

FINAL 4 Month Follow-up

Health eCommunities:

The Impact of ACOR Mailing lists on Cancer Patients and Survivors Follow-up Questionnaire

We cannot do it without you!

Thank you for being part of the Health eCommunities project. Your mailing list, ACOR and the team at University of North Carolina truly appreciate that you filled out the first 2 surveys over the past several months. We need you to complete this final questionnaire if we are to learn more about how mailing lists affect the online community. As before, your answers are confidential. This is the last of three surveys. We look forward to sharing the overall results with you at the end of the project, and are extremely grateful for your participation.

PROCESS QUESTIONS

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

1. 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)_____

2. **Since completing the last questionnaire**, have you unsubscribed (i.e., removed yourself) from any of the following ACOR lists? *Please check all that apply.*

- a. I have NOT unsubscribed from any ACOR list.....
- b. AML (Acute Myelogenous Leukemia)
- c. Carcinoid.....

- d. Caregivers
- e. CLL (Chronic Lymphocytic Leukemia)
- f. Colon
- g. CML (Chronic Myelogenous Leukemia)
- h. CTCL-MF (CTCLMycosis Fungoides).....
- i. Desmoid.....
- j. EC (Esophageal)
- k. Kidney-Onc
- l. L-M-Sarcoma
- m. LT-Survivors
- n. Lung-NSCLC (Non Small Cell Lung Cancer)
- o. MPD-NET (Myeloproliferative Disorders)
- p. Myeloma
- q. Ovarian
- r. Pancreas-ONC
- s. Prostate
- t. TC-NET (Testicular)
- u. Thyroid-ONC.....
- v. 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 other patients 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. **In the past 7 days**, have you read messages from the mailing list?

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

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

9. **During the past 7 days**, about *how many hours* did you spend each day reading 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. **In the past 7 days**, have you written or posted messages to the mailing list?

Yes No—(Please skip to question #20)

11. **During the past 7 days**, about *how many hours* did you spend 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. Answers range from “0” to “10 or more” (see preceding questions for samples).

12. **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 earlier questions for samples).

13. **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 preceding questions for samples).**

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

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 question for sample).**

15. **Since joining this mailing list**, have you arranged to meet any of its members in person?

Yes No

Group Development Questions

16. 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.**

| | Strongly Disagree | Disagree | Agree | Strongly Agree |
|--|--------------------------|--------------------------|--------------------------|--------------------------|
| Cohesiveness | | | | |
| a. Overall, my experiences were similar to others. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. I could relate to others' experiences about 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"/> |

| | Strongly Disagree | Disagree | Agree | Strongly Agree |
|---|--------------------------|--------------------------|--------------------------|--------------------------|
| Normalization, Role modeling | | | | |
| e. Others on the mailing list gave me good ideas about how to cope with cancer. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Conflict management | | | | |
| 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 others' statements. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

17. 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**.

| | Strongly Disagree | Disagree | Agree | Strongly Agree |
|---|--------------------------|--------------------------|--------------------------|--------------------------|
| Emotional support | | | | |
| 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"/> |
| Advice | | | | |
| 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"/> |
| Information Overload | | | | |
| h. There were too many messages to deal with. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

| | Strongly Disagree | Disagree | Agree | Strongly Agree |
|-----------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Humor | | | | |
| i. Others' humor helped me. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

18. *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 others give you? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. How much help did you give to others? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

19. **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 information about health. 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.

20. **In the past 30 days, how much attention did 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"/> |
| 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)

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

- Yes No (*Please skip to question #23*)

22. 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.....

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

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

The next questions are about your health care.

24. **In the last 90 days (3 months),** have you been to a doctor or other health care provider?
- Yes No (*Please skip to question #29*)

From HINTS Survey (NCI)

25. **In the last 90 days (3 months),** have you 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 #27*)

26. **In the last 90 days (3 months),** 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? *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

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

27. Please rate all your health care **in the last 90 days (3 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).....

(If “no visits”, please skip to question #29)

DOCTOR-PATIENT COMMUNICATION (From HINTS Survey-NCI)

28. Thinking about all your interactions with doctors and other health care providers **during the last 90 days (3 months)**, on average how often did they do the things listed in a through e below? *Please choose the response for each line that comes closest to how you feel.*

| Doctor/Provider activity | Not at all | Rarely | Sometimes | 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"/> |
| 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)

29. 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 1 | 2 | 3 | 4 | Very confident 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.

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

- Yes No

Suggested by Dr. Neeraj Arora, NCI:

31. **In the last 90 days (3 months)**, 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.

32. *Please choose the 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.

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

| PHYSICAL WELL-BEING | Not at all | A little bit | Some-what | Quite a bit | Very much |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 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"/> |

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

| SOCIAL/FAMILY WELL-BEING | Not at all | A little bit | Some-what | Quite a bit | Very much |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 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"/> |

| SOCIAL/FAMILY WELL-BEING | Not at all | A little bit | Some-what | Quite a bit | Very much |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 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 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 90 days (3 months).

35.

| In the last 90 days (3 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 | | |
|---|---------------------------|--------------------------|
| 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"/> |

36. **In the last 90 days (3 months), did you use CAM therapies to treat your cancer?**

Yes No

37. **In the last 90 days (3 months), did you use CAM therapies to help you deal with the side effects of cancer treatment?**

Yes No

38. **In the last 90 days (3 months)**, did you use CAM therapies instead of conventional or regular medical treatment for your cancer?

- Yes No

The next section asks about cancer clinical trials and advocacy groups.

39. **Are you now** in a clinical trial to treat cancer?

- Yes No

40. **In the last 90 days (3 months)**, have you asked your physician or another health care professional about being in a clinical trial?

- Yes No

41. **In the last 90 days (3 months)**, has a physician or other health care professional asked you to be in a clinical trial?

- Yes No

42. **In the last 90 days (3 months)**, have you refused a request to be in a clinical trial?

- Yes No

43. Has being on the mailing list prompted you to join an advocacy group for cancer?

- 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.

44. *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. 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 my efforts on doing something about my situation. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

45.

| 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 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"/> |

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

| EMOTIONAL WELL-BEING | Not at all | A little bit | Some-what | Quite a bit | Very much |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 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"/> |

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

| FUNCTIONAL WELL-BEING | Not at all | A little bit | Some-what | Quite a bit | Very much |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 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.

**(POST TRAUMATIC GROWTH INVENTORY (PTGI, Tedeschi & Calhoun 1996)
 adapted by Wenzel)**

CANCER SPECIFIC LIFE CHANGES

Next is a list of changes that sometimes occur in people's lives as a result of having had cancer. For each of the following statements, please indicate the degree to which this change occurred in your life as a result of having had cancer.

- Not at all** I **did not experience** this change as a result of having cancer
- Very small Degree** .. I experienced this change to a **very small degree** as a result of having cancer.
- Small Degree**..... I experienced this change to a **small degree** as a result of having cancer.
- Moderate Degree** I experienced this change to a **moderate degree** as a result of having cancer.
- Great Degree** I experienced this change to a **great degree** as a result of having cancer.
- Very Great Degree** .. I experienced this change to a **very great degree** as a result of having cancer.

48.

| | Not at All | Very Small Degree | Small Degree | Moderate Degree | Great Degree | Very Great Degree |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| a. My priorities about what is important in life have changed | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. An increased appreciation for the value of my own life | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. An increased feeling of self-reliance | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. A better understanding of spiritual matters | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e. Knowing that I can count on people in times of trouble | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

| | Not at All | Very Small Degree | Small Degree | Moderate Degree | Great Degree | Very Great Degree |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| f. An increased sense of closeness with others | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| g. An increased willingness to express my emotions | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

49.

| | Not at All | Very Small Degree | Small Degree | Moderate Degree | Great Degree | Very Great Degree |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| a. Knowing I can handle difficulties | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Being better able to accept the way things work out | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Appreciating each day more fully | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Putting more effort into my relationships | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e. I'm much more likely to try to change things that need changing | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| f. I have a stronger religious faith | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| g. I discovered that I'm stronger than I thought I was | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| h. I more readily accept needing others | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

The next questions are about your participation in face-to-face support groups.

50. For **any** of the conditions for which you are on an ACOR list, have you **ever** been in a face-to-face or in-person support group?

- Yes No

51. For **any** of the conditions for which you are on an ACOR list, are you **now** in a face-to-face or in-person support group?

- Yes No

The next question is about your opinion of your health.

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

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

53. In the last 4 months, would you say your health has:
- a. Improved
 - b. Declined
 - c. Stayed about the same

54. 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): _____

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

55. This questionnaire is:
- a. Too short
 - b. Too long
 - c. Just right.....

56. 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 if you have specific concerns or questions you want answered.

Thank You For Completing The Last Of Three Questionnaires.

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. Soon we will send you a summary of results.

Thank you so much!