

# **FINAL Existing Subscribers**

## **Health eCommunities:**

### **The Impact of ACOR Mailing Lists on Cancer Existing Subscribers - Patients and Survivors One-time Questionnaire**

## PROCESS QUESTIONS

**The first few questions are about Internet mailing lists (referred to as “mailing lists” here) and online resources.**

1. Through which mailing list did you enroll in this project?

**Answer choices will be in pull-down menu format for Internet respondents and open-ended for telephone respondents:**

▼
AML (Acute Myelogenous Leukemia)
Carcinoid
Caregivers
CLL (Chronic Lymphocytic Leukemia)
CML (Chronic Myelogenous Leukemia)
Colon
CTCL-MF (CTCL Mycosis Fungoides)
Desmoid
EC (Esophageal)
Kidney-Onc
L-M-Sarcoma
LT-Survivors
Lung-NSCLC (Non Small Cell Lung Cancer)
MPD-NET (Myeloproliferative Disorders)
Myeloma
Ovarian
Pancreas-ONC
Prostate
TC-NET (Testicular)
Thyroid-ONC

2. To which mailing list(s) are you now subscribed? *Please check all that apply.*

- a. AML (Acute Myelogenous Leukemia) .....
- b. Carcinoid.....
- c. Caregivers .....
- d. CLL (Chronic Lymphocytic Leukemia) .....
- e. CML ((Chronic Myelogenous Leukemia) .....
- f. Colon .....
- g. CTCL-MF (CTCLMycosis Fungoides).....
- h. Desmoid.....
- i. EC (Esophageal) .....
- j. Kidney-Onc .....
- k. L-M-Sarcoma .....
- l. LT-Survivors .....
- m. Lung-NSCLC (Non Small Cell Lung Cancer) ....
- n. MPD-NET (Myeloproliferative Disorders) .....
- o. Myeloma .....
- p. Ovarian .....
- q. Pancreas-ONC .....
- r. Prostate .....
- s. TC-NET (Testicular) .....
- t. Thyroid-ONC.....
- u. Other (please specify)\_\_\_\_\_

3. Besides ACOR list(s), do you use any of the following? *Please check all that apply.*

- a. Email mailing list (*other than ACOR lists*) .....
- b. Chat (e.g., IM, IRC, chat rooms, etc.) .....
- c. Message board or forum.....
- d. Weblog (blog) .....
- e. Livejournal .....
- f. Bulletin boards .....
- g. Guest books.....
- h. Other Internet community (please specify)\_\_\_\_\_

**USE OF MAILING LISTS**

*The next questions are about your reasons for being on the ACOR mailing list to which you subscribe. (If you subscribe to more than one ACOR group, please answer for the one in which you are most active.)*

4. Please tell us **how much you disagree or agree** with each of the following items.

I'm on the mailing list...	Strongly Disagree	Disagree	Agree	Strongly Agree
a. To get support from others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. To get information about how to deal with cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. To see how others with my cancer are doing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. To find out about the latest cancer treatments or post-cancer treatments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. To find out how to deal with the <u>side effects</u> of cancer treatments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. To find out how to deal with the <u>late effects</u> of cancer treatments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5. Please tell us **how much you disagree or agree** with each of the following items.

I'm on the mailing list...	Strongly Disagree	Disagree	Agree	Strongly Agree
a. To help others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. To get ideas about how to talk with my doctor about my illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. To help me make decisions about cancer treatment or post-cancer treatment for me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. To help reduce my uncertainty about which treatments are best for me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. To find other people with similar issues	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6. **During the past 7 days**, how much did your illness limit your ability to check your email for messages, or to read, write and post messages?

- a. Not at all.....
- b. A little bit .....
- c. Somewhat.....
- d. Quite a bit .....
- e. Very much.....

7. **During the past 7 days**, have you read, written and/or posted messages to the mailing list?

- Yes
- No—(Please skip to question #17)

8. **During the past 7 days, how many times** did you check your email for messages from the mailing list?

**Answer choices will be in pull-down menu format for Internet respondents and open-ended for telephone respondents:**

▼
None
1
2
3
4
5
6
7
8
9
10 or more

(If “none”, please skip to **#17**)

9. **During the past 7 days**, about *how many hours* did you spend each day reading and/or responding to messages from the mailing list?

**Answer choices will be in pull-down menu format for Internet respondents and open-ended for telephone respondents:**

30 minutes or less  
More than 30 minutes  
but less than 1 hour  
1  
2  
3  
4  
5  
6  
7  
8  
9  
10 or more

10. **During the past 7 days**, with about *how many different members* of the group did you exchange private emails (i.e., messages to other mailing list members, but not sent through the mailing list; also known as “off-list” email)?

number of members: **Answer choices will be in pull-down menu format for Internet respondents and open-ended for telephone respondents. Answers range from “0” to “10 or more” (see preceding questions for samples).**

(If “none”, please skip to #12)

11. **During the past 7 days**, about *how many times* did you exchange private emails with other group members?

number of times: **Answer choices will be in pull-down menu format for Internet respondents and open-ended for telephone respondents. Answers range from “0” to “10 or more” (see earlier questions for samples).**

12. **During the past 7 days**, about *how many times* did you call other list members on the phone?

number of members: **Answer choices will be in pull-down menu format for Internet respondents and open-ended for telephone respondents. Answers range from “0” to “10 or more” (see earlier question for sample).**

**Group Development Questions**

13. In questions a through g below, please tell us **how much you disagree or agree** with the following statements about the group, based on your participation in the mailing list **during the past 7 days**.

	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Agree</b>	<b>Strongly Agree</b>
<b>Cohesiveness</b>				
a. Overall, my experiences were similar to those of others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. I could relate to others' experiences with cancer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. I have something in common with others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. I felt that others understood what I was going through.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Normalization, Role modeling</b>				
e. Others gave me good ideas about how to cope with cancer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Conflict management</b>				
f. It was OK to express my opinions on the mailing list.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. It was OK to disagree with other others' statements.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

14. In questions *a* through *i* below, please tell us **how much you disagree or agree** with the following statements about the group, based on your participation in the mailing list **during the past 7 days**.

	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Agree</b>	<b>Strongly Agree</b>
<b>Emotional support</b>				
a. I found it comforting to read mailing list messages.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Others encouraged me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. I read others messages although I did not post anything.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Advice</b>				
d. Others gave me good advice.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. I got information I could not find anywhere else.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. The listowner (or listowners) gave information that list members needed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. The listowner (or listowners) helped the discussion.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Information Overload</b>				
h. There were too many messages to deal with.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Humor</b>				
i. Others' humor helped me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

15. *Please choose the response in each line that best describes how you felt about the mailing list during the past 7 days.*

	None	A little bit	Some	Quite a bit	Very much
a. How much help did other mailing list members give you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. How much help did you give other mailing list members?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

16. **When there were conflicts or disagreements among list members, how much did the listowner(s) help to resolve them?**

- a. Not at all.....
- b. A little bit .....
- c. Somewhat.....
- d. Quite a bit .....
- e. Very much.....
- f. There were no conflicts that I noticed .....

**From HINTS Survey (NCI)**

**Looking for Health Information**

*The following questions are about how you look for health information. Please include all sources of information such as the Internet, library, friends and health care professionals. For each item, choose the response that comes closest to how you feel.*

17. How much attention do you pay to information about health or medical topics from each of the sources listed below? *Please respond to each item.*

	None	A little bit	Some	Quite a bit	Very much
a. On TV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. On the radio	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	None	A little bit	Some	Quite a bit	Very much
c. In newspapers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. In magazines	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. In the medical literature	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. On the Internet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. From ACOR mailing list(s)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**From Pew Internet & American Life Project (December 2002 Tracking Survey)**

18. Do you ever send or receive e-mails from friends about health or medical issues?

- Yes                       No (*Please skip to question #20*)

19. How useful is email for communicating about health or medical issues with friends? *Please select one item below.*

- a. Very useful .....
- b. Somewhat useful .....
- c. Not too useful .....
- d. Not at all useful.....

20. How much did being on the mailing list change your decisions about cancer treatment or post-treatment?

- a. Not at all .....
- b. A little bit.....
- c. Somewhat .....
- d. Quite a bit .....
- e. Very much .....

**From GlaxoSmithKline – Landmark Survey with Patients (Harris Interactive Inc.)**

21. **During the past 30 days**, how often did you use the Internet (including the mailing list) for each of the activities listed below? *For each item, please choose the response that is closest to how you feel.*

	Not at all	Rarely	Some-times	Often
a. Find out more about cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Communicate with doctors or other health professionals (including email)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Communicate with other people who have the same condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Find general health information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Find information on prescription drugs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Find information on health-related products such as herbal remedies and vitamins	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

22. Have you **ever** talked to a doctor about any cancer-related information you got from the Internet? (This includes information from the mailing list.)

- Yes                       No (*Please skip to question #24*)

23. Overall, how has talking to your doctor about cancer information from the Internet changed how you get along with him/her? (*If you have talked with more than one doctor about information you got from the Internet, please answer about the doctor you see most often or the one who is most important for your cancer treatment and follow up.*) Has it made things a lot worse, a little worse, a little better, a lot better, or have things stayed the same? *Please choose the answer that comes closest to how you feel.*

- a. A lot worse.....
- b. A little worse .....
- c. No change .....
- d. A little better .....
- e. A lot better .....

**The next questions are about your health care.**

**Consumer Assessment of Health Plans Study – 2.0 Survey measures, 1998.**

24. Please rate your health care **in the last 12 months** from all doctors and other health providers. Use any number from 0 to 10 where 0 is the worst health care possible, and 10 is the best health care possible. How would you rate all your health care? *Please choose the number that comes closest to how you feel.*

- 0 .....(Worst health care possible).....
  - 1 .....
  - 2 .....
  - 3 .....
  - 4 .....
  - 5 .....
  - 6 .....
  - 7 .....
  - 8 .....
  - 9 .....
  - 10 .....(Best health care possible) .....
  - I had no visits in the last 12 months. ....
- (If “no visits”, please skip to question #26)*

**DOCTOR-PATIENT COMMUNICATION (From HINTS Survey-NCI)**

25. Thinking about all your interactions with doctors and other health care providers **during the past 12 months**, on average how often did they do the things listed in a through f below? *Please choose the response for each line that comes closest to how you feel.*

Doctor/Provider activity	Not at all	Rarely	Some-times	Often
a. Listen carefully to you	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Explain things in a way you could understand	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Doctor/Provider activity	Not at all	Rarely	Sometimes	Often
c. Show respect for what you had to say	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Spend enough time with you	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Involve you in decisions about your health care as much as you wanted	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Give you as much information as you wanted	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**PEPPI 5-item short form (Maly et al.; Cronbach's alpha = 0.83)**

26. How confident are you in your ability to do the things listed in a through e below?  
*Please choose the response for each line that comes closest to how you feel.*

How confident are you in your ability to...	Not at all confident				Very confident
	1	2	3	4	5
a. Know what questions to ask a doctor?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Get a doctor to answer all your questions?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Make the most of your visit with a doctor?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Get a doctor to take your chief health concern seriously?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Get a doctor to do something about your chief health concern?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Please tell us about your personal experience with cancer.**

27. When you were first told that you had cancer, what type of cancer was it, or in what part of the body did the cancer start? (If you have had more than one cancer, this refers to your first cancer.)

*Please choose all that apply.*

- a. Bladder cancer .....
- b. Bone cancer .....
- c. Breast cancer .....
- d. Cervical cancer (cancer of the cervix) .....
- e. Colon cancer .....
- f. Endometrial cancer (cancer of the uterus).....
- g. Esophageal cancer.....
- h. Gastrointestinal/GIST cancer .....
- i. Head and neck cancer.....
- j. Kidney cancer.....
- k. Leukemia .....
- l. Lung cancer.....
- m. Lymphoma (Hodgkin’s or Non-Hodgkin’s) .....
- n. Melanoma.....
- o. Skin Cancer other than melanoma .....
- p. Myeloma.....
- q. Oral cancer .....
- r. Ovarian cancer .....
- s. Pancreatic cancer.....
- t. Pharyngeal (throat) cancer .....
- u. Prostate cancer .....
- v. Rectal cancer .....
- w. Sarcoma .....
- x. Other (specify) \_\_\_\_\_

28. At what age were you first told that you had cancer?

AGE: |\_\_|\_\_|\_\_|

29. Are you **now** being treated for cancer?

- Yes     No

**Suggested by Dr. Neeraj Arora, NCI:**

30. **At any time since you were first diagnosed with cancer**, did any of the following occur? *Please select yes or no for each item.*

a. A doctor said that you were free of cancer (that is, you didn't have cancer in any part of your body).	Yes <input type="radio"/>	No <input type="radio"/>
b. A doctor said that your cancer had come back (that is, you had a recurrence).	Yes <input type="radio"/>	No <input type="radio"/>
c. Your cancer treatment ended.	Yes <input type="radio"/>	No <input type="radio"/>
d. You began a new treatment for your cancer.	Yes <input type="radio"/>	No <input type="radio"/>

***For the following question, we would like to know how you would prefer to make decisions about cancer tests and treatment, NOW or IN THE FUTURE.***

31. *Please choose the one statement that best describes you.*

- a. You would prefer to make the decisions with little or no input from your doctor. ....
- b. You would prefer to make the decisions after seriously considering your doctor's opinion. ....
- c. You would prefer that you and your doctor make the decisions together. ....
- d. You would prefer your doctor to make the decisions after seriously considering your opinion.....
- e. You would prefer your doctor to make the decisions with little or no input from you. ....

**QUALITY OF LIFE (FACT-G)**

*The next section contains statements that other people with your illness have said are important. Please indicate how true each statement has been for you during the past 7 days by choosing the response in each line that comes closest to how you feel.*

32. **During the past 7 days**, to what extent has each of the following statements been true for you?

<b>PHYSICAL WELL-BEING</b>	<b>Not at all</b>	<b>A little bit</b>	<b>Some-what</b>	<b>Quite a bit</b>	<b>Very much</b>
a. I lack energy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. I have nausea.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Because of my physical condition, I have trouble meeting the needs of my family.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. I have pain.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. I am bothered by side effects of treatment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. I feel ill.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. I am forced to spend time in bed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

33. **During the past 7 days**, to what extent has each of the following statements been true for you?

<b>SOCIAL/FAMILY WELL-BEING</b>	<b>Not at all</b>	<b>A little bit</b>	<b>Some-what</b>	<b>Quite a bit</b>	<b>Very much</b>
a. I feel close to my family and friends.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. I get emotional support from my family.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. I get support from my friends.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. My family has accepted my illness.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. I am satisfied with family communication about my illness.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

<b>SOCIAL/FAMILY WELL-BEING</b>	<b>Not at all</b>	<b>A little bit</b>	<b>Some-what</b>	<b>Quite a bit</b>	<b>Very much</b>
f. I feel close to my partner (or the person who is my main support).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. <i>Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please check this box <input type="checkbox"/> and go to the next section.</i> I am satisfied with my sex life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

***The next section contains questions on your use of Complementary and Alternative Medicines (CAM) over the past 12 months.***

34.

<b>In the last 12 months, did you use any of the following Complementary or Alternative Medicine (CAM) therapies to deal with your cancer? Please select yes or no for each item.</b>		
a. Alternative Medical Systems (such as homeopathy, naturopathy, traditional Chinese medicine, Ayurveda)	Yes <input type="radio"/>	No <input type="radio"/>
b. Mind-Body Interventions (such as relaxation training, guided imagery, meditation, hypnosis, biofeedback)	Yes <input type="radio"/>	No <input type="radio"/>
c. Biologically-based therapies (such as herbs, vitamins and dietary supplements, special diets)	Yes <input type="radio"/>	No <input type="radio"/>
d. Manipulative and Body-based Therapies (such as massage therapy, chiropractic, yoga, tai chi)	Yes <input type="radio"/>	No <input type="radio"/>
e. Energy Therapies (such as chi gung, Reiki, Therapeutic Touch, Polarity Therapy, magnet therapy)	Yes <input type="radio"/>	No <input type="radio"/>

35. Did you use CAM therapies to treat your cancer?

- Yes                       No

36. Did you use CAM therapies to help you deal with the side effects of cancer treatment?

- Yes  No

***The next section asks about clinical trials to treat cancer.***

37. Have you **ever** been or **are you now** in a clinical trial to treat cancer?

- Yes  No

38. Have you **ever** asked your physician or another health care professional about being in a clinical trial?

- Yes  No

39. Has a physician or other health care professional **ever** asked you to be in a clinical trial?

- Yes  No

40. Have you ever refused a request to be in a clinical trial?

- Yes  No

**Coping with Cancer – Abbreviated Brief COPE Scale**

***We are interested in how you usually deal with stress since you found out you had cancer.***

41. Please choose the one response in each line that comes closest to how much or how often you've been doing what the item says.

In the past 14 days ...	I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
a. I've been turning to work or other activities to take my mind off things.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

<b>In the past 14 days ...</b>		<b>I haven't been doing this at all</b>	<b>I've been doing this a little bit</b>	<b>I've been doing this a medium amount</b>	<b>I've been doing this a lot</b>
b.	I've been refusing to believe that this has happened.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c.	I've been using alcohol or other drugs to make myself feel better.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d.	I've been getting emotional support from others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e.	I've been giving up trying to deal with it.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f.	I've been focusing on doing something about my situation.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

42.

<b>In the past 14 days ...</b>		<b>I haven't been doing this at all</b>	<b>I've been doing this a little bit</b>	<b>I've been doing this a medium amount</b>	<b>I've been doing this a lot</b>
a.	I've been saying things to let my unpleasant feelings escape.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b.	I've been getting help and advice from other people.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c.	I've been trying to come up with a strategy about what to do.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d.	I've been looking for something good in what is happening.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e.	I've been learning to live with it.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f.	I've been blaming myself for things that happened.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g.	I've been praying or meditating.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

43. **During the past 7 days**, to what extent has each of the following statements been true for you?

<b>EMOTIONAL WELL-BEING</b>	<b>Not at all</b>	<b>A little bit</b>	<b>Some-what</b>	<b>Quite a bit</b>	<b>Very much</b>
a. I feel sad.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. I am satisfied with how I am coping with my illness.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. I am losing hope in the fight against my illness.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. I feel nervous.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. I worry about dying.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. I worry that my condition will get worse.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

44. **During the past 7 days**, to what extent has each of the following statements been true for you?

<b>FUNCTIONAL WELL-BEING</b>	<b>Not at all</b>	<b>A little bit</b>	<b>Some-what</b>	<b>Quite a bit</b>	<b>Very much</b>
a. I am able to work (include work at your home).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. My work (include work at home) is fulfilling.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. I am able to enjoy life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. I have accepted my illness.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. I am sleeping well.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. I am enjoying the things I usually do for fun.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. I am content with the quality of my life right now.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**WE'RE ALMOST DONE – PLEASE STAY WITH US.**

***The next questions ask about some background on you. This is so we can describe the group of people that responds. All of your answers are completely private and cannot be connected back to you.***

45. In general, would you say your health is:

- a. Excellent.....
- b. Very Good .....
- c. Good.....
- d. Fair .....
- e. Poor.....

46. Do you have any chronic health problems?

*Please choose all that apply.*

- a. Arthritis .....
- b. Asthma .....
- c. Chronic lung disease .....
- d. Diabetes or high blood sugar.....
- e. Chronic headaches or migraine.....
- f. Heart disease .....
- g. Ulcer .....
- h. Any other serious chronic health problem (please describe below): \_\_\_\_\_

47. In which month and year were you born?

MONTH |\_\_|\_\_|      YEAR |\_\_|\_\_|\_\_|\_\_|

48. Are you...

- Male                       Female

**Next are a few questions about your household.**

*For each of the following items, please choose the response that reflects your situation*

49. Are you **now**...*(Please choose one item. If you are both employed for wages and self-employed, please choose the category that accounts for more income)*
- a. Employed for wages .....
  - b. Self-employed .....
  - c. Out of work for more than one year .....
  - d. Out of work for less than one year.....
  - e. A homemaker .....
  - f. A student .....
  - g. Retired.....
  - h. Unable to work .....
50. Are you...
- a. Married or living as married, .....
  - b. Divorced or Separated,.....
  - c. Widowed,.....
  - d. Never married.....
51. Are there any children living in your household?
- Yes                       No
52. Are you Hispanic or Latino?
- Yes                       No
53. Which one or more of the following would you say is your race? Are you...
- Please choose all that apply.**
- a. American Indian or Alaska Native, .....
  - b. Asian, .....
  - c. Black or African American, .....
  - d. Native Hawaiian or other Pacific Islander, or.....
  - e. White .....

54. What is the highest grade of school you completed?

- a. Grades 1 through 8 (elementary/junior high school),.....
- b. Grades 9 through 11 (some high school), .....
- c. Grade 12 or GED (high school graduate), .....
- d. College 1 year to 3 years (some college or technical school).....
- e. College 4 years or more (college graduate) .....

55. Do you have any kind of health care coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicare?

- Yes                       No                       Don't Know

***Finally, we'd like to know what you think about this questionnaire, and offer you our thanks.***

56. This questionnaire is:

- a. Too short .....
- b. Too long .....
- c. Just right.....

57. If you have any comments about the questionnaire, your mailing list, or your cancer experience, please enter them below. These comments really help us to get a better picture of our respondents. All answers are confidential. Please email [acorsurvey@unc.edu](mailto:acorsurvey@unc.edu) if you have specific concerns or questions you want answered.

***Thank You For Completing This Questionnaire.***

***We Truly Appreciate Your Time!***

***You are now an important voice in what we hope will be the largest  
Internet survey of cancer patients and survivors.***