Enabling the California Cancer Registry to Measure and Improve Care

A Recap and Look to the Future

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What are the 5 key “Take Away” messages that we heard today?
What Have We Heard Today?

1. A lot of people get cancer... and relatively more will in the future.

Cancer Will Be Leading Cause of Death in US by 2030, Report Says
2. Treatment of cancer is of variable quality .... and often not as good as it could be.

“Coordination of complex cancer care, using a common electronic health record, with treating specialists who jointly discuss the patient’s case and then confer with the patient about their recommendations, is the exception and not the rule.”

Institute of Medicine
September 10, 2013
3. Treatment of cancer is very expensive.
What Have We Heard Today?

4. Patients, providers, payers, policymakers, and others need better information about cancer care.

Many Cancer Patients Don't Understand Role Of Chemotherapy, Study Finds

*Los Angeles Times* | Jon Bardin | October 12, 2012

People who receive chemotherapy for cancer often misunderstand the role of the therapy in their treatment plan, according to a new study published in the journal Cancer.

For people with cancer, chemotherapy can play different roles. For some, chemo is a way of trying to eliminate cancerous cells from the body, effectively curing the patient. But for many, chemotherapy is just one of many methods to prolong life, with no reasonable expectation that it can or will lead to a cure.

October 22, 2013

**Few patients warned of overdiagnosis regarding cancer screening, report says**

By Andis Robeznieks | Modern Healthcare
The Need for Better Information

FDA approves cancer drugs without proof they're extending lives

By John Fauber, Milwaukee Journal Sentinel | October 26, 2014

For decades, researchers have focused on developing new cancer drugs that save lives or improve the quality of life. But when the U.S. Food and Drug Administration allowed Inlyta, a $10,000 a month drug, on the market in 2012, there was no proof that it did either. Inlyta is not an exception to the rule.

A Milwaukee Journal Sentinel/MedPage Today analysis of 54 new cancer drugs found that over the last decade the FDA allowed 74% of them on the market without proof that they extended life. Seldom was there proof of improved quality of life, either. Nor has the FDA demanded companies provide such evidence. Instead, the agency approved the drugs based on surrogate measures, such as a tumor shrinking, rather than the gold standard and most reliable measure of cancer research, patients actually surviving longer. The problem is cancer is complicated — a tumor might stop growing or shrink in one spot, then reappear somewhere else, or even in multiple places.

Inlyta, manufactured by Pfizer, was allowed on the market based on a commonly used surrogate known as progression-free survival, which means patients survived longer before doctors detected a tumor worsening. Before Inlyta was approved, an FDA reviewer noted it would be the seventh drug for advanced kidney cancer approved by the FDA since 2005. Only one of them, a drug known as Torisel, had actually proven to help people live longer.
5. The foundation for a better cancer care information system already exists in the California Cancer Registry.
Evolving Needs for Information About Cancer

- A primary driver for enactment of AB 136 (1985) [H&SC Sect 103875-103885], which authorized mandatory reporting of cancer and creation of a statewide cancer registry, was the critical need for better information about the association of cancer occurrence with environmental agents (e.g., pesticides, PCBs, dioxin, radon) to address public concerns and inform public policy.

- An analogous additional need exists today for better information about cancer care to inform individual decision making about treatment and public policy regarding health care.
Evolving Needs for Information About Cancer

- Today, we need an integrated cancer information system that:
  - Can be used for multiple purposes, including public health surveillance, clinical quality improvement, enhancing access to care, research, and policymaking
  - Continues to provide easily accessible, timely and reliable information about the occurrence of cancer and, additionally, can especially be used to help inform patients and providers about treatment options
  - Ensures privacy and information security
  - Is adaptable, affordable, and sustainable
A Future California Integrated Cancer Information System

- Patients & Families
- Public health officials, Policymakers
- Payers, Insurers
- Researchers
- Providers - physicians, health plans, others

INTEGRATED CANCER INFORMATION SYSTEM
The real question is not whether the California Cancer Registry should be leveraged to improve the quality of cancer care, but instead, why are we not already doing this. ?????