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July 31, 2020

The Honorable Roy Blunt
Chairman
The Honorable Patty Murray
Ranking Member
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
Committee on Appropriations
United States Senate

The Honorable Rosa DeLauro
Chairwoman
The Honorable Tom Cole
Ranking Member
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
Committee on Appropriations
House of Representatives

Survivors of Childhood Cancer: Factors Affecting Access to Follow-up Care

According to the most recent cancer surveillance data available, approximately 465,000 childhood cancer survivors—children, adolescents, and adults who were diagnosed with cancer between ages 0 through 19—were alive in the United States as of January 1, 2017, and one estimate projected that the number of survivors may reach 500,000 in 2020.¹ Although cancer is the leading cause of childhood death by disease, the 5-year survival rate for childhood cancer has increased from about 62 percent in the mid-1970s to about 86 percent in the mid-2010s as

¹National Cancer Institute (NCI) Surveillance, Epidemiology, and End Results program *SEER Cancer Statistics Review 1975-2017*, Table 29.7, accessed April 22, 2020, https://seer.cancer.gov/csr/1975_2017/browse_csr.php?sectionSEL=29&pageSEL=sect_29_table.07; and L. Robison and M. Hudson, “Survivors of Childhood/Adolescent Cancer: Life-long Risks and Responsibilities,” *Nature Reviews Cancer*, vol. 14, no. 1 (2014): p. 61.

Unless otherwise specified, we use NCI’s definition of a childhood cancer survivor—a surviving individual of any age who was diagnosed with cancer from ages 0 through 19. As such, the definition includes individuals who are older than 19 if they were diagnosed as children. Survivors may or may not be receiving treatment for cancer.

a result of improved treatments and treatment protocols.² Treatment for cancer may include surgery, radiation, chemotherapy, immunotherapy, or a combination of these treatments. Childhood cancer survivors may face serious health effects over time—collectively known as late effects—that result from the original cancer and its treatment. These late effects may include developmental problems, neurocognitive problems, heart conditions, and development of subsequent cancers. Late effects require follow-up care throughout the childhood cancer survivor’s life. Follow-up care may include monitoring, medical treatment, psychosocial services (e.g., counseling), and palliative care (i.e., interventions such as pain management to prevent or reduce emotional and physical suffering for patients and their families because of life-threatening illness) from both primary and specialty care providers.

Stakeholders such as cancer advocacy organizations and researchers have raised questions about the ability of childhood cancer survivors to access needed follow-up care. While access to care is also important to the general population in the United States, childhood cancer survivors face a higher risk of experiencing serious health problems for which access to health care is needed over time. Enacted in June 2018, the Childhood Cancer Survivorship, Treatment, Access, and Research Act of 2018 (Childhood Cancer STAR Act) includes provisions for Department of Health and Human Services (HHS) agencies to support access to follow-up care for childhood cancer survivors, among other purposes. Such provisions aim to improve childhood cancer research and surveillance, assess the workforce of health care providers who care for childhood cancer survivors, and fund awards to study systems of care for survivors.³

The conference report accompanying the Department of Defense and Labor, Health and Human Services, and Education Appropriations Act, 2019 and Continuing Appropriations Act, 2019 included a provision for us to report on barriers to obtaining and paying for medical care for childhood cancer survivors, including psychosocial services and palliative care.⁴ In this report, we identify factors reported to affect access to follow-up care for this population. To supplement this information, we also present examples of activities within HHS to support access to follow-

²NCI Surveillance, Epidemiology, and End Results program, *SEER Cancer Statistics Review 1975-2016, Table 28.8*, accessed April 13, 2020, https://seer.cancer.gov/csr/1975_2016/browse_csr.php?sectionSEL=28&pageSEL=sect_28_table.08.

³Childhood Cancer Survivorship, Treatment, Access, and Research Act of 2018, Pub. L. No. 115-180, 132 Stat. 1382 (codified at 42 U.S.C. §§ 280e-3a, 284a, 285a-10, 285a-11, 285a-11a, 285a-11b).

⁴H.R. Rep. No. 115-952, at 525 (2018).

up care for childhood cancer survivors, including activities related to selected provisions in the Childhood Cancer STAR Act. (See enclosure I.)

To identify factors reported to affect access to follow-up care for childhood cancer survivors, we spoke with officials from the Centers for Disease Control and Prevention (CDC) and the National Cancer Institute (NCI)—agencies within HHS that conduct activities specific to childhood cancer survivors, including research about access to care for this population.⁵ We also interviewed stakeholders, including providers who care for childhood cancer survivors in specialized settings, advocacy groups, and professional associations.⁶ We reviewed peer-reviewed studies related to access to care for survivors, outcomes of treatment they may receive, and factors that may affect their access to follow-up care (such as psychosocial and palliative care).⁷ We focused our review on studies published between 2014 and early November 2019, including those based on data from the NCI-funded Childhood Cancer Survivor Study (CCSS), and also reviewed studies that stakeholders referred to us.⁸ We also reviewed relevant agency documents for context, such as published information from NCI’s Surveillance, Epidemiology, and End Results program, which provides information on cancer incidence and prevalence.⁹

⁵We focused on HHS agencies that conduct activities specific to childhood cancer survivors, including research related to access to care. Other HHS agencies (such as the Centers for Medicare & Medicaid Services and the Health Resources and Services Administration) that administer programs that pay directly for health care were outside the scope of this review because such programs are not specific to childhood cancer survivors.

⁶Advocacy groups and professional associations we interviewed included the Alliance for Childhood Cancer (an organization representing national patient cancer advocacy groups and professional medical associations), the American Cancer Society, the American Society of Pediatric Hematology/Oncology, the Association of Pediatric Hematology/Oncology Nurses, the Association of Pediatric Oncology Social Workers, and the Children’s Oncology Group. We selected these groups and associations because of their knowledge of issues related to childhood cancer, including access to care for childhood cancer survivors.

⁷We reviewed about 80 peer-reviewed studies that we identified through searching several bibliographic databases, such as CINAHL, MEDLINE, and Scopus.

⁸CCSS is a multi-institutional study conducted across 31 sites that produces the largest source of data on childhood cancer survivors, according to NCI officials. CCSS data include information on more than 35,000 childhood cancer survivors. Childhood cancer survivor participants in this study must have been younger than 21 when diagnosed with cancer and be at least 5 years past cancer diagnosis.

⁹This program collaborates with CDC’s National Program of Cancer Registries to collect cancer data on the entire U.S. population.

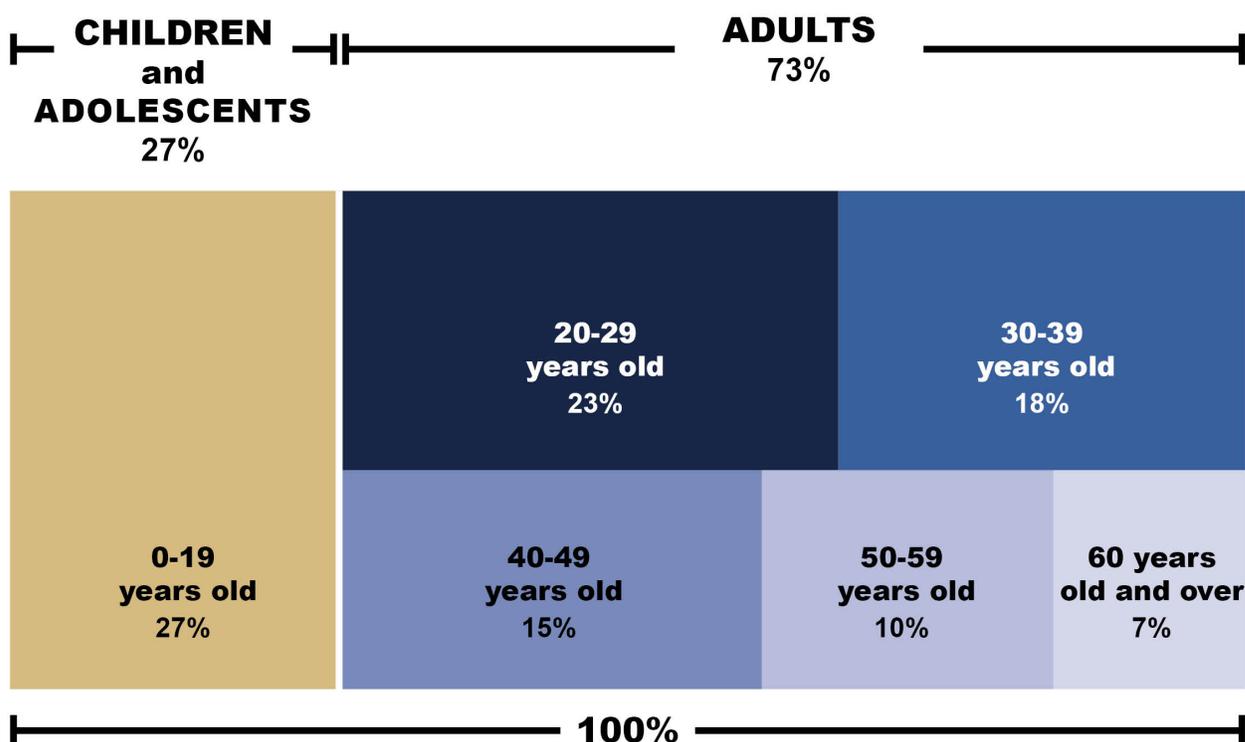
We conducted this performance audit from July 2019 to July 2020 in accordance with generally accepted government auditing standards. Those standards require that we plan and perform the audit to obtain sufficient, appropriate evidence to provide a reasonable basis for our findings and conclusions based on our audit objectives. We believe that the evidence obtained provides a reasonable basis for our findings and conclusions based on our audit objectives.

Background

Survivors of Childhood Cancers

Survivors of childhood cancer can be of any age, and the majority are adults age 20 or older. See Figure 1 for more detail on the ages of the childhood cancer survivor population.

Figure 1: Childhood Cancer Survivors by Age Groups, as of January 1, 2017



Source: GAO analysis of National Cancer Institute Surveillance, Epidemiology, and End Results data. | GAO-20-636R

Note: The figure represents the 465,169 childhood cancer survivors alive in the United States as of January 1, 2017 (the most recent date for which data are available). See National Cancer Institute Surveillance, Epidemiology, and End Results program, *SEER Cancer Statistics Review 1975-2017*, Table 29.7, accessed April 22, 2020, https://seer.cancer.gov/csr/1975_2017/browse_csr.php?sectionSEL=29&pageSEL=sect_29_table.07.

Survivors experienced different types of cancers during childhood, and some cancers are more common than others. As of the beginning of 2017, common types of childhood cancers (ages 0 through 19) include leukemia (a family of cancers that start in blood-forming tissues), brain and spinal cord tumors, neuroblastoma (cancer that forms in nerve cells), and lymphoma (cancer that starts in the immune system, categorized into Hodgkin and non-Hodgkin types).¹⁰

Late Effects of Childhood Cancer

Childhood cancers and their treatment can lead to late effects on survivors' health that they must face over time. Late effects may occur months to years after cancer treatment is completed. Further, the risk of developing a late effect increases with time. Examples of common cancer treatments and their associated late effects include the following:¹¹

- Chemotherapy (drug therapy that kills cancer cells) may cause heart and blood vessel damage, cognitive impairments, visual problems, dental problems, hearing loss, and fertility problems. The late effects vary depending on the type of chemotherapy used.
- Radiation therapy (high doses of radiation to kill cancer cells and shrink tumors) may cause damage to heart and blood vessels, lung problems (such as scarred lung tissue), hearing loss, dental problems, fertility problems, problems with bone development, and subsequent cancers. The late effects vary depending on the type, the amount, and the part of the body that was exposed to the radiation.

In addition, survivors may experience psychosocial problems that may develop from their experiences with childhood cancer, including cancer treatment. For example, a survivor may become depressed after cancer treatment or may experience anxiety about the cancer returning.

Childhood cancer survivors may require multiple types of follow-up care for late effects, such as receiving:

¹⁰Examples of relatively less common cancers in children include rhabdomyosarcoma (cancer that forms in certain muscles) and osteosarcoma (cancer in the bones). See NCI Surveillance, Epidemiology, and End Results program, *SEER Cancer Statistics Review 1975-2017, Table 29.7*.

¹¹Other treatments may include surgery, immunotherapy (a treatment that uses the body's immune system to fight the cancer cells), and stem cell transplant (a treatment to restore blood-forming stem cells that were lost as a result of side effects from high doses of chemotherapy or radiation therapy).

- services from primary care providers and specialists to monitor health, including screening for any late effects that have been linked to treatments for childhood cancers;
- psychosocial care (e.g., counseling, education, group support) to address the psychological and social effects of childhood cancer, which may be provided by a physician, counselor, therapist, social worker, or other health care professional; and
- palliative care to address the physical and emotional comfort of a patient and family as they face a life-threatening illness, including at the end of life.

Further, survivors may require follow-up care across multiple stages of their lives. For example, a child may receive chemotherapy to treat neuroblastoma, which may result in hearing loss and require speech therapy and the use of a hearing aid throughout adolescence and adulthood. As another example, treatment for an adolescent with leukemia may extend for years and result in post-traumatic stress disorder, which can require psychosocial treatment into adulthood. Some late effects may not appear until much later in life—for example, an adult survivor who received chest radiation to treat lymphoma as a child may have heart disease later in life, which may require surgery to repair damaged heart tissue.

Childhood cancer survivors can receive follow-up care in a variety of settings, including in primary care settings or in specialized outpatient multidisciplinary clinics, hereafter referred to as childhood cancer survivorship clinics. These clinics offer multiple providers with different specialties that a survivor can see in a single visit. Providers could include those who specialize in cardiovascular issues, psychosocial care, and oncology with an emphasis in survivorship. Guidelines from the Children’s Oncology Group—an organization dedicated to childhood and adolescent cancer research—are available to assist providers in managing late effects for childhood cancer survivors.¹² Specifically, the Children’s Oncology Group prepares and publishes guidelines to assist pediatricians, oncologists, and other specialists to increase their awareness of potential late effects and standardize follow-up care for survivors throughout their lives.

¹²See Children’s Oncology Group, *Long-Term Follow-up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers, Version 5.0* (Monrovia, Calif: Children’s Oncology Group, October 2018). The Children’s Oncology Group, which is primarily funded by NCI, operates a large network for childhood cancer clinical trials in addition to developing standards for follow-up care for childhood cancer survivors. According to the organization’s website, the Children’s Oncology Group is the world’s largest organization devoted exclusively to childhood and adolescent cancer research.

Affordability, Knowledge, and Proximity Affect Access to Follow-up Care for Childhood Cancer Survivors

Through stakeholder interviews and peer-reviewed studies, we identified factors that affect access to follow-up care for survivors of childhood cancers, which we grouped into three categories: care affordability, survivors' and providers' knowledge of appropriate care, and proximity to care.

Affordability

Survivors of childhood cancer may have difficulty paying for follow-up care, which can make them less likely to access this care. One study we reviewed found that childhood cancer survivors were significantly more likely to have difficulty paying medical bills and delay medical care due to affordability concerns when compared to individuals with no history of cancer.¹³ Stakeholders we interviewed and studies we reviewed provided multiple reasons that may contribute to survivors' difficulties with affording the care they need, including the following examples:

- Survivors may have more medical expenses than those who do not have a history of childhood cancer. For example, one study using CCSS data on nearly 700 survivors found that survivors pay more out-of-pocket expenses, were more likely to borrow money because of medical expenses, and were more likely to worry about the ability to get a needed medical procedure than their siblings who did not have cancer.¹⁴ Another study noted that greater medical expenses for survivors may lead to difficulties accessing health care, such as deferring care or not adhering to prescribed treatment.¹⁵
- Survivors may earn less money than individuals who do not have a history of childhood cancer. For example, one study that compared adult survivors of childhood cancer to those

¹³Karen A. Kuhlthau et al., "Health Insurance Coverage, Care Accessibility and Affordability for Adult Survivors of Childhood Cancer: A Cross-Sectional Study of a Nationally Representative Database," *Journal of Cancer Survivorship*, vol. 10 (2016): p. 964. This study examined a sample of childhood cancer survivors ages 21 to 65.

¹⁴Elyse R. Park et al., "Assessing Health Insurance Coverage Characteristics and Impact on Health Care Cost, Worry, and Access: A Report from the Childhood Cancer Survivor Study," *JAMA Internal Medicine*, vol. 177, no. 12 (2017): p. 1855.

¹⁵Ryan D. Nipp et al., "Financial Burden in Survivors of Childhood Cancer: A Report from the Childhood Cancer Survivor Study," *Journal of Clinical Oncology*, vol. 35, no. 30 (2017): p. 3474.

without a history of cancer found survivors' annual productivity loss—defined as loss from health-related unemployment, missed work days, and missed household productivity—to be over \$8,000 compared with \$3,000 for those without a history of cancer.¹⁶

- Survivors may fear losing their health insurance or have increased difficulty keeping health insurance or other health care coverage. For example, one study that used data from the CCSS on nearly 400 employed survivors found that one in four reported staying at a job to keep employment-related health insurance.¹⁷ Further, stakeholders we interviewed noted that some survivors may lose their health care coverage as they become adults. Children who are eligible for their parents' private health insurance may lose coverage at age 26, and children's eligibility for Medicaid—a joint federal-state health care program for low-income and medically needy individuals—may end at the age of 21 or 22.
- Certain types of follow-up care that significantly affect survivors' quality of life may not be covered by insurance or other coverage:
 - For example, according to peer-reviewed studies and Children's Oncology Group Guidelines, women who received radiation to the chest as part of childhood cancer treatment are at higher risk of developing breast cancer later in life, and they could benefit from early breast cancer screening. However, insurance may not cover this screening until later in life, according to one stakeholder, despite evidence from peer-reviewed studies and Children's Oncology Group guidelines.
 - Survivors are at risk for infertility due to certain cancer treatments. However, stakeholders noted that insurance or Medicaid may not pay for fertility preservation—procedures used to help maintain a survivor's ability to have children.
 - Stakeholders also noted that coverage for palliative care for children varies considerably. Specifically, one stakeholder noted that states' Medicaid programs vary in their coverage for palliative care services, while another stakeholder noted that insurance varies in coverage for these services.

¹⁶Gery P. Guy Jr. et al., "Annual Economic Burden of Productivity Losses Among Adult Survivors of Childhood Cancers," *Pediatrics*, vol. 138, no. S1 (2016): p. S15.

¹⁷Anne C. Kirchhoff et al., "'Job lock' Among Long-Term Survivors of Childhood Cancer," *JAMA Oncology*, vol. 4, no. 5 (2018): p. 707.

Knowledge

Survivors' access to appropriate follow-up care for late effects of childhood cancer can depend on both survivors' and providers' knowledge about such care.

Survivor Knowledge. Through stakeholder interviews and peer-reviewed studies, we learned that the extent of survivors' knowledge of appropriate follow-up care varies and can have lasting effects on accessing needed care. In particular, stakeholders told us that if survivors do not know the importance of follow-up care, then they might not access it, especially as adolescents transition to adult follow-up care. Knowledge can affect access to care in a variety of ways, including the following examples:

- Stakeholders told us that some survivors of childhood cancer, particularly those in young adulthood, may lack basic knowledge about the need to receive follow-up care or where to seek it. For example, some survivors may have been treated for cancer at an early age and lack detailed memory about their treatment.
- One study examining understanding of risks for late effects among childhood cancer surveyed survivors who were 16 or older and parents of younger survivors found that a majority of survivors did not know it was likely that they would develop certain late effects.¹⁸ Without understanding what the potential late effects could be, survivors may be less likely to pursue appropriate follow-up care.
- Studies suggest that receiving reminders about needed care can increase survivors' adherence to appointments. For example, one study using CCSS data found that mailed informational packets and reminder calls to educate survivors on the importance of screening for breast cancer resulted in reported mammograms nearly doubling among study participants.¹⁹

¹⁸Brooke Cherven et al., "Knowledge and Risk Perception of Late Effects Among Childhood Cancer Survivors and Parents Before and After Visiting a Childhood Cancer Survivor Clinic," *Journal of Pediatric Oncology Nursing*, vol. 31, no. 6 (2014): p. 339.

¹⁹Kevin C. Oeffinger et al., "Promoting Breast Cancer Surveillance: The EMPOWER Study, a Randomized Clinical Trial in the Childhood Cancer Survivor Study," *Journal of Clinical Oncology*, vol. 37, no. 24 (2019): p. 2131.

- Receiving follow-up care in a childhood cancer survivorship clinic had a positive effect on survivors' knowledge, which could thereby improve their access to care. For example, one study examining childhood cancer survivors who were treated at a survivorship clinic and were less than 15 years from their completion of cancer treatment found that they had a greater knowledge of their risk for late effects, compared to survivors who received follow-up care from a primary care physician or oncologist.²⁰ Further, NCI officials we interviewed noted that childhood cancer survivors who receive care in a survivorship clinic are more likely to follow their providers' recommendations for monitoring for late effects. Such clinics can facilitate convenience by coordinating multiple appointments for survivors and their families, thereby promoting adherence to follow-up care.

Provider Knowledge. Similarly, a provider's lack of knowledge of appropriate follow-up care can make it more difficult for a survivor to receive appropriate care:

- One study that surveyed 1,500 internal medicine and family practice physicians noted that a majority of these primary care providers reported that they had never utilized the guidelines published by the Children's Oncology Group.²¹ About 40 percent of these primary care providers reported that they had not provided care to a survivor of childhood cancer in their medical practices and the majority of these providers did not believe their training was adequate to recognize late effects in these survivors. Without familiarity with medical guidelines, including the risk for late effects, primary care providers may lack the knowledge required to recommend appropriate screening and monitoring for survivors.
- Another study similarly found that primary care providers did not always refer survivors for appropriate follow-up care. Specifically, primary care providers in the study did not consistently refer adult survivors of childhood cancer to receive mammograms—a recommended screening for female childhood cancer survivors who received chest radiation

²⁰Robert B. Lindell et al., "Knowledge of Diagnosis, Treatment History, and Risk of Late Effects Among Childhood Cancer Survivors and Parents: The Impact of a Survivorship Clinic," *Pediatric Blood & Cancer*, vol. 62 (2015): p. 1444.

²¹J. L. Sima, S.M. Perkins, and D.A. Haggstrom, "Primary Care Physician Perceptions of Adult Survivors of Childhood Cancer," *Journal of Pediatric Hematology/Oncology*, vol. 36, no. 2 (2014): p. 118. For the Children's Oncology Group guidelines, see Children's Oncology Group, *Long-Term Follow-up Guidelines*.

as part of their initial cancer treatment.²²

- Stakeholders we interviewed told us there is little formal training available on childhood cancer survivorship. Accordingly, providers who do not work in childhood cancer survivorship clinics may not be familiar with caring for this population, including the care needed to monitor for late effects.
- According to stakeholders, providers may not appropriately prioritize the need for psychosocial and palliative care, although psychosocial standards of care for childhood cancer survivors recommend routine evaluation for the need for psychosocial services and assessments for palliative care options as needed throughout the disease process.²³ Low prioritization of these services can lead to insufficient referral for psychosocial and palliative care, affecting survivors' access to appropriate follow-up care.

Proximity

Stakeholders we interviewed and studies we reviewed noted that childhood cancer survivors may not be close to locations where follow-up care is available and, therefore, may have to travel long distances to receive follow-up care. The lack of proximity can make it difficult for survivors—particularly those with limited financial resources—to adhere to recommended follow-up care.

- Stakeholders noted that childhood cancer survivorship clinics may have large “catchment areas”—areas from which their patients are drawn—and some patients may have to travel long distances to receive care. For example, one stakeholder noted that one survivorship clinic in the western United States serves patients from several other states.
- One study focused on a small population of childhood cancer survivors living in rural Utah found that they were willing to travel long distances to obtain planned appropriate care

²²Oeffinger et al., “Promoting Breast Cancer Surveillance,” p. 2131.

²³Lori Wiener et al., “Standards for the Psychosocial Care of Children with Cancer and Their Families: An Introduction to the Special Issue,” *Pediatric Blood & Cancer*, vol. 62, Suppl. 5 (2015): S419.

because they did not perceive such care was available in their communities.²⁴

- Additionally, stakeholders told us that some childhood cancer survivorship clinics may not be well equipped to care for adult survivors of childhood cancer, which further limits the availability of appropriate care options in close proximity to some adult survivors. In these cases, adult survivors may have to travel even farther to find appropriate care.

Agency Comments

We provided a draft of this report to HHS for review and comment. HHS provided us with technical comments, which we incorporated as appropriate.

We are sending copies of this report to the Secretary of Health and Human Services and other interested parties. In addition, the report is available at no charge on the GAO website at <http://www.gao.gov>.

If you or your staffs have any questions about this information, please contact me at (202) 512-7114 or farbj@gao.gov. Contact points for our Offices of Congressional Relations and Public Affairs may be found on the last page of this report. GAO staff who made key contributions to this report were Hernán Bozzolo, Assistant Director; Manuel Buentello, Analyst-in-Charge; Britt Carlson; and Samantha Piercy. Also contributing were Sonia Chakrabarty, Leia Dickerson, Diona Martyn, Vikki Porter, Jennifer Rudisill, and Caitlin Scoville.



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Enclosure

²⁴Echo L. Warner et al., "Health Care Concerns of Rural Childhood Cancer Survivors," *Journal of Health Care for the Poor and Underserved*, vol. 25 (2014): p. 901. This study used data from semi-structured interviews with 17 survivors living in rural communities.

Enclosure I: HHS Activities to Support Access to Care for Childhood Cancer Survivors, Including Implementing Selected Provisions in the Childhood Cancer STAR Act

Department of Health and Human Services (HHS) agencies—specifically, the Centers for Disease Control and Prevention (CDC) and the National Cancer Institute (NCI)—continue activities to support access to care for childhood cancer survivors. As of May 2020, these agencies have taken steps to implement three of the five provisions of the Childhood Cancer Survivorship, Treatment, Access, and Research Act of 2018 (Childhood Cancer STAR Act) relevant to access to care for childhood cancer survivors.²⁵ (See table 1.) In addition to the steps taken to implement the act, CDC and NCI are performing other activities relevant to supporting access to care for survivors, such as improving data sharing.

²⁵Childhood Cancer Survivorship, Treatment, Access, and Research Act of 2018, Pub. L. No. 115-180, 132 Stat. 1382 (codified at 42 U.S.C. §§ 280e-3a, 284a, 285a-10, 285a-11, 285a-11a, 285a-11b). For this enclosure, we examined provisions that we identified as most relevant to supporting access to care for childhood cancer survivors.

NCI's definition of a childhood cancer survivor is an individual of any age who was diagnosed with cancer from ages 0 through 19. As such, the definition includes individuals who are older than 19 whether or not they are receiving treatment for cancer.

Table 1: Examples of HHS Steps to Implement Selected Provisions of the Childhood Cancer STAR Act Regarding Access to Care

Childhood Cancer	Example steps taken as of May 2020
STAR Act provision description ^a	
<p data-bbox="203 346 646 401"><u>Improving Childhood Cancer Surveillance</u> (Section 102)</p> <p data-bbox="203 438 667 682">The Secretary of HHS may make awards to state cancer registries to collect information to better understand the epidemiology of cancer in children, adolescents, and young adults.^b Such awards may be used for several purposes, including identifying potential sources for reporting childhood, adolescent, and young adult cancer cases, among others.</p>	<p data-bbox="695 346 1414 646">In September 2019, the Centers for Disease Control and Prevention (CDC) made an award for a contract to develop a software tool that would aid pediatric cancer reporting facilities with rapidly submitting cancer incidence to state cancer registries. Timelier reporting of cancer incidence could help reveal inequities in treatment access and other issues. CDC officials stated that the agency has also begun compiling information about the potential use of the software through roundtables with registry representatives and an expert panel. CDC officials said they expect to select a cancer registry in December 2020 to test the software before implementation in other cancer registries through September 2024.</p>
<p data-bbox="203 751 591 831"><u>Grants to Improve Care for Pediatric Cancer Survivors</u> (Section 202)</p> <p data-bbox="203 869 634 1003">The Director of the National Institutes of Health (NIH) may continue to conduct or support pediatric cancer survivorship research in any of the following areas, among others:^c</p> <ul data-bbox="203 1045 654 1346" style="list-style-type: none"> • outcomes of pediatric cancer survivors, including minority or other medically underserved populations; • barriers to follow-up care; • impact of relevant factors, which may include familial, socioeconomic, and other environmental factors; and • development of indicators for long-term follow-up care and late effects of cancer treatment for pediatric cancer survivors.^d 	<p data-bbox="695 751 1333 806">NIH’s National Cancer Institute (NCI) is funding the following projects (among others):^e</p> <ul data-bbox="695 844 1409 1226" style="list-style-type: none"> • In September 2019, NCI made awards to three research institutions to study various interventions aimed at addressing adverse outcomes among childhood cancer survivors, such as the use of information technology among children and physical activity interventions among adolescents and young adults.^f • NCI has made numerous awards for investigator-initiated research on survivorship among children, adolescents, and young adults. One example is research on adolescents’ and young adults’ use of survivorship care plans, which are intended to help them navigate the health care system and understand recommended care. Another example is research on 2,000 young adult survivors (about 42 percent of whom are Hispanic) to study their health status, use of follow-up services, and other issues.^g
<p data-bbox="203 1392 626 1472"><u>Best Practices for Long-Term Follow-up Services for Pediatric Cancer Survivors</u> (Section 203)</p> <p data-bbox="203 1509 667 1694">The Secretary may facilitate the identification of best practices for childhood and adolescent cancer survivorship care and may consult with individuals with expertise in late effects of disease and treatment of childhood and adolescent cancers.</p>	<p data-bbox="695 1392 1414 1608">Through an agreement made with NCI in February 2020, HHS’s Agency for Health Care Research and Quality (AHRQ) is examining barriers to care for survivors, reviewing models of care for child and adolescent survivors (including for primary care), and reviewing the transition from pediatric to adult care for children with special health care needs. NCI officials said that AHRQ was scheduled to begin this work in May 2020, with final products ranging from late 2020 to early fall 2021.</p>

Source: GAO analysis of select provisions of the Childhood Cancer Survivorship, Treatment, Access, and Research Act of 2018 (Childhood Cancer STAR Act) and information from the Department of Health and Human Services (HHS), CDC, and NCI. | GAO-20-636R

^aSee Childhood Cancer Survivorship, Treatment, Access, and Research Act of 2018, Pub. L. No. 115-180, 132 Stat. 1382 (codified at 42 U.S.C. §§ 280e-3a, 284a, 285a-10, 285a-11, 285a-11a, 285a-11b).

^bA cancer registry is an information system to collect, store, and manage data on individuals with cancer.

^cThe Childhood Cancer STAR Act requires that research conducted on cancer survivors within minority or other medically underserved populations address both the physical and psychological needs of survivors as appropriate.

^dLate effects refer to serious health effects that may result from the original childhood cancer and its treatment. In addition to the development of subsequent cancers, late effects include other conditions such as developmental problems, neurocognitive problems, and heart conditions.

^eFor more information about NCI's research activities regarding the Childhood Cancer STAR Act, see <https://www.cancer.gov/about-nci/legislative/recent-public-laws#childhood-cancer-star-survivorship-treatment-access-research-act-public-law-no-115-180>.

^fNCI funded these three projects through its request for applications (RFA) titled "Improving Outcomes for Pediatric, Adolescent and Young Adult Cancer Survivors." As of May 2020, NCI officials had expected to make additional awards for new projects under this RFA by September 2020. See <https://grants.nih.gov/grants/guide/rfa-files/RFA-ca-19-033.html>. NCI officials also told us that they expect to make new awards to research institutions under a separate RFA beginning in July 2021. The aim of these awards is to conduct research on reducing morbidity and improving care (including follow-up care) for pediatric, adolescent, and young adult survivors. See <https://grants.nih.gov/grants/guide/rfa-files/RFA-CA-20-027.html> and <https://grants.nih.gov/grants/guide/rfa-files/RFA-CA-20-028.html>.

^gMore information on these two research studies is available on NIH's website. See https://projectreporter.nih.gov/project_info_description.cfm?aid=9673688&icde=46822973 and https://projectreporter.nih.gov/project_info_description.cfm?aid=9712752&icde=49983755.

As of May 2020, HHS had not taken steps to implement the two remaining selected provisions we examined:

- **Establishing pilot programs to study model systems of care for childhood cancer survivors (Section 201(a)).** Under this provision, the Secretary may make awards to eligible entities to establish pilot programs to develop, study, or evaluate model systems for caring for childhood cancer survivors throughout their lifespan, including evaluation of models for transition to adult care. HHS officials noted that the Secretary may choose whether or not to implement this provision, and no funds were appropriated for it in fiscal year 2019.
- **Conducting a review of HHS's activities regarding workforce development for childhood cancer survivors (Section 201(b)).** Under this provision, the Secretary shall conduct a review of the activities of HHS related to workforce development for health care providers who treat pediatric cancer patients and survivors. HHS officials told us that the department had not taken steps to implement this provision, which was required to be completed by June 5, 2019, because of resource constraints. HHS officials said that the ongoing implementation of Section 203—identifying best practices for follow-up services for childhood cancer survivors—will inform HHS's activities for this provision.

In addition to steps associated with the Childhood Cancer STAR Act, CDC and NCI officials identified other agency activities relevant to supporting access to care for childhood cancer survivors:

- NCI’s Childhood Cancer Data Initiative aims to improve data sharing about childhood cancer survivors to support childhood cancer research. Specifically, the initiative intends to facilitate sharing data from multiple sources—including clinical trials (such as those administered within the Children’s Oncology Group), state cancer registries, studies (such as the Childhood Cancer Survivor Study), and biospecimen repositories (including those collected as part of NCI projects associated with the Childhood Cancer STAR Act).²⁶ NCI officials said they expect this data sharing will improve research on prevention and treatment of subsequent cancers and other late effects.²⁷ Agency officials told us that NCI received a specific appropriation for this initiative in December 2019 and has begun to use this funding for activities, such as grants and contracts. Further, NCI officials told us that NCI’s Board of Scientific Advisors has established a working group to provide recommendations on this initiative. NCI also anticipates announcing additional funding opportunities related to this initiative by the end of fiscal year 2020.²⁸
- CDC is researching the transition from pediatric to adult follow-up cancer care with the Children’s Hospital of Philadelphia, which houses a childhood cancer survivorship clinic. The project intends to improve adherence to recommendations for follow-up care among adolescent and young adult survivors by using a mobile app to encourage healthy behavior. These behaviors include physical activity, improved sleep quality, and healthy eating. CDC reported that this project began in fiscal year 2016 and has been extended through

²⁶The Children’s Oncology Group, which is primarily funded by NCI, operates a large network for childhood cancer clinical trials and develops standards for follow-up care for childhood cancer survivors. According to stakeholders, approximately 60 percent of newly diagnosed childhood cancer patients participate in clinical trials, a proportion that is much higher than the approximately 3 percent of general (i.e., non-pediatric) oncology patients who participate in clinical trials. Childhood Cancer Survivor Study data include information on more than 35,000 childhood cancer survivors. Participants in this study must have been younger than 21 when diagnosed with cancer and be at least 5 years past cancer diagnosis.

A biorepository refers to a facility that collects and stores biological samples, such as blood, tissue and cells.

²⁷Late effects refer to serious health effects that may result from the original childhood cancer and its treatment. In addition to the development of subsequent cancers, late effects include other conditions such as developmental problems, neurocognitive problems, and heart conditions.

²⁸More information about the Childhood Cancer Data Initiative is available at <https://www.cancer.gov/research/areas/childhood/childhood-cancer-data-initiative>.

September 2020. One study describing the development of this intervention was published in 2019, and according to CDC officials, two more studies are to be published.²⁹

- NCI and the National Institute of Nursing Research are collaborating to fund studies examining the end-of-life and palliative care needs of adolescents and young adults with serious illness.³⁰ As of May 2020, NCI and the National Institute of Nursing Research have funded four projects. NCI officials said the funding opportunity remains open through early January 2022.³¹

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²⁹Lisa A. Schwartz et al., "Iterative Development of a Tailored mHealth Intervention for Adolescent and Young Adult Survivors of Childhood Cancer" *Clinical Practice in Pediatric Psychology*, vol. 7, no. 1 (2019): p. 31.

³⁰The mission of the National Institute of Nursing Research, within NIH, is promoting and improving the health of individuals, families, and communities by supporting and conducting clinical and other research and research training on health and illness.

³¹More information about this funding opportunity is available on NIH's website. See <https://grants.nih.gov/grants/guide/pa-files/PAR-19-136.html>.

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