

Survey to Assess Public Understanding of Risk Estimates through Visual Displays:
A Web-Based Survey to Communicate Cancer Risk Estimates

National Cancer Institute

PILOT SURVEY OF REACTIONS TO RISK COMMUNICATION MESSAGES

[Invitational/Introductory language]

You are invited to participate in a brief survey. The purpose of the survey is to learn how people understand different kinds of health information. If you qualify, the survey will take approximately 10 minutes to complete. To participate, simply click the link below or copy the URL into your browser: <http://www.addsurveylinkhere>.

[Once participant has clicked on URL and qualifies for survey]

Thank you for your interest in participating in this survey about health information. Your participation in this survey is completely voluntary. Please be assured that your responses will be kept confidential and will not be disclosed to anyone outside NCI or its contractor, Academy for Educational Development (AED), except as otherwise required by law. Data will be provided to the NCI in aggregate form only, with any potentially identifying information removed. You may skip any questions that you prefer not to answer.

Public reporting burden for this collection of information is estimated to average 10 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 (0925-0046-14). Do not return the completed form to this address.

Section I: Demographic information

This survey will be asking you about your beliefs and opinions on colon cancer. We have a few questions we need to ask you to find out if you are eligible to participate. Your responses to these question or any that follow will not be identified, disclosed, or released to anyone, or used for any purposes other than this research project.

1. First, have you ever been diagnosed with colon cancer?
 Yes [terminate]
 No

2. What is your age? _____ [terminate if under 40]

3. What is your sex?
 Female
 Male

4. What is the highest level of education you completed?
 - a. less than high school
 - b. high school graduate
 - c. trade or technical school
 - d. some college
 - e. college graduate
 - f. post-graduate degree

5. Are you Hispanic or Latino?
 Yes
 No

6. Which one or more of the following describes your race?
 American Indian or Alaska Native
 Asian
 Black or African American
 Native Hawaiian or other Pacific Islander
 White

7. Please select the U.S. state or territory where you live.
[Provide a drop down of the 50 U.S. states, DC, and U.S. territories.]

Section II: Informational message

Now we would like you to read through the following information about a new tool to educate people about their risk of colon cancer. Please take as much time as you need to carefully read this information, as we will later be asking your reactions to it.

Scientists at the National Cancer Institute are developing a computer program to calculate a person's chances of developing colon cancer in his or her lifetime. The program will calculate these chances based on a person's answers to questions about things that have been found to affect a person's chances of developing colon cancer. The computer program is simple to use, and can be used at home or anywhere on the Internet.

Section III: Your reactions to colon cancer risk information

In the questions that follow, we will be asking about your reactions to the colon cancer risk program you have just learned about. We'd like you to imagine that you tried out the computer program. Imagine also that the computer program calculated your chances of developing colon cancer in your lifetime, and the results are below.

*We would like to know your reactions to receiving this information. Do your best to imagine that your estimate is real. Thinking carefully about how this result would make you feel, please answer the following questions, circling the **one** number from 1 to 5 that best indicates your response. If you are unsure of your response, just indicate your best guess, as there are no "right" or "wrong" answers to these questions.*

Visual A:

Visual B:

Visual C:

Visual D:

Visual E:

□

Section IV: Educational script

How was the program developed, and how does it work?

The computer program was developed by studying large groups of people with colon cancer, and finding out what things these people have in common. So far, scientists have been able to identify 9 different things, called “risk factors,” that are more common in people with colon cancer than in people without cancer:

Factors that increase a person’s chances of developing colon cancer:

- 1) Being over age 50
- 2) Having a family history of colon cancer
- 3) Being overweight
- 4) Eating few vegetables
- 5) Not getting a colonoscopy or sigmoidoscopy to screen for colon cancer
- 6) Having a history of colon polyps
- 7) Not taking aspirin
- 8) Smoking cigarettes
- 9) Not exercising

Each of these 9 risk factors increases a person’s chances of getting colon cancer by a certain amount. By adding up how many of these 9 risk factors a person has, the computer program is able to calculate his or her chances of getting colon cancer.

What do the results of the computer program mean?

The computer program gives an estimate of someone’s chances, or “risk,” of getting colon cancer. To illustrate what this estimate means, imagine you have a friend, let’s call him “Mr. Jones,” who has 3 of the 9 risk factors in the list above: he is 60 years old, overweight, and eats few vegetables. Based on these factors, the computer would calculate that “Mr. Jones” has a 9% chance of getting colon cancer during his lifetime.

To understand what a “9% chance” means, we need to imagine a group of people with the same risk factors that Mr. Jones has. For example, imagine there are 100 men who, like Mr. Jones, are 60 years old, overweight, and eat few vegetables. A “9% chance” of colon cancer means that in this group of 100 similar people, 9 of them will develop colon cancer in their lifetimes. This gives us a general sense of how likely it is that Mr. Jones himself will get colon cancer.

Notice that the “9% chance” describes what happens to a group of people: 9 out of every 100 persons will get colon cancer. It does not really tell what will happen to Mr. Jones himself, because a single person like Mr. Jones has only one life to live, and either will or will not get colon cancer. The computer can calculate that 9 out of 100 persons like Mr. Jones will get cancer, but it cannot tell if Mr. Jones will be one of those unlucky 9 persons or not. Therefore, the computer program only gives us a general sense of confidence about what might happen in the future.

How accurate is the computer program?

The computer program has been shown to be very accurate at predicting what happens to large groups of people. For example, studies have shown that for every 100 people with the same risk factors as Mr. Jones, approximately 9 of them eventually do develop colon cancer.

However, the result provided by the computer program is just one estimate or “best guess” of a person’s chances of getting colon cancer, based on what scientists know today. A person’s true chances are unknown, and may be higher or lower than what the computer says. Mr. Jones’ true chances of getting colon cancer, for example, may be more or less than 9%. This is because scientists don’t know all the reasons why some people get colon cancer, while others do not. A person like Mr. Jones may have unique things in his life that raise or lower his chances of getting cancer, but that scientists have not yet discovered and that the computer program does not measure.

Section V: Risk perceptions

1. How confident are you that you understand what these results mean?

1	2	3	4	5
Not at all confident				Very confident

2. How accurate do these results seem to you?

1	2	3	4	5
Not at all accurate				Very accurate

3. How much would you trust a computer program like this?

1	2	3	4	5
Not at all				Completely

4. Based on these results, how would you describe your chances of developing colon cancer in your lifetime? Would you say your chances of getting colon cancer are:

1	2	3	4	5
Very low		Moderate		Very high

5. If I received these results, I would tend to believe that my true chances of getting colon cancer are actually...

- A lot lower than **5-13%**
- Somewhat lower than **5-13%**
- The same as calculated **5-13%**
- Somewhat higher than **5-13%**
- A lot higher than **5-13%**

6. How certain do you feel about the opinions you just offered regarding your chances of developing colon cancer?

1	2	3	4	5
Not at all certain				Very certain

7. If you received these results, to what extent would you feel worried about developing colon cancer?

1	2	3	4	5
Not at all worried				Very worried

Section VI: Attitudes about health information and risk

*In the questions that follow, we will be asking you about your attitudes towards health information and risk. Please read each question carefully, and circle the **one** number from 1 to 5 that best indicates your response.*

1. How interested are you in using a computer program like the one described, to find out your own chances of developing colon cancer in the future?

1 **2** **3** **4** **5**

Not at all interested

Very interested

2. To what extent do you believe it is possible to know an individual person's chances of a future health problem like cancer?

1 **2** **3** **4** **5**

Not at all

To a great extent

3. No matter what the statistics say about a person's chances of getting cancer, I believe anything can happen.

[Strongly Agree / Somewhat Agree / Somewhat Disagree / Strongly Disagree]

4. There are so many different recommendations about preventing cancer, it's hard to know which ones to follow.

[Strongly Agree / Somewhat Agree / Somewhat Disagree / Strongly Disagree]

5. How would you interpret the meaning of a 9% colon cancer risk estimate?
(Please check all that apply)

- a. Scientists are 9% confident that I will develop colon cancer in my lifetime.
- b. For every 100 persons like me, 9 will develop colon cancer in their lifetime.
- c. For every 100 persons like me, 91 have a greater chance of getting colon cancer than me.
- d. Other (please describe):

e. Don't know / unsure.