

Cancer survivorship practices, services, and delivery: a report from the Children's Oncology Group (COG) nursing discipline, adolescent/young adult, and late effects committees

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Abstract

Purpose To describe survivorship services provided by the Children's Oncology Group (COG), an assessment of services was undertaken. Our overall aims were (1) to describe survivorship services, including the extent of services provided, resources (personnel, philanthropy, and research funding), billing practices, and barriers to care and 2) to describe models of care that are in use for childhood cancer survivors and adult survivors of childhood cancer.

Methods One hundred seventy-nine of 220 COG institutions (81%) completed an Internet survey in 2007.

Results One hundred fifty-five (87%) reported providing survivorship care. Fifty-nine percent of institutions provide care for their pediatric population in specialized late effects

programs. For adult survivors, 47% of institutions chose models of care, which included transitioning to adult providers for risk-based health care, while 44% of institutions keep survivors indefinitely at the treating institution (Cancer Center Based Model without Community Referral). Sixty-eight percent provide survivors with a copy of their survivorship care plan. Only 31% of institutions provide a detailed summary of results after each clinic visit, and 41% have a database to track survivor health outcomes. Minimal time required for initial and annual survivorship visits is estimated to be approximately 120 and 90 min, respectively. The most prevalent barriers to care were the lack of dedicated time for program development and a perceived insufficient knowledge on the part of the clinician receiving the transition referral.

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Conclusions Not all COG institutions provide dedicated survivorship care, care plans, or have databases for tracking outcomes. Transitioning to adult providers is occurring within the COG. Survivorship care is time intensive.

Keywords Cancer survivorship · Late effect programs · Late effect services

Introduction

Advances in the treatment of childhood cancer, improved supportive care strategies, enhanced diagnostic testing, and enrollment on clinical trials over several decades have contributed to a growing number of cancer survivors. As a result, children are surviving their diseases such that there is an estimated 5-year survival rate of 80% [1] and an estimated 300,000 cancer survivors in the USA [2, 3]. Two thirds of survivors may exhibit some late effect of their therapy [4, 5]. These late effects may be mild to severe and include multiple physical and psychosocial health care problems, such as changes in physical appearance, organ dysfunction, infertility, neurocognitive impairments, cardiotoxicity, second neoplasms, endocrinopathies, musculoskeletal dysfunction, and challenges in social relationships [5–32].

Despite hope that more contemporary protocols may reduce the frequency and severity of late effects, lifelong risk-based care is recommended for childhood cancer survivors (CCS). Health care transition during young adulthood from pediatric to adult-oriented providers has been advocated as a means of continuing appropriate monitoring and management of late effects across the lifespan [33, 34]. However, the best clinical practices, models of survivorship care, costs of providing survivorship care, and transitioning practices linked to maximizing health care outcomes have not been fully delineated or evaluated. The Institute of Medicine and leaders in cancer survivorship have recommended that pediatric oncology begins the process of examining and evaluating services for survivors [2]. A first step in this process has been accomplished through general recommendations and via the development of several guidelines [35–38], which provide the foundation for further assessment of outcomes based on treatment exposures.

Our aims were (1) to describe survivorship services, including the extent of services provided, resources (personnel, philanthropy, and research funding), billing practices, and barriers to care and (2) to describe models of care that are in use for childhood cancer survivors and adult survivors of childhood cancer. Specifically included in this survey were questions assessing health care transition practices for young adult survivors, given the emerging importance of that issue as this population ages.

Methods

A 67-item online survey using Zoomerang™ (see Appendix A) was developed. The online survey asked about survivorship services, including the extent of services provided, program size, and resources (including personnel, philanthropy, and research funding), billing practices, and perceived barriers to care. Additional information was ascertained to describe survivorship services and models of care utilized for adult survivors of childhood cancer. Email announcements and introductory letters about the survey were sent over a 6-month timeframe in 2007 to existing COG member institutions in good and provisional standing via COG principal investigators (PIs), nursing responsible investigators (RIs), and clinical research associates (CRAs). Institutions were informed that survey responses would be reported collectively for the COG, not individually. One set of responses per institution was requested. Participants were allowed to skip questions at their discretion, and, in the case of multiple responses from institutions, the most complete set of responses was used. Responses to open-ended questions were tabulated into frequency distributions by two study investigators and grouped into themes and coded. Where coding varied, the study team shared findings and came to agreement for coding [39].

Results

Survivorship services in COG institutions

One hundred seventy-nine (81%) of 220 COG member institutions completed the online survey. Eighty-seven percent reported providing late effect (LE) services to survivors, while 13% of institutions reported that they did not. For those institutions that did not provide LE services, no further information was obtained.

Fifty-nine percent of institutions that offer care to cancer survivors reported providing that care in a specialized LE program by a designated LE provider, 23% in regular oncology clinic by a survivor's treating oncologist, 16% in oncology clinic by a health care provider staffing clinic that day, and a small number (2%) were beginning survivorship programs or using various combinations of health care providers when delivering care. Twenty-five institutions (14%) did not answer this question.

Questions were asked about selected subgroups of survivors, categorized as stem cell transplant survivors (SCTS), central nervous system survivors (CNSS), and survivors of non-oncologic conditions (e.g., those who may have received chemotherapy or irradiation for treatment of histiocytosis) in order to further define services for these groups. These survivors were eligible for late effects services in 94%, 97%, and 84% of institutions, respectively. Eligibility criteria for entry into LE services for these selected subgroups varied widely. Some

criteria were time dependent, some were protocol or diagnosis specific, some were dependent on current clinical status (i.e., no graft vs. host disease), and other criteria were dependent on the discretion of the treating physician.

Additional information about services for survivors who were not originally treated at each responding institution was ascertained. Eighty-eight percent of responding institutions provide clinical consultations to survivors originally treated at other institutions, and more than half (55%) do not offer consultation by phone. Patients can self-refer for LE services in 83% of institutions.

Pediatric survivorship services

General practices

Routines for pediatric cancer survivors Fifty percent of participants reported that survivors come to the LE clinic and are referred to specialists at alternate times. Thirty-five percent reported that survivors are seen by their general oncologist who manages their survivorship care and are referred to specialists at alternate times. Eight percent reported that survivors come to the clinic staffed by the LE team and required specialists, and 6% reported various combinations of the aforementioned responses. Sixty-seven percent of participants reported that risk-based screening (e.g., echocardiogram, bone density test), if indicated, would be done at the same LE clinic visit, while 33% reported that it would be scheduled on another day time.

Patient educational materials Sixty-eight percent of participants reported that they provide survivors a copy of their survivorship care plan (SCP)/oncology treatment exposure summary, while 32% did not. Sixty-nine percent of participants reported that they did not provide written documentation about results to survivors after each visit.

Average time for survivor-related services

Information was collected about the average amount of time health care personnel spend per survivor for (1) preparation of SCP, (2) scheduling of tests, (3) clinical “face to face” time for an initial visit, (4) clinical “face to face” time spent in annual visits, (5) gathering, interpreting, and compiling results, (6) post-clinic conferencing, and (7) communication of results. These data were collected in time interval ranges expressed in minutes (<15, 15–30, 31–60, 61–90, 91–120, and >120 min). Estimates were calculated for the minimum amount of time required to complete various activities related to a scheduled survivor evaluation (pre-clinic preparation, direct contact time, and post-clinic management) for both initial and annual visits. Each initial visit includes the preparation of the SCP and is estimated to require at least 122 min. Each annual visit

(without preparation of the survivorship care plan) was calculated to require about 91 min.

Adult survivorship services

Given the large number of survivors now entering adulthood we inquired “At what age (if applicable) are CCS referred outside the treating/pediatric center?” Out of 156 responses, 35% see adult survivors indefinitely at the treating institution and do not carry out transition elsewhere for continuation of risk-based care. Another 31% transition CCS when the survivor is ready, while others keep them to age 18 (5%), 21 (17%), 25 (4%), or 30 years old (1%).

For institutions reporting ≤ 50 survivorship visits annually, 67% continue seeing their adult patient indefinitely, whereas this is true for only about one third of larger programs. For medium-sized programs seeing 50–100 survivors per year, 26% send them to adult oncologists in an adult cancer center setting and 18% send them to their primary care provider. For larger programs seeing >100 survivors per year, the favored plan was to refer the adults to their primary care providers (approximately 30%).

To better understand which models are in use for adult survivor care, four recognized models were described (Table 1), and participants were asked to select from one of these or further describe their own [40]. The most commonly chosen model provided by 44% of the 161 participants was the “Cancer Center-based Model WITHOUT Community Referral.” This model has been described as a model where survivors are kept indefinitely at the treating institution for their cancer-related/late effects (LE) follow-up care. Generally care is with the same late effects or oncology clinicians who provide care to the pediatric survivor population. When examining the type of model utilized by institutional size, we found that in medium sized institutions (101–500 survivor visits/year), the four models were utilized in approximately equal proportions, whereas in the smallest and largest institutions, the predominant model was the Cancer Center Based Without Community Referral.

Barriers to care for pediatric and adult survivors

We asked participants to review a list of common barriers to (1) providing optimal long term follow up care and (2) transition, as previously described in the literature for pediatric and adult CCS. Participants were asked to select the three most common barriers in their institution. The most frequently chosen barriers are reported in Tables 2 and 3.

Survivorship databases

Less than half of the institutions (41%) reported having a database that was used to track survivors’ clinical health

Table 1 Models of cancer survivor care utilized for adult survivors 161 responses

Model	Description of model	Number of institutions selecting model	Percent
Cancer Center-Based Model Without Community Referral	Survivors are kept indefinitely at the treating institution for cancer-related care Generally, care is with the same survivorship team/oncology providers who provide care to the pediatric survivor population	70	44
Community Referral Model	Survivors are transitioned at adulthood to their primary care professional (PCP) for routine cancer-related care Survivors' routine testing is managed and coordinated by the PCP, with the survivorship team/oncology team serving as consultants to multiple PCPs	34	21
Hybrid model (Combined Cancer Center and Community Based Model)	Survivors are transitioned to adult health care providers generally within the same health care system, with established opportunities (e.g., a formal mechanism) for collaborative research, collaboration in clinical care and /or other resource sharing The survivorship team/oncology team and adult health care provider closely collaborate for survivor care.	38	24
Postal/Internet/phone based model	Survivors are dismissed from survivorship/oncology follow-up at the cancer center/treating institution Contact is made regularly to document survivor outcomes via postal, phone, or internet based inquiry	5	3
Adult oncologist	Survivors are referred to adult oncologists for their survivorship care	4	2
In process of establishing a model		6	4
Other		4	2

care outcomes or other pertinent clinical information. The databases that were used included ACCESS (49%), Excel (15%), ONCOLOG (7%), institutionally devised/proprietary (7%), and OTHER responses (e.g., web-based, tumor-registry-assisted databases, Optex, Pediatric Oncology Group of Ontario network databases) (22%).

Financial issues and support

Billing practices

We collected information about billing practices according to Current Procedural Terminology (CPT) codes [41]. Seventeen percent of institutions did not respond to this question, and of those who did respond, 10% reported that

they did not know their billing practices. Most US institutions bill at level 4/moderate complexity decision making (CPT 99214) or level 5/high complexity decision making (CPT 99215). The remainder of the billing practices is reflected in Table 4.

Financial support of program operations/activities

About half (51%) of institutions reported some level of institutional/hospital support, such as salary funding. Institutions provided information about the availability (in the previous five calendar years) of philanthropic funding for support of LE personnel salaries and clinical care. Philanthropic funding was available but limited. It included salary support in about one third of institutions, while 19%

Table 2 Barriers in caring for pediatric cancer survivors (266 responses)

Barrier	Number of responses
Perceived lack of dedicated time for late effects program development	76 (29%)
Not enough funding for support of program	53 (20%)
Perceived survivor knowledge deficit about the importance of maintaining cancer related follow-up	45 (17%)
Survivor lack of health care insurance or insurance limitations	34 (12.7%)
Perceived lack of survivor desire to be followed by the late effects team	19 (7%)
Lack of perceived need or support for LE services/program by other oncologists	18 (6.7%)
There are no barriers in my institution	12 (4.5%)
Other	9 (3%)

Table 3 Barriers in transitioning survivors to adult care providers for cancer related care (238 responses)

Barrier	Number of responses
Perceived lack of knowledge about late effects on the part of clinician being referred to	68 (28.5%)
Survivor lack of health care insurance or insurance limitations	48 (20%)
Perceived survivor knowledge deficit about the importance of maintaining cancer related follow-up into adulthood	34 (14%)
Perceived lack of survivor desire to leave the comfort of the treating institution or oncologist	31 (13%)
Lack of survivor access to a primary care provider for reasons other than insurance, such as geography	13 (5%)
We do not transition	11 (4.7%)
Conflict between COG recommendations for risk-based care and adult provider recommendations	10 (4.2%)
Perceived lack of oncology provider desire to “let go” of survivors	10 (4.2%)
We don’t have any barriers	8 (3.3%)
Perceived lack of interest in caring for survivors from adult health care providers	4 (1.6%)
Other	1 (1%)

reported philanthropic support for the clinical care of patients. Research funding specifically designated for clinical testing of survivors in the context of a research study (e.g., pulmonary function tests for survivors enrolled in a lung study) was available in about 22% of institutions.

Analysis of resources by program size revealed that institutions with more than 60 new patients per year reported availability of funding for program operations more often than smaller institutions. Further analysis of resources by program size showed that, except for the largest programs (more than 150 new patients/year), fewer than half reported philanthropic funding for salary support and clinical care. Similarly, in only the largest programs (>150 new oncology patients/year) did more than half (72%) report research funding for clinical care of patients.

Survivorship clinic personnel

Information was ascertained about various personnel known to be a part of survivorship programs or survivorship clinics. Specifically, we asked about the number of personnel in a particular role, not in full time equivalents for each role, including nurse practitioners, physician assistants, nurse coordinators, social workers, administrative support staff, clinical research associates,

nutritionists/dietitians, and neuropsychologists/educational specialists. Seventy-two percent of institutions have at least one nurse practitioner, 53% have a nurse coordinator, 87% have a social worker, 49% have a nutritionist/dietician, and 74% have a neuropsychologist/education specialist. Additionally three quarters of survivorship programs had a clinical research associate, and 72% had administrative support staff/secretarial support. Physician assistants were rarely utilized (5%). Thirty-nine percent of institutions reported that they provided dedicated personnel to solve insurance and /or employment related issues. Generally speaking, there was no clear association with institutional size and availability of these personnel.

Discussion

Survivorship services are expanding, and institutions are moving closer to reaching the goals set forth in the Institute of Medicine’s report [2]. Although the field of cancer survivorship and survivor outcome research is rapidly evolving, data about survivor programs have been slower to develop. Until recently, only a few studies have addressed the availability of programs or services for survivors [42–48],

Table 4 Reported level of billing for survivorship services 179 responses

^aOther responses reflect billing practices for institutions outside US reflecting universal health care or government health care practices

	Number of institutions	Percent
Level 2 (CPT 99212) straightforward medical decision making	3	2.0
Level 3 (CPT 99213) low complexity medical decision making	14	9.5
Level 4 (CPT 99214) moderate complexity medical decision making	47	31.8
Level 5 (CPT 99215) high complexity medical decision making	42	28.4
Other, please specify ^a	27	18.2
Unknown	46	27.3
Total	179	100.0

and our study is the first to collectively report on services within the COG. At the time of our survey in 2007, 155 of 179 responding institutions in COG (87%) reported providing LE services. This is an increase from a study approximately 10 years prior [43] in which 53% of Children's Cancer Group and Pediatric Oncology Group responding institutions ($n=96$) reported having a long-term follow up clinic at their institution. In our study, more than half of institutions (59%) provided survivorship care in a specialized LE program by a designated provider. Specific subgroups of survivors, such as CNSS, SCTS, and survivors of non-oncologic diseases with similar treatment exposures, were eligible for LE services. Historically, these groups have been followed by neuro-oncology specialists and transplant specialists or perhaps not monitored routinely for late effects. A previous study of programs for CNSS reports that care was provided in designated neuro-oncology long-term follow-up clinics (31.2%) or in general long-term follow-up programs for CCS (29.7%) [48]. In our study, 97% of CNSS were eligible for survivorship services, lending further support that this subgroup has access to LE specialists.

A recent study reports that there are approximately 300,000 CCS in the USA [3], and many may be lacking risk-based care. Recognizing that only a subset of this population is receiving risk-based care, we asked participants to quantify the total number of survivors eligible for a risk-based visit in the previous calendar year. If each institution participating in our study provided care for this entire population of approximately 300,000 survivors, then we estimate that each institution in our study would be accountable for the follow-up of some 2,000 survivors, in either direct care or through referral and transition to community providers. We asked participants to quantify the number of survivors they felt were eligible for LE services at their institution. Our participants had difficulty quantifying a number of eligible survivors in a blank response box, or in many cases used descriptive terms to describe the potential survivorship number, such as "greater than," "approximately," "about," and "unknown." This made the total number of survivors eligible for a survivorship visit uninterpretable. Of note, few participants identified quantities of >1000 survivors, so we conclude that only a small subset of the eligible survivor pool have their risk-based long-term care coordinated by institutions within the COG. This conclusion supports previously described findings, which suggest that a large number of CCS do not receive recommended risk-based care [49].

Transition to adult services

With an ever-growing number of survivors that challenge the capacity for their care [34, 50], institutions face the challenge of how to provide the "best" risk-based care in a time of

competing resources, reduction in resources, and lack of trained and experienced providers. Care that is longitudinal, risk based, shared, and encompasses formal transition to the adult setting has been advocated by many late effects clinicians, health care policy experts, and survivors [2, 34, 35, 40, 50–58]. Our data support recently published data [47] that survivors in some COG institutions are being transitioned outside of the catchment area of pediatric oncology for their continuing risk-based care. Formal transition of survivors to adult primary care providers with reciprocal and informative communication has been speculated to be rare [51], challenging [47], influenced by multiple barriers [34, 53, 59–61], and necessary [34] Although our study did not assess methods for facilitating transition nor did it evaluate communication strategies when transitioning, our data reveal that transitioning survivors to adult providers is occurring to varying degrees within COG. Literature on transitioning children and adolescents with other chronic diseases continues to emerge and may be informative to pediatric oncology in the future [62–70].

Various models for risk-based care for adult survivors of pediatric cancers have been reported in the literature. When asked to choose a specific model for adult survivors, the *single* most popular choice was the Cancer-Based Model Without Community Referral, the model where survivors are kept indefinitely at the treating institution for their risk-based care (44%). However, if one considers that three of the other models provided as choices (except for the postal/internet/phone based model), each included transitioning of survivors outside the realm of pediatric oncology in some capacity, such as to primary care physicians (21%), to adult health providers in the same health care system (24%), or to adult oncologists (2%), then an additional conclusion can be drawn. Cumulatively, it appears that almost equal numbers of COG institutions are transitioning adult survivors to adult providers (47%) as are keeping adult survivors indefinitely at the their institution (44%). Our findings support the work of others who have reported that a multitude of institutional, provider, and individual survivor circumstances influence the methods by which adult survivors are systematically followed. In the current study, we have not explored exactly how this care is provided or how carefully this care is planned and executed. Our data indicate there is no single approach that is utilized universally. We recommend an evaluation of specific components of transitional care services as well as studies of methods to address the problem of survivor follow-up attrition [34, 71].

In our study, the top three barriers to *providing care for pediatric survivors and for successful transition for adult survivors* were consistent with barriers previously reported [53, 72] and underscore the importance of educating survivors and future providers, especially primary care providers, about late effects of cancer treatment.

Approximately two thirds of institutions reported providing survivors with a copy of their SCP. This is far less than would be expected since this practice that has become commonplace in survivorship programs. It is hoped that our data underestimate current practice and reflect the time of the survey (2007). Survivorship care plans may facilitate survivor knowledge about treatment-related exposures and include important health information that may be used to guide systematic follow-up according to the Children's Oncology Group (COG) Long-Term Follow-up Guidelines for Childhood, Adolescent, and Young Adult Cancers [35]. The SCP can function as a communication tool for other clinicians to be knowledgeable about past exposures, and it can be useful in the event of a significant adverse event or when clinical decisions need to be made. Unfortunately, the additional provision of written documentation about pertinent findings after each survivor's health-related visit is *lacking* in most COG institutions (69%) and would be an area for improvement, especially in light of reported survivor knowledge deficits [73] and the perceived barrier of lack of clinician knowledge about late effects. The lack of databases for documentation of health outcomes and clinical information potentially compromises easy accessibility to survivorship data useful for research initiatives. Perhaps, a goal for the future preparation of SCP is for documentation to begin when therapy starts, especially for patients with anticipated good prognoses. If a list of exposures is compiled early, utilizing state-of-the-art database technologies or electronic medical records, it could ease the transition to survivorship care by saving time for those abstracting medical records. *Passport to Care*, developed by the Baylor College of Medicine and the Children's Oncology Group, is an example of an online resource designed to provide a readily accessible record of cancer treatment and associated individualized exposure-related recommendations [74].

Costs involved in caring for survivors

When survivorship services were in their infancy, clinicians recognized that more time would be required for a comprehensive survivorship examination as compared to a routine oncology visit. In an early study, leukemia survivors required an average of 52 min of provider time, as compared to 37 min for the other oncology patients [75]. Our data further support that survivor care is time intensive. Our time estimations were calculated for the minimum amount of time required by at least two thirds of institutions for completion of activities related to a survivor's evaluation (initial and annual visit), which includes pre-clinic preparation, direct contact time, and post-clinic management. Therefore, our estimations of time spent for various survivor-related activities were based on conservative

assumptions and are an underestimate of time spent. Our time estimations should be improved by newer computerized charting systems and advanced information technologies currently employed by many COG institutions. Promotion of optimal health outcomes in a time-efficient, cost-effective manner is necessary. Furthermore, knowledge of current billing practices as elucidated by this study needs to be coupled with more information derived from research regarding reimbursement patterns.

Limitations

Our study provides initial data about survivorship services that was easily attainable via a web-based survey. Limitations of the study are those inherent to survey-based research. Although we sought to target health care professionals who were most knowledgeable about LE services to provide a single institutional response, we recognize that responses were subjective and based on the individual participant knowledge. Not all questions were answered by all participants. In future surveys, we recommend shorter, targeted surveys with enhanced skip logic so that participants do not become fatigued, and inclusion of a status of completion bar so that participants can track their time to completion of the survey.

Implications for cancer survivors

Survivorship services are important because they improve early detection, enable preventative health care practices to modify risk, and enable improved physical and psychosocial care for CCS. Survivorship services are available in COG, including transition services, but best practices and models of care have not yet been fully defined. More research is vital for the evolution of survivorship care. Both survivors and future providers need to be educated about survivorship issues, health-related risks, health promotion behaviors, and early intervention strategies. Exploring ways to enhance this knowledge, evaluating strategies for effective teaching utilizing state of the art, cost effective technologies, and testing methods/models, which prevent survivor follow-up attrition would inform design of integrated and comprehensive transition models focused not only on the physical but the psychosocial needs of survivors. Finally, collaborative research with adult-focused providers and programs, utilizing survivor input, will be essential for defining and meeting the future needs of these young adult cancer survivors.

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Appendix A. State of Late Effects (LE) Services in COG

- 1 Only one set of answers is needed for each institution in COG.

Before proceeding please check with others at your institution to determine if your institutional information has already been submitted.

The survey will take approximately 15–20 minutes to complete. You can come back to re-enter data at any time; however, the program will not "remember" where you left off, so you will need to start from the beginning. Therefore, it is advisable to complete the entire survey at one time.

- 2 Please choose your institution from the drop down menu provided.

If you are having difficulty finding your institution, please contact Debra Eshelman-Kent via e-mail at debra.kent@cchmc.org or Karen Kinahan at K-Kinahan@northwestern.edu.

- 3 Please provide the following information.

Name (last, first)
 Credentials
 E-mail Address

- 4 Does your institution provide late effects care for childhood cancer survivors?

- 5 How does your institution provide late effects care? (choose only one)

In a specialized LE program by designated provider(s)
 In regular oncology clinic by health care professional staffing clinic that day
 In regular oncology clinic by survivor's treating oncologist
 Other, please specify

- 6 What are the eligibility criteria for entry into LE services at your institution? (check all that apply)

at least 2 years off treatment
 at least 3 years off treatment
 at least 5 years off treatment
 at least 5 years from diagnosis
 Other, please describe

- 7 Are BMT /stem cell transplant survivors eligible for LE services?

- 8 What are the BMT/stem cell transplant survivors' eligibility criteria for entry into LE services at your institution? (check all that apply)

at least 2 years off treatment
 at least 3 years off treatment
 at least 5 years off treatment

5 years from transplant
 No active GVHD
 Other, please explain

- 9 Are children with central nervous system tumors eligible for LE services?

- 10 What are the CNS survivor eligibility criteria for entry into LE services at your institution? (check any that apply)

at least 2 years off treatment
 at least 3 years off treatment
 at least 5 years off treatment
 5 years from diagnosis
 Other, please explain

- 11 Are patients treated for disease other than oncologic illnesses (ex: aplastic anemia, histiocytosis) eligible for LE services?

- 12 Does your program provide clinical consultations to survivors not treated at your institution?

- 13 Does your program provide phone consultations to survivors not treated at your institution?

- 14 Can patients self refer for late effects services at your institution?

- 15 Please supply demographic information that will be made accessible to survivors and health care professionals in the Late Effects Directory of Services.

Appendix B. General Information

- 16 Please choose the average number of new oncology patients treated at your institution annually.

Less than 30 new oncology patients/year

31–60 new oncology patients/year
 61–90 new oncology patients/year
 91–120 new oncology patients/year
 121–150 new oncology patients/year

Greater than 150 new oncology patients/year

- 17 In 2006, how many total survivors were eligible for late effects clinic visit/appointment?

- 18 Of the following choices, please pick the one which best depicts the

ACTUAL number of survivor VISITS in 2006.

Less than 50 visits
 50–100 visits
 101–300 visits

- 301–500 visits
 - 501–800 visits
 - Greater than 801 visits
 - Data not available
- 19 How frequently are childhood cancer survivor appointments scheduled in your clinic? (please choose one)
- one day/week
 - 2–3 days/week
 - 4–5 days/week
 - one day per month
 - two days per month
- Other, please specify
- 20 Per month, about how many survivors are typically seen (on average) in your late effects clinic setting/session.
- # of Survivors per Month
- 21 Please select which of the following routines describes how pediatric cancer survivors are followed in your institution for additional risk based care.
- Survivors come to the late effects (LE) clinic and are referred to sub-specialists at alternate times apart from their LE visit
- Survivors come to clinic staffed by LE team and required sub-specialists
- Survivors are seen by their general oncologist who manages their late effects care and are referred to sub-specialists at alternate times
- Other, please describe
- 22 If risk based screening is required (ex: echo) is it usually done at the same visit or on another day/time?
- Same visit Another day/time
- 23 Do all/almost all survivors receive a copy of their personal medical history, sometimes called an oncology medical summary or cancer treatment summary?
- 24 If “yes”, who usually prepares/abstracts the data provided in it?
- 25 Do survivors receive a detailed written account of their visit, with pertinent findings, after each visit?
- 26 Please describe the average amount of time spent (in minutes per patient) on preparation of treatment summary.
- 27 Please describe the average amount of time spent (in minutes per patient) on scheduling of appropriate tests/chart review prior to visit.
- 28 Please describe the average amount of time spent (in minutes per patient) on initial LE visit (one-on-one patient time).

- 29 Please describe the average amount of time spent (in minutes per patient) on annual LE visit (one-on-one patient time).
- 30 Please describe the average amount of time spent (in minutes per patient) on gathering, interpreting and compiling lab results, special tests results, etc.
- 31 Please describe the average amount of time spent (in minutes per patient) on post clinic conferencing.
- 32 Please describe the average amount of time spent (in minutes per patient) on communication of findings to patient.
- 33 What visit level are most routine/annual LE visits billed at? (If supplying information from outside the US, please use "Other" to free-text how billing is done.)

- Level 1 (CPT 99211)
- Level 2 (CPT 99212)
- Level 3 (CPT 99213)
- Level 4 (CPT 99214)
- Level 5 (CPT 99215)

Unknown
Other, please specify

- 34 On a routine LE visit, which of the following professionals seeing a survivor would submit a bill for their services? (check all that apply)

- MD
- NP
- PA
- RN
- Nutritionist
- Social Worker
- Education Specialist
- Neuropsychologist
- Psychologist

Other, please specify

Appendix C. Resources

- 35 Does your institution provide financial support for your program operations? (Ex: Nurse coordinator salary funded by the institution or affiliated medical school)
- 36 In the past 5 years has your institution had any level of philanthropic funding for salary support for some or all Late Effects personnel? (Not including government funding)

37 In the past 5 years has your institution had philanthropic support (not as a part of research funding) which enables clinical care for patients?

(Ex: Parents against leukemia organization pays for an echo on noninsured patients)

38 Does your institution currently have research funding specifically designated for clinical testing of patients in the context of a research study that the patient is enrolled in? (Ex: a free PFT for patients enrolled in a research study about lungs)

39 How many nurse practitioners (NP)/clinical nurse specialists (CNS) does your program have?

40 Approximately what percentage of the NP/CNS' job is spent on late effects?

41 How many designated physician assistants (PA) does your program have?

42 Approximately what percentage of the PA's job is spent on late effects?

43 How many RN clinical coordinators (i.e. a person different than an NP) does your program have?

44 Approximately what percentage of the RN clinical coordinator's job is spent on late effects?

45 How many designated social workers does your program have?

46 Approximately what percentage of the social worker's job is spent on late effects?

47 How many designated administrative support staff / secretaries does your program have?

48 Approximately what percentage of the administrative staff/secretary's job is spent on late effects?

49 How many designated nutritionists does your program have?

50 Approximately what percentage of the nutritionist's job is spent on late effects?

51 How many designated educational specialists or neuropsychologists does your program have to help with survivor issues?

52 Approximately what percentage of the educational specialist or neuropsychologist's job is spent on late effects?

53 How many designated clinical research associates (CRA) does your program have?

54 Approximately what percentage of the CRA's job is spent on late effects?

55 Does your program provide dedicated personnel to solve insurance and/or employment related issues?

56 Does your program have a database which is used to track survivor health care outcomes, and/or other pertinent clinical information about survivors?

If yes, type/name of database used (ex: Access, Oracle, etc.)

57 Is there a fee for phone consultations discussing recommendation for risk based management for survivors?

58 Is there a fee for preparation of cancer treatment summaries for any survivor?

Appendix D. Late Effects Services for Care of Survivors Once They Become Adults

59 At what age (if applicable) are cancer survivors referred outside the treating/pediatric center for their cancer-related follow-up care?

We see our former pediatric cancer patients indefinitely at the treating institution and do not transition them elsewhere for their risk based care.

No age limitations, we transition survivors when survivor is ready.

Our survivors are seen through age 16, then transition elsewhere.

Our survivors are seen through age 18, then transition elsewhere.

Our survivors are seen through age 21, then transition elsewhere.

Other criteria: Please Describe.

60 If your survivors are referred elsewhere in adulthood for their cancer related care (risk based late effects care) please pick the choice below that most accurately depicts how their cancer related/risk-based care is managed (select only one)

a) In a specialized program for adult survivors of childhood cancer utilizing a primary care provider, with linkage and flow of information to the treating institution

b) In a specialized program for adult survivors of childhood cancer utilizing a primary care adult practitioner and adult oncologist

By an adult oncologist in an adult cancer setting

c) We refer back to the survivor's general health care provider (family practice, internal medicine, gynecologist) in the community without specific flow of information back to us

d) Other, explain

The survey is almost complete. Just a few more questions.

- 61 Several models of cancer survivor care have been described in the literature. Please pick the one the most accurately depicts your LE services for adult survivors of childhood cancer. Please read all choices carefully before selecting your answer:
- Cancer center based model WITH community referral: Survivors are transitioned at adulthood to their primary health care professional for routine cancer-related (LE) care. All late effects routine testing is managed and coordinated by their PCP with the LE (oncology) team primarily serving as consultants to multiple PCPs. In this model the LE team/treating oncologist have little to no direct patient care, and may be only peripherally involved.
 - Cancer center based model WITHOUT community referral: Survivors are kept indefinitely at the treating institution for their cancer -related (LE) follow-up care. Generally care is with the same LE/ oncology providers who provide care to the pediatric survivor population.
 - Hybrid model (Combined cancer center and community based model): Survivors are transitioned to adult health care providers generally within the same health care system, with established opportunities (ie. a formal mechanism) for collaborative research, collaboration in clinical care, and/or other resource sharing. The LE (oncology) team and adult health care provider closely collaborate for survivor care.
 - Postal/internet/phone based model: Survivors are dismissed from LE (oncology) follow-up at the cancer center. Contact is made regularly about survivor outcomes via postal, phone or internet based inquiry.
 - None of the above (please describe below).
- 62 If none of the above models describe your model, please describe your model for LE services for adult survivors of childhood cancer in detail (limit 500 characters).
- 63 For your adolescent and young adult survivors, is specific information routinely provided by your late effects staff on the importance of health insurance and how to obtain/keep it?
- 64 For your adolescent and young adult survivors, is specific information and support routinely provided by your late effects staff on career planning, vocational pathways or other issues related to obtaining a job?
- 65 Please supply demographic information (as applicable) about your services for adult survivors of childhood cancer. This information will be made available on the COG Website to survivors and health care professionals pursuing adult late effects services.

Appendix E. Barriers

- 66 Please choose the 2 most problematic barriers in caring for your pediatric cancer survivors
- Lack of dedicated time for late effects program development Survivor lack of health care insurance or insurance limitations
 - Survivor knowledge deficit about the importance of maintaining cancer-related follow-up
 - Lack of survivor desire to be followed by the LE team
 - Not enough funding for support of program
 - Lack of perceived need or support for LE services/ program by other oncologists
 - There are no barriers in my institution
 - Other, describe
- 67 From your perspective what are the two most difficult barriers you face (if any) in transitioning your survivors to adult care providers for cancer related care? (Please choose 2)
- Lack of knowledge about late effects by the clinician being referred to
 - Survivor lack of health care insurance or insurance limitations
 - Survivor knowledge deficit about the importance of maintaining cancer related follow-up into adulthood
 - Lack of survivor desire to leave the comfort of the treating institution or oncologist
 - Lack of survivor access to a primary care provider for reasons other than insurance such as geography
 - Lack of oncology provider desire to “let go” of survivor
 - Conflict between COG recommendations for risk based follow-up and adult health care provider recommendations
 - We do not have any barriers
 - Other, please specify

68 Please describe any unique features about your LE follow-up that you feel have not been previously addressed (limit to 500 characters)

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