

**Draft Report on the Cancer Prevalence and Cost of Care  
Projections Website**

---

**Usability Evaluation**

**Conducted by User-Centered Design, Inc.**

**For the**

**National Cancer Institute's Division of Cancer Control and Population  
Sciences**

September 2013

User Centered Design Inc.  
20548 Deerwatch Place  
Ashburn, VA 20147  
(703) 729-0998

## Executive Summary

The Cancer Prevalence and Cost of Care Projections website, launched January 2011, has had more than 6000 unique visitors in 2012. It is likely that this site will continue to be widely used by researchers, policy makers, cancer advocates, and the scientific press. The site had not yet been assessed for possible usability issues since it's inception. The overall purpose of this project is to ascertain the usability of the website for its multiple diverse user groups and to determine the extent to which the website is operating as intended, in terms of its acceptability and clarity of use, and then use these findings to improve the website.

To carry out the objective of the project, User Centered Design Inc. (UCD) conducted a heuristic evaluation (expert review) of the website. Additionally, two rounds of usability evaluations were carried out on a mockup version of a potential new site design. Twelve (12) individuals participated in the usability evaluations (eight (8) in the first, and four (4) in the second), representing researchers, cancer advocates, and press or policy persons. Participants explored the website remotely and provided their feedback on the site.

Findings from the first round of evaluations showed that most participants could easily find information on the site, but some the data was hard to understand in its current format. By the next round, many changes to the labeling and formatting of text fixed issues that arose in the first evaluation. Further changes, such as adding more clarifying information and tweaks to the graph tool and header labels will increase the usability of the site.

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

<b>Executive Summary .....</b>	<b>2</b>
<b>Introduction .....</b>	<b>4</b>
<b>Method .....</b>	<b>5</b>
<b>Findings.....</b>	<b>6</b>
Expert Review.....	6
<i>Homepage .....</i>	<i>6</i>
<i>Create Your Own Chart.....</i>	<i>11</i>
<i>Projection Tables .....</i>	<i>16</i>
<i>Base Data Table.....</i>	<i>18</i>
Round 1 Usability Evaluations.....	19
<i>Homepage .....</i>	<i>19</i>
<i>Create Your Own Graph.....</i>	<i>25</i>
<i>Projection Tables .....</i>	<i>32</i>
<b>Round 2 Usability Evaluations.....</b>	<b>42</b>
<i>Site in General .....</i>	<i>42</i>
<i>Homepage .....</i>	<i>42</i>
<i>Create Your Own Graph.....</i>	<i>45</i>
<i>Data Tables.....</i>	<i>50</i>
<b>Conclusion.....</b>	<b>55</b>
<b>Appendix A: Facilitator’s Guide for Usability Evaluations.....</b>	<b>56</b>
<b>Appendix B: E-mail for Participant Request .....</b>	<b>61</b>
<b>Appendix C: Follow-Up Recruitment Screener .....</b>	<b>63</b>
<b>Appendix D: Verbal Informed Consent .....</b>	<b>65</b>
<b>Appendix E: Written Consent Form .....</b>	<b>66</b>

## Introduction

The Cancer Prevalence and Cost of Care Projections website, launched January 2011, has had more than 6,000 unique visitors in 2012. It is likely that this site will continue to be widely used by researchers, policy makers, cancer advocates, and the scientific press. The site had not yet been assessed for possible usability issues since it's inception. The overall purpose of this project is to ascertain the usability of the website for its multiple diverse user groups and to determine the extent to which the website is operating as intended, in terms of its acceptability and clarity of use, and then use these findings to improve the website.

UCD was contracted to help assess the usability of the Cancer Prevalence and Cost of Care Projections website. A heuristic evaluation (expert review) and two rounds of usability evaluations with participants who use or are likely to use the Cancer Prevalence and Cost of Care Projections website were performed. This final report documents the methods and findings of all activities.

## Method

Before the usability evaluations, an expert review was carried out on the site in November 2012. Two human factors engineers independently reviewed the site. Each used a heuristic evaluation approach based on an adapted version of Nielsen's "Ten Usability Heuristics for Interface Design" as well as their own knowledge of web standards and best practices. The findings of each engineer's evaluations were combined and were presented in a PowerPoint briefing delivered on November 26<sup>th</sup>, 2012. In the following months, changes were made to the site based on suggested recommendations in the feedback.

For the first round of evaluations, eight (8) participants successfully completed their sessions. This round was conducted in March 2013, and consisted of four (4) researchers, (2) advocates, and two (2) individuals who work in press and/or policy. Participants were recruited by e-mail from a list of individuals with appropriate backgrounds provided by the Health Services and Economics Branch (researchers), Office of Advocacy Relations (advocates), and the NCI Office of Media Relations (members of press and policy). An interrupted, task-based protocol was used to facilitate the usability evaluations. Each session was conducted remotely, via the online conferencing software, GoToMeeting.

Participants viewed the current website ([costprojections.cancer.gov](http://costprojections.cancer.gov)) and commented on the site's usability. Feedback from these participants was analyzed by UCD and aggregated into a PowerPoint briefing delivered on March 25<sup>th</sup> 2013. The website was again updated to reflect some changes that were suggested in the feedback from the first round.

The second round of evaluations was held in September 2013. Three (3) researchers and one (1) advocate participated in this round, for a total of four (4) participants. Similar to the previous round, an interrupted task-based protocol was used to facilitate the evaluations done for an updated version of the live site; and feedback was again analyzed and aggregated into a PowerPoint briefing delivered on September 19<sup>th</sup>, 2013.

## Findings

The findings of the expert review and both rounds of usability evaluations are described in this section. Screenshots of the website or other relevant materials accompany the findings when available.

## Expert Review

Findings from the expert review are broken down into four main categories: Homepage, Create Your Own Chart, Projection Tables, and Base Data.

## Homepage

**Accessing the Homepage:** Several different possible points of entry were identified for the website, including internet searches and other NIH/NCI websites. Figure 1 shows a link from a Division of Cancer Control and Population Sciences (DCCPS) site.

The screenshot shows the DCCPS website homepage. The header features the DCCPS logo and the text "CANCER CONTROL AND POPULATION SCIENCES" and "NCI'S BRIDGE TO PUBLIC HEALTH RESEARCH, PRACTICE, AND POLICY". A search bar is located in the top right corner. The main content area is divided into several sections:

- Public Use Data Sets:** A section with a heading and a paragraph describing the DCCPS's role in supporting research in surveillance, epidemiology, health services, behavioral science, and cancer survivorship. It mentions the translation of research into practice and the availability of public use data resources.
- Surveillance:** A section with a heading and a sub-heading "HD\*Calc". It includes a link to <http://seer.cancer.gov/hdcalc/> and a paragraph describing the Health Disparities Calculator (HD\*Calc) software, which is used to generate summary measures to evaluate and monitor health disparities. It also mentions the use of SEER\*Stat and other population-based health data.
- Small Area Estimates for Cancer Risk Factors & Screening Behaviors:** A section with a heading and a link to <http://sae.cancer.gov/>. It describes model-based estimates for states, counties, and health service areas developed based on two surveys: the Behavioral Risk Factor Surveillance System (BRFSS) and the National Health Interview Survey (NHIS).
- Colorectal Cancer Mortality Projections:** A section with a heading and a link to <http://cisnet.cancer.gov/projections/colorectal/>. It describes the NCI's Cancer Intervention and Surveillance Modeling Network (CISNET) and its role in helping cancer control planners, program staff, and policy makers consider the impact of risk factor reduction, increased early detection, and increased access to optimal treatment on future colorectal cancer mortality rates.
- Cancer Prevalence and Cost of Care Projections:** A section with a heading and a link to <http://costprojections.cancer.gov/>. This section is highlighted with a red box in the screenshot. It includes a sub-heading "See cost of care or prevalence by cancer site, sex, age, and year under various assumptions." and a paragraph describing the estimation and projection of cancer prevalence and cost of care through 2020 using incidence and survival data from the Surveillance, Epidemiology, and End Results (SEER) Program and population projections from the U.S. Census Bureau.

On the left side of the page, there are three navigation boxes: "Cancer Control & Population Sciences Home", "Information & Resources", and "Need Help?" with contact information for phone, web, and e-mail, and the number 1-800-4-CANCER.

**Figure 1: The DCCPS Website for Public Use Data Sets.**  
(<http://cancercontrol.cancer.gov/cr-dataset.html>)

The website can also be accessed from cancer.gov. References from "The Cost of Cancer" website are shown in Figure 2.

Cervix	\$1.55
Esophagus	\$1.33

\*More information at <http://costprojections.cancer.gov/>

### Costs in the Future

The cost of cancer in the year 2020 is projected to reach at least \$158 billion (in 2010 dollars). Assuming a 2 percent annual increase in medical costs in the initial and final phases of care, the projected 2020 costs increase to \$173 billion. Estimating a 5 percent annual increase in these costs raises the projection to \$207 billion. These figures do not include other types of costs, such as lost productivity, which add to the overall financial burden of cancer.

This information was released in a new study on January 12, 2011. More information about these cost projections is available at: <http://costprojections.cancer.gov/>.

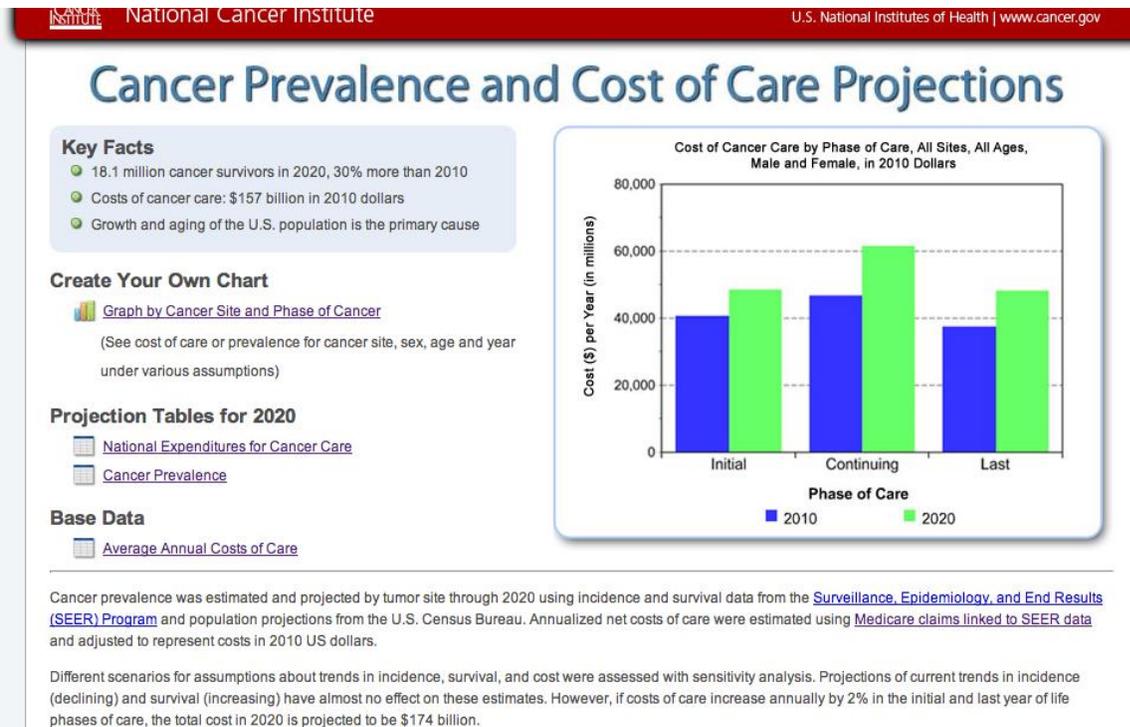
Figure 2: "The Cost of Cancer" Website on cancer.gov.  
 (http://www.cancer.gov/aboutnci/servingpeople/cancer-statistics/costofcancer)

The Health Services and Economics Branch (shown in Figure 3) is also listed as a match for "cost of care" when the phase was searched for on cancer.gov. However, a link to the CPCC website was not found on the site. Consider adding a link to the CPCC website from the Health Services and Economics Branch website.

The screenshot shows the 'Health Services and Economics' website. The header includes 'Health Services and Economics' and 'Cancer Control and Population Sciences'. The left sidebar has links for 'Cancer Control and Population Sciences Home', 'Applied Research Home', 'Applied Research Branches', 'Health Services and Economics Branch', 'Risk Factor Monitoring and Methods Branch', 'Outcomes Research Branch', 'Need Help?', and 'NCI at APHA 2012'. The main content area is organized into three columns: 'Tools for Researchers' (including SEER-Medicare Linked Database, Survey Instruments, and Health Disparities Calculator), 'Surveys & Studies' (including Medical Expenditure Panel Survey, National Health Interview Survey, and National Survey of Colorectal Cancer Screening), and 'Current Research' (including Active Grant Portfolio and Grantee Research Highlights). The right sidebar features a search bar and an 'Items of Interest' section with links to research funds, newsletters, and various reports.

Figure 3: Health Services and Economics Branch Website.  
 (http://healthservices.cancer.gov/)

**Cancer Prevalence and Cost of Care Projections Homepage:** The homepage (see Figure 4) fits entirely on the screen, which is good (slightly cut off in 1024x786). However, there is no connection to DCCPS (the URL suggests that it is on the same level as DCCPS). Consider mentioning DCCPS in introductory text or as a subtitle in the header if appropriate.



**Figure 4: The Cancer Prevalence and Cost of Care Projections Homepage.**

**Introductory Text on the Homepage:** Users may need some introductory text to orient them upon arriving to the webpage. Consider using the first sentence of this text at the bottom of the homepage (see Figure 5) as an introduction near the top. This page (<http://www.cancer.gov/aboutnci/servingpeople/cancer-statistics/costofcancer>) may have more information that may be suitable for intro text:

*“The financial costs of cancer care are a burden to people diagnosed with cancer, their families, and society as a whole. National cancer care expenditures have been steadily increasing in the United States. Costs also are likely to increase as new, more advanced treatments are adopted as standards of care. These newer, more expensive, targeted therapies attack specific cancer cells and often have fewer side effects than other types of cancer treatments.”*

This site is based on a study that estimates and projects the national cost of cancer care through the year 2020 separately for multiple cancer sites using the most recent available U.S. population projections, cancer incidence, survival, and cost-of-care data. More information about the methods, data sources and assumptions in: Mariotto AB, Yabroff KR, Shao Y, Feuer EJ, Brown ML. Projections of the Cost of Cancer Care in the U.S.: 2010-2020. *J Natl Cancer Inst.* 2011 Jan.

Figure 5: Descriptive Text from the Bottom of the CPCC Homepage.

**Homepage Design:** The elements on the website are supported by gestalt principle of “similarity” (or “grouping”). The “Key Facts,” pointed out in Figure 6, have good formatting – sectioned off, bulleted and easy to read. More testing may be necessary to determine the placement of the key facts box, the graphic and the navigational links to other parts of the website.

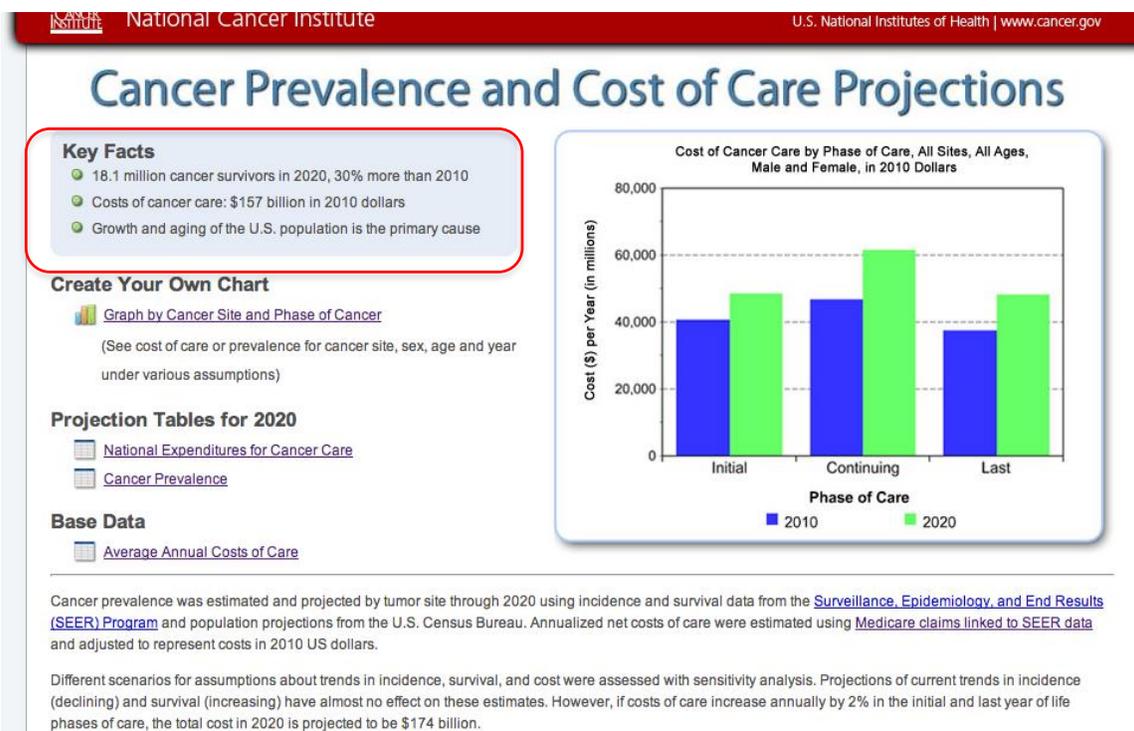


Figure 6: Key Facts Box on the Homepage.

**Homepage Graphic:** The graphic on the homepage (see Figure 7) gives visual interest and shows a summary of cost of care data. However, more information might be needed. Consider linking the graph to the “Create your own chart” section of the site which has the data from this chart pre-loaded so users can tweak it. Also consider including that the 2020 figures are projections and information on the definitions for each stage of care. Alternately, consider adding explanatory text about the graph if it does not get linked to the tool. The inclusion of a graphic might suggest that clicking it provides more info.

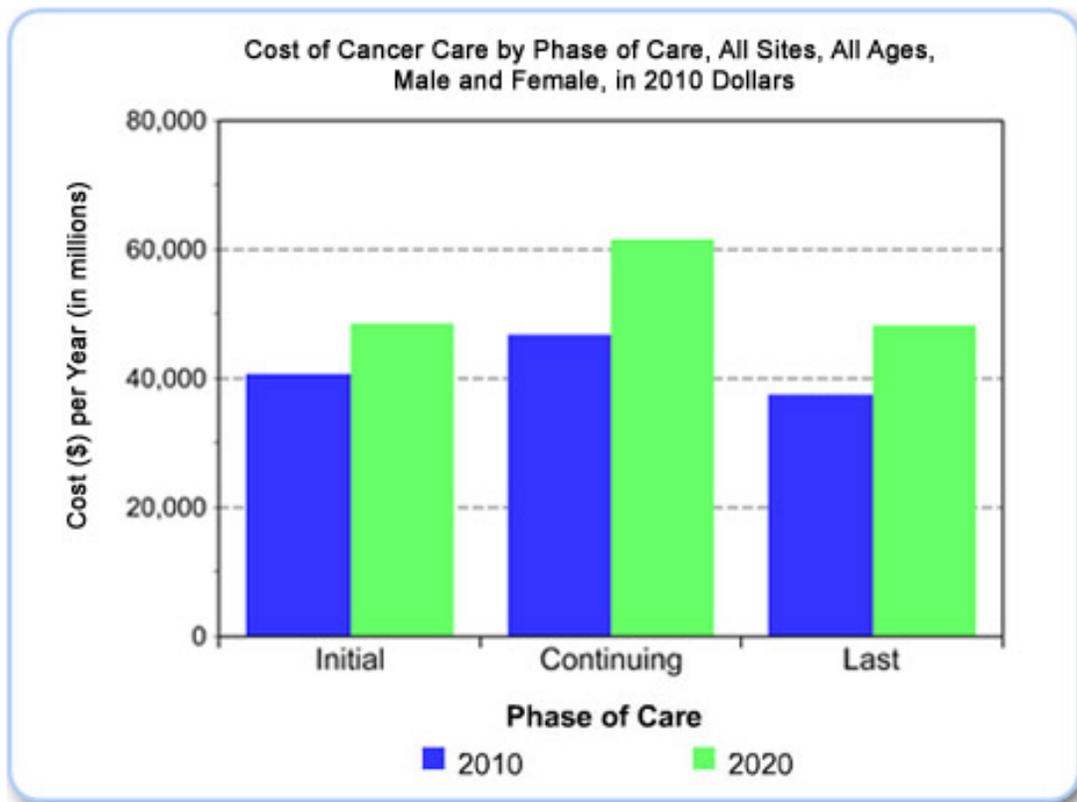


Figure 7: Chart Graphic That Appears on the Homepage.

**Homepage Text:** The text on the page is helpful, especially the links to where the data was taken from (see Figure 8). However, projections for cost of care in 2020 might be something useful for the key facts section. Consider reporting the 2020 estimate, including the annual 2% increase, in the key facts while having the “disclaimer” text at the bottom (with an asterisk).

---

Cancer prevalence was estimated and projected by tumor site through 2020 using incidence and survival data from the [Surveillance, Epidemiology, and End Results \(SEER\) Program](#) and population projections from the U.S. Census Bureau. Annualized net costs of care were estimated using [Medicare claims linked to SEER data](#) and adjusted to represent costs in 2010 US dollars.

Different scenarios for assumptions about trends in incidence, survival, and cost were assessed with sensitivity analysis. Projections of current trends in incidence (declining) and survival (increasing) have almost no effect on these estimates. However, if costs of care increase annually by 2% in the initial and last year of life phases of care, the total cost in 2020 is projected to be \$174 billion.

Figure 8: Text Near the Bottom of the Homepage.

**Homepage Navigation:** An explanation is given for the “Create Your Own Chart” link in Figure 9; however, no additional information on the other three items (projection tables and base data) is provided. (This information will help users understand why the information is important as well.) Additionally, the assumptions could be stated outright (following a trend, or constant). Base data seems especially unclear. Consider adding explanations for the other three items so users can determine their relationship.

## Create Your Own Chart



[Graph by Cancer Site and Phase of Cancer](#)

(See cost of care or prevalence for cancer site, sex, age and year under various assumptions)

## Projection Tables for 2020



[National Expenditures for Cancer Care](#)



[Cancer Prevalence](#)

## Base Data



[Average Annual Costs of Care](#)

Figure 9: Homepage Navigation Area with Description only for Create Your Own Chart.

## Create Your Own Chart

**Incidence and Survival Assumptions:** When changing graph type or assumptions, the changes are not reflected in the text, as seen here in Figure 10. Additionally, assumptions for cost still show on a prevalence graph (and the other way around). Consider only showing information relevant to the type of graph being shown.

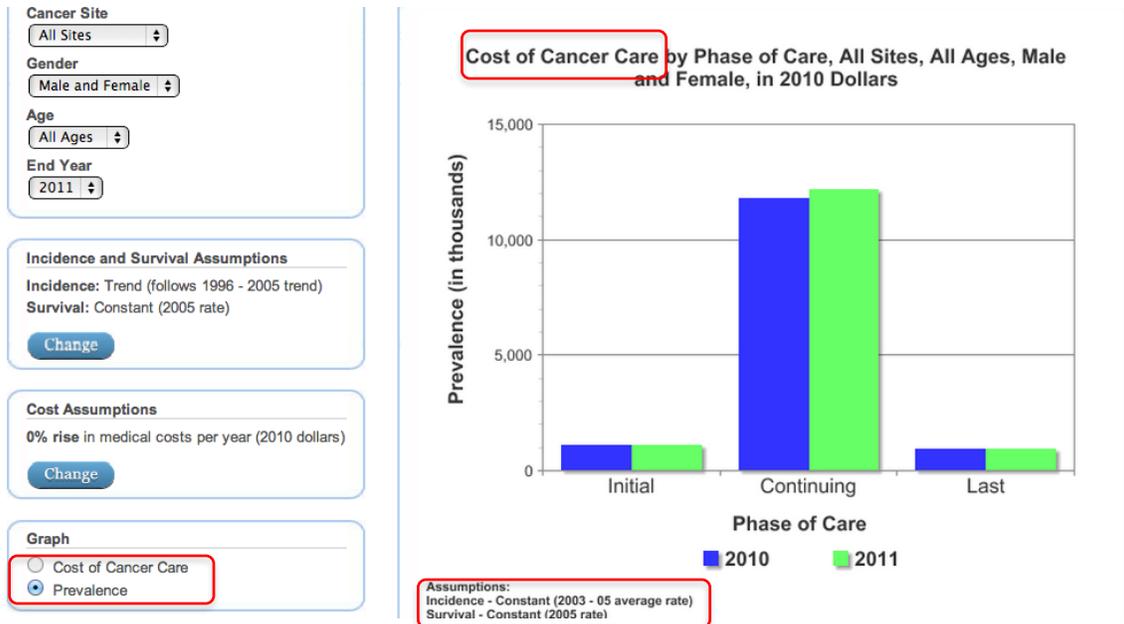


Figure 10: Demonstration of Places on the Graph Where Text on the Site Does Not Reflect Changes Made In The Assumptions.

The controls to change the incidence and survival assumptions are only accessible from what appears to be a help section (see Figure 11). (Further testing will confirm what type of help information would be useful and what format it could be in.) Consider putting this information on a separate page accessible through a help link, and keep the choices (“Constant Rate” and “Follow Trend”) on the page with other graph selections.

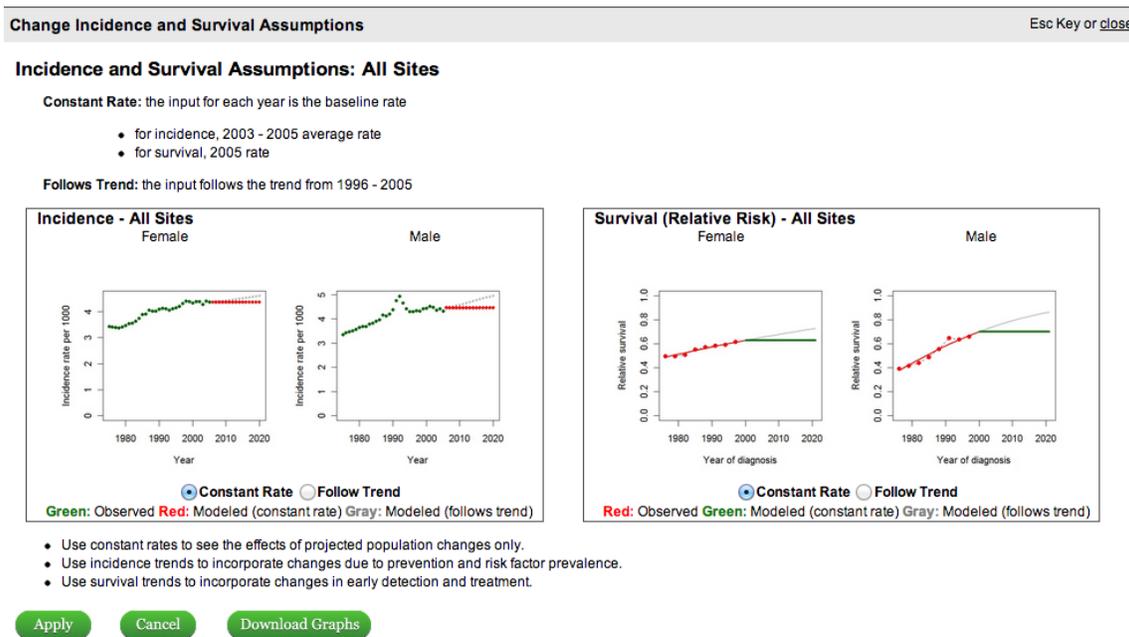


Figure 11: Dialog Box for Incidence and Survival Assumptions.

As another issue, the examples in Figure 11 mix functionality and explanation. [ie. When a different radio button option is selected, the example graph changes. Also it appears that the same data is being used to show the example, but is in a different format (a line graph).] Additionally, the example data is scaled so that it is hard to see the difference in the two types of assumptions. Consider zooming in on the data in an example, and have one static example graph accompany the help information.

**Button Labels for Incidence and Survival Assumptions:** The “Download Graphs” button seen in Figure 12 makes it unclear whether the graph in progress will be downloaded or the example graphs in the selection will be downloaded. Additionally, all the supporting text is downloaded as well. Consider rewording the button to “Save This Page” or remove it entirely.



Figure 12: Buttons for the Incidence and Survival Assumptions.

The Cancel button, also seen in Figure 12, appears similar to the Apply and Download button due to their green color. (This is the same for the Cost Assumptions as well.) Consider making the buttons slightly different (perhaps by separating the download button and using a grey color for cancel) and highlight the apply button as it is the positive choice.

**Incidence and Survival Light Box:** Additionally, the lightbox is quite big. If users are working with a small window, it may look like a different page altogether. Consider showing one example of a line following a trend for the selections, and consolidate supporting text to decrease the size of the lightbox area.

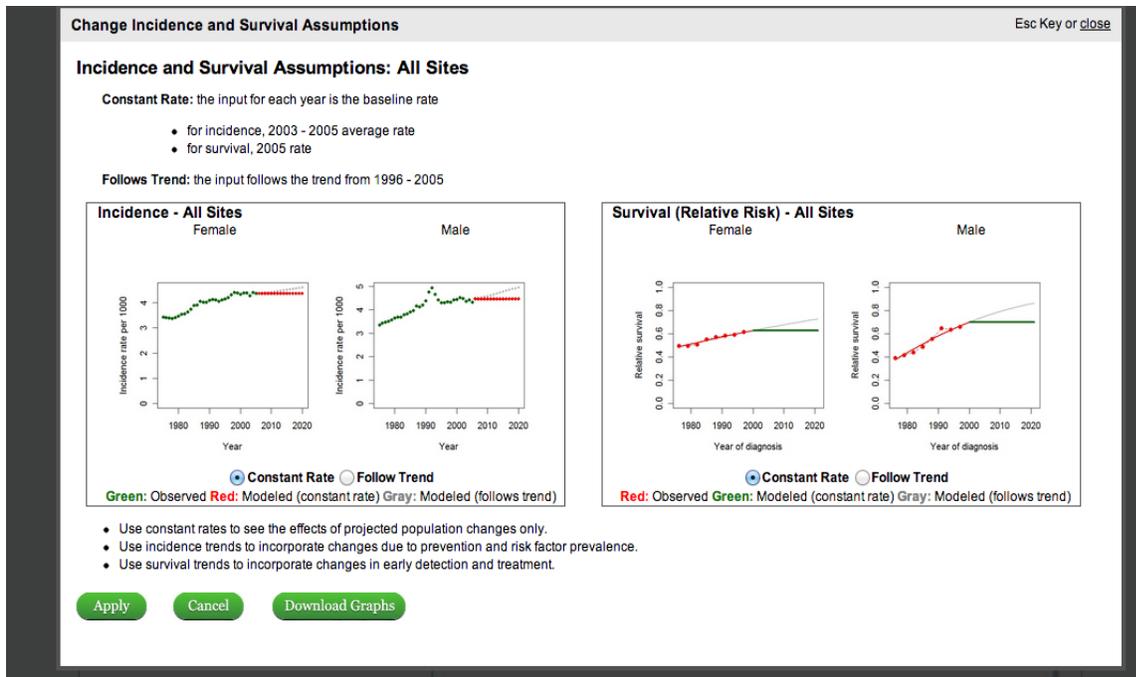


Figure 13: Demonstration of the Incidence and Survival Lightbox Size.

**Changing Incidence and Survival Assumptions:** When changing selections, the trend line turns blue on the incidence graph, and shows in green on the survival chart (switching places with grey, as seen in Figure 14). Consider using one color to highlight the trend line, or use a different pattern for the line (perhaps make it noticeably bolded).

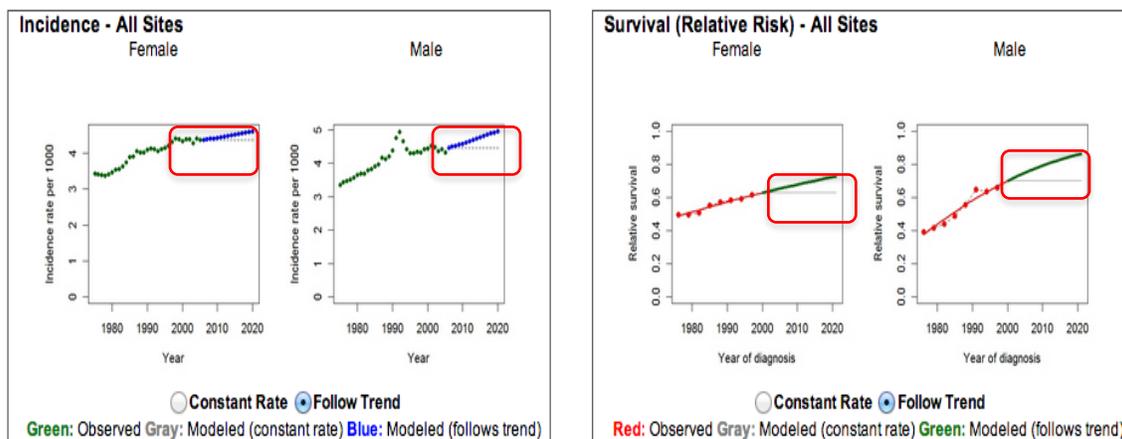


Figure 14: Graph Appearance on Selecting "Follow Trend."

**Cost Assumptions:** The cost assumptions selection in Figure 15 allows the user to adjust for inflation over time. Although seemingly unlikely, deflation could also occur, but the drop down menu does not allow for that projection. Additionally, the average annual inflation rate (slightly above 3%) could be given as a reference. Similar issues exist with the Apply vs. Cancel buttons (consider highlighting the positive choice). Consider an option for deflation and mention the average annual inflation rate of 3% for reference in the supporting text.

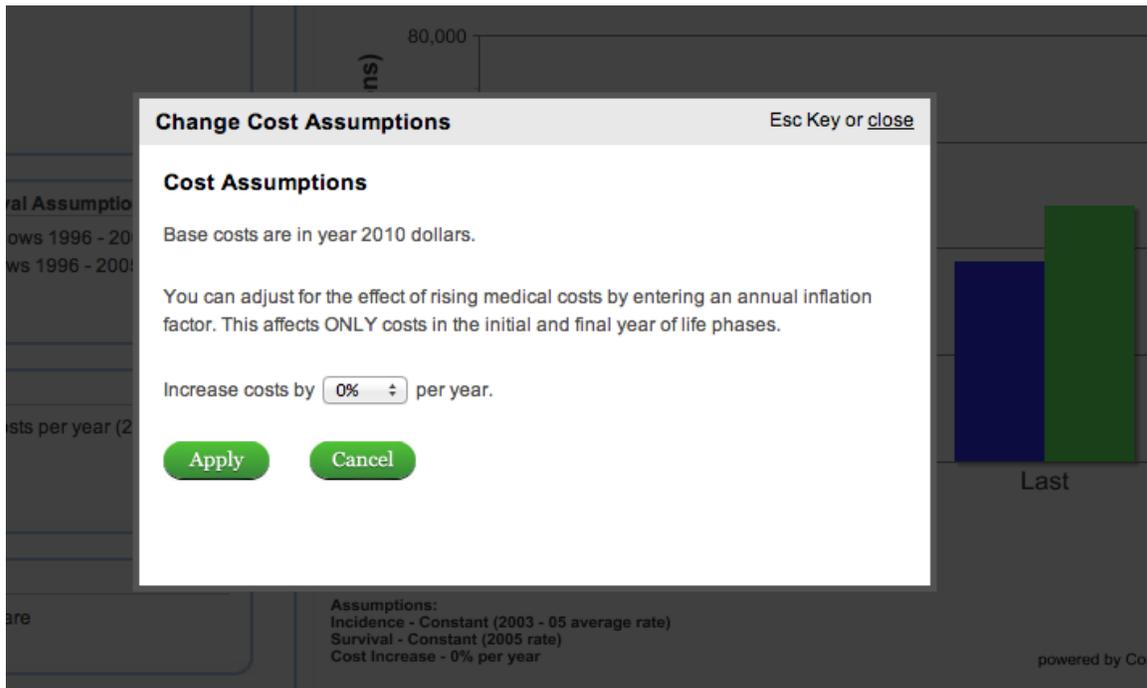
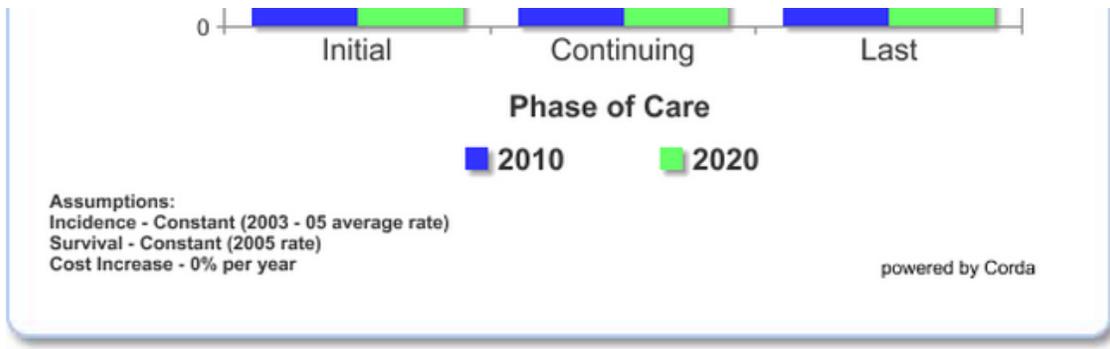


Figure 15: Cost Assumptions Dialog Box.

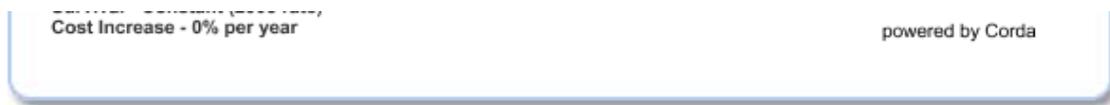
**Downloading the Graph:** Choosing the option to download the graph (see Figure 16) saves only the graphic (and not the table beneath it) in a PNG format. Consider adding a “Save Table” button and use a GIF or JPEG format since they are used more frequently.



Download Graph Download Full Dataset

Figure 16: Download Options on the Create Your Own Graph Page.

**Chart Table:** The download graph button is a great way to save the bar chart, however there does not seem to be a way to save the table beneath the buttons (see Figure 17). The full dataset is a spreadsheet that gives data for every year of the study – this might not be apparent with its position underneath the bar graph (it might be interpreted as only the data that generated the bar graph. Consider adding a “Save Table” button for this chart and for tables on other pages (such as the base data).



Download Graph Download Full Dataset

	Initial	Continuing	Last
2010	\$40,464	\$46,643	\$37,459
2020	\$48,317	\$61,373	\$48,077
Increase	19.4%	31.6%	28.3%

Costs (\$) per year in millions.

Figure 17: Download Buttons and Table for Graph Data.

**Projection Tables**

**National Expenditures for Cancer Care Intro Text:** The National Expenditures for Cancer Care page (Figure 18) gives some introductory text, but it seems more to be an explanation of the assumptions of the data rather than what the data is showing. Consider placing this text at the bottom of the graph and providing intro text before the table.

# Cancer Prevalence and Cost of Care Projections

Home » National Expenditures for Cancer Care

## National Expenditures for Cancer Care

Estimates of the national expenditures for cancer care in 2010 and 2020 in 2010 billion dollars under different assumptions of cancer incidence and survival trends: Base case assumes constant incidence and survival as estimated in 2002-2005, Trend incidence assumes projected incidence trend and constant survival, Trend survival assumes constant incidence and projected survival trend, Trend incidence & survival assumes projected incidence and survival trends.

	Cost in US 2010 Billions								
	2010	2020					Trend incidence & survival scenario and cost increase		
		Base	Base	Trend incidence	Trend survival	Trend incidence & survival	2% overall	2% in initial and last year phase cost	5% in initial and last year phase cost
Breast	\$16.50	\$20.50	\$18.91	\$20.69	\$19.08	\$23.24	\$21.37	\$25.64	
Colorectal	\$14.14	\$17.41	\$14.35	\$17.83	\$14.70	\$17.67	\$16.68	\$20.39	
Lung	\$12.12	\$14.73	\$12.14	\$15.23	\$12.53	\$15.19	\$14.73	\$18.84	
Lymphoma	\$12.14	\$15.26	\$15.00	\$15.71	\$15.44	\$18.66	\$17.27	\$20.69	

Figure 18: National Expenditures for Cancer Care Page with Intro Text.

**National Expenditures for Cancer Care Chart Elements:** If some researchers are anticipated to not understand the terms used in the chart labels (highlighted in Figure 19), consider showing tooltips that define the terms in the table. For example, it is not readily understood why the base for 2020 is different than the base for 2010.

# Cancer Prevalence and Cost of Care Projections

Home » National Expenditures for Cancer Care

## National Expenditures for Cancer Care

Estimates of the national expenditures for cancer care in 2010 and 2020 in 2010 billion dollars under different assumptions of cancer incidence and survival trends: Base case assumes constant incidence and survival as estimated in 2002-2005, Trend incidence assumes projected incidence trend and constant survival, Trend survival assumes constant incidence and projected survival trend, Trend incidence & survival assumes projected incidence and survival trends.

	Cost in US 2010 Billions								
	2010	2020					Trend incidence & survival scenario and cost increase		
		Base	Base	Trend incidence	Trend survival	Trend incidence & survival	2% overall	2% in initial and last year phase cost	5% in initial and last year phase cost
Breast	\$16.50	\$20.50	\$18.91	\$20.69	\$19.08	\$23.24	\$21.37	\$25.64	
Colorectal	\$14.14	\$17.41	\$14.35	\$17.83	\$14.70	\$17.67	\$16.68	\$20.39	
Lung	\$12.12	\$14.73	\$12.14	\$15.23	\$12.53	\$15.19	\$14.73	\$18.84	
Lymphoma	\$12.14	\$15.26	\$15.00	\$15.71	\$15.44	\$18.66	\$17.27	\$20.69	

Figure 19: Base Data Columns for the National Expenditures for Cancer Care Table.

**Mouse-Over Highlight:** A highlight appears upon hovering the cursor over a row of data, as demonstrated by Figure 20. This feature suggests function; however, it appears to only highlight the row. Highlighting rows may be helpful, but the user needs to keep the cursor still. Consider showing alternating background colors to help the chart's readability.

Cost in US 2010 Billions								
	2010	2020						
						Trend incidence & survival scenario and cost increase		
	Base	Base	Trend incidence	Trend survival	Trend incidence & survival	2% overall	2% in initial and last year phase cost	5% in initial and last year phase cost
Breast	\$16.50	\$20.50	\$18.91	\$20.69	\$19.08	\$23.24	\$21.37	\$25.64
Colorectal	\$14.14	\$17.41	\$14.35	\$17.83	\$14.70	\$17.67	\$16.68	\$20.39
Lung	\$12.12	\$14.73	\$12.14	\$15.23	\$12.53	\$15.19	\$14.73	\$18.84
Lymphoma	\$12.14	\$15.26	\$15.00	\$15.71	\$15.44	\$18.66	\$17.27	\$20.69
Prostate	\$11.85	\$16.34	\$15.32	\$16.43	\$15.41	\$18.53	\$16.67	\$19.02
Leukemia	\$5.44	\$6.95	\$6.66	\$7.24	\$6.94	\$8.38	\$7.78	\$9.35
Ovary	\$5.12	\$6.03	\$4.49	\$6.27	\$4.64	\$5.64	\$5.26	\$6.42
Brain	\$4.47	\$5.53	\$5.38	\$5.79	\$5.62	\$6.82	\$6.51	\$8.18

Figure 20: National Expenditures for Cancer Care with the "Lung" Row Highlighted.

**Manipulating Tables:** The table (see Figure 20 above) is static, and cannot be sorted. The current default is in descending order for 2010 base values. Consider including an option to sort columns. Additionally, when highlighting a column data on the table with the intention of copying it, the entire chart is captured. Consider the option to have each column captured separately.

### Base Data Table

**Average Annual Costs of Care:** Like the other tables, there is no introductory text to explain the data for the table in Figure 21. Since multiple labels are used for this data (ex. Average Annual Cost of Care, Base Data), introductory text may be helpful for users' understanding. Consider adding introductory text to explain the data shown. Additionally, further testing may be needed to see if users notice, understand, and/or find useful the footnotes and the information included at the bottom.

## Cancer Prevalence and Cost of Care Projections

[Home](#) » Average Annual Costs of Care

**Average Annual Costs of Care**

Annualized Mean Net Costs of Care by Age, Gender and Phase of Care (Per Patient). Costs in 2010 US Dollars.

Annual Costs of Cancer Care in US 2010 Dollars					
		Age 65+			
				Last Year of Life <sup>1</sup>	
Sex	Site	Initial <sup>1</sup>	Continuing <sup>1</sup>	Cancer Death	Other Cause
	Bladder	21,412	3,710	78,698	10,005
	Brain	108,168	8,803	140,891	39,893
	Breast	23,078	2,207	62,856	748

Figure 21: Information at the Top of the Average Annual Costs of Care Table.

## Round 1 Usability Evaluations

The findings from the first round of usability evaluations reflect participants' experience with the live CPCC site ([costprojections.cancer.gov](http://costprojections.cancer.gov)) that was current in March 2013.

### Homepage

**Pattern of Usage:** No specific pattern emerged for users' behavior on the homepage, which can be seen in Figure 22. Some participants read the Key Facts or looked at the graph, while others went directly to the hyperlinks.

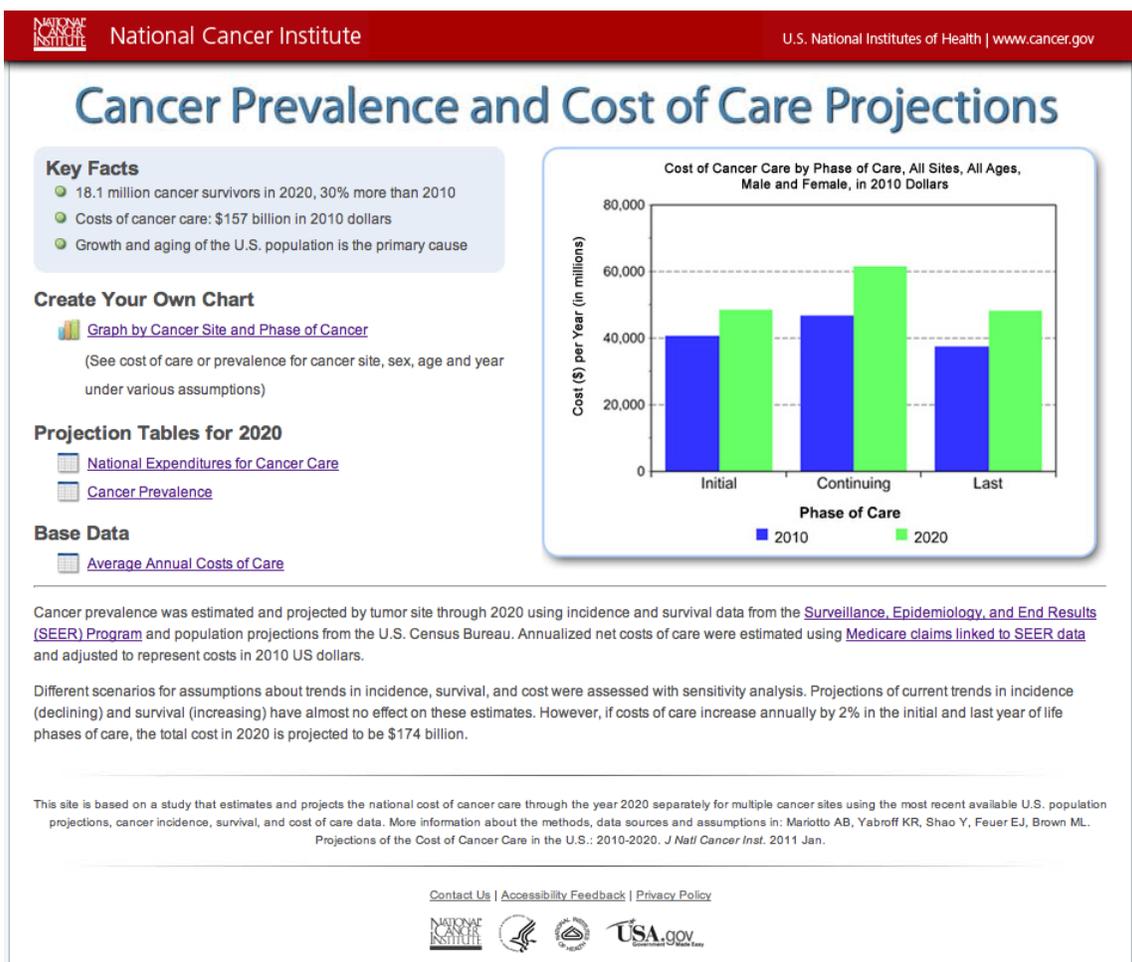


Figure 22: The Cancer Prevalence and Cost of Care Projects Website As It Looked in March 2013.

**Homepage Graph Labels:** Participants that looked at the graph on the homepage (highlighted in Figure 23) were uncertain what the terms “initial,” “continuing,” and “last” referred to. Consider hyperlinking each of these terms to provide a pop-up definition.

# Cancer Prevalence and Cost of Care Projections

## Key Facts

- 18.1 million cancer survivors in 2020, 30% more than 2010
- Costs of cancer care: \$157 billion in 2010 dollars
- Growth and aging of the U.S. population is the primary cause

## Create Your Own Chart

[Graph by Cancer Site and Phase of Cancer](#)

(See cost of care or prevalence for cancer site, sex, age and year under various assumptions)

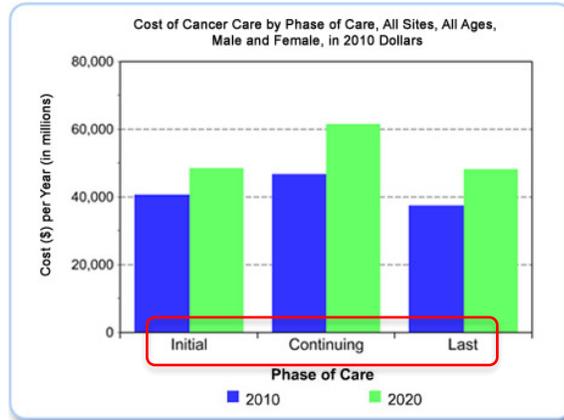
## Projection Tables for 2020

[National Expenditures for Cancer Care](#)

[Cancer Prevalence](#)

## Base Data

[Average Annual Costs of Care](#)



Cancer prevalence was estimated and projected by tumor site through 2020 using incidence and survival data from the [Surveillance, Epidemiology, and End Results \(SEER\) Program](#) and population projections from the U.S. Census Bureau. Annualized net costs of care were estimated using [Medicare claims linked to SEER data](#) and adjusted to represent costs in 2010 US dollars.

Different scenarios for assumptions about trends in incidence, survival, and cost were assessed with sensitivity analysis. Projections of current trends in incidence (declining) and survival (increasing) have almost no effect on these estimates. However, if costs of care increase annually by 2% in the initial and last year of life phases of care, the total cost in 2020 is projected to be \$174 billion.

This site is based on a study that estimates and projects the national cost of cancer care through the year 2020 separately for multiple cancer sites using the most recent available U.S. population projections, cancer incidence, survival, and cost of care data. More information about the methods, data sources and assumptions in: Mariotto AB, Yabroff KR, Shao Y, Feuer EJ, Brown ML. Projections of the Cost of Cancer Care in the U.S.: 2010-2020. *J Natl Cancer Inst.* 2011 Jan.

[Contact Us](#) | [Accessibility Feedback](#) | [Privacy Policy](#)



Figure 23: Unfamiliar Terms on the Homepage Graph.

**Homepage Link Order:** Participants tended to visit the hyperlinks in the order presented on the page. It may have been a test artifact, but only a few seemed to read the section titles and the text description beneath the chart link (circled in Figure 24). In other words, they picked an item of interest by the name of the hyperlink. The ability to create your own graph would logically seem to come second to the ability to see static data already on the site. Consider reversing the order of these links. A potential link order may be:

*First:* Base Data (consider adding “for 2010”)

*Second:* Projection Data for 2020

*Last:* Create Your Own Chart

# Cancer Prevalence and Cost of Care Projections

## Key Facts

- 18.1 million cancer survivors in 2020, 30% more than 2010
- Costs of cancer care: \$157 billion in 2010 dollars
- Growth and aging of the U.S. population is the primary cause

## Create Your Own Chart

[Graph by Cancer Site and Phase of Cancer](#)

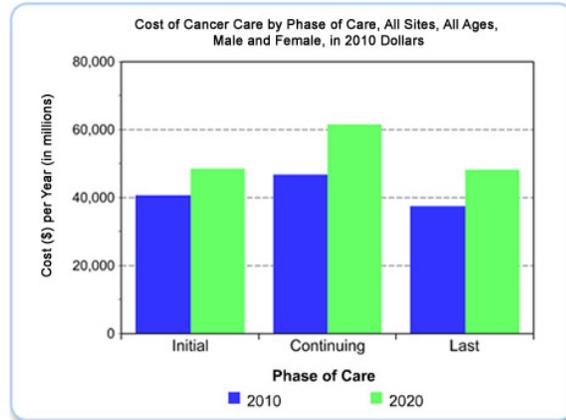
(See cost of care or prevalence for cancer site, sex, age and year under various assumptions)

## Projection Tables for 2020

- [National Expenditures for Cancer Care](#)
- [Cancer Prevalence](#)

## Base Data

- [Average Annual Costs of Care](#)



Cancer prevalence was estimated and projected by tumor site through 2020 using incidence and survival data from the [Surveillance, Epidemiology, and End Results \(SEER\) Program](#) and population projections from the U.S. Census Bureau. Annualized net costs of care were estimated using [Medicare claims linked to SEER data](#) and adjusted to represent costs in 2010 US dollars.

Different scenarios for assumptions about trends in incidence, survival, and cost were assessed with sensitivity analysis. Projections of current trends in incidence (declining) and survival (increasing) have almost no effect on these estimates. However, if costs of care increase annually by 2% in the initial and last year of life phases of care, the total cost in 2020 is projected to be \$174 billion.

This site is based on a study that estimates and projects the national cost of cancer care through the year 2020 separately for multiple cancer sites using the most recent available U.S. population projections, cancer incidence, survival, and cost of care data. More information about the methods, data sources and assumptions in: Mariotto AB, Yabroff KR, Shao Y, Feuer EJ, Brown ML. Projections of the Cost of Cancer Care in the U.S.: 2010-2020. *J Natl Cancer Inst.* 2011 Jan.

[Contact Us](#) | [Accessibility Feedback](#) | [Privacy Policy](#)



Figure 24: Order of Navigational Links Presented on the Site.

**Label for “Create Your Own Chart:”** Some of the participants failed to notice the larger “Create Your Own Chart” label (circled in Figure 25). Although this is possibly a test artifact, it is also common user behavior. Consider including this concept in the link text.

# Cancer Prevalence and Cost of Care

## Key Facts

- 18.1 million cancer survivors in 2020, 30% more than 2010
- Costs of cancer care: \$157 billion in 2010 dollars
- Growth and aging of the U.S. population is the primary cause

## Create Your Own Chart

 [Graph by Cancer Site and Phase of Cancer](#)

(See cost of care or prevalence for cancer site, sex, age and year under various assumptions)

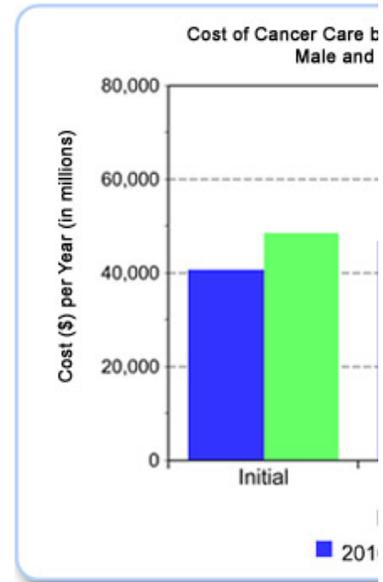
## Projection Tables for 2020

 [National Expenditures for Cancer Care](#)

 [Cancer Prevalence](#)

## Base Data

 [Average Annual Costs of Care](#)



Cancer prevalence was estimated and projected by tumor site through 2020 using incidence and survival data from the [\(SEER\) Program](#) and population projections from the U.S. Census Bureau. Annualized net costs of care were estimated and adjusted to represent costs in 2010 US dollars.

Figure 25: Label for "Create Your Own Chart" and Hyperlink.

**Text at the Bottom of the Homepage:** The first paragraph of text on the bottom of the homepage (see Figure 26) helped some participants understand the source of the data – particularly if they were aware of the Surveillance, Epidemiology and End Results Program (SEER).

[Graph by Cancer Site and Phase of Cancer](#)  
 (See cost of care or prevalence for cancer site, sex, age and year under various assumptions)

**Projection Tables for 2020**

- [National Expenditures for Cancer Care](#)
- [Cancer Prevalence](#)

**Base Data**

- [Average Annual Costs of Care](#)

Phase of Care	2010 Cost (\$ per Yr)	2020 Cost (\$ per Yr)
Initial	~38,000	~42,000
Continuing	~38,000	~42,000
Last	~35,000	~42,000

Cancer prevalence was estimated and projected by tumor site through 2020 using incidence and survival data from the [Surveillance, Epidemiology, and End Results \(SEER\) Program](#) and population projections from the U.S. Census Bureau. Annualized net costs of care were estimated using [Medicare claims linked to SEER data](#) and adjusted to represent costs in 2010 US dollars.

Different scenarios for assumptions about trends in incidence, survival, and cost were assessed with sensitivity analysis. Projections of current trends in incidence (declining) and survival (increasing) have almost no effect on these estimates. However, if costs of care increase annually by 2% in the initial and last year of life phases of care, the total cost in 2020 is projected to be \$174 billion.

This site is based on a study that estimates and projects the national cost of cancer care through the year 2020 separately for multiple cancer sites using the most recent available U.S. population projections, cancer incidence, survival, and cost of care data. More information about the methods, data sources and assumptions in: Mariotto AB, Yabroff KR, Shao Y, Feuer EJ, Brown ML. Projections of the Cost of Cancer Care in the U.S.: 2010-2020. *J Natl Cancer Inst.* 2011 Jan.

[Contact Us](#) | [Accessibility Feedback](#) | [Privacy Policy](#)

**Figure 26: Text Near the Bottom of the Homepage.**

However, the second paragraph has valuable information about the data on the site. There was no indication of any of the participants read this paragraph. Consider incorporating this site information above the gray line that separates the main content from the apparent footers.

**Understanding Difficult Terms:** There were a number of terms used on the site (one is circled in Figure 27) that would benefit from definitions. Some participants attempted to click on terms to get the definition, even though there was no visual indication that this was possible. Consider adding a broken underline to difficult terms that would hyperlink them to a pop up definition.

[Graph by Cancer Site and Phase of Cancer](#)  
 (See cost of care or prevalence for cancer site, sex, age and year under various assumptions)

**Projection Tables for 2020**

- [National Expenditures for Cancer Care](#)
- [Cancer Prevalence](#)

**Base Data**

- [Average Annual Costs of Care](#)

Phase of Care	2010 Cost (\$ per Year)	2020 Cost (\$ per Year)
Initial	~38,000	~42,000
Continuing	~42,000	~45,000
Last	~35,000	~42,000

Cancer prevalence was estimated and projected by tumor site through 2020 using incidence and survival data from the [Surveillance, Epidemiology, and End Results \(SEER\) Program](#) and population projections from the U.S. Census Bureau. Annualized net costs of care were estimated using [Medicare claims linked to SEER data](#) and adjusted to represent costs in 2010 US dollars.

Different scenarios for assumptions about trends in incidence, survival, and cost were assessed with [sensitivity analysis](#). Projections of current trends in incidence (declining) and survival (increasing) have almost no effect on these estimates. However, if costs of care increase annually by 2% in the initial and last year of life phases of care, the total cost in 2020 is projected to be \$174 billion.

This site is based on a study that estimates and projects the national cost of cancer care through the year 2020 separately for multiple cancer sites using the most recent available U.S. population projections, cancer incidence, survival, and cost of care data. More information about the methods, data sources and assumptions in: Mariotto AB, Yabroff KR, Shao Y, Feuer EJ, Brown ML. Projections of the Cost of Cancer Care in the U.S.: 2010-2020. *J Natl Cancer Inst.* 2011 Jan.

[Contact Us](#) | [Accessibility Feedback](#) | [Privacy Policy](#)

**Figure 27: Mention of "Sensitivity Analysis" on the Homepage Without a Definition.**

**Journal Citation:** Most of the participants did look at the bottom of the page (Figure 28) when they were asked where they would get additional information. However, the reference journal article does not include a hyperlink, which most participants expected.

In addition, the first sentence of this paragraph defines the data on the site, which none of the participants noticed at first. Consider moving this text to the top of the page just below the title.

[Graph by Cancer Site and Phase of Care](#)  
 (See cost of care or prevalence for cancer site, sex, age and year under various assumptions)

**Projection Tables for 2020**

- [National Expenditures for Cancer Care](#)
- [Cancer Prevalence](#)

**Base Data**

- [Average Annual Costs of Care](#)

Phase of Care	2010 Cost (\$ per Y)	2020 Cost (\$ per Y)
Initial	~40,000	~42,000
Continuing	~40,000	~42,000
Last	~38,000	~42,000

Cancer prevalence was estimated and projected by tumor site through 2020 using incidence and survival data from the [Surveillance, Epidemiology, and End Results \(SEER\) Program](#) and population projections from the U.S. Census Bureau. Annualized net costs of care were estimated using [Medicare claims linked to SEER data](#) and adjusted to represent costs in 2010 US dollars.

Different scenarios for assumptions about trends in incidence, survival, and cost were assessed with sensitivity analysis. Projections of current trends in incidence (declining) and survival (increasing) have almost no effect on these estimates. However, if costs of care increase annually by 2% in the initial and last year of life phases of care, the total cost in 2020 is projected to be \$174 billion.

This site is based on a study that estimates and projects the national cost of cancer care through the year 2020 separately for multiple cancer sites using the most recent available U.S. population projections, cancer incidence, survival, and cost of care data. More information about the methods, data sources and assumptions in: Mariotto AB, Yabroff KR, Shao Y, Feuer EJ, Brown ML. Projections of the Cost of Cancer Care in the U.S.: 2010-2020. *J Natl Cancer Inst*. 2011; Jan.

[Contact Us](#) | [Accessibility Feedback](#) | [Privacy Policy](#)

Figure 28: Journal Citation at the Very Bottom of the Homepage.

## Create Your Own Graph

**Graph Tool Page:** Participants did not have a particular problem interacting with the page for the Create Your Own Graph section, seen in Figure 29. However, a few participants commented that the selection of the data type is the logical first selection. This selection is currently last in the order (from top to bottom) of the other graph selections. Consider showing this selection first.

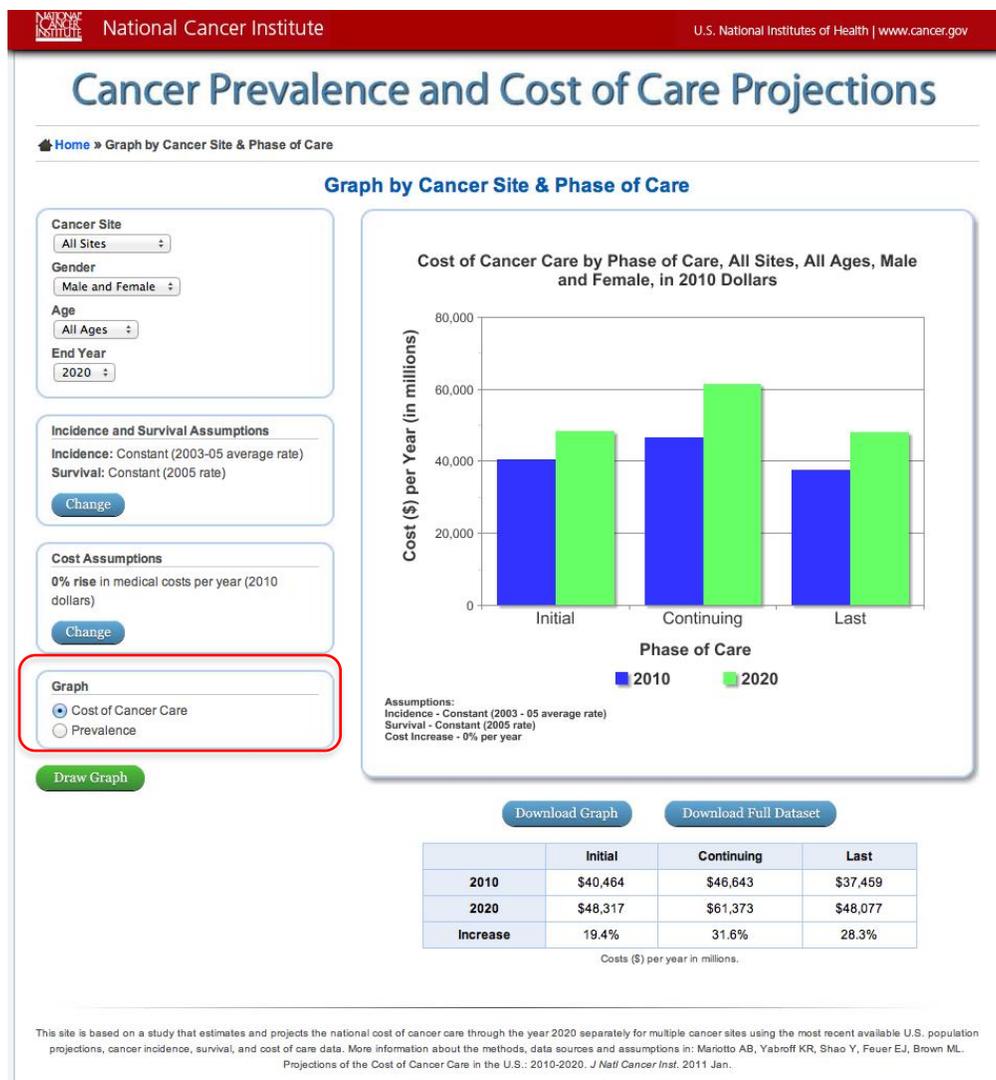


Figure 29: Type of Graph Selection at the Bottom of the Graph Selections List.

**Cost Assumption Default Value:** None of the participants had difficulty changing the cost assumptions for the graph, of which the dialog box is pictured in Figure 30. However, some commented that it was surprising the default value was set to zero. At least one participant indicated that they would need to look up the information in order to know what to set this value to. Others took a guess. One participant suggested 3% for the default value, as this was “generally known” to him as the typical projected increase.

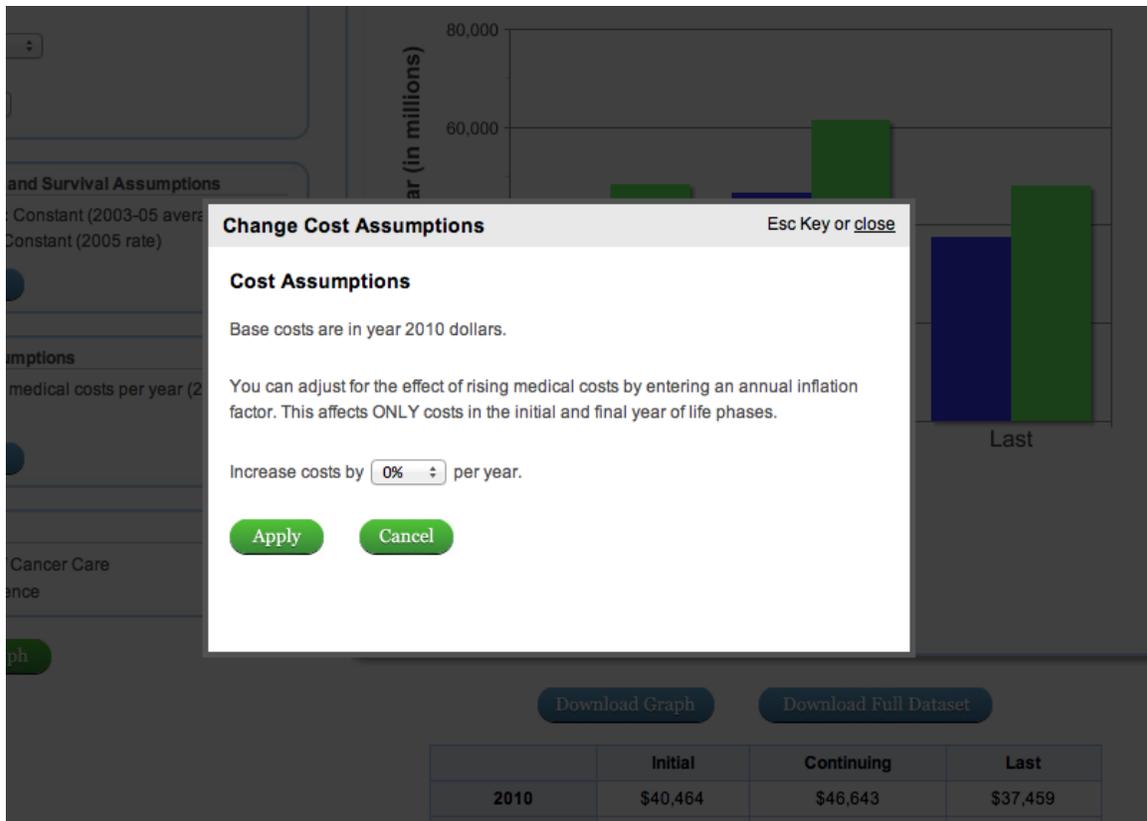


Figure 30: Cost Assumptions Dialog Box.

**Cost Assumption Instruction Text:** There was no indication that the participants read the text on the Change Cost Assumptions dialog box (Figure 30). This may have been a test artifact, but it is not unusual behavior. Consider removing the instruction indicating that the adjustment is for the rising medical costs. This fact was well understood and is intuitive. Also consider moving the text referring to 2010 near the drop-down selection. Finally, consider adding a “Note:” to draw attention to the fact that this change affects only costs in the initial and final phases.

**Incidence and Survival Assumptions:** Most of the participants had difficulty understanding the Incidence and Survival Assumptions dialog box, seen in Figure 31. Many of them commented that the graphs were too small to read comfortably, which may have contributed to this issue. Nearly all the participants assumed that it made more sense to follow the trend, so it is uncertain why constant rate is the default. Consider providing two pop-up dialog boxes (one for incidence and one for survival assumptions) to provide more space for a larger graph.

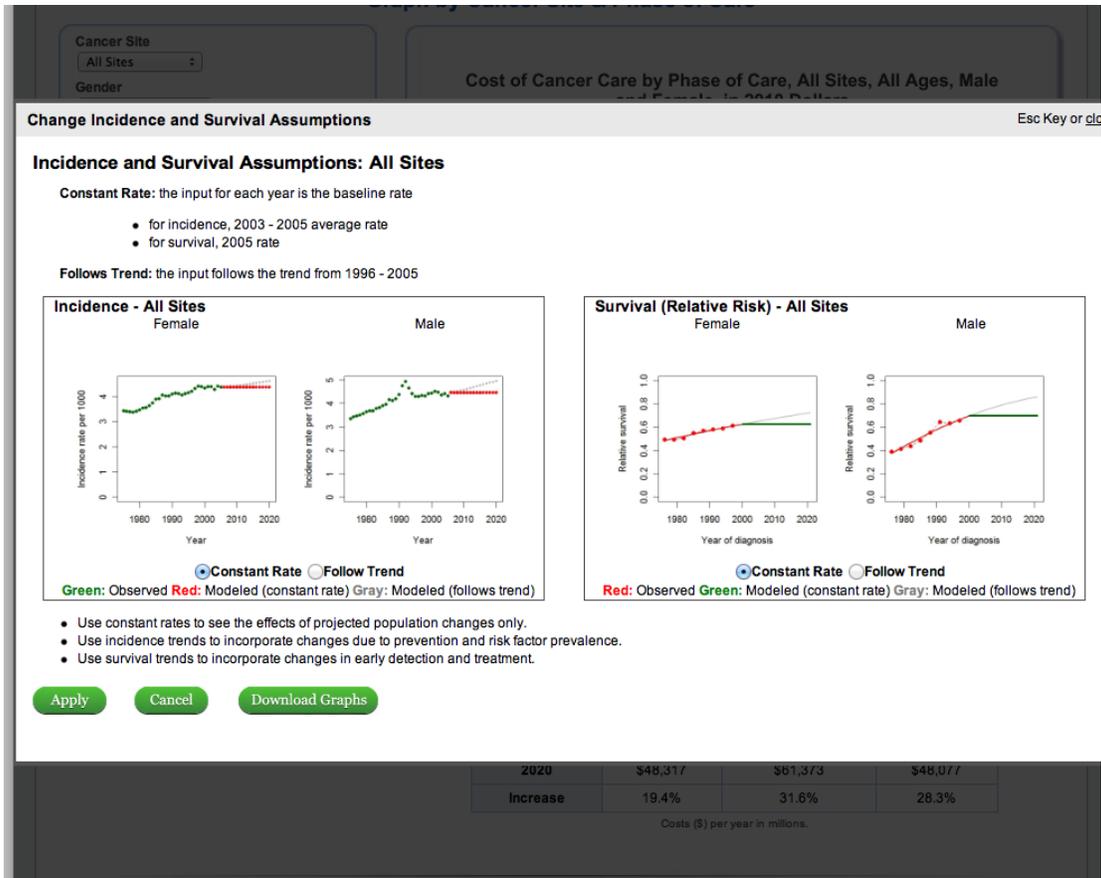


Figure 31: Incidence and Survival Assumptions Dialog Box.

There was no indication of the participants read the bullet points below the graphs, which provide instructions on when and how to set these options. Consider reversing the position of the definition (source) of the constant rate and the instructions/effect of changes to their assumptions. Also consider adding a visual indication such as “Note:” or “Instructions” to draw attention to the text.

The term used for the “apply” button confused most if not all of the participants. They assumed that applying the changes here would update the graph. Depending on how the light box is implemented, consider updating the graph automatically when the page is closed. Alternately, consider using the term “OK” instead of “Apply” and renaming the “Draw Graph” button to “Redraw Graph.”

**Accompanying Table on the Graph Page:** Some participants failed to notice the table below the graph, pictured in Figure 32. This may be caused by the break in the Gestalt created by the two buttons. When participants did view the table, many wondered why the values were not displayed on the graph itself. (The values do appear on mouse hover, but some participants

failed to discover this feature.) Consider displaying data labels on the graph directly and removing the table.



**Figure 32: Data Table on the Graph Page.**

**Downloading Options for the Graph:** Two buttons were available to participants underneath the graph image (see Figure 33). None of the participants had difficulty with the “download graph” feature, although they were surprised that the format of the download was a PNG file and not the more standard JPEG or BMP file. In addition, several the participants wondered if the resulting graph could be modified – such as changing the color or adding data labels.

Most participants initially believed that the download dataset option would download the data used to create the displayed graph. Several were surprised when the data set downloaded was the full data set for the site. Many found this overwhelming. Others felt that it was better to be able to download the data set and manipulate it themselves. Consider a feature to download only the data used to display the graph. This would provide the ability for people to create a graph of a different type or to change the display options on the currently displayed graph.



**Figure 33: Buttons for Options For Downloading Graph Data.**

**Graph Reference:** Consider adding a site reference to the graph so that the site is indicated as the source of this data.

**Graph Title Bug:** There appears to be a small bug with the title of the graph. When prevalence is selected, the title of the graph still refers to cost of cancer care. See Figure 34 for a screenshot example of this bug.

# Cancer Prevalence and Cost of Care Projections

Home » Graph by Cancer Site & Phase of Care

## Graph by Cancer Site & Phase of Care

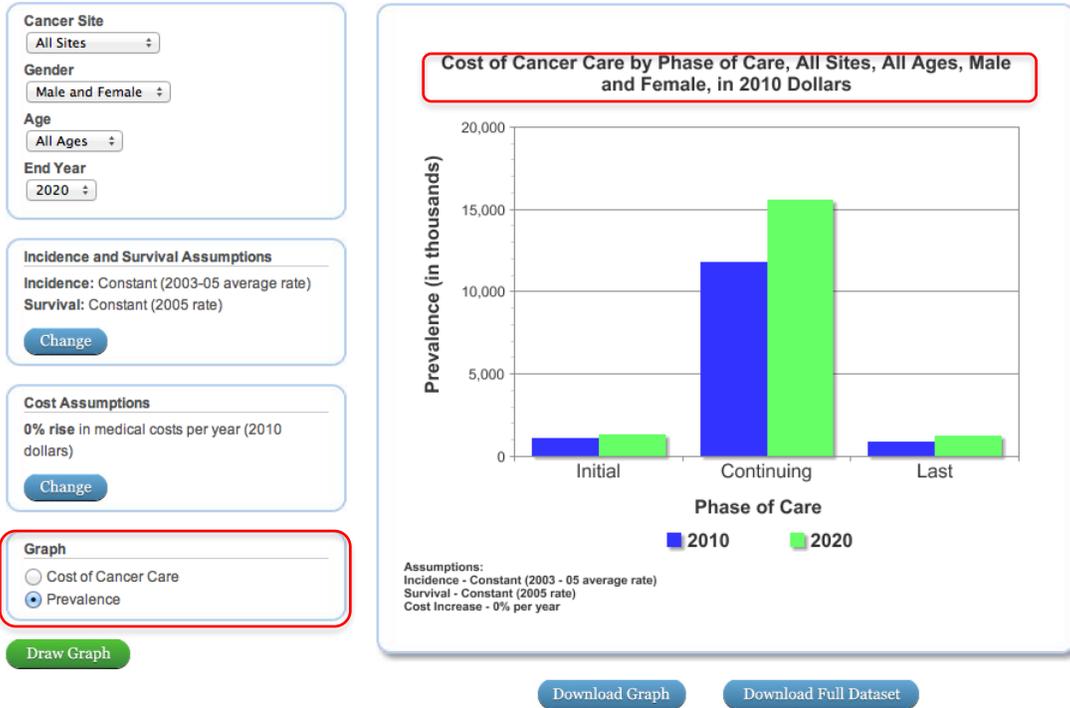


Figure 34: Screenshot of the Graph Demonstrating Title/Graph Type Inconsistency.

**Comparing Graphs:** Several of the participants made changes to the graph and then wanted to do comparisons. This is not easily supported without downloading the data. However, more significant is the fact that the scale changes to fit the data (See Figure 35). This change may preclude direct comparison or could lead to false conclusions and/or misreading of the data. Consider adding an option to use a fixed or variable scale.

# Cancer Prevalence and Cost of Care Projections

Home » Graph by Cancer Site & Phase of Care

## Graph by Cancer Site & Phase of Care

**Cancer Site**

**Gender**

**Age**

**End Year**

**Incidence and Survival Assumptions**  
 Incidence: Constant (2003-05 average rate)  
 Survival: Constant (2005 rate)

**Cost Assumptions**  
 0% rise in medical costs per year (2010 dollars)

**Graph**

Cost of Cancer Care

Prevalence

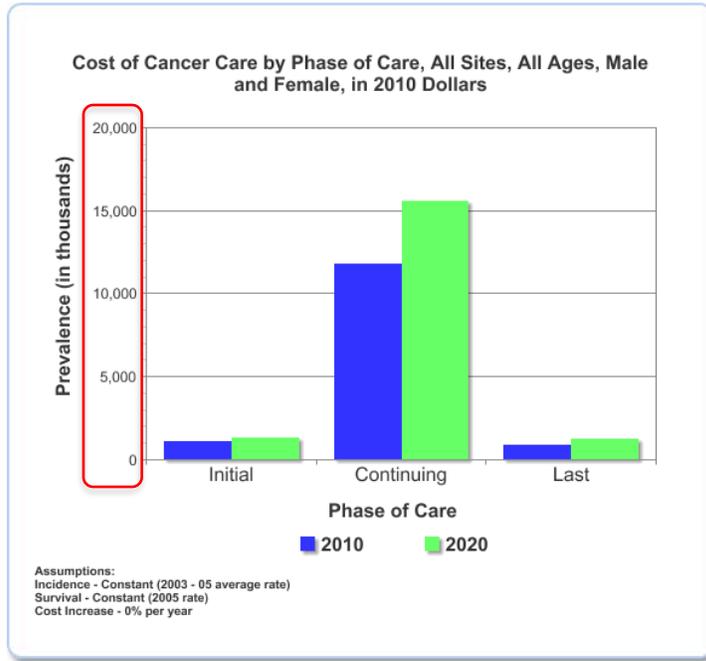


Figure 35: Graph Scale Highlighted on the Page.

## Projection Tables

**Text Associated With Table Data:** Many of the participants skipped over the explanatory text at the top of tabled data (shown in Figure 36). Participants that did read this text found it somewhat overwhelming both in terms of format and language. Consider providing this information in bullet form, which is generally less overwhelming in perception. Also consider moving some of the text to the bottom as footnotes to minimize the amount of text needed to be read before looking at the table.

# Cancer Prevalence and Cost of Care Projections

[Home](#) » National Expenditures for Cancer Care

## National Expenditures for Cancer Care

Estimates of the national expenditures for cancer care in 2010 and 2020 in 2010 billion dollars under different assumptions of cancer incidence and survival trends: Base case assumes constant incidence and survival as estimated in 2002-2005, Trend incidence assumes projected incidence trend and constant survival, Trend survival assumes constant incidence and projected survival trend, Trend incidence & survival assumes projected incidence and survival trends.

	Cost in US 2010 Billions							
	2010	2020					Trend incidence & survival scenario and cost increase	
		Base	Base	Trend incidence	Trend survival	Trend incidence & survival	2% overall	2% in initial and last year phase cost
Breast	\$16.50	\$20.50	\$18.91	\$20.69	\$19.08	\$23.24	\$21.37	\$25.64
Colorectal	\$14.14	\$17.41	\$14.35	\$17.83	\$14.70	\$17.67	\$16.68	\$20.39
Lung	\$12.12	\$14.73	\$12.14	\$15.23	\$12.53	\$15.19	\$14.73	\$18.84
Lymphoma	\$12.14	\$15.26	\$15.00	\$15.71	\$15.44	\$18.66	\$17.27	\$20.69
Prostate	\$11.85	\$16.34	\$15.32	\$16.43	\$15.41	\$18.53	\$16.67	\$19.02
Leukemia	\$5.44	\$6.95	\$6.66	\$7.24	\$6.94	\$8.38	\$7.78	\$9.35
Ovary	\$5.12	\$6.03	\$4.49	\$6.27	\$4.64	\$5.64	\$5.26	\$6.42
Brain	\$4.47	\$5.53	\$5.38	\$5.79	\$5.62	\$6.82	\$6.51	\$8.18
Bladder	\$3.98	\$4.91	\$4.41	\$4.98	\$4.47	\$5.38	\$4.90	\$5.71
Kidney	\$3.80	\$5.12	\$6.07	\$5.30	\$6.29	\$7.56	\$6.99	\$8.30
Head/Neck	\$3.64	\$4.34	\$3.79	\$4.40	\$3.84	\$4.65	\$4.40	\$5.46
Uterus	\$2.62	\$3.05	\$2.84	\$3.04	\$2.83	\$3.42	\$3.24	\$4.00
Melanoma	\$2.36	\$3.16	\$3.76	\$3.18	\$3.78	\$4.60	\$4.06	\$4.58
Pancreas	\$2.27	\$2.83	\$2.81	\$3.16	\$3.13	\$3.80	\$3.75	\$4.92
Stomach	\$1.82	\$2.26	\$1.81	\$2.40	\$1.92	\$2.31	\$2.25	\$2.88
Cervix	\$1.55	\$1.54	\$1.20	\$1.55	\$1.21	\$1.46	\$1.39	\$1.73
Esophagus	\$1.33	\$1.76	\$1.70	\$2.04	\$1.97	\$2.38	\$2.32	\$2.97
All sites	\$124.57	\$157.77	\$147.57	\$165.21	\$154.70	\$186.69	\$172.77	\$206.59

[Download Full Dataset](#)

Figure 36: Text Above the National Expenditures for Cancer Care Table.

**Understanding “Base” Data:** Some of the participants were unclear about the use of the term “Base.” The term “Base” (seen in Figure 37) used to indicate 2010 data appears to be clear, but it is also used to indicate data in the 2020 timeframe when incidence and survival are held constant at the 2010 rate. Consider an alternate term for the 2020 rate when the incidence and survival rates are kept at the 2010 value.

# Cancer Prevalence and Cost of Care Projections

Home » National Expenditures for Cancer Care

## National Expenditures for Cancer Care

Estimates of the national expenditures for cancer care in 2010 and 2020 in 2010 billion dollars under different assumptions of cancer incidence and survival trends: Base case assumes constant incidence and survival as estimated in 2002-2005, Trend incidence assumes projected incidence trend and constant survival, Trend survival assumes constant incidence and projected survival trend, Trend incidence & survival assumes projected incidence and survival trends.

	Cost in US 2010 Billions								
	2010	2020				Trend incidence & survival scenario and cost increase			
		Base	Base	Trend incidence	Trend survival	Trend incidence & survival	2% overall	2% in initial and last year phase cost	5% in initial and last year phase cost
Breast	\$16.50	\$20.50	\$18.91	\$20.69	\$19.08	\$23.24	\$21.37	\$25.64	
Colorectal	\$14.14	\$17.41	\$14.35	\$17.83	\$14.70	\$17.67	\$16.68	\$20.39	
Lung	\$12.12	\$14.73	\$12.14	\$15.23	\$12.53	\$15.19	\$14.73	\$18.84	
Lymphoma	\$12.14	\$15.26	\$15.00	\$15.71	\$15.44	\$18.66	\$17.27	\$20.69	

Figure 37: Use of the Term "Base" Twice in Consecutive Columns.

**Understanding 2020 Data Scenarios:** Participants that first encountered the table data on the site did not seem to understand that the first four columns for 2020 (see Figure 38) represented four different scenarios. Consider a generic term like “scenario” with a footnote to each of the four scenarios. This will allow more space to define the scenarios in greater detail.

# Cancer Prevalence and Cost of Care Projections

Home » National Expenditures for Cancer Care

## National Expenditures for Cancer Care

Estimates of the national expenditures for cancer care in 2010 and 2020 in 2010 billion dollars under different assumptions of cancer incidence and survival trends: Base case assumes constant incidence and survival as estimated in 2002-2005, Trend incidence assumes projected incidence trend and constant survival, Trend survival assumes constant incidence and projected survival trend, Trend incidence & survival assumes projected incidence and survival trends.

	Cost in US 2010 Billions								
	2010	2020				Trend incidence & survival scenario and cost increase			
		Base	Base	Trend incidence	Trend survival	Trend incidence & survival	2% overall	2% in initial and last year phase cost	5% in initial and last year phase cost
Breast	\$16.50	\$20.50	\$18.91	\$20.69	\$19.08	\$23.24	\$21.37	\$25.64	
Colorectal	\$14.14	\$17.41	\$14.35	\$17.83	\$14.70	\$17.67	\$16.68	\$20.39	
Lung	\$12.12	\$14.73	\$12.14	\$15.23	\$12.53	\$15.19	\$14.73	\$18.84	
Lymphoma	\$12.14	\$15.26	\$15.00	\$15.71	\$15.44	\$18.66	\$17.27	\$20.69	

Figure 38: The Four Types of Data for 2020.

**Understanding Cost Increase Columns:** Most participants eventually concluded that the 2% and 5% values seen in the last three columns of this table (in Figure 39) were referring to the cost increase but were still uncertain about the assumptions included here. The participants who were more successful in figuring out these last three columns wondered why there are two columns of data for 2% increases and only one column for 5%.

**National Cancer Institute** U.S. National Institutes of Health | www.cancer.gov

## Cancer Prevalence and Cost of Care Projections

Home » National Expenditures for Cancer Care

### National Expenditures for Cancer Care

Estimates of the national expenditures for cancer care in 2010 and 2020 in 2010 billion dollars under different assumptions of cancer incidence and survival trends: Base case assumes constant incidence and survival as estimated in 2002-2005, Trend incidence assumes projected incidence trend and constant survival, Trend survival assumes constant incidence and projected survival trend, Trend incidence & survival assumes projected incidence and survival trends.

Cost in US 2010 Billions								
	2010	2020						
						Trend incidence & survival scenario and cost increase		
	Base	Base	Trend incidence	Trend survival	Trend incidence & survival	2% overall	2% in initial and last year phase cost	5% in initial and last year phase cost
Breast	\$16.50	\$20.50	\$18.91	\$20.69	\$19.08	\$23.24	\$21.37	\$25.64
Colorectal	\$14.14	\$17.41	\$14.35	\$17.83	\$14.70	\$17.67	\$16.68	\$20.39
Lung	\$12.12	\$14.73	\$12.14	\$15.23	\$12.53	\$15.19	\$14.73	\$18.84
Lymphoma	\$12.14	\$15.26	\$15.00	\$15.71	\$15.44	\$18.66	\$17.27	\$20.69

Figure 39: Cost Increase Columns.

**Cancer Prevalence Table Cancer Site Listing:** The first column of the Cancer Prevalence table in Figure 40 appears to be in alphabetical order. However, breast cancer is referred to as “Female Breast,” and is listed with the ‘B’s’ instead of ‘F,’ its starting letter. Consider using the term “Breast (Female)” to keep the alphabetical order of the first letters.

### Cancer Prevalence

U.S. cancer prevalence estimates for 2010 and projections for 2020 under different assumptions of cancer incidence and survival trends: Base case assumes constant incidence and survival as estimated in 2002-2005, Trend incidence assumes projected incidence trend and constant survival, Trend survival assumes constant incidence and projected survival trend, Trend incidence & survival assumes projected incidence and survival trends. Percent change from 2010 base estimate.

Number of Cancer Survivors									
Site	2010	2020							
	Base	Base		Trend incidence		Trend survival		Trend incidence & survival	
	Base	No.	% change	No.	% change	No.	% change	No.	% change
Bladder	514,000	629,000	22%	576,000	12%	640,000	25%	587,000	14%
Brain	139,000	176,000	27%	174,000	25%	185,000	33%	182,000	31%
Female breast	3,461,000	4,538,000	31%	4,275,000	24%	4,597,000	33%	4,329,000	25%
Cervix	281,000	276,000	-2%	245,000	-13%	277,000	-1%	245,000	-13%
Colorectal	1,216,000	1,517,000	25%	1,327,000	9%	1,575,000	30%	1,376,000	13%
Esophagus	35,000	50,000	43%	48,000	37%	62,000	77%	60,000	71%
Head/Neck	283,000	340,000	20%	308,000	9%	346,000	22%	313,000	11%
Kidney	308,000	426,000	38%	487,000	58%	446,000	45%	511,000	66%
Leukemia	263,000	340,000	29%	328,000	25%	356,000	35%	342,000	30%
Lung	374,000	457,000	22%	392,000	5%	481,000	29%	412,000	10%
Lymphoma	639,000	812,000	27%	803,000	26%	841,000	32%	831,000	30%
Melanoma	1,225,000	1,714,000	40%	1,971,000	61%	1,724,000	41%	1,983,000	62%
Ovary	238,000	282,000	18%	232,000	-3%	296,000	24%	241,000	1%

Figure 40: Cancer Prevalence Table with Alphabetical Listing Issue.

**Cancer Prevalence Table “Survivor Definition:”** Participants seemed unclear about which definition of survivor was implied for the “Number of Cancer Survivors” on the Cancer Prevalence table (Figure 40). Most participants mentioned two types of “survivors” – individuals who were diagnosed and living with cancer, and individuals who had stopped treatment and were cancer-free.

**Obtaining Table Data:** When participants were asked how they would get the data from the tables, many said they would copy and paste the table into Word or PowerPoint. However, when they attempted this, the formatting did not line up properly in their document.

Unlike the other tables on the site, the Cancer Prevalence page (Figure 41) does not include an option to download data. It is unclear why this difference exists. The Average Annual Costs of Care table page also does not include a download option, and participants also felt it was unclear that it was missing from this page as well.

### Cancer Prevalence

U.S. cancer prevalence estimates for 2010 and projections for 2020 under different assumptions of cancer incidence and survival trends: Base case assumes constant incidence and survival as estimated in 2002-2005, Trend incidence assumes projected incidence trend and constant survival, Trend survival assumes constant incidence and projected survival trend, Trend incidence & survival assumes projected incidence and survival trends. Percent change from 2010 base estimate.

Number of Cancer Survivors									
Site	2010	2020							
	Base	Base		Trend incidence		Trend survival		Trend incidence & survival	
		No.	% change	No.	% change	No.	% change	No.	% change
Bladder	514,000	629,000	22%	576,000	12%	640,000	25%	587,000	14%
Brain	139,000	176,000	27%	174,000	25%	185,000	33%	182,000	31%
Female breast	3,461,000	4,538,000	31%	4,275,000	24%	4,597,000	33%	4,329,000	25%
Cervix	281,000	276,000	-2%	245,000	-13%	277,000	-1%	245,000	-13%
Colorectal	1,216,000	1,517,000	25%	1,327,000	9%	1,575,000	30%	1,376,000	13%
Esophagus	35,000	50,000	43%	48,000	37%	62,000	77%	60,000	71%
Head/Neck	283,000	340,000	20%	308,000	9%	346,000	22%	313,000	11%
Kidney	308,000	426,000	38%	487,000	58%	446,000	45%	511,000	66%
Leukemia	263,000	340,000	29%	328,000	25%	356,000	35%	342,000	30%
Lung	374,000	457,000	22%	392,000	5%	481,000	29%	412,000	10%
Lymphoma	639,000	812,000	27%	803,000	26%	841,000	32%	831,000	30%
Melanoma	1,225,000	1,714,000	40%	1,971,000	61%	1,724,000	41%	1,983,000	62%
Ovary	238,000	282,000	18%	232,000	-3%	296,000	24%	241,000	1%
Pancreas	30,000	40,000	33%	40,000	33%	50,000	67%	50,000	67%
Prostate	2,311,000	3,265,000	41%	3,108,000	34%	3,291,000	42%	3,132,000	36%
Stomach	74,000	93,000	26%	80,000	8%	103,000	39%	88,000	19%
Uterus	586,000	672,000	15%	638,000	9%	667,000	14%	634,000	8%
All Sites	13,772,000	18,071,000	31%	17,465,000	27%	18,878,000	37%	18,229,000	32%

This site is based on a study that estimates and projects the national cost of cancer care through the year 2020 separately for multiple cancer sites using the most recent available U.S. population projections, cancer incidence, survival, and cost of care data. More information about the methods, data sources and assumptions in: Mariotto AB, Yabroff KR, Shao Y, Feuer EJ, Brown ML. Projections of the Cost of Cancer Care in the U.S.: 2010-2020. *J Natl Cancer Inst.* 2011 Jan.

Figure 41: Cancer Prevalence Table Page Lacking a Download Button.

**View for “Cost of Care” Table:** Participants had little difficulty understanding the data on the Average Annual Cost of Care table, seen in Figure 42. However, they reported that it was difficult to make a comparison between males and females because of the table’s vertical orientation. Consider a horizontal layout to allow more direct comparison between the male and female data.

### Average Annual Costs of Care

Annualized Mean Net Costs of Care by Age, Gender and Phase of Care (Per Patient), Costs in 2010 US Dollars.

Annual Costs of Cancer Care in US 2010 Dollars					
		Age 65+			
Sex	Site	Initial <sup>1</sup>	Continuing <sup>1</sup>	Last Year of Life <sup>1</sup>	
				Cancer Death	Other Cause
Female	Bladder	21,412	3,710	78,698	10,005
	Brain	108,168	8,803	140,891	39,893
	Breast	23,078	2,207	62,856	748
	Cervix	45,174	1,425	78,553	7,949
	Colorectal	51,327	3,159	84,519	14,641
	Esophagus	79,532	6,853	104,278	41,051
	Head/Neck	41,980	4,826	86,602	10,064
	Kidney	38,397	6,255	73,843	24,607
	Leukemia	33,167	8,537	130,131	31,517
	Lung	60,533	8,130	92,524	18,897
	Lymphoma	57,881	8,622	109,842	20,462
	Melanoma	5,047	915	56,784	252
	Other	40,173	5,859	95,782	21,721
	Ovary	82,324	8,296	99,715	12,257
Pancreas	93,462	8,672	109,941	40,538	
Stomach	71,076	3,977	103,758	29,172	
Uterus	26,775	1,535	70,175	4,437	
Male	Bladder	20,960	4,677	75,772	8,446
	Brain	115,250	9,434	134,244	67,914
	Colorectal	51,812	4,595	85,671	15,068
	Esophagus	79,822	6,450	103,742	51,035
	Head/Neck	39,179	4,001	83,662	9,269
	Kidney	38,374	6,018	78,082	19,142
	Leukemia	36,036	10,249	133,183	35,941
	Lung	60,885	7,591	95,318	25,008
	Lymphoma	60,701	9,337	116,596	27,200
	Melanoma	5,437	1,951	62,436	546
	Other	41,161	7,363	97,473	25,758
	Pancreas	94,092	11,697	113,115	47,565
	Prostate	19,710	3,201	62,242	5,370
Stomach	78,453	4,282	107,130	25,800	

Note: All estimates adjusted for patient deductibles and coinsurance expenses

1. Phases of care: *Initial* year after diagnosis, *Last year of life*, and the period between (*Continuing*). Months of survival are first applied to last year of life, any remaining to initial phase, then to continuing.

Figure 42: Orientation and Formatting of the Average Annual Cost of Care Table.

**Average Annual Costs of Care Term – “Other Causes” of Death:** Participants were uncertain how to interpret the difference between a cancer death and a death from other causes while looking at this table (Figure 43). Specifically, it was noted that an initial diagnosis of cancer might metastasize to other organs and be the ultimate cause of death. It is unclear how this fact is represented on the table. One participant suggested the term “Specific Cancer Death” and that this would need to be identified as specific to the cancer site in the row of the table, perhaps through a footnote.

# Cancer Prevalence and Cost of Care Projections

Home » Average Annual Costs of Care

## Average Annual Costs of Care

Annualized Mean Net Costs of Care by Age, Gender and Phase of Care (Per Patient). Costs in 2010 US Dollars.

Annual Costs of Cancer Care in US 2010 Dollars					
		Age 65+			
				Last Year of Life <sup>1</sup>	
Sex	Site	Initial <sup>1</sup>	Continuing <sup>1</sup>	Cancer Death	Other Cause
Female	Bladder	21,412	3,710	78,698	10,005
	Brain	108,168	8,803	140,891	39,893
	Breast	23,078	2,207	62,856	748
	Cervix	45,174	1,425	78,553	7,949
	Colorectal	51,327	3,159	84,519	14,641
	Esophagus	79,532	6,853	104,278	41,051
	Head/Neck	41,980	4,826	86,602	10,064
	Kidney	38,397	6,255	73,843	24,607
	Leukemia	33,167	8,537	130,131	31,517
	Lung	60,533	8,130	92,524	18,897
	Lymphoma	57,881	8,622	109,842	20,462
	Melanoma	5,047	915	56,784	252
	Other	40,173	5,859	95,782	21,721
	Ovary	82,324	8,296	99,715	12,257
Pancreas	93,462	8,672	109,941	40,538	

Figure 43: "Cancer Death" and "Other Deaths" Columns on the Average Annual Costs of Care Table.

**Phase of Care Definitions on the Average Annual Costs of Care Table:** Many of the participants encountered the definition of "Initial," "Continuing," and "Last" year of life for the first time on the page for the Average Annual Costs of Care table (Figure 44). The definitions were considered useful to participants, so they wondered why they were not present on all pages where the terms are used.

### Average Annual Costs of Care

Annualized Mean Net Costs of Care by Age, Gender and Phase of Care (Per Patient). Costs in 2010 US Dollars.

		Annual Costs of Cancer Care in US 2010 Dollars			
		Age 65+		Last Year of Life <sup>1</sup>	
Sex	Site	Initial <sup>1</sup>	Continuing <sup>1</sup>	Cancer Death	Other Cause
Female	Bladder	21,412	3,710	78,698	10,005
	Brain	108,168	8,803	140,891	39,893
	Breast	23,078	2,207	62,856	748
	Cervix	45,174	1,425	78,553	7,949
	Colorectal	51,327	3,159	84,519	14,641
	Esophagus	79,532	6,853	104,278	41,051
	Head/Neck	41,980	4,826	86,602	10,064
	Kidney	38,397	6,255	73,843	24,607
	Leukemia	33,167	8,537	130,131	31,517
	Lung	60,533	8,130	92,524	18,897
	Lymphoma	57,881	8,622	109,842	20,462
	Melanoma	5,047	915	56,784	252
	Other	40,173	5,859	95,782	21,721
	Ovary	82,324	8,296	99,715	12,257
	Pancreas	93,462	8,672	109,941	40,538
Stomach	71,076	3,977	103,758	29,172	
Uterus	26,775	1,535	70,175	4,437	
Male	Bladder	20,960	4,677	75,772	8,446
	Brain	115,250	9,434	134,244	67,914
	Colorectal	51,812	4,595	85,671	15,068
	Esophagus	79,822	6,450	103,742	51,035
	Head/Neck	39,179	4,001	83,662	9,269
	Kidney	38,374	6,018	78,082	19,142
	Leukemia	36,036	10,249	133,183	35,941
	Lung	60,885	7,591	95,318	25,008
	Lymphoma	60,701	9,337	116,596	27,200
	Melanoma	5,437	1,951	62,436	546
	Other	41,161	7,363	97,473	25,758
	Pancreas	94,092	11,697	113,115	47,565
	Prostate	19,710	3,201	62,242	5,370
Stomach	78,453	4,282	107,130	25,800	

Note: All estimates adjusted for patient deductibles and coinsurance expenses.

1. Phases of care: *Initial* year after diagnosis, *Last year of life*, and the period between (*Continuing*). Months of survival are first applied to last year of life, any remaining to initial phase, then to continuing.

Figure 44: Phases of Care Definitions Shown As a Footnote.

**Inconsistency with Cost of Care Table:** A small inconsistency exists on the Costs of Care table (see Figure 45). The title reads “Average Annual Cost” but the subtitle refers to this as “Annualized Mean Net Cost.”

# Cancer Prevalence and Cost of Care Projections

Home » Average Annual Costs of Care

## Average Annual Costs of Care

Annualized Mean Net Costs of Care by Age, Gender and Phase of Care (Per Patient). Costs in 2010 US Dollars.

		Annual Costs of Cancer Care in US 2010 Dollars			
		Age 65+			
				Last Year of Life <sup>1</sup>	
Sex	Site	Initial <sup>1</sup>	Continuing <sup>1</sup>	Cancer Death	Other Cause
Female	Bladder	21,412	3,710	78,698	10,005
	Brain	108,168	8,803	140,891	39,893
	Breast	23,078	2,207	62,856	748
	Cervix	45,174	1,425	78,553	7,949
	Colorectal	51,327	3,159	84,519	14,641
	Esophagus	79,532	6,853	104,278	41,051
	Head/Neck	41,980	4,826	86,602	10,064
	Kidney	38,397	6,255	73,843	24,607
	Leukemia	33,167	8,537	130,131	31,517
	Lung	60,533	8,130	92,524	18,897
	Lymphoma	57,881	8,622	109,842	20,462
	Melanoma	5,047	915	56,784	252

Figure 45: Labeling Discrepancy Between Table Title and Subtitle.

## Round 2 Usability Evaluations

The findings from the second round of usability evaluations reflect participants' experience with the live CPCC site ([costprojections.cancer.gov](http://costprojections.cancer.gov)) that was current in September 2013.

### Site in General

**Purpose of the Site:** Two of the researchers in the second round were familiar with the report the site is based on. Their perception of the site was that it exists to visualize data from the report, as opposed to a site about cancer prevalence and cost of care projections in general. Will the site be updated if a new study comes out? For example, would the existing data be combined or kept separate from new data?

**Site Navigation:** Participants used their browser's buttons to navigate through the site (example in Figure 46). Many did not notice the breadcrumbs that were available beneath the title of the page. The problem may also be related to text size, as one participant suggested. Consider making the breadcrumbs more visible by removing the separator line that induce banner blindness and associating them with the page title.



Figure 46: Navigational Breadcrumbs.

### Homepage

**Pattern of Usage:** Similar to the first round, no specific pattern emerged for users' behavior on the homepage (Figure 47). Some participants read the Key Facts or looked at the graph, while others went directly to the hyperlinks.

# Cancer Prevalence and Cost of Care Projections

## Key Facts

- 18.1 million cancer survivors in 2020, 30% more than 2010
- Costs of cancer care: \$157 billion in 2010 dollars
- Growth and aging of the U.S. population is the primary cause

## Create Your Own Chart

[Graph by Cancer Site and Phase of Cancer](#)

(See cost of care or prevalence for cancer site, sex, age and year under various assumptions)

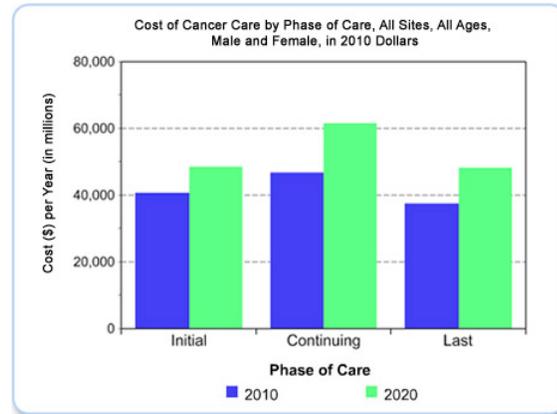
## Projection Tables for 2020

[National Expenditures for Cancer Care](#)

[Cancer Prevalence](#)

## Base Data

[Average Annual Costs of Care](#)



Cancer prevalence was estimated and projected by tumor site through 2020 using incidence and survival data from the [Surveillance, Epidemiology, and End Results \(SEER\) Program](#) and population projections from the U.S. Census Bureau. Annualized net costs of care were estimated using [Medicare claims linked to SEER data](#) and adjusted to represent costs in 2010 US dollars.

Different scenarios for assumptions about trends in incidence, survival, and cost were assessed with sensitivity analysis<sup>1</sup>. Projections of current trends in incidence (declines) and survival (improves) have almost no effect on these estimates. However, if costs of care increase annually by 2% in the initial and last years of life.

Figure 47: The Cancer Prevalence and Cost of Care Projections Website for Round 2.

**Site Audience:** After looking at the homepage (Figure 47), most participants identified several audiences who may use the data, including general public, researchers, and press and hill people. However, as they looked deeper into the site, it became harder to understand whom the data was for. It seemed like the site was for researchers, but it was not seen as not as powerful as they may need. One researcher participant said that it would not really be appropriate for public, press/policy people, or advocates.

**Homepage Link Order:** After exploring the site, one participant returned to the links on the homepage (Figure 48) and mentioned that the link to the Base Data could be listed first, since the data there is the basis for other information on the site. Creating a chart was interesting to people, but they may have gone to this part prematurely. Consider reversing the order of these links.

Potential order:

- First: Base Data (consider adding “for 2010”)
- Second: Projection Data for 2020
- Last: Create Your Own Chart

# Cancer Prevalence and Cost of Care Projections

## Key Facts

- 18.1 million cancer survivors in 2020, 30% more than 2010
- Costs of cancer care: \$157 billion in 2010 dollars
- Growth and aging of the U.S. population is the primary cause

## Create Your Own Chart

[Graph by Cancer Site and Phase of Cancer](#)

(See cost of care or prevalence for cancer site, sex, age and year under various assumptions)

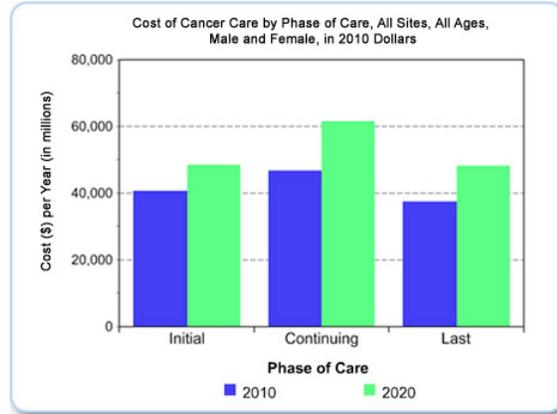
## Projection Tables for 2020

[National Expenditures for Cancer Care](#)

[Cancer Prevalence](#)

## Base Data

[Average Annual Costs of Care](#)



Cancer prevalence was estimated and projected by tumor site through 2020 using incidence and survival data from the [Surveillance, Epidemiology, and End Results \(SEER\) Program](#) and population projections from the U.S. Census Bureau. Annualized net costs of care were estimated using [Medicare claims linked to SEER data](#) and adjusted to represent costs in 2010 US dollars.

Different scenarios for assumptions about trends in incidence, survival, and cost were assessed with sensitivity analysis<sup>1</sup>. Projections of current trends in incidence (declines) and survival (increases) have almost no effect on these estimates. However, if costs of care increase annually by 2% in the initial and last year of life

Figure 48: Links on the Homepage.

**Phase of Care Definitions:** Definitions for Phases of Care were added to the homepage (see Figure 49). However, one participant went to the National Expenditures for Cancer Care table first, and only saw two phases, initial and last. Reading a reference to “continuing” in the definition confused her. The phases of care are referred to as proper nouns in the definition (also, “continuing” is not capitalized when referenced). These may be standard NCI terms, but may not be that familiar to other external researchers or other audiences. Consider providing a definition for these terms on every page they appear (and only the terms mentioned on that page).

phases of care<sup>2</sup>, the total cost in 2020 is projected to be \$174 billion.

<sup>1</sup> Sensitivity analysis: An evaluation of the impact of different assumptions about model inputs (e.g., future cancer incidence rates) that are uncertain.  
<sup>2</sup> Phases of care: *Initial* year after diagnosis, *Last* year of life, and the period between (*Continuing*). Months of survival are first applied to last year of life, any remaining to initial phase, then to continuing.

This site is based on a study that estimates and projects the national projections, cancer incidence, survival, and cost of care data. Moore et al. Projections of the Cost of Cancer Care in the U.S.: 2010-2020. JAMA.

Trend incidence & survival scenario and cost increase		
2% overall	2% in <b>initial and last</b> year phase <sup>1</sup> cost	5% <b>in initial and last</b> year phase <sup>1</sup> cost
\$23.24	\$21.37	\$25.64
\$17.67	\$16.69	\$20.20

Figure 49: Phases of Care Definitions and Columns from the National Expenditures for Cancer Care Table.

**Journal Citation:** All participants noticed and commented on the link at the bottom of the page (Figure 50). Adding this link for this round of testing was a positive change.

Cancer prevalence was estimated and projected by tumor site through 2020 using incidence and survival data from the [Surveillance, Epidemiology, and End Results \(SEER\) Program](#) and population projections from the U.S. Census Bureau. Annualized net costs of care were estimated using [Medicare claims linked to SEER data](#) and adjusted to represent costs in 2010 US dollars.

Different scenarios for assumptions about trends in incidence, survival, and cost were assessed with sensitivity analysis<sup>1</sup>. Projections of current trends in incidence (declining) and survival (increasing) have almost no effect on these estimates. However, if costs of care increase annually by 2% in the initial and last year of life phases of care<sup>2</sup>, the total cost in 2020 is projected to be \$174 billion.

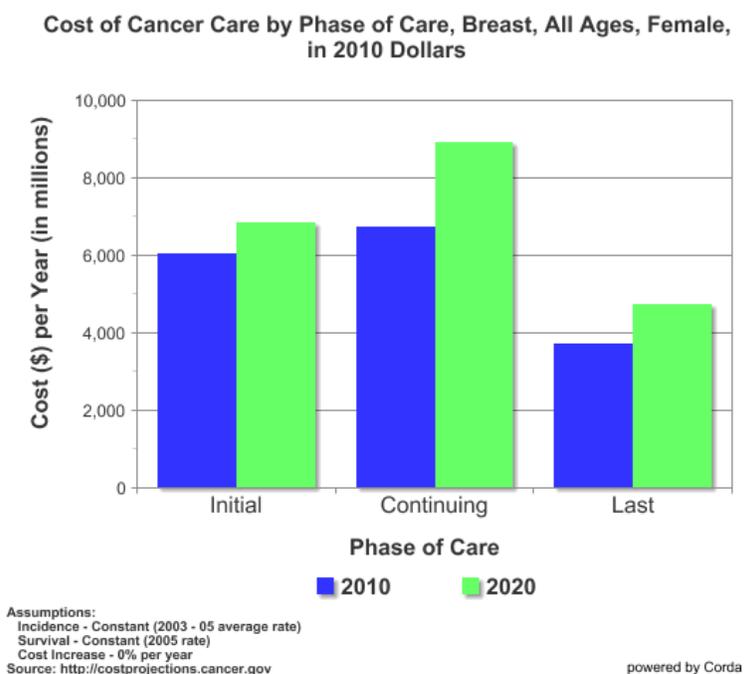
1. Sensitivity analysis: An evaluation of the impact of different assumptions about model inputs (e.g., future cancer incidence rates) that are uncertain.
2. Phases of care: *Initial* year after diagnosis, *Last* year of life, and the period between (*Continuing*). Months of survival are first applied to last year of life, any remaining to initial phase, then to continuing.

This site is based on a study that estimates and projects the national cost of cancer care through the year 2020 separately for multiple cancer sites using the most recent available U.S. population projections, cancer incidence, survival, and cost of care data. For more information about the methods, data sources and assumptions in: Mariotto AB, Yabroff KR, Shao Y, Feuer EJ, Brown ML. [Projections of the Cost of Cancer Care in the U.S.: 2010-2020](#). *J Natl Cancer Inst*. 2011 Jan.

**Figure 50: Hyperlink to the Journal Article Associated with the Site.**

## Create Your Own Graph

**Cost of Care Graph:** One participant pointed out that the costs of care would vary (between stage at diagnosis, etc.) and expected to see a caveat statement on the page with the graph (Figure 51). However, she said the simplicity of the information was a good thing, and that the data was “generalized.” Consider adding a footnote with more information at the bottom of the graph (with the Assumptions and Source).



**Figure 51: Cost of Care Graph with Information.**

**Incidence and Survival Assumptions:** This page (Figure 52) is complex because it is serving two purposes – it is used to make a selection between rates and trends, but it is also a data output display. Participants did not recognize that the data on this page represented data they had previously selected (ex. cancer site, age, etc.). Consider moving the data displays onto the primary output page.



Figure 52: The Incidence and Survival Assumptions Dialog Box.

**Incidence and Survival Assumptions Buttons:** This button on the Incidence and Survival Assumptions dialog box (Figure 53) was previously labeled “Apply,” and was not clear in function. All participants in the second round were able to figure out and use the button with its new label, “OK.”

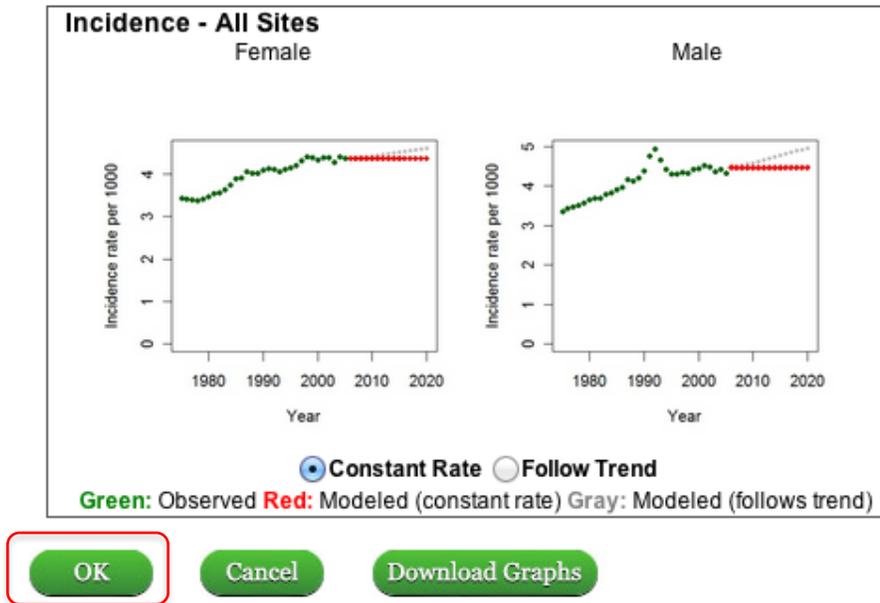
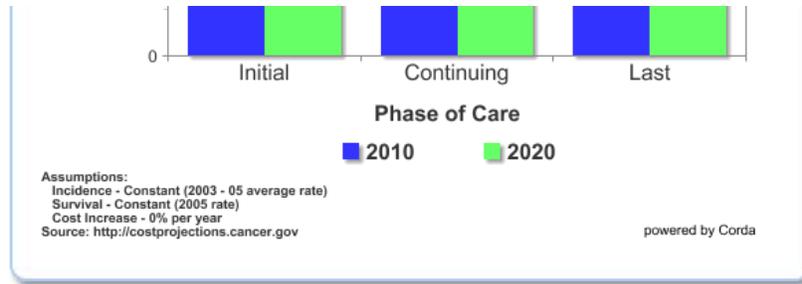


Figure 53: "OK" Button on the Incidence and Survival Assumptions Dialog Box.

**Download Dataset:** Most participants initially believed that the Download Full Dataset option (seen in Figure 54) would download the data used to create the displayed graph. Several were surprised when the data set downloaded was the full data set for the site, although most participants did not make that connection. Participants felt that it was good to be able to download the data set if you wanted to manipulate it yourself, although it seemed a little overwhelming.

Consider moving the Download Full Dataset feature to the homepage. Also consider adding a feature to download only the data used to display the graph. This would provide the ability for people to create a graph of a different type or to change the display options on the currently displayed graph. The full dataset for the site should still be available; however, the button to download it should be placed away from the graph to avoid association with the data shown on the user's current graph.



Download Graph

Download Full Dataset

	Initial	Continuing	Last
2010	\$40,464	\$46,643	\$37,459
2020	\$48,317	\$61,373	\$48,077
Increase	19.4%	31.6%	28.3%

Costs (\$) per year in millions.

Figure 54: Download Full Dataset Button.

**Graph Title Bug:** A bug on the site related to the title of the graph was fixed from the previous round of testing. However, the prevalence graph (Figure 55) still lists the data as being in “2010 dollars.”

#### Graph by Cancer Site & Phase of Care<sup>1</sup>

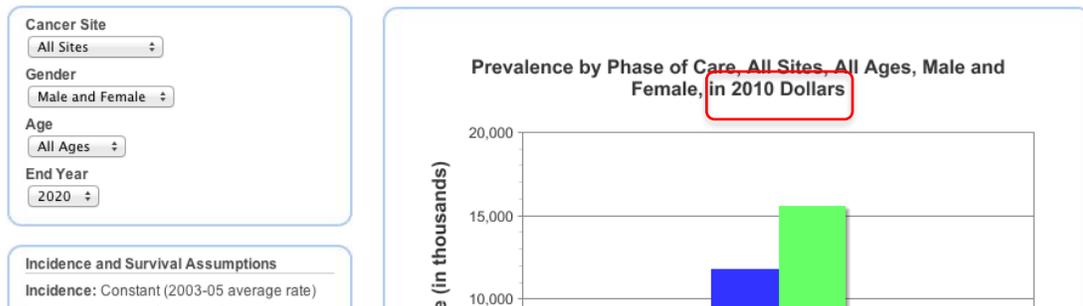


Figure 55: Prevalence Graph with Incorrect Title.

**Graph Button Label:** For the second round, the button at the bottom of the graph selections (see Figure 56) was labeled “Redraw Graph.” Participants did not exhibit any difficulty in generating a new graph after changing their selections, as was the case in the first round.

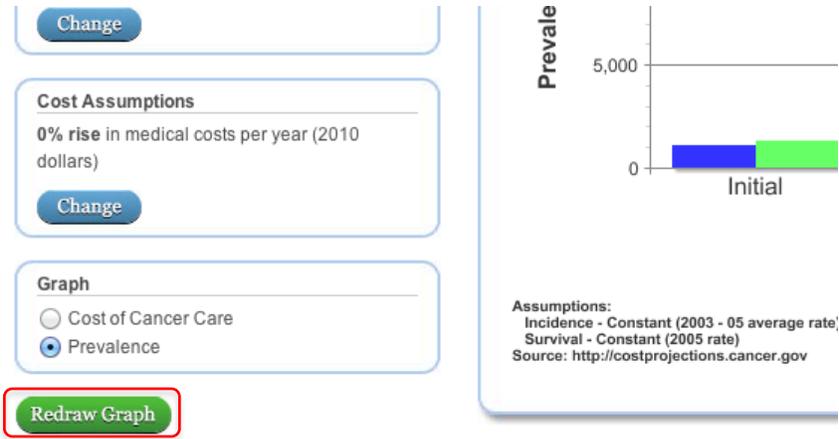


Figure 56: "Redraw Graph" Button.

**Comparing Graphs:** Several of the participants made changes to the graph and then wanted to do comparisons. This is not easily supported without downloading the data. One participant in the second round thought she would have to do comparisons by putting the data into Excel and re-creating graphs herself. She didn't suggest opening two browser windows of the site to show two different graphs, even though she was on a machine with two screens.

Consider relabeling the download graph button to indicate the reason for downloading a graph (e.g. to allow a comparison), as opposed to describing the action (i.e. download).

**Graph Source:** A source was added to the graph image to refer back to the site (see Figure 57). One researcher participant mentioned they might want to refer the actual source of data. Consider adding information about the source of the data beyond this website.

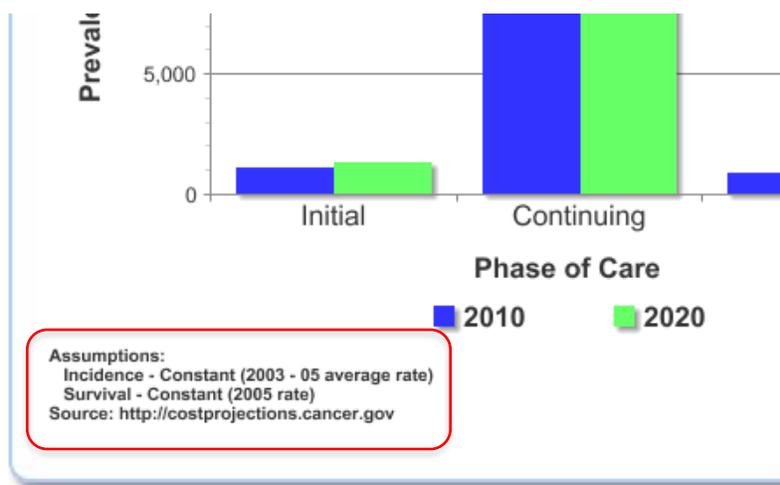


Figure 57: Source Information at the Bottom of the Graph.

## Data Tables

**Text Associated with Table Data:** Round 1 participants reported that the original format of the introductory table text was hard to read and seemed jargon-heavy. The bulleted format (shown in Figure 58) was well received by participants in round 2.

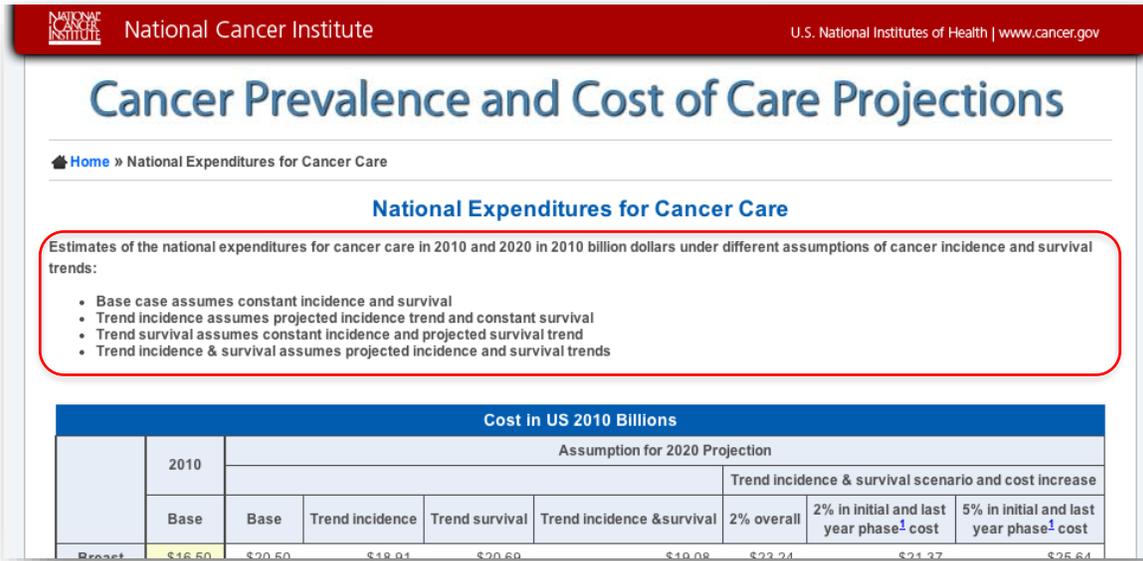


Figure 58: Text Above the National Expenditures for Cancer Care Table.

**2020 Data Scenarios:** All participants said that the empty cell in the table’s header (see Figure 59) “threw them off.” Consider merging the empty cell with the cells with the 2020 scenarios below.

## National Expenditures for Cancer Care

Estimates of the national expenditures for cancer care in 2010 and 2020 in 2010 billion dollars under different assumptions of cancer incidence and survival trends:

- Base case assumes constant incidence and survival
- Trend incidence assumes projected incidence trend and constant survival
- Trend survival assumes constant incidence and projected survival trend
- Trend incidence & survival assumes projected incidence and survival trends

Cost in US 2010 Billions									
	2010	Assumption for 2020 Projection							
						Trend incidence & survival scenario and cost increase			
	Base	Base	Trend incidence	Trend survival	Trend incidence & survival	2% overall	2% in initial and last year phase <sup>1</sup> cost	5% in initial and last year phase <sup>1</sup> cost	
Breast	\$16.50	\$20.50	\$18.91	\$20.69	\$19.08	\$23.24	\$21.37	\$25.64	
Colorectal	\$14.14	\$17.41	\$14.35	\$17.83	\$14.70	\$17.67	\$16.68	\$20.39	
Lung	\$12.12	\$14.73	\$12.14	\$15.23	\$12.53	\$15.19	\$14.73	\$18.84	
Lymphoma	\$12.14	\$15.26	\$15.00	\$15.71	\$15.44	\$18.66	\$17.27	\$20.69	
Prostate	\$11.85	\$16.34	\$15.32	\$16.43	\$15.41	\$18.53	\$16.67	\$19.02	
Leukemia	\$5.44	\$6.95	\$6.66	\$7.24	\$6.94	\$8.38	\$7.78	\$9.35	
Ovary	\$5.12	\$6.03	\$4.49	\$6.27	\$4.64	\$5.64	\$5.26	\$6.42	

Figure 59: Empty Cell in the National Expenditures for Cancer Care Table Header.

**Trend Incidence and Survival Scenario and Cost Increase:** One participant was able to figure out that the last three columns of the table shown in Figure 60 was showing data based on the previous column (“Trend incidence & survival”). However, the relationship was not clear at first glance. Consider one of the layouts in Figure 61.

## National Expenditures for Cancer Care

Estimates of the national expenditures for cancer care in 2010 and 2020 in 2010 billion dollars under different assumptions of cancer incidence and survival trends:

- Base case assumes constant incidence and survival
- Trend incidence assumes projected incidence trend and constant survival
- Trend survival assumes constant incidence and projected survival trend
- Trend incidence & survival assumes projected incidence and survival trends

Cost in US 2010 Billions									
	2010	Assumption for 2020 Projection							
						Trend incidence & survival scenario and cost increase			
	Base	Base	Trend incidence	Trend survival	Trend incidence & survival	2% overall	2% in initial and last year phase <sup>1</sup> cost	5% in initial and last year phase <sup>1</sup> cost	
Breast	\$16.50	\$20.50	\$18.91	\$20.69	\$19.08	\$23.24	\$21.37	\$25.64	
Colorectal	\$14.14	\$17.41	\$14.35	\$17.83	\$14.70	\$17.67	\$16.68	\$20.39	
Lung	\$12.12	\$14.73	\$12.14	\$15.23	\$12.53	\$15.19	\$14.73	\$18.84	
Lymphoma	\$12.14	\$15.26	\$15.00	\$15.71	\$15.44	\$18.66	\$17.27	\$20.69	
Prostate	\$11.85	\$16.34	\$15.32	\$16.43	\$15.41	\$18.53	\$16.67	\$19.02	
Leukemia	\$5.44	\$6.95	\$6.66	\$7.24	\$6.94	\$8.38	\$7.78	\$9.35	
Ovary	\$5.12	\$6.03	\$4.49	\$6.27	\$4.64	\$5.64	\$5.26	\$6.42	

Figure 60: Unclear Relationship of Columns in the National Expenditures for Cancer Care Table.

Base	Trend Incidence	Trend Survival	Trend Incidence & Survival	Trend Incidence & Survival		
0% overall cost increase	2% overall cost increase	2% in Initial and Last Year phase cost increase	5% in Initial and Last Year phase cost increase			
Base	Trend Incidence	Trend Survival	Trend Incidence & Survival	Trend Incidence & Survival		
				2% overall cost increase	2% in Initial and Last Year phase cost increase	5% in Initial and Last Year phase cost increase

Figure 61: Possible Layouts for The National Expenditures for Cancer Care Table Header.

**Cost of Care Table Data:** One participant was not sure what years the “annualized” data contained when looking at the Average Annual Costs of Care graph seen in Figure 62. They were specifically unsure about the years of data that comprised the mean costs. Consider a footnote to explain the annualized data.

[Home](#) » Average Annual Costs of Care

### Average Annual Costs of Care

Annualized Mean Net Costs of Care by Age, Gender and Phase of Care (Per Patient). Costs in 2010 US Dollars.

Annual Costs of Cancer Care in US 2010 Dollars					
		Age 65+			
				Last Year of Life <sup>1</sup>	
Sex	Site	Initial <sup>1</sup>	Continuing <sup>1</sup>	Cancer Death	Other Cause
Female	Bladder	21,412	3,710	78,698	10,005
	Brain	108,168	8,803	140,891	39,893
	Breast	23,078	2,207	62,856	748
	Cervix	45,174	1,425	78,553	7,949
	Colorectal	51,327	3,159	84,519	14,641
	Esophagus	79,532	6,853	104,278	41,051
	Head/Neck	41,980	4,826	86,602	10,064
	Kidney	38,397	6,255	73,843	24,607
	Leukemia	33,167	8,537	130,131	31,517
	Lung	60,533	8,130	92,524	18,897
	Lymphoma	57,881	8,622	109,842	20,462
	Melanoma	5,047	915	56,784	252
	Other	40,173	5,859	95,782	21,721
	Ovary	82,324	8,296	99,715	12,257
Pancreas	93,462	8,672	109,941	40,538	
Stomach	71,076	3,977	103,758	29,172	
Uterus	26,775	1,535	70,175	4,437	
Male	Bladder	20,960	4,877	75,772	8,446
	Brain	115,250	9,434	134,244	67,914
	Colorectal	51,812	4,595	85,671	15,068
	Esophagus	79,822	6,450	103,742	51,035
	Head/Neck	39,179	4,001	83,662	9,269
	Kidney	38,374	6,018	78,082	19,142
	Leukemia	36,036	10,249	133,183	35,941
	Lung	60,885	7,591	95,318	25,008
	Lymphoma	60,701	9,337	116,596	27,200
	Melanoma	5,437	1,951	62,436	546
	Other	41,161	7,363	97,473	25,758
	Pancreas	94,092	11,697	113,115	47,565
Prostate	19,710	3,201	62,242	5,370	
Stomach	78,453	4,282	107,130	25,800	

Note: All estimates adjusted for patient deductibles and coinsurance expenses

1. Phases of care: *Initial* year after diagnosis, *Last year of life*, and the period between (*Continuing*). Months of survival are first applied to last year of life, any remaining to initial phase, then to continuing.

Figure 62: Average Annual Costs of Care Graph.

**Inconsistency with Cost of Care Table:** A small inconsistency exists on the page for this table (see Figure 63) The title of the page reads “Annualized Mean Net Costs of Care” but the link on the homepage reads “Average Annual Costs of Care.”

The screenshot shows the National Cancer Institute website with the following elements:

- Header: National Cancer Institute | U.S. National Institutes of Health | www.cancer.gov
- Page Title: Cancer Prevalence and Cost of Care Projections
- Breadcrumb: Home > Average Annual Costs of Care (circled in red)
- Section Title: Annualized Mean Net Costs of Care (circled in red)
- Subtitle: Annualized Mean Net Costs of Care by Age, Gender and Phase of Care (Per Patient). Costs in 2010 US Dollars.
- Table: A table with columns for Sex, Site, and Initial... (partially visible)
- Table Data:
 

Sex	Site	Initial
	Bladder	21,411
	Brain	108,161
	Breast	23,071
	Cervix	45,171
- Section: Projection Tables for 2020
  - Link: National Expenditures for Cancer Care
  - Link: Cancer Prevalence
- Section: Base Data
  - Link: Average Annual Costs of Care (circled in red)

Figure 63: Two Different Titles for the Average Annual Costs of Care Page.

**Added Footnotes:** Several terms seemed unfamiliar to participants in the first round of evaluations. The added footnotes explaining terms throughout the site were helpful to participants in round 2 (see Figure 63).

Other	41,161	7,363	97,473	25,758
Pancreas	94,092	11,697	113,115	47,565
Prostate	19,710	3,201	62,242	5,370
Stomach	78,453	4,282	107,130	25,800

Note: All estimates adjusted for patient deductibles and coinsurance expenses

1. Phases of care: *Initial year after diagnosis, Last year of life, and the period between (Continuing)*. Months of survival are first applied to last year of life, any remaining to initial phase, then to continuing.
2. Cancer death: death from any cancer
3. Non-cancer death: death from causes other than cancer

This site is based on a study that estimates and projects the national cost of cancer care through the year 2020 separately for multiple cancer sites using the most recent available U.S. population projections, cancer incidence, survival, and cost of care data. More information about the methods, data sources and assumptions in: Mariotto AB, Yabroff KR, Shao Y, Feuer EJ, Brown ML. *Projections of the Cost of Cancer Care in the U.S.: 2010-2020*. *J Natl Cancer Inst*. 2011 Jan.

Different scenarios for assumptions about trends in incidence, survival, and cost were assessed with sensitivity analysis<sup>1</sup>. Projections of current trends in incidence (declining) and survival (increasing) have almost no effect on these estimates. However, if costs of care increase annually by 2% in the initial and last year of life phases of care<sup>2</sup>, the total cost in 2020 is projected to be \$174 billion.

1. Sensitivity analysis: An evaluation of the impact of different assumptions about model inputs (e.g., future cancer incidence rates) that are uncertain.
2. Phases of care: *Initial year after diagnosis, Last year of life, and the period between (Continuing)*. Months of survival are first applied to last year of life, any remaining to initial phase, then to continuing.

This site is based on a study that estimates and projects the national cost of cancer care through the year 2020 separately for multiple cancer sites using the most recent available U.S. population projections, cancer incidence, survival, and cost of care data. More information about the methods, data sources and assumptions in: Mariotto AB, Yabroff KR, Shao Y, Feuer EJ, Brown ML. *Projections of the Cost of Cancer Care in the U.S.: 2010-2020*. *J Natl Cancer Inst*. 2011 Jan.

Uterus	586,000	672,000	15%	638,000	9%	667,000	14%	634,000	8%
All Sites	13,772,000	18,071,000	31%	17,465,000	27%	18,878,000	37%	18,229,000	32%

1. Cancer survivor: any person diagnosed with cancer, from the time of initial diagnosis until his or her death.

This site is based on a study that estimates and projects the national cost of cancer care through the year 2020 separately for multiple cancer sites using the most recent available U.S. population projections, cancer incidence, survival, and cost of care data. More information about the methods, data sources and assumptions in: Mariotto AB, Yabroff KR, Shao Y, Feuer EJ, Brown ML. *Projections of the Cost of Cancer Care in the U.S.: 2010-2020*. *J Natl Cancer Inst*. 2011 Jan.

Figure 64: Definition of Terms on Several Pages on the Site.

## Conclusion

Analysis of both rounds of evaluations for the website provided valuable insight on how users and potential users find and interpret cancer prevalence and cost of care information. The following main points summarize the insight from the usability evaluations:

- Terms which are not standard (especially phases of care) should be defined on every page they appear, in order for people external to NCI to understand the data.
- Information about the data used in tables or graphs on the site should be available by citing the actual source, rather than the paper for which all data was collected.
- Clear formatting of table headers and columns will make interpreting, comparing, and extracting data easier for users of the site.
- Deciding how to update or maintain the site in the future once more data is available will determine the function of the website to either be a site for the latest information on cancer prevalence and cost of care for cancer, or for viewing and manipulating data only from the paper is based on.

## Appendix A: Facilitator's Guide for Usability Evaluations

OMB No.: 0925-0642-20 Expiration Date: 09/30/14

Collection of this information is authorized by The Public Health Service Act, Section 411 (42 USC 285a). Rights of study participants are protected by The Privacy Act of 1974. Participation is voluntary, and there are no penalties for not participating or withdrawing from the study at any time. Refusal to participate will not affect your benefits in any way. The information collected in this study will be kept private under the Privacy Act. Names and other identifiers will not appear in any report of the study. Information provided will be combined for all study participants and reported as summaries. You are being contacted by email so that we can find volunteers to help improve the website.

Public reporting burden for this collection of information is estimated to average 60 minutes (for the usability session) per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. **An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number.** Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to: NIH, Project Clearance Branch, 6705 Rockledge Drive, MSC 7974, Bethesda, MD 20892-7974, ATTN: PRA (0925-0642). Do not return the completed form to this address.

[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.]

### Pre-Test

[Administer the informed consent]

### Introduction

Thank you for agreeing to participate in this study.

The NCI is aiming to improve their Cancer Prevalence and Cost of Care Projections website, so today we are conducting a usability evaluation of the design. As a participant, you will explore the website and be given a set of tasks to do.

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 website:

First, we are evaluating the website and not you, so you cannot make any mistakes. The site is supposed to be intuitive and easy to use. If it isn't, that's a problem with the website – not with you.

Second, I did not create the design so you can't hurt my feelings with any criticisms 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.

I'd 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**

Before we actually get started with the website, I'd like to know a little bit about your background.

Where do you work and what sort of work do you do?

In your work do you look for cancer prevalence data? Cost of care projections for cancer? Where do you look for them? Tell me how that fits into your work.

### **Site Usage**

[Open the website <http://costprojections.cancer.gov> so users can see it so they will better remember what they've done. Tell them not to use it yet.] Have you ever used the Cancer Prevalence and Cost of Care Projections website? [If yes:] When was the last time you used the site? On average, how frequently do you use the site? [If no, skip to tasks.]

How long have you been using the website?

How did you initially find the website?

Did anything confuse you when you first started using this website?

Most websites have a learning curve associated with them. How hard or easy was it for you to learn this website? Do you think that others with your background will have about the same experience on the website?

[Probe: Have you used the site enough that you've changed your purpose in using the site?]

[Probe: What have your experiences taught you about using the website?]

Let's see if you can tell me some specifics about how you usually use the website.

When you look at projected cancer information, do you usually look at specific cancers or just "cancer," per se?

When you look at projected cancer information, do you look at the phase of cancer care (i.e., initial, continuing, and last) or do you look at overall care?

Tell me about the data that you obtain from the website. How do you use the data?

## Tasks

Now I'm going to ask you to do some specific tasks. Feel free to ask any questions that come to mind as you work, but I might not answer right away because I'd like to see if the design lets you find the answer on your own.

Explain to me the content on the homepage. [Probe on whether they use the information on the homepage directly.] Show me what you [would] usually do on the homepage. [Do you usually access more than one of the sections? If not described previously, ask "Do you have a routine in the way you use various links on the website?"]

[Previous users only:] What areas on the site have given you problems in the past? [Are there places where you get "stuck"?] Tell me about them. If you remember something later as we explore the site, feel free to mention it then.

Where would you look for **costs of cancer**?

Find and compare information on the national projected expenditures in 2020 that lists breast and prostate cancers. [Note if P goes to the **National Expenditures for Cancer Care** table.]

How would you use the information in this table? [Probe on terms such as base values, cost values, trend incidence, etc. Note P's understanding of how the site defines the terms.]

(Do they understand all parts of the table? Base 2010/2020, trend columns, 2% increase section, etc.) Tell me a bit about the parts of this table.

How do you normally obtain this information? [Probe on printing it, copy and paste, write it down on paper] How do you use the information in your work? [Probe on using it for a report, just referencing it, etc.].

[Probe on downloading data.]

"Are there any other areas you use on the site?" Where would you look for cancer prevalence data? [Note if the P goes to the **Cancer Prevalence** table.]

Take a look at the data for colorectal cancer. There are four different columns of prevalence data. Which one(s) would you use in your work? [Probe on whether P realizes the labels (e.g., base and trend) have the same definitions as they do in the National Expenditures for Cancer Care table.] (Is this the same as before?)

How do you normally obtain this information? [Probe on printing it, copy and paste, write it down on paper] How do you use the information in your work? [Probe on using it for a report, just referencing it, etc.].

[Probe on downloading data.]

Where would you look for annual costs of care data for cancer? [Note if P goes to the Average Annual Costs of Care table.]

What do you think the site means by “costs of care?” How does your definition of “costs of care” compare to the site definition?

How do you think the site divides initial, continuing, and final years costs? How is that division helpful to you?

Using the data, can you tell which cancer has the greatest average annual cost of care for the last year of life? [Probe on if the P understands the difference in data between death from cancer and other causes of death.]

The data on this chart is adjusted for patient deductibles and coinsurance expenses. What does this mean to you?

[Probe on downloading data.]

Start with a prevalence graph for brain cancer for males over 65 that compares data from 2010 and 2015. If you're comparing costs in the future, you might want to account for changes in cost. How might you do this? Then have them do a graph with a different cost assumption. There is one more feature you can change about the graph. Check it out and see if it makes sense to you.

[Probe that the P understands each selection and how it influences the output.]

Let's see the graph. [Once the graph has been rendered] I'd like you to tell me the meaning of the graph you've created.

Is there anything you would change about how the graph looks? [Probe on formatting (e.g., preference for bar graph), labels, etc.]

Probe on assumptions and type of graph. (Word apply suggests that it changes the chart – but it only adds it to the parameters of the graph; they need to redraw the graph to see the changes)

What is the table? What are the buttons? What data do you expect to get from the download?

### **Post Test Interview Questions**

Great, now I'd like to ask you a few questions.

This site displays data in graphs and tables. How would you use these? [Probe on whether they would put it into a report or briefing, or just use the data itself.]

Did you notice that you could download some of the raw data? [Probe to see if the P realized the site provides this capability for some material.]

Most websites have a learning curve associated with them. You [have used| haven't used] the present website very much, right? How hard or easy was it for you to learn this website? Do you think that others with your background will have about the same experience on the website?

Would you reflect on the things you liked and didn't like about the website? What three things did you like the most? What three things did you like the least?

[If not answered earlier:] The purpose of this site is to provide information to people in a quick and easy format. Is this sufficient for you, or do you need additional information? (Mention that researchers might need to download a dataset to do their own manipulation) [Probe on links such as the SEER data, etc.] (See if they can find out where the data comes from) [How complete is this site?]

### **Wrap up**

OK, we're done. Are there any questions you would like to ask me about the website or about today's experience that I did not ask you about?

Thanks again for your participation.

## Appendix B: E-mail for Participant Request

OMB No.: 0925-0642-20 Expiration Date: 09/30/14

Collection of this information is authorized by The Public Health Service Act, Section 411 (42 USC 285a). Rights of study participants are protected by The Privacy Act of 1974. Participation is voluntary, and there are no penalties for not participating or withdrawing from the study at any time. Refusal to participate will not affect your benefits in any way. The information collected in this study will be kept private under the Privacy Act. Names and other identifiers will not appear in any report of the study. Information provided will be combined for all study participants and reported as summaries. You are being contacted by email so that we can find volunteers to help improve the website.

Public reporting burden for this collection of information is estimated to average 5 minutes (for the email) per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. **An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number.** Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to: NIH, Project Clearance Branch, 6705 Rockledge Drive, MSC 7974, Bethesda, MD 20892-7974, ATTN: PRA (0925-0642). Do not return the completed form to this address.

Dear \_\_\_\_\_,

We are looking for individuals who are researchers who use or might use the National Cancer Institute's Cancer Prevalence and Cost of Care Projections website. Are you one of these individuals?

We plan to evaluate this website to determine if it is meeting the needs of its users. Would you volunteer to donate about an hour of your time to help us improve the website for your use?

We will have two ways that you can work with us. If you can come to our lab in Rockville, MD, on Tuesday, March 5th or Wednesday, March 6th, we can work with you in-person. Otherwise would you select a date and time for a "remote" meeting?

If you can help, please reply to this email and tell us your phone number. Tell us if you can come to the lab or what times would be convenient for you during the following time periods:

Phone Number \_\_\_\_\_

Come to the lab in Rockville on 3/5? \_\_\_\_\_

Come to the lab in Rockville on 3/6? \_\_\_\_\_

Selection of Remote Times (in Eastern Time):

Monday, March 4th between 10am and 5pm \_\_\_\_\_

Tuesday, March 5th (times TBA) \_\_\_\_\_

Wednesday, March 6th (times TBA) \_\_\_\_\_

Thursday, March 7th between 9am and 5pm \_\_\_\_\_

Friday, March 8th between 9am and 5pm \_\_\_\_\_

Thank you,

Danielle Smith  
User-Centered Design Inc.

## Appendix C: Follow-Up Recruitment Screener

OMB No.: 0925-0642-20 Expiration Date: 09/30/14

Collection of this information is authorized by The Public Health Service Act, Section 411 (42 USC 285a). Rights of study participants are protected by The Privacy Act of 1974. Participation is voluntary, and there are no penalties for not participating or withdrawing from the study at any time. Refusal to participate will not affect your benefits in any way. The information collected in this study will be kept private under the Privacy Act. Names and other identifiers will not appear in any report of the study. Information provided will be combined for all study participants and reported as summaries. You are being contacted by phone to complete this instrument so that we can find volunteers to help improve the website.

Public reporting burden for this collection of information is estimated to average 5 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. **An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number.** Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to: NIH, Project Clearance Branch, 6705 Rockledge Drive, MSC 7974, Bethesda, MD 20892-7974, ATTN: PRA (0925-0642). Do not return the completed form to this address.

Hello, thank you for responding to our earlier email. We would like to know just a bit about your experience with the Cancer Prevalence and Cost of Care Projections website. [These questions are to be asked to find some individuals who have used the website for a long time—hopefully since it was launched in January 2011—and others who are new to the site.]

How long have you been using the website?

- Never used
- Just a few days
- About a week
- Several weeks
- A month
- Several months
- For a year or more
- For about two years

When was the last time you used the website (if applicable)? \_\_\_\_\_

The following questions are to set up a specific type of usability test and the date and time for it.

3. In the email that you returned to us, you said that you could come to the lab on [date]. Let's set up a time for that. We will send you directions to the lab via email.

We look forward to seeing you at the lab at that time.

OR

3. In the email that you returned to us you indicated that [date and times] would be convenient for you to be available to test the website. Can we set up a specific time now?

Later you will receive a GoToMeeting invitation from us giving you contact information so we can conduct a remote usability test.

We look forward to meeting you remotely at that time.

## **Appendix D: Verbal Informed Consent**

As part of this research, I need to ask you to formally agree to this usability evaluation.

As part of a research project for the National Cancer Institute's Cancer Prevalence and Cost of Care Projections Website, we are seeking to evaluate the appropriateness and usability of the website. Individuals who we think would have an appropriate background are being asked to participate in a usability evaluation and to reflect on the 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 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. You are also free to stop at any time without penalty and without any questions being asked of you. Do you have any questions about the process of the usability evaluation?

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. Is this correct?

## Appendix E: Written Consent Form

OMB No.: 0925-0642-20 Expiration Date: 09/30/14

Collection of this information is authorized by The Public Health Service Act, Section 411 (42 USC 285a). Rights of study participants are protected by The Privacy Act of 1974. Participation is voluntary, and there are no penalties for not participating or withdrawing from the study at any time. Refusal to participate will not affect your benefits in any way. The information collected in this study will be kept private under the Privacy Act. Names and other identifiers will not appear in any report of the study. Information provided will be combined for all study participants and reported as summaries. You are being asked to complete this instrument so that we can help improve the website.

Public reporting burden for this collection of information is estimated to average 60 minutes (for this form and the following usability test) per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. **An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number.** Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to: NIH, Project Clearance Branch, 6705 Rockledge Drive, MSC 7974, Bethesda, MD 20892-7974, ATTN: PRA (0925-0642). Do not return the completed form to this address.

### Identification of Project

### Cancer Prevalence and Cost of Care Projections Website

### 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 Robin Yabroff and Susan Scott of the DCCPS of the National Cancer Institute, Rockville, MD 20852.

### Purpose

The purpose of this research is to test usability of the Cancer Prevalence and Cost of Care Projections website.

### Procedures

Participants will be asked to work with the interface, perform certain tasks, and answer questions about the experience. The total time involved, including instructions will be no more than 60 minutes.

### Confidentiality

All information collected in this study will be kept private 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 improve the usability of the Cancer Prevalence and Cost of Care Projections website in order to make the experience of future participants using this website easier. I am free to ask questions or withdraw from participation at any time and without penalty.

**Contact Information of Investigators**

Name: Robin Yabroff and Susan Scott

Position: Office of the Associate Director of DCCPS

Telephone: 301-594-1723 and 301-496-5410

Email: yabroffr@mail.nih.gov and scotts2@mail.nih.gov

Printed Name of Research Participant \_\_\_\_\_

Signature of Research Participant \_\_\_\_\_

Date \_\_\_\_\_