



Cancer Survivor Needs Report

2021 Addendum



Introduction

Each year the Michigan Department of Health and Human Services (MDHHS) reviews available surveillance data. The goal is to produce a Cancer Survivorship Needs Report every two years. The [July 2020](#) report is available on the MDHHS website and includes health disparity information. It provides data for Michigan communities, health care providers, public health professionals, and cancer survivors on the needs of cancer survivors, cancer caregivers, and draws attention to cancer disparities.

The purpose of this addendum is to look at data related to childhood and young adult cancers. Cancer in people under the age of 40 is rare with 7.1% of cancers (2014 – 2018) in Michigan being diagnosed under the age of 40.¹ Although rare, cancer in this age group brings many challenges. Cancer in childhood, adolescence, and young adulthood presents unique challenges to both the individual with cancer and their families.^{2,3}

Educate yourself on how cancer impacts this younger population. The needs of these individuals and their caregivers may be overlooked, leaving them struggling physically, emotionally, and socially. Supporting patients with cancer and preparing these individuals for potential aspects of cancer and its treatment, along with making appropriate referrals, has the potential to increase quality of life.² The needs of the younger population may include:

- 1. Fertility Preservation** – Cancer treatment can impact fertility.^{4,5}
- 2. Cancer Side Effects and Late Effects** – The effects of treatment will vary by cancer and treatment. Survivors need to know what to watch for and learn about interventions.^{6,7}
- 3. Social Support** – Connecting with other people with cancer who are of a similar age can be helpful.⁸
- 4. School or Career** – Cancer treatment and its side effects may take time away from school or the development of a career.⁹
- 5. Financial** – Cancer is expensive for everyone but time away from work for parents and young adults in new careers can increase the financial challenges.^{10, 11}
- 6. Mental Health** – There are many aspects of cancer and its treatment that can lead to feelings of fear, isolation, anxiety and depression.^{12,13}

Helpful Resources

Cancer Information and Resources:

- [Adolescents and Young Adults \(AYAs\) with Cancer | National Cancer Institute](#)
- [Adolescents and Young Adults with Cancer | National Comprehensive Cancer Network](#)
- [Childhood Cancer Resources | Cancer.Net](#)
- [Children with Cancer: A Guide for Parents | National Cancer Institute](#)

For Families:

- [When Your Brother or Sister Has Cancer | National Cancer Institute](#)

Work and School:

- [Cancer and Careers](#)
- [Managing School During and After Cancer | Cancer.Net](#)

Childhood Cancer – Ages 0 through 14

Cancer in children is rare. In 2021, it was estimated that there would be 10,500 new cases of cancer diagnosed and 1,190 deaths from cancer among children aged 0 through 14 nationwide¹¹. However, for that child and his or her family, the diagnosis of cancer is devastating. Losing a child to cancer is life changing.

In Michigan from 2014 to 2018, there were 1,496 children diagnosed with invasive cancer and 209 children who died from cancer¹. As seen in **Table 1**, the most common type of invasive cancer among children was leukemia followed by brain and other nervous system cancers¹.

Overall, invasive childhood cancer is slightly more common in boys (17.9 per 100,000 population) than girls (15.3 per 100,000 population)¹.

Table 1: Michigan’s Most Common Cancers Among Children Aged 0-14 (2014-2018)

Cancer Site	Percent
Leukemia	25.9%
Brain and Other Nervous System	19.7%
Bones and Soft Tissue	9.7%
Non-Hodgkin Lymphoma	8.1%
Kidney	5.0%
Hodgkin Lymphoma	3.2%
Liver	2.4%

Childhood Cancer – Ages 0 through 14 continued

Childhood cancer rates by race and ethnicity from 2014 to 2018 are found in **Figure 1**^{1,15}. Rates were suppressed when they were derived from cancer case count that is deemed too small, as was the case for American Indian and Alaska Native children throughout this entire figure. White children had the highest incidence rates of any group, although they were not significantly different from that of Asian or Pacific Islander and Hispanic children. Mortality rates were similar in white children and Black children (2.4 versus 2.5 per 100,000 population respectively), despite a higher incidence rate of invasive cancer in white children than in Black children (17.5 versus 13.4 per 100,000 population respectively).

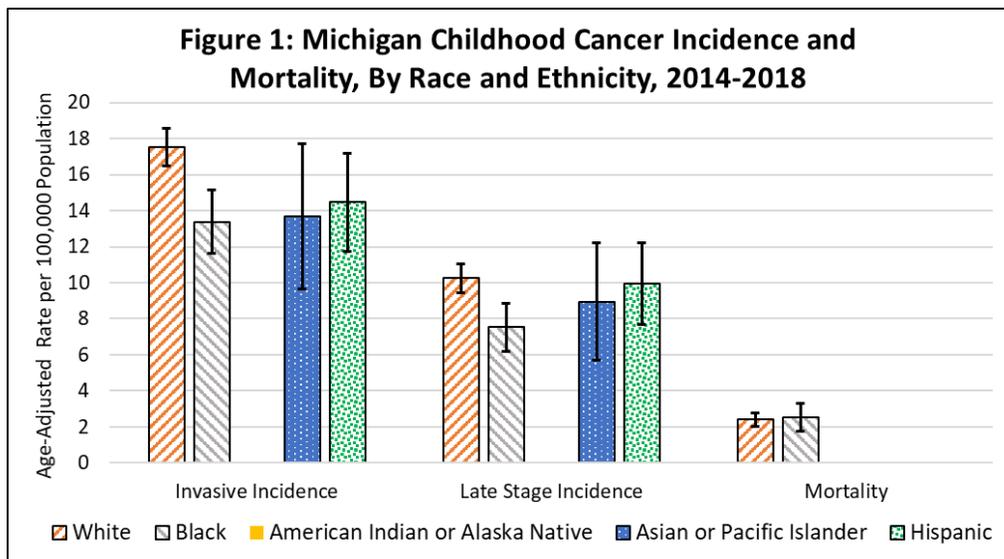
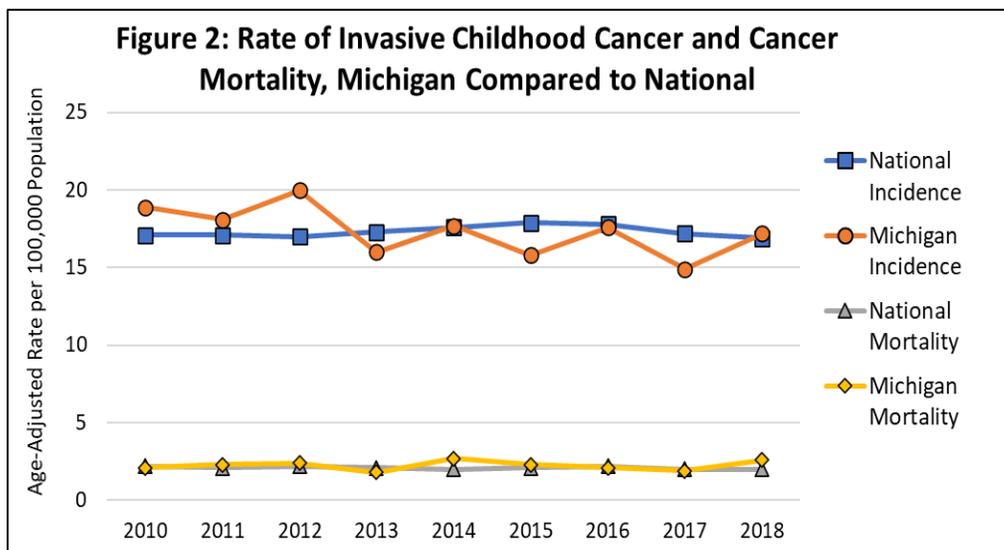


Figure 2 compares the annual rates of childhood invasive cancers and cancer deaths in Michigan with national rates^{16,17}. Except for the 2012 and 2017 incidence rates, the state and national rates are not significantly different.



Adolescent and Young Adult Cancer – Ages 15 through 39

Cancer is still very rare for adolescents and people in their 20s and 30s. However, as shown in **Table 2**, the most common cancer types start to change with progressing age¹. Lymphomas, leukemias, sarcomas, and brain and other nervous system cancers decrease in proportion with increasing age groups, whereas breast, cervical, and uterine cancers, as well as melanomas of the skin, increase¹.

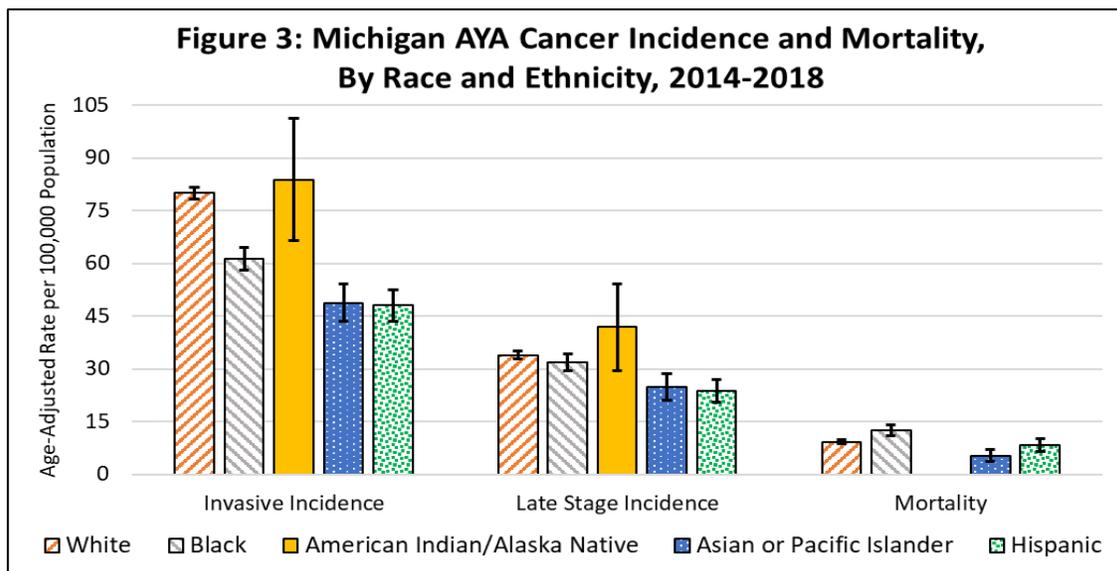
Table 2: Michigan’s Most Common Cancers Among AYA (2014-2018)

Cancer Site	Percent, Age 15-19	Percent, Age 20-29	Percent, Age 30-39
Bones and Soft Tissue	8.6%	4.3%	2.1%
Brain and Other Nervous System	10.1%	6.0%	3.4%
Breast	Suppressed	5.3%	18.8%
Cervix Uteri	Suppressed	3.0%	4.9%
Colon and Rectum	7.1%	6.0%	7.4%
Corpus Uteri	Suppressed	1.2%	3.4%
Hodgkin Lymphoma	17.0%	9.2%	2.8%
Kidney	Suppressed	1.7%	4.0%
Leukemia	11.7%	5.4%	3.1%
Melanoma of the Skin	3.1%	9.6%	10.0%
Non-Hodgkin Lymphoma	6.9%	6.4%	4.2%
Testis	5.2%	12.8%	5.8%

Additionally, testicular cancers make up a large proportion of adolescent and young adult (AYA) cancers, being the most common cancer among AYA aged 20-29¹.

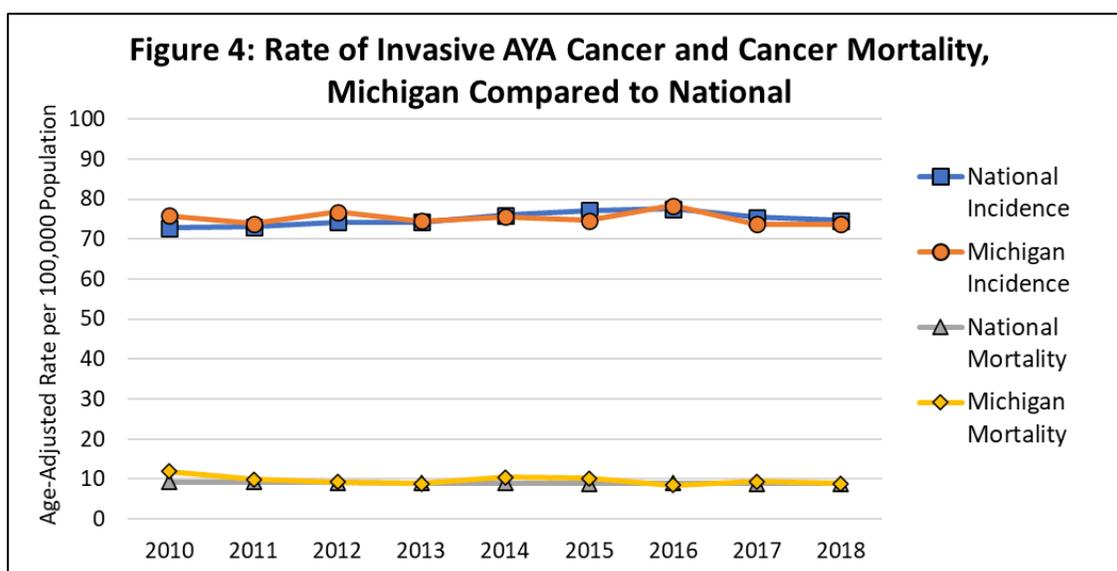
Unlike childhood cancers, invasive AYA cancers occur at a higher rate in females compared to males (93.6 versus 57.3 per 100,000 population)¹.

Figure 3 shows Michigan AYA cancer rates by race and ethnicity from 2014 to 2018^{1,15}. As was seen with Michigan children, incidence of invasive cancers was lower among Black AYA than white AYA (61.3 versus 80.1 per 100,000). However, Black AYA had a similar incidence rate of late-stage cancers and a higher rate of cancer mortality than white AYA.



Furthermore, American Indian and Alaska Native AYA had the highest rates of cancer incidence out of all groups, and those rates were significantly higher than that of Asian or Pacific Islander and Hispanic but not than white.

Figure 4 compares the annual rates of AYA invasive cancers and cancer deaths in Michigan with national rates^{16,17}. Except for the 2010 and 2014 mortality rates, the state and national rates are not significantly different.



Photovoice Project With Young Cancer Survivors & Thrivers

Photovoice is a research process where individuals take photos to represent their experience and share it with others. In 2021 MDHHS met with 17 young cancer survivors and thrivers aimed at understanding how cancer services can be improved for these individuals. They were asked to take pictures that answered the following questions:

1. What has helped you manage your cancer/cancer survivorship?
2. What is important for providers to know about the young person's experience with cancer?

Each participant was asked to provide two pictures for each question. In three different meetings the young survivors and thrivers discussed their pictures and the way they related to the questions. A video has been created aimed at sharing these experiences with health care providers. The video can be found on the [MDHHS provider webpage](#).

Themes:

Examples of themes identified by young survivors and thrivers and the photos they took for the photovoice project are below:

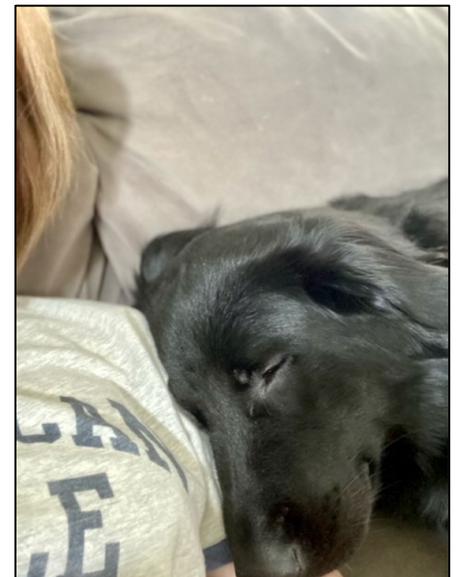
- **Balancing Cancer Care and Life**
 - "Sometimes I freak-out when my appointment is going late. I have to get back to work. I need my job; it is covering my treatment."
 - "The co-pays for my medication are insane."
- **Communication**
 - "No one told me that I would go into menopause instantly after my total hysterectomy."
- **Coping**
 - "My dog has helped me get through my cancer."
 - "I planned trips for my daughter and me. I collected travel magnets to remind me of life after cancer."
 - "Nature is a reminder that there is something bigger out there and a way to disconnect from the world."
- **End of Treatment**
 - "It feels like you just got pushed off the cliff."

Photovoice Project With Young Cancer Survivors & Thrivers

Themes:

Further examples of themes identified by young survivors and thrivers and the photos they took for the photovoice project are below:

- **Fertility**
 - “Cancer takes away so many things. We don't want cancer to take away our child.”
- **Mental Health**
 - “Once I was done with treatment, that's when everything hit me.”
 - “I can present as fine and going through life, but fear is always in me.”
 - “It felt isolating when it was hard to find other young survivors.”
- **Treatment Side Effects**
 - “After my mastectomy it was like my I didn't know my own body. I didn't feel like my arms were my own.”
- **Whole Person Care**
 - “My provider treats me not just the cancer. She looks at the whole picture looking at me as a complete individual. I feel like she is tailoring the treatment to the whole me.”



MDHHS Survivorship Grants

To address the needs of cancer survivors, MDHHS' Comprehensive Cancer Control Program, Program for Breast Cancer in Young Women (PBCYW), and Michigan Cancer Consortium (MCC) have collaborated with partners on several projects to support survivor quality of life. This has included policy and system change work, survivor education, patient navigation, and provider education. The information below highlights MDHHS' different survivorship projects and partners who are collaborating on this work.

Partner	Project
Facing Hereditary Cancer Empowered (FORCE)	Increase the number of health system navigators and genetic counselors who integrate a community resource referral plan to support cancer survivors and individuals with metastatic breast cancer into their standard practice using a toolkit developed for this purpose.
Henry Ford Health System	Develop an Epic-based surveillance tool to monitor survivor compliance with The National Comprehensive Cancer Network surveillance guidelines and reduce the number of patients lost to follow-up.
Office of Cancer Health Equity and Community Engagement, Karmanos Cancer Institute	Convening a Young Survivor Cancer Action Council to partner on research, services, and policy related to the needs of young survivors in the metro Detroit area.

Survivor Education

Partner	Project
Inter-Tribal Council of Michigan, Inc.	Develop the <i>Kwe Brave</i> media accounts to address breast health and support American Indian/Alaskan Native breast cancer survivors
PBCYW Partners	Collaborate on the development of educational webinars, including advance care planning , financial navigation , and physical activity .
Region 2 Area Agency on Aging Michigan Oncology Quality Consortium	Work with oncology providers to develop a process of referring cancer survivors to a chronic disease self-management workshop, Cancer Personal Action Toward Health (Cancer PATH): Thriving and Surviving.

MDHHS Survivorship Grants continued

Patient Navigation	
Partner	Project
Public Sector Consultants	<i>Wellness Interventions for Cancer Survivor</i> is a white paper that discusses the importance of wellness interventions in promoting survivors' long-term well-being.
Michigan Oncology Quality Consortium	Develop an Ovarian Cancer Patient Navigation Line to encourage referrals of patients with ovarian cancer to gynecologic oncologists for treatment. Call: 844-446-8727.
The Navectis Group	MDHHS has partnered with Dan Sherman and the Navectis Group on a webinar training to understand and treat oncology financial toxicity.

Provider Education	
Partner	Project
Michigan Cancer Consortium Public Sector Consultants	<i>Palliative Care for Adults Living with Cancer</i> is a white paper that describes the importance of palliative care and how it can be incorporated into practice.
Michigan Cancer Consortium Public Sector Consultants	<i>Cancer Survivorship Rehabilitation and Pain Management</i> is a white paper offering an overview of rehabilitation pain management approaches and direction for referring patients to rehabilitation services.
PBCYW Partners	PBCYW and its partner organizations have collaborated on a variety of provider education webinars on topics including cultural humility, financial navigation , palliative care , and survivorship programming .
University of Michigan Department of Obstetrics and Gynecology	The Oncocontraception Project is developing a CME provider training module on family planning and contraceptive care for young female cancer survivors and patients with metastatic breast cancer.
Young Survivors	A photovoice project with young survivors led to the development of an educational photo video for providers that describes the needs of young survivors and how they can be supported.

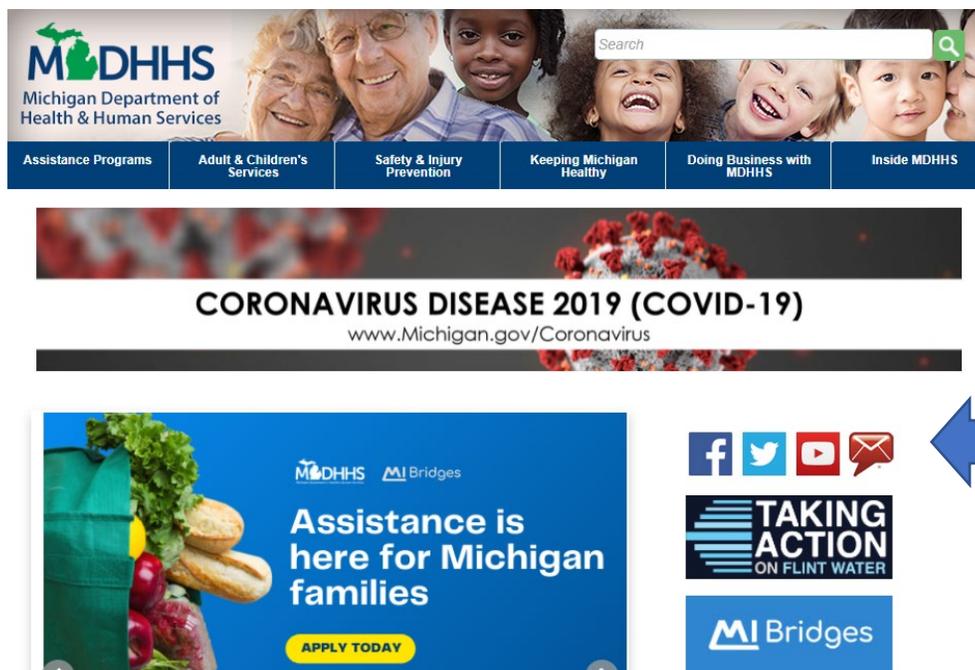
Learn More About Resources

MDHHS works with their partners to share resources, tools, webinars and trainings for survivors, caregivers, and providers. These are posted on their [survivorship webpage](#). This is also accomplished with email messages that are sent out through two listservs.

- **Cancer Survivorship Program Listserv:** Messages are sent out monthly with a focus on general survivorship resources and provider education.
- **Young Women with Breast Cancer Listserv:** Messages are sent out weekly with a focus on resources for these young survivors and caregivers. The listserv also offers resources and trainings for providers.

For **instructions** on how to sign up for the listservs through MDHHS, see the instructions below:

1. Visit the MDHHS listserv sign up page by clicking on the red message button (see image):
[Michigan Dept of Health & Human Services \(govdelivery.com\)](http://Michigan Dept of Health & Human Services (govdelivery.com))
2. Enter your subscription preference and information to receive messages.
3. On the next page, scroll through subscription topics to select “Cancer Survivorship Program” or “Program for Breast Cancer In Young Women” from the list of MDHHS listservs and complete sign up.



1. Michigan Resident Cancer Incidence File. Updated with cases processed through November 30, 2020. Division for Vital Records and Health Statistics, Michigan Department of Health and Human Services.
2. Jones JM, Fitch M, Bongard J, et al. (2020) The Needs and Experiences of Post-Treatment Adolescent and Young Adult Cancer Survivors. *Journal of Clinical Medicine*.9(5):1444.
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6. National Cancer Institute (2021) Late Effects of Treatment for Childhood Cancer (PDQ®)–Patient Version. Accessed at <https://www.cancer.gov/types/childhood-cancers/late-effects-pdq> on November 9,2021.
7. Chao, C., Bhatia, S., et. al. (2020) Chronic Comorbidities Among Survivors of Adolescent and Young Adult Cancer. *Journal of Clinical Oncology* 38(27):3161-3173.
8. Pennant, S., Lee, S.C., et.al. (2020) The role of social support in adolescent/young adults coping with cancer treatment. *Children* 7(1):2.
9. Sisk, B.A., Fasciano, K., Block, S.D., and Mack J.W. (2020) Impact of cancer on school, work, and financial independence among adolescents and young adults with cancer. *Cancer*. 26(19): 4400-4406.
10. Nathan, P. C., Henderson, T. O., Kirchoff, A. C., Park, E. R., Yabroff, K. R. (2018) Financial Hardship and the Economic Effect of Childhood Cancer Survivorship. *Journal of Clinical Oncology* 38(21): 2198 – 2204.
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13. Nathan, P.C., Nachman, A., et. al. (2108) Adverse mental health outcomes in a population-based cohort of survivors of childhood cancer. *Cancer* 124(9): 2045-2057.
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15. 1985 - 2018 Michigan Resident Death Files. Division for Vital Records & Health Statistics, Michigan Department of Health & Human Services.
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17. United States Cancer Statistics - Mortality: 1999 - 2018, WONDER Online Database. United States Department of Health and Human Services, Centers for Disease Control and Prevention; 2021. Accessed at <http://wonder.cdc.gov/CancerMort-v2018.html> on Nov 2, 2021.

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