



Cancer Survivorship Needs Report



September, 2018

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Background

A cancer survivor is traditionally defined as a person diagnosed with cancer, from the time of diagnosis throughout the person’s lifespan. In Michigan, there are an estimated 526,100 cancer survivors.¹ Michigan’s Cancer Plan includes a section on survivorship. Its goal is to, “optimize the quality of life for every person affected by cancer.”² To reach this goal, Michigan needed to better understand demographics and needs of this population.

Some survivors will lose their life to cancer, others will live with cancer as a chronic disease, and some may live cancer free for the rest of their lives. However, many post-treatment survivors have ongoing physical or emotional effects of cancer or its treatment.¹ The task for these survivors is to learn how to cope with the changes that come with cancer and to focus on health and quality of life¹. Ideally, services will be in place to assist cancer survivors during this transition.

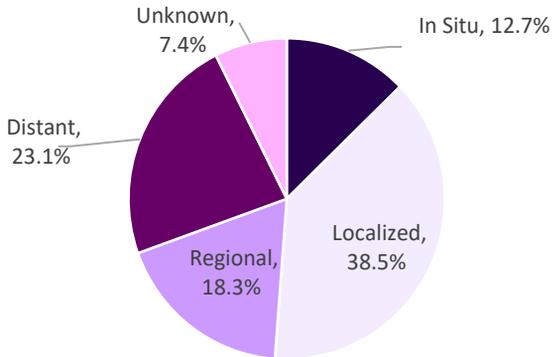
As part of a 3-year grant from the Centers for Disease Control and Prevention, Michigan identified surveillance data available to assist with understanding the survivor population. It was determined that there are limits to what surveillance data can tell us about the needs of cancer survivors. As a result, focus groups were held with cancer survivors in both rural and urban areas to provide a more comprehensive understanding of survivor needs. Throughout this project, the focus was on all cancers to allow understanding of the survivorship population as a whole. The purpose of this report is:

1. To describe surveillance data on cancer survivorship available through the Cancer Registry.
2. To describe surveillance data on cancer survivorship available through the Michigan Behavioral Risk Factor Surveillance System (MiBRFSS).
3. To report needs identified by cancer survivors in focus groups.



Part 1: Michigan Cancer Registry

Figure 3: Newly Diagnosed Cases by Stage, 2015 Michigan Cancer Surveillance Program



In 2015, about 38.5% of cancers were diagnosed at a localized stage (**Figure 3**). Early detection is one of the most important factors for success of treatment and survival.⁵ Diagnosis in the regional and distant stages dramatically affects the chance of survival. Cancer screening looks for cancer before the onset of symptoms and can assist with early detection. Cancer screening exists for the four most common cancers including lung, breast, prostate and colorectal cancers. Cancer screening is also available for cervical and skin cancer.

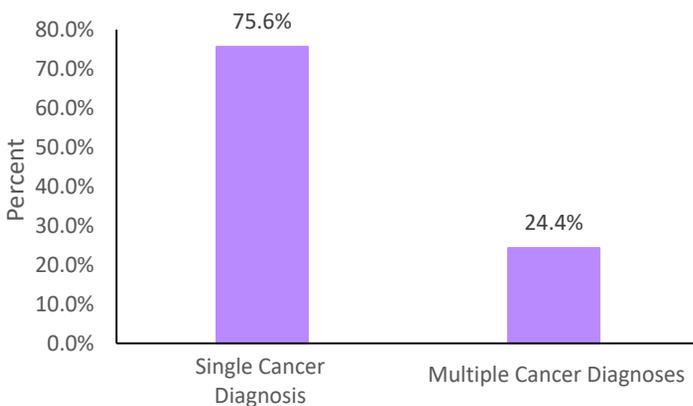
The 1-year survival rate for people diagnosed from 2008-2014 was 80.5%. The five-year survival rate for people diagnosed from 2008-2014 was 66.9%. For a localized cancer, the five-year survival rate was 90.9%; for distant stage, the rate drops to 26.2%.

Table 1 summarizes the one- and five-year survival rates for the four cancers with the highest incidence and/or death rates in Michigan.⁷

Table 1: Survival Rates for Select Cancers, 2008-2014 SEER

	One Year Survival Rate	Five Year Survival Rate
Lung Cancer	Male: 41.4% Female: 49.3%	Male: 15.5% Female: 22.0%
Breast Cancer	97.4%	89.7%
Prostate Cancer	99.3%	98.2%
Colorectal Cancer	Male: 84.4% Female: 82.8%	Male: 64.1% Female: 64.9%

Figure 4: Percent of Cancer Patients with a Single or Multiple Cancer Diagnosis, 2015 Michigan Cancer Surveillance Program



Cancer survivors are at greater risk of additional cancer diagnoses as compared to persons without a cancer history.¹ However, the diagnosis of a second new type of cancer happens infrequently. **Figure 4** shows that in 2015, 75.6% of cancer patients added to the registry had only one cancer diagnosis compared to 24.4% who had more than one diagnosis either in 2015 or in previous years.³ These data do not reflect recurrence of the same cancer. Survivors may be able to reduce their chances of a second cancer through life style interventions such as smoking cessation, physical activity, proper nutrition and limiting alcohol intake.⁶

Part 2: Michigan Behavioral Risk Factor Survey

The MiBRFS is an annual statewide phone survey of Michigan adults aged 18 years and older, which is coordinated with the Centers for Disease Control and Prevention (CDC). In 2011, the CDC developed a cancer survivorship module for the MiBRFS. Michigan asked the module in 2011 to one-third of the MiBRFS survivors and all MiBRFS survivors in 2015 to 2018. Due to changes in the questionnaire, data collected from 2016 to 2018 cannot be compared to the 2011 data. The results of these questions were used to determine the prevalence of cancer survivors and analyze relevant characteristic of this population.

In 2016, 12.8% of Michigan adults reported having cancer. Respondents who were cancer survivors were older compared to those who were not cancer survivors (67.6% vs. 24.7%). Because a cancer diagnosis is closely related to age, these estimates are age adjusted to the United States 2000 standard population to allow for a more accurate comparison between cancer survivors and the general population.

Statistical differences were found between cancer survivors and non-cancer survivors by gender, race, employment status and disability status. Notably, the proportion of non-Hispanic Black respondents who are cancer survivors was significantly lower compared to the proportion of non-Hispanic Black respondents who never had cancer. This may be related to the higher mortality rate of cancer in Black men and women, which would remove them from the pool of eligible survey respondents.³

A higher percentage of cancer survivors report their employment status as non-working compared to those who never have had cancer. This may be due to treatment, disability or a choice for early retirement.

Table 2: Age-Adjusted Demographics by Cancer Status, 2016 Michigan Behavioral Risk Factor Survey (MiBRFS)

		Ever Had Cancer % (95% CI)	Never Had Cancer % (95% CI)
Gender	Female ^a	63.1 (56.1-69.5)	51.0 (49.7-52.3)
	Male ^a	36.9 (30.5-43.9)	49.0 (47.7-50.3)
Race	Non-Hispanic White ^a	85.4 (79.0-90.1)	75.6 (74.4-76.8)
	Non-Hispanic Black ^a	6.5 (4.4-9.6)	14.2 (13.3-15.2)
	Hispanic	4.9 (1.9-12.4)	4.7 (4.1-5.4)
	Other	3.2 (2.0-5.0)	5.5 (4.9-6.1)
Income	Less than 20,000	18.5 (12.9-25.6)	18.5 (17.3-19.7)
	20,000 to 34,999	26.4 (19.6-34.6)	20.5 (19.3-21.6)
	35,000 to 49,999	12.2 (9.1-16.2)	14.8 (13.8-15.8)
	50,000 to 74,999	13.5 (8.8-20.2)	16.0 (15.0-17.1)
	\$75,000 or more	29.4 (22.3-37.5)	30.2 (29.0-31.5)
Education	Less than High School	9.1 (6.2-13.2)	11.0 (10.0-12.1)
	High School or GED	26.4 (20.6-33.3)	29.6 (28.4-30.8)
	Some College	39.1 (32.5-46.0)	34.3 (33.1-35.6)
	College Graduate or Higher	25.4 (20.1-31.5)	25.1 (24.1-26.1)
Employment	Employed ^a	47.4 (41.7-53.2)	58.6 (57.4-59.7)
	Unemployed	5.7 (3.0-10.8)	5.6 (5.0-6.2)
	Non-Working ^a	46.8 (40.7-53.0)	35.9 (34.8-37.0)
Marriage Status	Married	49.1 (44.3-53.9)	50.0 (48.8-51.2)
	Formerly Married	20.1 (17.1-23.5)	18.7 (17.8-19.6)
	Never Married	27.6 (23.5-32.0)	26.4 (25.4-27.5)
	Member of unmarried Couple	3.2 (1.5-6.8)	5.0 (4.4-5.7)
Disability	Yes ^a	36.7 (29.7-44.2)	24.0 (22.9-25.1)
Veteran	Yes	7.5 (6.3-8.8)	7.7 (7.2-8.4)
LGBTQ	Homosexual	4.3 (1.2-14.7)	1.8 (1.5-2.3)
	Transgender	0.7 (0.1-4.4)	0.0 (0.0-0.1)

^a Indicates a significant difference (p value < 0.05) between people reporting a history of cancer and those who report never having cancer.

^b Age at the time of survey

Part 2: Michigan Behavioral Risk Factor Survey

Physical and Mental Health

Quality of Life:

Quality of life is important for cancer survivors and includes physical, emotional, social and spiritual elements.¹ Healthy behaviors and palliative care interventions improve quality of life in cancer survivors.¹ The MiBRFS measures both physical and emotional health-related quality of life measures. In 2016, among Michigan’s cancer survivors (**Figure 5**):

- 28.1% experienced poor or fair general health.
- 22.5% reported having 14 or more days of poor physical health during the last 30 days.
- 13.2% reported 14 or more days of poor mental health in the last 30 days.
- 15.5% (95% CI: 12.8-18.6) reported being injured from a fall. This was significantly higher compared to those who have never had cancer (11.6%; 95% CI: 10.6%-12.6%)(Data not shown).

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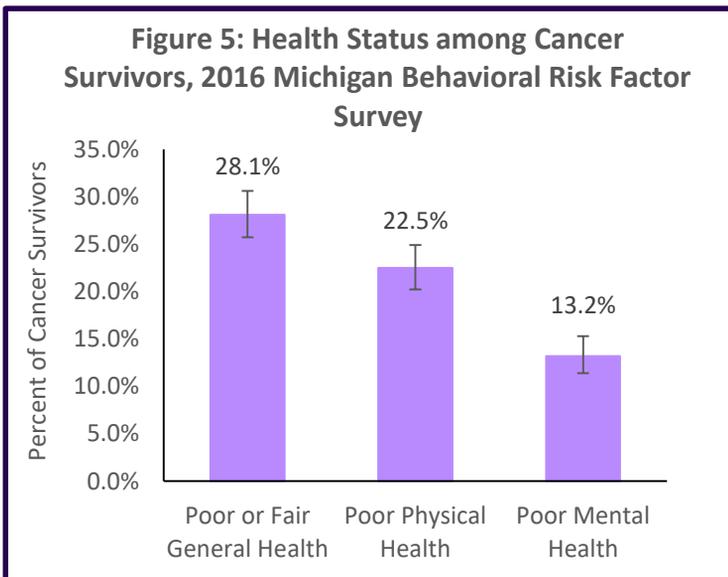


Table 3: Age-Adjusted Prevalence of Chronic Conditions by Cancer Status, 2016 Michigan Behavioral Risk Factor Survey

	Cancer Survivors % (95% CI)	Never Had Cancer % (95% CI)
Arthritis ^a	41.1 (35.3-47.2)	28.0 (27.0-29.1)
CVD ^{a, b}	14.7 (10.2-20.8)	8.0 (7.4-8.6)
COPD ^{a, c}	16.2 (11.6-22.1)	7.4 (6.8-8.1)
Obesity	33.8 (27.7-40.5)	32.7 (31.5-34.0)
Depression ^a	37.7 (31.2-44.6)	21.6 (20.5-22.7)
Difficulty Concentrating ^a	29.1 (23.3-35.7)	13.6 (12.7-14.6)
Diabetes	10.0 (8.5-11.7)	11.6 (10.6-12.6)

^a Indicates a significant difference (p value < 0.05) between people reporting a history of cancer and those who report never having cancer.

^b CVD= Cardiovascular disease

^c COPD= Chronic obstructive pulmonary disease

Multiple Chronic Conditions

Among cancer survivors, 69.1% (95% CI: 63.3-74.3) reported having two or more chronic conditions. Among those with no history of cancer only 21.9% (95% CI: 21.0-22.9) reported having two or more chronic conditions (data not shown). These estimates were age adjusted

Cancer survivors reported arthritis (41.1%) and depression (37.7%) more than respondents who never had cancer (**Table 3**). Both conditions were significantly higher compared to those who never had cancer. Interventions that address obesity, mental health, physical activity and smoking cessation assist cancer survivors in addressing these co-morbid conditions.⁷

Part 2: Michigan Behavioral Risk Factor Survey

Access to Care

Follow-up Care:

After cancer treatment ends, it is important that survivors maintain routine care (**Figure 6**).⁸

- 94.7% of cancer survivors had at least one healthcare provider.
- 85.1% of cancer survivors had a routine checkup.

Access to health care is not always equitable,⁹ which may negatively impact the number of survivors receiving checkups.

Immunizations:

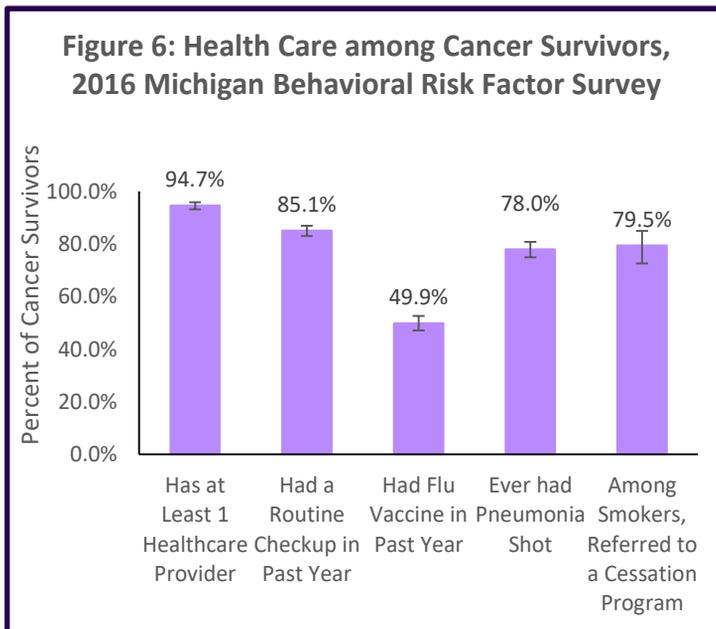
People with a history of cancer may be at greater risk of complications from influenza.¹⁰ All survivors are encouraged to receive a flu shot and the pneumonia vaccine is recommended for many cancer survivors (**Figure 6**).¹¹

- 49.9% of cancer survivors had a flu shot in the past year.
- 78.0% had a pneumonia shot.

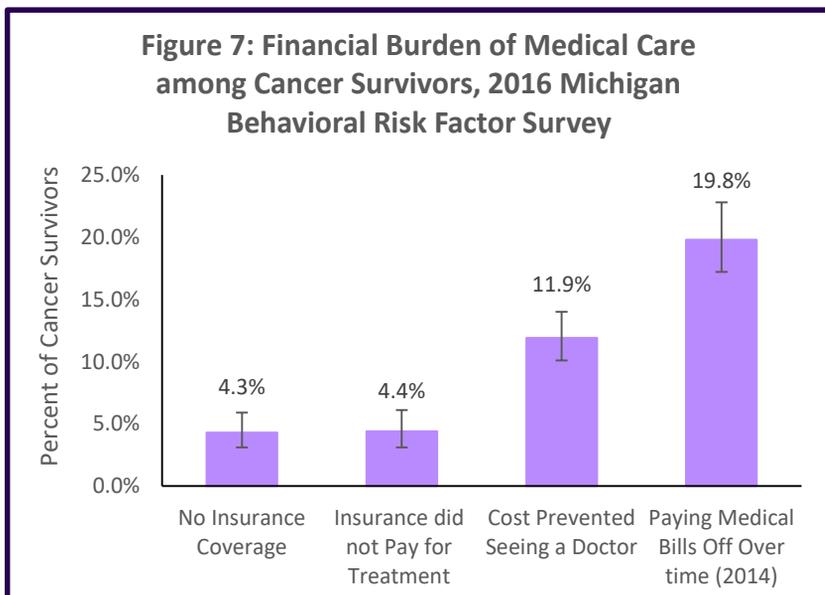
Referrals to Tobacco Cessation

Studies have shown smoking lessens the effectiveness of cancer treatment (**Figure 6**).¹²

- 79.5% had been referred to a cessation program.



Michigan survivors who would like help to stop using tobacco products can contact the Michigan Tobacco Quitline at: **1-800-Quit-Now (1-800-784-8669)** <https://michigan.quitlogix.org/>



Financial Toxicity:

Almost one-third of cancer survivors experienced financial hardships as a result of their diagnosis.¹³ The majority of cancer survivors reported having some type of insurance. However, despite wide insurance coverage, financial barriers remain (**Figure 7**).

- 4.3% reported no insurance coverage.
- 11.9% reported that cost had prevented them from seeing a doctor.
- 19.8% reported they were paying medical bills off overtime.

Part 2: Michigan Behavioral Risk Factor Survey

Health Behaviors

Healthy lifestyle behaviors can reduce the risk of a cancer recurrence and lessen the side-effects of cancer treatment.¹ Cancer survivors should be encouraged to take up certain healthy behaviors.

Nutrition and Physical Activity:

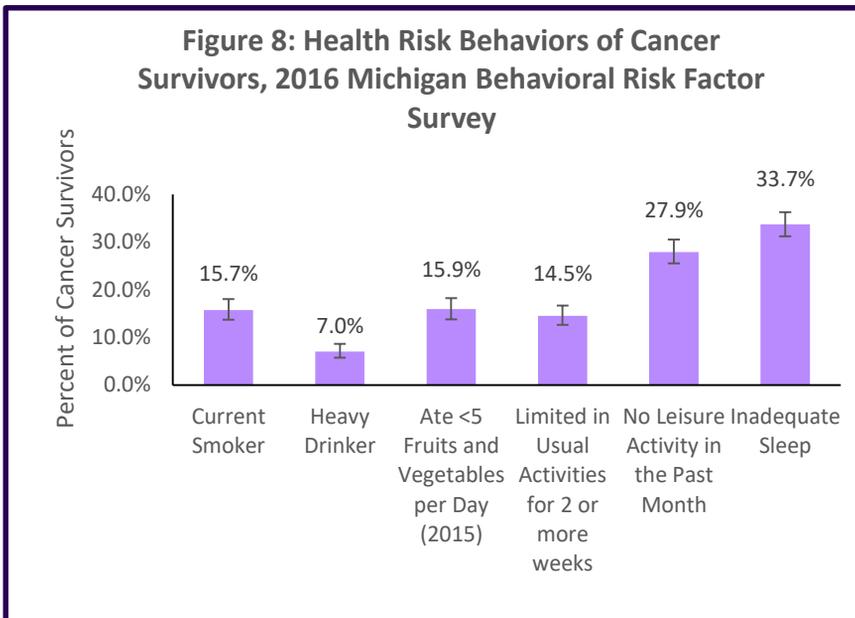
It is important for survivors to maintain a healthy weight through a healthy diet and physical activity (Figure 8).¹⁴

- 15.9% of survivors reported they did not eat the recommended amount of fruits and vegetables,
- 14.5% reported their usual activities were limited, and
- 27.9% reported partaking in no leisure activities.

Alcohol:

Alcohol can increase the risk for several cancers (Figure 8).¹

- 7.0% of cancer survivors reported being a heavy drinker.



Smoking:

Smoking can increase the risk of cancer recurrence or a second cancer (Figure 8).¹

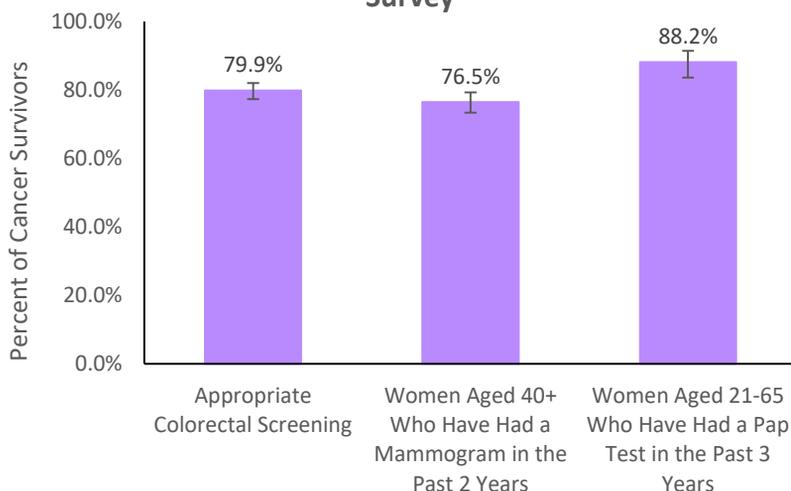
- 15.7% of Michigan cancer survivors reported being a current smoker.

Cancer Screening:

Ongoing cancer screening is important even after a cancer diagnosis (Figure 9).¹

- 79.9% of cancer survivors had received appropriate colorectal screening.
- 76.5% of female cancer survivors had received an appropriately timed mammogram.
- 88.2% of female cancer survivors had received an appropriately timed Pap test.

Figure 9: Cancer Screening Practices among Cancer Survivors, 2016 Michigan Behavioral Risk Factor Survey



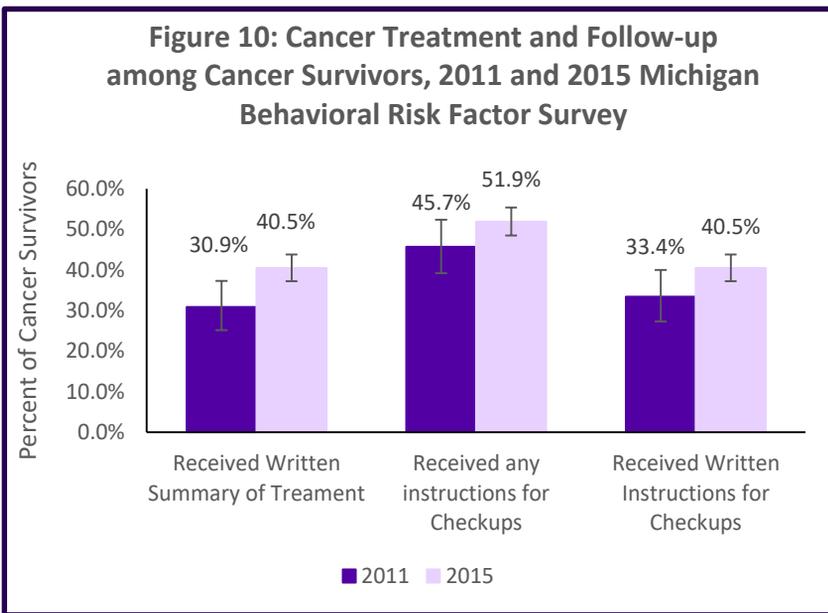
Part 2: Michigan Behavioral Risk Factor Survey

Survivorship

Survivorship Care Plans:

Survivorship care plans provide helpful information to survivors related to recommended healthy behaviors and ongoing cancer care, they also facilitate the sharing of health information between providers.¹ One priority for the Michigan Cancer Consortium (MCC) is to increase the number of cancer survivors who report received instructions about what to do for routine care after treatment. There has been an increase in survivors reporting that they received a written summary of their treatment. There has also been an increase in survivors reporting they received instructions. However, there is no significant difference between 2011 and 2015 (**Figure 10**).

- 51.9% of cancer survivors received instructions in 2015 compared to 45.7% in 2011.
- 40.5% of survivors received their instructions written down in 2015 compared to only 33.4% in 2011.

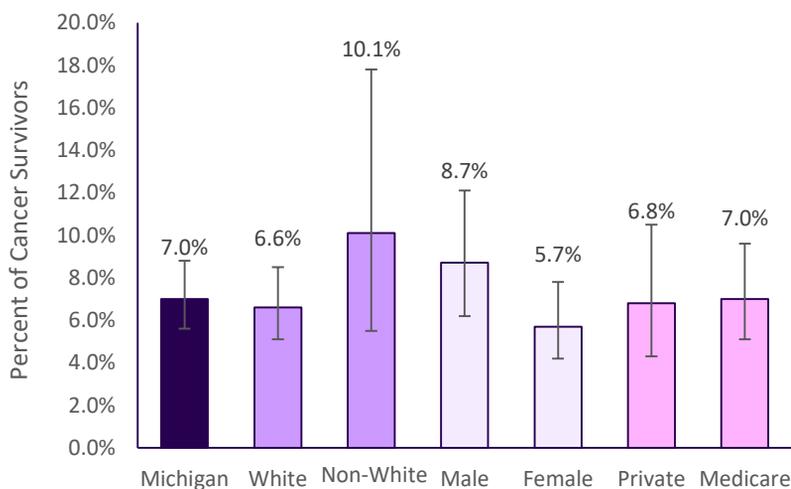


Clinical Trials:

Clinical trials are important as it is through the clinical trials process that new treatments for cancer and best practices for survivorship care are developed. Increasing the percent of adults in clinical trials is also an MCC priority. Barriers to clinical trial enrollment can include a lack of knowledge about available trials, suspicion of research and financial concerns.² Disparities in clinical trial participation exist, however due to a small sample size there is no significant differences amongst demographic groups (**Figure 11**).

- 7.0% of cancer survivors in 2016 reported participating in a clinical trial.
- 10.1% of non-White respondents reported participating in a clinical trial compared to 6.6% of White respondents.

Figure 11: Cancer Clinical Trial Participation among Cancer Survivors, 2016 Michigan Behavioral Risk Factor Survey



Part 2: Michigan Behavioral Risk Factor Survey

Survivorship Continued

Pain Management:

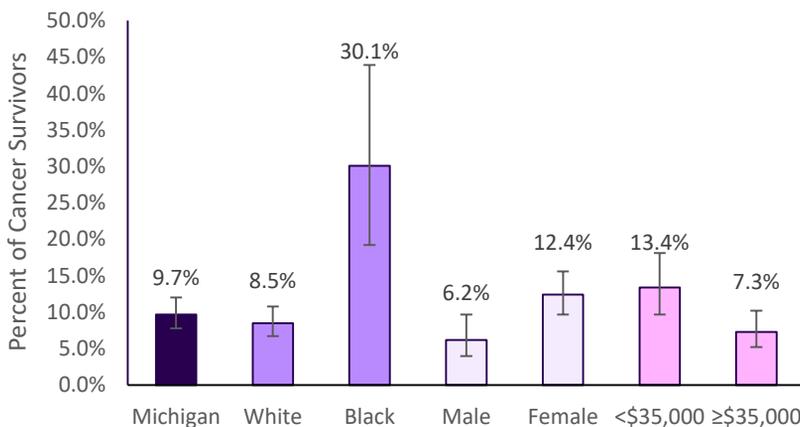
Pain can impact the quality of life of cancer survivors both during and after treatment.¹ Addressing cancer-related pain is a longstanding objective of the Michigan Cancer Plan (**Figure 12**).

- 9.7% of cancer survivors who had finished treatment reported being in physical pain.
- Among those in pain, 41.7% reported that their pain was currently under control (data not shown).

The type of pain experienced and the appropriate methods to control it are dependent upon a person's survivorship stage. Post-treatment survivors may benefit from non-traditional pain management strategies like a referral to rehabilitation services.



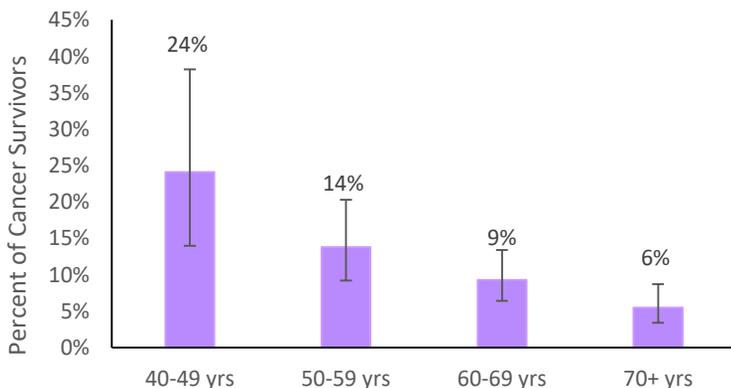
Figure 12: Cancer Survivors who are Currently in Pain by Race, Sex, and Income, 2016 Michigan Behavioral Risk Factor Survey



Disparities in Cancer Pain:

- The percentage of black cancer survivors who reported pain (30.1%) were significantly higher compared to white cancer survivors (8.5%) (**Figure 12**).
- A significant difference existed by income, with those with an income less than \$35,000 reporting pain more frequently than those with an income over \$35,000 (**Figure 12**).
- Cancer survivors with a disability (36.7%) were also more likely to report physical pain (17.3%) than those without a disability (4.8%) (data not shown).
- Younger cancer survivors are more likely to report that pain continues after treatment ends. For those survivors aged 40-49, 24% reported pain while only 6% of those over the age of 70 reported pain (**Figure 13**).

Figure 13: Cancer Survivors who are Currently in Pain by Age, 2016 Michigan Behavioral Risk Factor Survey



Part 3: Focus Groups

In 2017, seven focus groups were conducted with post-treatment cancer survivors in two regions of Michigan representing an urban and a rural setting. All focus groups were separated by gender. Survivors were asked three questions:

- What three things are different now that you are a cancer survivor?
- What are your needs related to being a cancer survivor?
- What surprised you the most about cancer or being a survivor?

Survivor responses were grouped by MDHHS staff to identify themes.

What is different now that you are a cancer survivor?

Attitudes, fear and anxiety:

- Cancer recurrence
- Family occurrence of cancer
- Anxiety with a new symptom or follow-up scans

Time management:

- Becoming more discerning on how time and energy was spent
- Avoiding negative relationships and focusing on relationships that sustained them

Family and friends:

- Families were closer after the experience of cancer treatment
- Friends or significant others were not supportive

Sexual function

- Decrease in sex drive

Physical changes or challenges:

- Weight gain and/or skin changes
- Occurrence of new health problems like lymphedema or digestive issues
- Increase in pain

Changes in daily activities:

- Changes in careers
- Planning life around digestive needs
- Relinquishing care-giving responsibilities
- Feeling lost after treatment because of not knowing how to fill their time
- Unable to continue hobbies

What are your needs?

Education:

- Assistance with finding reputable sources of information
- Healthy eating – what should I eat?
- What should I be doing?

Health care:

- Increased sharing of information between health care providers
- Clarification on what questions to ask of what providers
- Improved medical staff understanding of the cancer experience
- Improved training of primary care providers as they are not always aware of changes in screening tests or long-term effects of cancer treatments

Financial:

- Better insurance coverage for treatment of side-effects
- Assistance with medical bills, co-pays and assistance with “fighting” insurance companies

Resources:

- Transportation
- Home related resource needs including meal delivery, help with house cleaning and maintenance and grocery shopping
- Health resources needs including access to dietitians, opportunities for physical activity, yoga or massage provided by providers knowledgeable on survivor needs

Part 3: Focus Groups

What surprised you the most about cancer or being a survivor?

Positive Surprises*	Undesirable Surprises*
How strong I am – have ability to face fear and ambiguity	Who my true friends really are
My positive attitude and ability to give others hope	Where hair does and does not grow after treatment ends
The importance of the little things like the ability to clean my house or have my nails done	My diagnosis was a shock - I ate the right food and exercised, and I still got cancer
My high quality of life – I can do everything I did before, only in smaller doses	How much my cancer impacted my care givers/ significant others
The support of family, friends, nurses and oncology staff	"Chemo Brain" – How long it takes to recover
I am more appreciative	How hard it is to get back in to the “real world”
I am alive... I thought if you got cancer you would die	How much I mourn the time I lost to cancer. It took a part of my life
The importance of other survivors and the hope they can provide	The impact the side effects have had on my life

* The responses of survivors have been combined or modified in these statements to protect survivor identity.

Part 4: Cancer Experts

A group of cancer survivors and clinical experts selected through their involvement in the Michigan Cancer Consortium brainstormed a list of challenges and/or needs that cancer survivors may experience, this included but is not limited to:

- Health care access
- Isolation
- Deductibles/copays
- Adjusting to a new normal
- Sexual function
- Financial changes
- Cognitive changes
- Physical activity
- Spiritual care
- Healthy diet
- Pain
- Fatigue
- Depression
- Fertility
- Insurance
- Disability
- Care transition from oncology
- Neuropathy
- Energy balance
- Sleep deprivation
- Survivorship care access
- Return to work issues
- Advance care planning
- Symptom management
- Anxiety
- Managing medications

Conclusion

With the advancement of cancer care, the cancer survivorship population continues to rise making it critical to assess the needs of these people. Michigan's Cancer Plan has 16 objectives aimed at improving the quality of cancer treatment and improving the quality of life of cancer survivors. It is important to acknowledge this population is diverse and has a wide range of issues. For example, younger cancer survivors reported higher rates of pain in MiBRFS and also expressed different concerns in focus groups (i.e. fertility) compared to older cancer survivors. Data in this report indicates cancer survivors need additional help with financial navigation. Although the majority of cancer survivors had health insurance, navigating insurance and financial barriers still remained. Additional issues that need to be focused on include issues around genetic counseling, access to clinical trials, palliative care, advanced care plans and physical and mental health.

The Michigan Cancer Consortium (MCC) is working with its member organizations to change the way care is provided to cancer survivors and improve quality of life. Through collaborative approaches, changes can be made in patient care. For example, tobacco cessation has been a focus of a partnership between the MCC and the Michigan Oncology Quality Consortium since 2012. As of 2017, 38 oncology practices have policies and systems in place to refer patients to tobacco cessation services. One of the cessation services is the Michigan Tobacco Quitline, which has received over 5,000 cancer survivor referrals. Providing resources to cancer survivors can also assist with improving their quality of life. One example of this type of work is the availability of educational materials for prostate cancer survivors available at <https://www.prostatecancerdecision.org>. The 16 documents have been downloaded over 44,000 times in the last 3 years.

Several white papers have been developed to assist health systems with addressing the needs of cancer survivors these include a focus on health and wellness, [financial navigation](#) and the use of rehabilitation to address pain management.

Next Steps:

1. Identify health disparities in cancer survivorship by combining data from multiple years from MiBRFS.
2. Continue to monitor surveillance data to assess the progress of public health interventions to address cancer survivorship.
3. Work with the Michigan Cancer Consortium Survivorship Workgroup to develop strategies to address needs identified by surveillance data.

For more information on cancer survivorship in Michigan visit michigancancer.org



Methods

- The Michigan Cancer Surveillance Program defines a case as a person with any newly diagnosed cancer with a behavior code of 3 (malignant primary site). Age-adjusted rates are computed by the direct method, using as the standard population the age distribution of the total population of the United States for the year 2000. Data in the report include cases diagnosed in 2015 and is publicly available at: <http://www.mdch.state.mi.us/osr/index.asp?id=13>
- The Michigan Behavior Risk Factor Surveillance System, a weighting methodology known as iterative proportional fitting or raking was used in 2016 to allow for the incorporation of cell phone data and to improve the accuracy of prevalence estimates based on MiBRFS data. Estimates based on this weighting methodology were weighted to adjust for the probabilities of selection and a raking adjustment factor that adjusted for the distribution of the Michigan adult population by telephone source (landline or cell phone), detailed race/ ethnicity, education level, marital status, age by gender, gender by race/ethnicity, age by race/ethnicity, and renter/ owner status. Prevalence estimates and asymmetric 95% confidence intervals (95% CIs) were calculated using SAS-Callable SUDAAN (version 11.0.1), a statistical computing program designed for analyzing data from multistage sample surveys. If the 95% CIs for two estimates from different subpopulations or survey years did not overlap, they were considered to be statistically different. Unless otherwise specified, respondents who answered that they did not know or refused to answer were not included in the calculation of estimates. Cancer survivor is defined as answering 'yes' to at least one of the following questions from the MiBRFSS.
 - Has a doctor, nurse or other health professional ever told you that you had any of the following?
 - Ever told you had skin cancer?
 - Ever told you had any other types of cancer?
- In 2017, seven focus groups in two regions of Michigan representing an urban and a rural setting (South East Michigan representing urban and Northwest Michigan representing rural) were conducted by MDHHS staff. Survivors were recruited through health systems operating in each region. Health systems were instructed to recruit survivors who were post-treatment, though length of time since treatment did not matter. Focus groups were separated by gender. One rural-location group was canceled because of difficulty recruiting enough men to fill a group. Groups were not recorded but were conducted with two note-takers. The focus groups included four activities. The first activity was a general introduction designed to "break the ice". The second activity requested the survivors write down three things that were different now they were a cancer survivor. The third activity asked survivors to write down their needs related to being a cancer survivor and categorize them on a wall chart that was developed from the themes identified by cancer experts. The fourth activity requested survivors to develop a list of the things that surprised them the most about cancer or being a survivor. This project was classified as exempt by the Michigan Department of Health and Human Services Institutional Review Board.

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