# Beyond Being Lost In Transition: Reviewing the History and Progress in Cancer Survivorship Care

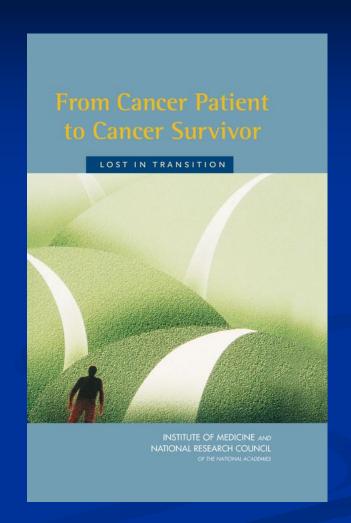
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July 24, 2017
Long-term Survivorship Care after Cancer Treatment: A Workshop
National Cancer Policy Forum

## From Cancer Patient to Cancer Survivor: Lost in Transition

Institute of Medicine 2005



## From Cancer Patient to Cancer Survivor: Lost in Transition Report Recommendations

The following recommendations, taken from the Institute of Medicine's report, From Cancer Patient to Cancer Survivor. Lost in Transition, are directed to cancer patients and their advocates, health care providers and their leadership, health insurers and plans, employers, research sponsors, and the public and their elected representatives.

Recommendation 1: Health care providers, patient advocates, and other stakeholders should work to raise awareness of the needs of cancer survivors, establish cancer survivorship as a distinct phase of cancer care, and act to ensure the delivery of appropriate survivorship care.

Recommendation 2: Patients completing primary treatment should be provided with a comprehensive care summary and follow-up plan that is clearly and effectively explained. This "Survivorship Care Plan" should be writen by the principal provider(s) who coordinated oncology treatment. This service should be reimbursed by thirdparty payors of health care.

Recommendation 3: Health care providers should use systematically developed evidence-based clinical practice guidelines, assessment tools, and screening instruments to help identify and manage late effects of cancer and its treatment. Existing guidelines should be refined and new evidence-based guidelines should be developed through public- and private-sector offorts.

Recommendation 4: Quality of survivorship care measures should be developed through public/private partnerships and quality assurance programs implemented by health systems to monitor and improve the care that all survivors receive.

Recommendation 5: The Centers for Medicare and Medicaid Services, National Cancer Institute, Agency for Healthcare Research and Quality, the Department of Veterans Affairs, and other qualified organizations should support demonstration programs to test models of coordinated, interdisciplinary survivorship care in diverse communities and across systems of care. Recommendation 6: Congress should support Centers for Disease Control and Prevention, other collaborating institutions, and the states in developing comprehensive cancer control plans that include consideration of survivorship care, and promoting the implementation, evaluation, and refinement of existing state cancer control plans.

Recommendation 7: The National Cancer Institute, professional associations, and voluntary organizations should expand and coordinate their efforts to provide educational opportunities to health care providers to equip them to address the health care and quality of life issues facing cancer survivors.

Recommendation 8: Employers, legal advocates, health care providers, sponsors of support services, and government agencies should act to eliminate discrimination and minimize adverse effects of cancer on employment, while supporting cancer survivors with short-term and longterm limitations in ability to work.

Recommendation 9: Federal and state policy makers should act to ensure that all cancer survivors have access to adequate and affordable health insurance. Insurers and payors of health care should recognize survivorship care as an essential part of cancer care and design benefits, payment policies, and reimbursement mechanisms to facilitate coverage for evidence-based aspects of care.

Recommendation 10: The National Cancer Institute, Centers for Disease Control and Prevention, Agency for Healthcare Research and Quality, Centers for Medicare and Medicaid Services, Department of Veterans Affairs, private voluntary organizations such as the American Cancer Society, and private health insurers and plans should increase their support of survivorship research and expand mechanisms for its conduct. New research initiatives focused on cancer patient follow-up are urgently needed to guide effective survivorship care.

Health care providers, patient advocates, and other stakeholders should work to raise awareness of the needs of cancer survivors, establish cancer survivorship as a distinct phase of cancer care, and act to ensure the delivery of appropriate survivorship care.





Cancer Survivors Plaza

"Cancer didn't bring me to my knees, it brought me
TO MY FEET."

~ Michael Douglas (Oscar Winning Actor)

CancerHawk.com | Knowledge is Everything

	Resource
Books	Feuerstein M, Ganz PA (eds): Health Services for Cancer Survivors: Practice, Policy and Research New York, NY, Springer Verlag New York, 2011
	Miller KD: Medical and Psychosocial Care of the Cancer Survivor, Burlington, MA, Jones & Bartlet Learning, 2010
	Stubblefield MD, O'Dell MW (eds): Cancer Rehabilitation: Principles and Practice, New York, NY Demos Medical Publishing, 2009
	Ganz PA (ed): Cancer Survivorship: Today and Tomorrow, New York, NY, Springer, 2007
	Feuerstein M (ed): Handbook of Cancer Survivorship, New York, NY, 2006
Reports	Hewitt M, Greenfield S, Stovall E (eds): From Cancer Patient to Cancer Survivor: Lost in Transition Washington, DC, National Academies Press, 2006
	Hewitt M, Ganz PA (eds): Implementing Cancer Survivorship Care Planning: Workshop Summar, Washington, DC, National Academies Press, 2006
Conferences and educational programs	Biennial Cancer Survivorship Research Conference (https://cancercontrol.cancer.gov/ocs/ resources/researchers.html)
	ASCO Annual Cancer Survivorship Symposium (http://meetinglibrary.asco.org/meeting/2016% 20Cancer%20Survivorship%20Symposium)
	The National Cancer Survivorship Resource Center at the George Washington University Cance Center (http://smhs.gwu.edu/gwci/survivorship/ncsrc)
Survivorship guidelines	American Society of Clinical Oncology (http://www.asco.org/practice-guidelines/cancer-care- initiatives/prevention-survivorship/survivorship/survivorship-compendium)
	National Comprehensive Cancer Network (http://www.jncon.org/content/14/6/715.full)
	American Cancer Society (https://www.cancer.org/treatment/ survivorshipduringandaftertreatment/nationalcancersurvivorshipresourcecenter/ toolsforhealthcareprofessionals/index)
	Children's Oncology Group (https://childrensoncologygroup.org/index.php/ survivorshipquidelines)
Survivor/advocacy organizations	National Coalition for Cancer Survivorship (http://www.canceradvocacy.org/)
	Children's Cause Cancer Advocacy (http://www.childrenscause.org/)
	LIVESTRONG Foundation (http://www.livestrong.com/)

Patients completing primary treatment should be provided with a comprehensive care summary and follow-up plan that is clearly and effectively explained. This "Survivorship Care Plan" should be written by the principal provider(s) who coordinated oncology treatment. This service should be reimbursed by third-party payors of health care.

#### lmpl Cancer Care

WORK

#### Provision and Discussion of Survivorship Care Plans Among Cancer Survivors: Results of a Nationally

Rep Car

CA Cancer J Clin. 2012 Mar; 62(2): 101–117.

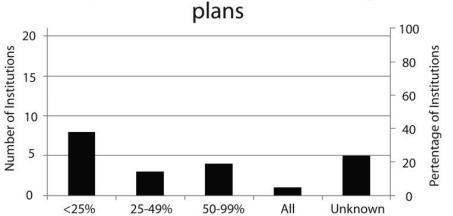
Published online 2012 Jan 12. doi: 10.3322/caac.20142
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Danie Figure 1

#### LIVESTR Fraction o Receive S

Less than one-third of 17 percent received a

## Proportion of survivors receiving plans



AUSTIN, Texas – June 18, 2015 – A survey distributed by the LIVESTRONG Foundation to 350 cancer survivors this spring revealed that a only small population of survivors are receiving survivorship care plans and treatment summaries from their physicians.

## Systematic Reviews of SCPs

- Brennan et al. (Br J Cancer 2014). "Emerging evidence shows very few measurable benefits of SCPs. Survivors reported high levels of satisfaction with SCPs. Resource issues were identified as a significant barrier to implementation."
- Mayer DK et al. (Cancer. 2015) "Evidence of improved outcomes associated with SCP is limited. Future research that addresses the methodological concerns of extant studies is needed regarding SCP use, content, and outcomes."
- Spears JA et al. (Oncol Nurs Forum 2017). "No differences were reported in QOL, but survivorship care required extensive use of resources. Survivorship care provided by APRNs demonstrated improvement in satisfaction, QOL, and process/cost efficiency."
- <u>Klemanski DL et al. (J Cancer Surviv 2016)</u> "This systematic review did not reveal conclusive evidence regarding the needs of survivors or providers regarding treatment summaries and survivorship care plans. A lack of rigorous studies contributed to this.

## Survivorship Care Plans

#### Toolkits

- ASCO
- Journey Forward
- Oncolink

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- January

VOLUME 24 · NUMBER 32 · NOVEMBER 10 2006

JOURNAL OF CLINICAL ONCOLOGY

REVIEW ARTICLE

Failing to Plan Is Planning to Fail: Improving the Quality of Care With Survivorship Care Plans

Craig C. Earle

From the Division of Population Sciences, Department of Medical Oncology, Dana-Farber Cancer Institute, Boston, MA.

Submitted March 14, 2006; accepted July 21, 2006.

Author's disclosures of potential conflicts of interest and author contributions are found at the end of this article.

#### ABSTRACT

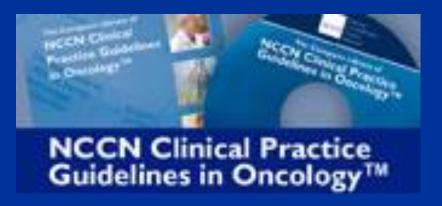
The recent Institute of Medicine report "From Cancer Patient to Cancer Survivor: Lost in Transition" recommended the creation of survivorship care plans for patients as they complete primary therapy for cancer to ensure clarity for all involved about patients' diagnoses, treatments received, and surveillance plans. Any previously existing follow-up guidelines for cancer survivors have been largely restricted to surveillance for recurrence of the primary disease. An important message of the Institute of Medicine report is that survivorship care plans must surpass this and address the chronic effects of cancer (pain, fatigue, premature menopause, depression/anxiety), monitoring for and preventing late effects like osteoporosis, heart disease, and second malignancies, and promoting healthy lifestyles. It should explicitly identify the providers

Health care providers should use systematically developed evidence-based clinical practice guidelines, assessment tools, and screening instruments to help identify and manage late effects of cancer and its treatment. Existing guidelines should be refined and new evidence-based guidelines should be developed through public- and private-sector efforts.

## Cancer Survivorship Guidelines

CHILDREN'S ONCOLOGY GROUP

The world's childhood cancer experts



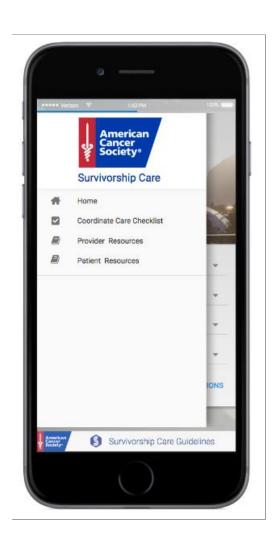


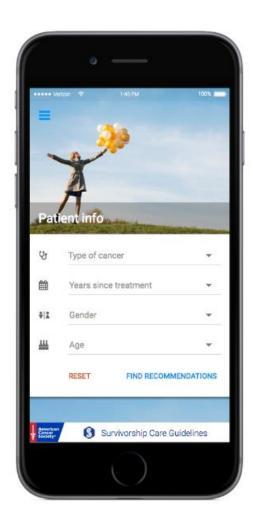


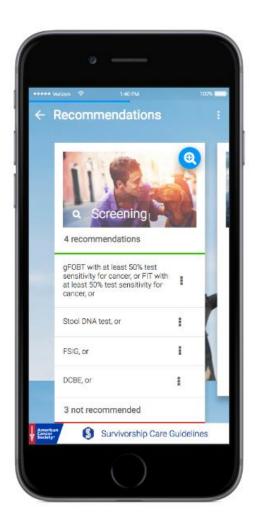
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#### ACS Cancer Survivorship Care Guidelines: Clinician Mobile App







Quality of survivorship care measures should be developed through public/private partnerships and quality assurance programs implemented by health systems to monitor and improve the care that all survivors receive.

## Assuring Quality Cancer Survivorship Care: We've Only Just Begun

Deborah K. Mayer, PhD, RN, AOCN, FAAN, Charles L. Shapiro, MD, Paul Jacobson, MD, and Mary S. McCabe, RN, BA, BS, MA

#### OVERVIEW

Clinical practice guidelines, quality metrics, and performance improvement projects are the key tools of the national movement to improve and assure quality cancer care. Each of these evaluation instruments is intended to assess quality from a unique perspective, including that of the individual provider, the practice/hospital, and the health care system. A number of organizations have developed or endorsed quality measures specific to cancer, however, these have not formally included survivorship measures. Fortunately, the American Society of Clinical Oncology (ASCO), the National Comprehensive Cancer Network, the American Cancer Society, and the American College of Surgeons (ACoS) have taken a leadership role in developing survivorship guidelines and quality metrics. Both ASCO and ACoS have focused their efforts on the treatment summary and care plan, a document that was proposed in the 2006 Institute of Medicine report on cancer survivorship. ASCO has proposed a care plan template for implementation and incorporation into the electronic health records (EHR), which will lend itself to structure, process, and outcome measurement. ACoS, conversely, has included the care plan in its cancer program standards with annual evaluation metrics. In addition, ASCO has developed a number of key survivorship-relevant metrics as part of its Quality Oncology Practice Initiative (QOPI), a tool developed to measure quality cancer care and assess adherence to guidelines across academic and community practices. Together, these efforts will direct us to more effective ways to disseminate guideline recommendations and to better methods of assessing quality survivorship care nationally.





The Centers for Medicare and Medicaid Services, National Cancer Institute, Agency for Healthcare Research and Quality, the Department of Veterans Affairs, and other qualified organizations should support demonstration programs to test models of coordinated, interdisciplinary survivorship care in diverse communities and across systems of care.











American Cancer Society®

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Centers for Medicare & Medicaid Services

Congress should support Centers for Disease Control and Prevention, other collaborating institutions, and the states in developing comprehensive cancer control plans that include consideration of survivorship care, and promoting the implementation, evaluation, and refinement of existing state cancer control plans.

#### Cancer State Plans

Some mention of cancer survivorship in cancer control plans, but variable outcome measures, reporting of progress, etc.



State Cancer Plans Priority Alignment
Resource Guide & Tool

February 2015

The National Cancer Institute, professional associations, and voluntary organizations should expand and coordinate their efforts to provide educational opportunities to health care providers to equip them to address the health care and quality of life issues facing cancer survivors.



#### Cancer Survivorship E-Learning Series for Primary Care Providers

A program of the National Cancer Survivorship Resource Center\*



According to the American Cancer Society, there are more than 13.7 million cancer survivors in the U.S., many of whom face physical, psychological, practical, informational, and spiritual challenges after the completion of cancer treatment. Primary care providers play a critical role in providing much-needed follow-up care for cancer survivors.

The Cancer Survivorship E-Learning Series is a free continuing education program that provides a forum to educate primary care providers (PCPs) (e.g., general medicine physicians, geriatricians, gynecologists, physician assistants, nurse practitioners, nurses) who may have patients who are cancer survivors about how to better understand and care for survivors in the primary care setting. Continuing education credits (CEs) are available at no cost to participants for each 1-hour module.

This program is available through the National Cancer Survivorship Resource Center

(The Survivorship Center), a collaboration between the Ameri George Washington University Cancer Institute funde agreement from the Centers for Disease Control and Pre

The audience will learn about caring for survivors of adult-on

- Module 1: The Current State of Survivorship Ca Care Providers
- Module 2: Late Effects of Cancer and its Treatm Comorbidities and Coordinating with Specialty
- Module 3: Late Effects of Cancer and its Treatn Psychosocial Health Care Needs of Survivors
- Module 4: The Importance of Prevention in Car Empowering Survivors to Live Well
- Module 5: A Team Approach: Survivorship Care
- Module 6: Cancer Recovery and Rehabilitation

The series consists of six (6) enduring online educational mod throughout the year. Self-paced modules can be completed in

- · One or more on-demand webinar presentations by clin
- Interviews with cancer survivors;



2016 Conference \* June 16-18 \* Omni Shoreham Hotel \* Washington, DC

## Cancer Survivorship Symposium: Advancing Care and Research

A Primary Care and Oncology Collaboration

JANUARY 15-16, 2016 SAN FRANCISCO MARRIOTT MARQUIS SAN FRANCISCO, CA



#### Survivorship Compendium

The Survivorship Care Compendium has been developed to serve as a repository of tools and resources to en improve survivorship care within their practices. The compendium serves as an accompaniment to the educat guidance ASCO offers on survivorship care. Although ASCO endorses the National Coalition for Cancer Survivor starting at the point of diagnosis, the focus of this compendium is on individuals who have completed curative maintenance or prophylactic therapy.



#### Original Contribution | CARE DELIVERY

The full version of this article may be viewed online at DOI: 10.1200/JOP.2015.009449

#### ASCO Core Curriculum for Cancer **Survivorship Education**

Charles L. Shapiro, MD, Paul B. Jacobsen, PhD, Tara Henderson, MD, MPH, Arti Hurria, MD, Larissa Nekhlyudov, MD, MPH, Andrea Ng, MD, MPH, Antonella Surbone, MD, PhD, Deborah K. Mayer, PhD, RN, and Julia H. Rowland, PhD

Irahn School of Medicine at Mt Sinai: New York University School of Medicine, NewYork, NY; University of Tampa, Tampa FL; University of Chicago, Chicago, IL; City of Hope, Duarte, CA; Harvard Vanguard Medical Associates: Dana-Farber Cancer Institute, Boston, MA; University of North Carolina, Chapel Hill, NC; and National Cancer Institute, Bethesda, MD

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Disclosures provided by the authors are available with this article at jop.ascopubs.org.

**CONTEXT AND QUESTION(S) ASKED:** The number of cancer survivors is increasing exponentially. Currently there about 15 million cancer survivors, and by 2025, there will be nearly 20 million. Who will provide survivorship care, what are evidenced-based or best care practices, what are best methods to disseminate this information and assess its impact on physician practice, and what are the most cost-effective health care delivery models to serve the majority of survivors?

SUMMARY ANSWER: The ASCO Survivorship Committee in collaboration with the ASCO Professional Development Committee developed a core curriculum and core competencies for physicians, allied health professionals, training programs, and policymaking organizations. Adapted from Institute of Medicine recommendations for survivorship care, the core curriculum and competencies include the following subheadings: surveillance for recurrence and second malignancies, long-term and late effects, health promotion and prevention, psychosocial well-being, special populations including adolescent and young adult survivors, older adult cancer survivors, caregivers of cancer survivors and communication

Employers, legal advocates, health care providers, sponsors of support services, and government agencies should act to eliminate discrimination and minimize adverse effects of cancer on employment, while supporting cancer survivors with short-term and long-term limitations in ability to work.

- Farley Short P, Vasey JJ, Moran JR: Long-term effects of cancer survivorship on the employment of older workers. Health Serv Res 43:193-210, 2008 56.
- Yabroff KR, Dowling EC, Guy GP Jr, et al: Financial hardship associated with cancer in the United States: Findings from a population-based sample of adult cancer survivors. J Clin Oncol 34:259-267, 2016 57.
- Ekwueme DU, Yabroff KR, Guy GP Jr, et al: Medical costs and productivity losses of cancer survivors—United States, 2008-2011. MMWR Morb Mortal Wkly Rep 63:505-510, 2014 58.
- Guy GP Jr, Yabroff KR, Ekwueme DU, et al: Estimating the health and economic burden of cancer among those diagnosed as adolescents and young adults. Health Aff (Millwood) 33:1024-1031, 2014 59.
- Nekhlyudov L, Walker R, Ziebell R, et al: Cancer survivors' experiences with insurance, finances, and employment: Results from a multisite study. J Cancer Surviv 10:1104-1111, 2016 60.
- Zafar SY, Abernethy AP: Financial toxicity, part I: A new name for a growing problem. Oncology (Williston Park) 27:80-81, 149, 2013 61.
- Zafar SY, Abernethy AP: Financial toxicity, part II: How can we help with the burden of treatment-related costs? Oncology (Williston Park) 27:253-254, 256, 2013

Federal and state policy makers should act to ensure that all cancer survivors have access to adequate and affordable health insurance. Insurers and payors of health care should recognize survivorship care as an essential part of cancer care and design benefits, payment policies, and reimbursement mechanisms to facilitate coverage for evidence-based aspects of care.

#### REVIEW ARTICLE

#### The Impact of the Affordable Care Act on Cancer Survivorship

Christine Leopold, PhD, MS, \* Elyse R. Park, †‡ and Larissa Nekhlyudov \*§

Abstract: In 2010, the Patient Protection and Affordable Care Act (ACA) was implemented with the aim of expanding access to quality, affordable care. In this review, we describe the ACA provisions that are most relevant for cancer survivors, provide available published evidence, and offer insights for future research. We found that provisions focusing on access to preventive care, access to quality and coordinated care, and coverage expansion and increased affordability suggest beneficial effects. However, we identified research gaps specifically addressing the intended and unintended consequences of the ACA on cancer survivorship care. Whether or not the ACA continues in its current form, research should address the effects of enhanced preventive services, innovative models of care, and payment structures that promote quality of care, as well as access to affordable, equitable care for a growing population of cancer survivors.

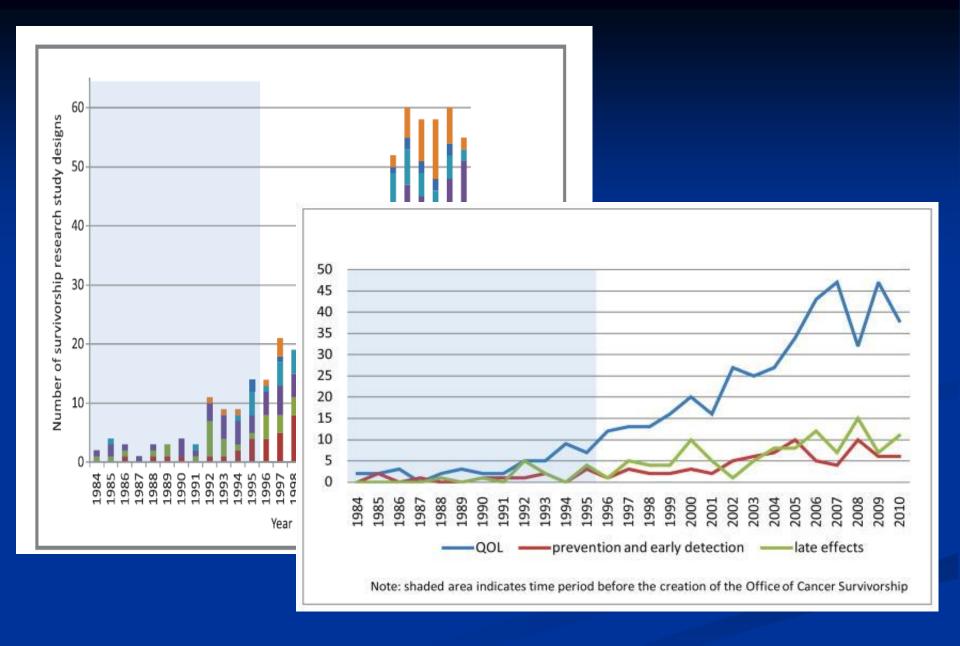
Key Words: Affordable Care Act, cancer survivorship, health care access, health care coverage

(Cancer J 2017;23: 181-189)

#### METHODS

We reviewed the provisions of the ACA13 and categorized them into the following themes: (1) access to preventive care: (2) access to quality, coordinated care; and (3) coverage expansion and increased affordability (Table 1). In order to provide evidence for this narrative review, we conducted a literature search in the PubMed database, as well as in gray literature (such as reports by various professional cancer organizations, the Department of Health and Human Services and the National Academies of Sciences, Engineering and Medicine). In the first round, we searched for the terms "Affordable Care Act and cancer survivors," which resulted in 17 articles. In a second round, we expanded the search to "Affordable Care Act and cancer" and found 213 articles, of which 75 were relevant for this review. The main inclusion criterion was whether the article offered sufficient information on the effects of the ACA on cancer patients. The search was conducted in November 2016 with a final update in January 2017. We used Zotero reference software to search and

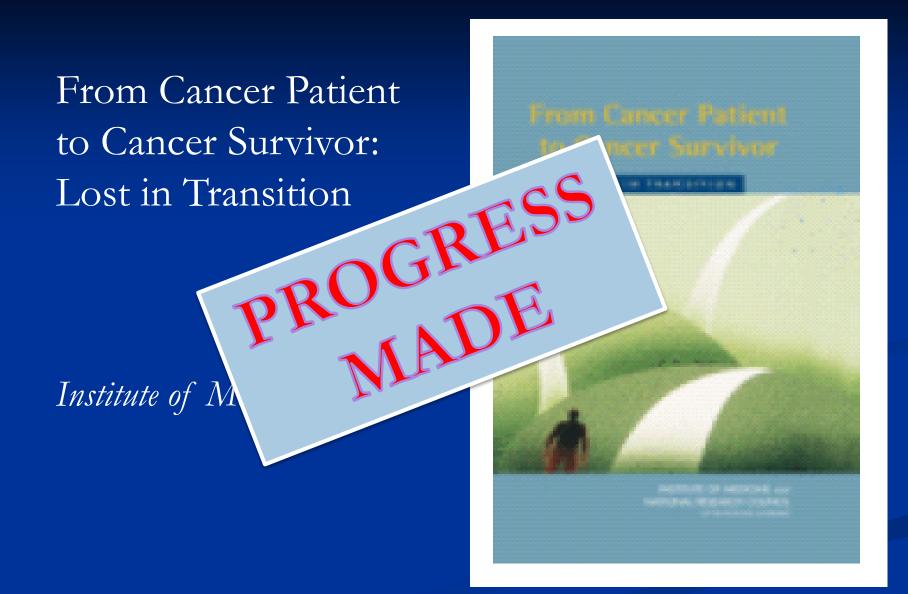
The National Cancer Institute, Centers for Disease Control and Prevention, Agency for Healthcare Research and Quality, Centers for Medicare and Medicaid Services, Department of Veterans Affairs, private voluntary organizations such as the American Cancer Society, and private health insurers and plans should increase their support of survivorship research and expand mechanisms for its conduct. New research initiatives focused on cancer patient follow-up are urgently needed to guide effective survivorship care.

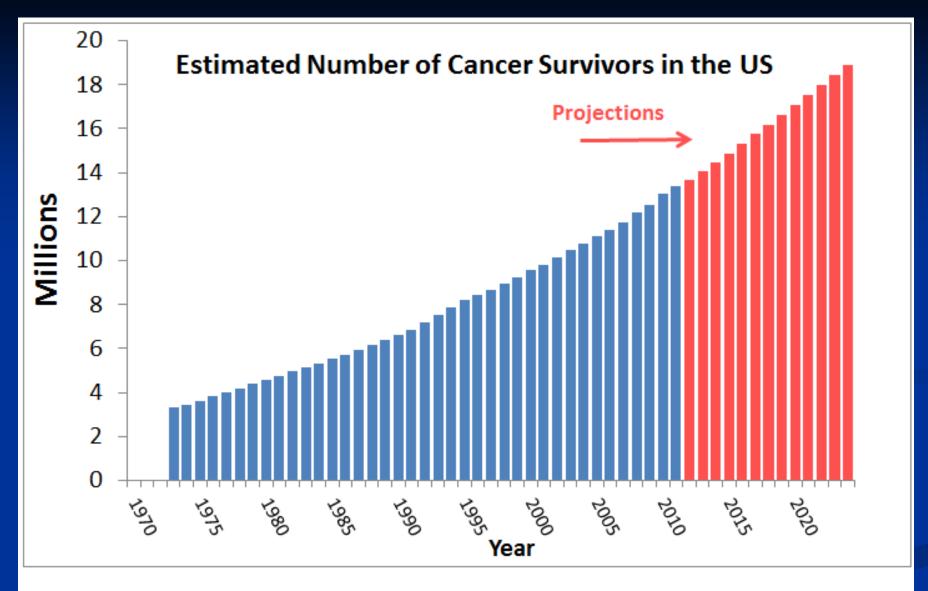


Harrop JP, Dean JA, Paskett ED. Cancer Epidemiol Biomarkers Prev 2011

## Research Gaps

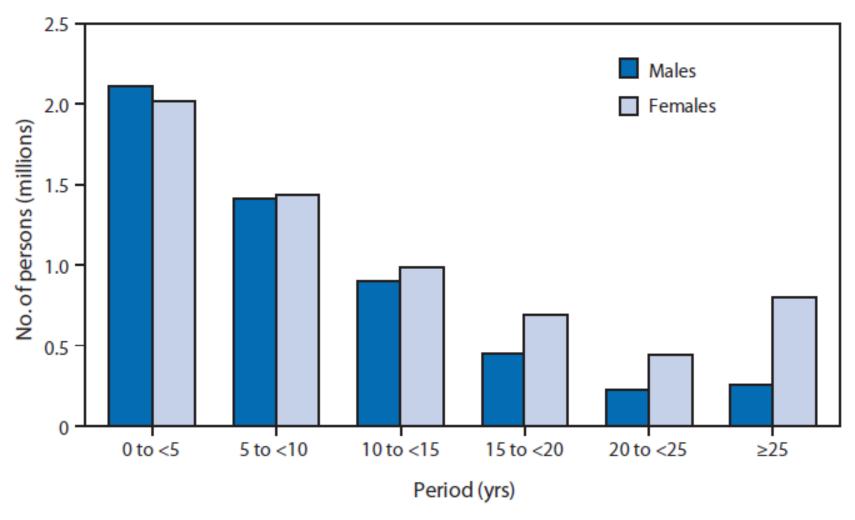
- Relative lack of research involving
  - Common cancers other than breast cancer
  - Older cancer survivors (current age > 65 years)
  - Long-term (> 5 years) cancer survivors
  - Interventional studies with younger (< age 21 years) cancer survivors
  - Biologic mechanisms and genetic factors related to recurrence and adverse effects
  - Patterns and quality of survivorship care





DeSantis C, Chunchieh L, Mariotto AB, et al. (2014). Cancer Treatment and Survivorship Statistics, 2014. CA: A Cancer Journal for Clinicians. In press.

FIGURE 2. Estimated number of living persons ever diagnosed with cancer, by sex and period since diagnosis — United States, January 1, 2007



**Source:** Altekruse SF, Kosary CL, Krapcho M, et al., eds. SEER cancer statistics review, 1975–2007. Bethesda, MD: National Cancer Institute; 2010 (based on November 2009 data submission). Available at http://seer.cancer.gov/csr/1975\_2007.

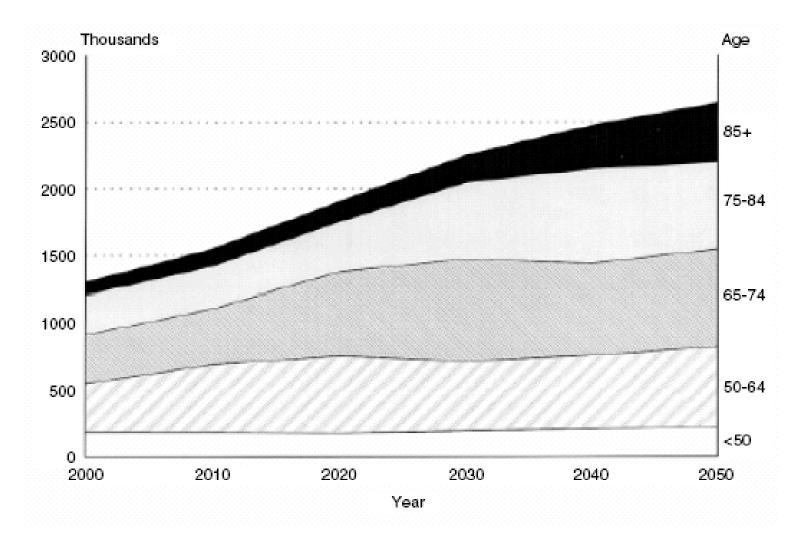


FIGURE 2-3 Projected number of cancer cases for 2000 through 2050. Projections based on (1) U.S. Census Bureau population projections (2000–2050) and (2) agespecific cancer incidence rates (1995–1999) from the Surveillance, Epidemiology, and End Results (SEER) Program and the National Program of Cancer Registries (NPCR), 1995–1999.





#### Next Decade?

- Reduce suffering and mortality among survivors,
   and promote return to life/work/school
- Test models of care delivery/risk stratification approaches that take into account the whole person
- Enhance education of survivors and all providers caring for this diverse population
- Provide survivorship care that is accessible, affordable and equitable

# LONG-TERM SURVIVORSHIP CARE AFTER CANCER TREATMENT

A WORKSHOP

JULY 24-25, 2017

WASHINGTON, DC

The National Academies of MEDICINE



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