



THE ESSENTIAL ELEMENTS OF SURVIVORSHIP CARE: A LIVESTRONG BRIEF

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THE NEED FOR CONSENSUS ON ESSENTIAL ELEMENTS OF SURVIVORSHIP CARE DELIVERY

There are approximately 12 million cancer survivors alive in the United States today, and that number is expected to grow to more than 18 million by 2020 (Mariotto, Yabroff, Shao, Feuer, & Brown, 2011). As a result of innovative research, improved detection, access to care and treatment, and a focus on life after treatment, more people are surviving cancer than ever before. However, it has become clear that when primary treatment ends, the cancer journey does not (Institute of Medicine [IOM] and National Research Council [NRC] of the National Academies, 2006). After treatment, many cancer survivors experience physical, emotional, and practical concerns, but they do not always receive the help they need (Rechis, Reynolds, Beckjord, & Nutt, 2010). With the increase in survivors over the past decade, post-treatment survivorship care has emerged as a new and evolving area of clinical practice and research (Jacobs et al., 2009). A challenge for the cancer survivorship community is how to best design and deliver high-quality survivorship care. Currently, there is little or no consensus on what survivorship providers must include, should include, or should strive to include in their approach to care. As the cancer survivor population continues to grow, building consensus is critical to preparing the cancer community to effectively respond to the challenges encountered by cancer survivors in the post-treatment period.

On September 15 and 16, 2011, LIVESTRONG convened the Essential Elements of Survivorship Care Meeting (Essential Elements Meeting) in Washington, DC. The goal of this meeting was to build consensus among key stakeholders on the essential elements of survivorship care that any effective cancer survivorship program must provide (directly or via referral) to post-treatment cancer survivors. It is important to note that the goal of the meeting was not to identify specific guidelines or standards for delivering care (e.g., surveillance for recurrence conducted at particular time points). LIVESTRONG, in partnership with meeting leaders who are experts from

different perspectives across the cancer community, convened 150 community leaders, stakeholders, cancer survivors, and cancer survivor advocates to build consensus on identifying the essential elements of survivorship care. Meeting participants used a series of consensus-building activities to facilitate agreement on and refinement of a list of the essential elements of survivorship care. These consensus-building activities were enhanced by panel discussions on key issues in survivorship led by experts in the field. Please note that the full agendas, bios of each meeting leader, and supplementary meeting materials can be found at LIVESTRONG.org/

EssentialElements. Additionally, all meeting attendees and meeting leaders are listed along the bottom of each page of this brief. Meeting leaders, including the LIVESTRONG Survivorship Centers of Excellence Network Directors and Steering Committee (referred to as the Network) as well as the Essential Elements Meeting Advisory Committee, are bolded in the list along the bottom of each page.

“Everybody wants to do a survivorship care program, but don’t know the minimum elements that are critical.”

— Essential Elements Meeting Participant

WHAT IS AN ESSENTIAL ELEMENT OF SURVIVORSHIP CARE?

Prior to the Essential Elements meeting, several steps were taken to ensure a successful outcome. The first step in the process of identifying essential elements of survivorship care required developing a working definition for an “element of survivorship care” and the criteria that an element must meet in order to be deemed “essential.” The Network agreed upon the following definitions:

An *element of survivorship care* is a descriptor of some component of health care that is as follows:

- discrete enough to be actionable (i.e., provides enough information to communicate how the element might function as part of survivorship care); and
- not overly prescriptive (i.e., does not include specific directions on implementation since specific needs will vary significantly across survivor populations and survivorship care settings).

The criteria for an element to be deemed an *essential* element of care is as follows:

- has a positive impact on morbidity, mortality, and/or quality of life for all cancer survivors;
- can be implemented across a variety of care settings; and
- is supported by an evidence base which exists in cancer survivorship

or exists in other related health domains; or, when an evidence base does not exist, the element embodies one of the following:

- addresses expressed needs of cancer survivors;
- has been agreed upon through consensus of the provider community; or
- can be tested through further research.

Once these important terms were defined, the next step was to create an expansive list of all possible elements. The *universe of elements* of survivorship care was organized using the framework outlined by the Institute of Medicine’s *Lost in Transition* report (IOM and NRC, 2006) for categorizing the four elements of survivorship care: Prevention, Surveillance, Intervention, and Coordination. This universe of elements was created using the following four steps:

1. A targeted literature review and a review of the survivorship programs in the Network and other comprehensive cancer centers conducted by the RAND Corporation on behalf of **LIVESTRONG**, which identified 81 elements of survivorship care delivery.
2. Review and feedback conducted on the list of 81 elements by the Network. This review and feedback expanded the universe to 101 elements of survivorship care delivery.
3. Review and feedback conducted on the list of 101 elements from

the Essential Elements Meeting Advisory Committee (Advisory Committee) and the Network. This review and feedback condensed the universe to 45 elements of survivorship care.

4. Final review and feedback conducted on the list of 45 elements of survivorship care from the Network and the Advisory Committee to confirm that the final universe was still exhaustive but also an actionable list of elements for the purposes of achieving consensus on essential elements of survivorship care at the Essential Elements Meeting.

“How do we make this [the essential elements] feasible and meaningful across settings? One size doesn’t fit all.”

— **Essential Elements Meeting Participant**

THE ESSENTIAL ELEMENTS MEETING CONSENSUS-BUILDING EXERCISES

During the Essential Elements Meeting, groups of six to eight individuals were seated at tables where they participated in a total of five consensus-building sessions based on a modified version of the Delphi Process (Brown, 1968). The Delphi Process offers advantages over less systematic methods of building consensus by using structured round table discussions and iterative



brainstorming sessions. The modified Delphi Process used at the Essential Elements Meeting, as described more thoroughly below, involved multiple iterations of individually selecting and ranking elements gleaned from group discussions at tables which were specifically seated with stakeholders from varying groups to incorporate multiple perspectives. Each table at the Essential Elements Meeting included at least one member of the Network, a cancer survivor or advocate, and a table facilitator. The table facilitators helped to guide discussions on the key issues, or themes, and reported information from the table's discussions in real time via computer. This

information was sent to a bank of two computers which were staffed by four individuals known as the theme team. Throughout the meeting, the theme team objectively analyzed the information entered by the table facilitators to identify common themes as they emerged. These themes and the results of each consensus-building exercise were reported to participants throughout the meeting so that they could use the outcome of one exercise to inform their input for the next. The first four consensus-building exercises involved group discussion followed by each participant selecting elements of survivorship care delivery from the universe of elements and



ranking selections based on most to least essential (see Figure 1). The total number of elements participants were instructed to select and the universe of elements they chose from changed throughout the day as participants provided feedback and input after each exercise. Additionally, some elements were combined because as participants discussed the essential elements, consensus emerged that certain elements were better understood and enacted in concert with other similar elements. For example, care plans, treatment

summaries, and psychosocial care plans were linked as one unified element of care.

The final consensus-building exercise took place on the second day of the meeting. This final exercise required table members to work as a group to identify tiers, or prioritized levels, of essential elements of survivorship care.

Finally, one week after the meeting, all attendees received a synthesis of the meeting outcomes and were asked to rate their confidence in both the

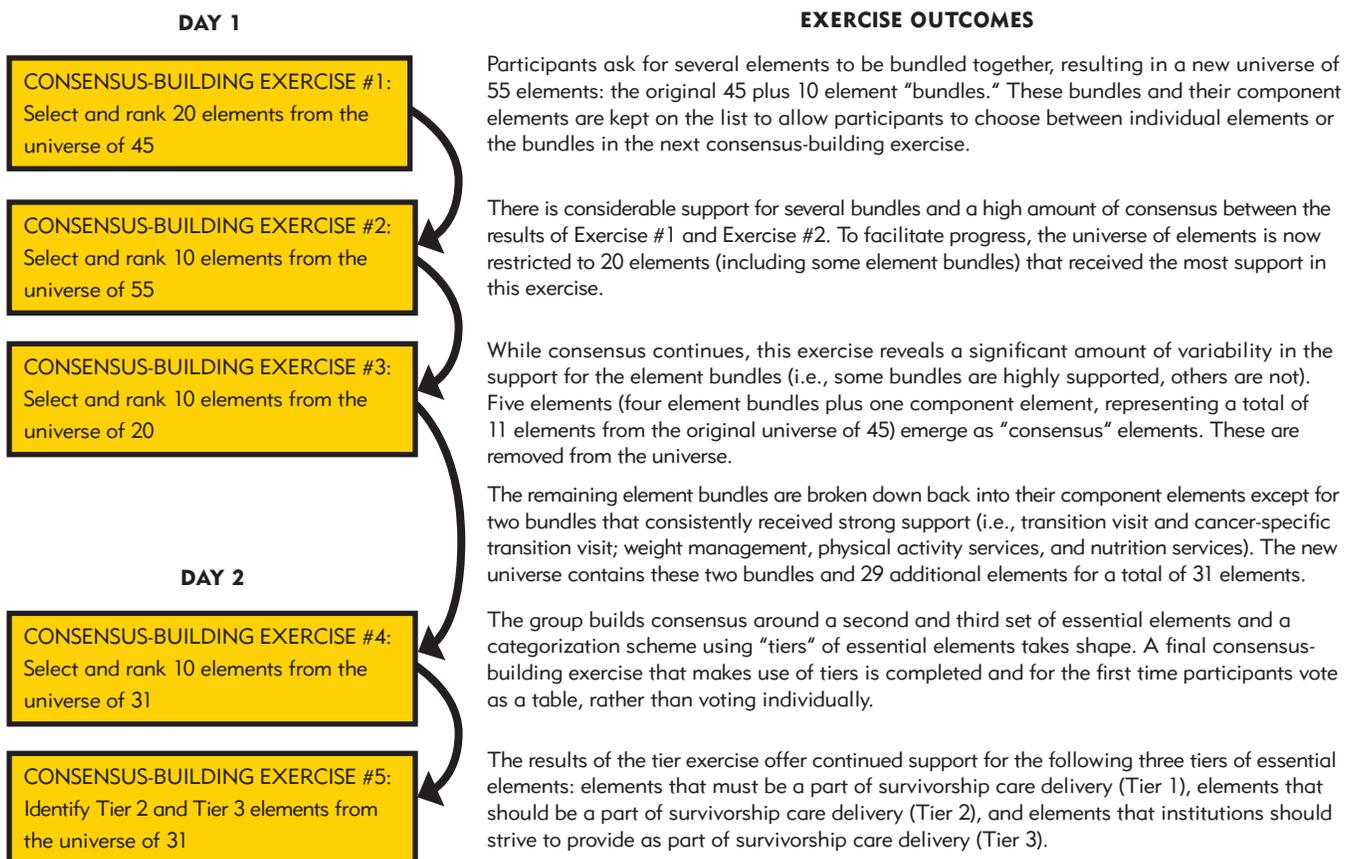
list of essential elements and the organization of elements into tiers.

RESULTS

The results of the five consensus-building exercises, as well as the themes that emerged over the meeting's discussions, support a list of 20 essential elements of survivorship care delivery (see page 8).

These 20 elements are organized into tiers, the definitions of which are intended to provide guidance to medical settings that might consider each in their design and delivery of

FIGURE 1. CONSENSUS-BUILDING EXERCISES.



survivorship care. Elements were placed in tiers in the order that most closely reflects their rank order based on the results of the consensus-building exercises.

Tier 1

Five elements, or Consensus Elements, were ranked consistently high in every consensus-building exercise. As a result, these five elements rose to the top as *consensus* essential elements of survivorship care. According to the definitions set out for this meeting, these are elements which all survivorship programs must, at the very least, provide access to, if not providing the service directly to survivors. These elements are shown in Tier 1 on page 8.

Tiers 2 and 3

Fifteen additional elements were identified as essential and are included in Tiers 2 and 3 on page 8. While the elements in Tier 2 and 3 were not ranked in the top five elements, meeting participants consistently identified these elements as necessary for inclusion in the list of essential elements of survivorship care.

Specifically, Tier 2 elements, or High-Need Elements, were in the top half of elements selected and ranked as essential in Exercises 1 and 2, represented 40% of elements selected as essential in Exercise 3, were in the top third of elements selected and ranked as essential in Exercise 4, and were selected as a Tier 2 or 3

element by more than half of the tables in Exercise 5.

Finally, Tier 3 elements, or Strive Elements, placed in the top two-thirds of elements selected, ranked as essential in the consensus-building exercises, and were selected as Tier 2 or 3 elements by more than two-thirds of tables in Exercise 5.

Meeting attendees further confirmed this list of elements with the final survey: 87% of respondents (N = 106) felt highly confident that the list of 20 elements contained the essential elements of survivorship care, and 78% of respondents felt highly confident that the tiers appropriately described the approach for considering these elements in the design and delivery of survivorship care.

“The Essential Elements should be available in every community – [They should] almost [be] a bill of rights for cancer survivorship.”

– Essential Elements Meeting Participant

NEXT STEPS

Through the Essential Elements Meeting process, participants made significant progress toward identifying the essential elements of survivorship care by reaching consensus on 20 essential elements of survivorship care that reflected the collective priorities of those in attendance. The

meeting also revealed these three specific next steps:

1. Refine the definitions of the essential elements of survivorship care delivery

Several meeting participants noted a need for clearer definitions for the elements of survivorship care so as to avoid significant overlap between some elements and confusion over the intent behind some elements. Additionally, participants expressed concern over the inclusion of elements across different tiers even when those elements are inherently linked (e.g., care coordination appears in Tier 1, the successful execution of which often involves referral to specialty care which does not appear until Tier 3). While continued work to resolve these issues is critical, this does not undermine the significant accomplishments made at the meeting. The qualitative analysis of results from the consensus-building exercises indicates that meeting participants agreed on issues far more often than they disagreed, and the strong levels of confidence in the list of essential elements indicate that the need for refinement and clarity of the definitions of the essential elements did not compromise the integrity of the meeting process. Nonetheless, over the next year **LIVESTRONG** will work to refine the definitions

of the elements of survivorship care and reconcile continued concerns with input from the cancer community.

2. Conduct research to expand the evidence base supporting the essential elements

Research is critical to the successful design and delivery of survivorship care. In order to make progress in survivorship care delivery, meeting attendees identified the following high-priority areas of inquiry:

- Determine the impact of delivering the essential elements of survivorship care on morbidity, mortality, and experiences of care for post-treatment cancer survivors, including patient-reported outcomes.
- Evaluate the economic impact of survivorship care delivery including the cost-effectiveness of the essential elements of care.
- Utilize comparative effectiveness research methods to leverage models of survivorship care outside the U.S. health care system against U.S. models to determine the optimal delivery of survivorship care.
- Examine the ways that health information technology, such as electronic health records, can facilitate the implementation of the essential elements.
- Conduct an environmental scan to comprehensively capture the state of survivorship care across multiple settings.

3. Integrate survivorship care into practice

Perhaps the most exciting outcome of the Essential Elements Meeting was the passionate and compelling conversations that were held by the motivated group of meeting participants dedicated to improving the lives of people affected by cancer. These individuals offered the following recommendations for how to make progress in translating the meeting outcomes into practice:

- Provide more education to the health care community about survivorship care (e.g., Continued Medical Education [CME], conferences).
- Develop a widely available repository of tools, including pocket guides or information technology applications, to facilitate survivorship care delivery for nurses and physicians (e.g., patient resources, practice guidelines).
- Improve communication and collaboration among all of the stakeholders including oncology and primary care providers, national nonprofit organizations, policy experts, academics, and cancer survivors.
- Empower cancer survivors to ask for the resources they need, including a survivorship care plan.
- Identify health information technology (HIT) solutions that reduce costs and improve resource allocations. This might include

motivating HIT vendors to create tools that incorporate elements of survivorship care delivery (e.g., assessments associated with the essential elements embedded into electronic health records).

- Consider policy solutions for supporting survivorship care delivery, such as defining survivorship as a “distinct phase of cancer” or integrating survivorship care into a rehabilitation model of care that can be reimbursed under current third-party payor systems.

While achieving consensus on a list of 20 essential elements of survivorship care marks significant progress, it is important to note that some elements—many of which were widely acknowledged to be extremely important in post-treatment survivorship—are not included on the list. For example, meeting participants felt strongly about including fertility services as a component of survivorship care but did not select these services as an essential element because many thought it should be addressed *before* the post-treatment phase of the cancer care trajectory. Additionally, while genetic testing received strong support, some participants felt that this element will not be “essential” until more progress is made in genomic science. Meeting participants agreed on the importance of having a program of research associated with survivorship care delivery but recognized some care delivery settings

may face significant challenges to participate actively in research. Finally, meeting participants indicated that when any assessment of survivors takes place there should be a corresponding set of available resources to address the needs identified in that assessment. Elements that were not identified as essential should not be considered unimportant or irrelevant to survivorship care. **LIVESTRONG** believes that all elements considered at the Essential Elements Meeting play a role in providing optimal survivorship services and that none of the elements should be eliminated from ongoing discussion about the provision of post-treatment care. However, prioritizing some elements of survivorship care delivery with a large group of experts and stakeholders has started a process for systematic delivery of optimal survivorship care. Our hope is that the list of essential elements shown here provides valuable guidance for existing survivorship care efforts and a starting point for those working to design and implement comprehensive survivorship care.

“We must invest in research to validate the elements.”

— Essential Elements Meeting Participant

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ESSENTIAL ELEMENTS OF SURVIVORSHIP CARE DELIVERY

LIVESTRONG convened the Essential Elements of Survivorship Care Meeting in Washington, DC, on September 15 and 16, 2011, with the goal of making progress in building consensus in the survivorship community around how to best address the needs of post-treatment survivors. A group of over 150 community leaders, stakeholders, experts, cancer survivors, and cancer survivor advocates achieved consensus on these 20 essential elements of survivorship care delivery.

TIER 1: CONSENSUS ELEMENTS	TIER 2: HIGH-NEED ELEMENTS	TIER 3: STRIVE ELEMENTS
<p>All medical settings MUST provide direct access or referral to the following elements of care.</p> <ul style="list-style-type: none">• Survivorship care plan, psychosocial care plan, and treatment summary• Screening for new cancers and surveillance for recurrence• Care coordination strategy which addresses care coordination with primary care physicians and primary oncologists• Health promotion education• Symptom management and palliative care	<p>All medical settings SHOULD provide direct access or referral to these elements of care for high-need patients and to all patients when possible.</p> <ul style="list-style-type: none">• Late effects education• Psychosocial assessment• Comprehensive medical assessment• Nutrition services, physical activity services, and weight management• Transition visit and cancer-specific transition visit• Psychosocial care• Rehabilitation for late effects• Family and caregiver support• Patient navigation• Educational information about survivorship and program offerings	<p>All medical settings should STRIVE to provide direct access or referral to these elements of care.</p> <ul style="list-style-type: none">• Self-advocacy skills training• Counseling for practical issues• Ongoing quality-improvement activities• Referral to specialty care• Continuing medical education

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LIVESTRONG serves people affected by cancer and empowers them to take action against the world's leading cause of death. Created as the Lance Armstrong Foundation in 1997 by cancer survivor and champion cyclist Lance Armstrong, the organization is now known publicly by its powerful brand—LIVESTRONG—and is a leader in the global movement on behalf of 28 million people around the world living with cancer today. Known for its iconic yellow wristband, LIVESTRONG has become a symbol of hope and inspiration to people affected by cancer around the world. Since its inception, the organization has raised more than \$400 million for the fight against cancer. For more information visit LIVESTRONG.org.