

**DEPARTMENT OF HEALTH AND HUMAN SERVICES
NATIONAL INSTITUTES OF HEALTH
NATIONAL CANCER INSTITUTE**

**MINUTES of the NCI DIRECTOR'S CONSUMER LIAISON GROUP
February 28 to March 1, 2005**

The 30th meeting of the National Cancer Institute (NCI) Director's Consumer Liaison Group (DCLG) was convened at 10:10 a.m., February 28, 2005, at the Holiday Inn Select, Bethesda, Maryland. Mr. Doug Ulman presided as Chair.

Members Present

Mr. Doug Ulman, Chair	Dr. Sylvia M. Ramos
Ms. Peggy L. Anthony	Mr. Eric Rosenthal
Ms. Vernal H. Branch	Ms. Mary Jackson Scroggins
Ms. Lourie Campos	Ms. Sue Sumpter
Ms. Nancy Davenport-Ennis*	Ms. Cece Whitewolf
Ms. Bobbi de Córdova-Hanks	Col. (Ret.) James E. Williams, Jr., USA*
Dr. Beverly Laird	

*These DCLG members were present only on February 28.

Speakers:

Dr. Anna Barker, Deputy Director, Advanced Technologies and Strategic Partnerships, NCI
Ms. Vernal Branch, DCLG
Dr. Mark Clanton, Deputy Director, Cancer Care Delivery Systems, NCI
Ms. Nancy Davenport-Ennis, DCLG
Dr. Greg Downing, Director, Office of Technology and Industrial Relations
Ms. Brooke Hamilton, Acting Director, Office of Liaison Activities, NCI
Ms. Mary Jackson Scroggins, DCLG
Dr. Beverly Laird, DCLG
Ms. Cherie Nichols, Director, Office of Science Planning and Assessment, NCI
Dr. Julia Rowland, Director, Office of Cancer Survivorship, NCI
Mr. Doug Ulman, Chair, DCLG
Dr. Nada Vydelingum, Deputy Director, Center to Reduce Cancer Health Disparities, NCI
Col. (Ret.) James Williams, Jr., DCLG

NCI Office of Liaison Activities Staff

Ms. Nancy Caliman, Executive Secretary, DCLG
Mr. James Hadley, Advocacy Program Manager
Ms. Brooke Hamilton, Acting Director
Ms. Jane Jacobs, CARRA Program Manager
Ms. Alissa Lewandowski, Health Communications Intern
Ms. Elizabeth Neilson, CARRA Program Coordinator
Ms. Bethany Piernikowski, Administrative Aide
Ms. Linda Ticker, Program Assistant

Other NCI Staff

Ms. Sarah Birkhead, Special Assistant to the Director of NCI
Ms. Nina Goodman, Operations Research Office, Center for Strategic Dissemination

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I. WELCOME AND SELF-INTRODUCTIONS

Mr. Doug Ulman thanked the DCLG members for participating in this meeting.

Conflict of Interest Statement. Mr. Ulman reviewed the rules governing confidentiality and conflict of interest, and Ms. Nancy Caliman determined that a quorum was present.

Introductions. Those present introduced themselves.

Minutes. A motion to approve the minutes of the DCLG's January 18, 2005, meeting was carried unanimously.

II. REPORTS FROM NCI

Update from the Office of Cancer Survivorship. Dr. Julia Rowland explained that NCI's Office of Cancer Survivorship (OCS) conducts an annual analysis of all cancer survivorship grants funded by the National Institutes of Health (NIH). Included in this informal portfolio review are those grants which evaluate survivors and/or their family members/caregivers a minimum of two months following completion of treatment. Studies that evaluate the status of or outcomes for survivors in active treatment or with recurrent or metastatic disease are not included in this analysis. Of the 212 of these types of grants identified across the NIH in FY2004, the majority (181 or 85%) were supported by the NCI, with most of these (148) being held by NCI's Division of Cancer Control and Population Studies, which includes OCS. Breast cancer continues to be the most studied cancer site, but the diversity of sites studied is growing. A majority of studies focus on psychological distress, but more investigators are beginning to address other issues, such as health behaviors and post-treatment effects.

Dr. Rowland announced several current OCS activities:

- The first meeting of the investigators funded by the Long-Term Cancer Survivors reissued request for proposals (RFA) took place in January 2005. This meeting was designed to foster a cadre of investigators committed to studying long-term effects (those seen in individuals five or more years post-diagnosis) of surviving cancer and to encourage the use of shared measures to make it possible to compare results.
- The Cancer Care Outcomes Research and Surveillance Consortium (CanCORS) is a very large study in six sites. A supplement is supporting research on caregiver burden.
- Two program announcements were issued to encourage investigators to study how patients make single decisions, such as whether to undergo a specific procedure, and multiple decisions over time, such as the many decisions involved in giving up smoking.
- The newly revised Health Information New Trends Survey (HINTS) is a large population-based survey that will collect information on health and health behaviors. The study population includes 700 individuals with a history of cancer for whom information seeking patterns and behaviors can be examined.
- NCI added a set of questions to the California Health Interview Survey to address the use of complementary and alternative medicines among cancer survivors.

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- Two SEER Rapid Response Studies are addressing late effects and the use of follow-up care among survivors of a) non-Hodgkin's lymphoma and b) four other major adult cancers: breast, colorectal, prostate and gynecologic cancers.

Upcoming events include the following:

- The next NCI/American Cancer Society (ACS) Biennial Cancer Survivorship Research Conference will take place in 2006. OCS will solicit the DCLG's participation in the planning committee for this conference.
- The Institute of Medicine will issue a report on adult survivorship in the fall of 2005.
- The President's Cancer Panel (PCP) will hold follow-up/stakeholder meetings to advance the recommendations from their reports on cancer survivorship and translation.
- OCS is using concept mapping to identify all of the activities at NCI that are related to cancer survivorship. This information should be available by the fall of 2005.
- The Third Annual Cancer Survivorship Teleconference Series, *Living With, Through, & Beyond Cancer* will take place on April 12, May 24, and June 14, 2005. These free telephone education workshops are geared to cancer survivors, their families and friends, and healthcare professionals and represent a partnership of NCI with Cancer Care, the Lance Armstrong Foundation, the Intercultural Cancer Council, Living Beyond Breast Cancer and the National Coalition for Cancer Survivorship.
- The *Translating Data into Action* meeting will take place on April 14-15, 2005. This meeting will provide the advocacy community with an opportunity to understand what is in NCI's Surveillance, Epidemiology, and End Results (SEER) dataset and how it is used, and to share input on what type of data provided in what format would be most useful to consumers.
- Plans are underway to expand and update the OCS website.

Dr. Rowland suggested that a question be posted on the *NCI Listens and Learns* website asking the community to identify the recommendations from the PCP report on survivorship that are most important to them, and to share their ongoing activities in those areas.

Discussion. Dr. Sylvia Ramos asked for information on the long-term survivorship grants. Dr. Rowland explained that the OCS website (<http://www.survivorship.cancer.gov>) has detailed information on the RFA. It also provides information on these as well as all of the other funded survivorship focused grants held by the OCS, including descriptive abstracts. DCLG members who want more details on survivorship studies should e-mail OCS, which will provide the requested information.

Ms. Mary Jackson Scroggins asked how NCI will promote the Follow-up Care Use Among Survivors (FOCUS) study. Dr. Rowland explained that this is a closed study, involving two California cancer registries that identify people who meet NCI's selection criteria and send them an invitation to participate.

Ms. Bobbi de Córdova-Hanks asked how grassroots organizations can find out about studies so that they can participate. Dr. Rowland replied that enrollment in most studies must be carefully controlled to obtain representative samples.

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Ms. Davenport-Ennis noted that the digital divide is an important barrier to many groups. The DCLG might be able to facilitate conference calls that OCS staff could use to collect ideas from grassroots groups. Ms. Scroggins suggested surveying some underserved and underrepresented populations to identify what they think of as barriers to participation in research studies?.

Ms. Cece Whitewolf pointed out that the SEER training provides funding for only a one-night stay and requires that participants pay for the conference with their own credit cards before being reimbursed. These are difficult barriers for many potential participants. Dr. Rowland offered to follow up with her SEER colleagues on this important issue.

Ms. Lourie Campos observed that cancer survivors often don't know what to do when their treatment ends. Dr. Rowland suggested that best practices are needed to follow-up with survivors for side effects and other issues beyond recurrence. The Children's Oncology Group has published some excellent, but very complicated guidelines for follow-up care on the Web. In addition, the American Society for Clinical Oncology (ASCO) is revising its guidelines for follow-up care for survivors of adult cancers. One challenge to good follow up care is that most survivors are treated in the community, not in cancer centers. Hence, reaching out to primary care physicians about survivors' needs after cancer is important. NCI plans to ask practitioners about these issues.

Ms. Davenport-Ennis encouraged NCI to engage the health plan community in these discussions, as they will have an influence on the implementation of any recommendations. Dr. Rowland replied that payers would want evidence of effectiveness because they cover follow-up care. Ms. Davenport-Ennis suggested encouraging providers to publish their experiences. Advocates can give information on the experiences of their constituencies.

Dr. Rowland noted that few federal mechanisms are available to support research on quality-of-care models. NCI focuses on basic science and the Agency for Healthcare Research and Quality (ARHQ) studies quality of care but has a very limited budget. NCI might need additional funding partners or very specific questions that can be asked with a model. The community must be involved in formulating those questions.

Ms. Peggy Anthony pointed out that survivors who participate in clinical trials are sometimes followed through the trials. Dr. Rowland said that most clinical trials focus on whether the patient is still alive and do not address quality of life. Further, HIPAA regulations make access to people who have been treated in the past very difficult. She surmised that advocates may need to help responsible researchers obtain this access.

Ms. Scroggins supported posting a question on *NCI Listens and Learns* about the PCP recommendations. She cautioned, however, that questions posted on the site must be clear, simple, and brief. Dr. Rowland proposed asking the question in two stages. The first would ask participants to rank the PCP recommendations in order of importance and the second would ask what community members were currently doing to address the recommendations.

Ms. Davenport-Ennis suggested surveying DCLG members' constituencies concerning the PCP recommendations. Ms. Brooke Hamilton explained that DCLG members are free to survey their

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own constituencies and provide feedback, but it is difficult for NCI to initiate surveys because of the clearance procedures that must be followed.

Update from the Office of Science Planning and Assessment. Ms. Cherie Nichols provided an overview of the Progress Review Group (PRG) process used by NCI. Since 1997, the PRGs have identified national agendas in disease-specific research. So far, NCI has sponsored 11 PRGs and led 1 PRG sponsored by the U.S. Department of Health and Human Services (DHHS). All of the PRGs have now developed recommendations and most are currently in the second phase, which involves integrating the priorities identified in the first phase. Progress reports are now available for breast and prostate cancer, and similar reports will be produced on colorectal and pancreatic cancer in 2005. All 12 PRG reports are available on NCI's website at <http://prg.nci.nih.gov>.

PRGs each consist of 25–30 individuals with relevant expertise who develop a national agenda for a given disease. These individuals assess the portfolio of current efforts and provide advice on how to address important gaps and needs. Each PRG plans a roundtable meeting at which breakout groups select short lists of priorities that are presented in the group's final report. NCI then determines the extent of activity in each recommendation area and develops a response report for the PRG. At this point, the integration phase begins.

Ms. Nichols characterized the advocacy groups that participated in the PRG process as the “workhorses of the PRG.” Every PRG breakout group had at least one advocate and many had two. Approximately 300 PRG members and 1,000 roundtable members participated in the process, which addressed 17 major disease sites.

Ms. Nichols presented several examples of progress made in prostate cancer since the Prostate Cancer PRG issued its initial report. For example, the PRG suggested increasing the number of investigators trained, and this number has more than doubled. No good animal models of prostate cancer were available in 1998, when the PRG issued its report, but an NCI RFA has resulted in the development of several prostate cancer mouse models. Funding for prostate cancer has tripled and the number of projects doubled over the last five years. Similarly, funding for breast cancer has doubled since the Breast Cancer PRG issued its report and the number of projects has grown from 1,000 to more than 1,500.

Ms. Nichols highlighted some selected implementation activities:

- The number of investigators on NCI pancreatic cancer studies increased from 28 in 2001 to 53 in 2003.
- NCI is working with the Pancreatic Cancer Action Network to develop a pancreatic cancer research map to enhance opportunities for collaboration.
- NCI has issued a Program Announcement in collaboration with the National Institute of Neurological Disorders and Stroke for research on understanding and preventing brain tumor dispersal.
- NCI plans to support seamless public/private partnerships that will take researchers from the discovery of a leading molecule to the implementation of new treatments that use their discovery. NCI provides seed money and the academic institution must provide matching funds.

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- The Institute has established an Integration and Implementation (I²) team to address lung cancer.
- NCI has teamed up with the Food and Drug Administration (FDA) to develop proteomic technologies for the early detection of ovarian cancer.

The PRG reports continue to shape NCI's research directions and outcomes. For example, several divisions use the recommendations in developing RFAs. In addition, advocates, researchers, and professional societies also regularly use the reports.

One of the unique outcomes of the PRG process has been the Common Scientific Outline (CSO). The need for a classification system for NCI's research became clear after the first PRGs issued their reports, so NCI developed the CSO in collaboration with the Department of Defense (DoD). The CSO is now used for NCI's Cancer Research Portfolio and International Cancer Research Portfolio.

Interviews with PRG members and roundtable participants have shown that the PRG process is a very effective, coordinated, and organized method of gaining input from the extramural community. PRG leaders have said that the process was critical to identifying the research areas most likely to have an impact on the diseases addressed.

Ms. Nichols posed the following questions to the DCLG:

1. What are the best ways to continue to use PRG reports and progress reports? What are the best ways to seek advice from all fronts?
2. What are some cross-cutting topics in cancer research of interest to the cancer advocacy community?
3. How can the cancer advocacy community become involved in implementing the PRG report recommendations?

Discussion. Col. James Williams expressed concern about the fact that members of the advocacy community have pushed for a focus on specific organs but the trend in research is to focus on general biomedical research that could impact all cancers. This means that members of the cancer advocacy community (CAC) must rethink their approach to advocacy.

Ms. Davenport-Ennis commended the steps that NCI Director Dr. Andrew von Eschenbach is taking with the Centers for Medicare and Medicaid Services (CMS) to address ways to reimburse for the costs of new discoveries. If disparities exist between the treatments that the scientific community can deliver and the reimbursement system, the result will be a system that could reverse the progress of disease but that can benefit very few people. As PRGs address progress in science, those who determine access and reimbursement must be included in the discussions. Ms. Nichols explained that Dr. Mark Clanton is working with CMS on these issues. Dr. Clanton oversees the Office of Science Planning and Assessment, so he is involved in the PRG discussions.

Ms. Vernal Branch asked whether advocacy participation is still needed for the national tissue bank. Ms. Nichols explained that the National Biospecimen Network will be piloted in the Specialized Program of Research Excellence (SPORE) program but the information will become widely available so that other groups can use it. Tissues are a very important part of moving the

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science along. At this point, the infrastructure needs to be in place so that the advocacy community can help researchers obtain the tissues they need.

Dr. Ramos pointed out that the ways in which race and ethnicity affect responses to cancer treatment and outcomes cut across all cancers. Ms. Nichols agreed, saying that several lung cancer studies are having difficulty with recruiting members of various ethnic populations.

Mr. Ulman proposed a PRG on young adults with cancer.

Ms. Kathie Reed of the Office of Science Planning and Assessment (OSPA) thanked the DCLG members for helping refine OSPA's question for the *NCI Listens and Learns* Web site. OSPA hoped to gather input that could be used for strategic planning, developing the annual Bypass Budget, and helping NCI identify ways of collaborating with advocates. Ms. Sue Sumpter emphasized the importance of brevity and clarity in questions posted on the site.

Update from the Center to Reduce Cancer Health Disparities. Dr. Nada Vydelingum explained that the Center to Reduce Cancer Health Disparities (CRCHD) is working with 10 divisions and centers (up from 7 in 2004) within NCI to address NCI's efforts—and, to some extent, those of NIH—in cancer health disparities. CRCHD is also working with several NIH institutes and with C-Change (formerly the National Dialogue on Cancer) and other groups outside the Department of Health and Human Services (DHHS).

The Center's Special Populations Network (SPN) program was very successful. In 5 years, SPNs conducted more than 1,000 cancer awareness activities, formed more than 300 formal partnerships with community-based organizations and government and non-government groups, and trained more than 2,000 community/lay health workers in cancer awareness. Almost 100 pilot projects were funded, more than 150 minority researchers were trained, and more than 100 peer-reviewed papers were published or are in press.

The SPN program has been reissued as the Community Networks program. This new program is designed to reduce cancer disparities in the community by increasing the use of beneficial cancer interventions and by providing community-based education and research, and training in disparities research. The Center plans to provide 5-year grants to 25 Community Networks.

Dr. Vydelingum highlighted the differences between the Community Networks program and the Centers for Disease Control and Prevention's (CDC's) REACH program. The major difference is that NCI's program deals only with cancer; the REACH program addresses cardiovascular disease, diabetes, immunizations, and other issues.

The Center received 41 applications for the Patient Navigator Program and hopes to make funding decisions for the program in the summer.

Discussion. Col. Williams noted that at its last meeting, the National Cancer Advisory Board (NCAB) discussed the trend toward basing sampling strategies on cancer disparities. He asked whether the Center's work addressed the fact that the demographics of many populations do not reflect the ways in which cancer affects them. Although NCI is trying to reach out into the

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community through cancer centers, many communities do not have access to a comprehensive cancer center. He wondered what NCI was doing to extend the influence of its cancer centers.

Dr. Vydelingum replied that the SPN program extended the reach of NCI cancer centers, with 18 locations and 100 different points of research across the country. The new Community Networks program is a cooperative agreement, so NCI will have a great deal of input into these networks. The CRCHD plans to work with the cancer center program directors at NCI.

Col. Williams asked for more details on the Patient Navigator Program to be supported by NCI. Dr. Vydelingum replied that the CRCHD has examined 125 patient navigator programs across the country, which ranged from a single laptop to a comprehensive program at a healthcare facility. The Center's RFA addresses a research question on what works, how it works, the cost-benefit ratio, and the differences in approach between rural and urban groups. This program uses a cooperative agreement funding mechanism and the Center will work with investigators to develop an evaluation component. The Patient Navigator Program has not yet been earmarked for funding but the Center will continue to review applications and hope that funds will be available toward the end of year. Otherwise, CRCHD will seek support for 2006.

Ms. Scroggins asked whether the Patient Navigator Program would provide technical support to minority institutions or Historically Black Colleges and Universities to encourage their participation. Dr. Vydelingum replied that the RFA was written in that spirit, but the Center has no control over the selections of the peer reviewers. The scientific review administrator will talk to the peer reviewers about the RFA and its intent.

Ms. Scroggins asked about the involvement of advocates from special populations in planning and developing RFAs. Dr. Vydelingum explained that the concept for the Patient Navigator Program was reviewed by the NCI Executive Committee and Board of Scientific Advisors. Ms. Nichols added that advocates are members of all the Institute's advisory groups and participate in the peer review groups. Dr. Vydelingum continued that prior to the receipt date for applications, the Center invited questions and comments from the community. However, the Center has no formal way to involve populations targeted by an initiative in its development.

IV. STATUS OF *NCI LISTENS AND LEARNS* WEBSITE

Status of *NCI Listens and Learns* Web site. Ms. Hamilton announced that NCI had officially launched the *NCI Listens and Learns* Web site on Wednesday, January 26, 2005. As of the end of February, 108 groups had registered for the site. During the first month, the site received 10,000 hits representing more than 3,860 visitors. The first question received 13 responses from advocacy groups and 14 from individuals. Ms. Hamilton thanked the DCLG members for their personal outreach to increase the number of groups participating in the discussions.

Promotional activities to publicize *NCI Listens and Learns* include a press release and an article in NCI's *Cancer Bulletin*. NCI's home page, which receives more than one million views a month, has a link to the site.

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A Web-based customer satisfaction survey has now been launched. The survey has been presented to site visitors 94 times but only 12 individuals have completed it. At least 300 responses to the survey must be received before the contractor will analyze them. To increase the number of responses, OLA has arranged for the questionnaire to pop up to all users who click on two places on the site. The survey had previously appeared to only 50% of individuals who clicked on three places on the site. OLA has also received permission from NIH to use a “persistent cookie” so that the survey will no longer pop up for individuals who have already completed it.

All of the posts so far have been appropriate and none have needed to be removed. The DCLG Operations Working Group has sent out weekly reports on the responses and OLA is studying ways to summarize comments from the public as well as those from cancer advocacy groups.

The second question had been posted earlier in the day and addressed the NCI Challenge Goal of eliminating the suffering and death from cancer.

Troubleshoot *NCI Listens and Learns* Issues. Ms. Nancy Davenport-Ennis, DCLG, lead the discussion of *NCI Listens and Learns* Issues.

American Customer Satisfaction Index (ACSI) Survey. Ms. Sumpter noted that some of the questions on the American Customer Satisfaction Index (ACSI) pop-up survey have little relevance to *NCI Listens and Learns*. Also, the font at the top of the page is too small to read on her computer and the survey is quite long. This may explain why so few people have completed it.

Ms. Hamilton explained that many of the questions are required because the survey was validated in the current format. Dr. Beverly Laird suggested that if the Web site proves to be easy to navigate, the survey may not be necessary.

Dr. Laird suggested asking the contractor for responses to the request for suggestions on improving the site before 300 completed surveys have been received. Ms. Hamilton will ask the contractor about this. The usual response rate is 3%–5% and *NCI Listens and Learns* has a 10% response rate.

Using the Site. Ms. Whitewolf experienced difficulty in signing up for the site using a very old and slow computer. She asked about support for users of the site. Ms. Hamilton explained that OLA could provide support when needed to help make this process more user friendly.

Ms. Sumpter noted that users might not be aware that they needed to click on the question to post a response. Also, it should be possible to format responses into paragraphs so they would be easier to read. Ms. Hamilton noted that OLA is working on the ability to format responses.

Ms. Sumpter also asked whether visitors to the site could view previous discussions. Ms. Hamilton replied that the feedback provided by the CAC would always be available, although it would move down the page as time goes on.

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Selecting Questions for the Site. Ms. Whitewolf asked about the process for selecting, editing, and approving questions posted on the site. Mr. Ulman explained that OLA has asked representatives from different NCI divisions to submit ideas for questions. OLA then asks for feedback on the question from the DCLG. Ms. Whitewolf suggested providing NCI staff with more direction on the types of questions suitable for posting.

Ms. Hamilton explained that Ms. Caliman has distributed draft versions of the questions to the DCLG by e-mail for feedback prior to posting them. She collects the responses from DCLG members and provides them to the individual who originated the question. The topics need to come from NCI program staff because they will respond to the feedback that is gathered. OLA and the DCLG cannot pick topics of general interest because someone within NCI must take responsibility for preparing NCI's response to the feedback.

Ms. Scroggins suggested a system in which the ideas for questions come from NCI but the DCLG reviews the questions prior to posting them. Perhaps the DCLG should develop guidelines for questions so that multi-part questions are not submitted. Ms. Davenport-Ennis said that each DCLG member could contribute a new thought to the question when it circulated. Ms. Caliman would then work with her team to refine the question.

Ms. Caliman asked the DCLG members to be open-minded about the formatting of the questions. She suggested trying several different formats and seeing how effective they are before deciding which is best. A balance must be maintained between what is useful to the advocacy community and what is useful to NCI. Some questions might be complicated because of the nature of NCI's work; if questions are overly simplistic, the responses might have limited value to NCI.

Ms. Nina Goodman of NCI's Operations Research Office offered her office's assistance in preparing the *NCI Listens and Learns* questions.

Increasing Traffic on the Site. Ms. Sumpter asked about sending reminders to organizations that have registered for the site when a new question is posted. Ms. Hamilton said that OLA sends a notice by e-mail when a new question is posted, and sometimes during the comment period. Almost 40% of the organizations that have registered for the site have not yet appointed a spokesperson.

Ms. Branch said that the DCLG's role is to help NCI include advocates in its processes. DCLG members must remind their constituents to respond to the questions. DCLG members need to send out reminders to their own constituents when a new question goes up and ask them to respond.

Ms. de Córdova-Hanks thought that members of her organization believed no one would be interested in what they had to say. She wondered why so many groups had not yet appointed a spokesperson. Ms. Sumpter suggested that national organizations might find it difficult to appoint a single individual to speak on their behalf. But the fact that they have signed up shows that they are interested.

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Mr. Ulman pointed out that the first question generated 12 responses from the 60 organizations that had registered and appointed a spokesperson. Perhaps DCLG members need to call or e-mail the groups that have not yet appointed a spokesperson.

Ms. Anthony said that her alliance found it difficult to select a single representative to speak for the entire organization. They decided that the chairs of all five groups would serve as spokespersons and the most relevant one would respond to each question.

Ms. Whitewolf suggested reconsidering the requirement that national organizations with chapters appoint a single spokesperson. This might make it easier for groups to appoint a spokesperson. Ms. Hamilton reminded DCLG members that they had already put a great deal of time and thought into the decision to require national groups to appoint a single spokesperson. The DCLG is asking national groups to poll their local and regional affiliates before posting a response.

Role of the DCLG. Ms. Hamilton said that OLA and the DCLG had focused primarily on encouraging organizations to register for the site and now they needed to begin encouraging national organizations to appoint a spokesperson.

Mr. Rosenthal expressed concern that questions might go out to the public that people cannot understand, and they might then blame the DCLG for the lack of communication. Ms. Davenport-Ennis suggested that the DCLG's role is to:

1. Engender the involvement of the broader patient advocacy community with the *NCI Listens and Learns* Web site.
2. Work collaboratively with NCI as it develops the questions that will be posted.
3. Serve as an early warning system regarding how to keep the site moving forward.

Mr. Ulman pointed out that the DCLG has a role in developing the questions. For example, he had proposed a question to Dr. Rowland a few months earlier and, after thinking about it, Dr. Rowland decided that she wanted to post the question. The DCLG should identify questions for consideration by NCI staff. Mr. Ulman challenged each DCLG member to think about what questions might be raised by the discussions with NCI staff earlier in the meeting.

Ms. Scroggins suggested that some groups might not understand the spokesperson's role. Mr. Ulman replied that this was a good reason to call the organizations that had not yet appointed a spokesperson.

Ms. Whitewolf suggested that the NCI leaders spend the entire day with the DCLG so that they could hear this type of discussion. Mr. Ulman agreed that having them participate in this discussion would be helpful.

Monitoring the Site. Col. Williams asked for feedback on the Operations Working Group's efforts to monitor the responses to the site. Dr. Laird characterized the group's reports as "invaluable" and asked the group to continue its monitoring. Ms. Sumpter agreed, noting that the working group's reports kept the topics in everyone's minds. But in the future, biweekly reports might be sufficient. Col. Williams agreed but noted that the group would probably not need to

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monitor the site as frequently as every two weeks. Dr. Laid agreed but emphasized the value of the Working Group's feedback.

Site Schedule. Ms. Hamilton noted that the current schedule called for posting each question for four weeks but this might be changed in the future.

Promoting the Site. Ms. Hamilton announced that *NCI Listens and Learns* marketing materials would be delivered shortly to each DCLG member who requested them. Ms. Scroggins, Ms. Davenport-Ennis, and Mr. Rosenthal asked for electronic copies of the materials.

Mr. Eric Rosenthal asked whether other media or newsletters had picked up the story of the *NCI Listens and Learns* launch. Ms. Hamilton said she would talk to the NCI Press Office about this.

V. COMPLETION AND APPROVAL OF *NCI LISTENS AND LEARNS* LOGIC MODEL AND EVALUATION PLAN AND WORK ON *NCI LISTENS AND LEARNS* SUMMIT LOGIC MODEL AND EVALUATION PLAN

Dr. Laird reviewed the draft logic model for *NCI Listens and Learns*. This model is a summary of the Web site's operations on one page. The items in the first columns are designed to lead to the outcomes and impact in the last columns.

Ms. Whitewolf asked that acronyms, such as CAC (Cancer Advocacy Community), be defined in a legend on the logic model. She also suggested using a larger font size so that people with limited vision could more easily read the logic model and evaluation plan.

Dr. Laird noted that the DCLG/NCI 2003 Survey of Cancer Advocacy Organizations had provided good baseline data that would be valuable in evaluating the Web site's impact. Perhaps the DCLG could field a survey after the site's first year, although it might want to include additional questions.

Mr. Ulman suggested that the word "satisfaction" is overly vague. Dr. Laird agreed that this term should be reconsidered for the follow-up survey. The survey should ask questions in a way similar to the initial survey but the purpose was not to write a scientific journal article, so the DCLG has some leeway in designing the follow-up survey.

General Public. Ms. Hamilton requested clarification on the items that were highlighted in the logic model. Dr. Laird explained that one of the issues is what to call the "general public." She asked whether *NCI Listens and Learns* was expected to serve as an avenue for the general public to have their needs and concerns heard. Ms. Hamilton suggested using "interested public" instead of "general public." Dr. Laird agreed to change the term throughout the logic model and evaluation plan.

Satisfaction with Access to and Quality of NCI Resources. Ms. Hamilton asked whether it was appropriate to include as long-term goals that CAC members, their constituents, and individuals in the community would be more satisfied with access to NCI resources (long-term outcome 2) and that these groups would be more satisfied with the quality of NCI resources

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(long-term outcome 3). She suggested that these outcomes were not purposes of *NCI Listens and Learns*. Mr. Ulman suggested that the goal was for these groups to have a say in NCI's process. The DCLG's original survey gave the impression that the CAC did not believe it had an avenue of communication with NCI.

Dr. Laird agreed that quality is probably not addressed by *NCI Listens and Learns* but access might be. Ms. Hamilton said that the site does not link viewers to other NCI resources. Dr. Laird suggested that access be interpreted more broadly to include the ability to interact with NCI.

Ms. Scroggins suggested that reading the *NCI Listens and Learns* questions and submitting responses to them might change the user's sense of his or her ability to access resources at NCI. Dr. Ramos said that the quality of NCI resources includes how useful and understandable information is from NCI.

Dr. Laird proposed deleting long-term outcome 3 concerning satisfaction with the quality of NCI resources. Col. Williams suggested deleting "resources" from long-term outcome 2 so that it addressed satisfaction with access to NCI.

American Customer Satisfaction Index (ACSI) Survey. Dr. Laird explained that NIH had provided the opportunity for OLA to use the ACSI survey at no charge. This survey is widely used by government agencies to evaluate the effectiveness of their Web sites. The survey will provide some customer satisfaction data however, at least 300 responses must be received in order for the contractor to analyze the data.

The survey includes required questions and custom questions that can be added at the request of the customer. Some of the custom questions were suggested by DCLG members and concern such aspects as the geographic location and the race/ethnicity of users. Other questions concern the ease of using the site and how it can be improved. Ms. Hamilton pointed out that if the DCLG were to develop its own survey, it would take a great deal of effort and several months to get clearance from the Office of Management and Budget. Ms. Branch noted that since the ACSI survey is available at no charge and has been cleared, the DCLG should take advantage of it.

Ms. Davenport-Ennis emphasized the importance of collecting baseline data and then doing a second survey within 6-12 months. Otherwise, it will not be possible to determine whether any changes have occurred.

Ms. Goodman said that most of the DCLG's activities fall under the clearance package that she oversees, which includes only pretesting and formative research. She offered to work with OLA to help the DCLG obtain its own OMB clearance so that it could do the proposed types of survey research.

Ms. Caliman clarified that the proposal is not to replicate the NCI/ DCLG 2003 Survey of Cancer Advocacy Organizations but to use some of the questions it contained. Dr. Laird said that the Evaluations Working Group will propose questions for a follow-up survey.

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Summarizing Public Input. Dr. Ramos suggested adding to the logic model evaluation overlay a question regarding whether the public comments have been summarized. Ms. Hamilton asked that this not be added until arrangements to summarize this input have been completed. Dr. Laird explained that the DCLG is still seeking appropriate software for this purpose, as well as someone who knows how to use the software. Ms. Goodman said that this software might be available through her office.

Encouraging Participation. Dr. Laird supported the idea of DCLG members contacting those who have signed up and urging them to participate in the site's discussions. Ms. Hamilton offered to send out notices when new questions are posted and to share information on who is responding to the questions.

Ms. Scroggins suggested that if some groups have still not responded by the time a few more questions have been posted, the DCLG should call these groups.

Next Steps. The Evaluation Working Group will send out another draft of the logic model and evaluation to the DCLG for its feedback.

VI. INPUT FROM THE PUBLIC

No public input was provided.

VII. PREPARE FOR MEETING WITH NCI DEPUTY DIRECTORS

Mr. Ulman asked for suggestions on discussion issues for the upcoming meeting with NCI Deputy Directors Mark Clanton and Anna Barker.

Ms. Sumpter expressed disappointment that Dr. von Eschenbach had been unable to meet with the DCLG. Mr. Ulman noted that NIH Director Elias Zerhouni spends the entire day with the Director's Council of Public Representatives (COPR) at the group's meetings and offered to request that Dr. von Eschenbach spend more time with the DCLG at its next meeting.

Ms. Branch cautioned that although it was important for Dr. von Eschenbach to participate in the DCLG's meetings, the group needed to meet on its own before reporting to the Director. Mr. Ulman noted that OLA now reports to Dr. Clanton, so his participation in the meeting is important. Ms. Hamilton responded that Dr. von Eschenbach has a shared governance management style, and his deputies speak for him.

Col. Williams suggested discussing the impact of the current flat budget on NCI's activities. Also, as many cancers are being treated like chronic diseases, this will cause changes in NCI. He wondered about the role of advocates in these changes.

Mr. Ulman suggested that in the current era of reduced funding, the Cancer Advocacy Community's (CAC) importance is growing. Mr. Ulman attended the Director's budget retreat, where Dr. von Eschenbach gave a presentation on the budget's implications for cancer research. Right now, saying yes to one thing means saying no to another because the current budget increase is the smallest ever received by NCI. The CAC must work with NCI and other agencies to make sure that the progress in cancer research does not slow down. At the retreat, Mr. Ulman emphasized to the scientists that they must work in partnership with the advocacy community to achieve their common goals. Sometimes a reduced budget can have a positive effect by leading to new discussions of the value of constituents and partners.

Ms. Anthony said that if NCI is moving away from disease-specific research, then CAC groups need to learn how to work together. This demonstrates the importance of the DCLG's work.

Dr. Ramos asked how the DCLG's activities are evaluated. Mr. Ulman said that this should be discussed with Dr. Clanton. Ms. Caliman said that all NCI committees are evaluated by the quality of their recommendations and what NCI does with those recommendations.

Ms. Jane Jacobs reminded the DCLG that advocates are directly involved in NCI activities through the Consumer Advocates in Research and Related Activities (CARRA) program.

Mr. Ulman referred DCLG members to the Fiscal Year 2006 Bypass Budget, which describes the directions that NCI wants to take. The plans described in the document will require more funding than NCI anticipates receiving. The CAC could identify what it is doing to further some of these goals. Ms. Branch said that over the past few years, many advocacy groups stopped thinking about the NIH budget because it was increasing. But now they need to start addressing the need for more money at NIH.

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Ms. Davenport-Ennis asked about bringing up issues that other CAC members have raised with the DCLG. Mr. Ulman is open to suggestions about how to do this. One possibility is to set aside time at each DCLG face-to-face meeting and teleconference to raise these issues. He also suggested that DCLG members send him these issues in advance of the meetings.

Ms. Whitewolf asked for information on whether an Indian desk has been established at NIH.

VIII. WORKING DINNER WITH NCI DEPUTY DIRECTORS

Mr. Ulman summarized the DCLG's recent activities for Drs. Mark Clanton and Anna Barker. He asked each DCLG Working Group chair to give a short report.

Col Williams reported that the *NCI Listens and Learns* Operations Working Group is currently monitoring traffic on the *NCI Listens and Learns* Web site. Participants in the dialogue have stayed on topic and have been very candid in their replies.

Ms. Scroggins distributed a report summarizing the recent activities of the *NCI Listens and Learns* Summit Working Group. The working title of the summit is "Listening and Learning Together". The summit will include sessions on demystifying NCI and a forum for the firsthand exchange of information. The Working Group does not yet have a budget for the summit, so it will build the summit it would like to have and then adapt as necessary once a budget is available. Next steps include obtaining input from the cancer advocacy community to make sure that the summit addresses what they need to know. The Working Group has started to identify its target audience and is developing a list of organizations that have been traditionally difficult to reach.

Mr. Rosenthal, reporting for Chair Bill Bro, said that the Promotions Working Group has had one meeting. The *NCI Listens and Learns* Web site launch was publicized through a press release and the *NCI Cancer Bulletin*, as well as through e-mail and a column by Mr. Rosenthal in *Oncology Times*. Mr. Rosenthal is affiliated with the Group Room radio show and will use that venue to let listeners know about the questions that are posted each month. The idea is to disseminate information about the site and let other organizations and media disseminate the information even further.

Dr. Laird said that the *NCI Listens and Learns* Evaluations Working Group has developed a logic model that will give the DCLG a common framework from which to work. The logic model and evaluation plan will soon be finalized. The Evaluations Working Group is also working with the Summit Working Group to develop a logic model and subsequent evaluation plan for the summit.

Mr. Ulman reported that the DCLG had heard presentations from several NCI staff members and had discussed NCI's budget limitations and ways in which the DCLG can help NCI identify partners. Now more than ever, the CAC must be in line with NCI to ensure that needed activities continue.

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Col. Williams pointed to changes in cancer research and at NCI. Such concepts as team science, personalized medicine, and cohort sampling based on disease disparities and not demographics are now being discussed. The research community is moving away from looking at cancer by organ and toward a molecular perspective. This will be a big challenge for advocates who approach cancer from the perspective of specific organs. Col. Williams asked how, in the context of a flat budget, DCLG members can support NCI's activities. The DCLG will play a key role in working with NCI to explain what it does to the community.

Dr. Ramos asked the Deputy Directors to explain what they and Dr. von Eschenbach are looking for from the DCLG, and how the DCLG will be evaluated.

IX. NCI DIRECTOR'S REPORT

Planning at NCI. Dr. Clanton suggested that to understand NCI, members of the advocacy community should come to NCI and spend time with its investigators and administrators.

Dr. Clanton reported that the 2015 Challenge Goal (the elimination of suffering and death due to cancer by 2015) has changed many of the planning processes at NCI. The goal is not just to create knowledge but to translate that knowledge into useful tools and make sure that everyone who needs those tools has access to them. NCI has begun to sort through a list of about 300 priorities collected throughout the NCI divisions by the Office of Science Planning and Assessment (OSPA).

With help from staff, the Executive Committee sorted through these 300 priorities and identified seven major areas in which to invest additional research dollars. These categories are:

- Molecular epidemiology
- Integrated cancer biology
- Strategic interventions
- Prevention, early detection, and prediction
- Integrated clinical trials system
- Bioinformatics
- Reducing cancer health disparities

NIH appears to be shifting away from disease-specific research and toward general biomedical research. To diminish the public health impact of cancer, researchers must pay attention to the processes that lead to the disease. Susceptibility begins at birth or before. In this early phase, some research will help predict who is susceptible to cancer and who, if exposed to certain factors in the environment, will develop cancer. The field of biomarker development will be critical to an understanding of susceptibility.

Modulation is the next phase. Cell growth and transformations that lead to tumors begin to occur. Some interventions in this phase will be very useful. Using biomarkers and advanced imaging, it might be possible to prevent cancer. Nanotechnology will also be useful for finding and imaging individual cancer cells to locate disease early. Specific therapies will be developed that are tailored to certain genetic predispositions. As science progresses, the impact of cancer on the lives of patients and their families must be addressed.

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NCI is investing heavily in the field of nanotechnology, which will make it possible to deliver chemotherapy directly into cancer cells. This will result in chemotherapies that are more effective and less toxic than those available today.

Much of what NCI is attempting to do is based on knowledge that is already available. For example, we know how to make nanotechnology devices. What is lacking is a national focus on quickly leveraging technology on a mass scale to develop treatments and diagnostic tools.

The seven areas above represent the first set of priorities on which NCI will focus. NCI plans to begin its investments with molecular imaging. If cells can be located before they have metastasized, conventional therapies can be used to save patients and prevent death and suffering from cancer. NCI needs to continue to push basic science, but that science needs to be translated into more effective diagnostic techniques and treatments. NCI also needs to ensure that these advances are delivered and available to all. By combining discovery, development, and delivery in this way, NCI will make a fundamental change in the impact of cancer.

Advanced Technologies. Dr. Barker explained that NCI is considering all of this change at this point in time because scientists now understand the very complex mystery of cancer as a systems problem with many interconnected pieces. Cancer is really a transition from a single molecular event to a series of expansions of genetic changes to imbue a cell with a new set of capabilities.

Cancer is increasingly understood as fundamental digital code, somewhat similar to a computer code. A starting point for understanding that code has come from the sequencing of the human genome –and an increasing understanding of the transcriptome and proteome. NCI is undertaking initiatives to understand the cancer genome and the way that cells function through the proteome. NCI is focusing on generating information, managing it, and turning it into knowledge that can be used for prevention, early detection, and treatment.

One class of initiatives is broad-based technology platforms that everyone can have at their disposal. Biomarkers are indicators of an event that signals a genetic or other kind of change in a pathway, or in some instances may indicate broader impact in the cell or organism. For example, the fact that tumor cells divide more quickly than normal cells can be a biomarker. Biomarkers are critical technologies for clinical trials, drug discovery and development and monitoring patient outcomes.

Dr. Barker predicted that the convergence of advanced technologies will produce a sudden, cascading, and disruptive impact on medicine, ethics, and economics. We are currently at an inflection point at which knowledge at all levels of the cell is moving so quickly that it is not possible to predict where progress will come from or how disruptive it will be. Biological material is now being merged with silicon, targeted agents are being found, and biomarkers are beginning to be important in assessing the impact of new agents in clinical trials.

Dr. Barker provided some examples of NCI's efforts to support advances in science and technology, beginning with NCI's Cancer Biomedical Informatics Grid (CaBIG), which she characterized as very likely the largest initiative undertaken to date in the area of bioinformatics

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to support biomedicine. CaBIG includes 50 cancer centers and other organizations working to manage data and build knowledge across the discovery, development and delivery research continuum.

NCI's efforts in the National Cancer Biospecimen Network may be one of the most important areas for survivor involvement. In the future, the relationship between researchers and patients will be critical to the development of personalized medicine –as a great deal of research will depend on the availability of high quality biospecimens. Collecting these samples will require a chain of trust and Dr. Barker expressed the hope that the DCLG would become involved in this issue. Although about 300 million tissue samples have been collected in the United States – many will not be usable in current research. More high-quality biospecimens will be needed because existing samples were not collected or processed in standardized ways. The samples collected in all of the NCI's biospecimen resources will need to be collected and standardized, and annotated in a manner that reflects the needs of a specific study. Several other countries have already created national biospecimen networks and the United States will need to work to deploy its considerable resources to catch up – and eventually lead in this area.

Dr. Gregory Downing described recent advances in nanotechnology, which involves chemistry at the atomic level. Tools are now available to assemble molecules and this has transformed electronic semiconductors for computers. The same technology can help overcome some unique barriers in cancer cells. Nanoparticles can focus materials into the membranes of cells and are already being used in clinical trials. Nanotechnology offers opportunities to develop molecular diagnostic platforms for the next generation of early detection devices. In a single drop of blood, it is possible to detect abnormal proteins in very sensitive ways –which could revolutionize diagnosis of cancer.

Several CARRA representatives have participated in planning for NCI's nanotechnology initiative and advocates have helped develop the Alliance for Nanotechnology in Cancer Web site. A key element in this initiative is multidisciplinary scientific teams. NCI has held symposia at cancer centers that bring together engineers and cancer scientists. NCI is also developing centers of cancer nanotechnology excellence that bring together teams to address cancer issues. Dr. Downing believes that the public input received by the Alliance is key to exploring this scientific opportunity.

Discussion. Ms. Whitewolf emphasized the importance of building a chain of trust with the advocacy community and the public but cautioned that this chain is weak in the Native American community. Ms. Whitewolf hoped that NCI would work with the Native American community to help explain these new technologies and the role of advocates and patients in advancing these technologies. She added that many Native Americans learn best through images.

Ms. Whitewolf also suggested that when NCI talks to cancer centers, it does not talk to Native Americans because they are not members of cancer centers. However, some Native American institutions, such as tribal colleges and schools, would be very receptive to NCI presentations.

Dr. Barker agreed that the chain of trust requires that patients feel secure that no harm will come to them as a result of contributing their tissues and that these tissues will be used appropriately.

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Tissue has become the “holy grail of genomics” but has also become the major hope and major fear of patients. NCI has developed “road shows” to teach academic centers about its nanotechnology and biospecimen initiatives, and it plans to talk to other communities about these projects. Dr. Barker suggested that if Native American communities believed that donating their tissues would make it possible for the research community to identify the major causes of cancer in their populations, they would donate their tissues. But major steps are needed for this to take place. The DCLG could help make it happen.

Dr. Downing described his recent activities as examples of NCI’s efforts to work with different communities. The previous week, Dr. Downing had met with a group of engineers who were very interested in NCI nanotechnology initiative. He also attended a nanotechnology and cancer symposium at Georgetown University that included Howard University Hospital. Later that week, he joined Drs. Barker and von Eschenbach at the University of New Mexico to discuss some of the issues raised by the DCLG with several tribal leaders. These discussions had a significant impact on Dr. von Eschenbach’s thinking about the biospecimen issue.

Ms. Branch said that the DCLG had talked about tissues a few years earlier and she was pleased to see how the issue has evolved. She asked whether advocates participate in the road shows mentioned by Dr. Barker. Advocates do not like to be brought in after the fact. Dr. Barker replied that advocates have been involved in every step of the process. For example, the Multiple Myeloma Research Foundation directed by former DCLG member Ms. Kathy Giusti has created its own biorepository, which will probably interface with the national initiative. Other advocacy groups are undertaking similar activities. NCI has not yet determined how to educate the general public and will need the full cooperation and help of the oncology community.

Ms. de Córdova-Hanks said that this is the most exciting news she has heard in the 18 years since she began battling this disease and became an advocate. However, she explained how she was unable to obtain a job for three years after her diagnosis and wondered whether patients who contribute their tissues will become “marked people.” Dr. Barker said that this was the major issue and that certain levels of access to and control of the data must be developed. She suspects that different levels of protection will be implemented. Some data will be anonymous and not linked to specific patients. But other data will have patient information because the progress of these patients will have to be followed. A “vault” will have to be developed for these data but it is not clear who will be responsible for the vault. This country has not yet had this conversation, although other countries have discussed this issue.

Ms. Sumpter pointed out that this issue is related to the first question that was posted on the *NCI Listens and Learns* website, which concerned the collection of personal data for a clinical trials database. Some people were very concerned about the possibility that the data would be used against them but others were very supportive of the idea. As our society becomes paperless, people are becoming more familiar with the concept of having their medical data stored in a database. Ms. Sumpter believes that the *NCI Listens and Learns* discussion shows that people would agree to contribute their tissue as long as NCI provided assurances that the information would be held securely.

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Dr. Clanton distinguished between two kinds of data: anonymous data and those that are specific to a patient's body. For the first kind, everyone who contributes to the database must remain anonymous. These data will be used by big studies on the correlations between proteins in the blood and diseases or on proteins that are expressed if a treatment is working. To obtain the needed data, all ethnicities will need to participate—otherwise the resulting data will lead to treatments and diagnostic tests that miss certain groups entirely. For data about individuals, the problems of protection have not yet been solved. The issues must be resolved for cancer because a single drug could cure one patient and kill another who had the same kind of cancer. If the scientist does not know which patient is which, then he or she cannot help them and could do them harm.

Dr. Clanton noted the design flaws in how we pay for medical care. Insurance is designed to pay for medical care, not health care, so it does not cover participation in clinical trials. The data collected on patients about their diagnoses need to be anonymous but available nationally, although some information on individual patients must also be available. When clinical research is designed so that it can happen simultaneously with medical care, the way that care is paid for can begin to be re-engineered. Unless the two can be merged, it will not be possible to solve any of the problems in cancer.

Ms. Branch asked if biospecimens are to be kept in a single location. Dr. Barker replied that NCI expects that a distributed system will be held in various places. Some repositories will probably be for general use, some for clinical trials, and others for fine genomics and proteomics research. Over time, a common bioinformatics platform will be developed.

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X. NCI LISTENS AND LEARNS WORKING GROUP MEETINGS

Evaluations Working Group. Evaluations Working Group members reviewed the logic model and evaluation plan for the *NCI Listens and Learns* Web site. The group made the following changes to the logic model:

- Long-term outcome 2 in column 4 will be changed to “CAC (cancer advocacy community) members, their constituents, and the interested public will be more satisfied with NCI resources.”
- Long-term outcome 4 in column 4 will be split into two outcomes: “Cancer patients, survivors, and their families/friends, as well as the interested public, will have more knowledge about government-sponsored research” and “Cancer patients, survivors, and their families/friends, as well as the interested public, will have more trust in government-sponsored research.”
- Long-term outcome 5 in column 4 (“There will be increased interaction/open dialogue among the CAC network”) will be moved to the summit logic model.
- Change long-term outcome 7 in column 4 to “Collaborative ties among the NCI and the scientific community, CAC, and the interested public will increase.”
- Questions in the logic model overlay that correspond to deleted outcomes will be deleted.

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The Working Group discussed whether the Web site will increase the perception of CAC members that cancer research funding is effectively allocated (long-term outcome 6). Ms. Campos suggested that visitors to *NCI Listens and Learns* might go on to explore the rest of NCI's Web site, so learning about cancer research funding might be a secondary result of *NCI Listens and Learns*. Dr. Laird suggested that this is related to long-term outcome 4, which concerns knowledge of and trust in government-sponsored research, but Dr. Ramos disagreed. Dr. Laird said that if the questions posted are used to guide public knowledge, then long-term outcome 6 might be the result, but this is not the intention of the questions. Ms. Caliman suggested leaving the outcome in and seeing what happens. She also pointed out that the DCLG's original survey showed that the CAC is dissatisfied with the way in which funds are allocated.

Dr. Laird suggested deleting question 11 from page 4 of the evaluation plan. This question asks whether collaborative ties among NCI, the scientific community, CAC, and individuals have increased.

Dr. Ramos pointed out that question 1 on page 3 of the evaluation plan specifies a percentage increase in the number of CAC members who agree that NCI clearly communicates how it sets its research priorities. The DCLG does not need to set numeric goals like this, but some may argue that the DCLG lacks measurable goals.

Dr. Ramos suggested thinking of this as a pilot project and waiting to develop numeric goals once some experience with the site has been gained. Dr. Laird pointed out that if the DCLG cannot show that the site is having a positive impact, then it will not be continued. But if the project is continued, numeric goals can be established at a later time.

Dr. Laird planned to discuss with Ms. Caliman whether baseline data exist for the questions on page 3 and whether it would be useful to collect follow-up data on these questions.

Dr. Ramos asked Dr. Laird to put dates on each new version of the logic model and evaluation plan.

Summit Working Group. Ms. Scroggins emphasized the need to obtain input from the CAC on its interest in the focus and themes of the summit. To that end, she suggested that a comprehensive list of community members be compiled and that the full DCLG contribute names of those who represent hard-to-reach populations. Ms. de Córdova-Hanks suggested obtaining group names from the Intercultural Cancer Council. Mr. James Hadley suggested using the NCI listserv as well

The DCLG should ask the CAC for feedback on the draft summit agenda so that community members do not mistakenly think they are being asked to set the agenda. The CAC should also be asked to recommend speakers. This feedback could be obtained through:

- A clear, brief question on the *NCI Listens and Learns* Web site.
- Advocacy group meetings attended by DCLG members.
- Personal phone calls.
- Information in groups' newsletters.

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- Mailings to hard-to-reach populations.

Working Group members agreed to develop a full and comprehensive agenda for the summit without regard to cost, then scale back as funding or other considerations dictate.

The CAC and the public have little awareness of the scope of NCI's work. Ms. Scroggins said that the focus of the summit should therefore be "NCI 101" and it should address how NCI works and what it does and does not do, including such issues as nanotechnology and tumor banking. This will give participants practical information that they can take back to their own constituencies. Ms. Whitewolf added that the summit should be an opportunity for NCI scientists to learn about the participants. The group agreed that the summit should be an interactive conference, with a free exchange of ideas from both sides. Ms. Whitewolf suggested that "building a chain of trust" be part of the focus.

Ms. de Córdova-Hanks stated that speakers should use understandable terms and this requirement should be made clear to them. They should also be asked to provide copies of their presentations prior to the summit. The Working Group decided to prepare guidelines to explain to the speakers who the audience would be and what kind of information was desired.

The Working Group agreed to:

- Continue to define and refine the focus of the summit.
- Compile a list of possible presenters/speakers.
- Set a date for the conference and make sure that the summit did not conflict with meetings that have already been scheduled.
- Develop lists of members of the CAC.
- Continue to think about mechanisms for reaching CAC members.
- Participate in a teleconference on April 6, 2005, from 3 p.m. to 5 p.m. EST.

The Evaluation Working Group arrived to discuss the Summit Evaluation/Logic Model with the Summit Working Group. Dr. Laird suggested that the two groups review the short- and long-term outcomes (column 4) of the logic model to evaluate whether these goals would be addressed by the summit. She noted that the wording of some of the outcomes might need to be changed slightly to reflect the needs of the Summit.

- Short-term outcome 3: "CACs will have an established forum to learn of and understand the issues/concerns facing other CACs." The summit should establish an ongoing mechanism for continued networking among the CAC, such as a "message board" so that groups can link and have dialogues. The group suggested adding the words "and ongoing mechanism" after the word "forum."
- Short-term outcome 4: "Interested parties will have an avenue to have their needs and concerns heard." The public is not invited to the conference, but this outcome should be left in as a possible placeholder to indicate the benefit of the summit to individuals who are not part of an organized group.
- Long-Term outcome 1: "Cancer patients, survivors, and their family/friends, as well as the interested public will be more familiar with NCI and how it works." Some use the term "survivors" to refer to patients and survivors, although others do not agree. In this

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and all the remaining long-term outcomes, the word “attendees” will replace “patients” and “survivors.”

- Long-term outcome 4: “Attendees will have more knowledge and trust in government-sponsored cancer research.” Dr. Laird pointed out that knowledge and trust were listed separately for measurement purposes.
- Long-term outcome 6: “Attendees will have an increased perception that cancer research funding is effectively allocated.” Participants asked whether the summit would lead to a feeling among attendees that the research funding is “effectively” allocated, particularly given the shift in funding away from specific cancers. A goal of the summit is for attendees to become more familiar with the allocation of research funding and gain a better sense of how and why allocations are made.
- Long-term outcome 7: “Collaborative ties among the NCI and the scientific community and the attendees will increase.” Ms. Whitewolf stressed the importance of saying that not only should attendees have a better understanding of the work of NCI, but also that the scientists should gain a better understanding of the work of attendees.

Operations Working Group. Ms. Branch served as chair in Col. Williams’s absence.

Ms. Sumpter said that she had examined the *NCI Listens and Learns* Web site comments for the second week of operations and Col. Williams had examined the comments for the first week. The comments had been cogent and to the point, although some were not relevant. Few comments had appeared so far. The space in which to post the comments was small, making the text difficult to read at times.

Each member of the Working Group will be assigned to monitor the site for a full calendar month and will review the comments twice—once in the middle of the month and once at the end. Ms. Branch volunteered to be the reviewer in March. Ms. Hamilton noted that NCI has assigned a person to perform daily monitoring, so the Operations Group members should perform a twice-monthly review and focus on large issues.

The group agreed that registered groups, especially the large organizations, probably needed more time to survey opinions within their membership before offering comments. No large groups have posted comments so far.

Mr. Ulman asked whether the group could recommend new questions to be posted on the site. Ms. Hamilton responded that NCI has been developing questions and, although input from the Working Group would be welcome, it would be best to wait until later in the year to propose additional questions. Ms. Sumpter suggested that Working Group members help NCI staff edit or revise the questions as they are developed.

Ms. Branch wondered whether more than one question (multiple topics) should be posted on the site during a given month.

Ms. Hamilton reported that about 45 organizations have not appointed spokespersons, despite having been reminded to do so through e-mail. Ms. Sumpter proposed that the Working Group members telephone these organizations, requesting that they identify spokespersons.

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With respect to the 65 organizations that have identified spokespersons but have not offered comments (except for a few), the Working Group members agreed to let more time pass before encouraging their greater participation—perhaps eventually through phone calls.

A third group of organizations have decided not to register for the site. The Working Group suggested a promotional campaign, headed by the Promotions Working Group, for this group and for other organizations. Ms. Hamilton estimated that about 100 groups could be identified as targets for such a campaign.

Ms. Sumpter encouraged the group to continue to consider the role of larger organizations in the dialogue. She was concerned that their influence might dominate that of smaller organizations.

Ms. Branch asked group members for comments on the guidelines for monitoring the Web site. Ms. Sumpter suggested that the guidelines include collecting raw data on how people respond and the types of organizations that do so.

The Working Group members agreed that site use should be evaluated eventually, perhaps at the 6-month point. At that time, the Evaluation Working Group might determine reasons why some organizations did not respond to the questions. The Operations Working Group would then contact those organizations.

Ms. Sumpter encouraged group members to communicate with their own organizations and communities to identify reasons for participation or its lack. She also suggested that the Cancer Information Service be encouraged to develop links to the Web site through its contacts with clinical trials.

Promotions Working Group. The Promotions Working Group meeting was cancelled.

XI. MEETING WITH DR. MARK CLANTON, NCI DEPUTY DIRECTOR, CANCER CARE DELIVERY SYSTEMS

Dr. Clanton reported that when he speaks to groups of individuals experiencing high levels of cancer disparities about how technology will change care, they all respond by asking how he can talk to them about technology when they cannot make available the most routine health care services. But, Dr. Clanton argued, those who pay close attention to technology and what is coming will be able to do better for themselves in health care and probably in economics. Those who pay attention to the effect of technology on the delivery system will be able to translate health care for those who cannot understand the new language of technology.

The health care delivery system is usually defined in terms of a single aspect of the system, such as the ability to pay for or the quality of care. However, even if quality of care and the ability to pay for it are available, people will not obtain the care they need if they lack access. The health care system resembles a complex adaptive system in that it is only effective if all of its elements are working.

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In cancer, we must understand all of these elements and how they do and do not work together to deliver all of the services and all of the promises from basic discovery and translation of new knowledge into effective tools for diagnosis and treatment. Health care is not viewed as a system and we do not expect all of these pieces to come together appropriately; instead, we look at the pieces and advocate for some attributes of certain pieces.

Every aspect of cancer is extremely complex. The study of delivery systems is about understanding how to make all of these complex things happen at the same time.

Dr. Clanton reported that clinical trials are being conducted to determine whether it is possible to deliver vaccine through food. Vaccines for hepatitis B can now be delivered through genetically altered potatoes. The concept of using food to vaccinate is a technology that will change the way we think about delivering health care. Dr. Clanton doubts that traditional insurance is ready for this change, or that physicians and nurses are ready to recommend low-cost, low-profit food that will deliver vaccines. If those growing food in United States are not ready, the Pacific Rim is ready to grow all the drugs needed.

One of the major problems in treating a person with a metastatic tumor today is that it is not possible to determine whether a given chemotherapy is effective for about 3 months. But advanced functional biological imaging will change this, and has already done so for gastrointestinal stromal tumors. Within six hours of giving a drug called Gleevec, a PET scan can show where the tumors are in the body and whether Gleevec is beginning to work. In another six hours, it is possible to see the tumors begin to shrink. If industries make advanced imaging more available, this will change how cancer is treated. It will be possible to switch drugs more quickly, give patients assurances earlier, and change how they and others feel about themselves. But these new imaging technologies will raise access and quality issues.

Technology will dramatically change every aspect of how healthcare is delivered and everyone, especially those interested in the underserved, must pay attention to the new technology. Dr. Clanton recommended that all DCLG members read a book by Juan Enriquez, *As the Future Catches You: How Genomics & Other Forces Are Changing Your Life, Work, Health & Wealth*. This book describes what is happening with the information revolution and how it affects the world's economies.

Dr. Clanton pointed out that the new technology is particularly important for cancer because it will only be addressed through advanced high technology. The Pap smear will become irrelevant when the human papillomavirus (HPV) vaccine becomes available in the next few years. The prostate-specific antigen (PSA) test will be replaced by tests on chips that show whether men have a protein pattern in their blood indicating prostate cancer. Changing cancer diagnostics and treatment depends on high technology, its availability, and its use.

If, instead of aiming to achieve the 2015 Challenge Goal, we were to continue our incremental efforts of getting more women to have mammograms, we would save many lives but would not change breast cancer. Changing the disease will require relying on genetic technology and advanced imaging. How we embrace that will be the big social question.

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Discussion. Ms. Whitewolf pointed out that food has been poisoning residents of the Pacific Northwest and Native Americans are very concerned about what food does to their bodies.

Ms. Whitewolf also said that many Indian reservations have undeveloped lands. She asked how to educate these tribes about the possibility of growing crops for medicine. Dr. Clanton said that it is easier to use agriculture to grow drugs and biologicals than to start a pharmacology or biotechnology company. The Pacific Rim has the natural resources to grow crops that deliver biological products and drugs and the cost of entering the business is relatively low. Many of these countries have already made the commitment to educate their youth, so they are growing the intellectual capital that will fuel the bioagricultural business. Anyone who can grow food and has land and educated workers can enter this business.

Dr. Clanton added that issues related to systems biology will require multidisciplinary teams. To participate in the opportunities of bioagriculture, the Indian community needs to become familiar with the systems science vision and the idea that those who can grow plants can produce drugs.

Ms. Branch asked if providers and insurers are aware of the developments discussed by Dr. Clanton. He replied that insurers have not participated in the discussions. NCI has developed a relationship with the Centers for Medicare and Medicaid Services (CMS), which has agreed to pay for NCI trials of off-label drugs for colorectal cancer. NCI will construct the trials and interpret the resulting data, which will help CMS understand whether a drug approved for one condition is effective for another. If the trial is successful, it will help provide a systems solution to a systems problem.

Ms. Branch asked how long it would take to complete the clinical trials. Dr. Clanton said the colorectal cancer clinical trial would be open to all Medicare enrollees, so it will be able to accrue large numbers of people in a short period of time. This will allow the trial to end earlier.

In response to a question from Ms. Scroggins, Dr. Clanton suggested that the advocacy community demand the development of advanced imaging tests that personalize therapy. Advocates should call for effective tools based on all that is now known about genes and proteins. Currently, capital is principally flowing to improvements on existing technology, rather than new technologies. It takes a different kind of leadership to say that we expect that tools and techniques will become available based on what we know now, so that more people understand what is possible and demand that taxes and the market deliver more personalized, effective care.

Ms. Scroggins said that the advocacy community does not have information about the new technologies. Dr. Clanton suggested that having this information is not necessary. Advocates can start by saying that expensive new drugs that only buy patients a few extra months are not good enough. No collective voice is doing this. Using potatoes to deliver vaccines provides too little profit to draw capital, so this technology will not be implemented until leadership and advocacy demand it.

Dr. Ramos wondered how to redirect capital from existing technologies to the new technologies that must be implemented to meet the 2015 Challenge Goal. Dr. Clanton explained that NCI is developing business plans for nanotechnology and a national bioinformatics structure that holds

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all clinical trial data. The Institute is working in partnership with industry and is focusing its priorities in ways that draw the market in.

Ms. Sumpter pointed out that several European countries have banned genetically modified foods, which could have an impact on the use of new technologies in those countries. Dr. Clanton predicted that if a country adopts the new low-cost technology and the health of its population improves, other countries will follow suit. The economic structure of an entire country can be changed by how much it spends on health care and by the health and productivity of its population.

Ms. Anthony pointed out that *NCI Listens and Learns* and the planned summit are small steps in the direction that must be taken. The DCLG needs to seek yet another vehicle to move itself forward in this area.

XII. REPORTS FROM *NCI LISTENS AND LEARNS* WORKING GROUPS

Summit Working Group. Ms. Scroggins reported that the Summit Working Group will ask the entire DCLG to help develop a list of hard-to-reach and mainstream groups. The Working Group will send out a reminder to all DCLG members to provide contact information for groups that are not linked to the Internet, as well as any additional groups that are not in the DCLG's existing list of advocacy organizations.

The group plans to provide guidelines to all summit speakers and request copies of slides in advance so that they can be included in the meeting notebooks. Group members agreed on the need for community input to ensure that the summit will cover the most important themes. The Summit will take place between the spring and fall of 2006 and the group will make sure that the date selected does not conflict with the dates of any other major events. The group will soon circulate potential dates to all DCLG members for their feedback.

Ms. Hamilton noted that healthfinder.gov lists all of the health observance weeks and months and a calendar of cancer-related meetings is available at calendar.cancer.gov. These can be consulted to identify times that might be busy for certain groups of advocates. Ms. Scroggins asked DCLG members to identify any conferences that they know will take place between May and September 2006.

In response to a comment from Ms. Sumpter, Ms. Scroggins explained that the summit will likely be held at NCI but no formal decision to this effect has been made.

Evaluation Working Group. Dr. Laird reported that the Evaluation Working Group has almost finalized its logic model. She will send it and the evaluation plan to the entire DCLG shortly. Ms. Campos will serve as the Evaluation Working Group's representative on the Summit Working Group. If Ms. Campos is not available for one of the Summit Group's meetings, another Evaluation Working Group member will participate in her place. Mr. Ulman asked Dr. Laird to let him know when the logic model and plan are final, so that it can be shared with NCI.

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Operations Working Group. Ms. Branch reported that the Operations Working Group decided to continue to monitor the *NCI Listens and Learns* website, but will now report to the DCLG on the 15th and the last day of each month. The group will follow this schedule for the next year. At the end of six months, OLA will prepare a report summarizing who has participated in the discussions. The Operations Working Group also asked all DCLG members to contact the 45 advocacy organizations that have not appointed a spokesperson. In another month or so, the Promotions Working Group should send promotional material by mail (not e-mail) to the 100 or so groups that have registered for the site but have not yet participated in the discussions.

Mr. Ulman reported the group's decision that draft questions to be posted on the site should be sent to the DCLG by the 15th of the prior month. The DCLG will have a week to provide comments on the questions and then Ms. Caliman will share the proposed changes with the question's originator and post the final question on the site. Mr. Ulman asked DCLG members to send their responses to the questions to the entire group to prevent duplication of feedback.

Discussion. Mr. Rosenthal plans to tape the questions that are posted for broadcasting on the Group Room radio program. OLA will develop a schedule for these tapings, which are likely to occur the day before the questions are released. The questions will now be posted on the first day of each month and the discussions will be open until the last day of the month.

Mr. Rosenthal suggested scheduling a brief radio interview with Mr. Ulman about *NCI Listens and Learns*. Ms. Hamilton reminded all DCLG members that they must obtain clearance for interviews of this sort. DCLG members should inform OLA of their plans and OLA will arrange clearance with NCI's Press Office. The DCLG already has clearance for taping the questions.

Ms. Sumpter pointed out that no large cancer organizations have posted comments yet, which is a concern. Perhaps this is due to the logistical difficulty of collecting input from several different affiliates prior to posting a response. This may provide smaller groups with an advantage, as they can respond immediately. This needs to be monitored.

Ms. Hamilton suggested that OLA assign to DCLG members the groups that have not yet appointed spokespersons. DCLG members can then identify any contacts they have with these organizations, and organizations can be assigned to DCLG members as appropriate.

Ms. Scroggins asked that the DCLG have its next teleconference soon after the Summit Working Group has drafted plans for the audience, presenters, and evaluation model, as the group will need feedback before it moves forward.

Ms. Caliman suggested that the DCLG have teleconferences in May and July and another face-to-face meeting in September. Ms. Hamilton asked that the May teleconference be held after the ASCO meeting, which ends on May 13.

Ms. Whitewolf asked if Dr. von Eschenbach could attend some of the DCLG's teleconferences. Ms. Birkhead will discuss this with Dr. von Eschenbach.

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Ms. Hamilton announced that Dr. von Eschenbach was very excited about *NCI Listens and Learns* and had asked that notice of the site be sent to congressional offices with an interest in health.

Mr. Ulman said that he would send out a communication shortly asking DCLG members to respond to several issues, such as questions for *NCI Listens and Learns*. The DCLG does not currently have a third question to post on the site.

Mr. Rosenthal will follow up with Mr. William Bro, who was unable to attend this meeting due to illness, on tasks for the Promotions Working Group.

PRG Process. Ms. Sumpter said that Ms. Nichols had asked for the DCLG's input on the Progress Review Group process and that the DCLG should respond to this request. Mr. Ulman asked the DCLG to consider the three questions posed by Ms. Nichols to the DCLG.

Ms. Scroggins said that the Gynecologic Cancers PRG participants were not informed about when the report would be published or what happened as a result of their recommendations. She suggested that NCI provide periodic updates on its progress in responding to PRG recommendations.

Ms. Sumpter noted that eliciting the desired responses in the advocacy community would require educating them about nanotechnology, genomics, and other issues. Ms. Whitewolf emphasized the need to focus educational efforts on the lay community. A lay version of the PRG reports should be developed, for example. Advocates cannot conduct advocacy without understanding the science.

Ms. Birkhead said that the American Association for Cancer Research (AACR) had recently presented some helpful slides to explain molecular characterization. She offered to obtain these slides for the DCLG. Ms. Campos asked that in addition to the slides, NCI provide the DCLG with education on recent advances in technology and research.

Ms. Whitewolf suggested that cross-cutting topics in cancer research be studied in the Indian population. Many native groups have close genetic ties and are good subjects for research. But this will require working with advocates.

Ms. Sumpter emphasized the importance of the long-term effects of treatment, as cancer becomes a chronic condition. Dr. Ramos added that individual variations in responses to treatment can be affected by socioeconomic status, ethnicity, and other factors and these need to be addressed.

Ms. Hamilton pointed out that the National Cancer Advisory Board (NCAB) meetings are broadcast on the Web and handouts from the meetings are also available on NCI's websites. The broadcasts are archived so that they can be viewed at any time. Ms. Hamilton encouraged DCLG members to view these broadcasts. A DCLG representative attends NCAB meetings whenever possible; Col. Williams attended the last one. Many important scientific concepts are discussed at these meetings.

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Ms. Scroggins said that the advocacy community will need to find new ways of collaborating because organizations currently focus very strongly on specific sites. Ms. Anthony believes that some of this shifting is already taking place in the medical community.

Ms. de Córdova-Hanks suggested that a future PRG could address reasons why multiple primaries occur in individuals who do not experience a recurrence. Ms. Anthony said that this relates to tissue banking and the DCLG might need to pose a question about that to the advocacy community. Mr. Ulman pointed out that the issue raised by Ms. de Córdova-Hanks highlights questions about survivorship and secondary prevention. Ms. de Córdova-Hanks added that the late effects of long-term survivorship are also related. Mr. Ulman suggested that the DCLG select an aspect of survivorship that cuts across various departments or divisions for a future PRG. Ms. Sumpter proposed that the focus be not just on killing the cancer but also on selecting doses of treatment that produce the smallest side effects.

Ms. Whitewolf emphasized the need to earn the trust of community members who will be asked to provide their tissue for research. NCI staff must use lay language to teach the community about this issue.

Ms. Scroggins pointed out that the period of time used to define long-term survival might need to change, as it has been at five years for a long time. Mr. Ulman agreed that this was an important issue because those who believed they had been cured after five years might be less likely to seek the screening and follow-up care they continued to need. Dr. Ramos does not believe that the medical community has established a definition for long-term survival. Appropriate tools are often not available to measure quality of life, which may be why it is not considered a scientific research topic. This must be addressed. Dr. Laird said that another important issue is the lag time between diagnosis and being able to treat the cancer. For example, women diagnosed with a genetic mutation for breast cancer face survivorship issues that may go unaddressed.

Ms. Branch noted that she had been a member of the quality of care committee now headed by Dr. Clanton, and some great research on quality of life and survivorship was being conducted. Ms. Anthony added that many nurses are conducting research in these areas and she would be happy to share articles on them with other DCLG members.

XIII. PUBLIC COMMENT

No input was provided from the public.

XIV. NEXT STEPS

Mr. Ulman asked Ms. Caliman to obtain a question for *NCI Listens and Learns* from Dr. Rowland by mid-March so that the DCLG can respond to the question in time for it to be posted in April. Mr. Ulman also planned to tell Ms. Nichols that the DCLG was preparing a response to her questions. The DCLG should also provide Drs. Barker and Clanton with initial reactions to their talks and questions concerning how the group might support their efforts.

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Annual Report. Ms. Branch and Mr. Rosenthal will prepare the DCLG's annual report. Once they produce a draft, the other DCLG members will give feedback. Mr. Rosenthal suggested that summit take place before the end of September 2006 so that it can be included in the DCLG's FY06 report.

Mr. Rosenthal requested copies of previous annual reports, so that the 2005 report can address how the DCLG has changed and its current tasks. The report might highlight some interesting stories that come up on *NCI Listens and Learns*. He asked the DCLG to look out for anecdotes from advocacy community members who access NCI resources through the work of the DCLG.

DCLG Representatives on Committees. Ms. Branch suggested that the DCLG offer to serve on one of Ms. Barker's committees. Ms. Sumpter suggested posting a question concerning tissue banking on *NCI Listens and Learns*.

Ms. Branch pointed out that the DCLG no longer has a representative on the quality of care committee headed by Dr. Clanton. Mr. Rosenthal noted that one of the DCLG's responsibilities is to serve on various committees to bring the voice of advocacy to these groups. Mr. Ulman said that in the past, serving on NCI committees was a major function of the DCLG.

Ms. Hamilton stated that the DCLG had moved away from this role in recent years because members were overburdened and found it difficult to focus on group activities. The DCLG needs to retain its special role of making recommendations to the NCI Director. CARRA members can represent the advocacy community on NCI committees. Ms. Caliman added that when DCLG members served on NCI committees, they provided feedback or recommendations directly to NCI program staff but the recommendations were not discussed by the full DCLG. This is one reason why the DCLG reassessed its role. Dr. von Eschenbach has asked that, at least for the time being, the DCLG focus on *NCI Listens and Learns*, as well as health disparities and survivorship.

Ms. Scroggins suggested that if NCI committees were addressing health disparities and survivorship, then having DCLG members on these committees would help to better inform the group and improve its ability to advise the Director.

Mr. Ulman recalled that when almost every DCLG member served on at least one committee, group members spent most of their time updating the group on committee activities. As a result, they did not address any area in much depth. Dr. Rowland has asked for DCLG representation on the planning committee for survivorship conferences in the past and she is likely to do so again. The DCLG should serve on committees when asked to do so by senior leadership, but should do so with caution.

Next Face-to-Face Meeting. Mr. Ulman said that although Drs. Barker and Clanton had discussed several advanced technologies, the Biospecimen Network was probably the issue in which the DCLG had the most to offer. He therefore suggested inviting Dr. Barker to discuss this issue with the DCLG at its next face-to-face meeting. Ms. Scroggins supported this plan, noting that the discussion should address how to build the needed chain of trust in communities.

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Ms. Hamilton noted that the chain of trust is needed not just for tissue, but also for clinical trials. DCLG members should provide comments on this issue to the clinical trials working group at: <http://integratedtrials.nci.nih.gov/ict/overview>.

Ms. Anthony would like to receive an update on the NCI/CMS clinical trials effort. Several DCLG members expressed an interest in learning about CARRA activities at the next meeting.

Mr. Ulman proposed obtaining copies of the presentations in advance to shorten talks at the meeting and leave more time for discussion. Since the DCLG's meetings are open to the public, the group can invite other groups to participate in its discussions. He asked the DCLG to provide suggestions for the format and content of the next meeting.

Dr. Laird suggested that each meeting include the opportunity to hear brief discussions of exciting activities at NCI that could be shared with members' constituencies. This will make it easier to work with the CAC to demand more research funding.

Ms. Hamilton suggested that the DCLG invite Ms. Marlys Popma, who is the sole public member on the NCAB, to the next meeting. She can serve as a liaison between the DCLG and the NCAB.

Ms. Caliman suggested that DCLG members keep track of articles in NCI's *Cancer Bulletin*. OLA can arrange for briefings on the issues discussed in this publication in which the DCLG is interested.

Ms. Hamilton encouraged the DCLG to take Dr. Rowland up on her offer to inform them about ongoing survivorship research. OLA can also help DCLG members locate information on NCI research projects.

NCI Listens and Learns Promotional Materials. Ms. de Córdova-Hanks suggested that DCLG members take promotional materials for the Web site with them to any meeting they attend. But she said that the materials need to be available in Spanish. Ms. Hamilton pointed out that the information is only available in English. However, Ms. Campos explained that her community is more comfortable reading in their own language although they can communicate in English.

Future NCI Listens and Learns Questions. Ms. Branch suggested that since the DCLG has been asked to focus on survivorship, clinical trials, and health disparities, it should solicit questions for *NCI Listens and Learns* from the NCI divisions that address these issues.

Ms. Scroggins suggested finding out how the CRCHD expects to involve advocates in its work. Few advocates are currently involved in the center's activities. Perhaps a question could be posted summarizing the Center's mission and asking how the advocacy community could help in its accomplishment.

Ms. Hamilton supported finding ways for advocates to increase their involvement in the CRCHD, but this question should not be raised on *NCI Listens and Learns* because of NCI's resource constraints. She reminded the DCLG that NCI's primary mission is to conduct and fund

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research. All questions posed on the site should be related to research. Ms. Anthony suggested asking about the kinds of patient navigator programs needed for cancer patients.

Ms. Campos suggested that advocates be involved in the new health policy branch.

Other suggested questions for *NCI Listens and Learns* were:

- Identifying the cancer health disparities experienced by communities.
- Informed consent forms because clinical trials are finding it difficult to obtain informed consent from the public.
- Discovering what cancer patients consider as barriers to care.

Announcements. DCLG members made the following announcements:

- National Recycling Day takes place in April and might provide an opportunity for advocacy organizations to obtain recycled computers.
- Ms. Branch is working with the National Institute for Environmental Health Sciences to recruit 50,000 sisters of women who have been diagnosed with breast cancer. The study needs more seniors, Latinas, African Americans, Asian and Pacific Islanders, and Native Americans. Ms. Branch can provide DCLG members who are attending meetings with promotional materials for this environmental and genetics study.

XV. ADJOURNMENT

Mr. Ulman thanked the DCLG members for their participation. The meeting highlighted a role for advocates in several new NCI initiatives and the DCLG will address these issues over the coming months.

The meeting adjourned at 2:30 p.m.

CERTIFICATION

I hereby certify that the foregoing minutes are accurate and complete.

Date

Chair, Director’s Consumer Liaison Group

Date

Executive Secretary
Director’s Consumer Liaison Group

Attachments:
Roster

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A complete set of handouts is available from the Executive Secretary.

DCLG ACTION ITEMS

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- Ms. Brooke Hamilton will work with NCI's Press Office to determine whether any media picked up the story of the launch of the *NCI Listens and Learns* Web site from the press release issued by NCI.
- The Office of Liaison Activities (OLA) staff will work on improving the *NCI Listens and Learns* website by:
 - Making it clear that users must click on the question in order to post a response.
 - Allowing users to format their responses into paragraphs.
- Ms. Hamilton will ask the contractor that manages the American Customer Satisfaction Index survey whether, prior to receiving 300 responses to the questionnaire, the DCLG can obtain responses to the question on suggested improvements to the Web site.
- OLA will develop a list of organizations that have registered for the Web site but have not yet appointed a spokesperson and will assign each DCLG member some names from that list. DCLG members will then telephone the organizations on their lists and encourage them to assign a spokesperson.
- Ms. Hamilton will send out a CD with the *NCI Listens and Learns* promotional material to Ms. Mary Jackson Scroggins, Mr. Eric Rosenthal, and Ms. Nancy Davenport-Ennis.
- DCLG members should contact Ms. Hamilton if they need hard copies of the *NCI Listens and Learns* promotional material.
- The following changes will be made to the draft logic model for *NCI Listens and Learns*:
 - Delete "resources" from long-term outcome 2 in column 4, "CAC members, their constituents, and individuals in the community will be more satisfied with access to NCI resources."
 - Delete long-term outcome 3 in column 4, "CAC members, their constituents and individuals in the community will be more satisfied with the quality of NCI resources."
 - Replace "general public" with "interested public" throughout the logic model.
- The Evaluations Working Group will distribute revised copies of the logic model and evaluation plan to DCLG members for their feedback.
- Ms. Alissa Lewandowski will develop a schedule for Mr. Rosenthal to use for recording the *NCI Listens and Learns* questions for broadcast on The Group Room[®] radio show.
- Ms. Sarah Birkhead will share with the DCLG slides that explain molecular characterization for lay audiences.
- The DCLG will invite Dr. Anna Barker to discuss the National Biospecimen Network with the DCLG at a future meeting.
- Ms. Nancy Caliman will consult with Dr. Julia Rowland about developing a question on survivorship for posting on the *NCI Listens and Learns* Web site in April.
- The DCLG will prepare a formal response to the questions posed by Ms. Cherie Nichols on the Progress Review Group process.
- Ms. Vernal Branch and Mr. Rosenthal will prepare a draft DCLG annual report, which will be circulated to all DCLG members for their comments.
- OLA staff will determine whether an Indian desk has been established at NIH or elsewhere within the Department of Health and Human Services, and will inform Ms. Cece Whitewolf of what they learn.

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- Ms. Hamilton will distribute to the DCLG the address for the Web site with the comments from the public to the Clinical Trials Working Group.
- Mr. Rosenthal will inform Mr. Bill Bro of the proceedings of this meeting, and especially items pertaining to the Promotions Working Group.
- The DCLG will meet by teleconference in May and July and face to face in September 2005.
- DCLG members should send Mr. Doug Ulman suggestions for the format of the next face-to-face meeting in September 2005.

Action Items of the Evaluations Working Group

- The following changes will be made to the draft *NCI Listens and Learns* logic model:
 - Long-term outcome 2 in column 4 will be changed to, “CAC members, their constituents, and the interested public will be more satisfied with NCI resources.”
 - Long-term outcome 4 in column 4 will be split into two outcomes: “Cancer patients, survivors, and their families/friends, as well as the interested public, will have more knowledge about government-sponsored research” and “Cancer patients, survivors, and their families/friends, as well as the interested public, will have more trust in government-sponsored research.”
 - Long-term outcome 5 in column 4 (“There will be increased interaction/open dialogue among the CAC network”) will be moved to the summit logic model.
 - Long-term outcome 7 in column 4 will be changed to “Collaborative ties among the NCI and the scientific community, CAC, and the interested public will increase.”
 - Questions in the logic model overlay that correspond to deleted outcomes will be deleted.
- Dr. Beverly Laird will determine whether baseline data are available for all of the questions on pp. 3-4 of the draft evaluation plan. If no baseline data are available for a given question or if a question will not yield useful data, the question will be deleted.
- Dr. Laird will print a date on all subsequent versions of the logic model and evaluation plan.

Action Items of the Operations Working Group

- The Operations Working Group will ask the Promotions Working Group to consider sending a mailing to organizations that were invited but have not yet registered for the *NCI Listens and Learns* Web site.
- Operations Working Group members will continue to monitor the *NCI Listens and Learns* Web site on the 15th and last day of each month.
- Ms. Vernal Branch will develop a schedule for Operations Working Group members to monitor the comments on *NCI Listens and Learns*.
- The Operations Working Group will encourage the Evaluations Working Group to evaluate who has participated in the *NCI Listens and Learns* discussions during the site’s first 6 months.
- The Operations Working Group will encourage the Cancer Information Service to link clinical trial participants to the *NCI Listens and Learns* Web site.

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Action Items of the Summit Working Group

- Ms. Scroggins will ask the full DCLG for the names of those who represent hard-to-reach populations so that they can be invited to the summit.
- Ms. Bobbi de Córdova-Hanks will provide group names from the Intercultural Cancer Council and Mr. James Hadley will promote the summit through the OLA advocate's listserv.
- Ms. Scroggins will consult a list of already-scheduled conferences for 2006 to prevent conflicts with the summit.
- Ms. Scroggins will suggest some dates for the conference for consideration by the DCLG.
- Working Group members will develop and suggest ideas to define the focus and agenda of the summit.
- Working Group members will rework the wording of the summit logic model to reflect the goals of the summit.
- Working Group members will compile lists of individuals to be contacted within the cancer advocacy community for input on the summit.
- Working Group members will continue to develop mechanisms for contacting the cancer advocacy community for its input on the summit.
- Working Group members will recommend possible speakers/presenters for the conference.
- Working Group members will suggest guidelines for speakers to address the audience, the summit focus, and the need to speak in lay terms.