

03 Making Cancer Surveillance Data More Accessible for the Public Through Dataspark.

**HEATHER CORCORAN, MATTHEW KREUTER,
CHRISTINA CLARKE**

ABSTRACT

This paper describes findings from an experiment to determine whether visual design could enhance the effectiveness of the presentation of cancer surveillance data online. The research team included designers who created an interface called Dataspark (DS) for California citizens to see incidence rates for colorectal cancer in the state. The design of the display used principles of relative scale, color, shape, and arrangement. In a randomized experiment, this interface was compared to two displays that are hosted by established cancer organizations but do not use principles of scale, color, shape, and arrangement in the same way. Approximately 550 California citizens participated in the experiment, during which they were assigned at random to use one of the three displays and then asked questions about understanding, ease of use, engagement and personal relevance. Results showed that the Dataspark display was significantly more effective in helping participants understand the data and explore the interface. User engagement and personal relevance were modest for all three displays. This paper analyzes the results and introduces some strategies to address engagement and personal relevance in future work.

> **A**pproximately 1 out of 2 Americans born today will be diagnosed with cancer in his or her lifetime (National Cancer Institute, 2011). Worse yet, those who are poor, African American, or uninsured are more likely to get cancer, be diagnosed at more advanced stages when cancer is more difficult to treat, and have a shorter period of survival after diagnosis compared to other Americans (American Cancer Society, 2013, 42).

Because cancer is one of the leading causes of death in the U.S., all 50 states have made the reporting of cancer diagnoses mandatory. Cancer registries compile and compute cancer incidence and mortality data, looking for trends over time and variability by geography, race, gender, age, and other variables. This work is part of the larger field of cancer epidemiology, the study of who gets cancer in populations and why. Many cancer registries are organized through the federally funded Surveillance Epidemiology and End Results program (SEER) which began in 1973.

Data collection has grown in virtually every aspect of life. But as information design and programming guru Ben Fry describes,

"We're getting better and better at collecting data, but we lag in what we can do with it." (Fry, 2008, 2)

For cancer registry data, the gaps between what is collected, what the public understands, and how individuals behave in response, are large.

In their 2009 book *Making Data Talk*, David Nelson, Brad Hesse and Robert Croyle describe the challenges associated with lay audiences sifting through health data on and off the Internet. (Nelson, Hesse and Croyle, 2009, 4) As they explain, "Unfortunately, examples of poor communication of data abound—on Web sites, in written materials (e.g., reports, brochures), during oral presentations, and during media interviews, leaving many people awash in a morass of confusing 'data smog.'" (Ibid.) (Shenk, 1997)

The project described in this article explores the development and testing of an interactive display to inform the public about variation in colorectal cancer rates across population sub-groups, using data from the state of California. The display is a transdisciplinary synthesis of principles of data selection, visual design, user interface and communications created to understand how the impact of cancer statistics on the public can be improved through better presentation.

The project addresses an emerging challenge in public health communications:

as data and their delivery systems become ever more individualized, robust, and search-driven, can they also be used to help people see the connection between individual behavior and population health?

This question is particularly important for addressing the health needs of populations at disproportionately high risk of cancer and other diseases, shown in our project by the comparatively high rates of colorectal cancer—a cancer thought to be preventable through screening—for certain population sub-groups, like African Americans.

To that end, we tested our interactive display against two content-equivalent displays already in the marketplace with 550 users from the state of California. We measured four outcomes—user understanding to see if the information could be made more clear, ease of use to see if the information could be more easily navigated, engagement to see if people would pay attention to the experience, and relevance to see if it had personal or lasting meaning. The prototype that we developed is referred to as “Dataspark” (DS) throughout this article. Dataspark is now an online visualization tool (available at <http://www.dataspark.org>), recently released to the cancer surveillance community, whose members can use it to visualize their own data and share it with their constituencies.

THE INFORMATIONAL LANDSCAPE: CANCER SURVEILLANCE DATA

The production and distribution of information at large is at a historical high. In 2009, there were 1.5 billion Internet users on the planet and 60% of the world's population had a wireless phone subscription (Castells, 2010, xxv–xxvi). Seven years before that, Peter Lyman and Hal Varian estimated that information production had reached five exabytes, or the equivalent of 37,000 libraries the size of the Library of Congress (Lyman and Varian, 2003). Their report from 2002 suggested that digital information production was growing approximately 30% each year. (Ibid.)

But the time spent consuming information is increasing by just 1.7% annually, according to John Seely Brown and Paul Duguid, authors of *The Social Life of Information*, also published in 2002 (Brown and Duguid, 2002, xiii). Brown and Duguid characterize this oversupply and lack of demand as an urgent problem for knowledge management. They conclude that “a critical task ahead will be to stop volume from simply overwhelming value.” (Ibid.)

The gap between production and consumption is just one factor in a kind of societal angst. In his classic text *Information Anxiety*, published ten years before *The Social Life of Information*, Richard Saul Wurman writes about a variety of manifestations. These include “not understanding information, feeling overwhelmed by the amount of information to be understood, not knowing if certain information exists; not knowing where to find information; and perhaps, the most frustrating, knowing exactly where to find the information, but not having the key to access it.” (Wurman, 1989, 44-45) These issues seem particularly relevant to cancer surveillance data today. Web analytics show that of the people who visit the SEER website, one of the most common resources for cancer registry statistics, close to 50% leave within 30 seconds (AWStats, 2011). While these data do not capture why people leave, they suggest an unsatisfying data experience.

The sheer quantity of information appears to be one of the problems. In a qualitative study conducted by the authors of this article in 2011 to assess the cancer data needs of five audiences—cancer control professionals, advocates, journalists, policy makers, and the public—all described the problem of feeling overwhelmed by a “tornado of data”. Other challenges found in the study, which featured in-depth interviews with 16 people, included the need for interpretation of information over complex statistics and usability over precision (Spray, 2011, 6).

For those immediately and urgently affected by cancer and thus seeking more personalized information, population-level surveillance data may be too broad and its findings not actionable enough to feel relevant. For example, people often desire extremely localized data. They may wish to know the answers to questions such as: What is my sister’s chance of survival? Not only are some of these questions difficult to answer, as data collection across the U.S. is variable by community, region and state, but even as the cancer surveillance community attempts to provide increasingly specific answers, researchers in the field believe that the big picture remains important...

Presenting statistics that reflect population risks while maintaining relevance to individuals is key. But this is difficult to achieve.

Public access to cancer statistics is a relatively new goal. Historically, cancer surveillance data and related statistics have been developed and distributed by epidemiologists to cancer control decision makers, primarily other scientists. With the aid of technology, the end user group has grown to include some members of the cancer-affected

public; hence data translators have come to play a more important role in the information delivery system, a trend which is likely to grow over time. These “infomediaries” include local and national journalists, local, regional, and national policy makers, healthcare professionals, and community advocates. In effect, the communications system for cancer surveillance data is in the process of becoming more complex and gaining constituents. How well that system works in serving its audience and maximizing the communicative potential of cancer surveillance data is an open question.

APPROACH

The goal of this project was to understand how end users respond to a tool specifically designed for their use, and how experiences with this tool compare to experiences with existing tools.

The findings should help improve the cancer surveillance communication system as the field looks to integrate informational tools for various audiences, including infomediaries. The project assessed users on a scale from understanding at one end, to ease of use and engagement, and finally, personal relevance at the other.

RESEARCH TEAM

Given the range of stakeholders and the complexity of data to be communicated, a transdisciplinary approach was adopted. This allowed a blend of cancer surveillance data expertise, including data selection and statistical analysis; visual design, usability, and programming; and experience in health communications science, human subject testing, messaging, and data analysis. The three primary sets of researchers were cancer epidemiologists from the Cancer Prevention Institute of California, one of the oldest cancer registries in the U.S., designers from the Sam Fox School of Design & Visual Arts at Washington University in St. Louis, and specialists from the Health Communication Research Laboratory, one of five national centers of excellence in cancer communication research, also from Washington University in the Brown School of Social Work.

PROCESS

Several key parts of the project, including data selection, audience research, iterative prototype development, and planning for user testing required sustained dialogue across the larger team. This group used a reflective methodology, creating and responding to paper and screen-based prototypes to frame feedback and expertise at every stage. In the book *The Reflective Practitioner*, Donald Schön describes reflection-in-action as a productive alternative to the

traditional “technical rationality” approach prized by professions such as Law and Medicine. As he explains, this approach focuses on the tacit knowledge acquired by practice that can seem to be beyond verbal description. For Schön, doing, making, and problem-solving are ways to make that valuable tacit knowledge explicit (Schön, 1983, 21–75). For our project, the benefit of a reflective process was two-fold: not only did we find that our ideas became more clear and specific when we put them into form and reflected upon them, but the reflective process also provided a critical platform for transdisciplinary conversation.

..... *In a sense, our project was about finding the tacit
..... in our group’s knowledge.*

Our development process roughly aligns to a seven-step approach described by Ben Fry in *Visualizing Data*. Once a goal is established, these stages include acquire, parse, filter, mine, represent, refine, and interact (Fry, 2008, 5-6). Our process began with the development of a goal and was followed by acquiring and filtering data, representation, refinement, and interaction. We measured the interactions through a randomized experiment and then analyzed our results in the context of our research goals. Each stage of the project included activities that were “owned” by a particular set of expertise. For example, the designers took the lead creating representations of the data through an iterative series of paper and digital sketches. These were viewed and refined not just on visual terms, but for clarity of the data, potential for the visual structure to house variations on similar kinds of data in the future, ability to capture and hold users’ attention and interest and help them connect to cancer data, conventions of web design, emerging influences of mobile on website design, and programming implications. In the development of the format for user testing, the health communications experts took the lead. Because of their broad-minded facilitation, all other team members were able to contribute to project’s testing goals, questionnaire items, and evaluation approach and methods.

..... *What made the process different from traditional, client- driven
..... projects in the field of design, or even academic projects
..... positioned solely within design, was the range
..... of expertise synthesized into the prototype.*

PRINCIPLES AND PRECEDENTS FOR INTERVENTION

Principles of graphic display, usability and communications processing, all well documented in literature, factored into the development of our interactive display and the formation of our testing model. Key principles taken from each field are described below.

GRAPHIC DESIGN: HIERARCHY AND GROUPING

The visual principles of hierarchy and grouping, documented in a variety of texts in the canon of print graphic design literature, were critical to the success of our prototype. Hierarchy refers to the relative prominence of elements in a visual field (Lupton and Phillips, 2008, 115). That translates to a set of design decisions that cause one element to be more or less important than another. Scale, shape, and color are among the factors influencing hierarchy. For example, in this infographic spread from Al Gore's book *Our Choice*, designed by New York design firm MGMT, the darkest circles rise to the top of the hierarchy (*figure 1*).

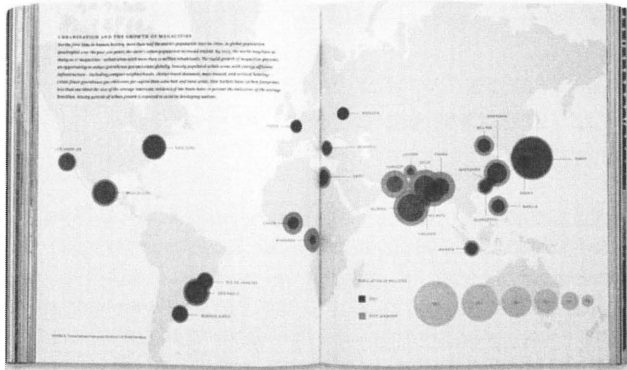


FIGURE 1 Spread from *Our Choice* by Al Gore, designed by MGMT.

Grouping refers to the way that our eyes tend to link elements in a visual field. Elements that are linked are often close in proximity, or of similar size, shape, or color. In the MGMT example, the three circles at the top of the map—in Europe—appear more visually connected than the three in North America. Their size is the same and they are closer to each other in space. Hierarchy rests on our ability to perceive difference; an element that looks different will tend to have more prominence in a hierarchy. In order to perceive difference, we must be able to group elements that are the same. These principles help to explain how we perceive visual patterns.

For decades, the principles of hierarchy and grouping have been applied successfully in areas such as business, education, and news media where customers, students, and the general public serve as primary audiences. But visual design has had a minimal role in fields that have not made systematic efforts to communicate to broad populations, such as cancer surveillance.

EASE OF USE AND GRAPHIC PRECEDENT

When information is disseminated digitally—on computer screens and mobile devices instead of paper—principles of user navigation become important. The field of usability has emerged in the last 15 years to explain the dynamics of interactive environments, in which multi-dimensional information is presented on a screen and the user makes choices to guide his or her experience. Usability.gov defines how well users can learn and use a product to achieve their goals and how satisfied they are with that process as the measures of success (Usability.gov, 2012).

Good usability is about ease. If navigation is intuitive for the user, then s/he will not notice it, but will know what to do. In *Don't Make Me Think*, Steve Krug puts it this way...

..... "I should be able to 'get it'—what it is and how to use it—without expending any effort thinking about it."
..... (Krug, 2005, 18)

Part of the reason that users “get it” is that they rely on conventions, which are described by historians Charles Kostelnick and Michael Hassett as a set of social principles that we identify over time through use (Kostelnick and Hassett, 2003, 10-23). For example, we understand that when a website contains a bold shape with type on it, it is meant to be clicked, and that it will take us to a new screen. We call this shape a button, much as buttons exist on elevators or electronic equipment. Our computer interfaces have functioned under the metaphor of a desktop (files, folders, etc.) since Apple introduced it in the early 1980s. The desktop is filled with graphic user interface (GUI) conventions; in the GUI landscape, what you see is what you get. As users begin to interact with mobile devices, the power of touch is changing the way that users relate to screens—in the mobile world certainly, but increasingly on the computer as well. Mobile device expert Rachel Hinman writes that...

..... "Natural user interfaces (NUIs) rely on our innate sense of the physical world where what you do is what you get."
..... (Hinman, 2012, 21-22)

This is important for interface design because it means that the context in which interactive data or elements appear on our screens has a role in determining what we think they mean, and how we interact with them. For example, the zoom and pinch feature of the iPhone allows us to expand or contract visual information. Using our fingers, we can move up, down, or across our screens, pulling in new material from “off-screen.” This functionality makes our interaction more nuanced

and less didactic, which in turn affects the way that we expect to use the mouse to move through a map or an environment on a computer screen.

An additional consideration, as Krug describes, is that the Internet is a place for scanning, not reading. Users move at high speeds to get what they need (Ibid, 17). Information delivery gets speedier all the time, pressuring graphic conventions to be intuitive. Krug advises developers to focus on straightforward navigation, descriptive copywriting, and clear labeling. He advocates for a strong visual hierarchy focusing on grouping, with appropriate consideration of existing graphic conventions. Poor usability blocks access to meaningful content, particularly when that content is complex, as is the case with cancer surveillance data.

COMMUNICATIONS

While principles of visual design and usability guided many aspects of the development of our project prototype, the psychology of persuasion informed the framework for its evaluation. In 1968, social psychologist William McGuire proposed an input/output model of persuasive communication. This model consists of five types of "input" variables (source, message, channel, receiver and destination) that can influence the effectiveness of a communication and 12 possible "outputs," or outcomes of communication (e.g., attention, comprehension, behavior change). The outcomes are successive, from affective and cognitive, to behavioral. McGuire proposes that for a communication to achieve higher order effects such as behavior change, outputs appearing earlier in the succession have to be reached (McGuire, 1989, 43-65). The progression of communication effects can stop anywhere in this sequence (McGuire, 1976, 302-219). In our model for cancer surveillance data, understanding is followed by usability, engagement, and then personal relevance. While we were not focused on a behavior change as an outcome of this project, we see our progression as a necessary and appropriate precursor to facilitating future behavior change.

PROTOTYPE DEVELOPMENT

DATA SELECTION

Colorectal cancer incidence rates in the state of California reflect significant disparity by race. For example, African Americans are diagnosed with colorectal cancer at nearly twice the rate of Asian and Hispanic populations and at higher rates than whites. It was primarily because of these pronounced disparities that we selected colorectal cancer as the content area for our prototype.

We divided California into ten geographic regions for this project. Regional incidence rates correlate to racial compositions of the regions.

While one might argue against this redundancy, our system of geographic division was important for two reasons: statistically, it broke the data into smaller granules. It also provided a potential personal connection for users; those tested were all living in one of ten regions of California.

In addition, we selected colorectal cancer because it can be treated if detected early. Non-cancerous lesions and polyps can be removed before they become cancerous, but this requires regular screening. According to a recent report from the U.S. Centers for Disease Control and Prevention (CDC), African Americans are less likely to be current with their colorectal screenings than whites (Centers for Disease Control and Prevention, 2012).

There are also gender gaps in colorectal cancer incidence rates in California and nationally. Men get colorectal cancer more often than women. But the gap between African Americans and other races is much more substantial. Because we wanted to focus the user's attention on racial disparity, we chose not to display the gender breakdowns.

VISUAL DESIGN

The Dataspark interface was designed to be a simple, interactive snapshot in which users can see and compare a general pattern of rates by race and region and simultaneously experience the specificity of particular rates. (figure 2)



FIGURE 2
Dataspark interface,
Africans Americans
living in Desert
Sierra highlighted.

..... While Californians should be able to locate themselves
 in the data, the context that the pattern provides
 is an important link to the larger story.

The design is a grid of circles in which each column (and color) is a category of race/ethnicity. Each row is a region in California. Circles are sized according to colorectal cancer incidence rate, age-adjusted. The highest incidence rate appears in the upper lefthand corner, providing an immediate answer to the question posed by the headline. The user can see who gets cancer most and how big the gap is between that group and the others around it.

Visual principles of grouping and hierarchy play important roles. Scale, color, and proximity of circles allow rates in a given category to group together visually; in that environment of sameness, differences in the scale of the circles are easy to detect and link to comparatively lower or higher rates.

The circles in the grid are rollovers. Each rate displays numerically when the corresponding circle is rolled over. In Figure 3, the user has rolled over African Americans living in Desert Sierra, a group with an incidence rate of 62 cases of colorectal cancer per 100,000 people. In Figure 4, Hispanics in LA County have a much lower rate of 35 cases per 100,000 people. Because the circles cannot be clicked, the user has the immediacy of scanning with the mouse. Nothing moves or changes during a rollover except the appearance of the large rate number, its supporting text, and a color highlight of the relevant region on a California map.

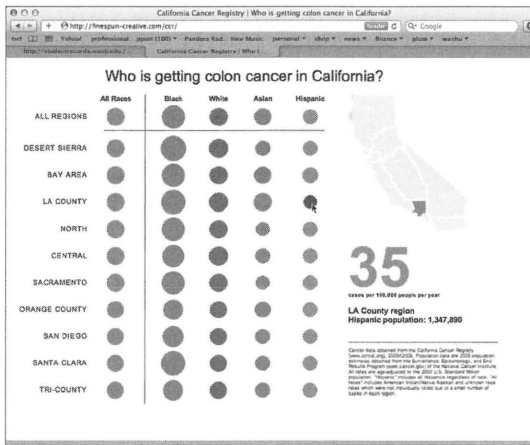


FIGURE 3 Dataspark interface, Hispanics living in LA County highlighted.

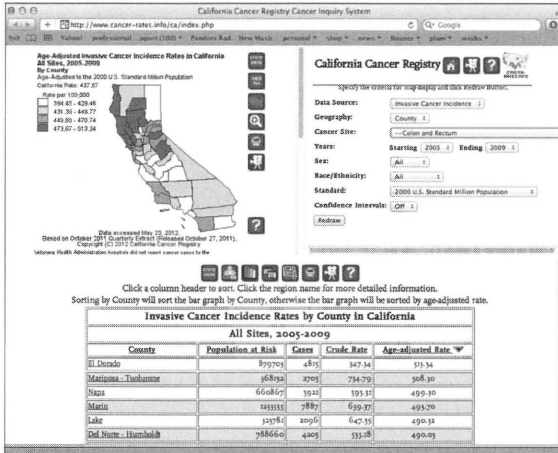


FIGURE 4 Common display of cancer registry data, California Cancer Registry display.

METHODS

We created our prototype for end users so that we could study the specific challenges associated with making the data meaningful for the lay public. We were interested in learning about their understanding, ease of use, level of engagement, and sense of personal relevance, all areas that we believed to be problematic for other interfaces containing cancer statistics.

We tested our prototype against two others produced by major sponsors of cancer registry data. Each participant was assigned randomly to one of three displays – 183 people to Dataspark, 184 to the California Cancer Registry (CCR), and 183 to the National Cancer Institute (NCI) – and asked an identical set of questions (figures 4, 5).

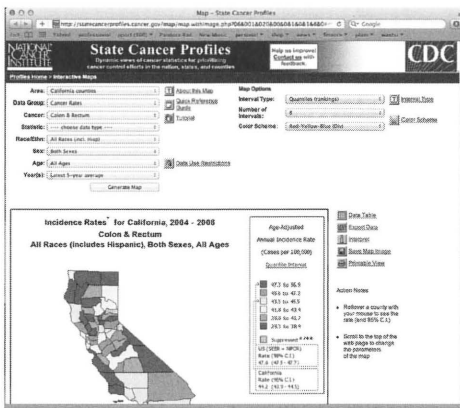


FIGURE 5 Common display of cancer registry data, State Cancer Profiles.

While created primarily for scientific and public health audiences, the CCR and NCI displays are publicly available and among the top results returned by search engines for many online cancer-related inquiries. For the experiment, each of these interfaces was set up to show California colorectal incidence data. Each of the interfaces contains data organized by race.

There were 550 participants in the experiment. Participants were registered voters in California, ages 50–79 (therefore age-eligible for colorectal cancer screening; mean age = 60.1). We did not require that participants had any experience with cancer. Each participant received a modest incentive as compensation for time spent completing the online experiment. Most participants were white (75%), had at least some education beyond high school (76%), and had an annual income of \$25,000 or more (76%).

The survey was conducted online and began with a set of questions about personal relationship to cancer and patterns of Internet use. Participants then spent 25 seconds viewing their assigned displays without interacting with them and were asked eight questions about their initial impressions, including whether the display looked intimidating, hard to use, out of date, attractive, easy to use, inviting, confusing, and overwhelming (agree/disagree). During the interactive session which followed, all participants had access to the full functionality of their assigned interface (e.g., rollovers, drop-down menus, etc). They took a short, multiple-choice quiz on the statistics to evaluate their understanding. Quiz questions asked about cancer facts available in the display (e.g., “Who gets more colorectal cancer in California, Blacks or Whites?”)

Quiz questions were followed by questions about ease of use, engagement, and personal relevance. Ease of use was measured by asking participants to respond to statements about how easy it was to use the interface (Likert Scale: 1= strongly disagree; 6=strongly agree) and find information (Likert Scale: 1=strongly disagree; 5=strongly agree). Engagement was measured by asking participants to respond to statements about how interesting the display was (Likert Scale: 1= strongly disagree; 6= strongly agree) whether they were interested in learning more about the subject (yes/no/not sure). Personal relevance was measured by asking whether participants sought information that was specific to their racial group or region (yes/no/no answer), and evaluating their connection to cancer (yes/no/not sure).

Following the interactive session, participants were asked a set of questions about the general usability of the interface, the believability of the presentation, and effort expended using the display. They also

provided further demographic information. Topics discussed are summarized in Figure 6. All data were analyzed using SAS v.9.2.

QUESTIONS ASKED WHEN?	TOPICS COVERED
Before viewing display (baseline)	Interest in topic Health information seeking and personal relevance Subjective numeracy Geographic literacy Duration of residence Objective regional knowledge Regional self-identification Internet usage patterns
After viewing display for 25 seconds: no interaction	Perceived ease of interpretation Engagement Basic understanding of idea
While interacting with display	Quiz on statistics Ease in Interpretation Learning / understanding Understanding gist Perceived personal risk
After interacting with display	Usability Believability Effort Cancer experience and perceptions Demographics

FIGURE 6 (TABLE 1) Survey topics for experiment

RESULTS AND ANALYSIS OF USER TESTING

UNDERSTANDING OF DISPLAY

After interacting with their assigned display (determined at random), participants were asked four fact-based questions about the data presented (figure 7). The Dataspark design produced significantly more correct answers than the other two designs for each of the questions. For example, when asked which racial group gets colorectal cancer the least, participants who viewed the Dataspark design answered correctly in 75% of cases; participants who viewed the California Cancer Registry rates answered correctly in 18% of cases. This result in particular and the outcomes in this category generally suggest that...

..... the visual design of Dataspark was effective for communicating statistics and ensuring understanding.

QUIZ QUESTIONS		DS	CCR	NCI
Who gets more colorectal cancer in California, people living in Orange County or in LA Country?	Correct answer	78%	53%	62%
	Wrong answer	7%	26%	11%
	Not sure	15%	21%	26%
Who gets more colorectal cancer in California, Blacks or Whites?	Correct answer	91%	36%	61%
	Wrong answer	4%	40%	22%
	Not sure	5%	24%	16%
Who gets more colorectal cancer the least in California?	Correct answer	75%	18%	16%
	Wrong answer	19%	55%	48%
	Not sure	7%	26%	35%
What best explains who gets colorectal cancer in California?	Correct answer	73%	33%	66%
	Wrong answer	8%	29%	12%
	Not sure	19%	38%	22%
PARTICIPANT REFLECTION				
How much, if at all, did your understanding of who gets colorectal cancer in California improve after exploring this webpage?	A lot	18%	9%	21%
	Some	46%	35%	34%
	Very little	21%	26%	20%
	None	14%	30%	25%

FIGURE 7 (TABLE 2) Results for Understanding

One of the features that differentiates Dataspark from the other two interfaces is simplification of data. This was achieved in part by showing one set of comparable rates instead of presenting crude rates and case number totals, rounding numbers to the nearest whole. A second important difference is that Dataspark's grid of circles allows for visual comparisons among races and regions and a macro view of the data upon entry. Additional differentiating features are the labels and copywriting which were written to be straightforward and minimal. Further testing could isolate these variables to assess their impact more precisely. We note that several of these design features grew out of transdisciplinary discussion, including the presentation of the visual grid.

Participants' observations about their general understanding were also positive. 64% of Dataspark participants reported that their understanding improved "a lot" or "some" compared to 44% of participants who viewed the CCR tool and 55% of participants who viewed the NCI tool ($p < .001$). For each of the four factual quiz items, participants who used Dataspark answered correctly significantly more often

than those assigned to CCR or NCI. Across the four items, Dataspark participants were correct 73-91% of the time, compared to lower rates of correctness for CCR (18-53%) and NCI (16-66%) participants (all $p < .0001$ for comparisons between tools).

Overall, Dataspark participants scored an average of 79% correct on the set of four quiz questions and 64% of Dataspark participants believed that their understanding improved. What we learn about understanding from this set of results is that data selection and visual design can aid the clarity with which material is understood, a key component of improving the impact of cancer surveillance data on the public.

EASE OF USE

Survey participants were asked about ease of use before and after interacting with the displays. (figure 8) For all three displays, there was significant contrast between perception and experience. For those randomized to the Dataspark design, the experience was much more positive than the first impression. For those randomized to CCR and NCI, the reverse was true.

SEEING, NOT INTERACTING		DS	CCR	NCI
Looks intimidating	Agree	55%	58%	49%
	Disagree	45%	42%	51%
Looks confusing	Agree	63%	59%	49%
	Disagree	37%	41%	51%
Looks easy to use	Agree	37%	36%	47%
	Disagree	63%	64%	53%
AFTER INTERACTING				
Easy to explore the webpage	1 strongly disagree	6.5%	23%	23%
	2	6.5%	25%	19%
	3	27%	19%	17%
	4	33%	16%	25%
	5 strongly agree	27%	16%	15%
Easy to figure out where to find information	1 strongly disagree	7%	20%	19%
	2	6%	15%	14%
	3	22%	21%	14%
	4	19%	16%	17%
	5	21%	17%	20%
	6 strongly agree	26%	11%	15%

FIGURE 8 (TABLE 3) Results for Ease of Use

When asked initially if they thought their assigned display looked easy to use, most participants responded that it did not (53-64% across all three designs). Approximately half of the participants responded that their interface looked intimidating and even higher percentages of people reported that the displays looked confusing. NCI's was seen as the least intimidating of the three, by a margin of 6%.

The 25-second preview session in the experiment setting created a false break in what the user's experience would have been otherwise. It is possible that users' initial impressions would have been more positive had they been able to interact with the interfaces before responding.

On the other hand, the result suggests the importance of the entry way into each of the three designs. This is perhaps most relevant for Dataspark which likely looked the most unfamiliar to its assigned users and did not have the benefit of an organizational brand identity. CCR and NCI, though less usable in the end, have well known, credible brand identities that participants may have recognized. Whether recognized or not, the CCR and NCI interfaces are designed using drop-down menus and other common conventions, so it seems possible that they would have been perceived as more familiar.

We propose two ideas that might address this entry way problem for Dataspark:

- 1 Provide data gradually. During the initial loading, material could appear on the screen in steps, instead of all at once. For example, in the Dataspark design, it might have been valuable to show the state totals without the regional breakdowns first. (figure 9) Perhaps clicking on each circle would cause the regional dots to drop down.

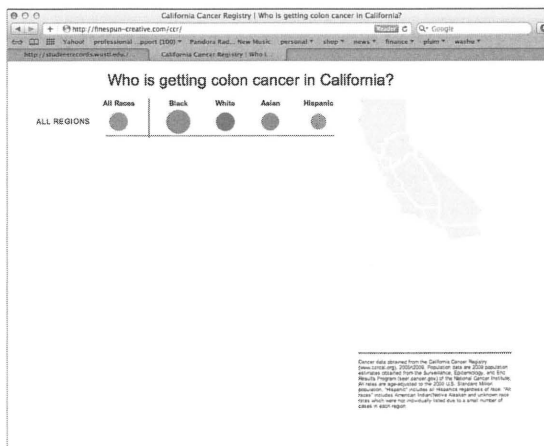


FIGURE 9 Manipulation of Dataspark design

2 Embed inside existing websites. If we had placed the display inside of an existing website with an established brand identity, providing related content and reinforcing the rollover approach to navigation, the user might have felt more comfortable at the outset.

After interacting with the displays and answering the quiz questions, all participants were again questioned about ease of use. On a scale of 1–5 (where 5 is easiest to use), 87% of those randomized to Dataspark responded with a score of 3, 4, or 5, compared to 53% of those randomized to CCR, and 58% of those randomized to NCI. For the authors, this result was the most important. The Dataspark approach was considered easy to use. Features of the design discussed above were likely important factors in that result.

In the larger conversation about engagement with cancer surveillance data, it seems critical that new approaches to usability that span computer screen and mobile device contexts be adopted.

ENGAGEMENT IN THE DISPLAY

The results suggest only modest participant engagement in all three of the displays (*figure 10*). There is some variability in the numbers that tends to skew positively toward Dataspark, but the differences are slight. Given that most Dataspark participants were successful in answering fact-based questions and found the interface usable, as described above, a lack of personal interest in the subject may be the culprit.

On the one hand, we might hope to test the display with participants personally affected by colon cancer. We believe that audience would find the Dataspark display more engaging than our convenience sample from the general public.

But the rationale for our experiment was that it allowed us to isolate best practices in data presentation, design, and usability. As we describe at the outset of this article, cancer rates and their disparities are social problems that affect us all. They are partially an outcome of individual and cultural behaviors; changing these would lower individual risk and collective rates over time, with significant implications for public health and healthcare costs. What we learn from this result is that the Dataspark display isolated and presented rates in a clear and usable way. For future work, we may want to design tools that address the content challenge more directly: people are unlikely to seek out this information in the absence of some personal connection. How can we build that personal connection?

		DS	CCR	NCI
The webpage is engaging.	1 strongly disagree	9%	16%	18%
	2	9%	15%	13%
	3	22%	18%	15%
	4	24%	22%	18%
	5	21%	15%	15%
	6 strongly agree	16%	14%	21%
The webpage's content interests me.	1 strongly disagree	10%	13%	19%
	2	13%	19%	13%
	3	16%	18%	10%
	4	22%	17%	19%
	5	24%	20%	22%
	6 strongly agree	15%	12%	16%
It is fun to explore the webpage.	1 strongly disagree	11.5%	18%	17%
	2	11.5%	16%	14%
	3	21%	22%	11%
	4	19%	17%	19%
	5	17%	16%	19%
	6 strongly agree	20%	10%	20%
Does this webpage make you want to learn more about who gets colorectal cancer in California?	Yes	35%	29%	37%
	No	49%	55%	49%
	Not sure	16%	16%	15%

FIGURE 10 (TABLE 4)
Results for Engagement

One way to address this problem is to experiment with the addition of new informational contexts for our prototype. For example, we could add an area of navigation at the bottom of our screen in which users are asked “What if” and allowed to select scenarios such as:

- “every citizen in California was screened for colorectal cancer at the age of 50?”
- “obesity rates in the state of California were cut in half?”
- “the smoking rate in California dropped from 13.7 to 5%?”

If users could watch the neutralizing effects of these changes on disparity, as well as the impact on the rates overall, engagement with the prototype (and also with screening, weight loss, and quitting smoking) might rise. Given what we learned from this experiment, we are now well positioned to design projects that isolate and prioritize engagement as an important factor.

PERSONAL RELEVANCE

Not surprisingly, given the results on engagement, the survey results also indicate modest levels of personal relevance of the interface (*figure 11*). This is likely because very few participants (<5%) across all three groups had been diagnosed with cancer in the past two years and over half of participants had no friends or relatives diagnosed with cancer in the same time period. Accordingly, only a small proportion of our participants reported having sought cancer information in the previous month.

DEMOGRAPHICS ON CANCER AND RACE		DS	CCR	NCI
In the last two years, have you been diagnosed with cancer?	yes	4%	7%	4%
	no	96%	93%	95%
	not sure	0%	0%	0%
In the last two years, have you had a close friend or relative who has been diagnosed with cancer?	yes	36%	38%	46%
	no	61%	58%	52%
	not sure	3%	4%	2%
In the past 30 days have you looked for information on cancer?	yes	14%	11%	17%
	no	85%	88%	82%
	not sure	3%	1%	3%
Please select one or more racial categories to describe yourself.	American Indian*	3%	3%	2%
	Asian	9%	8%	4%
	African American/Black	7%	8%	10%
	Native Hawaiian**	1%	0%	1%
	Caucasian/White	74%	76%	76%
	Other	6%	5%	7%
REFLECTIONS ON BEHAVIOR				
Did you look for information about how cancer affects the region where you live?	yes	56%	66%	53%
	no	41%	33%	44%
	refused/no answer	3%	1%	3%
Did you look for information about people in the same racial group as you?	yes	56%	19%	31%
	no	43%	80%	67%
	refused/no answer	1%	1%	2%

FIGURE 11 (TABLE 4)

Results for Personal Relevance

At the same time, more than half of all participants sought out information in the display about their own racial group; and more than half sought out information about the geographic region in which they live. This suggests some attempt to connect to the data through a personal lens. While that alone does not produce engagement or relevance, it does provide an insight about the importance of personal connection. If someone living in Los Angeles who is African-American reviews the display and notes that s/he is part of the group at highest

risk, is there an opportunity to introduce a story about community action that is specific to African-Americans in Los Angeles? One might imagine using such a tool on a smartphone and pulling open the big blue dot to get a deeper story. Results related to personal relevance did not differ significantly across the three different displays. From the authors' perspective, this highlights the importance of developing and framing the data and content in a way that is socially and then personally relevant, in addition to considerations of design and usability.

GENERAL ANALYSIS

Of the four questions posed initially, the results fell into two groups. The Dataspark design was successful in the categories of understanding and usability. Engagement and personal relevance ranked relatively low across the set of interfaces; the design and usability principles applied to the Dataspark interface did not make a significant impact in those outcome categories. We introduced our four categories as a range, in which understanding sits on one end and personal relevance on the other, with ease of use and engagement in the middle. We did this because we wanted to test whether baseline expectations of understanding and ease of use could be met. Our results validate this and we conclude that...

⋮ *data selection, design, and usability are critical and important factors in the display of cancer surveillance data.*

The Dataspark interface is significantly different from the other two interfaces—in data selection, usability, and visual design. Given that our goal was to translate data for the public, Dataspark has a more targeted communication goal—to show differences among rates according to race. Dataspark presents a smaller, more simplified dataset than CCR or NCI. This choice was made in direct response to general concerns about health information overload and a desire to cut through the clutter.

The user's access to that smaller dataset is controlled entirely by moving the mouse on the screen, not by making multiple-choice decisions.

⋮ *With Dataspark, users explore more than they decide.*

This is unlike CCR and NCI which require users to make choices about what they want to see, before they see it. For lay-people, these choices may be daunting or suggest a level of commitment that goes beyond their interest. We believe that Dataspark's rollover approach is appropriate for the general public. In addition, upon entry to the interface, the Dataspark user is presented with overview

data, organized by race and region. With CCR and NCI, the user is asked to make data selections from eight drop-down menus, and then to click “redraw” or “generate map” which generates a map. We believe that that initial presentation of data is important for the general public.

Dataspark’s data are displayed as a grid of circles, color-coded according to race, whereas the other displays plot the rates onto maps of California. With CCR and NCI, the user can select whether to show “all races” or individual races, but the interface does not generate a comparison between two groups with a single view. The purpose of the map in the Dataspark display is to reinforce where each region is located, not to show numerical data. Interestingly, the NCI site also allows the user to make map design selections, including interval, interval type, and color. This adds to the visual and textual complexity of the interface, perhaps making it even more daunting for the user. In both maps, color is used to represent a numerical range (darker colors representing higher rates), but hue shifts occur within ranges in some color iterations, which may obscure numerical clarity.

Dataspark attempts to assign specific visual properties to the communications challenges of rate (scale), race (color), and region (shapes within the map) in a clear and direct way. These individual elements are combined in the interface design according to principles of visual arrangement and hierarchy. Arrangement includes the matrix of dots grouped for visual viewing by race or region as well as the design of the interface itself which prioritizes the pattern of dots over components such as the map and supporting numerical data. Dataspark uses four different hues to represent race differences; scale shift describes numerical difference. The experiment did not ask participants to address these aspects of the visual design specifically, as it was thought that the synthetic nature of the design would make isolating particular elements challenging. But the differences in understanding and ease of use (after interacting) are dramatically in Dataspark’s favor—87% of Dataspark users responded with a 3, 4, or 5 to the prompt “It is easy to explore the webpage” whereas 51% of CCR users and 57% of NCI users did. The authors believe that the Dataspark display could now be refined further by testing variations with a set of users.

In spite of the impact of differences among the interfaces on understanding and ease of use, the categories of engagement and personal relevance appear to be unaffected. Engagement and personal relevance represent additional levels of effectiveness that we believe should be achieved through the development of digital tools such as Dataspark. Given the results of our experiment, we believe that we are now well positioned to focus attention on both of these areas. We are of two minds about this. On the one hand, cancer statistics

and surveillance information could be directed to people affected by cancer, or even a smaller subset such as people affected by cancer who wish to understand differentiated risks. Some of the people in the latter category might include policy makers and health professionals whose basic decision-making could be affected by tools such as these. If this is our audience, then we have made a good start in developing a tool that they are likely to find useful and relevant.

On the other hand, if we view the problem as causing cancer surveillance data to have impact for the population as a whole, then we have challenges in engagement and personal relevance that will require significant work. Improving communications to the public is already a priority in many corners of public health. For cancer surveillance data, we envision connecting rates to health and wellbeing opportunities in a given community defined along geographic, racial/ethnic, gender, age, or other lines. Technological innovation and social media have fueled our ability to design tools for users to navigate interfaces in nuanced, exploratory ways which we believe makes this more possible than ever.

Even in the face of the challenges of building engagement and relevance, our clear finding that design aids understanding remains important for communicating to the public.

It also has application for categories of health data far beyond cancer surveillance, many of which have been largely untouched by experienced designers.

These include research and experiments in disease risk and prevention, doctor and healthcare provider communication with patients, training materials for new doctors, and public or semi-public reporting of other systematically collected, government data. Large, national media outlets such as The New York Times have led the way in creating higher standards for communicating health data. But information production continues to swell. There are and will continue to be opportunities on local, regional and state levels that require urgent attention in order to improve health overall and reduce health disparities.

Our team's initial charge was to find ways of making cancer registry data more accessible and meaningful for the non-scientific public. We have since built a tool that empowers cancer registry scientists to do this themselves. The tool is an information graphics "generator" (dataspark.org) which allows scientists to upload spreadsheets of registry data and translate them into a designed, interactive output, with a dedicated url. The project is a direct outcome of the positive response of the Dataspark designs in the categories of understanding and usability. Scientists who use the tool are able to target

their audiences more specifically than our experiment did, which we believe will address some of the challenges of engagement and personal relevance, though perhaps not for the general public.

The transdisciplinary nature of this project allowed us to work with significant depth in the fields of epidemiology, health communication, design, and usability, while simultaneously working across them. We believe that fusions of disciplines such as this one will be critical in moving forward on the complex problems embedded in public health and policy.

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