

## American Society of Clinical Oncology Statement: Achieving High-Quality Cancer Survivorship Care

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### INTRODUCTION

Over the past several decades, the number of cancer survivors has increased dramatically as a result of improved early detection of first malignancies and effective therapies. There are more than 13 million cancer survivors in the United States today.<sup>1</sup> This number is expected to reach 18 million by 2022.<sup>1</sup> These data underscore the public health magnitude of cancer survivorship and the importance of efforts to characterize and address the health concerns of cancer survivors.

Although the cancer survivorship population is heterogeneous, many survivors face distinct and serious health care issues. Cancer survivors are at increased risk for long-term morbidity and premature mortality, related directly to the cancer itself, to pre-existing comorbidities, and to exposure to therapy. The risk-benefit ratios for many of the methods of disease prevention, screening, and treatment may be shifted in survivors because cancer- and treatment-related changes can lead to premature development of age-related changes, atypical presentations of common health conditions, an increased risk of developing these health conditions, and poor response to treatments that are usually effective for these conditions. Additionally, the higher prevalence of coexisting comorbidities in the elderly may become further exacerbated because of treatment. As a result, the many patients who become survivors will require preventive and general medical care subsequent to their cancer-related care.

Cancer survivors are an important group to receive risk assessment and prevention services, and oncologists are increasingly providing counseling and services to that group. In a 2004 survey of American Society of Clinical Oncology (ASCO) members, roughly three quarters of oncologists said they believe they should be involved in the ongoing care of patients who are survivors of cancer, including general health maintenance, screening, and prevention.<sup>2</sup> However, only 60% said they feel comfortable providing these services.<sup>2</sup> The survey also suggested that oncologists define their role in cancer prevention and risk assessment quite broadly and beyond

providing services in their own practices.<sup>2,3</sup> As more patients with cancer transition back to primary care, many groups have identified the need for greater coordination of care and increased attention to health promotion and disease prevention in survivors. These organizations are looking to oncology professionals to develop a coordinated strategy for providing follow-up medical care to the growing population of cancer survivors.

As the leading medical professional oncology society committed to conquering cancer through research, education, prevention, and delivery of high-quality patient care, ASCO is committed to improving the care of cancer survivors. ASCO first established a Cancer Survivorship Task Force in 2004 to address the growing issues related to cancer survivorship. In 2005, the task force led the ASCO partnership in cosponsoring a symposium on cancer survivorship with the Institute of Medicine (IOM) to chart a course for care of cancer survivors and fill gaps in patients' long-term care. This workshop focused on implementation of the 10 recommendations contained in the IOM report "From Cancer Patient to Cancer Survivor: Lost in Transition."<sup>4</sup> An outcome of the symposium was the prioritization of several key ASCO initiatives, including development of cancer treatment plan and summary templates, establishment of the Patient and Survivor Care Track at ASCO annual meetings, development of a survivorship guideline addressing fertility preservation, inclusion of survivorship topics in the ASCO core curriculum, and publication of numerous survivorship articles in ASCO publications. Additionally, ASCO partnered with the National Coalition for Cancer Survivorship to establish the Cancer Quality Alliance in response to the IOM call for public-private partnerships to monitor and improve the care that survivors receive.

In 2011, ASCO established the Cancer Survivorship Committee to provide long-term leadership and oversight of its growing number of cancer survivorship activities. In the past year, the committee has been working with appropriate groups within and outside of ASCO to enhance the quality and quantity of initiatives

addressing cancer survivorship. The committee has developed a comprehensive agenda to assist ASCO members in the delivery of quality survivorship care. The objective of this statement is to present ASCO recommendations for improving the care of cancer survivors and the role of ASCO in this important endeavor, as envisioned by the Cancer Survivorship Committee. Specific efforts will be concentrated on developing guidance for oncology care providers on the clinical management of cancer survivors, increasing collaboration between oncologists and primary care providers (PCPs) in the provision of cancer survivorship services, improving health professional education and training, increasing patient and family education and self-advocacy, supporting research on cancer survivorship, and promoting policy change to ensure cancer survivors have access to appropriate health care services, including improving the payment environment so that adequate, uniform reimbursement for prevention counseling, interventions, and therapies is provided by payers.

It is important to note that ASCO endorses the National Coalition for Cancer Survivorship definition of a cancer survivor as starting at the point of diagnosis. However, for the purposes of this discussion, a functional definition of survivorship will be used, focusing on individuals who have successfully completed curative treatment or those who have transitioned to maintenance or prophylactic therapy (eg, individuals receiving hormonal therapy after cytotoxic therapy for breast cancer).

## CURRENT STATE OF CANCER SURVIVORSHIP

The 2005 IOM report, "From Cancer Patient to Cancer Survivor: Lost in Transition," emphasized that a lack of definitive guidance on what constitutes best practices in caring for survivors contributes to wide variation in care. Additionally, PCPs are often unfamiliar with the consequences of cancer and its treatment and seldom receive explicit survivor care guidance about potential treatment effects from oncologists.<sup>4</sup> Increased efforts are needed to raise awareness of the medical, functional, and psychosocial consequences of cancer and its treatment, to define what constitutes a quality health care plan for cancer survivors and identify strategies to implement it, and to improve the quality of life of cancer survivors through policies that provide access to necessary medical and psychosocial services.

### Need for Standardized Models of Care

Much of what is known about how long patients with cancer should be observed, and by whom, comes from pediatric cancer studies.<sup>5,6</sup> Even among adult pediatric cancer survivors, many are lost to follow-up as they discontinue services with their pediatric oncology providers.<sup>7,8</sup> Less is known about the care of survivors of adult-onset cancers who most frequently receive their care in the community, in contrast to survivors of pediatric cancers. Much of the literature is based on secondary database analyses or surveys.<sup>9-14</sup> What is clear is that as time from an initial cancer diagnosis elapses, survivors are more likely to receive care from their PCPs,<sup>14</sup> and survivors with several comorbidities receive care from multiple providers.<sup>14,15</sup> This underscores the need to coordinate care among providers. Because no uniform standards for the care of survivors exist, significant efforts are required to understand the needs of survivors and to develop models of comprehensive, coordinated care that meet those needs.

### Lack of Clinical Guidance

A major clinical barrier to standardizing survivorship care is the lack of guidance on the management of survivors with diverse cancer types treated across an age spectrum with heterogeneous approaches and modalities that continue to evolve over time. To address this barrier, an exposure-based approach has been used to coordinate pediatric survivor care that includes health screening and counseling based on the specific chemotherapeutic agents, radiation doses and volumes, and surgical procedures.<sup>16</sup> Alternative approaches include a disease-based approach that focuses on the therapeutic modalities and health concerns related to a specific malignancy (eg, breast or prostate cancer), an organ-system approach that focuses on specific organs or organ systems affected by the cancer or cancer therapy (eg, cardiovascular or pulmonary outcomes), and a symptom-based approach (eg, fatigue or sleep disturbances). Regardless of the approach that is taken, guidance on the clinical management of cancer survivors is sorely needed to address the needs of this growing population.

### Access to High-Quality Survivorship Care

As in cancer treatment, racial/ethnic and socioeconomic disparities also exist in cancer survivorship care. Lack of access to survivor care services is a major barrier to the health and well-being of cancer survivors who lack health insurance or who experience exclusions or restrictions on their policies. Although the recently passed health reform bill—the Patient Protection and Affordability Act (PPACA)—addresses many of these issues, a comprehensive, coordinated approach to cancer care is still needed to ensure access to high-quality cancer care.

From a care delivery standpoint, survivorship care has been identified as an important but non-revenue-generating service because of the limited or lack of reimbursement for significant components of the care.<sup>17</sup> This phenomenon has resulted in a misalignment of care, whereby revenue-generating services (eg, surveillance testing) may be overused, and important but non-revenue-generating services (eg, aspects that might improve coordination of care) are underused. Developing evidence-based guidelines for survivorship care will provide the quality-based underpinnings to define the right care, making the case for increased reimbursement of these services stronger. These issues must also be considered in the context of care that is typically delivered in a variety of clinical settings, which may involve oncology, primary care, and subspecialty practitioners.

### Research Needs

Increased research is greatly needed to expand the evidence base required to define optimal care delivery, including the type or components of care delivered, the manner in which that care is delivered and by whom, and the efficacy of the various models of care. Economic constraints continue to pose barriers to federal and other research investment in studies designed to explore care models and improve our understanding of the late effects among cancer survivors.

## CANCER SURVIVORSHIP AND ASCO: KEY PRIORITIES, STRATEGIES, AND TACTICS

### Guidance on the Clinical Management of Cancer Survivors

The 2005 IOM report recommended that "health care providers should use systematically developed evidence-based clinical practice

guidelines, assessment tools, and screening instruments to identify and manage late effects of cancer and its treatment.<sup>14(p5)</sup> In pediatric cancer, survivorship care has been a consistent part of care for more than two decades because of the high rates of survival in pediatric cancers and the likelihood of treatment and post-treatment follow-up in multidisciplinary centers. Long-term follow-up of pediatric cancer survivors has led to an extensive evidence base linking specific therapeutic exposures with adverse outcomes as well as data to identify at-risk groups. This evidence base has been used by pediatric cooperative groups to develop guidelines for survivorship care that include systematic plans for screening, surveillance, and prevention.<sup>16</sup>

In contrast, survivorship care after treatment of adult-onset cancers more often focuses on surveillance for cancer recurrence and does not consistently address health promotion, primary or secondary cancer prevention, or symptom management of common long-term and late effects. Because of insufficient high-quality evidence to inform recommendations for follow-up care, previous efforts to develop guidelines have been unsuccessful.<sup>18</sup> Presently, there are no standardized practice guidelines for post-therapy management of survivors with respect to early detection of long-term complications and health promotion. Clinicians need a codified set of best practices to guide them in the follow-up care of cancer survivors, individualized by disease, stage, and treatment.

To address this need, ASCO aims to optimize the long-term follow-up of cancer survivors by developing guidance for their clinical management. This guidance will be consensus based and informed by the evidence in the extant literature regarding the associations between therapeutic exposures and the specific outcomes (recognizing that many of the data do not distinguish between specific cancer diagnoses and/or age of exposure). The guidance also will be informed by the moderating influences of comorbidities, lifestyle, and exposures, again drawing on evidence from the general population or extant literature in other diseases.

As a first step, the Cancer Survivorship Committee is partnering with the ASCO Clinical Practice Guidelines Committee to develop clinical guidance for oncologists on the management of late and long-term effects. This guidance will use the newly established modified Delphi approach of ASCO for obtaining expert consensus after systematic review of the literature.<sup>19</sup> In developing this guidance, ASCO will rely on the expertise of clinicians well versed in the care of cancer survivors when developing suggested recommendations for screening of late effects, in terms of who should be screened (at-risk population), what modalities should be used (screening tests), and the frequency (intensity) and duration of screening (period at risk). These recommendations will be evaluated periodically and updated when needed to reflect any new evidence in the literature. As these recommendations are used in clinical practice, they will be refined to reflect the clinical experience gained from their usage—both in terms of the yield of the screening tests, the extent to which effective treatments are available, and the cost effectiveness of using these recommendations. This will be accomplished through ASCO quality improvement mechanisms, as described later in this article.

### **Applicability to Nononcology Settings**

It also is important that evidence-based recommendations be accessible to nononcologists and serve as a foundation to codify best practices for all survivorship care settings.<sup>4</sup> For this reason, the ASCO guidance will be designed to be applicable to all medical settings, not just the academic setting, as well as disseminated broadly for imple-

mentation on a large scale to oncologists, patients, and other providers, including nurse practitioners, physician assistants, and primary care physicians.

### **Use of Existing Nononcology-Based Guidelines**

Importantly, ASCO acknowledges that other general health guidelines and guidance exist outside of the oncology spheres that are relevant when treating cancer survivors. Oncologists might not be up to date on this guidance specifically (eg, bone health monitoring, osteoporosis prevention, exercise and diet recommendations, smoking cessation and tobacco control, and sexual and reproductive health). For this reason, encouraging adherence to relevant general population guidelines is vital.

## ESTABLISHING PROVEN, EFFECTIVE MODELS OF SURVIVORSHIP CARE

In addition to evidence-based guidelines, optimal survivorship care requires a comprehensive, multidisciplinary care infrastructure or model of care. After the release of the 2005 IOM report, Oeffinger and McCabe<sup>20</sup> provided a rationale for survivor health care and articulated a taxonomy of models of survivorship care applicable across practice settings.<sup>4</sup> Since then, there has been a rapid growth of survivorship clinics and initiatives in academic institutions as well as in community oncology practices.

### **Academic Models**

Most academic cancer centers and programs in the United States, Europe, Australia, and Canada have developed, or are in the process of developing and evaluating, various models of care. Some clinics are embedded within a specific disease (eg, breast cancer) management team; others serve survivors of different cancers. Most groups have adopted either a consultative or a longitudinal model. In the former, survivors are seen for a one-time consultation, during which a cancer treatment summary/survivorship care plan is developed, and the survivor is provided with tailored information and, if needed, referral to specialized services are made. After this visit, the survivor returns for long-term care with his or her oncologist or PCP. Clinics adopting the longitudinal model receive survivors transitioned from their oncologist, generally 1 to 5 years after completion of therapy, and then provide ongoing survivorship care.

### **Community Practice Models**

In the community setting, many oncology practices have similarly implemented survivorship clinics or expanded the services they provide. The National Cancer Institute (NCI) provides funding to 30 community cancer centers in 22 states through the NCI Community Cancer Center Program (NCCCP).<sup>21</sup> A key aim of this program is to enhance cancer survivorship care services available at community hospitals. Resources developed through the NCCCP network are made available to other community cancer programs through publications, presentations at national meetings, and through the NCCCP Web site.<sup>21</sup>

### **Integration With Primary Care**

Regardless of the survivorship care model, the PCP must be better integrated into the system. Numerous surveys have described

the general lack of knowledge and discordance in management preferences among oncologists, PCPs, and cancer survivors.<sup>13,22-26</sup> Several studies have found that cancer- and non-cancer-related preventive services are more likely to be up to date for cancer survivors observed by both an oncologist and a PCP, in comparison with care by a single provider.<sup>9-11,27,28</sup> However, there is consensus that both types of health care providers (ie, cancer specialists and PCP) are important to the long-term health of the cancer survivor and that nurses and nurse practitioners are integral to this care, both within the oncologist's practice as well as in the PCP's office.<sup>4,20</sup>

Some cancer survivors, perhaps 20%, had low-intensity cancer treatment and have a low risk of recurrence. They may have few physical problems after their cancer, experience no lasting toxicity of therapy, and have minimal risk for late-occurring health problems related to the cancer therapy. At the other extreme, some survivors have either a high risk of recurrence, severe organ dysfunction persisting well beyond the cessation of cancer therapy, or a substantially high risk of serious late effects. In the middle of this continuum are most cancer survivors, who have varying risks that are modified by their comorbid health conditions, lifestyle health behaviors and practices, and genetic predispositions. Heretofore, most cancer specialists have treated all of the above in the same fashion, an approach that results in an inappropriate allocation of finite resources. With spiraling health care costs globally, a more parsimonious approach must be taken regarding the care of cancer survivors. The notion of an oncologist observing all cancer survivors for the rest of their lives may not be the best use of resources for every patient with cancer. Models of risk are needed to stratify cancer survivors into different levels of intensity and settings for follow-up care. Components needed in such models include risk of recurrence, persistence of moderate to severe toxicity of therapy, risk of serious physical late effects, and psychosocial status.

### Shared-Care Model

Ideally, a shared-care model, using a risk-stratified approach, can take advantage of the expertise of the cancer team and the PCP in coordinating survivor follow-up.<sup>20</sup> The United Kingdom National Cancer Survivorship Initiative is integrating a risk-stratified approach in the upcoming national plans for care of cancer survivors. Using this approach, when a patient is diagnosed with cancer, he or she is referred from the PCP to the cancer specialist. The cancer specialist then communicates with the PCP, providing a written cancer treatment summary. The cancer specialist is the cancer care provider for the patient throughout the period of cancer therapy and during the time post treatment when the patient is at highest risk recurrence, while the PCP continues to deliver non-cancer-related care. On completion of therapy, the cancer specialist provides a written treatment summary and survivorship care plan to both the patient and PCP.

### Use of Treatment Summaries and Care Plans

To ensure care coordination among oncologists, PCPs, and other providers, ASCO promotes the use of written treatment summaries and care plans, which communicate the survivor's health status, provide a care roadmap to ensure survivor-appropriate services, and clearly delineate which provider is responsible for which aspect of care.<sup>4,12,29</sup> Adherence to this practice is a core measure of the ASCO Quality Oncology Practice Initiative (QOPI) and is also an American College of Surgeons Commission on Cancer Program Standard for 2012.<sup>30</sup> ASCO recommends

**Table 1.** Components of Care to Consider When Developing Survivorship Care Plans

Component
Account for the fact that some survivors may be at increased risk for other chronic diseases, such as diabetes and cardiovascular disease, <sup>3</sup> and outline methods to address this risk
Assess and address psychosocial needs <sup>31</sup>
Include information about fertility planning for patients of reproductive age <sup>32</sup>
Include known side effects (persistent and late occurring) of cancer and cancer treatment <sup>29</sup>
Include screening guidelines and symptoms of cancer recurrence, including second primaries <sup>3</sup>
Discuss and incorporate survivors' values and preferences regarding their care <sup>31</sup>
Use discussions about cancer-related concerns as teachable moments to educate survivors about behavioral changes, such as tobacco cessation, obesity control, and alcohol usage reduction, regarding a variety of health issues <sup>3,29</sup>

providers take into consideration several components of care when developing survivorship care plans (Table 1).

Quality improvement data from QOPI consistently show low use of treatment summaries and care plans. An important issue is the significant time and resource barriers to developing the summaries and care plans in the community setting.<sup>33</sup> Ultimately, the patient can be transitioned (based on a risk assessment) to the PCP, who can then integrate his or her survivorship care into a comprehensive health care and wellness program. Grunfeld et al<sup>34-36</sup> have performed a series of studies showing that this approach is effective and cost efficient in the care of patients with breast cancer who have a low risk of recurrence and are without major cancer-related problems. The Cancer Survivorship Committee is partnering with the ASCO Quality of Care Committee to assess how to increase the utility and uptake of treatment plans and summaries and what changes are needed for this to occur. One important issue to address is better integration of treatment plans and summaries into electronic health records. In this respect, development of an automated, programmable application to expedite the process of treatment planning and care plan summaries is an important goal.

ASCO recognizes there is no established framework of optimal care and transitions across the survivorship spectrum; it is committed to working with other stakeholders in the oncology community to identify and promote survivorship care models that are coordinated and interdisciplinary and fit a variety of community and care settings. To this end, ASCO has begun development of a compendium of survivorship tools and resources for oncology providers. An important component of this compendium will be capturing the different models that are being used today by oncologists, including insight from providers on the resources needed, the pros and cons of the model being practiced, and lessons learned.

Ultimately, the testing of various models through demonstration projects is needed to identify optimal methods of care, and dissemination of information and education on these models to both providers and patients will be necessary. ASCO is committed to partnering with others in the oncology community to move the field in this direction.

## MONITORING AND IMPROVING THE QUALITY OF SURVIVORSHIP CARE

Although there has been much activity devoted to survivorship care worldwide, little has been published regarding the quality of the care

delivered. Evidence-based guidelines serve as a foundation from which quality metrics can be developed, allowing for quality of care to be continuously assessed and improved while also comparing different survivorship programs or models. Metrics important to consider when assessing models of care include adherence to surveillance for cancer recurrence, screening for physical and psychosocial late effects, assessment of appropriate testing levels, coordination of care with PCPs for noncancer health care needs, cost of services, patient/clinician measures of satisfaction, and adherence to general health preventive strategies. Furthermore, interventions need to be developed, tested, and promoted to optimize the sharing of care and ongoing communication to avoid redundancy of services while ensuring that survivors have appropriate monitoring and management of late effects of their cancer therapy, including providing all patients and their providers with a treatment summary and follow-up care plan.

The ASCO quality-of-care programs, notably QOPI and its emerging rapid-learning system, CancerLINQ, are frameworks that can leverage data being collected in medical records to build an evidence base for treatment and follow-up guidelines, and model of care assessment, with the overarching goal of improving quality of care. As recommendations for the care of cancer survivors are codified and used in clinical practice, ASCO quality improvement mechanisms will be instrumental in assessing adherence to these recommendations as well as in reflecting the clinical experience gained from their usage.

QOPI is an oncologist-led, practice-based quality improvement program. Participating practices can submit medical record data, and submitted data are analyzed and reported back as practice-specific data and compared with national benchmarks to support continuous quality improvement. QOPI reports more than 100 quality measures, including a subset focused on care coordination and survivorship. Although QOPI practices are completing the treatment summary process with increasing frequency, only approximately 25% of QOPI practices currently do so, a statistic ASCO is working to improve. As ASCO releases further guidance on survivorship care, additional QOPI measures will be introduced in line with ASCO guidance recommendations. Regardless of whether a practice is involved with QOPI, ASCO encourages all oncology and PCP practices to implement quality improvement programs to monitor and improve care at the general population level.

CancerLINQ will provide a framework for the collection and analysis of real-time clinical data from a patient's electronic medical record. CancerLINQ will facilitate the translation of scientific discovery into clinical practice via evidence-based clinical decision support (including support for rare diseases and characteristics), automated quality reporting, and observational data for research purposes.<sup>37</sup> This system is well positioned to integrate patient outcomes and current physician practices into models of ideal survivorship care. As a result, it will be possible to continuously inform and update guidelines in real time as outcome data are aggregated, providing unprecedented insight into long-term outcomes for survivors.

**EXPANDING AND COORDINATING EDUCATIONAL OFFERINGS FOR MEDICAL PROFESSIONALS**

Expanding and coordinating educational opportunities for medical professionals is a key strategy toward improving overall survivorship content within education curricula and promoting the shared-care model. Cur-

rently, ASCO has several platforms to increase core knowledge of cancer survivorship and post-treatment care delivery. These include training sessions developed for the Patient and Survivorship Care Track at annual meetings, online information about survivorship issues developed for the ASCO Web site (including the treatment summary and survivorship care plan templates), inclusion of survivorship issues in the ASCO University Focus Under Forty module, and regular inclusion of special topic issues on cancer survivorship published in *Journal of Clinical Oncology* and *Journal of Oncology Practice*. ASCO also published the *Cancer Prevention Curriculum* in 2007, which described the current state of cancer prevention science and included expert insights and commentary about our current understanding of cancer prevention among survivors. Although these initiatives have been successful in increasing awareness of the unique aspects of survivorship care, there is a need for ASCO to expand its educational portfolio to keep pace with the growing body of knowledge on the prevention, diagnosis, evaluation, and treatment of late and long-term effects of cancer and its treatment and their management. Moreover, ASCO should partner with primary care organizations to provide this information to PCPs in a way that is most valuable to them.

**Integrating Survivorship Into Graduate Medical Education**

Post-treatment survivorship care, as a distinct phase of the cancer care trajectory, is a relatively new concept, and current health professional academic curricula generally do not reflect this change. Several areas have been identified as essential for survivorship care training, listed in Table 2. According to an IOM review of the curricula for medical oncology in graduate medical education programs, only some of the required content areas are currently represented.<sup>4</sup> One content area of particular importance is planning follow-up care and coordination of care in a shared-care model. Oncologists remain uncertain about whether survivors receive survivor-appropriate care once in the primary care setting<sup>13</sup>; likewise, PCPs may be anxious about caring for survivors because of their lack of involvement in and communication about their patients' care during active cancer treatment.<sup>15,26,34,36</sup> This anxiety is exacerbated when a survivor's care is transferred back to the PCP, who may be unfamiliar with follow-up and long-term care

**Table 2.** Areas Essential to Survivorship Education Curricula

Essential area
Epidemiology of incidence and prevalence of cancers and major types of cancer
General discussion of survivorship (including quality-of-life issues)
Health care systems/quality assurance/models of care
Health promotion after cancer
Pain management, sleep management
Palliative care/end-of-life care
Prevention, diagnosis, evaluation, and treatment of recurrence
Prevention, diagnosis, evaluation, and treatment of secondary cancers
Prevention, diagnosis, evaluation, and treatment of nonmalignant long-term and late-occurring complications/sequelae of treatment
Psychosocial assessment and care
Rehabilitation services
Trends and statistics in health care access
Trends and statistics in survivorship (including the interface of cancer and aging)

guidance.<sup>39</sup> Furthermore, patients often expect oncologists to be the only providers of their cancer care and express concerns about PCPs' perceived lack of knowledge in providing survivorship care. Along with its efforts to increase provider confidence in providing survivorship care via the promotion of evidence-based educational opportunities, ASCO should develop an ongoing relationship with nononcology specialty boards to collaborate in determining the specific knowledge for which these boards require proof of proficiency for certification.

### EDUCATION FOR SURVIVORS AND THEIR FAMILIES

For survivors to obtain the best follow-up care, it is vital that both they and their providers are engaged in surveillance and management of cancer-related sequelae.<sup>24</sup> In addition to educating providers, ASCO should promote efforts to educate patients and their families and support patients' efforts to discuss long-term and late effects with their providers to ensure optimal long-term health.

ASCO recognizes the need for survivors to educate themselves, their families, and even their providers on their specific health care needs. The ASCO patient education Web site, Cancer.net, has an entire section devoted to survivorship. This section includes multimedia educational platforms, such as videos, patient booklets, downloadable forms, and other educational content on a variety of topics that specifically address the needs of cancer survivors. Included in the Cancer.net content is the popular ASCO downloadable booklet on survivorship, "Cancer Survivorship: Next Steps for Patients and Their Families," which is now also available in Spanish. This booklet provides information on the medical, psychosocial, and behavioral risks and challenges patients face after completion of their cancer treatment. This material is mirrored on the Cancer.net Web site, where patients can find in-depth information on childhood survivorship, cancer rehabilitation, and late and long-term effects and downloadable treatment summary forms they can give to their providers. ASCO updates this material regularly to keep this resource timely for patients with cancer.

There is a broad array of publically available information for survivors, of variable quality, and some survivors may become overwhelmed or confused. As such, ASCO recommends oncologists and PCPs become familiar and comfortable with a few expert and reputable information resources for the purposes of patient referral, both short and long term. Table 3 summarizes information physicians should consider when referring patients to educa-

tional resources. When combined, these resources can help educate and empower survivors and their families to advocate for their best interests throughout their survivorship. Also important, providers can provide instruction on how to recognize and avoid misinformation.

### INCREASING RESEARCH TO GUIDE EFFECTIVE SURVIVORSHIP CARE

Including survivorship as part of the cancer continuum and directing efforts at improving quality of life after cancer treatment are now integral parts of the science and practice of oncology.<sup>40</sup> Investigation and discovery have produced the evidence base that has been critical to the development of care standards and guidelines designated as best practices for the treatment of specific cancers. In the same way, a rational and robust research agenda should drive the planning, evaluation, and implementation of interventions designed to enhance the quality of survivorship.<sup>41</sup> Although cancer survivorship research has increased over the last several years, the volume of cancer survivorship research is dwarfed by research devoted to cancer treatment,<sup>4</sup> which may be the result of the relatively recent emergence of the discipline and the modest levels of research support available as well as of the inherent challenges of the research itself (ie, the need for extended periods of follow-up).<sup>4</sup>

#### Identifying Knowledge Gaps

Critical to the process of research planning and prioritization is the identification of knowledge gaps. Key areas of interest include the differential and/or cumulative impact of organ dysfunction and other morbidities that develop and become clinically detectable long after the active treatment of cancer. Improved understanding of correlations between comorbidities, genetics, treatment-related exposures, and quality of survivorship is essential. The development of a research agenda requires some degree of consensus on prioritizing efforts regarding specific outcomes of interest: second cancers, organ-system toxicities, and functional status in multiple domains, including psychosocial health, premature death, and testing of therapies to ameliorate long-term and late effects. Another broad area of likely research interest and importance relates to survivorship care delivery; thus, models of care specific to patient populations and practitioner and institutional resources, preferences, and limitations require defining best practices in the context of health services research.<sup>13,42</sup>

#### Inventory of Existing Research Activity

Essential to the process of strategic research planning is the development of an inventory of existing research initiatives and activities. Given the current environment, needless duplication should always be avoided. A recent literature review and summary of survivorship research activities at NCI-designated cancer centers provide a framework and justification for assessing ongoing or recently completed, peer-reviewed, and externally funded research projects outside of the cancer centers program.<sup>43</sup> A more holistic assessment of federally funded, state-funded, and private research portfolios could prove useful in determining the scope and breadth of research in this area. As a first step in capturing a broader representation of projects, ASCO is surveying its membership with a goal of ascertaining members' perception of the importance and their personal level of interest and

**Table 3.** Patient Referral Resources and Educational Information

Resource/information
Disease-specific organizations that provide programs, services, information, and support for people with cancer and their families
National or local disability rights resources, including employment and insurance coverage rights, such as the United States Equal Employment Opportunity Commission, Cancer Legal Resources Center, and cancerandcareers.org <sup>31</sup>
National, regional, and community resources, including support groups and local affiliates of national programs <sup>38</sup>
Referrals to social workers, mental health experts, patient navigators, cancer rehabilitation specialists, and genetic counselors, as appropriate <sup>31</sup>

engagement in survivorship research. A second aim is to generate data on study questions, patient populations examined, primary and secondary end points, participating sites, sample sizes and study designs, and funding sources. Analysis of these data will help to address knowledge gaps and prioritize research efforts moving forward.

**Leveraging NCI Reorganization to Better Integrate Survivorship Research**

The current redesign and reorganization of the NCI clinical trial enterprise represent an opportunity to advance a cancer survivorship research agenda within NCI-sponsored clinical trials. This could be achieved through expansion of existing special funding mechanisms such as the Biomarker, Imaging and Quality of Life Studies Funding Program from the Divisions of Cancer Treatment and Diagnosis and Cancer Prevention. ASCO can advocate for appropriate survivorship expertise representation on each of the NCI disease-specific steering committees directed by the NCI Coordinating Center for Clinical Trials. Similarly, the Quality of Life/Symptom Management Steering Committee can be tasked with assuring that survivorship research interests are adequately represented in trials supported by the Cancer Therapy Evaluation Program and the NCI Divisions of Cancer Therapy and Diagnosis and Cancer Prevention. Embedding survivorship objectives into specific front-line treatment trials may facilitate evaluation of the effects of multiple factors including sex, age, and pretreatment functional status on long-term health. This could in turn inform the design of subsequent intervention studies within similarly treated patient populations. Evaluating similar end points across a spectrum of trials for different diseases may prove helpful in uncovering exposure relationships between other clinical variables. The cooperative group/cancer center enterprise-wide implementation of a standardized clinical data management system will simplify the data submission and management requirements, as will the development of a limited, pertinent set of data elements. When validated and standardized, these would prove useful in the setting of cross-study comparisons of treatment effects on survivorship measures of interest.

**Promoting Innovative Research Methods**

Addressing real and perceived barriers to survivorship research requires innovative approaches to clinical research methods. Given the constraints on investigator and institutional resources, consideration should be given to maximally use methods of data self-reporting by study participants. As well, a uniform treatment summary, completed at the conclusion of protocol therapy, can facilitate the capture of details to evaluate possible exposure relationships and the risk of long-term and late effects.

**ADVOCATING FOR POLICY CHANGE TO IMPROVE SURVIVORSHIP CARE**

Efforts to improve survivorship care involve not just clinical, educational, and research efforts, but also policy change to ensure access to high-quality survivorship care. Policy change at a federal level can provide a foundation and impetus for system-wide improvements, particularly relating to clinical reimbursement, federal research funding, and public health initiatives. Although not focused directly on

survivorship, the PPACA addresses many of these areas by including many specific provisions that could help cancer survivors obtain necessary care while limiting the financial burden care can impose on survivors and their families (Table 4).<sup>44</sup> Despite this progress, ASCO believes a comprehensive, coordinated approach to cancer care is still needed.

**Leveraging Opportunities in Health Reform**

Survivors and their providers should look for opportunities to leverage the provisions of the PPACA designed to assist in care coordination, such as those addressing accountable care organizations (ACOs), community health teams, and medical homes, where available (Table 4). The recent federal rule defines an ACO as a group of providers or service suppliers working together as a team to coordinate care for original Medicare beneficiaries (this rule does not apply to Medicare Advantage).<sup>45</sup> Although controversial, the new policies governing ACOs have emphasized the need for patient-centered, coordinated care. The rule also recommends that ACOs develop care plans for high-risk individuals, a strategy that holds particular promise for cancer survivors who often must see multiple specialists and providers.<sup>45</sup> ACOs also emphasize evidence-based care, which, if achieved, could assure that survivors receive quality care from their medical teams. Although these provisions of the PPACA are promising, it is important that policymakers, at both the state and federal levels, adopt safeguards to help ensure that all cancer survivors have access to adequate and affordable care. In a similar vein, a PPACA provision for community health teams provides grants for health care entities to create coordinated interdisciplinary and interprofessional teams of health care providers with the goal of working with PCPs to integrate and coordinate care for patients outside of ACOs.<sup>46</sup> The medical homes provision allows states to use existing Medicaid care structures to encourage health professionals to provide, among other services, coordinated care for individuals with chronic diseases by paying these groups at an enhanced federal matching level.<sup>46</sup> For inclusion of follow-up care of cancer survivors within the medical homes framework, it is imperative that cancer be considered a chronic disease.

**Safeguards for Access Through Adequate Coverage and Reimbursement**

One major barrier to widespread implementation of coordinated care strategies for cancer survivors is the lack of coding and reimbursement policies that adequately reflect the delivery of survivor-specific

**Table 4.** Components of PPACA Benefitting Cancer Survivors

Component
Elimination of annual and lifetime benefit caps
Elimination of copayments for select preventive services (eg, mammograms and colonoscopies)
Elimination of preexisting condition clauses for new insurance plans
Focus on delivery of high-quality coordinated care through ACOs, community health teams, and medical homes
Inclusion of screening and follow-up services included as part of the essential health benefits package
Limitations placed on allowable amounts of out-of-pocket spending

Abbreviations: ACO, accountable care organization; PPACA, Patient Protection and Affordability Act.

**Table 5.** ASCO Recommendations for Achieving High-Quality Cancer Survivorship Care

<p>Recommendation</p> <p>Clinical guidance</p> <ul style="list-style-type: none"> <li>Develop and disseminate guidance to standardize the long-term follow-up care of adult cancer survivors</li> <li>Develop evidence-based clinical practice guidelines, assessment tools, and screening instruments to help identify and manage late effects of cancer and its treatment</li> <li>Make this guidance accessible to oncology providers in all practice settings as well as to primary care providers</li> <li>Use general health guidelines/guidance existing outside the oncology sphere when providing care for cancer survivors</li> </ul> <p>Models of survivorship care</p> <ul style="list-style-type: none"> <li>Promote successful models of survivorship care and tools that optimize the transition process between oncology and primary care providers</li> <li>Promote a shared-care model for survivorship care that includes communication between the oncology specialist and PCP and successful transition of the patient from the oncology setting to primary care setting post treatment, using a risk-stratified approach as part of the survivorship care plan</li> <li>Partner with other organizations to support demonstration programs to test models of coordinated, interdisciplinary survivorship care in diverse communities and across systems of care</li> </ul> <p>Assuring high-quality survivorship care</p> <ul style="list-style-type: none"> <li>Establish standardized ways to monitor and improve the quality of survivorship care provided to patients</li> <li>Promote strategies to ensure that every survivor receives a written coordinated treatment summary and follow-up care plan and that providers are reimbursed for this service by third-party payers</li> <li>Encourage all oncology practice settings to implement quality improvement programs, such as QOPI, to monitor and improve care for all cancer survivors</li> <li>Develop quality of survivorship care measures through public-private partnerships and quality assurance programs (eg, QOPI) to monitor and improve the care that all survivors receive, and integrate these measures as key components of the oncology rapid-learning system</li> </ul> <p>Provider education</p> <ul style="list-style-type: none"> <li>Expand survivorship-related education and training opportunities for oncology providers that promote interdisciplinary, shared-care models of survivorship care delivery</li> <li>Promote the evidence-based use of survivorship care plans and other tools to increase communication, coordination of care, and provider confidence in providing survivorship care within the shared-care model</li> <li>Advocate for increased medical education curriculum funding to provide all providers (including oncologists and PCPs) access to adequate tools, resources, and knowledge to care for the growing number of survivors</li> </ul> <p>Education for survivors and their families</p> <ul style="list-style-type: none"> <li>Increase education for cancer survivors and their families about information that can affect their survivorship</li> <li>Identify and promote action-oriented messages via the ASCO patient education and communication channels for survivors on the topics of health and wellness, secondary disease prevention, and psychosocial coping</li> <li>Encourage providers to identify expert and reputable survivor referral resources for their practice, with the goal of ensuring survivors and their families are well educated and capable of advocating for their best interests throughout their survivorship</li> </ul> <p>Research</p> <ul style="list-style-type: none"> <li>Increase survivorship research and expand mechanisms for its conduct</li> <li>Assess survivorship research portfolios funded by federal, state, and private entities, identify knowledge gaps related to underrepresented patient populations and health-related outcomes of interest, and build a strategy to address these gaps</li> <li>Leverage the NCI cooperative group reorganization to advance a cancer survivorship agenda within the context of NCI-sponsored clinical trials</li> </ul> <p>Policy and advocacy</p> <ul style="list-style-type: none"> <li>Ensure that cancer survivors receive the full range of services necessary to treat their disease by promoting policies to improve the quality of survivorship care for patients and their families</li> <li>Advocate for federal and state policymakers to act to ensure that all cancer survivors have access to adequate and affordable health insurance</li> <li>Improve Medicare reimbursement to cover survivorship services provided by health care providers, including services related to surveillance, prevention, management of late effects, and care coordination</li> <li>Define a set of essential health benefits for cancer survivors, and advocate for coverage of these services</li> <li>Educate policymakers on what cancer survivorship is and why it is important, and advocate for legislation to enhance survivorship care and funding of research to improve this care</li> <li>Advocate for Congress to push the CDC, other collaborating institutions, and states to develop comprehensive cancer control plans that include consideration of survivorship care and to promote the implementation, evaluation, and refinement of existing cancer control plans</li> <li>Advocate for increased funding for survivorship research to aid in the creation of evidence-based comprehensive survivorship care guidelines</li> </ul>
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Abbreviations: ASCO, American Society of Clinical Oncology; CDC, Centers for Disease Control and Prevention; NCI, National Cancer Institute; PCP, primary care provider; QOPI, Quality Oncology Practice Initiative.

services. With the elimination of consultations from Medicare as reimbursable services, a lack of a clear reimbursement structure exists for physicians treating survivors, leading to unfair and inadequate reimbursement for these services. The Comprehensive Cancer Care Improvement Act, reintroduced to Congress in December 2011, aims to address this issue by creating a Medicare reimbursement structure for cancer care planning while authorizing funding for educating health care professionals on the development of coordinated cancer care plans and grant funding for survivorship research.<sup>47</sup> ASCO supports the Comprehensive Cancer Care Improvement Act and recom-

mends physician reimbursement for survivorship care be adequate to support robust discussion of issues with patients with cancer and cancer care planning, including medical, psychosocial, and access issues.<sup>48</sup> In addition to cancer care planning, ASCO supports Medicare reimbursement to cover survivorship services related to surveillance, prevention, and management of late effects. In an effort to identify which health care services are essential to providing optimal health care to survivors, ASCO will work with stakeholders to identify a set of essential health benefits for cancer survivors and advocate for coverage of these services.



## Education of Policymakers

Increasing policymaker awareness of cancer survivorship issues is also important to ensuring widespread support and policy implementation of key quality survivorship care provisions. Policymakers at all levels should be educated on what cancer survivorship is, why it is important, and how survivors are affecting our health care system. Congress should encourage the National Institutes of Health, the Centers for Disease Control and Prevention, and other federally funded agencies to develop comprehensive cancer control strategies that include consideration of survivorship care. Also, Congress should promote the implementation, evaluation, and refinement of existing cancer control strategies. ASCO is committed to working with policymakers to increase awareness of the unique issues of cancer survivors and the policy changes needed to improve their care.

## Research

Because the need for additional clinical evidence on survivorship care is significant, advocating for financial support of research for survivorship care is key to moving survivorship care forward. The government should fund research to strengthen the evidence supporting cancer care recommendations and guidelines. When such guidelines are supported by more robust evidence, it will become easier for patients to secure coverage for guideline-recommended treatments.<sup>48</sup> ASCO is committed to ensuring that the long-term implications of survivorship issues remain at the forefront of our national cancer care discussion, especially when considering the ever-growing population of cancer survivors.

## CONCLUSION

Through the work of the Cancer Survivorship Committee, ASCO has developed a comprehensive agenda to assist the oncology community in the delivery of quality survivorship care and maintain survivorship issues as an important focus among ASCO priorities. ASCO recom-

mendations to this end are listed in Table 5. Key initiatives of the this agenda include: development of guidance recommendations to enhance and standardize the long-term follow-up care of cancer survivors, evaluation of models of survivorship care and methods to optimize the transition process between oncology and primary care providers, expansion of educational programs related to survivorship for both practicing clinicians and graduate medical trainees, development of education for survivors and their families on issues key to their long-term health and well-being, assessment of the federally funded survivorship research portfolio and identification of gaps not addressed in current studies, investigation of methods to facilitate integration of data collection pertinent to survivorship outcomes into clinical trials, and advocacy for legislation to assure access to survivorship care and funding of survivorship research. Collectively, these initiatives aim to assure the delivery of comprehensive, coordinated post-treatment care to all cancer survivors and provide the oncology community with access to adequate tools, resources, and knowledge to implement this survivor care as well as with appropriate reimbursement to cover all aspects of survivorship care, including screening, prevention, and care coordination.

## AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The author(s) indicated no potential conflicts of interest.

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