

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

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**INSTITUTE OF MEDICINE**

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# 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**

# Study Charge

**The IOM committee will examine opportunities for and challenges to the delivery of high-quality cancer care 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

# **The Cancer Care Delivery System is in Crisis**

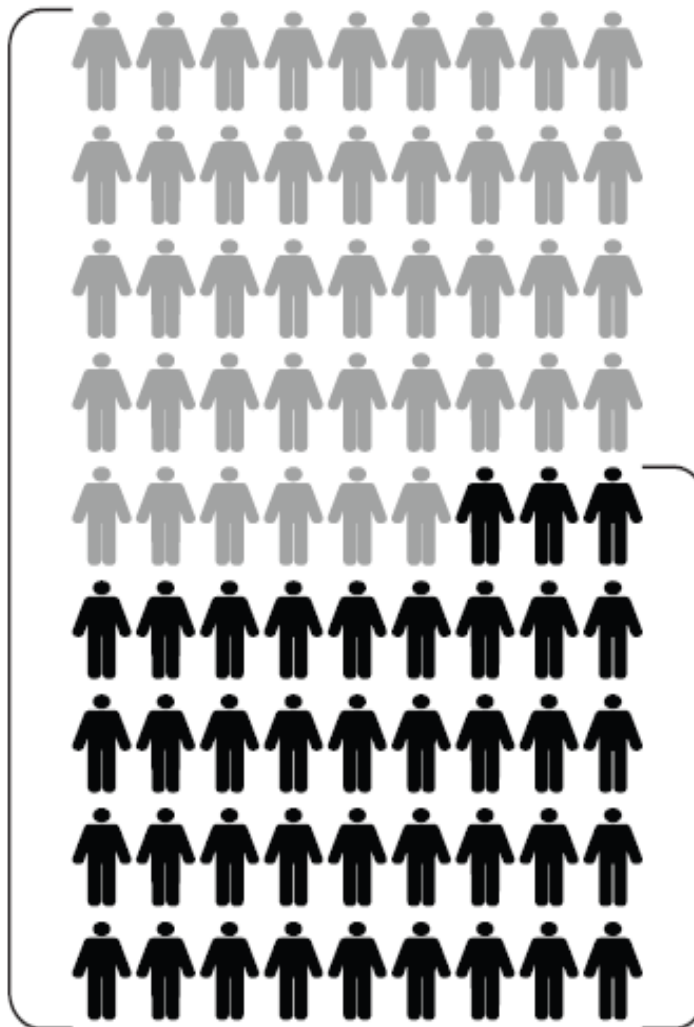
**Cancer care is often not as patient-centered, accessible, coordinated, or evidence based as it could be.**

# 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

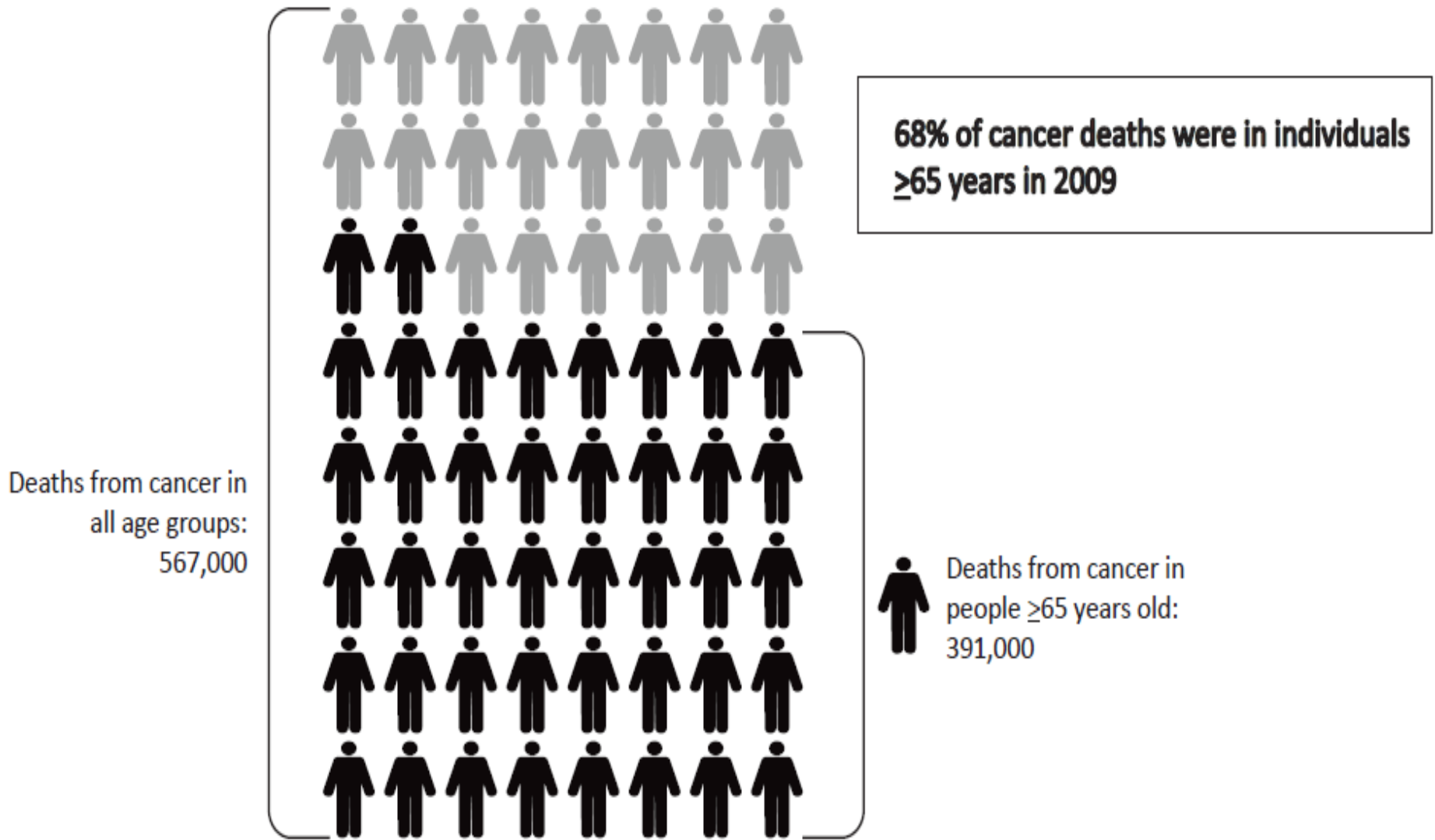
Total people  
diagnosed  
with cancer:  
1.6 million



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

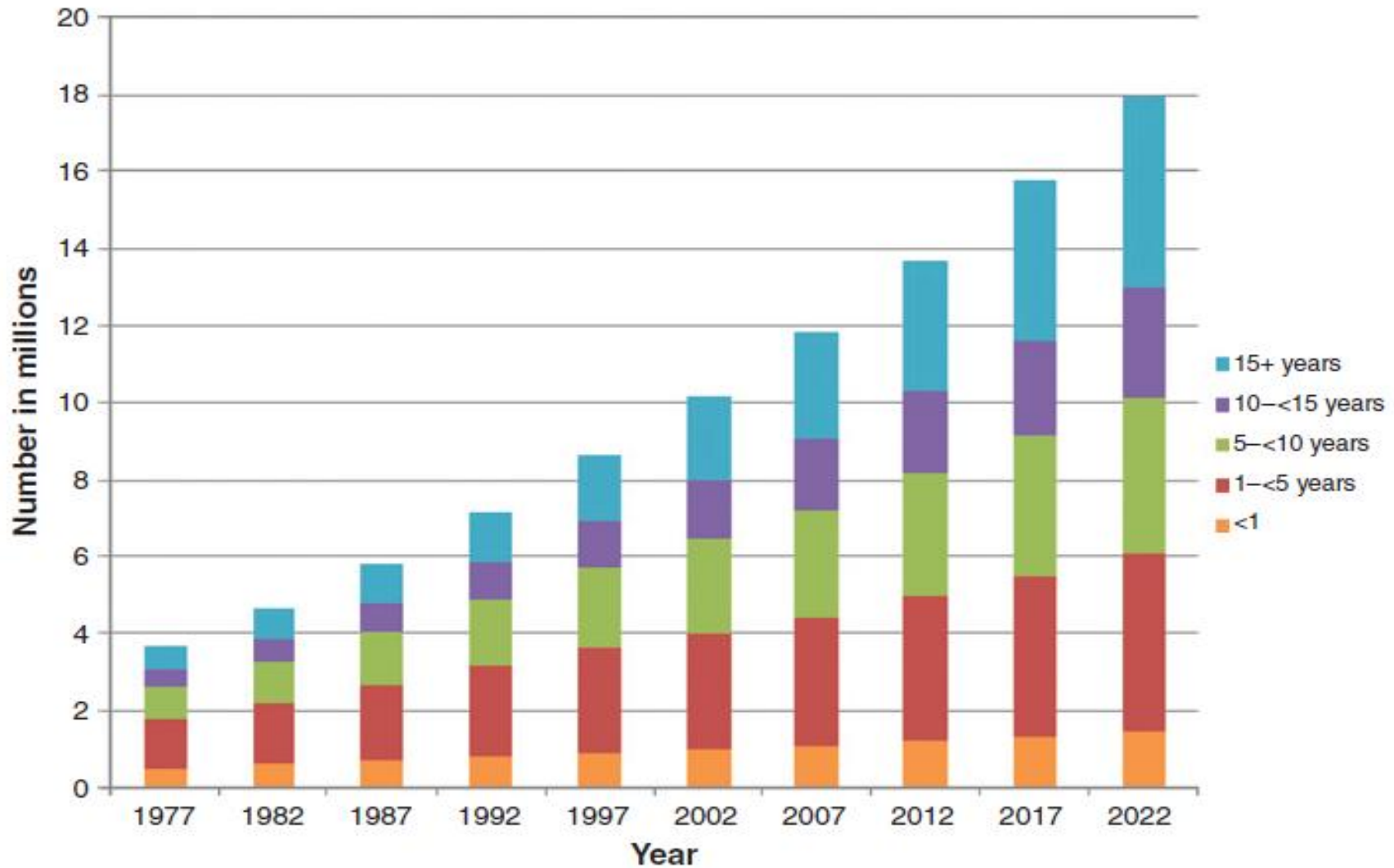


59% of cancer survivors were  $\geq 65$  years old in 2012



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

# 18 Million Cancer Survivors Projected in 2022

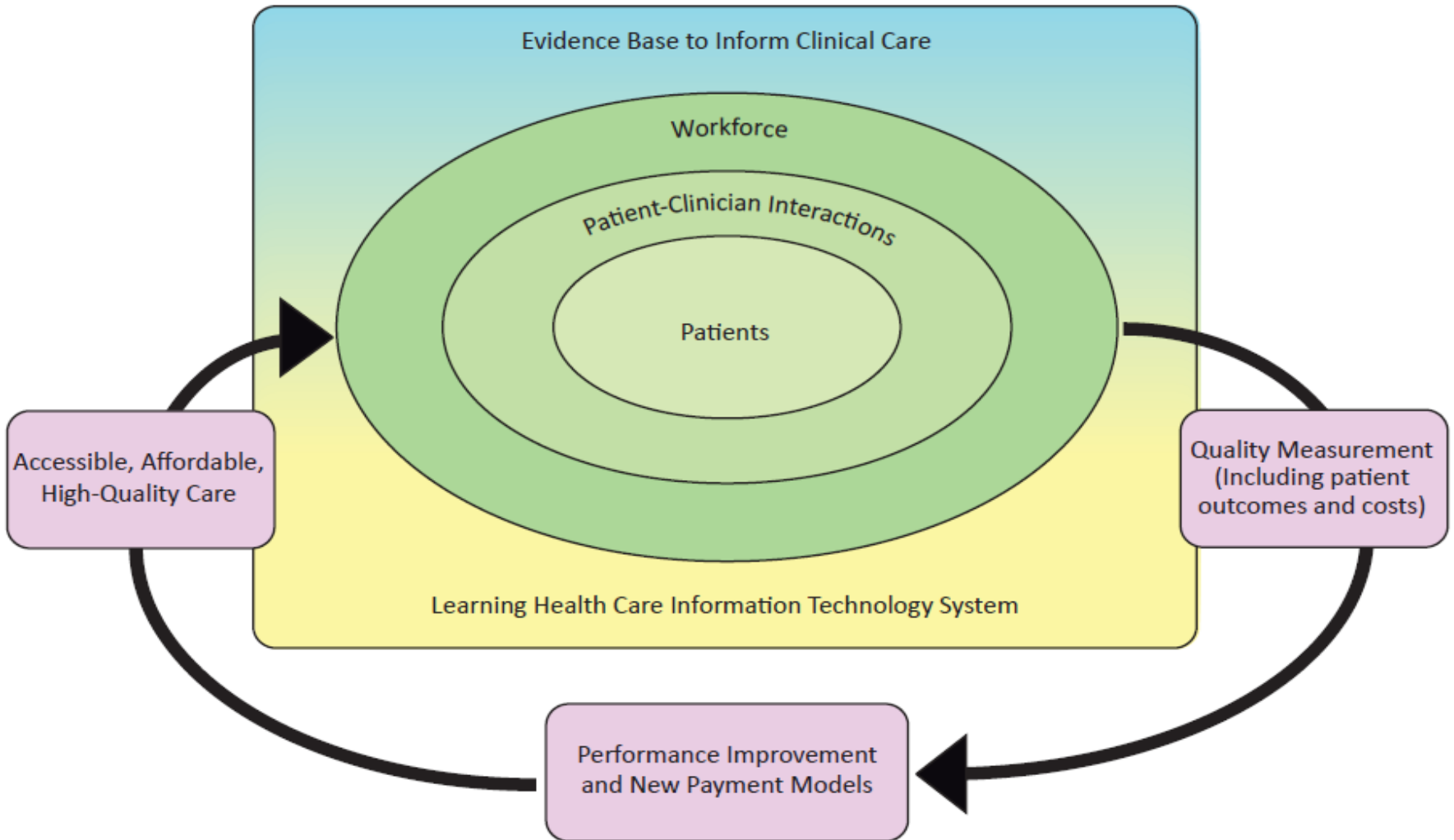


# Conceptual Framework

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

## Prevention and Risk Reduction

- Tobacco control
- Diet
- Physical activity
- Sun and environmental exposures
- Alcohol use
- Chemoprevention
- Immunization

## Screening

- Age and gender specific screening
- Genetic testing

## Diagnosis

- Biopsy
- Pathology reporting
- Histological assessment
- Staging
- Biomarker assessment
- Molecular profiling

## Treatment

- Systemic therapy
- Surgery
- Radiation

## Survivorship

- Surveillance for recurrences
- Screening for related cancers
- Hereditary cancer predisposition/genetics

## End-of-life Care

- Implementation of advance care planning
- Hospice care
- Bereavement care

- Care planning
- Palliative care
- Psychosocial support
- Prevention and management of long term and late effects
- Family caregiver support

Acute Care

Chronic Care

End-of-Life Care

## 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

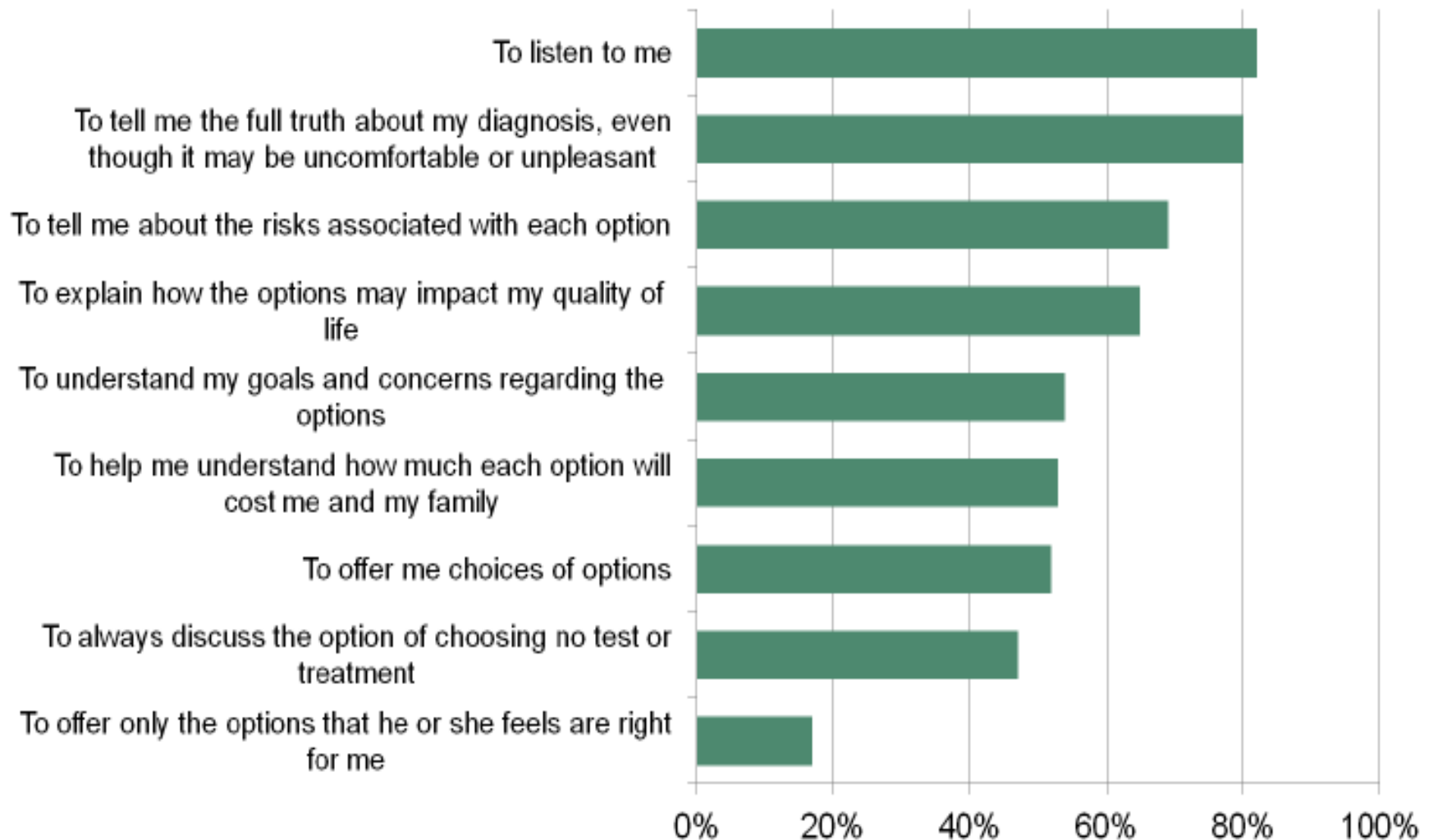
The cancer care team should provide patients and their families with understandable information on:

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

# 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..."*





# Recommendation 1

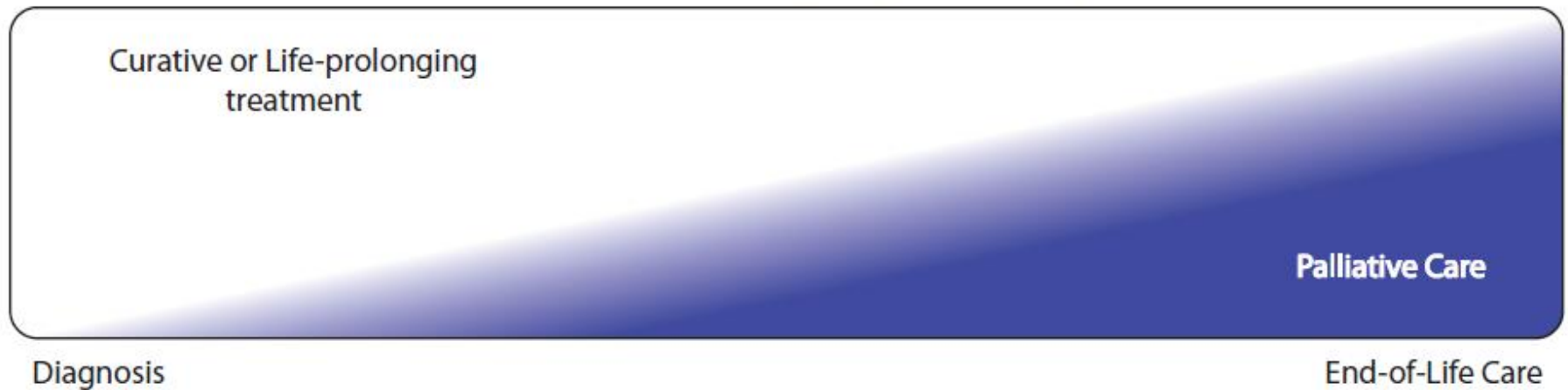
- The federal government and others should **improve the development and dissemination** of this critical information, using decision aids when possible.
- Professional educational programs should **train clinicians in communication.**
- The **cancer care team** should:
  - **Communicate and personalize**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

# 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



# 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

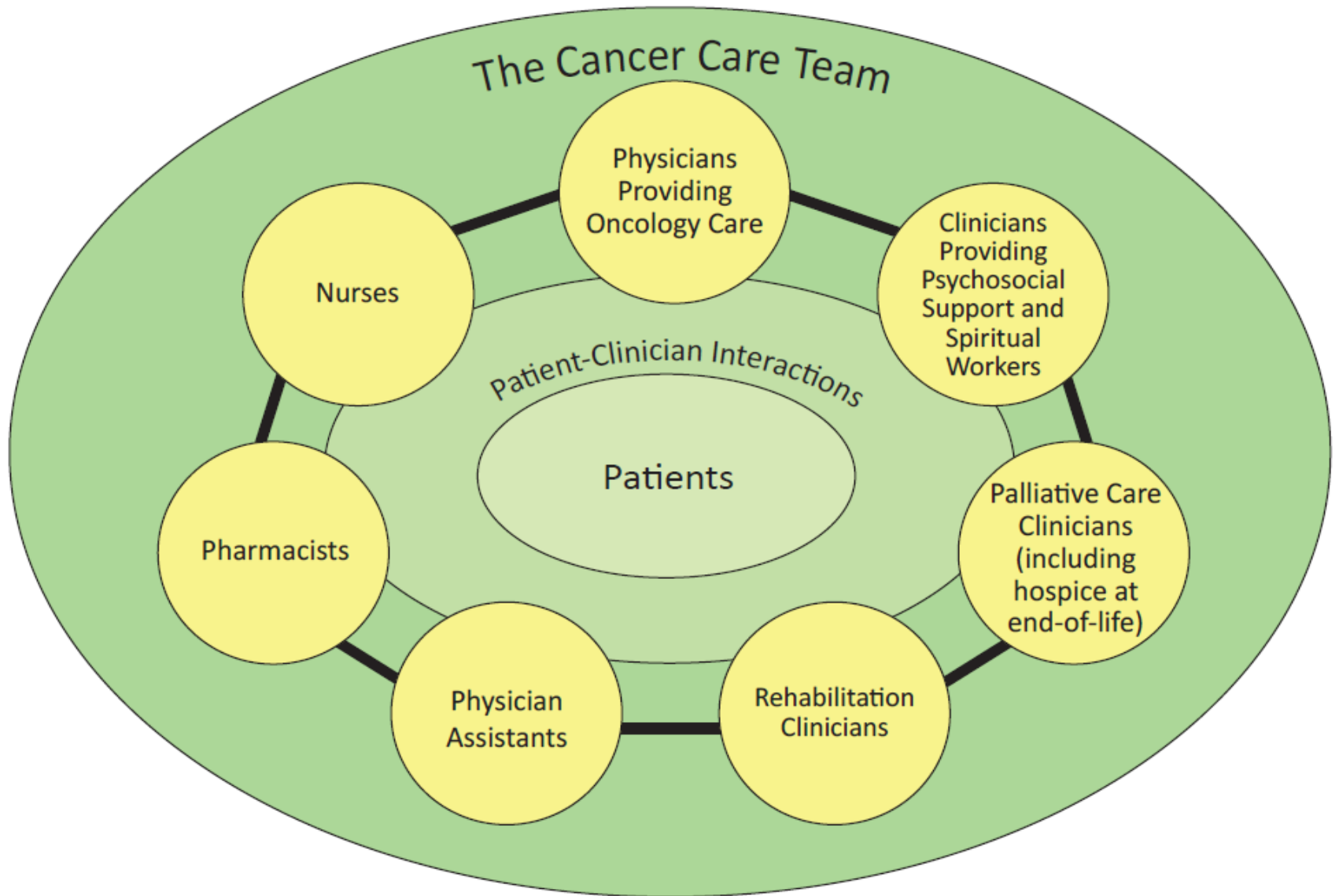
- Professional educational programs should **train clinicians in end-of-life communication**.
- The cancer care team should **revisit** and **implement** their patients' **advance care plans**.
- Cancer care teams should provide patients with advanced cancer:
  - **Palliative care**
  - **Psychosocial 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

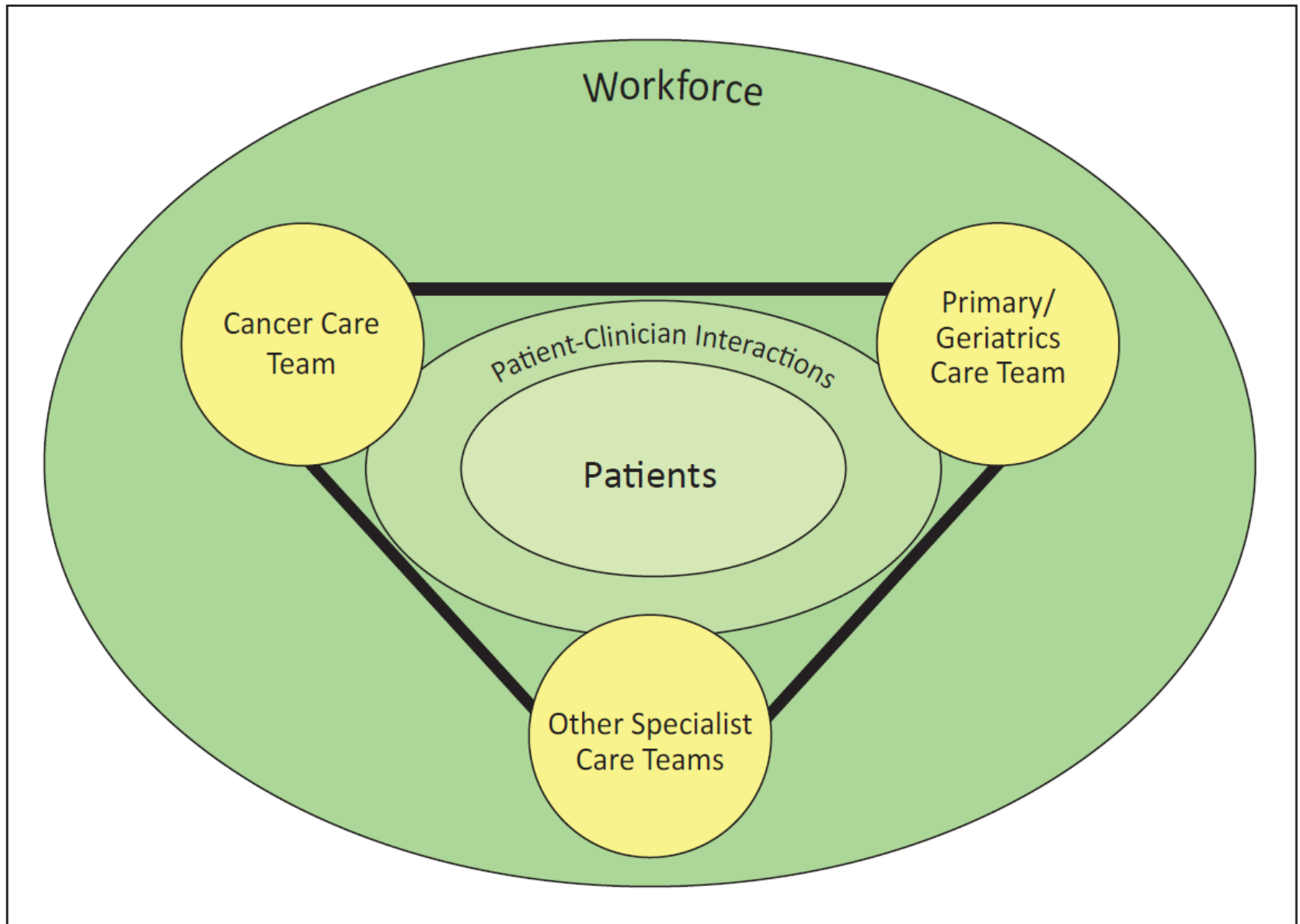
## GOAL 3

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

- The federal government and other funders should require researchers 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 and others should build on ongoing efforts to develop a **common set of data elements** that captures **patient-reported outcomes, relevant patient characteristics, and health behaviors** that researchers should collect from RCTs 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**.

**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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