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Report on the Formative User-Centered Testing of Consolidated Cancer Statistics on the Surveillance Epidemiology and End Results (SEER) Website

Reference Number: 11-4021 NCI

Usability Evaluation

Conducted by User-Centered Design, Inc.

For the

National Cancer Institute's Data Modeling Branch of the Surveillance Research Program

September 2012

Executive Summary

NCI's Surveillance Research Program (SRP) within the Division of Cancer Control and Populations Sciences (DCCPS) provides cancer information via the Surveillance Epidemiology and End Results (SEER) project. These data, spanning US incidence, prevalence, mortality, and survival, provide a means to measure progress in various aspects of the effort to reduce cancer

burden. To ensure usefulness of the data, SRP hopes to communicate these cancer statistics to many different audiences including researchers, health professionals, the media, and the interested public. To further improve the communication of cancer statistics, the collection of feedback via usability evaluations of SEER data visualizations was proposed in June 2011 and completed by September 2012.

To carry out the objective of this project, User Centered Design Inc. (UCD) conducted multiple heuristic evaluations (expert reviews) of concepts developed by the University of Washington in St. Louis (UWSTL). In addition to the heuristic evaluations, two user-based usability evaluations were conducted. The first usability evaluation focused on the needs of researchers and other "statistically savvy" users. The focus of the second usability evaluation was centered on the needs of the "concerned public" and the press (media), who were considered to be less "statistically savvy" users.

The first usability evaluation was conducted in July 2012 and explored the needs of statistically savvy users via the Google Public Data Explorer (GPDE) to visualize SEER data. Groups of datasets were developed that contained the different types of SEER data (incidence, prevalence, mortality, and survival) that allowed the GPDE to be used in the context of SEER data. Researchers who currently use SEER data for work were recruited to participate in this round of usability evaluations to determine what features of a tool might be useful.

The findings from the first round of interviews showed that sharing and exporting results were reported to be one of the most important features for SEER visualization tools. However, participants had difficulty learning how to use the GPDE and did not find it particularly useful for research purposes, particularly the "bubble graph" feature. There were also some limitations noted that suggested the need for more extensive data sets if this approach were used. One notable example was that all participants indicated they used different SEER registries and data sets depending on their data needs, so all data sets and registries would need to be represented in a useful tool. A visualization tool was seen as "nice to have" for researchers, however most participants reported that they would want more options than the GPDE had to offer.

The second round of usability evaluations was based on a series of static data visualizations developed by WUSTL and IMS. These displays were designed specifically to support the need for general/introductory cancer statistics at a less granular level than data used by cancer researchers. The purpose of this round of testing was to determine which displays were understood and preferred by less "statistically savvy" individuals, focusing on the content for an introductory "At-A-Glance" section.

Participants representing the general public indicated they would want to see one form of the following statistical data: estimated cases and estimated deaths, 5-year survival rate, and lifetime risk data as part of the “At-A-Glance” section. Many participants did not include the other types of visualizations for this section. Both the public and media audience provided feedback on what types of graphs were easily understood for incidence, mortality, survival, and risk data and whether terms often associated with them on the SEER website (such as “relative survival,” “joinpoint trends,” “new cases” vs. “incidence”) made sense. Recommendations for presenting graph scales, cases per population and trend data were provided.

Overall, feedback from 17 individuals was collected and interpreted as possible recommendations for improvements to cancer data visualizations. This report documents all the activities of this project as described above. All documents used for testing are attached in the appendix following the report.

Table of Contents

Introduction

The SEER website currently offers several tools for viewing cancer statistics. However, most of the current tools can produce only tables or fixed data visualization with limited customizability. Two parallel efforts were conducted to develop better more useful data visualizations in the hope of supporting two main audience types – individuals who use detailed statistical data (e.g., researchers) and those interested in cancer statistics yet potentially less statistically savvy (e.g., the public and the media).

The idea for a different tool that may better suit all primary audiences by producing customizable visualizations was conceived. Usability interviews were proposed in order to extract features and functions that were important to members of these audiences. Various alternate displays were developed to gain insight on the data potential users are looking for and how they want to visualize the data.

UCD was contracted to help assess the usability of the materials developed for this project. This final report documents the methods and findings of all activities.

Method

The project was conducted in two phases.

Usability Evaluation One

In July 2012, Usability interviews were conducted on a PDF mockup of a proposed design for the SEER website which used the GPDE for data visualization. The focus of this round of evaluations was to:

- Gain insight on how researchers use SEER data
- Explore functional requirements for a visualization tool
- Explore specific design elements inherent in the GPDE

A total of eight participants performed a combination interrupted, task-based protocol and a semi structured interview. Sessions were conducted remotely using the conferencing tool GoToMeeting and lasted approximately 60 minutes.

Participants were volunteers with varying levels of knowledge and experience using SEER data for research. They had varying affiliations, including universities, industries and state cancer registries. Most participants reported that they use the SEER*Stat software to obtain data, but use a separate analysis software/visualization tool to manipulate it. About half the participants reported that they create visualizations of the data to share with others. All participants were

familiar with SEER data and statistics types, even if they did not commonly view a particular statistic type for their research.

The PDF mockup provided navigation to the GPDE via a proposed design of the SEER website. "Data Explorer" was the section of the proposed website where the Google tool could be accessed. Participants were instructed to choose a data set from the "Data Explorer" tab's menu to visually explore. Three to four static screenshots of basic sample visualizations were shown as examples on the main page for each data set. Each display offered the hyperlinked option to "customize" the output with the GPDE (which offered the ability to manipulate the data). Participants clicked the "customize" link in the PDF, which opened the GPDE in a browser window, where they interacted with the tool on its external site. Feedback on the visualization output and experience with the GPDE was provided and recommendations for features to include on a potential SEER tool were reported.

Usability Evaluation Two

One round of usability testing was conducted for the SEER Cancer Overviews, which occurred in September 2012. The objective of testing was to explore if participants could accurately interpret the data from the visualizations shown, and if they preferred alternate displays (in terms of both content and format).

A total of 9 participants participated in this round. Six of the participants were recruited to represent the general public. They were recruited based on two criteria. The first was that they had some experience with cancer and seeking cancer information online. This experience could have involved finding cancer information for themselves, or for a family member or close friend. The second criterion was that they did not have a specific background in mathematics or statistics. These participants were recruited through a recruiting database. The six people who participated represented a mix of ages, genders, races, and backgrounds.

Three additional people were recruited to represent the media audience. This group, unlike the group representing the general public, was required to have a specific background in reporting cancer- or health-related statistical information to the public. Participants in this category were recruited by the National Cancer Institute's Press Relations office.

None of the general public participants stated they had any experience, or at least did not recall ever visiting, the SEER website. They did indicate that they had searched for cancer-related information on the web from various sources. These sources included groups known to have specific cancer information such as the American Cancer Society and Susan G. Komen for the Cure. In other cases, participants mentioned doing a browser search and clicking on whatever resources were returned. A few of the participants recruited indicated that they had specifically

sought out statistical or numeric information on cancer. However, they did indicate that they were often looking for other information (e.g., treatment options) but came across statistical information and took note of it.

The three participants representing the media indicated that they had sought out information for themselves on the SEER website; however, none of them were certain which parts of the SEER website they had used. After visiting the website as part of the evaluation, all of these participants indicated that they had used the current Fact Sheets section on the SEER website.

The participants representing the general public were shown all of the options for the "At-A-Glance" section of the proposed alternative layout for the cancer fact sheets. If alternatives were available, the participant was asked to explain which one they preferred and why. The detailed version of the data was shown to help determine if they had understood the summary graphic.

Participants representing the press were shown the fact sheet one element at a time. In doing so, they were able to see the graphic as a detailed description along with its accompanying text. They were allowed to pick the order they would like to see the various elements.

The findings of both usability evaluations are included below.

Findings

Usability Evaluation One

The findings are categorized into 4 groups: cancer terms and concepts, usability tasks, tool functionality, and tool interface issues.

Cancer Terms and Concepts

Incidence, Mortality, Prevalence, Survival and Risk statistic types were all represented in the datasets the participants were shown in the Data Explorer menu. All participants stated they were familiar with the statistic types mentioned in the datasets (see Figure 1). The types of data reported to be used most often were Incidence, Mortality, and Prevalence. One participant was unaware that Risk data was available on SEER.

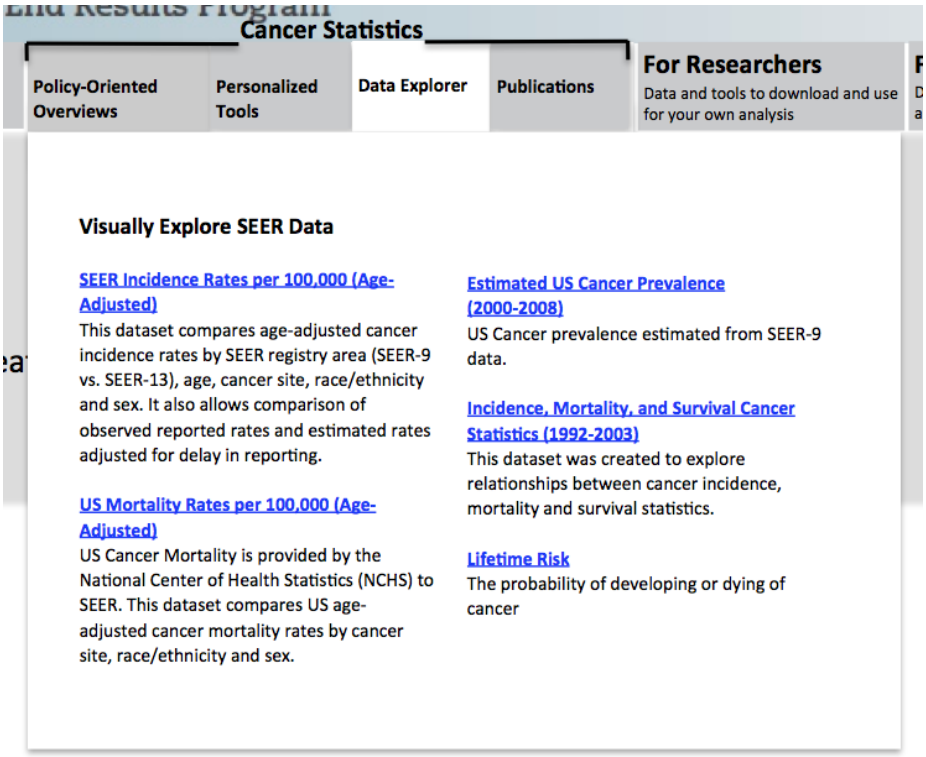


Figure 1: The Data Explorer Menu, Showing Available Datasets.

SEER Registries

When asked about the SEER registries, some participants mentioned they look for the data that has the greatest detail on race/ethnicity or is the most recent (at the time of testing, this was SEER 17). Others mentioned using SEER 9 when long-term comparisons must be made (noting this may be used when looking at prevalence).

> *Recommendation: If the concept of listing datasets is used, ensure that multiple registries are available in each dataset.*

Understanding Age-Adjusted Data

Participants understood the concept of age adjustment. However, some wanted to make sure they knew which age adjustments were being used and even wanted the ability to specify the type of age adjustment (e.g., US versus World). Age adjustment was mentioned in the title in the example shown in Figure 2, but it gave no additional description.

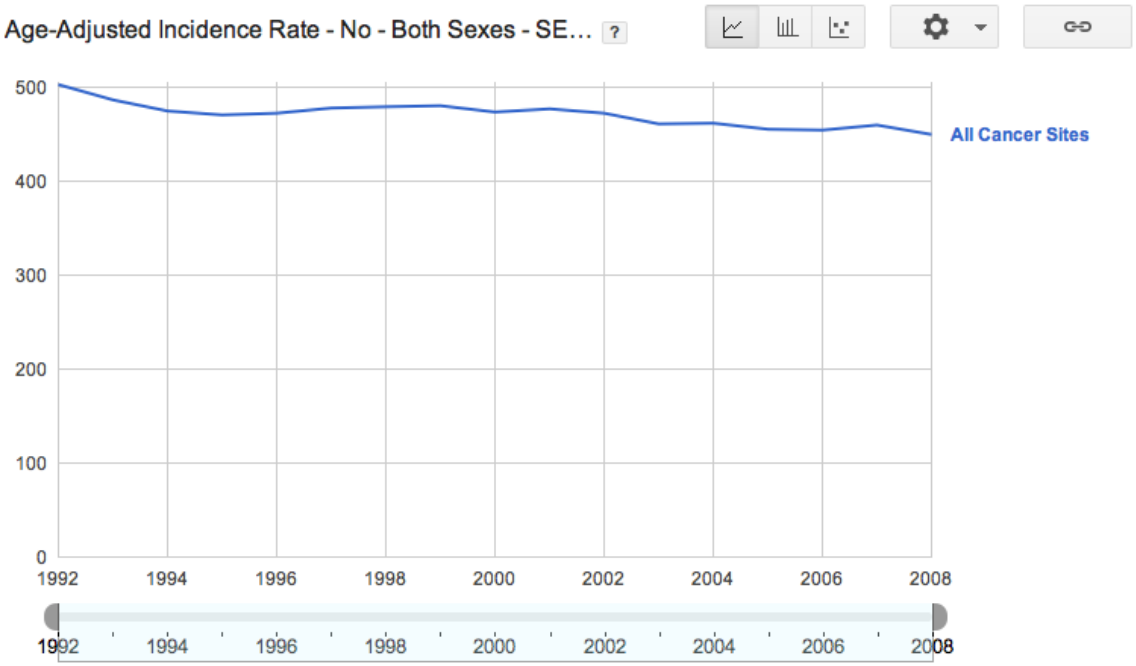


Figure 2: Example of Age Adjusted Data.

Understanding Delay Adjusted Data

While exploring incidence, participants were asked to comment on the term "Adjusted for Delay in Reporting." A few participants were unaware of the term, but found the explanation in the "?" box (located to the right of the title in Figure 3) to be sufficient. Some knew what the term was but they did not use these types of data in their work. Others knew both the term and the data.

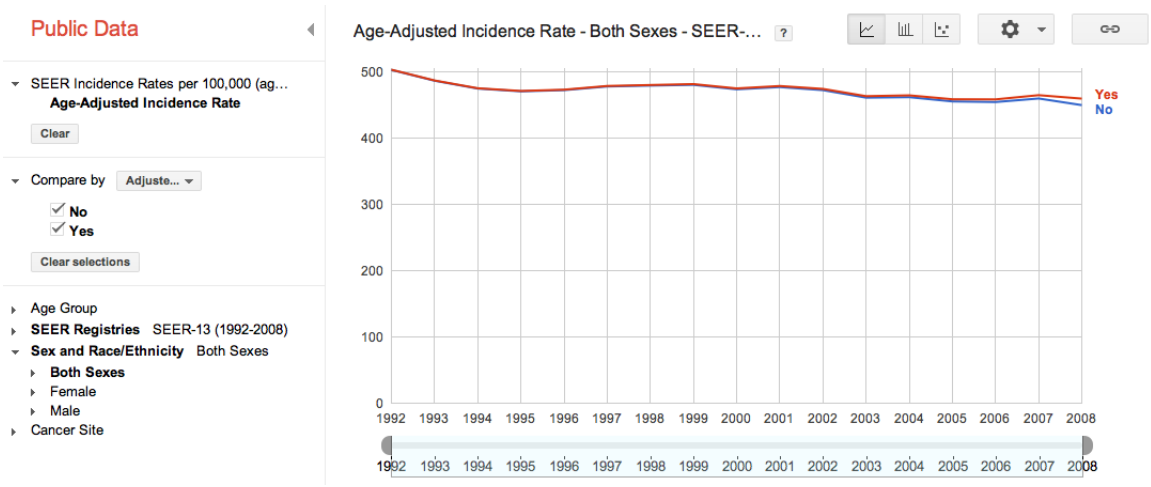


Figure 3: Example of Delay Adjusted Data.

Cancer Site Listing

When asked to discuss the listing of cancer sites in the tool, most participants agreed that alphabetical listings made sense. However, they did notice that each dataset had slightly different options. In Figure 4 below, an example is shown highlighting the different options for colon cancer. Two participants specifically questioned the mortality dataset's listing of both "Colon" and "Colon and Rectum." Most participants thought the grouping example for incidence made the most sense. One participant observed the "No Parent" drop-down on the incidence data and said she didn't know what it was (although this is an artifact of the GPDE).

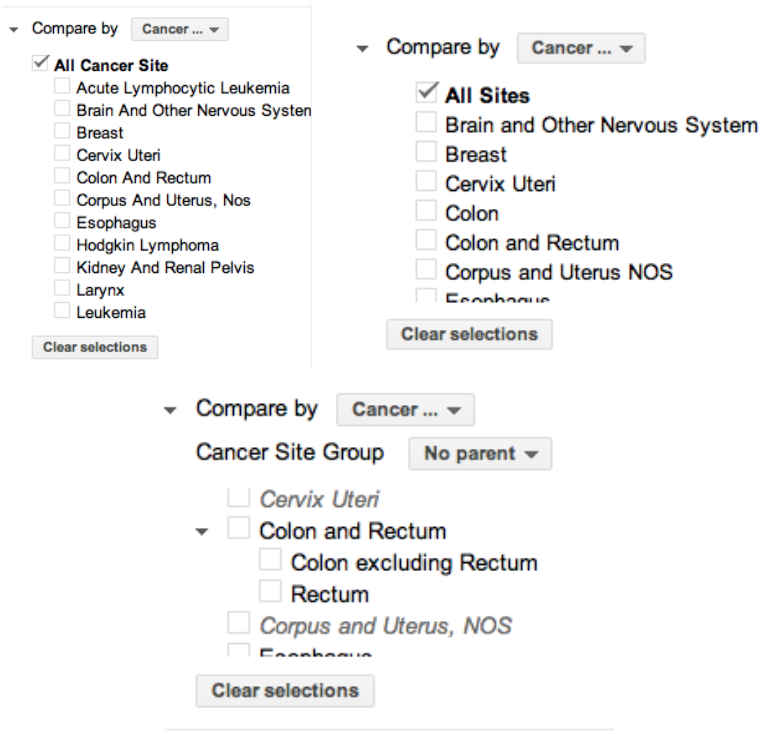


Figure 4: Examples of Variance in Cancer Site Listing.

Usability Tasks

Displaying the Top Five Cancers

When asked to create a graph displaying the top five cancers for that statistic type (example shown in Figure 5 below), about half the participants looked in the "Compare By" menu for an option to rank cancer types. A few were unable to create a graph without help, but most eventually found the bar graph to complete this task. It was mentioned that not all participants realized the bars were clickable, so one participant moved their cursor over the bar to read its label, then searched the cancer site list to select it. Some participants mentioned the labels overlapped and obstructed the data, and all commented about not being able to deselect the "All Sites" bar in the mortality dataset.

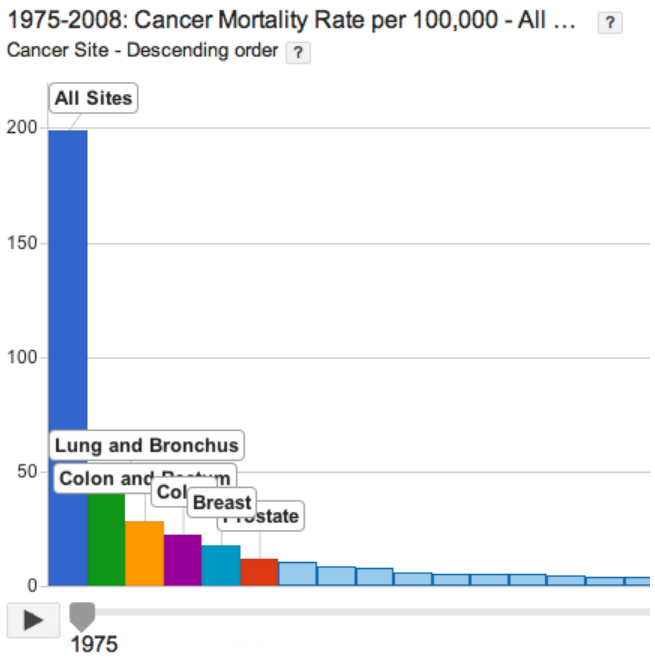


Figure 5: Top Five Cancers for Mortality Rate, Showing Overlapping Labels and "All Sites" Bar.

Comparing Male/Female Lung Cancer

When asked to create a graph comparing lung cancer in males to females, most participants created a graph like the one shown below in Figure 6. Almost all participants knew to look in the "Compare By" drop-down if they had discovered or were shown the function previously. However, since most participants started by selecting lung cancer while in the Compare by Cancer mode, they were unaware that their selection of lung cancer had been removed after choosing Compare by Sex. After this had been explained, it was common for them to mention that the title did not give clear indication on what cancer was selected.

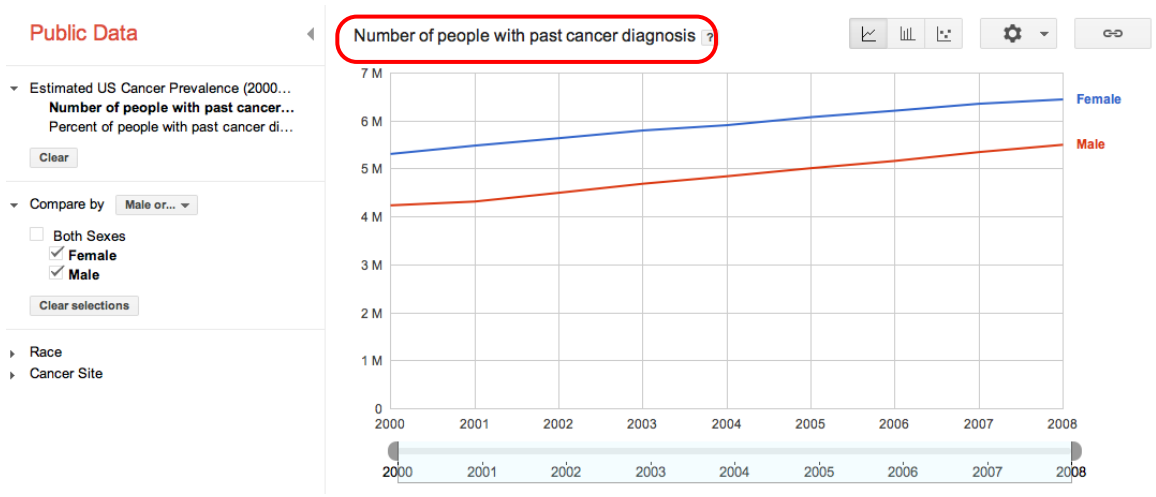


Figure 6: Cancer Prevalence for Males vs. Females, Where the Cancer Site Is Unclear.

Understanding and Creating Bubble Charts

While exploring the bubble chart display (example in Figure 7), participants seemed to experience difficulty in both selecting statistic types for the axes and arranging them to make a meaningful display. They also remarked that this was the most complicated part of the tool (the user is essentially viewing three types of statistics over time) and may have a high learning curve to produce valuable displays.

As for the utility of the bubble chart, most participants commented that a chart of this nature would not be useful for their work. A few commented that it might only be interesting to use in a PowerPoint presentation, but they weren't sure how to save the chart so that it would be interactive. The majority of participants also wanted to clear unselected cancer types to see only one or two cancer sites at a time, as all the additional bubbles made the chart confusing and overly complex.

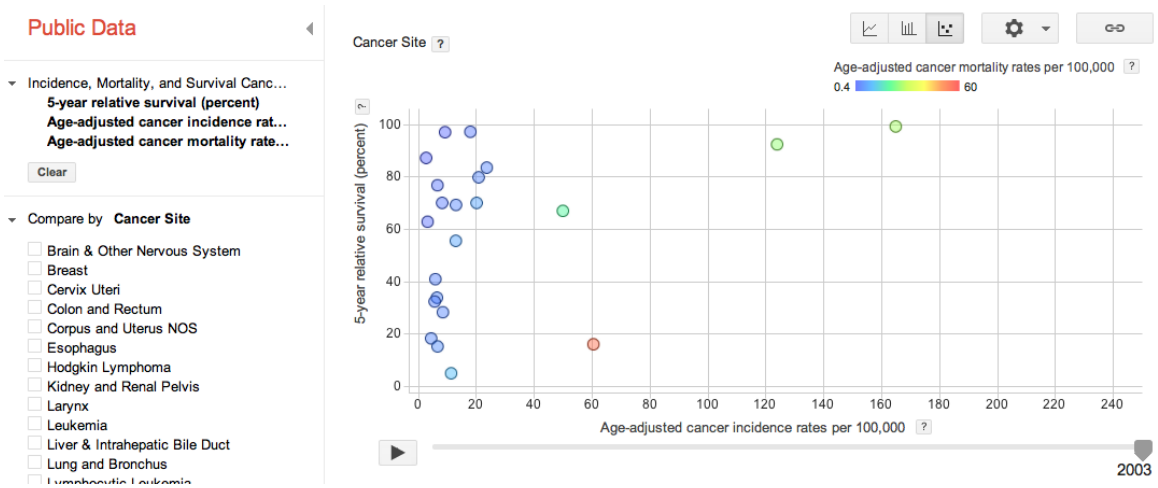


Figure 7: Bubble Chart Display in the Google Public Data Explorer.

Tool Functionality

Proposed Use of a Similar Tool

Participants described the GPDE as a good tool for a "first/quick look" or "preview" of data. Most participants said they could picture themselves using a tool like this for a slide for a presentation, a quick explanation, or for a class lecture, but not for research purposes. Additionally, all participants agreed that they would not want a similar tool to replace the tools they already used but believed a tool like this would be an additional tool offered by SEER.

Tool Branding

Participants stated that they would ideally want to remove the Google branding before sharing outputs from the GPDE. An example showing this is seen below in Figure 8. None of the participants had or knew of a third party screen capturing tool that could perform this task for them (e.g., SnagIt). They hoped the tool would provide a feature to perform this task automatically.

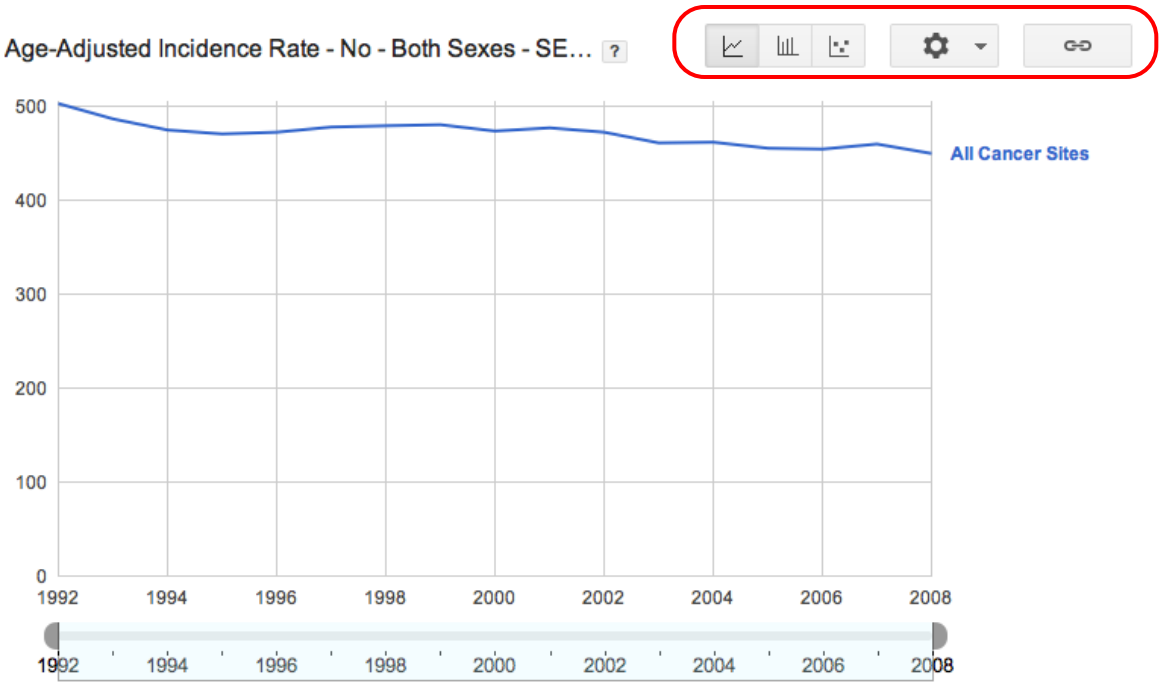


Figure 8: Google Branding Shown in an Output.

De-clutter Graph Labels

When selected by the user, the data labels almost always overlapped, which cluttered the display (see Figure 9). Participants mentioned they would want a cleaner look for their visualizations and did not figure out a way to move the labels.

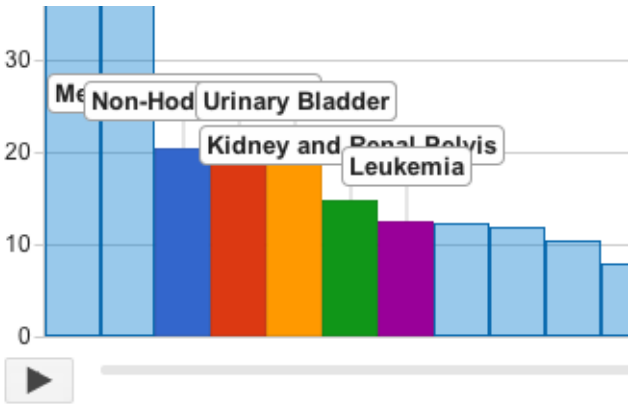


Figure 9: Close Up of Label Cluttering.

Adjust Appropriate Labeling Locations

Data labels on some of the outputs were an issue. In the example below in Figure 10, the label for the exact data point is shown to the left of the graph, away from the highlighted bar. Participants reported that this situation made it difficult to scan the display and compare to other bars. A change to both the formatting and the options for labeling were reported as desired features.

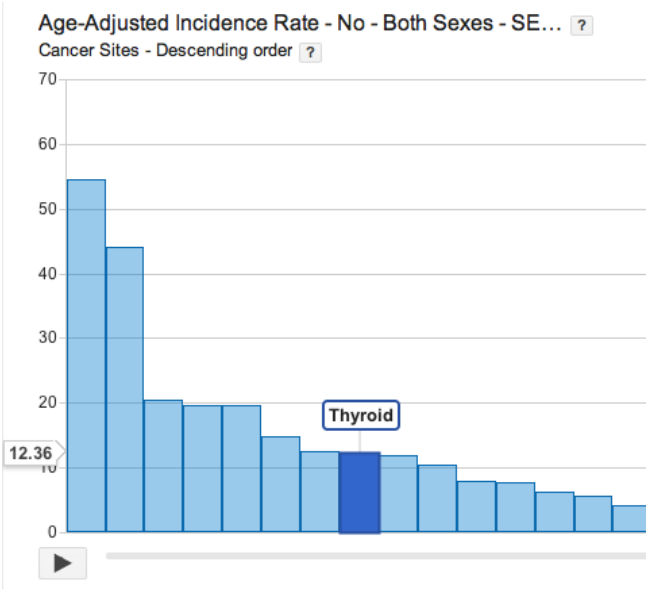


Figure 10: Undesirable Location of a Data Point Label.

Remove Unnecessary Data

Participants noted that unselected data points were distracting and wanted to visualize only data they had selected. An example of this problem is shown in Figure 11. Here, Breast and Prostate cancer are highlighted and labeled, but the other cancer sites can be seen (albeit as partially opaque) on the left side of the graph.

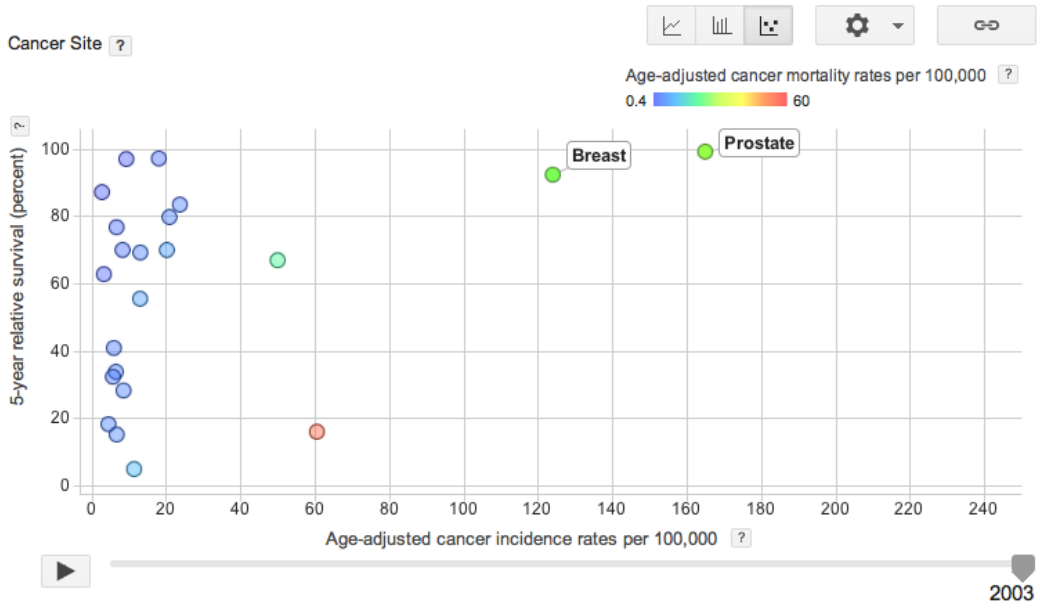


Figure 11: Example of Unselected Data Appearing on a Display.

Comparing Across More Than One Attribute

One of the most limiting aspects reported by participants was the inability to compare more than one attribute (e.g. race, gender, age). As seen below in Figure 12, the GPDE's "Compare By" menu only allows for one selection, and the combined sex and race/ethnicity category does not allow for comparisons such as Black Female vs. White Male.

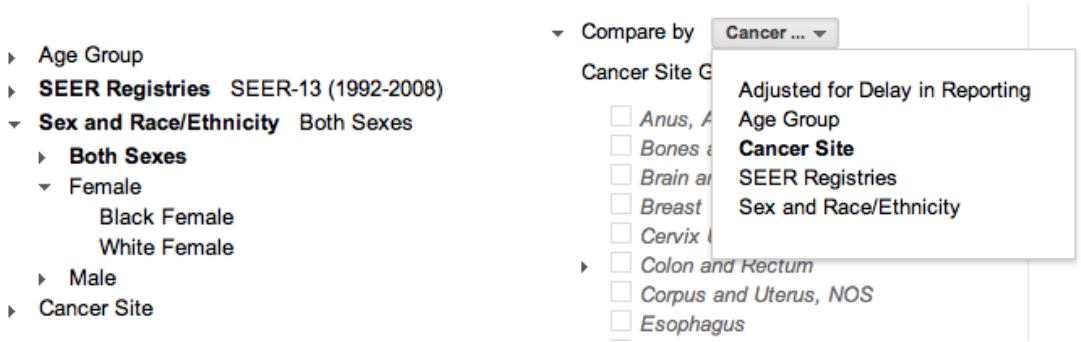


Figure 12: Example of Limitations in Comparing Across Multiple Attributes

Considerations for Sex-Specific Cancers

Some cancers are sex specific (e.g., prostate cancer). Other cancers are commonly displayed in a single gender view (e.g., Breast cancer is commonly only shown with data from females).

Participants were uncertain how the GPDE displayed these cancers and felt that some displays were incorrect. For example, prostate cancer is shown in the tool with the option of showing male prostate cancer, female prostate cancer, and prostate cancer for both sexes in Figure 13. The value of showing prostate cancer with a denominator representing the total population may have some utility, but the ability to view data for "female prostate" made participants question the validity of the tool.

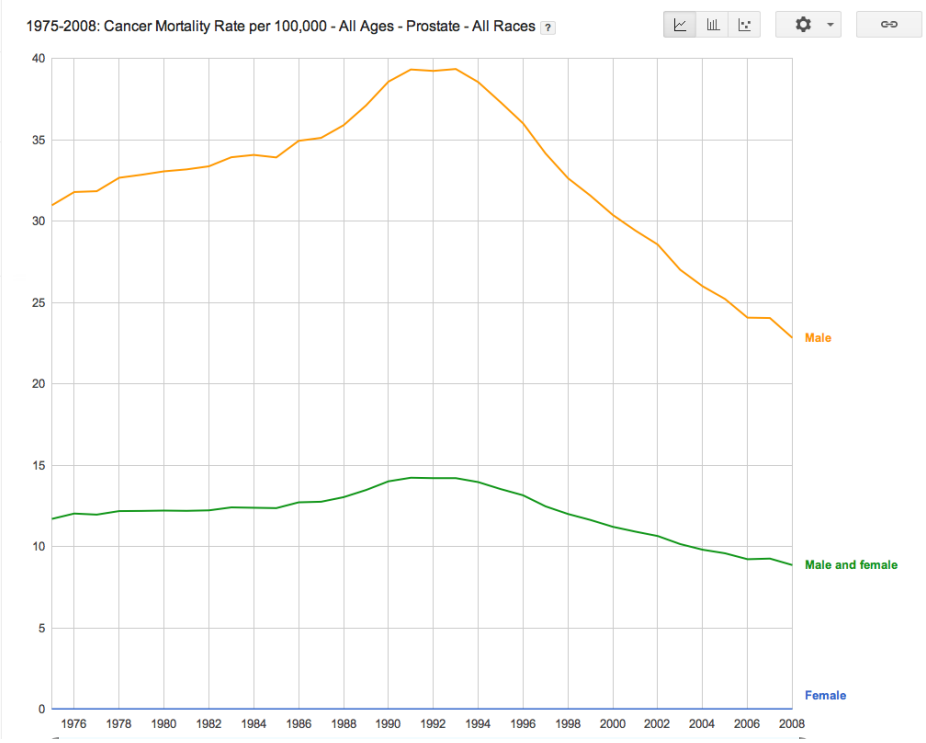


Figure 13: Prostate Cancer Mortality Shown Comparing by Sex

Breast cancer data had a near opposite problem. The GPDE shows breast cancer in a fashion consistent with other cancer types (the user can select male breast cancer, female breast cancer, and breast cancer that combines both males and females as shown as in Figure 14. This is consistent with the other cancer sites, but it is common to see an option for "female breast cancer" or "breast cancer (female)" when looking at breast cancer data. Due to their uncertainty, some participants tested multiple displays with the tool to ensure they knew which denominator was being used.

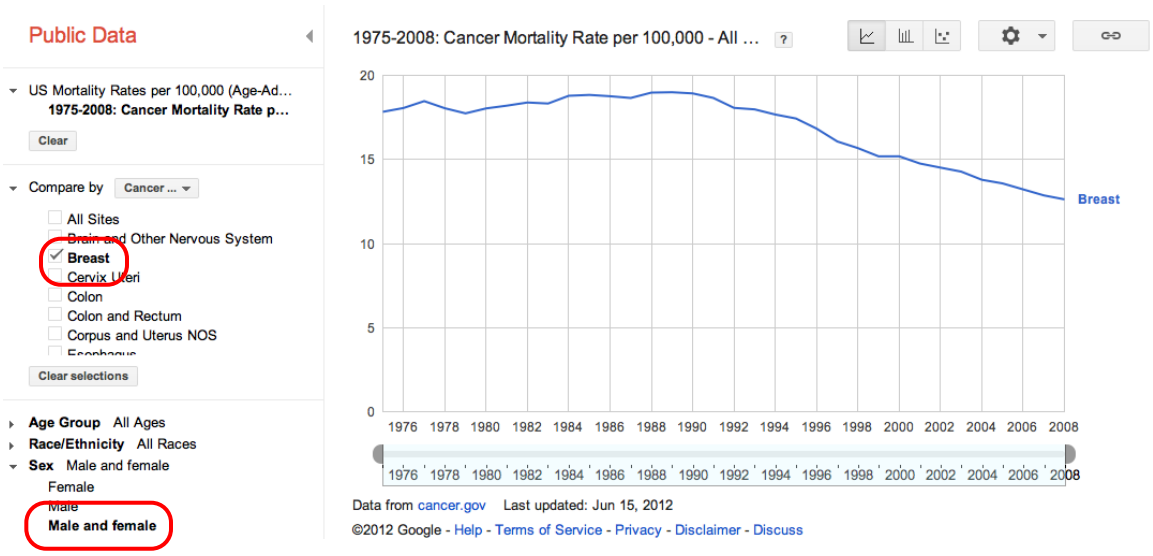


Figure 14: Breast Cancer Mortality Shown With Male and Female Sex Filter Selected.

Recommendation: Consider labeling all sex-specific cancer data with the sex represented in the data if only one sex is included (e.g., "Female Breast Cancer" or "Breast cancer [Female]").

Other Desired Functionality

Some participants mentioned they would want more specific functionalities, including the abilities to:

- Interact using histology/morphology codes
- See treatment data or data by region
- Break down data by each registry
- View data in a table format
- Obtain case listings

Almost all participants mentioned they would want options on exporting the data, both in raw form and as a PDF/graphic. This was mostly mentioned for ease of sharing, but one participant wanted to customize things like the title, colors, or scale. A few participants also noted they could not see how the GPDE would connect with other software (such as joinpoint, etc).

Tool Interface Issues

Display Controls

Almost all the participants found the controls for changing the display (shown in Figure 15) while checking the tool out. However, only a few participants noticed that the X -axis changed on the bar chart when switching between line and bar graphs.

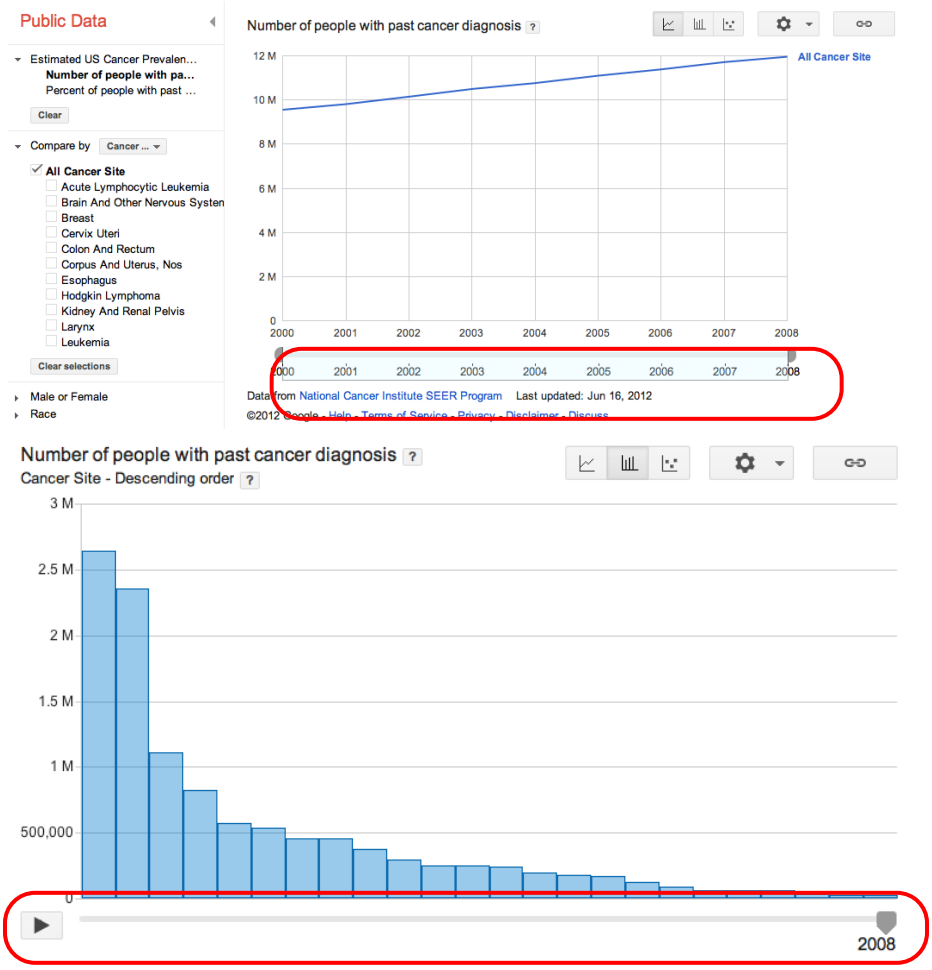


Figure 15: Different X-Axis for Line and Bar Graphs.

Issues While Exploring the Tool

The first item participants explored was the cancer site selection, followed by the sex and race selections (shown in Figure 16). However, all participants assumed they could select multiple sexes/races in their current view (most tried to ctrl click to multi-select). About half the participants needed to be shown the "compare by" drop down menu in order to perform their intended comparison. After being shown the menu, most participants then understood how to

interact with the drop down menu, except one participant who tried to click the "?" boxes to make selections.

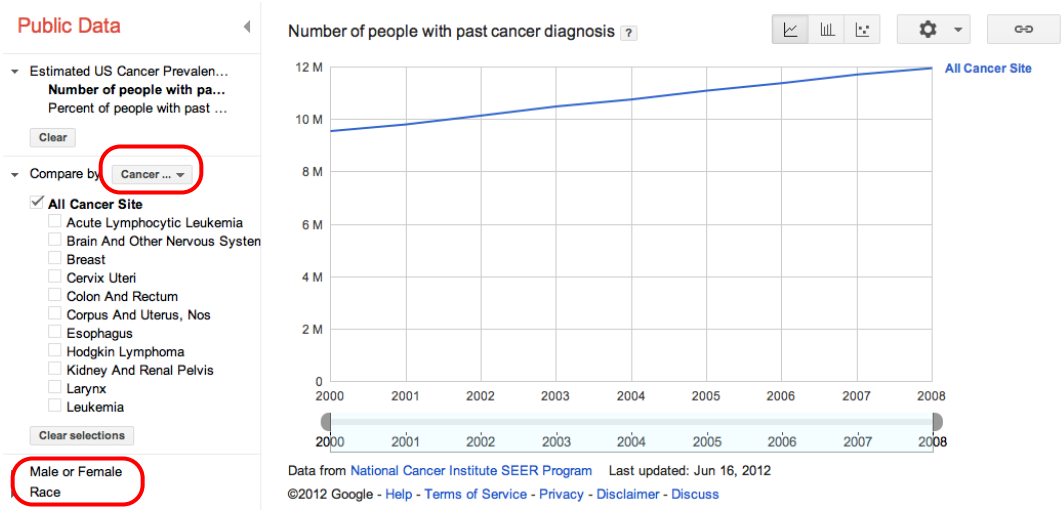
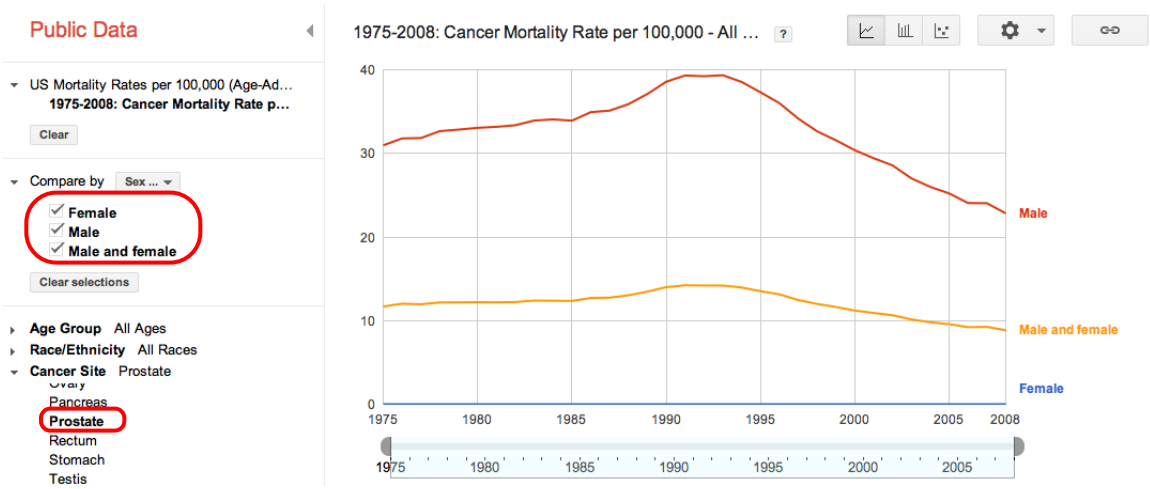


Figure 16: Areas of the Tool That Were Explored First.

Male and Female Rates for Sex-Specific Cancers

Another inconsistency noted by a participant was whether or not an error occurred by selecting the "wrong" sex for sex-specific cancer sites (such as prostate - female). For example, as seen in Figure 17, the mortality dataset shows lines for both male and female (with the female data line consistently perceived to be 0), but the incidence graph reports an error and does not show a display. It was also noted that some researchers might want to explore male breast cancer, and therefore would not be able to display data of interest.



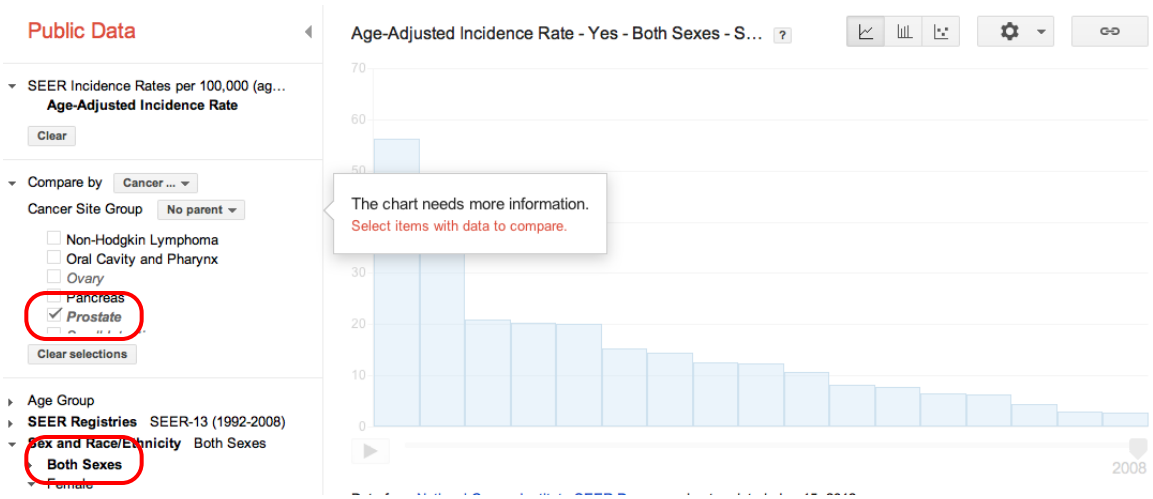


Figure 17: Inconsistency in Reporting Prostate Data by Sex.

Changing Selections in the "Compare By" Menu

After selecting the "Compare by" Male/Female option while viewing a "Compare by" Cancer Site display, participants were surprised to find that the cancer sites they previously selected had been removed (as seen in Figure 18). Many participants did not realize this had happened until they were told to double check which sites were selected. Again, participants noted the title of the graph was not descriptive enough to reflect this change.

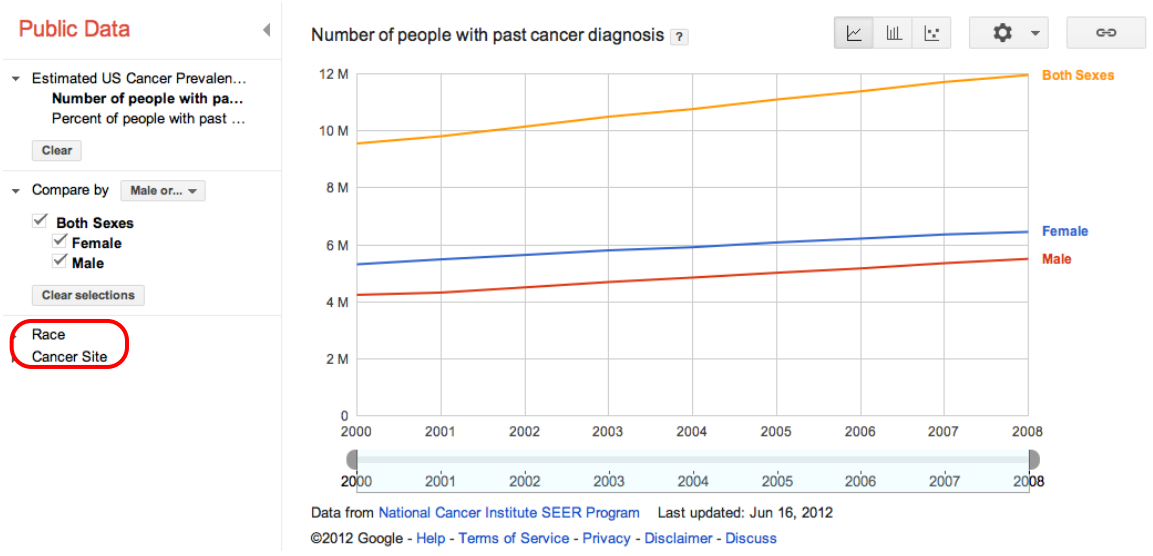


Figure 18: Male/Female Comparison Graph without Feedback on Cancer Site.

Timeline Slider

Some participants commented on the X axis having two timelines for graphs such as the one shown in Figure 19, but only a few discovered the sliders on the bottom line changed the timeframe for the data shown. After having this function demonstrated, most participants were unhappy with the scale of the data (assuming it would allow them to see a close up view).

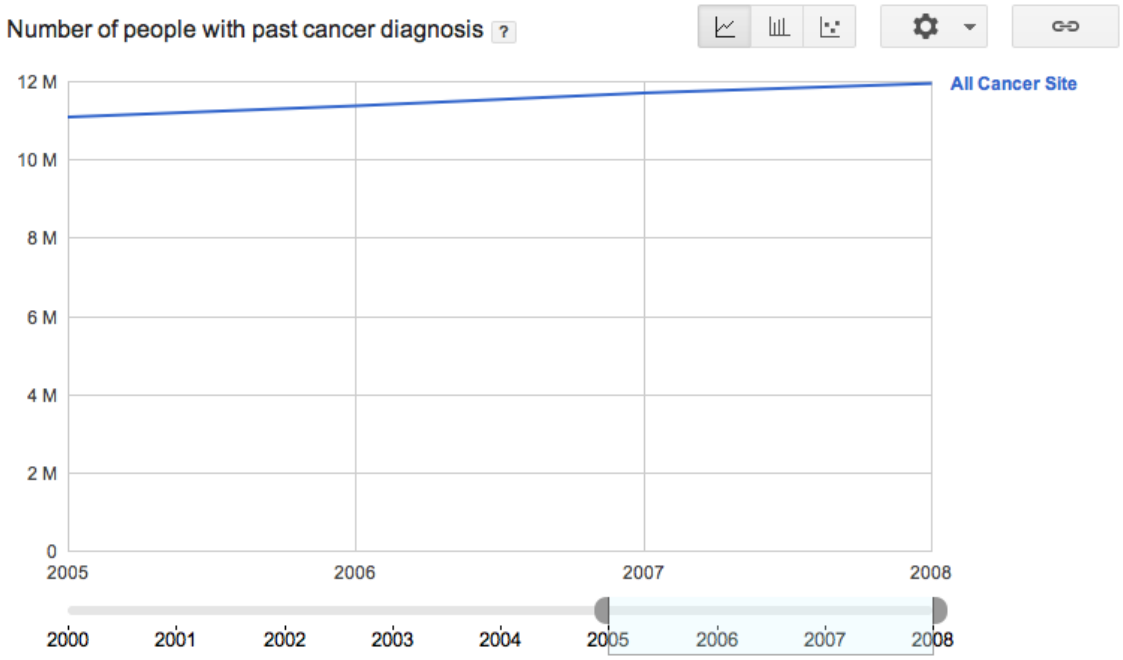


Figure 19: Example of the Data Display With Slider Scaled In.

Options Menu and Link Functions

Some participants found the options menu (see Figure 20) while checking out the display options, although no one elected to make any changes. Other participants explored this menu when asked to find a way to share or export the display.

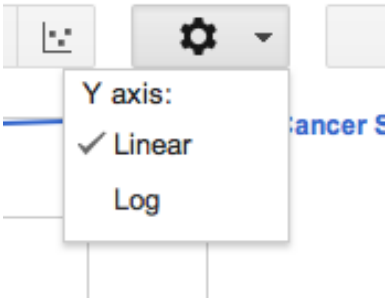


Figure 20: The Options Menu.

Most participants saw the hyperlink menu shown in Figure 21 while checking out the display options, and explored it when asked to find a way to share or export the display. The link function was understood but a few participants reported not understanding how the embedded HTML might be used (for example, if it could be copied and pasted directly into a PowerPoint presentation).

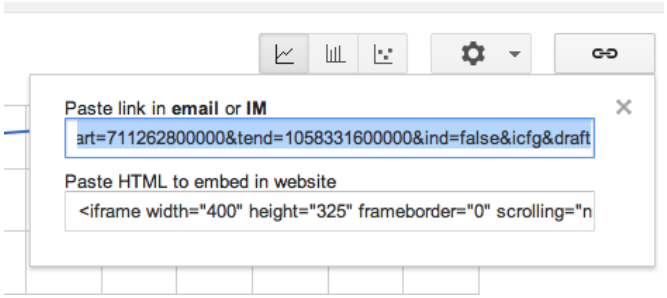


Figure 21: The Link Menu.

Bar Chart Functions

Most participants placed their cursor over the bars on the bar chart and saw the labels as shown in Figure 22. A few had specific cancer sites already checked before producing a bar graph display so those cancer sites appeared to be highlighted on the bar graph; however, almost all the participants were unaware that the bars could be clicked and highlighted from the graph. Most were also unaware the data could be "run" over time and had difficulty locating the "run button" when instructed to find it.

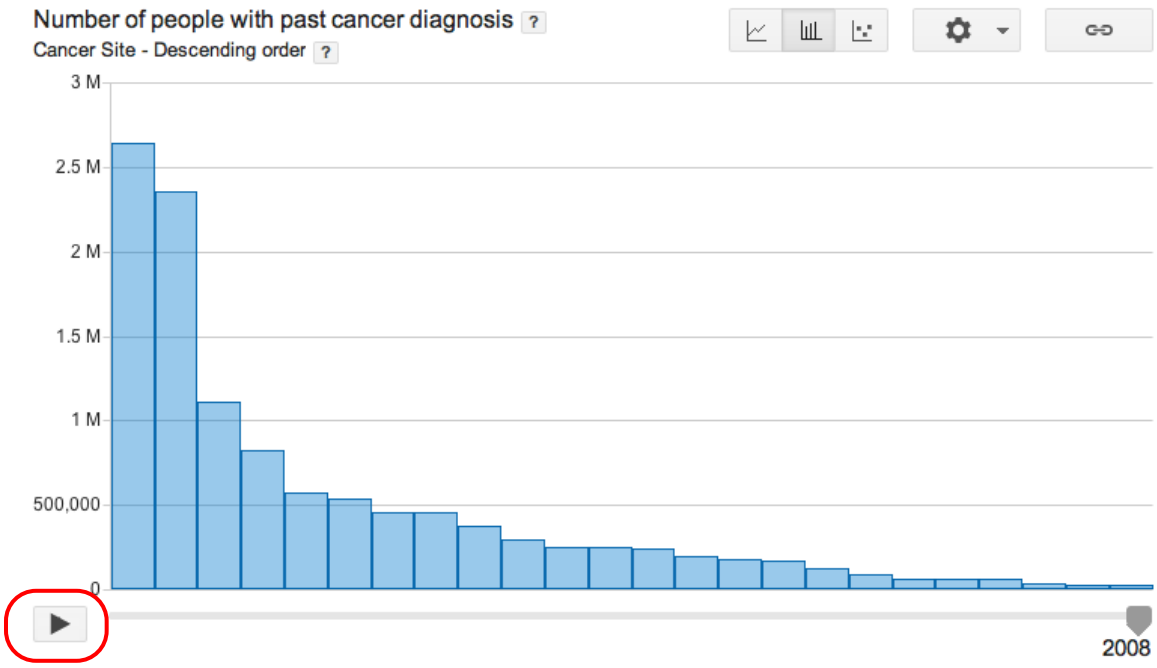


Figure 22: The Button Which Shows the Change in Data over Time on a Bar Chart.

Running Data Over Time

Almost all the participants responded positively to seeing the data change over time after pressing the "run" button at the bottom of the bar graph display. However, a few participants noticed that the bars on the graph seemed to change smoothly between years (and didn't "jump" to a different value each year). One participant assumed the data reflected monthly figures – that there might be twelve data points between two years, and that the "jump" between each point was not discernible. This participant dragged the slider slowly to see if he could determine the exact month in 1980 when prostate cancer surpassed colon and rectum in mortality rate. He was unable to tell, and the slider snapped between 1980 and 1981 when trying to click it incrementally (suggesting there is only yearly data). The difference in displays for those years is seen below in Figure 23.

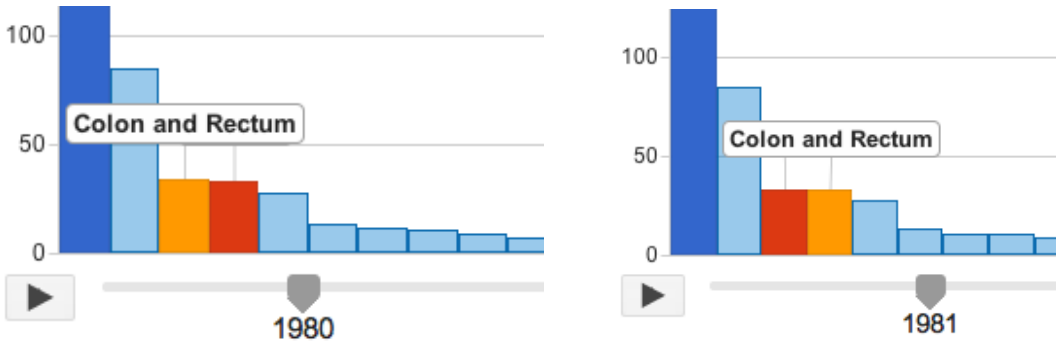


Figure 23: Slight Change in Data when Comparing Two Years.

Accessing Other Selections

A few participants experienced some trouble clicking the small arrow to open the options for the additional selections at the bottom of the left menu. The arrows to the drop down menus for Race and Cancer Site are shown below in Figure 24.

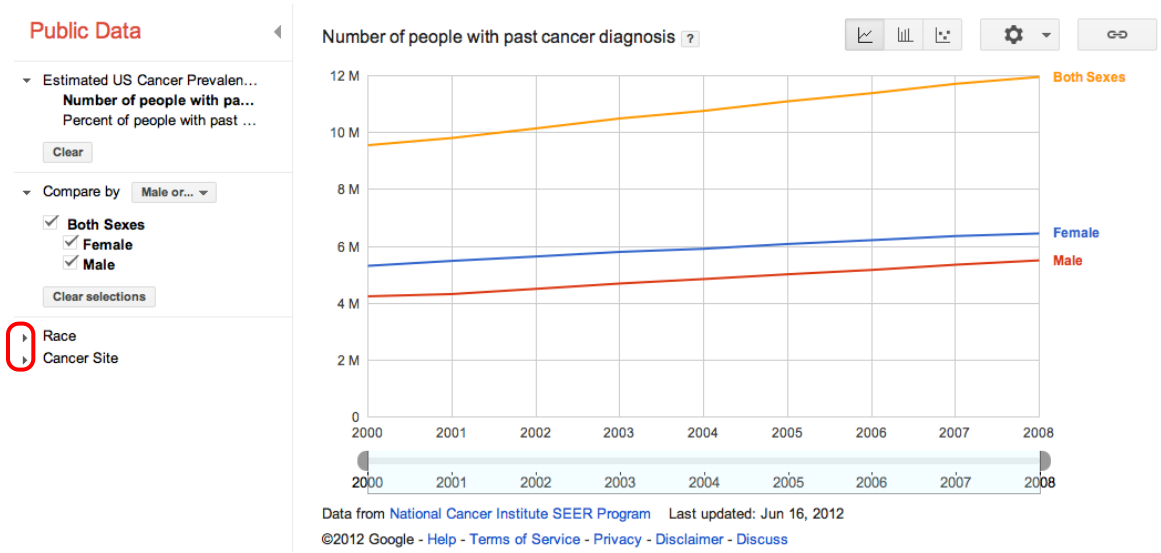


Figure 24: Small Arrows Were Difficult To Click.

Choosing "Sex and Race/Ethnicity"

When exploring the incidence dataset, some participants had trouble figuring out how to select the race/ethnicity for the data, shown in Figure 25. They saw the title "Sex and Race/Ethnicity," but it was not apparent that they needed to click the arrow to choose ethnicity

after the sex was specified. A few participants mentioned that combining those qualities made it impossible to make comparisons such as black females to white males.

Figure 25: Inability to Compare Between Sex and Race/Ethnicity.

Usability Evaluation Two

One round of usability testing was proposed for data displays geared toward use by non-researcher users, which occurred in September 2012. The objective of testing was to explore if participants could accurately interpret the data from the visualizations shown, to get feedback on alternate displays (in terms of both content and format), and determine which displays were preferred for an "At-A-Glance" introductory content summary. Statistics on new cases and deaths, incidence and mortality, survival, risk and trend data were shown to participants.

Findings from the second round of usability interviews are as follows:

New Cases and Deaths Data

Summary Displays

Participants were shown alternatives for displaying new cases and deaths for cancer. One version of this display included all of the data in a table format that showed both numeric cases and percentages of all new cancer cases (see Figure 26). The participants were shown an alternative that included a pie graph indicating the percent data and the numeric number of cases in tabular form (see Figure 27).

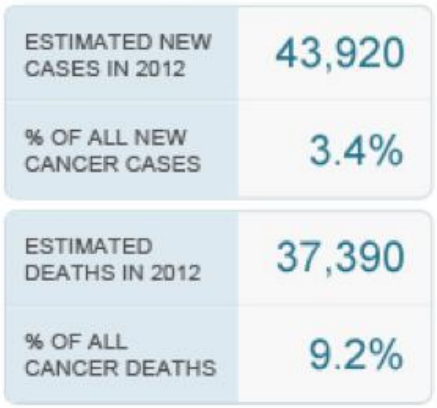


Figure 26: Estimated Cases and Deaths Table.

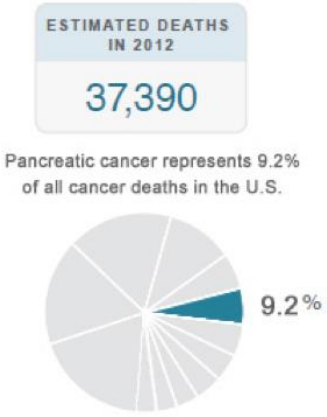


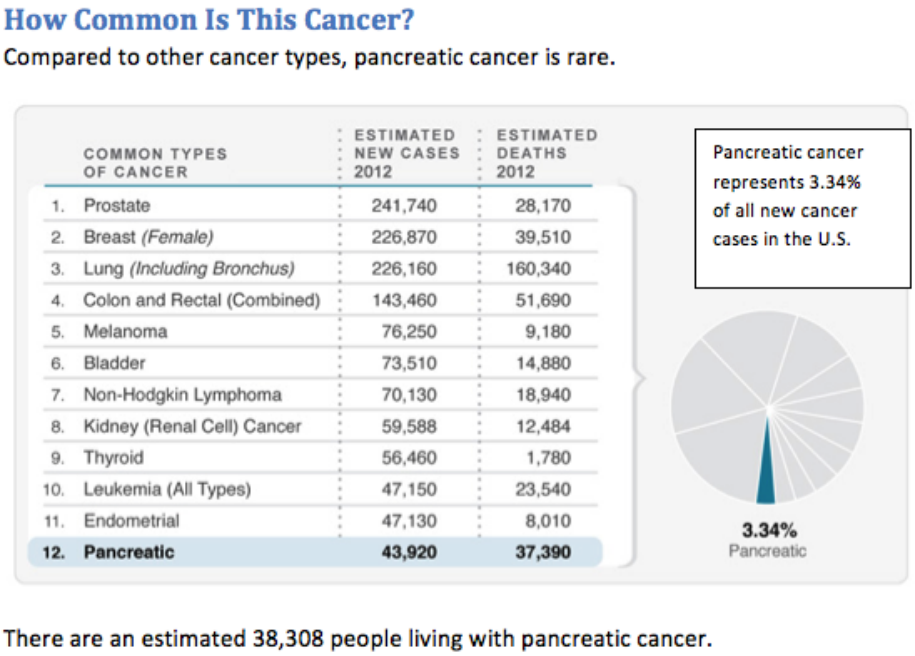
Figure 27: Estimated New Cases and Deaths Pie Chart.

Participants considered the version without the pie chart simpler to view. Participants had more difficulty with the version with the pie chart because of the low contrast ratio between the non-selected elements of the pie in the background. The pie chart also has various segments in it, which were not understood by looking at the summary alone. As a result, most people preferred the table version for this At-A-Glance element.

New Cases and Deaths Detail

The detailed version of these data were considered understandable by all participants (see Figure 28). From the table, it was clear to participants that pancreatic cancer is a rare form of cancer. The pie chart on this table also made more sense since the various segments of the pie chart could be mapped to the twelve table rows (ex. the pie piece to the left of the highlighted piece must be prostate cancer, and the size decreases in a clockwise direction). However, the

contrast ratio of the pie graph and the background could still be made higher to increase visibility.



How Common Is This Cancer?

Compared to other cancer types, pancreatic cancer is rare.

	COMMON TYPES OF CANCER	ESTIMATED NEW CASES 2012	ESTIMATED DEATHS 2012
1.	Prostate	241,740	28,170
2.	Breast *(Female)*	226,870	39,510
3.	Lung *(Including Bronchus)*	226,160	160,340
4.	Colon and Rectal (Combined)	143,460	51,690
5.	Melanoma	76,250	9,180
6.	Bladder	73,510	14,880
7.	Non-Hodgkin Lymphoma	70,130	18,940
8.	Kidney (Renal Cell) Cancer	59,588	12,484
9.	Thyroid	56,460	1,780
10.	Leukemia (All Types)	47,150	23,540
11.	Endometrial	47,130	8,010
12.	**Pancreatic**	**43,920**	**37,390**

There are an estimated 38,308 people living with pancreatic cancer.

Figure 28: Detailed Information for New Cases and Deaths.

New Cases and Deaths by Age and Race/Ethnicity

Participants reported understanding the graphs shown below in Figure 29, although there are two terms used – "incidence" and "new cases." Most participants believed that these were two different concepts).

Recommendation: Consider using the simpler term "new cases."

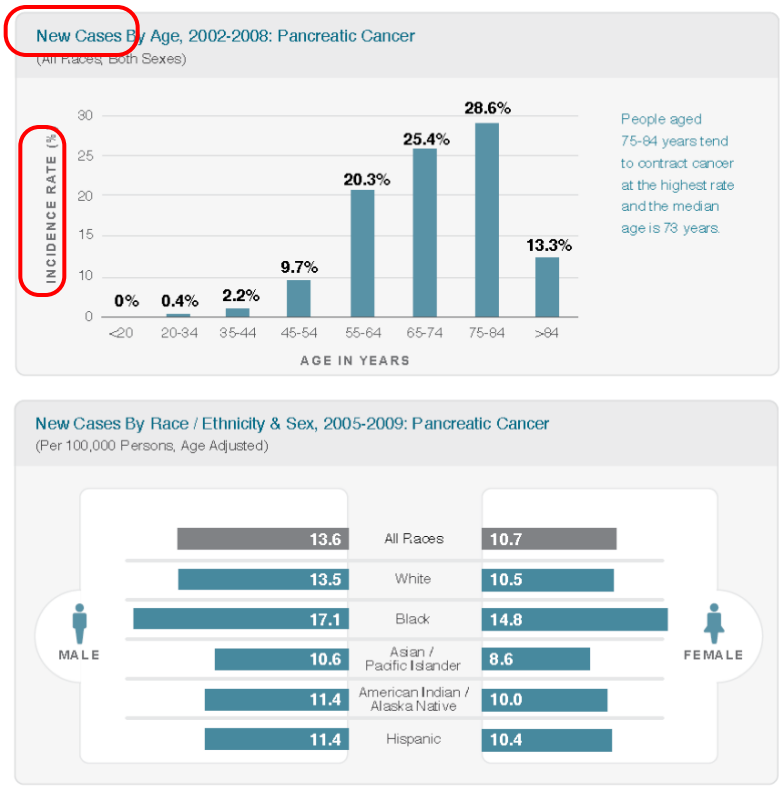


Figure 29: New Cases and Deaths Data by Age (Top) and Race/Ethnicity (Bottom) With Use of Terms "New Cases" and "Incidence."

Incidence and Mortality Data

Incidence and Mortality Line/Area Graphs

Participants were shown a combination line and area graph representing incidence and death over time (see Figure 30). Most of the participants failed to realize that the area on the graph was intended to show data. To these participants, this element of the display appeared to be a background and not data.

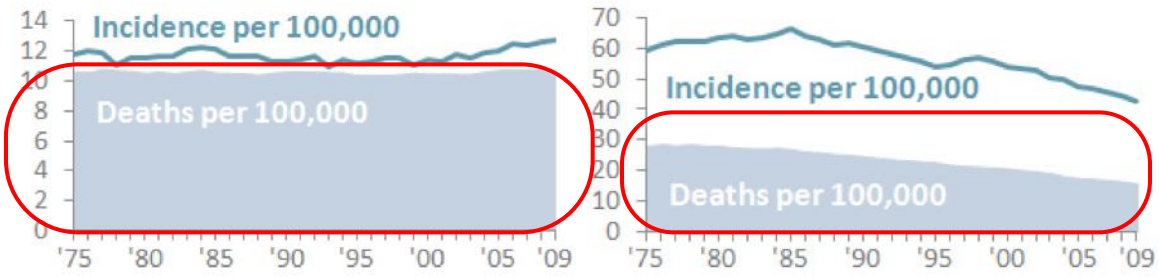


Figure 30: Line/Area Graphs Showing Incidence and Mortality Data.

Participants also had difficulty reading the scales. The scale across the bottom was perceived as years; most participants stated that they were uncertain but believed that that was the case. The Y-axis was more problematic since it could be perceived as percentages (as the upper right graph suggests). Some participants had difficulty determining what the value was and tried to use the "per 100,000" to rationalize the scale. This resulted in a misinterpretation of the scale; the most common interpretation was that it was per 1,000 people. For example, the starting point for the incidence line on the graph on the left of Figure 30 was perceived as 12,000 cases.

> *Recommendation: Consider providing a scale for the Y-axis. The X-axis may also benefit from a scale, but showing the full year may suffice.*

Incidence and Mortality Detail (Trends)

Of all the elements that were tested, participants had the most difficulty understanding the detailed versions of the incidence and mortality line graphs (see Figure 31). A surprising number of participants failed to notice that the graphs each contained two lines of data. The light grey line representing data for females was not noticed by a number of the participants and may have been perceived as an intended shadow of the other line.

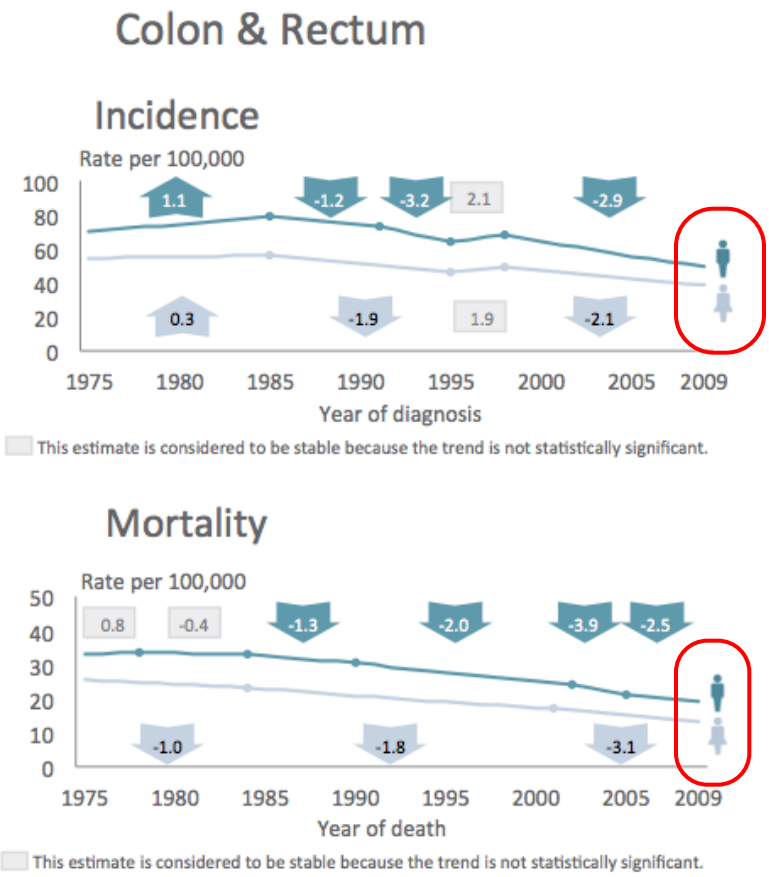


Figure 31: Incidence and Mortality Trend Detail.

There were also some problems with the arrowheads that point at the line. Some people perceived the arrowheads (circled in Figure 32) as telling the value of the line (i.e., number of cases) rather than the change in the line of the slope. In addition, the arrowheads for the line representing data for females appear to be pointing to the scale itself and not the line. The apparent lack of arrows pointing to the line for data on females may have reinforced the misinterpretation.

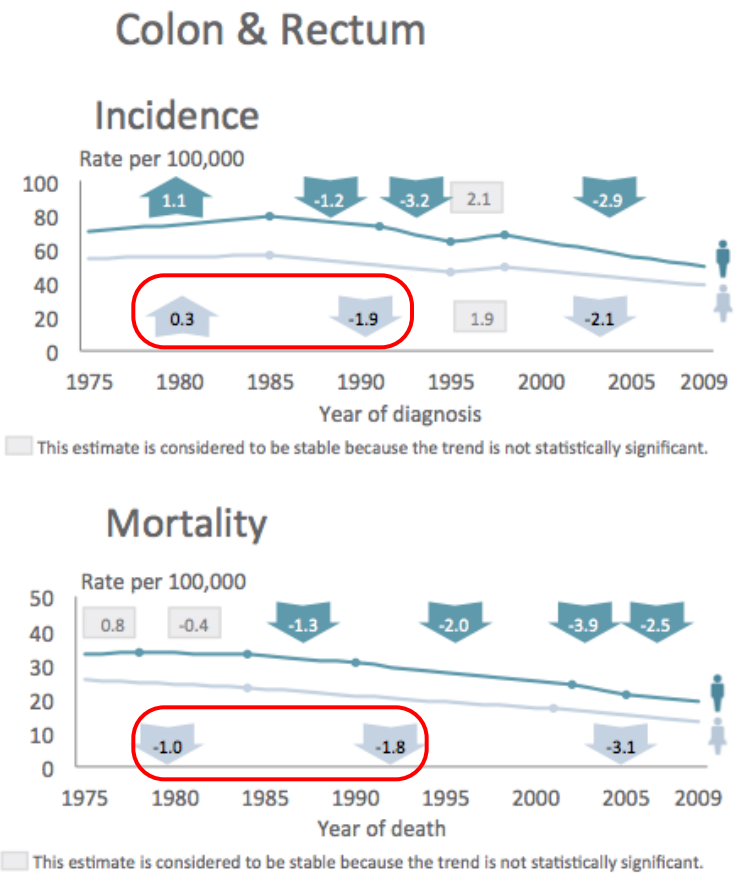


Figure 32: Incidence and Mortality Trend Graphs Showing the Arrowheads Pointing to the X-Axis.

There was also some confusion over the use of the negative sign in the arrowheads. One participant wondered if a negative value in an arrowhead (circled in Figure 33 below) suggested a double negative and that the rate was actually going up. Because of its size, and possibly as an attempt to disambiguate the symbol and the arrowhead, one person perceived this as a 'less than' symbol (e.g., rate of change for the second line segment for males in the top image was less than 1.2).

> *Recommendation: Consider including only positive values and having the shape of the arrow indicate the direction of the trend. Since both lines are recommended to be shown on the same graph, it may be better to consider removing the shape and provide the value close to its corresponding line segment.*

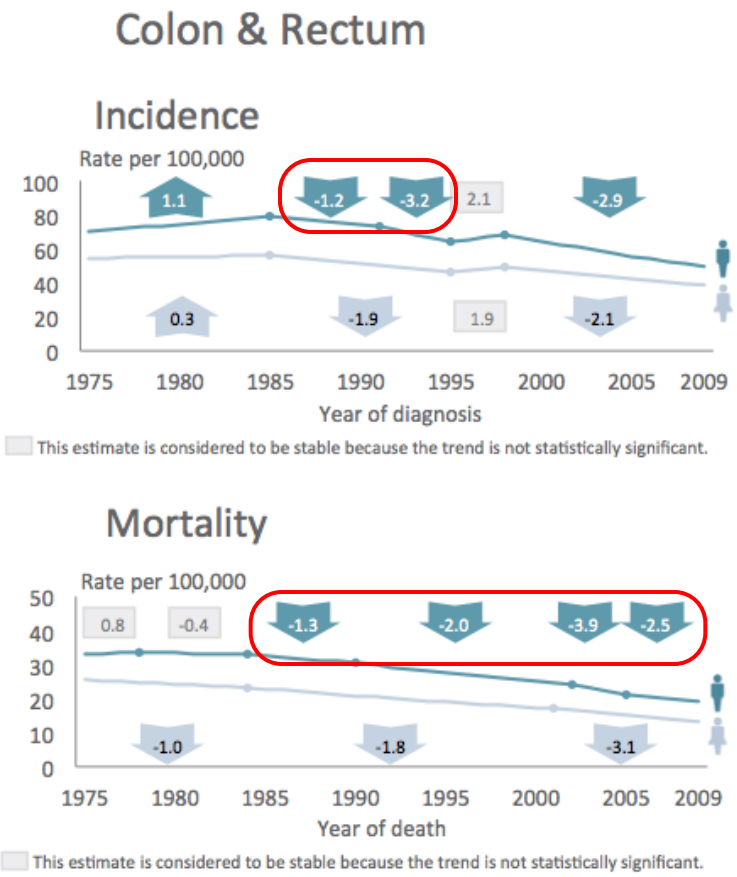


Figure 33: Incidence and Mortality Trend Graphs Showing the Arrowheads with a Negative Value.

The use of the squares to represent data that is not statistically significant confused all of the participants; most did not notice the legend (circled in Figure 34) below the graph. One of the participants, a press person with a reasonable understanding of statistical significance, ignored the fact that the value was shown in a square and not an arrowhead, and read the value within the shape as being equivalent to the other values. However, even when they noticed that there was a legend for the graph, participants failed to understand what this message was telling them.

> *Recommendation: Consider labeling the NS section of the graph as "stable." The footnote could then be used to explain that there was a variation in the data, making it stable. Consider using an asterisk to indicate the footnote (instead of a legend).*

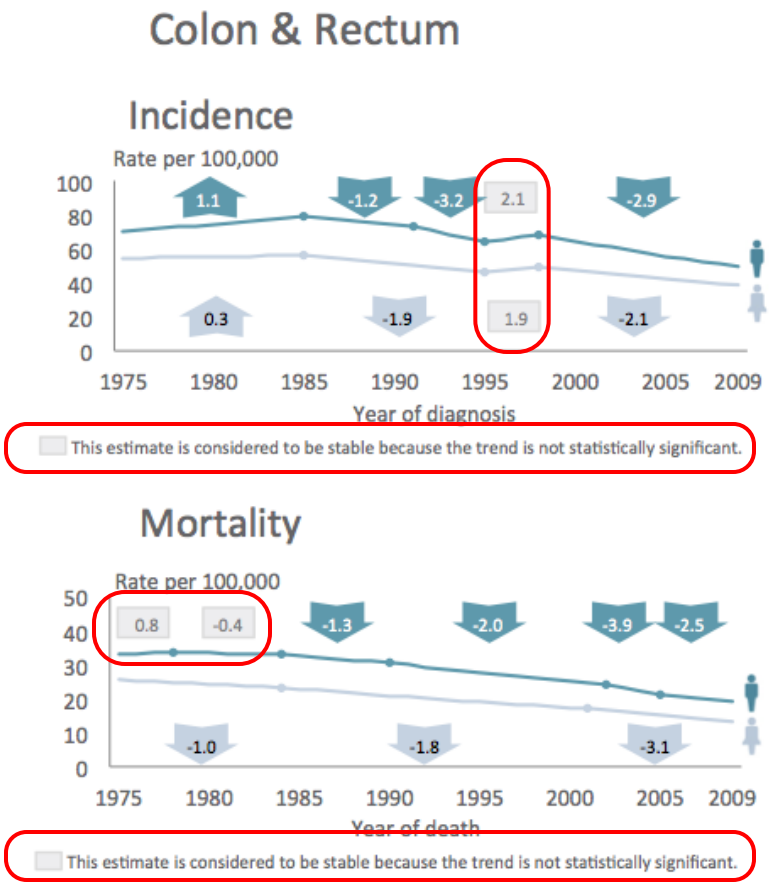


Figure 34: Incidence and Mortality Trend Graphs Showing Non-Significant Grey Boxes and Explanatory Footnote.

The value of the line was also hard for participants to discern from the graph. The same issues associated with understanding the Y-axis in previous graphs appeared here as well as in the summary version.

Incidence and Mortality Detail (Trends) - Alternate

Participants were also shown an alternative version for the incidence/mortality line graph overview (see Figure 35). In contrast to the other version, participants immediately recognized that this display contained two lines of data. This is probably due to the presence of the separator bar, and the display of the lighter gray line above the darker line. Participants commented positively on the specific year periods shown near the line segments. However, many participants failed to correctly interpret the data when asked which gender (male/female) had the higher rate.

Recommendation: Consider representing both lines on the same graph to facilitate comparison.

Figure 35: Alternate Version of Incidence and Mortality Trend Graphs.

Participants also showed confusion over what the change in slope indicates – whether a change over the entire time period or for each single year within the period. All participants claimed it seemed like a change over the entire period; however, they were confused by the mention of "Annual Percent Change" in the accompanying text. The term "Average Annual Percentage Change" did not seem to change the participants' perception of the relationship to the line segment.

Rates of new cases (incidence) and deaths (mortality) from pancreatic cancer have remained stable over the last 35 years. In other words, pancreatic cancer has not become more or less common during that time, and the chance of dying from it has not changed.

Incidence Trends: Pancreatic Cancer
(U.S. Joinpoint Trends, Annual Percent Change (%), 1975-2009, All Races, Both Sexes)

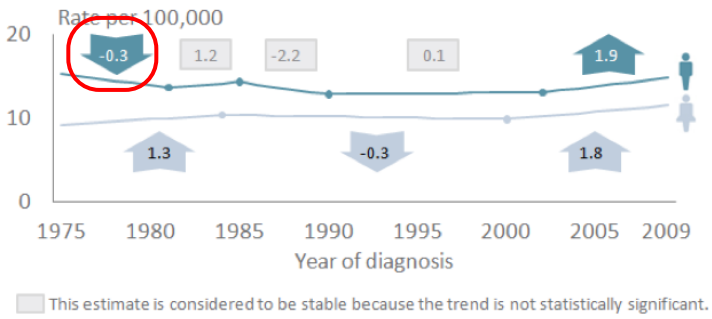


Figure 36: Incidence and Mortality Trend Graph Showing "Annual Percent Change."

Some participants noted an inconsistency in the accompanying text to this graph (see Figure 37). The text states that rates have remained stable over the last 35 years, however the graph suggests fluctuations (arrowheads). The rate may have the same start and finish point, but the line does not appear stable at all.

Rates of new cases (incidence) and deaths (mortality) from pancreatic cancer have remained stable over the last 35 years. In other words, pancreatic cancer has not become more or less common during that time, and the chance of dying from it has not changed.

Incidence Trends: Pancreatic Cancer
(U.S. Joinpoint Trends, Annual Percent Change (%), 1975-2009, All Races, Both Sexes)

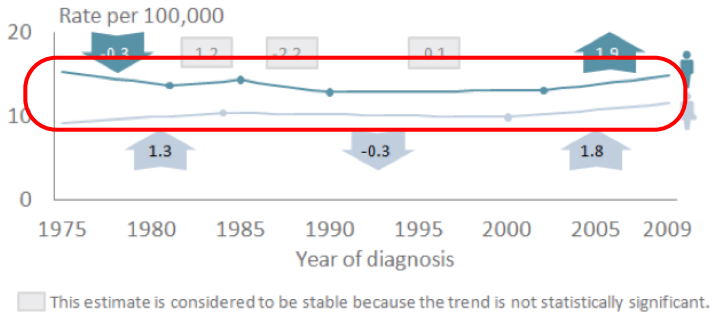


Figure 37: Incidence and Mortality Trend Graph Showing an Inconsistency between the Trend Lines and the Accompanying Text.

When asked about it, only one of the participants was aware of the concept of Joinpoint (see Figure 38). This participant was from the media audience and had recently interviewed a person who explained the concept. All other participants did not understand the term and ignored it.

Recommendation: If it is to be included, consider providing reference to Joinpoint as a footnote instead of the graph's subtitle.

Rates of new cases (incidence) and deaths (mortality) from pancreatic cancer have remained stable over the last 35 years. In other words, pancreatic cancer has not become more or less common during that time, and the chance of dying from it has not changed.

Incidence Trends: Pancreatic Cancer
(U.S. Joinpoint Trends, Annual Percent Change (%), 1975-2009, All Races, Both Sexes)

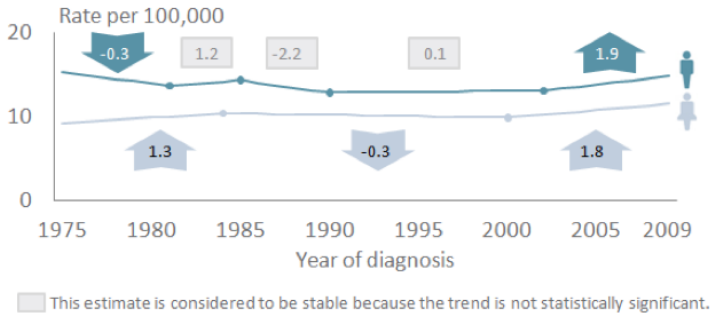


Figure 38: Incidence and Mortality Trend Graph with Mention of Joinpoint.

Trend Data

Summary Trend Displays

Participants were shown two versions of trend data - one version with trend data shown in arrowheads (on the left of Figure 39) and one version with rates and trend data (on the right of Figure 39). Though there was not a strong preference, more people tended to prefer the version with both trend and rate data. However, this may not be the best choice if rate data is also included in another element for the At-A-Glance section.

Figure 39: Trend Data Summary Displays.

The combination arrowhead/bar graph display element shown in Figure 40 had some of the same issues as the incidence/mortality graphs: The negative values in a downward-pointing arrow and non-significant values shown in a box. This is a potentially greater issue here, since a legend or footnote to explain the non-significant data is not included.

Recommendation: Consider removing the sign from the trend value and let the arrow indicate the direction. Also consider labeling non-significant rate changes as "stable."

Figure 40: Arrowhead and Grey Box with Trend Data.

Survival Data

Survival Summary Displays

Participants were also shown two versions of a survival rate - one version with just the rate (on the left in Figure 41) and one version with average rate plus the rate for the most common stage (on the right in Figure 41). Most of the participant preferred the version with just the average survival rate. More participants indicated they preferred the simple version of the survival data, as the stage information didn't seem important here.

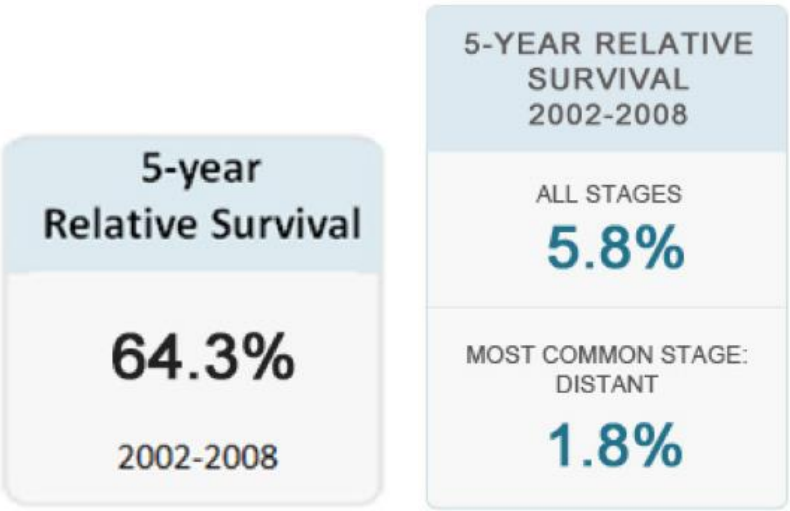


Figure 41: Five-Year Survival Summary Data Displays.

Survival Detail Display – Icon Array

Participants were also shown an icon array for average survival rate (see Figure 42). All of the participants understood this graph at first, though several of them misinterpreted the icon array's use of both males and females. Participants attempted to determine a difference in survival by gender from this image.

Recommendation: Consider providing a single icon type instead of two.

Figure 42: Detailed Survival Display with Male/Female Icon Array.

When asked to describe the concept shown on this survival diagram (Figure 42), all of the participants stated it correctly. However, when asked what the term "relative survival" meant, none of the participants understood it. When the participants were asked to read the accompanying text (shown in Figure 43) to get the definition, all of the participants had difficulty understanding the sentence. They did not understand the reference to healthy people and some even questioned their initial interpretation of the icon array (thinking the remaining icons represented healthy people). The second sentence was clear, but did not eliminate the confusion over the additional information in the first sentence.

Recommendation: Consider removing the concept of "relative survival" from the display element, or include it in a footnote beneath the display (e.g. "These data are technically called the "relative survival rate" due to …").

Relative survival statistics compare the survival of patients diagnosed with cancer with the survival of people in the general population who are the same age, race, and sex and who have not been diagnosed with cancer. It represents the percentage of people who survive their cancer five years after diagnosis. Because survival statistics are based on large groups of people, they cannot

Figure 43: Accompanying Text for the Survival Detail Icon Array Display.

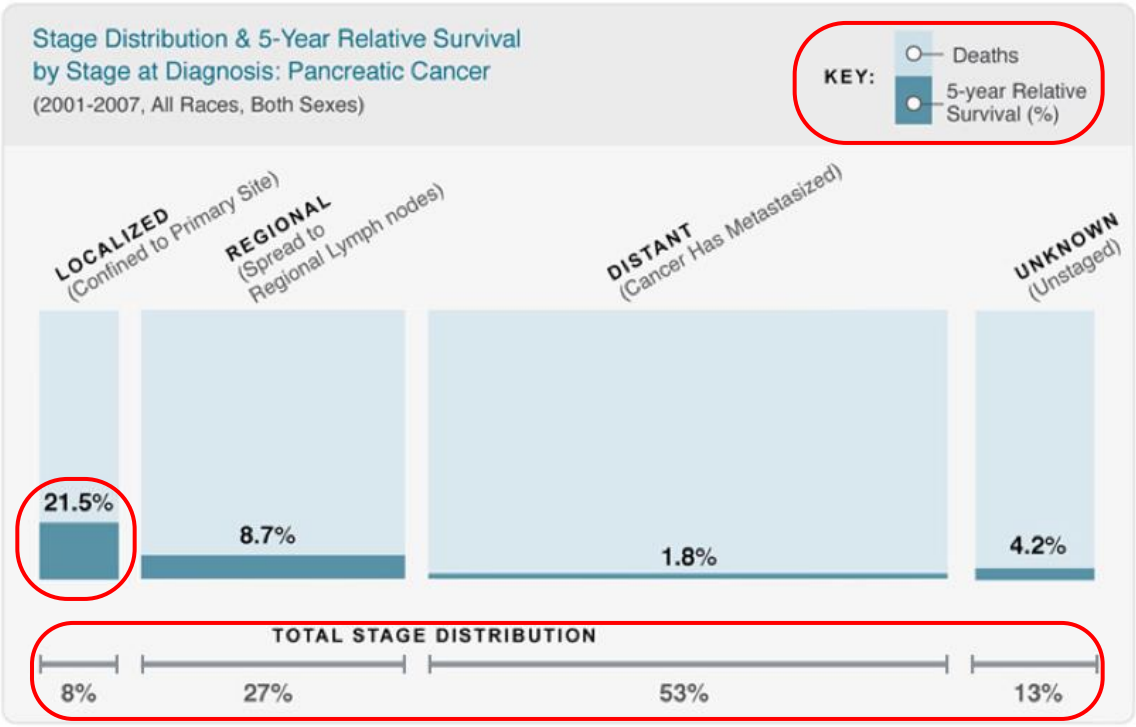
The rest of this text was not seen as specific to the icon array diagram.

Recommendation: Consider including this information as a general statement for the entire overview.

Survival Data Shown by Stage

Participants were shown a detailed diagram of 5-year survival rate by stage (see Figure 44). Many of the participants failed to notice the stage distribution line below the main graph. Of those that did, some did not make the connection between the bar width and the distribution data. This resulted in the participant misinterpreting data on the bar chart.

> *Recommendation: Consider showing stage dist. and survival rate as two different graphs that are interrelated (perhaps a pie chart), or represent both types of data on a single pie chart.*

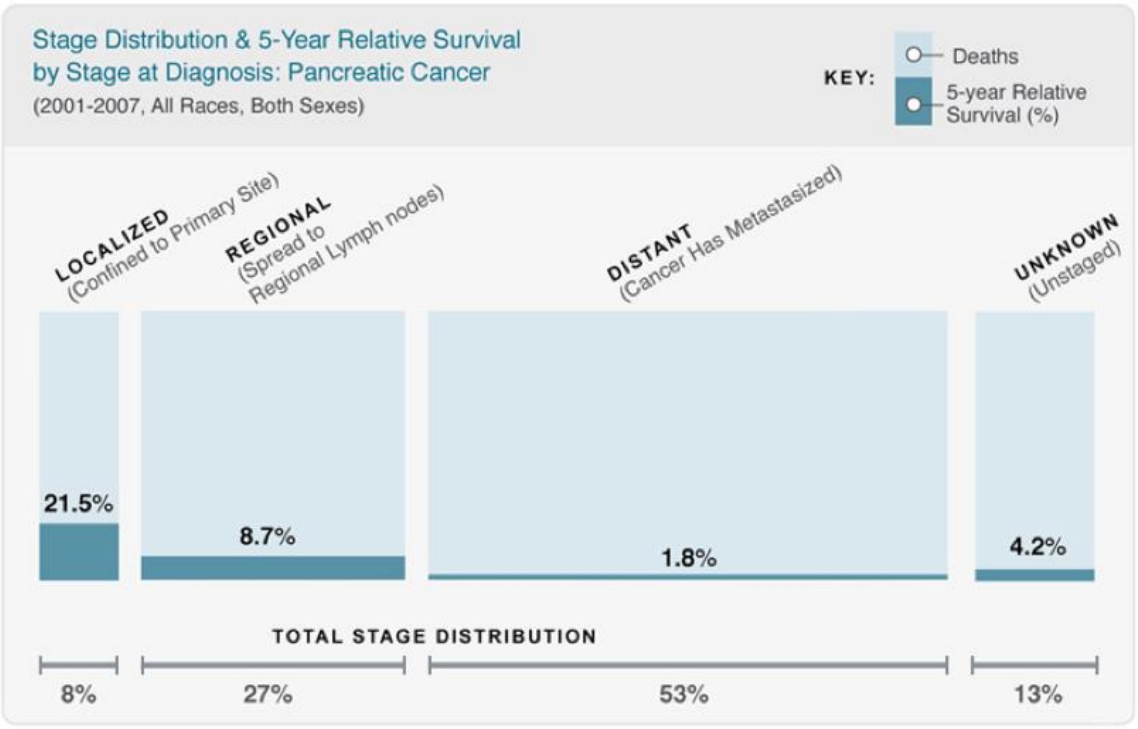


Stage refers to how much a cancer has spread. For example, cancer may be found only in the part of the body where it started (localized). Or, it may be found after it has spread all around the body (distant). How long a person survives has a lot to do with what stage the cancer is in when found. Most cases of pancreatic cancer are found after they have spread. It is not common for this cancer to be found before it has spread because there is no routine way of testing (screening) for it.

Figure 44: Survival Data by Stage.

In addition to the issues related to understanding the display, the text below the graphic (circled in Figure 45) appears to be a definition of staging and not a description of the data on the display (which is the case on previous displays). It states that staging refers to how the cancer has spread, although the NCI definition includes the "extent" of the primary tumor as well.

Recommendation: Consider showing this text as a footnote for the term "stage."

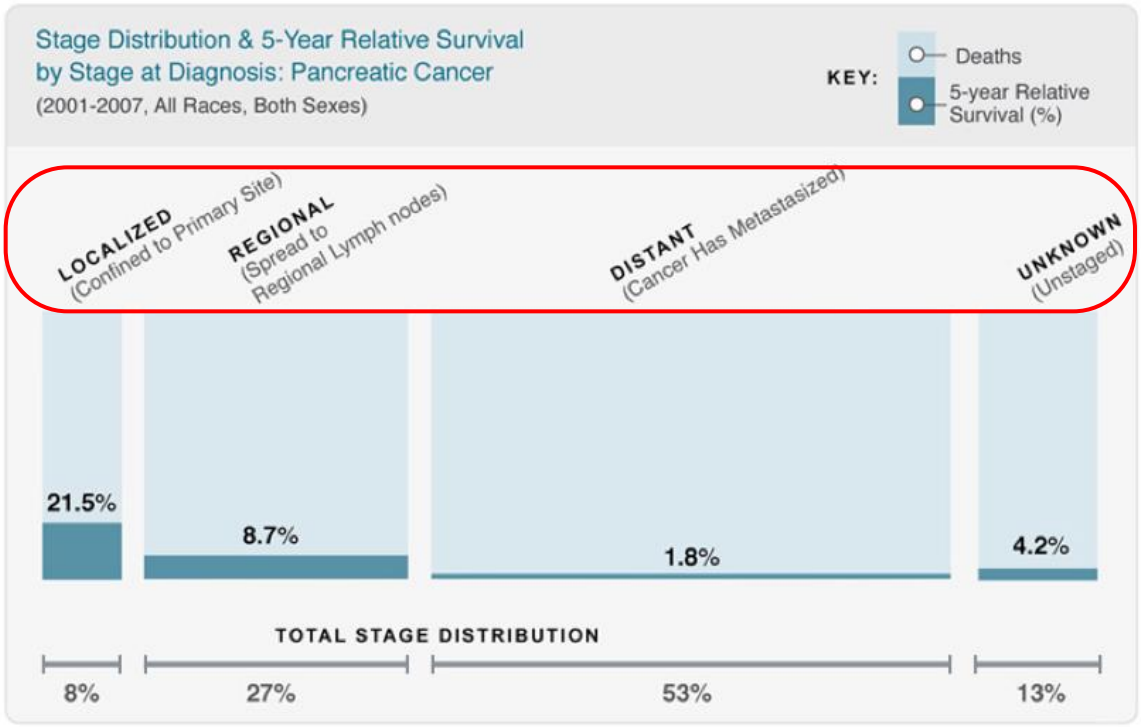


Stage refers to how much a cancer has spread. For example, cancer may be found only in the part of the body where it started (localized). Or, it may be found after it has spread all around the body (distant). How long a person survives has a lot to do with what stage the cancer is in when found. Most cases of pancreatic cancer are found after they have spread. It is not common for this cancer to be found before it has spread because there is no routine way of testing (screening) for it.

Figure 45: Accompanying Text to the Survival Data by Stage.

Most participants were aware of the concept of cancer stages (circled in Figure 46), but most thought of stage in terms of numbers (e.g. 1, II, III, IV). They assumed that different types of cancer might use different staging designation.

Recommendation: Consider stating or alluding to how stages of cancer may be classified and the staging system used in the display (e.g. ""Stage refers to how far a cancer has developed or spread, and there are multiple staging systems used. Colon cancer used the Dukes staging system which includes four stages.").



Stage refers to how much a cancer has spread. For example, cancer may be found only in the part of the body where it started (localized). Or, it may be found after it has spread all around the body (distant). How long a person survives has a lot to do with what stage the cancer is in when found. Most cases of pancreatic cancer are found after they have spread. It is not common for this cancer to be found before it has spread because there is no routine way of testing (screening) for it.

Figure 46: Staging Information in the Survival Data by Stage Display.

Risk Data

Risk Data Summary Displays

Participants were shown two versions of display elements showing the lifetime risk (see Figure 47). The only difference was the placement of the data from which this estimate was derived.

None of the participants detected the difference between the two display elements or had any preference between the two options once it was pointed out to them.

Figure 47: Two Displays Showing Risk Data.

Other Miscellaneous Findings

Rates per 100,000

Many of the displays used rates per 100,000 people for cases (see Figure 48 for two examples). Research data indicates that the use of values above "per 1,000" are difficult for users to understand (depending on their numeracy level).

> *Recommendation: Consider reporting data in terms of "per 1,000" or "per 100" (if the value is less than one). Values less than one should include a leading 0 to ensure users are aware of the decimal point. An alternate way could be to vary the denominator (ex. 1 in 70,000 people).*

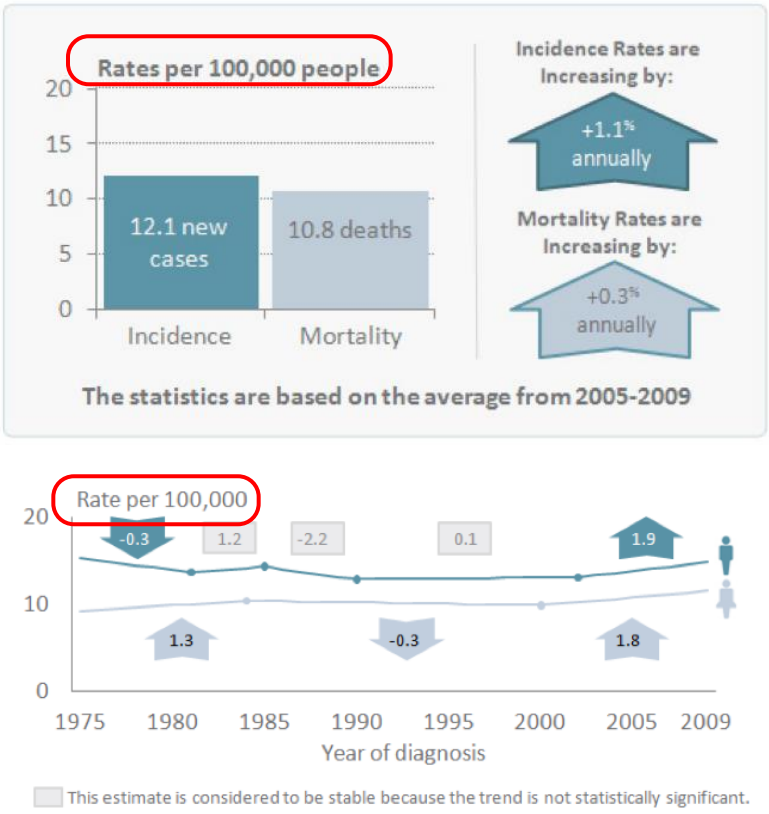


Figure 48: Two Example Graphs Showing Data with Rate Per 100,000.

Graph Scales

All graphs are shown using a scale that is adjusted to the specific data (see figure 49 for two examples). The lack of a fixed scale not only precludes accurate comparison between graphs, but also can lead to misreading the data.

References:

How to Lie with Statistics, 1954, Darrell Huff, W W Norton & Co, New York, NY, pp. 60-65

Graphical Presentation of Trends in Rates, (1995) Susan S. Devesa, Jennifer Donaldson and Thomas Fears, American Journal of Epidemiology. Feb 15;141(4):300-4.

Figure 49: Two Example Graphs That Lack a Fixed Scale.

Estimated Data

Some graphs provide what would be perceived as precise data, although the data are only estimates (see two examples in Figure 50). Research findings suggest the credibility of estimates is negatively affected when overly precise values are provided.

Recommendation: Consider using integer or single decimal point values for percent and case per 1,000 estimates. Estimates could also be rounded to the nearest 100 cases.

References:

Risk Estimates From an Online Risk Calculator Are More Believable and Recalled Better When Expressed as Integers. Holly O Witteman1,2, PhD; Brian J Zikmund-Fisher1,2,3,4, PhD; Erika A Waters5, MPH, PhD; Teresa Gavaruzzi6,7, PhD; Angela Fagerlin1,2,8,9, PhD

A Demonstration of ''Less Can Be More'' in Risk Graphics. Brian J. Zikmund-Fisher, PhD, Angela Fagerlin, PhD, Peter A. Ubel, MD

Against -The effects of communicating uncertainty in quantitative health risk estimates. Longman T, Turner RM, King M, McCaffery KJ.

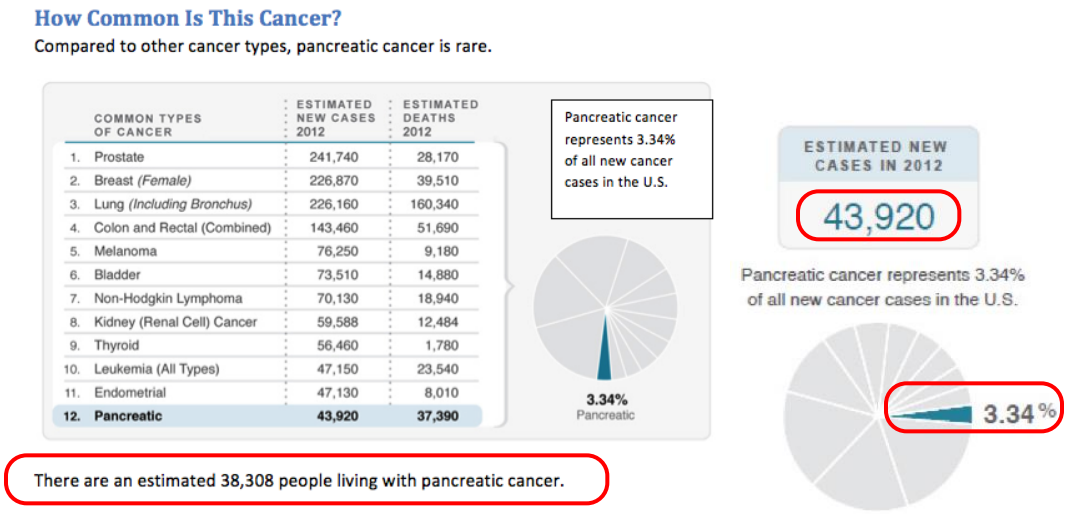


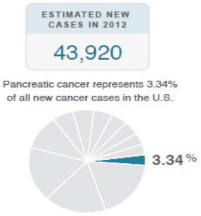
Figure 50: Two Example Displays with Precise Estimate Data.

Preference for "At-A-Glance" Display

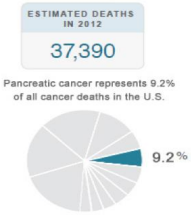
Members of the general public were asked to identify their preferred images for an "At-A-Glance" display. Participants indicated their preferred image for each data type evaluated during the session and created their own preferred an "At-A-Glance" display from those images at the close of the session. Participants were shown an example of an At-A-Glance display at the beginning of the evaluation but were not limited in their number of selections for their display.

The preference by element of the "At a Glance" section is shown in Figure 51. All participants representing the general public wanted to see one form of the estimated cases and estimated deaths as part of the "At a Glance" section, with an even split between the two options shown. Five of the six participants representing the general public wanted to see a version of the 5-year survival rate data, with the majority preferring the version without the stage data. Four of the six participants representing the general public wanted to see lifetime risk data but had no preference between the two formats. The remaining data elements are not preferred by a large number of the participants.

3/6



3/6



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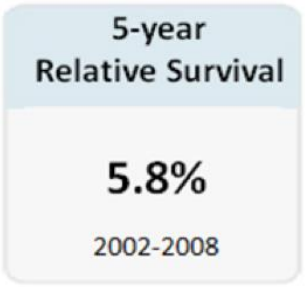
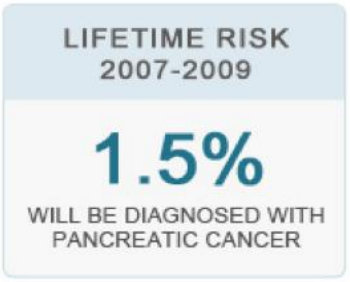
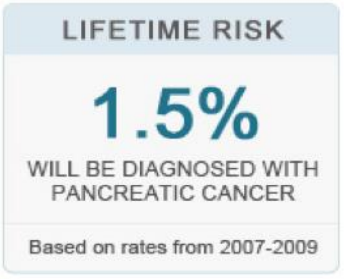
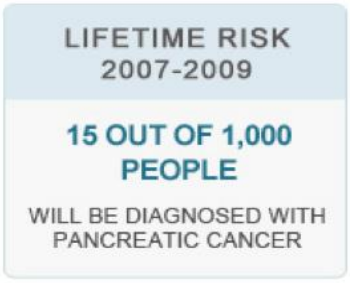


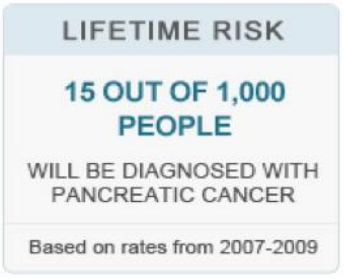
4/6

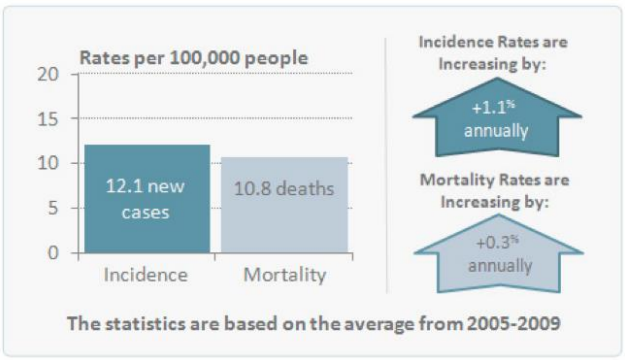




4/6







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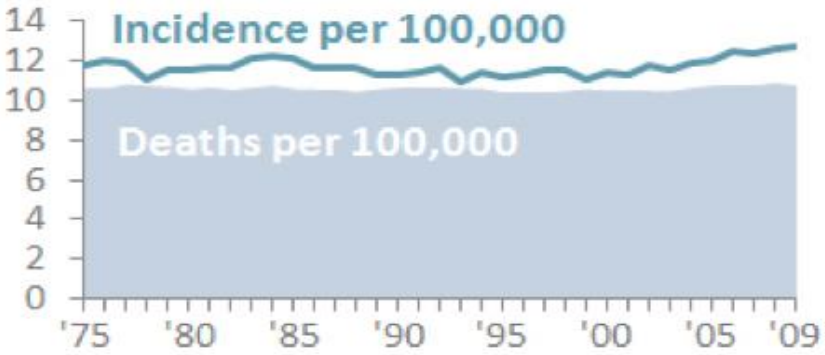

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Figure 51: "At-A-Glance" Elements Ranked by Number of Participants Who Chose to Include Them in the Summary.

Conclusion

Analysis of both the GPDE and the cancer overview displays provided valuable insight on how users of SEER cancer statistics view data. The following main points summarize the insight from the usability evaluations with researchers on SEER data visualization:

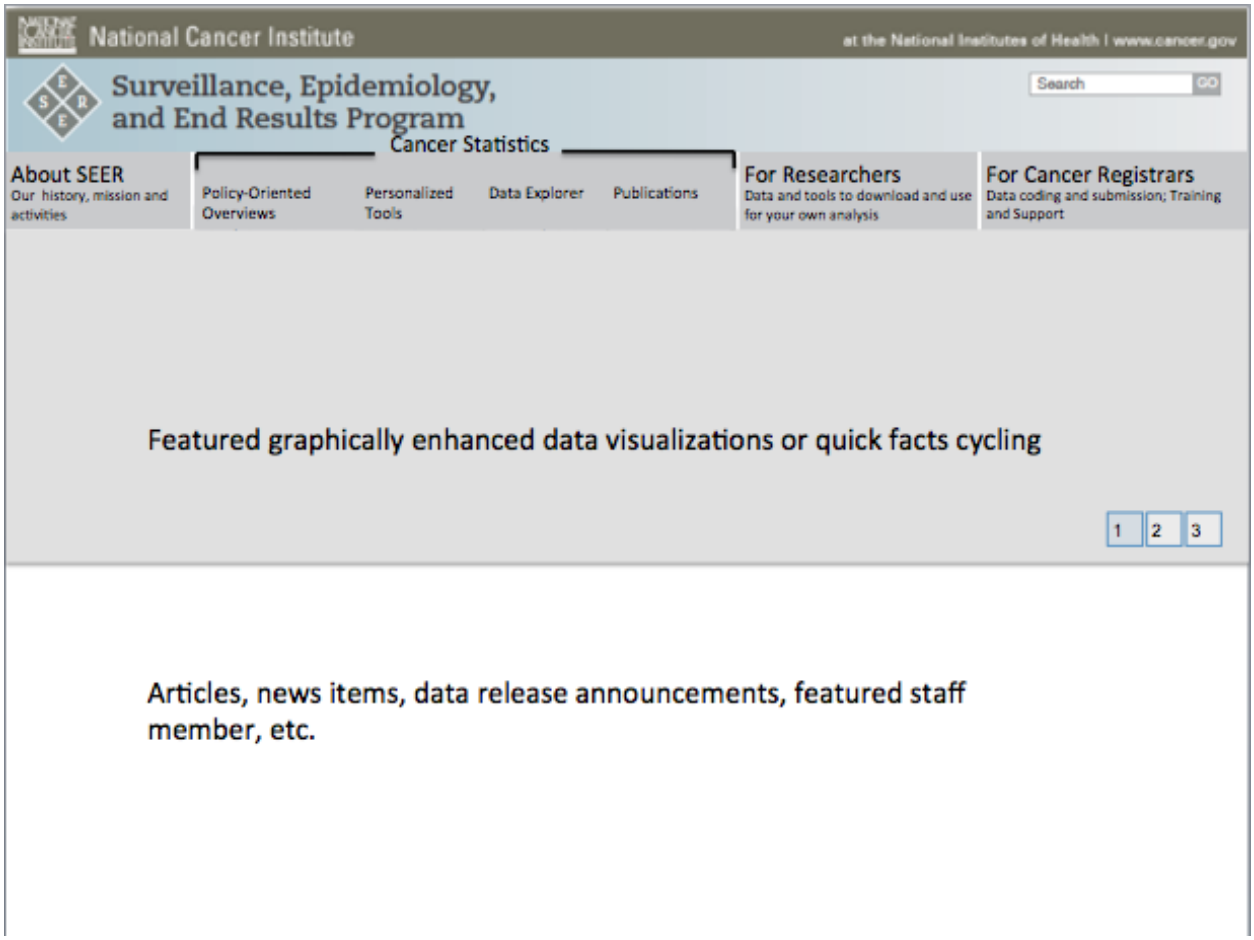
- Participants appeared to struggle to figure the [Google Public Data Explorer] tool out at first, but seemed to catch on to basic functionality with a little guidance and repetition.
- Almost all participants mentioned that the tool was "nice to have," but it wouldn't replace or augment current tools offered through SEER.
- The tool was seen as a good "first/quick look" or "preview" of the data, but most participants reported needing to manipulate the data well beyond the current functionality of the tool for it to be useful and it also lacks needed functionality.
- Sharing/exporting results were seen as one of the most important features this tool should offer.
- Datasets may have to be offered both individually and combined to create all possible views of the data.
- The tool has bugs and interface issues that would need to be addressed.

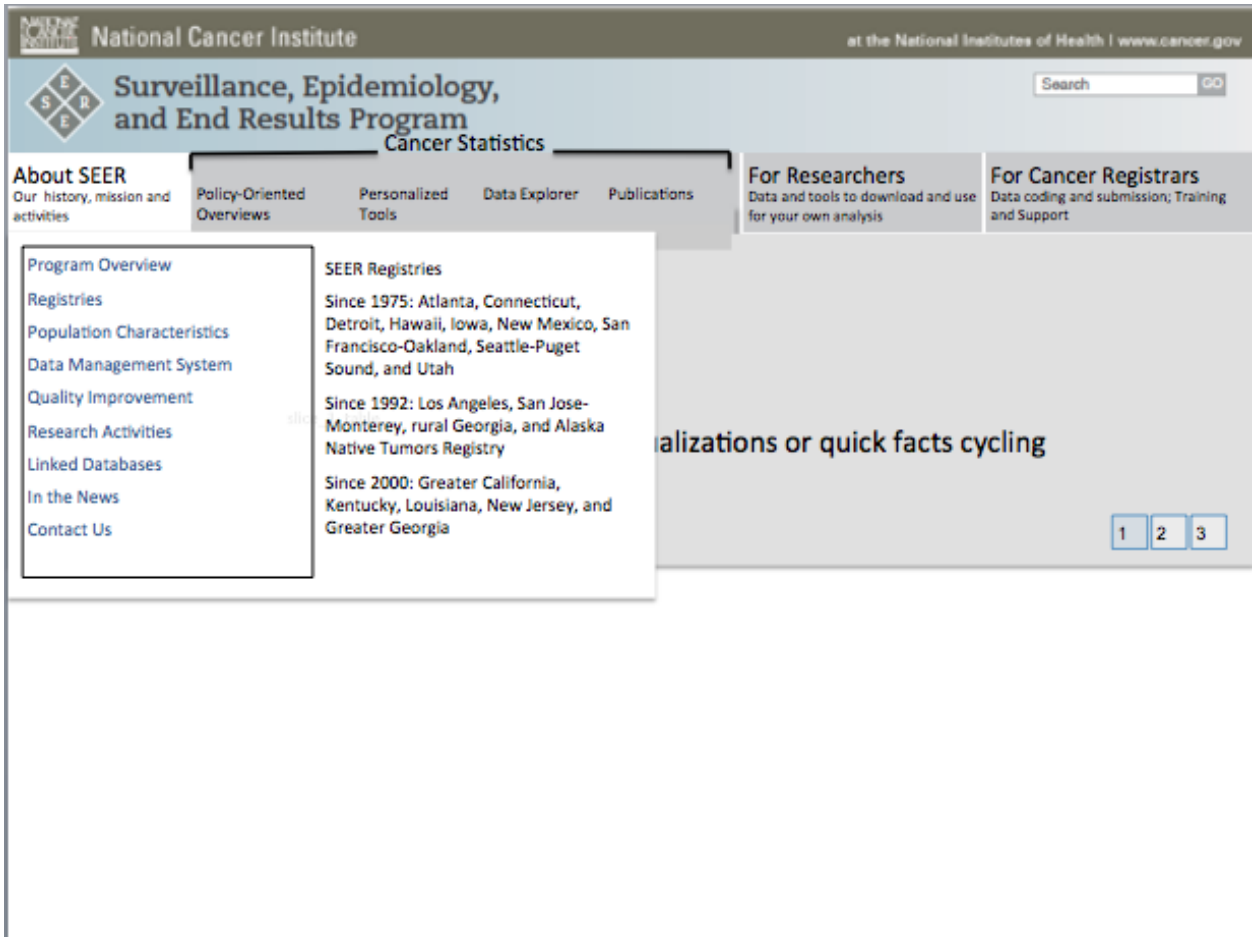
For the cancer data display usability evaluations with the public and the media, the takeaway points included:

- Participants from the media audience appeared to be slightly more "statistically savvy" than participants representing the public, however they made some of the same errors in interpreting some displays.
- Technical terms often used with SEER data (such as "Relative Survival," "Joinpoint," and "Average Annual Percentage Change") were not well understood by participants and may be better positioned as footnotes rather than graph subtitles.
- Non-highlighted portions of graphs that were grey in color often blended into the background and appeared to be less effective at conveying information. Other color and formatting issues affected the interpretations of some graphs.

- New Cases and Deaths, Survival, and Risk Data were the most commonly reported data that participants selected for an “At-A-Glance” summary.
- Use of cases per 100,000, lack of graph scaling, and precise figures for estimated data all may have contributed to the misinterpretation of several of the displays.
- Some text that accompanied graphs was either misunderstood or was perceived as incorrect to a few participants.

Appendix A – Participant Material for Round One Usability Evaluations

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Search
GO
Cancer Statistics
About SEER
Our history, mission and activities
Policy-Oriented Overviews
Personalized Tools
Data Explorer
Publications
For Researchers
Data and tools to download and use for your own analysis
For Cancer Registrars
Data coding and submission; Training and Support
Program Overview
Registries
Population Characteristics
Data Management System
Quality Improvement
Research Activities
Linked Databases
In the News
Contact Us
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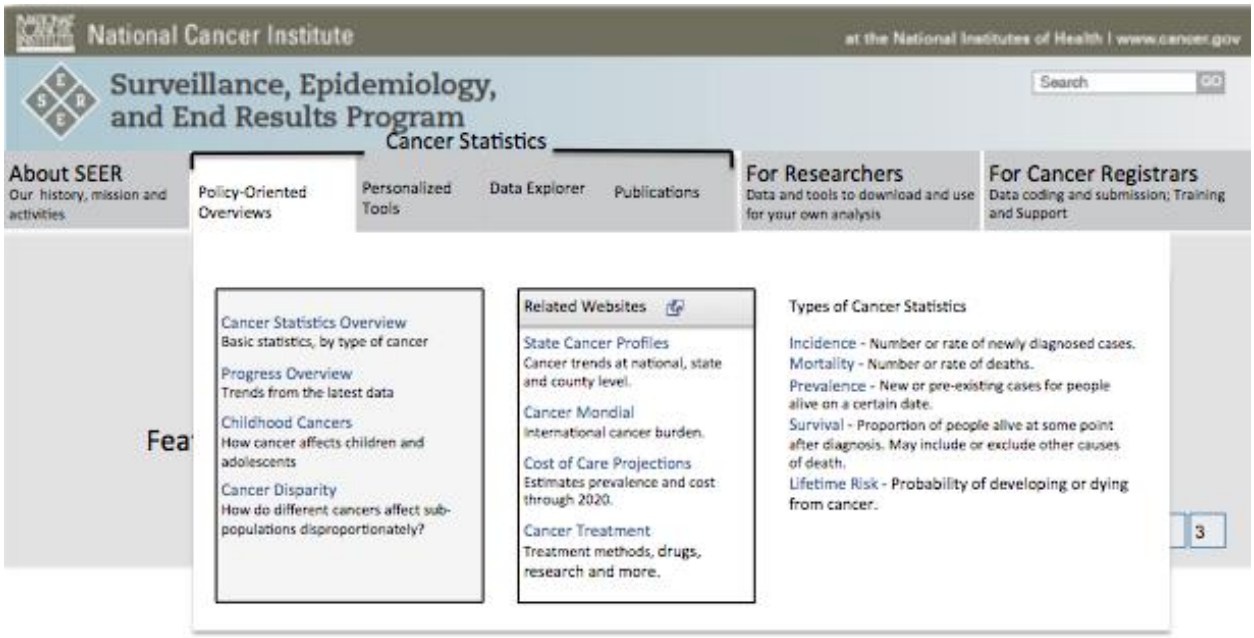
Since 1975: Atlanta, Connecticut, Detroit, Hawaii, Iowa, New Mexico, San Francisco-Oakland, Seattle-Puget Sound, and Utah
Since 1992: Los Angeles, San Jose-Monterey, rural Georgia, and Alaska Native Tumors Registry
Since 2000: Greater California, Kentucky, Louisiana, New Jersey, and Greater Georgia
alizations or quick facts cycling
1
2
3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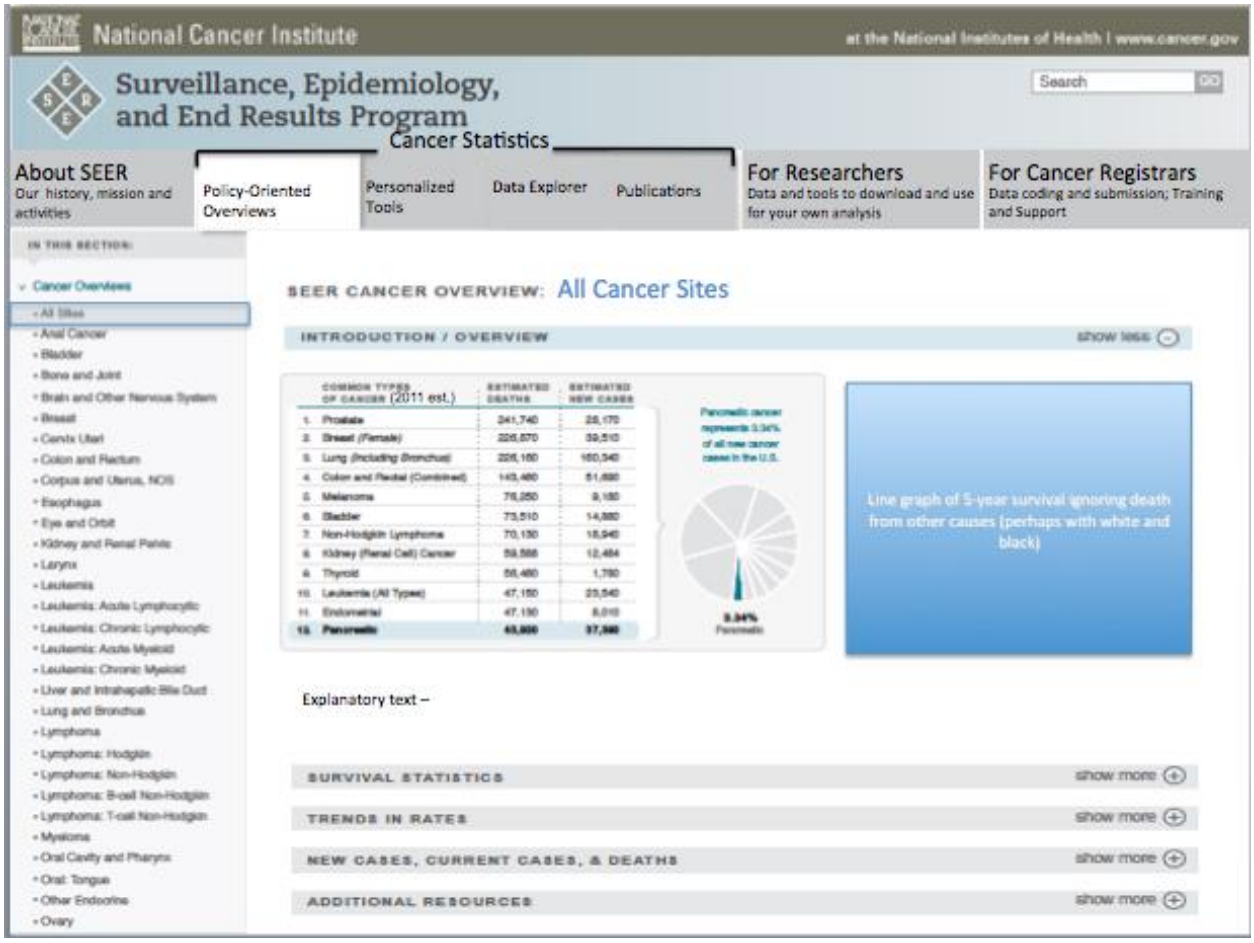
Search
GO
Cancer Statistics
About SEER
Our history, mission and activities
Policy-Oriented Overviews
Personalized Tools
Data Explorer
Publications
For Researchers
Data and tools to download and use for your own analysis
For Cancer Registrars
Data coding and submission; Training and Support
Cancer Statistics Overview
Basic statistics, by type of cancer
Progress Overview
Trends from the latest data
Childhood Cancers
How cancer affects children and adolescents
Cancer Disparity
How do different cancers affect sub-populations disproportionately?
Related Websites
State Cancer Profiles
Cancer trends at national, state and county level.
Cancer Mondial
International cancer burden.
Cost of Care Projections
Estimates prevalence and cost through 2020.
Cancer Treatment
Treatment methods, drugs, research and more.
Types of Cancer Statistics
Incidence - Number or rate of newly diagnosed cases.
Mortality - Number or rate of deaths.
Prevalence - New or pre-existing cases for people alive on a certain date.
Survival - Proportion of people alive at some point after diagnosis. May include or exclude other causes of death.
Lifetime Risk - Probability of developing or dying from cancer.
3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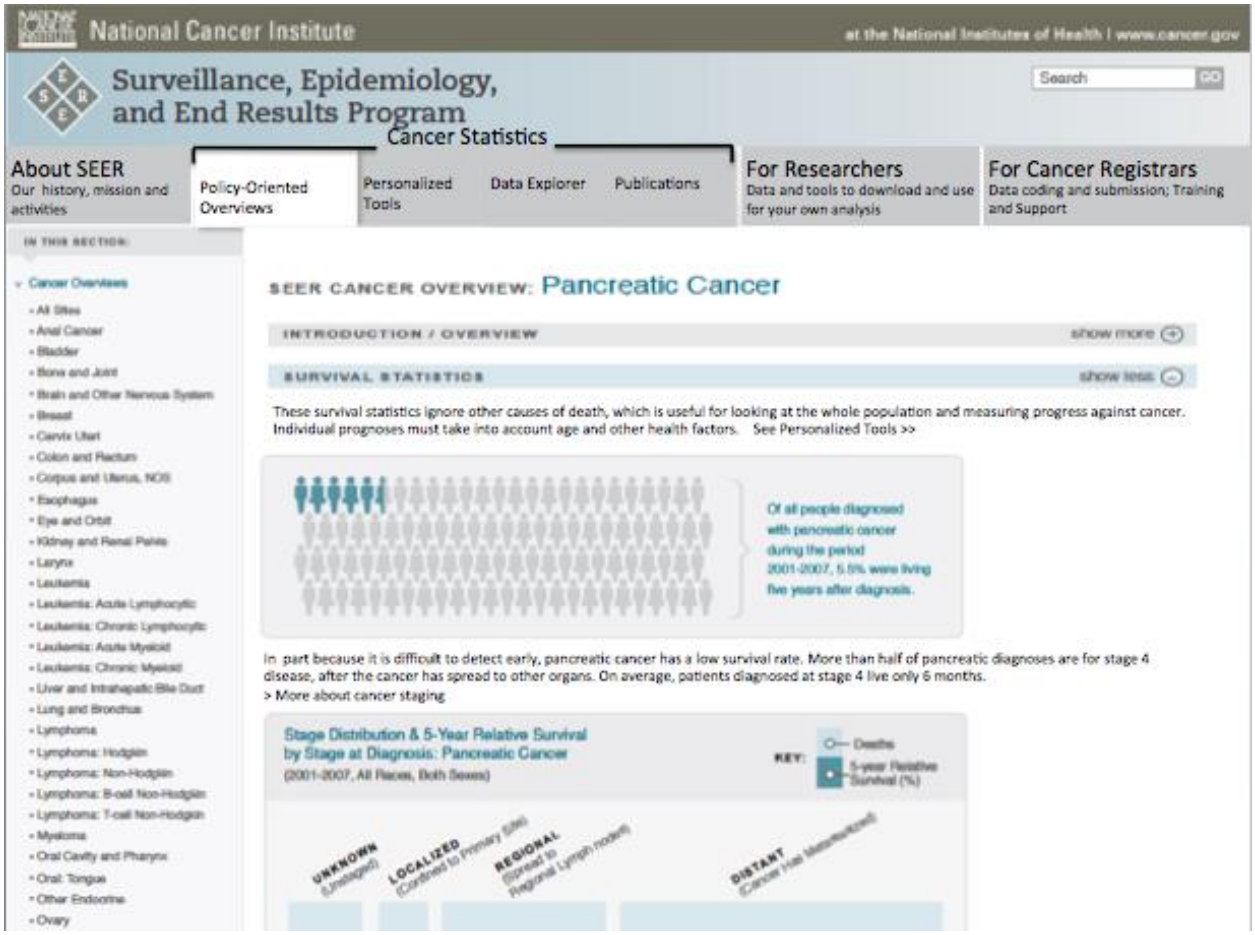
Search
Cancer Statistics
About SEER
Our history, mission and activities
Policy-Oriented Overviews
Personalized Tools
Data Explorer
Publications
For Researchers
Data and tools to download and use for your own analysis
For Cancer Registrars
Data coding and submission; Training and Support
IN THIS SECTION:
Cancer Overviews
All Sites
Anal Cancer
Bladder
Bone and Joint
Brain and Other Nervous System
Breast
Cervix Uteri
Colon and Rectum
Corpus and Uterus, NOS
Esophagus
Eye and Orbit
Kidney and Renal Pelvis
Larynx
Leukemia
Leukemia: Acute Lymphocytic
Leukemia: Chronic Lymphocytic
Leukemia: Acute Myeloid
Leukemia: Chronic Myeloid
Liver and Intrahepatic Bile Duct
Lung and Bronchus
Lymphoma
Lymphoma: Hodgkin
Lymphoma: Non-Hodgkin
Lymphoma: B-cell Non-Hodgkin
Lymphoma: T-cell Non-Hodgkin
Myeloma
Oral Cavity and Pharynx
Oral: Tongue
Other Endocrine
Ovary
SEER CANCER OVERVIEW: All Cancer Sites
INTRODUCTION / OVERVIEW
show less
COMMON TYPES OF CANCER (2011 est.)
ESTIMATED DEATHS
ESTIMATED NEW CASES
1. Prostate 241,740 28,170
2. Breast (Female) 226,870 39,510
3. Lung (Including Bronchus) 226,160 160,340
4. Colon and Rectal (Combined) 143,460 51,690
5. Melanoma 76,250 9,180
6. Bladder 73,510 14,880
7. Non-Hodgkin Lymphoma 70,130 18,940
8. Kidney (Renal Cell) Cancer 59,566 12,464
9. Thyroid 56,460 1,780
10. Leukemia (All Types) 47,150 23,540
11. Endometrial 47,130 8,010
12. Pancreatic 43,920 37,390
Pancreatic cancer represents 3.34% of all new cancer cases in the U.S.
3.34%
Pancreatic
Line graph of 5-year survival ignoring death from other causes (perhaps with white and black)
Explanatory text –
SURVIVAL STATISTICS
show more
TRENDS IN RATES
show more
NEW CASES, CURRENT CASES, & DEATHS
show more
ADDITIONAL RESOURCES
show more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Surveillance, Epidemiology, and End Results Program
Search
GO
Cancer Statistics
About SEER
Our history, mission and activities
Policy-Oriented Overviews
Personalized Tools
Data Explorer
Publications
For Researchers
Data and tools to download and use for your own analysis
For Cancer Registrars
Data coding and submission; Training and Support
IN THIS SECTION:
Cancer Overviews
All Sites
Anal Cancer
Bladder
Bone and Joint
Brain and Other Nervous System
Breast
Cervix Uteri
Colon and Rectum
Corpus and Uterus, NOS
Esophagus
Eye and Orbit
Kidney and Renal Pelvis
Larynx
Leukemia
Leukemia: Acute Lymphocytic
Leukemia: Chronic Lymphocytic
Leukemia: Acute Myeloid
Leukemia: Chronic Myeloid
Liver and Intrahepatic Bile Duct
Lung and Bronchus
Lymphoma
Lymphoma: Hodgkin
Lymphoma: Non-Hodgkin
Lymphoma: B-cell Non-Hodgkin
Lymphoma: T-cell Non-Hodgkin
Myeloma
Oral Cavity and Pharynx
Oral: Tongue
Other Endocrine
Ovary
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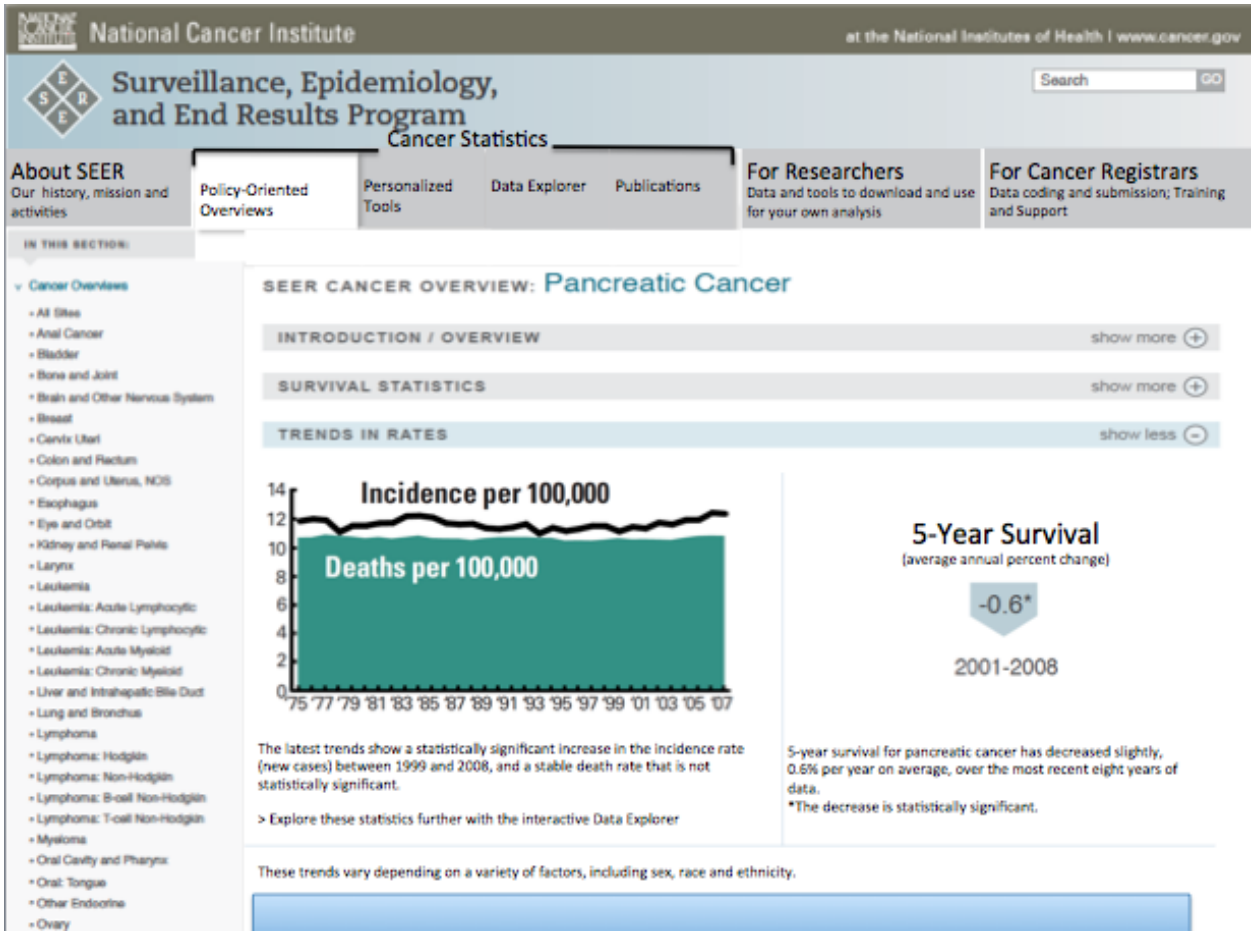
INTRODUCTION / OVERVIEW
show more
SURVIVAL STATISTICS
show less
These survival statistics ignore other causes of death, which is useful for looking at the whole population and measuring progress against cancer. Individual prognoses must take into account age and other health factors. See Personalized Tools >>
Of all people diagnosed with pancreatic cancer during the period 2001-2007, 5.5% were living five years after diagnosis.
In part because it is difficult to detect early, pancreatic cancer has a low survival rate. More than half of pancreatic diagnoses are for stage 4 disease, after the cancer has spread to other organs. On average, patients diagnosed at stage 4 live only 6 months.
> More about cancer staging
Stage Distribution & 5-Year Relative Survival by Stage at Diagnosis: Pancreatic Cancer
(2001-2007, All Races, Both Sexes)
KEY:
Deaths
5-year Relative Survival (%)
UNKNOWN
LOCALIZED
REGIONAL
DISTANT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Surveillance, Epidemiology, and End Results Program
Search
GO
Cancer Statistics
About SEER
Our history, mission and activities
Policy-Oriented Overviews
Personalized Tools
Data Explorer
Publications
For Researchers
Data and tools to download and use for your own analysis
For Cancer Registrars
Data coding and submission; Training and Support
IN THIS SECTION:
Cancer Overviews
All Sites
Anal Cancer
Bladder
Bone and Joint
Brain and Other Nervous System
Breast
Cervix Uteri
Colon and Rectum
Corpus and Uterus, NOS
Esophagus
Eye and Orbit
Kidney and Renal Pelvis
Larynx
Leukemia
Leukemia: Acute Lymphocytic
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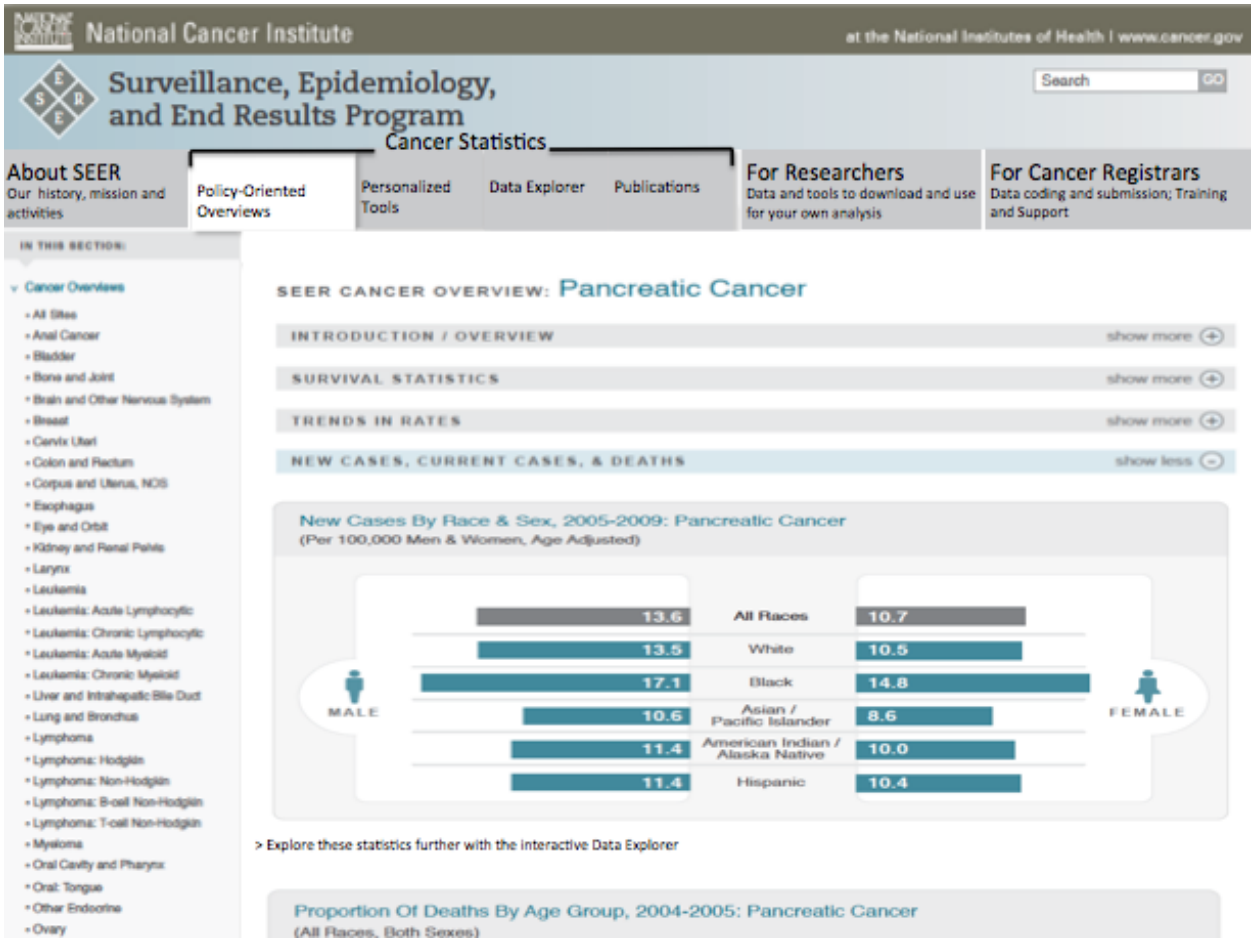
Lymphoma: T-cell Non-Hodgkin
Myeloma
Oral Cavity and Pharynx
Oral: Tongue
Other Endocrine
Ovary
SEER CANCER OVERVIEW: Pancreatic Cancer
INTRODUCTION / OVERVIEW
show more
SURVIVAL STATISTICS
show more
TRENDS IN RATES
show less
Incidence per 100,000
Deaths per 100,000
14
12
10
8
6
4
2
0
'75 '77 '79 '81 '83 '85 '87 '89 '91 '93 '95 '97 '99 '01 '03 '05 '07
The latest trends show a statistically significant increase in the incidence rate (new cases) between 1999 and 2008, and a stable death rate that is not statistically significant.
> Explore these statistics further with the interactive Data Explorer
5-Year Survival
(average annual percent change)
-0.6*
2001-2008
5-year survival for pancreatic cancer has decreased slightly, 0.6% per year on average, over the most recent eight years of data.
*The decrease is statistically significant.
These trends vary depending on a variety of factors, including sex, race and ethnicity.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Surveillance, Epidemiology, and End Results Program
Search
Cancer Statistics
About SEER
Our history, mission and activities
Policy-Oriented Overviews
Personalized Tools
Data Explorer
Publications
For Researchers
Data and tools to download and use for your own analysis
For Cancer Registrars
Data coding and submission; Training and Support
IN THIS SECTION:
Cancer Overviews
All Sites
Anal Cancer
Bladder
Bone and Joint
Brain and Other Nervous System
Breast
Cervix Uteri
Colon and Rectum
Corpus and Uterus, NOS
Esophagus
Eye and Orbit
Kidney and Renal Pelvis
Larynx
Leukemia
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Leukemia: Chronic Myeloid
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Lymphoma
Lymphoma: Hodgkin
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Lymphoma: T-cell Non-Hodgkin
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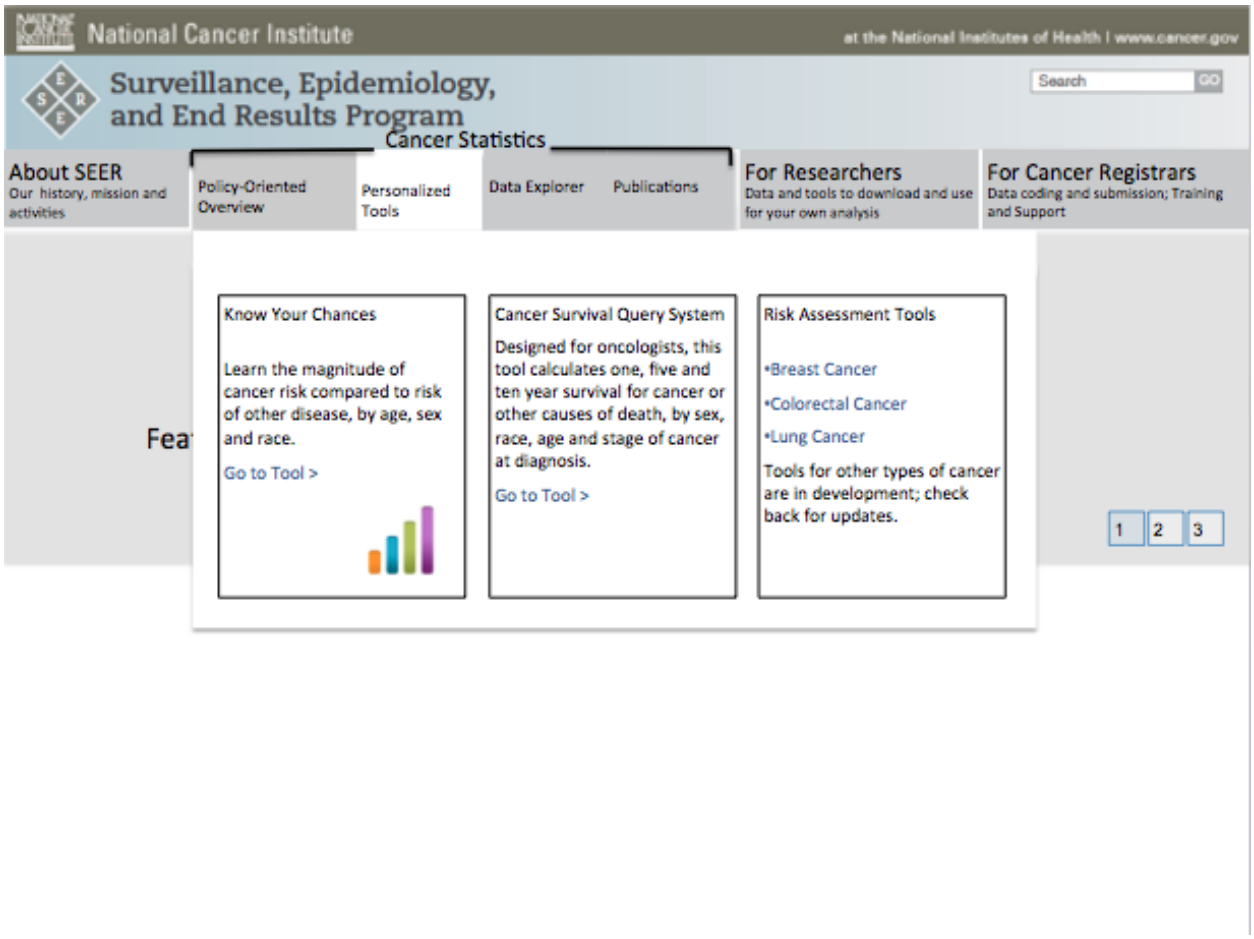
Oral Cavity and Pharynx
Oral: Tongue
Other Endocrine
Ovary
SEER CANCER OVERVIEW: Pancreatic Cancer
INTRODUCTION / OVERVIEW
show more
SURVIVAL STATISTICS
show more
TRENDS IN RATES
show more
NEW CASES, CURRENT CASES, & DEATHS
show less
New Cases By Race & Sex, 2005-2009: Pancreatic Cancer
(Per 100,000 Men & Women, Age Adjusted)
MALE
FEMALE
13.6 All Races 10.7
13.5 White 10.5
17.1 Black 14.8
10.6 Asian / Pacific Islander 8.6
11.4 American Indian / Alaska Native 10.0
11.4 Hispanic 10.4
> Explore these statistics further with the Interactive Data Explorer
Proportion Of Deaths By Age Group, 2004-2005: Pancreatic Cancer
(All Races, Both Sexes)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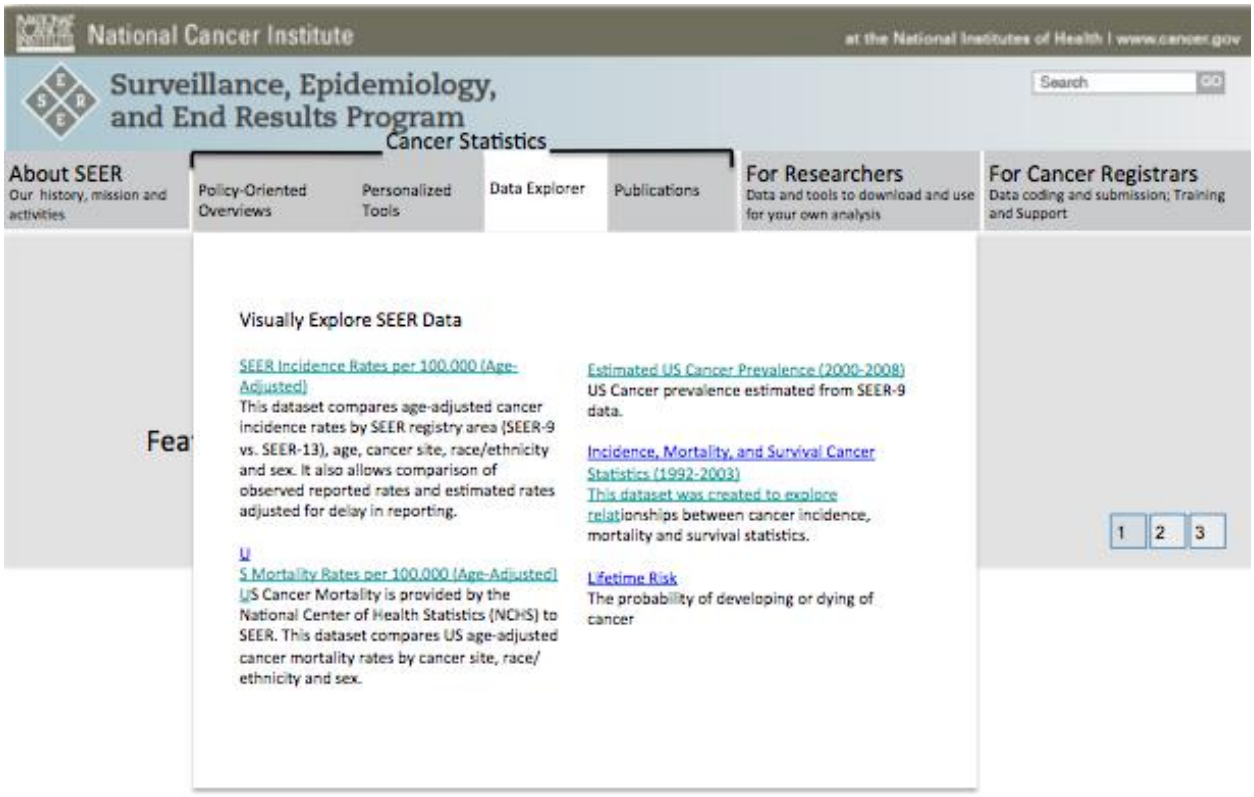
Surveillance, Epidemiology, and End Results Program
Search
GO
Cancer Statistics
About SEER
Our history, mission and activities
Policy-Oriented Overview
Personalized Tools
Data Explorer
Publications
For Researchers
Data and tools to download and use for your own analysis
For Cancer Registrars
Data coding and submission; Training and Support
Know Your Chances
Learn the magnitude of cancer risk compared to risk of other disease, by age, sex and race.
Go to Tool >
Cancer Survival Query System
Designed for oncologists, this tool calculates one, five and ten year survival for cancer or other causes of death, by sex, race, age and stage of cancer at diagnosis.
Go to Tool >
Risk Assessment Tools
•Breast Cancer
•Colorectal Cancer
•Lung Cancer
Tools for other types of cancer are in development; check back for updates.
1
2
3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Surveillance, Epidemiology, and End Results Program
Search
GO
Cancer Statistics
About SEER
Our history, mission and activities
Policy-Oriented Overviews
Personalized Tools
Data Explorer
Publications
For Researchers
Data and tools to download and use for your own analysis
For Cancer Registrars
Data coding and submission; Training and Support
Visually Explore SEER Data
SEER Incidence Rates per 100,000 (Age-Adjusted)
This dataset compares age-adjusted cancer incidence rates by SEER registry area (SEER-9 vs. SEER-13), age, cancer site, race/ethnicity and sex. It also allows comparison of observed reported rates and estimated rates adjusted for delay in reporting.
U
S Mortality Rates per 100,000 (Age-Adjusted)
US Cancer Mortality is provided by the National Center of Health Statistics (NCHS) to SEER. This dataset compares US age-adjusted cancer mortality rates by cancer site, race/ethnicity and sex.
Estimated US Cancer Prevalence (2000-2008)
US Cancer prevalence estimated from SEER-9 data.
Incidence, Mortality, and Survival Cancer Statistics (1992-2003)
This dataset was created to explore relationships between cancer incidence, mortality and survival statistics.
Lifetime Risk
The probability of developing or dying of cancer
1
2
3

Incidence

A cancer incidence rate is the number of new cancers of a specific site/type occurring in a specified population during a year, usually expressed as the number of cancers per 100,000 population at risk. That is, Incidence Rate = (New Cancers / Population) x 100,000.

From 2005-2009, the median age at diagnosis for cancer of all sites was 66 years of age. Approximately 1.1% were diagnosed under age 20; 2.6% between 20 and 34; 5.5% between 35 and 44; 14.2% between 45 and 54; 23.4% between 55 and 64; 24.9% between 65 and 74; 20.6% between 75 and 84; and 7.7% 85+ years of age.

The age-adjusted incidence rate was 465.2 per 100,000 men and women per year. These rates are based on cases diagnosed in 2005-2009 from 18 SEER geographic areas.

Next >

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Search GO

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Policy-Oriented Overviews | Personalized Tools | Data Explorer | Publications

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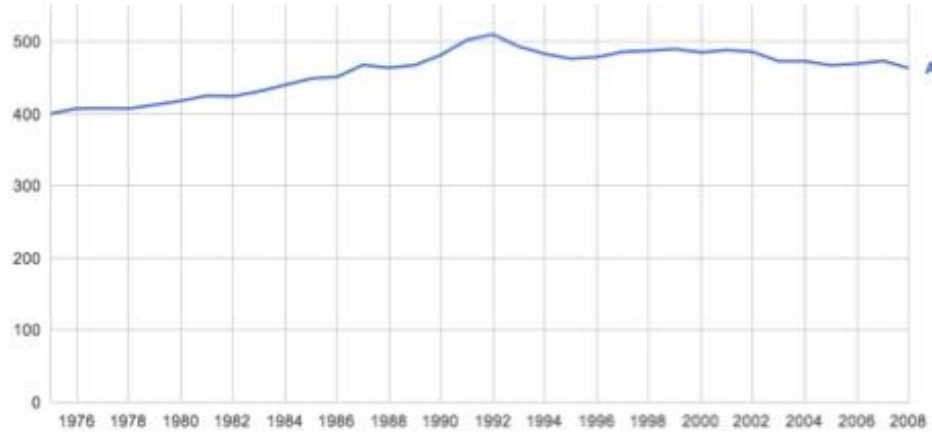
Age-Adjusted Incidence Rate - No - Both Sexes - SEER-9 (197...



< Back Customize Next >

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Search GO

Cancer Statistics

About SEER
Our history, mission and activities

Policy-Oriented Overviews | Personalized Tools | Data Explorer | Publications

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For Cancer Registrars
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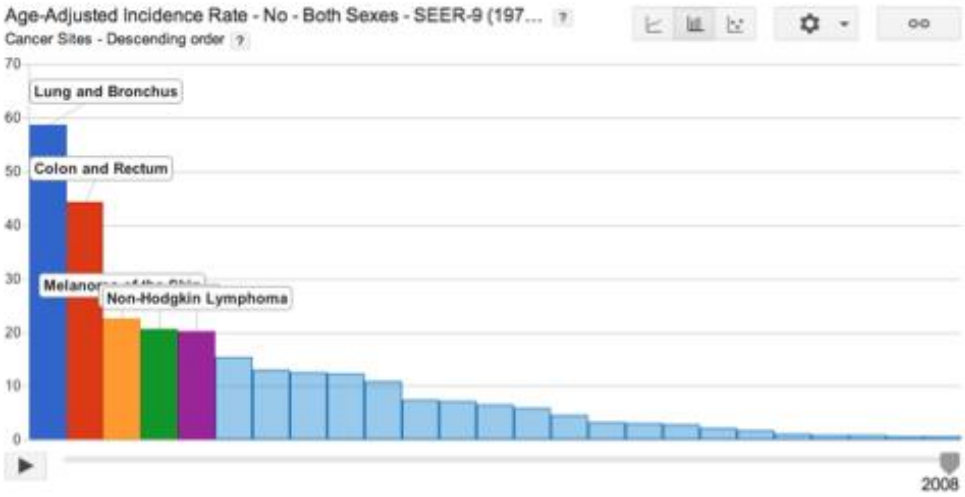

< Back Customize Next >

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Surveillance, Epidemiology, and End Results Program

Search

Cancer Statistics

About SEER
Our history, mission and activities

Policy-Oriented Overviews

Personalized Tools

Data Explorer

Publications

For Researchers
Data and tools to download and use for your own analysis

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< Back Customize

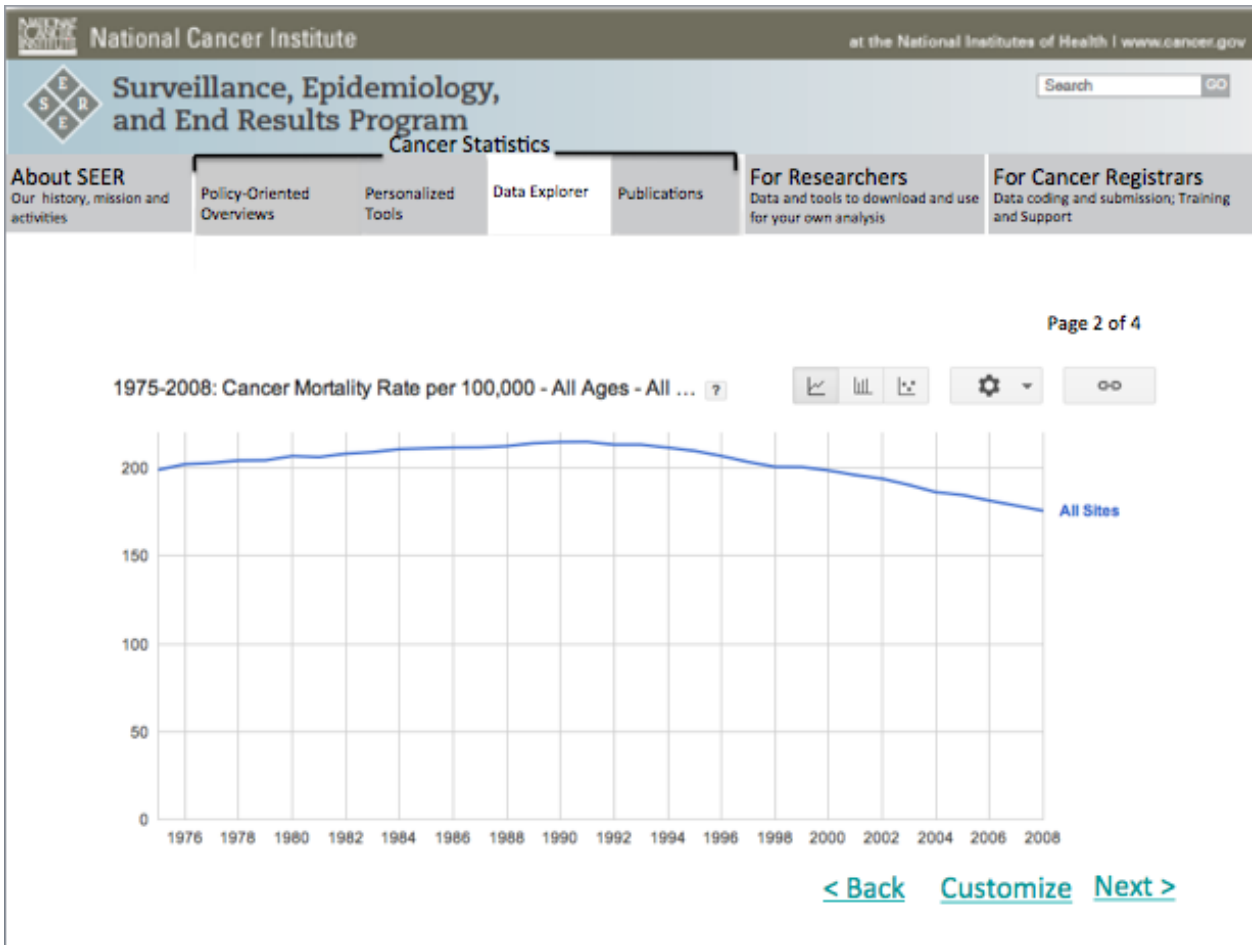
Mortality

A cancer mortality rate is the number of deaths, with cancer as the underlying cause of death, occurring in a specified population during a year. Cancer mortality is usually expressed as the number of deaths due to cancer per 100,000 population. That is: Mortality Rate = (Cancer Deaths/Population) x 100,000.

From 2005-2009, the median age at death for cancer of all sites was 72 years of age. Approximately 0.4% died under age 20; 0.8% between 20 and 34; 2.4% between 35 and 44; 8.9% between 45 and 54; 18.3% between 55 and 64; 24.8% between 65 and 74; 28.9% between 75 and 84; and 15.5% 85+ years of age.

The age-adjusted death rate was 178.7 per 100,000 men and women per year. These rates are based on patients who died in 2005-2009 in the US.

Next >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Surveillance, Epidemiology, and End Results Program
Search
GO
Cancer Statistics
About SEER
Our history, mission and activities
Policy-Oriented Overviews
Personalized Tools
Data Explorer
Publications
For Researchers
Data and tools to download and use for your own analysis
For Cancer Registrars
Data coding and submission; Training and Support
Page 2 of 4
1975-2008: Cancer Mortality Rate per 100,000 - All Ages - All ...
200
150
100
50
0
1976 1978 1980 1982 1984 1986 1988 1990 1992 1994 1996 1998 2000 2002 2004 2006 2008
All Sites
< Back
Customize
Next >

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Surveillance, Epidemiology, and End Results Program

Search

Cancer Statistics

About SEER
Our history, mission and activities

Policy-Oriented Overviews

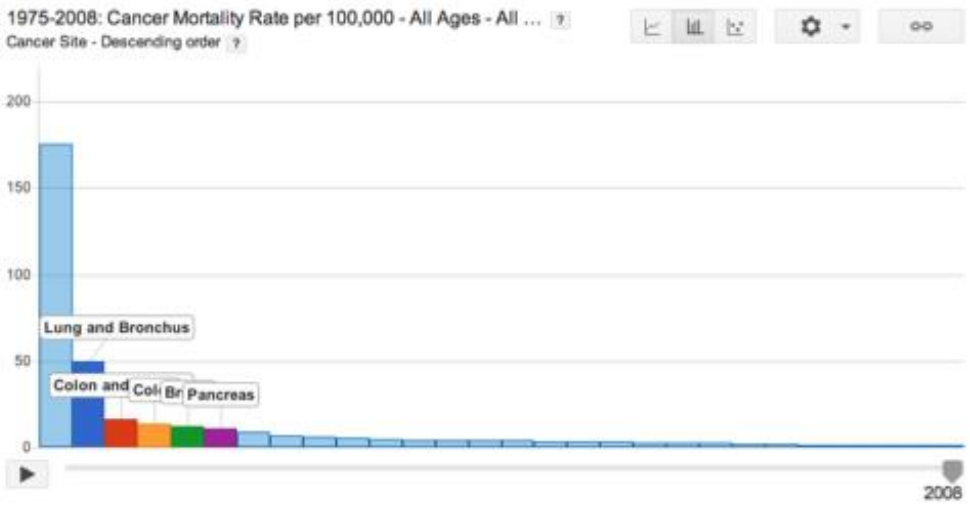
Personalized Tools

Data Explorer

Publications

For Researchers
Data and tools to download and use for your own analysis

For Cancer Registrars
Data coding and submission; Training and Support



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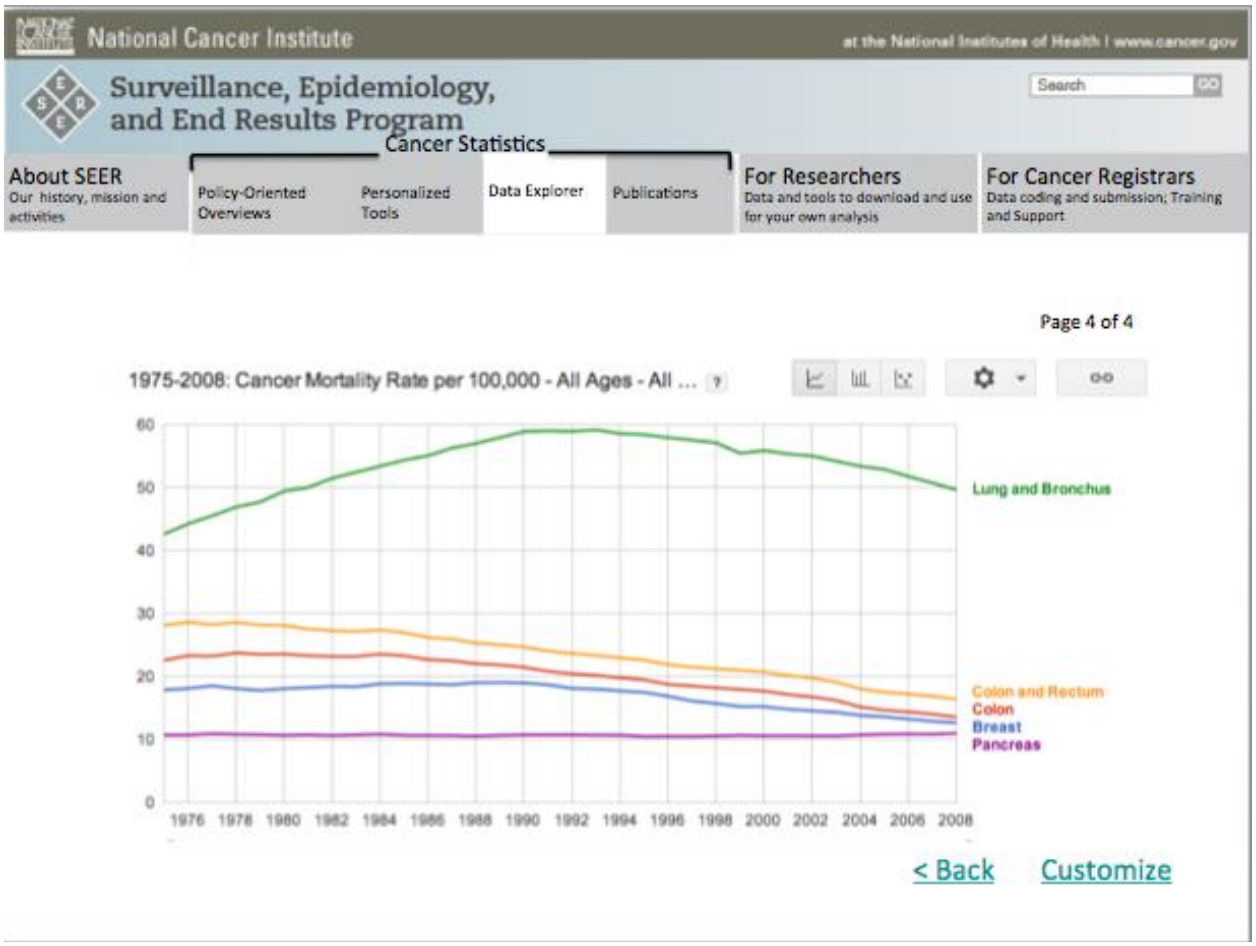
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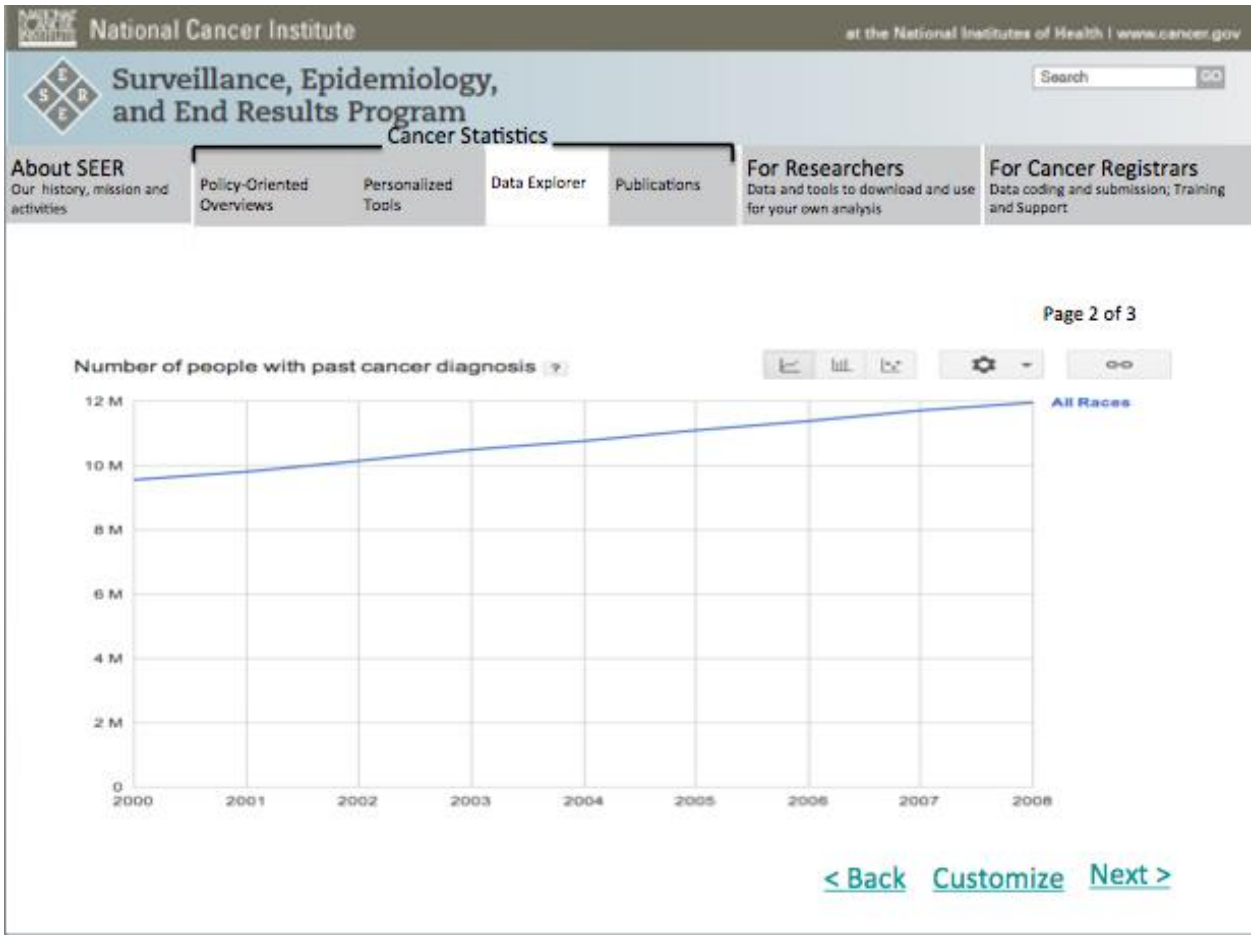
Search
Cancer Statistics
About SEER
Our history, mission and activities
Policy-Oriented Overviews
Personalized Tools
Data Explorer
Publications
For Researchers
Data and tools to download and use for your own analysis
For Cancer Registrars
Data coding and submission; Training and Support
Page 4 of 4
1975-2008: Cancer Mortality Rate per 100,000 - All Ages - All ...
60
50
40
30
20
10
0
1976 1978 1980 1982 1984 1986 1988 1990 1992 1994 1996 1998 2000 2002 2004 2006 2008
Lung and Bronchus
Colon and Rectum
Colon
Breast
Pancreas
< Back
Customize

Prevalence

Prevalence is defined as the number or percent of people alive on a certain date in a population who previously had a diagnosis of the disease. It includes new (incidence) and pre-existing cases and is a function of both past incidence and survival. Information on prevalence can be used for health planning, resource allocation, and an estimate of cancer survivorship. Overview of Cancer Prevalence contains a description of the methodology and the types of prevalence statistics.

On January 1, 2009, in the United States there were approximately 12,553,337 men and women alive who had a history of cancer of all sites -- 5,811,097 men and 6,742,240 women. This includes any person alive on January 1, 2009 who had been diagnosed with cancer of all sites at any point prior to January 1, 2009 and includes persons with active disease and those who are cured of their disease. Prevalence can also be expressed as a percentage and it can also be calculated for a specific amount of time prior to January 1, 2009 such as diagnosed within 5 years of January 1, 2009.

Next >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About SEER
Our history, mission and activities
Policy-Oriented Overviews
Personalized Tools
Data Explorer
Publications
For Researchers
Data and tools to download and use for your own analysis
For Cancer Registrars
Data coding and submission; Training and Support
Page 2 of 3
Number of people with past cancer diagnosis
All Races
12 M
10 M
8 M
6 M
4 M
2 M
0
2000
2001
2002
2003
2004
2005
2006
2007
2008
< Back
Customize
Next >

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About SEER
Our history, mission and activities

Policy-Oriented Overviews

Personalized Tools

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Publications

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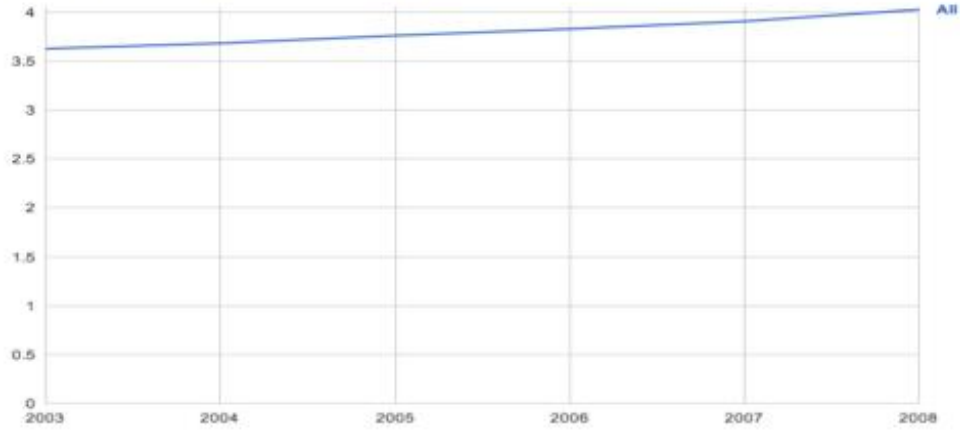
Data and tools to download and use for your own analysis

For Cancer Registrars
Data coding and submission; Training and Support

Page 3 of 3

Percent of people with past cancer diagnosis ?



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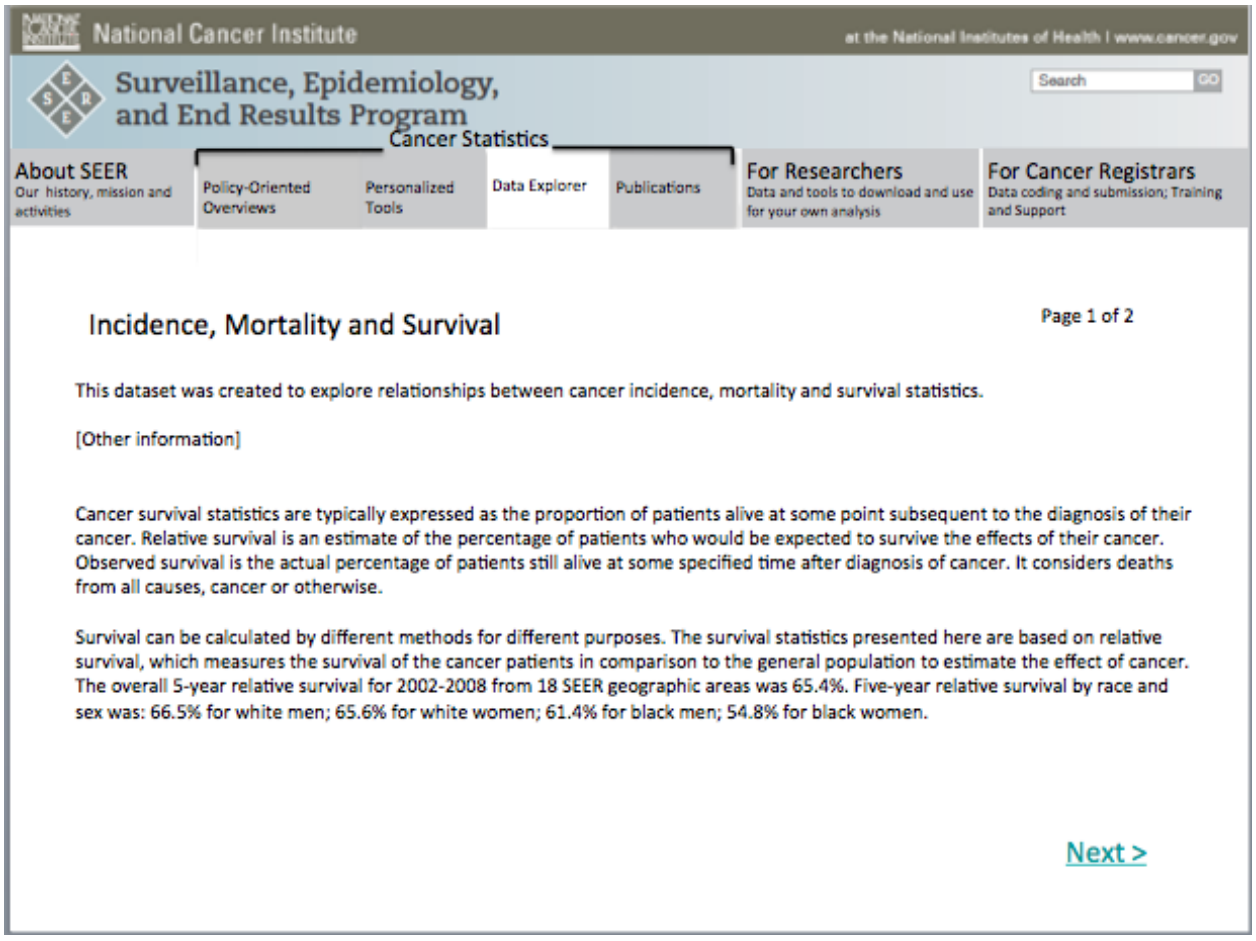
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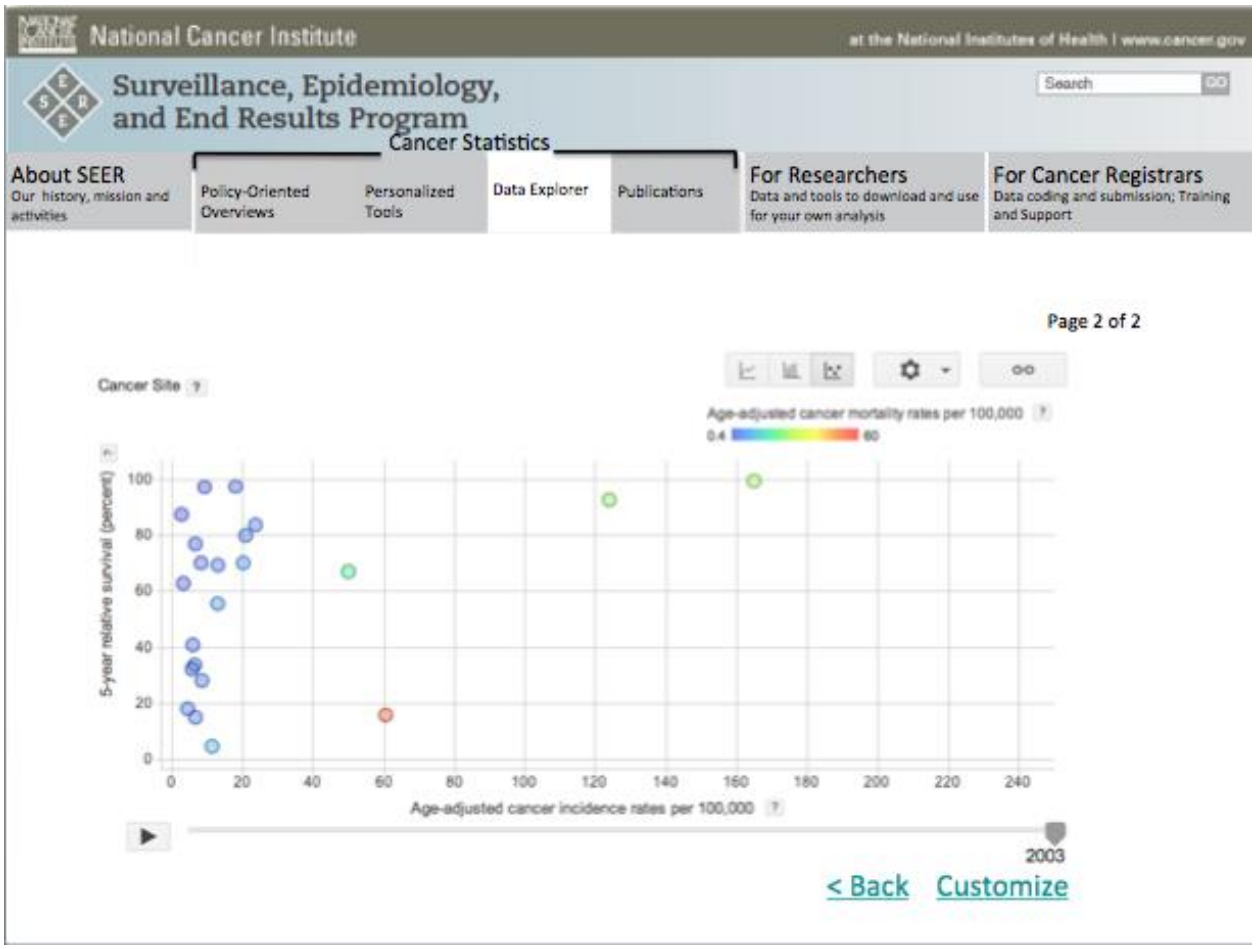
Search
GO
Cancer Statistics
About SEER
Our history, mission and activities
Policy-Oriented Overviews
Personalized Tools
Data Explorer
Publications
For Researchers
Data and tools to download and use for your own analysis
For Cancer Registrars
Data coding and submission; Training and Support
Incidence, Mortality and Survival
Page 1 of 2
This dataset was created to explore relationships between cancer incidence, mortality and survival statistics.
[Other information]
Cancer survival statistics are typically expressed as the proportion of patients alive at some point subsequent to the diagnosis of their cancer. Relative survival is an estimate of the percentage of patients who would be expected to survive the effects of their cancer. Observed survival is the actual percentage of patients still alive at some specified time after diagnosis of cancer. It considers deaths from all causes, cancer or otherwise.
Survival can be calculated by different methods for different purposes. The survival statistics presented here are based on relative survival, which measures the survival of the cancer patients in comparison to the general population to estimate the effect of cancer. The overall 5-year relative survival for 2002-2008 from 18 SEER geographic areas was 65.4%. Five-year relative survival by race and sex was: 66.5% for white men; 65.6% for white women; 61.4% for black men; 54.8% for black women.
Next >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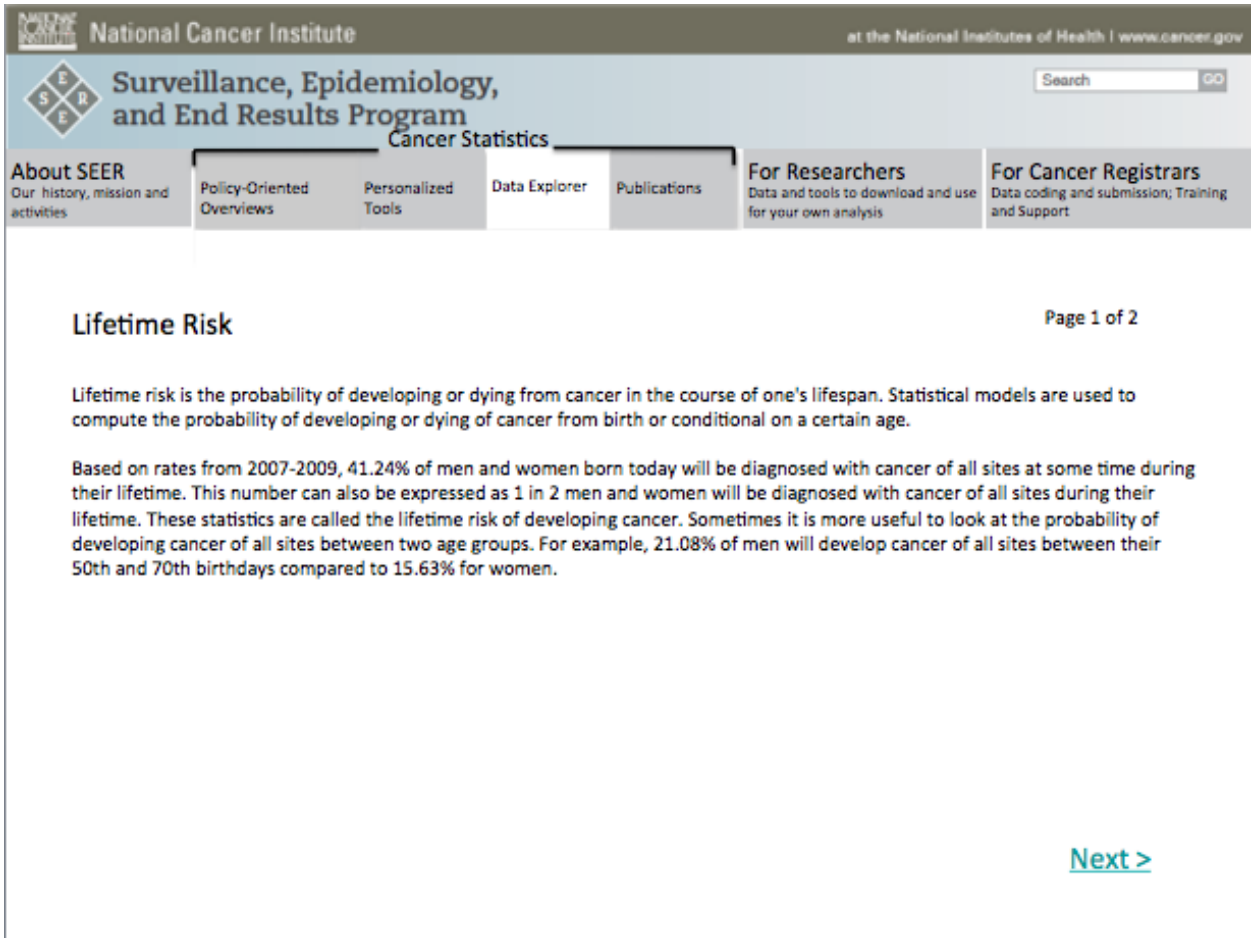
Cancer Statistics
About SEER
Our history, mission and activities
Policy-Oriented Overviews
Personalized Tools
Data Explorer
Publications
For Researchers
Data and tools to download and use for your own analysis
For Cancer Registrars
Data coding and submission; Training and Support
Page 2 of 2
Cancer Site
Age-adjusted cancer mortality rates per 100,000
0.4
60
5-year relative survival (percent)
0
20
40
60
80
100
120
140
160
180
200
220
240
Age-adjusted cancer incidence rates per 100,000
2003
< Back
Customize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Cancer Statistics
About SEER
Our history, mission and activities
Policy-Oriented Overviews
Personalized Tools
Data Explorer
Publications
For Researchers
Data and tools to download and use for your own analysis
For Cancer Registrars
Data coding and submission; Training and Support
Lifetime Risk
Page 1 of 2
Lifetime risk is the probability of developing or dying from cancer in the course of one's lifespan. Statistical models are used to compute the probability of developing or dying of cancer from birth or conditional on a certain age.
Based on rates from 2007-2009, 41.24% of men and women born today will be diagnosed with cancer of all sites at some time during their lifetime. This number can also be expressed as 1 in 2 men and women will be diagnosed with cancer of all sites during their lifetime. These statistics are called the lifetime risk of developing cancer. Sometimes it is more useful to look at the probability of developing cancer of all sites between two age groups. For example, 21.08% of men will develop cancer of all sites between their 50th and 70th birthdays compared to 15.63% for women.
Next >

< Back Customize


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Search
GO
Cancer Statistics
About SEER
Our history, mission and activities
Policy-Oriented Overviews
Personalized Tools
Data Explorer
Publications
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Statistical Reports
Annual Report to the Nation on the Status of Cancer
Cancer Incidence and Mortality Patterns among Specific Asian and Pacific Islander Populations in the US
United States Cancer Statistics: Cancer Incidence and Mortality Data
Monographs
An Update on Cancer in American Indians and Alaska Natives, 1999-2004
Selected Comparisons of Measures of Health Disparities
SEER Survival Monograph: Cancer Survival among Adults
More monographs...
SEER Bibliography
Searchable database of articles authored by SEER registry and program staff.
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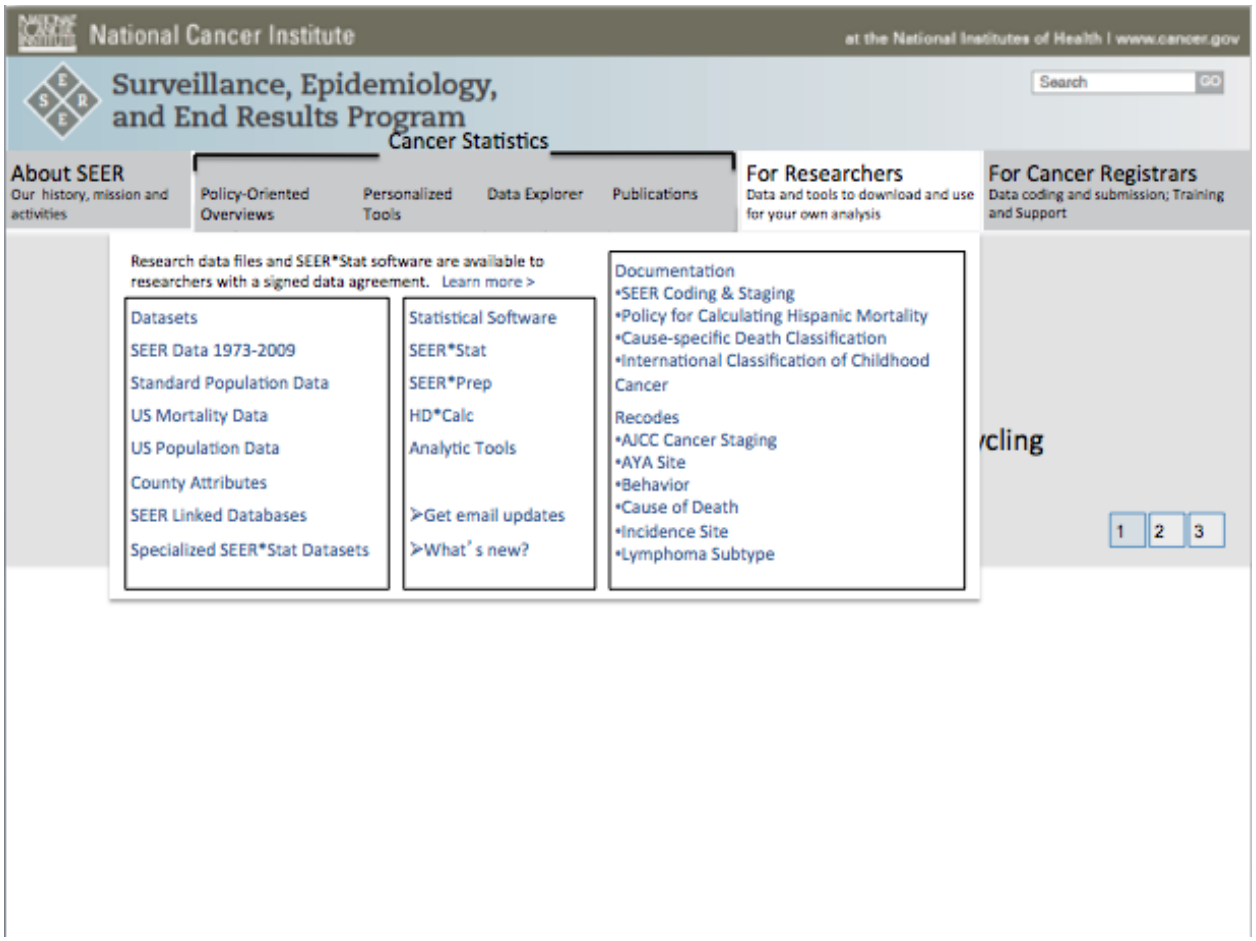
3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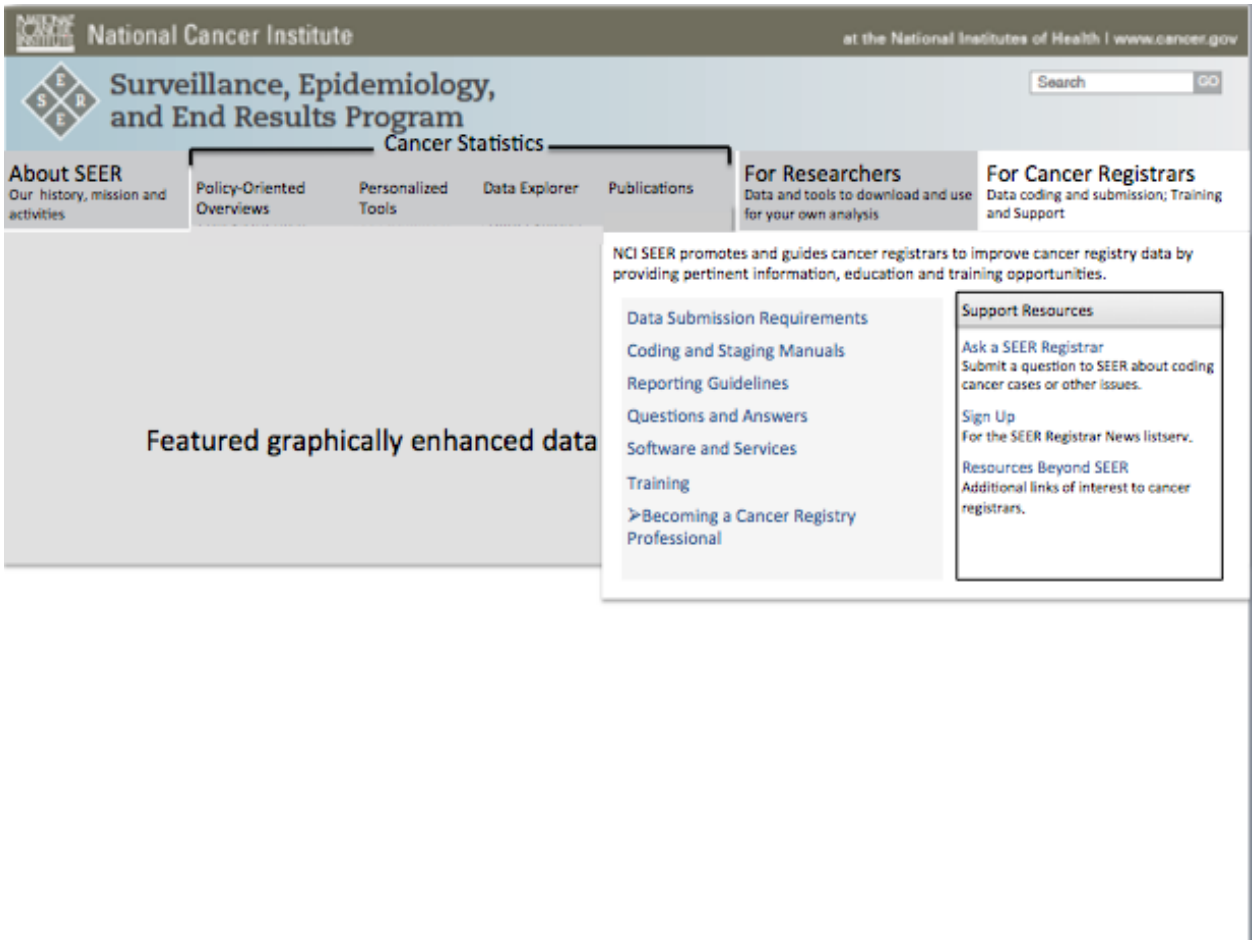
Research data files and SEER*Stat software are available to researchers with a signed data agreement. Learn more >
Datasets
SEER Data 1973-2009
Standard Population Data
US Mortality Data
US Population Data
County Attributes
SEER Linked Databases
Specialized SEER*Stat Datasets
Statistical Software
SEER*Stat
SEER*Prep
HD*Calc
Analytic Tools
➢Get email updates
➢What's new?
Documentation
•SEER Coding & Staging
•Policy for Calculating Hispanic Mortality
•Cause-specific Death Classification
•International Classification of Childhood Cancer
Recodes
•AJCC Cancer Staging
•AYA Site
•Behavior
•Cause of Death
•Incidence Site
•Lymphoma Subtype
1
2
3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About SEER
Our history, mission and activities
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Data coding and submission; Training and Support
Featured graphically enhanced data
NCI SEER promotes and guides cancer registrars to improve cancer registry data by providing pertinent information, education and training opportunities.
Data Submission Requirements
Coding and Staging Manuals
Reporting Guidelines
Questions and Answers
Software and Services
Training
➢Becoming a Cancer Registry Professional
Support Resources
Ask a SEER Registrar
Submit a question to SEER about coding cancer cases or other issues.
Sign Up
For the SEER Registrar News listserv.
Resources Beyond SEER
Additional links of interest to cancer registrars.

Appendix B- Facilitator's Guide for Round One Usability Evaluations

[Note: The purpose of this document is to guide the moderator. The questions and tasks contained herein may not be asked as written. The facilitator often draws on participant comments and the natural flow of the testing process to determine the flow of the session. While the facilitator will try to follow the order of the guide, many times tasks will come up ahead of time or in different order. The facilitator may allow the order of the tasks to change in order to let the process flow naturally.]

[Note: The purpose of this document is to guide the moderator. The questions and tasks contained herein may not be asked as written. The facilitator often draws on participant comments and the natural flow of the testing process to determine the flow of the session. While the facilitator will try to follow the order of the guide, many times tasks will come up ahead of time or in different order. The facilitator may allow the order of the tasks to change in order to let the process flow naturally.]

The following tasks are assumed to be correct for the proposed participants based on prior discussion on the purpose of the site. However, the ability of the site to support these tasks needs to be verified.]

Pre-Test

[Administer the informed consent.]

Introduction

Thank you for agreeing to participate in this study.

SEER has been working on redesigning how cancer statistics are provided on the Internet to individuals such as you. I'll be asking you questions about how you use cancer statistics, what you would be doing with that information, and how you would prefer to see it presented. To help with the evaluation, I will give you some tasks and will watch to see how easy or difficult they are for you.

As we go through the tasks, feel free to offer any comments or suggestions that occur to you. We are looking for things about the design that are working well, as well as things that could be improved. There are two important things you should keep in mind while you work with the design:

- First, I did not create the design so you can't hurt my feelings with any criticism you might have. If there are problems with the design I would like to discuss them with you to see if we can find a way to improve the design.
- Second, we are evaluating the design and not you, so you cannot make any mistakes. It is supposed to be intuitive and easy to use. If it isn't, that's a problem with the design – not with you.

I'd also like you to know that there are some observers with us today helping me by taking notes, but don't worry about them. You and I will work on this together and they'll just watch and listen.

Do you have any questions for me before we get started?

Background

Let's start with some questions about your background.

1. Can you tell me a bit about your job? Specifically, how do you use cancer statistics in the work you do?

2. We're going to be talking about ways to view cancer statistics data. Is there a particular format you use?

    a. [Probe on the format: graph, table, chart etc.]

    b. [Probe on if the way they view data differs depending on the data type (or some other way).]

    c. [Probe on the need for comparing data (by cancer type, statistic type, etc.).]

3. Can you describe an example of data that you've pulled from SEER in the past and how you've used it?
    a. [Probe on if they examine current/recent data or look at trends over time.]

4. What kinds of tools do you currently use when you want to "see" the data?

    a. Have you ever used the tools offered on the SEER site to display data? If so, which ones?

    b. If so, what is your impression of these tools (both their design and functionality)?

5. Are you familiar with SEER 9, SEER 13 and SEER 17? [If yes, probe on the differences.]

We'd like to show you a tool that produces some types of data displays. It is not the intended tool, but we'd like to use it to help discuss what you would want in an ideal tool. That includes the data, how you use the tool, the types of output it needs to produce, and details about the output.

Tasks

We'll start by looking at a mockup of a proposed website for SEER. The links in this document will work and will take you to a different location, just like a live website would. Some links may even open up in a separate browser window. However, keep in mind this is not the final solution – the design is still a work in progress. We're going to start by exploring the section of the site geared exploring data.

1. TO TEST UNDERSTANDING OF STATISTIC TYPES [No Dataset used]:
   Before we start, I'd like you to take a look at the various types of data available. [Show P the menu with statistic types listed (Slide 9).] Which types of data do you

currently use? [Probe on which ones seem unfamiliar and if they know them even if they don't use them.]

2. TO TEST PREVALENCE VS. INCIDENCE, CHANGING OUTPUT DISPLAY AND ADDING HIGHLIGHTING
   [Uses the "Prevalence B" Dataset]:
   Let's start by looking at the prevalence data. [Have the P explore the prevalence page.]
   a. Are you familiar with the term prevalence? What's the difference between prevalence and incidence? I always get them confused.
   b. [Open a prevalence display in the tool by directing the P to click "Customize."] Take a few minutes to check out this tool and see what options are available to you. Let me know if any of it is unclear.
      i. Probe on the following features:
         1. The ability to set each value.
         2. The ability to scale the x-axis scale
         3. The ability to "run" the scenario over time
         4. The ability to select different output types
   c. See what you can do to make it easy to tell which are the top 5 cancers in terms of percentage.

3. TO TEST THE LISTNG OF CANCER SITES, AND COMPARE BY CANCER SITE
   [Uses the "US Mortality Rates per 100,000 (Age-Adjusted)" Dataset]:
   Now let's look at mortality data.

   a. [Have P navigate back and select mortality and view the graph with the age-adjusted rate.]

   b. Can you see if you can create a display that compares lung cancer mortality to all sites of cancer combined? [Show P how to "compare by" cancer site if they do not find it.]

   c. Can you look at lung cancer comparing males and females?

   d. [When they are selecting cancer site, ask:] What do you think of how to select cancer sites? Are the groupings correct? Is that the usual way to list sites? Do you know of a better way? [Probe: alphabetically, nested in categories, grouped, etc.]

4. TO TEST THEIR UNDERSTANDING OF AGE ADJUSTMENT AND DELAY ADJUSTMENT [Uses the "SEER US Cancer Incidence" Dataset]:
   Now let's look at the Incidence Rate display.

   a. Did you notice the title says: "Age Adjusted Incident Rate." Is "Age Adjusted" a familiar term you're familiar with?

b. [Show the P the delay-adjusted graph in the tool.] Did you notice the line splits near the end? What does that mean? [If they don't recognize one is non-delay adjusted and one is delay-adjusted, show them and ask if they are familiar with the concept.] What would you do if you only wanted to show one of these lines? Can you see if you can do that here? [Note which one they decide to keep.]

5. TO TEST THE ABILITY TO MAKE A BUBBLE GRAPH [Uses the "Incidence, Mortality and Survival Cancer Statistics" Dataset]:
   Next let's talk about comparing multiple types of data. For example, would you ever want to compare incidence and mortality, or incidence and survival data?

   a. Open up the survival chart. [Be sure to use the dataset containing multiple statistics for comparison.] See if you can find a way to compare the survival rate to the incidence rate. [See if they know to go to a bubble chart and figure out how to set the X and Y axis. Also see if they know they can add color or size as well. See if they know they can animate it over time.]

Follow-up Questions

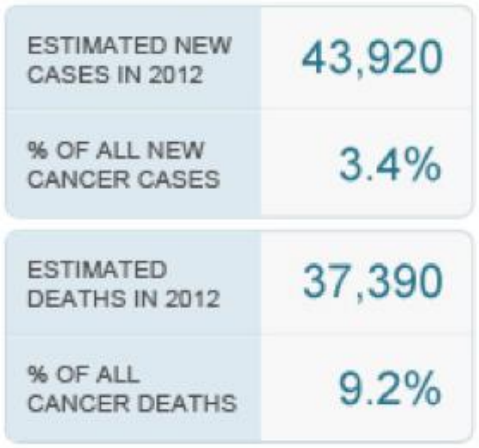
1. What are the types of displays you would need to have for a tool like this?
2. Was there any type of information missing that you would need on any or all of these displays?

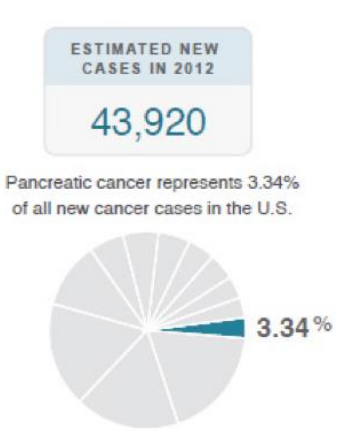
Wrap up

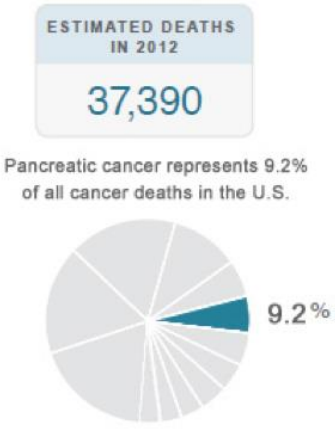
OK, we're done. Do you have any further questions or comments?

Thanks again for your participation.

Appendix C – Participant Material for Round Two Usability Evaluations







How Common Is This Cancer?

Compared to other cancer types, pancreatic cancer is rare.

	COMMON TYPES OF CANCER	ESTIMATED NEW CASES 2012	ESTIMATED DEATHS 2012
1.	Prostate	241,740	28,170
2.	Breast *(Female)*	226,870	39,510
3.	Lung *(Including Bronchus)*	226,160	160,340
4.	Colon and Rectal (Combined)	143,460	51,690
5.	Melanoma	76,250	9,180
6.	Bladder	73,510	14,880
7.	Non-Hodgkin Lymphoma	70,130	18,940
8.	Kidney (Renal Cell) Cancer	59,588	12,484
9.	Thyroid	56,460	1,780
10.	Leukemia (All Types)	47,150	23,540
11.	Endometrial	47,130	8,010
12.	**Pancreatic**	**43,920**	**37,390**

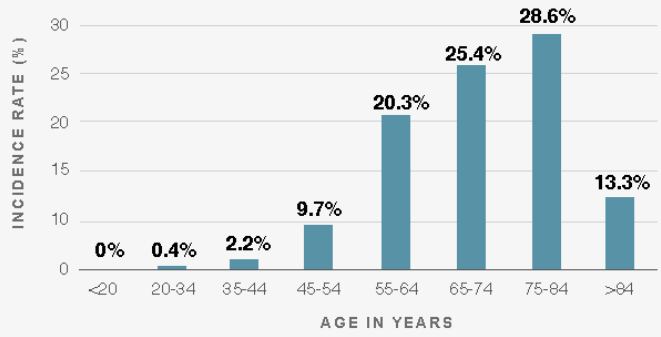
Pancreatic cancer represents 3.34% of all new cancer cases in the U.S.

3.34%
Pancreatic

There are an estimated 38,308 people living with pancreatic cancer.

New Cases By Age, 2002-2008: Pancreatic Cancer

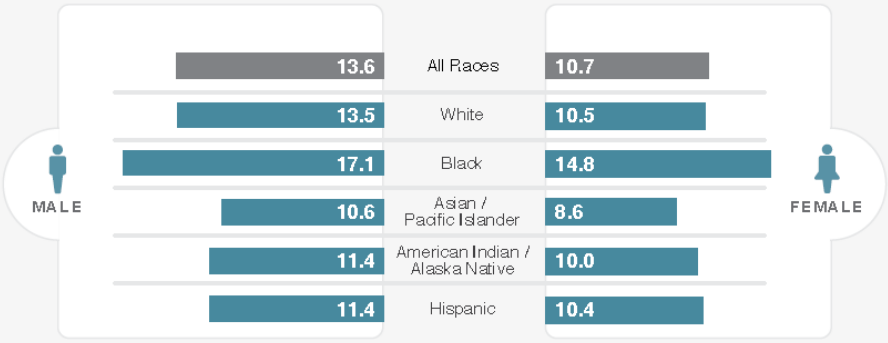
(All Races, Both Sexes)



People aged 75-84 years tend to contract cancer at the highest rate and the median age is 73 years.

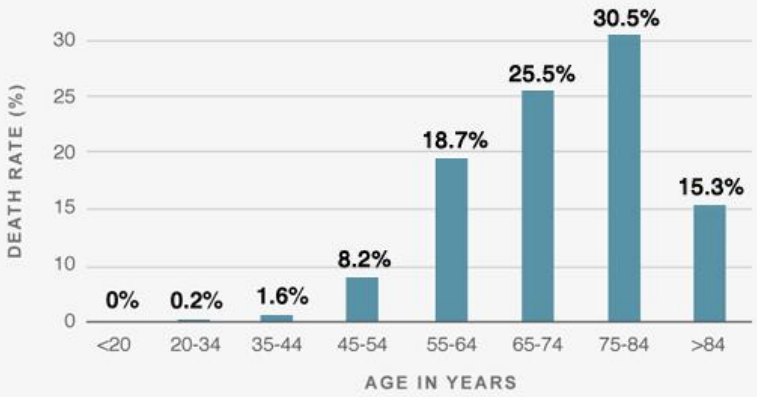
New Cases By Race / Ethnicity & Sex, 2005-2009: Pancreatic Cancer

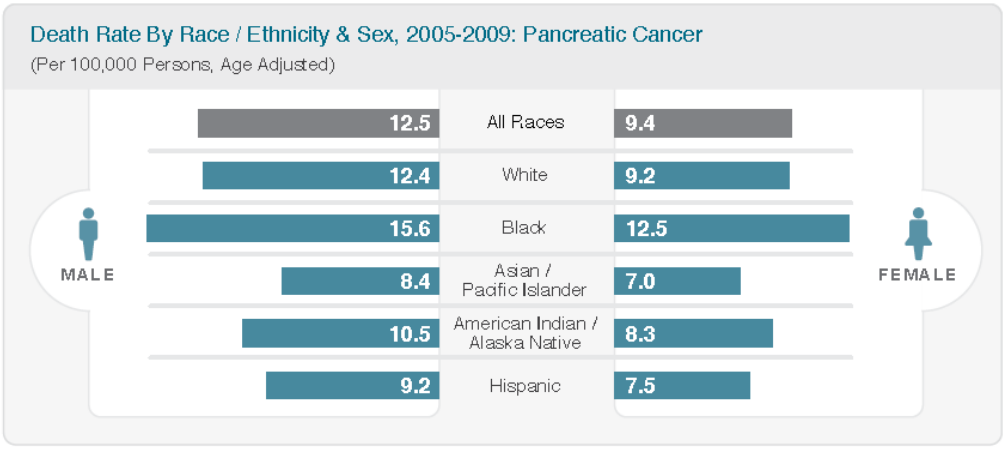
(Per 100,000 Persons, Age Adjusted)



Proportion Of Deaths By Age Group, 2004-2005: Pancreatic Cancer

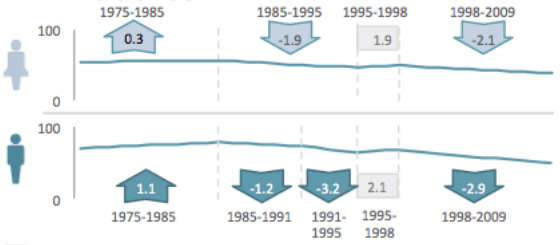
(All Races, Both Sexes)




Death Rate By Race / Ethnicity & Sex, 2005-2009: Pancreatic Cancer
(Per 100,000 Persons, Age Adjusted)
MALE
FEMALE
12.5
All Races
9.4
12.4
White
9.2
15.6
Black
12.5
8.4
Asian / Pacific Islander
7.0
10.5
American Indian / Alaska Native
8.3
9.2
Hispanic
7.5

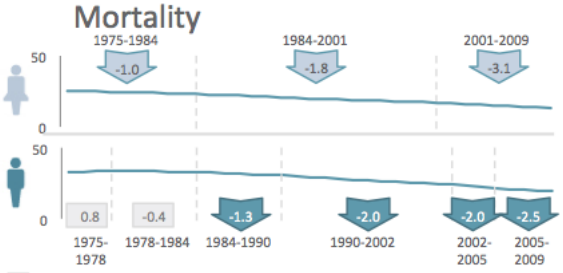
Colon & Rectum

Incidence



This estimate is considered to be stable because the trend is not statistically significant.

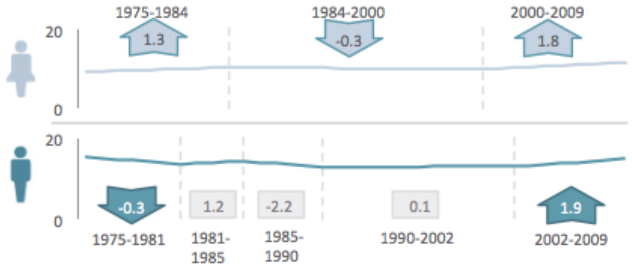
Mortality



This estimate is considered to be stable because the trend is not statistically significant.

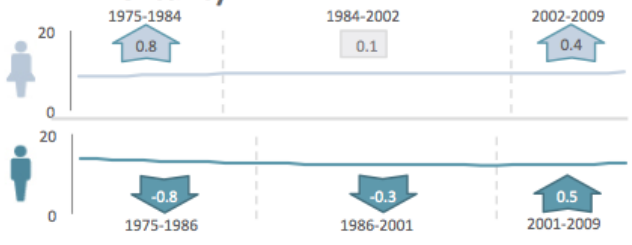
Pancreas

Incidence



This estimate is considered to be stable because the trend is not statistically significant.

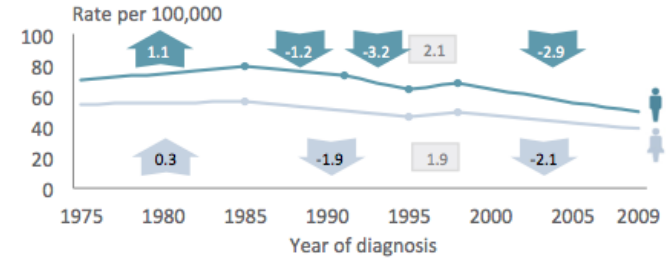
Mortality



This estimate is considered to be stable because the trend is not statistically significant.

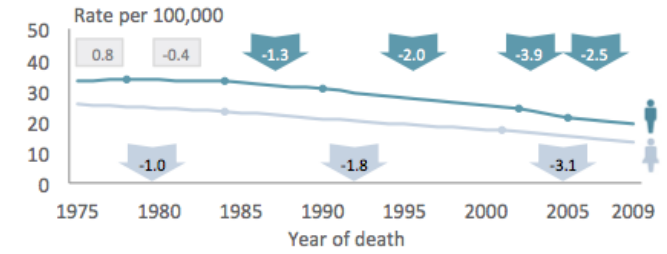
Colon & Rectum

Incidence

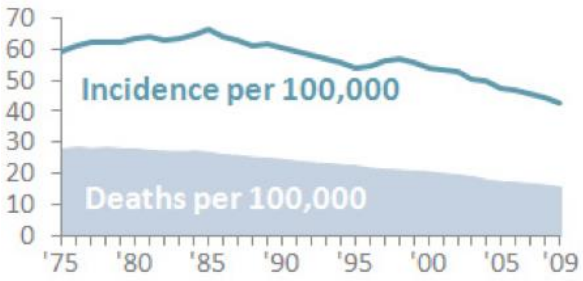


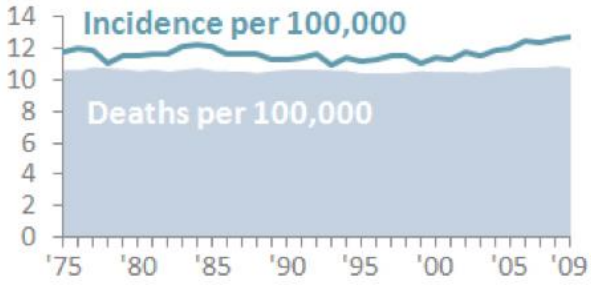
This estimate is considered to be stable because the trend is not statistically significant.

Mortality



This estimate is considered to be stable because the trend is not statistically significant.



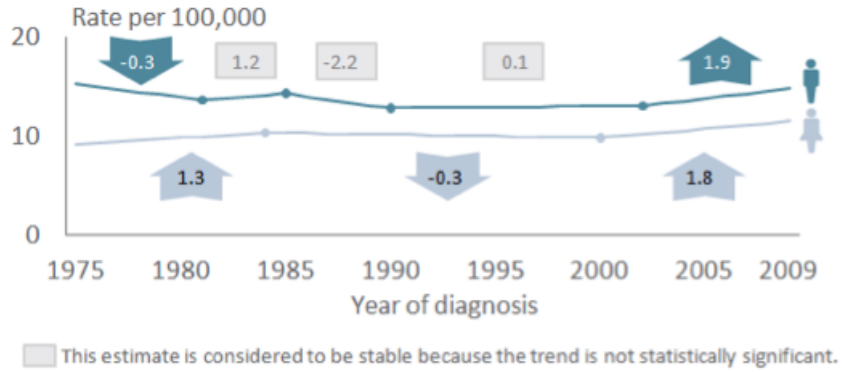


Changes Over Time

Rates of new cases (incidence) and deaths (mortality) from pancreatic cancer have remained stable over the last 35 years. In other words, pancreatic cancer has not become more or less common during that time, and the chance of dying from it has not changed.

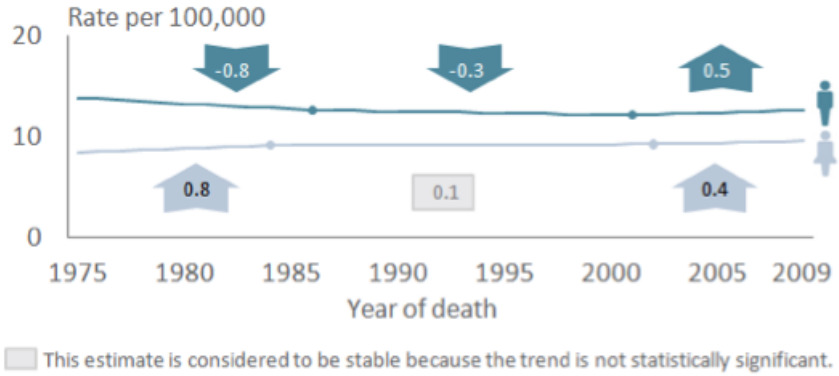
Incidence Trends: Pancreatic Cancer

(U.S. Joinpoint Trends, Annual Percent Change (%), 1975-2009, All Races, Both Sexes)



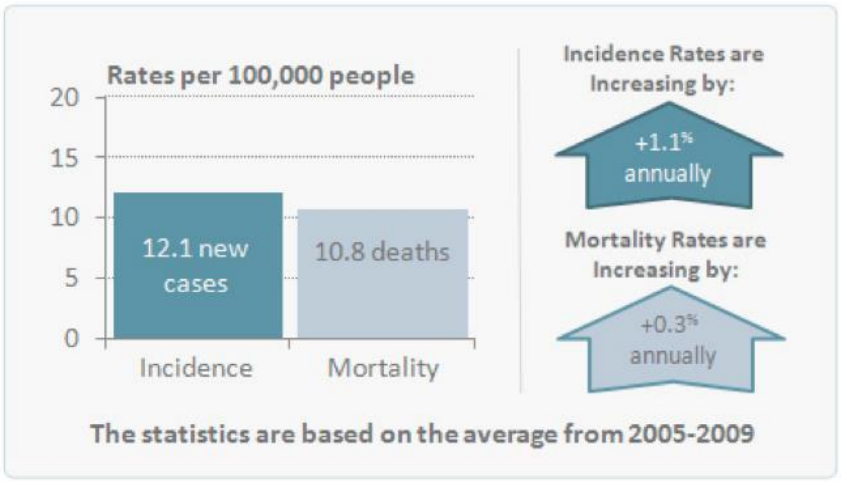
Mortality Trends: Pancreatic Cancer

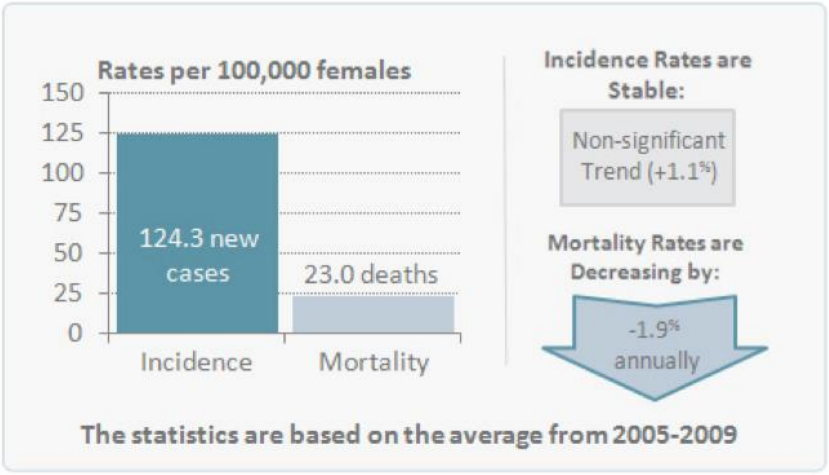
(U.S. Joinpoint Trends, Annual Percent Change (%), 1975-2009, All Races, Both Sexes)



Keeping track of the number of new cases and deaths over time *(trends)* can help scientists understand where progress is being made, and where additional research is needed to address challenges, such as improving screening or finding better treatments.

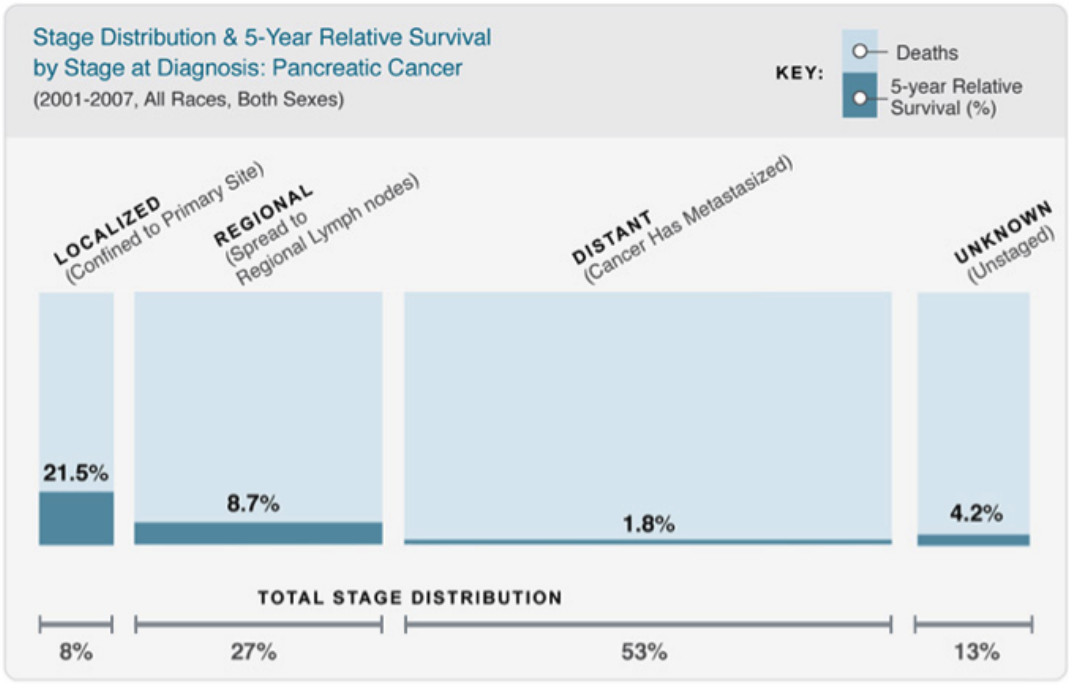

TRENDS
INCIDENCE RATES INCREASING BY:
1.1%
ANNUALLY
MORTALITY RATES INCREASING BY:
.3%
ANNUALLY
These statistics are based on the average from 2005-2009


Rates per 100,000 people
20
15
10
5
0
12.1 new cases
10.8 deaths
Incidence
Mortality
Incidence Rates are Increasing by:
+1.1% annually
Mortality Rates are Increasing by:
+0.3% annually
The statistics are based on the average from 2005-2009


Rates per 100,000 females
150
125
100
75
50
25
0
124.3 new cases
23.0 deaths
Incidence
Mortality
Incidence Rates are Stable:
Non-significant Trend (+1.1%)
Mortality Rates are Decreasing by:
-1.9% annually
The statistics are based on the average from 2005-2009

5-YEAR RELATIVE SURVIVAL 2002-2008	5-YEAR RELATIVE SURVIVAL 2002-2008
ALL STAGES	ALL STAGES
64.3%	5.8%
MOST COMMON STAGE: LOCALIZED	MOST COMMON STAGE: DISTANT
89.9%	1.8%

Survival By Stage



Stage refers to how much a cancer has spread. For example, cancer may be found only in the part of the body where it started (localized). Or, it may be found after it has spread all around the body (distant). How long a person survives has a lot to do with what stage the cancer is in when found. Most cases of pancreatic cancer are found after they have spread. It is not common for this cancer to be found before it has spread because there is no routine way of testing (screening) for it.

ADDITIONAL INFORMATION:

- More about cancer staging

5-year Relative Survival	5-year Relative Survival
64.3%	5.8%
2002-2008	2002-2008

How Many People Survive Pancreatic Cancer 5 Years Or More?

Relative survival statistics compare the survival of patients diagnosed with cancer with the survival of people in the general population who are the same age, race, and sex and who have not been diagnosed with cancer . It represents the percentage of people who survive their cancer five years after diagnosis. Because survival statistics are based on large groups of people, they cannot be used to predict exactly what will happen to an individual patient. No two patients are entirely alike and treatment and responses to treatment can vary greatly.

ADDITIONAL INFORMATION

- More about 5-year survival rates
- More about symptoms of pancreatic cancer


LIFETIME RISK
2007-2009
1.5%
WILL BE DIAGNOSED WITH
PANCREATIC CANCER
LIFETIME RISK
1.5%
WILL BE DIAGNOSED WITH
PANCREATIC CANCER
Based on rates from 2007-2009
LIFETIME RISK
2007-2009
15 OUT OF 1,000
PEOPLE
WILL BE DIAGNOSED WITH
PANCREATIC CANCER
LIFETIME RISK
15 OUT OF 1,000
PEOPLE
WILL BE DIAGNOSED WITH
PANCREATIC CANCER
Based on rates from 2007-2009

Appendix D - Facilitator's Guide for Round Two Usability Evaluations

[Note: The purpose of this document is to guide the moderator. The questions and tasks contained herein may not be asked as written. The facilitator often draws on participant comments and the natural flow of the testing process to determine the flow of the session. While the facilitator will try to follow the order of the guide, many times tasks will come up ahead of time or in different order. The facilitator may allow the order of the tasks to change in order to let the process flow naturally.
The following tasks are assumed to be correct for the proposed participants based on prior discussion on the purpose of the site. However, the ability of the site to support these tasks needs to be verified.]

Pre-Test

[Administer the informed consent.]

Introduction

Thank you for agreeing to participate in this study.

NCI's Surveillance Epidemiology and End Results (SEER) has been developing some new data displays for cancer statistics. To help develop this resource, we are conducting interviews for a proposed design for it. We'd like to get your opinion on what is being proposed. I'll be asking a few questions about cancer information displays and showing you a few example designs. To help with the evaluation, you will be given a set of tasks and I will watch to see how easy or difficult they are for you.

As we go through the tasks, feel free to offer any comments or suggestions that occur to you. We are looking for things about the designs that are working well, as well as things that could be improved. There are two important things you should keep in mind while you work with the website:

- First, I did not create the designs so you can't hurt my feelings with any criticism you might have. If there are problems with the designs I would like to discuss them with you to see if we can find a way to improve the designs.
- Second, we are evaluating the displays and not you, so you cannot make any mistakes. The designs are supposed to be intuitive and easy to use. If they are not, that's a problem with the displays – not with you.

I'd also like you to know that there are some observers with us today helping me by taking notes, but don't worry about them. You and I will work on this together and they'll just watch and listen.

Do you have any questions for me before we get started?

Background

We have invited people with a variety of backgrounds to participate in this activity, so I'd like you to tell me:

1. What is your connection to cancer?
2. We're going to be talking about ways to view cancer statistics.
    a. Where do you usually look for cancer statistics?
    b. In which kind of formats are the data presented? [Probe on graphs, tables, charts or written text]
3. Is there a particular format you would prefer to view cancer statistics?
    a. [Probe on graphs, tables, charts, or written text]

Tasks

Now I am going to show you several visualizations of cancer data. These displays show statistics for pancreatic cancer. Imagine that the data shown here is for a cancer you are interested in.

[The cancer overviews will be segmented by title and shown as separate sections to the participants. Half of the participants will be shown every section of the display at random.

The other half of participants will see the "At A Glance" section first (with the content presented as introduction material) with all other sections shown randomly after that.]

A) "At A Glance"

a. Look over the information in this section for a minute. [After the P is finished] What are these data telling you?

b. Where were these data collected, and from what population/kinds of people? How would you find out if you were interested in this?

c. What does this display tell you about the relationship between incidence and deaths? (Reference the line chart with the green)

d. Can you explain what the "Five Year Relative Survival" section means?

e. What do you think of the "note" at the bottom? How is this information useful to you?

f. Would you want to see this information presented in another format? [Probe on their preference for a line graph, chart, etc.]

g. Is there any information missing that you'd want to see in this section?

B) "How Many People Survive 5 Years Or More?"

a. Look over the information in this section for a minute. [After the P is finished] What are these data telling you?

b. Where were these data collected, and from what population/kinds of people? How would you find out if you were interested in this?

c. What kind of information is shown in the graphic?

d. Would you want to see this information presented in another format? [Probe on their preference for a line graph, chart, etc.]

e. Is there any information missing that you'd want to see in this section?

C) "Survival By Stage"

a. Look over the information in this section for a minute. [After the P is finished] What are these data telling you?

b. Where were these data collected, and from what population/kinds of people? How would you find out if you were interested in this?

c. What stage are people most frequently diagnosed at?

d. Which stage shows the highest rate of 5-year survival?

e. Would you want to see this information presented in another format? [Probe on their preference for a line graph, chart, etc.]

f. Is there any information missing that you'd want to see in this section?

D) "How Common Is This Cancer?"

a. Look over the information in this section for a minute. [After the P is finished] What are these data telling you?

b. Where were these data collected, and from what population/kinds of people? How would you find out if you were interested in this?

c. From what geographical population do you think these data are estimated from? [Probe on the US, A state, the world, etc.]

d. Would you want to see this information presented in another format? [Probe on their preference for a line graph, chart, etc.]

e. Is there any information missing that you'd want to see in this section?

E) "Who Gets This Cancer (Incidence)?"

a. Look over the information in this section for a minute. [After the P is finished] What are these data telling you?

b. Where were these data collected, and from what population/kinds of people? How would you find out if you were interested in this?

c. For the "New Cases By Race/Ethnicity & Sex" graph, what year/years does the number in the bar correspond to? [Probe on an individual year or a span of years]

d. What does the term "Age-Adjusted" mean to you?

e. Would you want to see this information presented in another format? [Probe on their preference for a line graph, chart, etc.]

f. Is there any information missing that you'd want to see in this section?

F) "Who Dies From This Cancer (Mortality)?"

a. Look over the information in this section for a minute. [After the P is finished] What are these data telling you?

b. Where were these data collected, and from what population/kinds of people? How would you find out if you were interested in this?

c. What do you think the percentage means in terms of death rate? [Probe on whether this is the percentage of people who already have the cancer, percentage of people who die from cancer in general, etc]

d. Would you want to see this information presented in another format? [Probe on their preference for a line graph, chart, etc.]

e. Is there any information missing that you'd want to see in this section?

G) "Changes Over Time"

a. Look over the information in this section for a minute. [After the P is finished] What are these data telling you?

b. Where were these data collected, and from what population/kinds of people? How would you find out if you were interested in this?

c. Has the rate of getting this cancer increased or decreased? Is this change significant? How would you find out that information?

d. What does the Mortality Trend graph tell you? Have rates gone up or down?

e. Would you want to see this information presented in another format? [Probe on their preference for a line graph, chart, etc.]

f. Is there any information missing that you'd want to see in this section?

H) "What Causes This Cancer [And other additional questions]"

a. Look over the information in this section for a minute. [After the P is finished] What are these data telling you?

b. Are these additional sections useful to see?

c. Would you want to see this information presented in another format? [Probe on their preference for a line graph, chart, etc.]

d. Is there any information missing that you'd want to see in this section?

[When all sections are completed:]

1) Is there any other information that you would like to see that we didn't already look at? [Probe on how they would like those data displayed.]

2) Now that we've looked at each of these sections, I'd like to have you organize them in the order that you'd like to see them in. There is no "right" order, just organize them in the order that would make sense for you. [Participants who saw the "At A Glance" section first

will start with that section first for the reordering task. The other participants may put any section they like as the first one. If the participant indicated they would like to see additional/different information, allow them to indicate where that would be in the order.]

Follow-up Questions

1. What did you like most about the displays?
2. What did you like least about the displays?
3. What surprised you the most?

Wrap up

OK, we're done. Do you have any further questions or comments?

Thanks again for your participation.

Appendix E – Verbal Informed Consent Script

As part of this research, I need to ask you to formally agree to this usability test and interview.

As part of a research project for the National Cancer Institute's SEER website, we are seeking to evaluate the appropriateness and usability of a new design. We are asking a total of about 14 individuals such as yourself to participate in a test of the seer.cancer.gov website. We are asking you for about 60 minutes of your time today plus the time you've already spent responding to phone calls and/or emails.

We won't be asking anything personal and identifying information is only collected so we can send you a token of our appreciation for your time. Identifying information will not be shared. Any findings will be reported in aggregated form.

Your participation is voluntary, and if you choose not to participate it will not affect your relationship with the National Cancer Institute. You may ask questions at any time during the interview. You are also free to stop the interview at any time without penalty and without any questions being asked of you. Do you have any questions about the process of the interview/usability test?

If you agree to participate, you are saying that you understand what I've told you and that any questions you have were satisfactorily answered. You are also saying that you are at least 18 years old, and that you voluntarily agree to participate. Do you agree to participate in this usability test and interview?

Appendix F - Written Informed Consent Form

Identification of Project	**SEER Consolidated Statistics Tool**
Statement of Age of Subject	I state that I am at least 18 years of age, in good physical health, and wish to participate in a program of research being conducted by the Office of Market Research and Evaluation of the National Cancer Institute within the National Institutes of Health.

Purpose	The purpose of this research is to explore various aspects of seer.cancer.gov to better understand how users navigate and find information for themselves or others on existing pages as well as to understand how well proposed designs work.
Procedures	Participants will perform information-seeking tasks on existing or proposed web pages or other materials and be asked about their thoughts and opinions related to how information is presented on seer.cancer.gov. The total time involved, including instructions will be no more than 60 minutes.
Confidentiality	All information collected in this study will be kept secure to the extent permitted by law. I understand that the data I provide will be grouped with data others provide for the purpose of reporting and presentation and that my name will not be used.
Risks	I understand that the risks of my participation are expected to be minimal in nature.
Benefits, Freedom to Withdraw, & Ability to Ask Questions	I understand that this study is not designed to help me personally but that the investigators hope to update and redesign the seer.cancer.gov site in order to make the experience of utilizing cancer statistics easier for users. I am free to ask questions or withdraw from participation at any time and without penalty.

Contact Information of Investigators	Name: Cheryl Burg, MA MS AGS Position: IT Specialist Telephone: 301-496-0152 Email Contact: Cheryl@mail.nih.gov

Printed Name of Research Participant _____

Signature of Research Participant _____

Date_____