

# Working with Care Teams After Cancer Treatment

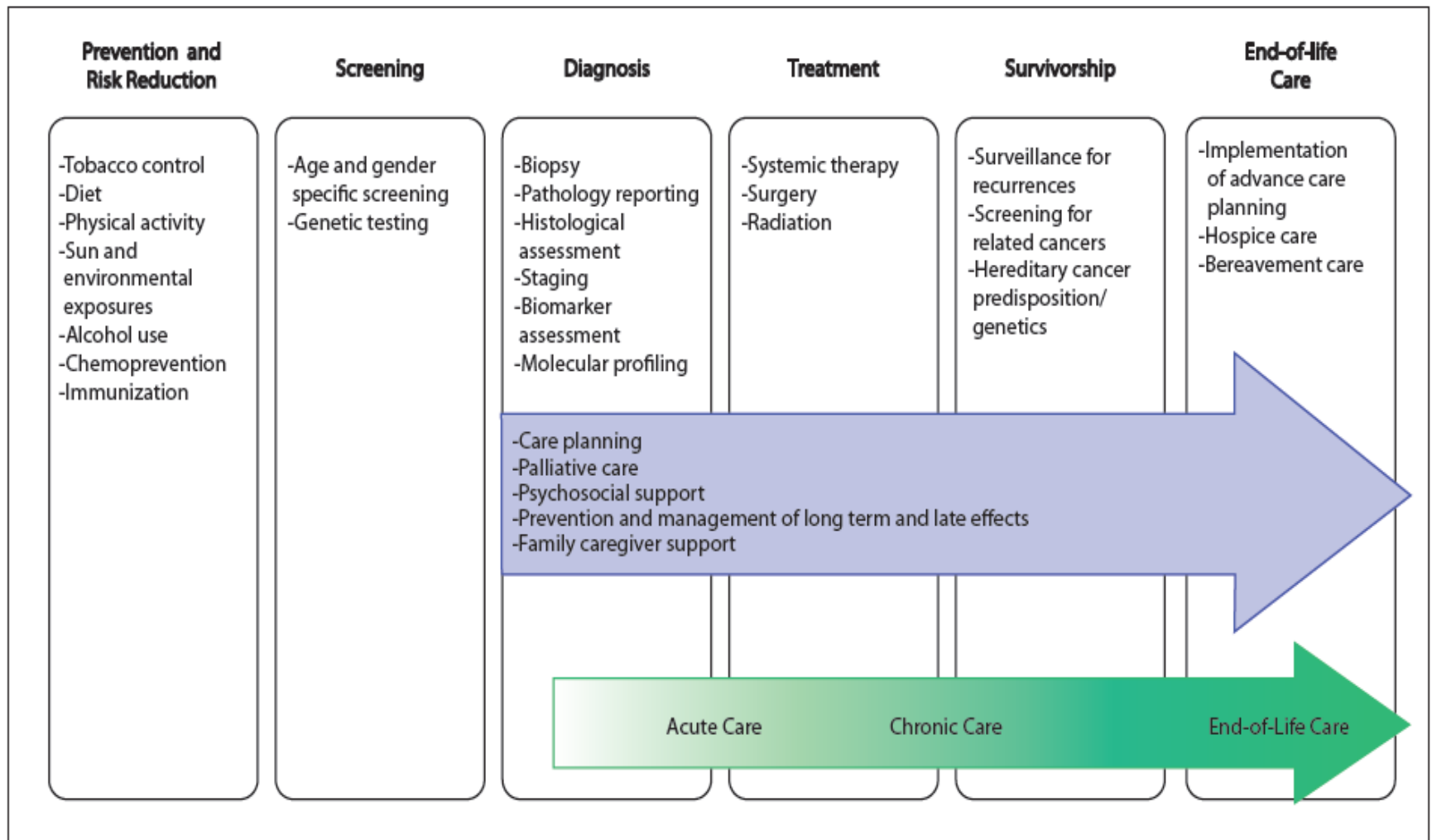
*Patient-Centered Primary Care Collaborative  
Webinar December 16, 2013*

Larissa Nekhlyudov, MD, MPH

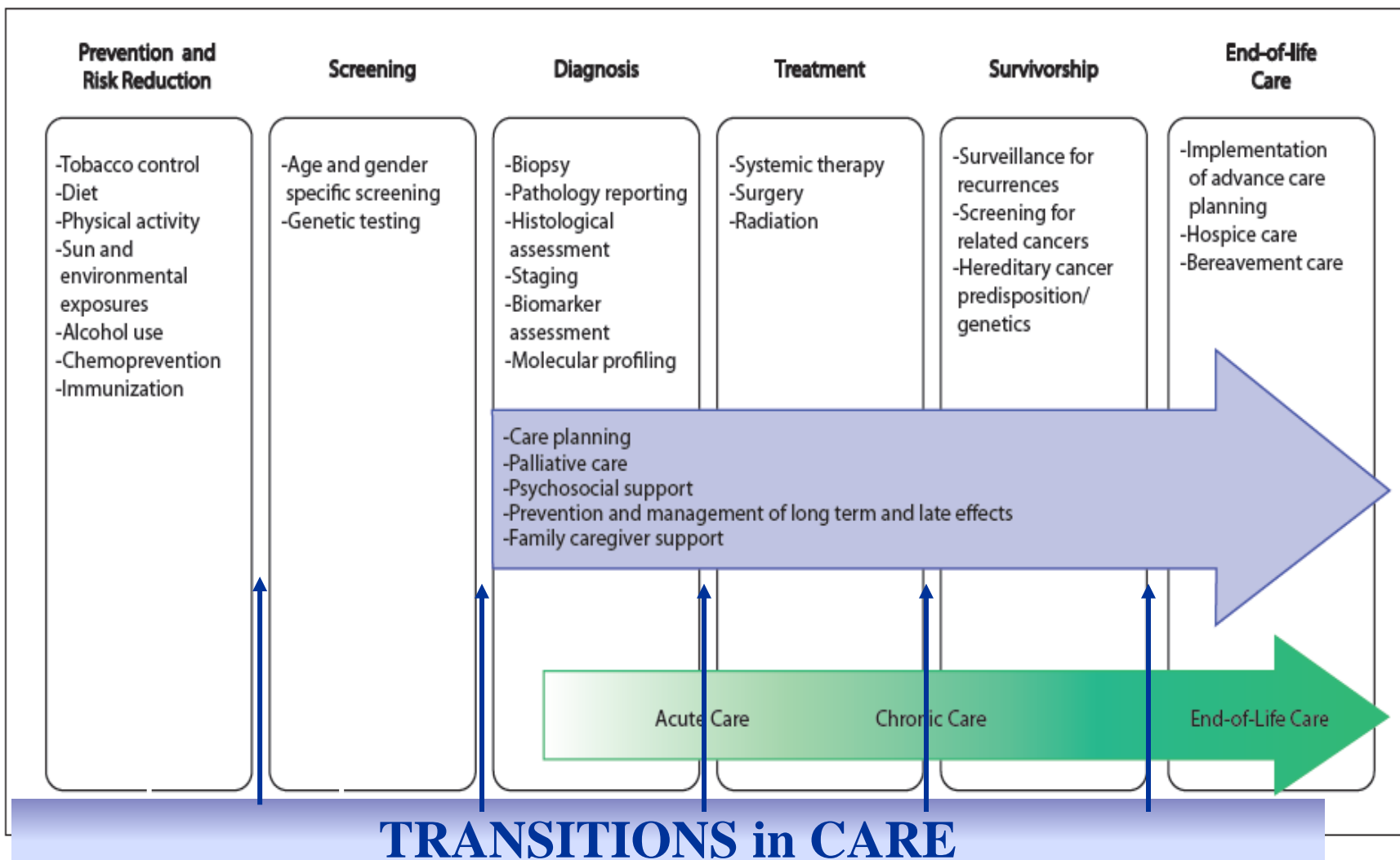
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Internist, Harvard Vanguard Medical Associates

# Cancer Care Continuum and the Role of Primary Care



# Cancer Care Continuum and the Role of Primary Care



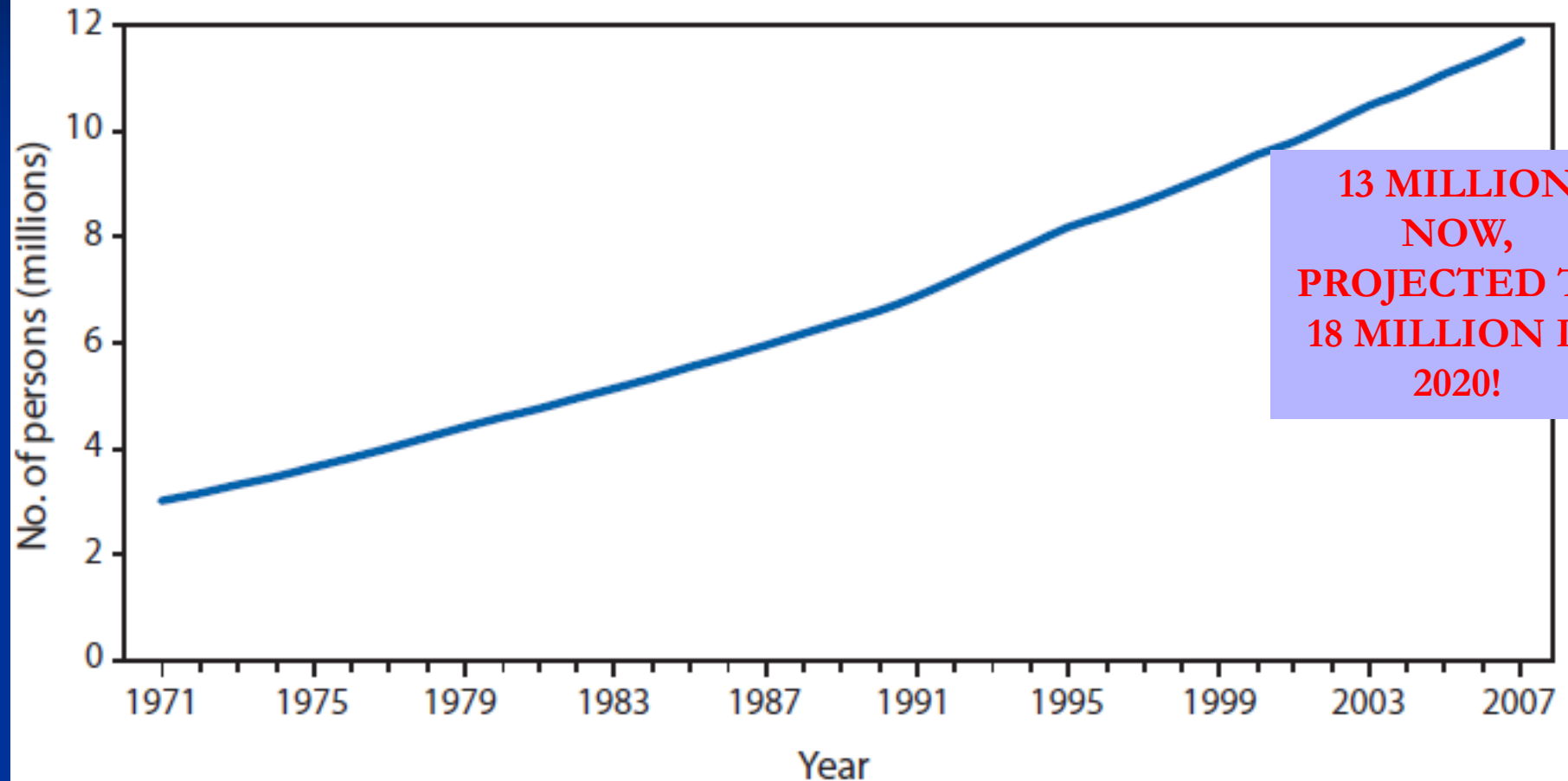
70 yo female with **BREAST CANCER** – Invasive lobular dx 2004, stage IIB, mastectomy, chemo (taxol/AC), XRT. Hormonal tx tamoxifen, AI. Neuropathy, joint aches.

- Surveillance with mammograms, surgical oncologist, oncology, GYN, PCP!!
- Up to date with other screening and prevention
- Numerous other medical conditions managed by other specialists
- Worried about cancer!



# Large population and growing

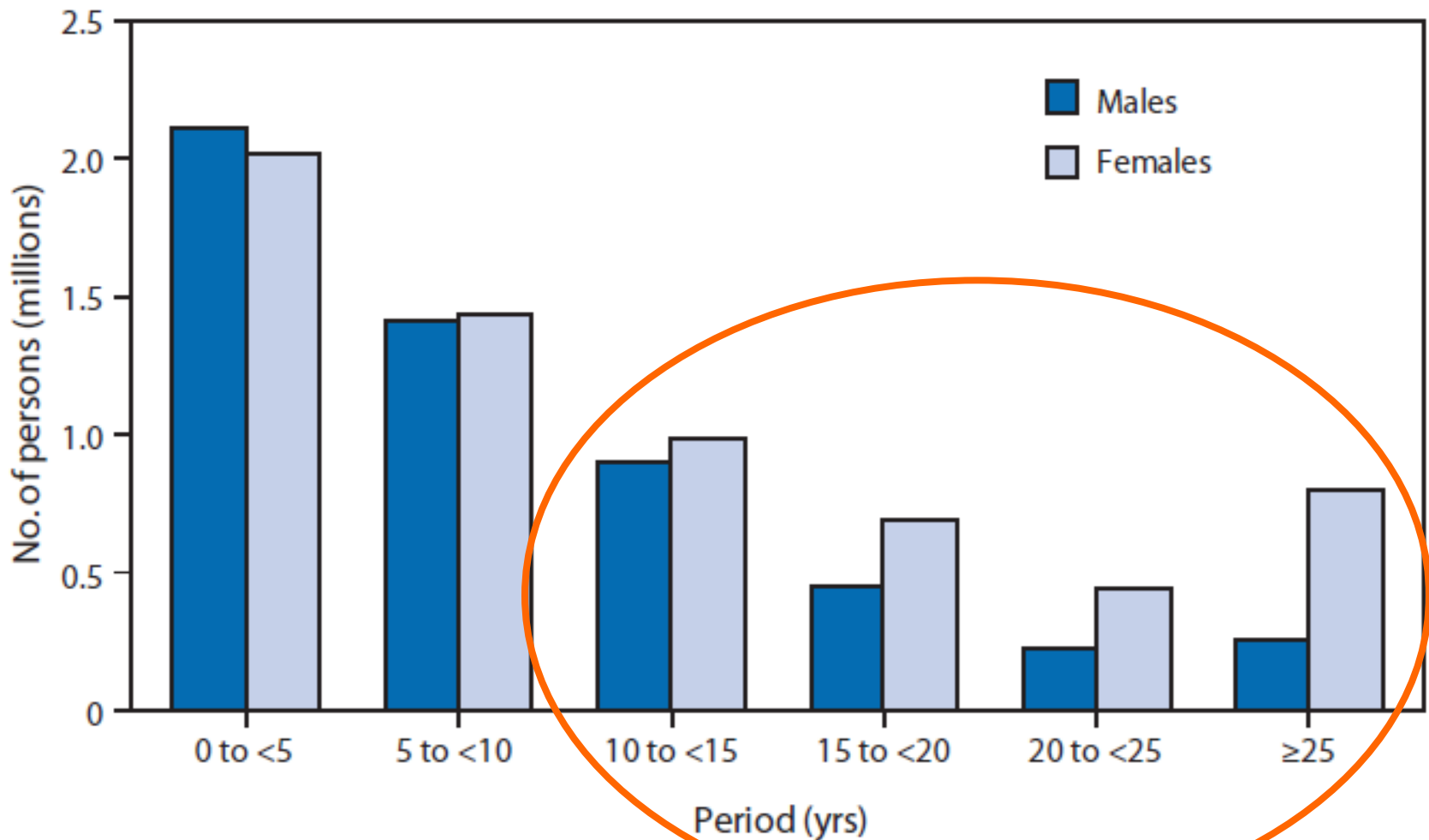
FIGURE 1. Estimated number of living persons ever diagnosed with cancer — United States, January 1, 1971, to January 1, 2007



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](http://seer.cancer.gov/csr/1975_2007).

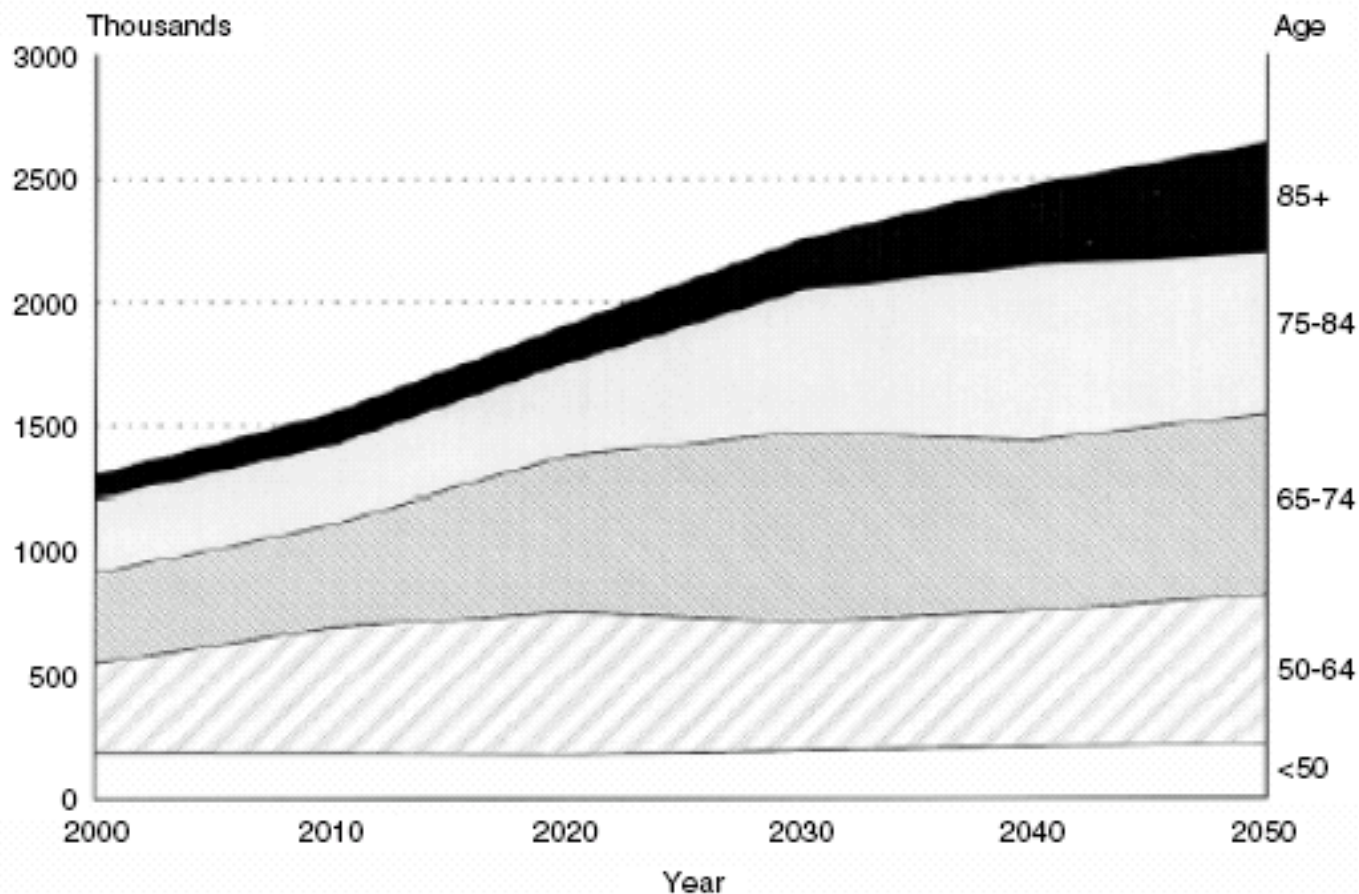
# Long-Term Survival → Ongoing Needs

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](http://seer.cancer.gov/csr/1975_2007).

# Growing Elderly → Comorbid Conditions



**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) age-specific cancer incidence rates (1995–1999) from the Surveillance, Epidemiology, and End Results (SEER) Program and the National Program of Cancer Registries (NPCR), 1995–1999.

# Components of Cancer Survivorship Care

## CARE FOR THE CANCER SURVIVOR

### Non-Cancer Related Medical Care

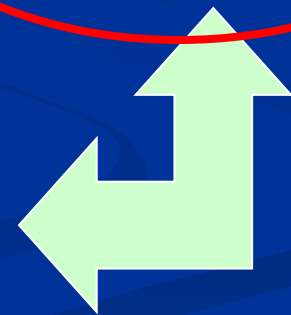
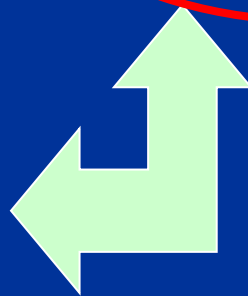
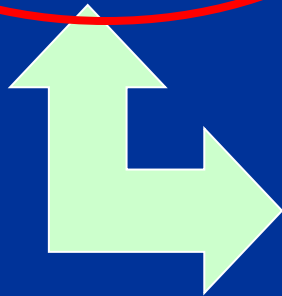
- Disease prevention/vaccination
- Chronic care (i.e. DM, CAD)
- Unrelated cancer screening

### Cancer Related Medical Care

- Surveillance for recurrence
- Complications of treatment
- Related cancer screening

### Psychosocial Issues

- Quality of life, financial burden
- Family/genetic counseling



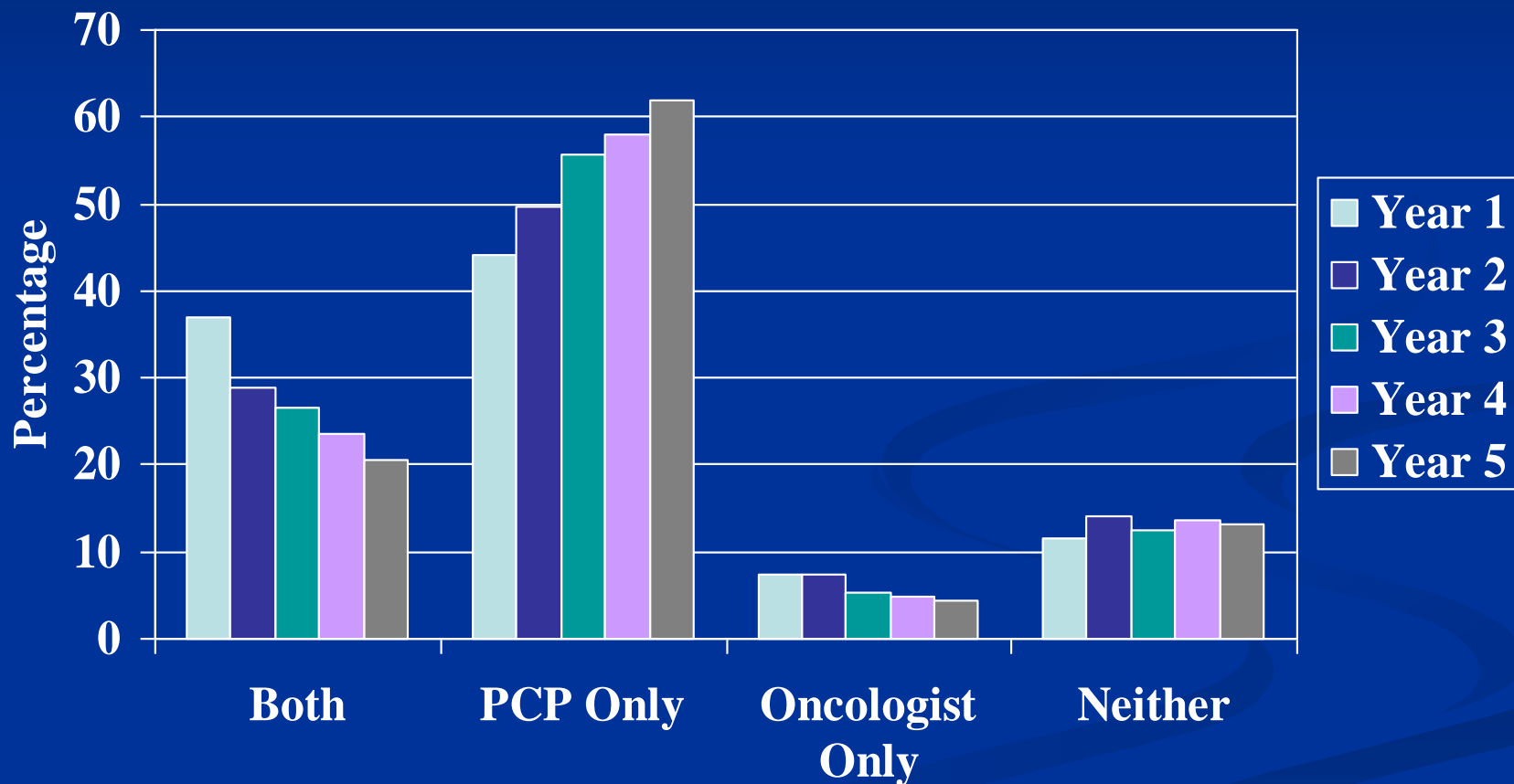
**Coordination of Care**



# Care for the Cancer Survivors

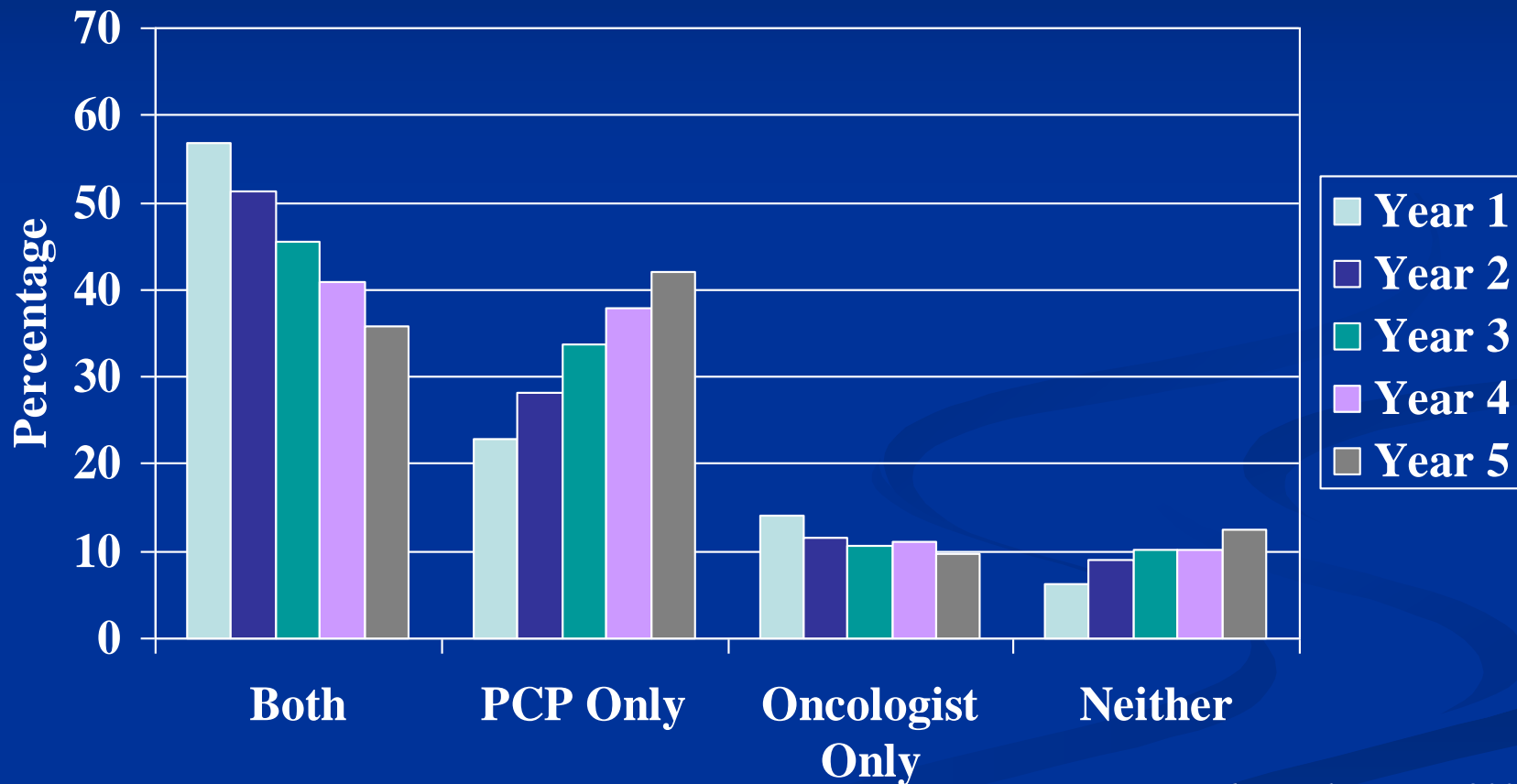
- Most cancer survivors are cared for in non-academic settings!
  - Oncologist only
  - Oncologist/primary care clinician
  - Primary care clinician only
  - Multiple oncology specialists +/- PCP
  - No care
- In the “real world” – cancer survivors mostly seen in primary care.

# Mix of Physician Specialties Visited: Colorectal Cancer Survivors



Source: Snyder et al., JCO, 2008

# Mix of Physician Specialties Visited: Breast Cancer Survivors



Source: Snyder et al., JGIM, 2009

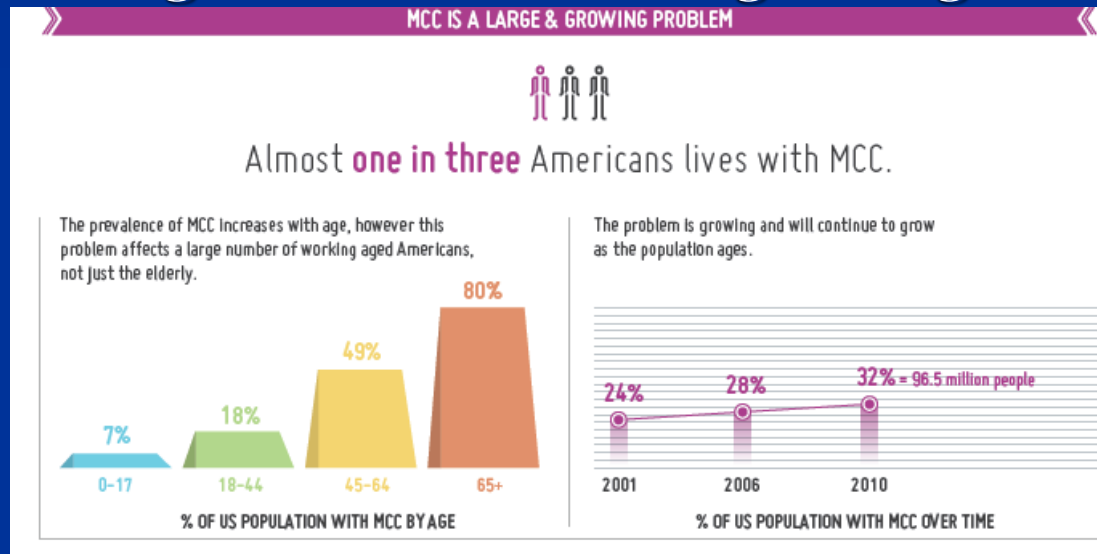
# Survivorship Care in Oncology Settings

- Oncologists get to know their patients and form a bond during time of crisis
- Oncologists expect to care for cancer survivors, particularly with respect to surveillance
- Oncologists do better in having patients participate in recommended cancer surveillance

*Mariscotti 2009; Cheung 2009; Snyder 2008; Snyder 2009; Hudson 2012*

# Challenges for Oncology Based Survivorship Care

- Oncologists not trained to provide general medical care and manage comorbidities in growing numbers of patients.



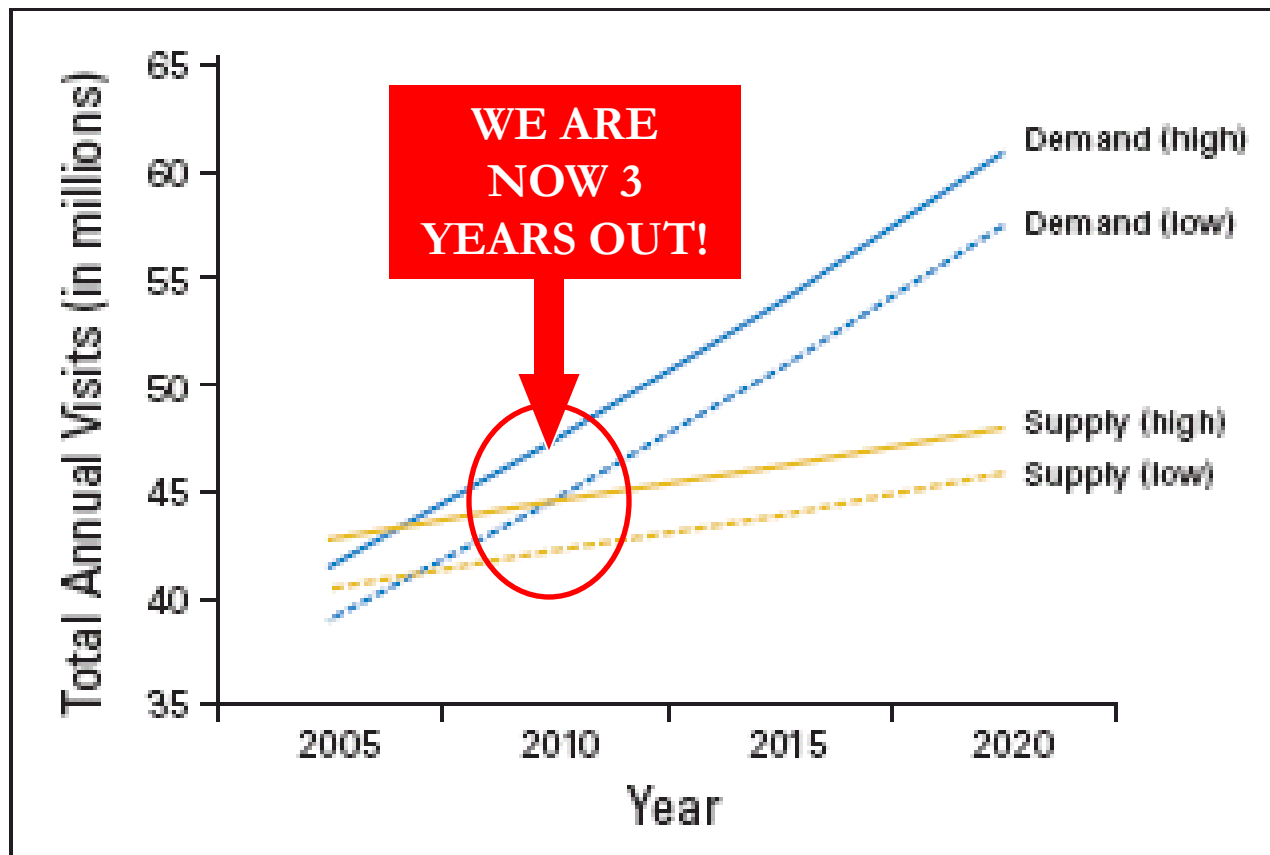
Source: AHRQ

- 7 out of 10 deaths each year are from chronic diseases.
- 1 in every 3 adults is obese.

Source: <http://www.cdc.gov/chronicdisease/overview/index.htm>

# Oncologist Supply $\neq$ Demand

Figure 2. Baseline projected supply of and demand for oncologist visits, 2005 to 2020.



# Survivorship in Primary Care Settings

- PCPs trained to provide comprehensive care to patients with chronic disease... such as CHF, DM, COPD
- More PCPs = better health outcomes
  - 1 PCP per 10,000 = 5.3% lower mortality
  - More PCPs = fewer hospitalizations, lower mortality
  - Data in general populations, not cancer survivors
- PCPs are willing
- PCPs focus on general medical screening and prevention
- No difference on mortality (breast cancer)

*Larson 2004, Macinco 2007, Chang 2011, DelGuidice 2009, Grunfeld 1995, Grunfeld 2009, Nissen 2007, Cheung 2009, Snyder 2008, Snyder 2009, Snyder 2011*

# Challenges for PCP Based Survivorship Care

- Inadequate information about the previous cancer and/or its treatment
- Some cancers rarely encountered in primary care, so not enough expertise
- Lack of knowledge and confidence about survivorship care
- Patient lack of confidence in PCP knowledge
- Competing demands on their time

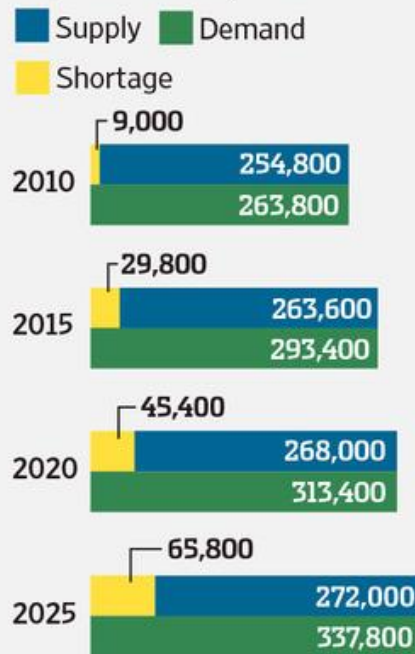


# Shortage of Primary Care Providers

## Doctor Gap, Pay Gap | The primary-care deficit

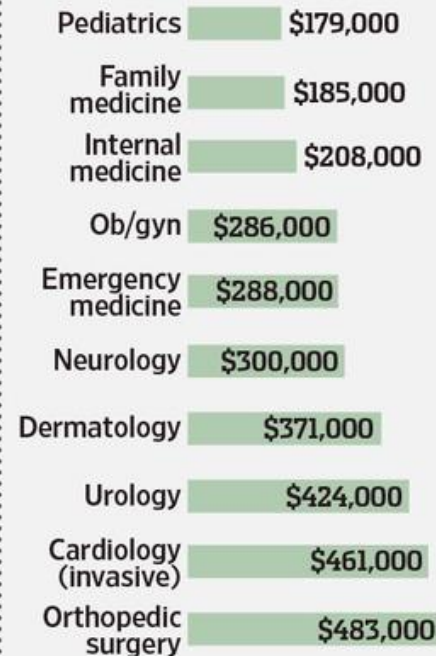
### Growing Shortage

Projected supply and demand for primary-care physicians in the U.S., in full-time equivalents



### Disincentive Pay

Average starting salaries are lower in primary-care fields than in other specialties



Note: Pay figures are for 2012-13; base salary or guaranteed income only; do not include production bonus or benefits. Higher Medicare payments under the Affordable Care Act may increase family-medicine pay roughly 2.5% and internal-medicine pay between 5% and 10%.

Sources: Association of American Medical Colleges (shortage); Merritt Hawkins (pay) based on 3,097 search assignments in the 12 months ended March 31, 2013

The Wall Street Journal

# Psychosocial Care

- Patients have expressed ongoing need for emotional support.
- Patients look to both oncology and PCPs, but data suggest that neither adequately address these needs.
- Comparing PCPs versus oncology
  - Patients have reported confidence in PCP caring for their psychosocial wellbeing

# Patients' Views on PCP care?

- Survey of 300 breast cancer survivors
  - Most confident in PCPs providing
    - General care (78%)
    - Psychosocial support (73%)
    - Health promotion (73%)
  - Less confident about knowledge of
    - Cancer follow up (50%)
    - Late effects of cancer therapy (59%)
    - Treating symptoms related to cancer (41%)

# But preferences vary...

*“If there’s anything, considering anything, in reference to cancer treatment, I would see my oncologist for it. [J]ust because that’s their specialty...I’d rather see the oncologist, someone that is familiar, who does it every day. I just wouldn’t think that a primary or my gynecologist would know, be as knowledgeable”*

*“You gotta have an oncologist. I would advise anyone not to go to a family doctor or a general practitioner, you gotta be an oncologist. You know, I’m a firm believer. My head hurts, I’m going to the head doctor. My foot hurts, I’m going to the foot doctor”*

# But preferences vary...

*“I mean, as far as being a liaison between me and that oncologist or me and the surgeon, that’s what my primary care is for, in my opinion. That’s how I used him, to be my go-between. To explain the things in the files that I didn’t understand”*

*“Um, maybe ob-gyn [could be involved in follow-up].... When I go there yearly for the clinical exam, they’ll usually question about the breast cancer and stuff like that”*

*“[Knowing my] history is OK..., too. But they should be involved together because...primary care knows more about...me other than the cancer”*

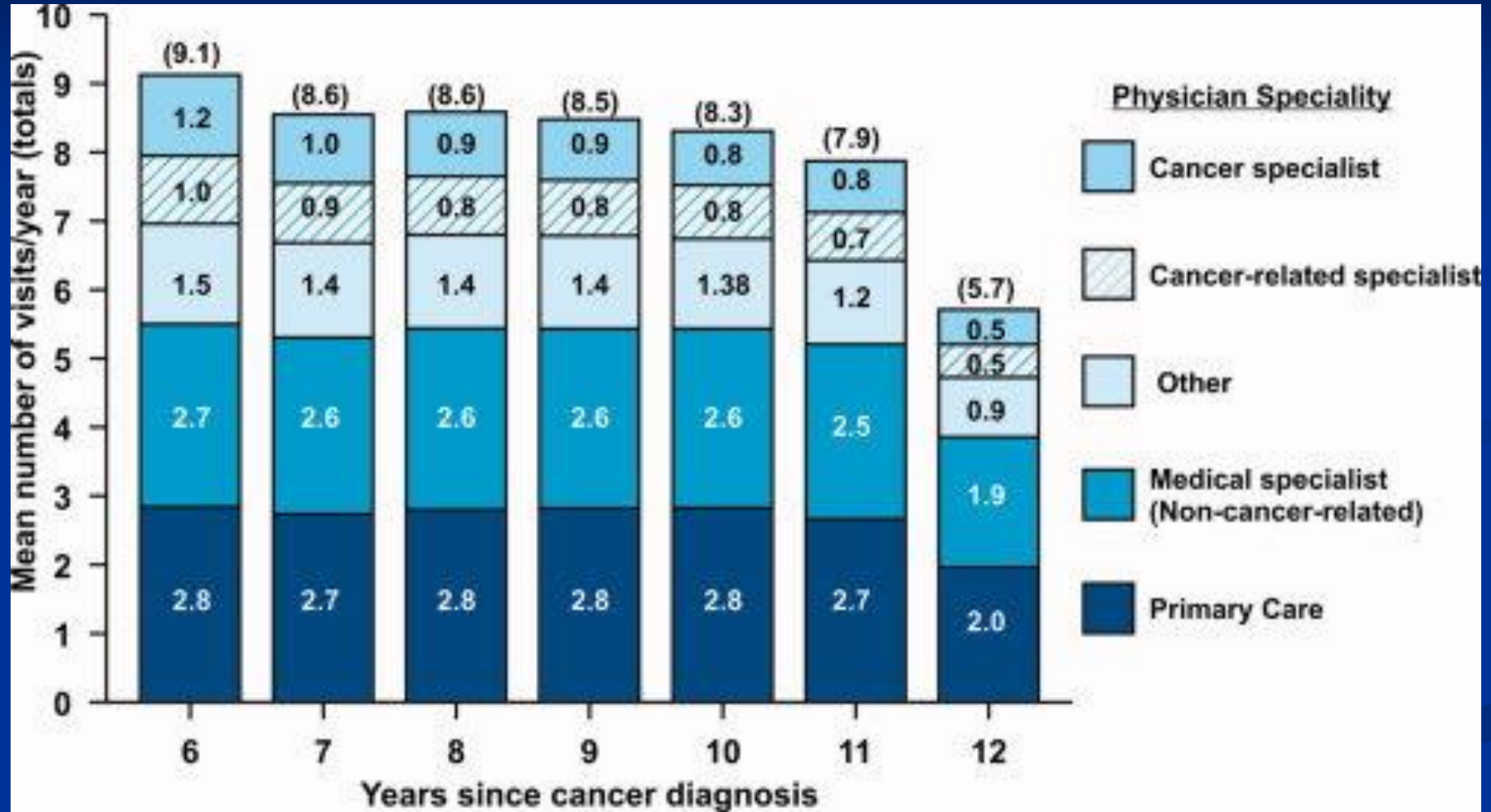
# Shared Survivorship Care

- The PCP and oncologist together participate in the care of a cancer survivor.
- All seem to like this approach (*Cheung 2009*)
  - Patients want their oncologists and PCPs involved in surveillance for cancer recurrence and other cancer screening
  - Oncologists expect a significant role in surveillance, but also share in the screening for other cancers and general prevention with PCPs
  - PCPs prefer focus on screening, general prevention and some in surveillance
- Appears to improve all indices of care for survivors.

# Challenges to Shared Care

- Often lack of clear communication between cancer specialist and primary care clinician
- Lack of supportive infrastructure within health care systems to share/transfer records (e.g., information technology, EMRs)
- In other disease states, inconclusive evidence for benefits of shared care (Cochrane 2007)
- No systematic way to delineate care and responsibilities
- Need to balance “too little” care and “too much” or duplication of care
- Is there an end to shared care???

# Providers seen by cancer survivors years later....



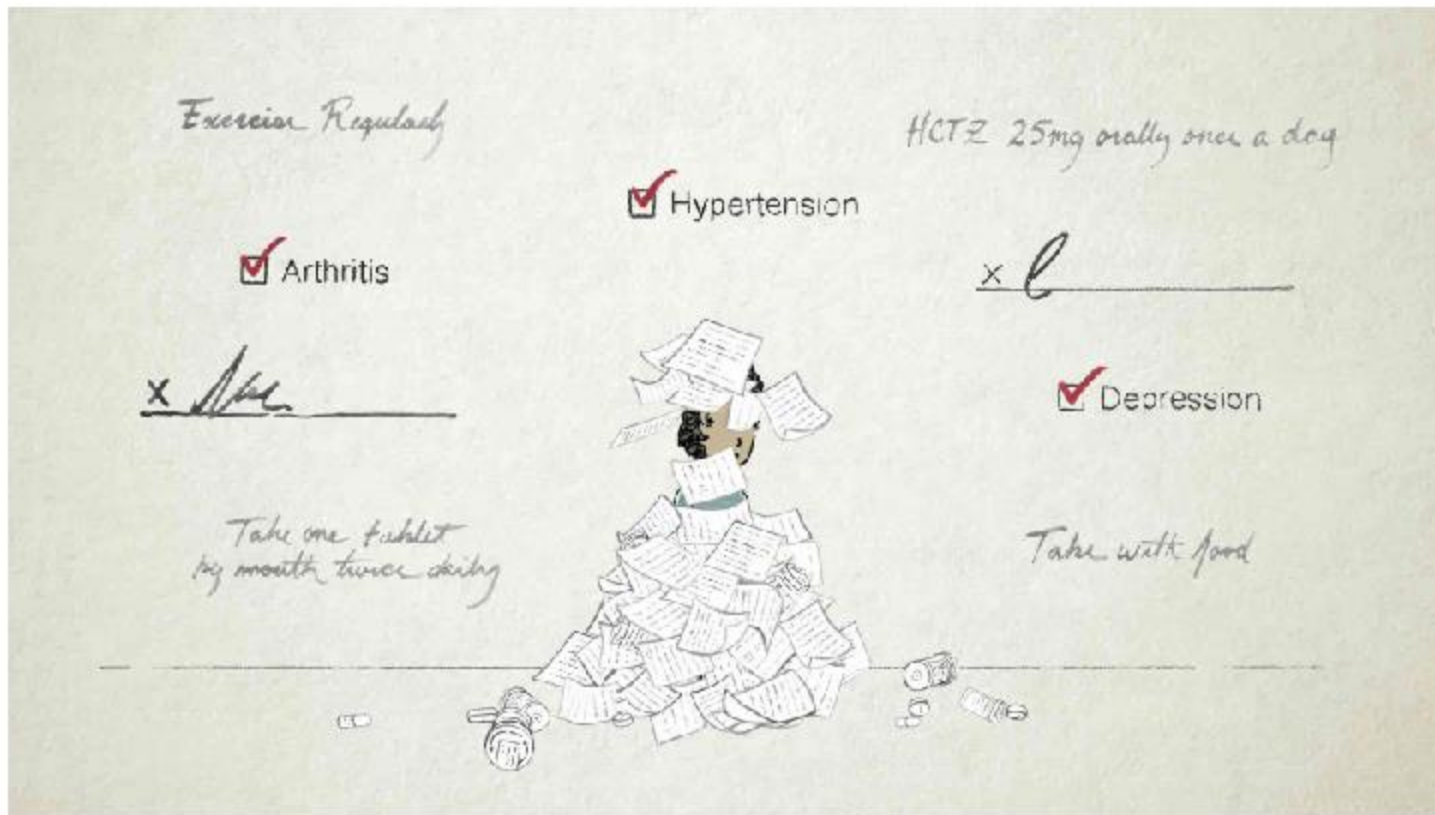
Source: Pollack, Cancer 2009



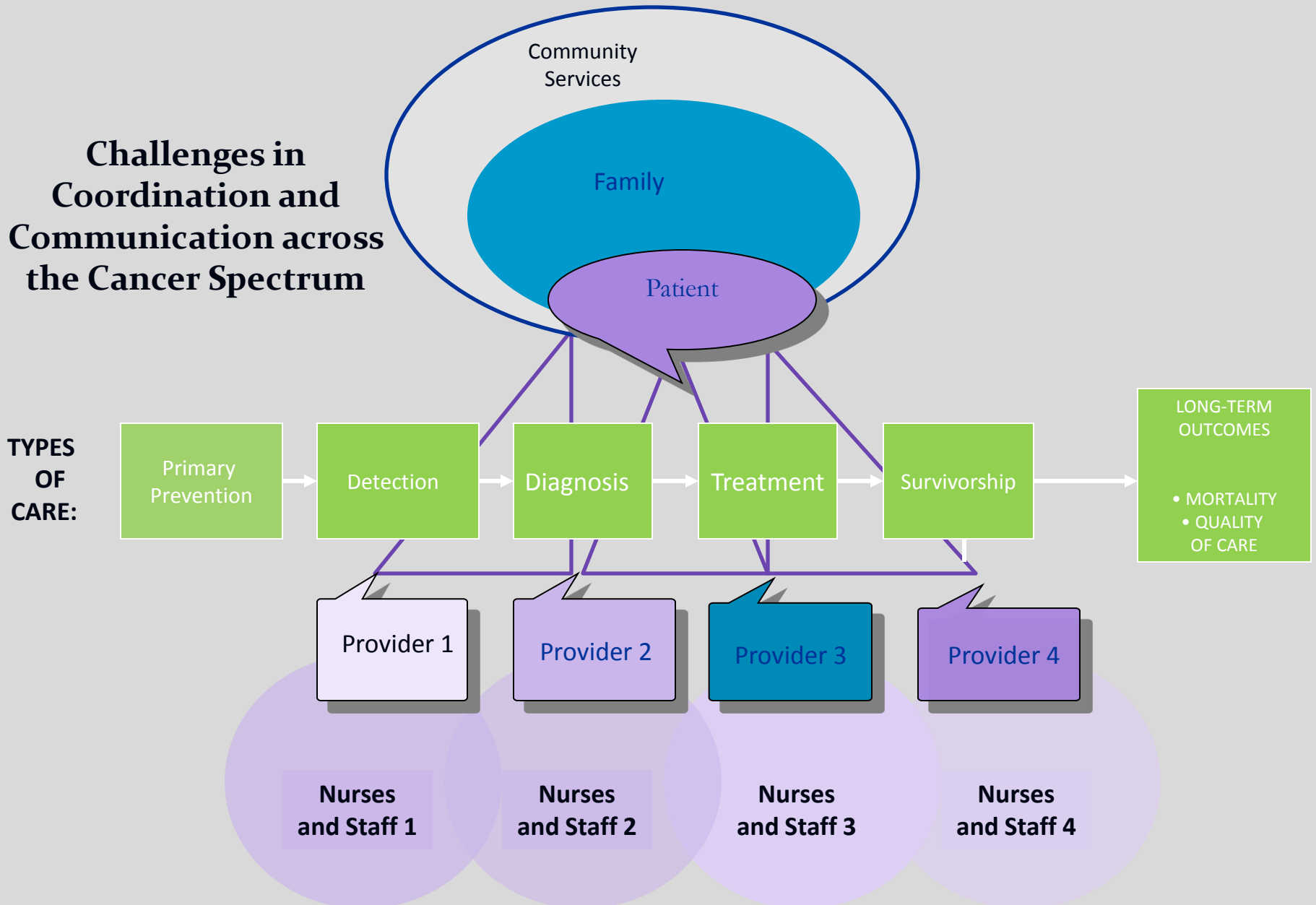
## Multiple Chronic Conditions: A Day in the Life (Audio/Video item)

**"Multiple Chronic Conditions: A Day in the Life"** centers around the experiences of Mae, a woman with multiple chronic conditions. Beginning at home with her family, we follow Mae as she visits one health care provider after another, struggling to keep track of the various instructions, treatments, and prescriptions she receives – all while trying to maintain a balanced life.

MCC video - Stage [  - 2 minutes]



# Challenges in Coordination and Communication across the Cancer Spectrum



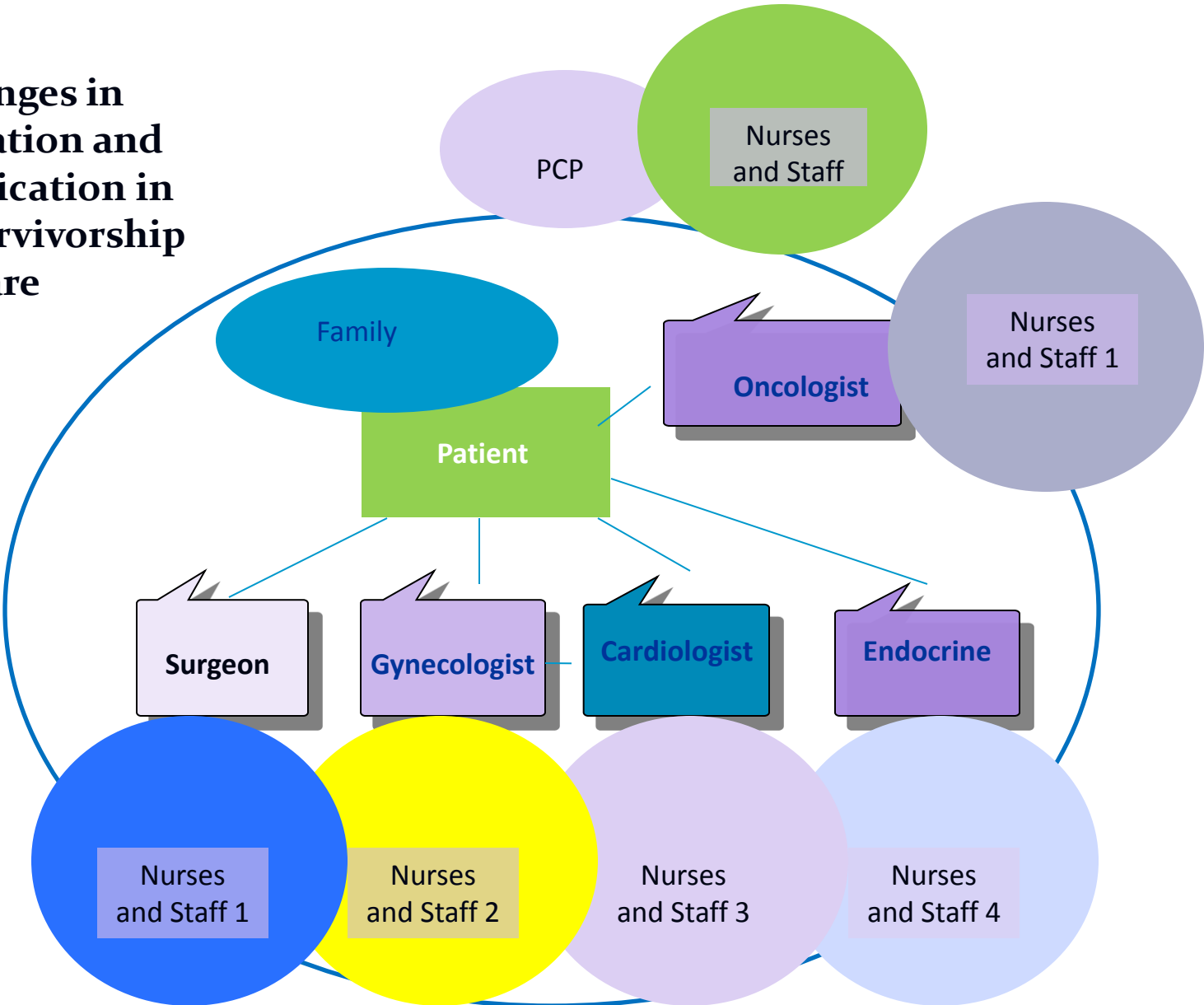
Adapted from Taplin et al JNCI Monographs. 2010.  
<http://jncimono.oxfordjournals.org/content/2010/40.toc>

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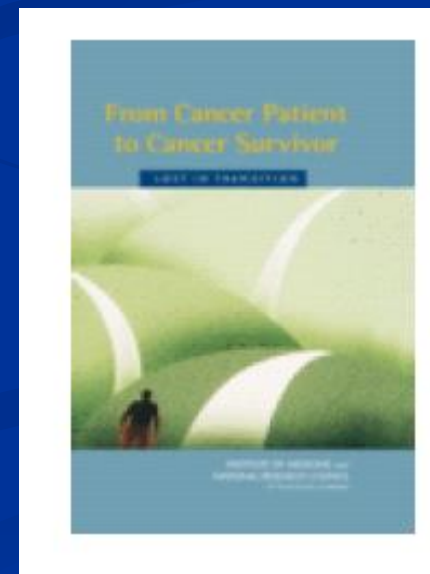
# Challenges in Coordination and Communication in Cancer Survivorship Care



*Are there any solutions?*

# Institute of Medicine Panel

- Convened in 2004-2005
- Reviewed state of cancer survivorship care
- Recommendations in Report,
  - “From Cancer Patient to Cancer Survivor: Lost in Transition.”



## 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 written by the principal provider(s) who coordinated oncology treatment. This service should be reimbursed by third party payors of health care.*

# How is this going?

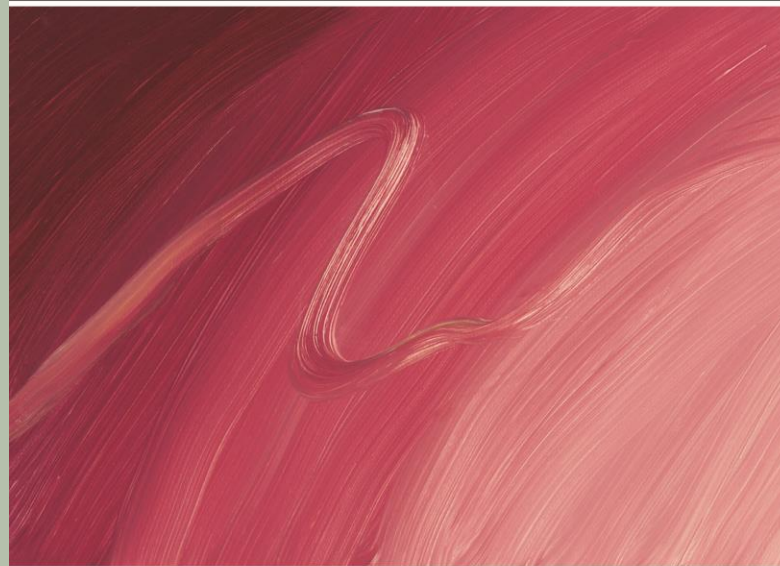
- Still a work in progress....
- Challenges in implementation, even in LIVESTRONG Survivorship Centers and NCI Cancer Centers
- Modifications being developed by ASCO
- SCPs soon requirement by COC

**Survivorship Care Plan  $\neq$  Survivorship Care Planning**



# DELIVERING HIGH-QUALITY CANCER CARE

*Charting a New Course for a System in Crisis*



INSTITUTE OF MEDICINE  
OF THE NATIONAL ACADEMIES

Report  
published  
in 2013

# The Crisis in Cancer Care Delivery

**Cancer care is often not as patient-centered, accessible, coordinated, or evidence based as it could be.**

## Goals of the Recommendations

1. Provide clinical and cost information to patients.
2. End-of-life care consistent with patients' values.
3. Coordinated, team-based cancer care.
4. Appropriate core competencies for the workforce.
5. Expand breadth of data collected in cancer research.
6. Expand depth of data collected in cancer research.
7. Develop a learning healthcare IT system for cancer.
8. A national quality reporting program for cancer care.
9. Reduce disparities in access to cancer care.
10. Improve the affordability of cancer care.

## Goals of the Recommendations

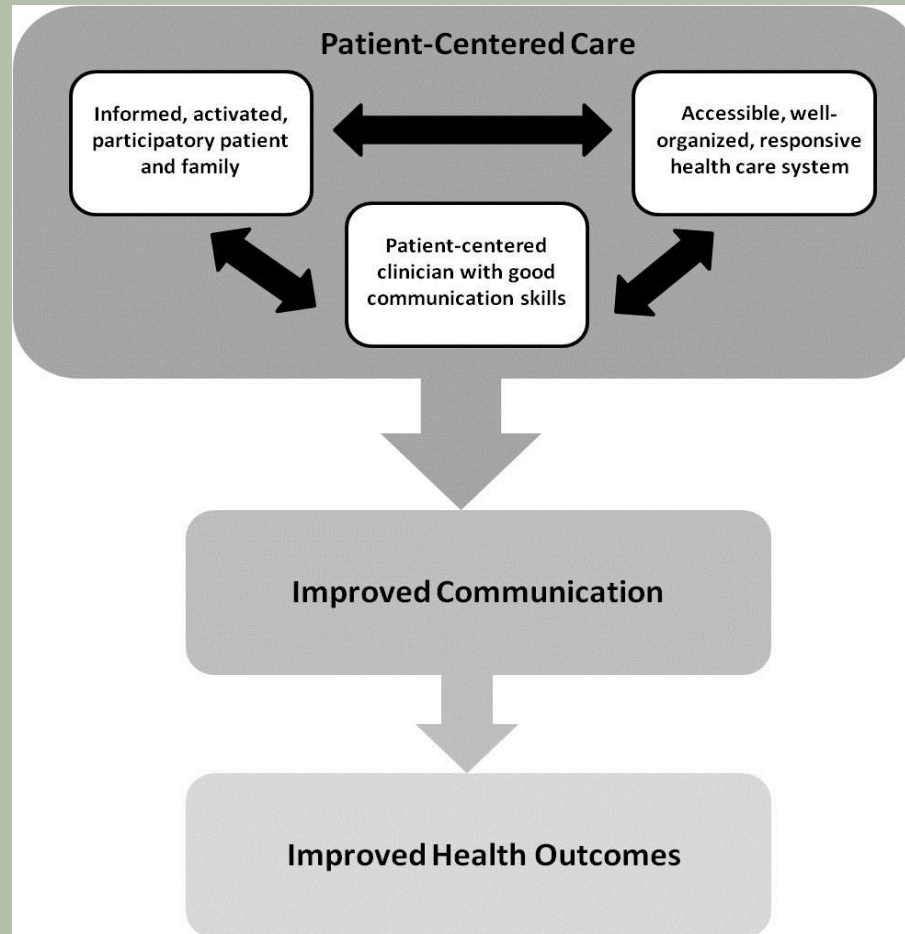
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# Engaged Patients

## GOAL 1

The cancer care team should provide patients and their families with understandable information on cancer prognosis, treatment benefits and harms, palliative care, psychosocial support, and estimates of the total and out-of-pocket costs of cancer care.

# Patient-Centered Care



# Recommendation 1

- The **cancer care team** should:
  - **Communicate** and **personalize** this information for their patients at key decision points along the continuum of cancer care, using decision aids when available.
  - **Collaborate with their patients** to develop **a care plan** that reflects their patients' needs, values, and preferences, and considers palliative care needs and psychosocial support across the cancer care continuum.

## Information in a Cancer Care Plan

- Patient information
- Diagnosis
- Prognosis
- Treatment goals
- Initial plan for treatment and duration
- Expected response to treatment
- Treatment benefits and harms
- Information on quality of life and a patient's likely experience with treatment
- Who is responsible for care
- Advance care plans
- Costs of cancer treatment
- A plan for addressing psychosocial health
- Survivorship plan



# Recommendation 1

- CMS and other payers should design, implement, and evaluate **innovative payment models** that incentivize the cancer care team to discuss this information with their patients and document their discussions in each patient's care plan.
- NCI, CMS, PCORI, patient advocacy organizations, professional organizations, and other public and private stakeholders **should improve the development of this information and decision aids** and make them available through print, electronic, and social media.

# Recommendation 1

- Professional educational programs for members of the cancer care team should **provide comprehensive and formal training in communication.**

# Engaged Patients

## GOAL 2

In the setting of advanced cancer, the cancer care team should provide patients with **end-of-life care consistent with their needs, values, and preferences.**

## Recommendation 2

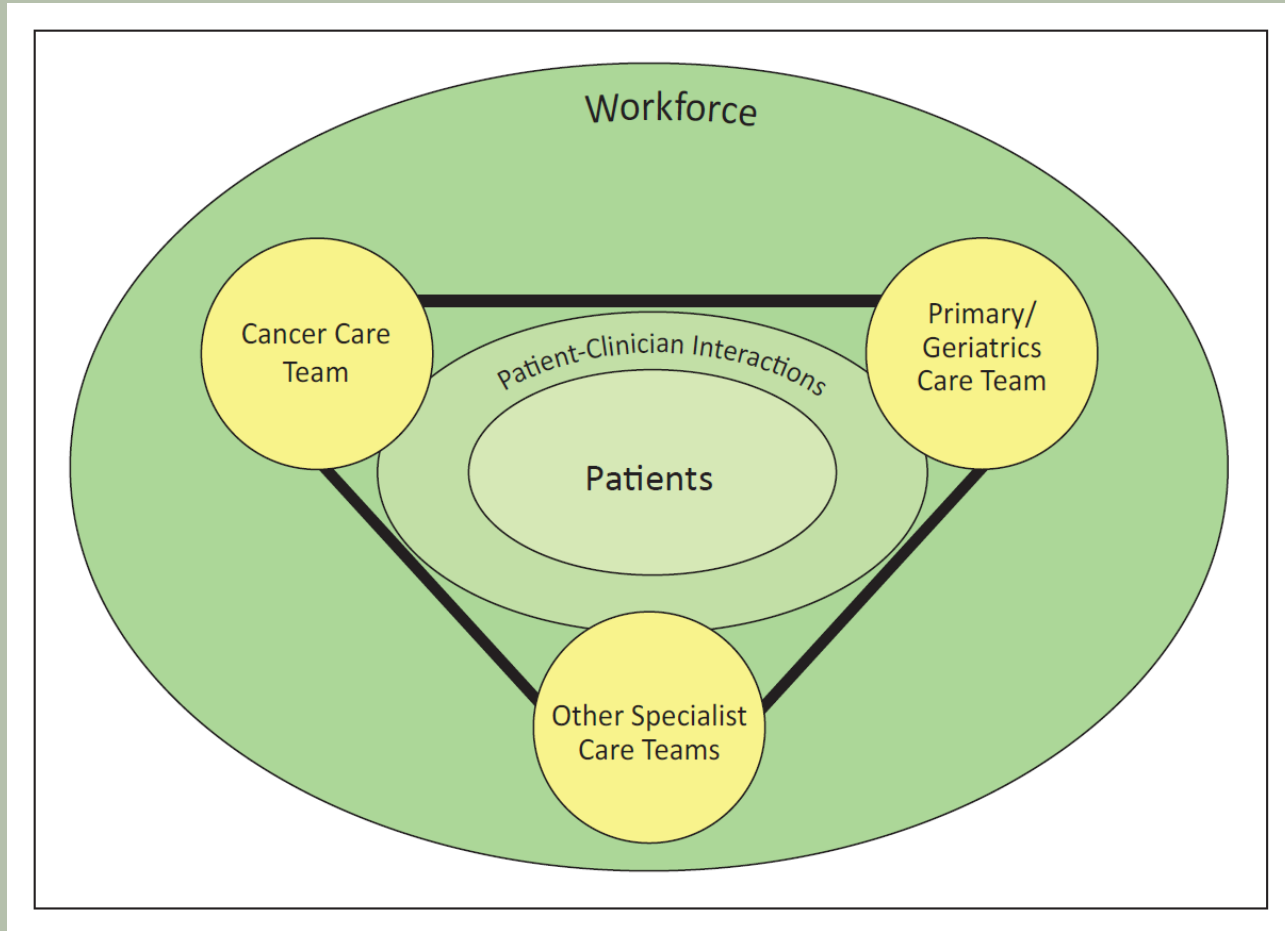
- Professional educational programs for members of the cancer care team should provide comprehensive and formal **training in end-of-life communication**.
- The cancer care team should **revisit** and **implement** their patients' **advance care plans**.
- The cancer care team should place a primary emphasis on providing cancer patients with **palliative care, psychosocial support, and timely referral to hospice for end-of-life care**.
- CMS and other payers should design, implement, and evaluate **innovative payment models** that incentivize the cancer care team to **counsel their patients about advance care planning** and **timely referral to hospice care** for end-of-life care.

# An Adequately-Staffed, Trained, and Coordinated Workforce

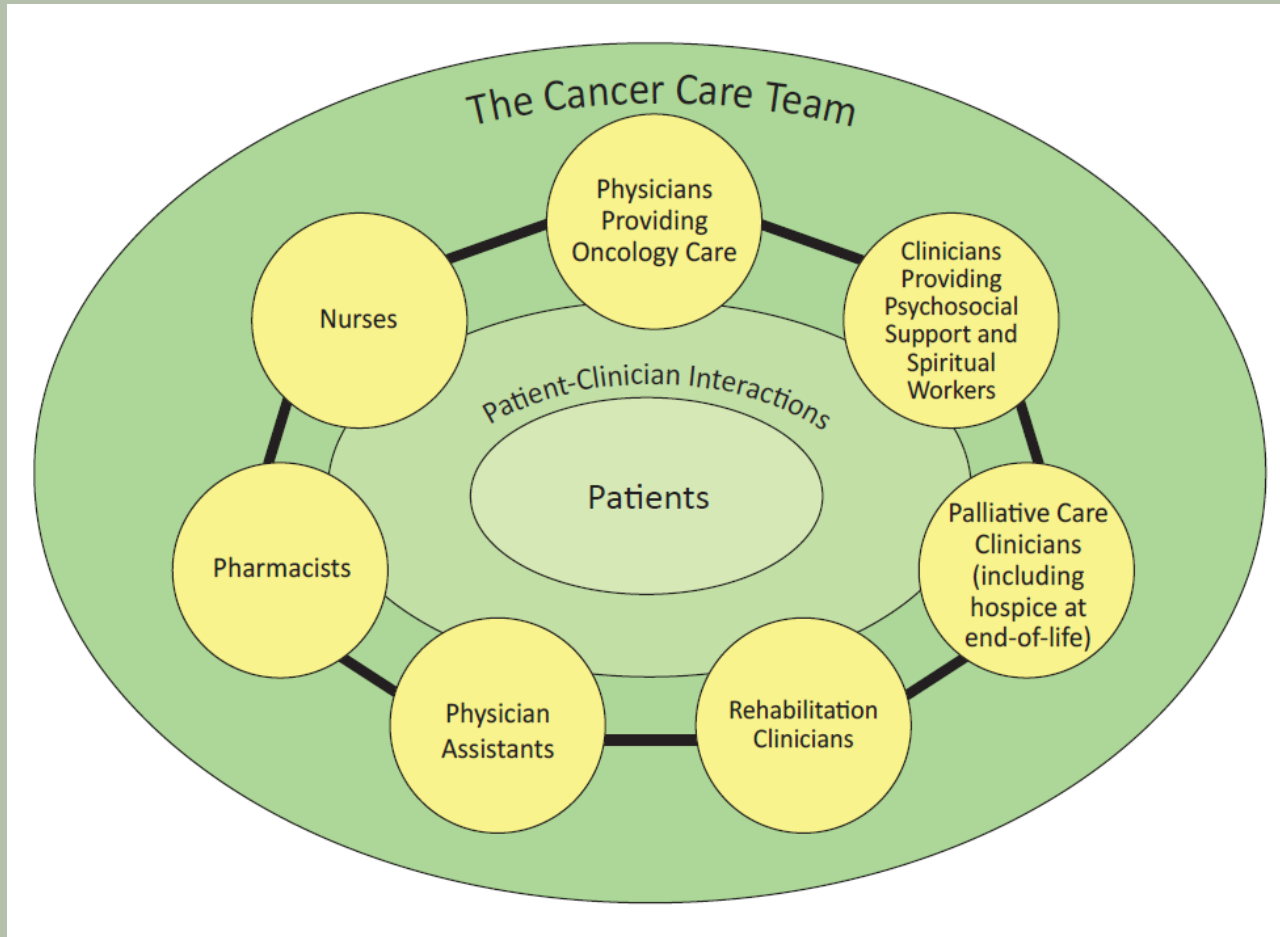
## GOAL 3

Members of the cancer care team **should coordinate with each other** and **with primary/geriatrics and specialist care teams** to implement patients' care plans and deliver comprehensive, efficient, and patient-centered care.

# A Coordinated Workforce



# A Coordinated Cancer Care Team



## Recommendation 3

- Federal and state legislative and regulatory bodies should **eliminate reimbursement and scope-of-practice barriers** to team-based care.
- Academic institutions and professional societies should develop **interprofessional education programs** to train the workforce in **team-based cancer care** and promote coordination with primary/geriatrics and specialist care teams.
- Congress should fund the **National Workforce Commission**, which should take into account the aging population, the increasing incidence of cancer, and the complexity of cancer care, when planning for national workforce needs.



# An Adequately-Staffed, Trained, and Coordinated Workforce

## GOAL 4

All individuals caring for cancer patients should have **appropriate core competencies.**

## Recommendation 4

- **Professional organizations** representing clinicians who care for patients with cancer should **define cancer core competencies** for their membership.
- **Cancer care delivery organizations** should require that the members of the cancer care team have the necessary competencies to deliver high-quality cancer care, as demonstrated through **training, certification, or credentials**.
- Organizations responsible for accreditation, certification, and training of **nononcology clinicians** should promote the development of relevant core competencies across the cancer care continuum.

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# IOM REPORT CONCLUSIONS

- **All participants and stakeholders** must reevaluate their current roles and responsibilities in cancer care and **work together** to develop a higher quality cancer care delivery system.
- By working toward this shared goal, the cancer care community can **improve the quality of life and outcomes** for people facing a cancer a diagnosis.

# DELIVERING HIGH-QUALITY CANCER CARE

*Charting a New Course for a System in Crisis*

To read the report online, please  
visit

[www.nap.edu/qualitycancercare](http://www.nap.edu/qualitycancercare)

To watch the dissemination video,  
please visit

[www.iom.edu/qualitycancervideo](http://www.iom.edu/qualitycancervideo)

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# Components of Cancer Survivorship Care

## CARE FOR THE CANCER SURVIVOR

### Non-Cancer Related Medical Care

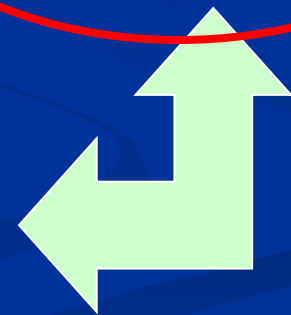
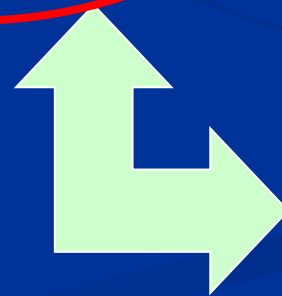
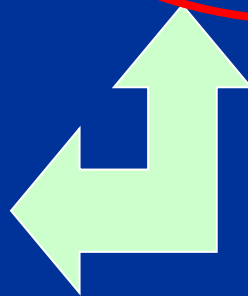
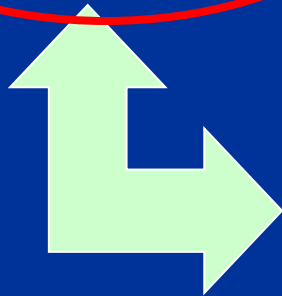
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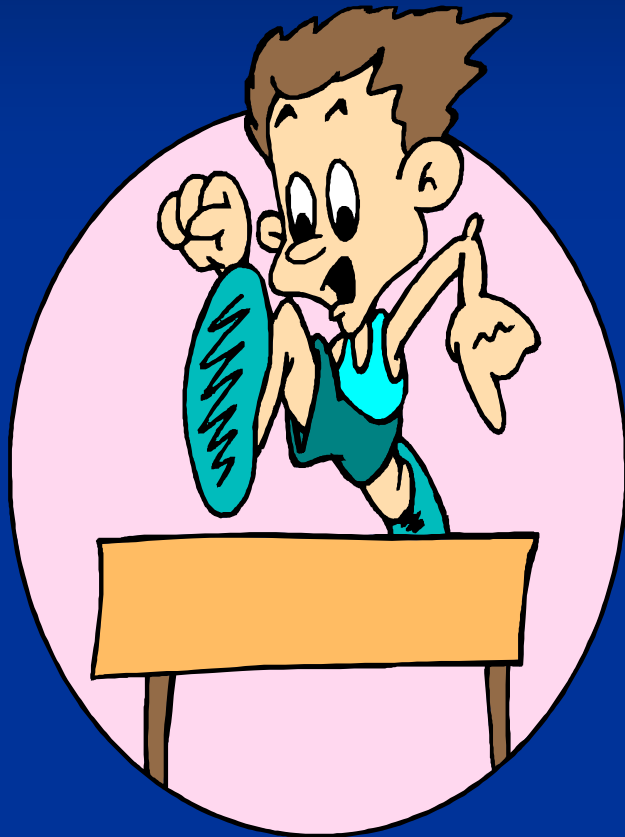
### Psychosocial Issues

- Quality of life, financial burden
- Family/genetic counseling



**Coordination of Care**

# Hurdles in Caring for Cancer Survivors!



- Cancer survivors are diverse!!!
- Some cancers rarely seen in primary care, so can't have enough expertise
- Inadequate information about the previous cancer and/or its treatment
- Lack of knowledge and confidence about survivorship care
- Patient lack of confidence in PCP knowledge
- Competing demands on PCP time
- Numerous specialists leading to gaps in communication/coordination
- Shortage!



# Global Challenges in Caring for Cancer Survivors

- Lack of clear, evidence-based guidelines on proper management and limited knowledge of evolving management of co-morbidities
- Lack of effective management and transfer of information between providers needed for coordination of care

# Cancer Survivorship Guidelines

**CHILDREN'S  
ONCOLOGY  
GROUP**

The world's childhood cancer experts



**NCCN Clinical Practice  
Guidelines in Oncology™**

**ASCO | GUIDELINES**

## Original Contribution

# Cancer Survivorship Care Plans: What Can Be Learned From Hospital Discharge Summaries?

*By Larissa Nekhlyudov, MD, MPH, and Jeffrey L. Schnipper, MD, MPH*

Harvard Medical School; Harvard Vanguard Medical Associates; Brigham and Women's Hospital; and Partners HealthCare, Boston, MA

### **Abstract**

The Institute of Medicine panel on cancer survivorship recommended that all patients with cancer and their primary care providers receive a written survivorship care plan that summarizes their initial treatment and provides guidance on post-treatment management. Cancer survivorship care plans aim to improve coordination of care and communication between pro-

viders as their patients transition from oncology to primary care settings. As such, survivorship care plans share similarities with hospital discharge summaries, focusing on improving the transition from inpatient to outpatient settings. In this article, we explore potential lessons that may be learned from hospital discharge summaries, which may be used to facilitate the development, implementation, and testing of survivorship care plans.



## Contents: Oncology

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# CANCER SURVIVORSHIP

in primary care

RESOURCES FOR PRIMARY CARE PROVIDERS

- Home
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- Clinical
- Research
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- About
- News
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Cancer Survivorship in Primary Care is a one-stop repository where primary care providers can quickly access resources for medical information and clinical guidance.

### Clinical

Information to help you care for your patients



### Research

Including clinical trials and funding sources



### Education

Opportunities to expand your knowledge and skills



### Patients & families

Resources for survivors and caregivers



There are close to 12 million cancer survivors in the US, and this population continues to grow.

Many survivors are living longer and most are elderly, with chronic medical conditions that also require care.

Primary care providers play an important role in caring for cancer survivors, yet research shows that their skills and comfort levels in managing issues related to cancer survivorship can be improved.



## News

6th Biennial Cancer Survivorship Research Conference, "Cancer Survivorship Research: Translating Science to Care," to be held at the Crystal Gateway Marriott in Arlington, Virginia, from June 14-16, 2012.

<http://bit.ly/AhNf5u>



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[www.cancerpcp.org](http://www.cancerpcp.org)

# Working with Care Teams After Cancer Treatment

*Patient-Centered Primary Care Collaborative  
Webinar December 16, 2013*

## ***QUESTIONS?***

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