Priority 6: stable and similar

Cervix (Females)

Thyroid (Males)

Uterus (Females)

Priority 7: stable and below

All Races

Priorities:

- Cervix (Females)
- Thyroid (Males)
- Uterus (Females)

Total:

- 384.80
- 523.80
- 69.82
- 433.20
- 498.83
- 87.71
- 457.63
- 521.16
- 413.62
- 573.47
- 1.0 per 100,000 men
- 426.17
- 379.03
- 100,000 women

American Indian/Alaska
Improving the Social Impact of Cancer Registry Data through Infographic Thinking

Tina Clarke
Matthew Kreuter
Heather Corcoran
Starting point

*Our data can have social impact.*
Stanford-backed study shows rising rates of melanoma among girls and women; tanning beds suspect

September 13, 2011

Study focuses on socioeconomic status by zip code

SACRAMENTO – Researchers at the Cancer Prevention Institute of California, UCSF and Stanford have found that the rate of melanoma has more than doubled among Californians most likely to use ultraviolet-emitting tanning beds. Girls and women aged 15 to 39 in high socioeconomic areas.

“Girls in affluent California communities especially are surrounded by the message that being tanned all year round is cool,” said study co-author Christina Clarke, PhD, of the Cancer Prevention Institute of California.

“Pop music star Katy Perry is even singing about it,” Clark added. “But there is nothing cool about sun exposure that increases your risk for deadly cancer.”

Clarke and her colleagues advocate more UV-exposure education for girls and young women, as well as greater restrictions on access to tanning beds, like those included in a measure by Sen. Ted W. Lieu, which is on the governor’s desk. If signed into law, Lieu’s Senate Bill 746 would be the first in the nation to ban children under 18 from using tanning beds.

This important study illustrates the dramatic rise in deadly melanoma among young Californian women,” Lieu said. “Other scientific research has shown conclusively that use of tanning beds causes skin cancer, and the younger kids are when they start using tanning beds, the greater the cumulative damage to their skin and the more likely they are to die of skin cancer.”

 Released at the end of March, the study, titled “Increases in Melanoma Among Adolescent Girls and Young Women in California” showed the melanoma rate among 3,800 non-Hispanic white girls and women aged 15 to 39 was 7.7% higher in 2010 compared to 1999.
Starting point

Our data can have social impact.
But often they don’t.
### Table 1.4
Age-Adjusted SEER Incidence and U.S. Death Rates and 5-Year Relative Survival Rates By Primary Cancer Site, Sex and Time Period

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<tr>
<th></th>
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<tbody>
<tr>
<td></td>
<td>Total Males</td>
<td>Females</td>
<td>Total Males</td>
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<td>Lip</td>
<td>2.8</td>
<td>4.2</td>
<td>1.7</td>
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<tr>
<td>Cms &amp; other oral cavity</td>
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<td>0.1</td>
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<td>0.3</td>
<td>0.1</td>
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<td>2.0</td>
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<td>Small intestine</td>
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<td>5.2</td>
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<td>Colon &amp; Rectum:</td>
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<td>42.6</td>
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<tr>
<td>Colon</td>
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<td>32.0</td>
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<td>Rectum</td>
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<tr>
<td>Anal, anal canal &amp; anorectum</td>
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<td>1.4</td>
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<td>Liver &amp; intrahep. bile duct:</td>
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<td>9.5</td>
<td>3.1</td>
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<td>1.5</td>
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<td>0.4</td>
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<td>1.1</td>
<td>0.7</td>
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<tr>
<td>Other digestive system</td>
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<td>0.6</td>
<td>0.5</td>
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<tr>
<td>Respiratory System:</td>
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<td>Nose, nasal cavity &amp; middle ear</td>
<td>67.5</td>
<td>82.1</td>
<td>54.4</td>
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<tr>
<td>Larynx</td>
<td>9.2</td>
<td>9.9</td>
<td>9.5</td>
</tr>
<tr>
<td>Lung &amp; bronchus</td>
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<td>6.2</td>
<td>1.2</td>
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<td>Pleura*</td>
<td>63.1</td>
<td>77.7</td>
<td>52.5</td>
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<tr>
<td>Trachea &amp; other respiratory organs</td>
<td>4.1</td>
<td>8.3</td>
<td>6.3</td>
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<td>Bones &amp; joints</td>
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<td>1.0</td>
<td>0.8</td>
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<tr>
<td>Soft tissue (including heart)</td>
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<td>3.8</td>
<td>2.7</td>
</tr>
<tr>
<td>Skin (excl. basal &amp; squamous)</td>
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<td>27.4</td>
<td>17.2</td>
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<tr>
<td>Melanoma of the skin</td>
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<td>15.8</td>
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<tr>
<td>Other non-epithelial skin</td>
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<td>2.4</td>
<td>1.4</td>
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<tr>
<td>Breast</td>
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<td>25.8</td>
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<tr>
<td>Breast (in situ)</td>
<td>15.8</td>
<td>29.6</td>
<td>-</td>
</tr>
</tbody>
</table>
Starting point

*Our data can have social impact.*
*But often they don’t.*
*New thinking can change that.*
New audiences

journalists
policy makers
advocates
healthcare professionals
patients and families
citizens
New goals

awareness
decision making
policy support
collective action
citizen participation
New strategies

accessible
engaging
relevant
interpretive
understandable
What is information design?
Transdisciplinary approach

cancer statistics

visual design

communications
Disseminating data
Disseminating data in a new way
Disseminating data *in a new way*
Integrating these principles

Conceptual Model
PROCESSING VISUAL INFORMATION

Visual Principles

HIERARCHY relative prominence of elements

CONSISTENCY & VARIATION change of elements over time

Information Processing Model

EXPOSURE > ATTENTION capturing audience > UNDERSTANDING comprehension of information > ELABORATION personal relevance > OUTCOMES
Core activities

Audience research

Prototype design

Evaluation
Broad question

How can information design and health communication increase social impact?
Experiment 1
Beyond the “problem”: Explanations & solutions
Problem
Problem

Explanation
Problem

Explanation

Solution
Random assignment

Understanding
Policy support
Political opinion

Problem
Explanation
Solution
Registered voters in Missouri (n=199)

- 22% smokers
- 57% women
- 71% white
- 84% > H.S.
Reason for high rate “a mystery to me”

Problem: [Map with percentages]

Explanation: [Map with percentages]

Solution: [Map with percentages]

46%

12%

9%

p < .0001
Cigarette tax is effective

Problem  Explanation  Solution  
41%  76%  73%  
p < .001
Smoking bans are effective

Problem
Explaination
Solution

42%
67%
66%

p < .01
States can do a lot to reduce smoking

40%

57%

67%

Problem | Explanation | Solution | p < .05
Not satisfied w/ MO efforts

48%

78%

75%

Problem  Explanation  Solution

p < .0001
Policy makers are responsible

Problem  Explanation  Solution

34%  64%  62%

p < .001
Support $1 increase in cigarette tax

Problem

Explanation

Solution

72%

85%

75%

ns
Explaining cancer data adds...

- understanding of problem
- awareness of solutions
- perceived responsibility
- (dis)satisfaction
Experiment 2
Enhancing cancer data graphics
Making data clear, believable & interesting
<table>
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<tr>
<th>Research funding</th>
<th>Research discoveries</th>
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</tr>
<tr>
<td></td>
<td>AC</td>
</tr>
<tr>
<td></td>
<td>ABC</td>
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</table>
Sample and Methods
(n=300)

- mean age = 42
- 55% women
- 61% white
- 18% African American
- 13% Asian

- Ordinal logistic regression (State, race, sex, education)
Information is **clear** and **easy to understand**

\[ A \text{ C} > \text{ A} \]

\[ \text{OR} = 2.03 \ (95\% \text{ CI} = 1.1, 3.7) \]
Information is interesting, I want to learn more

A B C > A

OR = 1.96 (95% CI = 1.1, 3.5)
Information is **trustworthy** and **believable**

\[
\begin{align*}
ABC & > A & \text{OR} = 2.19 \ (95\% \ CI = 1.2, 4.0) \\
AC & > A & \text{OR} = 2.26 \ (95\% \ CI = 1.3, 4.2)
\end{align*}
\]
Cancer data graphics can be more...

- understandable
- interesting
- believable
<table>
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<tr>
<th>Region</th>
<th>NH White Rate</th>
<th>NH White Pop</th>
<th>NH Black Rate</th>
<th>NH Black Pop</th>
<th>Hispanic Rate</th>
<th>Hispanic Population</th>
<th>NH Asian/Pa</th>
<th>NH Asian/Pacific</th>
<th>NH Latinos/Pa</th>
<th>NH American</th>
<th>NH American Ind</th>
<th>All Rate</th>
<th>All Race Population</th>
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<td>1,015,110</td>
<td>58</td>
<td>66,158</td>
<td>36.4</td>
<td>797,343</td>
<td>37.1</td>
<td>617,522</td>
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<td>10,155</td>
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<td>Central</td>
<td>46</td>
<td>1,327,625</td>
<td>53.9</td>
<td>149,865</td>
<td>35.7</td>
<td>1,582,477</td>
<td>36.3</td>
<td>187,072</td>
<td>28.5</td>
<td>31,672</td>
<td>43.4</td>
<td>3,278,411</td>
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<td>Sacramento</td>
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<td>1,973,311</td>
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<td>292,068</td>
<td>35.9</td>
<td>816,230</td>
<td>34.5</td>
<td>447,302</td>
<td>22.3</td>
<td>32,659</td>
<td>42.9</td>
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<td>30,698</td>
<td>35</td>
<td>525,904</td>
<td>35.8</td>
<td>86,016</td>
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<td>8,814</td>
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<td>Inland Empire</td>
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<td>1,643,312</td>
<td>61.6</td>
<td>320,514</td>
<td>35</td>
<td>1,926,628</td>
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<td>251,663</td>
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<td>31,216</td>
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<td>39,268</td>
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<td>San Diego</td>
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<td>1,086,261</td>
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<td>21,649</td>
<td>40.6</td>
<td>3,220,667</td>
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Who is getting colon cancer in California?
Strategies

1. Prioritize data.
2. Meaningful visual design.
3. Appropriate user interaction.
3-Group Randomized Experiment

1. New interactive data display
2. California Cancer Registry
3. NCI State Cancer Profiles
Who is getting colon cancer in California?

<table>
<thead>
<tr>
<th>Region</th>
<th>All Races</th>
<th>Black</th>
<th>White</th>
<th>Asian</th>
<th>Hispanic</th>
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<td>BAY AREA</td>
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<td>LA COUNTY</td>
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<td>NORTH</td>
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<td>TRI-COUNTY</td>
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</table>

Cancer data obtained from the California Cancer Registry (www.cancer.ca.gov). 2009-2010. Population data and 2009 population estimates obtained from the Surveillance, Epidemiology, and End Results Program (seer.cancer.gov) of the National Cancer Institute. All rates are age-adjusted to the 2000 U.S. Standard Million population. "Hispanic" includes all Hispanics regardless of race. "All races" includes American Indian/Alaskan and unknown race rates which were not individually listed due to a small number of cases in each region.
California Cancer Registry Cancer Inquiry System

Age-Adjusted Invasive Cancer Incidence Rates in California
All Sites, 2005-2009
By County
Age-Adjusted to the 2000 U.S. Standard Million Population
California Rate: 437.87
Rate per 100,000
- 364.45 - 429.46
- 431.36 - 458.77
- 469.80 - 470.74
- 473.67 - 513.34

Data accessed December 19, 2011
Based on October 2011 Quarterly Extract (Released October 27, 2011)
Veterans Health Administration hospitals did not report cancer cases to the

Click a column header to sort. Click the region name for more detailed information.
Sorting by County will sort the bar graph by County, otherwise the bar graph will be sorted by age-adjusted rate.

Invasive Cancer Incidence Rates by County in California
All Sites, 2005-2009

<table>
<thead>
<tr>
<th>County</th>
<th>Population at Risk</th>
<th>Cases</th>
<th>Crude Rate</th>
<th>Age-adjusted Rate</th>
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<td>El Dorado</td>
<td>879703</td>
<td>4815</td>
<td>547.34</td>
<td>513.34</td>
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<tr>
<td>Mariposa - Tuolumne</td>
<td>368132</td>
<td>2705</td>
<td>734.79</td>
<td>508.30</td>
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<td>Napa</td>
<td>660867</td>
<td>3921</td>
<td>593.31</td>
<td>499.30</td>
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<td>Marin</td>
<td>1233555</td>
<td>7887</td>
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<td>493.70</td>
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<td>Lake</td>
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<td>2096</td>
<td>647.35</td>
<td>490.32</td>
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<tr>
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<td>533.18</td>
<td>490.03</td>
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<td>6086</td>
<td>558.56</td>
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<td>12510</td>
<td>538.97</td>
<td>477.70</td>
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<td>547466</td>
<td>2888</td>
<td>527.52</td>
<td>476.81</td>
</tr>
<tr>
<td>Mendocino</td>
<td>430148</td>
<td>2520</td>
<td>585.84</td>
<td>473.67</td>
</tr>
</tbody>
</table>
State Cancer Profiles
Dynamic views of cancer statistics for prioritizing cancer control efforts in the nation, states, and counties

## State Cancer Profiles

**Area:** California
**Cancer:** Colon & Rectum

### This quick report contains:
- Rate/Trend Comparison by Cancer: Colorectal
- Rate/Trend Comparison by State/County
- Historical Trends (25 Years):
  - Mortality
  - Incidence
- 5-Year Rate Changes:
  - Mortality
  - Incidence
- Death Rates Table
- Death Rates Interactive Maps
- Incidence Rates Table
- Incidence Rates Interactive Maps

### Rate/Trend Comparison by Cancer: Colon

#### Death Rate/Trend Comparison by Cancer, death years through 2008
California Counties versus United States

**Colon & Rectum**
All Races, Both Sexes

<table>
<thead>
<tr>
<th>US Rate</th>
<th>Similar to US Rate</th>
<th>Below US Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Rising Trend</strong></td>
<td><strong>Stable Trend</strong></td>
<td><strong>Stable Trend</strong></td>
</tr>
<tr>
<td>Priority 1: rising and above 1</td>
<td>Priority 2: rising and similar</td>
<td>Priority 3: rising 1 and below</td>
</tr>
<tr>
<td>[none]</td>
<td>[none]</td>
<td>[none]</td>
</tr>
<tr>
<td>Priority 4: stable 1 and above</td>
<td>Priority 6: stable 1 and similar</td>
<td>Priority 7: stable 1 and below</td>
</tr>
<tr>
<td>[none]</td>
<td>Kings County</td>
<td>Imperial County</td>
</tr>
<tr>
<td>Inyo County</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sacramento County</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Printable View**
**Data Use Restrictions**

[Modify Data Table]
[Export Data]
[Data Use Restrictions]
Procedure

- Online experiment with CRC data
- Randomization to 1 of 3 groups
- 10-second static exposure
- Unrestricted use of assigned web page
Data collection

- Baseline (pre-exposure)
- Post-static exposure
- Post-unrestricted use
Study outcomes

- Initial impressions
- Factual knowledge
- User experience
- Trustworthiness of data
Sample

- CA residents (n=550)
- Ages 50-79 (mean=60.1)
- 75% White
- 24% ≤ H.S. education
- 22% < $25,000 income
Initial impressions
The display looks inviting
(n=550, p < .05)
The display looks confusing
(n=550, p < .05)
The display looks overwhelming

(n=550, p < .05)
Factual knowledge
Los Angeles or Orange County?

(n=550, p < .0001)
African Americans or Whites?

(n=550, p < .0001)
Racial/ethnic group with least CRC?

(n=550, p < .0001)
What best explains who gets CRC?

(n=550, p < .0001)
User experience
Easy to explore
(n=550, p < .0001)
Easy to find information
(n=550, p < .0001)

![Bar chart showing comparison between APRC, CCR, and NCI with percentages of 4.1, 3.2, and 3.4 respectively.](image-url)
Easy to read

(n=550, p < .0001)
Well suited to first-time visitors

(n=550, p < .0001)
Designed with people like me in mind

(n=550, p < .05)
Trustworthiness of data
The information looked like it was true

(n=550, ns)
The information looked accurate

(n=550, p<.05)
Summary of new data display

Less favorable
- initial impressions
- trustworthiness

More favorable
- factual knowledge
- user experience
data spark

bring numbers to life

www.dataspark.org
Takeaways

1. Statistics shouldn’t stand alone.
2. Explain the story.
3. How it looks affects understanding.
Future directions

1. Expand Dataspark tools
2. Audience-specific strategies
3. Efficiency through technology
Chris Casey
Christina Clarke Dur
Heather Corcoran
Giovanina Gardiner
Susan Gilham
Skye Giordano
Balaji Golla
Felicia Gonski
Kim Kaphingst
Matthew Kreuter
Choi Lai
Doug Luke
Jennifer Morgan
Lisa Moy
Sarah Nelson
Abram Siemsen