Ensuring Quality Cancer Care: 13 Years Later
Key Models That Influenced the “Ensuring…” Report

- Pediatric Oncology
- Patient advocacy (Ellen Stovall, Fran Visco)
- Guidelines, Pathways
- NCCN
Pediatric Oncology

- 50–90% on clinical trials, so...
- Guidelines for all: path, surg, chemo, follow-up standardized
- Outcomes measured
- Self-examination ➔ steps for improvement
- Results reported and compared
Pediatric Oncology

- Cure rate of childhood acute leukemia: 1962 = 0; 1975 = 40%; 2004 ≅ 80%
- No new frontline chemo agents since 1973!
- Systematic trial and error can work if well-planned and transparent
- Bonus: standards applied to all patients, on protocol or not
Guidelines and Pathways

- 1992 Clinton Health Plan threatened academic centers
- MSK instituted a “disease management” system in 1994
- NCCN formed guidelines
Institute of Medicine

- National Cancer Policy Board formed in late 1997
- Spent several meetings discussing (and arguing) over what our first project would be
- “Quality of cancer care” prevailed; opponents concerned about lack of data to support recommendations
- “Board” vs “Forum”
NCPB 1998–2005
(22 peer-reviewed reports)

“Ensuring Quality Cancer Care”
by the Institute of Medicine
(1999)

“Enhancing Data Systems to
Improve the Quality of Cancer Care”
(2000)

“Interpreting the Volume-Outcome Relationship in Cancer Care”
(2001)
Ensuring Quality Cancer Care–1999

NATIONAL CANCER POLICY BOARD – INSTITUTE OF MEDICINE

www.nas.edu/cancer
First Statement an *Expert Opinion* on Quality of Healthcare

“For many Americans with cancer, there is a wide gulf between the ideal and the reality, between what is known and the health care they receive.”

“Ensuring Quality Cancer Care,” IOM 1999
Apparent Impact of Recommendations
(according to JVS, no systematic data to support, some may be post hoc error)

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<thead>
<tr>
<th>Impact</th>
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<tr>
<td>Substantial</td>
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<td>Moderate</td>
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Improving Care

RECOMMENDATION 1

Ensure that patients needing technically procedures with higher mortality in low-volume settings receive care at facilities with extensive experience (high volume settings), e.g. esophagectomy, pancreatectomy.

Impact 1+, any change mostly due to economics
Improving Care

RECOMMENDATION 2

Use systematically developed guidelines based on the best available evidence for prevention, diagnosis, treatment, and palliative care.
Measure and monitor the quality of care using a core set of quality measures.

Impact 3+, ultimately responsible for QOPI, but
Ensure key elements of quality for all cancer patients: 1) initial treatment plan made by experienced pros; 2) agreed upon plan for goals of therapy; 3) access to all resources needed for plan; 4) access to clinical trials; 5) mechanism to coordinate services; 6) psychosocial support and compassionate care

Impact: 0-1+ nationally, 2+ in some organizations
Improving Care

RECOMMENDATION 5

Ensure quality of care at the end of life, in particular, the management of cancer-related pain and timely referral to palliative and hospice care.

Impact 0 or 1+, stubborn problems
Improving Care

RECOMMENDATION 6

Government and private research sponsors and health plans should invest in clinical trials to address questions about cancer care management.

Impact 0, NIH doesn’t consider this “research”
Improving Care

A cancer data system is needed that can provide quality benchmarks for use by hospitals, provider groups and managed care systems.

Impact 0 or 1+, most EMRs are digital file cabinets of non-digital data making analysis overly cumbersome or impossible; and CaBig was
Improving Care

RECOMMENDATION 8

Public and private sponsors of cancer care research should support national studies of recently diagnosed cancer patients to assess patterns of care and assess factors associated with receipt of good care.

Impact 0 or 1+, depends on point of view—e.g.
Services for the un- and underinsured need to be enhanced to assure entry to, and equitable treatment within, the cancer care system.

Impact 0, even if the ObamaCare mandate survives the Supreme Court, it won’t be because of the 1999 IOM report
Studies are needed to find out why specific segments of the population (e.g. certain racial or ethnic groups, older patients) do not receive appropriate cancer care. These studies should measure provider and individual knowledge, attitudes and beliefs and other potential barriers.

Impact 1+, studies certainly more numerous, but few are definitive
Some Key Influences of Report

- ASCO’s NICCQ study
- ASCO’s Quality Oncology Practice Initiative started in 2003
- Substantial growth of health services research in cancer
Lessons Learned

- Knowing of the rigorous review of formal recommendations brought more discipline to process
- Take time to shape and narrow goals of report
- Need a strong chair to keep the group on point
- Outstanding staff, esp. Bob Cook-Deegan and Maria Hewitt, made the NCPB look better than we were
Lessons Learned

- More impact when nascent efforts are already underway by providing a validating boost
- Addressing issues where there is no centralized pressure point(s) is not likely to have a major impact (e.g. hospice, pain)
Lessons Learned

- Focus on patients rather than providers—health care systems are too conservative and late to the party, e.g. IT
- Be bold: for its time, “Ensuring…” seemed bold; now it’s, “of course”