
**NATIONAL CANCER INSTITUTE
DIRECTOR'S CONSUMER LIAISON GROUP**

2003 SURVEY OF CANCER ADVOCACY ORGANIZATIONS

September 4, 2003

Submitted to:

**NATIONAL CANCER INSTITUTE AND THE
NCI DIRECTOR'S CONSUMER LIAISON GROUP**

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INTRODUCTION

The National Cancer Institute (NCI) contracted with ORC Macro, an independent market research and consulting firm, to conduct a survey of the cancer advocacy community to:

- Collect critical information on advocacy organizations to segment them appropriately and to target outreach accordingly
- Identify the priorities the advocacy community deems most important to improve cancer outcomes
- Measure and track advocacy organizations' perceptions of the Director's Consumer Liaison Group (DCLG)
- Measure and track advocacy organizations' perceptions of selected NCI communication and research activities.

Using quantitative research that was informed from qualitative interviews of select cancer advocates and internal NCI Staff, ORC Macro conducted a web-based survey of 152 cancer advocacy organizations. Between June 10, 2003 and July 23, 2003, ORC Macro received 80 completed surveys. The methodology is further described in the Methodology section of this report.

This report details the findings from the 2003 Survey of Cancer Advocacy Organizations and makes conclusions and recommendations.

CONCLUSIONS

This section summarizes ORC Macro's conclusions based on the findings.

CONCLUSIONS RELATIVE TO THE RESPONDENTS

- **NCI has informed respondents.** Overall, respondents reported being aware of NCI and DCLG—92% reported being either very aware or moderately aware of the NCI activities that advance its mission and 67% of respondents indicated they were aware of either most or some of DCLG activities. These strong levels of awareness indicate the respondents were able to provide informed perspectives relative to the rest of the survey questions.
- **In general, respondents are focused on serving cancer patients and their families.** When asked about the activities of their organization, the two most common responses [respondents could choose two] were education/constituent information (78%) and other services to a constituency such as help in the location of resources (44%). Of the audiences served by the respondents (respondents could choose three), the most common choices were patients (94%), families (70%), and caregivers (50%). When asked to rank the areas for which the organization dedicates resources (research, clinical trials, survivorship, health disparities and communication), most of the individuals surveyed felt that their organization focuses on communication and survivorship.

CONCLUSIONS RELATIVE TO RESPONDENTS' PERCEPTIONS OF NCI

- **NCI is making progress reducing the cancer burden—but there is more work to be done.** NCI received high marks in making overall progress in the fight against cancer. There was strong agreement relative to NCI's achievements in critical areas such as reducing the cancer burden (77% agreement) and making clinical trials available (84%). The cancer advocacy community did not respond as strongly relative to some of the more specific aspects of NCI's work such as NCI's effectiveness in translating research on cancer health disparities into effective community interventions (27%), and NCI's research being appropriately balanced across cancer types (22%).
- **NCI's communications vehicles for the cancer advocacy constituents are thought to be quite useful, however the respondents gave lower marks to how NCI communicates its strategy to the cancer advocacy community.** www.cancer.gov and 1-800-4-CANCER are considered useful resources for their constituents with 85% and 81% agreement on their usefulness, respectively. Lower agreement levels are noted on the statements, "The NCI Bypass Budget document helps my organization understand NCI's research priorities" (54%) and "NCI clearly communicates how it sets its research priorities" (28%). Few respondents indicated that they referred to the Bypass Budget often, and 45% indicated they had never referred to it.
- **Respondents' perceptions of NCI's achievements as described above does not appear tied to their perception of how well NCI has collaborated with the cancer advocacy community in these areas.** Respondents gave NCI relatively high ratings for its collaboration with the cancer advocacy community on communication (44% reporting NCI collaborated extremely well or very well), which also received high ratings for its effectiveness. Respondents provided less favorable ratings for NCI's collaboration relative to clinical trials (29%), although NCI received relatively high ratings for its effectiveness relative to clinical trials. This finding reflects only that they seemed to consider these questions independently.
- **NCI received mixed reviews relative to its collaboration with the cancer advocacy community.** While 35% indicated they feel NCI is collaborating extremely well or very well, nearly half (48%) gave the more lukewarm response of somewhat well. While only 17% indicated that, in general, NCI has not collaborated well with the cancer advocacy community, this perception increased when asked about NCI's collaboration in more specific areas. One notable area is around survivorship—57% of respondents indicated that survivorship is important for their own organization. In terms of collaboration with NCI, only 32% reported that NCI collaborated extremely well or very well.

CONCLUSIONS RELATIVE TO THE FUTURE FOCUS OF THE DCLG

- **Most respondents (54%) felt that helping facilitate better collaboration between NCI and the cancer advocacy community would provide the most value to their organizations.** The next choice, "provide the cancer advocacy community's perspective and recommendations to the Director of NCI" received 21%.

- **Respondents prefer that DCLG work at a strategic level with NCI.** When asked which type of activity would most benefit their constituency, again the respondents provide a clear response—69% of respondents felt that DCLG should work at a strategic level with NCI, rather than monitor or participate in the implementation of NCI's strategy.

DESIRED CHARACTERISTICS OF DCLG MEMBERS

- **Respondents suggested the DCLG members be leaders in their respective organizations and/or communities.** Decision-making ability was often mentioned along with leadership. Other characteristics included being knowledgeable on cancer and issues relative to the cancer advocacy community, as well as having direct knowledge through their own personal experience or the experiences of those near to them.
- **Respondents provided a variety of attributes to describe desired future DCLG members.** Recommended qualities for DCLG members included intelligence and someone who communicates well, is available, and is committed. The DCLG members must represent needs across the population, not just the population served by their organizations.
- **Respondents suggested that members be chosen to represent a diversity of constituent interests.** Most examples provided focused on gender distinctions, demographics, and minorities.

IMPORTANT AREAS ON WHICH DCLG SHOULD FOCUS ITS ACTIVITIES

- **Respondents indicated that it was important that DCLG be involved in all of the activities presented in the survey (research, clinical trials, survivorship, health disparities, communication).** Importance ranged from 89% (extremely important or very important) for survivorship to 79% for communication. Looking at the ratings of extremely important alone, clinical trials, survivorship, and research were perceived as extremely important somewhat more often (64%, 63%, and 61%, respectively) than health disparities and communication (50% and 49%, respectively).
- **Respondents showed more differentiation at the task level.** If respondents indicated that one of the five areas noted above was extremely or very important, they were asked to respond to more specific activities relative to that area. Because so many indicated that all five areas were important, there were relatively high numbers of respondents also responding to the specific activities. Looking at the ranking of extremely important alone, it is sometimes possible to discern some differentiation at the activity level.
 - **Research**—63% of respondents felt that it would be extremely important for the DCLG to help speed the development of promising agents for early translational research. Relatively low importance (39%) was placed on increasing the effectiveness of how NCI communicates its research priorities. This is interesting given that the cancer advocacy community felt that NCI was relatively less effective in this area.

- **Clinical Trials**—Of the two choices provided for clinical trials there appeared a clear preference that the DCLG work to increase the participation of patients in national trials (70% extremely important).
- **Survivorship**—In this area, the responses indicate similar levels of importance for all three activities suggested, follow-up care and monitoring of post treatment survivors (56%), the oversight committee for implementation of NCI's new Survivorship Extraordinary Opportunity (55%), and the quality of life and care of post-treatment cancer survivors and their families (47%). The difficulty in distinguishing between activities may be due to the respondents' views of the importance of the survivorship area as a whole—as mentioned in the previous section, 63% perceived this area as extremely important. Survivorship was also reported as one of the top areas of focus for the organizations themselves.
- **Health Disparities**—This is another area where the respondents seemed to feel that all four activities were relatively equal in importance. Providing input into the development of effective interventions, investigating factors influencing cancer care, improving cancer communication tools, and increasing underserved populations' access to clinical trial all received importance ratings between 52% and 59%.
- **Communication Activities**—Two activities were perceived to be extremely important in this area, identifying optimal methods to communicate to the cancer advocacy community (59%) and identifying unmet information needs (52%).

CONCLUSIONS RELATIVE TO COMMUNICATIONS WITH THE DCLG

- **E-mail, e-mail, e-mail.** This group clearly preferred e-mail to all other communication channels.
- **Interest in DCLG's activities and results.** A review of the open-ended comments shows that many respondents felt a need for more communication from DCLG about its activities and results.

RECOMMENDATIONS

Based on the above findings, ORC Macro makes the following recommendations:

RECOMMENDATIONS FOR NCI

- **Build on the positive.** NCI should use the positive perspective of the cancer advocacy community relative to NCI's achievements in critical areas such as the reduction in the burden of cancer as a platform to the development of stronger, collaborative relationships.
- **NCI must find ways to better communicate its strategy and how it sets priorities to the cancer advocacy community.** Better communications in this area may lead to an increase in the perception that research is appropriately balanced across cancer types and that research funding reflects the research priorities. The Bypass Budget does not appear to

fulfill this communication need, nor does the cancer advocacy community indicate that they want DCLG to focus on this type of initiative. NCI will need to explore other communication channels and strategies.

RECOMMENDATIONS FOR DCLG

- **This survey represents a critical viewpoint in the development of a new strategic direction for the DCLG – but only one viewpoint.** Because the DCLG is an advisory committee that was created to serve the NCI’s need for a more informed and collaborative relationship with the cancer advocacy community, the perspective of NCI must also be included in the development of a new vision for DCLG. ORC Macro recommends that senior members of NCI and the DCLG be involved in the development of recommendations for a new vision for DCLG.

[Note: This recommendation was made and accepted by the DCLG. A workshop has been scheduled on September 24, to develop final recommendations of a new strategic direction for DCLG.]

- **The cancer advocacy community was able to provide direction for the DCLG.** The Future of the DCLG Working Group must use these findings in tandem with their inherent understanding of NCI and other similar organizations operating in this environment to construct a conceptual draft of a new strategic direction for the organization that provides a unique and valuable contribution to NCI and the cancer advocacy community. ORC Macro will be pleased to support the development of such a draft for review by the Future of the DCLG Working Group.
- **Making decisions on where to focus the attention and resources of the DCLG will be difficult.** Clearly, to the advocacy community, all the activities that the DCLG identified as potential areas where DCLG could make a difference are also important to the cancer advocacy community. The DCLG will need to make difficult choices to narrow its efforts to those that can have an impact and are realistic relative to the resources it has available. Again, we recommend that this be done in tandem with senior staff at NCI—to choose those areas where there are the greatest opportunities for impact.
- **Communicate with the cancer advocacy community.** A review of the open-ended comments showed a desire to know more about the workings of the DCLG and the results of its work with NCI. As the DCLG implements its new strategic direction, DCLG should look to communicate more often with this critical audience. Certainly, the DCLG should acknowledge the important role played by the cancer advocacy community in the development of its new strategic direction. Communications should be a two-way street. Although surveys were not a preferred communication channel, a number of respondents volunteered that they appreciated this opportunity to provide their input to NCI.

INTRODUCTION

The National Cancer Institute (NCI) contracted with ORC Macro, an independent market research and consulting firm, to conduct a survey of the cancer advocacy community to

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- Identify the priorities the advocacy community deems most important to improve cancer outcomes
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- Measure and track advocacy organizations' perceptions of selected NCI communication and research activities.

This chapter provides a detailed description of the methodology used to design, administer, and analyze the 2003 NCI/DCLG Survey of Cancer Advocacy Organizations. Specifically, it includes sections on

- Survey design
- Potential respondents
- Data collection
- Profile of respondents
- Data analysis and reporting.

SURVEY DESIGN

During the survey design process, it was decided to conduct the survey under NCI's Generic OMB Clearance for Formative Research. As a result, the original scope and content of the survey was adjusted to fit under the purview of the clearance.

OLA, the NCI Office of Communications (OC), the Future of the DCLG Working Group, and ORC Macro collaborated on the design of the survey instrument through a series of meetings.

For the first step of designing the survey, ORC Macro conducted internal interviews with key NCI staff and members of the DCLG, along with external interviews with select members from advocacy organizations. ORC Macro conducted each of the interviews via telephone. The interviews provided ORC Macro a more cohesive understanding of who the DCLG serves. ORC Macro used the information in these interviews, combined with the results of previous interviews conducted by the DCLG, to design the content of the survey.

Once ORC Macro designed the survey, it was reviewed extensively by NCI and the Future of the DCLG Working Group. Before fielding, ORC Macro conducted a pretest to obtain feedback on the survey's content, clarity, and its software's functionality. The five individuals who pretested the survey were selected by the Future of the DCLG Working Group. ORC Macro provided these individuals with access to the survey and asked them to take the survey. Once the pretesters had

completed the survey, ORC Macro contacted each individual via e-mail to ask the following three questions:

1. Please explain any thoughts or concerns you may have had regarding the functionality of the survey you recently completed for NCI/DCLG. (Were you able to efficiently and effectively complete the survey?)
2. Approximately how long did it take you to actually fill out the survey? (If you had to pause and come back to the survey at a later time, exclude the time you were away.)
3. What were your thoughts regarding questions 15 and 16?

Using the responses to these three questions, ORC Macro worked with OLA and the Future of the DCLG Working Group to make final revisions and finalize the survey.

The final survey included the following four sections:

- Overall Familiarity with NCI
- Future Direction and Activities of the DCLG
- Preferred Communication Methods
- About Your Organization

The Final Survey was approved by the NCI Office of Communications under OMB no. 0925-0046 (Expiration Date: 08/31/03).

POTENTIAL RESPONDENTS

The Office of Liaison Activities maintains a database of approximately 700 cancer advocates, cancer advocacy and professional organizations, and other groups and individuals that have an interest in the work of NCI. OLA adds new organizations to the database based upon their request, referrals from advocates and NCI staff, and research of Web sites and media stories.

OLA provided ORC Macro with a list of approximately 200 cancer advocacy organizations that would be eligible to complete the survey. The DCLG and NCI chose these organizations for the survey from the larger database according to the following criteria:

- Have a national, regional, or statewide cancer focus
- Representative of various diseases and sites
- Representative of adult and childhood cancers
- Representative of African American, American Indian, Hispanic, Asian/Pacific Islander, Gay/Lesbian organizations.

After receiving the list, ORC Macro conducted some additional research to update the contact information for some of the listings. Following this research, ORC Macro and OLA decided that several organizations would be removed because ORC Macro could not obtain sufficient contact information. Also, the DCLG decided to eliminate the listed organizations that were branch offices or chapters of national organizations. The final list included 152 cancer advocacy organizations.

For each of the 152 eligible organizations, ORC Macro attempted to survey the Executive Director or a person with a similar role. Before administering the survey, the NCI Director, Dr. Andrew von Eschenbach, sent a letter addressed to these potential respondents. The message described the goals of the study and asked them to use the opportunity to provide feedback.

DATA COLLECTION

ORC Macro fielded the survey via the Internet from June 10, 2003 to July 23, 2003. ORC Macro used a data collection methodology that included the following three e-mail notifications to all potential respondents from the ORC Macro Project Director:

- An initial notification message
- A first reminder
- A final reminder.

ORC Macro sent the *initial notification* message on June 10, 2003 for Wave 1 to officially announce the fielding of the survey. The message included

- The purpose of the survey
- A request for the respondent's participation
- A statement of the promised anonymity of survey responses
- Detailed instructions for accessing the survey, including the unique login and password for each respondent
- The cut-off date for responses
- A toll-free telephone number and e-mail address to use for technical support
- A telephone number and e-mail address of the NCI contact to be used if the respondent had questions about the nature or the sponsorship of the study.

ORC Macro sent the *first reminder* to nonrespondents on June 17, 2003. This message contained much of the same information as the initial notification message and emphasized the importance of hearing from everyone in the cancer advocacy community.

ORC Macro sent the *final reminder* to nonrespondents on June 23, 2003. This message was much shorter than the previous messages and restated the final cut-off date.

ORC Macro provided technical support for the survey using a designated e-mail address and a toll-free telephone line.

One week after the final reminder message was sent, ORC Macro staff attempted to followup with nonrespondents by telephone. ORC Macro provided respondents with several options for completing the survey, including mail, fax, e-mail, or through the Internet.

ORC Macro terminated the fielding period on July 23, 2003. The survey administration resulted in 80 completed surveys for a response rate of 53%.

ORC Macro guaranteed survey respondents that their individual identities will not be provided to NCI.

A copy of all survey correspondence is included in Appendix 1: Survey Correspondence.

A copy of the survey is included in Appendix 2: Survey Instrument

PROFILE OF RESPONDENTS

The survey included several firmographics questions about the cancer advocacy organization:

- Organization reach (e.g., local, regional/multistate)
- Organizational activities (e.g., policy/legislation)
- Audience served (e.g., patients, families)
- Size of constituent database
- Number of paid staff
- Number of volunteers

The following is the self-reported profile of the 80 respondents who completed the survey.

Scope			Number of Listings	
Local	18%		100 or fewer	5%
Regional/multistate	10%		101-1,000	16%
National	50%		1,001-10,000	33%
International	23%		10,001-50,000	34%
			50,001-100,000	4%
			More than 100,000	5%
Activities*				
Policy/legislation	19%		No database	4%
Education/constituent information	78%			
Research/research funding	26%		Number of Paid Staff	
Other services to a constituency	44%		0	28%
			1-5	42%
Audience*			6-10	13%
Patients	94%		11-100	13%
Families	70%		More than 100	5%
Caregivers	50%			
Clinicians	19%		Number of Volunteers	
Nurses	3%		0	1%
Researchers	21%		1-5	14%
Pharmaceutical/biotech	4%		6-10	14%
Government/policymakers	13%		11-100	42%
Other	15%		More than 100	29%

* Respondents could choose more than one option

Note that the list of cancer advocacy organizations provided to ORC Macro did not contain the above information, so ORC Macro cannot make any conclusions about how well the respondents represented the diversity of organizations that were eligible for the study.

DATA ANALYSIS AND REPORTING

In this report, ORC Macro presents the results by the following topic areas:

- Awareness and Perceptions of NCI
- NCI Collaboration with the Cancer Advocacy Community
- Awareness of the DCLG
- DCLG Potential Areas of Focus
- Potential Role of the DCLG
- Communication Preferences

In many cases, this report will not follow the order of the survey instrument, but will combine relevant questions under each topic.

This report includes two basic types of statistical analysis:

- **Descriptive Analysis.** ORC Macro calculated the full range of relevant descriptive statistics, including frequency distributions and measures of central tendency (i.e., means, standard errors).
- **Segmentation and Other Cross-Tabulations.** ORC Macro segmented the data by relevant organizational information asked on the survey and reviewed other question-to-question relationships.

Following the discussion of the survey findings in each section, ORC Macro has provided any relevant segment-specific findings in the following display. Since ORC Macro conducted the survey as a “census,” meaning all eligible organizations were given the opportunity to respond, ORC Macro did not pull a sample. Therefore, sampling error and statistical significance do not apply. In this report, ORC Macro performed segment-level analysis using more subjective criteria—singling out segments that seemed to show a relatively high variance from the average based on the size of the variance and the number of respondents in that segment.

Also, note that some types of organizations received very few responses. For example, only eight respondents indicated that their organization was regional/multistate. In such cases, ORC Macro will not report any segment-level findings for the individual segments, but, if appropriate, may group them with other categories (e.g., group local and regional/multistate) for analysis purposes.

Segmentation At-A-Glance
Reach of the organization:
Activity of the organization:
Audience served:
Size of constituency database:
Full-time staff/volunteers:

BACKGROUND

ORC Macro asked respondents about their familiarity with NCI and its activities. ORC Macro asked respondents how aware they are of the mission of NCI, how well they feel NCI has collaborated with the cancer advocacy community in carrying out that mission, and their views on specific aspects of NCI’s work.

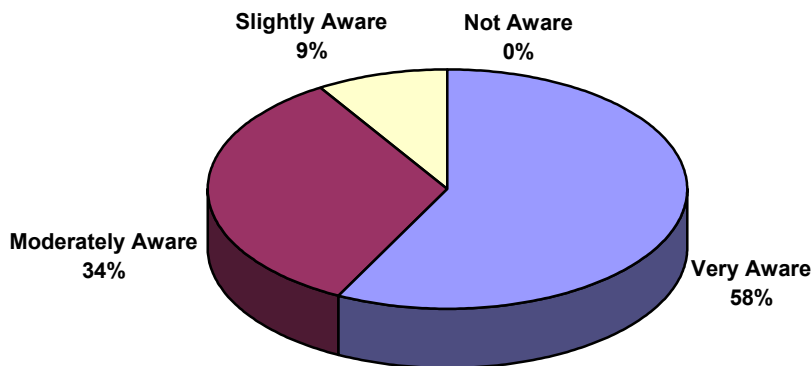
AWARENESS OF NCI ACTIVITIES

After describing the mission of NCI, ORC Macro asked respondents how aware they are of the NCI and the NCI’s activities that advance this mission. ORC Macro provided the following options:

- I am very aware of the NCI activities that advance this mission.
- I am moderately aware of the NCI activities that advance this mission.
- I am slightly aware of the NCI activities that advance this mission.
- I am unaware of the NCI activities that advance this mission.

None of the respondents reported being unaware of NCI’s activities. All 80 respondents surveyed reported being very aware, moderately aware, or slightly aware of NCI’s activities. In fact, 58% of all of the respondents reported being “very aware.”

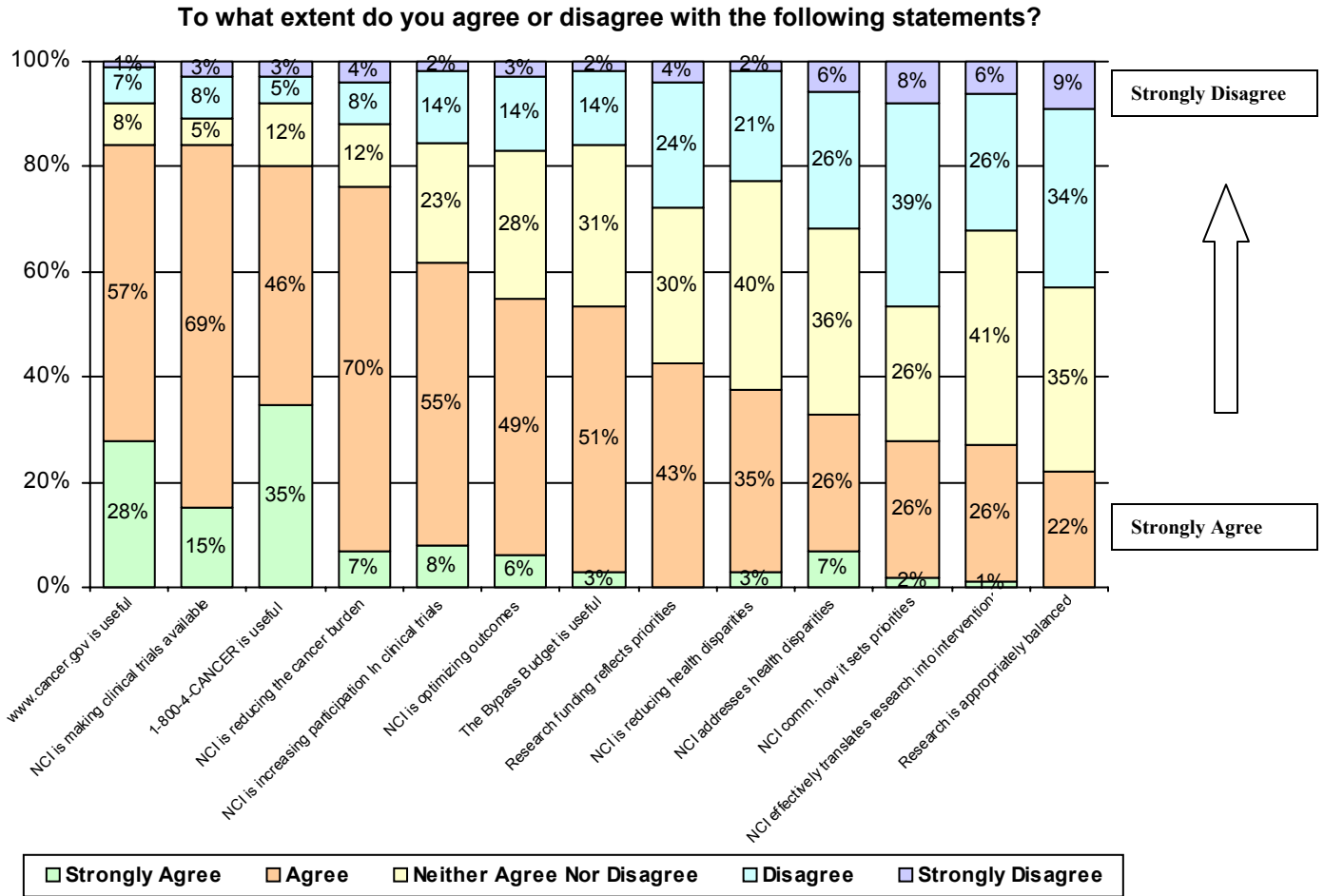
How aware are you of the NCI activities that advance this mission?



PERCEPTIONS OF NCI ACTIVITIES

ORC Macro then asked respondents to rate their agreement with several statements:

- NCI's research funding is appropriately balanced across cancer types.
- NCI's research funding reflects the research priorities identified by advisory committees such as Progress Review Groups.
- NCI clearly communicates how it sets its research priorities.
- NCI is making progress in reducing the cancer burden.
- NCI is having an impact on making clinical trials available to cancer patients.
- NCI is having an impact on increasing participation in (accruals to) cancer clinical trials.
- NCI is having an impact on optimizing outcomes for cancer survivors and their families.
- NCI addresses cancer health disparities appropriately.
- 1-800-4-CANCER is a useful resource for my constituents.
- www.cancer.gov is a useful resource for my constituents.
- The NCI Bypass Budget document helps my organization understand NCI's research priorities.
- NCI is effective in translating research on cancer health disparities into effective community interventions.
- NCI is having an impact reducing cancer health disparities.



More than 80% of the respondents strongly agreed or agreed that NCI is having an impact on making clinical trials available to cancer patients (84% agreement). Respondents also agreed that NCI is making progress in reducing the cancer burden (77%). The two communication statements, www.cancer.gov (85%) and 1-800-4-CANCER (81%) were perceived as useful. The Bypass Budget document was perceived as somewhat less useful (54%).

Respondents in general did not feel that

- NCI research is appropriately balanced (22% agreement).
- NCI is effective in translating research on cancer health disparities into effective community interventions (27% agreement).
- NCI clearly communicates how it sets its research priorities (28% agreement).

Also, disagreement ratings for each of these three statements were among the highest of the series of statements, conveying that it is not that they have no opinion or are neutral about these areas, but that they actively disagree.

Segmentation At-A-Glance

Reach of the organization

- National organizations reported being more aware of NCI's activities.
- International organizations reported somewhat low agreement that NCI's research is balanced across cancer types.
- Compared to international organizations, national organizations agreed more that NCI addresses cancer health disparities appropriately and that NCI has an impact on reducing cancer health disparities.

Audience served

- Organizations that serve caregivers were most likely to agree that NCI is effective in translating research into interventions.

Full-time staff/volunteers

- Organizations with 1 to 5 volunteers seemed to find 1-800-4-CANCER less useful.

BACKGROUND

ORC Macro asked respondents how well NCI has collaborated with the cancer advocacy community. The Future of the DCLG Working Group identified five potential areas of focus for future activities. These were provided to the respondents as follows:

- **Research**—Establish and pursue biomedical research priorities that ultimately lead to improved survival and quality of life.
- **Clinical Trials**—Maximize the effectiveness of NCI’s national clinical trials program.
- **Survivorship**—Reduce the adverse effects of cancer diagnosis and treatment, and optimize outcomes for cancer survivors and their families from the time of diagnosis to the end of life.
- **Health Disparities**—Understand the fundamental causes of health disparities in cancer, develop effective interventions to reduce these disparities, and facilitate their implementation.
- **Communication**—Increase knowledge about, tools for, access to, and use of cancer communications.

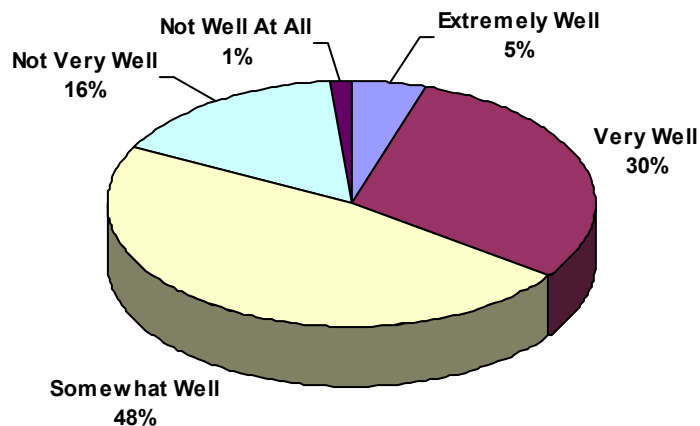
Next, ORC Macro asked respondents to rate NCI’s collaboration for each of the individual areas of focus.

Lastly, ORC Macro asked respondents which activities their organizations were involved in and dedicated resources to.

GENERAL COLLABORATION WITH THE CANCER ADVOCACY COMMUNITY

First, ORC Macro asked respondents how well they feel NCI has collaborated with the cancer advocacy community.

How well has NCI collaborated with the cancer advocacy community?



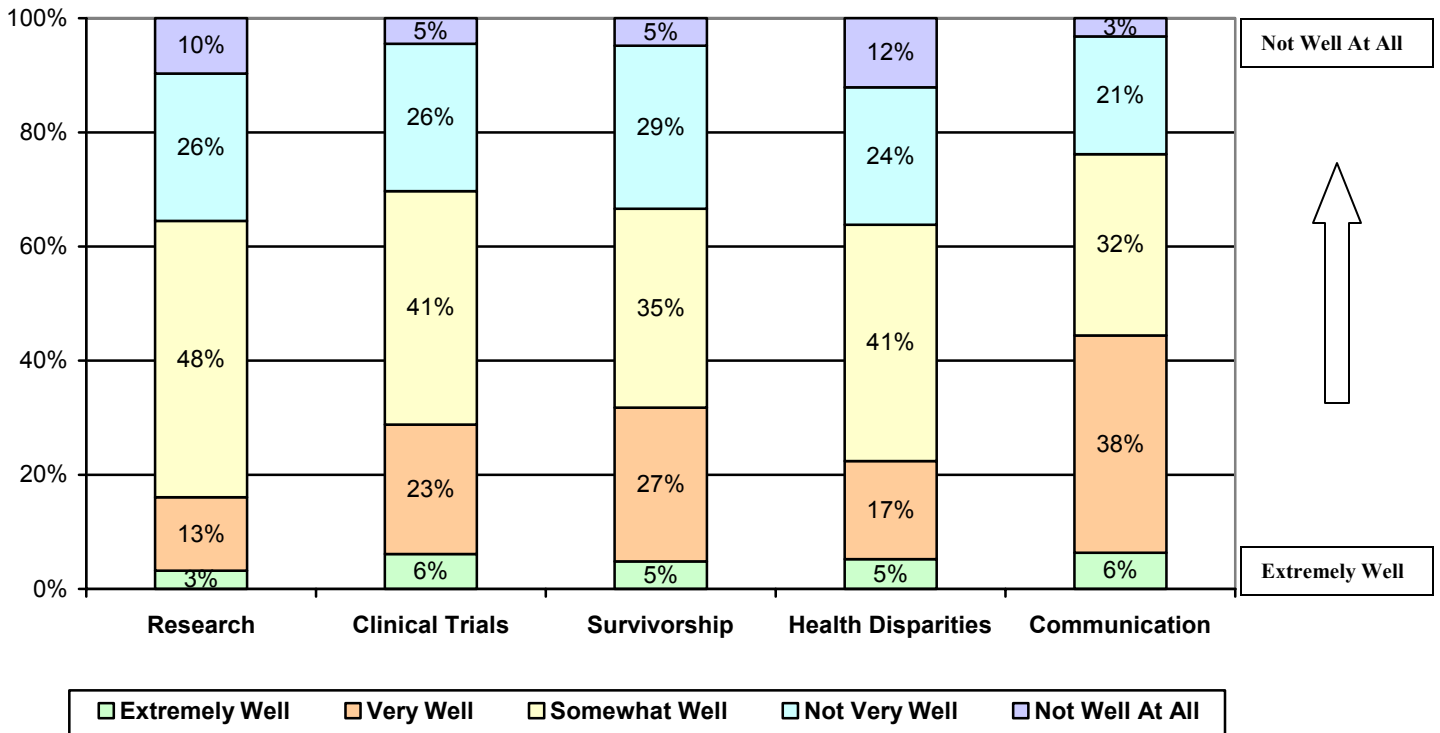
About one third of respondents (35%) indicated that they feel the NCI is collaborating extremely well or very well with the cancer advocacy community. An additional 48%—or about half of all

NCI COLLABORATION WITH CANCER ADVOCACY COMMUNITY

respondents—reported that the NCI collaborates somewhat well with the cancer advocacy community.

COLLABORATION WITH THE CANCER ADVOCACY COMMUNITY ON SPECIFIC ACTIVITIES

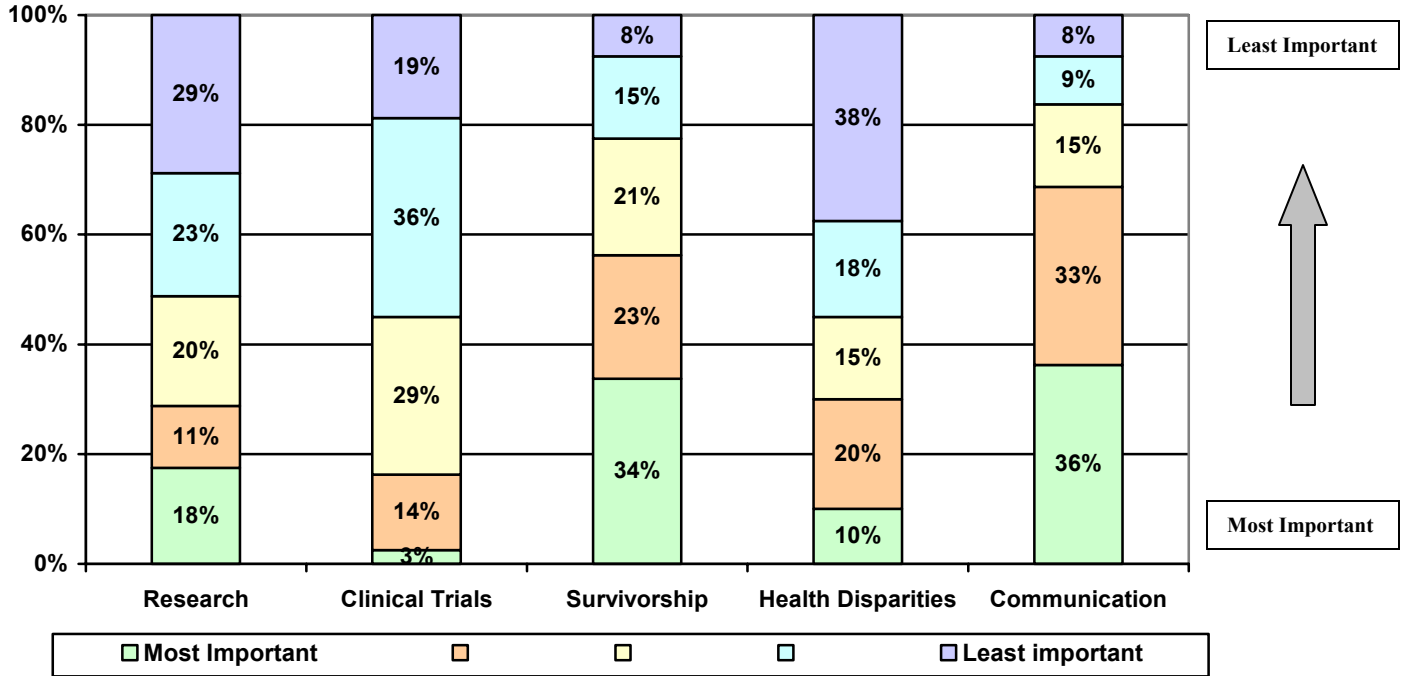
How well has NCI collaborated with the cancer advocacy community on this activity?



The highest percentage of respondents reported that NCI collaborates best on communication, with 44% stating that they collaborate extremely well or very well. In each activity, at least 24% of the respondents reported that NCI does not collaborate well.

AREAS OF INVOLVEMENT

Which of these areas does your organization actively work on and dedicate resources to?



Respondents were asked to rank these five areas in terms of importance to their organization. This question used an anchored scale, with “1” being most important and “5” being least important. Most of the individuals surveyed felt that their organization works on and dedicates resources to survivorship and communication. On the contrary, many respondents were relatively less focused on clinical trials, research, and health disparities.

Segmentation At-A-Glance

Activity of the organization

- Organizations that serve to educate or provide constituent information feel that the NCI has not collaborated well with the cancer advocacy community with regard to research or survivorship.
- Organizations that educate or provide constituent information were most likely to report that NCI collaborates with the cancer advocacy community.

Full-time staff/volunteers

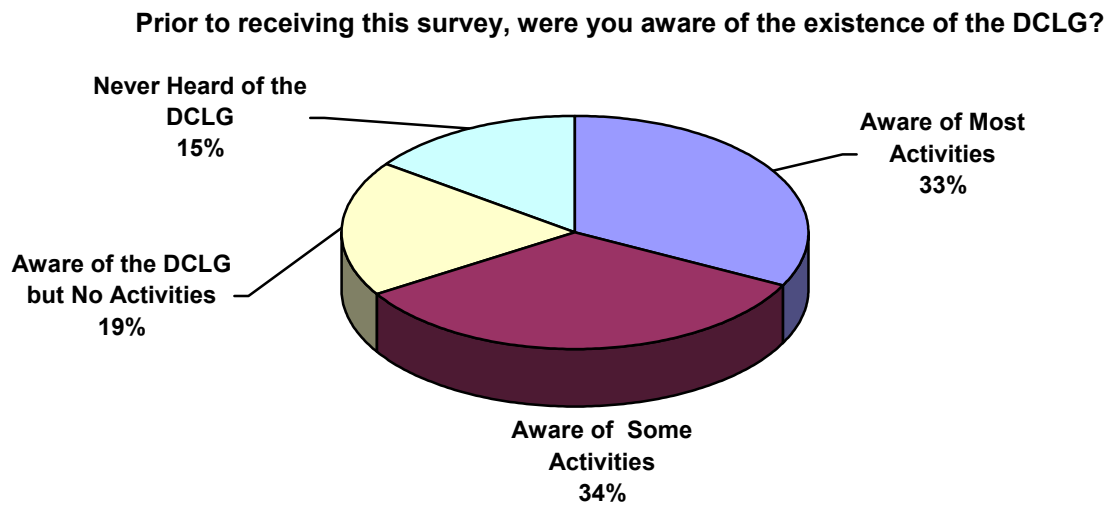
- Organizations that have more than 100 volunteers seem to feel that the NCI does not collaborate well with the cancer advocacy community in survivorship.

BACKGROUND

ORC Macro provided a description of the DCLG and its core functions as outlined in its charter. ORC Macro then asked respondents if, prior to receiving the survey, they were aware of the DCLG and its activities. Respondents could choose from the following options:

- Yes, I was aware of the DCLG and most of its activities.
- Yes, I was aware of the DCLG and some of its activities.
- Yes, I was aware of the DCLG, but was unaware of any specific activities.
- No, I had never heard of the DCLG.

AWARENESS OF THE DCLG



For the most part, respondents were aware of the DCLG. In all, 85% of the respondents reported at least being aware of the DCLG at some level. Further, 67% knew of the DCLG and at least some of its activities. Conversely, 15% of the respondents reported having never heard of the DCLG.

Segmentation At-A-Glance

Reach of the organization

- Prior to the survey, local organizations were least aware of the DCLG.

Activity of the organization

- Compared to other organizations, those that do research or research funding activities were more familiar with the DCLG prior to the survey.

Audience served

- Organizations that serve clinicians seemed less aware of the DCLG prior to the survey.
- Organizations that serve caregivers seemed relatively aware of the DCLG prior to the survey.

Full-time staff/volunteers

- Organizations with fewer volunteers seemed more aware of the DCLG.

BACKGROUND

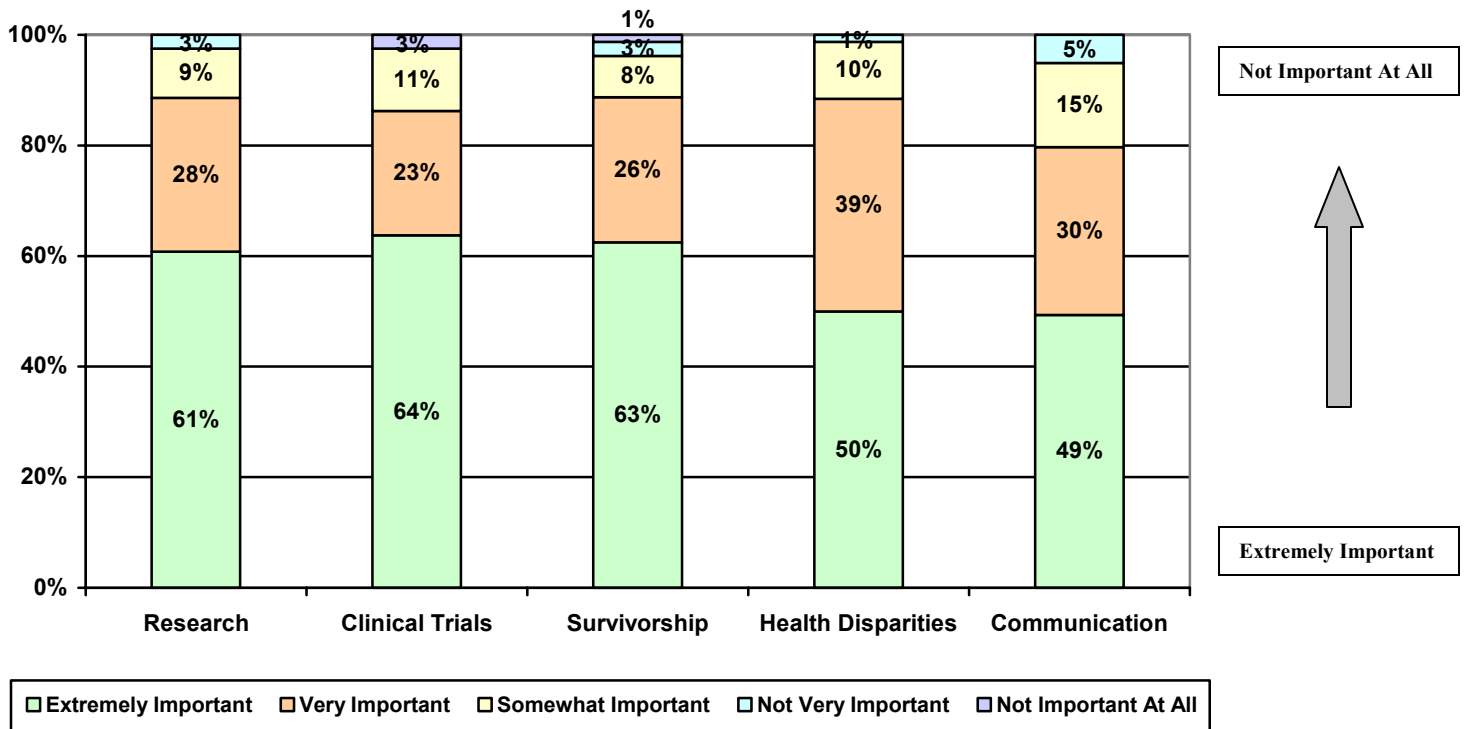
The Future of the DCLG Working Group identified five potential areas of focus for future activities. These were provided to the respondents as follows:

- **Research**—Establish and pursue biomedical research priorities that ultimately lead to improved survival and quality of life.
- **Clinical Trials**—Maximize the effectiveness of NCI’s national clinical trials program.
- **Survivorship**—Reduce the adverse effects of cancer diagnosis and treatment and optimize outcomes for cancer survivors and their families from the time of diagnosis to the end of life.
- **Health Disparities**—Understand the fundamental causes of health disparities in cancer, develop effective interventions to reduce these disparities, and facilitate their implementation.
- **Communication**—Increase knowledge about, tools for, access to, and use of cancer communications.

For each statement, ORC Macro first asked respondents how important it is for the DCLG to be involved in each of these activities and then how well NCI has collaborated with the cancer advocacy community on the activity.

IMPORTANCE OF GENERAL AREAS OF FOCUS

How important is it for the DCLG to be involved in selected activities?

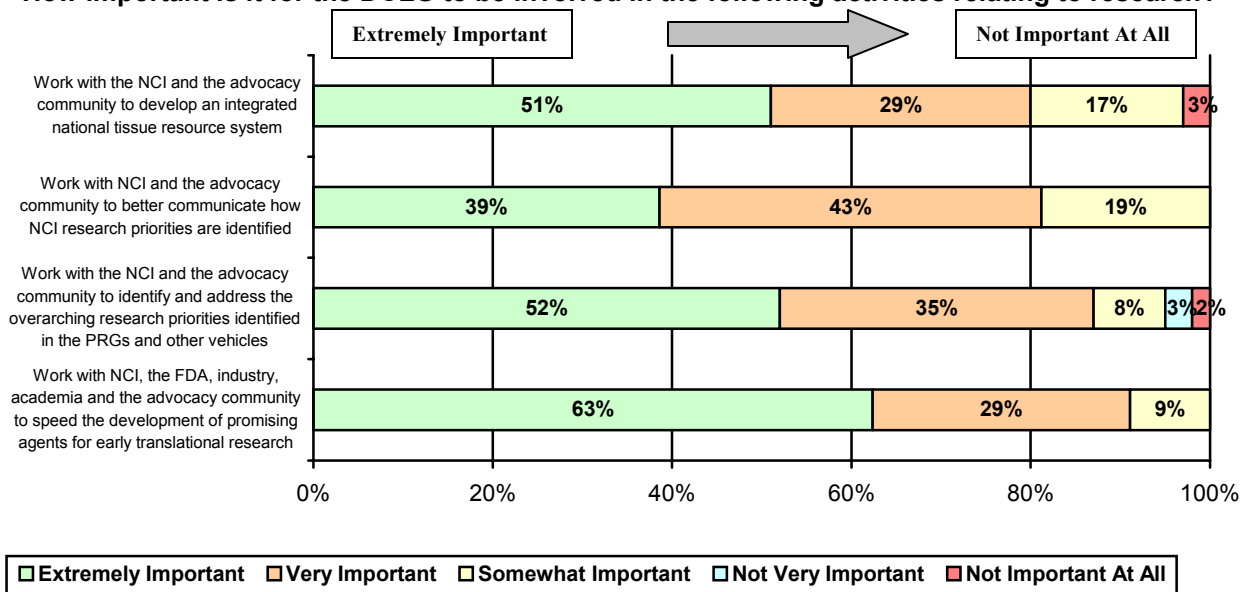


More than 60% of respondents reported that research, clinical trials, and survivorship were extremely important. Nearly all of the respondents seemed to think that each of the potential areas of focus was at least somewhat important.

For each general area that respondents indicated were either extremely important or very important, ORC Macro asked them to rate the importance of several more specific activities that the DCLG might perform.

IMPORTANCE OF RESEARCH ACTIVITIES

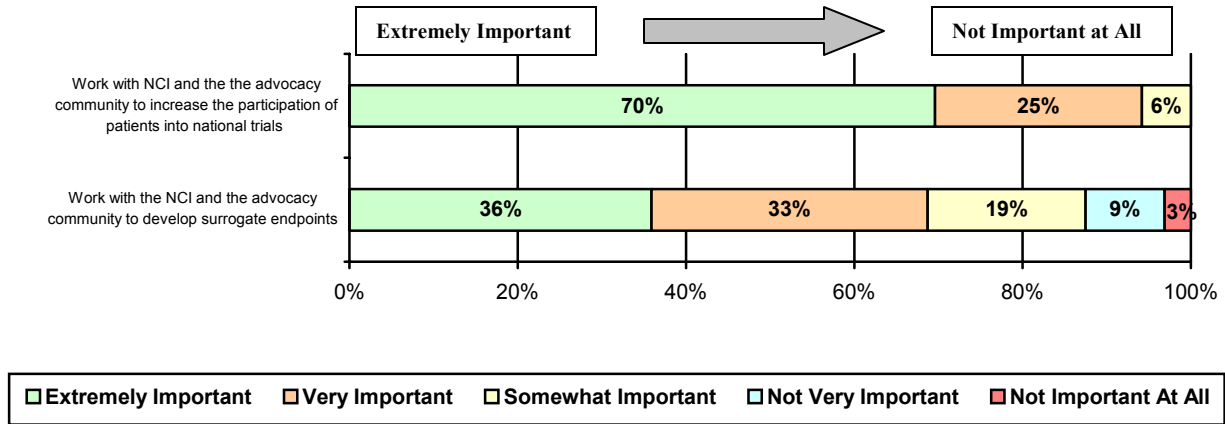
How important is it for the DCLG to be involved in the following activities relating to research?



Of the 70 respondents who reported that research is either a very or extremely important activity for the DCLG to be involved in, 92% indicated that it was most important for the DCLG to work with NCI, the Food and Drug Administration (FDA), industry, academia, and the advocacy community to speed up the development of promising agents for early translational research.

IMPORTANCE OF CLINICAL TRIAL ACTIVITIES

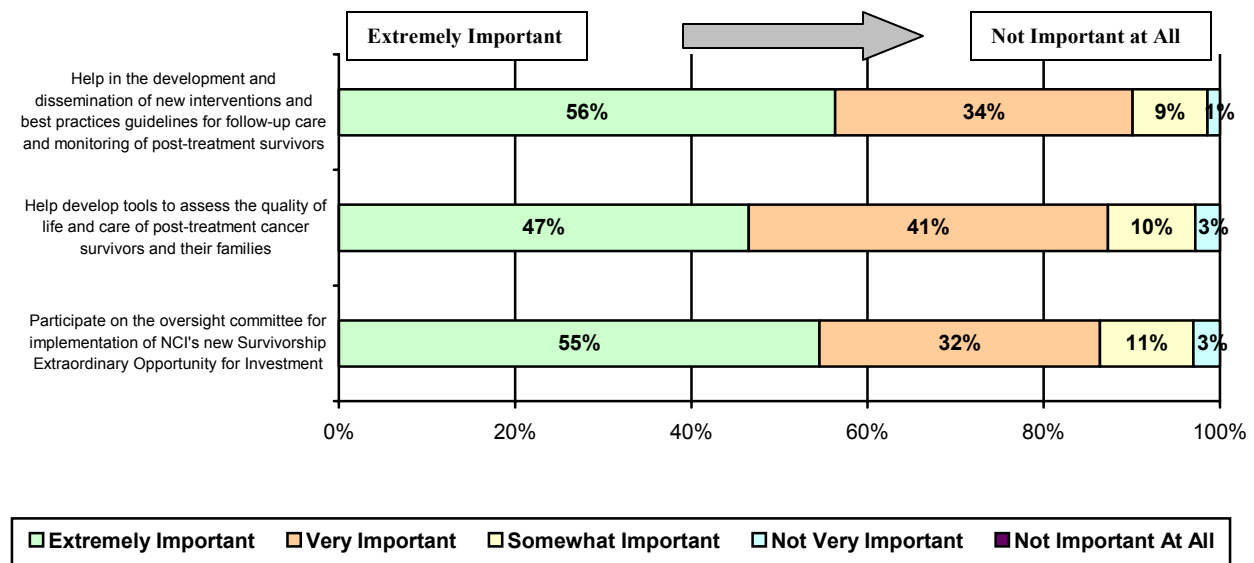
How important is it for the DCLG to be involved in the following activities relating to clinical trials?



Of the 69 respondents who reported that clinical trials are either a very or extremely important activity for the DCLG to be involved in, it is clear that most were interested in the DCLG working with NCI and the advocacy community to increase the participation of patients in national trials (95%).

IMPORTANCE OF SURVIVORSHIP ACTIVITIES

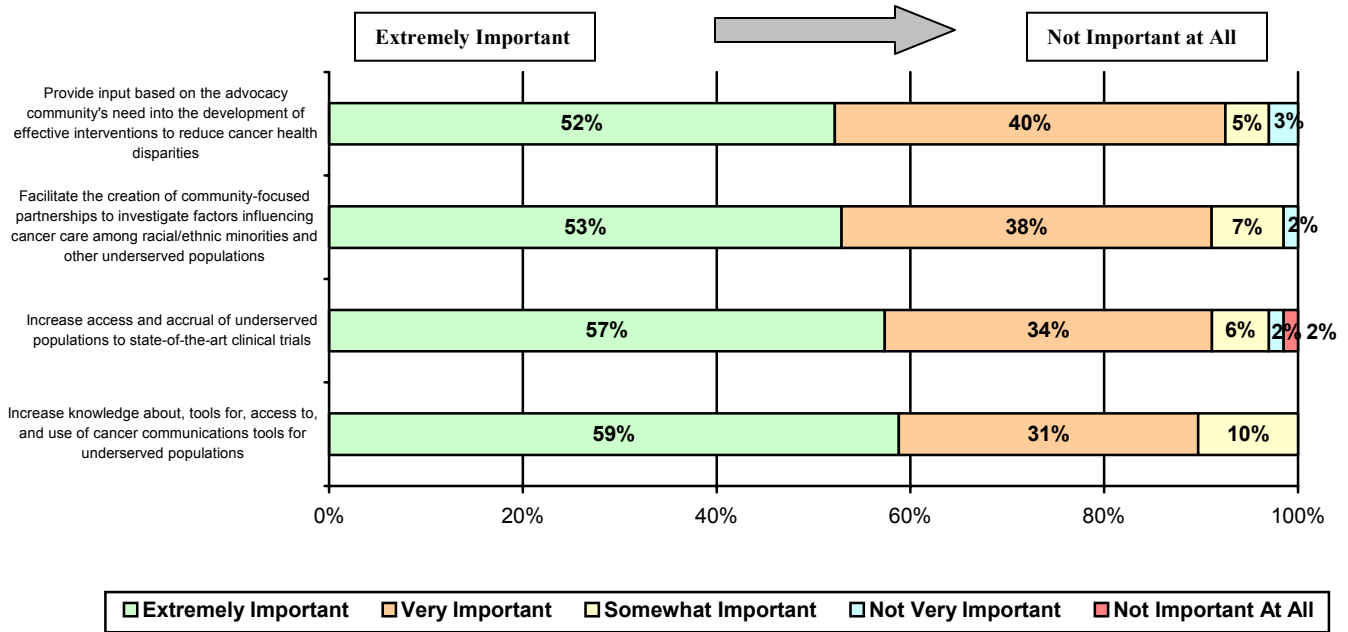
How important is it for the DCLG to be involved in the following activities relating to survivorship?



Of the 71 respondents who reported that survivorship is either a very or extremely important activity for the DCLG to be involved in, 90% indicated that help in the development and dissemination of new interventions and best practices guidelines for followup care and monitoring of posttreatment survivors was important to them. It should be noted that, for each specific activity, at least 87% reported that it was important.

IMPORTANCE OF HEALTH DISPARITIES ACTIVITIES

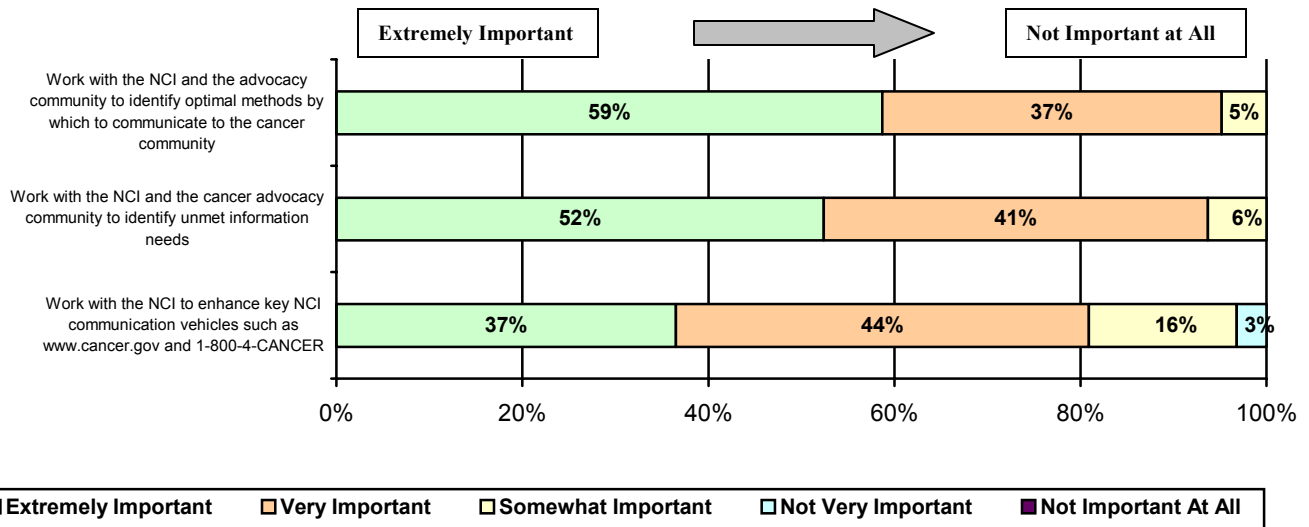
How important is it for the DCLG to be involved in the following activities relating to health disparities?



Of the 69 respondents who reported that health disparities is either a very or extremely important activity for the DCLG to be involved in, all four specific activities received very similar importance ratings (90 to 92% important).

IMPORTANCE OF COMMUNICATION ACTIVITIES

How important is it for the DCLG to be involved in the following activities relating to communication?



Of the 63 respondents who reported that communication is either a very or extremely important activity for the DCLG to be involved in, respondents indicated that they were relatively less interested with the DCLG working with NCI to enhance communication vehicles such as www.cancer.gov and 1-800-4-CANCER than they were in identifying unmet information needs and optimal methods to communicate to the cancer community.

Segmentation At-A-Glance

Activity of your organization

- Organizations that do research or work toward more funding for research feel that it is important for the DCLG to be involved in research and health disparities.
- Organizations that serve researchers or research funding reported that it is extremely important for the DCLG to work with the NCI and the advocacy community to increase patients' participation in national trials.

Full-time staff/volunteers

- Organizations that have more than 100 volunteers report that it is less important for the DCLG to be involved in clinical trials compared with smaller organizations.

BACKGROUND

ORC Macro asked several questions to determine what the role of the DCLG should be and then asked who should serve on the DCLG.

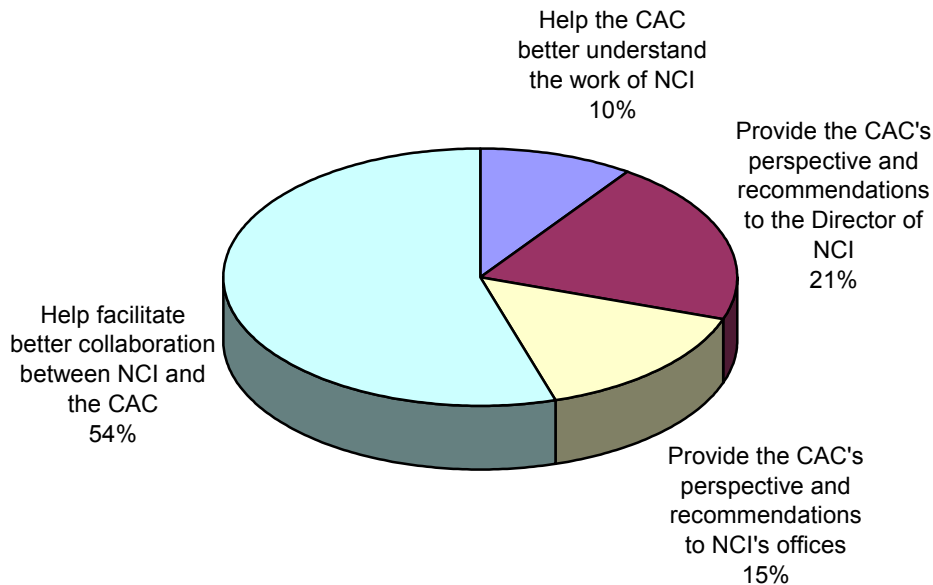
MOST VALUABLE POTENTIAL DCLG ACTIVITIES

ORC Macro presented the respondent with a list of four different ways that the DCLG could provide value to NCI and the cancer advocacy community (CAC). The respondents were asked to choose which option would provide their organization with the most value and which would provide their organization with the least value. The options were as follows:

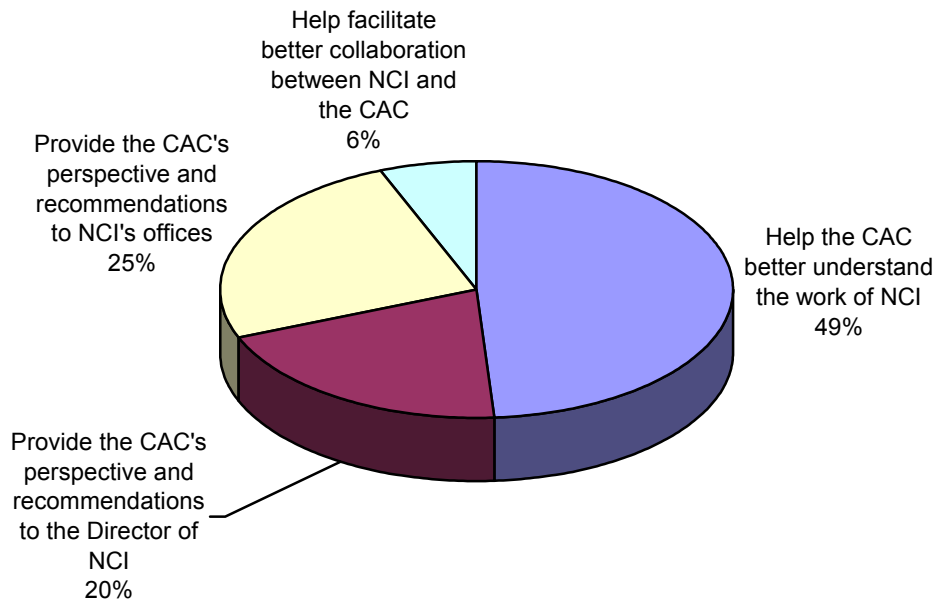
- Help the (CAC) better understand the work of NCI
- Provide the (CAC)'s perspective and recommendations to the Director of NCI
- Provide the (CAC)'s perspective and recommendations to NCI's Offices and Centers
- Help facilitate better collaboration between NCI and the cancer advocacy community.

ORC Macro also gave respondents the opportunity to provide input as to what would provide their organization with the most value. Those were recorded as open-ended comments.

Which activity would provide you with the most value?



Which activity would provide you with the least value?



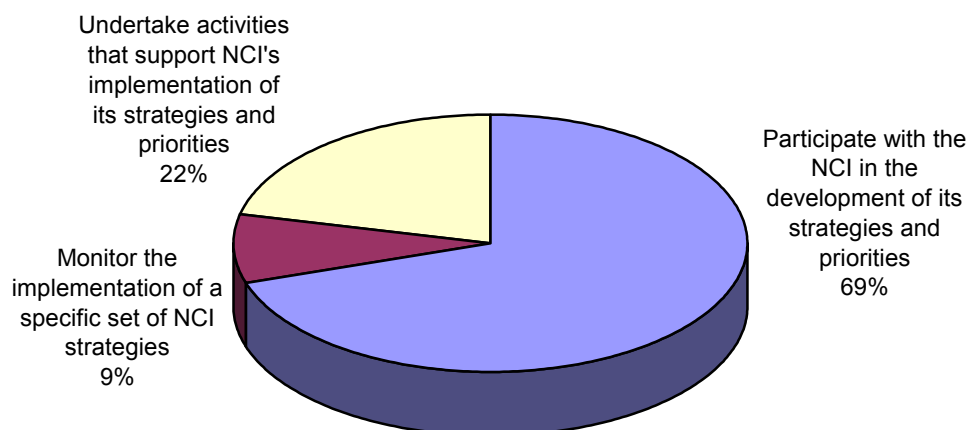
Responses to this question were clear. Most respondents indicated that it would be most valuable if the DCLG would help facilitate better collaboration between NCI and the cancer advocacy community. It was also clear that having the DCLG help the cancer advocacy community better understand the work of NCI would provide the least value of the options provided.

MOST VALUABLE BENEFITS TO CONSTITUENCIES

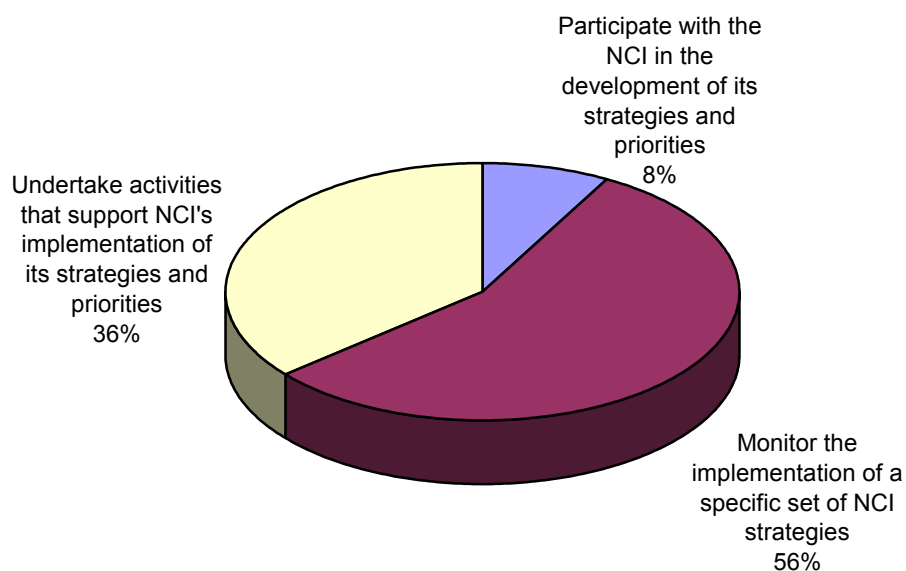
ORC Macro also gave respondents a list of three activities and asked which would most benefit their constituencies most and which least. The list of activities was as follows:

- Participate with NCI in the development of its strategies and priorities
- Monitor the implementation of a specific set of NCI strategies
- Undertake activities that support NCI's implementation of its strategies and priorities.

Which activity would most benefit your constituency?



Which activity would least benefit your constituency?



Again, respondents' reactions were relatively clear. Respondents felt that having the DCLG participate with NCI in the development of its strategies and priorities would most benefit their constituency. Conversely, they felt that having the DCLG monitor the implementation of a specific set of NCI strategies would least benefit their constituency.

From the open end comments received, it is clear that cancer advocates want the DCLG to be more involved in communication. Respondents suggested the DCLG hold town meetings, forums, on-line meetings, conferences, phone calls, or distribute e-mails, literature, or a newsletter.

In general, respondents felt that “there needs to be a better method of communication between advocacy groups and the DCLG.” However it is important to note here that the communication must occur both ways. Some respondents indicated that they have perceived the DCLG to be a “one-way street for NCI to get its messages out without soliciting or accepting input from its members.”

Also mentioned a few times was that the DCLG needs to better communicate to the advocacy community what the DCLG does and who they serve. Some of the comments indicated that respondents had been in the field for years before learning who the DCLG was and what it does. One respondent simply stated that the DCLG needs to “better publicize what they do and the impact they are having”.

Respondents also reported that the DCLG could help in identifying issues that NCI should focus its resources on. They mentioned issues such as survivorship, anticancer drug discovery, long-term effects of treatment, long-term survivors, and quality of life.

All of the comments received regarding how the DCLG could provide value to NCI and the cancer advocacy can be found in Appendix 3: Open-Ended Comments.

WHO SHOULD SERVE ON THE DCLG?

ORC Macro asked respondents what types of individuals should serve on the DCLG and how they would describe these individuals in terms of their role, background, and other important attributes. The full list of responses can be found in Appendix 3: Open-Ended Responses.

There seemed to be three main criteria for those who should serve on the DCLG. First, those who serve should be leaders in their respective organization, field, or community. These individuals should be “decision makers within their respective organizations.” They should be proactive rather than reactive.

Second, those who serve should represent a diverse group of individuals. The group should represent a broad spectrum of demographics such as low-income, low education, different races, different language proficiencies, etc. It was suggested to include individuals who span a broad range of knowledge areas such as children’s, women’s, and men’s cancer issues.

Third, those who serve should be knowledgeable of cancer and the issues affecting the cancer community. It is important that those who serve have experience and knowledge in cancer or at least the health field in general. It was reported that members should be able to “grasp scientific and medical terminology.”

It was mentioned by several respondents that the individuals should have either a personal or family history of cancer or should be cancer survivors themselves. This way, “they would truly represent the needs of the patient community without the bias of a clinician or researcher.” Individuals should “serve with a heart, not just the intellect.”

Qualities that these individuals should exhibit included intelligence, dedication, availability, and passion. They should be well educated, articulate, cooperative, committed, well informed, and should have the ability to see all sides of any particular issue. They should be able to identify

common needs across the population as a whole, not simply focusing on the population that their organization serves. Individuals that serve must have the ability to “put personal concerns and agendas aside and work on focused issues that benefit the larger population”.

Segmentation At-A-Glance

Full-time staff/volunteers:

- Organizations with 1 to 5 volunteers reported that the DCLG would provide the most value to them by helping the cancer advocacy community to better understand the work of the NCI.
- For the most part, organizations with more than 5 volunteers would like the DCLG to facilitate better collaboration between the NCI and the cancer advocacy community.

BACKGROUND

ORC Macro asked respondents how they would prefer that the DCLG communicate with them. The list of options was as follows:

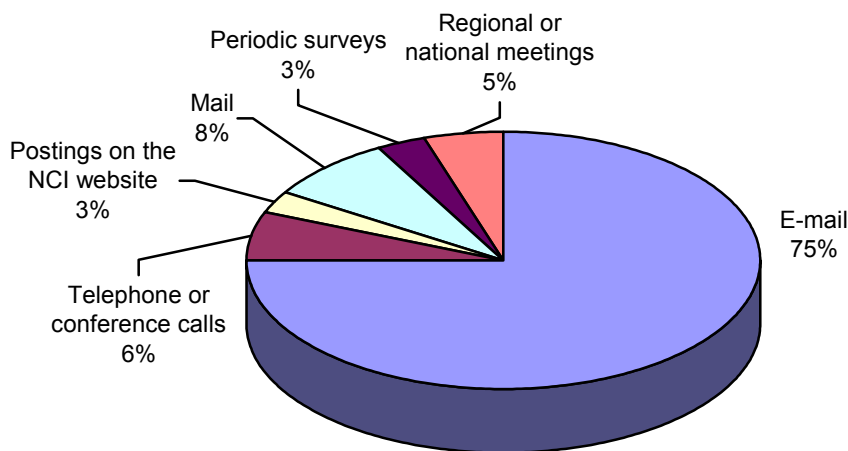
- ◆ E-mail
- ◆ Telephone or conference calls
- ◆ Postings on NCI’s Website
- ◆ Mail
- ◆ Periodic surveys
- ◆ Regional or national meetings.

Respondents were asked to select which method would be their first choice and which their second. Respondents were also allowed to provide an open end response.

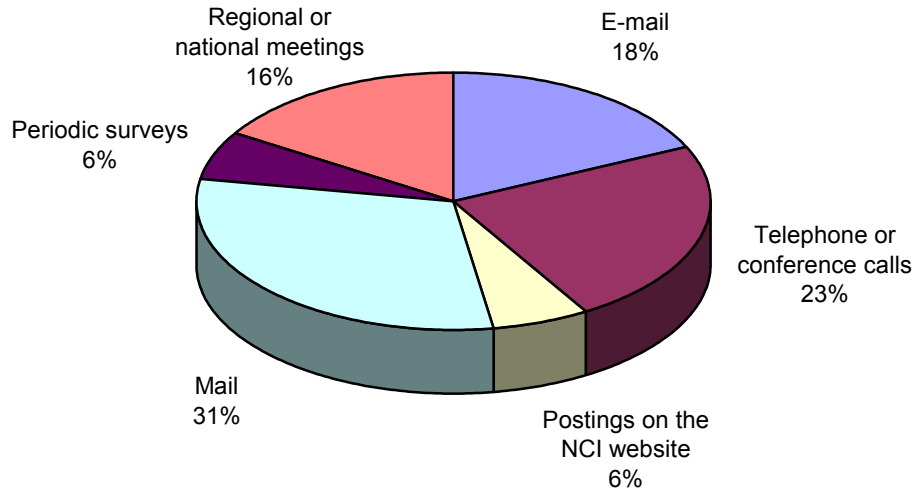
ORC Macro also asked respondents how often they referred to NCI’s Bypass Budget document.

PREFERRED COMMUNICATION METHOD

How would you prefer that the DCLG communicate with you? (First choice)



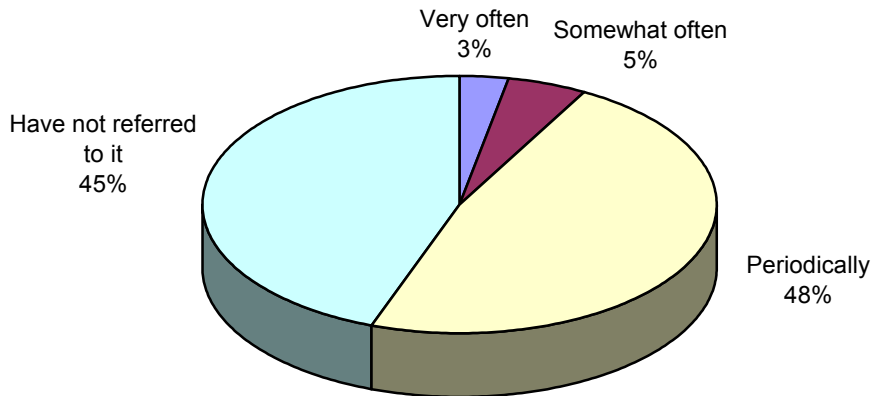
How would you prefer that the DCLG communicate with you? (Second choice)



Overwhelmingly, respondents want to be reached via e-mail: 75% made this their first choice. For second choice, respondents chose mainly mail (30%) and telephone or conference calls (23%).

USE OF NCI BYPASS BUDGET

In your work, how often do you refer to the NCI Bypass Budget document?



More than half of the respondents reported referencing NCI's Bypass Budget document at least periodically. Nearly half reported that they had never referred to it.

Segmentation At-A-Glance

- No findings.

PRE-NOTIFICATION FROM NCI

Date

Name
Organization
Address
City and State, Zip

Dear Name:

I am writing to encourage you to participate in a key activity for the National Cancer Institute (NCI). NCI and the NCI Director's Consumer Liaison Group (DCLG) are conducting a survey of cancer advocacy organizations to help determine how the DCLG may best function in the future. The DCLG, comprised of 15 members, makes recommendations to the Director of NCI from the consumer advocate perspective on a wide variety of issues, programs, and research priorities. The members, who are appointed to four-year terms, reflect the diversity among those whose lives are affected by cancer. The survey will request your opinions about the NCI research activities upon which the DCLG should focus, how the DCLG can be most effective in accomplishing its mission, and what kinds of individuals should serve on the DCLG.

The core functions of the DCLG are to:

- Provide recommendations to the Director, NCI, in response to specific advice and requests from the Director, NCI, and to the needs of the cancer advocacy community,
- Establish and maintain strong collaborations between NCI and the cancer advocacy community to reach common goals,
- Serve as a primary forum to discuss issues and concerns and exchange viewpoints that are important to the broad development of NCI program and research priorities,
- Assist in developing and establishing processes, and criteria for identifying appropriate consumer advocates to serve on a variety of program and policy advisory committees.

When NCI created the DCLG in 1997, it was the first all-consumer advisory group at the National Institutes of Health. At this point, as we embark upon an ambitious effort to eliminate the suffering and death due to cancer by 2015, NCI seeks your help in shaping the DCLG to make a major contribution to that effort. In a few weeks, you will be contacted by our survey contractor, ORC Macro and given instructions for completing the survey. Thank you in advance for helping cancer patients and advocates have a significant role at NCI.

Yours truly,

Dr. Andrew C. von Eschenbach
Director
National Cancer Institute

INITIAL NOTIFICATION

From: NCI@orcmacro.com

To: [Participant e-mail address]

Subject: NCI Requests Your Feedback

Dear [name]:

As mentioned in the letter you recently received from Dr. Andrew von Eschenbach, Director of the National Cancer Institute (NCI), ORC Macro is conducting a survey to help identify priority areas of mutual interest to NCI and the cancer advocacy community, and to determine how NCI and the Director's Consumer Liaison Group (DCLG) can best work with the advocacy community in the future.

Your participation in this survey is completely voluntary. Please be assured that your responses will be kept confidential and will not be disclosed to anyone outside ORC Macro, except as otherwise required by law. Data will be provided to the NCI in aggregate form only, with all identifying information removed. You may skip any questions that you prefer not to answer. This survey should take approximately 15-20 minutes to complete.

The survey is located on the Internet at <http://www.macrosr.com/NCISurvey>. You can access the survey easily by either clicking on the above address or by copying the address into your Internet browser. You will then be asked to enter your password from below.

Your password is: [insert unique password for each participant]

You will need this password to complete this survey. This password will enable you to exit the survey and re-enter at a later time and will protect any data you have entered if you experience any computer disruptions. ORC Macro will not share these passwords with the NCI at any time.

Please complete this survey no later than June 20, 2003. If you have any questions about the survey administration or are having problems entering the survey, please contact ORC Macro Technical Support at TechSupport@orcmacro.com or toll-free at (866) 481-2980.

If you have any general questions about the study itself, please contact Nancy Caliman of NCI in the Office of Liaison Activities (OLA) at calimann@mail.nih.gov or at (301) 496-0307.

Thank you in advance for your participation.

Carol Freeman
Project Director, ORC Macro

FIRST REMINDER

From: NCI@orcmacro.com

To: [Participant e-mail address]

Subject: Reminder: NCI Requests Your Feedback

Dear [name]:

Recently you should have received an e-mail message from ORC Macro asking for your participation in a survey to help identify priority areas of mutual interest to NCI and the cancer advocacy community, and to determine how NCI and the Director's Consumer Liaison Group (DCLG) can best work with the advocacy community in the future.

Your participation in this survey is completely voluntary. Please be assured that your responses will be kept confidential and will not be disclosed to anyone outside ORC Macro, except as otherwise required by law. Data will be provided to the NCI in aggregate form only, with all identifying information removed. You may skip any questions that you prefer not to answer. This survey should take approximately 15-20 minutes to complete.

If you have already completed the survey and have submitted your survey responses, please disregard this reminder. Your responses already have been recorded.

The survey is located on the Internet at <http://www.macrosr.com/NCISurvey>. You can access the survey easily by either clicking on the above address or by copying the address into your Internet browser. You will then be asked to enter your password from below.

Your password is: [insert unique password for each participant]

You will need this password to complete this survey. This password will enable you to exit the survey and re-enter at a later time and will protect any data you have entered if you experience any computer disruptions. ORC Macro will not share these passwords with the NCI at any time.

Please complete this survey no later than June 20, 2003. If you have any questions about the survey administration or are having problems entering the survey, please contact ORC Macro Technical Support at TechSupport@orcmacro.com or toll-free at (866) 481-2980.

If you have any general questions about the study itself, please contact Nancy Caliman of NCI in the Office of Liaison Activities (OLA) at calimann@mail.nih.gov or at (301) 496-0307.

Thank you in advance for your participation.

Carol Freeman
Project Director, ORC Macro

SECOND REMINDER

From: NCI@orcmacro.com

To: [Participant e-mail address]

Subject: Final Reminder – NCI Survey

Dear [name]:

This is the final reminder for the NCI Survey. The survey has been extended a few days and the cut-off date is now **Tuesday, June 24, 2003**. Please take this last opportunity to complete the survey via the Internet. It is critical that NCI and the DCLG receive as much feedback as possible so that they can best work with the advocacy community in the future. If you have already completed the survey, thank you for your participation.

You may access this survey at <http://www.macrosr.com/NCISurvey> by either clicking on the address link or copying this address into your browser. When prompted, please enter the following password:

Password: **[insert unique password for each participant]**

Only one survey can be completed under each password. Therefore, please do not forward this message to someone else.

Please be assured that your responses will be kept confidential and will not be disclosed to anyone outside ORC Macro, except as otherwise required by law. Data will be provided to the NCI in aggregate form only, with all identifying information removed. You may skip any questions that you prefer not to answer. This survey should take approximately 15-20 minutes to complete.

Please complete this survey no later than June 24, 2003. If you have any questions about the survey administration or are having problems entering the survey, please contact ORC Macro Technical Support at TechSupport@orcmacro.com or toll-free at (866) 481-2980.

Thank you in advance for your participation.

Carol Freeman
Project Director, ORC Macro

Welcome to the NCI/DCLG Survey of Cancer Advocacy Organizations

Please Enter Login: _____

Please Enter Password: _____

Introduction

When the National Cancer Institute (NCI) created the Director's Consumer Liaison Group (DCLG) in 1997, the DCLG was the first all-consumer advisory group at the National Institutes of Health. At this point, as NCI embarks upon an ambitious effort to eliminate the suffering and death due to cancer by 2015, the institute seeks your help in re-shaping the DCLG to make a major contribution to that effort.

Thank you in advance for completing this survey. In doing so, you will be helping cancer patients and advocates have a more significant role at NCI.

Part 1: Overall Familiarity with NCI

1. The mission of NCI is to coordinate a national research program on cancer cause, prevention, detection, diagnosis, treatment, rehabilitation, survivorship, and control. How aware are you of the NCI activities that advance this mission?

- I am very aware of the NCI activities that advance this mission
- I am moderately aware of the NCI activities that advance this mission
- I am slightly aware of the NCI activities that advance this mission
- I am unaware of the NCI activities that advance this mission.

2. Overall, how well do you think NCI has collaborated with the cancer advocacy community in carrying out its mission?

- Extremely well
- Very well
- Somewhat well
- Not very well
- Not well at all

3. Please give us your views of NCI by indicating how much you agree or disagree with the following statements:

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Do not know
a. NCI's research funding is appropriately balanced across cancer types.	O	O	O	O	O	O
b. NCI's research funding reflects the research priorities identified by advisory committees such as Progress Review Groups.	O	O	O	O	O	O
c. NCI clearly communicates how it sets its research priorities.	O	O	O	O	O	O
d. NCI is making progress in reducing the cancer burden.	O	O	O	O	O	O
e. NCI is having an impact on making clinical trials available to cancer patients.	O	O	O	O	O	O
f. NCI is having an impact on increasing participation in (accruals to) cancer clinical trials.	O	O	O	O	O	O
g. NCI is having an impact on optimizing outcomes for cancer survivors and their families.	O	O	O	O	O	O
h. NCI addresses cancer health disparities appropriately.	O	O	O	O	O	O
i. 1-800-4-CANCER is a useful resource for my constituents.	O	O	O	O	O	O
j. www.cancer.gov is a useful resource for my constituents.	O	O	O	O	O	O
k. The NCI Bypass Budget document helps my organization understand NCI's research priorities.	O	O	O	O	O	O
l. NCI is effective in translating research on cancer health disparities into effective community interventions.	O	O	O	O	O	O
m. NCI is having an impact reducing cancer health disparities.	O	O	O	O	O	O

Part 2: Future Direction and Activities of the Director's Consumer Liaison Group

Please read the following background information on the DCLG before continuing.

The Director's Consumer Liaison Group (DCLG) was created by the National Cancer Institute in 1997. It is NCI's only *all-consumer* advisory body. The DCLG provides the consumer advocate perspective to the Director of NCI on a wide variety of issues, programs, and research priorities. The DCLG is comprised of 15 members who reflect the diversity among those whose lives are affected by cancer. The members are appointed for four-year terms.

According to the charter, the core functions of the DCLG are to:

- ◆ Establish and maintain collaborations between NCI and the cancer advocacy community
- ◆ Provide recommendations to the NCI Director in response to the Director's requests and the needs of the cancer advocacy community
- ◆ Serve as a primary forum on issues important to the development of NCI program and research priorities
- ◆ Assist in developing processes for identifying consumer advocates to serve on NCI program and policy advisory committees

4. Prior to receiving this survey, were you aware of the existence of the DCLG?

- Yes, I was aware of the DCLG and most of its activities
- Yes, I was aware of the DCLG and some of its activities
- Yes, I was aware of the DCLG, but was unaware of any specific activities
- No, I had never heard of the DCLG

5. The DCLG is currently going through a strategic planning process to help develop its future activities. Listed below are four different ways that the DCLG could provide value to NCI and the cancer advocacy community. In your opinion, which one would provide you or your organization with the most value?

[Please choose only one response]

- Help the cancer advocacy community better understand the work of NCI
- Provide the cancer advocacy community's perspective and recommendations to the *Director of NCI*
- Provide the cancer advocacy community's perspective and recommendations to *NCI's Offices and Centers*
- Help facilitate better collaboration between NCI and the cancer advocacy community
- Other (Please specify _____)

6. Which one would provide you or your organization with the least value?

[Please be sure that your response to this question is different from that of the previous question.]

[Please choose only one response]

- Help the cancer advocacy community better understand the work of NCI
- Provide the cancer advocacy community's perspective and recommendations to the *Director of NCI*
- Provide the cancer advocacy community's perspective and recommendations to *NCI's Offices and Centers*
- Help facilitate better collaboration between NCI and the cancer advocacy community

7. Please provide your ideas on any other important ways in which you believe the DCLG could provide value to NCI and the cancer advocacy community.

8. Do you see any trends in the cancer advocacy community and/or the general environment that might influence the DCLG's future activities? If "yes," please explain.

APPENDIX 2: SURVEY INSTRUMENT

9. The DCLG has identified several current priorities as potential areas of focus for the future. For each one listed below, please do the following:

- a) Rate how important it is for the DCLG to be involved in each of these activities; and
- b) then rate how well you believe NCI has collaborated with the cancer advocacy community in each activity.

Potential DCLG Areas of Focus	(a) How important is it for DCLG to be involved?						(b) How well has NCI collaborated with the cancer advocacy community in this activity?					
	Extremely important	Very Important	Somewhat important	Not very important	Not important at all	Do not know/No Opinion	Extremely well	Very well	Somewhat well	Not very well	Not well at all	Do not know/No opinion
a. Research - Establish and pursue <u>biomedical</u> research priorities that <u>ultimately</u> lead to improved survival and quality of life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Clinical Trials - Maximize the effectiveness of NCI's national clinical trials program.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Survivorship - Reduce the adverse effects of cancer diagnosis and treatment, and optimize outcomes for cancer survivors and their families from the time of diagnosis to the end of life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Health Disparities - Understand the fundamental causes of health disparities in cancer, develop effective interventions to reduce these disparities, and facilitate their implementation.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Communication - Increase knowledge about, tools for, access to, and use of cancer communications.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

APPENDIX 2: SURVEY INSTRUMENT

10. If you noted that it is important for the DCLG to be involved in **research** in Question 9, please answer the following questions. NCI is interested in some more specific feedback in this area. How important is it for the DCLG to be involved in each of the following activities relating to research?

	Extremely important	Very Important	Somewhat important	Not very important	Not important at all	Do not know/No opinion
a. Work with NCI, the Food and Drug Administration, industry, academia, and the advocacy community to speed the development of promising agents for early translational research . [see last page for definition if needed]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Work with NCI and the advocacy community to identify and address the overarching research priorities identified in the Progress Review Groups [see last page for definition if needed] and other vehicles.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Work with NCI and the advocacy community to better communicate how NCI research priorities are identified.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Work with NCI and the advocacy community to develop an integrated national tissue resource system (a way of providing human tissue specimens for research to move cancer research forward).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

11. If you noted that it is important for the DCLG to be involved in **clinical trials** in Question 9, please answer the following questions. NCI is interested in some more specific feedback in this area. How important is it for the DCLG to be involved in each of the following activities relating to clinical trials?

	Extremely important	Very Important	Somewhat important	Not very important	Not important at all	Do not know/No opinion
a. Work with NCI and the advocacy community to increase the participation (accrual) of patients into national trials.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Work with NCI and the advocacy community to develop surrogate endpoints . [see last page for definition if needed]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

12. If you noted that it is important for the DCLG to be involved in **survivorship** initiatives in Question 9, please answer the following questions. NCI is interested in some more specific feedback in this area. How important is it for the DCLG to be involved in each of the following activities relating to survivorship?

	Extremely important	Very Important	Somewhat important	Not very important	Not important at all	Do not know/No opinion
a. Participate on the oversight committee for implementation of NCI's new Survivorship Extraordinary Opportunity for Investment . [see last page for definition if needed]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Help develop tools to assess the quality of life and care of post-treatment cancer survivors and their family members.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Help in the development and dissemination of new interventions and best practices guidelines for follow-up care and monitoring of post-treatment survivors.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

13. If you noted that it is important for the DCLG to be involved in **health disparities** initiatives in Question 9, please answer the following questions. NCI is interested in some more specific feedback in this area. How important is it for the DCLG to be involved in each of the following activities relating to health disparities?

	Extremely important	Very Important	Somewhat important	Not very important	Not important at all	Do not know/No opinion
a. Increase access and accrual (or participation) of underserved populations to state-of-the-art clinical trials.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Increase knowledge about, tools for, access to, and use of cancer communications tools for underserved populations.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Facilitate the creation of community-focused partnerships to investigate factors influencing cancer care quality among racial/ethnic minorities and other underserved populations.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Provide input based on the advocacy community's needs into the development of effective interventions to reduce cancer health disparities.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

14. If you noted that it is important for the DCLG to be involved in NCI’s **communication** initiatives in Question 9, please answer the following questions. NCI is interested in some more specific feedback in this area. How important is it for the DCLG to be involved in each of the following activities related to communication?

	Extremely important	Very Important	Somewhat important	Not very important	Not important at all	Do not know/No opinion
a. Work with NCI and the advocacy community to identify optimal methods by which to communicate to the cancer community.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Work with NCI and the advocacy community to identify unmet information needs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Work with NCI to enhance key NCI communication vehicles such as www.cancer.gov [see last page for definition if needed] and 1-800-4-CANCER.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

15. The following is a list of categories of activities where the DCLG could focus its resources in its work with NCI. In your opinion, which potential DCLG activity would most benefit your constituency?

[Please choose only one response]

- Participate with NCI in the development of its strategies and priorities
- Monitor the implementation of a specific set of NCI strategies
- Undertake activities that support NCI’s implementation of its strategies and priorities
- Other (Please specify _____)

16. Which potential DCLG activity would least benefit your constituency?

[Please choose only one response]

[Be sure to choose a different response from that in the previous question]

- Participate with NCI in the development of its strategies and priorities
- Monitor the implementation of a specific set of NCI strategies
- Undertake activities that support NCI’s implementation of its strategies and priorities

17. Given your responses in this section, what types of individuals would you recommend serve on the DCLG? (In describing the types of individuals, please describe their role in their organization, their background, or other attributes that would be important in their serving on the DCLG.)

Part 3: Preferred Communication Methods

18. How would you prefer that the DCLG communicate with you? Please denote your first choice below.

[Please choose only one response]

- E-mail
- Telephone or conference calls
- Postings on the NCI Website
- Mail
- Periodic surveys
- Regional or national meetings
- Other (Please specify _____)

19. How would you prefer that the DCLG communicate with you? Please denote your second choice below.

[Please choose only one response.]

[Please be sure that your response to this question is different from that of the previous question.]

- E-mail
- Telephone or conference calls
- Postings on the NCI Website
- Mail
- Periodic surveys
- Regional or national meetings
- Other (Please specify _____)

20. In your work, how often do you refer to the [NCI Bypass Budget](#) document [see last page for definition if needed], *The Nation's Investment in Cancer Research*?

- Very often
- Somewhat often
- Periodically, but not often
- I have not referred to the NCI Bypass Budget document

Part 4: About Your Organization

Please provide some basic demographic information on your organization to help with our analysis.

21. Would you consider your organization to be...?

[Please choose only one response.]

- Local
- Regional/Multi-state
- National
- International

22. Which of the following best describes the activities of your organization? Please check up to **two** responses.

- Policy/Legislation
- Education/Constituent Information
- Research/Research Funding
- Other services to a constituency (e.g., location of resources, clinical trials, emotional support services)

23. Which of the following areas does your organization actively work on and dedicate resources to? (Please rank these areas in terms of their importance to your organization, with “1” being most important and “5” being least important.)

[For example, when complete you should have a 1, 2, 3, 4, and 5.]

- Cancer research
- Cancer clinical trials
- Cancer survivorship
- Cancer communication
- Cancer health disparities

24. Which of the following communities does your organization actively serve? Check up to **three**.

- Patients
- Families
- Caregivers
- Clinicians
- Nurses
- Researchers
- Pharmaceutical/Biotech
- Government/ Policymakers
- Other (Please specify _____)

25. Approximately how many listings are in your constituent database?

- 100 or fewer
- 101 to 1,000
- 1,001 to 10,000
- 10,001 to 50,000
- 50,001 to 100,000
- More than 100,000
- Do not maintain a database
- Do not know

26. Approximately how many full-time paid staff or paid full-time equivalents (FTEs) work for your organization?

27. Approximately how many volunteers work for your organization?

28. Are there any additional comments that you would like to make about DCLG's future focus or activities?

On behalf of NCI and the DCLG, thank you for completing this survey!

If you have any questions about this survey, please contact the ORC Macro Project Director, Ms. Carol Freeman, at 301-572-0581.

Please submit your completed survey to **Matt Suljak** no later than **June 20, 2003**.

Fax:
(301) 572-0999

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Definitions:

Translational research: Taking basic laboratory discoveries and utilizing them to prevent or treat human disease.

Progress Review Groups are panels of experts that assess the state of the science for a single type of cancer or group of closely related cancers and make recommendations for future research.

Surrogate endpoint. Endpoints are what researchers measure to evaluate the results of a new treatment being tested in a clinical trial. Examples of endpoints include toxicity, tumor response, survival time, and quality of life. A **surrogate endpoint** is a measurement that may not be a direct measurement of how a patient feels functions or survives, but nevertheless is considered likely to predict benefit. An example is tumor shrinkage.

Extraordinary Opportunities for Investment are areas of discovery that build upon the most important recent developments in knowledge and technology and hold promise for making significant progress against all cancers. The goal of NCI's **Survivorship Extraordinary Opportunity** is to reduce the adverse effects of cancer diagnosis and treatment and optimize outcomes for cancer survivors and their families.

Bypass Budget is the National Cancer Institute's annual strategic plan and budget document.

Each year, as mandated by the [National Cancer Act of 1971 \(P.L. 92-218\)](#), the National Cancer Institute prepares this plan and budget proposal for supporting the cancer research workforce with the technologies and resources it needs, building on research successes, and ensuring that research discoveries are applied to improve human health.

The full title of the [print version](#) is *The Nation's Investment in Cancer Research: A Plan and Budget Proposal*.

The online version is called *The Nation's Investment in Cancer Research: Plans and Priorities for Cancer Research*.

The proposal is called the "Bypass Budget" because it is provided directly to the President of the United States in the fall of each year for use in formulating the budget request to Congress, "bypassing" ordinary budget channels at the National Institutes of Health and the Department of Health and Human Services.

OPEN-END COMMENTS

Q 5 The DCLG is currently going through a strategic planning process to help develop its future activities. Listed below are four different ways that the DCLG could provide value to NCI and the cancer advocacy community. In your opinion, which one would provide you or your organization with the most value? Other (Please specify _____)

Work with the cancer advocacy community to understand their perspective, make recommendations to the NCI's Director, Offices and Centers and ENACT CHANGE together.

Provide FREE information for us to pass out on related cancer and help us better act as a clearinghouse in getting the proper information on cancer out to our membership.

Simplify, simplify, simplify.

Have a special forum or focus group addressing rare cancers.

Have the DCLG conduct a town hall meeting for the cancer advocacy community and take these recommendations back to NCI.

Represent the interests of the vast majority of people with cancer using CAM.

Encourage the NCI to quickly release research and link the information as soon as possible to community programs.

Q 7 Please provide your ideas on any other important ways in which you believe the DCLG could provide value to NCI and the cancer advocacy community.

Serve as ambassadors from the advocacy community to promote the goals and values of the advocacy community to the NCI bureaucracy.

By having ALL cancers represented by at least one advocacy group. Since this is the first contact we have had from the NCI in the 7 (seven) years we have been up and running. [organization name deleted] I am not sure how best to answer this. I would like the opportunity to be involved and represent our constituents and voice. We feel we would have a lot to offer from the talents we have used to project our cause.

Create awareness of the needs of the cancer survivor that are not medical ... encourage research and funding in these non-medical areas

DCLG and NCI need to hold town hall meetings/forums to discuss priorities from NCI's perspective as well as allow communities to voice their needs around cancer programs and services.

The advocacy community is based on sharing information. Providing DCLG direction/suggestions to strengthen advocacy activities could prove very helpful.

It may be useful for the cancer advocacy community to be more aware of the ongoing activities of the DCLG. Providing updates or reports could demonstrate the progress that the DCLG is making toward its goals.

As a CARRA member, a program directly overseen by the DCLG they must implement a training for CARRA members to include but not limited to: an overview of the way NCI works, grant review training, ways for advocate to communicate constituents needs to NCI (appropriate offices to result in action), training on being an effective community advocate, etc. I feel the CARRA members are struggling to find ways to get our message heard in a meaningful way that can be processed by DCLG. There was no training provided to help us.

The DCLG could provide NCI with information on how to collaborate with the community-based advocacy groups who provide so much more value than the large national organizations.

Establish an ongoing "DCLG Newsletter" to better communicate to all involved and - include the "Mission" of DCLG in each publication as well as how readers can respond to DCLG. - Distribute copies of the "DCLG Newsletter" to all interested.

I think the NCI could rotate exhibits on the cancer quilts for breast, cervical, ovarian, prostate etc. (all cancers that have quilts or other related items that help put a personal face on the battle against cancer). [section deleted]

Helping to bring the cancer advocacy voice to the table where real change can be made. Also, helping to understand how the NCI works so the advocacy groups can better take that message back to the scientific communities and the opportunities that are available to the researchers.

While NCI's focus is research, the cancer advocacy community wants to find solutions to the problems that are faced by cancer patients/survivors and to see these implemented at the local level. Many things have been researched to death and we know what to do about them, but NCI's focus means that to move forward organizations must see the world in the same way. In other cases, little research has been done (i.e. fatigue, depression, pain). We need to encourage those who are interested in these issues to locate researchers who are willing to work along-side of them to answer the questions that are important to us as cancer advocates. Encourage NCI to allow for solution building and to fund those of us in the advocacy community who believe they have innovative ideas on ways to address issues.

People need to work together, both advocacy groups and gov'n't groups. Medical people need to be more educated on what is available.

Better communication of items available to non profit Cancer Resource orgs.

Important to truly connect with the outside community and become representatives of the patient and advocacy communities.

Consider survivorship issues as part of its research and funding.

If the NCI would be willing to work with and link up with Advocacy organizations.

More emphasis on translating basic research knowledge to clinical applications and more emphasis on clinical research training and funding.

Perhaps to also function as a clearinghouse for activities, educational opportunities, materials available by other organizations.

I am still trying to figure out the workings of NCI and all of its division. It is my perception that NCI is very well-intentioned but very complicated with multiple levels. In my opinion, the DCLG could provide value to the cancer advocacy community by convening several educational events that would help the cancer advocacy community first understand the system and then ways to better interact.

Better communication between the DCLG and advocacy groups - feedback on important issues that the DCLG has responded to as a result of input from the advocacy community.

The DCLG needs to urge far more funding of anticancer drug discovery isolated from marine invertebrates, terrestrial plants and microorganisms; we will not win the War on Cancer without it.

I have no experience with this group.

Study the research sources and criteria which determine the numerical pyramid positions of various cancers; examine the total dollars being allocated to primary cancers for the equity of these allocations; evaluate for duplications, and omission due to poor or inconsistent national methods of recording cancer incidents. For instance, the State of California does not count cancer patients who live in one county (much less another state) yet are treated in another county (mostly due to the need for diagnosis at a teaching hospital). In the case of rare primary cancers these statistics are vital regardless of the residency of the patients so NCI will have a fair and accurate picture of the diversity and location cancers.

Try to stop conflicting publicity.

On-line town hall meetings or other methods for cancer advocacy communities to express their concerns to the DCLG and NCI staff. While the members of the DCLG are from the advocacy community more widespread and diverse opinions and suggestions could be presented.

Set up outreach committees and meet with the different cancer organizations on a regular basis to learn emerging issues important to our constituents.

By continuing their excellent efforts to have the patient advocates participate in the dialogue. If we don't have a voice - how can NCI know what we need - So the NCI's work in this area is very important.

DCLG could also conduct focus groups with the actual patients to be most driven to the cancer patients' needs.

Have a series of informational symposia across the country, using members of DCLG and NCI professionals as speakers.

I do not see where the DCLG has had any real positive impact for our constituency (brain tumor patients). We have serious issues that the NCI is not addressing. I am not aware of any work the DCLG has done to help.

Can serve as a conduit for improved communication between the community and NCI.

The DCLG can provide value to NCI and the community by conveying the interests to the Director in a meaningful way, giving priorities. For example, the PRG reports outlined the priorities of the medical community and advocates which I believe were quite thorough in certain reports. It does not appear they were taken very seriously compared to the seriousness of the effort exhausted by those that participated. The PRG reports spoke to the issues from the medical, scientific and advocacy communities. It is important that their thoughts be considered carefully in regard to NCI's plans. The DCLG members could evaluate the progress of the collaboration between the institutes to encourage furtherance of progress and communication in the priorities that were outlined. I believe that is only one issue that might be given some additional consideration. Encouraging appointments to vacancies within the NIH might be an improvement too.

The critical one is making sure the NCI Director understands where the patient/advocate community stands on issues.

As a facilitator for participation by other consumer advocates in NCI forums where the patient's perspective should be represented, especially regarding training of advocates, peer support, and communication with NCI staff about what enhances the advocate's ability to make a meaningful contribution to NCI forums.

1. Disseminate information about DCLG to advocacy community - 2. Create a brief summary about the current focus of NCI, including types of research in progress - 3. Open lines of communication so that advocates understand what is being studied, and NCI understands the grassroots concerns about cancer diagnosis and treatments available.

DCLG should have equal voting membership when the NCI develops priorities. Consumers should sit at the table as equal collaborators in all aspects of the National Cancer Institute, including decision making. NCI needs to be transparent to consumers and the agenda influenced by consumers at all levels. Use the Department of Defense Breast Cancer Research Program model for including consumers at all levels of NCI decision making.

Ascertain issues (by organ site) of the various constituencies and attempt to address/resolve them. i.e. prostate screening" versus "testing"."

The DCLG could report its recommendations to the advocacy community and report what the results are on a yearly basis and forecast the future focus. At this point I have not read or received information on any activities between the Director and DCLG. It is very difficult for groups to maintain contact, maybe if an individual was assigned to each cancer group to help with communication of information.

I would imagine that the more communication between groups, be it at meetings, conferences, phone, literature, or email, the better each group would be in working together toward common goals.

I think it is extremely important that whatever the ultimate decision about what the DCLG is going to do, that there is a solid commitment from the NCI that recommendations from the group have a realistic opportunity to get implemented. Nothing is more frustrating than to serve on a group and feel that your efforts are not going anywhere.

In terms of the pediatric cancer community [section deleted], there has been little to no communication or representation of the littlest cancer patients via the DCLG. [section deleted] The childhood cancer patient population needs representation on the DCLG [section deleted]. Getting feedback and giving feedback to the actual families of children with cancer regarding the DCLG's activities would be a great step forward in terms of providing value to the littlest cancer patients in this country.

The DCLG could provide value by increasing awareness about on-line sources of information made available by NCI and the cancer advocacy community.

Continue and expand the process of integrating patient advocates into NCI's decision making process

The DCLG should be representing the entire cancer community. There needs to be a better method of communication between advocacy groups and the DCLG. So that those not at the table can give input to the DCLG on the most important needs of the groups not represented.

DCLG members should be chosen with a view toward - a) selecting only people who represent significant constituencies in the cancer advocacy community, and - b) selecting people who represent organizations that disagree with significant aspects of the NCI's approach

The DCLG should serve as a conduit between the advocacy community and NCI. The DCLG often appeared to be a one-way street for NCI to get its messages out without soliciting or accepting input from its members. The DCLG can and should provide the patient's voice in decision making about human research protections, clinical trials, peer review etc. The DCLG can also serve as the convener of advocacy experts and NCI professionals on specific issues of mutual importance.

The NCI should take a closer look at the cancer survivorship community, long-term effects of treatment, long-term survivors, and quality of life issues.

I think the involvement of advocates in advisory positions is important to everybody. From research to patient application, the 'consumer' perspective has to be represented. But I believe some training for the advocate is necessary in order to understand the 'language' of disease and research terms.

I was working in patient advocacy for three years before I found out what the DCLG was. It wasn't until I got involved with CARRA that I really understood the relationship between CARRA, DCLG and NCI. Getting information to the general public that you exist would be the first step. Letting people how to interact with the DCLG would be the second step.

Rethinking issues from the ground up. Currently the 'system' does not value people with cancer as the top of this pyramid. Rather it is corporate values that triumph most of the time. If it were not so, research would include large-scale clinical trials of combinations of natural substances, none of which can be patented, but which small studies show may be of IMMENSE value in reducing unwanted (side) effects, and possibly more.

Identify gaps in services, on a local and national level.

NCI needs to include advocacy participation when making decisions on funding research projects. This perspective will enhance the quality of the decision making process. From what I understand, all the NCI decisions are made in a vacuum, behind closed doors. They also need to be more accountable for the projects that they end up funding. They should be following the same system as the DOD Breast Cancer Research Program, which includes advocates at the table."

Include more people from outside of the Major Cities (i.e. consumers from the rural and small town areas) on panels.

Increased community outreach including multi-media educational materials; town hall meetings; teleconferences; video conferences; interactive web site conferences to foster cross communication and fertilization of ideas.

As stated previously, represent to NCI the importance of getting research information out as soon as possible. That information should be systematically channeled to cancer centers and community organizations for utilization as soon as possible. To meet the 2015 goal, this is imperative: more information distributed as quickly as possible.

Better publicize what they do and the impact they are having!

Improve the identification of major cancer advocacy groups by disease site. - Develop opportunities for joint programs between the NCI and the cancer advocacy groups with the strongest impact within the community

The DCLG could serve as a major forum for input from the grassroots level.

We need to know exactly what has been the impact of the DCLG. What evidence is there that they have made any differences in NCI or gained anything for the survivorship community?

Q 8 Do you see any trends in the cancer advocacy community and/or the general environment that might influence the DCLG's future activities? If "yes," please explain.

Difficulties in third-party payment for innovative cancer care are becoming more of a problem nationwide. -The present administration is not nearly as concerned about primary prevention and environmental causes of cancer as it should be. -A strong blame-the-victim mentality is arising- example, bodies such as [organization name] want to blame cancer on citizen's lack of exercise, etc. and to ignore environmental toxins. - There are efforts afoot to cause NCI to work more closely with industry rather than to be independent. This is the exact wrong direction for NCI.

With more and more small foundations being brought up by family members who lose a loved one it is important that an overview group assist in keeping all on track in a positive manner.

Survivorship, survivorship, survivorship! Infertility is a primary, important survivorship issue that require more research and more attention.

Need for more partnership, less duplication.

There are segments of the community (especially in certain priority populations) that are not as advanced in their cancer advocacy and grassroots efforts. DCLG will need to address how to ensure that all communities are able and aware of upcoming advocacy efforts that they can be involved in. In addition, cancer patients and survivors need to understand how they can advocate to state, national, and NCI leadership for cancer resources.

The advocacy community is more educated now than ever before. The continued flow of reliable and reputable information is crucial to enhancing the progress of cancer advocacy.

The consumer's voice is playing an expanding role in the cancer community. The DCLG provides a place for consumers to share information with individuals who can address the issues on a much larger scale. I can only see the DCLG taking on a larger role in the future if the consumer continues to participate in policy making decisions as well as in other ways.

Yes, more and more educated individuals are personally touched by cancer and have picked up the banner to help gain awareness of their particular cancer and try to begin to have an impact on translational research, dollars for research of their particular disease and survivorship issues. A disease specific forum with a representative of DCLG might help facilitate input.

The economy has created a devastating environment for most cancer advocacy groups. It is impossible to operate our organizations with mere in-kind support. Real dollars are needed

to support day-to-day operations. The absence of monetary support continues to widen gaps in health care and will worsen the disparities in the long run. Additionally, many organizations who've had no history in addressing health disparities are now receiving the fund to impact the problem. I believe the inequities that we seek to eliminate will not be abated.

Yes! -Research on behalf of specific cancers seem to be influenced by the amount of - public opinion advocacy. - - Research should be influenced by statistical scientific facts and future chances for successful results!

- Trends? Trends such as ??? I do not see any trends. The important thing is getting recent data=information=knowledge, out to cancer patients, family members and friends!

The cancer advocacy community is working better as a team and so collaborative projects need to be advanced.

There are more and more organizations and agencies addressing the cancer issue: NDC, ICC, PAF, UBC, Lance Armstrong Foundation, Komen, President's Cancer Panel and so on. We need to come together to list the gaps that still exist and take actions to address these in new and innovative ways at the local, regional, and national levels.

Yes, there are potential conflicts of interest that are increasing in advocacy as well as in scientific connections. Assistance is needed to start discussing and educating advocacy groups on both scientific and advocacy conflicts of interest.

Survivors are living longer.

Continuing decreases in funding available for clinical research, continuing decreases in time available for clinicians to do research, increasing complexity of basic and clinical research, all of which culminate in inadequate support for and focus on development of new therapies.

More networking and working together- less duplication of services.

Cost of health care - Insurance issues - Funding issues for the cancer advocacy community and ways to network services.

Cancer prevention research, new cancer treatments that are less or non-toxic, quality of life issues.

No.

No

It is delicate to raise issue with the national response to major PR campaigns which address the needs of specific cancer patients/conditions much less the overlapping or close to duplicate non profits which focus on major cancers. These major cancer groups are able to raise hefty contributions because of the public's awareness of said conditions. If they were assembled under one heading like, Breast Cancer, Prostate Cancer, Lung Cancer etc. with the

related organizations treated like the "committee" or "sub functions" of those major cancers, the top line management expenses could be reduced leaving more monies for the "less fortunate" cancer categories. However, the trend to use "public figures" to gain the attention of Congress or related government entities smacks of unfair "business" tactics. Do we need public figures to be diagnosed with rare cancers to get fair attention to a cancer because of numbers?

Media

Yes, more concern with underserved populations, more emphasis on health disparities, more interest in clinical trials and increasing participation and making this information known to the general public as well as patients newly diagnosed, more knowledge and concern about the ethical issues involved with clinical trials and IRB review and research in general.

Due to increasing research in cancer genetics an emerging population is one that we designate as cancer pre-vivors" (for survivor of a predisposition to cancer). Especially with the discovery of high-penetrant gene mutations that identify a population at tremendous risk for cancer, this population will be a growing one. These are people who have specific needs (including psychosocial needs) often not yet being addressed by cancer survivor organizations. This is a group that would benefit from standardized recommendations across the medical community regarding risk assessment, and risk management including early detection, chemoprevention, lifestyle changes, and surgery. There is a real need for access to credible information and unbiased support. There is a pervasive sense of distrust among many cancer advocacy groups with respect to hereditary predisposition testing to cancer. This distrust on the part of some advocacy groups with respect to genetic research is doing a disservice to those who may benefit from such research. Further it is leading to the disenfranchisement of high-risk patients. Instead of trying to meet the needs of the high-risk population, some organizations are instead further stigmatizing the genetically predisposed group by characterizing hereditary predisposition to cancer as being rare and therefore insignificant. To be identified with "risk" as opposed to cancer can lead to a host of separate issues from those of cancer survivorship. Rather than try to determine the needs of these populations arising from great advancements in genetic technology, often advocacy groups are determining policies and positions on genetic testing and research without including the high-risk community as stakeholders in these discussions."

More and more cancer patients wanting non-biased info on complementary/alternative treatments. More clients not speaking English and needing books like Dr. Susan Love's Breast Book available in Spanish, Chinese, Vietnamese, etc. etc. Having a lot more materials e.g. pamphlets available in multiple languages - it is very difficult and frustrating not to say embarrassing not to be able to provide equitable services to all of our clients. More clients need financial and legal assistance. More community groups need financial assistance. We have had to scale our programs back and the people who are most impacted are the low-income clients who don't have other resources for the services. More people are concerned with environmental causes of cancer - toxins, radiation (including medical x-rays inc. mammograms), pesticides, etc. More non-biased info is needed about these topics as well.

There is still a vast void in the general public between people who are educated - even moderately - about cancer and those that know nothing. The suggestion above might help if audiences are well targeted.

Our patients are much more active and vocal now. The NCI must be prepared to engage these people and use their energy as a resource.

Not necessarily. Various groups, coalitions and individuals are proactive and make positive contributions in a broad sense that might influence activities. Surveys, such as this one, might help provide some additional insights or directions for the DCLG to consider. If DCLG members know the interests, it should help them determine the topics that should be pursued as priorities. Are DCLG members strongly linked with their communities in a broad sense to know the issues, beyond their own organizations, etc.? Although the DCLG may have a voice, the question is whether it is or can be acted on.

It is largely becoming more entrenched and less action oriented.

Increasing interest in access to lay-friendly information about services of NCI.

1. Focus on prevention and/or making cancer a chronic disease, as is diabetes. - 2. Focus research on targeted malignant cells, not overall systemic treatments that also harm healthy cells.

Yes, consumers are being given a seat at the decision making table in many cancer advocacy communities. The NCI should model their DCLG after these models.

There seems to be a growing awareness on the part of newly diagnosed cancer patients regarding their disease, treatment options and side effects/QOL. This translates to better informed patients who take an active role (partnering) with their clinicians. The DCLG would be wise to capitalize on this trend.

The disparity trend in the general environment seems to acknowledge that the disparities do exist. The DCLG could highlight the disparity needs to NCI and make it more of a priority.

I think all of the objectives of the DCLG are good ones. However, I also believe the wave of the future will be to develop meaningful partnerships with the advocacy groups that again should be designed to truly produce results and not just frustration with the system. DCLG should be a prime mechanism to design such a system and see that it works.

In my humble opinion, the advocacy community includes individuals who don't necessarily represent the voice of the families and patients. Names/reputations don't necessarily equate with knowing the needs of the families in the trenches. From my perspective, the voice of many advocates can be easily influenced by money via pharmaceutical agendas etc. which sadly leaves the real voice of the families and the needs of the patients unheard...

The Childhood Cancer advocate and professional organizations are making an effort to work together in order to achieve outcomes for patients, survivors, and their families. There are

common needs that can be achieved through communication, understanding and the uniting of efforts.

Yes. Advocacy organizations are increasingly being used as “front” organizations for the pharmaceutical industry. It will be increasingly difficult -- and critically important -- for the NCI to be sure that it is getting advice from DCLG members who represent INDEPENDENT cancer advocacy organizations.

Many of the current issues of importance in the cancer advocacy community are reimbursement, Medicare reform, oral chemotherapy, increasing clinical trial accrual, etc. The last is definitely an area for DCLG involvement. Training could also be coordinated (not provided) by the DCLG to educate a larger pool of qualified advocates. The Coalition of National Cancer Cooperative Groups is developing a self-training program for Coop. Group advocates.

Yes, and I hope training will play an important part in this endeavor.

More collaboration between the smaller diseases may spur the need for research that is translational.

The awareness and interest in complementary, alternative, natural therapies is one area that really needs attention. People with cancer are leading the way. Will NCI follow? - - Survivorship issues are extremely important as more of us are surviving. We need more research on those lifestyle changes that may impact recurrence and second cancers.

I see more advocacy groups coming into existence. Each disease is trying for more of the funding pie.

No

Fostering of collaboration among and between the advocacy community, policy makers and the media to ensure representation of all cancer types, not just high profile causes.

Survivorship and quality of life as cancer survivors increase in numbers.

Patients and the general public are becoming more active in their health care management; the NCI needs to partner with advocacy groups on initiatives which maximize education, access and participation.

There seems to be a trend toward larger organizations having less direct contact with patients/survivors and their challenges. The DCLG could provide a crucial and continuing link with this basic constituency.

Local grass roots cancer support organizations have been left in the dust. In some communities they offer more hands on support and information than any other organizations or institutions. They are offering help to those facing cancer on a daily basis but get little recognition and little or no assistance from the cancer establishment nor from most consumer advocates.

Q 15 The following is a list of categories of activities where the DCLG could focus its resources in its work with NCI. In your opinion, which potential DCLG activity would most benefit your constituency?

Other (Please specify _____)

Raising awareness of what NCI can provide and the role of DCLG.

Make curing childhood cancer a #1 health priority.

Review all printed information on cancers from NCI and make sure they are current and represent needs of cancer patients, family members and friends. Info must be kept current and can be sent in mail, online, PDF format, etc and info should be provided for free.

Advocacy groups should be encouraged to help provide information to public.

Help develop and monitor strategy to determine the geo and ethnic incidents of rare cancers.

Monitor how the NCI's efforts dovetail with other cancer research efforts, public and private.

Work to achieve effective interaction between NCI and the grassroots.

Q 17 Given your responses in this section, what types of individuals would you recommend serve on the DCLG? (In describing the types of individuals, please describe their role in their organization, their background, or other attributes that would be important in their serving on the DCLG.)

Patient advocates who are not physicians, yet are knowledgeable concerning health issues and cancer issues. People who are not afraid to speak up and discuss fundamental systemic problems in the health care system and/or in NCI.

People that have shown their leadership roles by being able to communicate well. They should have the savvy to know how to reach their constituencies via multi media means. They are not afraid to be decision makers and to voice their opinions yet because they are good communicators they also have the ability to LISTEN, take in information BEFORE being heard. Our leaders within our organization are required to be VP's or above in their other" careers. Showing they can be leaders. Marketing, Communications, Public Relations are key backgrounds when you need to be able to take in information....sort through it and make decisions that then must be reflected back to the communities at large. Although scientific background may be needed at some levels when it comes to the dissemination of the "bottom line", the "heartfelt advocate with the above backgrounds are going to be the people that can then get the points driven home."

Advocacy group leaders. People who possess the skills, passion and drive necessary to implement the goals, objectives, strategies and action plans of the DCLG. In broad terms this is hard to say -- it boils down to the skills that need to be done to get the job done.

Members of the DCLG should have leadership roles in the advocacy community and be representative of the wide diversity of advocacy organizations. Professional experience as well as personal experience should be a consideration in criteria for membership.

Someone who is currently a community advocate (especially cancer advocate) that have vested community interest. The individuals should have the support of the community they are affiliated with or serving. There should be individuals from underserved priority populations (e.g. rural, Pacific Islander, LGBT, immigrant, etc.)

Educated cancer survivors willing to commitment time and energy needed to carry out the work. Whether staff or volunteer individuals must understand some science of cancer and the role of education and advocacy in the field.

Consumers with some knowledge of cancer care and/or advocacy. Physicians and nurses who have a particular interest and expertise in working with cancer patients and families and can convey the voice of survivors. Individuals with a role in educating the cancer community, i.e. Director of Education or Education and Outreach staff and those focused on survivorship issues for cancer organizations. Having individuals with a communications background in a cancer advocacy organization would be key if a larger communications role becomes part of the DCLG work.

Attributes: education level at B.S. or above, personally touched by childhood cancer, self educated on needs of childhood cancer community i.e. survivorship, access to new drugs - Their role: they should be viewed by the childhood cancer community as a whole as a leader, trusted and interested in better quality of life, less toxic treatments, streamlining approval of drugs for relapsed children, they clearly must have expertise in many areas, but positively impacting children with cancer should be their #1 priority not moving their organization into the public eye or personal gain.

The individuals who have a clear understanding of the cancer burden; one who is able to make decisions for their organizations, (the individual need not be a cancer survivor; however should have clear awareness of the cancer problem). Since African Americans suffer a greater burden it makes sense to increase the demographics of African Americans.

People that have had some personal experience with a person battling against cancer (i.e. spouse, child, parent) and may have a fair understanding of different areas on cancer related information, healthcare, etc.

People that are involved in patient programs and the dissemination of information in their organizations. Need to understand the reality of how patients and healthcare professionals receive information.

Cancer support advocates, leadership of grassroots cancer organizations, diverse community members with experience with cancer, public health educators, and others who work directly with cancer patients, or who are cancer survivors.

Patient advocates and health care professionals.

Those with knowledge, or involvement in cancer needs. Compassion and vision.

Advocates who are involved with research advocacy and understand the programmatic/strategic planning side of things. These advocates may come from business or other professional backgrounds, or may have served as leaders of volunteer organizations, such as help desks, setting up national programs, etc.

Individuals with vision who can see all sides of an issue. Can contribute to planning and implementation of strategies. Those with some medical community background, survivors who can communicate well.

Staff of advocacy groups, survivors and volunteers involved in advocacy groups.

Program directors - Patient service and education managers - Executive Directors of advocacy organizations.

Leaders in their respective organizations; personal experience with cancer (either themselves or a family member); some scientific knowledge - biology, chemistry etc., critical thinker, no hidden agendas, ability to focus on issues and work harmoniously in groups; really interested in scientific research and eradicating cancer; focused on both the big picture and facets making up the big picture; ability to debate issues and represent ideas and opinions of constituencies; serve with a heart not just the intellect.

Those who have fluency in the drug discovery process.

1) Informed advocates such as [Note: Provides names of individuals. Names provided to Office of Liaison Activities/NCI.]. 2) People with a medical background working in the community, like me.

Intelligent; dedicated; knowledgeable; available.

Experienced individuals either being diagnosed with cancer and for some types of cancer close relatives of those having been diagnosed with cancer. Individuals demonstrating a commitment and established ties to their communities for a relatively lengthy period. Leadership characteristics within their organizations and within their community. Demonstrated an ability to be proactive rather than reactive, e.g., developing and implementing programs benefiting their communities.

Consumers who represent patients across cancer sites and who represent different stages of the disease including those genetically predisposed to cancer. Representatives from all ethnic groups, and representatives from the health care service community. Representatives who deal with different aspects of cancer burden, including those who address psychosocial issues, access to care, policy and education.

It's important to have individuals with a personal stake in health issues and/or experience in health related field and/or individuals who represent individuals with personal stake. It's important to have diversity within the group including cultural and disease diversity.

Executive Directors/or Presidents - Social Workers - Clinicians - Researchers - -

People who accurately represent demographics - actual cancer patients, people whose first language isn't English, low-income people, people with a lower level of formal education, people of color, et.al. If you are meeting the needs of these constituents then you will also be meeting the needs of the general public.

At least 8-10 years experience as an advocate. Represent a disease that is under represented now as a disease of concern. Should be an active member of the organization's board or its executive cadre. A well documented history of advocacy.

Patients, caregivers and social workers -

I think it is important that individuals with direct community contact be involved and not just people with political connections. Cancer survivors should be involved as well as cancer control specialist and those dealing with special populations.

Motivated, willing to analyze the current status of the NCI and the issues of the community (Medical, scientific, patient, etc.). Knowledgeable in a broad sense (cancer related health issues and some of the political issues that directly affect the NCI.

I clicked on the wrong one on the last page. I should have put monitor as least important and undertake as most important. Ah well. -

A person with direct experience with cancer-burdened people; Able to grasp scientific and medical terminology; Familiar with laboratory and clinical trials; - Primarily an advocate for people with cancer particularly those who may have environmental or experimental sources of their cancers.

I think members of the DCLG need to come from a broad range of knowledge areas, including specific children's, women's, and men's cancers as well as rural entities. This is important so that we can be assured that a childhood cancer patient from rural North Dakota, Iowa etc with no health insurance will get the same kind of consideration as a wealthy white female from DC.

Experienced and knowledgeable advocates: - 1. have been involved in consumer breast cancer grant review (eg DoD, Komen)so that they have an understanding of the clinical research process and knowledge of the changing trends in technology; - 2. have been educated to lobby for state and federal cancer programs which creates an understanding of funding practices. - 3. have a passion to eradicate cancer.

Patient, caregiver or someone very actively involved with an advocacy organization. Someone who has a broad perspective about cancer in general and can work for the good of all cancer patients and not be disease specific.

Members who know and understand the issues important to those with cancer. DCLG members must be knowledgeable about the issues important to those with cancer and be

able to speak up with creative ideas to promote an active collaboration with the NCI and those in the cancer community.

It somewhat depends on what is decided as DCLG's work. If cancer survivor representing our constituency is key, then the medical experience/educational background would not be so important. And I believe survivors representing the minority diversity of our country is important to have in its representation, knowing that regional differences in minority groups are great.

Cancer Survivor active in advocacy/support activities at the local/state/ and national level. Executive level professional experience - excellent communicator - able to commit the time and effort necessary to adequately contribute. Knowledgeable about cancer and very knowledgeable about his/her own cancer.

Individuals with commitment/desire for truth; five years active with an advocacy organization; some education with understanding of DCLG goals; proven leadership skills.

There needs to be representation of the underserved, the regular" community, and the medical and research components. It might be necessary to have the medical and research components work together, and the community representatives work together. The "regular" community and the underserved cannot really understand what the medical components are doing or talking about, and they tend to take over any meetings. Possibly a representative or two from each group could form sort of a board and they could report to the group what went on in their meetings."

This is a difficult question to answer without knowing what decision is going to be made by the NCI about what it wants the DCLG to actually do in the future. I think the leaders of the various advocacy groups know the issues of their constituents better than anyone else and should be involved. However, if a prime issue is getting patients into clinical trials than at least a work group charged with this responsibility has to represent the appropriate gatekeepers and decision makers. I am not trying to sidestep answering this question, but it is difficult without knowing the final charge to the revised DCLG.

Strategic planners, information systems specialists, patients, health care practitioners (particularly nurses), professional advocates.

A combination of people who have either a personal or family cancer history, and those who have a medical/scientific background. Preferably, these people would be volunteers within their organizations, so that they would truly represent the needs of the patient community without the bias of a clinician or researcher, as these components are already well represented.

Members of the DCLG should be advocates that not only have knowledge of the cancer patient population that their organization serves but most of all they should demonstrate their ability to work with other organization to identify common needs across the population as a whole. It will be only through a spirit of cooperation that the greater cancer population will be served. There needs to be an openness to those not represented so that the needs of all can be heard.

See my answer to the earlier question.

The cancer community is very large and disparate, therefore the individuals selected for the DCLG must be willing to put personal concerns and agendas aside and work on focused issues that benefit the larger populace. Members should be decision-makers within their respective organizations, autonomous, not easily intimidated, and willing to expand their knowledge base. A PhD or MD should not be a requirement, but a training orientation and self-study course should be mandatory.

I would recommend cancer survivors, directors of cancer agencies, people of color, the working poor, and individuals from poor, rural, high minority states.

Trained, independent advocates are important because of minimal bias. Survivors are preferred but in some cases it is not possible to recruit them...childhood cancers, adults with fast growing cancer profiles. Independent advocates are difficult to recruit because of professional and financial conditions, nevertheless, it is important to have strong voices in this community. Regional representation is critical for balanced participation. Advocates have to have a flexible schedule.

Leaders who are passionate, educated, well informed, good communicators, and skilled in networking would be appropriate.

It would help to have medical knowledge for some of the activities, but it is not an absolute necessity. It is also important to have people who look at things in different ways. Traits: Strategic planning experience, willingness to put an individual cause secondary to look at the big picture.

A person with first hand experience dealing with another with a cancer diagnosis. A board member of their organization with responsibilities in legislative aspects.

People who have NEVER taken money from any of the 'players', e.g. pharmaceutical companies. People who have strong connections to the community of people with cancer. People who understand many of the issues from the broadest possible perspective. Those who have undertaken to educate themselves on science issues, survivorship issues and have some awareness of treatment modalities. These people would need to be able to inform their associates, organizations and communities. Perhaps a newsletter with articles from the DCLG, letting other groups know what is happening? Our organization would very much like to know that at least one person serving on the DCLG has sympathy and understanding for the almost 80% of people with cancer with an interest in complementary, alternative therapies.

Some "big picture" strategic thinkers; some "hands on" implementers. Individuals who are well-connected in the cancer-services arena in their geographic regions."

Individuals who are well-informed and have a strong background serving as volunteer advocates and leaders in their organizations would be excellent candidates for the DCLG. A background in working with cancer patients and survivors (or are survivors themselves) -

either directly through work as a health care provider or in an outside role would also be an important consideration.

Cancer Survivor, leader, college graduate, non-profit board member, political advocate, cooperative personality.

Unknown

[Note: Suggests specific individual. Information provided to Office of Liaison Activities/NCI.]

1. Close connection to an advocacy organization, preferably an officer or trustee - 2. He or she need not be a medical professional but should have considerable knowledge of cancer as well as the specific diseases of his/her organization. - 3. One must be willing to travel and to put in the time required. - 4. One must be articulate, able to express ideas orally as well as written.

Well informed advocates, experience on other national panels, good team player, access to constituency, national perspective.

Participants should be disease survivors and heads of their respective organizations. They should have demonstrated programs of accomplishment in serving their constituencies and should be creative in developing new opportunities for synergy with the NCI and the advocacy community. Ideally, they should be well-grounded in a background apart from their advocacy base that can bring a different perspective to the problem.

Experience with a broad-range of cancer types. - Direct and continuing patient contact. - Ability to communicate and basic knowledge of cancer process. - Experience with cancer personally or with close family. - Individuals would have roles in leadership and/or communication.

People working in local community cancer support organizations on a day to day basis.

Q 18 How would you prefer that the DCLG communicate with you? Please denote your first choice below.

Other (Please specify _____)

Surveys and/or e-mail

Q 19 How would you prefer that the DCLG communicate with you? Please denote your second choice below.

Other (Please specify _____)

Surveys an/or e-mail

**Q 24 I Which of the following communities does your organization actively serve?
Check up to three.**

Other (Please specify _____)

Community Based Organizations

Child Life, Social Worker, nurses, doctors

Those at high risk

Social workers

The DC Metropolitan area as a whole

General Public

Healthcare Workers

The general public

We don't serve gov't, or pharma/biotech but work closely with them

Community education, teens to mature women

All of the above

General Public

Survivors in all stages of survivorship

Q 28 Are there any additional comments that you would like to make about DCLG's future focus or activities?

Please continue to have a voice and let that voice be known.

I would like to see the DCLG focus on areas of survivorship and socioeconomic disparities and work to encourage the development of resources that address these issues.

There needs to be more communication between DCLG, NCI, and cancer advocacy organizations.

This is an extremely important group and I'm hopeful that this survey will enable the group to evaluate priorities to continue in a purposeful and progressive manner.

I think the work of the DCLG is important and we look forward to hearing more about the activities the group undertakes.

Better communication with CARRA members, emphasis on developing an in depth, comprehensive training for members to help them participate in grant reviews, site visits and other activities in a meaningful way.

Please advise me about DCLG by mailing to me your literature, mission, strategy, - goals, and participation needed from me. [Note: Provides name and mailing address. Information provided to Office of Liaison Activities/NCI.]

Your desire to get information through a feedback survey is fantastic. Keep up the great work!!!

Many people I knew who were very interested in making a contribution on DCLG were not selected. To utilize such commitment on the part of people perhaps it would be possible to form working groups on a variety of issues. Allow people to innovate and work toward solutions. As Lance Armstrong says, if you have the research to save peoples lives, you also have the obligation to make the quality of those lives of first priority."

No

Thank you for doing this survey.

Thank you for asking!

If I can help and be involved, let me know.

The scope of this survey infers an enormous amount of responsibility and activity -They are volunteers, are they not?

I think that groups that address the psychosocial needs of those affected by cancer are an important cornerstone of the advocacy community. - - As mentioned previously, our high-risk constituency would like to see issues of cancer Pre-vivorship be addressed. Further, it makes sense that when these issues are addressed that those organizations with experience dealing with those predisposed to cancer be included at the table for discussion on how to best serve this population's needs. - - Thank you.

The DCLG is an important adjunct to NCI. It should be allocated more funds and greater authority.

No

No

Keep the consumers/advocates in the loop.

Better communication about the DCLG and ways in which we can work more closely with the NCI to ensure that our members' needs are met.

Expand the role of cancer survivors and imbed them in all aspects of decision making at the NCI.

It is very good that this survey is being conducted to update and refine the work of the DCLG.

Good luck and keep up the good work. Anyone concerned and working on anything related to cancer, helps the rest of us, especially survivors.

I think this group has a tremendous potential to really help move the cancer community's agenda forward; to date I think it has fallen far short of its potential. I thank you for asking for input at this critical time about the future role and goals that the DCLG should pursue. If our organization can assist in any way we would be delighted to do so. Again, thanks for asking for our input.

The DCLG must be supported and promoted by the Director and Division heads, so that it has the ability to affect change and is recognized to have value to the Institute. It must set achievable and focused common goals.

The number of constituents in the database would not let me enter 10,000 through 50,000.

Participation depends on my schedule and the costs involved in the activity. We are an independent volunteer organization. No one is paid, planning fundraisers is difficult for us as we all work and some work on a rigid schedule more than others. Compensation is important when you may also have to give up a paycheck to do this work.

Once I was plugged into the system", the communication is great (e-mail)."

Areas of focus: rating the various areas as 1-5 diminishes the fact that most advocacy groups work on all of the areas. - - For example, we constantly and continually urge more clinical trials be held in the area of complementary, alternative (CAM), natural therapies. At the same time, we communicate, search out research in the area, care deeply about the way treatment and detection variabilities affect different populations. Survivorship is a strong issue with us as well, as we offer information, education, advocacy and awareness for people with cancer interested in CAM. These people are among the large subset most likely to make 'lifestyle changes'. And recent studies show that such changes even in our middle years, can make a difference.

No

The [name of organization] organization and I appreciate the fine work of the DCLG and the opportunity to provide feedback. We look forward to an ongoing collaboration with the DCLG, as there is a great deal of synergy in our priorities, work, and areas of focus.

Clarify mission and get the word out about its accomplishments!

Do a better job of communicating what the DCLG is, its current membership, the selection process and its measurable accomplishments.

Its focus should continue to include survivor concerns and two-way communications.