

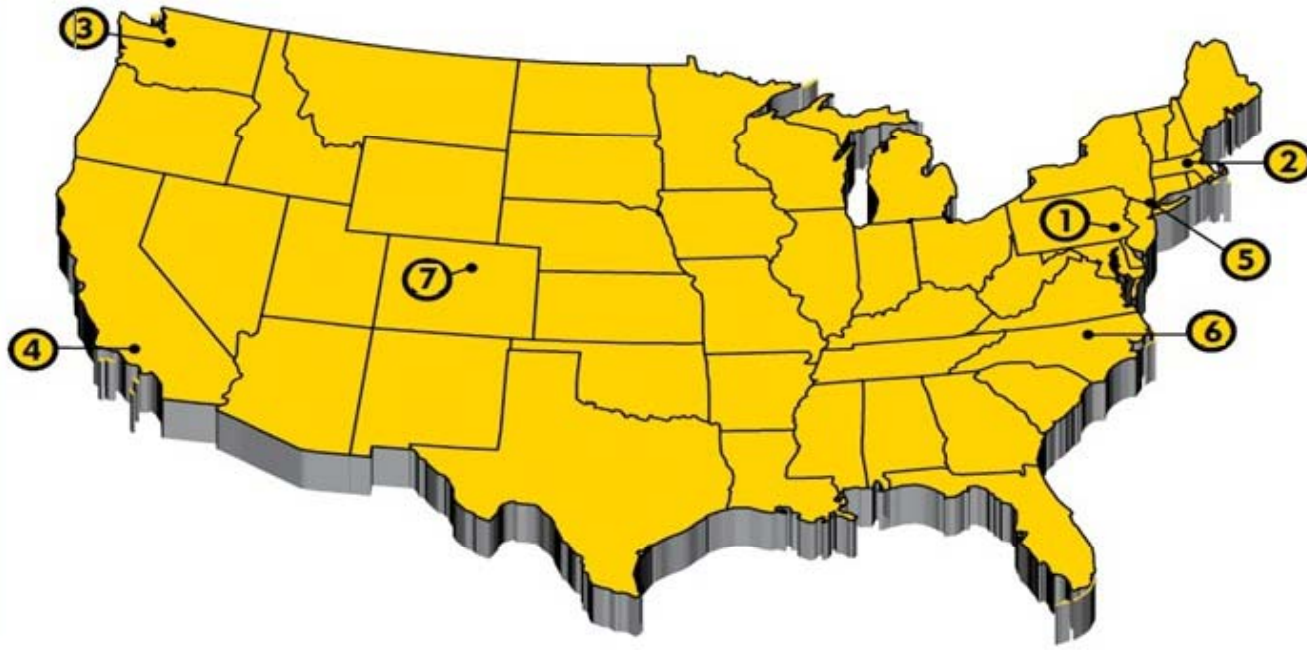
L I V E S T R O N G[®]

THE ESSENTIAL ELEMENTS OF SURVIVORSHIP CARE

**Sarah R. Arvey, PhD
Program Director
Research & Evaluation**

- **Background**
- **EE Meeting**
- **EE Meeting Outcomes**
- **EE Definitions & Recommendations**
- **Next Steps**

LIVESTRONG SURVIVORSHIP CENTER OF EXCELLENCE NETWORK



- ① Abramson Cancer Center, University of Pennsylvania
penncancer.org/cancerprograms
- ② Dana-Farber Cancer Institute
dana-farber.org/pat/surviving
- ③ Fred Hutchinson Cancer Research Center
fhcrc.org/patient/support/survivorship
- ④ Jonsson Comprehensive Cancer Center at UCLA
cancer.ucla.edu
- ⑤ Memorial Sloan-Kettering Cancer Center
mskcc.org/mskcc/html/58022.cfm

- ⑥ University of North Carolina Lineberger Comprehensive Cancer Center, N.C. Cancer Hospital
cancer.unc.edu/patient
- ⑦ University of Colorado Cancer Center
uch.edu/conditions/cancer/index1.aspx

L I V E S T R O N G TM

**SURVIVORSHIP CENTER
OF EXCELLENCE NETWORK**

To accelerate the pace of progress in addressing the needs of the growing survivor community.

- **Provide direct survivorship services**
- **Increase the effectiveness of survivorship care through research, the development of new interventions, and the sharing of best practices**

PURPOSE

L I V E S T R O N G TM

Lack of Evidence

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

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Consensus-building

EE Advisory Committee

- Richard Carmona, CRI
- Robert Croyle, NCI
- Mitch Golant, CSC
- Melissa Hudson, St. Jude
- Len Lichtenfeld, ACS
- Diane Meier, CAPC
- Paula Reiger, ONS

Network Directors & Steering Committee

- K. Scott Baker, FHCRC
- Jacqueline Casillas, UCLA
- Patricia Ganz, UCLA
- Marcia Grant, COH
- Mary Gullatte, ONS
- Alton Hart, UVC
- Linda Jacobs, UPenn
- Alison Jones, UCCC
- Margaret Kripke
- Kenneth Miller, Sinai Hospital
- Guadalupe Palos, MDAnderson
- Angie Patterson, GCC
- Donald Rosenstein, UNC
- Karen Syrjala, FHCRC

EE MEETING LEADERS

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- To build consensus among key stakeholders on the elements of survivorship care that any cancer survivorship program should provide (directly or via referral) to post-treatment cancer survivors.

- Agree upon and refine the essential elements of survivorship care delivery
- Develop strategies to overcome potential barriers to implementation
- Identify key areas to be addressed in future research
- Disseminate meeting outcomes

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Meeting Preparation

WHAT IS AN “ELEMENT” OF SURVIVORSHIP CARE?

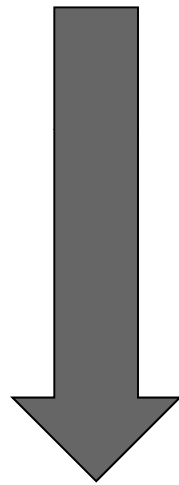
A descriptor of some component of healthcare that is:

- Discrete enough to be actionable
- Not overly prescriptive

CRITERIA OF AN ESSENTIAL ELEMENT

1. Evidence that the element, when implemented, has a positive impact on morbidity, mortality, and/or quality of life for all cancer survivors?
2. Can the element of care be implemented across a variety of settings?
3. Does an evidence base exist in cancer survivorship research and/or other related health domains?
4. When an evidence base does not exist, does the essential element address the expressed needs of cancer survivors; has consensus been achieved by the provider community; and/or can it be tested through (future?) research?

101 UNIVERSE OF ELEMENTS



45 UNIVERSE OF ELEMENTS

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Meeting Activities

- Groups of six to eight individuals per table
- Five consensus-building activities using modified Delphi Process
- Theme team conducting real-time qualitative analysis
- Panel discussions by experts on key issues in survivorship
- Post-meeting survey



ACTIVITIES

CONSENSUS-BUILDING EXERCISES

DAY 1

CONSENSUS-BUILDING EXERCISE #1:
Select and rank 20 elements from the universe of 45

CONSENSUS-BUILDING EXERCISE #2:
Select and rank 10 elements from the universe of 55

CONSENSUS-BUILDING EXERCISE #3:
Select and rank 10 elements from the universe of 20

DAY 2

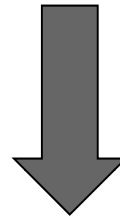
CONSENSUS-BUILDING EXERCISE #4:
Select and rank 10 elements from the universe of 31

CONSENSUS-BUILDING EXERCISE #5:
Identify Tier 2 and Tier 3 elements from the universe of 31

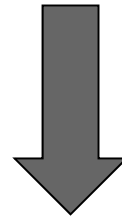
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Meeting Outcomes

101 UNIVERSE OF ELEMENTS



45 UNIVERSE OF ELEMENTS



20 ESSENTIAL ELEMENTS

All medical settings MUST provide direct access to or referral to the following elements of care:

- Survivorship care plan, psychosocial care plan & treatment summary
- Screening for new cancers & surveillance for recurrence
- Care coordination strategy created which addresses care coordination with primary care physicians and with primary oncologists
- Health promotion education
- Symptom management & palliative care

All medical settings SHOULD provide direct access to or referral to these elements of care for high need patients and to all patients when possible.

- 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 & caregiver support
- Patient navigation
- Educational information about survivorship and program offerings

TIER 2: HIGH NEED ELEMENTS

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All medical settings should STRIVE to provide direct access to or referral to:

- Self-advocacy skills training
- Counseling for practical issues
- Ongoing quality improvement activities
- Referral to specialty care
- Continuing medical education

96% of survey respondents agreed that at the Essential Elements meeting we took an important step forward towards addressing the needs of cancer survivors.

It was very empowering as a survivor to participate in this meeting. We rarely have the chance to provide input into processes that impact us so much, so I'm grateful for the opportunity.

*With the outstanding efforts of organizations like **LIVESTRONG** emphasizing the importance of cancer survivorship, I have every expectation that this is a mission that not only demands success, but will achieve success for our patients and our communities.*

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Meeting Recommendations

1. Refine the definitions of the essential elements of survivorship care delivery
2. Conduct research to expand the evidence base supporting the essential elements
3. Integrate survivorship care into practice

RECOMMENDATIONS

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Post-Meeting Activities

- “Essential Elements of Survivorship Care: A **LIVESTRONG** Brief”
- *Nature Reviews Clinical Oncology*
- *Journal of Clinical Oncology*

DISSEMINATION VIA PUBLICATIONS

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LIVESTRONG COE Network Research

Care Plan Study (2009-2011)

- Feasibility of providing TS & SCP to Breast Cancer survivors
- Determine patient satisfaction of receipt of TS & SCP

Patient Reported Outcomes Study (2011-2012)

- Survivors input PROs in online survey
- How does sending PRO to providers affect their care?

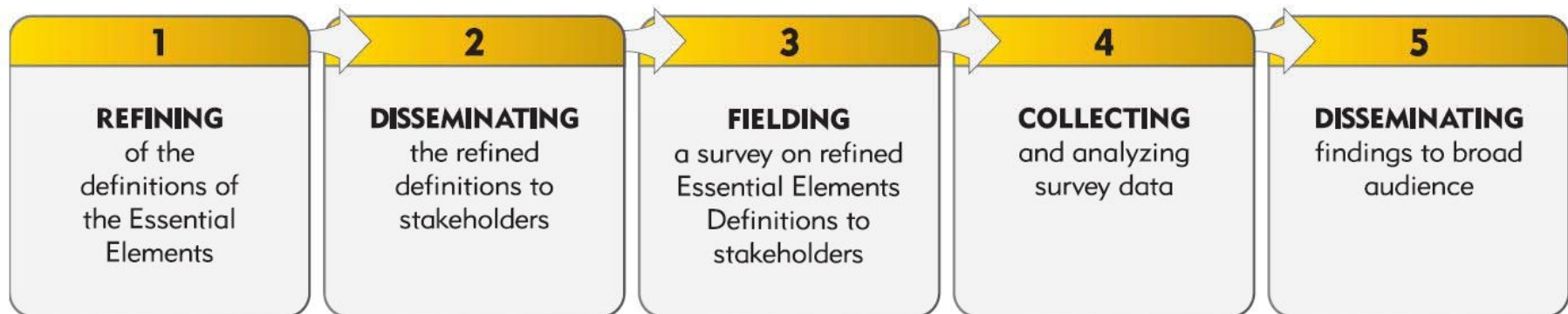
Young Adult Survivorship Study (2011-2014)

- Can we recruit YAs?
- Does the provision of EEs improve YA's health outcomes and HRQOL?

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**Definitions &
Recommendations**

NOW



EE DEFINITIONS AND RECOMMENDATIONS

Survivorship Care Plan, Treatment Summary and Psychosocial Care Plan

A survivorship care plan, developed from a patient-specific treatment summary and including medical and psychosocial components, informs the survivor and the clinicians involved in the care of the survivor. Important components of the survivorship care plan include information regarding treatment exposures and potential long-term or late effects, such as medical and psychosocial complications and their signs and symptoms.

Basic level: At a basic level, the survivorship care plan includes recommendations for screening for the surveillance of recurrence, second cancers and other medical and psychosocial long-term or late effects. These recommendations are based on information in the treatment records, including cancer diagnosis, date of diagnosis and treatments received (chemotherapy with names of drugs, surgery, radiation to include fields of radiation, and other cancer directed therapies). The survivorship care plan specifies healthy behaviors important to survivor recovery and in reducing health risks, and psychological, social and functional complications frequently seen in survivors. The care plan should identify resources within the survivor's community to address these potential complications. Examples of domains to be included are cancer surveillance and monitoring, screening for other cancers, cardiac monitoring, bone health, fertility, fatigue, sleep disturbance, pain, depression, cancer related distress, anxiety, physical activity and weight maintenance and tobacco cessation. This could be accomplished by completing of the **LIVESTRONG** Care Plan powered by Penn Medicine's OncoLink (www.livestrongcareplan.org), and augmented by resources in the survivor's community or referral to **LIVESTRONG** navigation services.

Enriched level: At the enriched level, the survivorship care plan should include all basic level recommendations, as well as an enriched treatment summary with information about cancer diagnosis, date of diagnosis and treatments received, including chemotherapy with names of drugs, surgery, radiation to include fields of radiation and other cancer-directed therapies. Information about stage and tumor characteristics, doses of cardio toxic drugs and radiation dosage, major complications, persistent symptoms, co-morbid conditions, and psychosocial, genetic, familial and socio-demographic risk factors are included in the treatment summary. The survivorship care plan specifies healthy behaviors important in survivor recovery and in reducing health risks and psychological, social and functional complications frequently seen in survivors. The survivorship care plan could identify resources within the survivor's community to address these potential complications. In addition, tailoring the care plan with direct recommendations and referrals and having the capacity for follow up on implementation of the care plan are important inclusions. This could be accomplished with Journey Forward Care Plan or a specific institutional enhanced care plan.

Related elements: psychosocial assessment; psychosocial care; care coordination strategy; late effects education, transition visit.

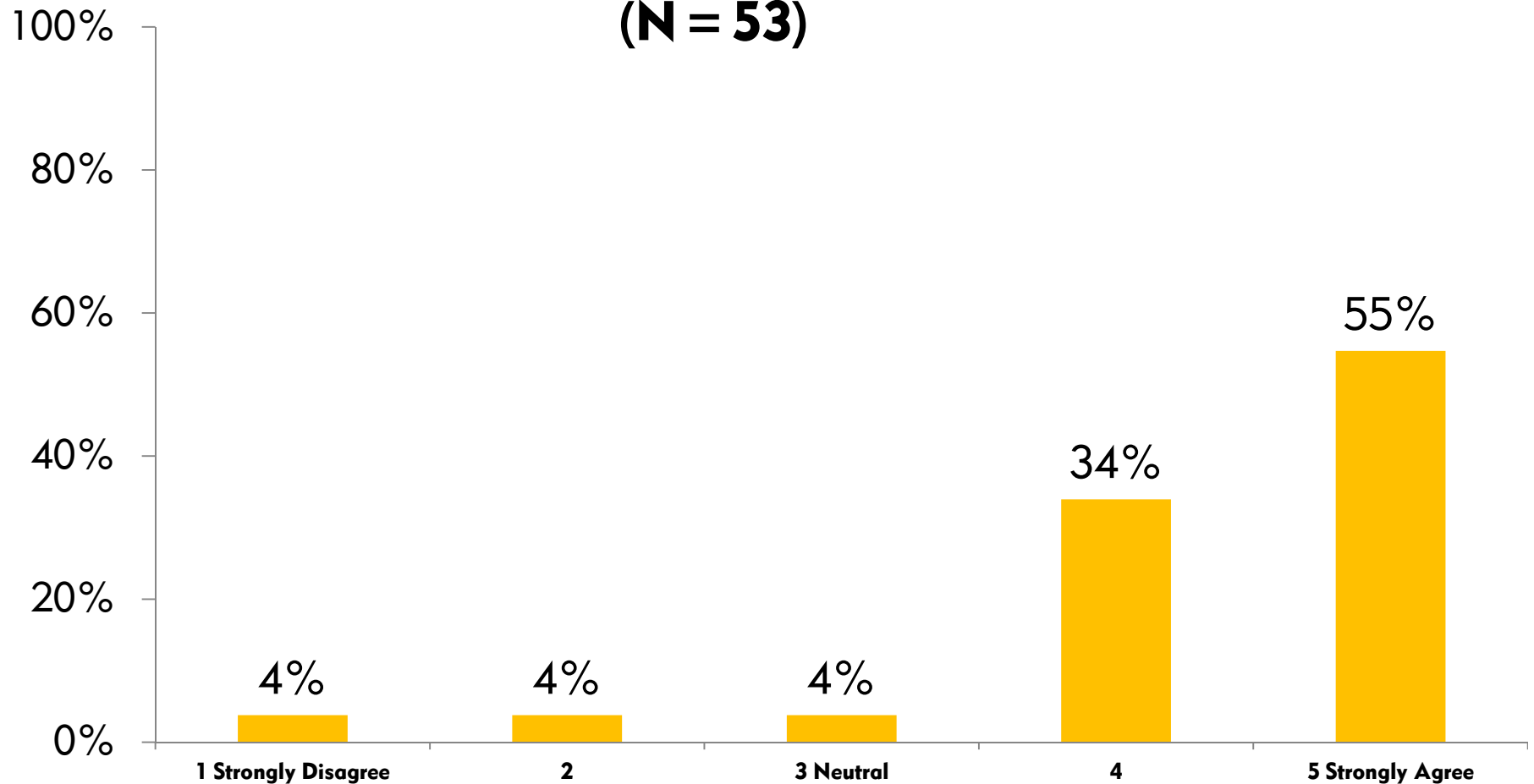
- Definitions & Recommendations sent to EE Meeting Participants
- Participants asked to respond to 12 question survey

LIVESTRONG Essential Elements of Survivorship Care

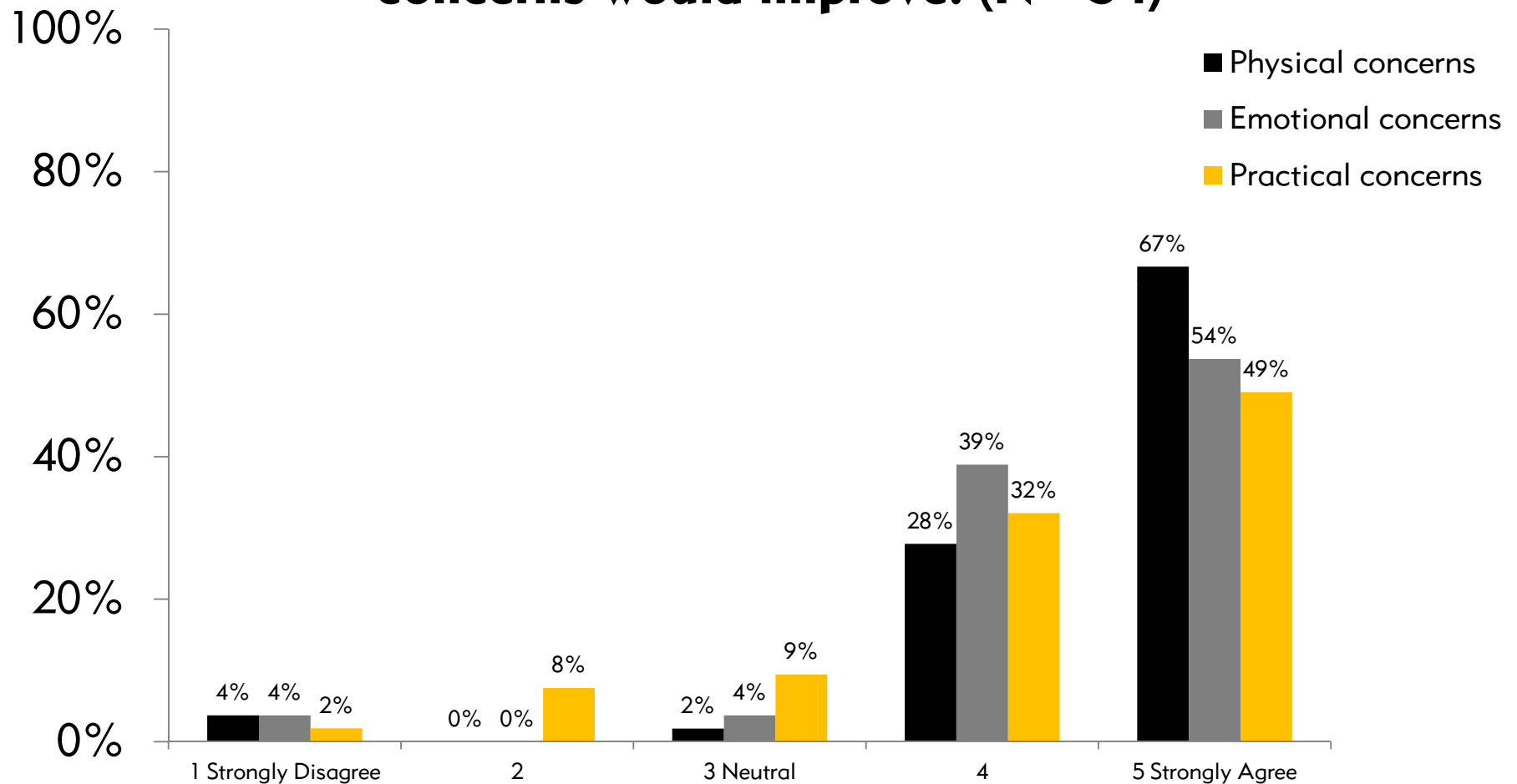
Definitions &
Recommendations

Survey Results

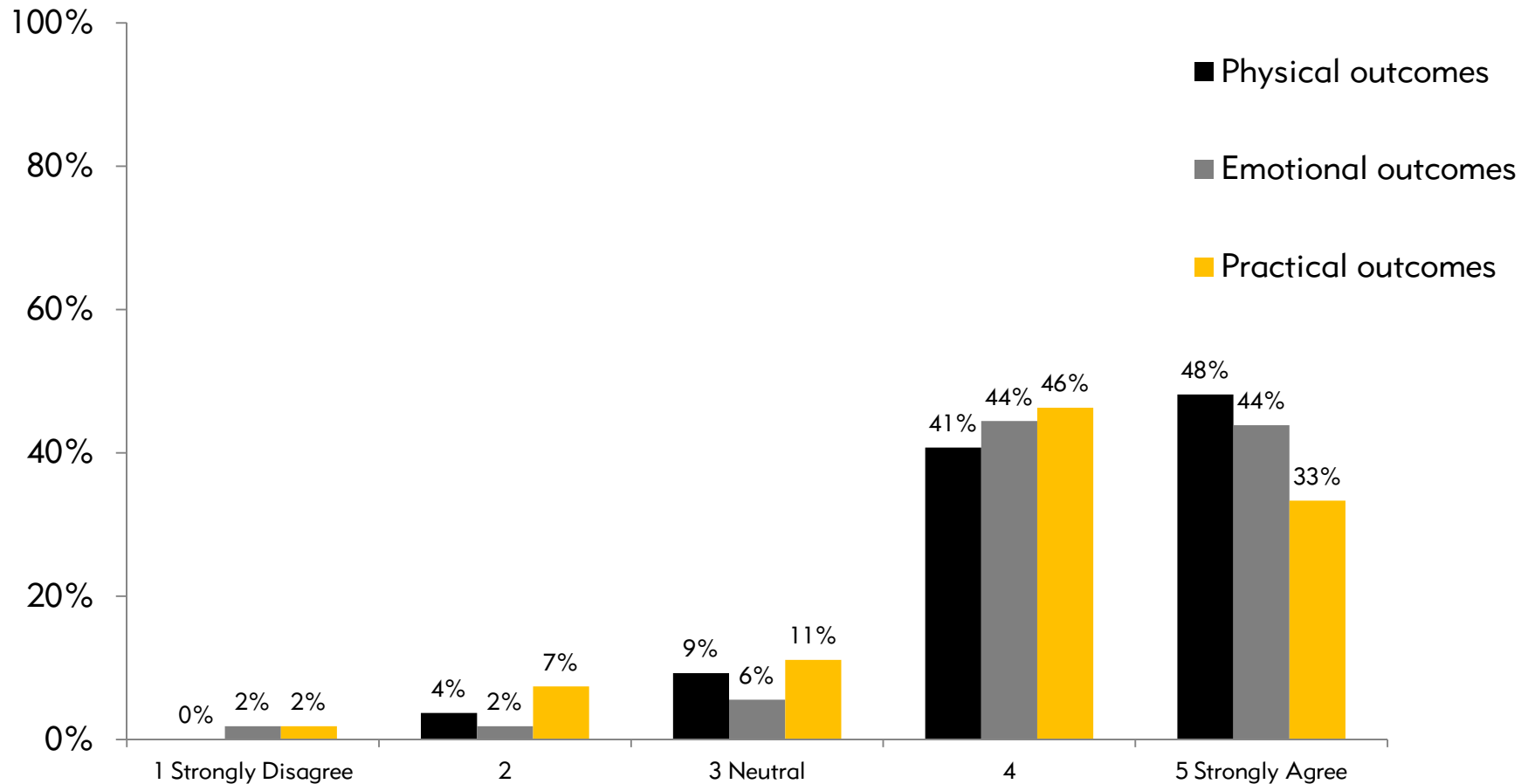
Percent who believe the Definitions & Recommendations accurately describe the 20 Essential Elements of Survivorship Care (N = 53)



If the EEs were provided, the **QUALITY OF CARE** for survivors' physical, emotional & practical concerns would improve. (N = 54)



If the EEs were provided, the **OUTCOMES** for survivors' physical, emotional & practical concerns would improve. (N = 54)



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Next Steps

1. Analyze survey data and disseminate outcomes
2. Create tools to facilitate implementation of EEs - Essential Elements Toolkit
3. Fund research to determine effectiveness of EEs – Network Collaborate Research

NEXT STEPS

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THANK YOU!

www.livestrong.org/essentialelements

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