

# **FINAL Caregivers**

## **Health eCommunities:**

### **The Impact of Mailing lists on Cancer Caregivers Questionnaire**

Notes:

***This survey is for caregivers of cancer patients and survivors. “Caregivers” are people actively caring for, supporting or helping a friend or relative who has or had cancer, as well as people who have done so in the past. We refer to all such people as “caregivers”. We want you to respond in terms of your “caregiver” role even if you also have or had cancer.***

## 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

**UNC 49152 Online Caregiver Survey.doc**

UNC-CH – Barbara K. Rimer

Health eCommunities - 49152

Prostate

TC-NET (Testicular)

Thyroid-ONC

**UNC 49152 Online Caregiver Survey.doc**

UNC-CH – Barbara K. Rimer

Health eCommunities - 49152

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 .....

**UNC 49152 Online Caregiver Survey.doc**

UNC-CH – Barbara K. Rimer  
 Health eCommunities - 49152

- 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 list, please answer for the list on 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	Does Not Apply
a. To get support from others	<input type="checkbox"/>	<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"/>	<input type="checkbox"/>
c. To see how others with my <b>friend's or relative's</b> cancer are doing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. To find out about the latest treatments for cancer	<input type="checkbox"/>	<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"/>	<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"/>	<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	Does Not Apply
a. To help others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**UNC 49152 Online Caregiver Survey.doc**

UNC-CH – Barbara K. Rimer  
Health eCommunities - 49152

I'm on the mailing list...	Strongly Disagree	Disagree	Agree	Strongly Agree	Does Not Apply
b. To learn how to talk to my friend or relative about cancer and its effects	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. To learn how I can best help my friend or relative	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. To get ideas about how to talk with my friend's or relative's doctor about his/her illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. To help my friend or relative make decisions about cancer treatment or post-cancer treatment for him/her	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. To help reduce my uncertainty about which treatments are best for my friend or relative	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. To find other people with similar issues	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. To help my friend or relative deal with issues of being a cancer survivor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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

- a. None.....
- b. 30 minutes or less .....
- c. More than 30 minutes but less than 1 hour .....
- d. 1 hour or more but less than 2 hours.....
- e. 2 hours or more but less than 3 hours .....
- f. 3 or more hours .....

*(If "None", then please skip to question #17)*

**UNC 49152 Online Caregiver Survey.doc**

UNC-CH – Barbara K. Rimer

Health eCommunities - 49152

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

**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

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

**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

**UNC 49152 Online Caregiver Survey.doc**

UNC-CH – Barbara K. Rimer

Health eCommunities - 49152

9. **During the past 7 days**, about *how many times* did you arrange to meet any members of the mailing list in person?

**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

10. **During the past 7 days**, about *how many times* have you been asked by your friend or relative to read and/or write mailing list messages?

**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

11. **During the past 7 days**, about *how many times* did you discuss with your friend or relative what you read and/or wrote to 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

**UNC 49152 Online Caregiver Survey.doc**

UNC-CH – Barbara K. Rimer

Health eCommunities - 49152

12. **During the past 7 days**, about *how many times* did you find information on the mailing list or Internet that was too upsetting to share with your friend or relative?

**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

**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 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 **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"/>

**UNC 49152 Online Caregiver Survey.doc**

UNC-CH – Barbara K. Rimer

Health eCommunities - 49152

	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Agree</b>	<b>Strongly Agree</b>
<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 group during the past 7 days.*

	<b>None</b>	<b>A little bit</b>	<b>Some</b>	<b>Quite a bit</b>	<b>Very much</b>
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 others?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. How much of what you read or wrote on the mailing list did you share with your friend or relative?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**UNC 49152 Online Caregiver Survey.doc**

UNC-CH – Barbara K. Rimer  
Health eCommunities - 49152

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"/>
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"/>

**UNC 49152 Online Caregiver Survey.doc**

UNC-CH – Barbara K. Rimer

Health eCommunities - 49152

18. 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

***Next, we'd like to know about your friend's or relative's use of mailing lists.***

19. Has your **friend or relative ever** been a member of a cancer-related mailing list?

Yes

No

Don't know

(If not Yes, skip to question #21)

20. Is your **friend or relative now** a member of a cancer-related mailing list?

Yes

No

Don't know

**Please tell us about your friend's or relative's experience with cancer.**

21. When your friend or relative was first told that he/she had cancer, what type of cancer was it, or in what part of the body did the cancer start? (If your friend or relative has had more than one cancer, this refers to his/her 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) \_\_\_\_\_

22. Is your **friend or relative now** being treated for cancer?

- Yes                       No                       Don't know

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

23. Has your **friend or relative ever** been or **is he/she now** in a clinical trial to treat cancer?

Yes

No

Don't know

24. Have **you ever** asked a physician or other health care professional about your **friend or relative** being in a clinical trial?

Yes

No

**The next section asks for some general information about your friend or relative.**

25. Is your **friend or relative** male or female?

Male

Female

26. What is your relationship to your friend or relative? **Are you his or her ...**

**Pull down menu** ▾

- Husband or Wife
- Parent
- Daughter or Son
- Sister or Brother
- Grandchild
- Daughter-in-law or Son-in-law
- Niece or Nephew
- Friend
- Other

27. Is your friend or relative still living?

Yes

No

*(If No, skip to question #35)*

**UNC 49152 Online Caregiver Survey.doc**

UNC-CH – Barbara K. Rimer  
Health eCommunities - 49152

28. How old is your **friend or relative** now?

<i><b>Pull down menu</b></i> ▼
Less than 30 years old
30-39
40-49
50-59
60-69
70-79
80 years or older

29. Is your **friend or relative**...?

<i><b>Pull down menu</b></i> ▼
Married or living as married
Widowed
Divorced or Separated
Never Married

***The next couple of questions are about how much time you spend on caregiving for the friend or relative you are helping.***

**From Clipp et al. – National Caregiver Research Study**

30. In a typical week, *how many days* do you provide care to your **friend or relative**?

NUMBER OF DAYS

31. In a typical 24 hour day, in which you have contact with your **friend or relative**, *how many hours* (not counting sleep) do you provide care or companionship?

NUMBER OF HOURS

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

***The next section is about how you feel and what you've been doing as a caregiver. There are 3 parts to this section. Below is the first part.***

**Caregiver Reaction Assessment – Given et al. (Cronbach's alphas: Esteem (positive)=.90; Family support (lack)=.85; Finances (strain)=.81; Schedule (disruption)=.82; Health (loss)=.80)**

32. **Since you became a caregiver for your friend or relative**, please check to what extent you disagree or agree with each of the following statements.

Caregiver Reaction Assessment	Strong-ly dis-agree	Dis-agree	Neither agree nor dis-agree	Agree	Strong-ly agree	Does not apply
a. I feel privileged to care for my friend or relative.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Others have dumped caring for my friend or relative on me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. My financial resources are adequate to pay for things that are required for caregiving.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. My activities are centered around care for my friend or relative.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Since caring for my friend or relative, it seems like I'm tired all of the time.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. It is very hard to get help from my family in taking care of my friend or relative.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. I resent having to take care of my friend or relative.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Caregiver Reaction Assessment	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Does not apply
h. I have to stop in the middle of work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

***This is Part 2 of a 3-part section. Some of these questions may seem like ones you've already answered, but they are different. Please stay with us. Your answers to these questions are vitally important to understanding your experiences as a caregiver.***

33. **Since you became a caregiver** for your **friend or relative**, please check to what extent you disagree or agree with each of the following statements.

Caregiver Reaction Assessment	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Does not apply
a. I really want to care for my friend or relative.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. My health has gotten worse since I've been caring for my friend or relative.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. I visit family and friends less since I have been caring for my friend or relative.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. I will never be able to do enough caregiving to repay my friend or relative.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. My family works together at caring for my friend or relative.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. I have eliminated things from my schedule since caring for my friend or relative.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Caregiver Reaction Assessment	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Does not apply
g. I have enough physical strength to care for my friend or relative.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Since caring for my friend or relative, I feel my family has abandoned me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

***This is the last part of the section asking how you feel and what you've been doing as a caregiver. Thank you for staying with us.***

34. **Since you became a caregiver** for your **friend or relative**, please check to what extent you disagree or agree with each of the following statements.

Caregiver Reaction Assessment	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Does not apply
a. Caring for my friend or relative makes me feel good.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. The constant interruptions make it difficult to find time to relax.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. I am healthy enough to care for my friend or relative.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Caring for my friend or relative is important to me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Caring for my friend or relative has put a financial strain on the family.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Caregiver Reaction Assessment	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Does not apply
f. My family (brothers, sisters, and children) left me alone to care for my friend or relative.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. I enjoy caring for my friend or relative.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. It's difficult to pay for my friend's or relative's health needs and services.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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

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

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

**UNC 49152 Online Caregiver Survey.doc**

UNC-CH – Barbara K. Rimer  
 Health eCommunities - 49152

36.

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"/>

***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 can not be connected back to you.***

37. In general, would you say **your** health is:

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

**UNC 49152 Online Caregiver Survey.doc**

UNC-CH – Barbara K. Rimer  
Health eCommunities - 49152

38. In which month and year were **you** born?

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

39. 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:*

40. 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 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 .....

**From Clipp et al – National Caregiver Research Study**

41. Are **you**...

- a. Married or living as married, .....
- b. Divorced or Separated,.....
- c. Widowed,.....
- d. Never married.....

42. Are there any children living in **your** household?

- Yes                       No

43. Are **you** Hispanic or Latino?

- Yes                       No

**UNC 49152 Online Caregiver Survey.doc**

UNC-CH – Barbara K. Rimer  
Health eCommunities - 49152

44. 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 .....

45. 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) .....

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

46. This questionnaire is:

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

47. 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, survivors and caregivers.*