The state of cancer survivorship programming in Commission on Cancer-accredited hospitals in Georgia

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Abstract
Purpose In Georgia, there are more than 356,000 cancer survivors. Although many encounter challenges as a result of treatment, there is limited data on the availability of survivorship programming. This paper highlights findings from two surveys assessing survivorship care in Commission on Cancer (CoC)-accredited hospitals in Georgia.

Methods In 2010, 38 CoC-accredited hospitals were approached to complete a 36-item survey exploring knowledge of national standards and use of survivorship care plans (SCPs), treatment summaries (TSs), and psychosocial assessment tools. In 2012, 37 CoC-accredited hospitals were asked to complete a similar 21-item survey.

Results Seventy-nine percent (n = 30) of cancer centers completed the 2010 survey. Sixty percent (n = 18) reported having a cancer survivorship program in place or in development. Forty-three percent (n = 13) provided survivors with a SCP and 40 % (n = 12) a TS. Sixty percent (n = 18) reported either never or rarely using a psychosocial assessment tool. Sixty-two percent (n = 23) completed the 2012 survey. Ninety-six percent (n = 22) were aware of the new CoC guideline 3.3. Thirty-nine percent (n = 9) provided a SCP and/or TS. Eighty-seven percent (n = 20) stated they were very confident or somewhat confident their organization could implement a SCP and/or TS by 2015.

Conclusions The data indicated the importance of collaboration and shared responsibility for survivorship care. Broad implementation of SCPs and TSs can help address the late and long-term effects of treatment.

Implications for Cancer Survivors Increasing knowledge on survivorship care is imperative as the Georgia oncology community engages oncologists and primary care providers to achieve higher quality of life for all survivors.

Keywords Cancer · Survivorship · Commission on Cancer · Late effects · Quality of life · Quality of care

Introduction
Advances in early detection and enhanced treatment options mean people are living longer after a cancer diagnosis. According to the National Cancer Institute (NCI), a cancer survivor is anyone who has been diagnosed with cancer, from the time of diagnosis until the end of life [1]. Today, there are nearly 14 million cancer survivors living in the USA; this number is expected to increase to 18 million by 2020 [2]. Fifty-nine percent of survivors are 65 years of age or older, and the most common cancer sites represented among survivors include female breast (22 %), prostate (20 %), colorectal (9 %), and gynecologic (8 %) [3].

State-level statistics reflect what is occurring nationally. In Georgia, there are more than 356,000 cancer survivors [4]. As the number of cancer survivors continues to grow, survivorship—the period of time spanning the completion of active treatment and end of life—has become increasingly important [5]. Cancer survivors often encounter physical, emotional, psychosocial, spiritual, and economic challenges as a result of their cancer diagnosis and treatment. Research on the late and long-term effects of cancer and its treatment has emphasized the need for survivorship programs that address the myriad concerns experienced by this growing population [6–9].
Many resources have been developed to assist healthcare providers with improving the quality of life for cancer survivors. Survivorship care plans (SCPs) and treatment summaries (TSs), for example, are integral components of the long-term care of cancer survivors [10–14]. These tools help educate healthcare professionals when the cancer survivor transitions from active treatment with an oncologist to survivorship care with a primary care provider (PCP). Providing a TS informs the PCP about the treatment the cancer survivor previously received. SCPs offer guidance on how best to care for a cancer survivor in the years following active treatment [15]. In addition, psychosocial assessment tools enable healthcare professionals to quantify the amount of anxiety and distress individuals experience as a result of a cancer diagnosis and treatment; this is crucial since mental health concerns are so prevalent among survivors [16].

Several national organizations have developed recommendations and standards to improve the quality of care for cancer survivors. In 2011, the LIVESTRONG Foundation developed the Essential Elements of Survivorship Care to emphasize the fundamental needs of cancer survivors and the ways in which healthcare systems can effectively meet these needs [7]. The Tier I Essential Elements, which LiveSTRONG suggests all medical settings provide direct access or referral to, are highlighted below.

The LiveSTRONG Foundation Tier I Essential Elements of Survivorship Care

1. Survivorship care plan, psychosocial care plan, and treatment summary.
2. Screening for new cancers and surveillance for recurrence.
3. Care coordination strategy that addresses care coordination with primary care physicians and primary oncologists.
4. Health promotion education.
5. Symptom management and palliative care.

The American College of Surgeons (ACoS) Commission on Cancer (CoC) also produces standards regarding quality cancer care [17]. In 2012, CoC updated standard 3.3, which directly addresses the use of SCPs and TSs [18].

American College of Surgeons Commission on Cancer: Cancer Program Standard 3.3

The cancer committee [must] develop and implement a process to disseminate a comprehensive care summary and follow-up plan to patients with cancer who are completing cancer treatment. The process [must be] monitored, evaluated, and presented at least annually to the cancer committee and documented.

Similarly, the National Comprehensive Cancer Network (NCCN) and the American Society of Clinical Oncology (ASCO) both produced guidelines related to survivorship care that address issues like psychosocial distress, fertility, and fatigue among cancer survivors [19, 20].

Given the significant number of cancer survivors living in the USA, it is remarkable how little is known about the survivorship programs and services offered. Although national organizations such as LIVESTRONG, CoC, ASCO, and NCCN have developed standards and recommendations based on the key needs of survivors, there are limited data demonstrating what survivorship programming is available in community practices and academic institutions. As a result, there is also limited knowledge of best practices in survivorship care.

This paper will highlight findings from 2010 to 2012 surveys developed by the Georgia Cancer Control Consortium and disseminated by the Georgia Center for Oncology Research and Education (Georgia CORE) that assessed the aspects of survivorship care offered in CoC-accredited hospitals in Georgia. These data serve to illustrate the state of survivorship care in Georgia and inform how best to proceed in order to meet updated standards and deliver the highest quality care to all cancer survivors in the state.

Methods

In 2009, the vice-president of Georgia CORE convened a diverse group of oncology professionals to begin developing ways to enhance survivorship programming in Georgia. This group included cancer survivors, administrators, oncologists, researchers, and navigators. The discussion led to the creation of a survey for completion by the CoC-accredited hospitals in Georgia to determine what aspects of survivorship care were being offered at the time. Further, the survey would highlight what areas of survivorship care needed to be improved in CoC hospitals throughout the state.

A 36-item survey was developed in 2010 to address various aspects of cancer survivorship. Topics included the availability of survivorship programming; knowledge of national standards in survivorship care; and use of SCPs, TSs, and psychosocial assessment tools in CoC hospitals. The following are sample items from the survey: “Does your organization currently offer a program that is considered to be a Cancer Survivorship Program?”; “Who is responsible for delivering Cancer Survivorship Services in your organization?”; and “Is
your organization familiar with the Institute of Medicine (IOM) guidelines as set out in, “From Cancer Patient to Cancer Survivor: Lost in Transition” and “Cancer Care for the Whole Patient”? The full survey instrument can be found in Appendix A. An online survey tool—SurveyMonkey—was utilized to develop and disseminate the survey to cancer center directors at Georgia’s 38 CoC-accredited hospitals in 2010. CoC hospitals with multiple sites were only asked to complete one survey. Consent was implied by participants voluntarily completing the survey. Although the survey collected identifying information, all survey data were de-identified and reported in aggregate.

After implementation of this survey in 2010, the Georgia Cancer Control Consortium Steering Committee discussed a revision of the state’s Comprehensive Cancer Control Plan (Plan). The five main work groups within the Plan included the following: prevention, early detection and screening, diagnosis and staging, treatment and palliation, and data and metrics. Initially, survivorship and cancer-related health disparities were viewed as overarching themes to be considered by all work groups. However, realizing that overarching themes were beneficial in guiding the work, but not effective for accomplishing tangible outcomes, a Survivorship Work Group (SWG) was developed in 2011. This decision to create a work group dedicated to survivorship was further supported by the dissemination of LIVESTRONG’s Essential Elements of Survivorship Care in 2011 and newly updated CoC Program Standards for survivorship care in 2012 [7, 18].

Guided by these new standards in survivorship care, the SWG determined one goal of the revised Plan would be to increase the percent of cancer survivors in Georgia who receive SCPs and TSs. The work group also recognized the impact CoC standard 3.3 would have on maintaining accreditation for CoC hospitals beginning in 2015. Accordingly, the SWG developed a second survey for CoC hospitals in 2012. This survey was different from the 2010 survey in that it more exclusively focused on the development, implementation, and evaluation of SCPs and TSs in Georgia’s CoC hospitals. Sample questions from the 21-item survey include the following: “Are you aware of the new CoC Guideline ‘Standard 3.3 Survivorship Care Plan’ that must be phased in by 2015?”; “Does your organization currently provide a survivorship care plan and a treatment summary?”; “Whose responsibility is it to initiate the survivorship care plan and/or treatment summary?”; and “Would you be willing to share lessons you’ve learned with other cancer programs to help them implement survivorship care plans and/or treatment summaries?” The full survey instrument can be found in Appendix B. This survey was distributed to the cancer center directors at Georgia’s 40 CoC-accredited hospitals in 2012 using SurveyMonkey. CoC hospitals with multiple sites were only asked to complete one survey. Consent was implied by participants voluntarily completing the survey. Although the survey collected identifying information, all survey data were de-identified and reported in aggregate.

Results

2010 survey results

Thirty of thirty-eight (79 %) cancer centers completed the 2010 survey. Thirteen (43 %) reported being located within Metro Atlanta, while 17 (57 %) were located outside this metropolitan area. Twenty-four (80 %) respondents identified their organization as a community cancer center.

Twenty-five (83 %) cancer centers reported having an established website focused on cancer care or a website in progress; 17 (57 %) stated that the website specifically targeted cancer survivors. Eighteen (60 %) cancer centers reported either having a cancer survivorship program at the time of the survey or that such a program was in development. Twenty-two (73 %) reported that communication between primary care physicians and oncologists was crucial to improving awareness of the survivorship programming available for cancer patients and survivors at their cancer center.

The survey explored several components of survivorship to determine what was offered through existing programs in the state. Issues like nutrition, palliative care, side effect management, and social support were often addressed at diagnosis, during treatment, and post-treatment at cancer centers with established programs. However, support for issues surrounding mental and sexual health, for example, was less prevalent. See Table 1 for additional results.

The majority of respondents reported body image, diet/nutrition, lymphedema, and pain as effects of treatment that were addressed successfully by their cancer centers, often through the use of print materials. See Table 2 for additional results.

Less than half of cancer centers reported providing survivors with a survivorship care plan (n=13; 43 %) or treatment summary (n=12; 40 %). Twenty-three (77 %) respondents stated their cancer center did not create a survivorship care plan for pediatric, adolescent, and young adult cancer survivors based on guidelines developed by the Children’s Oncology Group. Eighteen (60 %) cancer centers reported
either never or rarely using a psychosocial assessment tool to identify cancer survivorship needs within their cancer center.

When reporting on which healthcare providers were responsible for delivering survivorship care, respondents had the ability to check all that apply: 24 (80 %) respondents stated that both oncologists and nurses were primarily responsible for delivering the majority of survivorship services to cancer survivors, while 21 (70 %) reported patient navigators and dieticians and 17 (57 %) said social workers. Less than half (n=14; 47 %) the cancer centers reported being familiar with the Institute of Medicine (IOM) guidelines described in *From Cancer Patient to Cancer Survivor: Lost in Transition* and *Cancer Care for the Whole Patient*. Despite this, 16 (53 %) respondents stated their organization endorsed the IOM as an authority on best practices and guidelines for cancer survivorship care.

Regarding financial capacity of survivorship programs, 20 (67 %) cancer centers reported that survivorship services were funded through operational funds, with grant funding (n=13; 43 %), philanthropic funding (n=11; 37 %), and other sources of funding (n=5; 17 %) following. Only one program reported using patient charges as a funding source for survivorship services.

### Table 1  Data from 2010 survey (n=38)

<table>
<thead>
<tr>
<th>Components offered</th>
<th>During diagnosis and/or treatment</th>
<th>Post-treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>Percent</td>
</tr>
<tr>
<td>Alternative medicine</td>
<td>4</td>
<td>13.3</td>
</tr>
<tr>
<td>Acupuncture</td>
<td>6</td>
<td>20.0</td>
</tr>
<tr>
<td>Assessment and referral</td>
<td>23</td>
<td>76.7</td>
</tr>
<tr>
<td>Body/personal image</td>
<td>20</td>
<td>66.7</td>
</tr>
<tr>
<td>Caregiver educ/support</td>
<td>24</td>
<td>80.0</td>
</tr>
<tr>
<td>Complement medicine</td>
<td>8</td>
<td>26.7</td>
</tr>
<tr>
<td>Endocrinology</td>
<td>15</td>
<td>50.0</td>
</tr>
<tr>
<td>Exercise</td>
<td>15</td>
<td>50.0</td>
</tr>
<tr>
<td>Family support</td>
<td>18</td>
<td>60.0</td>
</tr>
<tr>
<td>Financial counseling</td>
<td>18</td>
<td>60.0</td>
</tr>
<tr>
<td>Infertility assistance</td>
<td>9</td>
<td>30.0</td>
</tr>
<tr>
<td>Integrative medicine</td>
<td>9</td>
<td>30.0</td>
</tr>
<tr>
<td>Meditation</td>
<td>5</td>
<td>16.7</td>
</tr>
<tr>
<td>Neuropsychology</td>
<td>5</td>
<td>16.7</td>
</tr>
<tr>
<td>Nutrition</td>
<td>27</td>
<td>90.0</td>
</tr>
<tr>
<td>Occupational health</td>
<td>13</td>
<td>43.3</td>
</tr>
<tr>
<td>Online support</td>
<td>7</td>
<td>23.3</td>
</tr>
<tr>
<td>Palliative care</td>
<td>20</td>
<td>66.7</td>
</tr>
<tr>
<td>Patient educ classes</td>
<td>17</td>
<td>56.7</td>
</tr>
<tr>
<td>Physical rehabilitation</td>
<td>22</td>
<td>73.3</td>
</tr>
<tr>
<td>Physiotherapy</td>
<td>6</td>
<td>20.0</td>
</tr>
<tr>
<td>Psychology</td>
<td>11</td>
<td>36.7</td>
</tr>
<tr>
<td>Sexuality</td>
<td>9</td>
<td>30.0</td>
</tr>
<tr>
<td>Side effect management</td>
<td>23</td>
<td>76.7</td>
</tr>
<tr>
<td>Smoking cessation</td>
<td>26</td>
<td>86.7</td>
</tr>
<tr>
<td>Social work</td>
<td>20</td>
<td>66.7</td>
</tr>
<tr>
<td>Support groups</td>
<td>24</td>
<td>80.0</td>
</tr>
<tr>
<td>Spiritual care</td>
<td>19</td>
<td>63.3</td>
</tr>
<tr>
<td>Yoga/tai chi</td>
<td>11</td>
<td>36.7</td>
</tr>
</tbody>
</table>
Twenty-three (77 %) cancer centers either had plans to expand or were expanding their survivorship programs. The majority of survey respondents reported that enhancing networking among cancer centers would provide a unique opportunity to share the best practices ($n=24; 80 \%) and learn from others’ experiences ($n=22; 73 \%).
cancer centers provided a SCP and/or TS. Twenty (87%) respondents stated that they were very confident or somewhat confident that their organization would be able to implement a SCP and/or TS by 2015.

Institutions that did provide SCPs and/or TSs reported utilizing various—and sometimes multiple—templates including Journey Forward (n=4; 17%), LIVESTRONG Care Plan (n=4; 17%), ASCO Cancer Treatment Plan and Summary (n=4; 17%), and unique templates developed in-house (n=6; 26%). In addition, respondents reported using several different electronic medical record (EMR) vendors. Nineteen (83%) cancer centers reported not having integrated their SCPs with their EMRs, and seventeen (74%) reported not integrating their TSs with their EMRs. See Table 3 for additional results.

Seven (30%) respondents stated that nurse navigators were primarily responsible for initiating and completing SCPs and/or TSs in their cancer centers; eight (35%) reported these individuals were also responsible for reviewing the SCP and/or TS with the patient.

Funding still presented an issue for cancer survivorship programs. Of the 14 individuals who responded to this question, zero reported that their cancer center received reimbursement for preparing SCPs or TSs. The top three resources identified to enhance cancer centers’ ability to implement SCPs and TSs by 2015 included the following: technology integration and technical support (n=18; 78%), billing and reimbursement (n=15; 65%), and workflow guidance (n=13; 57%). Similar to the 2010 survey results, 16 (70%) cancer centers reported that they would be willing to share lessons learned with other cancer programs in order to increase implementation of SCPs and/or TSs.

### Discussion

The 2010 survey yielded a high response rate (79%), offering a broad understanding of the survivorship programs available at that time through CoC-accredited cancer programs in Georgia. More than half of the cancer centers indicated having an established survivorship program. The majority also described the online presence of their cancer center, often with content specifically targeting cancer survivors and their unique needs. As the significance of survivorship care increases, both in the oncology and primary care arenas, these established programs in Georgia will continue to guide the development of additional survivorship programs in the state.

Many respondents emphasized the significance of communication between oncologists and primary care providers to promote high quality care for cancer survivors. Further, data indicated the importance of collaboration and shared responsibility for the various components of survivorship care. Oncologists, primary care physicians, nurses, navigators, social workers, dieticians, and mental health professionals must work alongside one another to effectively deliver survivorship services. Cancer center directors, eager to expand survivorship services at their institutions and share the best practices among CoC hospitals, can foster this collaboration in order to enhance the available programs.

Through existing survivorship initiatives, significant issues such as nutrition, palliative care, and side effect management seem to have been addressed for many cancer survivors in Georgia. However, despite the success of these programs at meeting some of cancer survivors’ unique needs, the data still revealed areas of unmet need, most notably mental health, sexuality, and the availability of SCPs and TSs. These findings align with what is seen in the literature. Research by Hewitt and Rowland [21], for example, illustrates the need for improved recognition of mental health problems among cancer survivors and reduced barriers to appropriate clinical services. Salz et al. [10] and Earle and Ganz [22] emphasize the challenges cancer centers face in developing and implementing SCPs and TSs for cancer survivors completing active treatment. These data are significant as broad implementation of SCPs and TSs

### Table 3 Data from 2012 survey (n=37)

<table>
<thead>
<tr>
<th>EMR vendors</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Allscripts</td>
<td>2</td>
<td>8.7</td>
</tr>
<tr>
<td>Cerner</td>
<td>5</td>
<td>21.7</td>
</tr>
<tr>
<td>Epic</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Eclipsys</td>
<td>1</td>
<td>4.3</td>
</tr>
<tr>
<td>GE Healthcare</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Meditech</td>
<td>4</td>
<td>17.4</td>
</tr>
<tr>
<td>McKesson</td>
<td>6</td>
<td>26.1</td>
</tr>
<tr>
<td>Siemens</td>
<td>1</td>
<td>4.3</td>
</tr>
<tr>
<td>Varian</td>
<td>11</td>
<td>47.8</td>
</tr>
<tr>
<td>Other</td>
<td>6</td>
<td>26.1</td>
</tr>
</tbody>
</table>
can assist in addressing late and long-term effects of cancer treatment, thereby improving quality of life for survivors.

Although the response rate of the second survey was lower (62%), it produced valuable data to assist in better understanding the use of specific resources such as SCPs, TSs, and psychosocial assessment tools in Georgia’s CoC-accredited hospitals. While many cancer centers reported a high awareness of CoC standard 3.3, which requires all accredited CoC hospitals to provide SCPs and TSs to cancer survivors by 2015, less than half of the respondents reported offering these resources. However, cancer centers were confident that they would be able to successfully implement strategies to increase the use of SCPs and TSs, particularly by using existing templates such as LiveSTRONG and Journey Forward. Integrating the SCP and TS into their electronic medical record is another important goal that will streamline the process and ensure the effective incorporation of these tools into clinical practice. Once again, collaboration is key; increasing communication among multiple specialties and providers can facilitate the growth and success of survivorship programs [14].

Data from both surveys highlighted funding as a significant issue facing the development and successful implementation of survivorship programs. Funding is crucial for various aspects of survivorship care such as end-of-treatment visits and the initiation and use of SCPs and TSs. Though reimbursement for end-of-treatment visits is becoming more prevalent, third-party payers rarely reimburse for things like SCPs and TSs. Other means such as grant and philanthropic funding are integral to establishing the capital needed to create and sustain effective survivorship programs [23, 24]. Improving reimbursement for services essential to long-term survivorship care could potentially improve care coordination, communication among patients and providers, and, perhaps most importantly, contribute to increased quality of life for survivors. Continuing to advocate for enhanced reimbursement and overall funding of survivorship initiatives, as well as assisting CoC hospitals with technology integration, technical support, and workflow guidance, will increase the likelihood that survivorship programs are improved and widely implemented in a sustainable manner.

While the data from these two surveys are beneficial in offering perspective on the state of survivorship care in Georgia, it is important to note that there are several limitations to this research. First of all, conclusions may not be generalizable to the entire state. Many of the respondents were from cancer centers in the Metro Atlanta area and most represented community cancer centers as opposed to academic institutions or larger healthcare systems. Similarly, while the two surveys were intended to be completed by cancer center directors, sometimes other staff such as clinical nurse directors or research nurse managers completed the surveys on their behalf. This may have caused some variability in the data given these individuals have differing perspectives on survivorship care. Further, the 2010 and 2012 surveys may not have been completed by the same individual for each institution.

In addition, although the overall aim of each survey was to assess survivorship programming in CoC hospitals in Georgia, the data from the two surveys cannot be directly compared since each survey has a somewhat different focus. In the future, more closely aligning the content would be beneficial in order to accumulate consistent data for analysis and reporting. Increasing the amount of time between surveys may also be beneficial to minimize participant burden, sustain a high overall response rate, and effectively track progress in survivorship care in Georgia over time.

The information derived from these surveys does provide an illustration of the availability of basic, but crucial, components of cancer survivorship programs in CoC hospitals in Georgia. It offers a starting point from which healthcare professionals in Georgia can work to enhance existing programs and expand these initiatives into other parts of the state where the needs of survivors are high, but the infrastructure and resources may be low. The data also help inform the direction of the Survivorship Work Group’s initiatives within Georgia’s Comprehensive Cancer Control Plan. Increasing knowledge on survivorship care is imperative as the Georgia oncology community engages both oncologists and primary care providers to assist in achieving a higher quality of life for all cancer survivors in the state.

Acknowledgments This research would not have been possible without support from the Georgia Center for Oncology Research and Education, Georgia Cancer Control Consortium Steering Committee, and Survivorship Work Group. Thank you also to the Commission on Cancer-accredited cancer centers in Georgia for completing the 2010 and 2012 online surveys for this research.

Conflict of interest The authors declare that they have no conflict of interest.
Appendix

Appendix A

2010 Survey Instrument

1. Please enter your demographic information below.
   - Name: 
   - Organization: 
   - Address: 
   - Address 2: 
   - City/Town: 
   - State: 
   - ZIP: 
   - County: 
   - Email Address: 
   - Phone Number: 

2. What is your organization's primary service area?
   - Rural
   - Urban
   - Suburban
   - Other (please specify) 
   - [ ]

3. What area of Georgia does your organization serve? (select all that apply)
   - Northwest Georgia
   - Northeast Georgia
   - Metro Atlanta
   - East Georgia
   - Central Georgia
   - West Central Georgia
   - Southeast Georgia
   - Southwest Georgia
   - Statewide
   - Areas in states surrounding Georgia
   - Individual Community (please specify)
   - [ ]
4. What number of clients does your organization serve annually?

<table>
<thead>
<tr>
<th># Of New Cancer Clients</th>
<th># of Cancer Survivors Continuing in FollowUp</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 50</td>
<td></td>
</tr>
<tr>
<td>50 - 99 clients</td>
<td></td>
</tr>
<tr>
<td>100 - 299 clients</td>
<td></td>
</tr>
<tr>
<td>300 - 649 clients</td>
<td></td>
</tr>
<tr>
<td>650+ clients</td>
<td></td>
</tr>
</tbody>
</table>

5. Does your organization have a website focusing on cancer?

- No (If NO, skip to # 7)
- In Progress
- Yes (Indicate url) www.

6. If so, does it feature materials targeted to the following groups? (select all that apply)

- Cancer Survivors
- Caregivers of people who have cancer
- Oncology Healthcare Providers
- General Public

7. What is your organization's area of practice? (select all that apply)

- Academic Cancer Center
- Community Cancer Center
- Community Private Practice office
- Home Care/hospice/palliative care program
- Other Clinical/Patient Care Service
- Statewide cancer organization
- Regional coalition
- Government Agency
- Other (please specify)
8. What portion of your efforts are focused specifically on cancer as opposed to other diseases? (heart disease, diabetes, stroke, etc.)

- All
- Most
- Half
- 25% or less

9. Does your organization currently offer a program that is considered to be a Cancer Survivorship Program?

- Yes
- No
- In Development

10. At what phase of cancer control does your organization serve clients? (select all that apply)

- At time of diagnosis
- During treatment
- After treatment is completed
- From diagnosis through end of life

11. How are Cancer Survivors made aware of your organization’s Cancer Survivorship Services? (select all that apply)

- Communications with physician (primary care/oncologist) recommending follow-up and wellness
- Communications with health care provider(s) other than a physician
- Communication with volunteer cancer survivor
- Communication with cancer patient navigator
- Promotions via website, posters, newsletters, calendar, mailings
- Other promotions such as advertising
- Other (please specify)

________________________
12. Which of the following components of a Cancer Survivorship Program does your organization offer? (select all that apply and when offered)

<table>
<thead>
<tr>
<th>Component</th>
<th>From diagnosis through treatment</th>
<th>Post-Treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alternative medicine</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Acupuncture</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Assessment &amp; Referral</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Body/personal image</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiver education/support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Complementary medicine</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Endocrinology</td>
<td></td>
<td></td>
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<tr>
<td>Exercise</td>
<td></td>
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<tr>
<td>Expression through arts/dreams/journaling</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family (spouse/child) support</td>
<td></td>
<td></td>
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<tr>
<td>Financial Counseling</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Infertility assistance</td>
<td></td>
<td></td>
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<tr>
<td>Integrative Medicine</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mindfulness/Meditation</td>
<td></td>
<td></td>
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<tr>
<td>Networking with survivors</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neuropsychology</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nutrition</td>
<td></td>
<td></td>
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<tr>
<td>Occupational health</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Online support</td>
<td></td>
<td></td>
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<tr>
<td>Palliative care</td>
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<tr>
<td>Patient Education Classes</td>
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<tr>
<td>Physical rehabilitation</td>
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<tr>
<td>Physiotherapy</td>
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<td>Psychology</td>
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<tr>
<td>Sexuality</td>
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<tr>
<td>Side effect management</td>
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<tr>
<td>Smoking cessation</td>
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<tr>
<td>Socialization</td>
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<tr>
<td>Social Work</td>
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<tr>
<td>Support Groups</td>
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<tr>
<td>Spiritual care</td>
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<tr>
<td>Survivorship care plan</td>
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<tr>
<td>Yoga/Tai Chi/etc.</td>
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<tr>
<td>Other (please specify)</td>
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</tr>
</tbody>
</table>
13. Who is responsible for delivering Cancer Survivorship Services in your organization? (Select all that apply)

- Dietitians
- Massage Therapists
- Nurses
- Nurse Practitioners
- Occupational Therapists
- Oncologists
- Other physician specialist
- Patient Educators
- Patient Navigators
- Primary Care Provider
- Psychiatrists
- Psychologists
- Physicians' Assistants
- Physiotherapists
- Social Workers
- Speech Language Pathologists
- Spiritual Care Providers (Chaplains)
- Survivors
- Volunteers
- Other (please specify)

14. Is your organization familiar with the Institute of Medicine (IOM) guidelines as set out in, "From Cancer Patient to Cancer Survivors: Lost in Transition" and "Cancer Care for the Whole Patient"?

- Unknown
- Very Unfamiliar
- Unfamiliar
- Familiar
- Very Familiar
15. Does your organization’s Cancer Program endorse the IOM as the authority on best practices guidelines in cancer survivorship?
   - Yes (Skip to # 17)
   - No

16. If you answered "No", does your cancer program follow other established guidelines for best practice? i.e. State or Provincial Guidelines
   - Yes
   - No
   - If you answered Yes, what guideline for best practice do you follow?

17. What client populations does your organization serve? (check all that apply)
   *If "adult male & female" only skip to #20*
   - Older Adult (age 60+)
   - Adult Male
   - Adult Female
   - Adolescent and Young Adult (age 18 - 39)
   - Pediatric (age 0 - 18)

18. Does your organization have survivorship services specifically designed for the geriatric population (aged 70+)?
   - Yes
   - No

19. Do you create a Survivorship Care Plan for your pediatric, adolescent and young adult cancer clients utilizing the "Children’s Oncology Group Long-Term Follow-Up Guidelines"?
   - Yes
   - No
20. Are your organization's Survivorship Services specifically oriented to individuals according to the following? (check all that apply)

- Gender
- Age
- Specific Diagnosis
- Type of Cancer
- Stage of Cancer
- Personal Interest
- Type of Treatment
- Other (please specify)
21. What types of cancer do your Survivorship Services address? (check all that apply)

- Bone Marrow Transplant
- Brain
- Breast
- General
- GI
- GU
- Gynecologic (ovarian)
- Head and Neck
- Leukemia
- Lung
- Neuroblastoma
- Non-Hodgkin's
- Lymphoma/Hodgkin's Lymphoma
- Melanoma (skin)
- Multiple Myeloma
- Musculoskeletal
- Pediatric
- Prostate
- Sarcomas
- Thoracic
- Wilms Tumors
- Other (please specify)

22. How often does your organization use a psychosocial assessment tool(s) to identify Cancer Survivorship needs?

- Never
- Rarely
- Occasionally
- Very Frequently
- Always
23. Would your organization be willing to share its assessment tool?

☐ Yes

☐ No

☐ Other (comments)

24. Would your organization be willing to share its results?

☐ Yes

☐ No

Other (comments)

25. Do you evaluate the programs you offer?

☐ Yes

☐ No

☐ If you answered yes, how do you evaluate the programs?
## 26. What late or persistent side effects of treatment does your organization currently address? (check all that apply and when they apply)

<table>
<thead>
<tr>
<th>Side Effect</th>
<th>From Diagnosis through Treatment</th>
<th>Post Treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Body Image</td>
<td></td>
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<tr>
<td>Bone and soft tissue</td>
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<tr>
<td>Cardiovascular</td>
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<tr>
<td>Cognitive impairment</td>
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<td>Cosmetic</td>
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<td>Delayed Puberty</td>
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<td>Dental/oral health</td>
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<td>Diet and nutrition</td>
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<td>Endocrine-gonadal</td>
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<td>Endocrine-pituitary</td>
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<td>Endocrine-thyroid</td>
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<td>Exercise</td>
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<td>Fatigue</td>
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<td>Failure to thrive/underweight</td>
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<tr>
<td>Growth Failure</td>
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<td>Immune system</td>
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<td>Impaired immune function</td>
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<td>Sexual dysfunction</td>
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<tr>
<td>Other (please specify)</td>
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</tbody>
</table>
27. How does your organization currently address these topics? (check all that apply)

<table>
<thead>
<tr>
<th>Topic</th>
<th>Lectures/Workshops</th>
<th>Printed Material</th>
<th>Audio-visual/Web-based Programs</th>
<th>Specialist Referral</th>
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</thead>
<tbody>
<tr>
<td>Body Image</td>
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<td>Sexual dysfunction</td>
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</tbody>
</table>
### 28. What components of a Survivorship Care Plan does your organization offer? (check all that apply and how the plan can be accessed)

<table>
<thead>
<tr>
<th>Component</th>
<th>Paper Copy</th>
<th>Electronic</th>
<th>Not Offered</th>
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</thead>
<tbody>
<tr>
<td>Risk Profile</td>
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<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Prevention/Screening Recommendations</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Summary of Care</td>
<td>☐</td>
<td>☐</td>
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<tr>
<td>Post-Treatment Care Plan</td>
<td>☐</td>
<td>☐</td>
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<tr>
<td>Other (please specify)</td>
<td>☐</td>
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</table>

### 29. Does your organization provide tailor-made client educational materials or use a trusted resource? (check all that apply)

- ☐ Tailor-made
- ☐ Credible resource (please specify: [Type of resource]

### 30. In which of the following languages are your services offered? (check all that apply)

- ☐ English
- ☐ Chinese
- ☐ French
- ☐ Spanish
- ☐ Vietnamese
- ☐ Hearing Impaired
- Other (please specify): [Language(s) other than those listed]

---

*Note: The above text is a transcription of a form or survey page, focusing on specific questions related to survivorship care plans and language services.
31. Do you have access to/use interpreter services?

☐ Yes

☐ No

32. Where are your organization’s educational programs held? (check all that apply)

☐ Hospital-based

☐ Community facility

☐ Other (please specify)

☐ 

33. How are your organization’s Cancer Survivorship Services funded? (check all that apply)

☐ Through the organization’s operating funds

☐ Pharmaceutical company funding

☐ Grant Funding

☐ Philanthropic support/Fundraising

☐ Patients are charged for services

☐ Other (please specify)

☐ 

34. Does your organization have plans to expand its Cancer Survivorship Program?

☐ Yes

☐ No

☐ In Progress
35. Would networking with other Cancer Survivorship Programs have any of the following benefits for your organization? (check all that apply)

- Share best practices
- Learn from other's experiences
- Assist patients leaving area in finding resources
- Provide guidance in program development
- Smooth referral to services not locally available
- Maximize organizational resources
- Build state reputation as a leader in cancer care
- Facilitate support, mentoring from colleagues
- Reduce provider stress and burnout
- Advocate for cancer survivors
- Discover new resources
- Grow number of cancer survivors served in Georgia
- Support cancer survivor research
- Other (please specify)

36. Does your organization host an annual cancer survivor celebration for people it has treated for cancer?

- Yes
- Yes, but it is open to all cancer survivors.
- No

37. Please use this space to share any additional comments you may have.
Appendix B

2012 Survey Instrument

Survey Questions

*1. Please enter your demographic information below.

Name: 
Organization: 
Address: 
Address 2: 
City/Town: 
State: 
ZIP: 
County: 
Email Address: 
Phone Number: 

*2. Are you aware of the new CoC Guideline "Standard 3.3 Survivorship Care Plan" that must be phased in by 2015?

☐ No
☐ Yes

*3. Does your organization currently provide: (check all that apply)

☐ A Survivorship Care Plan (SCP);
☐ A Treatment Summary (TS)
☐ Don't know

*4. If you are not currently providing these, how confident are you that your organization will be able to implement a Survivorship Care Plan and/or Treatment Summary by 2015?

☐ Very confident
☐ Somewhat confident
☐ Not confident
☐ Very concerned
☐ Don't know
5. If yes, select all of the current Survivorship Care Plan and/or Treatment Summary templates you are using:

- [ ] Journey Forward
- [ ] LIVESTRONG Care Plan
- [ ] ASCO Cancer Treatment Plan and Summary
- [ ] Prescription for Living
- [ ] Developed in-house
- [ ] Other (please specify)

6. Please select all EMR vendors you are currently using:

- [ ] Allscripts
- [ ] Cerner
- [ ] Epic
- [ ] Eclipsys
- [ ] GE Healthcare
- [ ] Meditech
- [ ] McKesson
- [ ] Siemens
- [ ] Varian
- [ ] Other (please specify)

7. Is the Survivorship Care Plan integrated with your Electronic Medical Record (EMR) system?

- [ ] No
- [ ] Yes

8. Is the Treatment Summary integrated with your Electronic Medical Record (EMR) system?

- [ ] No
- [ ] Yes
9. If they are not currently integrated, do you have plans to integrate the Survivorship Care Plan and/or Treatment Summary with your EMR?

☐ No

☐ Yes. When is it scheduled to be implemented?

10. Select all of the following qualities that apply to the Survivorship Care Plan and/or Treatment Summary template that your organization currently uses:

☐ Compatible with EMR system
☐ Easy to complete
☐ Easy for patient to understand
☐ Other (please specify)

11. Does your Survivorship Care Plan / Treatment Summary accommodate / is sensitive to multiple: (select all that apply)

☐ Languages
☐ Literacy levels
☐ Cultural factors

12. Whose responsibility is it to initiate the Survivorship Care Plan and/or Treatment Summary?

☐ Physician
☐ Nurse Practitioner Navigator
☐ Nurse Navigator
☐ Social Work Navigator
☐ Lay Navigator
☐ Clinical nurse specialist
☐ Other (please specify)

☐ Springer
13. Whose responsibility is it to facilitate completion of the Survivorship Care Plan and/or Treatment Summary?

☐ Physician
☐ Nurse Practitioner
☐ Nurse Navigator
☐ Social Work Navigator
☐ Lay Navigator
☐ Clinical nurse specialist

☐ Other (please specify)

14. How long does it take to complete the Survivorship Care Plan?

☐ 15 - 30 minutes
☐ 45 - 60 minutes

☐ More than an hour (please specify)

15. How long does it take to complete the Treatment Summary?

☐ 15 - 30 minutes
☐ 45 - 60 minutes

☐ More than an hour (please specify)

16. Is your organization reimbursed for preparing the Survivorship Care Plan?

☐ No
☐ Yes

17. Is your organization reimbursed for preparing the Treatment Summary?

☐ No
☐ Yes
18. Who reviews the Survivorship Care Plan and Treatment Summary with the patient?

- Physician
- Nurse Practitioner
- Nurse Navigator
- Social Work Navigator
- Lay Navigator
- Clinical nurse specialist
- Other (please specify)

19. Would you be willing to share lessons you’ve learned with other cancer programs to help them implement Survivorship Care Plans and/or Treatment Summaries?

- No
- Yes

20. What resources would help you fully implement Survivorship Care Plans and/or Treatment Summaries by 2015 (check all that apply):

- Workflow guidance
- Billing/reimbursement
- Cultural and/or linguistic translation
- Technology integration technical support
- Staff training
- Other (please specify)

21. Please share any other barriers or concerns you have to meeting the CoC 3.3 Survivorship Care Plan standard:
References