# Cancer Survivorship Needs Report

July 2020

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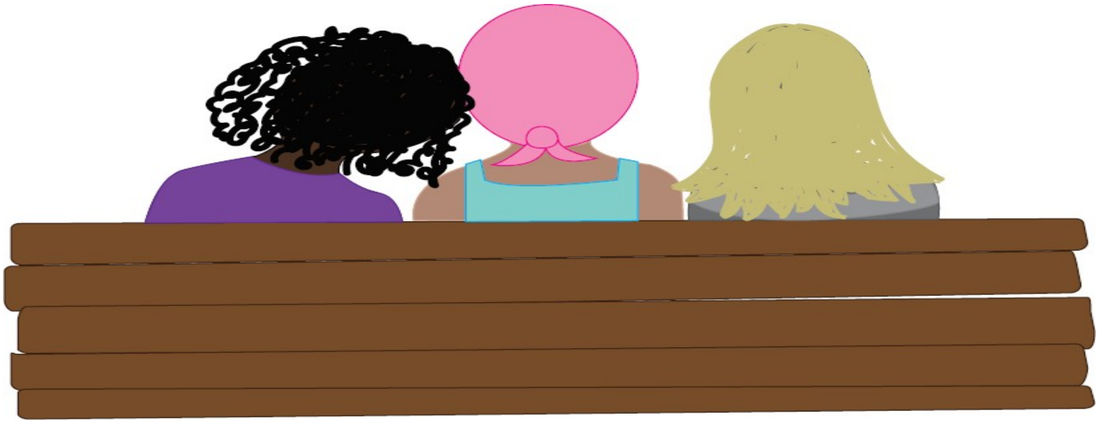
# Introduction

A cancer survivor is traditionally defined as a person diagnosed with cancer, from the time of diagnosis throughout the person's lifespan. The American Cancer Society estimates there are 570,760 people living in Michigan with a past diagnosis of cancer.[1] Some people diagnosed with cancer will lose their life to cancer, some will live with cancer as a chronic disease, while others will live cancer free for the rest of their lives.[1] Over the last several years cancer care has increasingly focused on the needs of post-treatment cancer survivors as many have ongoing physical or emotional effects of cancer or its treatment.[2, 3]

The purpose of this report is to provide data to Michigan communities, health care providers, public health professionals, and cancer survivors on the needs of cancer survivors, cancer caregivers, and to draw attention to cancer disparities in Michigan. Surveillance and focus group data can assist with understanding cancer survivors' health status, comorbidities, health behaviors, and access to care which informs program prioritization, design, and implementation. This data is also an important way to evaluate the effectiveness of public health interventions.

Michigan's biggest public health success in cancer survivorship is the reduction of the smoking rate among cancer survivors by 32.1% since 2011.[4] In 2012, a multi-partner collaboration focused on oncology providers referring their cancer patients who smoked to a tobacco cessation program. This increased referrals to tobacco cessation by 26.2%.[4] As a part of this project, the Michigan Department of Health and Human Services (MDHHS) provided free tobacco cessation services, including nicotine replacement therapy. Smoking cessation is important for cancer survivors as tobacco can reduce the effectiveness of chemotherapy.[5]



# Health Disparities in Cancer Survivorship

Receiving a diagnosis of cancer, undergoing treatment, and addressing quality of life concerns is challenging for all cancer survivors.[1] Unfortunately for some groups of individuals, cancer occurs more often, brings more health complications, reduces quality of life, and increases mortality rates.[6] People who identify as a member of a racial/ethnic minority, sexual minority, live in rural areas, have a lower socioeconomic status, and are uninsured or underinsured are examples of individuals who often have poorer cancer outcomes.[7]

Cancer Disparities in Michigan

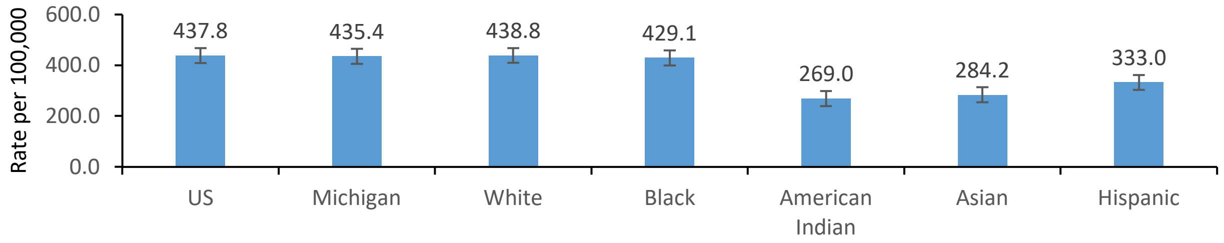
- Although the cervical cancer screening rate is similar between Black and white women,[4] a Black woman is diagnosed with late stage cervical cancer at a rate 2.4 times higher compared to a white woman.[8] As a result, Black women have a 50% increased risk of dying from cervical cancer compared to white women.[9]
- The odds of a Native American being diagnosed at a late stage for lung cancer is 1.4 times higher compared to white Americans.[8] Native Americans have a 40% increased risk of dying from lung cancer compared to white Americans.[9]
- The likelihood of not participating in a clinical trial is 90% higher among rural cancer survivors compared to cancer survivors who live in a suburb.[4]
- The odds of being a current smoker after a cancer diagnosis is 250% higher among those insured by Medicaid compared to those insured by private insurance.[4]
- The likelihood of reporting pain after cancer treatment is 220% higher among African Americans compared to white Americans.[4]
- The probability of being obese is 380% higher among Native American cancer survivors and 160% higher among Hispanic survivors compared to white survivors.[4]
- The odds of being depressed is 180% higher among cancer survivors with a family income of less than $15,000. The odds of being anxious is 110% higher among survivors with a family income of less than $15,000.[4]
- The probability of reporting poor mental health is 137% higher for those who are lesbian, gay, bisexual or transgender than those who are not.[4]

Other factors that can impact outcomes include heredity, health care access, chemical exposures, diet, and physical activity.[6] The differences in outcomes may also relate to issues in the provider-patient relationship. When patients are distrustful of the health care system it may impact their health care choices.[10] When providers have implicit biases toward groups of individuals it can impact the care they provide.[11] MDHHS is focused on improving the quality of care provided to all cancer survivors.

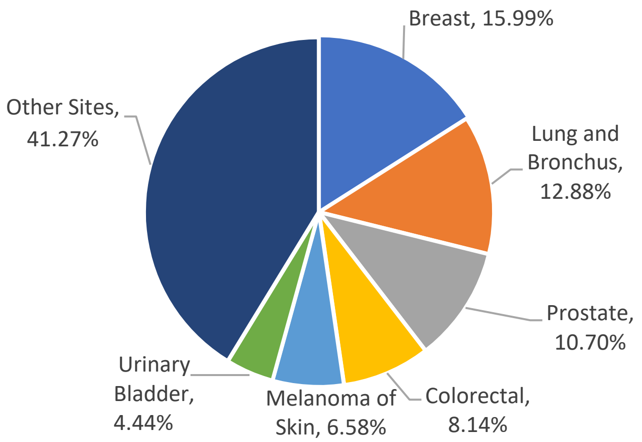
# Cancer Incidence

Cancer incidence is the number of new invasive cancers diagnosed over a defined period. It is typically reported as the number of cancers per 100,000 people.[12] Most cancer survivors (74.9%) have received a single cancer diagnosis in their life. However, single diagnosis does not include cancer recurrence (i.e. the appearance of the original cancer that was thought to be cured or in remission) and cancer metastases (i.e. the original cancer has spread to another part of the body).

Age-Adjusted Cancer Incidence Rates, 2017 CDC Cancer Statistics



Cancer Frequency by Site, 2017
Michigan Cancer Surveillance Program

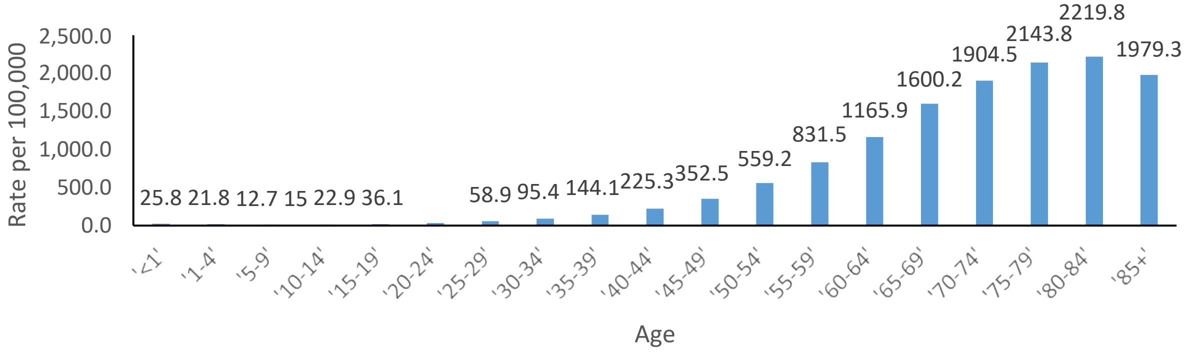


In Michigan, the six most common cancer types are breast, lung, prostate, colorectal, melanoma, and urinary bladder. Together these cancers make up over half (58.7%) of the cancer diagnoses in Michigan.[8]

There are an additional 20 cancer sites that are grouped in the “other sites” category.[8]

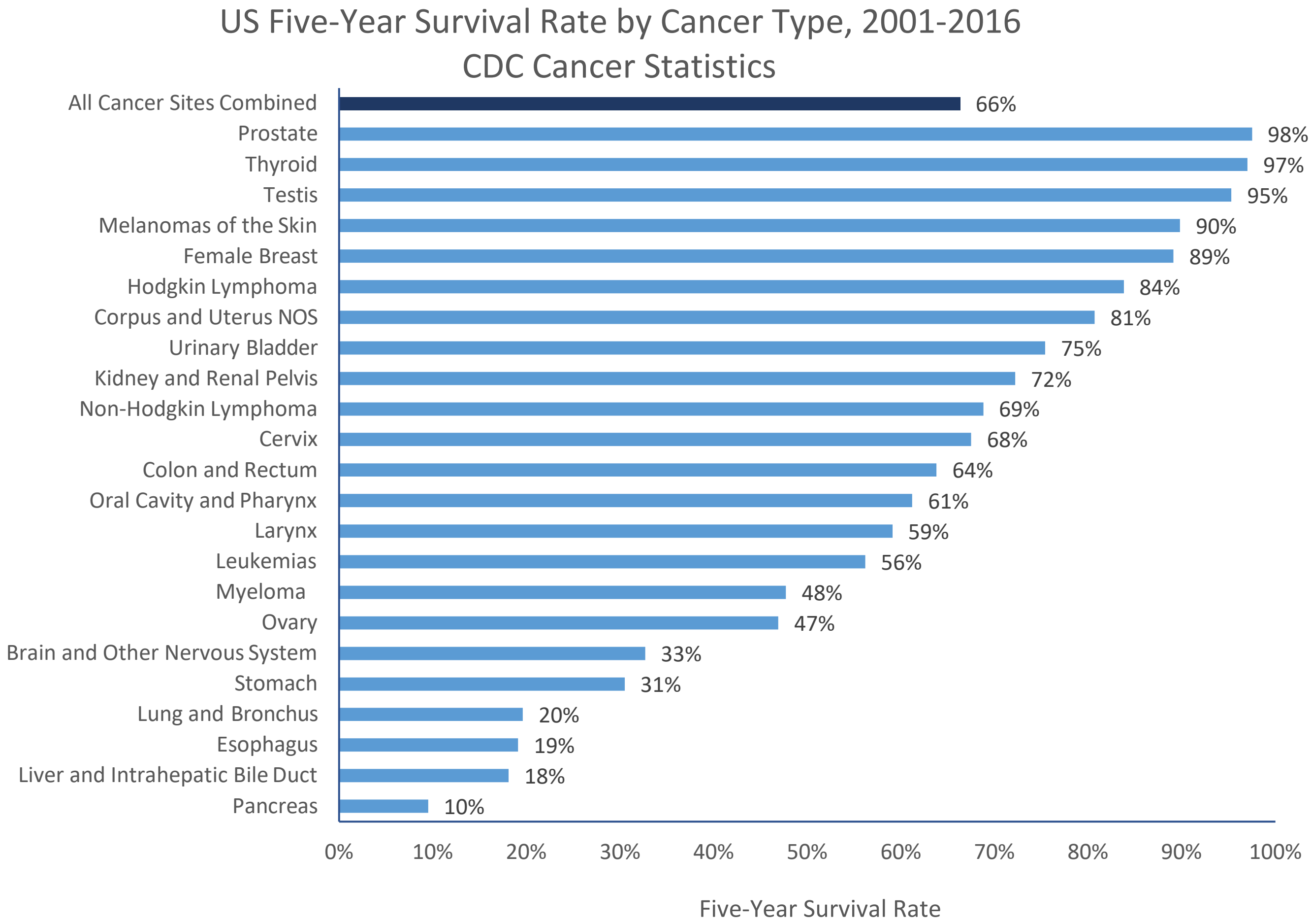
Age is an important factor, with cancer incidence increasing with age.[13] Organizations providing services to people with cancer will need to prepare for the large number of older cancer survivors. However, they cannot forget the unique needs of younger survivors.

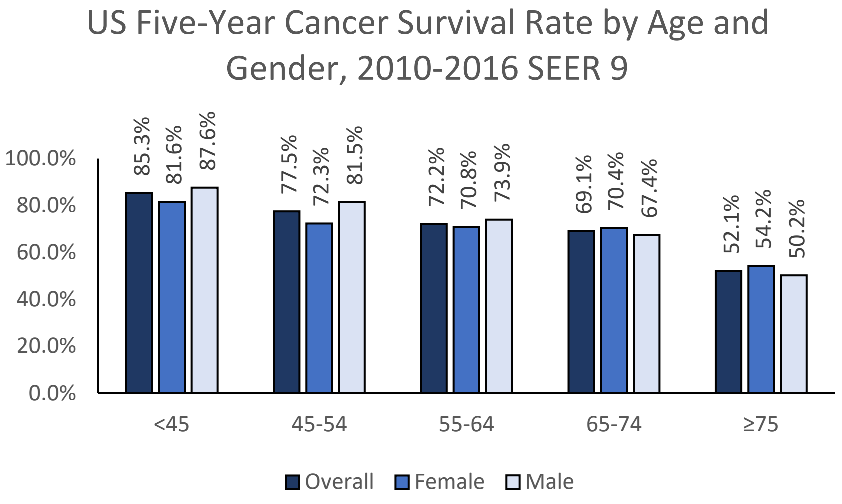
Michigan Cancer Incidence by Age, 2017 CDC Cancer Statistics



# Five-Year Survival Rates

The five-year survival rate is the percentage of people who will be alive five years after their cancer diagnosis; it does not include people who die from other diseases.[14] Cancer type is an important factor in the five-year survival rate of cancer. Nationally, the lowest five-year survival rate is for pancreatic cancer with only a 9.5% survival rate. The highest five-year survival rate is in prostate cancer with 97.5% of men living five years after their diagnosis.[13]

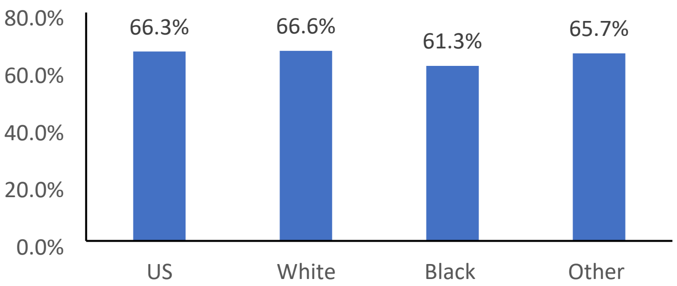

US Five-Year Survival Rate by Cancer Type, 2001-2016
CDC Cancer Statistics


US Five-Year Cancer Survival Rate by Age and Gender, 2010-2016 SEER 9

Sex, age at diagnosis, the stage at which the cancer is diagnosed and race (see page 6) also impact cancer survival. Males have a higher five-year survival rate compared to females when diagnosed at a younger age. This may be due to the difference in risk of developing certain types of cancers depending on sex.[15]

# Five-Year Survival Rates by Race

Black Americans, regardless of stage at diagnosis, are less likely to be alive five years after diagnosis compared to white Americans.[13,15] Due to limited data, no conclusions can be drawn about five-year survival rates in races in the "other" category. However, literature suggests that American Indians are another racial group that has a lower five-year survival rate.[16] A localized cancer is a tumor that has not spread. A regional cancer has spread out of its primary site to the adjacent tissue or lymph nodes. A distant cancer is a tumor that has spread beyond the primary site to distant lymph nodes or organs.

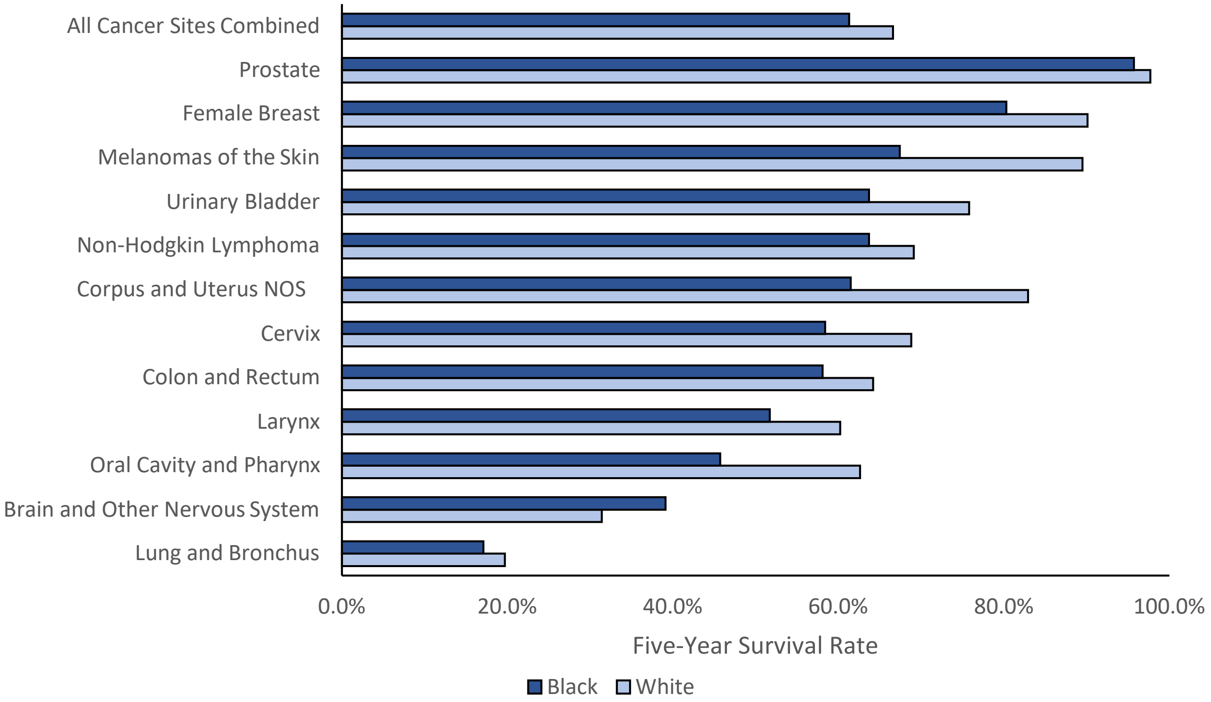

Overall Five-Year Rate Survival by Race, 2001-2016 CDC Cancer Statistics

US Five-Year Cancer Survival Rate by Stage, 2010-2016 SEER 18

| | All Races | White | Black |
|---|---|---|---|
| Localized | 91.0% | 91.0% | 89.9% |
| Regional | 66.2% | 66.7% | 60.7% |
| Distant | 27.7% | 28.1% | 24.1% |
| Unknown/ Unstaged | 37.5% | 34.4% | 33.9% |

In every type of cancer, except brain and other nervous system cancers, the five-year survival rate is much lower among Black Americans compared to white Americans. In some instances, the differences are very large. For example, in cervical cancer, the five-year survival is 58.4% among Black Americans compared to 68.8% in white Americans.[13] Many cervical cancers are preventable due to the HPV vaccination and cervical cancer screening.[17]

US Five-Year Survival Rate by Cancer Type, 2001-2016 CDC Cancer Statistics



# Cancer Survivor Demographics

- The Michigan Behavioral Risk Factor Surveillance System (MiBRFS) is an annual telephone survey. It provides information on the demographics, health behaviors, and barriers faced by Michigan cancer survivors. A limitation of this data collection source is that it cannot collect data on those who are too ill to participate in a telephone survey or have died. This means it may underrepresent some populations, like Black Americans who have a higher mortality rate.

- Respondents who are cancer survivors were older (65+) compared to those who are not cancer survivors (54.5% vs. 17.4%).[4] Because a cancer diagnosis is closely related to age, these estimates are age-adjusted to the United States' 2000 standard population to allow for more accurate comparisons between the two groups.

- There were some statistical differences between cancer survivors and non-cancer survivors. These differences were found in gender, employment status, and disability status.[4] Even after adjusting for age differences:
  - Cancer survivors were less likely to be employed and more likely to report that they were non-working.[4]
  - Cancer survivors were also more likely to report having a disability than those who have no history of cancer.[4]

**Table 2: Age-Adjusted Demographics by Cancer Status, 2018 Michigan Behavioral Risk Factor Survey**

| | | Ever Had Cancer % (95% CI) | Never Had Cancer % (95% CI) |
|---|---|---|---|
| Gender | Female [a] | 62.5 (54.9-69.6) | 50.6 (49.2-52.0) |
| | Male [a] | 37.5 (30.4-45.1) | 49.4 (48.0-50.8) |
| Race | Non-Hispanic White | 84.3 (76.8-89.7) | 75.8 (74.5-77.0) |
| | Non-Hispanic Black | 8.6 (4.5-15.5) | 14.3 (13.3-15.4) |
| | Hispanic | 4.3 (1.9-9.4) | 4.7 (4.0-5.4) |
| | Other | 2.8 (0.9-8.2) | 5.2 (4.7-5.9) |
| Income | Less than $20,000 | 19.6 (13.0-28.3) | 15.1 (14.0-16.3) |
| | 20,000 to 34,999 | 17.8 (11.5-26.6) | 19.3 (18.1-20.6) |
| | 35,000 to 49,999 | 12.9 (7.6-21.1) | 13.8 (12.7-14.9) |
| | 50,000 to 74,999 | 17.1 (11.8-24.1) | 16.3 (15.2-17.4) |
| | $75,000 or more | 32.6 (26.3-39.7) | 35.5 (34.1-36.9) |
| Education | Less than High School | 11.4 (7.7-16.6) | 10.3 (9.2-11.5) |
| | High School or GED | 29.3 (22.5-37.2) | 29.3 (28.1-30.6) |
| | Some College | 31.7 (25.1-39.1) | 34.6 (33.2-35.9) |
| | College Graduate or Higher | 27.6 (21.9-34.0) | 25.8 (24.7-26.8) |
| Employment | Employed [a] | 48.4 (40.8-56.0) | 60.3 (59.1-61.6) |
| | Unemployed | 8.3 (4.2-15.8) | 5.0 (4.5-5.7) |
| | Non-Working [a] | 43.3 (36.4-50.5) | 34.6 (33.5-35.8) |
| Marriage Status | Married [a] | 58.0 (50.9-64.8) | 49.6 (48.3-50.8) |
| | Formerly Married | 19.2 (15.6-23.6) | 18.6 (17.6-19.6) |
| | Never Married | 20.1 (14.5-27.2) | 27.1 (26.1-28.2) |
| | Member of Unmarried Couple | 2.7 (1.0-7.0) | 4.7 (4.1-5.4) |
| Disability | Yes [a] | 38.6 (31.5-46.2) | 24.6 (23.4-25.9) |
| Veteran | Yes | 10.6 (6.9-16.0) | 8.0 (7.4-8.8) |
| LGBTQ | Bi [a] | 0.6 (0.2-1.4) | 2.2 (1.8-2.6) |
| | Gay/Lesbian | 2.5 (0.7-8.4) | 1.5 (1.2-1.8) |
| | Trans | Suppressed | Suppressed |
| Age of Respondent | 18 to 34 [b,c] | 3.1 (2.0-4.8) | 33.1 (31.8-34.5) |
| | 35 to 44 [b,c] | 5.4 (4.0-7.2) | 16.3 (15.3-17.4) |
| | 45 to 54 [b,c] | 10.8 (9.0-12.9) | 16.4 (15.4-17.4) |
| | 55 to 64 [b,c] | 26.4 (23.7-29.2) | 16.8 (15.0-17.8) |
| | 65 to 74 [b,c] | 26.3 (23.8-28.9) | 11.2 (10.5-12.0) |
| | 75 and older [b,c] | 28.2 (25.5-31.0) | 6.2 (5.6-6.7) |

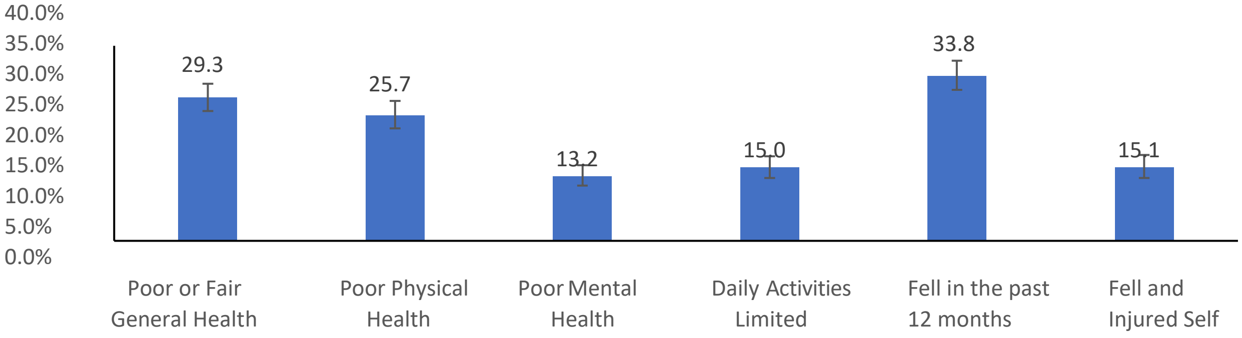
[a] Indicates a significant difference (p-value < 0.05) between people reporting a history of cancer and those who report never having cancer.

[b] Age at the time of survey.

[c] Estimates are not age-adjusted to the 2000 US standard population.

# Self-Reported Health Status

Health Status among Michigan Cancer Survivors, 2018 MiBRFS

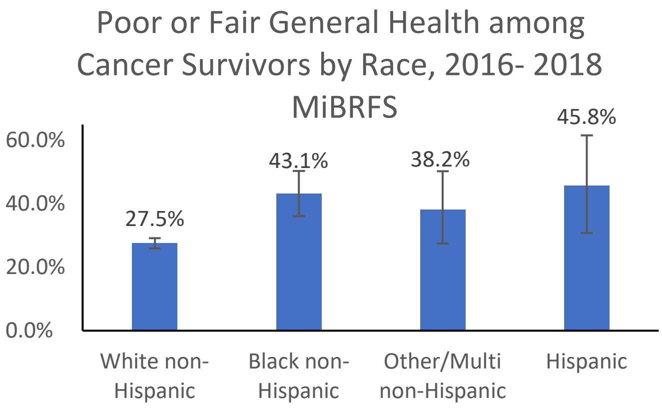


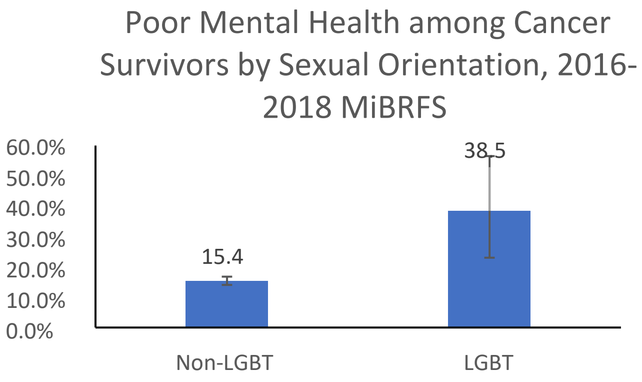
**Quality of Life:**

Quality of life is important for cancer survivors and includes physical, emotional, social, and spiritual elements.[1] Among Michigan's cancer survivors in 2018, there is reason to be concerned as:

- 29.3% experienced poor or fair general health.[4]
- 25.7% reported having 14 or more days of poor physical health during the last 30 days.[4]
- 13.2% reported 14 or more days of poor mental health in the last 30 days.[4]
- 15.0% reported having their activities limited.[4]
- 33.8% of cancer survivors fell in the last 12 months.[4]
- 67.4% of cancer survivors report being overweight or obese.[4]

Limiting exposure to cancer risk factors (i.e. smoking) and engaging in healthy behaviors (i.e. physical activity) may decrease the risk of future cancer, improve functioning, and increase quality of life.[1]


Poor or Fair General Health among Cancer Survivors by Race, 2016- 2018 MiBRFS


Poor Mental Health among Cancer Survivors by Sexual Orientation, 2016-2018 MiBRFS

**Disparities in Quality of Life**

- When the data is viewed from the perspective of race, it highlights disparities in quality of life in some groups as compared to white cancer survivors. Black, Hispanic survivors, and other/multi-(non-Hispanic) survivors report poorer general health than white cancer survivors.[4]
- The MIBRFS also highlights the importance of addressing the mental health needs of Lesbian, Gay, Bi-sexual, and Transgender (LGBT) individuals as they are more likely to report poor mental health than cancer survivors who are not LGBT.[4]

# Cancer Survivor Comorbidities

## Multiple Chronic Conditions

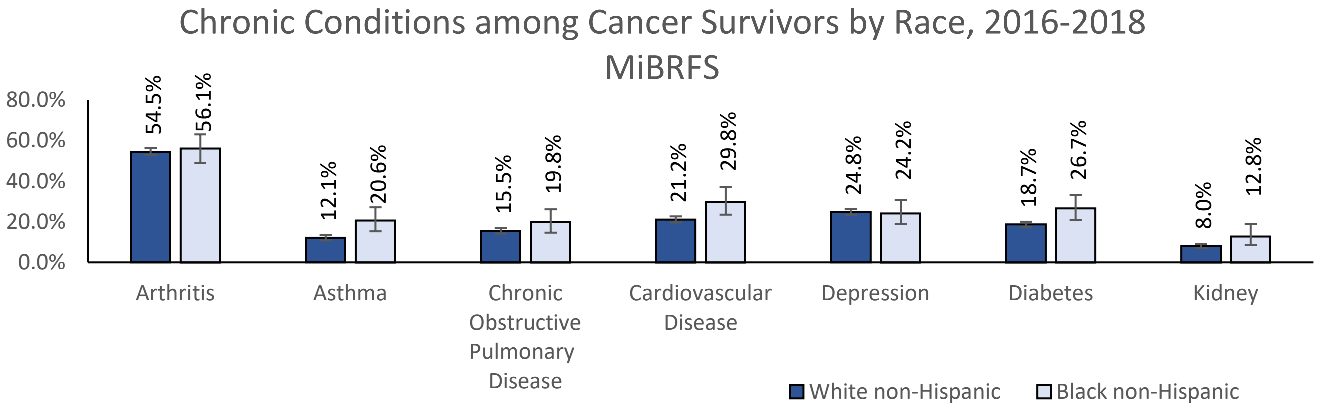
Since cancer is a disease most often diagnosed in older people, the rates of chronic diseases tend to be higher in people with cancer. These estimates are age-adjusted to the United States' 2000 standard population to allow for more accurate comparisons between the two groups.

- In addition to having cancer, 33.4% of survivors report having 2 or more additional chronic conditions compared to only 21.7% of people who have never had cancer.[4]
- When looking at specific chronic conditions, arthritis was the most common with 40.3% of cancer survivors reported having arthritis.[4]
- There are statistically significant differences in most chronic conditions between cancer survivors than those who have never had cancer including:
  - Arthritis
  - Asthma
  - Chronic Obstructive Pulmonary Disease (COPD)
  - Cardiovascular Disease
  - Depression

**Table 3: Age-Adjusted Chronic Conditions by Cancer Status, 2018 Michigan Behavioral Risk Factor Survey**

| 2018 MiBRFS | Cancer % (95% CI) | No Cancer % (95% CI) |
|---|---|---|
| Arthritis [a] | 40.3<br>(33.4-47.5) | 27.6<br>(26.5-28.8) |
| Asthma [a] | 28.9<br>(21.7-37.2) | 15.7<br>(14.7-16.7) |
| Chronic Obstructive Pulmonary Disease [a] | 10.9<br>(8.0-14.5) | 7.2<br>(6.5-7.9) |
| Cardiovascular Disease [a] | 18.7<br>(13.5-25.3) | 7.8<br>(7.1-8.5) |
| Depression [a] | 32.9<br>(26.7-39.6) | 23.0<br>(21.8-24.2) |
| Diabetes | 9.3<br>(7.4-11.6) | 9.9<br>(9.1-10.7) |
| Kidney Disease | 5.2<br>(2.9-9.0) | 2.7<br>(2.3-3.2) |

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


Chronic Conditions among Cancer Survivors by Race, 2016-2018 MiBRFS

## Chronic Condition Disparities

- When the data is viewed from the perspective of race it highlights disparities in chronic disease as compared to white cancer survivors. Significant disparities include Black cancer survivors having a higher rate of asthma, COPD, cardiovascular disease, and diabetes.[4]
- In Michigan, other racial groups are small enough that among the cancer survivor population their data is suppressed to avoid potential identification of survey respondents.

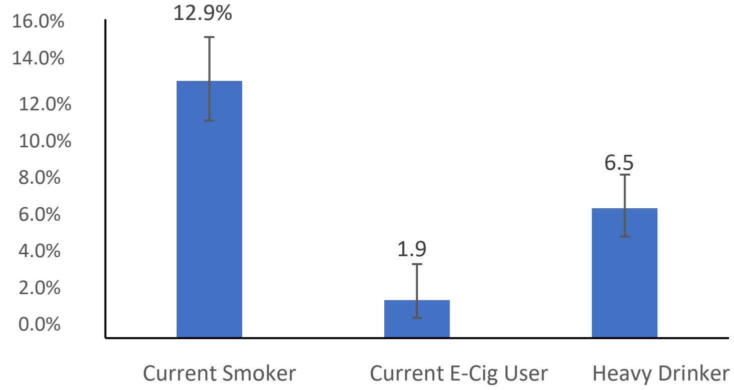
# Health Behaviors of Cancer Survivors

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

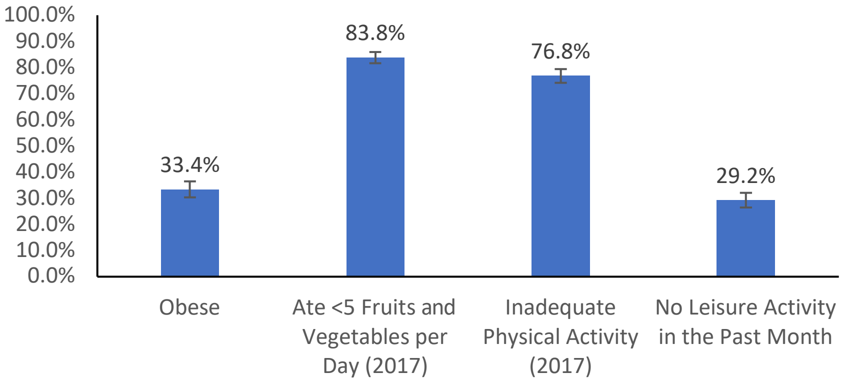
**Smoking**

- Smoking can increase the risk of cancer recurrence or a second cancer.[1] Yet, 12.9% of Michigan cancer survivors reported being a current smoker.
- In 2018, the smoking rate among survivors was 12.9%. This is a statistically significant decrease compared to the 2011 smoking rate of 19% in survivors. This highlights the importance of public health interventions for cancer survivors.[4]
- Among LGBT cancer survivors, 32.1% report being a current smoker (data not shown).[4]

Risky Behavior among Michigan Cancer Survivors, 2018 MiBRFS



Physical Activity and Nutrition among Michigan Cancer Survivors, 2018 MiBRFS



**Alcohol:**

- Alcohol can increase the risk for several cancers.[1] In Michigan, 6.5% of cancer survivors report being a heavy drinker.[4]

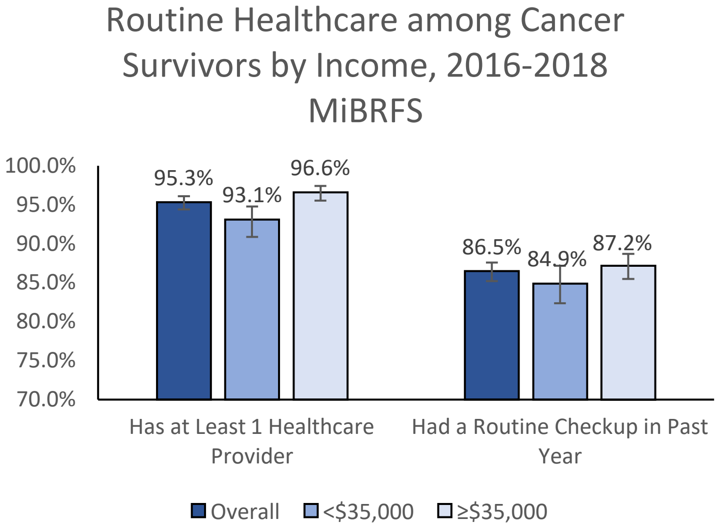
**Nutrition and Physical Activity:**

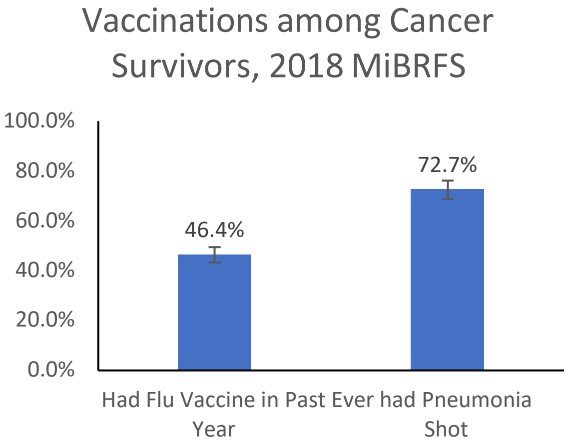
- It is important for survivors to maintain a healthy weight through a healthy diet and physical activity.[18] However, in Michigan:
  - 33.4% of survivors report being obese.[4]
  - 83.8% of survivors report they did not eat the recommended amount of fruits and vegetables.[4]
  - 76.8% of survivors did not receive adequate physical activity and 27.9% reported partaking in no leisure activities.[4]
- Black survivors were more likely to report partaking in no leisure activity compared to white survivors (36.4% vs 28.0%) (Data not shown).[4]

# Access to Care among Cancer Survivors

## Follow-up Care:

- After cancer treatment ends it is important that survivors maintain routine care.[19] Unfortunately, access to health care is not always equitable.[6]
    - Cancer survivors with an income of less than $35,000 were less likely to report having at least one health care provider or having a routine checkup in the past year.[4]
    - Among LGBT cancer survivors, only 66.6% reported having a routine checkup in the past year (data not shown).[4]


Routine Healthcare among Cancer Survivors by Income, 2016-2018 MiBRFS

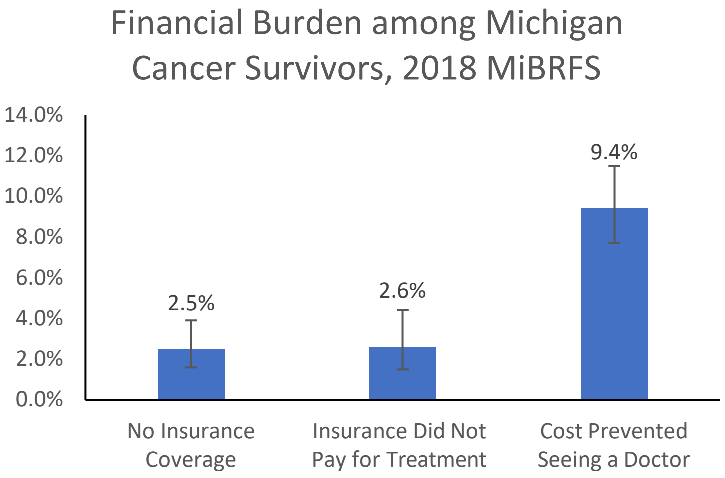

Vaccinations among Cancer Survivors, 2018 MiBRFS

## Vaccinations

- People with a history of cancer may be at greater risk of complications from the flu. All survivors are encouraged to receive the flu vaccine.[20] However, in Michigan, only 46.4% of cancer survivors had a flu vaccine in the past year.[4]
- The pneumonia vaccine is recommended for cancer survivors.[21] In Michigan, 72.7% of cancer survivors had a pneumonia shot.[4]
- Among Black survivors, only 34.1% reported receiving a flu vaccine and 59.7% received the pneumonia vaccine (data not shown).[4]

## Financial Toxicity

- Almost one-third of cancer survivors experience financial hardships as a result of their diagnosis. Unfortunately, those hardships can impact quality of life.[22]
- In Michigan, most cancer survivors reported having some type of insurance. Only 2.5% reported no insurance coverage.[4]
- Despite wide insurance coverage, 9.4% reported cost had prevented them from seeing a doctor.[4]

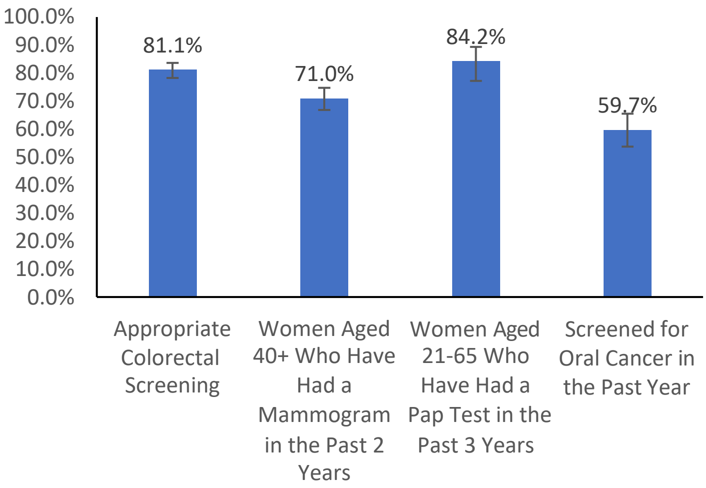

Financial Burden among Michigan Cancer Survivors, 2018 MiBRFS

# Health Care Services for Cancer Survivors

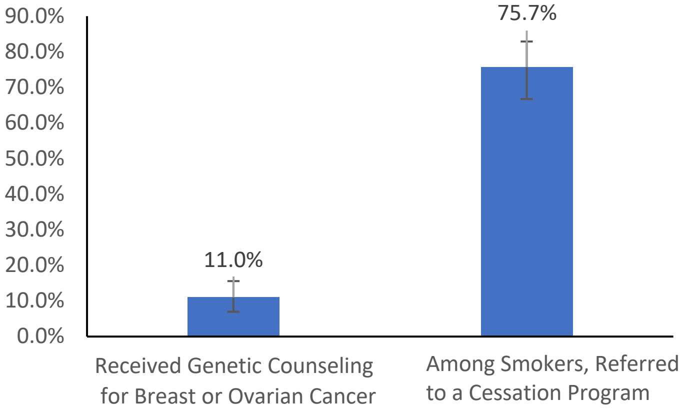
**Cancer Screening:**

- Ongoing cancer screening is important for cancer survivors as they can develop cancer in more than one location. Cancer screening identifies cancers at early stages when they are most treatable.[1]
- The U.S. Preventive Services Task Force recommends breast, cervical, colorectal, and lung cancer screening.[23]
    - Colorectal cancer (men and women): 79.9% of cancer survivors have received appropriate colorectal screening.[4]
    - Breast cancer: 76.5% have received appropriately timed mammogram.[4]
    - Cervical Cancer: 88.2% have received appropriately timed Pap test.[4]
- Among cancer survivors, women living in rural areas were less likely to report having a mammogram in the past two years compared to women in urban areas (69.9% vs 79.9%) (data not shown).[4]

Cancer Screening among Cancer Survivors, 2018 MiBRFS



Clinical Services among Cancer Survivors, 2018 MiBRFS



**Genetic Counseling**

- Genetic counseling is recommended for all women with ovarian cancer and for women diagnosed with breast cancer who were either diagnosed before the age of 50, have a strong family history of breast cancer, or are of Ashkenazi Jewish ancestry.[24]
- If testing is recommended and a pathogenic mutation (genetic change) is found, cancer survivors should inform family members and be counseled on risk management strategies to reduce their own risk of cancer recurrence.[24]
- Among female cancer survivors, 11.0% have received genetic counseling for hereditary breast or ovarian cancer.[4]
- This demonstrates the need to continue education on the importance of genetic counseling and to reduce barriers, including financial barriers, to genetic counseling.

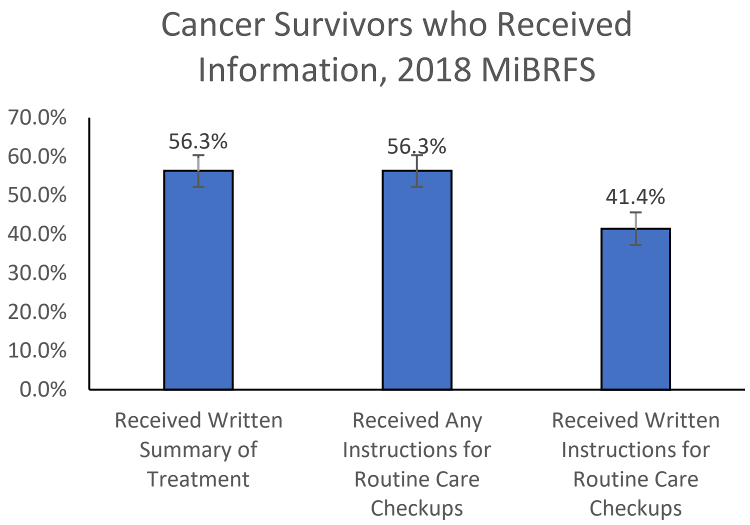
**Referrals to Tobacco Cessation:**

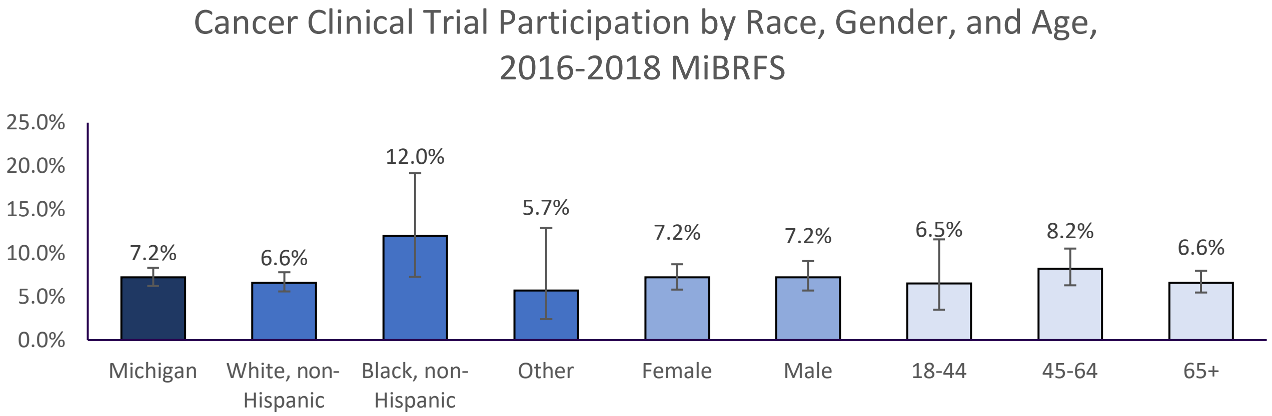
- Studies have shown smoking lessens the effectiveness of cancer treatment.[5]
- Of the 12.9% of cancer survivors who currently smoke, 75.7% had been referred to a cessation program. This is a statistically significant increase in referrals from the 60.0% referred in 2013.[4]

# Cancer Survivorship

**Survivorship Care Plans:**

- Survivorship care plans provide helpful information, improve care satisfaction, and increase follow through on recommended care if the plan was provided as a part of a conversation on cancer aftercare.[1]
- Increasing the number of survivorship care plans is a part of the 2016-2020 Michigan Cancer Plan.[25]
- From 2016 to 2018 there was a significant increase in the percentage of survivors who reported receiving a written summary of treatment (45.1% to 56.3%).[4]
- Among rural survivors, 21.4% reported receiving written instructions for routine care checkups. This was significantly lower compared to 27.5% of urban survivors.[4]


Cancer Survivors who Received Information, 2018 MiBRFS


Cancer Clinical Trial Participation by Race, Gender, and Age, 2016-2018 MiBRFS

**Clinical Trials:**

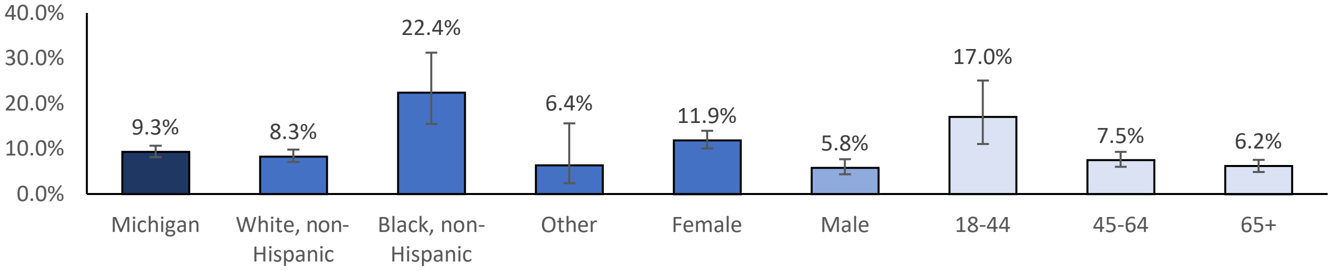
- Increasing the percent of Michigan adults in clinical trials is also an objective of the Michigan Cancer Plan. The goal is to reduce barriers to clinical trial enrollment, such as a lack of knowledge about available trials, suspicion of research, and financial concerns.[25]
- Clinical trials are important as it is through the clinical trials process that new treatments for cancer and best practices for survivorship care are developed.[26]
- Among cancer survivors, 7.2% reported participating in a clinical trial.[4]

# Pain Management for Cancer Survivors

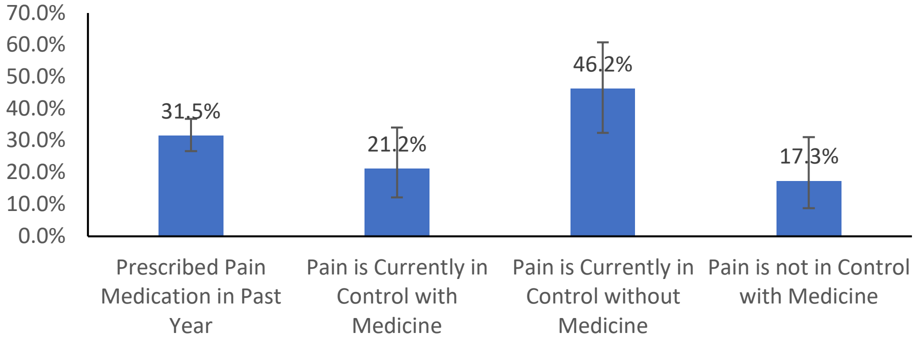
**Disparities in Cancer Pain**

- 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.[25]
- Among cancer survivors, 9.3% reported being in pain after finishing cancer treatment.[4]
- Black cancer survivors report pain at a significantly higher rate (22.4%) compared to white cancer survivors (8.3%).[4]
- Younger cancer survivors are more likely to report that pain continues after treatment ends. For those aged 18-44 who are cancer survivors, 17.0% reported pain while only 6.2% of those over the age of 65 reported pain.[4]

Cancer Survivors who Report Pain Post-Treatment by Race, Gender, and Income, 2016-2018 MiBRFS



Pain Management among Cancer Survivors, 2018 MiBRFS



**Pain Management:**

- 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, including a referral to rehabilitation services.[27]
- While 46.2% of cancer survivors report their pain is under control without using any medication, 17.3% report, despite being on medication, their pain is still not under control.[4]

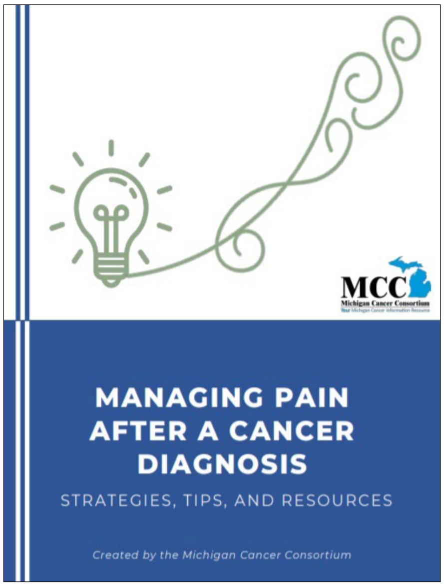
# Cancer Survivor Focus Groups – Pain Management

## Survivors and Shared Decision-Making

Michigan has coordinated with local partners to facilitate focus groups with survivors to learn more about pain management. The 2016-2020 Michigan Cancer Plan contained an objective to address pain following a cancer diagnosis.[25]

Focus groups have become an important way to ensure that resources and tools created for survivors incorporate feedback from the population for which they are developed.

A workgroup of providers, survivorship advocates, and survivors collaborated on the development of a shared decision-making document for cancer survivors that provides strategies, tips, and resources on managing pain following a cancer diagnosis. Focus group feedback (see below) contributed to the development of the document. The final document provides information on the importance of shared decision-making for the survivor and health care team, along with descriptions of various pain management strategies.



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MANAGING PAIN AFTER A CANCER DIAGNOSIS

STRATEGIES, TIPS, AND RESOURCES

*Created by the Michigan Cancer Consortium*

### Fall 2018 – Focus Groups

Two focus groups were held with survivors to gather feedback on the type of information and formatting that would be important to include in such a document.

- One focus group was conducted in a rural area of the state; the other in an urban area.
- Common themes and feedback from the focus groups included:
  - The importance of non-pharmacological methods of pain control.
  - An understanding of emotional pain.
  - Survivor self-education.
  - Questions to ask providers.

### Summer 2019 – Focus Groups

Following the first two focus groups, the workgroup conducted a literature review on the topics and themes identified. A draft of the shared decision-making document was created and then focus group tested by three additional groups of survivors across different areas of the state.

- Common themes and feedback from the focus groups included:
  - Emphasize the message that survivors need to be their own advocate.
  - Financial resources/insurance is an important part of pain management.
  - The document should include a section on discussing pain management with providers.
  - Survivors liked the section on non-pharmacological and alternative methods of pain control.

Focus group feedback was incorporated into the document and the final product was made available on the Michigan Cancer Consortium's website: https://www.michigancancer.org/PDFs/Resources/ManagingPainAfterCancerDiagnosis.pdf

# Cancer Survivor Focus Groups – Clinical Trials

## Increasing Knowledge about the Benefit of Clinical Trials

Michigan has also coordinated with local partners to facilitate focus groups with survivors and primary care providers to address the need to improve clinical trial enrollment among survivors.

The 2016-2020 Michigan Cancer Plan contained an objective to increase the percentage of Michigan adults participating in cancer treatment clinical trials.[25] A workgroup of providers, survivors, and clinical trial experts collaborated on the development of two infographics (one for patients and one for primary care providers) which promote clinical trials and their benefits. The workgroup determined important topics to be included in the infographics and prepared them for focus group review in September 2019.

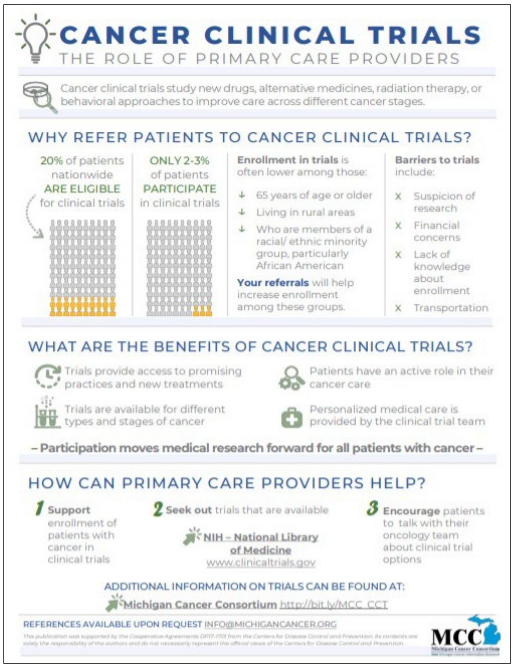
### Primary Care Provider Focus Group

Focus group feedback included:

- Providers wanted additional information on where to find clinical trials; such as the National Cancer Institute website.
- They appreciated information on barriers to clinical trials.
- They felt it important to include information on disparities in clinical trial enrollment.

Focus group feedback was incorporated into the infographic and made available on the Michigan Cancer Consortium's website:

[https://www.michigancancer.org/PDFs/Resources/ProviderClinicalTrialsInfo.](https://www.michigancancer.org/PDFs/Resources/ProviderClinicalTrialsInfo.)



**CANCER CLINICAL TRIALS**

THE ROLE OF PRIMARY CARE PROVIDERS

Cancer clinical trials study new drugs, alternative medicines, radiation therapy, or behavioral approaches to improve care across different cancer stages.

**WHY REFER PATIENTS TO CANCER CLINICAL TRIALS?**

20% of patients nationwide ARE ELIGIBLE for clinical trials

ONLY 2-3% of patients PARTICIPATE in clinical trials

**Enrollment in trials** is often lower among those:

- 65 years of age or older
- Living in rural areas
- Who are members of a racial/ ethnic minority group, particularly African American

**Your referrals** will help increase enrollment among these groups.

**Barriers to trials** include:

- Suspicion of research
- Financial concerns
- Lack of knowledge about enrollment
- Transportation

**WHAT ARE THE BENEFITS OF CANCER CLINICAL TRIALS?**

- Trials provide access to promising practices and new treatments
- Patients have an active role in their cancer care
- Trials are available for different types and stages of cancer
- Personalized medical care is provided by the clinical trial team

**– Participation moves medical research forward for all patients with cancer –**

**HOW CAN PRIMARY CARE PROVIDERS HELP?**

1 **Support** enrollment of patients with cancer in clinical trials

2 **Seek out** trials that are available

**NIH – National Library of Medicine**
www.clinicaltrials.gov

3 **Encourage** patients to talk with their oncology team about clinical trial options

ADDITIONAL INFORMATION ON TRIALS CAN BE FOUND AT:

**Michigan Cancer Consortium** http://bit.ly/MCC_CCT

REFERENCES AVAILABLE UPON REQUEST INFO@MICHIGANCANCER.ORG

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### Survivor Focus Groups

Focus group feedback included:

- Survivors suggested adding information on how to find clinical trials in their area.
- They felt it important to include information on the costs associated with clinical trials.
- Survivors liked the message that patients have an active role in their care.

Focus group feedback was incorporated into the patient infographic and was made available on the Michigan Cancer Consortium's website:

[https://www.michigancancer.org/PDFs/Resources/PatientClinicalTrialsInfo.pdf](https://www.michigancancer.org/PDFs/Resources/PatientClinicalTrialsInfo.pdf)

**CANCER CLINICAL TRIALS**

—WHAT YOU NEED TO KNOW—

**WHAT IS A CANCER CLINICAL TRIAL?**

A research study that involves people to find **new ways to improve cancer care**, such as with prevention, diagnosis, treatment, and managing side effects.

**IS A CLINICAL TRIAL RIGHT FOR YOU?**

- There are trials available for different types and stages of cancer
- Enrollment in a trial is always voluntary
- Could be an option for those who have had many treatments

***Ask your provider if there is a trial you should consider***

**QUESTIONS TO ASK YOUR PROVIDER**

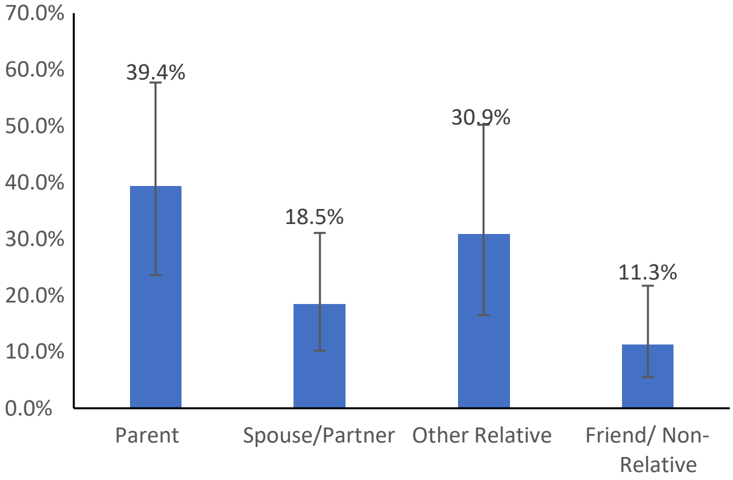
☐ What are the different requirements to participate?
☐ Will the trial replace my current treatment?
☐ What are the possible benefits and side effects?
☐ At what point in my treatment should I begin a trial?
☐ Who will coordinate my care?
☐ What types of treatments and medical appointments are part of the trial?
☐ What are the costs? Who pays?
☐ Will I have to travel to receive treatment?
☐ How long will the trial last? What happens if I leave early?

# Caregivers

Cancer caregivers include, "individuals (e.g., adult children, spouses, parents, friends, and neighbors) who provide care that is typically uncompensated and usually at home, involves significant amounts of time and energy for months or years, and requires the performance of tasks that may be physically, emotionally, socially, or financially demanding."[28]

According to the 2017 MiBRFS, approximately 21.6% of Michiganders provide some type of caregiving; 8.6% stated they cared for someone with cancer. Among those providing care to a cancer survivor, 39.4% cared for a parent and 18.5% cared for a spouse or partner. About a quarter of cancer caregivers report providing care for longer than five years (data not shown).[4]

Relationship to Person for Whom They Provided Care, 2017 MiBRFS



Unfortunately, the prevalence of cancer caregivers, their needs, and the burdens they face is unclear due to inconsistent/non-standardized national surveys. There is also no clear consensus who should be included in the definition of a caregiver.[28] When studies have been conducted, the findings are difficult to generalize since they are often done at large cancer centers with well-educated, non-Hispanic white populations.[28]

Cancer caregivers provide a crucial role and serve as a critical source of support for survivors during their cancer journey. As they work to care for survivors and address their needs, caregivers often struggle with their own unmet needs. Caregivers may experience a number of challenges including anxiety, depression, and financial difficulties. These may change depending on where the caregiving takes place and the type of support required, such as at the home or an in-patient setting.[29]

Support to caregivers can have a positive impact on the survivor. Strategies to address caregiver needs may include:

- Providing education on coping skills.
- Ensuring medical information and instructions are written at an appropriate health literacy level.
- Evaluating caregiver needs on a regular basis when evaluating the survivor's needs.[30]

Michigan will be working to determine how to collaborate among their various grants and partners to address caregiver needs across the cancer continuum.

# Conclusion

An easy thing to forget in cancer survivorship is the person behind the diagnosis. A cancer survivor can be a spouse or partner, a child, parent, or grandparent. Many survivors are still employed, some are students. Most survivors are not experts in cancer but are doing the best they can to understand the new information essential to their care. Cancer survivors also have emotional and spiritual needs and are remarkably brave as they face the vulnerabilities that accompany a diagnosis.

One of the things that may hinder effective survivorship care is implicit bias. An implicit bias is an unconscious assumption. Our brains receive a lot of data and have learned to make decisions about what to do with that data based on patterns we have seen in our environments over time. This process is mostly helpful, but it can lead to assumptions about cancer survivors that are untrue and harmful. Through training we can learn to spot implicit biases and ask individual cancer survivors how cancer is impacting them in order to incorporate their needs and wants into their treatment and survivorship interventions.[31]

Cancer care professionals can provide the best care to cancer survivors through assessment of survivor needs and referrals to follow-up services. Resources for cancer survivors and caregivers include:

1. **Smoking Cessation** – Michigan cancer survivors who would like help to stop using tobacco, can contact the Michigan Tobacco Quitline at: 1-800-784-8669.
2. **Nutrition** – MSU Extension Cooking Matters teaches participants how to eat healthy, cook, and grocery shop on a limited budget. Online classes are currently being offered due to COVID-19.
3. **Physical Activity** – Livestrong at the YMCA offers cancer survivors the opportunity to address fitness and quality of life through this 12-week program. No YMCA membership required.
4. **Cardiovascular Health for Low-Income Women** – The WISEWOMAN program provides opportunities for women to make healthy lifestyle choices.
5. **Breast and Cervical Cancer Screening for Low-Income Women** – Women under 250% of the federal poverty level who are uninsured or underinsured can call 1-844-446-8727 for help with screening.
6. **Caregivers** – Becoming a caregiver is a webpage from the Cancer Support Community offering helpful information to cancer caregivers.

Resources for cancer professionals include:

1. Wellness Interventions for Cancer Survivors – Information on health and wellness programs.
2. Cancer Survivorship Rehabilitation and Pain Management – Discusses the potential of rehabilitation services to address pain management.
3. Financial Navigation for People Undergoing Cancer Treatment

# Methods

**Definitions**

Cancer survivor is defined as answering ‘yes’ to at least one of the following questions from the MiBRFS:

Has a doctor, nurse, or other health professional ever told you that you had any of the following?

- Skin cancer?
- Any other types of cancer?

**Methods**

The Michigan Cancer Surveillance Program established a registry to record cases of cancer in 1984. Reports of diagnosed cancers are required of a facility diagnosing and/or treating cancer patients. A case is defined 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.

The Behavior Risk Factor Survey is a weighting methodology known as iterative proportional fitting or ranking 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 ranking 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 that was designed for analyzing data from multistage sample surveys. To examine disparities, multiple years of the survey were combined for analysis to reduce suppression. 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.

All focus group activity was reviewed by the Michigan Department of Health and Human Services Institutional Review Board and was classified as exempt. Focus group participants were recruited with the assistance of MDHHS partners. All focus groups were implemented by MDHHS staff trained in the implementation of focus groups.

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