.” Key findings from the 2020 survey include:

- Thirty-nine percent of respondents reported having biomarker testing, however 25% were unsure if they had been tested.
- Testing was covered by insurance for most (74%), particularly those with Medicare. While a majority (56%) reported no out of pocket costs, patients who did pay out-of-pocket mostly spent \$500 or less (31%); however, 15% indicated that they paid \$500 or more out-of-pocket for their testing.
- Of those tested, 68% agreed or strongly agreed the test helped providers better treat their cancer, 24% reported that their treatment protocol changed based on the test results and 4% joined clinical trial based on findings.
- Among those who discussed biomarker testing but did not get tested, 29% did not have it done because insurance would not cover it or their out-of-pocket costs would be too high.

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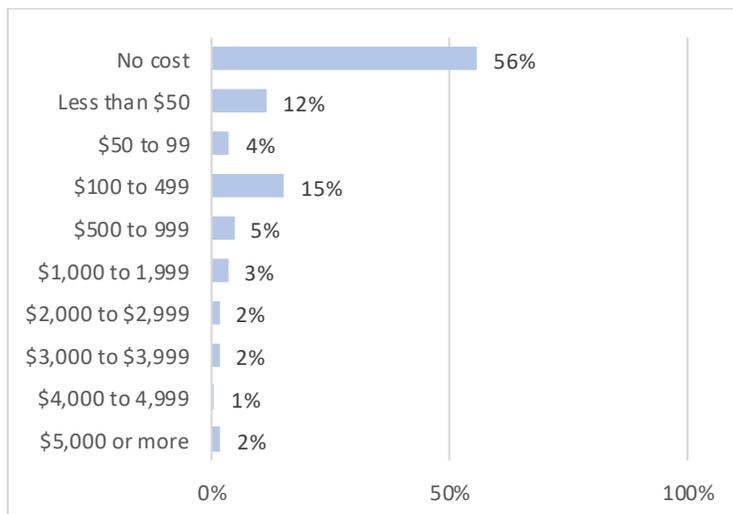
Survey Findings

The 2019 *Survivor Views* survey asked cancer patients and survivors about their baseline understanding of genetic testing. Most respondents (79%) indicated some understanding of genetics and their role in cancer, while 13% reported they were close to or had attained expert understanding, and 6% reported no understanding at all. Respondents were somewhat less confident in their understanding of biomarker testing: 57% indicated they know a little about it; 16% know a lot about it; 20% have heard of it but do not know what it is; and 8% who have never heard of it.

The 2020 *Survivor Views* survey focused on experiences of biomarker testing. One-quarter of respondents (25%) were unsure if they had ever had biomarker testing for their cancer. Of those who were certain, respondents were almost equally split between those who reported they had biomarker testing (39%) and those who had not (36%).

Focusing on those patients who reported having biomarker testing, 84% did so based on their provider's suggestion and 14% indicated that they asked for testing. Nearly three-quarters (74%) reported their insurance covered the test, and more than half (56%) paid no out of pocket costs for the test (Figure 1). Among those who did incur direct costs, most paid under \$500 (31% of all who were tested) and 15% of respondents indicated that they had paid \$500 or more out-of-pocket for their testing.

Figure 1: Out-of-pocket costs for biomarker testing



Insurance coverage for biomarker testing varied by type of insurance (Table 1), with respondents insured by Medicare most likely to report the test being covered, while those on privately purchased plans were least likely.

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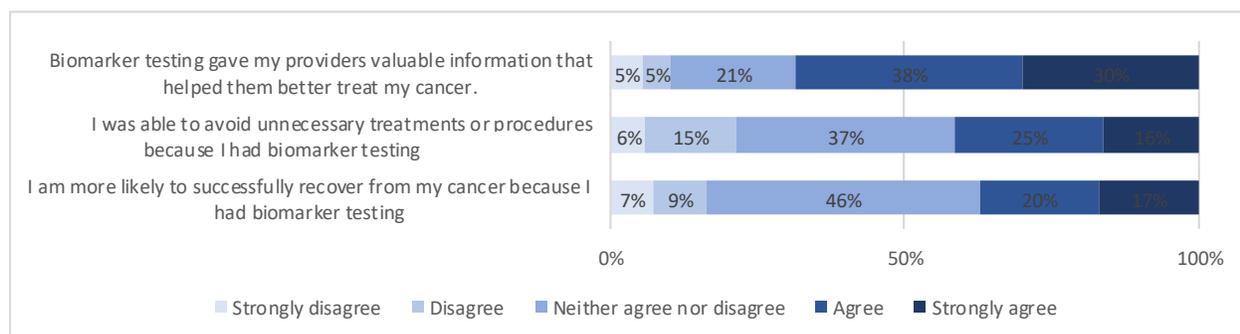


Table 1: Biomarker testing coverage by insurance type

	Primary insurance at time of treatment		
	Privately purchased (N=30)	Employer provided (N=246)	Medicare (N=32)
Testing covered	63%	74%	91%
Testing not covered	33%	13%	3%
Unsure	3%	10%	3%
Not applicable	0%	3%	3%

Of those tested, 64% reported the results did not change their treatment, but 24% did report a change in their treatment protocol and 4% enrolled in a clinical trial based on the findings. Respondents tended to report biomarker testing had positive effects on their cancer care (Figure 2). Sixty-eight percent report that biomarker testing provided valuable information that helped their provider better treat their cancer and 41% believe they were able to avoid unnecessary treatment thanks to biomarker testing. Respondents were less certain about the role of biomarker testing in their recovery, however, with 37% reporting they were more likely to successfully recover because of testing but 46% were unsure.

Figure 2: Sentiments about biomarker testing



Among those who did not have biomarker testing, the majority (69%) did not discuss it with their provider. Of the 13% who did discuss testing with their provider, 8% raised the issue themselves and 5% reported the provider initiated the discussion. For those who discuss biomarker testing with a provider but ultimately were not tested, 38% reported they were not good candidates for testing and 26% were not tested because insurance would not cover it. Sixty seven percent of those who did not have biomarker testing indicated that if they were a candidate, they would want to have it done.

Methodology

Survivor Views is an ACS CAN initiative 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.

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To ensure the protection of cohort participants as we pursue these objectives, all research protocols, questionnaires, and communications undergo review by the Morehouse School of Medicine Institutional Review Board.

The *Survivor Views* cohort is comprised of individuals who meet the following criteria:

- Diagnosed with and/or treated for cancer within the last five years
- Over the age of 18
- Reside in the US or US territories

Survivor Views collects data via web-based surveys. The 2019 survey was sent to 3,057 *Survivor Views* cohort members. The data were collected between November 20 and December 17, 2019. A total of 1,153 participants responded to the survey, a 38% response rate. This sample provides a margin of error +/- 3% and 95% confidence level.

The 2020 survey was sent to 3,054 *Survivor Views* cohort members. The data were collected between May 27 and June 17, 2020. A total of 933 participants responded to the survey, a 31% response rate. This sample provides a margin of error +/- 4% and 98% 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.