FINAL TRAINING EVALUATION REPORT

NCI Pilot Training Workshop: Preparing Cancer Advocates To Participate in Grant Review

May 10–12, 2004—Rockville, Maryland

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Table of Contents

Acknowledgments

I.   Executive Summary

Introduction: The National Cancer Institute (NCI) successfully piloted a 3-day training workshop, Preparing Cancer Advocates To Participate in Grant Review, in Rockville, Maryland, on May 10–12, 2004. Twenty-four members of the Consumer Advocates in Research and Related Activities (CARRA) program—selected by lottery from a pool of 90 CARRA members who had expressed interest in the training—participated in the workshop. With some CARRA members who had never experienced a peer review and some who had participated in several, they represented a diverse range of experience in their previous participation in NCI grant reviews. The purpose of the training was to prepare CARRA members to participate effectively in the NCI peer review process.

Participants were very satisfied with the workshop: Post-workshop evaluations indicated that almost all of the participants were very satisfied with the training. In fact, *82 percent of the respondents reported that they were "very satisfied" with the training. The remaining 18 percent said that they were "somewhat satisfied" with the training.* No participant expressed dissatisfaction with the overall event.

> **Most helpful aspects of the training—a sample of participant responses:**
>
> ➢ The interactions between groups and between professionals and trainers
>
> ➢ Mock review was excellent—<u>really</u> helpful
>
> ➢ The scientists and NIH and NCI staff participation
>
> ➢ Opportunity to have input and discussions
>
> ➢ Opportunity to learn from one another

The training prepared participants for peer review: *All participants reported that they felt the training prepared them to participate in NCI's peer review process.* A majority of the participants (19 of 23 respondents) reported that they were "very likely" to use the information they received at the training, while the remaining 4 participants reported that they were "somewhat likely" to use the information. No participants said they were not likely to use the information.

Participants increased their peer review knowledge: In addition to reporting on their overall satisfaction, participants also completed a 27-question pre-/post-assessment, reflecting the degree to which the training itself contributed to increased knowledge of peer review topics. *Overall, the training resulted in a 12 percentage point increase in participant knowledge*, with the average score increasing from 72 percent correct before the training to 84 percent correct at the end of the training.

The training team featured subject matter experts experienced in peer review: Staff from many NCI offices (including the Division of Extramural Activities [DEA] staff), CARRA members with experience in peer review, and scientists from local universities delivered technical presentations, served as resources for small and large group discussions, and assisted in carrying out a mock peer review. Participants reported the mock peer review, featuring NCI staff, local scientists, and CARRA members, to be the most useful single session of the training. An ORC Macro facilitator led the event, and ORC Macro's curriculum developer and/or evaluator observed all sessions. Staff from Palladian Partners, Inc., provided pre-workshop and onsite logistics support.

The curriculum was developed through a collaborative effort: The curriculum for this training was the result of a comprehensive process launched in 2002 by the NCI Office of Liaison Activities (OLA). OLA gathered a group of individuals (the CARRA Training Planning Group), consisting of staff from across NCI, representatives from the NCI Director's Consumer Liaison Group, as well as members of the CARRA program, to collect feedback on the development of the training workshop. Through a needs analysis of CARRA members, the Training Planning Group developed a set of learning objectives and a preliminary outline for a curriculum, which it

> *Preparing Cancer Advocates To Participate in Grant Review*
>
> **Workshop Goal:** Help CARRA members better understand the NCI peer review process so that they can be effective participants.
>
> **Specific Objectives:**
>
> ➢ Understand NCI's research mission and its extramural research activities
>
> ➢ Be familiar with information on the scientific, technical, and cultural aspects of the NCI peer review process, including how the process works
>
> ➢ Be familiar with key cancer concepts and terminology needed to participate in the NCI peer review process
>
> ➢ Demonstrate effective approaches for participation, reflecting the needs and concerns of the affected community
>
> ➢ Represent the collective views of survivors, patients, family members, and persons affected by and at risk for a disease
>
> ➢ Understand the CARRA/advocate member role and responsibility for participation in the NCI peer review process.

hoped could be further developed through the application of adult learning principles. With technical support in curriculum design and facilitation from ORC Macro, a curriculum was developed to support these learning objectives, incorporating adult learning principles and a participatory style. The Training Planning Group, additional DEA staff, and OLA staff were integrally involved in informing the focus and content of the curriculum through informal meetings and reviews of more than seven drafts.

Recommendations and next steps: Although the overall feedback on the pilot workshop was very positive, several areas for improvement have been identified for subsequent workshops. The recommendations outlined below are based on an analysis of participant feedback, as well as facilitator and curriculum developer observations. Each of these recommendations is discussed in further detail in the full report.

1. **Refocus the goal and objectives of the training so that they are more targeted to "the role of the advocate reviewer" in the NCI grants review process.**

2. **Ensure ample time for discussion and group activities.**

3. **Explore options for extending the total time of the training by approximately four hours.**

4. **Ensure effective use of participant prep work and homework.**

5. **Develop a speaker's packet to prepare speakers and panelists more fully.**

6. **Fine-tune logistics issues related to audiovisual support, supply preparation, and room setup for some sessions.**

7. **Rework curriculum content and flow to reflect the revised goal and objectives of the training, as well as the other recommendations made above.**

8. **Revise the workshop evaluation instruments to reflect modifications to the curriculum.**

9. **Incorporate a feedback mechanism on CARRA member performance in peer review into the ongoing evaluation of the CARRA program that is being conducted by OLA.**

It is anticipated that these recommendations will guide curriculum modifications in preparation for the next training workshop, scheduled for November 15–17, 2004.

Conclusion: This training program constitutes an exciting new activity available to NCI for preparing advocate reviewers to make effective contributions to the grants review process. The involvement of DEA and other NCI staff, as well as external scientists, is critical to the continued value of this program and to ensuring that advocates benefit from the wealth of experience that these individuals have to offer. Because of the program's positive results, OLA will continue to hold these training workshops for CARRA members. OLA's goal is to ensure that an effective and trained cadre of CARRA members is available to participate in peer review and other NCI activities.

II.   Evaluation Results

This section of the report presents the evaluation design, pre- and post-assessment results, overall assessment of the 3-day workshop, and participants' session-specific feedback.

A.   The Evaluation Design

The evaluation design is based on a transfer of training model. Positive transfer of training is defined as the degree to which trainees effectively apply the knowledge and skills gained in a training context to their role as consumer advocates in the grant review process. For transfer to have occurred, learned behavior must be generalized to the work context and maintained over a period of time. The three main factors that affect positive transfer are 1) trainee knowledge, 2) the training itself, and 3) the environment where the transfer is expected to occur. The evaluation collects data on each of these factors.

> ➢ Trainee knowledge. Knowledge gain was assessed through the use of a pre- and post-assessment form, which participants completed before the workshop began and again at the conclusion of the workshop.

> ➢ The pilot workshop. CARRA members completed daily feedback forms, which assessed their satisfaction with each of the training modules. At the end of the first and second days, the training facilitator, curriculum developer, OLA staff, and workshop presenters debriefed and reviewed the daily feedback forms that participants completed. On the basis of observations and participant feedback, the training facilitator and presenters made adjustments throughout the 3 days of training.

> ➢ Assessing the environment. The daily feedback forms also included questions regarding CARRA members' assessment of the facilitators, training process, participant materials, and facility. The facilitator and workshop presenters also reviewed CARRA members' responses and comments to these items and, as needed, made adjustments to better meet participants' learning needs.

Interpreting the Results—a Few Caveats

Caution should be exercised when attempting to interpret the results presented in this report, because of the following caveats:

Sample size: Although the participant feedback, for the most part, reflects input from all workshop participants, the sample size (n=24) is very small. Often, fewer than 24 participants responded to any one item. As a result, small differences in mean values cannot be relied upon to draw larger generalizations about workshop participants.

Self-reporting bias: Daily feedback and end-of-workshop evaluation forms were all self-reported; that is, they reflect individual perceptions of the quality of different aspects of the workshop at a given point in time. As a result, scores provided by respondents on a self-assessment form may reflect bias that is inherent to a self-assessment process. For example, different CARRA members may attribute different numerical values to similar levels of satisfaction. This bias may be increased in situations where respondents are more concerned about meeting the needs of the OLA and the CARRA program than openly reflecting on the issues that are most relevant to their needs. The analysis presented attempts to account for this possible bias by balancing individual scores with qualitative information gleaned from participants' responses to open-ended questions.

Potential design bias on a pre- and post-test: The questions in the pre- and post-assessment were written by the ORC Macro project team (evaluator, curriculum developer, and facilitator) and reviewed by OLA. This pilot delivery was, in a sense, a piloting of the assessment questions as well. It is possible that some of the questions were unclear and/or misunderstood by one or more respondents. As a result, caution should be used in attempting to draw hard-and-fast conclusions about knowledge gains during the pilot workshop.

With these caveats in mind, it is important to also recognize what the information in this report does describe:

General trends in satisfaction—Although the small sample does not provide enough statistical power to measure small differences in perception, it does provide a big picture of whether participants were generally satisfied or dissatisfied with specific elements of the training.

Clues to the sources of satisfaction—Open-ended comments added by participants provide some insights regarding factors that drove satisfaction or dissatisfaction with specific aspects of the training. This information, when combined with the quantitative information on general trends, can be used in possible modifications to the curriculum for future deliveries.

Specific suggestions for improvement—In some cases, individual participants offer specific suggestions for improvement of individual sessions. These suggestions are important tools for considering possible modifications to the curriculum, but they must

be balanced against the overall general trends in satisfaction and observations of the curriculum developer and facilitator, who understand the original intent of a specific session and how it fits into the overall design.

B. Overall Assessment of the 3-Day Workshop

A feedback form was distributed to each participating CARRA member at the beginning of each day. Members were encouraged to rate and comment on each session at its completion. On the last day, members were asked to reflect on the 3-day experience and provide their feedback about their overall satisfaction and intent to use the information gained at the workshop. Participants also provided feedback about the learning objectives, prep work, and homework assignments. A copy of each of the daily feedback forms can be found in appendix B.

1. *Overall Satisfaction with the Training and Preparedness for Peer Review*

Participants were asked to rate their overall satisfaction with the training. Response categories were as follows:

> 1 = very dissatisfied
>
> 2 = somewhat dissatisfied
>
> 3 = somewhat satisfied
>
> 4 = very satisfied.

Participants also rated the degree to which they felt prepared to participate in actual peer reviews by answering three yes/no questions.

The box below summarizes the findings in these areas.

> ➢ All respondents (100%, n=22) indicated that they were somewhat satisfied or very satisfied with the training.
>
> ➢ All respondents (100%, n=23) said that they were prepared to participate in the NCI peer review process.
>
> ➢ Ninety-six percent (96%, n=22) of the respondents felt that they could adequately represent the consumer's viewpoint at an NCI peer review.
>
> ➢ Ninety-five percent (95%, n=20) of the respondents felt that they could adequately evaluate the inclusion of women, minorities, and children in grant applications submitted for peer review.

2. *Level of Satisfaction with the Trainers, Training Methodology, Materials, and Facility*

Each day, CARRA members were asked to provide feedback on the training methods, materials, and facility. Response categories were as follows:

1 = very dissatisfied

2 = somewhat dissatisfied

3 = somewhat satisfied

4 = very satisfied.

> ➢ Participants were more satisfied with the trainers, training content, opportunity for discussion and questions and answers (Q&A), and mix of presentation styles on the second, full day of training, when the mock peer reviews occurred.
>
> ➢ Time constraints and the resultant lack of time for discussion and Q&A resulted in lower levels of satisfaction on the first day of the workshop.

The average scores are shown in table 1 by day of training.

Table 1: Average level of satisfaction with the training methodology, materials, and facility

Training methods, materials, and facility	Day 1		Day 2		Day 3	
	n	**O**	**n**	**O**	**n**	**O**
Sensitivity of the trainer(s) to the participants' issues, needs, and concerns	24	3.58	23	3.78	21	3.71
Ability of the trainer(s) to effectively present the training content	24	3.63	23	3.95	20	3.70
Opportunity for questions/discussion	23	2.87	24	3.38	22	3.14
A mix of formal and participatory presentations	21	3.43	24	3.71	22	3.59
Materials in the participants' binders	22	3.73	24	3.79	23	3.78
The training facilities	23	3.48	23	3.57	22	3.73

Several participants wrote comments for each of the items listed in table 1. A complete list of participants' verbatim comments can be found in appendix C. However, the key themes that seem to emerge from written comments, when examined against the quantitative scores in table 1, were the importance of allowing sufficient time for discussion and participatory learning activities, as well as the positive value of including qualified trainers, presenters, and panelists from NCI and the cancer research community.

3. *Learning Objectives, Prep Work, Homework, and Information Received*

> ➤ The pilot curriculum was designed to achieve six learning objectives. As shown by the participant feedback, most CARRA members felt that training was successful in helping them meet the objectives of the workshop.
>
> ➤ Each participant received background material/homework prior to the workshop. Slightly more than half of the respondents (52%) said that these materials provided them with the information they needed to attend the training. Some participants thought that it would have been more helpful if they had received a preliminary agenda, case study, overview information, a grant application "de-mystified" with explanatory notes, and/or the manual prior to the training.
>
> ➤ While the majority of respondents (95%) indicated that the nightly homework assignments were somewhat or very useful, a show of hands on the last day of training revealed that most people had not completed the homework assignments.
>
> ➤ Nearly all of the respondents (86%) said that they were very likely to use the information they received at the training. The remaining 14 percent were somewhat likely to use the information.

Learning Objectives

Six learning objectives were identified for this workshop through deliberation with the CARRA Training Planning Group, made up of key stakeholders. CARRA members were asked to rate how successful the training was in helping them meet each of the objectives. Response categories were as follows:

   1 = not very successful

   2 = somewhat successful

   3 = mostly successful

   4 = very successful.

Table 2 includes the number and percentage in each response category and the average score (mean) for each objective. The mean scores for the six learning objectives ranged from 3.30 (demonstrate effective approaches for participation that reflect the needs and concerns of the affected community) to 3.78 (understand the CARRA/advocate member role and responsibility for participation in the NCI peer review process).

Table 2: Level of success in meeting learning objectives

Learning objective	Not very successful		Somewhat successful		Mostly successful		Very successful		Mean score
	n	%	n	%	n	%	n	%	0
a. Understand NCI's research mission and its extramural research activities. (n=23)	0	0%	2	9%	8	35%	13	56%	3.48
b. Be familiar with information on the scientific, technical, and cultural aspects of the NCI peer review process, including how the process works. (n=23)	0	0%	1	4%	9	39%	13	56%	3.52
c. Be familiar with key cancer concepts and terminology needed to participate in the NCI peer review process. (n=22)	0	0%	3	14%	7	32%	12	54%	3.41
d. Demonstrate effective approaches for participation that reflect the needs and concerns of the affected community. (n=23)	0	0%	4	17%	8	35%	11	48%	3.30
e. Represent the collective views of survivors, patients, family members, and persons affected by and at risk for disease. (n=23)	1	4%	4	17%	6	26%	12	52%	3.26
f. Understand the CARRA/advocate member role and responsibility for participation in the NCI peer review process. (n=23)	0	0%	1	4%	3	13%	19	83%	3.78

A review of the data reveals that overall, participants appear to feel that the pilot was mostly to very successful in meeting the six learning objectives. As mentioned earlier in this report, small sample size makes it difficult to draw further conclusions about the utility of each objective solely on the basis of this information. Decisions about which, if any, objectives to modify or eliminate should also be made in conjunction with observations from the facilitator, curriculum developer, OLA staff, and workshop presenters.

Prep Work

Slightly more than half of the respondents (52%, n=11) reported that the preparation material helped prepare them for the training. Thirty-eight percent (38%, n=8) of the respondents said that the materials did not help them, and 10 percent (n=2) responded "yes" and "no" to this question.

Participants who reported that the materials were helpful were asked to further indicate how the materials helped them prepare for the training and what materials were particularly helpful. Likewise, participants who said that the materials were not helpful were asked what types of materials would have been more helpful. Table 3 shows some of the participants' comments. A complete list is available in appendix C.

Table 3: Prep work Sample Participant Comments	
Materials that were useful—	**Materials that would have been more useful—**
➤ The "quiz" or "homework" focused my attention. ➤ Video and written materials were good to set the stage for the seminar and what to expect/anticipate. ➤ Guideline provided me with information to help in the review process. The video. ➤ The video was helpful. However, a patient advocate needs to be included. ➤ Information on peer review/clinical trials.	➤ More detailed cheat sheets asking us to identify specific items in the grant application. I really like the "key" points to consider. ➤ I would have liked the manual in advance to read. ➤ Case studies; preliminary agenda; IRB [institutional review board] information; grant application "de-mystified" with explanatory notes; video with patient advocate participation and comments. ➤ Seeing advocates interacting. Couldn't you do a mock review on tape? How to focus on parts that concern advocates. ➤ I think it would have been more helpful to have overview information about CARRA and NCI rather than so much clinical information. There was too much that was complex without first having the foundation. ➤ More specifics on what we will do at the training. Maybe share previous CARRA functions and accomplishments—where and what CARRA members have achieved—in what programs—all anonymously.

Homework

Participants were asked the degree to which they thought the homework assignments they completed were useful. Response categories were as follows:

1 = not at all useful

2 = not very useful

3 = somewhat useful

4 = very useful.

Slightly more than half (59%, n=13) of the respondents said that the homework was somewhat useful. Thirty-six percent (n=8) of the respondents said that it was very useful, and 5 percent (n=1) said it was not very useful (O=3.32).

Information Received

Participants were asked to comment on how much new information they received in the training. Response categories were as follows:

1 = no new information

2 = a little new information

3 = some new information

4 = a lot of new information.

Fifty-nine percent of the respondents (59%, n=13) reported that they received a lot of new information. Thirty-two percent (32%, n=7) said that they received some new information, and 9 percent of the respondents (9%, n=2) said that they received a little new information (O=3.50).

Eighty-six percent (86%, n=19) of the respondents reported that they were very likely to use the information they received at the training. The remaining 14 percent (14%, n=4) of the respondents said that they were somewhat likely to use the information (O=3.86).

4. *Helpful Aspects of Each Day's Sessions*

Each day, participants were given an opportunity to identify the *most* helpful aspect of the sessions, as well as aspects that require attention or improvement. This information was used primarily by the training team to take the pulse of the group each day and to determine whether any changes of focus were needed for the following day. Feedback from day 1, for example, strongly suggested the need to allow more time for discussion and participants' Q&A, as well as a desire for a more focused approach to the role of

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CARRA members in peer review. The training team made an effort to address these issues on day 2, and feedback on that day reflected a higher degree of participant satisfaction with those elements of the training.

Appendix C contains a complete list of participants' verbatim comments. A more complete discussion of recommendations is given in Section III: Recommendations for Next Steps.

C. Pre- and Post-Assessment Findings

To assess participants' knowledge about the peer review process, role and expectations of the consumer advocate, conflict of interest and confidentiality issues, clinical trials, and NCI, the training facilitator asked participants to complete a pre-assessment form at the beginning of the first day and a post-assessment form at the conclusion of the workshop. The assessment, which can be found in appendix A, included 27 true/false and multiple choice items. These items were based on information that was to be conveyed to participants during the 3-day pilot workshop. These results are based on 22 matched pre- and post-assessment forms. Two participants who completed the pre-assessment form did not complete the post-assessment form because they left the workshop early.

Summary of Key Findings—Increased Knowledge

Participants' scores increased, on average, 12 percentage points. The percentage point spread between pre- and post-assessment ranged from –6 to 26 percent, with fourteen of the twenty two respondents showing knowledge gains of 10 percentage points or more.

By the end of the workshop, more participants understood that—

  ➢ It is not necessary to review the entire application when reviewing a grant application.

  ➢ Thinking about one's own personal experience with cancer is not appropriate when reviewing applications.

  ➢ A majority of NCI's funds go to other research institutions.

  ➢ The peer review process typically includes scientists, consumer advocates, and NCI staff.

  ➢ For research purposes, the National Institutes of Health (NIH) defines a child as an individual under 21 years of age.

At the end of the workshop, participants were still confused about—

  ➢ Whether there are standard review criteria that are used to rate all applications.

  ➢ Whether they should submit their questions and concerns about the application when they turn in their completed review.

  ➢ Whether CARRA members should solicit citizens to participate in clinical trials.

Pre- and Post-Assessment Percentage Point Change

The average pre-assessment score was 72 percent correct. On average, participants' scores increased 12 percentage points to 84 percent correct on the post-assessment. The percentage point spread between the pre- and post-assessment ranged from a 6 percent decrease to a 26 percent gain, with an average increase of 12 percentage points.

Table 4: Percentage correct on pre- and post-assessment and percentage change

Respondent number	Pre % correct	Post % correct	% change
1	55%	81%	26%
2	61%	84%	23%
3	48%	71%	23%
4	74%	90%	16%
5	71%	87%	16%
6	68%	84%	16%
7	81%	94%	13%
8	77%	90%	13%
9	74%	87%	13%
10	71%	84%	13%
11	71%	84%	13%
12	58%	71%	13%
13	77%	87%	10%
14	77%	87%	10%
15	81%	90%	9%
16	68%	77%	9%
17	87%	94%	7%
18	84%	90%	6%
19	71%	77%	6%
20	77%	81%	4%
21	71%	71%	0%
22	87%	81%	–6%

Table 4 shows the percentage of correct responses for each respondent on the pre-assessment, the percentage of correct responses on the post-assessment, and the percentage increase or decrease between the pre- and post-assessment. The table shows that fourteen of the respondents showed a knowledge gain of 10 percent or higher, while only one showed a decrease in knowledge by the end of the training. Individuals with lower pre-test scores (respondents 1, 2, 3, and 12) showed the greatest gains in knowledge. Participants with the highest pre-test scores (respondents 17, 18, and 22) showed lower overall gains in knowledge and, in the case of one respondent, a decrease in knowledge between the pre- and post-assessment.

As shown in table 4, pre-assessment scores ranged from 48 to 87 percent correct, and post-assessment scores ranged from 71 to 94 percent correct.

The number and percentage correct for each pre- and post-assessment question and the overall percentage point change for 22 respondents who completed the forms are shown in tables 5a and 5b.

Table 5 a: Pre- and post-assessment results, n=22[1]

Questions	Pre-assessment		Post-assessment		% point change
	n	%	n	%	
1. Most of what the National Cancer Institute (NCI) does is funding research, rather than conducting research itself. True	11	50%	17	77%	27%
2. The NCI is part of the Centers for Disease Control and Prevention. False	18	82%	21	96%	14%
3. Peer review is the process by which scientists' requests for research support are evaluated by a group of experts in the field. True	17	77%	20	91%	14%
4. The consumer advocate is a full participating member of the review panel and has equal voting status on evaluating both the scientific merit of applications and the budget of applications. True	16	73%	21	96%	23%
5. There are a standard set of review criteria that are used to rate all applications. False	1	4%	2	9%	5%
6. When reviewing an application, consumer advocates should always read the entire application. False	8	36%	18	82%	46%
7. About 10% of people with cancer participate in cancer clinical trials. False	14	64%	16	73%	9%
8. The consumer advocate serves as the lay representative of patient interests, giving patients and those who care for them a voice in the peer review process. True	22	100%	21	96%	–4%
9. Consumer advocates are encouraged to think about their own personal experiences with cancer when reviewing applications. False	7	32%	14	64%	32%
10. Consumer advocates are encouraged to contact the applicant and ask clarifying questions about the application during the review process. False	21	96%	21	96%	0%
11. Consumer advocates are encouraged to write down any questions and concerns they have about the application and submit them when they turn in their completed review. False	7	32%	6	27%	–5%

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[1] A nonresponse to questions 1 through 13 was counted as an incorrect response when calculating percentages.

Questions	Pre-assessment		Post-assessment		% point change
	n	%	n	%	
12. When reviewing an application, consumer advocates should: a. Understand the objectives that the particular funding mechanism is designed to achieve. True	21	96%	22	100%	4%
b. Understand the review guidelines. True	22	100%	22	100%	0%
c. Follow the scientific review administrator's (SRA) instructions regarding the review guideline, mechanics of the review, conflict of interest, confidentiality issues, and behavior and etiquette. True	21	96%	22	100%	4%
d. Understand the review criteria for use of human subject issues. True	21	96%	22	100%	4%
e. Be familiar with consent form issues, therapeutic and non-therapeutic trials, issues involving ethnicity and underserved populations. True	20	91%	22	100%	9%
13. An actual conflict of interest arises when a CARRA member has or would have official responsibilities with an outside organization named in a grant application up for peer review by the CARRA member with which the CARRA member has a financial interest or affiliation. True	21	96%	22	100%	4%

Table 5 b. Pre- and post-assessment results, n=22[2]

Questions	Pre-assessment		Post-assessment		% point change
	n	%	n	%	
14. Which of the following elements should consumer advocates evaluate regarding the protection of human subjects from research risk?					
Risks to the subjects	0	0%	0	0%	0%
Adequacy of protection against risks	2	9%	0	0%	−9%
Potential benefit of the proposed research to the subjects and others	1	4%	0	0%	−4%
Importance of the knowledge to be gained	0	0%	0	0%	0%
All of the above	19	82%	22	100%	18%
None of the above	0	0%	0	0%	0%
Missing	2	4%	0	0%	−4%
15. For research purposes, the NIH defines a child as an individual:					
Under 5 years of age	0	0%	0	0%	0%
Under 16 years of age	1	4%	3	14%	10%
Under 18 years of age	11	50%	5	23%	-27%
Under 21 years of age	8	36%	14	64%	28%
Missing	2	9%	0%	0%	−9%
16. What is the purpose of clinical trials?					
To answer scientific questions	2	9%	0	0%	−9%
To evaluate new prevention/treatment approaches	1	4%	1	4%	0%
To improve cancer care to patients	0	0%	0	0%	0%
All of the above	18	82%	21	96%	14%
Missing	1	4%	0	0%	−4%
17. A clinical protocol …					
States the study's design and who will be able to participate in the study.	2	9%	1	4%	−5%
Explains what the trial will do, how the study will be carried out, and why each part of the study is necessary.	2	9%	0	0%	−9%
Ensures that participants are treated identically no matter where they are receiving treatment.	0	0%	0	0%	0%
All of the above	17	77%	21	96%	19%
Missing	1	4%	0	0%	−4%

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[2] Correct responses are shown in bold. A nonresponse to questions 14 through 27 is listed as "missing."

Questions	Pre-assessment		Post-assessment		% point change
	n	%	n	%	
18. CARRA members participate in all of the following activities except . . .					
Developing and reviewing cancer education pamphlets, videos, and/or Websites	0	0%	0	0%	0%
Evaluating patient-oriented research at cancer research centers	1	4%	2	9%	5%
Soliciting citizens to participate in clinical trials	17	77%	16	73%	–4%
Participating in meetings	0	0%	1	4%	4%
None of the above	4	18%	3	14%	–4%
19.The peer review team typically includes:					
Scientists	0	0%	0	0%	0%
Consumer advocates	0	0%	0	0%	0%
NCI staff	0	0%	0	0%	0%
Scientists and consumer advocates	7	32%	1	4%	–28%
All of the above	15	68%	21	96%	28%
None of the above	0	0%	0	0%	0%
20.The SRAs try to facilitate the peer review process for first time consumer advocates. SRAs will:					
Telephone each consumer advocate and explain how to review the materials and what the advocate should concentrate on.	2	9%	3	14%	5%
Refer consumer advocates to the CARRA website for more information.	0	0%	1	4%	4%
Provide, upon request, a mentor for the consumer advocate.	1	4%	0	0%	–4%
All of the above	14	64%	17	77%	13
None of the above	0	0%	0	0%	0%
Missing	1	4%	3	14%	10%
21. About 80% of the annual NCI budget goes towards funding cancer research at other academic and medical institutions around the country. This is called ___ research in the NCI vocabulary.					
Outside	1	4%	0	0%	–4%
Intramural	0	0%	0	0%	0%
Bench	1	4%	0	0%	–4%
Extramural	17	86%	22	100%	14%
Missing	3	14%	0	0%	–14%

Questions	Pre-assessment		Post-assessment		% point change
	n	%	n	%	
22. Confidential information includes any information submitted to NCI for review. From the list below, which is <u>not</u> an example of confidential information?					
Grant applications	0	0%	1	4%	4%
Financial, professional, or personal information related to an individual or organization	1	4%	1	4%	0%
Peer review information on the CARRA Website	17	77%	17	77%	0%
Grant renewal/status reports	3	14%	2	9%	−5%
Missing	1	4%	1	4%	0%
23. NCI has the following expectation(s) of its consumer advocates…					
That they focus on human subjects' protection, recruitment of women, children and minorities in clinical trials, and generally represent the consumer perspective.	16	73%	19	86%	13%
That they review the science and lobby for their particular disease.	0	0%	0	0%	0%
All of the above	5	23%	3	14%	−9%
None of the above	1	4%	0	0%	−4%
24. Which one of the following is <u>not</u> a patient protection mechanism in clinical trials?					
Institutional Review Board (IRB)	0	0%	1	4%	4%
Scientific review by the clinical trial sponsor	7	32%	5	23%	−9%
Randomized study	14	64%	16	73%	9%
Informed consent	0	0%	0	0%	0%
Missing	1	4%	0	0%	−4%
25. Which of the following is a common myth about clinical trials?					
Only a small percentage of adults with cancer enroll in clinical trials	1	4%	0	0%	−4%
Cancer treatment clinical trials are the treatment of last resort	19	86%	21	96%	10%
Randomization in clinical trials prevents bias in research	0	0%	0	0%	0%
Standard treatment options may or may not be better than the new experimental treatment	2	9%	1	4%	−5%

Questions	Pre-assessment		Post-assessment		% point change
	n	%	n	%	
26. Of the following, which statement is <u>not</u> a responsibility of those conducting peer reviews at the NIH?					
To evaluate the proposed plan for the inclusion of minorities and both genders for appropriate representation	0	0%	0	0%	0%
To evaluate the proposed justifications when representation of women and minorities is limited or absent	2	9%	4	18%	9%
To evaluate the plans for recruitment/outreach for study participants	5	23%	3	14%	–9%
To ensure that minorities and women are always included	13	59%	13	59%	0%
Missing	2	9%	2	9%	0%
27. The outcome of a peer review is:					
A funding recommendation	22	100%	22	100%	0%
A funding decision	0	0%	0	0%	0%

D. Session-Specific Feedback

1. *Level of Satisfaction with the Individual Workshop Sessions*

At the beginning of each day, participants were given a feedback form, which they were asked to turn in at the end of the day. CARRA members rated their level of satisfaction with 13 different sessions. Response categories were as follows:

1 = very dissatisfied

2 = somewhat dissatisfied

3 = somewhat satisfied

4 = very satisfied.

Participants attended 13 sessions over a 3-day period. The mean score (O) for every session was at least 3.0, indicating that most people were somewhat to very satisfied with the session. The sessions that rated the highest were:[3]

- ➢ Mock Peer Review—Day 2 (O = 3.96)
- ➢ Roles and Responsibilities of CARRA Members in the Peer Review Process—Day 2 (O = 3.83)
- ➢ History of the CARRA program—Day 1 (O = 3.74)
- ➢ Challenging Scenarios in Peer Review—Day 3 (O = 3.74).

The sessions rated lowest were:

- ➢ Discussion of Center for Scientific Review (CSR) Video on Peer Review—Day 1 (O = 3.09).
- ➢ Identifying Appropriate Resources for Locating Current Information on Key Cancer Concepts (Computer Lab)—Day 3 (O = 3.26)
- ➢ Gallery Walk/Poster Session—Day 1 (O = 3.33)

Presented in Table 6 are the 13 sessions, the number of participants who responded to the item, the percentage for each scoring category, and the average or mean score for the session. Participants were also given an opportunity to write comments about each session. Sample comments are listed below each session. (Appendix C contains a complete list of participants' verbatim comments.)

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[3] The mean score can range from 1.0 to 4.0. The higher the score, the greater the participants' satisfaction with the session

Table 6: Level of satisfaction with the individual workshop sessions

Day/session	Very dissatisfied		Somewhat dissatisfied		Somewhat satisfied		Very satisfied		Mean score
	n	%	n	%	n	%	n	%	
Day 1									
History of the CARRA Program	0	0%	0	0%	6	26%	17	74%	3.74
Comments: ➢ Very interesting. ➢ Very informative.									
CARRA Members' Roles and Responsibilities	0	0%	0	0%	7	30%	16	70%	3.70
Comments: ➢ Slides different from what [is] in notebook. ➢ Very frank—I appreciate it. Could have used specific examples/sharing of examples from advocates. ➢ Please explain all acronyms (OLD, CTEP, etc.). ➢ Good discussion. ➢ I have a better understanding. ➢ I would have liked to have had a copy of entire presentation.									
Discussion of Center for Scientific Review (CSR) Video on Peer Review	0	0%	4	17%	13	56%	6	26%	3.09
Comments: ➢ Not enough time allotted. ➢ More focused discussion would have been helpful. It seemed to raise people's anxiety rather than address specifics. ➢ Too hypothetical—need to deal with specifics.									
Day 2									
Mission, Organization, and Budget of NCI	1	4%	1	4%	8	35%	13	56%	3.43
Comments: ➢ Need more time for questions. The presenter did well with a very dry and confusing subject. ➢ This was a great overview of NCI and the total system. ➢ Simplify and spruce up slides. ➢ Some handouts not appropriate for visually challenged. ➢ Thought too much of an emphasis.									

Day/session	Very dissatisfied		Somewhat dissatisfied		Somewhat satisfied		Very satisfied		Mean score Q
	n	%	n	%	n	%	n	%	
Gallery Walk/Poster	0	0%	4	17%	8	33%	12	50%	3.33

Comments:

> Tables too close together—making it too noisy and hard to hear. Good speakers and topics—great information.

> Give exposure to other aspects of NCI.

> Good idea—too much confusion—not enough time—needed more structure—the presenters were good—many questions left unanswered.

> Times too short for questions. Too much info to give in 5 minutes. I hope the materials I picked up will help, because I doubt I will retain any of the info from the sessions.

> Loved walking around! I wish there had been more emphasis on how we interacted with them, in very specific ways—everyone gave good info, but needed to be prompted for the tie-in.

Day/session	Very dissatisfied		Somewhat dissatisfied		Somewhat satisfied		Very satisfied		Mean score
The NCI Peer Review Process (Procedural Aspects)	0	0%	1	4%	9	38%	14	58%	3.54

Comments:

> Worksheet gave opportunity for good discussion.

> For me this was the most beneficial portion of the program so far—more dynamic byplay.

> It was information—again, just not enough time to address the points/questions raised.

> This was good, but it could have covered more territory with more input from several people. The SRA missed some of the questions. He could have listened more. Use the experience of the room.

Day/session	Very dissatisfied		Somewhat dissatisfied		Somewhat satisfied		Very satisfied		Mean score
The NCI Peer Review Process (Technical Aspects): Conflict of Interest, Confidentiality, and Lobbying	0	0%	0	0%	8	33%	16	67%	3.67

Comments:

> Excellent.
> Examples need to be clearer. #3 left me hanging—why is this a conflict?
> Helpful—good for discussion. Important concept for consumer advocates to understand.
> Important information—ran out of time.
> More discussion time.

Day/session	Very dissatisfied		Somewhat dissatisfied		Somewhat satisfied		Very satisfied		Mean score
	n	%	n	%	n	%	n	%	
The NCI Peer Review Process (Technical Aspects): Grant Mechanisms and Scientific Review	0	0%	0	0%	7	30%	16	70%	3.70

Comments:
  - Great information. I really appreciate the presenters presenting to us.
  - Made sense. Very understanding!
  - Important information—helps to give the consumer advocate a better understanding of the overall review process.
  - It would have been helpful to have this info presented earlier in the training.

Roles and Responsibilities of CARRA Members in the Peer Review Process	0	0%	1	4%	2	9%	20	87%	3.83

Comments:
  - Good presentation, opened up areas for discussion.
  - Very structured and understanding. Led to excellent discussion.
  - Better to "learn by doing"—this is too much blah blah. The discussion was very good.
  - More time should have been allotted to this discussion.

Mock Peer Review Process	0	0%	0	0%	1	4%	22	96%	3.96

Comments:
  - Excellent—continue this!!! Need to discuss written statements for advocates' comments. Is there a definitive form that these are written on?
  - More time!!
  - Most significant event! Excellent!
  - The panelists were really helpful and effective. Good process.
  - Real eye-opener. Help to bring things into focus.
  - 1st mock review—pick a review that involves the consumer advocate more. 2nd mock review—very helpful in providing a useful example of peer review exercise.

Day 3									
Clinical Trials	0	0%	3	13%	5	22%	15	65%	3.52

Comments:
  - Good way to teach this, even though quite a bit of time was allocated. It could have been longer.
  - Excellent information. The Jeopardy game was a cute idea; however, it created distractions. The plastic animals used to show randomization and stratification was a great idea. Need more time!!
  - How about patient experiences presentation/panel?
  - This information is critical. I would have gotten more from a true presentation and not so much time with game activity, IRB, Belmont Tuskegee issues. The presenter was wonderful but often not allowed to fully explain content.
  - Not enough time for full discussion.

Day/session	Very dissatisfied		Somewhat dissatisfied		Somewhat satisfied		Very satisfied		Mean score O
	n	%	n	%	n	%	n	%	
Challenging Scenarios in Peer Review	0	0%	1	4%	4	17%	18	78%	3.74

Comments:

- ➢ Needed more discussion/modeling—maybe do role-playing?
- ➢ I liked the group interaction.
- ➢ Excellent. Wonderful way to consider these situations. Need more time for discussion.
- ➢ The discussion highlighted information learned from earlier sessions. I found myself integrating otherwise unrelated pieces of information.
- ➢ Good exercise; very helpful. Advocated need to be more proactive and not be afraid to represent your convictions.

Day/session	Very dissatisfied		Somewhat dissatisfied		Somewhat satisfied		Very satisfied		Mean score
Identifying Appropriate Resources for Locating Current Information on Key Cancer Concepts	1	4%	3	13%	5	26%	10	53%	3.26

Comments:

- ➢ Screen not working at first, not sufficient time.
- ➢ We already know most of this.
- ➢ Good information but not necessary to use a computer lab, used time unnecessarily.
- ➢ I am a computer illiterate! This session helped me a lot.
- ➢ Already familiar with Web site and browsing. Perhaps divide group into two—one that needs computer assistance and the other to spend on another worthwhile related topic.

III. Recommendations for Next Steps

This section outlines recommendations for improving the training curriculum based on the experience with the pilot workshop. Recommendations reflect the observations and input of the workshop facilitator and curriculum developer (who participated as an observer in the pilot workshop), as well as a review and analysis of the participant feedback described in the previous sections of this report. Each recommendation is followed by a short discussion, which provides a rationale and suggested strategies for implementation.

1. **Refocus the goal and objectives of the training so that they are more targeted to "the role of the advocate reviewer" in the NCI grants review process.**

   Discussion: Sessions rated most useful by participants were those that related directly to the role of the advocate reviewer. Informal feedback from participants to the curriculum developer and facilitator during the course reinforced this sentiment. Furthermore, participants consistently expressed a desire to spend more time on discussions and to get into the role of the advocate reviewer more quickly on the first day.

   From a curriculum development perspective, realignment of the training's goal and objectives in this manner would not represent a major shift in the focus of the training, but it would help to guide any refocusing of the content or processes of specific sessions. The present goal statement for the training, "help CARRA members better understand the NCI peer review process so they can be more effective participants," might be restated along the lines of "help CARRA members better understand their role in the NCI grant review process, so that they can best represent the advocate perspective on peer review panels."

   Each module of the training would have to clearly link itself to the role of the advocate reviewer in NCI grants review. In practical terms, this will mean that in a revised curriculum, participants will be able to clearly understand how the specific content covered contributes to them being more effective peer reviewers.

2. **Ensure ample time for discussion and group activities.**

   Discussion: Participant feedback and facilitator observations suggest that participants most benefited from sessions that featured small group discussions and/or practical activities where they could apply their understanding of a specific concept. From a curriculum development perspective, it is important to allow sufficient time for these processes to work, so that participants do not

become frustrated because they are given a task but not enough time to complete it or debrief it.

In accordance with adult learning principles, it is important to vary the nature of the activities used to communicate the key concepts and skills sets of the training—not everything has to be a small group activity or a lecture from a technical expert. At the same time, it is important to allow ample time for questions after didactic presentations, as well as ample time for groups to understand, complete, and discuss their assignments when small group work is involved.

3.   Explore options for extending the total time of the training by approximately 4 hours.

Discussion: Participant feedback suggests that more time should have been allotted to a number of sessions. From a facilitation perspective, it was challenging to manage discussions and allow for sufficient questions and answers in every session. While it can be expected that there will occasionally be situations where the facilitator has to push the group to move on in the interests of time, sessions had to be cut off too often during the pilot delivery.

Originally, the training was envisioned as the equivalent of 2½ days (20 hours). However, because of room availability and concerns about participant travel schedules, the training was 14 hours and 15 minutes, excluding breaks and lunch.

It would be useful to explore the possibilities of starting the training 1 hour earlier on day 1 and adding a lunch break and 3 additional hours on the third day. This model would hopefully still allow participants to travel on the first day of the workshop and travel home on the third day.

4.   Ensure effective use of participant prep work and homework.

Discussion: Slightly more than half of all respondents reported that the preparation materials (52%) and the homework (59%) were useful. Facilitator and curriculum developer observations suggest that these levels of satisfaction may relate partly to the manner in which the preparation work and homework were utilized at the training event itself. Informal discussions with participants during the training suggested some level of frustration that the CSR video was not discussed in greater detail on the first day. Other participants found it difficult to fully absorb and analyze two grant applications on the evening of the first day in preparation for the Mock Peer Review on day 2—partly because they had traveled the same day and may have been tired, but also because they may

not have had the tools to guide them in how to most efficiently read a grant application (many tried to read each one from cover to cover, instead of looking systematically at key sections).

Work prior to the workshop allows participants to become familiar with the training content, gives the training team an opportunity to "cover" material that cannot be discussed in the training because of time constraints, and tests the participants' ability and willingness to work unsupervised. In future deliveries, it will be important to ensure that there is a clear link between any preparation work and the material covered in the actual training course, and that demands for evening work during the actual training course are minimized so that participants have an opportunity to absorb the learning from the day and network informally with their colleagues. Some specific recommendations for streamlining the preparation and homework in the future might include the following:

> The Center for Scientific Review video and questions only should be sent to participants 1 month in advance. Participants can be given the option of visiting the CSR Web site to review the full grants used in the CSR video if they would like more information. They should be asked to complete the sheet with questions and return it to OLA 10 days before the training. This will ensure that people actually do the work and will give staff an opportunity to spot those with difficulties before the training. The discussion of the video can be focused around gaps or questions that emerge from a review of the completed question sheets.

> The grants that accompany this video should not be sent, and participants should be asked to focus on how the grant review meetings are run, as well as the roles and responsibilities of the different participants in those meetings. This will be an appropriate focus for the video as part of an introduction to the advocate role on the first day.

> As part of the pre-workshop preparation, the guiding questions from the session on Web-based resources should be sent to participants, and they should be asked to practice going to some Internet sites. They should be asked to go to the CARRA site and answer some questions designed to test their ability to find the site, read the information, and use the information. This will cut down on the amount of CARRA information that needs to be presented at the training and will test participants' ability to use the computer to find

important information. If participants have difficulty, they may be instructed to contact OLA for technical assistance.

➢ The clinical trials workbook should be sent to participants for review prior to the training. Participants should be told that this information will be used for exercises during the training.

➢ Participants should be sent a handout (to be developed) called "the anatomy of a grant—guidelines for efficient grant review" and a copy of the grant that they will be asked to review for their participation in the mock review. They should be asked to use the handout to review the grant, explaining that this grant will be used during the mock peer review at the training.

➢ For homework each night, participants should be asked only to refresh their memories with a quick review of the relevant prep work materials that apply to the next day.

5.   Develop a speaker's packet to prepare speakers and panelists more fully.

Discussion: The pilot delivery required coordination with 19 different presenters or panelists representing NCI, CARRA members, and academic institutions. Some of these individuals were solely responsible for leading specific sessions, while others were responsible for copresenting or working together on a panel. OLA staff and the curriculum development team made multiple efforts to contact and orient each of these individuals; however, there were still instances in which individuals could not be contacted directly, did not prepare for their presentations until the last minute, changed key elements of their presentations after participant materials had been produced, or had to drop out at the last minute. While many of these things are a natural result of working with such a diverse group of presenters who have different schedules and commitments, presenter preparation should receive increased attention in future deliveries, with the goal of ensuring consistency of quality across all sessions at the training.

A speakers' packet would outline an explanation and the rationale for a participatory and experiential training approach, set forth speaker ground rules, give suggestions about preparation (e.g., reading the sessions right before and right after their own), and include the presentation materials and curriculum for the given session and other related sessions. Also, an alternate for key presentations could be identified in preparation for unexpected circumstances in which a presenter might not be present.

6.   Fine-tune logistics issues related to audiovisual support, supply preparation, and room setup for some sessions.

Discussion: Participant feedback indicates that logistics were generally smooth for the event—satisfaction with the training facilities and participant binders was high. Palladian Partners staff were responsive to unanticipated participant and facilitator needs, and participants seemed to be generally satisfied with their transportation and housing accommodations.

Individual participant comments, as well as the observations of the curriculum developer and facilitator, suggest several areas that might be fine-tuned in future deliveries to enhance the overall quality of the event:

> **Audiovisual Support:** The capabilities of the facilities for AV support were impressive, but there were several occasions where the table microphones at the front of the room did not function. The large screen at the front of the main room went all the way to the floor of the room, and it was not possible to project a presentation only on the upper part of that screen so that all participants could see from where they were sitting. By the second day, presentations used a portable projector connected directly to a laptop to address this issue.

> **Supply Preparation:** Palladian Partners did an excellent job in collecting a range of miscellaneous resources that were necessary for carrying out some activities (e.g., a deck of playing cards, different types of toy animals for a randomization activity). However, some of these materials were not "prepared" prior to their respective sessions (e.g., cards were not cut in half, items needed to be taken out of their packages in advance of training). It is recommended that in future trainings, the training team provide Palladian with a more detailed logistics checklist so Palladian has clear instructions on what to do with the logistics supplies it has organized.

> **Water at Tables:** Participants complained about not having the room "freshened with water" throughout the day.

> **Computer Lab:** During the curriculum development phase, the computer lab session was identified as an important session that should be retained for the pilot. However, the placement of this session as the last module of the training, paired with the need to transport participants to another facility for this session, was not ideal. From a facilitation perspective, it was difficult to transition participants from a valuable discussion about challenging scenarios

to the need to pick up their belongings and get on a bus to go to the computer lab, leaving enough time at the computer lab but still closing the training in time for people to catch cabs to the airport. Participants felt as if they lost about 30 minutes in the transition, which could have been better used for a continuation of the morning's activities.

➢ **Gallery Walk:** Some participants reported difficulties hearing their presenters at these sessions because the tables at which each NCI representative presented were too close together, and it was easy to be distracted by the other presentations that were occurring simultaneously.

7. Rework curriculum content and flow to reflect the revised goal and objectives of the training, as well as the other recommendations made above.

Discussion: The implementation of this recommendation will result in a revised curriculum to be implemented at the next delivery date. In addition to the curriculum-related issues outlined above, participants also requested greater focus on human subjects protection; recruitment of women, children, and minorities; how to read grants; and how to write up their reviews. Outlined below are some suggested guidelines for revisions to each specific day of the training, which would serve as a point of departure for discussions with OLA staff and key stakeholders about specific revisions to the curriculum. The participation of DEA staff in informing new content or changes to existing content will be important for ensuring that the training program best prepares participants for their roles in the peer review process.

Day 1

➢ Start an hour earlier.

➢ Reduce time for icebreaker.

➢ Review the roles of CARRA members in less time (participants will have read the information on the Web site as prep work; thus, this can be covered quickly).

➢ Devote more time to actually discussing the CSR video (no DEA speaker needed) and perhaps go over the anatomy of a grant.

➢ Consider an afternoon social event to welcome participants where they might mingle with each other, have lunch together, listen to welcoming comments from NCI staff, and ask informal questions.

Day 2

➤ Start with the roles of CARRA members in the peer review process. Consolidate the information from the procedural and technical aspects of peer review, as well as the roles and responsibilities of the CARRA members in the peer review process.

➤ Dedicate the entire afternoon to Mock Peer Review, devoting more time to discussing and deconstructing the first Mock Peer Review with examples of what a good writeup looks like. Likewise, give more time for discussion of the second Mock Peer Review. (Note: Find some grants that have more explicit examples of human subjects protection [HSP] and recruitment to clinical trials issues; develop checklists related to HSP and recruitment of minorities, women, and children to facilitate review of grants—these might be sent along with the prep work.)

Day 3

➤ Extend day 3—include a lunch break and close at 3:30 p.m.

➤ Allot more time to the clinical trials piece.

➤ Allot more time to the challenging scenarios piece.

➤ Cover computer information as a review of homework and perhaps a demonstration by the trainer—no need to go to the computer lab. Include a reference to NCI's mission as part of the Web-based homework and homework review.

➤ Include a panel presentation given by the other divisions rather than a gallery walk.

➤ Allot time for participants to develop and share individual action plans—provide immediate next steps for how they will apply what they have learned at the training and how they will share the information learned and their experiences in the training with others in their communities.

8. **Revise the workshop evaluation instruments to reflect modifications to the curriculum.**

The Pre- and Post-Assessment

A pre- and post-assessment is the most practical way to measure knowledge gains in individual participants within the context of the training. Alternatives would be to consider developing a system for tracking participants' knowledge

at the time that they actually participate in a grant review, or for assessing their actual performance on the review panel. These two alternatives would fall outside the scope of the training program itself and may have logistics and cost implications that outweigh the value of the investment in them.

The curriculum revisions recommended in this report will result in the redistribution of time allotments for some topics covered in the curriculum, which may result in a decreased emphasis on some issues to allow for increased attention to others. It will be important to realign the evaluation questions to account for these changes.

Specifically, OLA should consider the possibility of ORC Macro reviewing and, as appropriate, revising the assessment form on the basis of the revised curriculum. Some of the items included in the pre- and post-assessment were not covered in detail during the pilot study. Careful attention must be given to the wording of each item to ensure that it is clearly understood by the intended audience. Consideration should be given to conducting 8 to 10 cognitive interviews with CARRA members to ensure proper wording and use of questions. At a minimum, the instrument should be pre-tested. The number of type of items should be proportionate to the content modules, with more emphasis on questions specifically related to the peer review process.

Daily Feedback Forms

These forms are useful for taking the pulse of the group each day and collecting information on satisfaction with specific modules of the training. For the next delivery, it is recommended to maintain written daily feedback forms, since a new design will essentially be piloted. For future deliveries, it may be possible to get general participant feedback through other non-written mechanisms (such as a group brainstorm at the end of the day), but written feedback on specific sessions would not be collected at that point. Further discussion is required regarding the value of written feedback on individual modules.

Workshop Feedback Forms

It is recommended that these forms be retained, to create a historical record of participant satisfaction with the training across all the deliveries. Depending on the nature of curriculum modifications, slight adjustments may be made to the form.

9.   **Incorporate a feedback mechanism on CARRA member performance in peer review into the ongoing evaluation of the CARRA program that is being conducted by OLA.**

Discussion: The evaluation of the CARRA program that is being conducted by OLA presents an important opportunity for linking the learning that CARRA members experience in the training workshop described in this report with the actual performance of CARRA members in peer review meetings. OLA might consider the addition of a question or set of questions regarding performance of CARRA members on a written evaluation form completed by NCI staff at the time of a peer review process, or short interviews with NCI staff who participate on panels with CARRA members.

Appendix A

CARRA Pilot Pre- and Post Training Assessment Form

CARRA Pilot Pre- and Post Training Assessment Form

Please answer the questions below to the best of your knowledge. Your identity will remain anonymous. The ID number in the upper right hand corner will be used to match your pre– and post–assessment forms.

I. Please read each statement and check if it is true or false.

	True	False
1. Most of what the National Cancer Institute (NCI) does is funding research, rather than conducting research itself.	❏	❏
2. The NCI is part of the Centers for Disease Control and Prevention.	❏	❏
3. Peer review is the process by which scientists' requests for research support are evaluated by a group of experts in the field.	❏	❏
4. The consumer advocate is a full participating member of the review panel and has equal voting status on evaluating both the scientific merit of applications and the budget of applications.	❏	❏
5. There are a standard set of review criteria that are used to rate all applications.	❏	❏
6. When reviewing an application, consumer advocates should always read the entire application.	❏	❏
7. About 10% of people with cancer participate in cancer clinical trials.	❏	❏
8. The consumer advocate serves as the lay representative of patient interests, giving patients and those who care for them a voice in the peer review process.	❏	❏
9. Consumer advocates are encouraged to think about their own personal experiences with cancer when reviewing applications.	❏	❏
10. Consumer advocates are encouraged to contact the applicant and ask clarifying questions about the application during the review process.	❏	❏
11. Consumer advocates are encouraged to write down any questions and concerns they have about the application and submit them when they turn in their completed review.	❏	❏

	True	**False**

12. When reviewing an application, consumer advocates should:

   a. Understand the objectives that the particular funding mechanism is designed to achieve. ❑ ❑

   b. Understand the review guidelines. ❑ ❑

   c. Follow the scientific review administrator's (SRA) instructions regarding the review guideline, mechanics of the review, conflict of interest, confidentiality issues, and behavior and etiquette. ❑ ❑

   d. Understand the review criteria for use of human subjects issues. ❑ ❑

   e. Be familiar with consent form issues, therapeutic and non-therapeutic trials, issues involving ethnicity and underserved populations. ❑ ❑

13. An actual conflict of interest arises when A CARRA member has or would have official responsibilities with an outside organization named in a grant application up for peer review by the CARRA member with which the CARRA member has a financial interest or affiliation. ❑ ❑

II. Please read each statement and select the <u>one</u> best response.

14. Which of the following elements should consumer advocates evaluate regarding the protection of human subjects from research risk?

   ❑ Risks to the subjects

   ❑ Adequacy of protection against risks

   ❑ Potential benefit of the proposed research to the subjects and others

   ❑ Importance of the knowledge to be gained

   ❑ All of the above

   ❑ None of the above

15. For research purposes, The NIH defines a child as an individual:

   ❑ Under 5 years of age

   ❑ Under 16 years of age

   ❑ Under 18 years of age

   ❑ Under 21 years of age

16. What is the purpose of clinical trials?

❑ To answer scientific questions

❑ To evaluate new prevention/treatment approaches

❑ To improve cancer care to patients

❑ All of the above

17. A clinical trial protocol …

❑ States the study's design and who will be able to participate in the study.

❑ Explains what the trial will do, how the study will be carried out, and why each part of the study is necessary.

❑ Ensures that participants are treated identically no matter where they are receiving treatment.

❑ All of the above

18. CARRA members participate in all of the following activities except …

❑ Developing and reviewing cancer education pamphlets, videos, and/or Websites

❑ Evaluating patient-oriented research at cancer research centers

❑ Soliciting citizens to participate in clinical trials

❑ Participating in meetings

❑ None of the above

19. The peer review team typically includes:

❑ Scientists

❑ Consumer advocates

❑ NCI staff

❑ Scientists and consumer advocates

❑ All of the above

❑ None of the above

20. The SRAs try to facilitate the peer review process for first time consumer advocates. SRAs will:

   ❑ Telephone each consumer advocate and explain how to review the materials and what the advocate should concentrate on.

   ❑ Refer consumer advocates to the CARRA website for more information

   ❑ Provide, upon request, a mentor for the consumer advocate.

   ❑ All of the above

   ❑ None of the above

21. About 80% of the annual NCI budget goes towards funding cancer research at other academic and medical institutions around the country. This is called _____ research in the NCI vocabulary.

   ❑ Outside

   ❑ Intramural

   ❑ Bench

   ❑ Extramural

22. Confidential information includes any information submitted to NCI for review. From the list below, which is not an example of confidential information?

   ❑ Grant applications

   ❑ Financial, professional, or personal information related to an individual or organization

   ❑ Peer review information on the CARRA Website

   ❑ Grant Renewal/status reports

23. NCI has the following expectation(s) of its consumer advocates …

   ❑ That they focus on human subjects' protection, recruitment of women, children and minorities in clinical trials, and generally represent the consumer perspective.

   ❑ That they review the science and lobby for their particular disease.

   ❑ All of the above

   ❑ None of the above

24. Which one of the following is not a patient protection mechanism in clinical trials?

□ Institutional Review Board (IRB)

□ Scientific review by the clinical trial sponsor

□ Randomized study

□ Informed consent

25. Which of the following is a common myth about clinical trials?

□ Only a small percentage of adults with cancer enroll in clinical trials

□ Cancer treatment clinical trials are the treatment of last resort

□ Randomization in clinical trials prevents bias in research

□ Standard treatment options may or may not be better than the new experimental treatment

26. Of the following, which statement is not a responsibility of those conducting peer reviews at the NIH?

□ To evaluate the proposed plan for the inclusion of minorities and both genders for appropriate representation

□ To evaluate the proposed justification when representation of women and minorities is limited or absent

□ To evaluate the plans for recruitment/outreach for study participants

□ To ensure that minorities and women are always included

27. The outcome of a peer review is:

□ A funding recommendation

□ A funding decision

Thank you for completing this assessment.

Appendix B
Daily Feedback Forms

CARRA Pilot Training
Feedback Form—Day 1
May 10, 2004

Please take a few minutes and answer the questions below. Your feedback about this pilot training course is very important and will be used to guide the changes that are made to the training curriculum.

1. Please rate your satisfaction with each of the following aspects of <u>today's</u> training. (check *one* box on *each* line)

	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied	Very Satisfied
History of the CARRA Program session	❑	❑	❑	❑

Comments:

CARRA Members' Roles and Responsibilities session	❑	❑	❑	❑

Comments:

Discussion of Center for Scientific Review (CSR) Video on Peer Review session	❑	❑	❑	❑

Comments:

Sensitivity of the trainer(s) to the participants' issues, needs, and concerns	❑	❑	❑	❑

Comments:

	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied	Very Satisfied
Ability of the trainer(s) to effectively present the training content	❏	❏	❏	❏

Comments:

	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied	Very Satisfied
Opportunity for questions/discussion	❏	❏	❏	❏

Comments:

	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied	Very Satisfied
A mix of formal and participatory presentations	❏	❏	❏	❏

Comments

	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied	Very Satisfied
Materials in the participant's binder	❏	❏	❏	❏

Comments:

	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied	Very Satisfied
The training facilities	❏	❏	❏	❏

Comments:

2. What were the *most* helpful aspects of today's sessions?

3. What suggestions for improvement would you offer based on today's sessions?

Thank you for completing this form.

Please take a few minutes and answer the questions below. Your feedback about this pilot training course is very important and will be used to guide the changes that are made to the training curriculum.

1. Please rate your satisfaction with each of the following aspects of <u>today's</u> training. (check *one* box on *each* line)

	Very Dissatisfied	**Somewhat Dissatisfied**	**Somewhat Satisfied**	**Very Satisfied**
Mission, Organization and Budget of NCI session	❏	❏	❏	❏

Comments:

Gallery Walk/Poster session	❏	❏	❏	❏

Comments:

The NCI Peer Review Process (Procedural Aspects) session	❏	❏	❏	❏

Comments:

The NCI Peer Review Process (Technical Aspects) session—Conflict of Interest, Confidentiality, and Lobbying	❏	❏	❏	❏

Comments:

	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied	Very Satisfied
The NCI Peer Review Process (Technical Aspects) session—Grant Mechanisms and Scientific Review	❏	❏	❏	❏

Comments:

Roles and Responsibilities of CARRA Members in the Peer Review Process	❏	❏	❏	❏

Comments:

Mock Peer Review Process	❏	❏	❏	❏

Comments

Sensitivity of the trainer(s) to the participants' issues, needs, and concerns	❏	❏	❏	❏

Comments:

Ability of the trainer(s) to effectively present the training content	❏	❏	❏	❏

Comments:

	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied	Very Satisfied
Opportunity for questions/discussion	❑	❑	❑	❑

Comments:

	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied	Very Satisfied
A mix of formal and participatory presentations	❑	❑	❑	❑

Comments:

	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied	Very Satisfied
Materials in the participant's binder	❑	❑	❑	❑

Comments:

	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied	Very Satisfied
The training facilities	❑	❑	❑	❑

Comments:

2. What were the *most* helpful aspects of today's sessions?

3. What suggestions for improvement would you offer based on today's sessions?

Thank you for completing this form.

CARRA Pilot Training
Feedback Form—Day 3
May 12, 2004

Please take a few minutes and answer the questions below. Your feedback about this pilot training course is very important and will be used to guide the changes that are made to the training curriculum.

1. **Please rate your satisfaction with each of the following aspects of <u>today's</u> training.** (check *one* box on *each* line)

	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied	Very Satisfied
Clinical Trials session	❏	❏	❏	❏

Comments:

Challenging Scenarios in Peer Review	❏	❏	❏	❏

Comments

Identifying Appropriate Resources for Locating Current Information on Key Cancer Concepts (Computer lab)	❏	❏	❏	❏

Comments:

	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied	Very Satisfied
Ability of the trainer(s) to effectively present the training content	❑	❑	❑	❑

Comments:

Opportunity for questions/discussion	❑	❑	❑	❑

Comments:

A mix of formal and participatory presentations	❑	❑	❑	❑

Comments:

Materials in the participant's binder	❑	❑	❑	❑

Comments:

The training facilities	❑	❑	❑	❑

Comments:

2. What were the *most* helpful aspects of today's sessions?

3. What suggestions for improvement would you offer based on today's sessions?

Please reflect on the <u>entire</u> 3-day training experience when you respond to the questions below.

4. How successful was this training in helping you to meet the following learning objectives?

	Not Very Successful	Somewhat Successful	Mostly Successful	Very Successful
a. Understand the NCI's research mission and its extramural research activities.	❏	❏	❏	❏
b. Be familiar with information on the scientific, technical, and cultural aspects of the NCI peer review process including how the process works.	❏	❏	❏	❏
c. Be familiar with key cancer concepts and terminology needed to participate in the NCI peer review process.	❏	❏	❏	❏
d. Demonstrate effective approaches for participation that reflect the needs and concerns of the affected community.	❏	❏	❏	❏
e. Represent the collective views of survivors, patients, family members, and persons affected by and at risk for disease.	❏	❏	❏	❏
f. Understand the CARRA/advocate member role and responsibility for participation in the NCI peer review process.	❏	❏	❏	❏

5. Prior to the training, preparation materials were sent to you for review. Did these materials provide you with the background information you needed to attend this training?

   ❑ Yes. If yes, how did these materials help you prepare for the training? What material(s) were particularly useful?

   ❑ No. If no, what types of materials would have been more helpful?

6. How useful did you find the homework assignments you completed Monday and Tuesday nights?

   ❑ Not at all useful   ❑ Not very useful   ❑ Somewhat useful   ❑ Very useful

7. As a result of attending this training, do you think you are adequately prepared to participate in NCI's peer review process?

   ❑ Yes
   ❑ No If no, please explain why not.

8. As a result of attending this training, do you think that you can adequately represent the consumer's viewpoint at an NCI peer review in the future?

   ❑ Yes
   ❑ No. If no, please explain why not.

9. As a result of attending this training, do you think that you can adequately evaluate the inclusion of women, minorities, and children in grants submitted to NIH for peer review?

   ❑ Yes

   ❑ No. If no, please explain why not. What additional information do you need?

10. How much new information did you receive in the training? (check *one*)

    ❑ No New information   ❑ A Little New Information   ❑ Some New Information   ❑ A Lot of New Information

11. How likely are you to use the information that you received in the training? (check *one*)

    ❑ Not at All Likely   ❑ Not Very Likely   ❑ Somewhat Likely   ❑ Very Likely

12. Overall, how satisfied are you with the training? (check *one*)

    ❑ Very Dissatisfied   ❑ Somewhat Dissatisfied   ❑ Somewhat Satisfied   ❑ Very Satisfied

13. In what ways could this training be improved? (If you need additional space, please write on the back of this page.)

14. Please write in any additional comments or suggestions that you have about the training and/or the trainers. (If you need additional space, please write on the back of this page.)

Thank you for completing this form.

Appendix C

Open-Ended Comments

Open-Ended Comments
Day 1

Question	Verbatim Comments
1. **History of the CARRA Program session**	• Very informative. • Very interesting.
2. **CARRA Members' Roles and Responsibilities session**	• Slides different from what in notebook. • Very frank—I appreciate it. Could have used specific examples/sharing of examples from advocates. • Please explain all the NCI acronyms (OLA, CTEP, etc.). • <u>Good</u> <u>discussion.</u> • I have a better understanding. • I would have liked to have had the copy of entire presentation.
3. **Discussion of Center for Scientific Review (CSR) Video on Peer Review session**	• Not enough time allotted. • More focused discussion would have been helpful. It seemed to raise people's anxiety rather than address specifics. • Not long enough—need much more <u>time.</u> • Too hypothetical—need to deal with specifics. • Not enough time to point out key points of the meaning processed and individual reviewers participation. • Unfortunately not much time for discussion of video. • Not enough time for discussion.
4. **Sensitivity of the trainer(s) to the participants' issues, needs, and concerns**	• Rushed. • More discussion time!! • Very good!
5. **Ability of the trainer(s) to effectively present the training content**	• No comment.
6. **Opportunity for questions/discussion**	• Need more time for Q&A. • Not much opportunity. • <u>Need more time.</u> • Too rushed. • Would like more time.

Open-Ended Comments
Day 1

Question	Verbatim Comments
	• More time!
	• As is the case in most training, there was not enough time for questions.
	• Could use more time.
	• More time needed.
7. A mix of formal and participatory presentations	• This isn't really relevant.
	• Not much mix.
	• More participation and less "historic" information.
	• Would like more presentation from peers.
8. Materials in the participant's binder	• Gosh! Too much.
	• Haven't reviewed yet.
9. The training facilities	• Great.
	• Hard to see screen images, acoustics.
	• End seats on tables very poor.
	• Lighting problems.
	• Ran out of water.
10. What were the most helpful aspects of today's sessions?	• Question and answer session.
	• Kurt Vener discussion.
	• The questions and answers.
	• The compatibility among panel members.
	• Interaction.
	• Questions.
	• Networking.
	• Overview of CARRA.
	• <u>Please</u> give the "mic" to whomever is speaking!
	• Guidelines (general rules).

Open-Ended Comments
Day 1

Question	Verbatim Comments
	• Addressing the crossroads of knowledge—scientific and pt. advocates.
	• Potential for even more NCI—CARRA requests.
	• I need more time to think about this—mostly I appreciated the participant's input.
	• The interaction between participants—there was not enough time given to do this.
	• Very skilled trainers.
	• Well organized and thought through.
	• Introductions of participants roles and responsibilities of CARRA members.
	• Diverse knowledge base of people CARRA advocates.
	• Great overview/thanks/look forward to tomorrow.
	• The potential to come away with the experience and knowledge to be effective reviewer.
	• Overall info.
	• Dialogue among participants.
	• The discussions about what our roles are as advocates in the review process.
	• Interactions.
11. What suggestions for improvement would you offer based on today's sessions?	• More details about CARRA selection process for peer review process.
	• More Q&A.
	• More opportunities to learn from advocate peers about peer review process.
	• Longer time to ask questions and get answers.
	• Focus discussion time.
	• Focus on NCI, not DoD reviews.
	• People should give own bios.
	• Much more time scheduled for Q&A.
	• Dr. Vener—somewhat extraneous—he did not really add to information. Perhaps he would have been better with longer Q&A period.

Open-Ended Comments
Day 1

Question	Verbatim Comments
	- Have a presentation by a pt. advocate as part of the opening agenda. - Reduce the rushed atmosphere—the whole tenure of time interferes with my concentration on the material being presented. - Some of these questions are premature since we have not had time to review the binder materials. - We need a bag or case to transport all written materials back and forth to meetings and back home. - Will you send via mail or FedEx these materials to us at end of meeting? - <u>NONE.</u> - Build in more time for networking. - The "expectation" piece didn't click with me—not sure how helpful it was. - Do a West Coast training (not based on today). - We got stuck on the scoring thing—I would have liked a review of the video, either #1 or #3. - <u>None.</u> - More time for questions. Even though the seminar developers have an idea of what they want to cover, there should be a better balance—even to the point of asking participants if they would like to stay over <u>after</u> the formal program is over. - Introduce ourselves to save time? On the other hand, it was good to get to know others.

Open-Ended Comments
Day 2

Question	Verbatim Comments
1. Mission, Organization, and Budget of NCI session	• Need more time for questions. Brooke did well with a very dry and confusing subject.
	• Needed more time.
	• This was a great overview of NCI and the total system.
	• Brooke Hamilton is wonderful—her zest and enthusiasm are contagious—she is great—the subject is misplaced in my opinion—we're here to learn about peer reviews and our "jobs"—I don't need or want to know about these areas. This could be eliminated, thus providing more time for peer review information on discussion. I say keep the info on budget, etc., in the binder for those interested and offer to answer their questions after the meeting by e-mail?
	• Simplify and spruce up slides.
	• Very helpful "big picture" overview. I learned a lot. Presenter hint: Brooke, you can present with more confidence. It's good information!!
	• Some handouts not appropriate for <u>visually challenged.</u>
	• Best presentation on this topic I've seen. Tried to cover too much. Didn't need to keep commenting on how much she had to cover in the limited time.
	• Thought too much of an emphasis.
	• Very helpful and interesting in portraying the big picture of NCI.
	• Could use more discussion time.
2. Gallery Walk/Poster session	• Tables too close together—making it <u>too</u> noisy and hard to hear. Good speakers and topics—great information.
	• Give an exposure to other aspects of NCI.
	• Good idea—too much confusion—not enough time—needed more structure—the presenters were good—many questions left unanswered.
	• Some of the areas were interesting—but I was frustrated wanting to talk on issues directly involving peer review.
	• Helpful format! Liked the small group opportunity. The presenters were well-organized. It would be helpful if Leo had a handout.
	• Too noisy.

Question	Verbatim Comments
	• Needed more pre-info about what was to happen.
	• Very helpful.
	• Loved walking around! I wish there had been more emphasis on how we interacted with them, in very specific ways—everyone gave <u>good</u> info, but needed to be prompted for the tie-in.
	• Too boring—too little time.
	• Could have used more time.
	• Need to better rethink route consumer advocates would with particular opportunity if any.
	• Too busy; not enough time to get questions answered or comments heard.
	• Times too short for questions. Too much info to give in 5 minutes. I hope the materials I picked up will help, because I doubt I will retain any of the info from the sessions.
	• Too little time.
	• Tables too close—background noise from adjacent.
3. The NCI Peer Review Process (Procedural Aspects) session	• Very disturbing to have audiovisual personnel putting microphones in place.
	• Need more time for questions.
	• Worksheet gave opportunity for good discussion.
	• This was good but it could have covered more territory with more input from several people. The SRA missed some of the questions. He could have listened more. Use the experience in the room.
	• For me this was the most beneficial portion of the program so far—more dynamic byplay.
	• Brian Wojaik.
	• Excellent!!
	• Good! It was very helpful to have both Sue and Brian.
	• I have better understanding of how SRA helps.
	• Great—good discussion.

Question	Verbatim Comments
	• Brian was nice but talked too long and didn't always answer the question. Eve should have grabbed the mike. He got better as it went along. I would have worked off of written questions—ask people to submit questions in writing, so that they could be followed up on later. A lot of people wanted to share their experience—I didn't find all of the sharing that valuable.
	• It was very informative—again, just not enough time to address the points/questions raised.
	• Too lengthy—still a lot of personal opinions on the process.
	• More discussion time.
	• Still not enough time for questions, discussion.
4. The NCI Peer Review Process (Technical Aspects) session—Conflict of Interest, Confidentiality, and Lobbying	• Excellent.
	• Examples need to be clearer. #3 left me hanging—why is this a conflict?
	• I think this needs to be there, and it lived up to its boring introduction.
	• Important information—ran out of time.
	• The questions and answers were most rewarding.
	• She's a great teacher.
	• Helpful—good for discussion. Important concept for consumer advocates to understand.
	• More discussion time.
5. The NCI Peer Review Process (Technical Aspects) session—Grant Mechanisms and Scientific Review	• Very good.
	• Great information. I really appreciate Virginia and Ray presenting to us.
	• Made sense. <u>Very understanding</u>!
	• Great job.
	• Important information—helps to give the consumer advocate a better understanding of the overall review process.
	• More discussion time.
	• It would have been helpful to have this info presented <u>earlier</u> in the training.

Open-Ended Comments
Day 2

Question	Verbatim Comments
6. **Roles and Responsibilities of CARRA Members in the Peer Review Process**	• Well done—very interesting. • Good presentation, opened up areas of other questions. • Ray did a great job. Great information. Too bad Susan Butler was sick. • Very structured and understanding. Led to excellent discussion. • Better to "learn by doing"—this is too much blah blah. The discussion was very good. • Excellent overview. • More discussion time. • More time should have been allotted to this discussion.
7. **Mock Peer Review Process**	• Excellent—continue this!!! Need to discuss written statements for advocates comments. Is there a definitive form that these are written on? • <u>More time!!</u> • Very informative—and helpful. • Most significant event! Excellent! • The panelists were really helpful and effective. Good process. • Real eye-opener. • Helped to bring things into focus. • 1st mock review—pick a review that involves the consumer advocate more. • 2nd mock review—very helpful in providing a useful example of peer review exercise. • Learned a lot! • Extra good.
8. **Sensitivity of the trainer(s) to the participants' issues, needs and concerns**	• Very willing to answer and discuss <u>all</u> questions <u>but</u> problems of time constraints. • A walk after lunch? • Varied.

Open-Ended Comments
Day 2

Question	Verbatim Comments
9. Ability of the trainer(s) to effectively present the training content	• Varied. • Scientists were excellent.
10. Opportunity for questions/discussion	• Need more time! • More time for Q&A's and Consumer Advocates discussions. • Much better today—great discussion. • Not enough. • Much better today—need to stay on topic. • Never enough discussion time. Balance needs to go to discussion.
11. A mix of formal and participatory presentations	• Very good. • Microphone hassles shouldn't be happening. With all these scientists, you have no AV people?
12. Materials in the participant's binder	• Too much (too heavy). • This has been an outstanding addition. Easy to take notes and follow presenter. • Excellent! Thorough, well-organized. • Very good—thank you for all of your hard work putting it together. • But, some written materials <u>too</u> <u>small</u> print!
13. The training facilities	• Water pitchers not refilled or replaced for the afternoon sessions. • Audiovisual problems were distracting. AV personnel should not be working behind (and in front of speakers). • Wish there was an espresso stand! • Need water refilled and more bathroom breaks. • But, microphone problems! • More water on table.

Open-Ended Comments
Day 2

Question	Verbatim Comments
14. What were the most helpful aspects of today's sessions?	• Mock Review was excellent—<u>really</u> helpful.
	• Worksheet on Conflict of Interest—<u>very</u> helpful.
	• <u>All</u> discussions about the peer review process.
	• The interaction between groups; between professionals and trainers.
	• Opportunity to have input and discussions.
	• Opportunity to learn from each other.
	• Having the experts in the room and available to us.
	• The Mock Interview.
	• Much more interaction than yesterday. YAY!
	• Peer review.
	• The description of the process.
	• The overview of the NCI.
	• The Mock panel was great.
	• The Gallery walk was wonderful.
	• Seeing and participating in role-play.
	• The opportunity to interact with a room full of professionals from varying backgrounds. I learned a lot.
	• Mock Peer Review.
	• Brian and Virginia. I missed much of the mock review, which is too bad!
	• I appreciate Leo's willingness to push the schedule requirements on us—keeping us on track, on time is hard, and I think Leo's done a nice job.
	• Panel discussion.
	• The scientists and NIH and NCI staff participation.
	• It was all very helpful.
	• The allotment of questions; the comments from other CARRA members.
	• Mock Review.
	• Dialogue between the presenters and audiences.

Question	Verbatim Comments
	• Poster sessions and information presented were very helpful.
	• Focus of role of advocates and where advocates should concentrate their review time and comments.
	• The Drs joining our groups to discuss the points of the grant.
	• Hearing how the advocates enlightened Bill to want to change his score.
15. What suggestions for improvement would you offer based on today's sessions?	• The Gallery walk would really be improved by having each station further apart to decrease noise. It was too noisy to hear in many instances.
	• Audiovisual should be set up before session during breaks and lunch. Especially so that AV person is NOT showing us her underwear because of the positions she had to get into to put all the wires together.
	• More time spent on peer review process, less time on peripheral aspects of NCI.
	• <u>More time for discussions.</u>
	• Take out history, budget, non-panel participation related info.
	• How about a mock panel of just consumer advocates—by assuming scientific information—since, the small table group discussion for example was informative and exciting.
	• Improve slide presentations.
	• Provide written sample, that reviews could see.
	• More of the same.
	• Not necessary to change seats/count off.
	• Role-play the various situations for an advocate.
	• How is critique used?
	• More small discussion groups.
	• I would do a mock grant review at the very beginning of the training—working in small groups and getting us used to thinking out loud; instead of having <u>lectures from the SRAs, I would have rather had SMALL</u> mock reviews which illustrate the points and let us practice the etiquette.
	• Create a cheat sheet for the reviews—"hints for reviewing"—check list, with resources—use Virginia's "who what when where how."
	• Create a checklist for "conflict of interest."

Question	Verbatim Comments
	• More panel discussion.
	• Less info about NCI Table of Organization budget.
	• Overall observation—Need to have more representation from childhood cancer patients and survivors. Childhood cancer survivors/patients present a unique set of issues, concerns, etc., as opposed to the adult population, which seems disproportionately represented. I suggest a peer review training process for childhood cancer advocates. Childhood cancer patients/survivors lack a representative voice in the advocacy and peer review world. More often than not this population is not capable of advocating for themselves like the adult population.
	• Longer Q&A sessions.
	• More time to network.
	• Time allocated to the poster session was very limited.
	• Perhaps participants may choose/select the poster and have more questions and answers.
	• Does IRB approve before or after NCI approval is sought—when is informed consent prepared? Must it be a part of submission?
	• Need definitions of what meaning is of Phase 1, 2, 3, 4 of clinical trials
	• Are the standards for review different depending upon the phase proposed?
	• Are all clinical trials required to go through each phase—and then what?
	• When available to public—after phase 4?
	• Where differentiate role of NCI and FDA?
	• <u>Q</u>: Can there be partial approvals of a <u>part</u> of an application if it is capable of standing alone?
	• A question I didn't get to ask of Brian—If the scientists are worried about looking bad in front of their peers when they come to review their scores, why do they score at all prior to discussion Does it speed up the process or make the discussion move more cautiously? I understand writing reviews before they come, but why bother to score it until after they each can defend their opinions.
	• Are reviewers employees of NCI? If not, do reviewers get paid by NCI and how do they determine amount?

Open-Ended Comments
Day 3

Question	Verbatim Comments
1. Satisfaction with specific aspects of the training.	
Clinical Trials session	• Margo is great—needed more time and more "quizzing"—we need to automatically use the right language.
	• Judgment statement for each question asked. This could cause a potential questioner not to ask a question. Received good info on clinical trials. A whole day would have been great.
	• Good way to teach this even though quite a bit of time was allocated, it could have been longer.
	• Wish so many of this type of training …[illegible] of "freelancing" by participants …[illegible] from the presentation and forces the presenter to rush and not complete the …[illegible].
	• Learned a lot of new information—wished it could have been longer.
	• Need more time on this subject matter—don't rush it.
	• Should be a full day. Great facilitator. How this information is connected to and used in the peer review process. More discussion about human study protection—history background about clinical trials (Tuskegee), The African American community—…[illegible] about community leaders.
	• How about patient experiences presentation/panel?
	• Excellent presentations.
	• Excellent information. The Jeopardy game was a cute idea; however, it created distractions. The plastic animals used to show randomization and stratification was a great idea. Need more time!!
	• This information is critical. I would have gotten more from a true presentation and not so much time with game activity. IRB, Belmont Tuskegee issues—Margo was wonderful but often not allowed to fully explain content.
	• Margo is very knowledgeable and an excellent presenter. Best of all!
	• Good overview.
	• The game made it more energetic.
	• Wish we had more time on the education/outreach piece.
	• Not enough time for full discussion.

Question	Verbatim Comments
	• While I appreciate Margo using multiple approaches to teaching; the Jeopardy exercise went too long and became fragmented and lost focus. The minority recruitment was repetitive. Margo became a bit frustrated (it appeared) and became a bit condescending.
	• I have no suggestions for improvement, but it was long—confusing and helter-skelter—the info was great—present but not easily absorbed.
Challenging Scenarios in Peer Review	• Needed more discussion/modeling—maybe do role-playing?
	• I liked the group interaction.
	• I like this kind of training/learning.
	• Could have used more time.
	• Very good. Again, more time for discussions.
	• More of these throughout training.
	• Excellent. Wonderful way to consider these situations. Need more time for discussion.
	• The discussion highlighted information learned from earlier sessions. I found myself integrating otherwise unrelated pieces of information.
	• Good exercise; very helpful. Advocated need to be proactive and not be afraid to represent your convictions.
	• Nice examples. Good process.
	• Excellent exercise!
Identifying Appropriate Resource for Locating Current Information on Key Cancer Concepts (Computer Lab)	• N/A. I am very familiar with this.
	• Screen not working at first, not sufficient time.
	• We already know most of this.
	• Good information but not necessary to use a computer lab; used time unnecessarily.
	• This will be a resource that I will use and pass on to my research patients.

- I am a computer illiterate! This session helped me a lot.

- Already familiar with Web site and browsing. Perhaps divide group into two—one that needs computer assistance and the other to spend on another worthwhile related topic.

- Great to see the sites.

- Not very helpful—no specifics.

- Not present.

Sensitivity of the trainer(s) to the participants' issues, needs, and concerns

- Fine.

- Generally yes.

- I think trainers were highly qualified, accessible, and very effective.

- I didn't see any examples of this. The trainer was focused on keeping to a set schedule and time. Perhaps a facilitator (with knowledge of peer review, cancer issues/concerns, group dynamics) instead of a trainer for this type of workshop.

- I think you have (all) done an awesome job.

Ability of the trainer(s) to effectively present the training content

- Fine.

- I think the trainers need to bring balance managing presentations and participant involvement and queries.

- I think trainers were highly qualified, accessible and very effective. I feel that Leo was excellent!

- I didn't see any examples of this. The trainer was focused on keeping to a set schedule and time. Perhaps a facilitator (with knowledge of peer review, cancer issues/concerns, group dynamics) instead of a trainer for this type of workshop. There could be a co-facilitator for this workshop.

- Satisfied.

- Only issue—time constraints.

Opportunity for questions/discussion

- Plenary!!

- Don't rush it.

- Still need more time!

- Again satisfied—could have been handled better.

- Good, but may need more time allotted.

More participation by the group of advocates.

Open-Ended Comments
Day 3

Question	Verbatim Comments
A mix of formal and participatory presentations	• More participatory exercises. • Great! • Not sure. • Fewer formal please.
Materials in the participant's binder	• Very good. • Cut down paperwork, please. • Good. • Many times the binder helped more. • Materials are excellent and will be used for referencing in the future. • Somewhat confusing due to not being in order. • Would rather have contents of binder on a CD.
The training facilities	• The hotel would have been more optimal. NCI was okay. • Keep water out. • Good. Computer room hot and stuffy. • But, needs improvement with audio equipment.
2. What were the most helpful aspects of today's sessions?	• Margo's game was great. • Role-playing in small groups. • Speakers are very knowledgeable. • Interaction—scenarios, etc. • Group sessions. • The Jeopardy game and examples. • Margo's presentation—new and important infrastructure. • Clinical trials, computer view. • The design of group interaction. The use of the game model for learning about clinical trials. • The real-world examples (scenarios). • Outstanding presentation on clinical trials. • Discussion of scenarios. • Discussion of challenging scenarios—would be helpful to have more time.

Open-Ended Comments
Day 3

Question	Verbatim Comments

Question

Verbatim Comments

- Hearing from CARRA members who participated and peer review sessions.

- Margo leading us through the material.

- Clinical trial overview.

- Discussing scenarios and clinical trials.

- Group dynamics.

- All sessions—Computer time. Good to change tables. The materials for Margo's session. Meeting the OLA staff and other CARRA members.

- Going over the scenarios in the 4 small groups, I learned not to be so confrontational.

- Clinical trial session/best of training.

3. What suggestions for improvement would you offer based on today's sessions?

- More time or less material.

- More time devoted to clinical trials.

- Rather not play games—came to work.

- More time for networking, interacting, role-playing, etc.

- More time, don't rush.

- Again, more time!

- Include patient advocates in training, planning, and presentations.

- Give more time, (allocate) more time to the clinical trials session.

- The clinical trials portion was excellent—need more time. Should be done before mock review. No need to work in computer lab. Spend more time in discussion.

- Presentation for clinical trials—no game—info presented not easily followed, often audience interrupted speaker. IRB presentation needed more attention.

- More time on the scenarios.

- I wish I could tell you how I see my talents best used and see if there are other needs besides peer reviews.

- Full day session—with more on clinical trials.

- Drop the computer session unless there's something very novel and new. Also, simplify the whole clinical trial lesson—it was too much, too fast

Overall Assessment of the 3-Day Training

Question	Yes	No
1. **Prior to the training, preparation materials were sent to you for review. Did these materials provide you with the background information you needed to attend this training?**	• The "quiz" or "homework" focused my attention.	• More detailed cheat sheets asking us to identify specific items in the grant applications—I really liked the "key points to consider."
	• The video and questions.	• Because until I arrived, I was of the understanding that no advocate had a place in peer review. But, it was cleared up upon my arrival and participation.
	• The video was somewhat irrelevant.	• I would have liked the manual in advance to read.
	• Video.	• Case studies; preliminary agenda; IRB Information; grant application "de-mystified" with explanatory notes; video with patient advocate participation and comments.
	• For a peer review "atmosphere."	• These materials were very good for someone who has not previously participated in a review. The video was very good for a new person.
	• But I would have liked to have seen a "very good" patient advocate response for review.	• Seeing advocates interacting. Couldn't you do a mock review on tape? How to focus on the parts that concern the advocates.
	• Liked being exposed to the materials—wanted in advance??	• Should have mailed the binder!!

Overall Assessment of the 3-Day Training

	Yes	No
	• Video and written materials were good to set the stage for the seminar and what to expect/anticipate.	• I think it would have been more helpful to have "overview" information about CARRA and NCI rather than so much clinical information. There was too much that was complex without first having the foundation.
	• The video was good, but we never did anything with it during the workshop. The questions that came with the video received no discussions.	• More specifics of what we will do at the training. Maybe share previous CARRA functions and accomplishments—where and what CARRA members have achieved—in what programs—all anonymously.
	• Guidelines provided me with information to help in the process of review. The video.	
	• Video was not helpful. It would have been nice to review the assignment.	
	• But, I was disappointed that the "homework" was not called for/discussed/used at the sessions.	
	• The video was helpful. However, a patient advocate needs to be included.	
	• The material that stated "look at if you want to" (or whatever) should have been required and the first that we read. (Plus, I think the "Role of Peer Review" was in there, but not sure.)	
	• Information on peer review/clinical trials.	

Overall Assessment of the 3-Day Training

Question	Yes	No
2. **As a result of attending this training, do you think you are adequately prepared to participate in NCI's peer review process?**	• I am struck by the commonality between this, serving on cooperative groups and serving on FDA committees.	• The differences are mostly because "point in the process" is different.
3. **As a result of attending this training, do you think that you can adequately represent the consumer's viewpoint at an NCI peer review in the future?**	• Yes.	
4. **As a result of attending this training, do you think you can adequately evaluate the inclusion of women, minorities, and children in grants submitted to NIH for peer review?**	• I'd like to see an example of a grant that has good HSP language.	
5. **In what ways could this training be improved?**	• Start with role-playing, do more "games." • Leo was a good timekeeper—he talked a lot for my taste. I would have preferred fewer words. • Do more with electronic, less paper. • Avoid lectures. • Make goals and expectations more clear.	
6. **Please write additional comments or suggestions that you have about the training and/or trainers.**	• Margo is an excellent educator, as is Jane. Use them more.	