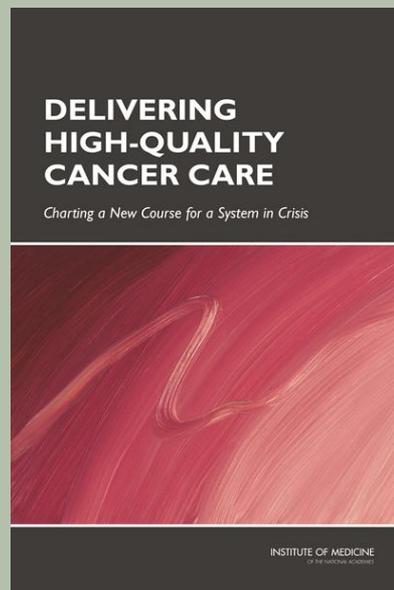


# Delivering High Quality Cancer Care: Charting a New Course for a System in Crisis



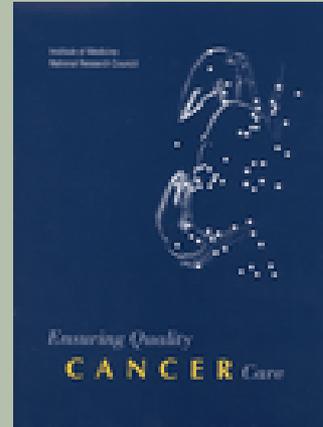
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# Ensuring Quality Cancer Care

- Original IOM report issued April 1, 1999

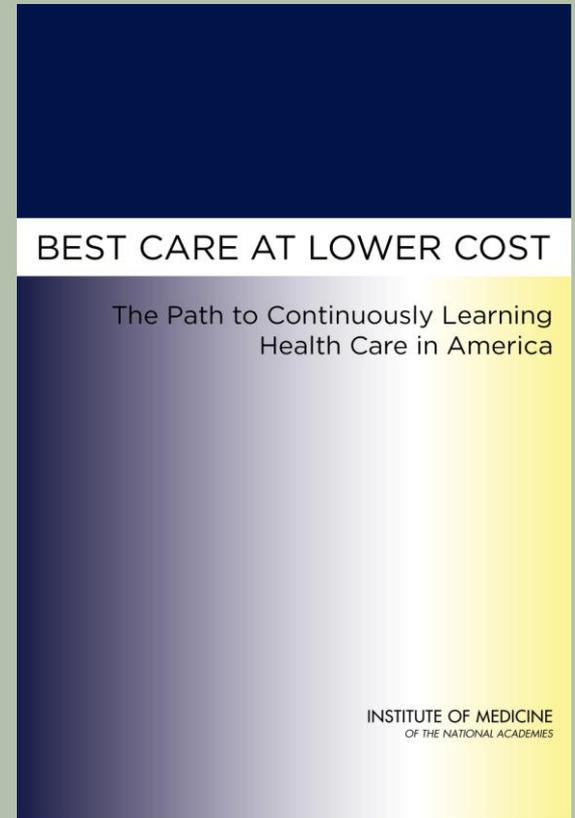
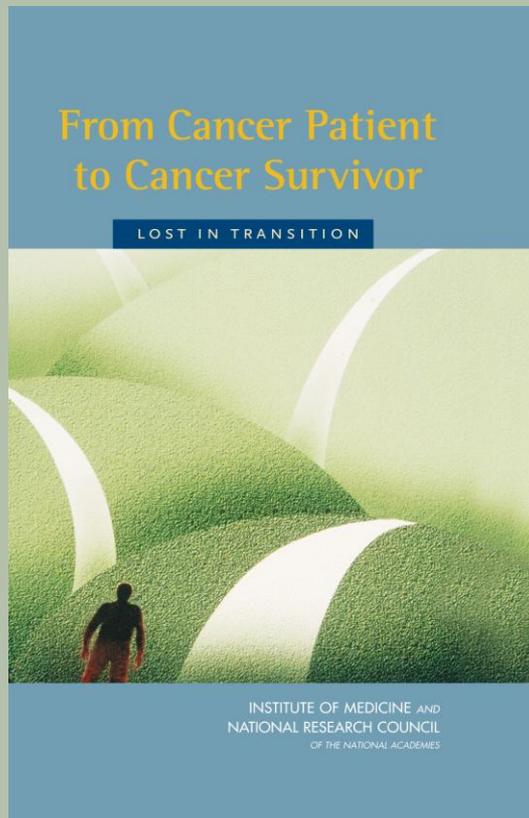
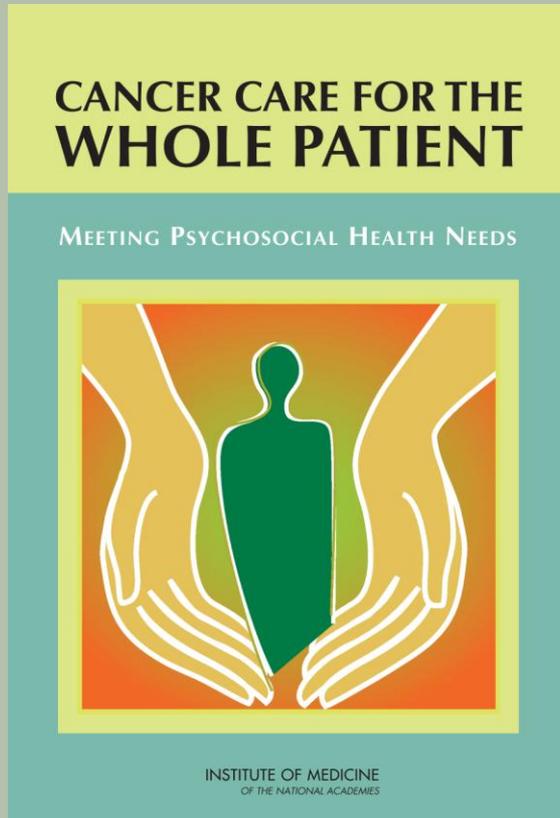


- “For many Americans with cancer there is a wide gulf between what could be construed as the ideal and the reality of their experience with cancer care”

# Ensuring Quality Cancer Care

- Ten recommendations for:
  - Evidence-based guidelines
  - Quality measures and electronic data collection systems
  - Coordinated, high-quality care, including at the end of life
  - Clinical trials and health services research
  - Access and disparities
- Some progress since 1999, but still many gaps

# Other Relevant IOM Consensus Reports





# Study Charge

**The IOM committee will examine opportunities for and challenges to the delivery of high-quality cancer and formulate recommendations for improvement.**

Specific issues reviewed:

- Coordination and organization of care
- Outcomes reporting and quality metrics
- Growing need for survivorship care, palliative care, and family caregiving
- Complexity and cost of care
- Payment reform and new models of care
- Disparities and access to high-quality cancer care

# Study Sponsors

- **The National Cancer Institute**
- **Centers for Disease Control and Prevention**
- **AARP**
- **American Cancer Society**
- **American College of Surgeons, Commission on Cancer**
- **American Society for Radiation Oncology**
- **American Society of Clinical Oncology**
- **American Society of Hematology**
- **California HealthCare Foundation**
- **LIVESTRONG**
- **National Coalition for Cancer Survivorship**
- **Oncology Nursing Society**
- **Susan G. Komen for the Cure**

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**SHARYL NASS**  
**ROGER HERDMAN**

# The Cancer Care Delivery System is in Crisis

# Trends Amplifying the Crisis

- The aging population:
  - 30%  in cancer survivors by 2022
  - 45%  in cancer incidence by 2030
- Workforce shortages
- Reliance on family caregivers and direct care workers
- Rising cost of cancer care:
  - \$72 billion in 2004  \$125 billion in 2010
  - \$173 billion anticipated by 2020 (39% )
- Complexity of cancer care
- Limitations in the tools for improving quality

# The Majority of Cancer Diagnoses are in Older Adults

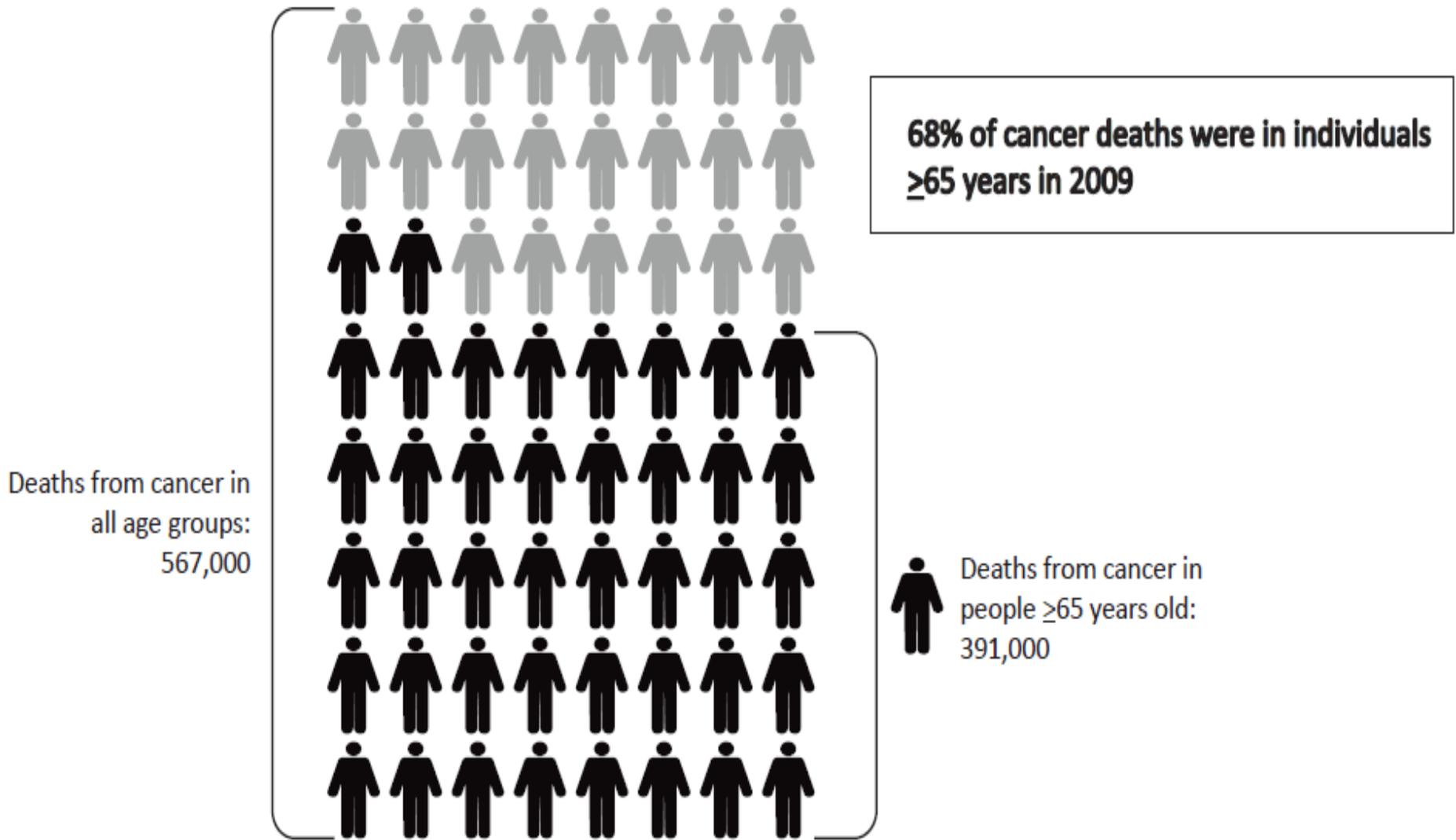
Total people  
diagnosed  
with cancer:  
1.6 million



53% of cancer diagnoses were in  
individuals  $\geq 65$  years old in 2012

Cancer diagnoses  
 $\geq 65$  years old:  
868,000

# The Majority of Cancer Deaths are in Older Adults



# The Majority of Cancer Survivors are Older Adults

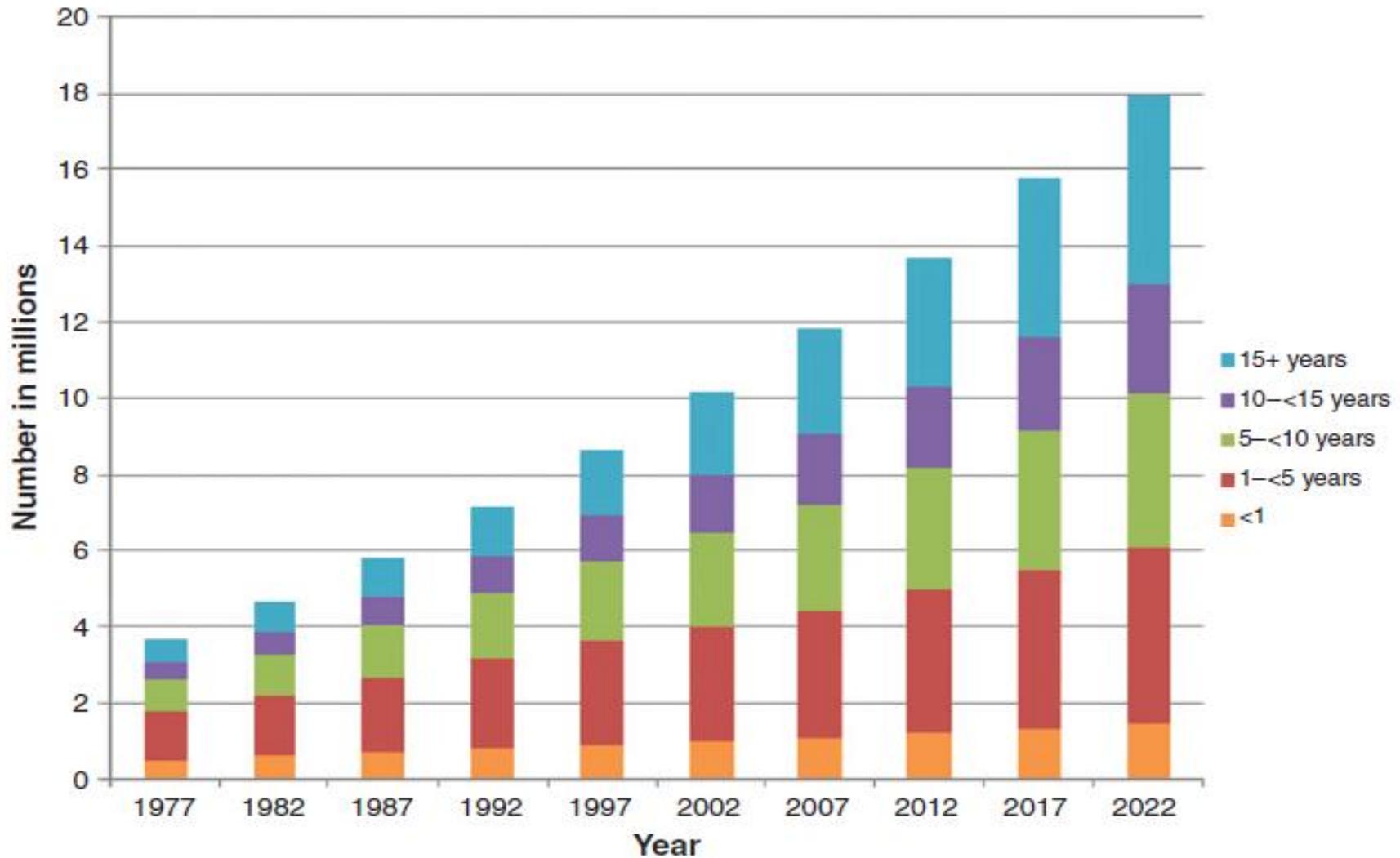
Total Cancer Survivors:  
13.7 million



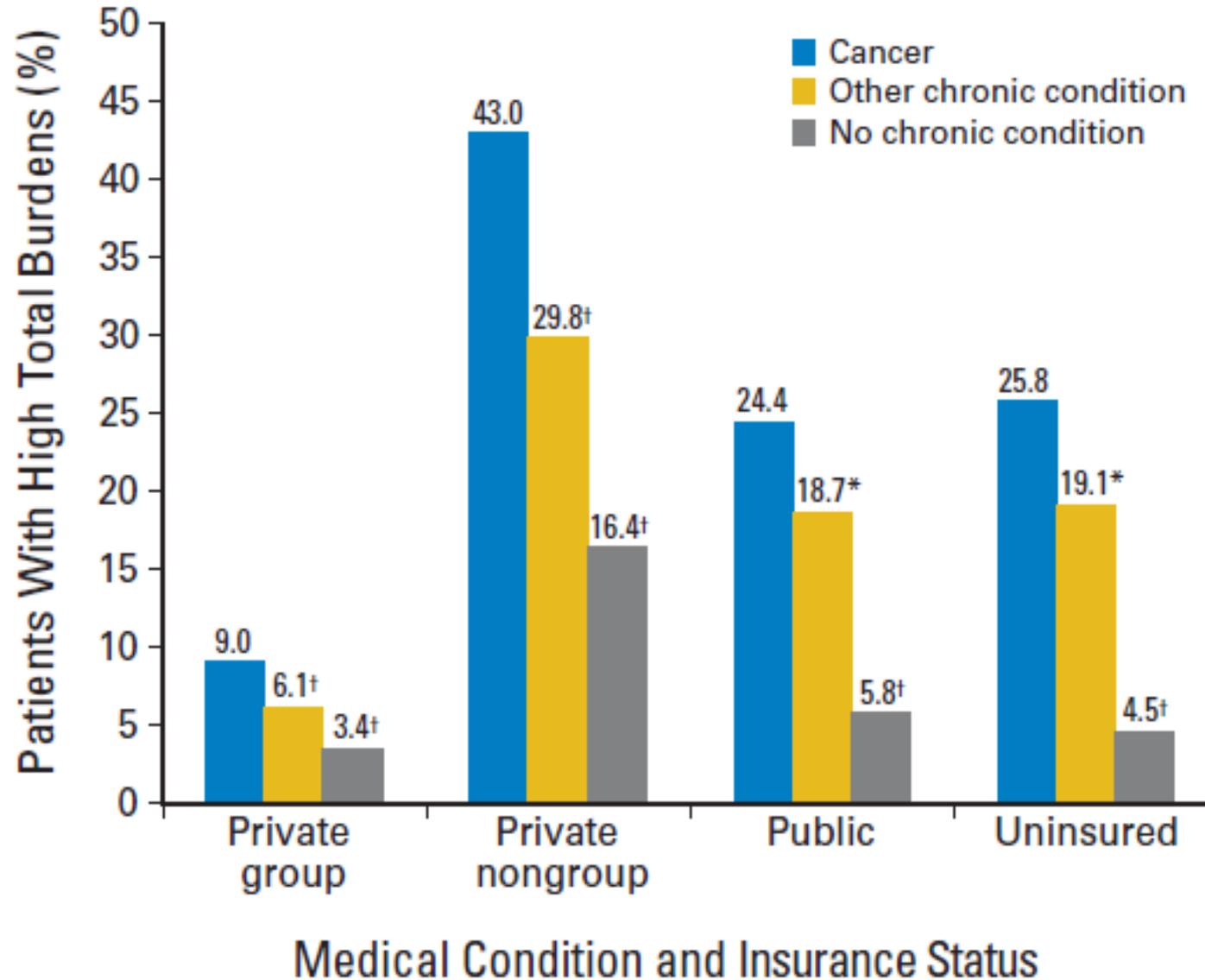
59% of cancer survivors were  $\geq 65$  years old in 2012

Cancer Survivors  
 $\geq 65$  years old:  
8+ million

# 18 Million Cancer Survivors Projected in 2022

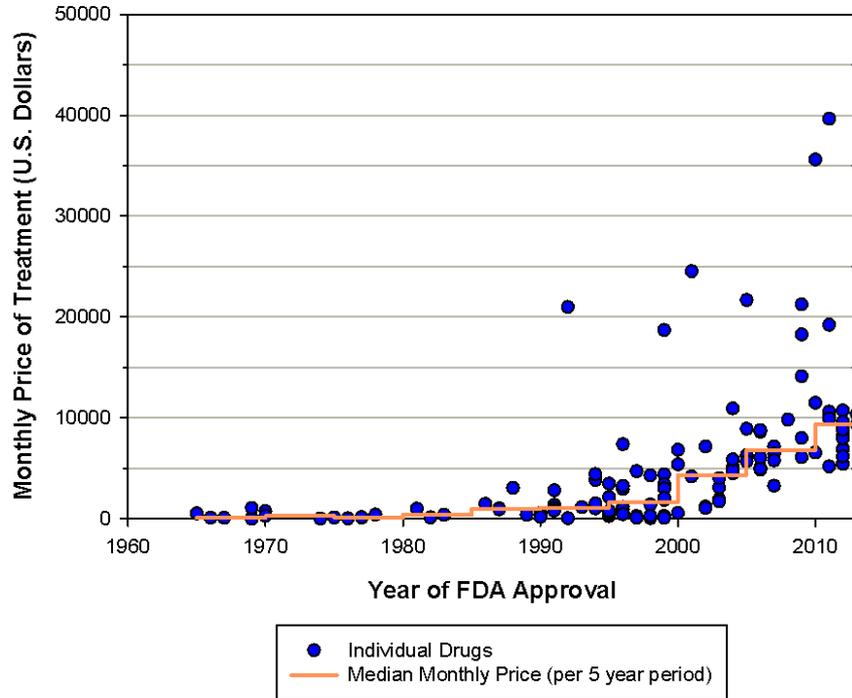


# Financial Burden of Cancer Care



# Increasing Cost of Cancer Drugs

Monthly and Median Costs of Cancer Drugs at the Time of FDA Approval  
1965 - 2013



**Table 1. Cost of Targeted Therapy**

Agent	Target	FDA-Approved Indication	Monthly or Per-Cycle Cost
Imatinib	BCR-ABL	CML	\$6,982
Dasatinib	BCR-ABL	CML	\$9,817
Nilotinib	BCR-ABL	CML	\$9,163
Bosutinib	BCR-ABL	CML	\$9,817
Sorafenib	VEGF, multikinase	RCC, HCC	\$10,555
Sunitinib	VEGF, multikinase	RCC, GIST	\$11,957
Everolimus	mTOR	RCC, breast	\$8,984
Temsirolimus	mTOR	RCC	\$6,355
Pazopanib	VEGF, multikinase	RCC	\$7,778
Bevacizumab	VEGF	RCC, colon, lung	\$11,684
Erlotinib	EGFR	Pancreatic, NSCLC	\$5,756
Cetuximab	EGFR	Colon, head/neck	\$24,092
Lapatinib	HER2	Breast	\$5,120
Trastuzumab	HER2	Breast	\$5,295
Brentuximab	CD30	Hodgkin lymphoma	\$16,768*
Crizotinib	ALK1	NSCLC	\$11,946
Ipilimumab	CTLA-4	Melanoma	\$36,540†
Vemurafenib	BRAF	Melanoma	\$12,282
Ruxolitinib	JAK2	Myelofibrosis	\$8,400
Lenalidomide	IMiD	Myeloma	\$10,103

P. B. Bach, 2009. NEJM. Limits on Medicare's ability to control rising spending on cancer drugs

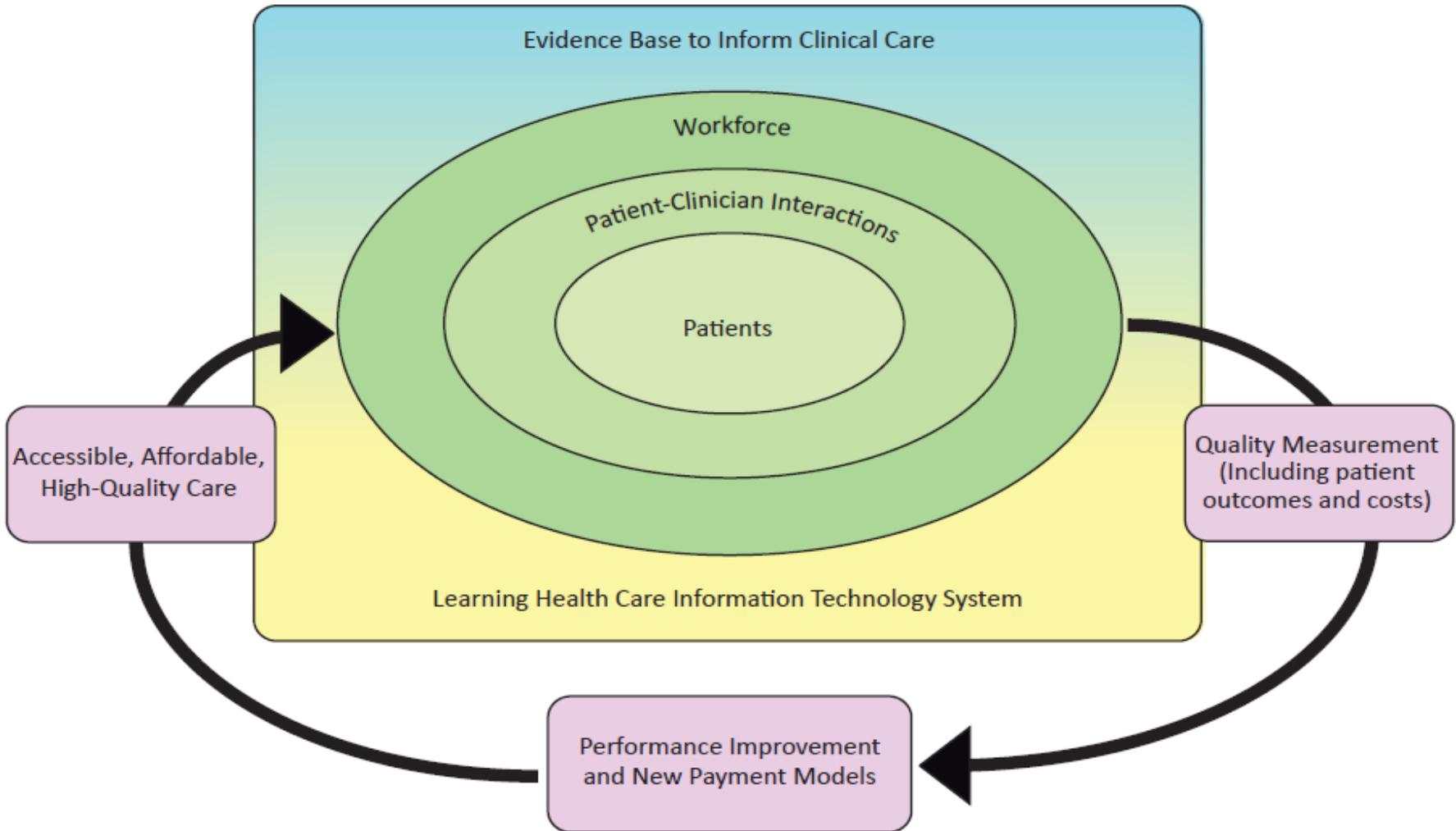
H. M. Kantarjian, T. Fojo, M. Mathisen, and L. A. Zwelling, 2013. JCO. Cancer Drugs in the United States: Justum Pretium—The Just Price.

# Conceptual Framework

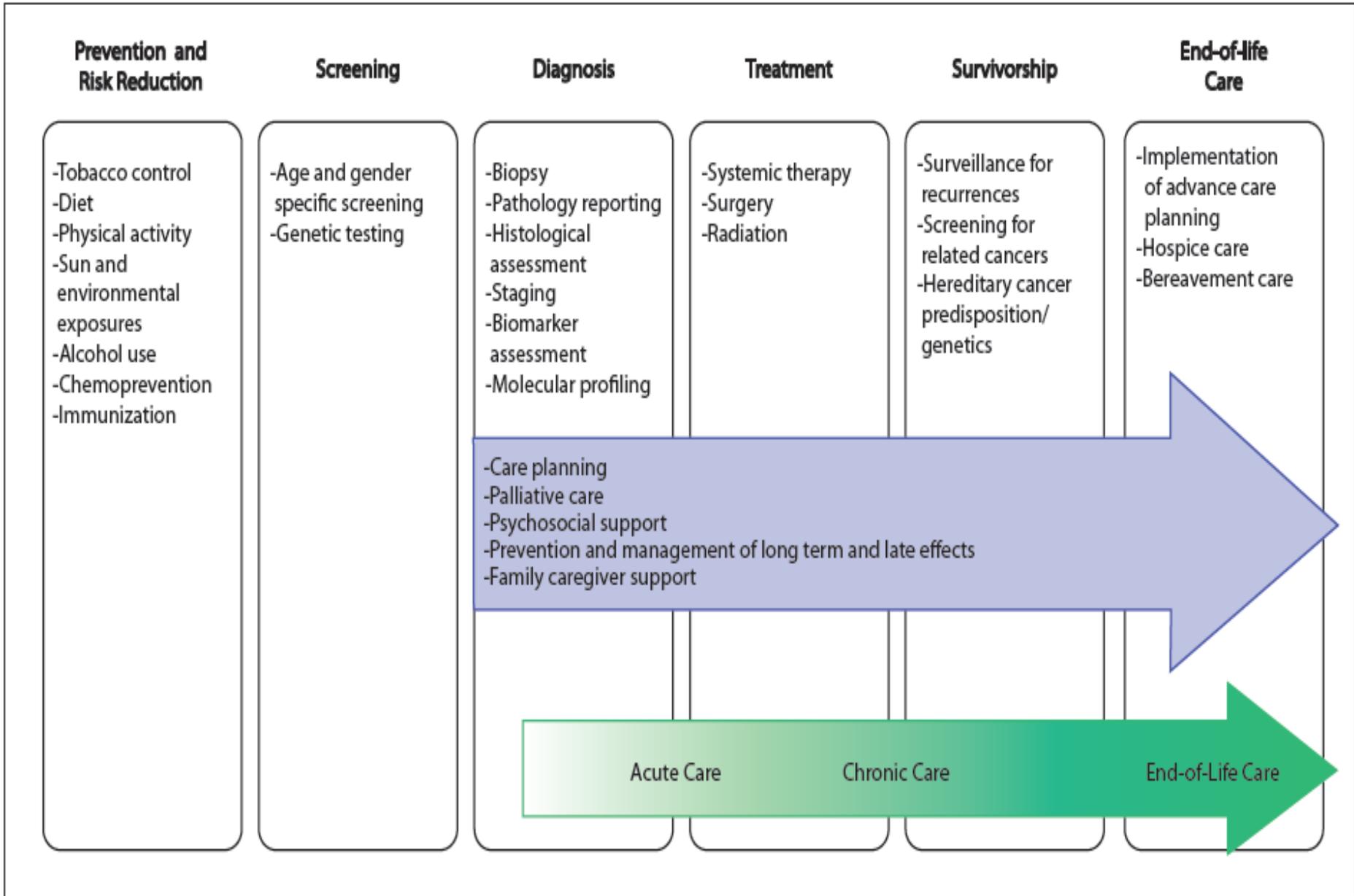
- 1. Engaged Patients**
- 2. Adequately staffed, trained, and coordinated workforce**
- 3. Evidence-based cancer care**
- 4. A learning health care IT system for cancer**
- 5. Translation of evidence into clinical practice, quality measurement, and performance improvement.**
- 6. Accessible, affordable cancer care**

# Conceptual Framework

## A High-Quality Cancer Care Delivery System



# Cancer Care Continuum



## 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. Core competencies for the workforce.
5. Expand breadth of cancer research data.
6. Expand depth of cancer research data.
7. Develop a learning health care 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.

# Engaged Patients

## GOAL 1

The cancer care team should provide patients and their families with understandable information on:

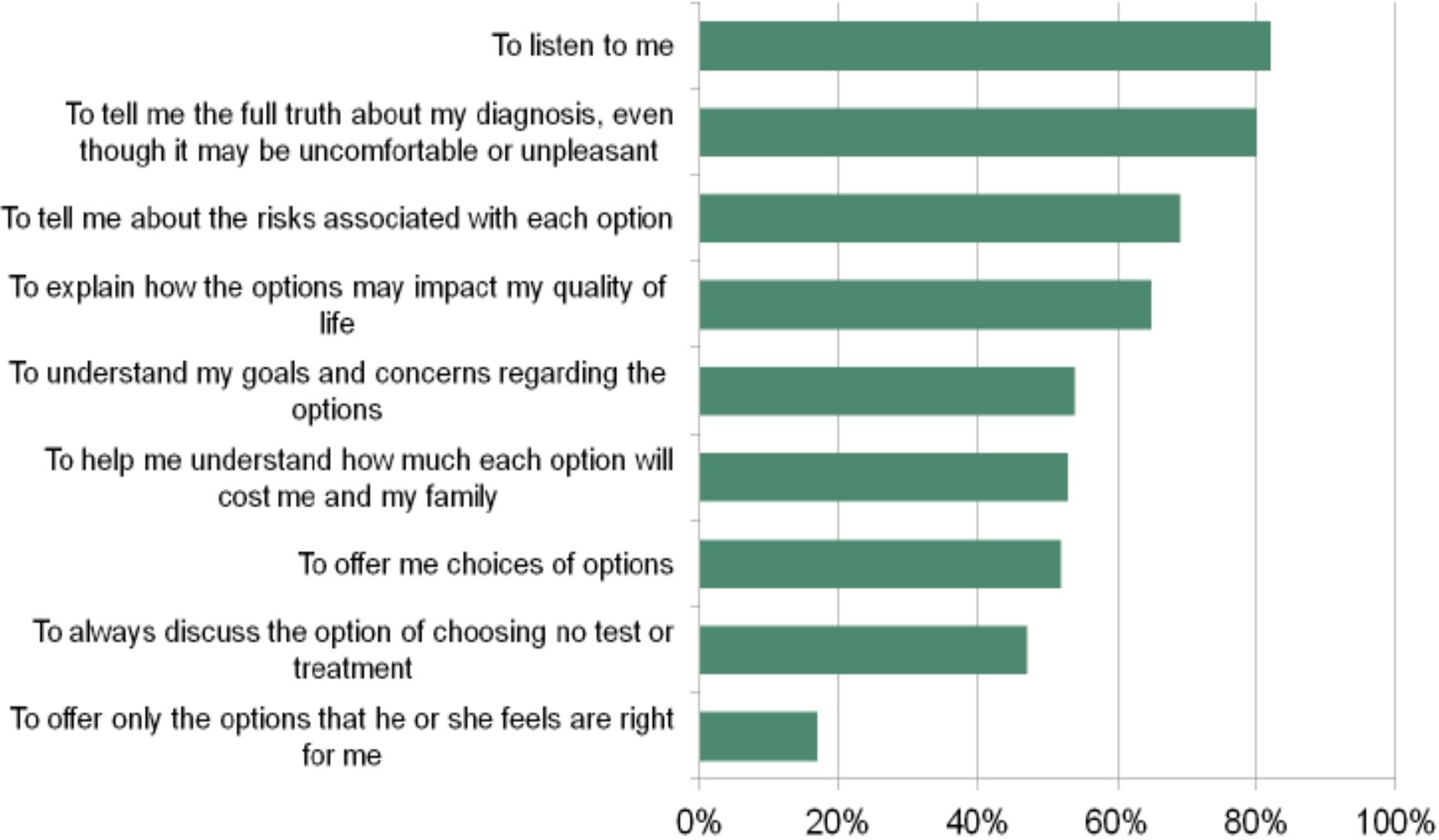
- Cancer prognosis
- Treatment benefits and harms
- Palliative care
- Psychosocial support
- Estimates of the total and out-of-pocket costs of care

# Recommendation 1

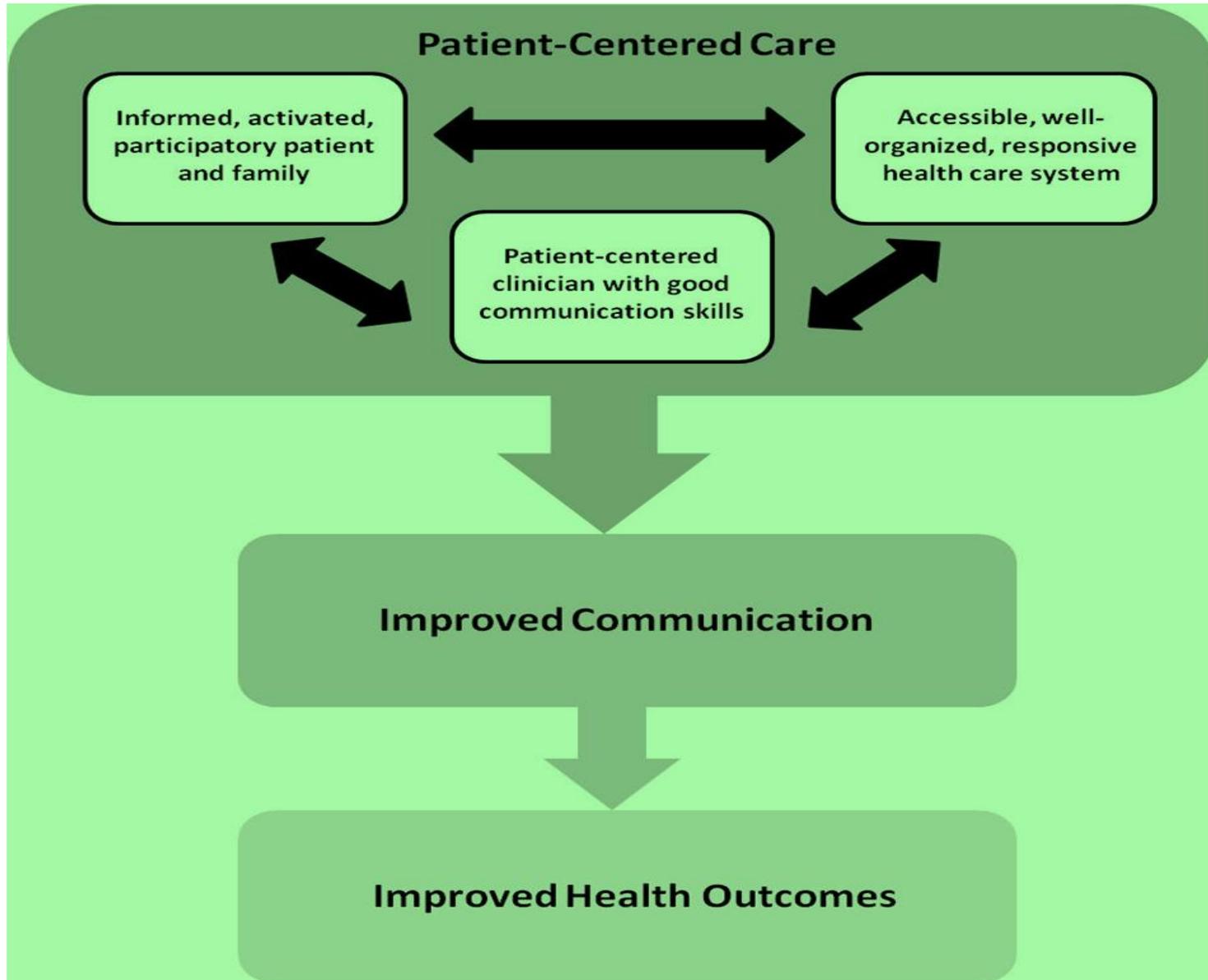
- The federal government and others should **improve the development and dissemination** of this critical information, using decision aids when possible.
- Professional educational programs should **train clinicians in communication.**
- The **cancer care team** should:
  - **Communicate and personalize** this information for their patients.
  - Collaborate with their patients to **develop care plans.**
- CMS and others should design, implement, and evaluate **innovative payment models.**

# Patients Want Involvement

**Figure 1. People want involvement in evidence and decisions**  
*Bars show the percent of people surveyed who strongly agree with the statement: "I want my provider..."*

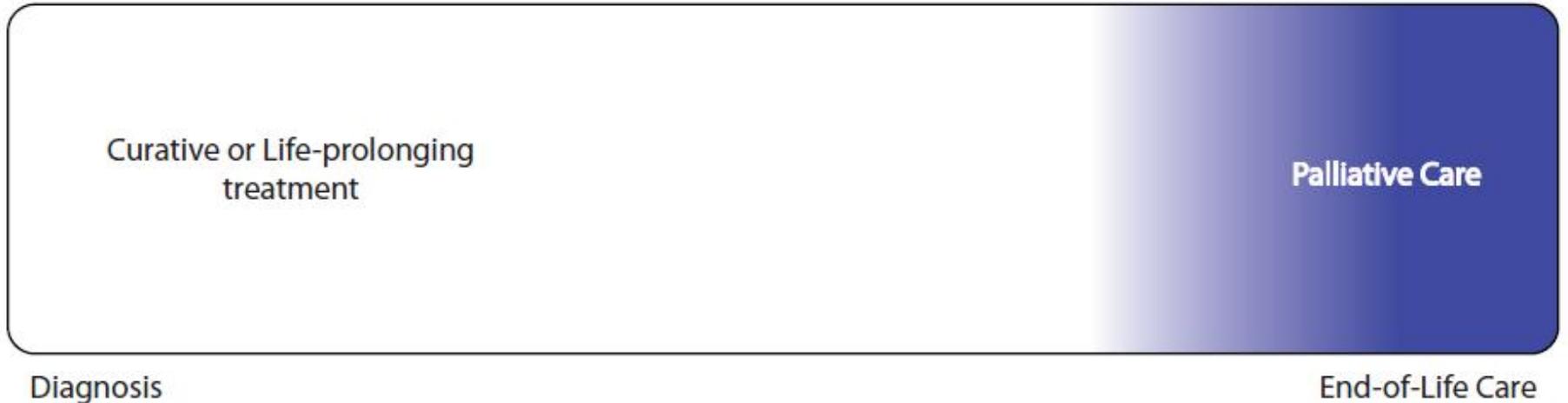


# Patient-Centered Care

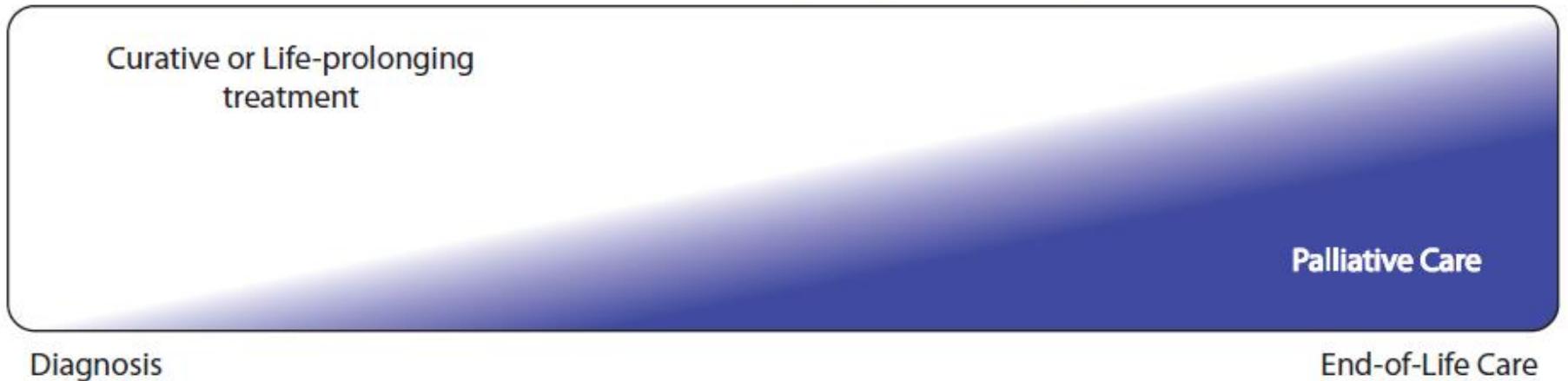


# Incorporation of palliative care across the care continuum

## Provision of Palliative Care Exclusively at End-of-Life



## Incorporation of Palliative Care Throughout the Cancer Care Continuum



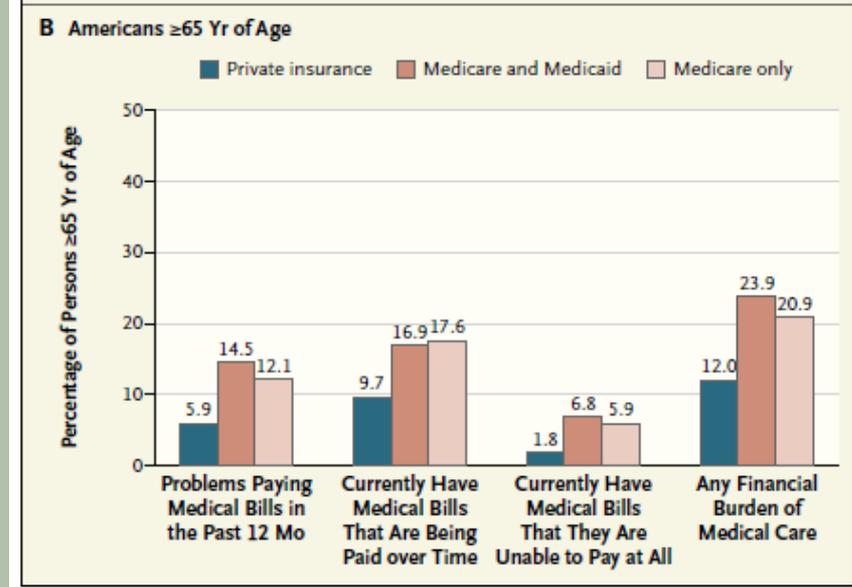
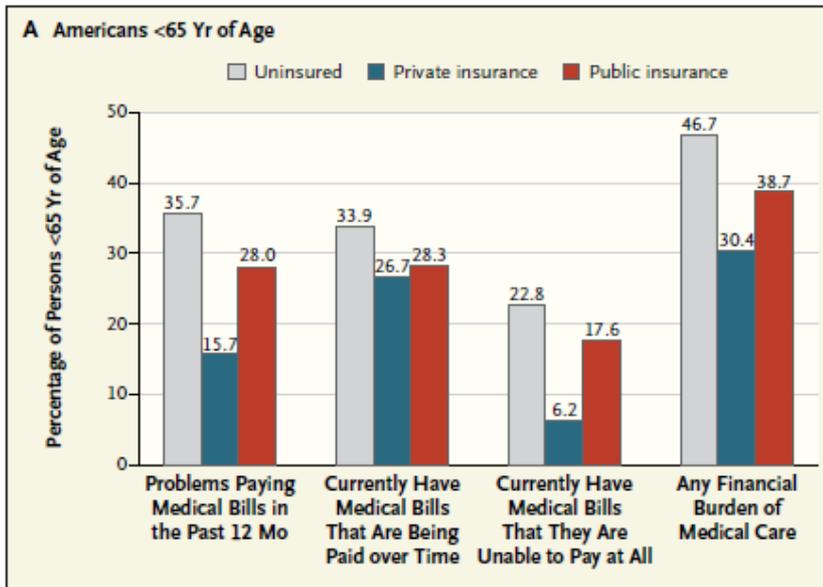
# Information in a Cancer Care Plan

- 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

# Full Disclosure — Out-of-Pocket Costs as Side Effects

Peter A. Ubel, M.D., Amy P. Abernethy, M.D., Ph.D., and S. Yousuf Zafar, M.D., M.H.S.

N ENGL J MED 369:16 NEJM.ORG OCTOBER 17, 2013



## Financial Burden of Medical Care.

Data are from the National Center for Health Statistics, Centers for Disease Control and Prevention.

# 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

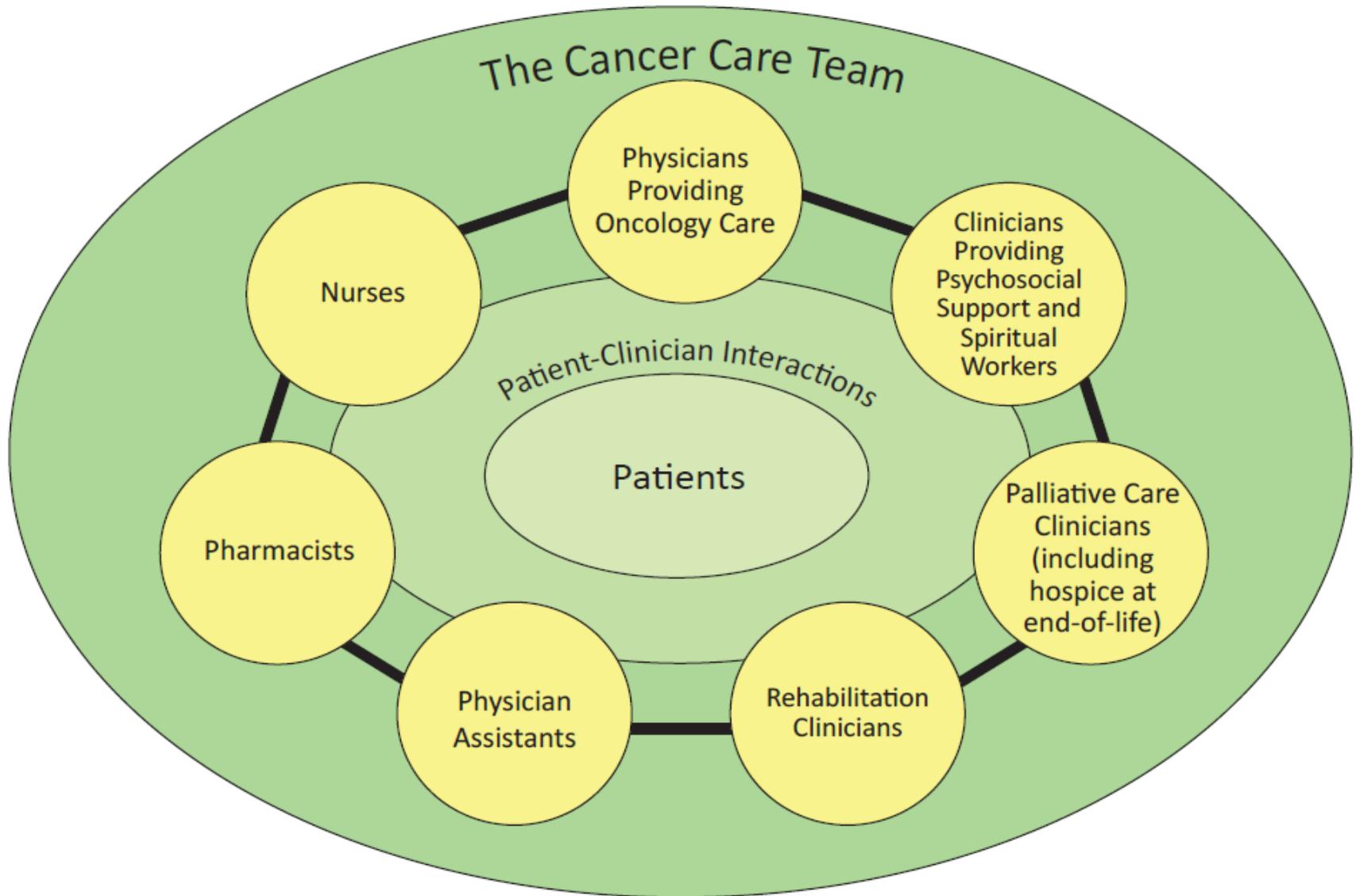
- Professional educational programs should **train clinicians in end-of-life communication**.
- The cancer care team should **revisit** and **implement** their patients' **advance care plans**.
- Cancer care teams should provide patients with advanced cancer:
  - **Palliative care**
  - **Psychosocial support**
  - **Timely referral to hospice for end-of-life care.**
- CMS and other payers should design, implement, and evaluate **innovative payment models**.

# An Adequately Staffed, Trained, and Coordinated Workforce

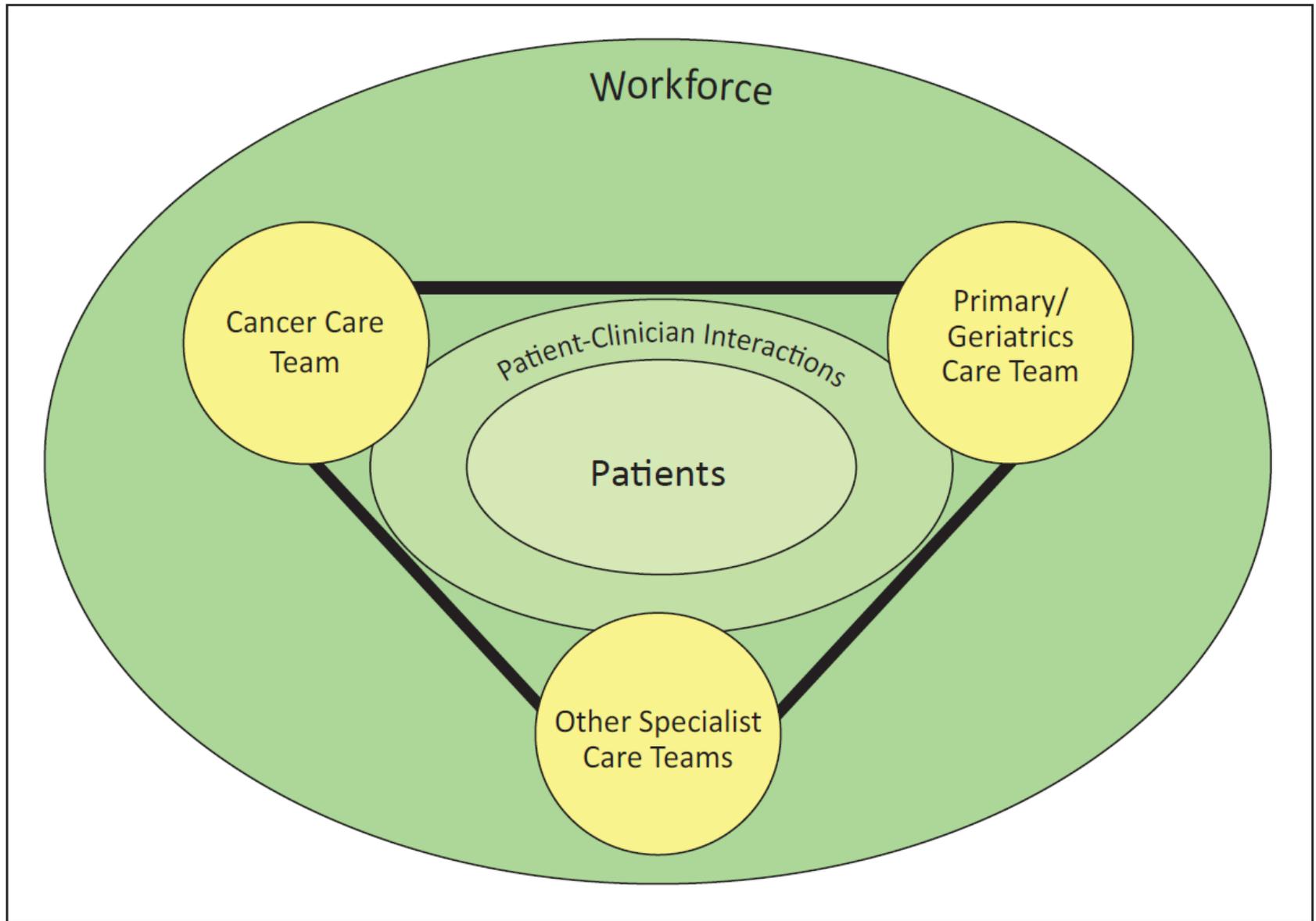
## GOAL 3

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 Cancer Care Team



# A Coordinated Workforce



## 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**.
- Congress should fund the **National Workforce Commission**.

# An Adequately Staffed, Trained, and Coordinated Workforce

## GOAL 4

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

## Recommendation 4

- Professional organizations should **define cancer core competencies**.
- Cancer care delivery organizations should **require** cancer care teams to have **cancer core competencies**.
- Organizations responsible for accreditation, certification, and training of **nononcology clinicians** should promote the development of relevant cancer core competencies.
- HHS and others should fund demonstration projects to train **family caregivers and direct care workers**.

# Evidence-Based Cancer Care

## GOAL 5

Expand the **breadth of data** collected on cancer interventions for **older adults** and individuals with **multiple comorbid conditions**.

## Recommendation 5

- NCI, AHRQ, PCORI, and other CER funders should **require researchers** evaluating the role of standard and novel interventions and technologies used in cancer care to **include a plan to study a population that mirrors the age distribution and health risk profile** of patients with the disease.
- Congress should amend patent law to **provide patent extensions of up to six months** for companies that conduct clinical trials of **new cancer treatments in older adults** or **patients with multiple comorbidities**.

# Evidence-Based Cancer Care

## GOAL 6

Expand the **depth of data** available for assessing interventions.

## Recommendation 6

NCI should build on ongoing efforts and work with other federal agencies, PCORI, clinical and health services researchers, clinicians, and patients to develop a **common set of data elements** that captures **patient-reported outcomes, relevant patient characteristics,** and **health behaviors** that researchers should collect from randomized clinical trials and observational studies.

# A Learning Health Care IT System for Cancer

## GOAL 7

Develop an ethically sound **learning health care IT system for cancer** that enables real-time analysis of data from cancer patients in a variety of care settings.

## Recommendation 7

- Professional organizations should design and implement the necessary **digital infrastructure and analytics**.
- HHS should **support the development and integration** of this system.
- CMS and other payers should **create incentives for clinicians to participate** in this system, as it develops.

# Quality Measurement

## GOAL 8

Develop a **national quality reporting program** for cancer care as part of a learning health care system.

## Recommendation 8

HHS should work with professional societies to:

- Create and implement a formal **long-term strategy** for publicly reporting quality measures.
- Prioritize, fund, and direct the **development of meaningful quality measures**.
- Implement a coordinated, transparent **reporting infrastructure**.

# Accessible, Affordable Cancer Care

## GOAL 9

Reduce **disparities in access** to cancer care for **vulnerable and underserved** populations.

## Recommendation 9

HHS should:

- Develop a **national strategy** that leverages existing efforts.
- Support the **development of innovative** programs.
- Identify and disseminate **effective** community interventions.
- Provide **ongoing support** to **successful** existing community interventions.

# Accessible, Affordable Cancer Care

## GOAL 10

Improve the **affordability** of cancer care by leveraging existing efforts to **reform payment and eliminate waste.**

## Recommendation 10

- Professional societies should identify and disseminate practices that are **unnecessary or where the harm may outweigh the benefits**.
- CMS and others should **develop payment policies** that reflect professional societies' findings.
- CMS and others should design and evaluate **new payment models**.
- If evaluations of specific payment models demonstrate increased quality and affordability, CMS and others should **rapidly transition** from fee-for-service reimbursements to **new payment models**.

# Conclusions

- Current **US cancer care system is in crisis:** aging population, unsustainable costs, fragmentation of care
- IOM report charts a course forward, with many activities already in process
- Heavy emphasis on affordability and reliance on professional societies (e.g., ASCO, ASTRO)
- Payment reform and new models of care are in development—**oncology professionals need to be engaged in the process as it evolves!**

**DELIVERING  
HIGH-QUALITY  
CANCER CARE**

*Charting a New Course for a System in Crisis*



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To read the report online, please visit  
[www.iom.edu/qualitycancercare](http://www.iom.edu/qualitycancercare)

To watch the dissemination video, please  
visit [www.iom.edu/qualitycancercarevideo](http://www.iom.edu/qualitycancercarevideo)

**Cover Art**

“Day 15 Hope,” Sally Loughridge, *Rad Art: A Journey Through Radiation Treatment*  
(American Cancer Society, Atlanta, GA)



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# Thank You

## Questions?



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