National Cancer Institute Office of Advocacy Relations Feasibility Study

Final Report

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Section 1: Introduction

1.1   Background

The National Cancer Act of 1971mandated representation by members of the public on the National Cancer Institute's (NCI) National Cancer Advisory Board (NCAB). In 1993, NCAB conducted a survey of advocacy groups and found that they had a strong interest in increasing communication and collaboration and fostering relationships with NCI. In 1996, NCI created the Office of Liaison Activities, now called the Office of Advocacy Relations (OAR), to help strengthen the Institute's communications, collaborations, and relationships with national advocacy and voluntary organizations who work with consumer advocates as well as scientific and professional societies concerned about cancer. The following year the NCI Director's Consumer Liaison Group (DCLG)—a Federal advisory committee composed of nonscientific consumer advocate members—was established. In December of 1997 OAR led the first meeting of the DCLG. Advocates were first formally involved in the NCI peer review process in 1998. With guidance from the DCLG, in 2001 OAR created the NCI Consumer Advocates in Research and Related Activities (CARRA) program to formalize the process of patient advocate involvement in NCI activities.

Currently the OAR fulfills four principal functions:

- Identifying opportunities for organizational collaborations between advocacy groups/professional societies and the NCI

- Engaging individual advocates in the research process at the NCI

- Engaging the NCI Director's Consumer Liaison Group (DCLG) effectively so they provide value-added advice to the NCI

- Acting as the subject matter expert for NCI administrative, programmatic, and scientific staff around how to most effectively communicate with and engage the advocacy community.

Through these components, the OAR works to:

- Increase the efficacy of the advocacy engagement process and be able to clearly articulate the outcomes of engaging advocates in NCI's research activities

- Help foster an organizational culture shift around advocacy engagement, resulting in an atmosphere that understands and values the contributions of research advocates

- Provide strategic guidance in the development and execution of NCI's relationships and communications with the cancer community in order to promote dialogue and understanding of important Institute developments

- Identify and facilitate opportunities for NCI to collaborate in ways that promote better research outcomes

- Serve as the Institute's expert and central resource for advocacy matters.

The OAR performs outreach to the advocacy community through its managed websites, teleconferences, and meetings. In addition to the information on the Science Serving People website, the OAR website is updated daily with advocate activities (upcoming meetings, conferences, workshops,

and other Federal programs opportunities for which consumer advocates may participate) and enables advocates to subscribe to the OAR Listserv for additional information. The OAR also conducts the Understanding NCI: Toll-Free Teleconference Series, which features key NCI program leadership and a member of the advocacy community to provide up-to-date and accurate information on critical cancer topics. Lastly, the OAR facilitates on-campus meetings between NCI staff and the leadership of organizations and professional societies to foster collaboration, assess shared priorities, and plan joint endeavors.

Individual research advocates are matched with specific opportunities to engage in the research process at NCI. OAR is responsible for supporting the NCI Divisions, Offices, and Centers in selecting, orienting, and preparing these advocates, as well as facilitating their entire engagement as appropriate.

OAR provides information on issues of critical importance to the Institute to the DCLG so that, as senior leaders, they are equipped to make recommendations to the NCI Director. The DCLG and NCI work together to ensure that those who experience the burden of cancer also help to shape the course of NCI's efforts to eradicate the disease.

The OAR Director requested that a feasibility study be conducted to assist in planning and guiding OAR's future direction. The Office has recently been reorganized and may be further restructured based on recommendations from the NCI Advocates in Research Working Group (ARWG) (http://dclg.cancer.gov/working-groups/involving-advocates#Recommendations). The ARWG was created in 2007 under the auspices of the DCLG in response to the charge by the NCI Director Dr. John Niederhuber to consider how to most effectively and consistently engage individual advocates in the research process at NCI to accelerate progress and benefit patients. The ARWG process involved more than 60 internal and external stakeholders who submitted recommendations in September 2009. The final report and recommendations will be available in late 2010.

In the past, OAR leaders have evaluated selected Office activities. For example, a number of evaluation activities have focused on the Consumer Advocates in Research and Related Activities (CARRA) program—a program initiated by the Office in 2001 and focused on involving consumer advocates in the activities related to scientific research and communication of scientific research at NCI. Shortly after the formation of the program, a baseline survey of NCI staff members was conducted to gain a better understanding of how NCI staff felt about the use of advocates. A series of three post-activity surveys of CARRA members and NCI staff was then conducted between 2004 and 2006. The focus of the post-activity surveys was not on the program design generally, but rather on actual experiences in using an advocate or participating as an advocate. Therefore, while specific OAR activities have been evaluated in the past, this feasibility study represents the first effort to evaluate the organization and scope of OAR.

1.2   Purpose of the Feasibility Study

In the future, the OAR hopes to conduct a comprehensive evaluation that will help the Office measure the efficiency and effectiveness of its activities, eliminate redundancies and reduce costs, maximize program impact, and ensure relevancy to target audiences. The purpose of this study was to determine the overall feasibility of developing and implementing a comprehensive process and outcome evaluation of OAR activities, by:

■   Reviewing existing data to provide information on key variables

■   Identifying new data collection efforts (if needed) and any associated clearance requirements

- Identifying appropriate study questions and corresponding key variables

- Developing an evaluation plan that measures process and outcome goals.

1.3   Key Questions Addressed in the Feasibility Study

The initial activity undertaken in the feasibility study was to articulate the key questions to be addressed by the study. These questions are:

- What study questions and corresponding key variables should be used to evaluate the OAR?

- What existing data can be used to evaluate the OAR?

- What other data collection efforts might be required to evaluate the OAR?

- What clearance requirements might be necessary to conduct the OAR evaluation?

- What are the advantages and disadvantages of different outcome evaluation designs and approaches? What specific design and approach would be most desirable to meet the needs of the OAR and would also inform other Institutes and Centers (ICs)?

- Is there adequate justification to conduct an outcome evaluation?

- What performance or process indicators should be developed, piloted, and implemented to help support the assessment of Office outcomes?

- Is the estimated cost of the proposed outcome evaluation reasonable given the budget of the Office?

- Are all appropriate stakeholders included in Office decisions?

Section 2:   Feasibility Study Design

This section describes the feasibility study methods and data collection approaches utilized to answer the key questions detailed in section 1.3.

2.1   Feasibility Study Methods and Data Collection Approaches

The OAR Feasibility Study followed a sequence of methodological steps in developing answers to the key evaluation feasibility study questions, including:

- Clarification of study objectives, issues, and questions

- Review of background materials and previous studies

- Review of OAR databases (OAR Advocacy and CARRA)

- Review of relevant websites and e-publications (OAR, Science Serving People, *NCI Nealon Digest*)

- Semistructured interviews with OAR staff members

- Analysis of findings

- Development of evaluation questions, variables, and indicators

- Recommendations for the design of a process and outcome evaluation of OAR.

Each of the data collection efforts is detailed in section 2.2. The summary of findings is presented in section 3 and the recommended design for a process and outcome evaluation is presented in section 4 of the report.

2.2   Data Collection

Four types of data collection approaches were utilized in the feasibility study—review of background materials and previous studies, review of existing OAR databases, review of relevant websites and e-publications, and semi-structured interviews with current and former OAR staff members.

2.2.1   Review of Background Materials and Previous Studies

A wide variety of background materials and previous studies were reviewed early in the course of the feasibility study. Reports reviewed related to the CARRA program include:

- *Initial Report on the Results of Post-Activity Surveys of CARRA Members and NCI Staff* (June 2005, revised August 2006)

- *Second Report on the Results of Post-Activity Surveys of CARRA Members and NCI Staff* (September 2006)

- *Assessment of NCI Staff Member Attitudes and Behaviors With Regard to the CARRA Program* (November 2006)

- *Assessment of NCI Staff Member Attitudes and Behaviors With Regard to the CARRA Program* Addendum (November 2006)

- *Third Report on the Results of Post-Activity Surveys of CARRA Members and NCI Staff* (January 2007)

- *Assessment of CARRA Member Attitudes and Behaviors with Regard to the CARRA Program* (March 2007)

- *Summary of Findings From CARRA Surveys* (May 2007)

- *Informal Cost-Benefit Analysis of Marketing Mechanisms and Materials—A CARRA Briefing Memo* (September 2007)

- *Recommended Marketing Strategies: Mechanisms and Materials—A CARRA Briefing Memo* (September 2007)

- *Reflections and Directions—Interviews and Focus Groups with CARRA Members and NCI Staff* (September 2007)

Materials reviewed related to the DCLG included agendas and summaries from several of the DCLG meetings; two PowerPoint presentations about the Advocates in Research Working Group background and final recommendations prepared for the DCLG; and evaluation forms from selected DCLG meetings.

Materials reviewed related to the Advocates in Research Working Group included *Advocates in Research Working Group (ARWG) NCI Organizational Analysis* (an attempt to present a comprehensive picture of advocacy involvement at NCI) and several draft versions of the *Final Report of the Advocates in Research Working Group*, including the Synopsis and Executive Summary.

2.2.2   Review of OAR Databases

The OAR Advocacy and CARRA databases were reviewed in depth to determine the specific fields and data elements captured by the databases and to ascertain which data elements were routinely collected as well as those which were not. Microsoft Excel files of summary data of CARRA activities by number of CARRA members requested and type of activity (one-time activity or multiple experience activity) for fiscal year (FY) 2002 through the first half of FY2010 were also reviewed.

2.2.3   Review of Relevant Websites and e-publications

The content of the OAR website and the Science Serving People website were reviewed. Several issues of the *NCI Nealon Digest* were also examined. The *NCI Nealon Digest* is a comprehensive electronic compilation of Federal cancer news, in digest form, from the most recent two-week period received via e-mail every other Wednesday by subscribers to the OAR Listserv with news tailored to the cancer advocacy community.

2.2.4   Semistructured Interviews with OAR staff

Interviews of current and former OAR staff members were conducted to collect information on their perceptions of the role of advocates and advocacy organizations at the NCI, as well as to determine how OAR staff members work with advocates and advocacy organizations. In addition, the interviews identified successful projects and interactions, detailed staff members' perceptions of Office activities, and provided information that could inform a future evaluation of the Office. A total of six interviews were initiated and five were completed. The completed interviews consisted of OAR leadership and four current or previous Advocacy Relations Managers. Interviews were conducted by a team of two staff members (an interviewer and a note taker) and each session was audiotaped, with permission from interviewees. The completed interviews were all individual, in-person (a partial interview with one staff member was conducted via phone), and included standard, open-ended questions (see Appendix). Questions were not provided to staff members in advance of the interviews and care was exercised to ensure that interview locations provided privacy and minimal distractions. Advocacy Relations Managers were informed that interview information would be analyzed and presented in summary form, that responses from individuals would not be shared outside the evaluation feasibility study team, and that responses would not be attributed to specific individuals.

Section 3:   Summary of Findings

3.1   Key Findings from a Review of Background Materials and Previous Studies

3.1.1   Findings from a Review of CARRA Program Documents

The review of documents related to CARRA revealed that the program has been extensively evaluated. Shortly after the formation of the Office, a baseline survey of NCI staff regarding overall attitudes and behaviors towards consumer involvement at NCI was conducted. The survey showed that while a large

majority of the respondents had generally positive attitudes towards consumer involvement in activities at NCI, many respondents had concerns regarding some of the day-to-day challenges of involving consumers in NCI activities as well as about the time it might take to involve advocates and how easy or difficult it might be to involve advocates. Some staff members were concerned about the quality of advocate participation, and almost half of the respondents believed that consumers should not be involved in the review of grants for funding decisions. Although both groups were supportive in general, senior NCI staff were more likely than more junior staff to believe that advocates should be involved in planning processes for setting scientific priorities; developing materials, such as brochures and websites, for the public; and their own NCI activities. Overall, 43% of the respondents reported that they had not involved advocates in their activities in the past year. Of those respondents who had involved advocates, almost half had never contacted the Office of Liaison Activities for recommendations.

In May 2002, the Office contracted with Westat, a social science research firm in Rockville, Maryland, to provide an external evaluation of the extent to which the CARRA program was meeting its goals. As part of these evaluation activities, a series of three surveys of CARRA members and NCI staff designed to capture their opinions on the efficacy of the program were conducted. The three surveys were administered during the following periods: Time 1—November 2004 through May 2005; Time 2—June 2005 through January 2006; Time 3—March 2006 through June 2006. Use of the same instrument during all three survey administrations enabled comparisons over time.

The first survey showed that CARRA members generally were quite satisfied with their participation experiences and felt that they were making a contribution in their role of bringing the consumer viewpoint to a wide range of cancer-related activities conducted by the NCI. NCI staff members were also positive about the program and felt that they were benefiting from the CARRA program and the participation of CARRA members in their activities. The second survey found that CARRA members continued to be quite satisfied with their participation experiences, and their satisfaction levels with respect to helpfulness of NCI contacts, opportunities to express the consumer perspective, match of activities meeting expectations, and willingness to participate in activities again was extremely high. While sometimes critical of CARRA members' human subjects information write-ups and the program's lack of precise clarity on roles, NCI staff members generally were also positive about the program and continued to feel that they were benefiting from the CARRA program and the participation of CARRA members in their activities. Virtually all NCI staff indicated they would request a consumer advocate again, and all respondents indicated that they would recommend the program to a fellow NCI colleague. Findings from the third survey were similar to those of the other two.

When responses across the three rounds of data collection were compared, several trends were noted. While interest in the program and level of satisfaction remained consistently high throughout, satisfaction with some materials available to the CARRA members declined in the third round of data collection. The proportion of CARRA members who accessed the CARRA website also declined over time. The overall working environment provided by the program was increasingly perceived as welcoming. Yet, while an increasing proportion of CARRA members felt supported in making written contributions, members' ratings with respect to making verbal contributions decreased over time. At the same time, NCI staff members reported a strong increase in satisfaction with regard to the CARRA members' verbal contributions. While an increasing proportion of the NCI staff expressed satisfaction with the levels of preparation among the CARRA members, they expressed decreasing satisfaction with request procedures. Overall the contributions made by the CARRA members were increasingly perceived as valuable and important.

Another survey of NCI staff members, identical to that conducted as a baseline survey in 2001, was conducted in 2005 to gather the opinions and attitudes of NCI staff about the value, level, and quality of CARRA member participation in NCI activities, as well as on the value of consumer advocates in general. Both users and non-users of CARRA program advocates were surveyed. NCI staff members who had actually used the program were much more positive in their responses than those who had not. Users were more positive about the value of involving CARRA members in the planning process to set scientific priorities, the scientific review of grants for funding decisions, and the development of materials for the public. They were also more positive regarding the quality of CARRA member participation and the value of consumer involvement in general. A special analysis of the responses by time worked at NCI disclosed that on 10 out of 15 survey items, respondents who worked at NCI for 16 years or longer had less positive attitudes toward the CARRA members and consumer advocates in general than respondents who worked at NCI for less than 16 years. The differences were most striking for items describing the value of CARRA member and consumer advocate involvement.

As evidenced by the document summarizing the findings of the various NCI staff and CARRA member surveys, OAR has synthesized the findings of the CARRA evaluation activities in order to inform future improvements of the CARRA program.

3.1.2   Findings from DCLG Materials

Review of the agendas and summaries of multiple DCLG meetings disclosed the depth and breadth of the DCLG's interests and activities. Review of the evaluation forms filled out by attendees at the conclusion of every meeting was informative and suggests that with the addition of a few questions, this vehicle could serve as a periodic tool for tracking specific issues and activities. Findings from the DCLG's ARWG are most pertinent to OAR and are detailed in the following section.

3.1.3   Findings from Materials from the Advocates in Research Working Group (ARWG)

One of the earliest activities of the Advocates in Research Working Group (ARWG) was to commission an organizational analysis of NCI to determine a baseline level of where and how advocates, and members of the public, were involved within NCI activities and NCI funded activities. This analysis was intended to present a comprehensive picture of advocacy involvement at NCI. Advocacy activities were placed in four broad categories—Advise, Design, Disseminate, and Review—and were inventoried by NCI Divisions, Offices, and Centers.

In its final report, the ARWG states that building a cadre of diverse, highly qualified advocates and NCI staff to effectively engage them is critical to realizing the benefits of involving advocates in the research process. "Engaging qualified advocates in a wide variety of activities will allow NCI to take full advantage of the experiential and diverse perspective advocates inherently bring to the research process." The current system for advocates to become involved with NCI is highly restrictive. In 2001 and 2004, NCI recruited advocates using a competitive application process. Upon selection, these advocates became part of the NCI CARRA program. Since that time, no additional advocates have been recruited, so advocates lost through natural attrition have not been replaced—nor have advocates with specific skill sets that align with NCI's current scientific needs been incorporated into the CARRA pool. Accordingly, NCI staff members and OAR often go outside the current pool of advocates to identify individuals who can meet the scientific needs of today's research. The current pool of advocates also does not reflect the diversity of either the general population or the populations most affected by cancer. Therefore, the current advocate pool cannot sufficiently represent the broad diversity of perspectives that make up the collective patient perspective. Additionally, when NCI investigators and staff identify the need to engage

advocates from a particular culture or background, the same individuals are repeatedly tapped, limiting the diversity of perspectives NCI obtains as well as potential opportunities for these and other individuals. Enhancing the current recruitment process will allow NCI to engage a larger number of highly qualified and diverse advocates and encourage more NCI staff to engage research advocates in their work.

The ARWG final report recommends that NCI:

- Recruit a cadre of diverse, highly qualified advocates and researchers to effectively engage them in the right activity at the right time

- Develop a robust assessment process to identify highly qualified research advocates

- Develop a matching process that focuses on identifying Institute needs and engages the right advocate in the right activity

- Provide training, coaching, and resources to advocates and researchers so they have the information and tools they need to be most effective

- Develop an area of centralized expertise to facilitate the engagement process

- Develop a systematic tracking process and use the resulting data to evaluate the process and outcomes of engaging advocates in research

- Develop a process for recognizing advocates and staff who successfully work together and promote these success stories throughout the community.

Clearly the ARWG recommendations will have a major impact on OAR and the Office will play a major role in their implementation. The design of the process and outcome evaluation of OAR will need to take these recommendations into consideration.

3.2 Summary of the Results of the Review of Existing Databases and Websites

The basic structure, organization, and data fields contained within the OAR Advocacy and CARRA databases are outlined in Exhibit 1.

Exhibit 1. Review of OAR Advocacy and CARRA Database

ADVOCACY DATABASE*					
BROWSE/EDIT TAB	**Name of organization**	**Primary Contact**	**URL**	**Actions/View**	

VIEW TAB	**Contact Information**
	• Organization E-mail
	• Organization Name
	• Main Phone
	• Alternate Phone
	• Toll Free Phone
	• *Fax*
	• Information Update Contact E-mail
	• Organization Main Address
	• Primary Contact Information
	  o Name/Title
	  o Main Phone
	  o *Fax*
	  o E-Mail
	  o Address
		Basic Information
		• *Acronym*
		• Website
		• Year Established
		• Tag Line
		• Mission Statement
		• Structure/Focus
		  o Audience Served
		  o Organization Type
		  o Org Structure
		  o IRS Designation (link with guidance)
		  o Cancer Focus
		  o Issue Focus
		  o Target Audiences
		  o *Special Populations*
		  o Org Activities
			Budget
			• *Fiscal Year End Date*
			• *Income*
			• *Expenditures*
			• Org Funding Sources
			• Org Funding Priorities
				Communications
				• Information Interests
					Staff
					• # Full Time
					• # Volunteers
					• Personnel, listed by position
					  o CEO
					  o *Research*
					  o *Policy*
					  o *Patient Services*
					  o *Outreach*
					  o *Media*
					  o *Communications*

SEARCH TAB	**Condition**	**Search Type**	**Search On**	**Operator**	**Searching For**

*As of May 28, 2010 the database contains 215 Advocacy Groups organized alphabetically. Entries range from professional societies and organizations to advocacy organizations of various sizes.**

Red italics represent data elements that are not consistently entered in the database.

CARRA DATABASE*					
BROWSE/EDIT TAB	Name	Primary Cancer Type	Actions/View		
VIEW TAB	**Contact Information** • Member Name • Address • Region/Division (based on U.S. Census) • Daytime Phone • Alternate Phone • *Cell Phone* • Fax • E-mail	**Cancer Experience** • Primary Cancer Type • Cancer Link • Cancer Type (Self) • Year(s) Diagnosed • Cancer Type (Others) • Interest in other cancer types?	**Membership Info** • Year Appointed • Term(s) • Trained in Peer Review Date • Status	**Interest Areas** • *Cancer Risk Factors* • Treatment/ Therapy Modalities • *Education, Training, and Outreach* • Cancer Prevention • Other Topics • Activity Interest	**Demographic Info** • Gender • Ethnicity • Race • Date of Birth
VIEW TAB CONT.	**Professional Information** • Employment Status • Current Occupation • Highest Educational Degree • Degree Background	**Track Preference** • Track Preference(s)	**Other Information** • Special Populations Representation • Participated in Clinical Trials • Smoker or Former Smoker • Frequency of Internet Use • Able to Travel	**Constituency Information** • Constituency Group • Constituency Group Website • Constituency Group Cancer Type • Role in Constituency Group	*Biography*
VIEW TAB CONT.	*Additional Information*	*Activities* • *Activity Title* • *Requestor/SRA* • *Review Type* • *Activity Type* • *Start/End Date*			

SEARCH TAB	Search On	Operator	Searching For		
	Request ID	**Request Title (data elements below)**	**Received**	**Requestor Name/Org**	**Status**
REQUESTS TAB ELEMENTS	**Basic info** • Request ID • Request Status • Activity Title • Review Type • Activity Type • Track • Request Channel • Activity Location	**Requirements** • # Advocates Needed • Travel Needed • Cancer Type • Skills Requested • *Populations Representation* • *Region/Division* • *Cancer Risk Factors* • *Treatment/ Therapy Modalities* • *Education, Training, and Outreach* • *Cancer Prevention* • Other Topics	**Requestor Info** • Requestor Name • Title • IC • NCI Organization • Organization Acronym • Organization Code • Phone • *Fax* • Email	**Dates** • Request Received • Activity Start • Activity End • Event Follow-up • Request closed	**Notes** *Suggested CARRA Member List*
ACTIVITIES TAB	**Activity Title (data elements below)**	**Requestor/SRA**	**Review Type**	**Start/End Date**	**Status**
ACTIVITIES TAB ELEMENTS	**Basic info** • Activity ID • Activity Status • Activity Title • Review Type • Activity Type • Track • Activity Location	**Dates** • Start Date • End Date • *Evaluation Follow-up*	**Requestor/SRA Info** • Name • Title • Phone • Fax • Email • IC • NCI Org. • Org Acronym • Org. Code	**CARRA Member Participant List**	*Additional Information*
REPORTS TAB	**Name**	**Date Created**	**Description**		

*As of May 28, 2010 the Database contains 218 individual advocates that are part of the CARRA program organized alphabetically, representing numerous cancer types and focus areas. *Red italics represent data elements that are not consistently entered in the database*

Both the OAR Advocacy and CARRA databases allow for the collection of a substantial number of data elements valuable for tracking and evaluating OAR activities. Both databases have the capacity to perform searches on a wide variety of items and to export the results of the searches as Microsoft Excel files. When reviewed in May 2010, the OAR Advocacy Database contained 215 Advocacy Groups organized alphabetically with entries ranging from professional societies and organizations to advocacy organizations of various sizes. As of May 2010, the CARRA Database contained the names of 218 individual advocates that are part of the CARRA program organized alphabetically and representing numerous cancer types and focus areas.

OAR has utilized the CARRA database to track the CARRA program by fiscal year from its inception in 2001 through the first half of FY 2010. Data items such as number of CARRA members requested (1 CARRA member, 2 CARRA members, 3-4 CARRA members, 5-10 CARRA members, 11-20 CARRA members, and more than 20 CARRA members) by type of activity (one-time activity or multiple experience activity) have been tracked over time. Activities can be further sorted into the following categories:

- Peer review committee

- Peer review meeting

- Peer review site visit

- Non-peer review committee

- Non-peer review editorial board

- Non-peer review educational materials

- Non-peer review informed consent

- Non-peer review meetings

- Non-peer review PRG

- Non-peer review research tool

- Non-peer review usability testing

- Non-peer review workshop

- Other.

At the beginning of the feasibility study, OAR staff members provided data tabulations from the CARRA database as part of the background materials on the Office. Some of these data are presented below. These examples of findings from the CARRA Database illustrate the types of data available and their potential applications. Exhibit 2 displays the number of NCI Advocates by Fiscal Year (FY) from FY 2002 to FY 2009.

Exhibit 2. Number of NCI Advocate Requests by Fiscal Year (Fiscal Years 2002—2009)
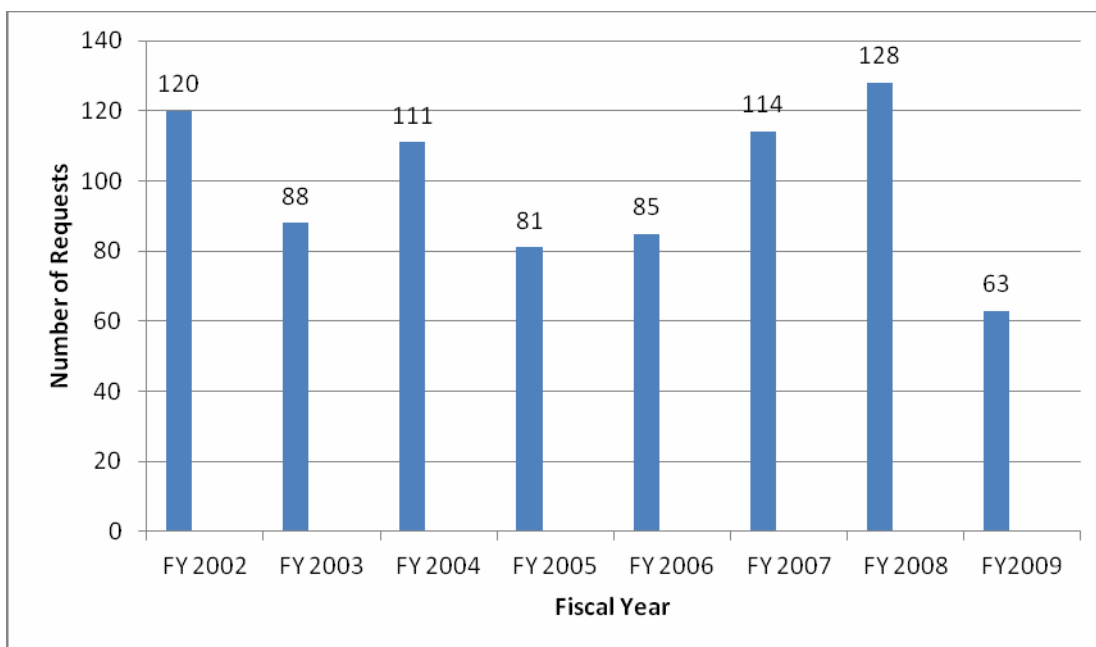
Exhibit 3 displays the distribution of requests by the number of Advocates requested over the same time period.

Exhibit 3. Number of NCI Advocates Requested Per Activity by Fiscal Year (FY 2002—FY 2009)

Number of CARRA Members Requested	Number of Requests	Percent of Requests
1 Member	538	67%
2 Members	119	14%
3-4 Members	53	6%
5-10 Members	57	7%
11-20 Members	8	1%
>20 Members	30	5%

CARRA Advocates can be invited to participate in a variety of peer review and non-peer review activities. Some of these activities are one-time activities and others are ongoing activities. Exhibit 4 portrays the distribution of requests for CARRA members to participate in one-time activities for fiscal years 2002 through 2009 compared with requests to participate in ongoing activities.

Exhibit 4. CARRA Requests: One-Time Activities vs. Ongoing Activities (FY 2002 to FY 2009)
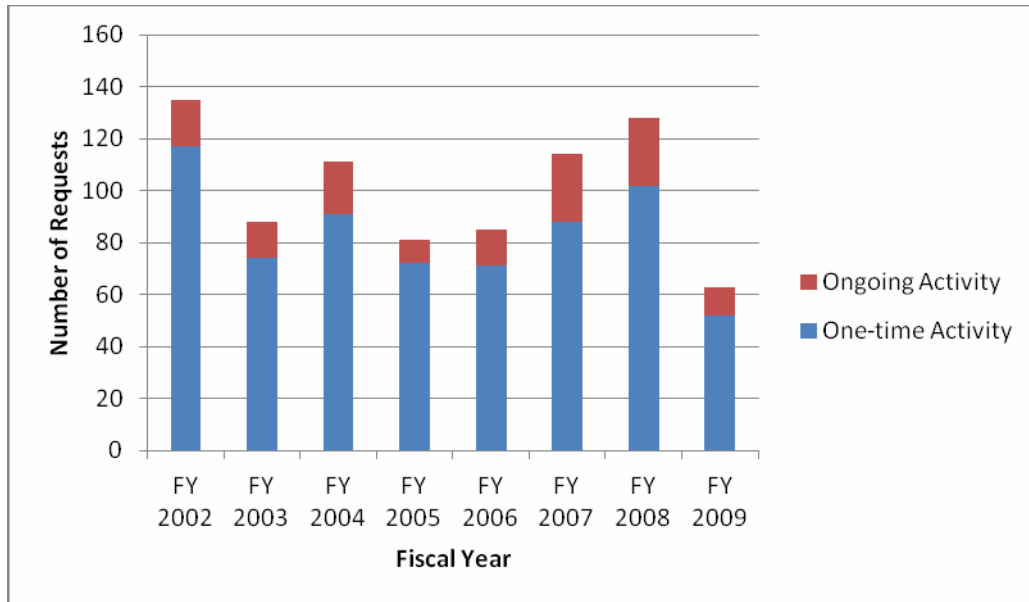
The numbers of requests by activity type and fiscal year are shown in Exhibit 5.

Exhibit 5. Types of Activities for Which CARRA Advocates Were Requested by Fiscal Year
(FY 2002-FY 2010)

Types of Activities	Fiscal Year									Total
	2002	2003	2004	2005	2006	2007	2008	2009	2010*	
peer review committee	4	2	1	2	3	5	1	5	1	24
peer review meeting	63	41	51	46	40	39	42	23	22	367
peer review site visit	24	22	8	1	1	2	3	1	3	65
non-peer review committee	9	6	14	4	6	16	17	6	2	80
non-peer review editorial board	1	1	1	0	1	1	0			5
non-peer review educational materials	16	6	16	13	10	23	18	12	2	116
non-peer review informed consent	1	1	0	0	0	1	1			4
non-peer review meetings	4	1	6	3	5	16	33	13	1	82
non-peer review PRG	1	2	0	1	1	0	0			5
non-peer review research tool	0	2	0	0	0	0	0			2

non-peer review usability testing	7	2	8	1	4	0	5	2	2	31
non-peer review workshop	3	1	3	6	8	1	0			22
other	2	1	3	4	6	10	8	1		35
Total	135	88	111	81	85	114	128	63	33	838

*Note: Data for FY 2010 are incomplete and were collected from October 1, 2009, through April 1, 2010.

Utilizing the data in Exhibit 5 it is possible to examine trends over time in specific types of requests. For example, Exhibit 6 shows how the number of requests for CARRA members to participate in peer review site visits changed over time compared with requests to participate in peer review meetings.

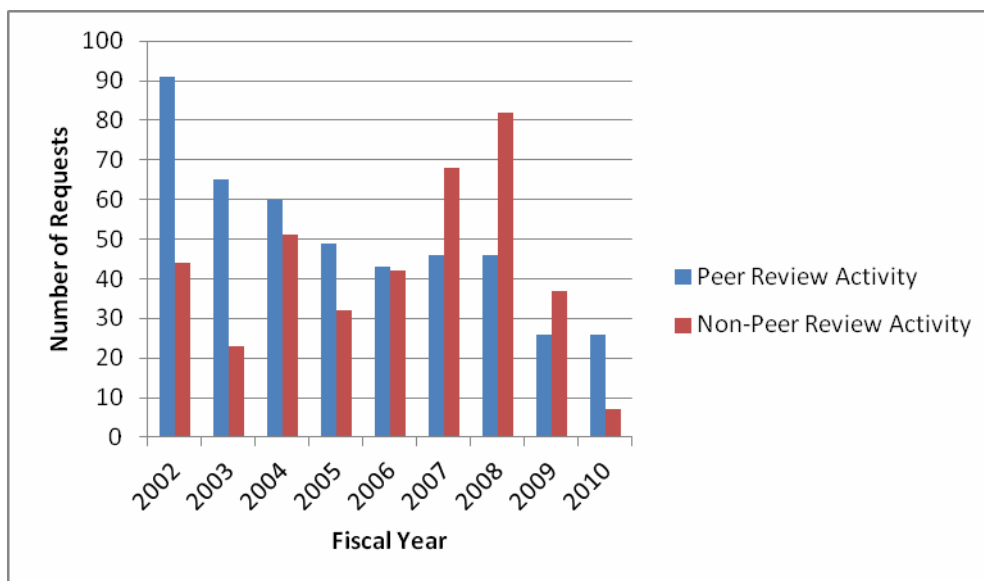*Exhibit 6. Peer Review CARRA Requests by Fiscal Year (FY 2002—FY 2010*)*
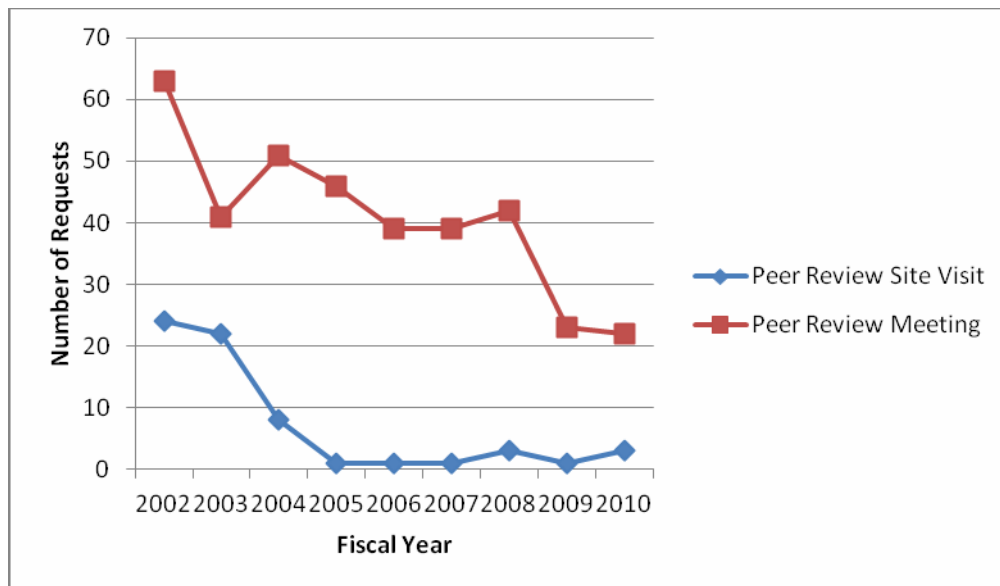
*Note: Data for FY 2010 are incomplete and were collected from October 1, 2009, through April 1, 2010.

It is also possible to examine trends in broader categories of activities over time. For example, Exhibit 7 shows changes from FY 2002 to FY 2010 in the numbers of requests for peer-review activities compared with non-peer review activities.

Exhibit 7. Number of Requests for CARRA Advocates to Participate in Peer-Review Activities vs. Non-Peer Review Activities by Fiscal Year (FY 2002- FY 2010*)

*Note: Data for FY 2010 are incomplete and were collected from October 1, 2009, through April 1, 2010.

Three factors limit the potential usefulness of the databases. First, several of the available fields are rarely populated. Second, the CARRA database is limited to individual advocates involved in the CARRA program and thus does not capture or track information on individual advocates outside the program. Third, CARRA advocates currently listed in the database were recruited in 2001 or 2004. No new CARRA advocates have been added to the database since 2004.

The OAR website provides an abundance of information about OAR (mission and history, values and rationale, information about OAR staff members, and OAR fact sheets), OAR programs, ways for advocates and advocacy organizations to become involved with NCI activities, an attention-getting textbox providing a direct link to the Science Serving People website, a number of convenient quick links to the ARWG, teleconferences, and cancer news headlines, as well as a link for NCI staff members to request a CARRA member. Under OAR programs, links are provided to the CARRA program and the DCLG. Another link on the OAR homepage allows readers to subscribe to the OAR Listserv and explains that subscription to the listserv provides biweekly e-mail receipt of the *NCI Nealon Digest* and periodic e-mail alerts for anyone interested in cancer research advocacy. The *NCI Nealon Digest* is an electronic publication delivered via e-mail every other Wednesday. It contains news tailored to the cancer advocacy community and provides a comprehensive list of all Federal cancer news, in digest form, from the most recent two-week period. Features include cancer news from NCI, NIH, HHS, and other Federal agencies; clinical trials and new treatment updates; new and updated reports, fact sheets, and websites of interest; opportunities for advocates and advocacy organizations to get involved; and NIH video casts.

3.3   Results from Interviews with OAR Staff Members

Although interviews were conducted individually with OAR staff members, there were a number of similarities and themes in staff responses. Following is a summary of common themes identified through content analysis of the interviews:

- Staff members identified several areas that are working well, including building relationships with advocacy organizations, increasing communications with advocates, and connecting advocates with the right people at NCI. Several specific project successes were identified, including the Patient Advocacy Steering Committee, the DCLG, peer review/advisory boards, and others.

- Staff unanimously identified several areas of opportunity for improvement, mainly focusing on the need for uniform tools or methods to track and/or monitor their interactions with advocates or NCI program staff. In addition, staff felt that the process for conducting OAR tasks/initiatives varies widely among OAR staff members and expressed that there is no "systematic approach" to supporting the needs of the internal or external communities.

- Staff consistently mentioned that they felt that there should be a comprehensive effort to evaluate the services that they are providing and discussed several barriers to evaluation, including the constantly evolving focus of the Office, difficulty in evaluating "relationships," and capturing how staff members help "shift conversations."

- Some staff members discussed the importance of "relationships" in assessing the role of OAR, while others focused on the importance of collecting data, since their interactions with advocates may only be for a short period of time (e.g., a brief phone conversation) versus an ongoing relationship.

- Several staff members noted that OAR has not conducted much formal outreach and as a result NCI staff, individual advocates, and advocacy organizations may not know that OAR exists and that might affect how the Office is evaluated.

- OAR staff also mentioned that although the Office is moving beyond "CARRA Advocates" to "NCI Advocates," there is still no formal "requirement" that advocates come through OAR and as a result, there is no method to evaluate all "NCI advocacy interactions."

The findings from the interviews are presented in several key areas: (1) role of OAR staff; (2) assessing staff needs; (3) communications and interactions; (4) engagement/relationships; and (5) evaluation.

3.3.1 Role of OAR Staff

At the onset of the interviews, staff members described their role as Advocacy Relations Managers and noted that they work primarily with different audiences (DCLG, NCI staff, individual advocates, advocacy organizations, and others). Staff members were asked a series of questions related to their role in the Office and their perceptions of their role among the internal and external audiences. When asked about their work and the kind of inquiries that they respond to, the majority of staff members mentioned that their role included responding to requests for advocates to fill various roles/positions.

Additional specific responses included:

Role	Responses
Requests for advocates to fill various roles/positions	3
Meeting Requests	2
Inquiries on how NCI works/research process	2
Policy Issues	2
Subject Expert Inquiries	2
Training Availability Options	2
Start-up Advocacy Organization Guidance	1

Assistance Navigating NIH/NCI	1
Tour NIH	1

Specific to their role in facilitating meeting requests, several staff members noted that advocacy meeting requests do not always come through OAR and therefore they do not have a way to capture, follow up, or assess those interactions.

Several staff members described the key roles that they could play in creating partnerships with NCI's Divisions, Offices, and Centers, as well as the larger advocacy community. They noted that OAR can:

■ Serve as an early warning system to address and identify strategic opportunities that can be mutually beneficial to both organizations

■ Bring forth valuable, specific, and "real" projects to begin dialogue with DOCs

■ Shift conversations with DOCs who have used advocates in the past to explore new opportunities for advocate involvement

■ Build relationships with DOCs and advocates to strengthen communication and interactions.

Sample respondent comments include:

■ *We have the ability to build peer relationships with other offices around the Institute to gain more insight into their work.*

■ *We need to find a way to get in the door and once we are there, we need to have something to talk about.*

■ *OAR staff members need to introduce themselves and educate people on the process for engaging advocates.*

■ *When working with the advocacy community, we can't be passive; we need to get out and develop relationships.*

3.3.2   Assessing Staff Needs

Another area of inquiry focused on identifying specific OAR staff needs. When questioned, almost all staff members mentioned the need for database improvements. They offered specific ideas for improvements, such as documenting the training that was provided and describing the interaction, as well as the results. In addition to creating tools, many staff members noted that OAR staff should be required to use them once they are developed because if they are not used consistently it will not be successful.

Sample respondent comments include:

■ *The database and tools haven't been mandatory so not everyone has used them.*

■ *We really need more streamlined information in the database. We have a lot of personal and professional information but we really need a section for feedback.*

In addition to improvements in processes and tools, staff members mentioned the need for a better understanding of NCI leadership goals. They would also like staff members of the other Offices and Divisions of NCI to regard OAR staff members as the experts on advocates and advocacy relations.

Sample respondent comments include:

- *We need a clear mission of the Institute to focus our efforts. Once we know the leadership priorities, we can use those to develop materials, such as talking points.*

- *Sometimes people across the Institute work directly with advocates and we really need to have everything come through OAR.*

OAR staff members also mentioned current communications vehicles, such as the *NCI Nealon Digest*, and many felt that the digest overall has been successful with communicating with the advocacy community, especially with its ease of access. Beyond the *NCI Nealon Digest*, staff members felt that there are many opportunities to improve existing communications vehicles to make them more robust and interactive. The group suggested identifying ways to engage two-way dialogue with the community. Overall they mentioned that improvements in communications vehicles used by OAR could provide staff members with information that can better support them in their role.

Sample respondent comments include:

- *Communications mechanisms seem to be working well and sharing information electronically is helpful for advocates.*

- *We should call people and make sure that they are on our list and then have people opt-out if they don't want to receive the* NCI Nealon Digest*.*

- *We need to create a promotion plan for the Office. Other offices have used such a plan and OAR can learn from what they have done to promote their offices and programs.*

- *The Director's Notes publication was effective and was a great opportunity for two-way communications around an issue. That was helpful because it allowed us to share and get feedback.*

- *The opportunity to interact with others is missing here at NCI; other Federal agencies use technology, such as video blogs, to give their organization a personality. We need to pose questions and drive conversations.*

3.3.3   Communications and Interactions

This area of inquiry detailed communications methods (both internal and external) and focused on staff interactions with other organizations. Regarding internal OAR communications, overall, staff noted that the small office environment allows them to have opportunities to share and be more aware of colleagues' interactions with program staff and advocates. Several noted that staff meetings and/or one-on-one meetings with leadership are held regularly and felt that there are opportunities for improvement.

Sample respondent comments include:

- *Generally, OAR staff stop by each other's offices to ask questions and relay information.*

- *Staff meetings can be more valuable by sharing outcomes and exchanging information more focused on relationships.*

Staff members were questioned regarding their methods for assessing needs, obtaining feedback, and following up. They mainly reported their method of assessing needs was through engaging in dialogue with NCI program staff, as well as the individual advocates. Generally, OAR staff noted that they assess needs through phone, in-person, or email, but they do not typically capture interactions with individual advocates or organizations. Staff members who worked mainly with CARRA advocates noted a more formalized method of obtaining feedback and assessing needs throughout the advocacy activities, although these methods are no longer utilized by the Office. Several staff members mentioned that they do not conduct any formal follow-up with advocates or NCI DOC staff.

Sample respondent comments include:

- *Previous OAR staff printed correspondence with DCLG members and placed the hard copy documents in files.*

- *There is a need for a process and concern that new OAR staff will have no historical records or context of what has taken place in the past with organizations and advocates.*

- *In the past, CARRA conducted follow-up or posted activity questionnaires for DOCs and advocates, but those methods are not currently being utilized.*

- *I sometimes personally follow up informally by contacting program staff and advocates to see how things went.*

When questioned on their methods for documenting interactions, overwhelmingly, staff members noted that there was "no standard method of capturing interactions" but they felt that there should be a process. Overall, staff mentioned that the current tools on the shared drive, as well as the database, are either not used or ineffective and need to be updated to include essential information.

Sample respondent comments include:

- *There are various methods that can be utilized to capture interactions; however there is no formal process in place.*

One staff member mentioned that obtaining feedback internally is difficult, since OAR leadership does not attend NCI leadership meetings; that might affect the ability to systematically identify problems at the NCI level.

3.3.4   Engagement/Relationships

The fourth area of inquiry focused on gathering respondents' thoughts and perceptions about relationships with NCI staff and the advocacy community. Specifically, participants were asked about perceived barriers to fostering relationships between NCI and advocates. Several barriers mentioned include:

- Past experiences may have broken trust with researchers

- Lack of training for advocates

- Missed opportunities for building relationships

■ Change in assignments of OAR staff.

Sample respondent comments include:

■ *There are often no set expectations or consequences for advocates.*

■ *Occasionally NCI staff fear that advocates will be activists.*

■ *Portfolio assignments for OAR staff should be determined in a more systematic way. Set portfolios help to build relationships with NCI and organizations.*

■ *We often change assignments so Divisions, Offices, and Centers don't have a connection with the staff in OAR and don't know "their representative."*

■ *We need to have formal introductions made by the OAR Director to DOCs informing them of their OAR representative.*

■ *OAR staff can be used at different levels to build relationships; however, staff may not feel prepared because we don't have any materials or information to promote the Office.*

Staff members mentioned several ways that advocate involvement could be enhanced, by OAR, including:

■ Playing a vital role in improving advocate involvement by helping to identify ways to bring advocates into the research of the Institute

■ Consistently assessing the NCI program staff and their need for advocate involvement (building on critical information captured by the ARWG)

■ OAR becoming more in tune with issues at the NCI and systematically identifying opportunities for collaboration.

When questioned on ways that NCI program staff members could support OAR staff, numerous examples were provided including:

■ Being more open to education around the strategic role of advocates

■ Determining the appropriate information needed to facilitate a project/activity in advance of beginning advocate interactions

■ Better articulating the role that they need the advocate to play in the activity.

3.3.5   Evaluation Methods

The final area of inquiry related to the value of evaluation of OAR activities, as well as barriers to effectively evaluating the Office. Staff members noted their perceptions of the importance of evaluating OAR. Ongoing evaluation would:

■ Provide data in an evidence-based culture

■ Communicate the value of the Office

■ Identify missed opportunities and offer new directions

- Provide an incentive for change for activities and programs that are not adding value

- Create metrics for success and return on investment

- Assist in capturing qualitative outcomes of OAR activities

- Provide a method to measure success.

Sample respondent comments include:

- *Having data is important in our evidence-based organization.*

- *Evaluation is important because it will help us to see if we are doing what we say we do and find out how well.*

- *It will help us to characterize the "soft things" that the Office does, such as relationship building.*

- *It will help us to measure success, not just numbers, but quality.*

A question specifically for OAR leadership around barriers to evaluating the Office provided additional insights, including:

- Staff often do not know what OAR should be doing

- The function of OAR evolves on a daily basis

- Staff are not currently logging interactions so that they can be tracked and evaluated

- Difficulty in evaluating how OAR is "shifting conversations" in the advocacy community

- NCI staff tend to evaluate advocates based on the wrong standards (e.g., disposition, whether they were on time, whether they read the information provided).

Section 4: Recommended Design for a Process and Outcome Evaluation of OAR

This section describes the recommended design for a comprehensive process and outcome evaluation of OAR and includes an overview of the recommended design for the evaluation, an evaluation framework, OAR goals, purpose of the evaluation, target populations, evaluation questions, key variables and data sources, data collections methods and sources, and clearance requirements.

4.1   Overview of the Recommended Process and Outcome Evaluation Design

The proposed process and outcome evaluation design is based upon a sound understanding of the structure and goals of the OAR. Based upon the review of background materials and previous studies, the review of OAR databases and relevant websites, and semi-structured interviews with OAR staff, we conclude that an ongoing process and outcome evaluation of OAR activities is both feasible and warranted. Although previous evaluations have assessed the CARRA program, there has never been a formal evaluation of the "value added" to NCI of OAR activities. Since the Office was established in 1996, the focus of advocacy relations, the context of advocates in the research process, and expectations regarding OAR activities has changed significantly. In addition, the Office has recently experienced

reorganization and may experience further restructuring based on recommendations from the NCI Advocates in Research Working Group (ARWG) 2010 final report. For these reasons, it is appropriate to assess OAR's internal (NCI staff) and external (the advocacy community) customers' utilization of OAR services, satisfaction with OAR services, and the nature, quality, and impact of relationships and collaborations resulting from OAR activities.

Since the review of OAR databases and interviews with OAR staff revealed that while the structure of the databases is relatively robust, many of the fields are rarely populated and entering data into the databases is not mandatory, it is recommended that the process and outcome evaluation be conducted in three phases. Phase 1 would involve developing and implementing tracking systems, revising and updating the OAR databases, revising relevant websites, and providing OAR staff training on relationship building and utilization of standardized processes and systems for capturing quantitative and qualitative information on OAR activities. Phase 2 would measure short-term outputs and outcomes and involve utilization of revised databases, including ongoing documentation of inquiries from individual advocates, advocacy organizations, and NCI staff, relationship building activities, and communication and dissemination activities. Phase 3 would measure intermediate and long-term outcomes and involve periodic web-based surveys of NCI program staff members, individual advocates' feedback, and advocacy organization membership surveys. This three-phase approach will allow for revisions to OAR systems and activities, ongoing assessments, and reporting of qualitative and quantitative outputs and outcomes.

The estimated timeline for the phased approach is shown in Exhibit 8:

Exhibit 8: Timeline for the Process and Outcome Evaluation

Evaluation Phase	Implementation	Timeline
Phase I	Development and redesign of databases, systems, and processes; OAR staff training	1-12 Months
Phase 2	Short-term outputs and outcomes	12-24 months and ongoing at regular intervals
Phase 3	Intermediate and long-term outcomes	24-36 months and ongoing at regular intervals

4.2   Evaluation Framework

Exhibit 9 provides an overall framework for the process and outcome evaluation of OAR, showing linkages between principal activities, outputs and intended outcomes. The framework is a blueprint for evaluating OAR, underscoring program activities, outputs, short-term, intermediate- and long-term outcomes, and the proposed data methods and sources. The activities describe the work of OAR in six broad categories: (1) engaging individual research advocates in the research process at NCI; (2) leading the Director's Consumer Liaison Group (DCLG); (3) developing collaborative efforts with community stakeholders; (4) serving as a central resource for NCI, providing support for advocacy engagement and coordination; (5) increasing the knowledge base about NCI and research within the advocacy community and creating two-way dialogue with external stakeholders; and (6) providing OAR staff with training in how to build effective and productive relationships with individual advocates, advocacy organizations,

and NCI staff. These activities provide the basis for the outputs and the links to short-term and intermediate- and long-term outcomes and results. The outcomes also capture OAR's effects on the NCI research enterprise. Individual components of the design are described in the following sections.

Exhibit 9. Evaluation Framework

Goals: OAR establishes and cultivates relationships with external stakeholders to identify common priorities, understand legislative initiatives, and resolve areas of concern. Specifically, OAR seeks to add value to NCI by;

- Increasing NCI's accessibility, credibility, and transparency
- Acting as an early warning system to identify and respond to issues important to the advocacy community
- Leveraging shared interests and building support for key Institute endeavors
- Facilitating a collective understanding of nonscientific barriers that inhibit research and catalyzing the community to address these barriers where possible and appropriate
- Improving understanding of NCI priorities and activities within the advocacy community
    - ◆ Influencing community expectations
    - ◆ Enhancing the ability to effectively communicate with other stakeholders
- Infusing a diverse (collective patient) perspective throughout the research process

Activities	Outputs	Short-Term Outcomes	Intermediate and Long-Term Outcomes	Methods/Data Sources
Engage individual research advocates[1] in the NCI research process: • Facilitate the engagement of individual research advocates in the research process; recruit, assess, train, match, facilitate, and evaluate such engagements. • Respond to inquiries from individual advocates verbally and/or in writing.	• A diverse cadre of highly qualified research advocates that meet the needs of NCI staff on an ongoing basis. • A robust assessment process to identify highly qualified research advocates. • A matching process that focuses on identifying NCI needs and engages the right advocate in the right activity. • Involvement of individual research advocates in the research process.	• Increased effectiveness of advocacy engagements. • Increased reports of meaningful outcomes. • Increased number of advocates engaged in: NCI advisory boards; review activities; developing new programs or enhancing existing ones; dissemination activities; and trans-NCI activities.	• Enhanced quality of research (examples include increased experiential knowledge, improved research feasibility, more innovative research questions, expanded scope of inquiry, increased choice of research tools, expedited recruitment, increased diversity of perspectives). • Increased advocacy community understanding and support of research (examples include increased transparency and accountability, regular conduit for communication between the advocacy community and researchers, enable advocates to better understand and justify the need for science).	• Secondary analysis of tracking data collected in the modified CARRA database utilizing the evaluation Follow-up function in database. • Ongoing web-based surveys of NCI Program staff members following completion of an activity utilizing an advocate. • Ongoing telephone follow-up by OAR Advocacy Relations Managers with individual advocates when an activity has ended to obtain perspectives on the activity and the advocate's contributions and entry of the feedback into the tracking database. • Advocacy Organization membership surveys.

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[1] "Research advocates" are a specific type of advocate involved in research activities. The Advocates in Research Working Group (ARWG) defines a research advocate as an individual who brings a nonscientific viewpoint to the research process and communicates a collective patient perspective. A patient perspective is created when a person goes through personal or professional experience with the disease, and a "collective" patient perspective is created when the person has knowledge of others' disease experiences. Research advocates embody a larger perspective than their own. A research advocate does not convey only his or her own perspective, that of relatives or friends, or even that of a cancer advocacy group. Advocates should be familiar with and able to convey the perspectives of many different populations of consumers or patients—even if they are associated with a cancer or health organization. This broad perspective is a requirement for advocates involved

Activities	Outputs	Short-Term Outcomes	Intermediate and Long-Term Outcomes	Methods/Data Sources
Lead the Director's Consumer Liaison Group (DCLG)[2]: • Identify nonscientific barriers and opportunities for the advocacy community to address these barriers. • Identify the information and tools stakeholders need to effectively address nonscientific barriers. • Identify opportunities for NCI to address nonscientific barriers.	• Identification and acknowledgement of nonscientific barriers to the research enterprise. • Identification of the information and tools stakeholders need to effectively address nonscientific barriers. • Development of new relationships and collaborations resulting from these meetings and/or information provided.	• Barriers effectively communicated to a broader advocacy and/or scientific community. • Championing of behaviors/projects identified as addressing nonscientific barriers. • Increased utilization by stakeholders of the information and tools needed to effectively address nonscientific barriers.	• Identification of specific measurable outcomes. • Alleviation of nonscientific barriers to the research enterprise. • Barriers in some way impacted as a result of the influence of the DCLG and the broader community as a result of their influence.	• Qualitative analysis of DCLG meeting summaries and DCLG meeting evaluations. • Ongoing OAR staff follow-up telephone contact with DCLG members to identify and document outcomes.
Develop collaborative efforts with community stakeholders: • Respond to inquiries from advocacy organizations verbally and/or in writing. • Arrange meetings for advocacy organizations with NCI scientific staff, program staff, and leadership. • Identify, create, and facilitate opportunities to collaboration between advocacy organizations and NCI.	• Identification, acknowledgement of, and alleviation of nonscientific barriers with the research enterprise. • Response time in answering inquiries from advocacy organizations. • NCI involvement in advocacy organization activities.	• Increased identification and documentation of successful collaborations with advocacy organizations. • Increased OAR outreach efforts. • Increased familiarity of external organizations with OAR's role as a central resource for identifying and facilitating opportunities for collaboration between NCI and external organizations.	• Enhanced quality of research. • Increased advocacy community understanding and support of research.	• Ongoing OAR staff follow-up telephone contact with each Advocacy organization after the completion of an activity and entry of the findings in the tracking database. • Secondary analysis of tracking data collected in the modified OAR Advocacy database. • Analysis of data collected as feedback in Science Serving People website.

in NCI activities and is one of the reasons advocates are valuable in research activities. A research advocate's role is to bring this collective nonscientist perspective to research activities even if he or she possesses a scientific background. (Page 7 of the 3-29-10 draft ARWG Report.)

[2] The NCI Director's Consumer Liaison Group is a Federal Advisory Committee comprised of advocate leaders chosen for their expert understanding of the perspectives and dynamics of the cancer research community. The DCLG indentifies and responds to issues and challenges facing the Institute at the request of the Director. The DCLG provides relevant, nonscientific skills and perspectives in order to improve research outcomes by identifying new approaches, promoting innovation, recognizing unforeseen risks or barriers, and identifying unintended consequences that could result from NCI decisions.

Activities	Outputs	Short-Term Outcomes	Intermediate and Long-Term Outcomes	Methods/Data Sources
Serve as a central resource for NCI, providing support for advocacy engagement and coordination: • Proactively communicate about upcoming issues NCI has identified as critically important.	• Presentations across NCI to engage NCI staff in effectively involving advocates. • Number of NCI programs that utilize OAR services to facilitate advocacy involvement. • Number of NCI staff within programs that utilize OAR services to facilitate advocacy involvement. • Identification of additional NCI programs that would benefit from advocacy involvement.	• Increased familiarity of NCI staff with OAR's role as a central resource for identifying and facilitating opportunities for collaboration between NCI and external organizations. • Increased number of NCI DOCs involving advocates in their work. • Increased number of opportunities identified. • Increased number of collaborations facilitated.	• Staff of NCI DOCs recognize OAR as the central resource for providing support for advocacy engagement and coordination and turn to OAR for their advocacy needs.	• Annual web-based survey of NCI Program staff members. • Periodic web-based surveys of Advocacy Organizations. • Secondary analysis of tracking data collected in the modified CARRA database. • Secondary analysis of tracking data collected in the modified OAR Advocacy database.
Increase the knowledge base about NCI and research within the advocacy community and create two-way dialogue with external stakeholders: • Develop relationships with individual advocates and with representatives of advocacy organizations. • Edit and disseminate the *NCI Nealon Digest*. • Identify opportunities develop and produce teleconferences. • Develop content, edit, and produce the Science Serving People website. • Identify other opportunities to develop and disseminate content critical to understanding NCI and the research process.	• Utilization of the *NCI Nealon Digest*. • Utilization of the teleconference series mechanism to convey strategic messages. • Utilization of the Science Serving People website.	• Enhanced ability to effectively communicate with external stakeholders. • Increased dissemination of research. • Improved usability of research to consumers. • Enhanced transparency and accountability. • Decreased barriers between the advocacy community and NCI researchers. • Improved channels for regular communication between the advocacy community and NCI researchers • Increased understanding of and ability to justify science among advocates.	• Increased advocacy community understanding and support of research. • Increased advocacy community trust.	• Track number of Internet hits on the Science Serving People website. • Track number of Internet hits on the *NCI Nealon Digest*. • Participate in teleconference series designed to convey strategic messages. • Content analysis of feedback data from the Science Serving People website. • Create a section on the OAR website where advocates can fill out a form to let OAR know how they are using OAR resources/information. • Request that advocates share links/materials that they disseminate. • Ask selected advocacy group representatives about methods and data sources.

Activities	Outputs	Short-Term Outcomes	Intermediate and Long-Term Outcomes	Methods/Data Sources
Provide OAR staff with training in how to build effective and productive relationships with individual advocates, advocacy organizations, and NCI staff.	• Number of OAR staff receiving training in building effective relationships. • Number of training sessions in building relationships being offered to OAR staff members.	• Increased application of relationship building skills to developing and fostering relationships with individual advocates, advocacy organizations, and NCI staff.	• Increased high-quality, long-term productive relationships between OAR staff and individual advocates, advocacy organizations, and NCI staff.	• Secondary analysis of tracking data collected utilizing the Evaluation Follow-up function in the modified CARRA database. • Annual interviews with OAR Advocacy Relations Managers. • Annual interviews with NCI program staff. • Qualitative measures .

4.3 OAR Goals

OAR establishes and cultivates relationships with external stakeholders to identify common priorities, understand legislative initiatives, and resolve areas of concern. OAR goals are to add value to NCI by:

- Increasing NCI's accessibility, credibility, and transparency

- Acting as an early warning system to identify and respond to issues important to the advocacy community

- Leveraging shared interests and building support for key Institute endeavors

- Facilitating a collective understanding of nonscientific barriers that inhibit research and catalyzing the community to address these barriers where possible and appropriate

- Improving understanding of NCI priorities and activities within the advocacy community

- Infusing a diverse (collective patient) perspective throughout the research process.

In order to achieve these goals, it is necessary to systematically document and assess specific activities, outputs, and outcomes. The evaluation should include descriptive information about OAR operations and activities that may help explain the outcomes. It is also necessary to assess periodically OAR's principal customers'—the NCI research community and the advocacy community—needs and suggestions for process improvement.

4.4 Purpose of the Evaluation

The purpose of the proposed process and outcome evaluation of OAR is to assess the activities, processes, outputs, and short- and long-term outcomes of current and future OAR collaborations and relationships with individual research advocates, advocacy organizations, and NCI program staff. Specifically, the evaluation will help OAR to: (1) measure the efficiency and effectiveness of its activities; (2) eliminate redundancies and reduce costs, (3) maximize program impact; and (4) ensure relevance to OAR audiences. The goal will be to improve and expand OAR services and activities and increase the added value to NCI.

The ongoing process and outcome evaluation, involving routine and ongoing collection of quantitative and qualitative data, will enable OAR to update its databases, processes and systems, make workflow process improvements, document accomplishments, more effectively support advocacy engagement and coordination, increase two-way dialogue with external stakeholders, and better communicate issues NCI identifies as critically important.

4.5 Target Populations

The target populations for the OAR process and outcome evaluation are past, current, and potential users of OAR services including individual advocates, advocacy organizations, community stakeholders, NCI staff, and the NCI Director's Consumer Liaison Group (DCLG). Each of these populations is described below.

Individual Advocates: The Advocates in Research Working Group (ARWG) defines a research advocate as "an individual who brings a nonscientific viewpoint to the research process and communicates a collective patient perspective." OAR matches individual research advocates to various NCI activities.

Advocacy organizations: Advocacy organizations include national advocacy and voluntary organizations that work with consumer advocates and scientific and professional societies concerned about cancer. OAR acts as a portal, helping organizations navigate the NCI and the NIH to gain information and achieve shared organizational goals.

Community stakeholders: Community stakeholders include the consumers of cancer research—patients, their families and friends, and the many others affected by the disease. OAR has several vehicles to keep the patient advocacy community informed about NCI: the *NCI Nealon Digest* (a biweekly E-newsletter); the *Understanding NCI* teleconference series; the *OAR Listserv*; and the NCI Website for advocates—*Science Serving People*.

NCI staff: NCI staff members who utilize OAR services to facilitate advocacy involvement to enhance the quality of research include the NCI scientific staff, program staff in NCI's DOCs, and NCI leadership. OAR works directly with NCI staff to identify opportunities for organizational collaboration and advocacy involvement.

The NCI Director's Consumer Liaison Group: The DCLG, chartered in 1997, is a Federal Advisory Committee comprised of advocate leaders chosen for their expert understanding of the perspectives and dynamics of the cancer research community. The DCLG identifies and responds to issues and challenges facing the Institute at the request of the Director. The DCLG provides relevant, nonscientific skills and perspectives in order to improve research outcomes by identifying new approaches, promoting innovation, recognizing unforeseen risks or barriers, and identifying unintended consequences that result from NCI decisions.

4.6   Evaluation Questions

A process and outcome evaluation of OAR should address questions about the Office's functioning and effectiveness, as well as questions regarding the measurement of the quality of research at NCI. Key questions to be addressed in the proposed process and outcome evaluation include the following. The questions and sub-questions represent a synthesis of questions suggested by OAR staff members.

1. What is the added value OAR brings to NCI?

2. How does OAR increase NCI's accessibility, credibility, and transparency?

3. How and to what extent does OAR leverage shared interests and build support for key Institute endeavors?

4. How does OAR facilitate a collective understanding of nonscientific barriers that inhibit research and catalyze the community to address these barriers where possible and appropriate?

5. How and to what extent does OAR improve the understanding of NCI priorities and activities within the advocacy community?

   5.1 How does OAR influence community expectations?

   5.2 How does OAR enhance the advocacy community's ability to effectively communicate with other stakeholders?

6. How and to what extent does OAR infuse a diverse (collective patient) perspective throughout the research process?

    6.1 How can OAR provide more proactive, timely interactions with NCI DOCs and the advocacy community?

7. What are other ways that OAR can add value to NCI?

4.7 Key Variables

The recommended design includes process variables, output variables, and short-term and intermediate and long-term outcome variables. Process variables will examine how OAR activities are implemented, how the Office operates, the types of services it provides, and the extent to which it reaches its target audience(s). Process activities include various operational characteristics such as coordination and communication, planning processes, training programs, and relationship building. Output variables include measures of what OAR's structure and activities have produced, such as: development of new relationships and collaborations; a robust assessment and matching process that engages the right advocates in the right activities; NCI involvement in advocacy organization activities; and the number of NCI staff utilizing OAR services. Short-term outcomes reflect the actual results arising from OAR activities and outputs. These variables are largely quantitative and measure and document OAR success and improvements in such areas as: increased outreach efforts; increased number of collaborations facilitated; increased dissemination of research; improved usability of research to consumers; and decreased barriers between the advocacy community and NCI researchers. Intermediate- and long-term outcomes reflect longer-term success and impacts such as: enhanced quality of research; increased advocacy community understanding and support of research; alleviation of nonscientific barriers to the research enterprise; and increased high-quality, long-term productive relationships between OAR staff and individual advocates, advocacy organizations, and NCI staff.

4.8 Data Sources and Data Collection Strategies

The evaluation design proposes a mixed-methods evaluation approach utilizing both primary and secondary data collection methods and sources. The secondary data sources will adequately address the key questions of an evaluation of OAR, particularly those regarding the implementation and productivity of OAR activities. The collection of information from primary data sources will enrich OAR's understanding of the long effects of OAR activities on the NCI research enterprise. Exhibit 10 describes the primary and secondary data sources with a brief description of each. Exhibit 11 shows the evaluation questions mapped onto the principal data sources.

4.9 Clearance Requirements

The proposed design relies mostly on secondary data sources: OAR, NIH, and advocacy organization databases and websites; and semi-structured telephone interviews. Therefore OMB clearance would not be required. The primary data collection—Web-based surveys of NCI program staff—would also not require OMB clearance since it is an internal NIH employee survey.

Exhibit 10. Principal Data Sources

Data Sources	Description
Primary Data Sources	
Survey(s) of NCI Program Staff	Periodic web-based surveys of NCI program staff following completion of an activity utilizing an advocate.
Advocate interactions	Ongoing documentation of OAR Advocacy Relations Managers' interactions (telephone contacts, email, etc.) with individual advocates and advocacy organizations. This includes ongoing telephone follow-up with advocates when an activity has ended to obtain perspectives on the activity, the advocate's contributions, and possible impact on the advocacy community.
Semistructured interviews with OAR staff	Annual semistructured interviews with OAR Advocacy Relations Managers and OAR leadership on relationship building activities; participating in OAR training; and use of OAR standardized procedures, systems and databases.
Secondary Data Sources	
CARRA Database (revised)	Secondary analysis of tracking data collected in the revised CARRA Database utilizing the evaluation follow-up function, online application module, online repository of training resources, advocacy engagements, etc.
Advocacy organization surveys	Secondary analysis of membership surveys conducted by advocacy organizations that interact with NCI and OAR.
OAR Advocacy Database	Secondary analysis of quantitative database elements including: organizational focus, cancer focus, target audience(s), information interests, etc.
DCLG meeting summaries	Qualitative analysis of DCLG meeting summaries, specifically identification of nonscientific barriers to the research enterprise, and case studies of advocate involvement in NCI research programs.
DCLG meeting evaluations	Qualitative analysis of DCLG meeting evaluations regarding participants' feedback and perceptions of the effectiveness of the meeting, specifically in terms of reaching outcomes that will ultimately help advance cancer research in the best interest of patients.
Science Serving People website	Utilization of the Science Serving People website and content analysis of feedback data collected on the website.

NCI *Nealon Digest*	Utilization of the web-based digest.
Teleconference series	Utilization of the teleconference series mechanism to convey strategic messages.

Exhibit 11: Evaluation Questions and Principal Data Sources

Principal Data Sources	Evaluation Questions						
	What is the added value OAR brings to NCI?	How does OAR increase NCI's accessibility, credibility, and transparency?	How and to what extent does OAR leverage shared interests and build support for key Institute endeavors?	How does OAR facilitate a collective understanding of nonscientific barriers that inhibit research and catalyze the community to address these barriers where possible and appropriate?	How and to what extent does OAR improve the understanding of NCI priorities and activities within the advocacy community?	How and to what extent does OAR infuse a diverse (collective patient) perspective throughout the research process?	What are other ways that OAR can add value to NCI?
Surveys of NCI Program Staff	✓	✓	✓	✓	✓	✓	✓
Advocate interactions	✓	✓		✓	✓	✓	✓
Semistructured interviews with OAR staff	✓	✓	✓	✓	✓	✓	✓
CARRA Database (revised)			✓	✓	✓	✓	
Advocacy organization surveys and websites		✓		✓	✓	✓	
OAR Advocacy Database			✓	✓	✓		
DCLG meeting summaries		✓	✓	✓	✓	✓	
DCLG meeting evaluations	✓	✓	✓	✓	✓	✓	
Science Serving People website		✓	✓	✓	✓	✓	
NCI Nealon Digest		✓	✓	✓	✓	✓	
Teleconference series		✓	✓	✓	✓	✓	

Appendix: Feasibility Study Interview Guide

Office of Advocacy Relations, National Cancer Institute

Feasibility Study Interview Guide

Background

As a part of the National Cancer Institute (NCI) Office of Advocacy Relations (OAR) effort to determine the overall feasibility of developing and implementing a comprehensive process and outcome evaluation of OAR's activities, individual interviews will be conducted with OAR staff in order to help establish their process for engaging advocates, determine specific activities that they are involved in, and demonstrate potential methods for data collection.

Approach

Interviews will be conducted with OAR senior leadership and current and former Advocacy Relations Managers. Each individual will be interviewed separately and this will ensure that the same information is collected from each interviewee. Standard, open-ended questions will be posed to all interviewees to allow for comparable results.

Pre-interview

Interview questions were developed and approved by OAR leadership. OAR leadership will inform staff of the feasibility study and request that staff members participate in interview sessions. Participants will not be provided the questions in advance of the interviews. Sessions will set-up in an OAR conference room in the building to minimize distractions.

Interview

The interviews will be conducted by a team of two staff members—a trained interviewer (who will conduct the interview) and a note taker (who will record the interview responses). In addition, the sessions will audio taped (with permission from participants) to provide backup information. The interview process will include the following:

- Welcome and introductions
- Brief mention of the purpose of the interview—to collect information regarding the role of advocates and advocacy organizations at the NCI and ways in which OAR staff works with them.
- Mention confidentiality—information will be shared only in aggregate and participants will not be identified by name.
- Discuss the format of the interviews—brief questions followed by responses by the interviewee.
- Ask participant if they mind being audiotaped.
- Ask interviewee to describe their role at OAR.
- Conduct interview (interview questions provided below).
- Ask if the interviewer has any additional information they want to share or if they have any questions.

Post-interview

Following each interview, the note taker will prepare a draft of the interview document summarizing the discussion and submit it to the interviewer for review and comments/edits. All audio recordings will be deleted after completion of the feasibility study.

Feasibility Study—Interview Questions

OAR Director

1. In your opinion, how does the NCI staff perceive the Office of Advocacy Relations (OAR)?

2. In your opinion, what is the advocacy community's perception of OAR?

3. Do you think advocates understand NCI's research priorities/activities and how they can become better engaged in research at NCI?

4. Do you feel that OAR is reaching its key constituents (individual advocates, advocacy organizations, patients, families, researchers, and healthcare professionals)? If not, which groups do you feel require additional outreach efforts?

5. How would you describe OAR's success in serving as a link between the research and advocacy community? What is working well? What could OAR do to improve its efforts?

6. What characteristics would you use to describe a successful advocacy engagement?

7. What do you see as barriers to working with advocacy organizations? How do you think these can be overcome?

8. What do you see as the ideal role for advocates? Advocacy organizations?

9. Where have you seen the most success working with advocates? Advocacy organizations?

10. Do you feel that internal and external audiences recognize the distinction between OAR advocates and advocates recruited through other mechanisms at NCI? In your opinion, should there be a distinction?

11. How do you currently measure OAR's Return on Investment (ROI)? What information would you need to better evaluate the office's ROI?

12. What are your plans for revising the OAR databases?

13. In which specific ways do you think activities in your office can be better evaluated?

14. Do you think OAR communications mechanisms (Nealon Digest, Teleconference Series, Science Serving People) are adequate in reaching advocates?

15. How can OAR shift the conversation in the advocacy community?

16. What do you feel are barriers to evaluating this office?

OAR Deputy Director

1. How do most NCI program staff members find out about OAR's services?

2. How have you promoted the services of the office to advocates and advocacy organizations?

    a. Any specific examples of how that has been able to work well?

    b. In terms of how you're able to capture those relationships, have you personally done anything to evaluate those relationships, any specific evaluation or survey?

3. What proactive measures do OAR staff members and you personally take to engage advocacy organizations? NCI researchers?

4. What formal or informal process or procedures do you conduct when engaging individual advocates and advocacy organizations?

5. Describe barriers, if any, that OAR staff may have in fostering stronger relationships between NCI researchers, advocacy organizations and individual advocates?

6. What are some of the best practices currently utilized by staff to identify the right advocate for the right activity?

7. How do you think advocates could be used at NCI in ways that they are not currently being used?

8. How do you capture your interactions with individual advocates, advocacy organizations and NCI researchers?

9. Specifically what kind of information would you like to see more readily available to you to help support your work and meet the goals and priorities of the office?

10. How do you think an evaluation could help OAR?

Current and Former Advocacy Relations Managers

1. What kind of inquiries do you respond to from individual advocates and advocacy organizations?

2. How do you obtain feedback and assess needs throughout the steps in an advocacy activity? How do you capture the information?

3. Do you feel that you are aware of how your OAR colleagues interact with or document their interactions with advocacy organizations and individual advocates?

4. How frequently do OAR staff members communicate with each other about activities/projects they are involved in?

5. How do you think advocates could be used at NCI in ways that they are not currently being used?

6. What do you see as the ideal role for advocates? Advocacy organizations?

7. Overall do you feel you get the information you need from program staff to engage advocates? What kind of information do you consistently need from them?

8. Describe barriers, if any, that OAR staff may have in fostering stronger relationships between NCI researchers, advocacy organizations and individual advocates?

9. What do you think OAR needs to modify or improve upon to create partnerships with NCI's Divisions, Offices, Centers and Individual Advocates and Advocacy Organizations

10. What, if any, follow up do you conduct with advocates after an activity to help evaluate their participation? How specifically do you follow up?

11. OAR utilizes various communication mechanisms to communicate with the advocacy community (*Nealon Digest*, Teleconference Series, Science Serving People). Do you think these mechanisms are adequate in reaching advocates? If not, what other methods should be considered?

12. Specifically what kind of information would you like to see more readily available to you to help support your work and meet the goals and priorities of the office?

13. How do you think an evaluation could help OAR?