

HEALTH INFORMATION SURVEY

Please mail back this form with your Follow-Up questionnaire (an envelope has been provided). For questions about completing either questionnaire, call 1-800-775-2167. Our mailing address is:

LONG-TERM FOLLOW-UP STUDY
MAYO MAIL CODE 715
420 DELAWARE ST SE
MINNEAPOLIS MN 55455-9940

Information about health and health care comes from many sources and in a variety of forms. In this survey we will be asking about your possible interest in seeking health-related information. We will also be asking about the ways in which you prefer to receive information and what types of information technology are available to you.

1. Which of the following do you have personal access to, where you can get private information?

Please mark all that apply.

- | | |
|---|---|
| <input type="checkbox"/> a. None | <input type="checkbox"/> e. Cell phone with Internet access |
| <input type="checkbox"/> b. Dial-up telephone access to the Internet | <input type="checkbox"/> f. Instant messaging |
| <input type="checkbox"/> c. High-speed Internet access (cable modem, DSL) | <input type="checkbox"/> g. Other (please specify): |
| <input type="checkbox"/> d. Email | |

2. Have you ever done any of the following? *Please mark all that apply.*

- a. Downloaded music from the Internet
- b. Used email or instant messaging
- c. Forwarded or downloaded email attachments
- d. Downloaded photos from email or a website
- e. Downloaded video from email or a website
- f. Got information from the Internet about a health issue that affects you or someone you know
- g. Got information from the Internet about things that are hard to talk about with other people
- h. Listened to the radio streamed through the Internet
- i. Accessed your personal health record online
- j. Visited a chat room
- k. Subscribed to a listserv
- l. Other (please specify):

Please! Do not mark below this line

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3. In general, how much attention do you pay to information about health or medical topics on radio and television, in newspapers and magazines?

- A lot
- Some
- A little
- None at all

4. How much do you trust information about health or medical topics from the sources listed below?

	A lot 1	Some 2	A little 3	Not at all 4
a. Radio	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Television	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Family or friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Internet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Doctor or other health care professional	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Newspapers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Magazines	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5. Thinking about your own health, how much would you like to receive health-related information or advice in the following ways?

	A lot 1	Some 2	A little 3	Not at all 4
a. By email	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. From an Internet web site	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. By watching a video tape or DVD ..	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. By listening to an audio tape or compact disc	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. By reading a pamphlet, newsletter, magazine, or some other publication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. By talking with a health professional, in person or over the phone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6. Still thinking about your own health, please indicate how much you like the options listed below.

	A lot 1	Some 2	A little 3	Not at all 4
a. Reading material that provides health information of interest to anyone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Reading material that uses information from your medical record to provide health-related information specific to you	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. A website where you could type in personal information, such as age, health history, smoking habits, etc., to receive health information specific to you	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. A website that provides health information of interest to everyone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. A secure website that uses information from your medical record to provide health-related information specific to you	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7. Still thinking specifically about your own health, about how often do you look for health-related information from any source? **Please mark only one.**

- Once a week
- Once a month
- Every few months
- Once or twice a year or less
- Never

8. Which of the following reasons would lead you to look for health or medical information?

- | | No | Yes |
|--|--------------------------|--------------------------|
| a. Experiencing new symptoms or a change in your health | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Being diagnosed with a new health problem | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Hearing or seeing something in the news that you wanted to learn more about | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Wanting to learn more about the effects of treatment for the cancer or similar illness you had when younger | <input type="checkbox"/> | <input type="checkbox"/> |
| e. Dealing with an ongoing medical condition, like diabetes or high blood pressure | <input type="checkbox"/> | <input type="checkbox"/> |
| f. Deciding to change your diet or exercise habits | <input type="checkbox"/> | <input type="checkbox"/> |
| g. Your doctor prescribed a new medication, test, or course of treatment. | <input type="checkbox"/> | <input type="checkbox"/> |
| h. Having unanswered questions after a visit to the doctor or clinic | <input type="checkbox"/> | <input type="checkbox"/> |
| i. Not having time to visit your doctor | <input type="checkbox"/> | <input type="checkbox"/> |
| j. Being unable to get a referral or an appointment for a health-related problem | <input type="checkbox"/> | <input type="checkbox"/> |
| k. Other | <input type="checkbox"/> | <input type="checkbox"/> |

Please specify:

9. Have you ever used the Internet to look for advice or information related to your health?

No Yes **→ Continue with Question 10, on the next page**



Skip to Question 14, on page 5

10. In the past 12 months, which of the following things have you done while using the Internet?

- | | No | Yes |
|--|--------------------------|--------------------------|
| a. Looked for health or medical information for yourself. | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Looked for health or medical information for someone else. | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Bought medicine or vitamins online | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Participated in an online support group for people with a similar health or medical issue | <input type="checkbox"/> | <input type="checkbox"/> |
| e. Used email or the Internet to communicate with a doctor or a doctor's office | <input type="checkbox"/> | <input type="checkbox"/> |
| f. Looked for information about physical activity or exercise. | <input type="checkbox"/> | <input type="checkbox"/> |
| g. Looked for information about diet or nutrition | <input type="checkbox"/> | <input type="checkbox"/> |
| h. Looked for information about protecting yourself from the sun | <input type="checkbox"/> | <input type="checkbox"/> |
| i. Looked for information about quitting smoking | <input type="checkbox"/> | <input type="checkbox"/> |
| j. Done anything else health-related on the Internet | <input type="checkbox"/> | <input type="checkbox"/> |

Please specify:

11. Have you ever talked to a doctor, nurse, or other health care provider about any kind of health information you have gotten from the Internet?

- No **→ Skip to Question 13**
- Yes
- Not sure

12. When you talked with a health care provider, how interested were they in hearing about the information you found online?

- Very interested
- Somewhat interested
- A little interested
- Not at all interested
- Don't remember

13. Thinking about the last time you used the Internet to look for information on health or health care, how much do you agree or disagree with the following statements?

	Strongly disagree	Somewhat disagree	Somewhat agree	Strongly agree
	1	2	3	4
a. It took a lot of effort to get the information I needed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. I felt frustrated during my search for the information.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. I was concerned about the quality of the information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. The information I found was too hard to understand.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

14. If you used the Internet to look for health-related information, how concerned would you be about the following:

	Don't know / no opinion	Not at all concerned	A little concerned	Somewhat concerned	Very concerned
	1	2	3	4	5
a. Being reminded about my health problems.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Having to answer too many personal questions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. My health information won't be kept private.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Learning things that would make me scared or worried about my health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

e. If you have other concerns besides those listed above, please specify:

15. Please list 2 or 3 things that would make you want to visit a health-related Internet website more than once:

The following questions relate to your having had childhood or adolescent cancer or a similar illness. In answering these questions, please consider all sources of information, such as news media, the Internet, the library, friends, and health care professionals.

16. How interested are you in the following?

	Not at all interested				
	Not very interested				
	Somewhat interested				
	Fairly interested				
	Extremely interested				
	1	2	3	4	5
a. Learning more about the kind of cancer or related illness I had when I was younger	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Learning more about my treatment for cancer when I was younger.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Learning more about screening tests my doctor might recommend	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Learning more about things I can do to avoid future health problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Hearing stories about people with health histories like mine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Joining an Internet discussion group where I could communicate with people like me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Being able to ask an expert questions about symptoms that concern me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Getting reassurance about my health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Finding Internet sites that talk about health issues related to life after cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. Locating books and articles about health issues related to life after cancer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

17. If a resource were available that provided information about issues related to cancer survivorship - things like health risks, healthy living habits, insurance, employment, and so on, which of the following best describes how you would use that resource? ***Please mark all that apply.***

- a. I would not use it
- b. I would use it if I developed a health problem
- c. I would use it to see what problems I might develop in the future
- d. I would use it to change my lifestyle and health habits
- e. I would discuss it with my doctor or health care provider
- f. I would discuss it with my family and friends
- g. Other (please specify):

18. Have you ever called the National Cancer Institute's cancer information hotline (1-800-4-Cancer)?

No Yes → 18a. Did you find it helpful? No Yes

19. Have you ever called the American Cancer Society's cancer information hotline (1-800-ACS-2345)?

No Yes → 19a. Did you find it helpful? No Yes

20. Have you found a website for cancer survivors that was helpful to you?

No Yes → 20a. Please describe it or give us the website name or address:

We welcome your comments:

THANK YOU!

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