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

Laura Levit, JD
IOM Study Director
World Cancer Congress
December 4, 2014
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 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
Committee Members

PATRICIA A. GANZ, M.D. (Chair)  
University of California, Los Angeles

HARVEY JAY COHEN, M.D.  
Duke University

TIMOTHY J. EBERLEIN, M.D.  
Washington University

THOMAS W. FEELEY, M.D.  
MD Anderson Cancer Center

BETTY FERRELL, PH.D., FAAN  
City of Hope National Medical Center

JAMES A. HAYMAN, M.D., M.B.A.  
University of Michigan

KATIE B. HORTON, J.D., M.P.H.  
George Washington University

ARTI HURRIA, M.D.  
City of Hope National Medical Center

MARY S. MCCABE, RN, MA  
Memorial Sloan-Kettering Cancer Center

MARY D. NAYLOR, PH.D., R.N., FAAN  
University of Pennsylvania

LARISSA NEKHLYUDOV, M.D., M.P.H.  
Harvard Medical School

MICHAEL N. NEUSS, M.D.  
Vanderbilt-Ingram Cancer Center

NOMA L. ROBERSON, PH.D.  
Roswell Park Cancer Institute (Retired)

YA-CHEN TINA SHIH, PH.D.  
The University of Chicago

GEORGE W. SLEDGE, JR., M.D.  
Stanford University

THOMAS J. SMITH, M.D.  
Johns Hopkins University

NEIL WENGER, M.D., M.P.H.  
University of California, Los Angeles

IOM Staff

LAURA LEVIT  
Study Director

ERIN BALOGH  
PAMELA LIGHTER  
MICHAEL PARK  
PATRICK BURKE  
SHARYL NASS  
ROGER HERDMAN
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
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
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...”

- To listen to me
- To tell me the full truth about my diagnosis, even though it may be uncomfortable or unpleasant
- To tell me about the risks associated with each option
- To explain how the options may impact my quality of life
- To understand my goals and concerns regarding the options
- To help me understand how much each option will cost me and my family
- To offer me choices of options
- To always discuss the option of choosing no test or treatment
- To offer only the options that he or she feels are right for me
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 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
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

Workforce

Patient-Clinician Interactions

Patients

Cancer Care Team

Primary/Geriatrics Care Team

Other Specialist Care Teams
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

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

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.
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.
• Don’t use antineoplastics in patients 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
• 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
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.
Quality vs. Sustainability

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

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!

Laura Levit
Laura.levit@asco.org