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Number 14

Models of Cancer Survivorship Care



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Models of Cancer Survivorship Care

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Preface

The Agency for Healthcare Research and Quality (AHRQ), through its Evidence-based Practice Centers (EPCs), sponsors the development of evidence reports and technology assessments to assist public- and private-sector organizations in their efforts to improve the quality of health care in the United States. The reports and assessments provide organizations with comprehensive, science-based information on common, costly medical conditions and new health care technologies and strategies. The EPCs systematically review the relevant scientific literature on topics assigned to them by AHRQ and conduct additional analyses when appropriate prior to developing their reports and assessments.

This EPC evidence report is a Technical Brief. A Technical Brief is a rapid report, typically on an emerging medical technology, strategy or intervention. It provides an overview of key issues related to the intervention—for example, current indications, relevant patient populations and subgroups of interest, outcomes measured, and contextual factors that may affect decisions regarding the intervention. Although Technical Briefs generally focus on interventions for which there are limited published data and too few completed protocol-driven studies to support definitive conclusions, the decision to request a Technical Brief is not solely based on the availability of clinical studies. The goals of the Technical Brief are to provide an early objective description of the state of the science, a potential framework for assessing the applications and implications of the intervention, a summary of ongoing research, and information on future research needs. In particular, through the Technical Brief, AHRQ hopes to gain insight on the appropriate conceptual framework and critical issues that will inform future research.

AHRQ expects that the EPC evidence reports and technology assessments will inform individual health plans, providers, and purchasers as well as the health care system as a whole by providing important information to help improve health care quality.

We welcome comments on this Technical Brief. They may be sent by mail to the Task Order Officer named below at: Agency for Healthcare Research and Quality, 540 Gaither Road, Rockville, MD 20850, or by email to epc@ahrq.hhs.gov.

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Key Informants

In designing the study questions, the EPC consulted a panel of Key Informants who represent subject experts and end-users of research. Key Informant input can inform key issues related to the topic of the technical brief. Key Informants are not involved in the analysis of the evidence or the writing of the report. Therefore, in the end, study questions, design, methodological approaches and/or conclusions do not necessarily represent the views of individual Key Informants.

Key Informants must disclose any financial conflicts of interest greater than \$10,000 and any other relevant business or professional conflicts of interest. Because of their role as end-users, individuals with potential conflicts may be retained. The TOO and the EPC work to balance, manage, or mitigate any conflicts of interest.

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Prior to publication of the final evidence report, EPCs sought input from independent Peer Reviewers without financial conflicts of interest. However, the conclusions and synthesis of the scientific literature presented in this report does not necessarily represent the views of individual reviewers.

Peer Reviewers must disclose any financial conflicts of interest greater than \$10,000 and any other relevant business or professional conflicts of interest. Because of their unique clinical or content expertise, individuals with potential non-financial conflicts may be retained. The TOO and the EPC work to balance, manage, or mitigate any potential non-financial conflicts of interest identified.

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Models of Cancer Survivorship Care

Structured Abstract

Background: The number of cancer survivors in the United States is projected to grow to 18 million by 2020. In addition to the unique post-treatment needs faced by all cancer survivors, adult cancer survivors have an increased risk for comorbidities that result in significant care coordination challenges. Few publications have described the structure, process, or outcomes of adult survivorship care models for this growing population with complex needs. The purpose of this Technical Brief is to describe existing and proposed models of survivorship care for survivors with adult-onset cancer who have completed active treatment.

Methods: The Technical Brief integrates discussions with Key Informants and targeted searches of published and gray literature on questions of background, context, research gaps, and future research directions. We also conducted a comprehensive and systematic search of the evidence to answer questions on outcomes associated with models of survivorship care.

Results: The literature review and Key Informant information consistently indicated considerable heterogeneity in models of survivorship care, components of models, survivor populations, and target outcomes. Models of survivorship care are highly individualized to the institution or setting where they are provided. Broad-based “usual care” for survivors does not exist. Although competing considerations and incentives may lead oncologists or oncology providers in many instances to continue seeing cancer survivors long after treatment ends, anticipated shortages in the oncology workforce may require other approaches such as the expanded use of nurse practitioners and physician assistants, shared care with primary care providers, and patient navigators. Concerns associated with these alternatives include payment considerations, adequacy of training, and the potential for fragmented care. Our systematic review of the literature for the Technical Brief identified nine empirical studies of survivorship care models, covering nurse-led models, physician-led models, models in which survivorship care plan development is a key component, and individual or group counseling models. Future research is needed to explore the optimal timing of survivorship models, tailoring of models based on patient characteristics and risk factors, and key outcomes.

Conclusions: The optimal nature, timing, intensity, format, and outcome of survivorship care models continue to be uncertain. The paucity of evidence limits our ability to make conclusions about the effectiveness of survivorship care models. Further research regarding survivorship care models, focusing on issues including settings, processes and continuity of care, payments, types of health care providers involved, collaborations and communications, outcomes, and differences associated with cancer type or patient sociodemographic characteristics, is needed before recommendations and conclusions regarding model development, implementation, and evaluation can be made.

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Background

The Increasing Population of Cancer Survivors and the Challenge of Transitioning From Cancer Treatment to Followup Care

As of January 2012, the United States had nearly 14 million cancer survivors, with 59 percent ages 65 years or older.¹ The number of survivors is projected to grow to 18 million by 2022.² Survivors (that is, patients who have completed active treatment) have unique physical, psychological, social, and spiritual health needs. Even as the oncology workforce is projected to experience substantial shortages,³⁻⁵ the number and needs of cancer survivors is projected to increase.

Relative to pediatric cancer survivors, adult survivors (i.e., survivors of adult-onset cancers) are understudied.⁶ Further, their health care needs differ from those of pediatric survivors—adult survivors may have an increased risk for comorbidities, presenting unique care coordination challenges. Consequently, this Technical Brief seeks to increase knowledge regarding survivorship care models for adult cancer survivors (19 years of age or older).

Cancer survivors have unique post-treatment needs, as these individuals may have higher risks of recurrence and secondary cancers; chronic or late-occurring effects of cancer or cancer treatment; comorbid conditions that may have been exacerbated by cancer treatment; and increased likelihood of preventable morbidity and mortality that can be reduced by health promotion activities. These unique needs highlight the importance of care programs specifically tailored for cancer survivors. As described in the Institute of Medicine (IOM) report “From Cancer Patient to Cancer Survivor: Lost in Transition,”⁷ survivorship care (i.e., the delivery of health care services specifically designed for cancer survivors) ideally includes (1) prevention of new (primary) and recurrent cancers and other late effects; (2) surveillance for recurrence or new cancers; (3) interventions for illnesses secondary to cancer and cancer treatment (including physical consequences of symptoms such as pain and fatigue, psychological distress experienced by cancer survivors and their caregivers, and concerns related to employment, insurance, and disability); and (4) coordination between specialists and primary care providers (PCPs)^{*} to ensure that all the health needs of survivors are met. Although these IOM recommendations form an important framework for examining cancer survivorship care, they are largely based on expert consensus.

Developing appropriate health care programs that provide needed supports and enhance relevant outcomes for individuals with cancer following completion of acute (i.e., potentially curative) cancer treatment can be difficult. Current cancer survivorship care often involves medical oncologists or other oncology health care providers following survivors for prolonged periods after treatment ends. Such a model may or may not represent the preferred approach for cancer survivors or for oncologists. Challenges to optimal care for cancer survivors (however “optimal” is defined) may include differing perspectives, lack of communication, or lack of clear expectations among PCPs and oncologists on their roles and responsibilities in delivering

^{*} PCPs include physicians, nurse practitioners, and physician assistants.

survivorship care.^{8,9} Limited evidence exists regarding the benefits of survivorship care programs, lack of knowledge among health care providers regarding the available evidence, and lack of consensus regarding which health care professionals should provide or coordinate survivorship care. These issues may result in inadequate care coordination, leading to the duplication or omission of prevention, detection, surveillance, or treatment services.¹⁰ This fragmentation of care may have significant adverse consequences for cancer survivors, including delayed detection of recurrences, suboptimal identification of symptom causes and treatments, overutilization of resources and care delivery inefficiencies, and worse outcomes including health-related quality of life. Furthermore, survivors may feel poorly informed regarding psychological, social, and sexual health issues,¹¹ and their risk for recurrence of cancer¹² and may be dissatisfied with care following cancer treatment.¹³ Certain survivorship care models, by involving additional clinical providers in the health care for an individual, may well lead to greater fragmentation of care and potential harms, especially if communication and coordination of care are not adequately addressed among providers and patients. Recent controversies regarding potential overscreening and overtreatment for cancer may suggest that survivorship care, if not appropriately coordinated and evidence-based, could result in inappropriate resource utilization and lack of benefit for certain populations of cancer survivors. Survivorship care programs may result in “care silos” that could undermine the coordination of care for patients with multiple chronic diseases.¹⁴ All of these issues highlight the importance of developing and evaluating evidence-based survivorship care models to address the multiple health care needs experienced by cancer survivors and to coordinate health care services among this diverse population.

The challenges associated with the transition of cancer survivors to followup care may be exacerbated by the concern among PCPs about their ability to deliver survivorship care,⁸ the rapidly growing number of cancer survivors in the United States, the projected shortage of oncologists and PCPs,^{3,15} and possible changes related to the Affordable Care Act¹⁶ (e.g., the development of Accountable Care Organizations may influence where and by whom cancer survivorship care is delivered¹⁷).

Models of Care Intended To Enhance Outcomes and Provide Supports Among Cancer Survivors

An initial challenge for this project was to define a “model” of cancer survivorship care. The term “model” is frequently used in the cancer survivorship literature but is rarely (if ever) defined. Research shows general agreement that a model of survivorship care involves a broad and holistic approach to followup care for cancer survivors, addressing multiple needs. As discussed by Gilbert et al.,¹⁸ although approaches vary, all models are directed toward the common goal of improving the quality of care provided to cancer survivors by delivering comprehensive, coordinated, and tailored followup care.^{18, p.435} Survivorship has various definitions and encompasses varying stages of the cancer survivor’s experience; this report focuses only on individuals who have completed active cancer treatment and are transitioning from acute to more long-term medical care objectives.

Multiple published studies examine the effectiveness of programs addressing a single need among cancer survivors, such as support or counseling for psychological distress.¹⁹⁻⁴² For the purposes of this report, however, a program addressing a single need was not considered a model of survivorship care. Similarly, a program providing a single service to cancer survivors, such as facilitating surveillance for cancer recurrence or the development of new cancers, would not be

considered a survivorship care model. For this report, we have defined a model of survivorship care as ***a program for cancer survivors that addresses two or more different health care needs*** as a minimum threshold for a model of care.

In this report, we refer to model “components” as the four categories of survivorship care identified by the IOM report *From Cancer Patient to Cancer Survivor: Lost in Transition*,⁷ namely, prevention, surveillance, intervention, and coordination. Cancer survivors experience multiple health care needs within each of these categories. Further, multiple health care services may be necessary to address each need. To clarify this terminology, consider a program designed to provide foot care for cancer survivors. This program could involve multiple health care services, including care from orthopedists to assess and potentially treat bone and joint abnormalities, podiatrists to diagnosis problems and potentially provide treatments including orthotics, and physical therapists to recommend exercises. However, all of these services focus on a single need: foot problems among cancer survivors. This hypothetical program does incorporate multiple health care providers and services, but we would not consider it a model of survivorship care because it addresses a single need only.

Cancer survivorship care will likely not have a “one size fits all” model. Many factors may influence which model will be most effective for a given situation, such as the number and type of survivors being served; available health care providers, services, and resources; risk of recurrence and level of symptoms or ongoing problems following cancer treatment; and patient preference regarding the type and source of survivorship care. Survivorship care models will need to be tailored based on all of these factors.

Different models of survivorship care have been described; a subset of the characteristics of these models is discussed in the Guiding Questions (GQs) below. Types of survivorship care models include community-based shared-care models, academically based comprehensive survivor program models, nurse practitioner-led shared care, and multidisciplinary programs for high-risk populations.⁴³ These models are based on the providers delivering the care and the structure of the program or services being offered. For example, an academically based program may be offered for specific disease groups, although such a program may not be possible in other settings. Resources for survivors may be offered within a program or as separately available services within the community to address unmet needs. For example, a comprehensive survivorship program may offer exercise, weight management, and smoking cessation programs, or a smaller program may partner with local health clubs, exercise centers, and other organizations to offer such programs for survivors.

According to a recent report on survivorship care from the American Society for Clinical Oncology, “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.”^{44, p.2} As discussed in this American Society for Clinical Oncology report, additional research is 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.”^{44, p.2}

A number of previous studies have described different models for delivering survivorship care and summarized research efforts in this area.^{7,44,45} However, few publications have described the process or outcomes of survivorship care models, or even specified the key outcomes that survivorship care should address. Therefore, the purpose of this Technical Brief is to describe different existing and proposed models of and services for survivorship care to promote understanding of the differences in care delivery and survivor outcomes associated with

these models. The Technical Brief will also present information on studies of survivorship care models, explore the breadth of information available on these models and gaps in this literature, discuss potential issues that are important to key stakeholders, and identify areas of future research needs.

Guiding Questions

The Guiding Questions (GQs) and subquestions that we used to collect information from published studies and Key Informants (KIs) are listed below and will be explored in this Technical Brief.

1. Overview of cancer survivorship care

- What different models of cancer survivorship care have been most widely used?
- What are the components of cancer survivorship care?
- What is the nature of usual care for survivors of cancer?
- What are the potential advantages and disadvantages of these models, when compared with one another and with usual care?
- What are the potential safety issues and harms?

2. Context in which cancer survivorship care is used

- What information do patients, clinical care providers, or other decisionmakers receive about survivorship programs or components of those programs?
- How do models of care vary based on the following:
 - Setting?
 - Organizational structure?
 - Provider type and responsibilities of varying provider types in medical care for survivors, including providers involved in the patient transition from acute cancer treatment to ongoing survivorship?
 - Payment considerations?
 - Patient characteristics such as age, race/ethnicity, cancer type, stage of disease, and other risk-stratification issues?
- What associated supportive care resources are commonly incorporated in or needed for survivorship care programs?
- How is risk stratification being (or could be) applied to cancer survivor programs?
- What kinds of resources (e.g., health information technology) are available or needed to share information among health care providers and with patients?
- What are important considerations for evaluating appropriate resource utilization, cost, quality of care, and outcomes for survivorship programs?
- How widely is survivorship care offered? For how long?
- What kinds of training and staffing are required? What modifications to current training and staffing are in development?

3. Current evidence on cancer survivorship care

- Characteristics of patients enrolled (age, race/ethnicity, cancer type, stage of disease)

- Type of survivorship model, if defined
- Setting
- Organizational structure of the health care entities involved in survivorship care and in the transition from acute care treatment to survivorship care
- Provider type
- Payment considerations
- Study design and size
- Comparator used in comparative studies
- Concurrent or previous treatments
- Length of followup
- Cost and resource utilization
- Outcomes measured
- Adverse events and unintended consequences of survivorship care

4. **Gaps in knowledge and future research needs**

- What are the key decisional uncertainties?
- What are the implications of the current level of diffusion or further diffusion of cancer survivorship care, given the current state of the evidence?
- Are any models of survivorship care planned but not yet implemented?
- What are the differences between existing models of survivorship care and new and emerging models of survivorship care?
- What are possible areas of future research?

Methods

Systematic reviews require some certainty around definitional issues and a body of studies to advance understanding of important issues. Technical Briefs, by contrast, are appropriate products for nascent fields with large uncertainties around definitional issues and limited or no evidence, precisely because they focus on uncertainties in definition, context, and outcomes. A Technical Brief does not attempt to rate the risk of bias of individual studies or grade the strength of the evidence of the literature. The purpose of a Technical Brief is to provide an overview of key issues related to the intervention such as current indications, relevant patient populations and subgroups of interest, outcomes measured, and contextual factors that may affect decisions regarding the intervention. Technical Briefs integrate discussions with Key Informants (KIs), targeted searches of the published literature and gray literature, and for questions on outcomes, a comprehensive and systematic literature review. Our protocol (available at www.effectivehealthcare.ahrq.gov) describes our a priori decisions and was posted on March 29, 2013.

Discussions With KIs

In consultation with our team and AHRQ, we identified distinct perspectives that were needed to inform the development of a Technical Brief in this area. Specifically, we sought to recruit the following as KIs: patient advocates, clinical providers (i.e., oncologists) offering survivorship services, primary care providers, nurses, policymakers, management and administration, financing and reimbursement, and researchers.

The KIs were particularly useful for shaping the Technical Brief because little empirical evidence exists about a gold standard model of survivorship care. The KIs contributed to understanding which components of the models are in current use and considered to be most effective across cancer types, where the models might fit into clinical care, and what the potential advantages or concerns are related to developing and implementing these models. Specifically, responses to GQs 1, 2, and 4 are based largely on KI discussions.

The 10 KIs that the Evidence-based Practice Center (EPC) interviewed represented various fields of expertise related to cancer survivorship: patient advocacy (n=2), policy (n=3), management and administration (n=2), financing and reimbursement (n=1), primary care (n=1), and research (n=4); some KIs represented multiple fields of expertise, including oncology practice. Others had personal experience as cancer survivors. More detail about the KI process is available in Appendix A.

Gray Literature Search

GQs 1, 2, and 4 listed above primarily relied on information from published narrative reviews and information in the gray literature. We used the gray literature (i.e., literature outside the peer-reviewed literature) to identify additional model components that are in piloting stages or not yet fully implemented. We identified 118 nonduplicated citations from the gray literature search.

Published Literature Search

Criteria for Inclusion/Exclusion of Studies in the Review

Table 1 lists the inclusion and exclusion criteria in our protocol. Although survivorship encompasses varying stages of the cancer survivor's experience, to try to eliminate any competing effects of active treatments, this report only includes studies of individuals who completed active treatment. Our preliminary inclusion criteria did not constrain included studies based on the comprehensiveness of the services offered. We included all studies that offered at least one of the four core Institute of Medicine (IOM) survivorship care components. During the literature review process, we identified numerous studies that addressed single needs of patients following cancer treatment. Our conversations with the KIs and our review of the literature in parallel led us to map our inclusion more closely to the construct of care coordination underlying models of survivorship care. We included studies that addressed multiple patient needs of one patient and excluded those that addressed single patient needs of one patient, regardless of whether single or multiple provider service(s) were offered. We further clarified categories of interventions as serving the following:

1. Multiple patient needs and multiple providers' services *or* multiple patients' needs and a single provider service. We included these studies for review.
2. Single patient's needs and multiple providers' services. (Eleven studies were excluded as "single need-multiple provider.")^{34-42,46,47}
3. Single patient need and single provider service. (Twenty-three studies were excluded as "single need-single provider.")^{19-33,48-55}

We added this construct to our inclusion criteria by requiring two or more service(s) for survivorship care within one or more of the four core IOM survivorship care components (prevention, surveillance, intervention, and coordination) intended to facilitate survivors' experience.

Table 1. Eligibility criteria for published studies of survivorship care

Criterion	Inclusion	Exclusion
Population	<ul style="list-style-type: none"> • Ages 19 or older • Survivor of adult cancer (any cancer type) • Currently in remission with no evidence of disease • Completed acute treatment 	<ul style="list-style-type: none"> • Ages 18 or younger • Adult survivor of childhood cancer • In relapse at enrollment in a survivorship study • Individuals with metastatic cancer
Intervention	<ul style="list-style-type: none"> • Two or more service(s) for survivorship care within one or more of the four core IOM survivorship care components (prevention, surveillance, intervention, coordination) intended to facilitate survivors' experience • Formal referrals to service(s) that facilitate survivors' experiences 	<ul style="list-style-type: none"> • Treatment with curative intent • Studies of a single service • Studies that provide information only on patient characteristics associated with using survivor services

Table 1. Eligibility criteria for published studies of survivorship care (continued)

Criterion	Inclusion	Exclusion
Comparator	<ul style="list-style-type: none"> Active comparison with other survivorship care models Active comparison of components of survivorship care Usual care No comparator (for case series) 	<ul style="list-style-type: none"> None
Outcomes	<ul style="list-style-type: none"> Any patient outcomes related to the survivorship care model Intermediate patient health outcomes Morbidity Mortality Quality of life Satisfaction with care Cost and resource utilization Adverse events 	<ul style="list-style-type: none"> Outcomes attributable to the cancer treatment (except for adverse events and other long-term consequences potentially resulting from cancer treatment) Outcomes among health care providers
Timing	<ul style="list-style-type: none"> All timing related to the start of survivorship care 	<ul style="list-style-type: none"> None
Setting	<ul style="list-style-type: none"> All care settings 	<ul style="list-style-type: none"> Acute inpatient care
Study design	<ul style="list-style-type: none"> Systematic reviews Randomized controlled trials Nonrandomized controlled trials Prospective and retrospective cohort studies Case-control studies Case series 	<ul style="list-style-type: none"> Case reports Opinions Commentaries Nonsystematic reviews^a Letters to the editor with no primary data
Other	<ul style="list-style-type: none"> English language 	<ul style="list-style-type: none"> Non-English language

^a Nonsystematic reviews may be used to inform our responses on GQs 1, 2, and 4.

Abbreviation: IOM = Institute of Medicine

Searching for the Evidence

We systematically searched, reviewed, and analyzed the available information for GQ 3 through August 22, 2013. We then reviewed studies identified as being of potential relevance for GQ 3 and for potential relevance to the other GQs. To identify articles for this review, we conducted focused searches of PubMed, CINAHL, Cochrane Library, EMBASE, and the gray literature sources. We scanned the reference lists of systematic reviews that are pertinent but do not meet inclusion criteria to identify studies that should be considered for this review to address GQ 1, 2, or 4 as background information. We reviewed each study identified through these “hand-search” processes against the a priori inclusion and exclusion criteria described in Table 1.

Data Abstraction and Data Management

We developed forms for the initial inclusion/exclusion process at the title/abstract and full-text review stages. Appendix B lists the sample forms used at both stages. After pilot testing and training team members, we used the forms to screen titles, abstracts, and full reviews and to gather information about study characteristics and the PICOTS (Population, Intervention, Comparator, Outcomes, Timing, and Setting) of each study.⁵⁶

Two members of the research team independently reviewed all titles and abstracts identified through the published and gray literature searches against our inclusion/exclusion criteria. Reviewers categorized the studies according to relevance by GQs. All studies relevant to GQ 3 marked for possible inclusion by either reviewer underwent full-text review. For studies relevant to GQ 3 without adequate information to determine inclusion or exclusion, we retrieved the full text and then made a determination. We tracked all results of the review in an EndNote® database (Thomson Reuters, New York, NY).

We team retrieved and reviewed the full text of all studies relevant to GQ 3 included during the title/abstract review phase. Two members of the research team independently reviewed all studies relevant to GQ 3 for inclusion or exclusion on the basis of the eligibility criteria described earlier and considered the appropriateness of each study in this group for the other GQs. If both reviewers agreed that a study did not meet the eligibility criteria, the study was excluded. If the reviewers disagreed, conflicts were resolved by discussion and consensus or by consultation with a third member of the review team. We team tracked all results in an EndNote database noting the reason that each excluded full-text publication did not satisfy the eligibility criteria. Appendix C provides a comprehensive list of such studies by their exclusion reason.

We then designed evidence table data abstraction forms to gather pertinent information from each article, including characteristics of study populations, interventions, comparators, outcomes, study designs, settings, and methods. For studies that met the inclusion criteria, the reviewers abstracted relevant information from each article into summary tables using the evidence table abstraction form. All data abstractions were reviewed for completeness and accuracy by a second member of the team. Appendix D includes complete evidence tables. Appendix E provides a glossary of terms.

Data Synthesis

To be consistent with the purpose of the Technical Brief, we did not conduct an analytic synthesis such as a meta-analysis but provides a summary of the evidence for each GQ in the following section. We considered the models used, study design, analytic methods, and the similarities and differences of included patients according to sociodemographic factors (e.g., age) and classified type of cancer detailed in the Findings.

We integrated data from the published literature with information from the gray literature and discussions with KIs. Because of the paucity of evidence, the responses to GQs 1, 2 and 4 were primarily informed by information from discussions with KIs and secondarily by published literature and gray literature or nonsystematic published reviews. When empirical evidence was not available, we focused on KI perspectives, even if these perspectives were based on individual experience and anecdote rather than empirical evidence. Responses to GQ 3 were primarily based on peer-reviewed, published literature and combined with information from the gray literature.

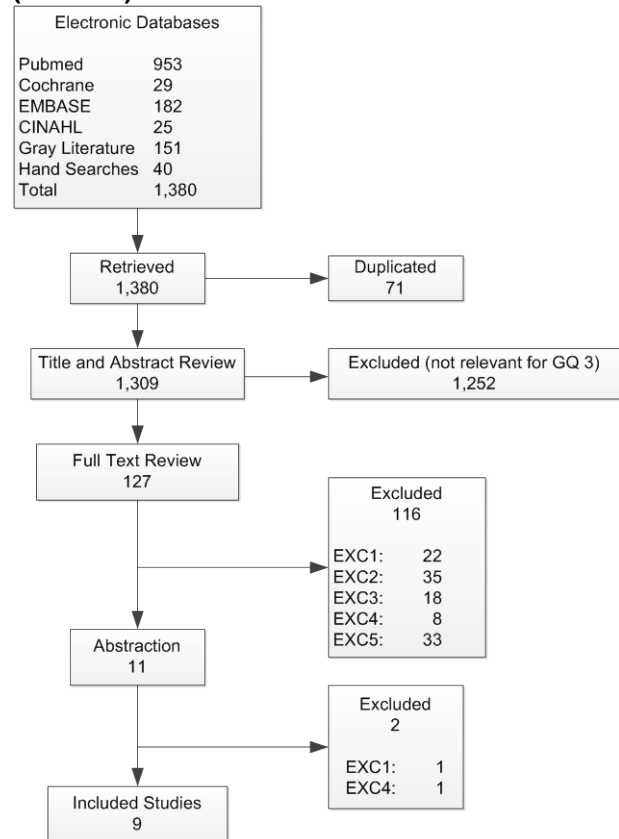
Peer Review and Public Comment

The draft report was available for peer review and public comment at www.effectivehealthcare.ahrq.gov from August 9, 2013 to September 5, 2013. Five individuals or organizations offered public comment. In addition, 15 peer reviewers provided us with feedback on the draft report. We revised the report in response to these comments where appropriate.

Findings

The findings from the literature search are presented in the order of the Guiding Questions (GQs) and qualitatively summarize findings from gray literature searches and interviews with Key Informants (KIs). For questions with empirical evidence or in-progress studies to inform the results, cross-cutting tables describe the state of evidence on study characteristics (e.g., number and types of study designs addressing each survivorship model or component), intervention characteristics, and types of outcomes planned or presented for each survivorship model. Figure 1 describes the number of studies at each stage of the literature search and review process that we identified for GQ 3 and the resulting studies for background (GQs 1, 2, and 4) included from this group. Appendix A lists the PubMed search terms. Appendix C lists the full exclusion reasons for exclusion codes EXC1-5. These studies describe models of survivorship care and are completed or in progress.

Figure 1. Survivorship preferred reporting items for systematic reviews and meta-analyses (PRISMA)



GQ 1: Overview of Cancer Survivorship Care

Models of Cancer Survivorship Care

As discussed in the Background section, although the term “models” is frequently used for survivorship care programs, this term is rarely defined. Similarly, although the cancer survivorship care literature identifies or describes a wide variety of models, no commonly accepted taxonomy exists. Although these categories are neither exhaustive nor mutually exclusive, we found that authors have generally focused on the type of survivors for whom care is being provided, the setting of care, the type(s) of clinician providing care, or the purpose of the survivorship care program. Models categorized by the type of survivor receiving care are described as either disease-specific or general.^{57,58} McCabe and Jacobs⁵⁸ describe a model specific to breast cancer as a means of meeting the needs of breast cancer survivors posttreatment. In this disease-specific model, directly after treatment ends, oncology nurses and physicians identify issues that survivors may experience (e.g., lymphedema, fatigue, psychological distress, difficulty returning to work) and provide an organized set of services to address these issues. By contrast, for a general survivorship model, nurse practitioners, oncologists, or primary care providers (PCPs) typically collaborate to provide care to survivors of all types of cancers. Both models may include a treatment summary, a care plan, or referrals for services not provided by the survivorship program.

Models categorized by setting of care generally focus on the difference between those based in “separate” survivorship clinics versus “integrative” models.^{57,58} Survivorship clinic models involve care for cancer survivors provided in a setting other than where the cancer treatment care was received. The setting for some survivorship clinic models may be referred to as a “consultative clinic” when a survivor is referred for a single survivorship visit. By contrast, as the name suggests, integrative models integrate survivorship care into broader oncology practice. In the integrated model, a team of health care providers may oversee survivorship care. A systematic review found that cancer survivors benefit from coordinated transition planning.⁵⁹

Models that are classified based on type of clinician providing care include physician-, nurse- or nurse practitioner-led models, and models led by other types of health care providers. In addition, models may be led by a care team, with different types of providers taking the lead for different aspects of survivorship care. In section GQ 3 below, we describe and compare clinical provider-led models in more detail.

Finally, survivorship care models may be classified based on the purpose of the survivorship care program. An example is the “transition to primary care” or “transition clinic” model.^{57,58} As the name suggests, the focus of this model is to transition cancer survivors away from care provided by oncologists and back to care provided by PCPs. This may involve a risk-based approach, where survivors are transitioned back to PCPs only when their risk for recurrence or late effects of cancer or cancer treatment is low. Another purpose-based classification is the multidisciplinary coordination model, characterized by clinical providers such as nurse navigators coordinating care for survivors across multiple providers.^{58,60} In other models, a key component is the development of a survivorship care plan (SCP) that can be provided to cancer survivors and potentially shared with their other health care providers (such as PCPs). Section GQ 3 describes examples of models in which SCPs are a key component.

The classifications for cancer survivorship care models described above are not exhaustive: other models may exist. Further, this classification is not mutually exclusive. The lack of a

consistent and agreed-upon classification schema for survivorship care models results in increased challenges for comparing structures, processes, and outcomes across different models.

In addition, the literature provides little information on frequency of use of models. One study identified several models of cancer survivorship care among eight LIVESTRONG Survivorship Centers of Excellence, including disease-specific clinics, separate survivorship clinics, and integrated models.⁵⁷ One systematic review listed disease-specific clinics, general survivorship clinics, consultative clinics, multidisciplinary clinics, integrated care, and transition to primary care models among the models examined.⁵⁸

In response to an open-ended question about what models of survivorship care have been widely used, the four KIs commenting on this question echoed the literature: they suggested a wide variety of models exist, but little information regarding the prevalence of use is available. One KI listed three models in his organization: a group-visit model for breast cancer survivors; a model involving an individual, one-time consultation with multiple providers for breast cancer survivors; and a model involving an individual, one-time consultation with multiple providers for adult survivors of childhood cancers. Another KI described a model where care continues to be provided by an oncologist after treatment is complete and a model that involves an oncology medical home. Two other KIs indicated that no single or most widely used model of cancer survivorship care exists. In practice, they said, models of survivorship care are highly individualized: the kind of survivorship care that a survivor receives depends on the relationship between the provider and the survivor, as well as the survivor's risk associated with the disease (e.g., late toxicity).

Components of Cancer Survivorship Care

As noted earlier, the Institute of Medicine (IOM) identified four essential components of cancer survivorship care: prevention of recurrent and new cancers, and of other late effects; surveillance for cancer spread, recurrence, or second cancers, and assessment of medical and psychosocial late effects; intervention for consequences of cancer and its treatment (e.g., medical problems such as lymphedema and sexual dysfunction; symptoms, including pain and fatigue; psychological distress experienced by cancer survivors and their caregivers; and concerns related to employment, insurance, and disability); and coordination between specialists and primary care providers to ensure that all of the survivor's health needs are met.⁷ In later sections of this report, we evaluate the extent to which empirical studies of survivorship care address these components.

A consensus exercise conducted by the LIVESTRONG foundation similarly identified a survivorship care plan, screening for new cancers and surveillance for recurrence, a care coordination strategy, health promotion education, and symptom management and palliative care as essential elements for which all medical settings must provide direct access or referral.⁶¹ The panel also identified other elements of care that medical settings should provide or elements for which to strive.

Several observational studies that assess the relationship between models of cancer survivorship care interventions and processes of care and/or outcomes contribute to this literature by describing components of the models.^{30,35,60,62,63} For example, one study assessed a model that involved a contract discharging survivors from an oncology clinic during a final visit.³⁵ Other studies assessed interventions targeted at coordination and prevention that included SCPs, end-of-treatment consultation, followup phone calls, exercise, rehabilitation,⁶⁴ counseling, and informational resources.^{30,62,63} KIs emphasized surveillance and intervention components as being critical to survivorship care. Specifically, one KI noted that SCPs were essential in

implementing ongoing surveillance and monitoring of cancer survivors. For the intervention component, KIs also noted that interventions should address patients' physical and emotional needs, address the needs of family caregivers and prevention efforts, and be designed based on patients' risk assessment for recurrence and late effects. Some KIs also highlighted the importance of offering these components across the continuum of care and ensuring that patient empowerment and engagement is an underlying principle for each.

A survey of administrators and clinical providers from Cancer Research Network sites¹⁴ highlighted the need for survivorship care programs to address fear of recurrence, provide information about long-term effects of treatment, offer nutritional and exercise guidance, provide additional psychosocial support, and help survivors understand how to manage and coordinate their followup care.

Nature of Current Clinical Practice for Survivors of Cancer

One observational study assessed cancer survivorship care in LIVESTRONG Survivorship Center of Excellence sites.⁶⁵ Self-reports of survivors ages 18 to 39 indicated that 71 percent attended an oncology survivorship clinic at the time of the survey, 48 percent reported that they did not have a treatment summary, and 55 percent reported that they had not received an SCP. Seventy percent reported that an oncologist was the "most important" provider for test and treatment decisions; 10 percent reported receiving care in a "shared-care model" that involved both PCPs and oncologists. In another study, survivors who were diagnosed with cancer as young adults (1839) reported a lack of age-specific survivorship care, such as fertility treatment; family, couples, and sexuality counseling; and assistance with reentry into the workplace.⁶⁶ Health care professionals in cancer centers and general practices in the United Kingdom reported viewing current survivorship care as reactive, focused on acute care, and incompatible with recommendations to provide proactive care.⁶⁷

At least 17 guidelines for survivorship care exist.^{36,68-81} Guidelines vary in type of cancer (breast, prostate, lung, colorectal, and rectal) and the components of cancer survivorship care addressed. Most guidelines addressed surveillance (i.e., routine followup care and screening), but only five addressed prevention (e.g., proper nutrition and increased physical activity).^{69,70,72,75,82} Similarly, only nine guidelines^{44,70-72,74,75,78,80,81} addressed coordination. For example, one guideline⁷² recommended coordination between PCPs and oncologists (i.e., shared-care model). Two guidelines recommended interventions such as the expansion of evidence-based research; survivorship education for health professionals, patients, and their caregivers; and the use of SCPs.^{44,72}

The themes that emerged from the KI interviews suggest that current clinical practice for cancer survivors reflects the variation across guidelines. First, KIs described current clinical practice as disjointed, uncoordinated, and highly varied. KIs described resources for cancer survivors including psychosocial support, assistance returning to the workforce, surveillance efforts, and prevention initiatives; however, KIs emphasized that these resources were uncoordinated and varied across cancer survivors and within cancer programs. One consequence of this lack of coordination that KIs identified was lack of clarity about roles and responsibilities among providers of cancer survivorship care. KIs suggested that a consequence of this lack of clarity about roles is the over- and underuse of surveillance testing. One KI summarized the theme of lack of coordination:

...[Current clinical practice] is still quite a hodgepodge although there is a lot of discussion about a more formal plan about how individuals should be followed once

they complete treatment and it's focused on recurrence. Also, the duration of followup is also very haphazard; there is no risk-based approach for how long people need to be followed by their oncologists. The testing that is done as part of this surveillance for recurrence is also extremely variable and physician-dependent, in part because there hasn't been guidance or guidelines developed until recently. There is beginning to be some, not evidence-based, but consensus-based ways of approaching this. Many people are trying various models that fit into their own practice settings. The models are being utilized and implemented based on feasibility of staff and finances, but not any outcome data.

A second theme that emerged from KI interviews related to challenges to coordinating care for cancer survivors. Challenges included providers' lack of confidence in providing survivorship care, financial incentives that discouraged survivorship care coordination, and ineffective integration of survivorship care into cancer treatment. One KI described the influence of the Centers for Medicare and Medicaid Services' (CMS') decisions on cancer survivorship care. This KI noted that unless CMS includes a service in a benefit category, the service will not be covered. Many features of optimal cancer survivorship care are not covered currently. For example, the IOM recommended SCPs as an important feature of optimal care, but providers are not reimbursed for counseling or time spent on developing an SCP. Another KI suggested that care coordination, one of the four dimensions of survivorship care identified by the IOM, is obstructed by lack of integration into cancer treatment. The KI indicated that lack of integration of survivorship care into cancer treatment has resulted in many providers and survivors viewing survivorship care as an optional supplement to treatment, not a cohesive stage of their care.

A third theme relates to new approaches to cancer survivorship care (e.g., patient navigation, consultative models, oncology medical homes, SCPs). These approaches have emerged to address the variation and lack of coordination that is characteristic of current clinical practices for cancer survivors. Some KIs acknowledged that uptake of these approaches has been poor.

Potential Disadvantages and Harms of Survivorship Care Models

Potential advantages and disadvantages of cancer survivorship care models compared with one another were not described in the literature or by KIs.

As described above, KIs described a lack of comprehensiveness and coordination among resources for cancer survivors. Many of the advantages of new models of cancer survivorship care address concerns related to current clinical practice. For example, some models address needs that are often not addressed in current clinical practice, such as integration back into the workforce and psychosocial issues, and they aim to prevent and detect new cancers or other chronic diseases more effectively and efficiently than current clinical practice.

KIs identified several disadvantages associated with new models of cancer survivorship care. Some disadvantages were logistical. Two KIs suggested that current financial regulations disincentivize new models. One KI suggested that oncologists have financial incentives to continue to care for cancer survivors. As noted earlier, CMS does not cover services that might be included in new models. Another logistical disadvantage of new models was their lack of integration into existing models of cancer treatment: One KI suggested that providers and survivors view survivorship care as an optional supplement to treatment, not as a cohesive stage of their care. Consequently, the KI suggested that cancer survivors may decide not to participate in new models of survivorship care.

A second category of disadvantages is related to the shift in practice patterns or clinical knowledge that may be needed for providers to accept new cancer survivorship care models. Two KIs suggested that some PCPs, who have a central role in many new models, are not confident in their ability to provide cancer survivorship care. Likewise, some oncologists question PCPs' ability to provide cancer survivorship care. Another KI suggested that providers of usual care for cancer survivors may feel threatened by new models. A third disadvantage of new models that KIs identified was their low levels of uptake, outside of early adopters.

KIs identified the following potential safety issues or harms associated with cancer survivorship care models: insufficient surveillance, intervention, and coordination; the risk of fragmentation of care with alternative approaches (e.g., models such as shared care that are intended to improve care coordination could result in care fragmentation if roles are not clearly delineated); and the risks of poorly managed latent effects due to the lack of adequate followup and coordination with current models of care.

In a survey of administrators and clinical providers from Cancer Research Network sites,¹⁴ some respondents indicated that survivorship-specific care might not add to other care already provided in oncology or primary care settings. Respondents further indicated that survivorship care programs may result in "care silos" that could undermine coordinating care for patients with multiple chronic diseases.

GQ 2: Context in Which Cancer Survivorship Care Is Used

Choice of and Information on Survivorship Programs

Although studies describe information needs among survivors, we found no studies that commented on whether patients and clinical care providers are informed of multiple programs and how they choose among survivorship care programs. The little information available suggests that patients are offered few choices, if any. Even treatment summaries, which can serve as a foundation for survivorship planning, are not commonly distributed. One mixed-methods study including a survey and focus groups of survivors of endometrial cancer in Canada found that only 23 percent of survivors had received some sort of treatment summary.⁸³

Input from KIs provided context for our inability to find studies on how patients and providers access information on and choose among survivorship care programs. KIs observed that patients do not really have choices regarding survivorship programs. Their clinical providers may be unaware of services or unable or unwilling to provide services even if patients should request it. Even when they do receive services, usually the patient's insurance decides where they go. If insurance companies do not make the decision, one KI suggested that the family decides, not the patient themselves. Another KI offered the example of adult children selecting care for older patients based on their own relationship with a hospital or a provider rather than the patient's relationship.

Sources of Variation in Survivorship Care

Organizational Structure and Setting

Although reviews of models of care noted settings in which these models had been implemented,⁵⁸ no study described how models might vary based on organization or setting. One study reported qualitative data suggesting that in integrated health delivery settings, a distinct survivorship care program may not be needed or seen as beneficial.¹⁴ In the absence of empirical

evidence, we describe anecdotal insights from KIs regarding potential variations by organization and setting.

One KI noted that “institutional flavors” of survivorship care exist. One KI suggested that variation across institutions is likely to be much greater than variation across providers and that no approach appeared to be evidence-based.

Regarding setting, one KI felt that community-based and online providers of survivorship-related resources tend to be related to wellness. The mismatch between resources and needs also emerged in KI interviews. Settings in rural areas have fewer resources but great need, and the onus for care coordination in such settings gets shifted onto the patient.

Provider Responsibilities and Type

One survey of concordance among patients, oncologists, and primary care providers found the greatest discrepancy between oncologists and primary care providers.⁸⁴ KIs and published studies⁴⁴ noted that substantial provider-to-provider variability in responsibilities exists, in part because the evidence base providing direction on what to do (as opposed to what not to do, such as ordering unnecessary scans) is weak. A survey of colorectal cancer survivors suggests an additional explanation in the variation in responsibilities and actions, namely that patient needs may differ. Survivors seen by most primary care providers were more likely to have three or more medical comorbidities than survivors seen by subspecialty physicians.⁸⁵

Regarding provider type, KIs echoed concerns in the literature about the impending shortage in the oncology workforce to address the needs of growing numbers of survivors,^{3,15} although, as one KI noted, community oncologists like to continue to see survivors because “it keeps them sane,” to balance their case load of severely ill patients with a poor prognosis with cancer survivors. A qualitative study supports this perspective, noting that oncologist “feel protective of and possessive of some patients”.^{86, p. S462}

The pending workforce shortage in oncology points to the need for nurse practitioners and physician assistants. KIs noted that patients view nurse practitioners as extensions of the oncologist and trust them. Regarding patient preferences for provider roles in survivorship, a survey of adult cancer survivors identified from hospital databases and clinic lists at a regional cancer center in Sheffield, United Kingdom, suggested that regardless of cancer type, cancer survivors preferred consultant-led (i.e., oncologist or other specialist) care to nurse-led, telephone, or general practitioner-led care.⁸⁷ A study of breast cancer survivors in the United found similar results when patients were asked about the effect of various followup visits on cancer-related worrying: visits with oncologist significantly decreased the odds of worrying compared with visits with primary care providers.⁸⁸

A possible explanation for the stated preferences for consultants might be patients’ preference for continuity of care and the value that survivors place on their relationship with specialists who treated their cancer.⁸⁹ Although survivors were receptive to the idea of greater involvement of their general practitioner in followup care in shared care with an oncologist⁸⁹ as well as nurse-led care,^{89,90} they noted concerns about lack of specialized training. Additionally, they expressed some concerns about reluctance on the part of primary care practitioners to take on survivorship care. This view is confirmed by a qualitative study of primary care practitioners themselves who note concerns with lack of access to information and poor communication with oncologists, the complexity of needs of survivors, and medical-legal implications of providing oncology followup.⁸⁶

A survey of primary care providers in Canada found willingness on the part of the participants to take on exclusive care of survivors but noted the need for a patient-specific letter from the specialist, printed guidelines, expedited routes of re-referral, and expedited access to investigations for suspected recurrence.⁹¹ A structured review of followup of breast cancer patients found evidence that general practitioner-led care is as effective as specialist care, but this review was evaluating empirical evidence of patients attending a routine followup service after treatment rather than broader survivorship care services.⁹² The review was based on studies from numerous countries including the United States, but the extent to which these findings vary by geographic setting is unclear. Likewise, the implications of these findings in a setting with predicted shortages in PCPs are also unclear.

Some KIs suggested that a shared-care model offers the greatest promise in common instances where community PCPs feel ill equipped to assume total care for cancer survivors. They noted that expecting PCPs to remember recommendations for all types of cancers is not realistic. Other KIs struck a note of caution regarding the shared-care model, noting the risk of fragmentation of care, lack of clarity about roles and responsibilities, and unnecessary tests.

A study of trends in followup and preventive care for colorectal cancer survivors found increasing numbers of visits to all physician types; these trends were statistically significant for oncology specialists and other physicians, but not primary care providers.⁹³ We did not see evidence that the increase in physician visits was accompanied by a shift in visits from specialists to primary care practitioners: one study of a convenience sample of young adult cancer survivors, recruited through the LIVESTRONG Survivorship Centers of Excellence Network, suggests modest anticipated changes in provider types. The majority (70 percent) of the convenience sample considered their oncologist as the doctor in charge of the most important treatment or test decisions. This sample included patients with very variable median time since diagnosis from 7 to 328 months. As many as 69 percent anticipated they would continue to rely on their oncologist for the next 6 months. Only 10 percent relied on a shared-care model as the approach addressing the most important treatment or test decisions, and the proportion expecting to continue to rely on shared care in the upcoming 6 months declined to 5 percent. The proportion relying on a PCP at the time of the survey was 4 percent; 10 percent anticipated relying on PCPs in the upcoming 6 months. Multivariate analysis suggested that the model of care was not a significant predictor of the level of confidence young adults had in managing survivorship care.⁶⁵

Payment Considerations

A fundamental constraint to financial feasibility of offering survivorship care is the cost of preparing treatment summaries and SCPs.⁵⁷ In addition to the issue of reimbursement for SCPs, coverage for clinical services can be a problem.⁵⁷ Several KIs, including clinical providers and patient advocates, also noted the difficulty, from the provider's perspective, in providing a financially sustainable model of care. In some cases, the reimbursement structure is such that oncologists may express interest in providing survivorship care, but they "always say they don't get paid for [SCPs] and it takes a lot of time." Therefore, to provide proper survivorship care or to transition the patient is difficult financially. One study also reported that the availability of resources, particularly in specialized clinics, as well as patient financial concerns and insurance reimbursement, were challenges to providing survivorship care.¹⁴

KI interviews also suggested some differences in the perception of the willingness of insurance companies to pay for such care. Some KIs suggested that most insurance (with the

exclusion of high-deductible insurance) would typically cover such services, but one clinical provider suggested that insurers were unlikely “to step up because there’s nothing in it for them. There’s no money involved.”

Nonetheless, KIs were in broad agreement that survivorship care services were not expensive. Several KIs focused on the enormous attention to and costs of treatment relative to survivorship care, with one KI asking, “Why do we dump all this money into treatment if we let patients fade out at end?”

Patient Characteristics Such as Age, Race/Ethnicity, and Cancer Type, Stage of Disease

Patient characteristics may predict interest in and uptake of survivorship care in addition to patient needs for survivorship care. Available literature and KIs suggest that the type of cancer may influence interest in and variation in survivorship care models. Following the launch of an Internet-based tool for the creation of SCPs, an evaluation of users found that breast cancer represented the most commonly reported primary cancer diagnosis (over 45 percent), followed by hematologic, gastrointestinal, gynecologic, and genitourinary malignancies.^{94,95} Likewise, the type of cancer may influence interest in specific services. In focus groups of self-selected participants, the breast cancer focus group in particular expressed a need for more spiritual support during active treatment and followup care.⁹⁰

KIs also identified age, race, socioeconomic status, and insurance status as key variables that might influence survivorship care needs. In a convenience sample of young adult cancer survivors recruited through the LIVESTRONG Survivorship Centers of Excellence Network, multivariate analysis showed that minority racial status and lacking a followup SCP were associated with greater odds of low confidence in managing survivorship care.⁶⁵ A survey of cancer survivors identified through the Pennsylvania Cancer Registry found that age, number of comorbidities, income, stage of disease, and the interaction between age and number of comorbidities predicted the level of unmet need.⁹⁶

Associated Supportive Care Resources Needed in Survivorship Care Programs

The literature on supportive care needs varies by the type of cancer survivors (younger adult,⁸⁷ cancer survivors with preexisting cardiopulmonary disease,⁹⁷ gynecological cancers,⁹⁸ breast cancer survivors,^{89,99,100} and patients from the Pennsylvania Cancer Registry⁹⁶). These studies include a range of data sources, including registry-based studies;^{11,96,101} a survey of cancer survivors identified from hospital databases and clinic lists at a regional cancer center in Sheffield, United Kingdom;⁸⁷ a secondary analysis of the LIVESTRONG survey of self-selected respondents from partner organizations and cancer coalitions of the Lance Armstrong Foundation;⁹⁷ several qualitative studies with cancer survivors in Australia,⁸⁹ New Zealand,⁹⁸ and the United States;^{100,102} and a literature review of qualitative and quantitative studies of patient perspectives.⁹⁹

Registry-based studies consistently show that survivors have significant unmet information needs years after diagnosis. One registry study found that nearly two-thirds of cancer survivors in Pennsylvania had at least one unmet psychosocial need as long as 3.0 to 4.5 years from diagnosis, and nearly half had over three unmet needs. The greatest need was expressed for emotional needs, followed by physical needs.⁹⁶ Similarly, the majority of endometrial cancer survivors in a Dutch registry-based study reported no information on psychological assistance,

rehabilitation, additional help, coping with cancer at home, and expected results of treatment on social and sexual life. These patients expressed interest for more information on possible cancer causes; prevention and risk of recurrence; possible side-effects of treatment, including effects of treatment on their sexual life; and psychological support.¹¹ Data from two cancer registers in California also found a wide range of health information need for survivors 4-14 years after diagnosis, particularly for younger and nonwhite patients.¹⁰¹

The LIVESTRONG survey suggested that physical needs are more likely to be met than either emotional (over 60 percent with unmet needs) or practical needs (over 70 percent with unmet needs).⁹⁷ The survey found that “fifty-four percent of respondents indicated they would have liked more followup support after completing treatment” and that “approximately one third left their doctor’s office with unanswered questions, and 25 percent reported that the health care team did not seem open to discussing their questions or problems.”^{97, p. 1353-1354} The need for additional information is echoed by the qualitative studies that highlighted the need for more discussion of or information on psychological well-being, postoperative expectations and the reality of functional limitations, and late physical effects.^{66,89,90,98-100,102}

KIs offered perspectives on the logistics of offering supportive care services to patients. One KI noted that because the specialist may not have information about counseling services, exercise, and physical therapy, the survivorship clinic is the only mechanism through which emotional needs, substance abuse, and other diagnoses are discovered. She noted that many supportive care services already exist and that there is “no reason to recreate the wheel and bring it in house.” Care providers can just refer patients out as needed. All settings need to be repurposed for survivorship care, but one “does not need to own the resource to use it.”

Another KI noted that planning for supportive care resources needs to start during therapy. The KI noted that patients are focused on their health status during treatment. She noted the importance of working with patients from the beginning so that therapy is more compatible with patients’ schedules. Patients need to get additional information that will assist them with their work life once their treatment is over. Patients need to know what their rights are, what kinds of accommodations they can get, what information to reveal when looking for a new job, and options for health insurance if they have quit working.

Application of Risk Stratification to Cancer Survivor Models

We did not find studies describing how risk stratification had been or might be applied to cancer survivorship models (although guidelines for specific conditions may account for underlying risk), although studies noted the importance of tailoring SCPs for the individual.^{83,90} KIs were in agreement, however, that SCPs need to be tailored for risk. As one KI pointed out, active treatment requires an assessment of risk, so survivorship care should as well. KIs also noted that evidence-based guidelines for survivorship do not account currently for risk stratification and that physicians do not really understand risk of new cancers and risk of recurrence.

Regarding specific sources of risk, comorbidities may influence the risk of poor outcomes following cancer treatment.¹⁰³ KIs noted that providers may use age as a proxy for comorbidities in risk stratification. Life course also matters: another KI pointed to research showing that a longer chemotherapy course in conjunction with a more cognitively demanding job results in poorer quality of life, worse self-reported health status, and delayed return to work for survivors.

When asked about incorporating patient characteristics into an assessment of risk that might influence the selection of a survivorship care model, one KI offered a three-tiered approach to

managing a heterogeneous survivor population. The KI suggested that patients can be characterized as (1) low-risk patients who can be transitioned immediately to a PCP because they do not have much need for long-term oncological care, (2) medium-risk patients who can be transitioned over a 2- to 5-year period to the PCP, and (3) high-risk patients who require ongoing care by both their oncologist and PCPs for life (e.g., transplant patients). Patient advocates also supported the idea of a continuum of need based on patient characteristics and the need for a matching process between patient characteristics and models of care.

Resources Needed To Share Information Among Health Care Providers and With Patients

A mixed-methods project that combined archival data with KI interviews of the leaders of the LIVESTRONG Centers of Excellence identified some frustration with information systems that were designed to support clinical care and billing but were not designed to extract information to develop treatment summaries and SCPs.⁵⁷ Communication also emerged as a key issue for both clinical providers and patient advocates among our KIs, but their perspectives on the resources needed to share information, particularly the role of patient navigators, differed substantially. Clinical providers noted their struggles communicating with all members of the team and with patients. Regarding communicating with other clinical providers, one KI noted that having a shared electronic medical record would ease communication among providers and organizations (as was noted in a study describing medical records as critical¹⁴), but the KI was unaware of any resources for provider communication. The KI noted that many hospitals do not have a single electronic health system, and the multiple systems within a hospital often do not communicate. Even when communication occurs (for instance, when an oncology nurse faxes information following a survivorship visit to the PCP's office), it is unclear how well that information is absorbed by the PCP. SCPs need to be kept cogent, short, and in a format that is likely to be read by all members of the care team, including the PCP.

As for communicating with patients, the KI noted that a study of a single survivorship visit found that although patients liked having the visit, they did not retain information presented during the visit, suggesting the need for reinforcement of education provided at the survivorship visit through other methods (e.g., mail, newsletter, additional visits, and telephone followup). Providers pointed to patient navigators (either virtual or in person) as a potentially promising avenue to explore in future research. A survey of concordance in expectations between patients, oncologists, and primary care providers found that better concordance between patients and oncologists was associated with improved followup care, but only if a discussion about cancer followup had occurred.⁸⁴

Patient advocates noted the same concerns as clinical providers did with the failure of electronic systems to communicate with one another. Not only are patients failing to receive care coordination in which providers communicate with one another, but they are also subject to treatment decisions from various providers who are working from different sources of information. Patient advocates noted that these gaps in communication place a tremendous burden on already stressed and ill patients to serve as “sole arbiters” of which doctor received which piece of information. Although one patient advocate noted the potential role of an ombudsman to take responsibility for patient coordination, both were cautious about the increasing emphasis on patient navigators. The implementation of patient navigation includes a lot of uncertainties regarding “who does what, how it is funded, [and] how people are held accountable.”

These insights suggest that beyond resources needed to share information, processes such as teamwork and team functioning and workforce training on teamwork also matter.

Considerations for Evaluating Appropriate Resource Utilization, Cost, Quality of Care, and Outcomes for Survivorship Programs

We did not find studies that listed considerations for evaluating survivorship programs. One KI noted these considerations are much bigger than the field of oncology. At the moment, no avenue exists to hold anyone accountable for the long-term survivorship care of people with cancer. A larger alignment of incentives, payment reform, and accountable care organizations might make a difference. Regarding specific evaluation considerations, KIs suggested focusing on level of patient satisfaction with their survivorship care, knowledge about their disease (including risks, recommended surveillance, and healthy behaviors), and subsequent patient behavior following education.

One KI with a payer perspective noted that coverage for care coordination is possible if care coordination demonstrates (i.e., with evidence) that it can improve patient care or provide clinically meaningful benefit to the patient. He noted that quality of life is a “soft” outcome in coverage determination, so quality of life alone may not be sufficient. Other meaningful measures of the consequences of services include decreased resource utilization rates (e.g., decreased hospitalization, decreased emergency room visits, or even decreases in certain medications that are expensive).

Uptake and Duration of Survivorship Care

We found no studies describing the uptake and duration of survivorship care on the whole. For studies with empirical evidence, the duration of the intervention ranged from 7 weeks⁶² to 4.2 years.¹⁰⁴ A structured review of followup of breast cancer patients found some discrepancies in the literature, with guidelines and data suggesting that the frequency and length of the followup service should be tailored to meet the needs of individual patients on the one hand and one study finding evidence of overutilization of followup visits on the other.⁹² In addition, we noted that based on a systematic review of 38 articles addressing followup care for breast cancer survivors, neither quality of life nor overall survival was affected by the frequency, duration, or type of followup care received.⁹² KIs generally did not comment on or were unaware of generalizable information on the uptake and duration of survivorship care.

Training and Staffing Needed for Survivorship Care

Studies described earlier identified concerns with the level of training or specialized knowledge held by PCPs and nurses. Existing literature suggests that development of training resources for adult survivorship care is at an early stage of development. The American Society of Clinical Oncology (ASCO) position statement drew particular attention to the importance of planning followup care and coordination of care in a shared-care model. The ASCO position statement also noted the importance of collaborating with nonspecialty boards to determine the specific knowledge needed for proof of proficiency for certification.⁴⁴ For primary care physicians, a position paper suggested the need for an internal medicine credential in cancer survivorship care.¹⁰⁵ KIs were in agreement that no survivor-specific training or certifications exist beyond the underlying certification for each discipline. Although KIs concurred on the need for continuing medical education as a way to train oncologists who are already practicing, they

offered different perspectives on how to train the workforce. One KI focused on a train-the-trainer model as a more promising approach than training an entire health care workforce on survivorship care through a specialized training track, but another KI noted the importance of better integration of survivorship needs in clinical provider curricula.

KIs agreed that targeting nurse practitioners in survivorship-related specific training or certification would be particularly helpful and that nurse practitioners had the right training and skills to address survivorship issues with patients.

GQ 3: Current Evidence on Cancer Survivorship Care

Based on the inclusion criteria described above, we identified nine studies that presented information on models of cancer survivorship care. As discussed in section GQ 1 (above), many taxonomies for survivorship care models are based on the health care provider leading the intervention (e.g., oncologist-led, PCP-led, nurse-led, or shared care), the site of care (e.g., academic center-based versus community-based), or the main purpose of the model (e.g., transition to primary care). In reviewing these nine identified studies, we identified four model categories based on the main foci of these studies: physician-led models, nurse-led models, models in which SCPs are a key component, and a model comparing group versus individual counseling. We discuss these studies in the sections below using these four model categories.

Substantial heterogeneity existed among these studies, including the specific survivorship care models, the type of cancer(s) for which survivors had been treated, and the duration and intensity of followup. Three studies compared differences in survivorship care programs led by physicians.^{104,106,107} All three of these studies involved comparisons between two or more survivorship protocols. Two of the identified studies examined nurse-led survivorship care models.^{108,109} Three studies featured SCPs as a key component.^{62,110,111} Although all three involved health care personnel (e.g., all included nurse-led components), a key component of these models is developing and disseminating a tailored SCP. We have therefore included these models in a separate category. In each of these three studies, the SCP was presented to the survivor during a nurse- or nurse practitioner–led visit and was shared with the survivor’s PCP. Finally, Naumann et al. examined individual versus group-based counseling and exercise training for cancer survivors.⁶³

We present details regarding the design and intervention characteristics of these studies in Tables 2 and 3, respectively. We also present information on dissemination and communications components of these studies in Table 4. The outcomes for each of these studies are available in Table 5.

Studies of Survivorship Care Models

Design Characteristics

Over half of the included studies (n=5) had a sample size of fewer than 100 patients; the sample sizes ranged from 10 to 968 (Table 2). Six of the studies were comparative in nature, but only three of these six randomized the survivors to a study arm (no studies involved randomization at the practice level). Other comparative studies involved following cancer survivors who had chosen different types of care programs; these studies correspond more to a “real-world” approach for survivorship care, but this approach increases the likelihood of substantial differences (and resulting bias) among participants in different types of survivorship care. All of the physician-led survivorship model studies were comparative. By contrast, fewer of

the other studies included comparisons. Similarly, most of the physician-led studies involved randomizing survivors to treatment arms whereas few of the other studies included randomization. Two of the nine studies^{106,110} included survivors with multiple cancer types: one included survivors with different types of hematological cancers¹⁰⁶ and the other included survivors of breast, gastrointestinal, lung, and hematologic cancers.¹¹⁰ All of the studies except the two involving survivors of hematologic malignancies (where stage is not applicable) included survivors who had been diagnosed at multiple stages of disease, although all studies excluded individuals with metastatic disease.

Both the Wattchow et al.¹⁰⁷ and Cannon et al.¹⁰⁶ studies appear to have examined “usual care” for survivors in that there is no specific intervention to modify standard practice patterns. The Kokko et al. study¹⁰⁴ involved what may have been more differences from usual care, in that survivors were randomized to different followup visit intervals and protocols for diagnostic testing (routinely performed versus performed only for clinical reasons).

Intervention Characteristics

The studies’ settings comprised cancer centers (both academic and community) and hospitals (Table 3). One study was based in a community cancer center.¹¹⁰ The three studies in which SCPs were a key component incorporated transition of care explicitly as a facet of the survivorship care model only.^{62,110,111} Three of the studies, from three different survivorship model categories, included analysis of economic considerations.^{104,108,110}

Five of the studies involved survivorship care interventions starting within 1 year following completion of active treatment. The Gates et al. study,¹⁰⁹ by contrast, required that enrollees had completed 5 years following active treatment. Five studies (not the same five with interventions starting within 1 year) included followup of survivors for less than 1 year. By contrast, the Knowles et al.¹⁰⁸ study followed survivors for up to 36 months (for colon cancer survivors) or 48 months (for rectal cancer survivors). Five of the models incorporated telephone contacts as a component of the planned survivorship care.

Information Dissemination and Communications

Four of the studies^{62,109-111} involved developing tailored materials for cancer survivors (Table 4). Of these, three were studies in which SCPs were a key component; by definition these interventions include tailored materials for survivors. All four of these studies also shared these individually tailored materials with the survivor’s other health care providers. Although other studies examined may have shared materials with survivors and their health care providers, this was not explicitly stated. Interestingly, none of these studies involved direct communications or care coordination between the clinical providers leading the survivorship care models and other providers involved in the survivor’s medical care.

Outcomes

Quality of life and satisfaction were the most commonly reported outcomes across the studies (Table 5). All but two studies^{109,110} included a quality of life outcome; interestingly, both of these studies included developing tailored materials for survivors. The three physician-led models were the only studies to include assessment of resource utilization, although only one of these three¹⁰⁴ explicitly assessed costs. Four studies explicitly included information on disease recurrence, although all models likely tracked recurrence for the period of survivor followup.

Only two studies included assessment of overall survival, possibly reflecting the short duration of followup for many of the models.

All three of the models in which SCPs were a key component examined both distress/anxiety and patient (i.e., survivor) satisfaction. However, in general, studies in the same survivorship care model categories did not assess the same types of outcomes. For example, the two nurse-led interventions did not have any outcomes in common. Depression and well-being were each explicitly assessed in only one study. However, these outcomes may have been incorporated in quality-of-life assessments included in other studies. Other outcomes present in only a single study included perceptions of health, engagement in health-promoting activities, cancer survivor's knowledge, care coordination/continuity, and unmet needs.

Beyond the studies addressing resource utilization or costs, all outcomes in the identified studies were at the patient level. There were no other provider- or systems-level outcomes presented.

IOM Components Addressed

Table 6 summarizes the IOM survivorship care components addressed by each reviewed model. The model examined by Wattchow et al. addressed two of the four IOM-recommended components of survivorship care: surveillance (for recurrence of colon cancer or development of new cancers) and intervention (to address symptoms potentially associated with cancer or cancer treatment).¹⁰⁷ We were unable to determine which IOM survivorship care components were addressed as part of the Cannon et al. study, although survivors being followed by multiple providers may have had coordination addressed. Similarly, although the Kokko et al. study explicitly addressed the IOM survivorship care component of surveillance, we were unable to determine if any other components were addressed.¹⁰⁴ The model reported by Knowles et al. appears to address only two of the IOM cancer survivorship model components (surveillance and intervention). The model in the Gates et al. study, by contrast, appears to address all four components.¹⁰⁹ In particular, the nurse-led program described by Gates et al. explicitly included components that did not appear to be present in the Knowles et al. model, specifically, educating survivors regarding adoption of healthy lifestyle behaviors (prevention component) and sharing the SCP with the survivor's PCP (coordination component).

The models reported by Curcio et al. and by Jefford et al. appear to address all four of the IOM survivorship care components.^{62,110} The model examined by Grunfeld et al. appears to address the surveillance, intervention, and coordination components; it is not clear whether it addressed the prevention component.¹¹¹

The group versus individual counseling model addressed the prevention and intervention IOM survivorship care components.

Table 2. Design characteristics of studies of survivorship care models

Type of Survivorship Intervention	Author and Year	Sample Size	Comparison Among Survivors Receiving Different Types of Care (e.g., Comparison With Usual Care, by Provider Types, Single vs. Multiple Providers, Resource Utilization Frequency)			
			Survivors Randomized to Study Arm	Survivors With Multiple Cancer Types Included	Survivors Across Multiple Stages of Disease Included	
Physician-Led Survivorship Care Models	Cannon et al., 2010 ¹⁰⁶	314	X	—	X	NA
	Kokko et al., 2005 ¹⁰⁴	472	X	—	—	X
	Wattchow et al., 2006 ¹⁰⁷	203	X	X	—	X
Nurse-Led Survivorship Care Models	Gates et al., 2012 ¹⁰⁹	60	—	—	—	NA
	Knowles et al., 2007 ¹⁰⁸	60	—	—	—	X
Survivorship Care Models in Which SCP Development Is a Key Component	Curcio et al., 2011 ¹¹⁰	30	—	—	X	X
	Grunfeld et al., 2011 ¹¹¹	968	X	X	—	X
	Jefford et al., 2011 ⁶²	10	—	—	—	X
Survivorship Care Models Comparing Group vs. Individual Counseling	Naumann et al., 2012 ⁶³	40	X	—	—	X

Abbreviations: NA = not applicable (for studies of survivors of hematologic malignancies); SCP = survivorship care plan.

Note: X indicates study reported the characteristic; — indicates that the study either did not have the characteristic or did not report it.

Table 3. Intervention characteristics of studies of survivorship care models

Type of Survivorship Intervention	Author and Year	Setting	Transition of Care Explicitly Incorporated Into Intervention	Economic Considerations Described	Survivorship Intervention Starts <1 Year After Completing Treatment	Survivorship Intervention Duration of <1 Year	Model Includes Care Provided by Telephone
Physician-Led Survivorship Care Models	Cannon et al., 2010 ¹⁰⁶	Teaching hospital system	—	—	—	X	—
	Kokko et al., 2005 ¹⁰⁴	Hospital department of oncology	—	X	—	—	X
	Wattchow et al., 2006 ¹⁰⁷	Multiple hospitals	—	—	X	—	—
Nurse-Led Survivorship Care Models	Gates et al., 2012 ¹⁰⁹	Public teaching cancer hospital	—	—	—	X	X
	Knowles et al., 2007 ¹⁰⁸	Hospital surgical department outpatient clinic	—	X	X	—	X
Survivorship Care Models in Which SCP Development Is a Key Component	Curcio et al., 2011 ¹¹⁰	Community cancer center	X	X	—	X	X
	Grunfeld et al., 2011 ¹¹¹	Tertiary care cancer centers and physician offices	X	—	X	—	—
	Jefford et al., 2011 ⁶²	Teaching hospital	X	—	X	X	X
Survivorship Care Models Comparing Group vs. Individual Counseling	Naumann et al., 2012 ⁶³	NR	—	—	X	X	—

Abbreviations: NR = not reported; SCP = survivorship care plan; vs. = versus.

Note: X indicates study reported the characteristic; — indicates that the study either did not have the characteristic or did not report it.

Table 4. Information dissemination and communications in survivorship care models studies

Type of Survivorship Intervention	Author and Year	Tailored Materials Prepared for Survivors	Materials Shared With Other Health Care Providers (Not Directly Part of the Survivorship Care Model)	Direct Care Coordination/ Communications With Other Health Care Providers (Not Directly Part of the Survivorship Care Model)
Physician-Led Survivorship Care Models	Cannon et al., 2010 ¹⁰⁶	—	—	—
	Kokko et al., 2005 ¹⁰⁴	—	—	—
	Wattchow et al., 2006 ¹⁰⁷	—	—	—
Nurse-Led Survivorship Care Models	Gates et al., 2012 ¹⁰⁹	X	X	—
	Knowles et al., 2007 ¹⁰⁸	—	—	—
Survivorship Care Models in Which SCP Development Is a Key Component	Curcio et al., 2011 ¹¹⁰	X	X	—
	Grunfeld et al., 2011 ¹¹¹	X	X	—
	Jefford et al., 2011 ⁶²	X	X	—
Survivorship Care Models Comparing Group vs. Individual Counseling	Naumann et al., 2012 ⁶³	—	—	—

Abbreviations: SCP = survivorship care plan; vs. = versus.

Note: X indicates study reported the characteristic; — indicates that the study either did not have the characteristic or did not report it.

Table 5. Outcomes of cancer survivorship models studied

Type of Survivorship Intervention	Author and Year	Quality of Life	Depression	Anxiety/Distress	Well-being	Satisfaction	Resource Utilization	Adherence to Planned Followup	Disease-free Period	Overall Survival	Recurrence	Perceptions of Health	Engagement in Health-Promoting Activities	Cancer Survivors' Knowledge	Coordination/Continuity of Care	Unmet Needs
Physician-Led Survivorship Care Models	Cannon et al., 2010 ¹⁰⁶	X	—	—	—	X	X	—	—	—	—	—	—	—	—	—
	Kokko et al., 2005 ¹⁰⁴	X	—	—	—	—	X	—	X	X	X	—	—	—	—	—
	Wattchow et al., 2006 ¹⁰⁷	X	X	X	—	X	X	—	—	X	X	—	—	—	—	—
Nurse-Led Survivorship Care Models	Gates et al., 2012 ¹⁰⁹	—	—	—	—	—	—	—	—	—	—	X	X	—	—	—
	Knowles et al., 2007 ¹⁰⁸	X		—		X	—	X	—	—	X	—	—	—	—	—
Survivorship Care Models in Which SCP Development Is a Key Component	Curcio et al., 2011 ¹¹⁰	—		X	—	X	—	X	—	—	—	—	—	X	—	—
	Grunfeld et al., 2011 ¹¹¹	X		X	—	X	—	—	—	—	X	—	—	—	X	—
	Jefford et al., 2011 ⁶²	X		X	—	X	—	—	—	—	—	—	—	—	—	X
Survivorship Care Models Comparing Group vs. Individual Counseling	Naumann et al., 2012 ⁶³	X	—		X	—	—	—	—	—	—	—	—	—	—	—

Abbreviations: SCP = survivorship care plan; vs. = versus.

Note: X indicates study reported the characteristic; — indicates that the study either did not have the characteristic or did not report it.

Table 6. IOM survivorship care components

Type of Model	Author and Year	Prevention	Surveillance	Intervention	Coordination
Physician-Led Survivorship Care Models	Cannon et al., 2010 ¹⁰⁶	—	—	—	—
	Kokko et al., 2005 ¹⁰⁴	—	X	—	—
	Wattchow et al., 2006 ¹⁰⁷	—	X	X	—
Nurse-Led Survivorship Care Models	Gates et al., 2012 ¹⁰⁹	X	X	X	X
	Knowles et al., 2007 ¹⁰⁸	—	X	X	—
Survivorship Care Models in Which SCP Development Is a Key Component	Curcio et al., 2011 ¹¹⁰	X	X	X	X
	Grunfeld et al., 2011 ¹¹¹	—	X	X	X
	Jefford et al., 2011 ⁶²	X	X	X	X
Survivorship Care Models Comparing Group vs. Individual Counseling	Naumann et al., 2012 ⁶³	X	—	X	—

Abbreviations: IOM = Institute of Medicine; SCP = survivorship care plan; vs. = versus.

Note: X indicates study reported the characteristic; — indicates that the study either did not have the characteristic or did not report it.

Conclusions From the Literature Review

Our review of the studies identified by this systematic review of the literature for the Technical Brief indicates a number of important findings regarding the model-of-survivorship care literature.

First, we reviewed a large body of literature, but we were only able to identify nine published studies that met our definition of survivorship models (i.e., programs for cancer survivors that addressed two or more different health care needs). Much of the available literature described only a single service for cancer survivors and thus did not correspond to a holistic and coordinated model or meet our inclusion criteria. However, less than a decade has passed since the dissemination of the IOM report that called for the recognition of the distinct phase of survivorship care (recommendation 1) and for CMS, the National Cancer Institute (NCI), AHRQ, and others to support demonstration programs to test models of care (recommendation 5). It is therefore not surprising that we identified few studies meeting the definition of survivorship models.

As discussed above, the nine identified studies are heterogeneous with respect to the type of survivorship care model, characteristics of the survivors participating, and intensity and duration of the interventions and outcomes measured. For example, time since completion of active treatment varied from essentially immediately following completion (Kokko et al.¹⁰⁴) to a median of 12 years (Gates et al.¹⁰⁹). This heterogeneity provides challenges in identifying trends or making comparisons across the different models. However, the heterogeneity in studies may reflect the heterogeneity of the cancer care delivery system, which involves multiple health care providers and often multiple practice locations. Thus, the models used by clinical providers that have become early adopters in the implementation of survivorship care may reflect the heterogeneous institutional and community resources that are available for survivors. At this point, the described models serve as “stand-alone” examples, with only limited ability to assess comparative effectiveness or draw generalizable conclusions for the overall survivor population.

Outcomes assessed across the identified studies were also heterogeneous. Many of the studies assessed health-related quality of life, but differing instruments were used. Some studies assessed knowledge, satisfaction, adherence to recommended followup, or resource utilization, but this was also variable. The lack of a standard or minimal set of metrics to evaluate the impacts of survivorship care models creates substantial barriers to making comparisons among alternative models. The models varied in terms of the IOM survivorship care components addressed. Most models addressed surveillance (for recurrent or new cancers) and intervention (for symptoms or conditions resulting from the cancer or cancer treatment). Fewer models addressed prevention (i.e., encouragement to adopt healthy lifestyle behaviors) or care coordination. Further, studies that did incorporate care coordination largely involved only sharing information (such as an SCP) with the survivor’s PCP. Models may need to explore more detailed approaches to care coordination, including the resources needed to exchange information among diverse groups of health care providers, survivors, and caregivers.

In general, nurse-led models and models in which developing SCPs is a key component appeared to address more IOM components. Overall, it is not surprising that the models identified for this study did not address (i.e., include interventions focused on) all IOM components. As reported by Salz et al.,¹¹² only 43 percent of NCI-designated cancer centers present SCPs to their breast or colorectal cancer survivors, and none of these address all components recommended by the IOM.

Within each study, participant characteristics were also heterogeneous; for example, several studies involved individuals diagnosed with stage I through stage III disease. None of the studies described specific risk stratification protocols, where survivors who had more extensive disease at diagnosis or who received more intensive therapy were provided with different types of information or different supports than were those with less extensive disease or treatment. Several of the review models included individualized components (e.g., SCPs), which may have been tailored to reflect individual risk levels, but this was not explicitly stated. Completeness of information reporting in these nine studies also varied and, for certain types of study data, information was largely absent. For example, none of the studies reported any adverse events or unintended consequences of the survivorship care model, such as overuse of services or duplicate testing. It may be that no such unintended consequences occur; however, it would be useful for researchers to explore this issue and comment on such negative results if that is the case. This may also be useful as an outcome measure for survivorship care reflecting effectiveness of communication and coordination of care.

Other than the report by Curcio et al.,¹¹⁰ the reviewed studies either included few nonwhite survivors or did not report the proportion of nonwhite survivors participating. Although some studies took place in countries with low proportions of nonwhite individuals (e.g., Finland), the low level of involvement of nonwhite survivors parallels low participation rates observed in therapeutic cancer clinical trials. African-American and Hispanic individuals are significantly less likely to participate in cancer clinical trials than white individuals.¹¹³ Patient-level barriers to participating in studies of survivorship care, such as sociocultural factors and distrust of the medical establishment; trial design factors such as eligibility criteria; and provider-level factors have been reported to limit participation by African Americans in therapeutic cancer clinical trials.¹¹⁴ Many barriers to participating in studies of survivorship care may also limit receipt of survivorship care among disparate populations. Developers of cancer survivorship care models should consider potential barriers to participation (in both studies and care programs) by racial/ethnic minorities and other underserved populations and provide information on enrollment by these disparate groups.

Several of the identified studies do not include a “usual care” arm. To evaluate the effectiveness of a survivorship care model and compare effectiveness among differing models, a common “baseline” of standard survivorship care is needed. The absence of comparisons with standard survivorship care practices (i.e., in the absence of a protocol-specified intervention) limits the ability to assess whether a more integrated or comprehensive model of survivorship care would differ from a less integrated or comprehensive model in clinical outcomes or efficiency of care delivery for cancer survivors. Similarly, the absence of comparison to usual care prevents assessment of the potential harms that may result from survivorship care models. Additional research is needed to explore whether (and how) various models of survivorship care are likely to improve outcomes for cancer survivors compared with current survivorship care practices.

A recent Cochrane collaboration review by Scott et al.¹¹⁵ identified published studies that examined the effectiveness of “multidimensional rehabilitation programmes” for cancer survivors. The differences between this review and the present Technical Brief illustrate important challenges in examining models of survivorship care. Scott et al. identified 12 published randomized controlled trials that included both physical and psychosocial interventions for adult cancer survivors. However, these 12 studies did not overlap with the 9 studies identified in this Technical Brief. Furthermore, these 12 studies were not identified in the

literature searches performed for the Technical Brief; separate and largely distinct search terms were used to identify studies for review. The search strategy used by Scott et al. started with publications involving neoplasms, and then searched for studies that included a range of intervention and health care service types (e.g., self-help groups, psychotherapy, social work, dietary services, physical therapy). In contrast, our literature search started with cancer survivors and then examined studies focused on delivery of health care, aftercare, models of care, and related topics. This approach resulted in a group of studies that were more focused on the specific aims for this Technical Brief.

Had we identified these 12 studies as part of our literature review, we would have excluded them. For example, some included a different definition of cancer survivors (i.e., differing from our definition of adults who had completed potentially curative treatment), and others did not appear to meet our inclusion criterion of interventions addressing two separate needs of cancer survivors. These differences do not imply that one approach is correct and the other wrong; rather, these two projects had different objectives. The review by Scott et al. identified interventions that may address the needs of individual survivors, but are not necessarily models of survivorship care. However, these differences further indicate the need to develop consensus and standards regarding definitions for “survivorship care models” as well as specifications for study populations or survivorship care models, types of care to be included, and outcomes to be assessed.

Findings From KIs

Several KIs provided information on survivorship care models. One KI commented that survivorship clinics at academic institutions, which provide medical care as well as address psychosocial needs, are the only model she is aware of.

Another KI described a survivorship care model that has been funded by the LIVESTRONG Foundation and the NCI’s Community Cancer Center Program. The initial survivorship visit is held on the same day as the first followup oncologist meeting. This survivorship visit is led by an advanced practice nurse and lasts 90 to 120 minutes. Components of the survivorship visit include developing a breast cancer treatment summary and care plan (for breast cancer survivors), assessing the survivor’s immediate health needs and signs of recurrence and late effects of treatments, offering assistance with coordinating the patient’s care among existing providers, and providing appropriate referrals. The KI and his colleagues have assessed changes in quality of life, satisfaction, and cancer concerns from baseline to 6 months for participants in this program.

Another KI described three survivorship care programs at her institution:

1. *Cancer “transition” health care delivery program.* This program is focused on breast cancer survivors but is expanding to other survivor populations. It involves a series of group medical visits with cancer survivor themes led by PCPs in partnership with oncologists. The program provides multidisciplinary, coordinated care delivery with an emphasis on cancer prevention and screenings. Survivors also complete an SCP.
2. *One-time consultation with multiple providers.* This approach assesses current needs and includes a care plan for preventative health care needs and surveillance. This consultation was a very resource-intensive model because it was not offered in conjunction with a patient’s oncology visit. Plans are to have more of the screening and

assessment of survivorship needs done in the disease site clinic; based on that screening and assessment, survivors will receive referrals to other providers to address those needs.

3. *Adult survivors of childhood cancers program.* This program involves one or two consultations with multiple health care providers. The survivors and PCPs receive a care summary that includes general health care prevention and surveillance strategies.

GQ 4: Gaps in Knowledge and Future Research Needs for Models of Adult Cancer Survivorship Care

The literature includes information on a number of different types of survivorship care programs.⁵⁸ Methods for developing and implementing survivorship care programs vary and depend on organizational and leadership support and the presence of an internal champion.⁵⁷ Different settings include academic models, community practice models, and shared care.⁴⁴ As noted in the discussion for GQ 3, little data exist on how many of these models have been implemented, evaluated, or compared with standard care. Few studies have evaluated the structural or process barriers or constraints to offering survivorship care, such as incentives and disincentives to continue surveillance of recurrence and resolution of side effects; reimbursement for survivorship care; survivors' perspectives on following up with their oncologists, with whom they may have become emotionally attached; and oncologists' perspectives on continued care provision for survivors who are doing well (which may provide emotional and economic benefits for oncologists). As survivorship care evolves, it will be important to include evaluation of the infrastructure needed for delivering optimal care as well as relevant outcomes.^{116,117} As we learn more about the needs and problems of long-term survivors, a one-size-fits-all model for survivorship care will likely not be as relevant as a triaged or tailored approach.

Gaps in Knowledge

First, little is known about the added value of developing “models of care” for cancer survivors to add onto complex health care delivery systems, particularly in comparison with efforts to engage health care providers to deliver components of survivorship care within existing settings. In a related vein, the use of risk stratification to direct patients to primary care, specialist care, or a “tapering” regimen of specialist care (e.g., for patients with tumors with low risk of recurrence) is untested. Likewise, the relative merits (or potential harms) of care from a single provider versus continued collaboration and communication among multiple providers is unclear.

Second, studies need to adequately describe the model(s) being examined and provide more detailed information to assist in comparing results of one study with those of other studies and assessing the generalizability of any one model. When possible, studies of survivorship care models should compare their structures, processes, and outcomes with data from the “standard of care” (which, as discussed in the “Next Steps” section below, is not well defined) or from other survivorship models.

Third, studies of survivorship care, whether presented as models or not, need to provide additional data on the long-term or late effects of treatments received by adult cancer patients. This crucial information may be obtained from large epidemiological databases and longer-term extension of cancer clinical trials in addition to studies of survivorship care. This type of information may support better risk stratification of survivors within models based on projected recurrence and late effects and facilitate different types or levels of survivorship care based on

individual risk profiles. For example, the needs of patients with low risk of recurrence or treatment effects (e.g., early-stage colon cancer) might be best served with a transition to a primary care model. On the other hand, patients at high risk for problems (e.g., bone marrow transplant survivors) might be better served in a disease-specific or multidisciplinary clinic. However, such risk stratification in survivorship care will be difficult without longitudinal data on survivors over long periods of time. Further, heterogeneity in the definition of survivors will also add challenges to this goal. A pragmatic approach may be to define a survivor as a person who has completed active acute cancer treatment and is receiving only observation or preventive/maintenance therapy when studying models of survivorship care.

Fourth, KIs identified a gap in understanding survivors' needs, especially in racial /ethnic minority populations. The literature reviews and interviews indicate that little information is available regarding development and implementation of culturally sensitive survivorship care models that would be acceptable and feasible for underserved patients in the United States.

Finally, an improved understanding of barriers to survivorship care is necessary. Regardless of the model adopted, barriers identified by KIs include financial incentives and disincentives, clinical information systems to identify candidates for survivorship care and to provide information, lack of organization support, and lack of health care provider training about survivorship issues. Additional barriers may reflect lack of patient awareness or interest/adherence in survivorship care programs and lack of provider knowledge regarding best processes for delivering coordinated care.

Future Research Needs

Research is lacking on models of survivorship care, their components, and their context. As a result, a number of areas need to be explored, such as fostering organizational changes to deliver survivorship care, determining the frequency and length of care for survivors,⁵⁷ measuring patient morbidity associated with followup appointments,⁹² developing evidence-based followup guidelines, and bridging the gap between oncologists and PCPs in delivering long-term followup care.⁵⁸ Other future research needs were identified in a recently published survey of clinical leaders, administrators, and medical care providers from Cancer Research Network sites.¹⁴ This report identified gaps in evidence including potential advantages of using different models of care; long-term treatment effects; effectiveness of different approaches to surveillance; effectiveness and cost-effectiveness of different care models; evaluation of existing survivorship programs and tools; and the costs and benefits of survivorship care. In addition, different models of care and components of care need to be evaluated, particularly on measures of over or underuse of health care.⁵⁷ Evidence-based surveillance plans currently exist for breast and colorectal cancers only and need to be expanded to other cancers. Long-term patient-reported outcomes should be collected to better predict higher and lower risk groups.

Understanding what contributes to organizational culture change to clinically support survivorship care is needed.

KIs and reviewers raised other questions, including the following:

- What are the needs of survivors over time?
- Given shortages among the oncology workforce, how should survivorship care be prioritized relate to acute cancer treatment?
- How can awareness of survivorship programs be improved among survivors, caregivers, and clinicians? Should survivorship care be imbedded in cancer care or provided as a separate service?

- How should an “oncology medical home” be defined? Is an oncology medical home important for survivorship care?
- Could a virtual patient navigator program facilitate transitions along the cancer continuum?
- What is the role of current and future financial incentives on survivorship care? For example, could financial incentives result in oncology providers discontinuing survivorship services if they receive greater reimbursement for providing curative treatment?
- How and when should rehabilitation professionals, gerontologists, or other subspecialists contribute to cancer survivorship care?
- What is the role of cultural and socio-economic context in influencing the feasibility and applicability of cancer survivorship care models?
- How should cancer survivorship care support or monitor long-term anti-cancer therapies (e.g., 10 years of adjuvant endocrine therapy)?
- What study designs are the most appropriate methods to evaluate survivorship programs?
- What key outcomes or endpoints should survivorship programs evaluate? Should programs evaluate costs routinely?
- What models of care have better outcomes?
- How do we optimize wellness in survivors? What is the role of self-management programs?

A broad range of ongoing research in cancer survivorship is underway, some of which is likely addressing these stated needs. For example, NCI has two Funding Opportunity Announcements (12-274 and 12-275) focused on survivorship care planning. Thus, the future research needs for survivorship care and gaps in knowledge are dynamic areas.

Summary and Implications

Existing evidence suggests that many needs of cancer survivors are unmet and that many cancer programs do not deliver any type of formal survivorship that might address these needs.^{11,14}

An overarching theme across the literature and KI interviews relates to the heterogeneity of existing practice and nascent research addressing these issues. Our systematic review of the evaluations of existing programs for the Technical Brief classified interventions into four categories: nurse-led, physician-led, SCP-centered, and individual or group counseling models. Within each category, we found substantial variation in the types of cancers; timing, components, intensity, and followup of care delivery; and types of outcomes evaluated. Although this report only includes studies of individuals who had completed active treatment, substantial heterogeneity also exists in how the field defines a “cancer survivor” and how survivor needs may differ. Furthermore, there is often substantial heterogeneity in terms of type of cancer and stage at diagnosis among survivors included in studies of a single model of survivorship care. Examining the outcomes of models for more homogeneous groups of survivors will be critical for developing this evidence base.

Another finding is the paucity of evidence regarding fundamental questions such as what constitutes “usual care” for a cancer survivor, what a survivorship care model is, and whether models of cancer survivorship care result in improved outcomes for patients when compared with usual care. As noted in the methods section, we focused on studies that addressed multiple needs of survivors. If we had elected to broaden our focus to studies addressing single needs of survivors, our yield would have been larger, but these studies would not have spoken to the issue of models of care.

A related question is whether programs addressing only two different needs for cancer survivors are sufficiently comprehensive to be considered models. We had discussed defining survivorship care models as programs that addressed all four of the components listed by the IOM, but we identified few studies of survivorship care models even using this expanded (two needs) definition. Other groups (e.g., LIVESTRONG) have also outlined elements of cancer survivorship care that may be used for future development of care programs. However, differences among the specified components of survivorship care from differing sources may also increase model heterogeneity and thus increase challenges in understanding and evaluating care models.

Our findings suggest that models of survivorship care are highly idiosyncratic, or individualized to the institution or organization where they are based; the care provided in these models may depend on the relationship between the provider and the survivor, the setting(s) of care, the type(s) of cancer and cancer treatment(s), the survivor’s risks associated with the disease, and the practice setting(s) where survivorship care occurs. Thus, it may be difficult to pull out commonalities among different models. This in and of itself is a gap in the survivorship care knowledge base that needs to be addressed in order to develop and evaluate care models. In addition, current reimbursement rules may disincentivize new care models, so oncologists continue to see cancer survivors. However, an anticipated workforce shortage of oncologists may require new approaches such as the expanded use of nurse practitioners and physician assistants, shared care with primary care providers, and patient navigators. Concerns about these alternatives include payment systems, adequacy of training, and greater fragmentation of care.

Limitations of This Technical Brief

Because a Technical Brief is intended to provide an overview rather than an exhaustive cataloging of the evidence, it does not capture the entirety of the evidence on every question (as a systematic review would). Due to constraints imposed by the Office of Management and Budget, we were limited to nine or fewer non-Federal key informants. In an emerging area of research with limited published empirical evidence, this constraint limited our ability to achieve a saturation of viewpoints.

Feedback from public review and peer review also raises other limitations. One reviewer noted that the field needs a review of existing survivorship programs and interviews with their directors to evaluate the types of models that currently exist and address their pros and cons. This type of activity is beyond the scope of our product.

Another reviewer noted that one possible limitation was in the KI question guide: the question on harms and disadvantages may not have had an appropriate probe, resulting in few comments on this topic. As a result, we may not have elicited information on harms such as allocation of resources away from curative treatment and additional worry and distress for patients. However, from our literature review, there appears to be little evidence regarding harms associated with survivorship care programs.

Next Steps

Based on the literature review and interviews with KIs, we identified a number of questions that need to be explored for optimal development of cancer survivor care models. For each question, we provide suggestions for the cancer survivorship community, including survivors, clinical providers, policymakers, and researchers, to address these questions.

1. What is a model of cancer survivorship care? How should models of care be defined or specified to differentiate them from other types of survivorship care services, and from models of care for other conditions (e.g., models for survivors of kidney transplant or traumatic brain injury)? What types of taxonomies and conceptual models will be useful to develop and examine survivorship care models?

Suggestions for addressing this question: Stakeholders in the cancer survivorship community need to agree on a common definition for “survivorship models” and on a taxonomy for types of models. A meeting with broad participation from key stakeholder groups may be useful for reaching consensus (or at least general agreement) on this topic.

2. In evaluating the outcomes associated with survivorship care models, what should constitute usual care? KIs interviewed for this report generally agreed that currently no standard survivorship care program exists.

Suggestions for addressing this question: Studies are needed to better understand the current experiences of cancer survivors, particularly those who do not receive followup care at academic centers. This will likely include analyses of existing data sets (e.g., claims data or electronic medical records) as well as focus groups or interviews with survivors, clinical providers, and other stakeholders.

3. What is the most opportune time following completion of active treatment to initiate a survivorship care program? Does this vary based on the type of cancer, stage of cancer at

diagnosis, or other patient sociodemographic and clinical characteristics? How does preparation for end-of-treatment transition to survivorship care get incorporated into existing cancer treatment?

4. What is the optimal period for repeated visits or other contacts with cancer survivors? Does this depend on patient sociodemographic or clinical characteristics? Are repeated face-to-face survivorship visits needed or does a one-time visit provide comparable outcomes?
5. What is the optimal followup period for a survivorship care model? What is the minimum period needed to assess the potential impacts of a model? What period is needed to capture a majority of the developments of late effects, recurrences, or new cancers among survivors?

Suggestions for addressing Questions 3, 4, and 5: Input from cancer survivors is needed regarding changes in their support needs at different periods following completion of active treatment. Clinical providers and researchers developing or implementing survivorship care programs and models need to consider this input and align programs with the needs of survivors from differing periods. Evaluations of survivorship care models should examine differences in outcomes based on time since completion of active treatment and should provide clear information on the time since treatment completion among participants and stratification of outcomes by time since completion. Cancer survivor risk stratification will also affect timing of support needs, although determining risk stratification for survivorship care is also an issue that has not been fully addressed.

Survivorship care programs need to provide repeated assessments over time of their key outcomes to explore how (or whether) outcomes change with additional followup interactions or increased duration of followup. Similarly, programs need to consider survivors who discontinue participation in programs, including whether participation for an initial period results in longer-term benefits and why survivors choose to discontinue participation. Once a reasonable body of information is available on how survivors' needs and program effectiveness vary by time since completion of active treatment and optimal periods for survivorship contacts and followup of care, recommendations can be developed to guide future models.

6. What minimum set of outcomes should be examined in all studies of survivorship care models and how should they be measured? At present, diverse and largely incompatible outcomes are assessed, presenting barriers to comparisons across differing models. Are new metrics needed to assess crucial elements of survivorship care, such as degree of care coordination versus fragmentation?

Suggestions for addressing this question: As with Question 1, answering this question likely requires discussions among a broad group of stakeholders in the cancer survivorship community to agree on a minimal set of outcome measures to be assessed by all survivorship care models. Clearly, models may wish to assess additional outcomes that are specific to the survivor population being targeted or the services being offered by a model. However, all models should provide at least an agreed-upon set of common outcome measures. Journals, conferences, and grant-funding organizations could require

this information from survivorship care programs and not accept those that are lacking the minimal set of outcomes.

7. For models involving SCPs, what are the key elements to include? What elements of SCPs do survivors and PCPs find most useful? How can programs balance the need to be comprehensive in the information provided versus overloading survivors with too much information?

Suggestions for addressing this question: A substantial body of literature exists regarding SCPs. Compiling a compendium of this literature and identifying and comparing the specific elements included in each SCP would provide a useful resource. Input from survivors as to the components of SCPs that were (or were not) useful will also be key. Certain elements will be required for all SCPs, such as details of the diagnosis and treatments received and recommended surveillance. However, future programs or models involving SCPs may want to explore including different subsets of SCP elements in two or more participant groups to assess the impacts of these elements on outcomes among survivors and their clinical providers.

8. How do survivorship care models differ with respect to resource utilization, cost, cost-effectiveness, and efficiency? Are some models more advantageous in settings with limited resources or finances? What resources are needed to implement different models of care? How do varying payment systems affect receipt of survivorship care?

Suggestions for addressing this question: As discussed repeatedly in this report, cancer survivorship models display tremendous heterogeneity. Therefore, at the present time, comparisons of resource utilization, cost, cost-effectiveness, and efficiency among survivorship models are not feasible; the resource utilization and costs from a model are likely not generalizable across survivor populations, settings, and model types. As survivor models adopt more common practices and outcome measures, comparisons of resource utilization and costs may become more feasible. Investigating the impact of payment systems on receipt of survivorship care may be currently feasible; that is, do variations in payment system influence the likelihood of receiving survivorship care services?

9. How should models be tailored to optimally benefit survivors from underserved populations, including those from racial/ethnic minorities, low socioeconomic status, older age groups, and low health literacy?

Suggestions for addressing this question: Most of the models examined for this report either included low numbers of survivors from underserved populations or did not report the proportion of underserved individuals participating. Survivorship care models should focus more strongly on recruitment and outreach to attract survivor populations that reflect the overall population of adults treated for cancer. In addition, the models we examined were largely based at academic centers or hospitals with substantial research experience. Models based in settings that focus on survivor care for underserved populations, such as Federally Qualified Health Centers or rural locations, are needed to collect information from and develop approaches tailored for these vulnerable groups.

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Appendix A. Key Informant Interview Methodology, Guiding Questions, Search Terms, and Gray Literature Methodology

We adhered to the Office of Management and Budget (OMB) requirements and limited standardized questions (the list of Guiding Questions [GQs]) to no more than nine nongovernment-associated individuals. As a result, we did not need to obtain OMB clearance for the interviews.

After review and approval of the completed Disclosure of Interest forms for the proposed Key Informants (KIs) by the Agency for Healthcare and Quality (AHRQ), over a 3-week period, we conducted interviews with 10 selected KIs, 2 of whom were government-associated individuals and did not count toward the OMB limit of 9 individuals who could be interviewed without clearance. The interviews were a combination of individual KIs and groups of KIs based on availability and concordance of perspectives. A co-investigator from the Evidence-based Practice Center (EPC) team led each of the KI interviews, and the Task Order Officer (TOO) was in attendance for all of the interviews along with other EPC team members. The recorded KI interviews ranged in duration from 0.5 hours to 1.5 hours. Following each interview, we summarized the interviews in writing by incorporating summary notes prepared by team members; interview recordings; and, for some, a professional transcription of the interview. We then submitted notes to the TOO for documentation. Using NVivo® qualitative software (v9.0), we coded the KIs' responses by relevant GQs and subquestions and generated summary reports by subquestion for analysis by the authors. Authors evaluated summary reports, corrected or added codes by referring to the original summary notes, and identified key themes from multiple perspectives. In addition, authors also identified unique perspectives from KIs.

We modified the order of the GQs to better align the topical content under the GQ domain. For instance, in KI interviews conducted for this project (described below), rather than initiating the interview with a question about models of care that have been widely used, we asked KIs to first describe usual care for survivors and then describe models of care. We also rephrased some of the questions to better clarify the intent of the question to facilitate KI discussions. For example, we combined two questions focusing on gaps in knowledge holding back the diffusion of survivorship care and new research necessary to reduce uncertainty in decisionmaking by asking, "Are gaps in knowledge holding back the diffusion of survivorship care? What are the most important knowledge gaps to fill through new research to reduce uncertainty in decisions?"

1. Guiding Question 1: Overview of cancer survivorship care

- Is it possible to generalize "usual care" for cancer survivors in the United States? If so, how would you describe the nature of usual care for survivors of cancer? If not, can you describe some of the most common care practices?
- How would you define a "model" of survivorship care as opposed to separate health care services that may be offered to cancer survivors? Are there specific components of care that need to be present for services to be considered a model?
- What different models of cancer survivorship care have been most widely used? *[For all KIs except for Research: What is your current or past experience with using different models of care?]*

- What are the advantages and disadvantages of these models, compared with one another and with usual care?
- How widely is survivorship care offered? For how long?
- Are there any potential safety issues and harms resulting from care provided in the models? If so, what are they?

2. Guiding Question 2: Context in which cancer survivorship care is used

- Do patients and clinical care providers choose among survivorship care programs? If so, how do they decide among programs? If not, why not? Are providers generally aware of (or affiliated with) only a single program, or are patients generally informed of more than one option for survivorship care?
- How do models of care vary based on
 - setting,
 - organizational structure,
 - provider type (including in the context of transitions of care),
 - payment considerations, and
 - patient characteristics such as age, race, cancer type, stage of disease, other risk stratification issues?
- What associated supportive care resources are commonly incorporated in survivorship care programs? What supportive care resources that are not present are needed? (*PROBE: Supportive care for caregivers/family of patient, or social support as a supportive care resource? Or both?*)
- How is (or could) risk stratification (be) applied to cancer survivor programs? [*For patient advocates only: If patients who are considered at higher risk for problems, that is, late effects, are there programs or resources that can address those specific needs?*)]
- What kinds of resources (e.g., health information technology) are available or needed to share information among health care providers and with cancer survivors?
- What are important considerations for evaluating appropriate resource utilization, cost, quality of care, and outcomes for survivorship programs? [*When you are considering your quality of care or minimizing costs what factors are important to weigh?*]
- What kinds of training and certification are required for providers involved in survivorship programs? What modifications to current training, certification, and staffing are in development?

3. Guiding Question 3: Current evidence

- Do you have any information that may be useful to us in our evaluation of the current evidence?

4. Guiding Question 4: Gaps in knowledge and future research needs

- Are gaps in knowledge holding back the diffusion of survivorship care? [*could suggest other gaps such as reimbursement or other factors, if prompted by interviewee*]
- What are the most important knowledge gaps to fill through new research to reduce uncertainty in decisions?

- Are any models of survivorship care planned but not yet implemented?
- What are the differences between existing models of survivorship care and new and emerging models of survivorship care?
- What are possible areas of future research?

Pub Med Search Terms (March 2013)

Search #1	Query	Items found
#9	Search "Survivors"[Mesh] OR survivorship OR survivor Filters: Humans; English	498,795
#10	Search "Neoplasms"[Mesh] Filters: Humans; English	1,609,728
#11	Search (("Aftercare"[Mesh]) OR "Continuity of Patient Care"[Mesh]) OR "Delivery of Health Care"[Mesh] Filters: Humans; English	586,760
#12	Search (("Patient Care Planning"[Mesh]) OR "Models, Nursing"[Mesh]) OR "Health Services/utilization"[Mesh]) OR "methods" [Subheading]) OR "standards" [Subheading] Filters: Humans; English	1,801,900
#13	Search (#9 AND #10 AND #11 AND #12) Filters: Humans; English	1,575
#14	Search (#9 AND #10 AND #11 AND #12) Filters: Humans; English; Adult: 19+ years	972
#17	Search (#9 AND #10 AND #11 AND #12) Filters: Editorial; Comment; Case Reports; Humans; English; Adult: 19+ years	38
#19	Search (#14 NOT #17)	934
Search #2	Query	Items found
#1	Search 23257892[uid]	<u>1</u>
#2	Search "Survivors"[Mesh] OR survivorship OR survivor	<u>771,137</u>
#3	Search "Neoplasms"[Mesh]	<u>2,411,985</u>
#4	Search (("Aftercare"[Mesh]) OR "Continuity of Patient Care"[Mesh]) OR "Delivery of Health Care"[Mesh]	<u>744,808</u>
#5	Search (((("Patient Care Planning"[Mesh]) OR "Models, Nursing"[Mesh]) OR "Health Services/utilization"[Mesh]) OR "methods" [Subheading]) OR "standards" [Subheading])	<u>2,854,158</u>
#6	Search (#2 AND #3 AND #4 AND #5)	<u>1,715</u>
#7	Search (#2 AND #3 AND #4 AND #5) Filters: Humans	<u>1,712</u>
#8	Search (#2 AND #3 AND #4 AND #5) Filters: Humans; Adult: 19+ years	<u>1,020</u>
#9	Search (#2 AND #3 AND #4 AND #5) Filters: Humans; English; Adult: 19+ years	<u>975</u>
#10	Search (#1 AND #9) Filters: Humans; English; Adult: 19+ years	<u>0</u>
#11	Search (#1 AND #9) Schema: all Filters: Humans; English; Adult: 19+ years	<u>0</u>
#12	Search (#1 AND #9)	<u>0</u>
#13	Search (#1 AND #9) Schema: all	<u>0</u>
#14	Search (("Survivors"[MAJR] AND "Neoplasms/therapy"[MAJR])) AND ("Aftercare"[Majr] AND "Delivery of Health Care"[Mesh])	<u>30</u>
#15	Search (#14 AND #1)	<u>1</u>
#16	Search (#14 NOT #9)	<u>19</u>

PubMed = 953 non duplicated results

Pub Med Update Search (August 2013)

Search #3	Query	Items found
#1	Search "Survivors"[Mesh] OR survivorship OR survivor	<u>797912</u>
#2	Search "Neoplasms"[Mesh]	<u>2457689</u>
#3	Search (("Aftercare"[Mesh]) OR "Continuity of Patient Care"[Mesh]) OR "Delivery of Health Care"[Mesh]	<u>761518</u>
#4	Search (((("Patient Care Planning"[Mesh]) OR "Models, Nursing"[Mesh]) OR "Health Services/utilization"[Mesh]) OR "methods" [Subheading]) OR "standards" [Subheading])	<u>2935558</u>
#5	Search (#1 AND #2 AND #3 AND #4)	<u>1810</u>
#6	Search (#1 AND #2 AND #3 AND #4) Filters: Editorial	<u>37</u>
#7	Search (#1 AND #2 AND #3 AND #4) Filters: Editorial; Comment	<u>69</u>
#8	Search (#1 AND #2 AND #3 AND #4) Filters: Editorial; Comment; Case Reports	<u>102</u>
#9	Search (#5 NOT #8)	<u>1708</u>
#10	Search (#5 NOT #8) Filters: Humans	<u>1705</u>
#11	Search (#5 NOT #8) Filters: Humans; English	<u>1575</u>
#12	Search (#5 NOT #8) Filters: Humans; English; Adult: 19+ years	<u>999</u>
#13	Search ("2013"[Date - Entrez] : "3000"[Date - Entrez]) Filters: Humans; English; Adult: 19+ years	<u>29790</u>
#14	Search (#12 AND #13) Filters: Humans; English; Adult: 19+ years	<u>19</u>
#15	Search (("Survivors"[MAJR] AND "Neoplasms/therapy"[MAJR])) AND ("Aftercare"[Majr] AND "Delivery of Health Care"[Mesh]) Filters: Humans; English; Adult: 19+ years	<u>19</u>
#16	Search (#13 AND #15) Filters: Humans; English; Adult: 19+ years	<u>0</u>
#17	Search (#13 AND #15) Schema: all Filters: Humans; English; Adult: 19+ years	<u>0</u>

Pub Med Search Terms (August 2013)

PubMed = 17 non duplicated results

Gray Literature Search

GQs 1 and 2 relied primarily on information from published narrative reviews and information in the gray literature. Sources for the gray literature included the following:

- LexisNexis® Academic: This source provides mostly full-text access to general, regional, and international news; company news and financial information; legal information (including law reviews, case law, and legal rulings); and other topics such as biographical information. LexisNexis Academic is a Web-based service that provides access to most of the information formerly available on the LexisNexis® Educational Program (approximately 75 percent of the titles).
- ProQuest Dissertations & Theses: This source indexes U.S. dissertations from 1861 to as recently as the last semester with full text available from 1997 on. Master's theses are covered more selectively and some full text is available. The database covers work done at more than a thousand institutions, primarily in the United States but also in Canada and Great Britain, and at other European universities for recent years. In addition to this database, the full text of most of the theses and dissertations completed at the University

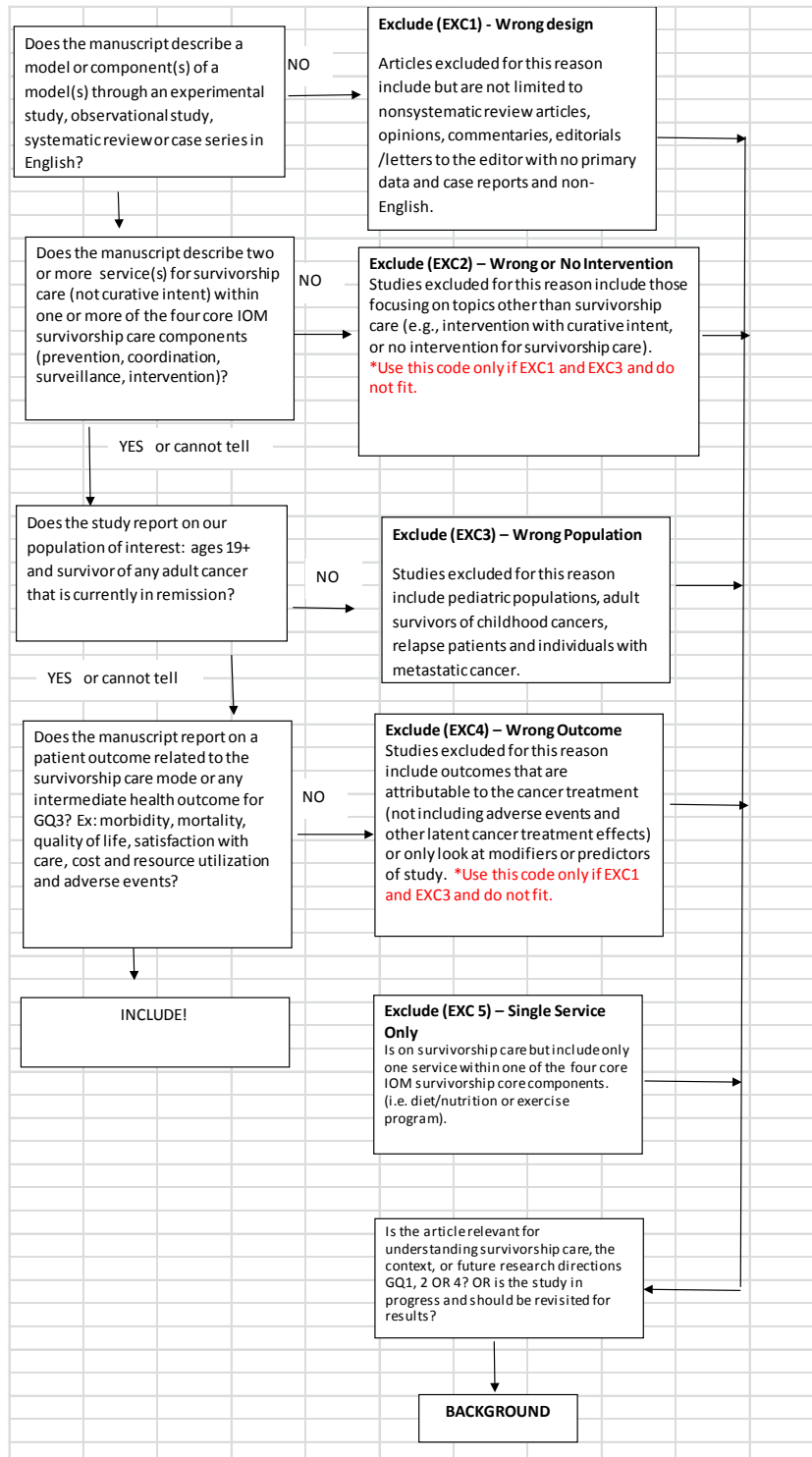
of North Carolina at Chapel Hill (UNC) from 2006, and all beginning in 2008, are freely available electronically from the UNC Health Sciences Library.

- NIH RePORTER database: The information found in RePORTER is drawn from several extant databases (eRA databases, MEDLINE®, PubMed® Central, the NIH Intramural Database, and iEdison), using newly formed linkages among these disparate data sources. The comprehensiveness of these databases varies, as does the quality of the linkages formed among them. We expect that the quality of RePORTER data will improve over time as a result of changes in both data collection (e.g., implementation of the NIH Public Access policy) and the increased ability to identify missing information that comes from making these data accessible to more people.
- HSRProj (Health Services Research Projects in Progress): HSRProj contains descriptions of research in progress funded by Federal and private grants and contracts for use by policymakers, managers, clinicians, providers, and other decisionmakers. It provides access to information about health services research in progress before results are available in a published form.

We included a Web site search of relevant organizations such as the American Society of Clinical Oncology, the American Cancer Society, and the National Coalition for Cancer Survivorship. We used the gray literature to search for additional model components that are in piloting stages or not yet fully implemented.

Appendix B. Sample Data Abstraction Forms

Title and Abstract Review Form



Abbreviations: GQ = Guiding Question; IOM = Institute of Medicine.

Full Text Review Form

	Reviewer
	RefID
	First Author Last Name
	Study Year
	Title
	Relevant for GQ3: Is a model of care or are components of model described? Is there evidence presented on the patients receiving the components of care?
	Only for GQ3 Specific services for survivorship described in article
	Only for GQ3 IOM survivorship care component
	Relevant for GQ1: Overview of Cancer Survivorship Care?
	Relevant for GQ2: Context in which cancer survivorship care is used?
	Relevant GQ4: Gaps in Knowledge and Future Research Needs?
	General Background (not specific to any GQ or "in progress" study)
	For All GQs Study Design (Specify "Other" in comments)
	Comments

Abstraction Form

Identifiers			
RefID	First author's last name	Year	Trial name <i>If present/applicable</i>

Population characteristics						
Type of cancer	Stage of disease at diagnosis	Treatment history	Time since active treatment	Baseline age mean (range)	Baseline % female	Baseline % nonwhite
Type of cancer: N (%)	Stage of disease at diagnosis: N (%)	As described	Preferably mean days/weeks/months (SD)	Overall and by group G1 is always the intervention group; the control group is always the last to be listed		Only report % nonwhite when possible; only give further breakdown if not possible to determine % nonwhite
				Overall: G1: G2:	Overall: G1: G2:	Overall: G1: G2:

Outcomes measured		
Intermediate, health, patient-centered outcomes	Adverse events	Cost and resource utilization
List all intermediate, health, and patient-centered outcomes measured. Describe the length of followup after the intervention ends, e.g., HbA1c (3 months)	List all unintended consequences measured. Describe the length of followup.	List all costs, ER visits, doctor visits, hospitalizations measured. Describe the length of followup.

Comments

Appendix C. List of Excluded Studies

(EXC1)—Wrong design

1. Collins RF, Bekker HL, Dodwell DJ. Follow-up care of patients treated for breast cancer: a structured review. *Cancer Treat Rev.* 2004 Feb;30(1):19-35. PMID: 14766124.
2. Howard-Ruben J. Nurses help patients thrive and survive from diagnosis to treatment and beyond. *ONS News.* 2005 Jun;20(6):1, 4-6. PMID: 15997995.
3. Jacobsen PB. Clinical practice guidelines for the psychosocial care of cancer survivors: current status and future prospects. *Cancer.* 2009 Sep 15;115(18 Suppl):4419-29. PMID: 19731353.
4. Jersild S. Programs work toward transitioning survivors to primary care. *Oncology (Williston Park).* 2007 Apr;21(4 Suppl):40-3. PMID: 17508501.
5. Katz A. Breast cancer and women's sexuality. *Am J Nurs.* 2011 Apr;111(4):63-7. PMID: 21451301.
6. Mitka M. Young adult cancer survivors face barriers to receiving primary care. *JAMA.* 2012 Oct 24;308(16):1618-9. PMID: 23093148.
7. Smith S, Landier W, Francisco L, et al. Development of a customizable, health promotion-oriented prostate cancer survivorship care plan. *Oncol Nurs Forum.* 2009;36(3):19-20. PMID: 43539818.
8. Vanchani C, Hampshire MK, Hill-Kayser C, et al. The essential role of nurses in the development and utilization of an online cancer survivorship care plan. *Oncol Nurs Forum.* 2009;36(3):6-. PMID: 43539574.
9. Goroncy N, Wheeler G, Dwyer M, et al. Sharing the care: an innovative health program for childhood and adult cancer survivors between the late effects clinic at Peter MacCallum Cancer Centre and their GP's. *Pediatr Blood Cancer.* 2011;57(5):826.
10. Juth V, Cohen Silver R, Sender L, et al. Stressors of pediatric cancer care: the influence of interpersonal interactions. *Clin Transl Sci.* 2011;4(2):131.
11. Rogers P, Barr RD, Schacter B. The Canadian task force on adolescents and young adults (AYA) with cancer; a process for change. *Pediatr Blood Cancer.* 2011;57(5):839.
12. Sullivan M, Yallop K, Simpson R, et al. Leap-it-a passport to health; an integrated late effects assessment programme and electronic health passport for long term follow-up of child cancer survivors in New Zealand. *Pediatr Blood Cancer.* 2011;57(5):710.

(EXC2)—Wrong or No Intervention

1. Absolom K, Eiser C, Michel G, et al. Follow-up care for cancer survivors: views of the younger adult. *Br J Cancer.* 2009 Aug 18;101(4):561-7. PMID: 19638979.
2. Barg FK, Cronholm PF, Straton JB, et al. Unmet psychosocial needs of Pennsylvanians with cancer: 1986-2005. *Cancer.* 2007 Aug 1;110(3):631-9. PMID: 17592828.
3. Becker H, Rechis R, Kang SJ, et al. The post-treatment experience of cancer survivors with pre-existing cardiopulmonary disease. *Support Care Cancer.* 2011 Sep;19(9):1351-5. PMID: 20658347.
4. Belkora J, Katapodi M, Moore D, et al. Evaluation of a visit preparation intervention implemented in two rural, underserved counties of Northern California. *Patient Educ Couns.* 2006 Dec;64(1-3):350-9. PMID: 16904859.
5. Binkley JM, Harris SR, Levangie PK, et al. Patient perspectives on breast cancer treatment side effects and the prospective surveillance model for physical rehabilitation for women with breast cancer. *Cancer.* 2012 Apr 15;118(8 Suppl):2207-16. PMID: 22488695.

6. Bishop MM, Lee SJ, Beaumont JL, et al. The preventive health behaviors of long-term survivors of cancer and hematopoietic stem cell transplantation compared with matched controls. *Biol Blood Marrow Transplant*. 2010 Feb;16(2):207-14. PMID: 19781657.
7. Brennan ME, Butow P, Marven M, et al. Survivorship care after breast cancer treatment—experiences and preferences of Australian women. *Breast*. 2011 Jun;20(3):271-7. PMID: 21236671.
8. Cappiello M, Cunningham RS, Knobf MT, et al. Breast cancer survivors: information and support after treatment. *Clin Nurs Res*. 2007 Nov;16(4):278-93; discussion 94-301. PMID: 17991908.
9. Casillas J, Syrjala KL, Ganz PA, et al. How confident are young adult cancer survivors in managing their survivorship care? A report from the LIVESTRONG Survivorship Center of Excellence Network. *J Cancer Surviv*. 2011 Dec;5(4):371-81. PMID: 22042661.
10. Clauser SB, Arora NK, Bellizzi KM, et al. Disparities in HRQOL of cancer survivors and non-cancer managed care enrollees. *Health Care Financ Rev*. 2008 Summer;29(4):23-40. PMID: 18773612.
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(EXC3)—Wrong Population

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(EXC5)—Single Service Only-Single Need/Multiple Providers

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Peer Reviewer and Public Commenters Handsearch Exclusions

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Appendix D. Evidence Tables

Evidence Table 1. Study characteristics—physician-led survivorship care models

Author, Year	Funding Source, Country	Study Design	Setting	Intervention Group(s) If Present/ Applicable	Comparator(s) If Present/ Applicable	Overall Sample Size If Present/ Applicable	Group Sample Sizes If Present/ Applicable
Cannon et al., 2010 ¹	Academic <i>United States</i>	Prospective cohort	Teaching hospital system	G1: Usual care, single provider G2: Usual care, multiple providers		314	G1: 214 G2: 100 Analyzed: G1: 214 G2: 100
Kokko et al., 2005 ²	NR <i>Finland</i>	Parallel RCT	Hospital department of oncology	G1: Frequent visits and routine tests G2: Frequent visits and no routine tests G3: Infrequent visits and routine tests G4: Infrequent visits and no routine tests		472	Randomized/assigned: G1: 125 G2: 114 G3: 118 G4: 115 Analyzed: G1: 125 G2: 114 G3: 118 G4: 115
Wattchow et al., 2006 ³	Multiple <i>Australia</i>	Parallel RCT	Multicenter (multiple hospitals)	G1: General practitioner followup G2: Surgeon followup		203	Randomized/assigned: G1: 97 G2: 106 Analyzed: G1: 82 (12 months) G2: 88 (12 months) G1: 76 (24 months) G2: 81 (24 months)

Abbreviations: G = group; NR = not reported; RCT = randomized controlled trial

Evidence Table 2. Study characteristics—nurse-led survivorship care models

Author, Year	Funding Source, Country	Study Design	Setting	Intervention Group(s) If Present/ Applicable	Comparator(s) If Present/ Applicable	Overall Sample Size If Present/ Applicable	Group Sample Sizes If Present/ Applicable
Gates et al., 2012 ⁴	NR <i>Australia</i>	Prospective cohort	Public teaching cancer hospital	G1: Nurse-led followup	G2: Healthy individuals	60	Assigned: G1: 30 G2: 30 Analyzed: G1: 0 (study ongoing) G2: 0 (study ongoing)
Knowles et al., 2007 ⁵	Multiple <i>United Kingdom</i>	Case series	Hospital surgical department outpatient clinic	G1: Nurse-led followup		60	Assigned: G1: 60 Analyzed: G1: 50–60

Abbreviations: G = group; NR = not reported.

Evidence Table 3. Study characteristics—survivorship care models in which SCP development is a key component

Author, Year	Funding Source, Country	Study Design	Setting	Intervention Group(s) If Present/ Applicable	Comparator(s) If Present/ Applicable	Overall Sample Size If Present/ Applicable	Group Sample Sizes If Present/ Applicable
Curcio et al., 2011 ⁶	NR <i>United States</i>	Case series	Community cancer center	G1: Survivorship protocol		30	Assigned: G1: 30 Analyzed: G1: 30
Grunfeld et al., 2011 ⁷	Multiple <i>Canada</i>	Parallel RCT	Tertiary care cancer centers and physician offices	G1: Usual care, SCP	G2: Usual care, no SCP	408	Randomized/ assigned: G1: 200 G2: 208 Analyzed: G1: 170 G2: 186
Jefford et al., 2011 ⁸	Foundation/ nonprofit <i>Australia</i>	Case series	Teaching hospital system	G1: SurvivorCare intervention		10	Assigned: G1: 10 Analyzed: G1: 8–10

Abbreviations: G = group; NR = not reported; RCT = randomized controlled trial; SCP = survivorship care plan

Evidence Table 4. Study characteristics—survivorship care models comparing group versus individual counseling

Author, Year Trial Name	Funding Source, Country	Study Design	Setting	Intervention Group(s) If Present/ Applicable	Comparator(s) If Present/ Applicable	Overall Sample Size If Present/ Applicable	Group Sample Sizes If Present/ Applicable
Naumann et al., 2012 ⁹	Program delivery grant from the Hospital Benefit Fund, <i>Australia</i>	Controlled clinical trial	NR	G1: Individual- based exercise and counseling G2: Group-based exercise and counseling	G3: Usual care	40	Randomized/ assigned: G1: 13 G2: 15 G3: 12 Analyzed: G1: 12 G2: 14 G3: 10

Abbreviations: G = group; NR = not reported.

Evidence Table 5. Intervention characteristics—physician-led survivorship care models

Author, Year Trial Name Type of Survivorship Model, if Defined Recipient of Intervention Component	Inclusion/Exclusion Criteria	Goal of Intervention Intervention Duration	Components of Survivorship Care	Intensity of Intervention	Delivery Agent (and Mode of Delivery)
Cannon et al. 2010 ¹ NR NR Patients	<p>Inclusion criteria:</p> <ul style="list-style-type: none"> Patients who were at least 19 years of age (age of consent in Nebraska) and who had completed cancer treatment at the University of Nebraska Medical Center were included. Because Nebraska has a low number of ethnic minorities and is a predominantly rural state, all racial/ethnic minorities and patients coming from rural areas were first included. 	<p>To study the association between number of followup providers among survivors of hematologic malignancies and serious medical utilization</p> <p>Average duration of interaction: 6 months</p>	<p>G1: Usual care with single provider (university-based oncologist or community physician [i.e., internist, family medicine physician, community oncologist])</p> <p>G2: Usual care with multiple providers (university-based oncologist and community physician or community-based oncologist and either an internist or a family medicine physician)</p>	NA	<p>G1: Intervention component 1: University-based oncologist or community physician (i.e., internist, family medicine physician, community oncologist (face-to-face, telephone))</p> <p>G2: Intervention component 1: University-based oncologist and community physician or community-based oncologist and either an internist or a family medicine physician (face-to-face, telephone)</p>

Evidence Table 5. Intervention characteristics—physician-led survivorship care models (continued)

Author, Year Trial Name Type of Survivorship Model, if Defined Recipient of Intervention Component	Inclusion/Exclusion Criteria	Goal of Intervention Intervention Duration	Components of Survivorship Care	Intensity of Intervention	Delivery Agent (and Mode of Delivery)
Kokko et al. 2005 ² NR NR Patients	<p>Inclusion criteria:</p> <ul style="list-style-type: none"> Female patients with localized breast cancer diagnosed in the area of Tampere University Hospital between May 1991 and December 1995 were enrolled after primary treatment. <p>Exclusion criteria:</p> <ul style="list-style-type: none"> Patients with metastatic disease and patients participating in other adjuvant clinical trials. 	<p>Incorporate information on both costs and health outcomes to compare more intensive with less intensive interventions</p> <p>Average duration of interaction: 4.2 years</p>	Routine followup visits (every third or sixth month); diagnostic examinations (routine or on clinical grounds)	<p>Intervention component 1: Routine followup visits every 3 months for G1 and G2; every 6 months for G3 and G4</p> <p>Intervention component 2: Blood tests every 3 months for G1, 6 months for G3, as clinically indicated for G2 and G4. Chest x-ray every 6 months for G1 and G3, as clinically indicated for G2 and G4. Liver ultrasound and</p>	<p>Intervention component 1: Department of oncology (face-to-face)</p> <p>Intervention component 2: Department of oncology (face-to-face)</p>

Evidence Table 5. Intervention characteristics—physician-led survivorship care models (continued)

Author, Year Trial Name Type of Survivorship Model, if Defined Recipient of Intervention Component	Inclusion/Exclusion Criteria	Goal of Intervention Intervention Duration	Components of Survivorship Care	Intensity of Intervention	Delivery Agent (and Mode of Delivery)
Kokko et al., 2005 ² (continued)				bone scan every second year for G1 and G3, as clinically indicated for G2 and G4	

Evidence Table 5. Intervention characteristics—physician-led survivorship care models (continued)

Author, Year Trial Name Type of Survivorship Model, if Defined Recipient of Intervention Component	Inclusion/Exclusion Criteria	Goal of Intervention Intervention Duration	Components of Survivorship Care	Intensity of Intervention	Delivery Agent (and Mode of Delivery)
Wattchow et al., 2006 ³ Provider-led Patients	<p>Inclusion:</p> <ul style="list-style-type: none"> • Surgery for colon cancer (including rectosigmoid) with histological grade Dukes stage A, B, or C (cases of disseminated cancer were excluded). • Completion of postsurgical chemotherapy (principally Dukes Stage C patients). • Followup by GPs and surgeons available. • Able to provide informed consent. <p>Exclusion:</p> <ul style="list-style-type: none"> • Rectal tumors (current practice for rectal cancer followup requires regular sigmoidoscopy that would not be undertaken by many GPs). • Significant polyps discovered at initial colonoscopy (or at subsequent completion colonoscopy) that indicated increased frequency of colonoscopic monitoring. • Any other condition that warranted increased intensity of surveillance with respect of colon cancer followup. 	<p>To determine whether, among these patients, the setting of followup impacts on our primary outcomes: quality of life, psychological well-being, and satisfaction with care</p> <p>Average duration of interaction: NR; patients were followed for up to 24 months</p>	Surveillance for recurrence/new cancers; symptoms	Patients expected to visit their treating provider for followup on a quarterly basis	<p>Intervention component 1: General practitioner (mode NR)</p> <p>Intervention component 2: Surgeon (mode NR)</p>

Abbreviations: G = group; GPs = general practitioners; NA = not applicable; NR = not reported; SD = standard deviation.

Evidence Table 6. Intervention characteristics—nurse-led survivorship care models

Author, Year Trial Name Type of Survivorship Model, if Defined Recipient of Intervention Component	Inclusion/Exclusion Criteria	Goal of Intervention Intervention Duration	Components of Survivorship Care	Intensity of Intervention	Delivery Agent (and Mode of Delivery)
Gates et al., 2012 ⁴ NR Nurse-led survivorship care (Draws on Pender's Revised Health Promotion Model) Patients	Inclusion criteria: <ul style="list-style-type: none"> Survivor participants: Had a diagnosis of HL; received upper torso radiotherapy at any stage during treatment, regardless of other therapies; at least 5 years postcompletion of curative treatment for HL; a new referral to the haematology late effects clinic at Peter Mac; over 18 years old; able to complete study requirements in English; had a sibling, partner, or significant other unaffected by a diagnosis of cancer who met eligibility criteria outlined below, and were willing to take part as a control participant. 	To establish whether receiving a health-promoting intervention from a specialist cancer nurse demonstrates capacity to improve HL survivors' knowledge of and motivation to adopt health-promoting behaviors. Average duration of interaction: 6 months	Nurse-led consultations include an education package tailored to the individual's health needs, screening for emotional distress, and delivery of an individualized SCP Phone calls to reinforce intervention	Intervention component 1: Nurse-led consultations Average number of sessions: 2 Intervention component 2: Phone call to reinforce intervention Average number of sessions: 2	Intervention component 1: Nurse (face-to-face) Intervention component 2: Nurse (telephone)

Evidence Table 6. Intervention characteristics—nurse-led survivorship care models (continued)

Author, Year Trial Name Type of Survivorship Model, if Defined Recipient of Intervention Component	Inclusion/Exclusion Criteria	Goal of Intervention Intervention Duration	Components of Survivorship Care	Intensity of Intervention	Delivery Agent (and Mode of Delivery)
	<p>Inclusion criteria (cont.):</p> <ul style="list-style-type: none"> • Healthy participants: A sibling, partner, or significant other of a study group HL survivor; never diagnosed with cancer (excluding nonmelanoma skin cancers); of comparable age (+/- 5 years) and gender to the study group HL survivor; over 18 years; able to complete the study requirements in English; no co-occurring serious and/or uncontrolled illness that impacted their functional status, including heart disease, stroke, respiratory disease, diabetes, dementia, and Alzheimer's disease. 				

Evidence Table 6. Intervention characteristics—nurse-led survivorship care models (continued)

Author, Year Trial Name Type of Survivorship Model, if Defined Recipient of Intervention Component	Inclusion/Exclusion Criteria	Goal of Intervention Intervention Duration Cointerventions	Components of Survivorship Care	Intensity of Intervention	Delivery Agent (and Mode of Delivery)
Knowles et al., 2007 ⁵ NR Nurse-led care Patients	<p>Inclusion criteria (cont.):</p> <ul style="list-style-type: none"> All patients having undergone surgery with curative intent for a colorectal cancer primary (Dukes A, B, and C) who would be considered eligible for surgical resection in the event of disease recurrence. <p>Exclusion criteria:</p> <ul style="list-style-type: none"> Patients with metastatic or recurrent colorectal disease. Patients who wished to remain in traditional followup care. Patients not deemed suitable for nurse-led followup by their surgeon/oncologist due to complications or complex comorbidities. Patients from outside of the Lothian Area who would routinely be followed up closer to home. 	<p>Pilot study designed to assess the feasibility of a followup program led by nurse specialists for patients with colorectal cancer</p> <p>Average duration of interaction: ~12 months</p>	<p>Telephone clinic; consultant clinic; nurse specialist clinics</p> <p>Investigations and assessments (e.g., pathology results, symptom assessment, clinical examination, wound examination, rectal exam, carcinoembryonic antigen marker, computed tomography scan) routinely required per-protocol varied per clinic interval</p>	<p>Intervention component 1: Telephone clinic</p> <p>Average number of sessions: 1</p> <p>Intervention component 2: Consultant clinic</p> <p>Average number of sessions: 1</p> <p>Intervention component 3: Nurse specialist clinics</p> <p>Average number of sessions: 3</p> <p>Average time in each session: 20–25 minutes</p>	<p>Intervention component 1: Nurse (telephone)</p> <p>Intervention component 2: Surgical consultant (face-to-face)</p> <p>Intervention component 3: Nurse (face-to-face)</p>

Abbreviations: HL = Hodgkin's lymphoma; NR = not reported; SCP = survivorship care plan; SD = standard deviation.

Evidence Table 7. Intervention characteristics—survivorship care models focused on SCP development

Author, Year Trial Name Type of Survivorship Model, if Defined Recipient of Intervention Component	Inclusion/Exclusion Criteria	Goal of Intervention Intervention Duration	Components of Survivorship Care	Intensity of Intervention	Delivery Agent (and Mode of Delivery)
Curcio et al. 2011 ⁶ NR NR Patients	<p>Inclusion criteria:</p> <ul style="list-style-type: none"> Patients who had completed acute treatment for cancer within the past 2 years. Acute treatment was defined as completion of any planned surgery, chemotherapy, or radiation therapy. Survivors who remained on hormonal treatments for their cancer were considered to have completed their acute treatment and were included. Survivors within 2 years of completing their acute treatment also were included. An additional inclusion criterion was being older than 18 years. <p>Exclusion criteria:</p> <ul style="list-style-type: none"> Having evidence of metastatic disease; receiving hospice services; or being unable to read, write, or speak English. 	<p>To improve cancer survivors' knowledge about their disease and decrease anxiety.</p> <p>Average duration: 1 month</p>	G1: Survivorship protocol (i.e., formalized mechanism to review IOM recommendations with the patient) visit in which an individualized SCP was reviewed with the patient and any questions were answered; a followup phone call to answer any remaining questions and assess their anxiety and knowledge	<p>Intervention component 1: Survivorship visit including review of individualized care plan</p> <p>Average number: 1</p> <p>Average time in each session (SD): 58.8 minutes (12.5)</p> <p>Intervention component 2: Phone call</p> <p>Average number of sessions: 1</p>	<p>Intervention component 1: Nurse practitioner (face-to-face)</p> <p>Intervention component 2: Nurse practitioner (telephone)</p>

Evidence Table 7. Intervention characteristics—survivorship care models focused on SCP development (continued)

Author, Year Trial Name Type of Survivorship Model, if Defined Recipient of Intervention Component	Inclusion/Exclusion Criteria	Goal of Intervention Intervention Duration	Components of Survivorship Care	Intensity of Intervention	Delivery Agent and Mode of Delivery
Grunfeld et al., 2011 ⁷ NR SCP Intervention component 1: Patients, PCPs also receive the patient's SCP Intervention component 2: Patients	<p>Inclusion criteria:</p> <ul style="list-style-type: none"> Women with early-stage breast cancer who completed primary treatment at least 3 months previously, except for continued use of tamoxifen or an aromatase inhibitor, and who were without recurrent or new primary cancer. <p>Exclusion criteria:</p> <ul style="list-style-type: none"> Patients were excluded if they were still experiencing complications of primary treatment, did not have a PCP to provide care, were previously enrolled on a study requiring oncology followup, were actively followed up for another primary cancer, or had a PCP who already had a patient enrolled in the trial (to avoid contamination). 	<p>To determine if an SCP for breast cancer survivors improves patient-reported outcomes</p> <p>Average duration: 2 years, although only results up to the 12-month visit were reported</p>	<p>A comprehensive SCP that consisted of the prescribed elements, including a personalized treatment summary, a patient version of the Canadian national followup guideline, a summary table of the guideline that served as a reminder system, and a resource kit tailored to the patient's needs on available supportive care resources. These documents were compiled in a binder and were reviewed with the patient during an educational session with a nurse, who also made an explicit statement that followup care was now the responsibility of the PCP and that access to the oncologist was available when needed. These documents were also sent to the patient's PCP together with the full followup guideline, a user-friendly summary version, and a reminder table</p>	<p>Intervention component 1: SCP binder delivery and educational session Average number of sessions (SD): 1 Average time in each session: 30 minutes Intervention component 2: Routine followup transferred to PCP</p>	<p>Intervention component 1: Nurse (face-to-face) Intervention component 2: PCP (face-to-face)</p>

Evidence Table 7. Intervention characteristics—survivorship care models focused on SCP development (continued)

Author, Year Trial Name Type of Survivorship Model, if Defined Recipient of Intervention Component	Inclusion/ Exclusion Criteria	Goal of Intervention Intervention Duration	Components of Survivorship Care	Intensity of Intervention	Delivery Agent and Mode of Delivery
Jefford et al., 2011 ⁸ NR NR Patients, although support people are encouraged to attend intervention component 1	Inclusion criteria: • Eligible survivors were (a) diagnosed with CRC (stages I–III), (b) completing primary treatment with curative intent (surgery, chemotherapy, radiotherapy, or combination) or had completed primary treatment with curative intent within the past 12 months, (c) older than 18 years, and (d) able to speak sufficient English to complete questionnaires and provide informed consent. Exclusion criteria: • Patients had severe cognitive or psychological difficulties, as determined by the treating provider.	This study aimed to develop and pilot test an innovative supportive care program for people with potentially curative CRC Average duration of interaction: ~7 weeks for intervention components 1 and 2	Provision of information—DVD, information booklet, question prompt list; an individualized SCP for the survivor, their GP, and oncology specialists; a face-to-face, nurse-led end-of-treatment session; followup telephone calls	Intervention component 1: End-of-treatment consultation Average number of sessions: 1 Average time in each session: 1 hour Intervention component 2: Followup telephone calls Average number of sessions: 3 Average time in each session: 10 minutes	Intervention component 1: Nurse (face-to-face or telephone) Intervention component 2: Nurse (telephone)

Abbreviations: CRC = colorectal cancer; G = group; IOM = Institute of Medicine; NR = not reported; PCP = primary care physician; SCP = survivorship care plan; SD = standard deviation.

Evidence Table 8. Intervention characteristics—survivorship care models comparing individual versus group counseling

Author, Year Trial Name Type of Survivorship Model, if Defined Recipient of Intervention Component	Inclusion/Exclusion Criteria	Goal of Intervention Intervention Duration	Components of Survivorship Care	Intensity of Intervention	Delivery Agent and Mode of Delivery
Naumann et al., 2012 ⁹ A review of literature provided compelling evidence that group psychotherapy and group exercise improve quality of life of cancer survivors, possessing unique advantages over individual interventions by providing additional opportunity for social support, social comparison, and modeling. Patients	<p>Inclusion criteria:</p> <ul style="list-style-type: none"> Women with confirmed stages I–III breast cancer, aged 35–70 years, sufficiently fluent in English, and not meeting current American College of Sports Medicine guidelines for adequate physical activity (<150 minutes per week). <p>Exclusion criteria:</p> <ul style="list-style-type: none"> Acute or chronic bone, joint, or muscular abnormalities that would compromise patient's ability to participate in exercise; failure of Physical Activity Readiness Questionnaire; presence of metastatic disease. 	<p>To assess the feasibility of a 9-week individual- or group-based exercise and counselling program and to examine if group-based intervention is as effective in improving the quality of life of breast cancer survivors as an individual-based intervention.</p> <p>Average duration of interaction: 9 weeks.</p>	<p>G1: Exercise training sessions (combination of cardiovascular training [cycle, cross-training, brisk walking], strength training, hydrotherapy, core training, patient-specific rehabilitation, flexibility) and individual counseling (client-centered approach based on individual needs)</p> <p>G2: Exercise training sessions (cardiovascular training [cycle, cross-training, brisk walking], strength training [weight training in gymnasium, pump class], core training [floor, Pilates], hydrotherapy, flexibility) and group counseling (in groups of 6 to 8 women).</p>	<p>Intervention component 1: Exercise training</p> <p>Average number of sessions: 27 for G1 and G2</p> <p>Average time in each session: 45 to 60 minutes per exercise training session for G1 and G2.</p> <p>Intervention component 2: Counseling</p> <p>Average number of sessions: 9 for G1 and G2</p> <p>Average time in each session: 1 hour for G1 and G2.</p>	<p>Intervention component 1: Accredited exercise physiologist (G1 and G2)</p> <p>Intervention component 2: Accredited counselor (G1 and G2).</p>

Abbreviations: G = group; SD = standard deviation.

Evidence Table 9. Patient characteristics

Type of Survivorship Intervention	Author and Year	Cancer Types(s) and Patient Numbers (%)	Stage of Disease at Diagnosis	Time Since Completion of Active Treatment	Baseline Age Mean (Range)	Baseline % Female
Physician-Led Survivorship Care Models	Cannon et al., 2010 ¹	Leukemia: 54 (17.2) Lymphoma: 234 (74.5) Myeloma: 26 (8.3)	NA	Single physician group: median 47 months Multiple physician group: median 38 months	Single provider: 59 (22–86); multiple providers: 55 (19–79)	50.3%
	Kokko et al., 2005 ²	Breast cancer: 472 (100.0)	Localized disease after primary treatment: 472 (100.0)	NR, apparently shortly after active treatment	Median 56.8–60.5, depending on study arm	100%
	Wattchow et al., 2006 ³	Colon cancer: 203 (100.0)	Dukes stages: A: 47 (23.2) B: 96 (47.3) C: 60 (29.6)	NR	NR	Overall: 42.4% G1: 38.1% G2: 46.2%
Nurse-Led Survivorship Care Models	Gates et al., 2012 ⁴	Hodgkin lymphoma: 30 (100.0)	N/A	At least 5 years	Median 44 (24–72)	40.0%
	Knowles et al., 2007 ⁵	Rectal/rectosigmoid cancer: 19 (31.7) Colon cancer: 41 (68.3)	Dukes A: 11 (18.3) Dukes B: 26 (43.3) Dukes C1: 18 (30.0) Dukes C2: 5 (8.3)	Telephone call 2–3 weeks following surgery; first visit 4 months following surgery	67.3 (29–94)	48.3%

Evidence Table 9. Patient characteristics (continued)

Type of Survivorship Intervention	Author and Year	Cancer Types(s) and Patient Numbers (%)	Stage of Disease at Diagnosis	Time Since Completion of Active Treatment	Baseline Age Mean (Range)	Baseline % Female
Survivorship Care Models Focused on SCP Development	Curcio et al., 2011 ⁶	Breast cancer: 16 (53.3) Hematologic cancer: 8 (26.7) Lung cancer: 3 (10.0) Gastrointestinal cancer: 3 (10.0)	Ductal carcinoma in situ: 3 (10.0) Stage I: 4 (13.3) Stage II: 14 (46.7) Stage III: 9 (30.0)	Within 2 years	64 (30–83)	83.3%
	Grunfeld et al., 2011 ⁷	Breast cancer: 408 (100.0)	Early stage: 408 (100)	At least 3 months	61.7 no SCP; 61.2 SCP	100%
	Jefford et al., 2011 ⁸	Colorectal cancer: 10 (100.0)	Stage 1: 1 (10.0) State 2: 1 (10.0) Stage 3A: 3 (30.0) Stage 3B: 3 (30.0) Stage 3C: 2 (20.0)	Within 2 weeks	55 (35–71)	50.0%
Survivorship Care Models Comparing Group vs. Individual Counseling	Naumann et al., 2012 ⁹	Breast cancer: 36 (100)	NR	Within 12 months	NR	100%

Abbreviations: NA = not applicable; NR = not reported; SCP = survivorship care plan; vs. = versus.

Evidence Table 10. Outcomes

Type of Survivorship Intervention	Author and Year	Type of Survivorship Intervention	Average Intervention Duration	Outcomes Assessed
Physician-Led Survivorship Care Models	Cannon et al., 2010 ¹	Comparison of usual care with single vs. multiple providers	6 months	QOL-MOS short form 12 (6 months); patient satisfaction—PSQ-18 (6 months)
	Kokko et al., 2005 ²	Comparison of visit frequency and use of diagnostic tests	4.2 years	Disease free time; overall survival
	Wattchow et al., 2006 ³	Physician-led	Patients expected to visit their treating provider for followup on a quarterly basis	Quality of life, depression, and anxiety at 12 and 24 months; satisfaction at 24 months; number of recurrences and all-cause deaths at 24 months; resource utilization at 24 months
Nurse-Led Survivorship Care Models	Gates et al., 2012 ⁴	Nurse-led followup	6 months	Perception of health—General Health Index (~2 weeks after each face-to-face, nurse-led consultation and again ~2 months after second phone call/last intervention component); engagement in health-promoting activities—Health Promoting Lifestyle Profile II (~2 weeks after each face-to-face, nurse-led consultation and again ~2 months after second phone call/last intervention component)
	Knowles et al., 2007 ⁵	Nurse-led followup	~12 months	Patient recurrence; quality of life—EORTC QLQ-C30 and EORTC QLC-CR38 (measured at each face-to-face visit); satisfaction with intervention—adapted rheumatology patient population questionnaire (measured at face-to-face 12-month visit)

Evidence Table 10. Outcomes (continued)

Type of Survivorship Intervention	Author and Year	Type of Survivorship Intervention	Average Intervention Duration	Outcomes Assessed
Survivorship Care Models Focused on SCP Development	Curcio et al., 2012 ⁶	Survivorship protocol	1 month	Improve cancer survivors' knowledge about cancer (1 month); decrease cancer survivors' anxiety—GAD-7 (1 month); fidelity to evidence-based followup (1 month); patient satisfaction—survey (immediately following the survivorship visit protocol)
	Grunfeld et al., 2011 ⁷	SCP	2 years (although only results up to the 12-month visit were reported)	Cancer-related distress—IES (questionnaires completed at 3, 6, 12, 18, and 24 months but only months 3, 6, 12 reported); general psychological distress—POMS (questionnaires completed at 3, 6, 12, 18, and 24 months but only months 3, 6, 12 reported); quality of life—SF-36 (questionnaires completed at 3, 6, 12, 18, and 24 months but only months 3, 6, 12 reported); patient satisfaction—PSQ (questionnaires completed at 3, 6, 12, 18, and 24 months but only months 3, 6, 12 reported); continuity/coordination of care—CCCQ (questionnaires completed at 3, 6, 12, 18, and 24 months but only months 3, 6, 12 reported)

Evidence Table 10. Outcomes (continued)

Type of Survivorship Intervention	Author and Year	Type of Survivorship Intervention	Average Intervention Duration	Outcomes Assessed
Survivorship Care Models Focused on SCP Development	Jefford et al., 2011 ⁸	SurvivorCare intervention	~7 weeks	Unmet needs—CaSUN (1 week); psychological distress—BSI-18 (1 week); quality of life—QLQ-C30 (1 week); satisfaction with intervention (unspecified)
Survivorship Care Models Comparing Group vs. Individual Counseling	Naumann et al., 2012 ⁹	Individual- vs. group-based exercise and counseling	9 weeks	Global QOL—FACT-B QOL Scale (measured at baseline and intervention completion); QOL Subscales: 1. Physical well-being (measured at baseline and intervention completion); 2. Social well-being (measured at baseline and intervention completion); 3. Emotional well-being (measured at baseline and intervention completion); 4. Functional well-being (measured at baseline and intervention completion); feasibility measurements: recruitment, retention, session attendance, adherence to exercise, adherence to counseling programs

Abbreviations: BSI-18 = Brief Symptom Inventory 18; CaSUN = Cancer Survivors' Unmet Needs measure; CCCQ = Clinical Cultural Competency Questionnaire ; EORTC = European Organization for Research and Treatment of Cancer; FACT-B = Functional Assessment of Cancer Therapy—Breast; GAD-7 = General Anxiety Disorder Assessment-7; IES = Impact of Event Scale; POMS = Profile of Mood States; PSQ-18 = Patient Satisfaction Questionnaire-18; QLQ-C38 Cancer Specific Quality of Life Questionnaire; QLQ-C30 = Cancer Specific Quality of Life Questionnaire; QOL = quality of life; QOL-MOS = Quality of Life-Medical Outcomes Study; SCP = survivorship care plan; SF-36 = Short Form (36) Health Survey ; vs. = versus.

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Appendix E. Glossary of Terms

1. For the purposes of this Technical Brief, we define cancer survivor as an individual who has completed the majority or all of the active treatment for cancer (i.e., treatment with curative intent).
2. Survivorship care: A health care service or combination of services for cancer survivors that has one or more of these four components as defined by the Institute of Medicine (IOM) Committee on Cancer Survivorship: Improving Care and Quality of Life, Institute of Medicine and National Research Council. (From Cancer Patient to Cancer Survivor: Lost in Transition. Washington, DC: The National Academies Press, 2006, page 3):
 - a. Prevention of recurrent and new cancers, and of other late effects;
 - b. Surveillance for cancer spread, recurrence, or second cancers; assessment of medical and psychosocial late effects;
 - c. Intervention for consequences of cancer and its treatment, for example: medical problems such as lymphedema and sexual dysfunction; symptoms, including pain and fatigue; psychological distress experienced by cancer survivors and their caregivers; and concerns related to employment, insurance, and disability; and
 - d. Coordination between specialists and primary care providers to ensure that all of the survivor's health needs are met.
3. Survivorship Research: Cancer survivorship research encompasses the physical, psychosocial, and economic sequelae of cancer diagnosis and its treatment among both pediatric and adult survivors of cancer. It also includes within its domain issues related to health care delivery, access, and followup care, as they relate to survivors. Survivorship research focuses on the health and life of a person with a history of cancer beyond the acute diagnosis and treatment phase. It seeks to both prevent and control adverse cancer diagnosis and treatment-related outcomes such as late effects of treatment, second cancers, and poor quality of life; to provide a knowledge base regarding optimal followup care and surveillance of cancers; and to optimize health after cancer treatment. (<http://dccps.nci.nih.gov/ocs/definitions.html>)
4. Cancer Survivorship Program (American Cancer Society): “comprehensive set of services provided by multidisciplinary groups working together to ensure effective medical care, education and emotional support.”
5. Models of survivorship care: The construct behind the term “model” relates to the cohesiveness of a program that infers more than one service. In the Technical Brief, we describe various types of models found in the literature.
 - a. Consultative model: the patient is primarily seen by primary care or survivorship care team, but periodically or on an as-needed basis refers to the oncology team for services.
 - b. Multidisciplinary clinic: specialty (i.e., oncology) clinics coordinate with primary care and other medical service clinics to provide survivorship care.

- c. Integrated care model: each member of the patient's survivorship care experience communicates with each other and within a commonly agreed-upon system of care that establishes pre-determined roles (may share features with shared-care).
- d. Transition to primary care: the patient moves from predominantly oncology team care during active treatment to primary care for survivorship services.
- e. Shared-care model: the primary care team and the oncology team both provide health care to the cancer survivor (may share features with integrated care). Does not have to occur in an integrated system.
- f. Survivorship care plan (SCP): medically guided instructions for patient care during the survivorship stage based on an assessment of patient needs.
- g. Patient navigator: a lay/peer health partner who serves as a resource to the patient about survivorship care and as a liaison between the patient and the medical team and services.