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

53% of cancer diagnoses were in individuals ≥65 years old in 2012

Total people diagnosed with cancer: 1.6 million

Cancer diagnoses ≥65 years old: 868,000

The Majority of Cancer Deaths are in Older Adults

68% of cancer deaths were in individuals ≥65 years in 2009

Deaths from cancer in all age groups: 567,000

Deaths from cancer in people ≥65 years old: 391,000
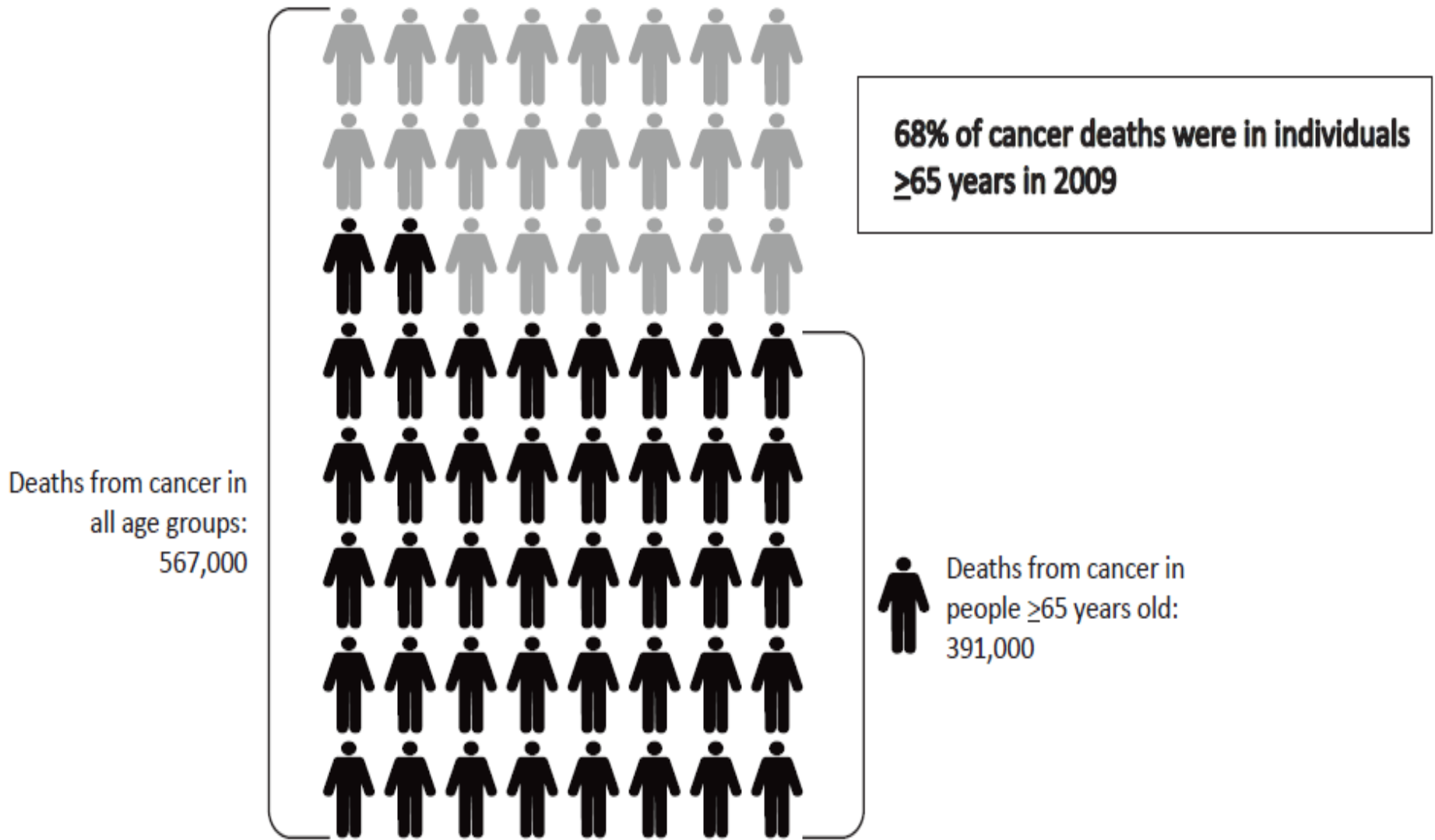
The Majority of Cancer Survivors are Older Adults

59% of cancer survivors were ≥65 years old in 2012

Total Cancer Survivors: 13.7 million

Cancer Survivors ≥65 years old: 8+ million

18 Million Cancer Survivors Projected in 2022

INSTITUTE OF MEDICINE
OF THE NATIONAL ACADEMIES

Advising the nation • Improving health
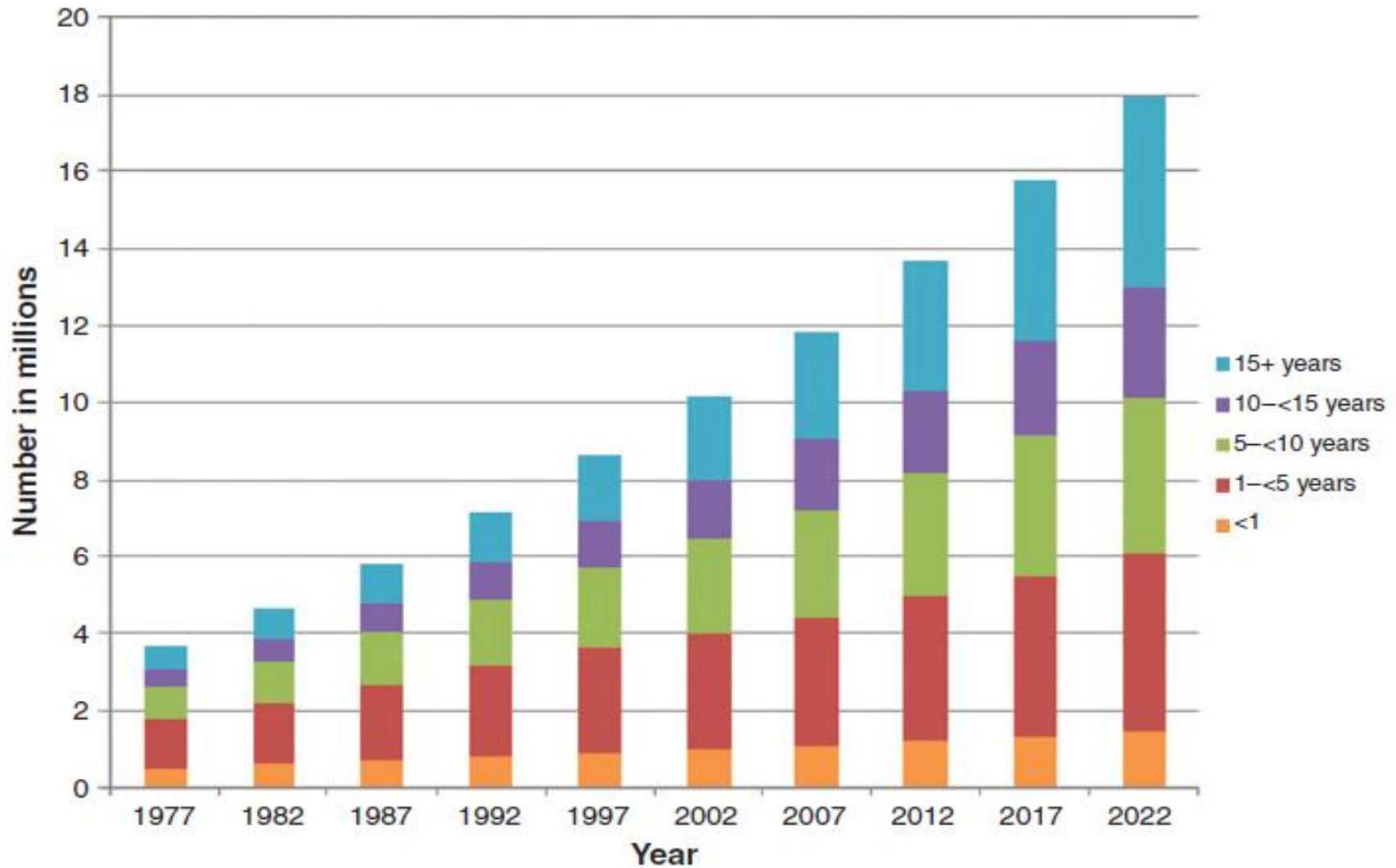
Conceptual Framework

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

Evidence Base to Inform Clinical Care

Workforce

Patient-Clinician Interactions

Patients

Learning Health Care Information Technology System

Accessible, Affordable, High-Quality Care

Quality Measurement (Including patient outcomes and costs)

Performance Improvement and New Payment Models
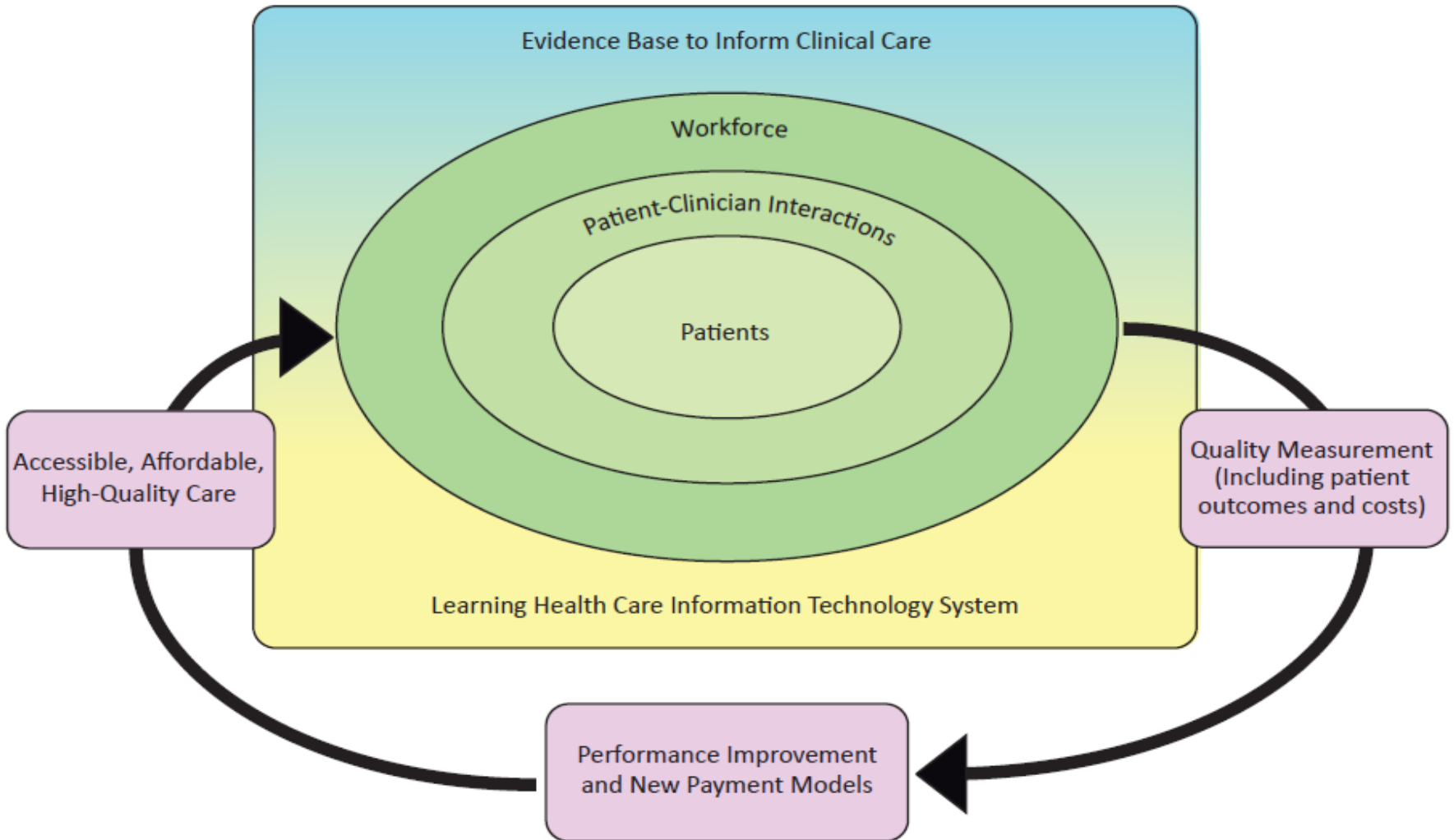
Cancer Care Continuum

Prevention and Risk Reduction	Screening	Diagnosis	Treatment	Survivorship	End-of-life Care
-Tobacco control -Diet -Physical activity -Sun and environmental exposures -Alcohol use -Chemoprevention -Immunization	-Age and gender specific screening -Genetic testing	-Biopsy -Pathology reporting -Histological assessment -Staging -Biomarker assessment -Molecular profiling	-Systemic therapy -Surgery -Radiation	-Surveillance for recurrences -Screening for related cancers -Hereditary cancer predisposition/ genetics	-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

INSTITUTE OF MEDICINE
OF THE NATIONAL ACADEMIES   Advising the nation • Improving health

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…"
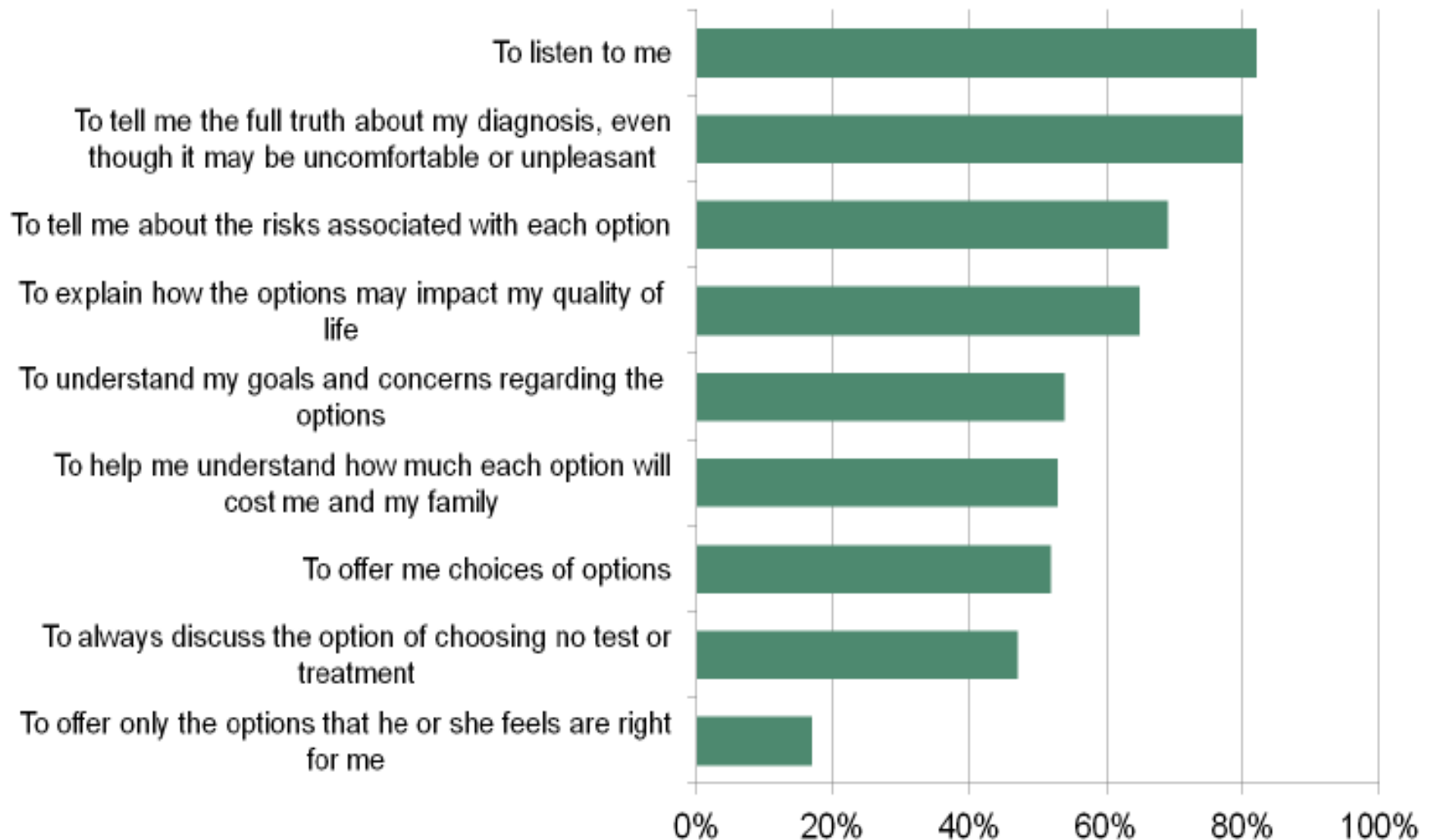
Recommendation 1

- 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

Curative or Life-prolonging treatment

Palliative Care

Diagnosis
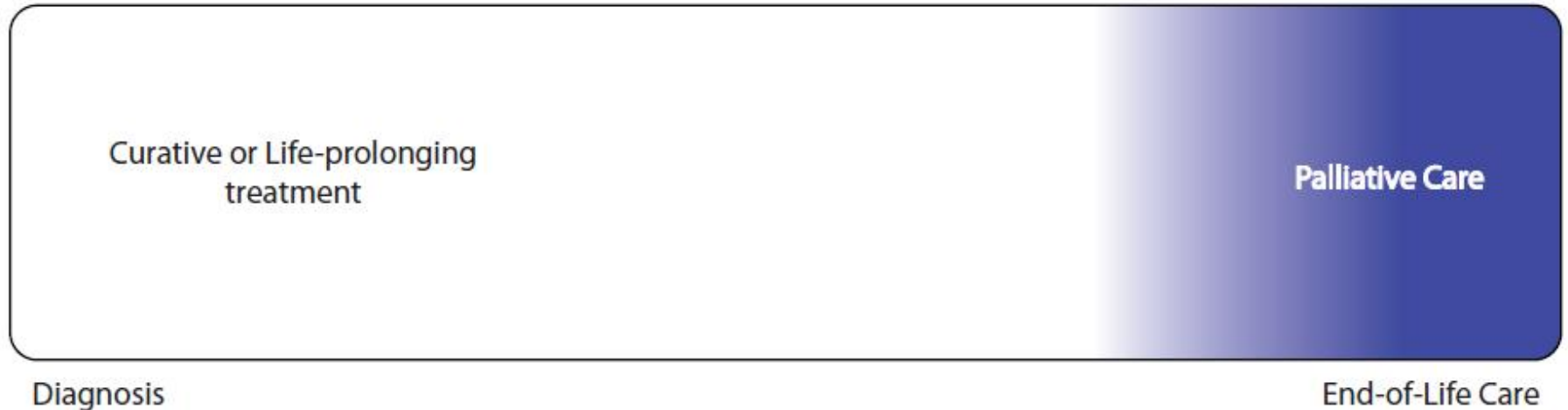
End-of-Life Care

Incorporation of Palliative Care
Throughout the Cancer Care Continuum

Curative or Life-prolonging treatment

Palliative Care

Diagnosis
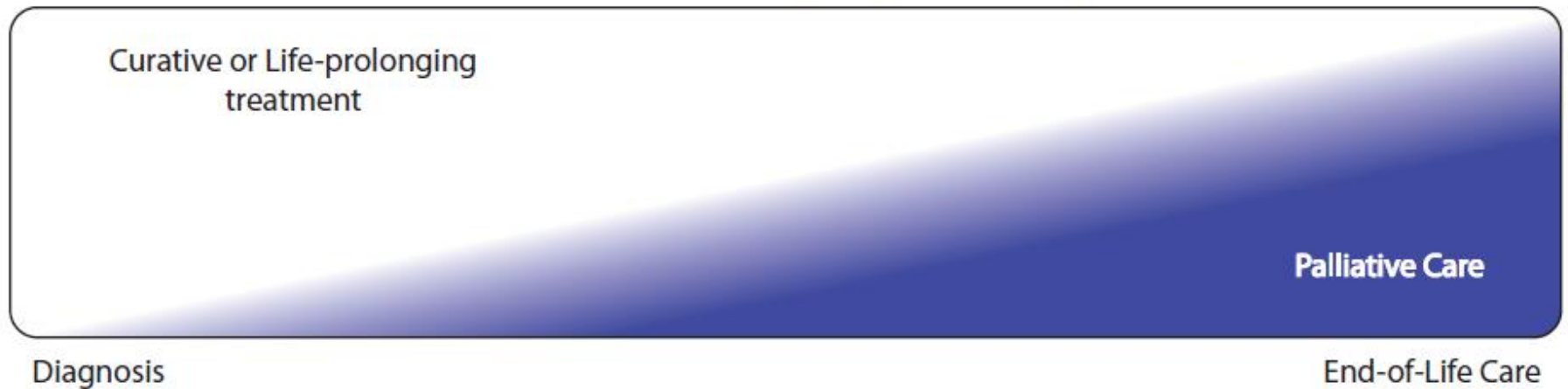
End-of-Life Care

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.**
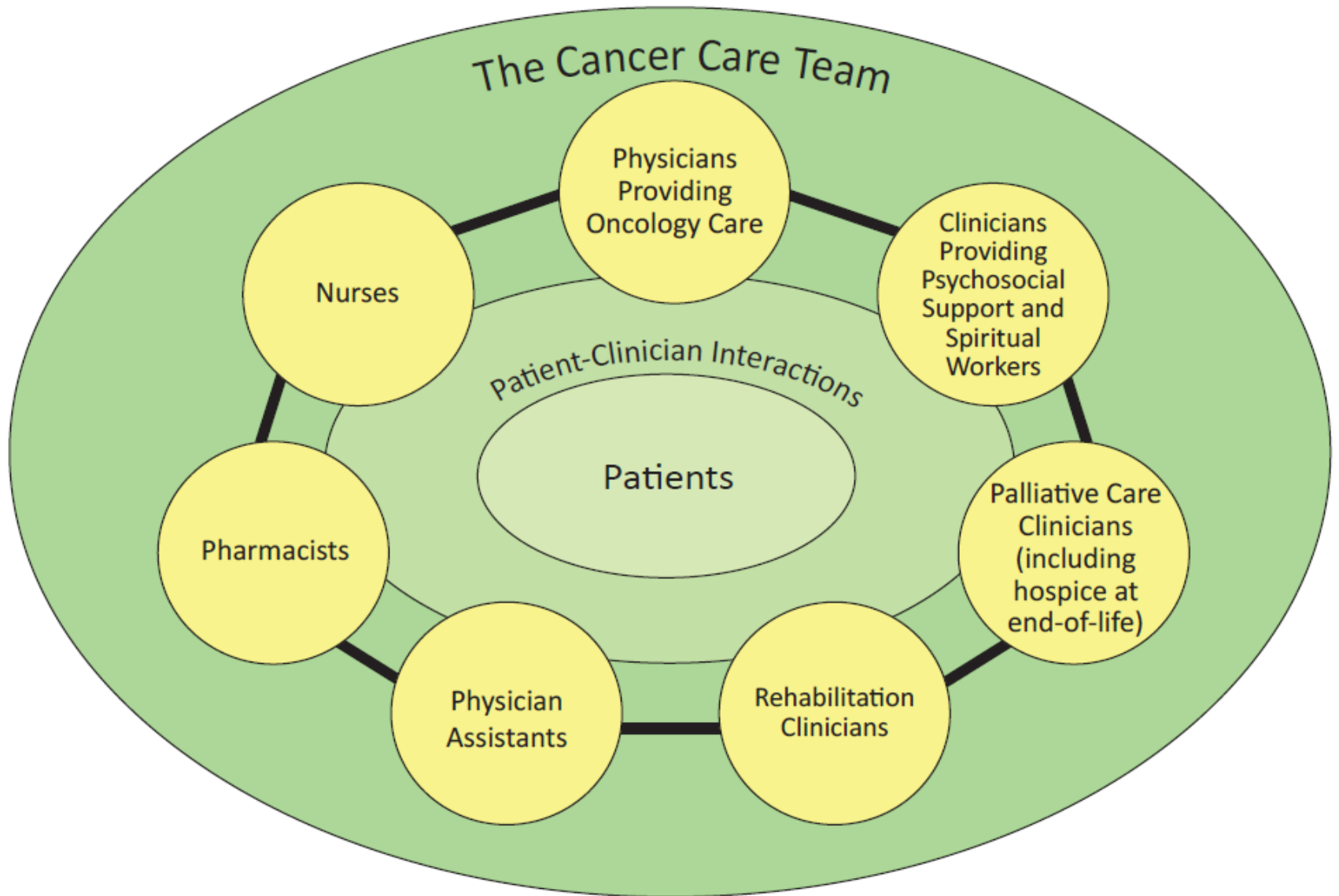
Recommendation 2

- 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**.

INSTITUTE OF MEDICINE
OF THE NATIONAL ACADEMIES

Advising the nation • Improving health

An Adequately Staffed, Trained, and Coordinated Workforce

GOAL 3
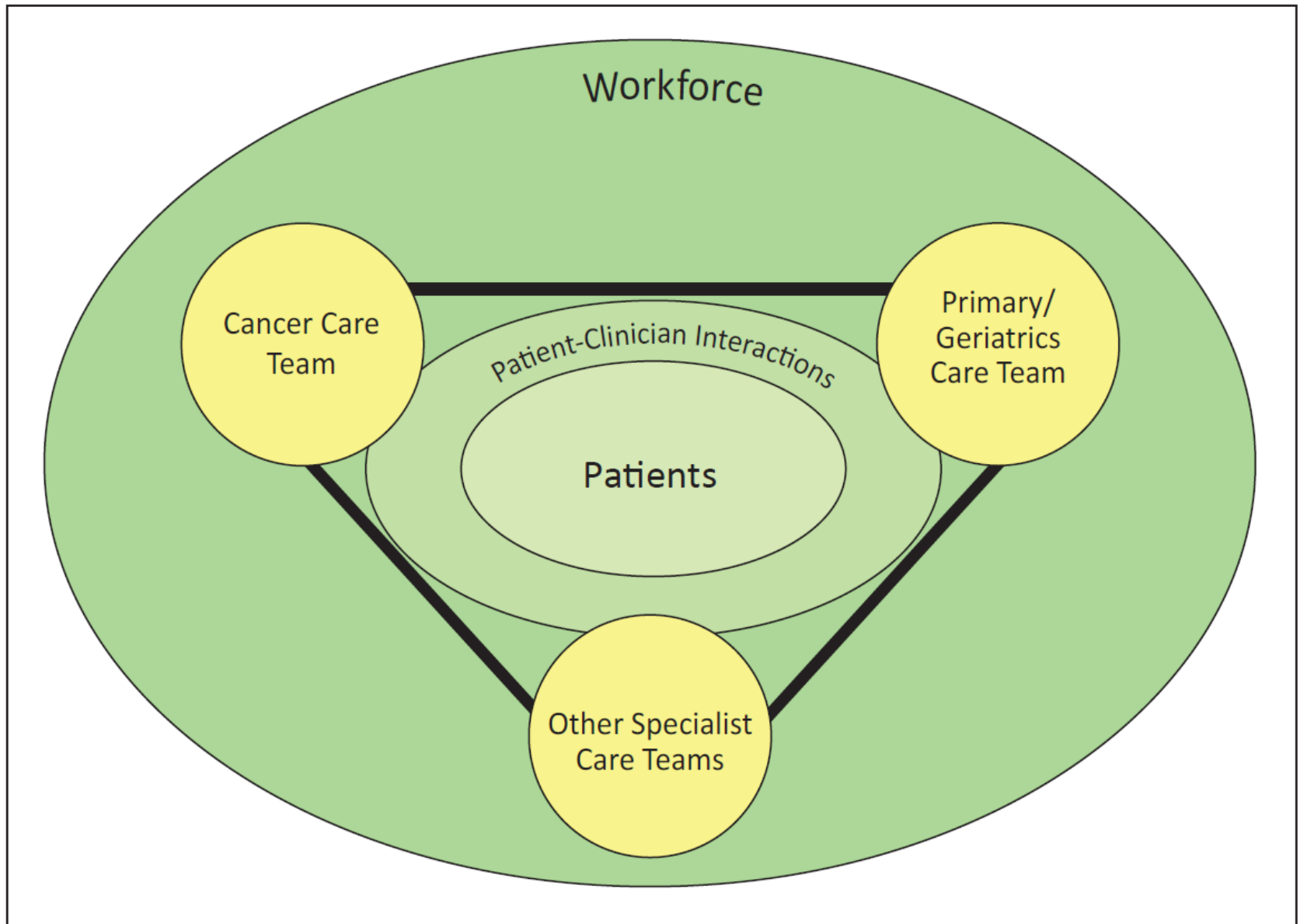
Members of the cancer care team **should coordinate with each other** and **with primary/geriatrics** and **specialist care teams** to implement patients' care plans and deliver comprehensive, efficient, and patient-centered care.

INSTITUTE OF MEDICINE
OF THE NATIONAL ACADEMIES

Advising the nation • Improving health

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.**

INSTITUTE OF MEDICINE
OF THE NATIONAL ACADEMIES

Advising the nation • Improving health

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.**

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.

INSTITUTE OF MEDICINE
OF THE NATIONAL ACADEMIES   Advising the nation • Improving health

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.**

INSTITUTE OF MEDICINE
OF THE NATIONAL ACADEMIES

Advising the nation • Improving health

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**.

To read the report online, please visit www.iom.edu/qualitycancercare

To watch the dissemination video, please visit www.iom.edu/qualitycancercarevideo

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

DELIVERING HIGH-QUALITY CANCER CARE

Charting a New Course for a System in Crisis

INSTITUTE OF MEDICINE
OF THE NATIONAL ACADEMIES

INSTITUTE OF MEDICINE Advising the nation • Improving health
OF THE NATIONAL ACADEMIES