New NCI Risk Web Site Aims at Consumers

Brian, a 49-year-old Chinese American, just learned that his co-worker has colon cancer, and now he’s concerned for himself. Brian doesn’t smoke, but he doesn’t exercise or eat right either. Now he’s wondering what can keep him from getting the disease.

Brian's is just one of the voices you hear on the new National Cancer Institute risk Web site, http://understandingrisk.cancer.gov. Using personal profiles, as well as other risk education materials, the site aims to help visitors make informed decisions about how to lower their cancer risk.

“Risk is extremely difficult to explain properly,” said Margo Michaels, executive director of the Education Network to Advance Cancer Clinical Trials and developer of the original proposal for the site. The site includes stories, personal risk ratings, tips for talking to your doctor, and issues in the news. “These approaches help to illustrate concepts in a user-friendly way, addressing the needs of different kinds of learners.”

Four-Part Site Design

The site’s design was guided by research showing that many people have an unrealistic view of their cancer risk and that most people have difficulty understanding numbers such as relative risk or absolute risk. One survey, for example, showed that women aged 40–50 years overestimated their chance of dying from breast cancer within 10 years by 2,000%. And smokers consistently underestimate their risk of developing lung cancer compared with that of nonsmokers.

“A lot of material we give people assumes that they understand what the numbers, such as relative and absolute risk, mean and what a risk factor is. What is different about this site is that it tries not to assume anything and starts off with the basics,” said Isaac Lipkus, Ph.D., who specializes in risk communication at Duke Comprehensive Cancer Center in Durham, N.C., and worked on the NCI site.

The site targets cancer-free adults aged 40 and older who will seek out information—those at increased risk of cancer, family members or friends of cancer patients, or people intrigued by a media story, explained Felicia Solomon, who spearheaded the effort to create the site. It is divided into four major sections:

1. What is Risk? contains basic information about risk and risk factors.
2. Can I Lower My Risk? focuses on the known risk factors for six cancers—breast, cervical, colon, lung, prostate, and skin—and guides consumers through an evaluation of their personal risk factors for each cancer and a strategy for reducing risk. Armed with this information, the site suggests a list of questions to include in the next doctor’s visit.
3. Is This News Story True? provides criteria to evaluate news stories that link risk factors to particular cancers.
4. Risk Assessment Tools will provide information about tools that estimate cancer risk (this section has not yet been released).

Throughout the new site are links to data from NCI’s primary Web site (http://www.cancer.gov), including clinical trials, treatment options, statistics, genetics, publications, and news reports.

Other Web Tools for Relative Risk

Other cancer sites, such as NCI’s and the American Cancer Society’s sites (see box), include information on risk and risk factors for various cancers, but it typically is buried among sections on statistics, clinical trials, treatment options, prevention strategies, and genetics. Sites that focus exclusively on risk usually provide an estimate of the user’s personal risk by directing him or her to answer questions about risk factors. For example, both the Breast Cancer Risk Assessment Tool (see box) and the Melanoma Risk Assessment Tool calculate absolute risk to give the probability of developing the disease in the next 5 years. Harvard’s School of Public Health site calculates the overall relative risk by comparing the visitor’s risk to that of a typical man or woman the same age. The risk is then displayed visually as a line on a bar graph, marked low, medium, and high.

The new NCI site is a hybrid. It resembles the assessment tools in its interactivity and focus on risk. In breast cancer, for example, it poses specific questions like If you have had breast cancer in one breast, you have an increased risk of getting it in the other breast. Does this risk factor apply to you? The visitor answers yes or no.
“It is trying to provide general background information so that the visitors to the site can use that information and apply it to themselves,” Lipkus said. Once they have a list of personal risk factors, users are asked what factors they want to change to lower their risk.

This interactivity is especially important in the section Can I Lower My Risk? said Michael Diefenbach, Ph.D., a psychologist and health behavior researcher at Mount Sinai School of Medicine in New York, who worked on the site. “Based on your personal risk factors, you build your own list of things to do to lower your risk, which you can then discuss with your doctor. This gives people an action plan.”

Unlike other sites, the NCI risk site does not calculate absolute or relative risk of a given cancer for an individual user, and its main thrust is to create an action plan to lower risk. Those differences are either good or bad depending on whom you talk to.

Diefenbach said the public isn’t very well served by providing either more reading material or a number describing risk. To be more educational, the site must involve the user. That’s why the group came up with profiles and the interactive format. Diefenbach explained that a numerical approach doesn’t encourage someone to take the next step to try to reduce his or her risk. However, the NCI site is linked to some of the traditional assessment tools if users want to know their risk of developing a particular cancer.

Dartmouth professor Steven Woloshin, M.D. who consulted early in the site’s creation, thought that another crucial element was missing from the news section. People need to ask whether the data in a news report come from an observational study or randomized trial—something the site does not address. “So much of what we see about diet and cancer in the media is from observational studies. Besides diet, people in the study may adopt a variety of behaviors, any of which could be linked to the reported change in risk. So, often we can’t be sure that changing a dietary factor will lower risk,” Schwartz said.

Cristine Russell, a former science writer at the Washington Post and current president of the Council for the Advancement of Science Writing, is impressed by several aspects of the site. “There’s a lot of very helpful information broken down into chewable bites. I liked the interactive aspect of it—the quizzes, the help with drawing up questions to assess your own risk and to talk to your doctors.” As a science writer she appreciated the section on how to be a critical news consumer. And she liked that the site made it clear that risk—in this case, breast cancer risk—increases with age. “There are too many ads

**Cancer Risk Web Sites Provide Information For Physicians, Patients**

The National Cancer Institute has created a new Web site designed to help the public understand their cancer risk, [http://understandingrisk.cancer.gov](http://understandingrisk.cancer.gov). There are many other Web sites that talk about cancer risk.

**Other General Risk Sites:**

- Harvard’s School of Public Health site is designed to help consumers find out their risk of developing cancer, heart disease, diabetes, and osteoporosis. It also gives personalized tips for preventing the diseases, [http://www.yourdiseaserisk.harvard.edu](http://www.yourdiseaserisk.harvard.edu)
- Central Pennsylvania Medical Oncology Group has created a cancer risk assessment questionnaire to identify cancer risk factors and warning signs and create an action plan to prevent cancer or catch it at an early stage, [http://www.hmc.psu.edu/cpog/risk/index.htm](http://www.hmc.psu.edu/cpog/risk/index.htm)
- Fox Chase Cancer Center has created a questionnaire to help the public determine whether they are at risk for breast, ovarian, prostate, skin, liver, or gastrointestinal cancer, [http://www.fccc.edu/cancer/risk-quiz.html](http://www.fccc.edu/cancer/risk-quiz.html)
- Cancer risk: What the numbers mean is part of a Web site created by the Mayo Clinic to help consumers understand absolute and relative risk, [http://www.mayoclinic.com/health/cancer/CA00053](http://www.mayoclinic.com/health/cancer/CA00053)

**Disease-specific sites:**

- The Breast Cancer Risk Assessment Tool is designed by scientists at the NCI and the National Surgical Adjuvant Breast and Bowel Project to help health professionals estimate a woman’s risk of developing invasive breast cancer, [http://www.cancer.gov/bcrisktool](http://www.cancer.gov/bcrisktool)
- The Melanoma Risk Assessment Tool is designed by scientists at the NCI, the University of Pennsylvania, and the University of California—San Francisco to help health professionals estimate a person’s risk of developing invasive melanoma, [http://www.cancer.gov/melanomarisktool](http://www.cancer.gov/melanomarisktool)
- The Lung Cancer Risk Assessment Tool was designed by Memorial Sloan-Kettering Cancer Center researchers to determine a long-term smoker’s risk of developing lung cancer in the next 10 years, [http://www.mskcc.org/mskcc/html/12463.cfm](http://www.mskcc.org/mskcc/html/12463.cfm)
- The Prostate Cancer Research Foundation of Canada developed a prostate cancer risk assessment questionnaire to evaluate whether the user’s risk is low, medium, or high, [http://www.prostatecancer.ca/english/prostate_owners_manual/risk_factors/risk/](http://www.prostatecancer.ca/english/prostate_owners_manual/risk_factors/risk/)
NEWS

featuring young women getting breast cancer, which make people think it’s more prevalent than it is,” she said.

One aspect she thought needed improvement was putting cancer risk in perspective with other risks. “How do deaths from cancer rank with heart disease or stroke? I don’t think people should be viewing cancer in isolation.” In a similar vein, she would include a discussion of the impact of good behaviors—eat better, exercise more, stop smoking—on both cancer and other chronic diseases. “This will allow the user to view cancer in a broader context,” she said. Russell and others thought the section on What is Risk? could benefit from more information and more graphics.

At some point in 2007, the working group for the Web site plans to find out what the consumer thinks. “We are thinking about how to evaluate the site and maintain it, so that it can become an even more credible resource to understand cancer risk,” Solomon said.

In the meantime, Michaels is delighted to see the Web site come to life. “I hope we can see a link to this site in every popular magazine that discusses cancer risk.”

—Nancy J. Nelson

© Oxford University Press 2006. DOI: 10.1093/jnci/djj483