

Evaluation of the National Cancer Institute Progress Review Group Process

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Prepared for:

National Cancer Institute
Office of Science Planning and
Assessment
Bethesda, Maryland

Prepared by:

WESTAT
1650 Research Boulevard
Rockville, Maryland 20850
(301) 251-1500

EXECUTIVE SUMMARY

The National Cancer Institute (NCI) supports basic, clinical, and population-based research to identify and study the biology, etiology, prevention, early detection, and treatment of cancer. Through years of dedicated research, NCI has amassed an enormous cancer knowledge base. This knowledge base, coupled with emerging technologies, provides a wealth of new scientific opportunities that, if pursued, should benefit individuals with cancer and those at risk for the disease. At the same time, increasing research needs and scientific opportunities require that limited resources are used optimally. Moreover, clear scientific priorities must be identified in order to provide guidance for the scientific community and to create a benchmark against which NCI can measure progress.

In 1997, NCI initiated a new mechanism for planning disease-specific research—the Progress Review Group (PRG) process—which has helped to guide the development of national agendas for such research. NCI has used a series of PRGs—each consisting of prominent members of the scientific, clinical, industry, and advocacy communities—to assess the state of the science and recommend future research-related priorities for a single type of cancer or a group of related cancers. In preparation for future PRGs and planning activities, NCI's Office of Science Planning and Assessment (OSPA) elected to conduct a critical evaluation of the PRG process to determine what was working well and what needed improvement.

The evaluation sought to answer three core research questions:

- Have the PRGs fulfilled their charge to develop disease-specific national research agendas?
- What are other outcomes of the PRG process?
- What are the strengths and weaknesses of the PRG process, and how can the process be improved?

Telephone interviews were used to examine the experiences and opinions of those who have been involved in one or more PRGs. Different selection strategies were used to gain representation from each of the four groups involved in the PRG process (i.e., PRG leaders, PRG members, roundtable participants, and members of the NCI Executive Committee). PRG leaders are involved in all phases and aspects of the PRG process. Thus, their feedback was deemed critical to the evaluation, and all PRG leaders were invited to participate in the evaluation.

Recognizing the challenges posed in asking PRG members and roundtable participants to recall aspects of the oldest PRGs (i.e., the first three PRGs convened), a decision was made to sample from these two larger groups for only the most recent PRGs. Thus, eligibility for the random selection of PRG members was restricted to those who had participated in one of the seven most recent PRGs; five participants were selected from each of the seven most recent PRGs, resulting in a total of 35 PRG members. Stratified random selection was used to choose 10 PRG roundtable participants from each of the seven most recent PRGs, including breakout co-chairs, researchers, industry representatives, and advocates. From these groups, 70 roundtable participants were selected.

NCI Executive Committee (EC) members have a very different role and, in some ways, less direct involvement. They participate in the selection of PRG leaders at the outset, and then approve implementation strategies developed after the response meeting. Given that role, all EC members were invited to participate in the evaluation.

The data collection period extended from October 1, 2002, through December 10, 2002. Six EC members, 30 PRG leaders, 32 PRG members, and 66 roundtable participants took part in this evaluation. Key findings related to each of the core research questions are presented below.

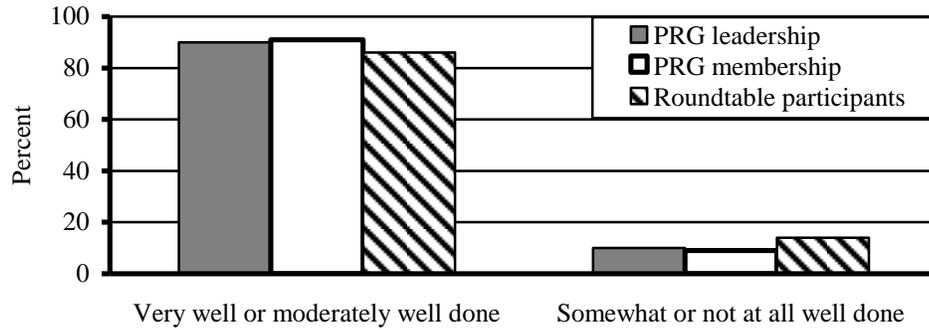
Have the PRGs fulfilled their charge to develop disease-specific national research agendas?

To assess the ability of PRGs to meet their charge, respondents were asked to rate the PRGs' performance in five areas, corresponding to components of the charge. Key findings are presented below for 1) identifying and prioritizing research opportunities and needs to advance disease-specific medical progress, 2) describing the resources needed to address identified research opportunities, 3) incorporating examination of the NCI research portfolio, 4) producing a written report describing the current state of the field, and 5) fostering discussion of NCI strategies for addressing the PRG recommendations among PRG members and NCI staff in the context of the response meeting. Finally, given the unique role played by NCI EC members in the PRG process, their ratings of PRG success in meeting charge components is summarized separately.

Identifying and prioritizing research opportunities and needs

- A majority of respondents rated the ability of PRGs to identify and prioritize research opportunities and needs quite favorably, with most rating it either very well done (72/127 or 57%) or moderately well done (40/127 or 31%).

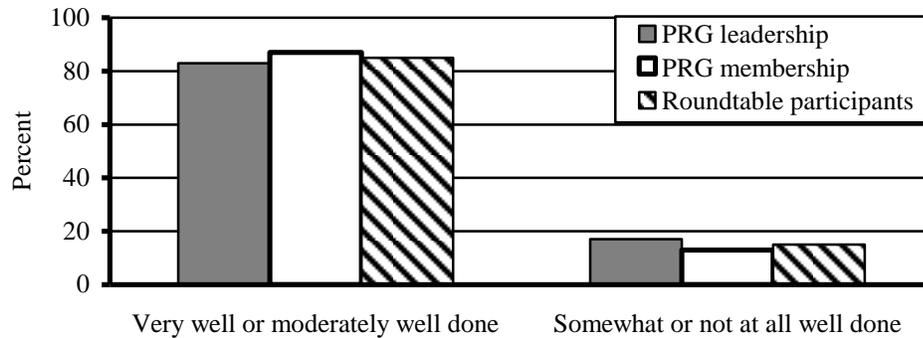
Figure 1.—Identifying and prioritizing research opportunities and needs



Describing resources needed to address research opportunities

- Respondents gave favorable ratings of the ability of the PRGs to describe the scientific resources needed to address the research priorities, with most rating it either very well done (63/123 or 51%) or moderately well done (42/123 or 34%).
- However, opinions differed greatly among respondents from the various PRGs.

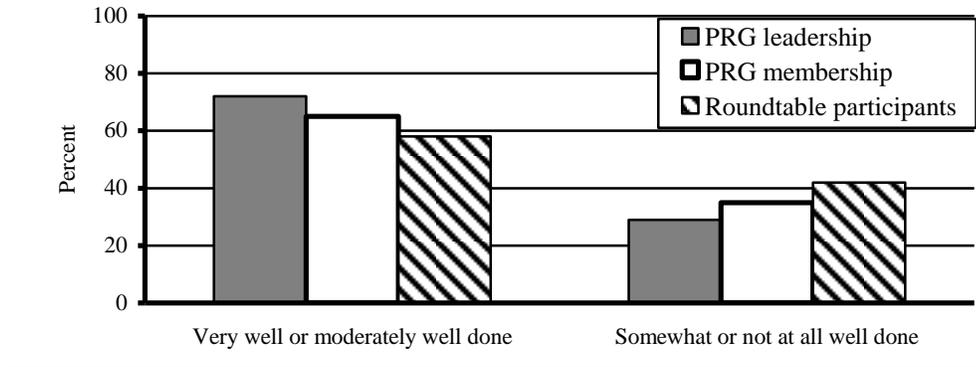
Figure 2.—Describing resources needed to address research opportunities



Incorporating examination of the NCI research portfolio

- A majority of respondents gave favorable ratings for how well examination of the NCI research portfolio was incorporated into the process, with most rating it either very well done (30/104 or 29%) or moderately well done (36/104 or 35%).
- Roughly one-third of respondents (38/104 or 36%) gave ratings of somewhat or not at all well done, with roundtable participants most likely to give these lower ratings.

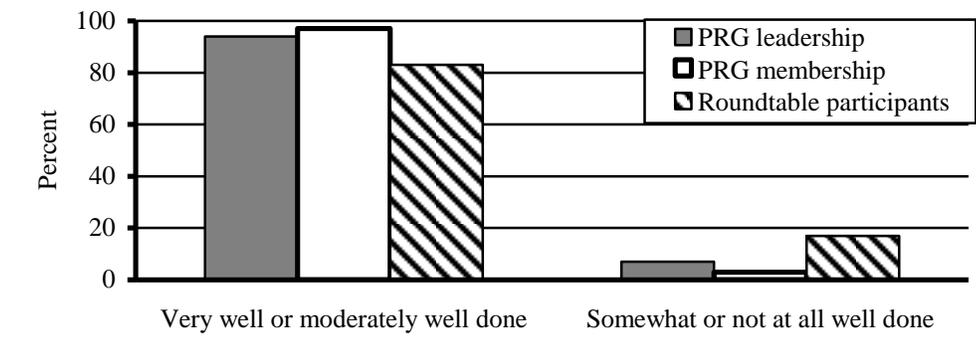
Figure 3.—Incorporating examination of the NCI research portfolio



Producing a written report

- A majority of respondents gave favorable ratings of PRG performance in producing a written report, with most rating as either very well done (76/122 or 62%) or moderately well done (33/122 or 27%).
- Respondents who gave less favorable ratings of the reports seemed more heavily influenced by the process used to prepare the reports than by their quality.

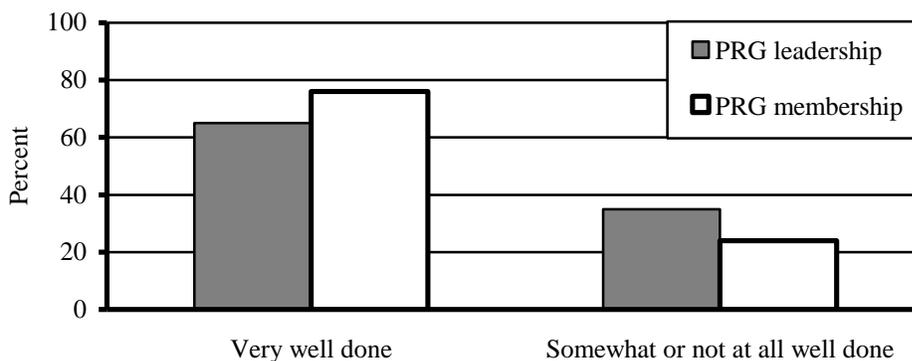
Figure 4.—Producing a written report



Fostering discussion of a plan of action

- A majority of responding PRG leaders and members gave favorable ratings for how well the process, through the use of response meetings (a Phase II activity), fostered discussion of a plan to ensure that identified priority areas were well addressed, with ratings of either very well done (16/40 or 40%) or moderately well done (12/40 or 30%).
- Nearly one-third of respondents (12/40 or 30%) gave ratings of somewhat or not at all well done; most of these respondents cited insufficient time for discussion or a lack of dialogue as the reason for their ratings.

Figure 5.—Fostering a discussion of a plan of action



EC member ratings of ability to meet the charge

- A majority of responding EC members rated PRG performance of most charge components they were asked to rate as moderately well done.
- A notable exception was the ability to produce a written report, which most rated as very well done.

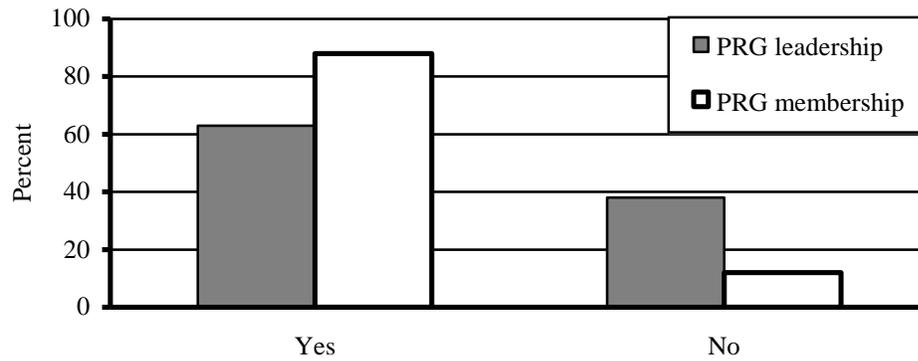
What are other outcomes of the PRG process?

Participants in the evaluation were asked to describe outcomes of the PRG process with regard to influencing NCI disease-specific priority setting, NCI planning, and overall disease-specific priority setting. In addition, participants described how the process affected their knowledge, opinions, beliefs, or practices related to cancer research, as well as collaborative or professional relationships. Finally, additional outcomes that occurred as a result of participating in the PRG process were described.

Key findings include the following:

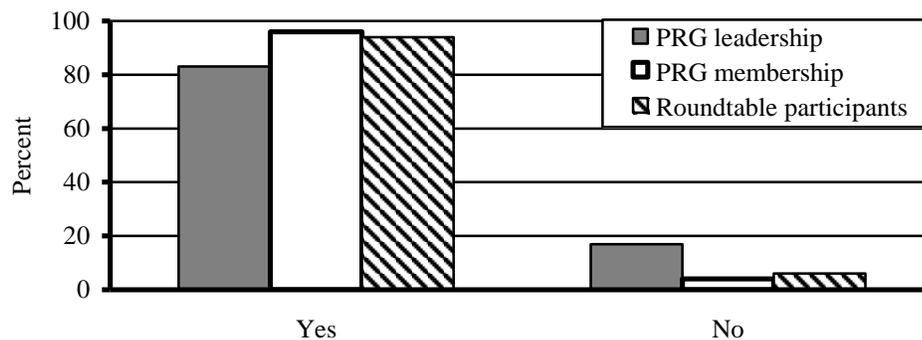
- **Influence on NCI priority setting.** Among all PRG leaders and members who expressed an opinion about the influence of the PRG process on NCI priority setting, 29/40 or 73% agreed that it had an effect. PRG leaders indicated that the process broadened the focus of NCI and provided the “only way to identify the areas of basic and clinical science that are most likely to be fruitful in a given specific disease setting.” EC members were unanimous in their belief that the PRGs had affected NCI priority setting.

Figure 6.—Influence on NCI priority setting



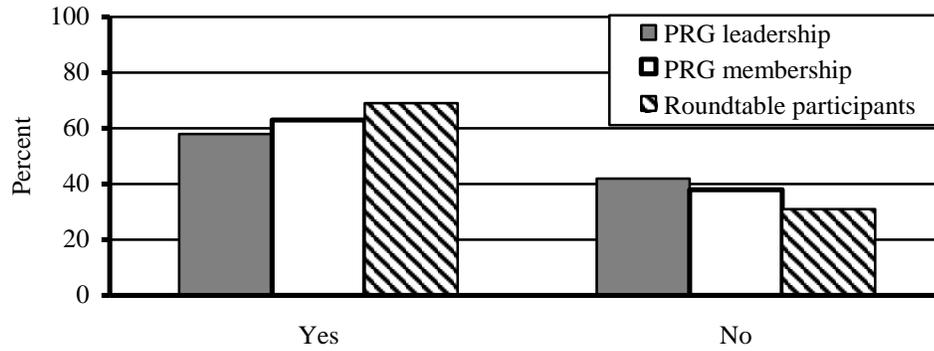
- **Influence on NCI planning.** Almost all PRG leaders, PRG members, and roundtable participants (98/106 or 92%) said that the PRG process was an integral part of NCI planning. Several respondents indicated that the PRG process provided NCI with a unique means of gaining input from the wider community. All EC members felt that the PRGs had affected NCI planning.

Figure 7.—Influence on NCI planning



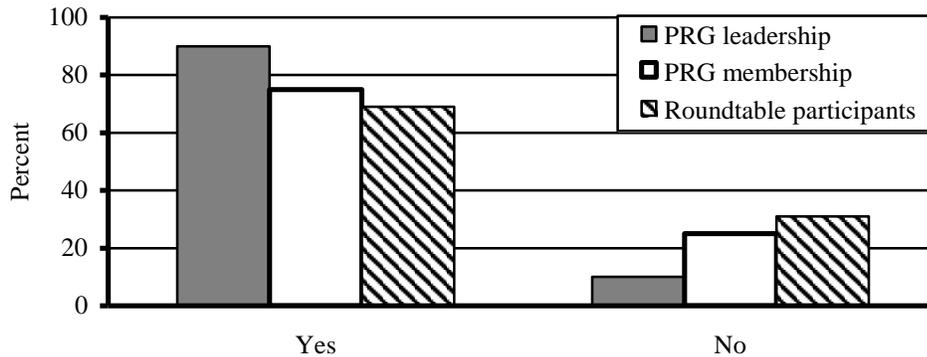
- Influence on overall disease-specific research priority setting.** A majority of respondents (56/87 or 64%) believed that the process had affected priority setting, and several were able to describe how that influence has been directly and indirectly manifested.

Figure 8.—Influence on disease-specific research priority setting



- Effects on participants.** Overall, the majority of PRG leaders, PRG members, and roundtable participants (96/127 or 76%) and five of five EC members reported that their knowledge, opinions, beliefs, or practices had been affected. Examples of such effects identified by PRG leaders include helping them understand more about basic research into clinically useful areas and giving them a more “global” perspective of the research environment.

Figure 9.—Effects on participants



- Additional outcomes.** The majority of PRG leaders, PRG members, and roundtable participants identified one or more additional positive outcomes of the PRG process. Most focused on the interaction between participants, the education and mobilization of participants, and the increased likelihood of funding. A few respondents mentioned negative outcomes as well, such as establishing unrealistic funding expectations and resentment from feeling left out of the NCI planning activities subsequent to the response meeting.

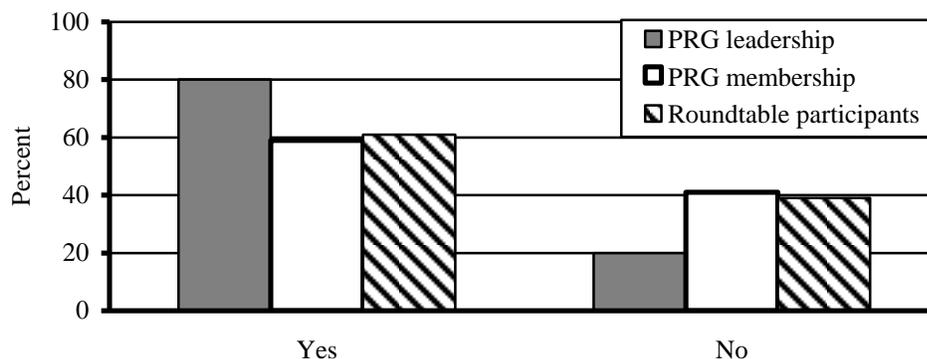
What are the strengths and weaknesses of the PRG process, and how can the process be improved?

The third core research question focused on elements of the implementation strategy for PRGs. Specifically, respondents were asked about the criteria and methods used to select PRG participants, the skills and expertise of the PRG participants, and the style of interaction among participants. In addition, they were asked about the process schedule and the materials and support they received throughout the PRG process.

Key findings include the following:

- **Criteria and methods used to select participants.** The criteria used by the PRG leaders and PRG members to select participants were very consistent across PRGs. Selection criteria included expertise in the field, interdisciplinary perspectives, time spent in the field, and diversity. When asked to suggest changes to the process used to select PRG members and roundtable participants, only a small number of PRG leaders indicated that any changes were necessary. The change most often suggested was that greater consideration be given to a broader group of qualified individuals when selecting participants.
- **Skills and expertise of participants.** Most respondents (82/126 or 65%) reported that the key areas of expertise were represented in the PRG process. Although a majority from each group shared this opinion, PRG leaders (24/30 or 80%) were more likely than either PRG members (19/32 or 59%) or roundtable participants (39/64 or 61%) to do so.

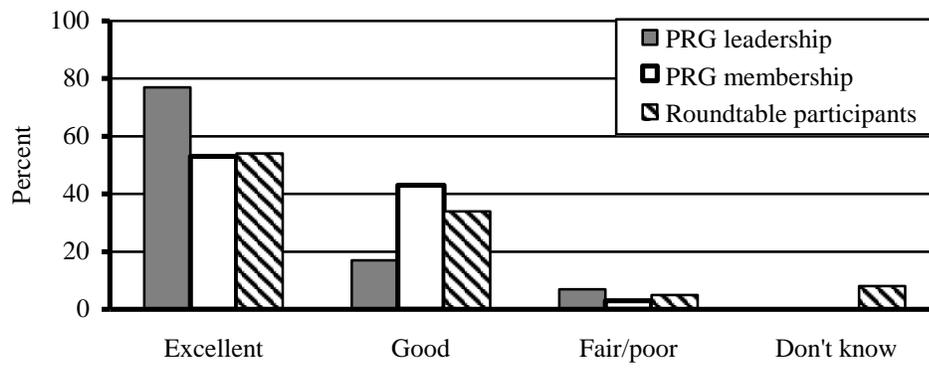
Figure 10.—Skills of participants



- **Style of interaction among participants.** The vast majority of PRG leaders, PRG members, and roundtable participants voiced favorable opinions about the group interactions. Leaders reported that the interactions among the groups resulted in a very productive process. PRG members described the interaction as collegial and serving to facilitate an open forum for honest discussions. Roundtable participants described the PRG process as an open exchange with cordial and positive interaction and collaboration. Nonetheless, some respondents noted that interactions were not always efficient due to the number of participants, there was limited exchange of ideas due to time restrictions, and some participants came with controversial personal agendas.

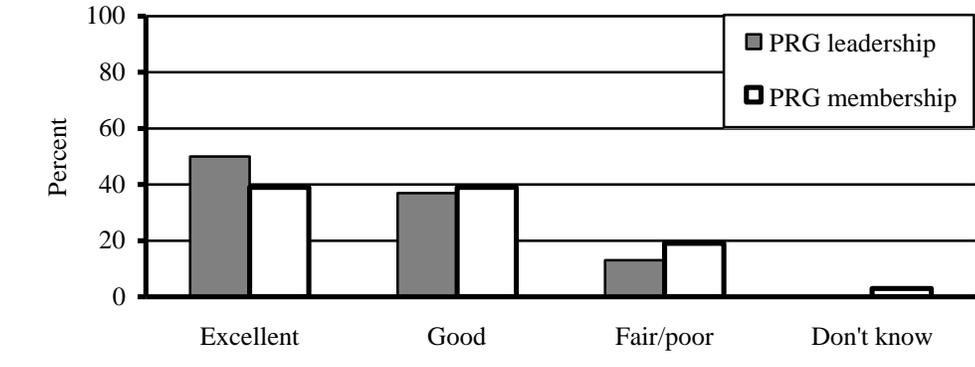
- **Process schedule.** Most respondents (94/128 or 73%) felt that the process schedule allowed just the right amount of time to fulfill the PRG charge.
- **Supporting materials.** The majority of PRG leaders, PRG members, and roundtable participants expressed favorable opinions about the PRG materials they had been provided (e.g., guidance on how the breakout sessions would be conducted; reports from previous PRGs). Generally, respondents reported that they had used the materials and found them useful. The notable exception to this finding was their appraisal of the NCI research portfolio for the disease site; respondents reported that the format of this document made it difficult to use and therefore less helpful.
- **Preference for electronic versus hardcopy materials.** Overall, PRG leaders, PRG members, and roundtable participants were evenly split between those who reviewed materials on-line or in hardcopy. Their preference for reviewing materials on-line or in hardcopy also was frequently evenly split.
- **OSPA support.** All PRG leaders, PRG members, and roundtable participants were asked to rate the support provided by OSPA. Most respondents rated OSPA support as either excellent (74/125 or 59%) or good (40/125 or 32%).

Figure 11.—OSPA support



- **Science writer support.** PRG leaders and PRG members were asked to rate the support provided by the science writers. Most respondents rated science writer support as excellent (27/61 or 44%) or good (23/61 or 38%).

Figure 12.—Science writer support



- **OSPA and division representative support to EC members.** EC members were asked how well OSPA staff and their representatives kept them informed. While generally more positive than negative in their reviews, most members saw some potential for improvement in OSPA performance; two rated the performance as very well done, and four rated it as moderately well done. As for the support provided by their representatives, one of six members reported being very well informed by the roundtable representative, three said they were moderately well informed, and two reported being somewhat well informed. The members provided identical ratings when asked how well they were kept informed by their working group representatives.

These findings indicate that the PRGs have achieved broad success in meeting their charge and fostering other positive outcomes. Many of the features of the PRG process, therefore, should be maintained, while others should be enhanced. Specific recommendations that result from this evaluation are presented below.

Recommendations

- Clarify expected PRG process outcomes and communicate them to the researchers, advocates, and patients who participate in the process.
- Clarify for PRG participants the role that budget constraints might have on desired funding for research.
- Continue to provide PRG-like opportunities for members of the extramural community to interact with each other and NCI staff, and to expand their professional understanding and awareness of research opportunities.

- Continue to provide PRG-like opportunities and seek additional means for NCI to receive input from members of the extramural community.
- Continue efforts to ensure that the PRGs represent the broad spectrum of perspectives found within the extramural community.
- Maintain the PRG schedule that has been used. However, given the number of participants, evaluate the level of opportunity individuals have to discuss issues.
- Continue to provide the same types of information to PRG participants that have been provided in the past. Although most participants prefer accessing the materials on-line, hardcopy versions should continue to be made available.
- Maintain OSPA's support role for the PRG process and evaluate ways to ensure continued participant satisfaction.
- Examine alternative formats for presenting the NCI research portfolio.
- Identify and make available additional information that would be useful to PRG participants, and determine how it might best be presented.
- Continue to evaluate and monitor the performance of science writers. Preliminary areas of inquiry might include: *Do the science writers have appropriate training to perform their role? Do they have sufficient time to perform the tasks they are assigned?*
- Implement an on-going system to evaluate the PRG process, based on periodic or event-specific schedules.

PRGs are a successful method of identifying disease-specific national research agendas. They have met the PRG charge and increased the opportunity for interaction between NCI and the extramural community. PRG participants also report expanded professional understanding and awareness of opportunities related to cancer research. Strengths of the PRG process should be maintained, and an on-going system to evaluate the PRG process should be developed to provide continuous feedback to NCI.

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1. BACKGROUND OF THE PROCESS REVIEW GROUP PROCESS AND OVERVIEW OF THE EVALUATION

1.1 Introduction

The National Cancer Institute (NCI) supports basic, clinical, and population-based research focused on the biology, etiology, prevention, early detection, and treatment of cancer. Through years of dedicated research, NCI has amassed an enormous cancer knowledge base. This knowledge, coupled with new technologies, is providing a wealth of new scientific opportunities that, if pursued, should further advance the knowledge and ability to care for individuals with cancer and those at risk for the disease. At the same time, increasing research needs and scientific opportunities require that limited resources are used optimally. Moreover, clear scientific priorities must be identified in order to provide guidance for the scientific community and to create a benchmark against which NCI can measure progress.

1.2 Progress Review Groups

In 1997, NCI initiated a new mechanism for planning disease-specific research—the Progress Review Group (PRG) process—which has helped to guide the development of national agendas for such research. The PRGs are panels of 20 to 30 prominent members of the scientific, clinical, industry, and advocacy communities who are selected to assess the state of the science and recommend future research-related priorities for a single type of cancer or a group of related cancers. The deliberations of each PRG include a roundtable meeting with a total of approximately 100 leaders from diverse disciplines and the advocacy community assembling to discuss their understanding of the disease, barriers to progress, and key research and resource priorities for the next five years. The PRGs use the input from the roundtable meeting to develop a comprehensive and widely distributed report on their recommendations used in establishing a national research agenda.

To date, NCI has successfully implemented 10 PRGs addressing a broad array of cancer sites, specifically, breast cancer; prostate cancer; colorectal cancer; brain tumor; pancreatic cancer; leukemia, lymphoma, and myeloma; lung cancer; gynecologic cancers; kidney and bladder cancers; and stomach and esophageal cancers.

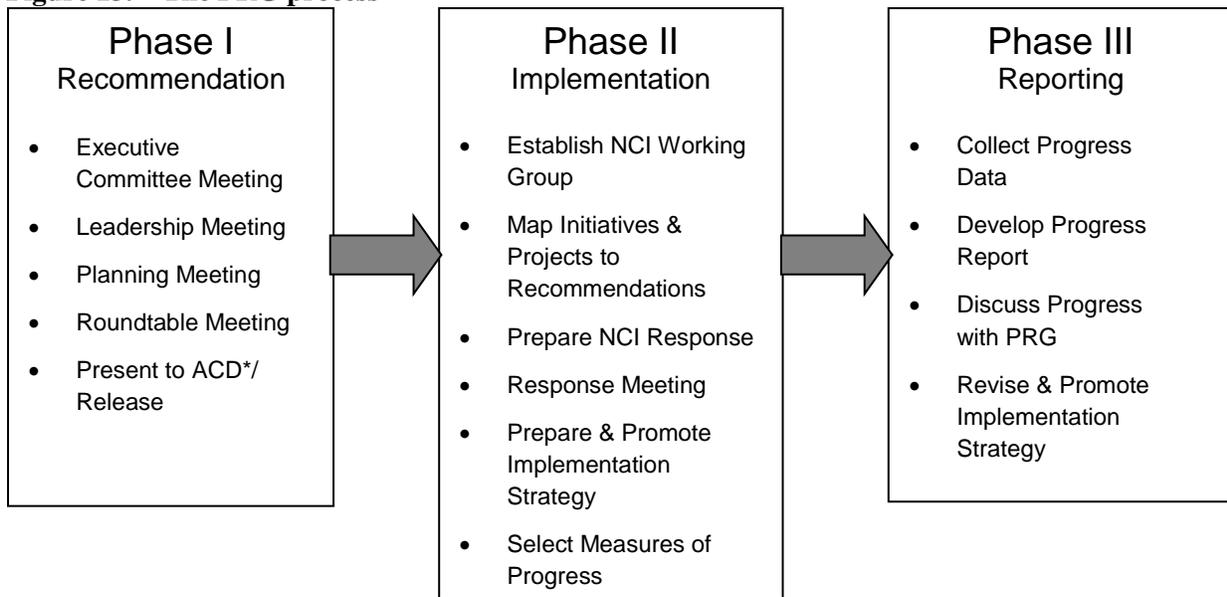
1.3 Overview of the PRG Process

Although the focus of each PRG is distinct, every PRG is guided by a common charge:

- Identifying and prioritizing research opportunities and needs;
- Describing resources needed to address research opportunities;
- Incorporating examination of the NCI research portfolio;
- Producing a written report; and
- Discussing a plan of action.

The PRG addresses this charge in a three-phase process (Figure 13).

Figure 13.—The PRG process



*Advisory Committee to the Director

1.3.1 Phase I: Recommendation

Phase I of the PRG process includes establishing the composition of the PRG. A list of subject-area research experts is compiled and presented to the NCI Executive Committee (EC) for review. From this list, two PRG co-chairs are selected to provide expertise, vision, guidance, and management for the various processes and products of the PRG. In addition, a prominent NCI scientist is selected as Executive Director to represent the federal government and act as liaison to the PRG. Together these

individuals constitute the PRG leadership and ensure that broad knowledge of relevant basic and clinical sciences is brought to bear in support of the process, and in developing recommendations and action plans.

To launch the PRG, the leadership meets with the NCI Director and appropriate Office of Science Planning and Assessment (OSPA) staff for an orientation to the PRG process and to review lists of candidate experts in the PRG planning meeting. Approximately 25 to 30 individuals are invited to serve as PRG members. These individuals represent a variety of different disciplines and perspectives, including the broad areas of research, industry, and advocacy.

PRG leaders, PRG members, and OSPA staff then participate in a planning meeting to develop plans for the roundtable meeting. Key activities include selection of breakout session topics (e.g., Biology, Progression, and Metastasis; Early Detection, Diagnosis, and Prognosis; Prevention; Treatment; Cancer Control and Survivorship); identification of PRG members to serve as breakout session co-chairs; nomination and selection of breakout session participants, including one to serve as co-chair; and drafting preliminary breakout session agendas. In selecting breakout session participants, attention is paid to inviting a group of experts with diverse backgrounds.

Approximately 100 experts participate in the roundtable meeting, including PRG leaders and members, invited breakout participants, and selected NCI division representatives. The meetings consist of both large plenary sessions and smaller breakout sessions that can vary in size. Breakout discussions concentrate on identifying key research recommendations and resource needs that must be addressed to advance medical progress against the disease. Breakout session co-chairs prepare summary reports for their respective sessions, with particular attention paid to the priorities identified as most critical in advancing progress against the disease.

Upon conclusion of the roundtable meeting, breakout session co-chairs finalize draft breakout reports in collaboration with breakout participants and science writers. In turn, PRG leaders review the breakout session reports and begin developing the content of the main PRG report. Critical gaps or needs that must be addressed to advance progress against the disease are culled from the individual reports and presented within the larger context of the burden associated with the disease. All PRG members are given an opportunity to review and comment on the content of the main report, which is ultimately approved by the entire PRG membership. All breakout session reports are typically included as an appendix to the main report.

Finally, the PRG leaders summarize findings and priority recommendations of the report and present highlights to the NCI Advisory Committee to the Director (ACD) for discussion, comment, and a decision on acceptance. Upon ACD acceptance, the PRG report is published, in electronic and print formats, and widely disseminated.

1.3.2 PHASE II: Implementation

Phase II of the PRG process commences with establishment of an internal working group comprising NCI scientists with comprehensive knowledge of the Institute's programs and initiatives. These individuals review all potentially relevant endeavors in the existing NCI portfolio and "map" or link them to the priorities and recommendations identified by the PRG. In this way, gaps, needs, and opportunities are identified. The working group prepares a summary document that describes both the PRG recommendations currently addressed by NCI-funded projects, and also those without relevant NCI-sponsored projects. This document is the framework for the NCI response.

NCI working group members develop proposed strategies for addressing PRG recommendations and discuss them with the NCI director in order to arrive at a set of proposed strategies to discuss with PRG members at the response meeting. The NCI Director, NCI working group, and PRG members then meet to review the NCI response and to discuss ideas for implementing activities to address the needs identified by the PRG. Based on response meeting discussions, a draft strategic plan is developed by the working group, reviewed by the NCI EC, finalized, and published.

A summary of the roles and responsibilities of the PRG participants during Phase I and II of the PRG process is depicted in Figure 14.

Figure 14.—Overview of the PRG – Phase I and II

Meeting	Role		
	PRG Leadership (n=3)	PRG Membership (n=25-30)	Roundtable Participants (n=75-100)
Leadership <ul style="list-style-type: none"> One day Determine membership of the PRG 	√		
Two- to Three-Month Interval			
Planning <ul style="list-style-type: none"> One to two days Develop agenda for roundtable meeting Identify breakout group co-chairs Nominate roundtable participants 	√	√	
Three- to Four-Month Interval			
Roundtable <ul style="list-style-type: none"> Two to three days Identify and prioritize recommendations and resources needed to make progress over next five years 	√	√	√
Three-Month Interval			
Advisory Committee to the Director <ul style="list-style-type: none"> Two-hour teleconference Summarize and discuss the PRG report 	√		
Three-Month Interval			
Response <ul style="list-style-type: none"> One day Discuss strategies NCI proposes to address PRG recommendations 	√	√	

1.3.3 Phase III: Reporting

Phase III commences three to five years after the conclusion of Phase II and includes an assessment of the progress made since the release of the PRG report. A variety of short- and long-term measures of progress are examined, including trends in NCI-supported projects, scientific advances, trends in clinical trials, new approaches to prevention and treatment, improved diagnostic and treatment technologies, and trends in disease statistics. A document summarizing progress relevant to the recommendations of the PRG will be produced.

1.4 Evolution of the PRG Process

Every iteration of the PRG process has led to modifications and improvements in subsequent PRGs, with each PRG having a degree of latitude in some aspects of the process. Consequently, though many essential elements have been similar across the PRGs, the process has not been identical in all aspects. For example:

- **Research portfolio analysis.** Assessment of the current disease-specific NCI research portfolio has been part of the PRG process from its inception, but both the method and the presentation have changed over time. For example, during the Breast Cancer PRG, an internal task force including the PRG Executive Director and NCI extramural and intramural staff reviewed the existing research portfolio in order to provide the PRG with a survey of NCI's research and resources in breast cancer. The resulting Research Portfolio Analysis document was distributed at the roundtable meeting. This method was also used in the Prostate Cancer PRG. However, for the Colorectal Cancer and Brain Tumor PRGs, the research portfolio was distributed at the planning meeting, and starting with the Pancreatic Cancer PRG, the research portfolio was also made available on-line. Over time, graphic representations of the research portfolio (pie charts) showing the distribution of relevant NCI projects and dollars invested by Common Scientific Outline (CSO) research categories were developed. For the two most recent PRGs, Kidney and Bladder Cancers and Stomach and Esophageal Cancers, the pie charts became the primary source of data in assessing the state of the science, and the portfolio analysis was only available on-line.
- **Number of recommendations.** The number of recommendations included in the PRG reports has also varied widely, with earlier reports generating larger numbers of more specific recommendations that were broadly prioritized, and later reports providing smaller numbers of broader recommendations, typically of equal priority. For example, the Prostate Cancer PRG identified 157 research questions (49 "Priority One," 62 "Priority Two," and 46 "Priority Three") and recommended specific actions to address all Priority One questions; the Gynecologic Cancers PRG identified one "Essential Priority," three "High-Impact Priorities," and six "Scientific Opportunities," and included specific recommended actions for the four priority recommendations; and the Kidney and Bladder Cancers PRG identified 13 "Priority" recommendations and included a summary rationale for each.
- **Number of roundtable participants.** The number of roundtable participants has ranged from 104 for the Gynecologic Cancers PRG to 167 for the Leukemia, Lymphoma, and Myeloma PRG, with the number of participants in the other PRGs falling somewhere between those two.
- **Other aspects.** Evolution has also taken place in terms of guidance and support materials available to PRG participants; the level of professional science writer support for report generation; the degree of pre-roundtable interaction among participants, particularly within breakout groups and for advocates; development of templates to facilitate breakout report generation and presentations; and use of on-line resources to convey information about PRG-related activities.

1.5 Evaluation of the PRG Process

The PRG process has been continuously refined on the basis of experience, on-going feedback, and internal discussions. However, no formal evaluation of the effectiveness of the overall PRG process had been conducted. Stimulated by discussions of the PRGs within both the NCI Board of Scientific Advisors (BSA) and OSPA, and in preparation for future PRGs and other science planning activities, a more formal critical review of the current process was initiated to determine what was working well and what needed improvement.

The purpose of the review was to answer three core evaluation questions:

- Have the PRGs fulfilled their charge to develop disease-specific national research agendas?
- What are other outcomes of the PRG process?
- What are the strengths and weaknesses of the PRG process, and how can the process be improved?

For each of these questions, NCI sought to obtain an in-depth understanding of the experiences and opinions of individuals who had participated in the various aspects of the PRG process. Interviews consisting of both open- and closed-ended questions were conducted with selected individuals representing different perspectives on the PRG process. This report describes the methodology and findings from the evaluation.

It is important to note that at the time of this investigation, the 10 PRGs conducted to date were at varying stages along the three-phase continuum as illustrated in Figure 15. This evaluation focused only on Phase I activities and the response meeting component of Phase II. Neither the Kidney and Bladder Cancers PRG nor the Stomach and Esophageal Cancers PRG had completed the response meeting by the time the data were collected. Therefore, the response meeting could not be assessed by participants in those PRGs.

Figure 15.—PRG three-phase continuum

Site	Phase I					Phase II					Phase III			
	Executive Committee meeting	Leadership meeting	Planning meeting	Roundtable meeting	Present to ACD/ release	Establish NCI working group	Map initiatives and projects to recommendations	Prepare NCI response	Response meeting	Prepare and promote implementation strategy	Collect progress data	Develop progress report	Discuss with PRG	Revise and promote implementation strategy
Breast Cancer										*				
Prostate Cancer										*				
Colorectal Cancer														
Brain Tumor														
Pancreatic Cancer														
Leukemia, Lymphoma, Myeloma														
Lung Cancer														
Gynecologic Cancers														
Kidney & Bladder Cancers														
Stomach & Esophageal Cancers														

* The Breast Cancer and Prostate Cancer PRGs developed informal implementation plans that have not been published.

NOTE: Shading indicates activity has been completed.

2. PARTICIPANT SELECTION METHODOLOGY

2.1 Participant Selection Rationale

The evaluation was largely qualitative in nature, therefore, the participant selection strategy relied on purposeful (or judgment) sampling. The strategy was developed to achieve the following goals:

- Support the full exploration of the research questions on which the evaluation was conceptually based;
- Reflect the range of views that were of interest;
- Represent the experiences and opinions of participants from each of the 10 PRGs that had completed the activities associated with Phase I of the PRG¹ and the Phase II response meeting;² and
- Represent the experiences and opinions of participants from each of the four groups involved in the PRG process (i.e., PRG leaders, PRG members, roundtable participants, and the NCI EC).

The methods used to achieve these goals are described in the following section.

2.2 Participant Selection Methods

Different selection strategies were used to gain representation from each of the four groups. PRG leaders are involved in all phases and aspects of the PRG process. Thus, their feedback was deemed critical to the evaluation, and all PRG leaders were invited to participate in the evaluation.

Recognizing the challenges posed in asking PRG members and roundtable participants to recall aspects of the oldest PRGs (e.g., the first three PRGs convened), a decision was made to sample from these two larger groups for only the seven most recent PRGs. Thus, eligibility for the random selection of PRG members was restricted to those 163 individuals who had participated in one of the seven most recent PRGs. The list of eligible members was sorted by PRG, and, once sorted, included

¹ Phase I activities include the leadership meeting, planning meeting, roundtable meeting, and presentation to the Advisory Committee to the Director for release. The 10 PRGs that had completed Phase I activities were Breast Cancer; Prostate Cancer; Colorectal Cancer; Brain Tumor; Pancreatic Cancer; Leukemia, Lymphoma, and Myeloma (LLM); Lung Cancer; Gynecologic Cancers; Kidney and Bladder Cancers; and Stomach and Esophageal Cancers.

² Note that neither the Kidney and Bladder Cancers PRG nor the Stomach and Esophageal Cancers PRG had completed the response meeting by the time the evaluation was performed.

between 20 and 25 eligible members from each PRG. Five participants were selected from each of the seven most recent PRGs, resulting in a total of 35 PRG members. Stratified random selection was used to choose PRG roundtable participants from the seven most recent PRGs. Roundtable participants include four subgroups: breakout session co-chairs, researchers, industry representatives, and advocates. From these groups, 654 individuals had participated in one or more of the seven recent PRG roundtables. Stratified random selection was conducted to ensure representation of these subgroups. Seventy roundtable participants were selected.

EC members have a very different role and, in some ways, less direct involvement. They participate in the selection of PRG leaders at the outset, and then approve implementation strategies developed after the response meeting. Given this role, all EC members were invited to participate in the evaluation.

Overall, 146 individuals were chosen, representing PRG leaders, PRG members, roundtable participants, and EC members (Table 1). Appropriate replacement procedures were implemented if a selected participant could not be located, was unavailable during the data collection period, or refused to participate.

Table 1.—Eligible and selected participants

Category	Number of eligible participants	Number of selected participants
Total	858	146
PRG Leadership	32	32
PRG Membership	163	35
Roundtable Participants	654	70
Executive Committee	9	9

3. DATA COLLECTION

3.1 Data Collection Instruments

Four data collection instruments, or topic guides, were developed. The guides, one for each group of respondents,³ consisted of a mix of closed-ended and open-ended questions. The closed-ended questions typically asked respondents to report their experiences or opinions on the study topics. The open-ended questions asked respondents to elaborate on those experiences and to explain the nature of their opinions. In addition, the topic guides included follow-up questions to be asked only when respondents rated performance as less than very well done. This design feature resulted in more detailed information about aspects of the PRG process in need of improvement.

Although the different guides overlapped substantially, each was tailored for the specific respondent group. Appendix A contains a crosswalk that lists the study topics and the corresponding question numbers that address each topic in each of the four guides. The final version of each topic guide is included in Appendix B.

3.2 Interviewer Training

The eight staff members assigned to conduct the interviews participated in a training session in which the overall background and purpose of the study and the various groups of respondents were described. Topic guides and other study materials also were reviewed, and staff were given an opportunity to ask questions. The session also included role-playing and a discussion on how to probe for further information.

3.3 Data Collection Methodology

Once the interview participants were selected, a recruitment email was sent to each individual, after which a telephone interviewer called to schedule the interview. Several days prior to a scheduled interview, each respondent received an email message with a reminder of the interview date and time.

³ The four respondent groups included PRG leaders, PRG members, roundtable participants, and EC members.

Discussion packets were prepared for use with each respondent. The packets included:

- A respondent information sheet containing all the contact information needed to reach the respondent;
- An introductory script, to be read to each respondent, explaining the purpose of the study and a request for permission to record the interview (see Appendix C);
- A copy of the appropriate topic guide; and
- Notes and other documentation from the scheduling activities.

At the scheduled time, an interviewer telephoned the respondent to conduct the interview; interviews averaged about 45 minutes. As the interview was conducted, the interviewer recorded the responses to open-ended questions verbatim and circled answers to closed-ended questions on the topic guides. If the respondent agreed, an audio recording of the interview was made. Upon completion of the interview, staff edited the completed topic guide and prepared a summary report of the open-ended responses, using the audio recordings to supplement their notes. The completed guides were given to data preparation staff for coding, keying, and verification of the closed-ended questions.

Data coding and editing specifications were prepared prior to data processing. The coding specifications led to the creation of coding manuals for each instrument and provided clear documentation of allowable responses, ranges, and formats, including codes for nonresponse and inapplicable questions. Using the coding manual and edit checks, data preparation staff coded and manually edited completed topic guides. Data from the coded guides were then keyed into an Access database. All keyed data were 100 percent verified using a rekey mode.

At the conclusion of data collection, 134 interviews had been completed. Table 2 shows the distribution of expected and completed interviews by group and the number of completed interviews by PRG.

Table 2.—Number of expected and completed interviews, by group and by PRG

Category	Number of expected interviews	Number of completed interviews
Total	146	134
Group		
PRG Leadership	32	30
PRG Membership	35	32
Roundtable Participants	70	66
Executive Committee.....	9	6
PRG¹		
Breast, Prostate, and Colorectal Cancers	—	9
Brain Tumor	—	18
Pancreatic Cancer	—	15
Leukemia, Lymphoma, and Myeloma	—	18
Lung Cancer	—	17
Gynecologic Cancers	—	17
Kidney and Bladder Cancers	—	17
Stomach and Esophageal Cancers.....	—	17

—Not applicable.

¹The sum of completed interviews by PRG is 128. The six interviews with EC members are not associated with a specific PRG.

4. THE PRG CHARGE AND ROLE IN THE DEVELOPMENT OF DISEASE-SPECIFIC NATIONAL RESEARCH AGENDAS: THE PERSPECTIVE OF PRG PARTICIPANTS

4.1 Overview

This chapter focuses on the first of three core research questions addressed by the evaluation: *Have the PRGs fulfilled their charge to develop disease-specific national research agendas?* To assess the opinions of PRG leaders, PRG members, and roundtable participants, respondents were asked the following five questions:

- How well did the PRG process identify and prioritize research opportunities and needs?
- How well did the PRG process describe the resources needed to address opportunities?
- How well did the PRG process incorporate examination of the NCI research portfolio?
- How well did the PRG produce a written report?
- How well did the PRG discuss a plan of action?

To rate the performance of the PRGs on each element of the charge, respondents used a four-point scale: very well, moderately well, somewhat well, or not at all well.⁴ Respondents who rated the PRG performance on any element as less than very well done were asked to elaborate on their answers.

Overall, respondents gave favorable ratings of the ability of the PRGs to identify and prioritize research opportunities and needs and the ability of the PRGs to describe resources needed to address opportunities. The majority of respondents rated the PRGs' performance on incorporating information about the existing NCI research portfolio into the PRG process as either very well done or moderately well done. In addition, respondents gave favorable ratings regarding the PRGs' ability to produce a written report. PRG leaders and members rated the PRGs in terms of discussing a plan of action, and the majority reported that PRGs performed this task very well or moderately well. Respondents did not suggest any changes to the charge.

⁴ The frequency of "not at all well" responses was quite low. For the purposes of this report, therefore, these responses were combined with the "somewhat well" responses.

4.2 Identifying and Prioritizing Research Opportunities and Needs

Overall, respondents rated the ability of PRGs to identify and prioritize research opportunities and needs quite favorably. Seventy-two of 127 respondents felt that the PRG process performed this task very well, and another 40 felt that the process performed the task moderately well (Table 3). The degree to which respondents favorably rated the performance of PRGs in identifying research opportunities and needs differed by group, with 20 of 30 PRG leaders and 21 of 32 members rating the task as very well performed, compared with 31 of 65 roundtable participants who provided this rating.

Table 3.—Extent to which the PRG process identified and prioritized research opportunities and needs, by group and by PRG

Category	N ¹	Very well		Moderately well		Somewhat or not at all well	
		Number	Percent	Number	Percent	Number	Percent
Overall	127	72	57	40	31	15	12
Group							
PRG Leadership.....	30	20	67	7	23	3	10
PRG Membership	32	21	66	8	25	3	9
Roundtable Participants	65	31	48	25	38	9	14
PRG							
Breast, Prostate, and Colorectal Cancers ²	9	6	67	3	33	0	0
Brain Tumor	18	8	44	9	50	1	6
Pancreatic Cancer	15	9	60	3	20	3	20
Leukemia, Lymphoma, and Myeloma	18	10	56	3	17	5	28
Lung Cancer.....	17	7	41	6	35	4	24
Gynecologic Cancers	17	12	71	5	29	0	0
Kidney and Bladder Cancers.....	16	9	56	6	38	1	6
Stomach and Esophageal Cancers.....	17	11	65	5	29	1	6

¹Data were not obtained for one case.

²Responses from the leaders of these PRGs have been combined due to small sample sizes.

NOTE: All percentages have been rounded, and totals may not sum to 100 percent.

Respondents indicated that the process, through the diversity of participants, resulted in a thorough evaluation of research opportunities and needs. For example, one respondent said, “I think it’s the best format. There is nothing better than this...bringing people together.” Those respondents who offered any specific criticism of the PRG’s ability to perform this task observed that the results tended to be vague. For example, a PRG leader called the result a “wish list” that did not reflect real priorities.

4.3 Describing Resources Needed to Address the Research Opportunities

Respondents also favorably rated the ability of the PRGs to describe resources needed to address the research opportunities. Sixty-three of 123 respondents felt that the PRGs performed this task very well, and 42 felt that they performed it moderately well (Table 4). However, opinions differed greatly among respondents from the various PRGs, ranging from two of nine Breast, Prostate, and Colorectal Cancers PRG respondents to 11 of 14 Pancreatic Cancer PRG respondents. Several respondents who rated PRG performance as being less than very well done felt that participants did not fully consider the impact of reallocation of resources on other initiatives when considering the scientific resources that would be needed to address the identified research priorities.

Table 4.—Extent to which the PRG process described the resources needed to address identified research opportunities and needs, by group and by PRG

Category	N ¹	Very well		Moderately well		Somewhat or not at all well	
		Number	Percent	Number	Percent	Number	Percent
Overall	123	63	51	42	34	18	15
Group							
PRG Leadership.....	29	16	55	8	28	5	17
PRG Membership	32	15	47	13	41	4	13
Roundtable Participants	62	32	52	21	34	9	15
PRG							
Breast, Prostate, and Colorectal Cancers ²	9	2	22	5	56	2	22
Brain Tumor	17	9	53	7	41	1	6
Pancreatic Cancer	14	11	79	2	14	1	7
Leukemia, Lymphoma, and Myeloma	18	6	33	5	28	7	39
Lung Cancer.....	15	9	60	6	40	0	0
Gynecologic Cancers	17	9	53	6	35	2	12
Kidney and Bladder Cancers.....	17	8	47	7	41	2	12
Stomach and Esophageal Cancers.....	16	9	56	4	25	3	19

¹Data were not obtained for five cases.

²Responses from the leaders of these PRGs have been combined due to small sample sizes.

NOTE: All percentages have been rounded, and totals may not sum to 100 percent.

4.4 Incorporating Examination of the NCI Research Portfolio

Overall, opinions were split among the 104 respondents who ranked the ability of PRGs to incorporate examination of the NCI research portfolio: 30 rated the performance as very well done, 36 rated it as moderately well done, and 38 rated it as somewhat or not at all well done (Table 5).

Roundtable participants were most likely to provide lower ratings: 19 of 45 roundtable participants

answered somewhat or not at all well to this query, compared with 11 of 31 PRG members and eight of 28 PRG leaders. A lack of technical expertise and familiarity with the portfolios was often cited as a reason for the lower ratings in this area. In the words of one roundtable participant, “The [roundtable] meeting did not enhance the participants’ knowledge of the portfolio...[this knowledge]...had to exist prior to the meetings.”

Table 5.—Extent to which the PRG process incorporated the examination of the NCI research portfolio before recommendations were developed and strategies for implementation were identified, by group and by PRG

Category	N ¹	Very well		Moderately well		Somewhat or not at all well	
		Number	Percent	Number	Percent	Number	Percent
Overall	104	30	29	36	35	38	37
Group							
PRG Leadership.....	28	10	36	10	36	8	29
PRG Membership	31	7	23	13	42	11	35
Roundtable Participants	45	13	29	13	29	19	42
PRG							
Breast, Prostate, and Colorectal Cancers ²	9	2	22	5	56	2	22
Brain Tumor	14	4	29	5	36	5	36
Pancreatic Cancer	12	4	33	4	33	4	33
Leukemia, Lymphoma, and Myeloma	14	2	14	4	29	8	57
Lung Cancer.....	14	4	29	5	36	5	36
Gynecologic Cancers	14	5	36	3	21	6	43
Kidney and Bladder Cancers.....	14	2	14	6	43	6	43
Stomach and Esophageal Cancers.....	13	7	54	4	31	2	15

¹Data were not obtained for 24 cases, most of whom were unsure whether the event occurred or felt that not enough time had elapsed to accurately rate this item.

²Responses from the leaders of these PRGs have been combined due to small sample sizes.

NOTE: All percentages have been rounded, and totals may not sum to 100 percent.

4.5 Producing a Written Report

Information from the roundtable deliberations is used to prepare a report that summarizes the findings and includes recommendations related to the site-relevant research addressed by the PRG process. *Among all respondents, 76 of 122 felt that PRGs performed the task of producing a written report very well, and another 33 said that PRGs performed the task moderately well* (Table 6).

Satisfaction with the performance of this task was related to the respondent’s role or level of involvement in the process and also varied by PRG. Among respondents who expressed an opinion, PRG members (24 of 32) were somewhat more likely than either PRG leaders (20 of 30) or roundtable participants (32 of 60) to indicate that the PRGs performed this task very well.

Table 6.—Extent to which the PRG process functioned to prepare a written report, by group and by PRG

Category	N ¹	Very well		Moderately well		Somewhat or not at all well	
		Number	Percent	Number	Percent	Number	Percent
Overall	122	76	62	33	27	13	11
Group							
PRG Leadership.....	30	20	67	8	27	2	7
PRG Membership	32	24	75	7	22	1	3
Roundtable Participants	60	32	53	18	30	10	17
PRG							
Breast, Prostate, and Colorectal Cancers ²	9	6	67	3	33	0	0
Brain Tumor	16	8	50	5	31	3	19
Pancreatic Cancer	14	9	64	2	14	3	21
Leukemia, Lymphoma, and Myeloma	17	9	53	5	29	3	18
Lung Cancer.....	16	11	69	4	25	1	6
Gynecologic Cancers	17	10	59	5	29	2	12
Kidney and Bladder Cancers.....	17	11	65	5	29	1	6
Stomach and Esophageal Cancers.....	16	12	75	4	25	0	0

¹Data were not obtained for six cases.

²Responses from the leaders of these PRGs have been combined due to small sample sizes.

NOTE: All percentages have been rounded, and totals may not sum to 100 percent.

Although answers given by respondents from most PRGs reflected the favorable opinions expressed by all respondents, the opinions of respondents from the Brain Tumor and Stomach and Esophageal Cancers PRGs were markedly different from respondents in general. Whereas overall, 76 of 122 respondents felt that PRGs functioned very well in the production of the reports, only eight of 16 Brain Tumor PRG respondents expressed a similar opinion. On the other hand, respondents from the Stomach and Esophageal Cancers PRG (12 of 16) were the most likely to indicate that the PRGs performed this task very well.

Respondents who held less favorable opinions of the reports seemed to be more heavily influenced by the process used to prepare the reports than by their quality. For instance, some PRG leaders mentioned that they had insufficient time to obtain adequate input from PRG members, and some PRG members and roundtable participants felt that time constraints prevented them from fully participating in the process.

4.6 Discussing a Plan of Action

As noted in Chapter 1, at the start of Phase II, PRG leaders and members participate in a response meeting to discuss proposed NCI strategies to address the PRG recommendations with the NCI director and staff. PRG leaders and members were asked to rate how well PRGs fostered the discussion of a plan to ensure that the identified priority areas were well addressed. *The opinions of each group were similar and were fairly evenly distributed: 16 of 40 said that the PRGs performed this task very well, 12 said moderately well, and 12 said somewhat or not at all well* (Table 7).

Table 7.—Extent to which the PRG process fostered the discussion of a plan of action to ensure that priority areas are well addressed, by group and by PRG

Category	N ¹	Very well		Moderately well		Somewhat or not at all well	
		Number	Percent	Number	Percent	Number	Percent
Overall	40	16	40	12	30	12	30
Group							
PRG Leadership.....	23	9	39	6	26	8	35
PRG Membership	17	7	41	6	35	4	24
PRG²							
Breast, Prostate, and Colorectal Cancers ³	8	4	50	3	38	1	13
Brain Tumor	7	4	57	2	29	1	14
Pancreatic Cancer	7	3	43	1	14	3	43
Leukemia, Lymphoma, and Myeloma	5	0	0	1	20	4	80
Lung Cancer.....	6	0	0	4	67	2	33
Gynecologic Cancers	7	5	71	1	14	1	14

¹Data were not obtained for 12 cases, most of whom were unsure whether the event occurred or felt that not enough time had elapsed to accurately rate this item.

²Since the Kidney and Bladder Cancers and Stomach and Esophageal Cancers PRGs had not completed this stage of the process at the time of this evaluation, PRG leaders and members from these groups were not asked these questions.

³Responses from the leaders of these PRGs have been combined due to small sample sizes.

NOTE: All percentages have been rounded, and totals may not sum to 100 percent.

Although the PRG leaders and members expressed similar opinions, those expressed by respondents from the various PRGs varied widely. For example, the proportions of those rating the task as very well performed ranged from five of seven respondents from the Gynecologic Cancers PRG to none of the six Lung Cancer and none of the five Leukemia, Lymphoma, and Myeloma (LLM) PRG respondents. In addition, four of five LLM PRG respondents said that the PRGs performed the task only somewhat or not at all well.

Two themes emerged to help explain the responses of respondents who provided lower ratings:

- **Insufficient time.** The most common perception was that insufficient time was devoted to the response meeting. Respondents characterized the meetings as brief and said that because of the brevity, discussions lacked sufficient depth to capture the nature of the reports.
- **Lack of dialogue.** A number of respondents from the LLM and Lung Cancer PRGs, the two groups providing the lowest ratings, perceived a lack of positive dialogue between PRG participants and NCI staff at the response meeting. For example, one respondent reported a lack of openness between the two groups and another said, "...there was very little role for interaction..."

4.7 Recommended Changes to the PRG Charge

PRG leaders, PRG members, and roundtable participants were asked to suggest changes to the PRG charge and to discuss whether or not they thought the current charge was appropriate.

Respondents did not suggest any changes;⁵ in fact, several expressed quite positive opinions about the appropriateness of the charge. For example, one respondent said that, "the best way to advance scientific fields and identify the way things are going or might be going is to just bring the guys together who are doing it and let them chat about it." Another expressed similar views saying, "I think the charge is excellent. It was more or less an open charge to look at what's going on and come up with a good set of recommendations and that was accomplished."

⁵ The few respondents who offered answers to this question did not focus on the charge itself. Rather, some described their uncertainty regarding how the PRG process—especially the recommendations included in the report—might influence the NCI research portfolio. Others described their uncertainty regarding the scope of the PRGs—whether PRGs should focus on disease-specific issues or on broader topics affecting multiple sites.

5. OTHER OUTCOMES OF THE PRG PROCESS: THE PERSPECTIVE OF PRG PARTICIPANTS

5.1 Overview

To assess the second core question, *What are other outcomes of the PRG process?* PRG leaders, PRG members, and roundtable participants were asked to report on outcomes of the process beyond those defined in the PRG charge. Specifically, the questions addressed effects that the PRG process might have had on the research environment (e.g., priority setting and NCI planning) and on the professional lives of participants (e.g., knowledge and collaborative relationships). Additionally, respondents were asked to identify any other effects they perceived stemming from the process.

The discussion in the following sections focuses on the positive outcomes of the PRG process. In addition, this chapter describes a few concerns expressed by some respondents about how the process might negatively affect the state of cancer research.

Overall, the majority of PRG leaders and members indicated that the PRG process had influenced NCI priority setting. The majority of PRG leaders, PRG members, and roundtable participants also believed that the PRG process had influenced overall research priorities for specific disease sites. Participants indicated that the PRG process had affected them personally; they believed that their participation in the PRG process affected their knowledge, opinions, beliefs, and practices related to cancer research. About half of respondents indicated that their participation led to new collaborative or professional relationships with others interested in cancer research.

5.2 The Influence of PRGs on NCI Priority Setting and Planning

Respondents were asked several questions to assess their opinions on the relationship between the PRGs and NCI planning and priority setting.

- PRG leaders, PRG members, and roundtable participants were asked whether the process was an integral part of NCI planning.
- PRG leaders and PRG members also were asked whether the process had influenced NCI priority setting.

Among all PRG leaders and members who expressed an opinion about the influence of the PRG process on NCI priority setting, 29 of 40 agreed that it had an effect (Table 8). Although majorities of both PRG leaders and PRG members felt that PRGs influenced NCI priority setting, the extent of agreement varied by group, with a greater proportion of PRG members (14 of 16) than PRG leaders (15 of 24) agreeing that the process had influenced NCI priority setting. However, the proportion of PRG members who did not respond to this question was larger than the corresponding proportion of PRG leaders.

Table 8.—Whether the PRG process influenced NCI priority setting, by group and by PRG

Category	N ¹	Yes		No	
		Number	Percent	Number	Percent
Overall.....	40	29	73	11	28
Group					
PRG Leadership	24	15	63	9	38
PRG Membership.....	16	14	88	2	13
PRG					
Breast, Prostate, and Colorectal Cancers ²	8	7	88	1	13
Brain Tumor	3	2	67	1	33
Pancreatic Cancer	6	5	83	1	17
Leukemia, Lymphoma, and Myeloma	6	3	50	3	50
Lung Cancer	4	3	75	1	25
Gynecologic Cancers.....	3	3	100	0	0
Kidney and Bladder Cancers	6	3	50	3	50
Stomach and Esophageal Cancers	4	3	75	1	25

¹Data were not obtained for 22 cases, most of whom were unsure whether the event occurred or felt that not enough time had elapsed to accurately rate this item.

²Responses from the leaders of these PRGs have been combined due to small sample sizes.

NOTE: All percentages have been rounded, and totals may not sum to 100 percent.

PRG leaders who expressed opinions were asked to elaborate on their responses. Overall, their answers suggest that the PRG process has been a very effective, coordinated, and organized method of gaining input from the extramural community. PRG leaders indicated that the process broadened the focus of NCI and provided the “only way to identify the areas of basic and clinical science that are most likely to be fruitful in a given specific disease setting.” However, several respondents were unsure about the NCI commitment to the PRG process or its outcomes, and none of the respondents identified any examples of how the results of the process have been used by NCI.

A number of comments made by PRG leaders indicate that their assessments may be related to a desire for increased communication with NCI. For example, one leader called for PRG leaders to serve on the NCI Advisory Committee to the Director as a means of ensuring that PRG priorities become

a part of the strategic plan. Another leader felt that having division directors and program directors serve as equal members of the PRG would be useful. Other suggestions included publishing a progress report card from each division regarding implementation of the recommendations and assembling PRG leaders for an advisory meeting when NCI is in the process of establishing budget goals for the following year.

Almost all PRG leaders, PRG members, and roundtable participants (98 of 106) said that the PRG process was an integral part of NCI planning (Table 9). This appraisal was shared among most respondents from all groups and PRGs. Several respondents indicated that the PRG process provided NCI with a unique means of gaining input from the wider community.

Table 9.—Whether the PRG process was integrated into NCI planning, by group and by PRG

Category	N ¹	Yes		No	
		Number	Percent	Number	Percent
Overall.....	106	98	92	8	8
Group					
PRG Leadership	24	20	83	4	17
PRG Membership.....	28	27	96	1	4
Roundtable Participants.....	54	51	94	3	6
PRG					
Breast, Prostate, and Colorectal Cancers ²	7	6	86	1	14
Brain Tumor	15	14	93	1	7
Pancreatic Cancer	14	13	93	1	7
Leukemia, Lymphoma, and Myeloma	13	12	92	1	8
Lung Cancer	16	14	88	2	13
Gynecologic Cancers.....	12	11	92	1	8
Kidney and Bladder Cancers	14	14	100	0	0
Stomach and Esophageal Cancers	15	14	93	1	7

¹Data were not obtained for 22 cases, most of whom were unsure whether the event occurred or felt that not enough time had elapsed to accurately rate this item.

²Responses from the leaders of these PRGs have been combined due to small sample sizes.

NOTE: All percentages have been rounded, and totals may not sum to 100 percent.

5.3 Influence of PRGs on Overall Disease-Specific Priority Setting

All respondents were asked whether the PRG process has influenced overall research priorities beyond NCI for specific disease sites and to explain the basis for their opinions. **Most respondents (56/87 or 64 %) believed that the process has, in fact, affected priority setting** (Table 10). Respondents from the Brain Tumor and Pancreatic Cancer PRGs were most likely (nine of 11 respondents from each group) and respondents from the Kidney and Bladder Cancers PRG were the least

likely (four of 10) to share this belief. Some respondents were able to describe how that influence has been directly and indirectly manifested. As examples of how the PRG process has affected priority setting, one PRG leader mentioned that the process led to new funding for site-relevant research and another mentioned the probable long-term effect of increased collaborative research resulting from assembling members of the scientific community.

Table 10.—Whether the PRG process influenced disease-specific priority setting, by group and by PRG

Category	N ¹	Yes		No	
		Number	Percent	Number	Percent
Overall.....	87	56	64	31	36
Group					
PRG Leadership	26	15	58	11	42
PRG Membership.....	16	10	63	6	38
Roundtable Participants.....	45	31	69	14	31
PRG					
Breast, Prostate, and Colorectal Cancers ²	8	5	63	3	38
Brain Tumor	11	9	82	2	18
Pancreatic Cancer.....	11	9	82	2	18
Leukemia, Lymphoma, and Myeloma	11	7	64	4	36
Lung Cancer	10	5	50	5	50
Gynecologic Cancers.....	13	9	69	4	31
Kidney and Bladder Cancers	10	4	40	6	60
Stomach and Esophageal Cancers	13	8	62	5	38

¹Data were not obtained for 41 cases, most of whom were unsure whether the event occurred or felt that not enough time had elapsed to accurately rate this item.

²Responses from the leaders of these PRGs have been combined due to small sample sizes.

NOTE: All percentages have been rounded, and totals may not sum to 100 percent.

5.4 The Effect of PRGs on Individual Participants

PRG leaders, PRG members, and roundtable participants were asked to describe whether their participation in the process 1) affected their knowledge, opinions, beliefs, or practices related to cancer research, and 2) led to any new collaborative or professional relationships with others interested in cancer research. **Overall, 96 of 127 respondents reported that their knowledge, opinions, beliefs, or practices had been affected** (Table 11). The majority of respondents within each group shared the opinion that participation resulted in this outcome, although there was slight variation by group.

Table 11.—Whether participation in the PRG process influenced respondents’ level of knowledge, opinions, beliefs, or practices regarding disease-specific research, by group and by PRG

Category	N ¹	Yes		No	
		Number	Percent	Number	Percent
Overall	127	96	76	31	24
Group					
PRG Leadership.....	30	27	90	3	10
PRG Membership	32	24	75	8	25
Roundtable Participants	65	45	69	20	31
PRG					
Breast, Prostate, and Colorectal Cancers ²	9	9	100	0	0
Brain Tumor	18	14	78	4	22
Pancreatic Cancer	15	12	80	3	20
Leukemia, Lymphoma, and Myeloma	18	11	61	7	39
Lung Cancer.....	16	8	50	8	50
Gynecologic Cancers	17	13	76	4	24
Kidney and Bladder Cancers.....	17	13	76	4	24
Stomach and Esophageal Cancers.....	17	16	94	1	6

¹Data were not obtained for one case.

²Responses from the leaders of these PRGs have been combined due to small sample sizes.

NOTE: All percentages have been rounded, and totals may not sum to 100 percent.

PRG leaders (27 of 30) were the most likely to report that the experience affected their knowledge, opinions, beliefs, or practices. As examples of such effects, a few mentioned that the process helped them understand more about basic research into clinically useful areas and gave them a more “global” perspective of the research environment.

Twenty-four of 32 PRG members and 45 of 65 roundtable participants also reported that they had been affected by their participation. The effect most frequently cited by these respondents was a better understanding of how interaction between the academic and private sectors, between advocates and industry representatives, and between researchers and NCI could spur action. For example, some roundtable participants mentioned learning more about the current state of research and the need for intensified efforts, and said that they were more motivated to apply what they had learned from the experience within their local communities.

Respondents from most PRGs reported having similar experiences, including all nine leaders from the Breast, Prostate, and Colorectal Cancers PRGs, and 16 of 17 respondents from the Stomach and Esophageal Cancers PRG, 12 of 15 from the Pancreatic Cancer PRG, 14 of 18 from the Brain Tumor PRG, and 13 of 17 from both the Gynecologic Cancers and Kidney and Bladder Cancers PRGs. Respondents from the LLM and Lung Cancer PRGs were less likely to report this experience. Only 11 of

the 18 LLM PRG respondents and eight of the 16 Lung Cancer PRG respondents said they had experienced a change in their knowledge, opinions, beliefs, or practices.

Sixty-seven of 124 PRG leaders, PRG members, and roundtable participants said that the process had led to new collaborative research relationships, and similar proportions of each group reported the formation of new relationships (Table 12). However, the likelihood differed by PRG, ranging from five of 17 LLM PRG respondents to 13 of 18 Brain Tumor PRG respondents reporting the formation of new relationships.

Table 12.—Whether participation in the PRG process influenced respondents’ collaborative or professional relationships, by group and by PRG

Category	N ¹	Yes		No	
		Number	Percent	Number	Percent
Overall	124	67	54	57	46
Group					
PRG Leadership.....	29	16	55	13	45
PRG Membership	31	14	45	17	55
Roundtable Participants	64	37	58	27	42
PRG					
Breast, Prostate, and Colorectal Cancers ²	8	5	63	3	38
Brain Tumor	18	13	72	5	28
Pancreatic Cancer	14	9	64	5	36
Leukemia, Lymphoma, and Myeloma	17	5	29	12	71
Lung Cancer.....	16	8	50	8	50
Gynecologic Cancers	17	8	47	9	53
Kidney and Bladder Cancers.....	17	8	47	9	53
Stomach and Esophageal Cancers.....	17	11	65	6	35

¹Data were not obtained for four cases.

²Responses from the leaders of these PRGs have been combined due to small sample sizes.

NOTE: All percentages have been rounded, and totals may not sum to 100 percent.

5.5 Other Outcomes of the PRG Process

Respondents from all groups were asked to identify outcomes of the PRG process in addition to those that had been specifically addressed during the interviews. ***The majority of respondents identified one or more positive outcomes.*** Most focused on the interaction between participants, the education and mobilization of participants, and the increased likelihood of funding. A few respondents mentioned negative outcomes as well, such as establishing unrealistic funding expectations and dissatisfaction based on feeling left out of the NCI planning activities subsequent to the response meeting.

6. STRENGTHS AND WEAKNESSES OF THE PRG PROCESS: THE PERSPECTIVE OF PRG PARTICIPANTS

6.1 Overview

NCI has convened 10 PRGs during the past six years. Since various features of this process could influence the degree to which any given PRG succeeds in meeting its charge, the third core question, *What are the strengths and weaknesses of the PRG process, and how can the process be improved?* focused on these features. Depending on their role in the PRG process (e.g., as a PRG leader, PRG member, or roundtable participant), respondents were asked to report their experiences and opinions on the following features of the PRG process:

- The methods and criteria used to select participants;
- The skills and expertise of participants;
- The style of interaction between participants;
- The schedule for conducting the tasks associated with the PRGs; and
- The quality of the support materials used by the participants.

Additionally, this chapter highlights specific suggestions and recommendations offered by the respondents for improving the experience and outcome of PRGs.

Overall, PRG leaders indicated that the selection criteria used to choose PRG members and roundtable participants were appropriate. The majority of leaders, members, and roundtable participants indicated that key perspectives were represented in the PRG process, with PRG leaders being the most likely to hold this viewpoint. Almost all roundtable participants rated the knowledge, skills, and backgrounds of those who participated in the PRG process as either very well or moderately well qualified. In addition, the majority of leaders, members, and roundtable participants believed they had a good understanding of core elements of the PRG charge. The majority of respondents also held favorable opinions about the style of interaction between among group members, the process schedule, and the quality of support materials. Respondents rated the usefulness of the research portfolio slightly less favorably than other support materials.

6.2 Methods and Criteria Used to Select PRG Participants

One of the responsibilities of PRG leaders and PRG members is to identify others who might participate in the PRG process. As described in Chapter 1, typically, each PRG has three leaders, who select about 25 to 30 individuals to serve as PRG members. In turn, the leaders and members select about 75 to 100 individuals to serve as roundtable participants. The roundtable meeting is organized to facilitate both small and large group discussions, with PRG members nominating individual roundtable participants to take part in specific breakout group discussions.

PRG leaders and PRG members were asked to discuss the methods they used to select participants and to describe any changes in the techniques they thought would be beneficial. PRG leaders were asked to describe criteria for selecting both PRG members and roundtable participants. PRG members were asked only about criteria for selecting the roundtable participants.

The criteria used by the PRG leaders to select PRG members were very consistent across PRGs and included the following:

- **Expertise in the field.** Individuals who have worked in clinical or research settings.
- **Breadth of understanding.** People with an ability to look beyond their area of expertise to understand more broadly disease-specific research needs.
- **Interdisciplinary perspectives.** People from various disciplines who represent different perspectives, including advocates.
- **Time spent in the field.** Individuals who are new to the field as well as those with established careers.
- **Diversity.** A mix of individuals in terms of gender, ethnicity, and geographic location.
- **Communication skills and enthusiasm.** Those who are likely to work efficiently and pleasantly.

When asked to suggest changes to the process used to select PRG members and roundtable participants, only a small number of PRG leaders indicated that any changes were necessary. The change most often suggested was that greater consideration be given to a broader group of qualified individuals when selecting participants. In this regard, one respondent stated, “It ended up being based on who you know and are you compatible with the person [recommending the selection].”

The criteria used by PRG members to select roundtable breakout session participants were largely consistent across PRGs and similar to those used in selecting PRG members, including:

- Expertise in the field;
- Diversity; and
- Representation of advocates.

Other considerations included the individual's type of research and sector (i.e., private and government).

6.3 Skills and Expertise of PRG Participants

Many of the respondents included diversity of background and expertise on the list of criteria used for selecting participants. Linked to this concept of diversity is the goal of including participants who represent the various perspectives of those interested in cancer research. PRG leaders, PRG members, and roundtable participants were asked to assess the success of this effort.

Most respondents (82/ 126 or 66%) reported that the key areas were represented in the PRG process (Table 13). Although a majority from each group shared this opinion, PRG leaders (24/30 or 80%) were more likely than either PRG members (19/32 or 59%) or roundtable participants (39/64 or 61%) to do so. The likelihood that respondents thought that the key areas were represented also varied by PRG, ranging from only six of 17 respondents from the Kidney and Bladder Cancers PRG to 14 of 17 respondents from the Stomach and Esophageal Cancers PRG.

Table 13.—Whether key areas were represented among PRG participants, by group and by PRG

Category	N ¹	Yes		No	
		Number	Percent	Number	Percent
Overall	126	82	65	44	35
Group					
PRG Leadership.....	30	24	80	6	20
PRG Membership	32	19	59	13	41
Roundtable Participants	64	39	61	25	39
PRG					
Breast, Prostate, and Colorectal Cancers ²	9	8	89	1	11
Brain Tumor	17	11	65	6	35
Pancreatic Cancer	14	10	71	4	29
Leukemia, Lymphoma, and Myeloma	18	10	56	8	44
Lung Cancer.....	17	10	59	7	41
Gynecologic Cancers	17	13	76	4	24
Kidney and Bladder Cancers.....	17	6	35	11	65
Stomach and Esophageal Cancers.....	17	14	82	3	18

¹Data were not obtained for two cases.

²Responses from the leaders of these PRGs have been combined due to small sample sizes.

NOTE: All percentages have been rounded, and totals may not sum to 100 percent.

Respondents who thought that one or more key areas were not sufficiently represented were asked to provide examples of additional types of participants that they felt should be included. They identified the following areas of expertise:

- End-of-life experts;
- Clinicians;
- Ethicists;
- Survivor group representatives;
- Experts in basic science;
- Experts in disease-specific conditions; and
- Regulators (e.g., Food and Drug Administration).

When asked, respondents from almost every PRG described at least one key area as underrepresented. Analysis of the respondents' comments indicates that given the unique characteristics of each cancer site, the process might have benefited from the use of more tailored sets of selection criteria. One respondent suggested that NCI assess critical issues by site and include a greater number of representatives from those areas at the roundtable. For example, for lung cancer, additional individuals

knowledgeable about early detection, either in the area of scanning technology or biological markers, might have been appropriate.

Roundtable participants were also asked to assess the knowledge, skills, and background of those who participated; they were nearly unanimous in their favorable assessment of participants. Forty-eight of 65 respondents rated the participants as very well qualified, and another 13 rated them as moderately well qualified (Table 14).

Table 14.—Extent to which roundtable participants felt PRG participants possessed the needed knowledge, skills, and background, by PRG

Category	N ¹	Very well		Moderately well		Somewhat or not at all well	
		Number	Percent	Number	Percent	Number	Percent
Roundtable Participants	65	48	74	13	20	4	6
PRG²							
Brain Tumor	10	6	60	3	30	1	10
Pancreatic Cancer	8	5	63	2	25	1	13
Leukemia, Lymphoma, and Myeloma ..	9	6	67	2	22	1	11
Lung Cancer.....	10	7	70	3	30	0	0
Gynecologic Cancers	9	7	78	1	11	1	11
Kidney and Bladder Cancers.....	9	7	78	2	22	0	0
Stomach and Esophageal Cancers.....	10	10	100	0	0	0	0

¹Data were not obtained for one case.

²Roundtable participants from the Breast, Prostate, and Colorectal Cancer PRGs were not eligible to participate in the evaluation.

NOTE: All percentages have been rounded, and totals may not sum to 100 percent.

Understanding of the Charge. PRG leaders, PRG members, and roundtable participants were asked to assess their own understanding of elements of the PRG charge. Specifically, they were asked whether they felt they had a good understanding of how the PRG process would:

- Identify and prioritize research opportunities and needs;
- Describe the scientific resources needed to address the priorities;
- Prepare a written report; and
- Discuss a plan of action.

Large majorities of all groups felt they possessed a good understanding of each of these elements.

- **Identifying and Prioritizing.** Overall, 117 of 127 respondents felt they understood the process of identification and prioritization (Table 15). The proportion was quite high across PRGs.

Table 15.—Understanding the PRG charge: Identifying and prioritizing research opportunities and needs, by group and by PRG

Category	N ¹	Yes		No	
		Number	Percent	Number	Percent
Overall.....	127	117	92	10	8
Group					
PRG Leadership	30	26	87	4	13
PRG Membership.....	31	26	84	5	16
Roundtable Participants.....	66	65	98	1	2
PRG					
Breast, Prostate, and Colorectal Cancers ²	9	9	100	0	0
Brain Tumor	17	17	100	0	0
Pancreatic Cancer	15	15	100	0	0
Leukemia, Lymphoma, and Myeloma	18	14	78	4	22
Lung Cancer	17	15	88	2	12
Gynecologic Cancers.....	17	17	100	0	0
Kidney and Bladder Cancers	17	15	88	2	12
Stomach and Esophageal Cancers	17	15	88	2	12

¹Data were not obtained for one case.

²Responses from the leaders of these PRGs have been combined due to small sample sizes.

NOTE: All percentages have been rounded, and totals may not sum to 100 percent.

- **Describing Scientific Resources.** Of 127 PRG leaders, PRG members, and roundtable participants, 106 indicated that they had a good understanding of the charge in terms of describing the scientific resources needed to address identified research opportunities and needs (Table 16). The likelihood that respondents reported this belief varied somewhat by PRG, ranging from 16 of 17 Brain Tumor PRG respondents to 12 of 17 Kidney and Bladder Cancers PRG respondents.

Table 16.—Understanding the PRG charge: Describing the scientific resources needed to address identified research opportunities and needs, by group and by PRG

Category	N ¹	Yes		No	
		Number	Percent	Number	Percent
Overall.....	127	106	83	21	17
Group					
PRG Leadership	30	26	87	4	13
PRG Membership.....	31	24	77	7	23
Roundtable Participants.....	66	56	85	10	15
PRG					
Breast, Prostate, and Colorectal Cancers ²	9	8	89	1	11
Brain Tumor	17	16	94	1	6
Pancreatic Cancer	15	12	80	3	20
Leukemia, Lymphoma, and Myeloma	18	15	83	3	17
Lung Cancer	17	14	82	3	18
Gynecologic Cancers.....	17	14	82	3	18
Kidney and Bladder Cancers	17	12	71	5	29
Stomach and Esophageal Cancers	17	15	88	2	12

¹Data were not obtained for one case.

²Responses from the leaders of these PRGs have been combined due to small sample sizes.

NOTE: All percentages have been rounded, and totals may not sum to 100 percent.

- **Preparing a Written Report.** Most respondents (104/127 or 82%) reported having a good understanding of how the report would be written (Table 17). The proportion reporting a good understanding varied somewhat by PRG, ranging from six of nine respondents from the Breast, Prostate, and Colorectal Cancers PRGs to 17 of 18 respondents from the LLM PRG.
- **Discussing a Plan of Action.** Most respondents (98/124 or 79%) felt they had a good understanding of how the plan of action would be developed. The proportion of respondents who held this belief ranged from six of nine respondents of the Breast, Prostate, and Colorectal Cancers PRGs to 16 of 17 respondents from the Stomach and Esophageal Cancers PRG.⁶

⁶ At the time these interviews were completed, some PRGs had not yet completed this process.

Table 17.—Understanding the PRG charge: Preparing a written report, by group and by PRG

Category	N ¹	Yes		No	
		Number	Percent	Number	Percent
Overall.....	127	104	82	23	18
Group					
PRG Leadership	30	26	87	4	13
PRG Membership.....	32	28	88	4	13
Roundtable Participants.....	65	50	77	15	23
PRG					
Breast, Prostate, and Colorectal Cancers ²	9	6	67	3	33
Brain Tumor	18	15	83	3	17
Pancreatic Cancer	15	11	73	4	27
Leukemia, Lymphoma, and Myeloma	18	17	94	1	6
Lung Cancer	17	15	88	2	12
Gynecologic Cancers.....	17	12	71	5	29
Kidney and Bladder Cancers	17	13	76	4	24
Stomach and Esophageal Cancers	16	15	94	1	6

¹Data were not obtained for one case.

²Responses from the leaders of these PRGs have been combined due to small sample sizes.

NOTE: All percentages have been rounded, and totals may not sum to 100 percent.

Table 18.—Understanding the PRG charge: Discussing a plan of action to ensure that priority areas are well addressed, by group and by PRG

Category	N ¹	Yes		No	
		Number	Percent	Number	Percent
Overall.....	124	98	79	26	21
Group					
PRG Leadership	29	22	76	7	24
PRG Membership.....	32	27	84	5	16
Roundtable Participants.....	63	49	78	14	22
PRG					
Breast, Prostate, and Colorectal Cancers ²	9	6	67	3	33
Brain Tumor	16	11	69	5	31
Pancreatic Cancer	15	11	73	4	27
Leukemia, Lymphoma, and Myeloma	18	14	78	4	22
Lung Cancer	17	14	82	3	18
Gynecologic Cancers.....	17	13	76	4	24
Kidney and Bladder Cancers	15	13	87	2	13
Stomach and Esophageal Cancers	17	16	94	1	6

¹Data were not obtained for four cases.

²Responses from the leaders of these PRGs have been combined due to small sample sizes.

NOTE: All percentages have been rounded, and totals may not sum to 100 percent.

Additional Respondent Comments on Understanding the Charge. Many of the respondents who thought they had a good understanding of these elements attributed it to one of three factors: previous experience serving on a PRG, conversations with colleagues who were familiar with the PRG process, or examples of materials from previous PRGs.

Most respondents who felt uncertain about how these elements would be addressed noted that their uncertainty was dispelled as the process got underway. In cases where confusion remained, respondents tended to attribute it to a lack of time to review sample materials, the technical nature of many of the materials and presentations, or insufficient instructions.

6.4 Style of Interaction Among Participants

In many organizational settings, the style of interaction among group members can influence the degree to which objectives are met. Group interaction can be affected by both the personalities of the individuals and the structure under which the group operates. To examine how group dynamics might influence the process, PRG leaders, PRG members, and roundtable participants were asked to describe both the style of their group interactions and how that style affected the outcome of the process.

The vast majority of respondents from all three groups voiced favorable opinions about the group interactions. Leaders reported that the interaction among all the groups resulted in a very productive process. They described constructive exchange of ideas across disciplines and minimal conflicts among the group members. PRG members described the interaction as collegial and serving to facilitate an open forum for honest discussions. Roundtable participants described the PRG process as an open exchange with cordial and positive interaction and collaboration; they said that group leaders did a good job of directing the discussions and that the groups succeeded in identifying needs.

Nonetheless, respondents did identify some shortcomings of the PRG process that seemed to affect group interactions. Specifically, they noted that interactions were not always efficient due to the number of participants, there was limited exchange of ideas due to time restrictions, and some participants came with controversial personal agendas.

In general, the positive and negative opinions expressed by the respondents tended to be consistent across PRGs. However, Lung Cancer PRG respondents expressed widely divergent descriptions of the interaction, ranging from well done, open, collegial, and honest, to “a sell job.” Based on the comments provided by the individual respondents, it was impossible to determine with certainty

the reason for these divergent viewpoints. However, these comments and others from Lung Cancer PRG respondents pointed to a recurring pattern of disagreement between those who were focused on tobacco-related issues and those focused on other issues.

6.5 Process Schedule

Respondents were asked to share their experiences working within the overall PRG schedule. Ninety-four of 128 respondents felt that the process schedule allowed just the right amount of time to fulfill the PRG charge (Table 19). Ten respondents thought that the schedule was too long, while 24 thought that there was insufficient time to complete the tasks. The proportion of respondents who felt that the process schedule allowed just the right amount of time varied by group: 25 of 30 PRG leaders, 20 of 32 PRG members, and 49 of 66 roundtable participants expressed this opinion.

Table 19.—Adequacy of time allotted in the PRG process schedule to successfully complete the tasks, by group and by PRG

Category	N	Too much time		Just the right amount of time		Too little time	
		Number	Percent	Number	Percent	Number	Percent
Overall	128	10	8	94	73	24	19
Group							
PRG Leadership.....	30	5	17	25	83	0	0
PRG Membership	32	5	16	20	63	7	22
Roundtable Participants	66	0	0	49	74	17	26
PRG							
Breast, Prostate, and Colorectal Cancers ¹	9	4	44	5	56	0	0
Brain Tumor	18	0	0	13	72	5	28
Pancreatic Cancer	15	2	13	11	73	2	13
Leukemia, Lymphoma, and Myeloma	18	0	0	15	83	3	17
Lung Cancer.....	17	1	6	10	59	6	35
Gynecologic Cancers	17	0	0	15	88	2	12
Kidney and Bladder Cancers.....	17	2	12	12	71	3	18
Stomach and Esophageal Cancers.....	17	1	6	13	76	3	18

¹Responses from the leaders of these PRGs have been combined due to small sample sizes.

NOTE: All percentages have been rounded, and totals may not sum to 100 percent.

Opinions expressed by respondents from the Brain Tumor and Lung Cancer PRGs were notable exceptions to the overall response pattern. Five of 18 Brain Tumor PRG respondents and six of 17 Lung Cancer PRG respondents thought that there was too little time to successfully complete the tasks.

Respondents who felt that the schedule provided too little time frequently mentioned that the schedule discouraged in-depth discussion of issues; this was particularly true in the case of the roundtable discussions. As an example, one respondent said that “the process wears you out trying to get it done in the amount of time allotted...there was not enough time to get all the ideas on the table.”

6.6 Quality of Support Materials

Throughout the course of the PRG process, various materials are prepared and shared with participants. This information is intended to provide participants with a comprehensive summary of the research issues and describe the operational structure of the process. The interviews included questions about many of these materials, specifically focusing on:

- The list of potential PRG members;
- Guidance on how the breakout sessions would be conducted;
- Other information related to the plans for the roundtable;
- Roundtable and breakout agendas from previous PRGs;
- The NCI research portfolio for the disease site(s);
- The list of current site-relevant initiatives;
- Reports from previous PRGs;
- Other guidance materials and the NCI initiative mapping document; and
- Conference calls and summaries.

Not all groups or PRGs received each of these materials. Respondent groups that had received each item were asked if they had reviewed it and whether they found it to be very useful, somewhat useful, not too useful, or not at all useful.⁷ In addition, those respondents who had reviewed items were asked if they had reviewed them on-line or in hardcopy, and which medium they would have preferred for their review. Finally, respondents were asked to describe any other information that would have been useful. Their opinions and differences by group and by PRG are discussed in the following sections. Tables associated with these opinions are presented in Appendix D.

⁷ Because of very low frequencies, the “not too useful” and “not at all useful” responses have been combined.

6.6.1 List of Potential PRG Members

All PRG leaders were asked if they had reviewed the list of potential members and, if they had, to rate its usefulness. All but one of 29 leaders who answered this question reported reviewing the list; 20 of them found it to be very useful and six considered it to be somewhat useful (Appendix Table D-1).

In addition, all PRG leaders who had reviewed the list were asked to report their actual and preferred method for reviewing the list. Fifteen of 27 leaders who responded to this question had reviewed the list on-line, and nearly all those who offered an opinion (15/18 or 83%) would have preferred an on-line review (Appendix Table D-2).

6.6.2 Guidance on Breakout Sessions

All PRG members and roundtable participants were asked about the review of guidance materials regarding how the breakout sessions would be conducted. Sixty-five of the 85 respondents had reviewed the materials (Appendix Table D-3). Roughly the same proportions of PRG members (20 of 26) and roundtable participants (45 of 59) had reviewed the materials. By PRG, the proportion ranged from 11 of 12 respondents from the Gynecologic Cancers PRG to eight of 12 respondents from the LLM PRG.

Sixty-one of the 65 respondents who had reviewed the materials rated their usefulness. Overall, 32 found them somewhat useful and 23 respondents found them very useful. Among the respondents who rated their usefulness, roundtable participants (17 of 41) were more likely than PRG members (six of 20) to rate them as very useful. By PRG, the proportion ranged from six of 10 respondents from the Kidney and Bladder Cancers PRG to one of nine respondents from the Stomach and Esophageal Cancers PRG.

Respondents who had reviewed the plans were asked about their method of review and which method they would have preferred to use. Of the 49 respondents who had reviewed the plans and reported the medium in which they reviewed them, 27 reported doing so on-line (Appendix Table D-4). Thirty-one of 51 who had reviewed the plans and reported a preferred method of review would have preferred to do so on-line, with PRG members being more likely than roundtable participants to hold that opinion (12 of 16 versus 19 of 35, respectively). It should be noted that, when asked, roughly half the PRG members and roundtable participants did not report their actual or preferred method of review.

6.6.3 Other Information Related to the Plans for the Roundtable

All PRG members and roundtable participants were asked if they had reviewed additional information about the roundtable in which they participated. Most respondents (66/85 or 78%) had reviewed other information related to their roundtable (Appendix Table D-5). Roundtable participants were more likely than PRG members to have done so (54/61 or 89% versus 12/24 or 50%, respectively).

Among the 66 respondents who reviewed this information, 61 expressed an opinion about its usefulness; 32 found it to be somewhat useful and 25 found it to be very useful. The proportions of respondents who reported finding the information very useful varied by PRG, ranging from four of five LLM PRG respondents to one of 10 Stomach and Esophageal Cancers PRG respondents.⁸

Fifty-five of the 66 respondents who reviewed the materials reported their method of review: 31 reviewed the materials on-line and 24 reviewed hardcopy (Appendix Table D-6). Among the 52 respondents who expressed a preference, 35 would have preferred on-line review. The preference for on-line review varied by PRG, ranging from nine of 10 Stomach and Esophageal Cancers PRG respondents to four of nine Lung Cancer PRG respondents.

6.6.4 Roundtable and Breakout Agendas from Previous PRGs

Most PRG leaders and PRG members were asked about review of the roundtable and breakout agendas from previous PRGs.⁹ Forty-four of the 51 respondents (86%) had reviewed previous agendas, with a higher proportion of PRG leaders than PRG members having reviewed them (22/24 or 92% versus 22/27 or 81%, respectively) (Appendix Table D-7).

The likelihood that respondents rated the agendas as very useful differed by group and by PRG. Although 15 of 22 leaders said that the agendas were very useful to them, only nine of 22 members held the same view. By PRG, the likelihood of rating the agendas as very useful ranged from five of six respondents from the Gynecologic Cancers PRG to two of six respondents from the Brain Tumor PRG.

⁸ Note that one of the six LLM PRG respondents did not rate the usefulness of the information.

⁹ These materials were not available to leaders of the Breast Cancer and Prostate Cancer PRGs. Therefore, respondents from these groups were not asked these questions.

Similarly, among respondents who had reviewed the agendas, there was variation in the method used and the method preferred (Appendix Table D-8). For example, the use of on-line review ranged from one of six respondents from the LLM PRG to five of six respondents from the Stomach and Esophageal Cancers PRG. Furthermore, although all respondents from several PRGs would have preferred on-line review, only two of six respondents from the LLM PRG expressed this preference.

6.6.5 NCI Research Portfolio for the Disease Site(s)

All respondents, including PRG leaders, PRG members, and roundtable participants, were asked if they had reviewed the NCI research portfolios; overall, 98 of 118 respondents (83%) had reviewed the portfolio (Appendix Table D-9). This proportion varied by group, with 30 of 30 PRG leaders and 31 of 32 members saying they had reviewed the documentation, compared with 37 of 56 roundtable participants.

Respondents who had reviewed the portfolios were divided on their usefulness. Among the 97 respondents who rated their usefulness, 41 said that they were very useful, 37 said that they were somewhat useful, and 19 said that they were not too useful or not at all useful. This pattern did not vary substantially by group or PRG.

Of the 81 respondents who reported their method of review, 43 said they had reviewed the portfolios on-line and 38 said they had reviewed hardcopies (Appendix Table D-10). Similar proportions of respondents from each PRG reported on-line review. Among respondents offering an opinion, most (52/76 or 68%) would have preferred to review the materials on-line, but once again there were exceptions by PRG.

6.6.6 List of Current Site-Relevant Initiatives

Leaders and members from all PRGs were asked about the review of current site-relevant initiatives. When asked whether they had reviewed the list of current site-relevant initiatives, 50 of 56 respondents said they had done so (Appendix Table D-11). The vast majority from both groups reported reviewing the list of initiatives, including 25 of 27 PRG leaders and 25 of 29 PRG members.

Respondents were split on their opinion of the usefulness of the lists: among the 49 who rated their usefulness, 24 found them very useful, 18 found them somewhat useful, and seven found them

not too useful or not at all useful. Respondents from the various PRGs reported a broad range of opinions about the usefulness of the list: from a high of five of six Gynecologic Cancers PRG respondents finding the list very useful to a low of one of seven LLM PRG respondents.

Forty-three respondents identified their method of review. Twenty-four respondents reviewed the lists on-line and 19 reviewed hardcopies (Appendix Table D-12). PRG members (13 of 21) were slightly more likely than PRG leaders (11 of 22) to use on-line review. There was wide variation in the method respondents from the different PRGs used to review the lists. For example, the proportion of respondents who reviewed the lists on-line ranged from six of six from the Stomach and Esophageal Cancers PRG to one of six from the LLM PRG. Among the 50 respondents who reviewed the lists of current site-related initiatives, 39 reported a preference for one of the methods of review. Twenty-nine would have preferred on-line review and 10 would have preferred hardcopy review.

6.6.7 Reports From Previous PRGs

Most respondents, including PRG leaders, PRG members, and roundtable participants, were asked about the review of reports from previous PRGs.¹⁰ Among these respondents, 85 of 114 said that they had reviewed reports in preparation for their roles (Appendix Table D-13). The proportion who indicated that they had reviewed the reports varied by group: all 24 PRG leaders, all but one of 29 PRG members, and 33 of 61 roundtable participants.

Of the 85 respondents who reviewed the reports, 84 rated their usefulness: 53 found the reports very useful, 30 found them somewhat useful, and one found them not too or not at all useful. Among the respondents who rated the usefulness of the reports, PRG leaders (18 of 24) were more likely to find the reports very useful when compared to roundtable participants (20 of 32) or PRG members (15 of 28).

Seventy-one of the 85 respondents who had reviewed reports from previous PRGs answered questions about method of review. Forty-two of these respondents had reviewed the reports on-line and 29 reviewed hardcopies (Appendix Table D-14). Although there was little variation in the proportions by group, variation was broad among members of the different PRGs. Use of on-line review ranged from

¹⁰ These materials were not available to leaders and members of the Breast Cancer and Prostate Cancer PRGs. Therefore, respondents from these groups were not asked these questions.

two of two Colorectal Cancer PRG respondents and eight of 10 Kidney and Bladder Cancers PRG respondents to only two of 11 LLM PRG respondents.

Among the 85 respondents who had reviewed the reports, 65 expressed a preference for method of review, with 41 preferring on-line review. This proportion varied by PRG; Pancreatic Cancer PRG respondents (five of five) were the most likely and LLM PRG respondents (three of eight) were the least likely to prefer on-line review.

6.6.8 Other Guidance Materials and the NCI Initiative Mapping Document

Most PRG leaders and PRG members were asked about review of other guidance materials and the NCI initiative mapping document distributed in the response meeting.¹¹ Thirty-two of 39 respondents had reviewed the materials, with nearly equal proportions of PRG leaders and PRG members having reviewed them (19 of 23 versus 13 of 16, respectively) (Appendix Table D-15).

Thirty-one of the 32 respondents who had reviewed the materials rated their usefulness. Although the same proportion of PRG leaders (eight of 19) and PRG members (five of 12) said that the materials were very useful, the proportions that found them somewhat useful and not too or not at all useful varied by group. Among the 19 responding PRG leaders, six found the materials somewhat useful and five found them not too useful or not at all useful. Among 12 responding PRG members, seven found them somewhat useful and none found them not too useful or not at all useful.

There was wide variation in the way members of the different PRGs rated the usefulness of these materials. For example, among those who rated the usefulness, the proportion rating them as very useful ranged from four of six Brain Tumor PRG respondents to zero of four Pancreatic Cancer PRG respondents.

Twenty-five of the 32 respondents who had reviewed the materials described their method of review (Appendix Table D-16). Overall, 15 reviewed hardcopies and 10 reviewed the materials on-line. Data suggest that PRG members (five of nine) were more likely than PRG leaders (five of 16) to have reviewed materials on-line. However, approximately half the respondents did not identify their method of review.

¹¹ These materials were not available to leaders and members of the Kidney and Bladder Cancers and Stomach and Esophageal Cancers PRGs. Therefore, respondents from these groups were not asked these questions.

6.6.9 Conference Call Agendas and Summaries

All PRG leaders were asked about the review of conference call agendas and summary materials. Twenty-three of 27 respondents who answered the question reported reviewing these materials, and the vast majority of those expressing an opinion (19 of 23) found them very useful in preparing for their roles (Appendix Table D-17).

Twenty respondents who had reviewed the materials described their method of review: 13 reviewed the materials on-line and seven reviewed hardcopies (Appendix Table D-18). Among the 18 respondents who expressed a preference, 16 would have preferred on-line review.

6.6.10 Other Desired Information

All respondents were asked to identify any other information that would have been helpful to them in their role on the PRG. Suggestions generally fell into one of two categories: 1) information about NCI and the research it funds, and 2) information on NCI's expectations for the PRG process and further explanation of the roles that they would play in the process. Respondents' specific suggestions are summarized below:

- Respondents wanted **more information on the relationships among different groups at NCI**. Although they may have been given an organizational chart, some respondents found it difficult to determine which initiatives came from which branches or programs. One person said, for example, "NCI may have just assumed we knew how the parts of NCI worked together."
- Respondents wanted to be able to **compare the NCI investment in research on the target site in relation to the overall NCI budget**.
- They were interested in viewing **related NCI and non-NCI research portfolios** (e.g., National Institute of Diabetes and Digestive and Kidney Diseases).
- They thought **a compilation of NCI clinical trials (detection, prevention, and therapy), including the scope of work, would be useful**.

Respondents, particularly roundtable participants, also expressed an interest in having more information on the purpose of the PRG and on the role that they would play in the process. Suggestions included:

- Present **clear guidelines** at the first meeting. “They needed to know why they were there and the nuts and bolts about what we should do. The guidelines should have been presented in outline form and should have clearly stated what we should do and the time frame we were to work in.”
- Provide a **list or outline of what should be discussed in each breakout session**.
- Provide a **better description of the format of the roundtable and more background information on the participants** (e.g., a short paragraph that described their research interests).
- Provide a **brief synopsis of relevant studies** to each breakout group.

6.7 Evaluation of Support

All respondents were asked to rate the support provided by OSPA, and PRG leaders and PRG members were asked to rate the support provided by the science writers. They were asked to describe the support as excellent, good, fair, or poor; in addition, they were given the option of answering “don’t know.”¹² When respondents answered fair or poor, they were asked to elaborate.

Overall, the vast majority of respondents rated OSPA support as excellent or good.

Among the 125 respondents who answered this question, 74 rated the support as excellent and 40 rated the support as good (Table 20). Ratings of excellent were more likely to come from the PRG leaders (23/30 or 77%) than from PRG members or roundtable participants (16/30 or 53% versus 35/65 or 54%, respectively). There was also a range in the ratings of OSPA support by PRG, with six of 15 respondents (40%) from the Pancreatic Cancer PRG rating OSPA support as excellent, compared with 13 of 17 respondents (76%) from the Stomach and Esophageal Cancers PRG providing this rating.

As for the science writers, 27 of 61 PRG leaders and PRG members rated their performance as excellent, 23 rated their performance as good, and 10 rated their performance as fair or poor (Table 21). The most positive review came from respondents of the Stomach and Esophageal Cancers PRG; the most negative review came from Gynecologic Cancers PRG respondents.

Based on the comments from PRG leaders and PRG members who were dissatisfied with the performance of the science writers, it seems that the consistency of quality was a key factor. For example, one PRG leader said “there was considerable turnover in the science writers and their grasp of the material was relatively low. The process of getting things written and getting them back and forth

¹² Because of very low frequencies, the fair and poor responses have been combined.

Table 20.—Ratings of OSPA support, by group and by PRG

Category	N ¹	Excellent		Good		Fair/Poor ²		Don't know	
		Number	Percent	Number	Percent	Number	Percent	Number	Percent
Overall	125	74	59	40	32	6	5	5	4
Group									
PRG Leadership	30	23	77	5	17	2	7	0	0
PRG Membership	30	16	53	13	43	1	3	0	0
Roundtable Participants	65	35	54	22	34	3	5	5	8
PRG									
Breast, Prostate, and Colorectal Cancers ³	9	6	67	3	33	0	0	0	0
Brain Tumor	17	12	71	4	24	0	0	1	6
Pancreatic Cancer	15	6	40	7	47	0	0	2	13
Leukemia, Lymphoma, and Myeloma	18	12	67	5	28	1	6	0	0
Lung Cancer	16	7	44	8	50	1	6	0	0
Gynecologic Cancers	16	9	56	4	25	2	13	1	6
Kidney and Bladder Cancers	17	9	53	6	35	1	6	1	6
Stomach and Esophageal Cancers	17	13	76	3	18	1	6	0	0

¹Data were not obtained for three cases.

²Because of very low frequencies, the fair and poor responses have been combined.

³Responses from the leaders of these PRGs have been combined due to small sample sizes.

NOTE: All percentages have been rounded, and totals may not sum to 100 percent.

Table 21.—Ratings of the performance of science writers, by group and by PRG

Category	N ¹	Excellent		Good		Fair/Poor ²		Don't know	
		Number	Percent	Number	Percent	Number	Percent	Number	Percent
Overall	61	27	44	23	38	10	16	1	2
Group									
PRG Leadership	30	15	50	11	37	4	13	0	0
PRG Membership	31	12	39	12	39	6	19	1	3
PRG									
Breast, Prostate, and Colorectal Cancers ³	9	6	67	2	22	1	11	0	0
Brain Tumor	7	4	57	3	43	0	0	0	0
Pancreatic Cancer	7	1	14	4	57	1	14	1	14
Leukemia, Lymphoma, and Myeloma	8	4	50	3	38	1	13	0	0
Lung Cancer	7	1	14	5	71	1	14	0	0
Gynecologic Cancers	8	1	13	3	38	4	50	0	0
Kidney and Bladder Cancers	8	5	63	2	25	1	13	0	0
Stomach and Esophageal Cancers	7	5	71	1	14	1	14	0	0

¹Data were not obtained for one case.

²Because of very low frequencies, the fair and poor responses have been combined.

³Responses from the leaders of these PRGs have been combined due to small sample sizes.

NOTE: All percentages have been rounded, and totals may not sum to 100 percent.

between the members was not very efficient.” Comments from others indicated that science writers sometimes did not possess the skills or commitment needed to perform their duties.

It is important to note that, in the course of conducting the PRGs, changes were made in processes that, in fact, address some of the areas identified as in need of improvement. For example, science writer performance was evaluated and subsequently monitored more closely. Science writing support was more highly rated in the most recent PRGs.

6.8 Other Suggested Changes to Improve the PRG Process

Respondents were invited to describe any other changes to the PRG process that they felt would improve the efficiency of the procedures or the usefulness of the results, and nearly all the respondents offered one or more suggestions. Several PRG leaders stressed the need for a more disciplined focus on prioritization during the PRG process and especially at the conclusion of the process. (As stated in Chapter 7, some EC members shared this opinion.) PRG leaders added that this focus must include greater efforts to define the products of the process and to communicate that information to all involved in it.

PRG members and roundtable participants focused on changes in the way groups communicate. Examples included:

- Giving PRG members and roundtable participants a greater voice during the planning stages (e.g., during the development of the agendas);
- Offering opportunities during the roundtable for unstructured discussions between groups, and formal sessions in which key researchers and chairs could meet with leaders of advocacy communities;
- Offering roundtable participants a greater opportunity to participate in the actual writing of the report and allowing them to review draft reports when broader input could still be valuable (before the final report is issued); and
- Holding discussions between NCI and the PRG members, at least once a year, to monitor progress on the recommendations and to identify gaps in the research portfolio.

7. THE EXECUTIVE COMMITTEE PERSPECTIVE ON THE PRG PROCESS

7.1 Overview

EC members were asked to describe their experiences and opinions related to the three core evaluation questions. Specifically, they were asked about the PRGs' success in meeting the charge and the effects of the PRGs on NCI priority setting and planning, and on their knowledge, opinions, beliefs, and practices. In addition, they were asked to evaluate the level of support received and to suggest ways the PRG process could be improved. Their responses are reported in the following sections, along with pertinent comments they made when asked to elaborate on those responses.

In general, EC members indicated that the PRGs performed moderately well in providing input useful to the development of the NCI research agenda. All felt that the PRG process had affected NCI priority setting and planning, however, many felt that the recommendations were only somewhat helpful in developing initiatives to address disease-specific research gaps and needs and moderately helpful in getting approval for such initiatives. EC members believed that the PRG process affected their own knowledge, opinions, beliefs, and practices regarding disease-specific research. In addition, EC members gave positive reviews for OSPA staff performance.

7.2 Success in Meeting the Charge

The PRG charge includes several components that, taken together, are designed to provide NCI with input useful in shaping the research portfolio for the next three to five years. EC members were asked to rate the performance of the PRGs on the following elements of the charge, using a four-point scale: very well, moderately well, somewhat well, or not at all well:

- Identifying and prioritizing research opportunities and needs;
- Describing resources needed to address the research opportunities;
- Incorporating examination of the NCI research portfolio; and
- Producing a written report.

When members indicated that the performance on an element was other than “very well,” the interviewer asked them to elaborate on their response.

In general, the EC members felt that the PRGs performed moderately well in providing input useful to the development of the NCI research agenda. Findings include the following:

- Four of six EC members rated PRG efforts to identify and prioritize research opportunities and needs as moderately well done, while two described the lack of focus on needs related to particular cancer sites as problematic. One member noted that the prioritized lists were “generic,” and another referred to them as “laundry lists.”
- Five of six EC members said that PRGs performed the task of describing resources needed to address opportunities moderately well. When asked to elaborate, a number of respondents indicated that the process did not result in a useful description of resources.
- Three of five EC members felt that PRGs incorporated examination of the NCI research portfolio moderately well.
- The performance of PRGs in producing written reports was the most highly rated element of the charge; four of five EC members rated this as very well done.

EC members expressed concern that the PRG charge tended to raise unrealistic expectations among researchers, advocates, and patients. For example, two members suggested that the phrase “to ensure that priority areas are well addressed” contained in the charge inflated the perceived role of PRGs in formulating NCI’s plan of action.

7.3 Effects of the PRGs on NCI Priority Setting and Planning

EC members were asked about the effects of the PRG process on NCI priority setting and planning, and they were unanimous in their belief that the process has affected these domains. Comments suggested that the process:

- Spurred initiatives based on PRG recommendations (at least during times of high budget flexibility);
- Helped shape the focus of activities led by extramural divisions (those overseeing the grant portfolio) as they planned initiatives, workshops, and working groups; and

- Allowed NCI to, as one member said, “better categorize and organize things that we were already doing which matched the identified needs of the investigators and the advocacy community.”

Although EC members noted these effects, many did not consider the PRG recommendations and reports to be very helpful to their own divisions/offices. Four of six members felt that the recommendations were only somewhat helpful in developing initiatives to address disease-specific research gaps and needs, and four of six found the recommendations moderately helpful in getting approval for initiatives addressing research gaps and needs. However, three of five members believed that the reports provided valuable information to the division/office and the field.

7.4 Effects of the PRGs on Member Knowledge, Opinions, Beliefs, and Practices

EC members believed that the PRG process affected their level of knowledge, opinions, beliefs, or practices regarding disease-specific research. All five members who responded to this question agreed that the PRG process affected them, although some noted that the effects came from the earlier PRGs and not the more recent ones. As one member said, “there may have been a few things that I had not been thinking about, but in general...once you read one PRG [report], the patterns were all similar.”

7.5 Evaluation of Support

In an effort to rate the level of support received during the PRG process, EC members were asked how well OSPA staff kept them informed. While generally more positive than negative in their reviews, most members saw some potential for improvement; two rated OSPA staff performance as very well done, and four rated it as moderately well done.

EC members also were asked to evaluate how well they were kept informed by their representatives at the roundtable meetings and working group sessions. One of six members reported being very well informed by the roundtable representative, three said they were moderately well informed, and two reported being somewhat well informed. The members provided identical ratings when asked how well they were kept informed by their working group representatives.

Although the members were not entirely satisfied with the level of information they received, they indicated little desire for additional information. When asked to elaborate on their ratings, three of six members said they could think of no additional information that they would have found helpful. One member said that information on logistical details of the meetings (e.g., when and where the meetings would occur) would have been helpful and that information on how to comment on the PRG recommendations would have been useful. Another member indicated that too much information had been provided.

7.6 Other Suggested Changes to Improve the PRG Process

EC members were asked to suggest changes to improve the PRG process. Several members stressed the need for a more disciplined focus on prioritization during the PRG process, especially at the conclusion of the process. One EC member also mentioned the need for greater involvement of higher level staff at NCI “to evaluate what can be realistically carried out,” and several mentioned the need to more seriously consider the budgetary factors associated with the recommendations.

8. SUMMARY AND RECOMMENDATIONS

8.1 Overview

During the past six years, NCI has used a series of PRGs—each consisting of prominent members of the scientific, clinical, industry, and advocacy communities—to assess the state of the science and recommend future research-related priorities for a single type of cancer or a group of related cancers. In preparation for future PRGs and other planning activities, the NCI’s Office of Science Planning and Assessment (OSPA) elected to conduct a critical evaluation of the PRG process to determine what was working well and what needed improvement.

The evaluation sought to answer three core research questions:

- Have the PRGs fulfilled their charge to develop disease-specific national research agendas?
- What are other outcomes of the PRG process?
- What are the strengths and weaknesses of the PRG process, and how can the process be improved?

Results from 134 telephone interviews conducted in late 2002 were used to examine the experiences and opinions of individuals who have been involved in one or more PRGs, including six members of the NCI Executive Committee, 30 PRG leaders, 32 PRG members, and 66 roundtable participants.

Lessons learned from the evaluation and suggestions for how the PRG process may be modified or implemented in the future are presented in this chapter. The discussion is presented in the following manner. Section 8.2 describes overall findings and recommendations related to the PRG charge, the first of the core questions listed above. Findings and recommendations related to the second core question, regarding other outcomes of the PRG process, are discussed in Section 8.3.

Aspects of the PRG process that respondents perceived favorably are highlighted in Section 8.4, and a discussion of features that could be improved is presented in Section 8.5. Recommendations for maintaining positive aspects of the process and improving others are made throughout these sections. Section 8.6 describes limitations of this evaluation and suggests an approach for on-going evaluation of the PRG process.

8.2 Meeting the PRG Charge

Respondents were asked to rate PRG performance on five common elements of the PRG charge:

- Identifying and prioritizing research opportunities and needs.
- Describing resources needed to address opportunities.
- Incorporating examination of the NCI research portfolio.
- Producing a written report.
- Discussing a plan of action.

Respondents generally felt that the charge was appropriate, and they expressed favorable opinions about the ability of PRGs to achieve the objectives of the charge. For example, one respondent said, “I think the charge is excellent. It was more or less an open charge to look at what’s going on and come up with a good set of recommendations and that was accomplished.” Specific findings related to PRG performance on meeting the charge include the following:

- Most respondents, including PRG leaders, PRG members, and roundtable participants, felt that PRGs performed very well on three elements of the charge: identifying and prioritizing scientific research opportunities and needs (72 of 127), describing resources needed to address opportunities (63 of 123), and producing a written report (76 of 122).
- Respondents from these groups rated performance on the incorporating examination of the NCI portfolio somewhat less favorably. Among the 104 respondents who expressed an opinion related to the portfolio, ratings were fairly evenly split with 30 respondents rating performance as very well done, 36 as moderately well done, and 38 as somewhat well or not at all well done. The lower ratings on this element of the charge may be due, in part, to the format in which the portfolio was presented.¹³
- Overall, respondents rated PRG performance on the fifth element of the charge (i.e., discussing a plan of action) as well done. Among the 40 respondents who expressed opinions, 16 rated the performance as very well done, 12 as moderately well done, and 12 as somewhat well or not at all well done. These findings may be related to the fact that for several PRGs, only a short time had passed between the completion of the PRG report and the date of the interviews for this evaluation. Therefore, it may have been too soon to accurately assess the performance of some PRGs on this task.

¹³ Additional findings related to the NCI research portfolio are reported in Section 8.5.

- EC members expressed generally favorable opinions of the ability of PRGs to meet the five elements of the charge, although they were more likely than other respondents to rate the performance as moderately well done. EC members expressed concern that that the PRG charge tended to raise unrealistic expectations among researchers, advocates, and patients. They stressed the need for a more disciplined focus on prioritization during the PRG process, evaluating the degree to which the recommendations are realistic in light of budgetary factors.

Recommendations

- Clarify expected PRG process outcomes and communicate them to the researchers, advocates, and patients who participate in the process.
- Clarify for PRG participants the role that budget constraints might have on desired funding for research.

8.3 Other Outcomes of the PRG Process

In addition to successfully meeting the charge, PRGs appear to offer other benefits to NCI, PRG participants, and the overall state of cancer research. Findings indicate that **PRGs increase the opportunity for interaction between NCI and the extramural community**. For example, respondents generally shared the opinion that the PRG process was a very effective method for NCI to gain input from the wider community and for individuals within the community to influence NCI priority setting and disease-specific priority setting. Nearly all PRG leaders, PRG members, and roundtable participants (98 of 106) said that the process was an integral part of NCI planning, and 56 of 87 believed that the process has affected disease-specific priority setting. EC members were unanimous in their belief that the process has affected NCI priority setting and planning.

While communication between NCI and the wider community was seen as a positive outcome of the PRG process, a number of PRG leaders, PRG members, and roundtable participants indicated their desire for more communication. Suggestions included asking PRG leaders to serve on the NCI Advisory Committee to the Director and having division directors and program directors serve as equal members of the PRG. Sharing information on the progress related to the recommendations in the PRG report was another suggested means of communication.

Respondents also indicated that participation in **the PRG process provided an expanded professional understanding and awareness of opportunities**. Ninety-six of 127 PRG leaders, PRG members, and roundtable participants believed that their participation affected their knowledge, opinions, beliefs, and practices related to cancer research; this was especially true among PRG leaders, with 27 of 30 expressing this belief. Five EC members (all those who responded to a question on this topic) also shared this belief.

PRG leaders, PRG members, and roundtable participants often reported that participation in the process exposed them to other perspectives, typically as a result of interacting with participants involved in other aspects of cancer research. Roughly half these respondents attributed the establishment of new collaborative research relationships to their participation in the PRG process.

Recommendations

- Continue to provide PRG-like opportunities for members of the extramural community to interact with each other and NCI staff, and to expand their professional understanding and awareness of research opportunities.
- Continue to provide PRG-like opportunities and seek additional means for NCI to receive input from members of the extramural community.

8.4 Strengths of the PRG Process

The evaluation examined several issues related to the PRG process, and identified several features that were very successful. First, findings indicate that **the PRGs were composed of individuals with the appropriate expertise and mix of perspectives**. For example:

- **Participant selection criteria.** PRG leaders, PRG members, and roundtable participants identified various criteria used to select PRG members and roundtable participants, such as expertise in the field and diversity in terms of gender, ethnicity, and geographic location. The vast majority of respondents thought that the criteria were appropriate and succeeded in identifying strong nominees.
- **Representation of key research areas.** Most respondents (82 of 126) thought that the key areas of cancer research were represented by the participants; PRG leaders (24 of 30) were the most likely to express this opinion.

- **Understanding the PRG charge.** Large majorities of all groups felt they possessed a good understanding of the elements of the PRG charge. For example, 117 of 127 respondents felt they understood the process of identification and prioritization, and 104 of 127 reporting having a good understanding of how the report would be written. Many of the respondents who thought that they had a good understanding of the elements of the PRG charge attributed it to one of three factors: previous experience serving on a PRG, conversations with colleagues who were familiar with the PRG process, or examples of materials from previous PRGs.

Schedule and group interactions. Respondents reported that **the PRG schedule and the style of interaction among participants were appropriate.** For example, 94 of 128 respondents felt that the process schedule allowed just the right amount of time to fulfill the PRG charge. The vast majority of PRG leaders, PRG members, and roundtable participants voiced favorable opinions about the group interactions. However, a minority suggested that the large number of roundtable participants, coupled with the time restrictions under which the groups operated, limited the opportunity for thorough discussions.

Support materials. PRG leaders, PRG members, and roundtable participants were asked about various materials, such as the list of potential PRG members, conference call agendas and summary materials, guidance on how the breakout sessions would be conducted, other information related to the plans for the roundtable, and reports from previous PRGs. Findings indicate that **the materials provided to participants in the PRG process were useful.**

- Overall, large majorities of respondents reviewed all the materials they were provided. For example, all but one of 29 leaders reviewed the list of potential PRG members, and 66 of 85 PRG members and roundtable participants reviewed the information related to the plans for the roundtable.
- Among respondents who reviewed the various materials, most found them to be useful. For example, among the 85 PRG leaders, PRG members, and roundtable participants who reviewed reports from previous PRGs, 53 found the reports very useful and 30 found them somewhat useful. Among the 23 PRG leaders who reviewed the conference call agendas and summaries, 19 found them very useful and three found them somewhat useful.

NCI has made the support materials available to PRG participants in hardcopy and electronic or on-line formats. Respondents were fairly evenly split in the method they used to access the materials. For example, 15 of 27 PRG leaders reviewed the list of potential PRG members on-line, and 20 of 40 PRG leaders and PRG members reviewed the roundtable and breakout agendas from previous PRGs on-line. Although they were often evenly split in the method they used, they expressed a stronger preference

for on-line review. For example, 15 of 18 PRG leaders who reported a preferred method of reviewing the list of potential PRG members preferred on-line review. Likewise, 28 of 38 respondents who reported a preferred method of reviewing the agendas preferred on-line review.

OSPA support of the PRG process. OSPA provides support throughout the PRG process; **respondents rated OSPA support favorably.** Among the 125 PRG leaders, PRG members, and roundtable participants who expressed an opinion, 74 rated the support as excellent and 40 rated the support as good. Among the six EC members who rated OSPA performance, two rated it as very well done and four rated it as moderately well done.

Recommendations

- Clarify expected PRG process outcomes and communicate them to the researchers, advocates, and patients who participate in the process.
- Clarify for PRG participants the role that budget constraints might have on desired funding for research.
- Continue to provide PRG-like opportunities for members of the extramural community to interact with each other and NCI staff, and to expand their professional understanding and awareness of research opportunities.
- Continue to provide PRG-like opportunities and seek additional means for NCI to receive input from members of the extramural community.

8.5 Aspects of the PRG Process Needing Improvement

Whereas **respondents found most aspects of the PRG process to be successful**, findings indicate that some aspects could be improved. As described above, **PRG leaders, PRG members, and roundtable participants generally found most materials to be useful.** This opinion held true for the NCI research portfolio materials as well. Among those who reviewed the portfolios and rated their usefulness, most rated them as very useful (41/97 or 42%) or somewhat useful (37/97 or 38%). However, some respondents indicated that the presentation format of the portfolios was confusing and difficult to follow.

Additional useful information. PRG leaders, PRG members, and roundtable participants also suggested that **additional information would be useful to future PRGs.** Their suggestions generally fell into one of two categories: information about NCI and the research it funds, and information on NCI's expectations for the PRG process and a more detailed explanation of the roles that participants play in the process.

Science writer support. Although respondents expressed very favorable opinions about OSPA support, **support provided by science writers was rated slightly less favorably.** Fewer than half the PRG leaders and PRG members (27 of 61) rated the performance of science writers as excellent, and 10 of the respondents rated it as fair or poor. Comments from the respondents who were dissatisfied with the performance cited consistency of quality as a key factor. It should be noted that ratings of science writers tended to be higher for more recent PRGs.

Recommendations

- Examine alternative formats for presenting the NCI research portfolio.
- Identify and make available additional information that would be useful to PRG participants, and determine how it might best be presented.
- Continue to evaluate and monitor the performance of science writers. Preliminary areas of inquiry might include: *Do the science writers have appropriate training to perform their role? Do they have sufficient time to perform the tasks they are assigned?*

8.6 Suggested Improvements for Future Evaluations of the PRG Process

This evaluation focused on the experiences of individuals who had participated in one or more PRGs during the past six years. As evidenced by the evaluation design (i.e., the exclusion of PRG members and roundtable participants from the first three PRGs), this investigation was limited due to the expectation that respondents would find it difficult to recall events that had taken place years earlier.

To overcome this limitation, participants in future PRGs could be asked to report their experiences and opinions throughout the process or at the conclusion of milestone events. For example, EC members might be asked to share their thoughts on an annual basis; roundtable participants might be asked to complete an “exit evaluation” immediately after a roundtable meeting is concluded.

Depending on the design, the on-going evaluation could meet three objectives:

- Identify aspects of the PRG process that need improvement.
- Indicate appropriate measures to achieve the improvements.
- Examine the outcome of improvement efforts over time.

Questionnaires could be developed for the evaluation process, building on the topic guides used for this evaluation. Data collection methods would depend on several factors, such as the number and complexity of questions, the number of individuals asked to respond, and the willingness of individuals to respond. Regardless of data collection mode, an on-going evaluation strategy would provide NCI with important information needed to maximize the utility of future PRGs.

In conclusion, the PRGs have been successful. For the most part, they have achieved each element of their charge and provided NCI and PRG participants with unique and valuable information. Some areas for improvement and remedies have been identified. Through on-going evaluation and interaction with participants in the PRG process, NCI should be able to further refine the process and make it even more successful.

Recommendation

- Implement an on-going system to evaluate the PRG process, based on periodic or event-specific schedules.

APPENDIX A

**STUDY TOPICS AND THE CORRESPONDING
QUESTION NUMBERS, BY TOPIC GUIDE**

Appendix A.—Study topics and the corresponding question numbers, by topic guide

Topic	Executive Committee	PRG Leadership	PRG Membership	Roundtable Participants
Success in meeting the charge				
▪ Identification and prioritization of research opportunities and needs	Q4/5	Q19/20	Q19	Q23
▪ Description of scientific resources needed to address the research priorities	Q6/7	Q21/22	Q20/21	Q24/25
▪ Incorporation of the existing NCI research portfolio into the PRG process.....	Q10/11	Q27/28	Q25/27	Q28/29
▪ Production of a report that summarizes findings from the PRG process	Q8/9	Q23/24	Q22/23	Q20/21
▪ Discussion of a plan of action based on the report.....	Q2/3	Q25/26	Q24/25	
Recommended changes to the PRG charge	Q13	Q34	Q33	Q31
Other outcomes of the PRG process				
▪ Influence of PRGs on NCI priority setting and planning.....	Q25/26	Q39/40, Q41	Q38/39, Q40	Q36, Q37/38
▪ Influence of PRGs on disease-specific priority setting	Q28/29	Q42/43	Q41/42	
▪ Effect of PRGs on individual participants				
1. Affected their knowledge, opinions, beliefs, or practices related to cancer research	Q22/23	Q29/30	Q28/29	Q15/16
2. Led to any new collaborative or professional relationships with others involved in cancer research		Q31/32	Q30/31	Q17/18
▪ Other outcomes of the PRG process	Q30/31	Q35/36	Q34/35	Q32/33
Strengths and weaknesses of the PRG process				
▪ Methods and criteria used to select PRG participants.....		Q7, Q8, Q11	Q7, Q8	
▪ Skills and expertise of PRG participants				Q8/9
▪ Interaction between participants		Q12	Q11	Q12
▪ Process schedule.....		Q5/6	Q5/6	Q6/7
▪ Evaluation of support materials				
1. List of potential PRG members.....		Q2ac		
2. Guidance on how the breakout sessions would be conducted.....			Q2bc	
3. Other information related to the plans for the roundtable			Q2cc	
4. Roundtable and breakout agendas from previous PRGs		Q2bc	Q2ac	Q3ac, Q3bc
5. The NCI research portfolio for the cancer site.....		Q2dc	Q2dc	Q3dc
6. List of current site-relevant initiatives		Q2ec	Q2ec	
7. Reports from previous PRGs		Q2fc	Q2fc	Q3cc
8. Need for other information		Q4	Q4	Q5
Evaluation of OSPA support	Q14	Q14	Q13	Q14
1. Rate science writers		Q16	Q15	
2. Other suggested changes to improve the PRG process		Q33	Q32	Q30
3. Information provided to the EC from roundtables and working groups	Q15, Q16, Q17			
Other suggestions	Q21, Q24			

APPENDIX B

TOPIC GUIDES

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**Interview Topic Guide
–PRG Leadership–**

Final Version

INTRO: *During the interview, I will be asking questions about your involvement in the PRG process. As a reminder, the process involved the Leadership Meeting, Planning Meeting, Roundtable Meeting, the preparation and presentation of a final report to the Advisory Committee to the Director, and the Response Meeting to discuss actions proposed by NCI to address the PRG's recommendations.*

1. As you began the [SITE] PRG process, did you think you had a good understanding of the PRG charge in terms of ...[INSERT a – d BELOW]

IF NO: Please explain why not.

Component of charge	Yes	No	If no, why not?
a. Identifying and prioritizing research opportunities and needs..	1	2	
b. Describing the scientific resources (e.g., infrastructure) needed to address the priorities	1	2	
c. Preparing a written report.....	1	2	
d. Discussing a plan of action with NCI to ensure that priority areas are well addressed	1	2	

2. I'd like to ask a few questions about the NCI-supplied information you may have reviewed for your role on the [SITE] PRG.

A. First, were you able to review the...[INSERT a – d BELOW]

B IF YES: How useful was [INSERT a – d BELOW]? Would you say very useful (1), somewhat useful (2), not too useful (3), or not at all useful (4)?

C. IF NO: Please explain why not?

	A. Reviewed?			B. If yes, how useful?	C. If no, why not?
	Yes	No	NA		
a. List of potential PRG members (for the Leadership Meeting)	1	2		1 2 3 4	
b. (NOT APPROPRIATE FOR BREAST AND PROSTATE) Roundtable and Breakout agendas from previous PRGs (for the Planning Meeting).....	1	2	3	1 2 3 4	
c. Conference calls and the information obtained to prepare for the Roundtable Meeting	1	2		1 2 3 4	
d. NCI Research Portfolio (i.e., NCI-funded site-relevant projects grouped by type of research) ..	1	2		1 2 3 4	
e. List of current [SITE] initiatives	1	2		1 2 3 4	
f. (NOT APPROPRIATE FOR BREAST AND PROSTATE) Previous PRG reports.....	1	2	3	1 2 3 4	
g. (NOT APPROPRIATE FOR K/B AND S/E) Guidance materials and the NCI Initiative Mapping document that matched initiatives and funded projects to priorities and identified gaps (for the Response Meeting).....	1	2	3	1 2 3 4	

[INTERVIEWER: PLEASE REVIEW THE RESPONSE TO Q2 PRIOR TO ASKING Q3. IF THE RESPONSE TO Q2 a-g, COL. A = NO, DO NOT ASK CORRESPONDING ITEM IN Q3.]

3. A. Did you access [INSERT a - g BELOW] on line?
 B. For these materials, would you have preferred them in electronic format or hard copies?

NCI-supplied material	A. Accessed on line		B. Preferred mode	
	Yes	No	Electronic	Hard copy
a. List of potential PRG members (for the Leadership Meeting)	1	2	1	2
b. (NOT APPLICABLE FOR BREAST AND PROSTATE) Roundtable and breakout agendas from previous PRGs (for the Planning Meeting)	1	2	1	2
c. Conference calls and the information obtained to prepare for the Roundtable Meeting	1	2	1	2
d. NCI Research Portfolio (i.e., funded site-relevant projects grouped by type of research)	1	2	1	2
e. List of current [SITE] Initiatives	1	2	1	2
f. (NOT APPROPRIATE FOR BREAST AND PROSTATE) Previous PRG reports	1	2	1	2
g. (NOT APPROPRIATE FOR K/B AND S/E) Guidance materials and the NCI Initiative Mapping document that matched initiatives and funded projects to priorities (for the Response Meeting)	1	2	1	2

4. Besides the information NCI provided, what additional information would have helped you fulfill your role?

5. Do you think the schedule for the overall process (i.e., Leadership Meeting, Planning Meeting, Roundtable Meeting, report completion, and the interval between the completed report and participation in the Response Meeting) allowed too much time, just the right amount of time, or too little time to successfully complete each task?

- Too much time 1
- Right amount of time 2 (*Skip to Q7*)
- Too little time..... 3

6. What part of the process was given too (much/little) time in the schedule?

7. What criteria guided your selection of PRG members?

8. In retrospect, would you suggest any changes to the selection process for the PRG membership?

9. Do you think there were any key areas of expertise not represented among the PRG members and Roundtable participants?

- Yes..... 1
- No..... 2 (*Skip to Q11*)

10. What areas of expertise were not represented?

11. In retrospect, would you suggest any changes to the selection process for the Roundtable participants? For example, do you have any suggestions for improvement, or is it adequate to have the Breakout co-chairs select the participants with PRG leadership, oversight, and suggestions?

12. How did the interaction of the PRG leadership and members, Breakout co-chairs, and Roundtable participants affect the PRG process or the resulting recommendations? **[INTERVIEWER: PROBE FOR OPEN DISCUSSIONS, COLLEGIAL EXCHANGE OF IDEAS, INTERDISCIPLINARY COLLABORATION.]**

I now would like to ask a couple of questions to get your feedback about the support you received during the PRG process.

13. Considering the NCI Office of Science Planning and Assessment (OSPA) support for the Leadership, Planning, Roundtable, and Response Meetings, would you rate the OSPA support as...

Excellent	1	<i>(Skip to Q15)</i>
Good.....	2	<i>(Skip to Q15)</i>
Fair	3	
Poor.....	4	
Don't know	8	<i>(Skip to Q15)</i>

14. Please explain why.

15. How would you rate the *science writers*? Would you rate them as...

Excellent	1	<i>(Skip to Q17)</i>
Good.....	2	<i>(Skip to Q17)</i>
Fair	3	
Poor.....	4	
Don't know	8	<i>(Skip to Q17)</i>

16. Please explain why.

17. How well do you think the [SITE] PRG report reflects the research recommendations of the PRG Membership and Roundtable participants? Would you say...

- Very well..... 1 (*Skip to Q19*)
- Moderately well 2
- Somewhat well..... 3
- Not at all well..... 4

18. Please explain why.

I now would like to ask a few questions about the specific components of the PRG charge.

19. How well do you think the PRG process identified and prioritized research opportunities and needs to advance disease-specific medical progress? Would you say...

- Very well..... 1 (Skip to Q21)
- Moderately well 2
- Somewhat well..... 3
- Not at all well..... 4

20. Please explain why.

21. How well do you think the PRG process described the resources needed to address identified research opportunities and needs? Would you say...

- Very well..... 1 (*Skip to Q23*)
- Moderately well 2
- Somewhat well..... 3
- Not at all well..... 4

22. Please explain why.

23. How well do you think the PRG process functioned to prepare a written report describing the current state of the field, stating the recommendations for research opportunities and needs, and identifying the needed resources? Would you say...

- Very well..... 1 (*Skip to Q25*)
- Moderately well 2
- Somewhat well..... 3
- Not at all well..... 4

24. Please explain why.

[INTERVIEWER: Q25 NOT APPLICABLE FOR K/B AND S/E]

25. How well do you think the PRG process fostered the discussion of NCI strategies for addressing the PRG recommendations among PRG members and NCI staff in the context of the Response Meeting? Would you say...

- Very well..... 1 (*Skip to Q27*)
- Moderately well 2
- Somewhat well..... 3
- Not at all well..... 4
- Not applicable 5 (*Skip to Q27*)

26. Please explain why.

27. How well do you think the PRG process incorporated the examination of the NCI Research Portfolio before recommendations were developed and strategies for implementation were identified? Would you say...

- Very well..... 1 (*Skip to Q29*)
- Moderately well 2
- Somewhat well..... 3
- Not at all well..... 4

28. Please explain why.

29. Did your participation in the PRG affect your knowledge, opinions, beliefs, or practices regarding [SITE] research?

- Yes..... 1
- No..... 2 (*Skip to Q31*)

30. What effect did it have?

31. Did your participation in the PRG lead you to form any new collaborative or professional relationships with others involved in [SITE] research?

- Yes..... 1
- No..... 2 (*Skip to Q33*)

32. What new relationships were formed?

33. How could the PRG process be improved to better fulfill its current charge?

34. Are there any changes that you would recommend to the charge of the PRG?

35. Do you think that the process had any other outcomes (positive or negative) in addition to those stated in the PRG charge?

- Yes..... 1
- No..... 2 (*Skip to Q37*)

36. What were the outcomes?

37. Do you see the PRG process as an integral part of NCI planning?

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

38. Please explain (why/why not).

39. Do you feel that the PRG process has influenced NCI priority setting?

Yes..... 1

No..... 2

40. Please explain (why/why not).

41. Do you have any suggestions regarding how the PRG process might be better integrated into overall NCI priority setting?

42. Do you feel that the PRG process has made a difference in priority setting for [SITE] research?

Yes..... 1

No..... 2

43. Please explain (why/why not).

Thank you.

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Office of Science Planning and Assessment

Office of Communications

Interview Topic Guide

–PRG Members–

Final Version

INTRO: *During the interview, I will be asking questions about your involvement in the PRG process. As a reminder, the process involved the Planning Meeting, Roundtable Meeting, the preparation and presentation of a final report to the Advisory Committee to the Director, and the Response Meeting to discuss actions proposed by NCI to address the PRG's recommendations.*

1. As you began the [SITE] PRG process, did you think you had a good understanding of the PRG charge in terms of ... [INSERT a – d BELOW]

IF NO: Please explain why not.

Component of charge	Yes	No	In no, why not?
a. Identifying and prioritizing research opportunities and needs.....	1	2	
b. Describing the scientific resources (e.g., infrastructure) needed to address the priorities	1	2	
c. Preparing a written report.....	1	2	
d. Discussing a plan of action with NCI to ensure that priority areas are well addressed	1	2	

2. I'd like to ask a few questions about NCI-supplied information you may have reviewed for your role on the [SITE] PRG.

A. First, were you able to review the...[INSERT a – d BELOW]

B IF YES: How useful was [INSERT a – d BELOW]? Would you say very useful (1), somewhat useful (2), not too useful (3), or not at all useful (4)?

C. IF NO: Please explain why not.

	A. Reviewed?			B. If yes, how useful?	C. If no, why not?
	Yes	No	NA		
a. (NOT APPROPRIATE FOR BREAST AND PROSTATE) Roundtable and Breakout agendas from previous PRGs (for the Planning Meeting).....	1	2	3	1 2 3 4	
b. Guidance materials on being a Breakout co-chair or any other information on how your Breakout would proceed (preparing for the Roundtable) ..	1	2		1 2 3 4	
c. Any other information on how the Roundtable would proceed?	1	2		1 2 3 4	
d. NCI Research Portfolio (i.e., NCI-funded site-relevant projects grouped by type of research) ..	1	2		1 2 3 4	
e. List of current [SITE] initiatives	1	2		1 2 3 4	
f. (NOT APPROPRIATE FOR BREAST AND PROSTATE) Previous PRG reports.....	1	2	3	1 2 3 4	
g. (NOT APPROPRIATE FOR K/B AND S/E) Guidance materials and the NCI Initiative Mapping document that matched initiatives and funded projects to priorities and identified gaps (for the Response Meeting).....	1	2	3	1 2 3 4	

[INTERVIEWER: PLEASE REVIEW THE RESPONSE TO Q2 PRIOR TO ASKING Q3. IF THE RESPONSE TO Q2 a-g, COL. A = NO, DO NOT ASK CORRESPONDING ITEM IN Q3.]

3. A. Did you access [INSERT a - g BELOW] on line?
 B. For these materials, would you have preferred to receive them in electronic format or hard copies?

NCI-supplied material	A. Accessed on line		B. Preferred mode	
	Yes	No	Electronic	Hard copy
a. (NOT APPLICABLE FOR BREAST AND PROSTATE) Roundtable and Breakout agendas from previous PRGs (for the Planning Meeting).....	1	2	1	2
b. Guidance materials on being a Breakout co-chair or any other information on how your Breakout would proceed (preparing for the Roundtable)	1	2	1	2
c. Any other information on how the Roundtable would proceed	1	2	1	2
d. NCI Research Portfolio (i.e., funded site-relevant projects grouped by type of research).....	1	2	1	2
e. List of current [SITE] initiatives	1	2	1	2
h. (NOT APPROPRIATE FOR BREAST AND PROSTATE) Previous PRG Reports	1	2	1	2
i. (NOT APPROPRIATE FOR K/B AND S/E) Guidance materials and the NCI Initiative Mapping document that matched initiatives and funded projects to priorities (for the Response Meeting)	1	2	1	2

4. Other than the information that NCI provided, was there any additional information that would have helped you fulfill your role?

5. Do you think the schedule for the overall process (i.e., Planning Meeting, Roundtable Meeting, Breakout Sessions, report completion, and the interval between the completed report and participation in the Response Meeting) allowed too much time, just the right amount of time, or too little time to successfully complete each task?

Too much time 1
Right amount of time 2 (*Skip to Q7*)
Too little time..... 3

6. What part of the process was given too (much/little) time in the schedule?

[INTERVIEWER: ONLY BREAKOUT CO-CHAIRS SHOULD BE ASKED Q7 AND Q8. IF THE RESPONDENT IS NOT A CO-CHAIR, PLEASE SKIP TO Q9.]

7. What criteria guided your selection of Breakout group participants?

8. In retrospect, would you suggest any changes to the selection process for the Breakout group participants?

9. Do you think there were any key areas of expertise not represented among the Breakout participants?

Yes..... 1
No..... 2 (*Skip to Q11*)

10. What areas of expertise were not represented?

11. What effect did the way the PRG leadership and members, Breakout co-chairs, and Roundtable participants interacted have on the PRG process or the resulting recommendations?
[INTERVIEWERS: PROBE FOR OPEN DISCUSSIONS, COLLEGIAL EXCHANGE OF IDEAS, INTERDISCIPLINARY COLLABORATION.]

12. Considering the NCI Office of Science Planning and Assessment (OSPA) support for the Planning, Roundtable, and Response Meetings, would you rate the OSPA support as...

- Excellent 1 (*Skip to Q14*)
- Good..... 2 (*Skip to Q14*)
- Fair 3
- Poor 4
- Don't know 8 (*Skip to Q14*)

13. Please explain why.

14. Considering the *science writers*: Would you describe them as...

- Excellent 1 (*Skip to Q16*)
- Good..... 2 (*Skip to Q16*)
- Fair 3
- Poor 4
- Don't know 8 (*Skip to Q16*)

15. Please explain why.

16. How well do you think the [SITE] PRG report reflects the research recommendations of the PRG Membership and Roundtable participants? Would you say...

- Very well..... 1 (*Skip to Q18*)
- Moderately well 2
- Somewhat well..... 3
- Not at all well..... 4

17. Please explain why.

I now would like to ask a few questions about the specific components of the PRG charge.

18. How well do you think the PRG process identified and prioritized research opportunities and needs to advance disease-specific medical progress? Would you say...

- Very well..... 1 (*Skip to Q20*)
- Moderately well 2
- Somewhat well..... 3
- Not at all well..... 4

19. Please explain why.

20. How well do you think the PRG process described the resources needed to address identified research opportunities and needs? Would you say...

- Very well..... 1 (*Skip to Q22*)
- Moderately well 2
- Somewhat well..... 3
- Not at all well..... 4

21. Please explain why.

22. How well do you think the PRG process functioned to prepare a written report describing the current state of the field, stating the recommendations for research opportunities and needs, and identifying the needed resources? Would you say...

- Very well..... 1 (*Skip to Q24*)
- Moderately well 2
- Somewhat well..... 3
- Not at all well..... 4

23. Please explain why.

[INTERVIEWER: Q24 NOT APPROPRIATE FOR K/B AND S/E)

24. How well do you think the PRG process fostered the discussion of NCI strategies for addressing the PRG recommendations among PRG members and NCI staff in the context of the Response Meeting? Would you say...

- Very well 1 (*Skip to Q26*)
- Moderately well 2
- Somewhat well..... 3
- Not at all well..... 4

25. Please explain why.

26. How well do you think the PRG process incorporated the examination of the NCI Research Portfolio before recommendations were developed and strategies for implementation identified? Would you say...

- Very well..... 1 (*Skip to Q28*)
- Moderately well 2
- Somewhat well..... 3
- Not at all well..... 4

27. Please explain why.

28. Did your participation in the PRG affect your knowledge, opinions, beliefs, or practices regarding [SITE] research?

- Yes..... 1
- No..... 2 (*Skip to Q30*)

29. What effect did it have?

30. Did your participation lead you to form any new collaborative or professional relationships with others involved in [SITE] research?

- Yes..... 1
- No..... 2 (*Skip to Q32*)

31. What new relationships were formed?

32. How could the PRG process be improved to better fulfill its current charge?

33. Are there any changes that you would recommend to the charge of the PRG?

34. Do you think that the process had any other outcomes (positive or negative) in addition to those stated in the PRG charge?

- Yes..... 1
- No..... 2 (*Skip to Q36*)

35. What were the outcomes?

36. Do you see the PRG process as an integral part of NCI planning?

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

37. Please explain (why/why not).

38. Do you feel that the PRG process has influenced NCI priority setting?

Yes..... 1

No..... 2

39. Please explain (why/why not).

40. Do you have any suggestions regarding how the PRG process might be better integrated into overall NCI priority setting?

41. Do you feel that the PRG process has made a difference in the priority setting for [SITE] research?

Yes..... 1

No..... 2

42. Please explain (why/why not).

Thank you

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**Interview Topic Guide
– Roundtable Participants –**

Final Version

- I'd like to start by asking about your involvement in the [SITE] Roundtable. Can you tell me what you were asked to do, or tell me in which Breakouts you participated? [SEE LIST]

- Did you think you had a good understanding of the PRG charge in terms of ...[INSERT a – d BELOW]

IF NO: Please explain why not.

Component of charge	Yes	No	If no, why not?
a. Identifying and prioritizing research opportunities and needs.....	1	2	
b. Describing the scientific resources (e.g., infrastructure) needed to address the priorities	1	2	
c. Preparing a written report.....	1	2	
d. Discussing a plan of action with NCI to ensure that priority areas are well addressed	1	2	

3. I'd like to ask a few questions about NCI-supplied materials you may have reviewed for your role in the [SITE] PRG Roundtable.

A. First, were you able to review the...[INSERT a – d BELOW]

B. IF YES: How useful was [INSERT a – d BELOW]? Would you say very useful (1), somewhat useful (2), not too useful (3), or not at all useful (4)?

C. IF NO: Please explain why not.

	A. Reviewed?		B. If yes, how useful?	C. If no, why not?
	Yes	No		
a. The Roundtable agenda or any other information on how the Roundtable would proceed.....	1	2	1 2 3 4	
b. A Breakout agenda or any other information on how your Breakout would proceed.....	1	2	1 2 3 4	
c. Previous PRG reports	1	2	1 2 3 4	
d. NCI research portfolio for [SITE]	1	2	1 2 3 4	

[INTERVIEWER: PLEASE REVIEW THE RESPONSE TO Q3 PRIOR TO ASKING Q4. IF THE RESPONSE TO Q3 a-d, COL. A = NO, DO NOT ASK CORRESPONDING ITEM IN Q4.]

4. A. Did you access [INSERT a – d BELOW] on line?
 B. For these materials, would you have preferred to receive them in electronic format or hard copies?

NCI supplied material	A. Accessed on line		B. Preferred mode	
	Yes	No	Electronic	Hard copy
a. Roundtable agenda or any other information on how the Roundtable would proceed	1	2	1	2
b. Breakout agenda or any other information on how your Breakout would proceed	1	2	1	2
c. Previous PRG reports	1	2	1	2
d. NCI Research Portfolio for [SITE]	1	2	1	2

5. Besides the information NCI provided, what additional information would have helped you prepare for the Roundtable Meeting?

6. Do you think the Roundtable schedule allowed too much time, just the right amount of time, or too little time to successfully identify priority recommendations?

Too much time 1
 Right amount of time 2 (*Skip to Q8*)
 Too little time..... 3

7. What part of the process was given too (much/little) time in the schedule?

8. Thinking about the people who participated in the meeting, to what extent do you think they had the knowledge, skills, and background needed to develop priority recommendations? Would you say that they were...

- Very well qualified 1 (*Skip to Q10*)
- Moderately well qualified 2
- Somewhat qualified 3
- Not at all qualified 4

9. Why do you think that was the case?

10. Do you think there were any key areas of expertise not represented by the Roundtable participants?

- Yes 1
- No 2 (*Skip Q12*)

11. What areas of expertise do you think were not represented?

12. What effect did the way the PRG leadership and members, Breakout co-chairs, and Roundtable participants interacted have on the PRG process or the resulting recommendations?

[INTERVIEWER: PROBE FOR OPEN DISCUSSIONS, COLLEGIAL EXCHANGE OF IDEAS, INTERDISCIPLINARY COLLABORATION.]

13. Considering the NCI's Office of Science Planning and Assessment (OSPA) support for the Roundtable Meeting, would you rate the OSPA support as...

- Excellent 1 (*Skip to Q15*)
- Good..... 2 (*Skip to Q15*)
- Fair 3
- Poor..... 4
- Don't know 8 (*Skip to Q15*)

14. Please explain why.

15. Did your participation in the Roundtable affect your knowledge, opinions, beliefs, or practices regarding [SITE] research?

- Yes 1
- No..... 2 (*Skip to Q17*)

16. What effect did it have?

17. Did your participation lead you to form any new collaborative or professional relationships with others involved in [SITE] research?

- Yes 1
- No..... 2 (*Skip to Q19*)

18. What new relationships were formed?

19. Since the conclusion of the meeting, have you had an opportunity to read the PRG report on [SITE]?

- Yes 1
- No 2 (*Skip to Q22*)

20. How well did the report reflect the recommendations of the Roundtable participants? Would you say...

- Very well..... 1 (*Skip to Q22*)
- Moderately well 2
- Somewhat well..... 3
- Not at all well..... 4

21. Please explain why.

I now would like to ask a few questions about the specific components of the PRG charge.

22. How well do you think the PRG process identified and prioritized research opportunities and needs to advance disease-specific medical progress? Would you say...

- Very well..... 1 (*Skip to Q24*)
- Moderately well 2
- Somewhat well..... 3
- Not at all well..... 4

23. Please explain why.

24. How well do you think the PRG process described the resources needed to address identified research opportunities and needs? Would you say...

- Very well..... 1 (*Skip to Q26*)
- Moderately well 2
- Somewhat well..... 3
- Not at all well..... 4

25. Please explain why.

26. How well do you think the PRG process functioned to prepare a written report describing the current state of the field, stating the recommendations for research opportunities and needs, and identifying the needed resources? Would you say...

- Very well..... 1 (*Skip to Q28*)
- Moderately well 2
- Somewhat well..... 3
- Not at all well..... 4

27. Please explain why.

28. How well do you think the PRG process incorporated the examination of the NCI Research Portfolio before recommendations were developed and strategies for implementation identified? Would you say...

- Very well..... 1 (*Skip to Q30*)
- Moderately well 2
- Somewhat well..... 3
- Not at all well..... 4

29. Please explain why.

30. How could the PRG process be improved to better fulfill its current charge?

31. Are there any changes that you would recommend to the charge of the PRG?

32. Do you think that the process had any other outcomes (positive or negative) in addition to those stated in the PRG charge?

- Yes 1
- No 2 (*Skip to Q34*)

33. What were the outcomes?

34. Do you see the PRG process as an integral part of NCI planning and priority setting?

Yes 1

No..... 2

35. Please explain (why/why not).

36. Do you have any suggestions regarding how the PRG process might be better integrated into overall NCI priority setting?

37. Do you feel that the PRG process has made a difference in setting priorities for [SITE] research?

Yes 1

No..... 2

38. Please explain (why/why not).

Thank you

Form Approved
O.M.B. NO.: 0925-0046
Expiration Date: 08/31/03

Office of Science Planning and Assessment

Office of Communications

Interview Topic Guide

–NCI Executive Committee–

1. Are the following components of the charge to the PRG appropriate?

Component of charge	Yes	No	If no, why not?
a. Identifying and prioritizing disease-specific research opportunities and needs	1	2	
b. Describing the scientific resources (e.g., infrastructure) needed to address the priority recommendations.....	1	2	
c. Preparing a written report	1	2	
d. Discussing a plan of action with NCI to ensure that priority areas are well addressed.....	1	2	

2. Are the PRGs a valuable way to receive input from the research and advocacy communities to assist NCI in setting a research agenda?

- Yes 1 (*Skip to Q4*)
- No 2

3. Please explain why.

4. How well do you think the PRG process identified and prioritized research opportunities and needs to advance disease-specific medical progress? Would you say...

- Very well 1
- Moderately well..... 2
- Somewhat well 3
- Not at all well 4

5. Please explain why.

6. How well do you think the PRG process described the resources needed to address identified research opportunities and needs? Would you say...

- Very well 1
- Moderately well 2
- Somewhat well 3
- Not at all well 4

7. Please explain why.

8. How well do you think the PRG process functioned to prepare a written report describing the current state of the field, stating the recommendations for research opportunities and needs, and identifying the needed resources? Would you say...

- Very well 1
- Moderately well 2
- Somewhat well 3
- Not at all well 4

9. If somewhat to not at all well, please explain.

10. How well do you think the PRG process incorporated the examination of the NCI research portfolio before recommendations were developed and strategies for implementation identified? Would you say...

- Very well 1
- Moderately well 2
- Somewhat well 3
- Not at all well 4
- Don't know 5

11. If somewhat to not at all well, please explain.

12. How could the PRG process be improved to better address its current charge?

13. Are there any changes that you would recommend to the charge of the PRG?

I would like to ask you a few questions to get your feedback about how well you were kept informed by each of the following groups during the PRG process.

14. How well did the Office of Science Planning and Assessment (OSPA) keep you informed? Would you say...

- Very well 1
- Moderately well 2
- Somewhat well 3
- Not at all well 4

15. How well did your representatives at the Roundtables keep you informed? Would you say...

- Very well 1
- Moderately well 2
- Somewhat well 3
- Not at all well 4

16. How well did your representatives on Working Groups keep you informed? Would you say...

- Very well 1
- Moderately well 2
- Somewhat well 3
- Not at all well 4

17. Was there any additional information you would have found helpful? If so, what?

Please respond to the following questions based on the PRG recommendations you reviewed.

18. Were the recommendations helpful to your division/office in developing initiatives to address disease-specific research gaps and needs?

Very helpful	1
Moderately helpful	2
Somewhat helpful	3
Not at all helpful	4
Don't know	5

19. Were the recommendations helpful to your division/office in getting approval for initiatives addressing research gaps and needs?

Very helpful	1
Moderately helpful	2
Somewhat helpful	3
Not at all helpful	4
Don't know	5

20. Overall do you believe the reports provide valuable information that is useful to your division/office and the field? Would you say...

Very helpful	1
Moderately helpful	2
Somewhat helpful	3
Not at all helpful	4
Don't know	5

21. Do you have further comments or explanations about PRG recommendations you reviewed?

22. Did the PRG reports affect your knowledge, opinions, beliefs, or practices regarding disease-specific research?

Yes	1
No	2

23. What effect did they have?

24. What would improve the usefulness of the PRG reports?

25. Do you feel that the PRG process has influenced NCI priority setting?

Yes 1 (*Skip to Q27*)
No 2

26. Please explain (why/why not).

27. Do you have any suggestions regarding how the PRG process might be better integrated into overall NCI priority setting?

28. Do you feel that the PRG process has made a difference in the priority setting for disease-specific cancer research?

Yes 1
No 2

29. Please explain (why/why not).

30. Do you think that the process had any outcomes (positive or negative) other than those stated in the PRG charge?

Yes 1
No 2

31. If yes, what were the outcomes?

Thank you

APPENDIX C

INTRODUCTORY TELEPHONE SCRIPT

SCRIPT FOR TELEPHONE INTERVIEWERS

Hello, my name is _____ and I'm calling from Westat on behalf of the National Cancer Institute. Recently, NCI sent an email message to you regarding an interview that we would like to conduct. The interview will focus on the SITE Progress Review Group activities that you participated in during YEAR. Today, I'd just like to schedule a time for the interview that would be convenient for you. The interview will last about 1 hour; a member from our project team will (CALL/VISIT) at the time you choose.

We hope to complete all interviews within the next few weeks. When would be a convenient time? Please tell me the day and time.

DAY _____

TIME: _____ AM / PM

I would also like to confirm the telephone number where we should contact you. Is NUMBER the best number to reach you?

RECORD BEST NUMBER

Thank you for your help with this evaluation.

APPENDIX D

SUPPLEMENTAL TABLES

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Table D-1.—Review of the list of potential PRG members and its usefulness, by PRG

Category	N ¹	Reviewed list		Usefulness ²					
				Very		Somewhat		Not too or not at all	
		Number	Percent	Number	Percent	Number	Percent	Number	Percent
PRG Leadership.....	29	28	97	20	71	6	21	2	7
PRG									
Breast Cancer.....	3	2	67	0	0	2	100	0	0
Prostate Cancer.....	3	3	100	3	100	0	0	0	0
Colorectal Cancer.....	3	3	100	2	67	1	33	0	0
Brain Tumor.....	3	3	100	2	67	1	33	0	0
Pancreatic Cancer.....	2	2	100	1	50	1	50	0	0
Leukemia, Lymphoma, and Myeloma.....	4	4	100	3	75	0	0	1	25
Lung Cancer.....	3	3	100	1	33	1	33	1	33
Gynecologic Cancers.....	3	3	100	3	100	0	0	0	0
Kidney and Bladder Cancers.....	2	2	100	2	100	0	0	0	0
Stomach and Esophageal Cancers.....	3	3	100	3	100	0	0	0	0

¹Data were not obtained for one case.

²Percentages are based on the number of respondents who reviewed the list.

NOTE: All percentages have been rounded, and totals may not sum to 100 percent.

Table D-2.—Actual and preferred method of reviewing the list of potential PRG members, by PRG

Category	Actual method					Preferred method				
	N ¹	On-line		Hardcopy		N ²	On-line		Hardcopy	
		Number	Percent	Number	Percent		Number	Percent	Number	Percent
PRG Leadership.....	27	15	56	12	44	18	15	83	3	17
PRG										
Breast Cancer.....	2	0	0	2	100	1	1	100	0	0
Prostate Cancer.....	3	1	33	2	67	2	1	50	1	50
Colorectal Cancer.....	2	1	50	1	50	2	1	50	1	50
Brain Tumor.....	3	2	67	1	33	2	2	100	0	0
Pancreatic Cancer ³	2	0	0	2	100	—	—	—	—	—
Leukemia, Lymphoma, and Myeloma.....	4	1	25	3	75	3	2	67	1	33
Lung Cancer.....	3	2	67	1	33	2	2	100	0	0
Gynecologic Cancers.....	3	3	100	0	0	2	2	100	0	0
Kidney and Bladder Cancers.....	2	2	100	0	0	2	2	100	0	0
Stomach and Esophageal Cancers.....	3	3	100	0	0	2	2	100	0	0

¹Data were not obtained for one case.

²Data were not obtained for 10 cases where respondents did not express a preference, the question or response options remained unclear to the respondent even after elaboration by the interviewer, or because of interviewer error.

³Although eligible to respond, none of the Pancreatic Cancer PRG leaders reported a preference.

NOTE: Percentages are based on the number of respondents who answered the question. All percentages have been rounded, and totals may not sum to 100 percent.

Table D-3.—Review of the breakout plan¹ and its usefulness, by group and by PRG

Category	N ²	Reviewed plan		Usefulness ³					
				Very		Somewhat		Not too or not at all	
		Number	Percent	Number	Percent	Number	Percent	Number	Percent
Overall	85	65	76	23	38	32	52	6	10
Group									
PRG Membership.....	26	20	77	6	30	13	65	1	5
Roundtable Participants	59	45	76	17	41	19	46	5	12
PRG⁴									
Brain Tumor.....	13	10	77	4	40	4	40	2	20
Pancreatic Cancer.....	11	8	73	2	29	4	57	1	14
Leukemia, Lymphoma, and Myeloma.....	12	8	67	2	33	4	67	0	0
Lung Cancer.....	13	9	69	3	38	5	63	0	0
Gynecologic Cancers	12	11	92	5	45	6	55	0	0
Kidney and Bladder Cancers.....	11	10	91	6	60	2	20	2	20
Stomach and Esophageal Cancers.....	13	9	69	1	11	7	78	1	11

¹PRG members were asked about guidance materials and being a breakout co-chair. Roundtable participants were asked about a breakout agenda. Both groups were asked about “any other information on how your breakout would proceed.”

²Data were not obtained for 13 cases where respondents did not express a preference.

³Percentages are based on the number of respondents who answered the question. Data were not obtained for four cases.

⁴PRG members and roundtable participants from the Breast, Prostate, and Colorectal Cancer PRGs were not eligible to participate in the evaluation.

NOTE: All percentages have been rounded, and totals may not sum to 100 percent.

Table D-4.—Actual and preferred method of reviewing the breakout plan,¹ by group and by PRG

Category	Actual method ²					Preferred method ²				
	N ³	On-line		Hardcopy		N ⁴	On-line		Hardcopy	
		Number	Percent	Number	Percent		Number	Percent	Number	Percent
Overall	49	27	55	22	45	51	31	61	20	39
Group										
PRG Membership.....	16	9	56	7	44	16	12	75	4	25
Roundtable Participants	33	18	55	15	45	35	19	54	16	46
PRG⁵										
Brain Tumor.....	9	5	56	4	44	10	5	50	5	50
Pancreatic Cancer.....	6	4	67	2	33	7	4	57	3	43
Leukemia, Lymphoma, and Myeloma.....	5	2	40	3	60	5	3	60	2	40
Lung Cancer.....	8	4	50	4	50	7	3	43	4	57
Gynecologic Cancers	7	3	43	4	57	7	3	43	4	57
Kidney and Bladder Cancers.....	6	3	50	3	50	7	5	71	2	29
Stomach and Esophageal Cancers.....	8	6	75	2	25	8	8	100	0	0

¹PRG members were asked about guidance materials and being a breakout co-chair. Roundtable participants were asked about a breakout agenda. Both groups were asked about “any other information on how your breakout would proceed.”

²Percentages are based on the number of respondents who answered the question.

³Data were not obtained for 16 cases where respondents did not remember if they had reviewed the material or because of interviewer error.

⁴Data were not obtained for 14 cases because the question or response options remained unclear to the respondent even after elaboration by the interviewer, or because of interviewer error.

⁵PRG members and roundtable participants from the Breast, Prostate, and Colorectal Cancer PRGs were not eligible to participate in the evaluation.

NOTE: All percentages have been rounded, and totals may not sum to 100 percent.

Table D-5.—Review of the roundtable plan¹ and its usefulness, by group and by PRG

Category	N ²	Reviewed plan		Usefulness ³					
				Very		Somewhat		Not too or not at all	
		Number	Percent	Number	Percent	Number	Percent	Number	Percent
Overall	85	66	78	25	41	32	52	4	7
Group									
PRG Membership.....	24	12	50	5	45	6	55	0	0
Roundtable Participants	61	54	89	20	40	26	52	4	8
PRG⁴									
Brain Tumor.....	13	11	85	3	30	6	60	1	10
Pancreatic Cancer.....	10	9	90	4	50	3	38	1	13
Leukemia, Lymphoma, and Myeloma.....	10	6	60	4	80	0	0	1	20
Lung Cancer.....	13	11	85	5	50	5	50	0	0
Gynecologic Cancers	13	8	62	4	50	4	50	0	0
Kidney and Bladder Cancers.....	12	11	92	4	40	5	50	1	10
Stomach and Esophageal Cancers	14	10	71	1	10	9	90	0	0

¹Roundtable participants were asked about the roundtable agenda. Roundtable participants and PRG members were asked about “any other information on how the roundtable would proceed.”

²Data were not obtained for 13 cases where respondents did not remember if they had reviewed the material.

³Percentages are based on the number of respondents who answered the question. Data were missing for five cases.

⁴PRG members and roundtable participants from the Breast, Prostate, and Colorectal Cancer PRGs were not eligible to participate in the evaluation.

NOTE: All percentages have been rounded, and totals may not sum to 100 percent.

Table D-6.—Actual and preferred method of reviewing the roundtable plan, by group and by PRG

Category	Actual method ¹					Preferred method ¹				
	N ²	On-line		Hardcopy		N ³	On-line		Hardcopy	
		Number	Percent	Number	Percent		Number	Percent	Number	Percent
Overall	55	31	56	24	44	52	35	67	17	33
Group										
PRG Membership.....	9	5	56	4	44	9	8	89	1	11
Roundtable Participants	46	26	57	20	44	43	27	63	16	37
PRG⁴										
Brain Tumor.....	9	4	44	5	56	10	6	60	4	40
Pancreatic Cancer.....	7	3	43	4	57	8	5	63	3	38
Leukemia, Lymphoma, and Myeloma.....	6	4	67	2	33	4	3	75	1	25
Lung Cancer.....	9	5	56	4	44	9	4	44	5	56
Gynecologic Cancers	6	3	50	3	50	4	2	50	2	50
Kidney and Bladder Cancers.....	8	5	63	3	38	7	6	86	1	14
Stomach and Esophageal Cancers.....	10	7	70	3	30	10	9	90	1	10

¹Percentages are based on the number of respondents who answered the question.

²Data were not obtained for 11 cases where respondents did not remember if they had reviewed the material.

³Data were not obtained for 14 cases because the question or response options remained unclear to the respondent even after elaboration by the interviewer.

⁴PRG members and roundtable participants from the Breast, Prostate, and Colorectal Cancer PRGs were not eligible to participate in the evaluation.

NOTE: All percentages have been rounded, and totals may not sum to 100 percent.

Table D-7.—Review of the roundtable and breakout agendas from previous PRGs and their usefulness, by group and by PRG

Category	N ¹	Reviewed agendas		Usefulness ²					
				Very		Somewhat		Not too or not at all	
		Number	Percent	Number	Percent	Number	Percent	Number	Percent
Overall	51	44	86	24	55	17	39	3	7
Group									
PRG Leadership	24	22	92	15	68	5	23	2	9
PRG Membership	27	22	81	9	41	12	55	1	5
PRG³									
Colorectal Cancer	3	3	100	1	33	2	67	0	0
Brain Tumor	7	6	86	2	33	3	50	1	17
Pancreatic Cancer	5	4	80	3	75	0	0	1	25
Leukemia, Lymphoma, and Myeloma	7	6	86	3	50	2	33	1	17
Lung Cancer	7	6	86	4	67	2	33	0	0
Gynecologic Cancers	7	6	86	5	83	1	17	0	0
Kidney and Bladder Cancers	8	7	88	3	43	4	57	0	0
Stomach and Esophageal Cancers	7	6	86	3	50	3	50	0	0

¹Data were not obtained for five cases.

²Percentages are based on the number of respondents who reviewed the agendas.

³Since the Breast and Prostate Cancer PRGs were the first convened, roundtable and breakout agendas from previous PRGs were not available. Therefore, PRG leaders from these groups were not asked these questions. PRG members from these groups were not eligible to participate in the evaluation.

NOTE: All percentages have been rounded, and totals may not sum to 100 percent.

Table D-8.—Actual and preferred method of reviewing the roundtable and breakout agendas from previous PRGs, by group and by PRG

Category	Actual method ¹					Preferred method ¹				
	N ²	On-line		Hardcopy		N ³	On-line		Hardcopy	
		Number	Percent	Number	Percent		Number	Percent	Number	Percent
Overall	40	20	50	20	50	38	28	74	10	26
Group										
PRG Leadership	21	10	48	11	52	17	13	76	4	24
PRG Membership.....	19	10	53	9	47	21	15	71	6	29
PRG⁴										
Colorectal Cancer.....	2	1	50	1	50	2	1	50	1	50
Brain Tumor.....	6	3	50	3	50	5	5	100	0	0
Pancreatic Cancer.....	4	2	50	2	50	2	2	100	0	0
Leukemia, Lymphoma, and Myeloma.....	6	1	17	5	83	6	2	33	4	67
Lung Cancer.....	6	2	33	4	67	5	3	60	2	40
Gynecologic Cancers	5	3	60	2	40	6	3	50	3	50
Kidney and Bladder Cancers.....	5	3	60	2	40	6	6	100	0	0
Stomach and Esophageal Cancers	6	5	83	1	17	6	6	100	0	0

¹Percentages are based on the number of respondents who answered the question.

²Data were not obtained for four cases.

³Data were not obtained for six cases because the question or response options remained unclear to the respondent even after elaboration by the interviewer.

⁴Since the Breast and Prostate Cancer PRGs were the first convened, roundtable and breakout agendas from previous PRGs were not available. Therefore, PRG leaders from these groups were not asked these questions. PRG members from these groups were not eligible to participate in the evaluation.

NOTE: All percentages have been rounded, and totals may not sum to 100 percent.

Table D-9.—Review of the NCI research portfolio and its usefulness, by group and by PRG

Category	N ¹	Reviewed portfolio		Usefulness ²					
				Very		Somewhat		Not too or not at all	
		Number	Percent	Number	Percent	Number	Percent	Number	Percent
Overall	118	98	83	41	42	37	38	19	20
Group									
PRG Leadership	30	30	100	11	37	13	43	6	20
PRG Membership	32	31	97	13	42	11	35	7	23
Roundtable Participants	56	37	66	17	47	13	36	6	17
PRG									
Breast, Prostate, and Colorectal Cancers ³	9	9	100	5	56	1	11	3	33
Brain Tumor	18	13	72	5	38	5	38	3	23
Pancreatic Cancer	13	11	85	4	36	5	45	2	18
Leukemia, Lymphoma, and Myeloma	16	13	81	4	33	6	50	2	17
Lung Cancer	15	13	87	6	46	3	23	4	31
Gynecologic Cancers	17	15	88	7	47	5	33	3	20
Kidney and Bladder Cancers	14	12	86	5	42	6	50	1	8
Stomach and Esophageal Cancers	16	12	75	5	42	6	50	1	8

¹Data were not obtained for 10 cases where respondents did not remember if they had reviewed the material.

²Percentages are based on the number of respondents who answered the question. Data were not obtained for one case.

³Responses from the leaders of these PRGs have been combined due to small sample sizes.

NOTE: All percentages have been rounded, and totals may not sum to 100 percent.

Table D-10.—Actual and preferred method of reviewing the NCI research portfolio, by group and by PRG

Category	Actual method ¹					Preferred method ¹				
	N ²	On-line		Hardcopy		N ³	On-line		Hardcopy	
		Number	Percent	Number	Percent		Number	Percent	Number	Percent
Overall	81	43	53	38	47	76	52	68	24	32
Group										
PRG Leadership	28	15	54	13	46	24	18	75	6	25
PRG Membership	23	14	61	9	39	26	18	69	8	31
Roundtable Participants	30	14	47	16	53	26	16	62	10	38
PRG										
Breast, Prostate, and Colorectal Cancers ⁴	8	4	50	4	50	6	4	67	2	33
Brain Tumor	10	6	60	4	40	11	8	73	3	27
Pancreatic Cancer	10	5	50	5	50	8	7	88	1	13
Leukemia, Lymphoma, and Myeloma	11	3	27	8	73	9	5	56	4	44
Lung Cancer	11	6	55	5	45	12	6	50	6	50
Gynecologic Cancers	10	5	50	5	50	10	5	50	5	50
Kidney and Bladder Cancers	10	6	60	4	40	10	8	80	2	20
Stomach and Esophageal Cancers	11	8	73	3	27	10	9	90	1	10

¹ Percentages are based on the number of respondents who answered the question.

²Data were not obtained for 17 cases where respondents did not remember if they had reviewed the material.

³Data were not obtained for 22 cases because the question or response options remained unclear to the respondent even after elaboration by the interviewer, or because of interviewer error.

⁴Responses from the leaders of these PRGs have been combined due to small sample sizes.

NOTE: All percentages have been rounded, and totals may not sum to 100 percent.

Table D-11.—Review of the list of current site-relevant initiatives and its usefulness, by group and by PRG

Category	N ¹	Reviewed list		Usefulness ²					
				Very		Somewhat		Not too or not at all	
		Number	Percent	Number	Percent	Number	Percent	Number	Percent
Overall	56	50	89	24	49	18	37	7	14
Group									
PRG Leadership	27	25	93	13	52	8	32	4	16
PRG Membership	29	25	86	11	46	10	42	3	13
PRG									
Breast, Prostate, and Colorectal Cancers ³	8	7	88	4	57	2	29	1	14
Brain Tumor	8	7	88	3	50	3	50	0	0
Pancreatic Cancer	7	7	100	3	43	3	43	1	14
Leukemia, Lymphoma, and Myeloma	8	7	88	1	14	5	71	1	14
Lung Cancer	5	5	100	1	20	1	20	3	60
Gynecologic Cancers	7	6	86	5	83	0	0	1	17
Kidney and Bladder Cancers	6	5	83	3	60	2	40	0	0
Stomach and Esophageal Cancers	7	6	86	4	67	2	33	0	0

¹Data were not obtained for six cases where respondents did not remember if they had reviewed the material.

²Percentages are based on the number of respondents who answered the question. Data were not obtained for one case.

³Responses from the leaders of these PRGs have been combined due to small sample sizes.

NOTE: All percentages have been rounded, and totals may not sum to 100 percent.

Table D-12.—Actual and preferred method of reviewing the list of current site-relevant initiatives, by group and by PRG

Category	Actual method ¹					Preferred method ¹				
	N ²	On-line		Hardcopy		N ³	On-line		Hardcopy	
		Number	Percent	Number	Percent		Number	Percent	Number	Percent
Overall	43	24	56	19	44	39	29	74	10	26
Group										
PRG Leadership.....	22	11	50	11	50	18	13	72	5	28
PRG Membership	21	13	62	8	38	21	16	76	5	24
PRG										
Breast, Prostate, and Colorectal Cancers ⁴	6	5	83	1	17	6	5	83	1	17
Brain Tumor	6	2	33	4	67	3	3	100	0	0
Pancreatic Cancer	6	3	50	3	50	5	4	80	1	20
Leukemia, Lymphoma, and Myeloma	6	1	17	5	83	6	3	50	3	50
Lung Cancer	5	2	40	3	60	4	2	50	2	50
Gynecologic Cancers	4	2	50	2	50	5	3	60	2	40
Kidney and Bladder Cancers	4	3	75	1	25	5	5	100	0	0
Stomach and Esophageal Cancers.....	6	6	100	0	0	5	4	80	1	20

¹Percentages are based on the number of respondents who answered the question.

²Data were not obtained for seven cases where respondents did not remember if they had reviewed the material.

³Data were not obtained for 11 cases where respondents did not express a preference or because of interviewer error.

⁴Responses from the leaders of these PRGs have been combined due to small sample sizes.

NOTE: All percentages have been rounded, and totals may not sum to 100 percent.

Table D-13.—Review of previous PRG reports and their usefulness, by group and by PRG

Category	N ¹	Reviewed reports		Usefulness ²					
				Very		Somewhat		Not too or not at all	
		Number	Percent	Number	Percent	Number	Percent	Number	Percent
Overall	114	85	75	53	63	30	36	1	1
Group									
PRG Leadership.....	24	24	100	18	75	6	25	0	0
PRG Membership	29	28	97	15	54	13	46	0	0
Roundtable Participants	61	33	54	20	63	11	34	1	3
PRG³									
Colorectal Cancer	3	3	100	3	100	0	0	0	0
Brain Tumor	16	10	63	6	60	4	40	0	0
Pancreatic Cancer	13	9	69	6	67	3	33	0	0
Leukemia, Lymphoma, and Myeloma	17	12	71	8	67	4	33	0	0
Lung Cancer	17	13	76	7	54	6	46	0	0
Gynecologic Cancers	17	14	82	8	57	5	36	1	7
Kidney and Bladder Cancers	16	14	88	9	69	4	31	0	0
Stomach and Esophageal Cancers.....	15	10	67	6	60	4	40	0	0

¹Data were not obtained for eight cases where respondents did not remember if they had reviewed the material.

²Percentages are based on the number of respondents who answered the question. Data were not obtained for one case.

³Since the Breast and Prostate Cancer PRGs were the first convened, previous PRG reports were not available. Therefore, respondents from these PRGs were not asked these questions.

NOTE: All percentages have been rounded, and totals may not sum to 100 percent.

Table D-14.—Actual and preferred method of reviewing previous PRG reports, by group and by PRG

Category	Actual method ¹					Preferred method ¹				
	N ²	On-line		Hardcopy		N ³	On-line		Hardcopy	
		Number	Percent	Number	Percent		Number	Percent	Number	Percent
Overall	71	42	59	29	41	65	41	63	24	37
Group										
PRG Leadership.....	21	12	57	9	43	19	12	63	7	37
PRG Membership	23	13	57	10	43	23	15	65	8	35
Roundtable Participants	27	17	63	10	37	23	14	61	9	39
PRG⁴										
Colorectal Cancer	2	2	100	0	0	2	1	50	1	50
Brain Tumor	8	5	63	3	38	9	4	44	5	56
Pancreatic Cancer	9	4	44	5	56	5	5	100	0	0
Leukemia, Lymphoma, and Myeloma	11	2	18	9	82	8	3	38	5	63
Lung Cancer	12	9	75	3	25	12	8	67	4	33
Gynecologic Cancers	9	5	56	4	44	10	5	50	5	50
Kidney and Bladder Cancers	10	8	80	2	20	11	8	73	3	27
Stomach and Esophageal Cancers.....	10	7	70	3	30	8	7	88	1	13

¹Percentages are based on the number of respondents who answered the question.

²Data were not obtained for 14 cases where respondents did not remember if they had reviewed the material or because of interviewer error.

³Data were not obtained for 20 cases where respondents did not express a preference, the question or response options remained unclear to the respondent even after elaboration by the interviewer, or because of interviewer error.

⁴Since the Breast and Prostate Cancer PRGs were the first convened, previous PRG reports were not available. Therefore, respondents from these PRGs were not asked these questions.

NOTE: All percentages have been rounded, and totals may not sum to 100 percent.

Table D-15.—Review of guidance materials and their usefulness, by group and by PRG

Category	N ¹	Reviewed materials		Usefulness ²					
				Very		Somewhat		Not too or not at all	
		Number	Percent	Number	Percent	Number	Percent	Number	Percent
Overall	39	32	82	13	42	13	42	5	16
Group									
PRG Leadership	23	19	83	8	42	6	32	5	26
PRG Membership	16	13	81	5	42	7	58	0	0
PRG³									
Breast, Prostate, and Colorectal Cancers ⁴	9	6	67	1	17	3	50	2	33
Brain Tumor	7	6	86	4	67	2	33	0	0
Pancreatic Cancer	5	5	100	0	0	4	100	0	0
Leukemia, Lymphoma, and Myeloma	7	6	86	3	50	1	17	2	33
Lung Cancer	6	4	67	2	50	1	25	1	25
Gynecologic Cancers	5	5	100	3	60	2	40	0	0

¹Data were not obtained for seven cases where respondents did not remember if they had reviewed the material.

²Percentages are based on the number of respondents who answered the question. Data were not obtained for one case.

³Since the Kidney and Bladder Cancers and Stomach and Esophageal Cancers PRGs had not completed this stage of the process at the time of this evaluation, PRG leaders and members from these groups were not asked these questions.

⁴Responses from the leaders of these PRGs have been combined due to small sample sizes.

NOTE: All percentages have been rounded, and totals may not sum to 100 percent.

Table D-16.—Actual and preferred method of reviewing guidance materials, by group and by PRG

Category	Actual method ¹					Preferred method ¹				
	N ²	On-line		Hardcopy		N ³	On-line		Hardcopy	
		Number	Percent	Number	Percent		Number	Percent	Number	Percent
Overall	25	10	40	15	60	21	11	52	10	48
Group										
PRG Leadership	16	5	31	11	69	11	6	55	5	45
PRG Membership	9	5	56	4	44	10	5	50	5	50
PRG⁴										
Breast, Prostate, and Colorectal Cancers ⁵	4	1	25	3	75	2	1	50	1	50
Brain Tumor	5	3	60	2	40	5	4	80	1	20
Pancreatic Cancer	2	1	50	1	50	1	1	100	0	0
Leukemia, Lymphoma, and Myeloma	6	1	17	5	83	5	2	40	3	60
Lung Cancer	4	2	50	2	50	4	2	50	2	50
Gynecologic Cancers	4	2	50	2	50	4	1	25	3	75

¹Percentages are based on the number of respondents who answered the question.

²Data were not obtained for seven cases where respondents did not remember if they had reviewed the material.

³Data were not obtained for 11 cases where respondents did not express a preference or because of interviewer error.

⁴Since the Kidney and Bladder Cancers and Stomach and Esophageal Cancers PRGs had not completed this stage of the process at the time of this evaluation, PRG leaders and members from these groups were not asked these questions.

⁵Responses from the leaders of these PRGs have been combined due to small sample sizes. Although eligible to respond, none of the Breast Cancer and Prostate Cancer PRG respondents reported a preference.

NOTE: All percentages have been rounded, and totals may not sum to 100 percent.

Table D-17.—Review of conference calls and summaries to prepare for the roundtable meeting and their usefulness, by PRG

Category	N ¹	Reviewed materials		Usefulness ²					
				Very		Somewhat		Not too or not at all	
		Number	Percent	Number	Percent	Number	Percent	Number	Percent
PRG Leadership	27	23	85	19	83	3	13	1	4
PRG									
Breast Cancer	1	1	100	0	0	1	100	0	0
Prostate Cancer	3	3	100	2	67	1	33	0	0
Colorectal Cancer	3	2	67	2	100	0	0	0	0
Brain Tumor	3	3	100	3	100	0	0	0	0
Pancreatic Cancer	2	2	100	1	50	0	0	1	50
Leukemia, Lymphoma, and Myeloma	4	2	50	1	50	1	50	0	0
Lung Cancer	3	2	67	2	100	0	0	0	0
Gynecologic Cancers	2	2	100	2	100	0	0	0	0
Kidney and Bladder Cancers	3	3	100	3	100	0	0	0	0
Stomach and Esophageal Cancers	3	3	100	3	100	0	0	0	0

¹Data were not obtained for three cases.

²Percentages are based on the number of respondents who reviewed the materials.

NOTE: All percentages have been rounded, and totals may not sum to 100 percent.

Table D-18.—Actual and preferred method of reviewing conference calls and summaries to prepare for the roundtable meeting, by PRG

Category	Actual method ¹					Preferred method ¹				
	N ²	On-line		Hardcopy		N ³	On-line		Hardcopy	
		Number	Percent	Number	Percent		Number	Percent	Number	Percent
PRG Leadership	20	13	65	7	35	18	16	89	2	11
PRG										
Breast Cancer	1	0	0	1	100	1	0	0	1	100
Prostate Cancer	3	2	67	1	33	2	2	100	0	0
Colorectal Cancer.....	2	1	50	1	50	1	1	100	0	0
Brain Tumor.....	3	3	100	0	0	3	3	100	0	0
Pancreatic Cancer ⁴	1	0	0	1	100	—	—	—	—	—
Leukemia, Lymphoma, and Myeloma.....	2	0	0	2	100	2	2	100	0	0
Lung Cancer.....	2	2	100	0	0	1	1	100	0	0
Gynecologic Cancers ⁵	—	—	—	—	—	2	2	100	0	0
Kidney and Bladder Cancers.....	3	2	67	1	33	3	2	67	1	33
Stomach and Esophageal Cancers.....	3	3	100	0	0	3	3	100	0	0

¹Percentages are based on the number of respondents who answered the question.

²Data were not obtained for three cases because of interviewer error.

³Data were not obtained for five cases where respondents did not express a preference.

⁴Although eligible to respond, none of the Pancreatic Cancer PRG leaders reported a preference.

⁵Although eligible to respond, none of the Gynecologic Cancers PRG leaders identified the method used to review the calls and summaries.

NOTE: All percentages have been rounded, and totals may not sum to 100 percent.