

Models of Care for Survivors of Childhood Cancer From Across the Globe: Advancing Survivorship Care in the Next Decade

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A B S T R A C T

With improvements in cancer treatment and supportive care, a growing population of survivors of childhood cancer at risk for significant and potentially life-threatening late effects has been identified. To provide a current snapshot of the models of care from countries with varying levels of resources and health care systems, stakeholders in childhood cancer survivorship clinical care and research were identified from 18 countries across five continents. Stakeholders responded to a survey and provided a brief narrative regarding the current state of survivorship care. Findings indicate that among pediatric-age survivors of childhood cancer (allowing for differences in age cutoffs across countries), resources are generally available, and a large proportion of survivors are seen by a physician familiar with late effects in most countries. After survivors transition to adulthood, only a minority are seen by a physician familiar with late effects. Despite the need to improve communication between pediatric oncology and primary care, only a few countries have existing national efforts to educate primary care physicians, although many more reported that educational programs are in development. These data highlight common challenges and potential solutions for the lifelong care of survivors of childhood cancer. Combining risk-based and patient-oriented solutions for this population is likely to benefit both providers and patients.

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INTRODUCTION

Worldwide, in 2012, 1,212,105 incident cancer cases were diagnosed among individuals age 0 to 39 years.¹ With sustained improvements in survival, the number of long-term survivors of childhood, adolescent, and young adult cancer continues to increase.^{2,3} Even with contemporary cancer treatment, damage to normal tissues and developing organ systems is sometimes unavoidable. Thus, as the oncology community has focused on reducing late effects of cancer therapy, a parallel effort concentrated on managing long-term survivors of cancer has burgeoned.

Since the establishment of the first survivorship clinics, models for caring for long-term survivors have evolved.⁴⁻¹¹ To assist clinicians in managing this high-risk population, guidelines have been developed and disseminated. Notable are the efforts by the International Late Effects of Childhood Cancer Guideline Harmonization Group (IGHG) to facilitate collaboration across the

globe.¹² Numerous observational and intervention studies are in progress worldwide, with the common aim of improving the long-term health and well-being of survivors of childhood, adolescent, and young adult cancer by optimizing their health care.

The aim of this paper is to provide a snapshot of survivorship care across countries with varying levels of resources and health care systems, to illustrate areas of variation and commonality, and to highlight key issues encountered by most countries. Different countries refer to survivorship clinics as long-term follow-up clinics, late effects clinics, aftercare clinics, and survivorship clinics. For this article, we have used the term survivorship clinic to refer to these types of clinics.

METHODS

We identified stakeholders from 18 countries across five continents to describe childhood cancer survivorship care in their country. Representatives from selected countries were solicited, with the goal of illustrating

variation and practice in health care systems. Each stakeholder was asked to complete a survey and provide a brief narrative focused on country-specific innovations or challenges.

RESULTS

Tables 1, 2, and 3 summarize survey responses. Among pediatric-age survivors, a large proportion is seen by a physician familiar with late effects (Table 1). After adulthood, far fewer survivors have access to a physician familiar with late effects (Table 2). When asked about efforts to bridge pediatric oncology and primary care providers (PCPs; Table 3), a few countries cited existing educational programs, although many more endorsed ongoing development of such programs. In the following paragraphs, innovation and advances in each country are briefly described in context with the respective health care systems.

Australia

Australia offers a range of care models within nine tertiary survivorship clinics. Major challenges are inadequate funding and

limited options for transitioning older survivors.¹⁰ To overcome the tyranny of distance in a sparsely inhabited country, the Survivorship subcommittee of the Australian and New Zealand Children's Haematology and Oncology Group is testing several electronic interventions to support survivors¹³ and parents¹⁴ and encourage healthy lifestyles. The Re-engage intervention uses a nurse specialist and telephone or online platform to interview survivors who are lost to follow-up. A multidisciplinary panel reviews the data from these encounters and advises future follow-up in primary care, nurse-led care, or attendance at a multidisciplinary survivorship clinic.

Brazil

Brazilian health care is notoriously heterogeneous. Structured and well-equipped cancer centers are located mostly in the southeast and southern states. Unfortunately, 83 million people live in areas where public health care lacks specialized professionals and essential technology. The management of survivors of childhood cancer is even more disparate: although most of the country

Table 1. Current Care for Survivors of Childhood Cancer Who Are Still Considered Children Among 18 Surveyed Countries

Question	AU	BR	CA	CH	CZ	DE	DK	FR	GB	IL	IN	IT	JP	NL	NZ	SE	TK	US
Health care coverage																		
Universal or single payer	x		x		x	x	x	x	x	x		x	x		x	x	x	
Mixed, all children with coverage		x		x										x				x
Mixed, most children with coverage																		
Mixed, many children without coverage											x							
Primary guideline used																		
National guideline			x			x		x	x				x	x		x		x
Mixture	x			x	x		x			x	x	x			x			
IGHG		x																
Institution specific																		x
Long-term survivors seen by physician familiar with late effects (%)*																		
Almost all (> 90)			x		x		x		x					x	x	x		
Most (60-89)	x			x		x		x										x
About half (40-59)										x								
Some (10-39)		x									x	x	x					x
Where are most long-term survivors seen?																		
> 75% at the cancer center	x	x	x	x	x	x	x	x	x	x	x		x	x	x	x	x	x
Mixture: 50% center, 50% PCP												x						
Use a risk-stratified approach																		
Yes	x			x	x	x	x	x	x		x	x		x		x		x
No		x	x							x			x		x		x	
Children with an SCP (%)																		
Almost all (> 90)	x				x				x									
Most (60-89)						x	x								x	x		
Approximately half (40-59)								x				x						x
Some (10-39)				x							x		x	x				
Just a few (< 10)		x	x							x								
APPs																		
Yes, in almost all programs																		x
Yes, but only in some programs		x	x		x	x	x		x					x				
No, country does not have APPs	x			x				x		x	x	x	x		x	x	x	
Young adult survivors formally transitioned																		
Yes, in almost all programs														x	x	x		
Yes, but only some programs	x		x			x		x	x									
Rarely		x		x	x		x			x	x	x	x					x

NOTE. Each country has a different cutoff for this age group, such as ≤ 16 years, ≤ 18 years, or ≤ 21 years.

Abbreviations: APP, advanced practice provider (ie, nurse practitioner or physician assistant); AU, Australia; BR, Brazil; CA, Canada; CH, Switzerland; CZ, Czech Republic; DE, Germany; DK, Denmark; FR, France; GB, Great Britain; IGHG, International Late Effects of Childhood Cancer Guideline Harmonization Group; IL, Israel; IN, India; IT, Italy; JP, Japan; NL, Netherlands; NZ, New Zealand; PCP, primary care physician; SE, Sweden; SCP, survivorship care plan; TK, Turkey; US, United States.

*Starting 2 to 5 years after the end of therapy.

Worldwide Models of Childhood Cancer Survivorship

Table 2. Current Care for Survivors of Childhood Cancer Who Are Considered Adults Among Surveyed 18 Countries

Question	AU	BR	CA	CH	CZ	DE	DK	FR	GB	IL	IN	IT	JP	NL	NZ	SE	TK	US
Health care coverage																		
Universal or single payer	x		x		x		x	x	x	x		x	x		x	x		
Mixed, all adults with coverage		x		x										x			x	
Mixed, most adults with coverage						x												x
Mixed, many adults without coverage											x							x
Long-term survivors seen by physician familiar with late effects (%)																		
Almost all (> 90)																		
Most (60-89)														x				
Approximately half (40-59)	x				x		x											
Some (10-39)			x	x		x		x	x	x			x		x	x	x	x
Just a few (< 10)		x									x	x						
Where are adults seen?																		
> 75% at the cancer center		x				x	x											
Mixture: 50% center, 50% PCP	x				x			x	x				x	x				
< 25% at center			x	x						x	x	x			x		x	x
Use a risk-stratified approach																		
Yes	x			x	x	x	x	x	x			x		x				
No		x	x							x	x		x					x
Adults with an SCP (%)																		
Almost all (> 90)																x*		
Most (60-89)																		
About half (40-59)	x				x	x	x	x	x									
Some (10-39)			x										x	x				x
Just a few (< 10)		x		x						x	x	x						x
APPs																		
Yes, in almost all programs																		
Yes, but only in some programs		x	x		x		x		x					x				
No, country does not have APPs	x			x		x		x		x	x	x	x		x	x	x	
Who manages comorbidities?																		
Treating oncologist																		
Survivorship expert																		
PCP in the community	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
PCP communicates with center								x						x				
Rare communication	x	x	x	x	x	x	x		x	x	x	x	x		x	x	x	x

Abbreviations: APP, advanced practice provider (ie, nurse practitioner or physician assistant); AU, Australia; BR, Brazil; CA, Canada; CH, Switzerland; CZ, Czech Republic; DE, Germany; DK, Denmark; FR, France; GB, Great Britain; IL, Israel; IN, India; IT, Italy; JP, Japan; NL, Netherlands; NZ, New Zealand; PCP, primary care physician; SE, Sweden; SCP, survivorship care plan; TK, Turkey; US, United States.
*Since 2006.

struggles with cancer screening and detection, some regions have pioneered cancer survivorship programs, offering multidisciplinary long-term follow-up since the late 1990s. Innovative initiatives, including a comprehensive evaluation by nine different professionals in a single visit, have been successful in enhancing survivor adherence and awareness.

Canada

The province of Ontario has a network of seven multidisciplinary clinics for children and adults treated for childhood cancer that is available and free to all patients. This network has positively affected emergency room use, as evident by a 19% lower rate of emergency room visits among survivors with at least one clinic visit compared with those who never had a survivorship clinic visit.^{15,16} Other provinces are building analogous programs for lifelong specialized care for survivors of childhood cancer; however, most provide specialized survivor care limited to the pediatric years.

Czech Republic

In the Czech Republic, children with cancer are referred to pediatric cancer centers at university hospitals that offer post-treatment

care in multidisciplinary survivorship clinics. High-risk survivors, such as those who have had hematopoietic cell transplantation, continue follow-up into adulthood at the pediatric cancer center. Other adult survivors receive survivorship care plans (SCPs) and are followed in adult primary care or oncology centers, while retaining the option of visiting the pediatric cancer center. To improve awareness about late effects, members of the Czech Society of Pediatric Haematology/Oncology hold seminars and publish articles about late effects.

Denmark

Information from the Danish Childhood Cancer Registry is used to organize an SCP that summarizes potential late effects and individual guidelines for long-term care. The SCP is included in the survivor's medical record and uploaded to a password-protected webpage for up-to-date hospital records for personal use or sharing with health providers.¹⁷ The research program, Adult Life after Childhood Cancer in Scandinavia, comprising more than 33,000 Nordic 1-year survivors of childhood cancer,¹⁸ has generated comprehensive data about treatment-related late effects risks.

Table 3. Formal Efforts to Bridge Between Pediatric Oncology and Primary Care Physicians Among 18 Surveyed Countries

Question	AU	BR	CA	CH	CZ	DE	DK	FR	GB	IL	IN	IT	JP	NL	NZ	SE	TK	US
National effort to educate PCPs																		
Yes														x	x			x
No, but one is in development	x			x	x	x		x			x	x	x			x	x	
No, and nothing is in development		x	x				x		x	x								
Treating center sends PCP a copy of the SCP (%)																		
Almost always (> 90)	x			x		x			x					x	x			
Most of the time (60-89)								x										
Approximately half of the time (40-59)							x											
Some of the time (10-39)			x										x			x	x	x
Rarely (< 10)		x			x					x	x	x						
How often do PCPs contact center to get more information? (%)																		
Very often (> 90)																		
Often (60-89)																		
Occasionally (40-59)	x																	
Some of the time (10-39)				x		x			x					x	x	x	x	x
Rarely (< 10)		x	x		x		x	x		x	x	x	x					
Trustworthy internet site for PCPs to get information																		
No				x	x			x		x	x	x	x					x
Yes, they use a site in our country		x				x	x		x					x	x	x		x
Yes, but we direct them to an internet site outside of the country	x		x															

Abbreviations: AU, Australia; BR, Brazil; CA, Canada; CH, Switzerland; CZ, Czech Republic; DE, Germany; DK, Denmark; FR, France; GB, Great Britain; IL, Israel; IN, India; IT, Italy; JP, Japan; NL, Netherlands; NZ, New Zealand; PCP, primary care physician; SE, Sweden; SCP, survivorship care plan; TK, Turkey; US, United States.

France

Until adulthood, survivors of childhood cancer have regular medical follow-up in French pediatric oncology units and receive SCPs. For adults with a history of childhood cancer, follow-up is heterogeneous. The French National Cancer Institute's Cancer Plan 2014-2019 has recognized survivorship care as a priority aim, yet the absence of care coordination makes its achievement difficult. To promote survivorship care, research programs such as the French Childhood Cancer Survivor Study for Leukemia (LEA)¹⁹ and the French national breast and thyroid cancer screening program (DeNaCaPST)²⁰ have been developed. Two notable recent major policy advances include coverage of after-cancer care expenses by national health insurance and passage of the right to be forgotten law, which prohibits the requirement to disclose a cancer history in a loan or mortgage application.²¹

Germany

In Germany, survivorship care is available at all pediatric cancer centers for survivors of childhood and adolescent cancer. Multidisciplinary clinics for adult survivors of childhood cancer are under development and aim to include oncology and general providers who will network to ensure seamless and optimal aftercare. A clinical and research network between all German survivorship clinics represents a unified approach for the future prospective collection of aftercare data.

Great Britain

In Great Britain, the National Cancer Survivor Initiative was recently organized to evaluate pathways for optimizing survivorship care.²² Four aftercare models were defined: cancer center-delivered medical follow-up, shared care with local hospitals or

PCPs, specialist nurse-led supported management, and survivor self-management. Key elements of successful risk-stratified care were identified: comprehensive information transfer by SCPs, care coordinators, effective transition between services, remote monitoring systems that alert survivors to recommended testing, and professional education. The principle of patient choice, or no decision about me without me, was highlighted as fundamental to the design and provision of services.

Israel

Israel has a universal health care system that insures all survivors of pediatric and adult cancer and provides access to treatment information via electronic health records. In hospital-based survivorship clinics, the same records are used for SCP creation and preparation for survivorship clinic appointments. Transparency of medical records across different points of care increases the efficiency of survivorship clinics and facilitates care coordination. Most pediatric hematology and oncology programs follow survivors within their clinic, usually without providing an SCP, although a few medical centers have designated pediatric and/or adult survivorship services, some of which include a formal transition from pediatric to adult services.

India

In India, state-funded social or economic support for any cancer care is either absent or limited, and access is strongly associated with variables such as caste, wealth, education, and geography.²³ Training and resources for survivorship care are lacking. No national or state-level policy addresses medical care, employment, or health insurance barriers for survivors of childhood cancer. Furthermore, survivors of cancer in India are not eligible for health or life insurance, regardless of time elapsed from

treatment. Several initiatives aim to improve this scenario: the After Completion of Therapy clinic at Tata Memorial Hospital in Mumbai has been following survivors of childhood cancer since 1991, with similar clinics developing at other high-volume centers; Ugam, an advocacy and support group for survivors of childhood cancer created under the umbrella of the Indian Cancer Society, has engaged more than 250 Mumbai-based survivors; the Indian Cancer Society's Project PICASSO (Partnership in Cancer Survivorship Optimization) promotes and facilitates hospital-based survivorship clinics; and the Indian Pediatric Oncology group has formed a late-effects study group to promote survivorship research.

Italy

In Italy, long-term care varies among the 53 Italian Association of Pediatric Hematology and Oncology (AIEOP) centers on the basis of local circumstances, availability of resources, and the presence or absence of a formal transition process. To harmonize follow-up care, Italy approved the use of the European Survivorship Passport (SurPass) for patients with cancer at all AIEOP centers. The SurPass is a web-based SCP, available in print and digital formats. The SurPass can be automatically translated into several European languages, is written in plain language, contains cancer history and therapy information, and provides guidance on survivor-specific long-term follow-up care. Organ-specific recommendations are based on available internationally accepted guidelines (International Late Effects of Childhood Cancer Guideline Harmonization Group/PanCareSurFup) or according to institutional criteria. Data can be shared through the Italian off-therapy registry.

Japan

For survivors of childhood cancer, most medical costs are covered by universal insurance, with recent enactment of expansion of coverage to 20 years of age. In an effort funded by the Ministry of Health, Labor, and Welfare, the Japanese Society of Pediatric Hematology and Oncology initiated health care team-training workshops, with the goal of achieving lifetime support for survivors of child, adolescent, and young adult cancer. The Ministry has also charged each prefectural administration with improving health and financial independence for children with chronic illness or cancer.

The Netherlands

In the Netherlands, all seven pediatric oncology centers have established a survivorship clinic for survivors of childhood cancer. Care focuses on education, early detection of late effects, and coordination of care for all 5-year survivors of childhood cancer. Risk-based surveillance is based on the Dutch Children's Oncology Group Long-Term Follow up Guidelines.²⁴ In addition to these efforts, survivors are actively recruited for participation in nationally supported late-effect studies. In 2014, an effort was initiated to centralize childhood cancer as well as survivorship care to the Princess Máxima Centre in Utrecht.

New Zealand

In New Zealand, survivorship care is available at three late-effects clinics. Risk-stratified care for survivors younger than 21 years is supervised by the primary oncologist or an oncologist with

an interest in late effects, working in concert with a clinical nurse specialist and/or psychologist. The National Child Cancer Network supports a survivorship working group, provides overall governance of the childhood cancer registry, and runs the Late Effects Assessment Program online database (LEAP-IT). Together, these resources offer New Zealand researchers access to a wealth of data for research purposes. In addition, Network members contribute to many international and local research initiatives to improve the outcomes of children diagnosed with cancer, including a successful effort to generate SCPs by linking registry data the LEAP-IT database.

Sweden

In Sweden, most children with cancer receive follow-up care at pediatric cancer centers until 18 years of age. Historically, follow-up of adults treated for childhood cancer was poor, although two survivorship centers have been established. In 2016, a new Swedish National Guideline and Care Program for survivors was approved and has been implemented by five of six childhood cancer treatment centers. Notably, the Swedish National Guidelines recommend a risk-stratified approach, such that many survivors can be discharged to PCPs. The National Registry for late effects within the Swedish Pediatric Cancer Registry, launched in 2012, provides the patients with an SCP that can also be sent to primary and other caregivers to facilitate shared care.

Switzerland

In Switzerland, children diagnosed with cancer before age 16 years are treated at specialized childhood cancer clinics affiliated with the Swiss Pediatric Oncology Group. Most survivors receive annual follow-up after completion of therapy for 5 to 10 years after diagnosis, depending on the tumor, age at diagnosis, and local pediatric cancer center. Until recently, Switzerland lacked standardized regional or national follow-up care and transition programs, so that follow-up care varied between hospitals or even between consultants within a hospital. However, many ongoing initiatives focus on survivorship care: Suivinet, a national online information platform for survivors;²⁵ a peer-to-peer mentoring program linking survivors and patients with newly diagnosed disease; and, in Bern, the organization of SCPs using Baylor College of Medicine's Passport for Care.²⁶ On a national level, implementation of the European Survivorship Passport is prepared in a working group of physicians, nurses, survivors, and parents. Last, a multidisciplinary survivorship clinic opened in Northern Switzerland (Liestal) that offers examinations with specialists tailored to the individual needs of survivors scheduled on a single day, during which results, treatment recommendations, and the SCP are discussed.

Turkey

Turkey has struggled to provide care for survivors of childhood cancer because of the lack of survivorship clinics and formal surveillance recommendations. The Turkish Pediatric Oncology Group plans to develop long-term follow-up guidelines. In addition, both families and health care providers in Turkey are unaware of late effects of cancer therapy. Therefore, an ongoing effort to publicize and promote the guidelines is planned for upcoming primary care meetings.

United States

Although the majority of pediatric cancer centers in the United States offer survivorship services, there is variability in the resources available in these programs and the methods for transition to adult providers.²⁷ For survivors in the pediatric age range, the care environment usually involves a specialized late-effects program, with multidisciplinary staff supervised by a designated survivorship provider. For the remainder, evaluations are undertaken in oncology clinics by the survivor's primary oncologist. Distribution of SCPs as well as risk-based surveillance for late effects as recommended by the Children's Oncology Group Guidelines^{28,29} represent the standard of care for survivors followed in pediatric cancer programs. Only a minority of programs provide such services for adults, with the majority facing transition of care to community clinicians who generally have limited knowledge of survivorship risks.^{30,31} In addition, health care of adult survivors of childhood cancer is often fragmented and suboptimal because of the frequent changing of health care plans by employers or survivors, the large deductibles associated with some health insurance plans, and the general high cost of care.³² As changes in the Affordable Care Act are debated, many survivors of cancer are concerned that they may lose their coverage because of having a preexisting condition.

DISCUSSION

As treatment and supportive care for childhood cancer has improved worldwide, the survivor population has grown.¹⁻³ In this review, we present perspectives from across the globe on the challenges and solutions, as well as the commonalities and exceptions, that unite patients and providers in childhood cancer survivorship.

Some countries experience exceptional challenges in providing risk-based care. For example, Australia is an enormous country (by land mass) that is home to a population of survivors of childhood cancer separated by the tyranny of distance and without an accepted framework to harmonize care.¹⁰ Childhood cancer survivorship is only one of the challenges in that setting, although scalable solutions are being sought.^{10,13,14,33} At the same time, our Indian coauthor describes intolerable health care policies and difficulties with health care delivery, including lack of health insurance for those with a history of cancer treatment.

Yet, common challenges can be identified as well. For those considered children, care at the pediatric cancer center is the norm. Nonetheless, apart from the Netherlands and New Zealand, young adult survivors are not uniformly transitioned to adult care. In Germany, the Working Group on Adolescents, Young Adults, and Transition was established to address this and other gaps in care. Their recent publication describes ongoing work to improve transitions to adult care and plans to establish a solid infrastructure for transition in cooperation with health authorities that could provide a model for other countries.³⁴

Australia, the Czech Republic, and Great Britain provide SCPs to almost all children with a history of cancer, but only New Zealand has accomplished this goal for adult survivors of childhood cancer. Prior research in the United States and Canada

suggests that SCPs are well-received by survivors³⁵ and are associated with better knowledge of cancer treatment and surveillance for late effects.³⁶ A recent article describing Passport for Care supports one widely used SCP model.²⁶ Therefore, improving transitions as well as promoting SCPs should remain international priorities.

For the most part, care delivery solutions demonstrate similar themes. In every country, clinicians caring for survivors of childhood cancer are advancing efforts to educate providers and patients. Many countries describe electronic or registry-based methods for generating SCPs, and web-based survivorship guidelines are universally invoked. Resource-poor settings tend to have less to offer survivors, but care coordination and risk-based care fall short even in more heavily resourced settings. Even jurisdictions with universal health insurance describe large numbers of survivors of childhood cancer without an SCP or a provider who is familiar with late effects. Because survivorship care has been associated with improved knowledge of cancer treatment and late effects risk,³⁷⁻⁴⁰ fewer emergency room visits and hospitalizations,¹⁶ as well as better surveillance practices,⁴¹ engaging patients and providers in this effort cannot be overvalued.⁴² Cost-effectiveness analyses may facilitate use of recommended testing.^{43,44}

Finally, some countries describe unique and noteworthy features of survivorship care. For example, in Denmark, a secure website provides patient access to medical records and test results. In Ontario, Canada, survivorship clinics for adult survivors of childhood cancer have been operational since 1999 and have demonstrated benefit to survivors in that province.^{15,16} Most notably, survivors of childhood cancer in every country are asked to be the guardians of their health care history, to share their SCP with providers, and to self-advocate for risk-based care in every setting. With the burden of risks and late effects these survivors endure,⁴⁵ requiring them to fight for the care they need may be too much to ask. Instead, providers and policy makers should establish and endorse the knowledgeable and reliable health systems infrastructure that survivors of childhood cancer deserve.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

Disclosures provided by the authors are available with this article at jco.org.

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REFERENCES

1. Ferlay J, Soerjomataram I, Ervik M, et al: GLOBOCAN 2012 v1.0, Cancer Incidence and Mortality Worldwide: IARC CancerBase No. 11. Lyon, France, International Agency for Research on Cancer, 2013
2. Robison LL, Hudson MM: Survivors of childhood and adolescent cancer: Life-long risks and responsibilities. *Nat Rev Cancer* 14:61-70, 2014
3. Birch JM, Pang D, Alston RD, et al: Survival from cancer in teenagers and young adults in England, 1979-2003. *Br J Cancer* 99:830-835, 2008
4. Aziz NM, Oeffinger KC, Brooks S, et al: Comprehensive long-term follow-up programs for pediatric cancer survivors. *Cancer* 107:841-848, 2006
5. Fardell JE, Wakefield CE, Signorelli C, et al: Transition of childhood cancer survivors to adult care: The survivor perspective. *Pediatr Blood Cancer* 64:e26354, 2017
6. Hjorth L, Haupt R, Skinner R, et al: Survivorship after childhood cancer: PanCare: A European Network to promote optimal long-term care. *Eur J Cancer* 51:1203-1211, 2015
7. Salz T, McCabe MS, Oeffinger KC, et al: A head and neck cancer intervention for use in survivorship clinics: A protocol for a feasibility study. *Pilot Feasibility Stud* 2:23, 2016
8. Oeffinger KC, Nathan PC, Kremer LC: Challenges after curative treatment for childhood cancer and long-term follow up of survivors. *Hematol Oncol Clin North Am* 24:129-149, 2010
9. Oeffinger KC, Wallace WH: Barriers to follow-up care of survivors in the United States and the United Kingdom. *Pediatr Blood Cancer* 46:135-142, 2006
10. Signorelli C, Wakefield CE, McLoone JK, et al: Models of childhood cancer survivorship care in Australia and New Zealand: Strengths and challenges. *Asia Pac J Clin Oncol* 13:407-415, 2017
11. Skinner R, Wallace WH, Levitt GA: Long-term follow-up of people who have survived cancer during childhood. *Lancet Oncol* 7:489-498, 2006
12. Kremer LC, Mulder RL, Oeffinger KC, et al: A worldwide collaboration to harmonize guidelines for the long-term follow-up of childhood and young adult cancer survivors: A report from the International Late Effects of Childhood Cancer Guideline Harmonization Group. *Pediatr Blood Cancer* 60:543-549, 2013
13. Sansom-Daly UM, Wakefield CE, Bryant RA, et al: Online group-based cognitive-behavioural therapy for adolescents and young adults after cancer treatment: A multicenter randomised controlled trial of Recapture Life-AYA. *BMC Cancer* 12:339, 2012
14. Wakefield CE, Sansom-Daly UM, McGill BC, et al: Acceptability and feasibility of an e-mental health intervention for parents of childhood cancer survivors: "Cascade." *Support Care Cancer* 24:2685-2694, 2016
15. Marr KC, Agha M, Sutradhar R, et al: Specialized survivor clinic attendance increases adherence to cardiomyopathy screening guidelines in adult survivors of childhood cancer. *J Cancer Surviv* 11:614-623, 2017
16. Sutradhar R, Agha M, Pole JD, et al: Specialized survivor clinic attendance is associated with decreased rates of emergency department visits in adult survivors of childhood cancer. *Cancer* 121:4389-4397, 2015
17. health.dk: Your health portal. www.sundhed.dk
18. Danish Cancer Society: ALiCCs: Adult life after childhood cancer in Scandinavia. www.aliccs.org
19. Berbis J, Michel G, Baruchel A, et al: Cohort profile: The French childhood cancer survivor study for leukaemia (LEA Cohort). *Int J Epidemiol* 44:49-57, 2015
20. Demoor-Goldschmidt C, Drui D, Doutriaux I, et al: A French national breast and thyroid cancer screening programme for survivors of childhood, adolescent and young adult (CAYA) cancers - DeNaCaPST programme. *BMC Cancer* 17:326, 2017
21. Dumas A, Allodji R, Fresneau B, et al: The right to be forgotten: A change in access to insurance and loans after childhood cancer? *J Cancer Surviv* 11:431-437, 2017
22. Glaser A, Levitt G, Morris P, et al: Enhanced quality and productivity of long-term aftercare of cancer in young people. *Arch Dis Child* 98:818-824, 2013
23. Balarajan Y, Selvaraj S, Subramanian SV: Health care and equity in India. *Lancet* 377:505-515, 2011
24. Dutch Childhood Oncology Group: DCOG-LATER guidelines. 2017. <http://later.skion.nl/>
25. Kinderkrebs Schweiz: Informations: Plattform Suvinet. <https://www.kinderkrebs-schweiz.ch/nachSORge/suvinet/web-plattform.html>
26. Poplack DG, Fordis M, Landier W, et al: Childhood cancer survivor care: Development of the Passport for Care. *Nat Rev Clin Oncol* 11:740-750, 2014
27. Eshelman-Kent D, Kinahan KE, Hobbie W, et al: Cancer survivorship practices, services, and delivery: A report from the Children's Oncology Group (COG) nursing discipline, adolescent/young adult, and late effects committees. *J Cancer Surviv* 5:345-357, 2011
28. Children's Oncology Group: Long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers. www.survivorshipguidelines.org
29. Landier W, Bhatia S, Eshelman DA, et al: Development of risk-based guidelines for pediatric cancer survivors: The Children's Oncology Group Long-Term Follow-Up Guidelines from the Children's Oncology Group Late Effects Committee and Nursing Discipline. *J Clin Oncol* 22:4979-4990, 2004
30. Singer S, Gianinazzi ME, Hohn A, et al: General practitioner involvement in follow-up of childhood cancer survivors: A systematic review. *Pediatr Blood Cancer* 60:1565-1573, 2013
31. Suh E, Daugherty CK, Wroblewski K, et al: General internists' preferences and knowledge about the care of adult survivors of childhood cancer: A cross-sectional survey. *Ann Intern Med* 160:11-17, 2014
32. Park ER, Kirchoff AC, Zallen JP, et al: Childhood Cancer Survivor Study participants' perceptions and knowledge of health insurance coverage: Implications for the Affordable Care Act. *J Cancer Surviv* 6:251-259, 2012
33. Rovers JP, Mages MD: A model for a drug distribution system in remote Australia as a social determinant of health using event structure analysis. *BMC Health Serv Res* 17:677, 2017
34. Escherich G, Bielack S, Maier S, et al: Building a national framework for adolescent and young adult hematology and oncology and transition from pediatric to adult care: Report of the inaugural meeting of the "AJET" working group of the German Society for Pediatric Oncology and Hematology. *J Adolesc Young Adult Oncol* 6:194-199, 2017
35. Spain PD, Oeffinger KC, Candela J, et al: Response to a treatment summary and care plan among adult survivors of pediatric and young adult cancer. *J Oncol Pract* 8:196-202, 2012
36. Hudson MM, Leisenring W, Stratton KK, et al: Increasing cardiomyopathy screening in at-risk adult survivors of pediatric malignancies: A randomized controlled trial. *J Clin Oncol* 32:3974-3981, 2014
37. Cherven B, Mertens A, Meacham LR, et al: Knowledge and risk perception of late effects among childhood cancer survivors and parents before and after visiting a childhood cancer survivor clinic. *J Pediatr Oncol Nurs* 31:339-349, 2014
38. Landier W, Chen Y, Namdar G, et al: Impact of tailored education on awareness of personal risk for therapy-related complications among childhood cancer survivors. *J Clin Oncol* 33:3887-3893, 2015
39. Ganju RG, Nanda RH, Esiashvili N, et al: The effect of transition clinics on knowledge of diagnosis and perception of risk in young adult survivors of childhood cancer. *J Pediatr Hematol Oncol* 38:197-201, 2016
40. Lindell RB, Koh SJ, Alvarez JM, et al: Knowledge of diagnosis, treatment history, and risk of late effects among childhood cancer survivors and parents: The impact of a survivorship clinic. *Pediatr Blood Cancer* 62:1444-1451, 2015
41. Szalda D, Pierce L, Hobbie W, et al: Engagement and experience with cancer-related follow-up care among young adult survivors of childhood cancer after transfer to adult care. *J Cancer Surviv* 10:342-350, 2016
42. Molassiotis A, Yates P, Li Q, et al: Mapping unmet supportive care needs, quality-of-life perceptions and current symptoms in cancer survivors across the Asia-Pacific region: results from the International STEP Study. *Ann Oncol* 28:2552-2558, 2017
43. Yeh JM, Nohria A, Diller L: Routine echocardiography screening for asymptomatic left ventricular dysfunction in childhood cancer survivors: A model-based estimation of the clinical and economic effects. *Ann Intern Med* 160:661-671, 2014
44. Wong FL, Bhatia S, Landier W, et al: Cost-effectiveness of the children's oncology group long-term follow-up screening guidelines for childhood cancer survivors at risk for treatment-related heart failure. *Ann Intern Med* 160:672-683, 2014
45. Bhakta N, Liu Q, Ness KK, et al: The cumulative burden of surviving childhood cancer: An initial report from the St Jude Lifetime Cohort Study (SJLIFE). *Lancet* 390:2569-2582, 2017

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AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

Models of Care for Survivors of Childhood Cancer From Across the Globe: Advancing Survivorship Care in the Next Decade

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