

Institute of Medicine's Recommendations for Addressing the Cancer Care Crisis in the United States

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INSTITUTE OF MEDICINE
OF THE NATIONAL ACADEMIES

Advising the nation • Improving health

Quality vs. Sustainability

- **Quality of Care** focuses on Individual patients
- **Sustainability of Care** focuses on future generations of patients

BUT, the characteristics of a high-quality and sustainable health care system are similar.

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

Study Sponsors

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

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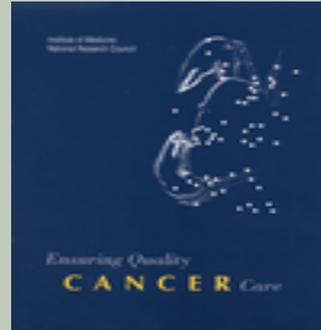
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Ensuring Quality Cancer Care

- Earlier IOM report issued April 1, 1999



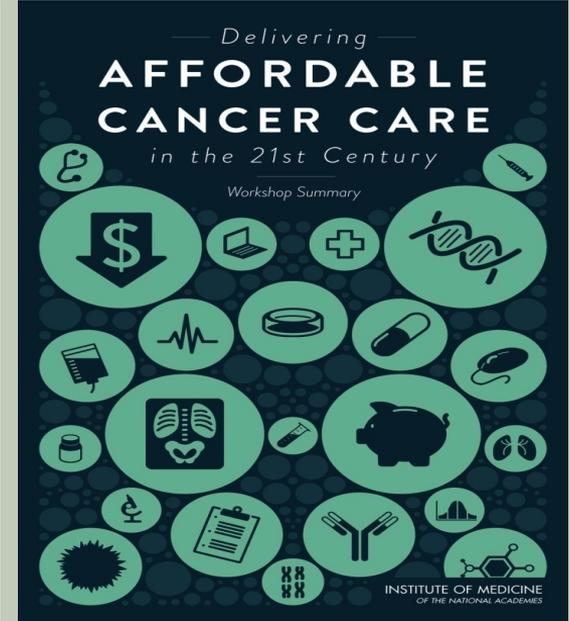
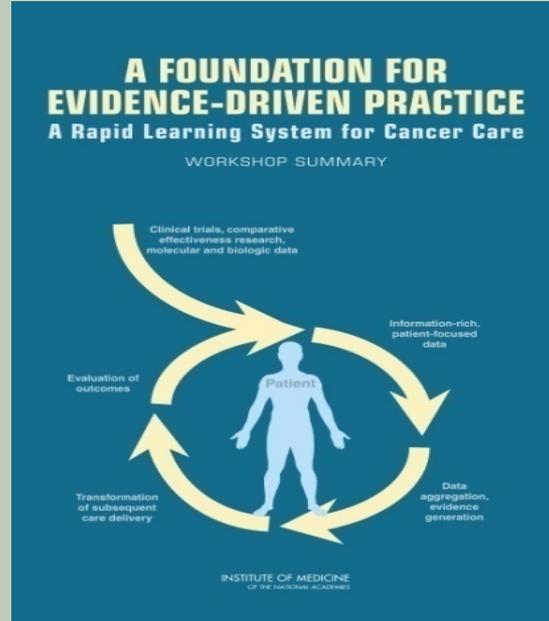
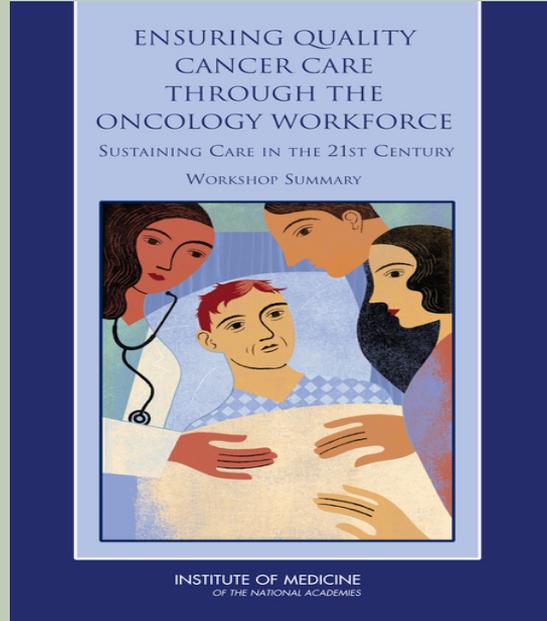
- “For many Americans with cancer there is a wide gulf between what could be construed as the ideal and the reality of their experience with cancer care”

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

Over past 14 yrs much progress but still many gaps

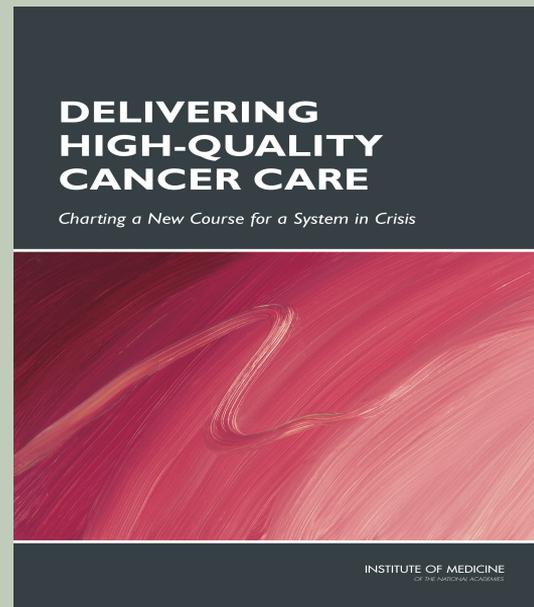
Examples of NCPF Workshop Reports



www.nap.edu

New IOM Report Released in September 2013

- Report concludes 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.”
- Recommendations for delivering high-quality cancer care.

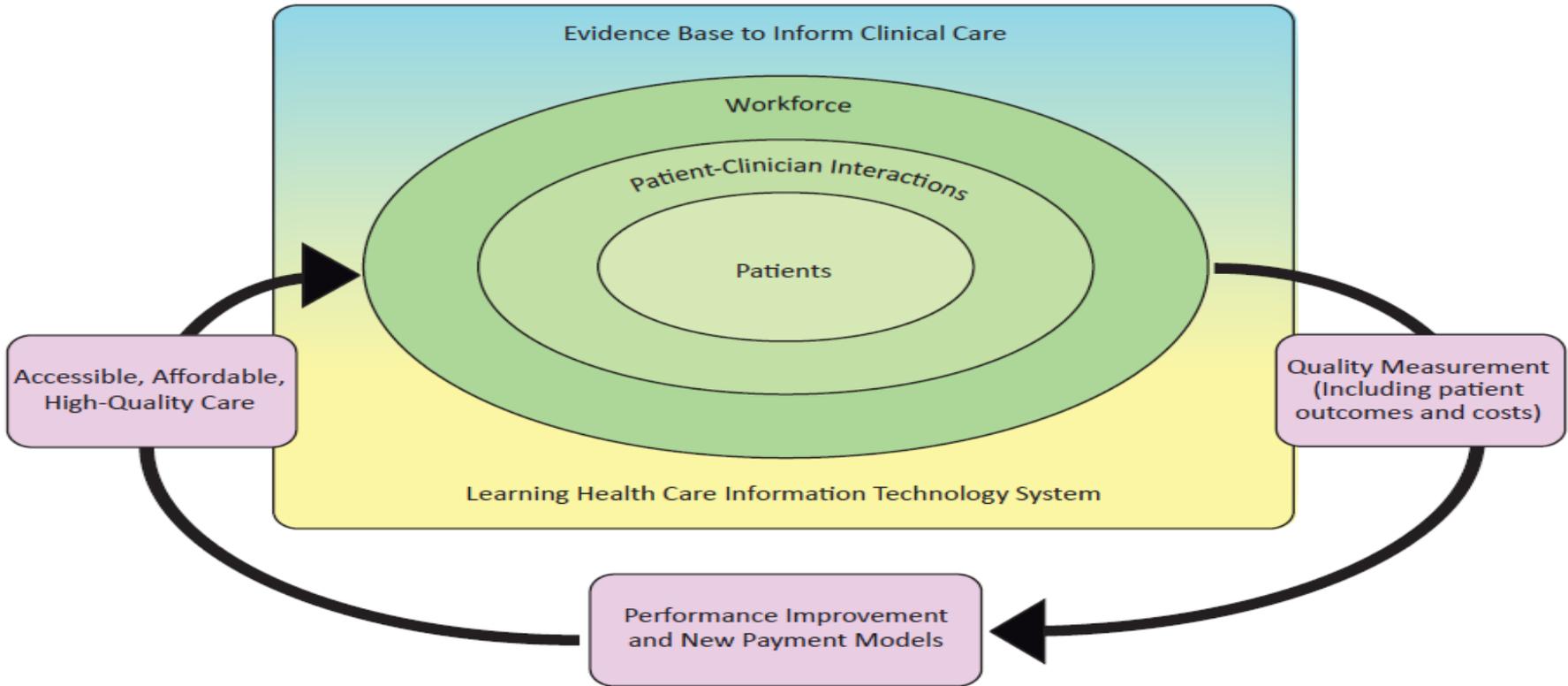


Trends Amplifying the Crisis

- 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

Conceptual Framework

A High-Quality Cancer Care Delivery System



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**

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

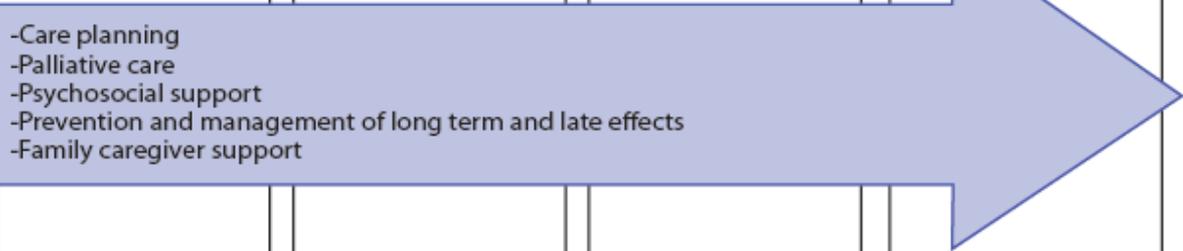
- Systemic therapy
- Surgery
- Radiation

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

The Recommendations

- The recommendations are structured around the six components of the conceptual framework
- Each recommendation includes:
 - An overarching goal
 - Specific suggestions on how to accomplish the goal

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 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

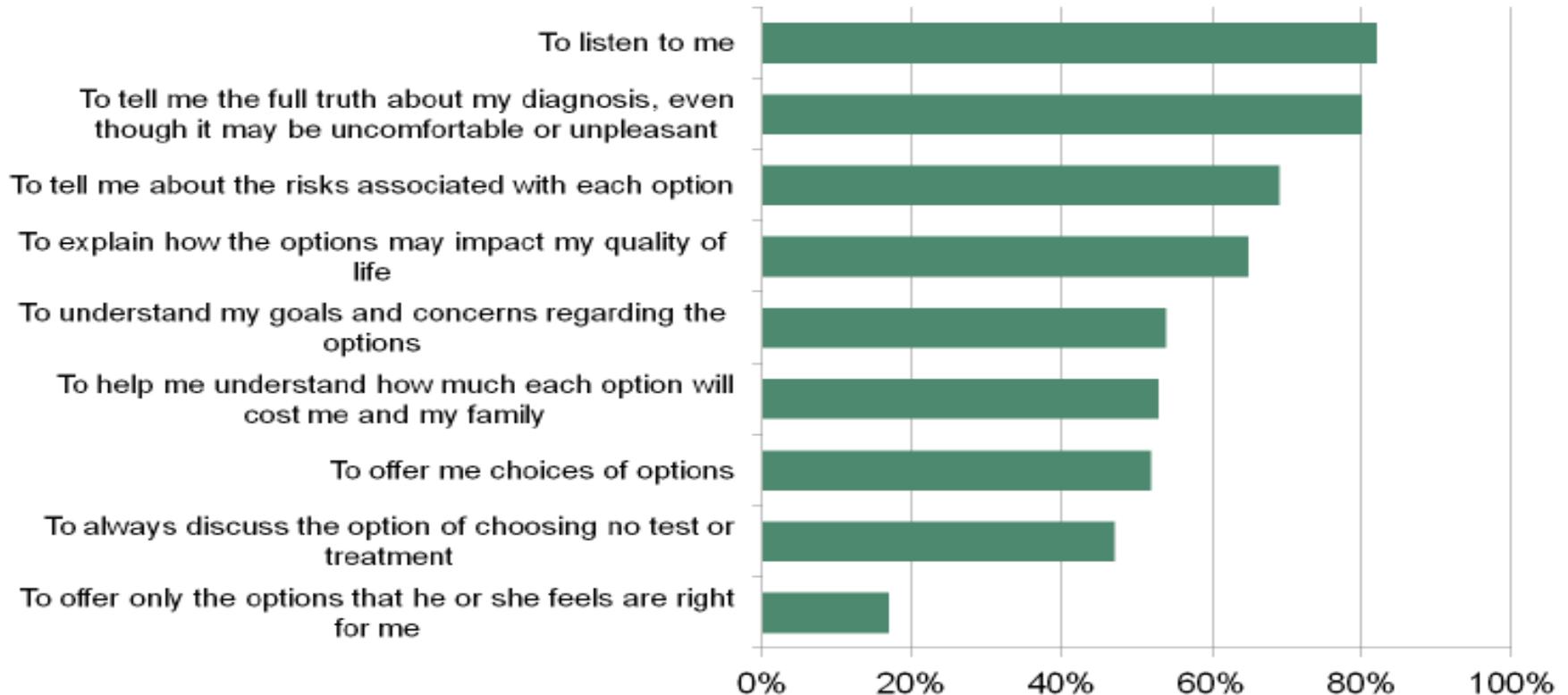
GOAL 1

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**.

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

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.**

Incorporation of palliative care across the care

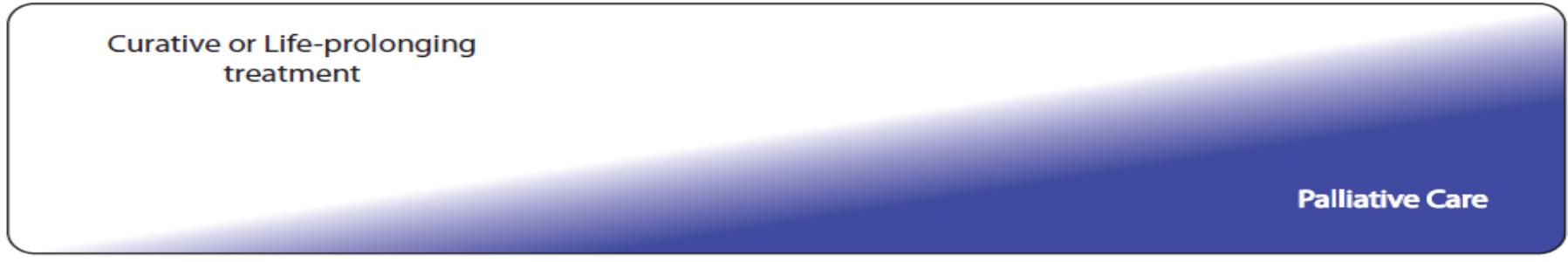
Provision of Palliative Care Exclusively at End-of-Life



Diagnosis

End-of-Life Care

Incorporation of Palliative Care Throughout the Cancer Care Continuum



Diagnosis

End-of-Life Care

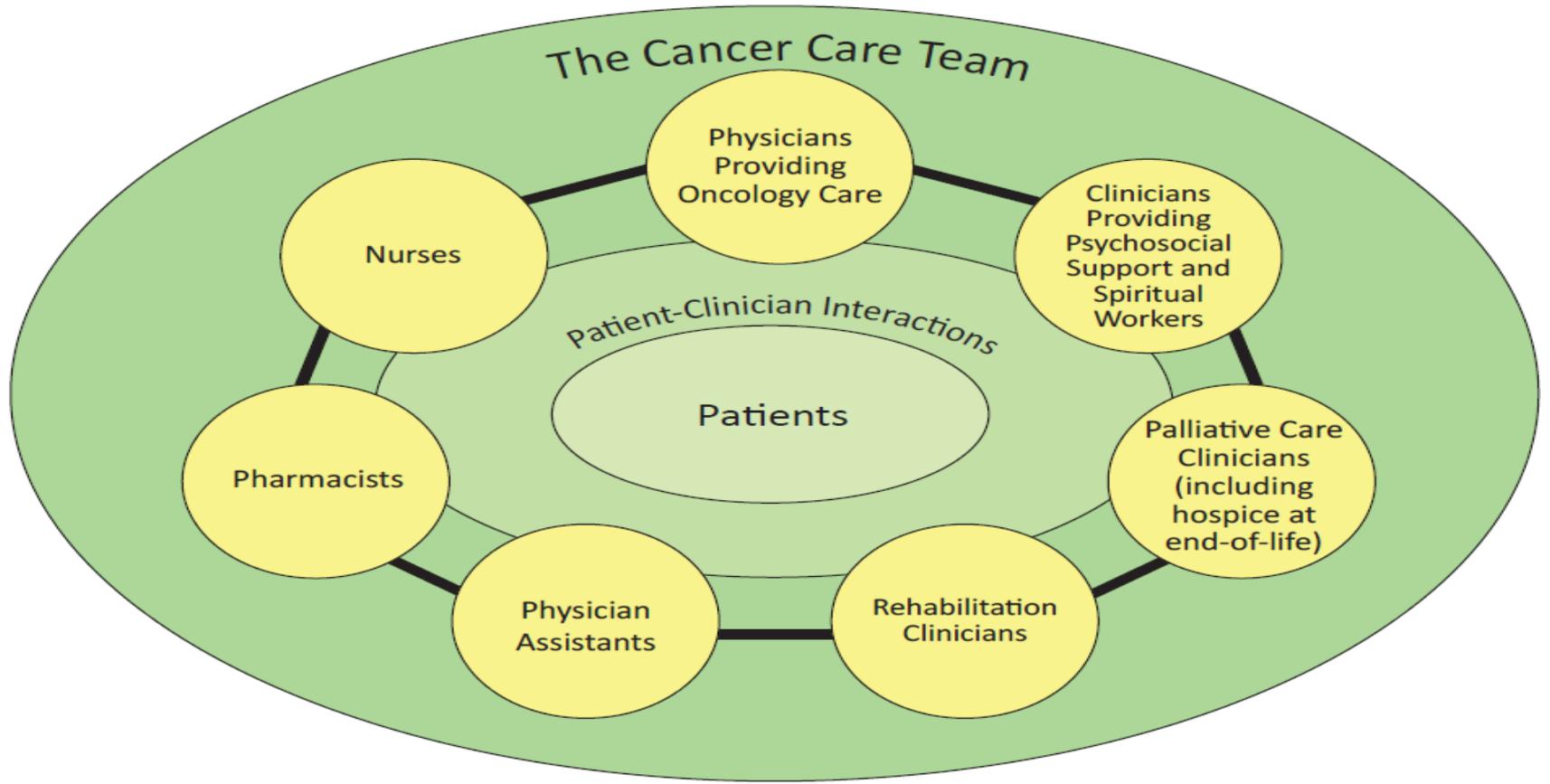


An Adequately Staffed, Trained, and Coordinated Workforce

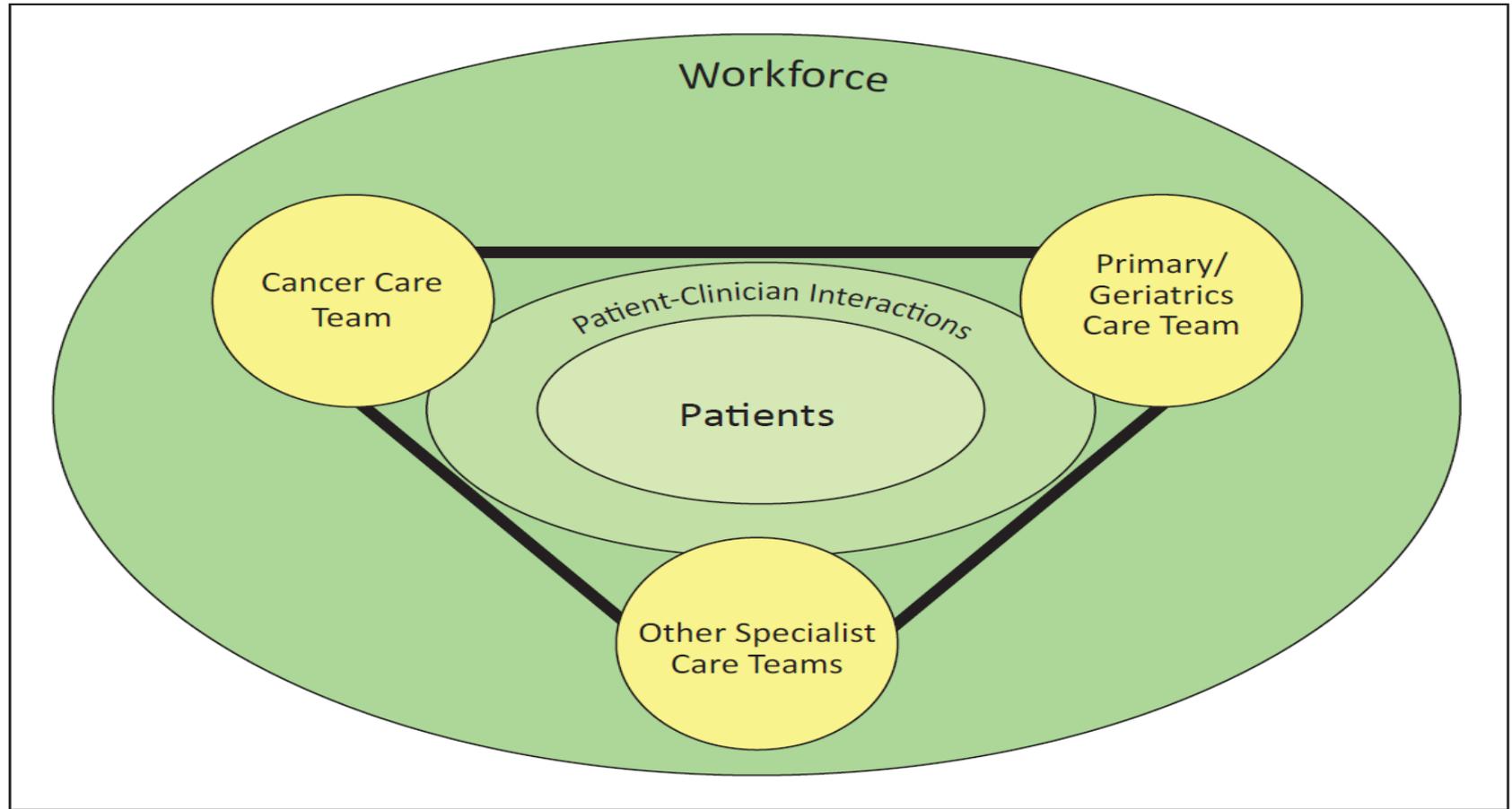
GOAL 3

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 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**.

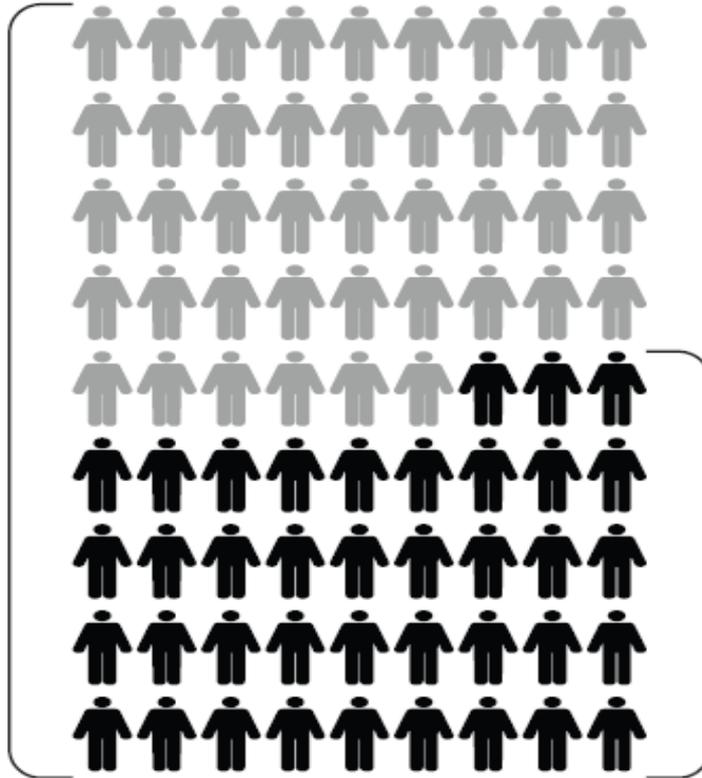
Evidence-Based Cancer Care

GOAL 5

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

The Majority of Cancer Diagnoses are in Older Adults

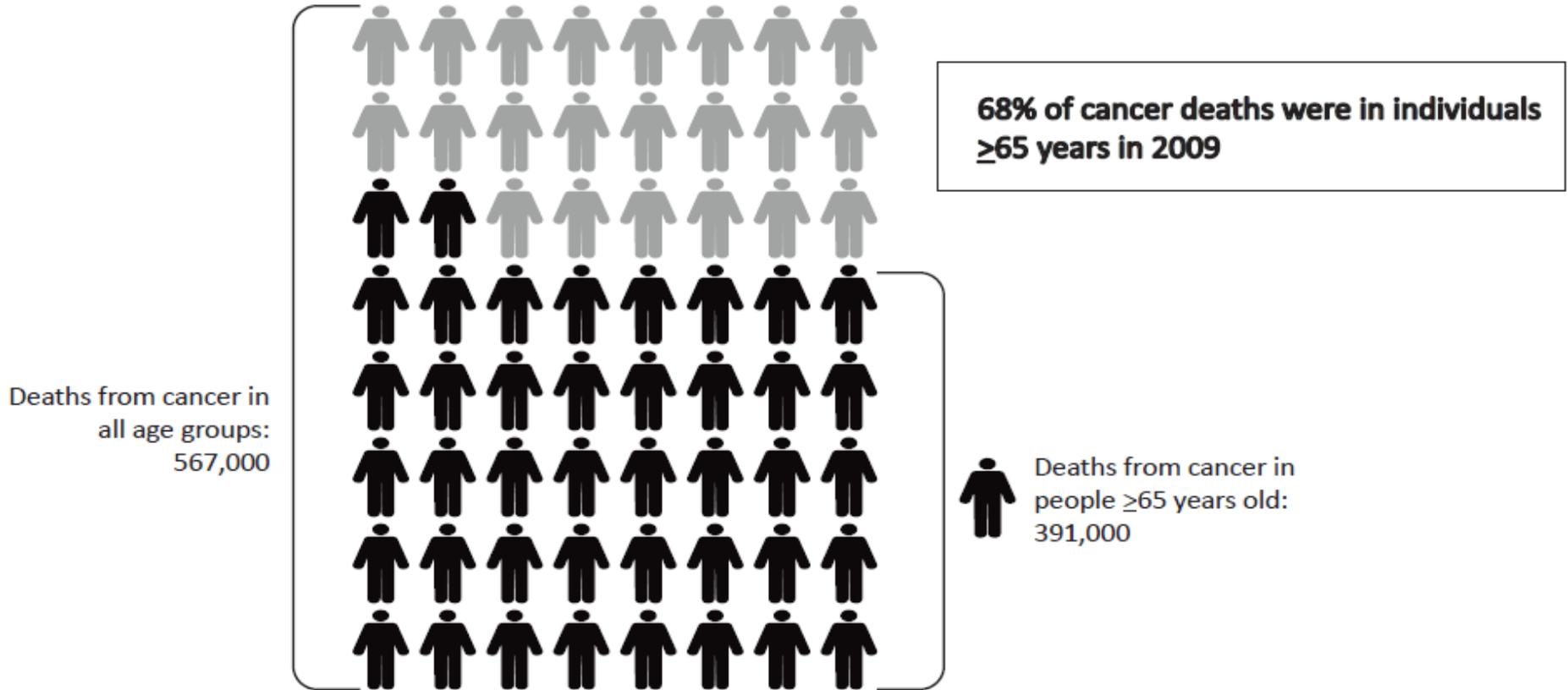
Total people
diagnosed
with cancer:
1.6 million



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

Cancer diagnoses
 ≥ 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 ≥ 65 years old in 2012

 Cancer Survivors ≥ 65 years old:
8+ million

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 **provide market exclusivity 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

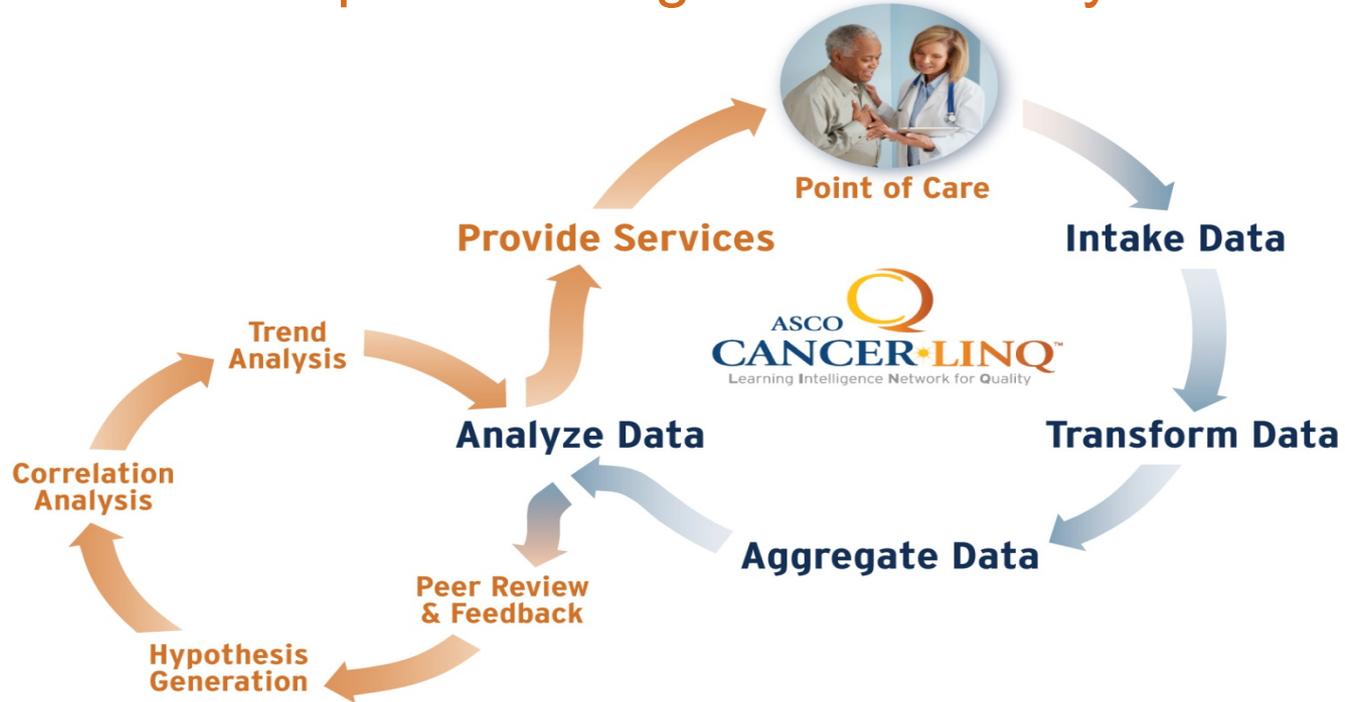
Develop an ethically sound **learning health care IT system for cancer** that enables real-time analysis of data from cancer patients in a variety of care settings.

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.

CancerLinQ

What is ASCO's Rapid Learning Healthcare System?



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**.

ASCO 2012



An initiative of the ABIM Foundation

About

Lists

Partners

Grantees

Resources

- Don't use antineoplastics in patient with low performance status, no prior benefit, off trial when there's no evidence that treatment helps
- Don't do PET, CT and Bone Scan in low risk prostate cancer patients
- Don't do PET, CT and Bone Scan in low risk breast cancer patients
- Don't do surveillance testing in asymptomatic patients after curative therapy
- Don't use WBC stimulating factors if there's less than a 20% risk

ASCO 2013



An initiative of the ABIM Foundation

About

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Resources

- Don't use antiemetics intended for highly emetogenic chemotherapy with low risk of nausea and vomiting
- Don't use multiagent chemotherapy in patients with metastatic breast cancer when single agent therapy is available
- Don't use PET scans in asymptomatic patients undergoing surveillance unless you can provide curative therapy on recurrence
- Don't do routine PSA testing in men with less than a 10 year average survival
- Don't use targeted therapies unless the target is present

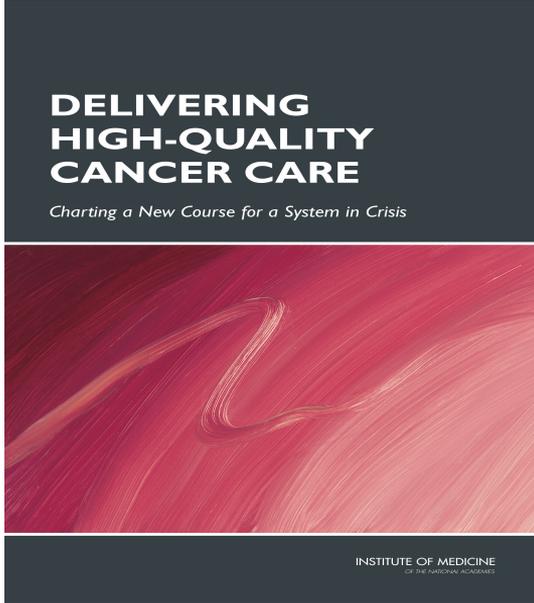
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The characteristics of a high-quality and sustainable health care system are similar.



To read the report online, please visit www.nap.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)



Thank you!

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