

Data Brief

2021 Behavioral Risk Factor Surveillance System Wisconsin Cancer Survivorship Report

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KEY POINTS

- In 2021, BRFSS surveyed over 700 cancer survivors in Wisconsin about their experiences for a second year in a row.
- Although the sample size was larger compared to the 2020 report, continued efforts to improve representation from different racial groups and LGBTQ+ populations are needed, so that the data can better reflect the survivorship experiences of all people of Wisconsin.
- Improved data collection and representative data sources are needed to ensure high-quality population-level data to inform statewide cancer control.

Introduction

A cancer survivor, as defined by the National Cancer Institute, is a person who continues to live and function from the time of diagnosis until the end of life.¹ Thus, survivorship care encompasses all phases of care including those related to the physical, psychological, social, and financial effects of a cancer diagnosis and treatment. Such care spans multiple disciplines and requires the work of several different specialists within medicine, psychology, and more.

The Behavioral Risk Factor Surveillance System (BRFSS) is an annual telephone survey conducted by the Centers for Disease Control and Prevention (CDC), in partnership with state health departments, to collect state-level data on chronic conditions, health-related behavioral risk factors, and preventive service use.² In 2020 and 2021, BRFSS questions on the topic of cancer survivorship were included in the survey, and this data was obtained by the Wisconsin Cancer Collaborative to monitor the unique needs of Wisconsin cancer survivors. The following report is the second iteration of this data analysis, limited to 2021 surveys, to monitor and assess cancer survivors' needs.

Methods

In 2021, Wisconsin residents were interviewed by telephone (N=6,106). BRFSS modules used in Wisconsin included cancer survivorship-related questions asked of participants with a self-reported history of cancer. Survey participants with no cancer history (N=4,996) or history limited to "other" types of skin cancer (i.e., non-melanoma skin cancers, N=277) were excluded from the analysis, so 722 cancer survivors were included in the analysis.

A total of 5,099 Wisconsin residents participated in the 2020 BRFSS survey, including 501 cancer survivors. That report and analysis can be referenced [here](#).³ Data are shown with weighted percentages per BRFSS recommendations. BRFSS provides survey weights so that results are representative of the demographic characteristics of the entire state of Wisconsin, not just the respondents. After accounting for

factors that may influence a person's decision to complete the survey, raw percentages were converted into weighted percentages to yield more representative results and to reflect the survey sampling.⁴

Estimates with relative standard errors greater than 30% and confidence intervals wider than 20% should be interpreted with caution due to insufficient sample size and/or large error terms. Although the data should be interpreted with caution, they are displayed for transparency but marked with an asterisk to indicate potential caution.

Results

Of Wisconsin cancer survivors surveys, the majority were non-Hispanic white (95%), older than 55 (89%), lived in an urban setting (75%), heterosexual (93%), and had completed cancer treatment (76%). More than half were female (60%) (Table 1).

The percentage of Wisconsin cancer survivors who received written treatment summaries of their cancer treatments varied across race and ethnicity categories, with more non-Hispanic Black survivors (89%)* receiving written treatment summaries than non-Hispanic White (53%) survivors (Table 2). Also, a greater percentage of urban survivors received a written treatment summary (54%) than rural survivors (44%)*. Fewer rural survivors (73%)* also received follow-up instructions about where they should return or who they should see for routine cancer checkups after completing cancer treatment compared to urban survivors (81%).

Colorectal cancer survivors had the highest written treatment summary receipt (68%)* of all cancer types while lung cancer survivors reported the lowest (38%) (Table 3). Similarly, more survivors younger than age 55 (87%)* received follow-up instructions than survivors older than age 55 (79%).

An estimated 98% of Wisconsin cancer survivors had health insurance that paid for at least part of their cancer treatment. Survivors younger than age of 55 are more likely to have pain related to their cancer or cancer treatment (25%)* compared to survivors older than 55 (10%). Differences also exist by gender and race, with female survivors more likely to have pain (18%) than male survivors (7%)*, and non-Hispanic Black survivors more likely to have pain (45%) than non-Hispanic white survivors (13%). Clinical trial participation was highest among colorectal cancer survivors (19%)* and lowest among lung cancer survivors (0%). Overall clinical trial participation was 9% (Table 2), which is higher than the most recent national estimate of 6.6%.⁵

Limitations

Sample sizes were limited for race and ethnicity identities other than non-Hispanic white survivors, non-heterosexual survivors, and survivors of certain cancer types. The margin of error for the results for these groups should be viewed in that context.

Implications for Cancer Control

The Wisconsin Cancer Plan 2020-2030 guides cancer control work in Wisconsin through its best practices, data, and concrete action steps.⁶ BRFSS is one of the data sources used in the Wisconsin Cancer Plan 2020-2030 to help inform measures and guide progress.⁶ BRFSS

survivorship module questions are used for three measures: percent of patients with physical pain from cancer or cancer treatment whose pain is under control, percent of cancer patients participating in a clinical trial as part of their cancer treatment, and percent of cancer survivors who have a Survivorship Care Plan (SCP).

Implications for Cancer Survivors

To acknowledge the diverse experiences of cancer survivors and ensure the relevance of future work to the communities of greatest need, including groups whose identities have been underrepresented in prior research studies should be prioritized. Measures to increase receipt of treatment summaries and follow-up instructions for survivors across rural-urban locations, racial groups, and cancer types may increase transparency of care to patients and improve future care for cancer survivors. Additionally, increased access to health care, regardless of pre-existing conditions, can lead to meaningful steps toward decreasing the financial burden of cancer treatment and survivorship care. Reaching more people of all races, genders, sexual orientations, and other identities will be necessary to illustrate the diverse experiences of all Wisconsin cancer survivors. Improving other data collection sources to best represent underrepresented populations is essential when BRFSS may not be the best data source for a population due to a small population or sample size.

Table 1: Cancer Survivor Survey Participant Characteristics

Survey Participant Characteristics	Number of Participants	Estimated/Weighted %	95% CI
Sex			
Male	290	40%	36.6-43.8%
Female	432	60%	56.2-63.4%
Residence			
Urban	544	75%	72.2-78.5%
Rural	178	25%	21.5-27.8%
Race and Ethnicity (Non-Hispanic=NH)			
White (NH)	678	95%	93.5-96.7%
Black (NH)	16	2%	1.2-3.3%
American Indian, Alaska Native (NH)	11	2%	0.6-2.4%
Hispanic	4	1%	0.0-1.1%
Other (NH)	1	0%	0.0-0.4%
Age			
Less than 55	83	12%	9.2-13.8%
55 and older	639	88%	86.2-90.8%
Sexual Orientation			
Heterosexual	655	93%	91.2-94.9%
Gay/Lesbian	14	2%	1.0-3.0%
Bisexual	13	2%	0.8-2.8%
Other or don't know how to answer	22	3%	1.8-4.4%
Treatment Status			
Active	99	14%	11.8-17.0%
Complete	524	76%	73.1-79.5%
Declined	6	1%	0.2-1.6%
Not Started	58	8%	6.4-10.5%

Note: Raw percentages were converted into weighted percentages to yield more representative results and to reflect the survey sampling.

Table 2: Cancer Survivor Responses by Race and Ethnicity

BRFSS Survivorship Experience Survey Question	Overall Number of Participants	Overall Estimated/Weighted %	Overall 95% CI	Number of Non-Hispanic Black Participants	Non-Hispanic Black Estimated/Weighted %	Non-Hispanic Black 95% CI	Number of Non-Hispanic White Participants	Non-Hispanic White Estimated/Weighted %	Non-Hispanic White 95% CI
Care Plan									
Received written treatment summary	274	53%	46.5-58.7%	8*	88.9%*	76.1-100.0%*	259	53%	46.9-59.1%
Received follow-up care plan	414	80%	75.4-85.1%	10	94%	82.3-100.0%	388	80%	75.1-84.8%
Insurance									
Insurance paid for all or part of treatment costs	504	98%	96.3-99.3%	11	97%	88.7-100.0%	474	98%	96.3-99.4%
Denied health or life insurance due to cancer	33	6%	3.3-9.0%	1*	1%*	0.0-2.4%*	29	6%	2.8-8.1%
Clinical trial participation	36	9%	5.4-12.3%	0	0%	--	35	9%	5.5-12.8%
Pain									
Experiencing current pain secondary to cancer or treatment	80	13%	9.3-17.1%	2	45%	40.5-48.6%	73	13%	9.2-17.2%

Note: Raw percentages were converted into weighted percentages to yield more representative results and to reflect the survey sampling.
 *Estimates should be interpreted with caution due to insufficient sample size and/or large error terms.

Table 3: Cancer Survivor Responses by Cancer Type

BRFSS Survivorship Experience Survey Question	Number of Breast Cancer Participants	Breast Estimated/Weighted % (95% CI)	Number of Prostate Cancer Participants	Prostate Estimated/Weighted % (95% CI)	Number of Colon/Rectal Cancer Participants	Colon/Rectal Estimated/Weighted % (95% CI)	Number of Lung Cancer Participants	Lung Estimated/Weighted % (95% CI)	Number of Other Cancers Participants	Other Cancers Estimated/Weighted % (95% CI)
Care Plan										
Received written treatment summary	73*	62%* (51.0-72.3)	30*	50%* (37.3-63.4)	14*	68%* (48.3-86.6)	8	38% (33.1-42.1)	137	50% (41.1-58.1)
Received follow-up care plan	102	79% (71.0-86.8)	51*	86%* (74.8-97.9)	19*	79%* (66.9-91.4)	11	84% (82.4-84.8)	211	81% (73.7-87.2)
Insurance										
Insurance paid for all or part of treatment costs	126	100% (98.5-100.0)	58	97% (92.6-100.0)	23*	93%* (75.8-100.0)	13	100% (99.8-100)	254	98% (96.8-100.0)
Denied health or life insurance due to cancer	9*	6%* (1.0-10.1)	4*	6%* (0.0-13.6)	0	0%	0	0%	20	8% (3.2-12.3)
Clinical trial participation	10*	6%* (1.0-10.9)	4*	12%* (4.3-19.1)	5*	19%* (0.0-48.0)	0	0%	17	10% (4.2-15.0)
Pain										
Experiencing current pain secondary to cancer or treatment	30	28% (18.3-37.9)	6*	5%* (0.0-12.2)	5	10% (3.5-15.9)	5*	16%* (2.3-29.5)	30	9% (4.3-14.1)

Note: Raw percentages were converted into weighted percentages to yield more representative results and to reflect the survey sampling.
 *Estimates should be interpreted with caution due to insufficient sample size and/or large error terms.

References

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