

ATTACHMENT 19
Formative Research to Understand the Needs, Attitudes, and Beliefs of NCI's Consumer Advocates in Research and Related Activities (CARRA) Members

OMB #0925-0046-17
Exp. Date: 10/31/2006

March 2006

Dear CARRA Member:

The Office of Liaison Activities has contracted with Westat, an independent research company, to conduct a survey of current and former CARRA members' attitudes and beliefs regarding the CARRA program. The survey asks about your participation with the CARRA program, including information sharing and suggestions for program improvement.

This survey should take approximately 15 minutes to complete. We know your time is valuable, and can assure you that your responses are important to ongoing development of the CARRA program. In short, your participation matters.

Please return the survey to Westat by *(insert date)*. We ask that you either fax the survey toll-free to 1-800-533-0239 or mail it to:

Westat
NCI/CARRA Survey
1650 Research Boulevard
Room TA2030F
Rockville, MD 20850

Your responses to the survey will be kept confidential, and will not be disclosed to anyone except as required by law. Any reporting associated with the survey results will be done in aggregate form only, and will not identify specific CARRA members. You may skip any questions that you prefer not to answer.

Thank you in advance for your feedback to the CARRA program. If you have any technical questions, concerns, or comments about the survey please contact Janice Lee (toll-free at 1-800-937-8281, ext. 4107, or janicelee@westat.com).

We look forward to hearing from you, and continue to appreciate your participation in the CARRA program.

Sincerely,

Brooke Hamilton
Acting Director, Office of Liaison Activities
National Cancer Institute, NIH, DHHS

CARRA Member Attitudes and Beliefs Survey

Please take about 15 minutes to respond to the following questions about your CARRA experience. The CARRA program staff values your opinions and attitudes as an integral element of program development and improvement. The questions ask for different types of responses, so please read carefully. If you are not sure of an answer, please give us your best judgment. Thank you!

1. *Consumer advocates join and participate in the CARRA program for many reasons. Please consider your own decision to become involved in the CARRA program, and rate how important each of the following reasons was to you in making the decision to become a CARRA member. (Please circle one response on each line.)*

| | Very important | Somewhat important | Not very important | Not at all important |
|---|-------------------|-----------------------|-----------------------|-------------------------|
| a. Providing a consumer perspective to NCI3 | 1 4 | 2 | | |
| b. Providing funding recommendations and peer review at NCI3 | 1 4 | 2 | | |
| c. Informing NCI about the specific views and concerns of those in my cancer community, constituency, or group.....3 | 1 4 | 2 | | |
| d. Bringing information about new scientific advancements back to my cancer advocacy community, constituency, or group.....3 | 1 4 | 2 | | |
| e. Impacting future policy decisions at NCI.....3 | 1 4 | 2 | | |
| f. Educating my cancer advocacy community, constituency, or group about NCI policies and research priorities3 | 1 4 | 2 | | |
| g. Other (<i>Please specify</i>) _____ _____ _____3 | 1 4 | 2 | | |

2. *CARRA members may be asked to serve in a variety of different NCI activities. A list of these activities appears below. For each activity, please indicate your current degree of interest in participating. Note: Because survey results will be reported only in aggregate form, your response on this question will have no relationship to the specific NCI activities in which you may or may not have the opportunity to participate. (Please circle one response on each line.)*

| | Very interested | Somewhat interested | Not very interested | Not at all interested |
|---|--------------------|------------------------|------------------------|--------------------------|
| a. Standing Committee (a committee that meets more than once).....24 | 1 3 | | | |
| b. Meeting (a one-time meeting).....24 | 1 3 | | | |
| c. Workshop (a one-time discussion and learning session)..... | 1 | | | |

| | | |
|--|---|---|
| | 2 | 3 |
| | 4 | |
| d. Peer Review Activity (in-person or phone review of grant applications)..... | 1 | 3 |
| | 2 | |
| | 4 | |
| e. Site Visit (on-site visit to a potential grantee)..... | 1 | 3 |
| | 2 | |
| | 4 | |
| f. Contract Review (review of responses to a request for research contract proposals)..... | 1 | 3 |
| | 2 | |
| | 4 | |
| g. Informed Consent Review (review of documents used to inform patients considering participation in a clinical trial about potential risks and benefits)..... | 1 | 3 |
| | 2 | |
| | 4 | |

2. (continued)

| | Very interested | Somewhat interested | Not very interested | Not at all interested |
|---|--------------------|------------------------|------------------------|--------------------------|
| h. Progress Review Group (PRG) (panel of prominent members of the scientific, medical, and advocacy communities who assess the current state of science for a type of cancer or related cancers and make research recommendations)..... | 1 | | | |
|2 | 3 | | | |
|4 | | | | |
| i. Editorial Boards (editorial board for NCI publications)..... | 1 | | | |
|2 | 3 | | | |
|4 | | | | |
| j. Educational Materials Development (review of print, electronic, or other medium educational materials)..... | 1 | | | |
|2 | 3 | | | |
|4 | | | | |
| k. Research Tool Development (review of surveys, interview guides, or other types of research tools)..... | 1 | | | |
|2 | 3 | | | |
|4 | | | | |
| l. Web Site Usability Testing (review of web site for readability and ease of navigation)..... | 1 | | | |
|2 | 3 | | | |
|4 | | | | |
| m. Other (any activity that does not fit into one of the above categories) <i>(Please specify)</i> _____ | | | | |
| _____ | 1 | | | |
| _____ | 3 | | | |
| _____ | | | | |

3. In approximately how many CARRA activities have you participated? *(Please count a standing committee as one activity, and please do not count any NCI activities where you participated in a non-CARRA role.)*

Number of times/activities:

0 _____

1 – 2 _____

3 – 5 _____

6 – 9 _____

10 or more _____

4. Which of the following best describes the type(s) of NCI activity(ies) in which you have participated as a CARRA member? *(Please circle all that apply.)*

| | |
|--|---|
| a. Did not participate in any activities..... | 1 |
| b. Standing Committee (a committee that meets more than once)..... | 2 |
| c. Meeting (a one-time meeting)..... | 3 |
| d. Workshop (a one-time discussion and learning session)..... | 4 |
| e. Peer Review Activity (phone or in-person review of grant applications)..... | 5 |
| f. Site Visit (on-site visit to a potential grantee)..... | 6 |

| | |
|---|----|
| g. Contract Review (review of proposals submitted in response to a request for research contract proposals)..... | 7 |
| h. Informed Consent Review (review of documents used to inform patients considering participation in a clinical trial about potential risks and benefits)..... | 8 |
| i. Progress Review Group (PRG) (panel of prominent members of the scientific, medical, and advocacy communities who assess the current state of science for a type of cancer or related cancers and make research recommendations)..... | 9 |
| j. Editorial Boards (editorial board for NCI publications)..... | 10 |
| k. Educational Materials Development (review of print, electronic, or other medium educational materials)..... | 11 |

4. (continued)
- l. Research Tool Development (review of surveys, interview guides, or other types of research tools)..... 12
 - m. Web Site Usability Testing (review of web site for readability and ease of navigation)..... 13
 - n. Other (any activity that does not fit into one of the above categories)
(Please specify)_____ 14
5. To what extent did the type of activity(ies) in which you participated match your interests? (Please circle one response.)
- Did not participate in any activities..... 1
 - To a great extent 2
 - To a moderate extent..... 3
 - To a very small extent..... 4
 - Did not match my interests at all..... 5
- If to a very small extent or not at all, please explain _____
6. Has your level of participation in CARRA activities been greater, the same, or less than you expected when you initially joined the CARRA program? (Please circle one response.)
- Greater than I expected 1
 - The same as I expected 2
 - Less than I expected 3
7. Have you ever decided not to participate in an activity for which you were recruited or requested to participate by an NCI staff member? (Please circle one response.)
- Yes..... 1 (If yes, please specify why you decided not to participate in the activity.)

 - No..... 2 _____
8. As a CARRA member, do you feel that you have been provided with a sufficient number of opportunities to participate in CARRA activities? (Please circle one response.)
- Yes..... 1
 - No..... 2
9. Since becoming a CARRA member, about how frequently have you shared information that you acquired specifically through your involvement with the CARRA program with other members of your cancer advocacy community, constituency, or group? (Please circle one response.)
- On a weekly basis 1
 - On a biweekly basis (i.e., every 2 weeks)..... 2
 - On a monthly basis 3
 - On a quarterly basis (i.e., 3-4 times a year)..... 4
 - Once or twice a year..... 5
 - Never 6

10. Participants in the CARRA program are strongly encouraged to share information about NCI with their individual cancer advocacy community, constituency, or group. How clearly was this expectation communicated to you by the Office of Liaison Activities when you joined the CARRA program? *(Please circle one response.)*

- Very clearly..... 1
- Somewhat clearly 2
- Not very clearly 3
- Not at all clearly..... 4

11. How helpful has the Office of Liaison Activities been in facilitating your efforts to share information about NCI activities with your individual cancer advocacy community, constituency, or group? *(Please circle one response.)*

- Very helpful 1
- Somewhat helpful..... 2
- Not very helpful..... 3
- Not at all helpful..... 4

12. Would you like to receive additional help from the Office of Liaison Activities in communicating to your cancer advocacy community, constituency, or group?

- Yes..... 1
- No..... 2

If “yes,” please describe the type(s) of help you would like to receive from the Office of Liaison Activities.

13. Since becoming a CARRA member, what types of communication have you had with the Office of Liaison Activities? *(Please circle all that apply.)*

- a. Received mailings (U.S. postal delivery mailings, not email)..... 1
- b. Received phone calls..... 2
- c. Initiated phone calls..... 3
- d. Received emails..... 4
- e. Initiated emails 5
- f. Participated in a teleconference (or listened to teleconference re-play)..... 6
- g. Something else? *(Please specify)* _____ 7

14. Since your CARRA membership began, how useful overall is the information that you have received from the Office of Liaison Activities (i.e., information you have received because you are a CARRA member)? *(Please circle one response.)*

- Very useful 1
- Somewhat useful 2
- Not very useful..... 3
- Not at all useful..... 4

15. Would you like to see any additions or changes made to the methods used by the Office of Liaison Activities in its communication with CARRA members? (NOTE: Different question than #12.)

Yes..... 1
 No..... 2

If “yes,” please describe the additions or changes you would like to see made to the Office of Liaison Activities’ communication methods.

16. Since its inception, how much of an impact do you believe the CARRA program has had on the following factors? (Please circle one response on each line.)

| | A great impact | A moderate impact | A very small impact | No impact at all |
|---|----------------|-------------------|---------------------|------------------|
| a. NCI’s accountability to those affected by cancer..... | 1 | | | |
|2 | 3 | | | |
|4 | | | | |
| b. NCI’s decisions in grant reviews..... | 1 | | | |
|2 | 3 | | | |
|4 | | | | |
| c. NCI’s current level of communication with the cancer community | 1 | | | |
|2 | 3 | | | |
|4 | | | | |
| d. Other (please specify)_____ | 1 | | | |
| _____2 | 3 | | | |
| _____4 | | | | |

17. To what extent has your participation as a CARRA member resulted in your...? (Please circle one response on each line.)

| | A great extent | A moderate extent | A very small extent | None |
|--|----------------|-------------------|---------------------|------|
| a. Disseminating up-to-date and precise information to your individual cancer community..... | 1 | | | |
|2 | 3 | | | |
|4 | | | | |
| b. Having a better understanding of the cancer research funding process..... | 1 | | | |
|2 | 3 | | | |
|4 | | | | |

| | |
|---|---|
| c. Having a better understanding of the research mission of NCI..... | 1 |
|2 | 3 |
|4 | |
| d. Communicating the specific views and concerns of your cancer community to NCI researchers..... | 1 |
|2 | 3 |
|4 | |
| e. Having a better understanding of the scientific research process..... | 1 |
|2 | 3 |
|4 | |
| f. Other (<i>please specify</i>)_____ | 1 |
| _____2 | 3 |
| _____4 | |

18. What do you think have been the three most significant outcomes of the CARRA program to date?
- a. _____
 - b. _____
 - c. _____

19. What do you think are the three most significant barriers that the CARRA program currently faces?
- a. _____
 - b. _____
 - c. _____

20. Please use the space below to make any additional comments regarding the CARRA program and/or to suggest improvements to the program.

THANK YOU FOR YOUR TIME AND YOUR FEEDBACK !

Please return this survey in the envelope provided, and send to Westat by *(date)*.