Overview of Cancer Survivorship

When Life Is Sewn Back Together, It Has Changed

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Objectives

- Describe cancer survivorship trends over time
- Define who is a cancer survivor
- Identify survivors needs across the cancer continuum
- Explore the role of patient engagement in survivorship care
- Discuss health care delivery implications of an increasing population


YOU ARE HERE

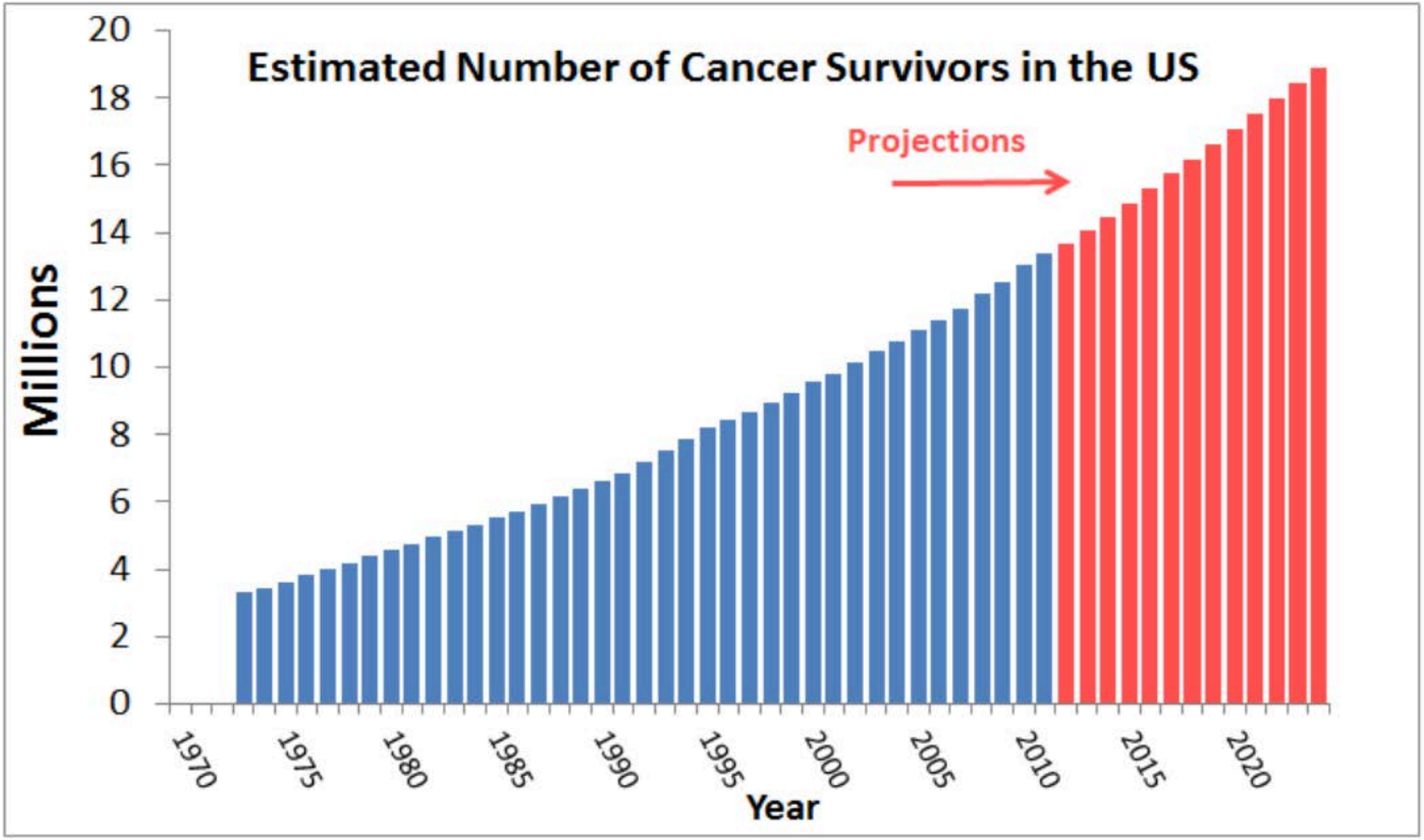
Cancer in the US

More Than a Statistic

Trends in Five-year Relative Survival Rates (%), 1975-2012

Site	1975-1977	1987-1989	2006-2012
All sites	49	55	69
Breast (female)	75	84	91
Colorectum	50	60	66
Leukemia	34	43	63
Lung & bronchus	12	13	19
Melanoma of the skin	82	88	93
Non-Hodgkin lymphoma	47	51	73
Ovary	36	38	46
Pancreas	3	4	9
Prostate	68	83	99
Urinary bladder	72	79	79

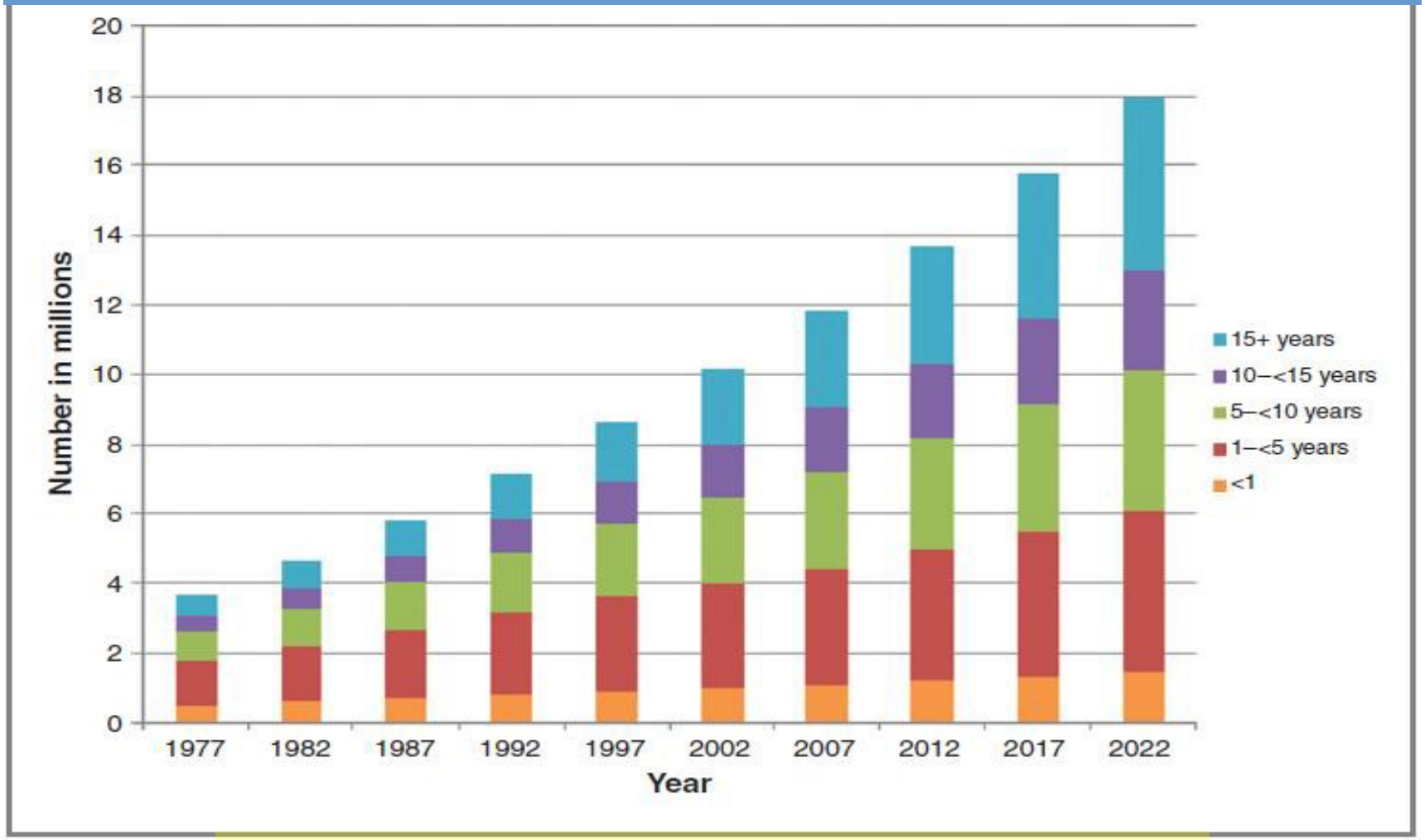
5-year relative survival rates based on patients diagnosed in the 9 oldest SEER registries from 1975-1977, 1987-1989, and 2006-2012, all followed through 2013.
Source: Surveillance, Epidemiology, and End Results (SEER) Program, National Cancer Institute, 2016.



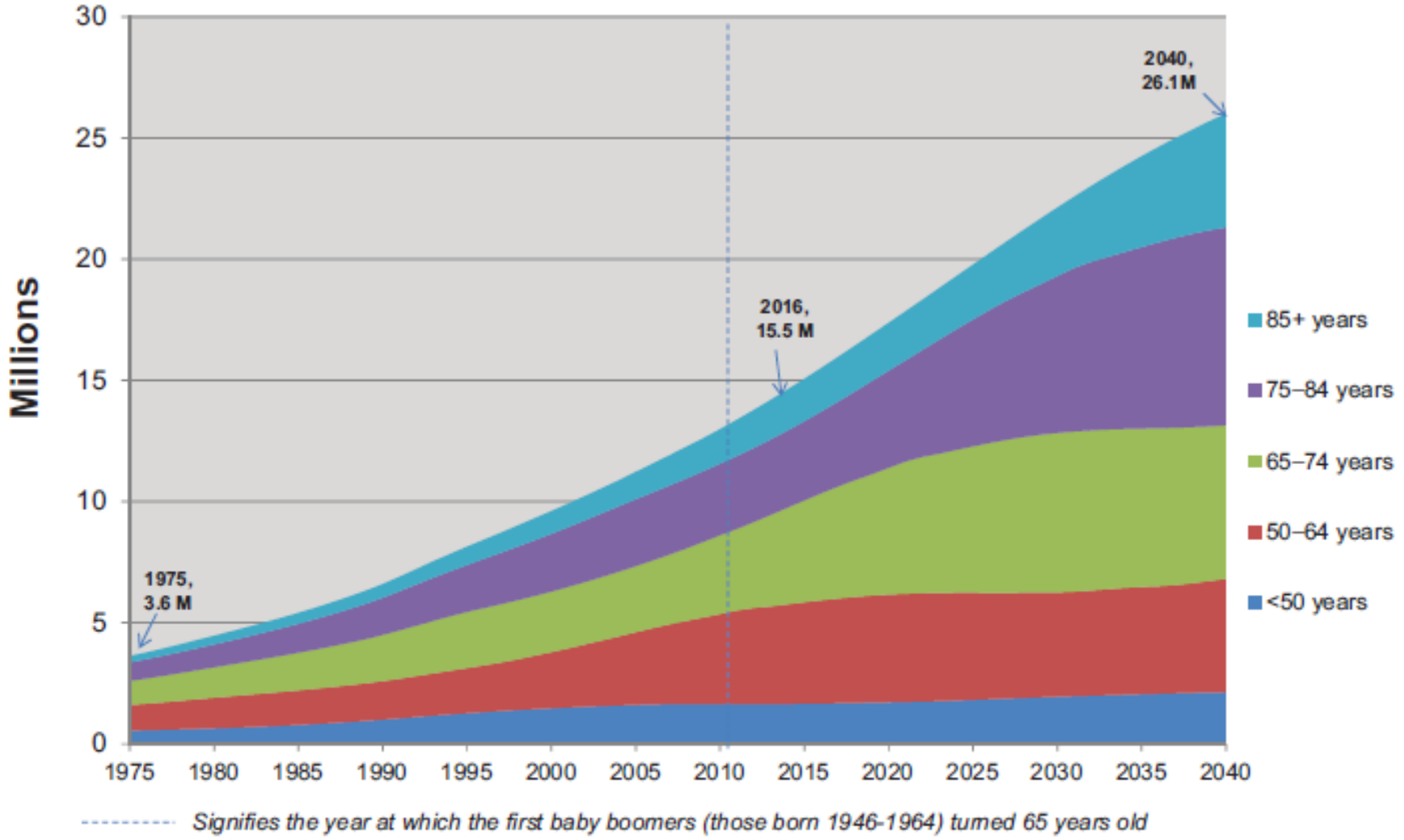
[1] DeSantis C, Chunchieh L, Mariotto AB, et al. (2014). Cancer Treatment and Survivorship Statistics, 2014. CA: A Cancer Journal for Clinicians. In press.

The number of cancer survivors is projected to increase by 31%, to almost 26 million, by 2040

Survivors Projected in 2022



Over next 10 years, the number of those living beyond 5 years will increase by 35% to 14 million



It is estimated that by 2040, 73% of cancer survivors in the United States will be 65 years or older.

JOURNEY OF HOPE

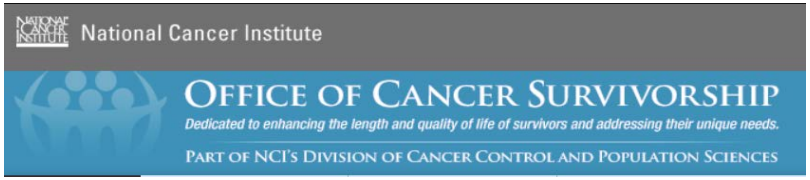
Survivorship Attributes

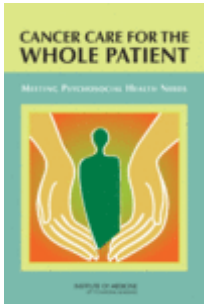
- Defined as those who have lived through a potentially deadly or life altering event.
- It is a dynamic process
- It involves uncertainty
- It is a life changing experience
- It has duality of positive and negative aspects
- It is an individual experience with universality
  - Doyle, N. (2008) Cancer survivorship: evolutionary concept analysis. *J Adv Nursing*, 62(4): 499-509.
  - Peck (2008) Survivorship: A concept analysis. *Nsg. Forum, 43(2), 91-102.*

Survivorship Defined

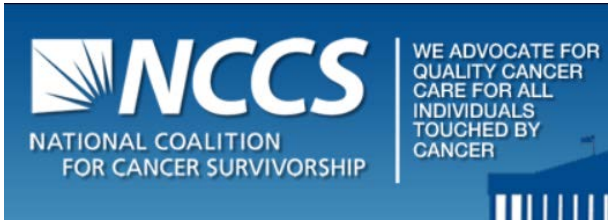
- Living cancer free
  - For remainder of life
  - Experiences ≥ 1 treatment complication
  - But dying after a late recurrence
  - But develops another cancer
- Living with cancer
  - Intermittent periods of active disease on/off treatment
  - Continuously without disease free period

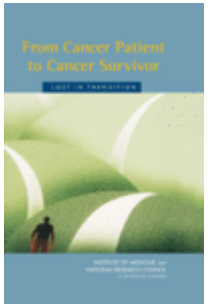
Survivorship Over Time





1950 5-yr survival = 30% → 1975 5-yr survival = 48% → 1986 → 1996 → 2005 → 2007 → 2010 5-yr survival = 68%



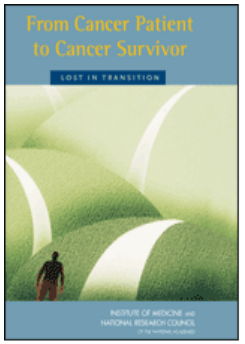


"Good Patient" "Empowered Patient"

"Victims" → "Survivors"

"War" → "Competition" → "Journey"

From Cancer Patient to Cancer Survivor: Lost in Transition



Essential Components of Survivorship Care:

- Prevention of recurrent and new cancers and other late effects
- Surveillance for cancer spread, recurrence or second cancers and assessment of medical and psychosocial late effects
- Intervention for consequences of cancer and its treatment
- **Coordination between specialists and primary care providers to ensure that all of the survivors health needs are met**

LIVESTRONG Essential Elements (2011)

TIER 1: CONSENSUS ELEMENTS

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

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

TIER 2: HIGH-NEED ELEMENTS

All medical settings SHOULD provide direct access 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 and caregiver support
- Patient navigation
- Educational information about survivorship and program offerings

TIER 3: STRIVE ELEMENTS

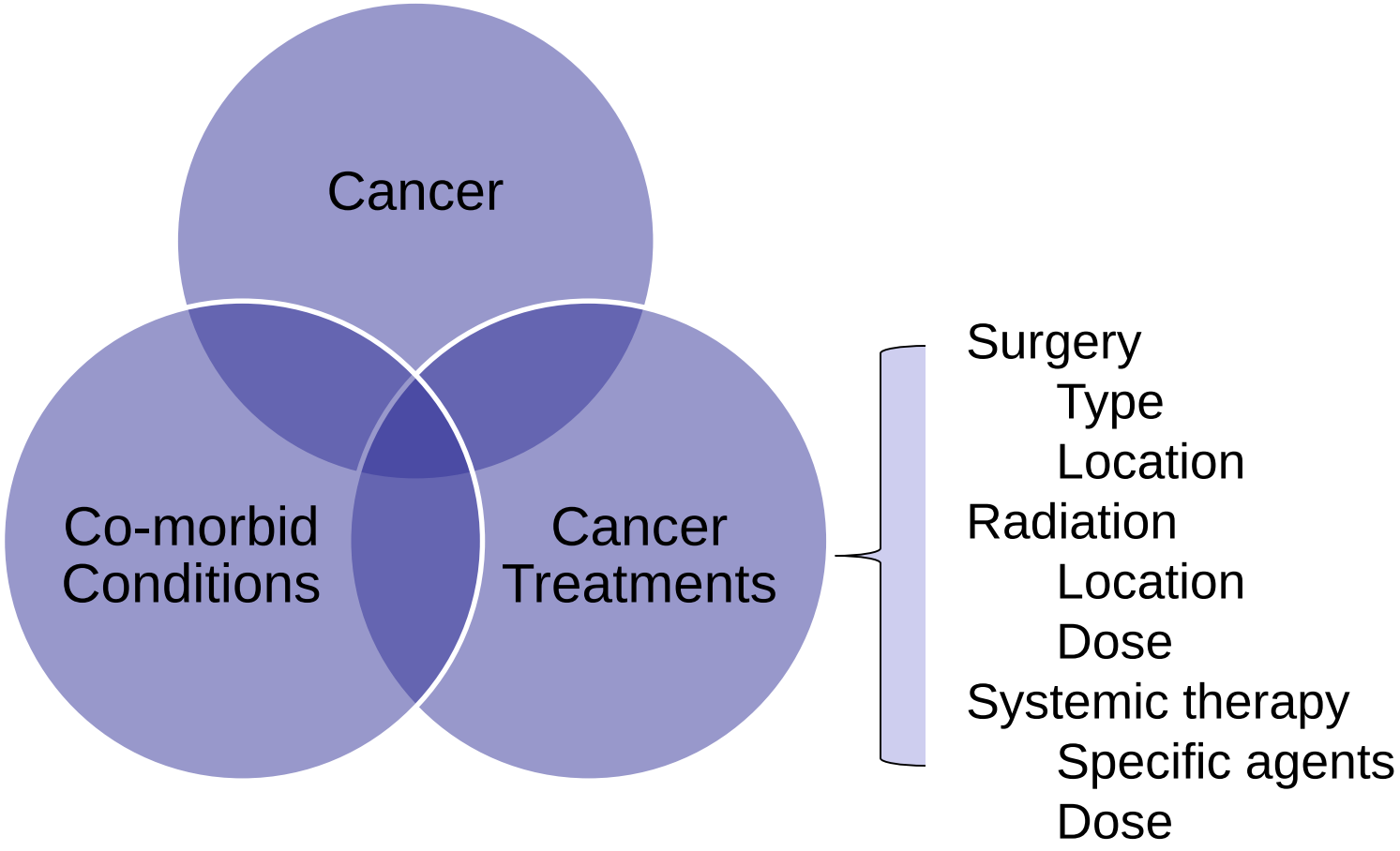
All medical settings should STRIVE to provide direct access or referral to these elements of care.

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

Need risk stratification and algorithms to triage recommended elements

Management of Long Term and Late Sequelae

Long-term and Late Effects



Source: *From Cancer Patient to Cancer Survivor: Lost in Transition*; page 24, Box 2-2.

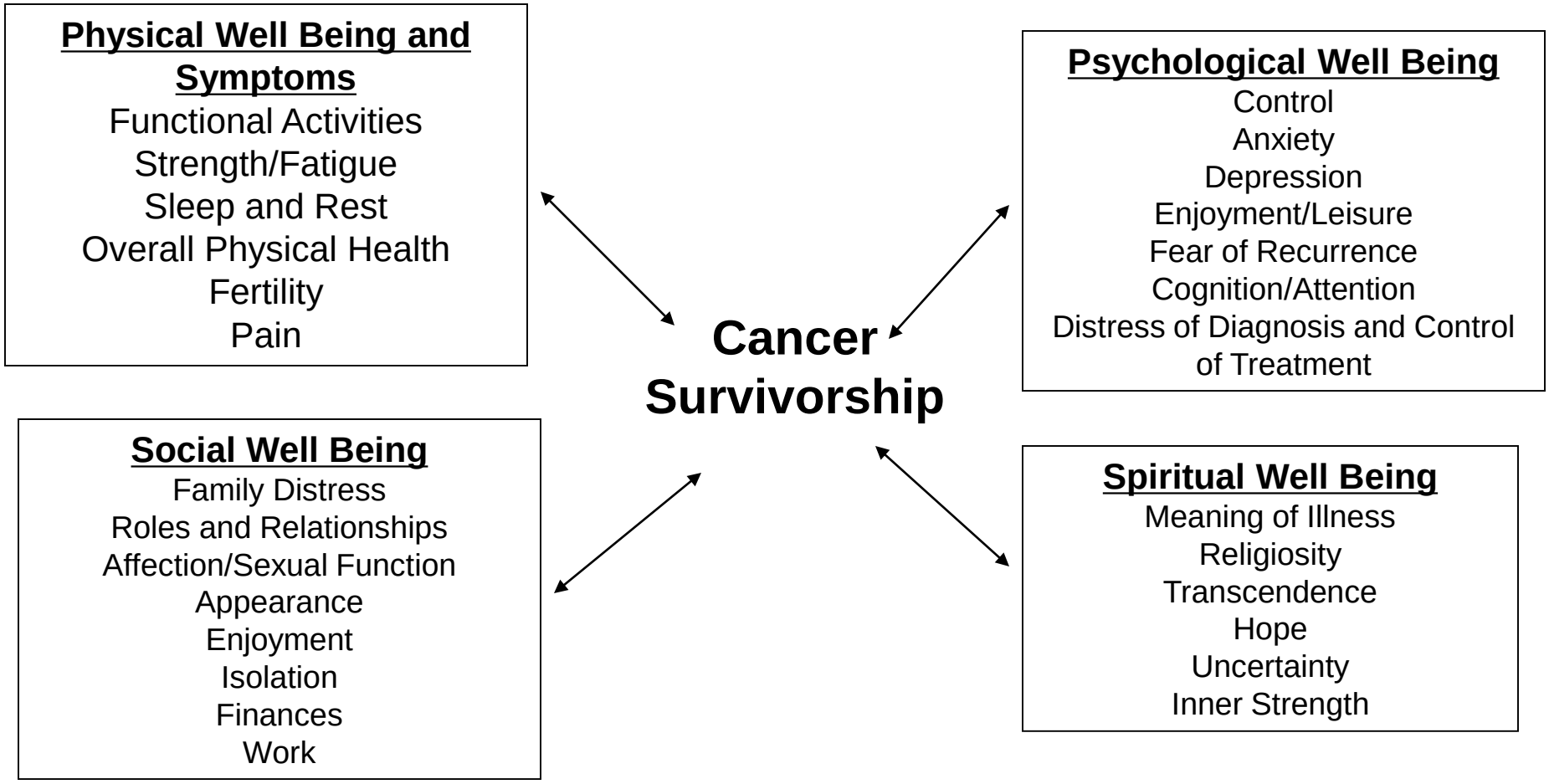
Common Comorbidities in Cancer Survivors

- Obesity
- Dyslipidemia
- Hypertension
- Diabetes
- Osteoporosis/osteopenia
- Hypothyroidism
- Depression
- Cognitive changes
- Age related changes

Comorbid Conditions in Long-term Cancer Survivors

- 1527 breast, prostate, CRC, gyn cancer survivors
- **Average of 5 conditions** (95% CI4.8, 5.1) with 1.9 (95% CI, 1.8, 2.0) after diagnosis
- Hypertension 54%, Eye/ear 48.2%, Arthritis 46.3%, Heart 35.3%, Lung 30.6%, GI 25.5%, Kidney 26.6%, Diabetes 21%, Thyroid 16.5%, Bone 19.7%
- Higher burden with older age, breast ca, living alone, BMI >25, physically inactive
  - » Leach (2015). J Cancer Surviv, 9: 239-251.

Quality of Life



Ferrell, BR and Grant, M. City of Hope Beckman Research Institute (2004)

Unmet Needs of Cancer Survivors (ACS Cohort)

- N=1514, 2, 5 and 10 year survivors
- **Not associated with time since diagnosis** but there were gender and age differences
- Unmet needs included:
  - Physical (38.2%)
  - Financial (20.3%)
  - Information (19.5%)
    - » Burg (2015) Cancer

Symptom Burden and QOL in Survivors

- **~1/3 of survivors experience symptoms after treatment equivalent to during treatment**
- Most common:
  - Fatigue
  - Depression or mood disturbance
  - Sleep disruption
  - Pain
  - Cognitive limitations
- Greater symptoms and poorer QOL with younger age, lower SES, increased co-morbidities
  - » Wu & Harden, *Cancer Nurs* 5/14/14 epub ahead of print
  - » Harrington et al (2010) *Int J Psychiatry Med, 40: 163*

Cardiovascular Late Effects

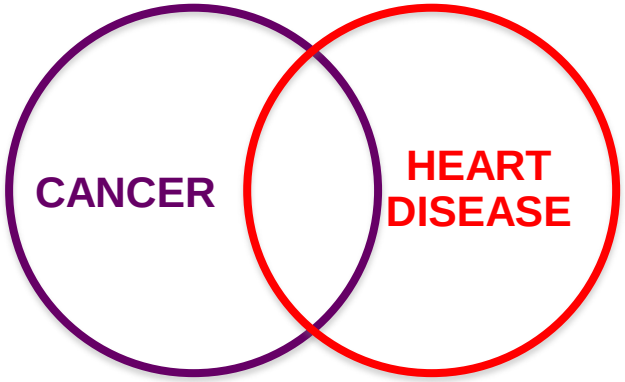
>1 in 3 Americans have ≥ 1 type of cardiovascular disease

Death rate for noncancer causes RR 1.37 compared to general population with almost ½ due to CVD

Cardiovascular disease is leading cause of death in cancer survivors when looking at all cause mortality

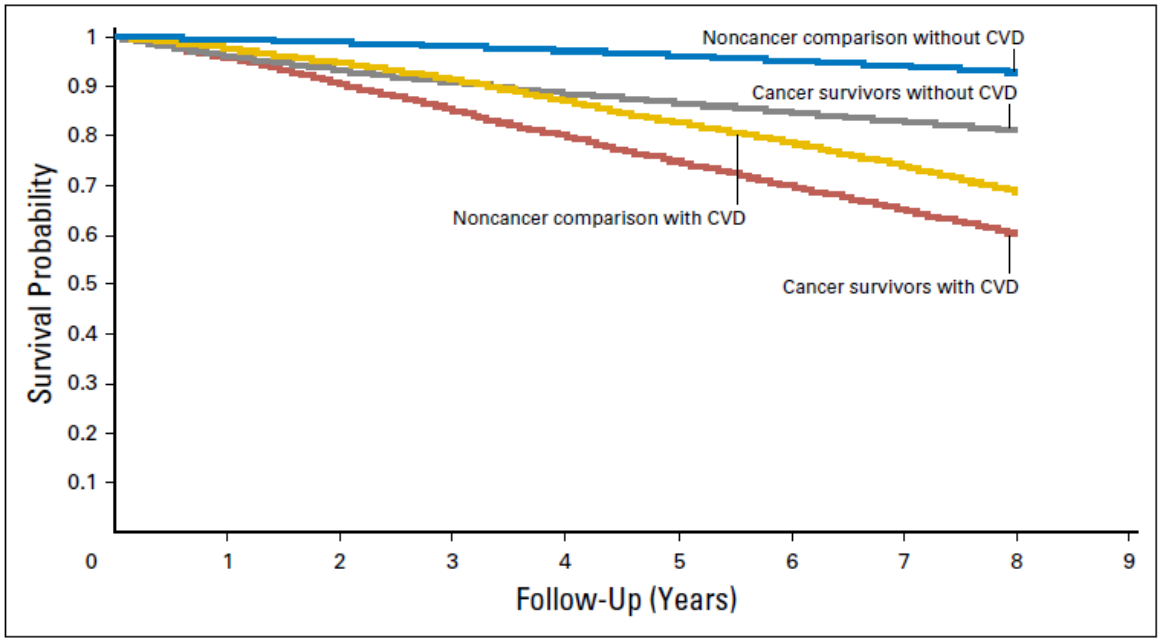
Brown et al. (2003). CA Cancer J Clin, 53(5):268-291.
Covielo, Knopf (2012)

Cancer increases risk of subsequent CV disease



- Survivors have a 10 times higher risk for **atherosclerosis**
- Survivors have a 5.9 times higher risk of **congestive heart failure**
- Survivors have a 6.3 times the risk for **pericardial disease**
- Survivors have a 4.8-fold greater risk for **valvular disease**
- Risks are particularly high among survivors who had received **anthracycline drugs** or **high-dose radiation** therapy to the heart as part of their cancer treatment

CVD in Long-term Cancer Survivors



- >36,000 2 year survivors of adult onset cancers
- CVD highest in lung, NHL, breast ca compared to controls
- ≥ 2 CVRF significantly higher rates of CVD
- Poorer survival in ca survivors with CVD than without (60% vs 81% at 8 years)

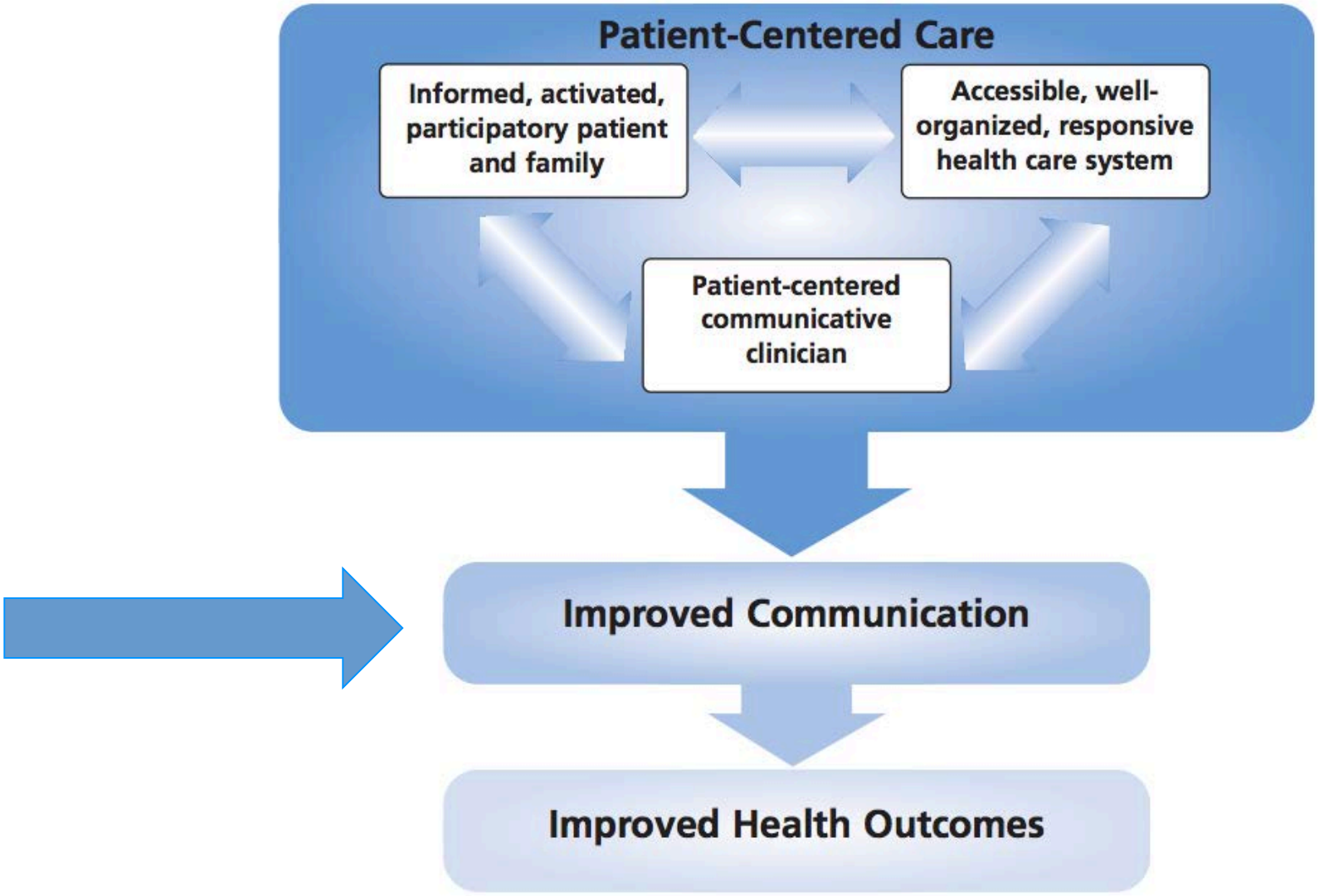
» Armenian (2016). J Clin Oncol, 34: 1122-1130

Health Promotion

The AHA endorses 7 metrics of ideal health that include a combination of *health behaviors* (not smoking, physical activity, low body mass index [BMI], and healthy diet) and *health factors* (blood sugar, blood pressure, and total cholesterol).

The World Health Organization estimates that >30% of cancer deaths could be prevented by *modifying or avoiding certain risk factors*, including tobacco use, obesity, unhealthy diets low in fruit and vegetable intake, inactivity, alcohol use, sexually transmitted human papillomavirus infection, urban air pollution, and indoor smoke from solid fuels.

The central goal is to deliver **patient-centered**, **evidence-based, high-quality cancer care that is accessible and affordable** to the entire U.S. population regardless of the setting where cancer care is provided.



IOM. *(2013). Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis.* Washington, DC.

Patient Engagement: Engagement Behavior Framework

- Actions individuals must take to obtain the greatest benefit from health care services available to them.
  - Active engagement in **managing health**
    - Prepare → Act
  - Active engagement in **managing health care**
    - Prepare → Interact

Gruman, J. et al (2010). *Pt Educ Couns* 78: 350-356.

Activation

Predictive of greater engagement in:

- Better Preventive behaviors
- Healthy behaviors
- Disease specific self-management
- More health information seeking
- Better outcomes
- Lower rates of health care utilization

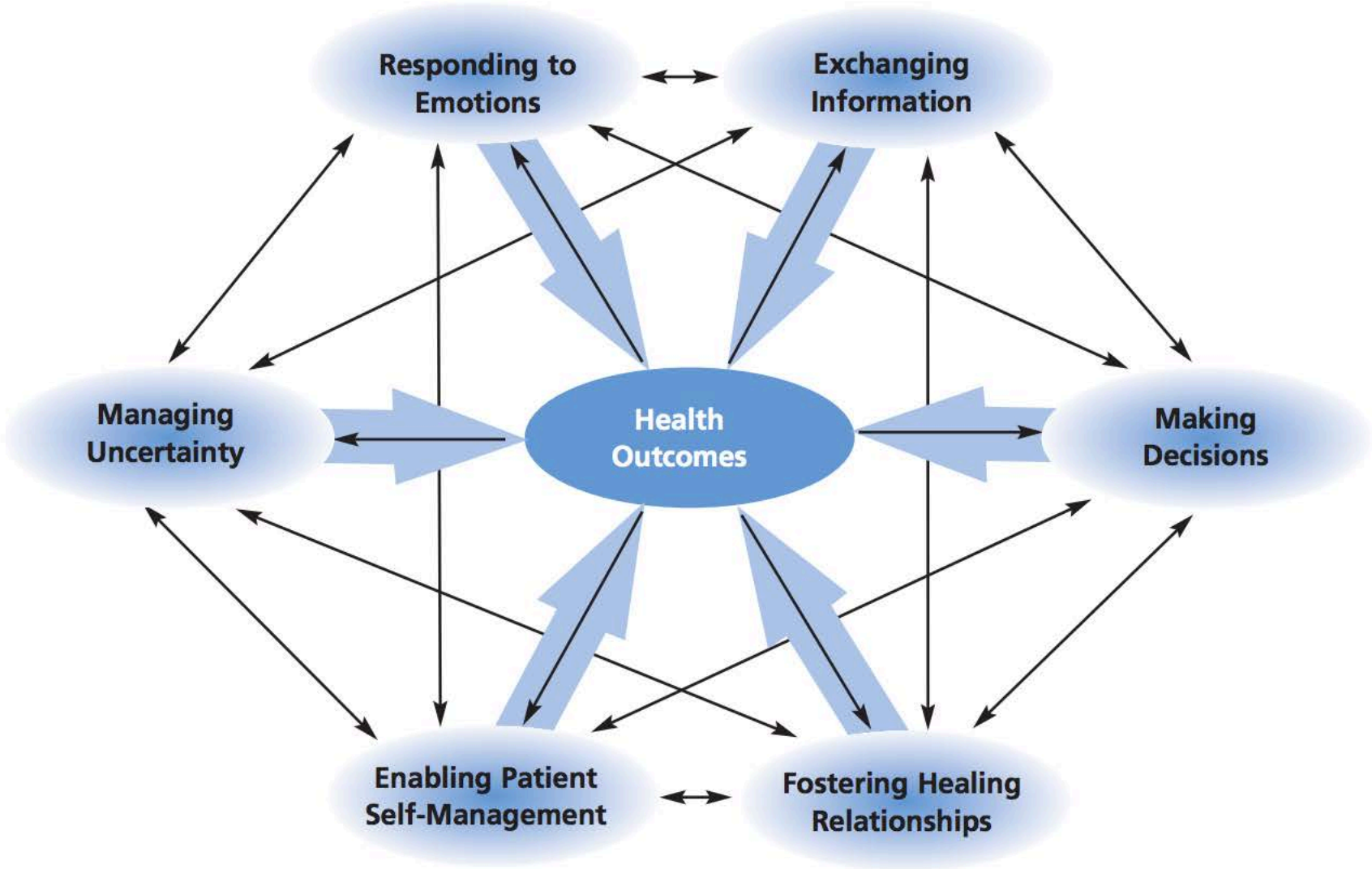
>350 studies

Activation Outcomes

- N ~ 3000 Cancer survivors
- Activated cancer patients (levels 3 &4) more likely to:
  - 9.5 x plan reflected patient values
  - 4.7 x to begin exercising
  - 4.5 x effectively manage symptoms
  - 3.3 x eat healthier
  - 45% more likely to adhere to medications
  - 10% more likely voice concerns

Hibbard, J. Mahoney, E., Sonet, E. (2017). *Pt Educ Couns*, 100:1276-1279.

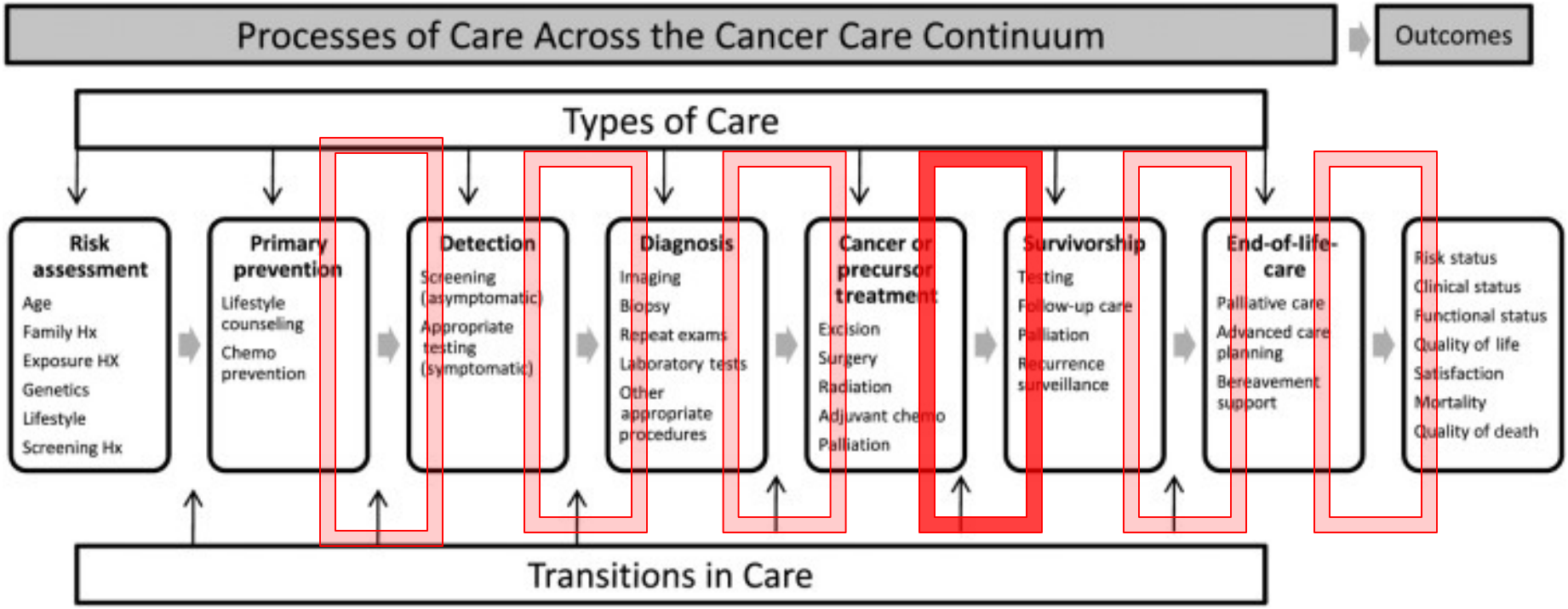
The six core functions of patient-clinician communication overlap and interact to produce communication that can affect important health outcomes.



Epstein RM, Street RL Jr. (2007) Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering. NCI, NIH Publication No. 07-6225. Bethesda, MD, 2007.

BEFORE…DURING…AFTER (2008)

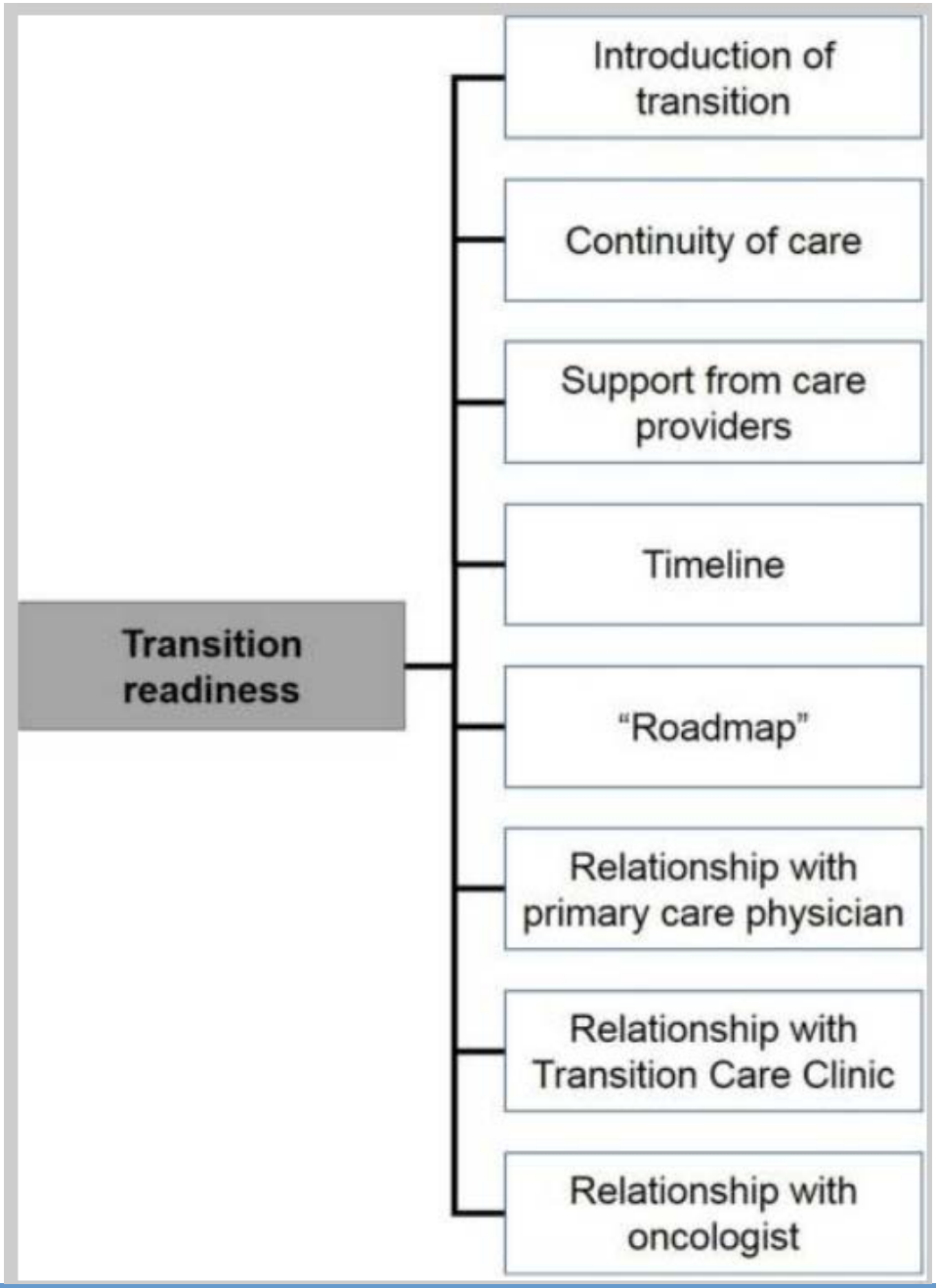
How can we facilitate coordinated care?



Coordination between specialists, primary care *providers and patients* to ensure that all of the survivors health needs are met.

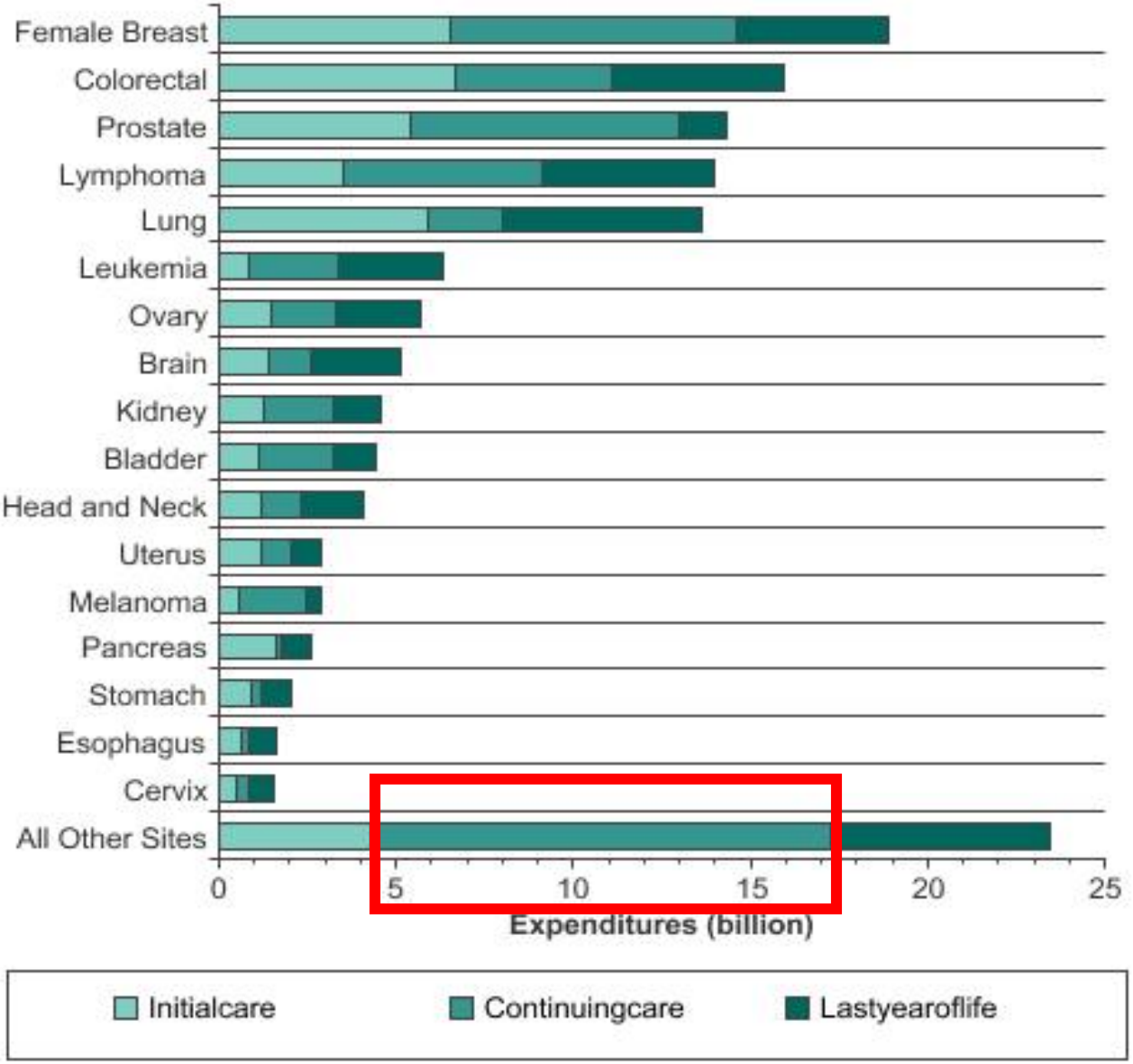
Taplin, Natl Cancer Inst Monogr (2010) 2010 (40): 3-10.

Transition Readiness from Oncology to Primary Care



Franco, et al. (2016) *Current Oncology* 23(6): 378.

Estimates Of National Expenditures For Cancer Care, By Site



Source: Mariotto AB, et al Projections of the cost of cancer care in the U.S.: 2010-2020. J Natl Cancer Inst 2011; 103(2):117-28.

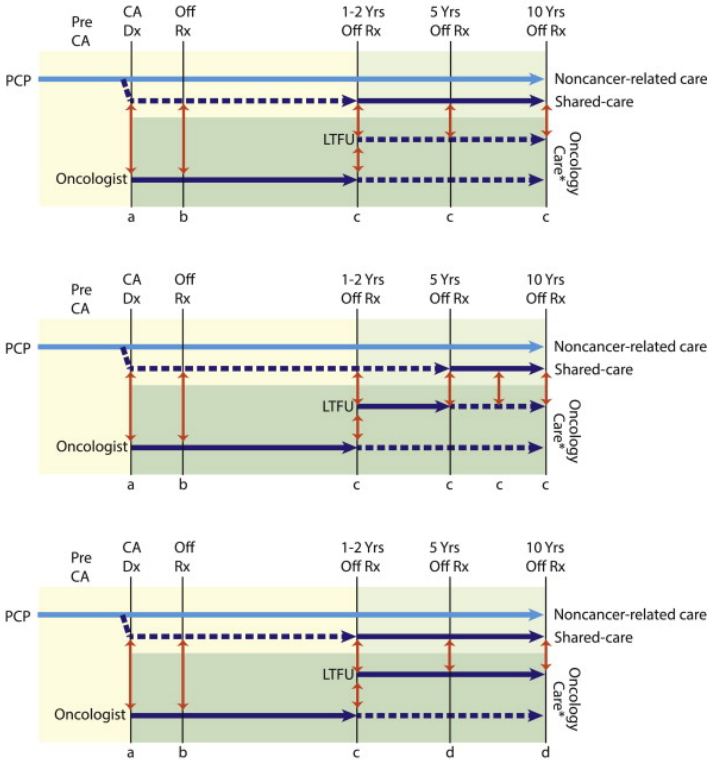
Cancer Prevalence and Cost of Care Projections: http://costprojections.cancer.gov/

Risk-Stratified Shared Care Model for Cancer Survivors

Low Risk:
All of the following:
- Surgery only or chemotherapy that did not include alkylating agent, anthracycline, bleomycin, or epipodophyllotoxin
- No radiation
- Low risk of recurrence
- Mild or no persistent toxicity of therapy

Moderate Risk:
Any of the following:
- Low or moderate dosealkylating agent, anthracycline, bleomycin, or epipodophyllotoxin
- Low to moderate dose radiation
- Autologous stem cell transplant
- Moderate risk of recurrence
- Moderate persistent toxicity of therapy

High Risk:
Any of the following:
- High dose alkylating agent, anthracycline, bleomycin, or epipodophyllotoxin
- High dose radiation
- Allogeneic stem cell transplant
- High risk of recurrence
- Multi-organ persistent toxicity of therapy



Communication Points with Primary Care Physician

[a] Cancer diagnosis and planned therapeutic approach, brief overview of chemotherapy, radiation therapy and/or surgery.
[b] Survivorship Care Plan: cancer diagnosis, cancer therapy, surveillance recommendations, contact information.
[c] Periodic update with changes in surveillance recommendations, and new information regarding potential late effects.
[d] Periodic update of survivor's health for primary care physician's record.

Abbreviations:
Ca=cancer; Dx=diagnosis; Off Rx=completion of cancer therapy; PCP=primary care physician; LTFU=long-term follow-up (survivor) program; Onc=oncologist
Primary responsibility for cancer-related care; PCP continues to manage noncancer comorbidities and routine preventive health maintenance.
*Cancer Center or Oncologist/oncology group practice; if there is not an LTFU/Survivor Program available, care in the box is provided by the primary oncologist.

McCabe MS, Partridge AH, Grunfeld E, Hudson MM. (2013) *Semin Oncol.*, 40:804-12

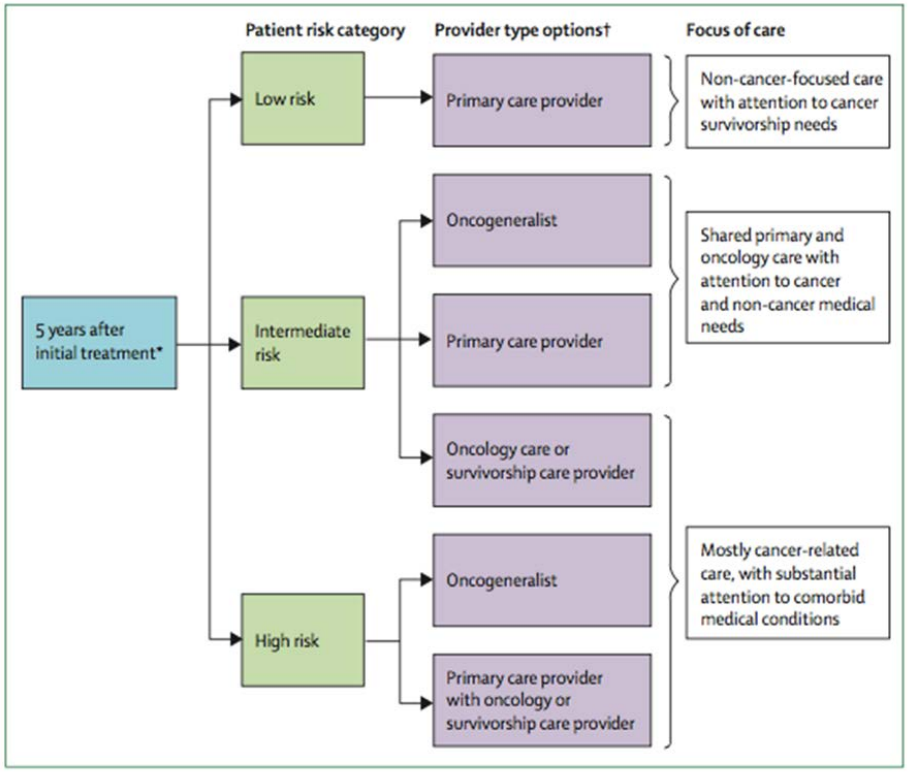
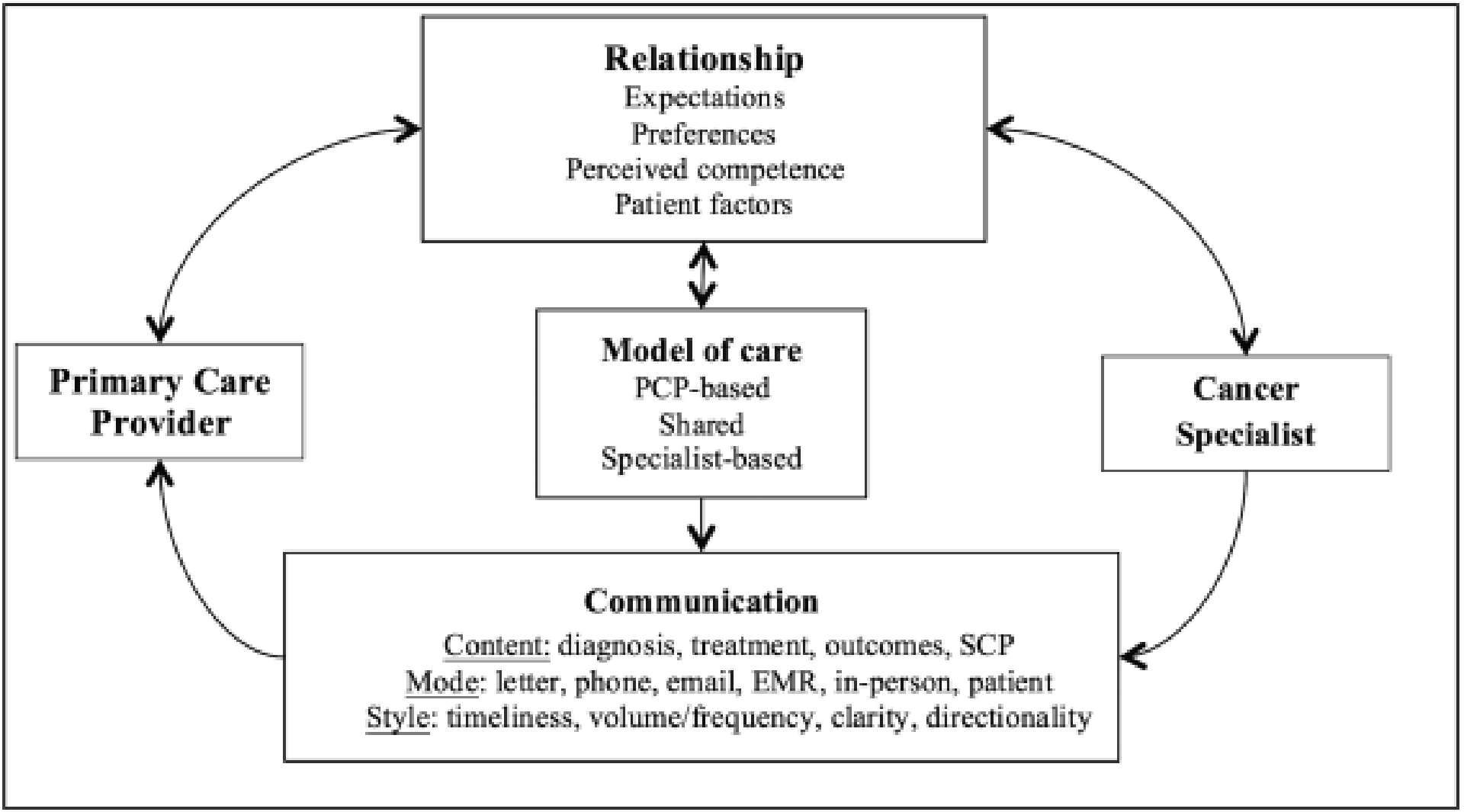


***Figure 2:* Survivorship care strategies**
*5 years is based on general recommendations in the cancer community; transition of care might vary. †Any of these models might be appropriate for nurse practitioner or physician assistant involvement.

Nekhlyudov L, O'Malley D., Hudson SV. (2017). *Lancet Oncology*, 18: e30-e38

The Primary Care Provider (PCP)-Cancer Specialist Relationship: A Systematic Review and Mixed-Methods Meta-Synthesis



Dossett LA, Hudson JN, Morris AM, Lee MC, Roetzheim RG, Fetters MD, Quinn GP. CA Cancer J Clin 2017;67:156–169.

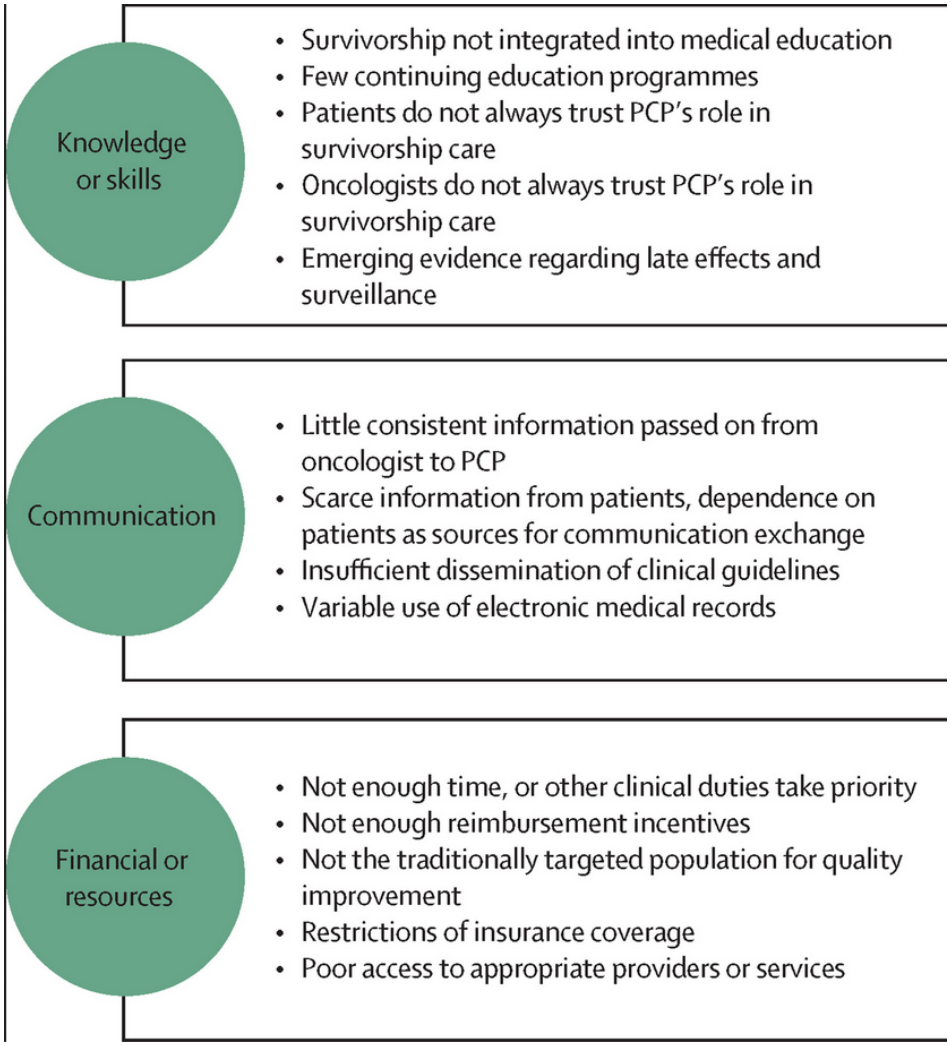
The Primary Care Provider (PCP)-cancer Specialist Relationship: A Systematic Review And Mixed-method Meta-synthesis.

Summary of Findings

Poor and delayed communication between PCPs and cancer specialists
Cancer specialists endorse a specialist-driven model of care
PCPs believe they play an important role in the cancer continuum
PCPs are willing to play a role in the cancer care continuum
Oncologists and PCPs are uncertain of PCPs' knowledge or ability to provide care
Discordance among expectations and perceived roles

Dossett LA, Hudson JN, Morris AM, Lee MC, Roetzheim RG, Fetters MD, Quinn GP. CA Cancer J Clin 2017;67:156–169.

Barriers to Integrating PCP in Survivorship Care

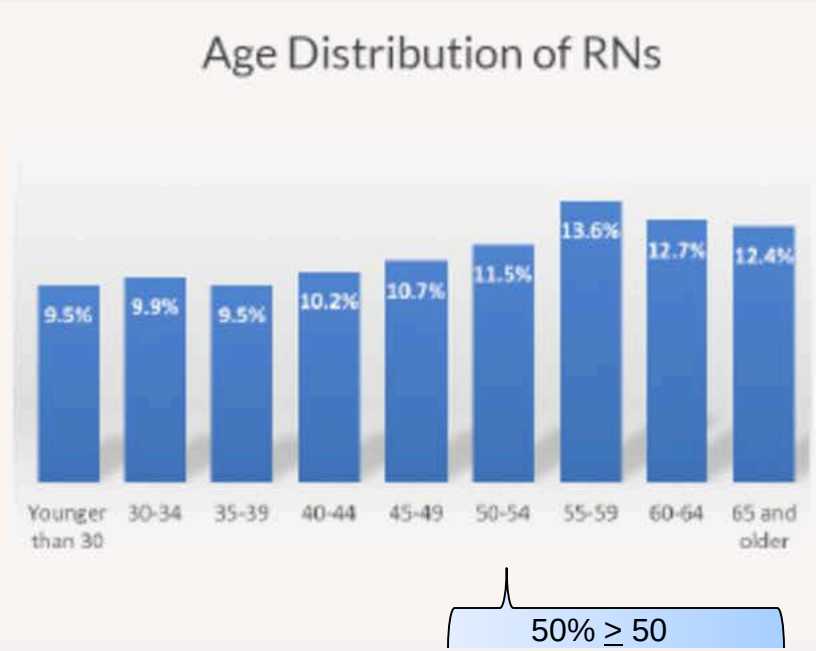


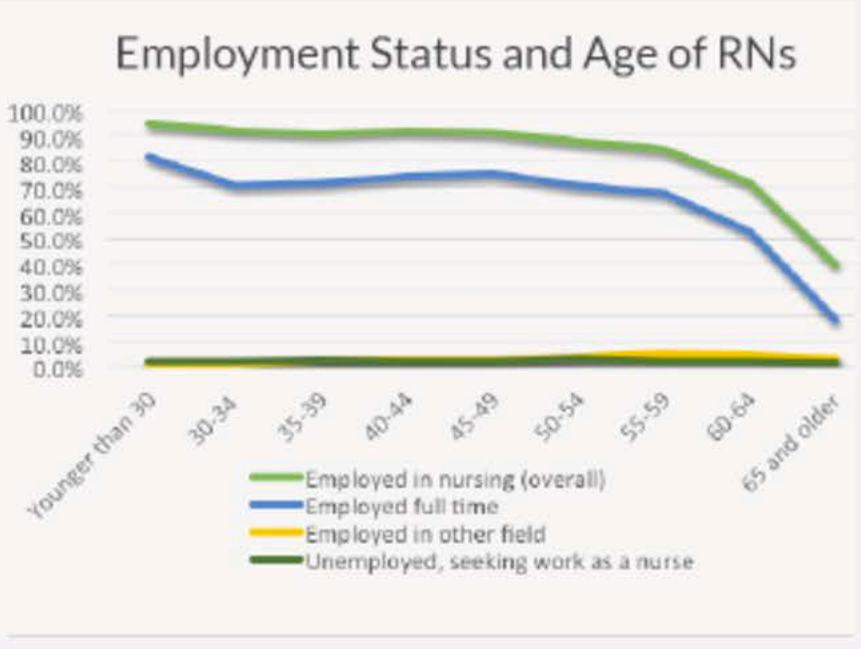
Nekhlyudov, et al (2017).*Lancet Oncology* 18: e30-e38.

Workforce Issues: ASCO

ASCO. State of Cancer Care in America: 2016 and 2017
Institute of Medicine. 2009. *Ensuring Quality Cancer Care Through the Oncology Workforce: Sustaining Care in the 21st Century: Workshop Summary*. Washington, DC: The National Academies Press.
Erikson, E, et al. J Oncol Pract 3: 79– 86,2007
http://www.asco.org/practice-guidelines/cancer-care-initiatives/workforce-initiatives

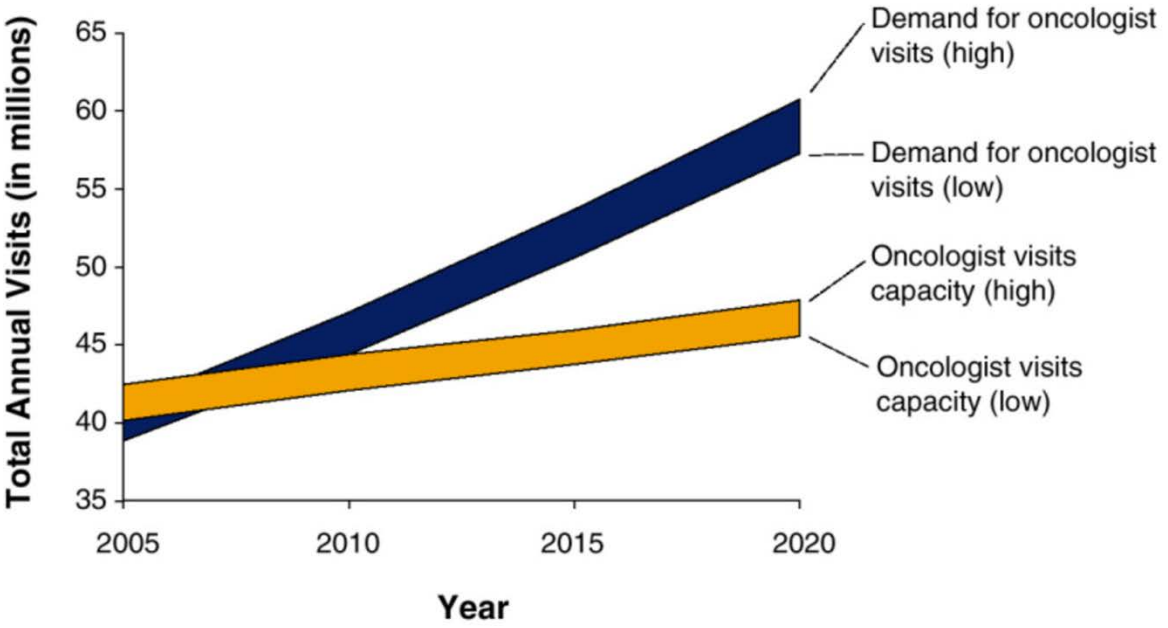
Nursing Workforce





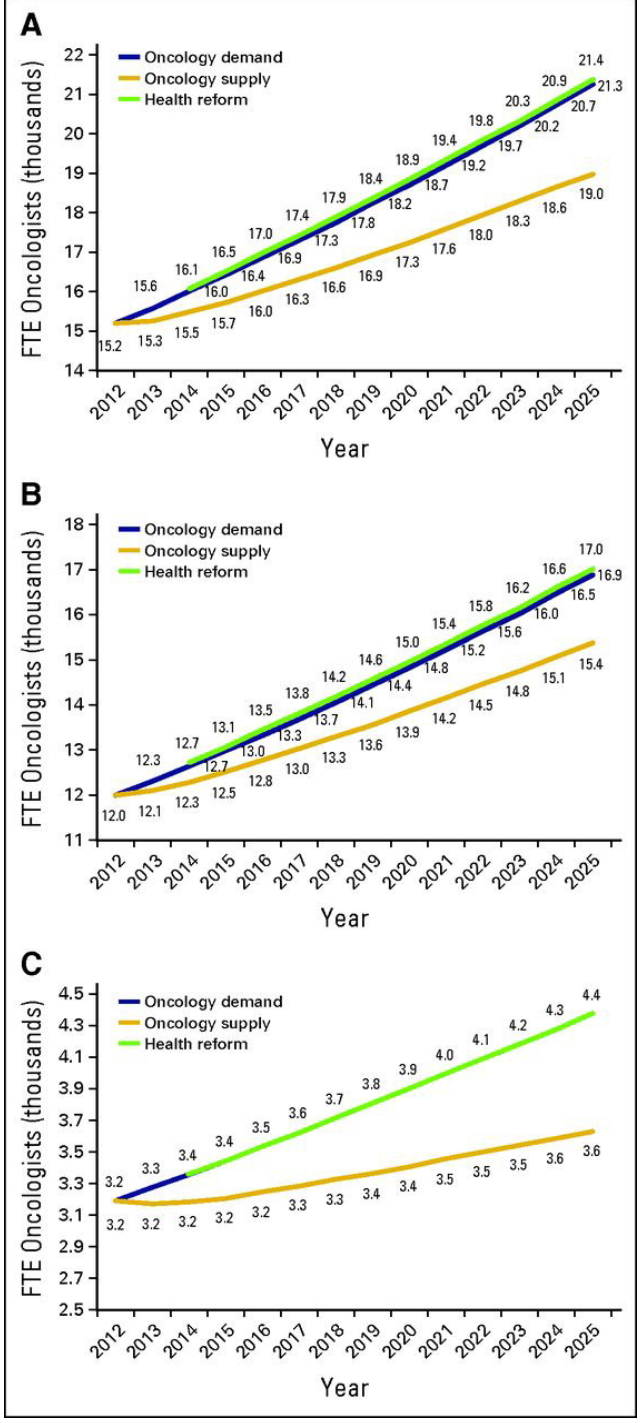
- With more than 500,000 seasoned RNs anticipated to retire by 2022, the U.S. Bureau of Labor Statistics projects the need to produce 1.1 million new RNs for expansion and replacement of retirees, and avoid a nursing shortage.
- Employment of registered nurses is projected to grow 16% from 2014 to 2024
- Employment of nurse practitioners is projected to grow 31% from 2014 to 2024

http://www.nursingworld.org/MainMenuCategories/ThePracticeofProfessionalNursing/workforce
https://www.bls.gov/ooh/healthcare/registered-nurses.htm
https://www.bls.gov/ooh/healthcare/nurse-anesthetists-nurse-midwives-and-nurse-practitioners.htm



PROJECTIONS OF ONCOLOGIST SUPPLY BY SCENARIO

A. Total Oncologists
B. Medical Oncologists
C. Radiation Oncologists



Benz presentation (October 20, 2008) and the Association of American Medical Colleges. 2007. *Forecasting the supply of and demand for oncologists: A report to the American Society of Clinical Oncology (ASCO) from the AAMC Center for Workforce Studies.*

Yang (2014) *JOP,* 10, 39-45.

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Cancer Survivorship Resources

SEARCHING: THE ANSWER IS OUT THERE

Survivorship Compendium

As an accompaniment to the educational opportunities and clinical-guidance ASCO offers on survivorship care, the Survivorship Care Compendium has been developed to serve as a repository of tools and resources to enable oncology providers to implement or improve survivorship care within their practices. Although ASCO endorses the National Coalition for Cancer Survivorship definition of a cancer survivor as starting at the point of diagnosis, the focus of the information and resources offered throughout this compendium is on those individuals who have completed curative treatment or who have transitioned to maintenance or prophylactic therapy.

Key Components of Survivorship Care

Building a Survivorship Care Program

Models of Long-Term Follow-Up Care

http://www.asco.org/practice-guidelines/cancer-care-initiatives/prevention-survivorship/survivorship/survivorship-compendium

Survivorship Guidelines (NCCN)

- Assessment By Health Care Provider at Regular Intervals (SURV-4)
- Survivorship Baseline Assessment (SURV-A)
- Anxiety and Depression (SANXDE-1)
- Cognitive Function (CF-1)
- Fatigue (SFAT-1)
- Female sexual functioning (SSFF-1)
- Male sexual functioning (SSFM-1)
- Definition of Survivorship & Standards For Survivorship Care (SURV-1)
- General Principles of the Survivorship Guidelines (SURV-2)
- Screening for Second Cancers (SURV-3)
- Survivorship Resources For Healthcare Professionals And Patients (SURV-B)
- Pain (SPAIN-1)
- Sexual Function
- Sleep Disorders (SSD-1)
- Healthy Lifestyles (HL-1)
- Immunizations and Infections (SIMIN-1)
- General Survivorship Principles
- Late Effects/Long-Term Psychosocial and Physical Problems
- Preventive Health
- Physical Activity (SPA-1)
- Nutrition and Weight Management
- Immunizations

National Resources

Cancer Survivorship E-Learning Series for Primary Care Providers

https://smhs.gwu.edu/gwci/survivorship/ncsrc/elearning

- Module 1: The Current State of Survivorship Care and the Role of Primary Care Providers
- Module 2: Late Effects of Cancer and its Treatments: Managing Comorbidities and Coordinating with Specialty Providers
- Module 3: Late Effects of Cancer and its Treatments: Meeting the Psychosocial Health Care Needs of Survivors
- Module 4: The Importance of Prevention in Cancer Survivorship: Empowering Survivors to Live Well
- Module 5: A Team Approach: Survivorship Care Coordination
- Module 6: Cancer Recovery and Rehabilitation
- Module 7: Spotlight on Prostate Cancer Survivorship: Clinical Follow-Up Care Guideline for Primary Care Providers
- Module 8: Spotlight on Colorectal Cancer Survivorship: Clinical Follow-Up Care Guideline for Primary Care Providers
- Module 9: Spotlight on Breast Cancer Survivorship: Clinical Follow-Up Care Guideline for Primary Care Providers
- Module 10: Spotlight on Head and Neck Cancer Survivorship: Clinical Follow-Up Care Guideline for Primary Care Providers

Cancer Survivorship in Primary Care

www.cancersurvivorshipprimarycare.org

National Resources

- National Coalition for Cancer Survivorship
  www.canceradvocacy.org
- American Society of Clinical Oncology
  http://www.asco.org
- American Cancer Society
  www.cancer.org
- National Cancer Institute-OCS
  www.survivorship.cancer.gov
- National Comprehensive Cancer Network
  www.nccn.org
- Lance Armstrong Foundation (LIVE**STRONG**)
  www.livestrong.org

Challenges for Cancer Care

- We need to rethink how we deliver care:
  - what care is needed
  - who needs that care
  - who delivers care
  - where care is delivered
- We need to optimize functionality and use of data and electronic tools (EHR, apps, mHealth) to extend our impact in delivering quality cancer care to all in need.

Future Directions

- Anticipated changes in cancer incidence and prevalence will require innovative strategies for delivering cancer care within a an evolving health care system
- Many transitions throughout cancer care require *written* plans-move upstream and repeat as needed across continuum
- Cancer care → focusing on recovery, health and well-being.
- Cancer care → shared care with PCP → PCP with survivor/family → supported self-management

LIVING WITH CANCER TAKES GUTS

Any questions?