



CALIFORNIA HEALTHCARE FOUNDATION

Enabling the California
Cancer Registry to Measure
and Improve Care

A Recap and Look to the Future

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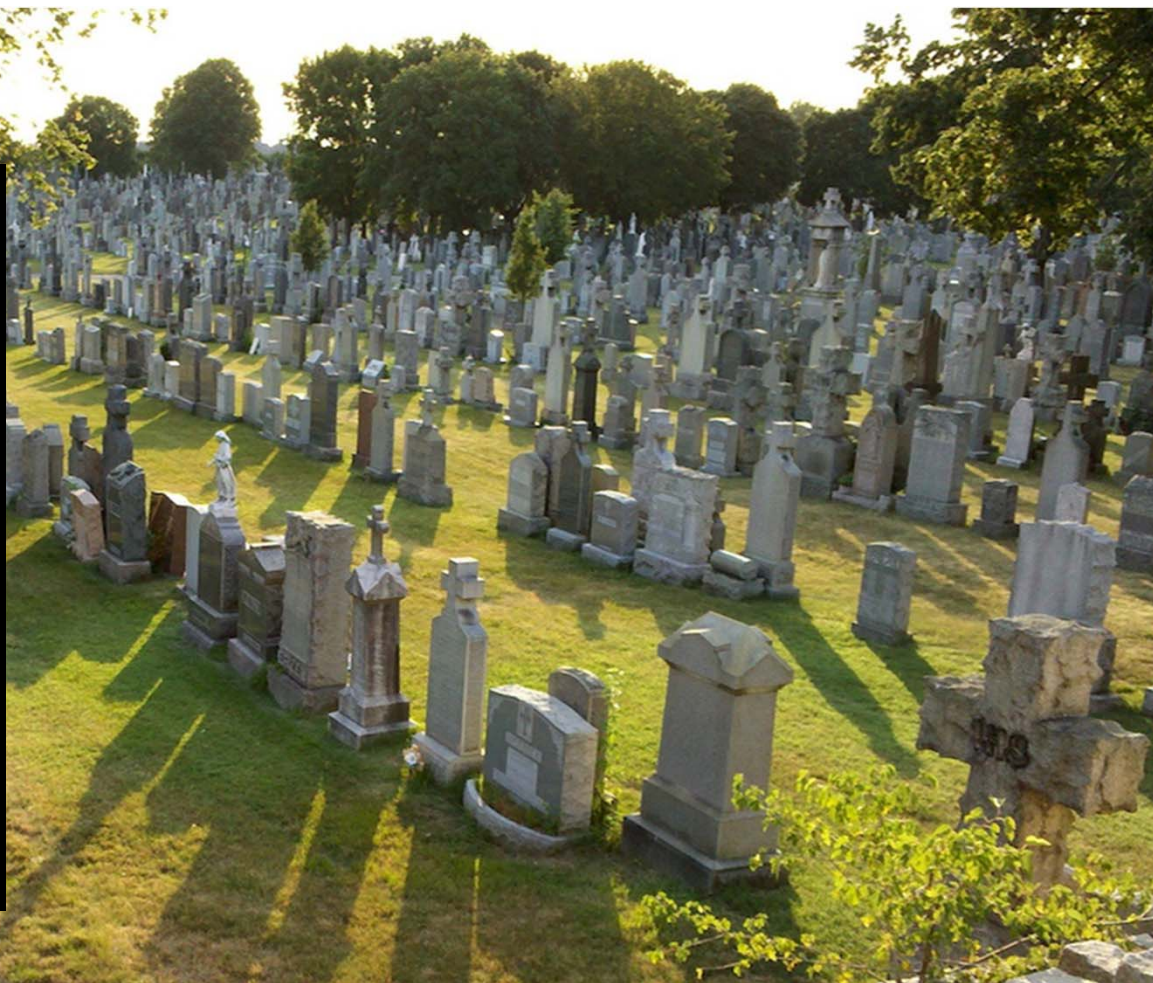


**What are the 5 key
“Take Away” messages that we
heard today?**

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**

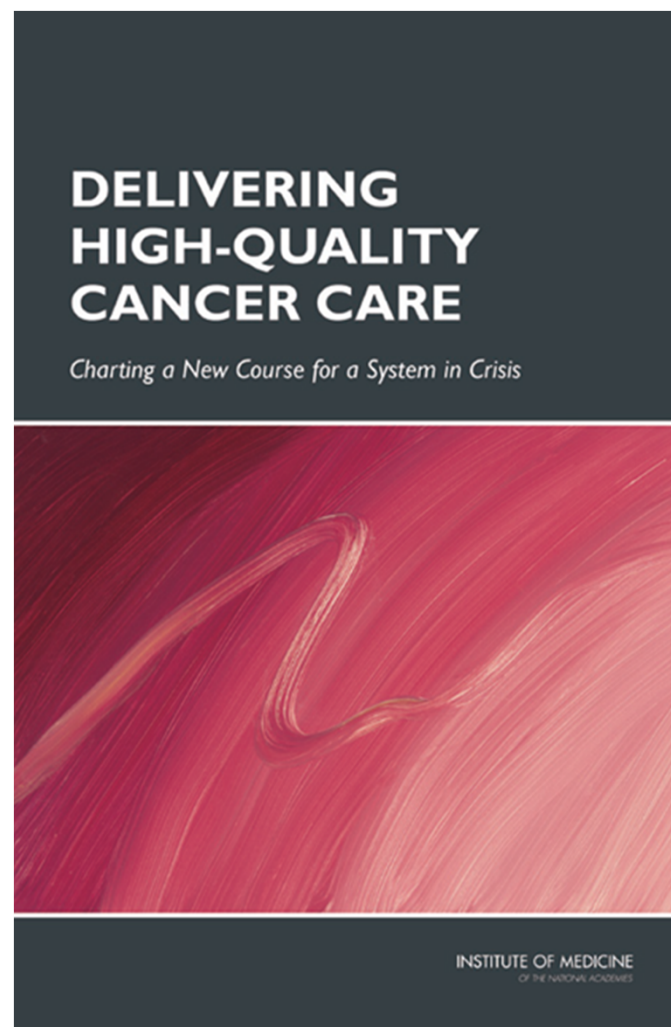


What Have We Heard Today?

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



What Have We Heard Today?

3. Treatment of cancer is very expensive.



2012'S PRICIEST PRESCRIPTIONS

These are the 10 most expensive specialty drugs the Food and Drug Administration approved in fiscal 2012

	Drug name	Company	Category	Review classification ¹	Price/ Month ²
1	KALYDECO	Vertex	Respiratory	Priority	\$24,500
2	ELELYSO	Pfizer	Respiratory	Standard	\$12,500
	ERWINAZE	Jazz	Oncology	Priority	\$12,500
4	FERRIPROX	ApoPharma	Iron toxicity	Standard	\$12,000
5	KYPROLIS	Onyx	Oncology	Standard	\$9,950
6	ZALTRAP ³	Sanofi	Oncology	Priority	\$9,600
7	STIVARGA	Bayer	Oncology	Priority	\$9,350
8	INLYTA	Pfizer	Oncology	Standard	\$8,900
9	BOSULIF	Pfizer	Oncology	Standard	\$8,200
10	ERIVEDGE	Genentech	Oncology	Priority	\$7,500

¹ The FDA gives priority review status to drugs that represent a significant medical advance over existing therapies.

² Price is as of time of approval

³ Sanofi told media outlets in 2012 that it would offer discounts of 50% on Zaltrap in response to criticism from oncologists about the price of the drug. A Sanofi spokesman declined to comment on the company's discount strategy.

Source: FDA, Modern Healthcare reporting

MODERN HEALTHCARE GRAPHIC

What Have We Heard Today?

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

October 22, 2013

Few patients warned of overdiagnosis regarding cancer screening, report says

By Andis Robeznieks | Modern Healthcare

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.

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.**

What Have We Heard Today?

5. The foundation for a better cancer care information system already exists in the California Cancer Registry.



Regional Registries



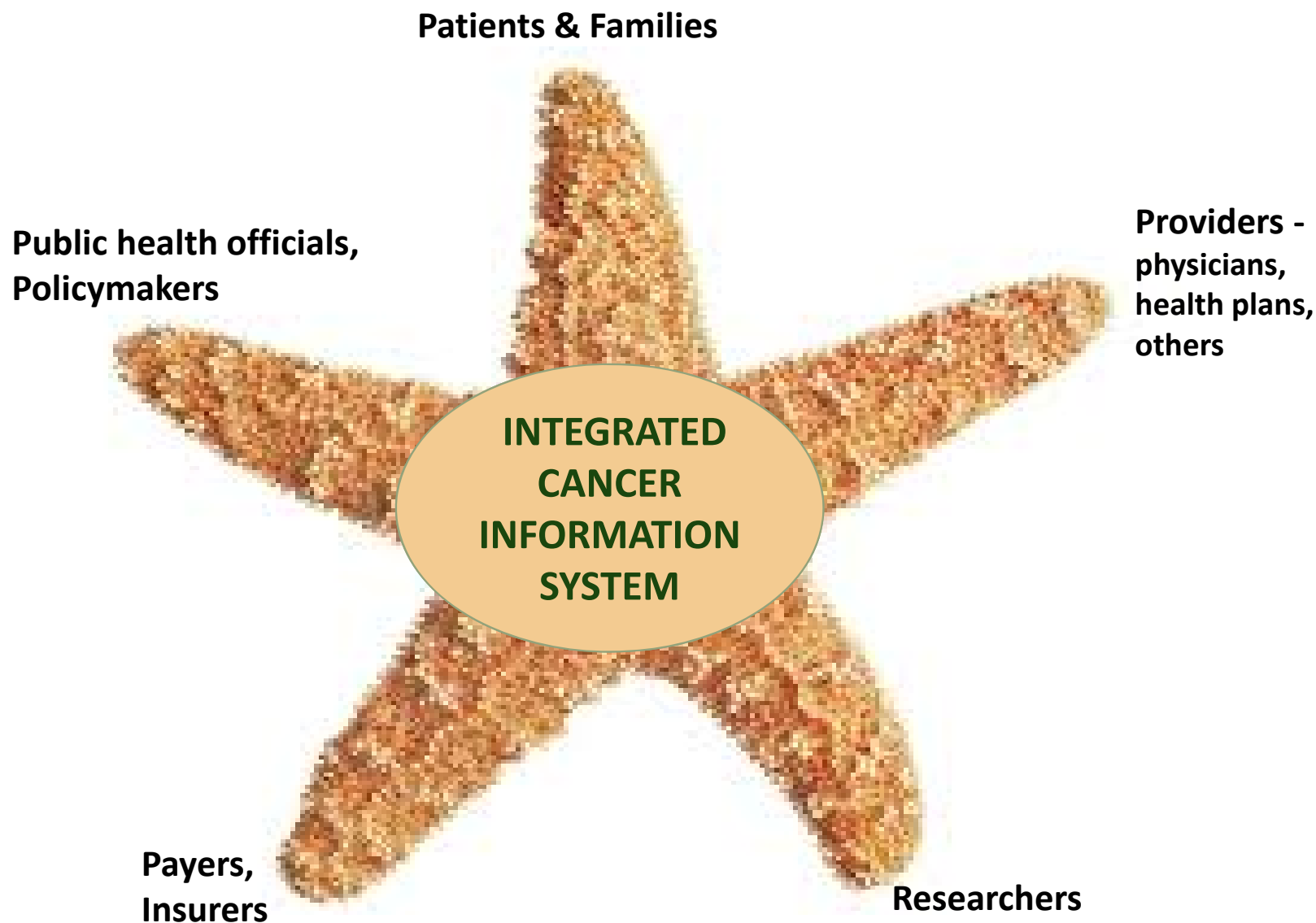
Evolving Needs for Information About Cancer

- **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



Conclusion

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.

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