CALIFORNIA HEALTHCARE FOUNDATION

Enabling the California Cancer Registry to Measure and Improve Care

Robert A. Hiatt, MD, PhD
Chair, Department of
Epidemiology & Biostatistics
University of California
San Francisco

November 14, 2014

Today's Agenda

1. What are the problems, and who cares?
2. What is the California Cancer Registry (CCR) and what does it do?
3. What *could* the CCR do based on the assessment of our workgroup?
4. Our recommendations.
5. Next steps – The time to act is now!

What Are the Problems?

Who Cares?

Background: Cancer's Burden on California and the Nation

- Cancer is the second leading cause of death in the United States and by 2030 will be the first.
- In California this year, there will be an estimated 155,920 new cancer cases and 56,000 cancer deaths, and the numbers are increasing.
- With earlier detection and better treatment there are now many people living after cancer treatment: Over 14 million in the US and over 1 million in California.
- The costs of cancer care are skyrocketing. National expenditures for cancer care are projected to increase to $173 billion by 2020, up from $72 billion in 2004.

Problem #1:
The quality of cancer care is variable.

- Up to 1 in 3 patients treated with chemotherapy do not receive a treatment regimen that is consistent with current medical evidence and best practices.[1]
- Patients are often hospitalized during treatment due to side-effects avoidable with less toxic treatments and appropriate supportive care.[2]
- Patients frequently get tests and treatment they do not need, putting them at risk of side-effects, and imposing additional care burden and cost.[3]

[1] J Clin Oncol 2011, 30:142-50; J Clin Oncol 2012, 30:3800-09; J Clin Oncol 2006, 24:626-34; Oncologist 2011;16:378-87;
[2] J Clin Oncol 2002 20:4636-42. JACR 2012, 9:33-41; JAMA 2013, 309:2587-95; J Clin Oncol 2013; 31:epub.
[3] Barr et al. J Oncol Pract. 2011;7: 2s-15s.

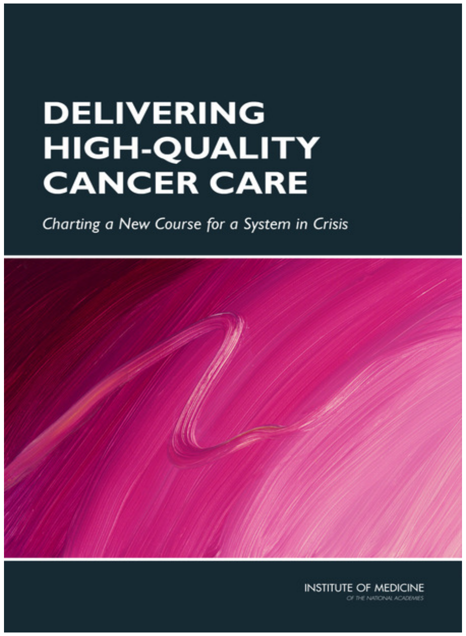
Problem #2:

There is no publicly available, meaningful information on cancer care quality by identified provider in California.

Who Cares?

- ***Patients*** navigate uncertain waters in choosing a cancer care provider because they have no information on the quality of cancer care.
- ***Providers*** do not have the information they need for quality improvement.
- ***Payers*** do not have useful data about care quality to help them incent care improvement and make informed networking/contracting decisions.
- ***Policymakers*** lack provider-specific information about variation in cancer care quality across the state that could inform policymaking.

Institute of Medicine:
A New Course for a System in Crisis


DELIVERING HIGH-QUALITY CANCER CARE

Charting a New Course for a System in Crisis

INSTITUTE OF MEDICINE

Institute of Medicine
2013

Care often is not patient-centered, many patients do not receive palliative care to manage their symptoms and side effects from treatment, and decisions about care often are not based on the latest scientific evidence.

IOM recommendations to improve the quality of cancer care include:

The need for a quality reporting program with meaningful quality measures across the nation.

California can lead the way!

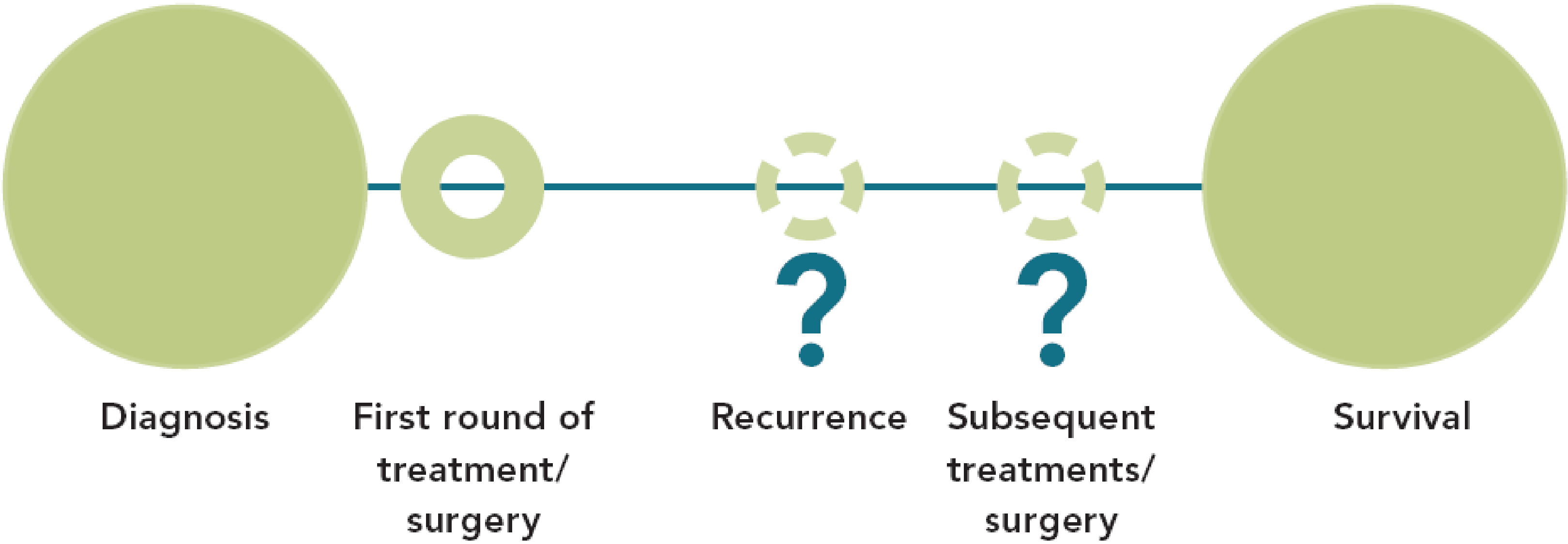
What Is the California Cancer Registry?

What Does It Do?

The California Cancer Registry

- Is a public health surveillance tool.
- Monitors new cancers to reveal trends, good and bad, for the whole population.
- Documents disparities by geographic region, age, gender, and racial and ethnic background.
- Provides the ultimate basis for judging the population health impact of therapeutic or preventive interventions.
- Serves as an essential tool for research.

Cancer Registries:
Data Strengths and Weaknesses



What *Could* the California Cancer Registry Do?

Goals of a Multi-disciplinary Workgroup of Experts Convened by CHCF

- To examine the barriers and opportunities for leveraging the California Cancer Registry for measuring and improving the quality of cancer care.
- To create a vision for a future system that specifically includes the public reporting of cancer quality metrics linked to providers.

Workgroup Members

Medical Oncologist	**Douglas Blayney, MD**	Stanford University
Registry Director	**Dennis Deapen, DrPH**	University of Southern California
Epidemiologist	**Robert Hiatt, MD, PhD**	UC San Francisco
Medical Informaticist	**Michael Hogarth, MD, FACP**	UC Davis
Health Quality Expert	**Kenneth Kizer, MD, MPH**	UC Davis
Health Economist	**Joseph Lipscomb, PhD**	Emory University
Cancer Outcomes Researcher	**Jennifer Malin, MD, PhD**	Anthem Blue Cross
Legal Counsel	**Stephen Phillips, JD**	Hooper, Lundy & Bookman
Patient Advocate	**John Santa, MD, MPH**	Consumer Reports Health
Medical Oncologist	**Deborah Schrag, MD, MPH**	Harvard University

Issues Considered by the Workgroup

- ***Technical:*** Timeliness, physician workflow, quality of care measures, costs.
- ***Stakeholder concerns:*** Provider concerns about reporting performance, patient privacy.
- ***Legal and regulatory***: Current statute prohibits public release of provider ID.

Vision for California

- Improved timeliness of data release through automation of data processing.
- Additional data linkages to California Cancer Registry.
- Bi-directional flow of useful information between registry and providers.
- Metrics to quantify quality of care among providers in order to understand aspects of care delivery and outcomes in a standardized way.

Recommendation #1

- The legislative mandate for the California Cancer Registry (California Health and Safety Code, Section 103885 et seq.) should be expanded to include use of registry data for quality of cancer care measurement and public reporting.

Recommendation #2

- The CCR, other relevant state agencies, and health care payers in the state should work toward developing a system for routinely linking CCR data with health insurance claims data.

Recommendation #3

- A strategy should be developed for linking clinical data contained in health system electronic health records (EHRs) and the CCR
  - Cancer care providers should be deeply involved in this effort from its inception.

Projected Impact

- Improved transparency of the quality of cancer care.
- Better information:
  - For patients, providers, payers, and policymakers to make decisions.
  - To address health disparities.
- Added value to the cancer registry program, where substantial investments have already been made.

It is time to act!

Thank you.

Appendix

The California Cancer Registry:
A Public Service & Research Tool

Welcome to California Cancer Registry (CCR)

CCR is a program of the California Department of Public Health's Chronic Disease Surveillance and Research Branch (CDSRB). The CCR is California's statewide population-based cancer surveillance system. We collect information about almost all cancers diagnosed in California. This information furthers our understanding of cancer and is used to develop strategies and policies for its prevention, treatment, and control. The availability of data on cancer in the state allows health researchers to analyze demographic and geographic factors that affect cancer risk, early detection, and effective treatment of cancer patients. The data also help determine where early detection, educational, and other cancer-related programs should be directed.

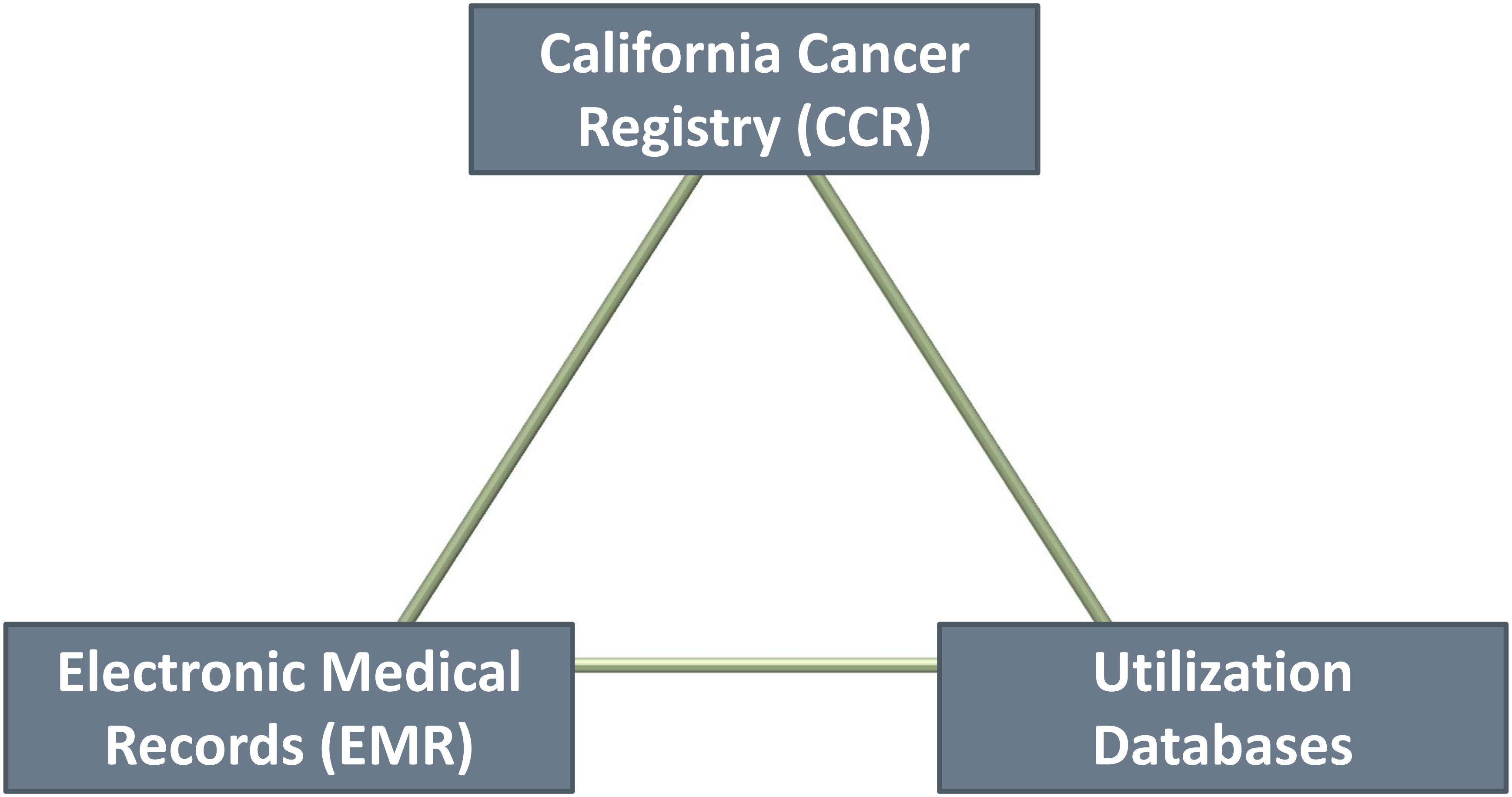
The CCR is recognized as one of the leading cancer registries in the world, and has been the cornerstone of a substantial amount of research on cancer in the California population. To date the CCR has collected detailed information on over 3.4 million cases of cancer among Californians diagnosed from 1988 forward, and more than 162,000 new cases are added annually.

California Cancer Registry website (www.ccrcal.org)

Cancer Registries Could…

- Be used for quality of cancer care assessment.
- Be merged with other existing data sources like claims data and electronic health records (EHRs) to examine medical care utilization, medication use, imaging and other aspects of care.
- Provide better and more transparent information for patients, providers, payers, policymakers, and other stakeholders to inform decisionmaking and improve the quality of cancer care.

Vision of New System



California Cancer Registry (CCR)

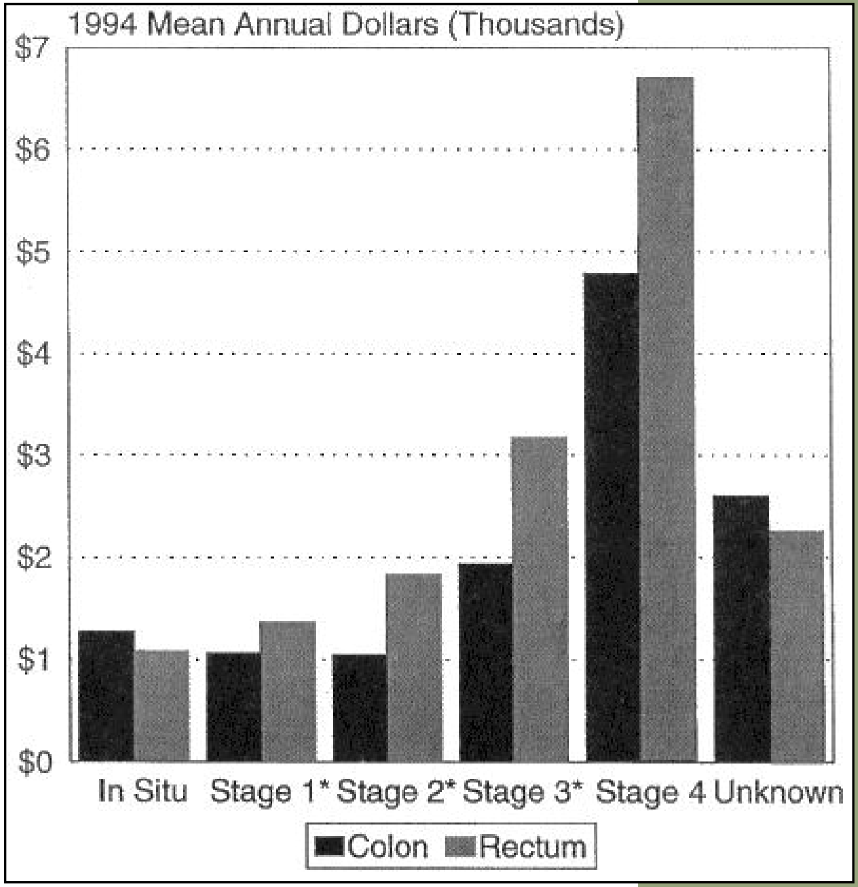
Electronic Medical Records (EMR)

Utilization Databases

Capacity for Linkage Already Exists

SEER-Medicare Database: What Have We Learned?

- Mammography is underutilized in older breast cancer survivors who are at high risk of recurrence.[1]
- The number of procedures performed by a surgeon is related to their patients experiencing urinary complications.[2]
- Can estimate medical costs associated with colorectal or rectal cancer by stage (graph at right).[3]



---

1. Schapira MM, McAuliffe TL, Nattinger AB. Underutilization of mammography in older breast cancer survivors. Med Care. 2000 Mar;38(3):281-9.
2. Begg CB, Riedel ER, Bach PB, Kattan MW, Schrag D, Warren JL, Scardino PT. Variations in morbidity after radical prostatectomy. N Engl J Med. 2002 Apr 11;346(15):1138-44.
3. Brown ML, Riley GF, Potosky AL, Etzioni RD. Obtaining long-term disease specific costs of care: application to Medicare enrollees diagnosed with colorectal cancer. Med Care. 1999 Dec;37(12):1249-59.

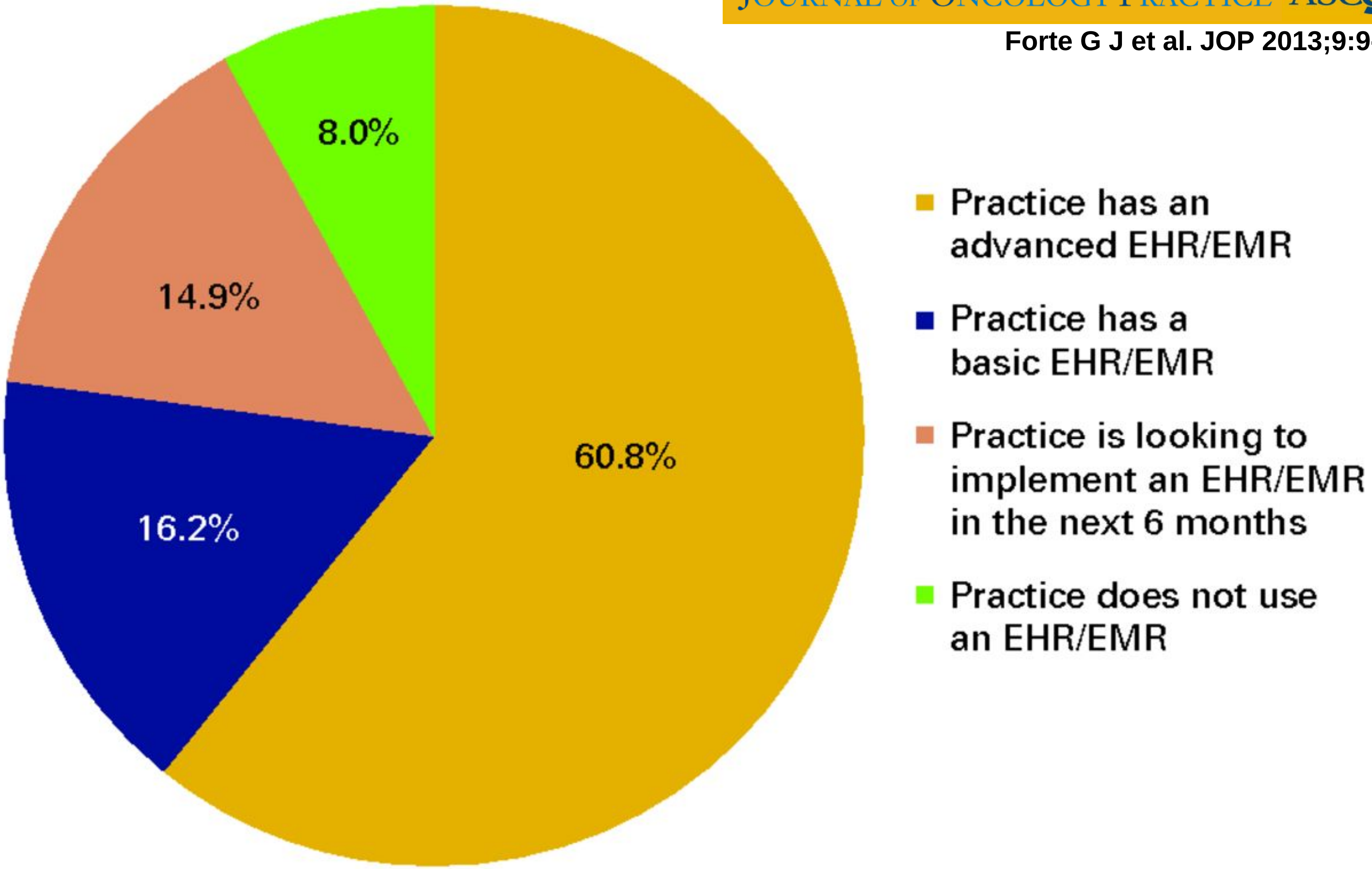
Limitations of Medicare Data

- Limited clinical information about treatment dosage and regimen
- Persons < 65 not included
- Radiation and chemotherapy treatment data incomplete

Uptake of EMRs

JOURNAL OF ONCOLOGY PRACTICE ASCO

Forte G J et al. JOP 2013;9:9-19



Practice electronic health record (EHR)/electronic medical record (EMR) use (n = 597 practices).

Issues for Consideration

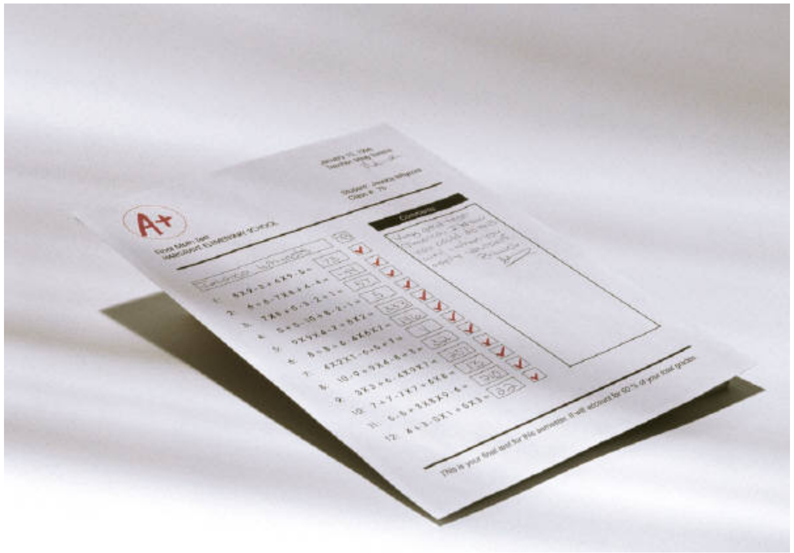
Technical

- Timeliness and rapidity of reporting
- Data capture and physician workflow
- Relevant domains of quality of care measures
- Costs

Issues for Consideration

Stakeholder Concerns

- Provider entities may be sensitive about making quality of care/performance data available to public.



- Patients are concerned about their privacy.

Issues for Consideration

Legal and Regulatory

- Current California Cancer Registry Statute prohibits public release of provider names.