



DEFINING SURVIVORSHIP CARE: LESSONS LEARNED FROM THE LIVESTRONG
SURVIVORSHIP CENTER OF EXCELLENCE NETWORK
A LIVESTRONG REPORT

LIVESTRONG
SURVIVORSHIP CENTER
OF EXCELLENCE NETWORK

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EXECUTIVE SUMMARY

The **LIVESTRONG** Survivorship Center of Excellence Network (Network) was established in 2005 to advance survivorship care and improve the health and quality of life of post-treatment cancer survivors. Over the course of the last five years, Network members have expanded knowledge of the field of survivorship, pioneered new interventions for cancer survivors and developed, evaluated and disseminated survivorship best practices to national and international audiences, including best strategies for – and challenges to – instituting a survivorship care program . By assessing and analyzing diverse practice patterns, the Network has uncovered four key findings: 1) Creating a “cultural shift” in the delivery of care to survivors is a major challenge but necessary for successful provision of survivorship services; 2) Garnering support from diverse institutional leaders is essential to successful integration of survivorship care; 3) Forging community connections is crucial to reaching underserved populations; and 4) Delineating the essential elements of care – rather than setting forth one specific care model – best ensures quality of care for survivors across diverse service delivery systems.

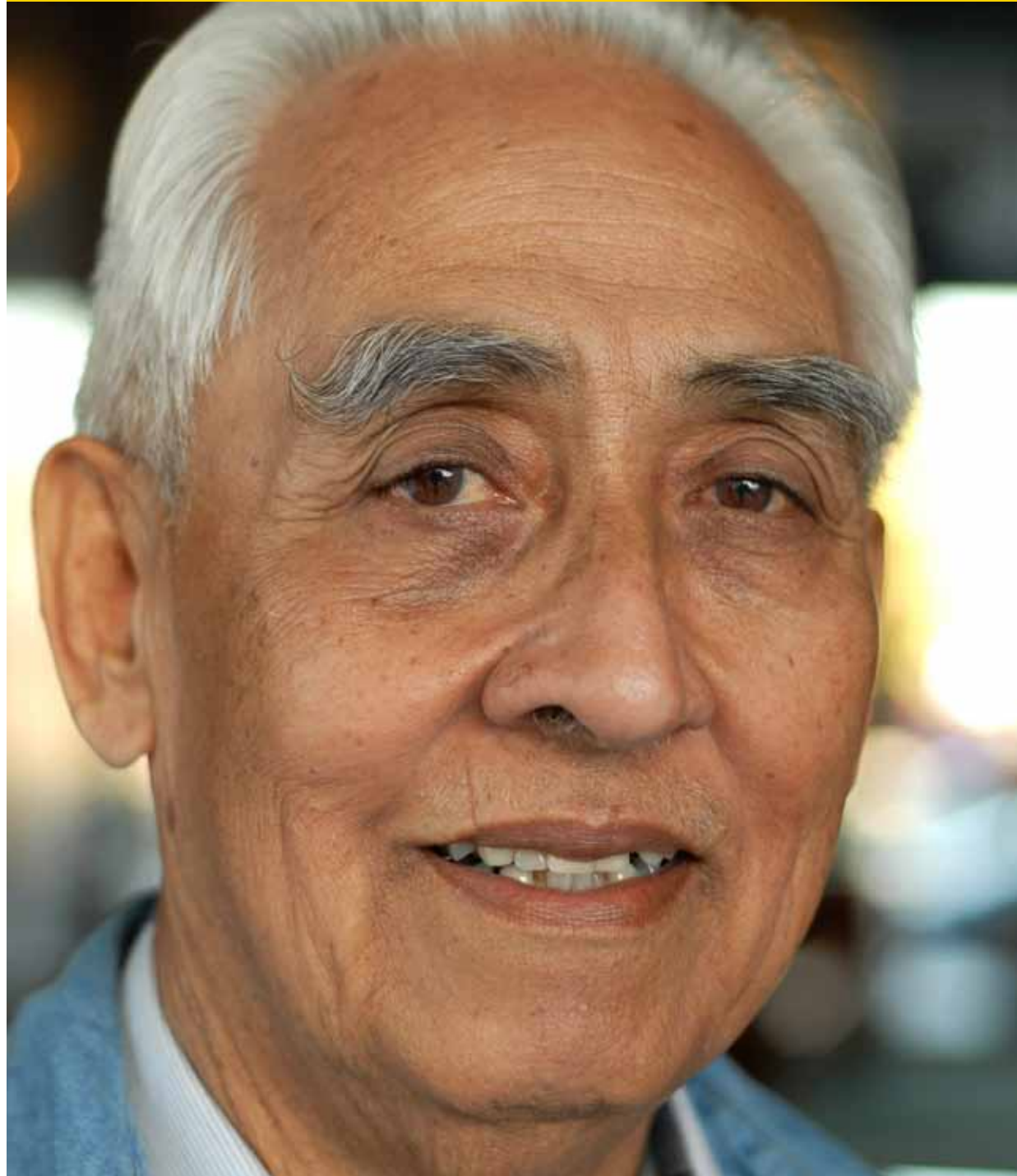
Utilizing the knowledge collected to date, along with insights from a deductive qualitative study of the collaboration, the Network is poised to continue moving the field of cancer survivorship care forward by focusing on three target areas:

- Standardization of metrics in survivorship
- Identification and dissemination of the essential elements of care delivery in survivorship
- Advocating for change within oncology practice, insurance and reimbursement mechanisms and funding mechanisms for care and cancer centers

By incorporating survivorship into the continuum of cancer care, the Network is changing the culture of oncology practice and providing visibility and leadership for the survivorship community at large. This report summarizes the contributions of the Network to date; provides information about the eight centers; offers insight from a qualitative deductive study conducted on the Network; and proposes next steps for accomplishing the goals set forth by the Network five years ago.

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INTRODUCTION AND OVERVIEW



Due to advances in early detection and treatment, more individuals are winning the battle against cancer than ever before. In this new environment, the cancer experience is shifting from acute illness to chronic condition. The Institute of Medicine (IOM) and other health advisory bodies worldwide are recognizing the range of medical, functional and psychosocial challenges facing individuals who have completed cancer treatment. Consequently, survivorship has become a distinct phase of cancer care. With one-third of the American population facing a cancer diagnosis at some point in their lives, it has become increasingly apparent that the long-term care of cancer survivors requires more focused attention.

The IOM report, “From Cancer Patient to Cancer Survivor: Lost in Transition,” cited specialized survivorship clinics as a promising model for delivering survivorship care (Hewitt, Greenfield, & Stovall, 2006). The report indicated that survivorship clinics could provide a coordinated approach to follow-up care and services that would allow any issues associated with an individual’s cancer treatment to be diagnosed and managed in one location. Further, the report indicated that such specialized care had the potential to reduce inaccurate diagnoses, limit unnecessary tests and procedures and increase the productivity

levels of survivors. Additionally, survivorship clinics would be able to conduct research on the late effects of cancer treatment, the results of which could ultimately improve survivorship care.

To that end, and to better meet the needs of the growing survivorship community, **LIVESTRONG** developed the **LIVESTRONG** Survivorship Center of Excellence Network in 2005. The Network is a group of National Cancer Institute (NCI) designated comprehensive cancer centers offering information, care and services to cancer survivors, their family members and health care providers. The original goals of the Network were to:

- Transform how survivors are perceived, treated and served
- Help create a body of knowledge, evidence and understanding of survivorship care
- Develop and deliver evidence-based treatment and care interventions
- Improve the quality and integration of survivorship services
- Strengthen the link between primary cancer treatment and survivorship care
- Increase accessibility to services among ethnically diverse and underserved survivors
- Help find sources of support to sustain survivorship centers over the long term
- Create insurance or reimbursement mechanisms to cover survivor care and services

Each of these goals was a significant challenge that required the collaborative efforts of dedicated experts. With this in mind, **LIVESTRONG** aimed not only to provide funding to individual centers to address these goals, but also to provide a mechanism to bring together these cancer centers and their community partners to address the most pressing issues of cancer survivorship. **LIVESTRONG** envisioned the Network as a comprehensive web of relationships and mutual discovery that would enhance the capacities of each contributing partner. Modeled after networks pioneered by the MacArthur Foundation, the Robert Wood Johnson Foundation and the Christopher Reeve Paralysis Foundation, the Network sought to harness the expertise, experience, creativity and productivity of leading cancer centers to accelerate progress in survivorship research, care and services.

Today, after five years of hard work from committed stakeholders, the Network includes eight Center of Excellence (COE) sites, each of which has been addressing the goals as they were outlined. These centers, recognized for their cutting-edge research, patient care, training, communication and outreach initiatives, are:

- Abramson Cancer Center, University of Pennsylvania
- Dana-Farber Cancer Institute
- Fred Hutchinson Cancer Research Center
- Jonsson Comprehensive Cancer Center at UCLA
- Memorial Sloan-Kettering Cancer Center
- The Ohio State University Comprehensive Cancer Center — Arthur G. James Cancer Hospital and Richard J. Solove Research Institute
- University of Colorado Cancer Center
- University of North Carolina Lineberger Comprehensive Cancer Center

Each **LIVESTRONG** Center of Excellence offers a variety of survivorship programs to cancer survivors. Although specific programs and services differ from site to site, all eight COEs broadly address the following areas through their survivorship interventions:

- Clinical services
- Patient education and health promotion
- Support groups and counseling
- Integrative/complementary medicine
- Community outreach
- Research

In addition, all **LIVESTRONG** COEs engage in active, ongoing program evaluation via internal review as well as follow-up with patients and practitioners who have participated in survivorship programs.

The Network also includes community affiliate sites that have been selected by and work in partnership with a “parent” COE. These community affiliates provide direct services to individuals living with, through and beyond cancer, often targeting those from traditionally underserved populations. Through the Network, the community affiliates have access to information, research findings, new interventions, expertise and personnel. In turn, through their community affiliates, each COE has access to patient referrals, clinical trial enrollees and information “from the trenches” regarding cancer survivors’ needs and how best to address those needs within the context of their communities.

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Over the last five years, collaboration at all levels—among the COEs and the community affiliates and between each COE and its community affiliates—has been central to the success of the Network. To facilitate collaboration, **LIVESTRONG** hosts semiannual Network meetings designed to build and strengthen relationships. These meetings serve as a forum for sharing ideas, strategies and data, creating joint projects, reporting on progress and refining shared processes. In the months between the semiannual gatherings, a tremendous amount of collaboration takes place to move forward those projects identified at the meetings, such as the 2009 “Excellence in Cancer Survivorship Care: Developing Sustainable Programs” executive management training (see sidebar). Additionally, the **LIVESTRONG** Survivorship Center of Excellence steering committee, a group of experts in survivorship care, supports the successful execution of all aspects of the Network by providing oversight, conducting site visits and collaborating with the Network at meetings and throughout the year.

In 2009, **LIVESTRONG** commissioned the University of North Carolina (UNC) to conduct a study to more fully understand how survivorship care was being provided across the Network. This report includes findings from that study, information from an article on the Network published in the *Journal of Cancer Survivorship* (Shapiro, et al., 2009) as well as supplemental data provided by each COE.

The next section of this report provides information about each COE.

PROJECT HIGHLIGHT

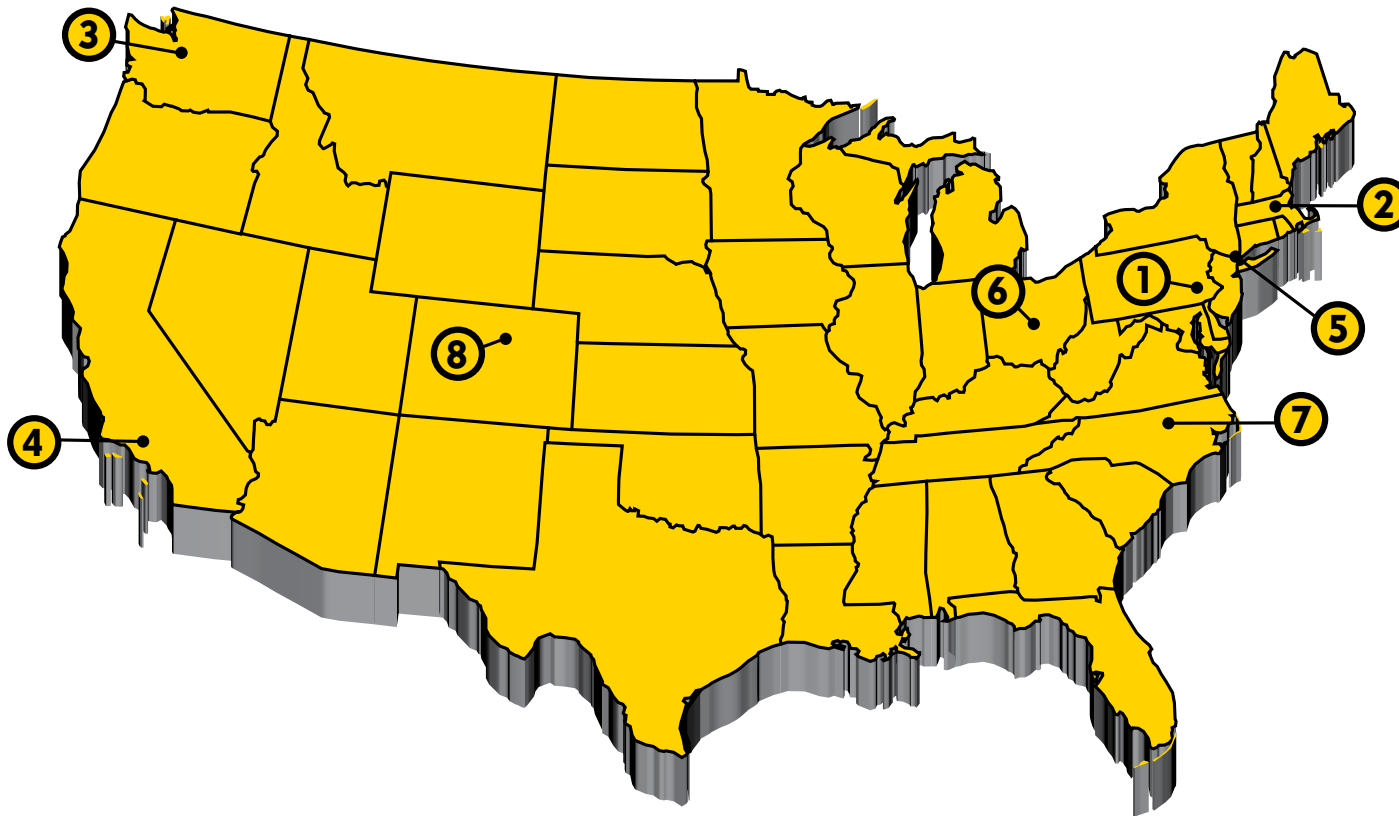
Excellence in Cancer Survivorship Care: Developing Sustainable Programs

In December 2009, the **LIVESTRONG** Survivorship Center of Excellence Network hosted the “Excellence in Cancer Survivorship Care: Developing Sustainable Programs” executive management training. The goal was to help attendees develop sustainable survivorship programs nationwide in order to better serve the nearly 12 million cancer survivors in America. **LIVESTRONG** Network leaders served as the conference faculty, ensuring that participants had opportunities to learn about a variety of institutions, evidence-based survivorship care models and disciplines.

A total of 60 administrators and clinicians representing 34 institutions participated in the training. There was geographic representation from across the United States as well as an international presence that included two teams from Canada, one from Australia and one from Israel. Post-conference evaluations show that 100 percent of participants agreed that they would make practice changes as a result of the training activities. In addition, 100 percent agreed that the education from the training would translate into improved quality of patient care at their institutions.



THE LIVESTRONG SURVIVORSHIP CENTER OF EXCELLENCE NETWORK MEMBERS



- 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 The Ohio State University Comprehensive Cancer Center-James
Cancer Hospital and Solove Research Institute
cancer.osu.edu
- ⑦ University of North Carolina Lineberger Comprehensive Cancer
Center, N.C. Cancer Hospital
cancer.unc.edu/patient
- ⑧ University of Colorado Cancer Center
uch.edu/conditions/cancer/index1.aspx

“The most important thing is broad, in that we’re putting survivorship on the map. That it’s getting attention, and I’m thinking of the patients who I see who feel so dropped off the face of the earth after their treatment’s over, that they are feeling like they are not alone and that there is some medical and emotional support for them. I feel like that didn’t exist before.”

— Survey Participant

Philadelphia, PA

Linda A. Jacobs, PhD, RN,
Program Director

penncancer.org

Joined Network: 2007

Type of care

- (Adult care only) integrative
- Adult survivors of childhood cancer
- Transition
- Long-term follow-up

Community affiliates

St. Joseph Medical Center,
Reading, PA (2007 to 2009)

Lancaster General Hospital,
Lancaster, PA (2007 to present)

St. Luke's Cancer Center,
Bethlehem, PA (2007 to present)

Children's Hospital of
Philadelphia, Philadelphia, PA
(2009 to present)

About the director

Linda A. Jacobs, PhD, RN, received her undergraduate and doctoral degrees from the University of Pennsylvania. She is board certified as an oncology and primary care nurse practitioner and has an appointment as a clinical associate professor at the University of Pennsylvania School of Nursing. Jacobs has served as the director of the Living Well After Cancer Program since 2001. She collaborated with Anna Meadows, MD, to develop the Living Well After Cancer Program into a national model for adult cancer survivor care. Jacobs consults with institutions across the country to help develop similar programs and has published numerous writings that focus on cancer survivorship.

About the program

The Living Well After Cancer Program (LWAC) is a clinical, research and education initiative focused on early intervention and prevention. The multidisciplinary program provides care and research opportunities to cancer survivors treated at the University of Pennsylvania and its Cancer Network hospitals. LWAC is involved in multiple initiatives, including:

- Comprehensive survivorship clinical visits offering complete medical and psychosocial evaluations, follow-up visits and referrals to other specialists, including endocrinology, neurology, orthopedics, gynecology and cardiology, and primary care for management
- Clinical survivorship visits provided to all patients by the treating oncology team at the end of treatment as a part of routine care
- Disease-specific clinical survivorship programs as well as a general survivorship program available to patients followed within the University of Pennsylvania system as well as patients followed at other institutions who would like a consultative visit
- Comprehensive treatment summary and care plans to assist cancer survivors in their follow-up care, as well as with their transition from oncology care to primary and specialty care
- Treatment summary and follow-up care plans extended to physicians and patients in community hospitals to help meet the needs of underserved populations

- Targeted follow-up programs to meet the particular needs of testicular cancer and breast cancer survivors, as well as survivors of childhood cancer
- Expansion of the Living Well After Childhood Cancer Program, a collaborative program with Children's Hospital of Philadelphia, to include more transitional services for adult survivors of childhood cancer
- Cancer rehabilitation program designed to address the needs of patients experiencing symptoms of cancer or cancer treatment
- Fertility preservation clinical and research program offered in collaboration with the Division of Reproductive Endocrinology at the University of Pennsylvania
- Patient-focused education conferences for patients and caregivers on every disease site that has in-treatment and survivorship tracks provided by the oncology staff at the University of Pennsylvania
- Hereditary risk assessment and genetic counseling clinical and research program for families and patients

Boston, MA

Ken Miller, MD, Program Director

dana-farber.org

Joined Network: 2004

Type of care

- Consultative for adults
- Long-term follow-up for pediatrics

Community affiliates

New Hampshire Oncology-Hematology,
Londonderry, NH (2004 to 2009)

Brookside Community Health Center, Boston, MA
(2004 to present)

Whittier Street Health Center,
Boston, MA (2004 to present)

Blum Mobile Van (2009 to present)

About the director

Ken Miller, MD, joined the Dana-Farber Cancer Institute as the co-director of the Perini Cancer Survivorship Center and the director of the Lance Armstrong Foundation Adult Survivorship Program in 2008. After undergraduate studies and medical school training at Tufts University in Boston, Miller completed an internal medicine residency at Yale University. He then trained in medical oncology at Johns Hopkins University and in hematology at the National Institutes of Health. Miller developed an oncology group practice in Maryland before returning to academics to become the founding director of the Connecticut Challenge Cancer Survivorship Program at the Yale Cancer Center. Additionally, he is the editor and author of several books on survivorship.

About the program

The Lance Armstrong Foundation Adult Survivorship Program provides clinical care and services for adult-onset cancer survivors, including research that focuses on finding solutions to key problems that adult survivors may face after cancer treatment. It also provides long-term follow-up care for survivors of pediatric cancer. Services offered include:

- Transition visits for all survivors who complete active treatment in disease-based clinics; visit includes a **LIVESTRONG** treatment summary and care plan that reviews treatments received, follow-up care needed, contact information for care team and educational information about healthy survivorship and ongoing survivorship care
- Long-term care clinic for cancer survivors at highest risk of late and long-term effects
- Survivorship Counseling Program for survivors and family members
- Sexual health program
- Nutrition counseling: “fighting cancer with a fork”
- Exercise counseling resulting in an exercise “prescription”
- Genetic counseling from a trained specialist
- Taking Cancer Survivorship on the Road, a survivorship program developed at Dana-Farber Cancer Institute, which uses a mobile van to provide survivorship care at community health centers

- Survivorship for Clinicians: Helping Cancer Survivors Live Well Beyond Cancer, an annual conference for clinicians focused on current issues and topics in survivorship care
- Survivorship sub-specialty care in oncocardiology, onconephrology, endocrinology and gynecology
- Follow-up care for adult survivors of childhood cancer, including transition services from the David B. Perini, Jr. Quality of Life Clinic for childhood cancer survivors to the Lance Armstrong Foundation Clinic
- Multidisciplinary clinics for bone marrow transplant, prostate cancer and head and neck cancer, all of which include medical, psychosocial and symptom management components

Seattle, WA

K. Scott Baker, MD, and
Karen Syrjala, PhD, Co-Directors

fhcrc.org

Joined Network: 2006

Type of care

- Consultative for adults
- Long-term follow-up for adults and pediatrics
- Transition

Community affiliates

Sacred Heart Medical Center,
Spokane, WA (2006 to 2009)

Harborview Medical Center,
Seattle, WA (2006 to present)

Providence Alaska Medical
Center, Anchorage, AK
(2006 to present)

Seattle Cancer Care Alliance
Network (SCCA), Seattle, WA
(2009 to present)

About the directors

K. Scott Baker, MD, is a member of the Clinical Research Division of the Fred Hutchinson Cancer Research Center and a professor in the University of Washington School of Medicine's Department of Pediatrics. He also leads the pediatric survivorship program at Seattle Children's Hospital, where he is a principal investigator in the multi-institutional Childhood Cancer Survivor Study, which follows nearly 20,000 childhood cancer survivors.

Baker has made significant contributions to cancer research through his studies of late-developing heart, lung, metabolic, renal, endocrine and reproductive effects in long-term cancer survivors. His National Institutes of Health-funded initiatives examine late cardiovascular complications that result from cancer therapy.

Karen Syrjala, PhD, is the director of the Biobehavioral Sciences Department and a Professor of Psychiatry and Behavioral Sciences at the University of Washington School of Medicine. She provides clinical services to oncology patients through a psychiatry/psychology consulting service. Syrjala's research has focused on examining long-term outcomes and late effects of cancer treatments, especially for blood and marrow transplant survivors. In longitudinal, prospective studies, survivors have been followed for up to 20 years. Her latest studies target the musculoskeletal problems of survivors and test communication methods for providing risk-adapted, self-care guidelines for cancer survivors.

About the program

The Fred Hutchinson Cancer Research Center Survivorship Program provides clinical care, patient education and research opportunities to patients who have completed their cancer therapy in order to evaluate them for the long-term and late effects of cancer and cancer therapy. All services are provided through the Hutchinson Center, the Seattle Cancer Care Alliance and Seattle Children's Hospital, and include:

- Cancer Survivor Program for pediatric survivors of childhood cancer at Seattle Children's Hospital; these survivors transition to the adult clinic at age 21
- Survivorship Clinic for adult-onset cancer survivors, including a fee-for-service clinic staffed by advanced practice providers, RNs and social workers, which is accessible regardless of where patients were treated and provides ongoing care

- Long-term follow-up for transplant patients who have undergone bone-marrow or stem-cell transplant through FHCRC/SCCA; provides lifelong monitoring and care
- Women's Wellness Clinic provides follow-up care and services for women who have completed treatment for breast or gynecological cancer
- Prostate Cancer Clinic provides care for prostate cancer patients from diagnosis through survivorship continuum
- Transition programs for several disease-specific clinics for survivors at the end of active treatment; survivors receive disease-specific treatment summary and survivorship care plan
- Comprehensive treatment summary including detailed needs assessments, follow-up and long-term care plans for survivors upon completion of active treatment—copies of the plan are also provided to the survivor's medical oncologist and primary care physician to ensure comprehensive care

Los Angeles, CA

Patricia A. Ganz, MD, and
Jacqueline Casillas, MD, MSHS,
Program Directors

cancer.ucla.edu

Joined Network: 2006

Type of care

- Consultative for adults
- Long-term follow-up for pediatric survivors and adult survivors of childhood cancer

Community affiliates

HealthCare Partners,
Torrance, CA (2006 to present)

Torrance Memorial Medical
Center, Torrance, CA
(2006 to present)

Olive View Medical Center,
Los Angeles, CA
(2007 to present)

About the directors

Patricia A. Ganz, MD, a medical oncologist, has been a member of the UCLA School of Medicine faculty since 1978 and the UCLA School of Public Health since 1992, and was a founding member of the National Coalition for Cancer Survivorship (NCCS) in 1986. Since 1993, Ganz has been the director of the Division of Cancer Prevention and Control Research at the Jonsson Comprehensive Cancer Center.

In 1997, Ganz established the UCLA Family Cancer Registry and Genetic Evaluation Program, which serves patients, survivors and those at high risk for familial/hereditary cancers. She became an American Cancer Society Clinical Research Professor in 1999 and was elected to the Institute of Medicine in 2007. She received her bachelor of arts from Radcliffe College at Harvard University in 1969 and her medical degree from UCLA in 1973.

Jacqueline Casillas, MD, a pediatric oncologist, is an associate professor of pediatrics in the Division of Hematology/Oncology at the David Geffen School of Medicine at UCLA. She is also the associate fellowship program director of the pediatric hematology/oncology training program, director of the Childhood Cancer Survivorship Program and a co-investigator for a newly funded seed grant from UCLA's cancer center to develop the pilot program of a text-messaging reminder and data acquisition system that aims to help adolescent and young adult survivors adhere to their follow-up care plans.

Casillas received her medical degree from the David Geffen School of Medicine at UCLA. She completed her training in pediatrics at Harbor-UCLA and her oncology training at UCLA.

About the program

UCLA-LIVESTRONG Survivorship Center of Excellence includes several clinical programs. Examples of the center's services include:

- The VITA Program, which provides clinical consultations with a multidisciplinary team of physicians, nurse practitioners, social workers and other specialists; personalized evaluations; and coordinated care with primary care doctors
- The Life After Cancer Clinic, which addresses childhood cancer survivors' medical and quality-of-life issues through comprehensive health evaluations, psychosocial assessments and targeted specialty

referrals; the program also helps survivors with educational, vocational and insurance coverage challenges

- The Healthy Lives After Cancer Program, which presents survivorship information and resources to young adult cancer survivors in the greater Los Angeles area; community outreach events include quarterly health seminars that are designed to empower adolescent and young adult cancer survivors
- Long-term follow-up care including late-effects counseling, further screening, nutrition and exercise counseling, specialty referrals and additional assistance with issues such as educational and vocational challenges and insurance coverage
- Treatment summary and survivorship care plan, which are put into the electronic medical record, and also mailed to the patient and any physicians the patient specifies

New York, NY

Mary S. McCabe, RN, MA,
Program Director

mskcc.org

Joined Network: 2005

Type of care

- Long term follow-up for pediatric survivors, adult survivors of adult-onset cancers and adult survivors of pediatric cancers

Community affiliates

SHAREing & CAREing,
Astoria, NY (2005 to 2010)

Queens Cancer Center,
Queens, NY (2005 to present)

Ralph Lauren Center for Cancer
Care and Prevention,
New York, NY (2005 to present)

About the director

As the Director of the Survivorship Initiative, **Mary S. McCabe, RN, MA**, is responsible for developing and implementing center-wide comprehensive programs for cancer survivors. She is also a faculty member in the Division of Medical Ethics at the Cornell Weill Medical College.

A graduate of Trinity College, Emory University and Catholic University, McCabe was previously the assistant director of the Division of Cancer Treatment and Diagnosis and the director of the Office of Clinical Research Promotion at the National Cancer Institute. She also was a faculty member in the Department of Bioethics at the National Institutes of Health.

McCabe has served on many national committees, frequently consulting for groups interested in developing survivorship programs. Her publications focus on new models of care for adult cancer survivors.

About the program

The Living Beyond Cancer Survivorship Program is a comprehensive initiative that includes clinical care services, a strong research agenda, education programs for health professionals and a unique fellowship program. Research topics range in scope from bone density to cognitive interventions to sleep disturbances.

The center provides disease-specific survivorship clinics for adult-onset cancers, long-term pediatric follow-up care for childhood cancer survivors and a program for adult survivors of pediatric cancers. Programs and services include:

- Clinic for Adult-Onset Cancers, including seven disease-specific clinics: breast, colorectal, prostate, thoracic, thyroid, bone marrow transplant and gynecology
- Pediatric Survivorship Clinic, available to children and adolescents who have survived childhood cancer; survivors are seen beginning two years post-treatment and are transitioned from this clinic to the adult clinic at approximately 18 years of age
- Clinic for Adult Survivors of Pediatric Cancers, which meets the needs of individuals with complex medical and psychosocial issues; survivors are seen by a multidisciplinary team including a physician, nurse practitioner, psychologist and social worker

- Patients in all clinics receive a treatment summary and care plan that is also provided to patients' primary care providers and updated following each visit; survivors can access treatment and care plans electronically through a patient portal
- Sexual medicine program offering medical and psychological care for men, women and couples with sexual difficulties resulting from cancer and its treatment
- Fertility preservation and parenthood program providing advice and guidance on options that may enable patients to preserve fertility prior to treatment and to build a family post-treatment
- Physical rehabilitation programs offering therapeutic exercise, neuromuscular training, patient and family education and pulmonary rehabilitation to decrease the burden of disease and its treatment and help patients regain their optimal functional capacity
- Hereditary cancer risk assessments and genetic counseling for people who are concerned about cancer in their personal and/or familial histories
- Survivorship visits that include surveillance for cancer recurrence, assessment of physical and psychosocial consequences of cancer treatment, recommendations for appropriate cancer screening and health promotion counseling for issues such as diet, exercise and smoking cessation
- Post-treatment resources provide education, professional consultations, peer support and advocacy services to guide and assist patients after cancer treatment; services include telephone information, seminars and workshops, professionally led educational meetings, individual and family consultations and practical advice on insurance and employment issues
- Provider education
- Caring for Survivors, a biannual symposium for all MSKCC nurses, also made available on internal website in video format
- Fertility Preservation for Cancer Patients: Current Options and Practical Strategies for Integration into Patient Care Conference
- Pediatric Survivorship Fellowship: a one-year program designed to train physicians to effectively evaluate and treat survivors of childhood and adolescent cancer

Columbus, Ohio

Barbara L. Andersen, PhD,
Program Director

[cancer.osu.edu/patientsandvisitors/
cancerinfo/survivorship](http://cancer.osu.edu/patientsandvisitors/cancerinfo/survivorship)

Joined Network: 2007

Type of care

- Consultative for adults
- Transition and long-term follow-up for pediatrics

Community affiliates

Holzer Medical Center,
Gallipolis, OH (2007 to 2010)

The Ohio State University
Hospital East, Columbus, OH
(2009 to 2010)

About the director

Barbara L. Andersen, PhD, is a professor with joint appointments in the Department of Psychology and Department of Obstetrics and Gynecology at The Ohio State University (OSU). She is also a member of the immunology and cancer prevention and control programs at Ohio State's Comprehensive Cancer Center.

Andersen has authored three books and more than 150 research articles on clinical psychology and behavioral medicine. Her research has been funded continuously since 1985, having received grants from the American Cancer Society, NCI, the National Institute of Mental Health and the Department of the Army to support her research on biobehavioral aspects of cancer. She holds a Research Career Award (K05) from NCI to conduct psychological intervention trials for patients at high risk for distress and disease progression.

About the program

The Ohio State University **LIVESTRONG** Survivorship Center of Excellence provides high-quality patient service and survivorship care with a holistic emphasis on biopsychosocial care. Examples of initiatives in survivorship clinical care, research and education/outreach include:

- Survivorship clinics delivering comprehensive biopsychosocial screening, assessment and follow-up, including a personalized treatment summary and care plan generated for each survivor through an electronic medical chart template that is automatically updated as additional care is provided
- Multiple government (P01, R01, R21, K series) and private foundation funded investigators with ongoing survivorship research programs in progress; current clinical intervention trials are recruiting patients coping with recurrence and gynecologic oncology patients with sexual difficulties
- Educational programming and outreach to all patients – particularly in underserved minority and Appalachian populations – such as a Survivorship 101 series, nutrition, exercise and other special event programs, support groups, disease-specific conferences and art and music therapy
- An online survivorship resource center, including information and enrollment information for current survivorship research studies and access to resources for pain and spiritual/emotional health

Denver, CO

Alison Faust Jones, ND, RN,
Program Director

[uch.edu/conditions/cancer/
index1.aspx](http://uch.edu/conditions/cancer/index1.aspx)

Joined Network: 2006

Type of care

- Consultative survivorship clinics for adult-onset cancer and adult survivors of pediatric cancer

Community affiliates

Denver Health Medical Center,
Denver, CO (2006 to 2010)

St. Mary-Corwin Medical Center,
Pueblo, CO (2006 to present)

St. Mary's Regional Cancer
Center, Grand Junction, CO
(2006 to present)

About the director

Alison Faust Jones, RN, ND, CNS, received her nursing doctorate degree from the University of Colorado Health Sciences Center in 1998. In addition to leading the survivorship program, she also serves as the psychosocial program director at the center. Her work focuses on survivorship clinics for adult survivors of pediatric cancers and adult-onset cancers, with an emphasis on transitioning patients from the oncology setting to primary care.

About the program

The University of Colorado Cancer Center Survivorship Program provides clinical care, educational programming and research in the field of cancer survivorship. The program includes the following:

- Two models of consultative clinics to transition both adult-onset cancer survivors and adult survivors of pediatric cancer from the oncology setting to the primary care setting with the use of treatment summaries and survivorship care plans
- Clinical model evaluations for feasibility, patient satisfaction, self-efficacy, psychosocial well-being and knowledge of follow-up recommendations
- Patient education and support program for patients, family members and caregivers from diagnosis, through treatment and beyond, focusing on the emotional, practical and physical aspects of cancer survivorship
- Multidisciplinary group education for physicians, nurses and related health professionals on key survivorship issues, late effects and the importance of treatment summaries and survivorship care plans
- Collaboration with three community-based centers; each community cancer center has established a patient support program for cancer survivors that brings education, resources and support to cancer survivors in Colorado and the Rocky Mountain region

Chapel Hill, NC

Marci K. Campbell, PhD,
and Don Rosenstein, MD,
Co-Directors

carolinawell.org

Joined Network: 2008

Type of care

- Adult comprehensive and integrative cancer survivor care
- Long-term follow-up clinic for pediatric cancer survivors

Community affiliates

Greensboro Area Health
Education Center at Moses
H. Cone Memorial Hospital,
Greensboro, NC
(2009 to present)

Leo Jenkins Cancer Center
at East Carolina University,
Greenville, NC (2008 to present)

Zimmer Cancer Center at New
Hanover Regional Medical
Center, Wilmington, NC
(2008 to present)

CommWell Health, NC
(2008 to present)

About the directors

Marci K. Campbell, PhD, a registered dietitian, is a full professor in the Department of Nutrition at the University of North Carolina (UNC), where she received her master's degree in public health in 1977 and her doctorate in health behavior and health education in 1992. Campbell's research focuses on nutrition and health behavior change for health promotion and disease prevention across the cancer continuum. She studies health communication strategies aimed at reducing risk factors for cancer and chronic diseases in minority and underserved communities, as well as peer support and tailored interventions for cancer survivors and the general population. Campbell is a member of the Society of Behavioral Medicine and the International Society for Behavioral Nutrition and Physical Activity. She is also the program leader for cancer prevention and control at the Lineberger Comprehensive Cancer Center and directs the CHAI (Communications for Health Applications and Interventions) Core of the Lineberger Cancer Center and School of Public Health.

Don Rosenstein, MD, is the director of the UNC Comprehensive Cancer Support Program, with joint appointments in the departments of psychiatry and medicine. He is also the President Elect of the Academy of Psychosomatic Medicine.

Rosenstein came to the university from the NIH, where he was clinical director of the National Institute of Mental Health (NIMH) and chief of the Psychiatry Consultation-Liaison Service. He also served as vice chair of the NIH Medical Executive Committee. For many years, Rosenstein chaired both the Clinical Center Ethics Committee and the NIMH Institutional Review Board. In 2008, he received the NIH Director's Award and also the NIMH Director's Career Award for Significant Scientific Achievement.

About the program

The Carolina Well Survivorship Program was created as part of the UNC Lineberger Cancer Center and with the support of a **LIVESTRONG** Center of Excellence grant and the V Foundation in order to improve cancer survivorship services for North Carolinians. The program works in collaboration with the Carolina Comprehensive Support Network and the UNC Cancer Outreach Program. To fulfill its mission, Carolina Well provides a variety of programs and services, including:

- A cutting-edge survivorship program at UNC Lineberger that includes survivorship care plans, clinical follow-up care, psycho-educational programs and resources and tools for wellness
- Pediatric survivorship clinic, transitions clinic and adult-onset survivorship clinics including testicular and breast cancer clinics; additional clinics providing cancer survivorship support include supportive care symptom management, psychopharmacology, coagulation, lymphedema and a clinic focused on chronic chemotherapy-induced nausea and vomiting
- Survivorship clinics offer patients a physical examination, blood work and scans (when appropriate), treatment summary, nutrition information, educational information and a wellness/health promotion consultation regarding wellness behaviors and risks related to being a cancer survivor
- **LIVESTRONG** Care Plan and "Journey Forward" treatment summary and care plan pilot programs in some survivorship clinics
- Partnerships with organizations across the state to help avoid duplication of services, identify current needs and refer survivors to local community resources
- Coordination with communities across the state to offer educational and training programs for cancer survivors and caregivers, including peer counseling and continuing education for health professionals

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METHODOLOGY



In 2009, **LIVESTRONG** commissioned the University of North Carolina (UNC) to conduct a detailed study of the ways in which survivorship care was being provided across the Network. The study's aim was to identify how best to move the Network forward, as well as to summarize lessons learned from this collaborative endeavor in order to share them with others in the field.

The study had three specific goals:

- Assess organizational and environmental characteristics of each of the eight COEs
- Obtain a broader understanding of instituting a COE within a comprehensive cancer center
- Characterize the different COE models

The study was informed by the Chronic Care Model (CCM). The CCM identifies the essential elements of a health care system – the community, the health system, self-management support, delivery system design, decision support and clinical information systems – that encourage high-quality chronic disease care (Wagner, Austin,

Davis, Hindmarsh, Schaefer, & Bonomi, 2001; Wagner, Austin, & Von Korff, 1996).

The CCM was a particularly useful framework for this study because it can be used to assess progress and quality improvement over time; this was helpful given that each COE in the study was at a different stage of implementation. Variations in stage of implementation included how long a site had been a member of the Network, whether it had existing survivorship programs in place before receiving the COE designation, the institutional structure and its cancer patient populations (please see pages 6–13 for more details about each member of the Network).

To fulfill the aforementioned goals, the researchers utilized the following qualitative and quantitative methods:

- Document review: From each of the eight COEs, researchers collected data about organizational and provider characteristics, specifically staffing levels overall and by job category. They also gathered statistics on the populations and geographic areas served. Researchers extracted the information from existing documents, proposals and interim reports. Each COE's web presence was reviewed, along with any files from **LIVESTRONG** as well as any presentations or articles.
- Key informant interviews: Interviews with key informants at each COE addressed the evolution of each center – its strategies for engaging other health care professionals and the local community, logic for decision making, infrastructure, institutional support and strategic planning. The questions targeted four job categories: administrative, principal investigator, community outreach and clinician. The researchers contacted principal investigators first and asked them to identify a key informant for each of the remaining job categories, each of whom then participated in the interviews as well.
- Assessment of Chronic Illness Care (ACIC) survey: Key informants were asked to complete the ACIC survey, an online quantitative survey instrument. With permission from the Improving Chronic Illness Care program, the ACIC questions were adapted to address the context and issues relevant to survivorship care and programs such as community linkages, self-management support, decision support, delivery system design, clinical information systems and integration of care. All surveys were anonymous, yet representation from each COE was assured by checking in with the sites to ensure compliance. A total of 40 surveys were returned.
- Site visits: Three site visits were conducted to serve as case studies in assessing the barriers and facilitators to developing effective cancer survivorship models of care. Before selecting sites to visit, the research team took into consideration location, patient demographics, type of cancer center, models of clinical care, community affiliate model, how long the site had been a COE and whether or not the site had survivorship programming prior to receiving **LIVESTRONG** funding.

Please note: the research team included individuals who do not work at the Center of Excellence at UNC.

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RESULTS



The results presented here are intended to provide an overview of the lessons learned after reviewing all sources of data. Analysis of the quantitative and qualitative methods are not included here; rather, those results have been synthesized to reveal overarching themes. However, presentations and publications of results analyzing specific and additional aspects of the study are in process (Campbell et al., 2010). The results are organized into three areas: characterizing models of care, creating change and the importance of champions and working with community affiliates.

CHARACTERIZING MODELS OF CARE

Across the Network, models of care have evolved over time based on continuous quality improvement, changes in leadership and feedback and recommendations from **LIVESTRONG**. All COEs were using either a consultative model, an integrative model or a combination of the two; each institution's specific context, history, capacity and resources determined the particular model of care used. Despite variations in the tools and approaches used by the COEs, there were many similarities across the Network. Specifically, all COEs:

- Provide care coordination via treatment summaries and care plans
- Conduct medical and psychosocial assessments
- Provide survivorship education and support, including a focus on health and wellness
- Provide surveillance for disease recurrence and for late and long-term effects of treatment through medical follow-up in the clinics

As might be expected, each of these four areas aligns with the recommendations in the IOM report for survivorship clinics to address (Hewitt, Greenfield, & Stovall, 2006). (See page 3 for more on the IOM report.)

CREATING CHANGE AND THE IMPORTANCE OF CHAMPIONS

Developing a COE was a process of organizational change and required the incorporation of innovation into existing practice. The COE had to remain flexible, recognizing and adapting to the needs of different groups within the organization rather than remaining frozen in extant patterns. Organizational commitment from the cancer center at the highest level was necessary, but was itself not sufficient to ensure that survivorship priorities were actualized. Commitment from the senior leadership of the cancer center did not guarantee buy-in from practitioners and administrators throughout the system, nor did it translate into adequate resources to support change. Changing the culture of oncology—actuating a “cultural shift” in the delivery of care to survivors—was considered a major challenge across the Network, particularly with respect to transforming awareness of survivorship issues.

Much of the success of the COEs could be attributed to the vision and hard work of institutional leaders who devoted time and energy to making survivorship a priority. Study participants overwhelmingly gave credit to the “dedicated, passionate staff” of their COEs in turning the tide in favor of survivorship care. Competing time demands, particularly in academic institutions, made it difficult to push the agenda of survivorship, so identifying and working with program champions and opinion leaders in the field was critical to influencing broader adoption of survivorship models.

LIVESTRONG's position as a champion and source of funding was the impetus that in many cases jump-started the institutions' commitment to developing and supporting survivorship care. The name and brand recognition of Lance Armstrong and **LIVESTRONG** was found to be invaluable in raising the profile of survivorship programs and services within the COEs and in their communities at large.

WORKING WITH COMMUNITY AFFILIATES

Community affiliates have been a key component in advancing the field of survivorship beyond the walls of comprehensive cancer centers. Because of their ability to reach traditionally underserved populations, community affiliates have great potential for public health impact; however, they too encounter challenges related to institutional culture and overall stage of readiness to develop survivorship initiatives at the time of affiliation. Despite the unique barriers facing community affiliates, it was noted that, overall, community affiliates have been

particularly successful in reaching low-income and ethnic populations who might not otherwise have access to the COEs. The study made it clear that community affiliates are more successful when they feel a sense of ownership and have the latitude to develop programs that fit their particular agendas, resources and environments. In order to gain a fuller understanding of the potential for partnership with the community affiliates, a more comprehensive and in-depth study would need to be undertaken.

“As we've tried different approaches and tried to do different things somewhat naively, not really knowing, we called them pilots. And we would pilot one approach, for example, doing a clinic for breast cancer survivors eight years ago would not fly. Now eight years later, with all the other initiatives in place, people are interested in doing that. So the models have changed and evolved based on what we've tried to pilot and whether or not it's worked.”

— Survey Participant

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CONCLUSIONS



Since 2005, the members of the Network have made great strides in both understanding and addressing the needs of people affected by cancer after treatment ends. After five years of delivering survivorship care in a comprehensive cancer care facility in partnership with community affiliates, the COE sites have gained extensive knowledge about best practices for establishing a program. The data collected from the Network to date provides important insights into the process of integrating survivorship care into a cancer program, and so for those institutions planning to establish survivorship programs and services, **we make the following three recommendations:**

1. Start where the institution stands. An understanding of organizational and environmental structure, key interests, stakeholders, norms and the overarching institutional culture is critical to moving a program forward. It may be more feasible to start small and develop just one or two priorities rather than try to launch a full-scale program, especially if resources are limited.
2. Find and work with program champions and key opinion leaders across disciplines to promote changes in practice related to adopting survivorship care models. These “early adopters” can then act as ambassadors to promote the benefits of the new model among the later adopters.
3. Build flexibility into the planning and implementation of survivorship care models, and expect the model of care that is initially chosen to change and evolve over time. Additionally, consider how care coordination, assessment, education and support and disease surveillance will be addressed through the program.

NEXT STEPS

The Network has been instrumental in prioritizing and supporting the development of survivorship models of care at each COE and community affiliate and fostering changes in clinical care and community relationships. Additionally, the Network has become a valuable national resource, providing expertise to other institutions interested in following its lead in the areas of survivorship practice and research. Yet there is still more work to be done in order to realize the full promise of this initiative.

Based on the results of this study and a review of the original goals of the Network, the Network has identified three critical areas of survivorship that require action. **LIVESTRONG** is committed to supporting the Network as it addresses these issues over the next several years.

Standardization of metrics in survivorship

Across the Network, program evaluation is an ongoing endeavor. Most COEs conduct needs assessments prior to developing new programs and services, and patient visits and short-term outcomes are tracked routinely. However, the study identified a need for standardized metrics and methods to evaluate long-term impacts of survivorship care. Standardized metrics also will expedite information gathering for treatment summary plans, survivorship care plans and programmatic evaluations. Additionally, standardizing metrics across the COEs will lead to harmonized data, which will enable more powerful and fruitful inquiries than any one COE could conduct in isolation. Electronic Health Records (EHRs) may facilitate metric standardization and data harmonization across the COEs, as the metrics can be built into the data collected by the EHRs.

Identification and dissemination of the essential elements of care delivery in survivorship

While the study shows that there is no “one-size-fits-all” model for survivorship care, there were similarities between the approaches of the COEs, and in interviews conducted with COE investigators, four core components for survivorship care were consistently mentioned: (1) patient education and wellness, (2) providing care coordination through the use of treatment summaries and care plans, (3) conducting medical and psychosocial assessments and (4) providing surveillance for disease recurrence and for late and long-term effects of treatment through medical follow-up in the clinics. These congruencies suggest that it is possible to identify the essential elements of care – rather than a specific care model – necessary to ensure quality of care for survivors. Formal compilation and dissemination of these elements will help transform how survivors are perceived, treated and served. One could imagine the development of a “menu” of essential elements from which future survivorship centers could choose those components fitting to their organizational and environmental structure, key interests, stakeholders, norms and overarching institutional culture.

A framework for defining the key components of survivorship care delivery can be reached via a thorough understanding of the models of care currently in use by each COE, as well as a review of models of care as discussed in the literature and in use throughout the world. Progress in identifying key components of quality care (i.e., best practices) also will be enhanced by progress in standardizing metrics for survivorship care (#1), as the use of standard metrics will enable collaborative research that addresses the effectiveness of care components such as care plan usage. Additionally, training, such as the Excellence in Cancer Survivorship Care: Developing Sustainable Programs, will be necessary for disseminating knowledge and ensuring implementation of the essential elements of care.

Advocate for change within oncology practice, insurance and reimbursement mechanisms and funding mechanisms for care and cancer centers

As more people live with cancer as a chronic condition, it has become necessary for current and new oncology practitioners to identify and embrace survivorship as a stage of cancer care. Progress has been made, but survivorship is not yet fully integrated into the culture of cancer care and cancer centers. Medical and nursing schools, professional organizations, advocacy groups and public stakeholders must be engaged in moving forward, since their support will be necessary to sustain widespread culture change.

Further, changes in the way that insurance or reimbursement mechanisms cover survivor care and services are a necessary part of this cultural shift. Evidence is needed to understand the cost implications of providing – or not providing – survivorship care in an integrated way. Sources of financial support to sustain survivorship centers and/or survivorship care in cancer centers over the long term are needed, and engaging policy makers and advocates in a discussion about opportunities for fee reimbursement and insurance coverage for survivorship care is essential. Ultimately, institutions of all financial scales should be encouraged to include survivorship care as a standard practice.

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